

## AYA Cancer Consumer Advisory Group – Terms of Reference

### Purpose:

For the AYA Cancer Network to have an engaged and dedicated AYA Cancer advisory consumer and co-design group who are empowered to influence and provide valuable contribution to the work and issues in AYA cancer in partnership with stakeholders, to better inform service provision, strategy, quality improvement initiatives and equitable access to high- quality medical and supportive care regardless of location.

### Objectives:

- 1.To create an AYA cancer consumer advisory group and co-design group for AYA cancer to give young people with lived experience (and stakeholders) an opportunity to influence and provide valuable contribution to the work and issues in AYA cancer, which has the potential to enhance the care delivered to this population
- 2.To have the AYA voice contributing to issues affecting AYA cancer to better inform:  
*Equitable access to high- quality medical and supportive care*  
*Service provision*  
*Strategy*  
*Quality improvement initiatives*  
*Research design*
- 3.To establish an AYA cancer consumer advisory group of young people with a focus on equity– ethnicity, gender, age, domicile and diversity, and to include a demographic reflective of the population wherein lies the greatest need
- 4.To ensure culturally appropriate methods of engagement reflective of make-up of the group
- 5.For AYA cancer patients to have the opportunity to actively participate in partnership with stakeholders on the development, implementation and evaluation of regional and national AYA cancer care programmes and services
- 6.To analyse, report on and utilise the qualitative data from consultations/focus groups to inform positive changes to service delivery and design
- 7.To create a policy on how AYAs will be supported and involved in decision making opportunities
- 8.To be transparent with AYAs on how much influence their opinions will have
- 9.To have clarity about how AYAs can participate in decision-making and what impact their involvement will have
- 10.To provide a youth friendly environment for the group utilising facilitator(s) trained in youth development
- 11.To establish the group and maintain regular engagement via face to face meetings/training, online, and teleconferences throughout the year

- 12.To provide training to the participants of the group so they feel confident and focussed in their contribution
- 13.To ensure that young people are informed about how their contributions have been utilised
- 14.To evaluate this process to gauge alignment to principles of youth participation (best practice)
- 15.To collaborate with other organisations
- 16.Commitment to continuous improvement for the effectiveness of young people's involvement

### **Responsibilities:**

#### **Clinical Lead and Programme Coordinator**

- To create a policy on how AYAs will be supported and involved in decision making opportunities
- To have clarity about how AYAs can participate in decision-making and what impact their involvement and opinions will have
- To provide a youth friendly and supportive environment for the group
- To establish the group and maintain regular engagement via face to face meetings/training, online, and teleconferences throughout the year
- To provide training to the participants of the group so they feel confident and focussed in their contribution
- To ensure culturally appropriate methods of engagement reflective of make-up of the group
- To ensure that young people are informed about how their contributions have been utilised
- To collaborate with other organisations
- Commitment to continuous improvement for the effectiveness of young people's involvement
- To analyse, report on and utilise the qualitative data from consultations/focus groups to inform positive changes to service delivery and design

#### **AYA cancer consumer advisory group members**

- To commit to and attend at least 80% of face to face meetings and teleconferences
- To provide subject matter expertise relevant to their lived experience of cancer as an AYA
- To actively engage in the group and attend all face to face workshops/meetings/training as well as teleconferences
- To work in partnership with the AYA Cancer Network and key stakeholders on the development, implementation and evaluation of regional and national AYA cancer care programmes and services

#### **Youth Facilitators (From NGOs such as CanTeen, LBC and AYA keyworkers)**

- Attends face to face and teleconference meetings
- Provides a safe and supportive environment for young people
- Engages and encourages young people to participate in group discussions
- Helps to facilitate workshop content as required utilising different modalities for different learning styles
- Facilitates engaging get to know you - games/energisers to enhance team work, concentration and formation of the group at workshops/training/meetings
- Interacts with young people on social media in relation to co-design activities
- Provides support to young people if required

## **Key Stakeholders/Subject Matter Experts**

- To work in partnership with the AYA Cancer Network and AYA cancer consumer advisory group on the development, implementation and evaluation of regional and national AYA cancer care programmes
- Provide subject matter expertise relevant topics to ensure best practice and quality of resources, information
- Attends workshops where required

## **Membership Skills and Expertise**

The group should include up to 20 AYAs who have had cancer aged between 16 and 26 years of age who have had cancer treatment in the last four years, with a focus on equity to include range of ethnicity, gender, age, domicile and diversity.

The group should also have stakeholders present at various points along the journey.

- AYA Key Workers**
- Nurses**
- Oncologists**
- Fertility providers**
- Whānau**
- Community groups**
- Palliative care team members**
- Senior management**
- NGOs – e.g. CanTeen, LBC**
- Working group representatives**
- Representatives will be appointed for a two-year period
- Membership will also include the National Clinical Lead and Programme Coordinator for the AYA Cancer Network as ex-officio
- If a member is unable to attend for 2 or more meetings in a year, their on-going availability to attend should be reviewed.
- Fifty percent of the core membership plus one must be in attendance for a meeting to go ahead and group decisions to be made. A quorum must include the programme coordinator and AYA Cancer Network clinical lead.

The group will review the TOR and discuss membership annually to assess any changes required

## **Support for the AYA Cancer Consumer Advisory Group:**

- The AYA Cancer Network will provide administrative and secretariat support to the consumer group. This includes distribution of the agenda and recording of meeting minutes.
- The agenda is to be circulated one week prior to the meeting and should include all briefing and background papers to be discussed.
- Minutes are to be circulated to members within 21 days of the meeting via email for confirmation.

- Costs associated with travel/transport and meals will be covered by the Network for members of the group

### **Workshop Arrangements:**

- Workshops will be one day in duration and held near the airport two to three times per year
- At the commencement of each calendar year workshop times and dates will be agreed for the year

### **Chair:**

There will be two appointed chairpersons for the AYA Consumer Advisory group. These chairpersons will be self-nominated and elected by a majority vote by the group. The period of tenure will be for 1 year. After one year this process will be repeated. A chairperson is able to be elected each year for a maximum of two years.

### **Responsibilities:**

- Ensure the group complies with the Terms of Reference (this document)
- Facilitation of face to face AYA consumer group meetings with the support of the AYA Cancer Network executive team
- Preparation of face to face AYA consumer group agendas through consultation with the group and the AYA Cancer Network executive team
- Encourage open communication where all members can contribute to conversations
- Preparation for and attendance at annual governance board meetings (see below for more detail)
- Be the spokesperson(s) for the AYA consumer advisory group and represent the views and representations of the group as required
- Tenure/commitment of 1 year

The AYA Cancer Network executive team (Heidi Watson and Alex Ritai) are to support the chairpersons when and as needed.

### **Governance:**

The chairpersons will need to be able to attend either in person or via videoconference/zoom at the annual AYA Cancer Network governance board meeting. The chairpersons will have specific time allocated within the agenda to update and discuss matters with the governance board and vice versa. The items to be discussed by the chairpersons will require approval from the majority of the AYA consumer group prior to the governance board meeting. There is an expectation that at least one chairperson will be able to attend for the entirety of the pre-determined allocated presentation time. Both chairpersons are invited to attend the full governance meeting but this is not compulsory. Following the meeting the chairpersons will feedback to the AYA consumer group. This includes bringing back questions from governance or items raised that had not been pre-discussed by the whole group.

### **Confidentiality:**

- The group members are expected to maintain confidentiality of agenda material, documents and other matters provided to them.
- Confidentiality will be maintained unless someone has disclosed harm to themselves, or others or they are at risk of being harmed