

Response to consultation on the Chief Scientist Office's Draft Research Strategy

Response from the British Heart Foundation October 2014

The British Heart Foundation (BHF) is the nation's leading heart charity. We are working to achieve our vision of a world in which people do not die prematurely or suffer from cardiovascular disease. In the fight for every heartbeat we fund ground breaking medical research, provide support and care to people living with cardiovascular disease and advocate for change.

The British Heart Foundation (BHF) welcomes the opportunity to respond to the consultation on the Chief Scientist Office Research Strategy 2014 and we would like to take this opportunity to draw your attention to the BHF's key priorities in the research environment both in Scotland and across the UK.

Research funding

The BHF has been funding research into cardio-vascular disease (CVD) for over fifty years and we have made a huge amount of progress. However, there is still far more to be done, with CVD still causing more than 161,000 deaths in the UK each year.

The British Heart Foundation spent £14 million in Scotland in 2013/14 (around 15% of our total spend), but we continue to be reliant on government investment to maintain the university sector within which researchers work. We are calling for the UK wide science budget to be ring fenced in the short term, with a view to an expansion in the longer term.

We would like to see longer term planning in science budgets, with a particular focus on capital expenditure. Increased certainty in relation to the science budget would benefit the research community, enabling better planning and promoting investor confidence. Medical research, in particular, is a lengthy process; it can often take decades between an initial laboratory discovery and a treatment being licensed for use in patients. Cohort studies, in which large groups of people are followed over the long term to understand the development of disease and efficacy of interventions, also require stable, long term funding.

Interdependencies of funders

The scientific eco-system is complex, with different bodies leveraging funding from one another, scientists interacting across disciplines, and public and private investors working together. For example, while the BHF funds project and programme grants, we are dependent on the Government to provide core funding to the universities where our researchers are based. We believe that, in order for the UK to lead the world in scientific research, all elements of the system

must be supported and maintained, including state, academic, charitable and industry funding of research. It is crucial that the government recognises and nurtures the interdependencies which exist within the system.

Therefore, we particularly welcome the CSO's focus on collaborative partnerships, both with NHS Scotland and with industry. We would also like to emphasise the importance of partnership working with medical research charities, such as the BHF, with over a third of all publically funded medical research in the UK currently being supported by the charity sector.

Regulation and Governance of Research

The regulatory and governance environment which surrounds research in the UK is complex and it can be challenging for researchers to navigate. We believe that as much researcher time as possible should be spent on their core scientific work and, as such, we argue for the research environment to be kept as streamlined as possible.

We welcome the CSO's aim to ensure that a proportionate approach is taken to the regulation and governance of research.

Development of a skilled workforce

The development and retention of talent is vital for a thriving research environment. Although ensuring an effective pipeline of research scientists is, of course, very important for the UK science base, in order for laboratories to function effectively, we also need highly skilled technicians and support staff. In particular, there is currently a shortage of informaticians and bioinformaticians, which urgently needs to be addressed. 'Big data' presents exciting opportunities for science, but these will not be realised unless we build an adequate skill set to analyse the data involved.

We note that the CSO has incorporated education into its key principles and would like to emphasise the importance of this strand in generating a sustainable research sector.

Research in NHS Scotland

NHS Scotland collects data which is used in epidemiological studies, recruits patients to clinical trials and carries out research in its own right. It is vital that practical support for research is maintained within NHS Scotland and that NHS Scotland in general has a culture which is conducive to medical research.

We are very pleased to see that collaboration with NHS Scotland is a key focus for the CSO Research Strategy.

Patient data

Patient data is vital to ongoing improvements in public health. It is used in large scale population studies which look at the causes and patterns of disease and is required for effective clinical trial recruitment. High quality data is also essential for effective care planning and clinical audit.

In order to maximise the potential benefits of patient data, it must be collected comprehensively, accurately and securely. Interoperability of systems to allow data linkage should be prioritised and, as discussed above, there needs to be a sufficient number of skilled informaticians to effectively analyse the data once collected.

The public benefits which can be gained from data must also be balanced against concerns of individual privacy. The public must be made to feel confident that their data is being handled ethically and securely and they should be fully informed about exactly how their data is being used, with the right to object to this use. However, the BHF does not believe that privacy concerns should be used as a reason not to collect and use data for research purposes. An appropriate balance between privacy and data access can, and should, be struck.

The BHF remains concerned that the draft EU Data Protection Regulation has the potential to significantly damage UK research by dramatically limiting researcher access to data. We are urging the UK government to engage in the negotiation process at EU level and ensure that the interests of UK science are appropriately protected.

We recognise that Scotland, in particular, has a strong base in the innovative use of data and data linkage in health research and are pleased to see the CSO playing to this strength in the Draft Strategy.

Research in Scotland following the Referendum

The BHF recognises that this is a significant time of change and uncertainty for Scotland in general. We would like to emphasise the importance of thoroughly considering the interests of biomedical research during this time.

The biomedical research base in the UK is one of our most valuable assets, both in terms of the economy and in terms of the huge health benefits it delivers to patients around the world. Scotland has a strong tradition of excelling in scientific research and the British Heart Foundation believes that it is vital that this continues into the future.

We would ask that any decisions being taken in Scotland ensure that science funding is protected and that there is a potential for increased investment in the future. We would also advise against introducing additional levels of complexity either into the regulation or the funding of research in Scotland.

Research is a fundamentally international pursuit and, in order to be world leading, Scotland must be able to attract the best scientists from around the world. As such, we would ask that any immigration policies take the needs of the research base fully into account.

The biomedical research sector saves and improves lives in Scotland, the UK and across the world. It is vital for our economy and for our health. Although our research is currently world leading, the sector is notoriously fragile – it is fast to damage and slow to repair. Therefore, we ask that within any decisions being made about the future of Scotland, the needs of research are fully considered.

We have fed these comments into the Smith Commission.

The BHF welcomes the level of ambition in the draft CSO Research Strategy and is very happy to see its commitment to supporting and increasing the level of high quality health research in Scotland. We would be very happy to be involved in any ongoing conversations on this subject and to support the development and implementation of this strategy in any way that we can.

For further information on any of the information contained in this response, please contact David McColgan, Policy and Public Affairs Manager at BHF Scotland, on <u>mccolgand@bhf.org.uk</u>.