

# Remeasuring the Units

An update on the organisation of alcohol-related liver disease services



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A report published by the National Confidential Enquiry into Patient Outcome and Death (2022)

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## BACKGROUND

Alcohol-related liver disease (ARLD) is an ongoing health concern. In 2021, 74% of deaths from ARLD occurred in hospital.<sup>[1]</sup> Furthermore, during the COVID-19 pandemic, rates of alcohol intake at potentially harmful levels increased markedly. Public Health England (PHE) reported that between March 2020 and March 2021, there was a 58.6% increase in people reporting that they were drinking at increasing and higher-risk levels (increasing risk >14 units per week, higher risk > 50 units per week (men), >35 units per week (women)).<sup>[2]</sup> The number of deaths from ARLD has also risen during this time,<sup>[3]</sup> highlighting the urgent need to prioritise care pathways for patients with ARLD.

In 2013, the NCEPOD report *'Measuring the units'*<sup>[4]</sup> examined the care of patients who died in hospital from ARLD. The report emphasised that admission with decompensated cirrhosis was a common medical presentation, with high (10-20%) in-hospital mortality. Alcohol dependence is often perceived as a lifestyle choice. However, it is a clinical diagnosis with implications for treatment, meaning that changing this perception is an important step in improving care provided. *'Measuring the units'* described a series of missed opportunities in relation to such care:

- Patients had often been to hospital at least once in the two years prior to the admission when they died, but not enough had been done about their harmful drinking at that time.
- There was a failure to screen adequately for harmful use of alcohol and, even when this was identified, patients were not referred for support.
- When patients were admitted with signs and symptoms of serious liver damage, there were opportunities to improve their care by doing simple things such as optimising fluid management and screening for, or treating, sepsis. These were often missed.
- Specialist review was often delayed or did not happen. When organ failure occurred and escalation of treatment was indicated, again the additional treatment that was needed was often not given.

*'Measuring the units'* made 28 recommendations to improve the reliability of care delivery and the organisation of hospital services for patients with ARLD. After the publication of the report, some immediate actions were taken. For example, the British Society of Gastroenterology and British Association for the Study of the Liver jointly developed a care - bundle for patients admitted to hospital with decompensated cirrhosis.<sup>[5]</sup> More recently, the National Liver Disease Intelligence Network (PHE) has used large scale data, to explore some of the same issues identified by NCEPOD.<sup>[6]</sup>

The short report presented here summarises the results of a survey undertaken across NHS hospitals in 2020/21 and a wider round table discussion on the topic that occurred in 2022 to discuss the survey findings and the current status of ARLD care. The report focuses on improvements that have been made across the system since *'Measuring the units'* was published and also highlights areas where known deficiencies in services and care remain.

# SURVEY and STAKEHOLDER GROUP SUMMARY

An online survey was run by NCEPOD in 2020/21, that related to 2019 data on alcohol-related liver disease (ARLD) services in hospitals in England, Wales and Northern Ireland. The purpose of the survey was to assess what real progress had been made in addressing specific recommendations made in '[Measuring the units](#)'. A round table discussion was then held with key stakeholders which helped to outline additional areas of improvement. It also highlighted that Alcohol Care Teams (ACTs) have increased in importance due to a rapid increase in both alcohol dependence and related harm over the last few years.

The results of the survey indicate that some progress has been made in the care of alcohol dependent patients.

- More ACTs have been established
- A decompensated chronic liver disease care bundle (endorsed by national specialist societies) has been developed.
- There has been progress in improving access to critical care in some hospitals.

However, unwarranted variations in care remain and there is further work to be done to:

- Increase the number of ACTs.
- Improve access to appropriate liver specialist care and to critical care when it is indicated.
- Improve consistent coding/data collection

It is hoped that the results of this survey, and the focus on other ongoing pieces of work, will help to drive the improvement needed in the provision of care for these patients.

The stakeholder group was of the opinion that:

- Accurate and consistent coding of ARLD is needed to assess the effectiveness of interventions
- Specific focus is needed on steps to reduce variations in care, including ensuring all hospitals are linked into a regional Liver Unit or Liver Transplant Unit through a liver disease clinical network. NHSE, Integrated Care Boards (ICBs), Welsh Government and the Department of health in Northern Ireland will be critical to the success of these.
- The provision of sustainable Alcohol Care Teams should be incorporated into standard medical care in all acute trusts/health boards.
- All patients with decompensated cirrhosis (of whatever aetiology) should be triaged to the care of a gastroenterologist or hepatologist.
- Guidance should be developed regarding the role of critical care support for patients with decompensated ARLD by critical care specialists and hepatologists.
- Care pathways that include early community alcohol support post-hospital discharge and early clinic follow-up should be established for patients with decompensated alcohol-related cirrhosis.

## Existing initiatives to improve patient care

The stakeholder group also raised awareness about several initiatives by other organisations which are either in place or planned with the aim of improving the care of patients with ARLD and are outlined below.

- **Cirrhosis and fibrosis tests for alcohol dependent patients (CQUIN indicator CCG9)<sup>[7]</sup>**

NICE Guidance recommends that people who drink alcohol at higher risk levels should receive a test for fibrosis and cirrhosis. The CQUIN indicator was introduced to improve the consistent investigation of patients at risk of ARLD. The aim is to increase the number of patients diagnosed at an early stage and accessing a pathway to deliver more effective treatment of alcohol dependence.

- **Management of patients with chronic liver disease admitted to hospital as an emergency, the UK Liver Alliance<sup>[8]</sup>**

The UK Liver Alliance is working across the liver disease community with patient groups, specialist societies, charities, medical royal colleges, NHS organisations and treatment providers. The aim is to detect liver disease earlier and thereby prevent more severe liver disease, to improve the care for patients with liver disease and to reduce mortality.

- **Decompensated cirrhosis discharge care bundle<sup>[5]</sup>**

A decompensated cirrhosis discharge bundle was developed to optimise hospital discharge with the aim of reducing variation in care. This bundle has now been endorsed by the British Society of Gastroenterology and the British Association for the Study of the Liver.

- **Optimal ACTs as part of an effective alcohol treatment system (NHS England and NHS Improvement with Public Health England)<sup>[9]</sup>**

This is aimed to support those in the NHS and local authorities involved in planning and commissioning hospital alcohol services and associated community services to secure optimal outcomes from existing services. It describes the case for optimising alcohol care teams (ACTs) as recommended for non-specialist acute hospitals in the NHS Long Term Plan.

- **ACT Core Service Descriptor<sup>[10]</sup>**

This is for NHS commissioners, acute trusts/health boards and their local partners wishing to implement or improve ACTs in order to deliver the optimal benefits in helping patients reduce alcohol-related harm. This guideline provides evidence on how an ACT should be configured.

## Research initiatives

- ProACTIVE – Programme of Research for Alcohol Care Teams: Impact, Value and Effectiveness (NIHR-funded)<sup>[11]</sup>
- Management of patients with chronic liver disease admitted to hospital as an emergency (MAP-CLD) (NIHR-funded)<sup>[12]</sup>
- Early detection of liver disease (2022-23 NIHR funding call)<sup>[13]</sup>

The following sections present the data discussed at the stakeholder meeting, including the current admissions and mortality data for ARLD and the NCEPOD survey method and results.

# CURRENT ARLD ADMISSIONS & MORTALITY DATA

Both local and national data from the 'Liver Disease Profiles' published by the Office for Health Improvements & Disparities indicate that hospital admissions in England for alcohol-related liver disease (ARLD), and death from ARLD are rising and were exacerbated by the COVID-19 pandemic.<sup>[3]</sup>

## Hospital admissions

Figure 1 shows that in the age standardised hospital admission rate for England has increased over the past decade. In 2020/21 there were 24,544 hospital admissions for ARLD (based on date of admission). The number of hospital admissions for ARLD increased by 57.4% between 2010/11 and 2020/21.

