



**Annual Report of Activity undertaken by CTRad
Consumers
April 2014 – March 2015**

Introduction:

The Clinical and Translational Radiotherapy Research Working Group (CTRad) was first set up by the NCRI in 2009 to provide leadership and to support the complex and challenging area of radiotherapy research in the UK. 'Working Group' is no longer an adequate description. CTRad has become a broad and multifaceted initiative with 82 members and a number of subgroups embedded within, or supervised by, its Executive Group and four Workstreams.¹

From the outset there has been consumer involvement (patients, carers and members of the public affected by cancer) in the work of CTRad, with consumer members sitting on each of the Executive Group and Workstreams. In order to make it easier to engage across the wide range of CTRad and satellite activities, CTRad consumers initiated an enhanced model of working whereby they meet as a group and work collectively across CTRad activities in addition to their individual involvement in one workstream. This is proving to be a successful approach allowing consumer members to work according to their interests and expertise, and offering a pool of consumer skills and experience for researchers.

As a result of their consumer involvement in the work of CTRad and on clinical trials, CTRad consumers are also invited to contribute at other radiotherapy-related events, both locally and nationally.

This report outlines the work of the CTRad consumer members during the year April 2014 until March 2015.

CTRad Consumer Membership:

Helen Bulbeck	Workstream 1 (Science Base) and Exec Group
Susan Campbell	Workstream 4 (New Technology, Physics, Quality Assurance)
Tom Haswell	Workstream 2 (Phase I/II trials)
Alf Oliver	Workstream 4 (New Technology, Physics, Quality Assurance)
Richard Stephens	Workstream 3 (Phase III Trials & Methodology)
Hilary Stobart	Workstream 3 (Phase III Trials & Methodology) and Exec Group

1. Activities undertaken April 2014 –March 2015

1.1 Contribution to the development of radiotherapy clinical trial proposals

CTRad consumers have continued to provide detailed comment from the patient perspective on radiotherapy trial proposals at various levels of development from being full members of early design working groups through the funding application process to support for studies already running.

Successful proposal guidance meetings were held in May 2014 and November 2014, at which 21 radiotherapy trial proposals were discussed. Consumers contributed to the discussions for all

¹ CTRad: National leadership in radiotherapy research – Achievements and vision, 2014
(<http://www.ncri.org.uk/wp-content/uploads/2014/10/2014-CTRad-Achievements-and-vision-WEB.pdf>)

proposals, including comments on some fundamental design challenges in some of the outline ideas.

Consumer views were given at CTRad Workstream meetings, and for RADCAS (Radiotherapy Clinical Trials Advisory Service) submissions. In addition consumer views were also provided as part of the CTRad review for a number of CTAAC (CR-UK Clinical Trials and Awards Advisory Committee) applications. Members of CTAAC have commented that the consumer input is a useful contribution to the committee's discussions. In addition consumer members have worked with clinical and scientific members in the radiotherapy research community as members of various Trial Working Groups, Trial Management Groups, Trial Steering Groups and in other roles to embed the patient perspective, including working with individual clinicians or researchers ahead of or following proposal guidance meetings.

1.2 Consumer contribution to the CTRad Executive Group

Two consumers, Helen Bulbeck and Hilary Stobart, have attended CTRad Executive Group face-to-face and teleconference meetings throughout the year. In particular they have contributed to the **CTRad: National leadership in radiotherapy research – Achievements and vision, 2014** and **Centres of Excellence** documents. They have, in collaboration with all CTRad consumers, produced a summary report of the work of CTRad for the NCRI Consumer Hub meeting with the aim of keeping the wider NCRI consumer community informed. It is expected that we will continue this by reporting to the newly-formed NCRI Consumer Forum.

1.3 CTRad Physics Grants Workshop, July 2014

Hilary Stobart and Alf Oliver participated in this very well-attended workshop for the radiotherapy physics community. The aim of the meeting was to encourage and aid physicists in their application for research grants, to improve the number of applicants. The meeting was well-supported with talks from all the main funders. Some of the barriers to application were perceived as high failure rate for applications in the past, and reluctance of some Trusts to back-fill posts. Several speakers raised the importance of good patient and public involvement in an application and consumer members supported this with information on how to engage and involve.

