

Terms of Reference (September 2019)

**Cancer Patient Experience Survey
Advisory Group (CPESAG)**

NHS England and NHS Improvement



Terms of Reference

Cancer Patient Experience Survey Advisory Group (CPESAG)

Publishing approval number:

Version number: 1.0

First published: September 2019

Updated: (only if this is applicable)

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This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact David Keddie, email: david.keddie@nhs.net, phone: 07702 408821.

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1. Introduction and Background

“Achieving world class-cancer outcomes: A strategy for England 2015-2020” recognises that a cancer patient’s experience of care is fundamental, from the point they first engage with the health service before their diagnosis, through to treatment and beyond.

Patient and carer experience data can add value at different levels – for performance management, accountability and service improvement, as well as to support reflective practice and to equip people affected by cancer with the information to drive change.

The National Cancer Patient Experience Survey (NCPES) has proved effective at highlighting good and poor aspects of care and at encouraging hospitals and other providers of care to implement changes to improve experience.

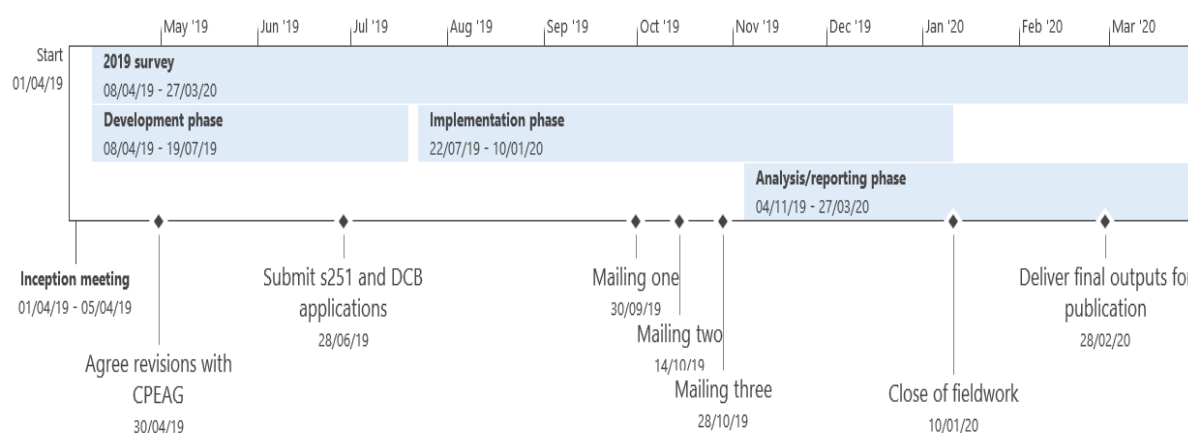
The survey is an important part of the national NHS Cancer Programme, which places patient experience on a par with clinical effectiveness and safety as a key strategic priority.

The Cancer Strategy and the NHS Long Term Plan recommends that NHS England continue the measurement and monitoring of patient experience through the continued commissioning of NCPES on an annual basis.

2. Role of the Cancer Patient Experience Survey Advisory Group (CPESAG)

The purpose of the Cancer Patient Experience Survey Advisory Group (CPESAG) is to guide the development and implementation of the NCPES and make recommendations to NHS England regarding any potential changes to the content or processes.

The key points of the current NCPES life cycle can be set out as follows:



The role of the group will be to provide a forum in which stakeholders of the NCPES can:

- Advise NHS England and the survey supplier and discuss key issues such as questionnaire content, sampling, data analysis, data presentation, reporting, dissemination and usability of the results
- Review and discuss the survey findings as they arise
- Provide any extra ideas for further analysis, tools and communications which might make full use of the results
- Raise any questions about the NCPES with NHS England and the survey supplier
- Help to disseminate and promote the survey to parties who might find the results useful

3. Responsibilities of members

Membership is drawn from a number of internal and external partner organisations.

From NHS England and NHS Improvement this includes representatives of the Insight and Feedback team, Analytical team, the Cancer Programme team and the Patient Experience team.

External partners include representatives from the survey supplier, NHS Trusts, CCGs, Cancer Alliances, academic survey experts and patient representatives.

For particular topics or workstreams it may be necessary to set up additional working groups, allowing for greater input in areas of particular expertise and greater responsiveness.

