Research and the Patient Revolution

“Defining both the problems and the solutions in healthcare has to be a partnership between professionals and the communities they serve. “

Jeremy Taylor. National Voices UK

Tessa Richards , BMJ Senior Editor /Patient Partnership

OVER £1 MILLION RAISED FOR CHARITY

"The current level of waste in health and medical research has been estimated to be over 85% of the nearly $200 billion annual global spend [1]. That amounts to around $500 million per day—equivalent to the annual budgets of several prestigious research institutes. That level of waste should be an international scandal."

Paul Glasziou and Iain Chalmers: Funders and regulators are more important than journals in fixing the waste in research

[1] http://www.thelancet.com/series/research

Stop this waste of people, animals and money

"Predatory journals have shoddy reporting and include papers from wealthy nations"
Nature News and Comment
David Moher et al. 6 September 2017

Biomedical research:increasing value; reducing waste

Lancet 5 part series Jan 8 2014

Evidence based medicine manifesto for better healthcare

A response to systematic bias, wastage, error, and fraud in research underpinning patient care   BMJ 2017;35:j2973 Carl Heneghan et al 20 June 2017

BMJ Research to Publication e learning resource (https://rtop.bmj.com)

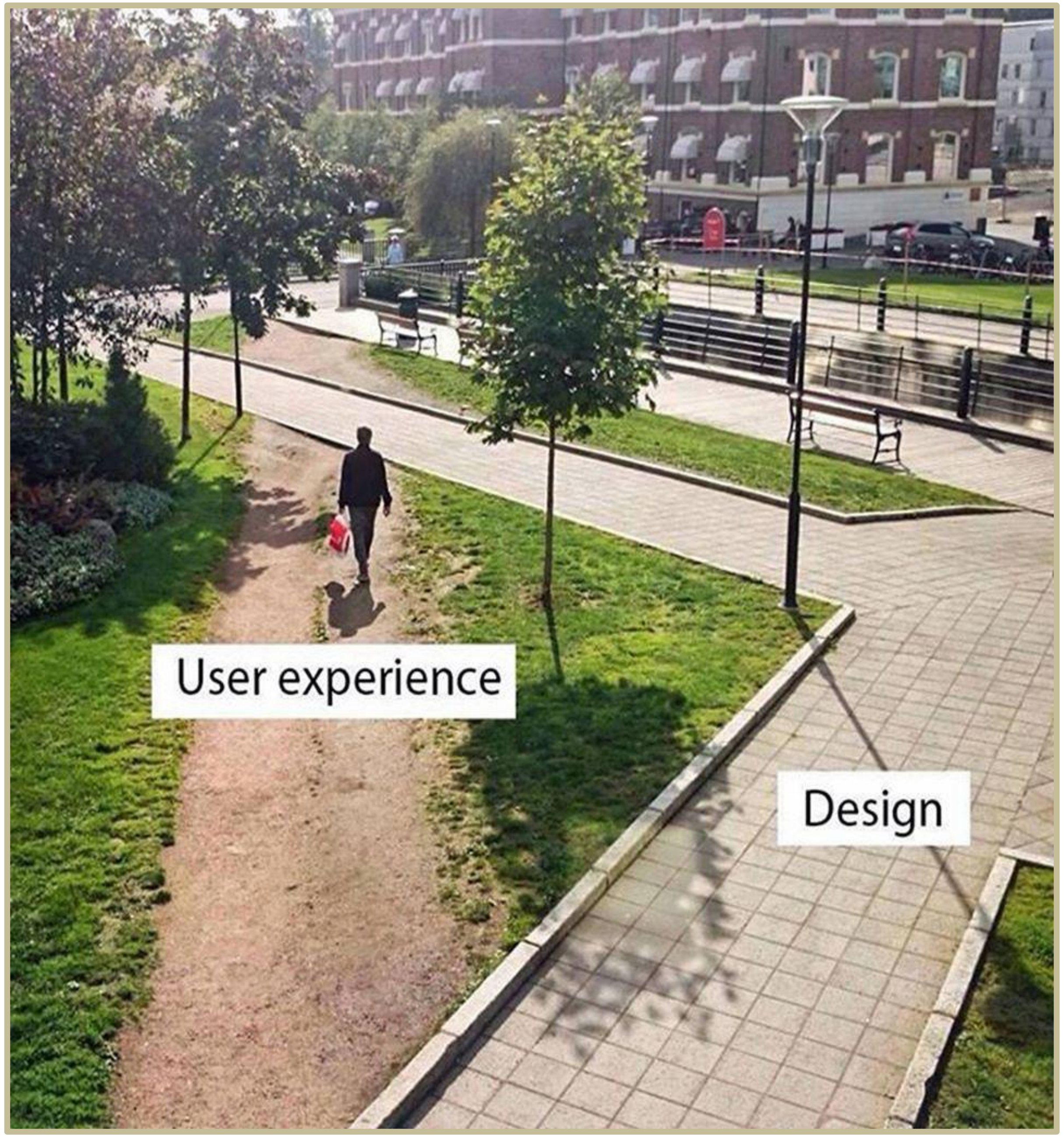
Key problems + what's being done about them

