

Public and patient involvement in child health research and service improvements: a survey of hospital doctors

Rachel Winch,¹ Martin Patrick McColgan,¹ Emma Sparrow,¹ Neena Modi,^{1,2} Anne Greenough^{1,3,4,5}

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¹Royal College of Paediatrics and Child Health, London, UK

²Section of Neonatal Medicine, Department of Medicine, Imperial College London, London, UK

³MRC & Asthma UK Centre in Allergic Mechanisms of Asthma, King's College London, London, UK

⁴Department of Women and Children's Health, School of Life Sciences, Faculty of Life Science and Medicine, Kings College London, London, UK

⁵NIHR Biomedical Research Centre at Guy's, St Thomas' NHS Foundation Trust, King's College London, London, UK

Correspondence to

Professor Anne Greenough;
anne.greenough@kcl.ac.uk

ABSTRACT

Objectives To determine whether paediatricians are supported by their organisations to encourage patient and public involvement (PPI) in research activities and clinical improvement work, the challenges they face and how they think these could be addressed by the Royal College of Paediatrics and Child Health (RCPCH).

Design A survey.

Setting UK consultant paediatricians and staff associate specialist and specialty (SAS) doctors who are members of RCPCH.

Main outcome measures The proportion of respondents who said that PPI was central to research and service improvements in their organisation, the type of local support for PPI activity, challenges in undertaking PPI and the support members wanted from RCPCH.

Results There was a response rate of 44.4% (n=1924). In their organisation, 29.1% of respondents stated PPI was central to research and 36.1% to service improvement; 46% were unaware of support for PPI and 15% said there was no support. The main challenges for PPI activity were a lack of clinician time, local support and funding. Respondents wanted RCPCH to advocate for protected time for PPI, provide access to PPI groups and deliver guidance and training.

Conclusions The majority of paediatricians feel unsupported to undertake PPI activity by their local organisation. The RCPCH has a key role to enable all paediatricians to work with children, young people and their carers to improve the quality of research and clinical services as demonstrated by RCPCH's ongoing activity in these crucial and important areas.

INTRODUCTION

The United Nations Convention on the Rights of the Child¹ emphasised that children and young people (CYP) have the right to have their opinions taken into account whether it is regarding service improvement, research or their own health and well-being. Patient and public involvement (PPI) in research is defined by INVOLVE as 'an active partnership between patients, the public and researchers in the research process, rather than the use of

What is already known on this topic?

- ▶ The United Nations Convention Rights of the Child emphasised children and young people (CYP) should have their opinions taken into account.
- ▶ The Royal College of Paediatrics and Child Health (RCPCH) has a long history of involving CYP and their families in its work.
- ▶ *Not Just a Phase* provides guidance to paediatricians, children's nurses and service leaders on CYP participation in the development and improvement of child health surveys.

What this study hopes to add?

- ▶ Forty-four per cent of consultant paediatricians and specialist and specialty doctors responded to a survey about patient and public involvement (PPI).
- ▶ Forty-six per cent were unaware of support for PPI in their organisation and 15% said there was no support.
- ▶ The main challenges they identified to supporting PPI activity included lack of clinician time, local support and funding.

people as 'subjects' of research'.² The Royal College of Paediatrics and Child Health (RCPCH) is committed to supporting its members in involving patients and public in all aspects of their work. Indeed, RCPCH has a long history of involving CYP and their families in its work. This includes the development of standards and guidelines such as *Not Just a Phase*,³ which was jointly produced by RCPCH and the RCPCH Young People's Health Special Interest Group (YPHSIG). This provides guidance for paediatricians, children's nurses and service leads on the participation of CYP in the design, development and improvement of child health services.

PPI is now appropriately regarded as an important part of a research ethics submission and a funding application. Thus, PPI is not just good practice, but a crucial aspect of research conduct. The aim of this study was to undertake a survey to determine whether RCPCH members feel supported by their organisations to undertake PPI activity in research activities and clinical improvement work and what challenges they perceived in conducting PPI. In addition, we wished to identify how members felt the RCPCH could support them in undertaking PPI activity. We have reported the work currently undertaken by RCPCH to address those needs.

