

# OPEN

Obesity Policy Engagement Network

## **‘Disease recognition: does it make a difference?’ – Learnings from Europe**

**PRESENTATION AT OBESITY WEEK**

**6 NOVEMBER 2020**

*The Obesity Policy Engagement Network (OPEN) is a partnership programme initiated and supported by Novo Nordisk to improve obesity care internationally. This meeting has been organised and funded by Novo Nordisk.*

# Welcome

## Facilitators



**Joe Nadglowski**  
.....

*President/CEO, Obesity  
Action Coalition (OAC)*



**Johanna Ralston**  
.....

*CEO, World Obesity  
Federation (WOF)*

## Speakers



**Dr Frank Nobels**  
.....

*Endocrinologist and  
President of the Belgian  
Diabetes Forum*



**Bart Torbeyns**  
.....

*Executive Director of the  
European Diabetes Forum  
(EUDF)*



**Dr Luca Busetto**  
.....

*President Elect of Italian  
Obesity Society, SIO and  
Co-Chair, Obesity  
Management Task Force,  
EASO*



**Dr Chiara Spinato**  
.....

*Executive Secretary,  
OPEN Italy*



**Melanie Bahlke**  
.....

*Patient Advocate and 1st  
Chairperson of the Obesity  
Surgery Self-Help Germany  
(AcSD e.V.)*



**Andreas Herdt**  
.....

*Chairperson Obesity  
Surgery Self-Help  
Germany (AcSD e.V.),  
DAA*



Today's meeting is scheduled to last **1.5 hours**



Please use the **hashtag** #OPENObesity and #OW2020 to tweet about this meeting



We have a **dedicated Q&A** section in the agenda for you to pose written questions to the speakers – please use the dedicated Q&A function in Zoom



This meeting is being **recorded live** through Zoom



# Today's agenda

<b>01:30-01:35</b> <b>5 mins</b>	<b>Welcome and Introduction</b>	<ul style="list-style-type: none"> <li>• <i>Joe Nadglowski, President/CEO, Obesity Action Coalition (OAC)</i></li> <li>• <i>Johanna Ralston, CEO, World Obesity Federation (WOF)</i></li> </ul>
<b>01:35-01:50</b> <b>15 mins</b>	<b>Disease recognition as an entry ticket: learnings from (Belgian) diabetes care</b>	<ul style="list-style-type: none"> <li>• <i>Prof. Dr. Frank Nobels, Dept. Endocrinology-Diabetology, OLV Hospital Aalst, Belgium, President, Belgian Diabetes Forum</i></li> </ul>
<b>01:50-02:10</b> <b>20 mins</b>	<b>OPEN Italy: Achieving Italian Parliament recognition of obesity as a chronic disease, and what's next? and interactive Q&amp;A</b>	<ul style="list-style-type: none"> <li>• <i>Dr. Chiara Spinato, Executive Secretary, OPEN Italy</i></li> <li>• <i>Prof. Dr. Luca Busetto, President Elect of Italian Obesity Society, SIO and Co-Chair, Obesity Management Task Force, EASO</i></li> </ul>
<b>02:10 - 02:30</b> <b>20 mins</b>	<b>DAA Germany: Impact and ramifications of disease recognition in German Bundestag and interactive Q&amp;A</b>	<ul style="list-style-type: none"> <li>• <i>Andreas Herdt, chairperson Obesity Surgery Self-Help Germany (AcSD e.V.), DAA</i></li> <li>• <i>Melanie Bahlke, chairperson Obesity Surgery Self-Help Germany (AcSD e.V.), DAA</i></li> </ul>
<b>02:30 – 02:50</b> <b>20 mins</b>	<b>Panel discussion and debate and interactive Q&amp;A</b>	<ul style="list-style-type: none"> <li>• <i>All</i></li> </ul>
<b>02:50 – 03:00</b> <b>10 mins</b>	<b>Closing remarks and wrap-up</b>	<ul style="list-style-type: none"> <li>• <i>Joe Nadglowski, President/CEO, Obesity Action Coalition (OAC)</i></li> <li>• <i>Johanna Ralston, CEO, World Obesity Federation</i></li> </ul>

