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Enhanced supportive care in cancer centres: national cross-sectional survey

Rachel Moya Helen Caulfield ,^{1,2} Lucy E Selman ,³ Jane Gibbins,⁴ Karen Forbes,^{3,5} Charlotte Chamberlain^{3,5}

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¹Population Health Sciences, Bristol Medical School, Bristol, UK

²Basingstoke and North Hampshire Hospital-Foundation School, Hampshire Hospitals NHS Foundation Trust, Basingstoke, UK

³Population Health Sciences, Palliative and End of Life Care Research Group, Bristol Medical School, Bristol, UK

⁴Royal Cornwall Hospitals NHS Trust, Truro, UK

⁵Supportive and Palliative Care, University Hospitals Bristol and Weston NHS Foundation Trust, Bristol, UK

Correspondence to

Dr Charlotte Chamberlain, Population Health Sciences, Palliative and End of Life Care Research Group, Bristol Medical School, Bristol, UK; charlotte.chamberlain@bristol.ac.uk

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ABSTRACT

Objectives ‘Early’ specialist palliative care (SPC) has been shown to improve outcomes for patients with advanced cancer, yet patients are often referred late. ‘Enhanced supportive care’ (ESC) aims to facilitate earlier integrated supportive care for those with incurable cancer. This study aimed to explore clinicians’ understanding of ESC/SPC delivery through description of current service provision.

Methods This national cross-sectional survey of 53 cancer centres had two parts. Part 1: Service details, was directed to lead ESC/SPC nurses or consultants about service configuration, and Part 2: Clinician understanding, targeting conceptual understanding of service aims including ESC/SPC teams and oncology consultants (n=262 surveys). Multiple-choice questions explored service provision, referral triggers and evidence of integration with oncology, with free-text responses. Quantitative results were analysed with Fischer’s exact test. Qualitative free text was line-by-line coded by two authors independently to derive themes.

Results 56% (30/53) of SPC and ESC teams and 14% (14/100) of oncologists responded. Those involved in ESC self-reported greater integration with oncology compared with non-ESC teams, for example, joint case discussions (64.3%, 9/14 vs 23.1%, 3/13, p=0.05), and timelier patient referral (>6 months before death vs <6 months) (10/14 vs 4/13, p=0.06). Qualitative themes described ambiguity in definitions of supportive and palliative terms and a perception of timelier identification of patients when ESC was involved.

Conclusion Providers of ESC perceive greater integration with oncology and potentially timelier referral for patients compared with teams not delivering ESC. Terminology around SPC and ESC remains uncertain across England.

BACKGROUND

Palliative care focuses on symptom control, psychological support and timely

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Referrals to ‘early’ specialist palliative care (SPC) remain late and evidence for the optimal model of early SPC is limited.

WHAT THIS STUDY ADDS

⇒ Enhanced supportive care (ESC) participants perceive improved integration with oncology, with earlier referrals, yet there is ambiguity around the terms of ESC and SPC.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Evaluation of SPC/ESC with agreed patient, carer and National Health Service (NHS) outcomes is needed to understand the value of early integrated palliative care to optimise existing services.

information sharing for patients with incurable illness, and their families.¹ ‘Early’ palliative care involvement for patients with cancer has been shown to improve patients’ symptoms and well-being, reduce carer burden and bereavement distress and decrease the likelihood of unplanned hospital admissions and of dying in hospital.^{2–8} However, hospital specialist palliative care (SPC) is involved in patients’ care, on average, only 19 days before death.²

Supportive care is ‘the prevention and treatment of the adverse effects of cancer and its treatment’ (MASCC 1990). It is described as allied to, but distinct from palliative care.⁹ Since the term ‘palliative care’ may be a barrier to referral due to its association with dying, supportive care is increasingly used interchangeably.^{10 11} Therefore, in clinical practice, the true difference between palliative care and supportive care is less clear.

