How to guide

East Midlands
Academic Health
Science Network
Igniting Innovation

How to involve the public as co-authors

30 October 2018

Contents

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[1] provide feedback, further insights will be used to update the paper. Please contact 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[2].

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[3]. 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[4].

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 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[5]. 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. Neither is the peer-reviewed

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2

journal article the only way to disseminate research findings, and so a team may prioritise community-facing outputs over products for academia. Co-authoring therefore forms just one of the many expressions of full and meaningful involvement, 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.

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[6], and this underlines the fact that publicly funded research should be accountable to the very people being researched.

- 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[7] 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' or 'participatory health research'[8]. Patient groups may wish to harness the influence of peer-reviewed publications to improve health outcomes, gain status for their experience, legitimise their perspective, share innovation, win funding, or develop an academic career.

- 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.

However, this practice is not without its hazards and detractors. Flicker and Nixon[9] note that people who have been marginalised may resent the time spent on writing for an academic audience in a style that may treat people as objects

rather than partners. The exercise may reinforce feelings of incompetence or create an unwelcome alignment with professionals.

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[10]. Through its work on public involvement, NIHR maintains a searchable [archive](#) of relevant publications, including information about authors. In September 2014, a total of 196 papers were listed, of which 89 (45%) were written or co-written by 'service users or carers'[11].

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[12].

Public co-authors have lived with and contributed to papers on a variety of conditions, including autism[13], burns[14], cancer[15], learning disability[16], mental health[17], old age[18], palliative care[19] and rheumatology[20].

However, notwithstanding the critical importance of having the public writing academic papers together with researchers and health professionals, international guidance[21] for authors on how to report public involvement in health research does not include any reference to public co-authors; while a systematic review[22] of various aspects of co-authorship found a distinctly thin evidence base. Despite this, there is a clear expectation that co-authorship will grow, and summary information for public co-authors setting out the GPP3 international standards has been produced[23]. Even the pharmaceutical industry is getting on board![24]

What kind of paper are you writing?

This guide is focused on co-authoring academic papers, but there are many other kinds of document. Some people really want to write a blog where they can vent their opinion; others want to publish a personal complaint about the low quality of care that they have received; yet others want to send out a single message, perhaps as short as a Tweet. Some budding co-authors may need to learn more about the nature of a scientific peer-reviewed paper before deciding if they want to be involved.

Then it is helpful to decide the format of the paper. Many scientific papers use the following standard subheadings: Introduction, Method, Results and Discussion[25], but this is obviously not the only approach. 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[26].

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4

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[27] that utilises these different approaches, varying the medium to reflect the origin and development of each chapter[28]. Similarly, Kathryn Church utilises a variety of these approaches in different kinds of work, sometimes blending them to create new variations:

> *"In one study[29], 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."[30]*

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. Alternatively, the process can be reversed in that the co-authors discuss what kind of product they want to produce and then seek out a suitable vehicle for it. For example, some journals welcome papers that are supported by materials presented in alternative formats[31].

Selecting a journal and finding out what they expect

A study carried out in 2014 found 28,100 active, scholarly, peer-reviewed journals that together publish 2.5 million papers per year and add to the stack of 50 million papers published between 1665 and 2009[32]. To help academics decide which journals have the most influence, a number of measures of impact have been generated[33] and critiqued[34]. A range of factors may influence the choice of journal[35].

Some journals publish first-person accounts from people with lived experience[36] or promote public co-authorship[37], while many include a summary for lay readers[38] and all provide guidelines for prospective authors on their website. The organisation PatientsIncluded has established a Charter[39] for journals that meet their standard for involvement. COPE is an international membership body[40] for editors which has developed guidance on difficult issues. A group of academics at the University of Leicester (the SAPPHIRE group[41]) have set out their own publishing principles[42] and tips[43] 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

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5

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.

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[44], co-authoring[45] and reporting on public involvement[46]. Be prepared to invest time and focused effort in co-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.

- You may want to have a conversation to clarify what kind of information is to be included in the paper. If you are writing an opinion piece, your own ideas will be of value, while a paper that reports on the findings of a research study will restrict its content to the evidence. Some academics like to 'salami-slice' their work in order to produce the largest possible number of narrowly-focused papers and so advance their careers.

