

IDF EUROPE ADVOCACY & COMMUNICATIONS TOOLKIT



This toolkit is endorsed by:



IDF Europe Advocacy & Communications Toolkit

Foreword

2011 was a turning point for diabetes. On 19 and 20 September of that year, the United Nations held a High-Level Summit on Non-Communicable Diseases (NCDs) in New York. A milestone in the history of global health, the Summit was only the second time the UN General Assembly devoted exclusive attention to a health-related issue.

During the Summit, world leaders made unprecedented commitments to accelerate global progress on diabetes and NCDs. The most significant outcome was the unanimous adoption of the [Political Declaration on the Prevention and Control of NCDs](#) by 193 Member States. The Political Declaration includes a set of commitments that firmly position diabetes and NCDs at the top of the global health and development agenda. Governments have finally taken ownership of the NCD problem and stated in definitive language: "We have a problem and we need to fix it."

One year on, the International Diabetes Federation European Region - IDF Europe - wants to take stock of the achievements made since the adoption of the UN Political Declaration, and the steps that still need to be taken in order to reach the goals that have been set, and ultimately to improve the lives of the millions of people living with diabetes and prevent others from developing this condition.

In order to support you in your future diabetes advocacy and communication work, IDF Europe has developed this step-by-step Advocacy and Communications Toolkit. Whether you are working for an organization that has a well-established advocacy and communication programme, or whether you have been tasked with establishing such a programme, we hope that you will find helpful advice and resources in this toolkit to guide you in this process.

Although this toolkit was developed by IDF Europe, it has been further improved and refined thanks to the very constructive feedback that we have received from the Danish Diabetes Association, Diabetes UK, the Finnish Diabetes Association, the Georgian Union of Diabetes and Endocrine Associations, and the Spanish Diabetes Association. We would like to thank them for their valuable support.

Through strong advocacy, and by sharing successful strategies amongst advocacy networks, we can make our voices heard and make a real difference for each and every individual living with diabetes.

We sincerely hope that you will find this toolkit useful and we welcome your feedback.

Sophie Peresson

IDF Europe
Regional Director

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Introduction

○ Why do we need advocacy?

Diabetes is a global epidemic affecting 366 million people worldwide.

Diabetes is also one of the most common non-communicable diseases (NCDs)¹ in the world. In 2011, estimates reveal that there are 52.8 million people living with diabetes in Europe - 8% of the adult population. This is expected to rise to 64 million by 2030.

In Europe, a third of the population is over 50, and this is expected to increase to over 40% by 2030. To a large degree, the high rates of type 2 diabetes are a consequence of the region's ageing population (the majority of people living with diabetes are between 40 and 59).

Diabetes in the young is also a growing concern. Europe is home to 116,100 children with type 1 diabetes - the highest number in the world. The region also has one of the highest incidence rates of type 1 diabetes in children, with 17,900 new cases in 2011².

The costs of diabetes are escalating and threaten to become unsustainable. This trend is due to continue given the ageing population and the rise in new cases of type 1 diabetes amongst children and young people.

Many working in the field of diabetes know that advocacy is essential to strengthen and stimulate national responses to diabetes. Advocacy plays a key role in raising the sense of emergency in the context of diabetes, and in increasing demand for prevention as well as proper management and care for diabetes.

The diabetes epidemic has been widely ignored for too long. This is why advocacy is essential to push for political action and reverse the diabetes epidemic in Europe and worldwide.

Advocacy is an on-going process to bring about change in attitudes, actions, policies and laws through influencing prominent stakeholders such as political leaders, decision-makers or organizations with power.

Communication seeks to increase awareness, influence social norms and bring about behavioural change by targeting individuals and 'sub-groups' of the general public and improving interpersonal communication and counselling between people with diabetes, their families and providers.

○ Who is this toolkit for?

This toolkit is for all diabetes advocates, healthcare professionals, community workers, people and other communities affected by diabetes.

We hope this guide will offer you valuable information that will support you in developing a powerful advocacy strategy to hold policy makers accountable and ultimately improve the lives of people living with diabetes.

Advocacy has a key role to play in setting the agenda of any decision-maker, be it a politician, a government or an institution, and in monitoring decision-makers' commitments on a particular issue. By acting as effective agents for change, advocates can ensure that appropriate policies, laws, programmes and resources are put in place to bring about real change in diabetes prevention, management and care.

¹ NCDs include diabetes, cardiovascular disease, cancer and respiratory diseases

² Data from the IDF Diabetes Atlas, 5th edition, November 2011

How to use this advocacy toolkit?

You will be guided through 9 steps to develop your own advocacy and communications strategies, tailored to your own context and environment.

Although these steps complement each other, your advocacy initiatives will not always include all of them. The clearly-divided steps will allow you to focus directly on the aspects of advocacy that you will need to develop your advocacy work according to your needs, your goals and your environment.

The key steps presented in this toolkit are:

1. DEFINING THE SITUATION

2. ESTABLISHING YOUR GOALS

3. IDENTIFYING YOUR TARGET AUDIENCE

4. DEVELOPING YOUR KEY MESSAGES

5. DEVELOPING EVIDENCE BASED ADVOCACY

6. CHOOSING SPOKESPEOPLE

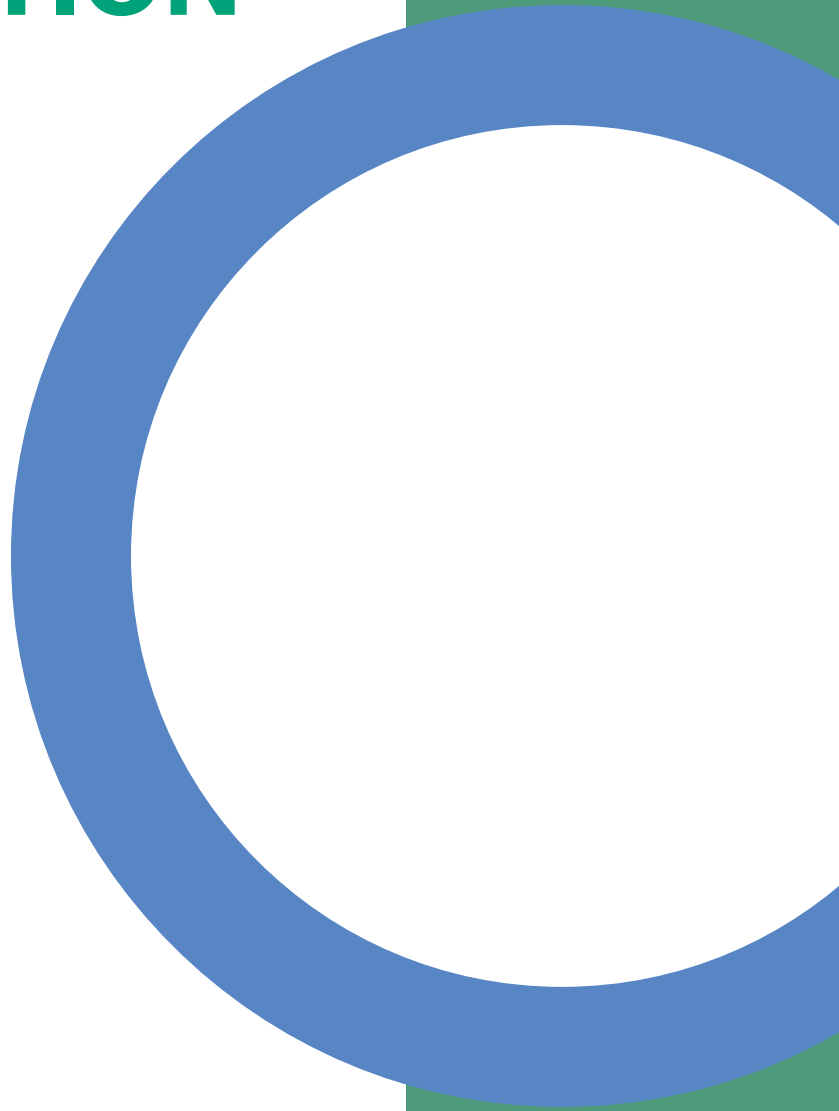
7. CAMPAIGNING

8. ENGAGING WITH THE MEDIA

9. MONITORING AND EVALUATION

At the end of the document, you will also find resources and reference documents to further help you plan and implement your advocacy strategy.

1. DEFINING THE SITUATION



1. Defining the situation

The first step in planning successful diabetes advocacy is to define the situation. Framing the issue you wish to address is essential as it will help both the people who collaborate with you and the people you want to influence understand the extent of the issue, identify where the problems lie and take appropriate and effective measures to address them.

Most importantly, defining the situation provides you with a reference framework that will help you set your advocacy goals and objectives as well as developing your key messages when communicating to your target audiences.

We have gathered below a few definitions, facts and figures to help you frame the diabetes issue.

○ What is Diabetes?

Diabetes is a chronic condition that arises when the pancreas does not produce any insulin, or not enough, or when the body cannot properly use the insulin it produces (known as insulin resistance). Insulin is a hormone produced by the pancreas that allows glucose to enter the body's cells and transforms it into energy needed for daily life. Failure to produce insulin, or enough insulin, leads to high blood glucose levels. This, in turn, is associated with long-term damage to the body.

There are three main types of diabetes:

Type 1 diabetes occurs when the body's immune system attacks the insulin-producing cells in the pancreas. The body can no longer produce the insulin it needs. Type 1 diabetes can develop at any age, but it usually occurs in children or young adults. People with this form of diabetes need injections of insulin every day in order to control the levels of glucose in their blood. Without this insulin, people with type 1 diabetes will die.

Type 2 diabetes is the most common type of diabetes. Type 2 diabetes develops when the body does not produce enough insulin or when the body cannot properly use the insulin it produces. This leads to a build-up of glucose in the blood. It usually occurs in adults, but is increasingly seen in children, adolescents and young adults. Much of type 2 diabetes can be prevented or delayed.

Gestational Diabetes Mellitus is diabetes first diagnosed during pregnancy. It generally develops when the body cannot produce enough insulin to meet the extra needs of pregnancy. Gestational diabetes can lead to serious pregnancy complications for mother and child and a life-time increased risk of type 2 diabetes.

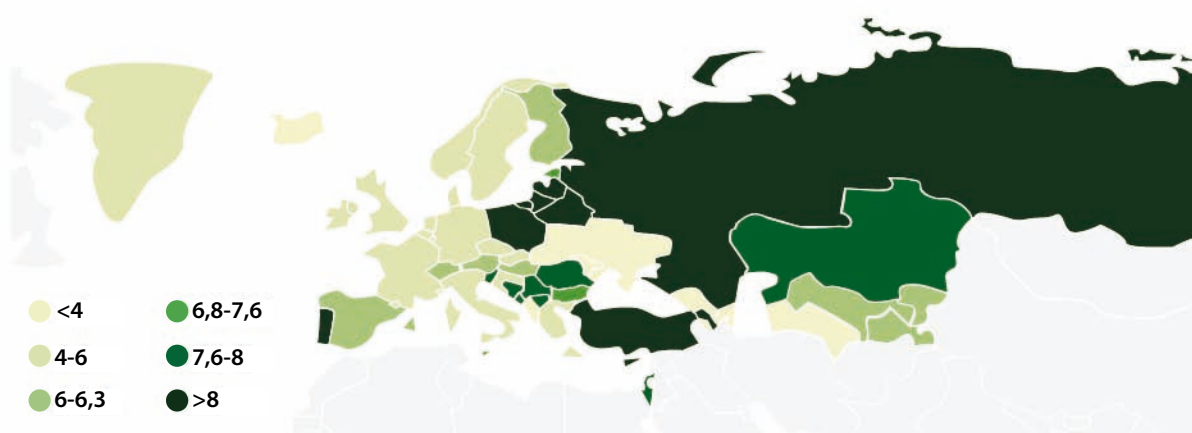
○ The Facts

- More than **52,8 million** people in Europe have diabetes; by 2030 this will rise to **64 million**
- Diabetes can lead to **serious and costly complications**
- Diabetes caused **600,000 deaths** in the Europe Region in 2011
- EUR **88,8 billion** were spent on treating diabetes in the region
- Europe is home to the **highest number** of children with **type 1 diabetes**

○ Mortality

One in 10 deaths in adults in Europe can be attributed to diabetes. This represented 600,000 people in 2011. The vast majority of these deaths - 90% - were amongst people over 50, which partly reflects the age distribution of the European population but may also be related to improved survival rates due to more responsive health systems. There are slightly more deaths due to diabetes in women compared to men (317,600 vs. 282,400 respectively).

Map : Prevalence*(%) estimates of diabetes (20-79 years), 2011, Europe Region



*comparative prevalence

source: IDF Diabetes Atlas, 5th ed. © International Diabetes Federation, 2011

Healthcare expenditure

Estimates indicate that at least EUR 88.8 billion was spent on healthcare due to diabetes in Europe in 2011. This accounts for almost one third of global healthcare expenditure on diabetes, and for around 8% of total healthcare expenditures in Europe. Just as there are wide differences in terms of diabetes prevalence in this region, the average of diabetes-related expenditures per person with diabetes per year considerably varies from EUR 7,400 in Luxembourg to just EUR 49 in Tajikistan.



