To: The Board

For meeting on: 26 March 2014

Agenda item: 8

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Report for: Discussion

TITLE: **Monitor's engagement with patient groups**

Summary:

Monitor exists to make the health sector work for patients. To do this the organisation needs to develop its expertise in how it engages with patients and the public in order to get input to its decision-making. Recruiting a specific team with a patient focus will be a key factor in this development. In the meantime the foundations have been laid for the new team to build on.

This paper sets out:

a) a broad overview of the patient and patient group engagement carried out over the past six months and planned activities in the short term.

b) research and recommendations by the Economics team into ways that Monitor can engage even better with patients and their representatives.

Board members are asked to note that the Economics team's Full Report into Patient Group Best Practice is available upon request from the Board Secretariat.

Recommendations:

1. The Board is asked to note both the patient group activity delivered over the past few months and the activities planned in the short-term to ensure there is no hiatus in engagement as the new patient and clinical engagement function is scoped and implemented.

2. The Board is asked to agree the recommendations from the Economics team's research on the approaches Monitor can take to engaging with patient organisations. There are three kinds of recommendations:

a. How Monitor makes better the approaches that it already uses to engage with patients and their representatives.
b. Tools that Monitor can add to its patient engagement toolkit.
c. Approaches to patient engagement which Monitor identified during its research but which does not think it appropriate for Monitor to take forward.

To operationalise the recommendations Monitor will:

a) promote appropriate use of the tools by the new patient engagement team and Communications Business Partners;

b) facilitate the inclusion of relevant tools (for example how to run an effective consultation) in the Policy team's Project Management Guide/Problem Solving Guide;

c) ensure that the monthly joint directorate meeting (see the Stakeholder Engagement team's short-term activities) facilitates co-ordination and operationalisation of these approaches so as to avoid 'overconsulting' the sector.

Public Sector Equality Duty:

Monitor has a duty under the Equality Act 2010 to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations between people from different groups. In relation to the issues set out in this paper, consideration has been given to the impact that the recommendations might have on these requirements and on the nine protected groups identified by the Act (age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, gender and sexual orientation).

It is anticipated that the recommendations of this paper are not likely to have any particular impact upon the requirements of or the protected groups identified by the Equality Act.

Exempt information:

None of this report is exempt under the Freedom of Information Act 2000.

Introduction

1. It is important for Monitor to engage with patients for at least four reasons:

   a) *Fulfilling our mission.* Monitor's mission is to make the health sector work for patients. To do this effectively, we need to understand the patient interest by developing further expertise in how we engage with patients and the public – and their representatives – when developing and communicating our policies on specific tools, guidance, and decisions.

   b) *Compliance*. The Health and Social Care Act 2012 (the 2012 Act) makes our main duty to protect and promote the interests of people who use healthcare services. The 2012 Act also requires Monitor to ensure that people who use healthcare services, and other members of the public, are involved to an appropriate degree in decisions we make about the exercise of our functions. Recommendation 62 of the Francis Report is that Monitor improves patient focus and should incorporate greater patient and public involvement into our structures, to ensure this focus is always at the forefront of our work.

   c) *Regulatory strategy*. Obtaining views from patients and their representatives (eg Healthwatch) when we seek information on providers or local economies will help helps ensure we make better informed decisions when deciding the right course of action.

   d) *System leadership*. There is a concerted attempt by all system partners to drive the patient voice to the heart of regulation and service planning. Many Arm's Length Bodies (ALBs) including the Care Quality Commission (CQC) and the National Institute for Health and Care Excellence (NICE) are already investing heavily in public involvement in their work and have declared their commitment to patient engagement. Moreover, as we have seen most recently with the mental health lobby, some of those patient groups will and do have an opinion on Monitor, an opinion which can be misinformed if we do not communicate and engage effectively.

2. Patient groups have, therefore, been identified as one of Moitor's six priority stakeholder groups.

3. Monitor's work in engaging patient groups and incorporating their feedback into our regulatory work is evolving and has grown significantly over the past four to five months. While this is a positive step, this development comes with potential risks to our reputation from unco-ordinated activity and message confusion. This proposition is supported by comments during recent patient group roundtables. Point 14 d) sets out how we will address this.