Enhanced supportive care (ESC) was a new initiative first developed at the

Christie Hospital, a UK specialist tertiary cancer referral centre as an outpatient-based service to allow earlier integration of supportive care. The programme's six main principles are: early involvement of supportive care services; supportive care teams working together; a positive approach to supportive care; evidence-based practice in supportive and palliative care; technology to improve communication and best practice in chemotherapy care.¹² National Health Service (NHS) England adopted the service, and commissioners and providers were encouraged to adopt ESC across England using funding from the Commissioning for Quality and Innovation framework (known nationally as a CQUIN) which supports improvements in service quality and the creation of new patterns of care.¹³ There are few published evaluations of ESC.^{14–16} In 2019, the National Institute for Health and Care Excellence concluded that there was insufficient evidence of substantial benefit to patients, carers or the NHS of early palliative care involvement. A greater understanding of the role and impact of ESC compared with palliative care is therefore needed.¹⁷

AIMS

The aim of the study was to increase understanding of current SPC, supportive care and ESC models in England, with objectives to explore timeliness of referrals, integration with oncology teams and healthcare professionals' interpretations of the meanings of SPC, supportive care and ESC.

METHODS

Methods are reported according to STROBE recommendations.¹⁸

A cross-sectional online/postal survey was distributed to all cancer centres in England.

The survey

The survey, developed by researchers and clinical academics using Jisc software, included a mixture of multiple choice and free-text questions. Each of the two parts took 10–15 min to complete.

- Part 1: Service details. Designed for the lead SPC/supportive care consultant or 'team champion' to include detail about the cancer centre, including demographics, the service, integration with other specialties and whether the service was part of the ESC CQUIN.
- Part 2: Clinician understanding, was sent to lead palliative care consultants, lead nurses and oncology consultants, focussing on health professionals' understanding of SPC, supportive care and ESC.

The survey was piloted by SPC professionals to ensure suitability and face validity. The survey is included in online supplemental material.

Recruitment and participants

Cancer centres (those hospitals providing chemotherapy, radiotherapy and SPC) were identified from a long-list of trusts designated as commissioned providers

of radiotherapy (published by NHS England).¹⁹ Evidence of provision of onsite chemotherapy and SPC and/or supportive care or ESC (defined as having at least one SPC consultant or nurse specialist with an honorary or substantive contract with the NHS cancer centre) was ascertained through websites and direct questioning of teams. SPC/supportive care and/or ESC lead/champion nurse or consultants were identified through the Trust website. Two oncologists from each cancer centre (subspecialties of lung and colorectal, two of the most common ESC subspecialties at the time) were also invited to participate in the survey.

A researcher (RMHC) contacted each team by telephone. A link to the survey was then emailed to individuals, or to an administrator to disseminate to nominated team members. The online survey was open from 4 February 2019 to 28 February 2019. Reminder emails were sent via the survey's website 10 days post opening and 48 hours before the survey closed. Teams who preferred were sent a paper version of the survey with a stamped, addressed return envelope. Two reminders were sent. Participants were anonymised and allocated a unique identification number by Jisc. Participants were given the opportunity to leave their email addresses to participate in further work.

Data analysis

Survey analysis was conducted using Jisc, Microsoft Excel and Microsoft Word. Jisc tabulates responses automatically. Data were exported from Jisc to Microsoft Excel for analysis including Fischer's exact test. Microsoft Excel qualitative data were transferred into Microsoft Word for coding. Free-text data were analysed using inductive thematic analysis, based on the principles of Glaser and Strauss.²⁰ Two researchers (CC, RMHC) independently coded all free-text responses, identifying codes inductively. An additional 20% of the responses were also coded by a third researcher (JG). Codes were amalgamated into higher-order themes and exemplifying data extracts and compared for all responses for each question (RMHC, CC, JG). Free-text responses were analysed by service (eg, SPC, supportive care and ESC) and by professional grouping (nurse/oncologist/SPC consultant).

RESULTS

Fifty-four cancer centres were identified (figure 1). Five SPC/ESC teams elected for postal surveys, and the remainder online survey completion. During the identification of cancer centres, it was noted that two teams each worked across two centres (both oncology and SPC). As both were within the same foundation trust these were treated as one team. Two sites had separate ESC and palliative care teams. These services were classed as separate and two participants from each service were asked to participate. Two cancer centre oncology departments declined to participate.

