



# Guide for CTR Experts by Experience

Care and Treatment Review  
expert advisers



This booklet is about becoming an expert by experience as an expert adviser on Care and Treatment Reviews. It tells you the main things about Care and Treatment Reviews, which are also called CTRs.

There is more information about the CTR policy, other documents and online learning at [www.england.nhs.uk/ctr](http://www.england.nhs.uk/ctr).

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## What is an expert by experience?



Experts by experience are important people in a Care and Treatment Review, also called a CTR. You might be a person with a learning disability, autism or both. Or you might be a family carer.

You have experience of services for people with a mental health problem or behaviour which is seen as challenging. You are paid for your work on a CTR.



An expert by experience is an **equal** member of the CTR Panel. You help the panel understand what someone's care is like. You help the panel think about how it can be better. You help the person and family carers have a good CTR.

## What is a CTR Panel?



The CTR Panel is usually made up of three people. **You**, a clinical expert and the chairperson.

The **chairperson** is usually the person's commissioner. The commissioner works for the NHS. Part of their job is to pay for the person's care.



The **clinical expert** is someone who is qualified to work in health care. It could be a nurse, psychiatrist or other health professional.

Sometimes there can be other advisers on the panel. This could be a social worker, or for a child someone who works in education.

## What is a Care and Treatment Review?



A CTR is an independent review of a person's care. It checks:

- That people are safe and getting the right care for them
- They have good care plans for the future
- Any problems with their health, safety or care get sorted out



CTRs are for people with learning disabilities, autism or both, who are in **hospital** because of a mental health problem, or because their behaviour is seen as challenging. It is also for people living in the **community** who might need to go into a learning disability or mental health hospital.



People of all ages can have a CTR. It is a bit different for **children and young people** as it also includes the person's learning needs. So it is called a **Care, Education and Treatment Review, or CETR**. It is the same in other ways.



Care and Treatment Reviews are part of **Transforming Care**. This is a big project which helps more people get the care they need in the community instead of in hospital. If people do need to go into hospital, it makes sure they can leave as soon as they are well enough. And that people get the right care when they leave. CTRs are an important part of this.

## Becoming an expert by experience



To be an expert adviser you have to go through a job recruitment process to make sure you have the right skills and experience. You will also need to have a **DBS** check. This is done by the Disclosure and Barring Service. They check whether people have a criminal record which might stop them from doing this work. Some experts by experience are recruited and supported by local **expert hubs**. If you are not part of an expert hub, the CTR chair will organise your training and support.

### What does an expert by experience do?



- Works as a member of the CTR panel
- Gets ready for and attends CTRs
- Takes part in CTR training as needed
- Follows rules about CTRs - before, during and after
- Helps the chairperson with the CTR report. This is about what needs to happen next - by when and by who.

### What knowledge or experience are needed?



- Personal experience of services for people who have mental health problems or behaviour which is seen as challenging, either in hospital or in the community
- Personal experience of services that work with people in learning disability and mental health hospitals and/or in the community
- Understanding of people's rights, equality and diversity
- Understanding of person centred support and how it helps with people's care
- Understanding of good care and support in the community
- Understanding or will learn about Positive Behaviour Support

## A good expert by experience is...



- Good at communicating with people who use services and their families in different ways
- Good at thinking about what a CTR report should say
- Good at keeping information private and confidential
- Good at noticing things and asking questions
- Good at knowing what is good care and poor care
- Good at getting to meetings on time
- Able to change plans quickly if needed
- Good at being part of a team led by somebody else
- Happy to be supported on some things if needed
- Able to travel to CTRs (with or without support) which can be outside of your home town
- Able to use email and phone

## Payment

The rate of pay for an expert by experience is usually £20 per hour, or £150 per day. This may be paid by cheque or to your bank.



Travel and expenses will be paid if you travel outside of your local area. Train tickets may be booked for you (please check) and you should keep receipts for other travel and expenses.



Payment will be in line with the paying organisations' policy on this. You may also need to check the policy on payment for additional support to carry out the work eg. a support assistant or childcare costs.

# Rules about CTRs



## Everything you hear and see is confidential

- You will be asked to sign a contract to keep all the information you see or hear private and confidential.
- You cannot take away any of the person's notes with you afterwards.
- You can only talk about the person and their care with people who are part of the CTR.

