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Ideas that change health and care

Independent Care (Education) and Treatment Reviews

Views of commissioners and clinicians

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About this report

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1 Background

Independent Care (Education) and Treatment Reviews

In November 2019, the Secretary of State for Health and Social Care announced that all people with a learning disability or autistic people in long-term segregation in inpatient settings were to have their care independently reviewed.

This led to the creation of Independent Care (Education) and Treatment Reviews (IC(E)TRs). Their purpose was to provide independent scrutiny and review of the current situation of the person in long-term segregation, both to ensure that the person was safe and to generate clear, feasible and implementable recommendations that focused on improving their care, treatment, and discharge plan.

To deliver the reviews, the IC(E)TR programme was jointly developed at pace by the Department of Health and Social Care (DHSC), NHS England and the Care Quality Commission (CQC). The programme built on (and sat alongside) the existing programme of Care (Education) and Treatment Reviews (C(E)TRs) (NHS England 2023) but introduced the roles of an independent chair (appointed by DHSC) and a Mental Health Act reviewer (appointed by the CQC). Independent chairs came from a variety of backgrounds but, as well as wider qualities, all had to demonstrate experience in both community-based support and inpatient settings for autistic people and people with a learning disability.

An independent Oversight Panel, chaired by Baroness Sheila Hollins, was established to oversee the case reviews.

The first phase of IC(E)TRs began in November 2019 and ended in June 2020, when 77 had been completed. The second phase began in November 2021. By 31 December 2022 (when this research concluded), a total of 169 IC(E)TRs had been carried out. A thematic review of 26 of the first 77 IC(E)TRs was carried out by Alicia Wood and Baroness Hollins, and published in July 2021 (Department of Health and Social Care 2021).

IC(E)TRs take place for people in a range of inpatient settings, including the NHS or independent care provider hospitals, Child and Adolescent Mental Health Services (CAMHS) or adult mental health services, non-secure or forensic mental health units, and learning disability specialist settings.

As well as the independent chair and Mental Health Act reviewer, the review panels include the commissioner of the patient's services, an expert by experience (someone with lived experience of having a learning disability or autism, or a family carer) and a clinical expert. Other attendees of the IC(E)TR meetings that we heard about in our research included the patient, members of their clinical team, family members, social care commissioners, administrators and solicitors.

IC(E)TR meetings take place over a day, at the hospital where the patient is staying (though some IC(E)TRs took place virtually during the Covid-19 pandemic). The process is intended to involve visiting and/or talking with the patient as well as talking with their care team, and also the patient's family, carer or a mental health advocate. The patient's care is discussed and recommendations made that are intended to help the care team move the patient back into community care. The review also involves looking at patient records and care plans, policies and other key documents.

The recommendations made by the panel are then shared with the patient and their family as well as with the care team. It is the responsibility of the NHS care commissioner to ensure that the recommendations made are followed up.

About this research

In February 2021, the Department of Health and Social Care commissioned The King's Fund to carry out a process evaluation of the operation of IC(E)TRs. At the time, IC(E)TRs had been paused because of Covid-19 but the intention was to restart them in June 2021. The research was commissioned to take the opportunity provided by the pause in IC(E)TRs to consider what, if any, improvements might be made to the process before they resumed. By February 2021, a total of 77 IC(E)TRs had been conducted, 36 of which had been carried out virtually due to Covid-19 restrictions.

This was subsequently honed down to a focus on the IC(E)TR process: participants' views of their purpose and experience of their planning, delivery and recommendations (*see* 'Research methodology' section).

Research was focused on commissioners and responsible clinicians since these were the groups about which the Department of Health and Social Care had least information with respect to IC(E)TRs.

It was also intended to include the views of patients and family members in the research. Initially, it was intended that these views would be gained through research by the CQC, but it subsequently withdrew its plans to do so, and The King's Fund agreed to carry out the work instead. However, this part of the research was not completed. We made extensive efforts to recruit patients and family members (*see* appendix 3) to the research but these were not successful; a key perspective is therefore missing from any evaluation of IC(E)TRs.

2 Research methodology

For the research with clinicians and commissioners, The King's Fund planned that:

- Semi-structured interviews, lasting up to 60 minutes, would be carried out with 16–20 participants (clinicians and commissioners), online using MS Teams.
- Interview schedules would include questions designed to explore participants' experiences of IC(E)TRs, focusing on three stages of their process of delivery: planning for and scheduling the review panel; delivery of the IC(E)TR on the day (either online or on site); and delivery and receipt of the recommendations for the patient generated during the IC(E)TR.
- The schedule would seek to identify what worked well and what worked less well from the perspective of commissioners and providers, and what changes they would like to see to improve the process, both for panel members and for the patient.

(For the full interview schedule, *see* appendix 1.)

The research project was reviewed by the Chair of the University of York's Health Sciences Research Governance Committee, who agreed that it was a service evaluation and therefore did not require additional ethical review. Research and development (R&D) departments at NHS hospital sites or senior members of employing organisations were contacted to gain approval before recruiting participants.

NHS England provided a randomly sampled list of commissioners and clinicians from across a specified range of settings (adult/CAMHS, NHS/independent, secure/non-secure). It included only those who had had a patient who had received an IC(E)TR.

The first wave of the research, with commissioners and clinicians, began in October 2021 and was completed in December 2022. Recruitment of commissioners, and particularly clinicians, proved more difficult than expected due to a range of factors. These included (but were not limited to) the following: lack of responsiveness

when seeking approval from employing departments; staff absences/short-staffing; limited replies from eligible individuals once site approval had been gained; and uncertainty on the part of some individuals about whether they had taken part in an IC(E)TR. We successfully completed interviews with 10 commissioners and 7 clinicians, who between them had taken part in at least 36 IC(E)TRs. The interviews generated around 17 hours of transcribed material.

Commissioners and clinicians had taken part in IC(E)TRs involving a range of providers, patient types, levels of security and modes of delivery, and had been involved in both virtual and face-to-face IC(E)TRs (a full table of participant details is available in appendix 2).

Research limitations

Limitations of our research include the following:

- The sample was restricted to those clinicians and commissioners who were willing to talk with us, so some views and experiences may not be represented. We did not talk to any commissioners or clinicians who saw themselves as providing inadequate care for their patients or who felt they were themselves responsible for the failure to move a patient out of long-term segregation and, ultimately, into the community. However, the evidence from the thematic review suggests such commissioners and clinicians exist (Hollins 2020).
- We were recording only the *perceptions* of commissioners and clinicians. We had no way of comparing these with the 'reality' of individual IC(E)TRs. If, for example, a commissioner told us that a panel member took little part in a meeting, we were not able to verify that from other sources. Individuals sometimes contradicted themselves during interviews (ie, their memory or perception of an IC(E)TR changed during the course of the interview).
- Perceptions varied *between* the individuals that we interviewed; some had had very different experiences from others. It is not possible for us to clearly identify factors that might account for differences of view since the sample size was relatively small. Although we have attempted to note in the findings where only commissioners or only clinicians converged on certain themes, it appears that this was predominantly due to their different roles within IC(E)TRs.

Change over time

Participants had taken part in IC(E)TRs that took place over a long period, from some of the very first IC(E)TRs (in winter 2019/20) to those that took place as late as autumn 2022. Participants noted several changes to the IC(E)TR process, or the wider environment affecting that process, over time. These included the major, obvious changes caused by the Covid-19 pandemic, which brought about a temporary move to virtual IC(E)TRs, and other changes, such as the introduction of a pre-meeting between the chair and other IC(E)TR panel members.

It was not possible for us to identify whether the date of an IC(E)TR was a significant factor in participants' perceptions of it. However, where participants had been engaged with IC(E)TRs over time, some of them described how the process had improved. When considering criticisms of the process by interviewees, it is worth bearing in mind that some of those criticisms relate to issues at a given point in time, which may have subsequently improved.

