

Patient Research Ambassador Initiative Information Pack

Please read this carefully before you apply.

Background information

Introduction

Clinical and health and social care research is important to patients in the NHS. It is one of the ways that we gather evidence to improve treatments and care. Patients and the public really care about clinical research, 95% of people recently surveyed said it was important to them that the NHS carries out clinical research. By taking part in clinical studies or other types of health research patients are helping others, and the NHS, to improve. There is also evidence that suggests taking part in research can improve patient care and have a positive effect on their health.

However, a National Institute for Health Research (NIHR) survey in 2014 showed that less than 21% of patients feel confident about asking their doctor about research. The NHS Constitution says that patients have a right to expect their NHS health practitioner to tell them about suitable research studies but this doesn't always happen. A "mystery shopper" campaign in 2012 showed that even in hospitals that ran research often there was no information available for patients to find out more.

At Bradford Teaching Hospitals NHS Foundation Trust we want to improvement the way we communicate with and listen to our patients about research.

The **Patient Research Ambassadors Initiative** is a joint partnership between several NHS organisations. These include:

- National Institute for Health Research (NIHR)
- NIHR Clinical Research Network
- NHS England.

The main aim of this initiative is to help improve access to research for patients and others, for example, carers. Part of this has been the development of a new Patient Research Ambassador (PRA) voluntary role.

What is a Patient Research Ambassador?

Patient Research Ambassadors (PRAs) are patients, carers or members of the public (sometimes called 'lay people') with an interest in health research. They have a commitment to help other patients in their local NHS to have information and choice about participating in research through the NHS.

Introducing the PRA role At Bradford Teaching Hospitals

We aim to:

- Promote patient-centred research that reflects patients NHS Constitution rights
- To help us raise awareness and open up conversations about research with patients and NHS staff
- To make good use of the expertise of people who have had some involvement in clinical or health research.
- To make sure that people using our local NHS have the best opportunities

What does being a PRA involve?

Please read the Role Outline on Page 5.

Some people who are already PRAs have written about their experience online. You can read these at <https://www.nihr.ac.uk/patients-and-public/how-to-join-in/patient-research-ambassadors/ambassador-stories/>

What induction and support will be provided?

PRAs will complete the Trust Volunteer Induction Programme so they understand the structure of the organisation and relevant Trust policies.

We will also provide a local induction to research in the NHS and the role of a PRA. This will cover:

- How research in the NHS is funded
- How it is delivered
- The roles of the different members of a research team
- Patient and public involvement in research

- A general introduction to PRA role
- Other training as needed, on an ongoing basis, including updating mandatory training required by the Trust

Which staff will PRA's be involved with?

The PRAs will work as a team with:

- The **General Manager, Research** for the Trust and Bradford Institute for Health Research - Tracy Watson
- The **Head of Nursing for Research and Innovation** - Angela Grange
- **Patient and Public Involvement (PPI) Facilitator** - Isla Skinner

The **General Manager, Research** will be responsible for the PRAs and they will be accountable to her. The **Head of Nursing, Research & Innovation** will act as a mentor to the PRAs, and with the **PPI Facilitator**, provide training and support. There will also be support from other relevant staff to help you in your role. You may also work with or alongside other staff across the Trust, for example in a particular department or area.

As a PRA you will be linked to the Trust research team and are likely to spend most of your time at BRI or St Luke's.

Once PRAs have settled into their role they will be linked into the **NIHR Clinical Research Network Yorkshire and Humber Partnership Group**. This meets every 3 months with representatives from all the organisations in the network area.

There are two lay members on this regional partnership group who will report on partner patient and public involvement activity, including recruitment of Patient Research Ambassadors. They also feed in any contributions from ambassadors in partner organisations.

There may be opportunities to attend or take part in regional or national events.

Are there any payments or allowances?

- **Out of pocket expenses** will be paid according to Trust Patient & Public Involvement policy. We will tell you more about this before you accept the role.

- **Parking Permit:** this will be provided for you to use when you are on Trust sites on PRA business. If you use it at any other time it will be withdrawn. :
- **Care costs** - our policy is to reimburse costs for essential care to allow people to take part in patient and public involvement activities, up to a set hourly rate, if these are not already met from another source e.g. Local Authority payment or Personalised Budget.
- **Meal costs** (when appropriate, or refreshments may be provided)
- **Overnight accommodation** (if necessary, for example attending an event too far from home to travel in one day)

Patient Research Ambassador: Role Outline

There are two types of Patient Research Ambassadors:

1. General PRA - People with a general interest in health research that can help us to work with staff to identify where we can make improvements to information and choices about research. This role is not linked to research in any particular area of health, illness or condition.

2. Specialist PRA - People with experience of a specific condition or illness as a patient or carer. They may work some or all of the time with a particular department. We may also ask them to support more general PRA work when needed.

We are only planning to recruit people for the General PRA role at the moment. In the future we will recruit more volunteers to become Specialist PRAs. It will be possible for a General PRA to move into a Specialist PRA if they want to do so and have the right experience for this role so you may want to apply now for the General Role rather than wait for the Specialist Role to come up.

