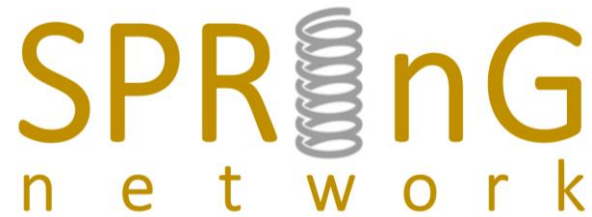


# End of life care in decompensated cirrhosis: a regional perspective


Dr Daniel Maggs and Dr Emma Saunbury  
on behalf of



BASL End of Life SIG Meeting  
21<sup>st</sup> October 2021

REVIEW

## Palliative care in liver disease: what does good look like?

Hazel Woodland <sup>1</sup>, Ben Hudson,<sup>2</sup> Karen Forbes,<sup>3</sup> Anne McCune,<sup>4</sup> Mark Wright,<sup>5</sup> On Behalf of the British Association for the Study of the Liver (BASL) End of Life Special Interest Group

RESEARCH

## Integration of palliative and supportive care in the management of advanced liver disease: development and evaluation of a prognostic screening tool and supportive care intervention

Benjamin E Hudson,<sup>1,2</sup> Kelly Ameshoa,<sup>1</sup> Anya Gopfert,<sup>1</sup> Rachael Goddard,<sup>1</sup> Karen Forbes,<sup>2,3</sup> Julia Verne,<sup>4</sup> Peter Collins,<sup>1</sup> Fiona Gordon,<sup>1</sup> Andrew J Portal,<sup>1</sup> Colette Reid,<sup>3</sup> C Anne McCune<sup>1</sup>

## Guidelines on the management of ascites in cirrhosis

Guruprasad P Aithal <sup>1,2</sup>, Naaventhana Palaniyappan,<sup>1,2</sup> Louise China,<sup>3</sup> Sivi Härmälä,<sup>4</sup> Lucia Macken <sup>5,6</sup>, Jennifer M Ryan,<sup>3,7</sup> Emilie A Wilkes,<sup>2,8</sup> Kevin Moore,<sup>3</sup> Joanna A Leithead,<sup>9</sup> Peter C Hayes,<sup>10</sup> Alastair J O'Brien <sup>3</sup>, Sumita Verma<sup>5,6</sup>



British Association for the Study of the Liver

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## END OF LIFE SPECIAL INTEREST GROUP

### End of Life Special Interest Group

The End of Life Special Interest Group (SIG) is linked to the Cirrhosis and its Complications CRN topic area. The SIG Lead is Dr Ben Hudson of Royal Devon & Exeter Hospital. The first meeting of the SIG was held in March 2018. If anyone wishes to join the group please contact the BASL secretariat at [Kim@basl.org.uk](mailto:Kim@basl.org.uk).

### Recommendations

- ▶ Patients with refractory ascites who are not undergoing evaluation for liver transplant should be offered a palliative care referral. Besides repeated LVP, alternative palliative interventions for refractory ascites should also be considered. (*Quality of evidence: weak; Recommendation: strong*)

# Project questions:

What degree of end of life care (EOLC) are patients with cirrhosis receiving regionally?

Can a prognostic screening tool be used to identify patients with cirrhosis with a likely prognosis of  $\leq 12$  months?



**Could we be initiating tailored EOLC at an earlier stage?**

# 'Poor prognosis' screening tool:

*Poor Prognosis Criteria	Tick
Child Pugh C	
>2 liver-related admissions in the last 6 months	
Ongoing alcohol use (in ArLD)	
Unsuitable for transplant work-up	
WHO performance status 3-4 <i>i.e. capable of only limited or no self-care, confined to bed or chair &gt;50% of waking hours)</i>	
<b>Total Score:</b>	<b>/5</b>

