

The James Lind Alliance

Research Priorities for Alcohol-Related Liver Disease

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Thank you

The Alcohol-related Liver Disease Priority Setting Partnership was formed by the James Lind Alliance and funded by the National Institute for Health Research and the British Society of Gastroenterology. This Priority Setting Partnership would not have been possible without the patients, current and bereaved carers, health and social care professionals, organisations and patient groups who disseminated and participated in the survey, prioritisation and workshop. The British Liver Trust was a key partner, helping us to engage with patients. The Alcohol Health Alliance enabled us to engage with a variety of useful organisations. Thank you all for your time and participation.

The National Institute for Health Research would like to thank the members of the Steering Group for all of their valuable input, Sheela Upadhyaya, JLA Adviser, for independently facilitating the partnership, and Amy Street for coordinating the project.



When in 2014 I was asked by the James Lind Alliance to join the Steering Group on Alcohol-Related Liver Disease (ARLD) as a patient representative member I was delighted to take on this role. From personal experience I know only too well the damage that can be caused by heavy drinking. For a number of years alcohol was the only important thing in my life – was my life – and nothing else mattered. Because of this my career came to an abrupt end. I was fortunate that with a great deal of medical help I was able to detoxify at the eleventh hour before I suffered irreversible liver damage. Many people who drink heavily are not so lucky and may suffer from ARLD, making it such an important and overdue area of research.

Through my involvement as a member of the Steering Group, I bring the patient's viewpoint and experience to the table, introducing different perspectives and hopefully leading to a greater understanding of the needs and concerns of patients. This PSP is an invaluable opportunity for patients' voices to be heard and their pressures, fears, and needs to be understood. Taking these factors into consideration makes a significant contribution to choosing the "Top 10" questions to be examined and answered by this vital research.

These chosen ten questions make it clear which areas most require research to be focused on them. This should lead to an improved treatment outcome for the serious and damaging condition of ARLD.

Diane Goslar, Steering Group Member, ARLD PSP



Diane Goslar,
patient representative on the
Priority Setting Partnership
Steering Group

1. Introduction: Why are research priorities for alcohol-related liver disease so important?

Alcohol-related liver disease accounts for the majority of UK liver disease, which is the third most common cause of premature death in the UK. It has had disproportionately little research attention or spending in the past, despite its impact on patients and their families, and there are still many questions about the diagnosis, treatment and care of the disease that remain unanswered.

Traditionally, the focus of medical research is decided by funders and researchers. There is often a mismatch between what gets researched and what would actually make a real difference to the lives of patients. The James Lind Alliance (JLA) offers a process to ask patients, carers and health professionals to identify and then prioritise the unanswered questions that concern them most. In 2014, the National Institute for Health Research (NIHR) asked the JLA to run a Priority Setting Partnership (PSP) to find unanswered questions about the prevention, diagnosis, treatment and care of alcohol-related liver disease that are important to the people it affects. This is the first known PSP involving an alcohol-related condition.

This report explains the process that was followed to reach the agreed list of research priorities, what the priorities were and who was involved to make sure that it was independent and fair.

Abbreviations

ARLD Alcohol-related liver disease

BSG British Society of Gastroenterology

JLA James Lind Alliance

NIHR National Institute for Health Research

PSP Priority Setting Partnership

About alcohol-related liver disease

Alcohol-related liver disease can be a range of liver damage varying from simple fatty liver, through fibrosis, to cirrhosis, portal hypertension and chronic liver failure, frequently accompanied by sudden episodes of acute or chronic cholestatic liver failure (termed alcoholic hepatitis).



“Alcohol-related liver disease is an important area for research and a growing problem for the population. Widespread in the UK, the number of people with alcohol-related liver disease has been increasing over the last few decades because of increasing levels of alcohol misuse. Death rates linked to alcohol-related liver disease have risen considerably in this time and alcohol is now one of the most common causes of death in the UK, along with smoking and high blood pressure. It’s vital that we bring together patients, carers and clinicians to decide jointly what the priorities for research are in this area, and the NIHR is pleased to support the James Lind Alliance in doing so.”

Professor Dame Sally C. Davies, Chief Medical Officer for England



“The gap between the burden of liver disease from alcohol and research efforts in comparison to other causes of liver damage has been stark, and so I really welcome this initiative. In particular it is good to see an emphasis on research that is important to patients.”

Professor Sir Ian Gilmore, Chair, Alcohol Health Alliance UK

“Liver disease is currently the fifth biggest killer disease in the UK and still the most common cause of liver disease is alcohol related - consequently this Priority Setting Partnership is extremely important in developing the most appropriate research to benefit those with and affected by alcohol-related liver disease (ARLD) and support all issues relating to ARLD from prevention and early detection through to best possible treatment and care.”

Andrew Langford, Chief Executive, British Liver Trust



2. The Top 10 priority areas for future research

- 1.** What are the most effective ways to help people with alcohol-related liver disease stop drinking?
- 2.** What are the most effective ways of delivering healthcare education and information about excessive alcohol consumption, the warning signs and the risks of alcohol-related liver disease to different demographics (including young people)?
- 3.** What is the most effective model of community-based care for patients with alcohol-related liver disease?
- 4.** What is the patient's experience of alcohol-related liver disease?
- 5.** Do attitudes to perceived 'self-induced illness' amongst healthcare professionals affect treatment, care provision and compassion for individuals with alcohol-related liver disease?
- 6.** What are the most effective strategies to reduce the risk of alcohol-related liver disease in heavy drinkers?
- 7.** Does the stigma associated with alcohol misuse affect the willingness of people with alcohol-related liver disease to ask for help?
- 8.** What interventions improve survival in individuals with complications of advanced alcohol-related cirrhosis?
- 9.** How should depression be managed in the context of alcohol-related liver disease?
- 10.** What models of involvement of palliative care services in advanced alcohol-related liver disease are most beneficial?

1.

What are the most effective ways to help people with alcohol-related liver disease stop drinking?

It is widely accepted that stopping drinking alcohol is the most important first step in treating alcohol-related liver disease, yet the most effective interventions, whether psychological or pharmacological, are uncertain. Greater evidence of how well abstinence interventions work could lead to their increased use, which is currently woefully low. Examples of the original questions which helped define this overall uncertainty are:

“What are the reasons why so very, very few ARLD patients are offered help with alcohol abstinence given that this aetiology is often a clinical manifestation and recovery can only be expected with this help?”

“There is little certainty about which treatments are available to people affected by alcohol-related liver disease that usefully (i.e. that there is a good evidence base of efficacy for) reduce alcohol consumption - and therefore ongoing disease progress. In particular, patients hospitalised with complications of cirrhosis, who are most at risk and who benefit most from stopping drinking, are excluded from most trials. There is one trial of baclofen, but no other agents with a role in alcohol relapse prevention have any evidence base yet. Given that the STOPAH study confirmed that resuming alcohol intake was the major cause of mortality in alcoholic hepatitis there is an urgent need for such studies.”

2.

What are the most effective ways of delivering healthcare education and information about excessive alcohol consumption, the warning signs and the risks of alcohol-related liver disease to different demographics (including young people)?

