

The funder perspective on owning open access platforms

Jocelyn LeBlanc

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.

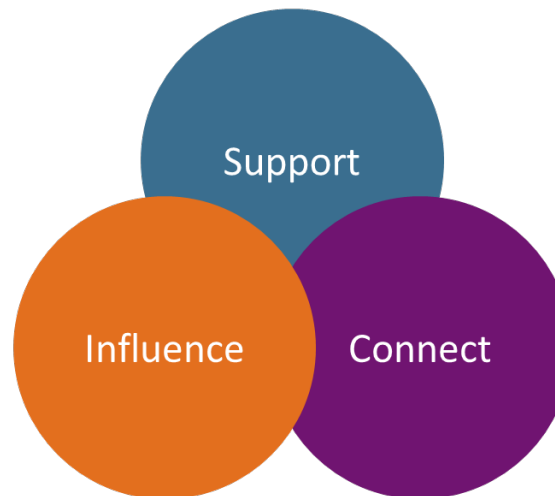
148 members

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

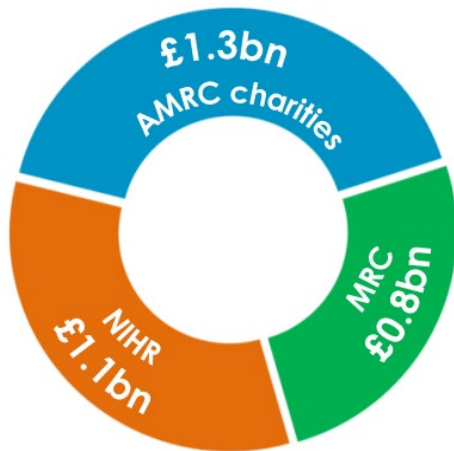


AMRC member charities

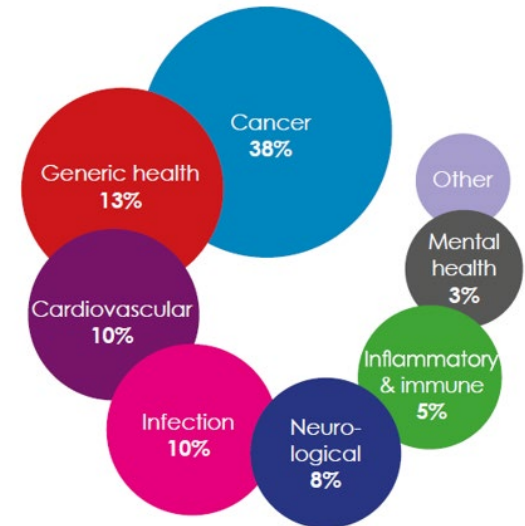


AMRC member charities

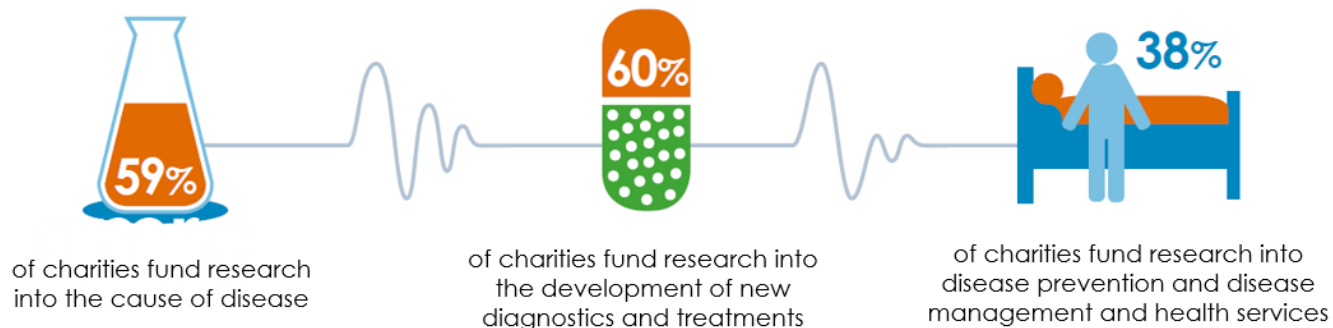
AMRC charities funded 41% of publicly funded medical research nationally in 2018



