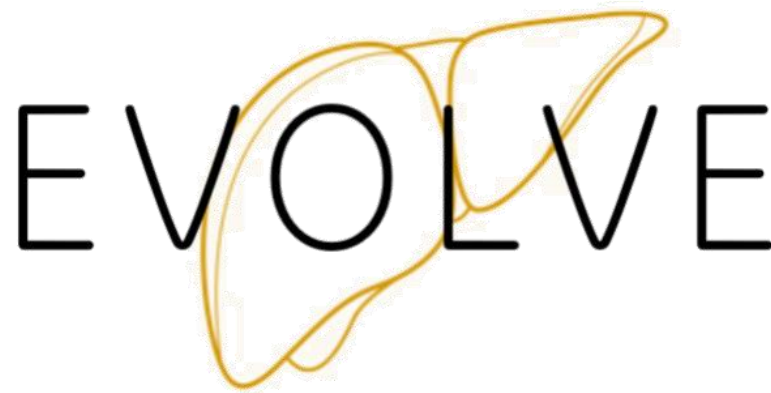


End of life care provision in patients with advanced chronic liver disease: data from the EVOLVE national audit



Dr Emma Saunsbury and Dr Daniel Maggs

EVOLVE co-leads

BASL End of Life SIG Meeting 19th Oct 2023

Disclosures



BRITISH SOCIETY OF
GASTROENTEROLOGY

Winner of BSG Research
Database and Statistical
Support Award

End of life care in adVanced chrOnic LiVEr disease (EVOLVE)

Palliative care within
the last year of life

Decompensated cirrhosis



October 2022 – April 2023





Pilot project:


Royal United
Hospital, Bath
1 site (n=52)



**South West
regional project:**

Severn and
Peninsula
deaneries

10 sites (n=204)

SPR**nG**
network

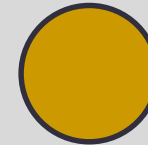


BSG funding

Introduction to
Trainee Research day
(April 2022)

Winner of BSG
Research Database
and Statistical
Support Award

BiCOPS support

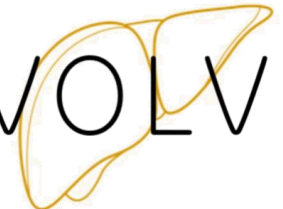


Currently:

93 sites
registered
UK-wide

83 sites
submitted data

n=803

EVOLVE



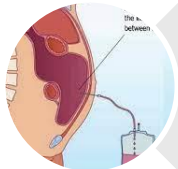
Objectives



To audit current EOLC provision for patients with ACLD in the UK



To identify whether institution and patient-related factors are associated with markers of quality EOLC



To determine current levels of service provision for patients with refractory ascites and utilisation of long-term abdominal drains (LTADs)

