

## How to involve the public as co-authors

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### 1. 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 members 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 first 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 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. Training is also available<sup>2</sup>.

## 2. 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>3</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, while the challenges facing the wider publishing industry<sup>4</sup> may also affect the academic press.

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>5</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>6</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 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>7</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. Neither is the peer-reviewed 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.

### 3. 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. The International Society of Medical Publication Professionals support the involvement of public co-authors<sup>9</sup> and advice is starting to appear<sup>10</sup>.
- 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>11</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’ or ‘participatory health research’<sup>12</sup>. 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<sup>13</sup> 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. Even advice about writing may favour one group at the expense of others, as pointed out so eloquently by Trisha Greenhalgh and other women academics<sup>14</sup>. So the very exercise of writing with academics may reinforce feelings of incompetence or create an unwelcome alignment with professionals. Pressure on academics to generate written scientific outputs may persuade them to abandon the slower participatory and co-productive methodologies and turn to approaches that seem faster and simpler to implement<sup>15</sup>.

#### **4. 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>16</sup>. Through its work on public involvement, NIHR used to maintain a searchable [archive<sup>17</sup>](#) 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'<sup>18</sup>. Patient authorship is a growing phenomenon<sup>19</sup> and evidence-based advice is available on how to do it well<sup>20</sup>.

Engaging public co-authors is routine in some teams, as shown by Professor Hewlett, who has published more than 45 papers with patient research partners<sup>21</sup>. Some commercial organisations, such as the international biopharma company UCB, have launched Patient Publication Steering Committees to oversee some of their output<sup>22</sup>.

Public co-authors have lived with and contributed to papers on a variety of conditions, including autism<sup>23</sup>, burns<sup>24</sup>, cancer<sup>25</sup>, learning disability<sup>26</sup>, mental health<sup>27</sup>, old age<sup>28</sup>, palliative care<sup>29</sup> and rheumatology<sup>30</sup>.

However, notwithstanding the critical importance of having the public writing academic papers together with researchers and health professionals, international guidance<sup>31</sup> for authors on how to report public involvement in health research does not include any reference to public co-authors; while a systematic review<sup>32</sup> of various aspects of co-authorship found a distinctly thin evidence base<sup>33</sup>. 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<sup>34</sup>. Even the pharmaceutical industry is getting on board!<sup>35</sup>

#### **5. 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 scientific publications are described as Plain Language

Summaries of scientific research, and, as it is particularly important that these are clearly understood by ordinary citizens, detailed advice on co-authoring these papers has been published<sup>36</sup>. Some budding co-authors may need to learn more about the nature of a scientific peer-reviewed paper and the perceived status of different modes of communication with specific audiences 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<sup>37</sup>, 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<sup>38</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<sup>39</sup>. In other writing projects, discussions lead to a consensus in which there seems to be no need to identify distinct voices, and in yet more, explicit approaches to collaborative writing are adopted<sup>40</sup>.

The Comensus Writing Collective have published a book<sup>41</sup> that utilises these different approaches, varying the medium to reflect the origin and development of each chapter<sup>42</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>43</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>44</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. 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<sup>45</sup>.

## 6. Selecting a journal and finding out what they expect

Academic journals are only one part of a comprehensive dissemination strategy which should include reporting your work in relevant community languages, in formats that are accessible to people using services (especially if the research has engaged with these communities) and reaching managers and commissioners who have responsibility to implement the findings.

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<sup>46</sup>. To help academics decide which journals have the most influence, a number of measures of impact have been generated<sup>47</sup> and critiqued<sup>48</sup>, with the star ranking system<sup>49</sup> is being used by some universities to monitor the output of their academic staff. A range of factors may influence the choice of journal<sup>50</sup>.

Some journals publish first-person accounts from people with lived experience<sup>51</sup> or promote public co-authorship<sup>52</sup>, while many include a summary for lay readers<sup>53</sup> and all provide guidelines for prospective authors on their website. The organisation PatientsIncluded has established a Charter<sup>54</sup> for journals that meet their standard for involvement. COPE is an international membership body<sup>55</sup> for editors which has developed guidance on difficult issues. A group of academics at the University of Leicester (the SAPPHIRE group<sup>56</sup>) have set out their own publishing principles<sup>57</sup> and tips<sup>58</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.

Published authors, including Public Co-Authors, may receive unwanted emails from journals that are of dubious quality or that are predatory. This means that they inviting authors to publish new work in their journal, but this is no more than a way to derive income from the fees they charge and the journal itself may have minimal circulation or credibility<sup>59</sup>.

## 7. 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>60</sup>, co-authoring<sup>61</sup>, reporting on public involvement<sup>62</sup> and any specific advice, such as that from the British Journal of Learning Disabilities for co-authors with learning disabilities<sup>63</sup>. 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'<sup>64</sup>. 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 message into this format may result in the loss of the co-author's authentic voice.