A. Overview of patient group activity at Monitor over the past six months

4. In the absence of the new Patient and Clinical Engagement directorate, we have continued to build relationships and engage patient groups in a range of ways, including:

Healthwatch

5. Given Healthwatch England's statutory powers and remit to advise Monitor, we have focused on developing an effective relationship with the national body and the local network. This relationship was initially driven by the stakeholder team, but the following examples show how Healthwatch is now involved in several areas of our work.

a) The Policy team, working with Stakeholder Engagement, is developing a Memorandum of nderstanding (MoU) with Healthwatch England detailing how we will work together in the future, taking into account their statutory powers. This is being finalised with Healthwatch England and will be presented to Monitor's Board for approval.
b) David Bennett, Monitor's Chief Executive, has met both the Chair and Chief Executive of Healthwatch England and Baroness Hanham, Monitor's Chairman, is due to meet their Chair on 31 March 2014.
c) Local Healthwatch are engaged on a regular basis as and when necessary by Provider Regulation. For example they have had discussions with a range of local Healthwatch including Peterborough, Staffordshire and Milton Keynes. This type of engagement will be formalised in the forthcoming MoU.
d) When assessing an applicant NHS foundation trust (NHS FT), the Assessment directorate communicates with the relevant local Healthwatch at the start of the process. This is also included in the MoU.
e) We briefed the local Healthwatch in the eleven local health economies included in the invitation to tender (ITT) for Joint Planning Support ahead of issuing our press release, as we do for many of our announcements. In addition the ITT included a request for advisors to ensure that local Healthwatch and other patient groups were engaged in the strategic planning process.
f) A local Healthwatch concern about a competition issue is being dealt with by our Co-operation and Competition directorate.

6. The Stakeholder Engagement team had initial discussions with recently met colleagues at Mind, Mencap, NHS Alliance PPI Forum, AvMA and the Royal College of GPs Patient Group to investigate wider areas for engagement/involvement going forward. Meetings are being arranged with other key groups including National Voices, The Patients Association and Action against Medical Accidents.

7. Monitor is a key part of the National Quality Board (NQB) Patient Engagement working group.

Patient group engagement on specific topics

8. We invited patient groups to attend the NHS Futures event jointly hosted by Monitor, the NHS Trust Development Authority (NHS TDA) and NHS England to explore new ways of delivering care.

9. Monitor's integrated care team, as part of the Integrated Care and Support Collaborative, continues to work on the Integrated Care Pioneers programme. A major selection criterion was the engagement of patients and users, and local approaches must show improvements to patient care. Earlier last year, the team was involved creating the Integrated Care Narrative, which was developed by National Voices on behalf of the Collaborative. The narrative was produced and refined throughout with patients and users, including at two roundtables, the last of which was in March 2013.

10. In both their walk-in centres and primary care research and subsequent reports, the Co-operation and Competition directorate engaged broadly across stakeholders including patient groups. The walk-in centre report, which examined the impact of service closures, included a survey of over 2000 patients using walk-in centres. National Voices supported and helped publicise our work, communicating to its members and relevant patient groups. The survey used was also promoted through Mumsnet to its members/browsers.

11. Additionally, Monitor’s Co-operation and Competition directorate’s Inquiries team is frequently contacted by patient groups with comments and complaints relating to areas such as audiology services and prosthetic limbs. We offer appropriate advice to help resolve issues, including working with patient groups to research the issue in question and establish if any action by Monitor could generate positive solutions.

12. Over the past three months, third sector providers, many of which are also patient representative bodies, have been engaged about the introduction of the licence for independent providers, including members of The Richmond Group. This will continue over the coming weeks and months to ensure all appropriate organisations have oversight of the change.

13. The Pricing team and the Strategic Communications directorate have held two crowdsourcing digital events (in addition to other events held last autumn), calling on broad communities to feed into the development of the NHS payments system. The most recent event, in February, was focused on mental health and community services, resulting in around 600 contributions from organisations including Mind and Rethink. Stakeholder Engagement and Pricing also hosted two roundtables inviting key national patient groups including National Voices and Healthwatch England. A patient-friendly leaflet aiding understanding of the long-term pricing plan was developed in the summer 2013, with input from Healthwatch England.

Planned engagement with patient groups in the short-term

14. It is important to ensure that there is no ‘hiatus’ in the further strengthening of relationships and awareness among patient groups, particularly in light of the developing new directorate. A range of activities is planned in the short-term, including:

    a) A targeted Executive Committee engagement programme with the ‘top 40’ stakeholders which includes a number of patient groups.

    b) Targeted speaking at key patient group board meetings.

    c) A proactive third party events strategy, eg the Executive Director of Assessment speaking at a patient safety conference in May.

    d) The Stakeholder Engagement Team will be hosting a monthly joint directorate engagement meeting starting from 3 April 2014. The meetings will involve representatives from all of the relevant Monitor teams and the purpose will be to ensure stakeholder intelligence and activity is co-ordinated across Monitor and any best practice examples are shared and adopted more widely where appropriate.

    e) A roundtable for Chairs of Patient Partnership Groups (‘PPGs’) across all of the Royal Colleges. A roundtable with the members of the Richmond Group of charities which includes Age UK and The Stroke Association.

    f) A meeting with the Mental Health Policy Group to discuss joint areas of work and how the relationship can be taken forward.