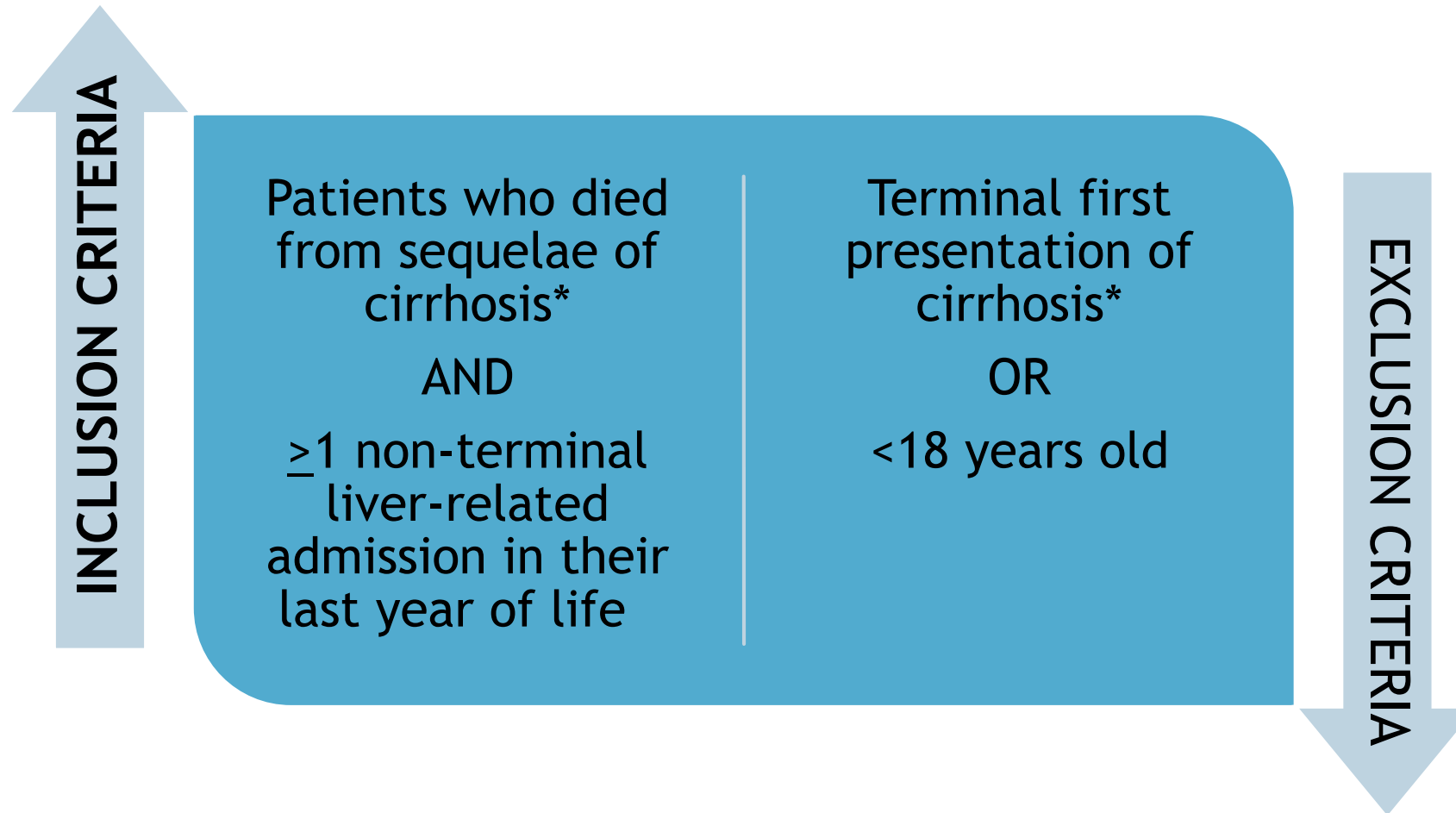
PPV for death  
within 12 months:

**81%**

(sensitivity 72%, specificity 84%)

**≥3/5 is significant**

# Inclusion/exclusion criteria:



\*This ICD 10 list is based on official clinical coding which has been used nationally as part of the Hepatobiliary and Pancreas - Cirrhosis of the Liver (Adults) Quality Dashboard 2018/19):  
<https://www.england.nhs.uk/wp-content/uploads/2018/03/hepatobiliary-and-pancreas-cirrhosis-of-the-liver-adults-metric-definitions-2018-19-v2.pdf>