- Assign one writer the role of lead author so that they 'have the last word'[47]. Have a candid discussion about what to do about spelling errors and whether the lead author will edit grammar or reorganise content into a new structure.

- Agree how you will share the outline structure and subsequent drafts around the writing team and that comments are welcome from all members of the team. It is easy to involve everyone in discussing and agreeing the short outline, while few team members have time to carry out multiple line-by-line critiques of longer documents.

- 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

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6

message into this format may result in the loss of the co-author's authentic voice.

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

A peer-reviewed journal will usually insist that the paper is submitted with the author's names on a separate sheet so that the reviewers can consider the paper without being influenced by the reputation of the author[48]. Some research teams include a Professional Medical Writer who acts under internationally agreed guidelines[49].

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[50]), or the person is being treated as a ghost writer[51] - a writer who does all the work but is not acknowledged as such.

On occasions, the name of a group[52] or pseudonym[53] for an individual might be the preferred option for public authors, especially where the topic is delicate and the person is willing to contribute, but may not wish their identity to become known[54]. The scientific community will need to have a mechanism for reaching the authors (this will normally be through the corresponding author), so that they can be reassured about the integrity of the work and the that the public author has met their obligations.

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[55], and particularly between medical and social sciences. They are likely to have been involved in at least two[56] 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.

In addition, all authors should be able to identify which co-authors are responsible for other specific parts of the work[57] and have confidence in their co-author's contribution and integrity. Medical journal editors require authors to sign a declaration that they have seen the full data and take responsibility for its integrity[58].

Sometimes there are ethical considerations that lead to people being excluded from the writing team. It was perhaps seen as a conflict of interest when four

learning disabled people who had moved from contributing to a piece of research as respondents and then become co-researchers, did not join the writing team for the report[59].

The model[60] 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[61]. Alternative approaches are available[62].

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[63], 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[64] 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.[65].

Professor Kosslyn's system	Points	Suggestions for public co-authors
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

Professor Kosslyn's system	Points	Suggestions for public co-authors
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'[66] 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[67].

While general guidance on payments for participation is available, the specific question about participation payments and authorship has not been very precisely addressed[68], [69]. Offering a payment that equates to a few hours at the rate at which salaried colleagues are remunerated would seem fair and avoid the accusation of bribery.

There is also a timing issue – for the researcher who has a permanent contract of employment, much of the writing may be done after the project is over and funding has ended. This can mean that the accounts have been closed down and there is no longer any provision to pay Public Contributors a participation payment or reimburse their expenses[70].

Few academic publishers pay authors for their work, but when books and journals are sold, lent from libraries or sections photocopied, sometimes some of the profit belongs to the author. You can ask the ALCS and PLR to collect this money on your behalf and send it to you.

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[71]. Outside the university, quite different journals are influential, and some employers include evidence of publication in their selection criteria when appointing staff.

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[72]. 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[73].

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. Finding a way to bring together these different approaches is part of the challenge of co-authorship.

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)

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11

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, has engaged patients and caregivers in this role since 2014[74], has 800 such reviewers on its books[75] and offers guidance to help reviewers 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 online learning materials are available[76]. 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[77].

Any writing project has a beginning, where creative and radical ideas may be welcome; a middle, which is largely a matter of editing and re-editing to ensure that the agreed messages are explained effectively and set out in a logical flow; and an end, which is largely a matter of checking. It is helpful to agree with your co-authors what stage the writing is at, so that you don't waste time working at the wrong issue (spellings and grammar at the early conceptual stage or structure at the checking stage. One way of framing this for a discussion is to set out the steps in writing like this, and then clarify what is required each time you work on the paper:

1. Re-order the structure of the paper to change the logical flow of ideas, so that the subheadings and paragraphs appear in a different sequence
2. Add significant new sections such as a new introduction or a piece on how a new audience felt about the research
3. Change the main messages
4. Spot embarrassing errors or missing viewpoints that can be fixed quite easily (such as noting that your findings might not work in another country, a landmark paper has not been cited or there is an easy application of these ideas in another part of the NHS)
5. Spot sentences that are unclear and edit them to get their intended message across more clearly.
6. Spot errors of spelling or punctuation and put them right.

One group found that spending time in some creative writing workshops developed their confidence. Glen Swanwick is a public co-author[78] 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

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 may eventually develop a robust approach to this[79] 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[80]. If this is not navigated carefully, some public co-authors may feel bruised by the feedback process, especially if it is cruel or dismissive. In response, some teams assign responsibility for dealing with feedback from peer reviewers to the lead researcher, and so in this scenario, co-authors do not see the work at all in the interval between first submission and publication[81].