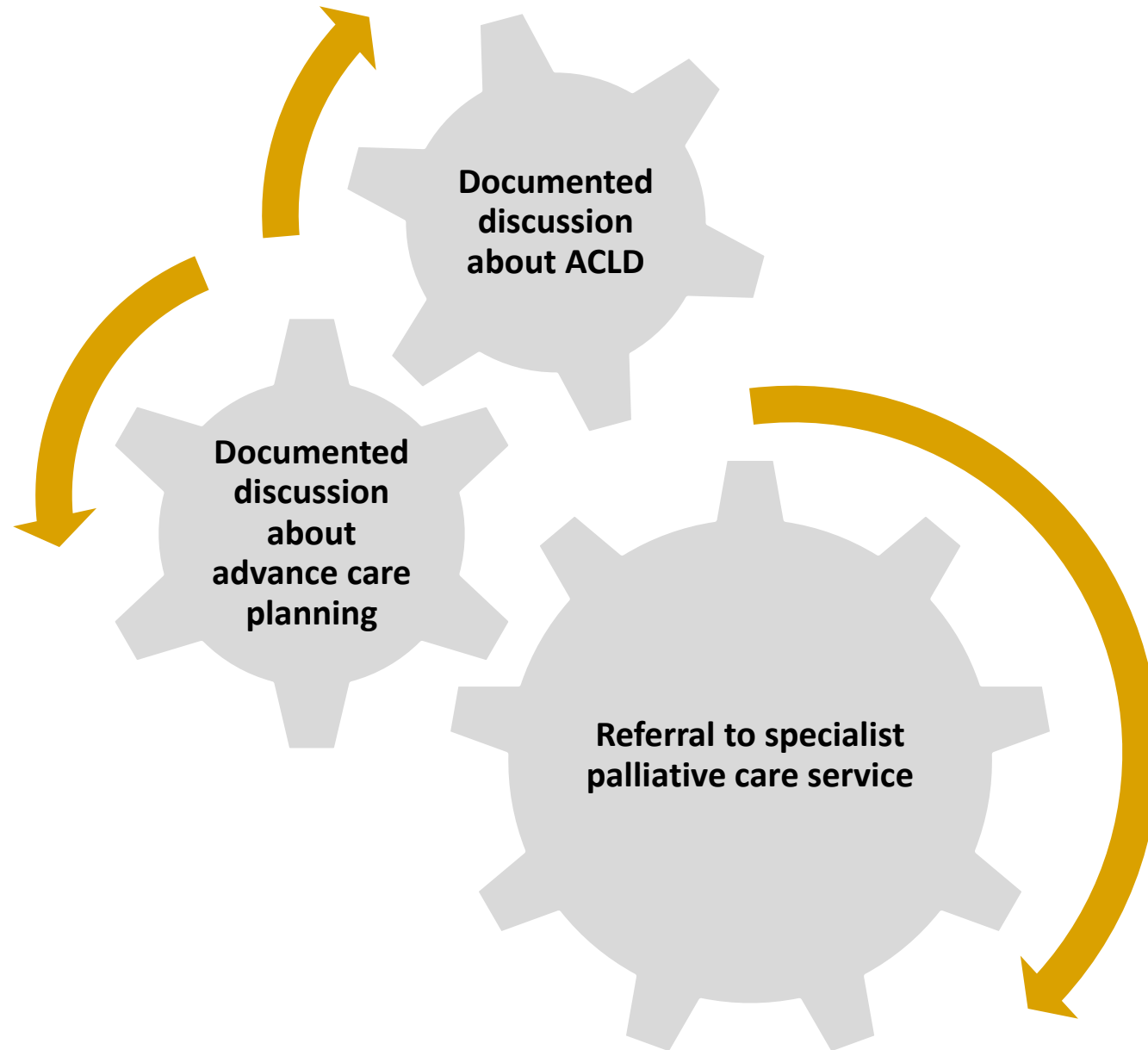


To determine if quality EOLC is associated with reduced burden inpatient bed days in the last year of life



To determine the impact of deprivation on EOLC in patients with ACLD

Outcomes



Audit standards

Practice Guideline > Gut. 2021 Jan;70(1):9-29. doi: 10.1136/gutjnl-2020-321790.

Epub 2020 Oct 16.

Guidelines on the management of ascites in cirrhosis

Guruprasad P Aithal^{1 2}, Naaventhana Palaniyappan^{3 2}, Louise China⁴, Suvi Härmälä⁵, Lucia Macken^{6 7}, Jennifer M Ryan^{4 8}, Emilie A Wilkes^{2 9}, Kevin Moore⁴, Joanna A Leithead¹⁰, Peter C Hayes¹¹, Alastair J O'Brien⁴, Sumita Verma^{6 7}

Affiliations + expand

PMID: 33067334 PMCID: [PMC7788190](#) DOI: [10.1136/gutjnl-2020-321790](#)

[Free PMC article](#)

“Patients with refractory ascites who are not undergoing evaluation for liver transplant should be offered a palliative care referral”

> Hepatology. 2022 Sep;76(3):819-853. doi: 10.1002/hep.32378. Epub 2022 Apr 22.

AASLD Practice Guidance: Palliative care and symptom-based management in decompensated cirrhosis

Shari S Rogal^{1 2}, Lissi Hansen³, Arpan Patel^{4 5}, Nneka N Ufere⁶, Manisha Verma⁷, Christopher D Woodrell^{8 9}, Fasiha Kanwal^{10 11}