Failure to address research questions and choose outcomes measures that matter to patients (+ clinicians) - *funders involving patients and the public include NIHR/PCORI/CIHR-SPOR/ZonMW*

Unjustifiable replication of work -*NIHR requires reference to relevant SRs in all funding applications for new research (Kamal Mahtani March 31 2017)*

Studies poorly designed, poorly conducted, badly analysed. *Publically available protocols+ plans for analysis. Better training of (non conflicted)research workforce (Ioannidis J. Lancet series)*

Selective reporting + failure to publish findings. "*Can it really be true that 50% of research is unpublished? "(Paul Glasziou and Iain Chalmers June 5 2017) All Trials campaign + https://trialstracker.ebmdatalab.net/#/*




Disease and doctor centric

Care fragmented
wasteful
and inefficient

Poor understanding of patients
values
experience
preferences
& resources

BMJ

Safeguarding adults at risk of abuse

Better management of multimorbidity

How safe is sitagliptin?

Autologous blood for tendinopathy

346:1-40 No 7908 ISSN 1759-2151
18 May 2013 | bmj.com

LET THE PATIENT REVOLUTION BEGIN

The vision

- Promote patient partnership and co production of health by “walking the talk” in our own editorial processes
- Advance debate + spread best practice on how to partner with patients, carers and communities in research/practice/education/policy to improve the value and sustainability of health systems.

Research

Increase relevance and reduce waste in research

Action: Mandatory statement on if/how
“patients involved” in research studies
Patient review, alongside peer review of articles,

Education

Increase focus on patients priorities + tap into their exper

Action: Patients as contributors/co authors of education a

Comment

Advancing understanding of the patients perspective/ how to involve and partner with patients/ listening to the patient and carers voice.

Action: Co- production in editorials, scholarly
Comment and Feature articles Patient led content

BMJ 2015;352:h6786 doi: 10.1136/bmj.h6786 (Published 18 January 2016) Page 1 of 1

PRACTICE

WHAT YOUR PATIENT IS THINKING

I chose reconstruction, but not to “look good”

Stella Duffy flags up problems of concentrating on aesthetics in breast reconstruction surgery. For series information contact Rosamund Snow, patient editor, rsnow@bmj.com

Stella Duffy

I have had breast cancer twice. The first time, when I was 36, I had a wide local excision, followed by chemotherapy and radiotherapy. In 2014, my annual mammogram showed ductal carcinoma in situ in breast tissue left from the original breast conserving surgery in 2000. Since the first cancer I had, naturally, been thinking about the possibility of recurrence. Therefore, it didn’t take long for me to agree to a mastectomy and breast reconstruction. My consultant told me that implants tend not to be recommended for patients whose skin has already been irradiated.

Making a choice

I chose a reconstruction for many reasons:

- I have had breasts for almost 40 years, and a two breasted person is how I perceive myself
- I do a lot of work in public. Women’s clothes are designed for two breasts and I didn’t want to feel self conscious when presenting
- Friends with prostheses say they are uncomfortable and heavy
- I live in a sexualised culture where a woman’s breasts are considered a prime signifier of her sex. As a feminist, there is an enormous amount to consider when understanding our relationship to our bodies, but I was eager to have the cancer out of me. I did not take a very long time to choose.

