Envision the Patient
Research in Patient Involvement
Patient involvement in preparing clinical research peer-reviewed publications or results summaries: a systematic review (Presented at ISMPP 2018)

Patient involvement in publications of industry-sponsored research: cross-sectional survey (Presented at ISMPP 2018)

Patient involvement...or not? Analysis of ‘Patient Involvement’ statements in clinical trial publications in The BMJ (Presented at ISMPP EU 2018 and ISMPP 2018)

Transparency and completeness in the reporting of stakeholder involvement in the development and reporting of research reporting guidelines (Presented at PRC 2017)

Who engages with patient-centered, peer-reviewed publications? Tweeting of JAMA Patient Page (Presented at ISMPP EU 2017)

Congress and journal practices in a digital and patient-centric era — hasten slowly? (Presented at ISMPP 2017)

Clinical trials: do the patients get the thanks they deserve? (Presented at ISMPP EU 2015)
Patient Involvement in Preparing Clinical Research Peer-Reviewed Publications or Results Summaries: A Systematic Review


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Presented at the 14th Annual Meeting of the International Society for Medical Publication Professionals (ISMPP); April 30–May 2, 2018; National Harbor, MD, USA
Objective

The importance of patient involvement in medicines development is recognized by many stakeholders (e.g., patients, funders, regulators, payers). However, patient involvement in publications or at a trial stage in the evidence life cycle is lagging behind patient involvement in other areas (e.g., clinical trial design). Evidence on patient involvement in publications should be assessed to help develop best practice guidelines.

Purpose: To conduct the world’s first systematic review to identify the quantity and quality of evidence on the benefits and harms of patient involvement in preparing peer-reviewed publications and clinical trial results summaries.

Methods

Patient Involvement...

Published evidence on patient involvement in results reporting is limited.

- Studies included in the systematic review are characterized by low evidence.
- The bulk of evidence is low-quality.

Quality of evidence is low.

- Grading scale (Newcastle-Ottawa Scale) for articles on the effects of patient involvement in preparing peer-reviewed publications.

Evidence on benefits and harms of patient involvement in publications.

Patient involvement... in the voice of the patient author.

- Limited evidence on benefits and harms.
- Future directions and recommendations.

Patient involvement... in the voice of the academic author.

- Academic members also learned from the project.
- Not overstating the case to say that patient and public involvement in research... the norm. Therefore imperative that both professional researchers and research partners (patients) receive appropriate support to acquire and enhance requisite skills.

Limitations

- The lack of standardized terms to describe patient involvement in clinical research, including results reporting.
- Additional searches (e.g., hand searches) will complement our database search, and the full results will be reported in a forthcoming publication.
- The GRIPP2 guidelines... for patient involvement in research.

Conclusions and Implications

- Published evidence on the effects of patient involvement in results reporting is limited.
- Published evidence on the effects of patient involvement in preparing peer-reviewed publications is limited.

- The quantity and quality of evidence should be enhanced to guide best practice. Those who involve patients in publications should:
  - Gain ethical and substantial input from patients (e.g., via publication steering committees, via patient authorship).
  - Report on their experiences of involving patients in publications.
  - Use the GRIPP2 guidelines... for the publication of patient involvement.
  - To help maximise benefits and minimise harms, the Good Publication Practice guidelines should be updated.
  - Guidance on patient involvement should be co-created with patient authors.
  - Twitter (GPP4) is being used to collect input for a guideline update.

References

Patient Involvement in Publications of Industry-Sponsored Research: Cross-Sectional Survey

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Presented at the 14th Annual Meeting of the International Society for Medical Publication Professionals (ISMPP); April 30-May 2, 2018; National Harbor, MD, USA

Purpose: To investigate the extent and type of patient involvement in publications and the barriers and opportunities for patient involvement in research, as well as the perceived willingness or ability to involve patients in publication planning and delivery?

Methods

The survey, which could be completed anonymously, was administered via SurveyMonkey. Pilot testing was conducted to validate survey questions investigated:

- How do you communicate with patient leaders, journal editors, industry sponsors and publication professionals?
- How would you describe your typical communication style?
- How do you identify patients for inclusion in publications?

