

Diabetes Strategic Framework Consultation Response Questionnaire

March 2016

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: phdconsultation@dhsspsni.gov.uk

Written: PHD Admin Team
Room C4.22
Castle Buildings
Stormont
Belfast
BT4 3SQ

Telephone: 028 9052 2059

Responses must be received no later than 31 May 2016

I am responding: as an individual ☐
on behalf of an organisation ☒ X

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This response has been submitted on behalf of the Institute of Public Health in Ireland. The remit of the Institute of Public Health in Ireland (IPH) is to promote cooperation for public health between Northern Ireland and the Republic of Ireland in the areas of research and information, capacity building and policy advice. Our approach is to support Departments of Health and their agencies in both jurisdictions, and maximise the benefits of all-island cooperation to achieve practical benefits for people in Northern Ireland and the Republic of Ireland.

Background

In Northern Ireland, at March 2015, there were 84,836 adults aged 17 and over living with Type 1 and Type 2 diabetes, approximately 90% of these cases are Type 2. Although it is estimated that 80% of Type 2 diabetes is preventable, because it is age-related, the prevalence of Type 2 diabetes will continue to rise as the population demographic profile ages.

Diabetes is one of the most common chronic medical conditions in children. The Diabetes Strategic Framework notes that there are 1,207 children with Type 1 diabetes attending paediatric diabetic clinics and sporadic cases of Type 2 diabetes are now being seen in Northern Ireland. In 2014, there were 140 new cases of Type 1 diabetes diagnosed in children under the age of 15, the largest number of children diagnosed in Northern Ireland to date.

Gestational diabetes is also increasing. In 2013/2014, there were 1,251 women who had diabetes in pregnancy with 1,270 infants born to those women, making up 5.2% of all pregnancies.

The Diabetes Strategic Framework (and implementation plan) has been developed as a result of a review of diabetes services commissioned in 2012 and led by the Department's Chief Medical Officer. The Diabetes Review report (2014) can be found

at: <https://www.dhsspsni.gov.uk/sites/default/files/publications/dhssps/report-of-diabetes-review-steering-group.PDF>

The review report made 11 recommendations to improve diabetes care in Northern Ireland. One of its recommendations was for the development of a strategic direction or 'roadmap' to address the gaps in services and emerging priorities identified by the review group and inform service development. This Diabetes Strategic Framework has been developed in response to this recommendation.

The aim of this Diabetes Strategic Framework is to realise a vision of care which improves outcomes for people living with diabetes, or at risk of developing Type 2 diabetes, including services that are:

- evidence-based and co-designed with people living with diabetes to achieve best clinical outcomes;
- person-centred and encouraging self-management; and
- seamless from the service user perspective, responsive and accessible.

The draft Strategic Framework therefore highlights the key challenges identified by the review group, reflects feedback from a stakeholder workshop (held April 2015) and considers how the recommendations contained in the diabetes review report can be taken forward.

A thematic approach has been adopted with 7 themes identified which reflect the key challenges for diabetes services identified in the diabetes review. The 7 themes are:

1. A Partnership Approach to Service Transformation - Clinical Leadership and User Involvement;
2. Supporting Self-management - Empowering People through Structured Diabetes Education;
3. Prevention, Early Detection and Delaying Complications;
4. Using Information to Optimise Services and Improve Outcomes for People Living With Diabetes;
5. Innovative Services for People Living with Diabetes, Particularly Those Requiring Bespoke Treatment and Care;
6. Enhancing the Skills of Frontline Staff; and
7. Encouraging Innovation.

Successful implementation of the Framework depends on enabling key stakeholders to work together, to innovate and to improve services, making best use of resources. Importantly, the Strategic Framework recognises the central role that people living with diabetes have as partners in the planning of

services and in self managing their condition to support the best outcomes for their personal health and well-being and quality of life.