Affiliations + expand

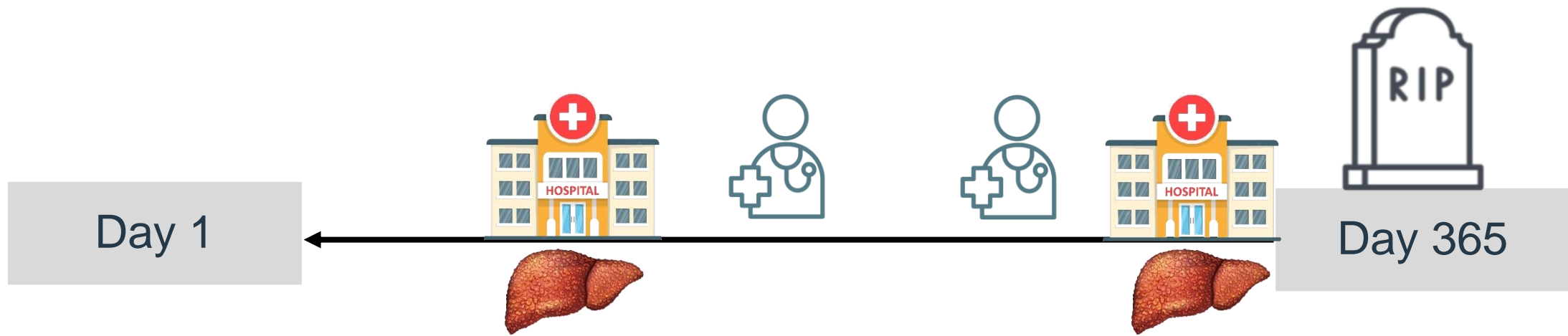
PMID: 35103995 PMCID: [PMC9942270](#) DOI: [10.1002/hep.32378](#)

[Free PMC article](#)

“Advance care planning is an iterative process that should start with a diagnosis of cirrhosis and preferably occur before hepatic decompensation and loss of decision-making capacity”

“Evaluation for unmet palliative care needs and specialty palliative care consultation should be considered for all patients with decompensated cirrhosis”

Inclusion criteria



1st Jan – 30th June 2022

Data

Institution level variables

- Dedicated inpatient hepatology service
- IQILS accreditation status
- Presence of ACLD MDT
- Access to specialised palliative care service
- Access to outpatient paracentesis service
- TIPS service status
- Availability of long term abdominal drains (LTADs)

Patient level variables

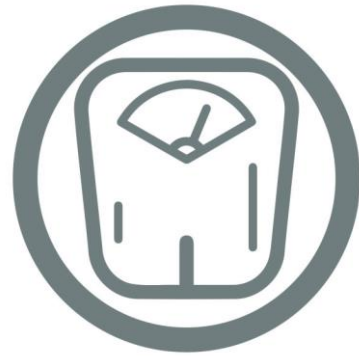
- Demographics: age, sex, postcode (for determination of Index of Multiple Deprivation)
- Aetiology
- Prognostic scores e.g. Child-Pugh, MELD-Na
- Transplant suitability
- Alcohol (in ArLD)
- Complications e.g. encephalopathy, ascites
- Refractory ascites data (where relevant)
- Encounters (admissions, outpatient attendances)

Site Characteristics	Proportion of patients
Separate Hepatology inpatient service	48.3%
IQILS accreditation	
Level 2	10.7%
Level 1	13.1%
Applied for accreditation	14.9%
Not applied for accreditation	61.3%
Access to specialist palliative care services	
Yes - Dedicated referral pathway	18.9%
Yes - Generic referral pathway	80.7%
No	0.4%
Outpatient paracentesis service	
Yes - via general ambulatory care	25.8%
Yes - Specialty-led	69.1%
No	5.1%
Did the hospital have access to a long-term abdominal drains (LTADs)?	
Yes – On site	69.0%
Yes - via referral to a level 2/3 unit	6.0%
No	25.0%

