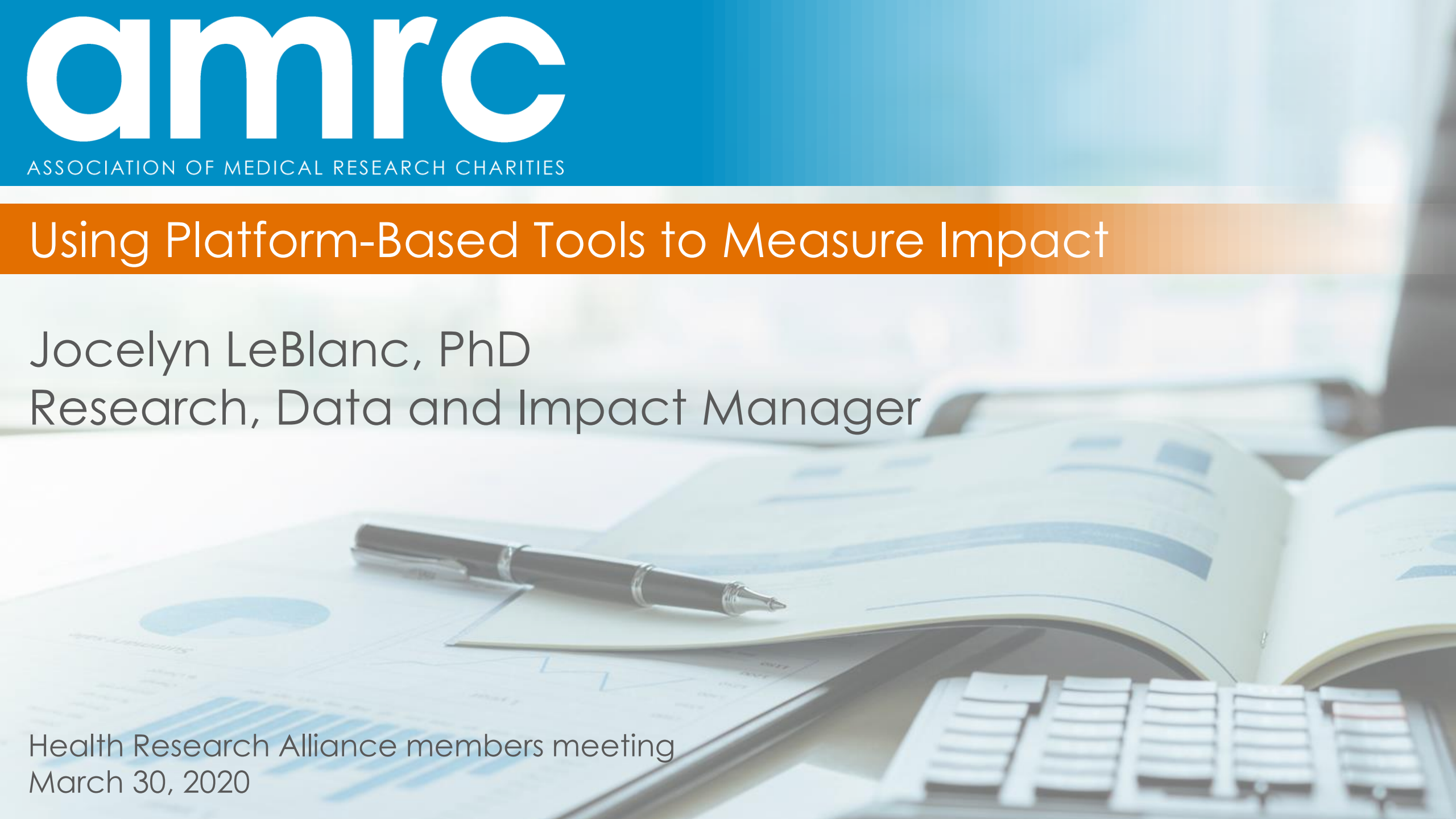
amrc

ASSOCIATION OF MEDICAL RESEARCH CHARITIES

# Using Platform-Based Tools to Measure Impact

Jocelyn LeBlanc, PhD
Research, Data and Impact Manager



Health Research Alliance members meeting
March 30, 2020

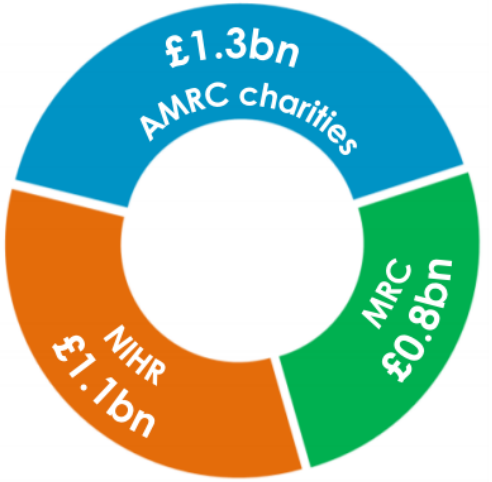
# Presentation outline

- Who is AMRC and its members?
- Why does demonstrating impact matter and what are the challenges?
- Researchfish – what is it, who uses it, and what does it track?
- Examples of how charities use Researchfish data
- AMRC's impact work

# Who is AMRC?

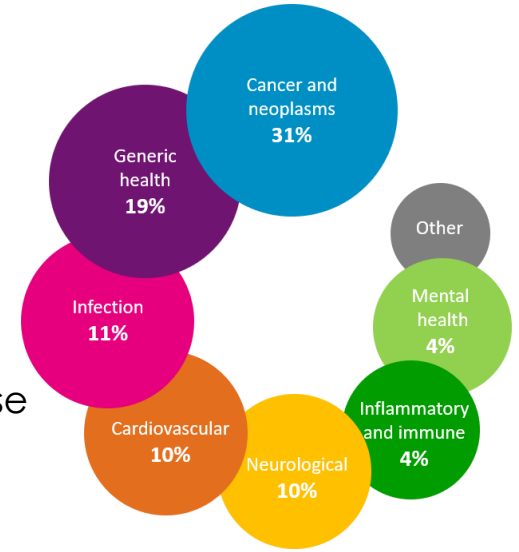
**Over 30 years ago** a small diverse group of medical research charities formed the Association of Medical Research Charities to unite the sector and provide it with a leading voice.

