



UK therapeutic

cancer prevention network

collaborating to prevent cancer

Patient & Public Involvement in Cancer Prevention

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&

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UKTCPN Vision

*Identify, develop and accelerate the translation of therapeutic cancer preventive agents and lifestyle interventions into **clinical trials and routine clinical practice***

UKTCPN 2016-2017 Aims

Raise profile & standing of the network to a position where we are the first call nationally for advice/opinions on therapeutic prevention to support policy makers

Raise the profile of the UKTCPN and wider ECMC internationally by building links and collaborations with European researchers

To maximise public involvement in therapeutic cancer prevention discussion

Organise scientific conferences, symposia and workshops

Provide collaboration among investigators and develop joint grant applications

TARGET 4 - Produce and agree a formal Strategy and Plan for patient, carer and public involvement and engagement

What can we do for prevention

- Public Awareness
- Why are we afraid of therapeutic cancer prevention?
- Get the message out that “*this can be possible*”
- Start with a health and active lifestyle
- Support research

How Can PPI Help You

- PPI is now a funding requirement
- Promote good effective PPI – “not tick the box”
- Honesty – if we think something is not right we will say so
- Provide letters of support, develop a PPI strategy
- Understand the needs of the patient
- What can be done and also what cannot
- We can help with links to local groups
- **Ask the awkward question????**

How We Do It

- Circulate material to members through Google group for online discussion
- Links with national & local PPI groups
- Collated comments are fed back to the researcher
- One or two members join study team
- Dragon's Den for new ideas – invite researchers to speak to us



The Value of PPI

- Research into what can PPI can do
 - Is it appropriate? Is it relevant?
 - Can it make a difference?
- YES IT CAN
 - Comments from a recent paper included ‘expert in lived experience’, the ‘creative outsider’, the ‘free challenger’, the ‘bridger’, the ‘motivator’

Research Papers

Health Expectations

An International Journal of
Public Participation in
Health Care and Health Policy

doi: 10.1111/hex.12479

Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK-based qualitative interview study

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Editorial

The Value of Patient and Public Involvement in Trial Design and Development

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Registered Charity no. 1138456

www.independentcancerpatientsvoice.org.uk

Things To Remember

- Give us time to respond - we are volunteers and have lives outside cancer
- Tips for PPI – check out the INVOLVE website www.invo.org.uk for information on engagement, good practice, payments & budgeting for PPI

Other resources

- CRUK involvement network
(involvement@cancer.org.uk)
 - a group of around 600 people affected by cancer who want to get involved in Cancer Research UK's work
 - Members can get involved in as much or as little as they like
 - Receive regular newsletter for updates and opportunities to get involved
 - researchers may use this to recruit people affected by cancer to their projects
 - Online and offline opportunities available
 - surveys/questionnaires
 - focus groups/workshops
 - patient advisory panels



PPI in primary care: Patient Groups

- An under-utilised source of help and assistance to practices and by working together patient experience and service delivery can be enhanced with little effort from the clinicians/staff.
- Facilitated by CCG
- High on the NHS agenda

Patient Groups Role

Cancer prevention advice can be championed via patient groups working with CCG's and stakeholders

Thank you!



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