An implementation plan has been developed as an integral part of the Strategic Framework. This plan refers to priorities identified now for the first 3 year phase of implementation, however it will be revised and updated annually. The Framework itself will be reviewed and updated after 5 years to ensure it remains fit for purpose.

In developing the Strategic Framework, account has been taken of a number of other key policies and strategies including *Transforming Your Care* (2011), *Living with Long Term Conditions* (2012) *Making Life Better* (2014). The Strategic Framework 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 diabetes services. The Department has worked closely with Diabetes UK in developing the Strategic Framework.

The consultation questionnaire

This questionnaire has been designed to support the consultation process relating to the Diabetes Strategic Framework.

The questionnaire seeks your views on the Strategic Framework, and should be read in conjunction with the Diabetes Strategic Framework consultation document which can be found at:

<https://www.dhsspsni.gov.uk/consultations>

It is particularly important to know whether the Strategic Framework will improve the quality of treatment, care and support for children, young people and adults living with diabetes, or at risk of developing Type 2 diabetes, in Northern Ireland.

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 8 March 2016 and will close on 31 May 2016.

If you have any queries regarding this consultation please contact the PHD Admin Team at phdconsultation@dhsspsni.gov.uk or (028) 9052 2059.

Content of the policy framework

Q1. Do you believe that implementation of this Diabetes Strategic Framework will help plan and develop more effective services to support people living with diabetes or at risk of developing Type 2 diabetes, and their carers?

Yes ☒

No ☐

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

IPH believes that this plan, if well implemented has the potential to reduce the overall population prevalence of diabetes in Northern Ireland. In particular, we welcome the emphasis placed on prevention, early detection and delaying complications.

IPH published a Diabetes Briefing report in 2012 detailing the prevalence of diabetes in Northern Ireland and the Republic of Ireland and forecasted population prevalence for 2020. Prevalence for Northern Ireland was based on data from the 2005/06 NIHSWB survey. It is estimated that almost 55,000 (4.0%) adults aged 18+ years in NI had ever been told by a doctor that they had diabetes (clinically diagnosed diabetes). This excludes undiagnosed diabetes and is an underestimate of the number of people with the condition. Clinically diagnosed diabetes was found to be more common among older people. In 2010 almost one in ten adults aged 55 years or over had clinically diagnosed diabetes. Rates of clinically diagnosed diabetes were similar among men (3.8%) and women (4.2%). By 2020 the number of adults with clinically diagnosed diabetes is expected to rise to almost 66,000 (4.4%). This represents a 20% increase (an additional 11,000 adults) in ten years.

Q2. Do you believe the aim of the Diabetes Strategic Framework is appropriate?

Yes ☒

No ☐

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

IPH agrees with the aim of this Framework. However, we would recognise that prevention of diabetes in the population and targeted responses to those at risk of diabetes require wide population health approaches as well as enhancements in service design and delivery. In particular the prevention and early detection elements should be integrated with the Fitter Futures strategy for obesity prevention and management as well as key national programmes relating to healthy eating, reducing sugar consumption, physical activity and weight management. In addition, we feel it is important for the framework to integrate with strategic developments in the disability sector to meet the needs of those with disabling long-term sequelae of diabetes including visual impairment, cardiovascular disability and lower limb

amputation.

IPH feels that it is important to recognise the implications of mid-life diabetes on the development of dementia in later life. As such, diabetes prevention in mid-life will likely lead to a reduction in dementia incidence in later life.

We would also caution that service users may have a greater or lesser capacity to self-manage their diabetes. As such, it is important that adequate resources and supports are provided to enable those who have less capacity to manage their own care, to experience the same quality of care provision and equal care outcomes as those who have the capacity for self-management.

Key Themes

Q3. Do you agree with the 7 key themes identified in the document as the primary drivers for improvement of diabetes services?

Yes ☒

No ☐

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

IPH recommends that prevention should be the first theme in the framework on the principle of prevention first. IPH supports the seven key themes in relation to the improvement of diabetes services. In particular, we feel a strong emphasis on prevention is required in this Framework to ensure that type 2 diabetes is prevented and complications delayed whenever possible.

