End of Life Care in Liver disease

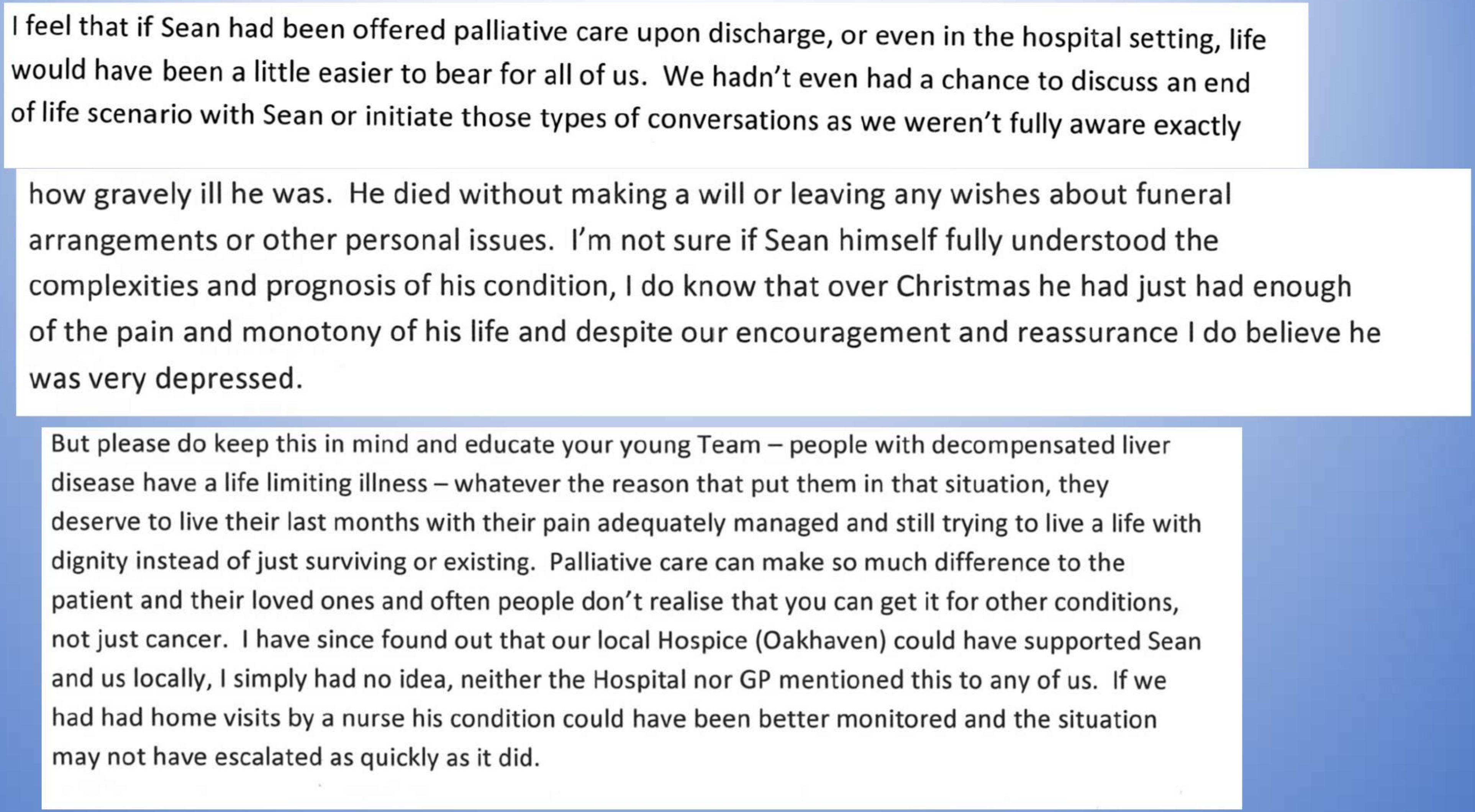
BASL Special interest group meeting

20th March 2019

The Aims of a SIG

- Interest itself
- Facilitate research
- Identify and share best practice
- Spread the word

How to achieve scalability



I feel that if Sean had been offered palliative care upon discharge, or even in the hospital setting, life would have been a little easier to bear for all of us. We hadn't even had a chance to discuss an end of life scenario with Sean or initiate those types of conversations as we weren't fully aware exactly how gravely ill he was. He died without making a will or leaving any wishes about funeral arrangements or other personal issues. I'm not sure if Sean himself fully understood the complexities and prognosis of his condition, I do know that over Christmas he had just had enough of the pain and monotony of his life and despite our encouragement and reassurance I do believe he was very depressed.

But please do keep this in mind and educate your young Team – people with decompensated liver disease have a life limiting illness – whatever the reason that put them in that situation, they deserve to live their last months with their pain adequately managed and still trying to live a life with dignity instead of just surviving or existing. Palliative care can make so much difference to the patient and their loved ones and often people don't realise that you can get it for other conditions, not just cancer. I have since found out that our local Hospice (Oakhaven) could have supported Sean and us locally, I simply had no idea, neither the Hospital nor GP mentioned this to any of us. If we had had home visits by a nurse his condition could have been better monitored and the situation may not have escalated as quickly as it did.

However, it cannot be stressed enough about the psychological effect on the patient and the carer which is not always obvious.

You are given a scenario with very few treatment options and the knowledge that there is just one way you are going and that is down. The hopelessness of our future took its toll on both of us. Over the years Jim changed from a sociable extrovert to a monosyllabic introvert. I began to comfort eat and not to be bothered undertaking any of my hobbies. I spent most afternoons just watching daytime television. All the energy I had went into keeping Jim alive.

What I can say is, he had the correct interventions at the correct time. He had excellent support right up to the end and he died (what most of us would wish for) a peaceful death.

Increasing participation in advance care planning for end of life care of patients with liver disease

NIHR Doctoral Research Fellowship Proposal

Dr. Roberta Jordan

Academic Clinical Fellow in Palliative Medicine, University of Leeds

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PLANNING
FOR YOUR FUTURE CARE
A Guide

Voluntary

Discussion with a patient

Patient education about the future

May choose to make wishes or express preferences for future care

These would be referred to if a patient loses capacity in future

Supported nationally

Prolonging life vs. maximising quality of life

Emergency plans for worsening symptoms or complications

Preferred place of care and death

Advance decisions and LPOAs

CPR decisions

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Talking about dying:
How to begin honest conversations about what lies ahead

October 2018

Patients with liver disease……

72% patients with cirrhosis ineligible for liver transplantation did not have documented resuscitation decisions (prognosis 52 days)

30% HCPs in Leeds were unfamiliar with ACP

57% rarely had end of life conversations with patients (2014)

Qualitative studies highlight a lack of ACP

4% patients dying in hospital in England have documented ACP

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What is the evidence behind ACP?

- Improved communication between healthcare professionals and patients/carers
- Increased decision-making confidence
- Increased awareness of decisions and reduced psychological distress for carers
- Increased documentation of patients' wishes/preferences for care
- Increased agreement between preferences for care and the care that is actually delivered
- Increased specialist palliative care involvement
- Reduced hospitalisation and intensive care unit admission rates
- Reduced healthcare costs

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Why do we need more research in advance care planning in liver disease?

Unpredictable disease trajectory with sudden life-threatening complications

Liver transplantation for minority of patients – possibility of cure for those with a poor prognosis

We know advance care planning isn't well implemented nationally

We know patients with liver disease have significant end of life care needs that aren't being addressed

We know there may be liver-specific implementation problems that affect the process of advance care planning

Complex social circumstances that reduce access to healthcare and hinder care planning

Hospital-centred care and lack of well-established community pathways

Hepatic encephalopathy preventing patient participation

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Research aim: to develop an intervention that will encourage healthcare professionals to increase patient participation in ACP for end of life in the context of liver disease

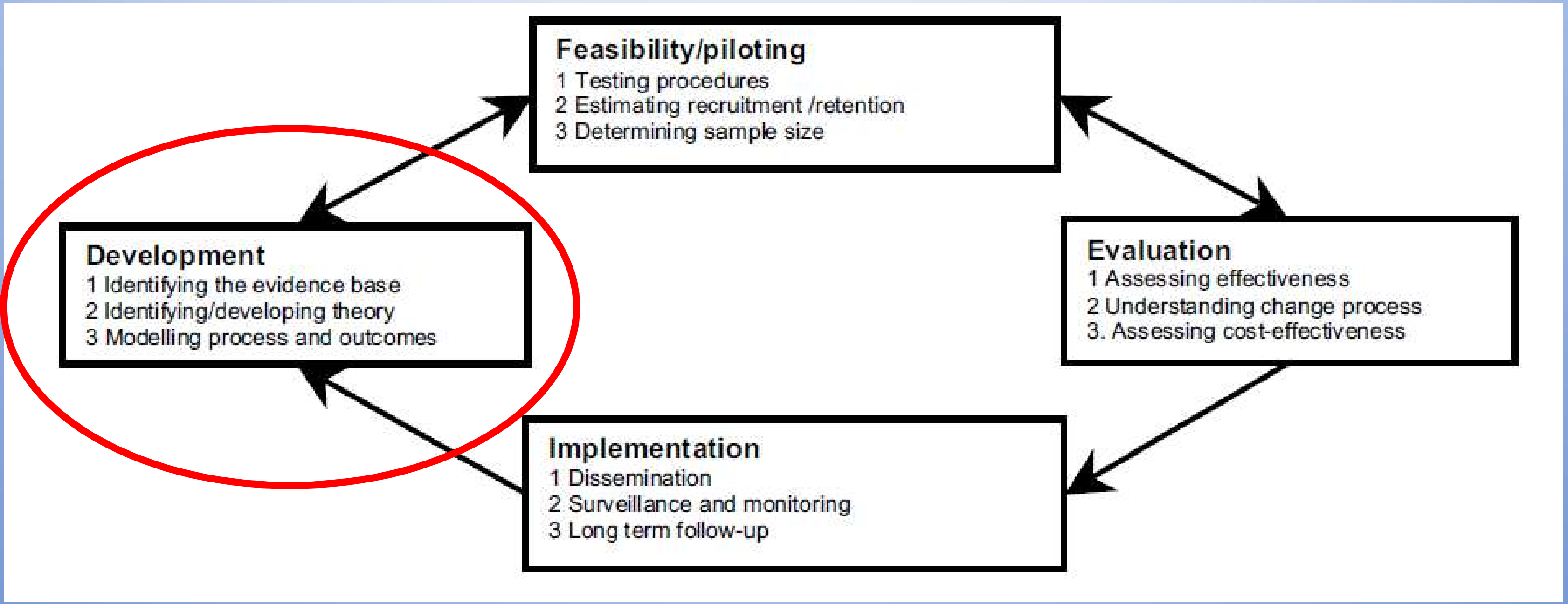
Objectives:

1. To understand attitudes towards advance care planning, barriers and facilitators to its implementation and opinions on its optimal conduct in liver disease and wider practice **(Phases 1 & 2)**

2. To design and manualise a behaviour change intervention for healthcare professionals, aiming to increase the participation of patients with liver disease in ACP **(Phase 3)**

3. To field-test the intervention, evaluating healthcare professionals' perceptions of behaviour change and patient acceptability of ACP in order to refine the intervention **(Phase 4)**

MRC Developing and evaluating complex interventions framework and guidance



Feasibility/piloting
1 Testing procedures
2 Estimating recruitment /retention
3 Determining sample size

Development
1 Identifying the evidence base
2 Identifying/developing theory
3 Modelling process and outcomes

Evaluation
1 Assessing effectiveness
2 Understanding change process
3. Assessing cost-effectiveness

Implementation
1 Dissemination
2 Surveillance and monitoring
3 Long term follow-up

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Phase 1 methods

Systematic review to identify evidence of:

Attitudes
Barriers
Facilitators
Optimal conduct

of
ACP in wider healthcare settings

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Phase 2 methods

12-16 patients with:

- Current or previous advanced disease (Child-Pugh score B/C)
- At least 1 hospital admission with decompensated liver disease

Qualitative study

using focus groups and interviews to identify

Attitudes
Barriers
Facilitators
Optimal conduct

of ACP in liver disease settings

12-16 carers:

- Identified by recruited patient
- Bereaved 1-5 years before recruitment

24- 32 HCPs:

Including consultants, GPs, junior doctors, transplant coordinators, specialist nurses, day care/inpatient nursing staff

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Phase 3 methods

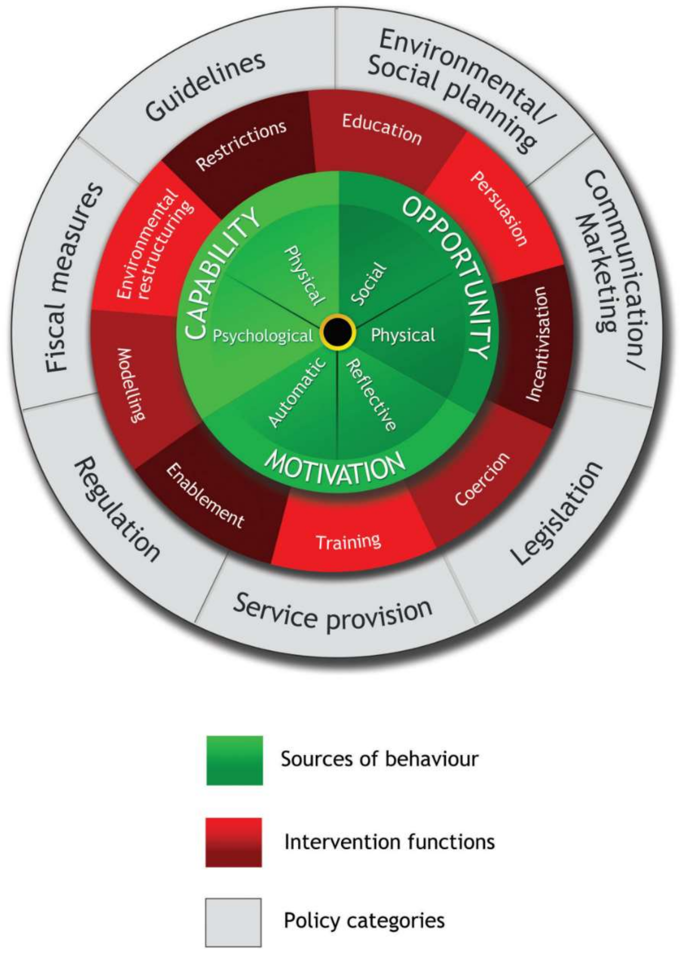
13 participants:

- 2 patients
- 2 carers
- 9 HCPs –
  - 3 hepatology/ gastroenterology consultants
  - 3 senior nurses
  - 2 GPs
  - 1 palliative medicine consultant

Participatory research

with stakeholder workshops

to develop a behaviour change intervention for HCPs



The Behaviour Change Wheel: A Guide to Designing Interventions
Susan Michie, Lou Atkins and Robert West

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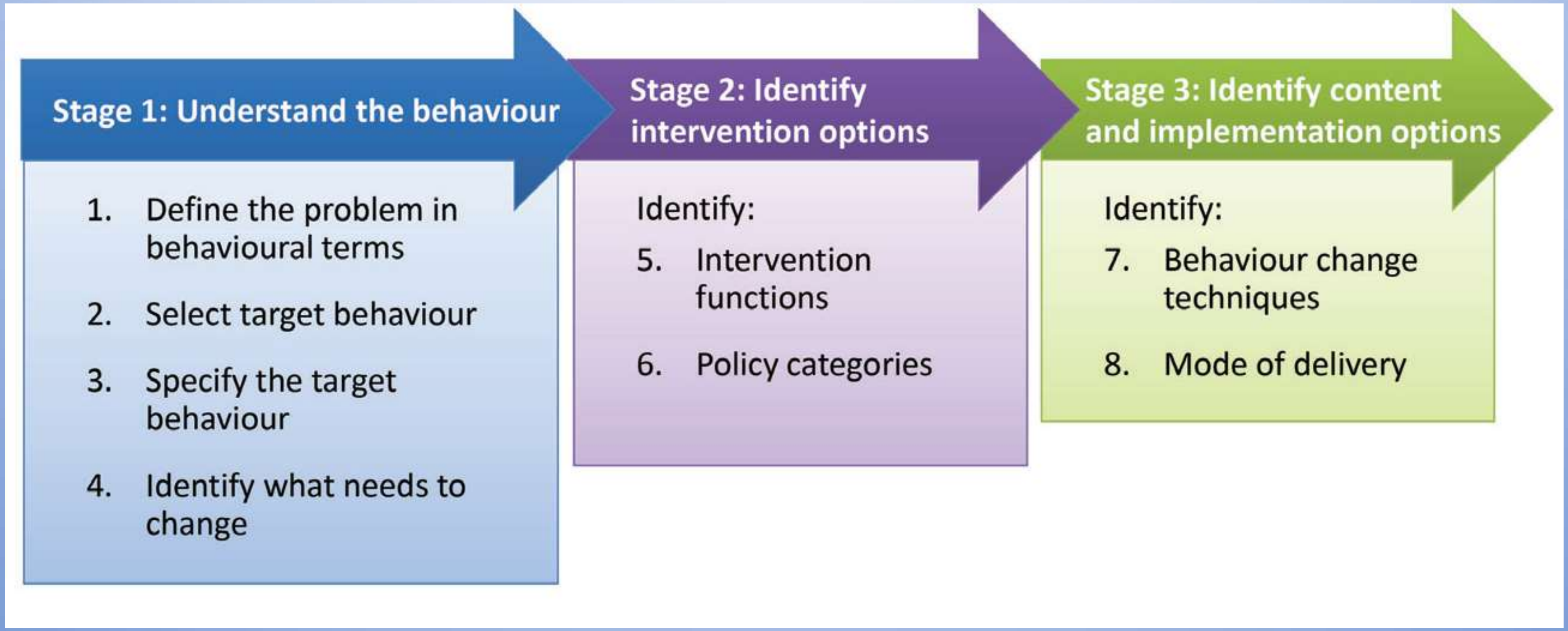
Phase 3



Stage 1: Understand the behaviour

1. Define the problem in behavioural terms
2. Select target behaviour
3. Specify the target behaviour
4. Identify what needs to change

Stage 2: Identify intervention options

Identify:

5. Intervention functions
6. Policy categories

Stage 3: Identify content and implementation options

Identify:

7. Behaviour change techniques
8. Mode of delivery

The Behaviour Change Wheel: A Guide to Designing Interventions
Susan Michie, Lou Atkins and Robert West

Phase 4 methods

Field-testing intervention

with HCPs

using before-and-after questionnaires

to identify:

- **perceptions of behaviour change**
- **patient acceptability of ACP**

6-9 HCPs:

- **Transplant unit**
- **Hepatology unit with no local transplant service**
- **Gastroenterology unit with no subspecialty hepatology**

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Final output: a refined behaviour change intervention, ready for further evaluation

Process analysis

Intervention feasibility testing/piloting

Recruitment

- Currently plans to recruit from:
  - **Leeds** – transplant unit
  - **Hull** – hepatology unit with no local transplant service
  - **Edmonton** Cirrhosis Care Clinic, Canada (HCPs only)

We would like to recruit participants from a Gastroenterology unit with no subspecialty hepatology

Please contact me if interested – r.i.jordan@leeds.ac.uk

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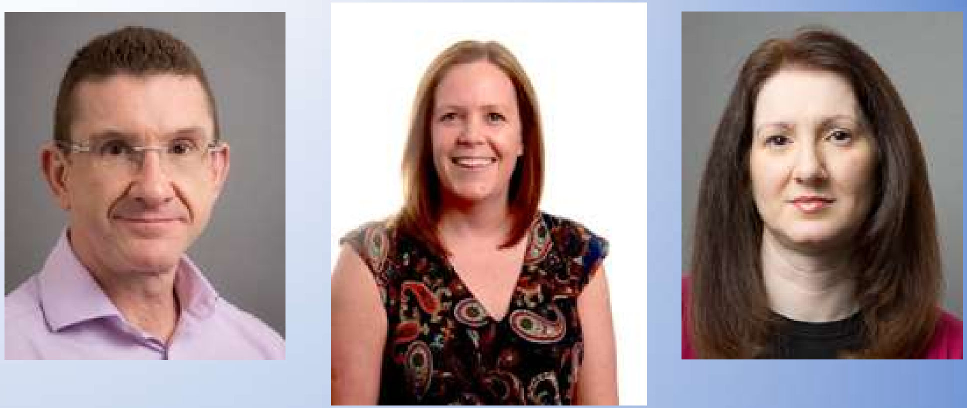
Acknowledgements

- Prof Mike Bennett
- Dr Shenaz Ahmed
- Dr Lynsey Corless
- Dr Jayne Dillon
- Dr Ben Hudson
- Dr Puneeta Tandon
- St James Liver Transplant Support Group
- LIVErNORTH



Liver NORTH
NATIONAL LIVER PATIENT SUPPORT
www.livernorth.org.uk
Charity no. 1087226

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References

NHS Liver Care. Getting it Right: Improving end of life care for people living with liver disease. 2013.

Hudson B, Hunt V, Waylen A, McCune CA, Verne J, Forbes K. The incompatibility of healthcare services and end-of-life needs in advanced liver disease: A qualitative interview study of patients and bereaved carers. Palliative Medicine. 2018;32(5):908-18.

Kimbell B, Boyd K, Kendall M, Iredale J, Murray SA. Managing uncertainty in advanced liver disease: a qualitative, multiperspective, serial interview study. BMJ Open. 2015;5(11):e009241.

Carbonneau M, Davyduke T, Spiers J, Brisebois A, Ismond K, Tandon P. Patient Views on Advance Care Planning in Cirrhosis: A Qualitative Analysis. Canadian Journal of Gastroenterology and Hepatology. 2018;2018:Article ID 4040518.

Poonja Z, Brisebois A, van Zanten SV, Tandon P, Meeberg G, Karvellas CJ. Patients with cirrhosis and denied liver transplants rarely receive adequate palliative care or appropriate management. Clinical Gastroenterology and Hepatology. 2014;12(4):692-8.

NICE. End of life care for adults Quality standard [QS13]. 2011.

Department of Health and Social Care. End of Life Care Strategy: Promoting high quality care or adults at the end of their life. 2008.

Royal College of Physicians. Talking about dying: How to begin honest conversations about what lies ahead. 2018.

NHS Improving Quality. Capacity, Care Planning and Advance Care Planning in Life Limiting Illness A Guide for Health and Social Care Staff. 2014.

National End of Life Care Intelligence Network. Deaths from liver disease: Implications for End of Life care in England. 2012.

Peng JK, Hepgul 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.

Low JT, Rohde G, Pittordou K, Candy B, Davis S, Marshall A, Stone P. Supportive and palliative care in people with cirrhosis: International systematic review of the perspective of patients, family members and health professionals. Journal of Hepatology. 2018;69(6):1260-73.

Allsop MJ, Ziegler LE, Mulvey MR, Russell S, Taylor R, Bennett MI. Duration and determinants of hospice-based specialist palliative care: A national retrospective cohort study. Palliative Medicine. 2018;32(8):1322–1333.

Phoolchund A, Murray S, Hogan B, O’Beirne J. OC-034 Outcome Of Patients Considered Unsuitable For Liver Transplantation – A Missed Opportunity For Palliative Care? Gut. 2014;63:A17.

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References

Hudson B, Round J, Georgeson B, Pring A, Forbes K, McCune CA, Verne J. Cirrhosis with ascites in the last year of life: a nationwide analysis of factors shaping costs, health-care use, and place of death in England. The Lancet Gastroenterology & Hepatology. 2018;3(2):95-103.

