Summary

Exiting the European Union presents a considerable challenge to medical research charities; it has the potential to significantly impact patients and the health of the public, as well as the economy.

Scotland’s future relationship with the EU needs to support the advancement of medical research for the benefit of the health and well-being for the people of Scotland and the EU. This can be achieved by:

1. Protecting patients; it is vital there is no impact on patients in terms of access to treatments, ability to take part in research studies/trials and standards of care;

2. Ensuring the medical research community has continued access to EU funding programmes and collaborative opportunities to progress the discovery and understanding of diseases and ill-health;

3. Maintaining the current ease with which researchers, and those involved in medical research including healthcare professionals, technicians and patients, are able to travel and work across the EU and Scotland; and

4. Ensuring an aligned and compatible regulatory framework between Scotland and the EU for medical research.

About AMRC and our response

The Association of Medical Research Charities (AMRC) represents 133 of the leading medical research charities funding research across the UK. In 2015, 55% of our members funded research in Scotland.

In 2015, AMRC charities invested over £600 million of research funding in Scotland, making it the second most popular area for AMRC member funding in terms of number of grants and the fourth most popular area in terms of money invested. Three Scottish universities feature in the top ten locations where our members fund research.

AMRC charities fund research focussed on the needs of patients for better treatments, therapies and interventions designed to improve the quality of life and ultimately prevent or cure their condition. Wherever possible, we highlight the patient perspective. This includes patients both in Scotland and worldwide.

We have focused our response on three key ways that EU membership affects medical research charities: funding and collaboration; people; and regulation and
patient access to treatments. These areas are not unique to researchers in Scotland. However, in light of the Scottish Government’s pledge to explore options for Scotland’s future relationship with the EU, we wish to promote awareness of these issues and we urge the UK Government to consider medical research when moving forward with negotiations to establish Scotland’s future relationship with the EU.

We have used data from a variety of sources to evidence our submission. One of the key sources used is AMRC impact data which is a rich dataset collected by 40 of our members (covering 45% of AMRC members’ annual research spend) via the online platform Researchfish, for grants they awarded between 2012 and 2014. Whilst this does not cover all AMRC members it provides insights that could not be gathered from any other dataset. Please contact the AMRC Policy and Public Affairs team for further information regarding how data were derived (policy@amrc.org.uk).

Medical research after the EU referendum

The UK, including Scotland, has a uniquely vibrant medical research charity sector which contributes to the UK’s international standing and competitiveness. Investment in science and research drives economic productivity; every £1 of public or charity investment in medical research generates annual monetised health benefits of 10p in perpetuity and additional spill over benefits.\(^1\)

The life sciences sector is one of Scotland’s assets. Scotland is home to one of the biggest clusters of life sciences industry in Europe.\(^2\) The Scottish life sciences industry had a gross value added (GVA) value of over £1.6 billion in 2013. In 2014, spending on research and development in this sector represented 32.4 per cent of the total Business Enterprise Research and Development (BERD) spend in Scotland.\(^3\) It is vital that this footprint is preserved; the Scottish Government should send a clear message to the rest of the world that Scotland is open for business; a place to invest, work and seek collaborators.

The outcome of the EU referendum presents a significant challenge to medical research charities. Science is a long term activity and requires stability; the current uncertainty is having immediate implications and raises many questions.

In order to ensure the stability of the sector, we urge the Scottish Government to work with the medical research community, including charities, to establish a clear understanding of the impact on medical research as a result of the UK’s decision to leave the EU. It is vital that there is no adverse impact on patients who benefit from medical research both in Scotland and worldwide.

Funding and collaboration

- AMRC and our member charities want the medical research community to have continued access to EU funding programmes and collaborative opportunities to progress the discovery and understanding of diseases and ill-health.

