

Living with Long Term Conditions

A Policy Framework

Consultation Response Questionnaire

February 2011

CONSULTATION RESPONSE QUESTIONNAIRE

You can respond to the consultation document by e-mail, letter or fax.

Before you submit your response, please read Appendix 1 about the effect of the Freedom of Information Act 2000 on the confidentiality of responses to public consultation exercises.

Responses should be sent to:

E-mail: primcaredev@dhsspsni.gov.uk

Written: Primary Care Development Unit
DHSSPS
Room D3
Castle Buildings
Stormont Estate
Belfast, BT4 3SG

Telephone: 028 9052 0248

Fax: 028 9076 5624

Responses must be received no later than Monday 20 June 2011.

I am responding: as an individual
 on behalf of an organisation

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Background

The aim of the document is to secure better outcomes and help people with long term conditions, and their carers, get the best from the health and social care system irrespective of the nature of their condition or the setting in which care is provided. The policy framework is not prescriptive in how people with long term conditions should be supported. Rather it sets out a number of high level principles and values which should be embedded in the overall approach to management and support.

The policy framework will provide a source of advice and guidance for Health and Social Care commissioners, HSC Trusts, the Public Health Agency, the voluntary and community sectors and independent care providers that will help them plan and develop more effective services to support people with long term conditions and their carers. The document is also intended to be a useful source of reference for people with long term conditions, setting out the services that they and their carers should expect as a result of working in partnership with care. Importantly it also outlines the contribution that self management can make in ensuring the best outcomes for their personal health and well-being and quality of life.

In developing this policy framework, account has been taken of relevant policies, strategies and service frameworks and it has been designed to complement these. It also builds upon the considerable amount of work that has already been undertaken by Commissioners and Health and Social Care Trusts, as well as the voluntary, community and independent sectors, to improve the planning and delivery of services. In particular, the draft document has been informed by the Long Term Conditions Alliance (NI) and many of its associated member organisations.

The consultation questionnaire

This questionnaire has been designed to support the consultation process relating to the policy framework for supporting people living with long term conditions and their carers.

The questionnaire seeks your views on the policy framework, and should be read in conjunction with the policy framework document which can be found at http://www.dhsspsni.gov.uk/index/consultations/current_consultations. It is particularly important to know whether the proposed policy framework will improve the quality of care and support for adults in Northern Ireland irrespective of the nature of their long term condition or care setting.

The questionnaire can be completed by an individual health professional, stakeholder or member of the public, or it can be completed on behalf of a group or organisation.

The consultation opened on 28 February 2011 and will close on 20 June 2011.

If you have any queries regarding this consultation please contact **Karen Dawson** (Karen.dawson@dhsspsni.gov.uk Telephone: 02890 520241) or **Yvonne Molyneaux** (Yvonne.molyneaux@dhsspsni.gov.uk Telephone: 02890 520248)

Content of the policy framework

Q1. Do you believe that implementation of this policy framework will help plan and develop more effective services to support people living with long term conditions and their carers?

Yes No

If you answered “no” to this question, or would like to qualify your “yes” response, please explain further.

The policy framework provides good guidance on the strategic direction of service development. While the guidance is in line with what one would expect of effective services, it doesn't define what “effective” services are, how they would be implemented, or how/if they would be evaluated.

Principles underpinning the care and support for people living with long term conditions and their carers

Q2. Do you agree with the 6 principles underpinning the provision of quality care and support for people living with long term conditions and their carers?

Yes No

If you answered “no” to this question, or would like to qualify your “yes” response, please explain further.

The principles provide good guidance on the strategic direction of service development. The document also highlights a number of links between the principles (eg working in partnership can facilitate supported self management which requires information on areas such as managing medicines). It might be useful to show the inter-relations between the principles in a schematic diagram.

Q3. Do you agree that implementation of these principles will result in improved care and support for adults in Northern people living with long term conditions and their carers?

Yes No

If you answered “no” to this question, or would like to qualify your “yes” response, please explain further.

The principles are in line with what one would expect of high quality services. However (similar to the response to Q1), they don't define what “improved” services are or how/if the improvements would be evaluated.

