

The NCRI and its Strategy 2017-22

The NCRI is a Partnership of researcher funders who wish to achieve more by working together. The NCRI's purpose is to improve health and quality of life by accelerating progress in cancer-related research, through collaboration.

The NCRI Strategy 2017-22 sets out four goals for the Partnership:

- Ensure a coordinated portfolio of research related to cancer
- Seize opportunities and address challenges in research relevant to cancer
- Continuously improve the quality and relevance of research related to cancer
- Accelerate the translation of cancer-related research into practice.

The Strategy has four Key Enablers for delivering these goals. Consumer Involvement is one of them, and the strategy itself was developed with consumers involved throughout the process:

“The voice of people affected by cancer (consumers) adds value to the work of the NCRI Partnership. Since its inception, the NCRI Partnership has embedded consumer involvement (involvement of patients, carers and others affected by cancer) in its activities. The contributions of people affected by cancer have brought strength to our work and have added value to our achievements. Continuation of relevant and useful involvement throughout the work of the NCRI Partnership relies on a committed pool of people affected by cancer working voluntarily with us. These people come from all walks of life and reflect the diversity of cancer. Through acting professionally, bringing fresh perspectives and judgements, they contribute effectively both as individuals and collectively through our Consumer Forum.

- We will continue to recruit, train, develop and communicate with a pool of engaged consumers to be involved effectively in our work
- We will continue to review and improve the ways in which we work with consumers to enable and support them to add value to our work
- We will seek opportunities to ensure that consumer involvement in cancer research in our Partner organisations and more widely is appropriately coordinated, developed and harnessed to improve the quality and impact both of the research itself and of the consumer contribution to it.”

Terms of Reference for the NCRI Consumer Forum (April 2015; developed jointly with consumers summer 2014 – spring 2015):

Purpose:

To create a professional, focussed and committed constituency of consumer research partners for NCRI who can help NCRI achieve its aims.

Specifically:

1. To provide a collaborative approach to providing effective consumer involvement across NCRI activities
2. To provide methods of evaluation of consumer impact in NCRI
3. To support and develop consumers for their roles within NCRI activities
4. To facilitate a more proactive role for consumers within their NCRI activities
5. To provide a pool of well-trained consumers to have input into NCRI and Partner research activities, committees and groups, as equal and valued partners
6. To provide individuals to lead on specific consumer led projects
7. To provide a pool of consumers who will act as ambassadors for NCRI activities
8. To provide a forum for consumers and their representatives working in cancer research beyond NCRI to develop and maintain mutually beneficial links with NCRI's consumers and consumer involvement
9. To encourage more people to become involved in cancer research

The Consumer Forum's Guiding Principle (developed and adopted by consumers, summer 2015):

Working together to build a community with the common purpose of providing patient and public perspectives throughout the research process, to deliver research with better outcomes and experiences for all.