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1. [http://www.kcl.ac.uk/sspp/policy-institute/publications/SpilloversFINAL.pdf](http://www.kcl.ac.uk/sspp/policy-institute/publications/SpilloversFINAL.pdf)
• The closest affiliation possible with EU research programmes that allows for this continued involvement and influence should be aimed for in negotiations. This includes continued access to Horizon 2020 as well as participation in future programmes, such as Framework Programme 9 (FP9).

• Loss of funding for UK medical research or reduction in collaborative opportunities would seriously hinder progress on new treatments and cures of diseases such as cancer, dementia, rare conditions and many more. This would be to the detriment of patients, not only in Scotland but across the world.

• Whilst participation in EU funding programmes and schemes offers significant financial benefit and support to Scottish medical research, the collaborative opportunities that are afforded are as crucial. Multi-nation collaboration is vital in order to address global health challenges.

• Special attention should be given to medical research for rare diseases as EU funding programmes and schemes are vital to facilitate research in this important area. In the interests of patients with rare conditions, AMRC members want to continue collaborating closely with EU partners on rare diseases.

• Medical research charities will not be able to plug funding gaps that may arise as a result of loss of EU funding schemes.

Medical research charities across the UK and EU funding programmes interact in a number of valuable ways. Some AMRC charities fund research across the EU, partner on EU projects, and receive support directly from EU sources. For others, the impact is less direct. Researchers funded by AMRC charities receive further funding from the EU, and are supported by funding schemes that promote collaboration, helping to ensure that the UK research environment, as a whole, continues to thrive.

In the AMRC impact dataset around 40% of the grants that AMRC members fund in Scotland involve active partnerships with other organisations. Of these, just under a quarter are based in EU member states, by far the most frequent partner location outside the UK (by comparison the next most frequently listed location, the USA, hosts just 13% of all partnerships).

In just a three year period (2012-2014) researchers in Scotland who are included in the impact dataset were awarded £103m of further funding from the EU. This amounts to half of all funding leveraged by medical research charity investment in Scotland during that time. Further funding is important as it provides additional funding for researchers to continue their research after an initial award has ended.

People

• The current ease with which researchers and those linked with medical research including health professionals, technicians and patients, are able to travel and work across EU member states must be maintained.

• An immigration policy that supports the movement of individuals who contribute to the advancement of medical science and research is vital.
• We recognise that immigration policy is reserved. There is an opportunity to position the UK, including Scotland, as a global science hub with both EU and non-EU partners.

Medical research is a global endeavour; the current ease of movement of UK and EU nationals across the EU makes a significant contribution to the advancement of medical research. Almost a quarter of researchers in Scottish universities are from other EU countries.4

Medical research relies on more than just the ease of movement of researchers; health professionals and technicians are just some of those who are also vital. The UK must have a migration policy that allows for all those helping to deliver improved health for patients to participate in research in the UK.

Regulation of medical research and access to treatments

• AMRC and our members want continued alignment and compatibility with EU regulatory frameworks for medicines and medical devices to ensure patients continue to have timely access to new health innovations.
• This should include regulatory frameworks for special populations including orphan medicines for rare and very rare diseases; children and elderly people. We recognise that most regulatory powers are reserved.
• In addition, the UK’s contributions to the regulatory bodies and frameworks must be maintained to ensure the UK remains a leader in life sciences.
• AMRC and our members are aware that opportunities may exist in future to diverge from EU regulations in order to advance innovation and research.

An aligned regulatory landscape, particularly for medicines and medical devices, provides stability and certainty for the life sciences sector.

The single authorisation for medicines within the EU via the European Medicines Agency (currently located in London) allows approval for new medicines in all EU member states at once. If the UK, including Scotland, was no longer part of this, pharmaceutical companies would have to go through a separate process to authorise their products in the UK. This may disincentivise medicines development and slow down the development of new treatments in the UK. It is crucial that there is no negative impact on patients’ ability to access new drugs.

In future, as medical research advances, there may be opportunities to diverge from EU regulations – particularly where the EU is slow to uptake new and emerging technologies. An effective balance must be struck between the potential to reduce regulatory ‘red tape’ while still maintaining rigorous ethical standards.