

MAP-BRONJ Information Sheet for Patients with a diagnosis of BRONJ**The multidisciplinary approach to the prevention of bisphosphonate related osteonecrosis of the jaw (BRONJ). A Qualitative study into the attitudes and perceptions of patients (MAP-BRONJ) – IRAS 216783****Why is MAP-BRONJ being carried out?**

A group of drugs called bisphosphonates are used to treat a number of conditions that affect bones, such as osteoporosis and certain cancers. Because we are living longer, more patients are being prescribed these drugs than ever before and a rare but important side effect, called osteonecrosis of the jaw, has been discovered.

This side effect causes problems with patient's jawbones, particularly if patients require a dental extraction. This condition can be difficult to treat and because of this healthcare professionals should try to prevent it from happening in the first place. In this study we are looking to find ways in which we can minimise this risk and how healthcare professionals can work better as a team to prevent it from occurring.

Why have I been invited to take part?

You have been asked to take part in this study as you have previously been diagnosed with osteonecrosis of the jaw. By speaking to patients like yourself, we can get a better understanding of the impact that this has had on you and how we can prevent it from happening to any other patients.

What would I have to do?

We would like your help with this study by asking you to talk to one of our team members for about an hour. We will audio record this conversation so that it is easier for us to make notes later about what was said. The interview can take place at your GP surgery, or we can come to your home to talk to you.

Will I be able to get my money back if I have to travel to take part?

Yes. We don't want taking part in the study to cost you anything. This means that we will give you the money for any bus fares or other travel costs which you have to pay to take part.

Will I get paid for taking part?

No. But we will be giving everyone who takes part a £10 gift voucher as a 'thank you' for taking part in our project.

What is the study for?

The information that we get from MAP-BRONJ will help us to know more about the expectations of patients and how healthcare professionals can work together. Potentially this could help the NHS and patients who use these medicines in the future.

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Are there any risks to me from taking part?

We don't think there will be any risks to you from taking part in the study. It won't make any difference to the medicines or treatment that you are getting.

How will my information be kept confidential?

We won't use your name on anything we write. We might use some of your words in our reports, but we won't say that it was you who said it. The audio file will be sent to an external transcription service that has been approved by the University of Sunderland. We will only keep your name and information about you in very safe places and the audio recordings will be destroyed once they have been transcribed and anonymised. If you are worried about that we can tell you more about it.

Will anyone else know that I've taken part?

Unless you tell us not to, we will let the person who prescribed your medicine know that you have helped us. We won't tell them what you've said, but by letting them know it means that you can ask them questions in the future and they will know that you've taken part.

Do I have to take part and can I change my mind?

Taking part in the study is voluntary. Even if you return a form to us to say you are happy to take part, you can stop taking part at any time and you don't have to tell us why. If you wish to stop taking part you should use the contact details below, you will not be asked to provide any reasons and stopping taking part won't affect your relationship with the study team, your doctor or pharmacist, or anyone else at your GP surgery.

We do need to tell you that once we've finished the study and written our reports, it will be too late to decide to stop taking part. So you need to let us know if you don't want to carry on as soon as possible.

Who can I contact if I have questions about MAP-BRONJ?

If you have any questions, we would like you to get in touch with us. You can do this by telephoning us on 0191 5152448 or you can email us on andrew.sturrock@sunderland.ac.uk

If you have any questions about your medicines, you should contact your doctor.

What will happen to the results of MAP-BRONJ?

Once we have collected all of the information from the people who take part, we will want to let others know what we have found. This might be through writing articles for journals, magazines or newspapers. We also might tell people about it at conferences. We hope that by telling others what we've found out, we can give better support to people like you. Don't worry though, if we use some of your words we will use a code or a different name, so nobody will be know these words are yours. You will be asked if you wish to receive a copy of the final study report during the interview, the report can be emailed or posted to the contact details that you provide. It is anticipated this should be available within 6 months of

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the end of the study.

Who is doing MAP-BRONJ?

The research is being done by a research team at the University of Sunderland. The Chief Investigator for the project is Andrew Sturrock. His title is 'Senior Lecturer' and he is based in the Department of Pharmacy, Health and Wellbeing.

Who is paying for MAP-BRONJ?

The study is being supported by the UK Clinical Pharmacy Association and Pharmacy Research UK who have given us some money to carry out the study.

Have other patients and the public helped with MAP-BRONJ?

A patient representative from the University of Sunderland patient involvement group was involved in the initial design of this study.

Has anyone checked that MAP-BRONJ is okay to do?

MAP-BRONJ has been reviewed by an NHS Research Ethics Committee (IRAS ID 216783) and it has also been approved by the University of Sunderland Research Ethics Committee. They are happy that MAP-BRONJ is okay to be carried out by the team, and that no harm will come to you or them.

If you're concerned and want to talk to someone independent of the MAP-BRONJ team, you can contact the Chair of the University of Sunderland Research Ethics Committee, Dr Etta Evans, on etta.evans@sunderland.ac.uk or 0191 5152624.

What should I do if I want to take part?

If you don't have any questions and would like to take part, please can you fill in the contact information slip and send it to us. Please let us know the best way for us to get in touch with you. We don't know how many people will want to help us so we might find we have too many and we may not need to ask for your help.

Once we have your form, someone from the MAP-BRONJ team will get in touch with you and let you know if we do need your help or not. If we do they will arrange the best time and place for you to meet and talk to us.

Thank you for taking the time to read this information.