




Research Agenda-Setting in Medicine: Shifting from a Research-Centric to a Patient-Centric Approach

Ania Korsunska^(✉) 

Syracuse University, Syracuse, NY, USA
akorsuns@syr.edu

Abstract. Traditional approaches to research agenda-setting focus on researchers and their ability to review and synthesize literature, identify gaps, prioritize their ideas, and find the resources to make them a reality. Recent initiatives in medical research have shifted the focus away from the researcher to other stakeholders. Through a series of semi-structured interviews with medical researchers, we illustrate both the traditional researcher-centric as well as the novel patient-centric approaches. The patient-centric approach allows patients to contribute their diverse perspectives and pose unique questions, which can direct more impactful research agenda-setting. This paper provides insights into how medical research agendas are established, what factors impact decision-making and how an innovative use of crowdsourcing can refocus attention on the patient and their needs.

Keywords: Research agenda-setting · Patient-centric approach · Crowdsourcing

1 Introduction

Traditionally, the scientific method dictates that new research should build on prior work, filling in gaps, synthesizing or testing prior findings [13, 24, 29]. Yet there are many incentives and constraints that affect researchers' decisions, shape their individual careers and, in aggregate, the direction of scientific discovery more broadly [9]. This means that both individual research agendas and broader disciplinary focuses do not necessarily align with what, in theory, is the most rational and necessary direction for the field to pursue at the time. These high stakes make it imperative to understand the evolving incentives that drive research agenda-setting, particularly in medical fields like immunology, which has wide ranging applications for diseases that affect millions of people daily, including the current COVID-19 outbreak.

Through a series of semi-structured interviews with medical researchers, we gain insights into how research agendas are established, what factors impact decision-making and how an innovative crowdsourcing approach can refocus attention on the patient and their needs. Crowdsourcing offers a potential solution to some of the chaotic and time-consuming problems researchers face. Engaging the public in setting agendas democratizes science, holds researchers accountable to their conduct, and helps them disseminate their results, which are often funded by public contributions. Bringing together and

directly engaging the target patient community echoes user-centered design principles. Thus, crowdsourcing is one potential solution to the problem of end-user involvement in the production of scientific knowledge, while streamlining research agenda-setting, promoting collaboration, and creating open access to knowledge.

2 Literature Review

Research agenda-setting, defined here as the process of determining what projects the researcher will pursue, has been a focus of study in sociology of science for decades [4, 10, 19]. Historically, the emphasis was primarily placed on researchers, but recently an emphasis on other stakeholder groups process has emerged. Medicine serves as an excellent case study for this area of inquiry. Despite the high stakes, medical research often lacks in quality and usefulness, and wastes billions of dollars in investment funds [6, 14, 17, 21]. By engaging patients in the research process, the responsibility of setting research agendas and the risk of potential failure is spread throughout a broader community, and more diverse ideas are considered. We will review the researcher-centric and patient-centric approaches in turn.

2.1 Researcher-Centric

It is commonly understood that research must be based on prior work. Literature reviews guide research agenda-setting by helping to define the theoretical foundation, identify the research problem and justify the value-add [24]. In practice, deciding what to focus on is often shaped by non-scientific constraints and can be a difficult and time-consuming task [13]. Keeping up with relevant research is becoming progressively more difficult as scientific publications have increased 527% annually since 1965 [28, 33]. Tools like Google Scholar make access to literature faster, but there are issues of algorithmic filtering. Though it catalogues between 2 and 100 million records [15], Google Scholar “does not index the majority of the scholarly materials indexed by commercial database vendors and it has never shared with the public their search algorithm” [18]. Difficulties with literature review are exacerbated by what is absent altogether, such as negative results, failed experiments, and disproven hypotheses [27].

