### TITLE AND AUTHOR

Will Hall, Maastricht University School for Mental Health and Neuroscience

℅ 624 W. 44th St. # 15, Kansas City, MO 64111 USA

+1 413 210 2803

will.hall@maastrichtunversity.nl

### STATEMENT OF COMPETING INTERESTS AND FUNDING SUPPORT

The author declares that no competing interests exist. The author has received no funding support for this work.

### STATEMENT OF SUBMISSIONS OF SIMILAR WORK

The author declares there is no submission of similar work

### TITLE

"Can Survivors Be Authors? Patient Contribution in an American Psychiatric Association Publication"

### MAIN ARTICLE WITH REFERENCES

Public participation, patient-researcher collaboration, and survivor research are all reshaping medical scientific research in the internet era. Public policy initiatives and leading research recommendations, such as the National Institute of Health Research in the UK, the Canadian Institutes of Health Research, and the Patient-Centered Outcomes Research Institute in the US, recognize the value and contribution of collaborative science. (Smith et al., 2019; Edelman & Barron, 2016) But do citizen and patient researchers also constitute *authors* in the context of scientific publication? Who decides, and what if there is disagreement across backgrounds and domains of expertise? What new mechanisms can determine the role of authorship contribution, prevent authorship disputes, and support successful patient collaboration in the future?

In the arena of mental health care, traditional relations of patients as receivers of care and objects of research is likewise giving way to active patient and citizen collaboration as co-equals in research settings.(Sacristan et al., 2016) The importance of "survivor researchers" as patient involvement has also been understood as addressing the power imbalances and legacy of mistreatment that has characterized much of psychiatry's history. (Russo, 2012) Social movements of patients and family members have advanced the disability rights imperative of "nothing about us without us," and sought to overcome tendencies of tokenism through recognition of partnership and establishment of more equal power relations. (National Survivor User Network, 2018)

Traditional researchers and their citizen collaborators may however have different understandings of contribution and credit around authorship. Equal participation may introduce equal expectation when research moves to the realm of publication. While publication represents the height and culmination of the research endeavor, adding to the sum of scientific knowledge and conferring recognition of and credit for the work done to advance knowledge, the role of survivor and citizen participants in authorship attribution represents new territory, especially vulnerable to misunderstanding and disputes. Participants without professional experience find themselves ill-equipped to understand publishing norms. (Russo, 2012; Newman, 2006). In this fraught terrain the vulnerabilities and asymmetrical power relations intrinsic to patient and public involvement in research encounters further compound the difficulties such disputes present.(Rasmussen, 2019)

The 2017 *Psychiatric Services* publication "Discontinuing Psychiatric Medications: A Survey of Long-Term Users" authored by Laysha Ostrow, Lauren Jessell, Manton Hurd, Sabrina M. Darrow, and David Cohen, faced an authorship dispute that illustrates these complexities. The paper resulted from a research study, the Psychiatric Medication Discontinuation Research Study(PMDR), composed of an internet survey of patients to explore their experiences and health outcomes. The research was initiated outside research institutions, and the research team was made up of professional researchers, people who have been patients, professionals with direct clinical experience working with people around the topic, and researchers with patient backgrounds, with several combining some or all of these. Authorship resulting from this research did not include several survivor researchers without professional research experience culminated in an unresolved authorship dispute. At the same time, these dilemmas presented lessons for preventing and overcoming these obstacles in the future.

At its inception the PMDR arose from patient participation. At patient support and advocacy groups in Western Massachusetts organized by the patient group Freedom Center, a number of academic researchers had visited or asked to visit. Conversations often turned to the question of who was controlling and initiating the research priorities of these visitors, and who was controlling the research and benefitting from the results. What if patients themselves set the agenda? What would we research? At the same time, some participants expressed skepticism about participating in research, some worried that "being a guinea pig" was a familiar role not easily overcome even in a collaborative context.

In the *Psychiatric Services* example, members of the original team claimed their contributions to research were substantial and warranted consideration for co-authorship; professionals on the team in positions of administrative authority disagreed. These patient researchers discovered that authorship disputes are common in academic research: a significant number of academic researchers will find themselves involved in a dispute about the credit, contribution, acknowledgment and appropriate ownership and control of research and the resulting publication, with harmful impacts on science. "High prevalence of authorship problems may have severe impact on the integrity of the research process, just as more serious forms of research misconduct." (Marušić et al., 2011) The egalitarian ethic of patient advocacy and activism found itself contrasting sharply with the unfamiliar context of authorship.

