

Diabetes Strategic Framework

CONSULTATION DOCUMENT

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Ministerial Foreword

I am delighted to present a draft *Diabetes Strategic Framework* for Northern Ireland.

When I became the Health Minister, it was apparent to me that the future sustainability of our health and social care system would be largely dependent on the support we offer to people living with long term conditions, such as diabetes. We have over 85,000 citizens living with diabetes and, if the trend continues, there will be at least another three thousand people newly diagnosed next year and every year thereafter. Approximately 1 in 20 adults in Northern Ireland now live with the condition. Apart from the impact of diabetes on individuals and their families, the health and social care system is under increasing pressure as, on average, 10 new people are diagnosed every day.

In developing the draft *Diabetes Strategic Framework*, I wanted a framework that would not only address existing challenges in the care for people living with diabetes, as identified by the Diabetes Review, but would take us confidently into the future. I particularly wished it to be shaped by principles which encourage prevention of Type 2 diabetes and the complications of diabetes, promote innovation and new ways of working and place people living with diabetes at the centre both of their own care and how services are designed and delivered.

This Framework is consistent with the ethos of both '*Making Life Better*' and '*Transforming Your Care*'. I have been very encouraged by the way in which health professionals who work with people living with diabetes and Diabetes UK have been instrumental in shaping the contents of this draft Strategic Framework. They have told us what they see as their priorities for the next three years and we have reflected this in the document.

I would encourage everyone who has an interest in shaping how we care for people living with diabetes in the future to consider the Framework and participate in this consultation.

Section 1 - Introduction

- 1.1 This Diabetes Strategic Framework and Implementation Plan, (Diabetes Strategic Framework/Framework) reflects the findings, conclusions and recommendations of the Diabetes Review published in June 2014¹ and the outcomes from a workshop for key stakeholders held in April 2015. The Framework has been developed in response to Recommendation 11 in the Diabetes Review, which stated that the key findings and recommendations should be consolidated appropriately to provide a strategic way forward or “roadmap” for diabetes.
- 1.2 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.
- 1.3 The Diabetes Review Group reported that, although progress has been achieved, there is still “inequitable provision of services across certain areas of diabetes care.....and undoubtedly a wide variation in patient experience depending on where patients live and where services are accessed. In certain instances, under-provision as well as inequity is apparent”.
- 1.4 The Diabetes Review identified the need for a strategic direction and action plan for diabetes services that would:
- be person-centred - including promoting self-management and patient empowerment;
 - drive better outcomes for all, but particularly for groups with special risk or vulnerability;
 - be pragmatic;
 - provide optimal pathways of care; and
 - enable integration between policy and service planning and delivery.
- 1.5 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

¹ The Diabetes Review was commissioned in January 2012 and was chaired by the Chief Medical Officer for Northern Ireland. The review report was published in June 2014

a central role in optimising personal health, well-being and quality of life for people living with diabetes.

- 1.6 The economic case for change is inarguable. In Northern Ireland, the estimated daily investment in health and social care services for people living with diabetes is £1 million, most of this spent on the treatment of avoidable complications. After physical inactivity, an important driver for increasing numbers of people with Type 2 diabetes is the ageing population. By 2028, if current demographic trends continue, 1 in 5 of the population will be aged 65 years or older, an increase of 44% in this age group².
- 1.7 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 can be found at Section 6. This plan refers to priorities identified now for the first 3 year phase of implementation however it will be revised and updated annually.

Structure of this document

- 1.8 This document comprises 6 sections.
- 1.9 **Section 1** – Introduction.
- 1.10 **Section 2** provides a context to the Diabetes Review and the development of the Strategic Framework, including the case for change and the policy context that has informed the review process.
- 1.11 **Section 3** sets out the main findings, conclusions and challenges identified by the Diabetes Review and the recommendations.
- 1.12 **Section 4** sets out the future strategic direction for diabetes services. This section has been developed around 7 key themes (see box overleaf).
- 1.13 Each of these themes has a supporting principle to underpin and reflect high quality care; a brief overview of the key theme, including a synopsis of what the diabetes review process and workshop participants told us in relation to that theme; an outline of how improvements can be achieved; and a cross-reference to the relevant recommendation(s) of the Diabetes Review.

² <http://www.nisra.gov.uk/archive/demography/population/projections/NPP14-Bulletin.pdf> access February 2016

- 1.14 A strategic objective has been identified for each theme, together with actions, lead responsibility and associated timescale.
- 1.15 **Section 5** sets out the governance arrangements that will support the implementation of the Framework.
- 1.16 Finally, **Section 6** contains an implementation plan for the first 3 year phase.
- 1.17 Since the Diabetes Review was published, significant change to the structure of Health and Social Care has been announced, specifically standing down the commissioning body, the Health and Social Care Board, and changing some of the functions of the Public Health Agency. These changes will be subject to consultation and, once finalised, may have an impact on this Framework with regard to where responsibility lies for some of the actions in the implementation plan.

Box 1: The Seven Key Themes

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.

Section 2 - The Case for Change

Why a Diabetes Strategic Framework is needed

- 2.1 The development of the Diabetes Strategic Framework has been underpinned by 4 key drivers:
- the changing demography of diabetes;
 - the economic case for change;
 - the move to more person-centred care; and
 - a population-based approach to health and well-being.
- 2.2 The development of the Strategic Framework has been influenced by two key policies, *Making Life Better* and *Transforming Your Care*.

The Changing Demographics of Diabetes

- 2.3 Diabetes continues to be one of the most challenging chronic conditions facing the people of Northern Ireland. Type 1 diabetes, caused by the body's failure to produce the hormone insulin, usually develops in children and young people and requires regular insulin injections as a life saving treatment. Type 1 diabetes is not preventable.
- 2.4 Type 2 diabetes is linked with obesity and increasing age and accounts for 90% of diabetes cases. It is caused by the body's failure to produce enough insulin or when the insulin produced does not work properly. As levels of obesity increase in the population, so the prevalence of Type 2 diabetes will increase. Up to 80% of Type 2 diabetes can be prevented or delayed.
- 2.5 At a UK level, a recent analysis published by Diabetes UK reports that the number of people living with Type 1 or Type 2 diabetes in the UK has risen by 59.8% in a decade³. The figures, extracted from official NHS data, show that there are now 3,333,069 people diagnosed with diabetes, an increase of more than 1.2 million adults compared with ten years ago and meaning that more than one in 20 people in the UK are living with diabetes.⁴
- 2.6 The 2003 CREST/Diabetes UK Joint Taskforce report '*A Blueprint for Diabetes Care in Northern Ireland in the 21st Century*', noted that in Northern Ireland at that time, an estimated 40,000 people were known to have diabetes. The report predicted that this number was likely to double by the

³ Diabetes UK - data published August 2015

⁴ The Cost of Diabetes; Diabetes UK 2014

end of the decade resulting in consequential pressures on health and social care services. As recent figures bear out, this prediction was accurate.

- 2.7 In Northern Ireland, at March 2015, there were 84,836 adults aged 17 and over living with Type 1 and Type 2 diabetes⁵. It would be reasonable to estimate that approximately 90% of these cases are Type 2. Although it is estimated that 80% of Type 2 is preventable, because it is age-related, the prevalence of Type 2 diabetes will continue to rise as the population demographic profile ages. The evidence with regard to how to organise primary prevention effectively at population level is still emerging.
- 2.8 Gestational diabetes is 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. There were just 100 such pregnancies reported in the CREST 2001 document on management of diabetes in pregnancy. This figure represents a 12-fold increase since the late 1990s with the trend likely to continue.
- 2.9 Despite considerable advances in the management of pregnancy in diabetes, this remains a high risk condition requiring particular care. Congenital malformation and perinatal mortality rates are 3-5 times higher than the background population⁶. The National Pregnancy in Diabetes Audit (2014) notes that combined 2013/2014 data confirmed high rates of adverse outcomes with 12.8 stillbirths per 1,000 live and stillbirths; 7.6 neo-natal deaths per 1,000 live births and 44.2 anomalies per 1,000 live and stillbirths. More than one third of women (34.3%) had babies that were large for gestational age.
- 2.10 Diabetes is one of the most common chronic medical conditions in children. 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.
- 2.11 The rise in the prevalence of diabetes impacts across our health and social care system. People living with diabetes are at risk of developing health problems which, if not prevented or detected early enough, can have serious repercussions. These can include renal disease, blindness, cardiovascular disease and lower limb amputation. People living with diabetes also have an

⁵ Quality & Outcomes Framework (QOF) register. The register records all those aged 17 and over with either Type 1 or Type 2 but does not distinguish between the types

⁶ Pregnancy in women with type 1 and type 2 diabetes in 2002/3: England, Wales and Northern Ireland Confidential Enquiry into Maternity and Child Health CEMACH 2005

increased rate of depression compared with the general population. Around half of the people with Type 2 diabetes already have complications present at the time they are diagnosed. Where people are living with diabetes, therefore, secondary prevention of complications will be a key focus.

The Economic Cost of Diabetes

- 2.12 It has been estimated that the UK currently spends 10% of the health and social care budget on the treatment of diabetes and its complications, equivalent to about £1 million daily in the context of Northern Ireland. This expenditure is projected to rise to 17% of the total budget by 2035.
- 2.13 The economic cost of complications arising from diabetes is immense. For example, in 2010/11, the NHS in England spent an estimated £639 – £662 million, that is 0.6–0.7% of its budget, on foot ulceration and amputation due to diabetes⁷.
- 2.14 In the UK over 100 amputations are carried out every week on people with diabetes due to complications arising from their condition and up to 80% of these are deemed to be preventable⁸. A report on foot care for people with diabetes by Insight Health Economics for NHS Diabetes highlights clinical and economic evidence which suggests that multi-disciplinary diabetic foot care teams, with strong links to community podiatry services, can improve patient outcomes and generate savings for the NHS that substantially exceed the cost of the team⁹.
- 2.15 Diabetes now accounts for more than a quarter of all newly diagnosed cases of end stage renal failure requiring dialysis in the UK. More than one in eight kidney transplants are carried out in patients with renal failure brought on by diabetes.
- 2.16 Primary care, community and hospital services are experiencing the impact on workload of the increasing numbers of people living with diabetes. For example, a recent audit of inpatient care in hospitals in Northern Ireland showed that people living with diabetes accounted for 16.5% of hospital inpatients on the day of the audit.
- 2.17 Once admitted to hospital, people with diabetes stay longer than people without diabetes. The majority are admitted for reasons other than their diabetes and are usually not under the care of a specialist diabetes team. It is

⁷ Foot Care for People with Diabetes: The Economic Case for Change. Insight Health Economics March 2012

⁸ The Cost of Diabetes, Diabetes UK 2014

⁹ Ibid

possible to reduce the excess length of stay by having specialist diabetes teams on duty that pro-actively seek out patients with diabetes after they have been admitted and ensure that the support and care they need are in place¹⁰.

- 2.18 People living with the complications of diabetes, such as foot ulcers, amputations and vision loss, may experience other adverse impacts such as lost working days, a reduced level of social independence, needing higher levels of social care and support, and mental health issues such as depression. A Diabetes UK report '*The Cost of Diabetes*' records that in the UK, 24,000 people each year die prematurely as a result of diabetes.
- 2.19 Another Diabetes UK report, '*Diabetes Education: the big missed opportunity*' notes the Department of Health in England estimation that the DAFNE programme for people with Type 1 diabetes could save the NHS £48 million per year nationally, or £93,133 per 100,000 of the population, if it is made available to everyone in the UK with Type 1 diabetes¹¹. The report also notes positive outcomes for Structured Diabetes Education programmes aimed at people living with Type 2 diabetes.
- 2.20 A systematic review of the international research literature¹² has identified that some interventions not only reduce the burden of diabetes but are actually cost-saving to the health service. From a policy perspective, it makes sense that these would be prioritised for implementation when resources are scarce. Comprehensive foot care to prevent foot ulcers is one of these cost-saving interventions and this is why it is prioritised for implementation in this framework.
- 2.21 Whilst the economic case for change can be demonstrated, at a personal and individual level, the cost for people affected by diabetes and who live with complications is incalculable. Given this context, innovative ways of meeting the need for diabetes care must be developed to meet the increasing level of demand.