# Who are AMRC members?




AMRC charities funded 41% of publicly funded medical research nationally in 2018

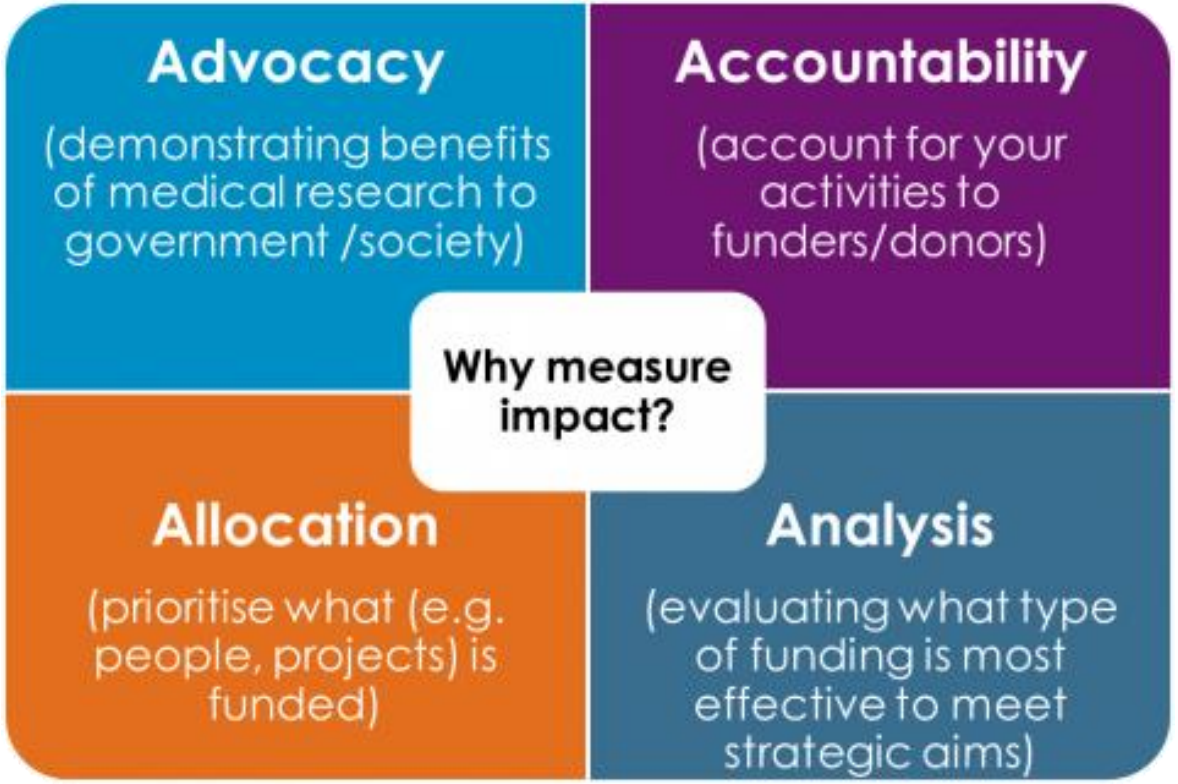
AMRC members fund essential research in all areas of health and disease




212,000 people in the UK were recruited into clinical studies or trials funded by AMRC charities in 2018

MRC: Medical Research Council
NIHR: National Institute of Health Research

# Why does demonstrating impact matter?





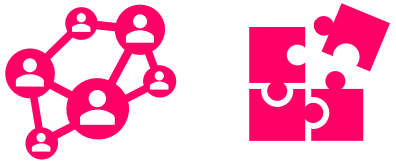
Morgan Jones, M., Grant, J. Making the Grade: Methodologies for assessing and evidencing research impact

# Why is demonstrating impact challenging?

Impact takes time

It involves asking busy people

You need to be proactive



…and many players

…who move on

…and communicate to different stakeholders

# Using Researchfish to track impact

researchfish by interfolio

An online platform for funders to collect research outcomes from award holders regularly, over time and using a shared, standardized question set

- 2008: Platform called e-Val for the Medical Research Council
- 2012: Separate company based in Cambridge, UK - 18 orgs using it
- 2014: Became multidisciplinary - all 7 research councils using it
- 2019: Acquired by Interfolio
    - American company providing software to help universities streamline academic hiring, review, promotion, and scholarly activity tracking

AMRC collaborating with Researchfish (with funding from MRC) for 6+ years – influence platform's development, enable smaller charities to use it,and create sector reports

# Who uses Researchfish to track impact?


**160+** funders

**100,000+** researchers

**160,000+** awards

**3.5 million+** outputs

**150+** countries logged in from

¼ researchers based outside of UK

https://researchfish.com/the-members/

# How does Researchfish work?

researchfish
by interfolio

- Funder/charity/research organization puts award details into the system
- Researchers receive invitations to the platform from Researchfish
- Researchers enter the information, automated as much as possible
  - Researcher enters info
  - Directly harvested using grant attributions
  - Select from suggestions (via APIs)
- Funder/charity/research organization downloads data and runs reports
- Data can be explored to gain insights, discover, predict and advise

# What does Researchfish track?

Common Outcome Types ***with*** sub-types

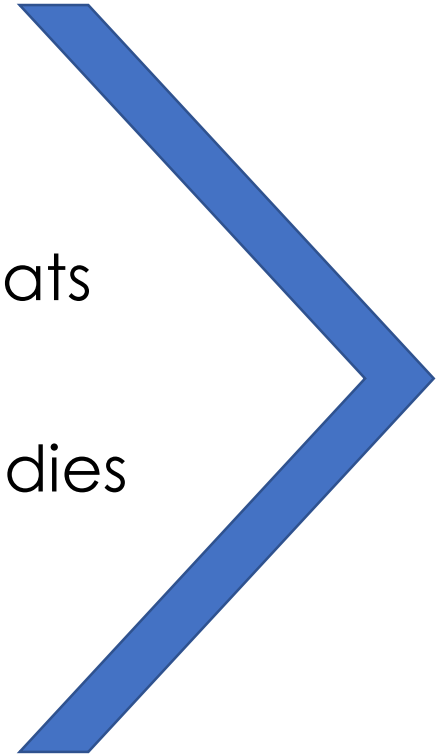
| **Publications** | **Further Funding** | **Engagement Activities** | **Influence on Policy, Practice, Patients & the Public** | **Research Tools & Methods** | **Research Databases & Models** | **IP & Licensing** | **Medical Products, Interventions and Clinical Trials** | **Artistic & Creative Products** | **Software & Technical Products** | **Awards and Recognition** |
|---|---|---|---|---|---|---|---|---|---|---|
| Book | Research grant (including intramural programme) | A formal working group, expert panel or dialogue | Implementation circular/rapid advice/letter to e.g. Ministry of Health | Biological samples | Database/Collection of data | Currently Copyright (e.g. software) | *Diagnostic Tool* - Imaging | Artefact (including digital) | Webtool/Application | Research prize |
| Book Chapter | Fellowship | A talk or presentation or debate | Influenced training of practitioners or researchers | Cell line | Data analysis technique | Patent application published | *Diagnostic Tool* - Non-Imaging | Image | Software | Medal |
| Book (Edited) | Studentship | A magazine or newsletter (print or online) | Citation in clinical guidelines | Technology assay or reagent | Computer model/algorithm | Patent granted | *Therapeutic Intervention* - Drug | Artwork | e-Business Platform | Awarded honorary membership, or a fellowship, of a learned society |
| Conference Proceeding / Conference Paper | Capital/infrastructure (including equipment) | Event, workshop or similar | Citation in clinical reviews | Model of mechanisms or symptoms - *human* | Data handling & control | Protection not required | *Therapeutic Intervention* - Vaccines | Composition/Score | Grid Application | Appointed as the editor/advisor to a journal or book series |
| Consultancy Report | Travel/small personal | Participation in an open day or visit at my research institution/facility | Citation in other policy documents | Model of mechanisms or symptoms - *mammalian in vivo* | | Trademark | *Therapeutic Intervention* - Cellular and gene therapy | Creative Writing | Physical Model/Kit | Poster/abstract prize |
| Journal Article / Review | | Media interview, press release, press conference or other response to a media enquiry | Citation in systematic reviews | Model of mechanisms or symptoms - *non-mammalian in vivo* | | | *Therapeutic Intervention* - Medical Device | Film/Video/Animation | New Material/Compound | Attracted visiting staff or user to your research group |
| Manual / Guide | | Engagement focused website, blog or social media channel | Membership of a guidance committee | Model of mechanisms or symptoms - *in vitro* | | | *Therapeutic Intervention* - Surgery | Artistic/Creative Exhibition | New/Improved Technique/Technology | NIHR Senior Investigator/Clinical Excellence Award |
| Monograph | | A broadcast e.g. TV/radio/film/podcast (other than news/press) | Participation in a national consultation | Physiological assessment or outcome measure | | | *Therapeutic Intervention* - Radiotherapy | Performance (Music, Dance, Drama, etc) | Systems, Materials & Instrumental Engineering | National honour e.g. Order of Chivalry, OBE |
| Policy Briefing Report | | | Participation in advisory committee | Improvements to research infrastructure | | | *Therapeutic Intervention* - Psychological/Behavioural | | Detection Devices | Prestigious/honorary/ advisory position to an external body |
| Scholarly Edition | | | Gave evidence to a government review | Antibody | | | *Therapeutic Intervention* - Physical | | | Personal invitation as keynote or other named speaker to a conference |
| Systematic Review | | | | | | | *Therapeutic Intervention* - | | | Honorary Degree |