METHODS

All consultants and staff associate specialist and specialty (SAS) doctors recorded in the RCPCH 2013 workforce census and any new certificate of completion of training holders in paediatrics qualifying up to May 2015 were identified (n=4768). SAS doctors typically are 4 years postqualification with at least 2 years in a given specialty. Of these, 435 were not contacted as they had either opted out of email or survey contact, had not provided RCPCH with their email address, or had retired or moved overseas. The remaining doctors (n=4333) were sent a survey using SurveyMonkey. Questions included whether PPI was central to service improvement and/or research (box 1). Other questions, which allowed multiple responses, included what support for PPI activity was available in their organisation, what works well in the respondents' experience (with a request to share best practice) and what challenges they perceived with regard to PPI. Finally, they were given a free-text section to document how they felt RCPCH could support them in PPI activity. The survey was conducted between May and July 2015. Three reminders were sent to encourage responses.

RESULTS

The survey had an overall response rate of 44.4% (n=1924) which included 45.3% of eligible paediatric consultants and 21.1% of eligible paediatric SAS doctors. Not all respondents answered all questions. Only 29.1% of 1526 respondents said that in their organisation PPI was central to research, 27% were not sure, 26.5% said that patients and the public were involved but their involvement could be tokenistic and 14.4% said there was little or no PPI in research (figure 1). Thirty-six per cent of 1527 respondents said PPI was central to service improvement in their organisation, 35.1% said that patients and the public were involved but that the PPI could be tokenistic and 14.5% stated there was little or no PPI.

Forty-six per cent of respondents did not know what support was available for public and patient engagement in their organisation. Twenty-two per cent stated there was a PPI team, 15.2% a CYP's volunteer group, 13.5% a parent and carer's volunteer group, and 10.3% a PPI lead. Fifteen per cent of 1530 respondents said there

Box 1 Survey questions relating to public and patient involvement in research and service development

Which statement best describes how you feel about public and patient involvement in research in your organisation?

- ▶ Patient and public involvement is central to research in my organisation.
- ▶ Patients and the public are involved in research in my organisation, but it can be tokenistic.
- ▶ There is little or no involvement of patients and the public in research in my organisation.
- ▶ I'm not sure.
- ▶ Other (please specify).

Which statement best describes how you feel about public and patient involvement in service improvement in your organisation?

- ▶ Patient and public involvement is central to service improvement in my organisation.
- ▶ Patients and the public are involved in service improvement in my organisation, but it can be tokenistic.
- ▶ There is little or no involvement of patients and the public in service improvement in my organisation.
- ▶ I'm not sure.
- ▶ Other (please specify).

What support do you have within your organisation to involve public and patients in research and service improvement? (Please tick all that apply)

- ▶ Public and patient involvement team.
- ▶ Public and patient involvement lead.
- ▶ Children and young people's volunteer group.
- ▶ Parent and carer's volunteer group.
- ▶ Mixed volunteer group.
- ▶ Don't know.
- ▶ None of the above.

Are there any other types of support available in your organisation not covered above? (Free-text)

In your experience, what works well, and why? (Free-text)

Please share your examples of best practice in patient and public involvement. Where possible, please include references or web links.

What are the challenges for you in involving the public and patients in research and service improvement? (Free-text)

How can RCPCH best support you in involving the public and patients in research and service improvement? (Free-text)

Would you be happy for us to contact you about working with RCPCH's children, young people and families' engagement network &Us?

- ▶ Yes
- ▶ No

was no support available with their organisation for PPI activity in research or service improvement.

A range of challenges to PPI was provided by the respondents. The most common was the lack of clinician time (34.8%). A second theme was the problem of engagement which included ensuring views were representative, lack of patient and parent time, and difficulties in communicating research to patients and parents. Other challenges reported by 478 respondents were a lack of support from their organisation and non-availability of funding to support PPI activity. Only 342 respondents ticked the question as to what worked well, but less than 30% provided any detail.

