

# The ExPAND Policy Toolkit on Diabetes



## The European Policy Action Network on Diabetes

**The European Policy Action Network on Diabetes** was created in 2011 to bring together national Members of Parliament (MPs), Members of the European Parliament and key diabetes stakeholders from across Europe to work together to drive a new generation of diabetes policies.

The ExPAND Policy Toolkit for Diabetes is the result of discussions between the ExPAND members that occurred over the course of 2012-2013. The development of this Toolkit was overseen by Suzanne Wait and Ed Harding at SHW Health Ltd., acting as secretariat for ExPAND. The contents of the Toolkit are fully endorsed by, and are the ownership of, the members of the network. Acknowledgements to Bristol-Myers Squibb, AstraZeneca and Roche Diagnostics for providing support to facilitate the regular meetings of the ExPAND network and for funding the development of this Toolkit.

# Contents

## Section 1 – Introduction to the Toolkit

Why this toolkit? .....	04
Executive summary .....	07
How to use the toolkit .....	12



## Section 2 – Priority areas for action

A whole population approach: diabetes as part of chronic disease prevention .....	14
Prevention and screening: preventing diabetes in people at risk and catching diabetes early .....	23
Multidisciplinary care: patient-centred care beyond glucose control .....	33
Patient empowerment: therapeutic patient education for self-management .....	42
Innovation and access to care: securing access to care and fostering innovation in diabetes .....	52
A special responsibility: children with diabetes and schools .....	60
A special responsibility: older people with diabetes .....	69



## Section 3 – Useful resources

Diabetes basics .....	79
Parliamentary brief on diabetes .....	85
Key diabetes policies and resources .....	90
Making an economic case for diabetes (Powerpoint presentation) .....	91
Background working papers .....	92



### FEND

Foundation of European Nurses in Diabetes

*“Many congratulations to all those who put together this significant resource. I am confident that it will inspire MPs and other parliamentarians to actively engage in establishing policies to meet the challenge of the diabetes epidemic.”*

**Anne Marie Felton President, Foundation of European Nurses in Diabetes (FEND)**

### PCDE

primary care diabetes europe

*“Compliments to all who contributed to this important project and established a closer collaboration between MP’s and the key diabetes stakeholders to improve the policies for diabetes”*

**Prof. Johan Wens, Chairman, Primary Care Diabetes Europe (PCDE)**

Special thanks and acknowledgment to Dr. Julie Edge, University of Oxford, for her expert contribution to ExPAND working groups and drafts.

**SECTION 1****Introduction to  
the toolkit**

## Why this toolkit?

**“The challenge now is to convert fine words in to real action.”**

Sir George Alberti after the publication of the UN Resolution on Diabetes (61/225, Dec 2006)

### Why diabetes?

**Diabetes kills more people than breast cancer and prostate cancer put together.<sup>1</sup> It costs society more than all cancers combined.<sup>2,3</sup>** Yet despite multiple policy reports and international declarations, action on and funding for diabetes still lags behind other chronic conditions like cancer or cardiovascular disease.<sup>4</sup> Meanwhile the clock is ticking: rising obesity and population ageing are pushing up the numbers of people with type 2 diabetes,<sup>5</sup> and there is a yet unexplained increase in type 1 diabetes, notably in children.<sup>6</sup> We cannot afford to be complacent - direct healthcare costs alone already stand at €109bn per year in Europe, and these are likely to rise in future.<sup>6</sup>

### Who we are

**The European Policy Action Network on Diabetes (ExPAND)** was created in 2011 to bring together Members of Parliament (MPs), Members of the European Parliament and key diabetes stakeholders from across Europe. We have been working together over the past year to build this toolkit and drive a new generation of diabetes policies.

As members of ExPAND, we firmly believe that governments should make diabetes a priority. They can make healthy choices easier and more affordable, shape the environment to encourage physical activity, foster education on diabetes for the whole population, help reduce socioeconomic inequalities and make sure that appropriate prevention and care are offered to all those who need it.

### Why this Toolkit?

We know what to do, now the challenge is implementation. This toolkit was created by us, for you, and is intended as a practical tool for MPs and other parliamentarians across Europe to **start making concrete changes in diabetes policies.**

As MPs and people who can make change happen, let's work together to make a real difference for people living with diabetes today and in future generations.



Adrian Sanders  
MP  
**Chair**



Georgios Papanikolaou  
**MEP**



Teresa Caeiro  
**MP**



Czeslaw Czechryra  
**MP**



Martin Gregora  
**MP**



Sophie Peresson  
**IDF-Europe**



Joao Nabais  
**IDF-Europe**



Umberto Valentini  
**Diabete Italia**



Maite Valverde  
**Sociedad Espanola de Diabete**



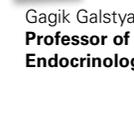
Margarida Jansa  
**Sociedad Espanola de Diabete**



Cristian Andriciu  
**The Romanian Federation of Diabetes, Nutrition and Metabolic Diseases**



Valentina Visconti  
**Diabete Italia**

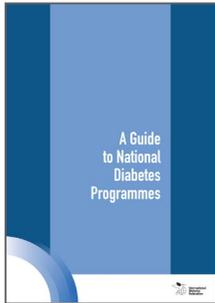


Gagik Galstyan  
**Professor of Endocrinology**

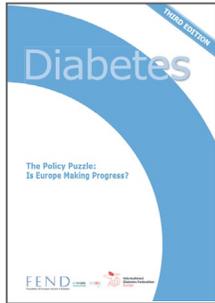
# Why this toolkit?

## A key piece of a bigger puzzle

We recognise the vital contributions of others to improving the prevention, care and management of diabetes in Europe. This toolkit has sought to add value to the existing family of diabetes resources by providing a practical and comprehensive diabetes policy toolkit that is **aimed specifically at parliamentarians across Europe.**



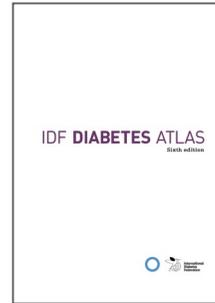
A Guide to National Diabetes Programmes  
**International Diabetes Federation, 2010**



The Policy Puzzle – is Europe Making Progress?  
**European Coalition for Diabetes (FEND, EURADIA, IDF Europe and PCDE), 2011**



Advocacy and Communications Toolkit  
**International Diabetes Federation-Europe, 2012**



IDF Diabetes Atlas 6th edition  
**International Diabetes Federation, 2013**



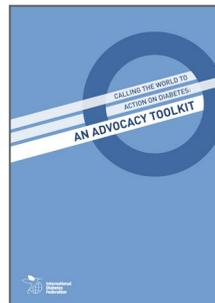
Take Action to Prevent Diabetes - A toolkit for the prevention of type 2 diabetes in Europe  
**European study group of the IMAGE Project, 2010**



Guidelines on Diabetes, Pre-diabetes, and cardiovascular diseases  
**European Society for Cardiology & European Association for the Study of Diabetes, 2013**



The Copenhagen Roadmap  
**European Diabetes Leadership Forum and OECD, 2012**



Calling the World to Action on Diabetes: an advocacy toolkit  
**International Diabetes Federation Europe, 2012**



Chronic Disease Alliance – a Unified Prevention Approach  
**European Chronic Disease Alliance, 2010**

Click on images to access documents

## Why this toolkit?

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## Executive summary: why action is needed now

### Diabetes is on the increase

- By 2035, 1 in 10 people will have diabetes in Europe – or 70 million people<sup>1</sup>
- Increasing numbers of people with type 2 diabetes linked to rise in obesity and ageing population<sup>2,3</sup>
- Unexplained increase of type 1 diabetes in children<sup>1</sup>

### Unmet health needs

- Up to half of all cases of diabetes are undiagnosed in Europe<sup>9,10</sup>
- Of those diagnosed, 50% do not achieve adequate glucose control, putting them at increased risk of heart disease, stroke, kidney disease and blindness<sup>10,11,12</sup>
- Limits to even the most basic diabetes care exist in some EU countries.<sup>2,8,13,14</sup>

### A huge toll on society

- Costs more than all cancers combined,<sup>4,5</sup> and kills more people than breast and prostate cancer together<sup>6</sup>
- 10% of total healthcare expenditure in Europe<sup>7</sup>
- Responsible for 1 in 10 deaths, or 619,000 deaths in Europe every year<sup>1</sup>
- Huge social costs in terms of lost productivity and dependence – at least €100bn<sup>8</sup>

### Health impact beyond diabetes

- Diabetes is the number one cause of:
  - End-stage renal disease<sup>15</sup>
  - New cases of blindness in adults of working age<sup>16,17</sup>
- Diabetes leads to a 3-5 times greater risk of heart disease<sup>18</sup> and doubles the risk of stroke<sup>19</sup>
- Diabetes increases the risk of foot amputation 23-fold.<sup>20</sup>



## Executive summary: what can be done

Diabetes policies need to focus on the **prevention of diabetes** as well as **improving the care of those with diabetes**. Moreover, we have **special responsibilities** towards certain, **more vulnerable groups of people with diabetes** - for example, children and older people – as they have specific needs that are often neglected in existing policies.

### 1. Preventing diabetes

#### Priority areas for action

**A chronic disease approach to preventing diabetes**

**Preventing diabetes in people at risk and catching diabetes early**

#### Why is this important?

Diabetes shares the same risk factors as many other chronic diseases (e.g. smoking, diet, exercise and overweight), which are often more common in people of low socioeconomic status

We could halve the number of people with type 2 diabetes through effective prevention. Up to half of all cases of diabetes are undiagnosed, and the delay to diagnosis can be as long as 7 years.

#### What can be done

- Population-level prevention programmes can tackle risk factors common to most chronic conditions, including diabetes.
- 'Health in all policies' approaches can design and build healthier communities through better housing, planning, employment and other social policies.
- Intensive behavioural change programmes can be targeted at people at high risk
- Screening programmes can help ensure much earlier diagnosis
- Community-based models can link the screening, prevention and care of diabetes

## 2. Keeping people with diabetes healthy and well

### Priority areas for action

#### Providing care for diabetes beyond glucose control alone

### Why is this important?

Diabetic complications (e.g. heart disease, stroke, renal failure,...) have the greatest impact on premature mortality and quality of life for people with diabetes. They are also the greatest driver of costs, particularly hospital costs.

### What can be done

- Patient-centred, multidisciplinary models of care can integrate the prevention of complications and management of co-morbidities with glucose control

#### Patient education and self-management

Up to 95% of management of diabetes is self-management, yet patient education is still a 'missing link' in diabetes care.

- Provide individualised patient education and support by trained diabetes professionals to all patients and their families
- Raise awareness of the importance of patient education in professional training and accreditation
- Adapt patient education to meet the needs of ethnic or disadvantaged groups

#### Securing access to care and fostering innovation in diabetes

Limits to even the most basic aspects of diabetes care (eg. glucose testing strips) exist in some countries. The economic crisis risks exacerbating existing gaps in diabetes care and strangling innovation.

- Aim to reduce inequalities in access to diagnosis, monitoring and care
- Use national diabetes plans to guide long-term innovation strategies and investments and ensure that incentives for innovation are maintained despite fiscal pressures



### 3. A special responsibility

#### Priority areas for action

#### Why is this important?

#### What can be done

##### Children with diabetes at school

Diabetes is the second most common disease in children after asthma yet schools often lack the training and resources to meet the needs of children with diabetes.

- Provide better training for schools on diabetes management
- Provide care guidelines that bridge education and health sectors, with each child having an individualised healthcare plan

##### Older people with diabetes

Older people are the single largest group with diabetes. Approximately one quarter of nursing home residents have diabetes.

- Establish specific standards and goals for the management of diabetes in older people in guidelines and care models
- Ensure better care provision for diabetes residents in care homes.



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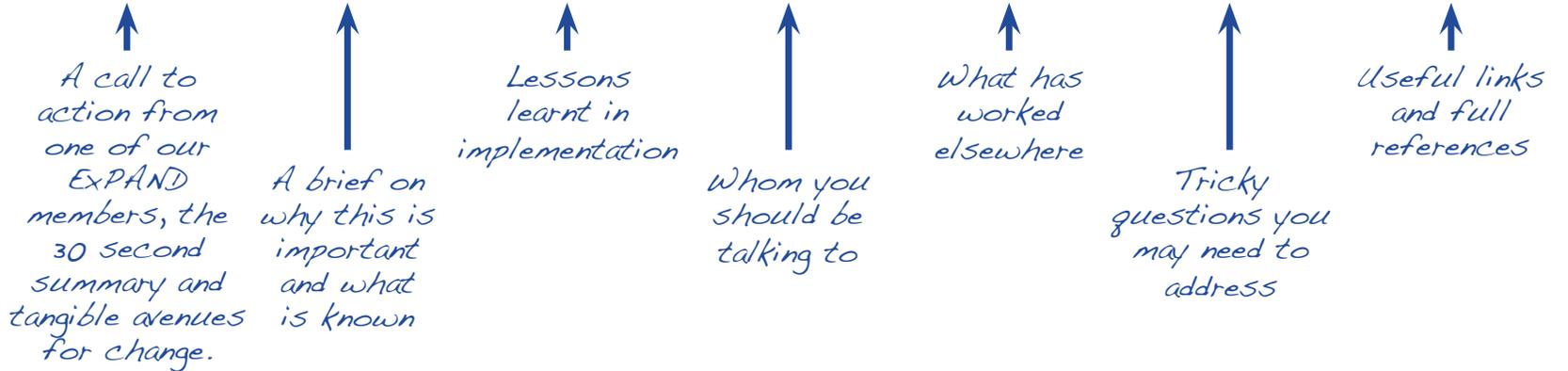
# How to use this toolkit: key icons and navigation

7 priority areas for action

*The toolkit is focused around 7 priority areas for action. Draw out the key areas you think are most important and work with your constituents and local stakeholders to find solutions that can work best within your local context.*



Each priority area for action is organised in a similar way.





INTRO



PRIORITY  
AREAS



USEFUL  
RESOURCES

A whole population  
approach

Prevention and  
screening

Multidisciplinary  
care

Patient  
empowerment

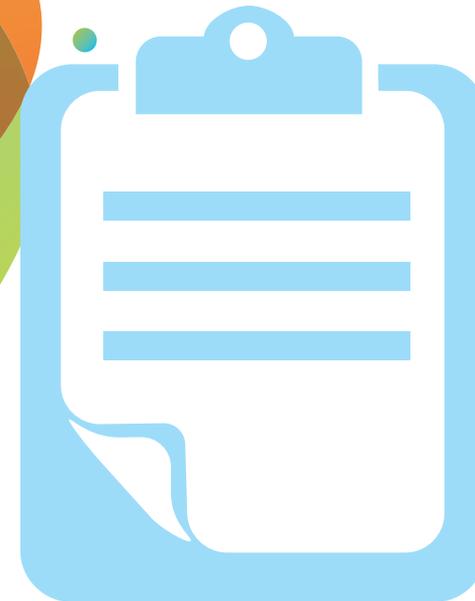
Innovation and  
access to care

Children  
in schools

Older  
people

## SECTION 2

# Priority areas for action



A whole population  
approachPrevention and  
screeningMultidisciplinary  
carePatient  
empowermentInnovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources

## A whole-population approach: diabetes as part of chronic disease prevention

### A. Essential briefing



**“Whole-of-society approaches are the only real solution to the diabetes epidemic. Diabetes is part of a much wider epidemic of chronic diseases, which is being driven by social, environmental and behavioural factors. We cannot simply ‘correct’ individual behaviours, we must understand their origins and work together across different sectors of society and government to promote healthier lifestyles for the whole population”**

Joao Nabais, President, International Diabetes Federation Europe

#### 5 things you need to know:

- 1. Most of the burden of type 2 diabetes is driven by preventable factors** such as obesity, poor diet, lack of physical exercise, smoking and alcohol consumption.<sup>1,2,3</sup>
- 2. These same factors are driving a wider chronic disease epidemic across Europe.**<sup>4,5</sup> This has been called ‘too big to fail’<sup>6</sup> – a serious threat to our social and economic future<sup>7,8</sup> that is comparable to the recent economic crisis.<sup>3,9</sup>
- 3. Existing efforts to prevent chronic disease are insufficient.**<sup>10,11</sup> As things stand, obesity could wipe out the health gains of successful cardiovascular health promotion and anti-smoking policies by 2020.<sup>4</sup>
- 4. The United Nations, the World Health Organisation and the European Parliament have all called for joint prevention models targeting chronic disease** to combat this epidemic,<sup>3,12,7</sup> which must involve concerted efforts across society if they are to succeed at scale.
- 5. Prevention must go beyond health policies alone.** Health behaviours are deeply influenced by complex social and environmental determinants, and change will be unlikely without tackling these root causes.<sup>7,13,10</sup>

#### Priorities for action

- **Governments can implement the European Chronic Disease Alliance’s Unified Prevention Approach** – a suite of actions across public policy to improve diet and exercise and reduce smoking and alcohol consumption.<sup>4</sup>
- **National, regional and local governments can work to build healthier communities and tackle the ‘obesogenic environment’** across planning, housing, transport, economic development, environmental protection and other areas.<sup>4,10</sup>
- **‘Health in all policies’ approaches can be adopted,**<sup>7,9</sup> for example by setting health as a public policy priority, and conducting health impact assessments across government departments.
- **National awareness campaigns** and social marketing to promote healthy choices can also be effective.
- **Research is needed to better understand population-wide approaches to health improvement,** and the economic and public health impact of ‘health in all policies’ approaches.<sup>3</sup>
- **No one group can lead this agenda on their own** – governments, professionals, patient advocates and the private sector can develop joint guidelines that span different chronic diseases and target shared risk factors. They can present a unified voice for change, consolidate interlinked initiatives, share learning and thereby reduce development and delivery costs.