At the same time, clarity about the definition of and criteria for appropriate authorship, and the practices of authorship and attribution, vary among researchers, institutions, and across disciplines. According to a survey of publications and contributors, 60% of authors in health research journals satisfy authorship criteria, and authors and editors, including in psychology were not familiar with or disagreed with criteria, (Marušić et al., 2011) Disputes can therefore arise simply from lack of understanding or training around authorship criteria, which then become lightning rods for pre-existing disagreement or conflict. In practice, junior research staff and those who are no longer employed in a unit when a paper is written are most often disadvantaged in assignment of authorship. (Digiusto, E. 1994) This was consistent with the role patient researchers found themselves in in the *Psychiatric Services* publication: newcomers to the field faced confusion about the criteria for authorship.

Criteria for Authorship

What constitutes an author therefore became fraught for the collaborators of the research that led to the *Psychiatric Services* publication. This was compounded by the broader context of controversy about authorship in general. "There is a disturbing and pervasive lack of understanding of what authorship on scientific papers means, of the responsibilities that it conveys, and of how it is determined." (Strange, 2008) Even where authorship is understood, misconduct is not uncommon and a looser application of standards can become an institutional norm. "In this 'publish or perish' era when researches are under pressure to publish frequently and preferably in high-impact journals, violations of authorship criteria are not uncommon (Supak-Smolcic et al., 2015)

More than 500 journals have officially endorsed the International Committee of Medical Journal Editors (ICMJE) guidelines for authors, and the ICMJE stands as the leading ethical standard for authorship practices in the medical research field. (Jacobs & Wager, 2005) The ICMJE criteria are: Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; drafting the work or revising it critically for important intellectual content; final approval of the version to be published; Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. All four criteria must be present to qualify for authorship; *Psychiatric Services* follows this general framework, but does not the ICMJE guidelines per se (ICMJE, 2019; Psychiatric Services, 2019)Surveys on the topic indicate that beyond ICMJE specific institutions, substantial contributions to conception and substantial contributions to research design are similarly held as cornerstone criteria for publication authorship.(Marušić et al., 2011), with one study showing 92% of postdoctoral fellows consider study design as central to authorship (Eastwood et al, 1996)

Despite this apparent clarity, authorship frequently does not conform to such guidelines in academic publishing.(Leash, 1997) One study found that less than one third of authors had actually made "substantial contributions," authors are included on a gift or honorary despite not meeting criteria, and authors frequently claim inclusion on unwarranted basis such as being the department head or managing study resources. (Leash, 1997) University of California, San Francisco, conducted a 1992 study where thirty-eight percent of respondents reported they had been listed as an author on a paper for which another author did not deserve authorship.(Eastwood et al., 1996) nearly a third said they would agree to claim an undeserving author as author to advance their own career or prospects for publication, which nearly doubled among those who had had previously unethical experiences with authorship inclusion, indicating the emergence of normative systematic disregard for accepted criteria for ethical publication. (Leash, 1997)

In the *Psychiatric Services* example, study design and collaboration comprised the dispute, as the researchers not invited to authorship sought to establish that their contribution was substantial and therefore met the ICMJE criteria. They contributed unique topic expertise not held by others on the team and participated actively and collaboratively in inception, design and development of the work. The contributors not did not claim to have met the full ICMJE criteria for authorship, which include drafting work, approval of the final manuscript, or taking responsibility for the published work: these were not at issue. Instead, the dispute rested on "denial of authorship," prior exclusion from the possibility to meet these other criteria, because they had not been invited to authorship despite their contribution being substantial. As the ICMJE notes,

These authorship criteria are intended to reserve the status of authorship for those who deserve credit and can take responsibility for the work. The criteria are not intended for use as a means to disqualify colleagues from authorship who otherwise meet authorship criteria by denying them the opportunity to meet criterion #s 2 or 3. Therefore, all individuals who meet the first criterion should have the opportunity to participate in the review, drafting, and final approval of the manuscript. (ICMJE, 2019)