These facts and figures can help you put the diabetes issue into its European context. However, we also advise you to use national or local data depending on the target audience you want to influence. You can find up-to-date and comparative information on diabetes in 47 countries in Europe in the 3rd edition of the [Policy Puzzle: Is Europe making progress?](#)

The time to act is now!

Recent policy developments worldwide and in Europe are marking a new era for diabetes. These developments have created a window of opportunity for new advocacy actions and have the potential to drive major action on diabetes worldwide and in Europe.

Close follow-up and well-planned advocacy are needed to convince decision-makers that diabetes prevention, management and care urgently require increased investment at national and local levels and that applying comprehensive and cost-effective solutions –which already exist- will bring substantial economic benefits to countries and their healthcare systems. The time to act is now!

- **On 19 September 2011**, the adoption of the first-ever [UN Political Declaration on the Prevention and Control of Non Communicable Diseases \(NCDs\)](#) marked a significant change in the diabetes policy landscape. World leaders unanimously adopted the Political Declaration recognizing that NCDs –including diabetes- were one of the major challenges of the 21st century, threatening to undermine social and economic development worldwide.

The declaration covers the spectrum of the diabetes and NCD response, and includes commitments on prevention, National NCD Plans, health system strengthening, treatment, resourcing, research and development, international cooperation, monitoring and evaluation. Significantly, the Declaration acknowledged the importance of improving health literacy and empowerment, and ensuring the active involvement of people with NCDs in the provision of care and services.

- At European level, the UN Declaration received strong support. This major development reinforced continued advocacy at EU level which saw a major breakthrough on **14 March 2012** with the adoption of the **European Parliament Resolution on Addressing the Diabetes Epidemic**.

The **European Parliament** adopted by a large majority a Resolution on Addressing the EU Diabetes Epidemic, calling on the Commission and Member States to develop and implement a targeted EU Diabetes Strategy in the form of an EU Council Recommendation on diabetes prevention, diagnosis, management, education and research. The resolution sends out a strong political message that the diabetes epidemic is a pressing issue. This development also adds to the political momentum of the UN Political Declaration.

- **25 May 2012** saw a landmark development for people living with diabetes and NCDs with the adoption by the **World Health Assembly** of the first-ever **global target to reduce premature deaths from non-communicable diseases by 25% by 2025**.

All governments will now have to collect data on diabetes and NCD deaths, take action to reduce those deaths and report regularly on progress to the United Nations. In addition to the overall 25% target, governments agreed to reach consensus, before the end of October 2012, on additional targets relating to the four main risk factors for NCDs, namely tobacco use, harmful use of alcohol, unhealthy diet and physical inactivity; and to consider further targets relating to obesity, fat intake, alcohol, cholesterol and health system responses, such as availability of essential, safe and efficient medicines for NCDs.

- Shortly after, on **22 June 2012, Rio+20 - the United Nations Conference on Sustainable Development** - saw governments adopt an **outcomes document** entitled '**The Future We Want**'. The document recognizes the fundamental need to act on the social and environmental determinants of health to create inclusive, equitable, economically productive and healthy societies. In addition, it identifies the global burden of diabetes and NCDs as a "major challenge for sustainable development in the 21st Century" and commits to strengthening NCD treatment and care and establishing multi-sectorial national policies for NCD prevention and control.



Advocacy in action

The Copenhagen Roadmap, a new powerful advocacy tool

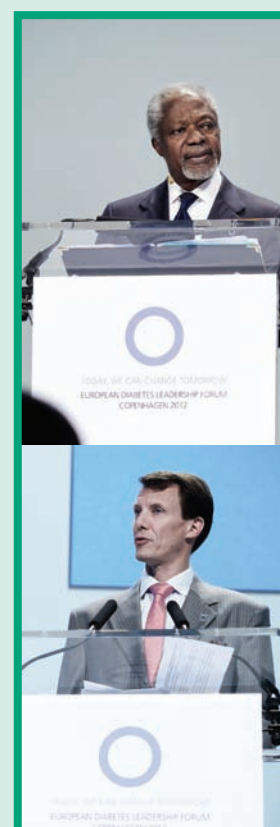
Turning major policy developments into concrete action is the aim of the **Copenhagen Roadmap**, a new European advocacy document which identifies practical solutions for all stakeholders to improve diabetes prevention, management and care. The roadmap presents the outcomes of the European Diabetes Leadership Forum, hosted by the Danish Diabetes Association and the OECD. The forum gathered more than 700 leading experts, policymakers, industry partners, NGOs and healthcare professionals to discuss and agree on priorities and actions to help reverse the curve of the diabetes pandemic in Europe and OECD countries.

The document was developed by the **Danish Diabetes Association**, with contributions from the **Organization for Economic Cooperation and Development (OECD)** and all the stakeholders who participated at the forum. The Copenhagen Roadmap outlines concrete initiatives which can be used independently or in combination to form the content of National Diabetes Programmes. Ultimately, it offers all national diabetes associations a powerful advocacy tool to hold their governments to account on diabetes policies.

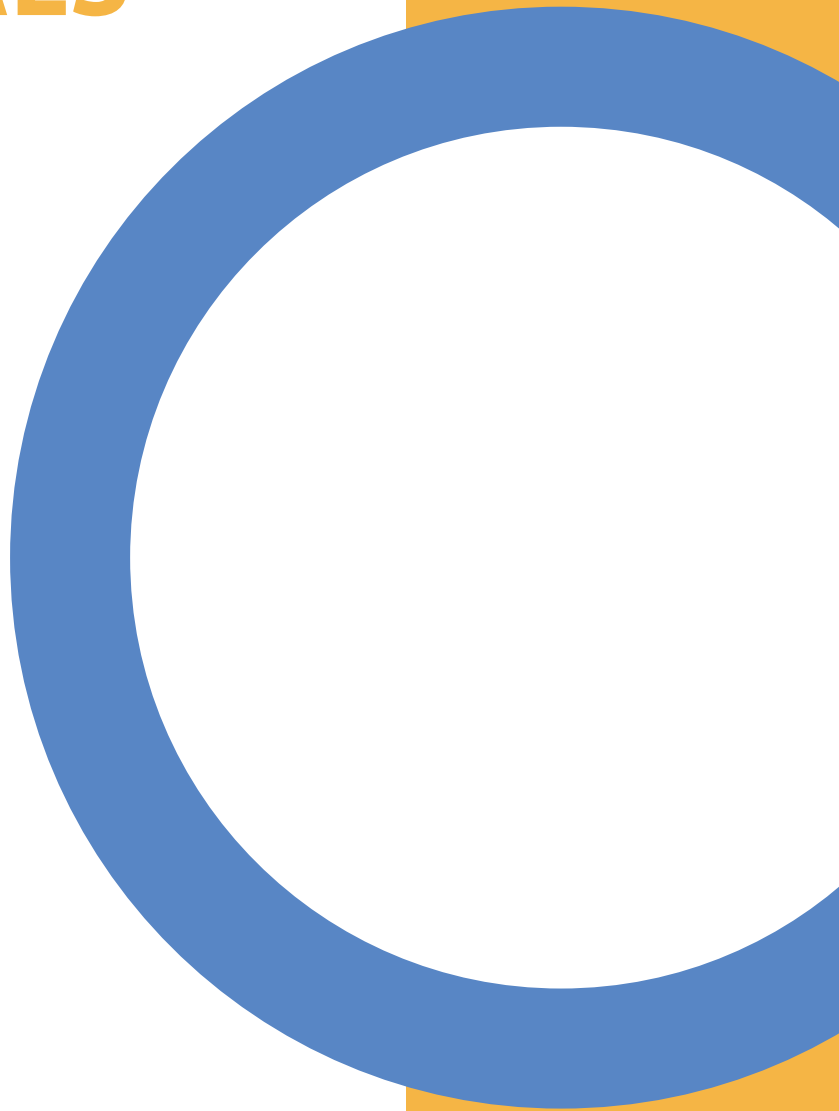
Another outcome of the European Diabetes Leadership Forum is the creation of the **Copenhagen Catalogue of Good Practices in Diabetes**. Acknowledging the existence of many great practices and initiatives across Europe, this catalogue was created to facilitate the sharing of knowledge and demonstrate how the Copenhagen Roadmap can be implemented.

Kofi Annan, former UN Secretary General, and His Royal Highness Prince Joachim of Denmark, patron of the Danish Diabetes Association, speaking at EDLF.

Source: Claus Bjørn Larsen



2. ESTABLISHING YOUR GOALS



2. Establishing your goals, objectives and priorities

After having defined the issue, the second step for successful advocacy is thorough strategic planning. It is therefore essential that you establish long-term goals and SMART (specific, measurable, achievable, realistic and time-framed) objectives around which you will then structure your advocacy plan.

When defining your long-term goals and short-term objectives, it is important that you keep in mind on immediate opportunities and obstacles. Here is a list of elements you need to consider:

- Scope and size of the issue;
- Political and economic context;
- Public opinion, support for change and public understanding of diabetes and related issues;
- Specific policies or actions you want to influence and what has already been achieved (i.e. tighter regulation on food labelling, measures to tackle obesity, etc.);
- Your available resources. If these are limited you need to focus on well-defined and achievable objectives.

Once you have identified all these elements, your advocacy work should be structured accordingly in order to plan for the most effective route forward. For example if common misconceptions and lack of understanding of diabetes are an obstacle, you might want to focus initially on an awareness campaign for the general public.

○ Goals and objectives

A GOAL

- **Long-term**
- A goal is often a **broad statement** that gives you an opportunity to clarify your **vision** and provides a focus for your work over the long term
- A goal is most of the time **not measurable** - it does not necessarily relate to specific numbers or specific timeframes

Example: Grant access to high-quality diabetes care to all European citizens

AN OBJECTIVE

- **Short-term**
- Objectives are **realistic targets** for your work. They indicate the steps you need to take in order to achieve your goal
- An objective **helps define and focus** your activities
- An objective will **answer some key practical questions** - who is doing what, by when, why and to what standard?

Example: By the end of next year, a majority of European countries will have a national diabetes prevention strategy

**Advocacy in action**

As an example, you will find here IDF Europe goals:

- Drive change at national and European levels, to prevent diabetes
- Develop and encourage best practices in diabetes policy, management and education
- Promote European diabetes treatment, prevention and cure through scientific research
- Promote and protect the rights of people with diabetes, ensure equal access to medication and combat discrimination in Europe
- Support the development of National Diabetes Associations and encourage their activities

More specific objectives can be, for example:

- Organize a campaign on prevention of diabetes and diabetes-related complications in the next 6 months
- Conduct a survey to evaluate access to diabetes care, treatment and medicines across Europe
- Secure 10 articles on diabetes in the general press over the coming year
- Create a group of Young Leaders in Diabetes to organize awareness-raising and education activities to galvanize the support of youth



Using SMART objectives as intermediate, realistic steps towards your goal helps you plan successful advocacy initiatives. Remember to be creative and innovative, and to tailor them to your own circumstance.



○ SMART objectives are:

Specific

Why are you doing this and for whom or what? i.e. to improve the lives of people living with diabetes, increase awareness, exchange best practice, etc.

Measurable

Is it measurable qualitatively or quantitatively? Measurement depicts movement and change - i.e. it has increased, decreased, progressed, etc.

Achievable

For example, can you achieve it in the proposed timeline or in a given political climate?

Realistic

Are you likely to achieve the desired result?

