[DRAFT] Minutes of the PPI Group meeting held on Friday 2 September 2005 at the General Chiropractic Council, 44 Wicklow Street, London WC1X 9HL

Present

General Chiropractic Council (GCC)

Philippa Barton-Hanson, Executive Officer, Communications Martin Caple, Lay Member (Chairman) Rebecca Stone, Executive Officer, Marketing

General Dental Council (GDC)

Tara Phillips, Head of Communications Caroline Abel Smith, Lay Member

General Medical Council (GMC)

Sophia Bhatti, Strategy and Planning Officer Fiona Peel, Lay Member

General Osteopathic Council (GOsC)

Paul Sommerfield, Lay Member Brigid Tucker, Head of Communications

General Social Care Council (GSCC)

Suzanne Brady,

Health Professions Council (HPC)

Catherine Dawson,

Nursing and Midwifery Council (NMC)

Angeline Burke, Consultation and Public Involvement Officer John Leece Jones, Lay Member Marie Saldanha, Assistant Consultation and Public Involvement Officer

Royal Pharmaceutical Society of Great Britain (RPSGB)

Eileen Neilsen, Head of Policy Development

Council for Healthcare Regulatory Excellence (CHRE)

Elisa Pruvost, Policy Manager

Apologies

Graham Ixer, Rachel Tripp and Sally Williams

Introductions

2. The meeting commenced with introductions.

Minutes of the Previous Meeting

3. The minutes of the previous PPI Group meeting of 4 July 2005 were agreed.

Matters Arising

4. Tara Philips explained that she had collated, on behalf of the group, a list of the exhibitions that each of the member organisations would be attending during 2006. This item would be covered in more detail under item 3.6 of the agenda (paras 67-69).

Joint regulators' conference/work-shop (item deferred from previous meeting)

- 5. John Leece Jones updated the group on the subject of the proposed conference/work-shop. He explained that the NMC events team could in a quiet period offer administrative support for event organisation.
- 6. The Chairman asked the group for their thoughts on a proposed event and it was concluded that:
 - a) A conference/workshop would not be held in February 2006 as had been mooted
 - b) An event must have a clear purpose and objective at the outset. Such an event should be an integral part of a specific project and not an end in itself. For example, to progress a consultation process on a specific regulatory policy/implementation issue or to support other areas of the Group's work plan such as training of staff and Council members on PPI issues.
 - c) Where it is proposed to invite patient/public representative Groups to attend an event, it must be seen to add value to their objectives and to help them to fulfil them. Failure to persuade hard pressed voluntary Groups of an event's relevance to their work would result in nonattendance.
 - d) There are means other than a conference/work-shop to achieve communication with the public, such as outreach work. It was suggested that, when appropriate, representatives from the PPI Group go to the patient representative Groups rather than expect them to come to us.
 - e) It is important to look at ways of reaching the public regionally.
- 7. **Action point:** Members of the PPI Group agreed to collate their top five policy issues upon which it would be helpful to have public and patient input. This would enable the PPI Group to facilitate public and patient contributions to key policy areas. Members of the PPI Group were asked to forward this information to Philippa Barton-Hanson or table it at the meeting of 6 October 2005.

Websites: a standard introduction to links to each regulator's website (deferred from previous meeting)

- 8. Philippa Barton-Hanson introduced a paper that outlined a proposal that each regulator's website (as far as their style guides and web-site design allow) could have:
 - a) A page that explains, briefly and clearly, the context of UK health and social care regulation. This could include:
 - b) Links to the web-sites of UK health and social care regulators; and
 - c) A downloadable version of the regulators' joint information leaflet (pdf or some other format).
- 9. The PPI Group considered draft text for this page based on the wording used in the draft patient information leaflet for consistency.

