



Current research funding methods dumb down health care and rehabilitation for disabled people and aging population: a call for a change

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Health care systems in Western societies are faced with two major challenges: aging populations and the growing burden of chronic conditions. This translates into more persons with disabilities and the need for more Physical and Rehabilitation Medicine (PRM) services. We raise the point of how these emerging needs are faced by the actual research funding. We briefly present the results of an analysis we made about research funding by the Italian National Health Service as an interesting case study, since it relates to Italy (the financer) and the United States, where National Institutes of Health (NIH) reviewers were identified according to their classification of research topics. The topics of potentially greatest interest for aging Western societies, like chronicity, disability and rehabilitation, were among those least often funded and considered in the traditional method of financing research projects. These results could be based on those PRM peculiarities that make the specialty different from all other classical biomedical specialties, namely the bio-psycho-social approach and its specific research methodologies. Moreover, PRM researchers are spread among the different topics as usually classified, and it is probable that PRM projects are judged by non-PRM reviewers. There are at least two possible ways in which research can be better placed to meet the emerging needs of Western societies (chronicity, disability and consequently also rehabilitation). One is to create specific keywords on these topics so as to improve the match between researchers and reviewers; the second is to allocate specific funds to research in these areas. In fact, the not coherence between emerging needs and research priorities have already been periodically addressed in the past with specific “political” and/or “social” initiatives, when researchers were forced to

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respond to new emergencies: some historical examples include cancer or HIV and viral diseases or the recent Ebola outbreak.

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Physical and rehabilitation medicine (PRM) takes a bio-psycho-social approach to patients, making it very different from biomedicine.¹⁻⁵ This difference continues into research where PRM developed its own perspectives and methodologies.⁶ The peculiarities of PRM can also impact on research funding. Financing research poses numerous challenges; in fact, though project value is the top criterion, there are clearly other political decisions that direct the preferential flow of funds in one direction or another. This is particularly critical in an era of economic uncertainty and shrinking budgets. Since research can provide one way out of the economic crisis, priorities for financing it should be clearer and more focused than ever before.

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TABLE I.—*Classification of research topics.*

AIDS and Related Research
Biobehavioral and Behavioral Processes
Bioengineering Sciences and Technologies
Biological Chemistry and Macromolecular Biophysics
Biology of Development and Aging
Brain Disorders and Clinical Neuroscience
Cardiovascular and Respiratory Sciences
Cell Biology
Digestive, Kidney and Urological Systems
Emerging Technologies and Training in Neurosciences
Endocrinology, Metabolism, Nutrition and Reproductive Sciences
Genes, Genomes and Genetics
Healthcare Delivery and Methodologies
Immunology
Infectious Diseases and Microbiology
Interdisciplinary Molecular Sciences and Training
Integrative, Functional, and Cognitive Neuroscience
Molecular, Cellular, and Developmental Neuroscience
Musculoskeletal, Oral and Skin Sciences
Neuroscience
Oncology
Population Sciences and Epidemiology
Risk, Prevention and Health Behavior
Surgical Sciences, Biomedical Imaging, and Bioengineering
Vascular and Hematology
Veterinary

Health care systems in Western societies are faced with two major challenges: aging populations and the growing burden of chronic conditions. This translates into more persons with disabilities and the need for more PRM services.³ The World Health Organization (WHO) Disability Report⁷ and the recently launched Action Plan⁸ clearly show that the healthcare scenario unfolding in Western societies will similarly take place in other countries, underlining the key role of PRM in this process.⁸ Developed countries have begun to shift chronic care to outpatient and community-based services and reserve inpatient services for acquired acute diseases. Since the restructuring of health care delivery is already well under way, there is an urgent need for PRM research to keep pace with future developments.

The question now is how these two factors (adequate financing of PRM to meet emerging health care demands and the bio-psycho-social peculiari-

ties of PRM) interact with respect to financing PRM research. Here, we briefly present the results of an analysis we made about research funding by the Italian National Health Service as an interesting case study, since it relates to Italy (the financier) and the United States, where National Institutes of Health (NIH) reviewers were identified according to their classification of research topics (Table I).

A case-study: the Italian Finalized Research Projects reviewed by US NIH researchers

Every year the Italian Health Ministry calls for the submission of research projects to be financed under the Finalized Research Program. Through this program, €134,731,095 were distributed during the period from 2011 to 2012. The research projects were classified as clinical or biomedical and at least 50% of funds had to be allocated to clinical projects. The NIH researchers independently reviewed the projects. Both reviewers and projects were classified according to a specific NIH classification scheme (Table I) to guarantee a match between reviewer competence and project topic. The final results were presented in early 2014 and the best projects, as judged by the NIH reviewers, were awarded funds.

