NCRI Consumer Forum
Patients Promoting Evidence-Based Medicine and Evidence-Based Policy

**Introduction**

Since its inception in 2000 the UK’s National Cancer Research Institute [NCRI](#) has committed to involve Consumers (patients and public) representatives in all aspects of its work.

Consumers are recruited in open competition, trained for specific NCRI roles, and supported to work beyond those roles.

**NCRI Consumer Forum** has 140 members. They come from all four UK nations, providing a pool of experienced advocates working in all areas of cancer research across the whole of the UK and beyond.

**Background**

75% of Consumers work with research funders or organisations outside the NCRI Partners.

In the 2021 census(1), more than 50 such organisations were identified, including local, national and international organisations, charities, NHS Trusts, online communities and patient groups.

**Results**

During the Covid-19 pandemic in 2020-21 the Consumer Forum worked collaboratively with the UK Coronavirus Cancer Monitoring Project (UKCCMP).

**NCRI Dragon’s Den**(2) was used to create a survey asking cancer patients what was important to them for Covid-19 and cancer research.

The survey was distributed via the Consumer Forum.

Results informed the direction of Covid-19 and cancer research in the UK by refocussing research priorities.

This collaboration continued with regular discussion around new research areas.

Collaboration on peer-reviewed journal articles:
- Vaccine effectiveness against COVID-19 breakthrough infections in patients with cancer [UKCCEP]: a population-based test-negative case-control study - The Lancet Oncology.

Consumers work/have worked with industry including big pharmaceutical companies, biotechs and medical device manufacturers.

Consumers serve on Trial Management/Steering Groups, sit on research funding committees and hold governance or accountability posts, eg Board members, Charity Trustees, NHS Commissioners.

**Conclusions**

The NCRI Consumer Forum has motivated and educated consumers working extensively to promote evidence-based medicine and evidence-based Policy in the UK and beyond.

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(1) 2021 Census: Survey of NCRI Consumer Forum members to collect key data points around characteristics, experience, activities and needs.

(2) A 'Dragon’s Den' workshop to improve research through Consumer involvement.

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All Consumers have worked on patient information, including websites, videos and audio.

Consumers work/have worked with strategic bodies in the UK and beyond eg NICE, MHRA, HRA, BBMRI-ERIC, EORTC.

Consumers have provided responses to two recent UK Government consultations:

- Inputting into the strategy of the UK regulatory environment via the MHRA clinical trials regulation
- Shaping the future strategy for cancer care and research via the national 10-year cancer plan.