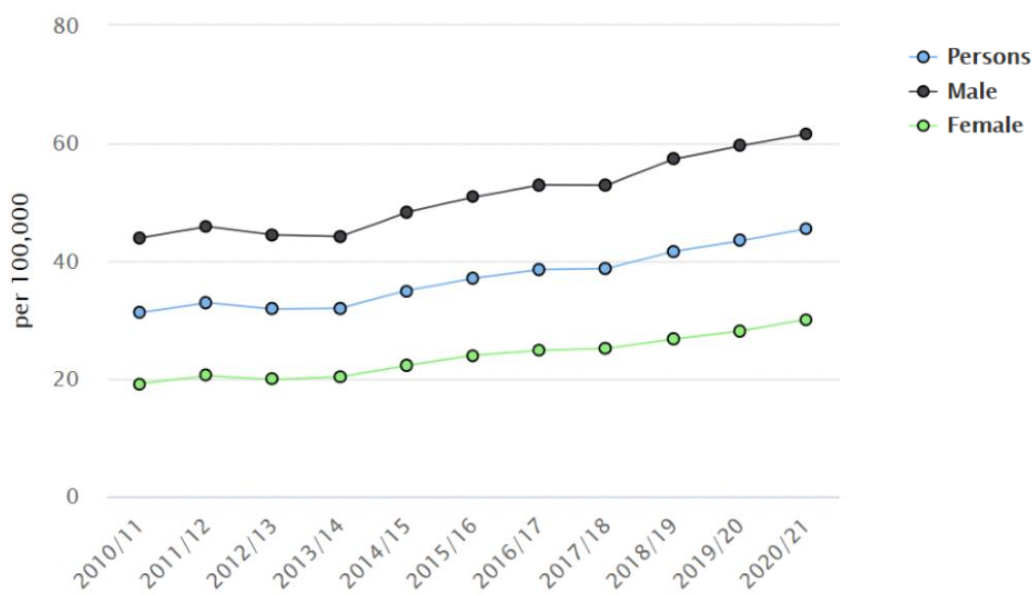


Figure 1. Hospital admission rates due to ARLD standardised rate per 100,000 (England)<sup>[3]</sup>

There was regional variation in hospital admissions which predated the COVID-19 pandemic, with the highest rates per 100,000 population seen in the North East, Yorkshire and the Humber and North West regions. However, given the varying population size of regions, the largest numbers of admissions were seen in the North West and Yorkshire and the Humber regions.

Figure 2 demonstrates the impact of area deprivation on hospital admissions for ARLD, with a 4.3 fold difference in rate of admissions between the most deprived decile and the least deprived in 2020/21. In general, men had higher rates of hospital admissions than women accounting for around two thirds of admissions, but this ratio varied geographically and the gap between hospital admissions per 100,000 population between men and women was much wider in the North East (48.9) than in the South East (20.8). The gap in Yorkshire and Humber had also widened over time, where the difference in rate was 27.7 per 100,000 population in 2010/11 and 50.9 in 2020/21.

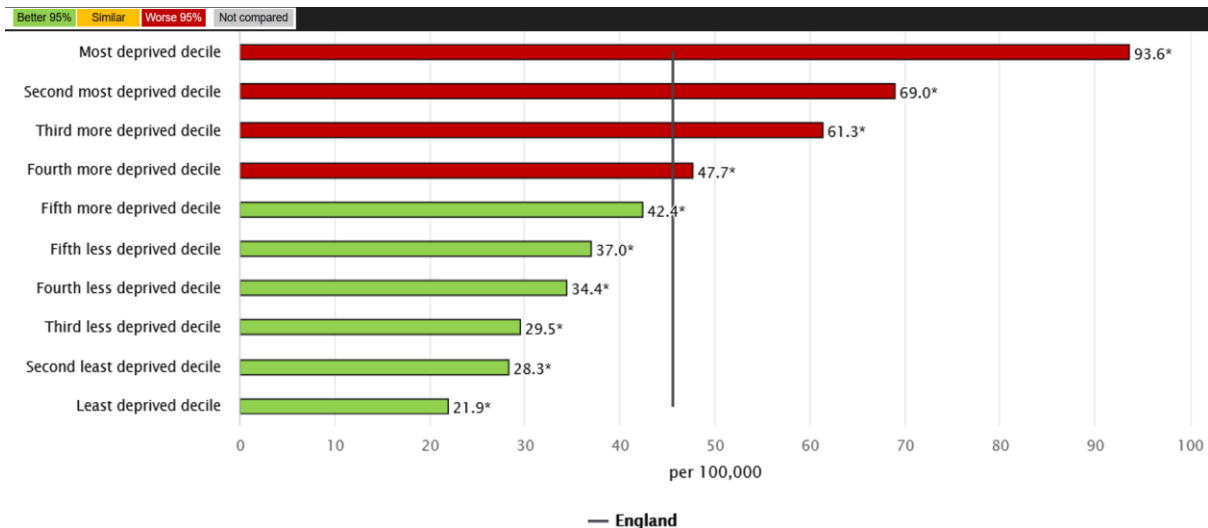


Figure 2. Hospital admission rate for ARLD in England in 2020/21 by deprivation decile<sup>[3]</sup>

## Mortality

The second Atlas of Variation<sup>[14]</sup> showed that liver disease was, overall, the fourth most common cause of Years of Life Lost (YLL) in those aged 75 years old and younger, and the second commonest cause of YLL in women of working age. It also demonstrated the marked variation in mortality from chronic liver disease according to geography and the strong correlation with deprivation; the median age of death from ARLD was 6 years younger for people living in the most deprived quintile area compared to the least deprived.

The standardised premature (<75 years) mortality rate for ARLD has increased, as shown in Figure 3. The mean age of death from ARLD was 56.5 years in England in 2020, lower than in 2019 when it was 57.1 years. Women, on the whole, died from ARLD at a younger mean age (55.7 years) than men (57.0 years). The gap between the mean age of ARLD deaths for men and women has been widening since 2001 (from 0.1 in 2001 to 1.4 years in 2020)<sup>[15]</sup>.

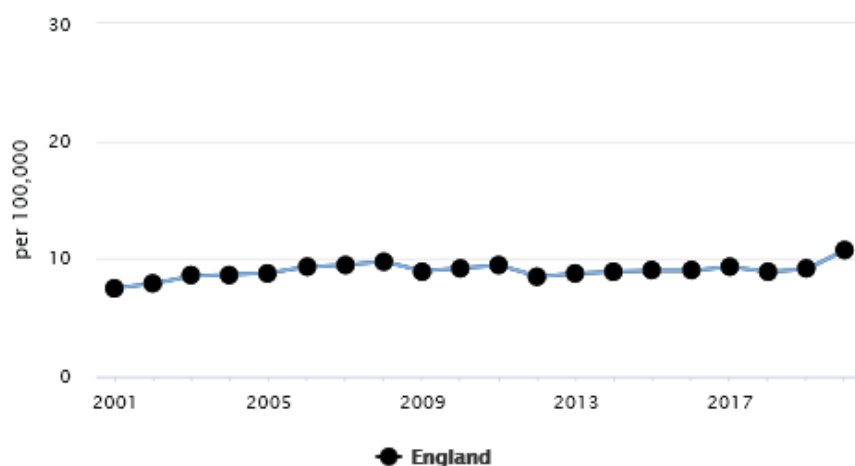


Figure 3. Age under 75 years mortality rates from ARLD standardised per 100,000 (England)<sup>[3]</sup>

There were 5,285 premature (<75 years) ARLD deaths in 2020, with a 18.5% increase in overall deaths from ARLD compared with 2019.<sup>[3]</sup> The majority of premature deaths from ARLD occurred in hospital<sup>[1]</sup>. During the first (23<sup>rd</sup> March-10<sup>th</sup> May 2020) and third (January



2021) COVID-19 lockdowns there was a sharp drop in deaths from premature ARLD in hospital while deaths at home increased. As seen in hospital admissions, there was a marked socioeconomic gradient with people living in the most deprived decile of lower super output areas having a 4.8 fold higher premature mortality rate than those living in the most affluent decile in 2020 (Figure 4).