Some examples of this included: being given more notice of an IC(E)TR than when they were first introduced (weeks, rather than – in some cases – days); greater clarity about who to invite to the meeting and a better attendance rate for the key participants; and greater familiarity with the process, resulting in clearer delineations of roles and responsibilities on the part of the individuals involved.

We include in each section a note about whether participants' views about specific aspects of IC(E)TRs appear to have improved over time, and we indicate whether they were involved in the first and/or second phases of IC(E)TRs.

3 Findings: participants' understanding of the purpose and value of IC(E)TRs

In our interviews, we asked: 'Can you tell me in your own words what you think is the purpose of the IC(E)TR process?' We found that participants did not have a common understanding of this, or of the potential value of IC(E)TRs and whether this was being achieved. This lack of clarity about purpose is important because it affects – and may well underpin – other concerns we heard about IC(E)TRs. These include: uncertainty about the relationship between the IC(E)TR and regular Care (Education) and Treatment Review (C(E)TR) meetings; unrealised expectations of the independent chair and NHS England in terms of ongoing support; uncertainty about the role of commissioners post-IC(E)TR; and lack of clarity about the respective roles of panel members.

We expand on these themes throughout this report.

Understanding of the purpose of IC(E)TRs among commissioners and clinicians

Not all participants were clear about the rationale and purpose of the IC(E)TR process. There was a wide, though not necessarily universal, perception that IC(E)TRs involved a degree of independent oversight of the patient's care, and that IC(E)TRs involved patients in long-term segregation.

The presence of an independent chair was also recognised. However, not all participants saw the presence of an independent chair as evidence that the IC(E)TR was a 'step up' from a normal C(E)TR, and there was confusion about the relationship and difference between C(E)TRs and IC(E)TRs (*see* subsequent sections).

There was also a lack of clarity about the definition of long-term segregation used for the IC(E)TR process, with some participants suggesting that the definition used

is not appropriate for patients who prefer to be separate but can still interact in a variety of ways with other patients or those in single occupancy settings. This could lead to confusion, particularly if it was not understood that IC(E)TRs were *only* for people in long-term segregation:

> *It felt like I was getting told I was doing something wrong and I must do something right and whatever. And I didn't understand, you know, because I was following all the policies. And like I said, I think that could have been avoided if it was made clear what the purpose was and if they'd said about long-term segregation…*
> (Clinician 78811, phase 1, 1 IC(E)TR, face-to-face)

Participants also told us that there was a difference between the definitions of long-term segregation used by NHS England and the Mental Health Act, which could cause confusion and anxiety. There was also a lack of clarity about the specific goals of IC(E)TRs. Two potentially contradictory perceptions were often expressed: that IC(E)TRs were intended to check that an individual was safe and receiving an effective service; and that IC(E)TRs were intended to be a catalyst for change, to unblock problems and re-energise a process that might have become stuck, preventing the patient from returning to the community. In practice, participants frequently said that the IC(E)TR process felt like it had 'validated' the care they were providing to individuals, even if they did not necessarily see this as its intended purpose. In fact, some participants had expected to be heavily scrutinised and perhaps criticised by the IC(E)TR.

Understanding the perceived value of IC(E)TRs among commissioners and clinicians

Commissioners and clinicians perceived several potential values of IC(E)TRs, as follows.

- The specific focus on patients who are 'stuck' in the system, with the aim of coming up with new solutions that had not previously been considered.
- The additional 'clout' relative to the C(E)TR process that the special nature of the IC(E)TR could provide to ensure that there was wider commitment to acting on its recommendations.
- The added value in terms of the extra expertise that IC(E)TRs are able to draw on (eg, Mental Health Act reviewer).

In practice, however, most interviewees did not feel that these benefits were being fully achieved and some felt there was little if any real value or benefit to the IC(E)TR process. Some participants said that this was due to the lack of follow-through for IC(E)TR recommendations and/or the lack of resources available to progress them.

There was a lack of clarity among participants about the relationship between C(E)TRs and IC(E)TRs, with some feeling that there was too much duplication, especially for people with particularly complex circumstances. It was felt that the recommendations were frequently the same, and that responsibility for implementing the recommendations remained with the C(E)TR, not the IC(E)TR.

> *I did think it was duplication and I think they would have probably got a lot more out of actually attending our C(E)TR and maybe watching and listening to the way we worked together and how we do things, which would have helped them to have that additional assurance around our action plans and the details of our action plans because they would have been able to see it in action. I think that might have helped them to maybe answer queries, get that extra assurance and maybe targeting on areas that they had any particular concerns around.*
> (Commissioner 71245, phase 1, 1 IC(E)TR, face-to-face)

Some participants also questioned whether IC(E)TRs were suitable for some patients, such as those who were awaiting transfer to high-security settings.

Participants' suggestions for improving the purpose and value of IC(E)TRs

Some people questioned whether there was a need for a separate IC(E)TR meeting and suggested that a scheduled C(E)TR should instead be adapted.

However, in contrast, one participant suggested that *all* C(E)TRs should become IC(E)TRs to ensure that there is no more 'reviewing own homework' by those involved in C(E)TRs.

One participant suggested that the IC(E)TR should focus on priority issues rather than going back over what was already known.

> *I think maybe it's about what's the priority for the day as to why the IC(E)TR's been requested, so if the issue isn't about the hospital per se, if the issue isn't about*

> *CAMHS, for example, but the issue is about social care, then in my mind I'd be saying, 'well, actually, agenda needs to be half the day with the local authority finding the resolution, and maybe a quarter about the hospital and a quarter about CAMHS', very simplistically if that makes sense. I think if we're going to get the essence of why we've got to that stage, then let's focus the day on what the issue is that needs resolving, let's not just go back over what we already know.*
> (Commissioner 73358, phases 1 and 2, 2 IC(E)TRs, face-to-face and virtual)

Further clarity over definitions of long-term segregation ahead of the meeting were also suggested, in order to prevent disagreements and confusion around eligibility of patients.

4 Findings: perceptions of the panel and other IC(E)TR attendees

Overview

We asked participants whether members of the panel had a good understanding of their roles (*see* 'Interview schedule', appendix 1) and sufficient knowledge and understanding of the specific circumstances of the patient who was the subject of the IC(E)TR. We prompted specifically about the difference made by the independent chair and the Mental Health Act reviewer, since these two roles were not involved in C(E)TRs.

Generally, participants felt that there was logic and potential value to the involvement of all of the panellists in IC(E)TRs and a sense that everyone – including other IC(E)TR attendees (and including family members) – could have an important role to play. However, this was not always demonstrated in the delivery of the IC(E)TRs that participants attended.

The role of the independent chair

There were mixed views on the importance of the role of the independent chair. Some participants could see the value of fresh eyes and a different voice. They thought that the chair could – in theory at least – apply more pressure for change, provide extra scrutiny, and could validate existing plans.

Some participants appreciated the specific experience or expertise of the chair because it meant (for example) that a chair who was a psychiatrist could pose good challenges to the clinical team. Some participants also highlighted the potential value of appointing an independent chair with specialist knowledge of the specific circumstances of the patient in question.

The perceived value of the independent chair, and the extent of challenge that would be accepted by participants, could depend on the chair's ability to run the meeting. This in turn could depend on the chair's ability to manage the quite complex emotions that could be present. One clinician said that whether or not teams felt like they were 'being done to' depended on the skill of the independent chair, and that teams did not mind a 'pummelling' if they felt they were getting something out of it for the patient afterwards.

