



PROSTATE CANCER FOLLOW-UP CARE: ONE SIZE DOESN'T FIT
ALL

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Follow-up Poll – Poll 1

Learning outcomes

- How to get the most from your follow-up appointments.
- Choosing the best follow-up for me.
- Understanding what follow-up is on offer.

Your Next Appointment
PLEASE GIVE 24 HOURS NOTICE IF YOU NEED TO CANCEL OR RESCHEDULE

DATE _____
TIME _____



Introduction

Traditionally, prostate cancer follow-up care has been within the hospital setting and includes regular visits to a specialist clinician/Clinical Nurse specialist, for several years, indeed, some patients are never discharged from follow-up.²

With growing numbers of prostate cancer survivors, it is argued that this model of care is economically unsustainable.³ In recent times the global covid-19 pandemic has also made it unsafe for patients to attend hospitals for face to face follow-up appointments.

Alternative non face to face approaches, such as video, telephone follow-up, and Supported self-management is now the norm and greater involvement of primary care, have been suggested.

Evidence suggests that these alternative approaches do not result in significantly different rates of recurrence, survival, adverse events, patient wellbeing or patient satisfaction up to five years following diagnosis.^{3,4,5,6}

But is this how you feel?

Primary care

v

secondary
care

- ❖ Prostate Cancer starts with the GP (Primary care).
- ❖ Prostate Cancer is diagnosed and treated in Hospital (Secondary care).
- ❖ Hormone treatment is started in secondary care and usually carried on in primary care.
- ❖ Follow-up, following treatment and during hormone treatment is usually in hospital.

What is best for me - Hospital?



FOR

- ✓ Seeing a specialist.
- ✓ Problems or complex needs investigated and addressed at appointment.
- ✓ Phlebotomy, x-ray, pharmacy etc all under one roof.
- ✓ Reassuring
- ✓ Access to electronic patient record system(EPR).

Against

- Travel
- Parking
- Risk of catching viruses
- Seeing different clinicians at every appointment
- Long waits.
- Do not have access to GP patient records.

What is best for me - GP?



FOR

- ✓ Local and accessible
- ✓ Sees the same GP or Practice Nurse every visit.
- ✓ Less waiting
- ✓ GP usually knows the patient and their other problems/conditions.
- ✓ Safer environment.

Against

- Not always easy to get an appointment.
- Only some GP's have a special interest in Urology Cancers.
- If blood tests, referrals, and further investigations are required it can take time.
- Not all GPs have access to hospital EPR

Supported self- Management



Supported Self-Management Follow-Up (SSMFU) is a model whereby patients manage their own follow-up, with back-up from clinical teams as needed, in order to limit risk and ensure a satisfactory patient experience closer to home. Patients access workshops, education and relevant detailed information to ensure they are adequately prepared.

For

- ✓ You have more control over your disease management.
- ✓ 24 hour computer access.
- ✓ Direct phone number to clinical team.
- ✓ No waiting for PSA result.

Against

- You must have computer skills.
- You must have access to a computer.
- You must have stable disease.
- You cannot see or speak to a clinician.

What kind of Follow-up is best for me?

Face to Face

- Easier if English is not your first language.
- Easier if English is not the clinicians first language.
- Easier if you are hard of hearing.
- Reassuring to see a clinician.
- If there is something you need a clinician to physically look at.

Non-Face to Face

- No traveling.
- Convenient.
- Works when everything is stable and you have no problems.
- Less waiting.
- More control.
- Safer environment

Tips For Getting The Most From Your Follow- up Appointment

- Write down any questions or concerns beforehand
- It's easy to forget what you want to say once you're at your appointment.
- Bring someone with you – Extra pair of ears.
- It can be hard to take everything in at your appointments. Some people find it helpful to take someone with them, to listen and discuss things with later. If your appointment is on the phone, you could ask a friend or family member to listen with you.
- Make notes
- It can help to write things down during or after your appointment. Prostate Cancer UK have a booklet called "Follow-up after Prostate Cancer Treatment - What Happens Next" There is room in this booklet to make notes.
- [Follow-up after prostate cancer treatment: What happens next? | Prostate Cancer UK](#)
- Ask to record your appointment
- You could do this using your phone or another recording device. You have the right to record your appointment if you want to because it's your personal data. But let your doctor or nurse know if you are recording them.
- Ask for help
- Don't be embarrassed to ask If there is anything bothering you, let your doctor or nurse know. 6

What Questions Should I Ask

Please explain my blood test results?