## 8. 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<sup>65</sup>. Some research teams include a Professional Medical Writer who acts under internationally agreed guidelines<sup>66</sup>.

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 or gift<sup>67</sup> without having earned it<sup>68</sup>), or the person is being treated as a ghost writer<sup>69</sup> - a writer who does all the work but is not acknowledged as such. Expecting to be recognised as a co-author and then finding yourself relegated would not be a pleasant experience, and mechanisms for resolving disputes between co-authors are weak<sup>70</sup>. A detailed flowchart is provided by Jones that provides a framework for discussions of authorship<sup>71</sup>.

On occasions, the name of a group<sup>72</sup> or use of a pseudonym or anonymity<sup>73</sup> 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<sup>74</sup>. 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 that the public author has met their obligations. Despite the frequent use of these options, some commentators declare that anonymity and pseudonyms are unacceptable<sup>75</sup>.

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>76</sup>, and particularly between medical and social sciences. They are likely to have been involved in at least two<sup>77</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.

In addition, all authors should be able to identify which co-authors are responsible for other specific parts of the work<sup>78</sup> 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<sup>79</sup>.

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<sup>80</sup>.

In a move from 'authorship' to 'contributorship'<sup>81</sup>, some peer reviewed papers include a declaration showing the roles taken up during the research by each author, as illustrated in Table 1 below<sup>82</sup>, where the eight authors are listed (for interest, note that IB is a public co-author).

*Table 1: Using the CRediT system to show who contributed to the work*

	PH	AP	AO'C	IB	JT	CM	SO	JD
Conceptualisation	•	•	•	•	•	•	•	•
Methodology	•	•	•	•	•		•	•
Resources	•							
Project Administration	•							
Data Curation	•							
Investigation	•	•	•					
Validation	•	•	•	•	•	•	•	•
Visualisation	•							
Writing – Original Draft Preparation	•					•		
Writing – Review & Editing	•		•	•	•	•	•	•

The different types of contribution to a paper which appear in the table above have been defined in the CRediT system<sup>83</sup> as shown in Table 2.

*Table 2: Defining the terms used in the CRediT system*

<b>Title</b>	<b>Definition</b>
Conceptualisation	Ideas; formulation or evolution of overarching research goals and aims
Methodology	Development or design of methodology; creation of models
Funding acquisition	Acquisition of the financial support for the project leading to this publication
Resources	Provision of study materials, reagents, materials, patients, laboratory samples, animals, instrumentation, computing resources, or other analysis tools
Supervision	Oversight and leadership responsibility for the research activity planning and execution, including mentorship external to the core team
Project Administration	Management and coordination responsibility for the research activity planning and execution
Software	Programming, software development; designing computer programs; implementation of the computer code and supporting algorithms; testing of existing code components
Data Curation	Management activities to annotate (produce metadata), scrub data and maintain research data (including software code, where it is necessary for interpreting the data itself) for initial use and later reuse
Investigation	Conducting a research and investigation process, specifically performing the experiments, or data/evidence collection
Formal analysis	Application of statistical, mathematical, computational, or other formal techniques to analyze or synthesize study data
Validation	Verification, whether as a part of the activity or separate, of the overall replication/ reproducibility of results/experiments and other research outputs
Visualisation	Preparation, creation and/or presentation of the published work, specifically visualization/ data presentation
Writing – Original Draft Preparation	Preparation, creation and/or presentation of the published work, specifically writing the initial draft (including substantive translation)
Writing – Review & Editing	Preparation, creation and/or presentation of the published work by those from the original research group, specifically critical review, commentary or revision – including pre-or post-publication stages

The model might be extended to encompass specific questions for Public Co-authors, as suggested in table 3 below.

*Table 3: Questions for Public Co-Authors arising from the CRediT system*

Title	Comment	Suggestions for Public Co-authors
Conceptualisation	The idea – generating the starting point for the work	Membership of an advisory group that regularly discusses what needs to be done, gaps and creative solutions.
Methodology	The design – how the idea is developed into a research proposal	A definite contribution to generating the detailed idea, developed through attendance at several meetings and active comment on early drafts of a research proposal.
Funding acquisition		
Resources	The implementation – creating the tools, documents and schedules for actually doing the work	Specific contribution to the design of patient information sheets, interview schedules, and other tools
Supervision		
Project Administration		
Software		
Data Curation		
Investigation	Conducting the work – shaping the work rather than merely following instructions	Collecting data, for example, conducting interviews and making adjustments in the light of lessons learnt through the process.
Formal analysis	Data analysis – devising creative ways to look at the data	Data entry, reviewing early theme analysis, discussing emerging findings and setting subsidiary questions for more detailed investigations.
Validation		
Visualisation		
Writing – Original Draft Preparation		Drafting sections of the final paper,
Writing – Review & Editing		Making significant edits to drafts created by others, making suggestions regarding the structure for the paper that are utilised.