Targeted healthcare education and information is a crucially important aspect of prevention due to widespread lack of knowledge, including many misconceptions, around alcohol-related liver disease and the risks associated with alcohol consumption. It covers establishing the most impactful messages, which may vary by demographics, and how best to deliver these: when, where and by whom. The risk to young people is a particular concern so the best way to engage young people, including the possible involvement of schools, needs to be addressed. Examples of the original questions which helped define this overall uncertainty are:

“How can you educate people about the dangers of alcohol without appearing to preach?”

“How are health professionals trying to make people aware of the addictive nature of regular consumption of alcohol?”

“Does early education of risks associated with alcohol reduce alcohol problems developing in young people?”

3.

What is the most effective model of community-based care for patients with alcohol-related liver disease?

The organisation and effectiveness of care and support in the home or community for patients with ARLD are important issues. There are two aspects to the care required in the community for this patient group. Firstly, support and input to facilitate and maintain abstinence from alcohol and secondly, monitoring of established liver disease. Care and support cannot solely be provided at hospital appointments and to be more successful needs to be delivered at, or closer to, home. Examples of the original questions which helped define this overall uncertainty are:

“What care models work best to support people who cannot stop drinking and their carers?”

“How does the structure of community alcoholic support services impact on the outcome of those with alcohol dependence, including those with alcohol-related liver disease?”

“Are there enough ARLD nurses available to support patients at GP practices or local support groups?”

“Currently most alcohol services will not provide input for people who continue to drink yet these are the people most at risk of serious health outcomes.”

“Which services in the community are most able to prevent alcohol-related liver disease?”

“How can we offer better support including outreaching more into the house?”

4.

What is the patient’s experience of alcohol-related liver disease?

Healthcare professionals looking after people with alcohol-related liver disease may have specific concerns and issues they feel it is important to address, but these may not match, or even overlap with, the patients’ concerns. A diagnosis of alcohol-related liver disease can affect other aspects of a person’s physical or mental health, and their relationships or interaction with members of their family and wider social circle. Examples of the original questions which helped define this overall uncertainty are:

“How does reported quality of life of ARLD patients compare to others with other physical disorders or conditions?”

“How do persons experience the diagnosis of ARLD within a medical, family and social context?”

“What are the symptom control and psychosocial needs of these patients?”

5.

Do attitudes to perceived 'self-induced illness' amongst healthcare professionals affect treatment, care provision and compassion for individuals with alcohol-related liver disease?

Stigmatisation of ARLD patients by the healthcare profession is of concern not just to patients/carers but also to professionals themselves. Understanding the prevalence and effect of this discrimination is the first step towards changing attitudes to ensure ARLD patients are properly cared for, resulting in more favourable outcomes. Examples of the original questions which helped define this overall uncertainty are:

"Is ARLD put as a lower priority because it is deemed self-inflicted?"

"Are people with ARLD treated as well as people with non-ARLD?"

"I have perceived at different times a lack of interest in actively managing the care of patients with alcohol-related liver disease because they have it in their power to make the single biggest difference to their health."

"It is important to understand the impact of such attitudes on treatment access and outcomes and how this issue may best be addressed. Compassion, dignity and respect given to patients can help them on a road to feeling safe to stop drinking so how can practitioners manage this?"

"What effect does the attitude of senior clinicians towards ARLD (i.e. sympathetic as a clinical aetiology or a 'self-inflicted' attitude) have on the mortality or positive outcome of their patients?"

6.

What are the most effective strategies to reduce the risk of alcohol-related liver disease in heavy drinkers?

This is an important question because it encompasses not just reduction in drinking but other measures and strategies which might help reduce the risk of ARLD in drinkers, for whom total abstinence is not always achievable. Examples of the original questions which helped define this overall uncertainty are:

"What are the preventive methods for alcohol-related liver disease?"

"Is prevention simply to stop drinking because that's not realistic."

"What could I have done to help prevent the onset of ARLD?"

"I have stopped taking any alcohol now I have been drinking quite heavily (mostly evenings) for over 20 years. What else can I do to help my liver function?"

"If u r a casual drinker, is there something to do to prevent it?"

7.**Does the stigma associated with alcohol misuse affect the willingness of people with alcohol-related liver disease to ask for help?**

A number of people who responded to the questionnaire felt that there is a prevalent attitude that this illness is self-induced, and that there is therefore little sympathy towards patients from the general population (including friends, family and work colleagues) and healthcare professionals. It was felt important to try to find out to what extent this stigma might be an obstacle, stopping people at risk of alcohol-related liver disease from seeking advice or support at an earlier stage when any harm can be better managed. Stigmatisation of patients with alcohol problems is seen as an issue by professionals, and to an extent by those using health services. Examples of the original questions which helped define this overall uncertainty are:

“What more can be done to ease stigma and prejudice towards people with alcohol issues to allow them to come forward for help more readily and before major damage has been caused?”

“Medics / Consultants are too quick to condemn and make the person feel inadequate because they have a drink problem making it more difficult for the person to ask for help and admit it.”

8.**What interventions improve survival in individuals with complications of advanced alcohol-related cirrhosis?**

Although it was recognised that important questions relate to detection of early alcohol-related liver disease and prevention of advanced disease, there was also an awareness that a very high number of people, often young, die in hospital with very severe alcohol-related liver disease. The term used covers a combination of complications of advanced alcohol-related liver disease, including severe alcohol-related hepatitis as well as complications of cirrhosis. This question therefore was felt to be of huge importance in attempting to improve survival in this condition. Specific areas of uncertainty were:

“Which patients with alcohol-related liver disease should be given long-term antibiotic prophylaxis against spontaneous bacterial peritonitis?”

“What is the optimal fluid resuscitation in patients with alcohol-related liver disease who develop sepsis?”

9.**How should depression be managed in the context of alcohol-related liver disease?**

A common feature of people who drink heavily is the presence of depression. This is sometimes a result of the heavy drinking, but can often contribute to a person starting to drink heavily in the first place. The development of a better understanding of how best to address this common combination of problems was felt to be important. This is a straightforward question related to the need to be aware that depression can be both a cause of, and result of, heavy drinking.

What models of involvement of palliative care services in advanced alcohol-related liver disease are most beneficial?

Death from alcohol-related liver disease is the most common cause of a liver-related death in the UK. Despite this, for people with severe alcohol-related liver disease, as well as other forms of cirrhosis, palliative care support is rarely provided in hospital or in the community, as palliative care services have most commonly been used only in the context of a cancer diagnosis. We need to better understand how hepatology care, in combination with palliative care, can best look after people with severe alcohol-related liver disease who have a high chance of dying. This would be of potentially significant benefit to patients. Examples of the original questions which helped define this overall uncertainty are:

“What are the barriers to this group of patients receiving palliative care?”

“How can we define better which patients need end of life care? This is a challenge in ARLD as if abstinence is achieved recovery may occur.”

“How can these patient services be developed/funded to allow them to stay at home for end of life care instead of having to go to hospital?”

