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Clinical ethics support services during the COVID-19 pandemic in the UK: a cross-sectional survey

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## ABSTRACT

**Background:** The COVID-19 pandemic highlighted the need for clinical ethics support provision to ensure as far as possible fair decision-making and to address healthcare workers' moral distress.

**Purpose:** To describe the availability, characteristics and role of Clinical Ethics Support Services (CESSs) in the UK during the COVID-19 pandemic.

**Method:** A descriptive cross-sectional online survey was developed by the research team. The survey included questions on CESSs characteristics (model, types of support, guidance development, membership, parent and patient involvement) and changes in response to the pandemic. Invitations to participate were widely circulated via NHS institutional emails and relevant clinical ethics groups known to the research team.

**Results:** Between October 2020 and June 2021, a total of 53 responses were received. In response to the pandemic, new clinical ethics support services were established, and existing provision changed. Most took the form of clinical ethics committees, groups and advisory boards, which varied in size and membership and the body of clinicians and patient populations they served. Some services provided moral distress support and educational provision for clinical staff. During the pandemic services became more responsive to clinicians' requests for



ethics support and advice. More than half of respondents developed local guidance and around three quarters formed links with regional or other local services. Patient and/or family members' involvement in ethics discussions is infrequent.

**Conclusions:** The pandemic has resulted in an expansion in the number of CESSs. Though some may disband as the pandemic eases, the reliance on CESSs during the pandemic demonstrates the need for additional research to better understand the effectiveness of their various forms, connections, guidance, services, and modes of working; and for better support to enhance consistency, transparency, communication with patients and availability to clinical staff.

## **BACKGROUND**

The COVID-19 pandemic raised a variety of healthcare and clinical ethical issues at social, policy-making, institutional and professional levels. One of the most frequently discussed, particularly early in the crisis, has been the allocation of scarce resources and patient prioritisation, especially concerning mechanical ventilators and intensive care. In the absence of national guidance on resource allocation early in the pandemic<sup>(1)</sup> the establishment of local protocols often fell to local Clinical Ethics Support Services (CESSs), which are services that offer support to healthcare professionals and institutions in dealing with clinical ethical issues.<sup>(2)</sup> Healthcare institutions and clinicians have also faced an increased and much broader array of ethical challenges, such as personal safety, reallocation of clinicians, resource allocation and triage, and the closing down or limitation of non-COVID-19 related services.<sup>(3–5)</sup> These changes and the great uncertainties posed by the pandemic increased the risk of healthcare providers experiencing moral distress,<sup>(6,7)</sup> defined by the British Medical



Association (BMA) as “*the psychological unease generated where professionals identify an ethically correct action to take but are constrained in their ability to take that action*”.(p.3, 8)

A recent systematic review suggests overall positive user satisfaction with the impact of CESSs prior to the pandemic, notwithstanding a paucity of research on their effectiveness.(9) Accordingly, the potential for CESSs to reduce unfair decision-making and healthcare workers’ moral distress was recognised in Royal College of Physicians(10) and British Medical Association(11) pandemic-related advice in early 2020 advising employers to provide clinical ethics support.

The number and forms of UK CESSs have long been difficult to establish. A 2001 survey identified 20 clinical ethics committees,(12) and Slowther et al’s 2010 survey of 82 services registered with the UK Clinical Ethics Network (UKCEN)(13) found that numbers were increasing but there was significant variation in processes.(14) Core competencies were helpfully promulgated by the UKCEN in 2010,(15) but in contrast to the US and other countries where CESSs are regulated in structure and remit, there is a lack of formal and binding guidance on CESS constitution, processes, remit and clinical and legal responsibilities.(16) The UKCEN maintains a list of ethics services but some choose not to register and relatively few can be identified by a website.(17–19)

At the time of writing (July 2021), the UKCEN website lists 44 committees and groups,(20) suggesting that numbers have dwindled. There is evidence that making a business case for a CESS before the pandemic was onerous and unappealing,(21) and issues with the constitution and operation of CESSs sometimes made them unapproachable or invisible to those who might utilise their services.(22)

In response to the increased and unprecedented demand for clinical ethics support during the pandemic, established CESSs have adapted their services(3,4) and new ethics provision has



been set up.(23) Considering a lack of official regulation and requirements, evidence is needed as to how ethics support is being provided across the UK, how established CESSs changed and the different roles these services are having in relevant institutions. A better understanding of current and emerging forms of CESSs will allow identification of inconsistencies, strengths, areas for improvement and inform further CESS development and research.

