

Leukaemia UK's Community Champions Pilot Terms of Reference

Introduction

Leukaemia UK is a registered charity whose aim is to support life-saving research into the causes and treatment of leukaemia and other blood cancers. We also have an important role in monitoring the health and research policy environment and acting as a patient advocate to ensure leukaemia and other blood cancer patients receive accurate and prompt diagnosis followed by the best available treatments and care.

We have a strong ambition to develop and expand our policy and advocacy work, and our community engagement to help raise the awareness of leukaemia and Leukaemia UK. As part of this work, it is our ambition to have a well-functioning community group in place. This will support the work of Leukaemia UK in its Policy Advocacy & Campaigning, Communications and Fundraising activities. The Community Champions Pilot will have the following responsibilities, outlined in these Terms of Reference.

Terms of Reference

- To authenticate our policy and advocacy work by reflecting the needs of patients and elevate their voices.
 - To help share their wealth of experience, through taking their experiences to communities and decision-makers.
 - To act as spokesperson in the community to raise awareness of signs and symptoms of leukaemia and expand the Leukaemia UK's brand and activity.
 - To build friends and connections for Leukaemia UK and ultimately help to raise funds for the Charity's work.
 - Encourage others to get involved in and supporting fundraising activity for Leukaemia UK.
- To provide a Leukaemia UK presence across the UK
- To share your stories and experiences, through case studies and media work.

Membership

Members: The Community Champions Pilot will comprise people who either have experience of leukaemia or related diseases such as Myelodysplastic syndrome (MDS) or those who just want to support Leukaemia UK and its work. Leukaemia UK will endeavour to ensure the Community Champion Pilot comprises a broad and diverse range of people from across the UK. As this is a pilot project there are currently no defined timelines. Members will have an option to opt out of the Pilot at any time or take a less active role. All members must be 18 years of age or older.

Meetings

Meetings will initially be held virtually. Any future decision to hold face-to-face meetings would be made based on the agreement of the members. There will be an initial meeting to introduce the Champions and thereafter online quarterly meetings.

Training

Training will be provided to ensure that all members are equipped with adequate knowledge on the signs and symptoms of leukaemia, as well as Leukaemia UK messaging.

Expenses

All members may claim reasonable out of pocket expenses and will be reimbursed in line with Leukaemia UK's financial procedures.

Privacy Policy

By signing up to Community Champions Pilot you agree to our privacy policy. We will automatically anonymise any information you share with us unless you explicitly give us consent not to. E.g., to share your story as a case study.

Updating

Leukaemia UK will review these Terms of Reference every two years.

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Notes:

Leukaemia UK Trustees:

Ian McCafferty CBE (Chairman)

Amanda Stewart (Vice Chair)

Chris Corbin OBE

Caroline Evans

Prof. Alejandro Madrigal

Jo Reynolds

Karen Cracknell

Miriam Jordan Keane

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