1.4 Route to Registration Workshop, Sept 23rd, 2014

This took place in September 2014 and was attended by clinicians, pharma, DoH, Helen Bulbeck and Tom Haswell. The workshop covered a number of topics including the challenges that lie ahead involving RT and new drug combinations and pharma involvement. Some of the challenges discussed were best study design, lack of strategy on part of pharma, potential for doing trials, standard protocols, prioritisation between large and small pharma, use of surrogate endpoints, regulatory input.

1.5 RCR Clinical Trials Workshop 14th October 2014

This clinical trials workshop, arranged jointly between CTRad and RCR, being run for the third year, was designed to develop skills and clinical trial expertise, and was over-subscribed. The CLG Chair and CTRad consumer, Richard Stephens was asked to repeat his presentation on the value

and impact of Consumer Involvement, where to find it and how best to make use of it. This talk was rated very highly by delegates on the day, leading to several email exchanges afterwards, and to some useful conversations between researchers and consumers on relevant CSGs.

1.6 2nd SCoR and CTRad Radiographers Think Tank meeting, November 2014

Richard Stephens and Hilary Stobart participated in a very lively meeting involving managers and radiographers from radiotherapy departments across the country. Topics like **Optimizing a Research strategy, Research and Collaboration with HEIs, the Radiotherapy Manager's Role in Research, Collaborative Service-centred Research as a corner-stone of Pre-registration Radiography Education** were presented and discussed. The consumer members were able to provide contact details for the NCRI Consumer Liaison Group (now Consumer Forum) and also some local contacts to several participants who were not yet sure how to engage with involved patients.

Consumer members were particularly encouraged to hear how the previous Think Tank in 2013 had specifically resulted in some departments setting in motion new strategies which they could now present in 2014. Also of encouragement was the range of departments attending, not just the ones normally thought of as research-active. Helping to disseminate these changes in practice may be a role for the new NCRI Consumer Forum.

A point made by one speaker that the quality of the new treatment scanning which takes place at the treatment machines during radiotherapy, e.g IGRT 4GT, means that radiographers now see scans where they may be the first clinical people to spot tumour growth, pneumonia etc. This means that they may be in a position to help patients at an earlier stage by alerting oncologists. However the training needed to make full use of these possibilities needs addressing in radiotherapy teaching courses. Consumer members were pleased to highlight at the March 2015 NAEDI Conference a poster showing research into this topic, which received an award from the conference's Patient Panel.

1.7 Proton Beam Therapy (PBT)

The Proton Beam Therapy Research Consortium planning group has a very clear brief – to define the research strategy for PBT when it arrives in the UK in 2018 and to ensure that it is integrated into the radiotherapy research agenda. Helen Bulbeck is the consumer representative on this group, and together with Alf Oliver and Sue Campbell participated in its meeting in April 2015. The first part of the meeting consisted of a series of presentations from the PBT community covering the breadth of activity in PBT research. The second part was a breakout group session designed to stimulate discussion to help develop a research strategy and progress the research agenda.

The aims of the breakout group were to consider the developing national research strategy and to consider:

- What are the PBT research priorities in the short term (next 5-7 years) and longer term (next 7-15 years)?
- What are the tools and facilities that the research community need to achieve these priorities?

- Will the necessary existing infrastructure achieve these priorities?

In the open discussion and feedback from the attendees, potential questions from the clinic were highlighted as key drivers for the research agenda. Of great importance to patients and carers in their consultations were the biological aspects from damage repair, late toxicity and the study of cells around tumours after treatment. The lack of published data from the USA was of particular concern.

1.8 RadCom (Radiotherapy-Drug Combinations Consortium)

Helen Bulbeck and Tom Haswell are the CTRad consumers on this group. This has been established by the NCRI Clinical and Translational Radiotherapy Research Working Group (CTRad) and Cancer Research UK's Centre for Drug Development (CDD). RaDCom is a collaborative network of laboratories working in partnership with the pharmaceutical industry, CRUK and other funding bodies. The key focus is to deliver high quality experimental (pre-clinical) data demonstrating that specific drugs can enhance radiotherapy treatment when used in combination. This evidence can then support early phase clinical trials of these combinations in patients. RaDCom's work includes the most appropriate tumour types, with accompanying biomarker data showing the effectiveness of the treatment where appropriate. RaDCom is engaging on a strategic level with industry, so that it becomes a key point for industrial partners seeking appropriate expertise for the delivery of pre-clinical radiotherapy-drug combination work.

