16th European Health Forum GASTEIN

Resilient and Innovative Health Systems for Europe

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European Health Forum Workshop 2: Patient-Centred Care

Wednesday 2nd October 2013, 09:00-12:00

Exploring barriers and solutions to putting people at the heart of chronic disease management in Europe, taking inspiration from diabetes as a model disease

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W2: Patient-Centred Care

Introduction and welcome

- Nick Fahy (Independent Consultant and Researcher)

Session 1: Barriers to Chronic Disease Management

- Presentation from Professor Angus Forbes, King's College London
- Panel discussion

10:30 – 10:45 Coffee break

Session 2: Overcoming the Barriers: Solutions to Patient-Centred Care

- Presentation from Professor Angus Forbes, King's College London
- Panel discussion

Workshop conclusions

- Nick Fahy

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DIABETES ATTITUDES WISHES & NEEDS

Session 1
Barriers to Chronic Disease Management

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The history of DAWN™

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- **5426** Adults with diabetes
- **3982** Healthcare professionals
- **13** Countries

Platform for stakeholder dialogue and engagement

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DAWN2™ Partnership

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International Diabetes Federation

steno diabetes center

FEND

International Alliance of Patients' Organizations
A global voice for patients

EASD

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DAWN2™: Why was a new study required?

371 million People with diabetes today will increase to 552 million by 2030

Every 10 seconds Three more people will develop diabetes

Primary health systems are under-resourced and poorly designed to deliver empowering and supportive preventive diabetes and chronic care

Active broad involvement of people with diabetes and their family members, use of chronic care models, and IT/mobile technologies are yet to be fully realised

DAWN2™ required to provide new global evidence and a partnership platform to drive long-term change for person-centred chronic care and prevention

DAWN2™: Long term goals

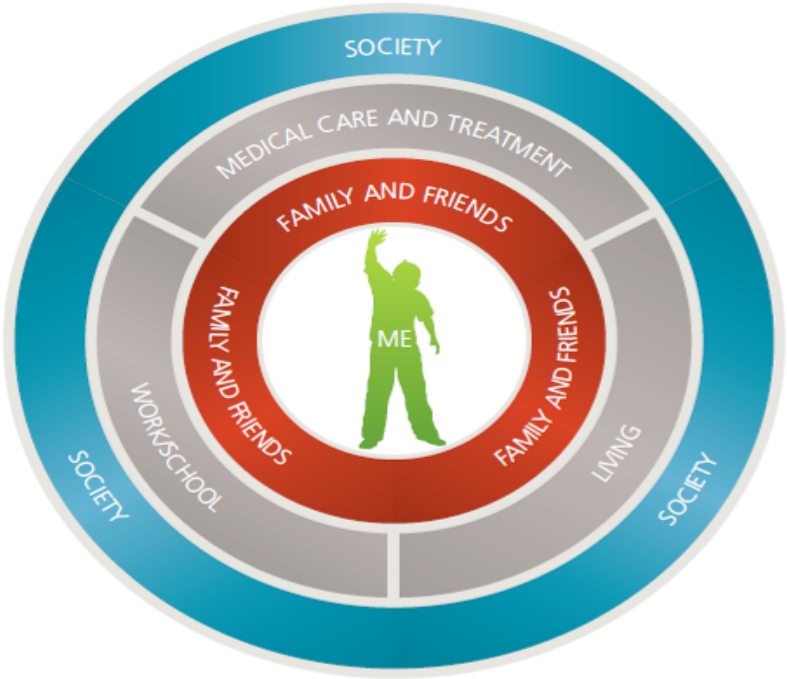
1. Raise awareness of the unmet needs of people with diabetes, their family members, and healthcare professionals

2. Facilitate collaboration to improve patient involvement and equal access to quality care, self-management education

3. Drive scientific benchmarking and better practice sharing

Goal:
To enable all people with diabetes to live full, healthy, and productive lives, and be actively engaged in preserving their own health and quality of life

A new needs model for diabetes



Me: Being able to cope with my condition, and living a full, healthy, and productive life

Family and friends: Emotional and practical support in all aspects of my condition

Community:
Medical care and treatment: Access to quality diagnosis, treatment, care, and information
Work/school: Support for, and understanding of, my condition
Living: Having the same opportunities to enjoy life as everybody else

