

Patient and public participation in health professional regulation

July 2011

About CHRE

The Council for Healthcare Regulatory Excellence promotes the health and well-being of patients and the public in the regulation of health professionals. We scrutinise and oversee the work of the nine regulatory bodies¹ that set standards for training and conduct of health professionals.

We share good practice and knowledge with the regulatory bodies, conduct research and introduce new ideas about regulation to the sector. We monitor policy in the UK and Europe and advise the four UK government health departments on issues relating to the regulation of health professionals. We are an independent body accountable to the UK Parliament.

Our aims

CHRE aims to promote the health, safety and well-being of patients and other members of the public and to be a strong, independent voice for patients in the regulation of health professionals throughout the UK.

Our values and principles

Our values and principles act as a framework for our decision making. They are at the heart of who we are and how we would like to be seen by our stakeholders.

Our values are:

- Patient and public centred
- Independent
- Fair
- Transparent
- Proportionate
- Outcome focused

Our principles are:

- Proportionality
- Accountability
- Consistency
- Targeting
- Transparency
- Agility

Right-touch regulation

Right-touch regulation means always asking what risk we are trying to regulate, being proportionate and targeted in regulating that risk or finding ways other than regulation to promote good practice and high-quality healthcare. It is the minimum regulatory force required to achieve the desired result.

¹ General Chiropractic Council (GCC), General Dental Council (GDC), General Medical Council (GMC), General Optical Council (GOC), General Osteopathic Council (GOsC), General Pharmaceutical Council (GPhC), Health Professions Council (HPC), Nursing and Midwifery Council (NMC), Pharmaceutical Society of Northern Ireland (PSNI)

Contents

1. Executive Summary	1
2. Introduction	3
3. Background	4
4. Examples from the health professional regulators	6
Surveys of patient and public views	6
Working with other organisations	6
Role playing and forum theatre	6
Reference and advisory groups	7
Information leaflets.....	8
5. What did we do?	9
6. Views on patient and public participation	10
Patients and the public.....	10
The regulators.....	10
Shared views	11
7. Five principles of effective participation	12
Principle 1: Be clear and focused	12
Principle 2: Use existing knowledge, networks and expertise	14
Principle 3: Make it easy for people to participate	15
Principle 4: Listen, act, and provide feedback.....	17
Principle 5: Make participation part of everyday business	17
8. Conclusions	19
9. Acknowledgements	21

1. Executive Summary

- 1.1 Participation by patients and the public is regarded as an essential aspect of healthcare regulation. Many regulators have built this into their constitution and governance structures and have adopted a wide range of practical approaches to allow participation. In our performance review of the health professional regulators for 2009/10, we said that we would identify the most effective methods and mechanisms for engaging patients and the public. This report presents our findings following a study of these activities amongst the regulators.
- 1.2 We gained the views of patients and the public by:
- Discussing the subject with those who attended our public meetings
 - Conducting a public survey through the CHRE website using a standardised set of questions
 - Speaking to people in more detail about their responses to the survey.
- 1.3 We also spoke to the health professional regulators to:
- Explore their organisational history of patient and public participation (PPP)
 - Hear about the initiatives that had worked well
 - Understand what benefits they felt their PPP work had brought to their organisation
 - Understand how they had evaluated its effectiveness.
- 1.4 We found that the regulators were carrying out a wide range of activities to allow the public and patients to participate in their work. Much of the work was carried out as part of a project, although there were a few examples of continuous involvement of patients and the public through advisory groups. A number of regulators were working towards embedding PPP in their everyday work.
- 1.5 Most regulators performed some form of stakeholder mapping to identify audiences, and to help focus their approaches. The regulators appreciated the fact that 'patients and the public' are not an homogeneous group, a view that was echoed by respondents to our survey.
- 1.6 Patients and the public who responded to our survey clearly stated what they saw as the benefits of allowing them to participate in the work of the regulators. They said that it fostered greater confidence in the regulator, made things simpler for everyone (by clarifying processes and procedures) and in some cases had initiated productive and ongoing relationships. Similarly, most of the regulators recognised the benefits of encouraging participation. These ranged from helping to develop policies, procedures and guidance which reflect the experience and needs of patients and the public through to improving public relations, staff development and wider organisational culture.
- 1.7 Formal evaluation of PPP work was not common amongst the regulators and most candidly admitted that they found this area difficult. Where evaluation had been carried out, it was normally as part of project evaluation which did not always consider the effectiveness of the patient and public element or whether broader project outcomes had been improved. Patients and the public who responded to

our survey said that they valued feedback or evaluation exercises once they had taken part and so the fact that this is rarely done suggests that robust feedback is difficult to provide on a routine basis.

