

Norfolk and Waveney Mental health transformation Expert by Experience Leader

Handbook



Improving lives **together**
Norfolk and Waveney Integrated Care System

Dear Expert by Experience Leader

Congratulations on starting your journey as an Expert by Experience Leader for mental health service transformation in Norfolk and Waveney!

We hope this will be an opportunity for you to draw on your experience of living with mental health treatment and support needs, to make a difference for others in the future, and to develop confidence, skills and new relationships.

In this induction handbook we have information that we hope will be helpful to you in your role.

If you have any queries or questions about being an Expert by Experience Leader or the information in this handbook, please feel free to contact:

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Welcome to the Lived Experience Reference Group

Your involvement, drawing on your own lived experience and representing collective lived experience priorities, will lead to positive developments and changes in mental health care and support in Norfolk and Waveney. Through being involved we hope you will see positive benefits for your own wellbeing.



You don't need to be anyone other than yourself, and you don't need to know everything. You are bringing insight and ideas based on your own lived experience and that of others from community listening.

It can feel daunting to be in a meeting/room with Experts by Training (EbTs who are health and social care professionals and commissioners), but this is a space for you, too. We will be working together based on coproduction values such as equity, wisdom, respect, creativity and kindness.

There are different ways to be involved in mental health service and system improvement in the Norfolk and Waveney Integrated Care System. This particular role is within the Adult Mental Health Transformation Programme. The activity of the Lived Experience Reference Group is focused on sustainable transformation that will happen over time.

Being an Expert by Experience Leader and part of the Lived Experience Reference Group does not prevent you from being involved in other ways in the Integrated Care System.



Who are Rethink Mental Illness?

Our mission is to lead the way to a better quality of life for everyone severely affected by mental illness. This includes carers, families and friends.

Our vision is equality, rights, fair treatment, and the best quality of life for all those severely affected by mental illness. Together, we run over 100 local groups which provide vital peer support in the community. We know, from our vast experience, that people severely affected by mental illness can have a good quality of life.

We support tens of thousands of people through our groups, services and advice and information. We train employees, employers and members of the public on how best to support someone affected by mental illness. All of this work guides our campaigning for the rights of people with mental illness and their carers.

We also support people in lived experience roles in service and system transformation, to work in partnership with people in other types of roles to achieve positive change for better access, experience and outcomes for people experiencing mental health challenges in Norfolk and Waveney.

Some benefits of being an

Expert by Experience Leader



Feeling empowered, building your confidence and self-esteem.

Enabling you to develop your skills in a safe environment.

Improving experience of services for others.

Meeting new people, and learning new skills.

Enabling you to be part of a shared purpose for positive change.

The benefits of coproduction

In 2019 the New Economics Foundation identified key outcomes relating to co-production in individuals with lived experience of mental health issues. This includes an increase in the levels of wellbeing, prevention, social connectedness, stigma, inclusion and personal competences and skills; they found wellbeing to be the strongest theme, including both physical and mental health. Additionally, there is a wealth of evidence highlighting the benefits of involvement on the quality of care received, improved quality of life, a reduction in the number of hospital admissions, improved relationships and overall outcomes for people with lived experience (National Voices). In other research around the benefits of involvement, people with lived experience identified the following as having a positive impact; being able to have a 'say' in decision making, service improvements, feeling listened to and many identified positive changes in recovery and self-esteem as a result.

What is coproduction

There is no single definition of coproduction, nor a single theory. In the world of health and care it is widely accepted that coproduction is people with lived experience working as equal partners with people working for service organisations.

Equal means where each perspective :

1. living with a mental/emotional long term condition
2. treating and supporting within an organisational system

is valued as equally important in considering and deciding plans and activity.

Coproduction can happen in many different situations, for example in discussions and decisions about individual care plans, through community conversations, and in system transformation discussions and decisions.

There are some factors that indicate whether you are coproducing with people with lived experience – which can be useful to reflect on at the beginning and end of projects:

- EbE Leaders involved from start to finish of specific projects
- EbE Leaders represent the views of others
- EbE perspective listened to and valued
- EbE ideas and suggestions taken forward
- EbEs kept up-to-date with developments
- EbE Leaders accredited/rewarded.