# Data collection:

- 31st Jan 2019 - 31st Jan 2020 (i.e. pre-COVID)
- Retrospectively looking at the last 12 months of life
- Electronic records only (discharge summaries, clinic letters, e-referrals)

Institutional Data	Patient Data
1) DGH vs tertiary 2) IQILS status 3) Liver MDT 4) Hepatology service	1) Demographics 2) Aetiology of cirrhosis 3) Child/MELD score within last year of life - Was this formally documented within last year of life? 4) Prognostic screening tool – meets $\geq 3$ criteria? - If yes, how many months prior to death were $\geq 3$ criteria met? 5) Drain-dependent ascites (+/- PleurX)? - If PleurX, inserted how many months before death? 6) Number of liver-related admissions in last year of life 7) Number of clinics (consultant vs SpR) in last year of life 8) Discussion re: advanced ('end stage') liver disease - If yes, how many months before death and in what setting? 9) Discussion re: palliative or EOLC planning - If yes, how many months before death and in what setting? - Was this only during terminal or final admission? 10) Inpatient palliative care referral - If yes, how many months before death? - Was this only during terminal or final admission? 11) Community palliative care referral - If yes, how many months before death? - Was this only during final admission? - Was this a CHC fast track referral? 12) Referred to a liver MDT 13) Poor prognosis letter sent to GP

# Project development



**Pilot project:**

- RUH, Bath (n=52)

**Extension to  
South West region:**


- Severn deanery
- Peninsula deanery

**Currently  
involved:**

- 10 sites
- 14 trainees

**Data collection ongoing:**

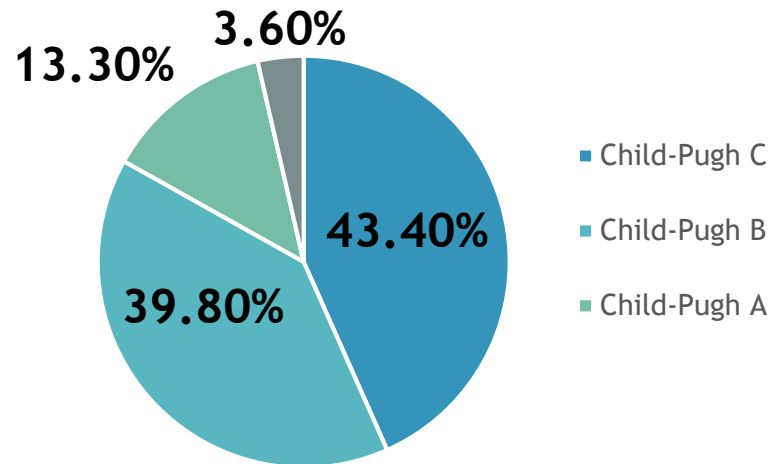
- n=83 so far
- n=140+ anticipated

**SPR**  **nG**  
network

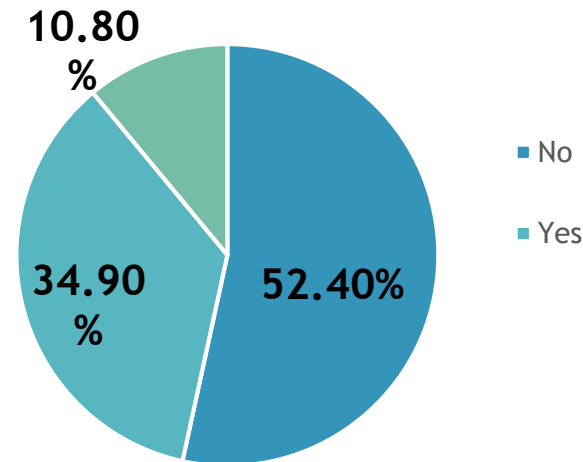


# Early data: prognostication

Child-Pugh score (retrospectively calculated)