All analyses reported here were derived from the official data of the Finalized Research Program issued by the Italian Health Ministry.⁹ Since the results were published in PDF format, they were converted into an Excel file to obtain a numerical database. This might have generated some systematic errors, which were specifically searched and none were found. The research projects were classified according to the following criteria:

- biomedical or clinical project;
- key words: reviewers' field of expertise according to the NIH scheme (Table I);
- strategic topics for National Health Service ("rehabilitation", "disability" and "chronicity"); these keywords were retrieved with a free-text search of the project titles using the words: "rehab*", "disabil*" and "chronic*". Because only titles were available in the final report, key words were searched only in titles.

For all classifications, we considered the final result (financed or not) and the scores obtained along a scale from 5 (best project) to 42 (worst project).

TABLE II.—*Financed clinical projects.*

	Total			Financed				Not financed			
	NHS-RF		NHS-TOP	NHS-RF		NHS-TOP		NHS-RF		NHS-TOP	
	Number	Number	%	Number	%	Number	%	Number	%	Number	%
Projects	3058	127	4.15%	372	12.16%	8	6.35%	2686	87.84%	119	93.65%
Clinical (% total)	N 1481	8	0.54%	167	11.28%	7	87.50%	1314	88.72%	1	0.85%
	% 48.43%	6.30%		44.89%		87.50%		48.92%		0.84%	
Biomedical	N 1577	119	7.55%	205	13.00%	1	1325.21%	1372	87.00%	118	0.85%
	% 51.57%	93.70%		55.11%		12.50%		51.08%		99.16%	

NHS-RF: National Health Service - Research Financed. NHS-TOP: National Health Service - Strategic Topics.



Figure 1.—The NIH classification of reviewers made a difference in terms of final approval.

The usual statistical procedures were performed: percentages, average, standard deviation and t-test as appropriate.

Of the 3058 finalized research projects presented for financing, 126 (4.1%) focused on strategic topics for the National Health Service, but only 15 out of 539 (2.8%) were financed. In the Strategic Topics category, the percentage of clinical projects was very low (8 out of 126): 6.3% *vs.* 49.3% of all finalized research projects. Almost all clinical projects in

the Strategic Topics category were financed (87.5%), unlike the biomedical projects that were less often financed than the general finalized research projects (Table II).

The NIH classification of reviewers made a difference in terms of final approval (Figure 1): projects in Oncology were generally awarded grants, while those in the Neurosciences were less often financed. Within the Strategic Topics for National Health Service category, “chronicity” and “rehabilitation” projects

