

OPTIMA recruiter tips: Engaging with patient preferences

Patient preferences are often cited as an obstacle to recruitment. Drawing on audio-recordings and interviews as part of the OPTIMA Qualitative Recruitment Study (QRS), this tips document takes a look at how patients come to have a preference and offers strategies for exploring and responding to these.

How do patients develop preferences?



Websites, social media, friends and family, and your fellow colleagues all have the potential to shape what a patient thinks about adjuvant treatment and OPTIMA.

What can you do about this?

Starting with your colleagues, please ensure your surgeon, breast nurse specialist and radiography colleagues are familiar with OPTIMA. When talking with patients about treatment following surgery, ask them to:

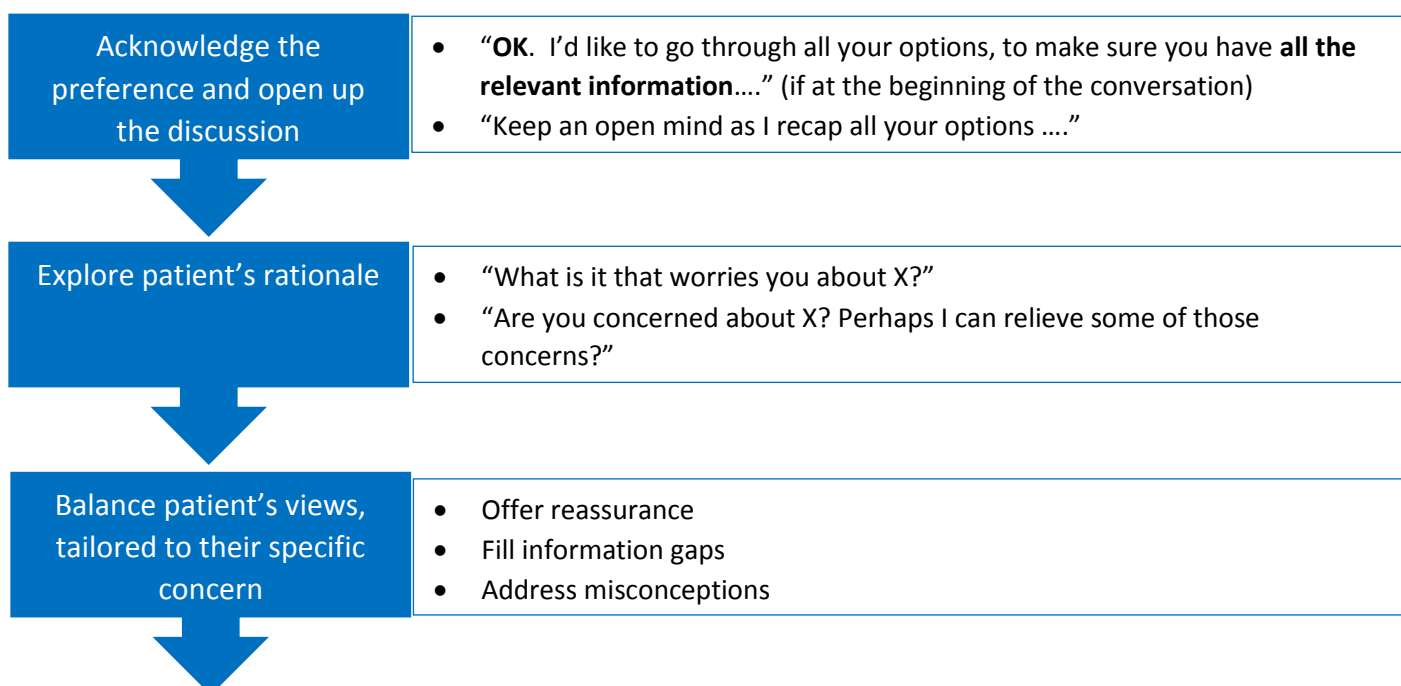
- Encourage patients to keep an **open mind** about follow-on treatment
- introduce **uncertainty of chemotherapy benefit for all**
- prepare patients for a discussion about OPTIMA with their oncologist

To help, we've produced an OPTIMA guide for surgeons and one for breast nurse specialists and a 2-sided patient information flyer for your colleagues to hand to patients at the post-surgery appointment. All are available from the OPTIMA team at Warwick (optima@warwick.ac.uk).

