

amrc

ASSOCIATION OF MEDICAL RESEARCH CHARITIES

Researchfish use by AMRC Members

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Research Manager - AMRC

15/11/2018

Who are AMRC



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

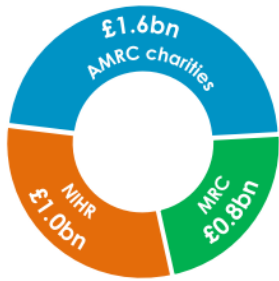
The AMRC will be the leading voice of the health and medical research charity sector, supporting charities to deliver high-quality research and champion impact for patient and public benefit.

Who are our members?



What do they fund

Research investment in 2017



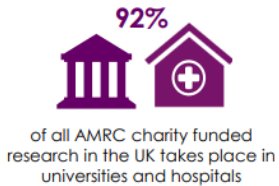
AMRC charities fund nearly half of publicly funded medical research nationally



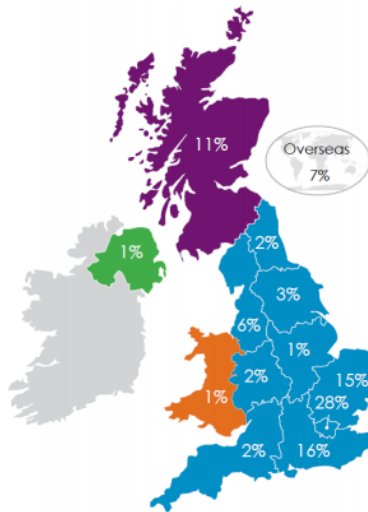
Over the past 10 years AMRC charities have spent £13bn on research in the UK



researchers' salaries were funded by AMRC charities, including 1,700 PhD students

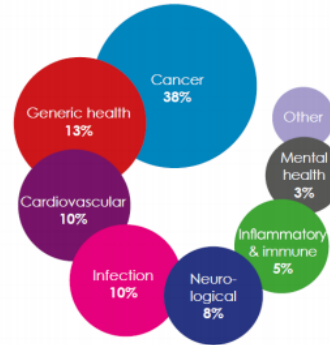


1 in 8 grants awarded by AMRC members were funded in collaboration with other organisations

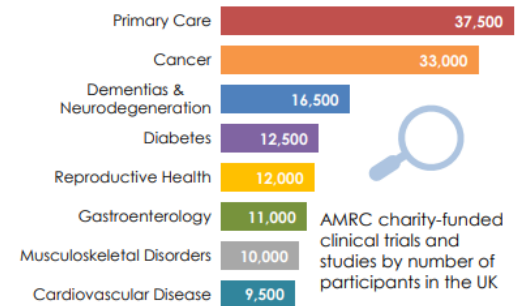
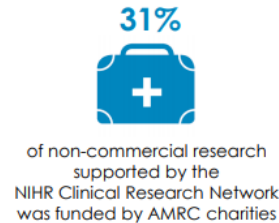
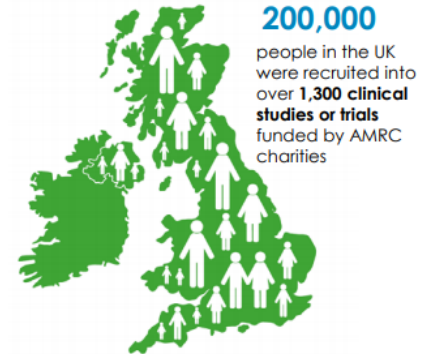


