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Advance care planning documentation strategies; goals-of-care as an alternative to not-for-resuscitation in medical and oncology patients. A pre-post controlled study on quantifiable outcomes

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TITLE PAGE

Title: End-of-life documentation strategies; Goals-of-Care (GOC) as an alternative to Not-for-Resuscitation (NFR) in medical and oncology patients. A pre-and-post controlled study.

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Tweet 140 Characters: In a cohort with a high disease burden, the implementation of the *goals-of-care* strategy conferred few advantages over the existing *not-for-resuscitation* form.

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The known The documentation of appropriate treatment goals in patients with advanced stages of incurable disease remains both underutilised and poorly communicated. Several new end-of-life forms have been devised but with minimal research to support their impact.

The new In a **patient** cohort with a substantial disease burden, the implementation of the new inclusive 'goals-of-care' strategy conferred limited quantitative advantages over the existing ad-hoc 'not-for-resuscitation' form.

The implications **Greater top-down governance and a cohesive, sustained clinical strategy is required before successful full implementation in substituting one end-of-life form for another.**

Abstract

Objective: Compare the clinical impact of two different health department sanctioned, end-of-life (EOL) documentation strategies.

Design: An unblinded, pre-and-post, controlled study over two corresponding six-month periods in 2016 and 2017 comparing the current ad-hoc not-for-resuscitation (NFR) with a new, inclusive goals-of-care (GOC) strategy supported with staff education.

Setting and participants: Patients admitted to two medical and oncology wards in a large private hospital.

Main outcome measures: The uptake of EOL forms per hospitalisation and the timing between hospital admission, EOL form completion, and in-patient death. Secondary outcomes included the utilisation of rapid response team (RRT), palliative and critical care services.

Results: Across both study periods **1303** patients (NFR=**650**, GOC=**653**) underwent **1,885** admissions (mean Charlson Score=**3.7**). Patients admitted during the GOC period had a higher uptake of EOL documentation (346 vs 150 EOL forms per 1000 admissions, $P<0.0001$), a higher proportion of EOL forms completed within the first 48-hours of admission (**58 vs 39%**, $P=0.0002$), but a higher incidence of altering the initial EOL level-of-care ($P=0.003$). All other measures including EOL documentation within 48-hours of death ($P=0.50$), activation of RRT ($P=0.73$), and admission to critical ($P=0.62$) or palliative ($P=0.81$) care services remained similar. Documentation of GOC forms was often incomplete with most sub-sections left blank between **74–87%** of occasions.

Conclusion: Despite an increased uptake of the GOC form, overall utilisation remained low, written completion was poor, and most quantitative outcomes remained statistically unchanged. Further research is required before a wider GOC implementation can be supported in private healthcare systems.

Introduction

Goals-of-Care (GOC) is a **revised and holistic** interpretation of an established, self-evident principle that aims to clearly **discuss and document** the extent to which medical care should be imparted on a patient, at any stage of their hospital journey. It weighs the likely burden and response of a given therapy against the severity of the disease process, a patient's life expectancy, quality-of-life and individual preferences. This most fundamental of all clinical decisions therefore delineates the direction for all subsequent healthcare and should be regarded as the cornerstone of any clinical management plan.

Presently, with Western Australian Health Department of Health (WADoH) approval, selected hospitals are piloting the GOC on the basis it will be a more universally applicable, proactive concept amenable to an improved shared decision-making process. This contrasts the prevailing clinical practice that currently utilises the discretionary "Not-for-Resuscitation" (NFR) order. The ad-hoc nature of NFR orders often relies on the unspoken assumption that healthcare providers intuitively understand the management priorities of any given patient, thus circumventing the need for detailed discussions until such time that a medical crisis mandates a reactive clinical intervention.

Thus, for GOC to be an effective successor to the NFR it must be more than an alternative written document. **Instead, it must be part of an overarching, senior clinician led, cultural change that re-focuses on earlier patient engagement and considers broader management strategies beyond cardio-pulmonary resuscitation status.** With this in mind, the aim of this study was to compare the utilisation and quantitative outcomes of an *inclusive* GOC against an *ad-hoc* NFR strategy in two dedicated oncology / general medical wards at a large Australian **private** hospital.

Methods

Setting

This study was conducted over a six month period in a large 578 bed Western Australia private hospital, which also has a dedicated chemotherapy day suite and busy oncology service.