## Before a CTR



- You will probably need to bring some proof of identity with you to a CTR, to show who you are. The chairperson or hub will send you a badge or help you if this is a problem.
- You will need to sort out your travel plans with the hub or chairperson and
- When and where you will meet the panel members on the day.
- If you know the person from having done their CTR before, that is OK. But if you know the person in another way, this can be a **conflict of interest**. If so, tell the chairperson.

## On the day of the CTR



- Allow time to get there – about half an hour before it starts.
- Remember - the panel and staff are there to help you.
- You will probably need to sign in. You might be told where to put your purse, wallet, phone or other personal things. This is so they are kept safe while you are there.
- You are there to ask questions, but you must also be polite.
- The chairperson is in charge of the CTR.

# Rules about CTRs

## After the CTR



- You can only talk about the CTR to panel members or someone the chairperson says it's OK to talk to.



- The chairperson of the CTR or hub will contact you afterwards to talk about how the CTR was for you and to answer any questions.



- You will be asked to check the CTR report. If you need support to do this, it can only be the chairperson or someone in the hub who is allowed to support you.



- At the end of the CTR the chair will talk to the panel about follow up actions. If you are concerned about something you saw or heard, you can ask the chair to let you know if the concern has been dealt with after the CTR.



## When do CTRs happen?



In the **community**, people should have a CTR in good time before it is decided if they must go into hospital.

If there is no time for this, **adults** should have a CTR within 4 weeks of going into **hospital**. **Children and young people** should have a CTR within 2 weeks of going into hospital.



CTRs for **adults** can happen **every 6 months** if they are in a **non-secure hospital**, like an assessment and treatment unit. If the person is in a **secure hospital**, the CTR can happen **every 12 months**.



CETRs for **children and young people** in hospital should happen **every 3 months**.

**Anyone having a CTR and those who support them can also ask for a CTR at any time.**

## How long does a CTR take?



A CTR usually takes most of a day. This gives the panel plenty of time to meet everyone, look at the person's notes and decide what needs to happen.



Sometimes a CTR happens on the same day as another care meeting, such as a CPA. If this happens, it might only last half a day. This works well for some people but if you feel it is not working for the person having the CTR, talk to the chairperson and the clinical expert about it. **You can only go into another care meeting for the person if the person says it is OK.**



**A CTR starts with a big meeting** to talk about the day, fix meeting times, find out more and ask for notes. Things to check in this meeting are:

- Does the person need time to decide about meeting the panel?
- Does the person want to meet all or some of you?
- Does the person want to meet the panel in private?
- Does he or she have communication or other needs to help them take part?
- Has the person invited their family member or advocate to take part?
- Does the person want you to meet them all at the same time?
- If a family member or advocate is taking part but can't be there, who will ring them and when?



## How long does a CTR take?



**Most of the CTR is spent talking to people and looking at notes.** Towards the end, the CTR Panel takes time to think about everything they have found out. This is when the panel decides what needs to happen next, who needs to do it and by when. These are called the **actions** and they go into the **CTR report**. The chairperson writes the report afterwards.



If at all possible, it is good if the panel can have a meeting with the main people who took part, **at the end of the CTR**. This should include the person having the CTR if they want to attend.



The aim of this meeting is to talk about the main actions you have agreed as a panel.

## Meeting the person and family carers



**People often want to meet the expert by experience, because it can feel easier talking to you.** It can be good to meet the person and family carers in pairs. This means you can support each other.

Some people have said they want to know more about the panel members too, because you find out a lot about them! It's good to say a bit about yourself and the role of the expert by experience when you meet the person and family carers.



### Supporting the person well

- The person might find it hard to talk about their care.
- They might feel unsure about meeting new people.
- Give the person time to decide when they are ready and
- When they want to stop or have a break.
- Would a few short meetings work better than one big one? And give all the panel a chance to meet the person?
- Would the person like to show you where they live eg, their room or ward? Can staff help with this?

### The 4 big questions in a CTR are:

1. Is the person safe?
2. Is the person getting good care now?
3. What are their plans for the future?
4. Does the person need to be in hospital for their care and treatment?



## Key lines of enquiry



Within these 4 big questions, the chairperson has a list of other questions which help to find out more and why.

These questions are called key lines of enquiry, or KLOEs for short. The answers to these questions help to show what needs to happen. They also help the chairperson write a report after the CTR.

The KLOE questions are in groups, under these subjects:



1. **Key areas of concern**
2. **Does the person need to be in hospital?**
3. **Is the person receiving the right care and treatment?**
4. **Is care person-centred?**
5. **Are the person's health needs known and met?**
6. **The right use of medication?**
7. **Clear, safe and positive approach to risk?**
8. **Autism needs being met?**
9. **Active planning for the future and discharge?**
10. **Are families and/or carers involved?**
11. **Are the person's rights upheld?**



The panel should look for proof or evidence. This might be in the person's care notes or in what people say. The chair needs to show how or why the panel decides on something.