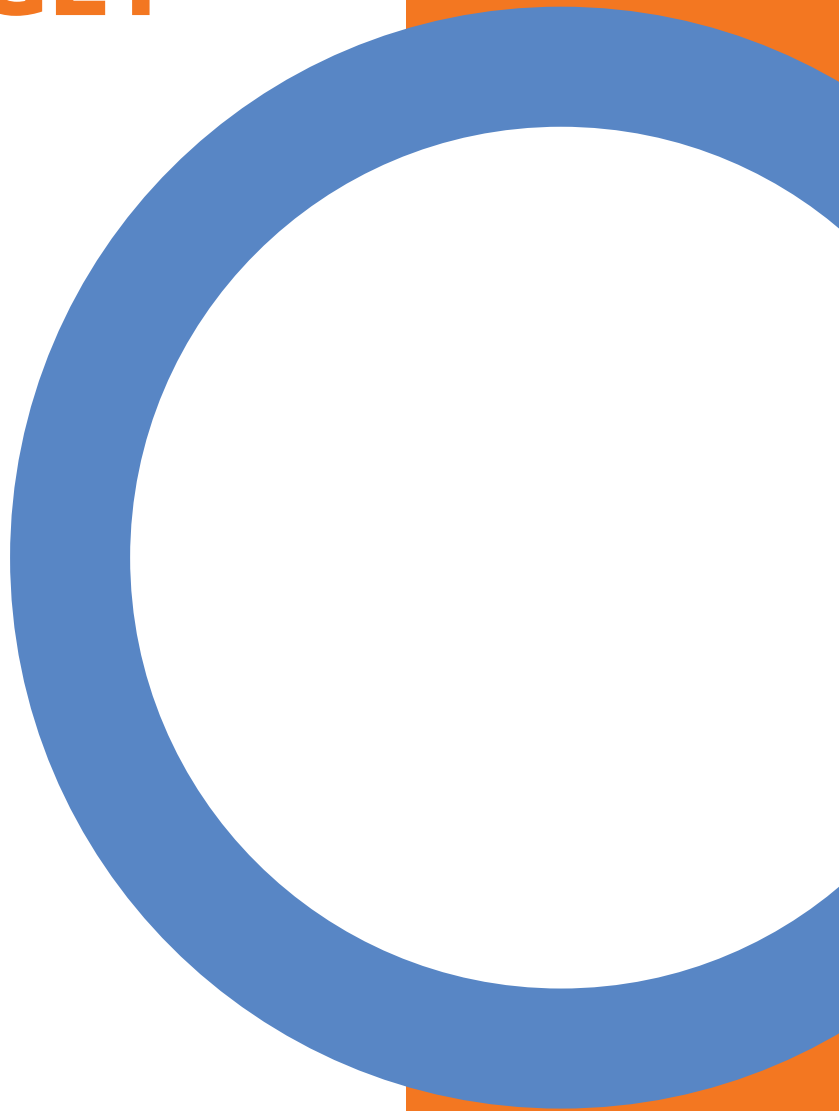
Time-framed

By when will you accomplish your goal?



You will find a series of European and national Policy recommendations at the end of the **3rd edition of the Policy Puzzle** that you can use as guidelines to set up your long-term goals and short-term objectives.

3. IDENTIFYING YOUR TARGET AUDIENCE



3. Identifying the target audience

○ How to identify your target audience?

In advocacy work, the two main audiences will usually be:

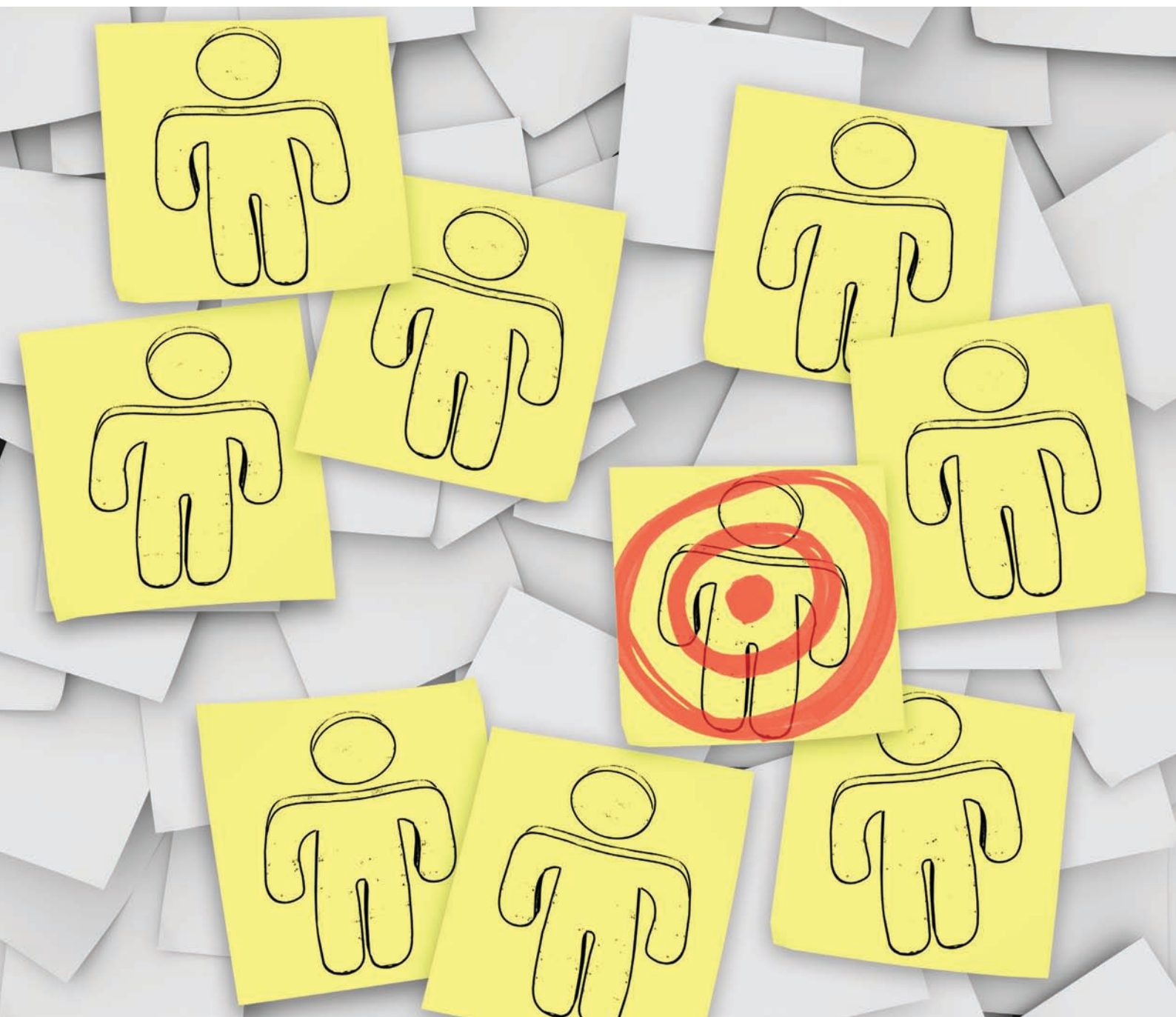
1 Decision makers: your primary audience

You can identify them by asking: Who are the individuals or groups who can take the decisions you want to be taken?

2 Influencers: your secondary audience

You can identify them by asking: Which individuals or groups influence decision-makers?

The more specific you are in identifying your audience, the more effective your communications will be. Also remember that different audiences will be at different stages of awareness and commitment. While some might already be experts on diabetes, others will need basic information to get a grasp of your issue. To be efficient, you need to target your audiences as individually as your resources allow.



1) Decision makers

Decision makers include:

- **Ministries and Parliament officials** such as:
 - Presidents and Prime Ministers
 - Health Ministers and their deputies
 - Budgetary decision-makers (e.g. cabinet, ministries of finance and planning)
 - Ministers of related sectors and their deputies (e.g. Ministers of education, transport, urban planning or agriculture)
 - Local politicians and decision-makers with responsibilities for e.g. local planning, delivering elements of healthcare
- **Donors and funding agencies**
- **Private sector employers** (e.g. national and local businesses and business associations and multinationals)
- **Community leaders**
- **Implementing NGOs**

○ How to influence political decision-makers?

Key to your success in influencing decision-makers is first to **find out what the awareness, views and actions of people you want to influence are** on such issues as public health, diabetes services and the extent and challenges of the diabetes problematic in your country. In most cases, political leaders' views are a matter of public record, which make them easier to track down.

You also need to analyze existing diabetes policies and/or laws as well as identify their shortcomings. Additionally, make sure you are aware of competing political priorities – in health and in other policy areas.

The second step is to **build a relationship with the decision-makers you have identified**. To be successful, your relationship needs to be based on the premise that you and the decision-maker(s) are ultimately working towards the same goal: improving the lives of people living with diabetes.



How to build a relationship with decision-makers?

- **Find out who the person is** – find out everything you can from every possible source, i.e. their interests, what they are committed to, their history, what action they have taken in the past, etc.
- **Establish contact through phone calls, e-mails and letters** – remember to be brief, clear, precise and solution-focused about what you want/the issue.
- **Organize face-to-face meetings** – it is the best way to communicate. Bring simple print material (which should be as tailored as possible to the person and include local information) to support your arguments and the actions you would like the person to take.
- **Relate to them as human beings** – not as an institution.
- **Find common ground** – there is always something!
- **Acknowledge them** – for meeting you, for some action they have taken, etc.
- **Offer to help** – provide information, case studies or resources, position yourself as an expert.
- **Ask what they need in addition to this to help move the cause forward** – see if you can provide that.
- **Be polite and clear with your messages** – they will listen if you have covered all the above points.
- **Follow-up on agreed action** – including your own and continue to follow up as appropriate with updates and progress.
- **Keep your promises** – as a model for them.
- **Generate genuine partnership** – it is easier and will serve both parties.



*** RESOURCES:** you will find a sample letter to a Member of Parliament in the resources section, p 42.



The 5 steps to work with decision-makers

1) Identification:

Which politicians do you need to influence? What role do they have? Why are they a target?

2) Engagement:

Reaching out and building a relationship/partnership.

3) Education:

What do they know, see and hear already? What else do they need to know? How can you best do this? Who can you introduce them to the issue?

4) Motivation:

What will push them to act? Why should they care?
What can you show them that will make a real difference?

5) Action:

What specific actions do you want them to take (and what outcomes do you expect or hope from these actions)? Who else can they work with on it?

Find your Champion

Change mostly takes place at national level. Therefore Members of Parliaments have a crucial role to play in helping to shape and influence national policies.

An effective way to influence policy is to create champions amongst the elected representatives in your national parliament and other governing bodies in your country. However, a champion is not someone who merely supports a bill or policy your organization is backing. A champion can be a Member of Parliament who takes on the diabetes issue as a priority and does their utmost to make sure change happens.



Advocacy in action

EXPAND: an EU network of Members of Parliament champions in diabetes

In a move to bring together a group of MPs and key stakeholders to push for specific diabetes policies in the EU, British MP Adrian Sanders recently called for the creation of the **EXPAND network**.

This network will specifically address diabetes-related issues through a series of meetings, which output will be transposed into yearly Call to Action and Roadmap for Implementation. An online community will further help exchange of information and follow-up of developments at national level.

EXPAND is a unique opportunity for Members of Parliament to bring their knowledge and experience of diabetes and policy-making together for the benefit of diabetes patients in their own countries and across Europe.

For more information contact: Sophie.Peresson@idf-europe.org

○ Everyday heroes

Everyday heroes are another powerful way to influence policy-making and also the general public. Think of young leaders, volunteers and board members of your diabetes associations, nurses, doctors or any other inspiring individuals that are committed to diabetes and could take part in your advocacy and campaigning activities. Raising the profile of these everyday heroes can have a great impact on policy-makers and the general public because they represent the human, daily-life aspect of your issue. This quality makes them perfect advocates for your cause and, most of all, it makes them representatives your target audience can relate to.



Section 8 ► **Influencing role of the media**

*Political decision-makers are also influenced by the media — both local and national. It is therefore crucial to know how to generate media interest. You can find more information on this in **section 8**, Engaging with the media.*

Section 7 ► **Influencing role of campaigns**

*Powerful campaigns can generate massive media and public interest. In turn, this can also push decision-makers to act on a pressing issue. Find out more on campaigning in **section 7**.*

1) Potential influencers

Potential influencers are these individuals or group of people who can influence decision-makers, and who therefore will be valuable partners in your advocacy activities.

Potential influencers / partners include:

- **Civil society:** formal and informal organizations and groups; NGOs
- **Opinion leaders:** community and business leaders, authors, activities, religious leaders, the media
- **Entertainment and sports personalities**
- Stakeholders such as **EU or United Nations agencies**
- More unexpected partners such as **academics** (a renowned economist for example) or **business people**. In the latter case, remember to be careful about who you choose as partner and how it might affect your credibility.
- **Teachers, professors and researchers**
- **Consumer groups such as patients' organizations**
- **Healthcare professionals**

○ Together we are stronger: partnership, coalitions and network of influence



Building partnerships, coalitions and networks of influence are vital for your diabetes advocacy. They will help you spread your message and give you more credibility. In addition, they can give you access to communities that are harder to reach.

In any partnership, it is essential that you also include people living with diabetes and their families. Bringing their perspectives and their own real-life experience is one of the most powerful ways to communicate your messages.

Each member of a partnership or coalition might have different approaches, expectations and demands. Make sure you find an overarching and **unifying goal** which everybody can support. Once you have achieved this, your coalition can be a powerful advocacy tool to engage in high-level dialogue with policy-makers and other influential leaders on broad policy issues and national policies with sometimes greater impact than organizations operating alone.

**Advocacy in action****The European Chronic Disease Alliance: the power of many voices with one message**

Founded in 2009, the European Chronic Disease Alliance (ECDA) unites 10 European public and professional health organizations active in diabetes, heart disease, stroke, hypertension, kidney disease, cancers, respiratory, obstructive pulmonary and liver diseases. All these stakeholders have joined forces to reverse the rise in chronic non-communicable diseases in Europe. ECDA is an influential coalition thanks to its weight: chronic non-communicable diseases affect more than one-third of the population of Europe – over 100 million citizens – and account for 86% of deaths in the WHO European Region.

