



PPI's Big Picture - How Can We Join The Dots?

Richard Stephens
ICPV Conference, Brighton, Sept 2012





*National Institute for
Health Research*

Cancer Research Network

ICPV

Our aim is to improve existing treatments for every cancer patient and develop new treatments by bringing the patients' voice into clinical research.

CLG – Update - Overview

- ✓ Full recruited... Nearly...
- ✓ “Impact of PPI 2001-2012” published... Nearly...
- ✓ PET DVD www.youtube.com/watch?v=JdlRoloYFVs

- ✓ 2013 Meetings planning:
 - Mar/Apr; London/Leeds; Trials/studies
 - Jun/Jul; Regional? PPI Focus?
 - Nov: Liverpool Conference; science/industry?

- ❖ One Budget
- ❖ Two membership categories
- ❖ Three organisations’ expectations - NCRI, NIHR, NCRN



Consumer Liaison Group (CLG): Patients as Partners in Research

- ✓ National network of cancer patients & carers; trained, supported and co-ordinated
- ✓ Ensuring research is accessible, acceptable and will benefit patients; problem-solving for the real world
- ✓ Ensuring information about research and clinical trials is easily understood and widely available
- ✓ Promoting participation in research
- ✓ **CLG was the first PPI group embedded in a national cancer research structure anywhere in the world. It remains the only such group.**



Working with the NCRI Clinical Studies Groups (CSGs)

- ✓ CSG - primary route through which new ideas for cancer trials are developed **in the UK, &** manage UK cancer trial portfolios within strategic framework and objectives
- ✓ Managed by NCRN CC on behalf of NCRI; funded by major cancer charities (esp CRUK) and MRC.
- ✓ 22 CSGs; 15 tumour specific + 6 generic/cross-cutting
- ✓ Expert involvement from academics and clinicians
- ✓ CLG Core Members deliver PPI input on every CSG; next logical step may be to move to QA and PM?|



Where are we delivering PPI and joining the dots in research cycle?





NCRI and PPI

“The NCRI Secretariat will continue to recognise and promote the intangible benefits of partnership which are less easy to measure. These include:

Maintaining an environment in which the involvement of patients and carers in research is considered to be the norm.”

NCRI Strategic Plan, 2012-2017



The NCRI Partners

NHS
National Institute for Health Research

Cancer Research Network



Llywodraeth Cynulliad Cymru
Welsh Assembly Government



CRUK

- ✓ Letter of thanks to participants
- ✓ Drug Development Office
- ✓ CTAAC Reps – Scoring applications
- ✓ CTAAC, CSGs and PPI
- ✓ Kate Law – Funders/Endorsers and PPI
- ✓ Peter Johnson – awareness raising

- ❖ Rebranding
- ❖ Financing applications; major vs others

Patient Partners and Pharma

- ✓ AZ - visit, newsletter, trial design, governance
- ✓ GSK – “Action On Access” report facilitation
- ✓ Pfizer – poss PPI on recruitment/information
- ✓ Roche – poss staff awareness-raising

- ❖ Lazarus Patients
- ❖ Orphan Drugs

“Action On Access”

- ✓ Open up health service culture to clinical research
- ✓ Increase awareness of clinical research
- ✓ Support clinicians - trial-friendly and trial-wise
- ✓ Make it routine practice to discuss trial suitability
- ✓ Improve equity of access to clinical research

- ✓ GSK funded production of report and meetings
- ❖ NCRI/NCRN to publish?
- ❖ CLG Chair to endorse?