AMRC charities fund medical research throughout the UK and overseas

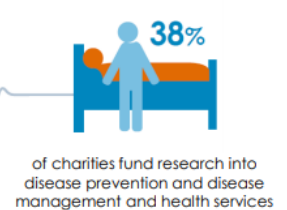
Making a difference for patients



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

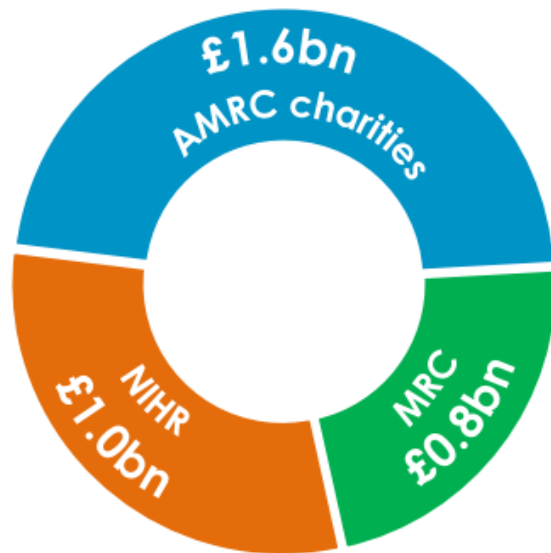


At all stages of the research process



What do they fund

Research investment in 2017



AMRC charities fund nearly half of publicly funded medical research nationally



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



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



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

17,000



researchers' salaries were funded by AMRC charities, including **1,700 PhD students**

The AMRC members that use Researchfish now cover over 90% of this spend

Why Monitor Research Outcomes/Impact?

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 depends 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