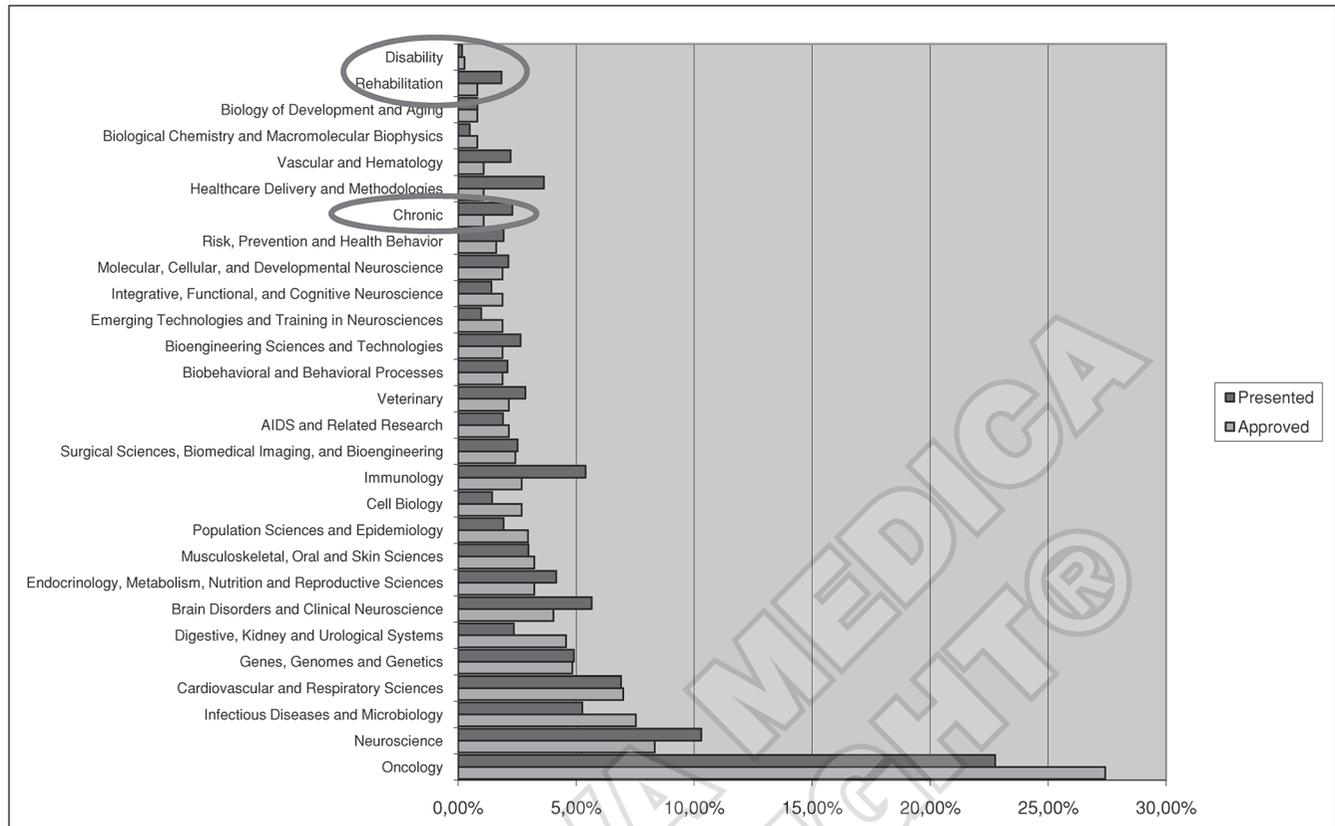


Figure 2.—Finalized research projects *versus* those financed.

were rarely financed, while Disability projects were neither awarded nor penalised. Most of the Strategic Topics projects were presented in the Neuroscience category, which was generally less often financed than other categories. Looking at the number of finalized research projects presented *versus* those financed, we found that Oncology was not only the most often financed category but also the category with the most projects presented for financing (Figure 2). Conversely, the second category in terms of number of projects presented was also the least financed: “Neuroscience”. The presence of Strategic Topics is scarce, particularly for “Disability” and “Rehabilitation”, while “Chronicity” was more frequently present.

Technological and basic sciences topics obtained the best scores (Figure 3), while the clinical topics were less awarded (Figure 3): all Strategic Topics projects were clinical and mainly in the Neuroscience area, which was the least awarded (Table III). Finally, Italian Regions (like Lombardy or Tus-

any) were more interested in chronicity, while research institutes preferentially looked at rehabilitation and disability (Table IV).

The power of tradition and the need to drive the changing needs of our societies

The topics of potentially greatest interest for aging Western societies, like chronicity, disability and rehabilitation, were among those least often funded and considered in the traditional method of financing research projects, at least in Italy. Nevertheless, this can be seen as a general case if we consider that the financed projects were selected by independent NIH reviewers, matched to the topics of research projects according to classical biomedical key words. Understanding this point requires some explanation.

Scientific value is the main reason for financing a research project. This value is judged by reviewers