- 1.8 We have listened to what the public and patients and the regulators have said about their PPP activities. From this, we have developed a set of principles for regulators to consider when planning and carrying out their PPP activities. These are:
- Be clear and focused
 - Use existing knowledge, networks and expertise
 - Make it easy for people to participate
 - Listen, act, and provide feedback
 - Make PPP part of everyday business.
- 1.9 These build on the principles of engagement outlined in the Report of the inquiry into children's heart surgery at the Bristol Royal Infirmary² and the practical examples of good practice outlined in the Joint Health and Social Care Regulators Patient and Public Involvement Group PPI Good Practice handbook.³

2 *The Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol*, Presented to Parliament by the Secretary of State for the Department of Health by Command of Her Majesty, July 2001. CM 5207(i)

3 Joint Health and Social Care Regulators' Patient and Public Involvement Group. 2010. *A PPI Good Practice Handbook for UK Health Care Regulators*. Available at: http://www.gcc-uk.org/files/link_file/PPI_Handbook_FINAL_17Dec10.pdf [accessed June 2011]

2. Introduction

2.1 Over the last few years, reforms to health professional regulation have increased the formal involvement of the public in the governance arrangements of individual regulatory bodies. The Councils of most regulators consist of equal numbers of public and professional members, in a clear and explicit move away from self-regulation of the professions. Alongside these formal developments in governance, the need to involve, engage and encourage the participation of patients and the public in the work of the regulators has been sustained. At CHRE, as the organisation charged with promoting the interests of patients and the public in this sector, we maintain a keen interest in the regulators' approach to this area of their work and the positive impact it can have on their role in public protection.

2.2 This paper reflects on recent work the regulators have done in the area of patient and public involvement. In the 2009/10 Performance Review, all of the regulators provided some evidence of activity. This varied between organisations, from the production of an information leaflet through to the commissioning of large pieces of focused research. Our 2009/2010 Performance Review of the health professional regulators identified the need for some further work:

The regulators now have greater public involvement in their governance arrangements and are actively involving public stakeholders in the design of their work. They are also seeking to overcome the challenges that achieving effective patient and public involvement incurs. It would, therefore, seem an appropriate time for CHRE to consider the most effective mechanisms for engaging patients and the public in the activities of the regulators⁴

2.3 In this analysis we have opted to take a broad interpretation of what may be considered examples of opportunities to involve, engage and encourage participation. This is often collectively referred to as patient and public engagement (PPE) or patient and public involvement (PPI). We have also emphasised the practice rather than the theory of these activities to meet our aim of sharing good practice and promoting learning between the regulators. For the purpose of this report we have opted to use the term patient and public participation (PPP) to cover this wide range of activity. The report looks at barriers that may stop people getting involved, discusses some examples of good practice, and considers how PPP may be planned and evaluated.

4 CHRE. 2010. *Performance review report 2009/10. Enhancing public protection through improved regulation*. London: CHRE. Available at: <https://www.chre.org.uk/satellite/311/> [accessed June 2011]

3. Background

- 3.1 Engaging with or involving the public and other stakeholders in the work of public bodies is a concept which has been in increasing use since the late 1990s. There is no single accepted model which is recognised as being the best but in the UK, stakeholder involvement and engagement is used in principle, to inform the planning, organising or funding of many aspects of public life.
- 3.2 Healthcare is no different and the absence of effective PPP in healthcare has been highlighted by a number of high profile incidents, reviews and inquiries, most notably that undertaken to investigate the management of the care of children receiving cardiac surgery at the Bristol Royal Infirmary between 1984 and 1995. The report of the inquiry set out the principles that should empower patients and the public in terms of healthcare provision. The recommendations were primarily aimed at NHS organisations but the Report also made it clear that those organisations that are not part of the NHS but have an impact on it – such as the Royal Colleges, the regulators of health professionals and services and CHRE – must also involve the public in their decision making processes.
- 3.3 Three of the guiding principles of engagement activities included in the Inquiry report were that these activities should be properly funded, evidence based and regularly evaluated. It is particularly important to demonstrate these principles equally because involvement is expected by patients and the public and they expect that their involvement will produce benefits. Correspondingly, many public organisations, including health professional regulators are increasingly seeking public and patient input but they need to ensure that this is effective, by making it evidence based, and that it provides good value for money.
- 3.4 All public bodies have a statutory duty to consult the public on aspects of their work and perhaps the most commonly used form of participation in the UK is public consultation. The health professional regulators are bound by different pieces of legislation which prescribe how they should consult on areas of their work and these requirements vary. These are complemented by statutory duties on NHS bodies to involve and consult patients and the public about the provision of healthcare services.
- 3.5 Public consultation is sometimes questioned, as there is a perception that only those groups that are influential are consulted with or listened to and the view is sometimes expressed that these exercises are used to co-opt the public to support decisions that have already been made. The concept of 'consultation fatigue' is also becoming apparent, resulting in a cycle of ever less representative views on a growing spectrum of issues.
- 3.6 Consultations are supplemented and complemented by other methods to promote PPP. Such as commissioned quantitative or qualitative research, online discussion forums, or deliberative citizens' juries. People may be asked for their views through customer service surveys or by becoming members of advisory groups.
- 3.7 Whatever the form and level of participation, to make an effective contribution, people need support to enable them to engage constructively. Timing of participation is important and good practice is to involve people early on and not