It has been long hypothesized, and recently quantitatively illustrated [10], that researcher’s agenda-setting choices are shaped by ongoing tensions between two forces: tradition and innovation, which Kuhn refers to as the “essential tension” [19]. Though both approaches are necessary, there are contradictory incentives: researchers are encouraged to focus both on quantity and quality, publishing frequently, while remaining innovative. These incentives are at odds. Scientists who adhere to a research tradition in their domain often achieve more publications, simultaneously limiting their ability to pursue novel ideas that might take the field in new directions. The pressure to publish for achieving tenure may exacerbate researchers’ risk-aversity due to the concern that failure will make them seem unqualified or unproductive [9, 10].

Common advice to overcome decision paralysis in research agenda-setting is to follow your interests [3]. But this could lead the researcher to ask unnecessary questions from the perspective of the discipline or common good [2]. Considering these limitations,

it seems apt to shift the focus and responsibility away from the researchers exclusively and allow external stakeholders to play a more dominant role.

2.2 Patient-Centric

Kuhn argued that paradigm shifts arising from scientific crises are necessary steps in the evolution of science [20]. Some have suggested that science is due for a paradigm shift from closed, hidden science to open science and data sharing [26]. Traditionally, medical research relies on academic experts, who select methods, gather data, apply for funding and exclusively own the results of their labor. The “open innovation” approach, by contrast, democratizes the scientific process. By utilizing crowdsourcing at different stages in the research process, diverse stakeholders collectively frame questions, prioritize studies, co-create data and raise funds, which creates more open access to intellectual property [31]. The medical research field has begun to explore these strategies, and this shift has started to reshape how the industry functions.

We define crowdsourcing as “an approach to problem solving which involves an organization having a large group attempt to solve a problem or part of a problem, then sharing solutions” [31]. This approach helps solve some of the issues of traditional research approaches and mirrors user-centered design principles, wherein “users have a deep impact on the design by being involved as partners with designers throughout the design process” [1]. Patients have already become contributors to research, resulting in high-quality outcomes and more open science [23, 31, 32, 35]. Crowdsourcing approaches have been used in various medical applications: in clinical trial design [22], data sharing and collaboration [26, 28] development of research questions and data analysis [25, 31, 35], development of antibiotics [7], drugs for lupus [12], antimalarial drugs [30], and the treatment of Castleman disease [8, 35]. There is growing consensus in the industry that without integrating the voices of the patient population, it becomes “impossible to identify the most clinically meaningful questions and research approaches to answering them” [35].

3 Methods

To look at the question of research agenda-setting we drew from a larger project which focuses on the sense-making and tool-use practices of medical immunology researchers. For this analysis, we utilized six 45–60 min interviews which were conducted between 8/10/2020 and 9/17/2020 (Table 1). We focused on three research questions, which were based on the traditional research-centric model:

- (1) How do researchers keep up to date on the research in their area of expertise and how do they identify knowledge gaps?
- (2) How do researchers make decisions as to their research agendas and how are ideas prioritized?
- (3) What role does funding play in research agenda-setting and prioritization?

Interviewees were identified via personal contacts, snowball sampling and Internet searches using keywords related to medical research. The broad scope of experiences,

degrees and seniority levels of the interviewees allows for varied approaches to research agenda-setting. The interviews followed a semi-structured protocol and were conducted remotely through Zoom. All interviewees agreed to be audio recorded. The recordings were transcribed with the software Otter.ai and manually edited for accuracy.

Table 1. Interviewee information

Interviewee	Job title	Graduate degrees	Years of experience ^a
1	Associate Professor Biochemistry at a university	PhD Chemistry	30
2	Research Scientist of Ecology and Evolutionary Biology at a university	PhD Biology	12
3	Research Scientist at a clinical laboratory company	PhD Biological and Biomedical Sciences	7
4	Assistant Professor of Medicine at a university	MD, MSc, MBA	8
5	Postdoctoral Researcher at a cancer research center	PhD Microbiology and Immunology	6
6	Lead of Marketing at a grant-giving organization	PhD Microbiology and Immunology	9

^aInterviewees' subjective estimates of "years working in their area of expertise".