The Move to More Person-centred Care

- 2.22 In recent years the Health and Social Care system has begun to adopt a more person-centred approach to care, with a focus on working in partnership with service users to deliver better outcomes for patients, clients and carers.

¹⁰ Inpatient Care for people with Diabetes: The Economic case for Change. Insight Health Economics. November 2011

¹¹ Department of Health (2009, updated 2013). *Quality and Productivity: Proven Case Study. Improving the quality of care for people with Type 1 diabetes: dose adjustment for normal eating (DAFNE)*

¹² <http://care.diabetesjournals.org/content/33/8/1872.full.pdf+html>

Transforming Your Care has emphasised a new model of care designed around the individual and with their active involvement in decision-making about how their treatment and care is provided. The model also looks to deliver more services in the community with access to specialist care where this is needed.

- 2.23 Within this model, primary and community based care is at the core of service delivery and should be the most appropriate setting in which to meet the majority of people's health and social care needs.
- 2.24 The meaningful involvement of people living with diabetes in how diabetes care is designed and delivered offers benefits to both individuals and to the community. In order to ensure meaningful involvement, partnership working is one of the themes underpinning the Strategic Framework.

A Population-based Approach to Health and Well-being

- 2.25 Understanding the wider context in which health and well-being is shaped is crucial if we are to effectively tackle the challenges of diabetes. Factors that play a part in determining our health and well-being include income, employment status, educational attainment, and our living, working and environmental conditions, all of which impact on the level of control people have in their lives and the choices they are in a position to make. The impact of lifestyle factors is a major contributor to the increasing prevalence of Type 2 diabetes.
- 2.26 The strategic framework for public health, *Making Life Better*, recognises the need to work across sectors to redress health inequalities and create the conditions for individuals, families and communities to take greater control of their own lives, and be enabled and supported to lead healthy lives.

Section 3 - Review of Diabetes Care in Northern Ireland

Background

- 3.1 Faced with the increasing challenge of diabetes and the drive to ensure high quality, person-centred services, in January 2012 the then Health Minister, Edwin Poots MLA, commissioned a review of diabetes care in Northern Ireland. A Diabetes Review Steering Group, chaired by the Chief Medical Officer, Dr Michael McBride was set up to lead the review with input from a range of stakeholders across the statutory and independent sectors, including Diabetes UK. The Terms of Reference for the review are at **Annex A**.
- 3.2 The Report of the Diabetes Review Steering Group was published in June 2014 and can be accessed at:
<https://www.dhsspsni.gov.uk/publications/report-diabetes-review-steering-group-reflecting-care-people-diabetes-2003-2013>
- 3.3 Key areas of progress highlighted by the Review Group included:
- more emphasis on community based initiatives and a greater range of public health strategies targeted at encouraging healthier lifestyles to prevent Type 2 diabetes and the onset of complications;
 - a higher level of provision of care for people with diabetes in primary care and an increased emphasis on supporting people to self manage their diabetes;
 - increased levels of provision of structured diabetes education, particularly for children diagnosed with Type 1 diabetes;
 - the establishment of a comprehensive screening programme for eye disease;
 - an increase in staffing levels, with particular increases seen in dietetics, and specialist nursing;
 - the introduction of new technology, for example insulin pumps and tele-monitoring;
 - improved services for children and for women living with diabetes who are pregnant or contemplating pregnancy; and
 - the development of clinical information systems based in hospitals and GP surgeries.
- 3.4 However, in reality this progress is being outstripped by increasing demand.

Challenges Identified by the Diabetes Review

- 3.5 The Diabetes Review set out a number of challenges. These challenges are summarised below and have formed the basis for the strategic themes in the Framework.
- 3.6 *Clinical Leadership and User Involvement*
Opportunities for user involvement in planning and design of services for people living with diabetes remain limited. Clinical leadership is required, not only at the level of individual organisations but at a regional and strategic level. Service users should be able to engage in an effective and meaningful way in service design by participating in the committees and groups that make key decisions to ensure services are responsive to their needs and concerns.
- 3.7 *Empowering Patients through Structured Diabetes Education*
A clear strategy is required at regional level to ensure that Structured Diabetes Education to support self-management is delivered in a consistent way and targeted at clearly defined groups or according to agreed criteria for prioritisation.
- 3.8 *Public Health, Epidemiology, Health Economics and Demographics*
Better prevention of Type 2 diabetes, through societal and public health measures, is a key challenge. Linked to this is secondary prevention and delaying the onset of complications through a combination of optimal clinical management and public health interventions.
- 3.9 *Building Capacity and Enhancing Skills in Frontline Staff*
Front line staff should have the necessary skills to provide treatment and care for most patients and to support people to self-manage their diabetes. Opportunities for health and social care professionals to undertake appropriate training, including the opportunity for multi-disciplinary training, should be linked closely to workforce planning and a strategic approach to enhancing competency and capacity on a multi-disciplinary basis.
- 3.10 *Ensuring Commissioning is aligned to the Complex Nature of Diabetes*
There should be an emphasis on co-ordination and synergy across different specialities and care sectors. Services and support for vulnerable groups are particular areas of concern with further emphasis required on the needs of children and pregnant women as well as other groups such as those with learning disabilities, the frail elderly in nursing homes and black and ethnic minority groups where there is evidence of increased prevalence and complication risk.

3.11 *The Age of Multi-morbidity*¹³

As people live longer and with more complicated health and social care needs, a key challenge for health and social care providers will be to ensure that services are offered in an integrated fashion.

3.12 *Managing New Technologies and Innovation*

Innovation - whether this relates to service design and delivery, new drugs or new technologies - should continue to be encouraged in a managed way that takes into account clinical and cost effectiveness and supports better outcomes for service users.

3.13 *Integrating Information Systems*

The need to optimise and integrate clinical information systems is seen as fundamental to improving care.

Recommendations from the Diabetes Review (June, 2014)

3.14 The Diabetes Review made 11 recommendations that reflected the findings, conclusions and challenges which the review group identified. In addition to the recommendation to develop a strategic framework for diabetes, the recommendations encompass important aspects of the prevention and management of diabetes and its complications.

3.15 The important principle of a partnership approach is recognised by the recommendation to develop an appropriate mechanism to enable health professionals, patient representatives and people living with diabetes to be engaged in developing services. Other recommendations focus on public health measures to help prevent Type 2 diabetes; improving access to Structured Diabetes Education; building capacity and skills in the workforce; improving services for children and young people, pregnant women and other at risk and vulnerable groups; and encouraging innovation in care for people living with diabetes. The need for integrated information systems to support optimal diabetes care and assessment of effectiveness is also highlighted.

3.16 The recommendations from the Diabetes Review can be found at **Annex B**.

3.17 The policy context which underpins the development of the Framework is summarised in **Annex C**.

¹³ Two or more co-existing conditions.

Workshop for Key Stakeholders (April, 2015)

- 3.18 To ensure that the proposed strategic way forward was informed by as wide a range of experience and expertise as possible, on 24 April 2015, the Department of Health, Social Services and Public Safety and the Public Health Agency convened a regional workshop for key stakeholders, including people living with diabetes.
- 3.19 The outcome of the workshop indicated a need for:
- regional agreement on standards and models of care;
 - improved communication and sharing of clinical information across care sectors;
 - public health measures to help prevent Type 2 diabetes;
 - improved access to Structured Diabetes Education;
 - a resilient and skilful workforce;
 - better recognition of, and services for, at risk or vulnerable groups; and
 - encouraging innovation in care for people living with diabetes.
- 3.20 The workshop also showed that establishing a shared understanding of what is working well currently within services has the potential to build momentum for scale and spread of innovative and improved models of care.
- 3.21 A summary report of the diabetes workshop can be found at **Annex D**.
- 3.22 The content of the Diabetes Strategic Framework is based on the recommendations made by the Diabetes Review, refreshed and updated through the proceedings of the diabetes workshop in April 2015 and of the Diabetes Task Group set up to draft this framework.

Section 4 - A Strategic Direction for Improving Diabetes Services

What Are We Trying to Accomplish?

- 4.1 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.
- 4.2 This vision can only be realised if all partners commit to working in collaboration for the long term, maintaining a focused holistic approach.
- 4.3 In implementing this Strategic Framework, our focus will be not simply to meet the challenges that have been highlighted, but to transform lives.
- 4.4 A focus on outcomes is critical. It is relatively easy to set targets around processes and activities, but these on their own will not deliver better outcomes for people living with diabetes or those likely to be at risk of developing Type 2 diabetes. Instead we need to measure the quality of our services by the extent to which they are making a real and positive difference in people's lives.
- 4.5 The key findings and recommendations made by the Diabetes Review and highlighted by participants in the workshop have provided the impetus for the development of this Strategic Framework. To realise the vision of the Framework will require an ongoing programme of work that will be reviewed and updated regularly as innovations and improvements are made and new priorities emerge.

How Should Care Be Delivered?

- 4.6 The majority of people living with Type 2 diabetes in Northern Ireland, and indeed the UK as a whole, are managed largely in primary care. General Practitioners (GPs) and practice nurses play a key role, supporting people to self manage their condition and helping them navigate a sometimes complicated health system. For some, specifically the frail elderly and housebound, the District Nursing Service will be the main provider of nursing care and support.

- 4.7 Where appropriate, for example when people have co-morbidities or more complex care needs, there should be ready access to multidisciplinary specialist diabetes teams for advice and referral. Specialist diabetes teams bring together clinicians, nurses, podiatrists, dieticians, social workers and clinical psychologists to provide direct care for people with more complex needs. Members of the specialist diabetes team can also provide advice and support for colleagues who are not specialists in diabetes.
- 4.8 Most people living with Type 1 and more complex Type 2 diabetes should be under the care of the specialist diabetes team. For people admitted to hospital, the input of specialist diabetes teams is an essential standard of care. The role of the team in supporting in-patient care is outlined at Theme 5.
- 4.9 People living with diabetes should have as a minimum an annual check up, including review of control of blood glucose, blood pressure, blood fats (such as cholesterol), kidney function, body weight and smoking habit as well as checking foot condition. There is a regional programme for eye screening. These are indicators of health status for people living with diabetes.
- 4.10 The key challenge facing our health and social care system is that every day, on average, 10 people are newly diagnosed with diabetes. Both primary care and specialist teams describe being overwhelmed by the increase in demand and in the complexity of need. To meet this challenge innovative approaches to service and workforce design, coupled with technological and other enablers of better self-management, are essential. 'Outside the box' thinking about new ways to support people who are currently hard to reach for traditional health and social care services is also necessary, for example through community and faith groups.
- 4.11 Diabetes pathways should be designed to facilitate seamless transition between services and professionals. Setting to one side the personal cost to the individual faced with navigating a complicated system of care, significant efficiencies may be achievable by improving reliability and by reducing waste and duplication in care processes.

What Changes Will Lead to Improvement?

- 4.12 The recommendations in the Diabetes Review have been grouped into seven key themes, which reflect the primary drivers for improvement and which form the basis for the Strategic Framework's implementation plan.
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
 7. Encouraging Innovation.
- 4.13 The first of these key themes - A Partnership Approach to Service Transformation - is essential for the implementation of the Framework. Only by taking forward actions in a collaborative and co-ordinated way that involves all partners will the other key themes be realised.

Measuring Progress and Impact

- 4.14 The effectiveness and impact of this Strategic Framework will be measured by improvement in outcomes that matter to people living with diabetes, by their experience of care and by more efficient use of resources. It will be measured by reductions in, and delay to, the onset of complications in those most at risk. It will also be measured by the extent to which unwarranted variation within and between services is reduced.
- 4.15 We have identified a number of indicators to enable us to track progress (**Annex E**). Although some indicators are not readily available yet, we will develop systems and processes to enable us to reliably report progress against these key indicators in the future.