Participants described a good independent chair as someone who was perceived as helping teams to 'see the direction of travel' and was not begrudged for pointing out things teams may have missed, although they may make the team frustrated with themselves for not noticing it. A good independent chair was also someone who had made an effort to speak with family members who were unable to attend the IC(E)TR. Other participants said that the presence of an independent chair was good to prevent teams from becoming 'too cosy'. Another clinician suggested that the independent chair role was helpful in terms of adding extra weight and further scrutiny to back up the recommendations made.

However, some participants felt that the role of the independent chair added little to the process. They said that the chair may have limited knowledge of the patient and limited knowledge of the local context, and was not involved in the follow-up to recommendations. Some participants criticised the preparedness and/or skills of the chair in a meeting they had attended.

> *I believe that [the independent chair] didn't [read the material before the meeting]. And I think maybe it was because of the short notice themselves, that they probably weren't as well prepared as what they could have been, because certainly in my feedback that I sent to the chair, I attached a copy of the letter that had come from the national team about what had been recommended. Because personally I don't feel that they'd seen it or taken it on board.*
> (Commissioner)

There are some indications from our research that the effectiveness of independent chairs improved over time. Some participants felt that the preparedness of chairs, the quality of discussion and the overall management of meetings improved as the IC(E)TR process progressed.

Some participants also expressed positive views about pre-meetings with the chair, which took place before some IC(E)TRs. One participant said the pre-meet helped build rapport and made 'a massive difference' to the clinicians in terms of expectations for the IC(E)TR. It also prompted greater openness and engagement with the IC(E)TR from the team, as well as making one clinician give more credence and value to the views of the independent chair.

The Mental Health Act reviewer

There were fewer clear views about the role of the Mental Health Act reviewer, with participants less likely to recall the reviewer's contribution to, or describe the role they played within, the IC(E)TR. This appeared to be associated with the perception that the reviewer had provided limited input and/or had limited impact compared with other panel members. However, several participants understood and valued the specific skills and experience of the Mental Health Act reviewer and their focus on the legality of care, with an acknowledgement that the presence of this expertise helped differentiate IC(E)TRs from C(E)TRs. Participants cited at least three areas of value added by the Mental Health Act reviewer:

- Identifying if there was something wrong with the care being provided.
- Alternatively, reassuring staff that care was in fact taking place in accordance with the Mental Health Act.
- Challenging clinicians on whether long-term segregation was justified and, if so, how it was being applied.

The commissioner

The formation of the panel raised questions for some participants, including commissioners themselves, about the role within IC(E)TRs of commissioners, who would normally chair C(E)TRs. Some commissioners understood their role in organising IC(E)TRs and providing information about the patient during the meeting, and also their responsibility for acting on the IC(E)TRs recommendations. By contrast, some clinicians seemed unaware that commissioners were responsible for receiving and then circulating recommendations to the wider clinical teams.

However, some commissioners felt that their role in the IC(E)TR was unclear and their contributions were not sufficiently valued by the independent chair.

> *I suppose I didn't really know what my role would be. So if I was leading the conversation, I was shut down quite quickly. And so, of course, then when you're used to having to have difficult conversations, then it's almost like you're not understanding what's happening, so you end up almost butting heads in a way.*
> (Commissioner 73795, phase 1, 1 IC(E)TR, virtual)

> *It irritates me if I don't get asked, because I think if you don't know your patients, then what's the point in doing… what's the point in doing your job. So I do know them reasonably well, so I feel like I can give a level of detail and I tend to have a view about what's stuck or what isn't stuck or what might work well and what might not.*
> (Commissioner 69574, phases 1 and 2, 3 IC(E)TRs, face-to-face and virtual)

Some commissioners in particular expressed a feeling of being 'done to' by the IC(E)TR. This was in contrast to the C(E)TR, for which commissioners tended to have greater oversight of the process. There were several factors behind these views: the initial communication and non-negotiability of meeting times; and participants' fears or expectations that they would come under scrutiny and/or not be trusted. Some participants gave examples of being undermined and cut out of meetings.

> *Once we got into that meeting, that virtual meeting, myself and [colleague's name] weren't included in those conversations. It was quite clear from the chair that they didn't want us initially as part of those conversations when we were trying to explain about what the purpose of it was… So we kept trying to explain about that. They were quite negative about… or quite dismissive, not negative, quite dismissive to myself and [colleague's name].*
> (Commissioner 73795, phase 1, 1 IC(E)TR, virtual)

We heard less from participants about other panel members and IC(E)TR attendees but we describe some of the opinions that were expressed about those other roles below.

The Expert by Experience

There were some positive comments about experts by experience. One participant observed that they bring value by asking 'unprofessional questions' that clinicians cannot. Another said that the expert by experience had a good understanding of their role and 'really good insight and knowledge', but could have been better matched to the patient in question. Another said that experts by experience could bring continuity but could also be perceived as a 'lone voice'.

The clinical team

We heard much more about the role of the wider clinical team than about the specific clinical expert on the IC(E)TR panel, though there was recognition that the clinical expert was present and contributed. Participants told us that various members of the clinical team contributed to the IC(E)TR on the day to explain the patient's case history and future plans. One commissioner felt that the clinical team (and community teams) 'know the patient inside out'. Another commissioner felt it important that the multidisciplinary team (MDT) was present because in their experience, an IC(E)TR without full engagement of the MDT was not as effective and could be perceived by the panel as 'hiding something' or evidence of a 'closed culture'. There were mixed views about how effective IC(E)TRs were in getting full attendance by the MDT and the extent to which clinicians' availability was prioritised when organising an IC(E)TR.

Patients

Participants recognised that not all patients would be able to take part in an IC(E)TR but felt that it was 'crucial' for panellists to at least see the patient's care setting. It was recognised that this was more difficult where an IC(E)TR took place virtually, but one clinician was disappointed that the IC(E)TR panellists had not even taken a virtual tour of the patient's environment.

It was recognised that there needs to be particular flexibility about the involvement of patients in the IC(E)TR. One commissioner suggested that the panel should have contact with the patient before the IC(E)TR to determine how best to do this. Another participant felt it might be important for panellists to speak with patients without the commissioner present, if the patient did not feel supported by the commissioner.

Family members

Participants felt strongly that it was important to involve the patient's family members in an IC(E)TR but cited several instances where the setting up of the IC(E)TR made it difficult for this to happen in practice. One clinician described 'pushing back' on a request for an IC(E)TR at 72 hours' notice because the family would not be given sufficient time to attend. A commissioner described a family member being given one day's notice to attend, resulting in their presence being only by telephone and the call being cut off.

It was acknowledged, however, that involvement of families may vary, and that in some cases, even if attempts were made to reach out to them, they may choose not to input to the IC(E)TR.

Participants' suggestions for improving the role of the panel and its members

While some participants saw the value of the panel's independence, there were some doubts about the need for a completely separate panel as well as C(E)TRs. Some participants also wanted more advance information about the panel members to better understand the role they played within the IC(E)TR process, and to understand when it might be appropriate to provide panellists with more information. Having a better understanding of the knowledge and experience of panellists gave clinicians and commissioners more confidence in their recommendations.

Many participants felt it would be valuable for the independent chair to have more expertise in some areas. Some called for improved knowledge about learning disability and autism, local services, current practice norms, and suggested that experience should be matched to the individual patient.

One additional suggestion was that experts by experience should ideally be ex-patients rather than family members where possible, and again their experience should be matched to that of the patient who is the subject of the IC(E)TR.

Finally, one clinician suggested that if a patient were to have more than one IC(E)TR, panellists should be consistent between meetings to provide continuity for the patient and their family, to improve panellists' understanding of the patient and their situation, and encourage better ownership of actions following the meetings.