Department of Health. First National VOICES survey of bereaved people – key findings report. 2012.

BASL. British Association for the Study of the Liver (BASL) special interest group (SIG) position statement on palliative and supportive care in patients with chronic liver disease. 2018.

Dixon J, Karagiannidou M, Knapp M. The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their Carers: a systematic review and critical discussion. Journal of Pain and Symptom Management. 2018;55(1):132-50.

Lim C, Ng RWC, Cheng N, Cigolini M, Kwok C, Brennan F. Advance care planning for haemodialysis patients. Cochrane Database of Systematic Reviews. 2016. Issue 7. Art. No.: CD010737. DOI: 10.1002/14651858.CD010737.pub2.

Martin RS, Hayes B, Gregorevic K, Lim WK. The effects of advance care planning interventions on nursing home residents: a systematic review. Journal of the American Medical Directors Association. 2016;17(4):284-93.

Klingler C, in der Schmitten J, Marckmann G. Does facilitated Advance Care Planning reduce the costs of care near the end of life? Systematic review and ethical considerations. Palliative Medicine. 2016;30(5):423-33.

Potosek J, Curry M, Buss M, Chittenden E. Integration of palliative care in end-stage liver disease and liver transplantation. Journal of Palliative Medicine. 2014;17(11):1271-7.

Goddard M, Smith P. Equity of access to health care services: Theory and evidence from the UK. Social Science & Medicine. 2001;53(9):1149-62.

Medical Research Council: Developing and evaluating complex interventions. 2006.

Jagosh J, Macaulay AC, Pluye P, Salsberg J, Bush PL, Henderson J, Sirett E, Wong G, Cargo M, Herbert CP, Seifer SD. Uncovering the benefits of participatory research: implications of a realist review for health research and practice. The Milbank Quarterly. 2012;90(2):311-46.

Michie S, Van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implementation Science. 2011;6(1):42.

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Any questions?

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Marie Curie Palliative Care Research Department
UCL Division of Psychiatry

Improving communication in Liver out-patient clinics for people with cirrhosis: The Development of a Question Prompt List (QPL).

Joe Low

MCPCRD, UCL Division of Psychiatry, 6th Floor, Wing B, Maple House, 149 Tottenham Court Road, London W1T 7NF

The wider multidisciplinary research team

- UCL, Marie Curie Palliative Care Research Department
  - Sarah Davis (Senior Research Nurse), Paddy Stone (Head of MCPCRD), Vicki Vickerstaff (Medical Statistician), Anna Gola (Senior Health Economist)

- Royal Free London NHS Trust, Sheila Sherlock Centre for Liver Disease
  - Doug Thorburn (Consultant Hepatologist), Aileen Marshall (Consultant Hepatologist), Lynda Greenslade (Clinical Nurse Specialist), Jen Clancy (Clinical Nurse Specialist)

- Royal Free London NHS Trust, Palliative Care
  - Cathy Carroll (Clinical Nurse Specialist, Enhanced Supportive Care), Jo Wilson (Macmillan Consultant Nurse in Palliative care), Rachel Craig (Consultant in Palliative Medicine)

- PPI representatives
  - Janet Walsh

Introduction

- Why QPL?
  - Communication difficulties
    - liver HP and patients/family discussing liver disease and its prognosis.
  - QPL promoted as a way of ↑communication
    - Developed in cancer/non-cancer
    - ↑ patient participation during the consultation about prognosis in advanced cancer
- Aims
  - To develop and pilot a liver specific QPL for use in out-patient clinics

3 Phases

Phase 1 – Item generation
  - Scoping literature review
  - On-line survey
  - Interviews/focus groups

Phase 2 – QPL development and refinement
  - Development - Expert panel
  - Refinement – interviews/focus groups

Phase 3 – Pilot study

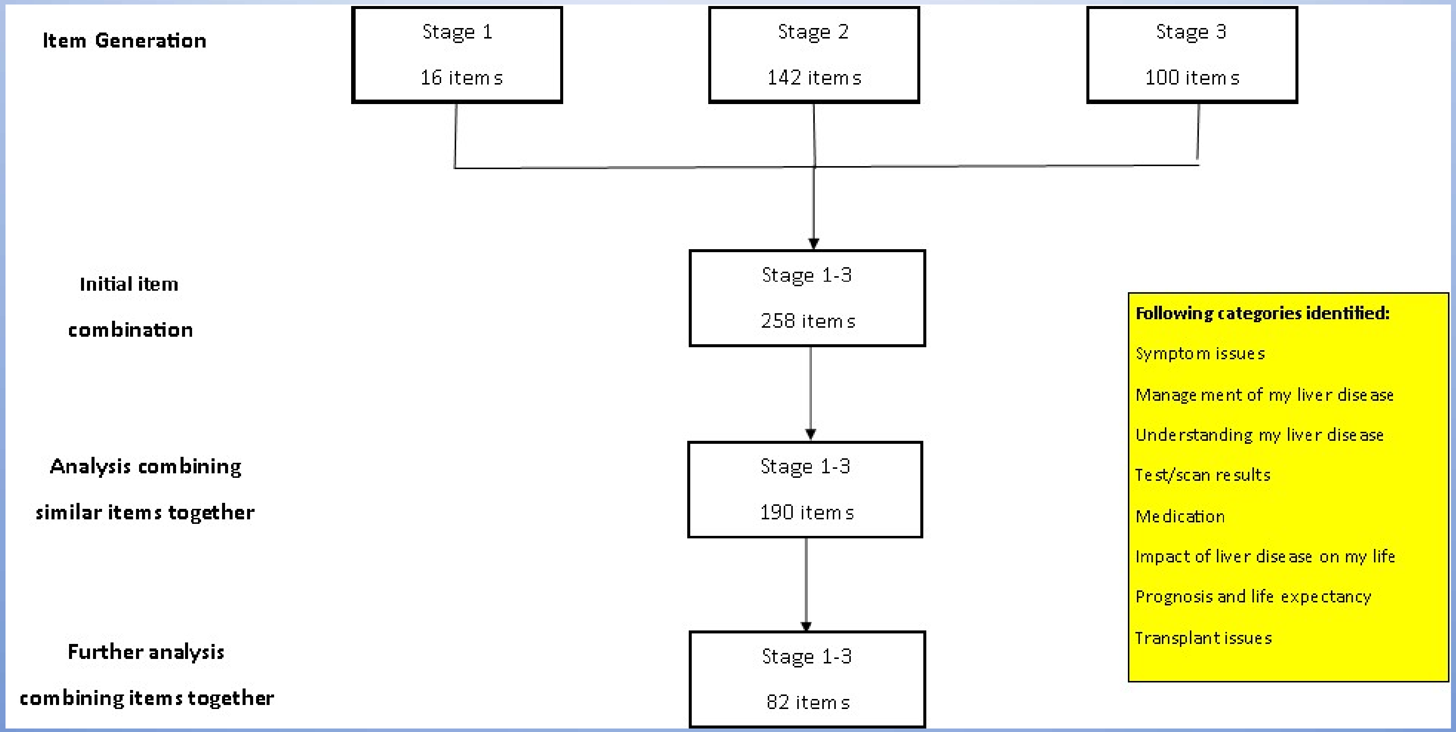
Item generation (Phase 1)

- Scoping literature review
  - 10 studies on unmet information needs in people with cirrhosis and their families
  - Key findings extracted to identify themes
- On-line survey
  - Questions asked/would have asked during OP consultations
  - Sent to 4 voluntary liver organisations
  - 78/278 respondents identified
  - Items extracted from responses

Item generation (Phase 1)

- Interviews/focus group work
    - Sample
        - 12 patients with cirrhosis, 6 family members, 14 HP
        - Hepatology out-patients from a liver tertiary unit (RFH)
    - Topics discussed
        - Questions asked
        - Question would have asked but did not
        - Different aspects of communication
    - Key findings extracted to identify themes

Item generation (Phase 1)



Item Generation

Stage 1

16 items

Stage 2

142 items

Stage 3

100 items

Initial item combination

Stage 1-3

258 items

Analysis combining similar items together

Stage 1-3

190 items

Further analysis combining items together

Stage 1-3

82 items

Following categories identified:

Symptom issues

Management of my liver disease

Understanding my liver disease

Test/scan results

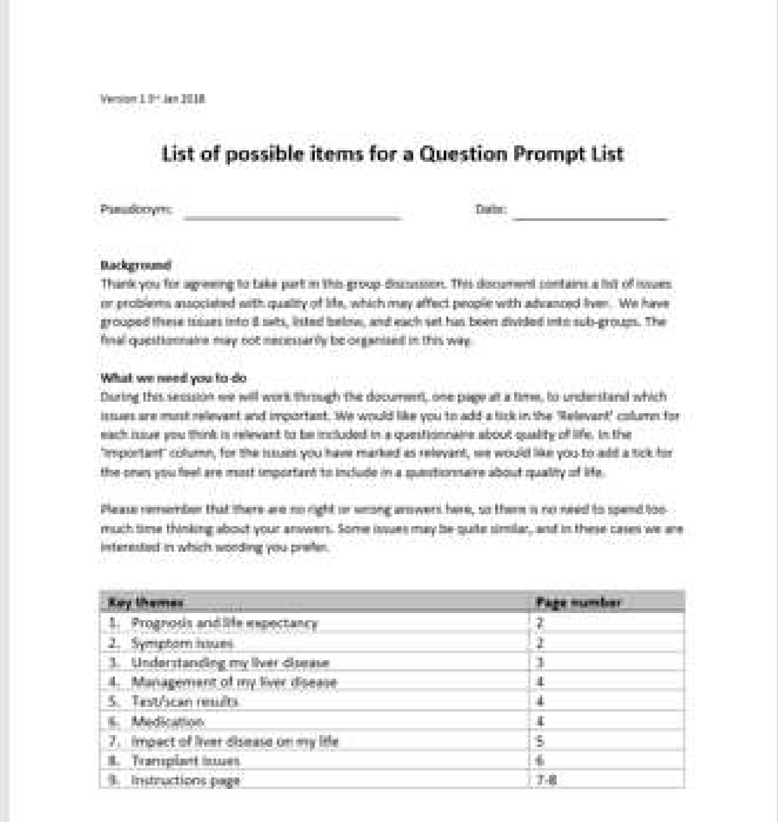
Medication

Impact of liver disease on my life

Prognosis and life expectancy

Transplant issues

Expert group – Issue lists



Version 1 3rd Jan 2018

List of possible items for a Question Prompt List

Pseudonym: ______________________ Date: ________________

Background

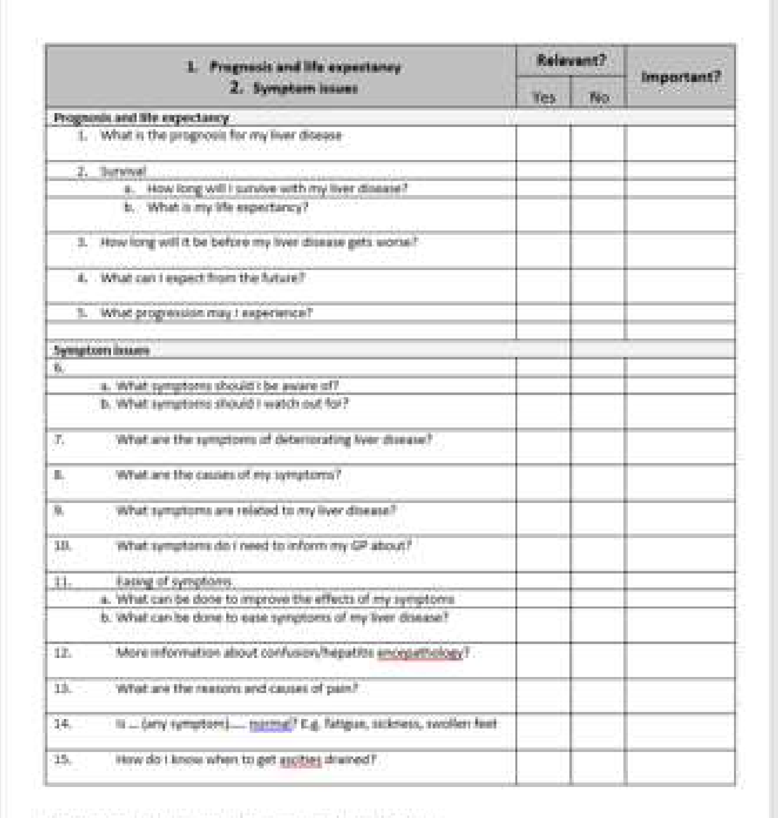
Thank you for agreeing to take part in this group discussion. This document contains a list of issues or problems associated with quality of life, which may affect people with advanced liver. We have grouped these issues into 8 sets, listed below, and each set has been divided into sub-groups. The final questionnaire may not necessarily be organised in this way.

What we need you to do

During this session we will work through the document, one page at a time, to understand which issues are most relevant and important. We would like you to add a tick in the 'Relevant' column for each issue you think is relevant to be included in a questionnaire about quality of life. In the "important" column, for the issues you have marked as relevant, we would like you to add a tick for the ones you feel are most important to include in a questionnaire about quality of life.

Please remember that there are no right or wrong answers here, so there is no need to spend too much time thinking about your answers. Some issues may be quite similar, and in these cases we are interested in which wording you prefer.

Key themes	**Page number**
1. Prognosis and life expectancy	2
2. Symptom issues	2
3. Understanding my liver disease	3
4. Management of my liver disease	4
5. Test/scan results	4
6. Medication	4
7. Impact of liver disease on my life	5
8. Transplant issues	6
9. Instructions page	7-8



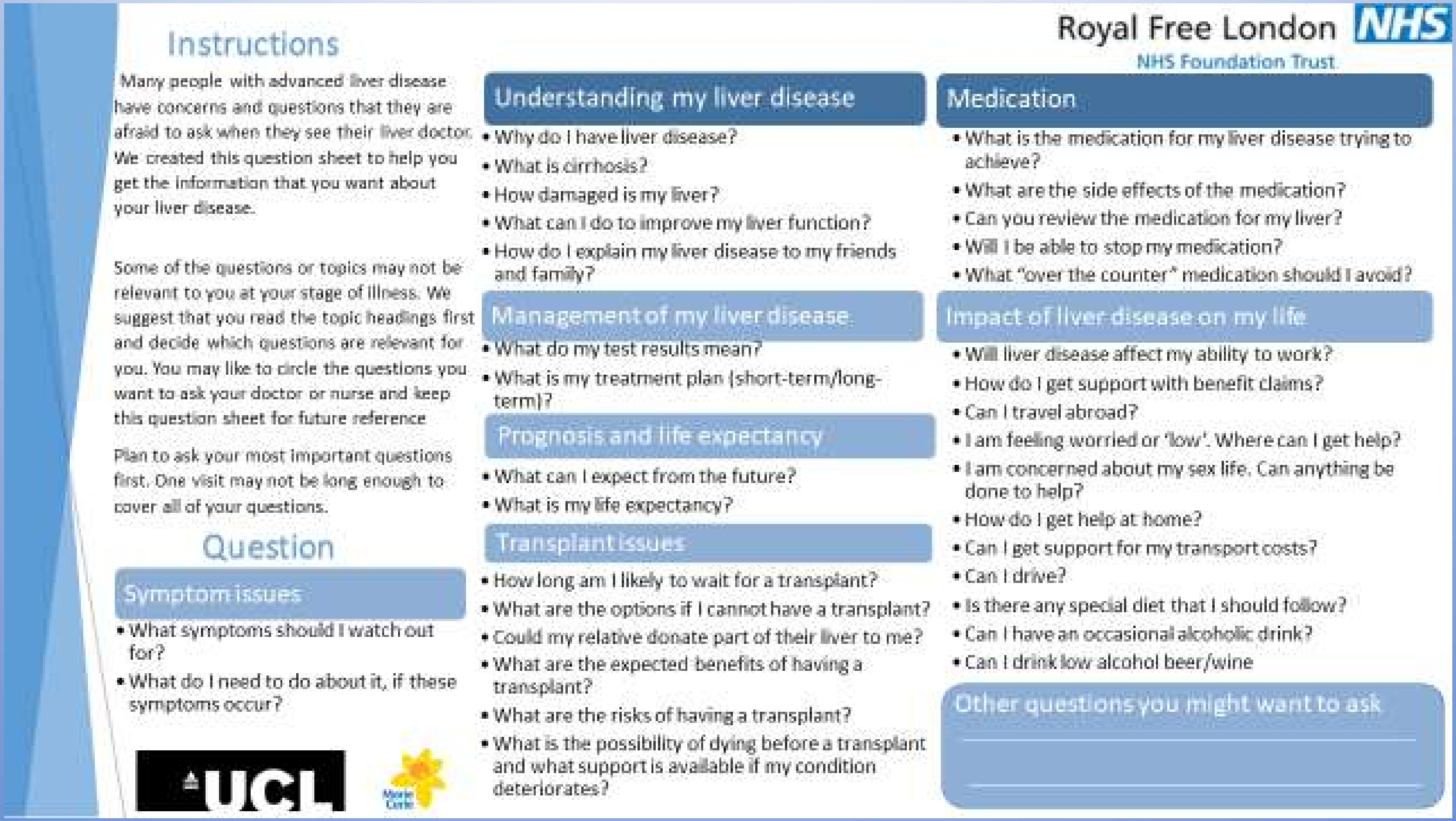
1. Prognosis and life expectancy **2. Symptom issues**	**Relevant?**		**Important?**
	Yes	No	
Prognosis and life expectancy			
1. What is the prognosis for my liver disease			
2. Survival			
a. How long will I survive with my liver disease?			
b. What is my life expectancy?			
3. How long will it be before my liver disease gets worse?			
4. What can I expect from the future?			
5. What progression may I experience?			
Symptom issues			
6.			
a. What symptoms should I be aware of?			
b. What symptoms should I watch out for?			
7. What are the symptoms of deteriorating liver disease?			
8. What are the causes of my symptoms?			
9. What symptoms are related to my liver disease?			
10. What symptoms do I need to inform my GP about?			
11. Easing of symptoms			
a. What can be done to improve the effects of my symptoms			
b. What can be done to ease symptoms of my liver disease?			
12. More information about confusion/hepatitis encepathology?			
13. What are the reasons and causes of pain?			
14. Is … (any symptom)…. normal? E.g. fatigue, sickness, swollen feet			
15. How do I know when to get ascites drained?			

QPL development (Phase 2)

- Expert Panel
  - Tasks
    1. To review all 82 items and reduce number of items, ideally to 30 items
       a) To rate which items are relevant and important
       b) To remove repetitive items
       c) To remove badly phrased/unclear items

    2. To finalise QPL instructions

QPL v0.1 - transplant



Royal Free London NHS
NHS Foundation Trust

Instructions

Many people with advanced liver disease have concerns and questions that they are afraid to ask when they see their liver doctor. We created this question sheet to help you get the information that you want about your liver disease.

Some of the questions or topics may not be relevant to you at your stage of illness. We suggest that you read the topic headings first and decide which questions are relevant for you. You may like to circle the questions you want to ask your doctor or nurse and keep this question sheet for future reference.

Plan to ask your most important questions first. One visit may not be long enough to cover all of your questions.

Question

Symptom issues

- What symptoms should I watch out for?
- What do I need to do about it, if these symptoms occur?

Understanding my liver disease

- Why do I have liver disease?
- What is cirrhosis?
- How damaged is my liver?
- What can I do to improve my liver function?
- How do I explain my liver disease to my friends and family?

Management of my liver disease

- What do my test results mean?
- What is my treatment plan (short-term/long-term)?

Prognosis and life expectancy

- What can I expect from the future?
- What is my life expectancy?

Transplant issues

- How long am I likely to wait for a transplant?
- What are the options if I cannot have a transplant?
- Could my relative donate part of their liver to me?
- What are the expected benefits of having a transplant?
- What are the risks of having a transplant?
- What is the possibility of dying before a transplant and what support is available if my condition deteriorates?

Medication

- What is the medication for my liver disease trying to achieve?
- What are the side effects of the medication?
- Can you review the medication for my liver?
- Will I be able to stop my medication?
- What "over the counter" medication should I avoid?

Impact of liver disease on my life

- Will liver disease affect my ability to work?
- How do I get support with benefit claims?
- Can I travel abroad?
- I am feeling worried or 'low'. Where can I get help?
- I am concerned about my sex life. Can anything be done to help?
- How do I get help at home?
- Can I get support for my transport costs?
- Can I drive?
- Is there any special diet that I should follow?
- Can I have an occasional alcoholic drink?
- Can I drink low alcohol beer/wine

Other questions you might want to ask

UCL

Marie Curie

QPLv0.1 refinement (Phase 2)

- Interviews/focus group
  - Sample
    - 8 patients with cirrhosis, 3 family members, 9 HP (3 interviews, 1 focus group) –
    - Patients/family members participated in Stage 3.
    - PPI input – leads of 2 voluntary organisations (BLT, LIVErNORTH)

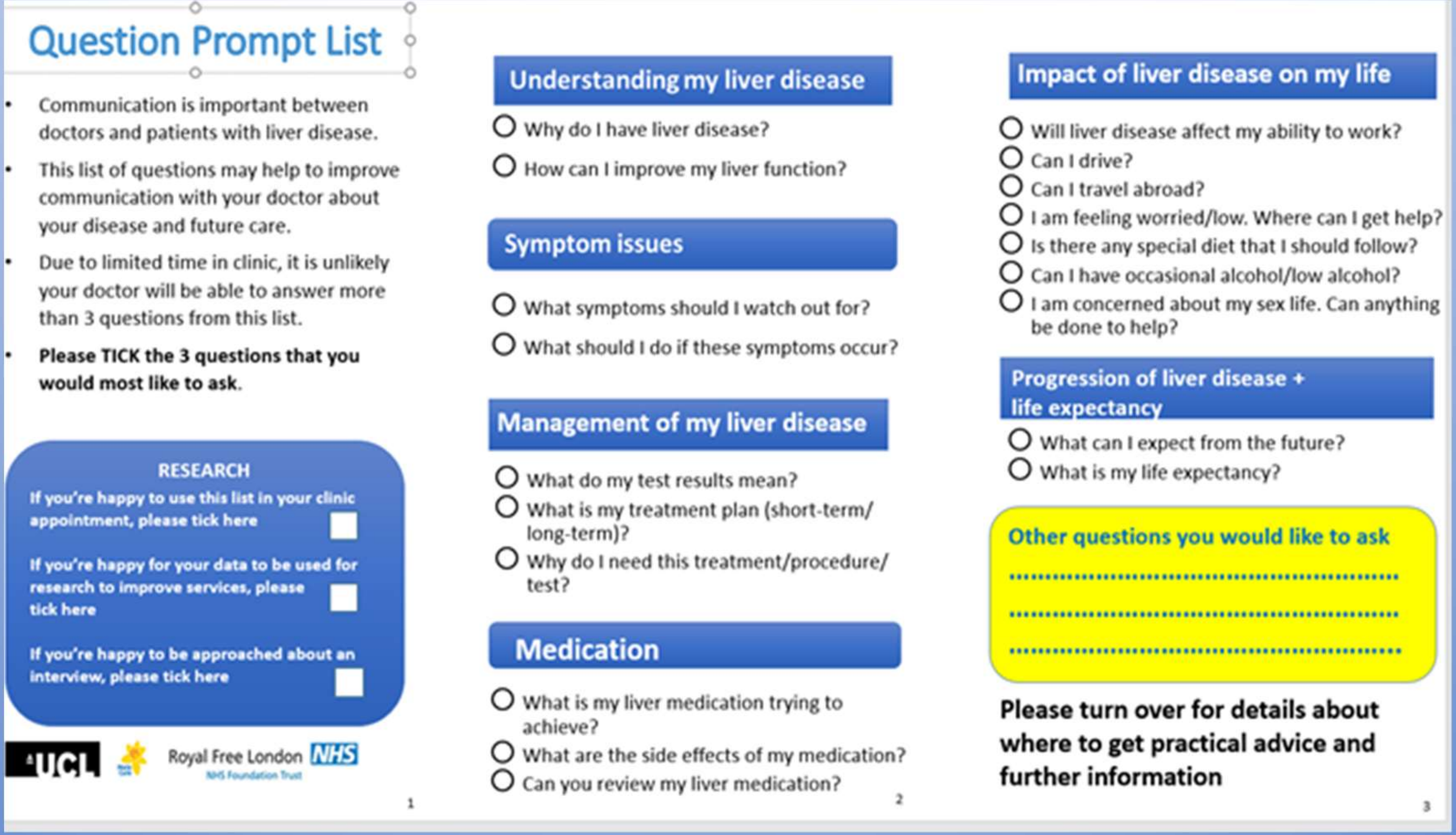
  - Topics explored
    - Clarity, relevance, appropriateness, additional questions
    - Practical issues about implementation
    - Acceptability of using QPL in out-patient clinic (HP)

QPLv0.1 refinement (Phase 2)

- Key findings
  1. All groups – happy with content
  2. Clinicians
     a) Shorten, reduce questions
     b) Remove transplant section
     c) Factual questions ⇨ specific information sheet

- Expert panel
  - Reconvened to discuss and finalise QPL layout

Current version QPL



Question Prompt List

- Communication is important between doctors and patients with liver disease.
- This list of questions may help to improve communication with your doctor about your disease and future care.
- Due to limited time in clinic, it is unlikely your doctor will be able to answer more than 3 questions from this list.
- **Please TICK the 3 questions that you would most like to ask.**

RESEARCH

If you're happy to use this list in your clinic appointment, please tick here ☐

If you're happy for your data to be used for research to improve services, please tick here ☐

If you're happy to be approached about an interview, please tick here ☐

UCL Royal Free London NHS
NHS Foundation Trust

Understanding my liver disease

○ Why do I have liver disease?
○ How can I improve my liver function?