RHT

Funding Start Year

Funding Organisation

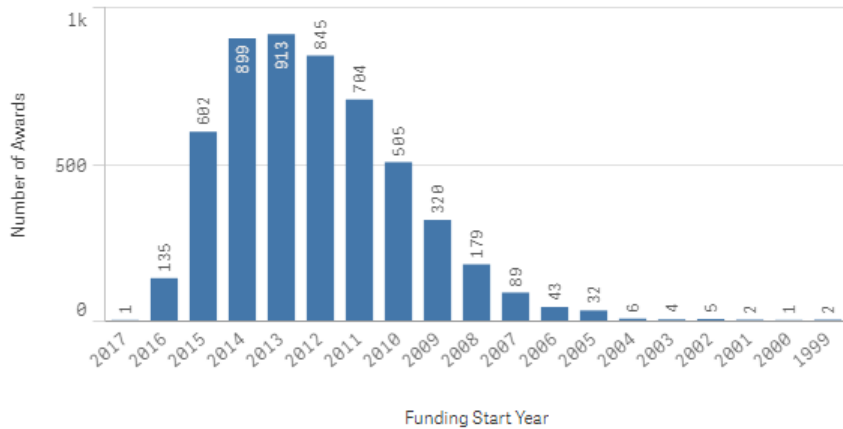
Funder Anonymised

Grant type group

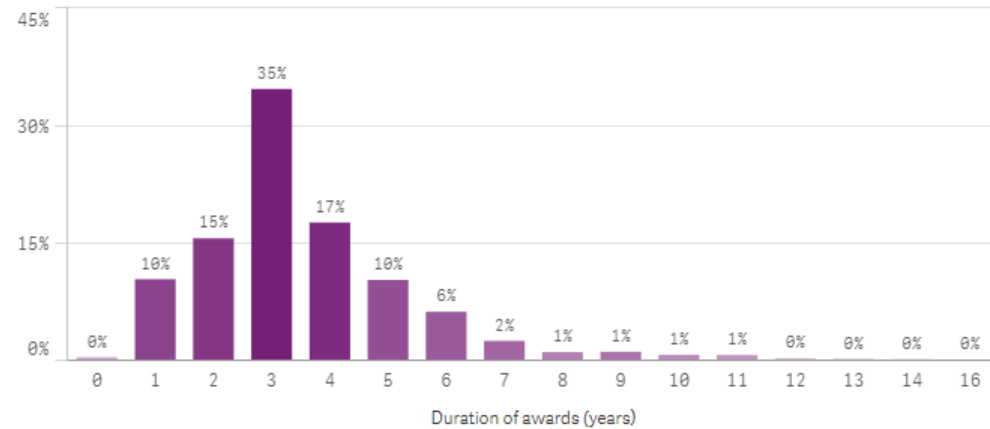
Health Code

Research Activity Group

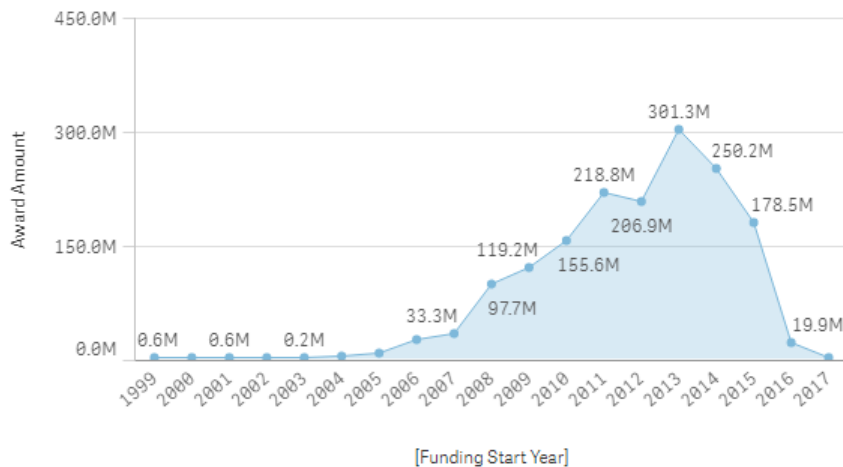
When did the awards start?



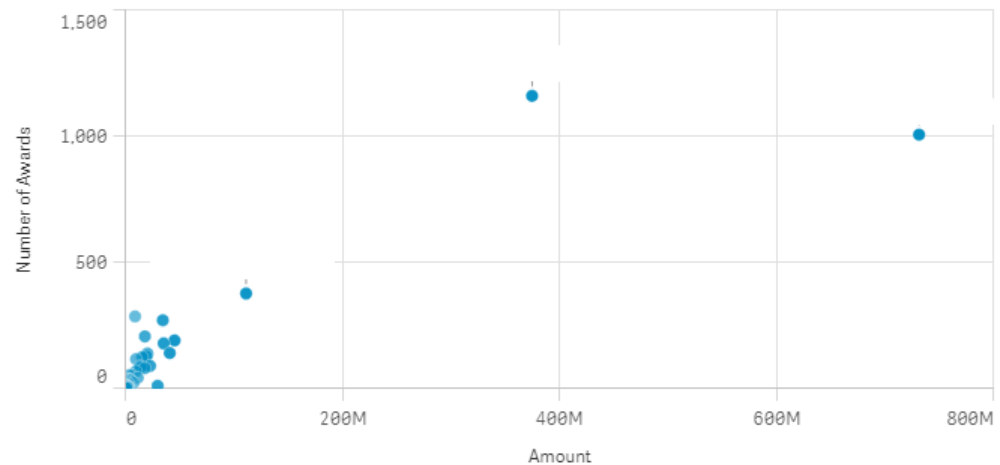
What is the duration of the awards?



Award value by funding start year



Number of awards and value by funder



Interactive analysis

No selections applied

B. Medical products, interventions and clinical trials

Funding Start Year Funding Organisation Grant type group Health Code Research Activity Group Grant Type

Note: 'Medical products, interventions and clinical trials' may be shortened to 'Medical products' for ease.

Number of awards with one or more ... *
Sections represent the number of medical products per award

Total and average number of medical products sinc...

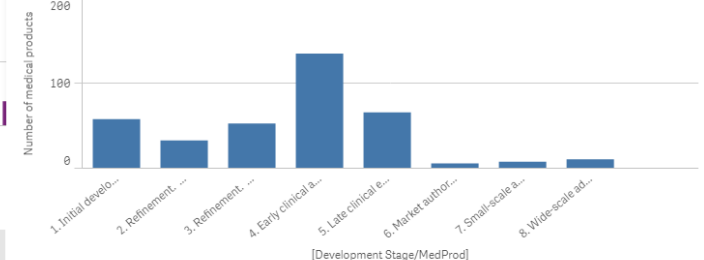
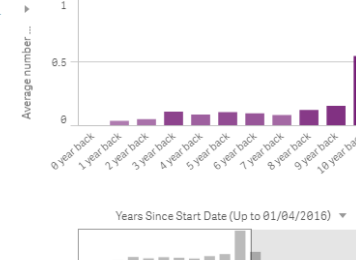
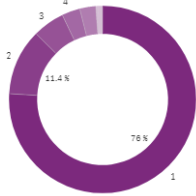
Medical product development stage

