thebmjawards

NHS
University Hospitals Bristol
NHS Foundation Trust

The Poor Prognosis Letter Project

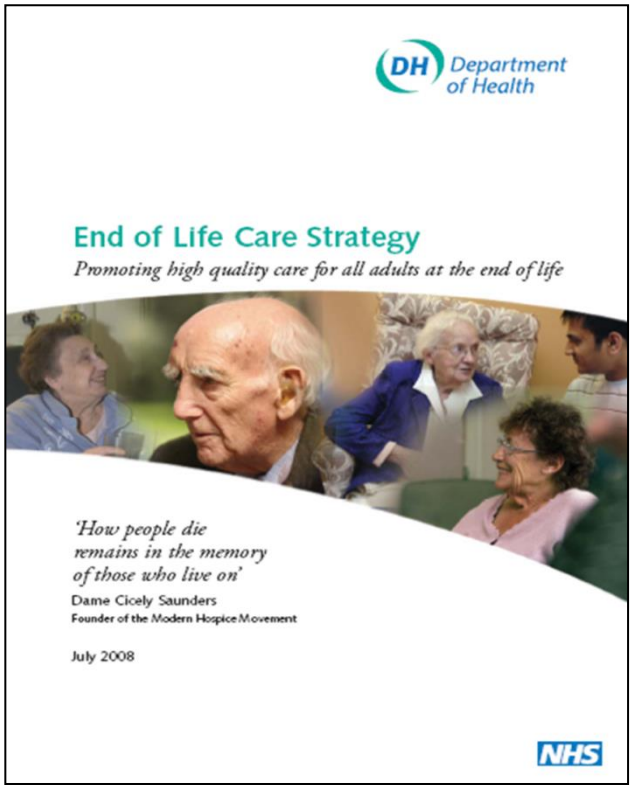
University Hospitals Bristol
Supportive and Palliative Care Team

Respecting everyone
Embracing change
Recognising success
Working together
Our hospitals.

