



My Independently Chaired Care (Education) and Treatment Review

Information, Consent form and Planner
for children, young people and adults in hospital
cared for in long-term segregation

This booklet belongs to:



About this booklet

This booklet is about Independently Chaired Care (Education) and Treatment Reviews. These are also called **IC(E)TRs**. We talk about Care (Education) and Treatment Reviews in this booklet. These are also called **C(E)TRs**. We will use **IC(E)TR** and **C(E)TR** for the rest of this booklet.

This booklet is about planning your **IC(E)TR**. Near the end, there is a section to help you record any actions that need to happen afterwards. The last section is a feedback form, to help you say how well your **IC(E)TR** went. And what could be done better.

Please keep this booklet in a safe place as it is your information. You will need it at different times.

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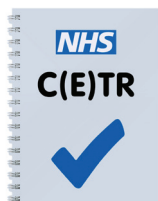


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What is an Independently Chaired Care (Education) and Treatment Review



You might have had a Care and Treatment Review before and know what they are about. An **IC(E)TR** is like an ordinary **C(E)TR**, but it has big differences too. We will explain the differences on page 5.



Every **C(E)TR** is about making sure you get the right care for you, whether you are a child, young person or adult.



You have a right to a **C(E)TR** if you are autistic or have a learning disability and are in hospital because of a mental health problem. Or if your behaviour is seen as challenging to services.



You can also have one if you are at risk of going into a learning disability or mental health hospital. The **C(E)TR** will check if it is the right thing to do.



If you are in hospital, or might be, a **C(E)TR** helps to make sure it is for the shortest time possible.

What is good about having a Care (Education) and Treatment Review



- It is all about you - what you say matters. And your family if they are involved
- It is not the same as other care meetings because it is independent. This means the people who provide your care are not in charge of the meeting
- It checks all your rights are being upheld
- It checks you are being treated with dignity and respect at all times
- It checks you are safe
- It checks the quality of care and treatment you are getting
- It checks the quality of education you are getting if you are a child or young person
- It finds out about your plans for the future. And if anything is stopping them from happening or can be done better
- It says what needs to improve - these are called actions
- It helps you have as much choice and control in your life as possible

The 4 big questions in a C(E)TR?

A **C(E)TR** uses Key Lines of Enquiry, or KLOEs. These are the things the people at the meeting (called the panel) need to think about on the day.



1. Are you safe?
2. Are you getting good care now?
3. What are your plans for the future?
4. Can your care be given in the community?

All about the Care (Education) and Treatment Reviews

How often can you have a hospital C(E)TR?



Adults - a **C(E)TR** can happen every 6 months if you are in an assessment and treatment unit or another type of non-secure hospital. If you are in a secure hospital a **C(E)TR** can happen every 12 months.



For children and young people - every 3 months, secure and non-secure. If there are good reasons for having one more often or less often, everyone involved can agree when they should happen.

How are Independently Chaired Care (Education) and Treatment Reviews different?



An **IC(E)TR** is for people who are often cared for away from other people. This is called long-term segregation. This means often being cared for in a separate room or area for more than 48 hours each time.



An ordinary **C(E)TR** is carried out by a panel of three people. But in an **IC(E)TR** there are five people. They are:



1. An independent chairperson who works for the Department for Health and Social Care
2. A Mental Health Act Reviewer who works for the Care Quality Commission (CQC)
3. The commissioner who buys and monitors your care
4. An expert by experience - either a person with a learning disability or autism or both. Or a family carer, with the right experience
5. A clinical expert - such as a qualified nurse or doctor.



What will an Independently Chaired Care (Education) and Treatment Review do?



Like an ordinary C(E)TR, the IC(E)TR finds out about:

- Keeping you and other people safe
- Your care and treatment now
- Your health and well-being, including your mental health
- Your medication if you take any
- Your education and plans to support you as you become an adult if you are a child or young person
- Where you live now and where you would like to live
- Any health and care plans for you in the future
- What you want for the future.



It will also look at

- Why you are being cared for away from other people, in long-term segregation
- How long it has lasted for and if it has happened before
- How it affects you
- How it affects your relationships with other people. Like family, friends, other patients or staff
- How it affects the quality of your care and treatment. And your education if you are a child or young person
- What you think must change. And your family if involved
- What the people who care for you say
- When the segregation will end.



What will an Independently Chaired Care (Education) and Treatment Review do?



The chairperson of the **IC(E)TR** will write a report with help from the people in the panel. This says if anything needs to happen for your care to get better or safer.

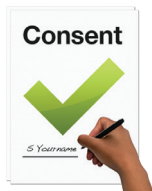


It says who needs to do what by when. These are called **actions**.



The chairperson and the Mental Health Act reviewer would also like to learn lessons from your situation. They will let the Government (Department for Health and Social Care) know if there are things that need to be changed for people being cared for in away from other people in long-term segregation.