Linking with a group of public co-authors[82] can provide both advice and emotional support[83]. 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 skills of the team is very

important. Gaining supportive but robust feedback on drafts from within your own team is also very helpful."

1 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 Carter, Kathryn Church, Michelle Cornes, Chris Craig, Sarah Flicker, Claire Goodman, Gordon Grant, Sarah Hewlett, Stephen Kosslyn, Antje Lindenmeyer, Fiona Marshall, Sharon McCulloch, Lisa McDaid, Stephanie Nixon, Stephanie Petrie, Vanessa Pinfold, Konstantina Poursanidou, Stefan Priebe, Rachel Purtell, Alan Simpson, Mike Slade, Rebecca Stack, Glen Swanwick, Maryrose Tarpey, Rebecca Toney, Paul Ward and Karen Woolley.

2 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 here.

3 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/

4 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

5 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.

6 Department of Health (13 Dec 2012) *Liberating the NHS: No decision about me, without me – Government response to the consultation.* Available here.

7 David Brindle, personal communication 10 December 2014.

8 See the 2013 position paper defining Participatory Health Research from the International Collaboration for Participatory Health Research here.

9 Flicker, Sarah and Nixon, Stephanie Ann (2016) Writing peer-reviewed articles with diverse teams: Considerations for novice scholars conducting community-engaged research *Health Promotion International* July 2016. DOI: 10.1093/heapro/daw059.

10 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.

11 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 endnote 1. To make a comparison with co-authoring practices between academic and non-academic partners coming from industry or other sectors of the community, see Inzelt A and Schubert A (2011) Collaboration between researchers from academic and non-academic organisations: A Case Study of Co-authorship in 12 Hungarian Universities *Acta Oeconomica*, Vol. 61, No. 4 (December 2011), pp. 441-463.

12 Professor Hewlett is at the University of the West of England (personal communication, 6 October 2014).

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

14 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.

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14

[15] 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

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[17] 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.

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[21] The GRIPP checklist is here.

[22] See https://cdn.instantmagazine.com/upload/18080/envision-patient-research-poster-book.3e44f7300085.pdf.

[23] See the lay summary at https://cdn.instantmagazine.com/upload/18080/envision_gpp3_summary_for_patient_authors.b82d705e3d80.pdf and the full GPP3 guidelines at http://annals.org/aim/fullarticle/2424869/good-publication-practice-communicating-company-sponsored-medical-research-gpp3. Five top tips from the commercial sector on how to engage with public co-authors can be seen at https://maps.instantmagazine.com/publications/elevate-magazine/patient-involvement-in-publications/. Consultation on the next iteration of these guidelines is taking place on Twitter at #GPP4.

[24] Envision Pharma Group (2018) *Patient Involvement in Publications: Prioritise or Perish?* Perspectives from the Envision the Patient Forum, London, UK, 25 January 2018.

[25] This is sometimes abbreviated to the acronym IMRAD – see here for an explanation and here for a commentary.

[26] For an example, see http://www.bmj.com/content/346/bmj.f3374

[27] 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

[28] Their approach is described at http://onlinelibrary.wiley.com/doi/10.1002/9781444323764.fmatter/pdf

[29] 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.

[30] Professor Kathryn Church, Director of the School of Disability Studies, Ryerson University, Canada – personal communication 29 October 2014.

[31] For example, *Acta Psychiatrica Scandinavica* encourages authors to submit video and audio podcast to accompany their article published in the journal.

[32] See https://www.researchgate.net/publication/229062236_Article_50_million_An_estimate_of_the_number_of_scholarly_articles_in_existence

[33] Various formulae have been used to derive an impact figure including Journal Citation Reports from Clarivate Analytics and also Eigenfactor. Impact is usually based on the number of occasions others reference the paper in their own writing (citations), rather than anything being done with the findings! As there are so many journals, comparisons are usually made within disciplines by comparing, for example, those for medicine with one another rather than with engineering. Access to the full list is often restricted to those willing to pay for the data.

