

Payments for Patient Authors

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Introduction

This short paper identifies a problem regarding patient authorship and suggests how the International Committee of Medical Journal Editors can help to solve it and support innovation.

The problem

Scandals from Andrew Wakefield to Jose Baselga² have rightly pressed the publication world to avoid any suggestion of bribery or corruption. However, controls designed to combat these egregious violations have three unintended consequences.

- They block appropriate financial recognition of patient authors. In many cases, academic researchers are paid for their work while patients write for nothing.
- Routine payments to academics (such as salary) do not trigger conflict of interest systems, while patient authors are burdened with the obligation to complete these submissions, implying that their integrity is in doubt compared to their academic colleagues.
- Worries about bribery are distorting the profile of publications across the sector by reducing the number of submissions from patient authors, inhibiting academic partners from forming writing partnerships with patients and reducing the likelihood that editors will accept submissions.

Recommendation

The ICJME should make a public statement informing members that proportionate payments made by a research institution to a patient author will be treated in the same way as the salary payments made by that institution to its employed researchers and clinicians. Editors should retain the right to inquire about undue influence but in future make no distinction in their arrangements regarding the remuneration of academic and patient authors.

¹ Correspondence to peter.bates@ndti.org.uk. This paper was written on 15 September 2018 and represents a personal view. My work involves patient participation; I am not an expert patient. I provide independent consultancy to the [Institute of Mental Health](#) and the [National Development Team for Inclusion](#).

² Dr Andrew Wakefield received nearly half a million pounds from the legal establishment in connection with his campaign to link MMR and autism that included publishing falsified evidence – see Boyce T (2007) *Health, Risk and News: The MMR Vaccine and the Media*. On 9 September 2018, it was alleged that , Dr. José Baselga had received over \$3 million from the private sector yet disclosed none of these connections in his publications – see [here](#).

Appendix – detailed explanations

The place of patient authorship

Across the world, patients are moving into more active roles in research production as well as in health service design, delivery and evaluation, and in shaping their own treatment. In the UK, public funds provide for the National Institute of Health Research and its patient participation organisation INVOLVE, which is a world leader in engaging patients as partners in research production. INVOLVE recommends that patients are involved in the whole process of research production – in priority setting, shaping research proposals, serving as co-applicants, membership of the Trial Steering Committee and management group, data collection and analysis and dissemination. One key element of this is the role of patients as authors and co-authors of peer-reviewed academic papers.

Who are the patients?

Several categories of people may be considered as set out in the bullet points below.

- Health research is founded on data provided by patients and healthy volunteers. These research subjects are not the focus of this paper.
- Some academic researchers and clinicians also have personal exposure to the disease under scrutiny. They may have received a diagnosis or treatment or supported a relative through the course of the disease. Efforts are being made in some places to apply disability and equality legislation by making reasonable adjustments to employment practices so that such individuals are no longer under-represented in the workforce or culturally obliged to keep their personal experience a secret in the workplace. However, these employees are receiving a salary through their employment and so are not the subject of this paper.
- Patient organisations are active in fundraising, support and advocacy on behalf of their patient group. When the organisation is large enough to employ staff, a professional group emerges who are salaried for their expertise in understanding the needs of this group of patients, managing their organisation and addressing the media. They receive a salary through their organisation and are not the subject of this paper.
- Individual patients and their relatives and friends are living the reality of the disease on a daily basis. They are unschooled in research and clinical practice but have a vital interest in the development of evidence-based treatment. They are commonly unemployed and so have time available to contribute their raw insights about the proposed research, use their outsider perspective to challenge its delivery, bring personal testimony to dissemination and check the clarity of published material. This is the group that is the particular focus of this paper, that are often dubbed 'expert patients' in recognition of their lived experience and knowledge of how the disease impacts a real life.

What is a patient author expected to do?

