## **Patient Forum**

## **Patient Representative Role Description &**

## **Person Specification**

### Version 4.2: November 2021

### Authors: Lisa Martin

### Status: Final

## **Summary of Role**

The Peninsula Cancer Alliance is looking for patient/ carer representatives to provide advice and share their experiences and knowledge of what matters to patients most, by becoming a member of its Patient Forum.

**What could you expect to get back in return as patient/ carer representative?**

Patient and carers who are involved with NHS organisations in such a capacity, often say they get a lot from their involvement experience. The following benefits to patients and carers have been recognised:

* A feeling of ‘giving something back’
* A feeling of making things better/ making a difference
* A renewed understanding of their own personal cancer journey
* Meeting other cancer patients and sharing experiences
* Increased confidence in speaking in public

## **Background Information**

## 

The Peninsula Cancer Alliance is one of 21 Cancer Alliances across England. It covers Devon, Cornwall and the Isles of Scilly. An Alliance brings together clinical and other senior leaders and patients across a defined area to:

* Plan and deliver the ambitions set out in the **NHS Long-term Plan.** For more information, please visit: <https://www.england.nhs.uk/cancer/>
* Reduce variation in outcomes and improve access to high quality, evidence-based care across whole pathways, and for the Alliance’s whole population.

In 2019, the NHS Long-Term Plan set out its ambition that by 2028, an extra 55,000 people each year will survive for 5 years or more following their cancer diagnosis. This will be achieved by improving our national screening programmes, giving people faster access to diagnostic tests, investing in innovative treatments and technologies, and making sure more patients can quickly benefit from precise, highly personalised treatments as medical science advances.[[1]](#footnote-1)

**Personalised care and support** under the NHS Long-Term Plan recognises that people are to have proactive, personalised conversations focusing on what matters to them by attending to their needs, wider health and wellbeing and the goals they want to achieve. Cancer Alliances offer a means for this to happen.

By ensuring that they is actively listen when engaging with patients and their families and carers, it will enable the Peninsula Cancer Alliance to prioritise local care, gather insights from patients and assure the quality of services.

For further information on Personalised Care and Support for Cancer please follow this link:

<https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/>

**Site Specific Groups (SSGs)**

Within the Peninsula Cancer Alliance, are 13 Site Specific Groups (a site referring to the site of a cancer e.g. Breast, Head & Neck etc.) each working with stakeholders to transform services and improve patient outcomes in line with best practice. Site Specific Groups provide a wealth of expert advice and play a fundamental role in helping the NHS to achieve its objectives set out in the NHS Long-Term Plan. **Members of the Patient Forum may already have roles within PCA SSGs.**

**Alliance Project Team members**

At any given time, the Peninsula Cancer Alliance is likely to be working closely with other patient and carer representatives to deliver specific projects. Just like the Site-Specific Group patient/ carer representatives, these patients/ carers will have a role description. **Members of the Patient Forum may already have roles on Alliance project teams.**

**Other key groups of people who can apply to be part of the Patient Forum**

The Peninsula Cancer Alliance is keen to hear the views of **anyone who has been treated or supported someone treated for cancer** at a time when the treatment has ended (two to five years later, ideally) at the following hospitals:

* Northern Devon Healthcare NHS Trust
* Royal Cornwall Hospitals NHS Trust
* Royal Devon & Exeter NHS Foundation Trust
* Torbay and South Devon Healthcare NHS Foundation Trust
* University Hospitals Plymouth NHS Trust

**Or have supported someone during either their diagnosis, treatment or beyond.**

The PCA is particularly keen to receive **Expressions of Interest (Appendix 1)** for this role from people who:

* Are from ethnic minority backgrounds
* Are disabled
* Are LGBTQ+
* Are between the ages of 18 and 24
* Have an unpaid caring role
* Have a rare or less common cancer such as Sarcoma or Brain CNS

## **Patient/ Carer Representative Role**

The PCA is looking for forward looking dynamic patient and carer representatives who can help support the Personalised Care and Support agenda and help reduce inequalities in experience and access in relation to cancer diagnosis and cancer care and treatment.

One part of a Patient Forum member’s role will be to share their unique perspective and contribute ideas to and opinion on the ‘bigger picture’ of providing cancer services in Devon, Cornwall and the Isles of Scilly. This could mean:

* Listening to plans about new services and commenting on their desirability from a patient and carer perspective;
* Listening to the results of patient surveys and offering up ideas to remedy any areas of concern;
* Listening to findings of Joint Strategic Needs Assessments (JSNA) and coming up with ways of addressing unmet need in the context of cancer

But it could also, at times if there is a need to, mean simply:

* Commenting on information intended for cancer patients;
* Inputting into the design of resources aimed at patients/ carers;
* Keeping up-to-date with local developments in cancer and national workstreams within the cancer-field such as the area of Genomics for example and the Faster Diagnosis Standard (FDS).

**Person Specification**

These are the attributes the Peninsula Cancer Alliance is looking for in its Patient Forum members.

### **Essential Criteria**

* The representative must be prepared to comply with our Standards of Conduct, which includes information on:

1. Declarations of interest
2. Confidentiality requirements – especially when it is made clear by the Chair that this is a requirement.

The Standards are contained within **Appendix 2** of your Information Pack.

