

1 **Abstract**

2 Evidence shows that patient and public involvement (PPI) can have a positive effect on the quality  
3 and relevance of health services research. This article describes the experiences of patient and public  
4 involvement contributors within a pharmacy practice doctoral research project. This includes  
5 practical examples of how PPI contributed to the project and the impact this made. In addition, the  
6 PPI contributors and doctoral candidates' reflections are presented along with learning points to  
7 support other doctoral researchers planning PPI in their research.

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9 **Key words**

10 Patient Satisfaction, Professional Training.

11 **1921 words [2,153 incl. references]**

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15 The aim of this article is to inspire patient and public involvement in pharmacy doctoral candidates  
16 projects. The article is written in three sections. Firstly, an introduction of what patient and public  
17 involvement is and its purpose. Then a description of the role of patient and public involvement  
18 within a single pharmacy practise doctoral project and finally general learning points to guide  
19 readers wishing to develop patient and public involvement within their projects.

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21 Patient and Public involvement or 'PPI', has been defined as "research being carried out 'with' or  
22 'by' members of the public (including patients and carers) rather than 'to', 'about' or 'for' them.[1]  
23 PPI is a collaboration between researchers and members of the public. In the UK, the National  
24 Institute for Health Research (NIHR), which funds a substantial volume of health services research,  
25 now expects PPI in all its funding streams.[2] Two reasons underpin this. Firstly, the moral argument  
26 that people affected by a condition should have input in decisions about research that may affect  
27 them. Secondly, more practically, PPI can improve the efficiency of the research process by ensuring  
28 the research is relevant, conducted ethically, and participant-friendly.[3] A recently published  
29 systematic review and meta-analysis showed PPI interventions significantly increased the odds of

30 participant enrolment in clinical studies.[4] PPI can aid researchers in securing funding, designing  
31 study protocols, and choosing relevant study outcomes.[5]

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33 Given the role of patients in pharmacy, there is a compelling argument for including PPI in all  
34 pharmacy practice research, even smaller projects such as those of internally or industry-funded  
35 doctoral candidates. In this article, we provide an overview of the processes, experiences, and  
36 reflections of PPI within a single pharmacy practice doctoral research project. By sharing these  
37 experiences, we aim to inspire and encourage other researchers and doctoral candidates to consider  
38 ways to incorporate meaningful PPI, while pragmatically balancing resource limitations such as  
39 time, experience, and cost.

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41 The text below describes the personal reflections with a single PhD project focusing on the clinical  
42 implementation of genetic testing to help prescribers personalise the choice and dose of medicines.

43

44 The priorities for including PPI in this project were as follows:

- 45 1. Provide a perspective to complement and challenge the researcher.
- 46 2. Improve the chances of the research being acceptable to patients so that patients and  
47 healthcare professionals are willing to participate.
- 48 3. Provide governance for the project by including lay knowledge to enhance the design and  
49 conduct of the research.

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51 Whilst these were the specific goals for including PPI in our project, incorporating PPI can also  
52 improve dissemination of results to a bigger audience; make research more equitable and ethical,  
53 particularly if publicly funded; help prioritise research questions that matter to patients, and in  
54 general reduce research waste by ensuring research conducted is meaningful, acceptable, ethical and  
55 useful.[6]

56

57 For this project, we decided to seek two PPI contributors. This was guided by the size of the project,  
58 and funding available. There is no formula to calculate the number of PPI contributors a project  
59 should have, and junior researchers should seek input from more experienced researchers in their  
60 field for guidance. From the experiences of this project, we would recommend more than one PPI  
61 contributor. A single PPI contributor may feel more pressure in their role if they are the only

62 layperson surrounded by researchers. This can impede the PPI contributor's ability to challenge the  
63 researcher, conflicting with the goals of PPI.

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65 We were fortunate that our institution already had a pool of PPI contributors with experience  
66 involving pharmacy practice research. Alternatively, for those without this option, charities often  
67 have a pool of PPI contributors who have lived experience of a condition or experience as a carer to  
68 someone living with a condition. Researchers can consider recruiting PPI contributors without PPI  
69 experience.

