

# Achieving person-centered healthcare: the role of civil society

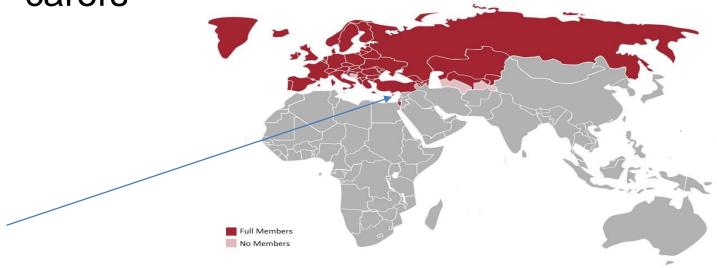
Maria Stella de Sabata, MA Regional Manager, IDF Europe stella.desabata@idf-Europe.org

2<sup>nd</sup> Bridge Health meeting of the EUBIROD Network Nicosia, Cyprus, 20 September 2017



#### **IDF EUROPE**

- 70 national diabetes Member Associations
- in 47 countries across the European region
- Representing people with diabetes AND their carers







### **Priority Work Areas**

- Advocacy –keep diabetes as a priority for decision-makers
- Communication with Member Associations and the wider community
- Partnerships with all concerned stakeholders
- Unifying Access to Care
- Youth

















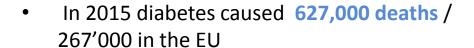
# Why do we need civil society to engage: (and why do we need good epi information) Facts on diabetes in Europe/ 2015

• 60 million people in Europe live with diabetes

(9 % of the population) /32 million in the EU Map 4.2 Prevalence\* (%) estimates of diabetes (20-79 years), 2015

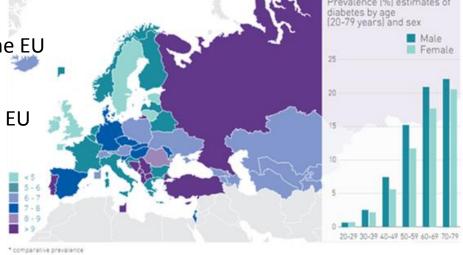
This number is expected to rise to
 71 million in 2040 unless we act now/36 in the EU

 One third of people with diabetes in Europe are undiagnosed /12 million in the EU



- € 145 billion was spent on treating diabetes in Europe in 2015 /€112 billion in the EU
- Europe has the highest prevalence of type 1 diabetes in children in the world









# Diabetes-related expenditure per capita in Europe

1 out of every 3 USD spent globally on diabetes healthcare was spent in Europe

Norway >11,000 USD

Tajikistan <125 USD





## Why do we need civil society to engage: what gets measured gets done

- International commitments
- National commitments
- Accountability
- Monitoring
- Evaluation