Moving on to your response – OPTIMA is a treatment de-escalation study with very different treatment arms. It is not surprising that some patients may have a strong initial reaction when the trial is presented to them. Try to engage with this initial response by inviting the patient to share with you what's behind their reaction.

We appreciate that engaging with preferences may be a little different to what you would normally do but in the context of recruiting to a study, it leads to better informed consent whatever the final decision. To help with this conversation, we share some strategies that have worked well for many recruiters.

Strategies for engaging with preferences



Responding to patients inclined towards chemotherapy

“I’m worried if I don’t have the chemotherapy it will come back”

“I want some mental guarantee going on”

“I just think that if the cancer has gone somewhere else, I would like it got rid of”

Points to raise when responding:

- Chemotherapy doesn’t provide a guarantee against the cancer returning
- Not all cancers are sensitive to chemotherapy, a person could have chemotherapy and cancer could still return
- If a patient doesn’t have chemotherapy through OPTIMA, it’s on the basis of a low Prosigna score – meaning that the patient is unlikely to benefit from it
- Chemotherapy carries risks and can lead to short and long-term side effects, hence the desire to target its use
- When it is unlikely to help, having chemotherapy can delay starting more effective (i.e. endocrine) treatment

Responding to patients inclined not to have chemotherapy

“It’s all a bit mind blowing because I didn’t think I would need chemotherapy”

“I don’t want to lose my hair”

Points to raise when responding:

- For patients who are keen to avoid chemotherapy, OPTIMA offers the possibility to do this in a controlled way
- Through randomisation, the patient might be assigned to the group where patients have their tumour tested and the outcome of the test could be a low score and thus hormone treatment alone
- The clinical team consider it reasonable to offer the patient chemotherapy to reduce the risk of the cancer returning, however there is uncertainty about its benefits for all patients
- For some patients, cold capping can help reduce hair loss and it usually grows back. A wig may also be an option

Responding to patients that are concerned about test-directed decision making

“If the result was no chemotherapy, would I always be thinking I should have had chemotherapy?”

“I just don’t like this waiting period, I’d prefer to get back on track”

Points to raise when responding:

- Patients with no involved nodes are routinely offered these tests on the NHS
- There is promising evidence that these tests can be used to determine chemotherapy benefit for patients with involved nodes, but we need more evidence for routine use in the NHS – hence OPTIMA study
- Independent experts and the NHS body funding the research have reviewed and approved the design and use of Prosigna in OPTIMA
- Acknowledge that waiting for a treatment allocation may be difficult but reassure that it is clinically safe

Responding to patients not so keen on taking part in research

“I don’t like the fact that I have no control which group I go in or any control over what is done to me”

Points to raise when responding:

- Set out the rationale for the study - this may prove more compelling than the process for allocating treatment.
- Provide the rationale for randomisation – to have two groups that are as equivalent as possible, with the only difference being whether Prosigna is used or not. This enables a fair comparison of patient outcomes
- Reassure the patient that you are happy for the decision about chemotherapy to be determined through the OPTIMA study provided they are equally happy

- Acknowledge the preference and open up the discussion
- Explore patient’s rationale
- Balance patient’s views, tailored to their specific concern
- Engaging with preferences strengthens informed consent whatever the final decision
- Move on when you are satisfied that the patient does not want or need further information.

For a fuller discussion about engaging with patient preferences and the opportunity for individual feedback, please contact the QRS researcher Carmel Conefrey on carmel.conefrey@bristol.ac.uk