The UK and EU: What people affected by cancer need from the future relationship
We are rightly proud of the UK’s world-class research environment and the benefits it has brought to people and families affected by cancer. Research has driven vital progress and seen cancer survival in the UK double since the 1970s. But UK cancer research, like all the best research, doesn’t happen in isolation. It is inherently international, with a mix of UK and international researchers working here and across borders to drive improvements in the ways we understand and treat cancers.

Cancer Research UK is the world’s largest charitable funder of cancer research, committing £546 million towards research into all 200 types of cancer in 2018/19. We receive no Government funding but do rely on the UK’s thriving research environment as we seek to support the very best research to drive progress towards our ambition to see 3 in 4 people survive their cancer by 2034.

So as the UK leaves the European Union, it is essential that the international collaboration which underpins our domestic research environment continues to flourish, to the benefit of patients here and across Europe.

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As attention increasingly moves beyond withdrawal from the EU to the future, we wanted to better understand the views of people affected by cancer – how they see our priorities and what, ahead of talks on the future relationship, they would want negotiators to know about the issues that matter to them.

By working collaboratively with other countries – especially in Europe – enables our researchers and clinicians to learn together, and hopefully improve the services and outcomes for UK patients.

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Those insights are detailed throughout this document, as well as further information on the ways the UK and EU cooperate to the benefit of patients and some of the projects Cancer Research UK are involved in.

There are many difficult questions to be answered during Brexit, but UK-EU research collaboration needn’t be one. For the sake of people affected by cancer, we call on negotiators to ensure brilliant researchers in the UK and EU can continue to work closely together to beat cancer.
Ensuring UK-EU clinical trials continue to deliver benefits to patients

99% of people affected by cancer we surveyed believe the UK and EU should reach a deal which allows cross-border clinical trials to operate as easily as they do now.

Clinical trials test if new treatments are safe and effective for patients. They also provide patients with opportunities to access potentially life-saving innovations at an early stage in their development. They are an essential part of cancer research, and of our work. Cancer Research UK funds nearly 99% of people affected by cancer we surveyed believe the UK and EU should reach a deal which allows cross-border clinical trials to operate as easily as they do now.

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In particular, we want the UK to be able to participate in the future regulatory system for clinical trials being rolled out in the EU, known as the Clinical Trial Regulation (CTR). The CTR is a major step forward over the current system for clinical trials, the Clinical Trials Directive. Improved safety reporting features will ensure patient safety is paramount at all times, while streamlining administrative processes will make trials quicker and easier to set up – meaning less delay in participants getting access to the most innovative new treatments.

The UK’s clinical trials community, the Medicines and Healthcare Products Regulatory Agency (MHRA), charities and patient groups were instrumental in driving the welcome changes that will be brought in through the CTR. UK researchers and patients must be able to benefit from these changes and continue to easily collaborate with European partners, even if the Regulation doesn’t come into force until after the EU. The Government has recognised that UK-EU collaboration on trials must continue, and in April 2018 pledged to align with the CTR as closely as possible. It is essential that this pledge is upheld, especially as researchers have started to plan for its implementation. But this promise, while welcome, does not go far enough. Access to the digital infrastructure which underpins the CTR must still be negotiated with the EU. This system will bring much needed improvements, including quicker trial set-up and improved data sharing. If the UK is outside of this system it will be harder to set up vital cross-border trials with our closest research partners in Europe.

UK Government must protect UK-EU clinical trials and make UK participation in the EU’s clinical trials regulatory framework, including access to the associated portal and database, a negotiating priority.

1. 148 of 150 responses Strongly Agreed or Agreed with the statement ‘The UK and EU should reach a deal which allows cross-border clinical trials to operate as easily as they do now.’
3. Statistics from CRUK’s internal databases and include clinical trials from our Clinical Research Committee, New Agents Committee and Centre for Drug Development.
4. Information on EU Regulation in Clinical Trials, adopt statement from non-commercial and commercial organisations at http://www.cancerresearchuk.org/sites/default/files/joint_statement_on_th_commissions_proposals_for_the_clinical_trials_ regulation.pdf

Case study – The ESPAC-4/ESPAF-SF trial for pancreatic cancer

Pancreatic cancer is one of the hardest cancers to treat and has one of the lowest survival rates. The European Study Group for Pancreatic Cancer (ESPAC) wants to change this. ESPAC formed in 1989, and their research has contributed to accelerated improvements in survival and quality of life for patients. Since the 1980s, short term survival has increased by around 60%.

But ESPAC know there is more to do. Just 1% of people diagnosed with pancreatic cancer in England and Wales survive for ten years or more. In 2008, they set up the ESPAC-4 clinical trial. By 2014, it had recruited 732 patients from the UK, Germany, Sweden, and France. Around half of trial participants received an innovative combination of chemotherapy drugs. The other half received the standard chemotherapy treatment. An extra 13% of patients on the trial lived for five years when given the combination of chemotherapy drugs.