Symptom issues

○ What symptoms should I watch out for?
○ What should I do if these symptoms occur?

Management of my liver disease

○ What do my test results mean?
○ What is my treatment plan (short-term/long-term)?
○ Why do I need this treatment/procedure/test?

Medication

○ What is my liver medication trying to achieve?
○ What are the side effects of my medication?
○ Can you review my liver medication?

Impact of liver disease on my life

○ Will liver disease affect my ability to work?
○ Can I drive?
○ Can I travel abroad?
○ I am feeling worried/low. Where can I get help?
○ Is there any special diet that I should follow?
○ Can I have occasional alcohol/low alcohol?
○ I am concerned about my sex life. Can anything be done to help?

Progression of liver disease + life expectancy

○ What can I expect from the future?
○ What is my life expectancy?

Other questions you would like to ask

……………………………………………………
……………………………………………………
……………………………………………………

Please turn over for details about where to get practical advice and further information

Current version QPL

Where to get practical advice and information

Please read through the next few pages for advice about where to get more information

Information about liver disease

If you want to know about the following, *please tick the relevant circle:*

○ What is liver disease ?
○ What is cirrhosis?

If you have ticked any of the boxes above, please ask your doctor in clinic for a brief summary sheet.

Alternatively, you can go on the websites of the following organisations

British Liver Trust
Helpline 0800 652 7330
https://britishlivertrust.org.uk

NHS choices Website
https://www.nhs.uk/conditions/cirrhosis

General advice and information

Do you need advice and information on the following topics?

Benefit claims
Debts and financial support
Transport costs
Help at home
Care, equipment etc.
Planning wills/Power of Attorney

If yes, your doctor can make a referral to the Support Hub at the Royal Free Hospital.

○ **Please tick if you would like your doctor to refer you the Support Hub**

Alternatively, you can visit the Royal Free Support Hub in person (see below)

Support Hub Royal Free Hospital
LG floor 0207 794 0500 ext 39963
Monday – Thursday 10 - 4pm
(except Bank Holidays)
rf.royalfreesupporthub@nhs.net

Health information – Contact details

For general health enquiries, contact

- **Your GP.**

*For help with specific liver disease problems **in office hours** contact*

Hepatology Clinical Nurse Specialist (non-transplant) on 0777 358 2584

*For help with specific liver disease problems **out of hours***

- **Call 111 if the problem requires immediate non-urgent advice**
- **Call 999 for emergencies**

Psychological support

Problems with mental health such as anxiety or depression

You can contact: **Samaritans 24 hr Helpline on**
Tel 116 123 (free from any phone).
OR Check the NHS choices Website
https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/

Pilot study (Phase 3)

- Aims
  - Feasibility and acceptability of QPL v0.2 in clinical setting
  - Finalise QPL layout
  - Determine optimum QPL delivery

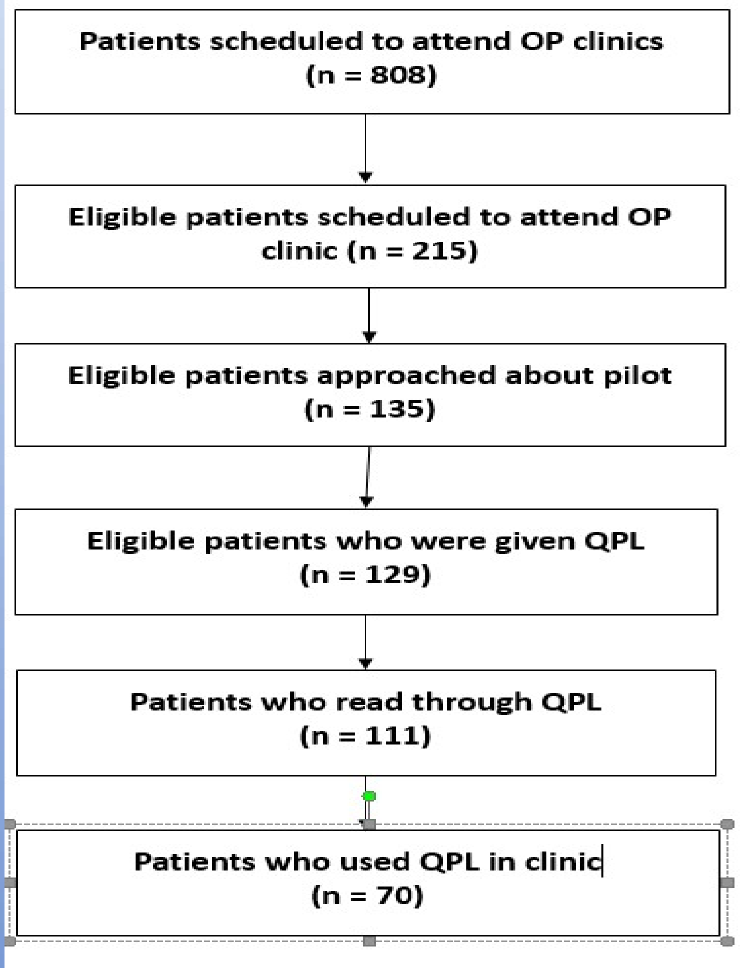
Procedure

- 3 months, 64 OP clinics (RFH)
  - Eligible patients given and asked to read QPL

  - All patients asked
    - Did they use the QPL?
    - If Y, what items were used. If N, why?

  - Detailed interviews - 10 patients and 1 family member
  - Future work: relevant HP to be interviewed about impact, benefits, burden.

Recruitment (since 13 Dec 2018)



Patients scheduled to attend OP clinics (n = 808)

Eligible patients scheduled to attend OP clinic (n = 215)

Eligible patients approached about pilot (n = 135)

Eligible patients who were given QPL (n = 129)

Patients who read through QPL (n = 111)

Patients who used QPL in clinic (n = 70)

Preliminary findings

- Demographics
  - Male (62%), white UK (67%),
  - Mean (SD), range: 62 years (12), 27-85

- General observations
  - Many patients found it useful
    - To generate questions
    - In T/x, people used it more as a prompt/reminder.

  - All questions on QPL asked at some point

Preliminary findings

- QPL users
  - Useful as needs change over time
  - Good source as a battery of questions

- QPL non-users
  - QPL more useful at an earlier stage
    - First referred to the RFH
    - First diagnosed with cirrhosis
    - Common response particularly with Tx patients
  - Language difficulties

Preliminary findings

- Other
  - Life expectancy question, symptoms and treatment plan – most frequently asked
  - Communication between Dr & patient clear, but useful to have responses in writing.
  - Patients can’t remember what they have been told.

Future directions

- Extend patient eligibility criteria
  - First OPA visit (tertiary liver services)

- Sites of recruitment
  - Extend to DGH?

- Time of delivery
  - As a resource on the internet
  - Enclosed in OPA reminder letters
    - Opportunity to discuss with other family members

Future work

- Directions
  - Extend patient pool
  - Extend recruitment sites

- Design of future study

- What is the main outcome of using QPL

Any questions?
Any thoughts?
Any comments?

Basl end of life special interest group meeting
education update: march 2019

Fiona Finlay

Consultant in Palliative Medicine

Queen Elizabeth University Hospital, Glasgow

Where we are

- Context
- Key Priorities
- Progress so far…

MARCH 2018

Interest/input

HEPATOLOGY

- Fiona Thompson (Birmingham)
- Pooja Khanna (Luton/Dunstable)
- Lynda Greenslade (Royal Free)
- Mary Martin (Glasgow)

PHE

- Julia Verne

PALLIATIVE MEDICINE

- Wendy Prentice (King's)
- Suzanne Ford-Dunn (Worthing)
- Yvonne Cartwright (Addenbrooke's)
- Carol Davis (Southampton)
- Lucy Bemand-Qureshi (London)
- Fiona Finlay (Glasgow)

NOVEMBER 2018

- Teleconference
- 4 pall med cons, 1 hepatologist, 1 liver CNS
- Key questions:
    - Who are we educating?
    - Where do we fit?
- Action points

Advanced renal care – a model?

ARC project

- Engaged renal physicians in developing own services
- Funded project: NHS Kidney Care
- Guy’s & St Thomas’s, King’s College NHS FT
    - Identified dialysis patients approaching last year of life
    - Systematic introduction of ACP including preferred place of care
    - **Advanced comms skills for nephrology professionals**
- Progress from this pilot

Priorities/scope

PRIORITIES

- liver specialists/gastroenterologists
- Nursing/medical staff working in these areas

INITIAL FOCUS

- Curricula (gastroenterology/core+advanced hepatology)
- Assessment/examination in specialty training
- Online resource development

CURRICULA

Gastroenterology curriculum

- Describe different disease trajectories and prognostic indicators and the signs that a patient is dying

- Know that specialist palliative care is appropriate for patients with other life threatening illnesses as well as those with cancer

- Describe the analgesic ladder, role of radiotherapy, surgery and other non-pharmacological treatments

- Recognising when a patient may be in the last days / weeks of life

Abdominal malignancy

- Can work in a multidisciplinary environment that includes the pain and palliative care teams and the oncologists
- Discusses the ethical issues involved in prolonging life and to weigh this up against quality of life
- Can speak honestly about often sensitive issues with the patient, carers, friends and family

Core hepatology curriculum

- Understands prognostic scoring systems including Child - Pugh, MELD, UKELD, Maddrey and disease-specific scoring systems

- Communicates effectively with at risk populations patients, their relatives in the context of their disease , its severity, prognosis and substance abuse

Sub-specialty/advanced hepatology curriculum

LIVER TRANSPLANT

- Can identify potential candidates for liver transplantation, as well as demonstrating an understanding of why patients with end-stage liver disease are not appropriate candidates for liver transplantation

Specialty exams

GASTROENTEROLOGY

- No questions specific to palliative/end of life care

PALLIATIVE MEDICINE

- Questions relating to life limiting illness (non-cancer)
- Pharmacology/therapeutics – hepatic impairment
- Symptoms relating to organ failure

(Shape of training)

- CMT replaced by IMT (internal medicine training) as of August 2019
- Pall Med SAC – contributed to 1 of 8 specialist CiPs

GASTRO/HEPatology CURRICULA

- Ian Gee: SAC Chair Gastroenterology
- Bill Griffiths, Mark Hudson: SAC Hepatology Leads

suggestions for curricular development

- Poor prognostic implications of end stage liver disease
- Identification of a deteriorating patient
- Communication skills around this
- Consideration of specialist palliative care input when patient referred for transplant

Interface with other bodies

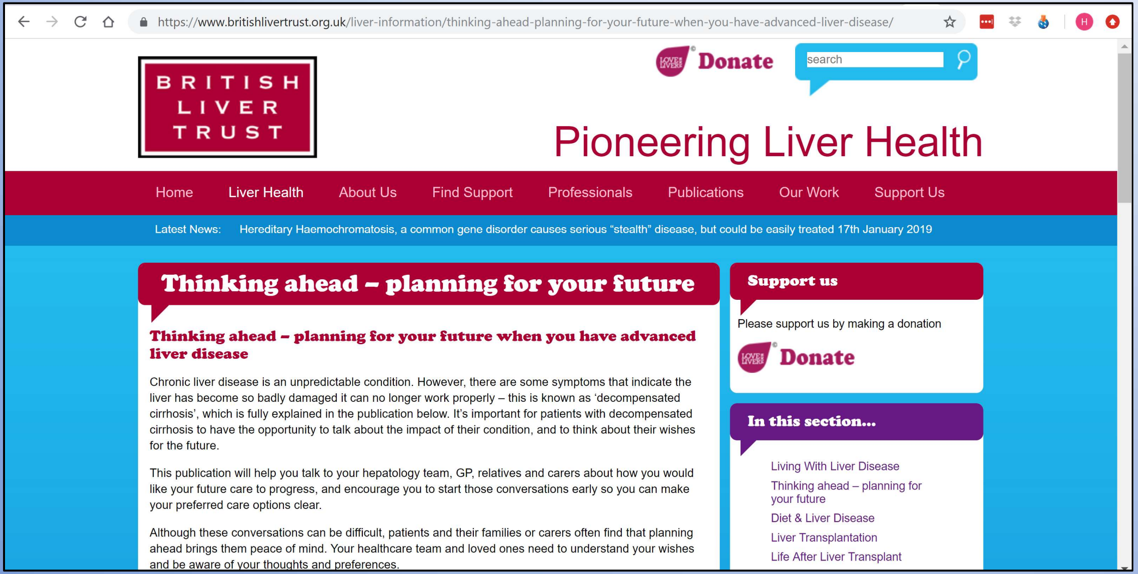
- APM Education Committee
  - In principle, keen to support joint conferences – stand alone, or under umbrella of RCP
  - RCP study day 2020: pall care in acute hospital environment - ?slot
  - ?key session at next BASL conference

WEBSITE AND Resources Update

Hazel Woodland

Clinical Research Fellow in Hepatology

British Liver Trust: Thinking Ahead



Pioneering Liver Health

Latest News: Hereditary Haemochromatosis, a common gene disorder causes serious "stealth" disease, but could be easily treated 17th January 2019

Thinking ahead – planning for your future

Thinking ahead – planning for your future when you have advanced liver disease

Chronic liver disease is an unpredictable condition. However, there are some symptoms that indicate the liver has become so badly damaged it can no longer work properly – this is known as 'decompensated cirrhosis', which is fully explained in the publication below. It's important for patients with decompensated cirrhosis to have the opportunity to talk about the impact of their condition, and to think about their wishes for the future.

This publication will help you talk to your hepatology team, GP, relatives and carers about how you would like your future care to progress, and encourage you to start those conversations early so you can make your preferred care options clear.

Although these conversations can be difficult, patients and their families or carers often find that planning ahead brings them peace of mind. Your healthcare team and loved ones need to understand your wishes and be aware of your thoughts and preferences.

Support us

Please support us by making a donation

Donate

In this section...

- Living With Liver Disease
- Thinking ahead – planning for your future
- Diet & Liver Disease
- Liver Transplantation
- Life After Liver Transplant

Thinking ahead:
Planning for your future with advanced liver disease

BRITISH LIVER TRUST

Pioneering Liver Health

Feedback from BLT Helpline

- *“Patient felt more prepared to discuss end of life care with her family after reading it”*

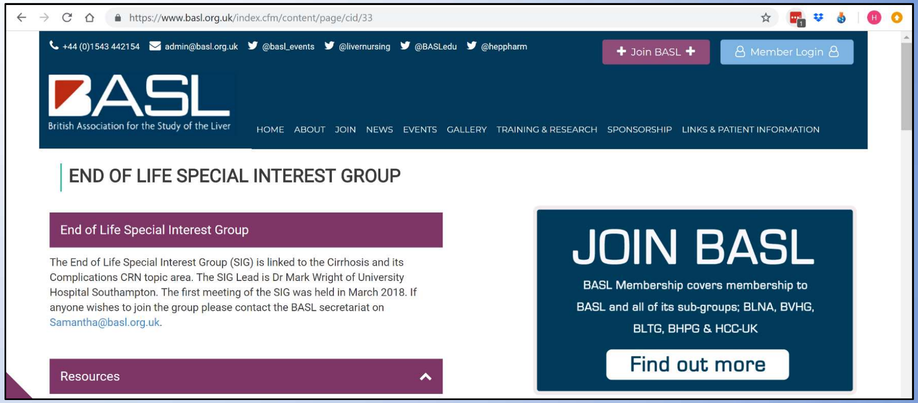
- *“Patient stated he did not even know that he could access palliative care or how to do so, but now he was aware”*

- *“Carer whose husband died last year of alcohol liver disease rang to say how absolutely amazing our ‘Thinking ahead’ publication is and how useful it would have been if she had read it last year”*

SIG Website

Currently

- Group reports
- Publications list
- Current projects + shared resources
- Useful websites

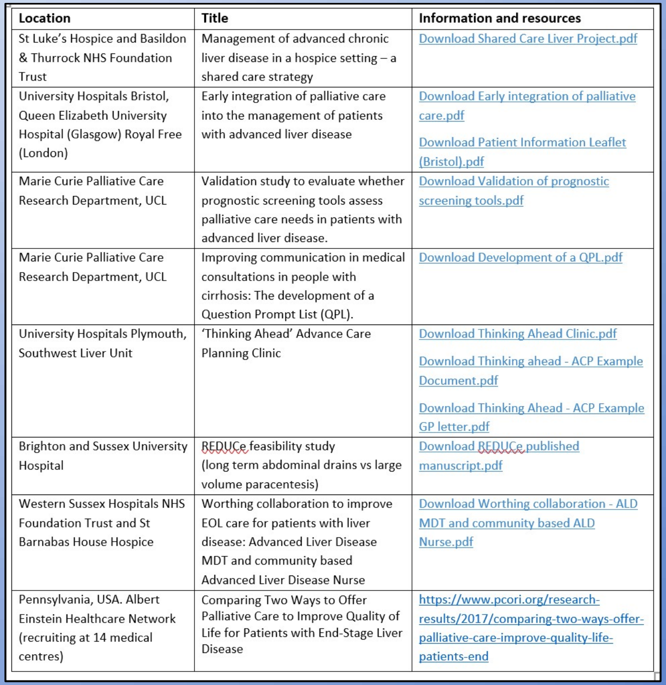


END OF LIFE SPECIAL INTEREST GROUP

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 Mark Wright of University Hospital Southampton. The first meeting of the SIG was held in March 2018. If anyone wishes to join the group please contact the BASL secretariat on Samantha@basl.org.uk.

BASL Membership covers membership to BASL and all of its sub-groups; BLNA, BVHG, BLTG, BHPG & HCC-UK



Location	Title	Information and resources
St Luke's Hospice and Basildon & Thurrock NHS Foundation Trust	Management of advanced chronic liver disease in a hospice setting – a shared care strategy	Download Shared Care Liver Project.pdf
University Hospitals Bristol, Queen Elizabeth University Hospital (Glasgow) Royal Free (London)	Early integration of palliative care into the management of patients with advanced liver disease	Download Early integration of palliative care.pdf Download Patient Information Leaflet (Bristol).pdf
Marie Curie Palliative Care Research Department, UCL	Validation study to evaluate whether prognostic screening tools assess palliative care needs in patients with advanced liver disease.	Download Validation of prognostic screening tools.pdf
Marie Curie Palliative Care Research Department, UCL	Improving communication in medical consultations in people with cirrhosis: The development of a Question Prompt List (QPL).	Download Development of a QPL.pdf
University Hospitals Plymouth, Southwest Liver Unit	'Thinking Ahead' Advance Care Planning Clinic	Download Thinking Ahead Clinic.pdf Download Thinking ahead - ACP Example Document.pdf Download Thinking Ahead - ACP Example GP letter.pdf
Brighton and Sussex University Hospital	REDUCe feasibility study (long term abdominal drains vs large volume paracentesis)	Download REDUCe published manuscript.pdf
Western Sussex Hospitals NHS Foundation Trust and St Barnabas House Hospice	Worthing collaboration to improve EOL care for patients with liver disease: Advanced Liver Disease MDT and community based Advanced Liver Disease Nurse	Download Worthing collaboration - ALD MDT and community based ALD Nurse.pdf
Pennsylvania, USA. Albert Einstein Healthcare Network (recruiting at 14 medical centres)	Comparing Two Ways to Offer Palliative Care to Improve Quality of Life for Patients with End-Stage Liver Disease	https://www.pcori.org/research-results/2017/comparing-two-ways-offer-palliative-care-improve-quality-life-patients-end

