Dear Lord Krebs,

The Association of Medical Research Charities is a membership organisation of the leading 121 medical and health charities funding research in the UK and overseas. We welcome the opportunity to respond to this consultation.

Key points:

- Scientific infrastructure underpins the medical research ecosystem in the UK and is vital for the development of new treatments to save and improve lives.

- Charities typically fund the direct costs of conducting research. Providing and maintaining the UK’s scientific infrastructure should be primarily a government concern although charities can and do partner with government to invest in, for example, specialist infrastructure.

- Donations to medical research charities are declining, reducing charities’ revenue and squeezing research spending.

- Government investment in infrastructure signals to charities and industry that the UK is serious about science, leveraging inward investment. This should be delivered in a planned and predictable strategy to foster confidence.

- The amount that charities are investing in infrastructure is falling. This may be caused by revenue pressure and also be in response to reduced government capital investment and uncertainty caused by the government’s policy of “one off” investments since 2010.

- Charities fund specialist infrastructure in areas of unmet need where they can make a unique contribution due to their close patient links, including DNA and tissue banks and disease registries.
• Long-term commitment from the government is required to meet the running costs of infrastructure.

• A highly-trained workforce is needed to run and utilise scientific infrastructure to maximize benefit.

• To be most effective, infrastructure needs to be joined up, allowing efficient sharing of resources, this is particularly true for biobanks.

1. Medical research charities are focused on improving healthcare for patients. Many charities have direct links with patients and work with leading scientists and clinicians in their specialist field, bringing together patient experience and research knowledge. This enables them to provide unique insights into research strategies and more widely, what is needed to support medical innovation. As not-for-profit organisations they are able to provide flexible and innovative funding strategies to meet the needs of patients and researchers. They often fund in partnership with each other, government and industry.

Charity spending on capital projects is declining

2. Our members fund research through project grants and commissioned research, invest in people through fellowships and studentships and make capital investments in infrastructure to increase research capacity. Examples of infrastructure funded by charities include DNA and tissue banks; disease registries, which benefit from charities’ close links to patients; and large pieces of equipment. In 2012, AMRC members invested over £1.2 billion into health research in the UK and over £46 million into capital projects to improve the UK’s scientific infrastructure.1 This capital spending by our members has halved over the past five years and as a proportion of total charitable expenditure reduced from 5% in 2008 to 2% in 2012.1 Our members are working hard to maintain their research spending but donations to medical research charities are falling; the estimated value of donations in 2012 was £9.3 billion, down from £11 billion in 2011.2 This reduction in revenue means that it is harder for them to make capital investments. Furthermore, the reduction in government capital spending announced in 2010 and subsequent policy of “one off” investments has created uncertainty and reduced opportunities for partnerships, further limiting charities’ ability to commit to large capital projects.
3. Charities are key partners with the government in determining the UK’s infrastructure needs. Many of our members have conducted gap analyses, consulting patients and researchers, to identify areas of unmet need that are impeding research and preventing the translation of discoveries into treatments.

4. In 2010, Breast Cancer Campaign established a breast cancer tissue bank following a gap analysis in 2006 of the needs of the breast cancer research community. Scientists told the charity they couldn't easily access good quality breast cancer tissue with relevant data associated with it, which was holding up the translation of basic research into treatments that could help patients. Breast Cancer Campaign therefore is investing over £6 million to establish and develop the Bank in its first five years. The Bank contains over 22,000 samples and has been available to researchers across the UK and Ireland since 2012. Samples that have so far been accessed are now being used by researchers to give a more accurate picture of how breast cancer spreads and to design new treatments to stop breast cancer in its tracks, which it is hoped will better inform treatment plans for women, leading to increased chances of survival and quality of life. Breast Cancer Campaign is now in the process of facilitating a ‘five-year follow-up’ to ensure that the roadmap for these priorities is maintained as a relevant and authoritative resource and this will hopefully be published in autumn 2013.

5. While much research has been published on MS, there remains a significant gap in the information required to improve services and generate further research on this highly variable disease. The MS Register3, launched in 2011, is a focused pilot study that combines an online patient portal with clinical NHS data. Anyone with MS in the UK can enter information about how the condition affects their lives. For patients attending one of the five pilot clinics, their online data can be linked to their treatment data and anonymised, making this combined data available for researchers.