3. Additional priority areas for research agreed by the PSP

11. Are there any early signs of alcohol-related liver disease?
12. What are the factors that determine who gets significant/advanced alcohol-related liver disease (affect progression)?
13. What effect would greater alcohol-related liver disease education/training of GPs and secondary care clinicians have on the mortality outcome of alcohol-related liver disease patients?
14. What is the relationship between alcohol-related liver disease and mental illness?
15. What dietary recommendations or supplements (including herbal and vitamins) are beneficial in patients at risk of or with established alcohol-related liver disease?
16. What effect does combining treatment of the liver disease with psychiatric support have on prognosis/mortality?
17. What are the most effective messages and how are they best delivered in helping a patient with alcohol-related liver disease understand the condition and the importance of abstinence?
18. Are there any effective treatments for alcohol-related liver disease apart from abstinence from alcohol?
19. What are the obstacles for individuals to modification of their alcohol consumption?
20. What lifestyle interventions improve outcomes in alcohol-related liver disease?
21. What level and pattern of drinking behaviour affects the risk of getting alcohol-related liver disease (taking into account other risk factors for alcohol-related liver disease)?
22. To what degree is established liver disease reversible?
23. What are the most effective interventions delivered in combined clinics in the setting of secondary care for alcohol-related liver disease?
24. What interventions improve survival in severe alcohol-related hepatitis?
25. Is there a difference between the outcome of alcohol-related liver disease patients treated by specialised liver disease units/hepatologists versus general gastroenterologists?

4. The remaining 20 unanswered questions

These were amongst the 45 unanswered questions identified by patients, carers and health professionals who responded to the original survey, but they were not shortlisted for the final priority setting workshop. They are listed here in no order of priority:

- Do specific interventions involving family members/social support improve maintenance of alcohol abstinence in individuals with alcohol-related liver disease?
- Does the type of alcohol (e.g. wine, beer, spirits etc.) affect the risk, or progression, of alcohol-related liver disease?
- Does the media portray excessive drinking in an inappropriately positive way and does this affect behaviour?
- What is the impact on drinking behaviour of the ready availability of alcohol in social environments, at home and elsewhere?
- Why is alcohol-related liver disease more prevalent in low socio-economic groups?
- What role do dietary factors have in susceptibility and prevention to alcohol-related liver disease?
- What interventions best aid patients with alcohol-related liver disease maintain and manage employment?
- What is the best screening test for alcohol-related liver disease and how should it be applied?
- Should there be routine screening for alcohol-related liver disease?
- Should screening for primary liver cancer in patients with alcohol-related liver disease be routinely performed?

-
- What is the best method for diagnosing alcohol-related liver disease and where is this best done?
 - What are the needs and best methods for delivering support to care-givers both for themselves and the patient with alcohol-related liver disease?
 - What are the optimal ways of staging alcohol-related liver disease?
 - What medications for other conditions are the most effective and safe for use in patients with alcohol-related liver disease?
 - What are the best means of diagnosing hepatic encephalopathy (HE)/what is the role of new methods of diagnosing HE?
 - What factors in a person with alcohol-related liver disease indicate a favourable outcome following liver transplantation?
 - What treatments are safe and effective in treating alcohol withdrawal in patients with alcohol-related liver disease?
 - What are the appropriate quality markers for care in alcohol-related liver disease?
 - Which liver-assist machines can help survival to liver transplantation?
 - What is the best way of identifying which patients with severe alcohol-related liver disease needing intensive care support will survive?

Out-of-scope themes

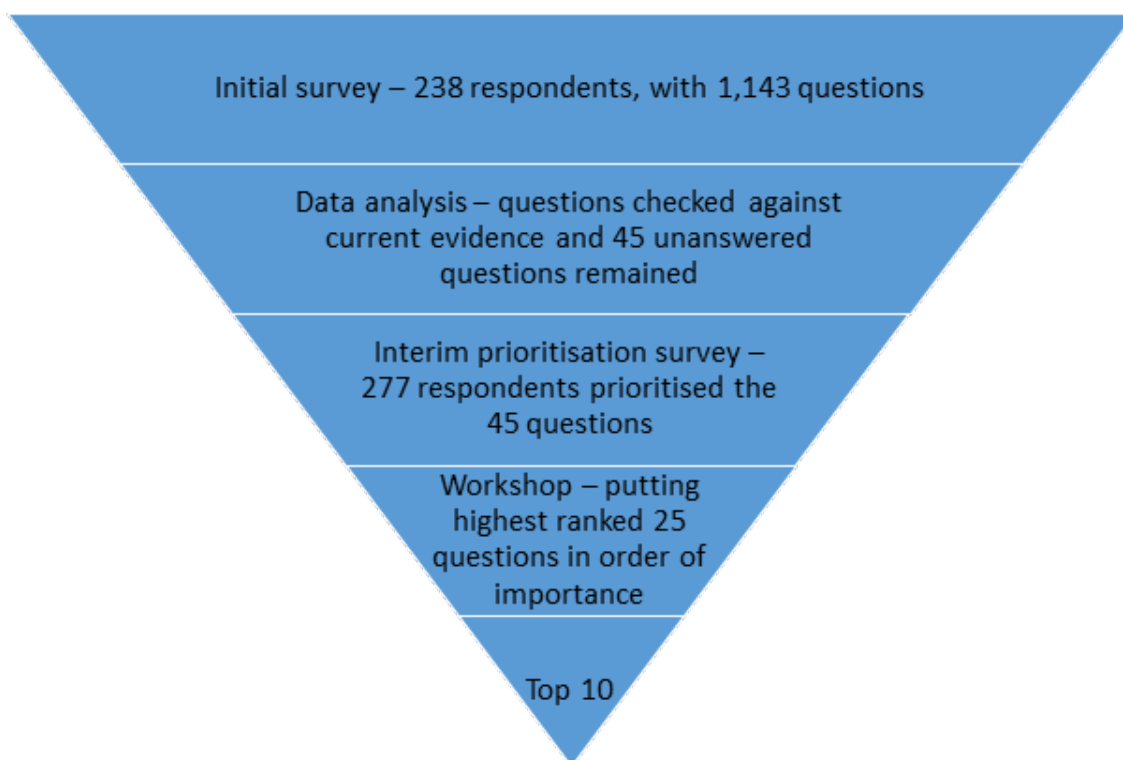
In response to the first survey to gather questions about ARLD, 326 questions were submitted that were outside the scope of the priority setting exercise. These were questions that were important to patients, carers and clinicians but were not included in the prioritisation exercise.

They related mostly to policy issues such as labelling and pricing, health service quality and personal observations.

There is commitment from the organisations represented on the ARLD Steering Group to review and consider how to make use of these questions.

5. The priority setting process

How we reached the Top 10 alcohol-related liver disease research priorities



Stage 1: Establishing the PSP and getting people involved

James Lind Alliance PSPs follow a tried-and-tested method which helps patients, carers and clinicians to set research priorities in equal partnership. The method is explained in detail in the JLA Guidebook at www.jla.nihr.ac.uk/jla-guidebook

This PSP commenced with an initial awareness meeting of a full range of ARLD interested parties in April 2014, following which a Steering Group was formed to represent the perspectives and interests of patients, carers and healthcare professionals. The Steering Group met monthly from October 2014. It agreed the scope and protocol of the project. It also drew up a list of individuals and organisations to invite as partners (those who could represent and communicate with groups of patients and clinicians) for maximum engagement from everyone with an interest in ARLD. The list of Steering Group members is included at Appendix A.

