

Institution: University of Plymouth		
Unit of Assessment: UoA3		
Title of case study: Advancing methods on allocating resources for research		
Period when the underpinning research was undertaken: 2008-present		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s): Dr Mona Nasser	Role(s) (e.g. job title): Associate Professor	Period(s) employed by submitting HEI: 2011-present
Period when the claimed impact occurred: 2014 - present		
Is this case study continued from a case study submitted in 2014? N		
<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>Biomedical research consumes almost a quarter of a trillion US dollars every year. Unfortunately, evidence suggests that a high proportion of this sum is avoidably wasted. University of Plymouth (UoP) research was dedicated to identifying and evaluating methods to ensure resources are allocated to research projects that are relevant to stakeholders and met high scientific quality standards. These innovative methods have been incorporated into guidelines of the World Health Organisation and Cochrane and have informed the work of organisations internationally. Subsequently, results of an Australian research prioritisation project using UoP methods has been incorporated in clinical guidelines in Germany and the UK (National Institute for Clinical Excellence). UoP methods have subsequently informed research funders' policies on how to add value to research, changing funder policies and practices around the world.</p>		
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>Dr Nasser's research was dedicated to identifying and evaluating methods to ensure resources are allocated to research projects that are relevant to stakeholders and meet high scientific quality standards. In addition, her work evaluates what processes can add value to research and reduce research waste within funding agencies.</p> <p>Nasser's priority-setting project started in 2008 and transferred to UoP in 2011. Nasser, alongside international collaborators, was funded by Cochrane to evaluate the priority-setting processes that were in place to inform the selection or prioritization of topics for Cochrane reviews. This research was imperative to ensure that decisions about health and health care were informed by high-quality, relevant and up-to-date research evidence. It found that less than half of the groups surveyed had priority-setting systems in place [3.1]. The project concluded that all Cochrane entities should have strategic plans in place to improve the inclusiveness and transparency of their own prioritization processes, and increase the likelihood of producing reviews that have positive effects on health outcomes. Subsequently, Nasser's research identified that there were few strategies that explicitly addressed the research priorities of individuals from different sociodemographic groups. Nasser developed and piloted an equity lens that could help researchers in developing a more equity-oriented approach toward priority and agenda setting in systematic reviews [3.2]. This resulted in a recognition of the need for a more accountable and systematic approach to selecting research questions for systematic</p>		

reviews, including recommendations on how to evaluate priority settings for research and how to incorporate subsequent issues around inequality in the process. Specifically, it identified the need for more research priority exercises with appropriate involvement of patients and members of public [3.3].

The framework and guidance developed were then used in other research projects including (i) a mapping of all the Cochrane library against the global burden of disease to identify gaps in Cochrane reviews, which then informed future research prioritisation, and (ii) research focusing on skin diseases to determine whether the number of Cochrane reviews reflected disease burden as measured by disability-adjusted life years (DALYs). This research found a discrepancy between the burden of disease and the research conducted to address it, with seven of the 15 studied skin diseases underrepresented and three overrepresented when matched with their disability metrics. These results provided high-quality and transparent data to inform future prioritization decisions [3.4].

Nasser's research subsequently focused on adapting a framework around enhancing the value of research for funding agencies. Reducing unnecessary and low-quality research is vital for funders. This research waste leads to non-publication which is bad value for funders where research output can be doubled by ensuring that all funded studies are published. This wasteful situation puts patients and clinicians at a substantial disadvantage when making informed decisions about health care. The adapted framework [3.5, 3.6] identified and highlighted issues including:

- (i) research priorities with no meaningful involvement of those who will use and be affected by the health-related research,
- (ii) a lack of robust research design, conduct and analysis,
- (iii) poor regulation and management of research conduct proportionate to risks,
- (iv) lack of information on research methods and
- (v) inaccessible findings.

This framework informed the evaluation that subsequently informed guiding principles of the Ensuring Value in Research funders forum.

3. References to the research (indicative maximum of six references)

3.1 **Nasser M**, Welch V, Tugwell P, Ueffing E, Doyle J, Waters E. Ensuring relevance for Cochrane reviews: evaluating processes and methods for prioritizing topics for Cochrane reviews. *J Clin Epidemiol*. 2013 May; 66 (5):474-82. doi: 10.1016/j.jclinepi.2012.01.001.

