

**Consumer Report to the NCRI's POS CSG**

**Consumer Representative: Elspeth Banks**

**Date of Meeting: 22 January 2016    Date of Report: 13 December 2015**

**Consumer members of CSGs are members of the NCRI Consumer Forum, whose purpose is:**

To create a professional, focused and committed constituency of consumer research partners for NCRI, who can help NCRI achieve its aims.

**The Guiding Principle of Consumer Involvement is that we are:**

Working together to build a community with the common purpose of providing patient and public perspectives throughout the research process, to deliver research with better outcomes and experiences for all.

**The report below shows the activities of one of the consumer members of this CSG. It aims:**

To show the activities of the CSG consumer

To show how these activities have contributed to the work of the CSG

To show how these activities have contributed to the work of the Consumer Forum

**1.0 Membership of subgroup/trial groups/committees/forums/support groups:**

- Membership of subgroup Lifestyle and Behaviour Change.
- Clinical Trials Executive Committee at Beatson WOSCC
- In-house Trials Advisory Board at Beatson WOSCC
- Umbrella Trials Steering Committee – sole independent consumer member of group at Beatson WOSCC
- ECMC – member of PPI Strategy Steering Group
- NCRI Consumer Forum member
- CRUK Patient Data Reference Group
- ICPV Trustee
- Advisory board for CRUK/Bupa Foundation funded feasibility study - Sexual Health eLearning Resources for Further Education Professionals to use with young men in cancer prevention
- EFFECT Intervention Study - Co-applicant and Trial Management Group member - subgroup study led by Gill Hubbard
- Feasibility trial of a community pharmacy intervention to support adherence to adjuvant endocrine therapy in women with breast cancer– co-applicant
- MENAC – co-applicant and trial steering group member
- CEPAT – co-applicant and trial management group member
- Mini-AFTER - co-applicant and trial steering group member
- Improving early detection by increasing female adolescent awareness of symptoms suggestive of melanoma, communication about melanoma within families, and skin self-examination: A cluster randomised controlled trial with embedded process evaluation - co-investigator
- Proact - Patient Reported Outcomes in cancer, impact of Age and Carer role demands associated with Treatment – patient advisor
- Novel approaches to understanding and treating fear of recurrence in breast cancer

survivors –co-applicant

- Constructing life beyond cancer with co-morbid disease: a qualitative multi perspective study - steering group member
- Non-invasive mesothelioma early detection in high-risk asbestos-exposed individuals: a feasibility study - steering group member
- Measuring the impact of advanced cancer and its treatment on patients and their informal caregivers – SHORE-C – Sussex University –advisory group member

## **2.0 Engagement with CSG activities and members since the last report:**

- Regular communications with Gill Hubbard in the following:
  1. Gill is my scientific mentor
  2. I serve as patient advisor member on the Lifestyle and Behaviour Change subgroup which is chaired by Gill
  3. I am co-applicant and Trial Management Group member in the EFFECT intervention study which Gill leads
  4. We are both members of the advisory group for a CRUK/Bupa Foundation funded feasibility study - Sexual Health eLearning Resources for Further Education Professionals to use with young men in cancer prevention
  5. Invited to join Gill, Mary and colleagues from various charities and organisations in planning and delivering a PPI awareness raising/involvement/ training event to be delivered in Edinburgh in October 2015
  6. Invited by Gill to be co-investigator and write lay summary for a melanoma intervention study
  7. Invited by Gill to join a working group charged with producing Public Engagement Guidance for the School of Health Sciences at the University of Stirling
- Communicate regularly with Eila Watson and Mary Wells on Feasibility trial of a community pharmacy intervention to support adherence to adjuvant endocrine therapy in women with breast cancer
- Working with Mary and Gill to plan a future two day event for patients on the topic of survivorship
- Communicate regularly with fellow consumer representative on CSG – Carolyn Morris

## **3.0 Major activities since the last report:**

- Member of panel that reviews study concepts and the patient information given to UK patients considering taking part in EORTC clinical research activities
- Lifestyle and Behaviour Change (CSG subgroup) EFFECT TMG member and co-applicant (Gill Hubbard)
- Feasibility trial of a community pharmacy intervention to support adherence to adjuvant endocrine therapy in women with breast cancer– Co-applicant, Steering group.
- Study - Constructing life beyond cancer with co-morbid disease: a qualitative multi perspective study – invited to comment on study proposal (Debbie Cavers) and in November 2015 invited to join steering group
- ICPV – contribute articles to ICPV Newsletters
- Invited to join Gill Hubbard and colleagues from various charities and organisations such as Alzheimer’s UK and Asthma UK in planning a PPI awareness raising/involvement/ training event
- cEPAT – Community Edinburgh Pain and Management Tool - Does the introduction of cEPAT improve advanced cancer pain control in patients at home compared to standard care? – reviewed protocol and PIS documents. Co-applicant and Steering Group