What was the scope of the PSP?

The Steering Group agreed that the scope of this PSP would cover primary, secondary and tertiary care. It was agreed that healthcare interventions would cover treatment, prevention, diagnosis, and service considerations and that the following groups of uncertainties would be within the scope of the PSP:

- Interventions for ARLD: Physical interventions, drugs, surgery, psychological, psychosocial, individual / community re-enforcement / education / workplace, diet and nutrition
- Addiction interventions
- Co-morbidities associated with ARLD
- Diagnosis and prevention
- Person centred care: patient pathway, commissioning, palliative care, service delivery
- Primary care
- Secondary care

5. The priority setting process

It was agreed that the following groups of uncertainties would be outside of the scope of this PSP:

- Non-alcohol fatty liver
- Other drug related liver disease
- Aetiology (causes of ARLD)
- Prognosis testing
- Any issues relating to changing policy
- Social research issues

Stage 2: Gathering questions

A PSP needs to collect from as wide a range as possible of patients, carers and health professionals all of the uncertainties they have which might be addressed through research.

A questionnaire was drawn up to gather these and was piloted by members of the Steering Group, following a template which had been used successfully by other JLA PSPs. Once finalised, the survey appeared on the PSP website and the link to this was promoted as widely as possible between June and September 2015. Paper copies were also available which could be returned by freepost.

The survey asked for responses from:

- People at risk of, or worried about alcohol-related liver disease
- People with alcohol-related liver disease, now or in the past
- Carers or family members of someone with alcohol-related liver disease, now or in the past
- Bereaved carers or family members of someone with alcohol-related liver disease
- Healthcare professionals or support workers, including community pharmacists and GPs
- Organisations representing the interests of people with alcohol-related liver disease.

An initial email was sent to the health professionals and patient and carer support groups that we were aware of, asking them to share the survey with their contacts. Requests for postal distribution were also taken. Details of the survey were made available at a number of national meetings and conferences and it was promoted via Twitter. A focus group of ARLD patients and family carers was also held to supplement responses to the questionnaire.

5. The priority setting process

Patients, carers and health professionals were asked:

- What questions, if any, do you have about the prevention of alcohol-related liver disease?
- What questions, if any, do you have about the diagnosis of alcohol-related liver disease?
- What questions, if any, do you have about the care and support of people with or affected by alcohol-related liver disease?
- What questions, if any, do you have about the treatment of alcohol-related liver disease?
- Do you have any other questions relating to alcohol-related liver disease?

The questionnaire can be seen at www.nihr.ac.uk/research-and-impact/research/the-james-lind-alliance/alcohol-related-liver-disease-priority-setting-partnership/

The survey received 238 responses, comprising 74 patients, 33 carers, 110 health professionals and 21 organisations / others. More details about who responded to the survey can be found in Appendix B.

Stage 3: Sorting the responses

From the 238 survey responses, 1,143 individual questions about ARLD were extracted. Those which fell out of the scope of the PSP were recorded. Of the in-scope-data, similar questions within each theme were combined and checked against existing research evidence to confirm that they had not already been definitively answered by research. This resulted in 45 unanswered questions.

Stage 4: Interim prioritisation

The 45 unanswered questions from Stage 3 were published in a second online and paper survey open from June - August 2016, where patients, carers and clinicians were asked to select the 10 most important. The survey was promoted widely, including to all those who had responded to the initial questionnaire. 277 patients, carers and health professionals responded and told us the most important questions in their experience.

In order to ensure that we had responses from a wide range of people we asked respondents to tell us a few details about themselves. Of the 277 who responded to the survey 269 answered the questions about themselves. More information about this is in the charts in Appendix B.

Ranking of all 45 questions was calculated through frequency of choice, weighted to give equal balance by patients / carers versus healthcare professionals / others. The Top 25 questions were then taken to a workshop to be discussed and prioritised.

A copy of the survey can be seen at www.nihr.ac.uk/research-and-impact/research/the-james-lind-alliance/alcohol-related-liver-disease-priority-setting-partnership/

5. The priority setting process

Stage 5: Agreeing the Top 10 priorities

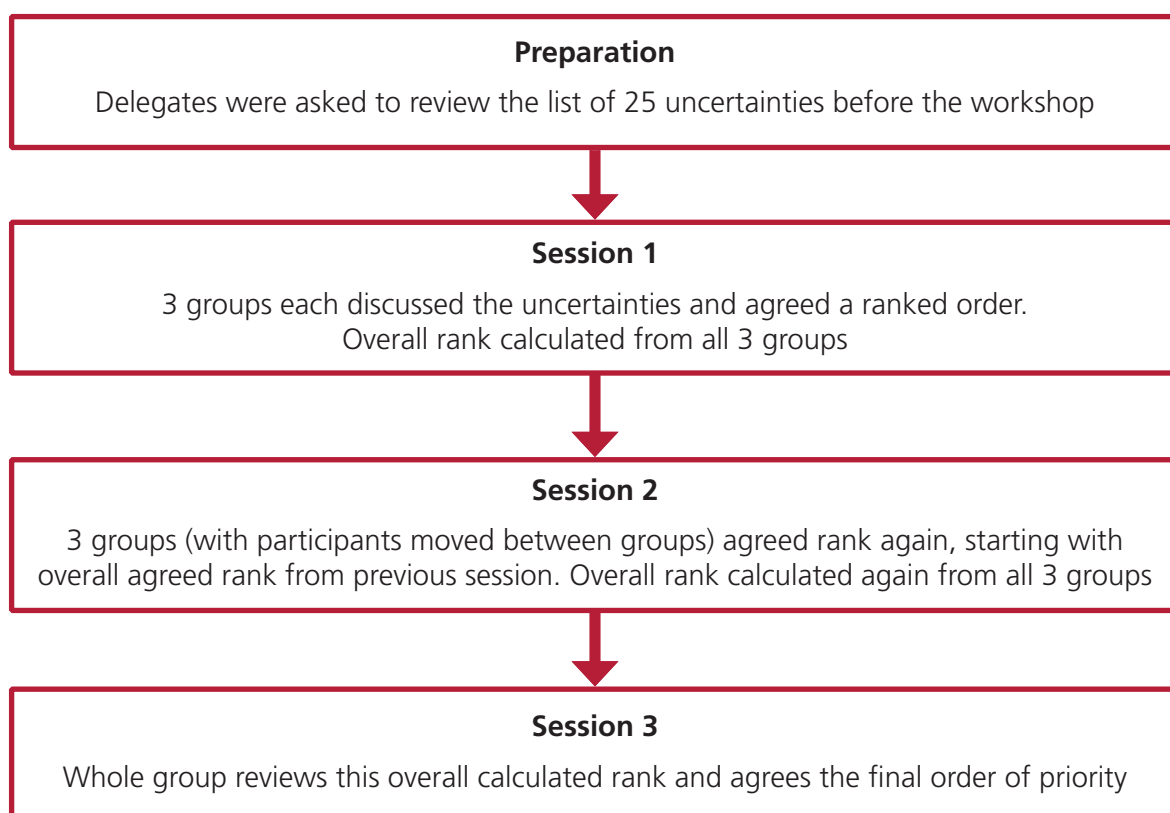
In a final priority setting workshop in September 2016, patients, carers and health professionals shared their knowledge and experience in discussing the 25 questions that had been voted as the most important. They jointly agreed on what the final order of priority should be, including the Top 10 most important questions. The final workshop comprised 5 patients, 1 Senior British Liver Trust employee representing patients, 3 carers and 10 health professionals, as well as JLA facilitators.

