

TRUSTEE APPLICATION PACK

Introduction

Thank you for your interest in Cancer52 and the role of Trustee. This application pack provides an introduction to the work of Cancer52, its Board of Trustees and the role of Trustee itself (including a role description and person specification at the end of the pack). We are looking for new Trustees who can support Cancer52's work and mission and are passionate about improving outcomes for rare and less common cancers and ending the inequalities that those with a diagnosis currently experience.

Once you have reviewed this pack, we hope you will be interested in applying. To do so, please:

- Send a CV (maximum two pages of A4) together with a supporting statement of no more than **500 words** explaining why you are interested in becoming a Trustee of Cancer52.
- Email your application to Ingrid Copperman ingrid.copperman@cancer52.org.uk by **5.00pm** on **Wednesday 14 November 2018**.

Shortlisted candidates will be invited to a face-to-face interview on the afternoon of **Wednesday 28 November after 3pm** in Central London. Please indicate your availability for this date.

If you wish to have an informal discussion about your interest in the role before applying, then please contact Ingrid Copperman at the above email address and we will arrange a date and time to speak with either the Chair or Chief Executive of Cancer52.

Who we are and what we do

Cancer52 is a national organisation which has been in existence since 2007 and was registered as a charity in England and Wales in September 2017. It acts as a membership body for charitable and not-for-profit organisations working in the field of rare and less common cancers. We currently represent nearly 100 predominantly small patient support group cancer charities united by their vision of seeing a better future for everyone affected by the rare and less common cancers, which account for more than half of all cancer deaths in the UK.

We aim to promote improved diagnosis, treatment and support for those affected by rare and less common cancers. Cancer52 works on matters that impact on the rare and less common cancer community – defined as all cancers outside the 'big four' of breast, prostate, lung and bowel. Current data shows that 46% of cancers diagnosed are rare and less common cancers, yet they account for 54% of cancer deaths.

Our vision

Our vision is an ending to the inequality in diagnosis, treatment and patient experience outcomes for those with a rare or less common cancer compared with the four most common cancers of breast, bowel, lung and prostate.

Our mission

Our mission is to provide a strong, unified voice for rare and less common cancer organisations by representing, speaking, informing, sharing and involving our members in our work to end the disadvantages in diagnosis, treatment and mortality outcomes experienced by people with rare and less common cancers compared with the four most common cancers of breast, bowel, lung and prostate.

Our values

All our work is underpinned by our values:

- Ambitious
- Outcomes-focused
- Collaborative
- Evidence-based
- Influential
- Honesty
- Integrity

Our achievements

Our work over the last 18 months has focused on the key policy objectives of continuing input to the cancer element for the new NHS long term plan and National Cancer Advisory Group, and working to gain increased access to data and to medicines. Three main workstreams have supported those objectives:

- consultation responses
- making our voice heard
- holding meetings and workshops to better inform and empower our members.

Consultations

We have submitted a number of consultation responses the last two years, including the following:

- NICE Centre for Health Technology Evaluation consultation – March 2018.
- All Party Parliamentary Group on Cancer’s Cancer Strategy Inquiry – August 2017.
- NICE Consultation on improving how patients and the public can help develop NICE guidance and standards - February 2017.
- Consultation on Commissioning Policies: Funding of Treatment outside of Clinical Commissioning Policy or Mandated NICE Guidance - January 2017.

Making our voice heard

In the last two years we have succeeded in raising the profile of a number of important issues in rare and less common cancers by:

- Publishing our “Clinical Nurse Specialists - working with people with rare and less common cancers - some personal perspectives” report.
- Presenting at a National Cancer Registration Analysis Service training day.
- Judging a poster competition at Cancer Research UK’S Early Diagnosis Conference.
- Attending roundtable discussions on cancer with Steve Brine, Parliamentary Under-Secretary of State for Public Health and Primary Care.
- Chairing a plenary session at Public Health England’s Cancer Outcomes Data conference
- Having a role or place on numerous important policy and practice forums related to cancer, including:

- Cancer Long Term Plan Task & Finish Group
- the Independent National Cancer Advisory Group
- Cancer Patient Experience Advisory Group
- Cancer Patient Experience Governance Oversight Group
- Public Health England Cancer Stakeholder Coordination Group
- ABPI Patient Organisation Forum Steering Group
- CQC Cancer Expert Advisory Group
- All Party Parliamentary Group on Cancer All Stakeholder Group
- Living With and Beyond Cancer PSP Steering Group

Workshops and meetings

As part of our commitment to empowering our member charities we held the following workshops over the last 18 months:

- Joint workshop with Teenage Cancer Trust at Public Health England's 2017 Cancer Data Outcomes Conference.
- Cancer52 member Toby Freeman, CEO of the Robin Cancer Trust ran a Social Media workshop.
- Joint workshop with Public Health England's Be Clear on Cancer team to input into abdominal symptoms campaign.
- Two joint workshop with NHS England Specialised Commissioning to review Recommendation 40 of Cancer Strategy which pertains particularly to 'rarer' cancers.
- Joint workshop with the National Cancer Registration Analysis on access to data.
- Joint workshop with PHE Getting Data Out team at Public Health England's 2018 Cancer Data Outcomes Conference
- How the Cancer Strategy is working for patients at Britain Against Cancer conference.
- Visit to West Yorkshire and Harrogate Cancer Alliance new diagnostic centres

Our quarterly meetings also served to inform our members with a very high calibre of speakers from organisations including NHS England, the Wellcome Trust, useMydata, the National Cancer Registration and Analysis Service and Public Health England.