Alternative approaches are available<sup>84</sup>. Others have set out guidelines to indicate the order in which authors should be listed, but there remain clear variations in the conventions in different disciplines and academic environments<sup>85</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>86</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.

## 9. 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. One publishing house asks potential authors to confirm that they hold expensive professional indemnity insurance – an ill-considered approach that will have a disproportionate negative impact on public authors<sup>87</sup>.

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>88</sup> and is generally frowned upon, while buying someone else's essay from an 'essay mill' and passing it off as one's own is fraud.

Many publishers use [RightsLink](#) to manage the process whereby they permit authors to use their own work, and permit readers to buy published materials.

A particular issue faced by writing teams arises when the individual authors have quite different writing styles. Rafaella van den Bosch wanted her co-author, Gustaaf Bos to correct her spelling and grammar so that she wouldn't be ashamed of the final product, while Gustaaf feared that such an action would reinforce the power difference in their working relationship<sup>89</sup>. This separates into two elements: first, the request for proof-reading, which could have quite easily been done by an independent person, and secondly, the question raised in section 13 of this paper about who has the final word in editorial decisions. For Rafaella and Gustaaf, the potential for a power differential was magnified by language difficulties, as Rafaella only speaks Dutch they had been invited to write in English.

## 10. Payment for co-authoring work

An effective 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 payment 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>90</sup>.

While general [guidance](#) on payments for participation is available, the specific question about participation payments and authorship has not been very precisely addressed<sup>91, 92</sup>. However, one international body has underlined their view that Public Contributors should be treated equitably with other authors<sup>93</sup>. 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<sup>94</sup>. There may be time periods during or after the study is complete when the Public Contributor is unavailable<sup>95</sup>.

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<sup>96</sup>.

## **11. 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. Getting material into the public domain is not easy, as only 40% of research projects get their research published within the required timeframe and another 40% are never published<sup>97</sup>.

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<sup>98</sup>. 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<sup>99</sup>.
- 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>100</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>101</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. Finding a way to bring together these different approaches is part of the challenge of co-authorship.

## 12. 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)*

### **13. 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<sup>102</sup>. The *British Medical Journal*, for example, has engaged patients and caregivers in this role since 2014<sup>103</sup>, has 800 such reviewers on its books<sup>104</sup> and offers guidance<sup>105</sup> 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<sup>106</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<sup>107</sup>. Indeed, while some writing is formed by collaborators who each spend the same amount of time 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>108</sup>.

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 and then clarify which of the following are 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.

The issue of power blankets every stage of the writing process and comes down to the question of who has the last word. Purists might argue that the output is not really co-authored at all if the academic always has the last word or only appears to comply

with the public author when they happen to agree anyway, or when descriptions of collaborative writing are sanitised, neutered accounts that neglect to report conflict and disagreement<sup>109</sup>.

One group found that spending time in some creative writing workshops developed their confidence. Glen Swanwick is a public co-author<sup>110</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.”*

#### **14. 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<sup>111</sup>, and a third group are highly competent authors already but may need to explore how collaborative writing works with this group of people<sup>112</sup>. 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<sup>113</sup> 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<sup>114</sup>. If this is not navigated carefully, some public co-authors may feel bruised by the feedback process, especially if it is cruel, dismissive<sup>115</sup> or inconsistent<sup>116</sup>. 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<sup>117</sup>.

Linking with a group of public co-authors<sup>118</sup> can provide both advice and emotional support<sup>119</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 skills of the team is very important. Gaining supportive but robust feedback on drafts from within your own team is also very helpful.”*

Finally, we note that things can go wrong, even with the best of intentions<sup>120</sup>.

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<sup>1</sup> Peter Bates has continued to add amendments and corrections from time to time since the original work was done. 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, Hariklia Nguyen, 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.

<sup>2</sup> See, for example, the online training at <https://wecanadvocate.eu/patients-in-publications/>.

<sup>3</sup> 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://peterbates.org.uk/wp-content/uploads/2017/04/11n - clients or what.pdf](http://peterbates.org.uk/wp-content/uploads/2017/04/11n_-_clients_or_what.pdf).

<sup>4</sup> For example, see Saha A & van Lente S (2020) *Rethinking ‘diversity’ in publishing*. Goldsmiths Press, 2020. Available to download as a pdf from: [https://www.spreadtheword.org.uk/wp-content/uploads/2020/06/Rethinking\\_diversity\\_in-publishing\\_WEB.pdf](https://www.spreadtheword.org.uk/wp-content/uploads/2020/06/Rethinking_diversity_in-publishing_WEB.pdf).