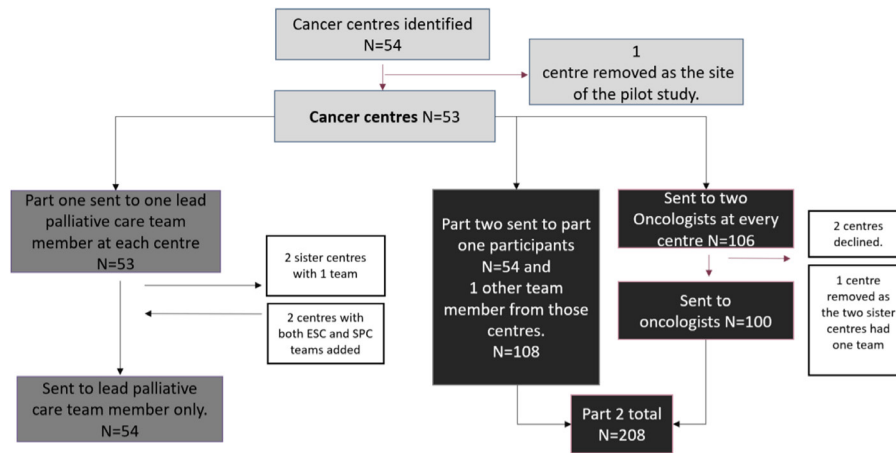


Figure 1 Study recruitment detailing inclusion and exclusion of centres summarising the numbers included at each stage. ESC, enhanced supportive care; SPC, specialist palliative care.

In total, 257 electronic surveys and five paper copies were sent (Part 1: service details and Part 2: clinician understanding).

Response rates

Service details (Part 1) included 30 respondents from 54 SPC/supportive care/ESC teams (response rate 55.6%). 66.7% (n=20/30) of participants identified their cancer centre as based in a tertiary referral centre, 30.0% (n=9/30) in a district general hospital and 3.33% (n=1/30) within a large teaching hospital. Of the 30 responses, 14 participated in the ESC CQUIN (all tertiary referral centres (46.7%)).

Clinician understanding (Part 2) had a response rate of 22.6% (n=47/208); 14.0% (n=14/100) for oncologists and 31.5% (n=34/108) for SPC/supportive care or ESC palliative care.

Service details

Adoption of ESC

Fourteen centres had participated in the ESC CQUIN. Six had participated for less than 3 years at the time of the survey, two ended their participation during the CQUIN's 3-year duration. Of these 14 centres, 64.3% (n=9/14) invested in existing SPC/supportive care services such as increasing staffing levels, and 14.2% (n=2/14) in a bespoke ESC service, separate to the existing SPC team. The remaining three centres could not identify changes made with the funding or the existence of extra funding 14.2% (n=2/14) 'don't know' and 7.14% (1/14) 'none available'.

Description/label of service

Participants described their current services and the relationship with oncology. The term SPC was used most frequently when services had not adopted the ESC CQUIN, and a mixture of SPC and ESC for services that had.

Outpatient services

Some centres offered separate supportive care and SPC outpatient clinics, others combined supportive care and SPC clinics. In total, 12 centres offered supportive care, 19 SPC and 12 combined supportive care and SPC clinics.

Out of hours service provision

All but one service (a CQUIN ESC centre) identified their centre as offering prompt in and out-of-hours advice to health professionals (29/30). Patient advice by telephone was available in half the centres, with little difference between CQUIN and non-CQUIN centres (p=0.25).

OUTCOME MEASURES

Online supplemental table 1 shows the range of patient outcomes employed by centres, the most common being patient experience (26/30), followed by the number of patients dying with 30 days of their last systemic anti-cancer therapy (SACT). Centres differed most around recording offering patient's referral to supportive and palliative care at the point of metastatic diagnosis (ESC CQUIN centre: n=10/14, compared with non-CQUIN centre: n=2/13). Centres commonly used non-validated questionnaires to monitor patient experience. The frequency of questionnaire distribution ranged from monthly to annually, 1–3 times during a care episode or opportunistic distribution.

Indicators of integration

The European Society of Medical Oncology (ESMO) indicators of integration between oncology and SPC were included in the survey²¹ (see online supplemental material for a full list of ESMO indicators) and were compared across CQUIN participating centres.