Number of medical products

404369
Unique medical products

Awards with a medical product

2545%
of all awards

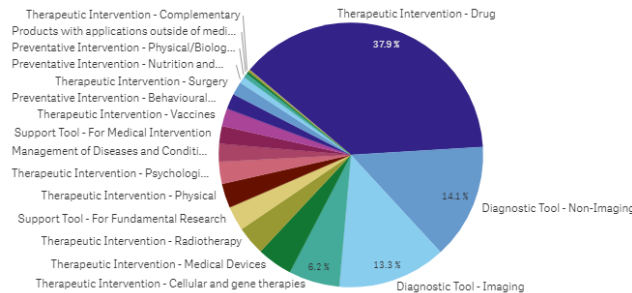


* The data set contains negative or zero values that c...

Click arrow on axis title(s) to change measure for analysis

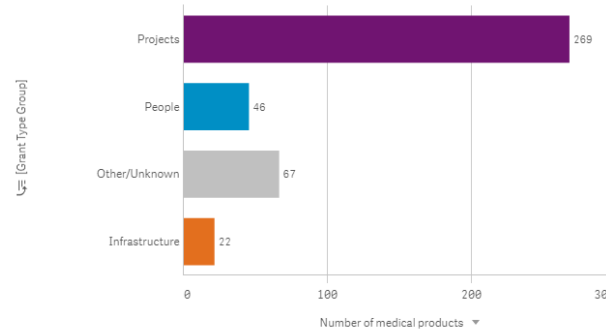
Unique number of medical products

Medical product type



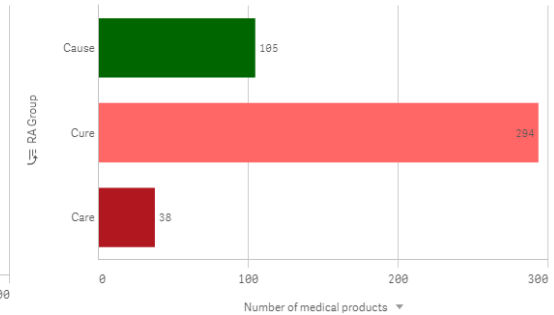
Unique number of medical products

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



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

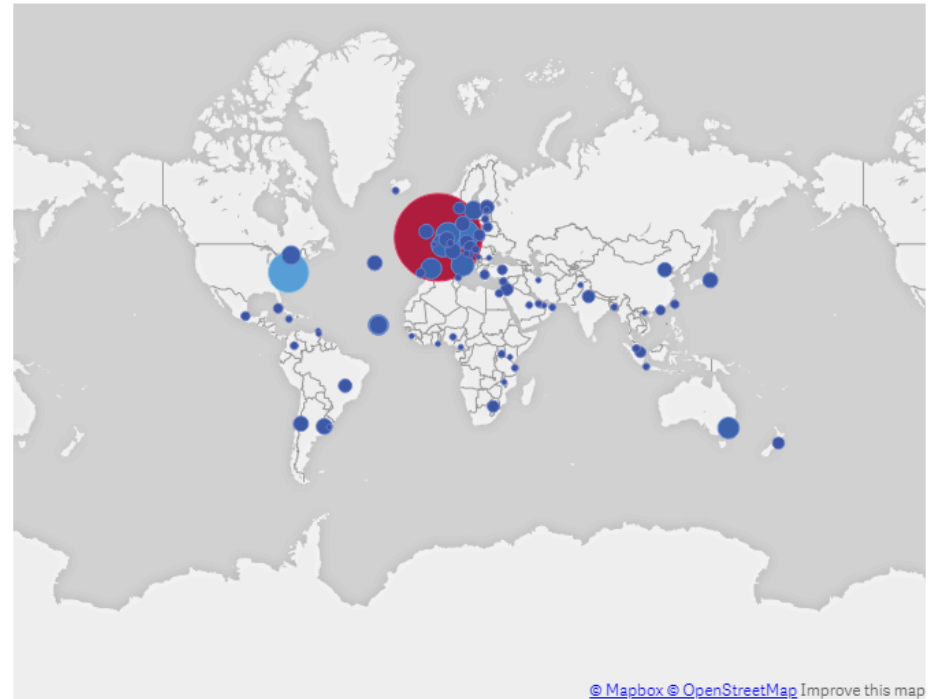
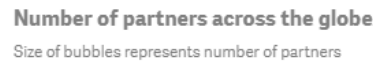
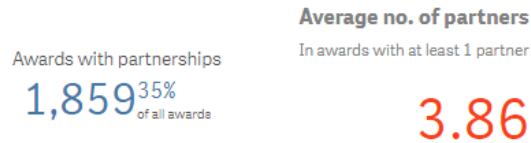
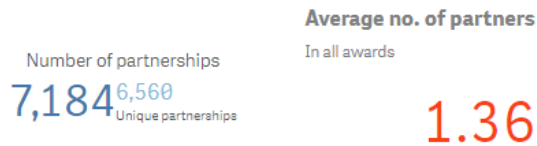
Total, average no. and average cost of products by research activities