only after major decisions have been made and cannot be changed.⁵ Barriers to participation can arise when people's aims and interests differ so they are unable to see value in participating. Other barriers may emerge from the method and approach selected. People may not have the time to take part in activities when they occur during working hours and there is no remuneration for someone's time.

5 Joint Health and Social Care Regulators' Patient and Public Involvement Group. 2010. *A PPI Good Practice Handbook for UK Health Care Regulators*. Available at: http://www.gcc-uk.org/files/link_file/PPI_Handbook_FINAL_17Dec10.pdf [accessed June 2011]

4. Examples from the health professional regulators

- 4.1 Alongside the use of public consultations, the regulators have used a range of other methods and approaches in their work with patients and the public.

Surveys of patient and public views

- 4.2 The GOsC conducted a survey to explore what patients and the public expect from osteopaths. Participants were recruited by registrants and there was a good response rate (>50%). Because of the retail model of this profession, questionnaires were handed to clients at the end of treatment so that treatment time was not affected. The research results highlighted areas of concern, for example about communicating risks, adverse events and understanding the complaints processes. This has been used to inform various areas of policy, PPI strategy and revision of guidance and leaflets as well as informing the Council's research direction
- 4.3 Through surveys, the HPC became aware that older people, who have frequent contact with their registrants, had a low awareness of the work of the HPC. They held focus groups for older people, targeted events aimed at this age group, and conducted other research which has been translated into policy to raise awareness of their work amongst older people.

Working with other organisations

- 4.4 The GPhC worked with the Black Health Agency (BHA) in Manchester for one of their engagement events. The BHA enjoys well established links with other networks concerned with health in the North West of England and this ensured a good attendance at the event. The BHA helped the GPhC to develop the format of the day and facilitated a focus group of methadone users to ensure that their views were given sufficient time
- 4.5 The NMC worked closely with Mencap to develop a questionnaire that would allow people with learning disabilities to participate in the development of their standards for pre-registration nursing education. Mencap were regarded as the experts and developed a questionnaire that was relevant and accessible. This enabled the NMC and Mencap to harness the wealth of experience and knowledge of nursing care as experienced by people with learning disabilities, an opportunity that would have been lost if they had approached this in a 'traditional' way.

Role playing and forum theatre

- 4.6 Role playing was used by the NMC to allow people with moderate to severe learning disabilities to participate as fully as possible in their review of standards for pre-registration nursing education. A focus group was organised and led by a professional facilitator from Mencap. It made use of realistic scenarios – developed by Mencap – and role play using mock equipment such as bandages and drips to help participants remember, act out, and talk about their experiences

in hospitals. Photographs of nurses working in different settings were also used to help participants answer questions that related to different types of nurses, for example, learning disability nurses and nurses working on general wards.

- 4.7 The GMC has also used theatre to engage with people when reviewing their guidance on consent. They used an interactive theatre performance to engage people with dementia, their carers and doctors on issues relating to making decisions when a patient's capacity to consent may be impaired. The GMC worked with the Alzheimer's Society to ensure the play was realistic and to recruit people with dementia and carers to take part. This was cited by the GMC as a very good way to identify good practice by consensus. Subsequently, the GMC has used forum theatre as part of a consultative conference on end of life care and to involve people with learning disabilities, carers and doctors to help develop a website for doctors on treating patients with learning disabilities.

Reference and advisory groups

- 4.8 The GCC's Communications Advisory Group includes volunteer members of the public and a chiropractic patient representative. They work alongside representatives from professional organisations, chiropractic education and GCC council members to facilitate the GCC's communications strategy and to provide advice to the GCC's Council. The GCC reported that patient and public members' contributions are integral to the work and dynamic of the group. They actively and effectively participate, which encourages all members to be thoughtful and aware of each others' perspectives and interests. This balance has meant the Group achieves better outcomes.
- 4.9 The GOC and the GMC have established their own reference groups. For them this approach has the following benefits:
- Membership is independently and transparently recruited
 - Available for use at short notice
 - Consistent source of advice
 - Good value for money
 - Fixed term appointments kept advice fresh, whilst allowing members to develop knowledge and expertise in that area
 - Develops a pool of experts who can then be drawn upon for committee or working group membership
 - Most work carried out virtually
 - Serves as a 'sounding board', allowing rapid assessment of policy direction and validation of thinking.
- 4.10 Some drawbacks were highlighted: these groups were comparatively expensive to establish due to recruitment costs and require induction and guidance in the early stages of joining.

