

# **BMA knowledge sharing event with patient/lay groups**

**7 February 2017**



## BMA knowledge sharing event with patient/lay groups

On 7 February 2017, the BMA hosted patient/lay representatives from 11 external medical professional organisations. The purpose of the event was to identify common challenges and opportunities, share best practice, discuss shared priorities, consider impact and how to best engage going forward.

The following groups were represented:

1. Patient & Lay Committee, Academy of Medical Royal Colleges
2. Lay Committee, Royal College of Anaesthetists
3. Patient Liaison Group, British Medical Association
4. Patient and Carer Partnership Group, Royal College of General Practitioners
5. Women's Network, Royal College of Obstetricians and Gynaecologists
6. Lay Advisory Group, Royal College of Ophthalmologists
7. Children & Young People's Engagement Team, Royal College of Paediatrics and Child Health
8. Patient and Carer Network, Royal College of Physicians
9. Lay Advisory Committee, Royal College of Physicians Edinburgh
10. Service Users' Forum, Royal College of Psychiatrists
11. Lay Advisory Board, Royal College of Physicians and Surgeons of Glasgow
12. Patient and Lay Group, Royal College of Surgeons of England

This report represents the discussions of the attendees at the workshop.

### 1. Challenges and opportunities

The purpose of lay groups is to represent the voice of patients and carers and provide a non-medical perspective in organisations whose primary focus is on representing the needs of their doctor members. Being part of the organisation means that they have a supportive function by acting as a 'critical friend' but they are also expected to provide constructive challenge to current ways of thinking. Lay groups bring together independently minded members of the public, patients and carers with a wide range of lived experience, skills and knowledge of healthcare issues. Lay members should have no vested interests and therefore provide an independent voice to their respective organisations.

These groups are able to feed in the lay perspective through a variety of mechanisms from sitting on committees and providing feedback on consultation responses to being directly involved in the education and training of doctors. They can also lead on the organisation's public and patient facing work, for example, developing and shaping leaflets and guidance for patients, as well as organising public engagement campaigns.

Attendees agreed that in order to be effective lay groups needed to be clear to stakeholders internally and externally about what their purpose is. Lay members provide an independent viewpoint, whether on generic health matters or, more specifically, a vital non-medical perspective on a medical condition and its treatment.

## 1.1 Building an effective patient/lay group

Internal	External
<ul style="list-style-type: none"> <li>– Having a clarity of purpose and function</li> <li>– Understanding and articulating strategic fit</li> <li>– Maintaining a unified voice</li> <li>– Communicating a clear message</li> <li>– Integrated in governance structures</li> <li>– Respected and supported by the organisation's senior management</li> <li>– All voices are heard</li> </ul>	<ul style="list-style-type: none"> <li>– Having a clarity of purpose and function</li> <li>– Prioritising stakeholders</li> <li>– Building relationships with relevant stakeholders including other lay groups</li> </ul>

### Establishing and maintaining a representative group

There should be a robust system of internal governance which includes a terms of reference and a recruitment process. In order to function effectively the group should also be provided with adequate policy and administrative support.

Some attendees found term limits of lay members to be helpful so that the group is able to draw from the experience of different people with diverse backgrounds. However, if the limit is too short or there is too much turnover this will affect the group's ability to influence. Some groups found it helpful to appoint members on a provisional basis for a few months to see if they are a good fit.

Although members are expected to give a rounded view, rather than representing a specific area, ideally there should be a good geographic spread of members across the UK. To improve representation an effort should be made to include voices from the devolved nations as these have different health systems.

### Being effective and providing a strong voice

Lay groups need to be aware of who they are and who they are not representing. A particular challenge can be to engage with groups whose voices may not be easily heard, including children and young people. It is important to be mindful of this when recruiting new members. Tapping into the networks of lay representatives can mitigate this issue and bring on board further views.