# Researchers have submitted data, what next?


- Artistic & Creative Products
- Awards & Recognition
- Collaborations & Partnerships
- Engagement Activities -
- Further Funding - with self funders
- Further Funding
- GeoMap with RF country names
- HRCS
- Influence on Policy
- Intellectual Property & Licensing
- Matching SF ID to funding orgs in other tables
- Medical Products, Interventions and Clinical Trials
- Next Destination
- Other Outputs & Knowledge - Future Steps
- Publications
- Research Databases & Models
- Research Tools & Methods
- RHT
- Software & Technical Products
- Spin Outs
- Stratification
- Use of Facilities & Resources

# How do funders use Researchfish data?

- Calculate key stats
- Identify case studies



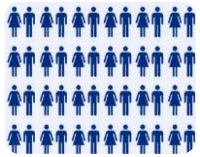
- Impact reports
- Infographics
- Website material
- Social media material
- Fundraising material
- Blogs
- Magazine articles
- Researcher newsletters
- Reports to their board
- Response to calls for evidence
- Portfolio analysis and strategic evaluation

# Ataxia UK

- Benefits of Researchfish to Ataxia UK
  - data is categorised and uniform
  - data is submitted during a submission period all at the same time, so it is easy to know what to include in an annual impact report
  - researchers have their Personal Portfolio on Researchfish, which could prompt them to include outcomes they might otherwise forget

- Also ask for project updates - free-text answers allow for more detail and opportunity to elaborate

- What data does Ataxia use the most?