* The representative should have recently completed treatment for cancer by one of the above Peninsula Cancer Alliance trusts in the past two to five years. Indirect representatives (carers) should have an indirect knowledge of treatment for cancer in a personal and unpaid capacity acquired in the last two years, at least.
* The representative should be prepared to comment on matters presented at meetings drawing not only from their experience (although this is very important) but ideally also from a number of other different cancer patient perspectives. They should therefore be able to demonstrate familiarity with experiences of people affected by cancer, at the outset of their Forum membership.
* The representative will need to be prepared to commit a minimum of four maximum of two-hour meetings per year plus extra time before each meeting to read papers and ask questions to the Patient and Public Engagement Lead in order to prepare sufficiently. At present, these meetings are planned to take place using Microsoft Teams (an online platform). Training can be provided for representatives who have not used Microsoft Teams in the past.
* The representative will also need to be prepared to link with other members of the Patient Forum, outside of the meeting, to gain fresh insight and also learn from more experienced and newer representatives (whichever applies). This doesn’t have to be in person but could be via e-mail or a social media platform. This will be supported by the Patient & Public Engagement Lead.
* The representative should be prepared to commit to a minimum of one year in the role which equates to attendance at four meetings. Although they can withdraw from the role during a ‘cooling off period’ of within two weeks of attending their first meeting.
* The representative should be able to join meeting remotely via Microsoft Teams (with support provided) and on some occasions, Covid-19 guidelines permitting, be able to travel within the region of Devon, Cornwall and the Isles of Scilly to attend a face-to-face meeting, once a year. Travel expenses will be reimbursed. A favoured location for face-to-face meetings is Lifton, in Devon.
* The representative will have the confidence to ask questions in front of others if they are unclear of anything that’s been said which could take the form of asking for information to be translated into plain English/ normal speak. This could be within an official Patient Forum meeting environment, attended by approximately 10 to 15 people. Being confident and assertive are key personal attributes for this role.
* The representative must be able to understand/ evaluate a range of information and evidence, some of which will be numerical. If numeracy is an issue for an applicant, best efforts will be made to support a representative with understanding the information.
* The representative must have a passion to improve the patient experience by sharing opinions formed by their own experiences and others from within their local community, if this applies.
* The representative has an awareness of and are committed to promoting equality of opportunity and valuing diversity in society and in this work.
* The representative is able to recognise and respect that different people will bring different perspectives to the same issue. They should be prepared to work with different people who hold different opinions to improve and design services for all, maintaining respect for others at all times.

*NB: Unfortunately, you are not eligible to apply if you are a current NHS employee or contractor.*

**Desirable Criteria**

* The representative is willing to learn and be coached/ supported by NHS staff.
* They are passionate about the NHS
* They have experience of and are willing to act as peer support for other patient/ carer representatives

**Support for the Representative**

The Peninsula Cancer Alliance will provide support in the following ways:

* Contact details for the Patient & Public Engagement Lead
* Provision of documents one week in advance of Patient Forum meetings
* Initial briefing before first meeting
* De-brief (informal meeting) after first meeting
* Provide an opportunity to acquire peer support using either social media or Microsoft Teams
* Coaching/ personal development with help from the Patient & Public Engagement Lead
* Where attendance to meetings involves travel, all reasonable travel expenses incurred from attending the meetings will be reimbursed by the Peninsula Cancer Alliance and refreshments provided at the meeting.

(See **Appendix 3** for the relevant Expenses Policy)

**Contact Information**

If you are interested in becoming a patient/carer representative on our Patient Forum, please contact: Lisa Martin (PPE Lead) Email: [lisa.martin3@nhs.net](mailto:lisa.martin3@nhs.net) Mobile: 07866 151565. Website: <https://peninsulacanceralliance.nhs.uk/>.

**Appendices – ‘Information Pack’**

1. Expression of Interest Pack:
   1. Expression of Interest Form
   2. Ethnic Monitoring Form
2. National Health Service England Standards of Business Conduct
3. Peninsula Cancer Alliance/ National Health Service England Patient and Public Voice Expenses Policy

**Glossary**

**Expression of Interest** – a formal way of registering your interest in a role with the organisation concerned.

**Faster Diagnosis Standard** – this standard requires NHS organisations to either diagnose cancer or rule it out within 28 days of a person being referred by their doctor for further urgent tests for suspected cancer.

**Genomics** – This is the study of the body’s genes and their functions. In cancer, genomic medicine can help identify the best kind of cancer treatment that will be most effective for people with certain genes.

**Joint Strategic Needs Assessment** - A Joint Strategic Needs Assessment (JSNA) is a process by which local authorities and healthcare commissioners (Clinical Commissioning Groups) assess the current and future health, care and wellbeing needs of the local community to inform local decision making.

A JSNA:

* Characterises the health and wellbeing status of the local population
* Identifies inequalities
* Illustrates trends
* Describes local community views
* Highlights the key findings

**NHSE** – National Health Service England. NHS England and NHS Improvement lead the NHS in England. To find out more about their work, please visit: <https://www.england.nhs.uk/ourwork/>

**Peninsula Cancer Alliance** – one of 21 NHS organisations (Alliances) that support other NHS organisations in a particular region to deliver national cancer-related initiatives and to address the needs of the whole population in that region in terms of cancer treatment and care, whilst reducing differences in quality and the experience of patients. To find out more about our work, please visit: <https://pensinsulacanceralliance.nhs.uk>

**Patient & Public Voice** – refers to those patients and members of the public who work with NHS organisations and with whom the NHS consults about changes and policies.

**Site Specific Group** – groups of clinicians who meet regularly to agree guidelines and patient treatment protocols who all should have at least one patient representative working with them as part of their meetings. A site refers to the site of the tumour that the clinicians work in. Breast and Head & Neck are examples cancer sites.

**Standards of Business Conduct** – the way in which people are expected to carry out their work duties and activities, whilst working for the NHS, even as a voluntary patient or carer representative.

1. The NHS Long Term Plan (Jan 2019) [↑](#footnote-ref-1)