Society: A healthcare system, government, and public that are willing to listen, change, and be supportive of my condition

A global perspective on diabetes

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15,438 respondents

- **8,956** people with diabetes
- **2,057** family members
- **4,785** diabetes care professionals
- **17** countries across 4 continents
- **EU countries**: Denmark, Germany, Italy, Netherlands, France, Spain, United Kingdom, Poland

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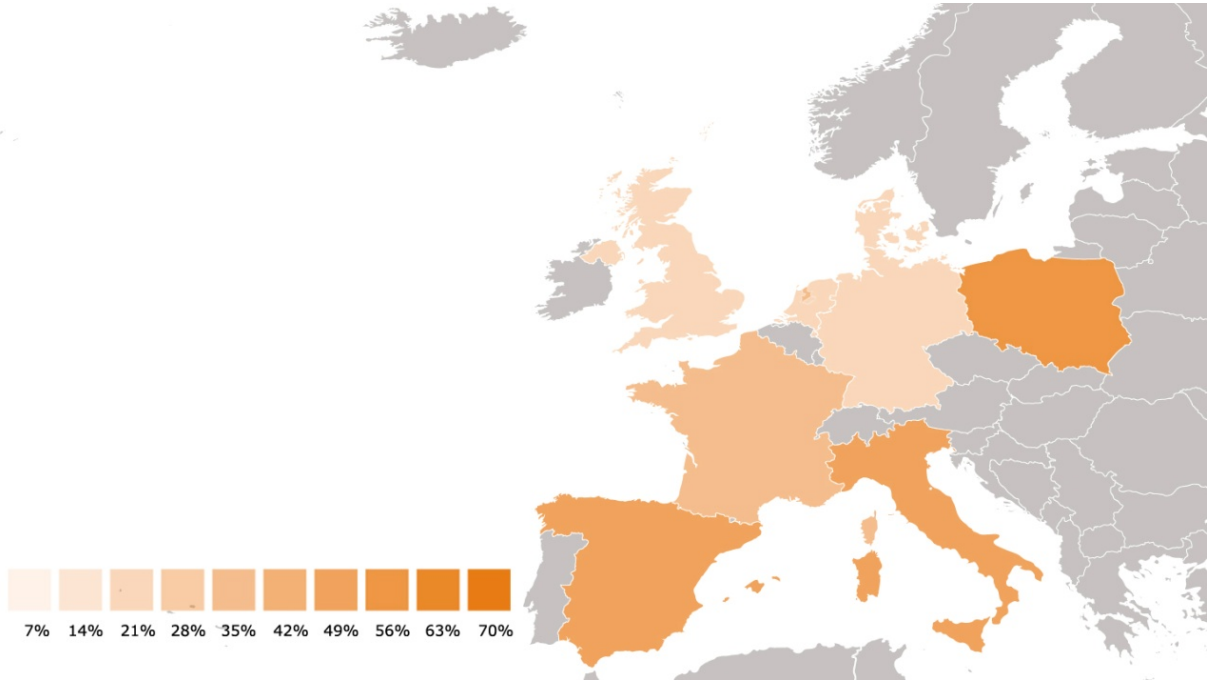
Prevalence of diabetes-related distress