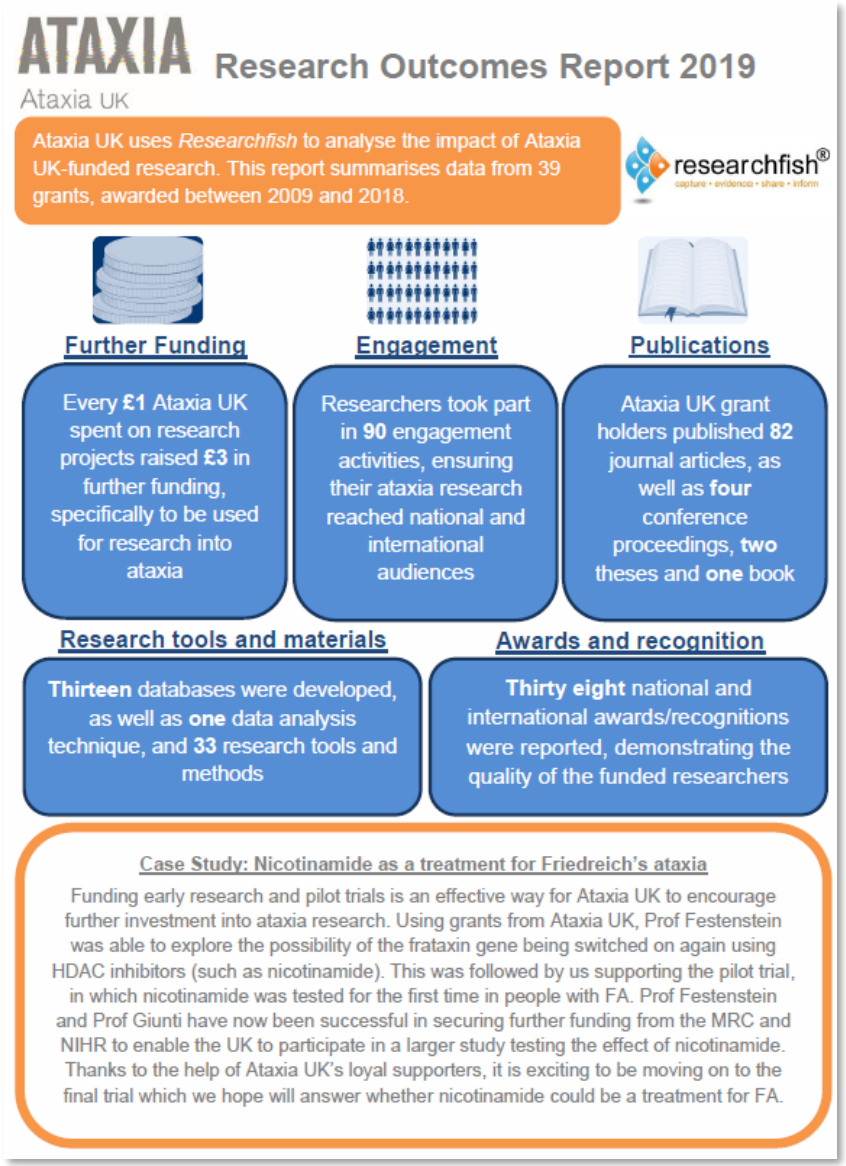
Engagement

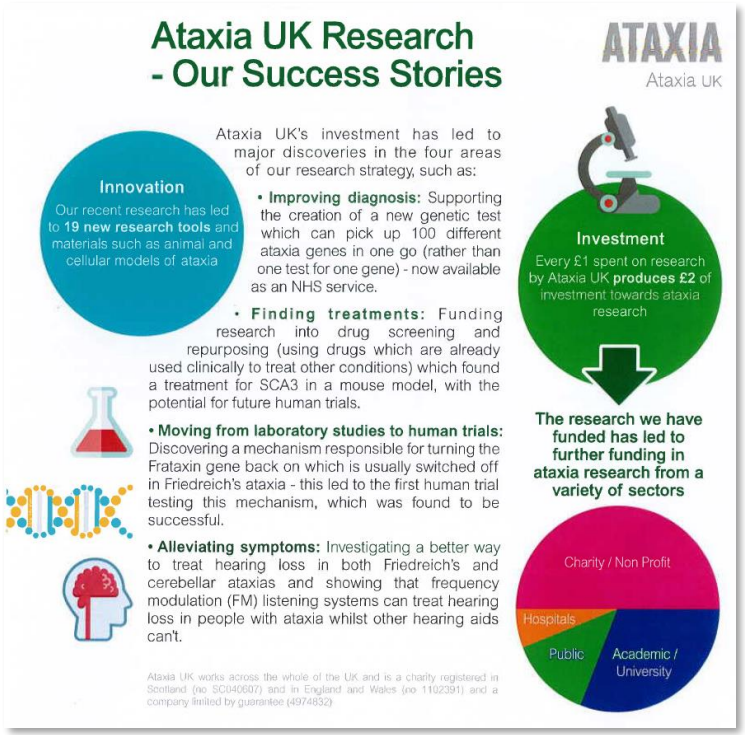
Research tools and materials

Further funding

Publications

# Ataxia UK





## Ataxia research

### Research Impact Report 2019

Earlier this year we asked Ataxia UK-funded researchers to tell us about the outcomes of their research. The research we fund produces a range of exciting outcomes, from developing new tools, to raising further funding for ataxia research. Read a summary of the ways in which Ataxia UK-funded research is having an impact in our Research Impact Report 2019.

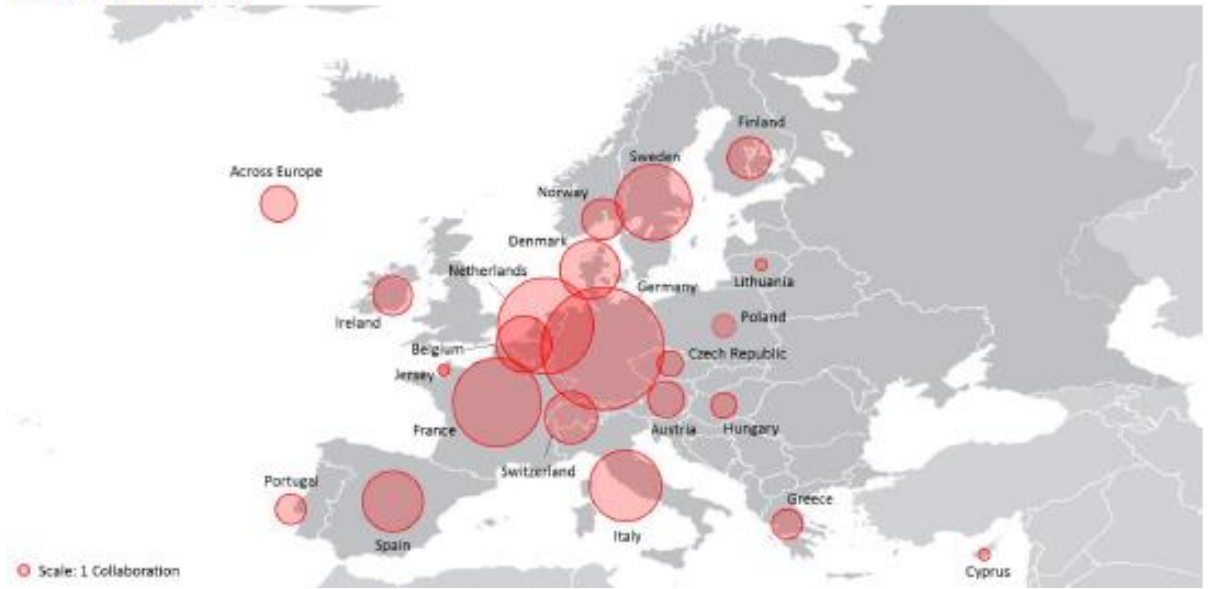
researchfish®
profoundly changing global research assessment

# British Heart Foundation

- **1600 scientific papers published in 2017**
- **16 patents reported, 1 new spin out company formed in 2018**
- **Two thirds of BHF researchers reported international collaborations across 50 countries**
- **6 major BHF-funded clinical trials reported results in the Lancet or New England Journal of Medicine**
- **£108.4 million for 230 new research awards from 591 full applications**
- **BHF funding contribution to partnership with others** *(Academy of Medical Sciences, European Research Area Network in Cardiovascular Disease, Alan Turing Institute, Health Data Research UK, UK Prevention Research Partnership)* **was £7.3 million for grants worth in total over £95 million**
- **Follow-on funding reported from BHF awards since 2012/13** *(awards worth £465m)* **is £760m of which £45m is from the private sector**

