

# How might patient and public involvement (PPI) improve recruitment and retention in surgical trials?

## A qualitative study exploring the views of trial staff and PPI contributors

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# Project team

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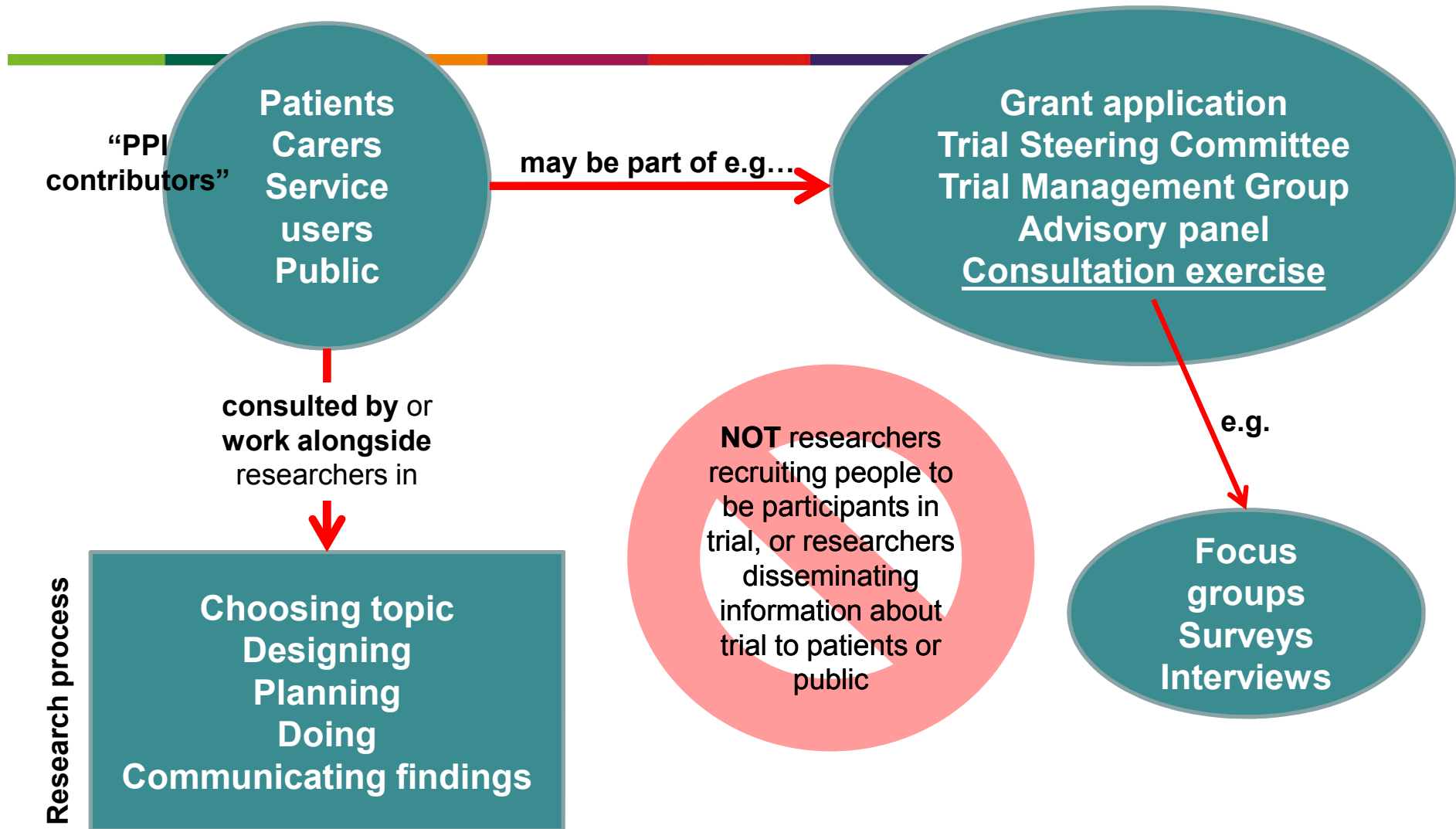
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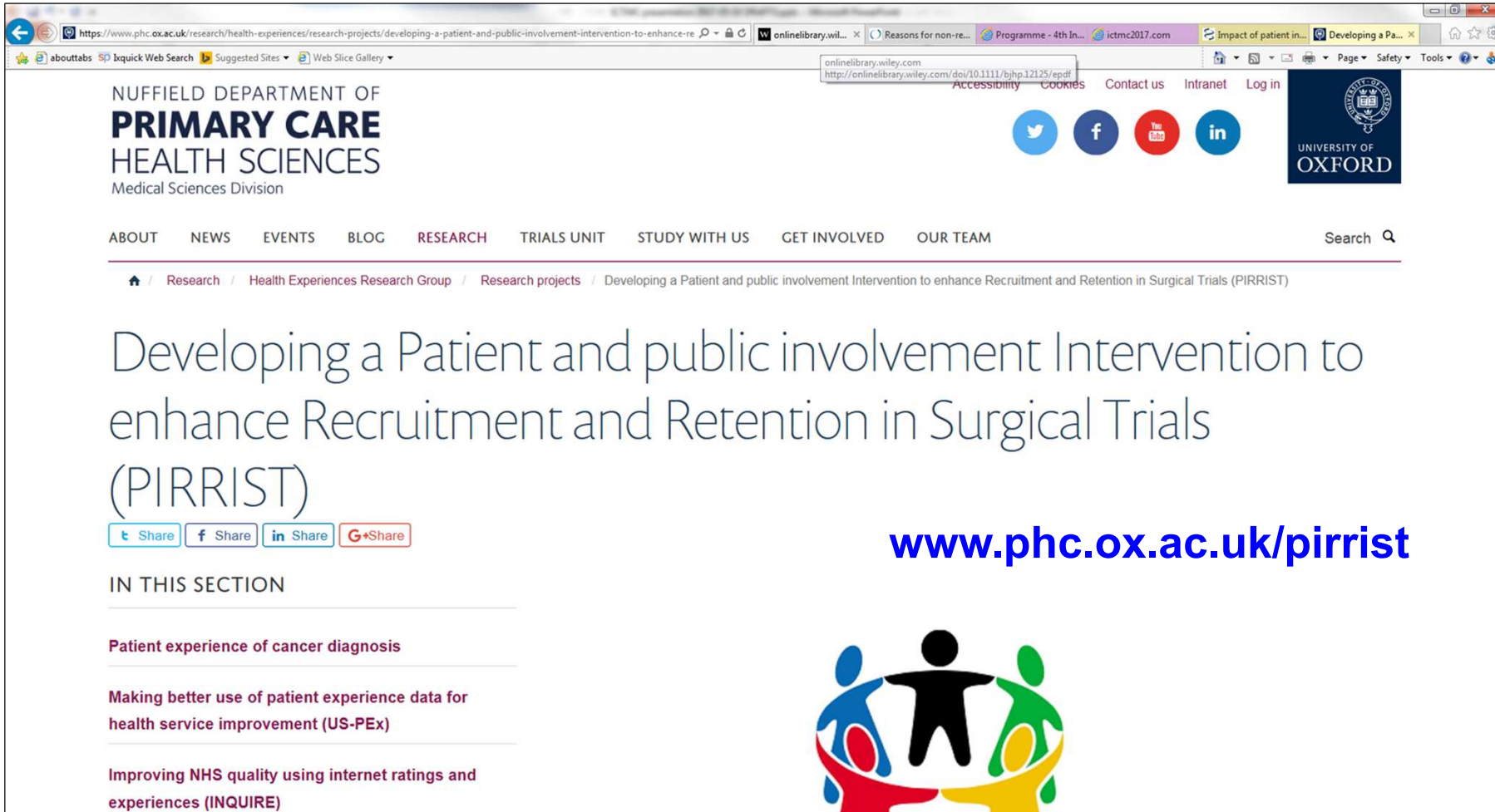
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# Definition of PPI



