# **Young Carers Alliance – Terms of Reference**

#### **Background and Purpose**

A young carer is someone under the age of 18 who looks after a family member or friend who has a physical or mental health condition, or misuses drugs or alcohol.

A young adult carer is someone between the ages of 16 and 25 who looks after a family member, partner, or friend who has a physical or mental health condition, or misuses drugs or alcohol.

Throughout the UK and globally, many young carers and young adult carers face immense pressure and emotional strain as a result of their caring responsibilities. Whilst young carers and young adult carers do generally value their caring role, if they are not identified and adequately supported at an early stage it can still have an extremely negative impact on their educational attainment, their social development, and ultimately their future life prospects. It can also significantly impact on their own physical and mental health.

## Aim of the Young Carers Alliance:

The aim of the Young Carers Alliance is to improve the identification, assessment, and support of young carers and young adult carers and ensure their voices are heard and acted upon.

Members of the alliance believe that no child or young person should be taking on inappropriate or excessive caring responsibilities which have a negative impact on their health, wellbeing, or ability to enjoy a good childhood.

The alliance (including young carers and young adult carers themselves) will develop and champion a Young Carers' Bill of Rights, setting out what we want to see for all young carers and young adult carers, and what change is required to make this happen.

The alliance will use the Bill of Rights to seek policy and practice improvements, and to have it recognised by decision-makers at all levels in order to benefit the lives of all young carers.

The Young Carers Alliance brings together:

- Participation
- Policy
- Practice
- Research

The Alliance will provide members with:

- Opportunities for sharing information, research evidence, and best practice
- Increased awareness of latest issues, trends, and support needs for young carers, young adult carers, and their families
- The ability to seek advice and peer support from individuals and organisations who work in a similar area around young carers and young adult carers
- Increased opportunities for collaboration

Bringing together these four strands will ensure an informed, collective and strong voice for young carers, young adult carers, and their families, and will also increase the number of opportunities to influence and campaign for sustainable support for all young carers and young adult carers.

#### How the Young Carers Alliance will achieve this aim:

The Young Carers Alliance will use a variety of methods to achieve the aims of the alliance. Members of the YC Alliance can get involved in as many or as few ways as desired. Being unable to participate in a particular type of activity of the Alliance (e.g. influencing or campaigning) does not stop organisations or individuals from becoming members.

Young Carers Alliance activities can include:

- An e-mail distribution list, which can act as an information-sharing channel and a vehicle to promote opportunities or seek support/advice
- Collaboration opportunities (across research, policy and practice)
- Conducting and collating research to help inform policy proposals and campaigning agenda
- Identifying opportunities for young carers and young adult carers to have their voices heard by decision-makers
- Networking and best practice events/workshops
- Policy influencing and campaigning to provide a unified collective voice to increase likelihood of effecting policy change
- Providing portals for research evidence, examples of best practice, and useful information

## Membership

Membership of the Young Carers Alliance is free and is open to:

- Academics and researchers whose research area includes young carers and/or young adult carers
- Any organisation who supports, or has an interest in supporting, young carers and/or young adult carers
- Decision-makers with an interest in, or who work in areas which impact on, young carers and/or young adult carers
- Individuals who work with, or who have an interest in the assessment and support of, young carers and/or young adult carers
- Young Adult Carers
- Young Carers (with parental consent this would be collected and held by the organisation providing administrative support for the Alliance and extends to any young carers who wish to get involved, including those who are not linked to a young carers organisation)
- Parents of Young Carers (in order to enable the voices of particular groups of young carers to be heard, or to help spread the work of the alliance further)

For organisations to join the alliance, there will need to be a named person for the application who has the authority to sign up on behalf of the organisation.

The names of the organisations who are members of the alliance will be listed on the webpage for the Young Carers Alliance, but names of individuals who are members will not. The only exception to this will be academics, who will be listed individually with the name of their institution alongside.

If any individual or organisation no longer wishes to be a member of the Young Carers Alliance, they will need to inform the organisation providing the administrative support for the alliance in writing.

#### Governance

The young carers alliance is a network of organisations and individuals. The alliance will not hold any funds in its own right – any funds for alliance activity, and any staff employed to support alliance activity, would be with a host member organisation.

Members of the alliance will maintain their individual identity and alliance activities will make clear if they are being organised by individual members of the alliance, or the alliance as a collective.

If the alliance is going to adopt a formal policy position, launch or promote a campaign or put out research in the name of the alliance, then members will be given the opportunity to feed into the formulation of the policy/campaign, and to declare if they are not able to put their name to it.

If any organisation is not able to support a proposed alliance policy/campaign, and an agreed position cannot be reached across all members, then it will be put out in the names of the individual organisations who are able to as members of the alliance.

This Terms of Reference will be reviewed by members of the alliance on a biennial basis with all members (including young carers and young adult carers) being invited to participate in the review.

If any individuals have any concerns with the activity/running of the alliance, then they can raise them with the organisation providing the administrative support, and if required a meeting of alliance members will be arranged to discuss the concerns.

### **Administration**

The Young Carers Alliance website and the email distribution list will be hosted by Caring Together – a Cambridgeshire-based social care charity – and any enquiries around the Young Carers Alliance will go to them. Where required, members of the alliance will be asked to assist with administration for specific activities/sessions.