6. The MS Register will serve as a model for registers of other conditions not served by larger, national datasets. The linked data it has collected can be used to improve the delivery of care and improve pharmacovigilance, identifying potential adverse drug reactions and monitoring the safety of new MS treatments.

Challenges for the medical research charity sector in funding infrastructure

7. **Partnerships are required to fund infrastructure**

Infrastructure costs are significant and often cannot be met by one organisation alone. Providing and maintaining the UK's scientific infrastructure should be primarily a government concern. However, where the infrastructure is meeting a specialist unmet need, medical research charities partner with each other, public funders and industry to meet the costs of infrastructure. Charities are not able to step in to compensate for reductions in government investment.

8. The Medical Research Council (MRC) has been a valuable partner to many charities, enabling them to establish key infrastructure necessary for researchers. Government commitment to infrastructure sends a strong signal that the UK is a secure place to invest and for this reason public money leverages further investment from charities and industry. Government strategies to nurture the private sector should also consider the importance of supporting and encouraging charitable funding of research in the UK.

3 [http://www.mssociety.org.uk/get-involved/msregister](http://www.mssociety.org.uk/get-involved/msregister)
9. Brain banks provide unique and invaluable resources to researchers from around the world, allowing them to tackle conditions such as dementia, which costs the UK economy £23 billion a year. Funding of brain banking has required sustained, long term investment from multiple funders. In the UK, brain banking is principally publically funded through the MRC Brain Bank network, with further funding coming from Alzheimer’s Society and Alzheimer’s Research UK through the Brains for Dementia Research programme, and MS Society and Parkinson’s UK for the MS/Parkinson’s Tissue Bank. Although there is no formal partnership agreement of funding, all funders benefit from the landscape and there is healthy collaboration at all levels. Support from multiple sources is essential to create centres of excellence and of critical mass to support brain banking; for example allowing centres to provide out-of-hours cover so that brains can be harvested with minimal delay and thus ensuring the highest quality samples are collected for research.

10. Infrastructure requires long-term funding
The upfront investment to establish infrastructure is not enough. A long-term commitment to continued funding is also required to meet running costs. Charities are able to make one-off investments according to the health of their finances but often cannot make long-term commitments due to possible future fluctuations in their income. Long-term commitment from public funders allows charities to commit large capital sums into infrastructure in the knowledge that running costs will be covered in the future. Therefore, instability in public budgets is a problem: the MRC for example can only currently commit funding to the MS/Parkinson’s Tissue Bank for 2013/14. If MRC were not able to continue to fund this key resource, Parkinson’s UK has told us that it would need to divert money from its other research activities to meet the costs.

11. Infrastructure also needs ongoing funding to keep it state-of-the-art to meet current and future research demands, including changing regulatory requirements. With the rapid pace of technology development, in areas such as genomic sequencing and electronic data for example, infrastructure can quickly become outdated. This continued investment is especially important to ensure data remains safe and secure as information technology advances.

12. Highly skilled people are necessary to run and use infrastructure
A highly-skilled workforce is essential to run large and specialist infrastructure. And wider training for a range of professionals is required to ensure infrastructure is fully utilised by those who can benefit from it. This is especially true for information infrastructure, such as genetic databases and patient data registries. We welcome the emphasis that the government’s genomic strategy, Building on our inheritance: Genomic technology in healthcare, puts on a trained workforce. From GPs entering patient information into linked databases for use in research to clinical scientists having the skills to use advanced bioinformatics when diagnosing disease, investment in infrastructure must be matched by investment in people.

13. The MND Association’s DNA bank and clinical database collected 3,400 samples from people with MND, their spouse or partners (as controls) and family members from 2003 to 2011, at a cost of around £1.75 million. Samples will be made available to the international research community from 2013. Researchers applying to the DNA bank receive expert support from the bank’s staff to ensure their research proposal is designed effectively to make best use of the data and that they are meeting relevant regulatory requirements.
14. **Infrastructure needs to be joined up**

For it to be most effective, infrastructure needs to be connected, allowing efficient sharing of resources. An infrastructure strategy must therefore take stock of what we already have and how it is used, address the needs of the whole scientific community and be forward-thinking.