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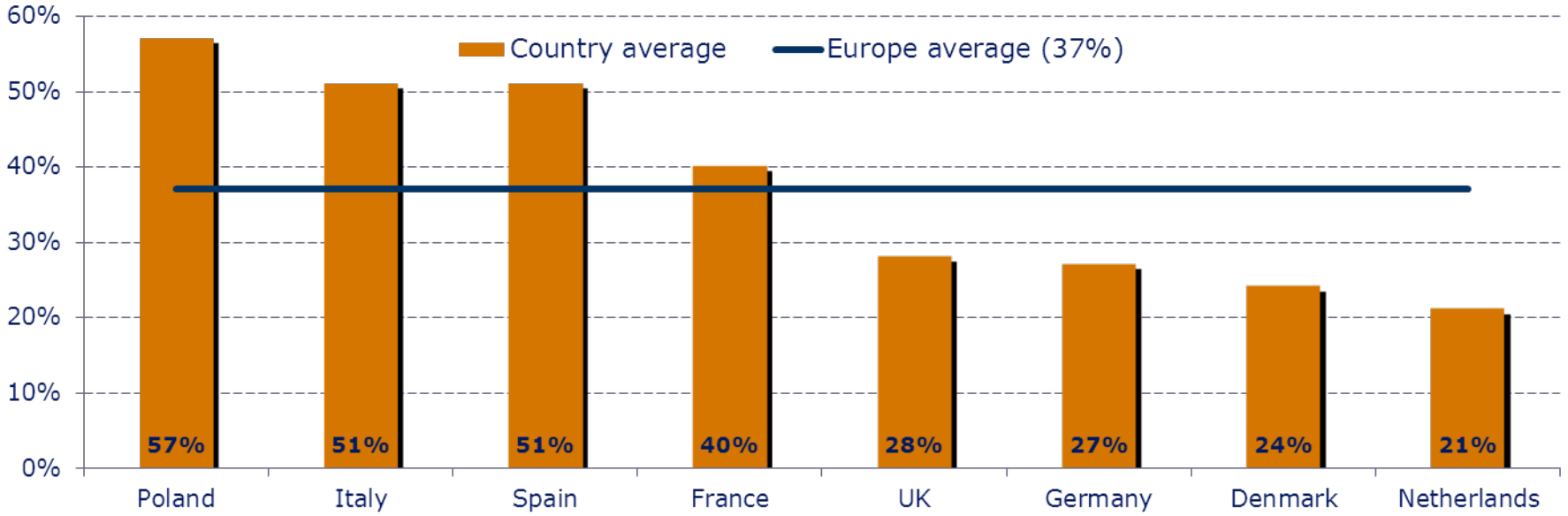
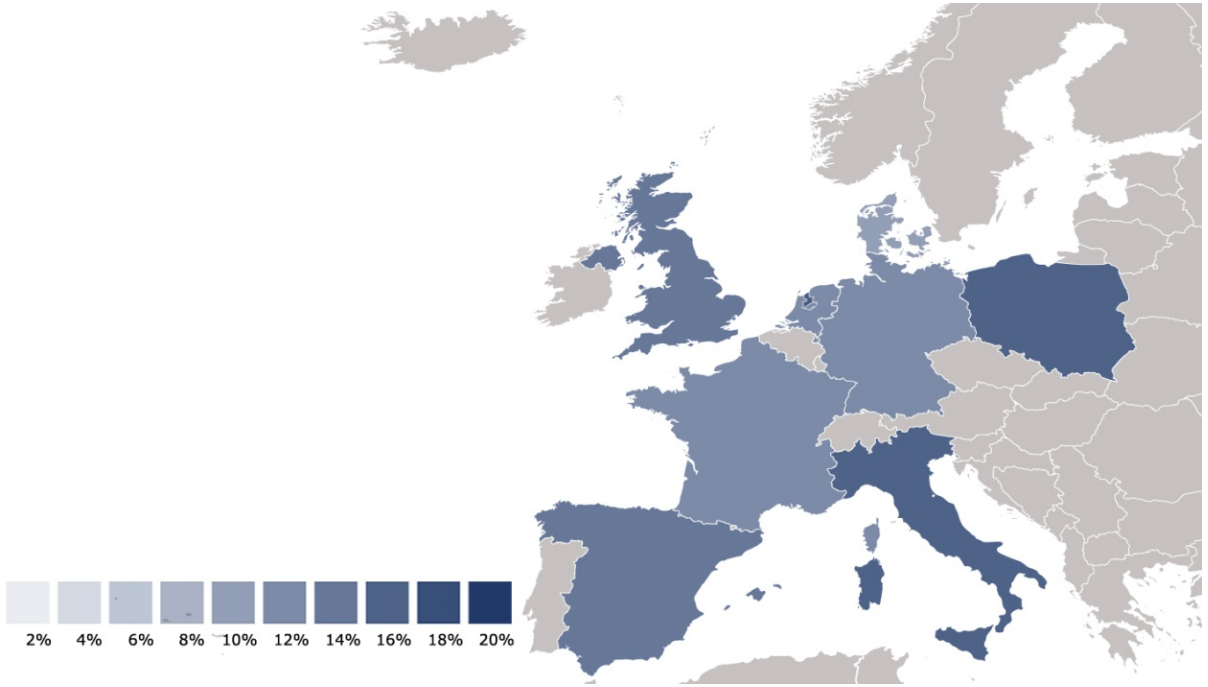