The Committee on Publication Ethics, formed to protect the integrity of the scholarly record across disciplines, describes a common scenario of a junior research who made substantial contributions but then their supervisor wrote up the work and didn't include them as an author:

The junior researcher would not qualify as an author according to the ICMJE criteria because he/she had no involvement in the writing of the paper nor final approval of the version to be published. However, the junior researcher may have had no opportunity to do so. He/she should have been offered this opportunity and at least included in the acknowledgment section if the opportunity was declined. (Committee on Publication Ethics, 2014)

Because authorship rests on contribution, the timing of the contribution or whether the research team has dissolved or changed is not relevant for authorship as long as the contribution has already been made. In the *Psychiatric Services* example, authorship was disputed only after the paper was published, because their contribution was already established despite being no longer on the research team and the researchers did not know where the publication was being submitted. Unresolved authorship disputes hinder the likelihood of publication and therefore provide incentive for researchers to reach an agreement, but with the *Psychiatric Services* paper there was no such opportunity. As Kevin Strange of Vanderbilt University notes, "No reputable journal that I am aware of will publish a manuscript if there are disagreements over its authorship or content. Therefore, failure to agree on authorship effectively renders the manuscript unpublishable. This is a disturbing but unassailable conclusion and underscores the critical importance of working diligently to avoid authorship problems from the outset." (Strange, 2008)

In the *Psychiatric Services* example, the published authors questioned whether the contributions made were indeed substantial. Authors argued that the work took place substantially after the other researchers had left, such as the analysis of data, creation of the literature review, and manuscript preparation; the contributors claimed that conceiving the study and participating in study design collaboratively in drafting the survey released amounted to a substantial contribution. Discussion among the published authors and researchers did not lead to a resolution, leaving authorship disputed.

### Resolving Disputes

Dispute resolution in academic contexts generally relies less on editorial norms than institutional ones, and rises up the chain of institutional hierarchy with more senior authors or researchers arbitrating conflict. Where research teams are constituted outside of formal institutional structures however, the dilemma of the original dispute is compounded. Not only is authorship itself at a contested impasse, but how to resolve the dispute itself arrives at a contested impasse. In the *Psychiatric Services* example, more than 5 institutions were involved, the lead researcher worked with an unaffiliated private company, and the survivor researcher collaborators had no academic affiliation at all. And because authorship questions are traditionally determined by institutional authority, this can magnify existing power imbalances survivor led research sought to redress. (Newman, 2006)

Such dilemmas are common in authorship disputes. A study of short-term contract researchers found that "because of hierarchy and the status of senior academics, there were often no formal avenues of appeal against authorship decisions made by the principal investigator. Resolution of difficulties was often too subjective and dependent on personality, instead of on policy." (Newman, 2006) The ICMJE and COPE recommends that authorship disputes be resolved by the researchers working out their differences on their own; journals are ill-equipped to investigate or mediate author disputes. (Albert & Wager, 2009) The problems with relying on internal dispute resolution include power differentials, misuse of power by senior faculty, and the greater likelihood of outcomes unfavorable to under-represented and vulnerable groups. (Faulkes, 2018) Elsevier recommends contacting the corresponding funding agency to work for resolution, but funders are interested parties and may not approach disputes impartially, may be reluctant to get involved, share an urgency to avoid any appearance of difficulty to protect their reputations, or may fear legal exposure. (Elsevier, 2019) Researchers affiliated with the *Psychiatric Services* paper did approach the Foundation for Excellence in Mental Health Care, the study's funder, but they declined to offer a pathway to resolution or disclose the contract associated with the research. Though internal resolution is typically out of reach, there are also no recognized avenues elsewhere to seek help. (Faulkes, 2018; Seeman & House, 2015)

Unresolved authorship disputes can result in "reputational harm" to the generation of innovative endeavors in research, setting back emerging fields and erecting new barriers to the incorporation of survivor leadership in new settings. (Rasmussen, 2019)

