Communications Committee 8 November 2011

# Service user engagement – update and review

## Executive summary and recommendations

### Introduction

This paper will update the Communications Committee on the service user engagement work currently being undertaken by the Executive. It will examine the work of the other health and social care regulators and the recommendations made by the CHRE in its recently published report ‘Patient and public participation in health professional regulation’. The paper also outlines the Executive’s next steps.

### Decision

The Committee is invited to discuss the attached document.

### Background information

See paper.

### Resource implications

There will be some resource implications arising from the workplan, in particular Executive time to carry out identified activities. This work will be completed using existing resources within the Communications Department.

### Financial implications

There are no financial implications in 2011-12

### Appendices

- Appendix 1: Health and Social Care regulators and stakeholder organisations involved in patient and public engagement
- Appendix 2: Patient and public participation in health professional regulation, CHRE report, July 2011

# Service user engagement – update and review

## Introduction

1. This paper provides an update for the Communications Committee on the service user engagement work currently being undertaken by the Executive. It examines the work of the other health and social care regulators and the recommendations made by the CHRE in its recently published report 'Patient and public participation in health professional regulation'. The paper also outlines the Executive's next steps.

## Background information

2. Engaging with or involving the public in the work of public bodies is a part of a wider social movement which has gathered momentum over the last few decades. Patient and public involvement, certainly within the context of the NHS and social care, has been widely adopted as a way of ensuring that people who use services are active participants in designing and delivering care.

3. Within the context of health and care regulation, the implementation of patient and public involvement is slightly more challenging as regulators are removed from the point of delivery of care. However, recent policy directives have led to an increase in the formal involvement of the public in governance arrangements as well as a commitment to adopting models of patient and public involvement as part of the regulatory process. This has been evidenced in White Papers, reports and Department of Health initiatives, in particular:

    - The 2007 the White Paper 'Trust, Assurance and Safety – The regulation of health professionals in the 21st century' advocated greater patient and public involvement[1] and stated that regulators should give a 'clear assurance about their overriding commitment to patient and public interest'.

    - A number of workstreams were established by the Department of Health after the publication of the 2007 White Paper. One of them looked at ways to enhance public confidence in regulation. Niall Dickson's 2008 report 'Enhancing confidence in healthcare professional regulators' stated that 'all healthcare regulators should continue to participate in the joint Regulators' PPI Group and each regulator should have an agreed set of arrangements which demonstrate that they are actively engaged with and involving patients and the public'.[2]

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[1] Department of Health, 'Trust, Assurance and Safety – The regulation of health professionals in the 21st century', 2007: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_065946

[2] Niall Dickson, Enhancing confidence in healthcare professional regulators, June 2008: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085162

- Furthermore, the Department of Health's 2009 report on 'Extending professional and occupational regulation' referenced the importance of involving patients, public and employers in decisions about regulation.[3]

## Context and understanding

4. The Committee will note that different organisations and individuals use a myriad of ways to describe their engagement or involvement with the public, for example patient and public involvement, patient and public engagement, patient and public participation.

5. The three main terms used seem to be 'involvement', 'engagement' and 'participation', all of which have different implications. Involvement can also take many forms and be done in many different ways and there are a number of levels at which service users can be involved in the development and delivery of services so it may be helpful to consider Amstein's ladder of involvement. This model can be used to identify the different levels and types of involvement that can be used by an organisation in its PPI activities.

## Ladder of participation[4]

| | |
|---|---|
| **FULL CONTROL:** | Service users control decision making at the highest level. |
| **SHARING POWER:** | Service users share decisions and responsibility, influencing and determining outcomes. |
| **PARTICIPATION:** | Service users can make suggestions and influence outcomes. |
| **CONSULTATION:** | Service users are asked what they think but have limited influence. |
| **INFORMATION:** | Services users are told what is happening but have no influence. |
| **NO CONTROL:** | Service users are passive consumers. |

6. For this paper, and to maintain consistency across documents, reference to the HPC's patient and public involvement activity is referenced as service user engagement. In this context, service users include those who use or have an interest in the services the HPC provides (eg members of the public) and those who use the services of someone we regulate or may regulate in the future.