Survey recipients were industry-sponsored researchers and agency staff (eg, publication planners, medical writers, editors, health care professionals) who had expressed an interest in patient involvement in publications or publication planning.

Results

Response rates were 31% (12/39) for industry and 47% (174/373) for agency staff. Patients expressed the most interest in the following opportunities:

- Patient involvement in publications (83.3%)
- Lay (plain language) summaries for clinical trial summaries and for peer-reviewed publications (82.2%)
- Involved in study design (81.4%)
- Patient involvement in reviewing and assessing clinical trial concepts/planning/development (80.9%)

Respondents selected answers based on the following options:

- Very rarely or never
- Rarely
- Occasionally
- Frequently
- Always

Conclusions and Implications

• Potentially high patient interest in involvement in publications
• Educate and raise awareness of patient involvement in publications
• Patient involvement is being encouraged by industry and agency staff

Generalisation of results may be limited by a single point-in-time survey, especially with patient involvement in publications emerging as a new and dynamic area.

Potential compliance concerns from involving patients in publications include:

- It is rarely or never considered an option to involve patients (26%
- It is considered an option' (28%)
- Assuming compliance concerns are not a barrier to involving patients (81%)

SOLUTIONS.

- Presenting the mandatory ‘Patient Involvement’ statement for research articles
- Addressing patient-reported contributions made
- Educating and raising awareness of patient involvement in publications

Abstract

Patient involvement in industry-sponsored research is being encouraged. However, there is limited real-world evidence on how patients are involved in publications and what reasons are limiting routine involvement of patients in publications or publication planning?
Patient Involvement in Publications of Industry-Sponsored Research: Cross-Sectional Survey

Dawn Lobb, Anne O’Dowd, D. Mary Swan, Ritu Verma

Objective

Patient involvement in industry-sponsored research is being encouraged. Our objective was to conduct the first international survey of industry and agency staff to investigate the extent and type of patient involvement in publications of industry-sponsored research, and to ascertain the experiences and views of industry and agency staff on patient involvement in publications.

Research design and methods

A cross-sectional survey was conducted (29/12/2017–10/01/2018) using an 8-item online questionnaire. Pilot testing was conducted for validity and content of the questionnaire. The survey was distributed via a secure email link to industry responders (eg, medical affairs, patient partnerships, medical writers, medical editors who have or may work on patient-authored publications) and agency responders (eg, publication planners, medical writers, who have or may have worked on patient-authored publications). One email reminder was sent to non-responders for completion of the survey.

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A cross-sectional survey was conducted (29/12/2017–10/01/2018) using an 8-item online questionnaire. Pilot testing was conducted to validate the survey functionality and estimate response time. The survey, which could be completed anonymously, was distributed via a secure email link to industry responders (eg, medical affairs, patient partnerships, medical writers, medical editors who have or may work on patient-authored publications) and agency responders (eg, publication planners, medical writers, who have or may have worked on patient-authored publications). One email reminder was sent to non-responders for completion of the survey.

Response rates were 31% (12/39) for industry and 47% (174/373) for agency staff. One email reminder was provided. No incentives for completion were offered.

Results

Response rates were 31% (12/39) for industry and 47% (174/373) for agency staff. One email reminder was provided. No incentives for completion were offered.

BARRIERS. Based on experience and observations, what reasons are limiting routine involvement of patients in publications or publication planning?

Highest ranked 'barriers by responders:

- Lack of involvement in designing the research questions
- Potential compliance concerns from internal stakeholders
- Author concerns about the risks of working with a patient author (eg, potential patient dropouts)

OPPORTUNITIES. Assuming compliance concerns could be addressed, which situations should be promoted to ensure patient involvement?

