



## **Cancer and Palliative Care Services**

### **Patient and Carer Partnership group**

#### **Terms of reference**

#### **1. Introduction**

1.1. York Hospitals Foundation Trust (YHFT) and Selby and York locality believe that patient and carer (user) involvement is central to the development of Cancer and Palliative care services within the locality. The views of patients and carers are actively sought and acted upon by both organisations to develop services. The NICE guidance for Improving Supportive and Palliative Care for adults with Cancer (2004) provides a framework for user involvement, that supports The Cancer Plan (DH 2000)

#### **2. Purpose**

- 2.1. To provide a recognised forum within the locality to enable users to influence through consultation, the development, commissioning, delivery and evaluation of cancer and palliative care services.
- 2.2. To provide a communication channel to the Network User Group, sharing views that reflect the broad spectrum of users within the Selby and York Locality.
- 2.3. To provide opportunities for users to develop their knowledge and skills to allow direct involvement in influencing services.

#### **3. Membership**

- 3.1. The group is open to any patient/ ex patient or carer/ family member who has been affected by cancer and has received care within the locality, health and social care professionals and representatives from self-help/ support groups. Proposed honorary members to be considered by the group on an individual basis.
- 3.2. All members will be provided with a welcome pack
- 3.3. A member may change their level of involvement or give up their membership at any time

#### **4. Frequency of meetings:**

- 4.1. The group will meet on a monthly basis alternating between afternoon and evening meetings the meetings will be hosted by YHFT and Selby and York Locality.
- 4.2. For a meeting to proceed five members must be present, patients/ carers must represent the majority. Sub group meetings may have fewer members, this will be agreed by the sub group with the main group.

#### **5. Expenses**

- 5.1. Members of the group can expect to be reimbursed for travel expenses (mileage/ parking fees) to attend partnership meetings. Funding for attending Local/ National events will be agreed on an individual basis.

#### **6. Ground rules**

- 6.1. **Confidentiality** - information discussed within the meeting will not be discussed outside the meeting unless agreed by the whole group.
- 6.2. **Respect** - all members will respect individuals views, giving time to speak and ensuring the focus is related to the agenda.
- 6.3. **Consultation** as opposed to confrontation - the group will seek to work in partnership with hospital, G.P's and community staff to achieve development in service.

#### **7. Terms of reference**

- 7.1. To raise awareness about the importance of user involvement within the locality.
- 7.2. The group is not a support group.
- 7.3. To be inclusive, to find ways to obtain a wide range of opinions of users of cancer and palliative care services, especially in under represented group (defined by age, social group, disability and ethnic background).
- 7.4. To affect change and innovation in cancer and palliative care through partnership working.
- 7.5. To provide a resource and contact point for health and social care professionals wanting to link with user in cancer and palliative care.
- 7.6. To link closely with the Yorkshire Cancer Network User Group and the Yorkshire Cancer Research Network User group and be aware of service developments across the YCN, to learn lessons and prevent duplication.

7.7. To influence and assist organisations to implement The Cancer Plan (DH 2000) and Improving Supportive and Palliative care (NICE 2004) guidance.

7.8. To report directly to the Cancer Strategy Group (Locality group).

7.9. Cancer Services Team communication link - Macmillan Lead Cancer Nurse.

## **8. Areas of work**

8.1. The users will determine the areas of work and priority. Potential areas could be identified from the 'Talking about Cancer' event, patient surveys and or feedback from Patient Advocacy Liaison Service (PALS) for example.

8.2. Group members will act as user representatives on the Cancer Strategy Group (Locality Group), Yorkshire Cancer Research Network User group and The YCN User group. As a representative they will be expressing the opinion for the users of Selby and York locality.

## **9. Roles of members**

### 9.1. The Chair

The chair will be a user or carer, elected by group member's for the maximum period of one year term. If there is a tie election result there may be two co chairs. When no chair is in place a temporary chair from the YHT/Selby and York Locality will act as chair on a short-term basis. The chairs responsibilities include: preparing the agenda for main group meetings, advising on issues relating to meetings, follow up of issues relating to relevant meetings, represent the group at the Cancer Strategy Group.

### 9.2. Users

Users bring experience, knowledge, skills and direct experience of cancer services and care.

### 9.3. Health and Social Care professionals

Professionals are a resource for the group and provide a mechanism, to feedback to respective organisations. Professional may at the request of the group facilitate meetings in the absence of a nominated chair.

### 9.4. Review

These terms of reference will be reviewed on an annual basis.