

What questions do you have about alcohol-related liver disease?

Why we need your help

Liver disease in the UK has increased by at least 60% in the last decade and up to 1 in 5 of the population is estimated to be at risk. It is now the third most common cause of premature death in the UK, with alcohol-related liver disease accounting for at least three-quarters of this.

Have you ever had an unanswered question about the prevention, diagnosis, treatment or care of people with alcohol-related liver disease which could benefit from research? If so, please take part in this survey. All your answers will be treated anonymously.

The purpose of this study is to find out what you think are the important questions about alcohol-related liver disease that have not yet been answered by research. Your answers will help us identify future research studies, with the ultimate aim of benefiting the lives of those with, or at risk of, alcohol-related liver disease. Please tell us your questions, no matter how big or small. All of your questions are important to us.

Who can get involved?

Please complete this survey if you are:

- ▶ a person at risk of, or worried about, alcohol-related liver disease
- ▶ a person with, or who has had, alcohol-related liver disease

- ▶ a carer for, or family member of, someone with, or who has had, alcohol-related liver disease
- ▶ a bereaved carer or family member of someone with alcohol-related liver disease
- ▶ a healthcare professional or support worker working with people with alcohol-related liver disease. This includes community pharmacists and GPs
- ▶ an organisation representing the interests of people with alcohol-related liver disease.

What will happen to my questions?

All responses will be gathered together.

- ▶ The questions for which answers are not already available will be published anonymously
- ▶ They will go through a process of prioritisation which you could be involved with
- ▶ This will result in a 'Top 10' list of research topics which we will use to influence future research decisions.

Please answer these questions from your own personal or professional experience. You do not have to answer all questions and please write as much or as little as you like. All answers will be treated anonymously.

1. What questions, if any, do you have about the **prevention** of alcohol-related liver disease? Please list your questions here. Please continue on a separate sheet if required.

Your questions:

2. What questions, if any, do you have about the **diagnosis** of alcohol-related liver disease? Please list your questions here. Please continue on a separate sheet if required.

Your questions:

3. What questions, if any, do you have about the **care and support** of people with or affected by alcohol-related liver disease? Please also include any questions you may have on self-care here. Please continue on a separate sheet if required.

Your questions:

4. What questions, if any, do you have about the **treatment** of alcohol-related liver disease? Please list your questions here. Please continue on a separate sheet if required.

Your questions:

5. Do you have any **other** questions relating to alcohol-related liver disease? Please list your questions here. Please continue on a separate sheet if required.

Your questions:

Some questions about you

To ensure we gather responses from a wide range of people, it would be helpful to know a little more about you. Your answers will be treated in confidence and no individual will be identified when the results are presented.

6. In column A, please tick which one of the following best describes you (please tick only one)

7. In column B, please tick any others that apply to you (please tick all that apply)

	A Best describes you	B Any others that apply to you
A person at risk of, or worried about, alcohol-related liver disease		
A person with alcohol-related liver disease		
A person who has had alcohol-related liver disease		
The carer/partner/relative of a person with, or who has had, alcohol-related liver disease		
The bereaved carer/partner/relative of a person who had alcohol-related liver disease		
A health or social care professional		
A support worker		
An organisation representing the interests of people with alcohol-related liver disease		

Other (please specify)

8. Are you (please tick one box)

<input type="checkbox"/>	Male
<input type="checkbox"/>	Female
<input type="checkbox"/>	Prefer not to say

9. Which of the following best describes your ethnic group? (please tick one box)

<input type="checkbox"/>	White
<input type="checkbox"/>	Mixed / Multiple ethnic groups
<input type="checkbox"/>	Asian / Asian British
<input type="checkbox"/>	Black / African / Caribbean / Black British
<input type="checkbox"/>	Other ethnic group
<input type="checkbox"/>	Prefer not to say