Health professionals at the workshop represented: Nursing (3), Gastroenterology/Hepatology (2), Psychiatry (2), General Practice (1), Dietetics (1), Pharmacy (1).

“We covered some very complex issues regarding alcohol-related liver disease... Using the premise that everyone was an equal partner in this process meant that all views were acknowledged purposefully as we moved forward to agree our priorities. It wasn't easy but it was very rewarding. To listen and learn from each other whilst respecting each other's knowledge and viewpoint was key to such a very successful day... This illness and its consequences, is without doubt one of the most serious issues of our time...”

Dawn Pallant, who attended the final priority setting workshop.

The final workshop process:



5. The priority setting process

Challenges and limitations of the PSP

Ensuring that the right people were involved in this Priority Setting Partnership presented a particular challenge for the condition of alcohol-related liver disease. ARLD has no well-recognised disease-specific society. The stigma attached to the condition may have made some patients reluctant to engage with the exercise. The complexity of ARLD, which in reality encompasses the two conditions of alcohol misuse and the consequent liver disease, presented a further challenge.

In order to secure patient input, clinicians asked patients directly in clinics if they would complete a paper survey. This helped engage patients.

Another limitation of this PSP is that some groups where ARLD is prevalent (e.g. south Indian, Chinese and eastern European groups), were not specifically targeted as we could not find a route to promote the survey within the timeframe.



Image right:
Discussions at the final workshop,
September 2016.

6. What's next?

The Top 10 was formally announced on 15th November 2016. The JLA will work with Steering Group members and the NIHR to promote the uncertainties to researchers and research funders. The NIHR will review the uncertainties for suitability for its research commissioning programmes.

What can you do to help?

Use the priorities

People with alcohol-related liver disease, their families and health professionals have taken time to tell the PSP what questions they want to see answered by research. As a medical research community, we owe it to them to make every effort to answer these.

Tell us how you are using the priorities

The more information there is about how the alcohol-related liver disease priorities are influencing what research is happening, the better the NIHR can understand the impact of its investment in this PSP. This will also help future PSPs to learn from past successes and become more effective.

Tell other people about the priorities

The more people who know about the alcohol-related liver disease research priorities, the more likely organisations and individual researchers are to tackle the questions that patients, carers and clinicians have told us they want answered. Please help to spread the word about what needs to happen.

"The more we understand the priorities and concerns of people with alcohol-related liver disease, their carers and those health professionals treating them, the more we can ensure that the research that is funded is relevant to their needs. So I am delighted to see the results of the NIHR and BSG PSP have launched today. I hope it will be the basis for future research collaborations between patients, carers, health professionals and researchers leading to new ways to care for and treat people with this terrible disease."

Simon Denegri, NIHR National Director for Patients and the Public in Research

Appendix A: The Steering Group

Steering Group members were identified to oversee the Priority Setting Partnership process while representing the perspectives and interests of patients, carers and healthcare professionals. They approved the aims and objectives of the process, tested and ensured written materials were accessible to a range of audiences, helped disseminate survey materials and provided expert opinions on data analysis and evidence checking.

The group was chaired by Sheela Upadhyaya from the James Lind Alliance. Sheela was responsible for facilitating the process, ensuring that it followed the JLA principles of transparency and equal involvement of patients, carers and clinicians. The work of the Priority Setting Partnership was coordinated by Amy Street from the JLA team at the NIHR Evaluation, Trials and Studies Coordinating Centre, University of Southampton. Robin Harbour, an independent information specialist, carried out the survey analysis, evidence search and supported the drafting of potential research questions.

The Steering Group members were:

- **Dr Michael Allison**, Consultant Hepatologist.
- **Simran Arora**, Clinical Specialist, Hepatology / Liver Transplant Dietician.
- **Dr Jane Collier**, Consultant Hepatologist.
- **Aisling Considine**, Senior Liver Pharmacist.
- **Dr Ranjita Dhital**, Post-Doctoral Research Pharmacist.
- **Dr Carsten Grimm**, GP.
- **Diane Goslar**, involved in a number of groups and committees in the Royal College of Psychiatrists, and also lectures at St. George's Medical School in South London. She attends an alcohol treatment centre now as an after-care patient.
- **Andrew Langford**, CEO of the British Liver Trust.
- **Beccy Maeso**, James Lind Alliance.
- **Dr Zul Mizra**, Emergency Medicine Consultant.
- **Lynn Owens**, Nurse Consultant - Alcohol services.
- **Dr Stephen Ryder**, Consultant Physician in Hepatology and Gastroenterology.