# OPEN

Obesity Policy Engagement Network

## **Disease recognition as an entry ticket: learnings from (Belgian) diabetes care**

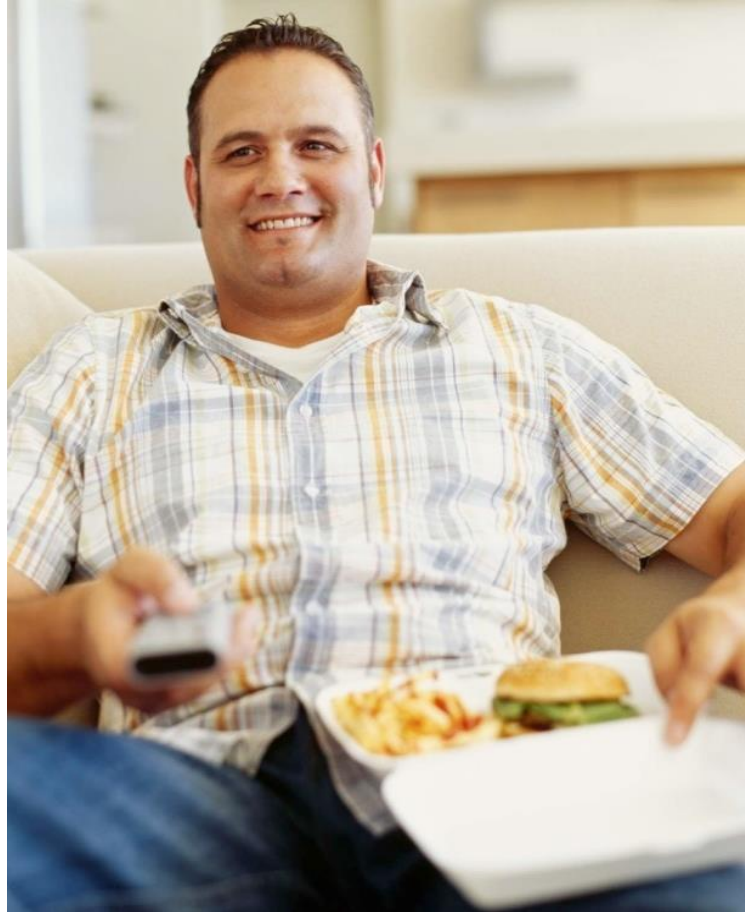
**PROF. DR. FRANK NOBELS**

**DEPT. ENDOCRINOLOGY-DIABETOLOGY, OLV HOSPITAL AALST, BELGIUM**

**PRESIDENT, BELGIAN DIABETES FORUM**


**Disease recognition helps**

**We didn't have to convince anyone that diabetes is a disease**





# DM type 1

  
≥3 inj or pump

## diabetes convention (1987)

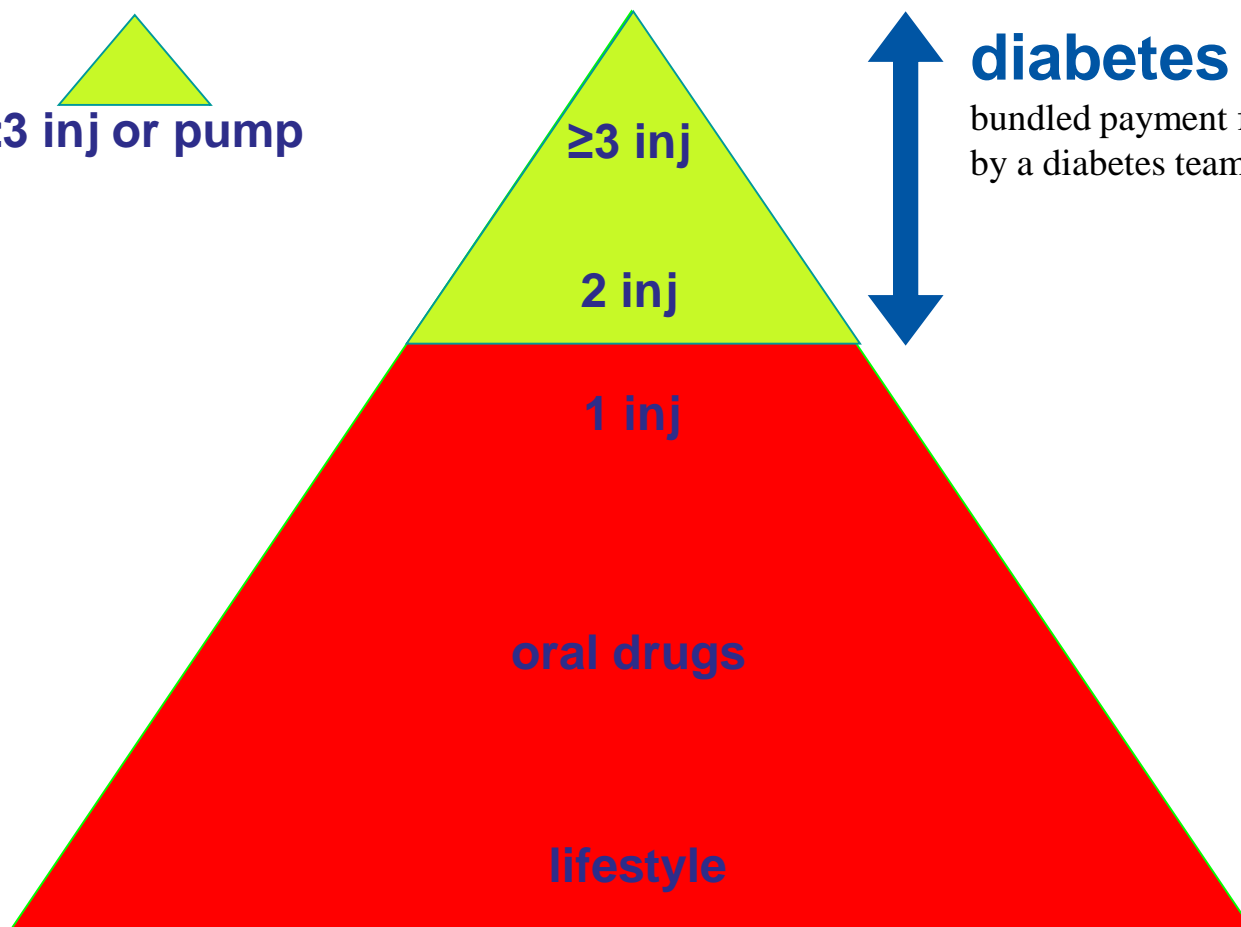
bundled payment for multidisciplinary care  
by a diabetes team (medical care, education, material)





# DM type 1 type 2

  
≥3 inj or pump



≥3 inj

2 inj

1 inj

oral drugs

lifestyle

**diabetes convention (1987)**

bundled payment for multidisciplinary care  
by a diabetes team (medical care, education, material)

**Use the power of  
advocacy initiatives**

# Diabetes Advocacy Timeline

FEND  
2020

1989	2004	2006	2007	2010	2011	2012	2013	2014	2016
St Vincent declaration	Diabetes: Europe rising to the research challenge (EP 12/11/04)	EP Written declaration on diabetes  E Council conclusions on healthy lifestyle and prevention of Type 2	UN World Diabetes Day Resolution 61/225	E Council conclusions Innovative approaches for chronic disease in public health and HC systems	UN political declaration of High-Level Mtg of GA on Prevention and Control of NCDs  EP resolution on EU position in advance of UN high level mtg on prevention and control of NCDs  E Council conclusions Closing health gaps in EU through action to promote healthy lifestyle	EP resolution on Addressing the EU Diabetes Epidemic	WHO global action plan Prevention and control of NCDs 2013–2020  UN follow-up to Political Declaration of High-Level Mtg of GA on Prevention and Control of NCDs  E Commission Joint Action (CHRODIS) Chronic diseases and promoting healthy ageing across life cycle (diabetes case study)		EP written declaration on diabetes  Berlin Declaration Driving early action in type 2 diabetes
	EURADIA informally established to ensure DIABETES included in FP6		FP7-DIAMAP Roadmap for diabetes research			FP7-Cardioscape 1 - CVD Research Funding  FP7-ROAMER Roadmap of mental health	FP7-InterConnect - global data for diabetes and obesity research		FP7-Mapping NCDs (major section on diabetes)
	Policy Puzzle 1st Edition	Vienna Presidency event. Major event on Type 2 Diabetes	EURADIA formally established	Policy Puzzle Delivering Diabetes in Europe 2 <sup>nd</sup> edn  Guide to national diabetes policies (IDF)	Policy Puzzle: is Europe making progress? 3 <sup>rd</sup> edn	Copenhagen Roadmap Diabetes epidemic and impact on Europe (European Diabetes Leadership Forum and OECD)	IDF Diabetes Atlas, 6th edn, 2012 update  Access to quality meds and med devices for diabetes care in Europe (IDF Europe)	Policy Puzzle Diabetes in Europe the State we are in 4th edn	

