Researchfish use by AMRC Members

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Established in 1987, the Association of Medical Research Charities (AMRC) is the UK’s national membership organisation for health and medical research charities.

We have over 140 member charities based across the UK

Our vision
The AMRC will be the leading voice of the health and medical research charity sector, supporting charities to deliver high-quality research and champion impact for patient and public benefit.
Who are our members?

https://www.amrc.org.uk/Pages/Category/member-directory
What do they fund

Research investment in 2017

- **£1.6bn**: AMRC charities
- **£1.0bn**: NHR
- **£0.8bn**: MRC

AMRC charities fund nearly half of publicly funded medical research nationally.

Over the past 10 years, AMRC charities have spent £13bn on research in the UK.

Researchers’ salaries were funded by AMRC charities, including 1,700 PhD students.

Every £1 spent on medical research returns 25p on investment annually.

Medical research is the top cause to which the UK public donates.

Making a difference for patients

- **200,000**: people in the UK were recruited into over 1,300 clinical studies or trials funded by AMRC charities.

AMRC members fund essential research in all areas of health and disease.

- **31%**: of non-commercial research supported by the NIHR Clinical Research Network was funded by AMRC charities.

At all stages of the research process

- **59%**: of charities fund research into the cause of disease.
- **60%**: of charities fund research into the development of new diagnostics and treatments.
- **38%**: of charities fund research into disease prevention and disease management and health services.

https://www.amrc.org.uk/2018-infographic
What do they fund

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The AMRC members that use Researchfish now cover over 90% of this spend.
It’s vital for charities to show the money their supporters donate is being spent wisely.

Collecting impact data allows charities to:

- Evaluate their research portfolio
- Inform new research strategies and funding calls
- Provide material for fundraising campaigns
- Create new comms content (newsletters, website, social media, etc)
- Report to key stakeholders, trustees, members
- Inspire and engage research community
- Demonstrate difference they are making to patients and families
### Collecting Impact Data

**Possible collection methods:**

- Standard progress reports or surveys
- Phone or in person interviews of award holders
- Online impact collection platforms
- Mining online data repositories (publications, patents, products)
- Publication metrics
- Online attention and activity (altmetrics)

**Methods charities use depend on:**

- Size of portfolio
- Breadth of portfolio
- Retrospective or prospective
- Staff resources
- Budget
- What types of impact they expect or want to assess?
AMRC and Researchfish

Since 2012 AMRC has worked in collaboration with MRC to support members in their use of Researchfish.

For the first 5 years MRC funded the Researchfish costs of AMRC member charities that chose to use the system.

We have just started a further four year deal in which costs for smaller charities are being split between the MRC and each eligible charity.

As part of these deals AMRC:

- Facilitates an AMRC Researchfish user group
- Provides 1:1 advice and support to members using Researchfish
- Represents members as part of the Researchfish steering board and other governance committees
- Supports members to maximise use of the data
- Enables data sharing between members
- Uses data from all members using Researchfish to evidence the impact of the sector
Exploring AMRC members Researchfish Data

• AMRC is in quite a unique position

• All data and outcomes submitted to AMRC members are also made visible to us (with members consent)

• This allows us to look at across multiple funders and start to investigate the value of comparative analysis, benchmarking and data sharing

• In 2016 we developed an interactive data analysis tool in Qlik

• This was shared with a subset of funders who were willing to make their data available to each other

• A strict data sharing agreement was in place
Interactive analysis

Number of medical products

404,369 unique medical products

Awards with a medical product

254,5% of all awards

Medical product type

Therapeutic Intervention - Complementary Products with applications outside of read
Preventive Intervention - Physical/Biological
Preventive Intervention - Nutrition and...Therapeutic Intervention - Surgery
Preventive Intervention - Behavioral
Therapeutic Intervention - Vaccines
Support Tool - For Medical Intervention Management of Diseases and Conditions...Therapeutic Intervention - Psychology
Therapeutic Intervention - Other
Support Tool - For Fundamental Research
Therapeutic Intervention - Medical Devices
Therapeutic Intervention - Cellular and gene therapeutics
Diagnostic Tool - Non-Imaging
Diagnostic Tool - Imaging

Total, average no. and average cost of products by award type

Total, average no. and average cost of products by research activities

Select specific grant type to see breakdown. Click arrow on axis title(s) to change measure for analysis.