Essential research in all areas of health and disease



At all stages of the research process



Charity-funded medical research



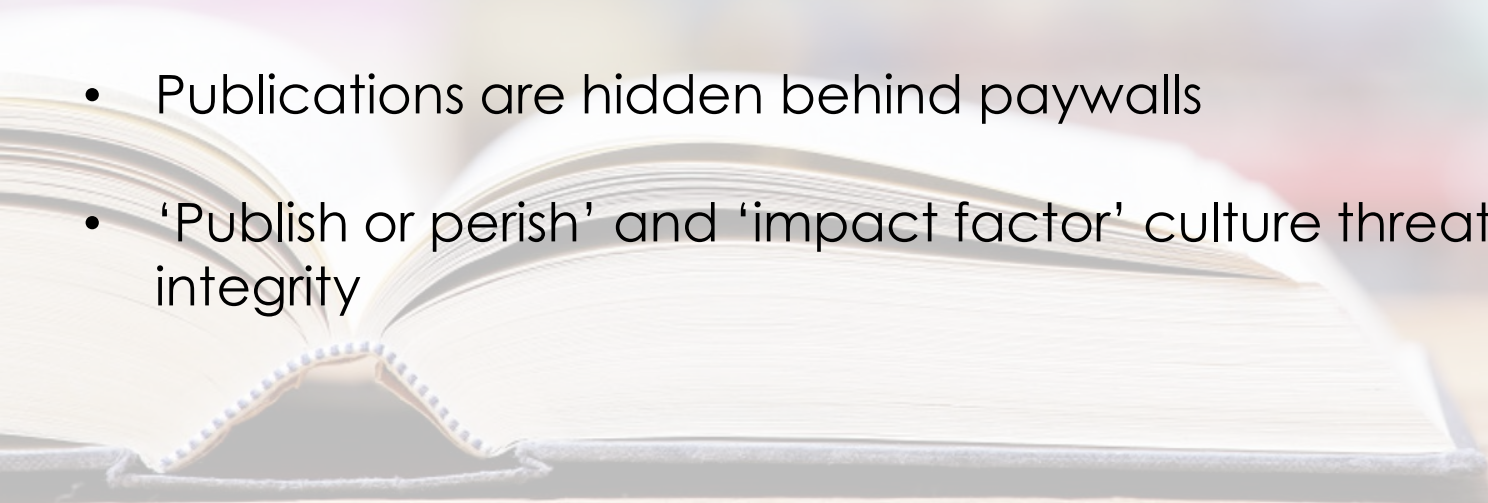
What is unique about charity-funded medical research?

- 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.



AMRC position statement – Open access and new publishing initiatives

amrc

April 2019

AMRC supports the principles of Open Access. Rapid and open dissemination of new knowledge resulting from research funded by our members is of vital importance to speed up further research and maximise efficiency by making sure that it can be built upon to bring benefits to all. This also aligns with the transparency principles of charities.

Open Access is in agreement with the patient-centric approaches which many charities adopt; these include involving patients and the public in strategy setting and decision making about research funding. We view that this is the direction of the scientific enterprise with research becoming more open with citizens increasingly getting involved in research studies – be that through financially supporting an AMRC charity, participating as a patient expert or taking part in a clinical study.

AMRC member charities want the research they fund to have the greatest possible impact in order to maximise its reach and potential to bring benefit to patients. As such, many of our members have explicit open access policies or encourage their charity-funded researchers to make their work open access.

Plan S

AMRC strongly supports the principles and goals of Plan S, the international initiative to drive a global switch to publish all research articles in an open access way from 2020. We are fully supportive of our members considering becoming signatories to Plan S and are monitoring key issues and providing guidance where appropriate.

At present, it remains difficult to confirm the full impact of Plan S on medical research charities, including financial and other risks. AMRC understands that such risks may be difficult for some of our members to take on and therefore, despite supporting the principle and intent of Plan S, they have decided not to become signatories at this time. We recognise that they are seeking clarifications and reassurances around the implementation plan to ensure that UK researchers can continue to do the best science possible. We want to emphasise that further developments in the field are expected that are likely to reduce risks over the coming months.