As its advocacy line, ECDA has chosen a message that can be supported by all its members: the need to address the four major lifestyle risk factors for all chronic diseases, namely tobacco, poor nutrition, lack of physical activity and excessive consumption of alcohol.

The ECDA is regularly contacted and referred to by the European Commission as an essential source of information on chronic diseases. Further recognition came in October 2010, when ECDA won the prestigious **2010 European Health Award** during the Gastein Health Forum, rewarding this public health initiative for their united prevention approach.

The ECDA helps IDF Europe to further spread its diabetes-related messages and to regularly engage with high-level stakeholders.

4. DEVELOPING YOUR KEY MESSAGES



4. Developing your key messages

Now that you have defined your issue, established your goals and objectives and identified your target audience, you need to focus on developing effective and powerful key messages. This is a crucial step in planning your advocacy activities as these messages will determine how your target audience will see you and understand your issue.



○ How to craft your key messages?

You need develop strong and effective messages that will convince decision-makers and influencers that action is needed. Keep in mind that it is always easier to motivate someone to act on existing convictions and beliefs rather than something completely new. Make sure you tailor your key messages to your specific audience.



Messages do not necessarily need to be invented. One way to develop your advocacy messages is to look at resolutions/recommendations of the key political documents mentioned at the beginning of this toolkit (you can find these documents in the References section, p. 50) and see if these are met in your country/region. You can then base your key messages on these resolutions or recommendations, bearing in mind your specific circumstances.

Here is a short list of what you need to consider when developing your messages:

- **Follow the 5Cs rule:** be Clear, Concise, Consistent, Compelling and Convincing.
- **Combine facts and figures with personal stories:** your messages will have a bigger impact if they reach for the hearts and minds of your target audience.
- **Target your message** to the needs, perceptions and preferences of your target audience. Answer the question “why should I care?”
- **Consider your aims, objectives and audience.** Do you want to call for action or to educate? As they are designed to prompt action, advocacy messages often follow the “problem – solution”, i.e. ‘We need to do A to solve problem B’. Educational messages, on the contrary, usually aim to explain issues and raise awareness to create the right context for action.
- **Never use jargon and acronyms**, or else you will lose your listeners’ attention.



Aim to develop messages that will convince your audience to **act**, rather than messages that simply communicate what you say.

Key messages will evolve as your campaign or advocacy activities progress. Following general awareness, you may wish to tackle misconceptions or move on to more action-oriented messaging targeted to key policy and decision-makers.



Advocacy in action

Key messages on the diabetes epidemic in Europe

To make a compelling argument, remember your key messages need be built and structured around **facts**. Once you have a broad message that is appealing to all audiences, you can support it with secondary key messages that will propose a course of action or a solution that will strengthen your argument.

Here are a few examples of key messages on the diabetes epidemic in Europe:

- There is a European diabetes epidemic: 52.8 million people live with diabetes in Europe.
- Almost one in ten adults in Europe has diabetes.
- Europe is home to the highest number of children with type 1 diabetes in the world.
- More research is needed into causes and a cure for Type 1 diabetes
- Type 2 diabetes can be prevented.
- Prevention, education and early diagnosis can prevent lifetime's complications such as amputation, losing eyesight, cardiovascular complications and kidney complications.
- Diabetes cost to society is escalating and could soon become unsustainable.
- EUR. 88,8 billion were spent on diabetes in Europe in 2011 – that amounts to 8% of total healthcare expenditure in the region.
- Solutions do exist. They can save lives and are highly cost-effective.
- Diabetes is not only a health issue: it has serious social and economic consequences.



As your key messages will be constantly repeated by different people and through different channels, make sure you do not have more than one overall key message and a maximum of 2 or 3 supporting messages. Too many messages risk confusing the audience and losing the focus of your advocacy and campaigning activities.



See IDF [national fact sheets](#) based on the 5th IDF Diabetes Atlas with European and national data that can be useful to develop your own key messages, pitches and talking points. More detailed information is also available in the country reports of [IDF Europe Policy Puzzle](#).



Use numbers carefully – if you use too many it can overload and confuse your audience. Make sure you balance statistics with stories that convey the human cost of diabetes.

The elevator pitch: 60 seconds to say it all

The elevator pitch is a short and compelling summary that presents your issue or campaign. "Elevator pitch" is named so because this summary should last no longer than the average elevator ride, i.e. 30 seconds to maximum 2 minutes.

An elevator pitch helps you get your point across quickly and acts as a hook for your target audience. For example, a pitch can be used at the beginning of a presentation, to make sure you catch your audience's attention. It also comes in handy when you have a very short meeting with an important stakeholder. What you achieve to say and how you say it in a very short amount of time will almost always determine the chances of your issue being taken into account and you being seen as a reliable partner.

An elevator pitch may be presented in oral, written, or video formats. Here are 5 elements to build your elevator pitch:

1. **Concise:** Your pitch should last no longer than 30 seconds to 2 minutes.
2. **Clear:** Use simple and powerful language that everyone understands.
3. **Visual:** Your message needs to tell a story to be memorable. You need to use words that will create an image in your listeners' mind.
4. **Targeted and goal-oriented:** Your pitch needs to be aimed for a specific audience. If you have different target audiences, prepare a pitch for each of them. In addition, always clearly mention what is it you want to achieve.
5. **Have a hook:** This is what will get your listeners interested – something that will strike a chord: a question, a short statement, etc.

Once your pitch is ready, make sure to **memorize** and **practise** it, but always remember you need to deliver it naturally. At last, **be prepared to tell more:** if you have convinced your listeners, they will want to hear more on your campaign so you need to be ready to give them more valuable content.



*** RESOURCES:** you will find a sample elevator pitch in the Resources section, p 43.

○ Talking Points



Talking points are longer statements that help build on and support your key messages. Key messages will capture your audience's attention and talking points will further keep their interest. After developing your key messages, make sure you also prepare several talking points under the form of stories, arguments or even images and/or photographs to reinforce your key messages.

When supporting your key messages, you might want to present the issue from a global or regional angle and then move to facts that are more specific to your own environment. Sound-bites are a powerful way to achieve this. Here is an example:

"4.6 million people died from diabetes worldwide in 2011. This is more than the total of people dying from HIV/AIDS, malaria and tuberculosis."

A sound-bite is a short sentence that you can easily remember and that is intended by the speaker to be suitable for media repetition.

○ Lines To Take

Another key document that will help you craft your key messages is called 'Line To Take'. Lines To Take are short documents that focus on a certain policy issue and include:

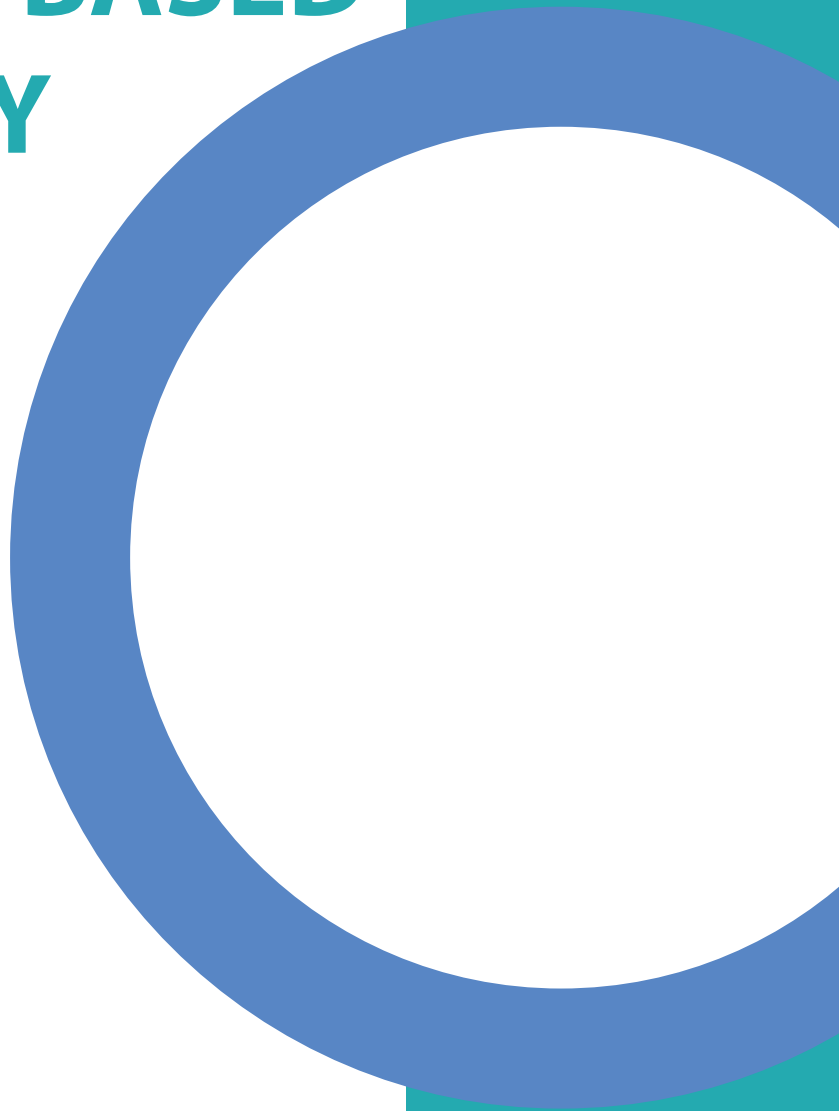
- Key facts and figures
- The latest policy developments
- Future policy developments
- Recommendations
- Links and references to find more information

Lines To Take are highly valuable documents when preparing your key messages for your advocacy activities. You can also use them as briefing sheets for anyone who will speak on a particular issue on behalf of your organization (speakers at events, spokespeople, etc.). They give clear and concise guidelines on what is your position on a certain issue and what arguments can be used.



*** RESOURCES:** You will find an example of Line To Take developed by IDF Europe in the resources section on p 43.

5. DEVELOP EVIDENCE-BASED ADVOCACY



5. Develop evidence-based advocacy

As an advocate on diabetes, you will be faced with strong competition from other health-related issues to get the attention of your target audience. Once you have developed powerful key messages to reach out to your target audience, it is essential that you further build your advocacy strategy on hard facts and evidence, but also on real-life experiences that will give a human focus to your advocacy strategy.

O Using research

Using comprehensive and up-to-date research is a crucial element of successful advocacy strategies. Not only is it a powerful way of showing your target audience why action needs to be taken on diabetes, but it also adds strength and credibility to your arguments.

Research can be scientific or public health research. You can also use research, reports and surveys carried out by renowned institutes, organizations and/or NGOs.

- You can use your own research or research from scientists, institutions or organizations that have national or international authority in diabetes or other health-related issues.
- Research is useful to back-up recommendations, give concrete facts and figures or share good practice.
- You might also be able to use research produced by your own target audience (government, healthcare body, etc.), which will make your arguments exceptionally powerful.



Hard research might not always be available. However, a large number of enquiries on a particular issue can suffice to raise the issue and build an advocacy strategy around it. In that case, you can back up your arguments with the fact that your issue is becoming a public concern.

Research produced by IDF Europe and IDF



DIABETES: THE POLICY PUZZLE

Diabetes: The Policy Puzzle is the only pan-European audit which documents the evolution of the diabetes epidemic and the disparate national policies and practices that currently exist across the European region. Covering 47 European countries, the research provides with detailed country reports, facts and figures and recommendations to act on the diabetes epidemic at European and national levels.

The report is produced by the International Diabetes Federation European Region (IDF Europe) in partnership with the Foundation of European Nurses in Diabetes (FEND), Primary Care Diabetes Europe (PCDE) and the Alliance for European Diabetes Research (EURADIA). Published every three years, The Policy Puzzle is now in its third edition which was released in November 2011. It builds on the 2 previous editions that covered EU member states.

Download the full report [here](#)

IDF DIABETES ATLAS

IDF Diabetes Atlas is an authoritative source of evidence produced by the International Diabetes Federation (IDF) on the burden of diabetes worldwide for health professionals, scientists, economists, policy-makers, and national and international agencies.

Published every 2 years, the report –now in its 5th edition– presents data on the extent of the diabetes epidemic, healthcare expenditures, morbidity and mortality across 216 countries in the world. The Diabetes Atlas also includes regional overviews, an analysis of the social and developmental burden of the disease and an overview of global advocacy on the issue. The survey is then completed by a list of recommendations for prevention, early detection and management of diabetes.

More information and an interactive map with country statistics are available at www.idf.org/diabetesatlas

○ Real-life stories

Real-life stories are a powerful means to reach out to your target audience when campaigning on diabetes. As much as you can, go out and talk to people who live with diabetes, know about diabetes or have personal stories about this condition. Using such stories gives you three advantages:

1. The reality of what it means to live with diabetes or die from this condition can affect a wide range of audiences, from the general public to politicians and including the media.
2. Success stories of people living with diabetes, from common individuals to famous athletes or celebrities, also reach a wide audience and are a powerful inspiration to drive change.
3. As you are competing to get attention, real-life stories allow you to get directly to the hearts of your target audience. Connecting emotionally with the people you want to influence will make it easier for you to obtain their support.