As part of a broader project examining ethical advice and ethics committees in the pandemic,(24) this study aimed to describe the availability, characteristics and role of CESSs in the UK during the pandemic.

## **METHODS**

We conducted a descriptive cross-sectional online survey to allow coverage of relevant CESSs across the UK considering time and resources available for the project. The survey is reported in accordance with the ‘Good Practice in the Conduct and Reporting of Survey Research checklist(25) as recommended by the EQUATOR Network for survey observational studies.

**Instrument:** We developed an online questionnaire using SurveyMonkey ®, which has been previously used for UK Trusts’ targeted web-based surveys.(26,27) The instrument included 21 multiple-choice questions, five-point Likert scales and free-text comments addressing CESSs characteristics (model, types of support, guidance development, membership, parent and patient involvement) and changes in response to the pandemic (Supplementary File 1). The instrument was pre-piloted by completion and feedback by two experienced Clinical Ethics Committee (CEC) members and one non-CEC member clinician, after which minor changes were suggested.

**Sampling and data collection:** As there is no definitive register of CESSs and some were in development, the invitation and electronic link to complete the survey was promulgated via



three routes; (i) Invitation sent out via the UKCEN mailing list; (ii) Where available, direct email contact with known CESSs (iii) Every NHS Trust in England, Wales, Scotland and Northern Ireland was emailed requesting that the invitation to participate be forwarded to the relevant person within their institution (England: 225 NHS Trusts, Wales: 7 Health Boards and 3 All-Wales NHS Trusts, Scotland: 14 Regional NHS Boards + 7 Special NHS Boards and Northern Ireland: 5 HSC Trusts). For routes (i) and (iii) a reminder email invitation was sent after two weeks. The web-link was initially open for responses between October to December 2020, and expanded until June 2021 to allow further participation through route (ii).

**Data analysis:** Responses with more than 50% missing answers (less than 10/21 questions completed) were excluded from analysis. Data was analysed using descriptive statistics and simple graphic analysis to summarise the results.

**Ethical considerations:** Responses were voluntary and could be made anonymously. Respondents were given the option to provide their CESS location and name. Participants consented to their participation, the analysis of their answers and the sharing of anonymised results within the academic community. The project has both Queen's University and Durham University ethical approval.

## RESULTS

Fifty-three survey responses were received between October 2020 and June 2021. Due to multiple distribution methods which resulted in some receiving more than one invitation to participate, it was not possible to calculate an accurate response rate, nor characteristics for those who did not participate.



**Prevalence:** Eight out of 53 respondents reported not having CESS provision prior to or during the pandemic. Twenty-six had an established CESS prior to the pandemic and 19 stated they had set up a CESS in response to the pandemic.

For subsequent analysis, 13/53 responses were excluded due to substantially incomplete answers, leaving 40 responses for analysis; 21 correspond to previously established CESSs and 19 to services established in response to the pandemic (See Figure 1).

[INSERT FIGURE 1. Response Flow Chart]

**CESS location and structure:** Reported CESSs were located in England (n=31), Northern Ireland (n=7), Scotland (n=1) and Wales (n=1) and served both adult and paediatric patients (n=27), adults only (n=9) and children only (n=2).

Within the services established pre-pandemic (n=21), one took the form of ethics consultants and the rest (19/21) as clinical ethics committees (CECs) (there was one missing response). The CESSs represent a range of bodies and institutions, including a single hospital, a single trust, multiple hospitals or a region. The majority changed their provision in response to the pandemic (18/21), most often by increasing the frequency of meetings or forming a sub-group of its members (n=14). Other changes included the addition of a regular agenda item on COVID-19 (n=7), special dedicated COVID-19 meetings (n=6), urgent subgroup meetings (n=2), on-call 24/7 rapid access ethics services (n=2), and daily meetings (n=2).

Of those who reported setting up a CESS in response to the pandemic, all 19 formed groups but four eschewed the term “clinical ethics committee” in favour of “Ethics advisory group”, “Ethics advice and support group”, “Clinical ethics forum” and “Ethical decisions advisory group”.