*Collaborations by country*

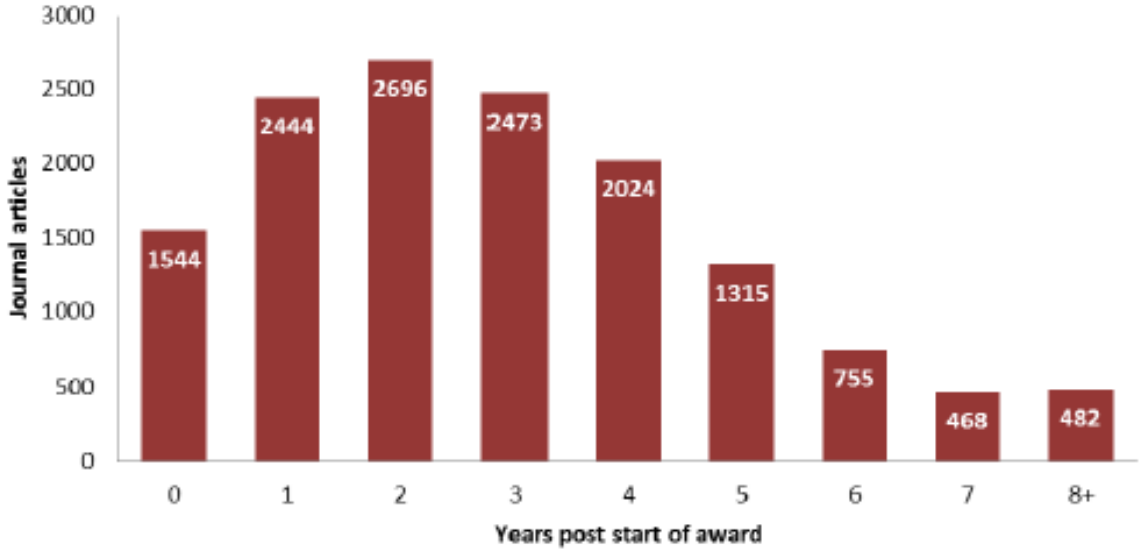

*European breakdown*



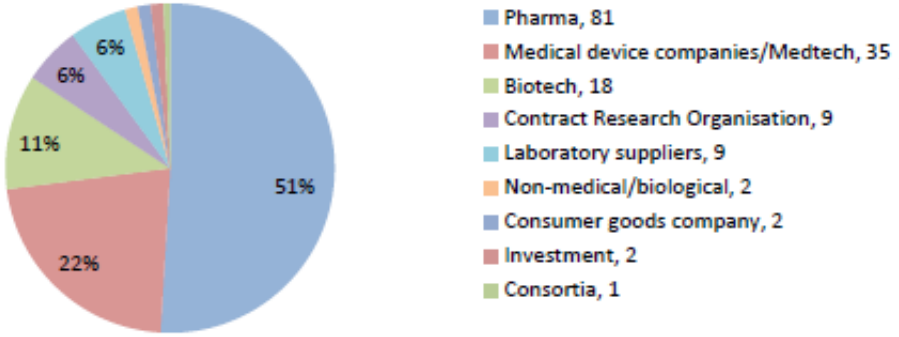

www.bhf.org.uk/-/media/research-funds/research-evaluation-report-2018.pdf?la=en

# British Heart Foundation

*Journal articles reported in Researchfish published according to years post award*




*Collaborations by private sector type*




| Institution | Number of patents |
|---|---|
| University of Cambridge | 6 |
| University of Edinburgh | 3 |
| Imperial College London | 3 |
| University of Oxford | 2 |
| University of Leicester | 1 |
| King's College London | 1 |

*Top 10 funders by value of follow-on funding*

| Organisation | Amount of further funding (£m) | Percentage of total further funding (%) | Amount of further funding (£m) reported in 2017 |
|---|---|---|---|
| British Heart Foundation | 214 | 28 | 193 |
| National Institute for Health Research | 109 | 14 | 88 |
| European Commission | 96 | 13 | 99 |
| Medical Research Council | 73 | 10 | 52 |
| The Wellcome Trust | 50 | 7 | 54 |
| Engineering and Physical Sciences Research Council | 35 | 5 | 31 |
| National Institutes of Health (NIH) | 17 | 2 | 10 |
| Medicxi Ventures | 14 | 2 | 0.6 |
| Biotechnology and Biological Sciences Research Council | 10 | 1 | 11 |
| The Leducq Foundation | 10 | 1 | 11 |

**Lunac Therapeutics – development of an anti-clotting agent without the risk of bleeding**

Dr Helen Philippou
University of Leeds

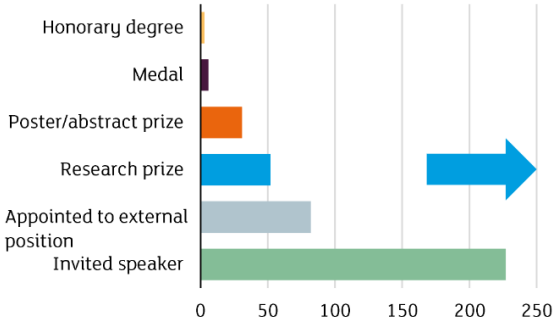
Prof Philippou received a Special Project Grant from BHF to develop a new first in class small molecule anticoagulant without the risk of bleeding. Patients with atrial fibrillation are at increased risk of stroke and are prescribed anticoagulants to reduce the likelihood of clot formation however current anticoagulants have a serious side-effect, an increased risk of bleeding. The grant allowed Prof Philippou and her team (including Dr Richard Foster) to investigate the mode of action of their novel compounds and identify a lead series of small molecules that achieve anticoagulant efficacy without increased risk of bleeding. This work, along with work funded by the Wellcome Trust and MRC has progressed the project significantly, identifying a lead series of potent and selective compounds. University of Leeds formed a spin-out company, Lunac Therapeutics, in April 2018. The company is currently engaging with investors to raise significant investment to continue the development of the drug so that it can be tested in clinical trials.
BHF Grant References: SP/14/1/30717

www.bhf.org.uk/-/media/research-funds/research-evaluation-report-2018.pdf?la=en

# Alzheimer's Research UK

## Recognising the success of our funded researchers

In 2018, ARUK-funded researchers were recognised for their achievements **88 times** through invitations to give key note talks and being awarded research prizes and medals. This means that there are now **400 awards and cases of recognition** attributed to the awards included in this year's submission period.

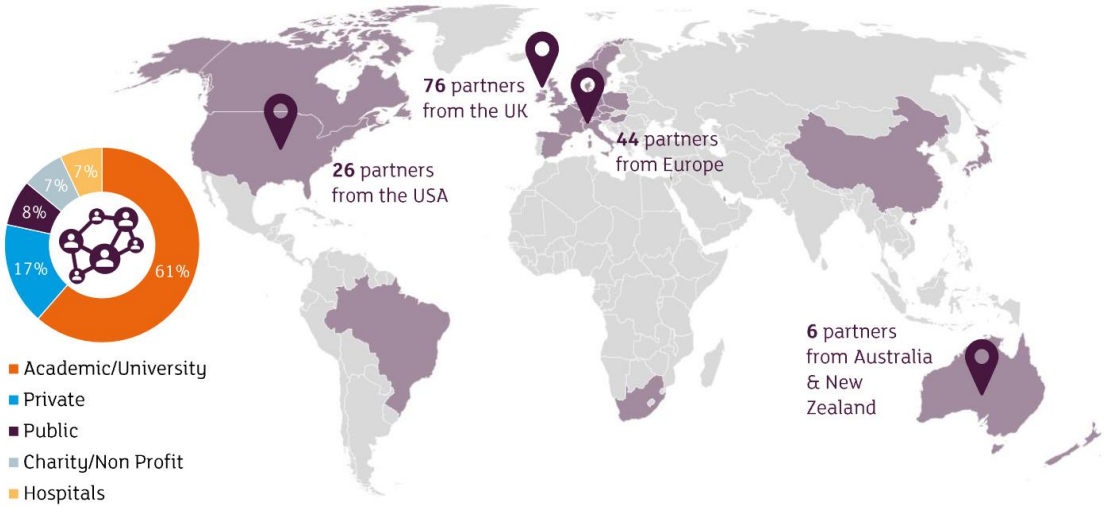



**Case study: The Cavanagh Prize 2019** awarded to Katie Lunnon by the British Neuropathological Society. Here, Prof Katie Lunnon, Professor of Epigenetics at the University of Exeter, was awarded the prize for her research into the role of epigenetic mechanisms in dementia.

