

# Patient and Carer Guide to Involvement



# Equality statement

We value diversity and welcome people who identify with different protected groups getting involved. Your experiences help us to ensure that our services are fair, inclusive and meet your needs.

religion or belief disability  
gender sexual-orientation  
gender reassignment race  
age pregnancy and maternity  
marriage or civil partnership



## Employment Law

Involvement activity is not paid employment. It is not covered by a contract of employment between an employer and employee. However, service users and carers who are paid back travel expenses for their involvement should contact their benefit office if they have any questions.

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# 1. Introduction to Involvement

Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust values the involvement of service users, their carers and the wider community. The Trust is looking for people with experience of its services to share their views and influence how we work.

Involvement comes under patient and public engagement which is different to mainstream volunteering. The Patient and Carer Involvement Team co-ordinate and facilitate service user and carer involvement, in specific short-term activities and projects like service design, planning and evaluation. We have set up an involvement bank to help us do this work.

This Guide to Involvement and the Involvement Bank registration form are available online at:



[www.cntw.nhs.uk/services/patient-and-carer-involvement](http://www.cntw.nhs.uk/services/patient-and-carer-involvement)

This Guide identifies ways to involve service users and carers in shaping future healthcare services. How much you get involved is up to you. There are three types of involvement:

## Individual

In assessment, formulation, care planning and goals, in self-management, in individual issues. This happens when you are in services.

## Development of services

Groups, wards and community meetings, food, Points of You (experience feedback tool), recruitment and selection, training, research and evaluation.

## In service change and improvement

More 'formal' consultation, involvement commissioning, change projects and initiatives.

Service users and carers who have experienced the Trust's services within the last four years and would like to be involved as a 'contributor', are encouraged to register with the Trust's Involvement Team.

If you want to get involved, please complete a registration form. (See appendix 2).



You are encouraged to share ideas and respect the needs and views of others. You will be given clear information, recognising and respecting confidential and sensitive content. You will receive support, guidance and honest answers about how decisions are made.

If you think that

- The Trust has not got involvement right
- Are concerned that anyone is not acting within the Trust's value and behaviours

This guide provides you with key information to help you on your involvement journey.



Talk to any member of staff or the Involvement Team.

# 2 The Involvement Team

Involving patients, carers and their families in making decisions about their care can lead to better outcomes and a better overall experience. We are looking at new ways to involve service users and carers in shaping future healthcare services.

We recognise and value the views of patients and carers. This is underpinned by our 'Together: Service User and Carer Strategy' and its commitment to offer effective and meaningful involvement. We firmly believe that a collaborative relationship with patients, third sector (non government such as voluntary organisations) and communities is key to service design.

## Main Office:

Patient and Carer Involvement Team  
St. George's Park  
Morpeth  
Northumberland  
NE61 2NU  
Tel: 01670 501 816

Email: [involvement@cntw.nhs.uk](mailto:involvement@cntw.nhs.uk)



Complaints: 0191 245 6672

## Patient Advice and Liaison Service

South of Tyne: 0800 328 4397

North of Tyne: 0800 232 0202

Safeguarding: 0191 245 6698



# 3 What Support is Available?

Support will be provided by the Involvement Team to enable you to meet your goals for involvement with the Trust. This will include training and appropriate support from the staff member leading the involvement activity you engage in.

Individual Patient and Carer Involvement Facilitators lead on each of the localities within the Trust; North (Northumberland and North Tyneside), Central (Newcastle and Gateshead), South (Sunderland and South Tyneside) and North Cumbria. If you have any questions please contact them via our main office for further guidance, information and support.

If you have any specialist needs for support, then please discuss this with your Patient and Carer Involvement Facilitator. You will also find that informal support is available from other service users and carers involved in the project.

In some areas of involvement confidentiality agreements or consent for certain activities will be used. These agreements will be explained and agreed with all those involved either prior to the involvement or on the day. There are also codes of conduct and terms of reference negotiated and agreed during meetings and activities.

# 4 How will you use my Information? (Privacy Notice)

The information you share in the registration form will only be used for the purpose of involvement activities within the Trust. It will be held in accordance with the Data Protection Act 2018 (General Data Protection Regulation GDPR 2016).

This information will not be shared with anyone outside of the Trust and will be held securely by Involvement staff for the purpose of any involvement activity that you may undertake.