We also recognise that there are risks in not adopting Plan S. As 76% of the world's research articles are only available to subscribers at publication, the opportunity for non-subscribers (such as other researchers, policy makers, small and medium enterprises, and the public) to access and reuse this research to help uncover new knowledge, is lost. Equally, the ability to constrain publication costs will only be successful if as many

Plan S and DORA FAQs

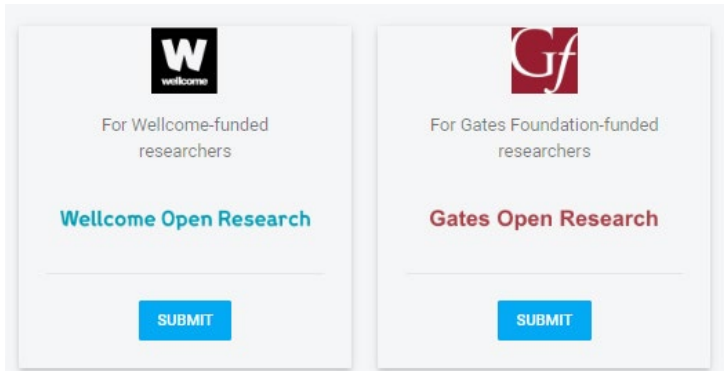
amrc

This document of frequently asked questions is intended to support AMRC's members in considering their open access policies in the changing landscape where Plan S and DORA are increasingly prominent.

Contents

1. What is Plan S?
2. Who supports Plan S?
3. Will researchers still be able to publish in their preferred journals?
4. What are the copyright obligations of Plan S?
5. Would Plan S negatively affect the finances of learned societies that publish their own journals?
6. Will international collaborations between scientists be affected?
7. Doesn't Plan S just promote the business interests of publishers like PLoS and Frontiers by encouraging Gold Open Access?
8. How much will Plan S cost?
9. Why don't you support mandating pre-prints without conditions? Don't they achieve the same goal as Plan S?
10. What is DORA?
11. What do funders have to do to comply with DORA?
12. What is the AMRC doing to help its members?
13. What about other open science initiatives – where is the field going over the next few years?

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

AMRC Open Research

[BROWSE](#)[HOW TO PUBLISH](#) ▾[ABOUT](#) ▾[MY ACCOUNT](#) ▾[SIGN IN](#)

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](#)

Powered by
F1000



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



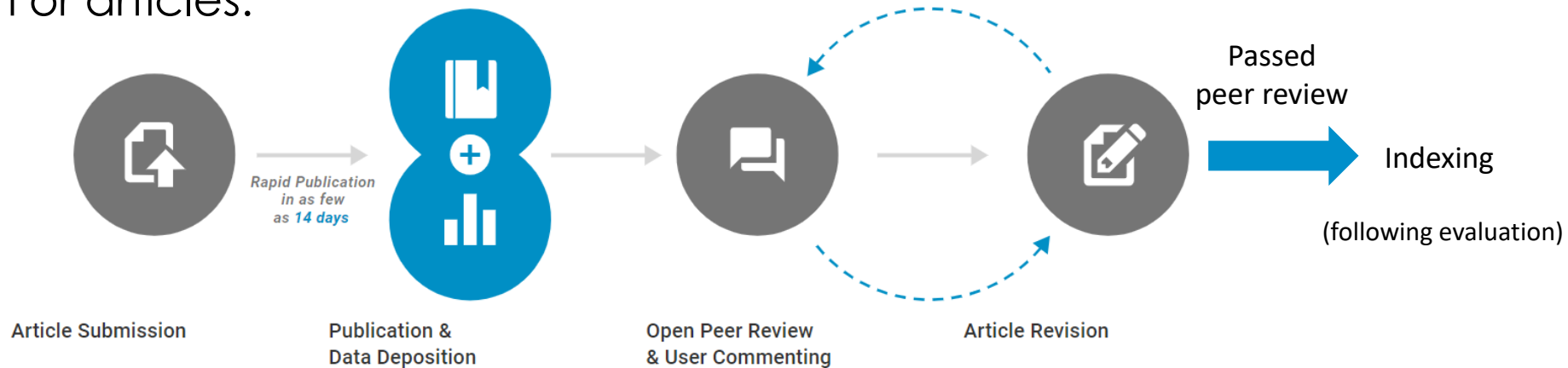
Uses an open research publishing model: publication within days of submission, followed by open invited peer review



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:



How does it work?

Open peer review


Open Peer Review

Current Referee Status: ?



Version 1

Referee Report 22 Nov 2017

Leah Shipton , Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada
Erica Di Ruggiero, Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada
Donald C. Cole, Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada

Views

1

Cite

? Approved with Reservations

The authors present an interesting review of integrated development approaches and are right to highlight this as an important area of research. The structure of the review is clear and easy to follow the argument and ideas of the authors.

