Poster #9

Publishing Company-Sponsored Research: A Patient Remuneration Guidelines Initiative

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This work represents the opinions of the authors and not necessarily that of their affiliations.

Patient involvement in publications is underpinned by the principles of ethics and compliance, both of which require equity and recognition of value

GPP
GOOD PUBLICATION PRACTICE

BACKGROUND

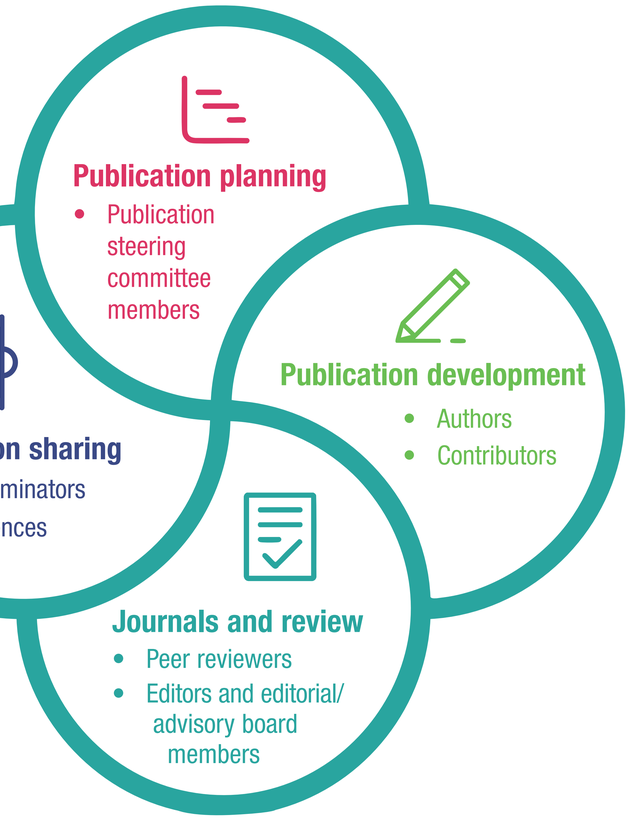
Good Publication Practice (GPP), including GPP 2022[1], allows remuneration for stakeholders including patients for peer-reviewed publication activities. Companies currently have varied approaches and need clearer guidance on patient remuneration for publication activities, including authorship

COMMITTEE DISCUSSIONS

GPP Steering Committee members recruited experts on patient participation (MAR, TB, and AR) to develop recommendations for remuneration by reviewing existing guidance and engaging in open discussion and intellectual exchange

ROLES FOR PATIENTS

Patients are increasingly participating throughout the publication development lifecycle. Roles for patients also exist outside of the individual publication lifecycle, for example in evaluation, training, and thought leadership[2,3]



KEY DISCUSSION POINTS

Transparency, conflicts of interest, and undue influence
Historical ethical challenges, such as paid guest authorship should not overshadow or hinder the fair inclusion of patient authors in the present publication landscape

External support for remuneration
- GPP 2022[1] specifically mentions remunerating patients
- ABPI[4] and EFPIA[5] support remuneration for patient collaborations with pharma

Parity with other authors (i.e. clinical, academic, industry authors)
- Equity for patient authors means fairly considering their situations and needs
- Patient participation is often an exhibition of beneficence outside of the context of a paid or salaried role
- Patient participation provides expertise, enriches literature, and forwards medical endeavor, all of which should be recognized and valued

Patients declining remuneration
Patients receiving various government benefits may not be able to accept remuneration, due to earning thresholds

Selection bias arising from not remunerating
Not providing payment can limit patient participation and create selection bias, affecting the quality of the publications. Diversity of input is reduced if only some patients can afford to participate

SOLUTIONS AND RECOMMENDATIONS

- Patients should be offered remuneration at fair market value rates for time spent on publication-related activities, including authorship
- Fair market value rate remuneration or alternatives to this should be detailed in (an addendum to) a contract that specifies the scope of responsibilities
- Patients should be able to opt out of payments (or opt for an alternative, like charitable donations)
- Declarations should be made in line with industry best practices for transparency
- Patients receiving remuneration for publication activities should be assured, in writing, that they can express their opinions openly, or be provided with a patient advocate or other advisor who can communicate with company representatives in their name to prevent undue pressure on the patient participant
- Local country laws and regulations should be respected
- Companies should develop internal standard operating procedures to ensure compliance and consistency with their policies and with ethical guidance

NEXT STEPS

We believe that remuneration, at fair market rate, is warranted for patients asked to serve in any capacity to support publication activities, including as authors. Further practical guidance to implement best practices will be included in a forthcoming peer-reviewed publication

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Disclosures and acknowledgements: MAR is an employee of Taylor & Francis group, however this work is independent of her employment. She is also a paid patient consultant for a pharmaceutical company but has no other disclosures to declare. TB undertakes paid and unpaid consultancy and advocacy for various stakeholders in the life sciences and healthcare industries, including pharmaceutical companies, medical communications agencies, medical publishers, academia, and patient organizations. She is a visiting lecturer at the Centre for Pharmaceutical Medicine Research, King's College London. She serves on the editorial boards of The Research Post and Neurology and Therapy, is on the Patient Advisory Panel of Therapeutic Advances in Drug Safety, and is a member of the PLS Advisory Panel for Taylor & Francis, Sage Publishing and Becaris, for which she receives honoraria for plain language summary reviews. She is also a member of the ISMPP Patient Engagement Taskforce and the ISMPP EU 2025 planning committee, as well as the Good Publication Practice Steering Committee. LDT undertakes paid and unpaid consultancy and advocacy for various stakeholders in professional societies, publishers, and academia. LD is a co-owner of Becaris Publishing Ltd. She undertakes paid and unpaid consultancy for stakeholders in the healthcare industry (including pharmaceutical companies and medical communication agencies) and the academic publishing industry. She receives an honorarium as a journal Editor-in-Chief. EH is an employee of Excerpta Medica, however this work is independent of employment. AR receives departmental funding from the Centre for Pharmaceutical Medicine Research, King's College London, for research on patient authorship and is an employee of Oxford PharmaGenesis, however this work is independent of these affiliations. DT has no disclosures to declare.

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