Emotional and physical challenges

‘I was living by myself and I had a hypoglycemic crisis. I was no longer able to understand anything; they told me I did not make sense when I talked and that I wasn't able to move, to sleep calmly, and to recognize my children’

Woman with type 2 diabetes, insulin medicated, age 70, Italy
20 years with diabetes

Prevalence of likely depression



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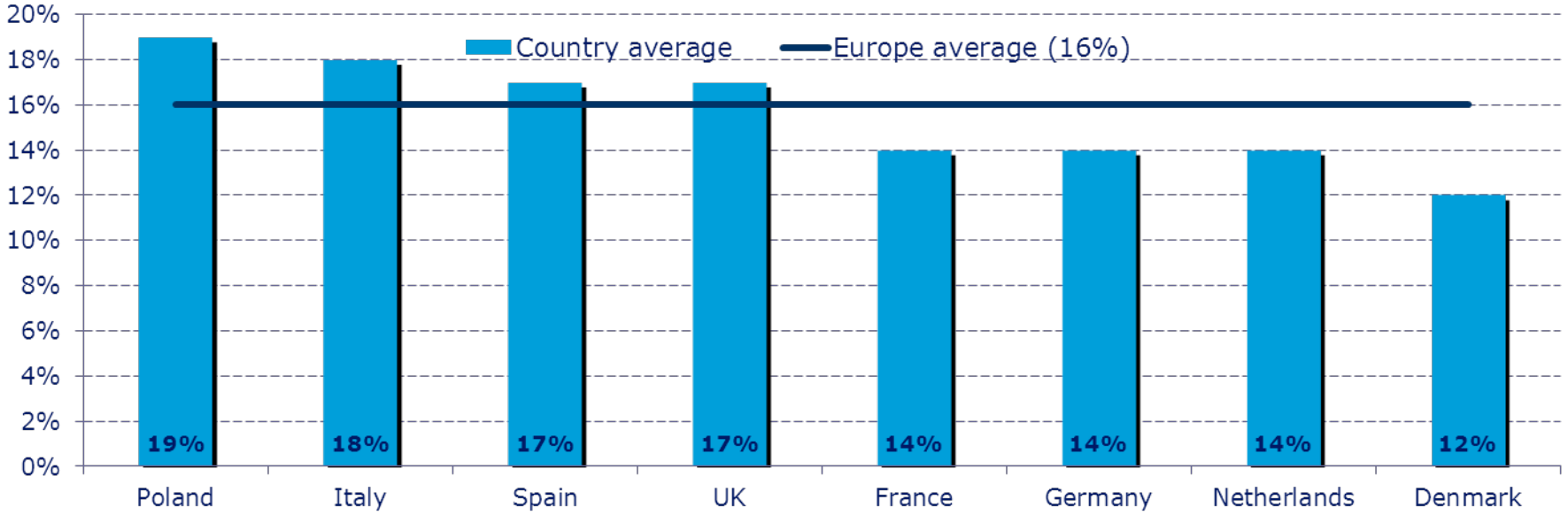

Living with depression

"Conquering the depression that burries me more every day in a bottomless well."

Woman with type 2 diabetes, insulin medicated, age 43, Spain, 6 years with diabetes
20 years with diabetes