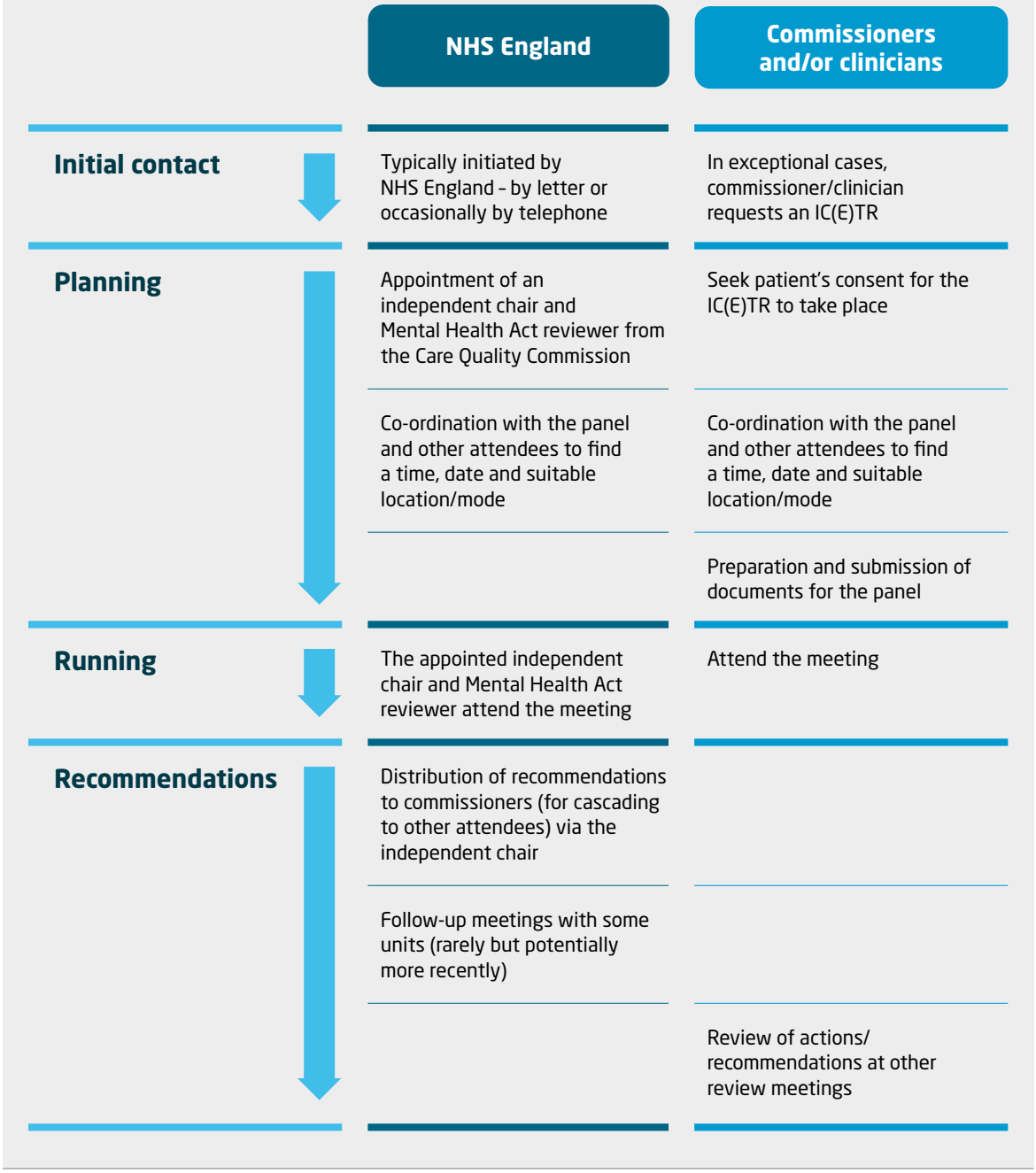
5 Findings: perceptions of how IC(E)TRs were organised

Overview

Participants expressed their views about the different stages of the IC(E)TR process, which is set out in Figure 1. Note that this figure represents a composite picture of the IC(E)TR process, drawing on many different participants' understandings of it, rather than a description of how all IC(E)TRs were intended to be.

In this section of the report, we focus on the planning and running of IC(E)TRs, and potential improvements to those stages. We also touch on some findings about the initiation of the IC(E)TR process. We also explore the recommendations stage of the IC(E)TR process and report on participants' views of the timeliness and appropriateness of recommendations, as well as the extent to which recommendations were thought to be implementable.

Figure 1 The IC(E)TR process according to commissioners and clinicians



Planning of IC(E)TRs

Where planning worked well, the reasons for this included the following.

- Participants felt that sufficient notice had been given for the IC(E)TR, with a lead-in time of between two and four weeks.
- Sometimes panel members were able to negotiate the date and time of the IC(E)TR depending on their availability or that of other attendees.
- There was a central/named point of contact at NHS England to co-ordinate finding a convenient date and time for the meeting.
- The IC(E)TR subsumed another existing review meeting such as a C(E)TR, which already has its own process for planning/setting up.
- In some cases, there was an administrator within a clinician's or commissioner's team who would typically liaise with panel members to ensure their attendance and book meeting rooms in the same way as they would for a C(E)TR.
- Panel members had spoken to the patient's family to make sure that they understood what to expect from the meeting on the day.
- Patient information was circulated by the site to assist with preparation for the meeting a few days or a week before the IC(E)TR took place.
- Fairly commonly, and more so over time, there was a pre-meeting with (or at the very least a conversation between) the independent chair and other panellists/attendees in advance of the meeting. This provided an opportunity to share opinions with the chair and provide relevant context to explain the decisions that had been made about the patient's care.

However, there was a great deal of negative feedback from participants about the planning of IC(E)TRs, particularly when they were first introduced. The most common complaint at this stage of the process was the lack of notice for when an IC(E)TR would take place. Participants felt 'imposed upon' by having to prepare for meetings at short notice and, in some cases, having no flexibility on dates. Some participants felt intimidated by the tone of initial communications from NHS England and felt unable to question or challenge the timing of the meeting.

> *Basically what I got was an email from NHS England or whoever it was at the time who was sending them out, saying, 'this is the date that's booked, this is what's going to happen, you need to get a panel, you need to get the documentation', et cetera, et cetera, et cetera, basically get on with it. And I just did.*
> (Commissioner 68976, phase 1, 2 IC(E)TRs, virtual)

There was concern about a lack of clarity about responsibilities, including extending invitations to the patient's family members and carers. There was also concern about the additional resource requirement that organising an IC(E)TR places on commissioners. The sheer co-ordination required in arranging meetings for 20 or more participants was frequently raised and described as a 'logistical nightmare'. Where there was flexibility on dates, this was compounded by the need to find one that was suitable for all participants:

> *To some extent, it has got better but it still is problematic in the sense of, you know, finding a date, agreeing that date with the person who's having the IC(E)TR, their family or carers, friends that might want to come to that meeting, the clinical team that's responsible, community providers that will be responsible for that person on discharge, local authority colleagues, the case manager that is the inpatient case manager from NHS England or the provider collaborative now. Along then with finding a panel, so the clinical reviewer and the expert by experience. Doing all that and then sending it to the Department of Health and Social Care to be told that they can't get a chair for that day.*
> (Commissioner 74733, phases 1 and 2, 3 IC(E)TRs, face-to-face, virtual and hybrid)

Where participants had been given just a few days to pull the meeting together, this felt like too tall an order and led to some of the trade-offs about whose attendance was prioritised. In these circumstances it was easy for the participation of some groups – notably the patient's family – to be sidelined:

> *I actually had multiple calls with the family before the day to explain, to go through, help them understand, enable them, work through what they wanted to bring, and I felt confident they understood what it was about, but I guess if I hadn't have done that, I don't know who would have done. Is that my role? I don't know.*
> (Commissioner)

At its worst, the barriers in organising the IC(E)TR could lead to a preoccupation with process rather than the original intention behind the IC(E)TR – specifically, to ask questions about what the patient and/or their family wants to happen:

