

Greater Manchester **Cancer**

**The involvement of people
affected by cancer**
A Charter

Version 3.0

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Coproduced with People Affected by Cancer

Introduction

Greater Manchester Cancer is committed to putting people affected by cancer at the heart of improving cancer services for the population of Greater Manchester and East Cheshire. It is also committed to learning lessons from the way in which patient and public involvement has been done in the past.

Greater Manchester Cancer has been working with Macmillan Cancer Support to develop its approach to the involvement of people affected by cancer in its work. In late 2013 Manchester Cancer (later to become Greater Manchester Cancer) included a Macmillan-facilitated stakeholder interview process in the appointment of 20 Pathway Clinical Directors to each lead the improvement of services across a cancer-specific pathway or cross-cutting area.

With Macmillan's support we held a user involvement event on 23rd June 2014. The event brought together the Pathway Clinical Directors, the Manchester Cancer core team, patient representatives from the existing Greater Manchester Cancer Partnership Group (the former cancer network group), other patient and carer representatives, and colleagues from Macmillan and strategic clinical networks. Through forum theatre from applied theatre specialists Dead Earnest and group working we began to develop Manchester Cancer's approach to the genuine involvement of people affected by cancer.

This Charter has been created using the rich information that came out of the Macmillan event. These documents represent the next stage of a process that we are only just beginning. This Charter outlines Greater Manchester Cancer's pledges to the people affected by cancer involved in its work, now and in the future, and what we expect from them in return.

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Our pledges

The fundamentals

- 1** We are committed to the involvement of people affected by cancer at all levels of our work.
- 2** The involvement of people affected by cancer is crucial to the development of cancer services and not simply a box to be ticked.
- 3** The people affected by cancer involved in our work will be giving up their time to influence and improve cancer services in the area. They should be made welcome and treated with respect.
- 4** We will make sure that the people affected by cancer involved in our work are listened to and that their contribution is valued.
- 5** We will provide the appropriate support and training to help those involved in our work make a valuable contribution.
- 6** We will make sure that the privacy of the people affected by cancer involved in our work is respected and that any information they share is kept confidential.
- 7** Good communication will underpin the effective involvement of people affected by cancer in the work of Greater Manchester Cancer.

Attracting new people

- 1** We will launch a recruitment drive in the summer and autumn 2015 and spring 2016 to attract new people affected by cancer who might be interested in getting involved in Greater Manchester Cancer.
- 2** All people affected by cancer interested in getting involved will be invited to participate in the current opportunities including the User Involvement Steering Group when vacancies arise.
- 3** We will support the steering group to meet and in its efforts to continuously recruit new members.
- 4** We will work with the steering group so that it is truly representative of the people affected by cancer in Greater Manchester and East Cheshire.
- 5** We will support the steering group as it develops to potentially take on extended roles, such as electing representatives for particular Manchester Cancer groups.

Providing different opportunities

- 1** We will make sure that the involvement of people affected by cancer in our work is not just about attendance at meetings.
- 2** We will provide a range of involvement opportunities to suit people with different interests and skills, and to fit with the time that they are able to commit.
- 3** We will provide opportunities for people affected by cancer to get involved in actual work as well as the important role of passing comment on the work of others.
- 4** We will provide clear descriptions of the menu of opportunities available to allow people to make an informed decision about how they may want to get involved.

Giving training and support

- 1** We will support people affected by cancer to help them make a valuable contribution and will work with our partners to provide all the training they need.
- 2** Every person affected by cancer who takes up an opportunity to be involved will receive a generic Greater Manchester Cancer induction before their involvement begins.
- 3** All people affected by cancer will also receive an induction specific to the type of involvement opportunity that they have taken up.
- 4** We will inform the people affected by cancer involved in our work when anything significant changes in the wider NHS that may have an impact on Greater Manchester Cancer.
- 5** If a person affected by cancer is invited to a meeting they will be given the opportunity to meet with a member of the team beforehand for a short briefing.
- 6** Similarly, each person affected by cancer will be given the opportunity for a debrief with the chair after the meeting to discuss any support or training needs.
- 7** People affected by cancer involved in regular meetings will be allocated a buddy to provide support both inside and outside of these meetings.
- 8** We will also provide training and support in the effective involvement of people affected by cancer for clinicians and the chairs of meetings.

Communicating with people affected by cancer

- 1 There will be a single named Lead for the involvement of people affected by cancer in the work of Greater Manchester Cancer.
- 2 We will use plain English as far as possible: where jargon is a necessity we will make sure that its meaning is understood.
- 3 We will produce a jargon-buster and will make this available as part of the induction programme for people affected by cancer.
- 4 We will make sure that when people affected by cancer have been involved in our work they get feedback about what happened following their involvement.
- 5 We will hold an annual conference for people affected by cancer at which the leadership of Greater Manchester Cancer can be held to account.

Taking part in meetings and events

- 1 We will work over time with the steering group to make sure that there are at least two people affected by cancer on all appropriate Greater Manchester Cancer groups.
- 2 We will be clear about the purpose of every meeting for the benefit of everyone in the room, not just the people affected by cancer.
- 3 The discussion of patient experience and user involvement will be given a prominent place on the agenda of every appropriate Greater Manchester Cancer meeting.
- 4 We will reimburse any reasonable expenses incurred by people affected by cancer in travelling to take part in meetings and events.
- 5 We will send meeting papers out in a timely manner – if they require it (and if we are able to) we will send people affected by cancer hard copies of papers by post.
- 6 We will provide tea and coffee at all meetings to which people affected by cancer are invited.
- 7 We will hold meetings and events in accessible venues and send clear directions to both the venue and the meeting room.

Our expectations

- 1** We want people affected by cancer to bring their own unique perspective to discussions.
- 2** We also need people affected by cancer to think beyond this direct experience when necessary and represent the wider patient and carer voice.
- 3** We need the people affected by cancer involved in our work to feed back what is happening in Greater Manchester Cancer to any other groups with which they are involved.
- 4** We expect people affected by cancer involved in Greater Manchester Cancer to respect and value the contributions of others and remain impartial and objective at all times.
- 5** We need people affected by cancer involved in our work to make it known if at any stage they need anything clarifying or explaining.
- 6** We ask that people affected by cancer understand the pressures that professionals work under and the impact that this may have on our work.
- 7** We ask that people affected by cancer understand that change in cancer services is sometimes complex and time-consuming.
- 8** We expect people affected by cancer to respect the confidentiality and sensitivity of the discussions that they will be party to while involved in our work.
- 9** We ask that the people affected by cancer involved in our work let us know if their personal circumstances change in a way that might affect their involvement.
- 10** We ask that if a person affected by cancer feels at any stage that this Charter is not being met that they let us know immediately.