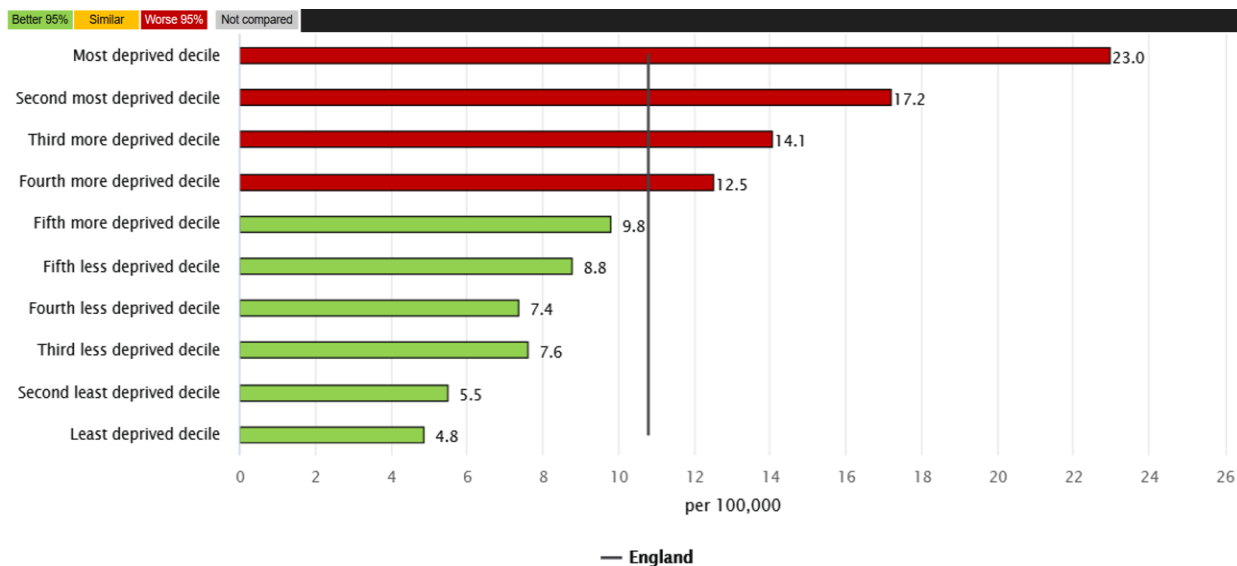


Figure 4. Under 75 mortality rates from ARLD (Persons) 2020, by deprivation decile in England (IMD 2019)<sup>[3]</sup>

# NCEPOD SURVEY: METHOD

An online survey was sent to the NCEPOD local reporter in each hospital, to be sent on to the gastroenterology/hepatology clinical lead. To help facilitate this process, details of the survey were communicated to all British Society of Gastroenterology (BSG) members, who were invited to share their details with NCEPOD should they be interested in their hospital participating. The clinician details were then shared with the corresponding NCEPOD local reporter.

To minimise the impact of the COVID-19 pandemic on the survey answers, data relating to 2019 was requested. Questions in the survey were specifically aimed at evaluating the areas of concern highlighted in *'Measuring the units'*, as well as what the response had been to the report recommendations.

## Information collected

Using specified ICD10 codes the number of alcohol-related liver disease (ARLD) hospital admissions and deaths, were requested.

Data were collected to identify whether the recommendation in *'Measuring the units'* for the use of a symptom-triggered alcohol withdrawal regimen in appropriate patients had been adopted.

Service organisation was evaluated in relation to ARLD management by asking firstly, whether patients admitted with decompensated cirrhosis were triaged to be under the care of a gastroenterologist or hepatologist, and secondly, whether the British Association for the Study of the Liver (BASL)/BSG Decompensated cirrhosis care bundle had been adopted and was in use.

A further area highlighted in *'Measuring the units'* was that there were some patients who would have benefitted from escalation to critical care but did not receive it. To assess the ease of access to critical care for this patient group when compared with patients with other cause liver disease, the opinion of the clinical lead was sought.

Information on palliative care input for patients who died in hospital with ARLD, as well as whether there was departmental mortality review of these patients was also requested.

In addition to the survey, and in relation to the management of alcohol-related harm, clinical review of 20 sets of case notes from randomly selected non-elective medical admissions was suggested to be undertaken locally. This was to look for evidence of an alcohol history being taken and whether a validated screening tool was used.

# NCEPOD SURVEY: RESULTS

Of 190 hospitals that were sent the online survey, 155 (81.6%) provided data. Where possible, the organisational data presented has been grouped to explore whether there was any difference in the arrangements for the care of patients with alcohol-related liver disease (ARLD) between liver transplant centres and hospitals with or without a 'liver unit', a liver unit being defined as those recognised by the British Liver Trust.<sup>[16]</sup> In addition, in 119 hospitals, sets of case notes were reviewed locally.

## Hospital admissions and deaths

Of the 155 surveys, 147 contained data on the number of hospital admissions for 2019. The total number of patients admitted with a primary diagnosis of ARLD was 20,876. The average number per hospital was 144 (median 99; range 4-970) (Figure 5). At least some contribution to the wide range was likely to be due to differences in coding between different hospitals.

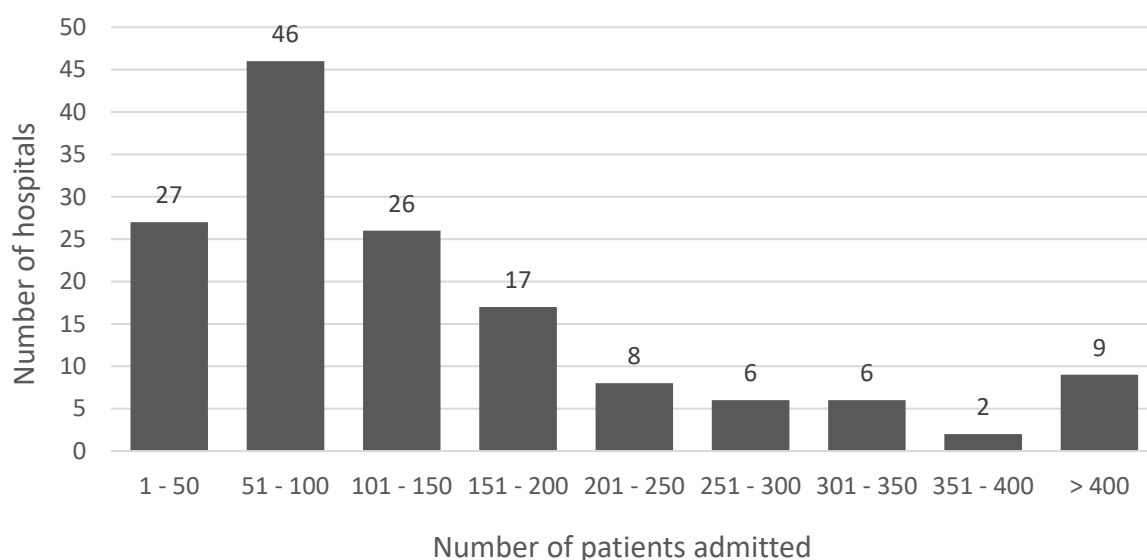


Figure 5. Number of admissions with a primary diagnosis of ARLD  
20,876 patients (147 hospitals), range 4-970, mean 144, median 99

The same hospitals reported a total of 2,481 ARLD deaths (Figure 6), which equated to 11.9% of the total number of admissions. This mortality rate is consistent with published data.<sup>[3]</sup>