Definitions of coproduction include:

“Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation. Co-production acknowledges that people with ‘lived experience’ of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives. Done well, co-production helps to ground discussions in reality, and to maintain a person-centred perspective.”

What is co-production? NHS England, 2020

“Co-production is a way of thinking about how our public services are designed, delivered and evaluated. It involves working in equal partnership with communities in spaces where power is shared, making services more effective and efficient, and in the long-term more sustainable. Nesta has described it as ‘the most important revolution in public services since the Beveridge Report in 1942’.

Coproduction an inconvenient truth, Kings Fund, 2016

"Coproduction occurs when people with lived experience of mental health issues and carers work together with staff as equal partners in a way that is meaningful and effective from the outset. It follows a process of co-creation and shared decision making that is reciprocal and jointly owned by all involved. Coproduction achieves a shared vision that transforms the balance of power and resources to a position of equal ownership."

Rethink Mental Illness Organisational Strategy, 2021

What is the difference between Expert by Experience (EbE), Expert by Experience Leader (EbEL) and Expert by Training (EbT)?

Experts by Experience (EbEs) are individuals living with mental health needs over time and understand how medical, clinical and social interventions fit in with their lives and needs – in a holistic way. Theirs is real life experience: 'lived experience'. They may have knowledge/understanding of mental health systems or they may not. Carers and family members are also experts by experience through caring for someone.

Expert by Experience Leaders (EbELs) are people who have their own lived experience of mental health services who engage in mental health service transformation. They are involved in equal partnership with Experts by Training (EbT) using a coproduction approach. They not only represent their own views but also reflect the views of other EbEs in improvement activity, concentrating on how the whole system works, and hopefully leading to better outcomes for people.

Experts by Training (EbTs) are staff working in the health and care system. They have expertise in particular practice areas. Theirs is experience/knowledge from learning and training: 'learned experience'. They have knowledge and understanding of the health and care system. Staff may have their own lived experience. As co-production intentionally brings two different perspectives together, they need to be clear about which perspective they are bringing to a consideration or decision.

Being an Expert by Experience Leader

You will agree what activity suits you best with your Rethink facilitator, according to your lived experience and life skills. It is helpful for EbE Leaders to come together in a team space regularly to share and reflect on their activity and shared purpose with EbTs.

There are different ways you can be an EbE Leader:

- You can be involved with the **Community Listening team** to connect with other EbEs across Norfolk & Waveney, sharing what you hear with other EbE Leaders. This way, what a wide range of people say can influence the collective lived experience priorities for improvements to access, experience and outcomes.
- You can be involved in **lived experience insights sessions**, to see how information gathered from community listening can go through collective lived experience priorities to strategic influencing.
- You can be involved in projects that are focusing on particular opportunities for lived experience to strategically influence developments within the **adult mental health transformation programme**. Here you will attend meetings with EbTs who are working on specific areas of mental health system and service improvement. You will share insights from community listening and champion the collective lived experience priorities in project meetings and steering groups.
- You can **co-design communication** (plans, messages, website content, leaflets, etc) about improvements to the adult mental health service offer. This is so people will be able to better understand the help options available, and how to access them.
- You can **co-design and co-deliver training**, either on coproduction practice or staff training in other approaches.

You can **co-facilitate or co-chair** project and steering group meetings. There are two EbE Leader regular meeting spaces:

1. **Lived Experience Reference Group** to discuss current focuses for lived experience influence on the adult mental health transformation programme, together with EbTs. Facilitated by Rethink. Held 2pm to 4pm on the first Tuesday of each month and 2pm to

4pm on the third Thursday of each month, on Microsoft Teams.

2. **EbE Leader Team meeting** to discuss collective lived experience priorities and the thread of influence, coproduction practice issues and anything that is helpful in relation to the collective purpose and EbE Leader role.