Key Themes, Principles and Strategic Objectives

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

Supporting Principle

The person living with diabetes, and their interests should be at the centre of all relationships, with individuals recognised as partners in the planning of services and how their care is provided. Services should be integrated and based on collaborative working.

- 4.16 The Diabetes Review recommended that an appropriate mechanism be put in place to enable service users, patient representatives and clinicians to engage in developing services for people living with diabetes. The Review Group's aim was to ensure that people living with diabetes are involved in decisions about their care at all levels, reflecting the concept *nothing about me without me*. Since the Review Group published its report, service user involvement in designing diabetes services has been improved through the work of Integrated Care Partnerships.
- 4.17 Participants at the workshop were clear that an immediate priority, at a strategic level, must be to transform how care is delivered, with the development of a model of care that promotes consistency of approach across Northern Ireland, better integration of services between primary and secondary care and better outcomes for people living with diabetes.
- 4.18 It was agreed that a partnership approach offers the best opportunity to mobilise all of those who have a contribution to make, to redesign and re-organise services sustainably and affordably, and to deliver better outcomes for both the individual and the population.
- 4.19 At a personal level, a partnership approach will ensure that the person living with diabetes is at the centre of the planning and delivery of their own care. Their expertise and knowledge about how their condition affects them physically, emotionally and socially should be key to improving the quality and experience of their treatment and care and ensuring their needs are met.
- 4.20 Fundamentally, decisions made in partnership, between the individual and his or her care provider, are more likely to achieve the desired outcome

How Can Improvement Be Achieved?

- 4.21 To underpin a partnership approach, a network will be established. This will support and enhance the involvement of service users and clinicians in decision-making about service redesign. It will be a vehicle for collaboration to improve diabetes care between the statutory, voluntary, community and independent sectors across Northern Ireland. For the purposes of this consultation document, this will be referred to as the ***Diabetes Network***, meaning ***a partnership structure which brings all the key stakeholders to the table to work together***.
- 4.22 There are numerous possible network models from which to draw learning and to inform the design of what is a critical success factor for the Framework. A workshop will be convened to ensure that the structure and Terms of Reference for the Diabetes Network are fit for purpose.
- 4.23 The Diabetes Network will:
- support better communication and integration across all sectors;
 - identify priorities for improvement;
 - provide regional oversight for improvements and innovation ;
 - act as a driver to better outcomes for people with diabetes;
 - ensure the development of appropriate standards for the provision of care for people living with diabetes;
 - provide a platform for sharing good practice; and
 - ensure a cohesive and targeted response to the challenges posed by the increasing prevalence of diabetes.
- 4.24 The Diabetes Network will formally determine how people will be engaged and involved at every level. Diabetes UK is a considerable resource for the Network to draw on for this work.
- 4.25 There is a need to actively support primary care teams, community teams¹⁴ and specialist diabetes teams to innovate, with investment in technology, in opportunities to test and learn about new models of care and in opportunities for multi-disciplinary training and development. The Diabetes Network should involve GPs and primary care teams at a strategic level, possibly through the new GP Federations, in developing a sustainable model for GP-led care for people living with diabetes. This should be informed by the work of Integrated Care Partnerships.

¹⁴ This term includes Trust staff working in community settings whose care touches people living with diabetes but who are not themselves specialists in diabetes, for example, district nurses

Strategic Objective 1		
Clinicians and people living with diabetes will be actively involved in decision-making about service development		
Lead responsibility	Actions	Timescale
DHSSPS	Establish a Diabetes Network to enable stakeholders to be fully engaged in transforming services for people living with diabetes	Immediate
Diabetes Network	Establish a work programme designed to measurably improve outcomes.	Within 12 months
	Define and test operational principles for achieving sustainable improvement	
Link to Diabetes Review Report: Recommendation 1		

Box 2: Structured Diabetes Education in the Northern HSC Trust

The Northern Health and Social Care Trust has the highest population of people living with diabetes with currently over 20,000 people diagnosed with the condition.

To address this the Trust has increased access to Structured Diabetes Education for 2 programmes: *DAFNE (Dose Adjustment for Normal Eating)* is for people with Type 1 diabetes and *DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed)* is for those with recently diagnosed Type 2 diabetes

Both the DAFNE and DESMOND programmes have arisen from multi-disciplinary, multi-centred collaborations that are firmly embedded in the NHS, have undergone randomized controlled trials, have a robust evidence base and are delivered throughout the United Kingdom.

Both programmes adhere to 5 key criteria that fulfill NICE requirements. These are:

- a patient-centred philosophy;
- a structured curriculum;
- trained educators;
- quality assurance and
- audit.

The Trust invested and became a recognised DAFNE centre. Two diabetes specialist teams consisting of a doctor, a dietician and a diabetes specialist nurse in each team undertook DAFNE training and started delivering DAFNE programmes to people with Type 1 diabetes in 2013.

In 2015 Integrated Care Partnership funding gained through prescribing savings was provided for the training of 5 DESMOND educators (2 practice nurses, 2 dieticians and 1 diabetes specialist nurse) and 1000 places on DESMOND programmes. It is anticipated that places for 500 newly diagnosed with capacity for 500 with ongoing diabetes will be provided during 2016.

Source: Diabetes UK

Key Theme 2 - Supporting Self-management - Empowering People through Structured Diabetes Education

Supporting Principle

Diabetes education should support self-management and provide people with the knowledge and skills they need to manage their diabetes more confidently to maintain or enhance their health and wellbeing.

- 4.26 Supporting people to manage their condition is a fundamental element of good diabetes care and central to the building of relationships in which people living with diabetes work with health and social care professionals to understand and take control of their condition more effectively.
- 4.27 Helping people to understand their diabetes and recognise its effects and how these can be managed better, can help them develop the confidence to take more responsibility for their self-management. For the individual this can lead to better informed lifestyle choices and diabetes control, reduced risk of complications, fewer GP visits and hospital admissions as well as an improvement in quality of life and general well-being.
- 4.28 Although Structured Diabetes Education (SDE) programmes are central to supporting self-management, the Diabetes Review found that the provision of such programmes was variable and insufficient to meet demand.
- 4.29 Workshop participants stressed the need to increase the availability of SDE programmes and prioritise target groups. A regional approach to improving access to SDE programmes for different diabetes groups (including refresher programmes) was seen as a priority.
- 4.30 Information to help people self-manage their diabetes should be made available in a variety of media and formats to suit individual needs and preferences. The way in which information is provided should take account of the language, the level of understanding, capacity and the cultural and social background of individuals. Where necessary assistance should be made available to help people access, understand and make sense of information and ensure it is interpreted correctly.
- 4.31 People will need different methods and strategies for managing their diabetes. People with diabetes should have a holistic needs assessment which considers what information, treatment and health and social care support are required to allow them to self manage their diabetes. This information should inform the development of personalised care plans tailored to the assessed

needs and ability of the individual. Such plans should address general lifestyle and physical, social and mental health and well-being.

How Can Improvement Be Achieved?

- 4.32 People who have been newly diagnosed with diabetes should be offered access to Structured Diabetes Education programmes within 6-12 months of diagnosis. An essential element to support this is to raise awareness of the importance of SDE. The potential for digital technology to assist and support the provision of SDE needs to be explored.
- 4.33 Social media may have a more general role to play in supporting self-management by engaging, empowering and informing patients and carers, including through the provision of reliable, up to date information from recognised sources. This too should be explored.

Box 3: #Type1West – Using Social Media to Support Self Management

In November 2014, the diabetes service of the Western Trust, Diabetes UK NI and volunteers living with Type 1 diabetes planned and delivered an event to bring together other people living with Type 1 diabetes in the western area to share experiences of living with Type 1 diabetes. One of the volunteers and Cara Dillon, a well known singer from the Dungiven area, talked about their lives and how they coped with Type 1 diabetes. The attendees went on to create a Facebook group and took on the name #Type1West. At the time of this publication the group has grown to 123 members over 1 year and they have also arranged several meet ups, inviting healthcare professionals to take part in some of the meetings.

The benefit to people living with Type 1 diabetes is best captured by the words of members themselves.

"Makes me feel normal! (almost!) and that I'm not a bad person just because my blood glucose isn't perfect."

"Yes, being newly diagnosed this group allows to feel less alone in my journey with T1. I feel assured that I can get advice on here outside of appointment times and also make some friends in the process...always a positive lol"

".....it's nice to be able to just pick up your phone and ask people in similar position for advice. The clinic was always a nightmare and somewhere you were petrified to go, not anymore of course! I've met some lovely people through #Type1West and I love that I can pass on my experiences....It's a brilliant forum and one I hope expands further."

"When this group was first put together I was pregnant and working and had no time but though I missed out on the meet ups I still felt part of it. It's almost like a safety net. In day to day life you're completely on your own with diabetes and even the people that live with you will never ever understand the physical and mental struggles you have with it. But just being able to rant or post something here helps. There are loads of online diabetes groups but when people have meet ups far away you feel alienated even though it's no one's fault you live away from them. It's nice to know there are so many people facing the same daily struggles as you in the same city. The possibility of meeting up, though lives are busy, is a valuable safety net."

The group continues to grow and further events in collaboration with Diabetes UK are planned.

Source: Dr Neil Black, Western Health and Social Care Trust

Strategic Objective 2		
For those who are able, people will be actively encouraged and given the skills to manage their own health		
Lead responsibility	Actions	Timescale
Diabetes Network	Agree a menu of quality assured Structured Diabetes Education (SDE) programmes, consistent with NICE criteria ¹⁵ , for Northern Ireland	Within 12 months
Diabetes Network (programme plan)	Establish a plan for delivery of SDE programmes in Northern Ireland with the goal that all newly diagnosed people with diabetes can be offered SDE within 6-12 months of diagnosis.	Within 24 months
Trusts (programme delivery)	Establish a 'catch up' plan to meet the needs of those already diagnosed who have not already been offered SDE and to meet the need for refresher programmes.	Within 3 years
Diabetes Network With Public Health Agency	Explore whether digital technology can be used to support delivery of SDE. Scope the role of social media in supporting self-management.	Within 24 months
Link to Diabetes Review Report: Recommendation 4		

¹⁵ NICE Quality Standard 6 (2011)

Key Theme 3 – Prevention, Early Detection and Delaying Complications

Supporting Principle

Efforts to help people understand how to reduce their risk of Type 2 diabetes should be increased. Public health interventions should complement and augment the clinical management of people living with diabetes to support secondary prevention of complications.

4.34 This recommendation has a broad scope, including both primary prevention of Type 2 diabetes and secondary prevention of complications for people already living with diabetes.

Primary Prevention

4.35 The Diabetes Review Report noted the considerable evidence that 80% of Type 2 diabetes can be prevented or delayed by promoting healthy eating, physical activity and a healthy lifestyle.

4.36 Workshop participants identified potential public health actions, namely:

- partnership with key stakeholders such as local councils on areas such as activity and well-being;
- influencing broader society and the environment; and
- influencing in the early years, for example through programmes which support parents.

4.37 These themes are also central to '*Making Life Better*' (MLB), the new Strategic Framework for Public Health and '*A Fitter Future for All*' the obesity prevention framework. The Public Health Agency (PHA) has been actively leading the implementation of both of these frameworks, working in conjunction with a range of cross sector partners to create the conditions to enable people to lead healthier lives. In Northern Ireland, the proportion of obese and overweight adults has changed only marginally from 59% in 2005/06 to 60% in 2014/15¹⁶.