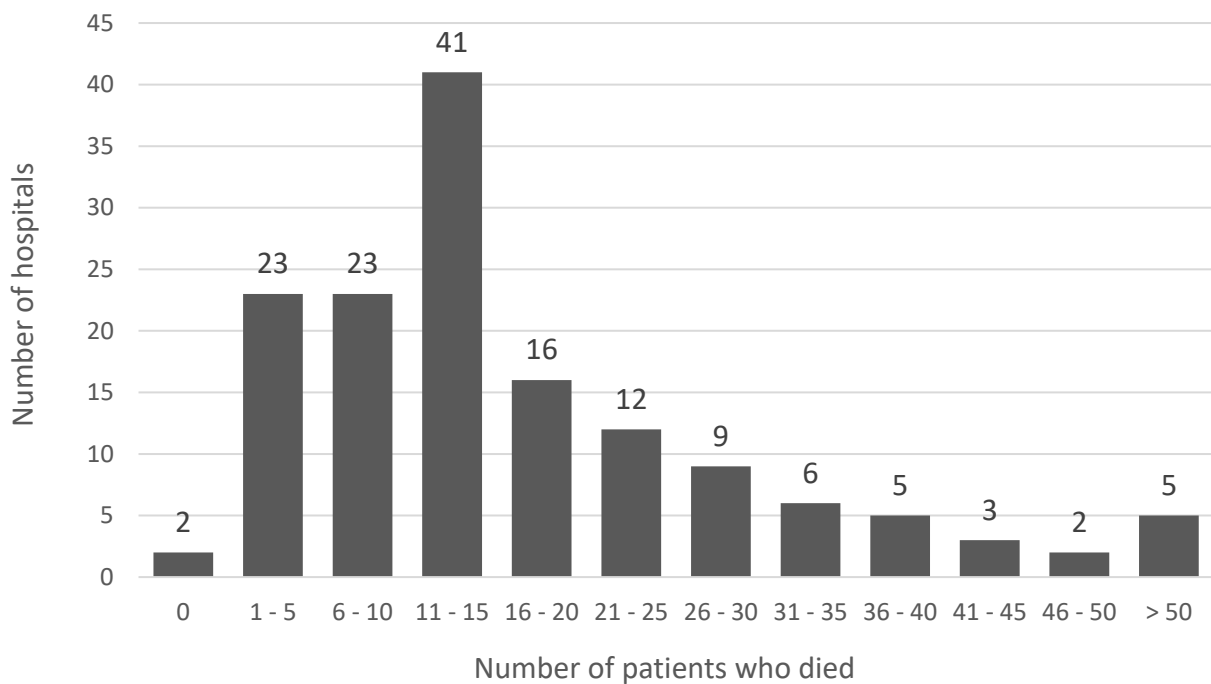


Figure 6. Number of patients who died with a primary diagnosis of ARLD  
 2,481 ARLD deaths (147 hospitals) range 0-93, mean 17, median 13

Analysis of the data provided looking at admission numbers with ARLD and mortality of this patient group for each participating hospital indicated wide variation in mortality rates (0% to 31%) between hospitals without a liver unit (Figure 7). In those with liver units, mortality rates also varied (3.2% to 21.4%) (Figure 8). No information was requested on patient demographics, case mix, or severity of liver disease for individual hospitals so it was not possible to draw strong conclusions from this data.

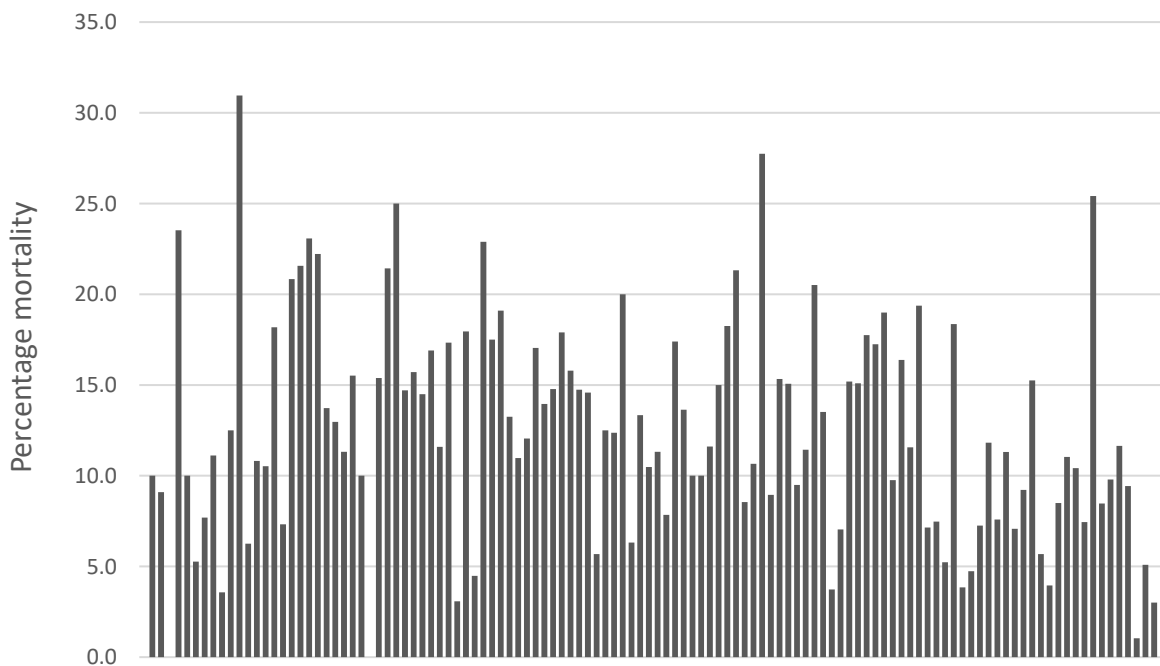


Figure 7. Variation in mortality rates in 118 hospitals defined as non-liver units

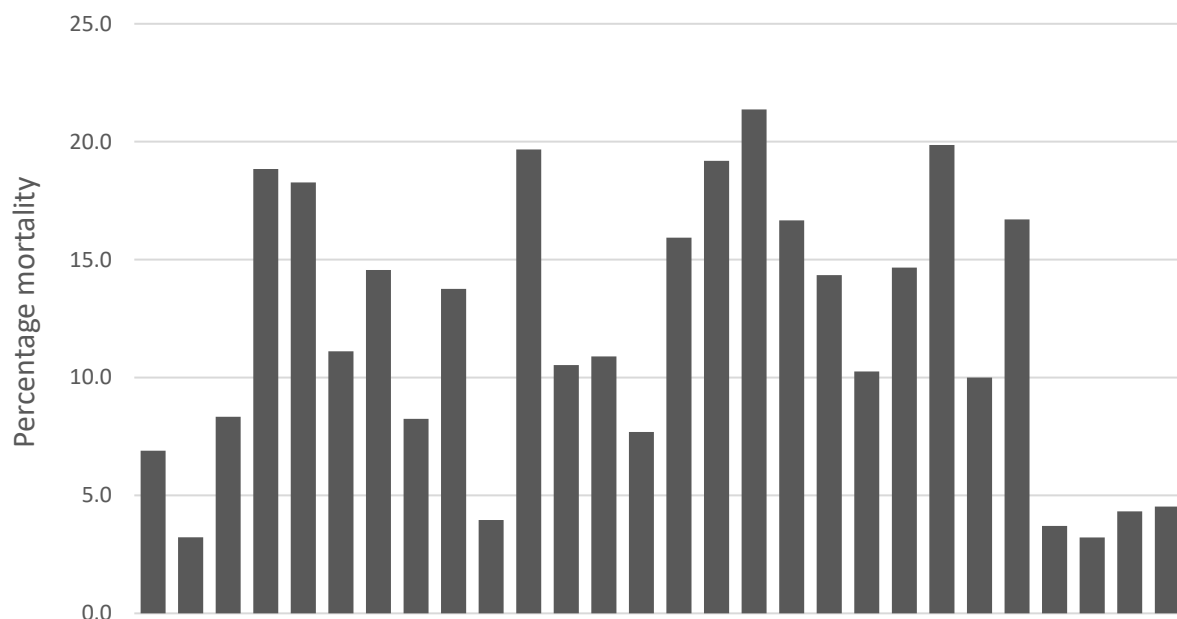


Figure 8. Variation in mortality rates in 28 hospitals defined as liver units

However, both the possibility that a patient with ARLD has a substantially higher chance of surviving their admission in one hospital compared to another, and the potential for inaccuracy of coding (or a combination of these) as explanations for the variation are not acceptable. The apparent wide variation in mortality for this patient group needs further investigation and accurate coding is required to understand whether the variation in outcome is a real problem, as well as to plan local services effectively.

### Identification of alcohol risk

The starting point for effective management of alcohol withdrawal is the identification of patients who are at risk. This starts with comprehensive and sustainable screening system for increased risk drinking in acute hospitals and taking an alcohol history in those who screen positive.