Fairness is crucial in the allocation of authorship to ensure that individuals are duly recognized for their contributions. This includes recognizing those who have contributed in ways that allow them to be considered co-authors, and also ensuring that others are recognized in a manner that is respectful of authorship criteria. Otherwise, established authorship parameters could be breached, which could foster unethical publication practices, be they gift-authorship (individuals who do not meet authorship criteria are named as authors) or the unfair exclusion of partners (individuals who have contributed to a publication, but are excluded from authorship because their contribution has not been valued fairly). Such practices contradict the aims of inclusivity and fair recognition embedded in [patient engagement in research] DNA, and would cast skepticism on the recognition of the contribution of [patient partners] to research. (Smith et al., 2019)

### Recommendations

Beyond the importance of good business practices (which may be unfamiliar to patient participants and survivor researchers new to professional research collaborations) such as documenting written agreements in writing, relying on clear contracts, and ensuring transparency of the written record as a condition for entering into a collaboration, the *Psychiatric Services* example suggests a number of lessons for the future. Such lessons may be especially important to protect the innovative and sometimes fragile efforts of patient involvement and survivor leadership in research, and help researchers succeed across differences in background, power, and experience.

Many sources, including COPE, emphasize the importance of planning authorship issues at the outset of a project. (Albert & Wager, 2009, Stocks et al., 2018) Authors should be familiar with ICMJE guidelines and advised that all authors collectively bear responsibility for the work, so that in the event of dispute all can be actively involved in the resolution. "The peer-reviewed literature is full of examples where people who claim credit are quick to abdicate their responsibility when the work was found to be fraudulent or flawed." (Clement, 2014) Alternative dispute resolution methods should be agreed to before entering into the collaboration, and funders should consider requiring impartial resolution agreement as part of funding contracts, to help mitigate the power imbalances often inherent in team collaboration. "People who now have the seniority to try to determine or influence authorship credit could have that power reduced if alternative dispute resolution services were well known and readily available to authors." (Faulkes, 2018) Recognizing the vulnerability of short-term researcher who may leave the project team, Kings College researchers recommended arbitration and appeal for dispute resolution, with consideration for potential conflict of interest address by identifying an external person or panel to make impartial determinations (Newman, 2006) Prior agreement that any journal submitted to should be advised of unresolved authorship disputes would create a strong incentive to resolve conflict or face manuscript rejection.

If a dispute is brought to an associated institution but the institution does not pursue an investigation, one solution is to attach Expression of Concern to the published article once it is available. Expressions of concern raise awareness to a possible problem in a published paper. They are a relatively new, rare, and non-standardized type of editorial notice compared to corrections or retractions with considerable differences among journals (Vaught et al., 2017). The COPE suggests editors might consider an expression of concern if they receive evidence of misconduct that is inconclusive; affiliated institutions are presented with evidence but will not investigate; they believe investigation has not been or would be impartial, or an investigation is underway but a judgment is not available at the time of publication. (COPE, 2018)

Peer review, including involvement of an ethics expert, is suggested as an alternative to mediation or arbitration, using an outside third party to investigate and complete a full review of the issues, with an option to appeal and also the option of more binding arbitration. (Master & Tenenbaum, 2019)

Conflict involving survivor-researchers may be magnified by the background of rights advocacy and protection informing survivor initiatives, and survivor researchers may approach disputes from a rights and legal framework. Intellectual property rights do form the basis for authorship ethics, given that intellectual property allows creators or owners of patents, trademarks, or copyrighted works to benefit from their own work or investment in a creation These rights arise from the United Nations Universal Declaration of Human Rights, which states, “Everyone has the right to the protection of . . . any scientific, literary or artistic production of which he/she is the author.” (Syed et al., 2015) However, especially in the US context, legal counsel may have a chilling effect on resolution, as different parties involved retreat from dialogue into litigious protection from perceived legal exposure.

Especially in the internet era of rapid availability of up-to-date information, some scholars have suggested a "contributor-guarantor" model may be better suited to prevent misconduct and conduct around authorship, where all contributors are described and those responsible for the work designated as "guarantors". (Leash, 1997) Such an approach would have the advantage of providing detailed transparency around the generation of the research and the creation of the resulting publication, rather than being confined to the less explicit author-acknowledgement model today. Published works could be linked to associated explanatory texts with details about each contributor and their precise role, rather than forcing readers and institutions to rely on more limited understanding of how a paper came to be published. It would also better fit with a survivor- research and advocate ethic emphasizing scrutiny of power relations in research contexts.