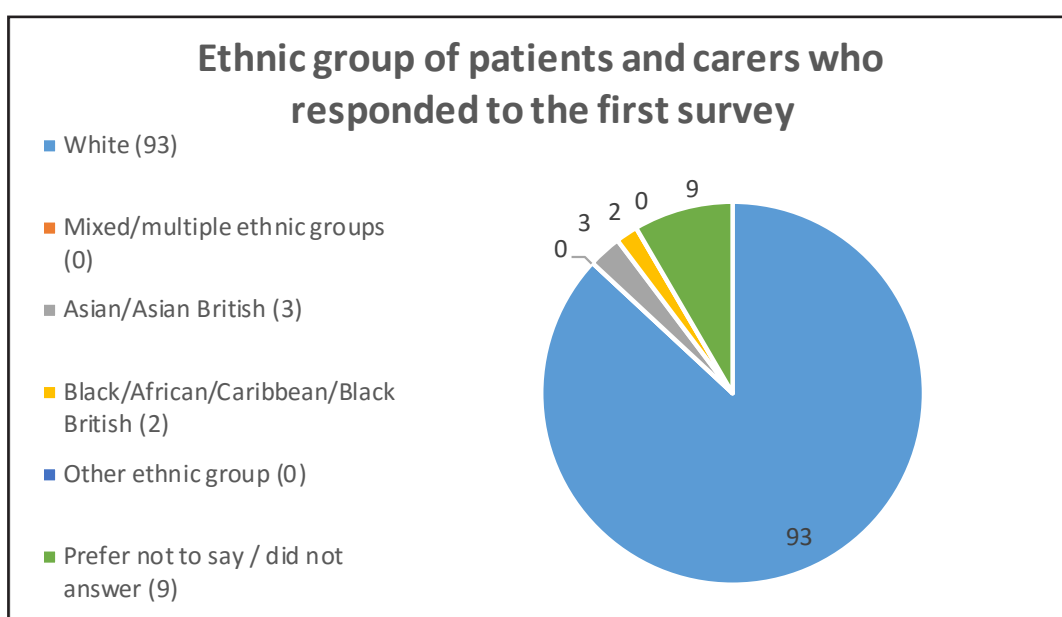
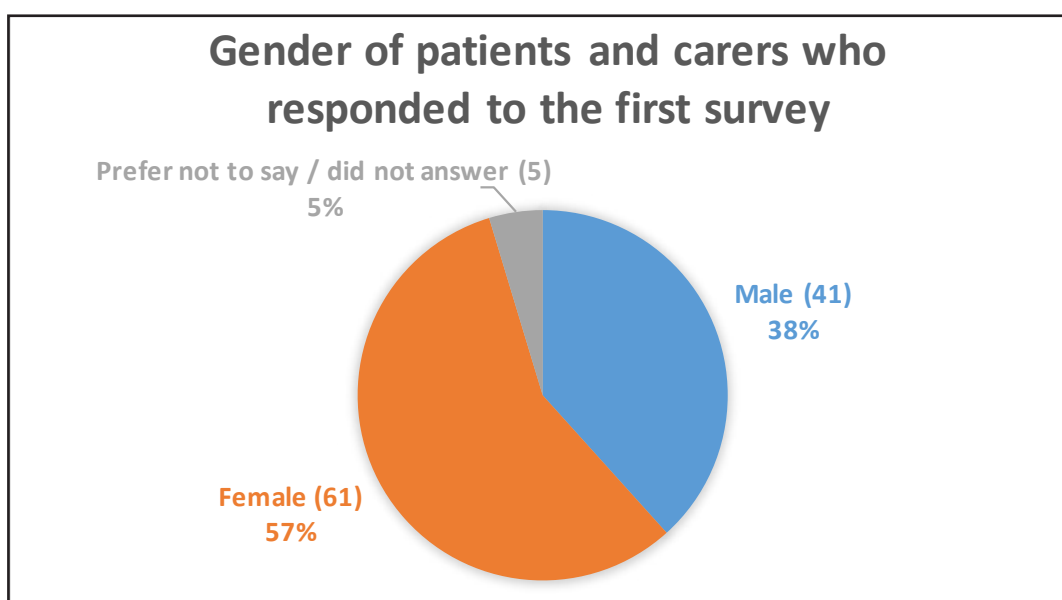
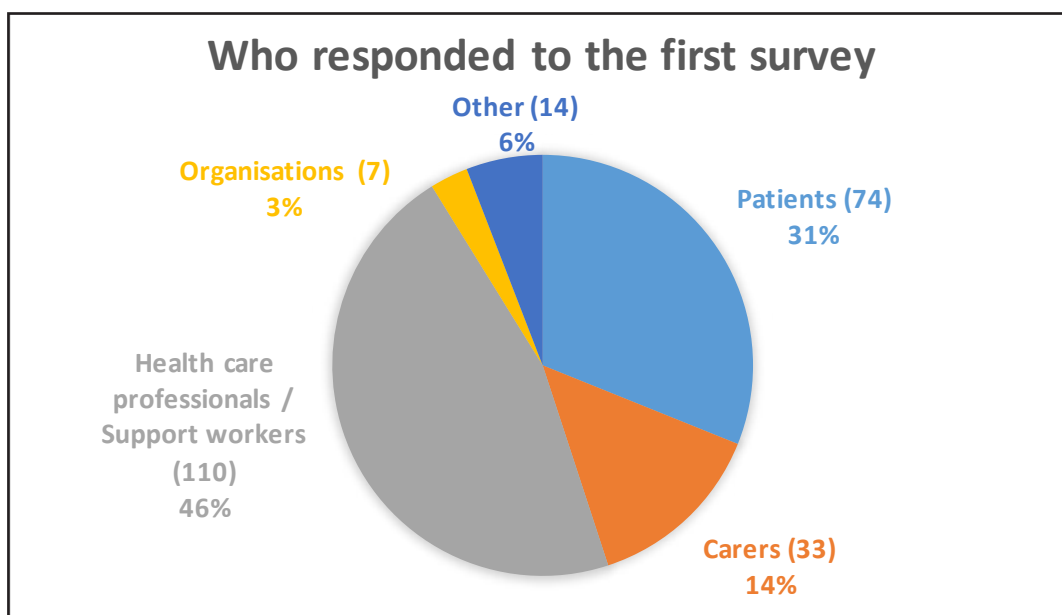
Appendix A: The Steering Group

- **Professor Nick Sheron**, Academic Hepatologist at the University of Southampton.
- **Dr Julia Sinclair**, Associate Professor in Psychiatry at the University of Southampton.
- **Amy Street**, James Lind Alliance.
- **Sheela Upadhyaya**, James Lind Alliance.
- **Ellie Walton**, Service user.
- **Lynda Waters**, a carer representative, who lost her partner to ARLD and is a Trustee of the British Liver Trust.
- **Dr Stephen Willott**, GP.

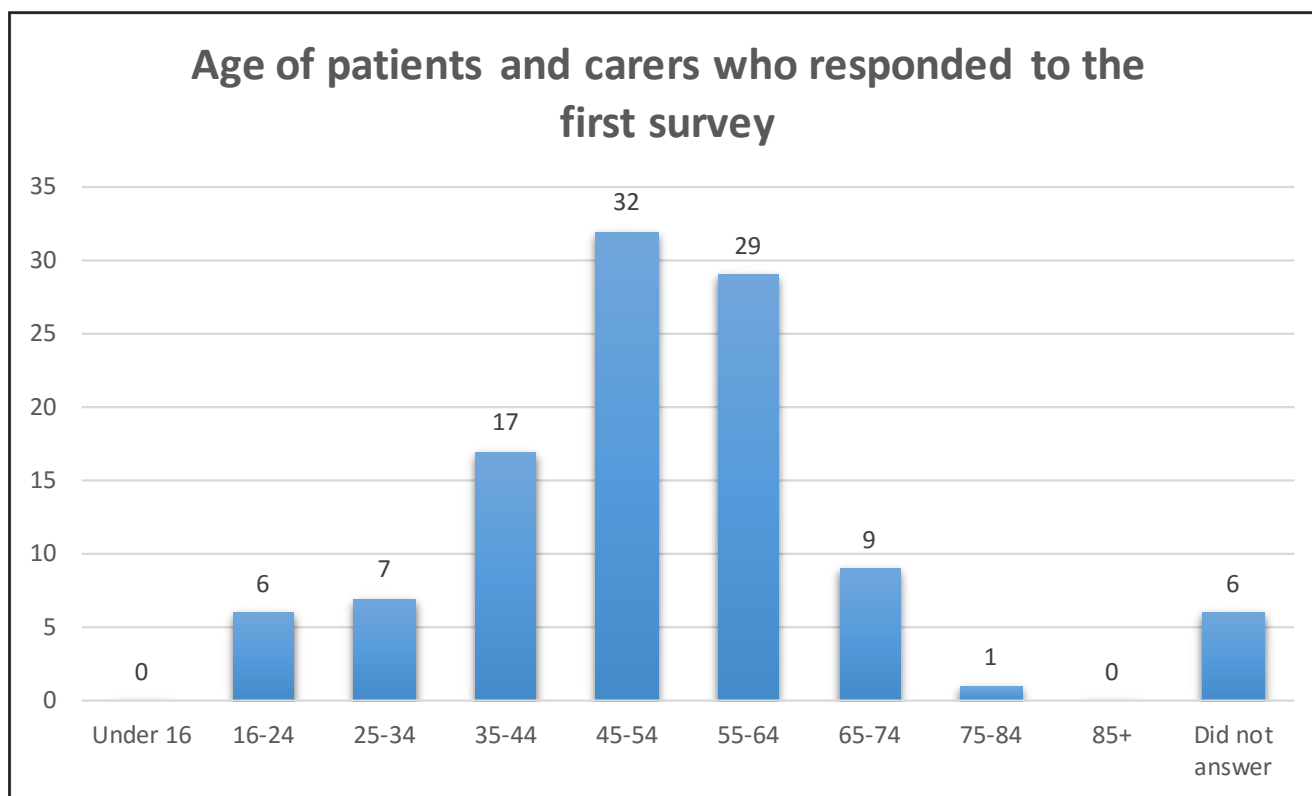
More information about members of the Steering Group, and the PSP protocol, can be found at www.nihr.ac.uk/research-and-impact/research/the-james-lind-alliance/alcohol-related-liver-disease-priority-setting-partnership/



Image right:
Discussions at the final workshop,
September 2016.