RaDCom is:

- Looking for proposals for pre-clinical radiotherapy-drug combination projects, in particular those which would benefit from a collaborative approach
- Making sure that projects are ready for funding
- Identifying and allocating work packages to laboratories, based on expertise and/or facilities available
- Monitoring projects successful in applying for funding, to ensure timely delivery
- Monitoring the existing radiotherapy-drug combinations pre-clinical and early phase portfolio, in order to ensure that areas of need are addressed.

Helen Bulbeck (on behalf of CTRad consumers) has produced, **We're None of Us as Smart as All of Us: Joint Working with the Pharmaceutical Industry, December 2014**, a paper in support of RaDCom). (<http://ctrad.ncri.org.uk/research-support/radiation-drug-combinations-radcom>)

1.9 National Radiotherapy Awareness Initiative

With the support of the CTRad Chair, Neil Burnet, CTRad consumers suggested to the new NRAI (National Radiotherapy Awareness Initiative) that they might benefit from a CTRad consumer as a member of the committee, to join the current consumer member, Caroline Morris. This was agreed and Hilary Stobart, supported by Tom Haswell, have fulfilled this role during the year, with the aim of highlighting the importance of awareness of radiotherapy research for patients. The work plan for the initiative is being developed, and one of the first pieces of work in which consumers have contributed, is a new survey on public attitudes to radiotherapy which is being run by YouGov in May/June 2015.

1.10 Clinical Oncologists' Trials Sandpit Day, 24th March, 2015

This one-day workshop was targeted at clinical oncologists (consultants and senior trainees) who wished to develop their own clinical trial proposals. There were three breakout groups, each group were given 3-4 concept presentations which were discussed and one concept from each group was presented to the delegates and a prize was awarded to the most innovative proposal. Sue Campbell and Alf Oliver contributed to the discussions along with Helen Bulbeck who gave an excellent presentation of consumer involvement.

1.11 CTRad Workshop – CRUK Grand Challenge idea scoping, 25th February 2015

This workshop was convened to discuss ideas which could be put forward for the CR-UK Grand Challenge. At the start there was emphasis that the winning challenge would need to be very large scale, with collaborative working, including with international input. There were five breakout sessions where individual ideas were discussed, and in which CTRad consumers contributed. Two of the CTRad consumers had previously undergone CR-UK training and practice session for the Grand Challenge day and were able to provide insight to the meeting on some of the CR-UK expectations for proposals, emphasizing again the scale of the challenge.

2. Presentations and Publications involving CTRad consumers

- 2.1 International Clinical Trials Day, 20th May 2014** : Alf Oliver was interviewed by the BBC and set out to explain the benefits of clinical trials, and the newer radiotherapy technologies like IMRT, IGRT, and SABR. He emphasized that today's clinical trials are tomorrow's standardised treatments.
- 2.2 ICPV Workshop, Brighton, July 2014**: "Consumer Involvement at CTRad – an evolving model", Hilary Stobart
- 2.3 CTRad Clinical Trials Workshop 14th October, 2014 for new RT researchers**: CLG Chair and CTRad consumer, Richard Stephens, presented on the value and impact of consumer involvement, where to find it and how best to make use of it.
- 2.4 We're None of Us as Smart as All of Us: Joint Working with the Pharmaceutical Industry, December 2014**, Helen Bulbeck (on behalf of CTRad Consumers) in support of the Radiotherapy-Drugs Combinations Consortium established by CTRad and the Cancer Research UK (CRUK) Centre for Drug Development (CDD). (<http://ctrad.ncri.org.uk/research-support/radiation-drug-combinations-radcom>)
- 2.5 Britain against Cancer Conference, 9 December 2014, London, UK**: "It's Our Data: Why patients need to be involved from the start", Hilary Stobart
- 2.6 Clinical Oncologists' Trials Sandpit Day, 24th March, 2015**
Helen Bulbeck gave a well-received presentation on the value and impact of consumer involvement.