Given the unlikelihood that biomedical researchers in all fields, institutions, and countries will soon come to full agreement with each other, let alone with journal editors, on detailed standards for biomedical authorship, it seems at present that explicit disclosure of each person’s role in the reported research is the most sensible way to discourage abuses of authorship, permit credit for all substantial contributions, and inform editors and readers of who stands behind each key portion of the work and who is prepared to vouch for the work as a whole. (Leash, 1997)

Finally, Faulkes noted that "rather than viewing authorship disputes as rare events that must be handled on a case by case basis, researchers and journals should view the potential for disputes as predictable, preventable, and soluble." (Faulkes, 2018) Such predictable difficulties might be better understood as opportunities for continued learning and growth, especially between researchers from across different backgrounds. "We are going to do research and publish together" may need to be reformulated as "We are going to do research and publish together and expect to encounter conflict that we will then approach generatively to further our research aims." Such an approach might replace acrimonious disputes, which set back shared goals, with creative opportunities supported by outside accountability. By bringing authorship dispute and misconduct allegations out of the shadows in this way, obstacles of conflict can be overcome to welcome future collaboration and promote continuation of the imperative for patient and survivor participation in research, while also reflexively ensuring ethical conduct and responsibility in scientific research.

BIBLIOGRAPHY

Albert, T., & Wager, E. (2009). *How to handle authorship disputes: A guide for new researchers*. Committee on Publication Ethics.<https://doi.org/10.24318/cope.2018.1.1>

Clement, T. P. (2014). Authorship Matrix: A Rational Approach to Quantify Individual Contributions and Responsibilities in Multi-Author Scientific Articles. *Science and Engineering Ethics*, *20*(2), 345–361.<https://doi.org/10.1007/s11948-013-9454-3>

Committee on Publication Ethics. (2018). *Notes from Forum Discussion Topic\_Expressions of concern\_final.pdf*.<https://publicationethics.org/files/Notes%20from%20Forum%20Discussion%20Topic_Expressions%20of%20concern_final.pdf>

Digiusto, E. (1994). Equity in authorship: A strategy for assigning credit when publishing. Social Science & Medicine, 38(1), 55–58. doi:10.1016/0277-

Eastwood, S., Derish, P., Leash, E., & Ordway, S. (1996). Ethical issues in biomedical research: Perceptions and practices of postdoctoral research fellows responding to a survey. *Science and Engineering Ethics*, *2*(1), 89–114.<https://doi.org/10.1007/bf02639320>

Edelman, N., & Barron, D. (2016). Evaluation of public involvement in research: Time for a major re-think? *Journal of Health Services Research & Policy*, *21*(3), 209–211.<https://doi.org/10.1177/1355819615612510>

Elsevier. (2019). *Elsevier—Authorship Complaints*.

Faulkes, Z. (2018). Resolving authorship disputes by mediation and arbitration. *Research Integrity and Peer Review*, *3*(1), 12.<https://doi.org/10.1186/s41073-018-0057-z>

Hall, W., Icarus Project (New York, N. Y. ), & Freedom Center (Northampton, Mass. ). (2012). *Harm reduction guide to coming off psychiatric drugs*. Icarus Project ; Freedom Center.

ICMJE. (2019). *ICMJE Recommendations Defining the Role of Authors and Contributors*.

Jacobs, A., & Wager, E. (2005). European Medical Writers Association (EMWA) guidelines on the role of medical writers in developing peer-reviewed publications. *Current Medical Research and Opinion*, *21*(2), 317–321.<https://doi.org/10.1185/030079905X25578>

Leash, E. (1997). Is It Time for a New Approach to Authorship? *Journal of Dental Research*, *76*(3), 724–727.<https://doi.org/10.1177/00220345970760030101>

Marušić, A., Bošnjak, L., & Jerončić, A. (2011). A Systematic Review of Research on the Meaning, Ethics and Practices of Authorship across Scholarly Disciplines. *PLoS ONE*, *6*(9), e23477.<https://doi.org/10.1371/journal.pone.0023477>

Master, Z., & Tenenbaum, E. (2019). The advantages of peer review over arbitration for resolving authorship disputes. *Research Integrity and Peer Review*, *4*(1), 10.<https://doi.org/10.1186/s41073-019-0071-9>

National Survivor User Network. (2018). *Survivor Researcher Network—Mental health knowledge built by service users and survivors Manifesto*.

