

# Fleshing out the data: supporting researchers to engage with and involve patients and carers

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How can we involve patients and the public in epidemiological research?

Unlike clinical trials, some health research, such as analyses of pre-existing datasets, does not present immediately obvious ways to **involve patients and the public**.

However, this involvement is vital in order to produce **relevant and robust research**.



The Cancer Survival Group at LSHTM co-hosted a 1-day meeting with the National Cancer Research Institute's Consumer Forum including a "**Dragons' Den**" session in which small groups of 'consumers' provided insight, advice and ideas on current or planned research.

Our '**Dragons**' were patients, carers and people affected by cancer, members of the NCRl Consumer Forum

After the event, we used semi-structured interviews to investigate this form of public involvement, to get feedback and develop broad recommendations for other future activities.

*Consumer 1:* "It's an opportunity to hear what other people think ... expanding my own learning and it gives me more experience that I can draw on in the future"

*Consumer 2:* "I enjoyed it very much and got a lot out of it"

*Researcher 1:* "I was thrilled at that opportunity to discuss with Consumers...it was a great experience, and I wish we had more opportunities to share about the work we do in that context"



*Researcher 2:* "I was excited to get some information from people with first-hand experience of cancer"

*Researcher 3:* "I thought it was a very useful exercise and the patient representatives were really active ... each of them really had something to say on the topic. So, I think it was a really useful interaction with patients"

## Research managers and administrators supporting patient and public involvement

Professional services staff supporting research have a **unique insight into academic research** while at the same time being able to bring a **non-researcher perspective** – a lay voice to help translate and make research more accessible - enabling us to provide a **link between researchers and the public**.

Looking for opportunities and encouraging researchers to become involved in **public engagement and involvement enriches the research environment** and all those that work within it.



Cancer  
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Group