Peter was diagnosed with pancreatic cancer when he was 61. When his doctor told him about ESPAC-4, he jumped at the chance to take part. “Survival rates for pancreatic cancer are low and the best way to change this is to develop new drugs and techniques, so I didn’t hesitate when I heard about the trial. I wanted to help in any way I could, and I’m so proud to have played a small role in the trial’s success.”

Running trials for rarer cancers across Europe means we can conduct research benefiting patients in UK and across the continent. We want groups like ESPAC to be able to continue their potentially life-saving work after Brexit.
The best cancer research is international, involving talent from around the world. At CRUK we recruit global scientific talent to drive our work – 76% of our funded postdoctoral researchers at our Institutes are not from the UK. And the flow of talent flows both ways, with 72% of UK-based researchers spending time at non-UK Institutions from 1996 to 2012.3

Researchers move to the UK to live and work, and our world-leading research environment is underpinned by the UK’s status as a destination-of-choice for international researchers. We need to make sure that the new immigration system protects and enhances our ability to attract, recruit and retain the best of global scientific talent at all professional levels, regardless of nationality.

Shorter-term travel is also crucial, as scientists move to and from the UK to share knowledge and work on vital shared projects like clinical trials. To support the work already underway and help foster future collaborations which will drive progress for patients, the Government must ensure researchers can continue to move easily across borders.

Government has been positive in recognising that the new rules must work for science and medical research. It is vital that this intent is translated into a system which ensures researchers and their families feel welcome in the UK, with full access to public services as they pursue their careers here. The system must minimise the bureaucracy faced by international researchers and employers, and ensure researchers are not inadvertently penalised by entry criteria. A salary threshold to encourage skilled migration, for example, risks excluding skilled research technicians who are the backbone of the research workforce, but whose pay often does not reflect this.

Researchers moving to the UK are currently faced with thousands² of pounds of costs, as are the employers recruiting them. This drains money available to put into vital medical research projects and, at worst, risks putting off researchers from moving to the UK at all. A new system must also minimise these costs.

The UK’s world leading medical research environment, which drives such vital improvements in outcomes for patients, relies on talent from around the world. It is vital Government: Designs a post-Brexit immigration system that enables us to attract, recruit and retain global scientific talent at all professional levels, regardless of nationality, and that facilitates collaboration with international partners.

and Reaches agreement with the European Union to protect the ability of researchers to quickly and easily move across borders to work on vital shared projects like clinical trials.

5 ’An Profile of International Visa systems’ https://drive.google.com/file/d/1ETU8hWw2M54h9kQ7WDti6GPFqVEdg9yu/view
7 A non-EEA researcher with no dependents moving to the UK would face: £1220 visa application fee for tier 2 visa; £200 a year Health Surcharge; £1000 a year Immigration Skills Charge. Based on analysis by the Together Science Can campaign, documented in Xn Profile of International Visa systems https://drive.google.com/Red/3GTY8HtWu2q5M6n3D7N9X0AGPq/Epqyf5vuy/view
Securing swift patient access to new cancer medicines

93% of the people affected by cancer we surveyed want the UK and EU to agree to close cooperation on the licensing of new medicines.

Cancer is a global challenge, and improvements in outcomes for people affected by cancer are achieved most quickly through international collaboration. That includes working in partnership to ensure cancer patients get the most innovative, potentially life-saving treatments as soon as possible.

As the UK leaves the EU, nothing must be allowed to affect or slow access to new medicines for patients.

The EMA has a key role in approving new medicines, by evaluating applications for “marketing authorisation” which allows these treatments to be routinely used in national healthcare systems. This authorisation verifies a medicine’s safety, effectiveness, and manufacturing quality. If the UK is outside of the EMA’s medicine licensing arrangements in the new relationship, companies will have to submit separate marketing authorisation applications to the EMA in the EU, and to the MHRA in the UK.

The EMA covers an area responsible for 25% of global pharmaceutical sales. The UK on its own makes up only 3%. Given the smaller relative market size in the UK, companies launching medicines will likely prioritise the EU market and the application to the UK would come later — meaning UK patients would get delayed access to the newest medicines.

The infographic above shows companies already prioritise the EU market over other countries — an advantage the UK risks losing if it diverges from the EMA’s regulatory framework.

And the MHRA working closely with the EMA doesn’t just benefit patients here, but all over Europe. The EMA’s work relies on input from national regulators, and the UK’s MHRA is recognised as a world-class organisation key to these efforts. Between 2008 and 2016, the MHRA acted as Scientific Advice Coordinator, proving expert advice to inform decision-making, in over 20% of the EMA’s centralised medicine approval procedures.

We believe the MHRA and EMA are stronger when they work together, and patients benefit as a result.

Post-Brexit arrangements which result in delays in companies submitting medicines for licensing in the UK, and potential delays in patients accessing to these medicines would be unacceptable and could have significant implications for the research and life sciences industry in the UK.

The UK Government must prioritise seeking the closest possible future relationship between the EMA and the MHRA, and ensure there will be no delays to patient access to new medicines following the UK’s exit from the EU.

This should include the MHRA’s active participation in the EMA’s processes, building on its reputation and expertise, to the benefit of patients here and across Europe.

The infographic across shows companies already prioritise the EU market over other countries — an advantage the UK risks losing if it diverges from the EMA’s regulatory framework.

