

## How to guide

# How to involve the public as co-authors

21/10/2017

See the most recent version of this at <http://www.emahsn.org.uk/public-involvement>



### Introduction

Members of the public who get involved in research or service delivery may want the opportunity to write something for publication, either as a sole author or as a co-author. Whilst this can involve a lot of work, it can be rewarding for the public author, especially when the writing helps others facing similar life challenges to their own; and for the academic author, especially when they have few other opportunities to collaborate with member of the public. However, everyone needs to be aware of what is involved in writing together, so the points below form an introduction.

This document was drafted by Peter Bates for the [East Midlands Academic Health Science Network](#) as part of its work on Public Leadership. Its purpose is to promote the involvement of the public in writing materials for publication and to refine our understanding of best practice. We hope it will help members of the public, researchers and health professionals in the East Midlands to make progress in this area. As readers<sup>1</sup> provide feedback, further insights will be used to update the

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<sup>1</sup> Comments and challenges to earlier drafts have been gratefully received from Tony Avery, Catherine Bewley, Lydia Bird, Jonathan Boote, Toby Brandon, David Brindle, Louise Bryant, Pam

paper. Please contact [shahnaz.aziz@nottingham.ac.uk](mailto:shahnaz.aziz@nottingham.ac.uk) to suggest improvements or tell us how you have made use of this paper.

## A note on language and the reach of this paper

In this paper, the term ‘public’ means patients, service users, carers and members of the wider public<sup>2</sup>.

We recognise that a host of media are available to disseminate information, including TV, newspaper and radio as well as online forms of publishing such as You Tube, Facebook and blogs. This paper is about writing papers for publication in the academic press, although some of its principles may be transferable to other media.

There are many pressures that inhibit this sort of collaboration. In some journalistic traditions, professional writers energetically defend their independence and so refuse to let the people see what has been written about them until it appears in print, while others actively seek out co-authors<sup>3</sup>. This kind of interview copy control or copy approval is vigorously denied by many journalists in the UK – see [here](#). Academics may be also hanging on to the value of publication in the peer-reviewed academic press as this helps their career, while public co-authors are more interested in achieving improvements in health services, where academic papers are rarely utilised<sup>4</sup>.

Many academic authors have personal experience of using health or social care services and are sometimes called *service user-researchers* or *consumer-researchers*. They have a kind of ‘dual identity’, as they are employed as researchers or healthcare professionals and they also live

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Carter, Kathryn Church, Michelle Cornes, Claire Goodman, Gordon Grant, Sarah Hewlett, Stephen Kosslyn, Antje Lindenmeyer, Stephanie Petrie, Vanessa Pinfold, Konstantina Poursanidou, Stefan Priebe, Rachel Purtell, Alan Simpson, Mike Slade, Rebecca Stack, Glen Swanwick, Maryrose Tarpey, Rebecca Toney, Paul Ward.

<sup>2</sup> We recognise that these are contested terms, and some people find the reference to the ‘public’ too vague, while alternative terms such as ‘service user’ or ‘carer’ also carry unwanted freight. See <http://www.peterbates.org.uk/uploads/11N.pdf>

<sup>3</sup> Differences arise in the approach to copy control taken by the media in different countries – see <http://blogs.lse.ac.uk/polis/2014/07/21/copy-approval-a-clash-of-journalism-and-citizen-ethics-between-sweden-and-britain/>

<sup>4</sup> An ethnographic study of commissioners found they were unlikely to have access to academic literature, lacked the time to read detailed study reports and experienced difficulties in applying it to their local situation, so it was unlikely to have any impact on their decisions whatsoever – see <http://www.dc.nihr.ac.uk/blogs/researchers-to-make-an-impact-write-less-and-talk-more/5933>

with a health condition or use services, and a specific academic discipline has recently grown up to theorise and develop academic rigour for work in this field<sup>5</sup>. Some people with dual identity have declared this fact in their writing, while others prefer to treat their personal circumstances as a private matter – but it may still influence their output.

The focus of this paper is not on authors who have this kind of dual identity. Rather it focuses on writing collaborations that bring together academics or healthcare professionals on the one hand, and members of the public on the other; collaborations between professionals and lay persons; between employees who *must* write and members of the public who *wish to* write.