Advocacy in action

“Limits only exist in people’s minds”, the story of Nenad Simunko

At 28, Nenad Simunko is a certified triathlete and a passionate advocate on diabetes. An active volunteer for the Croatian Diabetes Association, Nenad loves working with young people living with diabetes. “I’ve lived 22 years with diabetes now so through my experience I try to give them the best advice I can. Just seeing them smiling back at me is such a huge reward. This is really what keeps me going.”

Diagnosed with type 1 diabetes at the age of 6, Nenad recalls: “At first it was really hard. But diabetes taught me self-control and respect for my own health. Now I want to show people that diabetes is not something that should stop them doing what they truly want in life.”

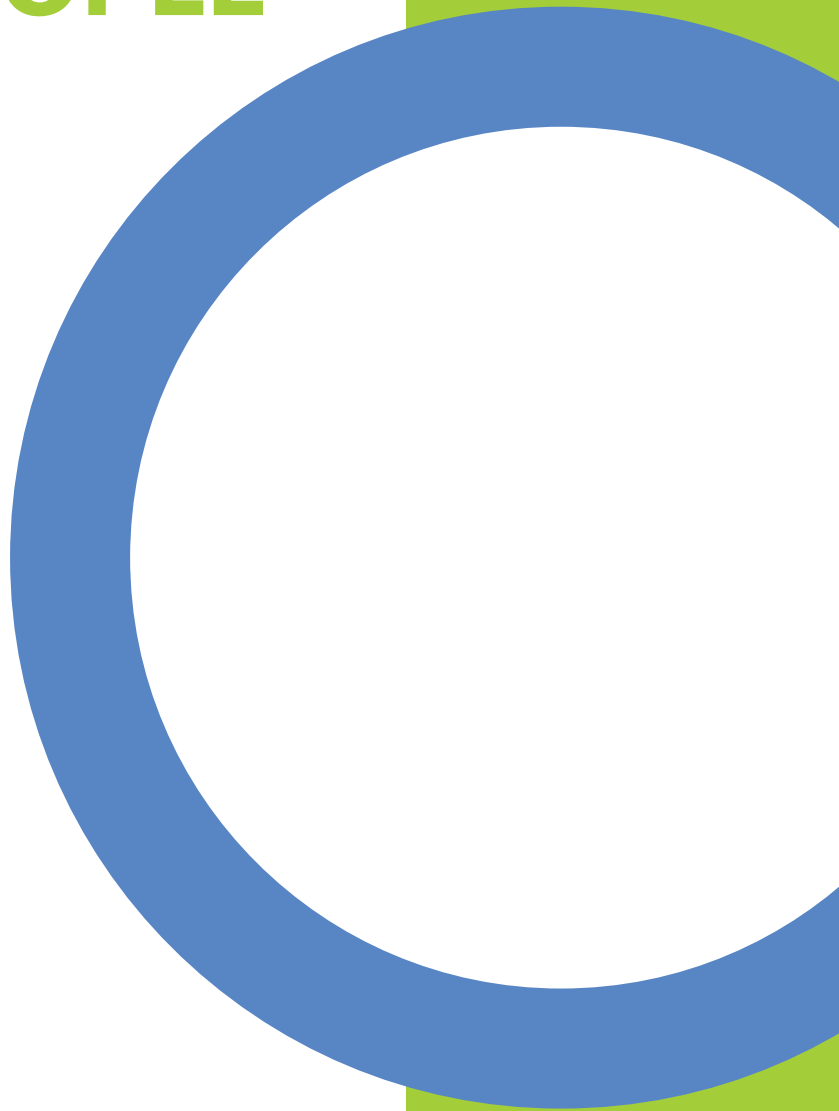
Being a student, Nenad was a total stranger to triathlon, the discipline he now excels in. “Back then I weighted 105 kilos. I was like a big bear. I was

dealing with diabetes on my own. I could manage my condition, but I was bitter about it.” That is until he met a girl named Lodeta Zrinka, who was preparing to complete a race called “Ironman” which consists of 3.8km swimming, 180km cycling and 42km running. Her story left Nenad speechless. Shortly after, he was introduced to triathlon by Lodeta’s partner. “Right then I understood I could achieve something. My first race was a real struggle. I almost drowned! But the sense of pride and happiness it gave me was something I had never experienced before.”

Since then Nenad has completed the simple and double ironman races. In July 2012, he became the first triathlete with type 1 diabetes in the world to run the triple ironman race. Nenad completed the race (11.4km swimming, 540km cycling and 126.6km running) in 51 hours. “Training is essential. But the real key is your will to achieve this. Without the right state of mind, you won’t finish the race”.



6. CHOOSING SPOKESPEOPLE



6. Choosing spokespeople

Convincing your target audience depends on the messenger almost as much as the message. Choosing effective spokespeople is therefore crucial to achieve your advocacy and campaign objectives.

When looking for spokespeople, you should look for the following qualities:

- Someone with great communication skills: your spokesperson needs to be a persuasive and powerful public speaker
- Someone with credibility and legitimacy: you need to think of who will best influence your audience. In other words, which individual(s) or groups are respected and trusted by your target audience.

Once you have chosen the right person, you also need to make sure -whenever possible- that they undergo media training. This will ensure that they successfully engage with the target audience and the media.

In this respect, you can opt for someone who is used to public speaking or who is used to media exposure such as famous sports figures, celebrities or leading international scientists or economists. Young leaders living with diabetes also make powerful advocates thanks to their first-hand experience of diabetes and their wide outreach through social media.

Depending on the audience you want to influence, spokespeople might be:

- Someone living with diabetes or family member
- Leading international or national scientists, academics or economists
- Renowned healthcare professionals
- Political leaders
- Community leaders
- Businesspeople
- Youth advocates
- Sports figures or celebrities



Advocacy in action **IDF Europe spokesperson:** **Michał Jeliński, Professional rower and Young Leader in Diabetes**

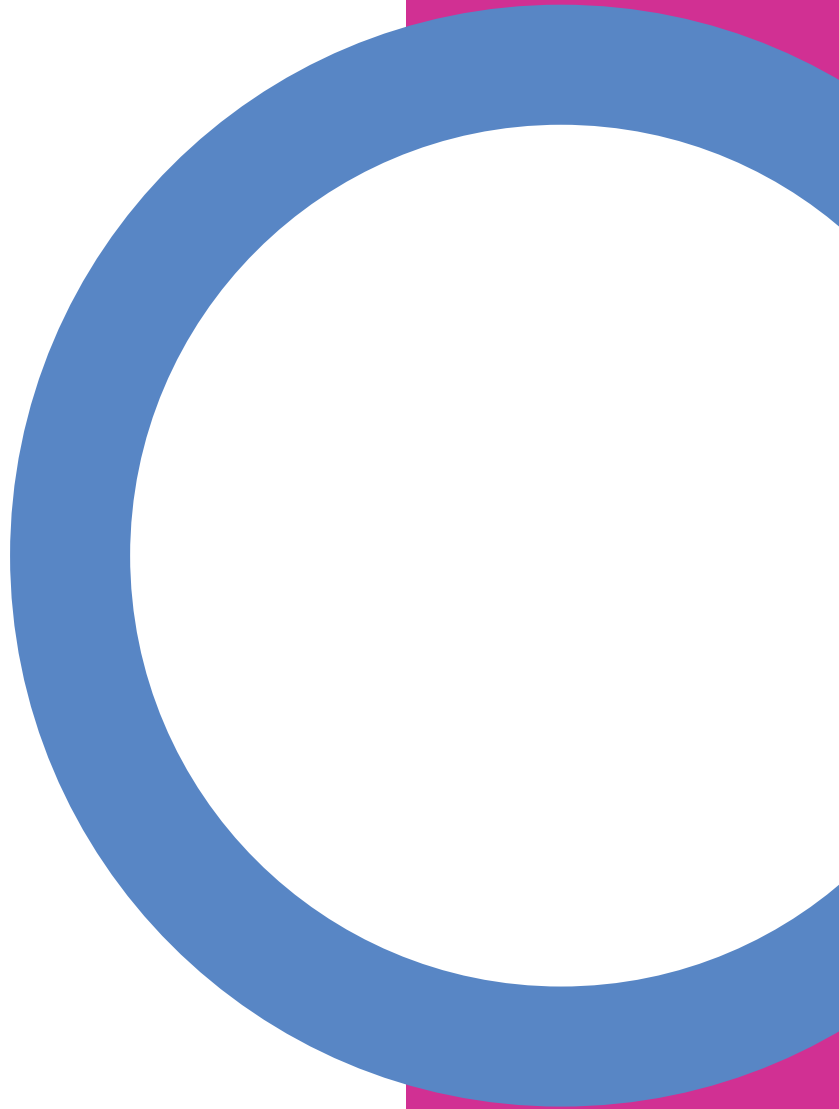
Michał Jeliński is a Polish professional rower (Quadruple Sculls). Born in 1980, Michał was diagnosed with type 1 diabetes in 2003, when he was 23.

Diabetes has however not kept him from winning. Since 2005, he has won an impressive amount of Championships: Michał and his team have won gold in the World Championships in 2005 (Gifu), 2006 (Eton), 2007 (Munich) and 2009 (Poznan). In 2008, the team won the gold medal in the Olympic Games in Beijing. In 2010, the team won another gold medal in the European Championship (Montemor-o-Velho).

With his motto 'The choice is yours, I guess it's worth trying,' Michał wants every person living with diabetes to know that determination, hard work, faith in your abilities and taking care of yourself will always allow you to make your dreams come true, whether it is to pass an exam, get a new job or even win gold at the Olympics.



7. CAMPAIGNING



7. Campaigning



As part of your advocacy work, campaigns can be a very powerful tool to deliver your messages. A campaign can be defined as a set of actions and activities aimed at influencing a specific group. A campaign may happen in a limited period of time (from one week to several years with milestones) and has a beginning and an end, contrarily to your advocacy work, which will be on-going.

As an advocate, you will have to deliver your message many times and in different ways to have an impact. There is a wide range of communication channels available for your campaigning activities. They will usually work better when used together rather than individually.

○ Campaigning ideas

There is a multitude of campaigning techniques and strategies. Be creative and innovative in planning your campaign, but also make sure you remember three essential elements:

- **Choose the appropriate advocacy activities:** the work done in steps 1 to 6 will help you do that, as you know by now what you want to achieve, what you want to say and who your target audiences are.
- **Consider the beneficiaries of your campaigning actions and try to involve them as much as possible:** for example, if you are running a campaign on type 1 diabetes in children, it will have a bigger impact to support a group of children with type 1 diabetes to meet a senior official rather than NGO representatives alone.
- **Draw a detailed action plan with clear timeline, who is responsible for what and what the expected outcome is.** It will further help you identify those activities that are necessary to reach your overall goals and will also be useful when assessing the impact of your advocacy activities.



*** RESOURCES:** you will find a matrix to help you plan your campaign in the resources section, p 47.

Below is a series of ways in which you can promote and gain support for your campaign. This list is not comprehensive – these are just some examples to help you generate ideas.

- Making presentations or speeches at conferences, meetings or public hearings.
- Attending diabetes-related events: this is the perfect opportunity to distribute advocacy or campaigning material to your target audience or reach out directly to some stakeholders you need to talk to.
- Organizing your own events: these can range from conferences to sports events or film/documentary screening with a debate, flash mobs, local community events, etc.
- Setting up an online petition campaign.
- Organizing a webinar.
- Producing an awareness-raising questionnaire.
- Make a short video that explains your issue: these can be low-budget productions. Get the community of people with diabetes involved. They can get simple and powerful messages across by sharing their life-experiences.
- Reaching out to celebrities (famous athletes, actors, singers) and ask them to endorse your campaign.
- Creating leaflets, posters and hand-outs.
- Creating online blogs: make sure to update them on a regular basis and make them open to discussions/comments.
- Produce newsletters.
- Reaching out through social media (Facebook, Twitter, etc.): this is a highly cost-effective way to reach out to a wide audience. Keep your messages short and compelling.
- Engaging with the press (radio, television, printed and online press): it is a powerful way to raise awareness amongst the general public and to reach out to decision-makers.



*** RESOURCES:** you can find tips on how to prepare and deliver presentations in the resources section, p 48.

More campaigning ideas can be found on IDF website, in the [World Diabetes Day section](#).

When planning your campaign, you also need to think about the level of your advocacy activities. A campaign can influence people or institutions at all levels (from a teacher at a local school to a Member of the European Parliament). For the sake of simplicity, we can identify 3 main levels of campaigning activities:

- **Local** (village, city, state, etc.)
- **National**
- **European/international** (more than one country)

The level of influence for your advocacy and campaigning activities will largely depend on:

- The scope and size of your issue
- Where you can have the greatest impact
- The mission of your organization
- Your resources
- Your network



Think strategically

When planning your campaign, make sure you make the most of each opportunity to work with the government, healthcare professionals, NGO partners or European/international institutions. Your diabetes advocacy and campaign activities are likely to have a bigger impact if you link them to a bigger event such as:

- The launch of a governmental programme
- World Diabetes Day, 14 November
- Other relevant national and international days
- Local or national elections
- A new EU Presidency
- etc.



