

Faculty of Medicine and Health Sciences

PPI, more than just an unfortunate abbreviation

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Collaboration for leadership
in applied health research
and care
East of England


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CONGRATULATIONS!

**40 years ago
called for**

**“participation in the
research process and
access to its products
should be freely and
widely available”**



Patient and Public Involvement – here and here to stay



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Examples of patient and public involvement reported in the Research Excellence Framework 2014 impact case studies



Examples of patient and public involvement reported in the Research Excellence Framework 2014 impact case studies

About this project

This project searched the **Research Excellence Framework (REF) 2014 Medical and Health Sciences database** for examples of how patient and public involvement was reported in the REF 2014 impact case studies.

Twelve examples drawn from this search are listed below which you can view by clicking on the individual links or by downloading a [pdf annotated summary](#) of the examples from our publications page. Further information about the Research Excellence Framework 2014 is available on the REF2014 website: <http://www.ref.ac.uk/>

List of examples:

Example 1: Involving peer led self-help groups and citizen research groups in the improvement and development of services [Anglia Ruskin University]

Example 2: Care Transition Experiences: developing a user and carer centred approach [University of Birmingham]

Example 3: Optimising Person-Centred Support in Social Care: the impact of the 'Standards We Expect' project [Brunel University]

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Patient and Public Involvement – here and here to stay

Blog | **BMJ Open** BMJ Open Topic Index Home

New requirements for patient and public involvement statements in **BMJ Open**
 Posted on March 23, 2018 by aaidcroft

 **CATEGORIES**
 Select Category



Partnering with patients

BMJ Open now requires a PPI statement for all submissions

The editorial team at *BMJ Open* have been inspired by the work of the patient involvement team at *The BMJ*. Following their lead, we are now requiring authors of all submissions to the journal to include a PPI statement.

The PPI statement should appear at the end of the Methods section. It should answer the following questions:

- How was the development of the research question and outcome measures informed by patients' experience, and preferences?
- How did you involve patients in the design of this study?
- How many patients were involved in the recruitment to and conduct of the study?
- How were the results disseminated to study participants?
- How were promised controlled trials, was the burden of the intervention assessed by patients themselves?
- How should advisers be thanked in the contributorship statement/acknowledgements.

• If patients were not involved, authors must state this.

• How does the contributorship statement aligns closely with *BMJ Open's* values of transparency and inclusiveness. We hope that the inclusion of PPI statements in all articles is the first step of many for *BMJ Open* in encouraging patient involvement.

• How many visits did you have today?
 2 visits today

Research methods
 Research

Frequency of reporting on patient and public involvement (PPI) in research studies published in a general medical journal: a descriptive study

Amy Price^{1,2}, Sara Schroter¹, Rosamund Snow², Melissa Hicks¹, Rebecca Harmston¹, Sophie Staniszewska⁴, Sam Parker¹, Tessa Richards¹

Author affiliations +

Abstract
Objectives While documented plans for patient and public involvement (PPI) in research are required in many grant applications, little is known about how frequently PPI occurs in practice. Low levels of reported PPI may mask actual activity due to limited PPI reporting requirements. This research analysed the frequency and types of reported PPI in the presence and absence of a journal requirement to include this information.
Design and setting A before and after comparison of PPI reported in research papers published in *The BMJ* before and 1 year after the introduction of a journal policy requiring authors to report if and how they involved patients and the public within their papers.
Results Between 1 June 2013 and 31 May 2014, *The BMJ* published 189 research papers and 1 (0.5%) reported PPI activity. From 1 June 2015 to 31 May 2016, following the introduction of the policy, *The BMJ* published 152 research papers of which 16 (11%) reported PPI activity. Patients contributed to grant applications in addition to designing studies through to coauthorship and participation in study dissemination. Patient contributors were often not fully acknowledged; 6 of 17 (35%) papers acknowledged their contributions and 2 (12%) included them as coauthors.
Conclusions Infrequent reporting of PPI activity does not appear to be purely due to a failure of documentation. Reporting of PPI activity increased after the introduction of *The BMJ's* policy, but activity both before and after was low and reporting was inconsistent in quality. Journals, funders and research institutions should collaborate to move us from the current situation where PPI is an optional extra to one where PPI is fully embedded in practice throughout the research process.
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There is a lot of guidance ...



Collaboration for Leadership in Applied Health Research and Care East of England

M.



PATIENT AND PUBLIC INVOLVEMENT (PPI) RESEARCH HANDBOOK

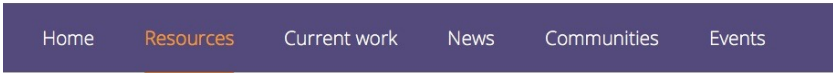
Working with our Patient and Public Voice (PPV) Partners – Reimbursing expenses and paying involvement payments (v2)

A handbook to support your planning and preparation for carrying out PPI activities in your research

Showing it means lot of things to many...

INVOLVE

BMA



Patient and public involvement:

Browse: Home /



for GPs

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- Contents
- Why is PPI important?
- Who should be involved?
- Why should patients be involved?
- What are the benefits of PPI?
- Your PPI toolkit:
 - How can patients and the public get involved?
 - Patients participation groups
 - Planning your approach
 - Ethics
 - How to ensure your PPI is effective
 - Evaluating your PPI
- References
- Further information

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Updated January 2015

Patient and Public Participation Policy



The role of the community

- Patient and Public Involvement is a form of volunteering and can be compared to being a magistrate, school governor and charity trustee.
- Like other forms of civic participation it has potential and limitations.

Criticisms

- Implementation levels are low and quality is patchy.
- Exclusivity and tokenism.
- A focus on Patient and Public Involvement practice might lead to other approaches like 'service user research' being side lined.

SUMMARY

- Patient and Public Involvement is a good idea and appears to be here to stay.
- There is a lot of guidance, seemingly meaning different things to different people.
- There is some serious criticism.
- It is a form of civic participation and we need to improve our understanding of its potential and limitations.
- Most of all we need to do it and do it right....

THANK YOU!

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