## A whole-population approach: diabetes as part of chronic disease prevention

### B. Summary of evidence



#### What this means

- **'Health in all policies'** approaches may enable health to be adopted as an overarching goal for governments. They may also clarify the contributions of different agencies and policy areas to improving health and wellbeing across the population.
- **Negative health behaviours are themselves driven by wider social and environmental determinants**, influence over which may be beyond the remit of traditional healthcare agencies.<sup>5,12</sup> Diabetes and chronic disease prevention initiatives must tackle these root causes if they are to work.<sup>10</sup>
- **Chronic diseases include heart disease, stroke, diabetes, kidney disease, cancer, respiratory and liver diseases.**<sup>3,4</sup> Some conditions like high blood pressure and high cholesterol are both chronic diseases in their own right as well as risk factors for other chronic diseases, such as diabetes.
- **Chronic disease alliances are emerging in recognition of shared risk factors such as** overweight, poor diet, lack of physical exercise, smoking and alcohol use across the major chronic diseases.<sup>4</sup>



#### Why this is important

- **Diabetes is closely linked to other chronic diseases.** Studies have shown that the prevention of cardiovascular health is equally, if not more, important to reducing mortality and morbidity in people with diabetes as blood glucose control.<sup>14,15</sup>
- **Chronic diseases generate an enormous societal burden.** They account for 86% of deaths in Europe and 77% of all healthcare spend,<sup>3</sup> yet most are treatable if not curable.<sup>4</sup>
- **Current health behaviours are a cause for serious concern.** The prevalence of obesity has tripled in the last 25 years,<sup>16</sup> yet only 1 in 4 Europeans aged 15 and over takes part in moderate to vigorous physical exercise, and only 1 in 3 eats one or more portions of fresh vegetables every day.<sup>17</sup>
- **Too little is invested in prevention.** The burden of ill health from chronic disease is largely preventable,<sup>4</sup> yet the vast majority of health budgets is currently spent on treatment and care of disease, with only a minor fraction going to prevention.



## A whole-population approach: diabetes as part of chronic disease prevention

### B. Summary of evidence (continued)



#### What the evidence says

- **Health behaviours** are a complex societal problem that has proved difficult to reverse by any one area in chronic disease policy acting alone.<sup>4,13</sup>
- **Investment in prevention returns economic benefits.** For example, a major US study of diabetes prevention showed a benefit in increased economic participation, saving 160 work days for each 100 people involved.<sup>18</sup>
- **Small change approaches can reap major benefits in other chronic diseases,** especially if adopted at scale:
  - Weight loss and increased physical activity have been shown to reduce cardio-vascular risk factors (blood pressure, cholesterol) in as little as 6 months.<sup>19</sup>
  - Just two and half hours of moderate physical activity per week can reduce the risk of diabetes by 44-66% as compared to those exercising for 1 hour or less.<sup>20</sup>
  - Increasing physical activity will reduce obesity, cancer, cardiovascular and respiratory diseases and improve mental health.<sup>4</sup>
- **Ninety per cent of heart disease** is caused by the 'big four' lifestyle behaviours (lack of exercise, unhealthy diet, smoking and alcohol overuse).<sup>4</sup>
- **Population-level prevention in diabetes is an emerging science.**<sup>19</sup> This suggests that whilst behavioural change will indeed prevent diabetes, investment in such approaches should be shared across the major chronic diseases.<sup>4</sup>



INTRO

PRIORITY  
AREASUSEFUL  
RESOURCESA whole population  
approachPrevention and  
screeningMultidisciplinary  
carePatient  
empowermentInnovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resourcesA whole-population approach: diabetes as part of chronic disease prevention

## C. Making it happen

### Key issues to think about

*lessons  
learnt in  
implementation*

Lessons learnt	Key issues to think about	Steps you need to take
In societies that encourage unhealthy behaviours, disseminating information or focusing on individual behaviour change will not be enough. <sup>10</sup>	How can we tackle the underlying determinants of health that affect everyday lifestyle choices?	
Multiple barriers to collaboration across different chronic diseases exist at the organisational and professional level.	Are we clear as to the multiple disincentives and/or barriers to collaboration which have obstructed joint prevention approaches to date? What will be different this time?	
Different populations will encounter very different barriers and socio-economic influences on health behaviours (i.e. economic, cultural, linguistic factors.)	Do we understand the needs and circumstances of different groups (older people, adolescents, ethnic minorities, vulnerable groups,...)?	
We need to move from patient education to citizen empowerment.	Behaviour change cannot be 'done' to people. Is our system able to motivate and empower people to help improve their own wellbeing and quality of life?	
Prevention may need 'invest to save' business cases to justify investment.	Can we articulate the returns that different public agencies may draw from investing in chronic disease prevention?	



**A whole-population approach: diabetes as part of chronic disease prevention**

**C. Making it happen**

**Whom to involve**

Whom to involve	Why are they important?	What would you want their role to be? Whom should you contact?
Patient advocacy groups for chronic diseases	Can provide a unified and powerful call to action to governments.	
Government ministries	To tackle underlying determinants of health and 'health in all policies' approaches, across <ul style="list-style-type: none"> <li>• economic development</li> <li>• town planning</li> <li>• transport</li> <li>• sports and leisure</li> <li>• environment</li> <li>• housing</li> <li>• education</li> <li>• welfare and social care</li> <li>• industry regulation</li> </ul>	
Issuers of national clinical guidelines	To clarify how combined chronic disease approaches can translate into routine good practice.	
Healthcare providers	Can help adapt health systems, workforce and infrastructure to deliver prevention programmes and early outreach across all chronic diseases.	
Professional associations (physicians, nurses, social care...)	Can lead efforts to ensure prevention programmes are valued and supported by their members.	
Private sector (life science industry, insurers and large employers)	Can be exemplar adopters of healthy workplaces and built environment design. A healthy workforce, workplace and access to healthy lifestyle choices in journeys to and from work, and whilst at work, has significant economic and productivity benefits.	
Universities and research bodies	Can conduct research into the economic case for investment in whole population approaches to prevention.	
Media (print, broadcast, internet and social)	Can raise awareness of healthy lifestyle choices nationally, within different societal groups.	

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**A whole-population approach: diabetes as part of chronic disease prevention**

**D. Case studies**

**Case study 1**

**The International Diabetes Federation National Prevention Plan<sup>21</sup> (IDF)**

The IDF has called for National Diabetes Prevention Plans that include:

**Advocacy**

- supporting national associations and non-government organizations
- promoting the economic case for prevention

**Community support**

- Providing education in schools re: nutrition and physical activity
- Promoting opportunities for physical activity through urban design (e.g. to encourage cycling and walking)
- Supporting sports facilities for the general population

**Fiscal and legislative measures**

- Food pricing, labelling and advertising
- Enact and enforcing environmental and infrastructure regulation, e.g. urban planning and transportation policy to enhance physical activity

**Engagement of private sector**

- Promoting health in the workplace
- Ensuring healthy food policies in food industry

**Media communication**

- Improving level of knowledge and motivation of the population
- Use of multiple outlets (press, TV, radio, social media)

**Case study 2**

**The 'Change4Life' programme (UK)<sup>22</sup>**

The UK "Change4Life" programme is a government led programme that aims to prevent people from becoming overweight by encouraging them to eat better and exercise more. The programme was intended as a 'social movement' to distinguish itself from earlier, largely unsuccessful government-led initiatives to promote behaviour change. The programme has targeted young families by advertising on television, in the press, on billboards and on the internet.

The campaign was partly experimental, but an evaluation in 2012 showed some encouraging successes. For example, public recognition of the campaign in target groups was high (9 out of 10 mothers with children under 11 recognised it), 1 million mothers have claimed to have made changes to their children's behaviours as a direct result, and 25,000 volunteers had been recruited to help their families and other people make positive health changes.

**Case study 3**

**DEHKO**

**The Finnish Development Programme for the Prevention and Care of Diabetes (Finland)<sup>23</sup>**

DEHKO was the first national strategy in the world to include the population-wide prevention of type 2 diabetes. It was built on the success of the earlier **Finnish Diabetes Prevention Study** and was run by the Finnish Diabetes Association, in close collaboration with the Finnish Heart Association. The alliance ran a new campaign called 'One Small Decision a Day' that included models for weight-management group education, instructor training and peer-group arrangements to help make lifestyle changes.

DEHKO was launched in 2000 with clear goals to be achieved by 2010, including 25 concrete recommendations for action. This included the mobilisation of the health workforce into a combined diabetes / heart health model, including access to new community nutritionist roles at the primary and occupational healthcare level, and the establishment of support groups for weight management as a permanent feature in local health-care centres and units of occupational health care.

A whole population  
approachPrevention and  
screeningMultidisciplinary  
carePatient  
empowermentInnovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources

## A whole-population approach: diabetes as part of chronic disease prevention

### D. Case studies (continued)

#### Case study 4

##### ECDA

##### The European Chronic Disease Alliance Call to Action (Europe wide)<sup>4</sup>

The ECDA has published a series of targets that any government can adopt as part of a population-wide prevention strategy for chronic disease. It outlines realistic measures that are achievable and supported by the existing evidence base for behavioural and lifestyle changes, and sets an overarching target to reduce preventable deaths from cardiovascular disease, cancer, diabetes, chronic respiratory kidney and liver diseases by 25% by 2025. Measures include fiscal policies, industry regulation, protection of children, reducing smoking prevalence, salt intake, and insufficient physical exercise, and strategies to integrate the health-system management of non communicable diseases especially at primary health care levels.

#### Case study 5

##### ESC and EASD Joint Guidelines – the European Society of Cardiology and European Association for the Study of Diabetes (Europe wide)<sup>24</sup>

The ESC and EASD recognised that diabetes and cardiovascular disease often present as ‘two sides of a coin’, and identified the need for a clear and shared protocol for clinicians to understand optimal management of both conditions, spanning screening, prevention and treatment. These guidelines provide a clear model for diagnosis and decision making, and an executive summary was put together for the practicing physician.

#### Case study 6

##### World Health Professions Alliance (WHPA) health score card (Global)<sup>25</sup>

The WHPA score card is intended as an easy-to-use, practical guide to help individuals and their health professionals monitor and reduce the risk of non-communicable diseases (NCDs). The scorecard helps individuals rate their behaviours on a “stoplight-type” fashion. Four biometric indicators (BMI, cholesterol, blood glucose, and blood pressure) and four lifestyle indicators provide a comprehensive assessment of the patient’s health status. The card aims to help professionals provide tailored advice and treatment to the individual as well as highlight the link between social determinants of health and NCDs – extending the scope to mental and oral health illnesses.

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**A whole-population approach: diabetes as part of chronic disease prevention**

**E. Questions and answers**

**Healthy living is an individual choice – there is nothing governments can do to change people’s habits**

It is true that each individual must be empowered to understand his or her own health, and not all people will wish to change their habits. But individual choices are heavily influenced by factors such as the built environment and the social and economic opportunities presented to each person.<sup>10;13</sup>

**Why should other government departments have to get involved in health issues?**

Healthcare systems alone cannot meet the challenge of preventing chronic diseases such as diabetes.<sup>7</sup> Diabetes is most prevalent in people of lower socioeconomic status,<sup>26</sup> and poor housing, diet, education and other social and environmental factors play an important part in driving up the number of people with diabetes and other chronic diseases.<sup>13; 7</sup> Thus a joined-up government response is needed that can tackle all of these factors, and not simply focus on traditional ‘health’ policy areas alone.<sup>3;75</sup>

**What return can other areas of government expect from investing in health?**

Health equals wealth:<sup>4</sup> healthier populations will lead to more productive societies, and the long term return to society will be improved societal and economic productivity across the whole population.<sup>79</sup> Health goals may also support other policy goals (e.g. more physical exercise means a reduced burden on transport systems and less pollution).

**Health in all policies approaches are too difficult and too complex to be practical.**

Not so, and it is the job of health ministries to take the lead in developing national strategies that identify effective and achievable contributions from different agencies – such as housing, education, transport, and other social policies. Such approaches may require new ways of thinking but they will be worth it: chronic diseases account for 86 per cent of deaths in Europe<sup>3</sup> and 70-80 per cent of all healthcare spend<sup>3</sup> yet much of this burden could be prevented.



A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

## A whole-population approach: diabetes as part of chronic disease prevention

# F. References and resources

## References

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A whole population  
approachPrevention and  
screeningMultidisciplinary  
carePatient  
empowermentInnovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources

## Prevention and screening: preventing diabetes in people at risk and catching diabetes early

### A. Essential briefing



**“Preventing diabetes is one of the greatest imperatives facing European healthcare systems in the 21st Century. We cannot afford to treat diabetes if it continues to grow at current rates. The evidence is very clear: in most cases we can halt or slow the onset of type 2 diabetes. Yet we still invest too little: the great majority of health budgets in Europe is currently spent on treatment and care of disease, with only a fraction going to prevention. The status quo is not a viable option”** Czeslaw Czechyra, MP (Poland)

#### 5 things you need to know:

- 1. Diabetes prevention is a fundamental issue for social and economic sustainability.** The United Nations, the World Economic Forum, the World Health Organisation and the European Parliament have all called on governments to act decisively to prevent diabetes and chronic diseases,<sup>1,2,4</sup> which have been called a 21st Century ‘epidemic’.<sup>5</sup>
- 2. Behavioural change is effective in diabetes prevention.** Proven models have been shown to halve the numbers of people developing diabetes,<sup>6,7</sup> which will mean reduced hospitalisations, healthcare costs and costs to economy and society.
- 3. We need better screening to catch diabetes earlier** – approximately half of all type 2 diabetes cases are undiagnosed,<sup>8,9,10</sup> and the delay to diagnosis can be up to 7 years.<sup>11,12</sup> Between 10-20% of Europeans are living with pre-diabetic conditions,<sup>8,13</sup> most of which are also undiagnosed.<sup>13</sup>
- 4. The challenge now is to roll out diabetes prevention across our communities.**<sup>14,15</sup> This is not easy but it can be done.<sup>16</sup>
- 5. Vulnerable, excluded groups will need tailored prevention programmes.** The burden of diabetes is greater in these populations<sup>17</sup> and prevention programmes will need tailored approaches to be effective in the face of linguistic, cultural and other barriers.<sup>19,20,16;18;21</sup>

#### Priorities for action

- **Identify diabetes and pre-diabetic conditions as early as possible.** Use existing population data and opportunistic screening to identify high risk individuals and invite them for diabetes testing.
- **Incentivise GPs and community healthcare professionals to provide screening by providing financial rewards for successful implementation.** Measures should include testing for glucose levels, cardiovascular health checks and behavioural change programmes to all those considered at high risk of diabetes.
- **Make every contact matter – make screening a shared duty** and establish referral protocols for timely blood glucose testing in all relevant community settings (i.e. via GPs, community care, citizen advice bureaus, civic and community centres, the workplace, etc).
- **Secure reimbursement** for behavioural change programmes proven to prevent type 2 diabetes.
- **Develop national quality standards for intensive behavioural change** based on international evidence of effectiveness and commence provider accreditation schemes.
- **Integrate new educator roles into primary care** to help individuals succeed in adhering to behavioural and lifestyle changes, using diabetes specialist nurses, but also community nutritionists, physical exercise therapists, group educators and counsellors.

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Prevention and screening: preventing diabetes in people at risk and catching diabetes early**

**B. Summary of evidence**

Summary of evidence 1:

**Diabetes prevention through behavioural change**



**What this means**

- The dominant models of diabetes prevention involve behavioural change to improve people’s diet, physical exercise, smoking and alcohol habits.<sup>19</sup>
- Interventions involve education about type 2 diabetes and the promotion of skills for adherence and self-management (e.g. goal setting, motivation, and psychological resilience).<sup>19,24</sup>



**Why this is important**

- Type 2 diabetes and ‘pre-diabetic’ conditions are closely associated with long term negative lifestyle habits and social and environmental determinants.<sup>17</sup> These habits and influences can be difficult to reverse,<sup>19</sup> meaning targeted support for behavioural change is often necessary.
- Combined but relatively modest lifestyle changes involving diet and physical exercise in high risk groups can have major benefits in reducing diabetes and promoting good health.<sup>19,27</sup>



**What the evidence says**

- The Finnish Diabetes Prevention Study and US Diabetes Prevention Programme both demonstrated that behavioural change interventions could reduce the development of diabetes amongst people at high risk by 43% at 8 years and 34% at 10 years respectively.<sup>6,7</sup>
- Studies have also shown that type 2 diabetes may be *virtually preventable* amongst those individuals prepared to make very significant behavioural changes across all five areas of healthy body weight, physical activity, and intake of fibre, fat and saturated fat.<sup>6,28</sup>
- Diabetes prevention is cost-effective: Some behavioural change programmes have been delivered for as little as €184 per year, per participant.<sup>14</sup> The US Diabetes Prevention Programme showed that for every 100 high risk adults enrolled in intensive behavioural change over 3 years, 15 new cases of diabetes could be avoided, 160 work days could be saved, and savings of €80,000 in healthcare costs could be achieved.<sup>14</sup>
- Pharmacological intervention has also been recommended as an option for those that have not responded well to lifestyle and behavioural-based interventions, although the evidence needs further development.<sup>19</sup>

Prevention through behavioural change

Screening and early identification

## Prevention and screening: preventing diabetes in people at risk and catching diabetes early

### B. Summary of evidence (continued)

Summary of evidence 2:

#### Screening, early diagnosis and 'pre-diabetic' conditions



##### What this means

- Screening is defined by the World Health Organisation as the identification of unrecognized diseases by the application of tests, examinations, or other procedures which can be applied rapidly. Screening tests are not a diagnostic, rather they separate apparently- well persons who probably have a disease from those who probably do not, and refer the first group to a clinician for diagnosis and treatment.<sup>22</sup>
- In the case of diabetes, screening may involve risk profiling followed by an invitation to have a blood glucose test. (see '*What is diabetes*')



##### Why this is important

- Like many chronic conditions, type 2 diabetes is a condition with slow onset and many patients may live for years unaware that they have diabetes or pre-diabetes.<sup>9,11;12;19,17</sup>
- The longer a patient lives with poorly controlled blood glucose, high blood pressure or cholesterol, the greater the risk of complications and disability.<sup>19,23</sup> Early identification of pre-diabetic conditions, diabetes, and associated cardiovascular disease is key to ensure good patient outcomes.<sup>5</sup>



##### What the evidence says

- It is estimated that around half of cases of diabetes are undiagnosed.<sup>13,8</sup> A UK study estimated that undiagnosed diabetes affects as many as 1.8% of the population, or around 1 million people in the UK alone.<sup>13</sup>
- Between 10-20% of people in Europe are thought to have a pre-diabetic condition and are at risk of deteriorating blood glucose control and developing type 2 diabetes.<sup>8,13</sup>
- Risk factors for diabetes are well evidenced, and straightforward to assess. They include high blood pressure, overweight, high cholesterol, lack of physical exercise and poor diet.<sup>19,24</sup>
- Simple and effective screening tools can be used by a variety of professionals in the primary care setting to help identify those at risk of diabetes.<sup>25,26</sup>

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Prevention and screening: preventing diabetes in people at risk and catching diabetes early**

**C. Making it happen**

**Key issues to think about**

*lessons learnt in implementation*

Lessons learnt	Key issues to think about	Steps you need to take
Preventative approaches may be challenging to healthcare systems based on the traditional 'medical model'.	What are the current barriers to delivering prevention – are they cultural, professional, financial, regulatory, organisational, legal?	
Implementing diabetes prevention programmes requires a complex, long term and multi-agency undertaking.	Where can prevention programmes fit within the existing health care delivery system? Does it make sense to have a national strategy for prevention?	
'Imposing' prevention at scale on the existing healthcare workforce may achieve little.	How do we ensure all professionals understand, value and collaborate effectively with prevention services?	
Behavioural and lifestyle change cannot be 'done' to people.	How will we deliver prevention through a new model of patient empowerment and self-management?	
Excluded, vulnerable and/or ethnic minority groups often carry the greatest burden of diabetes, yet experience the most barriers to accessing services.	Adaptation and outreach will be needed for different populations.	
All cost effectiveness is 'local' – and highly sensitive to local parameters.	What economic and feasibility studies will be needed? Is there a way to standardise cost-effectiveness models?	

