
Thank you for taking the time to answer our survey. Please answer the questions as accurately and thoroughly as you can.

Demographics

1. What is your professional background?

- Doctor
- Nurse
- Allied Health Professional
- Other [Please specify: ____________________________]

2. In which geographical (NHS) Regions do you work?

- England
- North of England
- Midlands and East of Anglia
- South of England
- London
- Wales
- Scotland
- Northern Ireland

What Trust do you work for? Name of Trust: ______________________________

What is the name of the Trust that you work in

3. Do you work in:

- Primary Care [if clicked, will take user directly to GP section]
- Hepatology [if clicked, will take user directly to liver specific section]
- Gastroenterology [if clicked, will take user directly to liver specific questions]
- Specialist palliative care [if clicked, will take user to 3(a)].

3a. Do you work in:

- Hospital
- Hospice
- Community

[After options in 3a answered, then take user to SPC section]
4a. In principal, do you accept referrals for patients with cirrhosis near the end of life from liver teams?

Yes / No

b) How many patients did you see with a diagnosis of end stage liver disease in the last year? (Please just give a rough estimate)

None  [ ] If this box ticked, go to 5
1-5  [ ]
6-10  [ ]
11-20 [ ]
21 +  [ ]

c) What percentage of your patient load has a principal diagnosis of cirrhosis/liver disease? (Please just give a rough estimate)  _____ %

d) Did any of these referrals originate from GPs?
Yes [if ticked, go to 5e]/ No [if ticked, go to 5f]

e) How many? (Please just give a rough estimate) _______

Of all referrals in the last year:

f) How many were for hospital Specialist Palliative Care? (Please just give a rough estimate)

None  [ ]
1-5  [ ]
6-10  [ ]
11-20 [ ]
21 +  [ ]

g) How many were for specialist palliative care at home? (Please just give a rough estimate)

None  [ ]
1-5  [ ]
6-10  [ ]
11-20 [ ]
21 +  [ ]

h) How many were for hospice admission? (Please just give a rough estimate)

None  [ ]
5. What were the reasons for patients with cirrhosis (near the end of life) being referred to Specialist palliative care by liver teams/General Practitioners?

Tick all reasons that apply:
- Symptom Control
- End of life issues
- Hospice/Palliative Care
- Communicating difficult news
- Ethical decision making
- Social/family
- Bereavement support
- Other

If other ticked, List main reason [Open text]: _________

6. Do you believe Specialist Palliative Care services have a role in patients with cirrhosis?

Yes/No/Don’t know

7. If you answered yes to question 6: In your view, when is the most appropriate time for referral? (tick all that apply)

Tick all reasons that apply:
- Initial diagnosis
- Deterioration in symptoms
- Consideration of advanced liver management
- Recurrent hospital admissions
- End-stage/end-of-life

8. If you answered no to question 6: Why not? (tick all that apply)

- lack of resources
- lack of beds (including respite bed facilities)
- implications for staff training
- organisational decision
- lack of expertise
- none/few referred (by liver team or GP)
- Cardiac professionals can do this
- Unable to provide specialised liver therapy
9. Do you feel you have the appropriate skills and knowledge to look after this group of patients?  
Yes/No

10. Please list what training (if any) you would need to improve your skills and knowledge in caring for this group of patients with cirrhosis.

Tick all reasons that apply:
- Education on assessment and management of decompensated liver disease
- Up to date information about advances in managing recurrent ascites
- Education on pharmacology in cirrhosis
- Information on prognostication
- Likely illness trajectory in cirrhosis
- Other

If other ticked, List main reason [Open text]: __________

11. What do you think are the barriers to providing care to this patient group?

Tick all reasons that apply:
- High frequency of complex and difficult social circumstances
- Lack of education of SPC providers on managing cirrhosis patients
- Lack of education of liver teams in end of life care
- Lack of possibilities for joint working between SPC/GP/liver teams
- Other

If other ticked, List main reason [Open text]: __________

12. Which of the following do you think would improve end of life care for patients with cirrhosis?

Tick your main answer:
- Improved liaison between secondary and primary care
- Improved provision of specialist palliative care
- More education opportunities in specialist liver units
- Other

Please specify what: __________

10a. Have you received any referrals for patients with hepatocellular carcinoma?  Yes/No
b) How many referrals for patients with hepatocellular carcinoma did you receive in the last year?  
(Please just give a rough estimate)

None  
1-5  
6-10  
11-20  
21 +

11. What are your key priorities for research in end stage liver disease?

OPEN TEXT

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Thank you for completing this questionnaire
Liver Teams

4a) Do you refer any of your patients to Specialist Palliative care?  Yes / No

Yes [if ticked, go to 4b] / No [if ticked, go to 4d]

b) How many patients from in-patient care did you refer to specialist palliative care in the last year?
(Please just give a rough estimate)
- None
- 1-5
- 6-10
- 11-20
- 21+  

If responses to 4[b] and 4[c] were BOTH ticked as None, go to 5 [ii] Otherwise, go to 5 [i]

5 i. What are the reasons for referral to SPC?