Prevalence of discrimination experienced by people with diabetes

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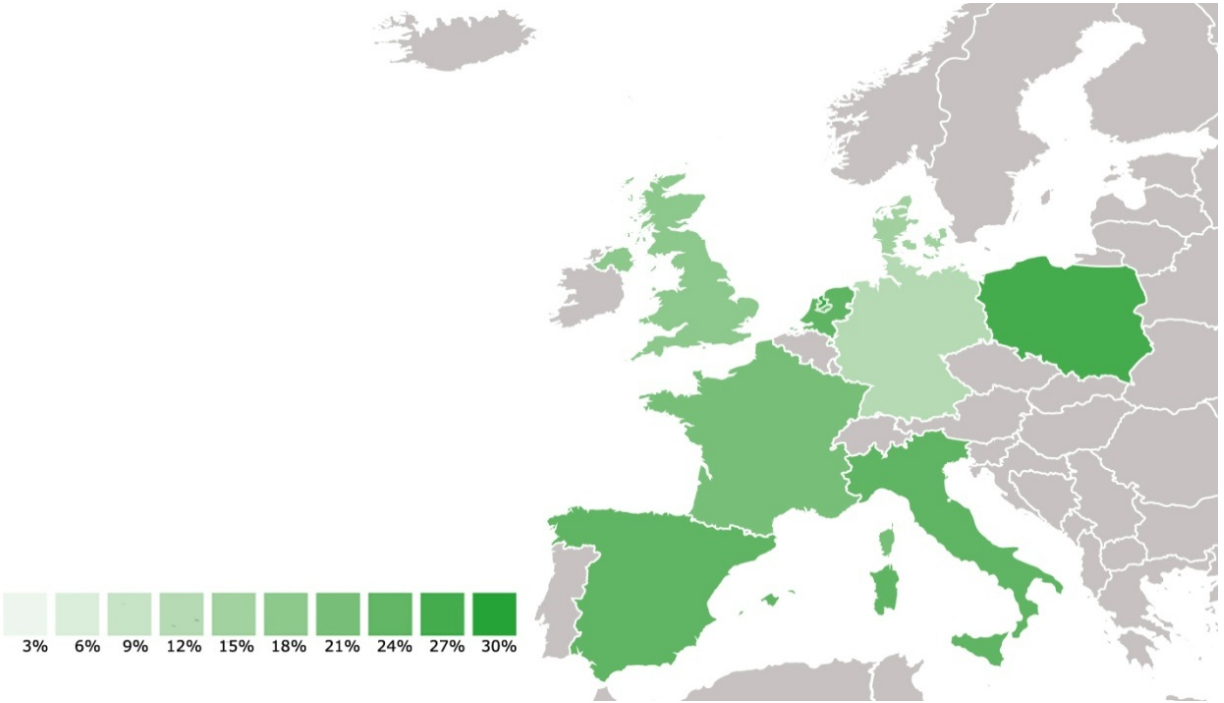

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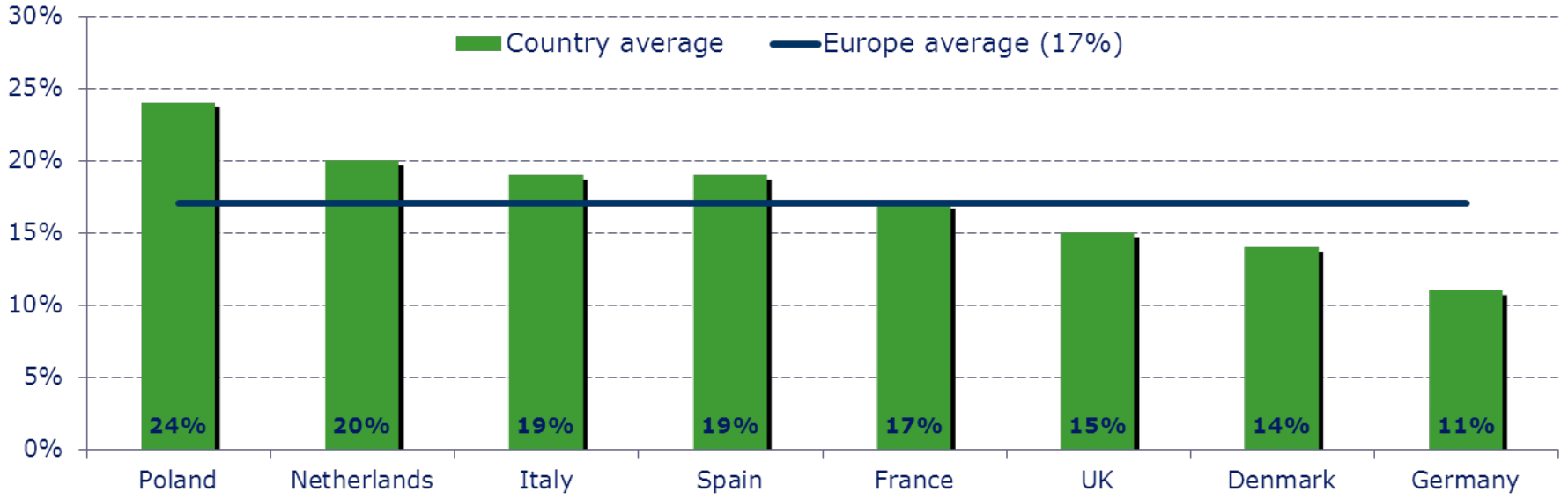

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Discrimination and lack of understanding can be widespread

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"I was invited to a restaurant and I went to the bathroom to do my shot, and there was a lady who treated me like a drug user."