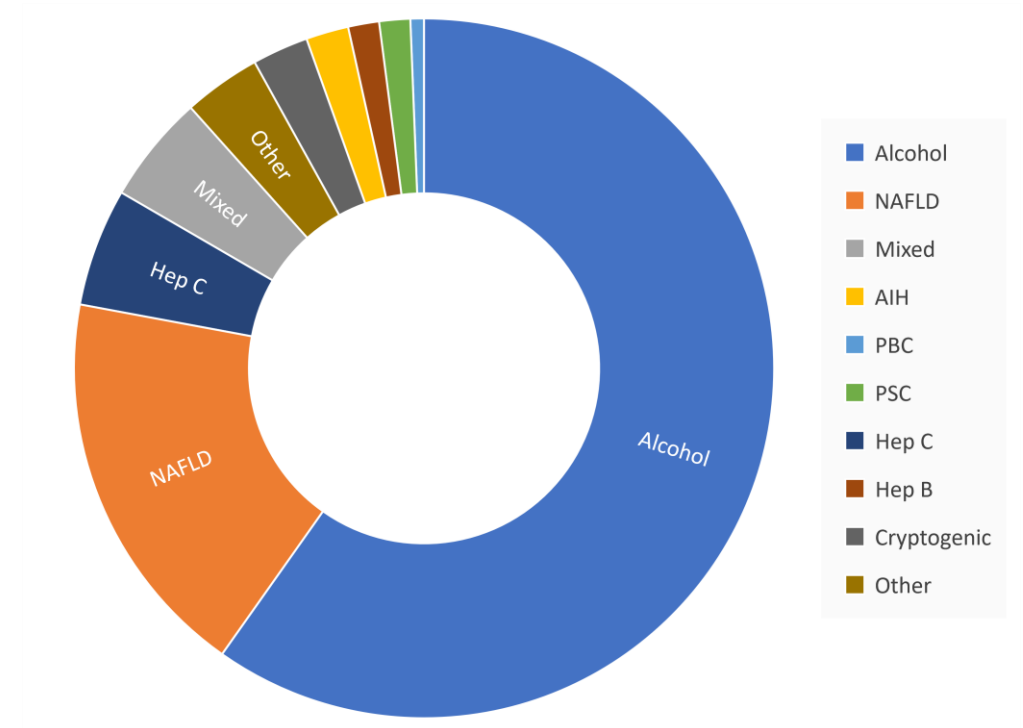
Results – aetiology



66.9% ArLD



20.3% MASLD



No significant difference in provision of EOLC between patients with different aetiology

Results – discussions / referrals



49.9% ACLD discussion
(61.4% IP vs 38.6% OP)

36.9% Advance care planning
(78% IP vs 22% OP)



46.9% IP palliative care referral
(**79.1%** during terminal admission)