How can I improve my waterworks? Bring in a voiding diary, ?

[7BHUK Bladder Diary \(bladderhealthuk.org\)](http://bladderhealthuk.org)

How can I manage the side-effects from the hormone treatment?

What is the chance that the cancer will come back? Should I watch for specific signs or symptoms?

What can I do to take care of myself and be as healthy as possible?

Can you suggest a support group that might help me?

What long-term side effects or late effects are possible based on the cancer treatment I received?

What follow-up tests will I need, and how often will those tests be needed?

What is normal for this stage of my follow-up/Treatment? 8

What
questions
should your
clinician ask

- How are you?
- How many times do you get up at night to pee?
- How is your day time peeing? Could you sit through a film without getting up to pee? Are you Urgent? Do you always make it to the loo in time?
- Do you have any pain associated with peeing?
- Are you dry? How many pads do you wear per day?
- How many times do you have your bowels opened per day? Do you have excess wind?, do you produce any slime or mucus? Do you have any rectal bleeding?
- sexual function?
- Do you have any side effects from your Hormone therapy?

HOW WOULD YOU LIKE YOUR FOLLOW-UP?

Poll 2



The Perfect Follow-up

In a place that suits you, GP Surgery, Hospital, at home

With a GP with special interest in Prostate Cancer (GPwSI),
Prostate Cancer CNS, Urology Cancer Oncologist.

Time to talk, not to feel rushed, clear understandable
dialect.

Feeling safe.

Information of what is out there to help with side effects,
alternative therapies, diet and exercise advice, anything!

Reassurance and motivation.

Booking next appointment and blood tests, imaging, plans
in place.

2. Davies N, Batehup L. Towards a personalised approach to aftercare: a review of cancer follow-up in the UK. *J Cancer Surviv* 2011; 5(2): 142-51
3. Lewis RA, Neal RD, Williams NH et al. Follow-up of cancer in primary care versus secondary care: systematic review. *Br J Gen Pract* 2009; 59(564): 234-47
4. Lewis R, Neal RD, Williams NH et al. Nurse-led versus conventional physician-led follow-up for patients with cancer: systematic review. *J Adv Nurs* 2009; 65(4):
5. Emery JD, Shaw K, Williams B et al. The role of primary care in early detection and follow-up of cancer. *Nat Rev Clin Oncol* 2014; 11(1): 38-48
6. Prostate Cancer UK July 2019 Follow-up after treatment.
7. Bladder Health UK voiding diary
8. National Cancer Institute Follow-up Medical Care



BLADDER DIARY

Name:

NHS No:

Date:

This Bladder Diary is to help you and the Healthcare team identify the reasons of your bladder control trouble. Please complete the diary for 3 days.

In order to complete the below tables please:

- Tick in the boxes every time you pass urine. If you wish you can also measure the amount of urine that you pass in a jug and write it on the chart as seen in the example below.
- Tick or write in the box every time you have a drink and finally
- Tick if you leak urine before reaching the toilet or at any other time (for example if you cough or sneeze).
- Use the last page to mark down any question you have.

| Day 1 | Urine Passed | Drinks | Leaks/ Accidents | What were you doing at the time? |
|---------------|--------------|-----------|------------------|----------------------------------|
| 10:00 - 11:00 | 100mls | Tea 1 mug | Yes | Exercising |

| Day 1 | Urine Passed | Drinks | Leaks/ Accidents | What were you doing at the time? |
|---------------|--------------|--------|------------------|----------------------------------|
| 01:00 - 02:00 | | | | |
| 02:00 - 03:00 | | | | |
| 03:00 - 04:00 | | | | |
| 04:00 - 05:00 | | | | |
| 05:00 - 06:00 | | | | |
| 06:00 - 07:00 | | | | |
| 07:00 - 08:00 | | | | |
| 08:00 - 09:00 | | | | |
| 09:00 - 10:00 | | | | |
| 10:00 - 11:00 | | | | |
| 10:00 - 12:00 | | | | |
| Midday | | | | |
| 13:00 - 14:00 | | | | |
| 14:00 - 15:00 | | | | |
| 15:00 - 16:00 | | | | |
| 16:00 - 17:00 | | | | |
| 17:00 - 18:00 | | | | |
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| 19:00 - 20:00 | | | | |
| 20:00 - 21:00 | | | | |
| 21:00 - 22:00 | | | | |
| 22:00 - 23:00 | | | | |
| 23:00 - 00:00 | | | | |
| Midnight | | | | |