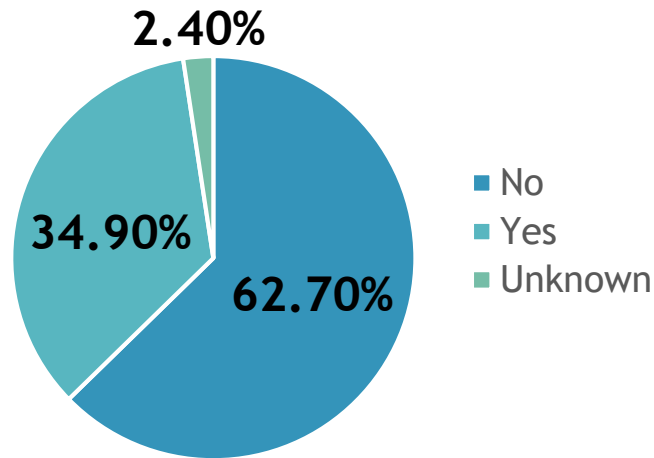
Meets  $\geq 3$  'poor prognosis' criteria



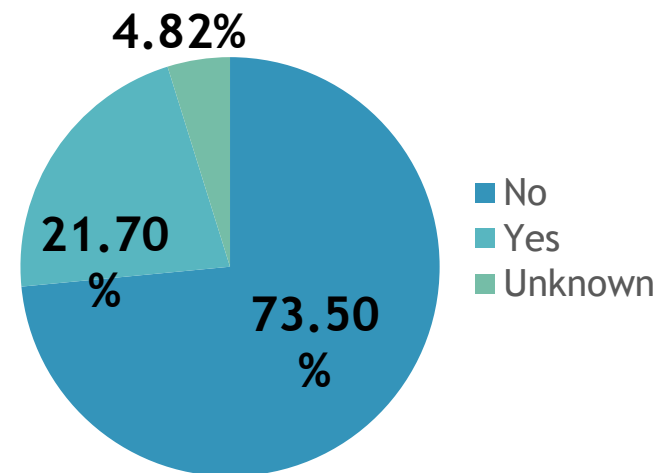
- 78.3% had no Child-Pugh/MELD-Na score documented in last year of life
- Poor prognosis score - would dynamic assessment be more helpful?

# Early data: end stage liver disease/EOLC

Discussion re: end-stage liver disease



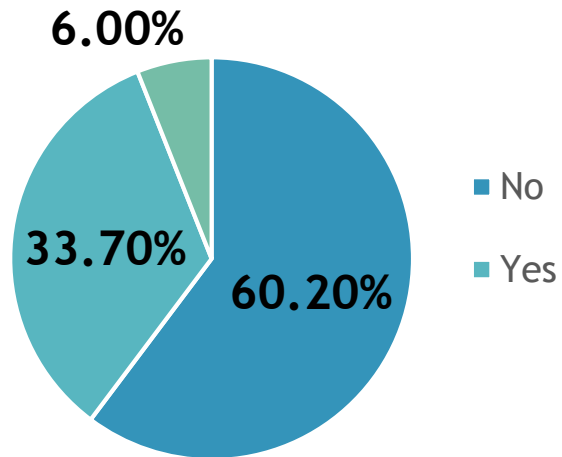
Discussion re: EOLC



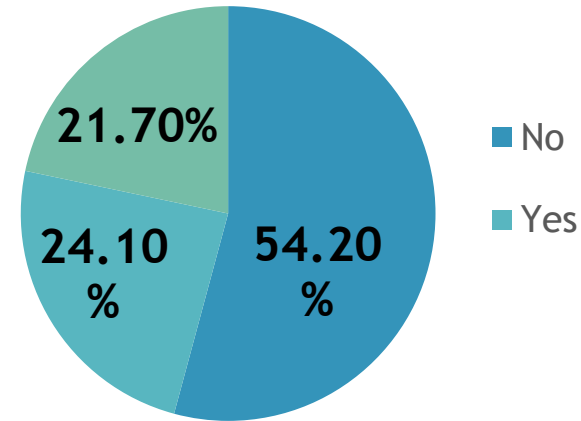
- Variation in setting (inpatient, outpatient, community, MDU/Amb Care)
- Of patients who received an ESLD diagnosis only 55.2% received counselling re: EOLC

# Early data: palliative care referral

Inpatient palliative care referral



Community palliative care referral



- Symptom burden in ESLD is significant and resembles that of patients with other advanced conditions

**Table 3.** Comparison of common symptom prevalence (range min to max) in end-stage liver disease and other advanced conditions.<sup>a</sup>