Chapter 1 - Working in Partnership

Q4. Should people with long term conditions, and where appropriate their carers, be recognised and involved as partners in how care is planned and delivered?

Yes No

If you answered "no" to this question, or would like to qualify your "yes" response, please explain further.

Working in Partnership (and Information to Service Users and Carers) are key principles for successful self management of long term conditions.

Q5. Should people with a long term condition have a personalised care plan, the content and detail of which reflects their own condition, needs and preferences for care and support?

Yes No

If you answered "no" to this question, or would like to qualify your "yes" response, please explain further.

The draft policy framework has a strong focus on a personalised care plan across the six principles. A personalised care plan can document the person's needs and can guide appropriate use of health and social care services.

Q6. Do you agree that care and support for people with long term conditions and their carers can be improved through co-operation between statutory, voluntary and independent sector organisations?

Yes No

If you answered “no” to this question, or would like to qualify your “yes” response, please explain further.

There are many factors that influence the development of, and living with, long term conditions. IPH believes that effective co-operation between the agencies responsible for these factors is extremely important in preventing and managing long term conditions. Co-operation with agencies responsible for the social determinants of long term conditions is particularly important.

Chapter 2 - Supporting Self Management

Q7. Should people be supported to develop their knowledge and skills to self manage their long term condition?

Yes

No

If you answered “no” to this question, or would like to qualify your “yes” response, please explain further.

Acquiring the appropriate knowledge and skills are necessary for successful self management of long term conditions.

Q8. Should self management support be a core element of care pathways for long term conditions?

Yes

No

If you answered “no” to this question, or would like to qualify your “yes” response, please explain further.

Yes, if the person is happy with supported self management and receives the level of support he/she needs.

Chapter 3 - Information to Service Users and Carers

Q9. Do you agree that people with long term conditions, and their carers, should have access to information, education and training programmes in a format and medium that best meets their needs?

Yes No

If you answered “no” to this question, or would like to qualify your “yes” response, please explain further.

Information to Service Users and Carers is a key principle for successful self management of long term conditions. It is important that the information/education/training is high quality, relevant, and accessible to all people with a long term condition.

Q10. Should options for a central Health and Social Care information resource be explored?

Yes No

If you answered “no” to this question, or would like to qualify your “yes” response, please explain further.

IPH has developed an all-island health information website (Health Well www.thehealthwell.info) that signposts users to information resources. We would be happy to explore the potential for working in partnership in this area.

Chapter 4 – Managing Medicines

Q11. Should people with a long term condition have a personal medicines management plan?

Yes No

If you answered “no” to this question, or would like to qualify your “yes” response, please explain further.

Managing medication can be quite complex so it is important that people have a medicines management plan in place. The medicines management plan could be a component of the person’s overall personal care plan.

Section 5 - Carers

Q12. Would the health and well-being of carers be improved by having access to the information and services they need to support them in their caring role?

Yes No

If you answered “no” to this question, or would like to qualify your “yes” response, please explain further.

Carers play an important, and often challenging, role in supporting people with long term conditions. Providing carers with the support they need is likely to benefit their health and well-being.

Chapter 6 – Improving Care

Mental Health and Well-being

Q13. Do you agree that the assessment of an individual’s needs and their care plan should include consideration of their mental health and well-being?

Yes No

If you answered “no” to this question, or would like to qualify your “yes” response, please explain further.

It is important for assessments and care plans to consider that living with a long term condition can have significant adverse effects on mental health and well-being.

Technology, Adaptations and Equipment

Q14. Should appropriate use be made of technology, adaptations and equipment to support people with long term conditions and their carers?

Yes No

If you answered “no” to this question, or would like to qualify your “yes” response, please explain further.

Yes, if the person is happy with supported self management and receives the level of support he/she needs.

Workforce Development

Q15. Do you agree that a skilled, competent and confident workforce should be in place to enable a more community-based model of care to be provided?

Yes No

If you answered “no” to this question, or would like to qualify your “yes” response, please explain further.

Equality Implications

Q16. Are the actions set out in this draft policy framework likely to have an adverse impact on equality of opportunity on any of the nine equality groups identified under Section 75 of the Northern Ireland Act 1998?