4.38 Although much of the emphasis in primary prevention of Type 2 diabetes has been on tackling obesity and promoting healthier lifestyle, there are other factors which are associated with an increased risk of developing Type 2 diabetes. Elderly people are more prone to develop Type 2 diabetes associated with the ageing process. Type 2 diabetes is up to 6 times more

¹⁶ Health Survey NI - First Results 2014/15; DHSSPS 2015

likely to develop in people of South Asian descent and up to 3 times more likely in African and African Caribbean people¹⁷. Some people who have learning disability are also at increased risk.

- 4.39 Whilst it seems sensible to direct prevention at those who, for whatever reason, are at increased risk in order to prevent them developing Type 2 diabetes, the evidence for what interventions are effective at population level for individuals at increased risk is still emerging. NICE has published Public Health Guidance on interventions aimed at shifting the risk of developing Type 2 diabetes at population level, including interventions to raise awareness of risk factors¹⁸ (PH35, May 2011) and on identifying and intervening with people identified as being at increased risk to prevent or delay onset¹⁹ (PH38, July 2012). The Framework will give impetus for the implementation of evidence-based approaches most likely to be effective in the Northern Ireland context.

Secondary Prevention and Early Intervention

- 4.40 Most of the care offered in primary care settings and by specialist teams to people living with diabetes is aimed at preventing or reducing harm to eyes, kidneys, blood vessels and nerves by optimising blood sugar control. Early and appropriately targeted interventions, based on complexity of need, can help ensure that those most at risk of developing complications receive the treatment, care and support they need to minimise those risks. NICE has developed guidelines for the treatment and care of people living with diabetes that explicitly address the prevention of additional complications. There is much evidence about what works. The challenge is one of ensuring that the evidence is translated into practice.
- 4.41 The primary care team has a key role in prevention and early detection of complications through the annual review offered to people living with diabetes.
- 4.42 Many of those who would benefit most from measures aimed at secondary prevention fall within groups that are considered to be particularly vulnerable or at risk, for example people with severe mental health difficulties or people with learning disabilities. This is explored further under Theme 5 which addresses how those identified as being at greater risk of complications can have those risks better managed and controlled.

¹⁷ *Association of glycaemia with macrovascular and microvascular complications of Type 2 diabetes: prospective observational study*. British Medical Journal 2000; 321: 405-412.

¹⁸ <http://www.nice.org.uk/guidance/ph35> accessed February 2016

¹⁹ <http://www.nice.org.uk/guidance/ph38> access February 2016

- 4.43 The Health and Social Care system in Northern Ireland employs more than 70,000 people, many of whom have regular contact with people living with diabetes. The Diabetes Review emphasised the opportunity that exists, if advice about smoking cessation, healthy eating and physical activity are part of routine practice, to reinforce those public health interventions which have a role to play in secondary prevention of complications.

How Can Improvement Be Achieved?

- 4.44 '*Making Life Better*', the framework for improving the population's health and well-being, and '*A Fitter Future for All*', the obesity prevention framework, both promote the importance of a healthy lifestyle. The Diabetes Network will be represented on the implementation groups taking forward these strategies.
- 4.45 NICE has published guidance on public health interventions to prevent Type 2 diabetes, which the Diabetes Review said it would be helpful to implement. An NHS Diabetes Prevention Programme (DPP) has been developed and is currently being tested by NHS England, Public Health England and Diabetes UK. Approaches to early intervention for people at increased risk of developing diabetes are being tested in a number of HSC Trusts. We need to take account of all these.
- 4.46 People who are identified as being at increased risk should have access to timely information, advice and support to raise awareness of risk and help them take positive steps to minimise this.
- 4.47 The need to address follow up services for women who experience Gestational Diabetes has been identified as a priority, because they are at increased risk of developing Type 2 Diabetes subsequently (see further under Theme 5).
- 4.48 Secondary prevention should be underpinned by agreed, evidence-based pathways designed for people living with diabetes in Northern Ireland. A regional group, supported by Diabetes UK, has developed an evidence-based Foot Care pathway. The pathway presents a secondary prevention approach that not only addresses foot care but can act to prevent deterioration of condition in others areas, such as the kidneys and the eyes. The implementation of this pathway, in terms of achieving better integration of services around the multitude of a person's needs, should be an exemplar for the Diabetes Network (see also under Theme 1).
- 4.49 At a regional level, a programme of work has been undertaken to enhance the eye screening programme. This work is being taken forward by its own Programme Board.

- 4.50 In the context of increasing need, it is a priority to find ways to identify and respond to those people most at risk of developing complications, for example, by risk stratification.

Box 4: Personalising Care through Risk Stratification

Diabetes care presents two significant challenges for general practice. The first is providing appropriate care to the whole population of patients with diabetes whilst identifying and enhancing care for patients with poor control amongst the increasing numbers of patients with diabetes - the challenge of risk stratification. The second is changing the locus of care from a doctor-centred model to a patient-centred model by engaging patients in really understanding and managing their own care - the challenge of individualising care. Several years ago Willowbank Surgery, Keady started to apply quality improvement methodologies to these problems. They developed a risk-stratification metric (the diabetic review score, DRS) using a care bundle of HbA1c, blood pressure, total cholesterol and eGFR (used to monitor renal function decline) which allowed the practice population to be “segmented” into high and low risk patients. A simple tag was developed to supplement the score providing a year to year summary of care and identifying patients with deterioration in their care.

Building on this work the practice recognised that real improvement required the involvement of patients in new ways and started to consider how to communicate this complicated data to patients to allow them to make decisions about their own care. A new care tool, the diabetes nudge chart, was developed. This tool is pre-populated with patient’s most recent monitoring and, led by the practice nurse during their review, helps patients understand their monitoring and “nudges” them to engage in improvement of their own care. Patients are able to compare their current care against what their general practitioner regards as optimal care for them.

Source: Dr Keith McCollum, GP, Keady

Strategic Objective 3		
Public health measures will be focussed on preventing people develop Type 2 diabetes and on preventing people living with diabetes develop complication		
Lead responsibility	Actions	Timescale
Public Health Agency	The Diabetes Network will be represented on the implementation groups taking forward ' <i>Making Life Better</i> ', the framework for improving the population's health and well-being, and the obesity prevention framework, ' <i>A Fitter Future for All</i> '.	Immediate
Public Health Agency	Establish an approach to the prevention of Type 2 diabetes for Northern Ireland which is congruent with emerging evidence	Within 24 months
Public Health Agency	Provide information, advice and support for people who are identified as being at increased risk	Within 24 months
Primary Care Teams and HSC Trusts supported by the Diabetes Network	Implement a foot care pathway that improves outcomes at individual and population level	Within 3 years
HSCB, Primary Care	Agree appropriate risk stratification in diabetes care.	Within 24 months
Link to Diabetes Review Report: Recommendation 3		

Key Theme 4 – Using Information to Optimise Services and improve Outcomes for People Living with Diabetes

The integration of information systems should underpin the development of diabetes services that are person-centred, flexible, timely and integrated across all sectors, with a focus on optimising outcomes for people living with diabetes.

- 4.51 The Review Group identified that the integration of clinical information systems is fundamental to good communication between, and co-ordination of, diabetes services across care sectors and to ensuring an outcome-focused approach to improving diabetes care and treatment. The Diabetes review said that “it is not possible to get an overview of the quality of diabetes care and of patient outcomes.....to make comparisons.....and to target resources based on need”²⁰.
- 4.52 Workshop participants also highlighted that the integration of information systems is crucial to the effective sharing of clinical data across care sectors, driving up the quality of treatment and care and supporting the measurement of service outcomes.
- 4.53 A number of clinical information systems are in place for capturing data about people living with diabetes in order to support individual treatment and care plans, as well as the planning and delivery of services at a more strategic level. However, the integration of datasets, particularly between secondary and primary care, remains problematic.
- 4.54 Clinical information systems currently in place include:
- GP based systems;
 - Diamond.net;
 - Twinkle.net;
 - PARIS - community information system;
 - Optimise (Eye Screening programme);
 - Northern Ireland Electronic Care Record (NIECR);
 - Renal Electronic Care Record (ECR); and
 - Queen’s University Belfast database for children living with diabetes.
- 4.55 The diabetes review has highlighted the need for baseline information that will support benchmarking of services and outcomes. Some work has already been undertaken at regional level to audit outcomes of hospital based

²⁰ Report of Diabetes Review Steering Group (2014), final paragraph, page 50.

diabetes care and outcomes of pregnancy for women living with diabetes. Audits have also been conducted at local Trust and general practice level.

How Can Improvement Be Achieved?

- 4.56 Developing an integrated care record for people living with diabetes and establishing accessible clinical data to inform outcome measurement and reduction in variations in care should continue under the direction of the Diabetes Network.
- 4.57 Planning new services and monitoring the effectiveness of existing services need to become more data driven. This will enable more transparent decision-making based on a combination of outcomes, quality and value for money. Whilst the Strategic Framework does not seek to suggest a mechanism to do this, the Diabetes Network should be charged with developing this area as a matter of priority to support all its work. Member organisations should contribute to making this happen across all sectors of health care.
- 4.58 The NIECR Team will continue to implement and test a diabetes care pathway embedded in the Electronic Care Record (ECR).
- 4.59 Patients should be able to track their own health information and clinical progress by means of a patient portal linked to the clinical information systems. The development of a patient portal is one of the key opportunities for self directed support and a shift away from traditional health care services and should be a focus for the Diabetes Network. The Network must also consider ways of engaging patients not able to use this kind of technology, for example, disadvantaged social groups and those with significant co-morbidities in both physical and mental illness.
- 4.60 To allow for a more comprehensive picture to inform service improvements, Northern Ireland will commence participation in the National Diabetes Audits²¹ from 2016.

²¹ <https://www.diabetes.org.uk/Professionals/Resources/National-Diabetes-Audit/> accessed February 2016

Box 5: Joining the Information Gaps - Technology Enabling Advance

The NI Electronic Care Record (NIECR) is the most widespread and successful technology enabling advance in Health and Social Care Northern Ireland.

Over the last 2 years, the NIECR Development Team has been working with diabetes healthcare professionals on a shared care record for people living with diabetes. This care record, when it is fully implemented, will bring together sources of information from all sectors, summarising care delivery, reducing duplication and co-ordinating person-centred care delivery. It will facilitate collaborative, integrated input to care for people with diabetes by multiple professionals based in different areas and backgrounds including primary and secondary care. Further developments such as a web-based Patient Portal will make this a truly integrated record. When it is fully implemented, it will facilitate audit for the assurance of quality of care.

Source: Dr Neil Black, Western Health and Social Care Trust

Strategic Objective 4		
Clinical information systems will be integrated		
Lead responsibility	Actions	Timescale
Diabetes Network	Agree an initial suite of indicators against which to measure improvement in care at local and regional level	Within 12 months
HSCB and HSC Trusts	Participation in National Diabetes Audits will commence in 2016.	Immediate
Diabetes Network supported by HSCB/PHA	Formalise the relationship between the Diabetes Network and the Northern Ireland eHealth Strategy Group with the goal of having: <ul style="list-style-type: none"> • a diabetes care pathway within the electronic care record; and • a portal through which people living with diabetes can manage their own health information and interact with clinicians. 	Immediate
Diabetes Network	Influence regional work to achieve integration of clinical information systems relevant for the care of people living with diabetes	Immediate
Link to Diabetes Review Report: Recommendation 2		

Key Theme 5 – Innovative Services for People Living with Diabetes, Particularly Those Requiring Bespoke Treatment and Care

Supporting Principle

Services should meet the needs of people living with diabetes. Where groups have been identified as vulnerable or at risk, services should be put in place which addresses their specific needs.

- 4.61 The Review Group identified the need for care that is seamless, accessible and effective, with services that are joined up and co-ordinated.
- 4.62 The Review Group identified a number of vulnerable and at risk groups for whom improvement in care is essential to ensure better outcomes and/or more effective prevention of complications. Participants at the diabetes workshop agreed with the need for explicit care pathways for vulnerable and at risk groups. They also identified the needs of hospital in-patients with diabetes.
- 4.63 The specific priorities identified under this theme are:
- Transition to adult services for children and young people with Type 1;
 - Pregnant women and those contemplating pregnancy;
 - Inpatient care for people with diabetes; and
 - Exploring how best to meet the needs of people at particular risk, for example people with mental illness or addiction, frail older people and ethnic groups known to have increased risk of diabetes.