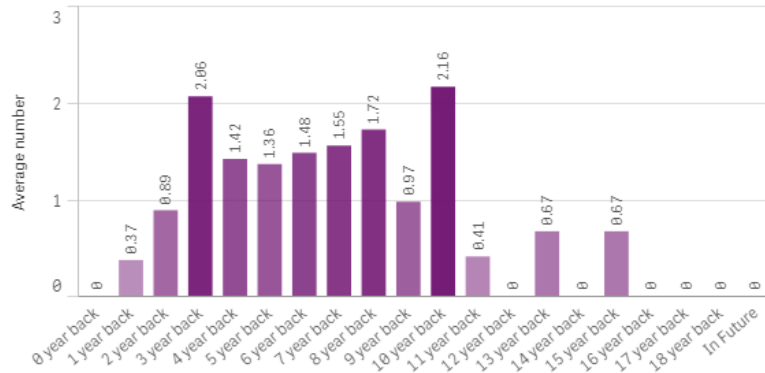
Select specific research activity to see breakdown. Click arrow on axis title(s) to change measure for analysis

Interactive analysis

D. Collaborations and Partners

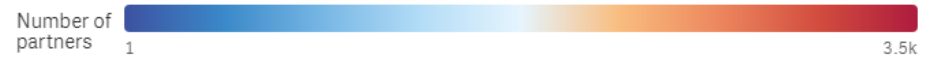


Total and average number of partnerships since awards started



Years Since Start Date (Up to 01/04/2016)

Select years to see partnerships per grant. Click arrow on axis title(s) to change measure for analysis'



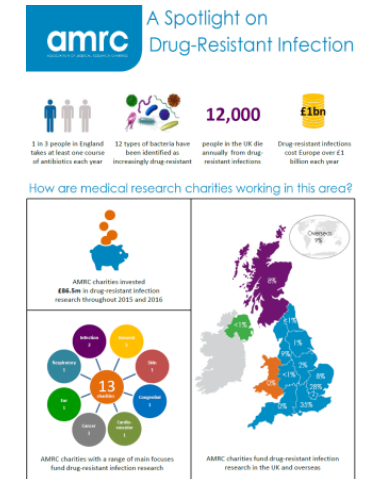
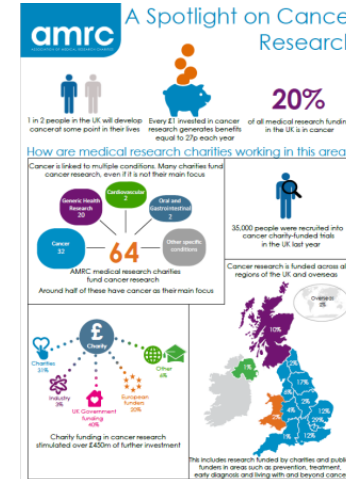
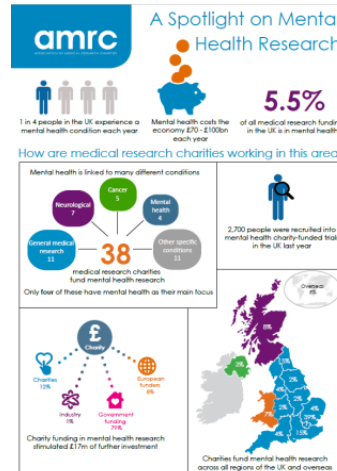
Number of unique partnerships

