

# Working with lay members and patient representatives

{Smart Guides}  
to ENGAGEMENT

*For better commissioning*

## Lay members and patient representatives

Part of the **Smart Guides to Engagement** series, this guide helps clinical commissioning groups (CCGs) engage well and work constructively with lay members and patient representatives.

## The outsider inside: the role of the lay member and representative

CCGs require at least two lay members – one overseeing elements of governance and one to help champion patient and public engagement (PPE). This guide focuses on the latter.

CCGs also need to work with other patient and community representatives. But, what's the difference between a CCG lay member and a patient representative?

The lay member is one type of outsider-inside representative. These all come from the community and have a patient/user perspective (outside) to try to influence the system (inside) and improve things for the people whose interests they articulate. It's a tricky role and requires them to be a:

- **Community channel** – externally facing, credible, in touch with local communities and bringing in wider perspectives
- **Critical friend** – internally facing, supporting the patient, offering strategic advice from a non-institutional perspective.

## A better name might be patient and public adviser

The lay member has more formal accountabilities than a representative (eg from LINK, HealthWatch, or supra patient participation group (PPG) reference group). They may have additional rights (such as voting rights) and responsibilities (eg ambassador for the organisation). If they are on the board, they will be rewarded as other board members are for their responsibility and contribution. They are more insiders than outsiders.

### Lay member internal scrutiny role

Wandsworth's governance arrangements for practice-based commissioning included the lay member of the professional executive committee (PEC) scrutinising outline business cases for cluster-level developments to ensure that PPE evidence supported the proposal. The PEC lay member was also part of the PCT's strategic commissioning group considering large bids for service redesign and also reviewed the adequacy of equality impact assessments (EIAs) for new business cases.

## PPE is still everyone's job

The CCG governing body should remain in tune with member practices, but equally with patients and the community. Its business focus is improvement of health and health services and good engagement. The lay member is crucial here, but the board has a collective duty for engagement and should not leave it to one person.

All governing body members should be leaders – demonstrating presence and engaging people by the way they communicate, behave and interact. The lay member is no exception and should have credibility with their peers. They may bring in different insights, but they share responsibility to ensure the CCG exercises its functions effectively, efficiently and economically in accordance with its constitution. This includes ensuring:

- Patient and community interests are at the heart of discussions and decisions
- The CCG acts in the best interests of the health of the local population
- It commissions the highest quality services and secures the best possible outcomes for patients within resources available and maintains a consistent focus on quality, integration and innovation
- Health provision is in line with the NHS constitution.

## So, what?

The lay member is one of the people (but not the only one) who ensure the public voice of the local population is heard and that opportunities are available for PPE.

But they can't know everything. Some expect a lay member to be a total content expert (ie in how the NHS works as well as everything to do with PPE). But it is their process skills that are key.

At the heart of these process skills is emotional intelligence: the ability to monitor one's own and others' feelings and emotions, to discriminate among them and to use this information to guide one's thinking and actions. This includes the skills of dialogue, especially listening; identifying and working with assumptions (their own and those of others) and asking. It also involves being able to develop trusted relationships and to influence. Not easy! All leaders – professional and patient – should aspire to these qualities.

The lay member should ask the powerful question - they are the so-what person because they ask questions such as:

- ***'So, what are we doing to ensure public and patients' views are heard and responded to? How are people's views making a difference?***

- ***'So, what difference will this discussion, decision, etc, make to patients and the local community?***

The lay member should not do engagement (they are not the engagement practitioner), but are the catalyst for the CCG to undertake high quality engagement. They scrutinise the process and outcomes.

They may not know everybody in the community or all the groups to go to, but should know a person who can help. This assists the CCG to build trusting relationships with LINKs/HealthWatch and others. It is, ultimately, the board's responsibility to assure the CCG that PPE-led intelligence is informing commissioning decision-making.

## Not an easy ride

It is not always comfortable for professionals to work with patient representatives or lay members, particularly as a critical friend and to ask challenging questions. This is shared decision-making at strategic level and not all professionals are used to doing it. Professionals often assume people have personal agendas.

People's experiences of using services or managing a condition will fuel their involvement - they are passionate about improving things for others. But, just as a GP with a special interest in diabetes needs to understand broadly what matters to clinicians, so lay members need to understand a wider picture of quality and patient experience.

A well-supported lay person working with the CCG should expect to:

- **Be valued and listened to as an equal in any debate**
- **Offer informed constructive challenge and interventions**
- **Draw on sources of information or support outside the CCG and bring them coherently into the discussion**
- **Initiate action, not merely respond to issues, including identifying topics for the CCG to consider.**

**A single lay voice is easily marginalised. Patient-centred CCGs will want to have more than the bare minimum of two (patient/public) lay members. Two people can support and substitute for each other if needed. And lay members require ongoing support and financial resources.**

## What matters to patients - the patients' dozen

The things that matter most to patients and representatives will help focus the CCG on these priorities.

1. **Getting better, feeling better (outcomes of care)**
2. **Getting the right care from the right people (clinical quality)**
3. **Being treated as a human being (humanity of care)**
4. **Information, communication, having a say (shared decision-making)**
5. **Being supported (practical and emotional)**
6. **Support for carers**
7. **A safe, clean, comfortable place to be (environment of care).**

The above should be there at each stage of our care. The following concern what those stages might be.