Children and Young People with Type 1 Diabetes

- 4.64 In 2014 in Northern Ireland, 140 children under 15 were diagnosed with Type 1 diabetes²². Childhood and adolescence are particularly complex and challenging times for managing diabetes. Workshop participants were particularly concerned about risks associated with transitions of care where young people move to adult services.
- 4.65 In 2015, recurrent funding was allocated to HSC Trusts to ensure that all children diagnosed with diabetes receive the CHOICE Structured Diabetes Education programme within 6-12 months of diagnosis and are offered refresher courses as required.

²² Provisional data – QUB Paediatric Diabetes Register

- 4.66 A key priority for improvement is the transition for young people to adult services. Expanding access to Continuous Subcutaneous Insulin Infusion (CSII) via insulin pumps is also a priority.

Pre-pregnancy and Pregnant Women

- 4.67 In 2013/14, there were 1,251 pregnant women living with diabetes (5.2% of all pregnancies). An increase in the levels of obesity amongst women of child-bearing age and more women delaying pregnancy and having babies at an older age have resulted in a higher rate of gestational diabetes and increases in the number of women with Type 2 diabetes who require insulin during pregnancy. Unlike Type 1 diabetes, whose management largely resides within specialist diabetes teams, many women with Type 2 diabetes will be managed exclusively in the community prior to pregnancy. Ensuring those women who might become pregnant have the right education and support requires staff in primary and community settings to be well-trained and alert to the possibility. Pre pregnancy counselling which can improve pregnancy outcomes and reduce the risk of congenital malformations is now available in all 5 HSC Trusts.
- 4.68 The Diabetes Review Group identified gaps in services for pregnant women living with diabetes, and in particular referred to the role of the diabetes specialist nurse and dieticians within the context of joint antenatal diabetes clinics within each Health and Social Care Trust.

Hospital In-patients' Care

- 4.69 At the workshop, participants highlighted the need for better diabetes care for hospital in-patients. Patient feedback consistently shows that patients with diabetes feel disempowered and helpless in hospital managing a condition they often manage expertly at home.
- 4.70 People with diabetes spend longer in hospital when they are admitted compared to their peers and, at any one point in time, at least 15% of hospital in-patients are people living with diabetes. In the majority of cases, diabetes is not the direct reason for admission.
- 4.71 From the time of admission a person with diabetes should, when medically fit, be actively involved with clinical staff in ensuring that their diabetes is managed effectively through, for example, blood glucose monitoring and appropriate diet.
- 4.72 There is consistent evidence that care can be improved in hospital settings by involving Specialist Diabetes Teams, that beds are freed up for the use of

others because length of stay is reduced and that care is less expensive because complications of poor care are avoided. Economic analyses show that the staffing costs for the Specialist Team are quickly recovered through greater efficiency and effectiveness of care for people with diabetes. Reducing length of stay for in-patients with diabetes is not just good for the person themselves but also frees up beds supporting more efficient throughput of patients and more effective bed use which can impact on waiting times.

Other at Risk and Vulnerable Groups

- 4.73 Other groups that may be vulnerable or at particular risk include people with mental health or addiction issues or learning disabilities, frail older people, black and ethnic minorities, travellers, immigrants and homeless people.
- 4.74 The increasing age profile of the population is contributing to the increase in Type 2 diabetes. The prevalence of Type 2 diabetes among people over 75 is high, and is often associated with other conditions. There is also an increasing number of older people living with Type 1 diabetes.
- 4.75 There is widespread evidence that those living with long term conditions who also have serious mental illness, addictions and learning disabilities are at risk of poorer outcomes. There are a number of models of care that have been developed to support these vulnerable client groups and the Network should explore how these models could enable better diabetes care, for example through ensuring that effective social care support is available as part of the model of care whilst working to better understand the needs of this population
- 4.76 The Diabetes Review Report noted that it had been difficult to ascertain extensive information for the development of services for these groups. For this reason, the strategic priority is to gather such information and experience as is necessary to understand better how to meet, prioritise and address the needs of these vulnerable groups. The Diabetes Network will have a key role to play.

How Can Improvement Be Achieved?

- 4.77 For young people, access to insulin pumps must be improved and better approaches to supporting transition to adult services need to be developed;
- 4.78 Given the risk of poor pregnancy outcomes in women with diabetes, continuously improving the model of care to meet identified need is important. More rigorous antenatal screening is required. The early detection of Gestational Diabetes and the development of an agreed pathway for follow up

of women who develop Gestational Diabetes would have important benefits for pregnancy outcomes and for a group identifiably at increased risk of developing Type 2 diabetes; the majority of women with Gestational Diabetes respond to dietary advice and modification;

- 4.79 Specialist diabetes teams should provide diabetes care for people with complex needs, including people in hospital settings. Specialist teams should also support primary care colleagues in providing care in the community, including appropriate social care, to keep people out of hospital; and
- 4.80 Further information, including appropriate research evidence, will be sought to assess the experience and outcomes of care for vulnerable and at risk groups in order to identify their needs, prioritise and ensure services are tailored to their particular requirements.

Box 6: EU INTERREG IVA funding was provided via Co-operation and Working Together (CAWT) to establish two cross border projects

Pre-pregnancy care for women living with diabetes: This has been delivered through the establishment of pre-pregnancy care clinics across the project region. These clinics are open to all women of child bearing age with Type 1 or Type 2 diabetes or a past history of gestational diabetes. At these clinics their diabetes control is optimised, eye health is checked, medications are streamlined to ensure safety in pregnancy and women are started on high dose folic acid.

Diabetes education for children and young people: This has been provided through Structured Diabetes Education programmes (CHOICE) for children and adolescents living with diabetes and their parents / carers. As part of the project, the CHOICE programme was expanded to cover all age groups and a pump module was developed. The website www.diabetesandme.hscni.net re-enforces the messages from the CHOICE programme. All children and young people will be offered CHOICE within 6 months of diagnosis and annual refresher programmes in subsequent years.

Both of these projects were funded recurrently by the Health and Social Care Board in 2014/15. All 5 Trusts have pre pregnancy clinics in place and the CHOICE programme is offered to all children who are newly diagnosed with diabetes and their families.

Source: Dr Brid Farrell, PHA

Strategic Objective 5		
Improving outcomes for Children and Young People, pregnant women and people living with diabetes who are particularly “at risk” and vulnerable		
Lead responsibility	Actions	Timescale
Diabetes and Paediatric Diabetes Networks with HSCB and HSC Trusts	Develop a plan to achieve measurable improvement in access to insulin pumps for young people Develop a plan to improve experience of transition to adult services for young people	Within 3 years
HSCB and HSC Trusts	Achieve measurable improvement in service capacity to meet the needs of pregnant women with diabetes	Within 12 months
Diabetes Network and HSC Trusts	Test and implement reliable systems to support early detection and follow up for women with Gestational Diabetes	Within 3 years
PHA	Achieve measurable increase in the number of women who are pre-pregnancy and at risk who avail of pre-pregnancy counselling services	Within 24 months
Diabetes Network and HSC Trusts	Improve the experience of care in-hospital for people living with diabetes but admitted for other reasons by enhancing the capacity for Specialist Diabetes Teams to provide care, advice and support.	Within 3 years
PHA	Conduct formal needs assessments for particularly vulnerable people (see page 38) in order to inform future service models and improve outcomes.	Within 3 years
Link to Diabetes Review Report: Recommendations 7, 8 and 9.		

Key Theme 6 – Enhancing the Skills of Frontline Staff

Supporting Principle

Staff who come into contact with people living with diabetes should have the skills and competence to understand their needs and to ensure that these needs are met in a way that is person-centred.

4.81 The Diabetes Review Group identified the need for HSC staff to have:

- an understanding of, and competence in, basic interventions to promote public health;
- the necessary consultation and patient engagement skills to be able to work with individuals to enhance motivation and optimise self-management;
- opportunities for multi-disciplinary training; and
- opportunities for staff who are not specialists in diabetes to have high quality diabetes training and education.

4.82 In addition, workshop participants agreed that understanding the psychological needs of people living with diabetes should be integral to all consultations. Up to three quarters of people living with diabetes do not make the necessary behaviour change to optimise control²³. All team members should have basic psychological skills and be able to draw on those as a routine to reach and benefit all clients, with the specialist input of Clinical Psychologists reserved for those with greatest psychological need.

4.83 The Review did not make specific recommendations about primary care or about training and development needs in community and primary care settings. However, the primary care team, along with district and community nursing services, and where appropriate social care services, is pivotal to good management and support for people living with diabetes as it is for every person living with a long term condition. Most people spend their first 10 years with Type 2 diabetes being managed in primary care. All staff involved in the diagnosis and management of people living with diabetes must remain up to date and current in their practice.

4.84 The strategic direction of this Framework is to ensure that even more people are cared for as close to home as possible. There is evidence of good practice in diabetes care within primary care settings; however GPs are reporting that resources are overstretched. In addition to this there is a

²³ Report of the Diabetes Steering Group (2014), paragraph 2, Page 33.

growing number of frail elderly with complex co-morbidities many of whom are in group residential settings and their care is increasingly complex to manage. Having both the right capacity and the right skills in primary care and community settings to meet this demand are essential for the successful implementation of this Framework.

- 4.85 Since the review was published, an audit of acute hospital in-patient care has been completed which identified significant workforce training and education needs in in-patient settings.
- 4.86 A more formalised approach to workforce planning, training and development is required based on a refined needs assessment that will help support both the deployment of diabetes specialists and the development of skills for staff who are not specialists in diabetes. In addition, the Department is committed to developing improvement skills in the workforce to accelerate spread of improvement and innovation.

How Can Improvement Be Achieved?

- 4.87 A workforce plan will be necessary to support the implementation of this Framework. It should reflect need and support models of care, once these are agreed. It should provide for adequately staffed specialist diabetes teams to meet the needs of the local population. The DHSSPS workforce policy group will be asked to provide expert advice and leadership to meet this strategic objective.
- 4.88 Workforce planning and development should recognise the need for an appropriate geographical spread of specialist teams, with adequate skill mix.
- 4.89 The need for staff who are not specialists in diabetes to have the skills to support people living with diabetes is also recognised, for example, district, practice and community nurses. There are established mechanisms for assessing the training needs for different professional groups and diabetes care should be given priority in the forthcoming assessment. The Commissioning Review of General Practice Nursing and the District Nursing Framework, which are currently underway, will inform this work.
- 4.90 As a general point, given the pressures on staff time and the constraints on training budgets, consideration should be given to optimising the balance between e-learning, blended learning and face-to-face learning. Project Echo may have a pivotal role to play, pending its evaluation.
- 4.91 There are competency frameworks for specialist diabetes nurses, dieticians, podiatrists and other staff which are relevant to diabetes care and to physical

activity and nutrition for people living with diabetes. These should be considered for use in Northern Ireland.

- 4.92 The ***Diabetes- think, check, act*** project has developed 5 eLearning modules http://www.qihub.scot.nhs.uk/media/697238/flash%20report_dec_final3.pdf
- 4.93 These provide practical advice to improve the care and management of people admitted to hospital with diabetes as a secondary condition (see earlier under Theme 5). These engaging interactive modules are designed to be accessible to busy staff in hospital settings who do not have specialist diabetes training but who regularly care for people with diabetes.
- 4.94 ***Diabetes – think, check act*** is a Quality Improvement initiative. Over the last decade, Scotland has invested in developing improvement skills in the workplace with the intention of building a workforce that not only delivers care but also can improve care. Patient safety indicators show a downward trend in harm during that time period. In order to accelerate the spread of improvement and innovation in Northern Ireland, the Department has set a target to have 10% of the workforce trained to level 1 in the Quality 2020 Attributes Framework for Leadership in Quality Improvement.

