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ASSOCIATION OF MEDICAL RESEARCH CHARITIES

investment research access health

Use research findings to make people healthier

Use research findings to inform policy and maintain independent scientific advice for the EU

Linking science with policy making is essential for Europe's future prosperity. Professor Anne Glover, European Chief Scientific Adviser, provides independent expert advice on any aspect of science, technology and innovation. Her role must be maintained after the 2014 election to support the EU's growth agenda, of which science is a crucial part. Introducing scientific advisers in each Directorate General of the European Commission, as the UK has in each of our government departments, would also be valuable to ensure impacts for science and research are considered at the outset of legislation.

Case study

Research demonstrating a link between smoking and cancer informs tobacco control legislation

In the 1990s Cancer Research UK (CR-UK) funded influential health research that supported the case for a ban on tobacco advertising. Such research later informed the smoke-free legislation that was introduced across the UK in 2007. Internationally, there is now a World Health Organisation Framework Convention on tobacco control and an EU Directive on tobacco products that led to the removal of misleading 'light' and 'mild' descriptions and the introduction of larger, more impactful warnings on cigarette packets. Anti-tobacco strategies informed by research from CR-UK and others have helped to reduce smoking rates by approximately a quarter over the past decade and, subsequently, prevented many thousands of cases of cancer in the future.[1] This is an example of where research findings can inform legislation in non-science areas to bring health benefits to the EU.

Fact...

Poor health costs the UK economy

In 2010, on average, each UK employee took 6.5 days sick leave which cost the economy £17 billion that year.[2]

Case study

Using scientific expertise to inform policy makers over access to latest cancer drugs for children

The Paediatric Regulation 1901/2006 is having an adverse impact on children's access to the latest cancer drugs. Pharmaceutical companies are exempt from the need to run paediatric clinical trials if a drug is not intended for a cancer occurring in children. However, these rules deny children adult cancer drugs which could be effective for them. Cancer drugs are increasingly designed against specific molecular mechanisms, rather than the location of the cancer, and these mechanisms may well be common to both adult and childhood cancers. The current system of exemptions in the Regulation does not recognise this, denying children access to cancer drugs they could benefit from. Scientists at The Institute of Cancer Research, London, in January 2014 proposed changes to the waiver system in a response to a European Commission consultation on paediatric drug development. The European Commission are currently considering changes to this waiver system to ensure children can access potentially life-saving cancer drugs.

Ensure research results are published and data are made accessible to those who need them for the continued benefit of patients

Patients want the opportunity to be involved in trials of new treatments in the hope that the treatment will benefit them and improve the treatment of others in the future. Transparency about how trials are conducted and the publication of their results is central to research progressing efficiently, helping other researchers to learn and make further advances. The underlying data must be handled safely and securely but can also be valuable to other researchers. Recognising this, discussions are underway at an international level to improve trial registration and publication and the sharing of information.

Case study

EU Clinical Trials Regulation promotes greater transparency

The Clinical Trials Regulation will introduce several requirements for greater transparency in clinical research including a requirement that all summary data are published. The ability of researchers to easily gain access to the findings and data from clinical trials will allow for more secondary analysis of trials which in turn builds a broader and more comprehensive picture of the effectiveness of treatments. Importantly the Regulation also requires the publication of a lay summary of the trial. This will give patients the opportunity to understand the results of the research they participated in.

Case study

Strong public call for research results to be published

Launched in January 2013, the AllTrials campaign calls for all past and present clinical trials to be registered and their results reported. The campaign has been picked up by over 63,000 people and 445 organisations and activity is underway at a UK, European and international level, giving a strong public dimension to work to improve transparency.[3]

Fact...

Patients want to be involved in research

72% of people tell us they want to be offered opportunities to be involved in clinical trials of new treatments.[4]

1. http://www.cancerresearchuk.org/cancer-info/cancerandresearch/progress/impact-on-cancer-types/Lung-cancer/#Smoking
2. Confederation of British Industry, (2011) *Healthy returns? Absence and workplace health survey 2011.* http://www.cbi.org.uk/media/955604/2011.05-healthy_returns_-_absence_and_workplace_health_survey_2011.pdf
3. http://www.alltrials.net/2014/alltrials-campaign-video-coming-soon
4. Ipsos MORI (2011), *Public support for research in the NHS.* http://www.ipsos-mori.com/researchpublications/researcharchive/2811/Public-support-for-research-in-the-NHS.aspx