<sup>5</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>6</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 Lesley Wye’ blog from 11 April 2017 at <https://www.dc.nihr.ac.uk/blog/researchers-to-make-an-impact-write-less-and-talk-more/5933>.

<sup>7</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>8</sup> Department of Health (13 Dec 2012) *Liberating the NHS: No decision about me, without me – Government response to the consultation*. Available [here](#).

<sup>9</sup> ISMPP members voted in support of the involvement of patients in publications at the ISMPP Annual Meeting April 30–May 2, 2018, National Harbor, MD, US and at the ISMPP European Meeting January 23–24 2018, London, UK

- <sup>10</sup> See, for example, Richards DP, Birnie KA, Eubanks K. et al. (2020) Guidance on authorship with and acknowledgement of patient partners in patient-oriented research. *Res Involv Engagem* 6, 38. <https://doi.org/10.1186/s40900-020-00213-6>.
- <sup>11</sup> David Brindle, personal communication 10 December 2014.
- <sup>12</sup> See the 2013 position paper defining Participatory Health Research from the International Collaboration for Participatory Health Research [here](#).
- <sup>13</sup> Flicker S & Nixon SA (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.
- <sup>14</sup> See Greenhalgh T (2019) Twitter Women's Tips on Academic Writing: A Female Response to Gioia's Rules of the Game *Journal of Management Inquiry* Vol 28, issue 4, pages 484-487. Published online: July 14, 2019; Issue published: October 1, 2019. <https://doi.org/10.1177/1056492619861796>.
- <sup>15</sup> See Jacquez F, Vaughn LM, Wagner E. Youth as Partners, Participants, or Passive Recipients: A Review of Children and Adolescents in Community-Based Participatory Research (CBPR). *American Journal of Community Psychology*. 2012;51(1-2):176-89. Also Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, ... & Erwin P (2014) Patient engagement in research: a systematic review. *BMC health services research*. 14;1(89).
- <sup>16</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.
- <sup>17</sup> By 28 June 2021, this archive was no longer available.
- <sup>18</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 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.
- <sup>19</sup> See. <https://ismpp-newsletter.com/2020/05/13/patient-authorship-three-key-questions-answers-for-medical-communication-professionals-part-a/>. PubMed is a large archive of academic papers at <https://pubmed.ncbi.nlm.nih.gov/>. Insert "patient author" [Affiliation] in the search bar and see what comes up. On 28 June 2021, this was 8 papers, indicating that the affiliation is still rare.
- <sup>20</sup> Arnstein L, Wadsworth AC, Yamamoto BA. et al. (2020) Patient involvement in preparing health research peer-reviewed publications or results summaries: a systematic review and evidence-based recommendations. *Research Involvement & Engagement* 6, 34. <https://doi.org/10.1186/s40900-020-00190-w>
- <sup>21</sup> Professor Hewlett is at the University of the West of England (personal communication, 6 October 2014).
- <sup>22</sup> See <https://www.ucb.com/our-science/magazine/detail/article/Patient-perspectives-on-publishing-research-outcomes>. In personal correspondence (June 2020), UCB explained 'The remit of the PPSC will be to co-create a Publication Plan based on non-product specific publications such as manuscripts on disease burden, unmet need and the patient journey, however the audience will include Health Care Professionals, funders and researchers as the manuscripts will be published in the peer-reviewed medical literature.'
- <sup>23</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>24</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>25</sup> Arain M, Pyne S, Thornton N, Palmer S & Sharma R (2014) Consumer involvement in cancer research: example from a Cancer Network *Health Expectations*, advance e-publication, DOI: 10.1111/hex.12143
- <sup>26</sup> Abell. S et al (2007) Including everyone in research: The Burton Street Research Group *British Journal of Learning Disabilities*, 35, 121-124
- <sup>27</sup> Simpson A, Jones J, Barlow S, Cox L. & 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>28</sup> Bindels J, Baur V, Cox K, Heijing S & Abma T (2014) Older people as co-researchers: A collaborative journey *Ageing & Society*, 34(6), 951-973.
- <sup>29</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 & 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>30</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>31</sup> Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S et al. (2017) GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research *BMJ* 2017; 358:j3453. See also Jones, J., Cowe, M., Marks, S. et al. (2021) Reporting on patient and public involvement (PPI) in research publications: using the GRIPP2 checklists with lay co-researchers. *Research Involvement & Engagement* 7, 52. <https://doi.org/10.1186/s40900-021-00295-w>.
- <sup>32</sup> See <https://cdn.instantmagazine.com/upload/18080/envision-patient-research-poster-book.3e44f7300085.pdf>.
- <sup>33</sup> For example, select the online ‘advanced search facility’ at PubMed, and then select the ‘all fields’ option. Select ‘affiliation’ and type in ‘Patient author’. Select search. In each item found, expand the ‘Affiliations’ to identify which author is listed as the Patient Author. On 19 October 2020, this returned just one paper. If more patient authors identified themselves in repositories, then this would represent the field more accurately.
- <sup>34</sup> See the lay summary at [https://cdn.instantmagazine.com/upload/18080/envision\\_gpp3\\_summary\\_for\\_patient\\_authors.b82d705e3d80.pdf](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.
- <sup>35</sup> Envision Pharma Group (2018) *Patient Involvement in Publications: Prioritise or Perish?* Perspectives from the Envision the Patient Forum, London, UK, 25 January 2018.
- <sup>36</sup> See the ‘Plain Language Summaries of Publications’ toolkit that can be downloaded from <https://www.envisionthepatient.com/plstoolkit/>. Plain Language Summaries should be made available as a separate document and given the most relaxed copyright status (usually the Creative Commons Attribution Licence known as CC-BY. They should be submitted as a separate file at the time of manuscript submission and go through the peer review process, but then made available as Open Access. The experience of co-authoring a Plain Language Summary has been evaluated via a Patient Author Experience self-evaluation tool. Patient and non-patient versions have been codesigned, used and reported on – see Woolley KL, Arnstein L, Hamoir AM, Lobban D, Stephens R and Yamamotoi B “Development and use of 2 tools to facilitate and evaluate patient authorship”. Poster presented at the 15th Annual Meeting of ISMPP, April 15-17, 2019, National Harbor, MD, USA.
- <sup>37</sup> This is sometimes abbreviated to the acronym IMRAD – see [here](#) for an explanation and [here](#) for a commentary.
- <sup>38</sup> For an example, see <http://www.bmj.com/content/346/bmj.f3374>
- <sup>39</sup> Wilkinson C & Wilkinson S (2017) Doing it write: Representation and responsibility in writing up participatory research involving young people. *Social Inclusion*. 5(3):219-27.
- <sup>40</sup> For an example of Collaborative Auto-Ethnography, see Groot BC, Vink M, Haveman A, Huberts M, Schout G & Abma TA (2019) Ethics of care in participatory health research: mutual responsibility in collaboration with coresearchers, *Educational Action Research*, 27:2, 286-302, DOI: 10.1080/09650792.2018.1450771.
- <sup>41</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>42</sup> Their approach is described at <http://onlinelibrary.wiley.com/doi/10.1002/9781444323764.fmatter/pdf>