I did not choose a reconstruction because I wanted my breasts to look “good” or “better” but because I wanted to feel like myself and—after having cancer twice—that was important. To feel physically and emotionally like myself, not the disease.

Remember the inside as well as the outside

Yet everything to do with the reconstruction was discussed in terms of how my reconstructed breast looked. Even when the pulse flap was checked every hour for the first 24 hours, I was told my breast looked good—I did not ask for such comments, but this view was constantly volunteered. I appreciate that it was generously meant, but at the time, in pain, the last thing I wanted was virtual strangers’ opinions on how my body looked.

In the run-up to the surgery, despite the competence, compassion, and generosity of the plastics team, at no point did anyone tell me that my breast would feel physically different.

Despite a few complications my scars have healed well, but the breast still feels different—not only the lack of feeling in the flap and the immediate surrounding area, but inside too. I can feel, sometimes with pain, where the piece of rib was removed to remove the mammary aorta. I feel the places where the flap taken from my stomach is attached. The breast pulls from the mid-point of my chest. It feels like something else, it does not feel like a breast.

Language is important

To have been advised that breast reconstruction can result in patients feeling physically different would have been helpful to inform my thinking about my choices. A mastectomy is, in effect, an amputation. A reconstruction is a rebuilding. Language can help us understand how it might be for us. Different language, possibly more brusque, but certainly clearer, would have helped prepare me better.

We live in a society where an inordinate emphasis is placed on appearance, but reconstruction is not merely about appearance. We also, each of us, live in and through our bodies, and to ignore the physical feelings relevant to a reconstruction is to ignore a great part of the process.

Competing interests: I have read and understood BMJ policy on declaration of interests and declare the following interests: none.

Cite this as: *BMJ* 2016;352:h6786

BMJ AWARDS: DEADLINE EXTENDED

A single blood test to rule out myocardial infarction?

Treatments for gestational diabetes

Can private firms run NHS hospitals?

Practice pointer: is it a stroke? CPD/CME hours

What your patient is thinking

NEW CLINICAL SERIES STARTS THIS WEEK

BMJ run events +campaigns

- PI in BMJ run and co run events
- PI involvement in campaigns
  - Universal health coverage
  - High Integrity healthcare
  - Preventing overdiagnosis/too much medicine
  - Tackling corruption in healthcare
  - AllTrials
  - OpenNotes