Select specific research activity to see breakdown. Click arrow on axis title(s) to change measure for analysis.

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES
D. Collaborations and Partners

Number of partnerships
- All partnerships: 7,184, 6,560 unique partnerships
- Partnerships with at least 1 partner: 1,859, 35% of all awards

Average no. of partners
- In all awards: 1.36
- In awards with at least 1 partner: 3.86

Total and average number of partnerships since awards started:
- X-axis: Years since start date (up to 01/04/2016)
- Y-axis: Average number

Number of partners across the globe:
- Size of bubbles represents the number of partners
AMRC Impact Report - Overview

- 40 AMRC charities
- Researchfish data
- Defines 5 impact areas
- 40 case studies included

AMRC Impact Report – Areas of Impact

5 Impact areas

Generating new knowledge

- Publications
- Research tools and methods
- Research databases and models

Stimulating further research via funding and partnerships

- Further funding
- Collaborations and partners

Creating evidence that will influence policy and engage wider audiences

- Influence on policy, practice and the public
- Engagement activities

Translating research into new products & services

- Medical products, interventions and clinical trials
- Software and technical products
- IP and licensing
- Spin outs

Developing the human capacity to do research

- Next destination and skills
- Awards and recognitions
- Use of facilities and resources
### Impact Report – Frequency of outcomes

From a total of 5287 awards:

<table>
<thead>
<tr>
<th>Section</th>
<th>Outcome</th>
<th>No. of awards with outcome</th>
<th>Total outcomes</th>
<th>Unique outcomes</th>
</tr>
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<tbody>
<tr>
<td>Generating Knowledge</td>
<td>Publications</td>
<td>3,271</td>
<td>29,181</td>
<td>26,828</td>
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<tr>
<td>Tools and Methods</td>
<td></td>
<td>853</td>
<td>1,580</td>
<td>1,447</td>
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<tr>
<td>Databases and models</td>
<td></td>
<td>296</td>
<td>401</td>
<td>371</td>
</tr>
<tr>
<td>Translating research ideas</td>
<td>IP &amp; Licensing</td>
<td>164</td>
<td>250</td>
<td>224</td>
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<tr>
<td></td>
<td>Spin outs</td>
<td>36</td>
<td>42</td>
<td>39</td>
</tr>
<tr>
<td></td>
<td>Technical products</td>
<td>69</td>
<td>111</td>
<td>102</td>
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<tr>
<td></td>
<td>Medical products</td>
<td>282</td>
<td>434</td>
<td>397</td>
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<td></td>
<td>Artistic and creative products</td>
<td>48</td>
<td>62</td>
<td>59</td>
</tr>
<tr>
<td>Influencing policy and other stakeholders</td>
<td>Influences on Policy</td>
<td>499</td>
<td>1,120</td>
<td>1,016</td>
</tr>
<tr>
<td></td>
<td>Engagements</td>
<td>1,998</td>
<td>9,917</td>
<td>8,445</td>
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<tr>
<td>Stimulating new research</td>
<td>Further funding</td>
<td>1,563</td>
<td>4,832</td>
<td>4,398</td>
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<tr>
<td></td>
<td>Partnerships</td>
<td>1,859</td>
<td>7,184</td>
<td>6,560</td>
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<tr>
<td>Developing the human capacity</td>
<td>Next destinations</td>
<td>1,075</td>
<td>2,120</td>
<td>2,039</td>
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<tr>
<td></td>
<td>Awards and recognitions</td>
<td>1,552</td>
<td>7,737</td>
<td>6,409</td>
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<tr>
<td></td>
<td>Facilities and resources</td>
<td>360</td>
<td>565</td>
<td>492</td>
</tr>
</tbody>
</table>
Chapter Five