The theme of prevention supports the concepts and actions in Making Life Better and builds upon these to identify specific actions that should lead to the prevention of type 2 diabetes and reduce the overall burden of diabetes in Northern Ireland. IPH believes that specific indicators should be measured at baseline to ensure there is a suite of indicators to measure progress on preventing type 2 diabetes at a population level. The actions identified under theme 3 should be addressed in the implementation plan and reviewed after 5 years.

Making Life Better states that *‘Service Frameworks are a key reference point for commissioning and designing services to secure better integration of service delivery along the whole pathway of care from prevention of disease /ill health to diagnosis / treatment and rehabilitation, and on to end of life.’* It also states that *‘Healthcare providers must build the promotion of good health into service and pathway design, contracts and service delivery and ensure that it is both integral to the care they provide and the work that they do with their communities.’*

Addressing the prevention of diabetes as a priority theme within this

Framework would provide a useful policy platform to ensure prevention and care of diabetes is more closely aligned and embedded in the healthcare services as espoused in Making Life Better as a key long-term outcome to empower healthy living.

A key aspect of the prevention of type 2 diabetes is the need to address health inequalities. Making Life Better identified the reduction of health inequalities as a key strategic priority for the overall health system and this is reflected in the Department's specific commitments to 'improve and protect health and wellbeing and reduce inequalities, through a focus on prevention, health promotion and earlier intervention'.

IPH believes that a greater focus on health inequalities in diabetes prevention is required under theme 3 on primary and secondary prevention of type 2 diabetes. A recent BMJ publication based on English data highlights a wide range of inequalities in the prevalence of diagnosed and undiagnosed diabetes as well as impaired glucose regulation (Moody, A., Cowley, G., Ng Fat, L. and Mindell, J.S. Social inequalities in prevalence of diagnosed and undiagnosed diabetes and impaired glucose regulation in participants in the Health Surveys for England series. BMJ Open, 2016;6). Prevalence was highest among Asian and Black communities and was also higher among people with lower income levels, less education, lower occupational class and greater deprivation. Obesity is one of the key risk factors for developing Type 2 diabetes. People who are obese are five times more likely to have doctor diagnosed diabetes than those with a healthy weight. Health Survey for England 2004, found that women from Black Caribbean, Black African and Pakistani ethnic groups are more likely to be obese and have a raised waist circumference than the general population. Obesity in childhood has been linked to a greater risk of developing Type 2 diabetes in adulthood.

Introducing performance indicators to measure differences in prevention and management between population subgroups would assist with planning and monitoring efforts to reduce inequalities in diabetes prevalence.

Q4. Do you agree that implementation of these key themes, and the associated principles and actions, will result in improved care and support for people in Northern Ireland with diabetes, or at risk of developing Type 2 diabetes?

Yes ☒

No ☐

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

IPH believes that the current Framework will result in improved care for people at risk of developing type 2 diabetes. However, without a clearly articulated strategic commitment to tackling inequalities the current approach will face challenges in reducing the population prevalence and burden of

diabetes in more at risk population sub groups such as those from more deprived communities and in the overall population in Northern Ireland. It will also lead to challenges for developing a self-care model that results in equal treatment and care outcomes for all. IPH advises that a model designed to reduce the potential for service design and delivery to compound existing inequalities at all stages of the patient journey from diagnosis to death is essential.

Theme 1 - A Partnership Approach to Service Transformation - Clinical Leadership and User Involvement

Q5. Should people living with diabetes, 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.

Recent NICE guidelines (NG 28 - NICE Pathway – Type 2 diabetes in adults: management) are underpinned by a recommendation that states healthcare professionals should adopt an individualised approach to diabetes care that is tailored to the needs and circumstances of those living with type 2 diabetes. It recommends that such individualised care should take into account a patient’s personal preferences, comorbidities, risks of polypharmacy and the patient’s ability to benefit from long-term interventions because of reduced life expectancy. IPH recommends that such approaches should be aligned to recommendations in Transforming Your Care.