Whilst academic and clinical authors may provide support to their patient author colleagues, I am not seeking any concessions on the usual requirements for claiming authorship. Patient authors are not guests or gift authors, and nor should they be relegated to the role of ghost authors – making a significant contribution throughout the life of the research but appearing in the acknowledgement paragraph rather than as a full author. If they meet the usual requirements, they should be acknowledged as authors and if they do not, then they must not claim authorship.

The role of the ICJME

To date, I believe that ICJME has been silent on the matter of remuneration to patient authors. This silence permits defensive practice and the resultant unfairness to continue. Members will fear that accepting papers written by remunerated patient authors will attract negative publicity and so may either reject papers or load additional administrative burdens on to patient authors. Academic researchers may continue to ask patients to write for nothing or will relegate patients to other phases of research production and deny them a place in publication.

As the drive for patient-centricity gains momentum this issue will become increasingly prominent. There is a real opportunity for the ICJME to pioneer and take the ethical high ground where reasonable patient remuneration is treated in the same way as ordinary remuneration for academics and clinicians. A clear signal from ICMJE may stimulate positive change throughout the sector.

Payments for patient authors

This recommendation addresses the way in which payments made by a research institution are viewed by editors. Current financial arrangements between publishing houses and authors, specifically payments by the publisher to authors in the form of fees for writing or royalties, are unaffected by this recommendation.

Research institutions pay patients in a variety of different ways – as employees, contractors or through honoraria, gifts or ‘participation payments’. This variety parallels the arrangements for academic authors, where the details of the relationship between the academic and the institution of which they are a part are not usually investigated. Some academics are salaried employees while others may be more loosely allied to the institution. Editors rightly inquire about the presence of any conflicts of interest, but do not routinely ask for copies of the employment contract.

My recommendation is that payments to patient authors are ‘reasonable’. This means that the payment to the patient author should be no more than the approximate hourly rate paid to the most well-paid member of the academic team. This provides a threshold for determining when payments are excessive and should trigger more detailed disclosures, declarations of interest and investigations, but this threshold is not to be taken as a recommendation for the actual level of remuneration to a particular patient.

The idea has been put forward that busy employed clinicians and researchers actually write their papers during their evenings and weekends, so can claim to be unfunded, just like unemployed patients. This suggestion is comprehensively dismissed.

Research institutions have a duty to operate within the employment law of their country, to support the taxation system and any welfare benefits system that may apply to the patient, to act ethically and to treat the patient with dignity and respect. Some institutions confine payments to patients who are not otherwise employed. By creating equitable arrangements for the remuneration of patient authors, the ICMJE will uphold the dignity of the patient, but these broader matters of employment, tax, welfare and ethics are beyond the scope of this recommendation.

What are the UK participation payments?

In the UK, INVOLVE recommend that expert patients contribute to every stage of research production and that research budgets include funds to enable the research team to offer 'participation payments' to unsalaried patients who comment on documents, attend committee meetings, speak at conferences and so on. These are commonly small amounts, ranging from £10 to under £500 and have the nature of gratuities, honoraria or gifts, offered in addition to the reimbursement of out-of-pocket expenses, such as travel or childcare costs.

INVOLVE have negotiated with the UK welfare benefits department and tax office to ensure that receipt of these participation payments does not indicate that a contract of employment is in place and whilst the funds should be declared, they will commonly be ignored in government calculations of the patients' benefit entitlement or tax liability. Patients may refuse to accept the offer of a participation payment and anything up to two thirds of people do refuse them, preferring the self-image of independence and volunteering that comes with entirely altruistic actions. Even the people who are regularly involved in several different projects receive only very small amounts of money in total and this occurs sporadically, sometimes with only a few such payments being received over the course of a year.

A strategy designed to increase patient participation will have several strands – create an organisational culture where patient experience is valued, recruit suitably qualified patients into academic and clinical posts, build partnerships with patient organisations that will provide the reach and broader constituency of viewpoint, and engage with individual patients who bring the integrity of their own experience to the table. Participation payments are designed to recognise and honour these individual voices.