Other Ideas

- Opportunities for research collaboration
- Models of care in practice

Suggestions

BASL
British Association for the Study of the Liver

NHS
University Hospitals Bristol
NHS Foundation Trust

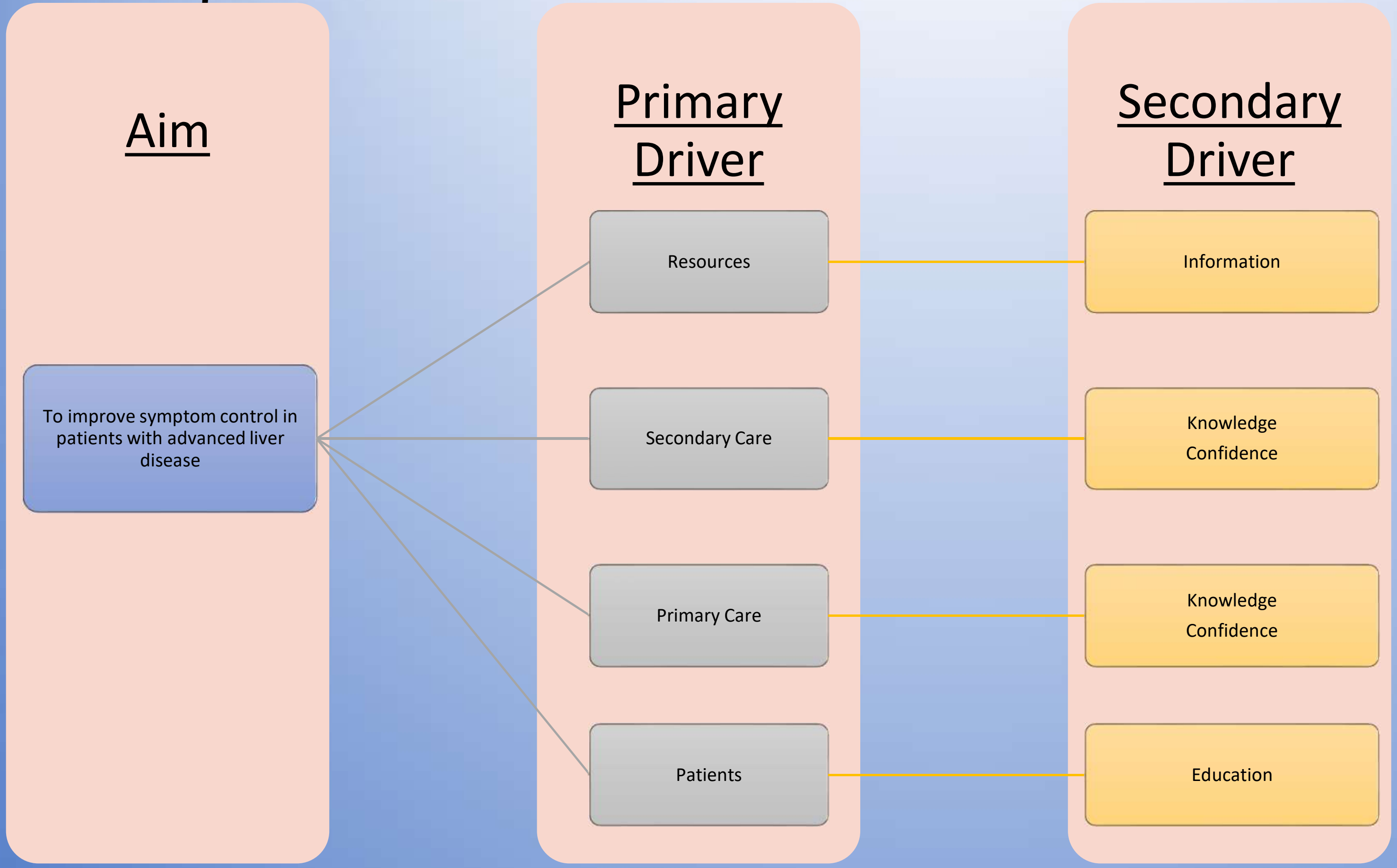
Improving Symptom Control in Patients with Advanced Liver Disease

Dr Bonita Stevens and Dr Sarah Case

BASL End of Life Special Interest Group Meeting, Bristol, March 2019

Background

Project Overview



Aim

To improve symptom control in patients with advanced liver disease

Primary Driver

Resources

Secondary Care

Primary Care

Patients

Secondary Driver

Information

Knowledge
Confidence

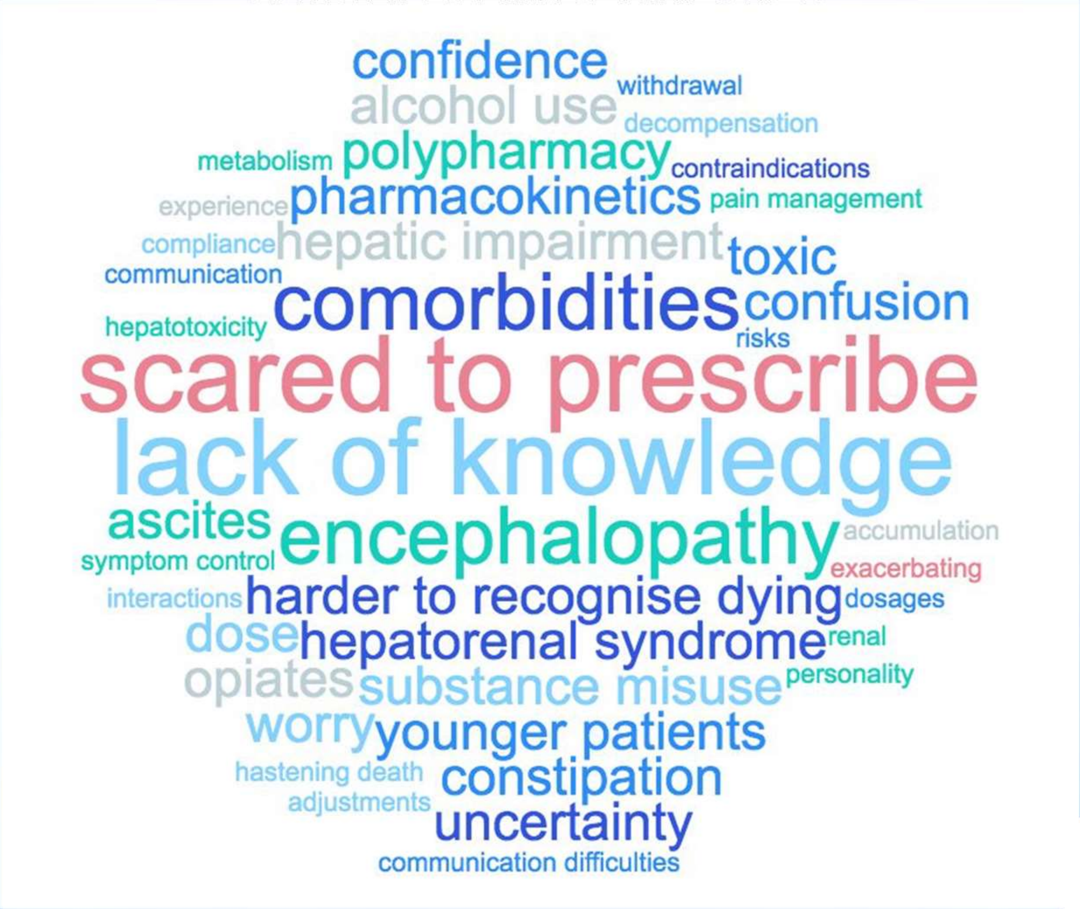
Knowledge
Confidence

Education

Evidence

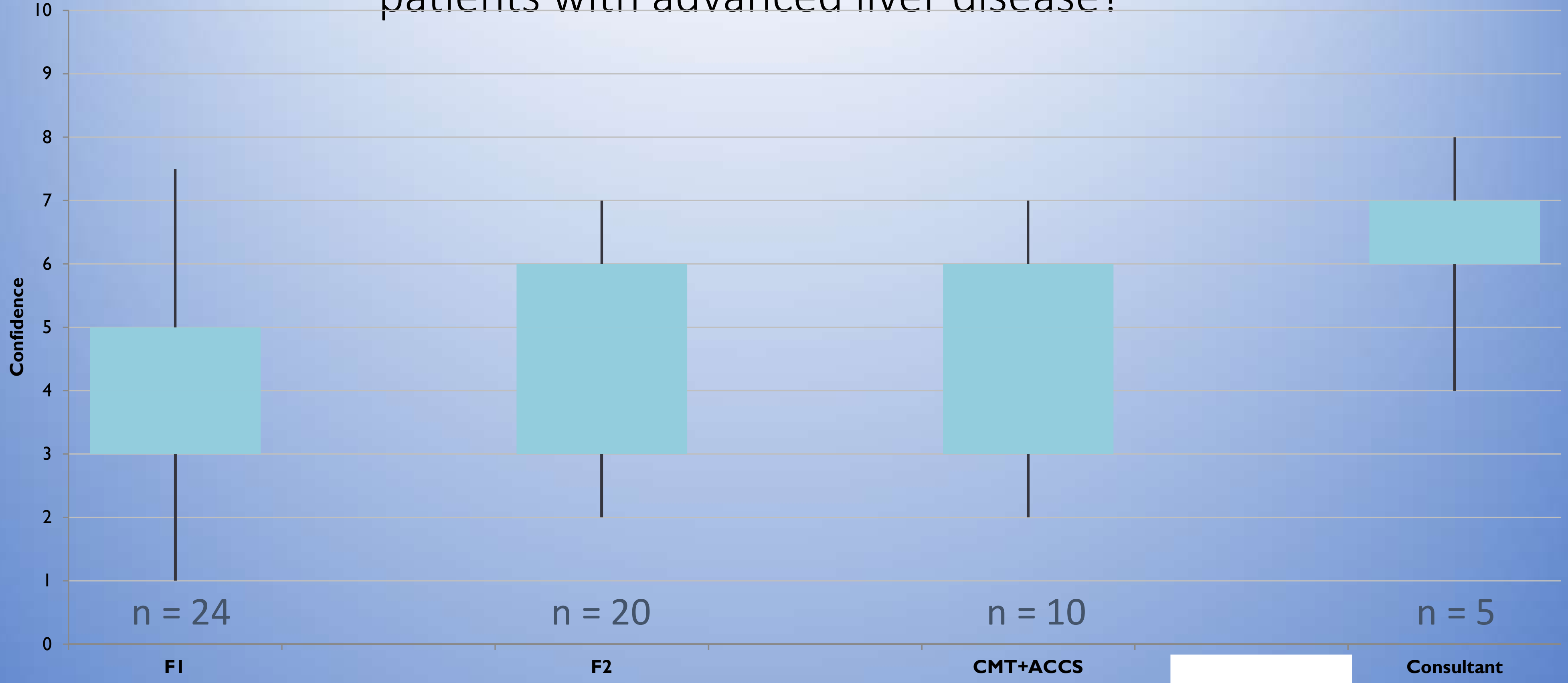
Doctor Survey

What are the main barriers to good symptom control in patients with advanced liver disease?



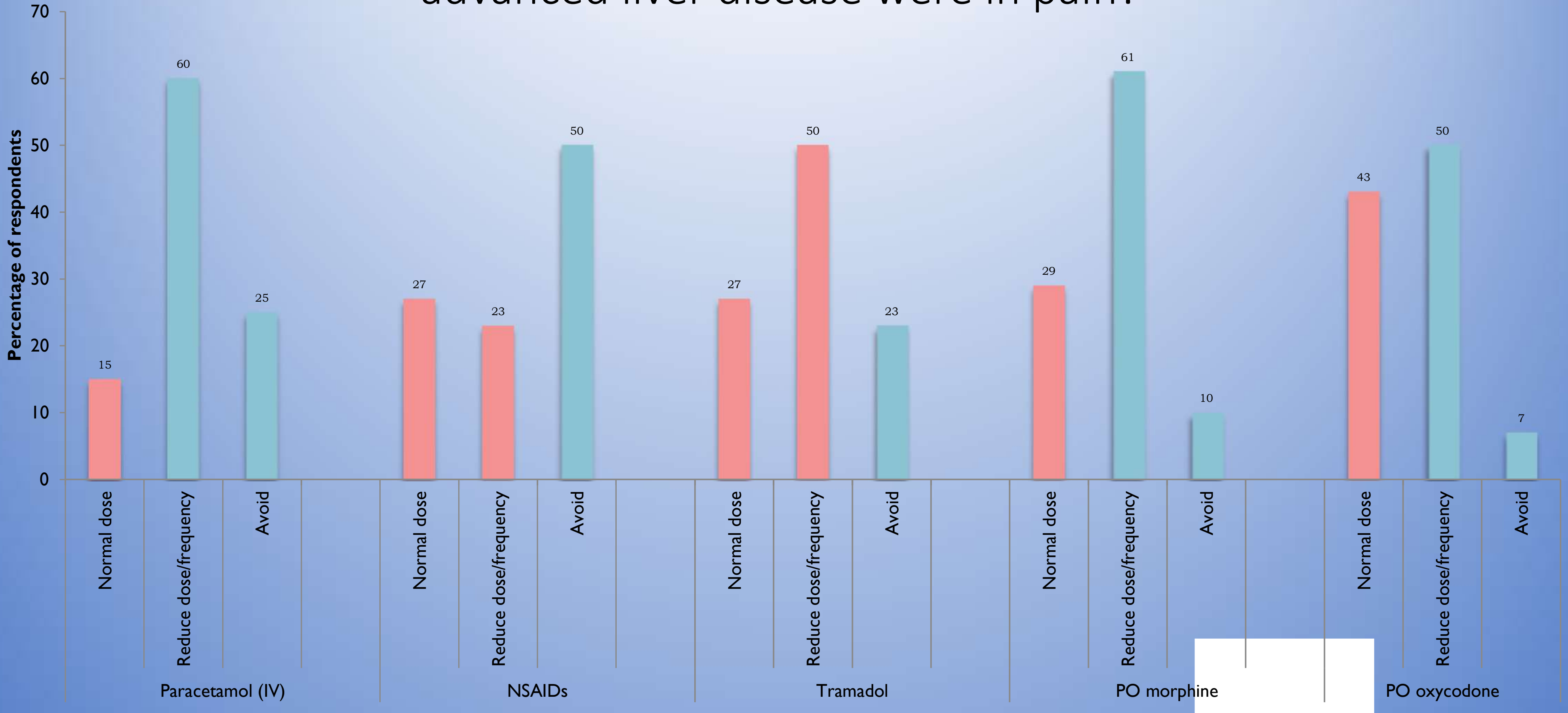
Survey of medical students, junior doctors and consultants; Bristol Royal Infirmary, UK; 2019

How confident do you feel prescribing medications for symptom control in patients with advanced liver disease?



Survey of junior doctors and consultants; Bristol Royal Infirmary, UK; 2019

How you would you prescribe the following medications if a patient with advanced liver disease were in pain?

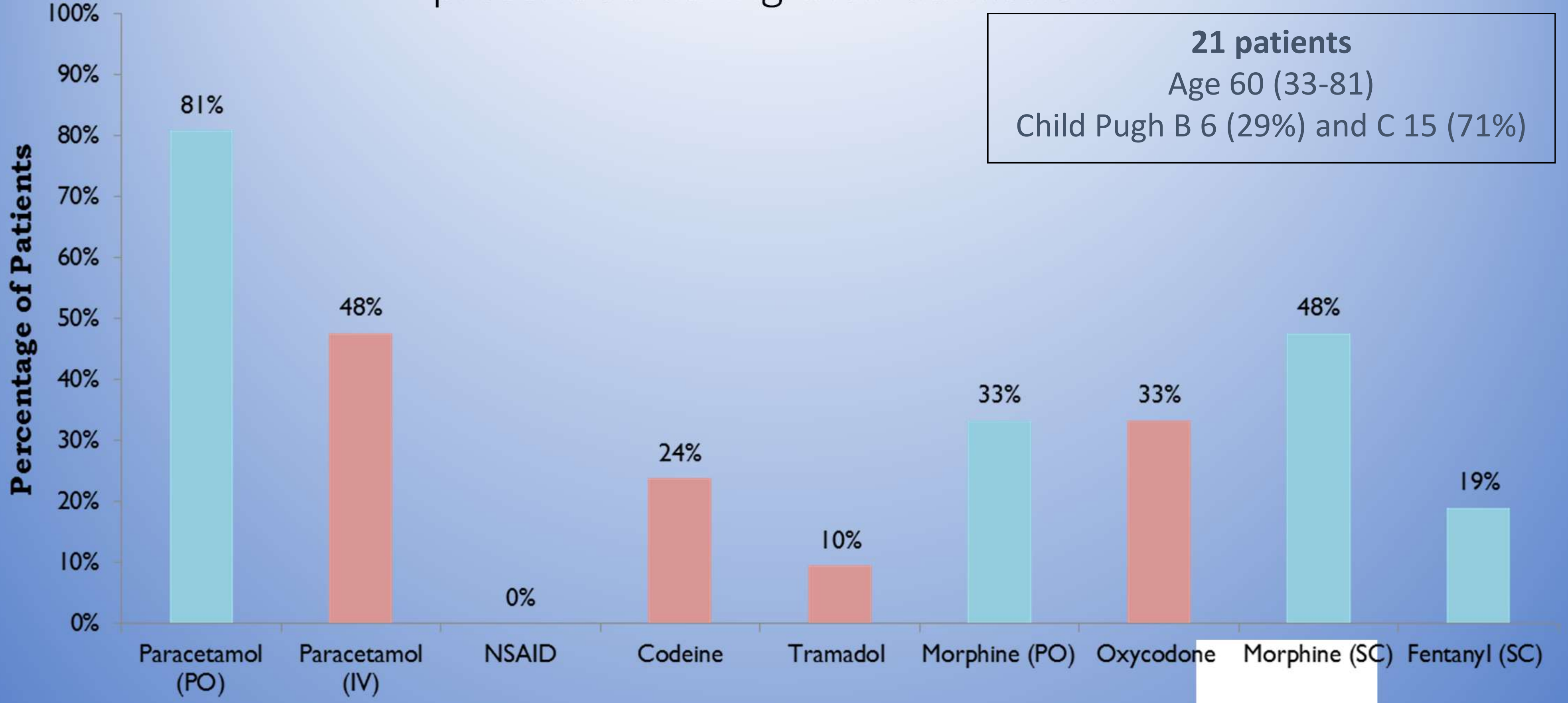


Survey of medical students, junior doctors and consultants; Bristol Royal Infirmary, UK; 2019

Evidence

Prescribing Practice

Which medications were patients with Child Pugh B or C cirrhosis prescribed during their admission?

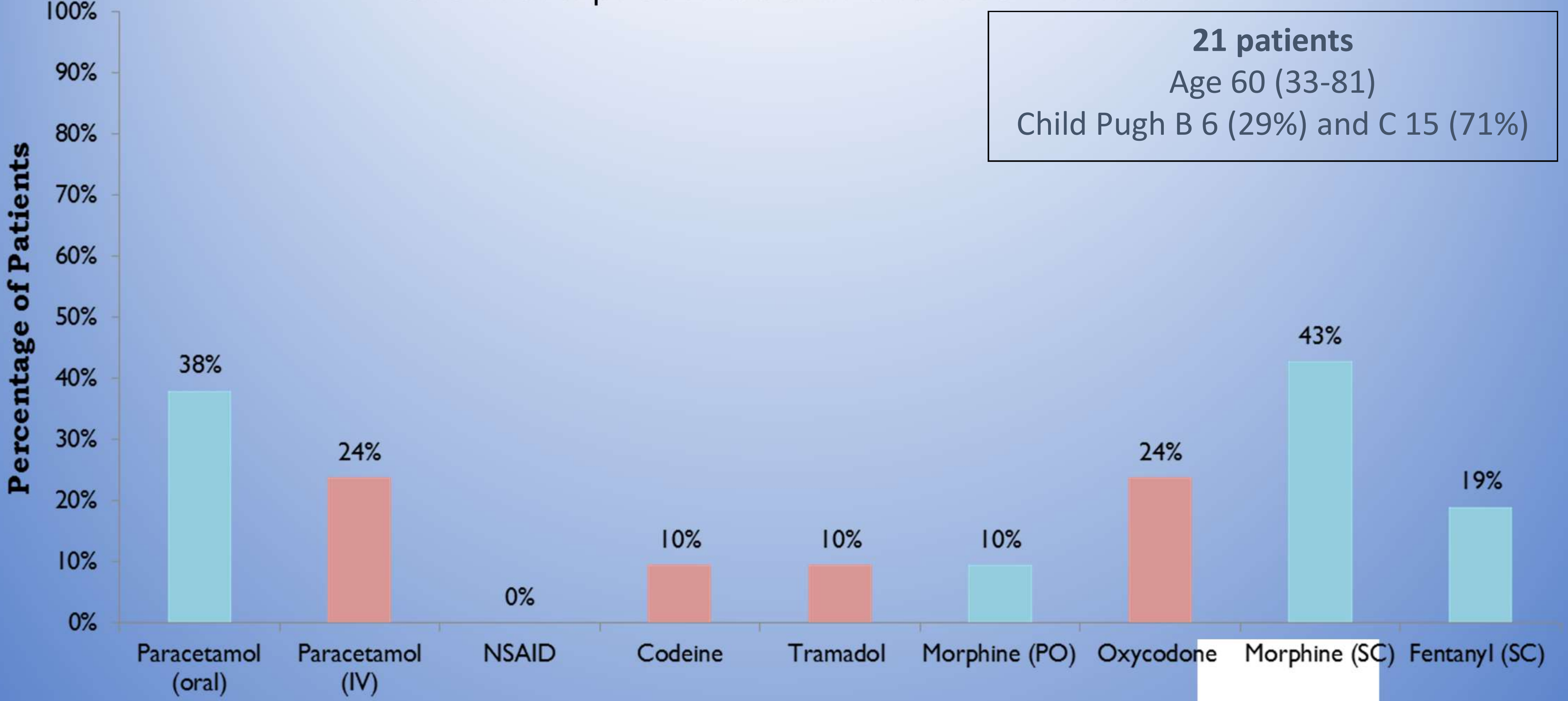


21 patients
Age 60 (33-81)
Child Pugh B 6 (29%) and C 15 (71%)

Review of medical notes; Bristol Royal Infirmary, UK; 2018

Which analgesics were patients with Child Pugh B or C cirrhosis who died on the ward prescribed in the last 24hrs?

21 patients
Age 60 (33-81)
Child Pugh B 6 (29%) and C 15 (71%)

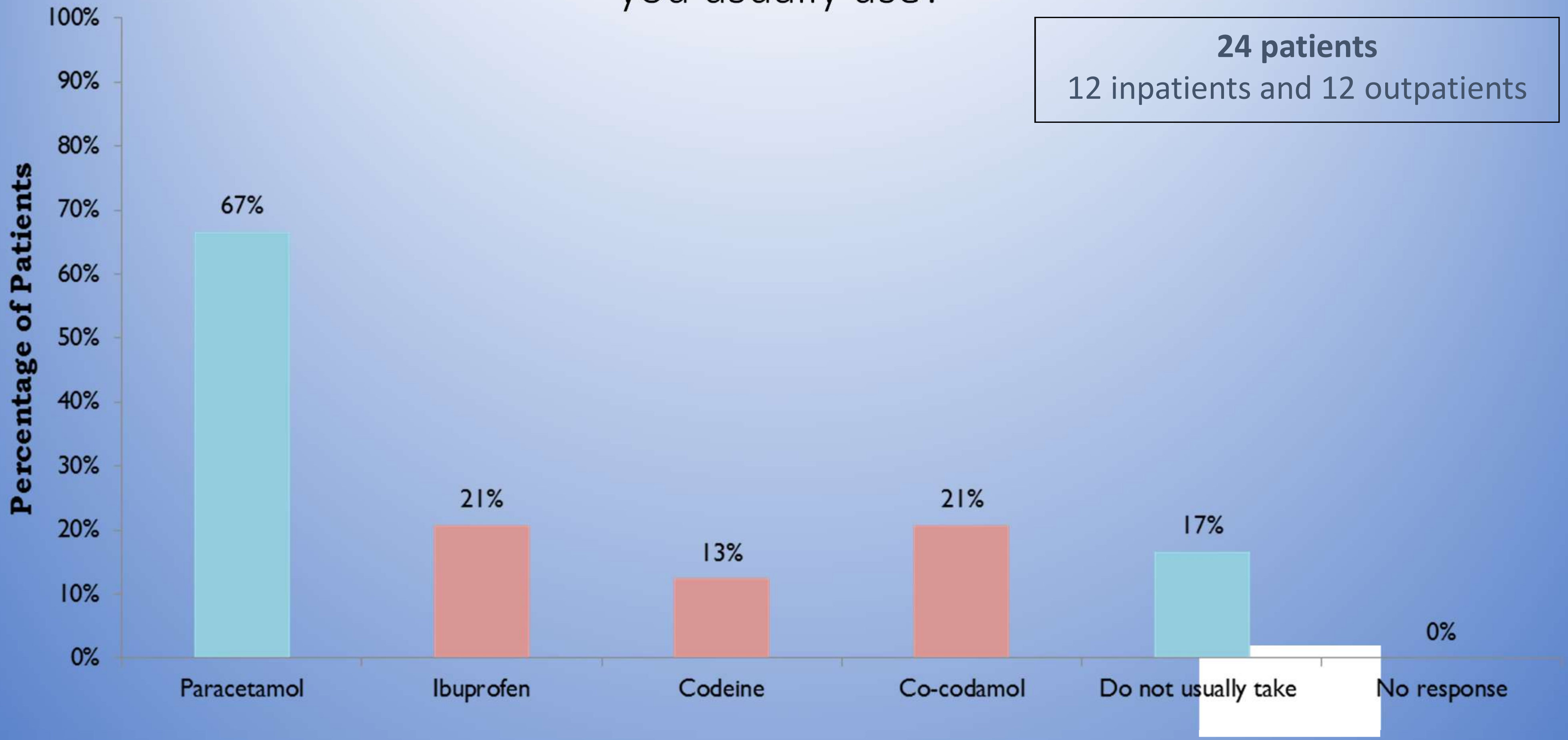


Review of medical notes; Bristol Royal Infirmary, UK; 2018

Evidence

Patient Survey

If you are in pain, which of the following over the counter medications do you usually use?

