

Involving people with leukemia in the design of a clinical trial testing vaccine strategies

Research theme



Cancer inflammation

Aim

Involve people with Chronic Lymphocytic Leukaemia (CLL) in the design of a clinical trial to test whether vaccine timing can help build antibodies in clinically vulnerable people. Their input ensured the study was accessible and acceptable to patients and minimised the burden for participants.

Involvement included

- Input into grant development and study design
- Design of participant information sheets and consent forms
- Input into recruitment to the trial
- Ideas about analysis, presentation and dissemination of results
- Providing a public perspective in trial oversight



6 public contributors
involved

Best practice

- PPIE was embedded throughout from pre grant stage to results dissemination.
- Public member was a co-applicant on the grant.
- Public views impacted study design, conduct and interpretation.
- Trial results were communicated to all participants and public contributors at the end of the study.
- PPIE ensured study was accessible and acceptable to people with CLL, barriers to participation overcome and trial burden for participants minimised.
- Video and infographic co-developed explaining the study

Impact of PPIE

- Public members made significant improvements to the participant information leaflet to aid recruitment, e.g. not using the term 'trial arm' as vaccines are given into the arm which could cause confusion.
- Contributed insight into factors likely to affect recruitment such as how patients with CLL were accessing their vaccination; issues with travel and hospital attendance at that time.
- Helpful feedback on plain English summary and accompanying letter for participants, e.g. making the trial result clearer i.e., there is no need to pause BTKI treatment while you have your COVID-19 jab.
- Public members advised that payment for participation wasn't necessary but instead should provide antibody test results to all.

Methods



Online
meetings