

SCC-AFTER

Optimising recruitment and informed consent in SCC-AFTER: Tips and guidance

We know that recruiting patients can be a difficult process. **This tips and guidance document is aimed to support you in your conversations with patients when recruiting to SCC-AFTER.** For further guidance and information about the Information Study please use these resources:

- [SCC-AFTER : Panopto](#)
- SCC-AFTER PARTICIPANT INFORMATION SHEET (PIS)
- The Information Study/ QRI+INCLUSION SWAP: A guide

Inclusive Recruitment



To support effective and inclusive recruitment, we recommend:

- Use the **summary information sheet** initially and **then layer** information by supplying the more detailed full patient information sheet.
- Consider whether **additional support or adjustments** are needed. For example, providing the information sheet in a large print version, a translation of the materials or use of an interpreter.
- Encourage the **involvement of a support person** (if the patient wishes).
- If attending radiotherapy appointments is a barrier, there may be **patient transport options**.

Introducing SCC-AFTER



- It is important to **approach all eligible patients** so that everyone has an opportunity to consider study participation.
- **Mention the study by name 'SCC-AFTER'** early in the conversation to help gain familiarity.

Discussing the study



- **Use the word 'study' rather than trial.** Talking about a 'trial' can make patients feel that they are taking part in something untested and experimental.
- **Explain the aim of SCC-AFTER:** to compare *radiotherapy and close clinical follow-up* with *close clinical follow-up*, so that in future we will know how best to treat high risk SCCs.
- It is good to mention that SCC-AFTER is **funded by the NIHR** (the NHS funding body) and is a **large national study** taking place in England, Wales, Northern Ireland and Scotland.

Patient preferences



- Patients may come with expectations of/preferences for one approach over the other. These may be based on partial or misleading information so it is still important to **discuss the study fully** so all patients can make informed decisions about their treatment.
- When **explaining the two approaches, try to keep a balance.** It's important to avoid presenting the study as 'treatment' vs 'no treatment'. Instead emphasise that it compares 'radiotherapy and close clinical follow-up' with 'close clinical follow-up' because we don't yet know whether the benefits of radiotherapy outweigh the costs. You could mention that

both approaches are currently in widespread use in the NHS because we don't yet have the evidence to show which is best, and hence the SCC-AFTER study.

- If a patient indicates a preference, **gently explore the reason to uncover any misunderstandings** so they can make an informed decision (see [Mills et al, 2011](#)).

Responding to patients inclined towards radiotherapy and close clinical follow-up

"I'm worried if I don't have radiotherapy, my cancer will reoccur"

"I want to have radiotherapy as opposed to having 'no treatment'"

Points to raise when responding:

- We don't know that radiotherapy is a guarantee against the cancer returning.
- Both radiotherapy or close clinical follow-up are currently used as standard practice in the NHS. Close clinical follow-up will involve actively attending appointments for three years to see if there is any sign of the cancer returning at which point radiotherapy may be an option.

Responding to patients inclined towards close clinical follow-up

"I don't want to have radiotherapy because of all the side effects"

"I would rather not have to travel to the hospital for six weeks"

Points to raise when responding:

- Skin radiotherapy is generally well tolerated by patients regardless of their age and usually causes minimal toxicity which is restricted only to the area of the skin that is treated.
- It may be the case that you will only need to attend the hospital for two weeks for radiotherapy (if randomised to that treatment approach). If however, you need to attend for four to six weeks, we've found that individuals have adapted quickly to the daily routine of radiotherapy. What is it about the travel that puts you off?

Describing randomisation

We recommend **avoiding the use of gaming related metaphors** such as 'flip of a coin' or 'rolling a dice', as this may be interpreted as a superficial way to determine treatment (see [Jepson et al, 2018](#)).

Randomisation as a concept can be difficult to convey. It is important that patients understand both **the purpose and process of randomisation**. Key points to cover are:

Purpose

- We need to make a fair comparison between the two approaches to know which is better;
- To do so we need two groups of people that are as similar as possible except for the approach received.

Process

- The surest way to get two groups of people that are as similar as possible is to allocate people to a group at random or by chance.
- You will have an equal chance of receiving either approach.



Thank you for supporting the SCC-AFTER study

Please aim to record all discussions with patients, providing they are happy for you to do so. This gives us an insight into what works so we can help you and others to recruit effectively. The Information Study team are here to help. For further questions and support, contact:

Sarah.Harding@bristol.ac.uk or julia.wade@bristol.ac.uk