Design

A quasi-experimental pre-and-post controlled study design over two corresponding 6-month periods in 2016 and 2017 comparing the WADoH sanctioned NFR and GOC forms. Patients were eligible if they were 18-years or older and admitted to one of two predominately medical or oncology wards under the primary care of a physician, haematologist, palliative care physician or oncologist. These wards were specifically chosen because they incorporate healthcare disciplines with a higher burden of advanced disease states and frailty requiring a greater awareness of end-of-life (EOL) issues. Patients discharged alive within 48-hours of hospitalisation were excluded to avoid including short-term chemotherapy or procedural admissions. Patients on other wards, not involved in the study, all used the NFR form throughout the study period. All forms were valid for the current admission only with the

study protocol mandating a separate form for any subsequent admission. Disease burden was compared using Charlson Comorbidity Scores.¹

The first six-month period (March – August 2016) was the control period and utilised the standard-of-practice NFR form (**see Supplemental File 1 - NFR Form**). The use of this form was discretionary for treating teams, only allowed physicians to define invasive limitations in therapy, and conformed with current state-wide WADoH practice.

The second 6-month period (March – August 2017) was considered the intervention arm and investigated the implication of an inclusive four-treatment phase GOC form (**see Supplemental File 2 – GOC Form**) adapted from previous local and interstate concepts.² Treating **senior clinicians** were strongly encouraged, but not mandated, to complete a GOC form within 48-hours of hospitalisation for every patient admitted to the involved wards. The inclusive concept is consistent with a similar policy employed by the Tasmanian Government Department of Health and Human Services.³ The GOC form design differs fundamentally from the NFR form by delineating broad care pathways for individual patients, offering four treatment phases including full supportive management without limitations. The GOC had not been previously used in **this** institution.

A six-month post intervention point prevalence study was conducted to assess ongoing uptake of the GOC form in March 2018.

Ethics approval & trial registration

Prior ethics approvals were granted from the StJOG Healthcare Human Research Ethics Committee (HREC #1070) and this trial is registered with the Australian New Zealand Clinical Trials Registry (<http://www.ANZCTR.org.au/ACTRN12617000105347.aspx>).

Outcomes

The main study outcomes were the uptake rates of both EOL (NFR and GOC) forms per 1000 hospitalisations and the timing between hospital admission, EOL form completion, and patient death. Following local consultation, 48-hours was chosen as the cut-off time for EOL completion both after hospitalisation and before death to allow for adequate patient assessment at admission and preparation before death while maximising overall healthcare awareness of the desired treatment goal.

Secondary outcomes included the utilisation of palliative and critical care services; the overall rapid response team (RRT) activation rate; the number of patients in whom a EOL order was completed within 24-hours of a RRT activation;^{4,5} the number of times an EOL form was altered in the course of a single hospitalisation; and frequency at which NFR or GOC forms are completed outside normal office hours suggesting a less planned approach to patients EOL care. Finally, the researchers wanted to investigate the “surprise question” concept by following through all patients for a minimum 4-months post admission to the year’s end by using a censor date of 31st December 2016 (NFR Phase) and 2017 (GOC Phase) to compare in-hospital EOL planning and form completion with subsequent short-term mortality.⁶ Extensive qualitative patient and clinical staff data was also collected but is the subject of a separate manuscript.

Data collection

All data was collected retrospectively at the completion of each study period by a single dedicated investigator with subsequent screening by a second investigator. Data was extracted from both electronic and hard copy inpatient hospital medical records using a pre-formatted data extraction tool.

Goals-of-care education and promotion

Coinciding with the introduction of the GOC form (intervention arm) a series of educational activities and changes to the ward-rounds format were implemented to foster increased GOC uptake (see **Supplementary File 3 – Supplementary Methodology**).

Community engagement

This study benefited from the contributions supplied by the St John of God Healthcare Consumer Advisory Group to help formulate the context of the study and determine the optimal role of EOL documentation in our hospital.

Statistical analysis

Categorical variables were described in absolute numbers and percentages with comparisons performed using the chi-squared test. Continuous variables were described in mean, standard deviation, median and interquartile range with comparisons performed using the unpaired Student's t-test for normally distributed data and the Mann–Whitney U test for non-parametric continuous data. All analyses were performed by SPSS for Windows (Version 22.0, IBM Corp., Armonk, NY, USA) with a '*P*' value < 0.05 taken as significant in this study. There were no missing patient files. Sample size calculations and other statistical methods can be found in **Supplementary File 3 – Supplementary Methodology**.