Transforming Care

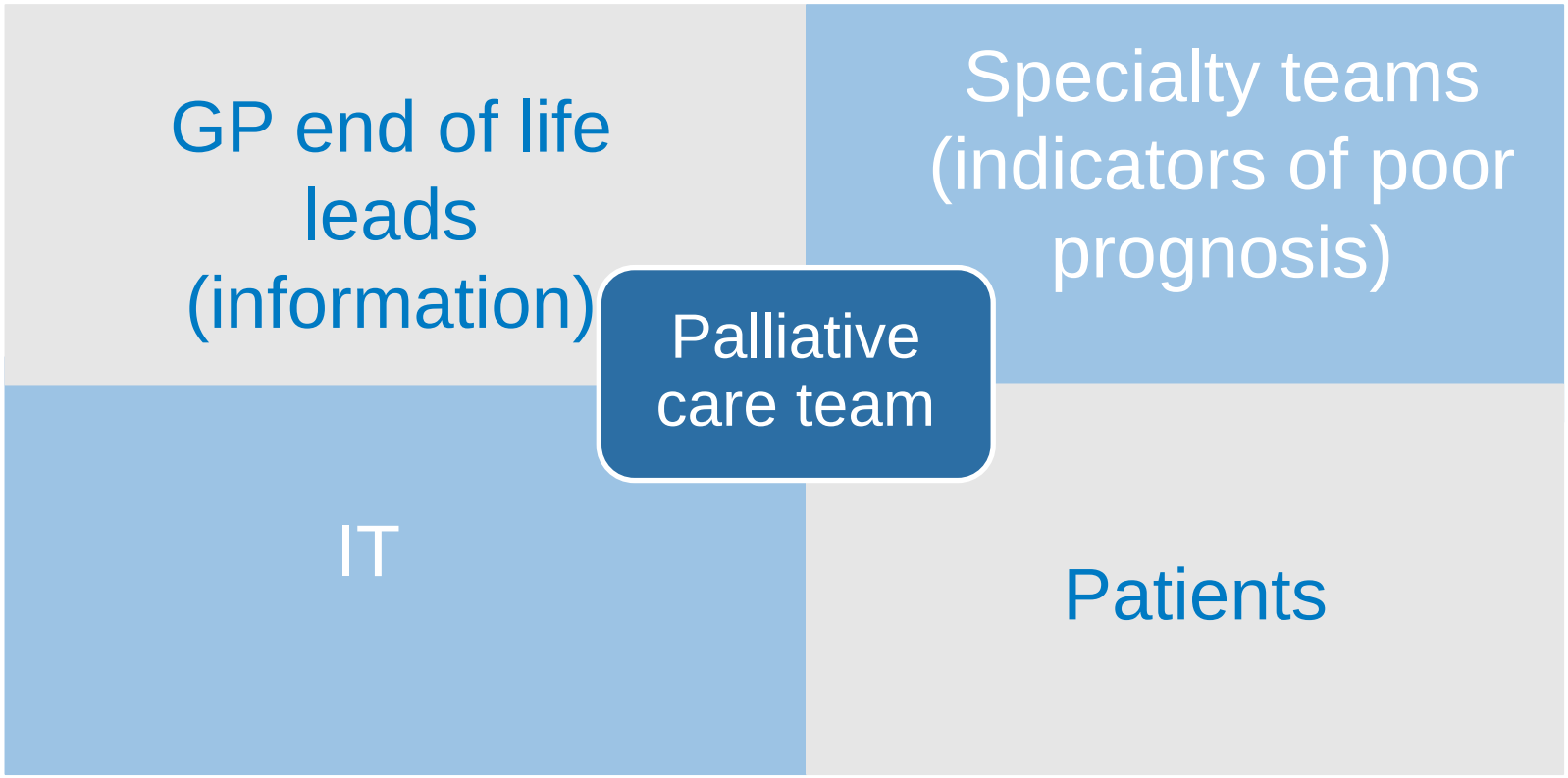
The Poor Prognosis Letter (PPL) journey

The problem



- Recognising the end of life
- Communication
- Patient choice

Process


GP end of life leads (information)
Specialty teams (indicators of poor prognosis)
Palliative care team
IT
Patients