Finally here, we note that co-authoring is not a total solution to the challenge of working together on the whole research project and cannot on its own represent the epitome of Patient and Public Involvement. Rather, co-authoring forms just one of the many expressions of full and meaningful involvement. It is just one of the many things that will all be needed if professionals are to genuinely share with the public the processes of knowledge production, dissemination and implementation.

### **Suggestions for producing good quality work**

When two or more people with varying levels of experience of writing in an academic style collaborate to produce a piece of writing together, it is helpful to have a candid discussion about how you will come to an agreement about the quality of the writing if there are disagreements. The following suggestions may be useful:

- Learn your craft by following sound advice about writing<sup>6</sup> and co-authoring<sup>7</sup>. Be prepared to invest time and focused effort in co-

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<sup>5</sup> Ethnography is the scientific study of individual societies. Autoethnography explores the researcher's personal experience and connects this autobiographical story to the way that explanations are formed in the wider society. For an example of autoethnographic writing in mental health, see Short NP, Grant A & Clarke L (2007) Living in the borderlands; writing in the margins: an autoethnographic tale *Journal of Psychiatric and Mental Health Nursing*, 14, 771–782.

<sup>6</sup> See, for example <http://blogs.lse.ac.uk/impactofsocialsciences/2014/09/04/seven-strategies-to-improve-academic-writing-dunleavy/?com>

<sup>7</sup> See <http://authorservices.taylorandfrancis.com/custom/uploads/2017/09/Coauthorship-white-paper.pdf>

authoring as it is a time-consuming process on both sides that involves a great deal of negotiation.

- You may want to check out each other's previous writing and publications (if they have any) before agreeing to work together, as this may show that one writer needs a lot of coaching or your different styles may need some care to bring together into a single article.
- Assign one writer the role of lead author so that they 'have the last word'. Have a candid discussion about what to do about spelling errors matter and whether the lead author will edit grammar or reorganise content into a new structure.
- Agree how you will share drafts around the writing team and that comments are welcome from all members of the team, so that everyone can comment on everyone else's contributions and the process goes on until all are happy with the result.
- Begin with a less ambitious publication, such as an abstract for a conference presentation) before agreeing to write a more challenging one together.
- Look at your target journal – read several papers and ensure the style you are writing in is consistent with this. Some journals will only accept papers written in a very particular structure and style, and forcing the message into this format may result in the loss of the co-author's authentic voice.

### **The rationale for co-authoring academic papers**

Co-authoring academic publications makes sense for many reasons, including the following:

- The principle of 'nothing about me without me' has been adopted by the United Kingdom government as a key shaper of public services<sup>8</sup>, and this underlines the fact that publicly funded research should be accountable to the very people being researched.

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<sup>8</sup> Department of Health (13 Dec 2012) *Liberating the NHS: No decision about me, without me – Government response to the consultation*. Available [here](#).

- As with many other aspects of research and service delivery, attending to the views of the public can tighten the focus of the work, enhance its relevance and speed its dissemination, especially where the person giving their views has lived through the experience being investigated. While academic papers must not ‘go beyond the data’, one professional journalist<sup>9</sup> commented,

*“Public co-authors will often cut unerringly to the point, a refreshing contrast to professional researchers’ hedging and obfuscating and the inevitable call for more research. Never let that directness be squashed!”*

- Paying attention to subjective reality as it is lived out by people going through the experience encourages the academic community to pay attention to experiential, embodied and tacit knowledge in addition to traditional scientific propositions, leading to a richer and more holistic understanding. Many of the ideas here are brought together into an approach sometimes called ‘action research’<sup>10</sup>.
- The expectations placed on academics about productivity and meeting targets makes it harder to find the time to build an effective writing partnership with members of the public - but it can help people to retain a focus on patient experience.

### **How commonplace is it to include public co-authors?**

The National Institute of Health Research (NIHR) is one of the most substantial funders of health research in England. They expect the public to be involved in all stages of the research<sup>11</sup>. Through its work on public involvement, NIHR maintains a searchable [archive](#) of relevant publications, including information about authors. In September 2014, a

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<sup>9</sup> David Brindle, personal communication 10 December 2014.

<sup>10</sup> See the 2013 position paper defining Participatory Health Research from the International Collaboration for Participatory Health Research [here](#).