**Membership:** Table 1 represents CESS membership by category. Overall, CESS membership ranged from 7 to 33 individuals. Doctors were represented in all CESSs (39/39) and the majority had representation of nurses (n=37), allied health professionals (n=37), Trust/NHS managers (n=30), lay members (n=26), academic or practicing lawyers (n=22) and Chaplain or faith leader (n=19). Several CESSs included a social worker (n=14) and academic ethicist/philosopher(s) (n=11). Other members reported by some respondents included patient/carer experience representatives, bereavement counsellors, safeguarding officers, researchers, and patient governors. In many cases where rapid response was initiated, CESS composition was adapted according to the case or issue being discussed.

CESS constitution by category was similar in previously and newly established services, except for Chaplaincy representation where 13/20 CESS established prior to the pandemic had at least one faith leader in its membership, compared to 6/19 of those established in response to the pandemic. Where CESSs include a chaplain or faith leader, a wide variety of religious denominations are represented with several respondents noting that faith representative's perspectives were not limited to their religious denomination. One referred to "*faith-related support rather than specific religious denominational support*" (P37).

| Table 1. Membership of CESS (valid responses n=39) |                                                                         |
|----------------------------------------------------|-------------------------------------------------------------------------|
| Category                                           | Number of CECs with at least one member in this category<br>(%, range)* |



|                                                                                                                                                                                            | TOTAL (n=39)    | Established previous to the pandemic (n=20) | Established in response to the pandemic (n=19) |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------|---------------------------------------------|------------------------------------------------|
| Overall                                                                                                                                                                                    | 7-33            |                                             |                                                |
| Doctor(s)                                                                                                                                                                                  | 39 (100%, 2-10) | 20 (3-10)                                   | 19 (2-10)                                      |
| Nurse(s)                                                                                                                                                                                   | 37 (95%, 0-6)   | 18 (0-6)                                    | 19 (1-6)                                       |
| Allied Health Professional(s)                                                                                                                                                              | 37 (95%, 0-5)   | 20 (1-3)                                    | 17 (0-5)                                       |
| Trust/NHS manager(s)                                                                                                                                                                       | 30 (77%, 0-10)  | 15 (0-4)                                    | 15 (0-10)                                      |
| Lay member(s)                                                                                                                                                                              | 26** (66%)      | 14                                          | 12                                             |
| Practicing/academic lawyer(s)                                                                                                                                                              | 22 (56%, 0-2)   | 14 (0-3)                                    | 8 (0-2)                                        |
| Chaplain/Faith leader(s)                                                                                                                                                                   | 19 (49%, 0-3)   | 13 (0-2)                                    | 6 (0-3)                                        |
| Social Worker(s)                                                                                                                                                                           | 14 (36%, 0-2)   | 7 (0-2)                                     | 7 (0-2)                                        |
| Academic ethicist(s)/philosopher(s)                                                                                                                                                        | 11** (25%)      | 7                                           | 4                                              |
| Ex-parent/patient                                                                                                                                                                          | 8 (21%, 0-5)    | 4 (0-3)                                     | 4 (0-5)                                        |
| <p>*Some responses were approximate numbers and some individuals have dual-role thus might be considered twice.</p> <p>**These categories were yes/no answers and no numbers provided.</p> |                 |                                             |                                                |

**Variation in ethics support:** Figure 2 shows the different forms of ethics support offered to clinical staff provided prior to and during the pandemic, and support established in response to the pandemic. In terms of the format of deliberations, the pandemic resulted in an increase in



telecommunication, and in small group ad hoc consultation. The ‘three wise persons’ approach whereby ‘three options are sought, typically from senior consultants, to inform challenging decisions on individual cases’(28) became more popular in the pandemic.

In terms of the categories of support offered, overall, there are reports of ‘no provision’ for every category listed in the survey. However, there were no new forms of support listed. Data suggests that rather CESSs enhanced aspects of provision, such as focusing on responding to moral distress or the production of local ethics guidance (discussed below).

Data from CESSs established in response to the pandemic indicates that some forms of support were being provided prior to and during the pandemic at institutions without an established CESS; including the three wise people approach (4/19), ethics discussion via telephone (1/19), proactive ethics consultation (1/19) and moral distress support for staff (2/19).