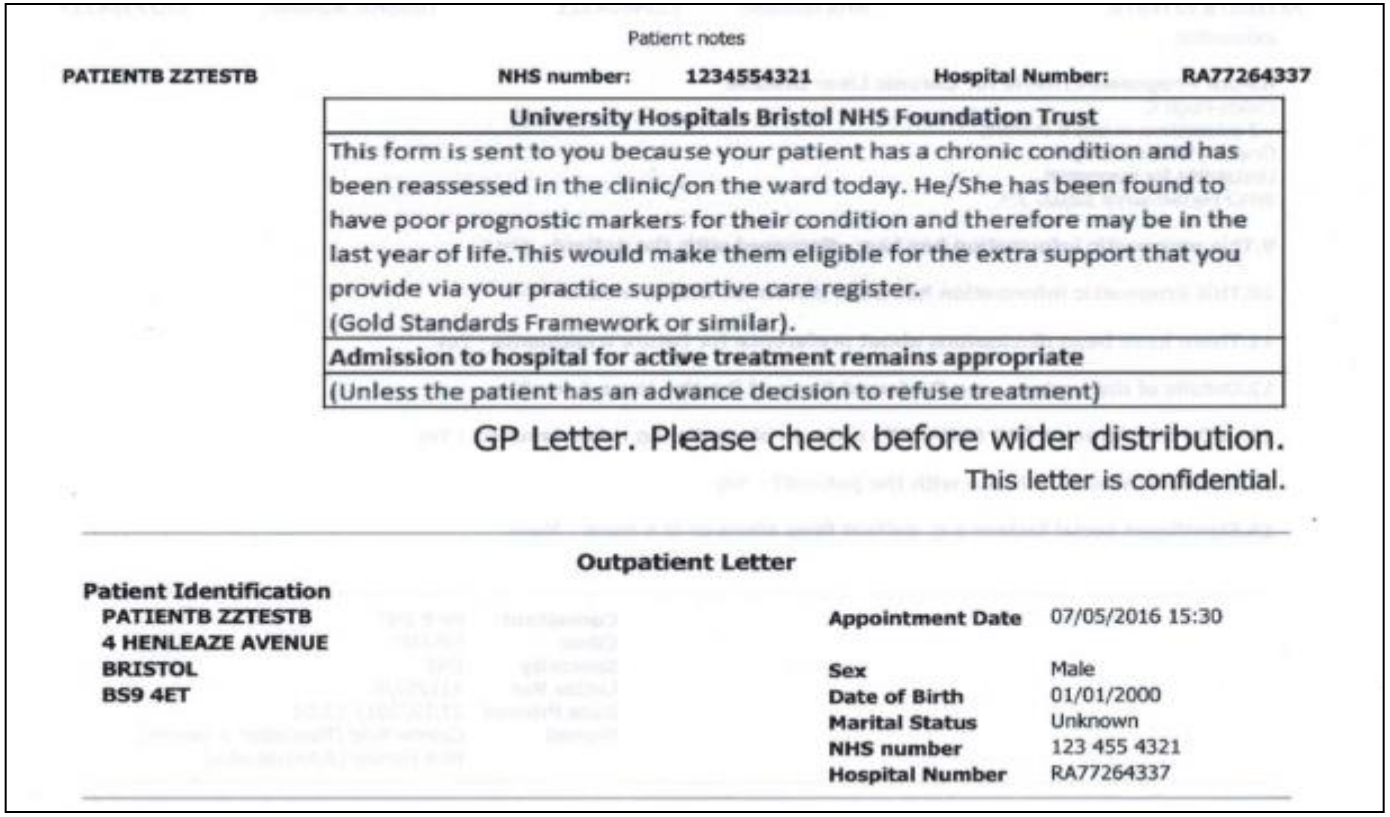
The Poor Prognosis Letter

Top box – admission to hospital

3. Prognostic criteria

9. Patient's understanding

11. Preferences for future treatment



Patient notes

PATIENTB ZZTESTB **NHS number:** **1234554321** **Hospital Number:** **RA77264337**

University Hospitals Bristol NHS Foundation Trust
This form is sent to you because your patient has a chronic condition and has been reassessed in the clinic/on the ward today. He/She has been found to have poor prognostic markers for their condition and therefore may be in the last year of life.This would make them eligible for the extra support that you provide via your practice supportive care register. (Gold Standards Framework or similar).
Admission to hospital for active treatment remains appropriate
(Unless the patient has an advance decision to refuse treatment)

GP Letter. Please check before wider distribution.

This letter is confidential.

Outpatient Letter

Patient Identification
PATIENTB ZZTESTB
4 HENLEAZE AVENUE
BRISTOL
BS9 4ET

Appointment Date	07/05/2016 15:30
Sex	Male
Date of Birth	01/01/2000
Marital Status	Unknown
NHS number	123 455 4321
Hospital Number	RA77264337

He/she is thought to be in the last year of life by the medical team and has the following poor prognostic criteria for advanced disease. .1. Poor prognostic criteria for cancer
World Health Organisation Performance Status 3 or 4
Metastatic disease with no anti-cancer treatments available

2.Poor prognostic criteria for chronic respiratory diseases
Forced Expiratory Volume in 1 second (FEV1) < 30% predicted
Very limited mobility due to breathlessness
Needed more than 2 hospitalisations during the previous year

3.Poor prognostic criteria for heart failure
NYHA Class IV
Presence of treatment-resistant peripheral oedema
Renal impairment (eGFR <30ml/min)
Repeated hospitalisations with decompensated heart failure or ICD shocks

4.Poor prognostic criteria for renal disease
Unintentional weight loss (non-fluid) > 10% over past 6 months
Serum albumin < 25mg/dl
World Health Organisation Performance Status 3 or 4
Conservative management patients (i.e. not on dialysis) with CKD 5

5.Poor prognostic criteria for neurological conditions
Progressive deterioration in physical and/or cognitive function in spite of optimal therapy
Muscular weakness leading to aspiration pneumonia or respiratory failure in spite of respiratory support

6.Poor prognostic criteria for dementia
Unable to walk without assistance
Urinary and faecal incontinence
No consistently meaningful verbal communication
Reduced ability to perform activities of daily living