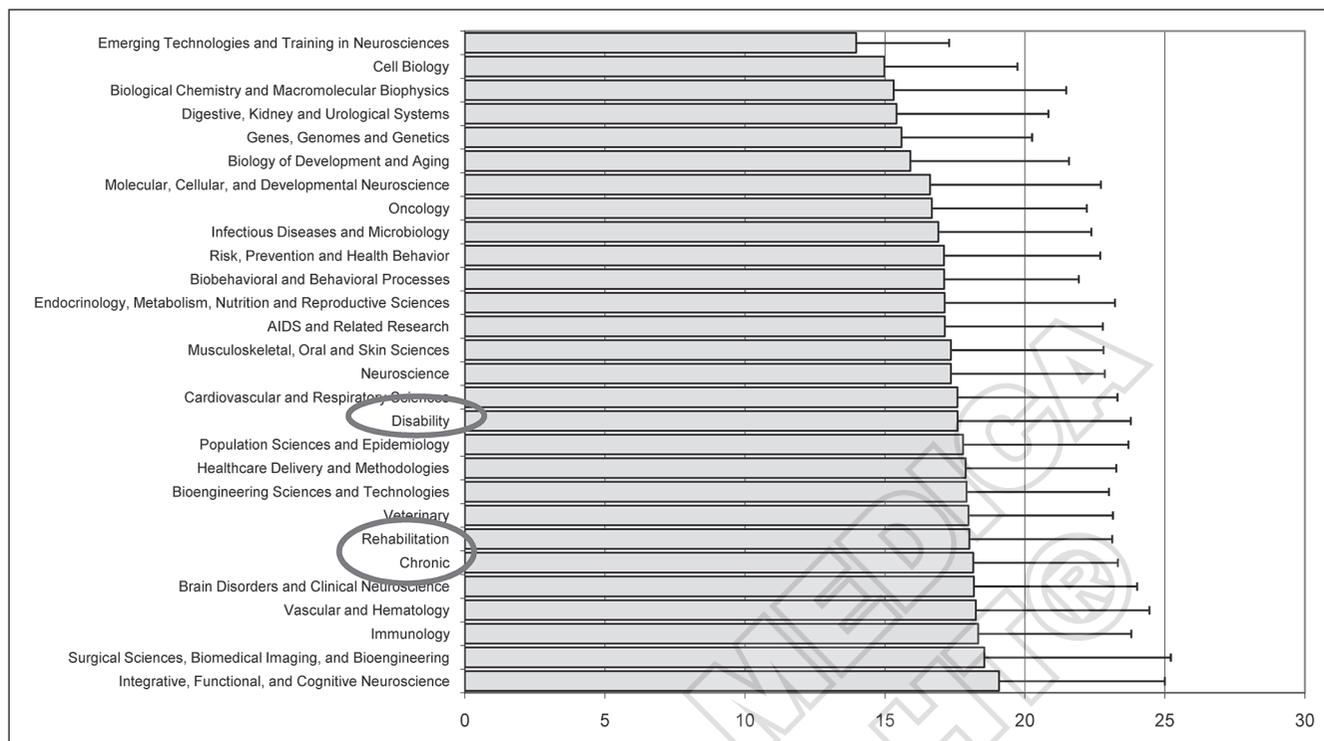


Figure 3.—Science topics obtaining the best scores.

TABLE III.—Awarded strategic topic projects.

	NHS-RF		NHS-TOP	
	Average	SD	Average	SD
Total	18.16296305	5.192023148	18.56707317	4.889985707
Financed	10.00268817	1.954500861	10.5	1.395144642
Clinical	17.84	5.46	18.19382022	4.830765633
Transitional	16.54	5.64	17.82142857	5.763977104
T-test	P<0.001		NS	

TABLE IV.—Field of interest.

	NHS-RF		NHS-TOP		Rehabilitation		Chronic		Diability	
	Total	Financed	Total	Financed	Total	Financed	Total	Financed	Total	Financed
Regions	1042	54	3	14	0	39	3	1	0	
Research institutes	1269	77	5	42	3	31	1	4	1	
Ratio	1.22	1.43	1.66667	3	0.79	0.33333	4			

who are deemed to be experts. Their expertise is defined by topics that, by convention, are classified as either body structure/functions or health conditions as described in the ICF model.¹ Usually, function, disability, activity and participation, but also chronicity (that are some of the main focuses of PRM) are

not included in such research topic classifications: an obvious exception being the PRM world.¹⁰ But because PRM deals with almost all body structures/functions and health conditions, PRM researchers are thinly scattered across different strategic topics as defined by the keywords (obviously, if present,

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since PRM is very young in terms of research).¹¹ This can easily lead to a mismatch between the PRM researcher and the PRM project reviewer.

Besides the research value, there are other factors that figure into the ways in which funds are distributed, including the appeal for the research community. Appeal for researchers is anything that falls within their research interest, and what lies outside that scope is not usually found appealing. Sometimes, what is beyond one's own field of interest is not even understood, since different fields have different research methodologies: in this respect, PRM has its own specific methodologies.¹² PRM researchers frequently encounter this situation when they submit their papers for publication in journals that are not specific to PRM. The chances of having a manuscript accepted can be even worse when the match between a research project and its research value is based only on hypothetically "neutral" keywords, with the result that the paper is reviewed by other specialists totally focused on specific body structures/functions.

Moreover, researchers have their own established scientific agendas, which are not necessarily those dictated by a country's evolving and emerging healthcare needs. This is critical for research, where innovation does not always completely match either tradition (by definition, classical fields of research) or by the number of researchers in a given field (coming from classical research areas and/or previous financing).

