

NHS Cancer Programme

Patient and Public Voices Forum

Terms of Reference

NHS England and NHS Improvement



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Terms of Reference for the NHS Cancer Programme Patient and Public Voices (PPV) Forum

1 Introduction

The NHS Cancer Programme has made great progress on delivering NHS England priorities to improve quality of care and access to cancer treatment.

1.1 The NHS Long Term Plan means we can go further for patients. It has set ambitious targets for the continued transformation of cancer care so that:

- an extra 55,000 people each year will survive for five years or more following their cancer diagnosis; and
- three in four cancers (75%) will be diagnosed at an early stage.

1.2 Engagement with patients and the public is essential to ensure services are responsive to the needs of people affected by cancer throughout their cancer journey. Our communities – and the voluntary community and social enterprise (VCSE) organisations that support them – are key to understanding what works locally. It is essential that the programme can work in partnership with patients and the public to transform cancer services.

1.3 We are strengthening the governance structure of the NHS Cancer Programme to put us on the front foot in delivering the Long Term Plan for cancer. Part of this shift includes redoubling our efforts to put patients and the public at the heart of the NHS Cancer Programme.

1.4 We have established a Patient and Public Voices Forum to involve our patient and public voice partners in our policy development and implementation.

1.5 The objectives of the Forum are:

- To bring actionable on-the-ground intelligence from communities and people affected by cancer into the Cancer Programme and to relevant decision-makers.
- To deliver advice, guidance and support to add value to the success of nationally-led Programme projects and policy.
- To generate mutual learning between project teams, communities, and people affected by cancer.

2 Role of the Forum

The Patient and Public Voices Forum will bring important views and perspectives into the NHS Cancer Programme. Forum members will represent service user, patient and/or carer/family perspectives, and play an essential role shaping our projects in partnership with the national team.

2.1 What is the role of Forum members?

The role of the Forum members is to:

- champion the patient, service user, carer and family perspective, to help the NHS Cancer Programme continue to consider and prioritise the needs of patients and the public;
- provide advice on the design of new national Programme systems, policies, procedures and guidelines;
- build their understanding of the NHS and the Cancer Programme.

2.1.1. Forum members will also be expected to:

- participate in collegiate and constructive challenges and debate relating to Cancer Programme activity;
- comply with the [Standards of Conduct](#), in relation to declaring conflicts of interest arising from:
 - any activity indicated in the ‘Declaration of interest’ form
 - any employment, commercial sponsorship or volunteering activity
 - receiving gifts or hospitality which may be regarded as a conflict of interest with the programme of work that the PPV partner is involved in; and
- respect the confidential nature of discussions when it is made clear by the Chair that this is a requirement.

2.1.2 To inform their representation of local patient, service user, carer and family perspectives, Forum members should be in regular contact with the Patient and Public Engagement leads for their local Cancer Alliance.

2.1.3 Forum members may also choose to get involved – through committees, working groups and other activities – in the governance and delivery of Cancer Alliance projects. Such activity however is not mandatory.

2.1.4 Forum members may wish to engage directly with a wide range of local people and communities to inform their representation of local patient, service user, carer and family perspectives and educate the public about the Cancer Programme. We encourage Forum members who wish to engage widely to seek support from their local Cancer Alliance.

2.2 What is the role of Cancer Alliances in The PPV Forum?

Cancer Alliances lead on bringing together community stakeholders and driving service improvement at the local level. The PPV Forum presents an additional opportunity to bring local issues and successes to the attention of the NHS Cancer Programme; particularly regarding how patients and the public are informing and shaping their work.

2.2.1 Members of the Forum should be able to draw on the views of patients in their communities via their links to their local Cancer Alliance patient and public network/s and bring key messages relating to local priorities to Forum meetings. We expect Cancer Alliances to leverage their links with local communities,

people affected by cancer, patient groups, and carers so their views may be reflected by Forum members.

2.2.2 Cancer Alliances should engage regularly with Forum members to support their understanding of local priorities, plans, and activities.

3 Values

The PPV Forum is committed to diversity and equal opportunities.

3.1 The PPV Forum recognises that its members will bring with them different beliefs, values and experience. All these perspectives should be valued and respected.

3.2 Each member should have an equal opportunity to contribute to discussions. Care will be taken to enable full participation. For example, it is important to check that the terminology used in meetings is understood by all and clarified if necessary.

