



Australasian Leukaemia and Lymphoma Group
Consumer Representative Terms of Reference Document

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FINAL

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1.0 BACKGROUND

1.1 Purpose of the ALLG

The ALLG is a clinical research organisation with over thirty years experience in successfully developing and conducting national multicentre trials in leukaemia, lymphoma and related blood cancers. The ALLG also collaborates with leading international clinical trials groups and is recognised as an important contributor to clinical research internationally.

Membership of the ALLG is open to all suitably qualified consultants in Australia and New Zealand. The ALLG currently has over 300 full Members and 280 Associate Members from more than 80 Australian and New Zealand hospitals and institutions.

In accordance with the constitution, the primary goal of the ALLG is to improve the outcome for patients with leukaemia, lymphoma and related blood diseases. The core business of the group is to carry out clinical research, both through appropriate clinical trials and applied laboratory research conducted in association with those trials. The trials primarily include patients from Australia, New Zealand and other countries in which ALLG members reside, so that the benefits of those trials flow directly to the citizens of those countries. Collaboration with other national and international clinical trials groups, however, is encouraged.

The strategic objectives of the ALLG are to:

1. Provide the framework to ensure that the group sponsors, conducts and participates in relevant clinical trials of significance for the development of improved treatment for patients with blood cancers.
2. Be regarded by local and international communities as the peak research body within our geographical sphere of operation and influence in the field of blood cancers.
3. Encourage all appropriately qualified clinicians and other professionals to be members of the ALLG and to be active participants in the trials sponsored by the group.
4. Ensure the long term maintainability of the group with good corporate governance and appropriate financial and human resources to carry out the ALLG Mission.

1.2 Mission of the ALLG

The ALLG's Mission Statement is:

“To improve the treatment and the lives of patients with leukaemia, lymphoma and other haematological malignancies by advancing ‘leading edge’ clinical trials in Australasia, and to be regarded by the local and international community as the peak research body for these diseases within our geographical areas of operation and influence.”

1.3 Primary aims of the ALLG

The aims of the ALLG are:

1. To improve the care of patients with leukaemia, Hodgkin and non-Hodgkin lymphoma and related diseases and to foster collaboration with other relevant groups both national and international.
2. To provide adequate funding for appropriate research and specific programs to reduce the burden of such diseases for present and future generations.
3. To increase the understanding of such diseases by appropriate research including clinical trials.
4. To increase the understanding of such diseases in the medical profession and the community through educational facilities.
5. To conduct and fund research programs to discover the causes of, and to improve the methods of treating, curing, and preventing such diseases.
6. To develop, in co-ordination with universities, medical schools, hospitals, and other institutions, centres devoted to research, education, and treatment of such diseases.

7. To maintain and promote relationships with any other organization interested in such diseases.
8. To raise, disburse, and administer funds in furtherance of these objects.

2.0 ALLG CONSUMER REPRESENTATIVES

Consumers play a vital role in research decision-making. Exposing research methods and results to informed public scrutiny and debate ensures integrity and accountability to the wider community for the quality of the research undertaken.

In general, involving consumer representatives in research organisations ensures:

1. that research outcomes reflect the priorities of the community, and
2. that the community has access to research results.

2.1 Requirements of ALLG Consumer Representatives

ALLG Consumer Representatives are Associate Members of the ALLG who voice the consumer perspective and take part in the decision making process on behalf of consumers.

ALLG Consumer Representatives should:

- have had exposure to blood cancer like leukaemia, lymphoma or myeloma through either personal experience, or as a carer
- have had experience in representing consumer interests at the local or national level
- understand consumer issues and have links to relevant consumers and consumer groups
- have the confidence and willingness to consult other consumers or consumer representatives
- have awareness of consumers' issues relating to cancer particularly blood cancers
- have the ability to work collaboratively in a team and with other organisations
- have good communication skills, including ease in the use of electronic communications and computers for accessing e-documents etc

2.2 Role of ALLG Consumer Representatives

ALLG Consumer Representatives provide a consumer perspective in the ALLG and help to action the group's strategic objectives outlined in section 1.1 above by becoming involved in ALLG activities. The ALLG Consumer Representatives can contribute to the activities of the group by;

1. Providing advice on what to research,
2. Providing advice on the best ways to conduct the research,
3. Contributing to research projects in progress, and/or
4. Helping to disseminate research results to the community.

2.2.1 Providing advice on what to research

Consumer Representatives may identify a community research need and work with researchers to investigate the issue. This will ensure that decisions on what to research reflect the priorities of both ALLG researchers and consumers.

2.2.2 Providing advice on the best ways to conduct the research

The specialist skills of researchers are required to determine scientifically valid ways to conduct research. However, consumers can strengthen study and protocol design by:

- Reviewing protocols of potential research projects to ensure that the proposed methods are 'consumer friendly',

- Helping to write or review information sheets about trials to ensure that the style and content is useful and the content and desired outcomes are clear/understandable for potential study participants (consumers are not expected to supply medical or technical content), and
- Suggesting alternative methods to increase participation in the research.