Results

Between the two corresponding six-month periods of March – August in 2016 and 2017 there were a total **1303** patients hospitalised on **1,885** occasions under **43** separate specialists (**5 of whom attended 1-hour consultant designated education sessions**). A total **538** EOL forms were generated across **477** admissions. The baseline characteristics of these phases is summarised in **Table 1**. Patients admitted under onco-haematology specialty teams (**NFR = 52.3%, GOC = 54.2%, *P* = 0.51**) comprised the majority of patients in both cohorts. Consequently, the Charlson Comorbidity Index in both cohorts reflected a high burden of disease (**NFR = 3.7, GOC = 3.7, *P* = 0.99**).

Table 2 displays the first main outcome of EOL uptake and designated level-of-care for each group with the GOC uptake significantly higher in all sections except for palliative level ward care (***P* = 0.77**). The bottom half of **Table 2** compares the association between EOL documentation and the polar treatment spectrums of RRT activation, intensive or coronary care admission and palliative care admission, plus subsequent hospital mortality. The differences in all these outcomes remained statistically non-significant.

Table 3 is restricted to all hospitalisations where an EOL form was completed during the admission. While all specialties increased their uptake of the GOC form above the NFR form, it was the medical specialties where the increases were the greatest. The time relationship between admission and EOL documentation within 48-hours was a main outcome and occurred significantly more often in the GOC group (**39.0 vs 58.1%, $P = 0.0002$**) with a resultant increase in the rate of GOC level-of-care alteration during an admission (**17.7 vs 41.4 EOL alterations per 1000 admissions, $P = 0.003$**). All other outcomes were not significantly influenced by the GOC.

Table 4 compares the association between all patients who died in-hospital with the frequency and timing of EOL form completion. The main outcome of GOC completion within 48-hours of death was not statistically significant between the two groups (**29.5 vs 34.9%, $P = 0.50$**).

EOL uptake rates changed with time, increasing every two months during the GOC phase (**NFR Mar-Aug 15.0%, GOC Mar-Apr 30.9%, GOC May-Jun 34.9%, GOC Jul-Aug 37.7%, $P < 0.0001$**) before declining in a six-month post-GOC phase point prevalence study to **27.9% (12 of 43 patients)** with **41.7% (5 of 12)** GOC completed with 48-hours of admission.

Table 5 examines EOL completion in patients who died before the end of each corresponding year with a minimum 4-month follow up. The premise being, “Would the specialist doctor be surprised if any of these patients died by year’s end?” and thus initiated EOL discussions in advance. Short-term mortality was high (**30.0%**) but there was no statistical difference in the number of patients with EOL orders between the two groups.

Supplementary eTable 1 displays the GOC form completion by sections. As the GOC level (A – D) only requires a “tick box” the desired accompanying information, important to understanding the decision rationale, was seldom documented with most sections left blank between **74–87%** of occasions.

Discussion

With the advent of successful resuscitation techniques in the 1960s came the antipodal necessity to develop adequate do-not-resuscitation (DNR) orders. The GOC is the latest generation of DNR/EOL forms existing in comparable formats as the Universal Form of Treatment (UFOT) in the United Kingdom or Physician Orders for Life-Sustaining Treatment (POLST) in the United States of America.^{7,8} This is the largest Australian controlled study to examine a series of quantifiable outcomes following the introduction of a new GOC form. Preceded by an extensive educational and promotional programme, uptake of the new form was significantly higher than the preceding ad-hoc NFR form, but well below previously published uptake levels.^{7,9,10,11} Aside from a higher percentage of GOC being completed within the first 48-hours of hospital admission, there were no other desirable statistical or clinical changes in a series of measurable outcomes.

Comparisons with previously published EOL literature is limited with the most influential work derived from the three-treatment phase UFOT form reported by Fritz et al in Cambridge.⁷ Smaller in size (1,090 admissions) and with less comorbid disease (Charlson Score < 2.3), this

control study demonstrated a substantially greater UFTO uptake rate (82%) with a corresponding reduction in harmful events in a cohort of medical patients. Most other international published controlled clinical GOC studies are restricted to dementia or nursing home patients.^{12,13} **In Australia there have been a handful of small ward-based studies primarily concentrating on GOC completion rates (with reported uptakes between 82 – 90%) and form content,^{9,10,11} while Orford and colleagues have reported on improving EOL documentation at the medical crisis juncture of unplanned intensive care admission.^{14,15}** It is on this limited clinical research that the GOC is now being deployed across a number of Australian states. This is important given that literature has also persistently demonstrated a discordance between patients at high-risk of dying, their family members and healthcare professionals regarding the communication and documentation of EOL preferences.¹⁶⁻²¹ Furthermore, *“Early discussions about goals-of-care are associated with better quality of life, reduced use of nonbeneficial medical care near death, enhanced goal-consistent care, positive family outcomes, and reduced costs”*,²⁰ with advanced care decision making for patients being regarded as an inherent component of good clinical practice, enshrined in Commonwealth healthcare policy (EQuIP 1, 9 & 12).²³