> *I think those key members need to be there, but there is something about… My experience is that they're not personalised enough, they're not front-ended enough with what does the young person want, what does their family want? And that's supposed to be the point.*
> (Clinician 70091, phases 1 and 2, 2 IC(E)TRs, virtual and hybrid)

Running an IC(E)TR

In contrast to the planning phase of the IC(E)TR, participants tended to speak much more positively about the running of the meeting on the day. Where it went well, participants noted the following factors:

- Participants felt 'listened to' and validated; panel members were 'approachable', acknowledged the complexities and difficulties of the case of the patient, and commended examples of good-quality care.
- A sense among participants that the meeting presented the opportunity to have a joined-up conversation centred around the outcomes for the patient rather than 'finger-pointing' and 'picking holes' in care plans.
- Confidence that the discussion was thorough and comprehensive (and sometimes long), indicating the commitment of all concerned to the importance of the meeting and its outcomes.
- The potential for the meeting, as part of the wider IC(E)TR process, to bring specialist skills and knowledge, cut through to the most important/relevant questions fairly quickly, provide an opportunity for panel members to visit the patient/facility in person, and bring in the voices of other attendees such as family members. Some participants questioned the effectiveness of virtual IC(E)TRs because seeing the patient's environment was considered to be core to the purpose of the meeting.

The main problems experienced by commissioners and clinicians in the running of IC(E)TRs were as follows:

- Key members of the panel were not in attendance, perhaps because of short notice, poor communication or lack of understanding of the importance of the IC(E)TR.

  I think, from what… again, from memory, the first meeting that was scheduled it didn't actually have the right panel members there. And again, I think something was lost, in terms of who would organise them because again, who is… except for a normal C(E)TR, that would be organised… It's down to us, we would come as an MDT [multidisciplinary team], but we wouldn't source the panel members, but I think they were wanting a commissioner to source the panel members. And it got complex, I think, with so many people involved. So, I think certainly co-ordination of it could have been a lot better. 'Cause, like I say, it resulted in the first meeting not being able to go ahead.
  (Clinician 70233, phase 1, 1 IC(E)TR, virtual)

However, as with the role of the independent chairs, there is some indication that participants felt attendance at IC(E)TRs improved over time, with key members more likely to be in attendance.

Other problems raised by some participants included the following:

- The challenge of entirely virtual meetings, particularly where the chair and panel lacked first-hand experience of the patient's living environment. For some participants, this point was related to the independent chair's lack of knowledge and understanding of a patient's situation and local 'politics', which led to long and 'formulaic' conversations to help enhance their understanding without advancing the conversation. Later, and as the independent chairs were perceived to be better prepared for meetings, it was felt that they 'cut to the chase' more quickly.
- Over-long or poorly managed meetings. One participant described a meeting starting two hours late; another referred to inappropriate jokes and attempts at humour, while a third described a panellist 'rolling their eyes' while the clinical team spoke. One participant described inappropriate reasons being given by some panellists for leaving the meeting early, including for a hairdresser's appointment.

Again, however, there was some indication that the quality of discussion and overall management of IC(E)TRs improved over time.

Participants noted the vital role of the independent chair in managing such a complex meeting. However, as referenced in the section 'Findings: perceptions of the panel and other IC(E)TR attendees', not all chairs were viewed as having the skills required, including setting and keeping to an agenda, asking the most relevant questions, and managing time well.

Participants' suggestions for improving how IC(E)TRs are organised

Participants suggested a number of different, sometimes contradictory ways in which the structure of IC(E)TRs could be adapted to make them most effective.

The timing/frequency of IC(E)TRs

- IC(E)TRs should be scheduled to be more responsive to changes in the patient's situation and to significant stages in the patient's care.
- For children and adolescents in particular, it was suggested that the frequency of IC(E)TRs be increased, as it was perceived that the time that passes between meetings is a 'large chunk of time for a young person'.
- Some clinicians also voiced a desire to be able to request an IC(E)TR as needed, to avoid repetition.

The planning of IC(E)TRs

For planning to work well, participants suggested it should involve the following:

- Sufficient notice being given for the IC(E)TR to take place, typically between two and four weeks.
- Ensuring that the date, time and format of the meeting is as accessible as possible for the patient and family members.
- Clearer information about what panellists expect from the meeting and the roles of the various attendees, to allow for better preparation at a local level.

- A pre-meeting or contact with the independent chair and others in advance of the IC(E)TR.

  I had a pre-IC(E)TR meeting with three of the panel… just to kind of give them a bit of an overview of the patient. So, that was really useful, so that they had my opinions, clinical opinions around this patient's needs, and where I see her in the future, hopefully in the near future. I shared emails around [name of housing organisation] that's working with the provider, so they're trying to get her out. Because this is a patient that's been served notice, as well, from [medical site], so obviously the team are anxious to get it right, and to get it right for her.
  (Commissioner)

- Being patient-centred and considerate of family and carers, understanding that family members often work and need adequate notice to attend.

  But it just feels very unfair that you've not taken account of the fact that people work. We can't just go at the drop of a hat… And it's always the case that we don't step back and think [that the family members] work… We should be courteous enough to give adequate notice. They've got employers.
  (Commissioner 68974, phase 1, at least 1 IC(E)TR, face-to-face)

  I think we expect families to go to lots of meetings and participate in lots of meetings and share their views, so I think it is about preparation work sometimes with lots of meetings that I just don't think families get enough support with or thinking about.
  (Commissioner 73358, phases 1 and 2, 2 IC(E)TRs, face-to-face and virtual)

- Managing the tension between inclusivity and practicality, particularly the balance between the sheer volume of potential participants, the logistics of meeting size, and the needs of the patient and their family.
- Some flexibility on dates and timings of IC(E)TRs to ensure that participants are able to be present and to avoid disruption to a patient's routine.
- A named, local administrator to co-ordinate with NHS England, liaise with panel members and sort out logistics such as booking of meeting rooms.

The running of IC(E)TRs

- There should be administrative support for the independent chair (for example, a note-taker).
- IC(E)TRs should be conducted in person, for the benefit of the patient, to ensure that the independent chair gets a feel for the patient's environment and to ensure buy-in from key attendees.

6 Findings: perceptions of the recommendations made by IC(E)TRs

A fundamental paradox in participants' views of IC(E)TRs was that while the content of the written recommendations was generally seen positively, when we asked whether they were 'implementable', there was often doubt as to whether they would make any difference to the patient. We discuss this further in this section.

> *I do [feel that the recommendations took into account the specific circumstances of the patient]. What [they] won't do though I suppose is make the placement available necessarily any quicker.*
> (Commissioner 69574, phases 1 and 2, 3 IC(E)TRs, face-to-face and virtual)

Timeliness and appropriateness of the recommendations

Most participants said that they felt the recommendations from the IC(E)TRs they had attended were thorough and appropriate. They felt that the recommendations acknowledged and reflected the complexities of the patient's case, and that they were tailored to the patient and were 'person-centred'.

The recommendations from an IC(E)TR were generally seen as being similar to those generated by a C(E)TR. For many participants, this was positive, with some saying that it was helpful that the recommendations supported the care they were providing, and that this came from an independent and authoritative source.

> *So it's helpful to have backing of someone external to say, 'no, the decision for the service user is correct, it's been looked at by a national panel and they do not feel he can – well, they are supportive of our current care plan for him'.*
> (Clinician 73762, phase 1, 1 IC(E)TR, virtual)

Other participants found the recommendations helpful because, while similar to the C(E)TR, they were more stretching.