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[3] Department of Health, Extending professional and occupational regulation, July 2009: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_102824

[4] Service user involvement: best practice guide, Ladder of participation: http://www.serviceuserinvolvement.co.uk/whatisit_laderOfP.asp?id=1

## Patient and public participation in health professional regulation – the Council for Healthcare Regulatory Excellence's (CHRE) perspective

7. In 2010-11, CHRE undertook a study of all the health regulators to identify the most effective methods and mechanisms for engaging patients and the public. They spoke to health regulators, patients and members of the public to gain their perspectives and hear about initiatives that had worked well in order to understand more about the benefits, evaluation methods and organisational history of patient and public participation in health regulation.

8. The resulting 2011 report 'Patient and public participation in health professional regulation' provided examples of public and patient involvement (PPI) from the health regulators, set out views on PPI from both the public and the regulators and reached a number of conclusions.[5]

9. The report noted that participation by patients and the public is regarded as an essential aspect of healthcare regulation and found that many regulators have 'adopted a wide range of practical approaches to allow participation'.[6] A full copy of this report accompanies this paper.

10. It also highlighted that much of the patient and public involvement (PPI) work was carried out on a project basis although there were some examples of continuous involvement through advisory groups and a number of regulators working to embed PPI in everyday work.

11. In the report, the CHRE also highlighted the benefits as perceived by the public and regulators, for example fostering greater confidence in regulation, making things simpler and helping to develop policies, procedures and guidance and identified that evaluation of PPI work was not common amongst the regulators except in cases where it had been part of project evaluation.

12. In reaching its conclusions, the CHRE made a number of recommendations for health regulators. These include:

    - introduce stakeholder mapping to identify likely audiences and participants;
    - involve patients and the public as early as possible;
    - introduce specific patient and public engagement strategies.
    - evaluate engagement activities in terms of effectiveness and value for money; and
    - introduce methods which allow regulators to continuously listen to patients and the public.

13. It has also developed a set of principles for regulators to consider when planning and undertaking patient and public engagement activities. These are:

    - be clear and focused;
    - use existing knowledge, networks and expertise;

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[5] Appendix 2: CHRE, Patient and public participation in health professional regulation, July 2011

[6] CHRE, Patient and public participation in health professional regulation, July 2011, p.1 http://www.chre.org.uk/satellite/282/

- make it easy for people to participate;
- listen, act and provide feedback; and
- make patient and public engagement part of everyday business.

14. Finally, the 2010-11 CHRE's 2010-11 performance review of the health regulators set out that the key areas of involvement are standards and guidance development and those areas which appear less easy to encourage involvement are fitness to practise and registration. The CHRE also noted in the review that in general the regulators approaches to patient and public involvement are targeted at the most appropriate groups. [7]

## Current position and work at the HPC

15. The HPC has been committed to the importance of service user engagement and awareness in its work since its inception and our statement of intent clearly sets out our activities related to this. The statement was approved by the Communications Committee in February 2010 and is on our website.[8]

16. Following the publication of the CHRE's report, the Communications Department has noted the conclusions, and drawing on the joint regulators' patient and public involvement group's 'a PPI good practice handbook for the UK health care regulators[9]' has undertaken a piece of work to review the HPC's current service user engagement activity. This activity is summarised in the paragraphs below.

17. In the good practice handbook a number of methods and approaches to public involvement are suggested. These include: exhibitions; leaflets and written documents; the press; citizens' panels; open surgeries; patient diaries; radio or live phone-ins; questionnaires; semi-structured one-to-one interviews; focus groups; meetings with patient and carer groups; public meetings; seminars; targeting interested people; citizens' juries; health panels; community development; and large group processes.[10]

18. The following information outlines the type of service user engagement work we currently undertake and provides an additional update to the activities set out in the published statement of intent.

19. **Joint regulators PPI seminar series** – the HPC has been actively involved in these good practice seminars which involve advocacy groups and patient representatives in discussion on what more regulators could be doing to enhance involvement. To date, the HPC has hosted three seminars, for people with communication disabilities, older people and people who use mental health services.