A whole population approach

**Prevention and screening**

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Prevention and screening: preventing diabetes in people at risk and catching diabetes early**

**C. Making it happen**

**Whom to involve**

Whom to involve	Why are they important?	What would you want their role to be? Whom should you contact?
Patient representatives	We must understand from patients themselves what is feasible and realistic for diabetes prevention based on behavioural change.	
Diabetes nurses	Can work with or lead behavioural change programmes, bringing experience of self-management and patient education approaches.	
Healthcare providers and voluntary sector	Can prepare workforce and community facilities to deliver prevention programmes.	
Universities and research bodies	Can assess emerging clinical evidence and best practice, and analyse cost effectiveness of prevention models in national or regional context.	
Health information systems	Can use existing population data to help identify high risk individuals or target groups. Should collect and monitor patient outcomes data to help evaluate the impact of prevention programmes.	
Ministries of health and other funders (eg. sickness funds)	Can reimburse behavioural change interventions, accredit individuals and organisations, and adapt or issue supportive national clinical guidelines.	
Professional associations	Can lead efforts to ensure prevention programmes are valued and supported by each professional group.	
Stakeholders from other chronic disease areas	Can help collaborate across chronic disease (e.g. cardiovascular disease, stroke, mental health).	
Private sector (life science industry, insurers, large employers)	May help create opportunities for public private partnerships.	

A whole population  
approachPrevention and  
screeningMultidisciplinary  
carePatient  
empowermentInnovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources

## Prevention and screening: preventing diabetes in people at risk and catching diabetes early

### D. Case studies

#### Case study 1

##### The Finnish DPS – The Finnish Diabetes Prevention Study (Finland)

**The Finnish DPS** was one of the first major trials to demonstrate the effect of lifestyle interventions in preventing Type 2 diabetes, *halving* the incidence amongst high risk groups after two years.<sup>6</sup>

The Finnish Diabetes Association has since led the Development Programme for the Prevention and Care of Diabetes in Finland, or DEKHO, over 2003–2010.<sup>29</sup> The programme provides an overarching strategy combining initiatives to promote the health of the entire population alongside efforts to promote early diagnosis, prevention and management of diabetes and its associated conditions. Pilot studies assessing practical models and cost effectiveness are on-going and wider population roll out is expected shortly.

#### Case study 2

##### USDPP

##### The US Diabetes Prevention Programme (USA)

**The USDPP** was the largest diabetes prevention trial ever undertaken. The study showed that lifestyle interventions, such as a 5%–7% weight loss and performing brisk walking for 150 minutes/week, could reduce the risk of developing type 2 diabetes by 58% after 3 years.<sup>7</sup>

As a follow up to the trial, the US National Diabetes Prevention Programme aims to recreate the success of the US DPP at scale and is composed of four main components:<sup>14</sup>

- Training: build a workforce able to deliver the programme
- Recognition and quality: quality assurance, sustainable funding, and programme registry
- Develop intervention sites: build infrastructure and provide the programme
- Health marketing: support uptake and referrals to the programme

To date, the programme has made real progress towards implementation, and has developed community-based group lifestyle programmes across 122 sites which cost less than €184 per participant per year. The US Diabetes Prevention Programme showed that for every 100 high risk adults enrolled in intensive behavioural change over 3 years, 15 new cases of diabetes could be avoided, 160 work days could be saved, and €80,000 saved in healthcare costs.<sup>14</sup>



A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

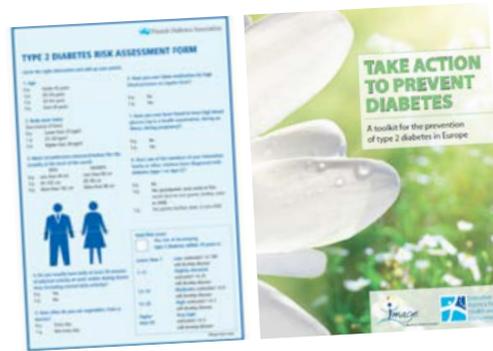
**Prevention and screening: preventing diabetes in people at risk and catching diabetes early**

**D. Case studies** (continued)

**Case study 3**  
**FINDRISC**

**The Finnish Type 2 Diabetes Risk Assessment Form (Finland)**

The **Finland Type 2 Diabetes Risk Assessment Form (FINDRISC)** is an example of a patient questionnaire used for diabetes screening. The test is simple, effective, and has been replicated around the world.<sup>30</sup> The test takes only a few minutes to complete and has been adapted to be carried out in pharmacies or at various public campaign events, and even provided via the internet.<sup>19</sup> It contains eight scored and weighted questions dealing with diabetic risk factors such as age, BMI, waist circumference, high blood glucose, physical activity, and diet. The final test score provides a probability of the interviewee developing type 2 diabetes over the following 10 years, and has also been proven to be a helpful indicator of 'pre-diabetes' and cardiovascular health.<sup>30</sup> The reverse of the FINDRISC form contains brief advice on what respondents can do to lower their risk of developing the disease, and whether they should seek advice or have clinical examinations.



**To find out more, please see the IMAGE toolkit on diabetes prevention:**  
[www.idf.org/sites/default/files/IMAGE%2520Toolkit.pdf](http://www.idf.org/sites/default/files/IMAGE%2520Toolkit.pdf)

**Case study 4**

**The International Diabetes Federation Blue Circle Test**

The **Blue Circle Test**, developed by IDF, is an interactive online tool that showcases the risk factors of type 2 diabetes and displays the positive actions that can be taken to reduce a person's risk.

**FOR MORE INFO:** [www.idf.org](http://www.idf.org)



A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Prevention and screening: preventing diabetes in people at risk and catching diabetes early**

**E. Questions and answers**

**We can't prevent diabetes**

This is true for type 1 diabetes, but not for type 2 diabetes, which makes up 90% of cases of diabetes.<sup>31</sup> The evidence suggests that as many as 50% of cases of type 2 diabetes could be prevented through behavioural change aimed at achieving a healthy body weight and increasing physical activity.<sup>19</sup>

**Prevention isn't cost effective**

Wrong. Diabetes prevention is cost effective – for example the US Diabetes Prevention Programme showed that for every 100 high risk adults enrolled in intensive behavioural change over three years, 15 new cases of diabetes were prevented, and 160 work days and €80,000 healthcare costs were saved over 3 year.<sup>14</sup> Prevention programmes can also have a positive impact on individual's mental and overall physical health and wellbeing, not just for diabetes.<sup>24,27</sup>

**With healthcare budgets under pressure, why invest in prevention?**

The prevalence and costs of diabetes (to the healthcare system as well as to society through lost productivity) are increasing<sup>32,33</sup> and will continue to do so if more investment is not put into improving prevention, treatment and care for diabetes. Today, only a small fraction of health budgets goes into prevention.

**Won't this mean cutting existing provision for those with diabetes to release extra investment?**

Not necessarily. Prevention is cost-effective,<sup>16</sup> meaning that the established models of prevention for those at a high risk of diabetes should free up more resources than they consume over the long term. For those who already have diabetes, early diagnosis will still be enormously helpful in avoiding the complications and costly hospitalisations that result from diabetes if left untreated.



**Prevention programmes are long term, complex and difficult to implement**

Wrong. Whilst successful prevention programmes will not bear fruit overnight, major benefits to individuals can accrue in as little as 2-3 years.<sup>6,14</sup> The dominant models of diabetes programmes are tried and tested, and involve behavioural change to improve a person's diet, exercise and alcohol and smoking habits.

**We can manage diabetes effectively with drugs and other treatments, why invest in prevention?**

Almost half of people with diabetes are undiagnosed,<sup>13,8</sup> and of those who are diagnosed, only half of patients control their blood glucose levels adequately.<sup>34,35</sup> This means prevention and early detection are absolutely crucial if countries are to tackle the diabetes epidemic.

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

Prevention and screening: preventing diabetes in people at risk and catching diabetes early

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### References

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A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

## Prevention and screening: preventing diabetes in people at risk and catching diabetes early

### F. References and resources

#### References (continued)

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#### Get this in word

A whole population approach

Prevention and screening

**Multidisciplinary care**

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Multidisciplinary care: patient-centred care beyond glucose control**

**A. Essential briefing**



**“Patient-centred care save lives and improves the quality of life of people with diabetes; it is the only credible model of care and management because it tackles the multiple risk factors and co-morbidities associated with diabetes, not just glucose control on its own. To deliver patient-centred care, we need community-based, multidisciplinary approaches.”**

Adrian Sanders, MP (UK)

**5 things you need to know:**

- 1. The United Nations, the World Health Organisation, the European Parliament, and leading diabetes guidelines** have all called for patient-centred care as a matter of urgency.<sup>1,2,3,4,5</sup> Patient-centred care has been defined as ‘care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions’.<sup>6,7</sup>
- 2. Leading models of patient-centred care offer combined interventions** that aim to stabilise blood glucose levels, but also control associated risk factors (for example, blood pressure, cholesterol and obesity) and prevent complications such as cardiovascular disease, damage to the eyes, kidneys, and nerves.<sup>1,8,9</sup>
- 3. Multidisciplinary care** is key to delivering patient-centred care. It involves the close collaboration of care professionals who provide joint and coordinated care and management of one or multiple conditions.
- 4. Patient-centred models of care are proven to be cost effective** – if all patients had access to them we could reduce the risk of heart disease, stroke and disability amongst people with diabetes by as much as half,<sup>8,9</sup> and reduce associated hospitalisation and other costs.
- 5. Patient-centred care is practical and achievable.** Some European countries have implemented models of patient-centred care at scale, using community-based, multidisciplinary approaches<sup>10,11</sup> and studies have shown that major benefits in reducing death and improving quality of life have been returned within as little as 2-3 years.<sup>8,12</sup>

**Priorities for action**

- **National clinical guidelines** should reflect the overwhelming evidence that patient-centred care is the only credible model for diabetes management.
- **Healthcare workforces must be realigned** to support multidisciplinary and patient-centred care, for example by creating new, non-clinical roles, such as care coordination and therapeutic patient education for self-management.
- **Implementation programmes** must test and roll out practical delivery models for multidisciplinary care that offer patient-centred care in the community setting
- **Barriers to multidisciplinary working** should be quickly identified at the national and local level and tackled on a cultural, professional, legal, financial and organisational basis
- **Financial remuneration and incentives for health care professionals** should reflect long-term patient outcomes (for example, the prevention of complications) and encourage patient-centred and multidisciplinary approaches to diabetes care.
- **Information systems** should be reconfigured to facilitate multidisciplinary working through the sharing of patient records and monitoring of outcomes for all facets of patient care.

A whole population  
approachPrevention and  
screening**Multidisciplinary  
care**Patient  
empowermentInnovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources**Multidisciplinary care: patient-centred care beyond glucose control**

## B. Summary of evidence



### What this means

- **Leading models of patient-centred care in diabetes** have combined interventions aimed at stabilising blood glucose levels, controlling for associated risk factors (for example, blood pressure, cholesterol and obesity) and preventing complications linked to diabetes (such as heart disease, damage to the eyes, kidneys, and nerves)<sup>8,9</sup>
- **Multidisciplinary care** is a key component for delivering patient-centred care. It involves the close collaboration of care professionals who provide joint and coordinated care and management of a given or multiple conditions. For diabetes, this may include general practitioners, specialists, nurses and specialist diabetic nurses, nutritionists, therapeutic educators, pharmacists, laboratory technicians, administrators, family carers and patients.
- **Within the multidisciplinary team, there should be a division of labour** with respect to care, monitoring, support, clinical oversight, and patient therapeutic education roles.



### Why this is important

- **Diabetes is rarely a 'stand alone' condition.** Damage to kidneys, eyes and nerves is common amongst people with diabetes.<sup>13</sup> Also, overweight, high cholesterol and high blood pressure are thought to affect up to 85% of people with diabetes.<sup>14</sup>
- **Complications are significant drivers of the risk of death, disability and quality of life<sup>15</sup> in diabetes.** Death rates increase several-fold and costs are 3-5 fold higher when complications are present.<sup>16,17,18</sup> Heart disease is the main cause of ill health and premature death amongst people with diabetes.<sup>1</sup>
- **Multidisciplinary teams are a sustainable delivery model in healthcare systems dominated by growing demand and chronic disease.** For example, they allow for the delegation of advice, support and monitoring to community nurses and pharmacists, reducing the workload on doctors and other specialists.
- **The United Nations, the European Parliament, the EU Diabetes Working Group and leading European clinicians** have all recognised the importance of patient centred care and multidisciplinary working in diabetes and have called for its implementation.<sup>2-4,19</sup>

A whole population approach

Prevention and screening

**Multidisciplinary care**

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

## Multidisciplinary care: patient-centred care beyond glucose control

### **B. Summary of evidence** (continued)



#### What the evidence says

- **Patient-centred care models are needed to reduce ill-health and premature death** for people with diabetes. Blood glucose control on its own is not enough.<sup>8,9,19</sup>
- **Leading models of patient-centred care have reduced hospitalisations caused by diabetic complications and could therefore have a major impact on costs.**<sup>8</sup> For example, some 34% of the total hospital inpatient days for diabetes patients are due to cardiovascular disease.<sup>20</sup>
- **All the major, successful trials of patient-centred care have relied on multidisciplinary working.**<sup>8,9,21,22</sup> For example, the UK Prospective Diabetes Study and the Danish Steno II study showed that the intensive targeting of multiple risk factors can reduce disability from micro-vascular complications (e.g. sight loss) and reduce by as much as a half mortality from cardiovascular and kidney disease.<sup>8,9</sup> In the case of the Steno II study, the benefits were maintained up to 8 years after the study commenced.<sup>9</sup>
- **Research comparing multidisciplinary care programmes for diabetes suggests there is no 'optimal' organisational model**<sup>23</sup> – what matters is that patient-centred care takes place in everyday practice. Achieving this is likely to mean identifying and challenging existing cultural, organisational, financial, professional or legal barriers to healthcare delivery.
- **There is good evidence to support the valuable contribution of a wide variety of professional roles** in improving care and outcomes for people with diabetes. For example, multidisciplinary teams with foot care specialists can reduce amputation rates by up to 85%,<sup>24</sup> and nurse-led care has been shown to improve glucose control and reduce urgent care/emergency room visits and hospitalizations for preventable diabetes-related causes.<sup>25</sup>
- **Patient-centred models of care must recognise that people with low health literacy are at higher risk of poor outcomes.** For example, a study of type 2 diabetes patients showed that inadequate health literacy was an independent predictor of poor glucose control. Given that people with low socioeconomic status are at particularly high risk of having low health literacy, approaches to care will need to be sensitive to the need to build individual health literacy.<sup>26</sup>

A whole population approach

Prevention and screening

**Multidisciplinary care**

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Multidisciplinary care: patient-centred care beyond glucose control**

**C. Making it happen**

**Key issues to think about**

*lessons learnt in implementation*

Lessons learnt	Key issues to think about	Steps you need to take
Healthcare systems are not configured to deliver patient-centred, multidisciplinary care models.	What organisational barriers may you face in trying to move towards patient-centred and multidisciplinary care?	
Health care professionals may be suspicious of multidisciplinary working.	How can you get different professionals to work together? What are the major barriers to achieving this?	
Decision-making may need to be shared or delegated between different professionals, affecting governance and accountability.	How will professionals share information and what training is needed to help them adapt to their new ways of working?	
There is no set model for multidisciplinary teams, and composition will depend on the needs of the patient populations being served.	How does one ensure multidisciplinary teams contain core roles yet can also be adapted to meet different patients' needs? Which professionals and roles are essential?	

A whole population approach

Prevention and screening

**Multidisciplinary care**

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Multidisciplinary care: patient-centred care beyond glucose control**

**C. Making it happen**

**Whom to involve**

Whom to involve	Why are they important?	What would you want their role to be? Whom should you contact?
Diabetes nurses	Provide a critical link between the patient and the health care system.	
Professional associations (physicians, nurses, etc.)	Can train professionals in patient-centred care and multidisciplinary working. Can lead efforts to change cultures and behaviours.	
Patient representatives	Can help determine what has the greatest impact on patient well-being and test new care models based on their daily life with diabetes.	
Stakeholders from other chronic disease areas	Can help establish the common ground between diabetes and other chronic disease models.	
Ministries of Health	Can lay out clinical guidelines for patient-centred care, and state expectations of multidisciplinary care.	
Local funding bodies	Should reimburse care based on patient outcomes, and work to remove financial barriers to multidisciplinary working.	
Universities and research bodies	Can lead clinical and economic evaluation of new care models, assess emerging clinical evidence and best practice.	
Health information systems	Can help facilitate multidisciplinary working through shared platforms and information sharing.	

A whole population approach

Prevention and screening

**Multidisciplinary care**

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Multidisciplinary care: patient-centred care beyond glucose control**

**D. Case studies**

**Case study 1**

**National guidelines to define the multidisciplinary team (UK)<sup>27</sup>**

The UK National Institute for Health and Clinical Excellence has stated that the range of professional skills needed for the delivery of optimal advice to adults with diabetes should be provided by a multi-disciplinary team. Such a team should include members having specific training and interest to cover the following areas of care:

- education/information giving
- nutrition
- therapeutics
- identification and management of complications
- foot care
- counselling
- psychological care

**Case study 2**

**Patient-centred care at scale (Germany)<sup>12</sup>**

The Saxon Diabetes Management Programme (SMDP) demonstrated that the mainstream implementation of integrated diabetes care was both possible and effective in improving patient outcomes at scale. At its heart, the programme involves a combination of care, management and patient education, delivered via close collaboration between Diabetic Specialist Nurses and GPs. Multidisciplinary structures, continuous quality management, and dedicated working sessions to promote mutual recognition and knowledge exchange.