Introduction - Rationale

- It would be helpful to have "integrated development intervention" defined earlier in the manuscript, especially because authors mention that there has yet to be consensus on a definition in the literature. Providing an example of an integrated development intervention (including a brief description of which features make it an integrated development intervention) would be helpful in explaining why they are so important in the context of the SDGs.
- The statement below was part of the rationale for conducting this study, but the objectives do not reflect this rationale and neither do the results or discussion sections of the study. Specifically, the authors do not analyze the circumstances when an integrated intervention works. I recommend that this sentence be removed or rephrased to reflect the objectives and results/discussion of the study.
 - "To effectively advocate for integrated, multi-disciplinary approaches to development, it behooves us to understand under which circumstances integrating two or more development sectors enhances impacts in amplified or synergistic ways."
 - The authors might consider circumstances participating sectors, funding available, or economic, etc – and this context needs to be reflected in the objectives and results/discussion of the study.

Introduction - Objectives

- The secondary objective of the review seems unnecessary because the authors should state the characteristics of the included studies in the results section as part of the systematic review, therefore this does not need to be an objective.

Author Response 23 Dec 2016

Charles 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 (8 references have been added). The response to individual points is given below.

Referee ratings:



Approved



Approved with reservations



Not approved

Minimal requirements for indexing:



or



Open Peer Review

Referee Status: ✓ ✓ ?

Invited Referees

Version(s)	1	2	3
REVISED Version 2 published 29 May 2018	✓ read report ↑	✓ read report ↑	? read report ↑
Version 1 published 06 Nov 2017	? read report	? read report	? read report

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

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.

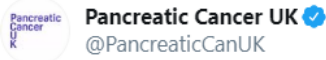
- Stroke Association

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

Abigail Thompson, Research Network Co-ordinator at Autistica

“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



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

“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

How is the platform being used so far?

Publications

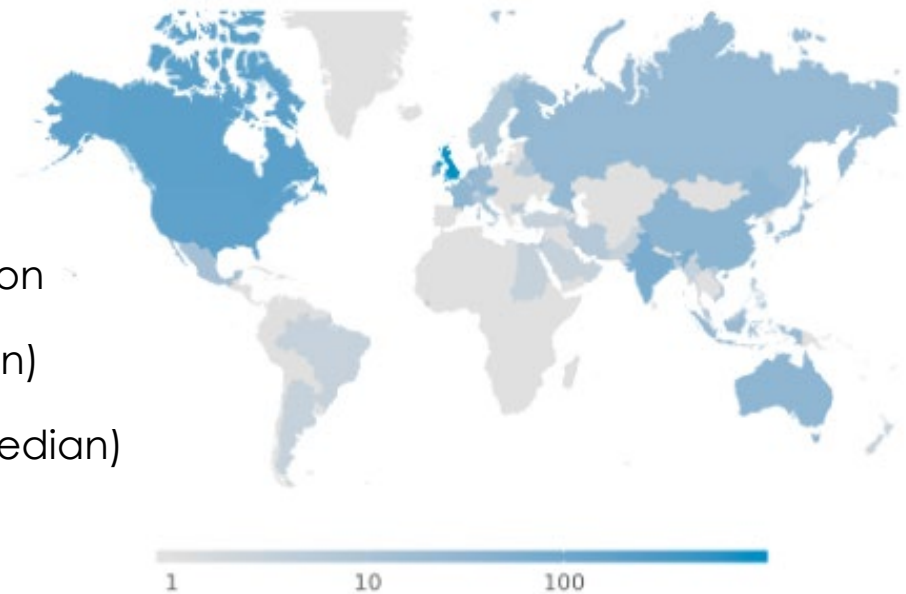
- 7 articles, 4 documents, 3 posters

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

Sessions per country



Case study: negative/null result

[Home](#) » [Browse](#) » [Post-stroke cognition with the Oxford Cognitive Screen vs Montreal...](#)


RESEARCH ARTICLE

Clinical trial

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](#) ¹, [Shuo Sun](#)², [Elise Milosevich](#)¹, [Kathleen Vancleef](#)¹

[+ Author details](#)


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


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Reviewer Reports

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13 Aug 19


[read](#)

1. [Niamh A. Merriman](#) , Royal College of Surgeons in Ireland, Dublin, Ireland

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Case study: systematic review

[Home](#) » [Browse](#) » [Adult family carers' perceptions of their educational needs when providing...](#)