3.3 Members are acting in a public service capacity and are expected to adhere to the Nolan principles for conduct in public life.¹

4 Membership

Membership of the PPV Forum will consist of at least one Patient and Public Voice partner from each Cancer Alliance Geography. They will not be current clinical NHS employees or contractors.

4.1 We will aim for membership that is reflective of the range of people affected by Cancer.

4.2 Initial engagement of Forum Members will be for one year, with the option of renewal for an additional year by mutual agreement. Members will have a maximum tenure of three consecutive years and no more than 6 years in a 9-year period.

4.3 Members should be able engage at a national level with senior leaders over strategic issues. Forum members will also need to advise and provide a perspective on wider issues which may be outside their immediate experience.

4.4 Forum members should have:

- confidence interacting with many senior stakeholders and contributing to group discussions;
- the ability to champion the diversity of PPV views, and not just to represent their own experience;

¹ Committee on standards in public life. *Guidance: The 7 principles of public life*. (May 1995)<https://www.gov.uk/government/publications/the-7-principles-of-public-life/the-7-principles-of-public-life--2>

- experience of working in partnership with healthcare organisations or programmes;
- the ability to understand and evaluate a range of information and evidence;
- the ability to make evidence-based, objective decisions with a clear rationale;
- an awareness of, and commitment to, equality and diversity;
- an understanding of the need for confidentiality; and
- a commitment to the 'seven principles of public life' (sometimes known as the 'Nolan Principles': selflessness, integrity, objectivity, accountability, openness, honesty, leadership).

4.5 Forum members will participate in meetings of the Patient and Public Voices (PPV) Forum twice a year. The total time commitment is estimated to be up to 36 hours per year.

4.6 Forum members may resign their role at any time by informing the Patient and Public Engagement Manager in writing.

4.7 The PPV Forum Chair

The Forum will be chaired by a Patient and Public Voice Partner.

4.7.1 The Chair should not normally have a clinical role in any NHS organisation.

4.7.2 The Chair should be skilled at managing relationships and communicating effectively with a range of senior stakeholders. The Chair should have demonstrable experience of being able to influence at the highest levels of national organisation/s.

4.7.3 An interim Chair will be appointed by the NHS Cancer Programme for a period of 6 months. Afterwards a new Chair will be selected, through interview with the Cancer Programme Director, from amongst the Forum members who express an interest in the role.

4.7.4 The Chair will be appointed for a maximum term of three consecutive years and no more than 8 years in a 20-year period; with an expected minimum term of one year.

4.7.5 The Chair will represent the PPV Forum group on the National Cancer Board.

4.7.6 The Patient and Public Engagement Manager will act as the first point of contact, and day-to-day liaison between the Chair and the NHS Cancer Programme.

4.7.7 The Chair may resign their role at any time by notifying the Cancer Programme Director and Patient and Public Engagement Manager in writing.

4.7.8 The Chair will attend, and chair meetings of the Patient and Public Voices (PPV) Forum twice a year. The Chair will be involved in the design of PPV Forum meetings. The Patient and Public Engagement Manager will work with the Chair to ensure that members are fully involved in the Forum and that their views and input of all members are given equal consideration.

4.7.9 The Chair will represent the Forum in internal and external meetings as required by the Programme, and act as the main point of contact for Programme leadership (National Cancer, and Cancer Programme Directors).

Therefore:

- The Chair will have membership of the National Cancer Board and will attend its meetings on a quarterly basis to represent the PPV group. The Chair will engage in regular informal meetings with the National Cancer Director and Cancer Programme Director.

4.7.10 The total time commitment required of the Chair is estimated to be up to 36 hours per year.

4.8 The PPV Forum Vice-Chair

The Forum Chair will be supported by a Vice-Chair.

4.8.1 The Chair should be Patient and Public Voice Partner and not normally have a clinical role in any NHS organisation.

4.8.2 The Vice-Chair should have skills as per those of the Chair, outlined above.

4.8.3 An interim Vice-Chair will be appointed by the NHS Cancer Programme for a period of 6 months. A new Vice-Chair will be selected after that period, through an interview with the Cancer Programme Director, from amongst the Forum members who express an interest in the role.

4.8.4 The Vice-Chair will be appointed for a maximum term of three consecutive years and no more than 6 years in a 9-year period; with an expected minimum term of one year.

4.8.5 The Vice-Chair will be accountable to the Chair.

4.8.6 The Patient and Public Engagement Manager will act as the first point of contact for the Vice-Chair.

4.8.7 The Vice-Chair may resign their role at any time by notifying the Cancer Programme Director and Patient and Public Engagement Manager in writing.