10. The PPI Group agreed:

- a) the proposed draft standard text with some minor factual amendments
- b) to obtain agreement from respective Executive/Councils as to whether they will implement the proposal
- c) that the deadline by when this project could be completed would be 31 December 2005
- d) that the proposal be put to the Communications Managers meeting of 12 September 2005
- 11. **Action point:** Following further discussion about the uses of a shared web-page and web-site, it was agreed that research would be undertaken by the GDC on the practicalities and costs associated with setting up a joint regulators' web-site (along the lines of the AURE web-site, a site hosted by another but with its own domain name) that could contain links and clear information for patients.

Possibly also including a diary of consultations, conferences and exhibitions. This would be put before the PPI Group, for consideration, at its meeting in [October 2005 or January 2006]

Draft budgeted work-plan for discussion, further development, and clarification of detail and priorities

- 12. At the PPI Group's previous meeting of 4 July 2005, members had stated that they needed information about possible costs arising from proposed PPI Group activities to enable them to allocate funds within their organisations' annual budgets. The PPI Group's meeting of 2 September 2005 was therefore specifically held to focus on a draft budgeted work-plan that listed the projects suggested by the PPI Group to date. The PPI Group acknowledged that the draft work-plan contains some ambitious projects and that it would be necessary to prioritise them carefully to take account of available resources.
- 13. Philippa Barton-Hanson introduced a paper that included a work-plan with notional costs, which consolidated projects, aims and objectives, previously mooted by the PPI Group and contained in:
 - a) PPI Group Member Strategies: Common PPI Themes Identified [March 2005, Prime Research & Development]
 - b) Developing a PPI Strategy and Work Plan [June 2005, Peaches Golding Marketing & Communications]
 - c) Minutes of PPI Group meetings of 7 January, 11 April and 4 July 2005
 - d) PPI Group's Terms of Reference.
- 14. The PPI Group was asked to consider the listed project specifications, timescales and priorities and the possible resource implications in terms of money and staff time. The Group noted that apart from two of the high priority projects already underway, precise costings have not been obtained because the Group's plans are at an early stage and the aims and utility of many of the projects listed had not been analysed or discussed in detail. The Group also noted that most of the listed projects may have long term budget implications to keep the products and processes instigated by the PPI Group up to date and fit for purpose.
- 15. The PPI Group agreed that the projects listed in the draft work-plan were an accurate representation of the projects suggested by the PPI Group to date. The Group were also reminded of the Terms of Reference which:
 - a) provides for each Group member to agree, or disagree, to participate in specific projects; and
 - b) the funding by Group members of specific projects is proportionate based on each member organisation's annual income.
- 16. The PPI Group agreed the following project category priority levels:
 - **High**: to be commenced/implemented/achieved between January 2005 January 2007
 - Medium: January 2007-January 2008Low: January 2008-January 2009
- The outcome of the Group's discussion of each project listed within the draft work-plan follows.

Standard information on web-pages

17. Purpose: to sign-post the appropriate regulator for the public/patient to contact when necessary.

- 18. The Group agreed that much of the detail of this project had already been agreed during discussion of a previous agenda item. [Ref. paras 8-7 above].
- 19. The Group confirmed that this was a high priority project, to be implemented by 31 December 2005 and that resource implications would in all likelihood be limited to staff time necessary to undertake amendments to web-sites. The matter would be considered by regulators' Communications Managers at the next opportunity. The PPI Group further agreed to keep this project under review.
- 20. **Action point**: Group members to report implementation progress at the meeting after next.

The production of a joint UK and social care regulators' patient information leaflet