Stimulating further research via new funding or partnerships

Types of partners:
- The majority (58%) were academic groups
- 14% were researchers in hospitals and public institutions
- 8% were private organisations

Countries where partners were based:
- Charity-funded researchers had collaborations and partnerships with groups across the world
- Most (53%) of the partnerships were with UK-based organisations
- There were also substantial numbers of partnerships across Europe (22%) and with the United States (10%)

35% of the awards involved 6,560 partnerships

Case study: Ataxia UK
Ataxia UK helped establish a collaborative drug development programme funded by Pfizer to develop a treatment for Friedreich’s ataxia.

Ataxias are a group of rare neurological disorders that affect balance, coordination, and speech in 10,000 adults and 500 children in the UK. Traditionally developing treatments for such rare diseases has been a significant challenge due to the small, geographically spread patient populations making it harder to collect samples for basic research and increasing the difficulty of running effective clinical trials.

One of Ataxia UK’s aims, set out in their 2012 research strategy, is to find a treatment or cure for one or more of the ataxias by 2020. To help achieve this goal the charity sought to increase engagement and collaboration with pharmaceutical companies. From an initial conversation with Pfizer at a rare disease conference Ataxia UK went on to gather and coordinate a group of ataxia academic experts helping them develop and submit a successful funding application to Pfizer’s rare disease consortia initiative.

Consequently the Friedreich’s ataxia collaborative drug development programme was established, giving world class ataxia academic researchers the funding, resources and expertise from industry scientists. Ataxia UK remains a critical part of the team due to their wealth of experience about the condition and their ability to bridge the gaps between patients, researchers and industry. This shows how even small research budgets can still play a huge role in driving research forward.

“Working in partnership with researchers, industry partners and patients is essential to drive research forwards at a fast pace.”

- Charity Perspective
Case study: Sparks

Researchers developed and patented a gas delivery-ventilator system to help protect long term brain function in babies starved of oxygen at birth.

Case study: Tenovus Cancer Care

Following research findings new guidance was issued to all UK radiotherapy departments to improve the safety of cancer patients with implanted cardiac devices.

Case study: Fight for Sight

A diagnostic tool that screens 176 genes at once has improved the accuracy and speed of diagnosis in patients with retinal dystrophy.

Case study: Stroke Association

Intervention delivered in an online virtual island designed to help people with aphasia practice everyday speech has been shown to improve functional communication.
Engagement with AMRC reports

- The impact report had great engagement on twitter
  - #charityimpact reached over 1 million people

- The impact animation has 1,500 views on YouTube

- Spotlight on mental health was the most popular AMRC publication in May 2017

- Spotlight on cancer was the second most popular AMRC publication in August 2017
How do charities use Researchfish Data?

Standalone Research Impact reports:

Research evaluation report
Outputs, outcomes and impact of BHF-funded research: 2014-15

Short presentations:

We know that CRUK researchers have published over 7000 publications

Researchfish Infographic for Researchers
No description
by Cancer Research UK on 26 June 2015

Infographics

- Marie Curie: Care and support through terminal illness
- 68 papers in peer-reviewed journals, 48 (71%) were open access
- 95 instances of informing policy and practice
- 15 countries around the globe where our researchers are involved in collaborations
- 4,432 people recruited to our studies
- £700k+ additional funding from external sources to support research in palliative and end of life care

...together helping to influence policy and practice.
How do charities use Researchfish Data?