<sup>11</sup> Although we may note that the final report proforma for Programme Development Grants (and perhaps other grants too) from the NIHR asks for the name of the principal investigator as the report author, but there is no provision to allow public co-authors of the report to be acknowledged.

total of 196 papers were listed, of which 89 (45%) were written or co-written by 'service users or carers'<sup>12</sup>.

Engaging public co-authors is routine in some organisations, such as Arthritis Research UK, where all projects include at least one patient research partner. In evidence of this, Professor Hewlett has published more than 45 papers with patient research partners<sup>13</sup>.

Public co-authors have lived with and contributed to papers on a variety of conditions, including autism<sup>14</sup>, burns<sup>15</sup>, cancer<sup>16</sup>, learning disability<sup>17</sup>, mental health<sup>18</sup>, old age<sup>19</sup>, palliative care<sup>20</sup> and rheumatology<sup>21</sup>.

However, notwithstanding the critical importance of having the public writing academic papers together with researchers and health professionals, international guidance<sup>22</sup> for authors on how to report public involvement in health research does not include any reference to public co-authors.

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<sup>12</sup> This includes some academic authors who identify as service users or carers. An email was sent to the lead author of 84 of these papers seeking advice on co-authoring in September 2014. Those who responded are listed in footnote 1.

<sup>13</sup> Professor Hewlett is at the University of the West of England (personal communication, 6 October 2014).

<sup>14</sup> McClimens, A. Evans, J. (2013) Credit Where It's Due: clients' contributions to academic research *Learning Disability Practice* vol 16 no 7 26-28

<sup>15</sup> Broerse, J., Zweekhorst, M., van Rensen, A. & de Haan, M. (2014) Involving burn survivors in agenda setting on burn research: An added value? *Burns*, 36(2), 217-231.

<sup>16</sup> Arain, M., Pyne, S., Thornton, N., Palmer, S. and Sharma, R. (2014) Consumer involvement in cancer research: example from a Cancer Network *Health Expectations*, advance e-publication, DOI: 10.1111/hex.12143

<sup>17</sup> Abell, S et al (2007) Including everyone in research: The Burton Street Research Group *British Journal of Learning Disabilities*, 35, 121-124

<sup>18</sup> Simpson, A., Jones, J., Barlow, S., Cox, L. and SUGAR (2014) Adding SUGAR: Service user and carer collaboration in mental health nursing research. *Journal of Psychosocial Nursing and Mental Health Services*, 52(1), 22-30.

<sup>19</sup> Bindels, J., Baur, V., Cox, K., Heijing, S. and Abma, T. (2014) Older people as co-researchers: A collaborative journey *Ageing & Society*, 34(6), 951-973.

<sup>20</sup> Goodman, C., Mathie, E., Cowe, M., Mendoza, A., Westwood, D., Munday, D., Wilson, P., Crang, C., Froggatt, K., Illiffe, S., Manthorpe, J., Gage, H. and Barclay, S. (2014) Talking about living and dying with the oldest old: Public involvement in a study on end of life care in care homes *BioMed Central (BMC) Palliative Care*, 10, 20

<sup>21</sup> Hewlett, S., De Wit, M., Richards, P. Quest, E. Hughes, R., Heiberg T & Kirwan J (2006) Patients and Professionals as Research Partners: Challenges, Practicalities, and Benefits *Arthritis & Rheumatism (Arthritis Care & Research)* Vol. 55, No. 4, August 15, 2006, pp 676-680. DOI: 10.1002/art.22091

<sup>22</sup> The GRIPP checklist is [here](#).

## What kind of paper are you writing?

Some co-authored papers are like a salad and others are like soup. In a salad, the separate ingredients remain distinct and identifiable, while in a soup it is all blended together into one. Thus, in some papers, there may be a distinct section written by the public author and another written by the professional, so readers can clearly identify the voice of each<sup>23</sup>.

Using narrative combined with quotations can inadvertently imply that the narrator holds the power and is therefore the one who is qualified to lead the reader through the world as they understand it, pointing out each quoted author in turn rather like a museum curator might point out exhibits. In other writing projects, discussions lead to a consensus in which there seems to be no need to identify distinct voices.