An evaluation conducted over 2000-2002 found that the number of ineffectively treated patients defined by HbA1c or blood pressure decreased by around 50% as a result of the programme.

**Case study 3**

**Integrated funding for multi-disciplinary care in the Netherlands**

In 2010 the Netherlands launched a national programme for the comprehensive management of diabetes, intended as a foundation for future initiatives in other chronic diseases.<sup>28</sup> The programme involves a new national network of integrated GP-led Diabetic Care Groups (DCGs) and performance-based reimbursement focused on better outcomes in treatment and health.

Each DCG is different, but all place GPs in the case management role for the majority of patients in the primary care setting, overseeing multi-disciplinary teams that provide eye and foot checks, regular health checks and laboratory analyses.<sup>11</sup> For patients with more complex needs, the DCG system is also complemented by specialist outpatient care for diabetic foot, retinopathy, and nephropathy.<sup>29</sup>

Despite challenges in IT and outcome monitoring, improvements have been observed in the organization and coordination of care, collaboration among health care providers, and adherence to care protocols.<sup>11,30</sup>

A whole population approach

Prevention and screening

**Multidisciplinary care**

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Multidisciplinary care: patient-centred care beyond glucose control**

**E. Questions and answers**

**Patient-centred care for diabetes is a luxury we cannot afford**

We can't afford not to. Diabetes already accounts for 10% of healthcare costs<sup>31</sup> and much of this is caused by diabetic complications.<sup>32</sup> The UN, the WHO, the European Parliament and many other leading commentators have recognised that effective care of diabetes is a critical issue for the sustainability of healthcare systems.<sup>33,3,4,34</sup>

**Is patient-centred care cost effective?**

Yes. Leading models of patient-centred and integrated care have been proven to be cost effective in diabetes.<sup>8,9</sup> Such models reduce the use of costly hospitalisations, meaning healthier, more productive people who can better contribute to society.

**What evidence is there that this will work in my country?**

Patient-centred models of care for people with diabetes have been led in the UK, Denmark, Germany, the Netherlands<sup>8,9,12,11</sup> and many other countries around the world. The question is how best to make patient-centred care a reality in our own system, and what multidisciplinary delivery models we need to do so.

**The evidence base for patient-centred care is ambiguous.**

False. The clinical evidence for leading models of patient-centred care and prevention of diabetes is beyond doubt.<sup>1,7-9;35,36</sup> Different models of care will continue to be tested and evaluated, but what matters is that we implement the most effective models into the mainstream.

**Changes to the way we treat diabetes will impact on frontline workers. Professionals may resist changes to the status quo.**

Whilst multidisciplinary, patient-centred care may require changes to existing ways of working, healthier patients should mean more satisfied care professionals. Any proposed changes to health delivery systems must be designed with collaboration and support from the relevant professional societies, so that appropriate changes to professional training and standards reflect the new ways in which diabetes care is to be delivered.

**Are multidisciplinary teams necessary in diabetes? Do we really need to include wider allied health professionals, such as nutritionists and podiatrists?**

Yes. Multidisciplinary teams with foot care specialists have been proven to reduce amputation rates by up to 85 per cent.<sup>24</sup> Those teams with nurse-led care have also been shown to reduce urgent care visits and hospitalisations for preventable diabetes related conditions.<sup>10</sup>



A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

## Multidisciplinary care: patient-centred care beyond glucose control

# F. References and resources

## References

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A whole population approach

Prevention and screening

**Multidisciplinary care**

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

## Multidisciplinary care: patient-centred care beyond glucose control

# F. References and resources

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## Get this in word

A whole population approach

Prevention and screening

Multidisciplinary care

**Patient empowerment**

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Patient empowerment: therapeutic patient education for self-management**

**A. Essential briefing**



**“Therapeutic patient education for self-management is key to the future of diabetes care and indeed of chronic diseases more widely. Most people with diabetes can become confident and informed patients, if health care systems provide them with flexible and high quality support that works in harmony with each person’s individual wishes for independence and quality of life and their ability to self-manage their condition.”** Maite Valverde, Diabetes Specialist Nurse, Barcelona

**5 things you need to know:**

- 1. Therapeutic patient education** (i.e. training patients in the skills and coping processes of self-managing a chronic disease<sup>1</sup>) is a missing link in diabetes care.<sup>2,3,4</sup> Leading commentators have recognised the limitations of ‘paternalistic’, traditional medical models in coping with chronic disease.<sup>1,4</sup>
- 2. Up to 95% of the management of diabetes is self-management,**<sup>5</sup> therefore patient education and empowerment is fundamental to improving health and making healthcare delivery more effective.<sup>6,7</sup>
- 3. Therapeutic patient education for self-management in diabetes has been shown to be cost effective** in improving glucose control, blood pressure and adherence to treatment, and achieving improvements to quality of life and reducing disability.<sup>6,8</sup> A number of different models have been tested and adopted at scale across different countries.<sup>9,10,11,12</sup>
- 4. eHealth solutions are an important strategic consideration for healthcare systems,**<sup>13</sup> and can be an enabler to self-management by helping to standardise the steps involved for self-management and offering patients practical tools that can help them achieve better control over their condition.<sup>14</sup>
- 5. Building the health literacy of people with diabetes remains a priority step in achieving effective therapeutic patient education.**<sup>6</sup> Health literacy levels are grossly inadequate across Europe, particularly in people of lower socio-economic status.<sup>15</sup>

**Priorities for action**

- **Therapeutic patient education for self management should be reimbursed** as a normal part of diabetes care and support.
- **Therapeutic patient education should feature in clinical guidance** and quality standards for diabetes care.
- **Therapeutic patient education should be a core part of medical training and professional accreditation,** alongside multi-disciplinary working and other key aspects of recognised chronic disease models.
- **The role of diabetes specialist nurses in therapeutic patient education should be recognised** and a basic curriculum framework should be established to define core competences of patient educators and help implement workforce development strategies.
- **Therapeutic patient education should be ongoing and adapted** to the individual, and should anticipate and be responsive to changing patients’ needs.
- **New models of therapeutic patient education and empowerment can be piloted and evaluated,** with the learning used to help roll out at national or regional level.
- **The potential of new technologies and IT to support patients to self-manage diabetes should be tested,** evaluated, and integrated into existing care models where proven to be effective.

A whole population  
approachPrevention and  
screeningMultidisciplinary  
carePatient  
empowermentInnovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources

## Patient empowerment: therapeutic patient education for self-management

### B. Summary of evidence



#### What this means

- **The World Health Organisation has defined therapeutic patient education** as the training of patients in the necessary coping processes and skills to manage the treatment of their condition and prevent avoidable complications, while maintaining or improving quality of life.<sup>1</sup>
- **Self-management of diabetes** means that patients are trained to actively monitor their glucose levels, to take appropriate actions and make lifestyle choices to manage their condition independently, with the support of their care team.<sup>7;14</sup>
- **In diabetes, leading models of therapeutic patient education have focussed on** health literacy (i.e. knowledge of the condition), self-managed insulin therapy, and diet and lifestyle choices.<sup>7;10;11;16;17</sup>



#### Why this is important

- **Therapeutic patient education for self-management is crucial to the prevention and management of diabetes and other chronic diseases**<sup>6;13,18</sup> – which have been recognised as a major social and economic threat in the 21st Century<sup>19,20</sup> that may overwhelm our healthcare systems.<sup>21</sup>
- **'Paternalistic', traditional medical models are now widely considered ineffective** in improving outcomes from diabetes,<sup>4</sup> particularly where limited patient information is focussed on achieving compliance with clinical treatment. Outcomes are improved when patients are involved in the whole care process.<sup>6,7;14</sup>

A whole population approach

Prevention and screening

Multidisciplinary care

**Patient empowerment**

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Patient empowerment: therapeutic patient education for self-management**

**B. Summary of evidence** (continued)



**What the evidence says**

- Structured therapeutic patient education for self-management is effective in stabilising blood glucose levels, reducing diabetes-related complications, improving patient quality of life and reducing the costs of care.**<sup>7,18</sup> It is also successful in preventative interventions.<sup>11</sup> One study demonstrated improved blood glucose control, reduced hospitalisation and reduced incidence of hypoglycaemia for those with Type 1 diabetes for up to 12 years post-intervention.<sup>22</sup> Others studies have shown that combining patient education with multi-disciplinary care could reduce amputations by as much as 85%.<sup>23</sup>
- Therapeutic patient education is effective within a variety of care settings.**<sup>7,12</sup>
- ‘Structured education’ models** (defined as ‘planned and graded programmes that are 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’)<sup>7</sup> tend to be more effective than one-off,<sup>24</sup> informal, generalised or partial education models<sup>7,24</sup>
- Therapeutic patient education programmes should be mindful of the underlying level of health literacy in the individuals they are targeting,**<sup>6</sup> and seek to improve health literacy. In particular, people over the age of 75, with low education, financial difficulties, severe limitations due to health problems, more than one long-term illness are more likely to have limited health literacy than not.
- Patient educators – ideally diabetes specialist nurses or other health care providers, such a diabetes nurses, pharmacists, dieticians or doctors with special accreditation – must be excellent teachers and communicators** able to understand and engage in patient motivation.<sup>7,25</sup> Goal setting, managing setbacks, and interventions to build self-discipline and psychological resilience are vital factors in the adoption of new behaviours, not simply optional extras.<sup>4,25</sup>
- All health professionals involved in patient education should follow a core curriculum,** as recommended by the Diabetes Education Study Group (DESG) of the European Association for Study of Diabetes (EASD)<sup>26,27</sup> Countries should also promote an accreditation programme similar to the European Nurses Diabetes Collaborative University Programme (ENDCUP)<sup>28</sup> recommended by Foundation of European Nurses in Diabetes (FEND) or the Board Certified-Advanced Diabetes Manager (BC-ADM) programme<sup>29</sup> in United States.
- Providing personalised IT support tools** that are adapted to patients individual characteristics can also help in improving therapy adherence and treatment outcomes.<sup>14</sup>

Prevention through behaviour change

A whole population  
approachPrevention and  
screeningMultidisciplinary  
care**Patient  
empowerment**Innovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources**Patient empowerment: therapeutic patient education for self-management****C. Making it happen****Key issues  
to think  
about***lessons  
learnt in  
implementation*

Lessons learnt	Key issues to think about	Steps you need to take
Patient education cannot be 'done' to people by healthcare providers.	How ready are we to recognise and empower the patient as an expert in their own wellbeing and quality of life?	
Healthcare systems may be poorly prepared for patient education and self-management.	What are the workforce and logistical demands for rolling out therapeutic patient education for self-management? Who will provide and support such approaches, and in what setting?	
Health professionals may not understand or value self-management.	What training, guidelines or culture change initiatives will help clinicians support such approaches?	
Diabetes specialist nurses are ideally placed to provide therapeutic patient education, however they are not necessarily available in all countries.	Which professionals might be the best educators? Could pharmacists play a role? How do you ensure patient educators have the core competencies required?	
IT can be an important enabler of patient self-management, however patients may differ in their preferences for IT-based tools.	How do you embed the most appropriate IT solutions into clinical practice and ensure that they are tailored to different patient preferences?	
Education and empowerment approaches are highly sensitive to language, cultural and other patient characteristics.	How will we adapt therapeutic patient education to ethnic minorities or excluded groups? How can you make sure proposed solutions are tailored to individual preferences?	



INTRO



PRIORITY AREAS



USEFUL RESOURCES

A whole population approach

Prevention and screening

Multidisciplinary care

**Patient empowerment**

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&amp;A

References and resources

**Patient empowerment: therapeutic patient education for self-management****C. Making it happen****Whom to involve**

Whom to involve	Why are they important?	What would you want their role to be? Whom should you contact?
Patient groups	Patients may help identify shortcomings in the current support and education they receive and identify what the best models may be to meet their needs.	
Clinicians	Clinical champions will be useful in building professional acceptance for the value and role of therapeutic patient education for self-management.	
Hospital and primary care managers	Need to include posts for patient educators (ideally diabetes specialist nurses) in their workforce plans.	
Pharmacists	May play an important role in training patients about medicines management and may help support therapeutic education initiatives.	
Governments	Can demand that therapeutic patient education feature in national policy, clinical guidelines and performance frameworks.	
Ministries of Health and/or payers	Can authorise reimbursement of therapeutic patient education as well as IT patient support tools to local providers, and/or request monitoring and evaluation of existing programmes.	
Medical and nursing colleges, training bodies	Can ensure therapeutic patient education for self-management feature in professional training.	
Pharmaceutical, diagnostics and medical devices industry	Have a common interest in ensuring appropriate use of their products and may be knowledgeable partners in developing educational solutions, through patient education materials and/or innovative IT solutions.	



INTRO



PRIORITY AREAS



USEFUL RESOURCES

A whole population approach

Prevention and screening

Multidisciplinary care

**Patient empowerment**

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&amp;A

References and resources

**Patient empowerment: therapeutic patient education for self-management****D. Case studies****Case study 1****DE-PLAN-CAT****The implementation of intensive lifestyle interventions in primary health care in Catalonia (Spain)<sup>30</sup>**

A cohort study in Catalonia, Spain, assessed the feasibility and effectiveness of implementing lifestyle interventions to prevent type 2 diabetes in 18 primary healthcare centres. Individuals were screened using the FINDRISC questionnaire<sup>31</sup> and glucose testing and then randomized into two groups: one was offered standard care, including information about diet and exercise, and the other was offered intensive lifestyle interventions. The latter were based on the DE-PLAN (Diabetes in Europe-Prevention using Lifestyle, Physical Activity and Nutritional) interventions, a public health programme which has demonstrated efficacy and cost-effectiveness within clinical trial settings.<sup>30</sup>

Over 4 years, intensive lifestyle interventions were associated with a relative risk reduction in diabetes incidence of 36.5%. Although lower than the impact seen in clinical trials, this difference was statistically significant and demonstrates the potential effectiveness of implementing lifestyle interventions to prevent type 2 diabetes in primary care settings.

**Case study 3****DAFNE****The Dose Adjustment for Normal Eating Programme (UK)**

The DAFNE model is recognised by the UK Department of Health as a classic example of a therapeutic patient education programme for people with Type 1 Diabetes and is based on earlier models from the 1970s, sometimes referred to as Geneva – Dusseldorf models.<sup>7</sup>

The original DAFNE study model comprised a 5-day therapeutic patient education course with a booster session 6 weeks later, delivered to groups of up to eight by two trained diabetes educators. It helped people to estimate carbohydrate in each meal and inject the right dose of insulin, so promoting flexible, intensive insulin therapy in support of a flexible, varied diet with no forbidden foods.<sup>10</sup>

An economic evaluation showed that the model had the potential to save an estimated £2237 per patient over 10 years, increase life expectancy of people with diabetes by 5 years, and could effectively pay for itself within 5 years due to reduced rate of development of diabetic complications,<sup>33</sup> and similar results were obtained in the wider implementation phase.<sup>10</sup>

**Case study 2****Tailoring diabetes therapeutic patient education to individual circumstances (USA)<sup>32</sup>**

A study of tailored approaches to diabetes education in the LifeMasters DM program, California, tested a model where diabetes educators worked with patients to measure their knowledge, skill, and confidence for self-management, and selected different approaches thought to be more suitable to the patient's circumstances. The system was flexible, and anticipated changing educational needs and re-evaluation as individuals moved through different stages of the care pathway. The study showed the approach had been successful in improving the health outcomes of people with diabetes relative to non-tailored education. Adherence to care and self-management regimens also improved, and hospital usage declined. The study authors concluded that tailored approaches to patient education would be helpful in improving both the outcomes and the efficiency of disease management programmes more widely.

A whole population approach

Prevention and screening

Multidisciplinary care

**Patient empowerment**

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Patient empowerment: therapeutic patient education for self-management**

**D. Case studies** (continued)

**Case study 4**

**ROMEIO**

**Rethink Organization to iMprove Education and Outcomes (Italy)<sup>12</sup>**

A 4-year pilot programme across thirteen hospital-based diabetes clinics in Italy showed that therapeutic patient education for lifestyle and behavioural changes for people with Type 2 diabetes could be reproduced as a cost-effective, successful intervention in the hospital setting.

Group sessions ran for 2 hours every 3 months, involved imaginative problem solving, real-life simulations and role playing. Sessions were complemented by a minimum of one individual consultation per year, with additional support if necessary.

The pilot achieved dramatic results, including lowered HbA1C, fasting glycaemia, cholesterol, blood pressure, body weight and BMI, improved health behaviours, quality of life and patient knowledge of diabetes. The programme leads highlighted the importance of rethinking traditional provider roles, resources and attitudes, and supporting local operational leads tasked with teaching materials, logistical support, and supervision.

**Case study 5**

**Implementing therapeutic patient education at scale (Germany)<sup>9</sup>**

Perhaps more so than any other European country, Germany has demonstrated the benefits of a national rollout of therapeutic education models across a full spectrum of diabetes care, despite the relatively decentralised nature of the insurance-based German Health care system.

Different programmes cater for the different needs of patients with non-insulin dependent Type 2 diabetes, those on conventional insulin treatment (types 1 and 2) and intensive insulin treatment (types 1 and 2).

All 3 programmes followed a similar path to implementation, including testing through clinical trials, and piloting and evaluation in 'real world' settings. Training in therapeutic education is now mandatory for healthcare professionals and several million patients have taken part across the different schemes.

**Case study 6**

**A 6-step cycle for personalized diabetes self-management<sup>14</sup>**

Much of diabetes self-management can be standardised, and standardisation may help patients monitor their glucose levels more effectively, resulting in better outcomes and safety. Ceriello *et al.* propose a 6-step cycle which allows for personalised diabetes self-management, aided by e-Health technology. The 6 steps are:

1. The patient receives structured therapeutic education to perform 'structured glucose testing' at set times during the day
2. Self-monitoring of blood glucose is conducted during the day
3. Electronic devices/software collect and document blood glucose monitoring data directly from the blood glucose meter
4. The system presents easy-to-read graphical data formats to help patients take informed actions (eg. alter diet), and inform health professionals and educators
5. Health professionals can adapt treatment based on the characteristics of the individual patient and his/her self-management blood glucose profile, as appropriate
6. Treatment effectiveness is assessed on a regular basis. If treatment targets are not achieved, the patient is referred back to restructured therapeutic education.