Fundraising Leaflets

Ataxia UK Research - Our Success Stories

Ataxia UK’s investment has led to major discoveries in the four areas of our research strategy, such as:

- **Improving diagnosis**: Supporting the creation of a new genetic test which can pick up 100 different ataxia genes in one go (rather than one test for one gene) - now available as an NHS service.
- **Finding treatments**: Funding research into drug screening and repurposing (using drugs which are already used clinically to treat other conditions) which found a treatment for SCAs in a mouse model, with the potential for future human trials.
- **Moving from laboratory studies to human trials**: Discovering a mechanism responsible for turning the Frataxin gene back on which is usually switched off in Friedreich’s ataxia - this led to a human trial testing this mechanism, which was found to be successful.
- **Alleviating symptoms**: Investigating a better way to treat hearing loss in both Friedreich's and cerebellar ataxias and showing that frequency modulation (FM) listening systems can treat hearing loss in people with ataxia whilst other hearing aids can’t.

Ataxia UK works across the whole of the UK and is a charity registered in Scotland (no SC040607) and in England and Wales (no 1102391) and a company limited by guarantee (0617483).

ATAXIA

The research we have funded has led to further funding in ataxia research from a variety of sectors

International Collaborations

We work with other ataxia charities to fund a variety of projects worldwide, promoting research and other enterprises in ataxia by pooling together our resources.

An example of this is the Friedreich’s ataxia collaborative drug development programme where we are collaborating with the pharmaceutical company Pfizer and three universities over a 3 year period.

We were pivotal in orchestrating the development of partnerships crucial to this programme and aided the researchers in designing their proposal.

Publications

10 recent grants resulted in 30 scientific articles published in high standard research journals.

Support our research

To donate to Ataxia UK, please visit our website: www.ataxia.org.uk

If you want to find out more about our research strategy, the projects we currently fund and other research activities, please visit the research section of our website: www.ataxia.org.uk/about-research

You can contact the research team directly at research@ataxia.org.uk

020 7582 1444
How do charities use Researchfish Data?

Retrospective Portfolio Analysis

**IMPACT REPORT RELEASED**
**AFTER AWARDING £5.2M TO RESEARCH IN LAST 10 YEARS**
21 September 2017

**THE POWER OF RESEARCH**
**10 YEARS OF CROHN’S AND COLITIS UK RESEARCH**

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81
We’ve funded over 80 ground-breaking research projects into IBD.

98
The research we’ve funded has featured in almost 100 peer-reviewed scientific publications.

1/3
Almost one third of projects have subsequently won further funding from other grant-making bodies.

1 in 10
10% of researchers have reported policy and practice changes as a result of our funded research.

76,138
How many page views our Take Part In Research section has received since it launched in April 2016.

50%
Almost half of our projects have involved patients in their design or delivery.
How do charities use Researchfish Data?

Identification of case studies

Successes

With the help of all our supporters, we have played a significant role in many medical breakthroughs for 65 years, starting with the development of the first UK polio vaccine. Here are some highlights.

Developing tests now used worldwide to help children with DCD

Developmental Coordination Disorder (DCD), also called dyspraxia, can make everyday activities and school work much more difficult. Action funding helped UK researchers to develop tests and guidelines that are now used globally to identify and support affected children and teenagers.

Mapping babies’ brains to predict and prevent future problems

Premature babies are at increased risk of developing disabilities but it is difficult to know which are most likely to be affected. Action funding has helped to develop a computer-aided tool to read MRI brain scans and identify abnormal development in newborn babies.

More successes

- Discovering gene faults that cause itchy skin
- Brain scanner for babies
- Communication aids for people with disabilities
- Finding a gene for cleft lip and palate
- Finding faulty genes and developing tests for rare diseases
- Improving survival from childhood liver disease
- Improving treatment and surgery for epilepsy in children and adults
- Pioneering hip replacements
- Repairing skull damage
What next?

- Second edition of our research impact report due to be published in the new year
- Continuing to represent our members on sub groups and steering boards
- Supporting the development of the Data Communicator tool
- Working to support work around increased data sharing where possible
- Helping new charities get started with Researchfish
- Increasing the use of Researchfish data
- Supporting our members with impact work more broadly through our impact coffee club and other activities
AMRC’s impact guidance – includes links to the impact report and animation: https://www.amrc.org.uk/Pages/Category/impact

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