7.Poor prognostic criteria for frailty
Multiple comorbidities with deteriorating day to day functioning
Combination of at least 3 symptoms of: weakness, slow walking speed, low physical activity, significant weight loss,

8.Poor Prognosis Criteria for Chronic Liver Disease
Childs-Pugh C
>2 admissions in last 6 months
Ongoing alcohol usage
Unsuitable for transplant
WHO performance status 3-4

9.This prognostic information has been discussed with the patient - Yes

10.This prognostic information has been discussed with the carer - Yes

11.There have been discussions about preference for future treatments - Yes

12.Details of discussions...e.g Preferred Place of Death - Home if possible

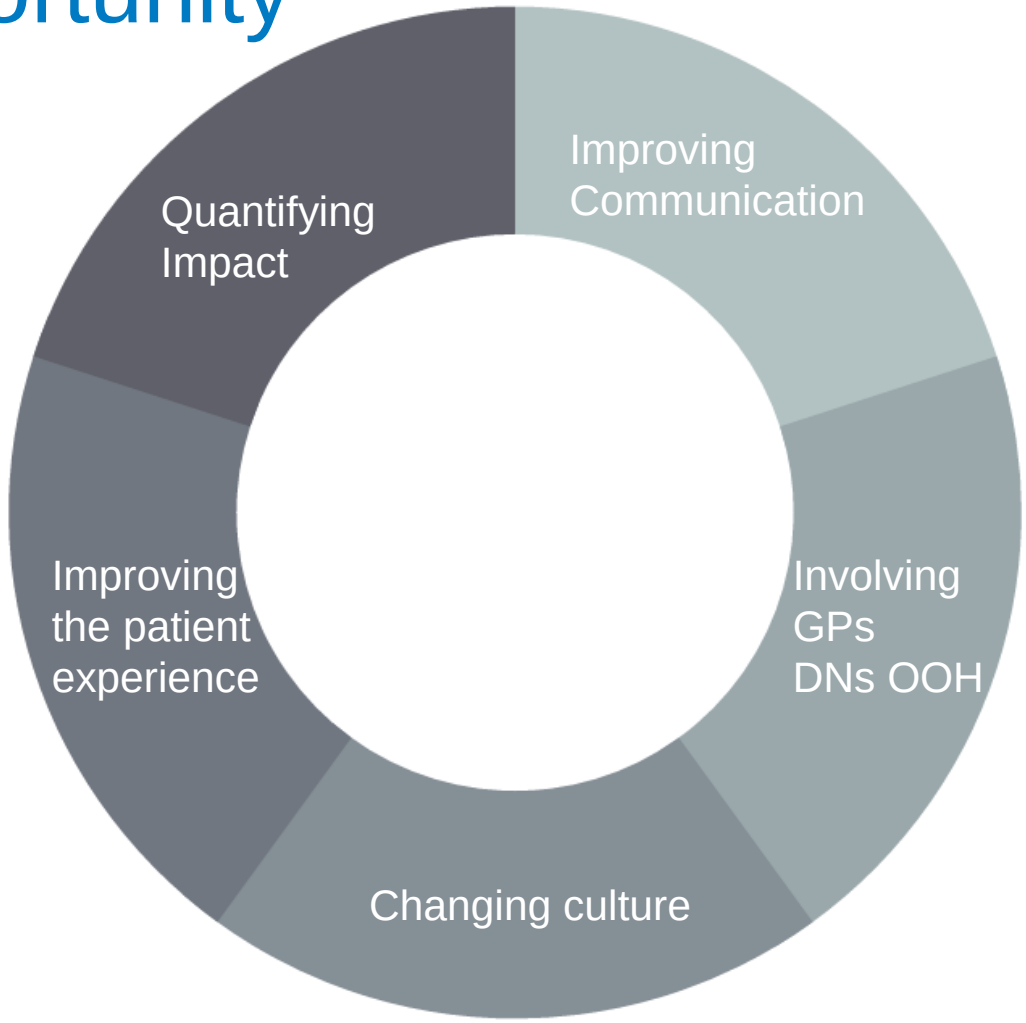
13. A Do Not Attempt CPR (DNACPR) order in place during this admission - Yes