A whole population  
approachPrevention and  
screeningMultidisciplinary  
care**Patient  
empowerment**Innovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources

## Patient empowerment: therapeutic patient education for self-management

### **E. Questions and answers**

#### **Developing a therapeutic patient education programme for patients is an expensive exercise, why bother?**

Providing therapeutic patient education to support patients to self-manage can have huge advantages: empowering people to better look after themselves can improve health, adherence to treatment and quality of life,<sup>6,12,18</sup> and is cost effective<sup>7</sup> – i.e. it is cheaper overall than paying for expensive medical treatment when things go wrong. Such models are practical and achievable, many have been tested and implemented into primary care and hospital clinic settings.<sup>7,9,10,12</sup>

#### **What return on investment can we expect?**

Structured patient education is cost effective:<sup>7</sup> it has been shown to stabilise glucose levels, reduce complications and hospital admissions and improve quality of life for patients.<sup>18</sup> One study showed that patient education for those with Type 1 diabetes reduced hypoglycaemia and improved quality for life of up to four years.<sup>16</sup> Others studies have shown that combining patient education with multi-disciplinary care could reduce amputations by as much as 85%.<sup>23</sup>

#### **Not all patients will want or be able to manage themselves.**

True. But many will. It is important that educators be trained to understand each patient's wishes and circumstances, and tailor support accordingly.<sup>25</sup> Therapeutic education for self-management approaches that do this have been shown to be more successful than those that offer 'one size fits all' solutions.<sup>32</sup>

#### **Don't health care professionals already educate patients? Why pay for something that should already be happening?**

Structured therapeutic patient education should be delivered by trained healthcare professionals, but is not usually part of standard diabetes care. Specialists are often too busy to offer diabetes patients the individualised and continuous education and support they require to achieve self-management. This role is ideally led by nurses working in a multi-disciplinary setting,<sup>18</sup> who require specific additional training and resources to deliver this support to patients.

Q

A

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

Patient empowerment: therapeutic patient education for self-management

F. References and resources

References

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A whole population approach

Prevention and screening

Multidisciplinary care

**Patient empowerment**

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

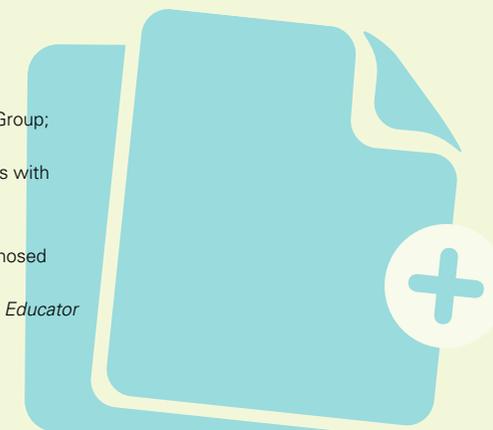
References and resources

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#### Get this in word

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

## Innovation and access to care: securing access to care and fostering innovation in diabetes

### A. Essential briefing



**“Even in times of economic crisis, it is vital that we do not strangle innovation. Investment in better diagnosis and care for people with diabetes will not only have benefits for public health, it will allow us to curb the exploding costs that diabetes poses to our health care systems and society. We cannot afford to take a narrow and short-termist view on investing in diabetes care.”** Teresa Caeiro, MP for Portugal

#### Priorities for action

#### 5 things you need to know:

- 1. Much still needs to be done to improve the prevention, diagnosis and care of people with diabetes.** Half of people with diabetes do not have adequate blood glucose control, putting them at increased risk of complications such as heart disease, and damage to the eyes, nerves and kidneys.<sup>1</sup>
- 2. Limits in access to even the most essential diabetes care exist in some countries.** Cuts in health care spending across Europe have resulted in limited access to diagnosis, treatment and care for many people with diabetes.<sup>2,3</sup>
- 3. We cannot afford to be complacent.** The prevalence and costs of diabetes are increasing in all European countries and huge inequalities in outcomes exist.<sup>4</sup>
- 4. Investment in optimal care is essential to drive down costs.** Offering people with diabetes effective prevention, detection and care is key if we want to stop the spiralling costs of diabetes to our health care systems and to society, and enable people with diabetes to lead healthy and productive lives.
- 5. Very little is invested in government-funded diabetes research compared to other chronic conditions.** Diabetes needs to be given a greater priority in resources devoted to research and innovation.<sup>5</sup>

- **Make investment in diabetes a priority and maintain incentives for innovation despite economic pressures** – for example, through the creation of innovation funds.
- **Encourage cross-sectoral collaboration involving governments, professional societies, patient advocates, the life science industry and regulators** to ensure that people with diabetes have optimal and equal access to the best diabetes management and care available.
- **Ensure that patients have access to multiple diabetes treatment options** to ensure that each patient is offered the most appropriate treatment combination to meet his or her individual needs.
- **Align priorities for innovation with goals set in national diabetes plans** and build in mechanisms to health delivery to ensure that new interventions are used as effectively as possible.
- **Encourage the life sciences industry and research community** to focus on addressing the most important unmet needs of people with diabetes.
- **Ensure that pricing and reimbursement processes are as efficient as possible** to avoid unnecessary delays in access to new interventions for patients.
- **Ensure that reimbursement bodies, Health Technology Assessment (HTA) Agencies and policymakers** consider the full clinical and economic costs and benefits of new interventions to patients, the healthcare system and wider society, instead of only considering the immediate impact on healthcare budgets.

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

**Innovation and access to care**

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Innovation and access to care: securing access to care and fostering innovation in diabetes**

**B. Summary of evidence**



**What this means**

- Within the current economic climate, it is essential to **ensure that people with diabetes have access to the best care possible**, but also that **investment in innovation** – in terms of models of care as well as interventions - is not undermined by immediate fiscal pressures.
- Traditionally, interventions in diabetes have been defined in terms of glucose control, yet the management of co-morbidities and prevention of complications are just as important.<sup>6</sup>
- Therefore, the **diabetes care processes and interventions that should be prioritised are those** that help patients control their **blood glucose** levels, **manage co-morbidities and prevent or delay the onset of complications**.



**Why this is important**

- Healthcare cuts brought on by the economic crisis are putting an **increased financial burden on patients** with diabetes.<sup>2</sup>
- **Limits in access to even the most essential diabetes care** exist in some countries.<sup>3,7</sup>
- **Outcomes for many people with diabetes remain inadequate** across Europe.
- Healthcare delivery and funding is **increasingly localised**, and system-wide incentives and processes are needed to avoid regional disparities in access to innovative care.
- **Diabetes is accorded a low priority in research budgets** compared to other chronic diseases<sup>5</sup>, despite its growing prevalence in all countries.



**What the evidence says**

***Outcomes for diabetes remain suboptimal – a lot still needs to be done to achieve ‘optimal’ levels of care for diabetes patients across Europe.***<sup>6</sup>

- Despite many advances in diabetes treatment and diagnostics over the past few decades, **only approximately half of patients with diabetes achieve good glucose control.**<sup>1</sup> Moreover, up to 50% of cases of diabetes in Europe are thought to be undiagnosed, and therefore remain untreated.<sup>6,8</sup>

## Innovation and access to care: securing access to care and fostering innovation in diabetes

### B. Summary of evidence (continued)



#### What the evidence says

##### **Disparities in access to diabetes interventions persist across Europe.**

- There is huge variability within Europe in the time it takes between regulatory approval of diabetes drugs and devices to their availability in clinical practice.
- Disparities in access have been found for: glucose monitoring strips, self-monitoring blood glucose meters<sup>3,8</sup>; medicines<sup>9</sup>; insulin pumps<sup>8</sup>; and diagnosis.<sup>2</sup>
- Such limited access has been shown to compromise patient care and limit patients' confidence in their ability to self-manage their condition.<sup>3</sup>
- Psychological support and therapeutic education are not reimbursed in many countries.<sup>8</sup>

##### **The financial burden on patients with diabetes is increasing.**

- Co-payments for medicines and medical devices are increasingly being used as a means by governments to cut health care expenditure.<sup>7</sup> Such measures have been shown to affect the most vulnerable and needy of patients disproportionately.<sup>7,10</sup>
- Limited reimbursement of glucose monitoring strips have been shown to deter many people with diabetes from self-managing their condition.<sup>3</sup>

**Measures of 'value' of existing and new interventions** should be more robust and take a **societal approach to evaluation** – taking into account the overall impact on health care delivery, patient quality of life and productivity, as well as the potential for more efficient use of health services (eg. reduced hospital admissions).

- **Hospital admissions are the main cost driver for diabetes**, accounting for close to half of direct costs.<sup>11,12</sup>
- Complications have the greatest impact on patients' quality of life and **increase the risk of death and costs several-fold.**<sup>11,13,14</sup>
- The impact of diabetes on **productivity** is a key concern to business leaders and employers.<sup>15</sup>
- Indirect costs of diabetes are likely to overtake direct medical costs in the years to come.<sup>16,17</sup>

##### **Innovative approaches to ensure the appropriate use of new interventions are needed.**

- Inappropriate use and poor adherence to diabetes medicines is a significant problem, therefore innovative models of care are needed that may improve adherence and appropriate use of diabetes medicines, monitoring and other interventions and remove existing barriers to care.<sup>6</sup>
- Improved adherence will not only improve patient outcomes but also reduce costs.<sup>18</sup>

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

**Innovation and access to care**

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Innovation and access to care: securing access to care and fostering innovation in diabetes**

**C. Making it happen**

**Key issues to think about**

*lessons learnt in implementation*

Lessons learnt	Key issues to think about	Steps you need to take
National policies on fostering better access to care may be ineffective given that health funding decisions are increasingly localised.	What mechanisms and processes can be built in to help avoid/reduce disparities in access across localities and ensure that best practices are spread throughout the system?	
When limits in access to even the most basic components of diabetes care exist, you will have to justify investment in new interventions in diabetes.	Can a joint platform for determining the value of interventions (old and new) be established, to ensure that interventions and care processes that offer the best value to patients, society and health care delivery are prioritised?	
Intersectoral collaboration is key to focus research in diabetes on where the greatest unmet needs are and agree a common definition of 'value' when assessing new and existing interventions.	Is there an existing forum for dialogue between regulatory agencies, Health Technology Assessment (HTA) bodies, industry and patient organisations? Who are the necessary players?	

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

**Innovation and access to care**

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Innovation and access to care: securing access to care and fostering innovation in diabetes**

**C. Making it happen**

**Whom to involve**

Whom to involve	Why are they important?	What would you want their role to be? Whom should you contact?
Patient representatives	May help identify which innovations (in care pathways, medicines, diagnosis and monitoring) are most needed from the patient perspective.	
Professional associations (physicians, nurses,...)	Guidelines and training should be aligned to encourage uptake of the best possible care in accordance with national plans and a shared vision for unmet needs in diabetes.	
Health information systems	Outcomes upon which care is evaluated should be built into monitoring systems to guide future funding decisions.	
Regulatory bodies, pricing and reimbursement, Health Technology Assessment (HTA) agencies	Should incorporate a common definition of 'value' into their decisions to fund/reimburse new interventions.	
Industry (diagnostics, monitoring, devices, insulin, pharma)	Major contributor of innovations – need to focus research efforts on areas of greatest unmet need; can collaborate with health care providers to make sure innovations are used appropriately.	



INTRO

PRIORITY  
AREASUSEFUL  
RESOURCESA whole population  
approachPrevention and  
screeningMultidisciplinary  
carePatient  
empowermentInnovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources**Innovation and access to care: securing access to care and fostering innovation in diabetes**

## D. Case studies

### Case study 1

#### The European Healthcare Innovation Leadership Network Type 2 diabetes working group

The **European Healthcare Innovation Leadership Network Type 2 diabetes working group** is a commercially-led initiative which aims to achieve intersectoral consensus on how the value of diabetes innovations should be defined.

The working group concluded that innovations in diabetes medicines should focus on three key areas:

- arresting disease progression
- reducing cardiovascular complications
- reducing the side effects of treatment – in particular hypoglycaemia, weight gain and cardiovascular risks.<sup>19</sup>

**FOR MORE INFO:** [www.tapestrynets.com/initiatives/healthcare/european-healthcare-innovation-leadership-network.cfm](http://www.tapestrynets.com/initiatives/healthcare/european-healthcare-innovation-leadership-network.cfm)

### Case study 2

#### DIAMAP (EU)

**DIAMAP (the Road Map for Diabetes Research in Europe)** is funded by the European Commission and proposes **a holistic approach to research planning in diabetes**, which takes into account all of the complexity of diabetes presentation and epidemiology across different patient groups. The underlying premise of DIAMAP is that sustained investment in diabetes research is needed to halt the diabetes epidemic.

**DIAMAP** offers a **RoadMap** for diabetes research planning and outlines a European strategy for diabetes research which addresses all aspects of diabetes (co-morbidities, prevention of complications, tailored therapies by subgroup, ...)

**FOR MORE INFO:** [www.diamap.eu](http://www.diamap.eu)

### Case study 3

#### The Innovation Scorecard

PriceWaterhouseCoopers has developed a Medical Technology Innovation Scorecard, which assesses nine countries' capacity and capability for medical technology innovation (Brazil, China, France, Germany, India, Israel, Japan, United Kingdom, United States). The scorecard may serve as an interesting example of how countries may wish to measure their own capabilities and investment in innovation not only in terms of medical technology but also in terms of other investments in diabetes care.

**FOR MORE INFO:** [www.pwc.com/us/en/health-industries/health-research-institute/innovation-scorecard/index.jhtml](http://www.pwc.com/us/en/health-industries/health-research-institute/innovation-scorecard/index.jhtml)

### Case study 4

#### Expedition diabetes (Netherlands)

The Dutch Diabetes Federation (NDF) has launched 'expedition diabetes', with aims to improve diabetes care by developing innovative new treatment options. The initiative works on the basis of set patient profiles, which may make it easier for a GP to define how much self-management a patient can cope with. Alongside this, the Netherlands has introduced innovative reimbursement schemes based on integrated care funding, which involve a lump sum reimbursement of GPs per patient, for all care including the costs of medicines. These initiatives have, so far, shown real improvements in diabetes outcomes.

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

**Innovation and access to care**

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**Innovation and access to care: securing access to care and fostering innovation in diabetes**

**E. Questions and answers**

**Why should we invest in diabetes as opposed to other disease areas?**

Diabetes costs more than cancer yet is still accorded relatively low priority compared to other diseases.<sup>5</sup> The prevalence and costs of diabetes (to the healthcare system as well as to society through lost productivity) are increasing exponentially and will continue to do so if more investment is not put into improving prevention, treatment and care for diabetes.

**Shouldn't we be putting all our money into prevention, not care?**

Preventing diabetes is vital, and more efforts and resources are needed to achieve more effective prevention – although not all cases of diabetes are preventable. But we also need to improve the outcomes for the millions of people who already have diabetes, by improving the care they receive and reducing their risk of developing complications and associated health problems.

**Wouldn't one expect differences in access to treatment and care for diabetes within the EU, as they reflect individual countries' ability to pay?**

Differences in uptake of innovative care across countries are not the reflection of countries' GDP or ability to pay, but depend on other factors such as regulatory hurdles.<sup>20</sup>

**Why invest in new diabetes medicines and devices when there are so many diabetes treatments already available?**

Whilst it is true that many treatment options currently exist, only half of patients who have diabetes are well controlled with the medicines at their disposal and adherence to existing medicines is low. Moreover, up to 50% of cases of type 2 diabetes in Europe are thought to be undiagnosed.<sup>8</sup> Therefore investment in the best care models, treatment, diagnostics and monitoring devices possible will be essential if we want to halt the burden posed by diabetes.

**Shouldn't we be focusing on sustainable financing of our health care systems, not investing in 'new' care?**

Fostering innovation and sustainable health care budgets should not be incompatible, as long as we build in mechanisms within health delivery systems to make sure that any new intervention is used appropriately so that full benefits may be derived from their use.

**How can we justify paying more for expensive new drugs and devices?**

Drugs only make up a small fraction of the total costs of diabetes.<sup>9</sup> The main cost drivers are hospitalisations, which are in great part due to the complications of diabetes (heart disease, stroke, etc).<sup>9</sup> The key questions we should be asking for any new intervention are: will its use help decrease hospital admissions? Will it allow patients to achieve better self-management? Improve their quality of life? Help prevent or delay complications? Enable them to remain productive and active citizens?



A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

## Innovation and access to care: securing access to care and fostering innovation in diabetes

# F. References and resources

## References

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## Get this in word

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

## A special responsibility: children with diabetes and schools

### A. Essential briefing



**“Children are a priority group within the diabetes population. Diagnosis at a young age may impact on a child’s personal and social development. Ensuring that a child’s medical needs are met throughout all aspects of their lives, and particularly during their time at school, is vital for their social integration - not to mention their health and well-being.”** Giorgios Papanikolaou, Member of the European Parliament

#### 5 things you need to know:

- 1. Diabetes is the most common chronic condition in children and adolescents** after asthma<sup>1</sup> and its prevalence is increasing for both type 1 and 2 diabetes.<sup>2,3</sup>
- 2. Type 2 diabetes is often a more serious condition when diagnosed in children** as compared to adults, with a greater risk of complications.<sup>2</sup> Despite this, it can be seen as an ‘adult disease’.
- 3. Legal frameworks protect the rights of children with diabetes** in terms of lack of discrimination and equal access to normal schools.
- 4. However in practice children with diabetes are often prevented from managing their condition effectively**, as most schools lack the knowledge, resources and training to meet the needs of children with diabetes during the school day, putting them at risk of immediate and long-term complications.
- 5. Diabetes in childhood can create a huge burden for parents**, who may have to be ready to deal with any situation that may arise and often have to give up full-time work to do so.<sup>4,5</sup>

#### Priorities for action

- **Provide systematic information on diabetes and its management to all schools and educational settings** to ensure that all school staff are familiar with the basics of diabetes and undue fears of liability are challenged.
- **Ensure that every child with diabetes has an individual healthcare plan** – which is co-signed by their treating physician, parents and the school, to ensure that roles and responsibilities are clearly defined and all caregivers are informed about the particular needs of each child with diabetes.
- **Bridge health and educational sectors** – through joint protocols, clear lines of accountability, and the embedding of standards into school inspections.
- **Invest in training on diabetes in schools through dedicated paediatric diabetes professionals in the community**, for example paediatric diabetic specialist nurses, who can provide appropriate training to volunteer school staff for the management of individual children.
- **Develop clearer legislation and guidance on the management of diabetes in schools** – to help schools plan for and put in place appropriate resources to meet the needs of children with diabetes.
- **Investigate opportunities for EU funding to develop targeted actions supporting children with diabetes**, for example through the European Youth programme.