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15

[34] See a critical evidence-based discussion about scholarly impact at http://blogs.lse.ac.uk/impactofsocialsciences/2018/03/02/beyond-impact-factors-an-academy-of-management-report-on-measuring-scholarly-impact/ and the evidence at http://aom.org/uploadedFiles/About_AOM/StrategicPlan/AOMScholarlyImpactReport.pdf

[35] Flicker and Nixon (2016 op cit) list the following factors that may influence the choice of journal - mandate of the journal, target audience, open access or subscription, impact factor, turn-around time for peer-review, cost to publish, word limit, format flexibility, acceptance rate, where are conversations about our topic already happening?

[36] See for example, *Psychosis* at http://www.tandfonline.com/toc/rpsy20/current#.VCPtF_m7GHQ

[37] See, for example, the strategy adopted by the British Medical Journal here. *Research Involvement and Engagement* is an interdisciplinary, health and social care journal focussing on patient and wider involvement and engagement in research, at all stages. The journal is co-produced by all key stakeholders, including patients, academics, policy makers and service users, but at least one of their peer reviewers insists that all authors adopt the traditional academic format for writing the paper. *Research for All* is a peer-reviewed journal focusing on research that involves universities and communities, services or industries working together.

[38] The EU Clinical Trials Regulation 536/2014 (Article 37) (EU CT Regulation) requires sponsors to provide summary results of clinical trials in a format understandable to laypersons. See https://ec.europa.eu/health/sites/health/files/files/eudralex/vol-10/2017_01_26_summaries_of_ct_results_for_laypersons.pdf.

[39] See https://patientsincluded.org/journals/

[40] The Committee on Publication Ethics.

[41] See http://www2.le.ac.uk/departments/health-sciences/research/soc-sci

[42] See http://www2.le.ac.uk/departments/health-sciences/research/soc-sci/pdf-resources/authorship-principles

[43] http://www2.le.ac.uk/departments/health-sciences/research/soc-sci/pdf-resources/authorship-good-practice-tips

[44] See, for example http://blogs.lse.ac.uk/impactofsocialsciences/2014/09/04/seven-strategies-to-improve-academic-writing-dunleavy/?.com. It is interesting to note that some otherwise excellent guidance on writing published as recently as 2017 makes no reference to public co-authors – see https://www.nottingham.ac.uk/praised/documents/discussion-paper-series-2-january-2017.pdf

[45] See http://authorservices.taylorandfrancis.com/custom/uploads/2017/09/Coauthorship-white-paper.pdf. Also Frankish, JA (1998) Principles of Authorship in Health Promotion Research *Canadian Journal of Public Health* Vol. 89 No. 2, March 1998, pp. 81-84.

[46] See this report on the effect of introducing reporting guidelines about Patient and Public Involvement in research at the British Medical Journal - https://bmjopen.bmj.com/content/8/3/e020452.

[47] In one case, there was a short section of the paper that was particularly contentious, so people came together to hammer out the text for these paragraphs, while the rest of it was constructed by one author and then emailed to others for suggestions and minor corrections.

[48] Rather than assuming that reviewers will cheat if they can, some take the alternative view. They send the potential reviewer the title of the paper and list of authors names, and then ask the potential reviewer to withdraw if they are conflicted. By this means they remove risks that the reviewer will know the author.

[49] See http://journal.emwa.org/writing-better/amwa-emwa-ismpp-joint-position-statement-on-the-role-of-professional-medical-writers/

[50] 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

[51] Carter S (2010) Authorship: Definitions and declarations—A perspective from the BMJ *The Write Stuff* Vol 19, No 1, p18.

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16

[52] For an example, see the role of 'Mentor Parent Group Members' in authoring the paper at https://www.ncbi.nlm.nih.gov/pubmed/?term=Mentor%20Parent%20Group%20Members%5BCorporate%20Author%5D

[53] While an individual pseudonym is less common than using a group name, the process is identical – the people involved can see their work has been recognised in print, they are contactable via the corresponding author and their individual identity is not disclosed. This meets criterion 4 of the ICMJE recommendations for authorship – accountability '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.' The use of pseudonyms by academic authors is discussed at http://peterbates.org.uk/home/garden-shed/can-authors-use-a-pseudonym/. Examples include: Anna Bissette and Juliana Bissette in JTSP vol 2, issue 1.

