



Involvement in
Cancer Research Trials

The Patient Experience

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Member NTCRN Consumer Research Panel

BACKGROUND

- 1999 diagnosed with Multiple Myeloma
- 2000 Bone Marrow Transplant
- 2002 Volunteer at Cavendish Centre
- 2004 Joined Consumer Research Panel
- 2008 Continuing treatment

WHY JOIN THE CRP?



- To gain lost confidence
- To boost self-esteem
- To fill spare time
- To feel useful
- To give something back



PERSONAL BENEFITS

- Meeting new people
- Feeling useful
- Learning new skills
- Increasing confidence
- Patient's viewpoint



PERSONAL DRAWBACKS

- Not enough time
- Still in 'cancer' world
- Financial implications
- Not being taken seriously



BENEFITS TO TRIALS

- We can 'tick boxes'
- Totally different perspective
- Actual real experiences
- Help with paperwork

DRAWBACKS TO TRIALS



- Just to 'tick boxes'?
- Is different perspective wanted?
- Reluctance of professionals
- Just a token?
- Does it cause more work?

WHAT DOES THE CRP DO?

- Analyse and comment on Documentation
- Participate in Workshops
- Attend Focus and Steering Groups
- Organise the Annual CRP Conference
- Report writing/dissemination
- Give opinions on Protocols, Bids etc

OTHER ISSUES



- Are we consumers/patients/service users?
- How to encourage patient involvement
- Do we need first hand experience?
- Do not need to be a CRP member?
- Provision of training
- Problems with funding

CRP INVOLVEMENT



- Two Myeloma Projects
- Over 70's Breast Screening Project
- MINDACT, QUARTZ, BISMARCK Studies
- PET Scanning Project
- TV Documentary on Palliative Care
- Oral History Project

MEMBERS OF:

- Clinical Trials Executive
- NCRI Breast Clinical Studies Group
- NTCRN Executive Steering Group
- Lung Cancer Clinical Studies Group
- North Trent Partnership Group
- NCRN Consumer Liaison Group

IS IT WORTH IT?

**From a Researcher
To CRP Member 2007:**

'I found your help invaluable and as a result have been working on revising the interview guides. You gave me insight into what it is like living with myeloma and how different my approach needs to be....'

YES!!