The future

The prevention, diagnosis, treatment and aftercare of rare and less common cancers is at a key juncture in the UK. With NHS cancer strategy and plans at different stages of development and implementation in the four nations of the UK, there is a clear understanding that national cancer targets will only be met if there is significant reform and improvement to the way we deal with rare and less common cancer diagnoses. In its 10 years as an organisation, Cancer52 has played an important role in raising awareness of the need for national policy to pay equal attention to rare and less common cancers, alongside the four common cancers of breast, lung, bowel and prostate.

Although Cancer52 is closely involved in the majority of the key policy initiatives related to cancer, including being a member of NHS England's National Cancer Advisory Group (a key influencing body for the implementation of the 2015 National Cancer Strategy), it is also at a key stage in its own journey as an organisation. Cancer52's membership has grown to close to 100 members and 2017 saw its registration as a charity. We have had considerable successes in our first decade and are now the only campaigning and influencing organisation solely focused on rare and less common cancers.

We are passionate about addressing the inequalities faced by people with a rare and less common cancer diagnosis and improving cancer outcomes. There is an opportunity to build on our work so far and take the next steps on developing the organisation so that it can achieve its vision and strategic objectives.

Following a period of review and planning, we approved a new strategy plan in early 2018 covering the next three years of our work. Underpinning the whole of our three-year strategy is the following ambitious objective:

“By 2030 everyone with a cancer diagnosis will have the same life chances.”

This means improving prevention, diagnosis, treatment and patient experience processes within rare and less common cancer so that they match those in common cancers, to bring an end to the current inequality whereby rare and less common cancers account for 54% of cancer mortality but only 46% of cancer incidence (a disparity that has worsened in the last 10 years).

Key to achieving this objective are the following key indicators or markers of step change, based on existing patient experience measures and/or data on cancer practice:

- Access to multi-disciplinary diagnostic centres/clinics (ensuring that rare and less common cancer cases make up an appropriate proportion of referrals and diagnoses).
- The 28-day Faster Diagnosis Standard (introduced from April 2018 in England) – ensure rare and less common cancers are not disadvantaged.
- The 62-day Cancer Waiting Time Standard (from urgent referral to first treatment) of 85% is met for rare and less common cancers.
- Access to a clinical nurse specialist (CNS) – All rare and less common cancer patients should be given the name of a CNS who will support them through their treatment (2016 NCPES levels: 90% for all cancer patients).
- Research funding – spending on research into rare and less common cancers should match that for the four common cancers.
- Taking part in cancer research – at least 40% of patients with rare or less common cancer should be given the opportunity to participate in research (2016 NCPES levels: 27% for all cancer patients).
- Genetic screening/molecular analysis – currently there is no standard access to genetic screening for the purposes of cancer diagnosis.

We have then identified a number of workstreams and related activities that will help us bring about the change we need to see if outcomes are to be dramatically improved for those with a rare or less common cancer diagnosis.

About Cancer 52’s Board of Trustees

Cancer52 is incorporated as a charitable company limited by guarantee and is a registered charity in England and Wales. It is governed by its Memorandum and Articles of Association, and the work, management, finances and strategy of the charity are overseen by a Board of Trustees, who are also the company directors.

The charity’s purposes are set out in its Memorandum of Association as follows:

“To promote and protect the health of sufferers of rare and less common cancers for the public benefit by:

- (a) advancing and promoting the understanding, awareness, research and learning about rare and less common cancers;
- (b) acting as a collective voice and advocating for the needs of individuals affected by a rare or less common cancer in order to improve the outcomes of diagnosis, treatment and long-term support; and
- (c) supporting, representing and empowering not-for-profit organisations working in the field of rare and less common cancer.”

The board of trustees meets at least four times a year to review the organisation’s work, finances and services, and to agree the strategic goals for the charity. The chief executive attends all meetings. The board is also establishing a process to review its own operation, effectiveness and governance.

The chair and a trustee with financial experience and expertise also speak separately with the chief executive and the charity’s accountant on a quarterly basis to monitor and scrutinise the charity’s financial strategy and operations, and make any necessary recommendations to the full board of trustees.