Each member of the Group will be responsible for:

- ensuring strategic and operational input from their areas is provided as needed
- providing constructive challenge in terms of implementation, strategy, and benefit realisation
- reviewing and commenting on relevant papers/materials and ensure active, informed participation in group debates and decision-making
- attending Group meetings regularly where possible, or dialling in, or contributing thoughts in advance of the meeting

Deputies must be agreed in advance with the Chair and the Chair may ask other officials to attend to assist with its discussions.

4. Confidentiality and information sharing

All materials and information shared with the Group are assumed to be confidential, unless otherwise stated. However, members are able to discuss broad, non-attributable meeting outcomes, once minutes have been shared.

Members will not disclose information or written material (such as agendas, minutes, discussion papers or other documents) to other parties, unless otherwise directed by the Chair.

Members of the Group are bound to a legal duty of confidence to protect personal information they may come into contact with during the course of their Group work, reflecting the common law duty of confidence, the Data Protection Act 1988 and the NHS Care Record Guarantee. Patient sensitive information must remain anonymous and not be included in written material to the Group or other parties.

Minutes detailing decisions and actions from each Group meeting are circulated to members.

5. Declarations of Interest

A conflict of interest is a set of circumstances by which a reasonable person would consider that an individual's ability to apply judgement or act, in the context of delivering, commissioning, or assuring tax payer funded health and care services is, or could be, impaired or influenced by another interest they hold.

All Group members should ensure that they are not placed in a position that risks, or appears to risk, compromising their role or the NHS public and statutory duties or reputation. Members must also not accept gifts or hospitality by virtue of their role in the Group.

Group members are required to declare conflicts of interest and the receipt of gifts, hospitality and/or sponsorship, in line with the national guidance to the NHS. Conflicts of interest should be declared in writing to the secretariat and specific conflicts should be raised at the start of any agenda item or discussion for which that conflict arises. A conflict of interest and a hospitality register will be maintained by the secretariat.

6. Membership

Debra Armstrong	Assistant Chief Nurse	Manchester University NHS Foundation Trust
Erin Barton	Policy Manager	Breast Cancer Care and Breast Cancer Now (Common Cancer Community)
Sarah Bengier	Deputy Director, Policy & Strategy	NHS England and NHS Improvement
Amrita Bose	Senior Research Analyst	Healthwatch England
Claire Bradford	Medical Director	Sunderland Clinical Commissioning Group
Dee Daly	Lead Cancer Manager	East Sussex Healthcare NHS Trust
Tim Elliott	Head of Cancer Policy, Acute Care and Provider Policy	Department of Health and Social Care
Clare Enston	Head of Insight and Feedback	NHS England and NHS Improvement

Emeline Gilhooley	Patient and Public Voice Partner	NA
Tiffany Gooden	Senior Research Associate	Picker Institute Europe
Rafael Goriwoda	Senior Analytical Manager	NHS England and NHS Improvement
Caroline Hayes	Programme Support Officer	NHS England and NHS Improvement
Ruth Hendy	Trust Lead Cancer Nurse	University Hospitals Bristol NHS Foundation Trust
Karen Henry	Macmillan Lead Cancer Nurse	Leeds Teaching Hospital NHS Trust
Alison Hill	Trust Lead Cancer Nurse	University College London Hospitals NHS Foundation Trust
Ruth Hudson	Insight and Feedback Specialist	NHS England and NHS Improvement
Taha Itani	Health Data Lead	Macmillan
David Keddie	Insight Account Manager	NHS England and NHS Improvement
Sue Kernaghan	Patient and Public Voice Partner	NA
Jenny King	Chief Research Officer	Picker Institute Europe
Jessica Lewington	Policy Manager	Bowel Cancer UK (Common Cancer Community)
Hope Lines	Senior Cancer Information Analyst	RM Partners West London Cancer Alliance
Jane Lyons	Chief Executive Officer	Cancer 52 (Less Common Cancer Community)
Georgios Lyratzopoulos	Professor of Cancer Epidemiology	University College London
Jo Mackintosh	Macmillan Engagement and Co Design Project Manager	Northern Cancer Alliance
Claire Marshall	Experience of Care Lead – Acute Care	NHS England & Improvement
Louise Metcalfe	Macmillan Primary Care Lead Nurse for Cancer	NHS Sheffield CCG
Terry Morgan	Senior Insight Account Manager	NHS England and NHS Improvement
Sophie Newbound	Head of Strategic Engagement, National Disease Registration Service	Public Health England
Pedro Oliveira	Senior Analyst	NHS England and NHS Improvement
Georgia Papacleovoulou	Senior Policy and Intelligence Manager, Pancreatic Cancer UK	Less Survivable Cancers Taskforce (Less Common Cancer Community)
Tracey Ryan	Macmillan User Involvement Manager	Kent and Medway Cancer Collaborative
Matt Sample	Policy Advisor	Cancer Research UK
Richard Stephens	Patient and Public Voice Partner	NA
Ben Sundell	Head of Policy and Public Affairs	Teenage Cancer Trust