Held on the second Friday of the month at 11.30am on Microsoft Teams

An email bulletin is sent out by a Rethink facilitator every week to summarise activity and influencing opportunities.

There are a variety of **project meetings and steering groups**. These include:

- Integrated service offer around individual needs, including personalised planning (Building on the Care Planning Approach meetings, Care Pathways meetings).
- Focus on treatment and support for Complex Emotional Needs (Personality Disorder and Complex Emotional Needs Workstream).
- Focus on treatment and support for Eating Disorders (Eating Disorder All Age Strategy Oversight Group).
- Focus on Supported Living (Supported Living Working Group, Supported Living Proposal Group and Complex Housing Working Group).
- Focus on Primary Care (Primary Care Network Mental Health Team Group).
- Focus on treatment and support around mental and emotional distress (Wellbeing and Crisis Hub Strategic Meeting).
- Focus on how to communicate what is changing (story of change) and how people can access treatment and support – including people currently underserved and experiencing inequalities of access, experiences and outcomes.
- Focus on how to get more people with lived experience involved in the change and the system – and co-production training.
- Community Mental Health Steering Group.
- Prevention and Wellbeing Steering Group.
- Urgent And Emergency Care and Inpatient Transformation Steering Group.

These groups are constantly being updated as new areas of work are decided upon.

Staying safe in meetings

Your wellbeing in your EbE Leader role comes first, and your Rethink facilitator will be able to support you to feel as safe as possible in your involvement activity

- When you become an EbE Leader, your Rethink facilitator will ask you what you need as an individual to be able to participate safely in group and working meetings, and to connect with other EbEs, and with EbTs. We will agree with you the best ways to support you in meetings, and can chat with you about your needs in one-to-one development meetings.
- It is important to keep in mind that you are not in meetings to tell your individual story, although you may wish to bring some aspects in as relevant in a way that is safe to you. We will support you in this. You are in meetings to influence, based on the collective lived experience priorities, and give a lived experience perspective that is based on your own lived experience and that of others.
- It can be helpful to do the Recovery College course in how to share your lived experience/story safely. Please ask your Rethink facilitator for details. We also offer training and coaching in psychological safety in meetings.
- Sometimes it can be helpful to have quick reminders at the beginning of meetings so that everyone can feel as safe as possible. Sometimes it's helpful to read out your group agreement.
 - We agree to keep this a safe space where we can think and speak freely about the topics on mental health and wellbeing support in the community?
 - There are no right or wrong answers, or silly questions?
 - We will respect each other's thoughts and ideas, even if we disagree with them?
 - We will actively listen, in an appreciative way?
 - We will actively contribute our knowledge, thoughts and ideas?
 - We won't share personal or confidential information?
 - We will focus on general lived experience needs rather than individual or personal stories – while understanding these can work well to illustrate strategic points?
 - We will use simple language and avoid jargon and acronyms?
 - We will respect our individual needs?
 - If you become distressed in any meeting or activity, please 'take 5 or more' by putting a quick 'need to take 5' message in the chat and turning off your camera and sound. Please do check in with your usual mental health support if you need to.

Support and training in your EbE Leader role

Rethink offers you a range of training about coproduction and your role – and your facilitator will let you know about this.

- Your Rethink facilitator will offer you one-to-one development and coaching sessions, reflecting on your involvement activity, how you're finding the EbE Leader role, and what your development goals are. Support provided by Rethink staff is not therapeutic in nature. It is around understanding information, how involvement happens, what has been discussed in meetings, what actions are decided, how to influence in meetings and outside meetings, how to engage with other EbEs, etc. You will also have the opportunity to reflect and learn together in EbE Leader spaces/meetings.
- Your Rethink facilitator will be able to link you with Rethink's advice and assistance telephone support services if needed.

Scope of the EbE Leader role

Please ask for guidance from your Rethink facilitator about the scope of your role and activities within it. You can refer to the EbE Leader role description. All coproduction activity will be organised through your Rethink facilitator, not directly with the NHS staff you see in workstream meetings. Please always ask your Rethink facilitator if you are unsure about what you are involved with or the nature of your involvement.