Some found it helpful to have the recommendations as a way of 'escalating' longstanding challenges with moving patients out of long-term segregation into other settings locally:

> *They were implementable, yes. Like I say, there was some wishes for things to be resolved that were out of our control, but I was happy for them to stay on, because they are things that we had recommended anyway, that I had been trying to escalate… And it's only through those knowing that they're outstanding actions that sometimes things get done.*
> (Commissioner 68976, phase 1, 2 IC(E)TRs, virtual)

In general, participants recalled that the recommendations included timescales for completion of the required actions and allocated those actions to specific individuals.

Some participants said they felt that the recommendations from the IC(E)TR had been shared with them in a timely fashion, though others said it took four or more weeks. The recommendations were sometimes shared with everyone responsible for a stipulated action and on other occasions just with the commissioner who would then cascade the recommendations to others as appropriate.

However, there were also concerns about the appropriateness of the recommendations. One complaint was that they did not always reflect the content of the IC(E)TR or the context of the patient in question. Some participants described factual inaccuracies in the Key Lines of Enquiry (KLOE) document and recommendations. For example, one participant described how a report included the recommendation that a care co-ordinator should be appointed to work with a patient when the patient's existing care co-ordinator had in fact been present for the meeting.

In other cases, the recommendations were not felt to be appropriate or fair because, due to Covid-19 restrictions and meetings taking place virtually, the IC(E)TR panel members had not visited the site or the patient in question.

> *We got the recommendations and we disagreed with them because they'd founded them on the fact that they'd never seen the environment.*
> (Clinician 74139, phases 1 and 2, up to 20 IC(E)TRs, face-to-face, virtual and hybrid)

Finally, some participants mentioned recommendations that seemed to be 'churned out' without a shared understanding of why they were necessary or important – for example, the recommendation that a clinical team complete a 'communication passport' for a patient despite them stating that they had already undertaken extensive communication assessments with the patient in question.

> *It has not helped one iota in moving the patient on, but we've done it because it was a recommendation.*
> (Clinician 70091, phases 1 and 2, 2 IC(E)TRs, virtual and hybrid)

Some participants said that they found the recommendations of the IC(E)TR they attended to be harsh and judgemental; that the implication of some of the recommendations was that they were not doing their job properly, leaving them feeling personally attacked in some cases.

Another complaint made about the recommendations by one participant (a commissioner) was that they were not accessible or written in language that would be meaningful to the patient.

Implementing the recommendations

Participants cited some instances where the recommendations had made a difference to the patient. In one case, it brought the community team and social care 'onto the same page with discharge planning'. In another, the IC(E)TR recommendations led to clarification about a patient's long-term segregation status and gave the participant reassurance that they were delivering care in line with the Mental Health Act.

However, many participants raised concerns about difficulties in implementing the recommendations for patients.

> *It's just like this stop, done, that's… we're finished. And actually, you know, for the person that had theirs in October, November last year, that person's still in segregation. So it's going back to the original thing and not just IC(E)TRs but C(E)TRs in general, what did it change, what did it make better? It's validated the circumstances but in terms of pushing things forward or putting pressure on a system to find a solution for someone, it's not done that.*
> (Commissioner 74733, phases 1 and 2, 3 IC(E)TRs, face-to-face, virtual and hybrid)

Some participants believed there was a lack of accountability on the part of the key people involved in a patient's care to deliver the recommendations beyond the IC(E)TR meeting. Commissioners acknowledged that they have a role to play in chasing up the recommendations and seeking progress updates from those tasked with various actions. One said it was 'our responsibility as commissioners' to take ownership of the recommendations and hold others responsible for the actions assigned to them (commissioner, phase 1, 3 IC(E)TRs, face-to-face and virtual).

However, another commissioner said they felt relatively powerless to do anything about it if they got no response when chasing up.

> *I monitor, I push, I ask questions, but I'm way down in the pecking order of telling an executive director what they need to do, they're not going to listen to me.*
> (Commissioner)

The infrequency of IC(E)TR meetings and the absence of a specific follow-up meeting was felt to compound this lack of accountability and progress in delivering the recommendations.

Participants tended to have varying views on where accountability for acting on the recommendations sits. Some believed there was a requirement to provide regular updates on how the recommendations were being implemented to NHS England (especially in the case of more recent IC(E)TRs) and said that this added some impetus to the need to take action on the recommendations.

There were mixed views and experiences about the role of the C(E)TR and other review meetings in embedding the IC(E)TR recommendations. Some participants said they expected that the recommendations would be reviewed in the ongoing C(E)TR meetings although, as one participant put it, there remained some uncertainty about whether or not this was the 'correct' process.

There was a sense among some participants that they did not feel any ownership of the recommendations and would not be held to account for implementing them:

> *So they're not your findings and recommendations but you then take ownership of them findings and recommendations, following them up and ensuring that there's an outcome. They don't generally then come back and check that it's happened.*
> (Commissioner)

There seemed to be a hope or an expectation among some participants that the IC(E)TR recommendations would 'add' something to those of existing review meetings. Where this was not the case, and where the IC(E)TR recommendations seemed to mirror those of (say) a C(E)TR meeting, it left some participants wondering what the point of the process had been.

> *I think there was nothing that was unrealistic, I think they were appropriate recommendations, absolutely, but they'd been made maybe four, five, six times before, and actually what I was hoping [for] was something different. So the recommendations still being x, but actually how we get to x. I was hoping the independent [chair] or the IC(E)TR would be suggesting something different if that makes sense… So I think everyone's coming from the same point, everyone's coming to the same endpoint, so they were absolutely appropriate, but it didn't bring any more emphasis on how to find a resolution.*
> (Commissioner 73358, phases 1 and 2, 2 IC(E)TRs, face-to-face and virtual)

There was particular disappointment that the IC(E)TR recommendations did not in practice have the extra force that some participants had anticipated. There was no additional, national support, funding and/or oversight to implement them, and recommendations were not binding on the parties involved. This meant that, even if the IC(E)TR process was able to identify routes to improve a patient's care, the recommendations might not be implemented.

> *I feel like there's lots of review and scrutiny of us when we're trying to do our best and try to see it more of a supportive process, but they are just recommendations rather than set in stone, or they have been so far, although I know there has been discussion about them being made more, 'you have to do them by this date'.*
> (Clinician 75266, phases 1 and 2, number of IC(E)TRs unclear, face-to-face and hybrid)

Participants' suggestions for improving recommendations of an IC(E)TR

Participants said they felt that there needs to be earlier and more timely delivery of the IC(E)TR recommendations to maintain momentum, and that they should be sent to all participants.

Several participants said it was important that there was greater accountability for recommendations and that they should have more 'bite'. It was thought there must be a mechanism for recommendations to be enforceable otherwise they would not be implemented. Participants suggested a number of ways to achieve this:

- There should be a statutory mechanism for follow-up and escalation if necessary.
- The chair should follow up recommendations and where they had not been implemented, explore the reasons for this.
- There should be a follow-up meeting after the IC(E)TR to discuss progress, rather than this being solely the responsibility of subsequent C(E)TRs.

Another suggestion was that IC(E)TRs should have access to resources such as consultants to support implementation.

Some participants thought that there was an opportunity for IC(E)TRs to share best practice and solutions to problems, operating like a quality network.

7 Research with clinicians and commissioners – summary

- Not all participants in our research were clear about the purpose of IC(E)TRs. IC(E)TRs were felt to hold potential for improving a patient's situation but many participants felt that this potential was not being fully realised.
- Participants expressed mixed views about the role of the independent chair in an IC(E)TR. They could see the potential value of the role but did not necessarily believe it had been realised. The role of the independent chair also raised queries about the purpose of commissioners in the IC(E)TR meeting.
- Participants could see the logic of including all of the relevant roles in an IC(E)TR panel but did not always see this potential being realised in the meetings they attended.
- There was a lot of initial negative feedback about the planning of IC(E)TRs. At its worst, this could lead to a preoccupation with process over purpose, and there was a risk that the patient's family was marginalised. However, the planning of IC(E)TRs was thought to have improved over time.
- IC(E)TR meetings tended to run smoothly and aspects that proved difficult initially – such as getting the required attendance – were again acknowledged to have improved over time.
- The written recommendations from IC(E)TR meetings were generally seen to have been timely and appropriate, but many participants had concerns about whether the recommendations could or would be implemented, and there was disappointment that IC(E)TRs did not confer the extra power to facilitate this.