[INSERT FIGURE 2. Forms of ethics support provided during the COVID-19 pandemic]

**Parent, patient and family involvement in ethics discussion (valid responses n=38):** Figure 3 shows different forms of patient/parent/family involvement in ethics discussion prior to or during the pandemic. Four out of 38 respondents confirmed that they did not and do not invite, nor inform patients, parents and/or family members about ethics meeting where their cases are discussed. Conversely, over half reported that they informed relevant parties about the ethics meeting outcome (24/38). Other forms of involvement were variable and relatively infrequent.

[INSERT FIGURE 3. Patient/parent/family involvement in ethics discussions]

**Ethical guidance:** Thirty-four out of 40 CESSs reported having used professional ethical guidance from the wide array promulgated during the pandemic (6 missing responses). From those who provided details about the used guidelines, the most frequently mentioned included



the British Medical Association (n=11) and the General Medical Council (n=8) guidelines. Other participants reported relying on the UKCEN website, Intensive Care Society(29) and Royal College of Physician(10) guidance. Additionally, government advisory documents and multiple other royal colleges guidance were also mentioned.

Twenty-six out of 40 CESSs developed their own local documentation in response to the pandemic, with varied focus; some reported development and/or adjustment to existing CESS terms of reference and/or referral pathways (n=7) and a majority produced ethical guidance documents (n=18) including ethical decision-making frameworks, triage guidance and visiting policies. Additionally, some were involved in either local, regional and national ethical guideline development. Some respondents mentioned these guidelines were developed based on existing published, national and national guidelines, which were adapted into “*short working documents*” (p37).

Twenty-seven CESSs reported having formed either formal or informal links with regional or other local CESSs prior to or during the pandemic, including provision of support to other Trusts, sharing guidelines, and setting up regional CESS groups.

**Resources:** The great majority of CESSs (33/40) reported having some form of administrative support. Provision of ethics training and allocated hours for CESS members were available in 20/40 and 18/40 CESS respectively.

## DISCUSSION

In contrast to National Health Service Research Ethics Committees (RECs), which have standard operating procedures, formal guidance and oversight from the Health Research Authority; and in contrast to many international clinical ethics committees, the UK’s clinical ethics support system is informal and unregulated and there is no requirement to register



services. The survey results suggest there were at least 45 CESSs in the UK active at the time of the survey, of which 19 were established in response to the COVID-19 pandemic. Twenty-two of the survey respondents are (at the time of writing) also listed on the UKCEN website, which refer to an additional 21 committees.<sup>(20)</sup> It is thus challenging to arrive at an accurate estimation for current CESS numbers in the UK, especially as some services established in the pandemic may not endure. The survey did not capture post-pandemic intentions and we suspect this would not have been predictable at the time. There is a resulting information gap concerning the changing forms and prevalence of local ethical advice during and beyond the pandemic.

It is clear from the survey that the number of CESSs grew in response to the pandemic, though 8 respondents reported no access to CESSs either prior to or during the pandemic, showing that there are gaps in provision. Even where a CESS is established, in each category of forms of support listed in the survey, there are reports of no provision from some respondents. Some support functions will be provided outwith a CESS, but the findings indicate that clinical ethics support was variable.

It is noteworthy that CESSs have provided assistance to those suffering from moral distress, something of particular pressing importance during the pandemic.<sup>(6,30,31)</sup> Such assistance is quite distinct from moral advice. Yet it is clearly related to an understanding of what it is morally appropriate to demand of clinical staff with evidence suggesting that some CESSs have a role in ameliorating moral distress.<sup>(9)</sup> Going forward, it would be useful to explore effectiveness and what training there is for CESSs to provide such support.

Most reported CESSs take the form of a CEC, but there is variation in membership, activity, form and purpose. Variability is not of itself problematic, provided it enables provision to match needs and resources. However, limited evidence of the effectiveness of different models



makes it difficult for healthcare institutions to know what model, form, constitution and remit is optimal to their needs. Poor understanding of what CESSs do could also lead to mismatched expectations from staff, patients and officials. Newly formed CESSs are more frequently replacing the term ‘clinical ethics committee’ with alternative titles such as ‘ethical advisory board’ or ‘group’. We can surmise that this flows from a desire to manage expectations as to their advisory and supportive function. There is evidence of growing expectations of CEC involvement in controversial decisions about end of life treatment in particular.<sup>(32)</sup> In a recent High Court case<sup>(33)</sup> some passages of Russell J’s judgment point to a conception of a hospital CEC as a decision-making body rather than an advisory group assisting clinicians in the selection of appropriate clinical options and patients or parents making informed choices.<sup>(34)</sup> There needs to be greater clarity about the proper role of any CESS. In particular, it needs to be clearer that CECs and advisory groups offer informed advice but do not act as decision-makers in the last analysis. This will ensure that everyone has realistic expectations of what a CEC can and will do, at the same time as it gives CECs greater confidence in the discharge of their role.