<sup>43</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>44</sup> Professor Kathryn Church, Director of the School of Disability Studies, Ryerson University, Canada – personal communication 29 October 2014.

<sup>45</sup> For example, *Acta Psychiatrica Scandinavica* encourages authors to submit video and audio podcast to accompany their article published in the journal.

<sup>46</sup> See

<https://www.researchgate.net/publication/229062236> Article 50 million An estimate of the number of scholarly articles in existence

<sup>47</sup> 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.

<sup>48</sup> 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](http://aom.org/uploadedFiles/About_AOM/StrategicPlan/AOMScholarlyImpactReport.pdf)

<sup>49</sup> See the Academic Journal Guide at <https://charteredabs.org/academic-journal-guide-2018/>

<sup>50</sup> 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?

<sup>51</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>52</sup> 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 welcomes submissions from patient authors and co-authors, as well as offering coaching for authors and engaging patients as peer reviewers. The managing editor of the *Journal of Participatory Research Methods* asserted ‘While we expect certain scholarly conventions like proper citation and attribution of other’s ideas, we would love to have a participant authored paper about participatory methods.’ (personal communication, 29 July 2020). Other journals that are reputed to be friendly towards Public Authors include the *Journal of Participatory Medicine*, *The Patient*, *Value in Health* and *Health Expectations*.

<sup>53</sup> 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](https://ec.europa.eu/health/sites/health/files/files/eudralex/vol-10/2017_01_26_summaries_of_ct_results_for_laypersons.pdf). A list of journals that routinely produce lay summaries is available at <https://elifesciences.org/inside-elifesciences/5ebd9a3f/plain-language-summaries-journals-and-other-organizations-that-produce-plain-language-summaries>.

<sup>54</sup> See <https://patientsincluded.org/journals/>

<sup>55</sup> The [Committee on Publication Ethics](#).

<sup>56</sup> See <http://www2.le.ac.uk/departments/health-sciences/research/soc-sci>

<sup>57</sup> See <http://www2.le.ac.uk/departments/health-sciences/research/soc-sci/pdf-resources/authorship-principles>

<sup>58</sup> <http://www2.le.ac.uk/departments/health-sciences/research/soc-sci/pdf-resources/authorship-good-practice-tips>

<sup>59</sup> There is more on predatory journals in Bates P (last updated 2021) [How to get a copy of an academic paper](#).