Patients Included

- Growing PI as a movement across the BMJ PG and other medical journals

Reporting patients' involvement in research: mandatory statement

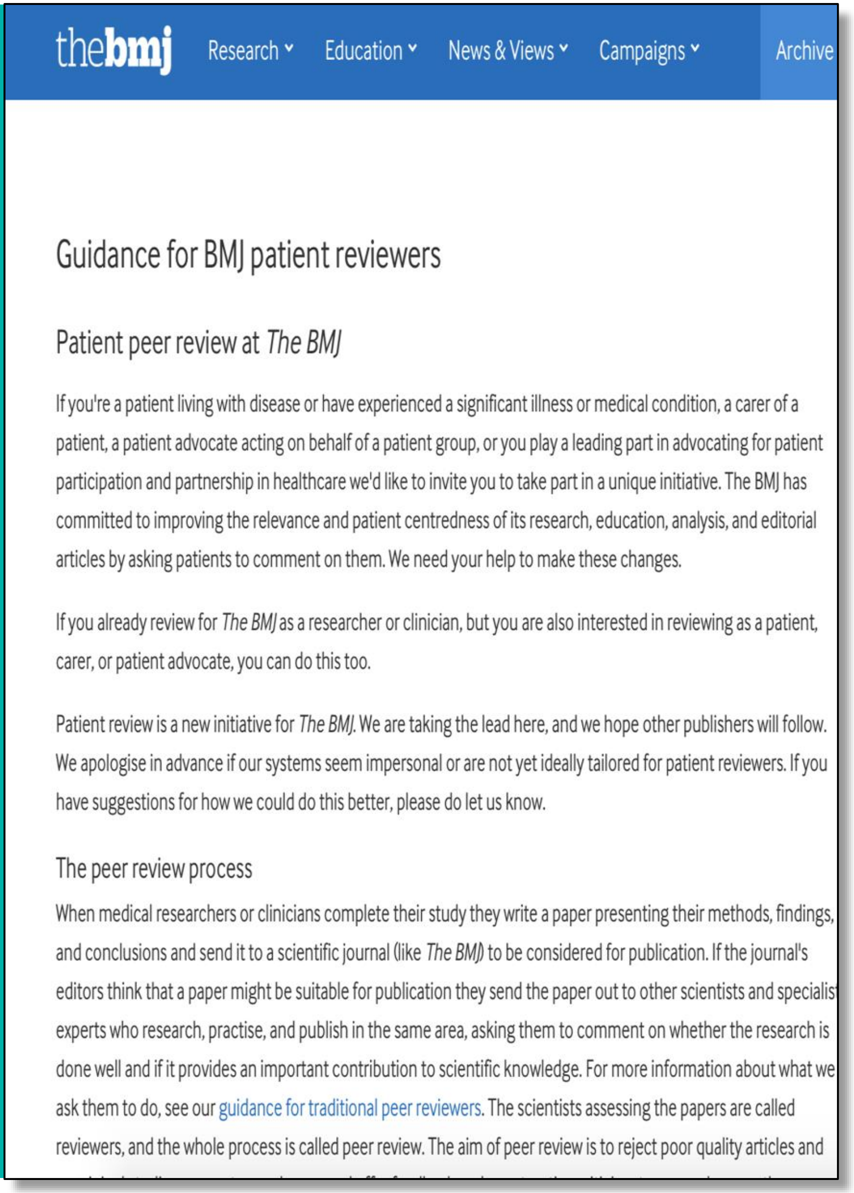
1. **How was the development of the research question and outcome measures informed by patients’ priorities, experience, and preferences?**
2. **How did you involve patients in the design of this study?**
3. **Were patients involved in the recruitment to and conduct of the study?**
4. **How will the results be disseminated to study participants?**
5. **For randomised controlled trials, was the burden of the intervention assessed by patients themselves?**
6. **If patients were not involved please state this.**

Established database of patient and carer reviewers to comment on research and other papers.

www.bmj.com/about-bmj/resources-reviewers/guidance-patient-reviewers

Patient reviews of research open access and online with peer reviewers comments

Feedback from BMJ editors positive re value of comments. Survey of authors views underway



Guidance for BMJ patient reviewers

Patient peer review at *The BMJ*

If you're a patient living with disease or have experienced a significant illness or medical condition, a carer of a patient, a patient advocate acting on behalf of a patient group, or you play a leading part in advocating for patient participation and partnership in healthcare we'd like to invite you to take part in a unique initiative. The BMJ has committed to improving the relevance and patient centredness of its research, education, analysis, and editorial articles by asking patients to comment on them. We need your help to make these changes.

If you already review for *The BMJ* as a researcher or clinician, but you are also interested in reviewing as a patient, carer, or patient advocate, you can do this too.

Patient review is a new initiative for *The BMJ*. We are taking the lead here, and we hope other publishers will follow. We apologise in advance if our systems seem impersonal or are not yet ideally tailored for patient reviewers. If you have suggestions for how we could do this better, please do let us know.

The peer review process

When medical researchers or clinicians complete their study they write a paper presenting their methods, findings, and conclusions and send it to a scientific journal (like *The BMJ*) to be considered for publication. If the journal's editors think that a paper might be suitable for publication they send the paper out to other scientists and specialis experts who research, practise, and publish in the same area, asking them to comment on whether the research is done well and if it provides an important contribution to scientific knowledge. For more information about what we ask them to do, see our guidance for traditional peer reviewers. The scientists assessing the papers are called reviewers, and the whole process is called peer review. The aim of peer review is to reject poor quality articles and

Questions for patient reviewers

- Does this issue matter to you, other patients, and carers?
- Any areas relevant to patients and carers missing?
- If the study was of an intervention or treatment, do you think it will really work in practice? What challenges might patient's face?
- Are the outcomes and issues discussed in the article important to patients? Are there others that should have been considered?
- Do you have any suggestions that might help the author(s) make their paper more useful for doctors to discuss with patients?