Safeguarding

Your Rethink facilitator will support you around any safeguarding considerations should this be needed in your activity. However, safeguarding is everyone's collective responsibility – so please let your Rethink facilitator know as soon as you have any concerns at all about the safety of anyone with care and support needs, or who may be at risk of harm, abuse and neglect. All children under the age of 18 are considered to be at risk.

You do not need a Disclosure and Barring Service (DBS) check for this role when you are always active in 'supervised' spaces including online.

Payment for EbE Leader involvement

On this programme, involvement payments of £18 per hour are offered for most activity. You do not have to claim if you don't want to. This is paid volunteering and it's your choice about whether you accept the payment offered. We have a separate Involvement Payments Policy which has all the details about claiming and what to do if you receive benefits (this involvement activity comes under a special category where some payments can be made without them affecting benefits). All activity must be pre-agreed with your Rethink facilitator. We will also pay should a meeting be cancelled with less than 24 hours' notice. Expenses such as travel are paid separately, and must also be agreed in advance.

Is this an employment role?

No, this is a category of lived experience participation that is categorised by the DWP as 'service user involvement'. Participation payments are paid through Rethink's payroll and are subject to statutory deductions including tax and NI dependent on individual earnings and tax codes.

As this is a service user involvement role, people who receive benefits can receive payment for a certain number of hours a month after notifying their benefits office. We can support people in this process, for more information see SCIE www.scie.org.uk/co-production/supporting/paying-people-who-receive-benefits and our payment policy.

To claim for payment we ask you to fill out a monthly claim form, and send it to your Rethink facilitator by the last day of the month you are claiming for. Payment will be processed on the 15th of the following month and paid straight into your bank account.

Rethink Mental Illness.
EXPERT BY EXPERIENCE PARTNER, SERVICE USER OR CARER CLAIM FORM

Name: _____ Payroll Number/Employee Number _____

Date	Activity	Project code	Hours / full day / half day	Agreed Payment (per hour, half day or full day)	Total
		4197		£18	

Typed in names are accepted
Completed by: _____

Travel Expenses

Travel expenses are paid at 45p per mile by car up to 1000 miles, 25p per mile thereafter, and 20p per mile by bike. These are all paid directly into your bank account after you claim. We will only pay for taxis if they have been agreed beforehand by Rethink staff based on participation access needs.

Bus and rail fares are reimbursed but you must provide receipts.

If you are involved between 12 noon - 14.00pm you will be able to claim expenses for your lunch up to the value of £5.50 (receipts required for payment).

NAME _____ (IN BLOCK CAPITALS) ADDRESS _____ (FULL POSTAL ADDRESS IN BLOCK CAPITALS)		Service Code : <input type="text"/> Please tick Box below			
Mileage Rate to claim is as follows: First 10,000 business miles in the tax year (per annum) 0.45p Each business mile over 10,000 in the tax year (per annum) 0.25p		SERVICE USER/EBE <input type="checkbox"/> Expenditure Code	<input type="checkbox"/> Expenditure Code		
		VOLUNTEER / CARER <input type="checkbox"/> Expenditure Code	<input type="checkbox"/> Expenditure Code		
		External Personnel <input type="checkbox"/> Expenditure Code	<input type="checkbox"/> Expenditure Code		
		The above to be completed by the service			
DATE	DETAILS DESTINATION & PURPOSE, PLUS OTHER RELEVANT DETAILS	MILES CLAIMED	AMOUNT CLAIMED FOR MILEAGE	OTHER EXPENDITURE	TOTALS
TOTALS DUE					
Cumulative mileage claimed since 1 April brought forward from previous claim Cumulative mileage claimed since 1 April carry forward to next claim				Insurance Cover Policy - It is the individual's responsibility to ensure that they have appropriate insurance cover for occasional business use and that Rethink Mental Illness does not accept any liability that might arise from failure to do so. In making this claim I certify that I have adhered to the insurance cover policy.	
If you wish to be paid directly into your account please complete the below;-		Please note finance will contact you to verify your details are correct or please ensure you complete either contact details or email			

Please ask your Rethink facilitator for this expenses claim form which is different to the involvement payment claim form.