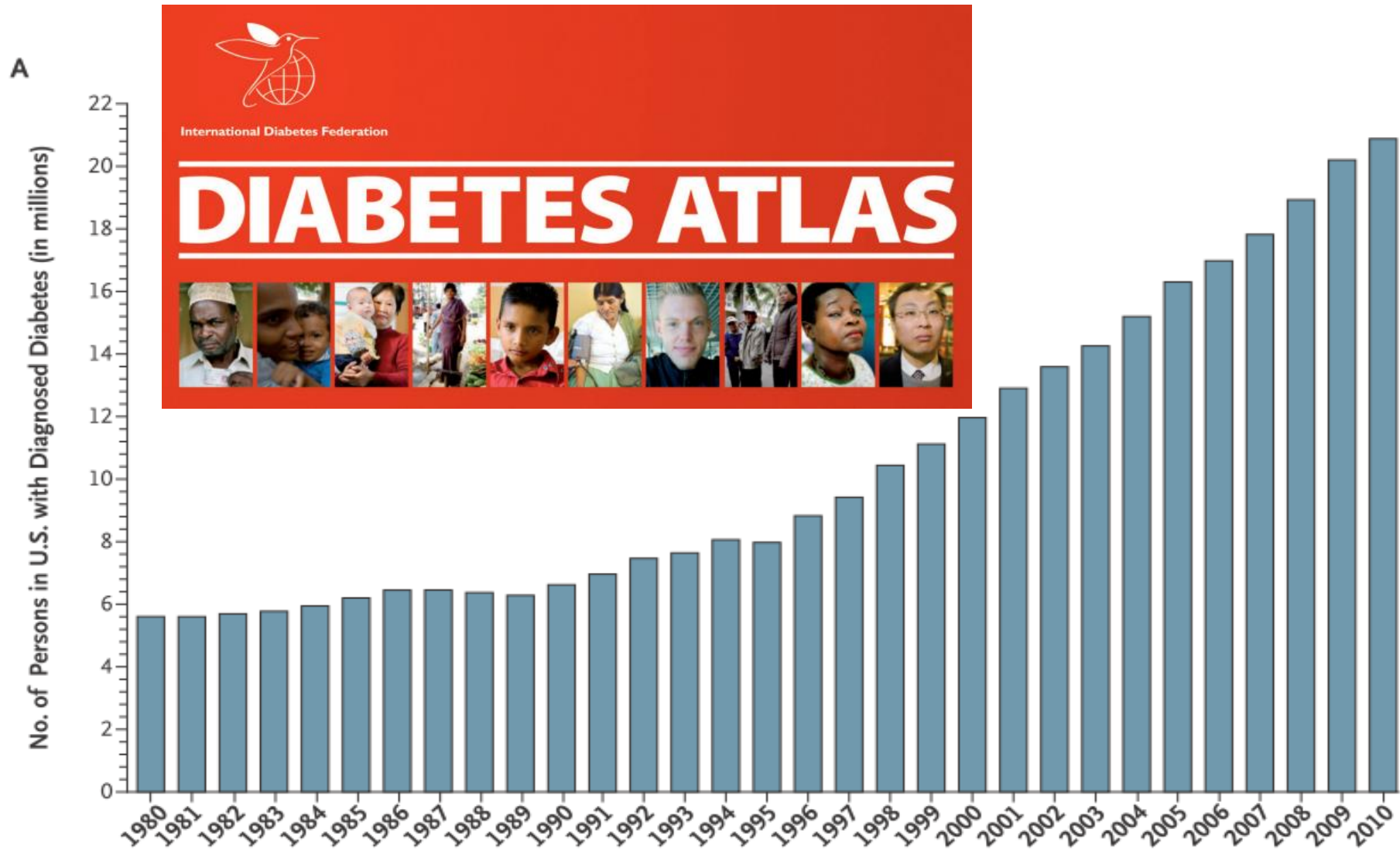
European  
Declarations  
Resolutions  
Events

Addressing  
Research

Addressing  
Policy



# diabetes 'epidemy'

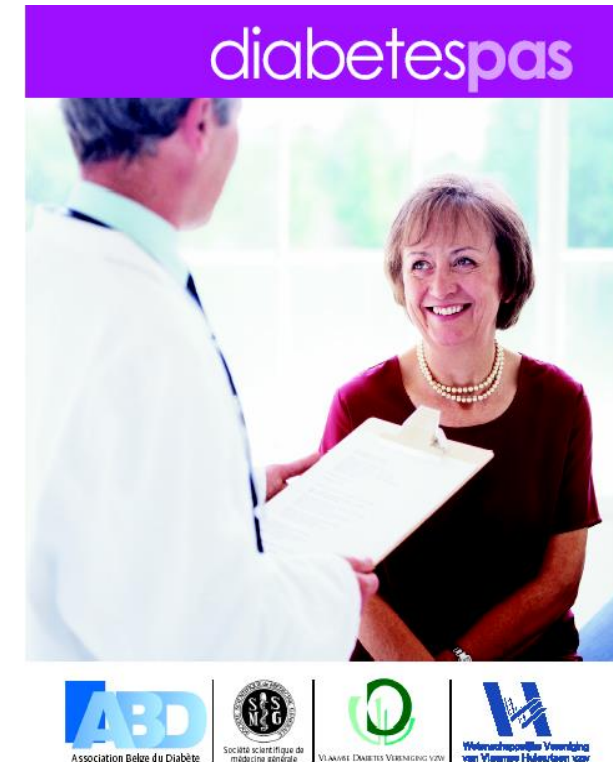


[http://cdc.gov/diabetes/statistics/prevalence\\_national.html](http://cdc.gov/diabetes/statistics/prevalence_national.html)



# St Vincent declaration 1989

- optimization of the diabetes convention
- introduction of diabetes passport
- reimbursement of dietician
- reimbursement of podiatrist
- recognition of multidisciplinary diabetes foot clinics