This case-study seems to confirm our hypothesis that the current research funding process, as represented here by the NIH classification (where the topics chronicity, disability and rehabilitation are not included), may misrecognize the real emergencies facing the National Health System. This study is based on the data available from the Ministry of Health. Other analyses, such as evaluating the qualification of the NIH researchers or the number of PRM physicians involved, could confirm or refute the hypothesis for an underestimation of the field. Another hypothesis is that researchers working in PRM did not apply for adequate and appropriate projects. This may occur. The philosophy of a comprehensive approach to a person, i.e. holistic rehabilitation, may mean interpreting PRM as a humanistic discipline,¹³ which is and should remain but not exclusively.^{6, 12, 14} A scientific approach, however difficult because of its methodological

and ethical limits which we cannot deal with here, must form the basis of research in this discipline. PRM is a patient-centred science. In other words, scientific research in proteins, function, plasticity, and regeneration serves the humanistic aim of helping patients heal and return to a healthy life as best possible. But it also should be a science with a specific methodology and strategy, which must be known by reviewers. Nevertheless, the fact remains that PRM topics are poorly researched and awarded grants, ensuing in unequal opportunity for PRM research funding.

These problems have been periodically addressed with specific "political" and/or "social" initiatives when researchers were forced to respond to new emergencies. Among the historical examples that come to mind are the research on cancer or HIV and viral diseases or the recent Ebola outbreak. Also, some "social" situations, like the controversial Stamina case or the Di Bella method in Italy, garnered interest from researchers.¹³ Cancer and HIV are now well established in the research landscape. But the question arises whether they have become overly attractive, distracting attention from the new emerging healthcare problems looming ahead. A telling example of the unequal distribution of funding concerns rare diseases, where chronic underfunding has to be topped off by the fundraising campaigns research foundations like Telethon conduct or through dedicated Health Ministry financing. Given the right incentive, however, scientists will search what would otherwise be easily overlooked. And in this respect, researchers are, in fact, quite neutral, since they usually go where the funds are and new undiscovered areas lie open for exploration, whereas industry interests follow the prospects of future profits.

The positive side is that it is quite easily possible to direct research efforts in useful directions considering society's external needs; the negative side is that, unless this is done, the majority of researchers will stay where they are and continue to work within classical areas and pathways.

There are at least two possible ways in which research can be better placed to meet the emerging needs of Western societies, and PRM specifically. One is to create specific keywords on topics so as to improve the match between researchers and reviewers; the second is to allocate specific funds to research in these areas. Beyond PRM, what our poli-

ticians and administrators should keep in mind is that research can help Western societies overcome the current economic crisis and improve the health and wealth of their aging populations. The burden of disability and chronic illness calls for enhanced PRM services and innovative therapeutic and management strategies. Without adequate funding, however, such research is destined to early failure or not even start.

Another very important reason for identifying a specific PRM research area are the characteristics of disability and its management. Disability is heterogeneous (in type, severity, functional limitations, support needs, etc.) and it is periodically discussed by political decision makers and PRM specialists, yet it is rarely often addressed in research projects. Research is usually conducted by medical and rehabilitation practitioners who have specialised in training around specific disabilities or pathologies. Rehabilitation research encompasses a broad field of disciplines and methodologies, covering the spectrum from basic to applied science. Important areas in rehabilitation research include prevention, improvement, restoration, and replacement of lost underdeveloped or deteriorating function.¹⁷ Rehabilitation research operates within three domains: 1) physiological function (molecule, cell, tissue, and organs), 2) physical and mental function, and 3) social and community integration and design and delivery of rehabilitation services.¹⁸

Finally, a relevant aspect of PRM is the active participation of patients, family members, caregivers and other significant persons throughout the whole process of care. Clinical rehabilitation activities, such as priority setting, identification of relevant treatment goal, and choosing from different options of interventions, require close cooperation and negotiation between the professionals and the persons served. These aspects should be translated from the clinical to the research field, as they could aid in the comprehensive evaluation of a project, including social value and practical relevance. The importance and the potential benefits of active involvement of consumers in health care policy and research, and in rehabilitation in particular, have been widely recognized.^{19, 20} Recommendations for participation of persons with disabilities in the development of research agendas have been issued by international bodies.⁸ This is not usually considered at either the review stage or when setting the research agendas.

In conclusion, the Italian case-study may be generalized to other systems, since the problems are typical to research financing. Research is not a stand-alone process. Left alone, research becomes a selfish monster that eats up the money it is fed. Is this really what our countries need? If the answer is no, then consequent decisions should be taken.

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