Box 7: Crossing Interfaces – How the NIAS diabetes pathway supports better care

The NI Ambulance Service has implemented a “hypoglycaemia pathway” in conjunction with the Western, Northern and South Eastern Trusts. When called to someone who has been hypoglycaemic, an algorithm helps NIAS paramedics in their clinical decision making and supports them to determine the most appropriate of a range of treatment options to meet the patient’s needs.

If tests indicate that the patient has recovered, and they have eaten carbohydrates and can be left in the care of a responsible person, then the Paramedics can offer to refer the patient to the specialist diabetes team rather than take them to the Emergency Department. In the first 9 months of operation, a total of 128 referrals have been made to the specialist diabetes teams.

Source: NI Ambulance Service

Box 8: Diabetes Knowledge Network

ECHO, which stands for Extension for Community Health Outcomes, is an innovative approach to developing capacity in health systems to address the growing need to support people living with long term conditions. The ECHO model uses **tele-mentoring** to up skill community teams in aspects of specialist care. Tele-mentoring refers to the practice of conducting a mentoring relationship remotely. In this case, the community teams are connected to the mentors using videoconferencing technology.

The key features of the ECHO model are:

- use of technology to facilitate a hub and spoke model;
- case based learning;
- standardisation of best practice; and
- evaluation of outcomes.
- The NI Executive Change Fund has supported the Health and Social Care Board to test a number of ECHO knowledge networks in Northern Ireland. In partnership with NI Hospice, HSC bodies have established five knowledge networks including one for diabetes care. The Diabetes Knowledge Network is being piloted between December 2015 and March 2016.

The specialist hub membership is drawn from a number of professional groups and relevant charities, giving a truly multi-disciplinary source of expertise. A number of endocrinologists are inputting alongside dieticians, specialist pharmacists and representatives from Diabetes UK. Thirteen GPs from across Northern Ireland are participating on the spoke end and using examples from their clinical practice as a basis for discussion and learning. A full curriculum has been developed to cover the didactic teaching sessions in each meeting of the knowledge network. Initial feedback from participants has been very positive but a formal evaluation will be conducted at the end of the pilot in keeping with the ECHO model.

Source: Dr Brendan O'Brien, HSCB.

Strategic Objective 6		
A well-trained workforce with a focus on sustainability		
Lead responsibility	Actions	Timescale
Regional Workforce Planning Group with support from Diabetes Network	Develop a workforce plan for diabetes services, which takes into account: <ul style="list-style-type: none"> • the changing epidemiology of the condition; • the need for an integrated, multidisciplinary approach to care; • future reconfiguration of services; and • the skills required to deliver a high quality service for people living with diabetes. 	Within 3 years
CNO / PHA	Prioritise training in diabetes care for nurses and Allied Health Professionals who are not specialists in diabetes but regularly come into contact with people with diabetes. For specialists in diabetes, a programme for basic training in psychological skills will be designed	Within 24 months
HSC Trusts	At least 10% of staff who are specialist in diabetes care will be trained to level 1 in the Attributes Framework for Quality Improvement	Within 12 months
DHSSPS	Expert advice in improvement science will be provided to the Diabetes Network	Immediate
Link to Diabetes Review Report: Recommendations 5 and 6		

Key Theme 7 – Encouraging Innovation

Supporting Principle

New interventions and technologies, where appropriate and effective, will be used to support treatment and care for people living with diabetes.

- 4.95 The Diabetes Review acknowledged that, over the last decade, there has been considerable innovation in drugs and technology available to support people living with diabetes. It identified the challenge of ensuring that innovation is encouraged and that the introduction of new technology is managed in a structured and considered way.
- 4.96 Participants at the workshop were concerned that training needs for health and social care professionals should be anticipated when new technology is being introduced.
- 4.97 There are formal approval mechanisms in place to ensure that people across Northern Ireland have access to new interventions, such as drugs and devices, in an equitable way with a clear focus on ensuring that such interventions result in better outcomes. Through the National Institute for Health and Care Excellence (NICE) process, Technology Appraisals, clinical and public health guidance are endorsed and implemented as appropriate for Northern Ireland.
- 4.98 Since the Diabetes Review was published, progress has been made across Northern Ireland in the design of patient pathways and of service models necessary to deliver high quality care flexibly and responsively. Integrated Care Partnerships have been playing a key role in this.
- 4.99 There is a vibrant community of academics and clinicians associated with diabetes research and innovation in Northern Ireland that has contributed to improvement in person-centred diabetes care, including using innovative technology to support self management. However, the pace at which successful innovations are enabled to scale and spread regionally could be improved.
- 4.100 There are a number of avenues open to support innovation in the public sector. For example, a bid for an initiative to address diabetes in pregnancy has been submitted to the EU funded Horizon 2020 programme. The Small Business Research Initiative (SBRI) is a well established process to address

public sector challenges²⁴ through generating innovative product solutions from industry. This generates new business opportunities for companies, provides Small and Medium Sized Enterprises (SMEs) with a route to market for their ideas and bridges the seed funding needed by many early stage companies.

How Can Improvement Be Achieved?

- 4.101 The Diabetes Network should tap into the resources already available such as the Diabetes Clinical Interest Group within the Northern Ireland Clinical Research Network, the Improvement Network for Northern Ireland and HSC Clinical Innovations in order to be at the cutting edge.
- 4.102 The Diabetes Network should act as a hub for sharing innovative thinking and practice and to facilitate and accelerate scale and spread across the region (see Theme 6 – Improvement Advice).
- 4.103 All opportunities to benefit from both European and local business and other partnerships should be considered. Innovations in care for diabetes could be developed through the SBRI which also promotes growth in the NI economy²⁵. The Diabetes Network is a forum through which these can be shared and scoped.
- 4.104 Where new technology is introduced, supporting infrastructure, including training and updating for staff, must be in place.

²⁴ In the HSC context, public sector challenges are defined as unmet clinical needs for which there is no product, technology or solution in existence.

²⁵ <https://sbri.innovateuk.org/> accessed February 2016

Box 9: D- NAV – Putting Control in the Hands of Patients

A nurse-supported insulin titration service has been piloted in the South Eastern Health and Social Care Trust that relies on a handheld device (known as d-Nav) to improve blood glucose control and provide patients with an insulin dose recommendation for each injection while they use the device to monitor their glucose levels.

Similar to the approach healthcare providers use during clinical assessments, the device analyses stored glucose trends and constantly titrates insulin dosage without healthcare providers' supervision. By coupling glucose monitoring and insulin dosage provision in a single device, the device simplifies the process of insulin management, without the need for constant supervision from a clinician.

People who have used the d-Nav have shown marked improvements in glycaemic control, allowing them to easily regulate their own insulin dosage and reduce dependency on diabetes care services. Sustained improvement in glycaemic control reduces diabetes complications and the associated healthcare costs.

There are now over 400 people with Type 2 diabetes using d-Nav in the South Eastern Trust area. A formal evaluation of the service is being undertaken.

Source: Dr R Harper, SE HSC Trust

Strategic Objective 7		
Encouraging innovation		
Lead responsibility	Actions	Timescale
Diabetes Network	Establish formal links with the Diabetes Clinical Interest group within the Northern Ireland Clinical Research Network, the HSC R&D Division, the Improvement Network for Northern Ireland and HSC Clinical Innovations. One measure of success will be the number of peer reviewed publications from the Diabetes Network	Within 12 months
Diabetes Network with HSC Innovations	Scope opportunities to support individuals and teams to innovate	Within 12 months
HSCB	Establish processes to ensure that the introduction of new drugs and devices is supported by appropriate infrastructure including training for staff	Within 12 months
HSCB	Assess outcome of evaluation of d-Nav system to establish viability of further roll-out	Within 12 Months
Link to Diabetes Review Report: Recommendation 10		

Section 5 - Making It Happen

- 5.1 The Diabetes Review Group identified the need for clarity on issues of leadership, resources, governance and accountability if the findings and recommendations of the review report are to be properly addressed.
- 5.2 Given the complex nature of diabetes, responsibility and accountability for improving diabetes care will involve a number of diverse stakeholders. Since implementation of the Diabetes Strategic Framework will commence at a time of structural change in the Health and Social Care system, it will be necessary, initially, to have a transitional arrangement for governance of the Framework. In this context, what is meant by 'governance' is 'the process for strategic oversight to achieve results'. This will be reviewed after the structural reorganisation is bedded down.
- 5.3 The transitional governance arrangement consists of five elements:
- A Department-led regional oversight group which will ensure that the strategic framework and implementation plan is being delivered across Northern Ireland and will hold key delivery partners to account;
 - the Diabetes Network;
 - the PHA which is responsible for public health measures to support the delivery of the implementation plan;
 - the HSCB which is currently accountable for commissioning decisions; and
 - Trusts and primary care which together are accountable for the quality of care they offer and the outcomes achieved.
- 5.4 The Diabetes Network will belong to the whole system rather than to a single organisation. It will be co-chaired to reflect the partnership approach that will be an intrinsic underpinning principle for how it will operate.
- 5.5 The membership will include service users and their representatives, representatives of the clinical and professional disciplines and other senior managers and leaders who can facilitate and support transformative change.
- 5.6 The Department will support the Diabetes Network to use the Triple Aim framework (outlined in **Annex C**) as its method for driving improvement. This will involve support to staff to develop skills in improvement science.
- 5.7 In practice the Diabetes Network will be responsible for:
- driving improvement in outcomes by reducing variation;

- encouraging innovation: giving space for transformative redesign and reform;
 - enabling people and professionals to work in partnership; and
 - co-ordinating how learning is shared across the health and social care system.
- 5.8 Over time, the Network should have autonomy over a specific budget for delivery of key elements of the implementation plan.
- 5.9 An implementation plan has been developed jointly by the Health and Social Care Board and the Public Health Agency involving other stakeholders. Whilst the Diabetes Network will have responsibility for actions in the plan, accountability for enabling implementation of these will continue to lie with the HSCB and the PHA (pending the consultation and any proposed changes on structural changes). Oversight of the process will be provided by a Departmental-led Group.
- 5.10 Trusts will be accountable for delivering improvements and innovations in their services arising from the work of the Diabetes Network and under the strategic direction of the Department. At a time of financial constraint, it is important that resources are used effectively and efficiently. In implementing the Framework account will be taken of affordability and available resources.
- 5.11 Reforming how services are organised and delivered is the only way in which the transformation required will be achieved. The main driver for improvement will be the ability that the Diabetes Network can leverage at every level to support staff to test new ways of delivering services, using existing resources differently, and then to scale and spread what works across Northern Ireland.

Section 6 – Implementation Plan

6.1 The implementation plan reflects the recommendations in the Diabetes Review and the views and prioritisation identified both at the Stakeholder Workshop and through the deliberations of the Diabetes Task Group. Once established, the Diabetes Network will bring together decision-makers who are key to ensuring that services are fully responsive to the changing needs of people living with diabetes as well as influencing the actions and interventions that are most likely to constitute a successful approach to primary and secondary prevention. This implementation plan provides the starting point for the work of the Diabetes Network.