Yes No

Please state the group or groups and provide details of any supporting qualitative or quantitative evidence.

Q17. Have the needs of the Section 75 categories been fully addressed in the draft policy framework?

Yes No

If you answered “no” to this question, or would like to qualify your “yes” response, please explain further.

Q18. Is there an opportunity for the draft policy framework to better promote equality of opportunity or good relations?

Yes No

If you answered “yes” to this question please give details as to how.

Q19. Please set out below any further comments, recommendations or suggestions you would like to make in relation to the policy framework for supporting people with long term conditions and their carers.

Comments:

The policy framework relates to “living with long term conditions” but it doesn’t explicitly state whether or not prevention is included in its scope. If prevention is beyond the scope, the document should explicitly state this and perhaps refer to the prevention aspect of *Investing for Health*. If prevention is not beyond the scope, IPH believes that the policy framework needs a much stronger focus on prevention of long term conditions.

IPH welcomes point 6.6 which relates to the use of GP registers to identify people with long term conditions. IPH has considerable expertise in estimating and forecasting the population prevalence of long term conditions. We believe that the concurrent development of GP registers and a systematic and rigorous approach to prevalence estimation can help plan and deliver services in a rational, needs-based way. We are happy to work in partnership to meet the information requirements of DHSSPS and key stakeholders.

IPH welcomes point 6.8 which relates to “external determinants”. We think that the point would be better placed in the Introduction because it is not limited to the sixth principle but applies generally to the development of, and living with, long term conditions.

IPH is also keen to promote and support collaboration across the island on the prevention and management of long term conditions.

**Please return your response questionnaire.
Responses must be received no later than 20 June 2011.
Thank you for your comments.**

Appendix 1

FREEDOM OF INFORMATION ACT 2000 – CONFIDENTIALITY OF CONSULTATIONS

The Department will publish a summary of responses following completion of the consultation process. Your response, and all other responses to the consultation, may be disclosed on request. The Department can only refuse to disclose information in exceptional circumstances. **Before** you submit your response, please read the paragraphs below on the confidentiality of consultations and they will give you guidance on the legal position about any information given by you in response to this consultation.

The Freedom of Information Act gives the public a right of access to any information held by a public authority, namely, the Department in this case. This right of access to information includes information provided in response to a consultation. The Department cannot automatically consider as confidential information supplied to it in response to a consultation. However, it does have the responsibility to decide whether any information provided by you in response to this consultation, including information about your identity should be made public or be treated as confidential.

This means that information provided by you in response to the consultation is unlikely to be treated as confidential, except in very particular circumstances. The Lord Chancellor's Code of Practice on the Freedom of Information Act provides that:

the Department should only accept information from third parties in confidence if it is necessary to obtain that information in connection with the exercise of any of the Department's functions and it would not otherwise be provided;

the Department should not agree to hold information received from third parties "in confidence" which is not confidential in nature; and

acceptance by the Department of confidentiality provisions must be for good reasons, capable of being justified to the Information Commissioner

For further information about confidentiality of responses please contact the Information Commissioner's Office (or see web site at: <http://www.informationcommissioner.gov.uk/>).

Appendix 2

Section 75 of the Northern Ireland Act 1998 requires the Department to “have due regard” to the need to promote equality of opportunity between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation; between men and women generally; between persons with a disability and persons without; and between persons with dependants and persons without. The Department is also required to “have regard” to the desirability of promoting good relations between persons of a different religious belief, political opinion or racial group.

In keeping with the above statutory obligations and in accordance with guidance produced by the Equality Commission for Northern Ireland, the Department has carried out a preliminary equality screening exercise to determine if the actions proposed in the Policy Framework - Living with Long Term Conditions are likely to have a significant impact on equality of opportunity and should therefore be subjected to an Equality Impact Assessment (EQIA). The Department has concluded that an EQIA is not appropriate for a number of reasons, for example,

- The preliminary screening showed no evidence of higher or lower participation or uptake by different groups;
- Interface meetings, and consultations with key stakeholders were already established as a key component in the development of the Policy Framework - Living with Long Term Conditions;
- The Policy Framework – Living with Long Term Conditions appears to promote equality of opportunity and good relations.

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