3.2 **Nasser M**, Ueffing E, Welch V, Tugwell P. An equity lens can ensure an equity-oriented approach to agenda setting and priority setting of Cochrane Reviews. *J Clin Epidemiol*. 2013 May; 66 (5):511-21. doi: 10.1016/j.jclinepi.2012.11.013.

3.3 **Nasser M**, Welch V, Ueffing E, Crowe S, Oliver S, Carlo R. Evidence in agenda setting: new directions for the Cochrane Collaboration. *J Clin Epidemiol*. 2013 May;66(5):469-71. doi: 10.1016/j.jclinepi.2012.08.006.

3.4 Karimkhani C, Boyers LN, Prescott L, Welch V, Delamere FM, **Nasser M**, Zaveri A, Hay RJ, Vos T, Murray CJ, Margolis DJ, Hilton J, MacLehose H, Williams HC, Dellavalle RP. Global burden of skin disease as reflected in Cochrane Database of Systematic Reviews. *JAMA Dermatol*. 2014 Sep;150(9):945-51.

3.5 **Nasser M**, Clarke M, Chalmers I, Brurberg KG, Nykvist H, Lund H, Glasziou P. What are funders doing to minimise waste in research? *Lancet*. 2017 Mar 11;389(10073):1006-1007.

3.6 Moher D, Glasziou P, Chalmers I, **Nasser M**, Bossuyt PM, Korevaar DA, Graham ID, Ravaud P, Boutron I. Increasing value and reducing waste in biomedical research: who's listening? Lancet. 2016 Apr 9;387(10027):1573-86.

4. Details of the impact (indicative maximum 750 words)

Funders of health-related research agree that although considerable research of high value exists, loss of any research because it asks the wrong questions, is poorly designed, is not published, or the reports are unusable is unacceptable. Chalmers and Glasziou estimated in 2009 that 85% of research finding was being avoidably wasted across the biomedical research area. UoP research contributed to addressing this issue through improving or evaluating the methods to prioritise or fund research across the research system and enhancing the approaches taken in health-related research funders.

Improving healthcare policy through research prioritisation

Nasser's research enabled The Centre for Health Communication, La Trobe University, Australia, to design their priority setting exercise, using the methods developed at UoP. The exercise was a wide-ranging consultation process to identify research/topic priorities which informed the most relevant and useful Cochrane reviews to be conducted [5.1]. One identified priority entitled "Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material" resulted in a Cochrane review that was incorporated in five clinical guidelines in Germany and one in the UK with the National Institute of Clinical Excellence (NICE) [5.2]. These guidelines ensure that research reviews are as useful as possible to the people who need to use, or might be affected by, the research, including health policy makers, health professionals, researchers, consumers and carers, and the wider community. Nasser's research has also been used by the UK partnership of patients, professionals and public who set the research agenda for ENT, hearing and balance conditions that was supported by ENT-UK and British Academy of Audiology. This directly influenced decisions about which high-value research should be developed and conducted to inform them about what treatments work best and how they can most effectively deliver care [5.3]. In addition, Karimkhani and Nasser's identification of acne as a disease with a high burden that is not adequately covered by systematic reviews in the Cochrane Library led to an identification of acne treatment uncertainties via a James Lind Alliance Priority Setting Partnership [5.4]. Nasser's research identified the need for more involvement of patients and members of the public as part of research priority exercises. This directly informed a national patient and public colorectal consumer consultation. This led to a prioritization of research topics with patients and the public in 2015 [5.5].

UoP priority setting work also shaped the WHO Guidance on Research Methods for Health and Disaster Risk Management [5.6] that informs the work of WHO and local offices. This Guidance offers practical advice about how to plan, conduct and report on a wide variety of quantitative and qualitative studies that can inform questions about policies and programs for health-related disasters and emergencies across different settings and level of resources.

Informing research funders' policies on how to add value to research

UoP research has influenced research funders' policies and practice to reduce avoidable waste, improve research integrity, transparency and ultimately the impact of the research they support.

The research informed the shaping of the Ensuring Value in Research (EViR) funders forum and contributed to the Adding Value in Research (AViR) framework.