Information leaflets

- 4.11 The GOC described their proactive response to providing information to people with healthcare problems that may affect their eyesight, for example diabetes. They had recruited a company for three months to merchandise information leaflets in GP surgeries and pharmacies. These leaflets were made available at counters and in waiting rooms but a version was also produced that could be given to the patient upon diagnosis. The GOC are using this project as a tool to develop understanding of the work of the regulator amongst the public, but also ensured that the contract included an element of evaluation so that improved knowledge could be measured before and after the leaflets were distributed.

5. What did we do?

- 5.1 We wanted to compare the views of patients, the general public and the regulators themselves on regulators' activities in this area.
- 5.2 We used the information provided as part of our performance review as the basis for further investigation of the regulators' approach to opportunities for PPP. We conducted a semi-structured interview with each regulator to explore their organisational history of public and patient engagement along with the initiatives that had worked well, what benefits the regulators felt their work with patients and the public had afforded their organisation and how they had evaluated their work. We also spoke to the General Teaching Council England, the Independent Reconfiguration Panel, and Mencap in more detail about their experiences of engaging with the public and with the regulators of health professionals.
- 5.3 We discussed these issues with patients and the public who attended our meetings across the UK in October 2010. In these events topics were raised across a number of different areas of the regulators' activities including governance, reference and advisory groups, consultations, methods of engagement and organisational culture. Building on the feedback we received during our October 2010 meetings, we conducted a public survey through the CHRE website. This survey ran for a period of four weeks and was open to anybody visiting the CHRE website to complete. The survey was brought to the attention of the CHRE public stakeholder network inviting them to complete the survey and we are grateful to those who took part. A small number of people who had indicated on the web survey that they were happy to be contacted again, were interviewed in more detail by a member of CHRE staff.
- 5.4 The work was not based on a representative or statistically significant sample of patients and the public. The views of the public and patients gained through the web based survey are not necessarily representative of the UK population.

6. Views on patient and public participation

Patients and the public

- 6.1 Thirty seven people responded to our web based survey. Four of these were contacted directly by phone and interviewed further. The majority of respondents lived in England, five lived in Scotland, four lived in Wales and one in Northern Ireland.
- 6.2 Twenty five respondents reported that they had taken part in public and patient involvement activities. However, many of these were not with regulators and appeared to be interactions with providers of healthcare. Of those that had participated in engagement activity before, 22 said that they would do it again.
- 6.3 Among those respondents who had not been involved in any engagement activity, the main reasons they gave for not doing so were that they had not been invited to engage or a did not have the time. Other reasons given were a lack of faith that anything would change as a result of their participation or previous experience of poor responses to complaints to healthcare providers.
- 6.4 When asked when regulators should involve them in their work, the majority thought this should be as early as possible or when the regulators were considering options. None of the respondents thought that the public should be involved when decisions had already been made about what to do about an issue.

The regulators

- 6.5 Most of the regulators independently told us that they have a duty, statutory or otherwise, to engage with or involve members of the public, patients and other stakeholders. Most regulators conducted this through engagement activities although there were some examples of ongoing involvement.
- 6.6 Most regulators stated that they carried out some form of stakeholder mapping exercise during the development phases of a piece of work and this was felt to be helpful in identifying audiences, developing communications strategies and targeting messages. Not all regulators had a specific PPP strategy with most considering it as part of specific projects rather than seeing it threaded through everything that they do.
- 6.7 The regulators used a wide range of methods with which to engage with the public including websites, leaflets, commissioned research and surveys, focus groups, and written consultations. Some regulators described the creative ways in which they had worked to make it easier for people to get involved in their work.
- 6.8 It was generally accepted that engagement is not always easy. Attempts to open up council meetings to the public had not been met with the increased attendance expected and most of the regulators had revised and improved access to web based resources and information to counteract this. The time, resources, skills and experience available to regulators may also have an effect on the engagement that is undertaken.

