

Appendix i: Paper version of the on-line survey titled “National e-survey – Provision of end of life care in patients with cirrhosis

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]

SPC – Specific Questionnaire

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 | <input type="checkbox"/> | If this box ticked, go to 5 |
| 1-5 | <input type="checkbox"/> | |
| 6-10 | <input type="checkbox"/> | |
| 11-20 | <input type="checkbox"/> | |
| 21 + | <input type="checkbox"/> | |

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 referral 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 | <input type="checkbox"/> |
| 1-5 | <input type="checkbox"/> |
| 6-10 | <input type="checkbox"/> |
| 11-20 | <input type="checkbox"/> |
| 21 + | <input type="checkbox"/> |

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

- | | |
|-------|--------------------------|
| None | <input type="checkbox"/> |
| 1-5 | <input type="checkbox"/> |
| 6-10 | <input type="checkbox"/> |
| 11-20 | <input type="checkbox"/> |
| 21 + | <input type="checkbox"/> |

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

- | | |
|------|--------------------------|
| None | <input type="checkbox"/> |
|------|--------------------------|

- 1-5
- 6-10
- 11-20
- 21 +

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

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

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

Yes [if ticked, go to 10b]/ No [if ticked, go to 11]

b) How many referrals for patients with hepatocellular carcinoma did you receive in the last year?
(Please just give a rough estimate)

- | | |
|-------|--------------------------|
| None | <input type="checkbox"/> |
| 1-5 | <input type="checkbox"/> |
| 6-10 | <input type="checkbox"/> |
| 11-20 | <input type="checkbox"/> |
| 21 + | <input type="checkbox"/> |
-

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

OPEN TEXT

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+

c) How many from out-patient 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: _____
-

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]: _____
-

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

Open TEXT

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 | <input type="checkbox"/> | |
| End of life issues | <input type="checkbox"/> | |
| Hospice/Palliative Care | <input type="checkbox"/> | |
| Communicating difficult news | <input type="checkbox"/> | |
| Ethical decision making | <input type="checkbox"/> | |
| Social/family | <input type="checkbox"/> | |
| Bereavement support | <input type="checkbox"/> | |
| Other | <input type="checkbox"/> | 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 | <input type="checkbox"/> |
| 1-5 | <input type="checkbox"/> |
| 6-10 | <input type="checkbox"/> |
| 11-20 | <input type="checkbox"/> |
| 21 | <input type="checkbox"/> |
-

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?

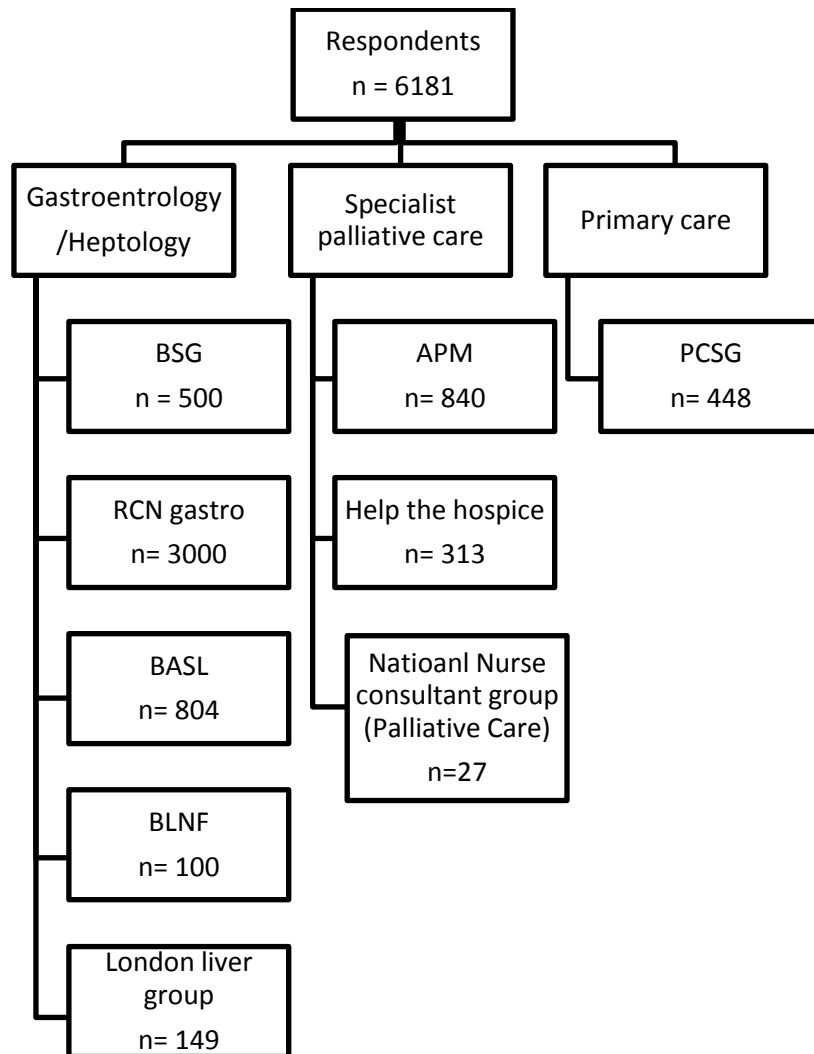
- Improved liaison between secondary and primary care
- Improved provision of specialist palliative care
- More education opportunities in specialist liver units
- Other Please specify what: _____

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.



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

| Respondents professional background | Respondents Speciality | | | | |
|-------------------------------------|------------------------|------------|---------------|-----------------------------|-------|
| | Gastro-entroylogy | Hepatology | Primary Care. | Specialist palliative care. | Total |
| AHP | 0 | 1 | 1 | 5 | 7 |
| Doctor | 55 | 72 | 19 | 160 | 306 |
| Nurse | 42 | 25 | 25 | 106 | 198 |
| Other | 0 | 0 | 1 | 2 | 3 |
| Total | 97 | 98 | 46 | 273 | 514 |

Appendix iv: Respondents' speciality by site of NHS Region

| In which geographical (NHS) Region do you work? | Number (percentage) of respondents | | | | |
|---|------------------------------------|------------|--------------|----------------------------|-----------|
| | Gastro-entriology | Hepatology | Primary Care | Specialist palliative care | Total |
| London | 15 (15) | 31 (32) | 5 (11) | 43 (16) | 94 (18) |
| Midlands and East of England | 17 (18) | 21 (21) | 7 (15) | 54 (20) | 99 (19) |
| North of England | 33 (34) | 15 (15) | 22 (48) | 100 (37) | 170 (33) |
| Northern Ireland | 1 (1) | 2 (2) | 0 (0) | 11 (4) | 14 (3) |
| Scotland | 7 (7) | 9 (9) | 5 (11) | 19 (7) | 40 (8) |
| South of England | 20 (21) | 15 (15) | 6 (13) | 33 (12) | 74 (14) |
| Wales | 4 (4) | 5 (5) | 1 (2) | 13 (5) | 23 (4) |
| Total | 97 (100) | 98 (100) | 46 (100) | 273 (100) | 514 (100) |