17.7% OP palliative care referral

Results – prognostication

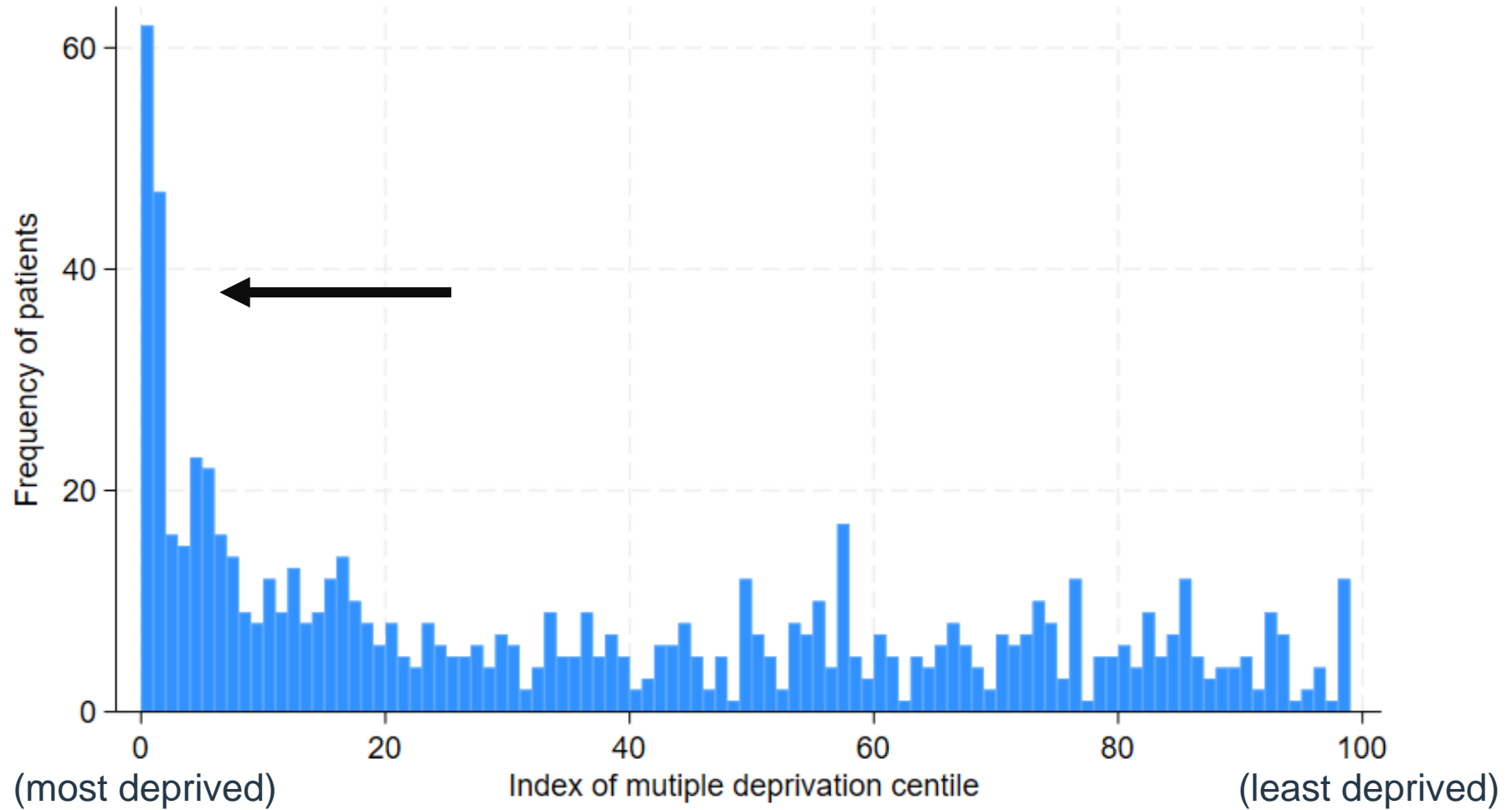


39.6% had a documented prognostic score

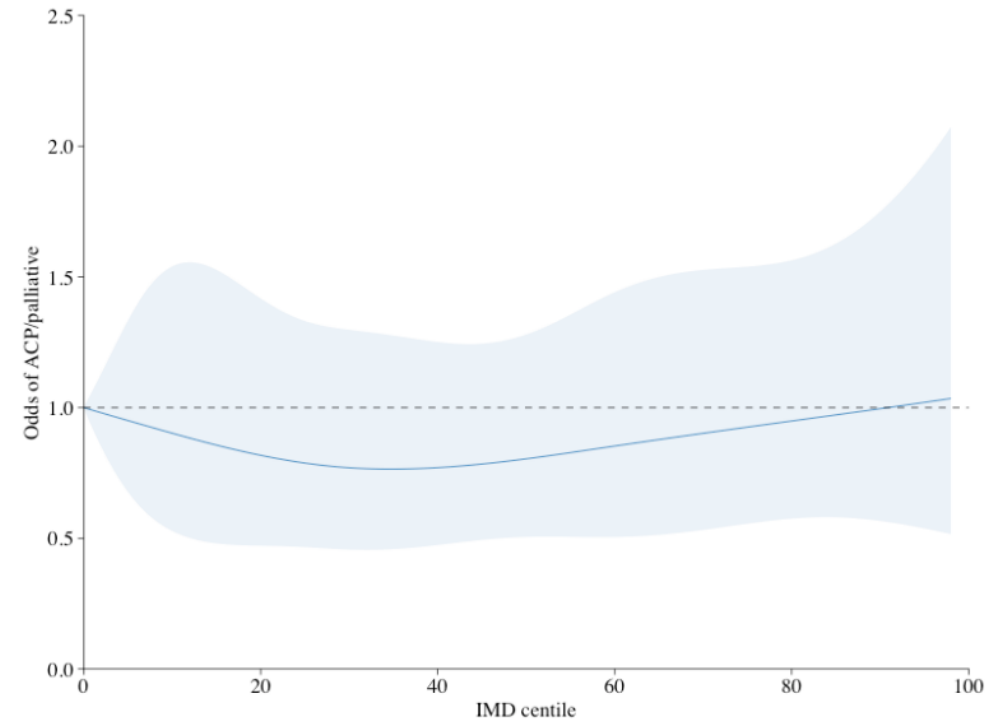
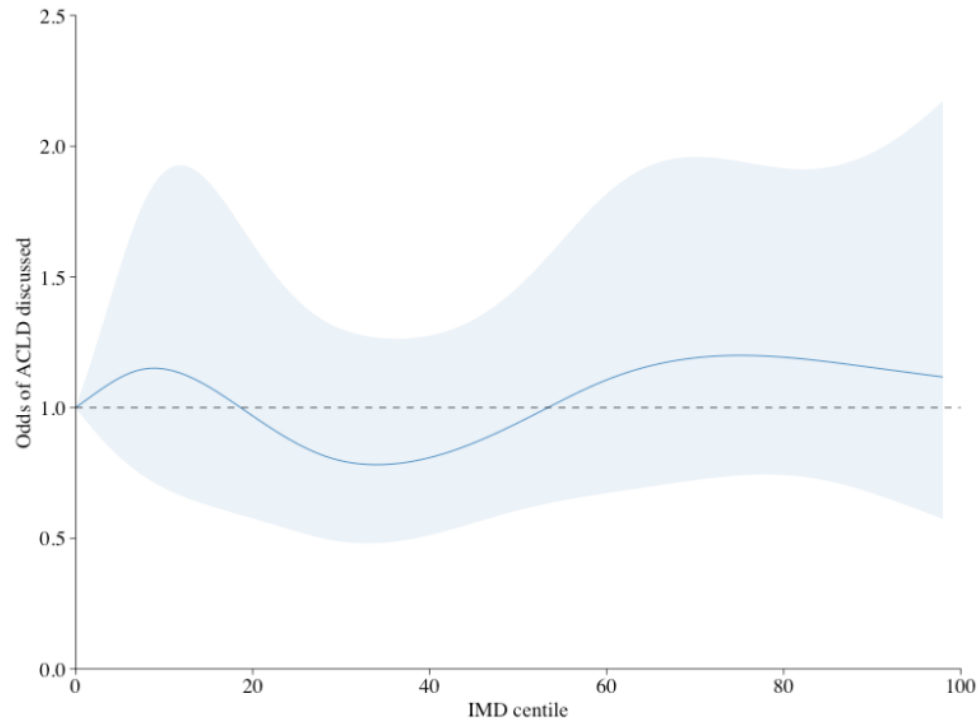
56.2% had a documented transplant status