Key Theme	Action	Lead Responsibility	Timescale
Theme 1: A Partnership Approach to Service Transformation - Clinical leadership and User Involvement	Establish a Diabetes Network to enable stakeholders to be fully engaged in transforming services for people living with diabetes	DHSSPS	Immediate
	Establish a work programme designed to measurably improve outcomes	Diabetes Network	Within 12 months
	Define and test operational principles for achieving sustainable improvement	Diabetes Network	Within 12 months

Key Theme	Action	Lead Responsibility	Timescale
Theme 2: Supporting Self-management	Agree a menu of quality assured Structured Diabetes Education programmes (SDE), consistent with NICE guidance ²⁶ , for Northern Ireland	Diabetes Network	Within 12 months
	Establish a plan for delivery of Structured Diabetes Education in Northern Ireland with the goal that all newly diagnosed people with diabetes can be offered SDE within 6-12 months of diagnosis	Diabetes Network (programme plan)	Within 24 months
	Establish a 'catch up' plan to meet the needs of those already diagnosed who have not already been offered SDE and to meet the need for refresher programmes	Trusts (programme delivery)	Within 3 years
	Explore whether digital technology can be used to support delivery of SDE	Diabetes Network With Public Health Agency (PHA)	Within 24 months
	Scope the role of social media in supporting self-management		

²⁶ NICE Quality Standard 6

Key Theme	Action	Lead Responsibility	Timescale
Theme 3: Prevention, Early Detection and Delaying Complications	The Diabetes Network will be represented on the implementation groups taking forward ' <i>Making Life Better</i> ', the framework for improving the population's health and well-being, and the obesity prevention framework, ' <i>A Fitter Future for All</i> '	Public Health Agency	Immediate
	Establish an approach to the prevention of Type 2 diabetes for Northern Ireland which is congruent with emerging evidence	Public Health Agency	Within 24 months
	Provide information, advice and support for people who are identified as being at increased risk	Public Health Agency	Within 24 months
	Implement a foot care pathway that improves outcomes at individual and population level	Primary care teams and HSC Trusts supported by the Diabetes Network	Within 3 years ²⁷
	Agree appropriate risk stratification in diabetes care	HSCB, Primary Care	Within 24 months

²⁷ Trend showing process improvement likely to result in improvement in outcomes is expected

Key Theme	Action	Lead Responsibility	Timescale
Theme 4: Using Information to Optimise Services and improve Outcomes for People Living with Diabetes	Agree an initial suite of indicators against which to measure improvement in care at local and regional level	Diabetes Network	Within 12 months
	Participation in National Diabetes Audits will commence in 2016	HSCB and Trusts	Immediate
	Formalise the relationship between the Diabetes Network and the Northern Ireland eHealth Strategy Group with the goal of having a diabetes care pathway within the electronic care pathway and a portal through which people living with diabetes can manage their own health information and interact with clinicians	Diabetes Network supported by HSCB/PHA	Immediate
	Influence regional work to achieve integration of clinical information systems relevant for the care of people living with diabetes	Diabetes Network	Immediate

Key Theme	Action	Lead Responsibility	Timescale
Theme 5: Designing Services for People Living with Diabetes, Particularly Those Requiring Bespoke Treatment and Care	Develop a plan to achieve measurable improvement in access to insulin pumps for young people Develop a plan to improve experience of transition to adult services for young people	Diabetes and Paediatric Diabetes Networks with HSCB and HSC Trusts	Within 3 years
	Achieve measurable improvement in service capacity to meet the needs of pregnant women with diabetes	HSCB and HSC Trusts	Within 12 months
	Test and implement reliable systems to support early detection and follow up for women with Gestational Diabetes	Diabetes Network and HSC Trusts	Within 3 years
	Achieve measurable increase in the number of women who are pre-pregnancy and at risk who avail of pre-pregnancy counselling services	Public Health Agency	Within 24 months
	Improve the experience of care in-hospital for people living with diabetes but admitted for other reasons by enhancing the capacity for Specialist Diabetes Teams to provide care, advice and support	Diabetes Network and HSC Trusts	Within 3 years
	Conduct formal needs assessment for particularly vulnerable people (see page 38) in order to inform future service models and improve outcomes.	PHA	Within 3 years

Key Theme	Action	Lead Responsibility	Timescale
Theme 6: Enhancing the skills of frontline staff	Develop a workforce plan for diabetes services, which takes into account; <ul style="list-style-type: none"> the changing epidemiology of the condition; the need for an integrated, multidisciplinary approach to care; future reconfiguration of services; and the skills required to deliver a high quality service for people living with diabetes 	Regional Workforce Planning Group with support from the Diabetes Network	Within 3 years
	Prioritise training in diabetes care for nurses and Allied Health Professionals who are not specialists in diabetes but regularly come into contact with people with diabetes. For specialists in diabetes, a programme for basic training in psychological skills will be designed	CNO/PHA	Within 24 months
	At least 10% of staff who are specialist in diabetes care will be trained to level 1 in the Attributes Framework for Quality Improvement	HSC Trusts	Within 12 months
	Expert advice in improvement science will be provided to the Diabetes Network	DHSSPS	Immediate

Key Theme	Action	Lead Responsibility	Timescale
Theme 7: Encouraging Innovation	Establish formal links with the Diabetes Clinical Interest Group within the Northern Ireland Clinical Research Network, the HSC R&D Division, the Improvement Network for Northern Ireland and HSC Clinical Innovations. One measure of success will be the number of peer reviewed publications from the Diabetes Network	Diabetes Network	Within 12 months
	Scope opportunities to support individuals and teams to innovate	Diabetes Network with HSC Innovations	
	Establish processes to ensure that the introduction of new drugs and devices is supported by appropriate infrastructure including training for staff	HSCB	
	Assess outcome of evaluation of d-Nav system to establish viability of further roll-out	HSCB	Within 12 months

Conclusion

7.1 In its report, the Diabetes Review Group acknowledged that there have been significant developments and improvement in diabetes services since the publication of the 2003 Joint Taskforce report. Despite this progress however challenges remain to be addressed including:

- An increase in the number of adults living with diabetes as a result of lifestyle and an ageing population;
- Greater numbers of women who have diabetes in pregnancy;
- Requirement to respond to the expanding evidence base for effective diabetes care;
- The need to develop new models of care to improve co-ordination between primary, secondary and tertiary services to deal with the increase in numbers and complexity of care required; and
- Optimising the role of technology, including insulin pumps.

7.2 For service providers, meeting these challenges will require new ways of working and new service models in health and social care. The cornerstone of care will be supporting people to self manage insofar as they are able and willing to do so. Pathways of care must be seamless to the service user, easily navigable, with specialists working in partnership with staff who are not specialists in diabetes and, for the majority, meeting people's needs in community settings, close to people's homes.

DIABETES REVIEW REPORT – TERMS OF REFERENCE AND RECOMMENDATIONS

The aim of the Review Group was to review the CREST/Diabetes UK Joint Taskforce Report (2003) in order to assess progress against the report objectives, identify current gaps in the service and highlight emergent priorities.

This involved:

- Assessment of the Joint CREST/Diabetes UK (2003) report in respect of progress against report objectives and hence the identification of gaps in service provision;
- Assessment of current standards of care relating to diabetes and whether they are deemed appropriate;
- Identification of emergent issues relating to the management of diabetes over the last decade. These include those influenced by technological advances, organisational and professional developments and demographic change; and
- Assessment of the new policy context (including Transforming Your Care) and proposed implementation mechanisms and how these can best be utilised and harnessed to ensure diabetes services are commissioned effectively.

DIABETES REVIEW REPORT RECOMMENDATIONS**Recommendation 1**

It is recommended that the Health and Social Care sector in Northern Ireland should develop an appropriate mechanism to enable service users, patient representatives and clinicians to engage with commissioners in developing services for people with diabetes. This could be configured as a “forum” or “Managed Clinical Network”. This should be adequately resourced in terms of administrative support, as well as ensuring there is appropriate clinical leadership, multidisciplinary participation and appropriate stakeholder engagement.

Recommendation 2

It is recommended that the current clinical information systems used across sectors of care for managing people with diabetes should be reviewed with the objective of facilitating appropriate sharing of data. This would enable optimal clinical management, assessment of needs and measurement of quality of diabetes related care across Northern Ireland.

Recommendation 3

It is recommended that healthcare staff should be more fully engaged in ensuring that public health interventions complement and augment clinical management of people with diabetes. The new Strategic Framework for Public Health should encourage capacity building and competency in public health skills amongst front line staff as well as the wider public health function in order to fulfil this role.

Recommendation 4

It is recommended that results from the baseline audit of structured patient education and self-management programmes are utilised as a basis for assessing provision and identifying unmet need for people with diabetes. The Long Term Conditions Policy Framework Regional Implementation Steering Group should lead on formulating priorities with a view to widening access to high quality, quality assured patient education and self-management programmes in an equitable manner across Northern Ireland.

Recommendation 5

Training needs should be assessed in respect of management of diabetes on a regional basis, for individual professional groups and across diabetes care teams. Access to multidisciplinary education opportunities in managing diabetes requires urgent attention.

Recommendation 6

It is recommended that a workforce plan should be developed for diabetes services which takes into account the changing epidemiology of the condition, future reconfiguration of services and the assessment of skills required in order to deliver a high quality service for people with diabetes.

Recommendation 7

It is recommended that the issues relating to gaps in services for children and adolescents are addressed and that commissioners including the current MCN for specialist diabetes services for children continue to build on the progress of the last decade. It is recommended that the CHOICE structured patient education programme continue to be funded beyond December 2013.

Recommendation 8

It is recommended that the gaps identified in services for pregnant women with diabetes are given urgent consideration by commissioners. The role of the diabetes specialist midwife requires assessment within the context of the joint antenatal metabolic clinics operating within each Health and Social Care Trust.

Recommendation 9

It is recommended that commissioners and service providers acquire further information including appropriate research evidence about the needs of vulnerable groups. This would include an assessment of patient experience and clinical outcomes within vulnerable and underserved groups and ensure services are tailored to their particular requirements.

Recommendation 10

It is recommended that a managed approach is taken to the introduction of new innovations ensuring that patients across the region have access to new interventions in an equitable way whilst ensuring that Northern Ireland continues to provide a leadership role in the introduction of new technologies and research. NICE Technology appraisals and public health guidance related to diabetes should be implemented as appropriate.

Recommendation 11

It is recommended that the key findings and recommendations of the review of the Joint taskforce Report (2003) are consolidated appropriately as a strategic way forward or “roadmap” for diabetes so that the gaps in services and emerging priorities identified by the Steering Group can provide the basis for a way forward for service development, enable priorities to be identified for commissioners and the formulation of appropriate standards for the provision of care for people with diabetes.

POLICY CONTEXT FOR IMPLEMENTATION OF DIABETES STRATEGIC FRAMEWORK

Making Life Better

'*Making Life Better*',²⁸ the Northern Ireland Executive's overarching strategic framework for public health, was published in June 2014. *Making Life Better* provides the strategic direction to improve health and well-being and reduce health inequalities. It emphasises the inter-relationship between health and well-being, disadvantage, inequality, childhood development and education, employment, the social and physical environment and economic growth, and the need therefore for collaboration between government programmes to achieve mutual benefits. It also provides strategic direction for work at both regional and local levels with public agencies, local communities and others working in partnership. The strategic framework aims to improve health and reduce health inequalities with a vision that all people are enabled and supported in achieving their full health and wellbeing potential.

A Fitter Future for All

The obesity prevention framework, '*A Fitter Future for All 2012-2022*'²⁹ (AFFFA), was launched in March 2012. The strategy aims to empower the population of Northern Ireland to make healthy choices, reduce the risk of overweight and obesity related diseases and improve health and well-being, by creating an environment that supports a physically active lifestyle and a healthy diet.

Living with Long Term Conditions - A Long Term Conditions Policy Framework

The Department's Policy Framework for adults '*Living with Long Term Conditions*'³⁰ was published in 2012. The overall aim of the Policy Framework, which is applicable across a wide range of conditions and all care settings, is to provide a strategic direction for the reform and modernisation of services for people with long term conditions and in doing so to help service planners and providers plan and develop more effective services to support people with long term conditions and their carers.

The Policy Framework focuses on 6 key development areas for improving services to optimise health and well-being outcomes for people living with long term conditions and outlines a range of actions to support this.

