CTRad Consumer Involvement – an evolving model

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NCRI Clinical and Translational Radiotherapy Research Working Group

- Tasked with focussing on clinical and translational issues relating to radiotherapy and radiobiology, including looking at trial development.

- Also tasked with actively promoting translation of new discoveries into practice.

- The term working group is hardly applicable. It is a broad and multifaceted initiative with 82 members, including at present 6 consumers and a number of subgroups embedded within, or supervised by, its Executive Group and four Workstreams, which are Science Base, Phase 1/II trials, Phase III trials and methodology, and New Technology, Physics and Quality Assurance

Radiotherapy research is particularly dependent on multiple disciplines and CTRad has successfully nurtured a greater dialogue between them.

As a result of this it has produced a number of new initiatives including

- **RADCOM** Radiotherapy-Drug Combinations Consortium (a joint venture between CTRad and the CRUK Drug Development Office)

- **RADCAS**, a clinical trials design advisory service

Radiotherapy research is dependent on having academic centres with adequate academic posts and activity in both radiobiology and radiotherapy and CTRad has helped deliver and nurture activity in these areas including

- Running proposals guidance meetings to help applicants fine-hone the radiotherapy aspects of their proposals.
- Supporting centres as they aspire to become centres of excellence
- Running workshops on academic grant development for the academic communities in both radiotherapy and physics
- The number of University chairs and fellowship and research posts linked to radiotherapy have increased.

Quality assurance is critical to radiotherapy research.

- The RTTQA Group, funded by the NIHR, has benefited from CTRad oversight and senior clinical and managerial support. The RTTQA team has made a major contribution to the implementation of complex techniques like IMRT,IGRT and SABR in radiotherapy centres around the country, providing benefit for patients receiving routine clinical care as well as those participating in trials.

- Attention is now also being turned to the need for high quality assurance in pre-clinical radiotherapy research

More work to be done

The earlier slides show only a flavour of the scope of the current work of CTRad. The scope of the work is set to increase.
For example there are

- The new proton therapy centres, and the need to develop a national program of research with protons
- Treatments like SABR , stereotactic radiotherapy and molecular radiotherapy
- Increased need for IGRT (image-guided radiotherapy) including 4 G techniques responding to volume change with time.
- A new CTRad Biomarker Support Network has just been launched

So what about the consumer voice ?

The initial aim was

- 2 consumer members on each workstream
- 2 of these as members of the overarching Executive Group
- a scientific mentor for each consumer member
- members of the CLG

The initial challenges

- not always a full complement of consumer members
- little content overlap between the Workstreams so broader overview could be missed
- of necessity quite a high proportion of tele-conferences
- not easy to understand connection with CSG and CLG.
- scientific mentorship varied in quality
- no peer mentorship
- difficult to see how to make role effective on some workstreams

New ways of working

We still have

- 1 or 2 consumer members on each workstream
- 2 of these as members of the overarching Executive Group
- a scientific mentor for each consumer member

We now have consumer-initiated improvements:

- a regular meeting of CTRad consumers, along with the NCRI secretariat members, chaired by a consumer
- a new clear statement of core roles , expectations and working models for consumer in CTRad
- All consumers are involved at Proposal Guidance and other All-workstream meetings
- Scientific mentors and their mentees have scheduled pre-meeting briefings before proposal guidance meetings
- Regular consumer attendance at the varied meetings which arise from CTRad

How has this helped?

- we feedback to each other from the different workstreams and from the executive group
- easier to keep abreast with the whole scope of CTRad
- we can speak as a group if we wish
- we can support one another peer to peer and have improved links with CSG consumers.
- a better forum for the discussion and creation of ideas
- can best use our time and expertise across varied meetings internal and external of CTRad
- Improved fruitful relationships with mentors

Some Specific Outputs

- the production of a succinct and useful guide on **How to write a Good Lay Summary ,** led by Helen Bulbeck
- **Opportunities for Public and Patient Involvement in Trial Design**, again led by Helen Bulbeck
- consumer involvement at training workshops for researchers
- ensuring a patient voice at initiatives like the proton , and SABR consortiums
- gaining a seat at the National Radiotherapy Awareness Initiative

Others outside NCRI have also evolved this model . It works well in big projects and programmes with multiple threads
A few examples are

- *Health Education England*
- *NIHR Cambridge Bioresource*
- *REQUITE (an FP7 framework project with multiple workstreams)*

It requires commitment and resources from the programme, but produces returns from the consumer group in terms of output and added-value, but these will need to be evaluated.

There are other major programmes with little or no patient involvement that would benefit from such an approach.

With thanks to