# PIRRIST project



The screenshot shows the website for the PIRRIST project. At the top, it identifies the Nuffield Department of Primary Care Health Sciences, Medical Sciences Division, at the University of Oxford. The main heading is "Developing a Patient and public involvement Intervention to enhance Recruitment and Retention in Surgical Trials (PIRRIST)". Below this, there are social media share buttons for Twitter, Facebook, LinkedIn, and Google+. A list of related projects is shown under the heading "IN THIS SECTION", including "Patient experience of cancer diagnosis", "Making better use of patient experience data for health service improvement (US-PEX)", and "Improving NHS quality using internet ratings and experiences (INQUIRE)". A logo with five stylized human figures in different colors (blue, black, green, red, yellow) is positioned to the right of the project list. The URL [www.phc.ox.ac.uk/pirrist](http://www.phc.ox.ac.uk/pirrist) is displayed in blue text.

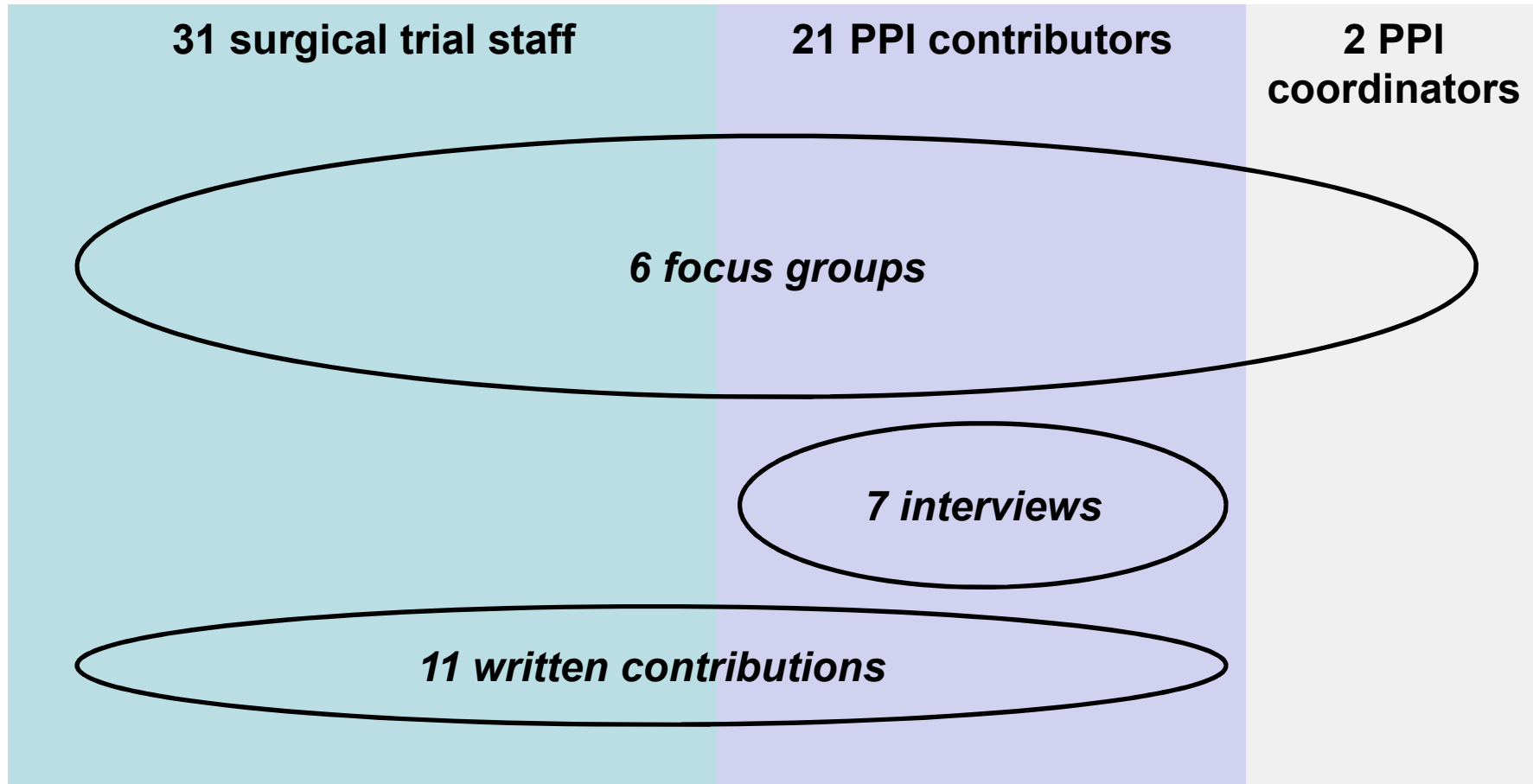
# Aims of qualitative study

To explore:

- 1) Needs and challenges
  - PPI in surgical trials
  - Recruitment & retention of participants in surgical trials
- 2) Views about impact of PPI on recruitment & retention**
- 3) Ideas for PIRRIST intervention



# Data collection & analysis



## Results: Impact of PPI on recruitment



- informing trial design / recruitment methods
- assessing patients' willingness to take part
- directly recruiting participants
- improving relevance of research question
- publicly endorsing trial

# Results: Impact of PPI on recruitment



## Recruitment methods

They [PPI contributors] had the idea of using social media as a possible avenue to approach patients because of the type of patients in the trial – they were younger and they're more inclined to use Twitter and Facebook... And with their input we started to develop entries for Facebook and to use on Twitter, and our recruitment virtually tripled as a result of using that.

(Staff FG2)



## Results: Impact of PPI on retention



- assessing burden/acceptability of follow-up methods
- making data collection tools more patient-friendly
- suggesting retention strategies
- communicating with participants during trial
- changing which/how outcomes collected
- challenging regulatory barriers to adopting new data collection methods