Highest ranked 'opportunities by responders:

- Better understanding of where patients fit in/unmet needs and evidence of added value
- Alignment of expectations, guidelines, processes and compliance tools
- Databases/technologies to facilitate patient involvement (eg, identification, education, tracking)

SOLUTIONS. What would make the biggest short-term (eg, within next 1-2 years) difference for clients’ willingness or ability to involve patients in publication planning and delivery?

- Better understanding of where patients fit in/unmet needs and evidence of added value
- Education/training for patients (and caregivers) and pharma when and how should patients be involved
- Alignment of expectations, guidelines, processes and compliance tools
- Databases/technologies to facilitate patient involvement (eg, identification, education, tracking)

Strong collaboration between patients, patient advocates, doctors, pharma, etc., and others.

Conclusions and Implications

- The limited duration of the survey period may have limited participation.
- Generalization of results may be limited by a single point-in-time survey, especially with patient involvement in publications emerging as a new and dynamic area.

- While patients are often thanked for their participation in clinical studies, they are rarely involved in other aspects of study design or conduct, analysis or dissemination of results or listed as authors on publications.

- Responders agreed that the main barrier limiting patient involvement in publications is that it is rarely or never considered an option.

- Lay (plain language) summaries were identified as the best opportunity for patient involvement.

- These survey results could be used to develop a series of recommendations, co-created with patients, patient leaders, journal editors, industry sponsors and publication professionals, to guide patient involvement in publications of industry-sponsored research.

- The next update to the Good Publication Practice guidelines should include evidence and guidance on patient involvement in publications.

Acknowledgements and Disclosures

Acknowledgements: We would like to thank the following for their contributions:...
Patient Involvement...Or Not? Analysis of ‘Patient Involvement’ Statements in Clinical Trial Publications in *The BMJ*

Anne Clare Wadsworth, a Lauri Arnstein, a Thomas Gegeny, b Rachel Jones, a Arabella Sargent, a Antonio Ciaglia, c Richard Stephens, a Beverley Yamamoto, a,k Karen L. Woolley, l,m

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Presented at the 2018 European Meeting of the International Society for Medical Publication Professionals (ISMPP): January 23-24, 2018; London, UK

Encored at the 14th Annual Meeting of the International Society for Medical Publication Professionals (ISMPP): April 30-May 2, 2018; National Harbor, MD, USA
Patient Involvement... Or Not?

Analysis of ‘Patient Involvement’ statements in clinical trial publications in The BMJ

Jenny Etheridge, Arla Westerlund, Michelle Mauck, Christiane Floch, Lizzy MacLachlan, Emily MacKenzie, and Anna Ratcliffe

ENVISION PHARMA GROUP

Abstract

Objectives: To quantify the extent of patient authorship in clinical trial research publications in The BMJ. Our primary objective was to quantify patient authorship.

Methods: We searched PubMed (journal: The BMJ; publication type: clinical trial; dates: 2015/01/01–2016/12/31) and electronically exported all retrieved articles. Non-research articles were removed. Two authors categorised patient involvement based on the verbatim 'Patient Involvement' and 'Involved in dissemination' questions or the outcome measures, nor were they asked to evaluate the impact of patient involvement. Results were cross-checked.

Results: Of the 52 articles evaluated, 13 (25%) had a patient co-author. The BMJ has required a 'Patient Involvement' statement since 2014, so patient involvement in clinical trial publications has increased. This is an analysis of a single journal, which has mandated reporting of patient involvement in publications; we anticipate that reporting in other journals could be less frequent.

Conclusions: This study evaluates patient involvement that was reported rather than submitted to The BMJ. Without peer review at The BMJ, patient involvement may have been less frequent. The low frequency of patient involvement in clinical trial publications limits impact analysis, including exploratory assessment of publication metrics.

Purpose: To quantify the extent of patient authorship in clinical trial publications in The BMJ.

Methods:

- Since 2014, The BMJ has required a 'Patient Involvement' statement in the methods section of research articles.
- This BMJ article reports a range of activities, including: (a) involvement of patients as research partners, eg, patient-co-authors; (b) patients involved to some extent (broad), eg, assist with recruitment; and (c) patients ignored, eg, not even thanked.

