

# amrc

ASSOCIATION OF MEDICAL RESEARCH CHARITIES

**Presentation to Health Research Alliance  
11<sup>th</sup> March 2024**

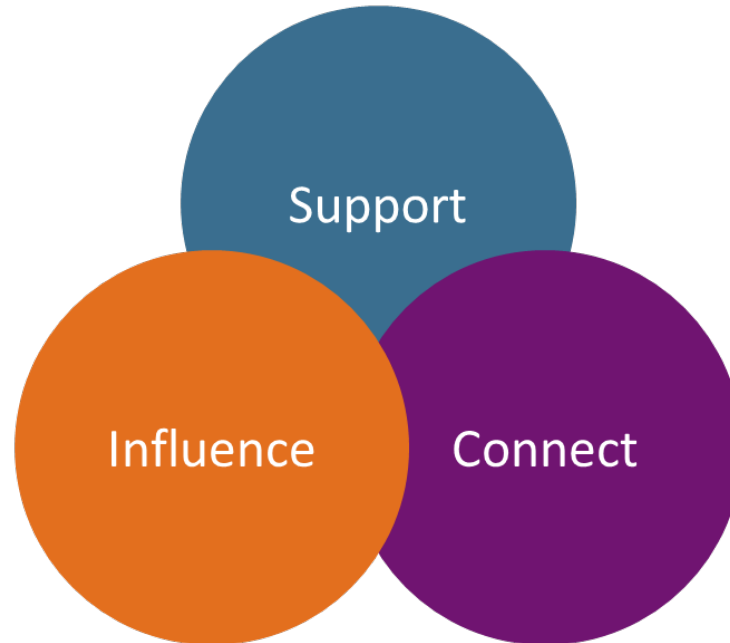
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# Who are AMRC?

## Who are we?

The Association of Medical Research Charities (AMRC) is a membership organisation dedicated to supporting medical research charities in saving and improving lives through research and innovation.



## Our mission

The AMRC brings together and supports health and medical charities to produce high-quality research. We do this by influencing policy and research, highlighting the sector's contribution to patient and public health.



# AMRC member charities cover a range of diseases and size







## Full member charities



## Introductory member charities



# What does it mean to be an AMRC member?

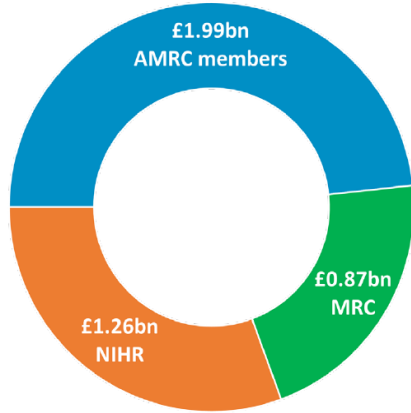
- 1**  
Be a registered charity who funds medical research in the UK  

- 2**  
Publish a research strategy  

- 3**  
Have a formal conflicts of interest policy  

- 4**  
Support AMRC's position on animal research  

- 5**  
Support AMRC's position on patient and public involvements  

- 6**  
Work in line with our principles of expert review  


We assess charities' compliance when they apply for membership and audit it every five years.

Members are also required to submit their research expenditure and grants data to AMRC every year.

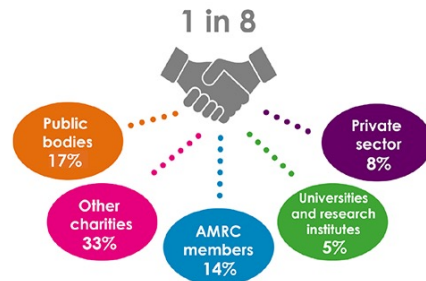
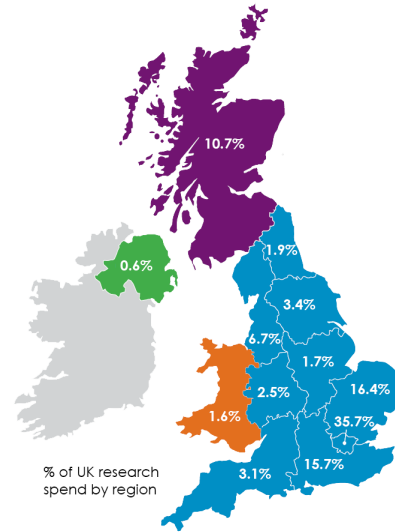


# What do our members do?



Together, AMRC members are a major public contributor to medical research in the UK

**£15.7bn** has been spent on research in the UK by AMRC members over the past 10 years



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

**85%**



of grants funded by AMRC members were awarded to universities

**14%**



of AMRC member research expenditure funded research overseas

**20%**



of grants awarded by AMRC members funded research into rare diseases

**63%**



of AMRC members co-fund research with other organisations

# Charities are vital partners in UK research because they...



## respond to patients' priorities

Patient priorities drive and shape charity research so that funding gets directed to where it will make the most difference to people's lives.



## tackle areas of unmet need

Charities invest in research that improves healthcare for people with unmet needs, such as those living with neglected conditions and rare diseases.