Despite a multifaceted and widespread educational campaign prior to the GOC (intervention) phase of this study, the uptake rate of GOC forms was limited (**344.4 forms per 1000 hospitalisations**) and well below the rates reported in smaller studies.^{7,9,10,11} This was an unexpected result given that in the Australian private health care system most specialist doctors have a long and established continuity-of-care **rapport** with their patients, in theory making it easier to discuss the sensitive and time-consuming matter of therapy limitations than with the less continuant public healthcare system. The limited GOC uptake rates in our private hospital were not inconsistent with one Australian point-prevalence study where, despite disappointing low levels of EOL form completion rates, public hospitals were statistically more likely to complete EOL documentation than in private hospitals (16.7 vs 7.1%, $P < 0.001$).⁵ Factors contributing to the reluctance of healthcare providers to broach EOL have been previously well described and remain difficult to address.^{24,25} Strategies to improve GOC discussion need to be multifaceted, incorporating greater postgraduate education, the inclusion of GOC documentation on ward rounds and clinical handover (attempted in this study), and specific physician reimbursement for EOL discussions (recently introduced in the USA). Ultimately, any successful strategy will necessitate a top-down approach with strong clinical leadership from senior clinicians and healthcare administrators. Finally, the high incompleteness rate of the GOC form, **particularly the important patient preference documentation**, suggests a design review may be pertinent.

Limitations

As a single centre, non-randomised study deliberately restricted to wards with known high-degrees of disease burden and frailty, the generalisability of our findings may be limited to other speciality wards. Perhaps the biggest limitation was not being able to mandate the use of the GOC form for every patient during the intervention arm of the study. It is the authors opinion that without the widespread cultural shift in EOL discussions then the GOC confers only a few advantages over the NFR form and represents a real challenge for its wider

application. **It may also be that within the time constraints of a busy private practice specialist-patient discussions are occurring but not being documented.** While these limitations reflect a real-world practicality, it was clinically disappointing given the private health system fosters a much greater specialist-patient continuity than in the public health system. Furthermore, there is a lack of internationally recognised outcome measures when researching EOL documentation. Finally, the initiation of treatment limitations is often a complex mixing of medical, psycho-social, cultural and personal factors that are not easily quantified. Beyond the scope of a single manuscript, this study also incorporated a detailed qualitative component with the intention of publishing this data as a separate manuscript.

Conclusion

EOL decision making remains a challenging component of modern healthcare. In cohort patients with a high burden of comorbid disease an increased uptake of the GOC form was achieved. However, the overall GOC form uptake remained well below previously reported rates, written GOC form completion was poor, and nearly all quantitative outcomes remained statistically unchanged. Further research is required before a wider rollout of the GOC form can be supported in Australia's private healthcare systems.

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REFERENCES

1. Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis* 1987; 40: 373-383.
2. Waldron N, Johnson C, Saul P, et al. Development of a video-based education and process change intervention to improve advance cardiopulmonary resuscitation decision-making. *BMC Health Serv Res* 2016; 16: 555.
3. Medical Goals of Care Plan. Tasmanian Government Department of Health and Human Services Specialist Palliative Care Service. http://www.dhhs.tas.gov.au/palliativecare/health_professionals/goals_of_care (Accessed May 15th 2017).
4. Bannard-Smith J, Lighthall GK, Subbe CP, et al. Clinical outcomes of patients seen by Rapid Response Teams: A template for benchmarking international teams. *Resuscitation* 2016; 107: 7-12.
5. Mills A, Walker A, Levinson M, et al. Resuscitation orders in acute hospitals: A point prevalence study. *Australas J Ageing* 2017; 36: 32-37.
6. Pattison M, Romer AL. Improving Care Through the End of Life: launching a primary care clinic-based program. *J Palliat Med* 2001; 4: 249-254.
7. Fritz Z, Malyon A, Frankau JM, et al. The Universal Form of Treatment Options (UFTO) as an alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders: a