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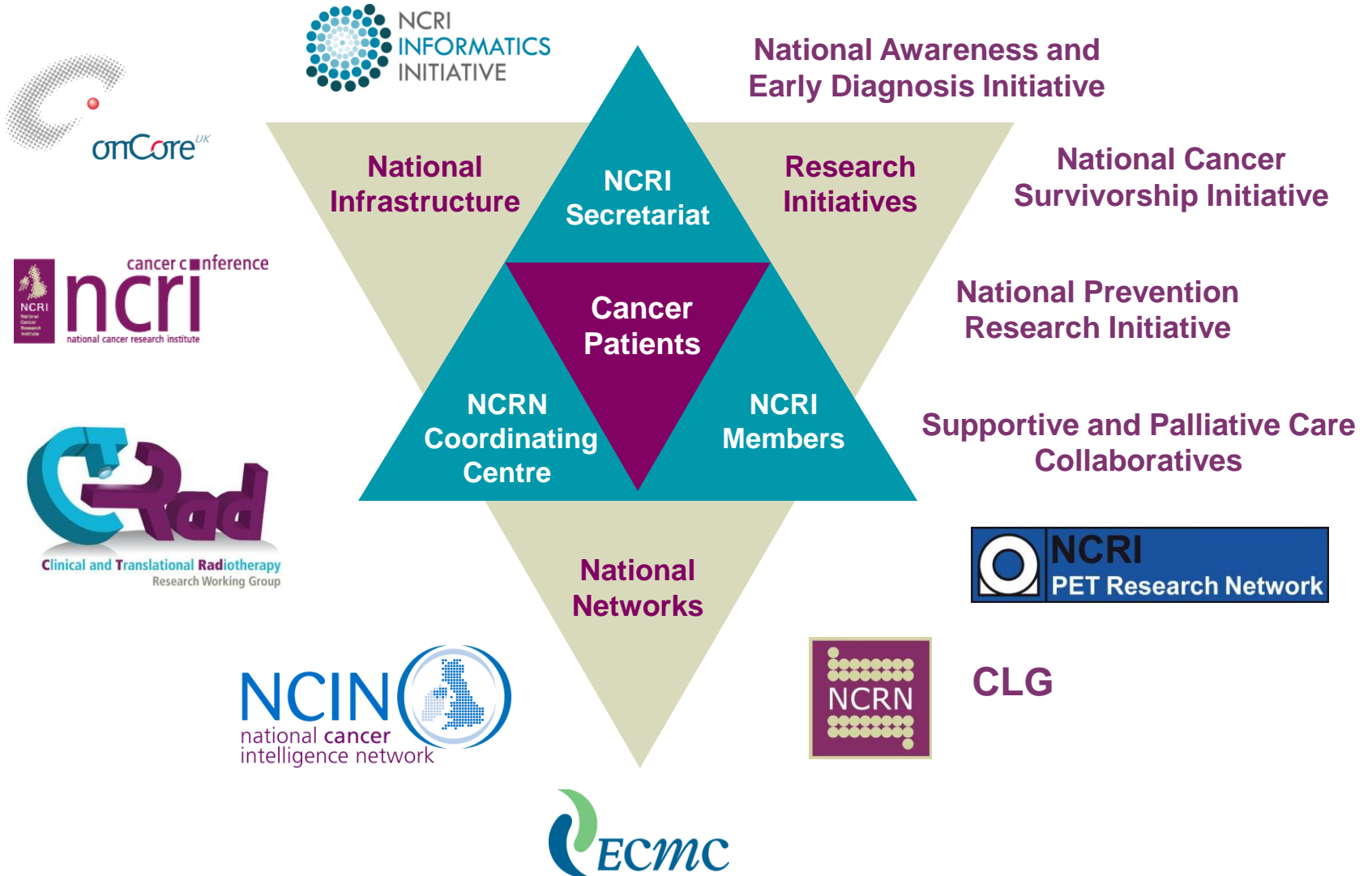


The NCRI Relationships



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CLG – Update – PPI On Strategic Stage

- ✓ Concord 2 – International PPI
- ✓ New PPI group for NCIN
- ✓ NCRI SPED (a work in progress)
- ✓ NCRI CTRad www.ncri.org.uk.ctrad
 - Plain English Summaries
 - Team approach – panel/pool
- ✓ Hub – longer meetings, extended membership
- ✓ NCRI Conference Planning – two new PPI reps
- ✓ End of Life Care – NCRI and NIHR

- ❖ “Survivorship” - pause for thought/redefine?



CLG – Update – NCRI Conference

- ✓ Mon 5th Nov – CLG Meeting
 - Jane Cope – How PPI has helped NCRI
 - Kate Law – What Funders & Enablers want from PPI
 - Dragons’ Den – researchers bring their ideas to us

- ✓ Tues 6th Nov - Consumer-led Parallel Session
 - Public/patient/participant perspectives – NCPES

- ✓ Wed 7th Nov – CTRad Trials Proposals Workshops



NCRN and the CLG - part of the NIHR PPI Programme

- ✓ Making it easier for patients and the public to be involved in research
- ✓ Supporting researchers to make best use of PPI in developing patient focussed research studies
- ✓ Sharing good practice, strengthening partnerships with organisations involved in PPI
- ✓ Promoting PPI as part of our core business
- ✓ **CLG has twelve years of unique experience and demonstrable achievement to share.**



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NIHR

- ✓ Deliver trials and studies in NHS
- ✓ Have impact on patients
- ✓ HTA – methodologies eg prostate risk; cost-effective
- ✓ RfPB – local/regional; services
- ✓ NETS-CC - publish and write-up incl PPI

- ❖ PPI may have role to play in CPD for NIHR staff

- ❖ Academic courses to have PPI people?

CLG – Update – Work In Hand

- ✓ NCIN Conference ideas (consumer-led session?)
- ✓ INVOLVE Conference ideas (Dragons' Den?)
- ✓ NCRN IMPACT group – does PPI routinely help?
- ✓ Britain Against Cancer – Better outcomes on trials?
- ✓ SPADE – exit interviews; survey CSG Reps/Chairs
- ✓ SPADE - “rapid response”

- ❖ National Clinical Trials Day – Mon 20th May 2013
- ❖ Tissue donation; unexpected results; post-mortem
- ❖ Consort Protocol 2012 (PROMs & QOL)



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