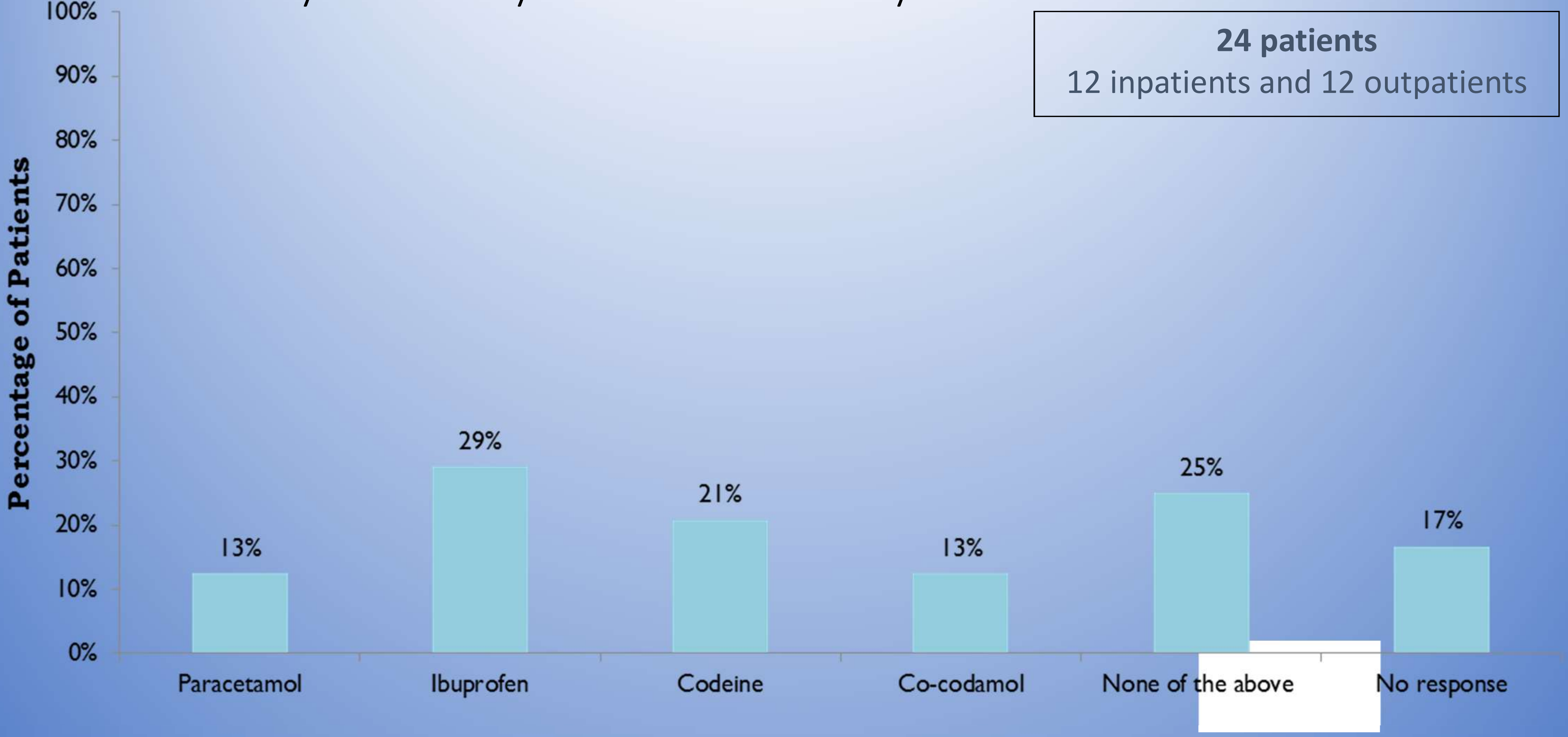


24 patients
12 inpatients and 12 outpatients

Survey of inpatients and outpatients with Child Pugh B and C Cirrhosis; Bristol Royal Infirmary, UK; 2019

If you are in pain, which of the following over the counter medications do you actively avoid because of your liver disease?

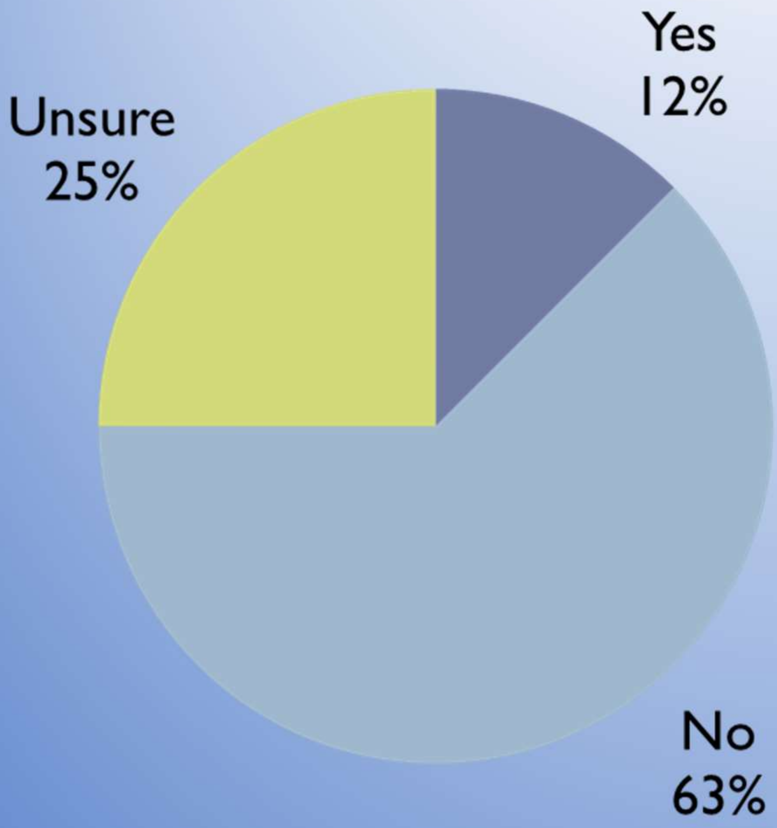
24 patients
12 inpatients and 12 outpatients



Survey of inpatients and outpatients with Child Pugh B and C Cirrhosis; Bristol Royal Infirmary, UK; 2019

Have staff at Bristol Royal Infirmary given you any advice about using painkillers in cirrhosis?

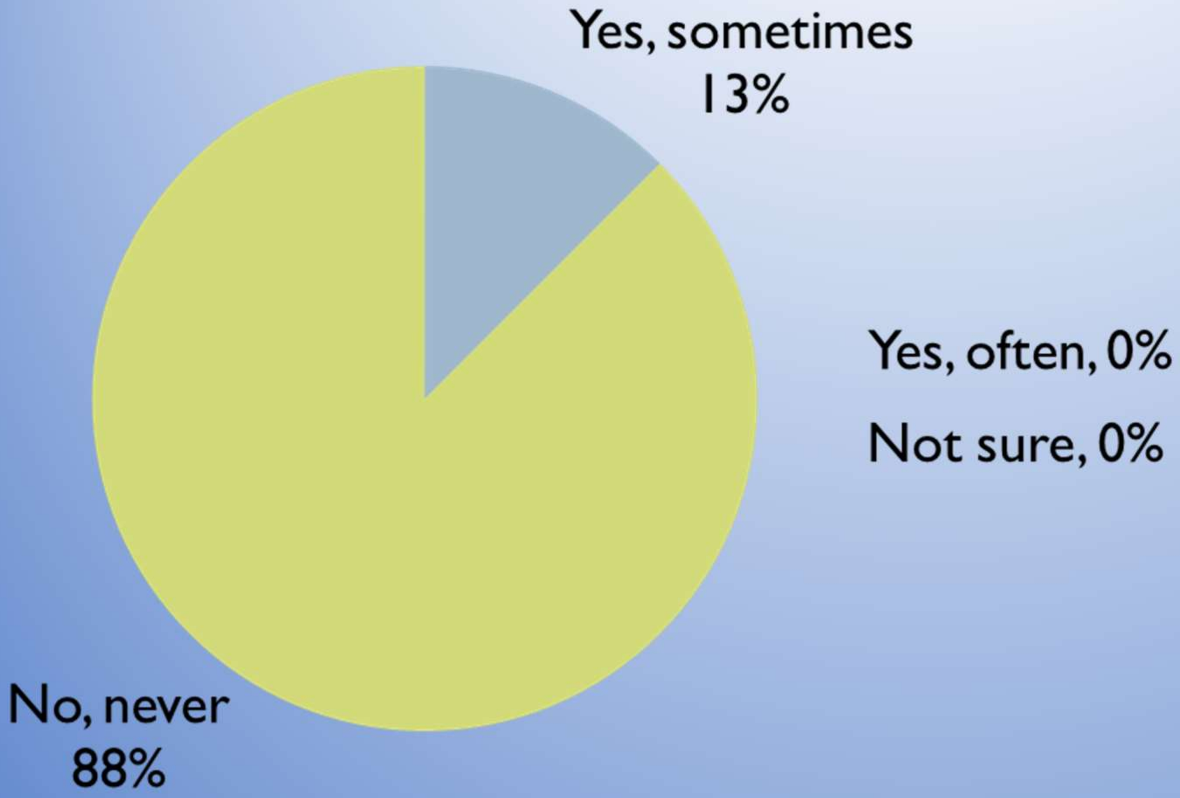
24 patients
12 inpatients and 12 outpatients



Survey of inpatients and outpatients with Child Pugh B and C Cirrhosis; Bristol Royal Infirmary, UK; 2019

Have you ever been left in pain because staff have been unsure which painkillers you can take because of your liver disease?

24 patients
12 inpatients and 12 outpatients



Survey of inpatients and outpatients with Child Pugh B and C Cirrhosis; Bristol Royal Infirmary, UK; 2019

Evidence

Literature review

Literature review

“90% of 108 patients with end-stage liver disease were prescribed medication for pain, but only 33% of them received favourable pain relief.”

Madan et al. Chronic pain among liver transplant candidates. 2012

Literature review

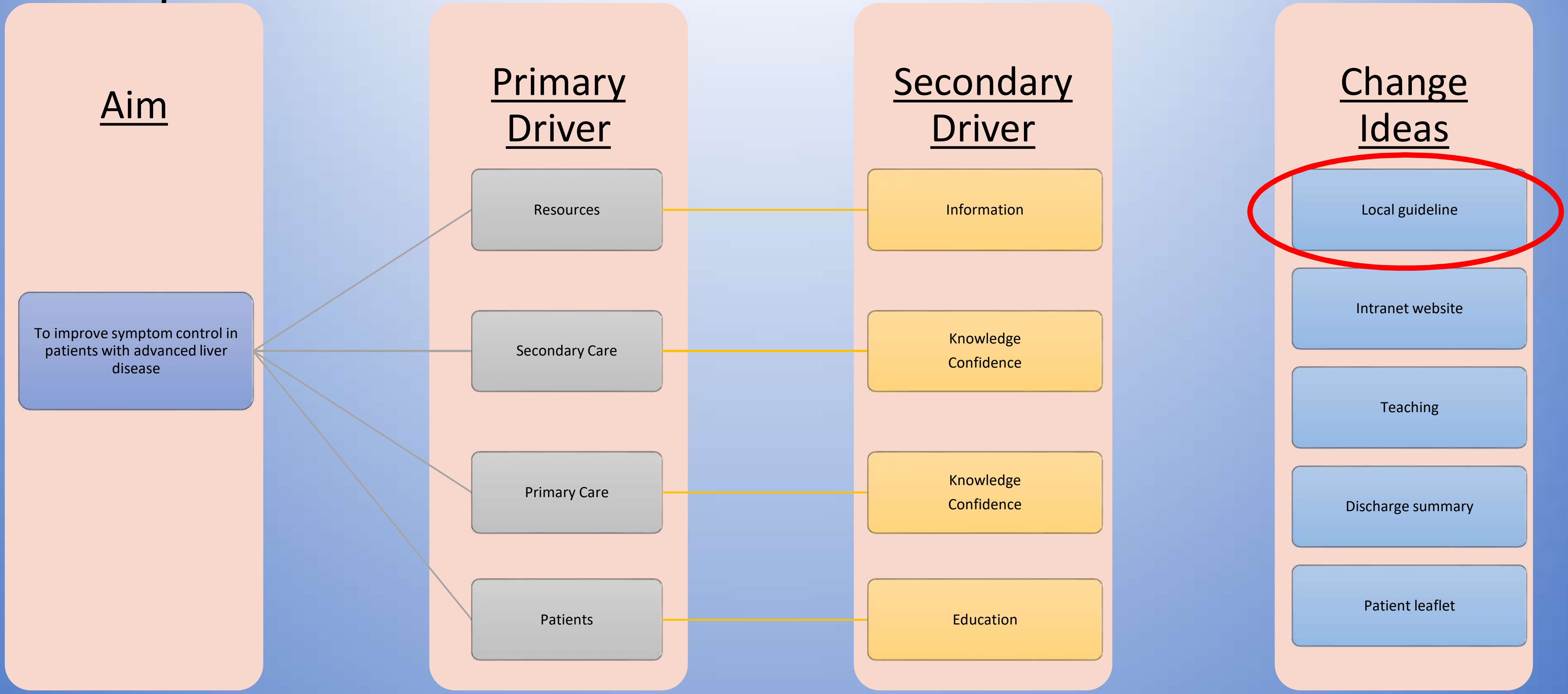
- *"Recommendations against the use of NSAIDs were significantly less common than recommendations against paracetamol use"*

- *"It was the recommendation of most respondents that over-the-counter analgesics should be avoided in patients with cirrhosis"*

Rossi et al. Use of over-the-counter analgesics in patients with chronic liver disease: physicians' recommendations. 2008

Project Overview

Project Overview



Aim

To improve symptom control in patients with advanced liver disease

Primary Driver

- Resources
- Secondary Care
- Primary Care
- Patients

Secondary Driver

- Information
- Knowledge Confidence
- Knowledge Confidence
- Education

Change Ideas

- Local guideline
- Intranet website
- Teaching
- Discharge summary
- Patient leaflet

Local Guideline

Local Guideline

- Why?
  - From results identified need for local guideline
  - Liver-specific
  - Easy to use for those with limited expertise
  - Safe
  - Specific doses
  - Pragmatic
  - Practical

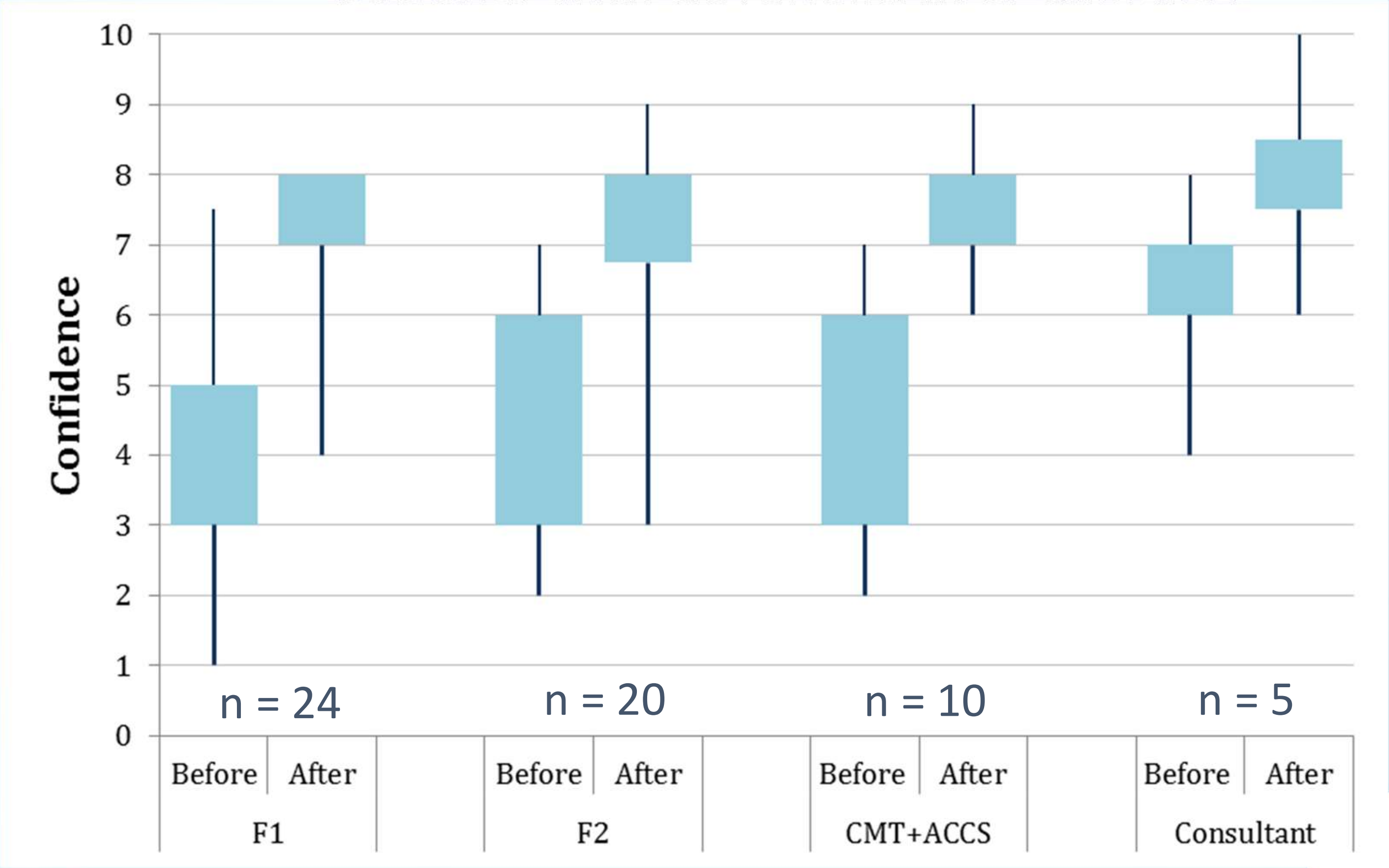
Local Guideline

- Considerations
  - Guidelines
    - Kings College Hospital
    - Pallaborative North West
    - Up to Date
    - Local guidelines/advice
  - Medicine Specific
    - Summary of product characteristics
    - BNF
    - Livertox
  - Practical
    - Formulations
    - Patient factors
    - Nursing factors

Local Guideline

- Take home messages
  - Oral paracetamol – reduce 24hr dose if using long term
  - IV paracetamol – try to avoid, maximum 3g / 24hrs
  - Avoid NSAIDs
  - Oramorph preferable to codeine and tramadol as step up
  - Try to avoid oxycodone
  - Try to avoid cyclizine; dose reduce metoclopramide & ondansetron
  - Consider renal impairment
  - Consider liver specific symptoms
  - Consider other issues specific to this patient group e.g. methadone

How confident do you feel prescribing medications for symptom control in patients with advanced liver disease?



Survey of junior doctors and consultants before and after teaching; Bristol Royal Infirmary, UK; 2019

Next steps

Further work

- Patient information leaflet
- Intranet page
- Discharge summary template
  - Standardised paragraph featuring OTC medications, signs and management of encephalopathy
- Work with primary care
- Teaching for nurses, site managers

Discussion

Discussion

- We would be keen to hear your feedback on…
  - Our guideline
  - Resources used at other trusts

Acknowledgements

- Dr Hazel Woodland
- Janki Jethwa, pharmacist
- Hepatology consultants, BRI
- Palliative Medicine consultants, BRI
- Clinical Pharmacy Team, BRI
- Dr Fiona Finlay, Consultant in Palliative Medicine, Queen Elizabeth University Hospital Glasgow
- Guidelines for prescribing for symptom control in patients with hepatic impairment, 2018, Kings College Hospital

Preparing for the end stage

living with kidney disease

Dr Barny Hole
University of Bristol
barnaby.hole@bristol.ac.uk
@barnyhole

Why kidney disease?

Is kidney medicine ahead of the game?

Is it easier to do this in nephrology?

Are kidney clinicians doing well?

Why kidney disease?

