Using Platform-Based Tools to Measure Impact

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Health Research Alliance members meeting
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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.

We CONNECT members to each other and other stakeholders by running events and networks and encouraging collaboration.

We SUPPORT our members by producing guidance and highlighting examples of best practice.

We INFLUENCE by campaigning for a supportive funding environment and by demonstrating the impact of the sector.
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

www.amrc.org.uk | @AMRC
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

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?

1. Funder/charity/research organization puts award details into the system
2. Researchers receive invitations to the platform from Researchfish
3. Researchers enter the information, automated as much as possible
4. Funder/charity/research organization downloads data and runs reports
5. Data can be explored to gain insights, discover, predict and advise

- Researcher enters info
- Directly harvested using grant attributions
- Select from suggestions (via APIs)
# What does Researchfish track?

<table>
<thead>
<tr>
<th>Common Outcome Types with sub-types</th>
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<tbody>
<tr>
<td>Publications</td>
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<tr>
<td>Book</td>
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<tr>
<td>Book Chapter</td>
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<tr>
<td>Book (edited)</td>
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<td>Conference Proceeding / Conference Paper</td>
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<td>Consultancy Report</td>
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<td>Journal Article / Review</td>
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<td>Manual / Guide</td>
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<td>Monograph</td>
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<td>Policy Briefing Report</td>
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<tr>
<td>Scholarly Edition</td>
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<tr>
<td>Systematic Review</td>
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</table>
Researchers have submitted data, what next?

I started the day with lots of problems.
But now, after hours and hours of work, I have lots of problems in a spreadsheet.

- 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
• Benefits of Researchfish to Ataxia UK
  o data is categorised and uniform
  o 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
  o 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?

  Engage
  ment

  Research tools and materials

  Further funding

  Publications
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 150 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 measuring (using drugs which are already used clinically to treat other conditions) which found a treatment for SOD1 in a mouse model, with the potential for future human trials.
- **Moving from laboratory studies to human trials:** Disclosing an immunohistochemical response for turning the Frataxin gene back on which is usually switched off in Friedreich’s ataxia - this led to the first human trial testing this mechanism, which was found to be successful.
- **Allaying symptoms:** Investigating a better way to treat hearing loss in both Friedreich’s and spinocerebellar ataxias and showing that frequency modulation (FM) listening systems can treat hearing loss in people with ataxia whilst other hearing aids can’t.

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

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.

Ataxia UK uses Researchfish to analyse the impact of Ataxia UK-funded research. This report summarises data from 39 grants, awarded between 2009 and 2018.
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

British Heart Foundation

Journal articles reported in Researchfish published according to years post award

![Bar chart showing the number of journal articles reported in Researchfish over years post award](chart.png)

Top 10 funders by value of follow-on funding

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Amount of further funding (£m)</th>
<th>Percentage of total further funding (%)</th>
<th>Amount of further funding (£m) reported in 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>British Heart Foundation</td>
<td>214</td>
<td>28</td>
<td>193</td>
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<tr>
<td>National Institute for Health Research</td>
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<td>14</td>
<td>88</td>
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<td>99</td>
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<td>The Wellcome Trust</td>
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<td>54</td>
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<tr>
<td>Engineering and Physical Sciences Research Council</td>
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<td>5</td>
<td>31</td>
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<tr>
<td>National Institutes of Health (NIH)</td>
<td>17</td>
<td>2</td>
<td>10</td>
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<tr>
<td>Medical Ventures</td>
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<td>2</td>
<td>0.6</td>
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<tr>
<td>Biotechnology and Biological Sciences Research Council</td>
<td>10</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>The Leukoc Foundation</td>
<td>10</td>
<td>1</td>
<td>11</td>
</tr>
</tbody>
</table>

Collaborations by private sector type

- Pharma, 81
- Medical device companies/Medtech, 35
- Biotech, 18
- Contract Research Organisation, 9
- Laboratory suppliers, 9
- Non-medical/biological, 2
- Consumer goods company, 2
- Investment, 2
- Consortia, 1

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

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

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

Recognising the success of our funded researchers

In 2018, ARUK funded researchers were recognised for their achievements **88 times** through invitations to give keynote 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 Lummon by the British Neuropathological Society. Here, Prof Katie Lummon, 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 Lummon’s work here: [https://www.exeter.ac.uk/news/featurednewsstory/708028_en.html](https://www.exeter.ac.uk/news/featurednewsstory/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.

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:

**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.**

- 36 new assays
- 26 new models
- 8 new cell lines
- 5 new antibodies
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

C. Influence on Policy, Practice, Patients and the public

Funding Start Year | Funding Organisation | Funder Anonymised | Grant type group | Health Code | Research Activity Group

Number of influences on policy

- 2,347 1,880 Unique IoPs
- Awards with IoPs: 875 (13% of all awards)
- Average no. of IoPs per award: 0.35
- Average no. in awards with at least 1 IoP: 2.68

Type of IoPs

- Implementation circular/ra...
- Gave evidence to a gov...
- Citation in other po...
- Participation in a...
- Participation in advisory...
- Membership of a guideline...

Influenced training o...

Total, average no. and average cost of IoPs by grant 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 IoPs by research activity

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

Note: ‘Influences on policy, practice, patients and the public’ is shortened to ‘IoPs’ for ease.
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, 90% of participants felt the collar helped them and wanted to carry on using it. This patented product is available through

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

Highlights version of the report

Making a difference
Impact of charity-funded medical research

AMRC charitable research
researchfish

44
6,700
£2.1bn

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

This project involved AMRC charities and 6,700 grants with start dates between 2005 and 2018. It 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
- Partnerships: More than 7,550 collaborations, spanning the UK and in 87 countries worldwide
- Enhanced skills and capacity: 50% of people tracking their progression reporting securing subsequent positions in research
- Awareness and engagement: More than 8,500 examples of engagement with patients or the public
- Economic growth: 64 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.

Charity-funded research makes a real difference - from improving prevention and early diagnosis to development of 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 other researchers presented evidence to the EMA that led to new MMR guidance restricting the prescription of sodium valproate to women of child-bearing age.

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 trialled with ambulance services and specialist stroke units and should enable quicker decisions about treatment and minimise disability.

Magnetic drug delivery allows treatments to reach inner ear
Initial investment from Action on Hearing Loss enabled a UK-based company (Otonomy) to receive £2.3 million in further funding from the NHS to develop more efficient ways to deliver treatments to the hard-to-reach inner ear.

Research evidence led the APRO 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 APRO on Pancreatic Cancer and this led to the publication of new NICE guidelines and the ‘demand-foster treatment’ campaign.

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.

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 treatment.

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 transplantation. The professor and his team were recognised by the House of Commons and received awards from national societies for their positive impact on patients.

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
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