<sup>60</sup> 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>

<sup>61</sup> 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.

<sup>62</sup> See this report on the effect of introducing reporting guidelines about Patient and Public Involvement in research at the British Medical Journal - Price A, Schroter S, Snow R, et al (2018) Frequency of reporting on patient and public involvement (PPI) in research studies published in a general medical journal: a descriptive study *BMJ Open* 8:e020452. <https://bmjopen.bmj.com/content/8/3/e020452>.

<sup>63</sup> See <https://wol-prod-cdn.literatumonline.com/pb-assets/assets/14683156/BLD-%20Information%20for%20Writers%20Sept%2019-1569841659640.pdf>

<sup>64</sup> 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.

<sup>65</sup> 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.

<sup>66</sup> See <http://journal.emwa.org/writing-better/amwa-emwa-ismpp-joint-position-statement-on-the-role-of-professional-medical-writers/>

<sup>67</sup> Von Bergen CW & Bressler MS (2019) Santa Claus comes to Higher Ed: balancing the costs and benefits of gift authorship *Journal of Business Cases and Applications* Volume 23. Downloaded from <http://aabri.com/manuscripts/182969.pdf> 13 Dec 2020.

<sup>68</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>. The practice of awarding honorary authorship was found to be quite common in an Indian study – see Shah A, Rajasekaran S, Bhat A, Solomon JM (2018) Frequency and Factors Associated With Honorary Authorship in Indian Biomedical Journals: Analysis of Papers Published From 2012 to 2013. *Journal of Empirical Research on Human Research Ethics*, 13(2):187-195. doi:[10.1177/1556264617751475](https://doi.org/10.1177/1556264617751475)

<sup>69</sup> Carter S (2010) Authorship: Definitions and declarations—A perspective from the BMJ *The Write Stuff* Vol 19, No 1, p18.

<sup>70</sup> Faulkes Z (2018) Resolving authorship disputes by mediation and arbitration. *Res Integr Peer Rev* 3, 12. <https://doi.org/10.1186/s41073-018-0057-z>.

<sup>71</sup> Smith E, Bélisle-Pipon J-C & Resnik D (2019) Patients as Research Partners; How to Value their Perceptions, Contribution and Labor? *Citizen Science: Theory and Practice*, 4(1), p.15. DOI: <http://doi.org/10.5334/cstp.184>.

<sup>72</sup> 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>

<sup>73</sup> 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. Verbatim quotes that include idiosyncratic language or style can reveal the identity of the speaker. Criterion 4 of the ICMJE recommendations for authorship requires 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 published between 1 January 2016 and 31 December 2018 include: (i) **JTSP vol 2, issue 1**. – papers by ‘Anna Bisette’ and ‘Juliana Bisette’ where these are pseudonyms; (ii) **Schizophrenia Bulletin** - Anonymous; (3 July 2018) Resolving Repression, *Schizophrenia Bulletin*, sby071, [DOI.org/10.1093/schbul/sby071](https://doi.org/10.1093/schbul/sby071) also Anonymous; Learning to Live With Schizoaffective Disorder: A Transformative Journey Toward Recovery, *Schizophrenia Bulletin*, Volume 44, Issue 1, 13 January 2018, Pages 2-3, [DOI: org/10.1093/schbul/sbx125](https://doi.org/10.1093/schbul/sbx125); also Anonymous; Intrusive Thoughts, Impulses, and Schizoaffective Disorder, *Schizophrenia Bulletin*, sbw107 <https://doi.org/10.1093/schbul/sbw107>. (iii) **Political Geography** - Anonymous. (2018). Rosewood Democracy in the Political Forests of Madagascar. *Political Geography*, 62 (January), 170-83; (iv) **Journal of Contemporary Asia** - Anonymous (2018) Anti-Royalism in Thailand Since 2006: Ideological Shifts and Resistance, *Journal of Contemporary Asia*, 48:3, 363-394, DOI: 10.1080/00472336.2018.1427021; (v) **Human Geography** - Daniel Paiva, Herculano Cachinho & 12 Anonymous Participants (2018) The first impression in the urban sonic experience: transitions, attention, and attunement, *Geografiska Annaler: Series B, Human Geography*, DOI: [10.1080/04353684.2018.1444943](https://doi.org/10.1080/04353684.2018.1444943); (vi) **Lancet Diabetes and Endocrinology** - Anonymous. (2017). Inpatient care and diabetes: putting poor glycaemic control to bed. *Lancet Diabetes and Endocrinology*, 5, 770; (vii) **Clinical Ethics** - Anonymous (1 September 2016) Ethics consultation in the context of psychological supervision: A case study *Clinical Ethics* Volume: 11 issue: 2-3, page(s): 97-104. DOI.org/10.1177/1477750916644931; (viii) **BMJ** Anonymous ‘Remembering the person’ *BMJ* 2018 Jul 18;362. Doi: 10.1136/bmj.k2512; (ix) **Thrombosis Research**. Krause M, Anonymous et al (2016) Impact of gender on safety and efficacy of Rivaroxaban in adolescents & young adults with venous thromboembolism. *Thromb Res* ;148:145-151. doi: 10.1016/j.thromres.2016.09.007. Epub 2016 Sep 13.