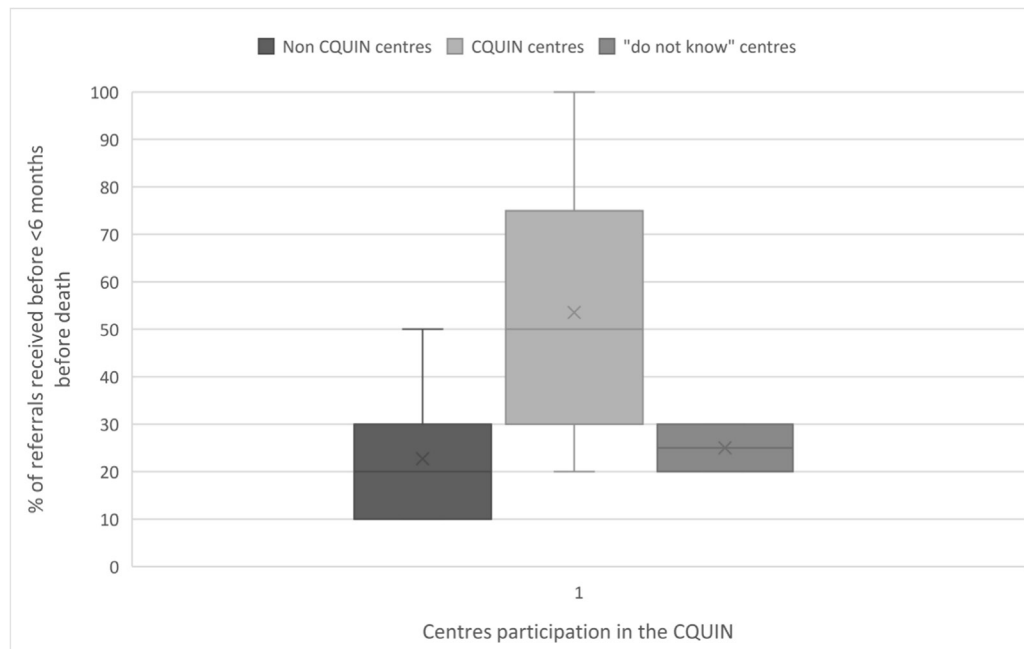


Figure 2 Box and Whisker Plot demonstrating median and IQRs of percentage of early referrals greater than 6 months prior to death in ESC and SPC services. CQUIN, Commissioning for Quality and Innovation; ESC, enhanced supportive care; SPC, specialist palliative care.

Timeliness of referral

Timeliness of referrals varied by participation in the CQUIN. Participating CQUIN centres described the estimated prognosis of most patients referred to supportive and palliative care as 6 months to 1 year ($n=10/14$), compared with non-CQUIN adopting centres ($n=4/13$). Fischer's exact test compared most referrals <6 months with most referrals 6 months to 1 year across centres (figure 2). There was weak evidence of a difference between CQUIN-adopting ESC and non-CQUIN adopting centres for timeliness

($p=0.057$). A corroborating survey question was asked about 'early' referrals, (referrals >6 months before death) with ESC-CQUIN centres self-reporting a higher median percentage of 'early' referrals than non-CQUIN centres.

Integration with oncology teams

ESC-CQUIN centres had more joint case discussions (64.3%, $n=9/14$ vs 23.1%, $n=3/13$; $p=0.05$) (Figure 3). Other indicators were similar in CQUIN and non-CQUIN participating ESC centres: joint

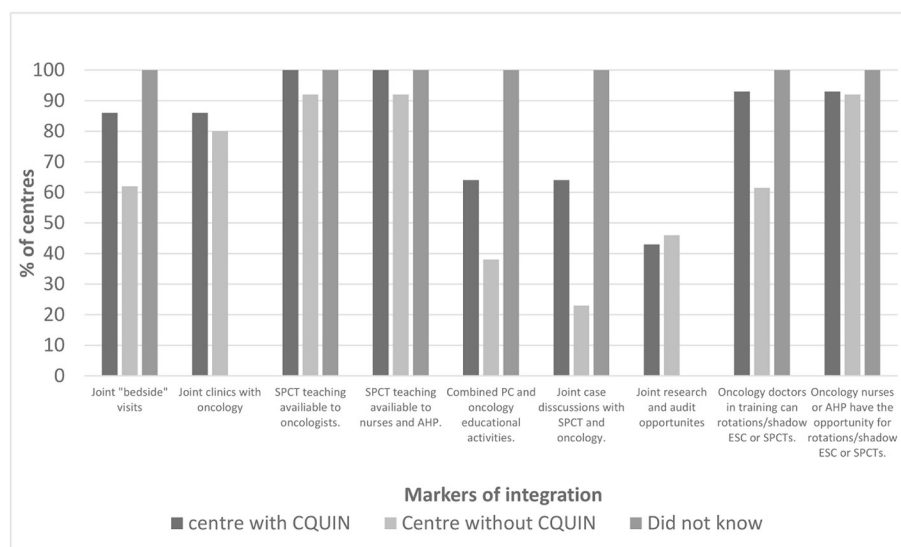


Figure 3 Bar chart depicting ESMO indicators of integration split by CQUIN participation status of centres. CQUIN, Commissioning for Quality and Innovation; ESC, enhanced supportive care; ESMO, European Society of Medical Oncology; AHP, allied health professional; SPCT, specialist palliative care team.