A whole population  
approachPrevention and  
screeningMultidisciplinary  
carePatient  
empowermentInnovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources

### A special responsibility: children with diabetes and schools

## B. Summary of evidence



### What this means

Children and adolescents with diabetes spend most of their time during the day at school, therefore it is critical that all necessary accommodations be made to the school environment to allow them to fully manage their condition. In particular, children should be allowed to:

- Test their glucose levels, inject insulin or take medication as needed throughout the day (in primary schools, children may need help from specifically trained staff to achieve this).
- Eat or drink and go to the toilet when needed.
- Participate in sports activities or excursions as appropriate with the child's abilities and needs.



### Why this is important

- **The incidence of type 1 and type 2 diabetes is growing** in children in Europe<sup>3,6,7</sup> yet most **schools lack the knowledge and resources** to be able to cope with the medical needs of these children.
- **Careful management is particularly important for children.**<sup>2</sup> Children who are not able to manage their condition safely and securely at school may be at **greater risk of complications** from diabetes.
- **Poorly controlled diabetes has a negative impact on children's learning.** Both high and low blood glucose levels will prevent children from concentrating and learning and will take teachers away from other children while they have to deal with them.
- **We have a duty to get diabetes care right from the start.** What happens at school will set the scene for children's future social and personal development – affecting their self-confidence, feelings of independence, and social integration.

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**A special responsibility: children with diabetes and schools**

**B. Summary of evidence** (continued)



**What the evidence says**

**1 The incidence of both type 1 and type 2 diabetes in children and adolescents is growing**

- There are approximately 130,000 children with type 1 diabetes in Europe<sup>7</sup>, and the greatest increase is in children younger than 5 years – rates are expected to double between 2005 and 2020.<sup>3</sup>
- Rises in childhood obesity have also caused an rise in the incidence of type 2 diabetes;<sup>6</sup> 45% of cases in adolescents are now type 2.<sup>6</sup>
- Type 2 diabetes is often a more serious condition when diagnosed in children as compared to adults, with a greater risk of complications and greater need for insulin therapy.<sup>2</sup>

**2 Legal frameworks across Europe support the rights of children with diabetes in school, however many schools are unprepared – or unwilling – to accept responsibility for the management of children with diabetes.** For example, in Spain one in four parents reported having a problem with their child’s school in terms of the management of their child’s diabetes.<sup>5</sup>

**3 Schools are often reluctant to take on responsibility for the management of a child’s diabetes for fear of liability and lack of specific training.** As a result, parents must be on call to ensure the safety of their child throughout the day, often causing them to give up full-time employment.<sup>5</sup>

**4 Perceived lack of support from schools may cause diabetes specialists to prescribe less intensive insulin regimens to children,** despite the fact that more intensive regimens are known to be more effective in achieving consistent glycaemic control.<sup>4,5</sup>

**5 Paediatric diabetic specialist nurses may provide a consistent link between the child’s health team and their school.** They also provide critical support to families and may offer training sessions for schools. Their presence has also been associated with reduced lengths of stay and hospital admissions for newly diagnosed children with insulin-dependent diabetes.<sup>8</sup>

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**A special responsibility: children with diabetes and schools**

**C. Making it happen**

**Key issues to think about**

*lessons learnt in implementation*

Lessons learnt	Key issues to think about	Steps you need to take
Funding for this issue may be difficult as responsibilities are split between health and education sector agencies.	Who may be willing to fund this? How do we encourage joint funding? What local or EU-level funding mechanisms exist?	
There is no established accountability between the health and educational sectors.	Are there any examples of joint or integrated care protocols that span across both sectors? Were they developed in partnership?	
How a school responds to the needs of children with diabetes varies from one school to another.	Can you embed targets and standards for addressing the needs of children with diabetes into school inspections as well as local public health audits? How can education and health Ministries collaborate to standardise approaches?	
Identifying who is going to provide training to schools (diabetes nurses, other health care professionals) is a major challenge.	What is the availability of community nurses or patient organisations who may play this role? What role can/should school nurses play?	
Many schools are reluctant to take responsibility as they fear liability if anything goes wrong.	What is the legal stance? Can you work with patient groups to inform parents and schools and set out clear guidance?	
High staff turnover and the movement of children through the school system makes it difficult to keep up training requirements to meet individual pupil needs.	How can you create a sustainable training programme for schools? Could it follow a 'train the trainer' approach?	

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**A special responsibility: children with diabetes and schools**

**C. Making it happen**

**Whom to involve**

Whom to involve	Why are they important?	What would you want their role to be? Whom should you contact?
Associations of school headteachers	Provide leadership in the community and in individual schools.	
Children with diabetes and their parents – patient associations	Need key advocates to drive change and provide ‘reality check’ on any actions being proposed.	
Diabetes paediatric specialists	Powerful voice to lobby government and local authorities for change.	
Community nurses, paediatric diabetes nurses,...	Key linkage between health and educational system, may provide training to schools for each child.	
Diabetes professional societies	May help provide guidelines and adapt professional training to ensure appropriate support to schools.	
Local health and education authorities	Must work together to implement change and set standards locally.	
Teachers’ unions	Traditionally have been reluctant to allow members to take any responsibility for children’s medical needs.	
Ministry of Health and Ministry of Education	May help promote national guidance; national steer on integrated care.	

A whole population  
approachPrevention and  
screeningMultidisciplinary  
carePatient  
empowermentInnovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources

## A special responsibility: children with diabetes and schools

### D. Case studies

#### Case study 1

##### Specific legislation to improve the care of children with diabetes at school (Spain)<sup>9</sup>

In 2010, the Spanish government passed a bill to help improve the social integration of children with diabetes, asthma or severe allergies in schools. Central proposals included:

- Individual Healthcare Plans for each child, to be developed jointly by health services, educational centres and patient/parent associations;
- Training of all teaching and canteen staff on how the condition may manifest itself in children;
- Exchange of information on best practices between schools;
- Better integration into school of children with such conditions in all settings and activities at school.

**FOR MORE INFO:** [www.congreso.es/public\\_oficiales/L9/CONG/BOCG/D/D\\_411.PDF](http://www.congreso.es/public_oficiales/L9/CONG/BOCG/D/D_411.PDF)

#### Case study 2

##### Paediatric diabetes specialist nurses (UK, Scandinavia)

In the UK and some Scandinavian countries, each child is assigned a diabetes specialist nurse at the hospital, who runs training sessions at the school and at the hospital for each child they have under their care.<sup>11</sup> This ensures that a consistent link is maintained between the child's health care team and their school. It should be noted, however, that there is a shortage of paediatric diabetes specialist nurses in the UK.<sup>11</sup>

#### Case study 3

##### Practical guidance to schools on the management of children with diabetes (UK)<sup>10</sup>

The Royal College of Nursing in the UK issued practical guidance to schools on how they could help meet the needs of pupils with diabetes, providing helpful templates and support documents.

**FOR MORE INFO:**  
[www.rcn.org.uk/\\_data/assets/pdf\\_file/0008/267389/003\\_318.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0008/267389/003_318.pdf)

#### Case study 4

##### Resource packs for parents of children with diabetes to give to schools (UK, Germany)

Patient organisations can play a critical role in supporting parents of a child with diabetes to engage with their school. This has included good practice models, training materials and information which parents may use to initiate the dialogue with their school about how to meet their child's needs. Some example of materials available in the UK and Germany feature below:

**FOR MORE INFO:**

**UK** - [www.jdrf.org.uk/life-with-type-1/school-resources](http://www.jdrf.org.uk/life-with-type-1/school-resources)

**Germany** - [www.diabetes-kinder.de/modularx/include/module/dateimanager/data/kindergartenbroschuere\\_07-2010.pdf](http://www.diabetes-kinder.de/modularx/include/module/dateimanager/data/kindergartenbroschuere_07-2010.pdf)

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**A special responsibility: children with diabetes and schools**

**D. Case studies** (continued)

**Case study 5**

**SWEET**

**Better control in pediatric and adolescent diabetes: working to create Centres of Reference (EU)**

SWEET is an EU-based project, funded by the European Commission, which aims to improve the prevention, diagnosis and control of type 1 and type 2 diabetes in children and adolescents. To achieve this it supports the spread of learning and clinical best practice through the development of Centres of Reference (CORs) for pediatric and adolescent diabetes services across the EU. The project aims to create a 'Pediatric Diabetes Toolbox', which would include recommendations on best practice, patient education programmes, and training programmes for health professionals. It also aims to establish a definition and criteria to guide the establishment of new Centres of Reference. There are currently 13 countries participating in the project.

**FOR MORE INFO:** [www.sweet-project.eu/](http://www.sweet-project.eu/)

**Case study 6**

**Joint advocacy positions for the healthcare needs of children in schools (UK, Ireland)**

In the UK and Ireland, diabetes patient organisations have joined forces with organisations in areas such as asthma and epilepsy to raise awareness of the need to respond to the medical needs of children in school.<sup>12,13</sup>

**FOR MORE INFO:** [www.medicalconditionsatschool.org.uk/](http://www.medicalconditionsatschool.org.uk/)

**Case study 7**

**Joint protocols on the management of children with chronic conditions across the health and educational sector (Spain, Italy)**

Regional framework agreements exist in many regions of Spain (*protocolos de actuacion*) and Italy (*Intese*) on the management of chronic conditions at school – particularly on the administration of medication. These agreements outline the entire chain of care linking educational and health services and define roles and responsibilities of all agencies involved. Agreements usually involve the schools, the local health service, parents, and the relevant local/regional educational and health authorities.

**FOR MORE INFO:**

**Andalucia** - [www.feteugtandalucia.org/files/a\\_sanitaria\\_protocolo.pdf](http://www.feteugtandalucia.org/files/a_sanitaria_protocolo.pdf)

**Tuscany** - [www.agd.it/leggitos/pdf/scuola\\_protocollo\\_farmaci.pdf](http://www.agd.it/leggitos/pdf/scuola_protocollo_farmaci.pdf)

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**A special responsibility: children with diabetes and schools**

**E. Questions and answers**

**Children with other conditions face similar issues – why should we focus on diabetes?**

Diabetes is one of the most common chronic conditions facing children and its incidence is growing – we need to plan for the needs of both current and future generations. But that being said, many of the challenges faced by children with diabetes are similar to those of children with asthma, epilepsy or other conditions who require medical care at school. In a number of countries, patient organisations representing these conditions have joined forces to create joint campaigns and support materials for schools addressing all of these conditions.

**It is too much to ask of teachers to learn how to monitor glucose or inject insulin to a child.**

Parents of children with diabetes receive specific training to manage all aspects of their child’s diabetes, therefore it is perfectly feasible for teachers to learn how to do the same. Sweden actually changed its legislation to state that monitoring of glucose levels and administering insulin (and other aspects of diabetes management) should be considered ‘self-care’ (ie not medical care), meaning that non-clinically trained school staff were able to do it without fear of liability.

**Teachers’ unions have been very clear that they consider the administration of medication (particularly injections) by teachers as outside the duty of care.**

This is correct in many countries (eg.the UK), however, undue fear of liability is often what prompts this position by teachers’ unions. If better information and systematic training were offered to school personnel on how to manage all aspects of diabetes effectively, such reluctance on the part of teachers’ unions may decrease. Governments may also need to clarify legal duties and liabilities.

**Surely this is the role of the school nurse or doctor?**

Most schools do not have a school nurse or doctor on site. Also, a child with diabetes has many needs, ranging from needing to go to the toilet more frequently to doing regular glucose measurements. It is important that the school staff who are with that child on a regular basis (eg. their teacher) be aware of their pupils’ needs to make sure that these needs can be met as naturally as possible, causing the child the least amount of disruption and potential embarrassment possible.

**Legal frameworks already protect the rights of children with diabetes from discrimination at school. So why should we need more legislation?**

More legislation is not necessarily the answer, but clearer guidance and information for schools to understand and fulfil their duties is urgently needed. Surveys from a number of countries suggest that the experience of children with diabetes currently varies from school to school and depends mostly on the goodwill of individual teachers.

**It is dangerous to suggest that children with diabetes should participate in sports or other physical activities.**

This is not true – children with diabetes have better blood glucose levels if they exercise regularly. A child’s individual healthcare plan will inform staff how exercise can be managed safely, and the rare occasions when children should not take exercise.



A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

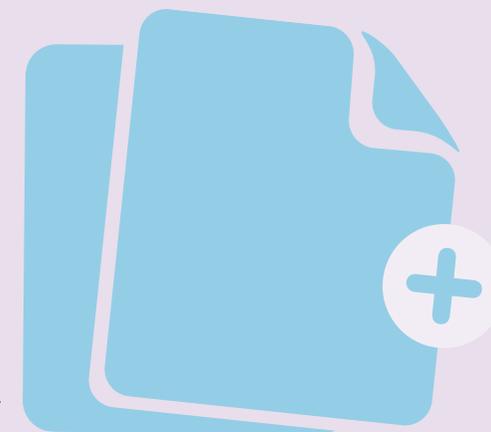
References and resources

## A special responsibility: children with diabetes and schools

# F. References and resources

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## Get this in word

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

## A special responsibility: older people with diabetes

### A. Essential briefing



**“Older people make up a fifth of our population but over half of the population of people with diabetes. Appropriate care for older diabetes patients requires a multidisciplinary, individualised and integrated approach, where the needs of each patient are taken into consideration. Unfortunately, our health care systems have a long way to go before meeting this objective.”** Cindy Franssen, MP for Flanders and Member of the Belgian Senate

#### 5 things you need to know:

- 1. Over half** of people with a known diagnosis of diabetes are over the age of 60 and by 2030, this figure will reach 60%.<sup>1,2</sup>
- Diabetes management and treatment goals may need to be adapted to the specific needs of older people<sup>3</sup>** as frailty, functional limitations, cognitive dysfunction, managing multiple medications, and the presence of other chronic conditions (co-morbidities) may all affect older people’s ability to manage their condition,<sup>4</sup> and affect their response to treatment.<sup>1,5-7</sup>
- Approximately one quarter of care home residents have diabetes<sup>8</sup>,** yet few specific provisions are made for people with diabetes in institutional care.<sup>1</sup>
- Older people tend to have more complications<sup>3</sup> and higher rates of emergency hospital admissions** than younger people with diabetes.<sup>9,10</sup> Preventing these complications through better management can lead to considerable cost savings.<sup>11</sup>
- Older people, particularly those with co-morbidities, have traditionally been **excluded from clinical trials** and many health care systems **do not provide structured care** for older people with diabetes.

#### Priorities for action

- **Ensure that clinical guidelines include specific recommendations for older people,** which take account of their particular needs and address their heterogeneity.
- **Foster the implementation of integrated care at the local level,** as this holds the greatest promise of delivering person-centred and multidisciplinary care for older people with diabetes.
- **Include standards for the management of older people** in performance-based remuneration schemes for physicians.
- **Deliver appropriate healthy lifestyle education and promotion programmes** (eg. on nutrition and physical activity) in community or institutional settings where they are likely to reach older people.
- **Provide community-based training and support programmes** to older people and their caregivers by nurses or other community-based health care professionals to help reduce rates of hospitalisation and encourage adherence to treatment.
- **Develop regulatory guidance to ensure that clinical trials in diabetes are more relevant to older people,** either by including an appropriate proportion of older people, particularly those suffering from multiple conditions or through models which allow for extrapolation of findings to older populations.
- **Establish a regulatory framework for care homes and other similar institutions** to ensure staff are appropriately trained on the management of diabetes and standards are built into quality monitoring systems and processes.<sup>7</sup>

A whole population  
approachPrevention and  
screeningMultidisciplinary  
carePatient  
empowermentInnovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources

### A special responsibility: older people with diabetes

## B. Summary of evidence



### What this means

Diabetes management in older people may present particular challenges linked to frailty, functional limitations, cognitive dysfunction and other chronic conditions (co-morbidities), which may impact on the ability of many older people to manage their diabetes<sup>4</sup> and affect their response to treatment.