Sickness and holidays

As this is not an employed role we do not pay for sickness and holidays.

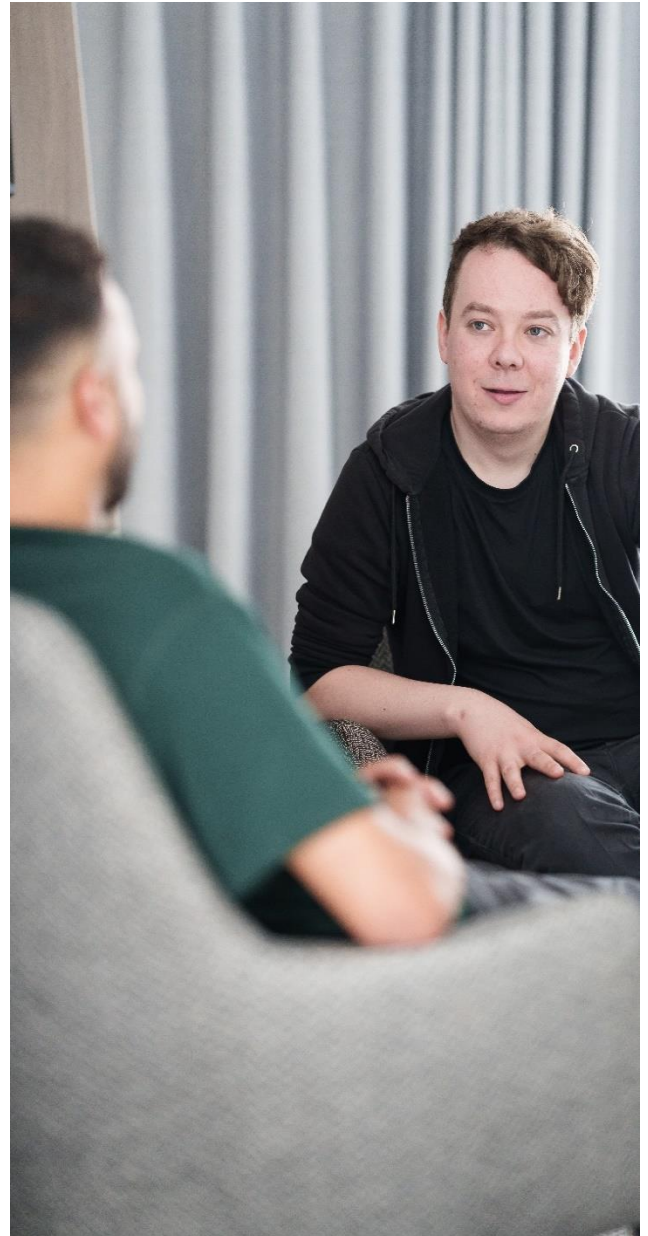
If you are unwell or unable to attend a session/meeting, could you please contact your Rethink facilitator as soon as possible.

As this is a lived experience role, it's fine if you need to take a break from activity. Just let us know beforehand. Before you come back we will ask to meet with you to understand any support needs or possible conflicts of interest.

Respect for others and acceptance of difference

Rethink encourages Experts by Experience and Experts by Training to demonstrate the following approaches when working together:

- Consideration for the possibility that what we do or say could negatively affect others.
- Sharing positive and negative experiences in ways that are constructive and not blaming.
- Active listening to understand different opinions.
- Respect for confidentiality and the right of others to privacy.
- Mutual support so that everyone can participate to the best of their ability, regardless of their background.
- Being as democratic as a situation allows or ensuring that everyone has at least had an opportunity to be heard.
- Raising awareness of and challenging stigma and discrimination.
- Acceptance of and adherence to equality and diversity laws.
- Recognising the value of different types of knowledge, including expertise derived from lived experience, including caring experience.
- Being willing to support creative approaches.