²⁸ Making Life Better: A Whole System Framework for Public Health 2013-2014; DHSSPS (2014)

²⁹ A Fitter Future for All: Framework for Preventing and Addressing Overweight and Obesity in NI 2012-2022; DHSSPS (2012)

³⁰ Living with Long Term Conditions - A Policy Framework for Adults in Northern Ireland; DHSSPS (2012)

Quality Strategy

The Department's Quality 2020 strategy, published in 2011³¹, established a framework to protect and improve quality within health and social care over the next 10 years. The Strategy defines "quality" for health and social care in terms of three key components: safety, effectiveness and patient/client focus. The ethos of the Quality Strategy, and its focus on person-centred care, should underpin diabetes services across Health and Social Care in Northern Ireland.

Transforming Your Care

Transforming Your Care³² set out a strategic direction for the future of health and social care in Northern Ireland and a new model of care for Northern Ireland focused on people rather than institutions. A key element of TYC was the development of Integrated Care Partnerships (ICPs) to bring together statutory and non-statutory health and social care providers as well as service user representatives in collaborative networks. These networks aim to make sure that services are designed in a way that ensures service users receive more effective and efficient care.

The initial focus of ICPs is on the frail elderly and long term conditions, namely diabetes, stroke care and respiratory conditions. Work to improve treatment and care for people living with diabetes is being taken forward by the 17 ICPs working across Northern Ireland. In doing so, ICPs have been reviewing diabetes care pathways in their respective areas to identify opportunities to enhance service provision and improve outcomes for people living with diabetes, with a focus on risk stratification, information sharing, care planning and evaluation, supported by action plans to deliver more integrated care.

Donaldson Report

Professor Sir Liam Donaldson's report, '*The Right Time, The Right Place: An expert examination of the application of health and social care governance arrangements for ensuring the quality of care provision in Northern Ireland*' was published in January 2015. In its recommendations, the Donaldson report recognised the need to ensure that the patient voice was strengthened and also acknowledged the role of patient education to support self-management for people with long term conditions.

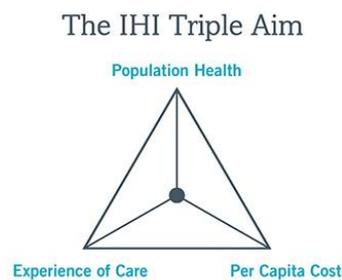
Institute for Healthcare Improvement (IHI) Triple Aim Framework

³¹ Quality 2020 A 10-year Strategy to protect and Improve Quality in Health and Social care in NI; DHSSPS (2010)

³² Transforming Your Care - A Review of Health and Social Care in Northern Ireland; 2011

The IHI Triple Aim is a framework developed by the Institute for Healthcare Improvement which describes an approach to purposefully transforming the system of care for a population³³. At the heart of the framework is a focus on achieving measurable improvement in outcomes across three key dimensions:

- improvement in experience of care for the individual (including quality and satisfaction);
- improvement in health and well-being for the population; and
- improvement in use of available resources.



Quality improvement tools and techniques are used to ensure that improvement, whether it results from innovative ideas or improved reliability from known processes, is reproducible at scale across the system of care. Training in improvement methods can be acquired on the job or, for a minority, through specialist training programmes.

DHSSPS is currently engaged with the Institute for Health Improvement (IHI) in exploring the application of the IHI's 'Triple Aim' framework to improvement in services for older people. There is a significant opportunity to apply the framework to the implementation of the Diabetes Strategic Framework.

³³ Pursuing the Triple Aim: The First 7 Years. Whittington et al. Institute for Healthcare Improvement; Millbank Quarterly, Vol 93, No. 2, 2015

SUMMARY OF DIABETES WORKSHOP

Key stakeholders from across the diabetes community attended a workshop on 24 April 2015. Entitled 'Meeting the challenge for Diabetes care in the 21st century', the objectives for this session were to:

- provide space and time to discuss the challenges and opportunities for delivery of diabetes care;
- capture and agree key priorities to be taken forward as part of the implementation plan for diabetes – including areas for early action (where possible); and
- discuss the transition arrangements for leadership and coordination for diabetes across the Region, moving forward.

Using a world café approach, approximately 50 participants from across the Health and Social care Sector were given the opportunity to share their perspectives and insights across 7 key themes (based on the 11 recommendations outlined in the review of diabetes), and contribute to development of the Implementation Plan:

- 1) Future models of care - what models of care should be put in place in Northern Ireland?
- 2) Innovation & new technology – how do we better ensure that innovation is encouraged and delivered in a more managed way for the benefit of service users?
- 3) Service user support and self-management - what is required to drive this in Northern Ireland?
- 4) Targeting high risk groups - how do we better target these groups at the outset and during transition?
- 5) Prevention & early detection – what is required to drive this in Northern Ireland?
- 6) Workforce opportunities - how do we better equip our workforce to address the challenges we face?
- 7) Delivering the diabetes plan - what needs to happen or change at local and regional level to deliver the plan?

In these discussion sessions, participants were asked to:

- Share and capture their ideas based on their own experiences and backgrounds (and reflecting on what had been presented during the workshop);
- Identify the top 4-5 big priorities to be taken forward in the implementation plan over the next 2 years (including outcomes and benefits); and
- Provide a view on what practical next steps should take place in the next 6-12 months against each of the top priorities (including who should be involved and the measures of success for each).

In Summary, the following emerged from the discussions around the 7 key workshop themes.

Future models of care - What models of care should be put in place in Northern Ireland?

The discussions favoured an agreed model of care for people living with diabetes with consistency of approach across the region. Key priorities included improved communication and sharing of clinical information across service providers and a focus on measurement and quantification of activity and outcomes. It was felt this would be best achieved by a mechanism which would provide effective regional oversight of service developments in diabetes.

Innovation & new technology – How do we better ensure that innovation is encouraged and delivered in a more managed way for the benefit of service users?

The participants felt that new technology was not being introduced systematically across the region with a particular disconnect between procurement and the supporting infrastructure to sustain implementation. Existing projects needed to be more closely integrated across sectors. Short term priorities include training for HSC professionals in the use of new and existing technologies and improved regional coordination and oversight of the process linked to evidence based assessments of effectiveness and economic benefit.

Service user support and self-management - What is required to drive this in Northern Ireland?

The discussion groups stressed the need to increase capacity in respect of structured patient education in order to improve access and to specify and prioritise target groups for the resources currently available. A regional approach to commissioning and procuring programmes, quality assurance and standardisation of curriculums were seen as priority areas for early action.

Targetting high risk groups - How do we better target these groups at the outset and during transition?

The participants recognized there were a number of high risk/vulnerable groups such as those with learning difficulties, travellers and ethnic minorities for whom care may be suboptimal. Patients with diabetes cared for in wards where staff did not specialize in diabetes were also seen as “vulnerable”. Children undergoing transition from paediatric to adult services were also seen as a priority. The development of clear care pathways for these groups required development.

Prevention & early detection – What is required to drive this in Northern Ireland?

A range of public health measures were put forward by discussion groups including a focus on health eating and physical activity. Targeted case finding and risk stratification were seen as important measures to facilitate early detection. Utilising and developing public health capacity and skills within the current HSC was also seen as a priority.

Workforce opportunities - How do we better equip our workforce to address the challenges we face?

There was a broad consensus that up-skilling the workforce across the board was a priority. This included those who primarily work in diabetes as well as the wider workforce who will encounter people living with diabetes within their usual role. Priorities for early action included agreeing models of care and developing a workforce and training strategy based around these.

Delivering the diabetes plan - What needs to happen or change at local and regional level to deliver the plan?

Clear clinical leadership, an effective regional infrastructure for oversight and delivery underpinned by robust performance measures were seen as priorities for the effective delivery of a diabetes action plan.

DIABETES INDICATORS

It is vital to measure whether the improvements as described in this Framework have achieved their desired effect. To this end a number of indicators for success are presented here. Some of these measures are currently available; others will require further development.

Population based measures

Incidence of type 2 Diabetes per 100,000 population.

Circulatory disease mortality rate under age 75 per 100,000 population.

Age group specific diabetes mortality rate per 100,000 population.

Processes of Care

Basic processes of care include on an annual basis:

Measurement of HbA1c, BMI, smoking status, urinary albumin, serum creatinine, blood lipids, foot assessment and retinopathy screening.

The percentage of people receiving some and all of these processes should be measured.

% persons who have attended structured diabetes education within 12 months of diagnosis.

% persons disengaged from diabetes care (see care processes above)

Glycaemic, Lipid and Blood pressure Control

% persons with HbA1c < 58mmol

% persons with a systolic blood pressure < 140mmHg

% persons with a cholesterol < 5mmol/l

Children and Young People

% in defined age groups with HbA1c < 58mmol/l

% Children achieving normal growth

% Children and young people receiving Diabetes Structured Education within 12 months of diagnosis.

Pregnant women with diabetes

% of successful pregnancy outcomes in women with diabetes.

% of pregnant women with diabetes who were in receipt of pre pregnancy counselling.

Secondary Complications

% of people with diabetes with sight threatening retinopathy or blindness

% of people with diabetes with a new foot ulcer

% of people with diabetes related limb amputation.

% of people with diabetes reaching end stage renal failure or requiring renal replacement therapy

Hospital Admission

People living with diabetes; compared to non diabetic population

Number of emergency admissions to hospital

Readmission rate

Average length of stay

Other useful measures

% of people with diabetes who are current smokers

% of people with diabetes using an insulin pump

% of people using other assistive technology (eg d-Nav, continuous glucose monitoring)

% of people with diabetes who experienced a glycaemic emergency

% of people with diabetes who are satisfied with their care

Glossary

Anomalies		<i>A deviation from the common rule, type, arrangement, or form.</i>
Congenital Malformation		<i>A condition existing at or before birth regardless of cause.</i>
CREST/Diabetes Taskforce	UK	<i>Established in 2001. The Taskforce published a framework for the development of services for people with diabetes in 2003. The framework contains a wide range of recommendations covering the full spectrum from screening for people with a high risk of developing diabetes to the prevention and treatment of the condition.</i>
Demography		<i>The study of statistics such as births, deaths, income, or the incidence of disease, which illustrate the changing structure of human populations.</i>
Gestational Age		<i>The age of a foetus or a newborn, usually expressed in weeks dating from the first day of the mother's last menstrual cycle.</i>
Gestational Diabetes		<i>A type of diabetes that affects pregnant women, usually during the second or third trimester. Women with Gestational Diabetes don't have diabetes before their pregnancy, and after giving birth it usually goes away. In some women diabetes may be diagnosed in the first trimester, and in these cases the condition most likely existed before pregnancy.</i>
Health Inequalities		<i>Disparities in health outcomes between individuals or groups. They arise from differences in social and economic conditions that influence people's behaviours</i>

and lifestyle choices, their risk of illness and actions taken to deal with illness when it occurs

Neo-Natal Deaths	<i>The death of a young, liveborn infant.</i>
Patient Empowerment	<i>A generic term popular in the UK for encouraging the active participation of patients and carers in choosing management options, including eliciting quality-of-life utilities and preferences by discussion, viewing of interactive videos, etc.</i>
Perinatal Mortality Rates	<i>Refers to the death of a foetus or neonate and is the basis to calculate the perinatal mortality rate</i>
Podiatry	<i>A branch of medicine devoted to the study of, diagnosis, and medical and surgical treatment of disorders of the foot, ankle, and lower extremity.</i>
Secondary Prevention	<i>Secondary prevention deals with latent diseases and aims to detect and treat a disease early on. Secondary prevention consists of "early diagnosis and prompt treatment" to contain the disease and prevent its spread to other individuals, and "disability limitation" to prevent potential future complications and disabilities from the disease.</i>
Self-Management	<i>A term used to support people living with long-term health conditions</i>
Stillbirths	<i>A baby born with no signs of life at or after 28 weeks' gestation.</i>

Structured Diabetes
Education

A planned and graded programme that is comprehensive in scope, flexible in content, responsive to an individual's clinical and psychological needs, and adaptable to his or her educational and cultural background