<sup>74</sup> 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.’

<sup>75</sup> See, for example, Elliott J, Lodmore M, Minogue V & Wellings A (2019) *Public Co-applicants in research – guidance on roles and responsibilities* Southampton: INVOLVE.

<sup>76</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 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.

<sup>77</sup> 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.’

<sup>78</sup> This recommendation comes from the International Committee of Medical Journal Editors guidance – see <http://www.icmje.org/icmje-recommendations.pdf>

<sup>79</sup> 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>.

<sup>80</sup> 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.

<sup>81</sup> Vasilevsky NA, Hosseini M, Teplitzky S, Ilik V, Mohammadi E, Schneider J, Kern B, Colomb J, Edmunds SC, Gutzman K, Himmelstein DS, White M, Smith B, O’Keefe L, Haendel M & Holmes KL (2021) Is authorship sufficient for today’s collaborative research? A call for contributor roles, *Accountability in Research*, 28:1, 23-43, DOI: [10.1080/08989621.2020.1779591](https://doi.org/10.1080/08989621.2020.1779591)

<sup>82</sup> Hoddinott P, Pollock A, O’Cathain A et al (2018) How to incorporate patient and public perspectives into the design and conduct of research [version 1; peer review: 3 approved, 2 approved with reservations]. *F1000Research* 7:752 <https://doi.org/10.12688/f1000research.15162.1>.

<sup>83</sup> Allen L, O’Connell A, Kiermer V (2019) How can we ensure visibility and diversity in research contributions? How the Contributor Role Taxonomy (CReDIT) is helping the shift from authorship to contributorship. *Learned Publishing* Jan;32(1):71-4.

<sup>84</sup> See, for example, the flowchart developed by Envision at [https://cdn.instantmagazine.com/upload/18080/envision\\_patient\\_authorship\\_flowchart.c3768fa19906.pdf](https://cdn.instantmagazine.com/upload/18080/envision_patient_authorship_flowchart.c3768fa19906.pdf). Also Kosslyn SM (2014). Authorship: Credit where credit is due. In 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>85</sup> As an example of the extent to which views vary on this matter, see [here](#).

<sup>86</sup> For an example of a paper where the public contributor was first author, see <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0120-4#Bib1>.

<sup>87</sup> Tweet from Trisha Greenhalgh 11/9/19, quoted with permission.

<sup>88</sup> Advice from the Committee on Publication Ethics on how to deal with text recycling is available [here](#).

<sup>89</sup> Gustaaf Bos and Rafaella van den Bosch ‘About the ‘co’ in co-writing: Challenges from a Dutch university researcher co-researching with people with intellectual disabilities’ Case 5.2 *in* Banks S & Brydon-Miller M (2019) *Ethics in Participatory Research for Health and Social Well-Being: Cases and Commentaries* Abingdon: Routledge. Page 124.

<sup>90</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](#). It has been reported that 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](#).

<sup>91</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. 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. On 10/9/2018, ICMJE agreed to discuss the matter at ‘the next meeting of the ICMJE’ but no update has been provided – chased up on 19/11/18 and 8/2/19.

<sup>92</sup> 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.

<sup>93</sup> See the declaration from the International Committee of Medical Journal Editors at <http://peterbates.org.uk/home/garden-shed/payment-for-authors/>.

<sup>94</sup> Hamilton S (2016) *Influencing the debate – peer research in academic journals*. See <http://mcpin.org/influencing-the-debate-peer-research-in-academic-journals/>.

<sup>95</sup> It is good practice to check out availability at an early stage in the writing project. See <https://ismpp-newsletter.com/2020/05/26/patient-authorship-three-key-questions-answers-for-medical-communication-professionals-part-b/>

<sup>96</sup> In 2021, ALCS also began to collect a share of the sale price of second-hand books from certain retailers and to transfer these funds to authors. ALCS members are automatically enrolled in this scheme which is called AuthorSHARE.

<sup>97</sup> DeVito NJ, Bacon S, Goldacre B. Compliance with legal requirement to report clinical trial results on ClinicalTrials.gov: a cohort study. *The Lancet*. 2020 Feb 1;395(10221):361-9.