Membership varies across reported CESSs, although the survey results suggest membership composition is similar in both previously and newly established services. Considering the deliberative role of CESSs, it is remarkable that only 25% of responding CESSs have at least one academic ethicist/philosopher in their membership. This is down from around 60% reported in Slowther et al’s 2010, survey.<sup>(13)</sup> However, it is possible that other members have postgraduate qualifications in clinical / medical ethics, but do not work as academics, as has been reported in previous surveys.<sup>(14)</sup>

The survey revealed that support in decision-making was sometimes provided through the involvement of a hospital chaplain or faith leader. But whereas, according to Slowther et al in 2010, 84% of CECs surveyed had a chaplain member,<sup>(14)</sup> our survey indicates a drop to 49%



of participating CESSs in 2021. NHS chaplaincy guidance recognises that hospital chaplains extend beyond religious care to non-religious pastoral and spiritual care.<sup>(35)</sup> The value of involving faith leaders in CESSs requires further investigation given their roles in supporting organisations, clinicians and patients through ethical dilemmas and providing a bridge between the medical and lay perspectives.<sup>(36)</sup> Is their role to ensure the trust of those with religious convictions? Or is it to ensure a distinctively valuable approach to a full ethical appreciation of those issues CESSs deliberate on?

More generally, building on the UKCEN's 2010 core competencies framework,<sup>(15)</sup> as the services offered by CESSs have evolved, it would be helpful to review what is required of CESS members, such that core competence and skills can be identified. These may be complementary and not of necessity possessed by each and every member.

Whilst most services informed patients about the meeting outcome, it was far from common prior to and/or during the pandemic to actively involve patients in ethics deliberations. This has been the case for some time: a 2009 UK survey found that fewer than half of CECs (17/40, 43%) had contact with patients and families,<sup>(37)</sup> and a 2011 survey reported that only 11/45 CECs invited patients to the meetings.<sup>(12)</sup> Our survey suggests that there have been no significant changes to this practice in the last decades, nor in response to the pandemic. There is no standard rule for patient and family involvement in ethics discussion and the practice varies across Europe and within the UK.<sup>(38)</sup> Remarkably, in a recent High Court case,<sup>(33)</sup> Russell J was critical of a CEC for not involving the family in a particular CEC deliberation during the pandemic, expressing concern as to the lack of guidance regarding patient and family involvement in ethics discussion.

The issue of patient and family involvement is controversial.<sup>(38)</sup> Patients might be involved to different extents; from receiving information about the meeting and its outcomes, to the ability



to refer cases and participate in meetings.(37) Assessing the implications of patient and families' involvement requires normative and empirical analysis,(39) which is currently limited.(40) Reports of benefits from both clinicians(41) and patients/parents(3) focus on the better understanding of patients' perspective and promotion of their autonomy in decision-making(37) as a component of patient-centred care.(42) However, there are also concerns that patient involvement could lead to misuse of CESSs as a complaints forum as well as fears that patient involvement could limit the openness of discussions and complicate decision-making and consensus achievement.(37)(41)

The survey provides evidence of the adaptability of ethics services to provide more timely responses. Case consultations (where they are provided) have been increasingly held remotely through phone or teleconferencing, which can be advantageous in terms of costs and time.(43) Pre-pandemic reports have also raised the potential for remote consultations to enhance accessibility.(44,45) However, as shown in other healthcare fields, remote consultations require adequate technical support and skills and might not be suitable for all patient groups.(46,47) There is a need for appropriate regulatory frameworks to ensure standards of care, and patient privacy and confidentiality, and for further evaluations of the feasibility, acceptability and impact of remote clinical ethics support on patient care.