8 Discussion

During the course of the research, we observed a number of issues in relation to IC(E)TRs. We have touched on these in the findings sections, but now discuss them in more detail.

Distinction between C(E)TRs and IC(E)TRs

We did not hear the wide distinction between C(E)TRs and IC(E)TRs that we expected when we began this project. There is clearly some confusion among commissioners and clinicians about the distinction between the two processes and how they relate to each other. We also found that some sector organisations with whom we engaged and representatives of families of people with a learning disability and of autistic people often assumed we were researching C(E)TRs; there was much less understanding of IC(E)TRs. This suggests to us that there is a problem distinguishing between the two processes, which is not assisted by the IC(E)TR name (and sound) being so similar to C(E)TR.

Unintended consequences of the key role of the independent chair

The central role of the independent chair in the IC(E)TR process was widely understood by participants, and finding a date when the chair was able to attend was understandably a priority for organising the IC(E)TR meeting. However, there is a risk that this central role may have unintended consequences for the process, including a lesser focus on the availability of family or carers. We heard from several participants that families and carers were not central to the planning process.

Degree of central oversight

The lack of a central 'database' of IC(E)TR patients and families was a key reason why it proved extremely difficult to recruit patients and families who had taken part in IC(E)TRs to our research (*see* appendix 3). Based on the initial findings of commissioners and clinicians, this lack of centralised knowledge may illustrate a wider problem for the IC(E)TR process in that it may be difficult to effectively monitor and evaluate the roll-out, development and ultimately the impact of the

IC(E)TR programme. This may be a significant issue for a programme whose key feature is central intervention in what is largely a local process. As noted earlier, commissioners and clinicians who did value the potential of the IC(E)TR process were sometimes disappointed that there was little central support for, and monitoring of, how the recommendations were implemented.

Extent of impact

The commissioners and clinicians we spoke to held views that ranged from being appreciative of the insights provided by IC(E)TRs through to being somewhat dismissive of them. We heard examples of value being added by the IC(E)TR process, sometimes by adding more weight to recommendations than a C(E)TR might have provided, but we did not hear any examples of clinicians or commissioners saying that an IC(E)TR had been a catalyst resulting in fundamental change for the patient. This may partly be explained by the focus of this research, as commissioned, which was on the IC(E)TR process rather than its outcomes. Nonetheless, in practice, clinicians and commissioners did sometimes talk about outcomes and we would have expected that they would mention any significant, positive changes.

Ongoing role of commissioners and clinicians

We heard some resentment from commissioners and clinicians to the effect that the IC(E)TR model was perceived to involve assumed criticism of current commissioner and/or clinician roles. Whether or not this criticism is reasonable, these perceptions are important because implementation of the recommendations made by IC(E)TRs can only take place through local commissioners and clinicians. If they feel disengaged or hostile to the process, then it may be that recommendations are less likely to be implemented. Acting on participants' suggestions as to how to improve the IC(E)TR process might therefore help to ensure wider buy-in in future.

> *People get quite anxious that they're going to be blamed for things or they're going to be kind of told that they're not doing a good-enough job, when actually that's not been the outcome of some IC(E)TRs. Some IC(E)TRs have been supportive of the type of care [the patient is receiving]. So I think it's that getting people to*

understand the process and why it occurs, but in a way that it's not seen as a negative thing…
(Commissioner)

There's that question of where's the trust that as commissioners we are doing this job properly. And I understand the frustration for the Department of Health [and Social Care] and others like Baroness Hollins. We are just as frustrated that we can't move these very complex individuals on. There are multiple problems. It's multifaceted as to why that is, which we've raised with NHS England… As I said, with this individual we tried and it failed, and [they] ended up back in hospital.
(Commissioner 68974, phase 1, at least 1 IC(E)TR, face-to-face)

Alternative mental models of IC(E)TRs

Our research may suggest that the clinicians and commissioners with whom we spoke hold different mental models of IC(E)TRs (though, as we acknowledge in the Research methodology section, there may be other mental models held by clinicians and commissioners with whom we did not speak).

Some clinicians and commissioners – perhaps the minority – did see IC(E)TRs as a 'catalyst' for significant change, at least for some patients. However, they felt frustrated because IC(E)TRs do not have the extra 'clout' necessary to make sure that the recommendations are fully implemented.

Other clinicians and commissioners felt that IC(E)TRs offer the potential to 'validate' what they consider to be already effective care and perhaps improve some elements of it. For this group, their concern was feeling 'done to' by the process rather than supported by it, as well as the additional work involved, particularly where this duplicates the work that would take place in C(E)TRs anyway.

These mental models can perhaps be reinforced further by the IC(E)TR meeting itself, when emotions can run high for all involved, and different and competing needs may emerge.

Table 1 Mental models of participants in research

	Perceived function of IC(E)TR	Perceived values offered by IC(E)TR	Concern about effectiveness of IC(E)TR
1. Catalyst	Help patients who are 'stuck' in the system	Offers insight; offers challenge; provides extra 'clout' to recommendations	Not always extra insight; no extra power or resource to implement recommendations
2. Improver/ validator of care	Ensure that the care being provided is safe and effective	Offers insight from 'experts'; offers support for current approach	Existing staff feel 'done to'; extra work; duplicates C(E)TR process

Whatever the views of the clinicians and commissioners involved, a key question is: what, if any, changes can be made to the IC(E)TR process to maximise engagement and buy-in from these two roles that will ultimately be responsible for implementing any recommendations made.

Appendix 1: Interview schedule

Preamble to the interview

- Introduce researchers/interviewee and explain presence of additional researcher as necessary
- Confirm receipt of consent form
- Confirm they have read information sheet
- Provide overview of IC(E)TRs and reiterate their purpose, signposting the participant to the information we will have sent them on this
- Explain that DHSC wants to be sure that the IC(E)TR process is as efficient and effective as possible, both for patients and staff involved in their care
- Explain that the purpose of these interviews is to gain learning from commissioners and providers which can be passed on to the DHSC to improve the IC(E)TRs for everyone involved – therefore their insights are vital for patients and for themselves.
- Reassure regarding confidentiality and anonymity and use of quotes
- Ask them not to provide any patient identifiable information
- Explain how long they have to withdraw from evaluation – up until data analysis [insert date]
- Invite questions
- Explain notes will be taken due to volatility of technology
- Double-check consent to record
- Start recording
- Go through consent statements and get participant consent only if written consent not provided.

Questions

I'm going to lead you through the various stages and characteristics of IC(E)TRs – right from planning for them to take place, up until receiving the recommendations from the panel. For each one, I want you to think of your own experiences and reflect on what you thought worked, what didn't, and if improvements could be made.

- Ask how many IC(E)TRs they have done and in what format and when was the most recent one, roughly (to identify whether they have carried out first batch pre-lockdown or latest batch post-lockdown).
- If you have experience of the previous CETR process we would like to hear how you think the IC(E)TR process compares: if you have not, we would still like to hear your experience of the IC(E)TR process.
- If you have experience of both online and face-to-face IC(E)TRs, we would like to hear of any significant differences between the two.