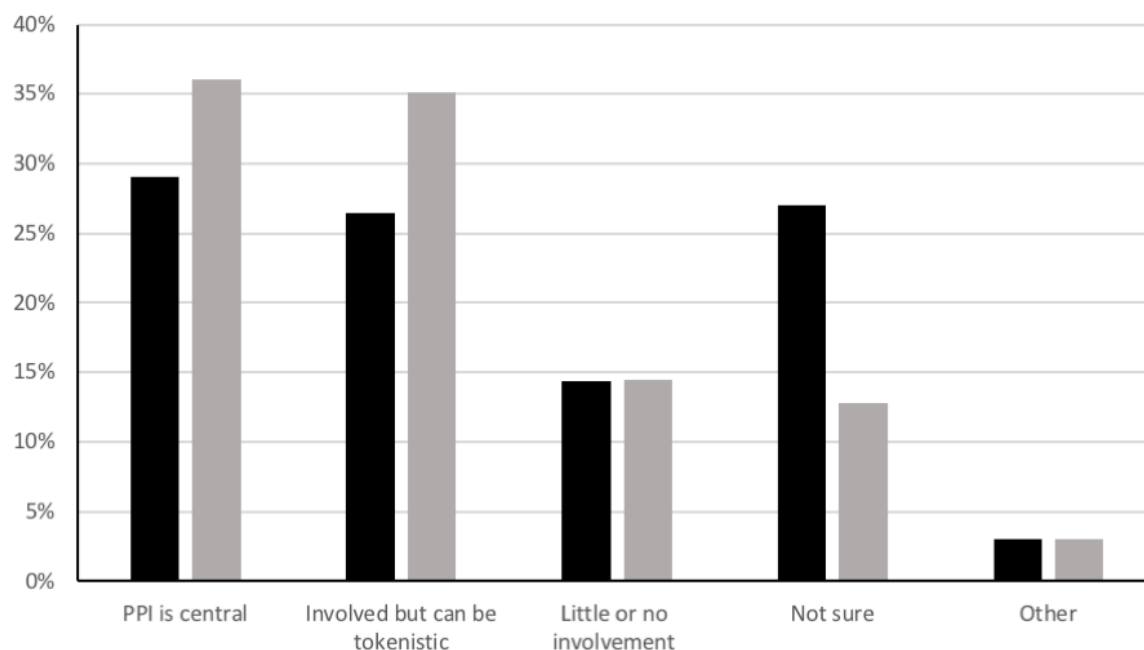


Figure 1 Respondents' views on how patient and public involvement (PPI) was viewed in their organisation. ■ in research; □ in service improvement.

Suggestions as to how RCPCH could support PPI activity were made by 541 of 1924 respondents (28.1%); the suggestions included providing funding, resources and/or personnel, and reducing staffing pressures. Respondents felt that RCPCH could support them by ensuring they had appropriate supporting professional activity time within their contracts (n=114), which could be achieved by providing clear guidance and working with employers and policy makers to ensure that time for continuing professional development was valued (n=67). Respondents also wanted RCPCH to provide access to PPI groups to support the research process (n=73). Others suggested that RCPCH should provide more guidance, training and information regarding involvement in PPI activity (n=26); for example, by publicising best practice examples and provide peer support/networking opportunities. It was felt that RCPCH should raise awareness of the importance of PPI in research (n=63) to organisations and increase the awareness of current research activity and funding opportunities.

DISCUSSION

We have demonstrated that less than a third of paediatricians felt that PPI was central to research in their organisation and only 36% thought it central in relation to service improvement. The greatest challenge articulated by RCPCH members regarding engagement in PPI was a lack of dedicated time. Our survey was sent to all the consultants and the SAS membership. We had a 44% response rate and although their responses may not be

reflective of all the membership, their comments suggest that RCPCH needs to more effectively publicise to our members what we are doing to support PPI activity (see below) and this will be done.

In 2014, a qualitative study was undertaken to assess whether plans for PPI were implemented within clinical trials and to identify the challenges and lessons learnt by the research teams involved.⁴ The interview accounts highlighted that some researchers described PPI within their trials as tokenistic, as others have done.^{5 6} Those results echo our respondents' comments regarding tokenistic PPI activity in some of their organisations. The researchers reported difficulties finding 'the right' PPI contributors and advised caution when involving investigators' current patients. Hence, we describe below the importance of the networks that have been established to support PPI in child health research.

In 2012, the RCPCH report 'Turning the Tide' looked at existing networks established to support PPI in child health research and identified INVOLVE and The Medicines for Children Research Network as examples of best practice. The National Institute for Health Research Young Persons Advisory Groups worked together to host their first GenerationR meeting in 2013 with a follow-up meeting in 2015, to explore the challenges faced in PPI in child health research. The meetings of young people, researchers and other key stakeholders identified similar concerns as expressed in the RCPCH Survey. These included greater support on the ground, education, time and resource, to support

involvement in child health research. RCPCH launched its *&Us* network in 2015,⁷ which is a platform for children, young people, parents, carers and families to join with RCPCH in improving child health. RCPCH continues to develop *&Us* and widen the membership to ensure it is truly representative of service users with different healthcare experiences, as well as from a range of socioeconomic and ethnic/cultural backgrounds. The RCPCH's *&Us* delivers UK-wide engagement road shows and an online platform for CYP and families to share and use to campaign for change. Respondents felt that RCPCH should support them by providing access to and facilitating PPI groups. It is clear that we need to better advertise to members the various groups that are available to facilitate PPI activity.