B. Research and recommendations by the Economics team into ways that we can engage even better with patients and their representatives

15. As a first step in developing our expertise, the Economics team has undertaken research to identify ways that we can improve our toolkit for engaging with patients and their representatives. In this section, we set out our methodology, findings, and recommendations.

Methodology

16. There were two steps in our method for identifying good practice:

    a) Through desk research and interviews with other ALBs and regulators1, we generated a list of commonly used approaches to consumer/patient engagement.
    b) To understand which approaches in this list are most appropriate for Monitor, we held two roundtables with a total of 31 patient organisations to canvass their views on the commonly used approaches.

Summary findings

17. The advice that we received from the patient groups that we spoke with was relatively consistent on the characteristics of a good programme:

    a) The tools should allow input directly from patients and, for complex issues, from a source that represents patients' interests.
    b) The toolkit should allow input at national and local levels depending on Monitor's question. For example, enforcement work might require input from local patient groups and tariff work might require input from larger, national groups.
    c) For some policies it will be appropriate for end users to be involved from the outset (problem definition stage) and for others it will be during policy implementation. The toolkit should be able to accommodate these requirements and those in between (options generation, consultation, etc).

18. The following table identifies which of the engagement approaches can be used for key characteristics of a good programme:

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[1] Care Quality Commission, Civil Aviation Authority, Department of Health, Financial Conduct Authority, Food Standards Agency, Legal Services Board, NHS England, National Institute for Clinical Excellence, Ofcom, Office of Rail Regulation, Ofgem, OFT, Ofwat, Public Health England, and the Trust Development Authority.

Table 2: Which engagement approaches help to meet the essentials of a good engagement toolkit

	Degree of policy complexity		Geography		Stage in policy development	
	Less complex - Engage patients	**Complex - Engage experts representing patients**	**Local**	**National**	**Early (policy scoping)**	**Late (policy/option evaluation)**
Engagement policy statement	✓	✓	✓	✓	✓	✓
Sign posting					✓	
Public consultation		✓	✓	✓		✓
Research programme	✓			✓		✓ (typically an ex-post review)
Strategic partners	✓ (Partners' members)	✓	✓	✓	✓	✓
Lay panel	✓		✓	✓	✓	✓
Expert panel		✓		✓	✓	✓

Recommendations

19. Our research found that a 'good' engagement toolkit includes many of the tools detailed in the findings – there is no single engagement 'big win'. At a general level, patient groups would like to be more engaged with Monitor and for Monitor to ensure it effectively coordinates its engagement with other ALBs to avoid duplication. Specifically, we make three areas of recommendations:

    a. **Monitor can use better its existing engagement tools.** For example, Monitor already conducts consultations and calls for evidence but patient organisations, however, told us that a 'good' consultation:

        a) Is well sign-posted in advance
        b) Shows how the views of the organisations being consulted have been taken into account;
        c) Where appropriate, ensures that hard to reach and minority groups are engaged;
        d) Is accompanied by a 'plain English' version and allows for a variety of response media (for example: face-to-face meetings, written, roundtables); and
        e) Is targeted at organisations that are interested and able to contribute.

    b. **Monitor can use new engagement tools.** Monitor should develop its strategic partners programme, lay and expert panels, and produce a statement of patient and public engagement. We have developed a variation on a strategic partners programme[2] with ‘top 40’ stakeholders around which most engagement happens. However, a true partners’ programme will further facilitate local and national engagement at particular points or throughout policy development. It can also be used to canvass views directly from patients or their respective organisations.

c. **Monitor should not duplicate some areas of research.** We do not recommend that Monitor pursues a programme on annual patient research. We think that this kind of research is already conducted in the system (for example, the Friends and Family test) and therefore it is not necessary for Monitor to pursue as it would create duplication.

20. To operationalise our recommendations we will:

a) promote appropriate use of the tools by the central patient engagement team and Communications Business Partners.
b) facilitate the inclusion of relevant tools (for example how to run an effective consultation) in the Policy team’s Project Management Guide/Problem Solving Guide.
c) ensure that the monthly joint directorate meeting (see the Stakeholder Engagement team’s next steps) will facilitate coordination and operationalization of these approaches so as to avoid ‘overconsulting’ the sector.

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[2] A partnership programme is a long term investment in relationships with key end user representative organisations. It builds on the relationships that the regulator has already established with representative organisations by developing opportunities to involve the partners in reference groups (the patient/consumer group is part of the regulator’s quality assurance process); and opportunities for collaboration with the partners on policy development and decision making (the patient/consumer group is part of the policy team).