AMRC use of Researchfish Data

Impact report



Spotlight reports



Impact Animation



Infographics



AMRC Impact Report - Overview



Making a difference: Impact report 2017

Chapters | Website | 



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

Making a difference:
Impact report 2017

AMRC Impact Report – Areas of Impact

5 Impact areas

Generating new knowledge



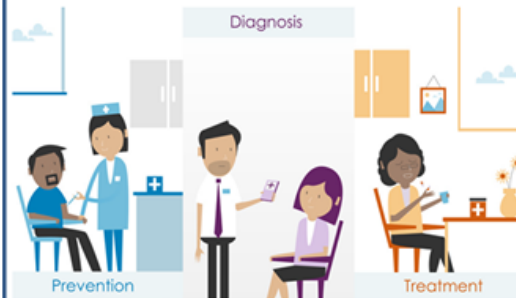
- Publications
- Research tools and methods
- Research databases and models

Stimulating further research via funding and partnerships



- Further funding
- Collaborations and partners

Translating research into new products & services



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

Creating evidence that will influence policy and engage wider audiences



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

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:

Section	Outcome	No. of awards with outcome	Total outcomes	Unique outcomes
Generating Knowledge	Publications	3,271	29,151	26,828
	Tools and Methods	853	1,580	1,447
	Databases and models	296	401	371
Translating research ideas	IPs & Licensing	164	250	224
	Spin outs	36	42	39
	Technical products	69	111	102
	Medical products	282	434	397
	Artistic and creative products	48	62	59
Influencing policy and other stakeholders	Influences on Policy	499	1,120	1,016
	Engagements	1,998	9,917	8,446
Stimulating new research	Further funding	1,563	4,832	4,398
	Partnerships	1,859	7,184	6,560
Developing the human capacity	Next destinations	1,075	2,120	2,039
	Awards and recognitions	1,552	7,737	6,409
	Facilities and resources	360	565	492

AMRC Impact Report - Partnerships



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 consortium initiative.

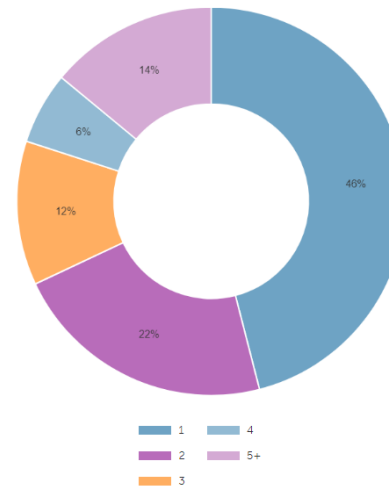
Consequently the Friedreich's ataxia collaborative drug development programme was established, giving world class ataxia academic researchers the funding, resources and expertise from industry scientists.

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."