Progress and plans

- Tracking co-production to targets.
- Evaluations of impact of strategy ongoing
- Develop PPS across the BMJ Publishing Group. Grow patients columnists/partnership in action, podcasts, twitter chats. Develop learning resources for PI
- Patients Manifesto on Rights in Research?

Co-production of research : Better conversaions
INVOLVE JLA PSPs go global
http://www.jla.nihr.ac.uk/top-10-priorities/

The Patient Voice in Ophthalmic Research

http://blogs.bmj.com/bmj/2017/08/15/a-collective-effort-is-needed-to-encourage-patient-centricity-in-opthalmic-research/

....reliance on routine visual function tests led to a disconnect between doctors views of patients visual experience. Visual loss for patients goes beyond the mechanisitic and includes psychological,emotion and social challenges..."you say my tests have improved but I can't see any better, the charts are different to real life, I still can't drive, and the tablets you have given me make me feel sick"

Priorities for research in ideopathic Intracranical Hypertension - underway

Sharon Terry
USA
CEO
Geneticalliance.org

Sara Riggare
Sweden
Parkinson's disease: quantified self

Tim Omer
England
Diabetes advocate and hacker

#wearenotwaiting

http://www.disruptivewomen.net/2017/06/15/using-citizen-scientists-and-crowdsourcing-to-spur-medical-progress/

thebmj

The case for a Paterson inquiry p 212
Gluten does not increase CHD risk p 219
Improving stroke care decisions p 220
Call to end costly routine blood tests p 224
1 CPD hour in the education section

Give all patients access to records
If Sweden can do it, why can't we?

thebmj

WINTER APPEAL: HELP MSF

Google, doctors, and the right to be forgotten
Type 2 diabetes and the risk of cancer
Intravenous fluid therapy in adult patients
Heparin induced thrombocytopenia
CPD/CME hours

Should doctors encourage patients to record consultations?

BMJ

No 7212 18 September 1999

Embracing patient partnership

Research: do less, do it better, do it with patients

Seventy five trials and eleven (no make that 26) systematic reviews a day: how will we ever keep up?
Bastian H, Glaziou P, Chalmers I. PLoS Med.2010 Sep 21;7(9)e1000326

As for the perpetual demand "more research is needed" a better strategy would be to do less, do it better , focus on patients needs,, and ensure research is carried out for the right reasons" Ian Chalmers. Testing Treatments

The phrase "patient centricity" makes us all feel good. Health professionals adopt the term, try to push the policy envelope a bit further. Thank you for this...but the pace and scope are too slow and narrow... participatory medicine is a quiet revolution going on under the noses of most medical professionals and health systems.
Mike Gill RA. Dragon claw http://blogs.bmj.com/bmj/category/patient-perspectives/