Relationships and issues

Rethink aims to treat everyone fairly and equally and aims to facilitate resolution of problems in the most informal and practical ways possible.

If you have a problem with another Expert by Experience, Expert by Training or member of Rethink staff, we ask that first you ask for support from a Rethink member of staff and work out the best way of approaching this. If you have a problem with a Rethink member of staff, you should contact their line manager in the first instance.

We have an EbE Agreement which sets out what you can expect from Rethink staff in relation to your role, and what our expectations are of you. This is intended as helpful information when you start your EbE Leader role, and to refer to when needed. Please ask your Rethink facilitator if you have any questions about this Agreement.



Health and Safety

Although this is not an employment or volunteer service role, there may be activities in person or in the community where it is important to be aware of health and safety considerations. In these situations, we ask you to:

- Take reasonable care of your own health and safety and that of others who may be affected by your acts or omissions.
- Undertake tasks as instructed and in line with training received.
- Report to your Rethink facilitator any health and safety concerns.
- Not misuse or interfere with any equipment provided to ensure safe working practice.
- Report any accident, involving injury, damage to premises and equipment, or potential injury, damage, or loss.
- Not undertake any activities in the community on your own but always with a Rethink staff member.



Confidentiality

Rethink takes confidentiality very seriously. Your personal information is stored securely, and we will not give out your details without permission. We will write to you annually to ask for your permission to keep your details on our database. Emergency contact names and numbers will be required should an incident occur.

As an EbE Leader, we ask you to keep confidential any personal or sensitive data –both yours and others. This includes not sharing others' personal details or information, such as email addresses, phone numbers, social media addresses. Please ask your Rethink facilitator if you are unsure.

Rethink facilitation contacts

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Norfolk and Waveney
Coproduction Manager

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Sam Holmes

Head of Integrated Care System
Coproduction and Involvement

07483 171437

Samantha.Holmes@rethink.org

Louise Tailford

Senior Coproduction Officer

Contact via MS Teams call

Louise.Tailford@rethink.org

Duygu Guzeltas

Community Engagement Officer

07467 838487

Duygu.Guzeltas@rethink.org

Sources of information and support around your mental health.

Rethink Advice and Information Service

0808 801 0525

(9:30am – 4:00pm Monday to Friday except bank holidays)

E-mail: advice@rethink.org

Webchat: www.rethink.org/about-us/our-mental-health-advice
(10am - 1pm Monday to Friday except for bank holidays)

Rethink Mental Health and Money Advice

An online service helping with debt problems

www.mentalhealthandmoneyadvice.org

NHS 111

For urgent medical help fast, but not a 999 emergency.

Telephone – 111 press 2

www.england.nhs.uk/urgent-emergency-care/nhs-111/

Samaritans

Offering emotional support 24 hours a day

Telephone - 116 123Free
(24/7 365 days a year)

www.samaritans.org

National Debtline

This organisation provides free, independent and confidential advice about debt. You can contact them over the telephone, by e-mail or letter.

National Debtline Tricorn House, 51-53 Hagley Road, Edgbaston, Birmingham B16 8TP

Telephone - 0808 808 4000 Freephone

(Monday - Friday 9am to 8pm and Saturday 9.30am to 1pm)

www.nationaldebtline.org

SaneLine

Offering specialist mental health emotional support 6am-11pm everyday. And you can also email through their website.

Telephone - 0300 304 7000

(4pm – 10pm every day.)

www.sane.org.uk

support@sane.org.uk

No Panic

A national support helpline for people experiencing anxiety, panic, OCD and related disorders including withdrawal from tranquillizers. No Panic also provides support for the carers of people who suffer from anxiety disorders.