- 21. Purpose: to produce and distribute a leaflet/information that raises public awareness of the regulators and their roles.
- 22. The PPI Group agreed that this was a high priority project.
- 23. The PPI Group noted once more that this project is divided into two phases.
- 24. Phase One: the trial period including development of design, and testing the effectiveness of the leaflet through piloting with patient representative groups. The outcome of the piloting stage will inform the implementation of the Phase Two of the project launch, distribution (quantities and targets) and review and reprinting processes. Hence, the Group noted that it is difficult to predict the likely costs of Phase Two, without yet knowing the outcome of Phase One.
- 25. The PPI Group agreed that the pilot leaflet, of which a 1000 copies will be printed for Phase One, should be written in English and translated into Welsh only. Production costs will include design, images, Plain English Campaign fee and possible redesign and amendments following input from patient representative groups. The overall estimated costs of Phase One is £9K and are likely to be payable by December 2005.
- 26. The PPI Group noted the possible costs associated with printing and distribution of the leaflet in a range of quantities. The general view of the Group was that it would not be appropriate to produce the leaflet in pdf form only for use on web-sites.
- 27. Group members also noted that the outcomes of the CMO's and Foster Reviews may have implications, in the longer term, upon the work of the Joint PPI Group.
- 28. It was agreed that the outcome of the Phase One of the project would be reported by the Leaflet Working Group lead (Sophia Bhatti GMC) as soon as possible this is likely to be at the Group's meeting in January 2006. It was also agreed that the Leaflet Working Group would further research appropriate distribution targets, likely quantities needed to fulfil aims and whether or not appropriate partner organisations would wish to contribute to the costs. The Leaflet Working Group will also provide a projection of possible costs associated with the implementation of Phase Two of the project.
- 29. **Action point:** Interim progress report to be presented to the PPI Group at the next meeting on 6 October 2005. A full report on the outcome of Phase One of the project and fleshed-out detailed proposals for the implementation of Phase Two (including resource implications) to be considered by the PPI Group at its meeting in January 2006. (Sophia Bhatti, GMC).

Benchmarking good PPI practice

30. Purpose: to identify good practice in PPI then develop, and share, practical methods for implementing and auditing it.

- 31. The PPI Group noted that the first two benchmarking projects listed had already been completed and had been funded by the GCC. They are:
 - a) PPI Group member strategies common PPI themes identified (March 2005, Lindsay Mitchell, Prime Research & Development); and
 - b) Developing a Public and Patient Involvement Strategy and Work Plan: facilitated discussion and Report (June 2005, Peaches Golding Marketing & Communications).
- 32. It was suggested that the documents be kept under review given that they could form the basis for audit tools.

Joint Regulators' PPI Good Practice Handbook

- 33. Purpose: for use by regulators' staff and members to help implement and audit PPI strategies.
- 34. The PPI Group noted that the first draft of the PPI Good Practice Handbook would be considered at their next meeting on 6 October 2005. Lindsay Mitchell, whom the PPI Group had commissioned to produce the Handbook, will be present at that meeting.
- 35. The PPI Group noted that the Handbook is predominantly intended for internal use. However, some issues about distribution and presentation remain to be resolved, such as the medium through which the document will be circulated: for example, in-house produced pdf document, Word document or a professionally type-set pdf document for ease of reading on a web-site and clarity when downloading and printing off hard copies. On this latter point, The PPI Group noted that to have the Handbook professionally type-set would cost no more than £1K. It was also suggested, for consideration at a future meeting, that the Handbook could be offered for sale.
- 36. The PPI Group agreed unanimously that the Handbook should not be a 'glossy' document but one that looks professional and properly produced. Sophia Bhatti agreed that the GMC's reprographics department had the capacity to undertake a small print run (100-200 copies) of the Handbook.
- 37. The PPI Group acknowledged that the PPI Good Practice Handbook, by its very nature, will need to be kept updated and reviewed no less than every 12 months. It was suggested that either this work could be contracted out or a member organisation could hold responsibility for undertaking this project by tasking a staff member to take ownership of it.
- 38. **Action point:** comments and suggestions about the Handbook's text, together with minor modifications to be considered at the next meeting. Issues relating to distribution, presentation and review to be resolved. The draft Handbook will be circulated to the Group before its meeting on 6 October and a covering paper will be prepared. (Philippa Barton-Hanson/Lindsay Mitchell).

Develop good practice guidelines on consultation exercises

- 39. Purpose: to ensure that consultations are conducted in an open, equitable and effective fashion.
- 40. The PPI Group wished to see the draft PPI Good Practice Handbook before considering this item further. It is possible that the Handbook may contain guidance on good practice when conducting consultation exercises.