### Why this is important

- **Older people are the largest single group of people with diabetes.** One in five older people has diabetes and a similar proportion is thought to have undiagnosed diabetes.<sup>7</sup> This rate will increase 4.5 fold (as compared to 3-fold in the total population) by 2050.<sup>4,8</sup>
- **There is a gap in evidence and good practice.** Most international clinical guidelines in diabetes ignore the issues of frailty, functional limitation, changes in mental health and increasing dependency that characterise many older people with diabetes.<sup>7</sup>
- **Approximately one quarter of residents in care homes have diabetes.**<sup>8</sup> These residents have more falls, higher rates of heart disease and depression, more functional impairment and cognitive decline than residents without diabetes.<sup>8,12,13</sup>
- **Rates of complications tend to be higher for older people, as do their rates of emergency hospital admissions.**<sup>9,10</sup> Preventing these complications through better management can lead to considerable cost savings – for example, in the UK reducing by 50% late referrals to specialist foot teams could save the health care system €42 million per year.<sup>11</sup>



### What the evidence says

#### Older people may have particular needs that must be accounted for in treatment plans

- The effective management of older patients with diabetes requires an emphasis on safety, diabetes prevention, early treatment for vascular disease and functional assessment of disability because of limb problems, eye disease and stroke.<sup>1,2,7,8,14</sup>
- Older people with multiple morbidities and poor nutrition may be at particularly high risk of hypoglycaemia, making its prevention a priority in this age group.<sup>4</sup>
- Glucose control goals have to be adapted for older people who are either frail or have co-morbidities.<sup>5,6</sup>

A whole population  
approachPrevention and  
screeningMultidisciplinary  
carePatient  
empowermentInnovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources[A special responsibility: older people with diabetes](#)

## B. Summary of evidence (continued)



### What the evidence says

#### **Individualised treatment and management approaches are needed<sup>8</sup>**

- Evidence suggests that the health care goals that matter most to older patients are maintaining functional status and independence.<sup>8,15</sup>
- Individualised management plans for older people should consider patient-centred measures such as patient preferences, quality of life, changes in cognition, balance and the risk of falls, the need to manage multiple medications and minimise caregiver burden.<sup>5,6</sup>

#### **Lifestyle interventions are particularly effective in older people**

- Large-scale studies of behavioural interventions focused on weight loss and exercise have been shown to be particularly effective in older people with diabetes. For example, in the US Diabetes Prevention Programme, such interventions reduced the risk of developing diabetes by 71% in persons over the age of 60.<sup>16</sup>

#### **Appropriate screening should be included into care plans for older people with diabetes, in particular for:**

- Depression and cognitive dysfunction – often under-recognised and undertreated in older people.<sup>7</sup>
- Frailty and co-morbidities<sup>17</sup> to help identify any functional loss, measure levels of disability and allow for therapy to be tailored appropriately to individual needs.<sup>6,7</sup>
- Risk of malnutrition, through systematic nutritional screening.<sup>7</sup>

#### **Specific standards for the management of people with diabetes in care homes and similar institutions are needed**

- A high proportion of people with diabetes live in care homes, yet care is often poorly structured, leading to high rates of hospital admission and preventable complications.<sup>1</sup>
- Regular monitoring and education of staff and patients may make a big difference in improving the care of older residents in care homes with diabetes.<sup>1</sup>

**A special responsibility: older people with diabetes**

**C. Making it happen**

**Key issues to think about**

*lessons learnt in implementation*

Lessons learnt	Key issues to think about	Steps you need to take
Older people are a very heterogeneous population, therefore 'one size fits all' approaches will not be successful.	How can the appropriate balance between individualisation of care and standardisation of best practice be reached?	
Both malnutrition and obesity may be a problem in older people.	How can you ensure a careful balance of measures which address both risks?	
High levels of staff turnover make care homes a challenging environment for reform.	What measures can you take to ensure continuity and sustainability of any changes you try to implement?	
Implementation of multidisciplinary care may be difficult in practice.	What are the barriers currently to implementing multidisciplinary care? How can they best be addressed?	
Ongoing training and development is key in any health system reform, otherwise changes may just be seen as being imposed on health care professionals. <sup>18</sup>	Who is responsible for training of different health care professionals? How can the appropriate information be filtered into their training curricula?	



INTRO

PRIORITY  
AREASUSEFUL  
RESOURCESA whole population  
approachPrevention and  
screeningMultidisciplinary  
carePatient  
empowermentInnovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources

### A special responsibility: older people with diabetes

## C. Making it happen

### Whom to involve

Whom to involve	Why are they important?	What would you want their role to be? Whom should you contact?
Older patient associations	May help improve awareness about diabetes and its prevention in the older population.	
Caregivers and family	Need to be engaged in decision-making and appropriately trained/informed to assist their older relatives in self-managing their diabetes and adhering to treatment.	
Geriatricians, geriatric societies	Provide a specialist perspective on the needs of older patients, appropriate screening tools, etc.	
Diabetes specialist nurses (or their equivalent)	Critical in providing patient and caregiver education and support.	
Community centres, recreational centres, gyms,...	Settings where older people may be reached in terms of prevention programmes – 'make every contact matter'.	
Primary care professional societies	May help include specific training on diabetes in older people into the basic training and continuing education curricula for all primary care physicians.	
Care homes and long-term care policy leads	May help ensure that diabetes is considered fully within long-term care policies.	

A whole population  
approachPrevention and  
screeningMultidisciplinary  
carePatient  
empowermentInnovation and  
access to careChildren  
in schoolsOlder  
peopleEssential  
briefingSummary of  
evidenceKey issues to  
think aboutWhom to  
involveCase  
studies

Q&amp;A

References and  
resources

## A special responsibility: older people with diabetes

### D. Case studies

#### Case study 1

##### Geriatric diabetes clinics (USA)

The Joslin Centre in the United States offers an interesting prototype of a dedicated clinic for diabetes in older people. The clinic “evaluates the physical, social and emotional/ cognitive status of patients and identifies specific barriers patients and families have in performing diabetes self-management skills.” Each patient undergoes a comprehensive assessment, which looks at factors such as ability to self-manage, hypoglycemia severity and frequency, cognitive function, nutritional intake and physical activity and offers a multidisciplinary and individualised model of diabetes management.

**FOR MORE INFO:** [www.joslin.org/care/diabetes\\_and\\_the\\_elderly.html](http://www.joslin.org/care/diabetes_and_the_elderly.html)

#### Case study 2

##### Linking physician remuneration to the achievement of specific outcomes in older people (France)

In France, GPs are bound by a ‘payment by performance’ scheme called the Rémunération sur objectifs de santé publique (ROSP), or P4P. The ROSP rewards GP performance against a list of clinical targets in three areas, of which the management of chronic conditions, including diabetes, is one.<sup>19</sup> GPs are rewarded financially according to how many targets they meet. Targets are fixed for three years and include that:

- 75% of diabetic patients should be referred for an eye exam
- > 65% of diabetic patients should have at least 3 or 4 HbA1c tests per year
- > 75% of men over the age of 50 and women over the age of 60 should be prescribed a statin to help prevent cardiovascular events.

#### Case study 3

##### Include care checks that focus on the prevention of complications into the quality monitoring for diabetes care (UK)

The National Service Framework for Diabetes was set up in 2001 in the UK to provide clear minimum standards for what constitutes good diabetes care. Amongst these were nine basic care processes which check for the early signs of avoidable diabetic complications, such as blindness and kidney disease and treatment targets for the management of blood glucose, blood pressure and cholesterol to minimise the risk of diabetic complications developing.<sup>20</sup> These are of particular relevance to older patients who are at greatest risk of such complications and were included into the **Quality Outcomes Framework**, the national reimbursement and performance regime for GPs.<sup>21</sup> They were also reinforced in clinical guidelines published by the **National Institute for Health and Clinical Excellence (NICE)** in 2010.<sup>22</sup>

A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**A special responsibility: older people with diabetes**

**D. Case studies** (continued)

**Case study 4**

**Collaborative guidance between diabetes and geriatric professional societies (Europe)**

**The European Diabetes Working Group for Older People (EDWPOP)** was established in 2004 to ensure that older people with diabetes receive consistent and high-quality diabetes care throughout their lives.<sup>1</sup> It was instrumental in bringing forth European guidelines that ensure that older people with diabetes receive appropriate management and treatment.<sup>23</sup> In 2011 it launched a joint Position Statement with the International Association of Gerontology and Geriatrics (IAGG) and the International Task Force of Experts in Diabetes.<sup>7</sup> This is a powerful model that could be replicated at national levels.

**FOR MORE INFO:** [www.orquideatech.com/eventmobi/diabetes2day/DIABET\\_Guis\\_clinicas\\_EDWPOP.pdf](http://www.orquideatech.com/eventmobi/diabetes2day/DIABET_Guis_clinicas_EDWPOP.pdf)

**Case study 5**

**Development of common guidance and methodologies for care pathways for multi-morbid patients (Europe)<sup>24</sup>**

Work Package 3 of the European Commission-sponsored **Joint Action on Chronic Conditions** aims to identify good practices on the management of multi-morbid patients and identify conditions for scaling up and replication of such initiatives. It also aims to develop innovative and cost-effective interventions for the management of multimorbid patients, with a focus on secondary prevention, early diagnosis and better adherence to treatment; and develop case management training programmes for care personnel, for application across various healthcare settings across Europe. Implementation of the Work Package is ongoing in a number of European countries.

**FOR MORE INFO:** [www.ec.europa.eu/eahc/documents/health/calls/2013/Workshop\\_on\\_Joint\\_Action\\_2013/working\\_paper\\_JA\\_chronic\\_diseases.pdf](http://www.ec.europa.eu/eahc/documents/health/calls/2013/Workshop_on_Joint_Action_2013/working_paper_JA_chronic_diseases.pdf)



A whole population approach

Prevention and screening

Multidisciplinary care

Patient empowerment

Innovation and access to care

Children in schools

Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

References and resources

**A special responsibility: older people with diabetes**

**E. Questions and answers**

**What is the point of spending money on preventing long-term complications in older people with diabetes who have very few years left to live?**

Studies have shown that survival rates even for older patients with diabetes can be quite good, therefore we have to think very carefully about not offering preventive therapies for complications of diabetes to older diabetes patients as these therapies may still confer some benefit. It may indeed be difficult or otherwise unacceptable to attempt to identify older patients with diabetes whose life expectancy is so low that prevention efforts are not warranted.<sup>4</sup>

**Do older people really benefit from lifestyle interventions?**

Yes, in fact some large-scale prevention studies suggest that older people benefit from behavioural interventions such as weight loss and increased physical activity more than younger people with diabetes.<sup>16</sup>

**Isn't it assumed that older people are already considered in guidelines and diabetes plans? Why do we need specific guidance for this group of patients?**

Older patients with diabetes have a greater risk of having other conditions (or co-morbidities), taking multiple medications, and having problems linked to physical functioning, cognitive dysfunction and frailty. These may affect their ability to cope with complex diabetes management and the potential effectiveness of therapies being offered to them. Therefore specific recommendations focused on older people are needed to make health professionals aware of their particular needs and circumstances. Moreover, health systems are still poorly set up to deal with the needs of older people with diabetes.

**The older population is very heterogeneous – isn't it wrong to bulk all older people with diabetes together?**

Recognising that there is huge diversity in the functional ability, health status and preferences of people with diabetes over a given age is critical – but this does not mean that specific recommendations aimed at this group of patients is not warranted, merely that this heterogeneity should be considered in all guidelines and recommendations.



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Patient empowerment

Innovation and access to care

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Older people

Essential briefing

Summary of evidence

Key issues to think about

Whom to involve

Case studies

Q&A

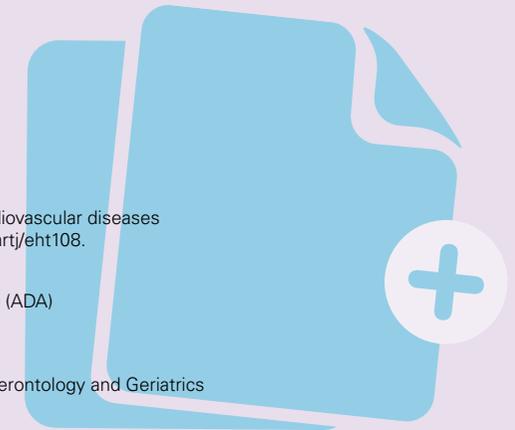
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## A special responsibility: older people with diabetes

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INTRO



PRIORITY  
AREAS



USEFUL  
RESOURCES

Diabetes  
basics

Parliamentary brief  
on diabetes

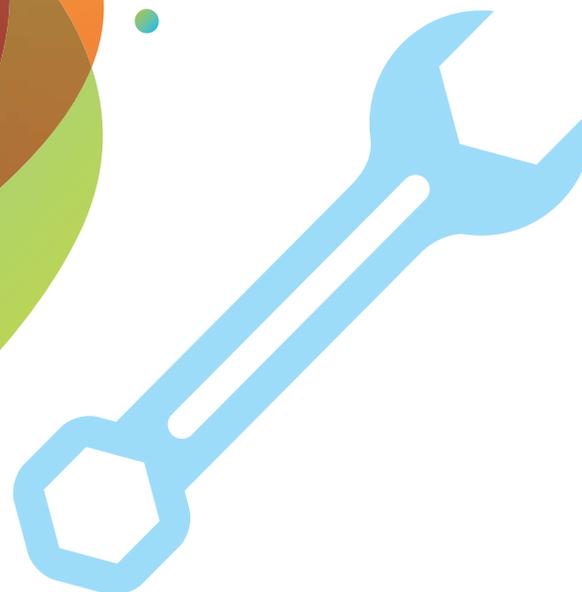
Key diabetes policies  
and reports

Making an economic  
case for diabetes

Background working  
papers

## SECTION 3

# Useful resources





## Diabetes basics

### What is diabetes?

Diabetes mellitus (diabetes) is a chronic disease that occurs when the pancreas is no longer able to make insulin, or when the body cannot make good use of the insulin it produces.<sup>1</sup> We need insulin to convert the **glucose** (sugar) we obtain from food into energy.

**Type 1 diabetes** occurs when the pancreas cannot produce insulin anymore. It is a so-called 'auto-immune' disease, in that the body's defence system destroys the insulin-producing cells in the pancreas. In **type 2 diabetes**, the pancreas does not produce enough insulin or the insulin cannot be processed properly.<sup>1</sup> Up to 90% of all diabetes cases are type 2.<sup>2</sup> Obesity or being overweight increases one's risk of having type 2 diabetes.

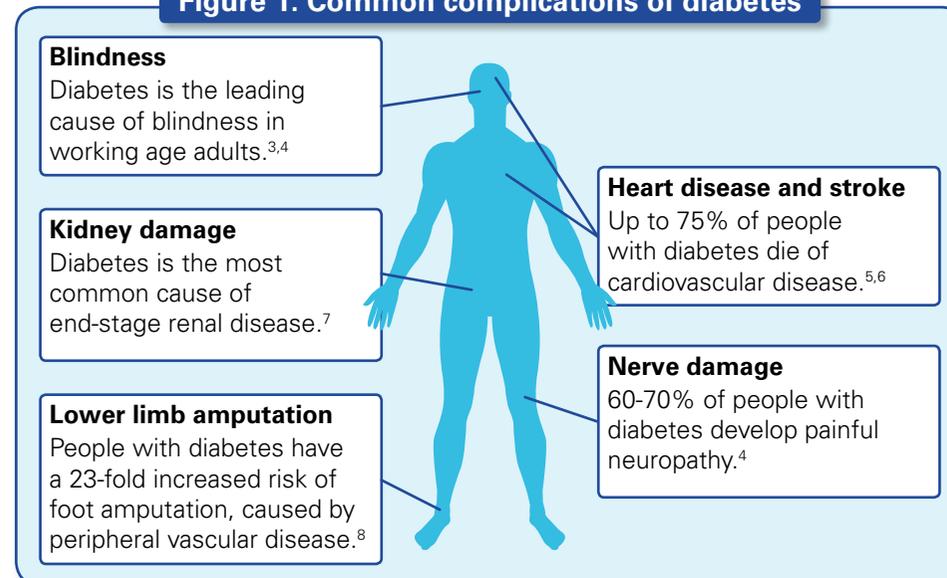
### What are the consequences of diabetes?

When the body is not able to produce insulin or use it effectively this leads to raised glucose levels in the blood (known as **hyperglycaemia**). Over the long-term, high glucose levels can lead to serious diseases affecting the heart and blood vessels, eyes, kidneys, and nerves. These consequences are referred to as the **complications** of diabetes.

### How many people are affected by diabetes?

- Close to 56 million adults in Europe have diabetes, and by 2035, this figure will rise to 70 million people,<sup>10</sup> or 1 in 10 Europeans.
- Diabetes causes more deaths than breast cancer and prostate cancer combined.<sup>9</sup> Diabetes accounts for 1 in 10 deaths, or 619,000 deaths in adults in 2013.<sup>10</sup>
- Most people with diabetes die from the **complications** of diabetes, such as cardiovascular disease and kidney failure.<sup>1,2</sup>
- Increases in prevalence of type 2 diabetes are due for the most part to the rise of obesity<sup>11</sup> but also to the ageing of the population and to socio-economic disadvantage.<sup>12</sup>
- Europe also has the highest prevalence of type 1 diabetes in children of any region of the world, and this prevalence is increasing.<sup>10</sup>

Figure 1. Common complications of diabetes



Diabetes affects more people and causes more deaths than breast cancer and AIDS combined.



## Diabetes basics

### What is the cost of diabetes?

The economic impact of diabetes is considerable – to our healthcare systems as well as society at large. In fact, diabetes costs more than all forms of cancer (\$245 billion<sup>13</sup> vs. \$201 billion<sup>14</sup> per year in the U.S. for example).

