

Cancer Research UK response to Health Research Strategy

April 2009

Introduction

Cancer Research UK greatly welcomes the opportunity to respond to this consultation and contribute to the development of an updated Health Research Strategy. We also look forward to discussing these proposals in more depth as this strategy is developed.

Cancer Research UK¹ is the world's largest independent organisation dedicated to cancer research. Our vision is that together we will beat cancer. We funded £333 million of research in 2007-08. Cancer Research UK funds research into all aspects of cancer from exploratory biology to clinical trials of novel and existing drugs as well as population-based studies and prevention research. We carry out world-class research to improve our understanding of cancer and to find out how to prevent, diagnose and treat different types of the disease.

Cancer must remain a key priority in the research strategy. If we are to continue to see improvements for those diagnosed with cancer high quality research into the different aspects of cancer must be undertaken and supported.

NHS Scotland provides a unique opportunity for carrying out research that gives Scotland and the UK a strong position near the top of global clinical research. The need for a consistent, long-term, high-level strategy to drive a research-centred NHS cannot be overstated. Cancer Research UK is strongly supportive of the intention of this new strategy. A national strategy that will help support the provision of expensive resources, such as new technologies, and centres of excellence will clearly benefit research across the NHS.

Research is widely recognised as indispensable in providing the evidence central to improving health, reducing inequalities, and increasing the wealth of the nation. In respect of this we welcome the acknowledgement that NHSScotland will work in partnership with other funders including government departments, and importantly, the voluntary sector.

Whilst acknowledging that health is a devolved issue, collaborations between academic clinicians across the UK have a vital role to play in the success of research within the NHS. Consideration should therefore be given to how this new strategy will impact on such collaborations.

Comments and questions

CHAPTER 1 – INTRODUCTION

¹ Registered charity no. 1089464

1.1 Do you support this general approach towards emphasising translation of research into improved care? Are there other issues to which a higher priority should be assigned?

We support any work that bridges the gap between the outcomes of basic research to an improvement in care and services for patients. Given the relatively small size of the CSO research budget, it would seem like an efficient way of using the funds. We recommend that the CSO funding will complement existing funding streams and not replicate them, and that distribution of these funds is done to complement the work of other funders, such as Cancer Research UK, to maximise their impact.

1.2 Do you support the focus on translational research and sustaining success?

We agree that the focus on sustaining existing research successes is vital. We recommend that if the CSO aims to catalyse research in certain areas that it does so in cooperation with other funders, to ensure that any research initiated will be maintained. In this way the limited funding available will have the greatest impact.

CHAPTER 2 – VALUING AND INVESTING IN NHS RESEARCH

We applaud the responsive funding mechanism in place in Scotland. It allows researchers and clinicians to tackle the problems they encounter with the most robust and appropriate research methods that, over time, provide the most efficient and effective use of research funding. However, we believe that more needs to be done to develop a culture that both increasingly values research and creates a supportive environment within which research can be conducted. We recommend that there is more incentive for health professionals to undertake research whilst pursuing careers in NHS Scotland.

As a significant funder of research we recognise that processes must be put in place to ensure that funding applications are dealt with appropriately. However, the bureaucracy involved in obtaining support for clinical research from NHS Scotland is overly complicated and burdensome. We recommend that a clearer process is established to enable a supportive environment for clinical research.

Cancer Research UK provides the direct costs for research but does not routinely pay the indirect costs in universities or the service support costs for clinical trials in the NHS. These costs are met in various ways by the different UK governments and are a crucial part of the way that our research is supported. Our estimates, based on the situation in the NHS in England, is that if our clinical trials did not receive the service support costs, Cancer Research UK would only be able to fund half the number of trials. We were not sure whether the current review would address this funding stream, but if it does, we would want to see this maintained.

We acknowledge the need to restructure resources for improving efficiencies, and we appreciate the limitations for research funding in the current economic climate. However, we hope that there will be no reduction in overall funding for research within NHS Scotland.