Results:

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Transparency and Completeness in the Reporting of Stakeholder Involvement in the Development and Reporting of Research Reporting Guidelines

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Presented at the 8th International Congress on Peer Review and Scientific Publication; September 10–12, 2017; Chicago, IL, USA
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Abstract

Purpose: To investigate the involvement of patients, carers, and publication professionals in developing research reporting guidelines and the quality of their reporting involvement.

Methods: We systematically searched Medline, Embase, CINAHL, PsycINFO, and the Cochrane Library to identify reporting guidelines for the main study types, as listed on the EQUATOR Network website. We pilot-tested and standardized a data collection tool to report the extent of involvement of patients, carers, and publication professionals in the development of the reporting guidelines.

Results: There were 33 guideline publications; most had multiple stakeholders. Patients, carers, and publication professionals were not reported as authors of reporting guidelines. There were 33 guideline publications; most had multiple stakeholders. Patients, carers, and publication professionals were not reported as authors of reporting guidelines.

Patients, carers, and publication professionals were rarely reported as members of working groups or steering committees.

Leaders from organizations representing patients, carers, and publication professionals were not reported as authors or other stakeholders on four reporting guidelines. There were 33 guideline publications; most had multiple stakeholders. Patients, carers, and publication professionals were not reported as authors of reporting guidelines.

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Conclusions and implications

It is important to seek feedback and criticism from all stakeholders regarding the reporting guidelines. The involvement of patients, carers, and publication professionals in the development of research reporting guidelines enhances the credibility, dissemination, and use of guidelines. Stakeholder involvement in the development of reporting guidelines can enhance the credibility, dissemination, and use of guidelines.

Implications for guideline development

• Potential involvement of patients, carers, and publication professionals in the development of research reporting guidelines can enhance the credibility, dissemination, and use of guidelines.

Limitations

• Most reporting guidelines were developed before the availability of the AGREE Reporting Checklist.

Acknowledgments and disclosures

The authors have no conflicts of interest to declare.

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Who Engages With Patient-Centered, Peer-Reviewed Publications? Tweeting of JAMA Patient Page

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Presented at the 2017 European Meeting of the International Society for Medical Publication Professionals (ISMPP); January 17–18, 2017; London, UK


Results:

The public may be more powerful than health care professionals (HCPs) in promoting evidence dissemination. Peer-reviewed Patient Pages that were designed, primarily, to help healthcare professionals promote credible evidence to patients; with growing patient-centrism, the public may now be the primary promotors. We investigated the difference between Patient Pages or JAMA articles (28 vs 9; P < .001), and MEDLINE® articles (controlling for free-access, MEDLINE®-listed articles (controlling for journal matched articles for topic and time, and controlled for journal independent statistical support was provided by The University of Auckland, New Zealand, December 2016)

2. Publication type (JAMA Patient Page, JAMA Scientific Article, MEDLINE® Scientific Article) 1. Audience type (public vs HCP) 2. Journal (The Journal of the American Medical Association (JAMA) publishes

Background Methods:

For this research design and methods: sequential free-access JAMA Patient Pages1 from November 2013 to November 2015 as the top tweeting country (JAMA) publishes

90 80 70 60 50 40 30 20 10 0

The USA dominates tweeting about JAMA articles; 93 88 83 78 73 68 63 58 53 48

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Presented at the International Society for Medical Publication Professionals European Meeting; January 17–18, 2017; London, UK

Conclusions and implications

The public may amplify awareness of: • The primary aim of our study was to • Independent statistical support was provided by The University of Auckland, New Zealand, December 2016

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3. Tweeting of JAMA Patient Pages

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Abstract

Objective: Since 1998, JAMA has published peer-reviewed Patient Pages to help health care professionals (HCPs) promote credible health information to patients; with growing patient empowerment and access to social media, the public may now be the primary promoters of JAMA's Patient Pages on Twitter.