Data from *'Measuring the units'* showed that an alcohol history was not documented at all in almost one in six patients. When an alcohol history was documented, it was not considered to be adequate in between a third and a half of patients. As a result, the following recommendation was made:

*“All patients presenting to hospital services should be screened for alcohol use. An alcohol history indicating the number of units drunk weekly, drinking patterns, recent drinking behaviour, time of last drink, indicators of dependence and risk of withdrawal should be documented.”*

In order to embed screening for alcohol risk into clinical practice, NHS England introduced a CQUIN<sup>[17]</sup> for screening and brief advice for both alcohol and tobacco use for acute trusts in England in 2019.

Data from 119 hospitals in which case notes were reviewed for the survey showed that there were still a third of patients (698/2,236; 31.2%) who did not have an alcohol history taken. A screening tool was used for 794/2,236 (35.5%) (Figure 9).

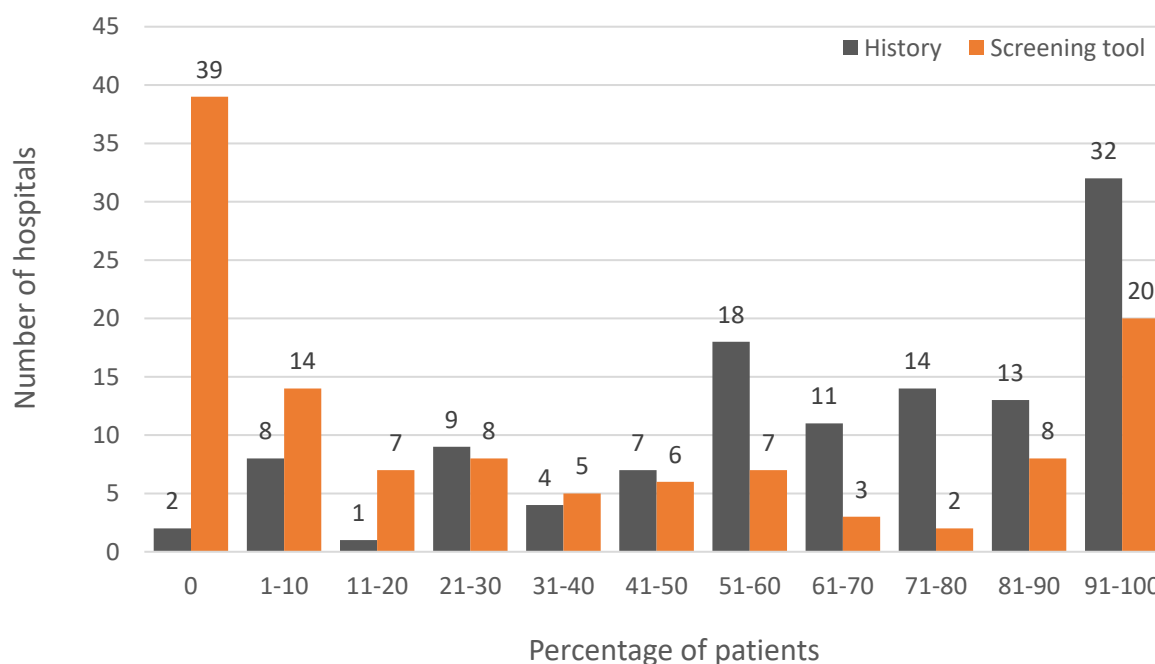


Figure 9. The percentage of patients who had an alcohol history taken and/or screening tool used

## Management of alcohol withdrawal

*'Measuring the units'* also found that the majority (58.6%) of patients were not assessed for risk of alcohol withdrawal. In those patients at risk of alcohol withdrawal, a clinical policy for the management of alcohol withdrawal needs to be in place in Acute Trusts, with appropriate monitoring of signs and symptoms of the trajectory of alcohol withdrawal. This can either be as a symptom triggered withdrawal protocol or a fixed dose reducing regimen.<sup>[18,19]</sup>

In *'Measuring the units'*, a recommended alcohol withdrawal protocol, and monitoring was only documented in 32/322 (9.9%) of the cases reviewed. Use of the NICE recommended withdrawal scale<sup>[18,19]</sup> was highlighted in the following NCEPOD recommendation:

*"Alcohol withdrawal scales should be used, as suggested in NICE guidance, to guide treatment decisions to prevent the alcohol withdrawal syndrome."*

The survey results showed that the majority of the hospitals that provided data had introduced a protocol to guide management of alcohol withdrawal. The survey asked

specifically about the NICE-recommended symptom-triggered alcohol-withdrawal regimen. It is accepted that in certain scenarios alternative, fixed-dose regimens, are appropriate. There were still, however, just over one in ten hospitals that were not using a specific protocol (Table 1).

Table 1. Hospital policy to use a symptom-triggered alcohol withdrawal management tool to aid clinical judgement

	Number of hospitals	%
All relevant patients	119	76.8
On specific wards	18	11.6
No	18	11.6
<b>Total</b>	<b>155</b>	

### Alcohol Care Teams (ACTs)

The logical follow-on from having systematic alcohol screening and clinical history taking for patients seen in the emergency department is to have a pathway in place for those identified with alcohol dependence. As part of this, a position paper published in 2010, by the British Society of Gastroenterology (BSG), Alcohol Health Alliance UK and British Association for Study of the Liver (BASL) recommended that an ACT be established in each acute trust/health board.<sup>[20]</sup> The role of the ACT was proposed to supervise the safe care of patients in alcohol withdrawal, give interventions to facilitate abstinence and to link patients in with local community alcohol services to improve long-term outcomes. At the time of *'Measuring the units'* there were 47/203 (23.2%) hospitals that had a multidisciplinary ACT.

One of the recommended elements of a fully functional ACT that was specified was that it should be led by a consultant with sessions dedicated to the role. *'Measuring the units'* showed that there were only 35/204 hospitals (17.2%) that had a lead consultant with sessions dedicated to the ACT. The report therefore made the following recommendation:

*“A multidisciplinary Alcohol Care Team, led by a consultant with dedicated sessions, should be established in each acute hospital and integrated across primary and secondary care.”*

The survey results showed that just over half of the hospitals who responded (80/155; 51.6%) had an ACT in place (Figure 10). This service was available seven days per week in 26/80 (32.5%) of these hospitals. Where the information was provided, transplant centres and hospitals with a liver unit were more likely to have an ACT (27/35; 77.1%) (Table 2).

There appears to have been an improvement in the number of hospitals with recommended arrangements in place, but there remains considerable room for improvement in the availability of these services.



Figure 10. Number of hospitals with a multidisciplinary ACT

Table 2. Presence of a multidisciplinary ACT by type of unit

Type of unit	A multidisciplinary ACT in the hospital?			Total
	Yes	No	%	
No liver unit	53	67	44.2	<b>120</b>
Liver unit	23	6	79.3	<b>29</b>
Transplant centre	4	2	66.7	<b>6</b>
<b>Total</b>	<b>80</b>	<b>75</b>	<b>51.6</b>	<b>155</b>

A specific component of the 2019 NHS Long Term Plan action on prevention and health inequalities relates to alcohol care. This supports fully establishing ACTs to improve care of alcohol dependent patients, reduce emergency department attendances, bed-days used and readmissions.<sup>[21]</sup> In partnership with the NHS National Prevention Programme, the Alcohol Care Team Innovation and Optimisation Network (ACTION) supports ACTs within acute trusts/health boards. In November 2019, advice was published outlining the Core Service Descriptors for ACTs.<sup>[10]</sup> Although this was after the survey results were collected, it can be used to help those establishing a new service or to develop services that do not cover all of the areas recommended. The services provided by each ACT at the time of the survey are listed in Table 3.



Table 3. Services that the ACT provided

	Number of hospitals	%
Facilitate widespread case identification and brief advice	70	87.5
Comprehensive alcohol assessment	77	96.3
Contribute to nursing and medical care planning	73	91.3
Psychosocial interventions	64	80.0
Manage medically assisted alcohol withdrawal	73	91.3
Plan safe discharge, including referral to community	77	96.3

Answers may be multiple; n=80 hospitals

Figure 11 shows that there were still 68/155 (43.9%) hospitals with no lead consultant for their alcohol care services. Of the remaining hospitals where a lead was in place, the majority of clinicians did not have any dedicated time in their job plan to undertake this role (56/87; 64.4%). Overall, just over one in five hospitals (31/155; 20.0%) had a lead consultant with dedicated sessions in their job plan. Therefore this recommendation had not led to the improvement required in local leadership over the last decade.