## accelerate health impact

Charities **bring people and organisations around the world together**, building partnerships and attracting investment for promising research to deliver benefits to patients sooner.

# In 2023 we held a festival of partnership to showcase the variety of partnerships charities are involved in



Prioritising research topics



Choosing what research to fund



Designing the research



Carrying out the research



Sharing the research



Monitoring the research



Influencing research decisions



Making involvement diverse

• <https://www.amrc.org.uk/2023-charities-in-action-partnering-for-research>

# Many of our charities partner to fund research



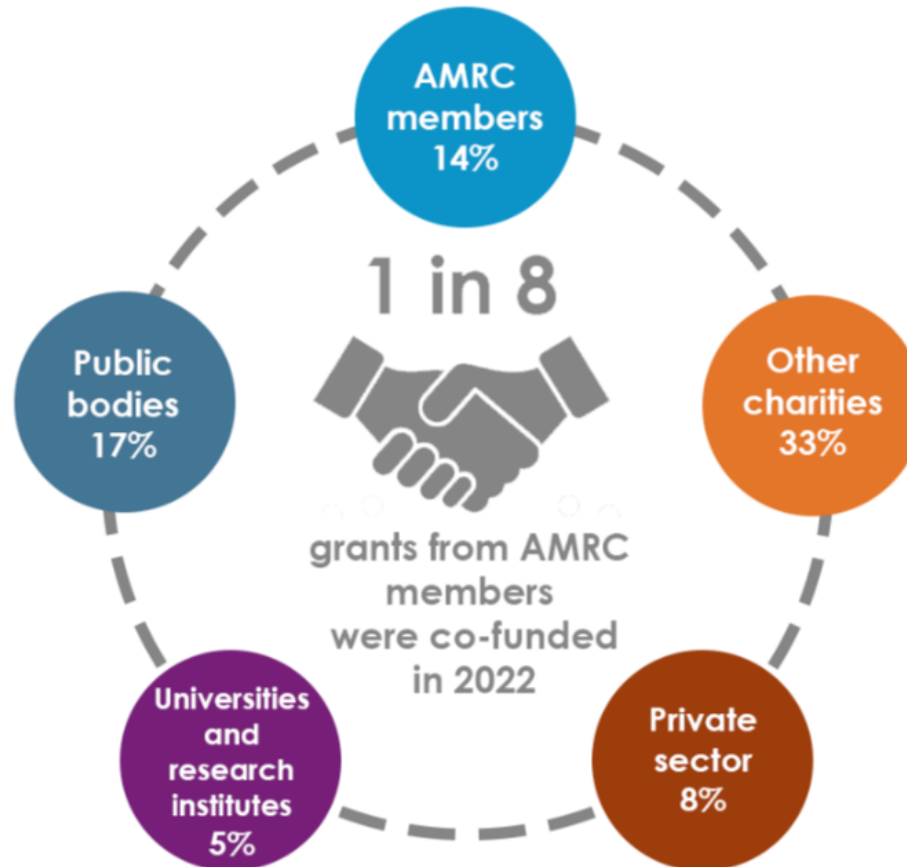
**75%**

of AMRC members have co-funded at least one grant since 2018



**27**

AMRC members co-fund fellowships with the MRC and/or NIHR



**>1800**

co-funded grants have been awarded by AMRC members since 2018



**78**

AMRC members have been involved with JLA priority setting partnerships



# How do we partner to set priorities?

## Priority Setting Partnerships: Epilepsy Institute

James Lind Alliance (JLA) Priority Setting Partnerships (PSPs) bring together stakeholders involved in an area of health and care to agree on research priorities and address evidence gaps, providing a valuable opportunity for patients and clinicians to shape the research agenda. In 2022, Epilepsy Research UK funded and led the UK Epilepsy PSP, which established future research priorities for the condition. This partnership brought together clinicians and people affected by epilepsy in addition to patient groups and UK epilepsy charities, including AMRC member Epilepsy Action. Importantly, it underpinned the future strategy development of the charity, culminating in it becoming the Epilepsy Research Institute. The Institute was launched in October 2023 with the support of founding partners, to serve as the central hub for the epilepsy research community. The Institute's mission is to radically advance research into epilepsy and its associated conditions. The comprehensive research strategy developed by the national research collaborative #Every1EndingEpilepsy will provide the foundation for this and incorporates all ten UK Epilepsy PSP research priorities. The Institute aims to strengthen the epilepsy research ecosystem by driving strategic investment and developing partnerships between academia, the NHS, industry, funders, patient groups and people affected by epilepsy.

<https://www.jla.nihr.ac.uk/priority-setting-partnerships/>

# But medical research charities as patient facing organisations have even more to offer



PROXIMITY TO PATIENTS



END TO END  
UNDERSTANDING OF A  
DISEASE OR CONDITION



NEED FOR SPEED



DIFFERENT STAKEHOLDERS

# So what did we learn from all these examples and experience: Setting up the partnership

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## Ensure clarity of purpose

Strong foundations underpin successful partnerships – and the most important starting point for any collaboration is agreeing a common goal. Define the project and ensure clarity on what you're aiming to achieve at the outset. This includes identifying shared objectives and red lines, as well as developing an understanding of everyone's strategic priorities and values.