Thank you : it's a joint endeavour

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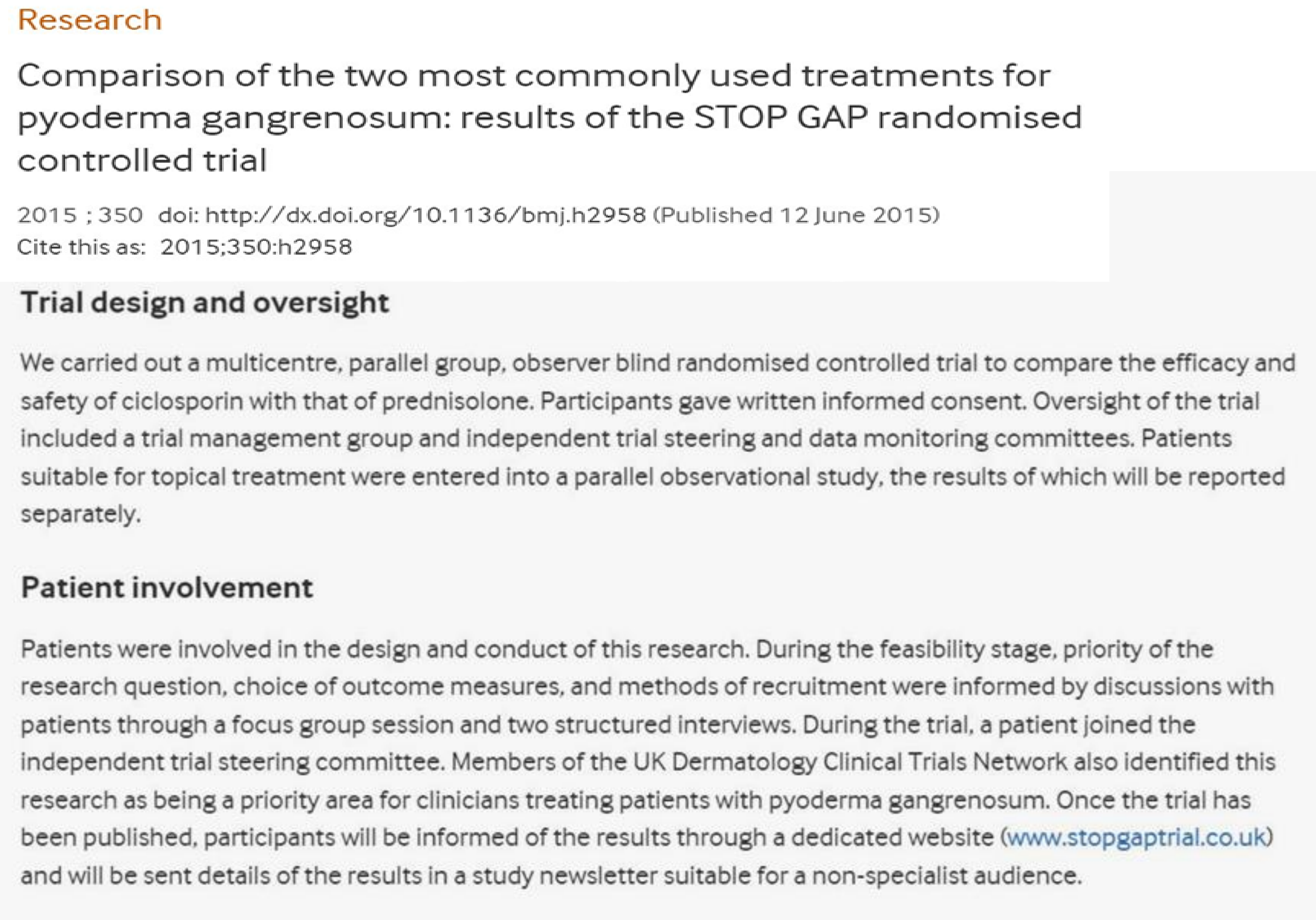
Example of a patient involvement statement in a research article



Research

Comparison of the two most commonly used treatments for pyoderma gangrenosum: results of the STOP GAP randomised controlled trial

2015 ; 350 doi: http://dx.doi.org/10.1136/bmj.h2958 (Published 12 June 2015)
Cite this as: 2015;350:h2958

Trial design and oversight

We carried out a multicentre, parallel group, observer blind randomised controlled trial to compare the efficacy and safety of ciclosporin with that of prednisolone. Participants gave written informed consent. Oversight of the trial included a trial management group and independent trial steering and data monitoring committees. Patients suitable for topical treatment were entered into a parallel observational study, the results of which will be reported separately.

Patient involvement

Patients were involved in the design and conduct of this research. During the feasibility stage, priority of the research question, choice of outcome measures, and methods of recruitment were informed by discussions with patients through a focus group session and two structured interviews. During the trial, a patient joined the independent trial steering committee. Members of the UK Dermatology Clinical Trials Network also identified this research as being a priority area for clinicians treating patients with pyoderma gangrenosum. Once the trial has been published, participants will be informed of the results through a dedicated website (www.stopgaptrial.co.uk) and will be sent details of the results in a study newsletter suitable for a non-specialist audience.