Deciding whether to give your consent



You can choose if you would like to have an **IC(E)TR**.
If you choose to have one this is called giving your consent.



You can invite family carers, an advocate or someone important to you if you want to.

You will be asked for your consent each time you are offered an **IC(E)TR**.



What will happen to my information?

Your information is private and confidential. The **IC(E)TR** panel will not take away any of your care notes after the day.

What is my consent for?

Like in an ordinary **C(E)TR**, you are consenting to share your information with the **C(E)TR** panel and people who are, or will be, involved in your care.

You are also consenting to share anonymous information. This will not include your name or any personal information about you.



Unlike an ordinary **C(E)TR**, it also includes sharing anonymous information with a group which is helping to improve the care of people in long-term segregation. This group is run by the Department for Health and Social Care for the government.



Deciding whether to give your consent



What is my consent for?

If you say **yes**, this means you give your **consent**. It means you are happy to have a review of your care. And for lessons learned about your care to be shared.



If you do not want to have an **IC(E)TR**, you can say **no**. Saying no will not affect your day to day care.

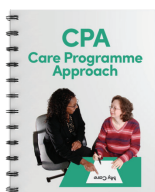


When you have all the information you need and you understand about **IC(E)TRs** please fill in the consent form on page 13. You can say if you do or do not give your consent.

The IC(E)TR report can only be shared with:



- You and people important to your **IC(E)TR**
- People in charge of your health and social care who are or will be providing or paying for your care
- People in confidential care meetings like Care Programme Approach (CPA) meetings or Mental Health Tribunals
- If the report says you or others might not be safe, some or all of your **IC(E)TR** report might be shown to people who the law says must look at it
- **Everyone must keep your information private and safe.**



Deciding whether to give your consent

The Independently Chaired Care (Education) and Treatment Review report can only be shared with:



Some anonymous information from the report will be sent to a group run by the government which is making sure that long-term segregation is being used properly.



This group will make recommendations to the Department of Health and Social Care, NHS England and CQC.



This information will not include your name or any other information which could identify you. It will include information about your age, whether you are male or female and your ethnicity. Also why you are being cared for in long-term segregation and if anything is stopping you from moving on.



Some anonymous information may also be shared with other people in the NHS to check that everyone's care and treatment and **IC(E)TRs** are going well.

TheKingsFund>



The Kings Fund are a charity that work to improve health and care in England. They are doing a review of the **IC(E)TR** process. They want to talk to some people who have had an **IC(E)TR**. They want to find out what could be done better in the future. They would need your contact details. See page 13 - question 3 on the consent form. If you agree they will contact you. They will check again if you are still happy to help.

Deciding whether to give your consent

You should be given all the help you need to decide.



If you are not able to decide for yourself (this is called not having capacity) your guardian or legal appointee must decide.



If you are **younger than 16** a parent, guardian or legal appointee must decide.



If you need but do not have someone who can legally decide for you, there must be a **Mental Capacity Assessment and Best Interests meeting**. The right people who help care for you will then decide.

Your consent form



A copy of your consent form will be sent to the Independent Chairperson of the **IC(E)TR** to show if you do or do not want to have an **IC(E)TR**.

A copy of your consent form will be kept in a safe place.



You can change your mind at any time.

Deciding whether to give your consent



Your care co-ordinator can help

Your care co-ordinator will know where the copy of your consent form is kept. This person can help if you want to change your consent.



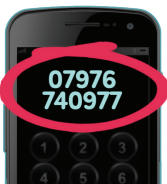
If you are not sure who this is, ask a member of staff, your social worker or family carer. You can keep their details here.



My care co-ordinator is



They work at



Telephone



Email

The **consent form** is on the next page.



For an Independently Chaired Care (Education) and Treatment Review for someone cared for in long-term segregation

We will ask for your consent before every IC(E)TR.



1. Would you like to have this IC(E)TR?

☐

Yes I would like to have the IC(E)TR

☐

No I do not want the IC(E)TR

If you say no, you only need to fill in number 5.

We hope you will want to take part in the meeting.

You can decide on the day if you want to take part or not.

2. Would you like to invite a family carer, advocate or someone important to you to take part?

☐

Yes

☐

No

Name of carer or carers

Name of advocate

Other people

3. Can The Kings Fund contact you to ask about your experience of IC(E)TR process?

☐

Yes

☐

No

My telephone or email is...



4. Is there anything else that will help to make it go well for you? For example, any reasonable adjustments that need to be made:



5. About you



My first name

My surname



My address



My signature



My birth date

Today's date

If consent is required by a parent, guardian or legal appointee, please see next page.

Consent by a guardian or legal appointee



If you are signing this consent form for a young person over 16 or an adult who does not have capacity to decide, please complete the form on pages 13 and 14. Then add your details here:

Name

Address and Postcode

I am the guardian / legally appointed deputy* for

Name

Signed

Date

Best Interests Decisions

The right process must be followed if the person lacks capacity and does not have anyone who is legally allowed to sign on their behalf.