The Comensus Writing Collective have published a book<sup>24</sup> that utilises these different approaches, varying the medium to reflect the origin and development of each chapter<sup>25</sup>. Similarly, Kathryn Church utilises a variety of these approaches in different kinds of work, sometimes blending them to create new variations:

*“In one study<sup>26</sup>, we had a monologic voice (mine, largely) in the main body of the document - though I worked from group discussion, and I worked iteratively from group feedback on a number of drafts. But we knew that we didn't completely agree (with the monologue). So, we had personal insertions throughout the document to allow each person who wanted to comment their personal space for writing....their point of view on the topic.”<sup>27</sup>*

It is helpful to discuss your plans at the start of your writing collaboration, and ensure the resulting plans fit the format of the target journal.

## Selecting a journal and finding out what they expect

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<sup>23</sup> For an example, see <http://www.bmj.com/content/346/bmj.f3374>

<sup>24</sup> McKeown M, Malihi-Shoja L & Downe S (2010) *Service User and Carer Involvement in Education for Health and Social Care* Oxford: Wiley-Blackwell. Details at <http://onlinelibrary.wiley.com/book/10.1002/9781444323764>

<sup>25</sup> Their approach is described at <http://onlinelibrary.wiley.com/doi/10.1002/9781444323764.fmatter/pdf>

<sup>26</sup> Mental Health “Recovery” Study Working Group (2009), *Mental Health “Recovery”: Users and Refusers*. Available at [http://www.wellesleyinstitute.com/wp-content/uploads/2011/11/Mental\\_Health- Recovery.pdf](http://www.wellesleyinstitute.com/wp-content/uploads/2011/11/Mental_Health- Recovery.pdf).

<sup>27</sup> Professor Kathryn Church, Director of the School of Disability Studies, Ryerson University, Canada – personal communication 29 October 2014.

Some journals publish first-person accounts from people with lived experience<sup>28</sup> or promote public co-authorship<sup>29</sup>, while all provide guidelines for prospective authors on their website. The organisation PatientsIncluded have established a Charter<sup>30</sup> for journals that meet their standard for involvement. There is also an international membership body<sup>31</sup> for editors that develops guidance on difficult issues. A group of academics at the University of Leicester (the SAPPHIRE group<sup>32</sup>) have set out their own publishing principles<sup>33</sup> and tips<sup>34</sup> for good practice. We have not found any evidence to show whether journals adapt their selection criteria when considering papers submitted by public authors.

Some papers are peer-reviewed. This means that the submitted paper is sent to experts in the field who advise the journal editor on whether it is covering new ground, scientifically valid and reaches reasonable conclusions. The reviewers sometimes ask for extensive changes to be made to the paper before it is accepted for publication. Arrangements will vary for peer-reviewed papers and for non-peer reviewed journals and press releases.

## **Conventions on who is listed as an author in a peer-reviewed journal**

A peer-reviewed journal will insist that the paper is submitted with the author's names, sometimes on a separate sheet so that the reviewers can consider the paper without being influenced by the reputation of the author.

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<sup>28</sup> See for example, *Psychosis* at [http://www.tandfonline.com/toc/rpsy20/current#.VCPTf\\_m7GHQ](http://www.tandfonline.com/toc/rpsy20/current#.VCPTf_m7GHQ)

<sup>29</sup> See, for example, the strategy adopted by the British Medical Journal [here](#).

<sup>30</sup> See <https://patientsincluded.org/journals/>

<sup>31</sup> The [Committee on Publication Ethics](#).

<sup>32</sup> See <http://www2.le.ac.uk/departments/health-sciences/research/soc-sci>

<sup>33</sup> See <http://www2.le.ac.uk/departments/health-sciences/research/soc-sci/pdf-resources/authorship-principles>

<sup>34</sup> <http://www2.le.ac.uk/departments/health-sciences/research/soc-sci/pdf-resources/authorship-good-practice-tips>



Some papers have the authors listed at the beginning and other people who have made smaller contributions are named at the end in an acknowledgements section. **It is best to make sure that everyone is clear before they begin whether and where their name will appear.** This helps to avoid the impression that some authors are no more than guests or honorary authors (i.e. they have been given the title of author as an honour without having earned it<sup>35</sup>), or the person is being treated as a ghost writer<sup>36</sup> - a writer who does all the work, but is not acknowledged as such.

Anyone who is named as an author will normally have made a substantial contribution to the paper, although conventions vary somewhat between different academic disciplines<sup>37</sup>, and particularly between medical and social sciences. They are likely to have been involved in at least two<sup>38</sup> of the following activities:

- contributed some of the ideas that influenced the choice of topic and shaped the way in which the work was done
- helped with collecting, analysing and interpreting data
- drafted or revised the text
- approved the final version.