1. To start, can you tell me in your own words what you think is the purpose of the IC(E)TR process?

2. Were you involved in planning the IC(E)TR process? If so, how straightforward was it to organise the IC(E)TR meeting itself? Consider:

    a) Did you have enough time and resources to arrange the meeting?

    b) Were there any challenges to planning to involve more people than the previous C(E)TRs did? For example, the independent chair or the CQC Mental Health Act Reviewer?

3. On the day, did the IC(E)TR meeting run effectively and efficiently? Consider:

    a) Did members of the panel have a good understanding of their role and responsibilities? (Independent chair, MHA Reviewer, expert by experience, clinician, etc)

    b) Did members of the panel have sufficient knowledge and understanding of the specific circumstances of the patient under discussion?

c) What difference, if any, did having an independent chair present make?

d) What difference, if any, did having the Mental Health Act Reviewer present make?

4. Turning to the recommendations made by the panels, can you tell me about your perceptions of these? – Consider:

   a) Did the recommendations take account of the specific circumstances of the patient under discussion?

   b) Do you have a clear understanding of when these recommendations needed to be implemented by?

   c) Did you have a clear understanding of whether and how implementation of these recommendations would be monitored?

   d) Were you confident as a commission (provider) that the recommendations of the panel were implementable?

5. Following the panel, do you think the recommendations were seen in a timely manner by the people who were needed to implement them?

6. Based on your experience, would you make any changes to the IC(E)TR process?

7. Is there anything else about the IC(E)TR process that you want to mention that you think DHSC could help with?

Check if there's anything else they wanted to share that we didn't ask about.

Stop recording

- Reiterate confidentiality and when and how the report will be shared.
- Ask them if they would like a link to the report sent directly to them – likely due Autumn 2022.
- Flag how long they have to withdraw from participation – up until analysis starts [insert date].
- Flag emails for follow-up questions/concerns.

Appendix 2: Details of research participants

	Commissioners	Responsible clinicians	Total
Number interviewed	10	7	17
Provider	NHS = 7 Independent = 3	NHS = 6 Independent = 1	NHS = 13 Independent = 4
Patient type	Adult = 7 CAMHS = 2 Both = 1	Adult = 6 CAMHS = 1	Adult = 13 CAMHS = 3 Both = 1
Security level	Secure = 2 Non-secure = 4 Mix = 4	Secure = 4 Non-secure = 3	Secure = 6 Non-secure =7 Mix = 4
Number of IC(E)TRs	N = at least 18 Range = 0*-3 Mean = 1.8	N = at least 18 Range = 1-<20	N = at least 36 Range 0-<20
Phase of IC(E)TRs**	P1 = 5 P2 = 1 Both = 3 NA = 1	P1 = 3 P2 = 1 Both = 3	P1 = 8 P2 = 2 Both = 6 NA = 1
Mode of delivery	Face-to-face = 8 Virtual = 7 Hybrid = 2 Unknown = 1	Face-to-face = At least 2 Virtual = At least 6 Hybrid = At least 2	Face-to-face = At least 10 Virtual = At least 13 Hybrid = At least 4 Unknown = 1

* Despite sampling parameters described above, at the time of interview it was found that one commissioner had not been aware that their patient had received an IC(E)TR until after the event.

** Two phases of IC(E)TRs took place, the first from November 2019 to June 2020, and the second from November 2021 to March 2023.

Appendix 3: Research with patients and families

Efforts to recruit patients and family members with experience of IC(E)TRs proved very difficult and we were not ultimately able to recruit any participants to this research project. We set out in this appendix the approach we took and our analysis of why we were unsuccessful in recruiting.

Approach

As there was no available central list with contact details and names of patients and families who have had IC(E)TRs, our intention was to use three recruitment routes:

1. The CQC was planning to begin a series of follow-up interviews with people who had had an IC(E)TR and were willing to identify a sample of those interviewees who would be invited to take part in our research. We expected this to be the most reliable recruitment approach. Unfortunately, the CQC interview programme did not go ahead.

2. We asked commissioners to identify patients and/or family members who were willing and able to speak to us. An invitation to take part in the research was also included in the booklet that every person attending an IC(E)TR is supposed to receive as part of the informed consent process for the reviews ('My IC(E)TR planner'). These commissioners were the same ones approached to take part in the research with commissioners and clinicians.

3. We approached patient and family support networks and asked them to share information about the research with their members. We worked with the National Development Team for Inclusion (NDTi), and two experts by experience, to develop recruitment materials and created easy-read versions of them. A dedicated phone line and email address were set up for people to contact the team. We went through three different and gradually wider networks:

    a) NDTi reached out to organisations who directly connect with people and families, self-advocacy and family groups, and provided information

for them to share with their networks. These were organisations that have been involved in supporting C(E)TRs in their areas, or supporting the groups of people we were seeking to find. We took the perspective that people would be most willing to get involved if they heard about the research through people and networks that they know and trust.

b) When this did not lead to anyone getting in touch, we put the call out more widely, using some of the national networks such as the Restraint Reduction Network and Learning Disability England. These groups have links with providers, self-advocacy groups, family groups and individual members. We asked each group we approached to put out the call more than once. Many of those who we asked to share the call for us said they would, but some felt they could not circulate research calls to their members, and one or two said they felt there was a conflict of interest in doing so. The majority of those we approached said they would share it in their regular newsletters or communications.

c) Finally, both NDTi and The King's Fund made public the call to get involved, using social networks such as Twitter.

Results

All of these recruitment routes proved unsuccessful. For a number of reasons, commissioners and clinicians proved unable to put forward patients or family members and, though materials have been circulated via support groups, the only responses we received were from people who have had C(E)TRs, not IC(E)TRs. We concluded that recruitment of patients and family members to the research project was severely hampered by at least three factors.

- Some patients are not capable of participating, and commissioners and clinicians have therefore been unable to recommend them for participation.
- A relatively small number of IC(E)TRs have taken place, a relatively long time had elapsed between some of them and the start of the research, and family/carers were not involved in all of the IC(E)TRs.
- There appears to be some confusion between C(E)TRs and IC(E)TRs. In discussion with support groups, it seems possible that patients and their families may not necessarily know they had taken part in an IC(E)TR, as opposed to a C(E)TR or other meetings to discuss the patient's care.

This suggests that future attempts to fully understand the views of patients and families might need to consider the following steps:

- making it easier to contact patients or families who have taken part in IC(E)TRs
- reprioritising family involvement within IC(E)TRs so that more family members are able to attend
- creating a stronger distinction between C(E)TRs and IC(E)TRs and/or improving understanding of the IC(E)TR process.

For researchers, there may be a need to consider alternative forms of recruitment and/or put greater weight on recruitment in planning research. This might need to include adopting purposive recruitment and/or approaching a larger number of inpatient sites.

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The King's Fund Ideas that change health and care

In November 2019, the Secretary of State for Health and Social Care announced that all people with a learning disability or autistic people in long-term segregation in inpatient settings were to have their care independently reviewed. This led to the creation of Independent Care (Education) and Treatment Reviews (IC(E)TRs), meetings that were intended to provide independent scrutiny and review of the current situation of the person in long-term segregation.

This report looks into what commissioners and clinicians involved in IC(E)TRs think about how these meetings are planned, how they are run on the day, and if the recommendations to improve people's care are put into practice. The King's Fund spoke to 10 commissioners and 7 clinicians and found that, while not all participants were clear about the purpose of IC(E)TRs, many felt the meetings did have potential to improve a patient's situation.

The King's Fund found that while meetings may not have been well planned at first, this had improved and meetings were generally thought to have been well run. The written recommendations from an IC(E)TR were generally viewed as being good, there were concerns about whether or not they could be implemented. However, some participants also thought that the establishment of IC(E)TRs was an implied criticism of their performance.

The report concludes by considering what changes could be made to the IC(E)TR process to improve engagement and buy-in from the commissioners and clinicians who will ultimately be responsible for implementing any recommendations made.

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