This individualised approach is particularly important to ensure that treatment and care is managed in the context of a patient’s other pre-existing or undiagnosed conditions ie multimorbidity. Adults living with diabetes are at risk of polypharmacy if they have co-existing conditions. It is important to liaise directly with the patient to ensure that care providers are aware of the risks of polypharmacy and that such risks are effectively managed.

Individualised care refers to a continual approach where the patient’s care is reassessed regularly with a view to maintaining the most effective approach to that patient’s treatment and care management. Appropriate involvement of patients and their carers should focus on the holistic wellbeing of people with diabetes rather than a disease specific focus to encompass aspects of mental health, social support and social inclusion.

In addition, the individualised care approach enables care providers to note and any disabilities which may compromise the normal course of treatment and management for type 2 diabetes such as visual, hearing or mobility impairment.

Q6. Do you agree that services for people living with diabetes, 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.

No further response.

Q7. Do you believe that a Diabetes Network will support a partnership approach?

Yes ☒

No ☐

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

No further response.

Theme 2 – Supporting Self Management - Empowering People Through Structured Diabetes Education

Q8. Should Structured Diabetes Education to support self-management be a core element of diabetes care?

Yes ☒

No ☐

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

This should be designed to ensure effective approaches to enabling people from high risk sub population groups to effectively manage their diabetes with additional supports as and when required.

Q9. Should people newly diagnosed with diabetes have access to Structured Diabetes Education within 6 to 12 months of diagnosis?

Yes ☒

No ☐

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

Q10. Should the potential role for digital technology in Structured Diabetes Education be explored?

Yes ☒

No ☐

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

IPH believes that this measure should only be introduced as an option and should not serve to further alienate patients who do not have the skills or access to technology to take advantage of such educational approaches.

Q11. Should the potential role for social media in self-management and peer support be explored?

Yes ☒

No ☐

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

IPH believes that approaches to better communicate and support self-management should also meet the needs of those who are unable to use digital devices.

Theme 3 - Prevention, Early Detection and Delaying Complications

Q12. Do you believe that prevention of Type 2 Diabetes should be linked to the wider public health agenda being taken forward through ‘*Making Life Better*’, the framework for improving the population’s health and well-being, and the obesity prevention framework, ‘*A Fitter Future for All*’?

Yes ☒ No ☐

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

Aligning the prevention theme to the wider public health agenda is important and will lead to increased capacity for diabetes prevention in the future. This ensures that prevention measures are streamlined across policy. However IPH also believes that preventative measures specific to diabetes prevention should be developed by the Framework to support the implementation of the Framework and should be supported by wider public health policy.

Q13. Do you agree that people living with diabetes in Northern Ireland should have access to evidence-based pathways for prevention of complications, for example the foot care pathway?

Yes ☒ No ☐

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

No further response.

Theme 4 - Optimising Services and Outcomes through Better Information

Q14. Do you believe participation in the National Diabetes Audit(s) will lead to improvement in diabetes care?

Yes ☒

No ☐

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

No further response.

Q15. Should integrated information systems be a strategic priority for improving diabetes care?

Yes ☒

No ☐

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

IPH sees the development of integrated care systems as integral to developing and delivering a high quality of care for type 2 diabetes patients. In particular this is important for ensuring effective management of multimorbidity and polypharmacy.

Q16. Do you believe a patient portal - which allows people to manage their own health information and to communicate with their healthcare providers - would support better diabetes care?

Yes ☒

No ☐

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

This should be designed to ensure effective approaches to enabling people from high risk sub population groups to effectively manage their diabetes with additional supports as and when required.

Theme 5 – Innovative Services for People Living with Diabetes, particularly those requiring Bespoke Treatment and Care

Q17. Do you agree with the groups prioritised under this theme (Children and Young People, Pre-pregnancy and Pregnant women, Hospital In-patients)?