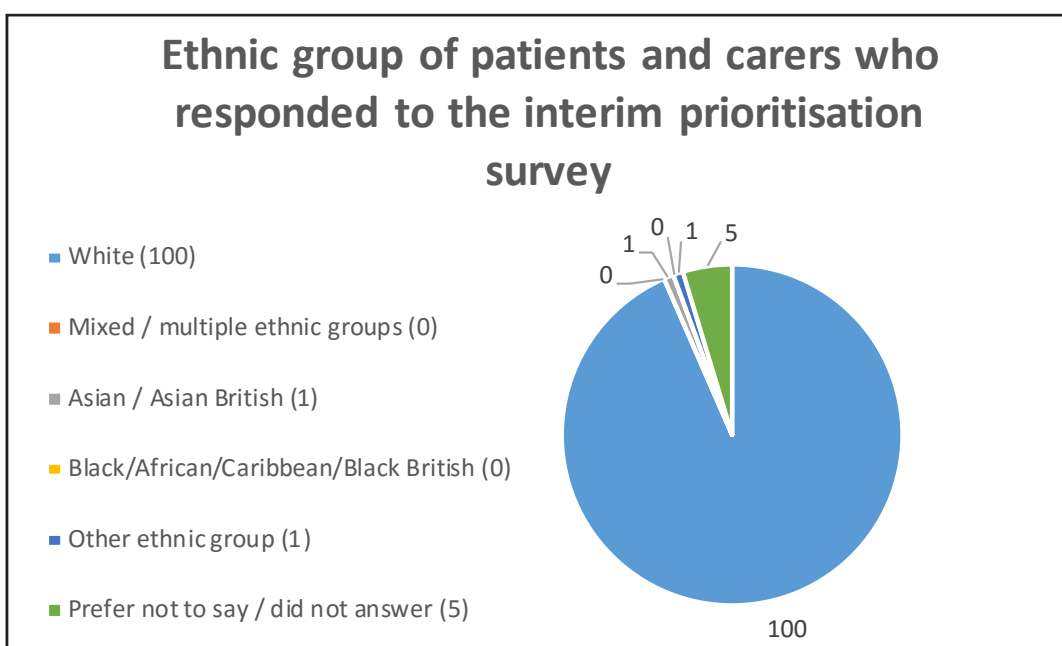
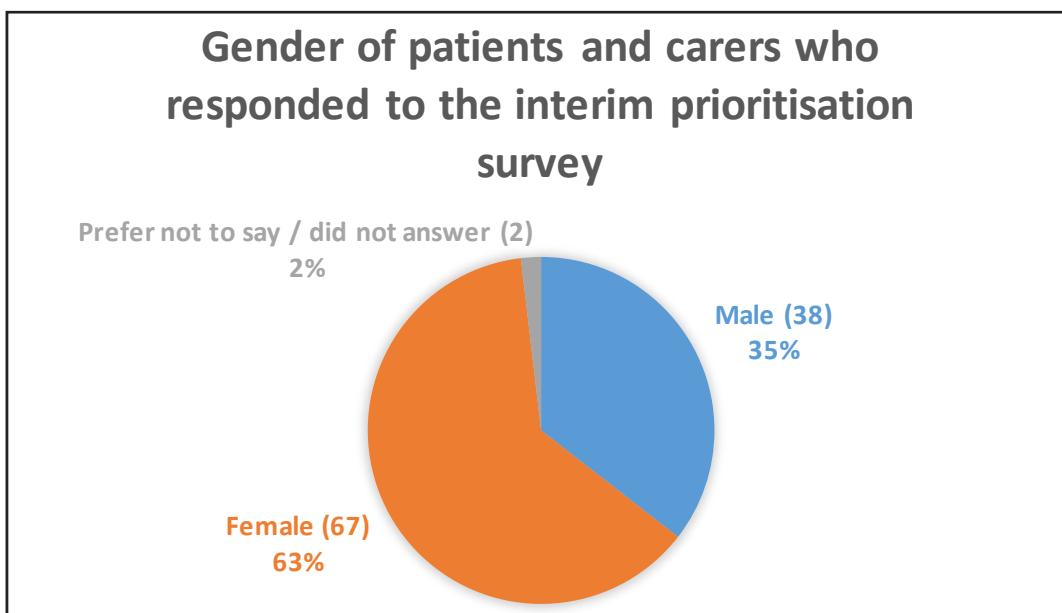
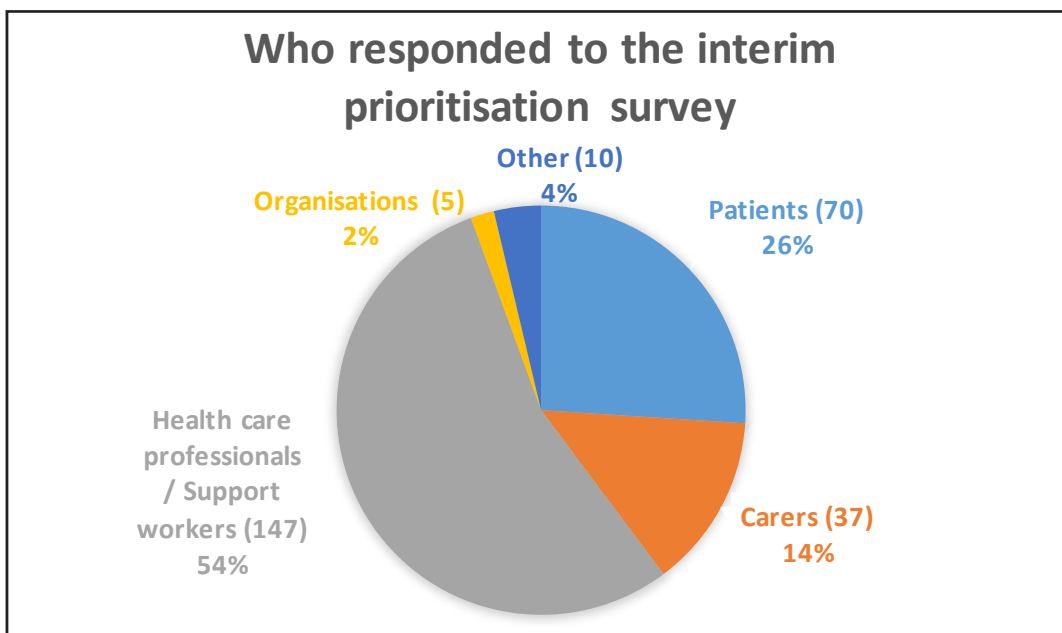
Appendix B: Who responded to the first survey?