Shared views

- 6.9 A common theme was that 'one size does not fit all' and that 'patients and the public' are not an homogeneous group. This was a view expressed both by the regulators and patients and the public who responded to our survey suggesting that approaches to participation need to be focused and tailored to suit both the audience and the issue being engaged upon. The regulators also expressed that NHS models cannot be readily transferred to the work of the regulators, a point which reinforces the need to be creative and innovative as well as considering the audience carefully during the planning phases of participatory activities.
- 6.10 Patients and the public who responded to our survey clearly stated what they saw as the benefits of allowing them to participate in the work of the regulators, stating that it fostered greater confidence, made things simpler for everyone and in some cases had initiated productive and ongoing relationships with the regulators. Similarly, most of the regulators recognised the benefits of encouraging participation. These ranged from helping to develop policies, procedures and guidance which reflect the experience and needs of patients and the public through to improving public relations, staff development and the culture of the organisation.
- 6.11 Formal evaluation of PPP work was not common amongst the regulators and most candidly admitted that they had identified this as an area for improvement. Where evaluation had been carried out, it was normally as part of project evaluation which did not always consider the effectiveness of the PPP element. Patients and the public who responded to our survey said that they valued feedback or evaluation exercises once they had taken part and so the fact that this is rarely done suggests that robust feedback is difficult to provide on a routine basis.
- 6.12 Following an analysis of these research results we identified five principles that should be used to guide participation activities across the regulators. These five principles are discussed in detail in section 7, illustrated with examples of the principles in action from the regulators' recent work.

7. Five principles of effective participation

- 7.1 Based on what we were told during this study, we have developed a framework of five principles that we think the health professional regulators should base their strategic and organisational approaches to PPP on. These are to:
- Be clear and focused
 - Use existing knowledge, networks and expertise
 - Make it easy for people to participate
 - Listen, act, and provide feedback
 - Make PPP part of everyday business.
- 7.2 These principles build on the information contained in the PPI Good Practice Handbook for UK Health Professional Regulators⁶ and can be cross referenced to the principles of good PPP set out in the Bristol Inquiry.
- 7.3 The following section expands upon these principles and gives practical examples of how some regulators are already implementing them.

Principle 1: Be clear and focused

- 7.4 The views and experiences of patients and the public should inform all areas of the regulators' work. However, in practice this could quickly become unwieldy and unproductive if regulators tried to engage on all aspects of their work, so taking a proportionate and targeted approach is useful. Therefore there is a need to provide a clear focus on the subject under discussion so that participation is meaningful and of value. One of the respondents to our survey gave us an example from their experience that illustrates the potential pitfalls of failing to be focused in participation: A healthcare provider established a multidisciplinary maternity services panel and recruited patient and public members. The average age of the representatives was 72 years. Whilst these participants undoubtedly had good experience of healthcare systems, their experience was unlikely to be directly relevant to the business of the panel.
- 7.5 The public and patients who responded to our web survey expressed their frustration with unfocused opportunities. On some occasions, this was because their particular issue of interest or concern was not given enough consideration, reiterating the need for regulators to be clear at an early stage about the scope of the work. Respondents to the survey highlighted the fact that consultations were often thought to lack focus and were unclear about what was required from patients and the public and this discouraged people from responding.
- 7.6 There is a need to balance clear and focused work with encouraging participation. Methods to do this may include improving organisational knowledge of engagement, so that thinking begins at the early stages of work (see Example 1) or formalising this approach to form a detailed engagement assessment and

6 Joint Health and Social Care Regulators' Patient and Public Involvement Group. 2010. *A PPI Good Practice Handbook for UK Health Care Regulators*. Available at: http://www.gcc-uk.org/files/link_file/PPI_Handbook_FINAL_17Dec10.pdf [accessed June 2011]

action plan similar in approach to conducting an Equality Impact Assessment. The potential benefits of this approach are described in Example 2.

Example 1: Engagement Toolkits

- To help their staff think about PPP when developing a piece of work, the GMC have produced a comprehensive Engagement Toolkit. This resource outlines their approach to engagement and provides guidance on methods of stakeholder mapping and involvement, policy development, methods of consultation and communications activity. It also includes checklists and tips to help plan and evaluate PPP activity. The GOC has a Consultation Framework, recently revised in collaboration with its reference group that acts as a how-to guide for staff involved in consultations. This includes planning consultations, groups to target, methodology, patient public involvement and using the consultation feedback

Example 2: Engagement analysis

- During several interviews, parallels were drawn between the early stages of engagement and the general duty to ensure equality in policy development, usually in the form of an Equality Impact Assessment. The potential benefits of this approach are that it provides a framework for regulators that:
 - Ensures that the organisation systematically consider the needs of patients and the public
 - Is an effective way of improving policy development and service delivery
 - Facilitates evidence-based, modern policymaking
 - Provides an audit trail of organisational thinking
 - Allows an early opportunity for evaluation
 - Allows efficiency savings through more effective services.

7.7 All of the regulators stated that they used a process of stakeholder mapping or similar analysis early on in the process to identify likely audiences and participants. Although the regulators approached this in different ways, the intended aim of such exercises was essentially the same; to get the right people involved to get a high quality input. This process then allowed them to tailor their messaging and communications strategies. Regulators who had access to reference groups were able to use them to rapidly review such plans and provide suggestions for change and this resulted in a more focused and relevant approach.