Research design and methods: For this controlled cross-sectional analysis, tweets of JAMA articles were matched for topic and time to JAMA articles (controlling for journal, article type, and month of publication) and to free-access, MEDLINE® articles (controlling for access, topic, and journal). Altmetric.com and Twitter between an independent academic statistician. Read for Patient Pages (n=30), JAMA articles (28 vs. 22), and MEDLINE® articles (35 vs. 40). The median number of Tweeters was higher for the JAMA articles (49; 226,719; 42; 88%) than related MEDLINE® articles (1; 183; 1; 22%).

Results: Public outperforms HCPs 1. JAMA scientific articles 2. Free-access MEDLINE® articles to JAMA articles (controlling for journal; n=86) and to free-access, MEDLINE® articles (controlling for access, topic, and journal; n=86). Altmetric.com and Twitter data were analysed by an independent academic statistician. Read for Patient Pages (n=86) and JAMA articles (n=86).

Conclusions: The public may be more powerful promoters of peer-reviewed publications, whether patient-centric or not, than HCPs. Tweeters from the US were the strongest promoters of JAMA's Patient Pages on Twitter.

Background

In an era of patient empowerment and social media, publication professionals should respect patients as publication partners and recognize the power of social media for evidence dissemination.

The Journal of the American Medical Association (JAMA) publishes peer-reviewed Patient Pages that were designed, primarily, to help health care professionals (HCPs) share evidence with their patients.

We hypothesized that patients may engage with patient-centric publications directly (ie, not only via their HCPs) and may amplify awareness of published evidence via Twitter.

The primary aim of our study was to compare engagement with JAMA's Patient Pages between the public and HCPs, based on Twitter activity.

Methods

**Source**

JAMA Patient Pages are published on the website and via Twitter at @JAMA_patient_pages.

**Research period:**

November 2015 to November 2016.

**Data collection**

- Statistical analysis

1. Audience type (public vs HCP)
2. Publication type (JAMA Patient Page, JAMA Scientific Article, MEDLINE® Scientific Article)

**Results**

Public outperforms HCPs

- JAMA scientific articles
- Free-access MEDLINE® articles
- JAMA Patient Pages

**Conclusions and implications**

- Patients and social media are challenging the traditional methods of disseminating peer-reviewed published evidence.
- Publication managers should take into account that:
  - The public is interested in credible, peer-reviewed, patient-centric publications.
  - The public may amplify awareness of:
    - Peer-reviewed publications more than HCPs.
    - Both patient-centric and scientific publications.

- Customization strategies (eg, local language, local journals) may be required to enhance the international reach of patient-centric publications.
- The patient voice should be heard throughout the publication lifecycle.

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Congress and Journal Practices in a Digital and Patient-centric Era — Hasten Slowly?

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Presented at the 13th Annual Meeting of the International Society for Medical Publication Professionals (ISMPP); May 1-3, 2017, National Harbor, MD, USA
Congress and journal practices in a digital and patient-centric era — hasten slowly?

Tania Dickson PhD, Thao Le MBBS, PhD, Sue Sutch PharmD and Karen L. Woolley PhD  

Background

- The pharmaceutical industry and publication environment are evolving in response to new trends, such as digital delivery and patient-centricity.

- Digital delivery options and patient-centricity may influence authors' selection of congresses and journals and, thereby, affect publication planning.

Objectives

- To investigate the extent to which leading congresses and journals have embraced digital delivery and patient-centricity.

Methods

- A large database of congresses and journals was used to identify digital delivery options and patient-centricity.

- Sources included journal and congress databases, websites, and patient-led clinical leadership initiatives.

Results

- Most congresses offer digital options.
- Most journals offer digital options.
- No congresses or journals met the Patients Included™ accreditation criteria.

Conclusions

- A selection of leading congresses and journals, targeted by authors of industry-funded research, have embraced digital delivery options.

- In contrast, none was sufficiently patient-centric.

References

4. Presentations at the 13th Annual Meeting of ISMPP, May 1-3, 2017, National Harbor, MD, USA.
Study Design

Clinical Trials: Do the Patients Get the Thanks They Deserve?

