Diabetes Strategic Framework and Implementation Plan

Consultation Responses Summary Report

November 2016

Consultation Summary

Background

On 8th March 2016, the Minister for Health, Social Services and Public Safety launched a public consultation on a draft Diabetes Strategic Framework and Implementation plan (Diabetes Strategic Framework).

The overall aim of the 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
- seamless from the service user perspective, responsive and accessible.

The Framework establishes the strategic direction for services for people living with diabetes and for prevention of Type 2 diabetes over the next 10 years. Importantly, the Framework recognises that self-management has a central role in optimising personal health, well-being and quality of life for people living with diabetes.

Successful implementation of the Framework depends on enabling key stakeholders to work together, to innovate and to improve services, making best use of available resources. There will be a review after 5 years to ensure the Framework remains fit for purpose. An implementation plan has been developed as an integral part of the Framework and was included within the consultation document. This plan referred to priorities identified for the first 3 year phase of implementation however it was envisaged that it would be revised and updated annually.

Between 8th March 2016 and 31st May 2016, views were sought on the draft Framework. The consultation document and questionnaire were available through the Department’s website. During the consultation period Diabetes UK also facilitated a series of events across Northern Ireland in order to encourage feedback on the draft Framework.

Overview

Details of Responses	
Total number of responses received	79
Organisations	35
Individuals	44

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 and their carers? (n=74)**

Yes 91% No 9%

Respondents were generally supportive of the broad aims of the document. In particular they felt a Framework would drive up standards, encourage a regional approach to provision of care and promote equity. However, some respondents cited concerns about adequate funding to support the implementation of the framework and wanted more detail on implementation including resources and timescales. There were also concerns about the evidence base behind the ability to prevent Type 2 diabetes and the perceived lack of detail as to how this would be achieved.

Some respondents stated there was too much emphasis on Structured Diabetes Education (SDE) and cited evidence that outcomes from these approaches demonstrated only limited benefit. Respondents also emphasised the effect of poor mental health on diabetes outcomes and the need for robust psychological approaches in line with individual needs. Individual professional groups such as Pharmacists and GPs as well as the Pharmaceutical Industry highlighted their potential contribution to the implementation of the Framework. These issues are addressed in the revised text including references to the value of clinical psychology and the contribution of a range of professions including Pharmacists.

Q2. Do you believe the aim of the diabetes Strategic Framework is appropriate? (n=71)

Yes 94% No 6%

The respondents overwhelmingly agreed that the aim of the Framework was appropriate and reinforced its emphasis on prevention, and evidence-based, seamless services, with users given a voice on service design. However, some commented that there needed to be a greater emphasis on measurable outcomes and a clearer commitment that there would be resources to support the Framework.

A number of professional groupings emphasised their potential contribution in achieving the aims of the framework. Clinical Psychology services for example were highlighted by respondents. Other observations included that the Framework needed to be more closely aligned to other strategy and policy areas linked to obesity prevention, the management of long term conditions and disability. Some respondents also wished to emphasise that not all Type 2 Diabetes is preventable as genetic/familial factors are also important. These issues are addressed in the revised text including reference to familial and genetic aspects of Type 2 Diabetes and reference to the wider ‘obesogenic’ environment.

Q3. Do you agree with the seven key themes identified in the document as the primary drivers for improvement of diabetes services. (n=68)

Yes 97% No 3%

There was strong general consensus that the seven key themes would act as effective drivers for improvement and change in services for people living with diabetes. However, several respondents argued that carers should also be included, particularly in Key Themes 1, 2 and 5. It was suggested that theme 5 could be reworded to replace bespoke care with the provision of care for people with ‘complex needs’.

It was suggested by a respondent that prevention should be the most important theme and that the links between ‘A Fitter future for All’ and ‘Making Life Better’ needed greater emphasis. The importance of multi-sectoral involvement, particularly in prevention was also highlighted. Some respondents argued that Key Theme 2 was too narrow in its scope and needed to go beyond structured diabetes education. The importance of mental health was again emphasised including the links between poor glycaemic control and the onset of dementia. One respondent felt that the Framework should acknowledge that in certain areas pressures on services were increased by the influx of new immigrants who had complex needs. These issues are addressed in the revised text and the value of alignment with wider public health strategy and policy is acknowledged.

