

# Challenges to NCIN from the patient perspective ...

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&

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**June 25 2009**



# Challenges to NCIN from one patient ..



- GPs – low (or no!) index of suspicion
- Year of delay ...
- Stage C cancer – surgeon who did audit
- No chemo
- Survival – luck not good judgment!

# Months after op for advanced bowel cancer ...



# European Cancer Patient Coalition .. Patients as partners ...

- ECPC - 300 member groups in 41 countries
- Launched in 2003 – transparency of funding & independence vital
- Working with politicians – Secretariat for MEPs Against Cancer
- Helped to get cancer back on the official European agenda



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# First challenge to NCIN

Great research – but how will it really help us?

- Can the public get access?
- What will the media do with your research?



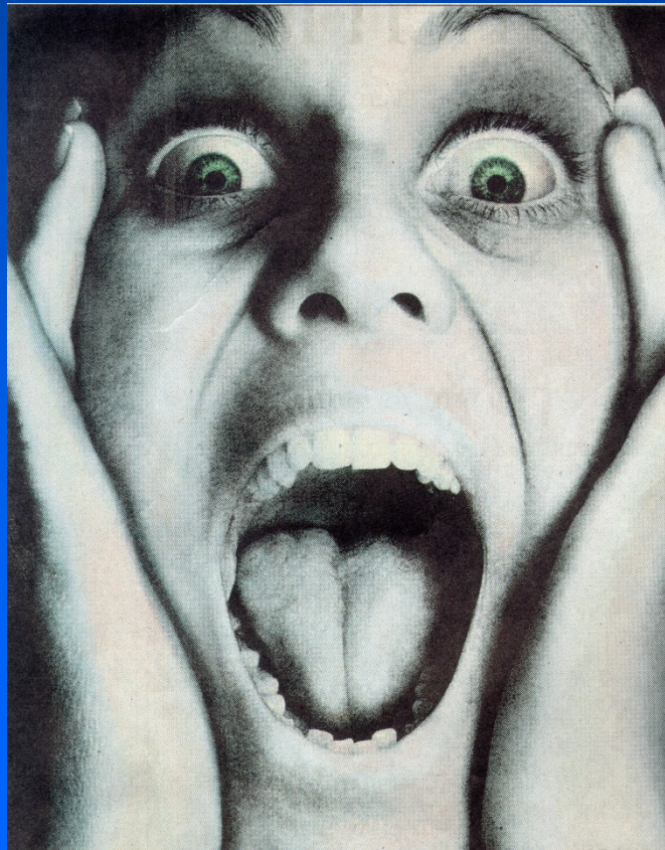
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*Alarmist news stories are making us paranoid about the 'c-word'. Bryony Gordon reports*

# Cancer: how scared should we be?



Lynn's  
**bowel  
cancer**  
campaign

 EUROPEAN  
CANCER  
PATIENT  
COALITION



# Next challenge .. influencing the medical profession ...

How can we get better reporting of audit, pathology ..

... change poorer to best practice for us?

... change custom & practice/lack of up-to-date skills/equipment/training to best practice?



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# Women with breast cancer and mastectomies ...



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# Challenge – what if it's good news from NCIN ..?

- Will the media want to know?
- Will charities want to know?
- Cancer patients **will** want to know ....



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# My best friend Sarah



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# The TV programmes we made on cancer ...

BBC said: “people won’t watch ...”

- ITV World in Action: “Doctor Knows Best” on GP training in cancer symptoms ...
- **10.2 million viewers**
- ITV World In action: “Bobby Moore & Me” investigation into bowel cancer
- **6.5 million viewers and 28,000 letters!**



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## Two hospitals missed Sarah's cancer ...



# Challenge – health literacy - how to reach the hard to reach ..

- Bowel cancer recorded symptoms hotline – first day – 2 slots on GMTV
- **156,000 attempted calls ...**



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# Challenge from NCIN to cancer patients

How can we help you?

- Data protection
- Asking for MDTs, surgical teams who do audit ..



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# Challenges for NCIN ...

- Agree data set and don't make it too long – data collection fatigue ...
- Length doesn't equal strength – don't ask for too much, don't take too long and feed back to the people who collected it ...
- Link in things which make a change – commissioners, networks .. public!
- Communicate results!



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# Tops communication tips ...

- If you don't touch people – you don't change behaviour
- Think “Sun” readers
- Say it, say it and say it again



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- Credits
- Presented by Lynn Faulds Wood
- Animation by Nick Stapleton
- Aged 13 - who is very glad his mum is still alive!



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