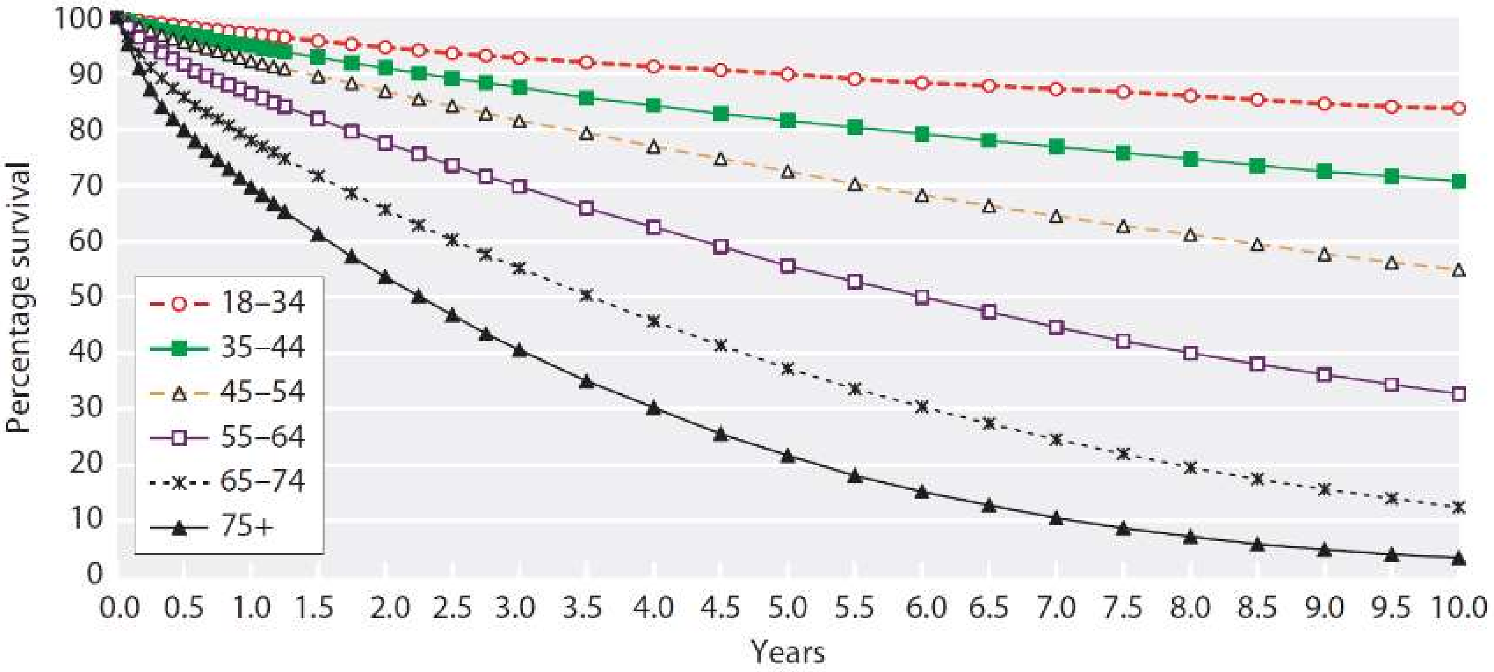
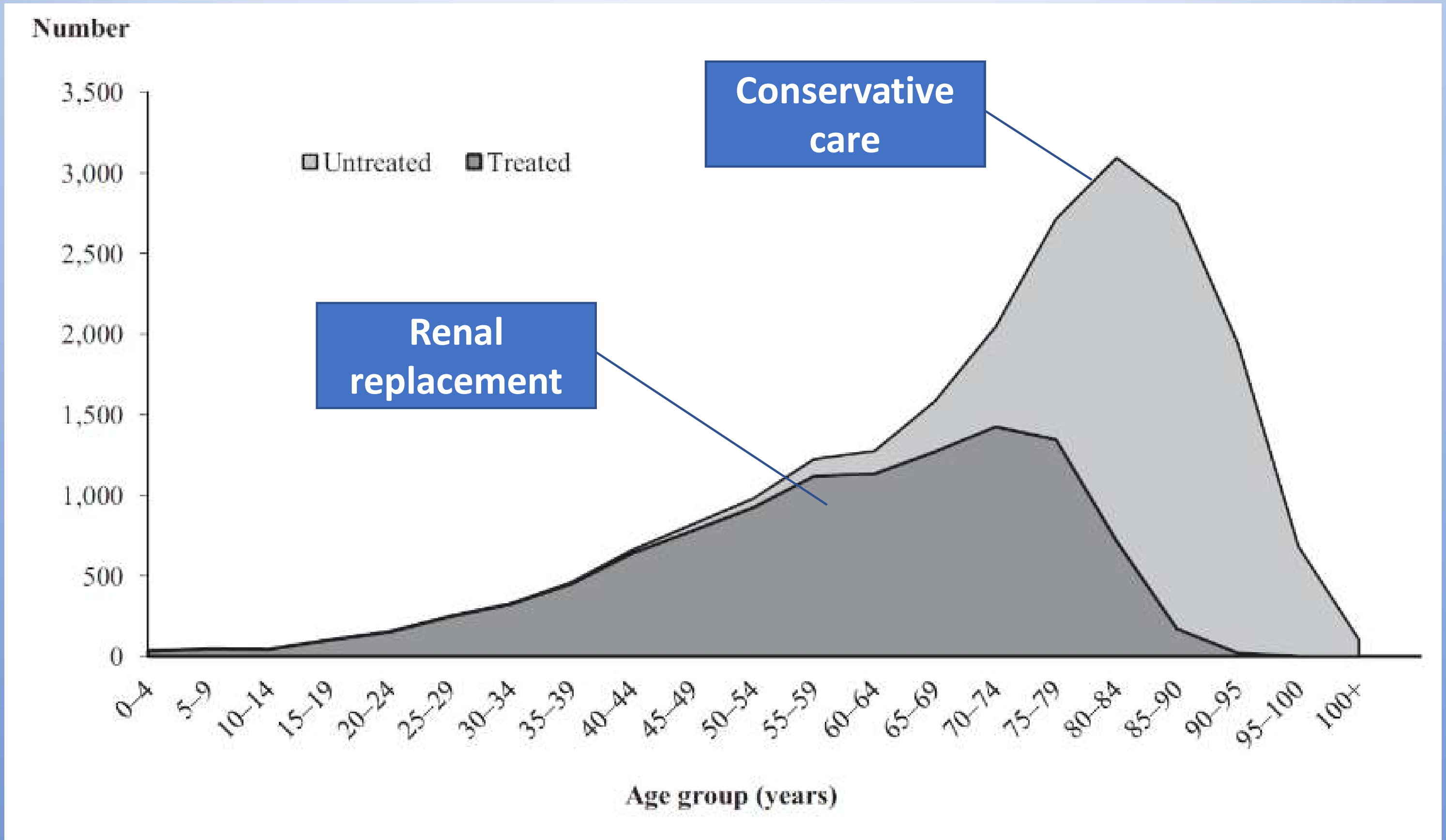


Fig. 5.4. Survival of incident RRT patients (unadjusted), 1997–2015 cohort (from day 0)

Steenkamp *et al.,* 2018. UK Renal Registry 20th Annual Report: Survival and Cause of Death in UK Adult Patients on Renal Replacement Therapy in 2016. Nephron. 139(suppl1):117–150. DOI: 10.1159/000490963

Why kidney disease?



Conservative care

Renal replacement

Sparke, et al. Estimating the Total Incidence of Kidney Failure in Australia Including Individuals Who Are Not Treated by Dialysis or Transplantation (2013) *Am J Kidney Dis.* 61(3):413-419.

Why kidney disease?

	Dialysis	Conservative Care	Last day of life
Fatigue	71%	86%	
Itch	55%	84%	
Pain	48%	73%	42%
Breathlessness	37%	80%	25%
Nausea	33%	59%	12%
Restless legs	30%		28%
	Murtagh et al. Adv Chr Kidney Dis 2007	*Murtagh et al. JPSM 2010*	*Cohen et al. Am J Kidney Dis 2000*

Why kidney disease?

"…the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"

World Health Organization
www.who.int/cancer/palliative/definition/en/

Why kidney disease?

Is kidney medicine ahead of the game?…

Is kidney medicine ahead of the game?...

Is kidney medicine ahead of the game?...

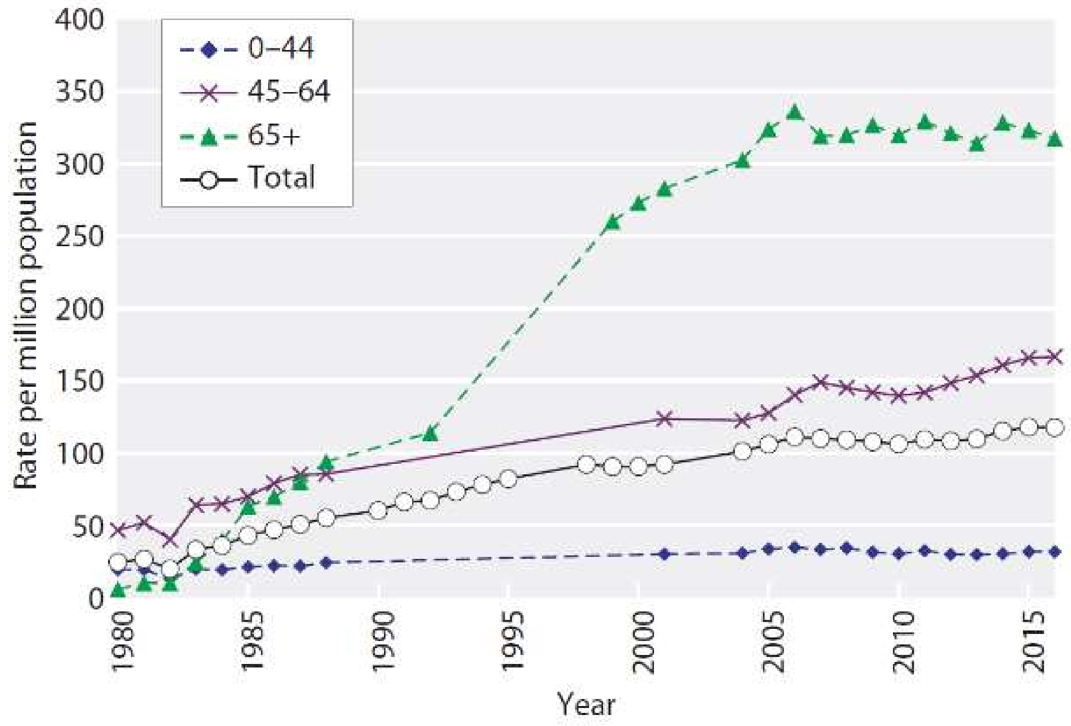


Fig. 1.4. RRT incidence rates between 1980 and 2016

Hole *et al.,* 2018. UK Renal Registry 20th Annual Report: UK Renal Replacement Therapy Adult Incidence in 2016. Nephron. 139(suppl1):13–46. DOI: 10.1159/000490959

Nationa
Framew ces – 2005

“[People should]...
receive t heir
prognosi the choices
available se near the
end of life iative care
plan, built ual needs
and prefer

DH Department of Health

The National Service Framework for Renal Services

Part Two: Chronic Kidney Disease,
Acute Renal Failure and End of Life Care

February 2005

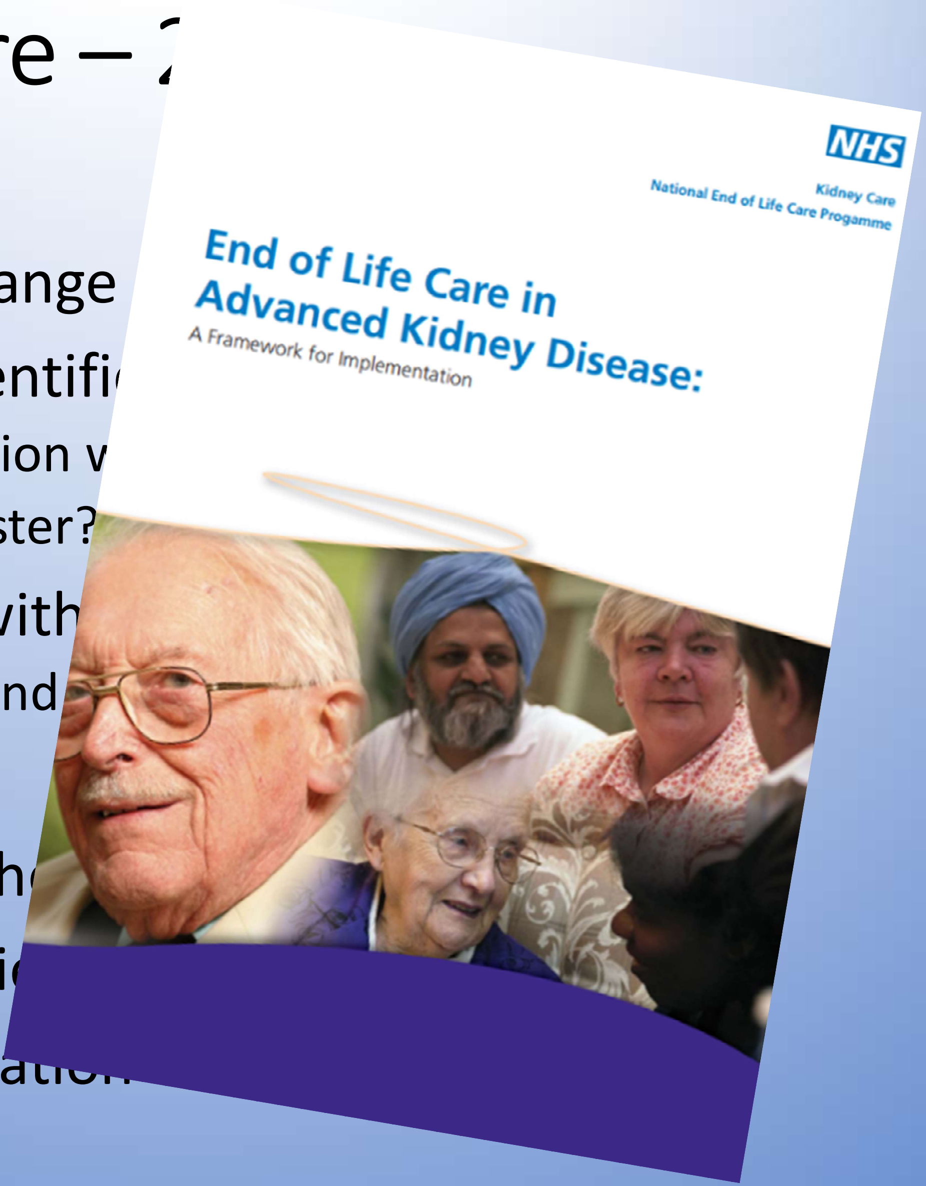
National Service Framework for Renal Services – 2005

“[People with kidney failure should]... *receive timely evaluation of their prognosis, information about the choices available to them, and for those near the end of life a jointly agreed palliative care plan, built around their individual needs and preferences*”

NHS Kidney Care –

Recommendations

- Recognise culture change
- Unit-wide patient identifi
  - Who agrees registration w
  - What to call the register?
- Advance care plans with
  - Recognise the time and
- IT systems that work
- Coordination with oth
- Support carers, famili
- Training and identificatio



NHS
Kidney Care
National End of Life Care Progamme

End of Life Care in Advanced Kidney Disease:

A Framework for Implementation

NHS Kidney C

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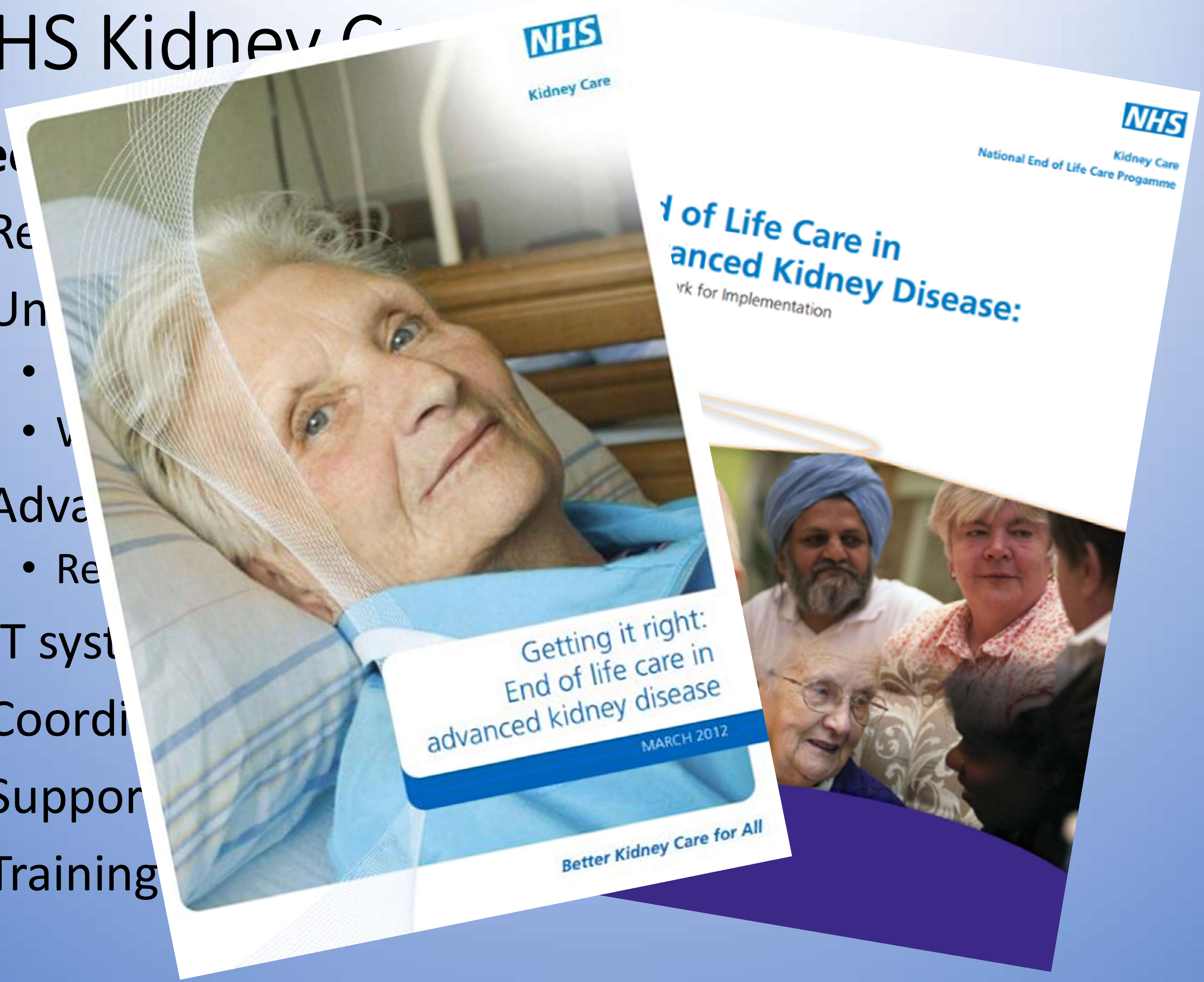


NHS
Kidney Care

Getting it right:
End of life care in
advanced kidney disease

MARCH 2012

Better Kidney Care for All

NHS
Kidney Care
National End of Life Care Progamme

of Life Care in
anced Kidney Disease:
rk for Implementation

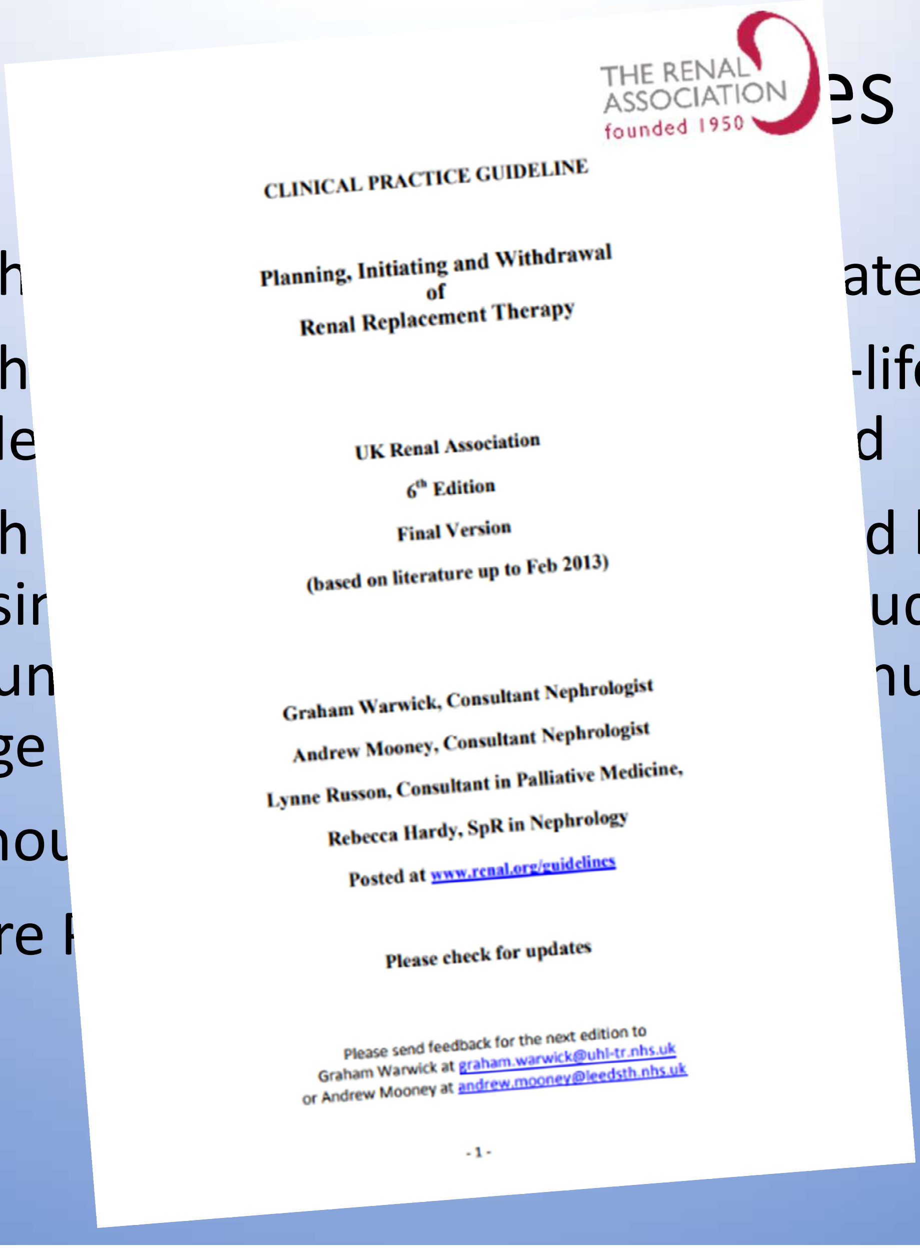
NHS Kidney Care – 2012

Recommendations

- Recognise culture change needed
- Unit-wide patient identification and registration
  - Who agrees registration with patient?
  - What to call the register?
- Advance care plans with all dialysis patients
  - Recognise the time and work that this will take
- IT systems that work
- Coordination with other organisations
- Support carers, families and staff
- Training and identification of appropriate staff

UK Renal
es - 2013

- Patients with
ated prognosis
- Patients with
-life care needs
should be ide
d
- Patients with
d be
identified usir
uding co-
morbidity, fun
nutrition,
advanced age
- A register shou
- Advance Care F



THE RENAL ASSOCIATION
founded 1950

CLINICAL PRACTICE GUIDELINE

Planning, Initiating and Withdrawal
of
Renal Replacement Therapy

UK Renal Association

6th Edition

Final Version

(based on literature up to Feb 2013)

Graham Warwick, Consultant Nephrologist

Andrew Mooney, Consultant Nephrologist

Lynne Russon, Consultant in Palliative Medicine,

Rebecca Hardy, SpR in Nephrology

Posted at www.renal.org/guidelines

Please check for updates

Please send feedback for the next edition to
Graham Warwick at graham.warwick@uhl-tr.nhs.uk
or Andrew Mooney at andrew.mooney@leedsth.nhs.uk

- 1 -

UK Renal association guidelines - 2013

- Patients with CKD4/5 should be given estimated prognosis
- Patients with CKD4/5 with imminent end-of-life care needs should be identified and their care prioritised
- Patients with less than one year to live should be identified using a combination of criteria including co-morbidity, functional status, evidence of malnutrition, advanced age and the ‘surprise question‘
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- **SET OF AUDIT MEASURES DEFINED**

