

## ARVO International Advocacy Toolkit: United Kingdom

1. Which organization(s) are significant sources of research funding? (e.g., national/local governments; private funding/foundations/charity groups; large non-governmental organizations (NGOs); industry/pharmaceutical companies)

### **National Institute for Health Research (NIHR)** (<https://www.nihr.ac.uk/funding-and-support/funding-opportunities/>)

- Government/National Health Service (NHS) funded agency (similar to National Institutes of Health (NIH) in the USA) that funds a broad area of clinical research including translation of basic discoveries into practical products, treatments, devices and procedures.
- The NIHR will not consider any research proposal involving laboratory animals.
- Largest funder of clinical research in Europe (Budget in excess of £1 billion in 2015/16)

### **Wellcome Trust** (<https://wellcome.ac.uk/funding>)

- Non-governmental charity supporting biomedical research and public understanding of science.
- Major funder for basic science / early translational laboratory research.
- Supports international collaborations with industry and non-UK funding agencies.
- Second wealthiest charitable foundation in the world with an endowment of £23.2 billion (2017).

### **Medical Research Council** (<https://www.mrc.ac.uk/funding/>)

- Publicly funded government agency funding medical research in the United Kingdom.
- Major funder for basic science / early translational laboratory research.
- Research budget in excess of £750 million in 2016/17.

### **Fight for Sight** (<https://www.fightforsight.org.uk/apply-for-funding/funding-opportunities/>)

- UK charity funding research into the prevention and treatment of blindness and eye disease.
- Largest national charity dedicated to funding eye research in the UK.
- £20 million funding from 2012-2017

### **International Glaucoma Association** (<https://www.glaucoma-association.com/research>)

- Awarded £220,000 to help with the detection, diagnosis and treatment of glaucoma 2017-2018

- Predominantly small grants for clinical research
- Forthcoming policy change planned to also support laboratory work

**National Eye Research Centre** (<https://www.nerc-charity.org.uk/research-applications>)

- Charity funding basic science and clinical eye research
- Twice yearly funding call
- £1.2 million awarded in research grants 2016-2017

## 2. What does the normal science funding/policy decision-making process look like?

Most UK funders require a component of Public and Patient Involvement (PPI) in grant applications. This involves active involvements of patients in the development of all aspects of eye research projects in order to maximize impact and relevance to patients with the disease. A good summary of what this involves can be found on <http://www.brcophthalmology.org/patient-and-public-involvement>

## 3. Which patient advocacy groups, if any, are active in the area?

**Royal National Institute of Blind People** (<http://www.rnib.org.uk>)  
**International Glaucoma Association** (<https://www.glaucoma-association.com>)  
**Guide Dogs UK Charity for the Blind and Partially Sighted** ([www.guidedogs.org.uk](http://www.guidedogs.org.uk))  
**The Macular Society** ([www.macularsociety.org](http://www.macularsociety.org))  
**Thyroid Eye Disease Charitable Trust** ([www.tedct.org.uk](http://www.tedct.org.uk))  
**Nystagmus Network** ([www.nystagmusnetwork.org](http://www.nystagmusnetwork.org))  
**Thomas Pocklington Trust** (<http://www.pocklington-trust.org.uk>)  
**Blind Veterans UK** (<https://www.blindveterans.org.uk>)

## 4. Are there existing national/regional organizations that work towards improving research funding/policy (advocating for increased research funding/better policies)?

The Royal College of Ophthalmologists ([www.rcophth.ac.uk](http://www.rcophth.ac.uk)) is the major professional body for ophthalmologists in the UK and actively advocates with the UK government regarding ophthalmic clinical care, and research funding to a lesser extent.

## 5. How do scientists currently contribute to the existing funding/policymaking/advocacy process, if at all?

Scientists do have a voice, however as the major governmental funding sources are patient-centered there is greater impact on policy from patients themselves. This strategy has been successfully adopted by scientists, clinicians advocating together with the patient communicating the impact of research upon their lives to policy makers.

## 6. When are science funding/policy decisions made?

Science funding policy decisions are made on an ad-hoc basis, often in five-year cycles that frequently correspond to changes in government or major fiscal policy changes.

The bulk of governmental health care research funding in the UK is ring fenced as a part of the budget of the UK National Health Service. This has meant that it has been protected from more radical cuts in recent years, even in the recent period of “austerity”.

## 7. What kinds of opportunities exist for scientists to interact with funders and policymakers?

Can scientists invite decision makers to their lab/institution to see their work firsthand?

Yes, although this rarely happens in the U.K.

Do the funding/policy organizations hold open meetings or solicit comments from the public that researchers can participate in?

Yes. Many funders and charities hold patient engagement events as a part of their PPI policy. These opinions really drive and influence research priorities. A recent example of this is The Sight Loss and Vision Priority Setting Partnership Survey performed in 2012. This asked patients, carers and eye health professionals to identify unanswered questions about the prevention, diagnosis and treatment of sight loss and eye conditions that they wished to see answered. Most current research proposals need to fit this remit.

[www.sightlosspsp.org.uk](http://www.sightlosspsp.org.uk)

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