Number of Partners per Award



AMRC Impact Report – Case studies

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

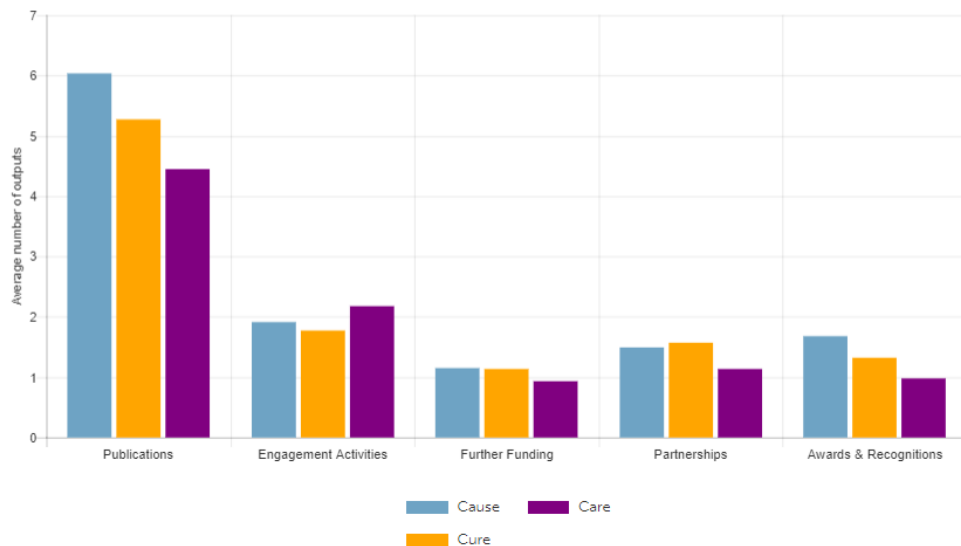
A diagnostic tool that screens 176 genes at once has improved the accuracy and speed of diagnosis in patients with retinal dystrophy.

Case study: Stroke Association

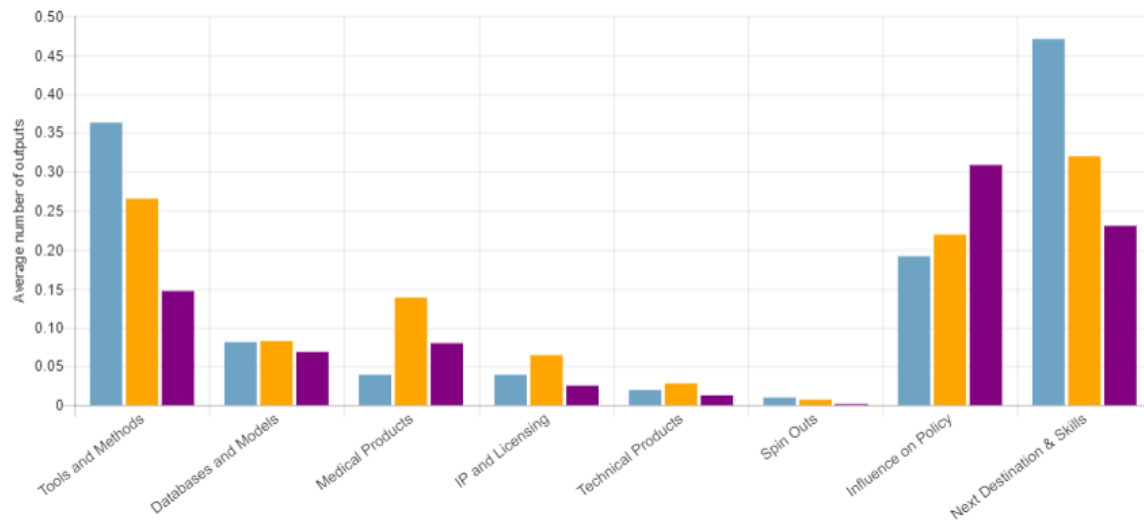
Intervention delivered in an online virtual island designed to help people with aphasia practice everyday speech has been shown to improve functional communication

AMRC Impact Report – Research Activity

Average Number Of Outputs By Research Activity



Average Number Of Outputs By Research Activity



Type of research activity	Total Number of Awards
Cause	3,118
Underpinning	725
Aetiology	2,393
Cure	2,598
Detection and Diagnosis	835
Treatment Development	1,063
Treatment Evaluation	700
Care	646
Prevention	148
Disease Management	379
Health Services	119
Grand Total	6,362