Woman with type 2 diabetes, insulin medicated, age 58, France
20 years with diabetes

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Prevalence of people who have participated in a diabetes education programme

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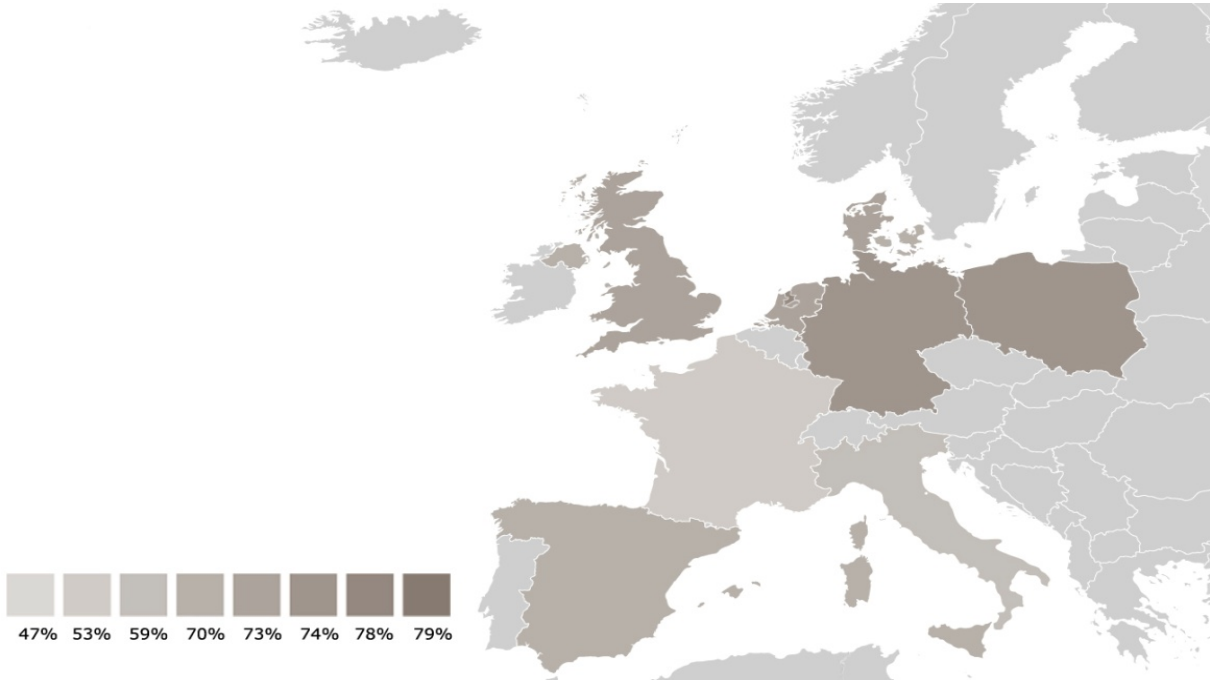