In order to be fully effective lay groups need to be fully integrated in the organisation's policy and decision-making structures. The onus should be on the organisation to ensure that the lay group is represented across the organisation's key committees, workstreams and working groups but also on the lay group to proactively raise awareness of the needs of patients and carers.

In order to provide a strong voice lay groups also need to manage their resources as effectively as possible. Stretching beyond capacity will run the risk that their voice will be diluted. Patient perspectives can be provided by various methods, for example, inviting a member of the lay group to a committee meeting or asking for input via virtual means. A flexible approach should be taken for requests for input as attendance in person is not always necessary.

### **Case study: Increasing patient involvement**

The Royal College of Obstetricians & Gynaecologists Women's Voices Involvement Panel is an online group of around 300 women who are consulted on a regular basis. This group works alongside the Women's Network which is the College's patient/lay group which is made up of 17 people. The panel was established in order to give a wide and diverse group of women the opportunity to feed in their perspective. Engagement can take a variety of forms, mostly through email but members of this group may also be offered to attend focus or working group meetings.

### **Influencing others**

In raising awareness of patient and public issues and interests, lay groups have to be influencers both internally and externally. Depending on the internal structural 'barriers' it can be a gradual process to make internal stakeholders appreciate their added value. Lay and patient representatives should not fulfill a token role and should be empowered to provide honest perspectives and constructive challenge.

It is important that lay members have the confidence to work with clinicians and senior staff. Some members may find it challenging to be the only lay person in a room full of clinicians. Effective and inclusive chairing is crucial to ensure that a wide variety of views are encouraged and listened to during meetings.

### **Case study: Formalising patient input**

The Royal College of General Practitioners' Patient and Carer Partnership Group has produced a 'checklist' which committees are asked to complete in order to ensure that the patient perspective is included in policy discussions, where appropriate. By implementing this it puts the onus on the committee chair to ensure that a lay perspective has been sought.

### **Continually assessing impact and performance**

Patient/lay groups face peaks and troughs in workload. In times of greater demand, being able to effectively prioritise is key. Lay groups can run the risk of saying 'yes' to all requests for input and becoming reactive or unreliable. Producing a workplan for the year will help ensure that objectives are achieved and projects completed on time.

Last minute and ad-hoc requests will need to be dealt with carefully. Many attendees commented that they would be consulted on issues but would not be given sufficient time to respond in the detail they would have liked. If the group is not able to provide useful input (for example, there is not enough time to provide comments on a long technical document or there has been a last-minute request for a lay representative to attend a meeting) this should be communicated as soon as possible to the requesting party. Setting up specific workstreams and identifying leads was found by some lay groups to be an effective way to provide feedback on policy documents and consultation responses quickly which can then be shared with the wider group for approval.

### **Ensuring a good two-way communication**

When being invited to send a representative to a committee it is important to establish early on what the expectations are and what the committee wants to 'get out' of it. Feedback should be sought continually in order to ensure that the group is able to add value and contribute effectively. An example was mentioned where a lay group agreed to send a representative to attend regular committee meetings but when feedback was sought it came back negative because the committee was looking for a service user with lived experience of a specific long-term condition. Once this misunderstanding was discovered it was decided that there would be no value in sending a representative as there was no one on the lay group who would fit the specific profile.

## 1.2 Recommendations

- Lay groups require robust support and processes, including financial, in order to be effective – all groups should have a programme of induction which may include mentoring, buddying and training (such as developing leadership skills and chairing a meeting)
- Lay groups are encouraged to produce an annual workplan which includes priorities/objectives, actions, and outputs with timeframes
- Early engagement with new initiatives or programmes is often key to achieving a focus for lay and patient involvement and can avoid later confused or wasted effort. Such engagement is best done through dialogue between lay members and relevant committee chairs/secretariat
- Lay groups should request regular feedback from internal stakeholders (e.g. committee chairs) in order to ensure that it is able to contribute effectively
- To improve representativeness, explore setting up a wider group or network to comment on consultation responses and engage with external stakeholders
- Lay groups should be proactive in engaging with 'hard to reach' groups in order to more effectively raise awareness of needs of all patient groups