R. Bhatia, B. Anthony

Envision Pharma Group, Horsham, United Kingdom

Presented at the 2015 European Meeting of the International Society for Medical Publication Professionals (ISMPP); January 20-21, 2015; London, UK
Clinical trials: do the patients get the thanks they deserve?
Bhatia R, Anthony B
Envision Pharma Group, Horsham, UK

Introduction

- Patient-centric initiatives were becoming more common as healthcare policy has shifted towards a more active role for patients in disease management.
- Relevant publication professionals, authors, and sponsors. The BMJ will assess whether patient-dependent articles (ie, using patient data) address the questions in Table 1.
- Purpose: To investigate how often patients are thanked in patient-dependent publications in The BMJ.

Methods

Study Design
- We conducted a search in PubMed in August 2014, limited to the journal field for “BMJ”.
- The search was ordered by most recent publications first.
- Articles involving analysis of patient data were identified from the first 400 publications and assessed for:
  - Acknowledgments
  - Thanksing patients, ie, if a statement was included within the contributorship statement or the acknowledgments section of the manuscript that specifically thanked them.
  - Funding source.
- Acknowledgments were further broken down by:
  - Study design.
  - Patient population (adult, pediatric, or mixed).
  - Therapeutic area.
  - Geographic location of the corresponding author of the publication.

Results

- A total of 425 patient-dependent articles were identified.
- The most recent article was published on 3 July 2014, and the earliest article was published on 9 January 2012.

Groups Acknowledged
- A total of 62 articles (46.9%) included a statement that thanked patients/subjects (Figure 1).
- However, the most commonly acknowledged groups were participating staff of the research centers (56.0%) and study collaborators (56.0%) (Figure 2).

Study Type
- The majority of articles used data from randomized control trials (69.9%).
- Of these, 63 (69.0%) articles thanked patients, whereas only 58 (25.7%) articles that were not randomized control trials thanked patients.

Patient Population
- Most articles involved adult-only populations (94/125; 75.2%) followed by pediatric-only populations (17/125; 13.6%) and mixed (adult + pediatric) populations (14/125; 11.2%).
- A total of 59/94 (41.5%) adult-only populations thanked patients.
- Of 17 studies involving only pediatric patients, 15 (88.2%) thanked patients.
- In mixed population studies, 8/14 (57.1%) studies thanked the patient group for their data.

Therapeutic Area
- Patients were thanked in a higher proportion of manuscripts in the therapeutic areas of Managed care/Pharmacoeconomics and Pediatrics (83.3%) and Ophthalmology (80.0%, respectively) (Figure 3).
- The therapeutic area least likely to thank patients was Oncology (14.3%).

Conclusions

- In patient-focused publications in The BMJ, patients were thanked more often in randomized control trials (53/87; 60.9%) versus other types of studies (9/38; 23.7%).
- The therapeutic areas with highest patient acknowledgments were Pediatrics (80.0%) and Pharmacoeconomics (83.3%).
- Publications from the UK, rest of Europe, Scandinavia, and North America were more likely to thank patients.
- Of these, two (20.0%) publications thanked the patients for contributing their data to the study compared with 60/115 (52.1%) non-commercially sponsored manuscripts.

Acknowledgments

- The British Medical Journal (The BMJ) will be important to conduct a similar analysis in the future to assess the impact of the initiative and whether the aims of the initiative have been realized.
- Publication professionals could use our results to highlight to authors and sponsors the importance of thanking patients in patient-dependent publications.

Table 1. Questions asked by The BMJ from authors of patient-focused research
1. Did you involve patients/services users/carers/family people in the design of this study?
2. Was the development and/or selection of outcomes informed by patient priorities and experience?
3. Were patients/services users/carers/family people involved in developing plans for participant recruitment and study conduct if so, please specify how.
4. How do you plan to disseminate the results of the study to patients?
5. Are patients thanked in the contributorship statement or a acknowledgment?
6. For articles reporting randomized controlled trials, did you use the burden of the intervention on patient’s quality of life and health? If so, what evaluation method did you use and what did you find?