Telephone - 0300 7729844

(10.00 am - 10.00 pm every day of the year. During the night hours the crisis message is played)

Jargon Buster

Glossary of terms:

- Approved Mental Health Practitioner (AMHP)
- Autism spectrum disorder (ASD)
- Black Asian Minority Ethnic background (BAME) – better to use ‘people with minority ethnic backgrounds/people with specific background
- CCG (Clinical Commissioning Group) planning, funding, evaluating services
- Child and Adolescent Mental Health Services (CAMHS)
- Children and Young People (CYP)
- Cliff-edge: idea that you reach the end of a particular service with no continuity of care/have to be referred again
- Co-production (expert by experience leaders working as equal partners on service transformation)
- Community Mental Health Teams (CMHTs)
- Community engagement/listening: a two way process of understanding needs/ideas from people who use or may use services in future, and families and carers, and sharing developments
- Covid 19 (C19)
- Care Programme Approach (CPA): being phased out as either ‘on’ or ‘off’
- Complex or co-occurring needs: where people’s health and lives are affected by several different types of stressors eg illnesses + money worries + housing worries
- Crisis Alternatives: crisis cafes or sanctuaries run by VCSE as alternative to A&E
- Crisis Assessment and Treatment Teams (CATT)
- Crisis Resolution and Home Treatment (CRHTT) Team
- DIALOG+: holistic personal planning and outcomes approach
- Did not attend (DNA)
- Delayed transfer of care (DTOCs)
- Ecosystem: idea of joined up, partnership working across organisations, including small community organisations and groups (grassroots)
- Emergency Department (ED/A&E)
- Goal Based Outcomes (GBO): holistic personal planning and outcomes approach
- Health Based Place of Safety (HBPoS) – used to be called S136 suites
- Health inequalities: addressing differences in the status of people’s health and/or the care that people receive and the opportunities that they have to lead healthy lives
- Holistic care: help with all factors that affect mental health (clinical and social)
- Integrated Care Partnership (ICP)
- Integrated Care System (ICS)
- Intensive Treatment Unit (ITU)
- Key Performance Indicator (KPI)
- Learning and Development (L&D)
- Local Authority (LA)
- Learning Disability and/or Autism (LDA)
- Liaison Psychiatry Service (LPS): psychiatric service in A&Es
- Long term conditions (LTC)
- Multi Disciplinary Team (MDT)
- Mental Health Act (1983) (MHA)

- Mental Health, Learning Disabilities and Autism (MHLDA)
- New Model of Care (NMOC)
- NHS Long term plan (LTP)
- NHS Mental Health Trust: organisation delivering NHS services
- Occupational Therapist (OT)
- Out of area (OOA)
- Out of area placements (OAP)
- Peer Support Worker: intentional support role based on sharing lived experience (PSW)
- People with and intellectual disability (PWID)
- Personal Protective Equipment (PPE)
- Primary care networks (PCNs) – groups of GP practices working together
- Patient Reported Experience Measure (PREM)
- Patient Reported Outcome Measure (PROM)
- Recovery House (residential rehabilitation after hospital)
- Red Amber Green rating (RAG) – for project management
- Rehabilitation (intensive holistic support after hospital)
- Recovery and Quality of Life (ReQuoL): holistic personal planning and outcomes approach
- Research and Development (R&D)
- Serious Mental Illness (SMI)
- Service User Involvement: a statutory duty for services to involve people who use services, may need to use services in future, carers and families
- Single point of access (SPA)
- Specialised services: eg range of community and hospital mental health specialisms
- Step Up, Step Down: idea of service users being able to move without thresholds between different levels/types of services
- Threshold: level of need for a particular service
- Triangle of Care: regular communication between service user, carer and practitioner
- THRIVE model: originally developed for children, young people and their families Thriving, Getting Advice and Signposting, Getting Help, Getting More Help and Getting Risk Support
- Trauma informed approach/care: approach based on appreciating how people have been affected by adverse events or abuse?
- Trusted assessment: where organisations work in partnership, staff ‘trust’ assessments of need made by colleagues in other organisations so avoiding the person having to repeat their story/needs
- Voluntary, Community, Faith and Social Enterprise sector (VCFSE)
- Warm transfer/introduction: where staff introduce service users to another service, including across organisations, keeping relationships open until the transfer is made
- Whole System Integrated Care Dashboard (WSIC)

<https://www.rethink.org/advice-and-information/browse-all-topics/>