Develop a joint consultation list

41. Purpose: to ensure a co-ordinated approach to undertaking consultation exercises so that public patient representative groups aren't overloaded with invitations to comment.

- 42. The Group noted the suggestion that a joint consultation diary and the possibility of a joint consultation list could be maintained on a shared web-site (ref para 67 above). It was also possible that some of these issues could be addressed in the Good PPI Practice Handbook.
- 43. **Action point**: Tanya Philips (GDC) agreed to research the viability of including a joint consultation diary and a consultation list on a shared web-site i.e. a simple site, hosted by another site but with a separate domain name (ref. para 11). This will be considered by the PPI Group at the next possible opportunity.

To facilitate the implementation of the PPI Group work plan and strategy and keep it under regulator review

- 44. The PPI Group agreed that this is its core role and responsibility. The Group's activities are supported by GCC administration and meeting facilities the use of which commenced in January 2005. It was formally agreed by the Group in July 2005 that this would continue for a further 12 months.
- 45. The cost of facilitating PPI Group work currently is mostly hidden in terms of the PPI Group's overall budget. The PPI Group therefore agreed that set criteria for measuring costs need to be established and the outlay reported annually. For example staff costs and members' expenses, cost of hosting the meetings, fair fees/expenses to be paid to public/patients who contribute to consultations/focus groups.
- 46. In relation to the payment of fees to volunteers, Suzanne Brady (GSCC) informed the PPI Group that the DH had published a guidance document on this subject: Just Rewards and Recognition Involving Service Users.
- 47. **Action point**: Establish purpose to which this information will be put once gathered. Establish criteria for measurement. For future consideration of the PPI Group (October 2005/January 2006).

Further development of 'benchmarking' projects

- 48. It was agreed that this would be reviewed at the January 2006 meeting of the PPI Group.
- 49. **Action point:** Sophia Bhatti (GMC) to produce a brief summary paper, supported by Philippa Barton-Hanson (GCC)

Establishing a range of indicators to measure the impact of the work of the PPI Group

- 50. It was agreed that the draft work plan contains some ambitious targets and that specific projects needed to be carefully prioritised and measured. It was further agreed that an evaluation of the impact of each specific project should be undertaken.. It was suggested that one measure of the PPI Group's success/outcomes that could be adopted would be the take up of specific projects by PPI Group member organisations. The categories (or data sets) used within the tables of Lindsay Mitchell's document of 30 March 2005: Common PPI Themes (e.g. see page three of that document) provide some useful benchmarks.
- 51. The PPI Group considered the utility of undertaking a baseline MORI poll and generally there was no great support for using this method to ascertain the impact the PPI Group had made as a whole. However, the PPI Group considered such polls could be useful when measuring the impact of specific projects or public perceptions of specific issues.

Joint conference/consultation workshop

52. As agreed earlier in the meeting, there would be no 'stand alone' event in the immediate future (Ref paras 5-7 above).

Policy design: a single complaints portal

- 53. Given that there is work being undertaken elsewhere on this matter it was agreed that there would be limited benefit of the group commencing its own background research.
- 54. It was agreed that the item should remain on the work plan. However, a briefing/background paper outlining the current position would not now be needed for the October meeting of the PPI Group as had been previously agreed.