8. **Right treatment at the right time (access 1)**
9. **Right treatment in the right place (access 2)**
10. **Smooth transitions (continuity)**
11. **Continuous care (after care)**
12. **Support for independence.**

Beyond these, specific groups or individuals from different parts of society face particular barriers to get the things they need. Therefore, diversity, equality and human rights issues are central to all 12 dimensions.

## Working with patient leaders

Lay members are a subset of a wider pool of lay representatives on groups, committees and projects. In turn, representatives are a subset of an emerging pool of patient leaders keen to lead change and improve health. These include health champions, community development practitioners, community researchers, peer-to-peer support workers or even patient entrepreneurs.

So, we have two sorts of patient leaders:

- **Transformers – system-facing leaders wanting to improve the health and social care system (representatives and advisers)**
- **Enablers – community-facing leaders wanting to improve health and wellbeing in their community.**

CCGs can benefit from patient leaders operating at every level, but only if they are clear about roles and the processes needed to identify, nurture and support them.

People may come from particular surgeries or from patient interest groups. There is huge potential to grow a wider pool of local talent and patient leadership. They may play increasing roles on patient participation groups, supra-PPG reference groups, QIPP programmes, service improvement work and partnership boards, as well as other formal lay membership roles (eg on health and wellbeing boards, foundation trust governors).

## Don't forget the learning

Professional development is a well-recognised term after decades of investment. Patient leader development is almost non-existent. What is available is often too focused on institutional needs and combining things that don't fit. It is didactic. Giving everyone the same induction means stuffing them with knowledge and boring detail about structures, committees and acronyms. No wonder people turn off.

There is a need to develop new patient leaders – to widen the pool of talent and provide systematic approaches to learning and development that support a broader array of engagement opportunities. Learning should be co-produced with patients and carers. It must focus on what matters to them – for instance, how to deal with professionals and navigate the system, therefore building their emotional competence and literacy to build trusting relationships, influence decision-making and develop the skills of dialogue.

### Training for effective representatives

**The collaboration for leadership in applied health research and care (CLAHRC) in northwest London commissioned InHealth Associates to run three pilot learning programmes for representatives. The effective patient and community representative programme, based on action learning principles, was independently evaluated and achieved significant outcomes, such as increased confidence to influence decision making and catalysing community-led projects. Participants have included FT governors, LINK members, members of PPGs and patient groups. The programme is being rolled out in other areas.**

## Foundations of leadership

Leadership is essential for effective engagement. Clinical, managerial and patient (service users, carers, public) are three different overlapping arenas for leadership. All are needed for meaningful decision-making.

Commissioners and providers must appreciate that clinical leadership and clever managers are not enough. If they are divorced from PPE-led change, then frustration and contention are the likely outcomes. QIPP-type reconfiguration – which usually can't be done without decommissioning and reinvestment – will not get any easier. Patient leadership is not a magic bullet, but patient leaders are integral to the process of doing things differently and better.

## Here are practical steps to get your CCG working well with lay members and patient representatives:

- **Share the role – PPE is everyone’s business in the CCG. Ensure lay people are in at the beginning of a process, including planning and drawing up terms of reference.**

- **Be clear about the role, purpose and benefits of lay membership and representation. Provide clear guidance on the role, including time commitment, accountability and identifying conflicts of interest.**

- **Clarify the role to the rest of the committee or group and their status as an equal member. If it is a voting body, be clear about the rationale for which members vote.**

- **Avoid unnecessary terminology. Make it clear which papers and sections of meetings contain confidential information. Be clear with all members about confidentiality of patient-sensitive information, data protection requirements and how to handle media contacts.**

- **Financial or other recognition arrangements, including paying expenses must be agreed in advance. Make arrangements for reimbursing travel or other out-of-pocket expenses (eg taxis when individuals cannot use public transport or child care). Cover whether a carer representative is needed, or if the lay member/user representative is a carer, whether a carer or personal assistant is required. Check if on-the-spot cash is needed.**

- **Time constraints of lay member/user representatives should have equal weighting to anyone else involved in the committee. Time meetings conveniently. Send papers at least one week ahead of the meeting. Ensure lay members/representatives have information, training and support, including IT skills or special arrangements for someone with a sensory impairment.**

## Get Smarter – find out more

Gilbert D: The Rise of the Patient Leader, Health Service Journal, January 2012  
<http://bit.ly/HxrjaW>

Recognition and reward: the Principles and Practice of Service User Payment and Reimbursement in Health and Social Care (Department of Health, 2006)  
<http://bit.ly/H6sCNC>

For information about the other guides in this series:  
[www.networks.nhs.uk/nhs-networks/smart-guides](http://www.networks.nhs.uk/nhs-networks/smart-guides)

## Acknowledgements

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Smart Guides to Engagement are a co-production by organisations and individuals passionate about engaging patients, carers and the public more fully in healthcare. The series editors are Andrew Craig and David Gilbert.

Andrew is a partner in Moore Adamson Craig LLP, an organisation with many years' experience in the involvement and engagement of users of public services:  
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The editors would like to thank the authors for their generous unpaid contributions and the Department of Health for its support.