Read more about Prof Lunnon's work here: https://www.exeter.ac.uk/news/featurednews/title_708028_en.html

## Fostering new collaborations

In 2018, our submitting researcher's established **44 new collaborations** – taking our total to **287 partnerships** with **171 partners** across all sectors and from countries all around the world.



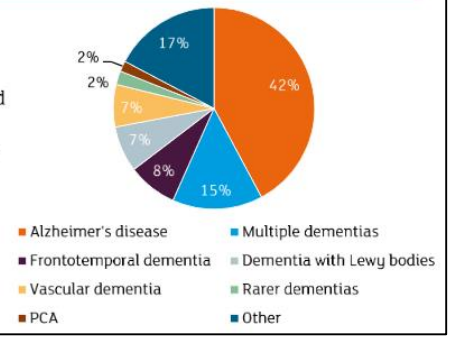


Researchfish® is an essential platform for Alzheimer's Research UK to accurately measure and report the impact of our funding on the dementia research landscape. During our last submission period (Feb-Mar 2019), we received updates on **271** Alzheimer's Research UK-funded awards. Here are some of the key outputs they have reported.

## Generating new knowledge

Alzheimer's Research UK-funded awards included in the last submission period had a total of **1,255** publications attributed to them, with **76%** of awards leading to at least one new publication. Articles were published in **362** different journals, with articles in ***Neurobiology of Ageing***, the ***Journal of Alzheimer's Disease*** and ***Brain*** being the most common.

Together these publications represent a multitude of new discoveries made by ARUK-funded researchers investigating the many diseases that cause dementia.




## New methods and tools to fuel dementia research

A total of **71 awards** included in this year's submission period have a research tool or method attributed to them – resulting in over **100 new resources**. Many of these have already been shared and used by the wider dementia research community and include:

**36** new assays

**26** new models

**8** new cell lines

**5** new antibodies

**Case study: A new method for microdissection of post-mortem brain tissue** developed by Prof Julie Simpson and Prof Stephen Wharton, University of Sheffield. This approach uses a combination of immunohistochemistry and laser capture microdissection to isolate individual cell types from complex heterogeneous populations.

# Pooling AMRC member data


# Creating a medical research impact framework

## 5 Impact areas

### Generating new knowledge

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

### 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

### Stimulating further research via funding and partnerships

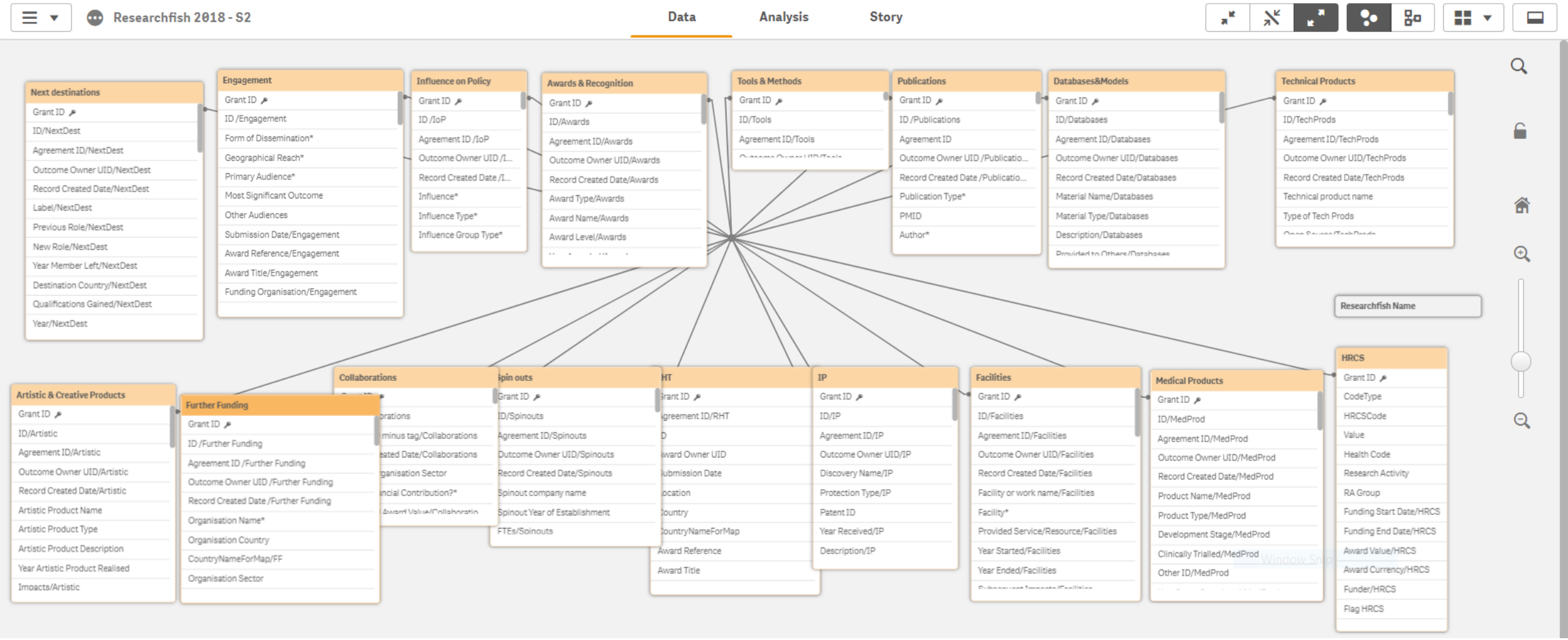
- Further funding
- Collaborations and partners