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<sup>35</sup> One must wonder whether this was the case for Yuri Struchkov, whose prodigious output averaged one academic paper every 3.9 days throughout the 1980s. See <http://www.theguardian.com/education/2008/mar/11/highereducation.research>

<sup>36</sup> Carter S (2010) Authorship: Definitions and declarations—A perspective from the BMJ *The Write Stuff* Vol 19, No 1, p18.

<sup>37</sup> The expectations set out in the main text above hold true in most academic areas, but some exceptions occur. In mathematics, the Hardy-Littlewood system dictates that anyone who has made any contribution whatsoever is included in an alphabetical list of authors (see Teixeira da Silva J, Dobranszki J (2013) Should the Hardy-Littlewood axioms of collaboration be used for collaborative authorship? *Asian and Australasian Journal of Plant Science and Biotechnology: Special Issue. 1*, 72-75.) A [systematic review of authorship practices](#) found an example from the study of physics that has 2,080 authors and another paper has 3,034 names (Aad G, Bentvelsen S, Bobbink GJ et al (2009) The Atlas Collaboration. *Nuclear Physics*. 83, 925c-940c). The SAPPHERE group note that some researchers work simultaneously on several projects and so may remain below the threshold for authorship in each individual one, which seems unfair. They advise project managers to take this into account and arrange workloads so that the researcher can spend more time on one study and so become entitled to authorship status.

<sup>38</sup> The SAPPHERE principles say that in exceptional circumstances, just one item from this list will justify authorship. They also indicate that usually, 'just one of the following does not, on its own, justify authorship: obtaining funding; general supervision of research; collecting data; clerical support; basic coding; reviewing a manuscript draft.'

In addition, all authors should be able to identify which co-authors are responsible for other specific parts of the work<sup>39</sup> and have confidence in their co-author's contribution and integrity.

The model<sup>40</sup> shown below is used by Stephen Kosslyn at Harvard University and may be adapted for use by public co-authors. Professor Kosslyn asks his team to distribute a fixed total of points between members of the research team for each stage of the project. Those who are assigned more than 10% of the total points count as authors and are listed in descending order. The points he awards are shown in the left-hand column of the following table, with potential public contributions added by the author of this document on the right. Such 'author contribution' calculations and statements may be popular in some journals, but others view them as unnecessarily formulaic and their value has been questioned<sup>41</sup>.

Some, but not all readers give additional status to the first, second and final name in a list of authors. Academic co-authors should consider whether the public contributor should be listed first<sup>42</sup>, while public contributors will want to check if their academic partner's career may be affected by the success of the paper and their position in the author list.

Guidelines exist, such as those from Vancouver and software has been developed<sup>43</sup> to help people decide on the order in which authors should be listed, but there remain clear variations in the conventions in different disciplines and academic environments.<sup>44</sup>.

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<sup>39</sup> This recommendation comes from the International Committee of Medical Journal Editors guidance – see <http://www.icmje.org/icmje-recommendations.pdf>

<sup>40</sup> Kosslyn, S. M. (2014). Authorship: Credit where credit is due. R. J. Sternberg & S. T. Fiske (Eds.), *Ethical challenges in the behavioral and brain sciences: Case studies and commentaries*. New York: Cambridge University Press, pp. 50 - 52.

<sup>41</sup> See a survey and blog discussion on this from the field of ecology [here](#).

<sup>42</sup> Gill Baker had a paper accepted in June 2015 in which the public contributor was first author.

<sup>43</sup> See [http://www.authorder.com/index.php?option=com\\_content&view=frontpage&Itemid=53](http://www.authorder.com/index.php?option=com_content&view=frontpage&Itemid=53)

<sup>44</sup> As an example of the extent to which views vary on this matter, see [here](#).