A	We will continue to recruit, train, develop and communicate with a pool of engaged consumers to be involved effectively in our work				
B	We will continue to review and improve the ways in which we work with consumers to enable and support them to add value to our work				
C	We will seek opportunities to ensure that consumer involvement in cancer research in our Partner organisations and more widely is appropriately coordinated, developed and harnessed to improve the quality and impact both of the research itself and of the consumer contribution to it.				
	Metrics To Capture Consumer Activities and the Value Added By Our Collective Involvement	Source	Link to NCRI Strategy	Link to Forum ToR	Comments
1	a) % of new CSG studies that are funded (or endorsed) via CRUK, that have had effective NCRI Consumer involvement that can be evidenced	Consumers on CRUK CRC	A – Effective Involvement that can be evidenced	1,2	Evidence: a) statements in the study application b) comments from consumers on CSG, CTRad etc c) other consumer involvement or endorsement evident (eg letter of support from patient group) NB “effective” to be defined by reviewers
	b) Number of studies that have NCRI Consumers on TMG/TSG/TSC etc	NCRI Consumer Template Reports	A – Effective Involvement that can be evidenced	1,2	VIM is studies not consumers – value added to research not the activity of individuals (see also 3 below)
2	a) Number of NCRI Consumers who are NIHR CRN PRAs	NCRI Consumer Template Reports/NIHR CRN lists	C – Involvement in Partner organisations	1,7,8,9	Feeds into NIHR CRN’s own metrics
	b) Number of NCRI Consumers who have taken the MOOC	NCRI Consumer Template Reports	B – Training and development	1,7,8,9	Feeds into NIHR CRN’s own metrics
	c) Number of NCRI Consumers involved in NIHR LCRN-linked groups (or equivalent in devolved nations)	NCRI Consumer Template Reports	C – Involvement in Partner organisations	1,7,8,9	le any local group that has input into research, over and above patient support or service delivery
3	a) Number of NCRI Consumers working directly with NCRI partners	NCRI Consumer Template Reports	C – Involvement in Partner organisations	1,5,7,9	Includes committee posts, workstreams or ad hoc work such as reviewing or focus groups; “work” includes membership.
	b) Number of NCRI Consumers working with cancer research funders or charities who are not NCRI Partners	NCRI Consumer Template Reports	C – Involvement beyond NCRI	8,9	Includes committee posts, workstreams or ad hoc work such as reviewing or focus groups; “work” includes membership.

	c) Number of NCRI Consumers working with Industry	NCRI Consumer Template Reports	C – Involvement beyond NCRI	8,9	Includes committee posts, workstreams or ad hoc work such as reviewing or focus groups; “work” includes membership (eg ABPI POF)
4	a) Number of NCRI Consumers published in peer-reviewed academic journals	NCRI Consumer Template Reports	C – Quality and impact of research	4,6,7,8	Intention is for a running total, but is annual figure also needed? Papers not authors?
	b) Number of NCRI Consumers on strategic bodies (eg NICE, CCGs)	NCRI Consumer Template Reports	C - Quality & impact of wider consumer contribution	4,6,7,8	Formal roles, not engagement as a patient rep (see 2a, 2c, 3a, 3b, 4c)
	c) Number of NCRI Consumers presenting at strategic-level events and meetings	NCRI Consumer Template Reports/Event Report	C - Quality & impact of wider contributions		Includes conferences, trial or strategy days, annual meetings of Trusts or regional groups
5	a) % of posts filled (snapshot at 1/9)	Exec stats	A – Maintaining the pool	3, 4, 5.	Currently 96% (17.8.17)
	b) % of posts filled first time	Exec stats	A - Recruitment	3, 4, 5.	Currently 80% (for 2016-17)
	c) % of NCRI CSG Consumers who serve for full 3 years	Exec stats	A – Developing engaged consumers	3, 4, 5.	Currently 90% (at 1.1.17)
	d) % NCRI CSG Consumers who have first term extended	Exec stats	A – Consumers who are involved effectively	3, 4, 5.	Currently 80% (at 1.1.17)
	e) % CSG consumers co-writing CSG Annual Report	CSG Annual Review Panel	B - Consumers reviewing effective involvement	3, 4, 5.	Aim for 100% of all CSG consumers, subject to vacancies/recruitment/experience
6	a) Number of Forum meetings held (funding assumes 2pa)	CFSG	A&B – Developing and supporting Consumers	1,3,4,5,7,8	2 in 2017 to date; 1 @conference planned 3 in 2016 (incl conference) 1 in 2015 (conference)
	b) % attendance (by Core and by Affiliate members)	Consumer Admin	A – Engaging a pool of consumers	5,7	Average for 2017 is 45%
	c) feedback ratings from attendees	Consumer Admin	B – Improving how we work	5,7	Consistently good/very good (eg 4 out of 5)
	d) Feedback from external attendees/co-hosts	Consumer Admin	C – Consumer Involvement beyond NCRI	4,5,7,8	Consistently very good. There is an increasing amount of interest in bringing things to Consumer Forum meetings