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. (n=69)

Yes 96% No 4%

Once again there was general consensus that the implementation of the key themes would be of benefit to people living with diabetes or at risk of developing the condition. However, some respondents expressed uncertainty as to whether the resources would be available to implement the actions in the draft framework. Once more, the importance of outcomes as opposed to processes was highlighted by respondents. The need for a focus on reducing inequalities in health was also expressed. These issues are addressed in the text including the value of outcomes and indicators to measure progress.

Q5. Should people with diabetes, and where appropriate, their carers be recognised and involved as partners in how care is planned and delivered. (n=73)

Yes 100% No 0%

There was very strong consensus that patients and carers should be involved as partners in the planning of care and its delivery. A number of respondents observed that the existing Patient, Public Involvement (PPI) arrangements in the HSC already embedded this thinking. Respondents also pointed out that tools were needed to measure user satisfaction and that support and training was required to enable users and carers to participate effectively. Some pointed out that Diabetes UK should not be considered to be the sole conduit for patient and carer representation and other non-affiliated service users views ought to be sought as well. Services needed to take into account the range of needs of individuals when designing services. Both Community Pharmacists and the Pharmaceutical Industry highlighted their potential contribution to the process. Some respondents suggested that the term “carer” should be used advisedly as people with diabetes had varying needs in respect of direct care from others. References to carers where appropriate are included in the revised text.

Q6. Do you agree that services for people living with diabetes, and their carers can be improved through cooperation between statutory, voluntary and independent sector organisations. (n=73)

Yes 99% No 1%

Whilst agreeing strongly with this point, and accepting more collaboration was to be welcomed, some responses indicated that here was a danger that the statutory services may water down their responsibilities or that the voluntary sector may not be properly resourced if taking on more direct provision. A number of respondents pointed to the d-Nav service in the SE Trust as a positive example of collaboration with the independent sector.

Others pointed to little actual evidence of existing cooperation between the different sectors and duplication of services. One respondent highlighted limited opportunities for referral into Public Health programmes such as those for exercise on prescription or enhancing cooking skills although examples of such programmes existed. The concept of integrated care pathways which involved the different sectors was highlighted as generally very beneficial for the development of services.

Q7. Do you believe that a Diabetes Network will support a partnership approach? (n=71)

Yes 96% No 4%

There was general consensus that a Diabetes Network would support a partnership approach. However, some respondents emphasised that a Network should build on existing networks or at least draw on the expertise already available. They pointed out to successful professional networks such as those for paediatrics, dietetics and specialist nursing and regional resources which had been generated from these groupings. Respondents from the pharmaceutical industry emphasised the importance of representation on any future network as it would also enable more effective coordination of their current support for diabetes related activities. Some respondents however questioned if potential conflicts of interest should bar industry from participation.

A number of respondents emphasised the importance of comprehensive representation from patient and carer groupings as well as ensuring that a range of professionals were able to be on a proposed Network. Leadership and accountability were also deemed as being important. The draft framework, was by a number of respondents not deemed to provide sufficient detail on the modus operandi of a future network. The revised text includes a clearer explanation of the role and operation of the Diabetes Network.

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

Yes 98% No 2%

There was significant support for structured diabetes education amongst respondents who saw it as an important element of the care for people living with diabetes. However, there were a number of comments relating to the importance of ensuring that there was equitable access to SDE and the large numbers of people who had never received SDE since diagnosis.

Early access following diagnosis was deemed desirable but respondents expressed concern about the backlog of patients to be dealt with and arrangements for young people undergoing transition from paediatric services. Some respondents felt that given the large number of patients, formal courses should be augmented with input from front line professionals and the employment of digital solutions and e-learning.

The long term outcomes of SDE were also questioned compared to other interventions. Some respondents also felt that SDE should not be considered to be the only element in approaches to encouraging self management. Given the large throughput of patients, it was suggested that dedicated regional education centres be set up as a more efficient means of delivering programmes. Again, other professional groupings such as psychologists, dieticians and occupational therapists highlighted their potential contribution to educating patients. Revisions to the text have been made as appropriate.

Q9. Should people newly diagnosed with diabetes have access to structured diabetes education within 6-12 months of diagnosis? (n=73)

Yes	93%	No	7%

Respondents generally supported this time frame. However, a number of respondents also stated that the exact timing of commencement of SDE was often dependent on the needs of individuals and their carers. Whilst many would benefit from SDE soon after diagnosis to promote self management, others would need longer to come to terms with their condition and may benefit from SDE after a longer period.