## Reading care notes



The notes can be difficult to understand. The clinical expert on the panel is there to help you and the chairperson make sense of them. So if you find them hard to follow ask the clinical expert to help.



Person-centred plans and documents for the person should be written in a way the person will understand. They show how well the person is involved in planning and deciding about their care. Do they show what the person wants and decides?

## Meeting other people



If possible, it is best to meet each person separately, so each person feels free to say what they think. Working in pairs with a panel member means you will ask different sorts of questions and it is easier to write down the main things the person says. If you do not understand what somebody says, ask them to explain.



You will see things that others don't, and ask questions that others don't. It does not matter how simple a question seems. They are often the best questions!

## The CTR report



After the CTR, the chairperson will write a report which shows what the **actions** are. Sometimes it is hard not to use difficult words. But the report should not be too hard to understand.

You will be sent a copy of the report to make sure it looks OK. The CTR report will be sent to you in line with NHS Information Security. At the end of the CTR, the chairperson will talk to you about what this means and how you will have to destroy your copy of the report after you have seen it.



You will not be sent any other copies of the report. This is because it is only for the person, their family or advocate and care team. This information is private and confidential.



The finished report should go out within **2 weeks** of the CTR. The chairperson will make sure that the report is followed up to make sure the actions are happening on time.

## What makes a good CTR?



A CTR is about each **person** as an individual. So we have used the letters that spell out the word **PERSONAL** to explain the **principles** of a good CTR:

**P**erson centred and family centred

**E**vidence based

**R**ights led

**S**eeing the whole person

**O**pen, independent and challenging

**N**othing about us without us

**A**ction focused

**L**iving life in the community



# What do the PERSONAL principles mean?



## Person centred and family centred

The person, their family and advocate if invited, should be at the centre of the CTR. The CTR checks that the people who provide the person's care are working in a person and family centred way. That people get all the information and support they need to have an active part in the CTR before, during and after. In the way that works best for the people involved.



## Evidence based

The CTR Panel should have the information they need to understand what is working or not working about the person's care. And that care is carried out to a high standard. So they can decide with the person and others if anything needs to change or get better.



## Rights led

The person has the right to be treated as an equal in their CTR and to have all the support they need to take part. The CTR should uphold the person's rights. Rights are things like choice, contact with family, independent advocacy and being able to say what one thinks. Other rights are being treated well, and having a good quality of life. And respect for one's personal life and beliefs.

## What do the **PERSONAL** principles mean?



### Seeing the whole person

A CTR is not just about a person's mental health or how they behave. It is about seeing the whole person. Their quality of life, likes, dislikes, choices, hopes and fears.



### Open, independent and challenging

Each person on the CTR panel can say if something does not seem right about the person's care. They can ask questions and say if something needs to change to make it better. Together the panel will decide what needs to happen to make it right – this is called an **action**. It will go into the CTR report that is agreed by the panel after the CTR.



### Nothing about us without us

The person, and their family carers if taking part, should be fully involved in the CTR. From giving consent, to getting ready, taking part, getting a copy of the CTR report and knowing what is happening afterwards. The CTR report should also be written in words the person will understand.

If a family carer wants to take part but cannot attend, can they take part by phone or video link? The person and their family should be kept informed about the progress of the actions.

# What do the PERSONAL principles mean?

## Action focused

The CTR report after the meeting should have clear actions. Actions are things that need to be done. The actions should be easy to understand. The report will say who needs to do each action and when it should happen by. The actions should improve the care the person receives now and in the future. The commissioner will check these things are happening. And that the person knows the reason if any action cannot be carried out on time.



## Living life in the community

CTRs are about what is needed to help people live well in their communities. When someone is in hospital, a CTR will ask if they need to be there. Or if their care can be provided safely in the community. It will also look at how people are supported to access the community while they are in hospital. The CTR will check there are good plans in place to keep the person and others safe in the community. The CTR will also check that the plans still give the person the chance to lead as full and independent a life as possible.



# Thank You.

To the CTR steering group and all the people who have helped with this booklet.

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You can find out more about **Care and Treatment Reviews** and download this booklet and other documents at: [www.england.nhs.uk/ctr](http://www.england.nhs.uk/ctr)



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