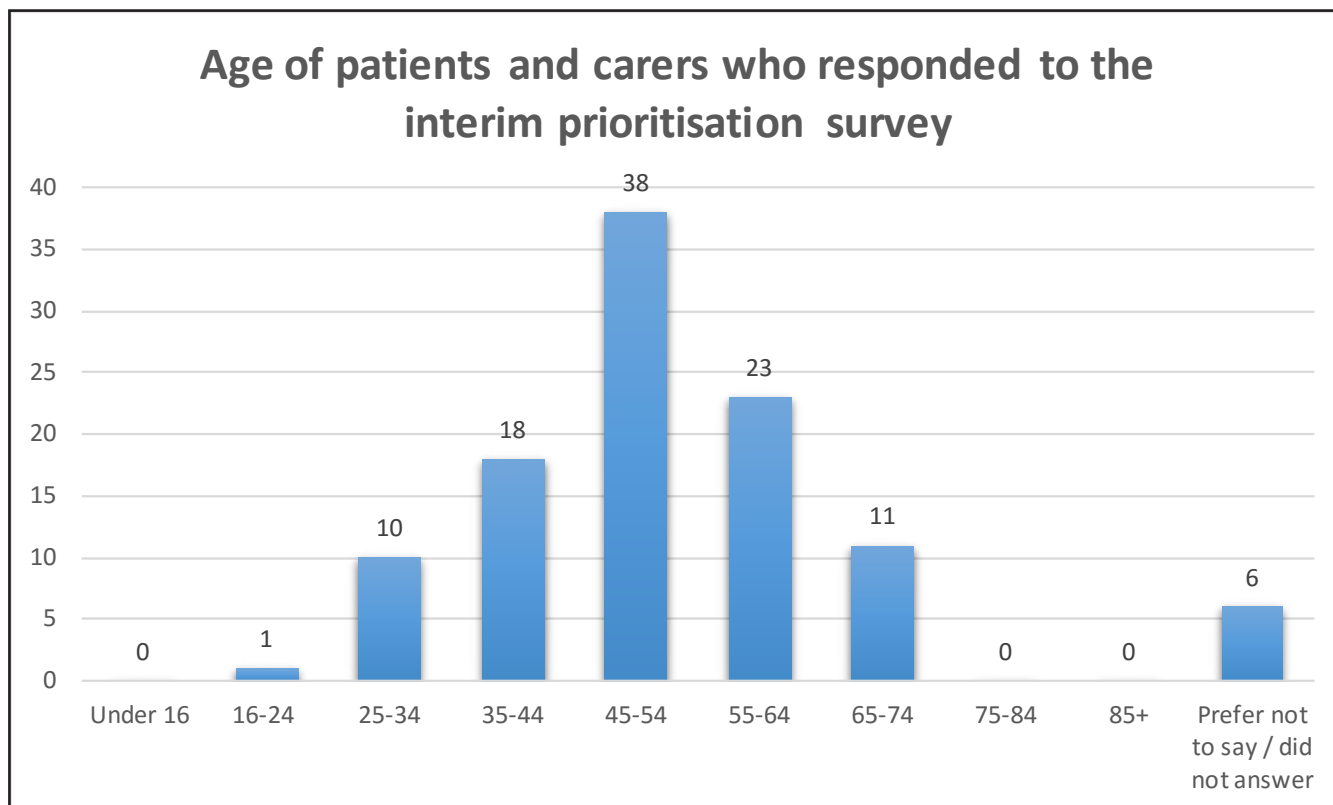
Types of health professionals who responded to the first survey

Doctor	52
Nurse	28
Allied Health Professional	12
Hospital Pharmacist	8
Social Worker	5
Community Pharmacist	3
Psychologist	2

In this PSP, when we refer to 'patients' we mean people with ARLD now or in the past, and people at risk of or worried about ARLD. 'Carers' includes current and bereaved carers or family members.



Appendix B: Who responded to the interim prioritisation survey?



Types of health or social care professionals who responded to the interim survey

Nurse	53
Doctor	49
Other	13
Allied Health Professional	8
Hospital Pharmacist	7
Psychiatrist	6
Community Pharmacist	3
Psychologist	3
Community Worker	1
Social Worker	1

We note that Psychiatrists could also be included in the category of Doctor. These were the categories agreed by the PSP Steering Group and therefore the demographics that were collected in this survey.

Appendix C: Resources involved

The direct costs of this PSP were in the region of £30,000, funded by the NIHR and the BSG, which includes the cost of a JLA Adviser to independently oversee the project, and an Information Specialist to analyse the survey responses, form the research questions and check existing research evidence. Administrative coordination was provided by JLA staff based within the NIHR Evaluation, Trials and Studies Coordinating Centre, University of Southampton.

Patients and carers on the Steering Group were offered an honorarium for their participation in Steering Group meetings. Expenses incurred by all Steering Group members when travelling to Steering Group meetings were reimbursed, as were expenses incurred by everyone who attended the final priority setting workshop.



Image left:
Discussions at the final workshop,
September 2016.

What is the James Lind Alliance (JLA)?

The JLA is an independent, internationally recognised non-profit organisation with an established, transparent process of bringing together people with health conditions, carers and healthcare professionals to identify and prioritise research needs, whilst taking into account existing evidence. They've worked with a wide range of health conditions, including diabetes, depression, bipolar, mesothelioma and asthma. JLA partnerships have often been successful in encouraging research spend in the areas identified by the process.

What are Priority Setting Partnerships?

These are groups of people – those with a particular health condition and organisations representing them, together with carers and healthcare professionals – who work together to identify and prioritise unanswered research questions.

Who was involved in the ARLD partnership?

The partnership was funded by the National Institute for Health Research and the British Society of Gastroenterology. It was overseen by a Steering Group made up of doctors, nurses, a psychiatrist, a pharmacist, patients, carers, the British Liver Trust, the British Society of Gastroenterology and JLA representatives, with support from partner organisations including Alcohol Research UK, Soberistas, The Royal College of Psychiatrists and Cranstoun. A full list of Steering Group members can be seen at Appendix A.

How do you know these are the true views of people affected by ARLD?

By involving partner organisations we were able to reach out to a wide range of individuals, families and professionals. Respondents' demographic data, including age, gender, ethnic group and location, were collected and monitored, and we targeted our communications to ensure that as far as possible, a diversity of responses was received. Health professionals responding to the survey were asked to indicate their role and the setting in which they worked, again to enable the targeting of under-represented groups. The Steering Group advised on any gaps and discussed strategies for addressing them.

Contact Information

For further information or support on alcohol-related liver disease, please contact The British Liver Trust on 0800 652 7330 or visit www.britishlivertrust.org.uk

For further information relating to this PSP please contact:

James Lind Alliance

National Institute for Health Research

Evaluation, Trials and Studies Coordinating Centre

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