4.8.8 The Vice-Chair will attend meetings of the Patient and Public Voices (PPV) Forum twice a year. In the absence of the Chair, the Vice-Chair will chair PPV Forum meetings.

4.8.9 The Vice-Chair will support the Chair by working closely with the Patient and Public Engagement Manager to:

- Design PPV Forum meetings;
- Support PPV Forum development; and
- Monitor and evaluate the PPV Forum

4.8.10 The total time commitment required is estimated to be up to 36 hours per year.

5 The role of the NHS Cancer Programme

The NHS Cancer Programme will:

- Provide a dedicated member of the national team of the NHS Cancer Programme to act as key point of contact and support.
- Facilitate contact between Forum members and their local Cancer Alliance.
- Support Forum members to develop in their role. Facilitate access to training and development opportunities provided by the Participation Team at NHS England.
- Provide Forum members a range of opportunities to be involved in the development and delivery of national projects.
- Provide necessary background information in a timely manner to support Forum members' involvement in national projects and meetings.
- Commit to using plain, jargon free language in meetings and an explanation of all acronyms.
- Communicate regularly with Forum members and provide timely feedback on how advice from the group has been used and the outcomes of work carried out in partnership with Forum members.
- Hold meetings in accessible venues.

6 Operation

The Forum will meet formally on a 6-monthly basis. Its meetings will provide opportunities for exchange and learning between the national Programme team, and Forum members to shape approaches to patient experience and engagement; and delivery of the NHS Long Term Plan for cancer.

6.1 Activities may include deep-dive exercises on aspects of the programme and its projects; deliberative dialogues; informal consultations; share and learn discussions and design workshops.

6.2 Programme teams will be able to draw on the skills and experience of Forum members informally between meetings as needed.

6.3 After 12 months there will be opportunities for Forum members to reflect on the year and shape any changes to its future operation to improve members' experience and/or the Forum's effectiveness.

7 Support for members

The Chair and Vice-Chair will have reasonable out of pocket expenses covered in line with NHS England's [PPV Partners Expenses and Involvement Payments Policy](#), and receive an involvement payment of £75 per half day (4 hours or less) and £150 per day (between 4 and 8 hours).

7.1 Forum members will:

- be reimbursed reasonable out-of-pocket expenses incurred in line with NHS England's [PPV Partners Expenses and Involvement Payments Policy](#). Expenses usually cover travel and any subsistence requirements that arise. PPV partners should highlight any barriers to participation, for example, the costs of a carer that may need to accompany a PPV partner.
- Receive involvement payments of £150 per day (more than four hours) or £75 per half day (four hours or less) for any strategic and accountable leadership and decision-making, or activities to make recommendations to committees that have delegated authority of the NHS England.

7.2 The NHS Cancer Programme will indicate in advance whether an activity will come with an involvement payment. The lead contact for the relevant project or activity will agree involvement payments with Forum members.

8 Membership

Cancer Alliance	Member name
East Midlands Cancer Alliance	Julie Wolfarth
	Ian Jackson
East of England Cancer Alliance	Paul Osman
Greater Manchester Cancer	Mike Thorpe
	Annie Diamond
Kent & Medway Cancer Alliance	Craig Brown
	Michelle Gardener
North Central & East London Cancer Alliance	Andrew Ryder
	Noel Judge
Northern Cancer Alliance	Tina Murray
	Chris Walker
Peninsula Cancer Alliance	Aileen Mary Heal
RM Partners Cancer Alliance	Bonnie Green
	Selene O'Kane
Thames Valley Cancer Alliance	Patrick McGuire
	Dr Loretta Light
Wessex Cancer Alliance	Keith Cockerton
	Joanna Jayne Calder
West Midlands Cancer Alliance	Simeon Greene
	Sue Stocks
West Yorkshire & Harrogate Cancer Alliance	Lucy Deakin
	Liz Spice
	Paul Vose

9 Confidentiality

Materials and information shared with the Patient and Public Voices Forum should usually be assumed to be confidential. Materials that may be disclosed or shared outside of the group, will be identified as such by the Chair or by the NHS Cancer Programme team. If you would like to disclose information or share materials beyond these parties, please approach the Patient and Public Engagement Manager, Kaz Obuka for advice – email: kalu.obuka1@nhs.net tel: 07557744914.