Some respondents also emphasised the need for education centres with dedicated staff in order to facilitate more systematic throughput as opposed to tagging SDE on to the workload of front line staff. Barriers to uptake were identified which included the time commitment and the ability to take time off work for attendees. Alternatives such as e-learning were also suggested. A number of respondents highlighted that the d-nav system was a highly beneficial alternative to SDE. One respondent made the point that SDE should be positive and empowering as opposed to focussing on the negative consequences of poor control of the condition. The revised text has noted that timing of access to SDE is crucial.

Q10. Should the potential role digital technology in Structured Diabetes Education be explored. (n=71)

Yes	93%	No	7%

This question was interpreted in a number of different ways which included the use of digital electronic devices, through to ‘on line’ learning resources. There was general support for increased utilisation of digital technology and many felt it would be beneficial as it would increase accessibility to a range of support. Respondents felt that young people in particular would benefit as they are more comfortable with this technology. The converse was that disadvantaged groups may not be able to afford the necessary equipment or be able to use it. Some respondents felt that digital technology wouldn’t be a suitable substitute for contact with a health professional. The issue of patient confidentiality was also cited in respect of upload of patient data to servers and “clouds”. The need to validate and quality assure online resources was also mentioned.

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

Yes 94% No 6%

There were a number of detailed responses to this section. Different facets of social media were cited including ‘Facebook’ , ‘YouTube’ and the use of apps and podcasts. Most respondents were positive about the use of social media particularly for young people.

Social media was considered as a useful vehicle for peer support, education and interaction between service users and health professionals

However caveats included the potential for misinformation, the need for effective moderation of forums and safeguarding patient confidentiality. Quality assurance of signposted educational materials was deemed important.

The potential exclusion of those uncomfortable with, or unable to use social media was also discussed. A number of respondents also cited the lack of evaluation of the evidence base for the effectiveness of social media in improving outcomes. Evaluation of utilisation of social media is addressed in the revised text.

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’ and ‘a fitter future for all’.

Yes 96% No 4%

Various respondents favoured a particular emphasis on primary prevention, early detection of diabetes and pre diabetes and prevention of complications.

Most respondents agreed with the concept of public health interventions as a means of preventing Type 2 diabetes however some questioned whether a breadth of interventions was genuinely available or accessible. However, some cautioned against directly blaming people living with Type 2 diabetes for their condition as they felt in many cases it was caused by genetic factors and not lifestyle choices. A number of respondents questioned the evidence base behind whether Type 2 diabetes could be prevented and which interventions were effective. Others thought that prevention should include a wider remit than just Type 2 for example the prevention of gestational diabetes.

Professional groups such as community pharmacists also described their potential role in early detection, patient compliance with treatment and the prevention of secondary complications. The role of other sectors of society including Local Government was also highlighted in the contribution to public health measures and the overall effects of the “obesogenic” environment. The potential of bariatric surgery was mentioned by a few respondents. A small number of comments stated that a diabetes strategy should focus on secondary prevention and public health measures for primary prevention are best kept within extant public health strategies. The revised text references the NICE guidance which highlights a range of interventions for managing obesity including pharmaceutical and surgical intervention

Q13. Do you agree that people living with diabetes should have access to evidence-based pathways for prevention of complications, for example the foot care pathway. (n=72)

Yes 100% No 0%

Respondents cited the value of foot care pathways and retinopathy screening in particular. Effective care pathways were seen as vital for preventing complications, reducing morbidity and mortality and optimising resources by, for example reducing length of stay. Many felt that regional guidelines and care pathways were an achievable aim for a relatively small health economy and should be developed and implemented. People living with diabetes should also be able to interface directly with care pathways. Chiropodists and podiatrists in particular articulated their contribution to care pathways through patient education and risk stratification. Pharmacists and dieticians also mentioned that they had an important role in secondary prevention and should be integral to evidence based care pathways.

The importance of tight glycaemic control in secondary prevention was highlighted by a number of respondents.

Q14. Do you believe participation in the National Diabetes Audit will lead to improvement in diabetes care. (n=68)

Yes 97% No 3%

Respondents overwhelmingly supported the proposal to participate in the National Diabetes Audit. This was seen as vital in benchmarking the quality of services, making national and regional comparisons between performance and sharing good practice. The current lack of audit data in Northern Ireland was seen as hampering service improvements. However, a number of respondents emphasised the need for audit to drive improvement and not merely be an activity in itself. Moreover, others cautioned against audit as being a vehicle for both censure and sanction and should be seen as a supportive process. A number of respondents mentioned current involvement in the GAIN diabetic foot audit and also requested that participation in the National Paediatric diabetes audit be considered. The potential of the

NIECR, use of large datasets and development of regional performance and outcome indicators were seen as important areas for development.

