The funder perspective on owning open access platforms

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Association of Medical Research Charities
Outline of presentation

1. Who is AMRC and its members?
2. Why did we set up AMRC Open Research?
3. How does it work and what are the benefits?
4. How has it been received?
5. What challenges have we faced?
The Association of Medical Research Charities

30 years
Formed in 1987 by a small group of diverse medical research charities to unite the sector and provide it with a leading voice.

148 members
Membership has grown over the past 3 decades to 148 members across the UK

14 staff
Day to day work is carried out by a small team based in London

Hallmark of quality research funding
AMRC member charities
AMRC member charities

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

Essential research in all areas of health and disease at all stages of the research process.

- 38% of medical research
- 60% of research into disease prevention and disease management
- 59% of research into the cause of disease
Charity-funded medical research

What is unique about charity-funded medical research?

- Patient-centric
- Emotive
- Urgent
- Dependent on donations
- Addresses un-met need
- Leverages further investment

Demonstrating impact is key!
Limitations of traditional publication models

- Prioritisation of novel and positive results and bias against replication studies and negative and null results
- Delays of months or years from submission to ultimate publication
- Wasted time and effort spent re-formatting and re-submitting
- Full methods and underlying data are often missing
- Publications are hidden behind paywalls
- ‘Publish or perish’ and ‘impact factor’ culture threatens research integrity
Making open access a priority

Growing concerns over the wider issues of research integrity, reproducibility and research waste.

More responsibility placed on funders to address these issues.
Why launch an AMRC platform?

- Inspired by Wellcome and the Bill and Melinda Gates Foundation
- Increased efficiency by funders joining together under AMRC branding
- Affordability for smaller charities
- Strength in numbers to drive culture change
- Lead by example
Participating charities
AMRC Open Research: launched Feb 2019

Immediate & Transparent Publishing
A platform for rapid author-led publication and open peer review of research funded by AMRC member charities

Submit Your Research  Browse Articles

Enables researchers to publish any research they wish to share, supporting reproducibility, transparency and impact

Uses an open research publishing model: publication within days of submission, followed by open invited peer review

Includes citations to all supporting data, enabling reanalyses, replication and reuse
How does it work?

For articles:

- Peer review after publication
- Fully transparent peer review
- Access to source data
- Versioning for revisions, corrections, updates

For posters, slides and documents:

- Submission
- Publication
- DOI

Rapid Publication in as few as 14 days
Open peer review

Referee ratings:
- Approved
- Approved with reservations
- Not approved

Minimal requirements for indexing:
- ✔ ✔ ✔ or ✔ ✔ ?

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Author Response 23 Dec 2015
Chaldea Bangham, Department of Immunology, Imperial College London, UK
Lewin et al. — response to reviewers

We thank the three pairs of reviewers of our article, each of whom made helpful suggestions and raised salient points for clarification or further discussion. We have revised the article in the light of these comments, and cite further relevant literature (see references have been added). The response to individual points is given below.

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Open Peer Review

Referee Status: ✔ ✔ ?

Invited Referees

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What makes AMRC Open Research unique?

Fast – articles can be published within a week. Posters and slides published immediately.

Inclusive – *all* research outputs are suitable: research articles, methods, software, data sets, protocols, negative and confirmatory results, etc.

Open – fully open access. Everyone can access the results, including the charities’ communities.

Reproducible - source data published alongside article

Transparent – open, author-led publishing and peer review

Collaborative – multiple distinct funders focusing on different conditions coming together
Benefits of AMRC Open Research

**Benefits for Researchers**
- All types of research can be published rapidly: standard research articles, clinical trial findings, systematic reviews, study protocols, data sets, negative/null results, case reports and more
- Authors, not editors, decide when to publish and what to publish
- Authors can suggest peer reviewers most appropriate to their subject and the transparent review process permits constructive open dialogue between author and reviewer

**Benefits for Research**
- Rapid open access publication enables others to build upon new ideas right away, wherever and whoever they are
- Removes obstacles to collaborative research through data sharing, transparency and attribution
- Shifts the way research and researchers are evaluated by supporting research assessment based on the intrinsic value of the research rather than the venue of publication

**Benefits for Society**
- Maximises the value and impact of public donations by enabling publication of all aspects of charity funded research
- Makes research results freely available to everyone, including those living with and affected by the conditions being studied and the general public
- Accelerates the progress of research meaning new insights, innovations and treatments become available to those who need them more rapidly
Individual perspectives

"All too often the results of research are published slowly, held behind paywalls, or never published at all. By launching this platform the participating charities are helping to ensure that all results of the research they fund can be rapidly and widely shared to limit duplication of effort, accelerate the progress of research and most importantly bring benefits to patients sooner."