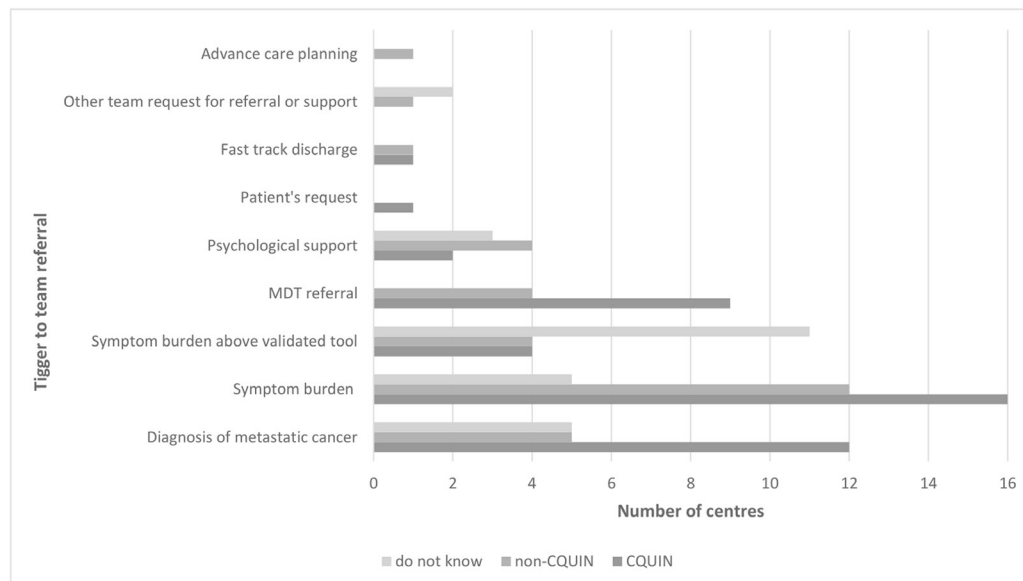


Figure 4 Bar chart depicting triggers for referral to ESC/SPC services, split by CQUIN participation status of the centre. CQUIN, Commissioning for Quality and Innovation; ESC, enhanced supportive care; MDT, multidisciplinary team; SPC, specialist palliative care.

clinics (85.7%, n=12/14 vs 76.9%, n=10/13; p=0.65); joint educational activities (64.3%, n=9/14 vs 38.5%, n=5/13; p=0.26); joint bedside visits (85.7%, n=12/14 vs 61.5%, n=8/13; p=0.21); oncology medical trainees shadowing SPC/supportive care or ESC teams (92.8%, n=13/14 vs 61.5%, n=8/13; p=1.00); Oncology nurses or Allied Health Professionals (AHP) having the opportunity for rotations/shadowing specialist palliative care (SPC) teams or ESC (93%, n=13/14 vs 92%, n=12/13; p=0.96); joint research and audit opportunities (42.9%, n=6/14 vs 46.2%, n=6/13; p=1.0); SPC teaching to oncologists (100%, n=14/14 vs 92.3%, n=12/13; p=0.41); SPCT shadowing for nurses and AHPs (92.8%, n=13/14 vs 92.3%, n=12/13; p=0.16). However, free-text responses (n=7/47 SPC and n=6/7 oncologists) defined ESC based on its 'superior integration with oncology'.

Clinician understanding

Centres were asked about triggers for referral to their services. Participants could select as many as applied. ESC-CQUIN centres relied most heavily on symptom burden, a diagnosis of metastatic cancer and multidisciplinary teams (MDTs) as a trigger for referral (Figure 4).

FREE TEXT

Three themes emerged from free-text responses:

1. Ambiguity in terminology and service definitions.
2. ESC offers timely access to services for patients.
3. The number of staff continue to limit patient access to services.