- mixed methods evaluation of the effects on clinical practice and patient care. *PLoS One* 2013; 8: e70977.
8. Tolle SW, VP Tilden, CA Nelson, and PM Dunn. A prospective study of the efficacy of the physician order form for life-sustaining treatment. *Journal of the American Geriatrics Society* 1998; 46: 1097-1102.
 9. Thomas RL, Zubair MY, Hayes B, Ashby MA. Goals of care: a clinical framework for limitation of medical treatment. *Med J Aust* 2014; 201: 452-455.
 10. Johnson CE, Chong JC, Wilkinson A, et al. Goals of patient care system change with video-based education increases rates of advance cardiopulmonary resuscitation decision-making and discussions in hospitalised rehabilitation patients. *Intern Med J* 2017; 47: 798-806.
 11. Brimblecombe C, Crosbie D, Lim WK, Hayes B. The Goals of Patient Care project: implementing a proactive approach to patient-centred decision-making. *Intern Med J* 2014; 44: 961-6.
 12. Volandes AE, Brandeis GH, Davis AD, et al. A randomized controlled trial of a goals-of-care video for elderly patients admitted to skilled nursing facilities. *J Palliat Med* 2012; 15: 805-811.
 13. Hanson LC, Zimmerman S, Song MK, et al. Effect of the Goals of Care Intervention for Advanced Dementia: A Randomized Clinical Trial. *JAMA Intern Med* 2017; 177: 24-31.
 14. Orford NR, Milnes S, Simpson N, et al. Effect of communication skills training on outcomes in critically ill patients with life-limiting illness referred for intensive care management: a before-and-after study. *BMJ Support Palliat Care* 2017 Jun 28 [Epub ahead of print]
 15. Orford NR, Milnes SL, Lambert N, et al. Prevalence, goals of care and long-term outcomes of patients with life-limiting illness referred to a tertiary ICU. *Crit Care Resusc* 2016; 18: 181-8.
 16. Heyland DK, Barwich D, Pichora D, and the ACCEPT (Advance Care Planning Evaluation in Elderly Patients) Study Team; Canadian Researchers at the End of Life Network (CARENET). Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Intern Med* 2013; 173: 778-87.
 17. Mack JW, Cronin A, Taback N, et al. End-of-life care discussions among patients with advanced cancer: a cohort study. *Ann Intern Med* 2012; 156: 204-210.
 18. Audrey S, Abel J, Blazeby JM, et al. What oncologists tell patients about survival benefits of palliative chemotherapy and implications for informed consent: qualitative study. *BMJ* 2008; 337: a752.
 19. Abdul-Razzak A, Heyland DK, Simon J, et al. Patient-family agreement on values and preferences for life-sustaining treatment: results of a multicentre observational study. *BMJ Support Palliat Care* [Epub ahead of print] 2017 July 22.
 20. Tang ST, Liu TW, Lai MS, et al. Concordance of preferences for end-of-life care between terminally ill cancer patients and their family caregivers in Taiwan. *J Pain Symptom Manage* 2005; 30: 510-518.
 21. Raskin W, Harle I, Hopman WM, Booth CM. Prognosis, Treatment Benefit and Goals of Care: What do Oncologists Discuss with Patients who have Incurable Cancer? *Clin Oncol (R Coll Radiol)* 2016; 28: 209-214.

22. Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med* 2014; 174: 1994-2003.
23. National standards and accreditation. Australian Commission on Safety and Quality in Healthcare. <https://www.safetyandquality.gov.au/our-work/assessment-to-the-nsqhs-standards/nsqhs-standards-second-edition/> (Accessed 10th February 2018).
24. Curtis JR, Engelberg RA, Wenrich MD, et al. Missed opportunities during family conferences about end-of-life care in the intensive care unit. *Amer J Respir Crit Care Med* 2005; 171: 844–849.
25. You JJ, Downar J, Fowler RA, and the Canadian Researchers at the End of Life Network. Barriers to goals of care discussions with seriously ill hospitalized patients and their families: a multicenter survey of clinicians. *JAMA Intern Med* 2015; 175: 549-556.