Many CESSs extended their services to respond to clinicians needs, providing educational support, interpreting guidance and preventing or responding to moral distress. A recent British Medical Association survey indicates that 8 out of 10 doctors experienced moral distress in their pandemic work.(8) Whilst the nature of the problems will change post pandemic, a more agile and pervasive format is developing that could reinvigorate the case for ethical advice in a wider clinical context.



A worrying observation is the time and effort that was required by local CESSs in developing terms of references and operating procedures which could potentially have been more effectively shared. NHS Providers (a membership organisation of NHS organisations) stated that:

We understand that NHS England and Improvement is soon to publish additional guidance for trusts' ethics committees and we would urge them to expedite that to ensure consistency of approach across the country.(28)

We are not aware of any such guidance having been published to date.

We can also surmise that the great number of CESSs developing ethics guidance was at least in part a response to the lack of national guidance on resource prioritisation in the early stages of the pandemic.(1) One respondent reported that their early guidance to clinicians was superseded by guidance from the Intensive Care Society.(29) Our data does not allow us to analyse quality and content of locally developed guidelines, but most respondents reported that they were based upon existing guidelines. There were multiple professional ethical guidelines available, which generally advocated common principles.(48) However, these principles were abstract and required operationalisation,(48) which might have been the intention when CESSs report adapting the guidelines to their local context.

It is not essential that all CESSs follow the same guidance. CESSs may understandably develop forms of guidance that are sensitive to the particularities of their own situation and local practices. However, it should be expected that there is substantial congruence in such guidance, not least because there are available nationally agreed statements of ethical practice that CESSs would be expected to follow. Such congruence meets the worry that ethical advice is inconsistent across different CESSs. Having said all of that, what matters most is that CESSs have robust and transparent procedures for arriving at their determinations of advice.



Resources should be available to train CESS members so that they can be updated on key legal decisions, new guidance of relevance to their work, and have an understanding of the principles and values that should inform good ethical advice.

In many cases, facilitative administrative support has been provided to CESSs, but the lack of dedicated hours and formal training combined with the need to urgently develop local guidance in many cases, and to interpret a vast array of swiftly promulgated professional guidelines as the first wave drew on, put a significant strain and workload on ethics services in the pandemic. We owe them a debt of gratitude which extends to the UKCEN which enhanced guidance and put new services in touch with established bodies to smooth their transition.

**Strengths and limitations:** This survey offers valuable and timely information on the provision of clinical ethics support across the UK during the COVID-19 pandemic. By reaching out via several mechanisms, we were able to identify some newly established CESSs that were not registered with the UKCEN. In terms of limitations, given the multiple mechanisms used to approach participants, it is not possible to calculate the response rate and potential non-response bias. Moreover, it is clear that not all functioning CESSs responded – for example, not all CECs registered with the UKCEN completed the survey. This may be due in part to the high workload during the pandemic. The low number of responses received and the lack of complete responses from multiple respondents is an important limitation of this study. Additionally, although the survey was pre-piloted, some questions need careful interpretation; for membership categories, it was noted that some individuals have dual roles and/or categories might overlap (for example academic philosophers and academic ethicists), and therefore numbers might be overestimated. Some questions invited participants to offer free text comments when responses were positive (for example on the use of national/professional, ethical guidance, development of local ethical guidance) limiting our understanding about reasons for negative responses.



## CONCLUSIONS

The pandemic has resulted in an expansion in the number of CESSs. Though some may disband as the pandemic eases, reliance on CESSs in the pandemic emergency indicates their potential to provide clinicians with advice and support in difficult ethical challenges. The pandemic has shown that the service can adapt both to make advice more timely and responsive and to incorporate a wider range of proactive services such as education, support for staff moral distress and local guidance provision. The currently infrequent and mostly passive level of patient and family involvement needs further discussion.

We would recommend that NHS England and Improvement establishes a register of CESSs in their various forms. It is important to capture the number and range of services in order to enhance consistency and to facilitate quality evaluations. A formal register would enhance transparency and awareness amongst clinicians whilst enabling emerging services to choose relevant features from the various models that best suit their services. Results also highlight a need for additional research to better understand the effectiveness of CESS forms, connections, guidance, services, and modes of working; and for better support to enhance consistency, transparency, communication with patients and availability to clinical staff.

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