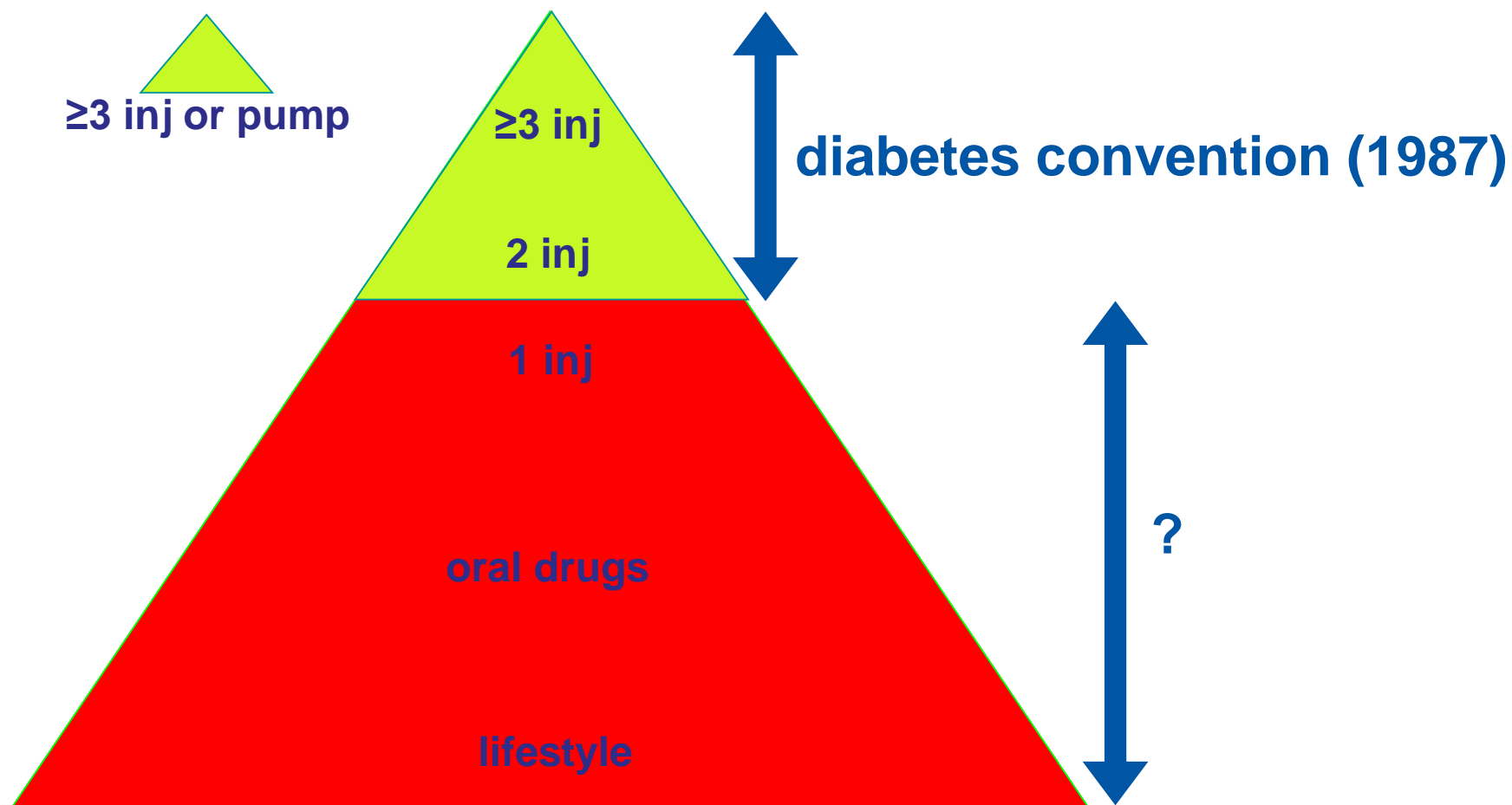


*St. Vincent declaration. Diabet Med 1990;7:360*

**Engagement and concrete  
proposals from the field help**



# DM type 1    type 2

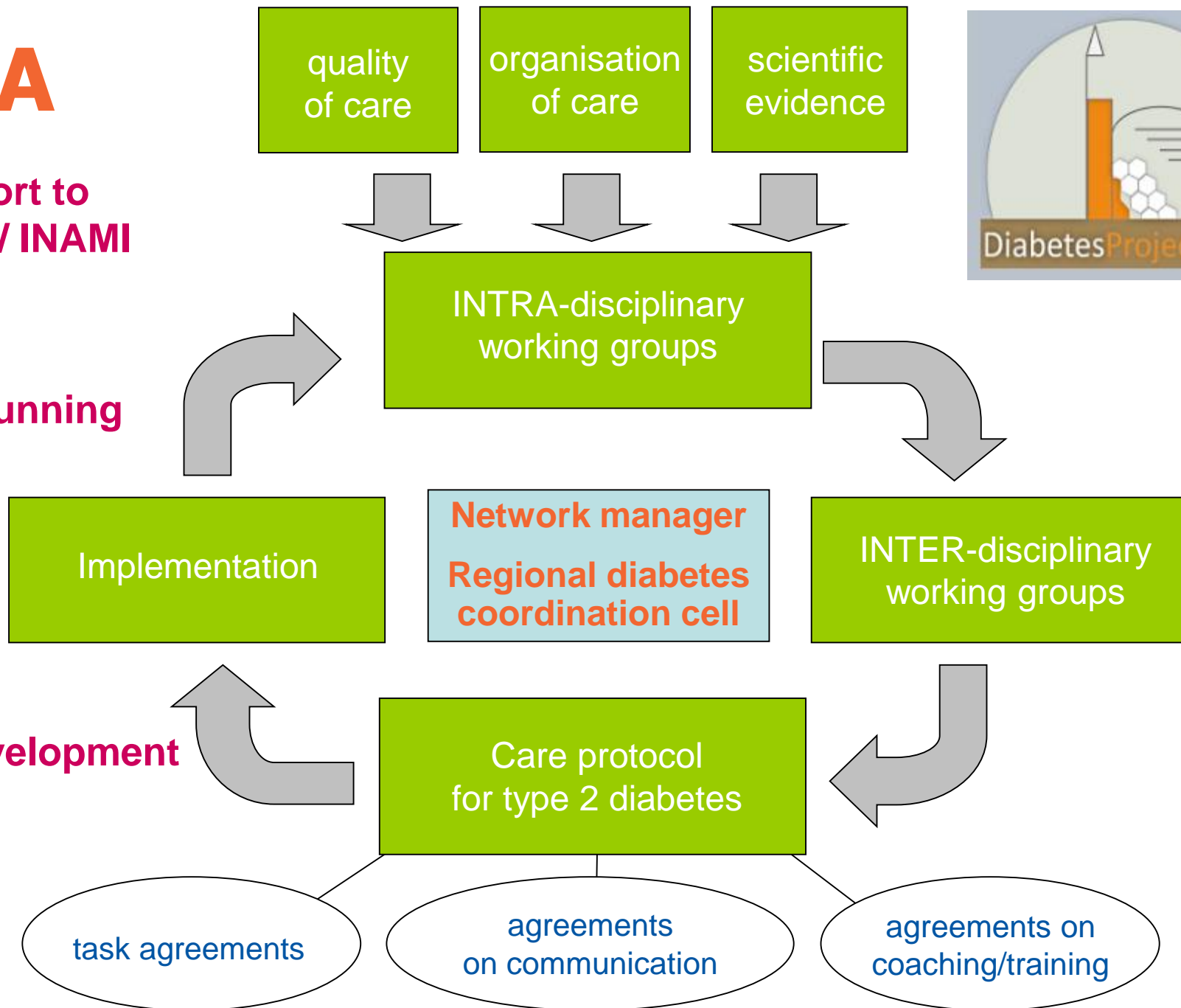


# DPA

report to  
RIZIV / INAMI

±1y running

±1y development



# Diabetes care trajectories

**GP care, supported by specialist**



**↑ collaboration**  
**↑ mutual appreciation**

**facilitates individualized care  
in an era of increasing  
treatment complexity**

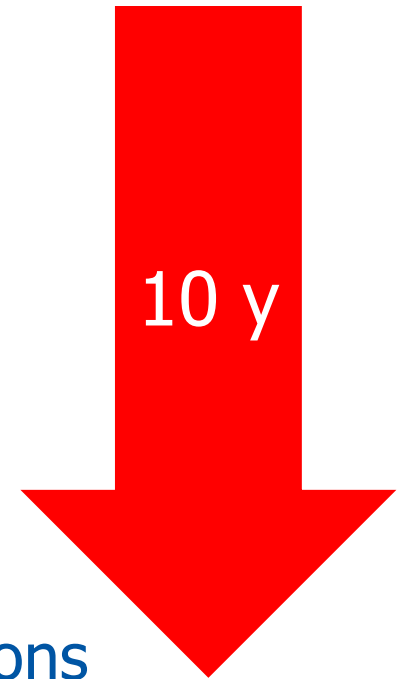




# Persevere !



- 1998: meeting with Dr. G. Vereecke (RIZIV/INAMI)
- 2001: Royal Decree 'care innovating projects'
- 2003-2007: Diabetes Project Aalst-Leuven
- 2009: diabetes care trajectory only for pt on injections





unite for diabetes

UN Resolution on Diabetes WDF05-155



RISICO OP  
TYPE 2 DIABETES?