An iterative thematic analysis [5] was conducted by the author, utilizing the qualitative analysis software Atlas.ti. The transcripts were coded into preliminary themes, which were then synthesized into concise categories (Table 2). The quotations in the following section have been minimally cleaned, removing filler language and identifying information.

4 Funding

Traditionally, the question of how researchers set their agendas has utilized a researcher-centric approach. Through the interviews and analysis, we discovered that there is a movement in the medical field towards a patient-led, collaborative approach. The two approaches are reflected in the themes identified in the analysis and Table 2 summarizes the finding elaborated below. The broad topics in Table 2 correspond to the three research questions described prior.

Table 2. Questions and themes

Broad topics	Theme category	Focus	Theme
What do we want to know and what don't we know?	Knowledge Gap	Researcher	Search & Synthesis
			Algorithms
			Academic trust
		Patient	Negative Results & Data
			Crowdsourcing Research Questions
		Crowdsourcing Analysis	
How are things normally done around here and what's in it for me?	Incentives & Constraints	Researcher	Academic Freedom
			Lab PI & Mentorship
			External need-driven research
		Patient	Science Communication
Are there resources to do this?	Role of Funding	Researcher	Research Prioritization
			Matching or Avoiding Trends
		Patient	Researcher + Grant Matching

4.1 Researcher-Centric

Knowledge Gap. First, we identified the practices the interviewees utilize to keep up to date on the literature and identify new directions, as a part of research agenda-setting.

Search and Synthesis. All of interviewees expressed a strong preference for receiving literature via automated alerts, from academic databases (e.g., PubMed and SciFinder) and Google Scholar, rather than conducting searches manually. They expressed a feeling of responsibility of staying up to date on their field and demonstrating familiarity with its “core” literature. There were concerns about missing tangentially related papers and lacking the time to pursue them.

Algorithms. A few researchers utilize Google.com directly for literature searches, as “it’s way faster, the stuff that’s relevant is on the first page, it accounts for my horrible spelling, and it finds stuff that’s adjacent to what I’m actually looking for”. Another interviewee explained: “If Google missed something, it’s probably not important for me to know”.

Academic Trust. Due to time constraints and proliferation of literature, interviewees said it is increasingly difficult to rely on heuristics alone to determine what is trustworthy and avoid biases towards big name journals and Western literature.

Negative Results and Data. Another concern is not knowing what a gap in the literature signifies - whether it is a novel idea worth pursuing, or a complicated task that many have tried and failed. This becomes a factor in agenda-setting: “when you find a large gap in the science. And you ask, why does this exist? It seems like a really good question to be asked. It probably means that it’s really hard to answer.”

Incentives and Constraints. Many of the researchers discussed tensions between the freedom of choosing a research agenda, and the need to contribute to scientific literature, further their own career and potentially benefit society.

Academic Freedom. One interviewee mentioned getting distracted by personal interests: “There are things that I’m interested in, that’s absolutely useless. [...] And I got distracted by that, and that’s academia, it allowed me to do that”, later adding that he regrets not directing his efforts on more significant problems. Another interviewee noted that pressures between the incentives are not equal:

“If you don’t publish, if you don’t get grants, you don’t maintain your job, and then you don’t feed your family. [...] This works exactly how the system is set up –90% personal gain 10% societal benefit.”

This includes the pressure to publish work in order to achieve a tenured position: “You can choose easy problems, or you choose the problems that are easy to publish on, just so you can survive.”

Lab PI Lead and Mentorship. Researchers’ freedom can be constrained by their lab’s or direct supervisor’s preferences. Many of the researchers discussed the importance of power structures in setting the lab research agenda and the role of a good PI mentor.

External Need-Driven Research Agenda. Problems concerning freedom of choice can also be solved through external factors, such as direct interest from physicians, or a current trend in the world, such as the needs around the COVID-19 pandemic.

Funding.