In 2015, the Nuffield Council on Bioethics published detailed guidance on children and clinical research ethical issues, echoing the need for enhanced practical guidance for researchers on involving CYP at all stages of the research process from design to dissemination. Other guidance on how to effectively involve young people in research includes INVOLVE's *A Guide to Actively Involving Young People in Research*,⁸ Young Minds' *Putting Participation in Practice* which focuses on mental health and well-being,⁹ and the RCPCH 'Research &Us – useful resources' guide which is available online.¹⁰ The National Children's Bureau supports a group of research-trained young people aged 12–21 years who consult and collaborate on research projects. The group has published guidance on how to involve young people in research.¹¹ Another useful document is an article entitled 'Public and patient involvement in research'; it contains a table of 10 tips to involve young people (and families) in research.¹² Despite these documents being in the public domain, the results of our survey suggest the majority of paediatricians had not accessed them. In 2017, RCPCH launched a monthly research bulletin which highlights impactful research outputs and current funding opportunities from UK Child Health Research Collaboration members.¹³ Going forward, it is clear that this should be used as another vehicle to signpost PPI documents and activity.

RCPCH has developed the *&Us* Engagement Collaborative which brings together engagement leads from across health, education, social care, government, the voluntary sector, child health charities and professional bodies. The collaborative, launched in 2016, facilitates mutual support, sharing good practice, collaboration on consultation responses and quality improvement; it has over 700 members. The Engagement Collaborative was involved in the launch of *The State of Child Health*¹⁴ and in ongoing campaigning activity. In 2016, over 1000 CYP and families took part in engagement sessions, consultations and projects across the UK. In 49 sessions, there were discussions on areas including *The State of Child Health*,¹⁴ reviewing service standards, guidelines and resources, information for parents and carers about children's renal conditions (InfoKid)^{15 16} and involvement in child health research.

This led to the design of the lay materials for the RCPCH suite of standards for high quality, and safe and sustainable acute general paediatric services. The results were included in the *Facing the Future's* lay materials¹⁷ and engagement resources which were developed to support healthcare professionals in their PPI work.¹⁸ In addition, the RCPCH and Research &Us Infants, Children and Young People's Research Charter was reviewed and views were shared on best practice for communication.¹⁹ Regarding guidance for PPI and access to best practice examples and PPI resources, *Not Just a Phase*³ was updated in 2017. Twenty-seven Engagement Collaborative organisations were involved in the 2017 RCPCH's Annual Conference 'Healthy child, Healthy Future'.²⁰ The RCPCH CYP's engagement team with YPHSIG captures examples of their voices in health settings. Organisations can join the Engagement Collaborative without charge via www.rcpch.ac.uk/and_us.

There are strengths and some limitations to our study. We had only a 44% response rate, but this represented the views of 1924 paediatric consultants and SAS doctors. We do not have the demographics of the respondents, but have given their overall level of experience. Elsewhere we have commented on their research experience.²¹ It is likely some of the respondents may have taken part in multicentre trials, but may have been unaware of the extent of the PPI work by the chief investigator and their organisation. Some of our survey questions might be considered to have an element of leading questions, for example, 'patients and the public are involved in service improvement in my organisation, but it can be tokenistic'. We did, however, give respondents the opportunity to choose from a number of other options.

In conclusion, the majority of paediatricians reported that they thought PPI was not central to their organisation with regard to either research or service improvement. RCPCH has a key role to enable all health professionals to work with CYP and their parents and carers to improve the quality of research and clinical services as demonstrated by RCPCH's ongoing activity in these crucial and important areas.

Contributors RW, MPM and AG developed the survey, which was based on sections of the 2011 RCPCH survey of all paediatric consultants and SAS doctors. NM was involved in the design of the 2011 survey. A working group which included AG, the RCPCH Officer for Workforce Planning and the RCPCH Participation and Advocacy Coordinator further developed the question set relating to paediatricians' participation in research and patient and public involvement. RW and AG undertook the analysis of the data. All authors were involved in the production of the manuscript and approved the final version.

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