2.1 Do you support these moves towards developing Scotland-wide collaborative structures?

Coordination of R&D activities will reduce the need for further multiple reviews of multicentred research/trials that have already been through peer review, ethical

review, funding committees and specialist committees (such as the Chemotherapy & Pharmacy Advisory Service, NCRI Clinical Studies Groups). It will also allow for oversight of recurring bottlenecks in the approval process so they can be addressed promptly. We support this as it would remove unnecessary steps in the system and hopefully improve clarity.

We feel that unifying structures with the NHS Research Scotland (NRS) strapline is a positive move that would result in greater collaboration. This is based on our assumption that the reporting structure currently in place wouldn't change. We feel it would be detrimental if it was to change.

Given that the new National Research Ethics Service is UK wide, and therefore has representation in Scotland we feel that 'NRS Ethics' as an additional structure could be confusing. We recommend that further clarification on exactly what NRS Ethics would entail is required.

The establishment of the UK Clinical Research Network to support clinical research and facilitate the conduct of clinical studies across the UK has been a vital recent development. One of the first networks set up by NHS Scotland was in cancer, and we have been supportive of the lead the Chief Scientist Office has taken on this. Therefore, in the development of NRS Networks (which we are assuming is further development of those networks already in place) we feel that it is vital that the existing links with the UK Clinical Research Network are not lost.

2.2 Is providing the aforementioned stability in the Support for Science allocations for 3 financial years a sensible approach?

The retrospective nature of Support for Science and requirement of service support departments to manage the minutiae of costing each research event (counting samples) can mean these departments don't see any return for research activity. Supporting additional clinical work through salaries e.g. technicians in pathology, pharmacy will make a big difference for multi-centre cancer research – specifically the translational sub-studies. This will incentivise participation in multicentred research and speed up the process of gaining authorisation from that department pre-R&D review – particularly in the smaller Health Boards. We therefore support this approach to provide stability in the allocations.

2.4 More generally should CSO aim for a wider rationalisation of the NHS funding streams at the end of the transition period comprising 2 main funding streams – Support for Science and NHS Infrastructure support?

We have no comments on the details of the split between the Support for Science budget and the NHS Programmes budget. However, we want to be sure that any CSO funding that is currently used to support Cancer Research UK clinical trials is retained, whatever the funding mechanism.

2.5 Is the principle of R&D Management being made more accountable for its performance accepted? Is there scope for a wider rationalisation of Health Board R&D Management arrangements? If so, what might such a model look like?

Yes, we agree with the principle of R&D Management being made more accountable as this is currently lacking and as a consequence the variation in performance/function across Health Boards is significant. There should be transparent objectives and accountability for performance. However, a punitive approach to Health Boards with lower research activity may make it harder to

increase the activity. We therefore support a reward system rather than penalty system to be the most effective model.

CHAPTER 3 – RESEARCH TRANSLATION FOR HEALTHCARE BENEFIT

We acknowledge the support of the CSO in the Experimental Cancer Medicine Centres in Glasgow and Edinburgh that were established in collaboration with Cancer Research UK. These centres are vital in driving translation research in cancer. We feel that through these centres of excellence, which combine laboratory and clinical patient-based research, the speed of development of new therapies and biomarkers will be greatly increased. We support UK wide initiatives such as this that provide truly collaborative environments to encourage translational research.

3.4 Should CSO do more to support testing of healthcare technologies in the NHS? If so what form should this take?

We recognise that improvements are being made in the early diagnosis of cancers. However, Scotland continues to perform poorly in terms of the stage at which cancer is diagnosed compared to other European countries. We know that this is partly to do with public awareness of symptoms and GPs' access and education but more research must be done to understand why this is and to develop interventions to address this.

For cancer, earlier detection and diagnosis has the potential to significantly reduce mortality. CSO is already engaged in the research workstream of the National Awareness and Early Detection Initiative (NAEDI). This initiative also includes a workstream looking for ways to improve primary care access to diagnostics. Scotland has a strong track record in primary care research in cancer, and the CSO may wish to consider if NAEDI might provide an opportunity to capitalise on this.

CHAPTER 4 – RESEARCH TO IMPROVE SCOTLAND'S HEALTH

We welcome the investment to date into primary care research. However, there is still a lack of evidence in certain areas such as primary care management, and we recommend that there must be a continued commitment in investment.