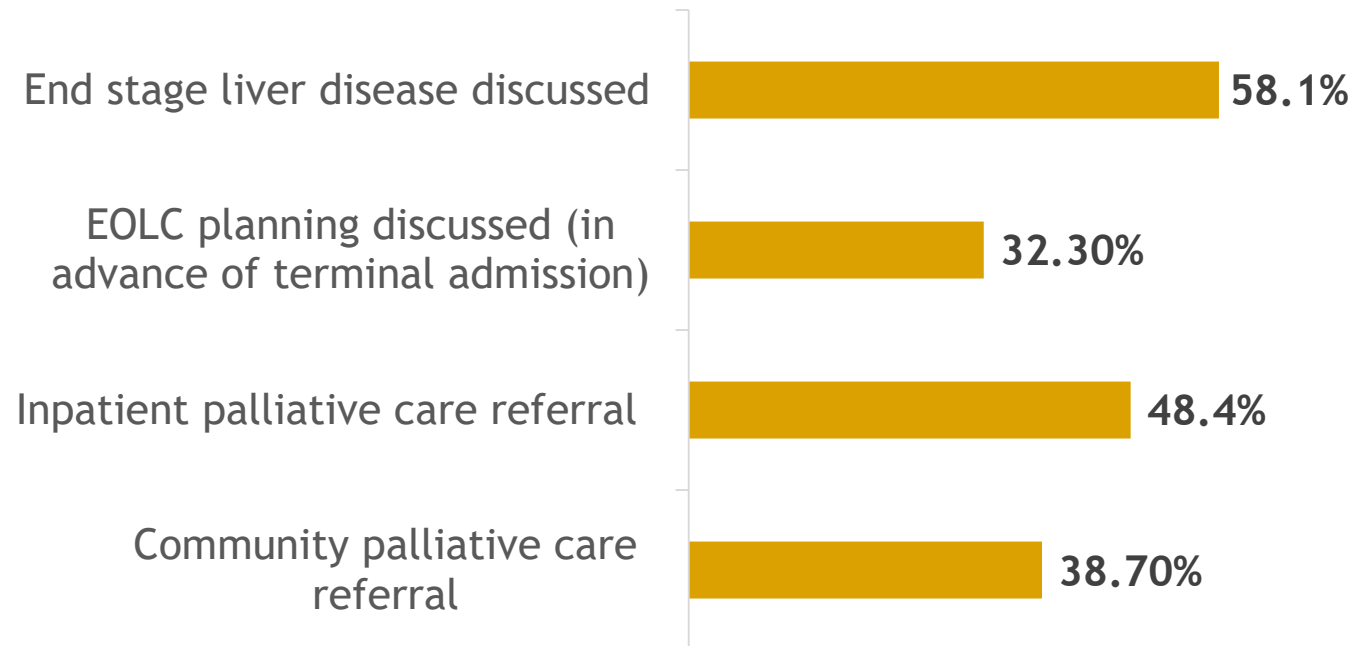
Symptom	ESLD	Cancer <sup>a</sup>	COPD <sup>a</sup>	CHF <sup>a</sup>	ESRD <sup>a</sup>	Dementia <sup>a</sup>	MND <sup>a</sup>	MS <sup>a</sup>
Pain	30–79	30–97	21–77	14–78	11–83	14–63	52–76	68
Breathlessness	20–88	16–77	56–98	18–88	11–82	12–52	81–88	26
Insomnia	26–77	3–67	15–77	36–48	1–83	14	24–33	
Fatigue	52–86	23–100	32–96	42–82	13–100	22		80
Anorexia	49	76–95	64–67		38–64			
Nausea or vomiting	58	2–78	4	2–48	8–52	8		26
Depression	4–5–64	4–80	17–77	6–59	2–61	46	23	15
Anxiety	14–45	3–74	23–53	2–49	7–52	8–72	19	24

ESLD: end-stage liver disease; COPD: chronic obstructive pulmonary disease; CHF: congestive heart failure; ESRD: end-stage renal disease; MND: motor neuron disease; MS: multiple sclerosis.