International consensus - 2015

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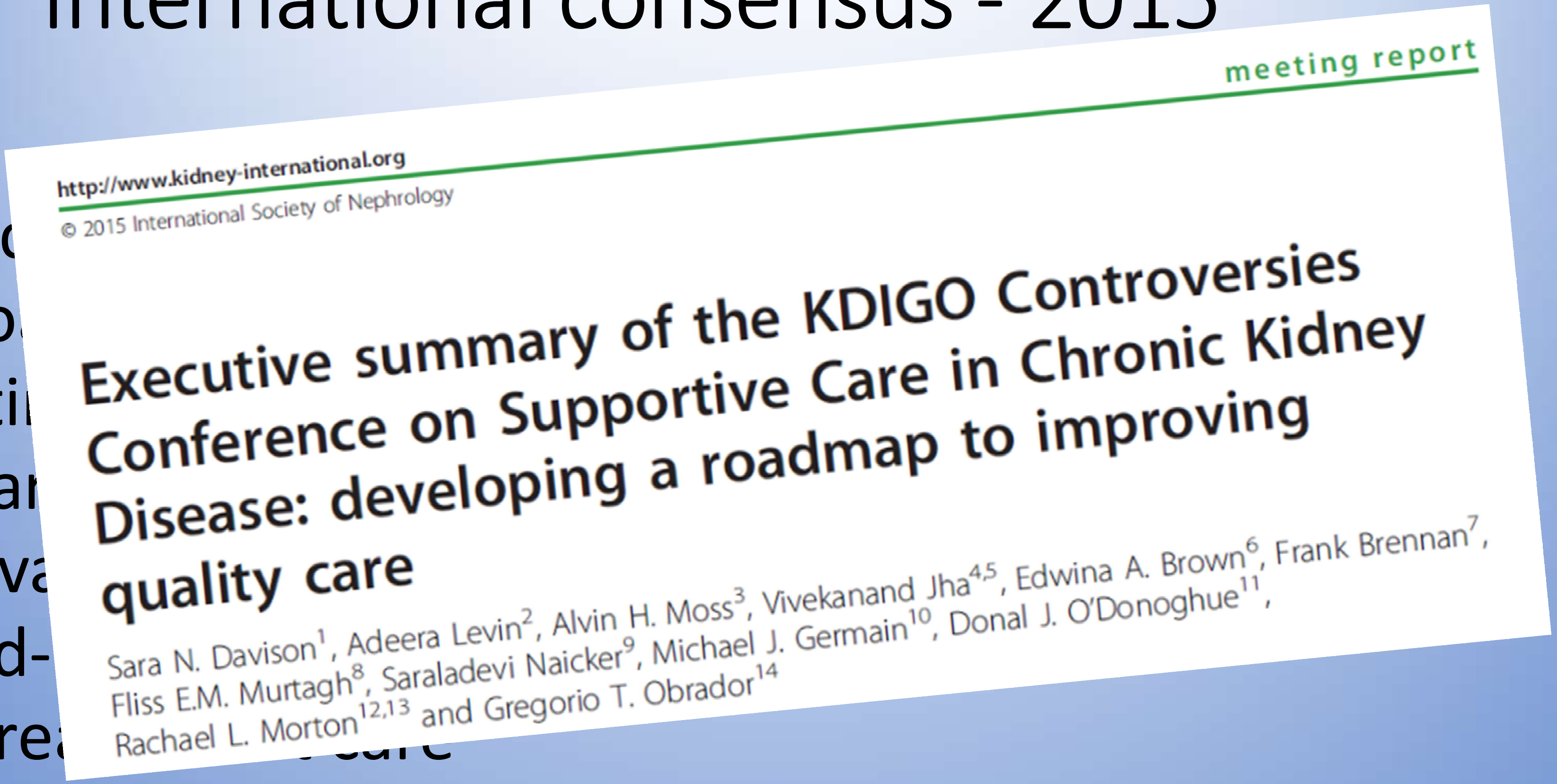


meeting report

http://www.kidney-international.org

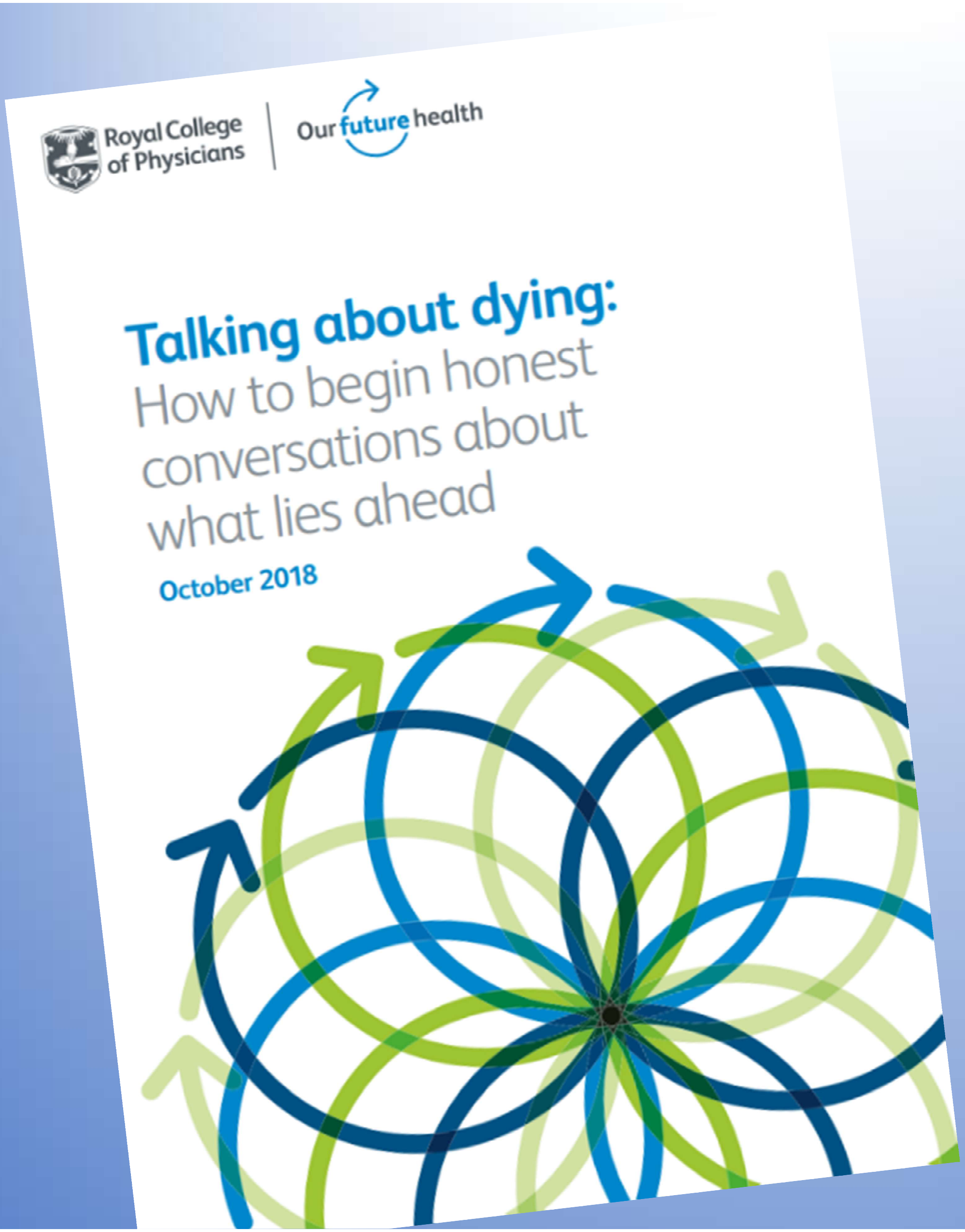
Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care

Sara N. Davison[1], Adeera Levin[2], Alvin H. Moss[3], Vivekanand Jha[4,5], Edwina A. Brown[6], Frank Brennan[7], Fliss E.M. Murtagh[8], Saraladevi Naicker[9], Michael J. Germain[10], Donal J. O'Donoghue[11], Rachael L. Morton[12,13] and Gregorio T. Obrador[14]

International consensus - 2015

Key components of renal supportive care

- Proactive symptom assessment and management
- Estimation and communication of prognosis
- Shared decision making
- Advance care planning
- End-of-life care
- Bereavement care



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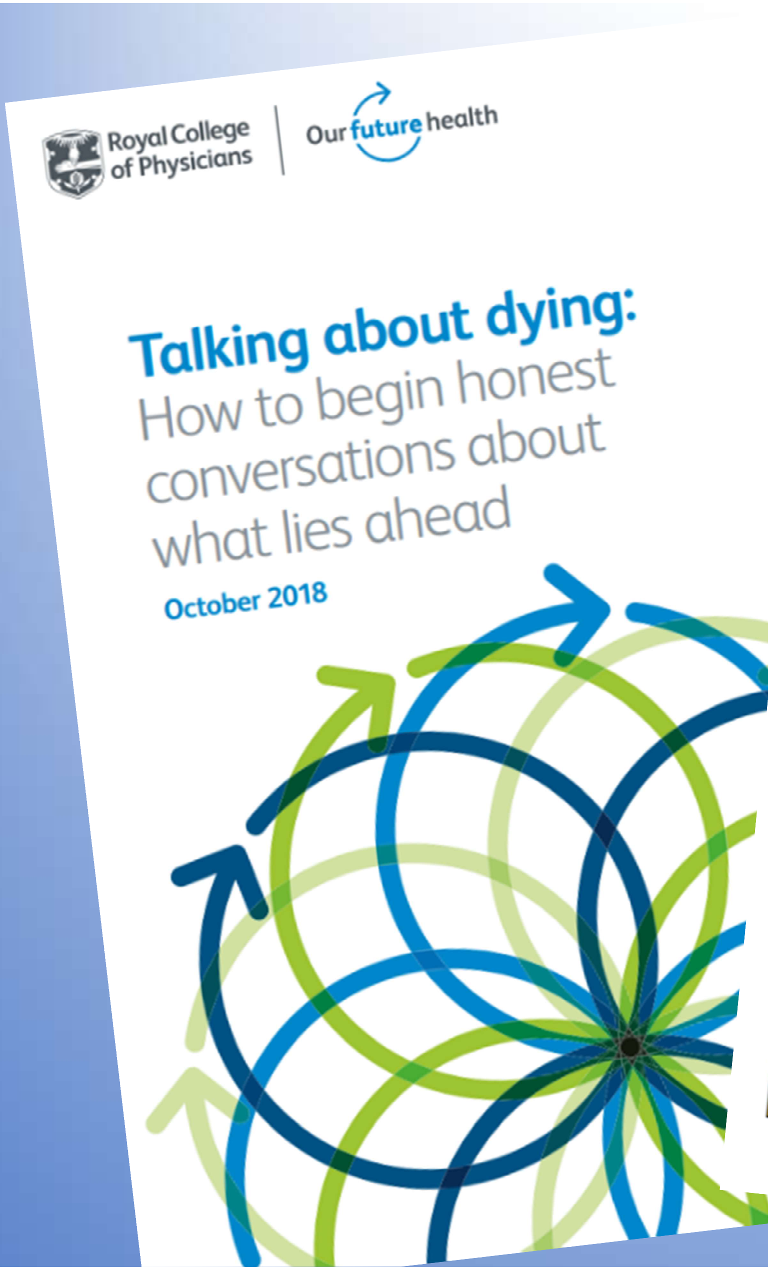
Our future health

Talking about dying:

How to begin honest conversations about what lies ahead

October 2018



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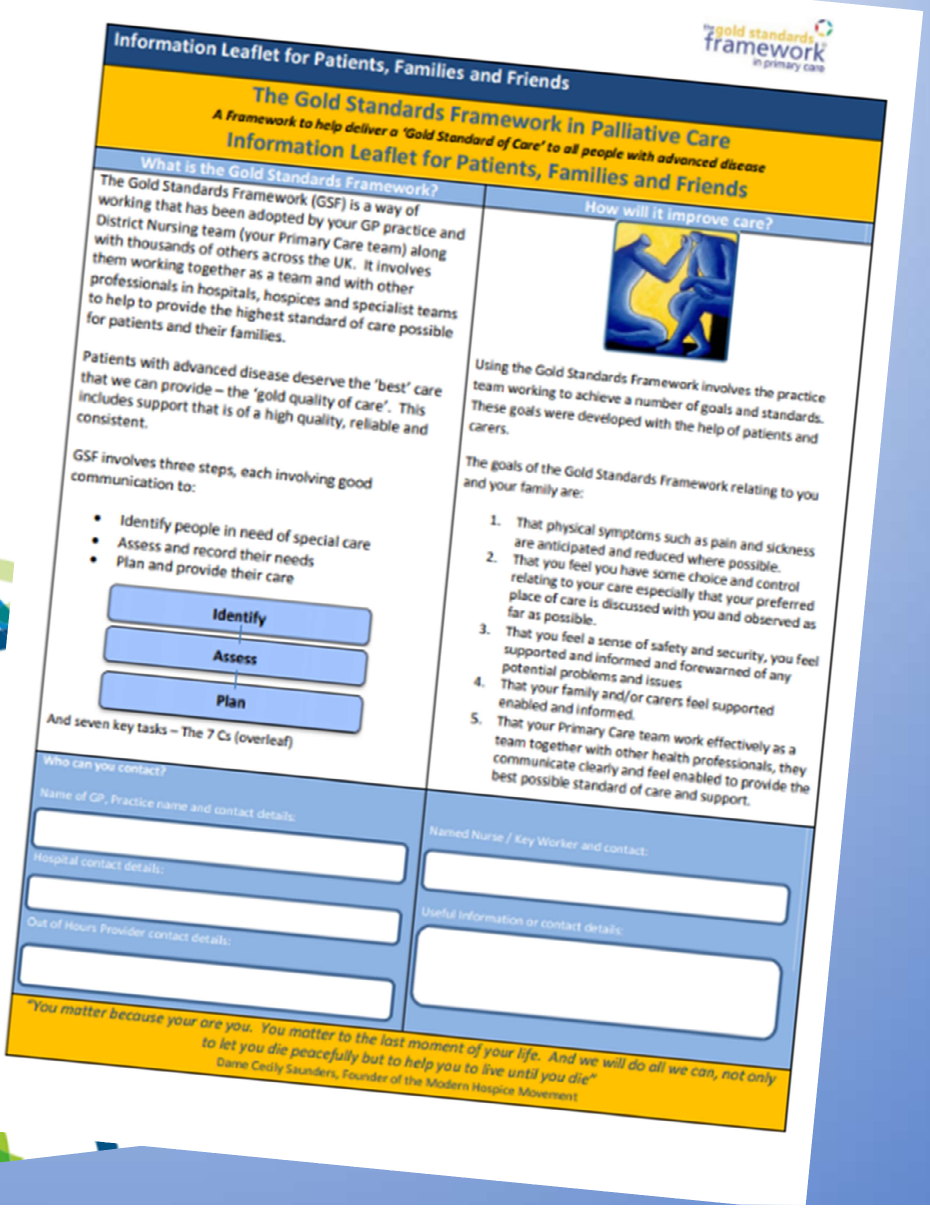

gold standards framework in primary care

Information Leaflet for Patients, Families and Friends

The Gold Standards Framework in Palliative Care

A Framework to help deliver a 'Gold Standard of Care' to all people with advanced disease

Information Leaflet for Patients, Families and Friends

What is the Gold Standards Framework?

The Gold Standards Framework (GSF) is a way of working that has been adopted by your GP practice and District Nursing team (your Primary Care team) along with thousands of others across the UK. It involves them working together as a team and with other professionals in hospitals, hospices and specialist teams to help to provide the highest standard of care possible for patients and their families.

Patients with advanced disease deserve the 'best' care that we can provide – the 'gold quality of care'. This includes support that is of a high quality, reliable and consistent.

GSF involves three steps, each involving good communication to:

- Identify people in need of special care
- Assess and record their needs
- Plan and provide their care

Identify

Assess

Plan

And seven key tasks – The 7 Cs (overleaf)

How will it improve care?

Using the Gold Standards Framework involves the practice team working to achieve a number of goals and standards. These goals were developed with the help of patients and carers.

The goals of the Gold Standards Framework relating to you and your family are:

1. That physical symptoms such as pain and sickness are anticipated and reduced where possible.
2. That you feel you have some choice and control relating to your care especially that your preferred place of care is discussed with you and observed as far as possible.
3. That you feel a sense of safety and security, you feel supported and informed and forewarned of any potential problems and issues
4. That your family and/or carers feel supported enabled and informed.
5. That your Primary Care team work effectively as a team together with other health professionals, they communicate clearly and feel enabled to provide the best possible standard of care and support.

Who can you contact?

Name of GP, Practice name and contact details:

Hospital contact details:

Out of Hours Provider contact details:

Named Nurse / Key Worker and contact:

Useful information or contact details:

"You matter because your are you. You matter to the last moment of your life. And we will do all we can, not only to let you die peacefully but to help you to live until you die"

Dame Cecily Saunders, Founder of the Modern Hospice Movement

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Observation and preparation

- Active observation of an end-of-life care conversaton
- Debrief with a senior colleague, focusing on what questions or concerns may arise in a second conversation

Experiential learning

- Particpation in second conversation

Feedback and reflection

Facilitated reflection with a senior colleage

- What went well?
- How did you feel?
- What could have gone better?

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nts, Families and Friends

How will it improve care?

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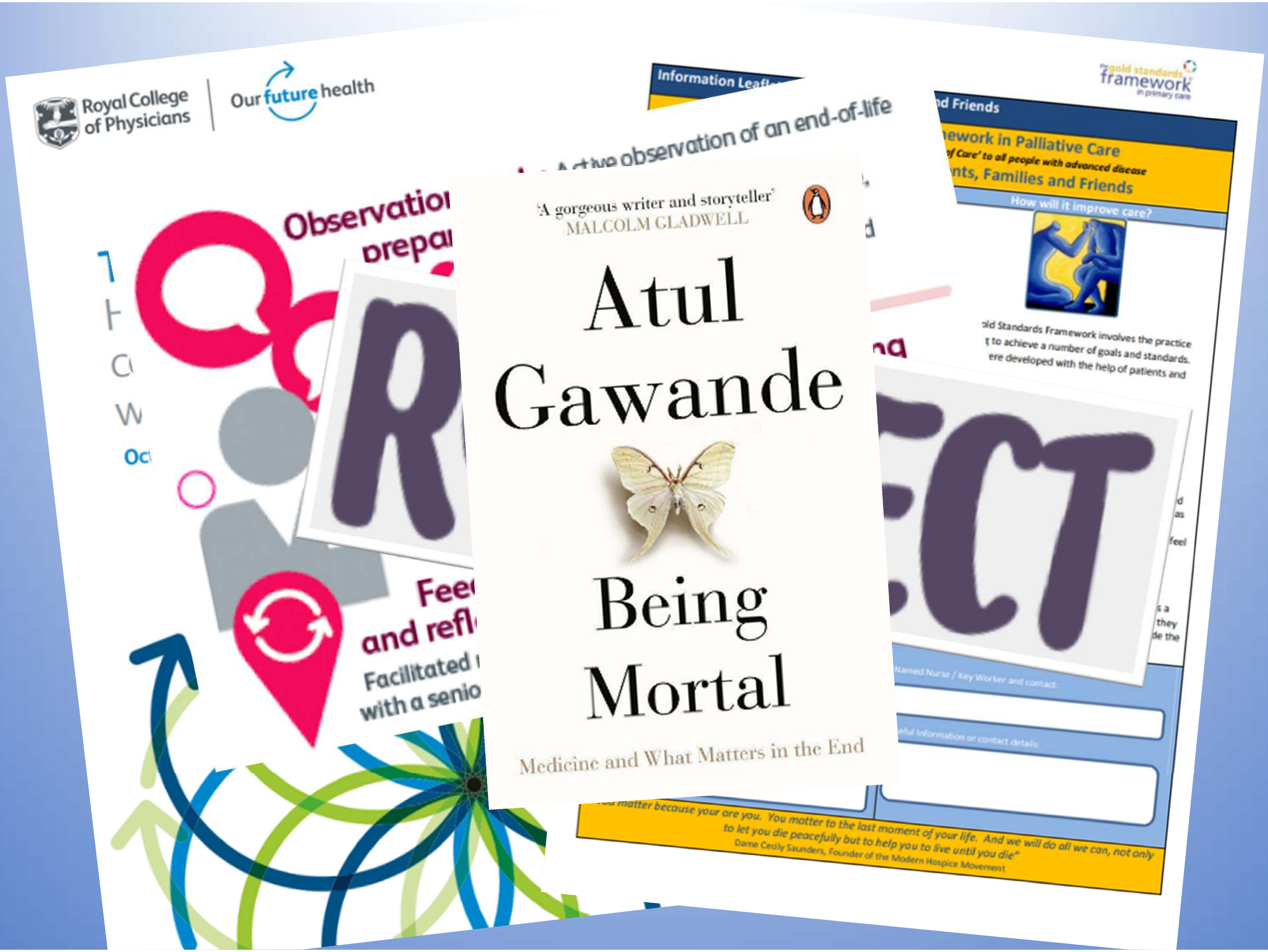

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Active observation of an end-of-life

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'A gorgeous writer and storyteller'
MALCOLM GLADWELL

Atul Gawande

Being Mortal

Medicine and What Matters in the End

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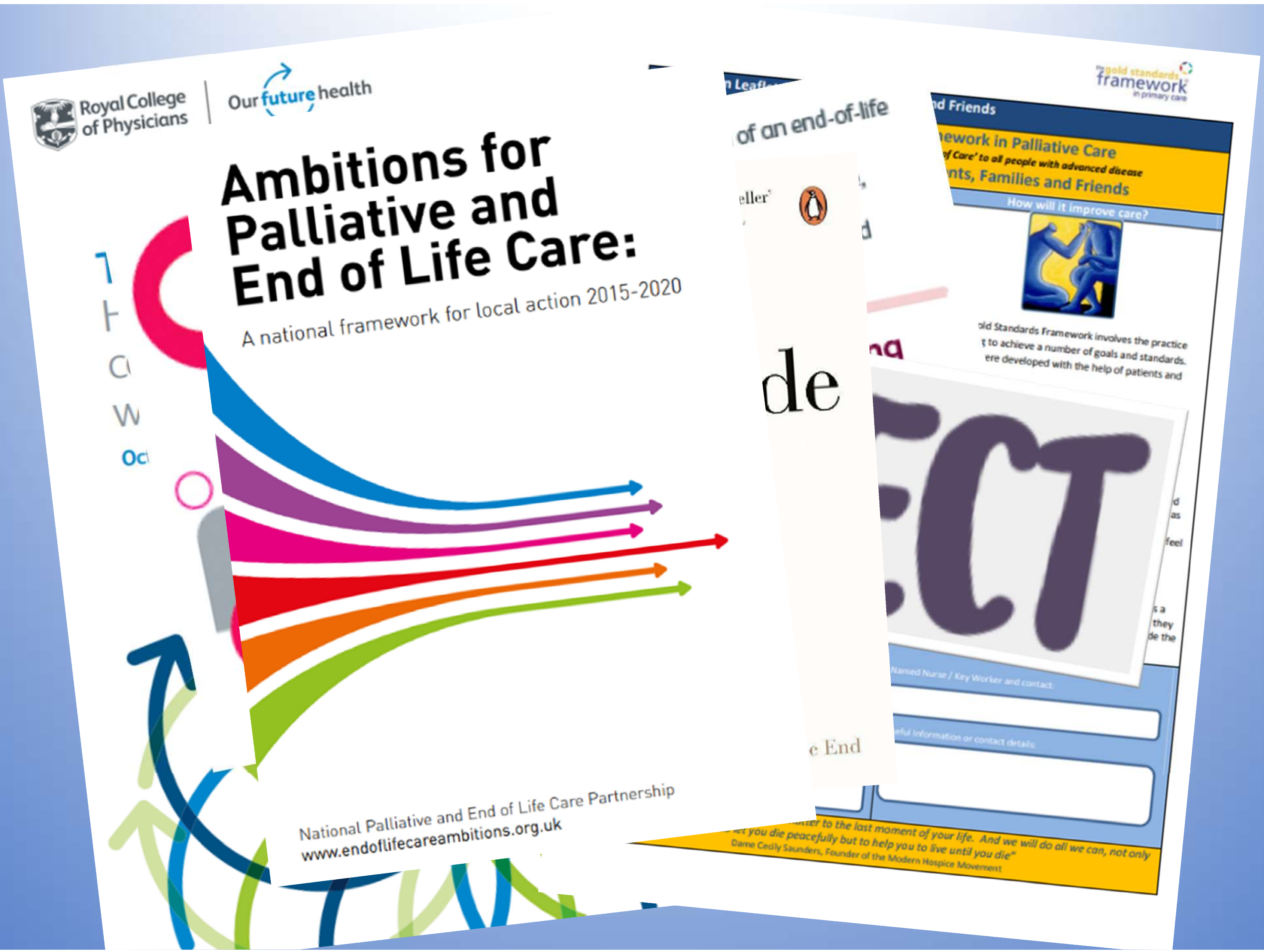

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Ambitions for Palliative and End of Life Care:

A national framework for local action 2015-2020

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

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A national frame...