In addition, Cancer52 runs a Policy and Public Affairs Steering Group (PPASG) and an Access to Data Working Group. Both report into the CEO and Board of Trustees. The PPASG brings together key policy/public affairs staff from a number of cancer support/campaigning organisations, so that they can develop and advise on Cancer52’s external policy positions, whilst the Data group similarly receives considerable input from a number of Cancer52 charities.

In the remaining pages of this pack you will find more information on the role of Trustee and a person specification. We hope you will be interested in applying and, if so, please refer to the information on the application process in the introduction to this pack.

There is further information on our website www.cancer52.org.uk.

Role description: Trustee

Role:	Trustee
Duration:	Retirement by rotation annually (in line with the articles of association), with the option of re-election
Term of tenure:	Two terms of three years each (ie, a total of six years); in exceptional circumstances, the Board of Trustees may approve a third and final term of three years
Time commitment:	10 days per year (including reading and preparation time for meeting; travelling to and attendance at meetings)
Remuneration:	Voluntary role, although reasonable travel and role-related expenses may be reimbursed

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Overall purpose of the role of trustee

The Board of Trustees is responsible for the overall governance and strategic direction of the charity, developing the organisation’s aims, objectives and goals in accordance with the charity’s governing documents, and legal and regulatory obligations and guidance. The Trustees are also the company directors of the organisation. The Board supports Cancer52’s work and provides mission-driven leadership and strategic governance.

Day-to-day management responsibility is delegated to the Chief Executive.

Key relationships

Other Trustees, Chief Executive, representatives of Cancer52 member organisations, key influencers and opinion leaders within national healthcare/cancer policy and practice.

Main duties and responsibilities

- To ensure that Cancer52 complies with its governing documents (memorandum and articles of association), charity law, company law and any other relevant legislation or regulations.

- To ensure that the organisation pursues its objects as defined in its governing documents.
- To ensure the organisation uses its resources exclusively in pursuance of its objects, and not for other activities.
- To contribute actively to the Board of Trustees' role in giving firm strategic direction to the organisation, setting overall policy, defining goals and setting targets and evaluating performance against agreed targets.
- To safeguard the good name and values of the organisation.
- To ensure the effective and efficient administration of the organisation.
- To ensure the financial stability and solvency of the organisation.
- To protect and manage the property of the charity and to ensure the proper investment of the charity's funds.

Other duties

- To review outcomes of Cancer52's work and activities for the purpose of evaluating impact and regularly measuring the organisation's performance.
- To approve the annual budget, audit/independent examination and material business decisions.
- To be informed and ensure that the charity meets all legal and regulatory requirements and responsibilities, including taking professional advice where necessary.
- To contribute to the annual performance review of the Chief Executive.
- To assist the Chair of the Board of Trustees and Chief Executive in finding other Board members.
- To work with the Chief Executive to ensure that Board decisions are carried out.
- To serve on committees or take on additional project work, as required.
- To represent Cancer52 to stakeholders and act as an ambassador for the organisation.
- To support Cancer52's fundraising efforts.
- In addition to the above, each Trustee should use any specific skills, knowledge or experience they have to help the Board of Trustees reach sound decisions. This may involve scrutinising Board papers, sitting on committees or task groups, leading discussions, focusing on key issues, providing advice and guidance on new initiatives, or other issues in which the Trustee has special expertise.

Person specification: Trustee

Composition of the Board – skills, knowledge and experience

Cancer52 seeks to appoint and maintain a Board of Trustees/Directors with the following skills, knowledge and experience:

Knowledge and experience

The Board of Trustees has determined that it is **essential** that the following knowledge and experience should be present **within the Board** as a whole:

- Personal experience of rare or less common cancer, as a patient or carer
- Senior management or board level experience within a rare or less common cancer charity or not-for-profit organisation
- Expertise or previous experience in financial or business management
- Experience of fundraising
- Public relations knowledge or experience
- An understanding of how the NHS works as it related to cancer policy and practice
- Charity governance experience
- Relative scientific background, particularly molecular science.

In addition, it would be **desirable** for the Board of Trustees to have the following knowledge and experience:

- Experience and knowledge of the provision of cancer care as a healthcare professional
- Experience of human resources management
- Knowledge of data analysis and epidemiology.

Skills and abilities

- Excellent communication and interpersonal skills.
- Analytical ability and good independent judgement.
- Capacity for clear, creative and strategic thinking and vision.
- A willingness to speak their mind.
- Understanding and acceptance of the role of a Board of Trustees for a charitable organisation (including the legal duties, responsibilities and liabilities of trusteeship).
- A willingness and ability to devote the necessary time and effort to attend Board and other meetings, including preparing and reading for those meetings, and to participate in the effective governance and management of the organisation.

Qualities

- A passionate enthusiasm for supporting people affected by rare and less common cancers.
- Nolan's seven principles of public life: selflessness, integrity, objectivity, accountability, openness, honesty and leadership.

Additional matters

- Member organisation representation on the Cancer52 Board of Trustees – at least two-thirds of the Board membership must be drawn directly from member organisations of Cancer52.