PRA Activities

The PRA role can include a wide range of possible activities. **We don't expect any one person to do *all* of these things.** We will agree specific areas with each person about the focus of their role. This focus will reflect people's knowledge, interests, skills and experience.

Some broad examples of the kind of activity PRAs might be involved in are:

- ❖ Being part of the public-facing team for research in our Trust and the communities we serve, raising awareness of clinical research and helping to improve access to it for patients and carers
- ❖ Helping the Trust improve information and communication about research and how people can take part in it

- ❖ Sharing ideas and learning with other PRAs in the region and helping to develop the role.

We hope that PRAs will set up links with research teams in our Trust and may attend some of their meetings. They may also spend time with research staff to build up their knowledge about how research is carried out and how it fits into treatment plans.

Time Commitment

We would like people to be able to commit to the role for 2 years. We understand that sometimes unexpected things happen and you can always talk to us if you feel you can't continue with the role or need some time out from it.

We will ask you to think about the number of hours you can realistically allocate to the volunteer role. We hope that people will be able to volunteer for at least 8 hours per month.

Your individual regular time commitment can vary depending on the type of activities we plan together, and what you can offer. We understand that some people have more time than others. We will discuss this with you to agree a reasonable time commitment per month. We will work out an achievable plan together focusing on how your strengths and interest link to the types of activity we need to develop.

You will need to have time to do some personal reading or other preparation for meetings or activities, especially during the induction and training period.

The PRAs, General Manager, Research, Head of Nursing, Research & Innovation and PPI Facilitator will meet every 4-6 weeks at the Bradford Institute for Health Research at Bradford Royal Infirmary.

We may need to meet more often at the start to complete the induction and training for the role.

If an ambassador does not come to three consecutive meetings we will talk to them about their role and membership of the group. A PRA may be asked to leave the group if they can no longer carry out the role.

Patient Research Ambassador: Person Descriptor

Who can apply to be a PRA?

Our Patient Research Ambassadors need to be enthusiastic about the place of clinical and health research in the NHS. This role is open to anyone aged 18 or over who has a strong interest in helping us:

- Raise the profile of clinical / health research in the Trust
- Improve information for patients and the public about research
- Improve access to research for local people

More than one position is available. We are keen to have a range of people involved, of different ages, gender, culture and ethnicity so that the team reflects the diversity of the local area and our patients.

If you want to carry out this role as a representative of a group or organisation rather than as an individual please:

- i) Share the information about the PRA initiative and role with the organisation/group & discuss being their representative as a PRA
- ii) Ask them to write to us stating you will be a representative of the organisation or group
- iii) Be able to represent the views of the group or organisation, not just your own views - this means you would need to have regular discussions with them about the PRA work so you can represent their views

What knowledge, skills or experience are needed to be a PRA?

No particular knowledge is needed but a good general level of education will be helpful. Background knowledge about the NHS, science or health research, experience of taking part in health research, or involvement as a patient representative it would be useful, but it is not essential. Local knowledge, a good understanding of the needs of people, and being

able to communicate well with a range of people is just as important. If you have particular knowledge about area of health or a condition or an interest in it, please tell us about this when you apply.

Please tell us as soon as possible about any adjustments we need to make for you to be able to apply for this role, or to carry it out if you become a PRA. We will do all we can to support you in line with legislation and our policies.

Useful skills and characteristics for a PRA

These include:

- Confidence to talk to patients and members of the public, and NHS staff
- Good listening skills
- Be able to build relationships with people and work co-operatively
- Well organised
- Honesty
- Able to reflect and evaluate on your own contribution to the role and team
- Basic IT skills e.g. sending and receiving e-mails and attachments, using the internet to search for information. Help will be available. Paper copies of documents can be provided if you need or prefer this.

What will happen if I am invited to become a PRA?

- We will do a Disclosure and Barring Service (DBS) check (this has replaced CRB checks). There will be no charge to you for this. For more information about this see <https://www.gov.uk/government/organisations/disclosure-and-barring-service>
- We will meet to agree ways of working together, and arrange your induction and training. You will have a general induction as a Trust volunteer, then specialised induction for this role

- We will ask you to sign a volunteer agreement and follow the NHS Code of Conduct (we will provide a copy of this)
- You must understand the need for confidentiality and be willing to sign a confidentiality agreement

How do I apply for this role?

Please fill in the Volunteer Application form. In Section 6a and 6b of the form make sure you tell us:

- Why you are interested in health/ clinical research and in this role
- What skills and experience you have that you think will be helpful in this role

Send your completed form to:

**Volunteer Services Department,
Main Corridor, Level One,
Bradford Royal Infirmary,
Duckworth Lane,
Bradford BD9 6RJ**

Or by **email** to Volunteer.Information@bthft.nhs.uk

If you have any questions or need more information before you apply please contact:

Dr Angela Grange (Head of Nursing, Research & Innovation)

Telephone: 01274 366809 / 07968 472411 (Tuesdays-Thursdays)

Email: angela.grange@bthft.nhs.uk