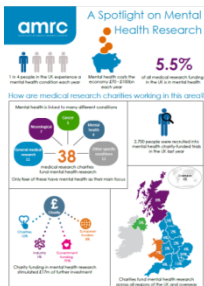
Engagement with AMRC reports



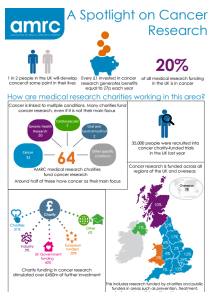
- The impact report had great engagement on twitter
 - #charityimpact reached over 1 million people



- 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:



The image shows the cover of a research evaluation report. In the top left corner is the British Heart Foundation logo, which consists of a red heart with a white pulse line and the text 'British Heart Foundation' below it. To the right of the logo, the word 'RESEARCH' is written in large, bold, red capital letters. Below this, the text 'Research evaluation report' is centered, followed by 'Outputs, outcomes and impact of BHF-funded research: 2014-15' in a smaller font. At the bottom center, the number '1' is displayed.

Short presentations:



The image is a screenshot of a Researchfish infographic. At the top, it says 'We know that CRUK researchers have published over' followed by a large blue '7000' and a circular icon containing a document with '27%' written on it. Below this, the word 'publications' is written in a smaller font. The infographic is presented in a video player interface with navigation arrows and a 'Hidden' button. Below the player, there are 'Share', 'Embed', and 'Like' buttons. The title 'Researchfish Infographic for Researchers' is displayed, along with 'No description' and 'by Cancer Research UK on 26 June 2015'. A 'Tweet' button is also visible. A 'Popular presentations' section is partially visible at the bottom right.

Infographics



The infographic for Marie Curie features a yellow flower icon. Below it, the text 'Marie Curie' is written in blue, followed by 'Care and support through terminal illness' in a smaller blue font. To the right, six metrics are listed, each with an icon and a value:

- 68**: Papers in peer-reviewed journals – 48 (71%) were open access (Icon: stack of books)
- 95**: Instances of informing policy and practice (Icon: megaphone)
- 15**: Countries around the globe where our researchers are involved in collaborations (Icon: globe)
- 4,432**: People recruited to our studies (Icon: group of people)
- £700k+**: Additional funding from external sources to support research in palliative and end of life care (Icon: coin)

At the bottom, the text '...together helping to influence policy and practice.' is written in blue.

How do charities use Researchfish Data?

Fundraising Leaflets

Ataxia UK Research - Our Success Stories

Innovation

Our recent research has led to **19 new research tools** and materials such as animal and cellular models of ataxia

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 SCA3 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 (4974832)

ATAXIA
Ataxia UK

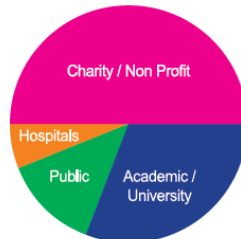


Investment

Every £1 spent on research by Ataxia UK **produces £2** of investment towards ataxia research



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.



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

ATAXIA
Ataxia UK

At Ataxia UK, we fund studies ourselves but also instigate collaborations between other organisations, and help ataxia researchers to find funding wherever possible.

Publications

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

Distribution

The 2015 International Ataxia Research Conference which we co-organised was the **biggest gathering of ataxia researchers** anywhere in the world to date!

This leaflet is supported by the following Pharmaceutical Company which has contributed with financial or non-financial support:

Takeda Development Centre Europe Ltd

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

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?

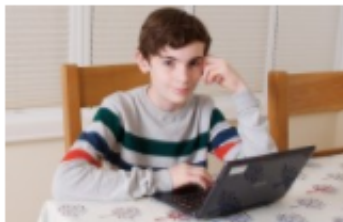
Identification of case studies



Successes

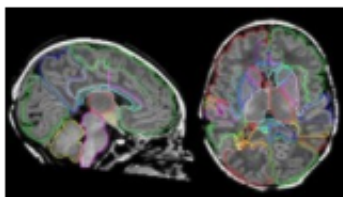
With the help of all our supporters we have played a significant role in many medical breakthroughs for 65 years, starting with the development of the first UK polio vaccine. Here are some highlights.

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

Find Out More

AMRC's impact guidance – includes links to the impact report and animation:
<https://www.amrc.org.uk/Pages/Category/impact>

AMRC contacts:

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