26.2% were discussed at an ACLD MDT

Results - deprivation



Deprivation – the good news?



There was no significant difference in provision of EOLC dependent on deprivation

Results - service provision



No service factors were identified which significantly reduced the burden in inpatient bed days in the last year of life

Limitations



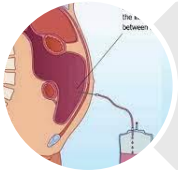
Next steps



Awaiting full data analysis for publication



Recommendations re: documentation of prognostic scores and transplant status






Subgroup analysis of patients with refractory ascites re: regional variation of care



Development of a UK-based guidance document

With thanks to...

CO-CHIEF INVESTIGATORS	
Dr Daniel Maggs <i>Gastroenterology Registrar, Somerset NHS Foundation Trust</i> daniel.maggs3@nhs.net	Dr Emma Saunbury <i>Hepatology Registrar, Cambridge University Hospitals NHS Foundation Trust</i> emma.saunbury@nhs.net
PROJECT MANAGEMENT WORKING GROUP	
Dr Giovanna Sheiybani <i>Gastroenterology Registrar, Royal United Hospitals Bath NHS Foundation Trust</i>	Dr Kushala Abeysekera <i>Hepatology Registrar, University Hospitals Bristol and Weston NHS Foundation Trust</i>
Dr Keith Pohl <i>Hepatology Registrar, University Hospitals Plymouth NHS Trust</i>	Dr Oliver Tavabie <i>Hepatology Registrar, Kingston Hospital NHS Foundation Trust</i>
Dr Sarah Bowers <i>Palliative Medicine Registrar, NHS Tayside</i>	
PROJECT OVERSIGHT	
Dr Shaji Sebastian <i>Chair of the BSG Research Committee</i>	Dr Ben Hudson <i>BASL End of Life Special Interest Group Lead</i>
PROJECT MANAGEMENT	
Dr Laura Magill <i>Birmingham Centre for Observational and Prospective Studies (BiCOPS)</i> bhamred@contacts.bham.ac.uk @bicops	
Dr Michala Pettitt	
Dr Elizabeth Li	

-  **@EVOLVE_EOLC**
-  **@esaunbury**
-  **@dan_maggs**