### Developing the human capacity to do research

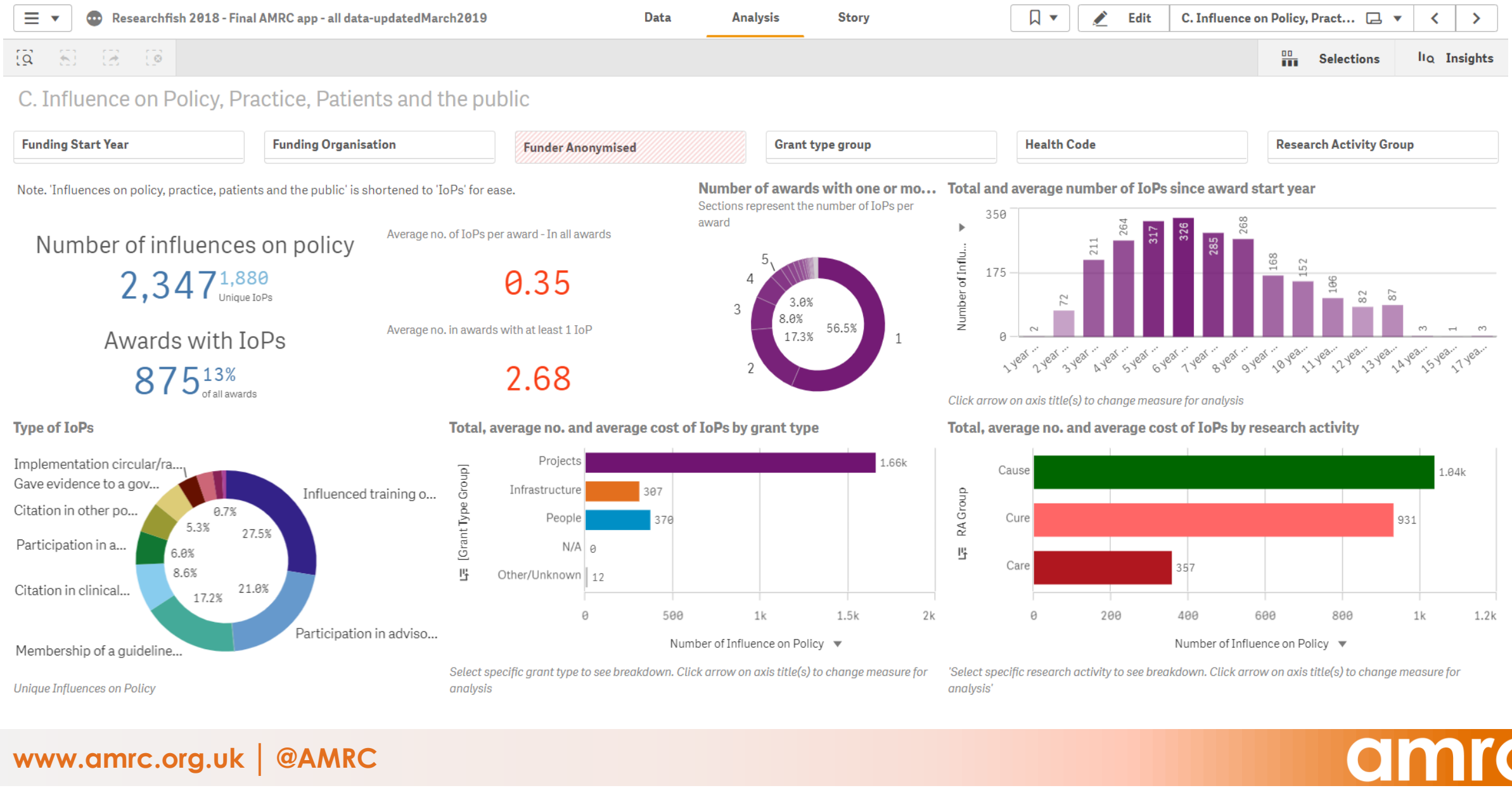
- Next destination and skills
- Awards and recognitions
- Use of facilities and resources

- Impact report 2017
- Animation

# Data analysis using Qlik



# Data analysis using Qlik



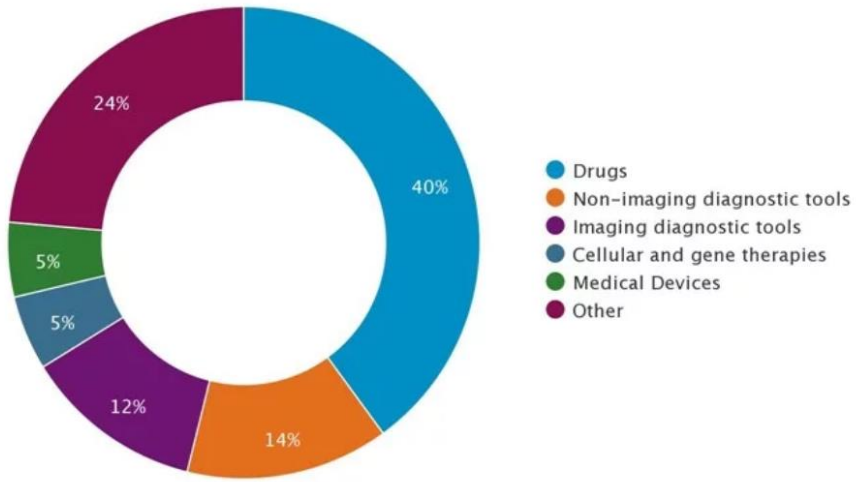
# AMRC impact report: medical products & interventions

## Medical products and interventions

Translating research can lead to the creation of medical products and interventions which can be tested in clinical trials.

**6%** of awards generated **568** unique developed and tested medical products and interventions.

The majority were drugs, followed by non-imaging and imaging diagnostic tools.




**The "Head Up collar" is a neck support system that improves quality of life for people with motor neurone disease**

Motor neurone disease (MND), also called ALS, is a life-shortening illness where the death of nerve cells that control movement leads to muscle weakening and wasting. There is no cure for MND but some symptoms can be managed in order to lessen the impact on day to day life. One consequence of the disease can be loss of neck muscle strength, making it difficult or impossible for some people with MND to hold their heads up straight. People living with MND reported that existing products were uncomfortable, unattractive and restrictive. They identified better head and neck support as a priority to improve their quality of life.

With funding from the MND Association, the NIHR Invention for Innovation (i4i) programme and Sheffield Hallam University, a revolutionary new support collar was designed and created with input from people affected by MND. The entire process, from initial conception to distribution, took about 7 years in total. The product was designed with input from people with MND and was tested in a clinical trial where 100 participants across 10 sites in the UK and Ireland tried out the collars. When the trial concluded, 80% of participants felt the collar helped them and wanted to carry on using it. This patented product is available through

https://www.amrc.org.uk/making-a-difference-impact-report-2019

# AMRC impact report: partnerships

## Partnerships

Research is a collaborative endeavour and the ability of researchers to forge partnerships with other researchers, companies and patient organisations allows research ideas to develop and be translated into new treatments, products or areas of understanding that will ultimately help patients.

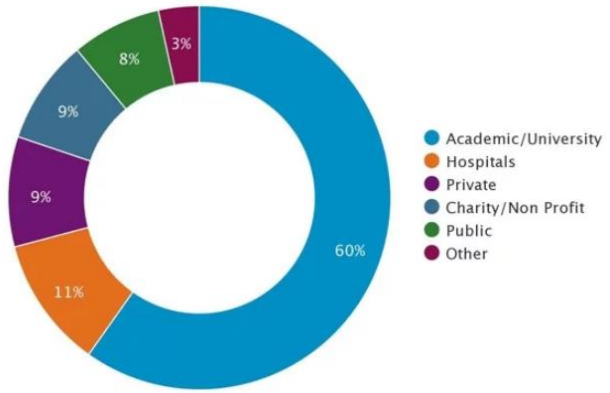
**46%** of awards generated **13,096** partnerships, **7,581** of these were unique

Of these partnerships:

- Most (43%) were linked to a single partner
- Almost a quarter (22%) were linked to two partners

Countries where partners were based:

- Charity-funded researchers had collaborations and partnerships with groups in 87 countries across the world
- Most (61%) of the partnerships were with UK-based organisations
- There were also substantial numbers of partnerships across Europe (21%) and with the United States (13%).
- The top 3 partnering countries in Europe were Germany, The Netherlands and France.