Table 1

1. Baseline characteristics comparing the not-for-resuscitation (control) and goals-of-care (intervention) phases over two separate, corresponding six-month periods.			
Characteristic	NFR Phase* (n=650)	GOC Phase† (n=653)	P
Age - years, Mean [SD, median, IQR]	70.9 [13.8; 72.8; 64 – 80]	70.4 [14.0, 72, 62 – 80]	0.51
Gender – female, n (%)	385 (59.2%)	396 (60.6)	0.27
Primary speciality‡, n (%)			0.23
Oncology	293 (45.1)	317 (48.5)	
Haematology	47 (7.2)	37 (5.7)	
Palliative care	35 (5.4)	36 (5.5)	
Internal medicine	109 (16.8)	82 (12.6)	
Respiratory medicine	81 (12.5)	100 (15.3)	
Gerontology	58 (8.9)	56 (8.6)	
Other medical specialties§	27 (4.1)	25 (3.8)	
Charlson Comorbidity Index Mean [SD, median, IQR]			
Standard	3.73 [2.72; 4; 1 – 6]	3.66 [2.58, 3, 2 – 6]	0.99
Age adjusted	6.30 [2.89; 6; 4 – 9]	6.26 [2.83, 6, 4 – 9]	0.72
Main Diagnosis‡, n (%)			
Malignant disease			0.32
Solid cancer – no metastatic disease	119 (18.3)	114 (17.5)	
Solid cancer – with metastatic disease	222 (34.2)	256 (39.2)	
Haematological cancer	45 (6.9)	39 (6.0)	
Non-malignant disease			< 0.001
Heart disease	16 (2.5)	6 (0.9)	
Respiratory disease	84 (12.9)	110 (16.8)	
Kidney disease	9 (1.4)	2 (0.3)	
Liver disease	1 (0.2)	0 (0.0)	
Neurological disease	15 (2.3)	21 (3.2)	
Excessive age / frailty	60 (9.2)	78 (11.9)	
Other diseases	79 (12.2)	27 (4.1)	
Number of Admissions, n (%)			0.24
1 Hospitalisation	484 (74.4)	466 (71.4)	
2 Hospitalisations	109 (16.8)	112 (17.1)	
> 2 Hospitalisations	57 (8.8)	75 (11.5)	
Hospitalisation LOS - days, mean [SD, median, IQR]	8.7 [10.1; 5.9; 3 – 10]	9.0 [9.6, 5.9, 3 – 10]	0.48

NFR = not-for-resuscitation form. GOC = goals-of-care form, SD = standard deviation, IQR = interquartile range, LOS = length-of-stay.
 * NFR period March – August 2016. † GOC period March – August 2017. ‡ First medical specialty admitted under in the observation period. § Includes infectious disease, nephrology, neurology, gastroenterology, cardiology and rheumatology.

Table 2

2. Treatment level-of-care, end-of-life documentation, acute and palliative care resource consumption, and mortality outcomes comparing the not-for-resuscitation (control) and goals-of-care (intervention) groups based on the number of hospital admissions over two separate, corresponding six-month periods.			
Characteristic	NFR Phase* (n=905)	GOC Phase† (n=990)	P
Final treatment level-of-care‡, n (%)			
Full resuscitation (undocumented)	769 (85.0)	649 (65.6)	< 0.001
Full resuscitation (documented)	0 (0.0)	131 (13.2)	< 0.001
ICU with limitations	12 (1.3)	51 (5.1)	< 0.001
Ward level care with RRT activation	22 (2.4)	52 (5.3)	0.001
Palliative level ward care	102 (11.3)	107 (10.8)	0.77
End-of-Life documentation			
Absolute number of completed EOL forms, n (%)	136 (15.0)	341 (34.4)	
EOL uptake rate, per 1000 hospitalisations [95%CI]	150.3 [126.6 – 177.2]	344.4 [309.3 – 382.5]	< 0.001
EOL uptake rate – excluding full resuscitation (Goal A), per 1000 hospitalisations [95%CI]	150.3 [126.6 – 177.2]	212.1 [184.9 – 242.3]	0.002
Rapid response team			
Absolute number of RRT activations, n	70	74	
RRT activation rate, per 1000 hospitalisations [95%CI]	77.3 [60.8 – 97.1]	72.8 [57.4 – 91.2]	0.72
Number of hospitalisations with multiple RRT activations, n (%)	13 (1.4)	12 (1.2)	0.69
Intensive or coronary care			
Absolute number of ICU or CCU admissions, n (%)	20 (2.2)	18 (1.8)	
ICU or CCU admissions rate, per 1000 hospitalisations [95%CI]	22.1 [13.9 – 33.5]	18.2 [10.8 – 28.7]	0.55
Palliative care admissions			
Absolute number of palliative care admissions, n (%)	35 (3.9)	36 (3.6)	
Palliative care admission rate, per 1000 hospitalisations [95%CI]	38.7 [26.9 – 53.8]	36.4 [25.5 – 50.3]	0.80
Mortality			
Total In-hospital, n (%)	78 (12.0)	83 (12.7)	
In-hospital rate, per 1000 hospitalisations [95%CI]	86.2 [68.6 – 107.0]	83.8 [66.4 – 102.4]	0.86

NFR = not-for-resuscitation, GOG = goals-of-care, ICU = intensive care unit, EOL = end-of-life, CI = confidence intervals, RRT = rapid response team, CCU = coronary care unit.
 * NFR period March – August 2016. † GOC period March – August 2017. ‡ Final EOL form level-of-care. Where written documentation did not exist, full resuscitation was the assumed level-of-care.