halt<sup>2</sup>  
diabetes  
Diabetes Liga



ZOET ZWANGER?  
WACHT NIET LANGER,  
PRAAT EROVER MET JE ARTS.

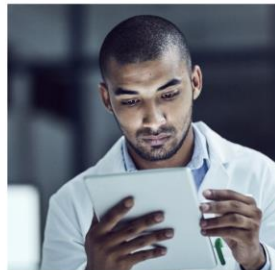
WAT NA ... ZWANGERSCHAPSDIABETES

[WWW.ZOETZWANGER.BE](http://WWW.ZOETZWANGER.BE)

**Z**zoetzwanger  
Diabetes Liga

## IMPROVING OUTCOMES FOR PEOPLE WITH DIABETES

The role of health data,  
access to innovation and  
rethinking care



### RETHINKING HEALTH SYSTEMS: SHARING EXPERIENCES GATHERED FROM THE EFPIA AND PRIMARY CARE DIABETES EUROPE (PCDE) DIABETES ROUNDTABLE, BELGIUM, SEPTEMBER 2019

#### 🇩🇰 CENTRE FOR DIABETES, COPENHAGEN, DENMARK

The centre is a central element in the Copenhagen municipality's diabetes action plan. The centre aims to bring together various components of diabetes management into one place to make it easier for people with type 2 diabetes to navigate the healthcare system. An essential element is the focus on a continuous collaboration between patients, hospitals, primary care practitioners and civil society. This is based on strong communication, leadership and data-driven decision making to target care effectively. A collaboration amongst healthcare professionals, municipalities and hospitals – the so-called healthcare triangle – is essential to improve cross-sector communication and understanding of the needs and hurdles faced by the different stakeholders involved in the continuum of care.

#### 🇧🇪 DIABETES PROJECT AALST, BELGIUM

This project provides chronic disease management in a primary care setting. It focuses on establishing an integrated care team, including diabetes educators, that helps patients self-manage their condition. Coaching is also provided by secondary care specialists. Care is organised around a Regional Diabetes Coordination Cell which coordinates interdisciplinary working. 69% of primary care physicians within the Aalst region signed up to participate. The project has led to a significant improvement in patient outcomes within a short period. The rapid success of the project led to adoption and promotion of this approach by the national authorities across Belgium.

#### 🇵🇹 ASSOCIATION FOR PEOPLE LIVING WITH DIABETES (APDP), LISBON, PORTUGAL

APDP has evolved into a nationwide institution which provides healthcare and a wide range of other services to people with diabetes. Stemming from the fact that education is a vital part of the care provided, APDP organises training courses for healthcare professionals, for people with diabetes, their families and caregivers in order to promote better disease management and thus increased quality of life for people with diabetes. APDP has developed a number of projects focused on the community, providing screenings and educational programmes to encourage behavioural lifestyle changes in those at risk of developing type 2 diabetes.





**Never take your achievements  
for granted**

**Every time we had to adjust the diabetes convention it was questioned again.**



# measure the quality: convince that the money is well spent

DIABETIC Medicine

DOI: 10.1111/j.1464-5491.2007.02378.x

**Original Article: Clinical Care and Delivery**

**Organization of a quality-assurance project in all Belgian multidisciplinary diabetes centres treating insulin-treated diabetes patients: 5 years' experience**

N. Debacker, F. Nobels\*, H. Vandenberghe<sup>1</sup>, P. Van Crombrugge\*, A. Scheent† and V. Van Casteren

PRIMARY CARE DIABETES 9 (2015) 354–361

Contents lists available at ScienceDirect

**Primary Care Diabetes**

journal homepage: <http://www.elsevier.com/locate/pcd>

ELSEVIER

PCDE  
primary care diabetes Europe

primary care diabetes

**Original research**

**Care trajectories are associated with quality improvement in the treatment of patients with uncontrolled type 2 diabetes: A registry based cohort study**

Geert Goderis<sup>a,\*</sup>, Viviane Van Casteren<sup>c</sup>, Etienne Declercq<sup>d</sup>, Nathalie Bossuyt<sup>c</sup>, Carine Van Den Broeke<sup>a</sup>, Katrien Vanthomme<sup>c</sup>, Sarah Moreels<sup>c</sup>, Frank Nobels<sup>e</sup>, Chantal Mathieu<sup>f</sup>, Frank Buntinx<sup>a,b</sup>

CrossMark

**Try to string  
everything together!**



# A Guide to National Diabetes Programmes

## WHAT IS A NATIONAL DIABETES PROGRAMME

## WHO SHOULD BE INVOLVED?

## PURPOSE AND SCOPE OF THE GUIDE

### SECTION 1 - GETTING STARTED

Making the Advocacy Case for Diabetes

Developing a Framework for a National Diabetes Programme

Establishing a National Diabetes Organisation

### SECTION 2 - DETERMINING THE EXTENT OF THE PROBLEM

Conducting a Situation and Needs Analysis

Conducting a Baseline Prevalence Survey

Assessing the Cost of Diabetes

Assessing Community Awareness

### SECTION 3 - PREVENTING THE PROBLEM

Primary Prevention: The Individual / High Risk Approach

Primary Prevention: Environmental Approaches

### SECTION 4 - ADDRESSING THE PROBLEM

Developing a Community Awareness Campaign

Early Diagnosis of Type 2 Diabetes

Routine Care and Monitoring of Diabetes

Providing Patient Education

Psychological Issues in Diabetes

Developing and Implementing Guidelines

Developing the Diabetes Workforce and Services

### SECTION 5 - EVALUATING PROGRESS

Collecting Diabetes Data

Evaluating National Diabetes Programmes

### SECTION 6 - WHERE TO NEXT?

National Diabetes Programmes of the future

Standards for National Diabetes Programmes

### SECTION 7 - WHO CAN HELP?

IDF Global Infrastructure

IDF Regional Infrastructure

IDF Task Force on Diabetes and NCD Prevention, Policy and Practice

### SECTION 8 - ADDITIONAL INFORMATION

List of Suggested Readings

Useful Definitions



**Euro Diabetes Index**

**2014**



European  
Diabetes Forum



BELGIAN  
DIABETES  
FORUM

**The Belgian Diabetes Forum  
brings together multiple  
stakeholders from across the  
diabetes landscape in Belgium.**

## Mission

It is the Forum's mission to identify what is going well, what is missing and what can improve in diabetes prevention and care in Belgium, and based thereon, to provide guidance for policy makers for filling the gaps, and for aligning existing initiatives regarding prevention, care and well-being in a cost-effective way.