AISLING BURNAND
Chief Executive, Association of Medical Research Charities

"This innovative publishing platform is a step into the future of science publishing."

Abigail Thompson, Research Network Co-ordinator at Autistica

"In order to develop new and effective therapies, whether they are to prevent stroke, treat acute stroke, or for rehabilitation, it is important that researchers have access to all existing evidence."

- Stroke Association

"Publishing with AMRC Open Research has meant our article is available in a timely manner. Also being open access will certainly increase readership, impact and the reach of this article."

Geri Keane, Kings College Hospital

"Most attractive is the quick turnaround time... Early career researchers are always keen to get their science into the public domain as soon as possible and the AMRC Open Research platform offers such an opportunity."

Terry Quinn, University of Glasgow

We use @AMRC #OpenResearch to ensure our research results are published in a matter of days for everyone to see. We believe that everyone should be able to read about the results of research made possible through donations from the public: amrcopenresearch.org
How is the platform being used so far?

Publications
- 7 articles, 4 documents, 3 posters

Peer review:
- 12 days from final submission to publication
- 24 days to first peer review report (median)
- 76 days to second peer review report (median)

Article views: 2397
Case study: negative/null result

Post-stroke cognition with the Oxford Cognitive Screen vs Montreal Cognitive Assessment: a multi-site randomized controlled study (OCS-CARE) [version 1; peer review: 1 approved]

Nele Demeyere, Shuo Sun, Elise Milosevich, Kathleen Van Cleeft

Abstract

Background: Cognitive impairment is common following stroke. The Oxford Cognitive Screen (OCS) was designed to assess focal post-stroke cognitive deficits in five domains. Here, we investigated whether results generated by the OCS vs the domain-general Montreal Cognitive Assessment (MoCA) at baseline impacted patient outcomes at 6 months follow-up.

Methods: Patients < 2 months post-stroke were randomized to receive either the OCS and corresponding information leaflet or standard care with the MoCA at baseline. After 6 months, patients received both the OCS and MoCA. The primary registered outcome measures were the Stroke Impact Scale (SIS) and change in stroke severity (National Institutes of Health Stroke Scale; NIHSS) at 6 months. The secondary outcome was change in cognitive performance from baseline to 6-month follow-up. The relationship between scores from the two cognitive screens at follow-up...
Abstract

Background: There is an increasing emphasis on the importance of the palliative and end-of-life care being provided in the community. Key to the success of this is the availability of information and educational support to facilitate carers in their role. The aim of the paper is to explore the educational needs of adult carers providing physical and other care to people at the end of life.

Methods: A qualitative evidence synthesis was conducted using meta-ethnography. Five electronic databases were searched to January 2014, combining terms for: cancer, chronic obstructive pulmonary disease, neurodegenerative conditions, renal disease, heart failure and dementia, with terms for carers and education.

Results: A total of 35 papers were included in the review, reporting the experiences of over 900 carers. Throughout the illness trajectory, carers were either enabled or hindered in their role by the nature and way information and education were provided. Enabling factors included: a sense of trust in health professionals; timely and accurate information delivered compassionately; access to professionals for information and support particularly during out-of-hours. Where carers experienced a lack of information or support this added to the strain of caring. Carers then felt the need to take on a more active role, acting both as an advocate and decision maker.

Conclusions: Carers express information and educational needs throughout the illness trajectory. The quality of health professionals' communication with carers was fundamental in ensuring carers felt confident and supported. Timely access to information and support from appropriately qualified health professionals should be made available to carers, including the out-of-hours period.

Keywords

Carers, education, end of life, qualitative evidence synthesis, meta-ethnography
Case study: other outputs

Posters

Protocols or methods
Challenges encountered so far

- Participating charities have varying open access policies
- Participating charities have variable stances on paying APCs
- Lack of awareness about the platform within the research communities
- Overcoming the ‘impact factor’ phenomenon
- Understanding the different use cases for the platform
- Some participating charities’ content is already being published on Wellcome Open Research
Addressing these challenges

- Learn from what has worked well
- Increase awareness about the platform amongst researchers
- More emphasis on non-traditional outputs (protocols, negative/null findings, posters, etc.)
- Support charities to develop open access policies
- Encourage charities to commit to changing research assessment criteria
Thank you

Questions?

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