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71 PPI contributors should be remunerated in recognition of their time, skills, and expertise. The NIHR  
72 has produced some guidance on costings for activities and expenses.[7] It is also encouraged to  
73 create a plan and share it with potential PPI contributors for timescales of the project and frequency  
74 of meetings. For example, in the advertisement for PPI members for our project, the total length of  
75 project (3 years) and expectations for monthly meetings were described from the outset.

76

77 Our initial meeting was a 90-minute semi-informal meeting in order to introduce each other, describe  
78 the project, define, and agree on roles and answer any questions. We believe having a small  
79 introductory meeting was key to building an egalitarian collaboration. PPI can contribute at every  
80 stage in the research cycle from conceptualisation of the project at funding stages to dissemination of  
81 project results. Doug and Sujata's (PPI members) first contributions were reviewing the study  
82 protocol and patient materials for the proof of concept study. Their input resulted in greater clarity of  
83 language in study documentation noted at the research ethics meetings. They also helped support  
84 thinking through the practicalities of recruiting patients for the study under COVID-19 conditions.  
85 One suggestion was to include a short biography and profile picture in the contact information  
86 section of the study advertisement. Doug and Sujata suggested this may help recruitment as it gives

87 patients a face to the person they contact through email or phone personalising the process more.

88 After discussion, we agreed as a group to amend the study documentation as suggested.

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90 The second study for the PhD was a systematic review covering the barriers and enablers to genetic  
91 testing for prescribing from a patient and healthcare provider perspective. For the patient perspective  
92 data, we were interested in obtaining some input from patient representatives as we thought this  
93 would improve the quality of analysis. Initially, we worried the psychology theory-based framework  
94 [8] underpinning the qualitative analysis methodology may be too complex for Doug and Sujata to  
95 contribute. To overcome this, we spent a session as a group where Essra (the researcher) explained  
96 what a systematic review was, why it was important and the framework methodology used for the  
97 analysis. At a follow-up session, Essra then presented the data extracts which were from a patient  
98 perspective and framework analysis. As a group, we spent the session talking through the extracts  
99 and framework. This worked well, and because of the conversations with Doug and Sujata, we  
100 changed the mapping of some of the extracts. Being challenged by PPI can help you think more  
101 critically and highlight the biases you may carry into your data analysis in much the same way  
102 reflexivity can. This can improve the trustworthiness and validity of qualitative research findings.

103

104 Finally, Doug and Sujata helped with the dissemination of the results for a modelling study. Their  
105 input helped improve an infographic we produced for a general audience on Twitter to direct traffic  
106 for a publication produced. Table 1. contains a summary of all the ways Doug and Sujata contributed  
107 to the project.

108

109 PPI contributors often have a personal story for why they want to be part of a research project. In our  
110 case, both Doug and Sujata had experiences as either a patient or carer to someone with chronic

111 conditions. In this way, they had strong motivations from the outset to center the research around the  
 112 patient voice. Box 1 and 2 show both Doug and Sujata's reflections in their own words.

113

114 We think PPI has been hugely valuable in shaping the PhD project. Despite the challenges of  
 115 COVID, meeting regularly via virtual meetings has helped build and maintain a good personal  
 116 working relationship with all parties. As the project progressed, we ended up involving PPI members  
 117 in ways we had not imagined at the outset: for example, in the systematic review. Doug and Sujata  
 118 were naturally quite inquisitive and prepared to undertake training to support the project. As a result,  
 119 we built in time for this training and created summaries of key references to enable them to assist in  
 120 analysis. On a broader note, PPI can help the researcher question the assumptions underpinning their  
 121 researcher. Frequently in our meetings, Doug and Sujata would ask a question that required us to  
 122 clarify or justify methodology each logical step in the research process. Furthermore, their role is  
 123 always to advocate for the patient or the public. This influence can help remind researchers of the  
 124 central purpose of their project and re-ignite their excitement for their research. With careful  
 125 planning, and a flexible approach PPI in doctoral research can be meaningful and impactful even  
 126 with resource constraints.