All interviewees working in academic institutions noted that applying for grants is crucial to their work, and the availability of funds impacts the agenda-setting process. This makes grant-giving organizations responsible for directing the scientific fields to pursue certain projects. One interviewee compared research to building a spider web, with funding prioritizing novel research:

“Research is spider webbing out and there are more funding agencies interested in adding on to the tips, building new stuff, then filling in the webbing. [...] you can imagine all the spaces in between that you’re really missing out on.”

Research Prioritization. Another noted that even if they have a prioritized research agenda, if lower-priority studies get funded first, priorities will change. This may not happen if the study was not already planned or does not fit the agenda.

Matching or Avoiding Trends. Most interviewees shared that they have experienced needing to present their work in a way to make it fundable, whether putting it into the context of wider application or making it sound unique and novel.

These themes speak from the researcher-centric lens to the complexity of staying informed on current literature, identifying gaps, making decisions on next steps, prioritizing these steps, and finding the resources to make them a reality. Next, we look at these questions utilizing a patient-centric approach.

4.2 Patient-Centric

Knowledge Gaps. From the patient-centric view, gaps are questions based on community knowledge and personal experience, which are not captured by the researcher-centric approach.

Crowdsourcing Research Questions. An interviewee described their preferred practice of directly asking the physicians, researchers and patients in the community to generate research questions. After gathering the ideas, the community prioritizes them, and a panel of experts in the field selects the most promising to pursue first. Through this collaboration, the broader patient community helps to direct research.

Crowdsourcing Analysis. Another step in the research process that can involve the patient community is data analysis, which distributes the workload, diversifies insights and engages the citizen science community: “Anyone who thinks they might have insights into some data set, can then contribute [...] The more minds looking at the data, the better.”

Incentives and Constraints. A theme that surfaced throughout the interviews was the responsibility to communicate with the public.

Science Communication. Interviewees argued that many grants are given by government organizations, meaning they are taxpayer-funded, which makes communication with the public “an obligation”, whether it’s through traditional media - “an invisible importance” one interviewee called it as it indirectly benefits the researcher - or through the community involvement model.

Funding. Another innovative approach is the practice of pitching research projects to the researchers who have the right skillset to complete the project.

Research + Grant Matching. One interviewee described how they integrate this approach into their work: “We say - we’re from this foundation, we’ve got money, we’ve got samples, and we’re willing to coach you through the process, [...] you just have to do the research”. This approach allows the most qualified minds to engage with research chosen by the patient population and removes the need for the researcher to complete preliminary steps. The interviewee from the grant-giving organization mentioned that they help organizations choose which grants to apply for, minimizing wasted effort.

5 Conclusion

There is no doubt that research should build on prior work, but a sole focus on the researcher during the research agenda-setting process, risks overlooking crucial stakeholders. From the researcher perspective, the gaps that research can fill are found in the literature; for patients, concerns often emerge from community knowledge and personal experience. By incorporating patient voices, researchers can minimize the effects of traditional constraints. By communicating with the public, research institutions can increase transparency and address decreasing levels of trust in science [11, 16, 34]. The patient-centric approach could allow medical research to more quickly improve the quality of people's lives. There are already examples of such approaches impacting their disease fields: one interviewee described the work of the Castleman Disease Collaborative Network as spearheading this novel strategy. Through its integration of patient-centered research agenda setting, they have made incredible progress toward finding a cure for Castleman Disease, and other rare disease fields have started utilizing their approach [35].

5.1 Limitations

The six interviews presented are part of an ongoing project, and the work presented here reflects preliminary findings and theory building. This sample of researchers does not enable us to make generalizable conclusions regarding the breadth of experiences and practices in immunology, medicine, or scientific research more generally. Moreover, the patient-centered approach may not be suited for all forms of scientific work. Potential limitations of crowdsourcing are also relevant to consider [31].

5.2 Future Research

This project will continue to accumulate insights through interviews with various medical researchers, but also expand to analysis of online ethnography of the patient discussion boards that many crowdsourcing-focused research organizations utilize. Finally, we intend to interview representatives of government grant-giving organizations to better understand their research agenda-setting practices and to compare the role of researcher versus patient-raised funds in driving research.

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