# Results: Impact of PPI on retention



## Data collection tools

One of the tasks that I had to do was actually to review the patient diary... and say, you know, "Does this make sense to the average patient?" [...] It was a big task but then in some cases there was no consistency from one page to another, you know, and it wasn't severe but, you know there were gaps and what I found particularly refreshing is when I went back with my comments, and the changes were made.

(PPI FG6)

## Results: Impact of PPI on recruitment/retention



### **PPI unhelpful / less helpful if:**

- Involved too late
- Different from trial target population
- Literacy level too high (PILs)
- Bigger barriers are operating

## PPI unhelpful/less helpful if...



### **Literacy level too high**

[PPI contributors] are very good and they're commenting on... all aspects of the trial and, you know. But perhaps when you send the patient the information sheet to look at, they might... be reading it at a higher level than a lot of the people you might be contacting.

(Staff FG4)

## PPI can have a negative impact...

One trial we paid for translations of information sheets which, well I thought was good. But we also paid for recordings of the translations as well which we were told by a PPI person, and by one of the research nurses involved in the trials management group as well, was going to be a very good thing, and... **it's the costliest PPI thing we've ever done...** All the recordings are available online, so we know how much they're used, and we can also compare when, you know translations were distributed or recordings were distributed and see if there's any change in recruitment, and there wasn't.  
(Staff FG2)

# Conclusions

- Potential for PPI to **improve** recruitment & retention in various ways
- Potential for PPI to be **unhelpful** or **harmful**
  - **Plan** carefully in advance
  - Involve as **early** as possible
  - Include patients with target **condition**
  - Seek **diverse** perspectives



# Some final words of caution...



I see [PPI] more as improving the research process, to be honest, rather than just trying to get people into trials... Because, from my perspective, there's no point in trying to get people into trials that are not going to be worthwhile.

(PPI I50)

# Thank you



- **All participants for their time and generosity**
- **Project team**
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