20. **Joint regulators PPI group** – the HPC has been a member of this group since its inception 6 years ago.

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[7] CHRE performance review 2010/11, p26 and p7: www.chre.org.uk/satellite/402
[8] HPC website, About us, Working with stakeholders: http://www.hpc-uk.org/aboutus/stakeholders/ppi/
[9] A PPI good practice handbook for UK health care regulators, updated October 2010: www.hpc-uk.org/assets/documents/100032B6A_PPI_Good_Practice_Handbook_for_UK_Health_Care_Regulators.pdf
[10] A PPI good practice handbook for UK health care regulators, updated October 2010, Appendix 1.

21. **Targeted campaigns** – the continuation of the ‘Be Healthwise’ campaign which is aimed at older people and their carers continues to raise awareness of the HPC through attendance at public facing events. This campaign was devised following focus groups and interviews with older people, their carers and managers of care homes. We recently ran a media broadcast campaign designed to raise awareness of the protected title ‘physiotherapist’ and this was developed using online research with members of the public.

22. **Meetings with patient and carer groups, questionnaires, focus groups and one to one interviews** – we regularly use service user feedback to inform our work.

23. For example, we have recently undertaken a series of meetings with public and client facing stakeholder organisations to inform our communications workplan for the transfer of social workers in England, and we have written to organisations, individuals and patient groups with an interest in what we do for the current consultations on draft standards of proficiency for social workers in England and the threshold level of qualification for entry to the Register for social workers in England.[11]

24. The Policy and Standards Department has commissioned two pieces of research to look at service user involvement.

    - The first is a project looking at service user involvement in the design and delivery of education and training programmes leading to registration with the HPC and to assist the HPC in reaching conclusions about whether service user involvement might be more explicitly required as part of our Standards of education and training and supporting guidance. This research is being undertaken by Kingston / St George’s (University of London) and the results of the project are due to be considered by the Education and Training Committee in March 2012. The research approach includes a literature review, case studies, an online survey with higher education institutions, and a consensus workshop with key informants.

    - The second project will be undertaken by the Picker Institute Europe and looks at service user feedback tools for the HPC and how they might be used to contribute to improved professional practice. This research falls under our work on revalidation and has been funded through a Department of Health grant. The results from the research are due to be considered by the Council in December 2011. The research approach for this project includes a literature review, leading to recommendations.

25. The Fitness to Practise Department has commissioned Ipsos MORI to undertake several user-focused pieces of work. The first focused on the expectations of complainants and the second on user and registrant perceptions of the use and value of mediation in regulation. The first project led to changes in the HPC literature and the production of an online DVD about the fitness to practise process, as well as greater insight into the challenges of making a complaints process more accessible. The second project is ongoing and Council, at its October meeting, approved a pilot mediation programme.

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[11] Current consultations, HPC website: http://www.hpc-uk.org/aboutus/consultations/

26. In July 2011 the Communications Department commissioned Ipsos MORI to undertake public and registrant opinion polling. As part of this we have polled members of the public and held focus groups with service users and members of the public. The findings of this work will be reported to the Communications Committee at this meeting and will be used to inform strategies and workplans.

27. **Conferences and exhibitions** - as part of our public facing work we regularly attend conferences with a public focus. For example, Naidex (Glasgow and London), which is a disability and rehabilitation exhibition open to members of the public and professionals. At the most recent event in London we had approximately 500 visitors to our stand including service users and members of the public. We also attend Citizens Advice conferences and from our recent attendance at the Citizens Advice Scotland conference, where we had a stand, we have developed an e-learning toolkit for advisers. This provides information about our public protection role, standards and how to raise a concern.

28. **Leaflets and written documents** - standards and guidance are available at our exhibitions and events and public information material is distributed to GP surgeries twice per year. We are committed to using the Plain English Crystal Mark and relevant publications are run through the Plain English process to ensure accessibility, for example this year two new publications ('An introduction to our education processes' and 'Who regulates health and social care professionals') were awarded the Plain English Crystal Mark. An Easy read version of 'How to make a complaint' has recently been published - HPC commissioned a group with expertise specialising in developing accessible information and which involved people with learning disabilities in the design of the leaflet.