10. How old are you? (please tick one box)

<input type="checkbox"/>	Under 16
<input type="checkbox"/>	16-24
<input type="checkbox"/>	25-34
<input type="checkbox"/>	35-44
<input type="checkbox"/>	45-54
<input type="checkbox"/>	55-64
<input type="checkbox"/>	65-74
<input type="checkbox"/>	75-84
<input type="checkbox"/>	85+
<input type="checkbox"/>	Prefer not to say

11. Where do you usually live? (please tick one box)

<input type="checkbox"/>	North East England
<input type="checkbox"/>	North West England
<input type="checkbox"/>	Yorkshire and Humber
<input type="checkbox"/>	East Midlands
<input type="checkbox"/>	West Midlands
<input type="checkbox"/>	East of England
<input type="checkbox"/>	London
<input type="checkbox"/>	South East of England
<input type="checkbox"/>	South West of England
<input type="checkbox"/>	Scotland
<input type="checkbox"/>	Wales
<input type="checkbox"/>	Northern Ireland
<input type="checkbox"/>	Outside of UK

***You only need to answer questions 12, 13 and 14 if you are a health or social care professional, or support worker. All other respondents please move on to Next steps.**

12. Which of the following best describes your work setting? (please tick one box)

<input type="checkbox"/>	Hospital
<input type="checkbox"/>	GP Practice
<input type="checkbox"/>	Community Pharmacy
<input type="checkbox"/>	Community Support
<input type="checkbox"/>	Mental Health Setting
<input type="checkbox"/>	Hospice
<input type="checkbox"/>	Prison Care

Other (please specify) _____

13. Which of the following best describes you? (please tick one box)

<input type="checkbox"/>	Doctor
<input type="checkbox"/>	Nurse
<input type="checkbox"/>	Community Worker
<input type="checkbox"/>	Allied Health Professional
<input type="checkbox"/>	Hospital Pharmacist
<input type="checkbox"/>	Community Pharmacist
<input type="checkbox"/>	Psychiatrist
<input type="checkbox"/>	Psychologist
<input type="checkbox"/>	Social Worker

Other (please specify) _____

14. What is your job title? _____

Please continue on to the next page

Next steps

Would you like more information about the next stage of the project, where the research questions will be prioritised?

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
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If you answered 'Yes' to the previous question, please supply your contact details so that we can give you more information. This consent and contact page will be kept separate from your survey responses to ensure anonymity of your questions and in accordance with the Data Protection Act.

Contact details (Please only complete if you would like to hear from us further)

Name: _____

Email address: _____

Postal address if you would prefer us to contact you by post: _____

Consent

By participating in this survey you are agreeing to allow us to anonymously publish the questions you identify in the UK Database of Uncertainties about the Effects of Treatment (UK DUETs – www.library.nhs.uk/duets)

Your personal information is held and used in compliance with the Data Protection Act 1998 ('the Act'). We will only use your information in relation to activities to do with this survey. We will not pass your details to any third party. You can ask for your details to be removed from our database at any time.

The Department of Health, National Institute for Health Research (NIHR) is committed to protecting privacy and to processing all personal information in a manner that meets the requirements of the Act.

	Please tick one box
I agree to my personal information being used as above	<input type="checkbox"/>
I do not agree to my personal information being used as above	<input type="checkbox"/>

For further information on the survey

You can visit our website at www.psp.nihr.ac.uk/alcohol-related-liver-disease or contact the Project Co-ordinator, Amy Street, at ila@southampton.ac.uk or on 02380 597830.

Unfortunately we cannot respond to enquiries about individual cases of alcohol-related liver disease. If you need further information or support, please contact The British Liver Trust on 0800 652 7330. Or visit www.britishlivertrust.org.uk

Thank you for taking the time to complete this survey. Your participation is important to us. Please submit your responses **as soon as possible**.

Please return the survey to: Amy Street, NETSCC, Alpha House, FREEPOST, RTHT-TBHY-ZJJR Highfield, Southampton, SO16 7NS

Please pass the details of this survey on to anyone else who might be interested.

You can tweet about us @LindAlliance #ARLDPSP