

A Patient and Public Involvement (PPI) Strategy for LhARA

DRAFT for Discussion

PURPOSE - To ensure that the views of cancer patients and the general public are taken into account in the design and execution of the project to ensure that it can contribute to a transformative improvement in radiotherapy cancer treatment which meets a real need as perceived by those whom it is meant to benefit most directly. A complementary purpose is to contribute to awareness of the project amongst patients and the general public.

AIMS

There are two main aims for the PPI strategy of LhARA which overlap and are mutually supportive:

- (a) To promote a dialogue between the research staff of LhLARA and patient representatives to enable the project to take into account the views, priorities and concerns of cancer patients as well as their suggestions for how things can be improved. This aim is to be complimentary to the input from clinicians regarding clinical priorities and patient benefit.
- (b) To create, among patients and the general public, awareness of and interest in the LhARA research programme and its goal of producing a transformational change in the delivery of radiotherapy. This aim should assist in generating general support in the community for the project and in promoting the involvement of industrial partners and the securing of support and resources from potential sponsors.

General Methods

Discussions will be facilitated between project staff and groups of patients who have personal experience of cancer treatment in order to gain from their perspectives and knowledge. There will be an emphasis on explaining the project, responding to questions/comments and consideration of the information and suggestions they contribute.

STRATEGY for achieving the above aims

- (a) To work initially through the lead on PPI activities at Imperial NHS Trust to arrange presentations on the LhARA project to the PPI group of patients that she coordinates. Two particular patient representatives have already been attached to the project and are members of the Steering Group. They have already made useful contributions in terms of advising on preparations for the project and on documentation. In addition, they are already members of the LhARA steering group.
- (b) These representatives will be involved with discussions on the objectives, methods, technical developments and research topics and would seek to ask questions, to make suggestions regarding project plans, in order that the project takes account of the actual priorities of patients in improving radiotherapy in terms of effectiveness of treatments, reductions in risks

and side-effects, and addresses questions of practicality, quality of life and availability of radiotherapy.

- (c) To recognise that this involves considerable dedication and work on the part of the representatives and so there will be a willingness to respond to their questions and to consider their suggestions.
- (d) To engage in public information activities which will seek to raise general public awareness of the nature of the project and its long term goals. This may involve interacting with appropriate organisations which operate in this domain.
- (e) To create and maintain a common information hub on LhARA to help with patient and public engagement. This will contain explanations in everyday language and a glossary of terms as well as information on progress.
- (f) To recognise that the scale of the project implies that PPI measures should become more widespread geographically as the project develops.
- (g) To review progress made in PPI and to make changes and improvements in response to evolving needs and feedback.
- (h) To devote appropriate resources to a Work Package in the project which will refer to the above implementation measures and to quality control.

These notes written by Gareth Jones on 5 Sep 2020