29. **Press** - we liaise with the press on a daily basis, responding and issuing statements where relevant. This allows us to be open and transparent as an organisation and in turn assists us in informing the general public about our role as a regulator.

## Review of work by other organisations

30. The CHRE report highlighted examples from the health regulators, for example the General Osteopathic Council's survey which explored what patients and the public expect from osteopaths, the General Pharmaceutical Council's work with the Black Health Agency in Manchester for an engagement event, the NMC and GMC's use of forum theatre to review standards and guidance and the General Chiropractic Council's use of volunteer members and a patient representative in their Communications Advisory Group.

31. Many of the other UK regulators are also involved in the joint regulators' patient and public involvement group, attending meetings and regularly participating in the good practice seminars.

32. The Communications Department has also identified further examples of work undertaken on patient and public engagement by the other regulators and full details of this are set out in Appendix 1**.**

## Conclusions

33. The CHRE report concludes that ‘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’. It also notes that ‘there are many ways this can be achieved.’

34. There is not one standard approach amongst the UK health regulators surveyed by the CHRE. Each has adopted a different approach and applied a different range and level of resource to their activities. It is, therefore, difficult to draw conclusions or benchmark HPC’s activities against the other regulators, however, the Executive is committed to proportionate service user engagement activities which will improve knowledge and understanding of the HPC and provide greater confidence in the regulator.

## Workplan

35. In addition to the activities set out in the statement of intent and the work currently being undertaken within the Policy & Standards, Fitness to Practise and Education Departments, the Communications Department has identified a number of additional initiatives to take forward.

36. These are set out in the workplan overleaf.

| Main activity | Description | Lead | Timescale |
|---|---|---|---|
| **Undertake mapping of UK-wide advocacy and patient groups (as part of stakeholder mapping work) and continue to develop relationships** | • identify key groups<br>• ensure consultation list continues to be up to date (Policy)<br>• provide information where relevant<br>• seek meetings where relevant | Mark Potter | To be incorporated into the 2012-13 communication workplan |
| **Update dedicated pages on the website** | • review the current 'members of the public' section on the website ensuring relevant information about how to get involved is included, for example consultations | Sarah Oliver | By end January 2012 |
| **Consider the development of a service user engagement toolkit for employees** | • Research and develop ideas | Ebony Gayle | To be incorporated into the 2012-13 communication workplan |
| **Update Statement of intent** | • Review content, make recommendations and update | Sarah Oliver | By end November 2012 |
| **Consider specific project work Including:**<br>**• Service user engagement in the review of Standards of conduct, performance and ethic**<br>**• Engagement with social work service users** | • Discuss with Director of Policy and Standards<br>• Agree scope<br>• Incorporate as relevant into 2012-13 workplans | Jacqueline Ladds<br>Michael Guthrie | By February 2012 for inclusion in the 2012-13 workplans |

## Appendix 1: Health and Social Care regulators and stakeholder organisations involved in patient and public engagement

### General Chiropractic Council (GCC)

1. The General Chiropractic Council (GCC) has a Communications Advisory Group which is made up of volunteer members of the public and a chiropractic patient representative. Their role is to facilitate the GCC's communications strategy and provide advice to the GCC's Council.

2. The CHRE noted in their performance review for 2010/11 that the GCC now require education providers to produce evidence of involvement of patients and carers in the review and delivery of education programmes and in the teaching and assessment of students.[12] This provides patients and carers with the opportunity to influence the education and training of student chiropractors with their needs.