Q15. Should integrated information systems be a strategic priority in diabetes care? (n=70)

Yes 99% No 1%

There was general agreement that this should be a priority. Integrated information systems were seen as important in sharing data between professionals, avoiding duplication of investigations and facilitating audit. The NIECR was seen as an important vehicle in achieving this objective. Patient confidentiality was once more discussed as it was deemed that certain clinical data may be particularly sensitive (for example psychological clinical data) and may require additional controls.

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.(n=71)

Yes 89% No 11%

There was a high degree of support from respondents for a patient portal. It was seen as an important method of enabling people living with diabetes to have more information about their condition and to interact with healthcare professionals. However, it was stressed that those using the system would need to have some training to understand the implications of the clinical information and how this related to personal targets.

Respondents also stressed that accessibility would be an issue for some groups of patients. An appropriate audit trail would also be required if users were requesting support from health professionals through the portal. Reservations to the proposed system also included, little evidence thus far of patient portals being successfully taken up by users. Integration of information systems was seen as a greater priority by a number of respondents as was greater emphasis on achievement of glycaemic control. A number of respondents pointed to the d-nav system and how further development will enable users to download and assess their personal health data. The examples of an extant portal for patients on renal dialysis and the maternity hand held record were also cited.

Q17. Do you agree with the groups prioritised under theme 5 (Children and young people, pre-pregnancy and pregnant young women, Hospital inpatients) (n=72)

Yes 75% No 25%

There was a high degree of support for the prioritised groups named in the draft framework. Many respondents gave specific examples where the needs of younger people and those in transition services were not being met adequately. Access to insulin pumps and continuous glucose monitoring were seen as problematic areas. A number of respondents also felt the needs of older people with Type 1 should not be neglected. They also agreed that pregnant women and those contemplating pregnancy should be prioritised. However, this support has to be put in a context where some respondents also expressed the view that a small minority of patients with Type 1 diabetes should not be prioritised over a substantial majority with Type 2 whose needs were not necessarily being met. People with learning difficulties, mental illness, the frail elderly and BME groups were also described as requiring special attention. The point was also made that socio-economic and educational disadvantage could also contribute to the complexity of needs of individuals. The text strongly reflects the need to manage Type 2 diabetes effectively through the key themes.

Q18. Do you agree that the actions identified will improve the outcomes for these groups (Children and Young People, Pre-pregnancy and Pregnant women, Hospital inpatients) (n=66)

Yes 94% No 6%

There was general agreement that the actions identified would bring about improvement in outcomes for these groups. However, a number of respondents expressed the view that the actions should highlight more of the individual contributions of particular professional groups to the new care pathways/services proposed, for example DSNs and dieticians. Some respondents described the resource intensive nature of the insulin pump programme, including the need for professional support. One respondent questioned the evidence base behind the outcomes of insulin pump therapy versus multiple daily injections. NIAS pointed to the benefits to patients of their direct referral pathway. A focus on antenatal care was welcomed but respondents highlighted the need to follow up women with gestational diabetes from a secondary prevention perspective post pregnancy. This latter point is reflected in the text.

Q19. Do you agree with the groups identified as being “at risk” and vulnerable. (n=67)

Yes 75% No 25%

There was general agreement with the vulnerable groups identified and a number of respondents referred to their answers to question 17. The frail elderly (particularly those that are socially isolated) were particularly highlighted as a group which required attention. One respondent pointed out that a number of groups deemed as being vulnerable should not be grouped together in a single paragraph as they all had their own unique complex needs. It is acknowledged in the text that everyone living with diabetes has a complex condition to manage.

Q20. Do you agree that a workforce plan should be developed to support implementation of the strategic framework? (n=70)

Yes 92% No 8%

There was general consensus that a workforce plan would be supportive for to the framework. Individual professional groups pointed to their own competency frameworks as a basis for supporting this. A workforce plan was seen as vital for ensuring sustained capacity as well as effective succession planning particularly as numbers of new diagnoses were rising sharply. There also needs to be a particular focus on Primary Care as that is where most of the new patients are presenting. The point was made that a condition specific workforce plan should not detract from individual professionally focused plans, for example nursing.