127

<b>Projects</b>	<b>Involvement in research activities</b>	<b>Impact</b>
Qualitative modelling study estimating volume of prescriptions annually affected by genetic testing.	<ul style="list-style-type: none"> <li>Reviewed dissemination plans.</li> </ul>	<ul style="list-style-type: none"> <li>Infographic of results changed by doctoral candidate after discussion with PPI contributors.</li> </ul>
Narrative synthesis and systematic review of barriers and enablers to the implementation	<ul style="list-style-type: none"> <li>Researcher provided a training on theoretical domains framework, TDF, mapping. This involved a 90-minute interactive presentation on the TDF.</li> <li>Reviewed data extraction of patient reported barriers from systematic</li> </ul>	<ul style="list-style-type: none"> <li>Quotes mapped to different domain by doctoral candidate after discussion with PPI contributors.</li> <li>Discussion with PPI contributors led to greater contextualisation of literature</li> </ul>

of multi-drug PGx testing.	review and mapped to TDF with researcher.	identified patient barriers to implementation.
Proof of concept study involving genetically testing a small group of patients in primary and secondary care,	<ul style="list-style-type: none"> <li>• Reviewed and commented on: <ul style="list-style-type: none"> <li>○ Protocol</li> <li>○ Participant information sheets</li> <li>○ Participant consent forms</li> <li>○ Plain English summary for NHS ethics submission</li> <li>○ Topic guide for interview</li> </ul> </li> <li>• Role played patient research interviews</li> </ul>	<ul style="list-style-type: none"> <li>• Strengthened ethics application. Ethics committee specifically asked about PPI contributor involvement in production of study materials.</li> <li>• Significant changes made to plain English summary, patient participant information sheets, patient participant consent forms, and topic guide.</li> </ul>

128 **Table 1. Summary of Patient and Public involvement within the ‘Personalised Medicine’**  
129 **research project**

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*I retired in December 2012 having spent 40+ years in various Senior Purchasing roles mainly in the automotive industry. I feel passionately that it's crucial that in retirement one is kept both physically and mentally active. In February 2015 I had a heart attack and subsequently a triple bypass operation at the Royal Papworth Hospital. 8 weeks later whilst attending a cardiac rehabilitation session I noticed a pamphlet for the ‘Norfolk Zipper Club’ a charity that supports patients before and after open-heart surgery and raises funds to purchase additional medical equipment for the Papworth Hospital. Along with other organisations, we were invited to an Open Charities event at the UEA in October 2017 and from that, I was invited to join their PPI Group and have worked with the UEA on various pharmacy projects.*

*I was invited by their UEA pharmacy program coordinator to join Essra's project and quickly responded as I am on 6 daily medications and I believe that my work experiences plus my exposure to pharmacy practices have assisted Essra with her pharmacogenetic (PGx) testing research. I have a vested interest and believe that PGx testing is the way forward.*

**Doug Mellor- PPI contributor**

133

134 **Box. 1 PPI contributor reflections on role within research project**

*My name is Sujata and I am one of two PPI members. Being part of my GP Practice PPI group, I quickly became extremely interested in Public and Patient involvement and soon saw the benefits of the interaction between professionals and the patients. So, when I saw an email asking for public involvement with Essra's PhD on Personalised Medicine and genetic testing Project, I was keen to take part!*

*As a lecturer of Early Years and Health and Social Care, I have always been interested in education and health. Together with my own early experiences when I accompanied my mother who was not an English speaker for various medical appointments where I translated what was being said. I really feel that if personalized medicine or even listening to the patient had existed, her experiences would have been quite different. Although I have not had medical complications, my blood tests have always shown low iron and vitamin deficiencies and yet nothing more is ever followed up hence making me incredibly determined for the patient voice to be heard.*

*With genetic testing being so new, it has been a privilege to be part of this research which will contribute to the way medicines will be prescribed in the future. Essra has always encouraged discussion and answered our questions in a truly clear and inclusive way, always encouraging further questioning and understanding.*

*Due to COVID, we have met virtually once a month for 1.5 hours which has surprisingly worked well but I do feel a few face-to-face meetings would help more spontaneous discussion. My impact on this project has been my contribution as a patient/public perspective for example encouraging simple English to explain complicated medical and research 'speech'. I do feel having PPI involvement for Essra's PhD has made her research and her personal learning much richer overall.*

**Sujata Walkerley- PPI contributor**

135 **Box. 2 PPI contributor reflections on role within research project**

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