<b>Professor Kosslyn's system</b>	<b>Points</b>	<b>Suggestions for public co-authors</b>
The idea – generating the starting point for the work	250	Membership of an advisory group that regularly discusses what needs to be done, gaps and creative solutions.
The design – how the idea is developed into a research proposal	100	A definite contribution to generating the detailed idea, developed through attendance at several meetings and active comment on early drafts of a research proposal.
The implementation – creating the tools, documents and schedules for actually doing the work	100	Specific contribution to the design of patient information sheets, interview schedules, and other tools
Conducting the work – shaping the work rather than merely following instructions	100	Collecting data, for example, conducting interviews and making adjustments in the light of lessons learnt through the process.
Data analysis – devising creative ways to look at the data	200	Data entry, reviewing early theme analysis, discussing emerging findings and setting subsidiary questions for more detailed investigations.
Writing	250	Drafting sections of the final paper, making significant edits to drafts created by others, making suggestions regarding the structure for the paper that are utilised.

## **Original work and intellectual property**

The principle of intellectual copyright or intellectual property means that the person or people who create original work have the right to be identified as its creator, control its distribution, object to its distortion and obtain economic rewards for their efforts. When an item is submitted for publication, the contract transfers some of these rights from the author to the publisher.

Journals may require authors to sign a legally binding declaration to say that the material has not been published before and is the original work of the authors. They often require several online documents to be completed and signed by each author to register on the publisher's database and clarify who owns the intellectual property contained in the paper, and this can be a time consuming, bewildering and laborious process. These online systems may also be automated so authors who try to make late submissions or amendments are locked out.

Using another person's work without acknowledging it as theirs is called plagiarism and breaches intellectual copyright, so these days, publishers utilise special software to detect it. Re-using one's own previously published text in a new paper is sometimes called 'text recycling'<sup>45</sup> and is generally frowned upon.

### **Payment for co-authoring work**

An effective working relationship between public and academic members of the research team will be underpinned by proper arrangements to budget for the costs of involvement and reimburse out of pocket expenses, along with real clarity about whether involvement in the research project is remunerated in any way. The issue is complex, because on the one hand individuals should receive pay for work, and most academics receive a regular salary for a job role which includes writing for publication, whereas most members of the public do not. On the other hand, paying people to write may lead to perceived conflicts of interest, especially if the payment comes from a pharmaceutical company and the article is submitted to a medical journal<sup>46</sup>.

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<sup>45</sup> Advice from the Committee on Publication Ethics on how to deal with text recycling is available [here](#).

<sup>46</sup> Payment may encourage public authors to promote their financial sponsor or its products in the text. One study found readers to be more sceptical of articles with declared pharmaceutical industry involvement (see Chaudhry S, Schroter S, Smith R, Morris J. Does declaration of competing interests affect reader perceptions? A randomised trial. *BMJ*. 2002;325:1391–1392). This scepticism is justified, as some parts of the pharmaceutical industry have biased scientific reporting to favour of their own commercial interests (Langdon-Neuner, E. (2008). Medical Ghost-Writing. *Mens Sana Monographs*, 6(1), 257–273 available [here](#). 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*.

While general [guidance](#) on payments for participation is available, the specific question about participation payments and authorship has not been very precisely addressed<sup>47</sup>.

Few academic publishers pay authors for their work, but when books and journals are sold or sections photocopied, sometimes some of the profit belongs to the author. You can ask the [ALCS](#) (a membership company limited by guarantee) to collect this profit on your behalf and send it to you in respect of your publications in all books and in journal articles for a period of three years after publication.

### **Challenges faced by university staff in working with public co-authors**

Universities and their staff are evaluated against the [Research Excellence Framework](#) that includes a rating of publications. Journals and individual papers are considered more prestigious by academics if they are referred to frequently in subsequent publications. Specialist websites keep track of which papers are quoted, and perhaps add the opinion of experts to form a 'citation index' (such as this [one](#) for medicine and this [one](#) for business studies), that is used to judge the importance of a journal or an individual paper. Outside the university, quite different journals are influential, and some employers include evidence of publication in their selection criteria when appointing staff.