### General Dental Council (GDC)

3. The General Dental Council (GDC) – published a paper entitled 'Communications and Engagement Strategy Development – PPI'. The GDC's engagement strategy states that all projects must include a clear engagement plan at the outset to identify how and when the GDC will engage, the purpose of that engagement and with whom it should be undertaken. They also aim to involve patients and the public as early as possible. The GDC plan to undertake annual surveys of public and patients to gather a standardised set of data. This will enable them to benchmark progress over time.[13]

4. The GDC have dedicated webpages for members of the public, where members of the public can access information about the GDC including fact-sheets and leaflets.[14]

5. In the CHRE performance review 2010/11 the CHRE note that the GDC have amended their approach to patient and public engagement and are moving towards a system which will target engagement activities for each piece of work it undertakes at the most appropriate groups.[15]

6. The GDC have also consulted on a draft version of its 'Principles for ethical advertising' publication and have undertaken a piece of reach to focus on patient and public attitudes to inform the guidance.[16]

7. The GDC have tried to improve registrants understanding of fitness to practise processes and learning which has arisen from cases through articles in their newsletter.[17]

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[12] CHRE performance review 2010/11, p 8
[13] CHRE, Patient and public participation in health professional regulation, July 2011, p.18
[14] GDC website: www.gdc-uk.org/Membersofpublic/Pages/default.aspx
[15] CHRE performance review 2010/11, p 36
[16] CHRE performance review 2010/11, p 38
[17] CHRE performance review 2010/11, p 44

## General Medical Council (GMC)

8. The General Medical Council (GMC) have established their own reference groups and communities for consultations and policy reviews. They have also used theatre to engage with people when reviewing their guidance and to communicate with hard to reach groups, such as people with dementia, learning disabilities, their carers and doctors.[18]

9. They have produced a comprehensive engagement toolkit to help staff think about patient and public participation (PPP) when developing work.[19] The resource outlines their approach to engagement and provides guidance on methods of stakeholder mapping and involvement, policy development, methods of consultation and comms activity. It is also includes checklists and tips to help plan and evaluate PPP activity.

10. The GMC have noticed better quality responses to their consultations since they have begun summarising consultations and asking a short series of high level questions.[20] They have also developed discussion guides to support patient and public engagement in consultations.

11. The GMC have set up a working group to produce new guidance on child protection. As part of this the working group have held oral evidence sessions to gather evidence from a wide range of groups representing parents' and family interests; including Roma, black and ethnic minorities, disabled children and parents.[21]

12. The GMC have also created draft guidance for education providers on patient and public involvement in the quality assurance of education providers which outlines key principles relevant to them.[22]

13. As part of its consultation work on revalidation the GMC held eleven events across the UK which concentrated on patient and public views.[23]

14. The GMC have dedicated webpages for patients and the public which hold links to consultations, polling and other opportunities for patients and the public to have their say.[24]

## General Optical Council (GOC)

15. The General Optical Council (GOC) have standing Stakeholder Reference Groups (one made up of patients and public, one of optical stakeholders) who give advice, and suggestions on projects and policy. Their Council is made up of 50 per cent lay members, and their committees also have lay members.

16. The GOC send invitations out to take part in ad hoc consultation events. These include various face-to-face events on particular topics, online surveys,

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[18] CHRE, Patient and public participation, July 2011, p 7
[19] CHRE, Patient and public participation, July 2011, p 13
[20] CHRE, Patient and public participation, July 2011, p 15
[21] CHRE performance review 2010/11, p 47
[22] CHRE performance review 2010/11, p 46
[23] CHRE performance review 2010/11, p 49
[24] GMC website: www.gmc-uk.org/information_for_you/patients_and_public.asp

traditional consultation documents and the opportunity to present to Council on ideas for strategic aims.

17. The new Chair and CEO of the GOC are currently meeting their counterparts from all our major stakeholder bodies, including public and patient ones.

18. The GOC are attending relevant third party events where the public can hear their views. For example, all party parliamentary groups (APPGs), health-related conferences, seminars and events organised by the optical sector, seminars organised by the PPI Group and are exhibiting at conferences such as Citizens Advice and Trading Standards.