Newman, A. (2006). Authorship of research papers: Ethical and professional issues for short-term researchers. *Journal of Medical Ethics*, *32*(7), 420–423.<https://doi.org/10.1136/jme.2005.012757>

Ostrow, L., Jessell, L., Hurd, M., Darrow, S. M., & Cohen, D. (2017). Discontinuing Psychiatric Medications: A Survey of Long-Term Users. *Psychiatric Services*, *68*(12), 1232–1238.<https://doi.org/10.1176/appi.ps.201700070>

Psychiatric Services. (2019). *Information for Contributors | Psychiatric Services*.<https://ps.psychiatryonline.org/ps_ifora#01>

Rasmussen, L. M. (2019). Confronting Research Misconduct in Citizen Science. *Citizen Science: Theory and Practice*, *4*(1), 10.<https://doi.org/10.5334/cstp.207>

Russo, J. (2012). Survivor-Controlled Research: A New Foundation for Thinking about Psychiatry and Mental Health. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *13(1), Art. 8,* 22.

Russo, J., & Beresford, P. (2015). Between exclusion and colonisation: Seeking a place for mad people’s knowledge in academia. *Disability & Society*, *30*(1), 153–157.<https://doi.org/10.1080/09687599.2014.957925>

Sacristan, J. A., Aguaron, A., Avendaño, C., Garrido, P., Carrion, J., Gutierrez, A., Kroes, R., & Flores, A. (2016). Patient involvement in clinical research: Why, when, and how. *Patient Preference and Adherence*, 631.<https://doi.org/10.2147/PPA.S104259>

Seeman, J. I., & House, M. C. (2015). Authorship Issues and Conflict in the U.S. Academic Chemical Community. *Accountability in Research*, *22*(6), 346–383.<https://doi.org/10.1080/08989621.2015.1047707>

Smith, E., Bélisle-Pipon, J.-C., & Resnik, D. (2019). Patients as Research Partners; How to Value their Perceptions, Contribution and Labor? *Citizen Science: Theory and Practice*, *4*(1), 15.<https://doi.org/10.5334/cstp.184>

Stocks, A., Simcoe, D., Toroser, D., & DeTora, L. (2018). Substantial contribution and accountability: Best authorship practices for medical writers in biomedical publications. *Current Medical Research and Opinion*, *34*(6), 1163–1168.<https://doi.org/10.1080/03007995.2018.1451832>

Strange, K. (2008). Authorship: Why not just toss a coin? *American Journal of Physiology-Cell Physiology*, *295*(3), C567–C575.<https://doi.org/10.1152/ajpcell.00208.2008>

Supak-Smolcic, V., Mlinaric, A., Antoncic, D., Horvat, M., Omazic, J., & Simundic, A.-M. (2015). ICMJE authorship criteria are not met in a substantial proportion of manuscripts submitted to Biochemia Medica. *Biochemia Medica*, 324–334.<https://doi.org/10.11613/BM.2015.033>

Syed, S., Tran, D. Q., Kemper, A. R., Geme, J. W. S., & Lantos, J. D. (2015). Authorship Concerns and Who Truly Owns a Research Idea? *PEDIATRICS*, *136*(5), 969–973.<https://doi.org/10.1542/peds.2015-1421>

Vaught, M., Jordan, D. C., & Bastian, H. (2017). Concern noted: A descriptive study of editorial expressions of concern in PubMed and PubMed Central. *Research Integrity and Peer Review*, *2*(1), 10.<https://doi.org/10.1186/s41073-017-0030-2>

### ABSTRACT

Public participation and survivor led research in mental health is widely recognized as vital to the field. At the same time, the role of patient collaborators can present unique challenges to determining authorship. Using dispute around a publication in the American Psychiatric Association's *Psychiatric Services* journal, authorship and contribution are addressed. Recommendations are suggested to respond more effectively to potential prevent dilemmas and achieve responsible research credit inclusion for successful future patient-researcher collaboration.