7.8 Following stakeholder analysis, some of the regulators identified particular groups of people who needed to be targeted during the course of a piece of work. Regulators stated that this could sometimes be difficult to achieve. However, there as we report in section 4 there are examples of how productive work has been carried out. This could also be done by tapping into existing networks (see Principle 2).

Principle 2: Use existing knowledge, networks and expertise

- 7.9 The value of using existing knowledge, networks and expertise was cited frequently both by regulators and patients and the public alike. There are many groups who have a wealth of views and experiences that can be used by regulators to inform their policy and strategy. These groups have a good understanding of other networks and also have local or specialised knowledge. Further benefits of working with other organisations include that people feel more comfortable in familiar groups and environments meaning that they have more opportunity to contribute and that the quality of their input may be more valuable. This was seen in the examples from the GPhC and the NMC above.
- 7.10 Existing expertise can be used in other ways. For example, we heard about organisations such as the Patients Council, based in the North West of England, who have developed specific services such as Patient Focused Proof Reading and patient surveys to assist collaborative working and understanding between providers of healthcare and patients and the public. They provide training and support to their representatives and can tailor patient and public contributions according to the needs of organisations.
- 7.11 There are rich sources of people's experiences freely available and some of the regulators described how they were analysing passively collected sources of information for trends. Examples were providing 'live feeds' of trends derived from complaints into the policy and communications departments. Other examples include the database created by The Health Experience Research Group of personal and patient experiences through in-depth qualitative research into over 40 different illnesses and health conditions, the results of which are published on two websites:
- www.healthtalkonline.org deals with adult experiences
 - www.youthhealthtalk.org deals with children's' and young peoples experiences.
- 7.12 These websites are aimed at patients, their carers, family and friends, doctors, nurses and other health professionals. The information is of high quality and is specifically aimed at assessing and presenting the patient experience and perspective. Some of this information is directly relevant to the work of the regulators. For example, there are valuable opinions on nursing care and receiving information and news from doctors when somebody is living with a particular condition or illness. These could prove useful in the scoping phase of projects or when reviewing standards.
- 7.13 Most regulators who had carried out research, surveys or other studies had used third party organisations to do this. This was thought to have advantages over conducting research in-house because it was easier to demonstrate an objective and independent approach to the research and meant less pressure was exerted on internal resources. These agencies also helped to shape the content and methodology of the research and, crucially, allowed the regulators to build in elements of independent evaluation and feedback into their research contracts.
- 7.14 Specific pieces of qualitative and quantitative research were described by a number of regulators ranging from exploring the expectations of patients to very specific pieces of research on a particular subject. The results were used in

different ways, mainly to inform policy and the content of standards and guidance. Because regulation of health professionals is a niche area, research projects such as these add to the evidence base that the regulators can use to build an effective patient and public engagement strategy. Regulators should share these data with each other to identify transferable themes or evidence and also consider collaborations when they identify issues that are common to their respective organisations, for example, when trying to capture the views of seldom heard groups.

Principle 3: Make it easy for people to participate

- 7.15 Participation must be possible in all areas of the regulators' work. Many regulators were of the view that patients and the public were not qualified to, or would not be interested in, participating in certain aspects of their work, with fitness to practise and registration frequently cited. The reasons given were that the content was often too technical or specialised.
- 7.16 To a certain extent, this was echoed in comments from members of the public who expressed frustration at the use of jargon and technical terms during consultations and engagement events. One member of the public we interviewed felt that it could be damaging to allow public and the patients who were not experienced enough to participate in such activities as this allowed organisations to 'tick the engagement box' without receiving a considered view. However, one person who responded to our web based survey made the comment that the regulators should never presume what people may, or may not, want to participate in.
- 7.17 Consultations were often cited as a poor example of engagement. This was felt both in terms of their detailed content and sheer frequency, but also because they were either too restrictive in what they asked for or were too expansive in terms of content and detail, ie, they lacked focus. Some of the regulators reported disappointing returns to consultation exercises that they had clearly invested significant resources in. Respondents to our survey also said that they may only want to provide high level suggestions in the early stages of participatory work with an expectation that the regulator would take this away and act upon it. For example, in response to a consultation on professional standards a patient may only want to say 'I want to be treated with respect.' The onus is then on the regulator to take this comment away and ensure that, not only is it reflected in the standard, but that measures are put in place to ensure that this is translated into practice.
- 7.18 Patients and the public clearly want to participate and regulators need to facilitate this, even where they feel this may be difficult or potentially unproductive. The examples of the use of role play and theatre above highlight one way the regulators have tackled this issue. Another approach for consultations is described in Example 3, below. Responses to our web survey independently highlighted this as a welcome approach which allowed people to participate more readily.