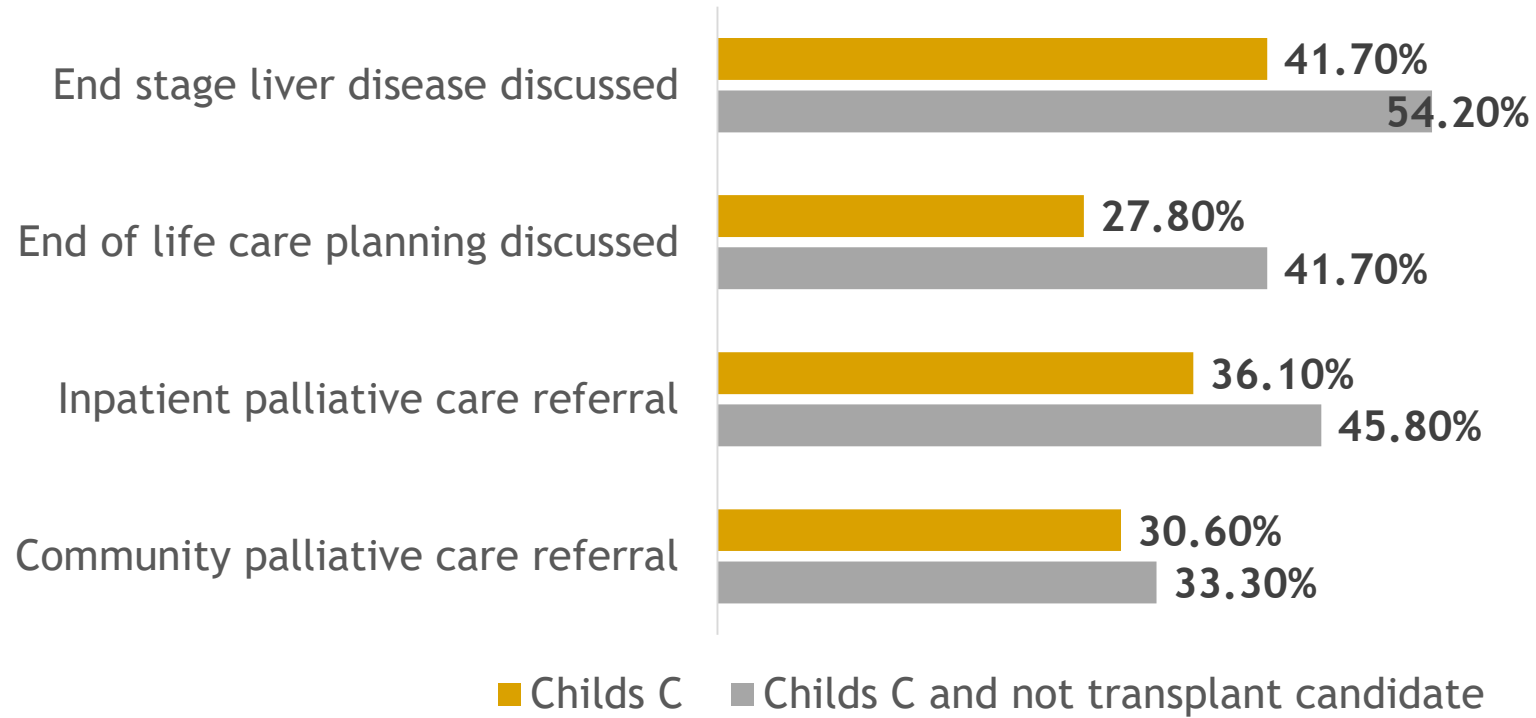
Adapted from Moens et al.<sup>105</sup>  
<sup>a</sup>Data on prevalence of symptoms.

Peng J-K, Heggul N, Higginson IJ, Gao W. Symptom prevalence and quality of life of patients with end-stage liver disease: A systematic review and meta-analysis. *Palliative Medicine*. 2019;33(1):24-36.  
doi:10.1177/0269216318807051

# Early data: drain-dependent ascites



# Early data: Child-Pugh C



# Future focus

- Commentary on regional provision of EOLC (with subgroup analysis)
- Is there a significant difference in provision between centres?
- Regional validation of a ‘poor prognosis’ screening tool?
- Future work - opportunity for national expansion via ToRcH

Thank you.  
Are there any questions?

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