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<sup>47</sup> For example, the ICMJE policy says [here](#) that 'Authors should avoid entering in to agreements with study sponsors, both for-profit and non-profit, that interfere with authors' access to all of the study's data or that interfere with their ability to analyse and interpret the data and to prepare and publish manuscripts independently when and where they choose.' Also 'editors may request that authors of a study sponsored by a funder with a proprietary or financial interest in the outcome sign a statement, such as "I had full access to all of the data in this study and I take complete responsibility for the integrity of the data and the accuracy of the data analysis."' The ICMJE secretary (personal communication 25/05/2017) added that (1) Funding of any kind should be disclosed, irrespective of its source (whether from for-profit and non-profit organisations and for salary or honoraria) and individual circumstances may dictate the specific response from editors. The source of funding per se should not influence the judgement of journal editors about the merit of the submission; (2) The crucial matter is research integrity and independence; and so in testing this, journal editors should not treat patient authors more leniently or sternly than academics or clinicians; and (3) Everyone receiving a payment, should make a potential conflict of interest declaration, so that journal editors can be equally alert to issues of bias in the salaried academic or clinician as they are to the patient author who receives a participation payment or honorarium. Surveying the guidance issued by individual journals might shed some light on whether these principles are upheld in everyday practice.

Recent changes in the university environment may threaten attempts to work with public co-authors for the following reasons:

- increases in the demand for high-status publications threatens co-authoring which is, of necessity, more time consuming than writing alone or with academic co-authors.
- a new focus on individual success in competition with one's peers is at variance with collaborative, relational and participatory approaches.
- while the public co-author is free to walk away from the unfinished writing project, the academic co-author is under an obligation to achieve published output, with or without public partners - and this difference can strain the collaboration.
- short-term and fixed-term employment contracts reinforce a traditional hierarchical culture which is at odds with the ideals of emancipation, equality and democracy which underpin public co-authorship.

Since April 2013, any research that has been publicly funded by one of the seven UK Research Councils must provide open access to their publications, so that the papers can be read by anyone without charge<sup>48</sup>. Lead authors therefore need to make the arrangements to ensure that the paper is freely available, and this may involve obtaining access to the funding needed to do this<sup>49</sup>.

Producing publications to a timescale is all part of the academic environment and staff are assessed on their ability to meet deadlines and achieve targets. In contrast, some public co-authors are writing in their own time, perhaps between holding down a job, managing caring responsibilities and navigating their own health condition. Public co-authors may produce material from time to time, rather than all in one go, and may wish to offer their work long after the research project is supposed to have finished. There are no easy answers here, apart from patience and persistence.

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<sup>48</sup> Open access improves the dissemination of scientific information – see <http://www.fasebj.org/content/25/7/2129.short> For the UK policy, see <http://www.rcuk.ac.uk/RCUK-prod/assets/documents/documents/RCUKOpenAccessPolicy.pdf>. This policy is currently under review – see <http://www.rcuk.ac.uk/research/openaccess/2014-independent-review-of-implementation/>.

<sup>49</sup> Some journals charge for publishing open access papers and the average fee is £1,750, according to [http://www2.le.ac.uk/library/find/lra/openaccess/rcuk\\_faq](http://www2.le.ac.uk/library/find/lra/openaccess/rcuk_faq)

## An example

*“I have primarily involved patient partners in the construction of qualitative manuscripts. Often the authoring experience begins when we’re constructing the qualitative themes, and deciding what the key messages of the paper are. At this stage, patient partners blind code a section of the data, pull out what they believe are the important messages and then we meet to discuss and reach a consensus, and then we construct the paper. Most often patient partners prefer to meet to discuss their ideas, and we have a note taker in the room to ensure their ideas are captured. It’s then their first author’s job to make an “executive decision” about what the final manuscript looks like and includes.*

*The paper is then sent to and reviewed by the patient partners (in a way that’s similar to other academic co-authors). Patient partners in some cases do provide me with written feedback (using ‘track changes’), but most often this is done over the phone or as part of a face to face meeting. Often patient partners highlight areas which are contrary to their experience as a patient, what the implications of the paper are for patients, and what future research should be considering. Therefore, I’ve found their greatest contribution is in constructing the results and constructing a critical discussion and conclusion.*

*To date, patient partners have not led on writing any particular section of a manuscript, but we are working towards this as people develop in skills and confidence.”*

Dr Rebecca Stack

## Getting started as a co-author: suggestions for the public

One place to start may be to become a volunteer reviewer of papers submitted to a journal. The *British Medical Journal*, for example, seeks patients and members of the public who are willing to take up this role<sup>50</sup> and offers guidance that helps reviewers to understand what is needed in a journal article.