Example 3: Shortening or personalising consultations

- The GMC told us that by summarising consultations and asking a short series of high level questions they had seen better quality responses. This approach allows patients and the public to quickly gain a good understanding of the

issue and provide their views without having to read the detail of the document (although they could do so if they so wished). The GMC also regularly develop discussion guides specifically to support patient and public participation in consultations. These are used at focus groups and consultation events, and are sometimes cascaded through established networks to encourage wider participation.

- The PSNI stated that when possible, they personalise consultations by addressing them to individuals. These approaches have generated much better responses and also allow the Society to evaluate uptake and response rates.

7.19 Regulators could also consider ways in which to develop the knowledge and skills of patients and the public. There is evidence from PPP activities in healthcare provision that developing knowledge promotes participation and improves outcomes. This was raised by a number of respondents to our survey who said that the public should be trained and supported so that they could develop expertise and understanding in particular areas. Most of the regulators had approached this by increasing accessibility to their website, providing leaflets and ensuring that participants were fully briefed before engagement events. Two of the regulators with reference groups described the ways in which they were investing in these groups and are described in Example 4.

Example 4. Support and training for reference groups.

- The GOC and GMC described how they provide comprehensive induction programmes and give detailed briefings on specialised areas such as revalidation or fitness to practise to their reference groups. The GMC has experimented with seminars by mixing of members from their public and professional groups to promote debate and learning. The GOC encourages reference group members to take on other roles in the organisation after their appointment term has finished. The GOC hopes that this will encourage longer term partnerships.

7.20 Making participation easier is not just about improving the provision of information. Respondents to our survey said that they preferred face-to-face meetings and that events should be held locally as far as possible. Regulators had tried to do this by holding council meetings around the country but reported that these tended to be poorly attended. Two regulators were experimenting with the use of webcasts of council meetings so that people could participate without having to travel. However, this approach may not apply to all participation activities.

7.21 Sometimes it is simply that people are unaware of opportunities to get involved. This suggests that opportunities to participate, in events and consultations need to be promoted more widely, or through existing networks such as reference groups. One respondent stated that they were busy at work and also providing care for a relative but, had they been given more notice, they would have been able to make arrangements to attend.

7.22 There are wider benefits to raising awareness of opportunities to participate. The GPhC highlighted the benefit of encouraging staff and council members to get

involved both as a way of promoting the understanding and benefits of PPP throughout their organisation but also as a personal development opportunity.

Principle 4: Listen, act, and provide feedback

- 7.23 Developing opportunities for people to get involved and share their opinions and experiences is essential preparatory work. Once people are engaged and willing to participate, it is important not to overlook the need to hear and understand what people have to say. Listening to people, respecting their views and engaging in a respectful and open manner is vital for success. It helps to demonstrate the value placed on the contribution made by participants, and it influences people's confidence in the process.
- 7.24 Once people have participated and regulators have acted on what they have heard, providing feedback to participants, particularly on what had been done with their contribution, is vital. This was a consistent theme in responses from patients and the public. It encouraged people to become involved again in the future if they were provided with feedback that described how their input had been used.
- 7.25 The regulators we spoke to suggested that this can be difficult in practice because many of the documents they consult upon are high level and cannot make reference to this kind of detail. However, they were able to demonstrate how they had taken people's views into account by publishing a consultation response analysis explaining how comments had been used or providing a rationale where responses had not been accommodated.
- 7.26 However, feedback does not always need to be formal. Patients and the public told us about examples which made them feel that their voice had been heard, particularly if this was personalised in some way. These included text messaging after events saying thanks and letting people know what would happen next, mentioning names in documents and/or attributing comments or changes to individuals.

Principle 5: Make participation part of everyday business

- 7.27 The majority of regulators reported that they carry out PPP as part of a specific project and do not regard it as everyday business. In practice, opportunities for patients and the public to participate arose as needed by regulators. With the exception of those organisations that had access to a reference group there were no real examples of continuous participation.
- 7.28 However, some regulators described how they were working towards embedding PPP in everything that they do so that it was regarded as an integral part of their business and not seen as an element of project-based work. They had done this by reviewing their existing strategy and developing ways of evaluating progress in the form of indicators or other measures. By reporting in this way, regulators can measure their progress over time and make informed plans for future developments. Some regulators described how they were analysing trends in complaints and enquiries and feeding these into policy areas or responding with research.