## Case study: Partnering for better stroke care

**A collaboration between academia and industry resulted in the development of a blood test for paramedics to determine who is experiencing a stroke and transfer the patient to the nearest specialist unit.**

Stroke is a leading cause of death worldwide and contributes to a large burden on health and social care. The length and extent of recovery relies heavily on the accuracy of initial diagnosis and a fast emergency response, but there are many other conditions which create identical symptoms such as migraine and seizures. Paramedics are often the first to see patients in the crucial period following a stroke, but it can be challenging to identify actual stroke and to choose the best immediate course of action.

Dr. Christopher Price, a clinical researcher at Newcastle University who the Stroke Association has been supporting through fellowships since 2013, partnered with the UK-based company Sarissa Biomedical in 2016 to show the accuracy of a finger prick blood test in helping paramedics diagnose stroke at the scene or en route to the hospital. This test measures levels of a substance in the blood that rises after oxygen deprivation, which occurs in the brain during stroke, but stays low in other conditions producing the same symptoms. The collaborative team behind the development of this test won a Small Business Research Initiative award from Innovate UK.

This blood test is now being trialled in a multisite study with three ambulance services and four specialist stroke units. The blood test when used in conjunction with the well-established FAST test (facial drooping, arm weakness, speech difficulties) should improve the ability of paramedics to quickly and correctly distinguish between stroke and other conditions within 5 minutes. This will enable a decision about which is the most appropriate hospital destination and use limited NHS resources more efficiently by avoiding sending people along the stroke treatment pathway who need other types of care. For stroke patients, it may lead to greater confidence in the initial diagnosis and faster administration of treatments which can greatly minimise the disability caused.

https://www.amrc.org.uk/making-a-difference-impact-report-2019

# Highlights version of the report

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

## Making a difference

Impact of charity-funded medical research

researchfish®

This report presents outcomes from grants reported by researchers online using a standardised question set

**44**
AMRC charities participated in this project

**6,700**
grants with start dates between 2005 and 2018 were analysed

**£2.1bn**
is the collective value of the 6,700 grants

So far these 6,700 medical research grants have led to...

### medical products
at least 550 new medical products including drugs, diagnostic tools and other interventions

### new knowledge
more than 43,000 scientific publications

### policy & practice influences
over 1,500 influences on policy, practice and training of healthcare professionals

### partnerships
more than 7,500 collaborations sparked throughout the UK and in 87 countries worldwide

### further investment
more than £2.7bn of funding leveraged from government, industry and charities

### enhanced skills & capacity
90% of people tracking their career progression reported securing subsequent positions in research

### awareness & engagement
over 8,500 examples of engagement with patients or the public

### economic growth
61 spin out companies that generate more jobs in the life sciences sector

Most of these grants will continue to be tracked in Researchfish so the full extent of the impact is yet to be revealed.

Thank you to Researchfish, the Medical Research Council and the 44 AMRC charities who participated.
Full digital report: https://www.amrc.org.uk/making-a-difference-impact-report-2019

Charity-funded research makes a real difference - from improving prevention and early diagnosis to developing new interventions and treatments - it leads to better care and quality of life.

**New prescription guidelines prevent foetal exposure to sodium valproate**

Epilepsy Research UK supported a researcher at key points in her career, helping her to become an expert on the negative effect of some antiepileptic drugs on foetal brain development. She and others presented evidence to the EMA that led to new MHRA guidance restricting the prescription of sodium valproate to women of child-bearing age.

**Online tool assesses heart age and suggests preventative lifestyle improvements**

The British Heart Foundation and partners designed a test on the NHS website to assess heart health through a set of questions. The tool prompts people to make simple changes to improve their health. The test has been completed more than 1.9 million times and 4 out of 5 people have a heart age older than they are.

**Blood test enables quick identification of people having strokes by paramedics**

A clinical researcher supported by the Stroke Association partnered with a biotech company to optimise a blood test that helps distinguish strokes from other conditions with similar symptoms. The test is being trialed with ambulance services and specialist stroke units and should enable quicker decisions about treatment and minimise disability.

**Researchers raise awareness and facilitate early diagnosis of rare forms of dementia**

A UCL research team, supported by Alzheimer's Research UK, engaged with the public and health practitioners to spread awareness of a rare form of dementia that affects vision. Researchers launched a free online course, directed a transdisciplinary centre and collaborated with optometrists to facilitate early diagnosis.

**Magnetic drug delivery allows treatments to reach inner ear**

Initial investment from Action on Hearing Loss enabled the US-based company Otomagnetics to receive $2.3 million in further funding from the NIH to develop more efficient ways to deliver treatments to the hard-to-reach inner ear.

**Biomarker test helps personalise treatment of childhood arthritis**

Long-term projects supported by Sparks and Great Ormond Street Hospital Charity led to the development and introduction of a biomarker test into clinical practice to predict how children with juvenile idiopathic arthritis will respond to drugs.

**Research evidence led the APPG on Pancreatic Cancer to recommend fast track surgery**

Pancreatic Cancer UK funded a pilot programme to fast track patients into surgery after a pancreatic cancer diagnosis. The positive outcomes were presented to the APPG on Pancreatic Cancer and this led to the publication of new NICE guidelines and the 'demand faster treatment' campaign.

**Warm perfusion of donated kidneys before transplantation maximises success**

Kidney Research UK funded a professor to develop a novel technique that revives and repairs donor kidneys before transplantion. The professor and his team were recognized by the House of Commons and received awards from national societies for their positive impact on patients.

**An innovative neck collar improves quality of life for people with motor neurone disease**

Funding from the MND association contributed to the development of a new support collar that was designed with input from people with MND. The patented device provides comfortable neck support for people with reduced neck muscle strength so that they can hold their heads up.

**A tool to facilitate person-centred care is introduced into clinical practice**

A tool called SNAP was developed to help people with progressive incurable conditions identify and communicate their needs to healthcare professionals. Marie Curie funding is enabling this tool to be validated and used in primary, community and secondary care settings.

Read more: https://www.amrc.org.uk/case-studies

[Link to 2-page report]

# Challenges for charities

- Engaging with researchers
- Staff resource and budget
- “Dirty data”
- Data overload
- Oversimplification/overinterpretation of stats
- Combining information from different sources
- Tailoring communication to different audiences and stakeholders

ASSOCIATION OF MEDICAL RESEARCH CHARITIES

# Thank you!

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Useful links:

- Impact resources
- Sample impact reports
- AMRC infographics and reports
- AMRC impact report 2017
- AMRC impact report 2019
- Researchfish website