

Patient and Public Voice (PPV) Partner

Application Information Pack:

Rare Diseases Advisory Group
(RDAG) member

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Introduction

Thank you for your interest in becoming a PPV Partner with NHS England and NHS Improvement.

NHS England and NHS Improvement is committed to ensuring that public and patient voices are at the centre of shaping our healthcare services. Every level of our commissioning system needs to be informed by insightful methods of listening to those who use and care about our services. Their views should inform service development and improvement. Our commitment to supporting our PPV Partners is set out in our [PPV Partners Policy](#).

Please read this application information pack before completing the application form for this role, to ensure you fully understand the application process, and to determine whether you have the skills and time to become a PPV Partner.

The deadline for applications is 16 January 2022.

NHS England and NHS Improvement will reimburse reasonable out of pocket expenses in line with the PPV Partners Expenses and Involvement Payments Policy. This post is a level 4 PPV role which attracts an involvement payment.

Involvement payments may be classed as earnings or income by Her Majesty's Revenue and Customs service (HMRC) or the Department for Work and Pensions (DWP). Role 4 PPV Partners will be paid their involvement payments through the NHS England and NHS Improvement payroll system. The payment will go directly to their bank account. Payments will be subject to statutory deductions including tax and national insurance (NI), although this will be dependent on individuals' earnings and tax code.

If you are in receipt of state benefits, you should seek advice from the relevant agency, for example JobCentre Plus, ideally in advance of applying and certainly before accepting an offer of a role which attracts an involvement payment, even if you intend to decline the payment.

For further information see the [PPV Partners Expenses and Involvement Payments Policy](#) or the [PPV Partners Policy](#).

Please note that correspondence will be primarily via email, unless otherwise requested. If you do not have access to email and would like to be contacted via telephone or post, please state this on your application form.

How to apply

Please complete and return the following accompanying documents:

- Application Form
- Equal Opportunity Monitoring Form

Please return these documents by email to england.voice-crg@nhs.net.

If you would like support to enable you to apply for this role, and/or information in another format please contact email england.voice-crg@nhs.net.

The deadline for applications is 16 January 2022.

We will rely on the information you provide in the application form to assess whether you have the skills and experience required for this role.

Diversity and equality of opportunity

NHS England and NHS Improvement values and promotes diversity and is committed to equality of opportunity for all. To help us understand if we are achieving this, we ask you to fill out an **Equal Opportunity Monitoring Form** as part of the application process.

Please let us know if you have support needs so that we can understand how we can support you to participate fully.

Once we receive your application

The steps will be as follows:

- i) We will acknowledge receipt of your application form via email.
- ii) Applications will be shortlisted by a panel, including members drawn from RDAG.
- iii) Applications will be assessed against the skills and experience required, outlined in this application pack. Selection will be made on the basis of the content of the application form.
- iv) Interviews will take place via video conference.
- v) Please note that two references will be taken up for successful applicants before involvement can commence.
- vi) This role does not require Disclosure and Barring Service (DBS) clearance (formerly known as a 'Criminal Records Bureau' (CRB) check').
- vii) All applications will receive a successful or unsuccessful notification. The successful notifications will include information about next steps.

If you wish to be informed about future involvement opportunities with NHS England and NHS Improvement, please [sign up to NHS England and NHS Improvement and NHS Improvement's In Touch newsletter](#), which includes details of current opportunities.

If you have any queries about the application process, or would like an informal discussion about the opportunity – please contact england.voice-crg@nhs.net.

Background, context and aims of the programme

NHS England and NHS Improvement continues to play a key role in the Government's vision to modernise the health service with the key aim of securing the best possible health outcomes for patients by prioritising them in every decision it makes. NHS England and NHS Improvement is committed to ensuring that public and patient voices are at the centre of shaping our healthcare services. Our commissioning system will embed patient and public voice representatives across our governance frameworks to ensure citizen insight is at the heart of developing our work.

One of the responsibilities of NHS England and NHS Improvement is to commission services for people with rare diseases. [The Rare Diseases Advisory Group \(RDAG\)](#) makes recommendations to NHS England and NHS Improvement, NHS Scotland, NHS Wales and NHS Northern Ireland on which highly specialised services or technologies should be considered for investment; this includes services or technologies already commissioned and services or technologies that have not previously been commissioned. Highly specialised services are those prescribed services concerning usually no more than 500 patients and/or provided in four or fewer specialist centres.

RDAG is seeking to appoint several new PPV representatives. Candidates will need to have a genuine commitment to patients and to the promotion of excellent health and social care services, as well as an understanding of national strategy development. The ideal candidate will bring significant board level experience, with a strategic healthcare focus and strong intellect, commercial and political astuteness and a willingness to challenge. They will be expected to apply their skills, knowledge and experience to support the group to make complex decisions that will drive forward NHS England and NHS Improvement's ambition to deliver world-class, patient-centred care.

Role of the group

RDAG makes recommendations to NHS England and NHS Improvement and the devolved administrations of Scotland, Wales and Northern Ireland on developing and implementing the strategy for rare disease and highly specialised services. Highly specialised services are provided to a smaller number of patients compared to specialised services; fewer than 500 patients per year. For this reason, they are typically best delivered nationally through a very small number of centres of excellence. Examples of highly specialised services include Heart & Lung and Liver Transplant Services, Lysosomal Storage Disorders, Proton Beam Therapy for some cancers.

The role of the group is to make recommendations on how highly specialised services should be commissioned. This includes recommending which expert centres should be nominated (or should no longer be nominated) to deliver highly specialised services.