19. They invite patient and public groups to write pieces for their publications.

20. The GOC is planning to conduct annual surveys with stakeholder reference groups and members of its committees to measure the effectiveness of its codes of conduct and competency frameworks and ensure that they prioritise patient safety and patient centred care.[25]

21. The GOC has targeted webpages for the public which includes information on consultation events and a current survey on fitness to practice information on the register.[26]

## General Osteopathic Council (GOsC)

22. The General Osteopathic Council (GOsC) conducted research via a survey to explore what patients and the public expect from osteopaths.[27] Participants for this were recruited by registrants. The results have been used to inform areas of policy, PPI strategy and revision of guidance and leaflets as well as informing the Council's research direction. The results have also informed the development of a range of public information material to raise public awareness of regulation, standards and treatment.[28]

23. The GOsC has developed new patient and public involvement and communications strategies. They have also commissioned research into newly qualified registrants' preparedness for practise.[29]

24. The GOsC also has dedicated public and patient webpages.[30]

## General Pharmaceutical Council (GPhC)

25. The General Pharmaceutical Council (GPhC) have a proactive approach and have a member of staff whose main role is patient and public engagement. The GPhC has developed an approach which tailors its engagement activities according to pieces of work and has a patient and public centred approach.

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[25] CHRE performance review 2010/11, p 57
[26] GOC website: www.optical.org/en/audiences/general_public.cfm
[27] CHRE, Patient and public participation, July 2011, p.6
[28] CHRE performance review 2010/11, p 62
[29] CHRE performance review 2010/11, p 62
[30] GOsC website: www.osteopathy.org.uk/information/about-osteopathy/

26. The GPhC has engaged with patients and the public throughout the UK on its revision and development of its standards. As part of this work the GPhC used external organisations to run engagement events to engage with the public and harder to reach groups including methadone users and homeless people.[31] For example, they worked with the Black Health Agency (BHA) in Manchester for one of their engagement events.[32] The BHA enjoys well established links with other networks concerned with health in the North West of England and this ensured 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. The GPhC have established links and relationships with a number of patient groups including National Voices.

27. The GPhC has webpages which are targeted at the general public and include information on their patient and public engagement strategy.[33] This includes consulting with patient groups and patients where appropriate and their Council consists of 50 per cent lay members.

## Nursing and Midwifery Council (NMC)

28. The Nursing and Midwifery Council (NMC) has a proactive approach as a result of having dedicated patient and public engagement staff members. They have worked closely with other organisations in developing their work. For example, they 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.[34] As part of this work the NMC used role play at a focus group for people with moderate to severe learning disabilities which enabled them to participate as fully as possible.

29. The NMC recently started a project to improve the way they and their existing networks involve European patient, service user and citizen organisations in its international work. They also have a reward, reimbursement and accessible involvement policy.

30. The NMC's quality assurance process measures patient and public involvement and input into the curriculum design, development and student assessment.[35]

31. As part of work on a review of the Midwives' rules and standards the NMC spoke to representative groups and asked which parts of the consultation document would be most relevant to the people that the groups represented. They then tailored the supporting information with the consultation document for each group to make it more accessible.[36]

32. The NMC have dedicated webpages for the general public.[37]

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[31] CHRE performance review 2010/11, p 72

[32] CHRE, Patient and public participation, July 2011, p.6

[33] GPhC website: www.pharmacyregulation.org/i-am-patient-or-member-public

[34] CHRE, Patient and public participation, July 2011, p.6

[35] CHRE performance review 2010/11, p 89

[36] CHRE performance review 2010/11, p 91

[37] NMC website: www.nmc-uk.org/General-public/

## Pharmaceutical Society of Northern Ireland (PSNI)

33. The PSNI have begun to personalise consultations by addressing them to individuals. This has generated better response rates and allows them to evaluate uptake.

34. They also have a dedicated page for public and patients on their website.[38] This page includes information on various topics of interest to public and patients including their patient and public forum. The forum meets every three to four weeks to consider issues from a public perspective. It consists of representatives from patient groups and members of the public. The group considers issues on guidance, planning and policy.

## Care Council for Wales

35. The Care Council for Wales aim to ensure the social care workforce in Wales is safe to practice and has the right skills and qualifications to work to a high professional standard.

36. Their service user and carer participation strategy outlines their principles and standards for how they enable engagement and participation in their work.[39]

37. The Care Council for Wales has a webpage dedicated to and targeted at service users, carers and the public.[40] This page provides information on how to get involved in consultations, give feedback and attend Council meetings.

38. They are also running a confidence in care campaign with the aim of raising awareness of the Code of Practice for Social Care Workers amongst the general public.