Advocacy in action

Debunking the diabetes myth: breaking misconceptions on diabetes

As part of its 2011 World Diabetes Day campaign, IDF Europe developed a questionnaire called **“Debunking the diabetes myth”**. The questionnaire is made up of 11 short statements on diabetes, with a true-or-false box to tick, and a factsheet providing the correct answers. Such a tool is a good example of a simple, cost-effective and efficient tool to raise awareness and fight misconceptions on diabetes amongst your target audiences.



Advocacy in action

Diabetes care in schools: the Finnish success story

Make sure that every child with diabetes receives appropriate care at school: this was the objective of a campaign carried out by the Finnish Diabetes Association (FDA).

Until recently in Finland, no one had the responsibility to provide diabetes care for children living with diabetes at school. The care provided to children therefore depended on the school they were enrolled in, a situation that created huge inequalities. In the most extreme cases, parents had to visit their children at school several times a day to help them measure their blood sugar, inject their insulin or count carbohydrates.



In 2006, the Finnish Diabetes Association launched a campaign to address this issue by collecting data, meeting with key decision-makers and by educating the general public:

- The association conducted a **survey to assess the situation nationwide**. The results of the survey were presented to the Ministry of Education and Ministry of Social Affairs and Health which, based on this, set up a working group.
- The FDA then produced **a document to safeguard the well-being of children with diabetes at school**. The document offered a tool to parents and schools to agree on diabetes care until an official guideline was issued by the government. It was launched at World Diabetes Day events in 2007 and received television and printed-press coverage.
- The association continued consulting both school staff and paediatrics, acting as a channel between the political level and educational institutions. The advocacy campaign also heavily involved a large number of **parents who made direct contacts with ministries and Members of Parliament**, which had a considerable impact at political level.

A first battle was won when a ministry recommendation was adopted. The text included general guidelines on the different actors responsible for providing diabetes care for children at school and instructions how to educate stakeholders to provide diabetes care.

Full-out victory came in May 2011, when a new healthcare act was adopted on diabetes care at schools. The act stipulates that schools have full responsibility to provide diabetes care to children during school day in Finland. The ministry recommendation completes the healthcare act and gives indication on how to properly implement the act.



Campaigning tools

How to organize events

Events such as conferences, meetings or workshops to discuss diabetes policy or research, or other events such as sports tournaments, flash mobs and exhibitions can be a very powerful and effective way to reach out to your target audience and raise awareness. However, every event needs to be carefully planned. Here are a few tips you need to take into account when organizing your event:

- **Choose your audience, time and venue strategically:** invite the most inspirational speakers and target participants to make sure you invite those people you most need to reach out to, as well as those already supportive who can most effectively help get across the message you are promoting. As mentioned before, your event will have a bigger impact in a certain context (World Diabetes Day, elections, launch of publication, etc.). Make sure your venue suits your event and is easy to reach.
- **Develop a clear and focused agenda** and share it with all stakeholders involved
- **Invite the press:** many events are media-friendly. Remember to invite journalists.
- **Prepare your material:** do you need visuals, a video, a presentation or leaflets?
- **Know your audience:** make sure you know who is attending and think of how to best communicate with them.
- **Focus on your message:** make sure you, your speakers and partners are briefed and know your key messages.



Campaigning tools

Making your voice heard online

The Internet is a very powerful tool for advocacy and campaigning activities. It gives you an easy, wide and cost-effective reach to a large audience. It also gives you access to information that you can use for your own campaigns.

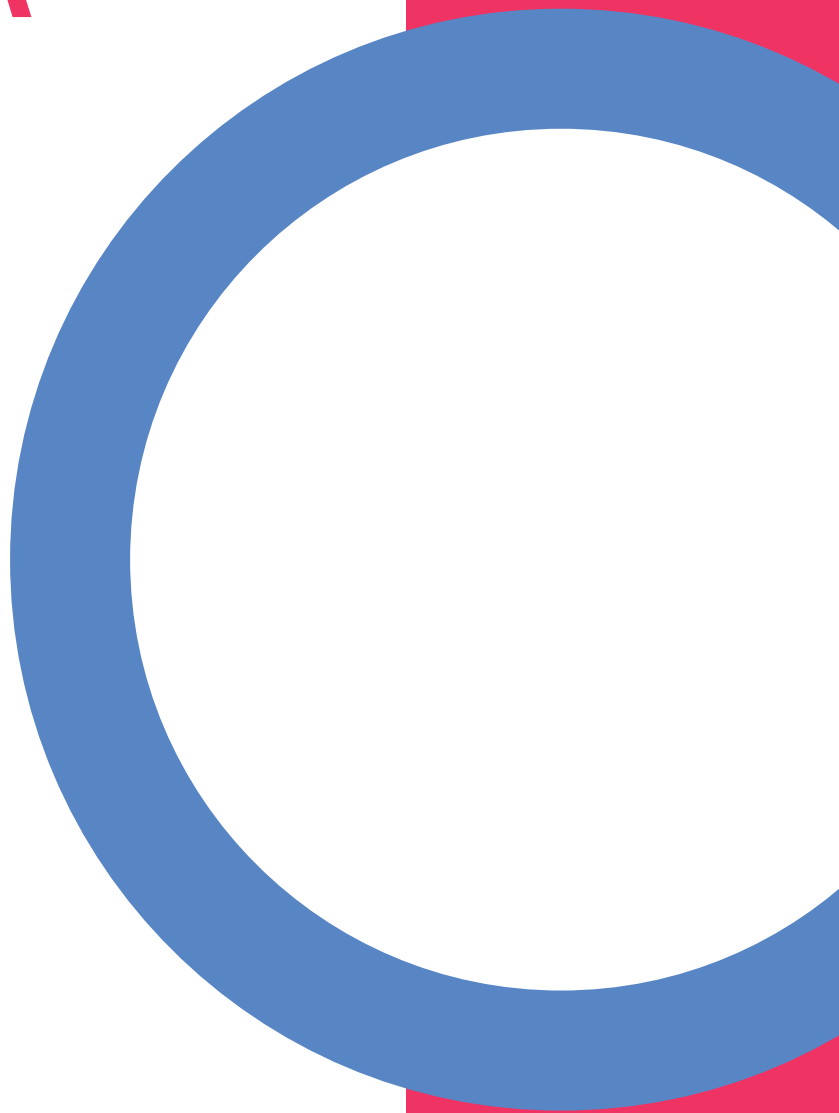
While creating a user-friendly website might require professional skills and/or financial resources, there are other cost-effective ways to use online communications:

- **Create blogs or online discussion groups** on diabetes prevention, care and management or on diabetes policies. Make sure to keep the information to-the-point, update regularly and leave your blog open for discussion
- **Engage with your audience on social media** using tools such as Facebook, Twitter, etc. These give you a wide reach through your own network on these platforms and beyond thanks to people who will share your posts. Using social media allows you to be more interactive, for example by sharing 'on-the-spot' pictures of your events, or sharing comments on unfolding events which you are attending, etc. Make sure to post short, attractive and compelling messages.

These channels are perfect to generate discussions and debates, as everybody can react and post replies.



8. ENGAGING WITH THE MEDIA



8. Engaging with the media

Working with the media is critical for the success of your campaigns and advocacy work in general. Part and parcel of your campaigning activities, achieving media coverage and build strong relationships with journalists are two powerful ways to raise awareness, educate the general public and persuade your target audience to take action. The two most common approaches in media relations are:

- Creating news stories to raise awareness, educate people or urge them to act. This is mainly done through sending out press releases to journalists.
- Writing comment or opinion pieces in the form of editorials or letter to editors, which can be more influential but which are also much more difficult to secure.

○ How to catch journalists' interest?

In today's world, there is a multitude of pressing health issues. You therefore need to make diabetes stand out from the crowd. To get journalists' attention, your story must:

- **Be something new:** the diabetes epidemic, no matter how serious and devastating, may not be news. New findings, a research or a report on diabetes will be.
- **Be powerful, attention-grabbing or exciting.**
- **Be real-life stories:** journalists are fond of heart-wrenching life experiences or success stories that allow you to connect emotionally with your audience and bring your issue to life.
- **Be linked to major news or events:** you need to make diabetes relevant to its context by linking it to big issues that are already on the news agenda. This can include an economic crisis, a health scandal or an election campaign. Journalists always look for new angles to run major news stories, and local media often cover bigger international or national news the day after it breaks.
- **Be linked to a celebrity,** a political leader or a sports figure.

Remember that journalists work with very tight deadlines. Providing them with clear and thorough information, concrete examples and even photographs will increase the chances of your story being picked up by the press.

You also need to know your media and target audience. Indeed, different publications have different interests and different audiences. Mainstream media cover issues that affect people's lives or society in general and reach a broad audience. Specialised press -a scientific journal for example- will be more interested in research and will reach health experts.



○ How to build strong media relations?

Understanding how media work and what pushes journalists to publish a story is essential to build strong and effective media relations. Here is a checklist of what you need to do to make sure that your story gets picked up and that you and your fight on diabetes is presented the right way:

- Have **clear and powerful messages**.
- **Plan in advance** and consider media deadlines.
- **Identify journalists who cover health issues:** it is crucial to have an up-to-date list of health reporters to avoid sending press releases to journalists who have no interest in your issue.
- **Build personal relationships with journalists:** networking is key for good media relations. As news agencies receive hundreds of press releases a day, most of the time communication via e-mail is not enough. Make sure you establish contact with journalists with follow-up phone calls or ask them to meet for coffee so that you can pitch them your story and explain your advocacy initiatives into more details.
- **Be prepared to answer media calls:** when sending out a press release, make sure you have all the information at hand to answer journalists' queries.
- **Have a list of spokespeople** who are trained on the issue and prepared to communicate with the media: journalists love good public speakers that put a human face on your issue and make the story livelier.

On the other hand, when dealing with the media make sure you DO NOT mislead journalists or give false or incomplete information. If you do not know the answer, just say so. Also, do not issue press releases that are poorly written or lack interest, as you run the risk of being ignored in your future communications.

○ How to communicate your story to the media?

There are different ways to reach out to the media:

- Send a press release, an opinion piece or an editorial on your issue (always remember to follow-up with a phone call).
- Contact journalists, pitch them your story and offer an interview with one of your spokespeople.
- Invite journalists to events or conferences, or organize media breakfasts: this can be an effective and more informal way of presenting your activities and the issues you will be covering to journalists.



PRESS RELEASES

Press releases are the most common way to reach out to the media as they are an effective tool to flag your issue to journalists. Here are a few golden rules you should always bear in mind when writing a press release:

- Have a catchy headline
- Your first paragraph needs to catch the reader's attention. Include the most important information there.
- Make sure you answer the **five W's** in the first paragraph: **Who, What, Where, When and Why?**
- Include facts and figures
- Include a powerful quote from a senior spokesperson
- Be thorough and complete but don't be too long: whenever possible, your press releases should not be longer than one page.
- Always include notes to editors and contact details for follow-up and more information.

FEATURE ARTICLES

Feature articles are longer pieces that can be also be published in magazines or newspaper supplements. These articles may not necessarily contain news but they still need to be current and relevant.

