

**CONSUMER
RESEARCH
CRAG
ADVISORY
GROUP**

Service User Research Enterprise at the Institute of Psychiatry, KCL

The Service Users Research Enterprise (SURE), co-ordinated by Dr Diana Rose, provides training for service users, clinicians and academics in how to collaborate through the research process. It is part of SURE's remit to involve as many local service users as possible in research and to build the capacity of local users to be involved in a way that is meaningful to them.

The Consumers in Research Advisory Group (CRAG) at the Institute of Psychiatry / South London and Maudsley NHS Trust, which provides support to service users who sit on the R&D Steering Group, has set out what it views as being the different levels of user involvement in research. The ultimate goal is that users should be involved in all stages of research - from design through conducting research to dissemination.

The Trust R&D Steering Group and the Consumers' Research Advisory Group (CRAG) SLaM/IOP Research and Development Steering Group (R&D SG) is responsible for managing SLaM's research and development activity. As such it is an extremely powerful and influential committee in terms of both defining and implementing SLaM's research priorities.

Meaningful user involvement in this kind of committee is very rare and the Trust R&D Committee has provided a budget to overcome some of the pitfalls. To avoid an unstable arrangement that depends on one or two individual users and which could be open to accusations of tokenism, the Consumers' Research Advisory Group (CRAG) was established in 2002 and has been meeting for two years now. It has two interrelated functions: to facilitate and support user involvement in the R&D SG and to identify local users' views about research. The CRAG consists of up to twenty local users and currently has members from Southwark, Lewisham, Lambeth and Croydon as well as the Addictions and Older People's Directorates.

Members of the Consumer Research Advisory Group (CRAG) had a brainstorming session in order to discuss their views on the Cooksey Review. Firstly they felt that it was of the utmost importance that the priorities and needs of the NHS from the views of key stakeholders should be monetary and that service users are paid for their time and expertise within research. It was also widely agreed that the end result of research in which they are involved should translate directly into the services they use and to service users. They felt that there should be more groups like CRAG who play a role in shaping the service users agenda from a grass roots level. They also felt that other service users should be more aware of where they can go and what they can do in research and so more needs to be done to encourage wider user involvement. Here are some of their views, relevant to questions that they felt were most relevant to them.

3. What should be the Government's priorities for health research? Is there anything it should stop doing or funding? What is it not doing or funding that it should do, and, in the absence of further sources of support, what can it lower in order to release the necessary funds?

CRAG members feel that the government should not draw money away from primary care trusts that fund user groups as a result of government pressures to save money. Instead, money should be channelled in a way which supports user involvement. The CRAG also believes that mental health should be prioritised highly in term of funding and research and development. There was also strong agreement that there is a distinct need for research and development to investigate the connection between mental and physical ill health. Some members felt that removing bureaucracy and red tape would make getting grants for research that was specifically user focused much easier so that existing mental health speeding can be spread more evenly and be used for users priorities.

4. How should decisions be taken on the balance between the long-term economic and social benefits of a high quality biomedical research base; and the needs for research to improve healthcare and other public services? What is the appropriate balance between public funding for investigator-led and priorities led research? How do we balance funding for basic science, translational science and applied science? Is this something that should vary over time? What mechanisms should be used to make judgements about this balance?

CRAG believes that that research needs to be priority led as opposed to investigator led.

5. In your experience, how have the results of publicly-funded health research in the UK been used, both in the development of new treatments and to influence / change wider policy and healthcare practices? What lessons can usefully be learned to improve the uptake of advances in science and medicine?

Service users need to be involved in alternative therapies, different medical models and investigations into medicinal side effects.

6. How might better links be forged between 'basic', translational and applied researchers, working across the whole field of health research, from the laboratory bench to the front line of the NHS? How might better links be forged across disciplines, e.g. with engineers, physicists, and social scientists?

Better links can be forged by increasing the level of user involvement between different types of research. Also improved communication between different research bodies and agencies should result in more effective links.

7. How can the Government encourage translation, entrepreneurship and innovation in health research to improve public services in the UK?

CRAG believes that having funding available to carry out health research from a user perspective would be beneficial. Also, CRAG members who are interested in conducting independent research have found it very difficult to access electronic journals or have access to the same kinds of resources that paid researchers do. They would appreciate it if there was a better system in place for independent researchers to access funding, resources and support.

Yours truly,

The Consumer Research Advisory Group