Table 3

3. Outcome comparisons between hospitalisations with at least one completed NFR (control) or GOC (intervention) form over separate, corresponding six-month periods.			
Characteristic	NFR Phase* (n=136)	GOC Phase† (n=341)	P
Age - years, Mean [SD, median, IQR]	73.1 [13.2, 75.3, 66 – 82]	72.3 [13.3, 72.6, 65 – 82]	0.55
Gender – female, n (%)	68 (50.0)	202 (59.2)	0.08
Hospital LOS - days, mean [SD, median, IQR]			
All admissions with an EOL form	16.6 [15.9, 13.5, 7 – 20]	11.9 [10.8, 8.2, 5 – 15]	< 0.001
Admissions with limitation-in-treatment EOL form‡	16.6 [15.9, 13.5, 7 – 21]	14.5 [12.1, 10.1, 6 – 20]	0.12
Primary speciality§, n (%)			< 0.001
Onco-haematology	82 (60.3)	143 (41.9)	
Medical specialties	26 (19.2)	152 (44.4)	
Palliative care	28 (20.5)	46 (13.5)	
Final documented treatment level-of-care¶, n (%)			< 0.001
Full resuscitation	0 (0)	131 (38.4)	
ICU with limitations	12 (8.8)	51 (15.0)	
Ward level care with RRT activation	22 (16.2)	52 (15.2)	
Palliative level care	102 (75.0)	107 (31.4)	
Number of EOL forms per hospitalisation¶, n (%)			0.86
1 EOL Form	120 (89.0)	300 (88.0)	
2 EOL Forms	14 (10.3)	40 (11.7)	
3 EOL Forms	1 (0.7)	1 (0.3)	
4 EOL Forms	1 (0.7)	0 (0.0)	
Hospitalisations where the EOL form level-of-care was altered, per 1000 hospitalisations [95%CI]	17.7 [10.1 – 28.7]	41.4 [29.7 – 56.2]	0.003
EOL Documentation Timing			
First EOL form completed within 48 hours of hospital admission, n (%)	53 (39.0)	198 (58.1)	< 0.001
Final EOL completed by non-consultant staff, n (%)	46 (33.8)	126 (36.9)	0.34
EOL form completed outside of normal office hours**, n (%)	54 (33.8)	107 (28.1)	0.12
EOL form completed within 24-hours of a RRT activation††, n	12 (1.3)	11 (1.1)	0.68
Time between admission to hospital and first treatment limitation EOL order completed – days‡, mean [SD, median, IQR]	5.9 [7.9, 3.0, 0.3 – 8]	4.6 [6.4, 1.6, 0.2 – 7]	0.09
Hospitalisations where the EOL form was rescinded or de-escalated, n (%)	0 (0)	0 (0)	

NFR = not-for-resuscitation form. GOC = goals-of-care form, LOS = length-of-stay, ICU = intensive care unit, EOL = end-of-life, SD = standard deviation, IQR = interquartile range, RRT = rapid response team.
 * NFR period March – August 2016. † GOC period March – August 2017. ‡ Excludes 131 full resuscitation orders in the GOC group. § Final documented EOL form level-of-care. ¶ Multiples of EOL forms include either new or substantially altered EOL forms where a change in the ceiling-of-treatment occurred. ** Based on all EOL forms (NFR=154, GOC=381) completed during the study period. Outside of normal office hours = 18:00 - 08:00 Monday to Friday and all weekends. †† Based on total number of admissions.

4. Relationship between all in-hospital deaths, the timing of hospital admission, and the use of end-of-life forms during both six-month periods.

