



Registered Charity No. 292157

Your Health Your Way: Personal Plans Workshop to explore patient/public perspectives Longton, 16th December 2008

Introduction

Eleven PPG and N.A.P.P. members attended this workshop to learn more about work currently being undertaken by the Department of Health and to share their views on it. Angela Hawley (Long Term Conditions Self Care Lead at the Department) introduced her work and then delegates had the opportunity to explore the Your Health Your Way section of the NHS Choices website.

In the afternoon, Tracy Morton (Long Term Conditions Care Planning Lead) provided an overview of the project to offer care plans to everyone with a long-term condition and invited feedback. PPG members were also asked to reflect on how they might be able to support the work of the Department of Health with respect to long term conditions.

As part of the introductory section, Joanne Harding described her role as the long term conditions lead for West Midlands Strategic Health Authority (SHA). This oversees the work of 17 Primary Care Trusts, each of which has a lead manager on commissioning services for people with long term conditions and a separate lead manager on providing services for people with long term conditions.

The SHA has a programme called “towards consumer directed care” that includes personal care planning, use of new technologies to support people at home, developing personal budgets to cover health as well as social care and workforce training and development. Joanne stressed that Primary Care Trusts do have the resources and need to work with patients to get a deep sense of priorities and move away from the mainstream conditions.

Initial feedback

Delegates commented that:

- Carers, especially young carers, need a higher profile in this work
- PCTs may be well resourced but social care is not, leading to notable inequalities in the care that is available
- Confidentiality constraints often undermine the ability of family members to provide support to look after people at home: too often they are not seen as partners in the caring process
- The approach seems sound but it is not new: what is going to be different this time?
- It is not clear that people will recognise themselves as having a long-term condition and so may not find the work relevant to them.

Your Health Your Way

<http://www.nhs.uk/yourhealth/Pages/Homepage.aspx>

Angela Hawley explained that one of the differences in this initiative is the scale and depth of the high level commitment to improve the support and care that is available for people with long term conditions. Crucially, she wants users and carers to be aware of what is or should be available so that they can be “armed and dangerous”. Part of that process has been to develop an information prospectus that is currently hosted on the NHS Choices website.

Angela acknowledged that this cannot be the only form of communication and they are working on other methods to reach out to people who do not use the internet, do not read, do not speak English etc. A national campaign will begin in April 2009 to promote the website. Delegates then worked alone or in pairs to review the site and the comments were captured by Angela and will be discussed within her team. They included:

- Information intended for children around cystic fibrosis was well judged
- Relevant section of the NHS Choices website is rather hidden at present
- Need to consider whether the work needs its own identity rather than being part of an all singing all dancing site
- Your Health Your Way is well structured and the five main headings are well chosen
- Many will find the site rather complex and will need support to access it
- Terminals in every GP surgery could be valuable and would make the service and information much more accessible
- More thought needs to be given to how information is provided to people with complex conditions (could people be asked to list their conditions and then get some tailored information, for example?)
- Services identified should not just be the nearest geographically but also those that are most relevant (ie within one’s own PCT)
- A request for a 500 word article introducing the website which can be featured in individual PPG newsletters (N.A.P.P. will circulate that once received).

Personalised Care Planning

After lunch, Tracy Morton described the Department’s Vision for Gold Standard Personalised Care Planning. This is to be offered to all patients with a long-term condition. They would be asked to say what matters to them and to set goals that they find important and valuable. Information and Choice will be important components, as will contingency planning and crisis management arrangements. The contents of the care plans can be aggregated to provide important learning for higher level commissioning.



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Delegates commented as follows:

- Some felt that this was already happening and is part of the core business of district nursing, for example.
- Others worried that, if this is indeed new work, it would be an unmanageable burden on staff
- The view was also expressed that the plan may be good but the services may still not be right (eg discharge might still be poor, single assessment is still not commonplace and health and social care are still separate organisations in most places)
- The language of care planning seems out of step with the intention to focus on the individual and what matters to them. Health Plan would be preferable although alternatives could be tried out through wider research. In any case, the language should be chosen to suit users and carers rather than professionals.
- It will be great if the process can capture unmet need and lead to service improvements.
- Those involved in the care plan need to work to the same agenda and carer involvement is likely to be highly beneficial.

The role of Patient Participation Groups

PPG members explained what their Groups do and how they might help.

- There was a further plea for greater support to young carers and PPGs can help publicise and promote what is available
- PPGs can comment on the plans and strategies of the Department of Health so that they are more likely to be well-received at the grass roots
- PPGs can promote awareness of this work (through newsletters, websites etc) and related initiatives (such as self care week if that comes to pass)
- PPGs can encourage other PPGs to form so that their coverage is more universal and their impact more reliable
- PPGs are influencing practice redesign and that could include a community room which might provide information and support to people with long term conditions
- PPGs can improve communication between practices and patients

In all of these areas, we need to recognise that some PPGs rely on a relatively small number of people and they, too, need supporting.

Our thanks go to everyone who attended and to Kate Ansell for matchmaking N.A.P.P. with the long term conditions team.

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