If you have not received training in how to write for an academic audience, your academic co-author will be able to help. In addition, some

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<sup>50</sup> Details are available [here](#).

online learning materials are available<sup>51</sup>. However, ensure that the training does not silence your authentic voice or shut out your experience by teaching you to write as if you were an academic. Indeed, while some writing is formed by collaborators who each spend the same amount at the keyboard and generate about the same number of words, most are lopsided partnerships where one person does the majority of actual writing after the co-authors have met to discuss their ideas for the paper. The process by which a group synthesises academic and public perspectives has been examined<sup>52</sup>.

One group found that spending time in some creative writing workshops developed their confidence. Glen Swanwick is a public co-author<sup>53</sup> who has offered the following advice about getting involved with a research project. It is worth observing that his advice is mostly about building a good relationship between the academic and public co-authors. A sound relationship is foundational to a positive writing collaboration, while failed attempts to co-author can usually be traced back to a poor working relationship and lack of proper involvement throughout the project. Glen said:

*“It is vital to have the confidence and ability to contribute to conversations with the professor and other academics – so have no fear of what the others say and remember that you are equal to others. However, don't hog the meeting with your own problems. It will get easier to contribute as you get to know the people. Enjoy the first meeting even if you feel out of your depth. You really need to learn about the project and get your facts right so that you don't make things up (no bullshit!). Read all the papers, and don't miss meetings, as it will be harder to catch up if you do. Best of all, enjoy the experience.”*

## Learning the writer's craft: the importance of support and training

<sup>51</sup> See the study skills section <http://www.rlo-cetl.ac.uk/whatwedo/rlos/completedrlos.php#ethics>. For more general advice on writing, see [here](#).

<sup>52</sup> Abell, S. Ashmore, J., Beart, S. (et al) (2007) Including Everyone in Research: the Burton Street Research Group *British Journal of Learning Disabilities* 35, pp 121-124. Also McClimens, A. (2008) This is my truth, tell me yours: exploring the internal tensions within collaborative learning disability research *British Journal of Intellectual Disabilities* 36, pp 271–276. Also Bewley C (2006) *Let Me in - I'm a Researcher!: Getting Involved in Research*, Department of Health learning Difficulties Research Team.

<sup>53</sup> Glen Swanwick has co-authored a paper in *The Lancet* [here](#).



Some co-authors may need several opportunities to try out their writing skills and grow in confidence before making a formal submission, others will benefit from training, and a third group are highly competent authors already. So, at the same time as obtaining early agreement over who will be an author, the team should set out in writing how the support and training requirements for each author will be met.

A specific issue which might cause difficulty when public and academic co-authors work together is the process of giving and receiving critical feedback on early drafts. Academics commonly develop a robust approach to this and both give and receive vigorous and candid feedback in a way that is quite unlike the cautious and perhaps over-polite exchanges that are commonplace in British culture. If this is not navigated carefully, some public co-authors may feel bruised by the feedback process.

Linking with a group of public co-authors<sup>54</sup> can provide both advice and emotional support<sup>55</sup>. Here's what Dr Vanessa Pinfold from the McPin Foundation says about this:

*"We work from the principle that a user-led or community-led study must have public authors. All authors need support in this role – writing for academic publication is challenging and a skill developed over many years. Working through study design, data collection, thematic coding and analysis to writing requires team work. Everyone needs to allocate time for writing and specific training, mentoring and support may be required. While some authors struggle, others excel, and so being honest within the team is essential. Peer reviewers can be brutal, especially in those journals that have many more submissions than they can publish, so selecting the right journal and developing the resilience and*

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<sup>54</sup> See, for example, the range of publications generated by Independent Cancer Patients' Voice at <http://independentcancerpatientsvoice.org.uk/icpv-publications/members-publications/>. General support for those wishing to write for publication can be obtained from groups like <https://www.facebook.com/groups/879852725366045/>.

<sup>55</sup> In a historic research study (<http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=6577844>), 12 high profile papers that had already been published in prestigious journals were anonymised and resubmitted for a fresh round of peer review. 90% of them were rejected for publication. The editor of The Lancet has said ([https://en.wikipedia.org/wiki/Richard\\_Horton\\_%28editor%29#Peer\\_review](https://en.wikipedia.org/wiki/Richard_Horton_%28editor%29#Peer_review)) that peer review is "unjust, unaccountable ... often insulting, usually ignorant, occasionally foolish, and frequently wrong."

*skills of the team is very important. Gaining supportive but robust feedback on drafts from within your own team is also very helpful.”*