

Site Specific Group

Patient Representative Brief & Job Description

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Summary of Job purpose

The Peninsula Cancer Alliance is looking for patient/ carer representatives to support our Site Specific Groups (SSG) in considering and prioritising the needs of the patient and the public. You have been invited to become a core member of the Skin Specific Group for the unique perspective that you can provide on the cancer pathway from diagnosis, to treatment and to Living With and Beyond Cancer (now referred to as Personalised Care).

Background Information

In July 2015, the Independent Cancer Taskforce report¹ set out 96 recommendations to help transform the care provided by the NHS. One of those recommendations was the formation of Cancer Alliances to drive forward the changes needed to progress existing cancer services over the coming years.

The Peninsula Cancer Alliance (PCA) is one of 19 Cancer Alliances across England; an Alliance brings together clinical and other senior leaders and patients across a defined geography to:

- Plan and lead locally to deliver the ambitions set out in the NHS long-term plan.
- Reduce variation in outcomes and improve access to high quality, evidence based interventions across whole pathways, and for the alliances whole population.²

In 2019, the NHS Long-Term Plan set out its ambition that by 2028, and extra 55,000 people each year will survive for 5 years or more following their cancer diagnosis. This will include 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.³

¹ Report of the Independent Cancer Taskforce (2015) "Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020"

² https://www.canceralliance.co.uk/who-we-are/

³ The NHS Long Term Plan (Jan 2019)



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 outcomes that they want to achieve. Cancer Alliances offer a vehicle for this to happen.

By ensuring that there is meaningful engagement with service users, this will enable Alliances to prioritise local care, gather insight and assure quality.

Site Specific Groups (SSG)

Within the PCA are 13 site specific group 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 Long-Term Plan.

Each Site Specific Group meets at least twice a year, drawing together leading clinical expertise and multidisciplinary team members for specific cancer tumour sites:

- Brain and Central Nervous
 System
- Breast
- Cancer Unknown Primary and Acute Oncology
- Colorectal
- Endocrine and Thyroid
- Gynae- Oncology

- Haematology
- Head and Neck
- Sarcoma
- Skin
- Thoracic (Lung)
- Upper Gastrointestinal
- Urology

Within the Peninsula Cancer Alliance, Site Specific group meetings represent cancer services provided by the following NHS Hospital Trusts:

- 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

For some tumour sites, this also includes:

- Taunton & Somerset NHS Foundation Trust
- Yeovil District Hospital NHS Foundation Trust

Membership to the site specific group will have as a minimum:

- Representatives from each of the providers (named above)
- Representatives from a range of professionals involved within that service
- Patient or carer representative

For further information please refer to the Site Specific Group Terms of Reference in your application pack. (**Appendix 1**)

Patient Representative Role

The PCA would like to have one/two patient representatives at each SSG meeting. Each representative would be asked to champion the Quality Markers for each service as well as the delivery of the Personalised Care (previously 'living with & beyond Cancer') agenda.

Please refer to the Quality Markers in your application pack. (Appendix 2)

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/



Essential Criteria

- The representative must be prepared to comply with our Standards of Conduct, which includes information on:
 - a) Declarations of interest
 - b) Confidentiality requirements especially when it is made clear by the Chair that this is a requirement.

The Standards are contained within **Appendix 4** of your application pack.

- Each patient representative should have recently been treated for cancer by
 one of the above Peninsula Cancer Alliance trusts in the past two years.
 Indirect representatives (carers) should have 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 policies and guidelines from a number of different patient perspectives and must be able to demonstrate familiarity with experiences of people affected by cancer.
- The representative will be prepared to commit a minimum of two working days per year to attend the Site Specific Group meetings on a voluntary basis, plus extra time before the meeting to read papers and ask questions in order to prepare sufficiently. There will be a need for the patient representative to commit further time to discuss outcomes and developments from the Site Specific Group with other users or support group members. A carer representative will need to do the same. There is the potential that the representative could be required to attend other Cancer Alliance meetings once a year for other work streams.
- The current minimum tenure in the role the representative would need to be committed to is **one year**.
- The representative should be able to join meeting remotely via Microsoft teams (full support provided) and on some occasions be able to travel within the Southwest region.
- They have the confidence to ask for information to be translated into lay terms within an official meeting environment with approximately 10 to 15 members of NHS staff present.



- They must be able to understand/ evaluate a range of information and evidence.
- They have a passion to improve the patient experience by sharing opinions formed by their own experiences and others from within their local community.
- They have an awareness of and are committed to Equality & Diversity

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

Desirable Criteria

- They are willing to learn and be coached by NHS staff
- They are passionate about the NHS and the delivery of the Long-Term Plan for cancer
- They have experience of and are willing to act as a mentor for other user representatives

Support for the Representative

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

- Contact details for the Macmillan Patient & Public Engagement Lead and Support Manager for the SSG meetings.
- Provide an opportunity for peer support (regular patient rep meetings or forums)
- Clinical Nurse Specialist support for first meeting
- Coaching/ Personal development with help from the Macmillan Patient & Public Engagement Lead
- Peninsula Cancer Alliance SSG Support Manager will provide sufficient documentation prior to the meeting and provide a debrief on items contained in the meeting's agenda
- Where attendance to meetings involves travel, all reasonable travel expenses incurred from attending the SSG meetings will be reimbursed by the Peninsula Cancer Alliance and refreshments provided at the meeting.



(See **Appendix 5** for PCA/ NHSE & NHSI Expenses Policy)

Contact Information

If you are interested in becoming a patient representative at one of our SSG meetings, please contact:

Lisa Martin (Macmillan Patient & Public Engagement Lead)

Telephone: 01392 675286 Mobile: 07866 151565

Email: lisa.martin3@nhs.net

Link to website: https://peninsulacanceralliance.nhs.uk/

Appendices - separate attachments

1. SSG Terms of Reference

2. NHSEI RDC Quality Markers v0.6

3. Application Pack:

3.1 Application Form

3.2 Ethnic Monitoring Form

- 4. NHSE Standards of Business Conduct
- 5. PCA/ NHSE PPV Expenses Policy
- 6. Patient Representative Milestones