Characteristic	NFR Phase*	GOC Phase†	P
Number of in-hospital deaths	78	83	
Time between admission and in-hospital death - days, mean [SD, median, IQR]	14.8 [12.5, 11.7, 6 – 20]	16.4 [13.6, 13.6, 6 – 24]	0.44
Relationship between EOL form documentation and in-hospital death			
Number of in-hospital deaths with prior EOL form completion, n (%)	75 (96.2)	74 (89.2)	0.13
Time between admission and first EOL form completion - days, mean [SD, median, IQR]	6.9 [8.2, 3.9, 0.7 – 10]	5.2 [7.1, 1.9, 0.2 – 7]	0.07
Time between final EOL form completion and in-hospital death - days, mean [SD, median, IQR]	7.7 [8.4, 4.9, 1.6 – 11.6]	8.2 [8.8, 5.6, 1.8- 11.5]	0.80
Number of EOL forms first completed within 48 hours of death‡, n (%)	23 (29.5)	29 (34.9)	0.50

NFR = not-for-resuscitation Form. GOC = goals-of-care Form. SD = standard deviation, IQR = interquartile range, EOL = end-of-life.

* NFR period March – August 2016. † GOC period March – August 2017. ‡ Includes patients with no EOL documentation

5. In-hospital end-of-life documentation and subsequent short-term mortality between 1st March – 31st December in 2016 (NFR) and 2017 (GOC) with minimum 4-month follow up.

Characteristic	NFR Phase* (n=650)	GOC Phase† (n=653)	P
Follow up time - entire cohort‡, days, mean [SD, median, IQR]	186.7 [87.6, 201.4, 136 – 257]	176.1 [86.8, 185.5, 121 – 249]	0.03
Number of deaths to 31st December 2016/17			
Total deaths, n (%)	191 (29.4)	199 (30.5)	0.67
Time between first admission and death by 31 st December 2016/17 – days, mean [SD, median, IQR]	65.0 [70.0, 33.4, 14 – 109]	49.3 [49.2, 35.7, 14 – 67]	0.35
Number of deaths with prior in-hospital EOL documentation			
Number of deaths with any prior in-hospital EOL form completed, n (%)	105 (55.0)	124 (62.3)‡	0.15
Number of deaths with prior documented limitations-in-therapy (Goal B, C or D)§, n (%)	105 (55.0)	119 (59.8)	0.36
Number of deaths with prior documented palliative (Goal D) limitations-in-therapy	88 (46.1)	88 (44.2)	0.76
Time between final EOL form and death – days, mean [SD, median, IQR]	23.7 [46.7, 9.7, 4 – 20]	30.7 [41.8, 11.7, 4 – 42]	0.21

NFR = not-for-resuscitation form. GOC = goals-of-care form, SD = standard deviation, IQR = interquartile range, EOL = end-of-life.

* NFR period March – August 2016. † GOC period March – August 2017. ‡ Includes five Goal A – full resuscitation EOL § From initial admission date and excludes EOL with full resuscitation (Goal A). NFR n=650 patients, GOC n=653.

eTable 1. The written completion rate of significant GOC form sub-sections by clinical staff						
	Full resuscitation Goal A (n = 131)		Limitations in treatment Goals B, C or D (n = 210)		All treatment levels Goals A, B, C or D (n = 341)	
	GOC Section Completed	GOC Section Not Completed	GOC Section Completed	GOC Section Not Completed	GOC Section Completed	GOC Section Not Completed
Consultant review, n (%)	104 (79.4)	27 (20.6)	176 (83.8)	34 (16.2)	280 (82.1)	61 (17.9)
Primary disease, n (%)	4 (3.1)	127 (96.9)	84 (40.0)	126 (60.0)	88 (25.8)	253 (74.2)
Advanced health directive, n (%)	1 (0.8)	130 (99.2)	43 (20.5)	167 (79.5)	44 (12.9)	297 (87.1)
GOC discussion with patient, n (%)	3 (2.3)	128 (97.7)	76 (36.2)	134 (63.8)	79 (23.2)	262 (76.8)
GOC discussion with NOK, n (%)	2 (1.5)	129 (98.5)	76 (36.2)	134 (63.8)	78 (22.9)	263 (77.1)
Medial assessment, n (%)	2 (1.5)	129 (98.5)	67 (31.9)	143 (68.1)	69 (21.2)	272 (79.8)
Mental capacity assessment, n (%)	2 (1.5)	129 (98.5)	62 (29.5)	148 (70.5)	64 (18.8)	277 (81.2)
Patient preferences, n (%)	2 (1.5)	129 (98.5)	56 (26.7)	154 (73.3)	58 (17.0)	283 (83.0)
Decision rationale, n (%)	2 (1.5)	129 (98.5)	73 (34.8)	137 (65.2)	75 (22.0)	266 (78.0)

GOC = goals-of-care,