When you register with the Involvement Team, you will be added to the Trust's electronic system and assigned a unique Involvement number. Your unique number ensures that travel payments claimed are paid to you. It is important that you include this number on any forms so there are no payment delays.

As you do involvement activities this information will be added to your record on the register. We will also add any training you undertake, so we can help you get involved in the right activities.

If at any time you wish to be removed from the register please contact the Involvement Team who will arrange to have your details deleted.

If any of your information changes please let us know as soon as possible so we can update your record.



# 5 What Information will I Receive?

Opportunities to get involved are sent out by email or post, depending on your preference. Some involvement is for specific geographical areas, or services, so will just be sent to those people matching that criteria on the register. Where possible, involvement opportunities are circulated with at least four weeks' notice and contain the following information:

- 1 Details about the involvement opportunity and the contact person
- 2 Any specific knowledge and skills required in order for you to be involved
- 3 The time commitment required
- 4 Details of any training that may be required for the activity
- 5 Details on travel expenses being offered (for most opportunities, other than personal attendance at conferences or training, public consultations)

# 6. Confidentiality

We all have a personal responsibility to protect and maintain confidentiality of both Trust and patient information. This continues after the involvement activity unless information comes into the public domain. By registering with the Involvement Team you agree that:

**'You will not, during or after your involvement with the Trust (except so far as is necessary and proper in the course of your involvement) disclose, use, divulge or communicate to any person, form, company or organisation, any confidential information acquired or discovered by you relating to the private or medical affairs of any patient, carer or staff member of the Trust.'**

Unless you are disclosing information to comply with a court order or statutory obligation or with the consent of the patient, carer or staff member concerned.



# 7. Health and Safety

The Trust attaches the greatest importance to the safety of service users, carers and staff.

We all have to work together positively to achieve a situation, compatible with the provision of proper services to patients, where personal injuries and hazards to the health of everyone can be reduced to a minimum.

# 8. Safeguarding

All staff, service users and carers who are involved in the Trust's activities have a duty to safeguard and promote the welfare of adults and children at risk.

This duty will take precedence over the duty of confidentiality where there is a risk of significant harm or where a criminal offence has occurred or is likely to occur. Any concerns you have about Service Users, Staff or Visitors should be raised immediately with the Involvement Team, senior staff on duty or the Trust's Safeguarding Team (see contact details).



# 9 Travel Expenses

We will reimburse reasonable travel expenses and a random selection of claims will be checked with AA route finder or equivalent.

Travel expenses are set in line with Her Majesty's Customs and Revenue Service (HMRC) recommendations. When claiming mileage your vehicle must have valid insurance, tax and an MOT certificate.

You must complete a service user and carer Involvement Expenses claim form, which will be provided by the Involvement Team when needed. You must attach receipts for public transport and car parking within 12 weeks of travel.

If you have a return rail or parking ticket a member of staff will sign to say it has been seen in order that you can keep the ticket for your return journey.

## Reimbursements can be claimed for:

- Receipted Public Transport
- Car mileage - at current rate per mile
- Parking - reimbursement with a receipt



Taxis can be used on an exception basis, with prior agreement by the Patient and Carer Involvement Team. Once agreed, a taxi will be pre-booked for you with the relevant local company the Trust has an account with.

Payments will usually be made directly into your bank account. If there is an open cash office on site your travel expenses may be reimbursed in cash on the day.





# Patient & Carer Code of Conduct (our shared agreement)

## Appendix 1

We greatly value the contribution of service users and carers in involvement activity, who support staff to deliver the highest standards of care to our service users. We recognise the responsibility that comes with this and are committed to supporting you in your role. To help you and promote best practice we have developed a set of core standards of behaviour in this Code of Conduct. The standards outlined are not exhaustive and act as guiding principles to help us promote safety, care and compassion to our service users and to enable you to

The code should be read as part of a wider package of Trust policies and procedures that apply to staff, volunteers and members of the involvement bank, which include Health and Safety, Confidentiality, Equality and Diversity and Smoke free.

It is intended to prevent, where possible, situations which could cause problems for you, our service users and carers, to our staff and for the reputation of the Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW Trust).