**<http://belgiandiabetesforum.be/>**

# Yes, disease recognition helps, ...

- use the power of advocacy initiatives
- engage, come with concrete proposals
- be patient, persevere
- never take your achievements for granted
- measure quality, prove the money is well spent
- try to string different initiatives together in a national plan



福  
Good Luck



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## Q&A



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## **OPEN Italy: Achieving Italian Parliament recognition of obesity as a chronic disease, and what's next?**

**DR. CHIARA SPINATO, EXECUTIVE SECRETARY, OPEN ITALY /  
PROF. DR. LUCA BUSETTO, PRESIDENT ELECT OF ITALIAN OBESITY SOCIETY, SIO  
AND CO-CHAIR, OBESITY MANAGEMENT TASK FORCE, EASO**

# Disease recognition: does it make a difference?

## *The Italian perspective*

Chiara Spinato



Luca Busetto



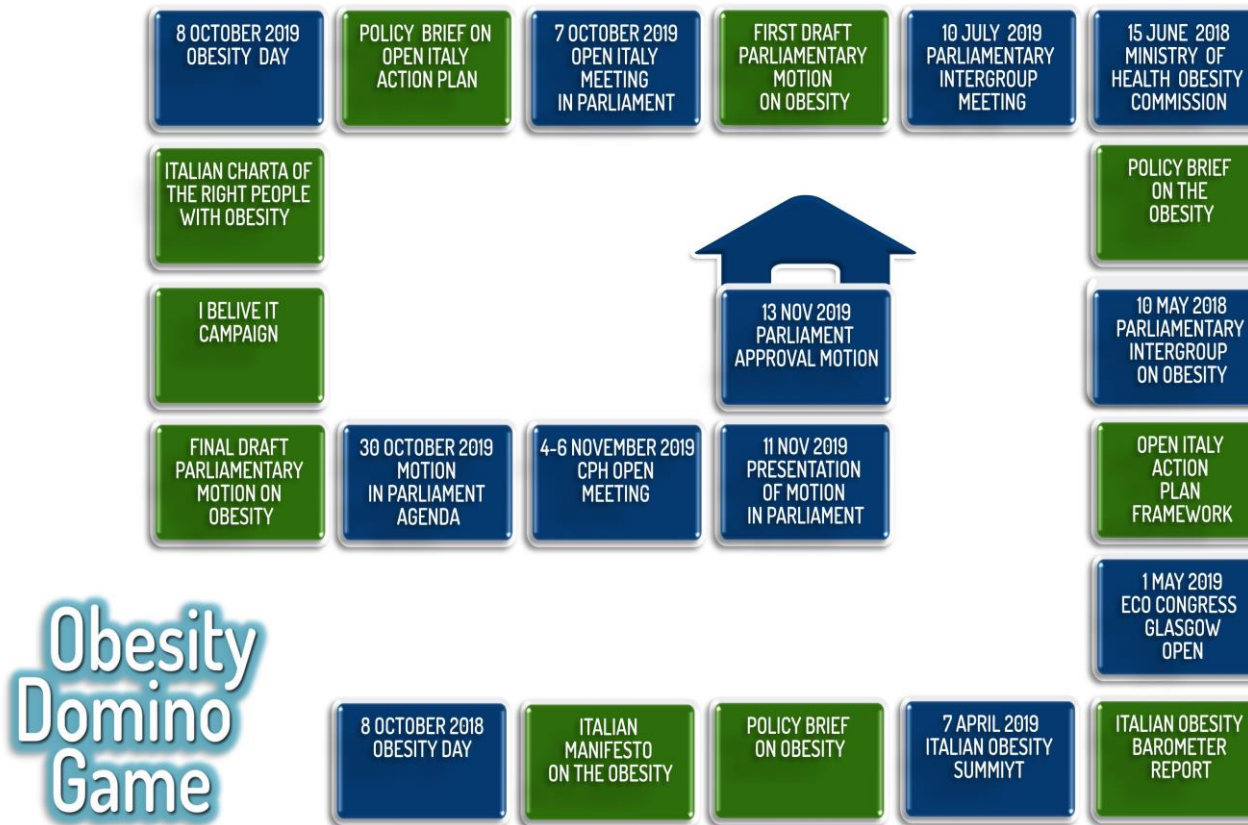


# Disease recognition: does it make a difference?

## *The Italian perspective*

6<sup>th</sup> November - OBESITY WEEK 2020

...where we were last time...



Disease recognition: does it make a difference?

*The Italian perspective*

6<sup>th</sup> November - OBESITY WEEK 2020

## THE CHARTER OF RIGHTS AND DUTIES OF THE PERSON WITH OBESITY

### RIGHTS OF THE PERSON WITH OBESITY

**The rights of people with obesity are the same human and social rights as people without obesity.** The rights include equal access to information, therapeutic education, the treatment of obesity and the diagnosis and treatment of complications.

The health system must guarantee the person with obesity the use of appropriate diagnostic, care and therapeutic methods, **homogenously throughout the national territory.**

The right of people with obesity to live a social, educational, working life on an equal footing with people without obesity must be considered **the primary objective of government actions at national and regional level, considering obesity a disease.**



# Disease recognition: does it make a difference?

## *The Italian perspective*

6<sup>th</sup> November - OBESITY WEEK 2020

Approval of the parliamentary motion act (13<sup>th</sup> Nov 2019) is a fact:  
**OBESITY IS UNANIMOUSLY RECOGNISED AS A CHRONIC DISEASE**



# Disease recognition: does it make a difference?

## *The Italian perspective*

6<sup>th</sup> November - OBESITY WEEK 2020

### WHAT DIFFERENCE DID IT MAKE?

- High increase in the general awareness of national policy makers
- Full involvement of the local institutional dimension (= Mayors)
- Higher commitment of media towards the disease narrative
- Strengthening of OPEN ITALY network
- Improvement in communicating social stigma: insertion in bullism law

# Disease recognition: does it make a difference?

## *The Italian perspective*

6<sup>th</sup> November - OBESITY WEEK 2020

...our domino game continues...

