SWEET

Prompts to Aid Follow Up Completion

There can be many barriers and reasons why a participant may not want to complete the SWEET Follow Up Questionnaires. We believe many of these reasons stem from the misunderstanding that their contribution may no longer be valid…whether this be because:

- They have ceased hormone therapy
- They don't have side effects
- They feel the questionnaire is no longer relevant to them for any other reason.

The items below are soft prompts split into categories to highlight to the participant how important and valid their contribution is, irrespective of their current status with hormone therapy.

Value of different experiences:

- Women have different experiences when they have had breast cancer. Whatever your experience has been, even if you have stopped taking hormone therapy, it is important for us to understand it. Completing the questionnaire helps us learn what support women need in real life.

- We're really interested in understanding what happened for women during the study, whether things went smoothly or whether there were difficulties along the way. That's why hearing from everyone is so important, regardless of whether women have continued with or stopped hormone therapy.

- Your questionnaire is important to ensure the study reflects the experiences of all women who took part, not just some of them. If we only get responses back from women who have continued with hormone therapy that will not give us a true picture.

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Importance of last questionnaire:

- The final questionnaire is particularly valuable because it tells us what life has been like for you over the last few months, around 18 months since you were first prescribed hormone therapy Whether you've now stopped taking it – or you are getting on fine - your answers help us understand the impact of breast cancer and its treatment on women's lives.

- The final questionnaire is especially valuable because it provides information that we can't get from the earlier questionnaires alone. It helps us understand women's experiences across the whole 18 months of the study.

- The earlier questionnaires tell us where women started, but the final questionnaire helps us understand where they are after 18 months at the end of the study. That's why this stage is particularly important.

Even if nothing has changed:

- Even if you feel nothing much has changed since your last questionnaire, that’s useful information for us to know.

Value of resource use questionnaire:

- Some of the questions ask about appointments and health services you have used. This information helps us understand what kinds of support women use and what services may be needed in the future.

- I appreciate that some of the questions about appointments, services and costs can feel repetitive. They are important because they help us understand what services women use and whether our support programme offers good value for the NHS.

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For women who have stopped HT:

- Please don't worry if you've stopped taking your hormone therapy. We are interested in understanding all women's experiences and how they have been getting on. If we only get responses back from women who have continued with hormone therapy that will not give us a true picture.

- Please don't feel that the questionnaire is only for women who are still taking hormone therapy. Decisions about treatment are personal and can be influenced by many different factors. We'd still very much value your views and experiences, whatever those have been. If we only get responses back from women who have continued with hormone therapy that will not give us a true picture.

Helping other women in the future:

- By completing the questionnaire, you're helping us understand how care and support might be improved for future patients.

- One of the aims of the study is to understand what kinds of support are most useful for women. We can only do that if participants tell us about their experiences and how they have been doing, whatever those experiences have been.

- One of the reasons we're doing this study is to improve support for future women with breast cancer. If women who have found treatment difficult, or have stopped taking hormone therapy, don't complete the questionnaires, we may miss some of the most important lessons about how support could be improved.

Making the most of your previous contribution to the study:

- You've already contributed a great deal to the study. Completing the final questionnaire means we get a full picture of what your experience has been when the study results are analysed.