Our members tell us that biobanks increasingly need to join together to share samples and data, even across different diseases. As more genetic and post-genomics links are identified between diseases, there will be an increasing need to look at biomarkers in multiple tissue types and process complex datasets to look for relationships. This will bring infrastructure challenges in terms of IT and linking different databases and data types together. Although charities work together to do this, as described above, the future scale and complexity of research using electronic infrastructure means that a leading role from the government is essential.

**Infrastructure is part of a larger research ecosystem**

15. We recognize that the Committee has limited its definition of infrastructure to large and medium sized equipment and electronic infrastructure for the purposes of this inquiry. Of course infrastructure goes beyond this to include the people, systems and networks that support research in its many forms. For example, the Wellcome Trust-, government- and industry-funded Stevenage Bioscience Catalyst aims to provide small biotech and life science companies access to the infrastructure normally enjoyed by large pharmaceutical companies. NHS infrastructure too should be considered an integral component of the UK’s research ecosystem. *Our vision for research in the NHS* sets out how this can be strengthened, building on the excellent progress made by the National Institute for Health Research (NIHR).[^9] The NIHR Clinical Research Network recruited 595,000 patients to clinical studies on its portfolio in 2011/12, representing a 5% increase on the previous year and a doubling of patient numbers in the past five years.[^10] The Clinical Practice Research Datalink is another example of public investment in electronic infrastructure that will underpin both academic and industry-led research, providing benefit to both the health and wealth of the UK.

16. The Stevenage Bioscience Catalyst[^11] is a £38 million partnership between the Wellcome Trust, UK government, GlaxoSmithKline, the East of England Development Agency and the Technology Strategy Board, to develop a bioscience park adjacent to GSK’s R&D facilities in Stevenage, Hertfordshire. Pioneering a culture of open innovation, the park is designed to stimulate innovation in product development and accelerate the delivery of cutting-edge healthcare solutions. This unique bioscience community will provide small biotech and life sciences companies with access to the expertise, networks and scientific facilities traditionally associated with multinational pharmaceutical companies. Tenants retain full independence and the freedom to interact with any commercial partners.

17. The NIHR Clinical Research Network provides funds to NHS Trusts to employ research nurses and other clinical research delivery professionals, and in doing so it has improved the infrastructure for delivering clinical research in the NHS. 99% of NHS Trusts now undertake some research studies – which includes traditionally “hard to reach” specialist and smaller Trusts. Working together, local Networks began to build delivery capacity in primary care in

Kent through the DARE\textsuperscript{12} research study, engaging seven sites and more than 100 recruits in less than three months.

18. Delivering the DARE study in GP surgeries has had other positive impacts. The work in primary care is having a snowball-effect on the wider region, with secondary care also coming on board as a result of positive feedback from participating surgeries. In addition, the DARE study is being used as an opportunity to develop the skills of practice nursing staff, by providing on-the-job training to them in the research arena which should help them feel able to conduct future studies more comfortably.

19. The Clinical Practice Research Datalink\textsuperscript{13} (CPRD) is the new English NHS observational data and interventional research service, jointly funded by the NHS National Institute for Health Research (NIHR) and the Medicines and Healthcare products Regulatory Agency (MHRA). CPRD services are designed to maximise the way anonymised NHS clinical data can be linked to enable many types of observational research and deliver research outputs that are beneficial to improving and safeguarding public health. The CPRD has been developed as a service from the well-recognised General Practice Research Database together with lessons and knowledge gained from the Research Capability Programme.

20. The UK research ecosystem benefits from a unique combination of public, private and charitable funders. Where appropriate to their research strategy, charities can invest in infrastructure, but government commitment is essential to underpin this. Long-term investment, a joined up approach across departments and institutions, and a collaborative approach with charities and industry is required to ensure UK research is underpinned by an effective infrastructure that will drive improvements in health and support a sustainable economic recovery.

21. If you have any further questions please do not hesitate to contact us.

Yours sincerely,

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Chief Executive

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\textsuperscript{12} \url{http://www.diabetesgenes.org/content/diabetes-alliance-research-england-dare-previously-known-exeter-research-alliance-extra-stud}

\textsuperscript{13} \url{http://www.cprd.com/intro.asp}