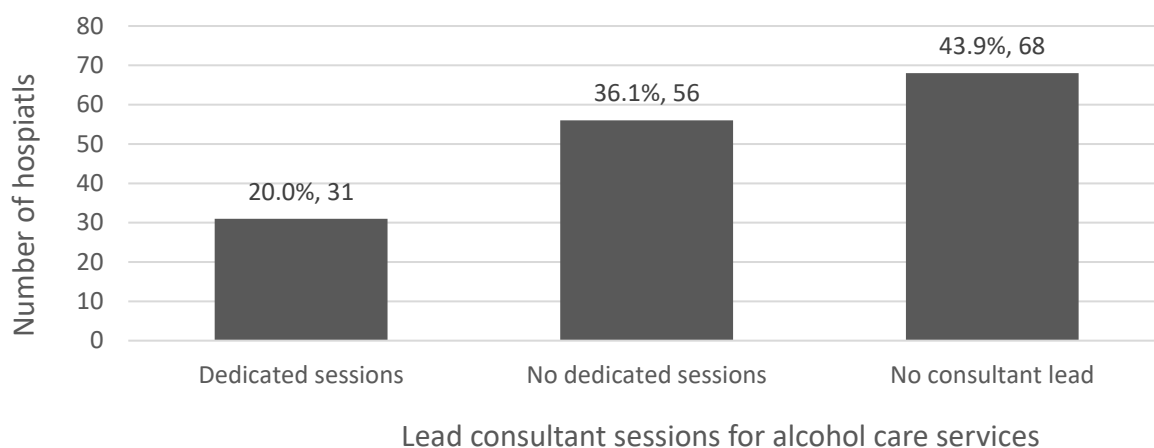


Figure 11. Availability of lead consultants for alcohol care services

Hospitals with a liver unit or transplant centres were more likely to have a lead consultant (Table 4). Where data were provided, even in transplant centres and hospitals with a liver unit, time was only allocated in the job plan of the lead in half of those hospitals (Table 5).

Table 4. Lead consultant for the alcohol care services at the hospital by type of unit

Type of unit	There is a lead consultant for the alcohol care services at this hospital			Total
	Yes	No	%	
No liver unit	59	61	49.2	120
Liver unit	22	7	75.9	29
Transplant centre	6	0	100.0	6
<b>Total</b>	<b>87</b>	<b>68</b>	<b>56.1</b>	<b>155</b>

Table 5. Lead consultant has dedicated session for alcohol care services by type of unit

Type of unit	Consultant has sessions dedicated to alcohol services in their job plan			Total
	Yes	No	%	
No liver unit	17	42	28.8	59
Liver unit	11	11	50.0	22
Transplant centre	3	3	50.0	6
<b>Total</b>	<b>31</b>	<b>56</b>	<b>35.6</b>	<b>87</b>

## Specialist care

Patients admitted to hospital with decompensated cirrhosis are complex with a high in-patient mortality. Attention to detail in their initial assessment and management is important. Evidence from *'Measuring the units'* showed that patients were only admitted under the care of a gastroenterologist or hepatologist in 99/489 (20.2%) cases. In more than half of the patients reviewed, appropriate screening tests for liver disease were not done. Initial care was considered to be good in only 185/375 (49.3%) cases reviewed.

In many hospitals it would be impractical to admit all of these patients under a gastroenterologist but the following recommendation from *'Measuring the units'* was designed to improve access to specialist review for these patients:

*"All patients admitted with decompensated alcohol-related liver disease should be seen by a specialist gastroenterologist/hepatologist at the earliest opportunity after admission. This should be within 24 hours and no longer than 72 hours after admission to hospital."*

The survey results suggests that there is still room to improve the pathway for this patient group. In more than a quarter of hospitals (42/155; 27%), care was not routinely provided by a specialist specifically trained in the management of decompensated cirrhosis (Table 6).

Table 6. Patients diagnosed with decompensated cirrhosis are always transferred to the care of a gastroenterologist/hepatologist

	Number of hospitals	%
Yes	113	72.9
No	42	27.1
<b>Total</b>	<b>155</b>	

Care was more likely to be provided by a liver specialist in hospitals with a liver unit or liver transplant unit (31/35; 88.6%) than in those without (82/120; 68.3%) (Table 7). However, there remained the potential for improved design of patient pathways in all types of hospital.

Table 7. Patients diagnosed with decompensated cirrhosis are always transferred to the care of a gastroenterologist/hepatologist by type of unit

A patient diagnosed with decompensated cirrhosis, is always transferred to the care of a gastroenterologist/hepatologist				
Type of unit	Yes	No	%	Total
No liver unit	82	38	68.3	120
Liver unit	26	3	89.7	29
Transplant centre	5	1	83.3	6
<b>Total</b>	113	42	72.4	155

Acknowledging that immediate specialist review for all patients was not practical, and to improve the initial care of patients on admission to hospital, prior to specialist review, *'Measuring the units'* recommended the development of a toolkit to aid the non-specialist in the management of these patients:

*"A toolkit for the acute management of patients admitted with decompensated alcohol-related liver disease should be developed and made widely available to all physicians/doctors involved in the care of patients admitted to acute hospitals."*

This recommendation was taken up by specialist organisations and a care bundle for use in these patients was produced and endorsed by BASL and BSG and published in 2014. This care bundle was stated to be in use in 107/155 (69%) of the hospitals that responded to the survey (Table 8). A local trust/health board guideline was in place in a further 24 hospitals, but there remained more than one in seven (24/155; 15.5%) hospitals where this was not in place. Where it was reported that a care bundle was not used, the hospitals were less likely to have a consultant lead than those where the bundle was used (7/24 vs 80/131). Although the survey data suggested a high level of uptake, a recent national audit conducted by gastroenterology/hepatology trainees, indicated that an admission care bundle was actually being used in 11.4% of hospitals; this was the BSG/BASL bundle in 9.2% of instances.<sup>[22]</sup>

Table 8. The BSG/BASL decompensated chronic liver disease care bundle was used in this hospital

	Number of hospitals	%
Yes	107	69.0
No, but local trust/health board guideline	24	15.5
No	24	15.5
<b>Total</b>	<b>155</b>	

## Alcohol care pathways and care after hospital discharge

In addition to the admission care bundle, the BSG has now produced a Cirrhosis Care Bundle.<sup>[5]</sup> This was published in 2020 and serves as a checklist to remind medical staff about key aspects of follow-up care of a patient admitted with decompensated cirrhosis. Its use should be encouraged as it will enhance the delivery of effective care.

Given the importance of abstinence from alcohol as a prognostic determinant in patients with decompensated alcohol-related cirrhosis, once patients are discharged from hospital, measures to improve abstinence, and to reduce morbidity and mortality from harmful alcohol use should be the top priority. This can be done most effectively by ensuring contact is made with community alcohol services.

In England, the newly established Integrated Care Systems offer an opportunity for fully integrated alcohol care between community services, primary and secondary care. Similar arrangements are in place in other parts of the United Kingdom. Each local system should therefore, ensure the appointment of an Alcohol Lead, with responsibility for the delivery of effective system-wide care pathways. This aligns with the NHS Long Term Plan action on prevention and health inequalities, which also links to the increasing recognition of the importance of early detection of liver disease and that a CQUIN for 2022/2023 (CCG9) is that people identified as being alcohol dependent should have testing for cirrhosis and fibrosis.<sup>[7]</sup>

## Escalation to critical care

At the time of *'Measuring the units'*, there was a clear theme that patients with ARLD were at times inappropriately denied treatment in critical care when this had the potential to improve their outcome. There were 189 patients identified in the original report where the case note reviewer considered that a ward transfer for escalation of care was required. Of these, 59 (31.2%) did not receive the escalation in treatment needed. A recommendation was made suggesting that:

*“Escalation of care should be actively pursued for patients with alcohol-related liver disease, who deteriorate acutely and whose background functional status is good. There should be close liaison between the medical and critical care teams when making escalation decisions.”*

Although difficult to assess in the same way through a survey, liver specialists were asked to give their opinion about access to critical care for this patient group, where appropriate.