*"You have to identify the common purpose, and then the partnership follows from there."*

Cathy Yelf,  
Chief Executive Officer,  
Macular Society

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## Align expectations

When setting up a new partnership, aligning and agreeing on expectations is key. Take time to decide what each partner will contribute, accounting for each organisation's size and capacity, as well as what they'll gain from the partnership. Ensure that all partners are committed and engaged. Do your due diligence. Make sure you understand each organisation's culture and values. Building in time for a kick-off meeting with all partners can be a useful first step.

*"Get involved as early as possible and be realistic on the time needed to ensure you add and get value. As the saying goes 'the amount you put in will determine the amount you get out'. As a group, taking time to develop a common goal, that everyone can get behind, is a critical enabler to a partnership working."*

Tamara Kahn, Chief Executive Officer, Oracle Cancer Trust

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## Plan the practicalities

Before starting a new collaboration, ensure that you have a plan that runs throughout the lifespan of the partnership. This should cover practical aspects such as governance, financials and resourcing. This can take the form of a written framework or agreement, such as a Memorandum of Understanding (MoU), to outline the parameters of the partnership. Another key consideration is branding and deciding if/how the partnership should be recognised and publicly acknowledged.

# So what did we learn from all these examples and experience: Sustaining the partnership

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*"When you think you've communicated enough, communicate more."*

Jennie Evans, Director of External Affairs, British Society for Immunology

## Communicate, communicate, communicate

Be prepared to invest time in communicating with partners as well as with internal colleagues to instil a strong understanding of the partnership and its goals. Keep channels of communication open and be prepared to listen and compromise. Accommodate and respect the differences between organisations. Transparency and honesty is also important. When describing the partnership, use harmonised language to prevent miscommunication.

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## Nurture relationships

Relationships can underpin a successful partnership. Take time to build good relationships and understand different perspectives and passions. Work through challenges respectfully. Try to ensure that the partnership does not depend on only a few individuals, for example by celebrating successes across an organisation, which can help to build wider buy-in and maintain institutional memory.

*"Make sure that not just one person holds those experiences by celebrating successes as an organisation. Facilitate meetings across the whole team, including researchers where applicable. And keep good, up-to-date databases!"*

Sarah-Jane Hill, Partnerships Manager, World Cancer Research Fund

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## Value each member of the partnership

Working collaboratively can be an excellent way to deliver outcomes, pool resources and broaden the reach of your organisation. Recognise the value of the partnership and what each organisation brings to the table. Recognise that different organisations bring different outlooks, experiences and skillsets, and play on different strengths.

*"My one tip would be to take the time to understand your partners priorities, needs and ways of working. Charities often operate differently from one another and from funders, universities and companies developing new treatments or products."*

Heather Thom, Patient Partnership Coordinator, Asthma & Lung UK



# So what did we learn from all these examples and experience: Evaluating and monitoring the partnership

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## Develop common measurement frameworks and metrics

Develop a shared framework for measuring the impact of the partnership and revisit this as the project matures. Success metrics should consider both individual and shared impacts. If one partner takes the lead on evaluation, results and analysis should be shared to prevent duplication of effort and reduce bureaucratic burden. Consider that success can be measured in different ways and don't assume that you are speaking the same language as your partner.

*"While working with the Medical Research Council on the Advanced Pain Discovery Platform, we were aware that their impact focus differed from our charity. When developing the joint impact framework, we shared our expertise in public and patient involvement to ensure that this was included and tracked."*

Clare Farmer, Research Programme Manager,  
Versus Arthritis

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## Showcase the benefit of doing this in partnership

Partnerships can achieve things that one organisation alone cannot. It is important to monitor progress and outcomes to ensure that the collaboration is fulfilling its purpose. This could include regular reviews to ensure that all partners are happy and milestones are delivered. It is also important to demonstrate and communicate why the partnership is greater than the sum of its parts and highlight the impact of doing this together.

*"Our partnership with the Little Princess Trust allows us to share knowledge and resources between our organisations, providing a huge boost to childhood cancer research in the UK. Both organisations have taken the time to assess how the partnership is working, with regular reviews and a full sense check on the relationship a few years in – making sure the collaboration was working for both organisations and finding some areas for improvement."*

Ashley Ball-Gamble, Chief Executive Officer, Children's Cancer and Leukaemia Group

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*"If you are transparent, honest, reasonable, leave egos at the door, are willing to share the limelight and have shared goals, then things shouldn't be too difficult."*

Jeremy Barratt, Head of Research,  
Wellbeing of Women

## Think beyond the partnership

As a partnership or project concludes, take time to think through the next steps. This could include growing the partnership or scoping what comes next. Knowing when to end the partnership is also important. Finally, remember to celebrate successes within and across partner organisations. Shout about your achievements and share tips and best practice.

- <https://www.amrc.org.uk/top-tips-for-partnering>