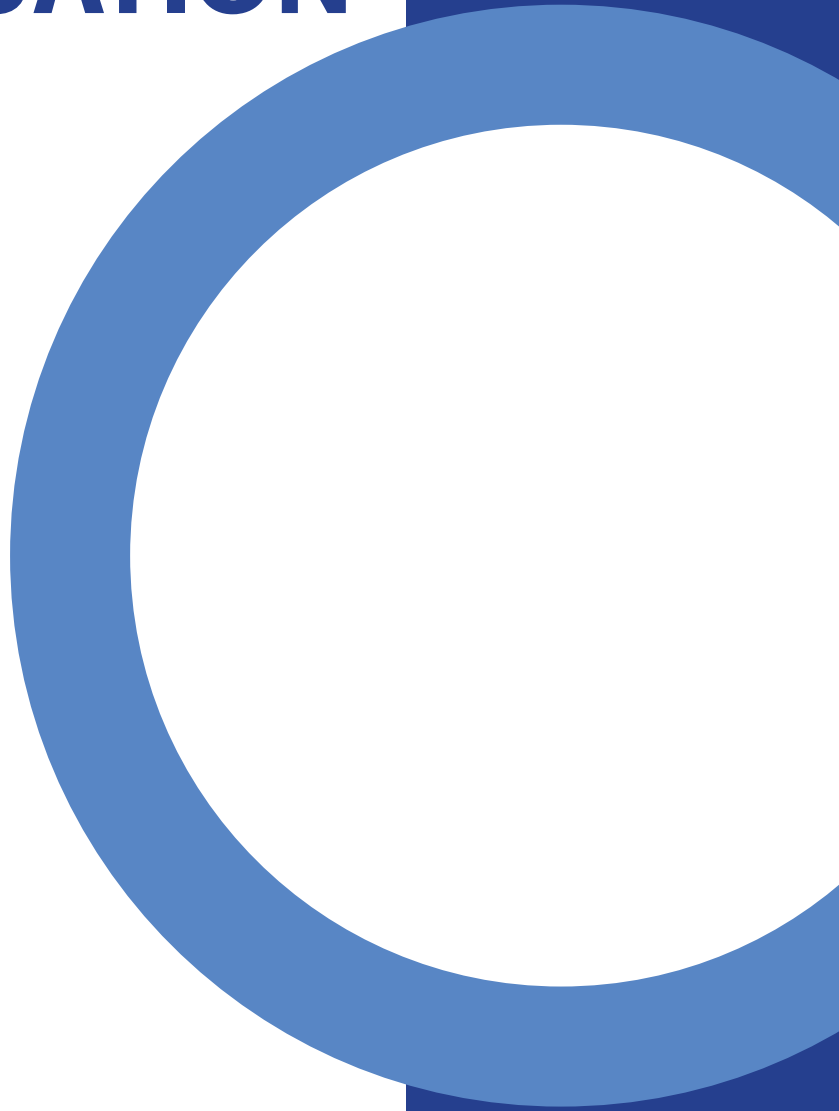
Being an ongoing human issue, diabetes is also a powerful subject for feature articles. On the other hand, as feature stories are longer and more detailed, they are an effective way of raising awareness on diabetes. When writing a feature story, you should:

- Write a longer piece (1000 words or more) including comments and opinions
- Focus on people: feature stories are perfect to convey your message through powerful real-life experiences.
- Include photographs to bring your story to life.



*** RESOURCES:** you can find a sample press release in the resources section, p 49.

9. MONITORING AND EVALUATION



9. Monitoring and Evaluation

Monitoring means measuring the progress made towards achieving your goals and objectives and identifying which activities are effective or not.

Evaluation means making judgement about the quality of your advocacy work and its impact. It looks more into why certain actions went well and others not.

○ Why are monitoring and evaluation so important?

In your advocacy work, it is vital that you build trust and understanding with stakeholders, partners and donors. Part of that process means being able to demonstrate that you are delivering on your commitments. Therefore, you will need to develop reasoned arguments about how your actions have contributed to your overall goals. Effective evaluation will also help motivate supporters and stakeholders, telling them the successes your advocacy activities have achieved and pointing out where progress still has to be made.

More than a sign of professionalism and credibility for external stakeholders, monitoring and evaluation are also highly beneficial for you. Time and resources will often be limited for most advocates, but spending time assessing what worked and what went wrong will save you a considerable amount of time and make future work more effective.

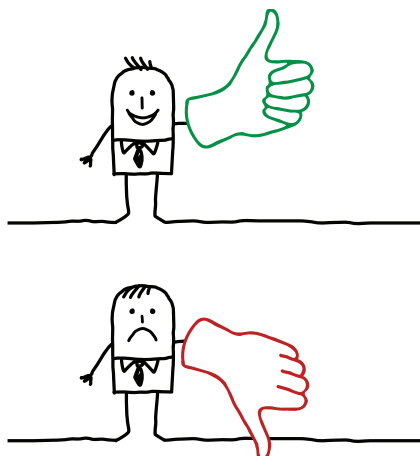
Admittedly, it is very difficult to know precisely what has contributed to policy change and what impact those changes have on the ground. The main reasons it is difficult to monitor and evaluate advocacy are:

- **Complexity of determining cause and effect.**
- **A moving target:** policy and programme change happens in an external environment which are in constant evolution, requiring you to adapt how you monitor and evaluate your work.
- **Difference of opinion:** what constitutes a successful outcome for one group may not be seen as such by another.
- **Timescale:** advocacy is a long-term activity and change may only be seen over a long period of time.

The above, in addition to country specific issues, poses a real challenge in developing useful methods to support meaningful learning in the area of advocacy work.

However, monitoring and evaluation are possible and can be made easier by using:

- **Well-defined objectives.** They often make it obvious what indicators are needed to assess the impact of your advocacy work.
- **Agreed definition of success and agreed indicators** that will show the situation is improving. For example, setting up a media strategy with specific targets (number of mentions in the press) and a list of publications you want to reach out will make it easy to monitor a press campaign.
- **Qualitative indicators** (public opinion, stories, perception of your issue, feelings) and **quantitative indicators** (statistics, numbers, etc.)



○ What should be monitored and how?

Monitor your target audience

- Record and observe changes in the rhetoric of your target audience. Gather descriptive information about change.
- Notice what they are saying about your advocacy work.
- Establish if they are moving closer to your position, adapting to or adopting any of your language or recommended actions.

Monitor your reputation

- Record the sources and numbers of inquiries that you receive as a result of your work.
- Are you getting to the people you targeted?
- How and where have they heard of your work?
- How accurate are their preconceptions about you and your work?

Monitor your relationships

- Record the frequency and content of your meetings with external sources and target audiences.
- See if you are discussing new ideas.
- Ascertain if you are becoming a source of information and/or advice.

Monitor public opinion

- Analyse the climate of public opinion through telephone polling, commissioned surveys or focus groups.
- Make use of online surveys, e.g. Survey Monkey.

Monitor media

- Count the column inches on your issue and the balance of 'for' and 'against' comments.
- Count the number of mentions for your organization or campaign in the press (for example, have you secured articles in national newspaper or renowned publications?)
- Analyse if the media is adopting your language.

○ How to evaluate impact?

Evaluating the quality and impact of your diabetes advocacy work can be more difficult since reliable and objective criteria are harder to find. However, evaluation doesn't necessarily need to be a complex process. It can be a simple analysis resulting from a discussion within your organization or with your partners. Here are a few useful questions to start your evaluation process:

- Have you achieved your objectives?
- Have you reached out to your target audience?
- Has the situation improved? If yes, by how much? If not, do you need to change your approach or your goal and objectives?
- If you didn't achieve your objectives, why so? What can you do in the future to improve your work?
- Are your partners happy with the advocacy activities and their results?

Ultimately, you need to assess your work focusing on the series of impacts it has generated:

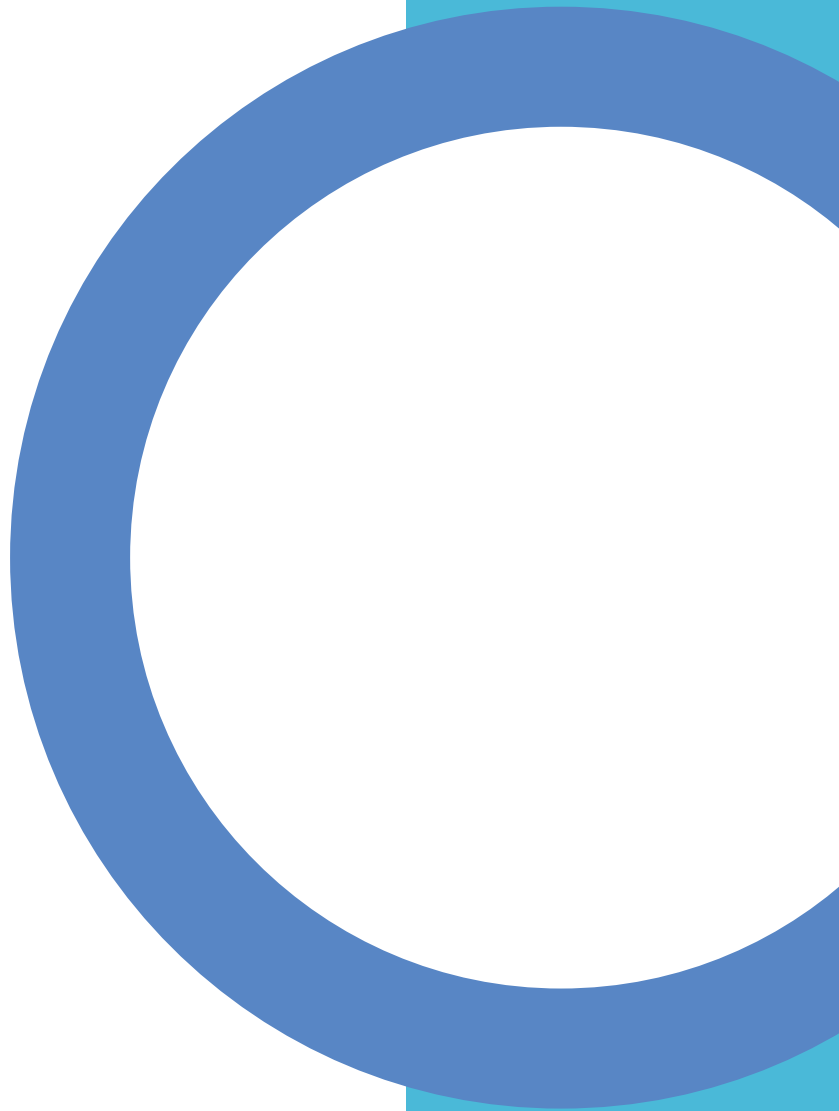
built awareness

change policy

**measure impact on
people's lives**

In each phase there are policy and grassroots activities, both of which need to be monitored. The relationship between these activities is also important, and the more integrated they are the more successful the project is likely to be.

RESOURCES AND REFERENCES



Resources and references

I. Resources

In this section you will find useful resources (matrix, sample letters and templates) to support you in planning and implementing your advocacy work. You can download and edit these documents for your own use at www.idf.org/regions/EUR/advocacytoolkit.

- A. Sample letter to Member of Parliament**
- B. Sample elevator pitch**
- C. Example of Line To Take**
- D. Matrix to plan your campaigning activities**
- E. Tips to write and deliver a presentation**
- F. Sample press release**

A. Sample letter to Member of Parliament

Adapted from campaign material developed by Diabetes UK

[Insert address]

[Insert date]

Diabetes care: too little, too late, too variable

Dear Member of Parliament, [always check the correct protocol]

Diabetes has become one of the biggest health challenges of our time, [insert figure] people with diabetes in [insert country name], including an estimated [insert figure] who have not been diagnosed and [insert figure] people at high risk. Each year, diabetes results in [insert figure] excess deaths [You can adapt the statistics according to the data available in your country/region].

The rising tide of diabetes threatens to swamp our healthcare budget. In 2011, healthcare expenditures on diabetes was approximately [insert figure], [insert figure] per hour or [insert figure] % of the healthcare system budget. [insert figure] % of spending on diabetes goes in to managing potentially preventable complications.

[Name of your association] is committed to tackling this health crisis. We urgently need your help to make sure diabetes is a priority in the government's agenda and ensure that people who are living with diabetes get the levels of care and treatment that they are entitled to.

Please find enclosed a copy of [insert report name] together with an analysis of diabetes in our country which shows the care your constituents with diabetes are currently receiving. As you can see, there are areas where people with diabetes are being let down by the health services in your area. This is simply not good enough.

The good news is that there is a solution which is not about having more money, but simply using what is there and making it work better by investing in risk assessment and early diagnosis, patient education and effective delivery of essential care processes to reduce expensive and life threatening complications and premature death.

[Name of your association] is calling for the delivery of a national implementation plan for diabetes that recognizes and addresses the seriousness of diabetes and what needs to be done.

We are asking on you to act on behalf of the thousands of people with and at risk from diabetes in who are currently getting a raw deal.

Please write today to [Name of Minister], Minister of health, and urge him/her to take immediate action to implement a national plan for diabetes to improve lives and reduce costs.

[Name of your association] is committed to tackling this health crisis. You can help us to make a difference by campaigning to make sure that citizens in our country get the levels of diabetes treatment and care that they deserve and are entitled to. For further information please contact [name of contact person, telephone number and e-mail address].

We will follow this letter by a phone call. We would welcome the opportunity to further discuss in a meeting with you how we can address the major public health crisis that is diabetes.

Yours sincerely,

[Insert name and signature]
[Insert function]

B. Sample elevator pitch

Adapted from campaign material developed by Diabetes UK

Here is a sample elevator pitch that you can adapt to your needs for written e-mail campaigns or as introduction for speeches. The present pitch aims at pushing political leaders into action on diabetes, call on the Minister of Health to implement a national diabetes plan and invite them to meet with diabetes advocates.

'Diabetes is one of the biggest health challenges of our time, with [insert your country's/region's statistic here] people with diabetes in [country/region name], and people at high risk.

The rising tide of diabetes threatens to bankrupt our healthcare system. In 2011, health spending on diabetes was approximately [insert your country's/region's statistic here], i.e. [insert your country's/region's statistic here] per hour.

The good news is that there is a solution which is not about having more money, but simply using what is there and making it work better by investing in early diagnosis, patient education and effective delivery of essential care to reduce expensive and life threatening complications and premature death.

We are [name of your association], the leading charity that cares for, connects with and campaigns on behalf of all people affected by and at risk of diabetes in [country/region name]. We are calling on you to act on behalf of the thousands of people with and at risk from diabetes in your constituency.