## 2. Best practice examples

Best practice examples shared by attendees included the following:

### Case study – Articulating the patient and carer voice

When it was established over a decade ago, the Royal College of Physicians (RCP) Patient and Carer Network led the way in mapping and articulating the challenges that patients and carers experienced when accessing health services. It is very much thanks to the RCP's original vision that the patient and carer voice remains at the centre of the RCP's decision making. Members of the Patient and Carer Network (PCN) get engaged and work in a variety of different ways:

- The PCN contribute the patient and carer view to: Committees, working parties Boards and reviews carried out by the RCP
- The PCN comment on strategies, documents and reports produced by the RCP
- The PCN offer the patient and carer view to physician examinations and education and training boards
- And the PCN attend training sessions, events and conferences

### Case study – Patient representation on committees

The Royal College of Physicians and Surgeons of Glasgow encourages its lay group members to sit on various sub-committees within the College where they can bring to bear various non-medical skills and perspectives to discussions. In total there are 11 sub-committees that focus on issues such as membership, travel medicine, surgical medicine, medical education, training and professional development, which lay members are able to participate in. Lay member participation on these groups has provided very helpful input and open dialogue across different medical and non-medical perspectives.

### Care study – Co-production

Through the [Future Hospital Programme \(FHP\)](#) the RCP Patient and Carer Network (PCN) have learnt what it means to be a full and equal partner. The FHP now has eight development sites and on each of these the PCN have or have had members who work closely with local lay representatives. They are making sure patients are engaged at every stage and that person-centred care is delivered in each of the projects.

- The PCN were involved in designing the site criteria
- The PCN were involved in reviewing the applications
- The PCN were involved in interviewing the applicants
- The PCN are involved in collecting data on the patient experience (the PCN are adopting an evidence-based approach and have been given the chance to learn from the work of Annie Laverty, Director of Patient Experience at Northumbria Healthcare NHS Foundation Trust)
- The PCN will also be involved in the evaluation of the FHP, assessing the difference patient and public involvement has had on delivering person-centred integrated care.

### Case study – Training & education

The Royal College of Ophthalmologists develops and reviews the curriculum and examinations of ophthalmic specialist trainees. Members of the College's Lay Advisory Group have the opportunity to set exam questions as well as sit with clinicians during some of the examinations.

The Royal College of Psychiatrists Service Users' Forum members have taken part in training videos for doctors to help doctors communicate better with patients.

The Royal College of Paediatrics and Child Health lay members design tests for junior doctors so that they can communicate better with children and young people.

### Case study – Patient facing guidance

The Royal College of Anaesthetist's Lay Committee write and review patient information leaflets to ensure that the language is accessible to the public. When reviewing these leaflets the committee ensures that these are focused around the needs of patients rather than what doctors might think patients need.

The Royal College of Ophthalmologists Lay Advisory Group regularly reviews the College's guidelines for the treatment of specific conditions and public information leaflets.

The Royal College of Surgeons of England's Patient and Lay Group has developed information materials for patients, for example, *'It's OK to ask'* – a diary which encourages surgical patients to ask questions and to record their thoughts during their treatment.

### Case study – Guidance for doctors

The Royal College of Physicians of Edinburgh Lay Advisory Committee has participated in the development of a visual chart of the patient journey through hospital which has received positive feedback from doctors.

### **Case study – Involving devolved nations**

The RCGP Devolved Nations have their own independent patient and lay groups. The Chairs of these groups meet on a quarterly basis through the UK Patient and Carer Partnership Group (PCPG) in order to share information and discuss issues.

### **Case study – Outreach to patients**

The RCPCH's Children and Young People's Engagement team has built and maintained wide networks in order to ensure that the views of children, young people and families influence and shape the College's policy:

- The Engagement Collaborative is a virtual network of child health engagement leads which is used to share good practice, contribute to consultation responses and develop local engagement champions.
- The &Us network provides opportunities for members of the public to feed in comments through social media, online surveys and workshops.