14.This form was sent home with the patient? - Yes

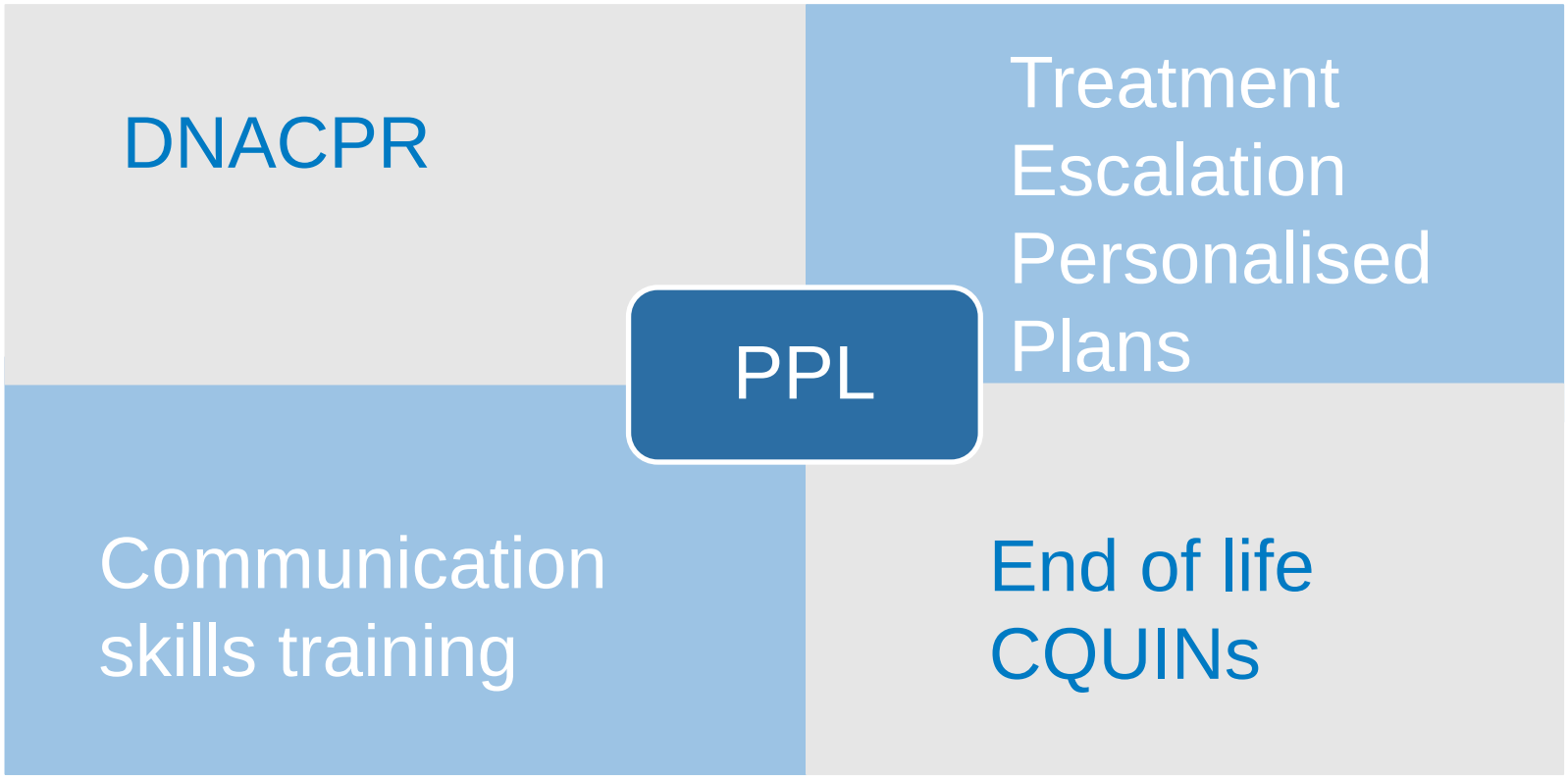
15.Significant social factors e.g. patient lives alone or is a carer - None