Please write today to [name of Minister] Minister of Health, and urge him/her to take immediate action to implement a national plan for diabetes to improve lives and reduce costs.

We also invite you to hear from your constituents at our [event title and information] to discuss with them action that needs to be taken to improve the services and care people with diabetes in your constituency receive.'

C. Lines To Take

Below you will find an example of Line To Take (LTT) developed by IDF Europe on clinical trials. IDF Europe regularly updates its LTT documents. More Lines To Take are available on IDF Europe's website.

Line to Take

Last updated: 08.08.12

Author: IDF Europe

SUBJECT: Clinical Trials

- The grand challenge of **curing diabetes** and **preventing its onset** will only be met through **increased research**.
- Europe is well placed to play a leading role in this research effort in terms of existing expertise. However, success will depend on increased funding, more rational use of research funds and better coordination of research across the region. Recruitment of volunteers is also essential.

Background

DEFINITION: Clinical trials are investigations in humans intended to discover or verify the effects of one or more investigational medicinal products.

Requirements for the conduct of clinical trials in the EU are provided for in the Clinical Trials Directive: Directive 2001/20/EC of the European Parliament and of the Council of 4 April 2001 on the approximation of the laws, regulations and administrative provisions of the Member States relating to the implementation of good clinical practice in the conduct of clinical trials on medicinal products for human use.

IDF Europe welcomed the opportunity to contribute to the Commission's second public consultation on the **assessment of the functioning of the Clinical Trials Directive (Directive 2001/20/EC)**. We believe the review process should have as its objective a better functioning, more proportionate and more patient-centred approach to the design and regulation of clinical trials.

To ensure this, it is necessary to meaningfully incorporate the patients' views in the review. In particular, we strongly believe that this review is an opportunity for reform towards more patients' involvement throughout the research process, greater trust and confidence in medical research and improved participation rates.

Although the Clinical Trials Directive aimed to improve the protection of patients in relation to clinical trials, and has been partially successful, several gaps remain that should be addressed.

In preparation for the review of the Directive, the European Commission published a **concept paper** to outline options for revising the Directive, and launched a second public consultation to which IDF Europe responded in May 2011. We felt it was key to provide a strong position in this review, as we believe this is an opportunity for reform towards more patients' involvement throughout the research process, greater trust and confidence in medical research, and improved participation rates.

The effectiveness of clinical trials throughout the EU is of fundamental importance for IDF Europe and its members, as ultimately this influences patients' access to new and improved medicines and treatments responding to unmet medical needs. A good regulatory framework incorporates and balances all relevant stakeholder inputs and expectations, holding these in a creative tension, not an overly rigid, stifling framework.

In order to have a genuinely patient-centred vision of clinical trials, the following issues need to be addressed:

- **Ensuring meaningful patients' involvement across all aspects of clinical trials:**

Patient involvement leads to better design and outcomes of trials

Experiences of patient involvement are positive

Patient involvement can improve declining participation rates

Patient involvement improves patients' commitment and adherence

Patients' representation in Ethics Committees is key

- **Giving patients access to quality information regarding clinical trials:**

Patients' access to quality information is closely linked, but not limited to the ethics review question. Information is a crucial aspect having implications for patients' willingness to participate in clinical trials, as well as their commitment and adherence within trials.

- **Meaningful informed consent:**

Informed consent should be regarded as a pre-condition for the start of any clinical trial. It should be provided in a language which is accessible and understandable for the patient and/or their representative. Unrealistic expectations need to be dealt with at this stage; it is also important that patients do not feel that they have been coerced into participating in trials thinking that otherwise they will not get appropriate treatment.

- **Transparency concerning the results of clinical trials:**

At micro level, patients often have little access to the results of the clinical trial. Trial results are usually published in scientific journals to which individual patients and patient organizations often have no access. Lack of information on the results of the clinical trial in which a patient has participated has been shown to decrease the willingness to participate in a follow-up or second trial. At macro level, even trials that have failed can reveal significant information for patient groups, particularly in certain disease areas.

IDF Europe welcomes the positive developments linked to the EudraCT database of clinical trials (<https://www.clinicaltrialsregister.eu>), where the European Medicines Agency is currently addressing this issue, making certain results-related information accessible to the public.

- **Access to treatments after the end of clinical trials.**

Free availability of the treatment being tested – assuming it turns out to be the best one for the patient – is a key issue for patients following the end of a trial. However, despite patients reporting that they would like this to be part of the protocol, access is not always available.

Ensuring appropriate access to post-trial treatment is beneficial to sponsors and researchers, as it can be a major motivation for patients' willingness to participate in clinical trials, and thus can help sustain a high level of patient participation.

Annex – Key Documents

- **Revision of the Clinical trials Directive**

Adoption of the proposal for a “Clinical Trials Regulation”

On **17 July 2012**, the Commission has adopted a [“Proposal for a Regulation of the European Parliament and of the Council on clinical trials on medicinal products for human use, and repealing Directive 2001/20/EC”](#) (hereinafter “Clinical Trials Regulation”).

The adoption was announced in a **Press release**, supported by a ‘**Questions and answers**’ document.

- [Press release](#)
- [Questions and Answers](#)

The Commission proposal is accompanied by an **Impact assessment report** and a **Summary**. In addition, a **Citizen's summary** has been published.

- Impact assessment report [Volume I](#) and [Volume II](#)
- [Summary](#)
- [Citizen's summary](#)

The proposal has been submitted to the [European Parliament](#) and the [Council](#) who engage in ordinary legislative procedure. You find an overview of this procedure [here](#). To follow the proposal in the different steps of the procedure, please consult the [“legislative observatory” of the European Parliament](#) or [PreLex](#), the EU-database on interinstitutional procedures.

- **Preparation of the Commission proposal**

In its Communication of 10 December 2008 to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions on “Safe, Innovative and Accessible Medicines: a Renewed Vision for the Pharmaceutical Sector”, the Commission announced that an assessment would be made of the application of the Clinical Trials Directive.

This assessment would consider, in particular, various options for improving the functioning of the Clinical Trials Directive with a view to making legislative proposals, if appropriate, while taking the global dimension of clinical trials into account.

In **2009**, a **public consultation** document along this line was published [here](#). The responses have been published [here](#). A summary document of the responses is available [here](#).

A ‘roadmap’ of the Commission impact assessment, setting out the main structure and the next steps, was made available [here](#).

On **9 February 2011**, a **public consultation** on a [concept paper on the revision of the ‘Clinical Trials Directive’ 2001/20/EC](#) has been launched. The concept paper presented:

- A 'preliminary appraisal' of which option appeared to be the most suitable one to address some of the key concerns of the Clinical Trials Directive, on the basis of the current state of the impact assessment;
- The main figures used to evaluate the impacts of the different policy options.

The responses to this public consultation are published [here](#). A summary of the responses is [here](#).

- **Useful contact points**

For further information, please find below the relevant contact points:

- [Concerning the regulatory framework for clinical trials](#)
- [Concerning guidelines on inspections](#)
- [Concerning EudraCT](#)
- [Member State contacts](#)

- **Other useful links**

- Guidelines on clinical trials of the [International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use \(ICH\)](#)
- [Council for International Organizations of Medical Science \(CIOMS\)](#)
- [World Medical Association \(WMA\)](#)
- [International Clinical Trials Registry Platform \(ICTRP\)](#) of the [World Health Organisation \(WHO\)](#)

D. Matrix to plan your campaigning activities

Objectives	Target audience(s)	Activities	Resources and Budgets	People in charge	Partners and their roles	Timeline	Expected results

E. How to write and deliver a presentation

A presentation gives you the opportunity to present your messages face-to-face to an audience. It can range from a brief and informal talk to a small group, to a formal presentation in front of hundreds of people at a conference. Giving a presentation can be a major source of stress. Here are some tips to help you plan and deliver successful presentations.

Step 1: Planning

Proper planning and preparation will considerably lessen the stress load of delivering a presentation. The first thing you need to do is to review all the factors that will shape/affect your presentation:

- Who is your audience?
- What is their level of interest/knowledge about your issue?
- Is it a formal or an informal presentation?
- How much time do you have? Does this include time for questions and answers?
- What equipment will be available (computer, projector, microphone, etc.)?
- If you are at an event: What is the broader theme of the event? Can you link your presentation to other speakers' intervention?

Step 2: Writing

- According to your preferences, use bullet points or write the text in full.
- Your presentation needs to have a beginning (introduction), a middle (where you expose the main content), and a summary or conclusion.
- Start your presentation with a bold statement, an anecdote or a question to your audience. You have 60 seconds to catch their attention. Your presentation needs to be instantly real and human to them.
- Use facts and/or concrete examples to support each of your arguments.
- If you use visuals (for example a PowerPoint presentation), make sure they are clear, interesting and bring an added value to your presentation.
- DO NOT write the full text of your presentation on your visuals. It will take your audience's attention away from your speech.
- Make sure not to use too many visuals (not more than 5 slides for a 20-minute presentation).

Step 3: Delivering your presentation

- Check the equipment before your presentation starts to make sure everything works.
- DO NOT read your written text aloud. Memorize it and use bullet points as a memory aid.
- Speak clearly, loudly and slowly enough, and remember to vary your intonation.
- Look at your audience and at different person in the audience while you speak.
- Show enthusiasm: it will help people become enthusiastic about your issue.
- Respect the time you were allocated for the presentation.

Step 4: Dealing with questions

- If the question is complex, repeat it or re-phrase it to make sure everybody in the audience has understood. It also gives you more time to think about the answer.
- Answer to the whole audience and not just the individual who asked the question.
- Always think before answering.
- If you don't know the answer, just say so. You can then throw the question back at the audience or say you will find out the answer and get back to them.

F. Sample press release

PRESS RELEASE

Pressure grows for National Diabetes Plan

For immediate release / Embargo: xxxx (insert release date)

Pressure is growing on the [country name] government to adopt a National Diabetes Plan to improve the lives of the hundreds of thousands of people living with diabetes and prevent a growing number of people from developing the condition.

Today, [name of Prime Minister/President] received a powerful plea to respond to the mounting public health crisis provoked by diabetes. In a letter sent together with a petition that was signed by more than [figure] people throughout the country, [name of your association] urged the President to design and implement a National Diabetes Plan to give the necessary resources for strong and harmonized diabetes prevention, education and management all over the country.

"We are profoundly concerned that no progress has been made at national level to address the major public health crisis that is diabetes. Costs associated with diabetes already threaten to bankrupt our healthcare system. Growing obesity epidemic and an ageing population mean the situation is only going to get worse. We need urgent action now more than ever," commented [Name of senior spokesperson].

Estimates show that [figure] % of the adult population lives with diabetes, which amounts to more than [figure] people. Furthermore, [figure] % of the

total healthcare budget is spent on diabetes. However, the cost for treating diabetes-related complications, morbidities and hospitalizations largely exceeds what is spent on the treatment of disease itself.

Without a National Diabetes Plan, the country is deprived from strong and common policies on vital issues such as prevention, screening, access to diabetes care and medicines and reimbursement. This leads to stark inequalities. Today in [country name], [insert figure] people still do not have access to more efficient diabetes treatments. This means fewer people are able to properly control their condition, leading to numerous serious, costly and sometimes deadly complications. This is why [Name of your association] stresses it is vital for the [insert country name] government to design and implement a comprehensive National Diabetes Plan to avoid putting the health of thousands of citizens at risk.

"We have achievable, cost-effective solutions to reduce the burden of diabetes on our society. We have the tools, and we have the skills to implement these solutions. All we need now is political leadership to make it happen and make a real change for the thousands of people living with diabetes and those at risk," concludes [insert name of senior spokesperson].

Include notes to editors

- Sources for all of your estimates and figures
- Short description of your organization and its activities
- Short description of what is diabetes

Include contact details for further information

II. References

In this section you will find the full reference documents mentioned throughout this toolkit as well as other milestones documents in diabetes advocacy. These will provide you with the necessary content and background information to develop your advocacy work.

More reference documents are available on IDF Europe's website at www.idf.org/regions/EUR/resources

- A. [UN Political Declaration on the prevention and control of Non Communicable Diseases](#)
- B. [European Parliament Resolution on addressing the Diabetes epidemic](#)
- C. [World Health Assembly global target to reduce premature deaths from non-communicable diseases by 25% by 2025](#)
- D. [Moscow Declaration following the First Global Ministerial Conference on Healthy Lifestyles and Non-communicable Disease Control](#)
- E. [Council Conclusions on "Health in all policies and promotion of healthy lifestyles and prevention of type 2 diabetes"](#)
- F. [Council conclusions on "Innovative approaches for chronic diseases in public health and healthcare systems"](#)
- G. [UN Resolution on World Diabetes Day](#)
- H. [World Health Organization Europe Resolution on the Prevention and control of non-communicable diseases in the WHO European Region](#)
- I. [Declaration of the European Parliament on diabetes](#)
- J. [St Vincent Declaration](#)



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