The survey results suggested that in more than a quarter of hospitals (46/155; 29.7%) the responding physician said they still found it more difficult to have their patients with decompensated ARLD admitted to critical care (Table 9). However, free text comments indicated that in some hospitals, improvements had been made in this regard and these were influenced by better working relationships between the gastroenterologists/liver specialists and the critical care team.

Table 9. In the opinion of your liver specialists, is it more difficult to get the intensive care unit to admit patients with decompensated ARLD than other decompensated liver disease patients

	Number of hospitals	%
Yes	46	29.7
No	109	70.3
<b>Total</b>	<b>155</b>	

“Historically, there was a negative perception of ARLD with regard to prognosis. However, in recent years, there has been excellent multidisciplinary working between hepatology and ITU, and there is more inclination to admit and treat such patients. So perhaps now it is not more difficult.”

“Admission of ARLD patients is highly dependent on the ICU physician in attendance. Stigma of ARLD as perceived by some ICU physicians counts against patients.”

### Critical care admissions

To understand patterns of critical care admission of patients with ARLD to critical care, hospitals were asked to provide data on the number of critical care admissions in this patient group using established ICNARC (Intensive Care National Audit and Research Centre) codes.

Figure 12 shows that there were 1,690 primary liver disease critical care admissions from 128 hospitals, mean 13, median 7, range 0-175. There were 1,277 primary/secondary ARLD disease critical care admissions from 123 hospitals, mean 10, median 6 range 0-118. Although variation in the number of admissions to critical care in different hospitals was to be expected, based on hospital size and population served (as well as prevalence of liver disease in the area), the wide variation in numbers of patients with ARLD as the primary or secondary reason for critical care admission was more than anticipated. The data suggested that in 53 hospitals there were between none and five admissions in a calendar year. This was despite the survey questionnaire stipulating which nationally used disease codes to use to identify patients (see appendix). One explanation may be that there is a substantial variation in the threshold for critical care admission in this patient group.

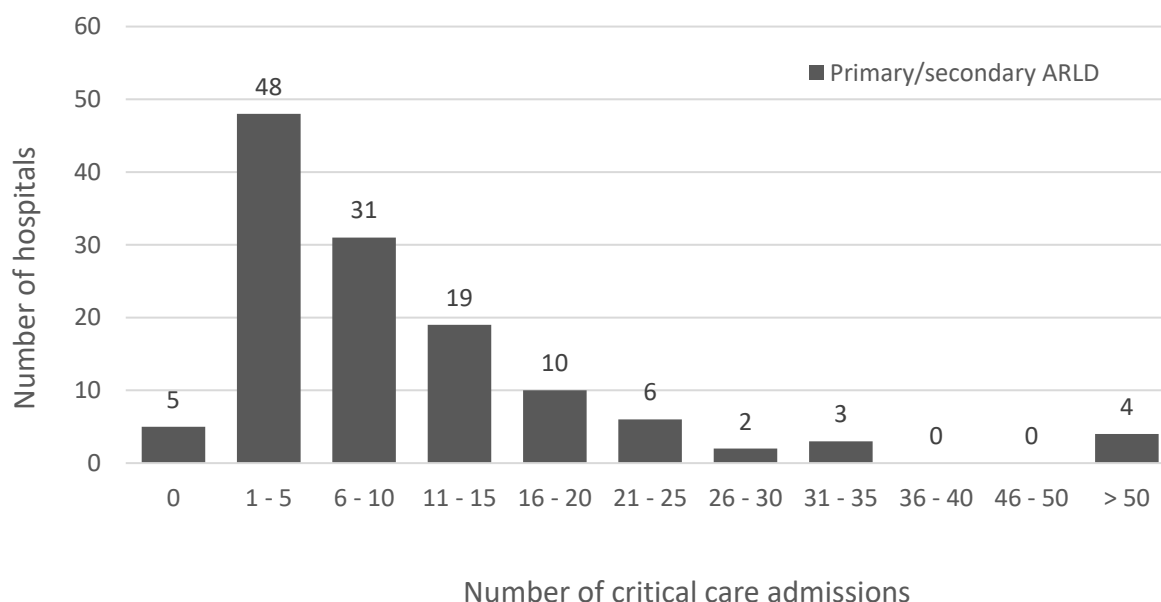


Figure 12. Number of critical care admissions

### End of life care for ARLD patients who died in hospital

There has been increased recognition over the last decade of the importance of managing the symptoms of patients with advanced organ failure, not just with patients with incurable primary liver cancers, but also including advanced decompensated cirrhosis. A consensus statement has been produced by the BASL End of Life Care Special Interest Group.<sup>[23]</sup> It is now recommended that palliative care input is integrated into standard care for patients with advanced decompensated chronic liver disease. This can be done in parallel with ongoing active management.

In order to assess the palliative care input into the care of patients dying with ARLD in hospital, each hospital was asked to provide data on the number of deaths as well as the number of these patients who had evidence of palliative care involvement. There were 557/2,427 (23%) patients with ARLD who died that had coded evidence of palliative care input. The percentage of ARLD cases coded as having palliative care input varied widely between hospitals. In 29 hospitals (20%), no patients were coded as receiving palliative care (Figure 13). In the majority (119/136; 87.5%) of hospitals 50% or fewer ARLD patients who died were coded as receiving palliative care input.

However, it is important to note that comments included in the questionnaire response commonly noted that palliative care input was often not coded despite evidence that it was provided being recorded in the medical records.

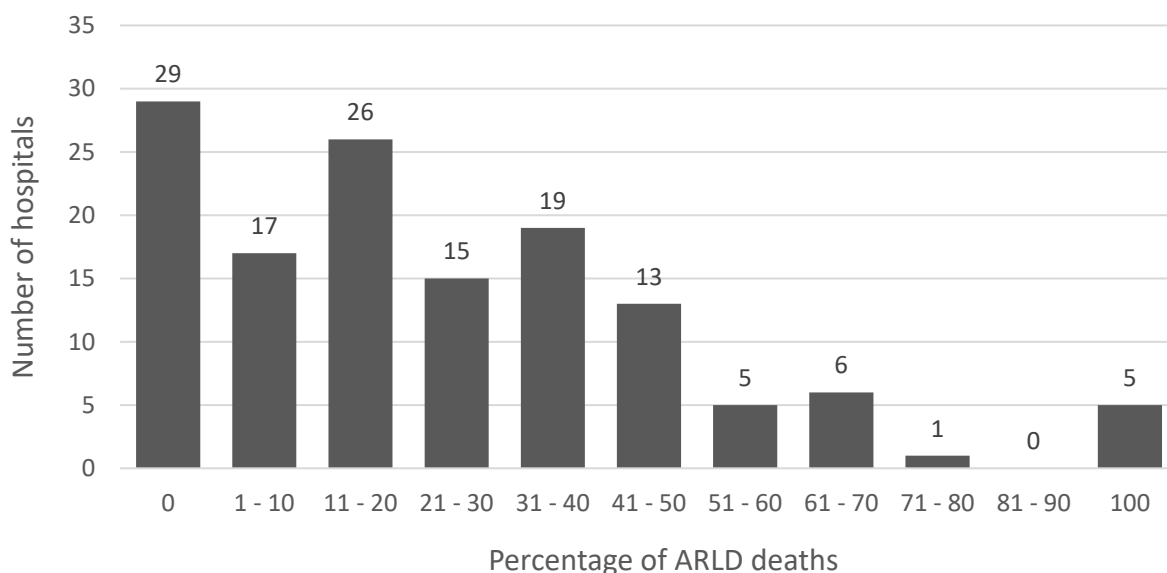


Figure 13. Percentage of ARLD deaths with clinically coded evidence of palliative care input

## Liver networks

It is accepted that not all hospitals can have access to specialist liver care on-site. For those hospitals, it is important to be in a clinical network so that transfer of care to a liver unit or a liver transplant centre can occur if needed. This has been recommended in the Lancet Commission Report in 2015.<sup>[24]</sup> Table 10 shows that just over 121/149 (81.2%) of hospitals responding were linked to a liver transplant unit, but almost 1 in 5 were not.