Consultant	Mr E ENT
Clinic	OP ENT
Specialty	ENT
Letter Ref	411257/0
Date Printed	27/02/2017 13:04
Signed	Colette Reid [Requester + Doctor] Nick Harvey [Administrator]

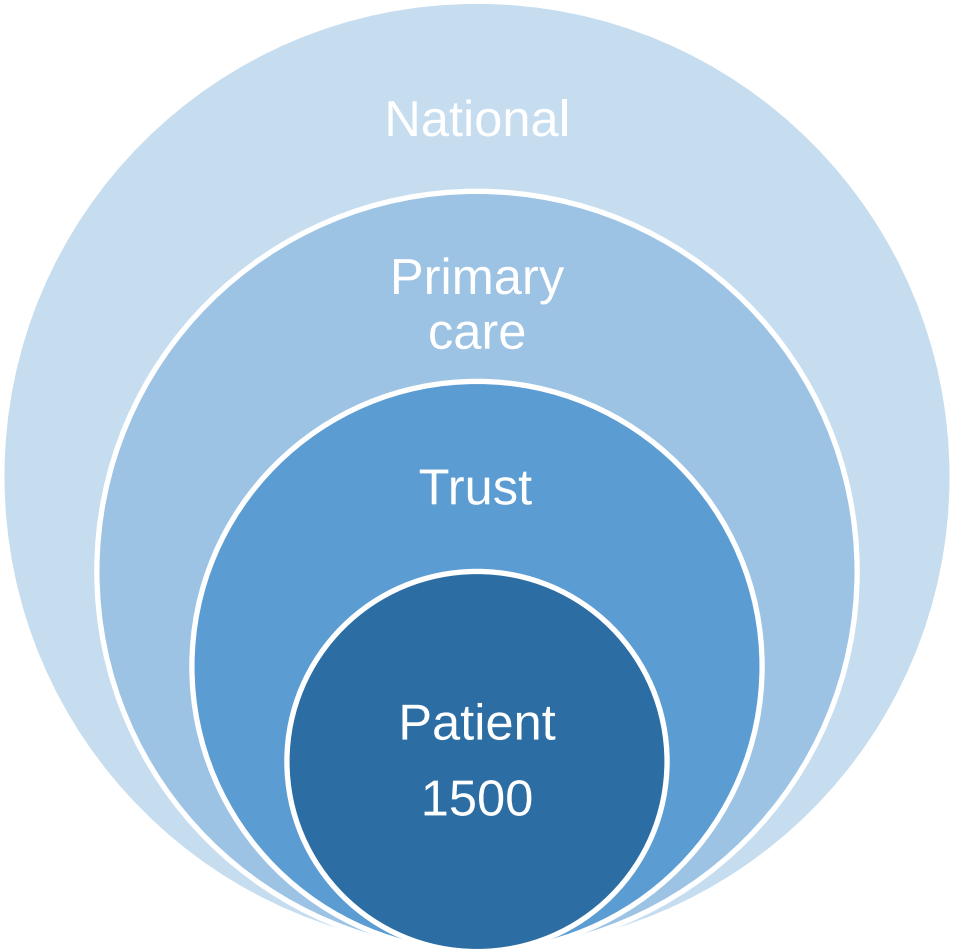
The opportunity



Embedding in UHBristol end of life care initiatives



Impact



Data so far – poor prognosis letter audits

Date	No pts with PPC	Pts with PPC discharged	No (%) with PPC with PPL to GP
Jul 2014	56	43	8 (19)
Mar 2015	32	28	23 (82)
Sep 2015	41	25	11 (44)
Feb 2016	47	30	28 (93)
Sep 2016	22	18	9 (50)

Audit of PPLs in general surgery

University Hospitals Bristol NHS Foundation Trust

Retrospective audit of patients from 2015/16

26 patients had letters sent; all had died

All patients had been referred to community palliative care services

Prospective audit Sept-Nov 2016

16 patients identified as having a prognosis of less than 12 months

12/16 patients survived until discharge; 6 had PPLs sent to GP

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Transforming Care

Impact so far – examining a sample of PPLs

- 185 patients had a letter completed April – October 2015
- All patients had died – median survival 31.5 days
- 68/185 (36%) patients died in hospital
  - (Bristol CCG average = 46% currently)
- 13/24 GPs of patients who had PPLs sent October 2016 contacted successfully
  - 7 positive
  - 3 neutral
  - 3 ‘out of area’ GPs

Feedback from the GPs

Really good letter, really clear… makes a GP stop and think I need to do something.