### **Case study – Regulation**

The Royal College of Anaesthetists' Lay Committee members take part in hospital visits under the [Anaesthesia Clinical Services Accreditation scheme](#) to assess whether the College's quality standards are implemented. These visits are followed by a report which benchmarks against the College's standards and provides targeted advice. Both the CQC and NICE recognise the value of this accreditation as a useful source of information on the quality of anaesthetic service.

### 3. Evaluating impact – qualitative vs quantitative

Increasingly lay groups are becoming more discerning about engagement and increasingly aware about impact. However, measuring impact is not an exact science although using a mix of qualitative and quantitative evaluation of engagement is helpful.

	Internal/self-assessment	External feedback
<b>Qualitative</b>	<ul style="list-style-type: none"> <li>– Use workplans that tie into an annual plan.</li> <li>– Regular self-assessment questionnaires – for example, RCP use the following questions:               <ul style="list-style-type: none"> <li>– What have you done since the last meeting?</li> <li>– What are you going to be working on before the next meeting?</li> <li>– Do you think you were able to raise the issues that concern you?</li> <li>– What difference have you made?</li> <li>– How confident did you feel about contributing?</li> </ul> </li> <li>– Organise 'meet the team'/ internal staff awareness weeks.</li> <li>– Annual self-assessment questionnaire (this is done informally by the RCGP, usually via a verbal update)               <ul style="list-style-type: none"> <li>– Do you feel you have had an impact on the committees you have been involved in?</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>– Capturing positive/negative feedback</li> <li>– External bodies to undertake a review</li> </ul>
<b>Quantitative</b>	<ul style="list-style-type: none"> <li>– Count volunteer hours (this is done by the RCP)</li> <li>– How many hours do you spend per week?</li> </ul>	<ul style="list-style-type: none"> <li>– Social media: Counting click-throughs, re-tweets, leaflet/guidance downloads</li> <li>– Counting number of meetings, seminars and conferences attended (e.g. NHS England, CQC)</li> </ul>

## 4. Priorities

The attendees were asked to discuss the priorities their respective patient/lay group was working on which included the following:

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### Policy

- Integrated care
- Person-centred care
- Patient empowerment
- Self-care
- Improving patient literacy & education
- Patient responsibility – changing patient behaviour/effective use of resources
- End of life
- Resuscitation
- New healthcare professionals – physician associates
- Service re-design – ensuring patients are fully considered
- NHS and social care funding – properly resourced services
- Crisis in General Practice/shortage of trainees
- Service improvement
- STPs
- Access to medical record
- Ageing population
- Doctors wellbeing/morale and professional development
- Compassion in healthcare
- Mental health
- Improving doctor-patient communication
- Safe-guarding

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### Administration and internal processes

- Recruitment
- Clarifying role and remit
- Developing priorities and setting the agenda
- Getting representation on committees right
- Managing relationships with internal and external stakeholders
- Managing resources
- Measuring and evaluating impact
- Adequate staff support
- Updating website

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### Member support

- Supporting the College/Association and its members
- Building and refreshing trust

The attendees agreed that deepening engagement between lay groups would improve patient representation and provide more clout when negotiating with external stakeholders.

## 5. Going forward

In order to promote greater cross-working and collaboration between lay groups in future the following ideas and proposals were discussed:

### Short term

- Regular catch-ups between secretariats
- Regular networking and knowledge sharing opportunities on specific policy topics
- Hold joint conferences and road shows
- Organise joint communication/public engagement campaigns
- Produce joint letters and consultation responses
- Share annual reports and strategic plans
- Organise a follow up event in a year's time

### Long term

- Capture skills/experience/geographic location of lay members and share with other groups
- Capture location of lay members in order to have greater geographic coverage
- Encourage a cross-organisational system of training for new lay members
- Encourage a cross-organisational system of buddying, shadowing and mentoring
- Develop a cross-organisational system of recruitment

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