SYSTEMATIC REVIEW

Adult family carers' perceptions of their educational needs when providing end-of-life care: a systematic review of qualitative research [version 1; peer review: 3 approved with reservations]

 [Kate Flemming](#) ¹, [Karl Atkin](#)¹, [Chris Ward](#)², [Ian Watt](#)¹

 [Author details](#)

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


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Reviewer Status   



Reviewer Reports

Invited Reviewers

	1	2	3
Version 1 19 Feb 19	 read	 read	 read

1. [Nancy Preston](#) , Lancaster University, Lancaster, UK
2. [Gunn Grande](#), University of Manchester, Manchester, UK
3. [Emma Carduff](#) , Marie Curie Hospice, Glasgow, UK

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Case study: other outputs

Posters

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POSTER

NOT PEER REVIEWED

VIEW FULL SCREEN

Palliative and end of life care Priority Setting Partnership (PeolcPSP) 63

Current palliative care research neglects out of hours care which is ranked the top end-user research priority

Palliative and end of life care Priority Setting Partnership

Authors: Florence Todd Fordham, Sabine Best, Sanjay Thakrar and Bill Noble, March 2019

1,403 responses to our initial survey
48% professional; 35% bereaved carers; 13% current carers; 4% patients

From the survey responses, **83** unanswered interventional questions were formulated

PROSISTION

The **Top Ten** unanswered questions in palliative and end of life care were published on 15th January 2019

TOP PRIORITY
What are the best ways of providing out of hours palliative care to avoid crises and help patients to stay in their place of choice?

INTRODUCTION AND AIM
In 2013/14 the Palliative and end of life care Priority Setting Partnership (PeolcPSP) used the James Lind Alliance (JLA) methodology to establish the top ten list of unanswered questions relating to palliative and end of life care research. These were ranked in accordance with responses from current and bereaved carers, healthcare professionals and people in the last years of life. The JLA methodology identifies questions that are either not answered by a current systematic review or for which no systematic review exists. Nevertheless, there might be current research projects in progress which look into the question, either directly or in a way in which the results might be relevant to the question in an indirect way. This aim of this paper is to review the ways in which current research is addressing the top research priority through a grant mapping exercise.

METHODS
Grant mapping facilitates the visualisation of the current research landscape in palliative and end of life care, highlighting the research questions that are currently being addressed and those where there is less or no attention/funding. To conduct the mapping project, the recently published UKCRC's Health Research Classification System database was used. This dataset, which is composed of £2 billion of UK health research funding for 2014, was analysed for links between the abstracts and the PSP questions. The following analysis specifically looks at the results relating to the top priority: Out of hours palliative care.

OUT OF HOURS PALLIATIVE CARE
The out of hours period covers from 18.30 to 08.00 on weekdays, and from 18.30 on a Friday through to 08.00 on a Monday, and on bank and public holidays. Out of hours palliative care is just one component, albeit an important one, of the out of hours services needed by patients in the last years of life living at home.

RESULTS AND ANALYSIS
14,534 grant abstracts were searched using keyword searches for all 83 priorities. Of these, only 12 related to the priority on out of hours palliative care. These 12 grants amount to £1,366,820 of funding, which is 0.08% of the total health research spend in the 2014 HRC dataset. The distribution of this funding is displayed in the graph below.

Distribution of funding in palliative out of hours care

Using keyword searches, the HRC dataset was searched for relevant grant abstracts. The keywords brought up 4,420 grants of which 594 were manually mapped. The keyword searches that were specific to the out of hours palliative care priority were: palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, working hours.

Distribution of grant funding relating to out of hours care by health category

As is highlighted above, the stroke health category received the highest proportion of the total funding relating to out of hours care.

Current palliative care research neglects out of hours care which is ranked the top end-user research priority

Florence Todd Fordham, ✉ Sabine Best¹, Sanjay Thakrar, Bill Noble

PUBLISHED 24 OCT 2019 (<https://doi.org/10.21955/amrcopenres.1114898.1>)

Protocols or methods

DOCUMENT

NOT PEER REVIEWED

VIEW FULL SCREEN

FINAL 1.10.14

Methodology for UK Mental Health Funding Landscape Analysis 2008 - 2013

By Anne Kirtley Ph.D.

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TECHNICAL REPORT

Methodology for UK Mental Health Funding Landscape Analysis 2008 – 2013

✉ Anne Kirtley¹

PUBLISHED 26 FEB 2019 (<https://doi.org/10.21955/amrcopenres.1114888.1>)



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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