Her son is forceful about what he wants done for his mother and the letter has helped with that.

Useful and thought provoking.

It's a good initiative.

I sat down and spoke to the patient regarding his wishes…it made me think about what's going on and what I need to do next.

Hepatology

RESEARCH

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

Benjamin E Hudson,[1,2] Kelly Ameneshoa,[1] Anya Gopfert,[1] Rachael Goddard,[1] Karen Forbes,[2,3] Julia Verne,[4] Peter Collins,[1] Fiona Gordon,[1] Andrew J Portal,[1] Colette Reid,[3] C Anne McCune[1]

Poor prognosis screening: **cirrhotic patients only**	
Criteria	Tick
Child Pugh Grade C	
> 2 liver-related admissions last 6 months	
Ongoing alcohol use (ARLD patients)	
Unsuitable for transplant work-up	
WHO performance status 3-4	

Total score:	
If total score > 2, consider:	
Poor prognosis discussion with patient/family	
Poor prognosis letter to GP	
Advance care planning discussions	
Specialist palliative care referral	
Allocation of hepatology specialist nurse	

February 2017

BASL (British Association for the Study of the Liver) – meeting devoted to end of life care at King's College Hospital

Hudson BE et al. *Frontline Gastroenterology* *http://dx.doi.org/10.1136/flgastro-2016-100734*

Challenges

- Median survival only 31 days – prognostication still overcautious

- Some teams remain resistant to identifying patients with poor prognosis

Aspirations for the future

- Prospective database to allow us to monitor median survival and place of death

- To shift the care of patients in the last year of life from the ‘technological imperative’ to a ‘good death imperative’

Aspirations for the future

- Prospective database to allow us to monitor median survival and place of death
- To shift care of patients in the last year of life from the ‘technological imperative’ to a ‘good death imperative’
- To remind us that the only person who can tell us what is important at the end of their life is the patient

- What's happened since May 4th?
  - Numerous requests for the letter across the UK
  - Invitation to speak at the Hospice UK conference in November
  - Loss of End of Life CQUIN – so no resources
  - Personal feedback from ITU consultant about a PPL being used to make a decision re ITU admission
  - Teaching feedback from senior doctors about its usefulness in recognising the dying patient and shifting goals of care to end-of-life care

ALL END OF LIFE LETTERS CREATED AND NOT DELETED AS OF THE RUN DATE

DATA FROM ICE (double click the pivot to get hospital numbers)

Run Date	03/11/2017 12:18

Row Labels	Letter completed	Letter not completed	Grand Total
Feb	42	0	42
Mar	50	2	52
Apr	33	2	35
May	32	2	34
Jun	27	0	27
Jul	34	2	36
Aug	23	0	23
Sep	38	0	38
Oct	25	0	25
Nov	19	0	19
Dec	28	0	28
2016			
Jan	37	0	37
Feb	36	0	36
Mar	47	0	47
Apr	36	1	37
May	41	0	41
Jun	56	3	59
Jul	51	0	51
Aug	36	3	39
Sep	32	0	32
Oct	47	1	48
Nov	38	1	39
Dec	30	2	32
2017			
Jan	47	2	49
Feb	43	1	44
Mar	72	14	86
Apr	31	4	35
May	40	1	41
Jun	42	4	46
Jul	52	3	55
Aug	43	8	51
Sep	32	0	32
Oct	50	8	58
Nov	4	3	7
Grand Total	**1499**	**74**	**1573**

- Lessons learnt
  - Anything worth doing takes time and effort (the only place success comes before work is in the dictionary)
  - Use junior medical colleagues as allies – they see everything and go everywhere
  - Don’t give up