Table 10. The hospital was part of a clinical network with a liver transplant unit

	Number of hospitals	%
Yes	121	81.2
No	28	18.8
<b>Subtotal</b>	<b>149</b>	
Not applicable, (liver transplant unit)	6	
<b>Total</b>	<b>155</b>	

A record of patients referred for consideration of liver transplantation was kept in only 68/155 (44%) hospitals. Furthermore, 31/68 45.6% of respondents stated they did not know how many patients with ARLD had been referred for liver transplant assessment.

## Mortality review for patients dying with ARLD in hospital

In England, it is recommended that all hospitals have a process in place to learn from deaths.<sup>[25]</sup> In addition, the care of all patients who die in hospitals in England and Wales should now be reviewed by a medical examiner in order to learn from and improve care.<sup>[26]</sup> Many previous NCEPOD reports have shown that opportunities are frequently not taken to learn from deaths and to improve services. Survey results showed that almost a quarter of hospitals (36/152; 23.7%) did not hold a department mortality review meeting (Table 11). In

those that did, most (111/118; 94.1%) stated that they kept a record of these reviews and 65.3% (77/118) undertook mortality reviews at least monthly. However more than a third of hospitals (48/118; 40.6%) were unable to say if patients with ARLD had been discussed in 2019 (Table 12). This raises questions about how useful their systems are for systematically learning from deaths.

Table 11. There was a gastroenterology/hepatology departmental mortality review meeting

	Number of hospitals	%
Yes	118	76.1
No	37	23.9
<b>Total</b>	<b>155</b>	

Table 12. Patients who died from ARLD were discussed at mortality review meetings in 2019

	Number of hospitals	%
Yes	65	92.9
No	5	7.1
<b>Subtotal</b>	<b>70</b>	
Unknown	48	
<b>Total</b>	<b>118</b>	



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# APPENDIX: SURVEY QUESTIONS

## NUMBER OF ADMISSIONS

Please can you liaise with your information department to answer the following questions regarding number of admissions.

1a. How many patients were admitted to hospital with a primary diagnosis of alcohol related liver disease in 2019?

*ICD10 codes K70.0, K70.1, K70.2, K70.3, K70.4 and K70.9*

1b. How many patients died in hospital with a primary diagnosis of alcohol related liver disease in 2019?

1c. How many patients that died in hospital with a primary diagnosis of alcohol related liver disease in 2019 had clinically coded evidence of palliative care input?

*ICD10 code Z51.5 - encounter for palliative care*

## SCREENING FOR ALCOHOL MISUSE

One of the principal recommendations from the NCEPOD 2013 report was that every patient presenting to hospital services should be screened for alcohol misuse.

Please look at 20 non-elective medical admissions from 2019 and answer the subsequent questions.

We would like to stress the importance of this part of the questionnaire, however, if case review is not possible, please answer No to the first question

2a. Was case review undertaken?

2b. If answered "Yes" to [2a] then: How many acute medical admissions were reviewed?

2c. If answered "Yes" to [2a] then: How many of the patients reviewed had an alcohol history taken?

2d. If answered "Yes" to [2a] then: For how many patients was an alcohol screening tool used? *Tools include FAST alcohol screen, Paddington Alcohol Test, AUDIT-C*

## ALCOHOL TEAMS AND HOSPITAL POLICIES

3a. Is there a lead consultant for the alcohol services at this hospital?

3b. If answered "Yes" to [3a] then: Do they have sessions dedicated to alcohol services in their job plan?

3c. Is there a multidisciplinary Alcohol Care Team in the hospital?

3d. If answered "Yes" to [3c] then: Does the alcohol care team work 7 days a week?

3e. If answered "Yes" to [3c] then: Who is the team made up of?

3f. If answered "Yes" to [3c] then: Which of the following does the team provide?

- Facilitate widespread case identification and brief advice (IBA)
- Comprehensive alcohol assessment
- Contribute to nursing and medical care planning
- Psychosocial interventions
- Manage medically-assisted alcohol withdrawal
- Plan safe discharge, including referral to community services

- 4a. Does the hospital use a tool for symptom triggered alcohol withdrawal management (e.g.CIWA-Ar) to aid clinical judgement?
- 4b. If answered "Yes on specific wards" to [4a] then: Please expand
- 4c. If answered "No" to [4a] then: What alcohol withdrawal regimen is used?
- 5a. When a patient has been diagnosed with decompensated cirrhosis, is their care always transferred to a Gastroenterologist/Hepatologist?
- 5b. If answered "No" to [5a] then: Who remains responsible for their care?
- 5c. Is the BSG/BASL decompensated chronic liver disease care bundle used in this hospital?
- 6a. Is endoscopic variceal therapy available on-site?
- 6b. If answered "Yes" to [6a] then: Is this service available 24/7?
- 6c. If answered "Yes" to [6a] and "No" to [6b] then: How is this service accessed out of hours?
- 6d. If answered "No" to [6a] then: How is endoscopic variceal therapy provided?

#### INTENSIVE CARE ADMISSIONS DATA

The large majority of hospitals submit data to the Intensive care national audit & research centre (ICNARC). Please liaise with your ICNARC responsible person(s) who should be able to interrogate the data they supply to ICNARC using the codes for liver disease and alcohol related liver disease.

- 7a. Does this hospital submit data to The Intensive Care National Audit & Research Centre?
- 7b. Does your critical care use any form of flagging system for particular types of patients?
- 7c. If answered "Yes" to [7b] then: Are alcohol related liver disease patients flagged in critical care?
- 7d. If answered "Yes" to [7a] then: How many liver disease patients were admitted to critical care in 2019?

*Please use the following primary ICNARC data codes: 2.3.7.28.2 (alcoholic cirrhosis), 2.3.7.28.3 (acute alcoholic hepatitis), 2.3.7.28.5 (chronic cirrhosis, cause not defined), 2.3.7.28.6 and 2.3.7.30.3 (sclerosing cholangitis), 2.3.7.28.8 (autoimmune hepatitis), 2.3.7.41.3 (hepatic vein thrombosis). If a flagging system is used then please incorporate this into your answer.*

- 7e. If answered "Yes" to [7a] then: How many alcohol related liver disease patients were admitted to critical care in 2019?

*ICNARC primary or secondary data codes 2.3.7.28.2 (alcoholic cirrhosis) and 2.3.7.28.3 (acute alcoholic hepatitis). If a flagging system is used then please incorporate this into your answer.*

- 7f. In the opinion of your liver specialists, is it more difficult to get the intensive care unit to admit patients with decompensated ALCOHOL RELATED liver disease than other decompensated liver disease patients?

#### LIVER TRANSPLANTS

- 8a. Is your Hospital in a Clinical Network with a Liver Transplant Unit?
- 8b. Does your hospital keep a record of all patients under its care referred for liver transplant assessment?

8c. If answered "Yes" to [8b] then: How many patients with alcohol related liver disease were referred for liver transplant assessment in 2019?

8d. Are all appropriate patients with alcohol related liver disease in your hospital referred for consideration of liver transplantation?

8e. If answered "No" to [8d] then: Please expand

8f. If answered "Not applicable, this hospital is a liver transplant unit" to [8a] then: Is a record of all liver transplant referrals to this hospital kept centrally?

This question is for liver transplant units

8g. If answered "Not applicable, this hospital is a liver transplant unit" to [8a] and "Yes" to [8f] then: What percentage of liver transplant referrals in 2019 were for patients with alcohol related liver disease

#### MORTALITY REVIEW

9a. Is there a Gastroenterology/Hepatology departmental mortality review meeting?

9b. If answered "Yes" to [9a] then: How frequent are the meetings?

9c. If answered "Yes" to [9a] then: Does your hospital keep a record of all mortality reviews?

9d. If answered "Yes" to [9a] and "Yes" to [9c] then: What was the total number of patients reviewed at the mortality meetings in 2019?

9e. If answered "Yes" to [9a] and "Yes" to [9c] then: Were any alcohol related liver disease patients discussed at mortality review meetings in 2019?

9f. If answered "Yes" to [9a] and "Yes" to [9c] and "Yes" to [9e] then: How many alcohol related liver disease patients were reviewed in 2019?