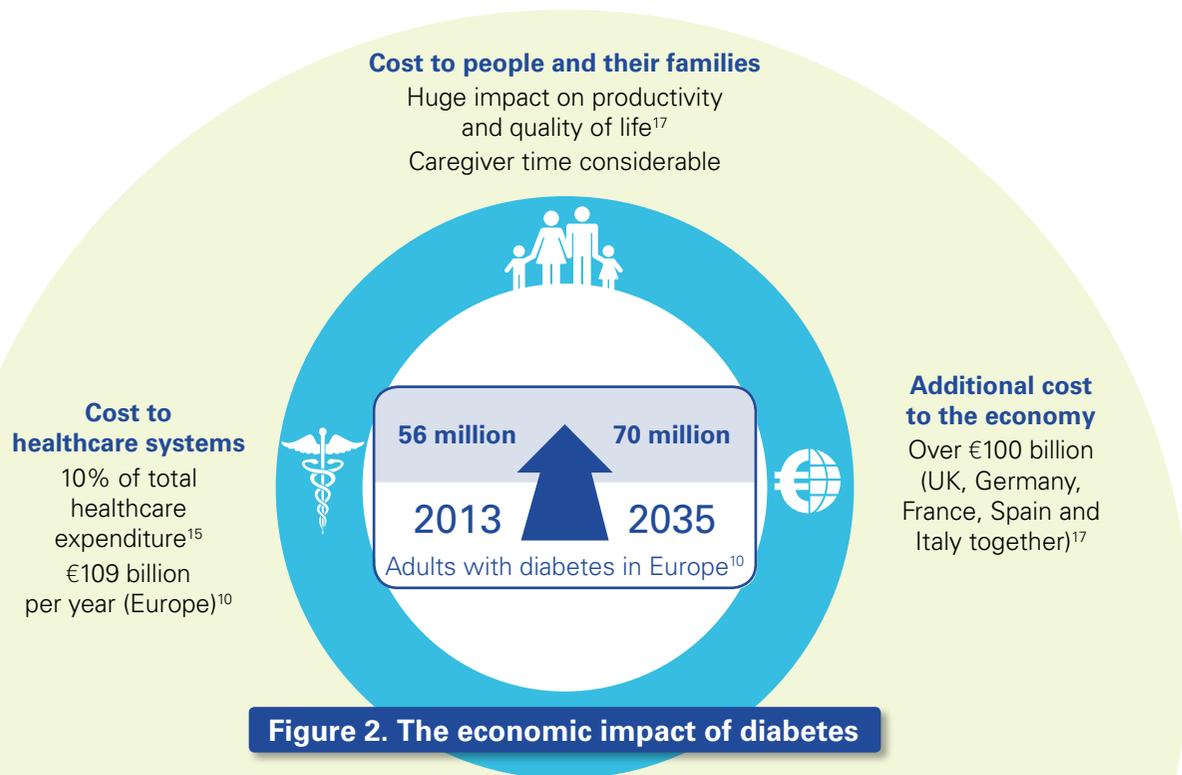
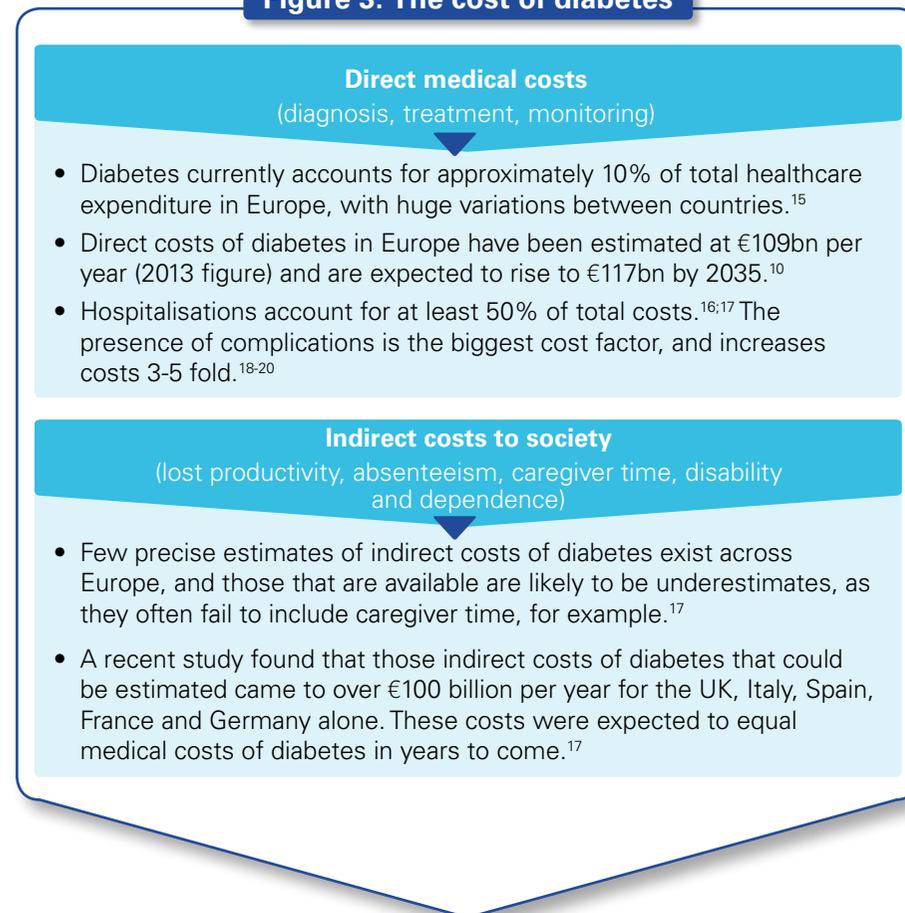


Figure 3. The cost of diabetes





## Diabetes basics

### Is diabetes preventable?

At present, type 1 diabetes cannot be prevented.

The situation is very different for type 2 diabetes. Evidence suggests that lifestyle changes, particularly achieving a healthy body weight, engaging in regular, moderate physical activity and maintaining a healthy and balanced diet can help prevent the development of type 2 diabetes. Amongst people at high risk of diabetes such changes can prevent or delay the onset of type 2 diabetes by as much as 50%.<sup>21,22</sup>

### What is pre-diabetes?

People who are at high risk of developing Type 2 diabetes are often referred to as being 'pre-diabetic'.<sup>23,24</sup> In these individuals, blood glucose levels can be described as somewhere between healthy glucose tolerance and a diagnosis of diabetes.<sup>25</sup> However, there are different opinions within the scientific community as to how helpful this term is, for example because not all people who are 'pre-diabetic' will necessarily progress to diabetes.<sup>24</sup> In any case it is helpful to think of elevated blood glucose as a continuum as opposed to drawing arbitrary distinctions between 'normal' populations and those at risk.<sup>23,24</sup>

### How can one detect diabetes?

- Diabetes can be diagnosed at an early stage through simple, inexpensive blood tests.
- However, up to half of cases of diabetes are undiagnosed in Europe.<sup>26,27</sup>
- **Early detection** is critical as it may help prevent or delay the onset of complications, which will have the greatest impact on overall outcomes<sup>23,28</sup> and costs<sup>19</sup>
- Efforts are needed by health care professionals to implement **screening** programmes for people at risk of type 2 diabetes and to inform their patients about the risks and symptoms of diabetes, so that they may seek diagnosis early if they suspect they have diabetes and make the necessary lifestyle adjustments to try to prevent it.<sup>23,1,13</sup>

**Figure 4. Risk factors for type 2 diabetes**

Although the precise reasons for developing type 2 diabetes are still not known, there are several important risk factors:<sup>10</sup>

Obesity

Poor diet

Physical inactivity

Advancing age

Family history of diabetes

Ethnicity

High blood glucose during pregnancy affecting the unborn child

**Potentially  
modifiable**



## Diabetes basics

### How is diabetes treated?

One of the main components of diabetes treatment is the maintenance of stable blood glucose levels (**glucose control**) in order to help delay or prevent the onset of diabetes complications.<sup>1</sup> This is achieved through medication and various degrees of therapeutic patient education for self-management. People with type 1 diabetes have to take insulin, which is administered through self-injection or devices such as pumps. Treatment for type 2 diabetes depends on its severity and includes lifestyle changes, oral medication (pills) and, in some cases, insulin treatment.

But glucose control alone is not enough – it is also critical to control individuals' blood pressure and cholesterol levels<sup>1,29</sup> (i.e. **co-morbidities**) and to do everything possible to prevent or delay the onset of complications – through regular foot care, screening for damage to the eyes, nerves, heart, kidneys and nerves.

### Therapeutic patient education for self-management

**Self-management** is a key component of diabetes care,<sup>1</sup> as it has been estimated that 95% of diabetes management is self management.<sup>30</sup> **Therapeutic patient education to encourage self-management** should be offered to all patients with diabetes by a trained diabetes professional, preferably a **diabetes specialist nurse**. This should involve providing patients with sufficient information, knowledge and skills to be able to monitor their glucose levels, manage multiple medications and treatments, make necessary lifestyle changes and continually monitor for any developments or changes in their condition, for example the development of foot ulcers or eye problems.<sup>29,31-33</sup>

The components of therapeutic patient education in diabetes are helpfully depicted in an illustration opposite from Diabetes UK.<sup>30</sup>





## Diabetes basics

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## Diabetes: Parliamentary Brief

However you start the debate, you may need quick facts and compelling arguments about the basic overall facts of diabetes, its costs and impact on society.

This Parliamentary Brief has been adapted from the International Diabetes Federation's Advocacy Toolkit to fit the European context. We hope it will make a useful companion to the information featured in this toolkit on different topics, or provide a helpful top line brief in its own right.

### 1. Diabetes is a huge and growing problem

Soundbite	Key message
Diabetes costs more than all cancers combined	Diabetes costs more than all cancers combined <sup>1,2</sup> but is still given relatively low priority compared to other diseases. <sup>3</sup> Direct health costs in Europe run as high as €109bn per year. <sup>4</sup>
Diabetes is a 21st century epidemic.	56 million Europeans have diabetes. By 2035 this will be 70 million, meaning one in ten Europeans aged 20-79 will have diabetes. <sup>4</sup>
Diabetes is a serious threat to the economy. <sup>5,6</sup>	Leading experts have called diabetes and other chronic diseases 'too big to fail' for Europe <sup>7</sup> i.e. an equivalent challenge to our economy as the recent financial crisis. The World Economic Forum have called diabetes a 'clear threat' to global development.
We are already paying the price for failure.	Diabetes costs around 10% of national healthcare spend in Europe, <sup>8</sup> and the greatest share of this is from hospitalisations <sup>2,9</sup> that could have been prevented.

## Diabetes: Parliamentary Brief

### 2. Diabetes kills and reduces quality of life

Soundbite	Key message
Diabetes is one of Europe's leading causes of death. <sup>10</sup>	Diabetes doubles the risk of death compared to people of equivalent age without diabetes. <sup>11</sup> Within Europe, diabetes accounts for over 619,000 deaths per year and it affects approximately 9.2% of the population aged 20-79 years. <sup>4</sup> The number of people affected is growing. <sup>4</sup>
Diabetes is a major cause of poor quality of life and ill-health.	Diabetes doubles the risk of stroke <sup>12</sup> and increases the risk of heart disease up to 3 fold for men and 5 fold for women. <sup>13</sup> It is the number one cause of blindness in adults of working age <sup>11:14</sup> and end-stage kidney disease in adults. <sup>15</sup> People with diabetes have a 23-fold increased risk of foot amputation <sup>16</sup> and 60-70% of people with diabetes develop nerve damage. <sup>11</sup>
Diabetic complications are the main drivers of cost.	The presence of complications (see above) increases the cost of diabetes by up to 5 times. <sup>17</sup> For example, 34% of total hospital inpatient days for diabetes are due to stroke and heart disease alone. <sup>18</sup> Heart disease is also more severe and more expensive when it occurs in people with diabetes as compared to those without diabetes. <sup>19</sup>

### 3. Diabetes is a neglected issue for the social and economic sustainability of Europe

Soundbite	Key message
Diabetes is a major cost to our healthcare systems	Diabetes accounts for around 10% of total health expenditure <sup>8</sup> , as high as €109bn for Europe in 2013. <sup>4</sup> This means billions of Euros per year – roughly €20 billion in the UK, or €40 billion in Germany. <sup>9</sup> That's the equivalent of €2.25 - €4.5 million an hour respectively. <sup>9</sup> This may even be an underestimate, as many diabetic complications are not recorded properly and are therefore excluded from cost estimates. <sup>9</sup>
Diabetes costs will keep rising	Direct costs to health care systems in Europe are expected to increase to as much as €117 billion per year by 2035. <sup>4</sup>
Diabetes stops people from working and leading productive lives	Over €100 billion per year in the UK, Italy, Spain, France and Germany is lost every year to diabetes in terms of lost productivity and worker absenteeism, <sup>9</sup> and the true cost for society is likely to be much higher (for example, taking into account the impact on family caregivers).
Industry leaders are worried about chronic diseases like diabetes	A survey conducted by the World Economic Forum showed over half of business leaders expected non-communicable diseases to impact on their company profitability in years to come. <sup>20</sup>



## Diabetes: Parliamentary Brief

### 4. We have cost-effective solutions – but we are not implementing them enough

Soundbite	Key message
We could prevent most cases of Type 2 diabetes.	10% to 20% of people are thought to be at high risk of developing Type 2 diabetes, <sup>21;22</sup> but too few people with diabetes are offered effective prevention. Prevention programmes have shown we can halve the number of people developing Type 2 diabetes, <sup>23,24</sup> saving money on expensive care and keeping people healthy.
For people with diabetes the care and support they receive is often too little, too late	Early diagnosis and treatment is vital <sup>13;25</sup> , yet up to half all cases of diabetes are undiagnosed, <sup>22,26</sup> and people with diabetes can wait as long as 7 years to be diagnosed. <sup>27;28</sup> Amongst people known to have diabetes, only half have well controlled blood glucose, <sup>29,30,26</sup> and adequate care of complications and co-morbidities is highly variable, and very often poor. <sup>9,31</sup>
Economic pressures cannot be allowed to take us backward	Limitations in access to suitably trained clinicians and some basic aspects of care are being reported across Europe as a result of economic pressures. <sup>9,10</sup> This even includes vital tools for self-management such as blood glucose monitoring strips. <sup>32</sup>
Patients who receive targeted education about diabetes are better able to look after themselves	Therapeutic education to allow people to manage their condition (i.e. self-management) is a missing link in diabetes. <sup>33,34</sup> Therapeutic patient education for self-management has been proven to improve quality of life, blood glucose control, and reduce hospitalisation and healthcare costs. <sup>13,35,36</sup> Yet most people receive little or no such education. <sup>31</sup>
Multidisciplinary care for diabetes will save lives and improve quality of life	Multi-disciplinary teams working together to treat diabetes and its complications can reduce mortality and disability by as much as a half <sup>37,38</sup> paying for itself in saved treatment costs. But too few people with diabetes benefit from such models. <sup>31</sup>
We must ensure that the economic crisis does not strangle innovation in diabetes.	Diabetes is accorded a low priority in research budgets compared to other chronic diseases <sup>3</sup> despite its growing prevalence. Innovative approaches to care and management of diabetes are urgently needed if we want to reduce the burden posed by diabetes in years to come. <sup>6</sup>



## Diabetes: Parliamentary Brief

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## Diabetes: Parliamentary Brief

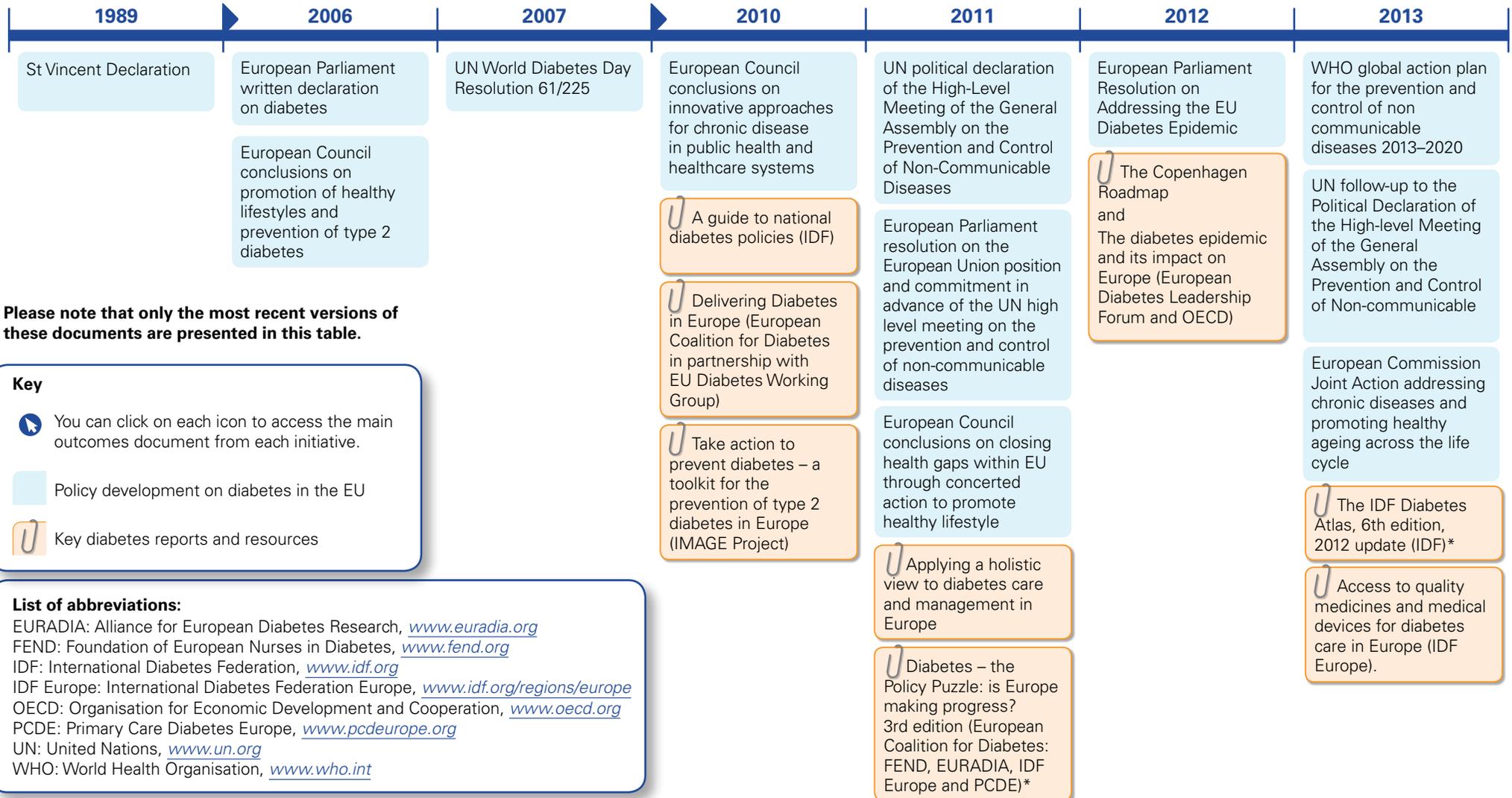
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## Key diabetes policies and resources

In 1989, the St. Vincent Declaration challenged European countries to adopt national diabetes plans. Since then, diabetes has received increasing attention in EU policies, as a standalone condition as well as within an overall prioritisation of non-communicable disease (NCDs).

The following figure shows the development of key policy initiatives and landmark reports on diabetes over time in Europe.



\* Please note that only the most recent versions of these documents are presented in this table.

### Key

 You can click on each icon to access the main outcomes document from each initiative.

 Policy development on diabetes in the EU

 Key diabetes reports and resources

### List of abbreviations:

EURADIA: Alliance for European Diabetes Research, [www.euradia.org](http://www.euradia.org)  
 FEND: Foundation of European Nurses in Diabetes, [www.fend.org](http://www.fend.org)  
 IDF: International Diabetes Federation, [www.idf.org](http://www.idf.org)  
 IDF Europe: International Diabetes Federation Europe, [www.idf.org/regions/europe](http://www.idf.org/regions/europe)  
 OECD: Organisation for Economic Development and Cooperation, [www.oecd.org](http://www.oecd.org)  
 PCDE: Primary Care Diabetes Europe, [www.pcdeurope.org](http://www.pcdeurope.org)  
 UN: United Nations, [www.un.org](http://www.un.org)  
 WHO: World Health Organisation, [www.who.int](http://www.who.int)

## Making an economic case for diabetes

The economic case for investment in diabetes is often the first and most important argument to win. Please **click below** for a Powerpoint which can help you make a strong economic case for diabetes as a policy priority.





INTRO



PRIORITY AREAS



USEFUL RESOURCES

Diabetes basics

Parliamentary brief on diabetes

Key diabetes policies and reports

Making an economic case for diabetes

Background working papers

## Background working papers

During the course of 2012-13 the members of ExPAND worked together to build the toolkit and develop content and key themes. The working papers below contain addition research and material that may be useful.