Consumers may also assist researchers to understand consumer perspectives on issues such as:

- the decision process around deciding to participate in a trial,
- the benefits of participating in a trial,
- access to and storage of genetic material,
- consent and privacy and confidentiality.

2.2.3 Contributing to research projects in progress

Consumer Representatives can add value to ALLG projects in progress by providing oversight of the research as it progresses. This could involve:

- Providing a consumer perspective on issues such as ethics, data privacy, confidentiality and consent,
- Raising public awareness of the activities of the ALLG (e.g. as a member of the Marketing Committee) and research in progress,
- Providing lay summaries of research in progress or proposed research for the website, annual research reports, grant proposals and reports etc.,
- Contributing to the preparation of grant proposal and reporting documents, and
- Providing consumer oversight of the ALLG trials program by participating in the Safety and Data Monitoring Committee (SDMC).

2.2.4 Helping to disseminate research results to the community

ALLG Consumer Representatives can contribute to the dissemination of ALLG research results to people who participate in studies, sufferers of blood disorders and to the wider community in general. Consumer Representatives may:

- Assist with or review ALLG website content and design,
- Assist or review ALLG promotional and marketing/communication/fund raising materials,
- Contribute to the preparation or review of scientific and lay publications,
- Disseminate the research findings of the group through their consumer and community networks, and
- Contribute to the development of clinical practice guidelines to assist in implementing research results.

2.3 Responsibilities of ALLG Consumer Representatives and Researchers

Consumer participation in research also brings with it responsibilities for both consumers and researchers: the responsibility to be respectful of each other's knowledge, to share information with each other about research issues and to be open about potential interests in the outcomes of research and maintain confidentiality. The shared responsibility of consumers and researchers is to ensure the ethics and value of the research.

2.4 Expectations of ALLG Consumer Representatives

Consumer representatives are **not** expected to:

- speak for the ALLG,
- have technical or medical background in the subject under discussion other than a consumer perspective, and

- undertake consumer consultations beyond what is required to inform their own input at the meeting.

Consumer Representatives **are**:

- treated as an equal member of the ALLG,
- heard, listened to and understood by the rest of the ALLG,
- able to seek clarification and more information, including medical or technical jargon,
- given all relevant information and an agenda for meetings with enough time to read, review, understand and consult before the meeting,
- comfortable that the committee system allows you to return to your support system, and
- able to disagree with the rest of the committee and have this recorded.

3.0 SUMMARY

The ALLG recognises the central role of health consumers and community members in its work and is building partnerships whereby researchers and consumers shape decisions about research priorities, questions and design. These partnerships are flexible and vary depending on the nature of the research in question.

ALLG Consumer Representatives can contribute to the activities of the ALLG in a number of ways. ALLG Consumer Representatives may:

- Ensure that proposed research methods are consumer friendly,
- Help to write information/fact sheets about trials to ensure that the style and content is useful and understandable for potential study participants,
- Suggest alternative methods to increase participation in ALLG trials,
- Provide a consumer perspective on issues such as ethics, data privacy, consent and confidentiality,
- Raise public awareness of the activities of the ALLG and research in progress,
- Provide lay summaries of research in progress or proposed research for the website, annual research reports, grant proposals and reports etc.,
- Contribute to the preparation or review of grant proposal and reporting documents,
- Provide consumer oversight of the ALLG trials program by participating in the Safety and Data Monitoring Committee (SDMC),
- Assist with or review ALLG website content and design,
- Contribute to the preparation or review of both scientific and lay publication content,
- Contribute to or assist in the preparation of marketing/communication/fund raising materials,
- Disseminate research findings of the group through consumer and community networks, and
- Contribute to the development of clinical practice guidelines to assist in implementing research results.

4.0 SUPPORT DOCUMENTS

Further information on the role of consumer representatives in research organisations can be found in the following publications.

National Health and Medical Research Council (2005) *A Model Framework for Consumer and Community Participation in Health and Medical Research*. Consumers' Health Forum of Australia
http://www.nhmrc.gov.au/files_nhmrc/file/publications/synopses/r33.pdf

National Health and Medical Research Council (2002) *Statement on Consumer and Community Participation in Health and Medical Research*. Consumers' Health Forum of Australia.
<http://www.nhmrc.gov.au/publications/synopses/r22syn.htm>

National Health and Medical Research Council (2005) *Resource Pack for Consumer and Community Participation in Health and Medical Research*. Consumers' Health Forum of Australia.
http://www.nhmrc.gov.au/files_nhmrc/file/publications/synopses/r34.pdf

Cancer Australia (2009) *Consumer Participation Guide*. Cancer Australia: Canberra.
http://www.canceraustralia.gov.au/sites/default/files/user-upload/publications/cpg_complete.pdf