Open Letter on impact of COVID-19

ECOICOonline2020

2<sup>nd</sup> Italian Obesity Summit  
1<sup>st</sup> Obesity Patient Summit  
1<sup>st</sup> OPEN ITALY Conference  
***Obesity Monitor Barometer***

Analysis on diabetes, obesity and mortality (*Nicolucci et al.*)

Policy Brief on clinical stigma (*Busetto et al.*)

# Disease recognition: does it make a difference?

## *The Italian perspective*

6<sup>th</sup> November - OBESITY WEEK 2020

### WHAT'S NEXT?

**19<sup>th</sup> November 2020**  
Meeting with the  
Vice ministry of Health

The diagram features a horizontal timeline arrow pointing to the right. A vertical line descends from a point on this arrow to a box containing the date and meeting information. A horizontal line then extends from the right side of this box to another box containing a recommendation.

Obesity should be inserted in “LEA”, i.e. the essential levels of assistance, through the examination of the request by the devoted LEA Commission, to promoting appropriateness of our National (*public*) Health System and to guaranteeing homogenous access to cares and equal treatments in the national territory.

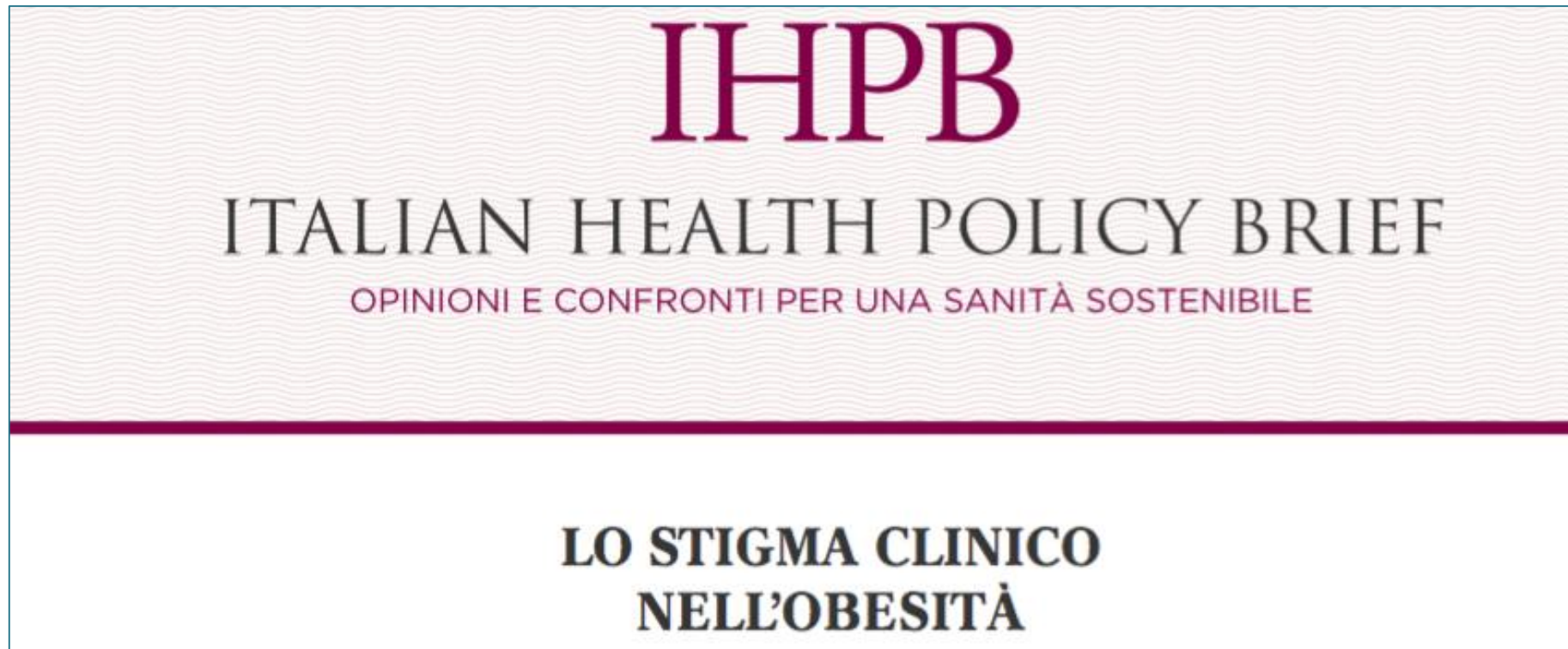
Disease recognition: does it make a difference?

*The Italian perspective*

6<sup>th</sup> November - OBESITY WEEK 2020

## ITALIAN HEALTH POLICY BRIEF: THE CLINICAL STIGMA TOWARDS PWO

*by Luca Busetto et al.*





## PREMISES

Stigma against PwO has been frequently reported even among HCPs.

Evidence suggests that physicians spend less time in appointments and provide less education about health to patients with obesity compared with thinner patients.

Patients who report having experienced weight bias in the healthcare setting have poor treatment outcomes and might be more likely to avoid future care.

**Rubino F et al. Nature Medicine 2020;26:485**

## DEFINITION OF CLINICAL STIGMA

Many public and private health insurers (including the Italian National Health Service) do not provide coverage or have substantive limitations in the delivery and coverage of effective anti-obesity interventions, including structured life-style modification programs, anti-obesity drugs and bariatric/metabolic surgery.

These attitudes are in stark contrast with coverage of treatment for other chronic diseases (for example, cancer, heart disease, and osteoarthritis) that are not conditional to similar restrictions, and for which use of similarly arbitrary coverage criteria would be socially indefensible and ethically objectionable.

**Rubino F et al. Nature Medicine 2020;26:485**

## CAUSES OF CLINICAL STIGMA

Widespread and unproved persistent narrative that body weight is entirely controllable by lifestyle choices and that self-directed efforts can reverse even severe forms of obesity. Overweight and obesity as the consequences of «wrong» individual behaviours, lack of willpower, gluttony, and so on.

In contrast, obesity needs to be described as a complex chronic disease resulting from the interaction between multiple genetic, epigenetic and environmental causes, and sustained by alteration in the neuro-endocrine mechanisms regulating energy balance and body weight.

**Busetto L et al. IHPB 2020**

## *HOW THIS CAN BE CHANGED (IN ITALY)?*

1. Official recognition of obesity as a chronic disease.
2. Insertion of obesity care in the essential levels of assistance, in order to mandate the local articulations of the Italian NHS to promote, organise and guarantee homogeneous access to obesity care in the national territory.
3. Improve knowledge of the biological basis of obesity as chronic disease in HCPs.
4. Promote at the local (regional) levels the implementation of obesity care services.

**Busetto L et al. IHPB 2020**

# Disease recognition: does it make a difference?

## *The Italian perspective*

6<sup>th</sup> November - OBESITY WEEK 2020

### key message 1

being an active comprehensive alliance is winning point

→ *OPEN ITALY becomes a formal Association*

### key message 2

we need to fight against social and clinical stigma to change obesity

→ *OPEN ITALY advocates for insertion of obesity in LEA*





## Q&A



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## **DAA Germany: Impact and ramifications of disease recognition in German Bundestag**

**ANDREAS HERDT, CHAIRPERSON OBESITY SURGERY SELF-HELP GERMANY (ACSD E.V.), DAA**

**MELANIE BAHLKE, CHAIRPERSON OBESITY SURGERY SELF-HELP GERMANY (ACSD E.V.), DAA [TBC]**

# Obesity is a Disease! Isn't it?

## Obesity Week 2020

**Andreas Herdt**

Vice Chair of AcSD e.V.