As a patient or carer representing the Involvement Team we expect you to:

### 1. Adhere to Trust Values

#### Caring and compassionate

- Put ourselves in other people's shoes
- Be approachable
- Listen and offer hope
- Focus on recovery
- Be sensitive and considerate
- Go the extra mile
- Be helpful

#### Respectful

- Value the skills and contribution of others
- Give respect to all people
- Respect and embrace difference
- Encourage innovation and be open to new ideas
- Work together and with our partners

#### Honest and transparent

- Have no secrets
- Be open and truthful
- Accept what is wrong and strive to put it right
- Share information
- Be accountable for our actions

## 2. Undertake your role effectively

- a. Meet the needs of service users and carers in your role as explained by the Patient and Carer Facilitator, and do not undertake tasks that exceed the boundaries of your contributor role. Under no circumstances should you undertake clinical duties.
  - b. The involvement bank should not be a platform to promote, impede, direct or intervene in social, political, economic, legal or environmental reforms.
  - c. Recognise and respect the roles and expertise of staff, and work in partnership with them.
  - d. Ensure your role remains safe and effective by attending agreed training, support, and group huddles.
  - e. Wear your ID badge whilst undertaking Involvement work only. Return the badge upon leaving the service and report any lost badges immediately.
  - f. Inform the Involvement Team staff when you are unable to attend your contributor role or feel unprepared and have not been supported.
  - g. If you have a complaint, inform your Involvement Facilitator who will direct you to the appropriate channels.
  - h. If provided with an electronic device, it is your responsibility to look after the equipment, only using it for the purposes of involvement bank activities and returning it when asked.
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## 3. Report Safeguarding Concerns

- a. Follow guidance relating to Safeguarding Adults and Safeguarding Children where required.
  - b. Listen to service users and do not disregard any concerns raised.
  - c. In line with guidance ensure you report safeguarding concerns.
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## 4. Promote Equality and Diversity

- a. Promote and support equality and diversity by treating everyone fairly irrespective of difference.
  - b. Respect the beliefs and cultures of others, even when you do not share them.
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## 5. Maintain Confidentiality

- a. All personal information provided by a service user, carer or member of staff must remain confidential. Situations may occur however when a person discloses information that has cause for concern e.g. their intent to cause harm to themselves or others. In this instance the information should be passed on to the Involvement Facilitator, a member of the Involvement Team, or a senior member of the ward or community staff. If safe to do so the service user will be informed that this information will be passed on and it should be explained that this is being done in the best interest of themselves and others.
- b. Members of the Involvement Bank should not access any written material, notes or data containing personal information about service users, carers, staff or other involvement contributors either by computer or from manual files or notes.

- c. If someone you know is being treated in a team or service you are undertaking your involvement activity in, please let the Activity Lead Officer / Involvement Facilitator know.
- d. Details of service users, carers or staff should not be discussed on social networking sites. Please discuss any issues or concerns with the Team.
- e. Do not take photographs or make videos of service users, carers, staff or other contributors

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## 6. Embrace A Culture of Health and Safety

- a. Do not put yourself or others at unnecessary risk.
- b. Comply with Health and Safety Policies and Procedures.
- c. Liaise with the Involvement Team to report any accidents or incidents.
- d. Do not attend your role if you believe that your health may impact on the safety of service

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## 7. Protect Service Users By Acting Responsibly

- a. Personal information should not be shared with service users or carers.
- b. Personal gifts or money from service users should not be accepted. Inform the Involvement Team if any gifts are offered to you. Neither lend nor borrow money.
- c. Do not swear, make offensive comments, bully, intimidate or use aggressive behaviour.
- d. Do not attend your Involvement activity while under the influence or in possession of alcohol or illegal non-prescribed drugs.
- e. Do not offer service users any form of medication including legal highs (now referred to as

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## 8. Accept Recognition For Your Efforts

- a. Allow the Trust to offer our sincere thanks and appreciation to you for your valued contribution as a Member of the Involvement Bank.
- b. Recognition payments can be claimed whilst engaged in involvement activities and it is the contributor's responsibility to submit a claim in line with the recognition payments policy in order for payment to be made.
- c. It remains the contributor's responsibility to ensure that recognitions payments have no

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**This Code of Conduct is aimed to promote and encourage best practice and does not under any circumstances form a contract of employment or imply any contractual agreement. The list is not exhaustive and some projects may require further expectations specific to the role. Disregard for the Code of Conduct will be investigated fairly by the Head of the Involvement Service and may in some circumstances result in removal from**

Signature

Date



Caring | Discovering | Growing | **Together**