Yes ☒

No ☐

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

IPH agrees with these groups but also believes that there should be a focus on targeting at risk population subgroups for prevention of diabetes. These include individuals living in more deprived communities and those with lower educational status as well as Asian and Black communities.

Q18. Do you agree that the actions identified will improve outcomes for these groups (Children and Young People, Pre-pregnancy and Pregnant women, Hospital In-patients)?

Yes ☒

No ☐

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

IPH believes that a more structured approach to tackle inequalities in diabetes prevention would lead to a reduction in the prevalence of diabetes in these and other vulnerable groups and would augment the potential achievements of the current approach.

Q19. Do you agree with the groups identified as being at risk and vulnerable?

Yes ☒

No ☐

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

IPH believes that other population sub groups who are more at risk of diabetes should also be targeted as priority, including individuals living in more deprived communities and those with lower educational status as well as Asian, Black and traveller communities.

Theme 6 - Enhancing the Skills of Frontline Staff

Q20. Do you agree that a workforce plan should be developed to support the implementation of this Strategic Framework?

Yes ☒

No ☐

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

IPH believes that strengthening health promotion approaches throughout the health service would enhance the capacity of the Framework to deliver on its actions.

Q21. Do you agree that staff who are not specialists in diabetes and who regularly care for people living with diabetes should have the opportunity for appropriate training and development?

Yes ☒

No ☐

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

No further response.

Theme 7 –Encouraging Innovation

Q22. Do you agree that a more co-ordinated approach to innovation has the potential to improve services and outcomes for people living with diabetes?

Yes ☒

No ☐

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

No further response.

Q23. Do you agree that the Diabetes Network should act as a hub for sharing innovative thinking and practice?

Yes ☒

No ☐

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

No further response.

Q24. Do you agree that processes should be in place to support the introduction of new drugs and devices?

Yes ☒

No ☐

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

No further response.

Human Rights and Equality Implications

Section 75 of the Northern Ireland Act 1998 requires Departments in carrying out their functions relating to Northern Ireland 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.

In addition, without prejudice to the above obligation, Departments should also, in carrying out their functions relating to Northern Ireland, have due regard to the desirability of promoting good relations between persons of different religious belief, political opinion or racial group.

Departments also have a statutory duty to ensure that their decisions and actions are compatible with the European Convention on Human Rights and to act in accordance with these rights.

In accordance with guidance produced by the Equality Commission for Northern Ireland and in keeping with Regulation 75 of the Northern Ireland Act 1998, the Diabetes Strategic Framework has been equality screened and a preliminary decision has been taken that a full EQIA is not required. This preliminary decision is subject to change following analysis of feedback received during this consultation.

The Department is inviting responses to the following questions:

Q25. Are the actions set out in this draft Diabetes Strategic 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 ☒

If Yes, please state the group or groups and provide comment on what you think should be added or removed to alleviate the adverse impact.

Q26. Are you aware of any indication or evidence – qualitative or quantitative – that the actions/proposals set out in the consultation document may have an adverse impact on equality of opportunity or good relations?

Yes ☐ No ☒

If you answered “Yes” to this question, please give details and comment on what you think should be added or removed to alleviate the adverse impact

Q27. Is there an opportunity for the draft Strategic 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.

Q28. Are there any aspects of this Strategic Framework where potential human rights violations may occur?

Yes ☐ No ☒

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

Please set out below any further comments, recommendations or suggestions you would like to make in relation to the Diabetes Strategic Framework for supporting people living with diabetes or at risk of developing Type 2 diabetes, and their carers.

Comments:

No further response.

**Please return your response questionnaire.
Responses must be received no later than 31 May 2016.**

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 website at: <https://ico.org.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 Diabetes Strategic Framework 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 Diabetes Strategic Framework;
- The Diabetes Strategic Framework appears to promote equality of opportunity and good relations.

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8 March 2016