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? (n=66)

Yes 84% No 16%

There was strong agreement with this aspiration. Professional groups felt that basic training in diabetes care needed to be augmented and could be delivered by outreach teams from specialist centres into Primary Care and the Community. General upskilling of staff who come into contact with PLWD was seen as desirable. Once more, Pharmacists highlighted their role in supporting PLWD in the community in terms of advice and potentially public health interventions and medicine use reviews. Audits of training currently available were suggested. Ensuring that staff were adequately supported by employers in order to access training was also seen as an important factor. Training in psychological interventions such as motivational interviewing was also seen as important for front line staff. However, some cautioned that provision of training for ‘non specialists’ should not detract from investment in specialist training such as for DSNs.

Q22. Do you think that a more coordinated approach to innovation has the potential to improve services for and outcomes for people living with diabetes. (n=67)

Yes 90% No 10%

Respondents were in agreement and pointed to perceived lack of coordination in the introduction of new technologies such as insulin pumps and continuous glucose monitoring. Some pointed to a need for greater partnership between industry and the health and social care sector. Some respondents also wished to emphasise that innovation was not just about devices and technology, but about new ways of working, citing professionally led initiatives as examples.

Q23. Do you agree that the Diabetes Network should act as a hub for sharing innovative thinking and practice? (n=68)

Yes 95% No 5%

There was general support for this idea; however some respondents wanted greater clarity about how this aspect of the Network would operate and who would be represented on it. The latter point is picked up with more detail in the revised text.

Q24. Do you agree that processes should be in place to support the introduction of new drugs and devices. (n=69)

Yes 96% No 4%

Respondents agreed that this should be the case. There were a number of concerns about the introduction of insulin pumps and the self funding by PLWD of continuous glucose monitoring. The Diabetes Network was seen by a number of respondents as the vehicle for assessing the introduction of new technologies.

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 (n=66)

Yes 12% No 88%

The general consensus was that the Framework would not have an adverse impact. However, a small number of respondents expressed that since particular groups had been prioritised, for example younger people with diabetes, this may have an adverse effect on services for others. However, the text clearly states a commitment to ensuring the needs of a range of vulnerable groups including the frail elderly are assessed.

Q26. Are you aware of any indication or evidence quantitative or qualitative-that the actions or proposals set out in the consultation document may have an adverse impact on equality of opportunity or good relations. (n=59)

Yes 8% No 92%

As above, there was general consensus that the Framework would not have an adverse impact; however once again, a few respondents felt that people living with Type 2 Diabetes were not being prioritised to the same extent as younger people with Type 1 Diabetes and pregnant women.

Q27. Is there an opportunity for the draft strategic framework to better promote equality of opportunity or good relations. (n=57)

Yes 68% No 32%

A few respondents expressed the view that the Framework should focus on the totality of those with diabetes as opposed to a few specific prioritised groups.

Q.28 Are there any aspects of the Framework where potential human rights violations may occur? (n=63)

Yes 6% No 94%

Appendix list of organisations that responded

BHSCT, Belfast City Hospital

Boehringer Ingelheim

British Dietetic Association

British Obesity and Metabolic Surgery Society

Chinese Community Association

College of Podiatry/ Society of Chiropodists and Podiatrists

Commissioner for Older People NI

Diabetes Specialist Dieticians Group NI.

Diabetes Specialist Nurse Group NI

Diabetes UK Northern Ireland

Guide Dogs

Hygieia Medical LTD

Institute Public Health Ireland

Kinnear Consulting

Lisburn & Castlereagh City Council

MediCare Pharmacy Group

National Pharmacy Association

Newry Mourne and Down District Council

Northern Health and Social Care Trust

Northern Ireland Primary Care Diabetes Society

Patient Client Council

Pharmacy Forum NI

Roche Diabetes Care

Royal Belfast Hospital for Sick Children

Royal College of General Practitioners NI

Royal College of Midwives NI

Royal College of Nursing

Royal College of Physicians

Royal National Institute for the Blind

SANOFI

Society of Chiropodists & Podiatrists Faculty of Management NI

South East Health and Social care Trust

The Association of the British Pharmaceutical Industry

The British Psychological Society

The College of Occupational Therapists

The NI Practice and Education Council for Nursing and Midwifery

Ulster University

Western Trust Paediatric Diabetes Team

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