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**Patients Survey**

**Experience of Bisphosphonates in Primary Breast Cancer**

**We invite you to take part in this survey**

Before you decide whether or not to accept the invitation to take part in this survey, it is important for you to understand why this survey is being done and what taking part would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us (please see in page 2 how to contact us) if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for considering participating in our survey.

**Important things you need to know**

* We want to find out more about the experience that patients with primary breast cancer (breast cancer that **hasn’t spread beyond the breast or the lymph nodes (glands) under the arm**) have or had with treatment called bisphosphonates. Bisphosphonates (e.g. zoledronic acid, clodronate, Ibandronic acid) are bone drugs which they might be also called bone-hardening or bone-strengthening drugs. Research has shown bisphosphonates may reduce the risk of breast cancer spreading to the bones and elsewhere in the body in some groups of women with primary breast cancer who have gone through menopause. They are given after primary breast cancer surgery, usually for a period of 3 years.
* Your participation in this survey will help us to understand what patients think about this treatment, how easy it is to take, any problems they have experienced, to help us improve future patients’ experience with this treatment.
* Participating in this survey will involve you answering online questions. Survey should take 10 minutes to complete.
* The online survey is anonymous, and it’s done by researchers from the University of Sheffield (UK) with the help of Breast Cancer Now. Your name will not be identified.
* You can stop participating in this survey at any time, without giving a reason.

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**How to contact us**

If you have any questions about this survey please **contact the Research Team.**

Elisavet Theodoulou, Clinical Research Fellow, University of Sheffield

[Elisavet.theodoulou2@nhs.net](mailto:Elisavet.theodoulou2@nhs.net)

1. **Why are we doing this survey?**

Bisphosphonates (such as Zoledronic Acid, Ibandronic Acid and Clodronate) are drugs which are known to strengthen bones. Clinical trials have shown that in women with primary breast cancer (breast cancer that **hasn’t spread beyond the breast or the lymph nodes (glands) under the arm**) and who have gone through the change (also called the menopause), bisphosphonates can reduce the risk of breast cancer coming back and spreading to the bones.

Since 2018, Bisphosphonates have become standard of care in the UK for women with primary breast cancer who have gone through the menopause. As this is a fairly new treatment, we want to ask patients to share their experience of taking bisphosphonates, to help us improve future patients’ experience with this treatment.

Researchers from the University of Sheffield are doing this survey with the help of Breast Cancer Now.

1. **Why am I being asked to take part?**

You have been asked to take part in this survey because we think you might have taken, or you are currently taking, bisphosphonates as part of your primary breast cancer treatment. You have agreed to be contacted by the Breast Cancer Now for research/survey purposes. Your contact details are not known to the University of Sheffield research team, and they have not been shared with them. It is your decision whether to participate in the survey or not. You are free to withdraw at any time, without giving any reason.

1. **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to give an anonymous electronic consent by selecting the Agree box (consent acknowledgement) at the second page of the online survey. You are free to withdraw at any time without any consequences. You do not have to give a reason. If you wish to withdraw from the survey, please contact the research team.

Research Team Contact Details

Elisavet Theodoulou, Clinical Research Fellow, University of Sheffield

[elisavet.theodoulou2@nhs.net](mailto:elisavet.theodoulou2@nhs.net)

Please note that that by choosing to participate in this survey, this will not create a legally binding agreement, nor is it intended to create an employment relationship between you and the University of Sheffield or the Breast Cancer Now.

1. **What will happen if I take part? What do I have to do?**

If you decide to participate to the online survey then please follow the link below to complete the survey. It should take 10 minutes to complete. Participation in this survey will not affect any breast cancer treatment you are having, or you might have in the future. Your breast cancer doctor (Oncologist) or nurse or your GP will not be made aware of your participation in this survey. Your participation is anonymous, and your name will not be identified. Breast Cancer Now or the University of Sheffield will not know if you have participated in the survey or not.

**\*Survey link\*:** [**https://www.surveymonkey.co.uk/r/breastcancerBPs**](https://www.surveymonkey.co.uk/r/breastcancerBPs)

1. **What are the possible benefits and disadvantages of taking part?**

Your participation in this survey will help us to understand what patients think about bisphosphonate treatment in primary breast cancer, how easy it is to take, any problems they have experienced, to help us improve future patients’ experience with this treatment.

Whether you decide to participate in the survey or not will not impact your current or future treatment. Your breast cancer doctor (Oncologist) or nurse or your GP will not be made aware of your participation in this survey.

1. **What will happen to information about me?**

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that ‘processing is necessary for the performance of a task carried out in the public interest’ (Article 6(1)(e)).

All the information that we collect about you during the course of the survey will be kept strictly confidential and will only be accessible to members of the research team. You will not be able to be identified in any reports or publications, but your words may be quoted in publications, reports, web pages, and other research outputs. You will not be named in these outputs. The survey is anonymous. Your breast cancer doctor (Oncologist) or nurse or your GP will not be made aware of your participation in this survey. Breast Cancer Now or the University of Sheffield will not know if you have completed the survey or not.

1. **What happens when the survey ends?**

When the survey closes, we plan to publish the results in a medical journal and present the findings in medical conferences, so that the wider medical community and patients can benefit from the findings. The published results will be accessible to everybody. Also, we plan to share our findings with the Breast Cancer Now and generate a summary suitable for lay people to share the experience. It will not be possible to identify individual patients in any publications or results that we share but your words may be quoted. If you would like to receive a copy of the published results please let us know.

1. **What if I have concerns?**

If you are dissatisfied with any aspect of this survey and wish to make a complaint, please contact Professor Ingunn Holen, Department of Oncology and Metabolism, University of Sheffield (email address: [i.holen@sheffield.ac.uk](mailto:i.holen@sheffield.ac.uk)) in the first instance. If you feel your complaint has not been handled in a satisfactory way you can contact the Head of the Department of Oncology and Metabolism, University of Sheffield, Professor Allan Pacey (email address: [a.pacey@sheffield.ac.uk](mailto:a.pacey@sheffield.ac.uk)). If the complaint relates to how your personal data has been handled, you can find information about how to raise a complaint in the University’s Privacy Notice: <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

1. **Contact details for further information**

If you have any questions about this survey please contact:

Elisavet Theodoulou, Clinical Research Fellow, University of Sheffield [Elisavet.theodoulou2@nhs.net](mailto:Elisavet.theodoulou2@nhs.net)

\*Breast Cancer Now Person\*

**Thank you for taking the time to consider taking part in this survey**