Tick all reasons that apply:
- Symptom Control
- End of life issues
- Hospice/Palliative Care
- Communicating difficult news
- Ethical decision making
- Social/family
- Bereavement support
- Other  If other ticked, list main reason [Open text]: _________

5 ii) Patients were not referred to specialist palliative care for the following reasons;
Tick all reasons that apply:

- Patients were not identified as at the EOL
- The liver team were able to manage the patients’ needs
- Palliative care do not accept referrals for liver patients
- No palliative care service to refer to
- Other

Please specify: ________________

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6. Do you believe Specialist Palliative Care services have a role in patients with cirrhosis?  
   Yes/No/Don’t know

7. If you answered yes to question 6: In your view, when is the most appropriate time for referral? (tick all that apply)

Tick all reasons that apply:
- Initial diagnosis
- Deterioration in symptoms
- Consideration of advanced liver management
- Recurrent hospital admissions
- End-stage/end-of-life

8. If you answered no to question 6: Why not? (tick all that apply)

- Lack of resources
- Lack of beds (including respite bed facilities)
- Implications for staff training
- Organisational decision
- Lack of expertise
- None/few referred (by liver team or GP)
- Cardiac professionals can do this
- Unable to provide specialised liver therapy
- Other

If other ticked, List main reason [Open text]: __________

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9. How could care for patients with cirrhosis at the end of life be improved?

   Open TEXT

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10. Please list what training (if any) you would need to improve your skills in caring for this group of patients with cirrhosis near the end of life.

*Tick all reasons that apply:*
- Symptom Control
- End of life issues
- Communicating difficult news
- Ethical decision making
- Social/family
- Bereavement counselling
- Other

Please specify what: ____________

11. Which of the following do you think would improve end of life care for patients cirrhosis?

- Improved liaison between secondary and primary care
- Improved provision of specialist palliative care
- More education opportunities in specialist liver units
- Other

Please specify what: ____________

12. What are your key priorities for research in end stage liver disease?

OPEN TEXT

Thank you for completing this questionnaire
Primary Care

4) a) Do you receive referrals from liver centres for palliative care/end of life care? Yes/No
   b) Do you routinely provide end of life care for your patients? Yes/No
   c) Do you take part in a GSF? Yes/No

5) Do you feel you have the skills to manage patients with cirrhosis near the end of life in the community? Yes/No

6) Have you referred ANY patients with cirrhosis to specialist palliative care? Yes/No
   If Yes, go to 7; If No, go to 9

7) For those who have referrals to Specialist PC, reasons for your referral?
   Tick all reasons that apply:
   Symptom Control
   End of life issues
   Hospice/Palliative Care
   Communicating difficult news
   Ethical decision making
   Social/family
   Bereavement support
   Other
   If other tick, List main reason(s): ____________

8) How many patients with cirrhosis have you referred in the last year? (Please just give a rough estimate)
   None
   1-5
   6-10
   11-20
   21

9) a) Do you think that patients with cirrhosis can be adequately managed in the community? Yes/No/Don’t Know
   b) Please give a reason for your responses?
      Open TEXT
10) Please list what training (if any) you would need to improve your skills in caring for patients with cirrhosis near the end of life.

Tick all reasons that apply:
Symptom Control
End of life issues
Communicating difficult news
Ethical decision making
Social/family
Bereavement counselling
Other  Please specify what: ____________

11. Which of the following do you think would improve end of life care for patients with cirrhosis?

Improved liaison between secondary and primary care  
Improved provision of specialist palliative care
More education opportunities in specialist liver units
Other  Please specify what: ____________

12. What are your key priorities for research in end stage liver disease?

OPEN TEXT

Thank you for completing this questionnaire
Appendix ii: Number of potential respondents identified from each organisation by professional group.

Respondents  
\[n = 6181\]

Gastroenterology / Hepatology

- **BSG**  
  \[n = 500\]

- **RCN gastro**  
  \[n = 3000\]

- **BASL**  
  \[n = 804\]

- **BLNF**  
  \[n = 100\]

- **London liver group**  
  \[n = 149\]

Specialist palliative care

- **APM**  
  \[n = 840\]

- **Help the hospice**  
  \[n = 313\]

Primary care

- **Natioanl Nurse consultant group (Palliative Care)**  
  \[n = 27\]

- **APM - Association for Palliative Medicine**

**Key:**

PCSG - Primary Care Society for Gastroenterology

BASL - British Association Study Liver

BSG - British Society of Gastroenterology – Liver section

BLTNF - British Liver Trust Nurses Forum

RCN - Royal College of Nursing gastro-enterology section

APM - Association for Palliative Medicine
Appendix iii: Respondents professional background by speciality

<table>
<thead>
<tr>
<th>Respondents professional background</th>
<th>Gastro-entrology</th>
<th>Hepatology</th>
<th>Primary Care.</th>
<th>Specialist palliative care.</th>
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Appendix iv: Respondents’ speciality by site of NHS Region

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<thead>
<tr>
<th>In which geographical (NHS) Region do you work?</th>
<th>Number (percentage) of respondents</th>
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<tbody>
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<td>5 (5)</td>
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<tr>
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