Cancer Research UK response to the Health Research Authority Strategy for Public Involvement December 2013

Cancer Research UK is the world’s largest independent cancer charity dedicated to saving lives through research. We support research into all aspects of cancer through the work of over 4,000 scientists, doctors and nurses. In 2012/13 we spent £351 million on research.

We are a leading funder of clinical research in the UK, supporting around 250 clinical studies. In 2012/13, over 35,000 cancer patients were enrolled on Cancer Research UK supported studies. We provide core funding for seven Clinical Trials Units (CTUs) across the UK. These are specialist research units that have expertise in coordinating clinical trials, including their design, management and data analysis.

We welcome the Health Research Authority (HRA) Strategy for Public Involvement. We think that public involvement in the work of the HRA will be important. The HRA is well placed to evaluate and communicate the benefits of public involvement to partner organisations and should use its position to do so. Our key recommendations are:

- To identify members of the public to involve in their work, the HRA should call upon an ‘Advisory Group’ when a timely response is required and advertise for public contributors when a wider perspective of public opinion is needed.
- The HRA should gather, evaluate and communicate evidence to demonstrate how public involvement benefits patients and impacts on research design, regulatory approvals, and the conduct and analysis of research.
- HRA should develop good practice guidelines and minimal standards of public involvement in consultation with researchers to ensure that the type and level of involvement is practical and proportionate.
- Support should be provided to establish and maintain public involvement groups and to help researchers identify individuals to involve in their work.

Involving the public in the work of the HRA

We agree that the HRA should involve the public in its work in order to better understand their interests in health research. We believe that by doing so the HRA will be better placed to protect and promote those interests.

Principles and standards for public involvement

Overall we agree with the HRA’s principles and standards for public involvement as outlined in appendix C of the strategy. We are pleased to see that the strategy includes provision of resources for information, training, expenses and funding to support public involvement. Appropriate resourcing will be essential to

deliver this strategy and we believe that this should be reflected in the allocation of funding to the HRA by the Department of Health (DH).

The HRA states that the nature and extent of public involvement should depend on the work in question. We agree with this proportionate approach and support the aim to evaluate and promote transparency on the impact of public involvement on HRA’s work.

Objectives

In order to identify members of the public to involve in the HRA’s work, we would recommend that the approach taken should depend on the task. Of the options presented in question 12 of the HRA Public Involvement Strategy Feedback survey we think that approach ‘A’ would offer a greater number of people the opportunity to be involved and to do so for specific topics of interest to them. However, this approach is likely to require more resource and would not be appropriate if input was required quickly. Individuals would be ready and available to give input if approaches ‘B’ and ‘C’ were employed, but individuals on an ‘Advisory Group’ or ‘Panel’ may become increasingly expert and less able to function as lay representatives.

Key recommendation 1
We recommend that the HRA adopt both approaches ‘A’ and ‘B’, drawing on an ‘Advisory Group’ when a timely response is required and advertising for public contributors when a wider perspective of public opinion is needed.

Encouraging and supporting researchers and organisations to involve the public

Evaluating the impact of public involvement on research

Our CTUs consider public involvement to be fundamental to their research. In particular, they have highlighted the importance of public involvement for identifying aspects of trial design or protocol procedures that would be potentially undesirable or not feasible for patients. Our CTUs have also emphasised the value of public input on the structure, content and readability of patient information sheets (PIS).

The HRA is well placed to encourage and support researchers and organisations that fund and manage health research to involve patients and the public in their own work. In order for the HRA to achieve this, it will be important for the HRA to analyse and communicate the impact of public involvement on research design, regulatory approvals and the conduct and analysis of research. The HRA should also research and communicate the additional benefits of public involvement. For example, the impact of public involvement on the accessibility and usefulness of PIS and consent forms, and on the patients’ experience of research.

INVOLVE’s work to promote public involvement in research is held in high regard among patient groups and researchers and INVOLVE has well established relationships with these communities. We consider INVOLVE to be well placed to disseminate the benefits of public involvement and we encourage a close working relationship between the HRA and INVOLVE. It will be important for the HRA to coordinate their
work with the Medicines and Healthcare products Regulatory Agency (MHRA), the Human Fertilisation and Embryology Authority (HFEA), and the Human Tissue Authority (HTA) to ensure that efforts to promote public involvement are not duplicated. We suggest that the HRA engages with the press to promote their messages, both directly and through health charity press offices.

**Key recommendation 2**
The HRA should gather, evaluate and communicate evidence to demonstrate how public involvement benefits patients and impacts on research design, regulatory approvals, and the conduct and analysis of research.

**Developing good practice guidelines and minimal standards**
We are supportive of the HRA developing better guidance for researchers and Research Ethics Committees regarding public involvement but it is important that any best practice or minimal standards are developed in consultation with researchers, including our CTUs. Such consultation would help to ensure that the type and level of involvement is practical and proportionate. For example, our CTUs have suggested that any standard wording for inclusion in the PIS should be succinct (maximum of one sentence) as they are already required to include a large amount of information and PIS are at risk of becoming unwieldy and ineffective.

It is important to acknowledge that all public involvement is not equal and does not necessarily represent the view of the public. There are difficulties, for example, with lay contributors becoming ‘experts’. While such factors do not diminish the importance of the input, there should be sufficient flexibilities in guidance and minimal standards to take into account the potential variability of input and the context of the source.

**Recommendation 3**
HRA should develop good practice guidelines and minimal standards of public involvement in consultation with researchers to ensure that the type and level of involvement is practical and proportionate.

**Identifying patients for public involvement**
Within cancer, public involvement is well established and supported by the National Cancer Research Network (NCRN). Our CTUs actively involve the public in their work and do so by engaging with lay members of the National Cancer Research Institute (NCRI) Clinical Study Groups, NCRN consumer liaison groups, Independent Cancer Patients’ Voice and patient support organisations such as Butterfly Thyroid Cancer Trust and NET Patient Foundation.

However, it can still be difficult to identify individuals that are interested in being involved, particularly in poor prognosis patient groups or those undergoing treatment that limits the ability of the patient or their carer to be involved. It is also not clear how well supported individual groups are and how consistently this is done.
If there is an increased expectation or requirement for public involvement, then the establishment and maintenance of public involvement groups that are accessible to all researchers will be essential. Support should be provided to help researchers identify potential members of the public interested in being involved. The provision of emotional and financial support for these individuals would be helpful.

Our CTUs would also welcome flexible guidance from the HRA on the recruitment of individuals for public involvement in their work. For example, guidance on:

- Methods for advertising and whether ‘role profiles’ would be appropriate
- Interview and selection processes
- The duration of an individual’s involvement

**Recommendation 4**
Support should be provided to establish and maintain public involvement groups and to help researchers identify individuals to involve in their work.

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