Consent for a child



For children under the age of 16, this form must be completed and signed by a parent or someone with parental responsibility:

Your Name

Your Address and Postcode



I am the parent of, or I have parental responsibility for:

Name

Signed

Date

Planning your Independently Chaired Care (Education) and Treatment Review



You can use the form on pages 19 and 20 to help you plan for the day.

You can also use it on the day, to help you say what you want to say.

You are the most important person in your IC(E)TR, so it is really good if you can take part. You can decide about this on the day.



The panel members want to know what you think about your care. And your family if involved. They will ask other people too.

The next few pages are about what you think. You can ask someone to help you fill it in.



There is space at the end for you to write down any questions. You can write down things you do or do not want to happen on the day. Or you can say this on the day.

Tips to remember on the day of your Independently Chaired Care (Education) and Treatment Review



- ✓ You are the most important person in your **IC(E)TR**
- ✓ The **IC(E)TR** panel, staff and others will do everything they can to make it a good experience for you
- ✓ They want to understand how you feel about your care
- ✓ You can say what matters to you and what you think
- ✓ You can ask questions whenever you like
- ✓ You can say if you need anything or if there is a problem
- ✓ You can meet people in the way that feels best for you.



Things that might help

- It is OK to decide on the day about meeting people on the **IC(E)TR** panel
- You can meet just one person if that feels better
- Or you can say hello first and then decide if you want to meet them later
- You can have a family carer or advocate or staff member with you when you meet people. You should be given as much choice as possible
- It is OK if you want to stop or have a break
- If you do not want a particular person to hear what you say, tell the panel.



Ideas to help you with your Planning Form

You can use any of these ideas or say something different. It is your choice.

Do I feel safe?



- Do I feel safe with other people here?
Do staff understand my needs?
- Does the room or hospital meet my needs?
- Am I upset by my environment or because I am not understood?
- Do I only feel safe if I am not with other people?
- Do I get a lot of medicine to keep me calm or help me sleep?
- Am I restrained if I get upset?
- Do I understand my rights?
- Do I have good support from an advocate to help me speak up?
- How are my feedback, concerns or complaints dealt with?



Am I getting good care and treatment now?



- What is good about it now?
- Is my autism understood?
- Is my learning disability understood?
- Do staff do anything to help with my learning disability or autism?



This might be reasonable adjustments such as information that is easy to understand. Or activities that help me feel calm or quiet time. Or regular friendly staff who give me extra time and support to do things.

Ideas to help you with your Planner



What could be better now?

- Is there anything I am worried about?
- Are my family and friends able to spend time with me?
- Are my family and friends able to contact me and see me?
- How could my care and treatment be better?
- How could segregation be better?

What are my hopes and fears for the future?



- Do I get the help I need to help me achieve my hopes for the future?
- Is there anything about my future that worries me?
- Am I involved in making plans for my future?
- Am I happy with those plans?

Other comments or questions



- What would you like to happen on the day of your **IC(E)TR**? Or not want to happen?
- If you are a child or young person, do you feel like your education is going well or not? Why?

Planning my Independently Chaired Care (Education) and Treatment Review



My Planning Form

You can use extra pieces of paper if you need to.



My name is



When is my IC(E)TR?

- 1. What is important to me:
Hobbies, friends family, every day?**



- 2. Do I feel Safe?**



3. Am I getting good care now?



What is good now?



What could be better?

4. What are my plans for the future?



What is the plan so far?



My hopes



My fears

5. Can my care be given in the community?



Any questions or comments?

My Independently Chaired Care (Education) and Treatment Review Report

You should receive your **IC(E)TR** report from the **IC(E)TR** chairperson within **2 weeks** of your **IC(E)TR**. It should be written in words you understand. If there are difficult words ask someone to help. You can write what needs to happen here, to help you check these things happen on time.

What needs to happen

**By when
and by who?**

1

2

3

4

5

6

My Independently Chaired Care (Education) and Treatment Review Report

You can use this page to draw or make notes about what needs to happen. This can help you check that these things are happening on time.

My Independently Chaired Care (Education) and Treatment Review Feedback Form



This form can be used by anyone who took part in an **IC(E)TR**. Your information will be kept safe. You do not have to tell us your name or date of your **IC(E)TR**, but if there was a problem this will help to get it sorted out. Please fill in this form and send to the chairperson of the **IC(E)TR**.



Name if you want to say

Date of IC(E)TR

If you or someone else wants a reply, please give contact details



1. Did you get help and information before the IC(E)TR?

2. What was the IC(E)TR like on the day?

3. What would have made the IC(E)TR better?

4. What difference did the IC(E)TR make for you?

5. Have you got any other comments or questions?



Thank You.

To everyone who has helped with this booklet.

You can find out more about Care, Education and Treatment Reviews and download this and other documents at www.england.nhs.uk/my-ctr

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www.england.nhs.uk



www.see-communications.co.uk