Theme 1: ambiguity

Comparison of participants' descriptions of the key terms 'palliative care', 'supportive care' and 'enhanced supportive care' revealed ambiguity. Definitions of palliative care frequently included reference to 'symptom relief' and 'holistic'. However, there was much overlap in terminology and descriptors for all three terms (supportive care, SPC and ESC) independent of participation in the ESC CQUIN.

[Palliative care is] a broad holistic approach to patient care and care of their family and those close to them including attention to detail in physical, psychological, spiritual and cultural domains. Although palliative care is usually seen as a service for ill people who are probably in the last year of their life it can be appropriate early in the disease course regardless of diagnosis (Palliative care consultant A, ESC-CQUIN centre)

One participant described supportive care and ESC as the 'same' as palliative care. Two palliative care consultants proposed the CQUIN was a rebranding of palliative care to avoid the negative perceptions associated with SPC, and perhaps it was easier for clinicians to refer to an ESC service, as patients did not associate this with death and dying.

We call our clinics this to avoid frightening patients away (Palliative care consultant B, ESC-CQUIN centre)

[ESC is the] same as palliative care but made available to patients who may not have advanced progressive illness. I do worry that ESC is a rebranding of palliative care, avoiding a term which sometimes patients find frightening. ... really, we should be honest and reassuring with patients about what the

service is rather than just renaming it (Palliative care consultant C, ESC-CQUIN centre)

Participants suggested faster referral (n=20/47) and access to the service while undergoing treatment (n=11/47) as key descriptors of ESC.

The introduction of supportive and palliative care earlier into the patient's cancer journey, in the outpatient setting while still receiving active cancer treatment (Oncologist A, ESC-CQUIN centre)

Theme 2: timeliness of ESC

Only participants from ESC-CQUIN centres were asked to respond to questions evaluating the service (n=20/47). Positive ESC experiences included increased clinic frequency (n=8/20), earlier patient referral (5/20), greater access for patients (n=4/20) and reduced pressure on inpatient services (n=5/20).

Other participants could not identify any significant change in service provision.

(Traditionally) reactive service seeing over 2500 new referrals of acute hospital inpatients per annum. Strong multidisciplinary Hospital Palliative Care Team. Seven day working ... Growing range of proactive palliative care initiatives – our longstanding description of what others call supportive care (Palliative care consultant D, ESC-CQUIN centre)

Theme 3: staffing

Concerns about staffing levels (n=8/20) were flagged across both ESC-CQUIN and non-CQUIN centres, and by those who did not know if they were participating. Participants suggested that staffing levels will be key if ESC services were to include more cancer sites. The fact that ESC accepted referrals from a limited number of cancer sub-specialties was reported as a limitation to the service (n=4/20).

Given the work that I have given the team, if all of my colleagues used them to the same extent the team would be completely rushed off their feet (Oncologist B, ESC-CQUIN centre)

DISCUSSION

This is the first national cross-sectional study aiming to describe current understanding and practice of ESC with teams who work in these services, from palliative and supportive care and oncology. Our findings suggest heterogeneity in the practice of ESC. For instance, some centres used CQUIN funding to support existing SPC/supportive care teams; others developed new and separate services.

Given there is known service heterogeneity in SPC services, it is unsurprising perhaps that there continues to be heterogeneity in a service development built on these foundations.²² Interestingly, participants perceived there was little difference between early palliative and supportive care and ESC. This may reflect

the survey being done when ESC was in its infancy, and all services having the potential to see the same cohort of patients. It may also reflect ongoing controversy in defining palliative care, which, although first outlined 30 years ago by the WHO, has seen several iterations. ESC providers are generally trained in palliative medicine whose curriculum matches the concepts of supportive care. This may contribute to the suggestion from some participants that ESC, while in theory a new service, merely represents 'rebranding'.^{23 24} While rebranding itself has been shown to facilitate earlier referrals to palliative care, Berman and Davies suggest there are systematic differences in ESC, particularly in the knowledge required to provide these services:

Palliative care professionals have an important role in supportive care, as do healthcare professionals from many other areas of medicine. But if healthcare professionals are to provide a comprehensive supportive care service, they will need appropriate knowledge about supportive care problems ... Some palliative care teams have rebranded themselves as supportive care teams, although they may not yet be providing a truly comprehensive supportive care service.²⁵

Misunderstanding terminology may be a symptom of wider uncertainty around what an essential palliative or supportive care intervention is and how it should be measured and compared with usual practice.