Chair of Adipositas Hessen e.V.

Founding member of DAA



# Breakthrough



July 3rd 2020

The German Parliament recognised obesity as a disease



# Looking back



OPEN met at Obesity Week 2018

German delegation

Patient org: **Melanie** and myself

Member of Parliament: **Alexander Krauß**

MD: Christine Stier

Health insurance

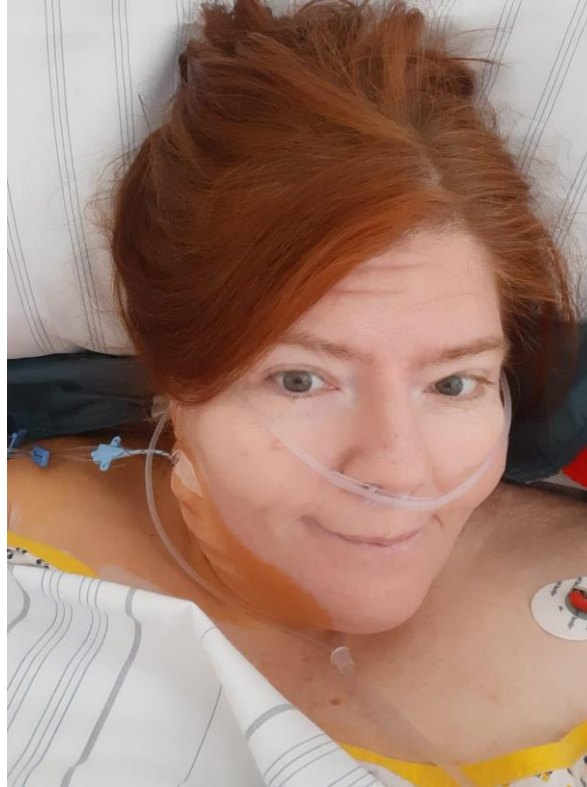
Industry





# Melanie

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Melanie does what patients do  
She is in hospital

# Work

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The breaks included lots of team meetings to regroup and discuss OPEN

# Fun

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We spent a lot of time together and chatted about our first hand experience of obesity



To be continued in Berlin, Germany  
Deutsche Adipositas Allianz - DAA

# Deutsche Adipositas Allianz (DAA)

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The partnerships are growing ...





# Patient Alignment

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We are starting to align patient group organisations to ensure they are united across the board

# Looking forward

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July 3rd 2020  
Remember that guy?

# Fun facts

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1. It is not the job of the German Parliament to recognize diseases
2. It just isn't
3. Alexander Krauß did not care
4. The motion was about starting a National Diabetes Plan
5. Obesity was put in there like Greek soldiers in a Trojan horse
6. Our Odysseus was Alexander
7. The ruling parties voted in favour of the motion
8. No other party voted against

# Hard facts

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1. Obesity is mentioned as a risk factor for diabetes (that's how it got in there)
2. Obesity is called a disease
3. Obesity has been mentioned several times at the same level as diabetes
4. Acknowledgment: People living with obesity are being stigmatised and discriminated
5. Prevention and (treatment) research shall be promoted
6. Medical university curricula as well as continuous medical education shall be adapted
7. Interdisciplinary, multimodal therapies for obesity shall be made available and paid by insurance

*Government can  
do this on its own*

*Government needs  
to work with  
medical society*

*Government needs to  
work with  
joint federal committee*

# Mission completed?

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It's a marathon, not a sprint

Walk the talk

The devil is in the details

## Next steps

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Never stop

Closely monitor progress

Be a counterpart on working out details



# Alexander Krauß

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# Deutsche Adipositas Allianz (DAA)

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Thank you...



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Obesity Policy Engagement Network

## Q&A

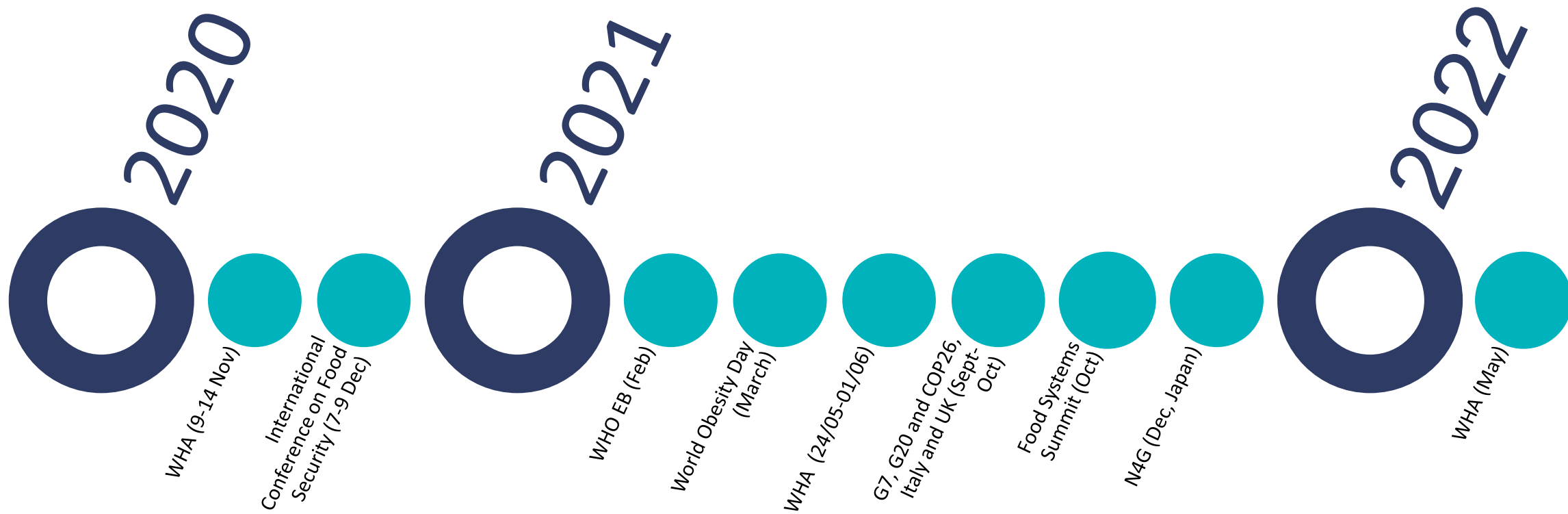


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## PANEL DISCUSSION AND DEBATE

# The Next Eighteen Months







Obesity Policy Engagement Network

## **CLOSING REMARKS AND WRAP-UP**





**THANK YOU**