- Advocate for/ support registries/ health information
- •





#### **International Commitments on Diabetes**

1989 St. Vincent Declaration

1999 Istanbul Commitment

2006 EP Written Declaration on Diabetes

2006 UN Resolution on Diabetes

2008 CIS Agreement on Diabetes

2011 CoE Resolution and Recommendation on Diabetes

2011 UN Political Declaration on NCDs

2012 EP Resolution on Diabetes

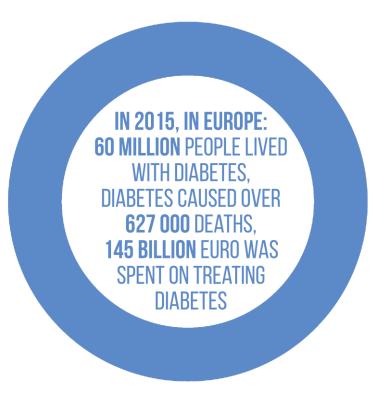
2016 EP Written Declaration on Diabetes





# Delivering on Commitments? what gets measured gets done-or does it?



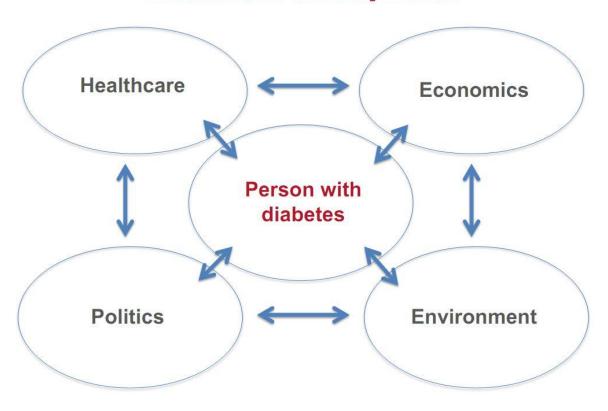






### Bridging the know-do gap

#### **Diabetes ecosystem**



Diabetes is everybody's business!

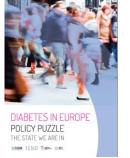




#### «If you fail to plan, you plan to fail»

(and you need good information for planning)

**National Diabetes Plans in Europe** 



29 European countries have a National Plan in place, 10 countries will have such a plan in the future.

EU: 20/28

Diabetes Policy Puzzle, 2014



25 / 47 European countries have a National Framework Plan for Diabetes in place Diabetes Policy Puzzle, 2011



EU: 11 / 25 countries have a National Framework Plan for Diabetes in place Diabetes Policy Puzzle, 2005

### **Evidence-based advocacy**

Position papers-fostering "one voice":
 Added Sugar (2016), Mobile Apps (2017)
 Biosimilars (Q4 2017)



Diabetes



Publications –evidence for policy change:
 Policy Puzzle

Access to Quality Medicines and Medical Devices for Diabetes Care in Europe

Integrating Diabetes Evidence into Practice:
Challenges and Opportunities to Bridge the Gaps (Q4, 2017)

Mobilizing policy-makers: IMPACT diabetes





# Integrating Diabetes Evidence into Practice: Challenges and Opportunities to Bridge the Gaps Prof K.Khunti (UK), Chair

- map gaps and non-adherence patterns in the implementation of evidence in the practice of Diabetes management
- put in place systematic processes for secondary prevention
- identify opportunities and challenges in health systems, at micro and macro levels, to bridge these gaps

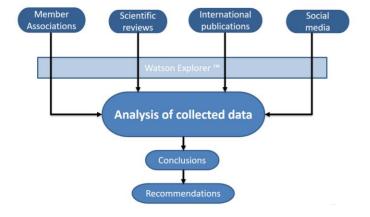
unite for diabetes



### Three main areas of research

- To identify barriers and solutions related to:
  - Health Policy and Health System management
  - Health Care Professionals
  - Persons with diabetes
- Conclusions and recommendations for each area

#### Research Process and Stakeholders







### **Research Questions**

- Is there a public policy and interest in preventing and treating diabetes?
- Are there instruments and resources to support such policies?
- Are the persons with diabetes and their organizations aware of their role, rights and responsibilities in the everyday management of diabetes? HCP
- Are there available and accessible essential resources to guide policy makers, health professionals or persons with diabetes in learning about the existing best practices and recommendations?
- Are there common denominators and what are those?
- To what extent is the implementation dependent on local conditions, where and how can IDF Europe support national organizations to improve implementation of best practices and enhance the quality of life in the member countries?





# What gets measured gets done – preliminary update on NDPs from the «Gap survey»

To date, IDF Members from 36 European countries responded:

- 22 countries have a National Diabetes Programme (NDP) or a national strategy for diabetes (6 in East Europe, 6 in Central Europe and 10 in Western Europe).
  - Of these programmes, 10 include the general population, 19 include persons at risk of developing diabetes, 22 include persons with T1D, 22 include persons with T2D, and 17 include women with gestational diabetes.
- 13 countries monitor the implementation of the National Diabetes Programme or strategies
- 13 countries evaluate the impact of these programmes or strategies
- In the countries with NDPs or strategies there is a perception above average regarding the priority for primary prevention





### **Next steps**

- Disseminate -World Diabetes Day, IDF World Congress....
- Engage with other stakeholders to discuss/ complete information