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

Serious Illness Conversation Guide

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. ***Set up the conversation*** - Introduce purpose - Prepare for future decisions - Ask permission	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**"
2. ***Assess understanding and preferences***	"What is your **understanding** now of where you are with your illness?" "How much **information** about what is likely to be ahead with your illness would you like from me?"
3. ***Share prognosis*** - Share prognosis - Frame as a "wish...worry", "hope...worry" statement - Allow silence, explore emotion	"I want to share with you **my understanding** of where things are with your illness..." *Uncertain:* "It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility." OR *Time:* "I **wish** we were not in this situation, but I am **worried** that time may be as short as ___ *(express as a range, e.g. days to weeks, weeks to months, months to a year).*" OR *Function:* "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."
4. ***Explore key topics*** - Goals - Fears and worries - Sources of strength - Critical abilities - Tradeoffs - Family	"What are your most important **goals** if your health situation worsens?" "What are your biggest **fears and worries** about the future with your health?" "What gives you **strength** as you think about the future with your illness?" "What **abilities** are so critical to your life that you can't imagine living without them?" "If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" "How much does your **family** know about your priorities and wishes?"
5. ***Close the conversation*** - Summarize - Make a recommendation - Check in with patient - Affirm commitment	"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, **I recommend** that we ___. This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
6. ***Document your conversation***	
7. ***Communicate with key clinicians***	

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How will it improve care?

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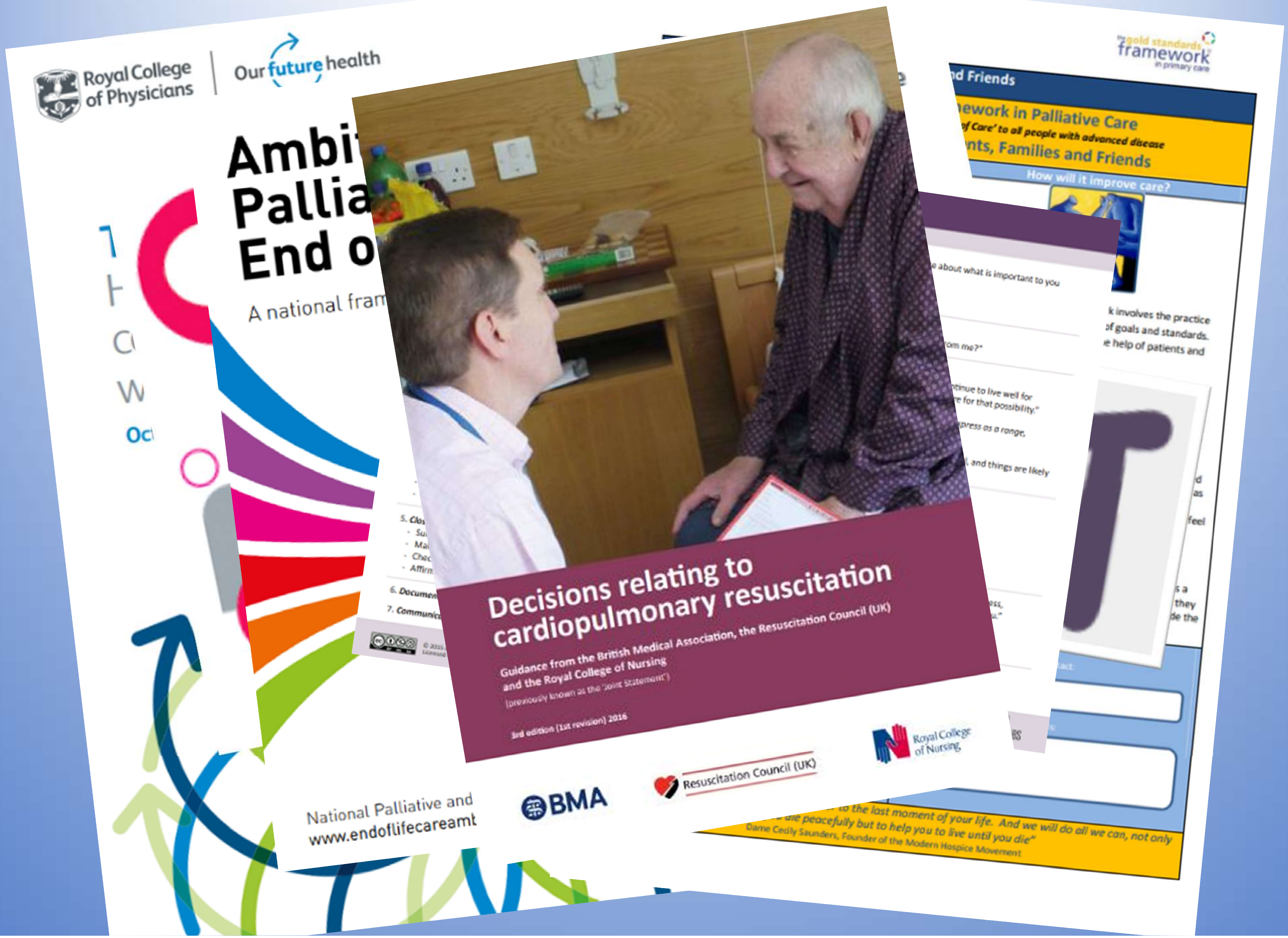

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Decisions relating to cardiopulmonary resuscitation

Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing
(previously known as the 'Joint Statement')

3rd edition (1st revision) 2016

BMA
Resuscitation Council (UK)
Royal College of Nursing

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NICE National Institute for Health and Care Excellence

NICE quality standard

End of life care for adults

Quality standard
Published: 28 November 2011
nice.org.uk/guidance/qs13

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National Palliative and
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NICE National Institute for Health and Care Excellence

NICE guideline

Care of dying adults in the last days of life

NICE guideline
Published: 16 December 2015
nice.org.uk/guidance/ng31

(previously known as the 'Joint Statement')

3rd edition (1st revision) 2016

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Resuscitation Council (UK)

Royal College of Nursing

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Treatment and care towards the end of life:

good practice in decision making

Working with doctors Working for patients

General Medical Council

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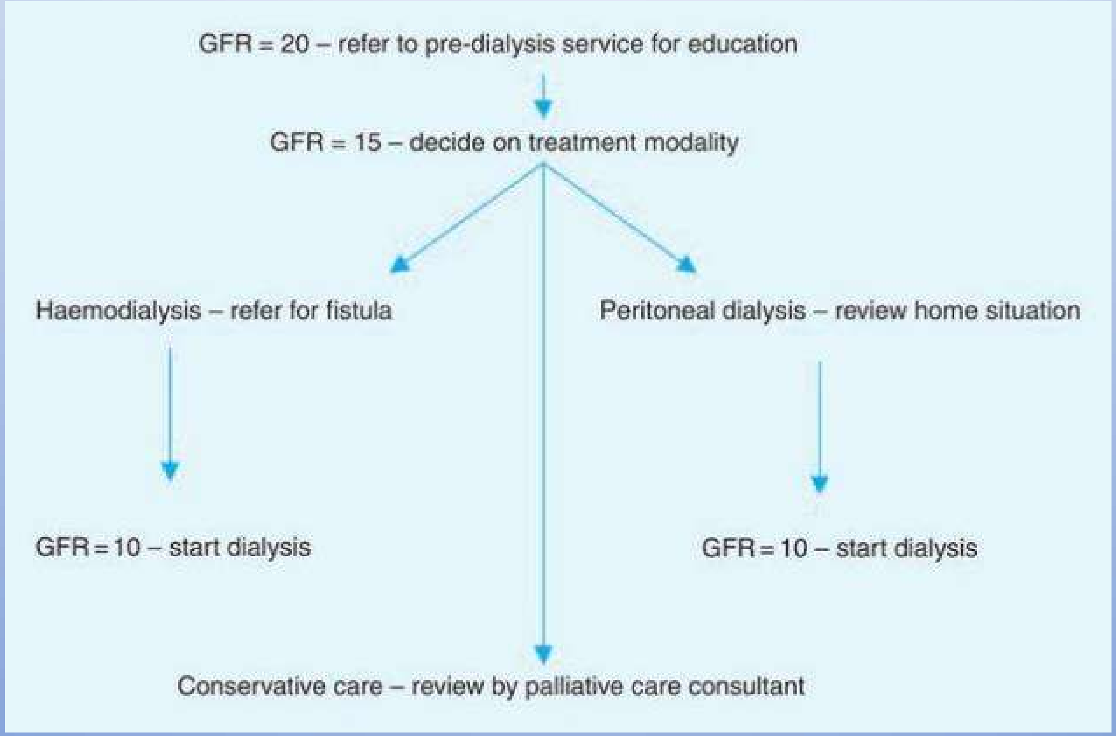
Is kidney medicine ahead of the game?...

Is it easier to do this in nephrology?

Are kidney clinicians doing well?



GFR = 20 – refer to pre-dialysis service for education

GFR = 15 – decide on treatment modality

Haemodialysis – refer for fistula

Peritoneal dialysis – review home situation

GFR = 10 – start dialysis

GFR = 10 – start dialysis

Conservative care – review by palliative care consultant

Russon & Mooney, Clin Med 2010

Are kidney clinicians doing well?

Davison et al **Longitudinal validation of a modified Edmonton symptom assessment system (ESAS) in haemodialysis patients** *Nephrology Dialysis Transplantation*, Volume 21, Issue 11, 1 November 2006, Pages 3189–3195.

Raj et al **Validation of the IPOS-Renal Symptom Survey in Advanced Kidney Disease: A Cross-sectional Study.** J Pain Symptom Manage. 2018 Aug;56(2):281-287.

Are kidney clinicians doing well?

RENAL ASSOCIATION

UK RENAL REGISTRY

Are kidney clinicians doing well?

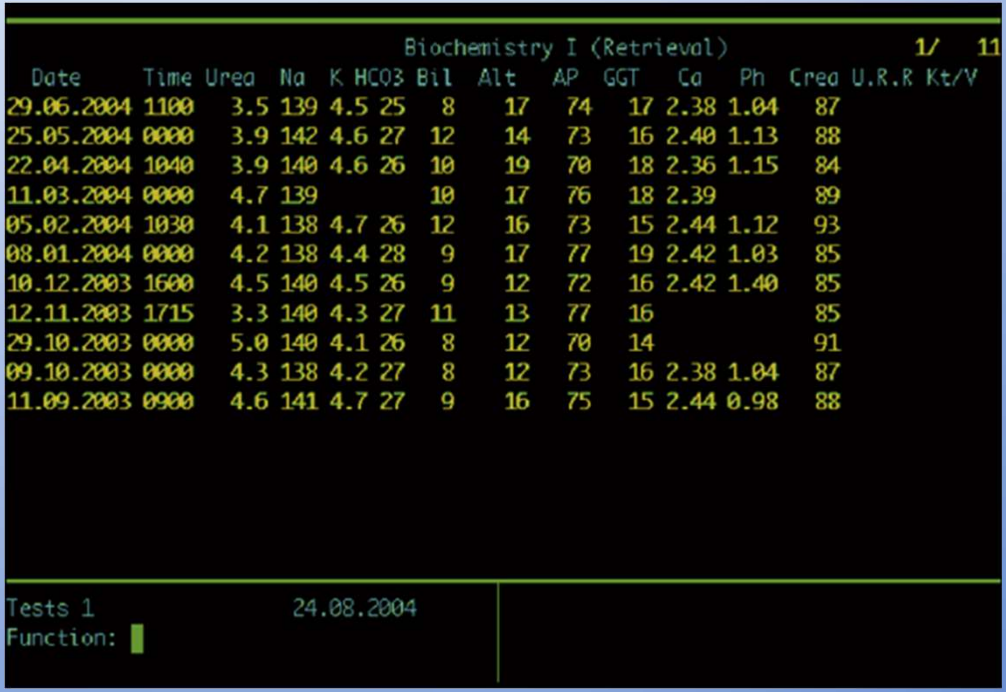
NIHR | National Institute for Health Research

Are kidney clinicians doing well?

PatientView

Are kidney clinicians doing well?

PatientView



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25.05.2004 0000   3.9 142 4.6 27   12     14   73   16 2.40 1.13   88
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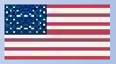
Are kidney clinicians doing well?

- 55% of units used a register to identify patients approaching end of life
- 25% of units had renal nurses whose time was specifically allocated for palliative care
- 13% of units had palliative care specialists involved in ACP
- 15% had funding dedicated to providing conservative care
- Specialist palliative care services within the hospital were used by 91% of units

Roderick et al 2015 A national study of practice patterns in UK renal units in the use of dialysis and conservative kidney management Health Services and Delivery Research, No. 3.12

Are kidney clinicians doing well?

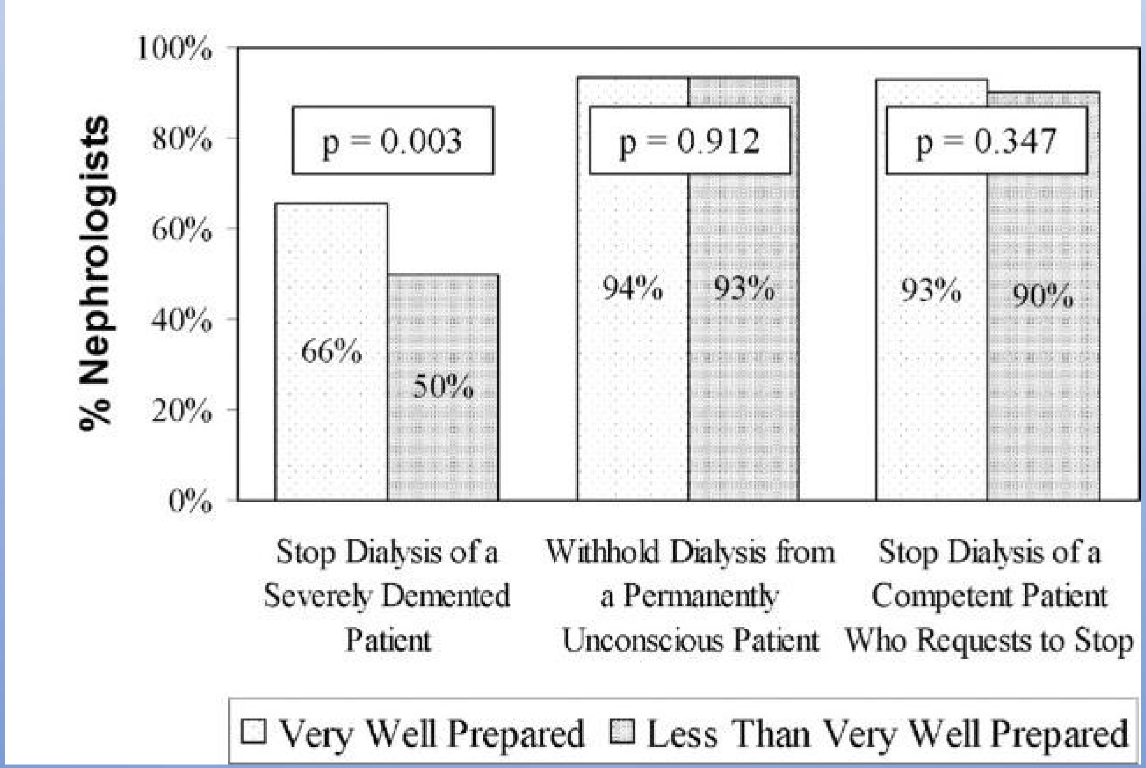


Only 22.2% of 436 dialysis and conservative care patients possessed a correct understanding of palliative care

Davison et al. 2016 BMJ Support Palliat Care

Are kidney clinicians doing well?

Thirty-nine percent of nephrologists perceived themselves to be very well prepared to make end-of-life decisions



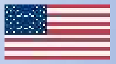
Davison et al 2006 CJASN

Are kidney clinicians doing well?

Patients significantly more optimistic than their nephrologists about 1- and 5-year survival and more likely to think they were transplant candidates….

Wachterman et al. 2013 JAMA Intern Med

Are kidney clinicians doing well?



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…Among the 62 interviewed patients, no patients reported that their nephrologist had discussed an estimate of life expectancy with them…

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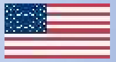

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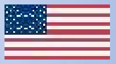

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…Among the 62 interviewed patients, no patients reported that their nephrologist had discussed an estimate of life expectancy with them…

…nephrologists reported that they had done so for only 2 interviewed patients…

…nephrologists provided us with estimates of life expectancy for 89% of patients, but reported that, if the patient insisted on an estimate, they would refuse to provide any estimate for 60%.

Wachterman et al. 2013 JAMA Intern Med

Are kidney clinicians doing well?

Half of patients who died with ESKD received palliative care consultations

- 74% for people with cancer
- 61% for people with dementia

Approximately one-third of patients with ESKD died in the ICU

- 13% cancer
- 9% dementia

Rates of excellent end-of-life care quality reported decedents’ families 54% ESKD

- 59% cancer
- 59% dementia

This quality advantage was mediated by palliative care consultation, setting of death, and do-not-resuscitate order: adjustment for these variables rendered the relationship between diagnosis and overall end-of-life care quality non-significant…

Wachterman et al. 2016 JAMA Intern Med

Preparing for the end stage

Thank you

Comments and questions?

Dr Barny Hole

University of Bristol

barnaby.hole@bristol.ac.uk

@barnyhole

How to achieve scalability

- What have we achieved so far?
- What have we still to achieve? (and why have we not yet?)
- What are we going to do next?

- What have we achieved so far?
- What have we still to achieve? (and why have we not yet?)
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- What have we achieved so far?
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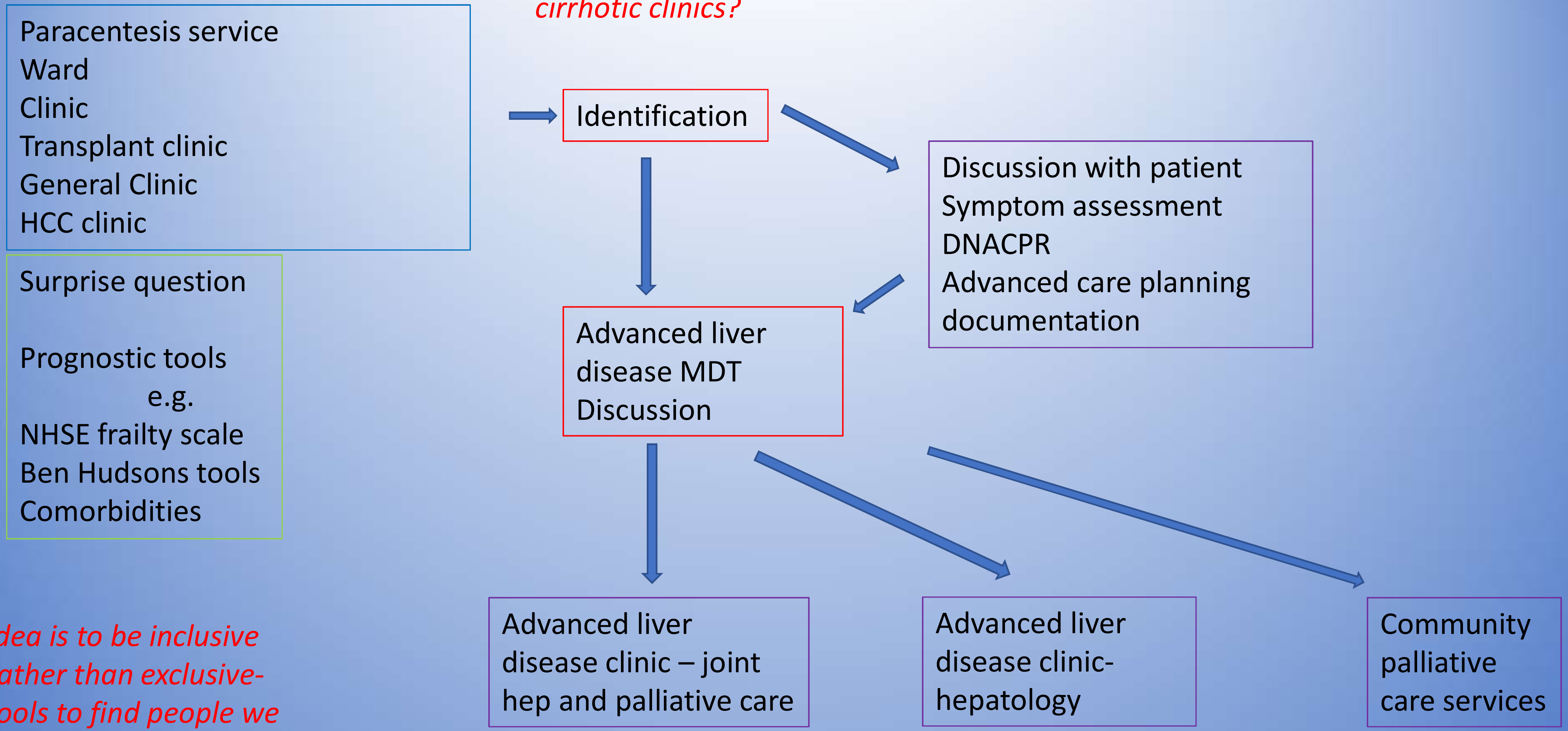
System of prompts in cirrhotic clinics?



Paracentesis service
Ward
Clinic
Transplant clinic
General Clinic
HCC clinic

Surprise question

Prognostic tools
e.g.
NHSE frailty scale
Ben Hudsons tools
Comorbidities

Identification

Discussion with patient
Symptom assessment
DNACPR
Advanced care planning
documentation

Advanced liver disease MDT Discussion

Advanced liver disease clinic – joint hep and palliative care

Advanced liver disease clinic- hepatology

Community palliative care services

Idea is to be inclusive rather than exclusive- tools to find people we might not have considered

What is the aim of the work?

- Increase confidence in identification of poor prognosis
- Improve Carer/Patient understanding of diagnosis/ prognosis and likely events
- Continuity of care (primary, secondary. Within Hospital between teams.
- Escalation plans and communicating them. Pre-emption
- Admission avoidance

Minimum data set for an MDT

- HCC/ Varices screening?
- Endoscopy in event of bleeding
- TIPS?
- Transplant assessment?
- Escalation status
- DNA CPR
- Need for supportive care status
- Candidate for long term drain/ other

Agenda for extended Hepatology appointments

- What do patients want
- Understanding of diagnosis, progression, prognosis, complications
- Screening plans
- Transplant options
- Medication review
- Carer support/ housing situation
- Contact details in case of issues
- Resources for help in future.

Next Steps