Policy design: provide patient feedback mechanisms for complaints processes

- 55. It was agreed that some PPI Group member organisations that have already implemented patient/public/complainant feedback mechanisms within their fitness to practise procedures, could share their knowledge and experience with the PPI Group rather than the PPI Group commencing a new project from scratch.
- The PPI Group further noted that many of the project's categorised as 'medium term priority' within the 'benchmarking' section of the draft work-plan are linked to the statutory functions of regulatory bodies. It was therefore agreed that the aim of then PPI Group is not to repeat the work already undertaken by individual regulators but to disseminate information about PPI related activities, and advise the PPI Group's member organisations of its shared thinking/ learning.
- 57. It was agreed that as part of the learning and sharing experience of the group, representatives from the PPI Group member organisations would be asked to present or hold a seminar at future PPI Group meetings.
- 58. **Action point**: future agenda item/s for the PPI Group (ref. paras 71-75 below)

Training in PPI implementation for PPI Group member organisations (staff, Council members and others)

- 59. The PPI Group noted that some PPI Group member organisations have already implemented, or are in the process of implementing, training on PPI methods for staff and Council members.
- 60. It was suggested that in the short term the Good PPI Practice Handbook may help to address some of the needs outlined in this project. Further, the PPI Group may wish to focus on helping the trainers by giving them good practice guidelines. In addition, there's a possibility that if the training would be similar for all PPI Group members, there may be economies of scale in introducing a 'standard' training programme for all PPI Group members who would wish to take advantage of it.
- 61. It was noted that all PPI Group member organisations are at different stages on this subject. So it was agreed that it would be best to pull together good practice and experience, and review the position in an agenda item in about 6 months time.
- 62. **Action point**: for the PPI Group's further consideration in about six months.

PPI training within Education Criteria

- 63. The PPI Group considered that this would be a medium to long term project. It was noted that most regulators were introducing, or had already introduced, elements of PPI within their Education Criteria. The PPI Group acknowledged that there was scope to learn from each other.
- 64. **Action point**: for the PPI Group's further consideration in about six months.

Linking national regulators and PPI member organisations with local activity

65. It was agreed that this item in the work plan needed to be moved to a high priority task.

The PPI Group noted, and generally favoured, the suggestion that PPI Group members should undertake more 'outreach' work i.e. rather than expecting PPI representative groups to come to us, we go to them. This method could be used for specific projects within the draft PPI Group work plan.

A proposal for a single exhibition stand and a joint diary of conference attendance

- 67. Tara Philips (GDC) reported that the work on mapping all exhibition activity between the various councils had begun and a table of the various conferences to be attended over the next year was circulated to the Group. [Ref. para 4 above]
- 68. It was suggested that when regulators attend exhibitions, they obtain exhibition space close to each other to show unity and help raise the profile of regulation.
- 69. It was suggested that the Citizen Advice Bureau exhibition would be good to attend. It was emphasised once more that a joint diary of conference attendance could be linked to a suggested joint diary of consultation processes on a joint web-site to assist in co-ordination.

Establishment of the need for public and patient involvement

70. The note of the PPI Group's brain storming session of 11April 2005, made reference to establishing a network of 3rd party endorsers for use in case studies, public appearances and supporting media initiatives, training patient and celebrity champions. The PPI Group, on reflection, did not generally favour this approach.

Identification of patient needs

- 71. One fundamental role for the PPI Group could be to assist PPI Group member organisations to obtain public patient input into issue specific matters. The PPI Group noted that common issues that arise for all regulators are, for example, the ethics, conduct and practice concerning patient confidentiality and chaperones.
- 72. PPI Group members had agreed earlier in the meeting [see para 7 above] to forward their organisations' top five 'issues' and projects for which it would be helpful to have the input of the public and patients.

Consultation on public and patient involvement plans

- 73. It was agreed that this item is a high priority and could be achieved through inviting patient groups to the PPI Group meetings or by outreach work as discussed earlier.
- 74. Eileen Neilson (RPSGB) suggested that she, or a member of the PPI Group, could make a start by giving a presentation to the UK Patients' Forum. The PPI Group favoured this idea.
- 75. **Action point**: further patient groups to be identified and the specific projects where this approach would be useful. For further consideration of the PPI Group within the next six months (October 2005/January 2006) and objectives and deadlines agreed for public/patient participation in PPI policy development.

Date of next meeting/s

76. The next meeting is scheduled for 6 October at 10 am. Dates for subsequent meetings would be emailed but are expected to be in January and April 2006.

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