The UK and EU are stronger when they work together to improve public health. In the European Medicines Agency, MHRA expertise and capacity is crucial. For the UK, full participation in the EMA allows swift access to the newest medicines and treatments. A continued strong relationship will benefit patients across Europe and we must not allow political barriers to get in the way of this.

Thomas Lönngren, Executive Director of the European Medicines Agency (2001 – 2010)

There is too little information about the long-term medical implications of Brexit for future treatments of patients — everything seems focussed on short term panics about stockpiling drugs. We need plans in place for the next 5, 10 and 20 years, not just the next few weeks.

Response to our survey of people affected by cancer

8 BMI Research, Pharmaceutical sales, USDbn, 2015
9 139 of the 350 surveyed Strongly Agreed or Agreed with the statement “The UK and EU should agree to close cooperation on the licensing of new medicines.”

Protecting collaboration between UK and EU medical researchers

94% of the people affected by cancer that we surveyed want the UK to continue to participate in, and fund, EU research programmes.

We want the UK to remain a world-leader in cancer research, with the benefits passed on to patients here and across the world. And that means continuing to play a key role in the international research ecosystem, working with international partners towards our common goal.

Collaboration is an essential feature of medical research. Researchers work across borders to share expertise, pool data and work at a scale they could not do on their own. And cancer research is no different – it is estimated nearly half of all UK cancer research involves international collaboration. Working with international colleagues also makes research more impactful – publication citation scores almost double the world average when the UK and EU work together.

Cancer is on the rise globally, with 18.1m people diagnosed in 2018, and deaths projected to rise from 9.6m to 13m worldwide by 2030. In the UK, 1 in 2 people will develop cancer at some point in their lives. Governments, research funders and others are taking joined up action to strengthen the prevention, diagnosis and treatment of cancer through international research collaborations, policy change and increased investment.

The European Union is a hotbed of such collaboration, and European countries are key research partners – in 2017 Cancer Research UK researchers were partnering with over 400 organisations in the EU alone. The EU encourages research and innovation through its Research Framework Programmes – flagship, multi-year initiatives which provide funding and encourage partnerships across countries and between the public, private, and third sectors.

The UK excels in these initiatives, and between 2007 and 2017 the UK was the most active EU country in terms of participants in research projects supported by the Programmes. Such partnership supports innovative research and science, including some of the vital cancer research detailed in the PHITT case study (overleaf). And the Programmes foster collaboration between scientists in different countries, whether it be during joint applications, when working on the same project or initiative, or as a direct result of grants aimed to facilitate cross-border links.

As the UK establishes a new relationship with the EU, we want to ensure this vital research collaboration can continue. A new EU Research Framework Programme, Horizon Europe, is due to be launched in 2021. Horizon Europe will have nearly €100bn of funding across 7 years, open to researchers across the continent.

And, for the first time, Horizon Europe will have a special focus on tackling cancer, with plans for a ‘Cancer Mission’ to co-ordinate efforts across Europe to deliver much-needed research to prevent, diagnose and treat cancer more effectively. While the Programme is coordinated by the EU, the door is open to non-EU countries if they seek association and make financial contributions.

But as things stand, the UK will not automatically have access to Horizon Europe funding and support – and has not confirmed its intention to seek association. Without access to the programme, UK researchers will be unable to secure vital funds and use their expertise to help direct these cross-border efforts to beat cancer. For the UK to lose access to and influence in Horizon Europe at this crucial moment would be a significant setback for our brilliant cancer researchers and their much-needed work.

Cancer Research UK does not directly receive Government funding, from the UK or the EU. But we believe it is crucial researchers in the UK can continue to rely on European funding to support their work and foster vital collaborations in cancer research. And we believe the UK can play a vital role in European efforts to beat cancer in years to come.

UK Government should seek to associate to Horizon Europe and similar research programmes, and ensure UK researchers can continue to collaborate with partners in the EU and access European funding.

Case Study – The PHITT Trial

The Paediatric Hepatic International Tumour Trial (PHITT) investigates the success of different therapeutic techniques for young patients suffering from rare liver cancers that account for 1% of paediatric tumours. PHITT is part of a larger collaborative international project called the Children’s Liver Tumour European Research Network (ChLTERN).

This project is funded 100% by EU sources via the Horizon 2020 Programme, and ChLTERN has received almost 8 million euros from EU grants to carry out this clinical trial. Professor Keith Wheatley, the project lead for ChLTERN says “Importantly, the EU funding allows us to develop and deliver the trial contemporaneously in all EU participating countries rather than a disconnected approach where each country identifies its own funding stream. The amount of funding and coordination this project would not be available from a single source funder within one country. And as such the Horizon 2020 funding provided by the EU Commission is imperative to such a multi-country collaboration.”

International collaboration is crucial if progress is to be made in rare cancers. These types of collaborations allow more patients to participate, provide a greater source of funding, and give the UK at the centre of globally significant research.

[UK negotiators should] make sure EU funding for science in the UK stays the same and collaboration between scientists within Europe remains optimal. Fighting cancer is a global fight.