#### **IMPACT diabetes:**

the Initiative to Mobilize Parliamentarians to Act to Prevent, Care and Treat diabetes

Consolidating a pan-European network of parliamentarians to hold governments to account

- Create ad hoc advocacy and policy documents to support the efforts of our Members and Parliamentarians at the national level
- Establish an inclusive, multi-stakeholder online platform
  coordinated by IDF Europe where our Members, current or former MPs,
  MEPs as well as policy advisors dedicated to the diabetes cause can
  share expertise, experiences, best practice and tools in a spirit of shared
  learning
- Conduct advocacy and policy capacity-building workshops during which IDF Members in the European region can learn first-hand from and exchange with MPs, MEPs, political and other skilled advisors how best to mobilize and interact with policy-makers; an opportunity for policymakers to receive first-hand information from PWD and HCP

unite for diabetes





#### IMPACT diabetes: the Initiative to Mobilize Parliamentarians to Act to Prevent, Care and Treat diabetes

I PLEDGE TO LEND MY SUPPORT TO PROMOTING DIABETES PREVENTION, SCREENING, TREATMENT AND CARE BY COMMITTING TO THE FOLLOWING ASKS:

- O STRIVE TO CONVENE PUBLIC DISCUSSIONS BRINGING TOGETHER PATIENTS, CAREGIVERS, CONSUMER GROUPS, PROVIDERS AND PAYERS WITH THE AIM OF IMPROVING THE LIVES OF PEOPLE WITH DIABETES AND THOSE AT RISK BY ENGAGING IN INCLUSIVE MULTISTAKEHOLDER DIALOGUES
- SUPPORT NATIONAL DIABETES ASSOCIATIONS AND NATIONAL EFFORTS TO DEVELOP / IMPLEMENT / MONITOR / EVALUATE NATIONAL DIABETES PLANS AND STRATEGIES
- O SUPPORT NATIONAL INITIATIVES AIMING TO GUARENTEE EQUITABLE ACCESS TO PREVENTION AND QUALITY HEALTHCARE FOR ALL PEOPLE WITH DIABETES
- AIM TO ACHIEVE HEALTH LITERACY FOR ALL
- COMBAT HEALTH INEQUALITIES FOR PEOPLE WITH DIABETES IN ACCESS TO HEALTH SYSTEMS AND DISCIRMINATION IN OTHER AREAS OF LIFE INCLUDING EDUCATION, EMPLOYMENT AND SERVICES
- PROMOTE THE EXCHANGE OF BEST PRACTICE ON DIABETES PREVENTION AND SCREENING
- SUPPORT CONTINUOUS EDUCATION FOR PEOPLE WITH DIABETES AND THEIR CAREGIVERS ON ALL ASPECTS OF DIABETES MANAGEMENT
- LEND SUPPORT TO THE EUROPEAN DIABETES COMMUNITY AND THOSE AT RISK BY ENCOURAGING MEMBERS OF THE EUROPEAN PARLIAMENT TO JOIN THE EU DIABETES WORKING GROUP AND ACTIVELY SUPPORT ITS WORK



### World Diabetes Day – 14 November

#### European level

26 September, Committee of the RegionsOctober (tbc) Council of Europe14 November, European Parliament15 November, European Commission





#### National/local level

70 very active national diabetes associations and more – YOU?





IN 2015, IN EUROPE:
60 MILLION PEOPLE LIVED
WITH DIABETES,
DIABETES CAUSED OVER
627 000 DEATHS,
145 BILLION EURO WAS
SPENT ON TREATING
DIABETES

Together
advocating for diabetes
across Europe
improving access to care and
creating dynamic new
partnerships between people
with diabetes, healthcare
providers and other
stakeholders

IDF EUROPE IS THE VOICE
FOR THE GROWING
NUMBER OF PEOPLE
LIVING WITH DIABETES
IN EUROPE, THEIR CARERS
AND THOSE AT RISK





# IDF Europe Prizes in Diabetes: Young Researcher Long-Standing Achievement