<sup>98</sup> Or see the [Academic Journal Guide](#) for a general ranking of journals. These matters are considered critically by the [Lancaster Literacy Research Centre](#).

<sup>99</sup> Groot B & Abma T ‘Partnership, collaboration and power’ chapter 2 in Banks S & Brydon-Miller M (2019) *Ethics in Participatory Research for Health and Social Well-Being: Cases and Commentaries* Abingdon: Routledge. Page 38.

<sup>100</sup> Open access improves the dissemination of scientific information – see <http://www.fasebj.org/content/25/7/2129.short> For a review of UK policy see [Review of the implementation of the RCUK Policy on Open Access](#) (March 2015) at <https://www.ukri.org/funding/information-for-award-holders/open-access/open-access-policy/>.

<sup>101</sup> Journals may charge anything up to £3000 for publishing open access papers See [https://en.wikipedia.org/wiki/Article\\_processing\\_charge](https://en.wikipedia.org/wiki/Article_processing_charge).

<sup>102</sup> The role of the lay reviewer is discussed by Lynn Laidlaw (Public Contributor) and Elspeth Mathie (researcher) at <https://arc-oe.nihr.ac.uk/news-insights/news-latest/blog-why-we-need-invest-people-who-lay-review-journals>.

<sup>103</sup> See <https://scholarlykitchen.sspnet.org/2018/06/19/interview-bmjs-patient-review-initiative-novel-expansion-peer-review/>

<sup>104</sup> Details are available [here](#). The Canadian Medical Association Journal also includes patient reviewers – see [here](#).

<sup>105</sup> See <https://www.bmj.com/about-bmj/resources-reviewers/guidance-patient-reviewers>

<sup>106</sup> For general advice on writing, see Storyshop [here](#).

<sup>107</sup> For an example of the value of reflecting on the co-authoring process, see Case 5.4 About the 'co' in co-writing: Challenges for a Dutch university researcher co-researching with people with intellectual disabilities Gustaaf Bos and Rafaella van den Bosch in Banks S & Brydon-Miller M (2019) *Ethics in Participatory Research for Health and Social Well-Being: Cases and Commentaries* Abingdon: Routledge.

<sup>108</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>109</sup> Jordan and Lynne ask questions about this, wondering why even the Plain English Summary of research funding applications is often written for rather than by Public Contributors. See <https://blogs.ucl.ac.uk/public-engagement/2020/12/15/co-production-and-involvement-in-health-research-why-arent-we-showing-our-working/>.

<sup>110</sup> Glen Swanwick has co-authored a paper in *The Lancet* [here](#).

<sup>111</sup> Professor Helen Sword trains people in academic writing. See her books at <https://www.helensword.com/books-on-writing>.

<sup>112</sup> Lowry PB, Curtis A, & Lowry MR (2004) Building a Taxonomy and Nomenclature of Collaborative Writing to Improve Interdisciplinary Research and Practice. *The Journal of Business Communication* 41 (1): 66–99.

<sup>113</sup> There are many examples of highly influential papers that were rejected multiple times before being accepted by editors. Evidence-based advice on handling manuscript rejection is available at [https://journal.chestnet.org/article/S0012-3692\(09\)60153-7/fulltext](https://journal.chestnet.org/article/S0012-3692(09)60153-7/fulltext).

<sup>114</sup> 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.

<sup>115</sup> In an evaluation of 1491 sets of reviewer comments, 12% of comment sets included at least one unprofessional comment towards the author or their work and 41% contained incomplete, inaccurate or unsubstantiated critiques. See Gerwing TG, Allen Gerwing AM, Avery-Gomm S, Choi C-Y, Clements JC & Rash JA (2020) Quantifying professionalism in peer review. *Res Integr Peer Rev* 5, 9. <https://doi.org/10.1186/s41073-020-00096-x>.

<sup>116</sup> Bornmann's team found low levels of inter-rater reliability between the feedback comments of journal submission reviewers. See Bornmann L, Mutz R and Daniel HD (2010). A reliability-generalization study of journal peer reviews: A multilevel meta-analysis of inter-rater reliability and its determinants. *PLoS ONE* 5(12).

<sup>117</sup> 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.

<sup>118</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>119</sup> In a historic research study carried out in 1982 (<http://journals.cambridge.org/action/disAbstract?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 that peer review is "unjust, unaccountable ... often insulting, usually ignorant, occasionally foolish, and frequently wrong." – see [https://en.wikipedia.org/wiki/Richard\\_Horton\\_%28editor%29#Peer\\_review](https://en.wikipedia.org/wiki/Richard_Horton_%28editor%29#Peer_review)

<sup>120</sup> Retraction Watch have recorded over 2000 papers that have been retracted since 2010, revealing that mistakes can be made and published. See <https://retractionwatch.com/retraction-watch-database-user-guide/>.