The National Institute for Health Research (NIHR) is the major applied health research funder in the UK focusing on research that can improve patient care. Following a presentation at the NIHR Strategy Board, Nasser's research informed the NIHR review to understand its performance and in turn led to the identification of a number of gaps which they are now addressing [5.7]. For example, the work informed internal continual improvement programmes and resulted in changes in NIHR policy that will have an impact on the entire research community they support: Any changes or improvement in their processes can shift what research gets funded and improves patient care. Nasser's review was also influential in the EViR forum, developing its ten guiding principles which set out the areas all funders should focus on to ensure value, reduce waste and improve transparency and integrity of research [5.8]. These guiding principles were developed by funders to implement in each of their organisations. Eleven research funders publicly endorsed these guiding principles and committed to implementing them in full:

1. Forte (Sweden)
2. Graham Boeckh Foundation (Canada)
3. Health and Care Research Wales - Welsh Government (UK)
4. Health Research Board Ireland (Ireland)
5. Marie Curie (UK)
6. Ministry of Health Salute (Italy)
7. NIHR - National Institute for Health Research (UK)
8. PCORI – Patient Centered Outcomes Research Institute (USA)
9. The Scar Free Foundation (UK)
10. Association of Dutch Health Foundations (SGF)
11. ZonMW – The Netherlands Organisation for Health Research and Development (Netherlands)

Other funding agencies who are part of the forum implemented some aspects of these principles (e.g. Canadian Institute of Health Research and the National Health and Medical Research Council, Australia).

“These principles are now changing funder policies and practices around the world. [Nasser's work] highlighted the importance of audit and monitoring of practices and how they contribute to reducing research waste and a number of policies, and actions of the EViR forum are aligned with that conclusion.” NIHR operations director and Chair of EViR Forum [5.8].

This subsequently resulted in funding agencies undertaking internal audits and advancing their processes and practices. Health Board Ireland (HBI) undertook a systematic audit of their practices against potential areas of research waste to focus on areas where they could make the biggest difference. *“Analysing what you and your co-authors consider to be of likely great value to ensure value in research and factors less likely to relate to the framework was helpful in the re-phrasing of research call documentation... your ongoing academic contribution to support this is very valuable for this continuous improvement”*. Head of Pre-Award, HBI [5.9].

5. Sources to corroborate the impact (indicative maximum of 10 references)

- 5.1 The research priority setting exercises conducted by Cochrane Consumers and Communication review group. The materials reference the usage of our priority setting articles. <http://www.latrobe.edu.au/chcp/projects/research-priority-setting>
- 5.2 Uo'Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information' material
https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD004563.pub2/related-content#guidelines_data
- 5.3 The Research Agenda for ENT, Hearing and Balance Care A UK Partnership of Patients, Professionals and the Public.
<https://www.entuk.org/sites/default/files/files/Research%20Agenda%20ENT%20Hearing%20and%20Balance%2030%2011%2015.pdf>
- 5.4 Layton A, Eady EA, Peat M, Whitehouse H, Levell N, Ridd M, Cowdell F, Patel M, Andrews S, Oxnard C, Fenton M, Firkins L. Identifying acne treatment uncertainties via a James Lind Alliance Priority Setting Partnership. BMJ Open. 2015 Jul 17;5(7):e008085
- 5.5 McNair AG, Heywood N, Tiernan J, Verjee A, Bach SP, Fearnhead NS; ORACLE Collaboration. A national patient and public colorectal research agenda: integration of consumer perspectives in bowel disease through early consultation. Colorectal Dis. 2017 Jan;19(1):O75-O85.
- 5.6 WHO Guidance on Research Methods for Health and Disaster Risk Management.
https://extranet.who.int/kobe_centre/en/project-details/GUIDANCE_ResearchMethods_HealthEDRM
- 5.7 Adding value in research - NIHR website on adding value in research framework
<https://www.nihr.ac.uk/about-us/our-contribution-to-research/how-we-are-improving-research/adding-value-in-research.htm>
- 5.8 Testimonial from NIHR operations director and chair of EVIR Forum
- 5.9 Testimonial from Health Research Board in Ireland