



Royal College
of Physicians

Lay representative and patient involvement evaluation – RCP committees, boards and working groups



Purpose

In May 2018, the Patient Involvement Unit (PIU) and Patient and Carer Network (PCN) began looking at how the RCP involves patients and carers across its work. An evaluation exercise was carried out to ensure that patient and carer involvement in RCP committees, boards and working groups remains meaningful and targeted and, ultimately, has a positive impact on patient care.

The PIU and PCN worked together to come up with questions for committees and lay representatives to review patient involvement.

They were asked to comment on how well the following principles of patient involvement were being implemented:

- Meaningful involvement: having real impact in order to improve health and healthcare for all
- Support and collaboration: building understanding that working together leads to better outcomes
- Accessible information: communicating information clearly, openly and in accessible formats
- Impact and feedback: measuring and sharing success and good practice.

The findings are summarised below. The PIU and PCN have used these findings to develop guidance and recommendations for committees, boards and working groups on best practice for involving lay representatives in their work.



Responses

The RCP currently supports 49 committees and boards, not including the special advisory committees and audit and accreditation projects. The PIU received 23 responses to the request for feedback. While this figure is relatively low in comparison to the number of lay representatives and committees, the information obtained was informative and has given us some clear direction for production of guidance and recommendations.





Lay representative feedback

Lay representatives who responded to this evaluation are all members of the PCN. PCN lay representatives on committees may have condition-specific patient experience but also may have previous experience of lay representation, working in health and/or an interest in the area of specialty.

Lay representatives who completed feedback shared mixed experiences of being involved on committees. Details of their feedback are given below.

> Valued and involved

On the whole, lay representatives feel valued and involved in committees. However, a number reported that this takes time as it can be a long process of building self-confidence and developing relationships with other committee members. The tenure of 3 years was raised under this issue, suggesting that if the tenure was longer it would give lay members more time to build meaningful relationships and establish themselves as equal members of the committee.

A number of individuals fed back that *'the chair taking the time to speak with them before the first meeting, and introduce them to other committee members was very beneficial.'*

It was also reported that at times lay representatives found it difficult to have their voice heard during meetings. Lay representatives felt that committees needed clear guidance on the role and remit of the lay member and the chair needed to take responsibility for ensuring the lay representative was consulted and included as a matter of course.

It was also noted that the PIU could do more to help prepare and support lay members through training and better networking opportunities.

> Timely and accessible information

Most lay representatives fed back that the information they received was available to them when they needed it.

Committee managers were praised by lay members for being helpful and supportive in sending and explaining information.

Some lay representatives fed back that information could sometimes be difficult to understand, containing jargon and acronyms that aren't readily explained.

'You will only feel confident joining a committee if you already have an understanding of the language and terminology used by its members.'

A number of lay members highlighted the need for at least two lay representatives on committees in order to feel confident sharing ideas and information. Mentoring was also suggested as a useful way of introducing new lay members to committees.

> Skills and expertise fully utilised

Although a number of representatives reported they felt their skills and expertise were used well during committee meetings others felt they were more of a tick box exercise, suggesting that they were a 'nice to have' addition rather than an equal member and decision maker.

A challenge highlighted by one representative was the idea that lay members are expected to come with a particular skill set and understanding of the committee prior to attending. The reality is that this builds over time but the expectation of lay members' expertise and experience is set quite high from the outset. This does not necessarily lend itself to a diverse and representative network of lay members.

> Representing the overall patient view

Overall, lay members felt they could confidently represent the views of the wider patient experience on committees. Most lay representatives have direct or indirect experience of the area of specialty and can therefore draw from their personal knowledge as well as offer a more general perspective.

It was highlighted that for some specialties it is imperative that there is an individual who can offer direct patient experience as well as including a general lay representative.

Feedback suggested that there needed to be better mechanisms for lay members to report back to the PCN and PIU.

> Lay representative impact on committee outcomes

Some lay members found it difficult to comment on this as they felt that their impact was hard to measure. The overall view was: the lay representative is crucial to bring the focus back to the patient voice and experience, if patient involvement is lost, committees will lose the vital grounding needed to improve patient care.