The group receives recommendations from various sources. It formulates its advice by calling on sources of sound evidence from outside the NHS, such as professional bodies and patient groups. It observes the highest standards of impartiality, integrity and objectivity in relation to the advice it provides.

The membership of the group is broad and includes representatives from Royal Colleges, commissioners, professionals such as a geneticist and an ethicist and the patient and public voice representatives. There is also representation from the devolved administrations of Scotland, Wales and Northern Ireland.

The Chair is Alastair Kent OBE; previous executive director of Genetic Alliance UK, the alliance of over 200 patient support organisations for those with rare and genetic disorders for over 25 years.

RDAG is open to public scrutiny and accountability and plans to have its agendas and minutes published on the NHS England and NHS Improvement website, and by having an independent patient and public voice included in the membership.

What is the role of PPV Partners on the group?

The role of the PPV partner is to bring important views, perspectives and challenge into RDAG. This role is essential in championing a public, service user, patient and/or carer/family viewpoint, ensuring that the committee considers and prioritises the service user, patient, carer and family perspective. The PPV Partner role is to:

- Champion the diversity of PPV views, and not just to represent their own experience.
- Provide 'critical friend' challenge into the group.
- Champion and advocate for increasing patient and public awareness of the programme's outcomes and achievements.
- Review and comment on documentation.
- Comply with the Standards of Conduct, respecting the confidential nature of discussions when it is made clear by the Chair that this is a requirement.

Skills and experience are required for this role

PPV members on RDAG use their skills and personal experience as patients, carers or members of the public to:

- Commit to working to, and encouraging within the group, the highest standards of integrity and governance and a commitment to abide by the rules of confidentiality as laid out in the Seven Principles of Public Life.
- Provide independent judgement and advice on issues of strategy, vision, performance, resources and standards of conduct in respect of the scope of RDAG.

- Constructively challenge, influence and help RDAG develop strategies in respect of complex clinical prioritisations.
- Ensure that the patient and public voice is heard and informs RDAG proposals.
- In accordance with agreed RDAG procedures, to be assured that the performance and conduct of the group is meeting agreed goals and objectives, including the preparation of public reports as required.
- Bring independent judgement and experience from a patient and citizen perspective and apply this to the benefit of RDAG and its stakeholders.
- Engage positively and collaboratively in discussion of agenda items and act as an ambassador for patient and public voice.
- Link with other PPV groups within NHS England and NHS Improvement including Patient and Public Voice Advisory Group.

Time commitment

- Membership of the committee is for 12 months initially, at which point membership will be reviewed and possibly extended to a three year term.
- You will be required to attend meetings approximately every three months and will generally take place during working hours, most often lasting between 3-4 hours.
- Any face-to-face meetings, including briefing and induction sessions are most likely to be in London. However currently, all meetings are taking place via video conferencing.
- Prospective applicants should also be aware that many of the documents and programmes will be complex so will require reading time prior to the meeting.

Support for PPV Partners

- NHS England and NHS Improvement asks that all new PPV Partners complete an interactive online induction session. This webinar lasts an hour and will provide some background information to NHS England and NHS Improvement and the work that we do as well as wider support available to PPV Partners.
- Briefing for all RDAG members to enable them to support full participation of patient and public voice members of RDAG – in particular highlighting this in the responsibilities of the chair and vice chair.
- Meeting documents, and if necessary, pre-meeting briefings will be provided.
- There are a range of [learning and development opportunities](#) available to PPV Partners, details can be found on the Involvement Hub.
- Completion of several mandatory training courses will be required.

Exclusions

Exclusions to being appointed to the group apply to the following:

- Anyone who has had an earlier term of appointment as the chair or member of a public body terminated in certain circumstances.
- Anyone who is suspended from, has been removed from or is subject to conditions on registration of any professional body.

- Anyone who has previously been removed from trusteeship of a charity by the court or the Charity Commissioners.

Reimbursement and expenses

- Reimbursement of out of pocket expenses incurred in line with NHS England and NHS Improvement and NHS Improvement's PPV Expenses Policy. Expenses usually cover travel, and/or any subsistence requirements that arise. PPV partners should highlight any barriers to participation - please email england.voice-crg@nhs.net to discuss any support requirements that you might have.
- There will be an honorarium available to claim of £75 per half day and £150 per full day (for those people not representing or supported by an organisation) covering travel time, attending the quarterly meetings and pre-reading for an estimated maximum time commitment of 8 days per year.

Advice if you receive state benefits



Citizens Advice Bedford

Advice for PPV partners involved with NHS England and NHS Improvement and their programmes of work

Do you receive any of these benefits?

- Personal Independence Payment (PIP)
- Disability Living Allowance (DLA)
- Employment Support Allowance (ESA)
- Housing benefit
- Tax credits
- Income support
- Child benefit

NHS England has had to make some changes to way in which involvement payments are made to Role 4 Patient and Public Voice (PPV) partners. These changes are to ensure that PPV partners receive the payments in a tax compliant way, in line with Her Majesty's Revenue and Customs (HMRC) guidance.

From 1 April 2021, Role 4 PPV partners will be paid through the NHS England's payroll system. The payment will go directly to their bank account rather than receiving a cheque. Payments will be subject to statutory deductions including tax and national insurance (NI), although this will be dependent on individuals' earnings and tax code.

Citizens Advice Bedford helpline

Email: contractsadmin@bedfordcab.org.uk

Telephone: 01234 330604

Staff on the confidential helpline can help answer your questions about receiving involvement payments and claiming expenses related to being involved in NHS England or NHS Improvement's work.