Member.(Marie Fallon)

- MENAC – a new approach to cachexia treatment - reviewed revised protocol for second funding application, to Marie Curie. Trial Management Group member and co-applicant (Barry Laird)
- Study - Improving early detection by increasing female adolescent awareness of symptoms suggestive of melanoma, communication about melanoma within families, and skin self-examination: A cluster randomised controlled trial with embedded process evaluation. Invited to be co-investigator and to write lay summary (Gill Hubbard)
- Study - An open label randomised trial using serial cardiac troponin I measurements to guide angiotensin converting enzyme inhibitor (ACEi) and beta blocker (B-blocker) treatment to prevent cardiac toxicity in breast cancer patients receiving anthracycline and/or trastuzumab adjuvant chemotherapy – asked to manage consultation on proposal with ICPV (Peter Hall/Iain McPherson)
- Study - A mixed methods study to explore the influence of a prior primary cancer on a subsequent second primary cancer (SPC) experience – invited to review the protocol and provide feedback (Debbie Cavers)
- Study - Measuring the impact of advanced cancer and its treatment on patients and their informal caregivers – SHORE-C – Sussex University – invited to become a member of the advisory group for this project (Val Shilling)
- Study – Mini-after - Acceptability and deliverability of a telephone intervention (Mini-AFTER) for the management of fear of recurrence in breast cancer survivors. Invited to be co-applicant and member of steering group (Debbie Fenlon)
- Evaluating cancer services across the NHS in Scotland, Wales and Northern Ireland - The main focus of this evaluation is on early diagnosis of cancer, patient access to world class cancer treatments, as well as broader strategic factors such as Cancer Plans and national cancer policy and leadership. Invited by Scottish Cancer Surveillance Unit to test run the telephone interview for stakeholders and to provide feedback on the accessibility of the questions
- Study - Proact - Patient Reported Outcomes in cancer, impact of Age and Carer role demands associated with Treatment - invited by Dr Val Shilling to act as advisor.
- Study - Defining Mechanisms of hormone therapy in breast cancer, risk reduction and biomarkers of response – reviewed lay summary and PIS
- Study – Novel approaches to understanding and treating fear of recurrence in breast cancer survivors – Colette Hirsch/Jo Armes – invited to review documents and to be co-applicant
- NCIN Conference in Belfast (June)
- NCRI Conference in November (Liverpool) where activities included NCRI Consumer Forum meeting, Dragons’ Den and NCIN Data Workshop
- Scotland Cancer Conference in November (Edinburgh)
- Britain against Cancer Conference in December (London) – facilitated table discussion on the use of patient data
- Inaugural CRUK Patient Data Reference Group meeting (London)

#### **4.0 Forthcoming involvement/events:**

- ECOM PPI Strategy development meetings (London)
- ECOM Network Meeting (London)
- CRUK Patient Data Reference Group meetings(London) and teleconferences
- ICPV events and Trustees meetings throughout the year
- Planning group for PPI Involvement in Research event 2016
- Planning group for two day event to take place at the University of Stirling
- Monthly Clinical Trials Executive Committee meetings at Beatson WOSCC

- Bi-monthly In-house Trials Advisory Board meetings at Beatson WOSCC
- Regular Umbrella Trials Steering Committee meetings at Beatson WOSCC
- Invited to support recruitment of new patient members and in further developing the PPI remit and role at the Beatson WOSCC.

#### **5.0 Messages for the CSG:**

1 CRUK PDRG - I have become increasingly involved in discussions and workshops on the use of patient data and was interviewed for membership of the newly formed CRUK Patient Data Reference Group. The British Heart Foundation is working in partnership with CRUK which brings another dimension to this important work. The inaugural meeting took place on 7 December 2015

2 NCRI 2016 Conference – two Consumer Showcases are proposed for inclusion in the next NCRI Conference and there is a request from the Consumer Forum for information about trials that have good or innovative consumer involvement. This request goes out to all CSGs and is an opportunity for CSGs beyond those who usually offer such examples and a chance for the smaller portfolios or rarer cancers to be included.

#### **6.0 Collaboration, Advice, Views or Support (if any at this time) required from fellow CSG members:**

- I know that Jo, Gill and Carolyn and other group members are available to offer advice and support and am appreciative of this
- Currently working in partnership with Mary and Gill to plan a future two day event for patients on the topic of survivorship.