Example 5: GDC review

- The GDC recognised that its communications and engagement strategy lacked emphasis on patient and public communications activity. Although they had developed a patient leaflet and developed their website, their approach to involvement was uncoordinated and not based on agreement on a set of fundamental principles and aims. They developed a set of aims, namely to embed involvement in their approach to regulation and in their strategic planning and project development process. Evaluation was regarded as an integral part of this and one way of doing this was to implement an annual survey of the public and patients. This would gather a standardised set of data which would allow the GDC to benchmark progress against issues such as awareness of the GDC, the most effective ways for GDC to communicate and the most important factors that contribute to confidence in dental professionals. In addition, a series of bespoke questions could be used to gather information on issues related to regulatory or policy issues where input from patients and the public is needed. The key findings from the survey will be drawn upon as part of the GDC business planning processes and will be used to evaluate and develop the involvement activity plan as part of the Communications and Engagement Strategy.

- 7.29 Continuous engagement, for example through regular meetings, sharing business plans with important stakeholder groups, developing strategy in conjunction with stakeholders can be done regularly and allows early input to shape policy and ideas as well as identifying novel approaches to engagement.
- 7.30 Many people and organisations may wish to engage but only at a high level. For example, rather than providing detailed responses to specific parts of standards, stakeholder groups may wish to express an expectation that Fitness to Practise standards are applied equitably and that the regulator needs to take steps to ensure that this happens and also demonstrate that this happens. The onus is then on the regulator developing those standards to ensure that such comments are reflected in the detail of the standards and in the way in which they are applied during hearings. Potential benefits are that policy and direction are shaped early on in the process and engagement can be more focused and productive later on in the process.

Example 6: GMC evaluation of its Reference Community

- The GMC has evaluated the impact of its reference group, known as the Reference Community. The evaluation drew on the views of GMC staff, members of the Reference Community, and information about the set up and running costs. As well as offering value for money, the GMC found that the Reference Community was a useful sounding board, particularly early on in the policy development process, to test views and validate thinking on issues. It was useful as a source of public views on sometimes technical issues, and also in situations where deadlines might be tight.

8. Conclusions

- 8.1 The overriding aim of health professional regulation is public protection. Given this, it is essential to develop effective, productive and useful opportunities to learn from the experience of patients and the public and to gather their views and opinions on issues relating to regulation and the quality of care. There are many ways this can be achieved. Learning from previous experience allows us to focus on good practice, begin to identify what works and understand how participation may be widened.
- 8.2 The CHRE Performance Review asked us to look ‘at any current barriers to achieving wide representation of views, what mechanisms have worked well so far for the regulators and the impact that effective public and patient involvement can have on the performance of the regulators.’⁷ The health professional regulators have told us about the wide range of activities they have adopted to allow members of the public and patients to participate in their work. They have told us what has worked well but also, told us about what they have found difficult and the ways in which they have worked around these challenges. While there has been progress in evaluating the impact of participation in individual projects – as seen in section 4 – there is less evidence around the impact the delivery of wider regulatory functions. Patients and the public also told us what they see as ‘good’ ways to participate and they also told us what frustrated them and stopped them from getting involved in engagement work.
- 8.3 We have listened to these views and proposed five principles for effective PPP that we think will help the regulators develop their existing approach:
- Be clear and focused
 - Use existing knowledge, networks and expertise
 - Make it easy for people to participate
 - Listen, act, and provide feedback
 - Make PPP part of everyday business.
- 8.4 Following our review, we are encouraged by progress in this area. There are evident benefits to regulation of well-designed opportunities to hear the views of patients and the public and using these to improve policy and practice. We think that the regulators should build on existing expertise and knowledge and continue to learn from each other, and from the experience of patients and the public. In practice this could include collaboration and cooperation where feasible, to add to the evidence base upon which future activities can be based and evaluated.
- 8.5 Building on experience across the sector, regulators should continue to move from solely engaging when needed to an approach that balances these opportunities alongside other methods that allows them to continuously listening to patients and the public. Regulators should also think about how they evaluate their engagement with patients and the public in terms of effectiveness and value for money. This should be considered, not simply as part of a project, but also in

⁷ CHRE. 2010. *Performance review report 2009/10. Enhancing public protection through improved regulation*. London: CHRE. Available at: <https://www.chre.org.uk/satellite/311/> [accessed June 2011]

terms of the wider impact that patient and public participation has on the delivery of their regulatory functions.

9. Acknowledgements

We are grateful to everyone who contributed their time, views and experience to help us with this project, including

- Those who attended our meetings in Belfast, Edinburgh, London, Manchester and Taff Wells in October 2010 to share their views with us on this subject. Their views and experiences helped to shape the online survey and interviews we carried out in early 2011
- To everyone who responded to our web survey and provided their views
- To colleagues in the regulatory bodies and other organisations who were interviewed as part of this study.

Council for Healthcare Regulatory Excellence
157-197 Buckingham Palace Road
London SW1W 9SP

Telephone: **020 7389 8030**
Fax: **020 7389 8040**
Email: **info@chre.org.uk**
Web: **www.chre.org.uk**

© CHRE July 2011

