

## Patient information Sheet: Identifying the most important factors in the care and patient experience of outer ear infections

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We would like to invite you to take part in this survey which aims to identify which factors are most important for you in your experience of an outer ear infection (also known as *otitis externa*). Before you decide whether you would like to participate or not, we would like to provide you with some information on why we are conducting the survey and what taking part will involve.

The first part of this information sheet will tell you about the purpose of the survey, and what will happen to you if you participate.

The second part will explain in more detail what the survey involves.

There is a contact email address at the end of this information sheet if you would like any more information.

### Part 1

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#### Why is this study needed?

Outer ear infections (*otitis externa*) are common and affect a wide range of patients each year in the UK. They can be very painful and can have a significant impact on patients' lives. Currently, little is known about what factors patients think are important in the management of *otitis externa*, or about what areas we should prioritise in the research of *otitis externa*.

#### What is the purpose of this study?

We are a group of doctors involved in the treatment of patients with *otitis externa* looking to improve research of this condition. As a first step we would like to get your opinion based on your personal experience of *otitis externa* to find out which aspects of this condition are important to you.

This information will be used to create a *Core Outcome Set*, which is a recommended list of compulsory items which should be included when reporting on any research of *otitis*

*externa*. We hope this will improve the standard of research and the care of patients with this condition.

### Why have I been invited?

Patients and healthcare professionals will be contributing to this survey. We are inviting patients to take part who have been affected by *otitis externa*, to get a better understanding of their experiences.

### What would taking part involve?

If you agree to take part, you will be asked to complete 3 fifteen-minute on-line surveys. These are anonymous and your identity will only be known to the core research team analysing the responses. You will be asked to rate the importance of different aspects of *otitis externa* are to you on a scale of 1 to 9. There are no right or wrong answers and not all questions may apply to you.

If you are happy to participate in all 3 rounds please provide your email address to your doctor. Your email address will only be used to send you the survey link to the online survey.

### Do I have to take part?

No. Participation is completely voluntary.

## Part 2

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### If I take part in the survey, what is required of me?

If you take part in the survey, we will request that you complete 3 online questionnaires which will explore the factors most important for you in your experience an outer ear infection (*otitis externa*). Each questionnaire is anticipated to take approximately 15 minutes to complete.

### How long will I be involved?

We ask that you complete each of the questionnaires within 2 weeks of receiving the online link. There will be a few weeks between the 3 survey links being sent out, to allow time for us to analyse and prepare the data to be presented to you for the next rounds. We anticipate the whole process being complete within a couple of months, though each questionnaire should take only 10-15 minutes.

### Are there any benefits to me in taking part in the survey?

Whilst there are no immediate benefits if you participate in this study, you may improve your understanding of *otitis externa*. Your shared experiences will help develop future research that will improve the care provided to patients.

### Are there any risks/inconveniences to me in taking part in the survey?

There are no identified risks of taking part in this study. However, your participation may take you away from your normal commitments for a time. We will try and keep these time commitments to a minimum

### What will happen if I don't want to carry on with the study?

You can stop your involvement at any time. Whether you choose to participate or chose not to, your NHS care will not be affected in any way.

### What will happen after the study?

The results of the survey responses will be used to decide on the most important outcomes to be measured in patients with *otitis externa*. These outcomes will be published in a scientific journal and allow future researchers to ensure that their studies are more patient centred, consistent and transparent. The results will also be published on the website [entintegrate.org](http://entintegrate.org) for you to access in the *For Patients* section.

### How will my information be kept confidential?

The study is organised and run by an ENT doctors research group called INTEGRATE. We will not request any details by which you could be identified. INTEGRATE is registered with the Information Commissioner's Office and is fully compliant with the Data Protection Act 1998. We only plan to keep your email address for the purpose of conducting this study. Your email address will be stored securely in a password protected database. Only the key members of the study team will have access to it. Your email address will be deleted once the study is complete. Your responses will remain anonymous and you will not be contacted for any other purposes after completion of all the surveys. No individuals participating in the study will be identified in any subsequent publications or presentations.

If you decide to change the email address we hold for you, the previous email address will be permanently deleted from our secure database system.

If you decide to withdraw from the study, your email address will be permanently deleted from our secure system. Survey responses you have already provided may have already been used to inform the research process.

The responses you provide us with will be analysed together with all other participants' responses. The responses will be kept for a maximum of two years from the date they are collected.

### Who to contact if I have questions?

If you have any questions about the study, please email us at [info@ENTIntegrate.org](mailto:info@ENTIntegrate.org)