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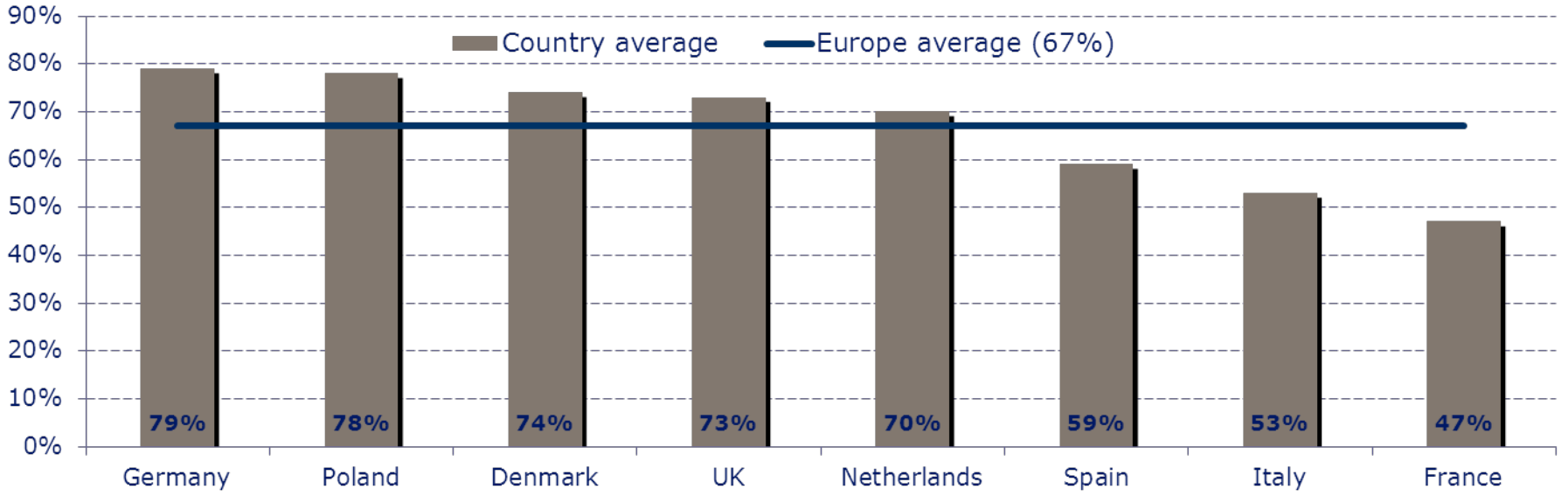

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Need for education

"Regarding the side effects of the medicine, I think that there ought to be better information, instead of the information on the labels that is pasted on the medicine."

Man with type 2 diabetes, Non-insulin medicated, age 67, Denmark, ***6 years with diabetes***

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The family members' perspective

- The burden of diabetes also impacts family members' **quality of life**
- Family members reported a negative impact on **emotional well-being**, **finances**, **leisure activities**, **physical health**, **work/ studies**.
- Family members want to help, but **many do not know how best to help**
- People with diabetes can more confidently face the hardship of diabetes when the family is involves

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Diabetes: a family matter

"My main challenge in managing diabetes is having to do it on my own. My husband enjoys bringing me treats but they are the worst things that he can bring me - chocolate, ice cream, desserts, etc. I have tried losing my temper and telling him he is killing me but I am not sure whether he understands. Help with diabetes should include the partner to ensure that both parties are aware of what is likely to happen."

Woman with type 2 diabetes, Non-Insulin Medicated, age 59, UK, ***one year with diabetes***

Global study highlights

- Diabetes has a significant and diverse psychosocial impact on people with the condition as well as their families.
- Significant opportunities exist for the improvement of care outcomes through greater involvement of people with diabetes, improvements in self-management education and psychosocial support.
- The global DAWN2 study provides a new scientific dialogue platform for identifying better practices and benchmarking progress.

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Panel discussion

Nick Fahy
Annemarie Bevers
Jens Kröger
Marco Comaschi
Søren Skovlund

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Coffee break

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Session 2
Overcoming the Barriers: Solutions to Patient-Centred Care

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Policy areas examined as part of DAWN2™

- **Patient involvement** in diabetes **health policy processes**
- Public efforts to advance **person, family and community-centred chronic illness and diabetes care**
- Use of **"patient reported outcomes"** to improve diabetes care and education
- National policies and initiatives for **access to education**
- Formal standards and policies on **quality of self-management education and support for people with diabetes**
- Formal standards and policies for **psychological support**.

Areas of focus: Education and psychological support

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- **Psychological support as a standard** in chronic disease care
- Care standards that require **QoL/mental health monitoring** as part of chronic disease care
- **Evidence-based guidelines** and **quality standards** for self-management education
- Availability of **certified education for HCPs** in person-centred care
- Trained educators and specialized psychologists
- Tele-health solutions to be more widely available

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