[54] Sarah Flicker wrote (personal communication 7 August 2018) 'we have had some success with the strategy of naming an NGO or First Nation rather than a person in instances where the collective wants to be recognized rather than as individuals. This has worked in *Social Science and Medicine*, the *Journal of Action Research* and *International Journal of Indigenous Health*. I have also seen folks use pseudonyms as authors in book chapters, particularly youth co-authors who DO NOT want to be identified as homeless, HIV+ or marginalized etc long term, but do want their voice acknowledged in the immediate. I imagine editors would negotiate this on a case by case basis.'

[55] 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 SAPPHIRE 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.

[56] The SAPPHIRE 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.'

[57] This recommendation comes from the International Committee of Medical Journal Editors guidance – see http://www.icmje.org/icmje-recommendations.pdf

[58] Dr Peter Wilmshurst gave evidence to the UK Government Science and Technology Committee in March 2017, including the following statement, 'In cases when corporations send a doctor (usually an opinion leader) a paper and ask him to submit it to a journal as his own work in return for a payment to the doctor (a practice known as "gift authorship" in medicine, but in other walks of life known as fraud), it is customary to make a false declaration and say that one has seen the data when one has not. See paragraph 18 of http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/science-and-technology-committee/research-integrity/written/68813.html. . Prof Jennifer Byrne and Cyril Labbe have been developing software to identify fraudulent academic papers – see http://www.theaustralian.com.au/higher-education/jennifer-byrne-cyril-labbe-use-software-to-detect-gene-knockdown-paper-faults/news-story/e99f0ebcfc0622e0224aaaed2b43788a.

[59] Duckett PS and Fryer D (1998) Developing empowering research practices with people who have learning disabilities. *Journal of Community & Applied Social Psychology* 8: 57–65.

[60] 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.

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17

[61] See a survey and blog discussion on this from the field of ecology here.

[62] See, for example, the flowchart developed by Envision at
https://cdn.instantmagazine.com/upload/18080/envision_patient_authorship_flowchart.c3768fa19906.pdf.

[63] Gill Baker had a paper accepted in June 2015 in which the public contributor was first author.

[64] See http://www.authorder.com/index.php?option=com_content&view=frontpage&Itemid=53

[65] As an example of the extent to which views vary on this matter, see here.

[66] Advice from the Committee on Publication Ethics on how to deal with text recycling is available
here.

[67] 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*. More recently, Dr. José Baselga
admitted he had received over $3 million from the private sector yet disclosed none of these connections
in his publications – see here.

[68] 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. The
Good Publication Practice guidelines, known as GPP3 available at
http://annals.org/aim/fullarticle/2424869/good-publication-practice-communicating-company-sponsored-medical-research-gpp3 do not add any further clarity on the payment issue.

[69] An email inquiry was sent to CMAJ to ask about their approach on 29 May 2018 and followed up on 24 July
but no response has yet been received.

[70] Hamilton S (2016) *Influencing the debate – peer research in academic journals.* See
http://mcpin.org/influencing-the-debate-peer-research-in-academic-journals/.

[71] Or see the Academic Journal Guide for a general ranking of journals. These matters are considered critically by the
Lancaster Literacy Research Centre.

[72] 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/.

[73] 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

[74] See https://scholarlykitchen.sspnet.org/2018/06/19/interview-bmjs-patient-review-initiative-novel-expansion-peer-review/

[75] Details are available here. The Canadian Medical Association Journal also includes patient reviewers – see here.

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

[77] 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.

[78] Glen Swanwick has co-authored a paper in *The Lancet* here.

[79] Evidence-based advice on handling manuscript rejection is available at https://journal.chestnet.org/article/S0012-3692(09)60153-7/fulltext.

[80] We might be over-estimating the amount of politeness in the world of publishing. A review of articles that reported on patient data published by the British Medical Journal between 2012 and 2014 found only half of them thanked patients. See https://cdn.instantmagazine.com/upload/18080/envision-patient-research-poster-book.3e44f7300085.pdf page 16.

[81] The journal *Research Involvement and Engagement* has rejected the usual practice of providing anonymous feedback and includes the name of each reviewer with their review, as well as publishing the reviews of successful papers online as part of the paper's publication history.

[82] 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/.

[83] In a historic research study carried out in 1982 (http://journals.cambridge.org/action/dispAbstract?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) that peer review is "unjust, unaccountable ... often insulting, usually ignorant, occasionally foolish, and frequently wrong."