## General Social Care Council (GSCC)

39. The General Social Care Council (GSCC) is the regulator of the social work profession and education in England.

40. The GSCC launched a web-based service user awareness campaign in January 2011 with the aim of providing information to service users that social work is a regulated profession. Of the 22 organisations contacted, 41 per cent of organisations contacted agreed to promote the GSCC and disseminate their campaign messages.[41]

41. In a report published in March 2011 the GSCC reported on a piece of research which looked into the contribution and impact made by their 'visitors'.[42] The GSCC use visitors alongside their social work education inspectors and are people who have experience of using social work services. They help to

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[38] PSNI website, patient and public: www.psni.org.uk/consumers/

[39] Care Council for Wales, Service user and carer participation strategy: www.ccwales.org.uk/your-voice/get-involved/participation-strategy

[40] Care Council for Wales website, Service users, carers and the public: www.ccwales.org.uk/service-users-carers-and-public

[41] GSCC service user awareness campaign evaluation

[42] Inspecting social work degree courses: A report on the contribution and effectiveness of people who use social work services, GSCC
www.gscc.org.uk/cmsFiles/Publications/Inspecting_social_work_degree_courses.pdf

represent the views of service users based on their own experiences and raise awareness of diverse needs and perspectives. Overall the wider involvement of visitors is valued by the higher education institutions and their user groups, and is seen as a positive example of involvement. Recommendations arising from the report are that the role of the visitor may need to be more clearly defined, and that standards for involvement may need to be developed.

42. The GSCC also has dedicated pages for service users and the public providing information on how to make a complaint, how to get involved with the work of the GSCC, the Codes of practice for social workers and highlighting their online community.[43]

## Northern Ireland Social Care Council (NISCC)

43. The Northern Ireland Social Care Council (NISCC) is the regulatory body for the social care workforce in Northern Ireland.

44. The NISCC have various user and carer reference groups to provide their perspective on the development of registration, regulation and training.[44] The NISCC have also established a participation group which builds on the work of the reference groups to look at how the NISCC engages with users and carers. This group is developing principles and standards to encourage best practice in terms of patient and public involvement. The NISCC commissioned a piece of research in 2008 to look at effective user involvement and are currently addressing the recommendations resulting from this, including the development of a participation group, improving communications to users and carers, developing principles for involvement, feeding back to service users after participation and having organisational champions for user involvement.

## Scottish Social Services Council (SSSC)

45. The Scottish Social Services Council (SSSC) is responsible for registering people who work in social services in Scotland and regulating their education and training.

46. The SSSC have dedicated pages for the public which provide information on searching the register, complaints and codes of practice.[45] Information on current consultations and their e-bulletin newsletter can be found on their homepage.

## Children and Family Court Advisory and Support Service (Cafcass)

47. Cafcass is an organisation which champions the interests of children involved in family proceedings, advising the family courts in England on what it considers to be in the best interests of individual children.[46]

48. In August 2006 they produced an engagement and participation strategy to set out their approach to working with their partners, stakeholders and service

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[43] GSCC website: www.gscc.org.uk/
[44] NISCC, Users and carers: www.niscc.info/UsersandCarers-4.aspx
[45] SSSC website, Public: www.sssc.uk.com/sssc/public/are-you-a-carer-or-do-you-use-services.html
[46] Cafcass website: www.cafcass.gov.uk/about_cafcass.aspx

users and how they will engage with these groups at all levels of the organisation.[47] Examples of their engagement include, providing involvement opportunities for children and young people through events, consultations, the Young People's Board, regular updates via their monthly newsletter, consultation, surveys and research forums.

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[47] Engagement and participation strategy, Cafass, August 2006: www.cafcass.gov.uk/PDF/Engagement%20and%20Participation%20Strategy%20final.pdf

# Patient and public participation in health professional regulation

July 2011

council for
healthcare
regulatory
excellence

## 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 bodies[1] 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.

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[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

1.1 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 Infirmary[2] 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]

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[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 regulators*[4]

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.

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[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.

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[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 Regulators[6] 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

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[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

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[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.

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