Participants who were part of an ESC team reported improved communication and integration with oncology and earlier patient referral. This study measured perception and was not designed to quantify whether greater integration truly occurred in ESC centres. It cannot conclude whether, if greater integration existed, it was a direct consequence of ESC. However, given that there is randomised-controlled trial (RCT) evidence that early palliative care involvement improves outcomes identified as important to patients and carers (symptom control; essential timely information; considering preferences and plans for the future, and not being a burden to family members),^{26 27} it is essential to understand barriers to earlier integration. Traditionally, referrals to palliative care teams are late. In an English study, the median duration of palliative care before death was 34 days, significantly shorter than the evidence for 'early' palliative care at more than 6 months.^{28 29} Participants in this study perceived that rebranding and referrals triggered by an incurable cancer diagnosis or MDT to ESC may enable a more integrated service allowing earlier access to SPC/supportive care services.

In a narrative review of models of the delivery of outpatient palliative care, interdisciplinary clinics for delivery of early palliative care, similar to those modelled in ESC, are regarded by experts as the ideal service.³⁰ However, there is no RCT evidence for the optimal content, timing and design of service which

delivers best care to patients with incurable cancer in the UK.

Strengths and limitations

The strengths of the survey include (1) cancer centres were systematically defined to capture all ESC-eligible centres, (2) all centres were telephoned in advance to optimise response rates and (3) it was piloted by relevant health professionals prior to roll out. The low response rate of oncologists has meant these results were not fully reported or emphasised in this manuscript due to the inevitable selection bias in responders.

While there is evidence of perceived timely referral to supportive and palliative care and greater integration of services in ESC centres, we cannot say this is causal, and may reflect responder bias. Several centres had dropped out of the CQUIN. Unfortunately, it was not possible to ascertain the reasons for this reliably, nor include all areas of the ESMO indicators of integration to keep the survey to a practical length. While *p* values have been included as part of the analysis, due to the number of categories assessed, these are an indication of the strength of the evidence but should not be read in isolation.

IMPLICATIONS FOR PRACTICE THEORY OR POLICY

Greater attention needs to be paid to defining and categorising the different supportive and palliative care service delivery approaches, and their outcomes. To facilitate evaluation of ESC, key performance indicators (KPIs) have now been defined for all participating centres. There is an urgent need for further research into the effectiveness and cost-effectiveness of palliative care and ESC models comparing these outcome measures. Further research should include these KPIs along with qualitative research with health professionals, patients and carers, about unplanned admission rates, duration of stay and SACT in the last 30-days of life. Patient and carer reported outcome measures will be invaluable. It is unclear currently whether ESC delivers the anticipated benefits of early integrated palliative care described in RCTs from the USA and Canada.^{5 29} However, this study suggests that ESC is perceived to change the timeliness of referral to palliative and supportive services which is worthy of further investigation.

CONCLUSION

Study participants described difficulty distinguishing between SPC, supportive care and ESC terminology. There was evidence of service heterogeneity in delivery of these. Participants perceived that ESC facilitated more timely identification of patients who may benefit from palliative care and described improved integration with oncology teams. Further studies are needed to explore whether ESC does enable early access to care and improved integration with oncology, as well as improved outcomes for patients and their carers.

Twitter Lucy E Selman @Lucy_Selman

Contributors RMHC and CC are the main investigators and authors. They wrote the proposal, developed the questionnaire, performed the literature searches, identified participants, distributed and collected the questionnaire results, analysed the data and co-authored the paper. CC has overall responsibility for the work. JG assisted in the analysis of data, helped to author the paper and reviewed the drafts of the paper. LES is a scientific advisor and critically reviewed study proposal, questionnaire drafts, results and paper. KF served as scientific advisor and critically reviewed study proposal, questionnaire drafts, results and paper.

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Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved. Ethical approval was obtained from the University of Bristol Faculty of Health Sciences Research Ethics Committee (January 2019, code 80362). Participation in the survey indicated written consent. They were sent the link to the questionnaire with a participant information sheet. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Raw data are available upon reasonable request including the de-identified responses from questionnaires and can be made public if this is the reviewer/editor's wish with the acknowledgment that some information may need to be redacted to protect participants' anonymity should this be an essential aspect of publication.

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ORCID iDs

Rachel Moya Helen Caulfield <http://orcid.org/0009-0009-3137-0702>

Lucy E Selman <http://orcid.org/0000-0001-5747-2699>

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