



Survey Questionnaire

Calling everyone affected by liver disease!



What questions do you want answered by research into liver cirrhosis?

This survey is for people affected by liver cirrhosis, their loved ones, carers and healthcare professionals. What do you think are the most important questions on liver cirrhosis, where research should focus?

Please spare 10 minutes to do this short survey to suggest the research needed to improve care and treatment for liver cirrhosis. Please share your questions, no matter how important or trivial you may think they are.

We are a group of patients, carers, care professionals and researchers who are passionate about liver disease research. We are running this project through a James Lind Alliance Priority Setting Partnership, with the UK CLIF Network and the British Liver Trust.

Why this is important - Liver cirrhosis is the name for the advanced stage of chronic liver disease. While many people with liver cirrhosis can lead a normal life, it can be a serious condition that is life limiting for some.

Cases of liver disease are increasing in the UK and although a lot of research is being done, we have not developed a new treatment for liver cirrhosis in the last 20 years. Research is needed to help improve the lives of people living with liver disease.

What happens with the survey results – The results will be shared with researchers, research funders and others working with people affected by liver cirrhosis.



Tell us a bit about yourself:

Tick column A for your main role related to the survey

In column B tick any others that apply

I am:	A Main role Tick one	B Other roles Tick all that apply
A person with liver cirrhosis		
A carer for someone with liver cirrhosis		
Loved one/ friend of someone with liver cirrhosis		
A person bereaved due to liver cirrhosis		
A healthcare professional working with people with liver cirrhosis		
Staff or volunteer with a group supporting people with liver cirrhosis		
Other? Please specify:		

Your questions about liver cirrhosis

Think about what you would like to see answered by research into liver cirrhosis. In your own words and using your own experiences, tell us what is important to you.

What questions do you have about liver cirrhosis? Research could look into:

- Diagnosis
- Symptoms or symptom control
- Treatment and care
- Other aspects of liver cirrhosis

E.g. For diabetes someone might write:

What sort of exercise is likely to be helpful to stop diabetes symptoms getting worse?

My questions about liver cirrhosis:

Please help us understand who has responded to this survey and from where in the country:

Which of the following best describes your ethnic group?

(Please tick one box)

Asian / Asian British	
Black / African / Caribbean / Black British	
Mixed / Multiple ethnic groups	
White	
Prefer not to say	
Other ethnic group <i>please write in:</i>	

Are you: *(please tick one box)*

Female (including trans woman)	
Male (including trans man)	
Non-binary	
Trans woman	
Trans man	
Prefer not to say	

Where in the UK do you usually live? *(Tick one box)*

North East England		North West England	
Yorkshire and Humber		East Midlands	
West Midlands		East of England	
London		South East England	
South West England		Scotland	
Wales		Northern Ireland	
Outside the UK			

Healthcare professionals only:

a) Which describes you best? *(Tick one box)*

I am a nurse	
I am a doctor <i>(GP/ Hospital Doctor? Doctor in training)</i>	
I am a pharmacist	
I am an allied health professional e.g. physiotherapist, psychologist, dietician	
I am a social care professional	
I am part of an organisation/charity representing people with liver disease	
Other – please state:	

b) Do you work primarily in? *(Tick one box)*

Primary/community health care	
Secondary health care	
A tertiary care centre for liver disease	

Both primary and secondary care	
Community social care	
Other - please state:	

What will happen with my information?

All personal information will be kept confidential. No links will be made in the published results to individual people or organisations.

What happens next?

We would like to get back to you to help us to put the research questions into order of importance and urgency.

If you would like to be part of this next stage, please add your contact details below.

Name:

Address:

Email:

Thank you for making a difference!

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