The inequality in cancer death rates remains absolutely unacceptable. The research underway is allowing us to develop a better understanding of the issues and how they arise. However, there must be continued investments to fund and support the collection of data on the demographics of cancer patients, and on the uptake of screening services by different groups. This will help understand how to tackle inequality issues by adapting services to meet the needs of the population.

We believe that research must be undertaken to identify solutions to the issue of providing highly speciality care as effectively as possible. This is a significant problem not just for cancer patients but for health care generally. Possible solutions may include integrated and shared care but the evidence base must be established.

It is anticipated that the next decade will see increased emphasis on studies aimed at understanding why certain subgroups of patients will benefit from particular therapies and how to identify these patients. In the long term such studies have the potential to reduce the drug costs for the NHS by only treating those that will benefit. It remains

the responsibility of Government to ensure that such studies are carried out, and the cost of the resulting diagnostic approaches is met.

4.4 Should CSO change the current ceilings for response mode grants, potentially at the expense of the number of available awards?

Without knowing exactly what projects have been funded, it is difficult to comment in too much detail on whether the caps are appropriate. However, from our experience the £225,000 limit does sound very low. Over three years, and taking into account full economic costs, this is roughly £42,000 per year for the direct costs of research. Cancer Research UK's cap for three year project grants is £100,000 per year, and we estimate that our average cost is about £70,000 per year, without full economic costs. We recommend that the CSO considers providing adequate funding for fewer, high-quality projects, rather than maintain the number of grants currently on offer.

4.5 What should CSO do to increase dissemination of research findings and foster uptake of research evidence into practice?

Cancer Research UK is also keen to make sure that the results of the work we fund are disseminated and have an impact on clinical practice. There are two particular things we do that support this.

Our Terms and Conditions for Research Grants and Awards include the following obligation:

All opportunities to promote Cancer Research UK must be fully exploited and principal/chief investigators and the host institution are obliged to cooperate with Cancer Research UK over any publicity or fundraising activity arising from Cancer Research UK-funded research.

For all our grants, we ask our external peer reviewers to comment on the quality of the research. However, for clinical trials, we ask reviewers to answer the following additional question:

What impact do you believe that the successful completion of the proposed study might have on developing new therapeutic, preventative or diagnostic strategies?

No clinical trial application will receive a rating at the top end of our range unless the applicant can show it is:

Workwhich will have an important and substantial impact on understanding, policy or practice.

This ensures that only those clinical trials where the results are likely to be taken up in clinical practice will get funded.

We therefore recommend that criteria such as these are instrumental in enshrining increased dissemination and uptake of research findings.

CHAPTER 5 – DEVELOPING AND MAINTAINING RESEARCH PLATFORMS: RECORD LINKAGE, BIOBANKS AND OTHER LARGE DATASETS

Access to patient data is especially important in cancer. Epidemiological research is pivotal to our understanding of cancer as a disease, in a way that is not true for many other conditions. As two-thirds of cancers are potentially preventable, patient data have been especially important to help identify some of the factors that put people at risk of cancer in the first place.

Although it is essential that patients' interests are protected by proper safeguards on access to their medical records, some of this information can also be a vital resource for research. Properly used, this will be the key to improving treatments for the future.

We feel that it is essential that the work of Scottish Health Informatics Platform for Research (SHIP) is carried out with mind to that of Connecting for Health in England, and the equivalents in the other nations.

CHAPTER 6 – DEVELOPING CAPACITY

6.2 What forms of postgraduate research funding provide the most beneficial basis to establish a research career?

We think that one of the most important ways of using research funding to benefit career development in clinical research is to be as flexible as possible. There is a lot of variation in clinical and allied health professional training, and research funding must be flexible enough to dovetail with the individual's training requirements. This does not necessarily mean a proliferation of funding streams, or a reduction in the quality of research being funded, but simply an ability to adjust the way funding is provided to meet the needs of the applicant.

We would be happy to provide any further information or detail as required. Please contact Vicky Crichton, Public Affairs Officer for Scotland at vicky.crichton@cancer.org.uk or on 0131 243 2641.