7. Frequency of meetings

The Group will meet up to four times per year, scheduled to coincide with key points in the NCPES lifecycle. Regular meetings will be timetabled, with additional meetings as needed.

8. Quorum

The Group will be considered quorate when both of the following criteria are met:

- 50% of full members or their nominated deputies are present;

Meetings that are not quorate may take place but are not authorised to make any decisions impacting the programme.

9. Secretariat

The Group will be chaired by Clare Enston, in her role as Head of Insight and Feedback at NHS England.

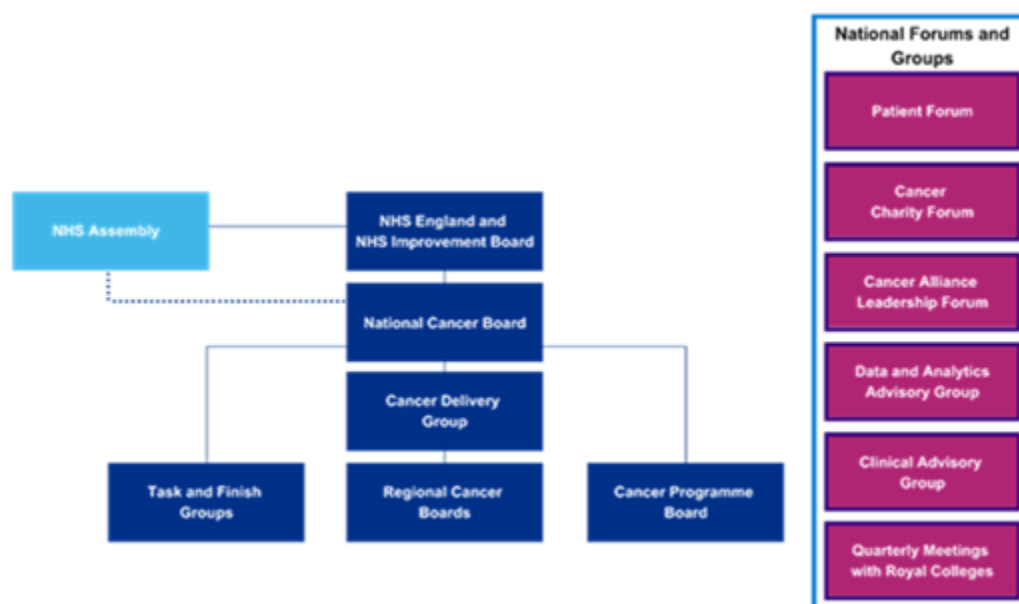
Secretariat for the group will be provided by the NHS England Insight and Feedback team.

The agenda and papers for the meeting will be sent to members at least one week ahead of the meeting. Items for inclusion on the agenda are subject to prior agreement by the Chair.

10. Governance and accountability

The Group will play an advisory role in the running of the survey and stakeholder views will be sought on key issues such as questionnaire content, sampling, data analysis, data presentation, reporting, dissemination and usability of the results.

NHS Cancer Programme Governance Structure



11. Standing items

The following table sets out the standing agenda for meetings of the CPESAG. Agendas for specific meetings will reflect the level of discussion required on each topic, and additional topics where required.

1	Welcome and apologies	Chair
2	Minutes of previous meeting	Chair
3	Declaration of Interests	Chair
4	Standing items	Chair
5	AOB	Chair

12. Reporting and communications

Reporting and communication of the activity of the group will be achieved as follows:

- Meeting minutes (decisions & actions) from each meeting will be prepared and circulated to members and once agreed the notes can be shared with other parties as directed by the Chair.
- The CPESAG will keep the Senior Leadership Team of the NHS Cancer Programme apprised of its work and decisions / outcomes from the meeting.