'I think that my involvement has led to outcomes that are generally more sensitive to the needs and vulnerabilities of patients who are not so able to navigate the system' and who do not necessarily feel confident to challenge or ask questions in a specialist healthcare setting.'

> Thoughts on an alternative approach to patient involvement on committees

Feedback from lay representatives implied there could be another approach to the way patients and lay members are involved in committees. However, a clear alternative was not proposed.

One member's response to the question was to acknowledge that there could be a range of approaches to patient involvement on committees but to have effective and meaningful patient involvement – 'Committees need a clear remit/work agenda, a chair that can instil an inclusive approach, follow up on priorities from committee discussion and work towards agreed outcomes.'

It was clear from lay representative responses that the patient voice and patient involvement should be central to the work of improving patient care across specialties.

'I think patient involvement in committees is vital because they have a key role in the work of the RCP.'



Committee feedback

Committees that responded to the evaluation covered a relatively broad range of the RCP specialties. The questions asked were similar to those put to the lay representatives from the PCN. Not all committees followed the questions directly, some gave a more general response relating to the specific involvement of their lay representative.

Committees meet three to four times a year, have their own terms of reference and do not necessarily include lay representatives from the PCN. Some committees have recruited their own lay members who are external to the PCN and may come from a condition-specific charity/organisation that offers direct patient experience in the area of specialty.



➤ What impact has patient involvement had on the committee's work, activities and outputs?

The majority of committees responded to this question suggesting lay involvement had been valuable, offered a different perspective to discussions and gave a better understanding as to, *'the impact of proposed innovation and guidance.'*

'It is important to have a patient representative because this committee deals with patient safety issues.'

A number of committees also fed back that at times it was difficult to get specialised input from lay members who had condition-specific experience and therefore impact was limited.

One committee reported that, *'Patient involvement has ensured that we take a broad view of issues related to [name of condition] and ensures that we work closely with the charity sector.'*

➤ What outcomes does the committee want to achieve through patient involvement?

Answers to this question varied. It would appear that none of the committees that responded have clear aims or outcomes for patient involvement or including the patient voice. However, this does not mean that it isn't happening.

One committee reported they have been working collaboratively on a national plan which has patient involvement at its core.

The feedback suggests that specialty committees require buy in, understanding and interest in supporting their area of specialty in order to develop and move work forward. Committees acknowledged that patient involvement is a key part in this process and can be vital in helping to influence government policy.

➤ What model of patient involvement would help the committee achieve its aims and objectives?

The current model works well for some committees but others fed back that it would be beneficial to explore different ways of engaging and involving patients.

'A group of engaged service-users in a specialist focus group would be more productive than generic individuals sitting on the committee.'

As a result of the evaluation, one committee is keen to look at how they involve the PCN more proactively in specific consultations in order to inform their work. It was clear from feedback that involvement has to be the best use of everyone's time, as well as all participants having a shared understanding of expectations and outcomes.

➤ What does the committee need from patient representatives/representation in order to achieve its objectives?

It was clear that the answers to this question were very much dependent on the committee's aims and objectives. Some committees felt they needed an overall perspective from their lay representative, while others were keen for the lay member to have direct experience in order to help develop its work.

'It would be more helpful if a patient representative could be well-informed about patient issues in the NHS, rather than being well-informed about their particular condition.'

'There are advantages to both general patient representatives, particularly where generic issues are being discussed, but there are times when condition-specific feedback would be really helpful and having experience of conditions or attendance at [name of condition] services is important.'

For other committees this question got them to think about what they were trying to achieve, particularly in relation to patient involvement and what might be a suitable alternative to single lay representation.

'We need to work out what we are trying to achieve with a lay person.'

'We might be better off having engagement with appropriate patient groups, as and when needed, rather than having a patient representative who attends each committee meeting.'



Guidance and recommendations

Taking into account the feedback from the evaluation exercise, the PIU and PCN have produced some guidance and recommendations for committees, boards and working groups on best practice when involving and working in partnership with lay representatives. We hope this guidance can be implemented across the RCP where lay members are recruited. We believe the recommendations will strengthen patient involvement at the RCP and complement the PCN's strategic aims.

Please see our separate **Guidance and recommendations** document.



Further info

To find out more about the PCN, visit the RCP website or contact the Patient Involvement Unit.

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