Integrating Health Literacy in Diabetes Self-management

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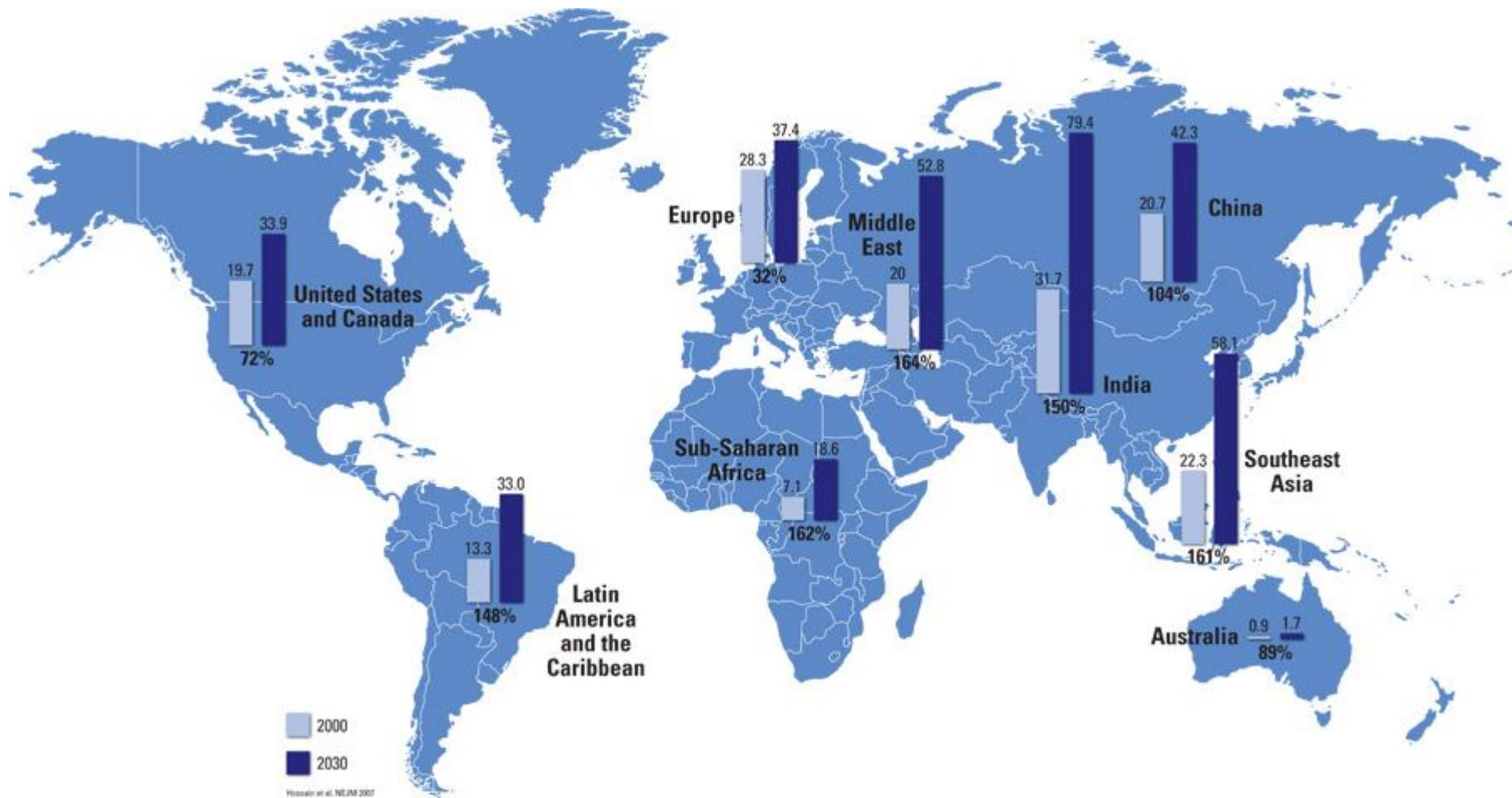Pattaya, Thailand, Aug 25-29 2013

On the research horizon

The challenge of diabetes

- Affects 32 million patients worldwide

  50% of them do not know they have diabetes

- 4th cause of death in the EU

  300.000 deaths per year

- 5 to 15% of health care costs
- Related to overweight and obesity
- Impact of an ageing population:

  ➔ Increased number of people with diabetes

  ➔ Increased health care costs related to diabetes

Worldwide expected prevalence of diabetes

United States and Canada: 19.7 (2000), 33.9 (2030), 72%

Europe: 28.3 (2000), 37.4 (2030), 32%

Middle East: 20 (2000), 52.8 (2030), 164%

Russia area: 79.4 (2030)

China: 20.7 (2000), 42.3 (2030), 104%

India: 31.7 (2000), 150%

Southeast Asia: 22.3 (2000), 58.1 (2030), 161%

Sub-Saharan Africa: 7.1 (2000), 18.6 (2030), 162%

Latin America and the Caribbean: 13.3 (2000), 33.0 (2030), 148%

Australia: 0.9 (2000), 1.7 (2030), 89%

Legend: 2000, 2030

Hossain et al. NEJM 2007

Source: Hossain et al. NEJM 2007 *(million people)*

Self-management as a critical success factor

- Self-management
  - The ability of patients to manage their own health and care process
  - As diabetes requires intensive self-care, self-management is a key determinant of treatment outcome
- Enhancing self-management capacity requires health education and patient empowerment
- Questions
  - What is the nature of existing diabetes self-management programs?
  - What is the (cost)- effectiveness of different approaches?
  - What are the conditions for effectiveness ?

    characteristics of health care system, quality of implementation, …
  - What patient characteristics moderate the effectiveness?

Different educational approaches

- Most diabetes education programmes are based on individual education

  - ✓ Effectiveness

  - ✗ Cost

- Methods based on group education, self-help support or IT supported education may be more (cost-) effective

- Comparative studies of (cost-) effectiveness of different approaches for diabetes education are scarce

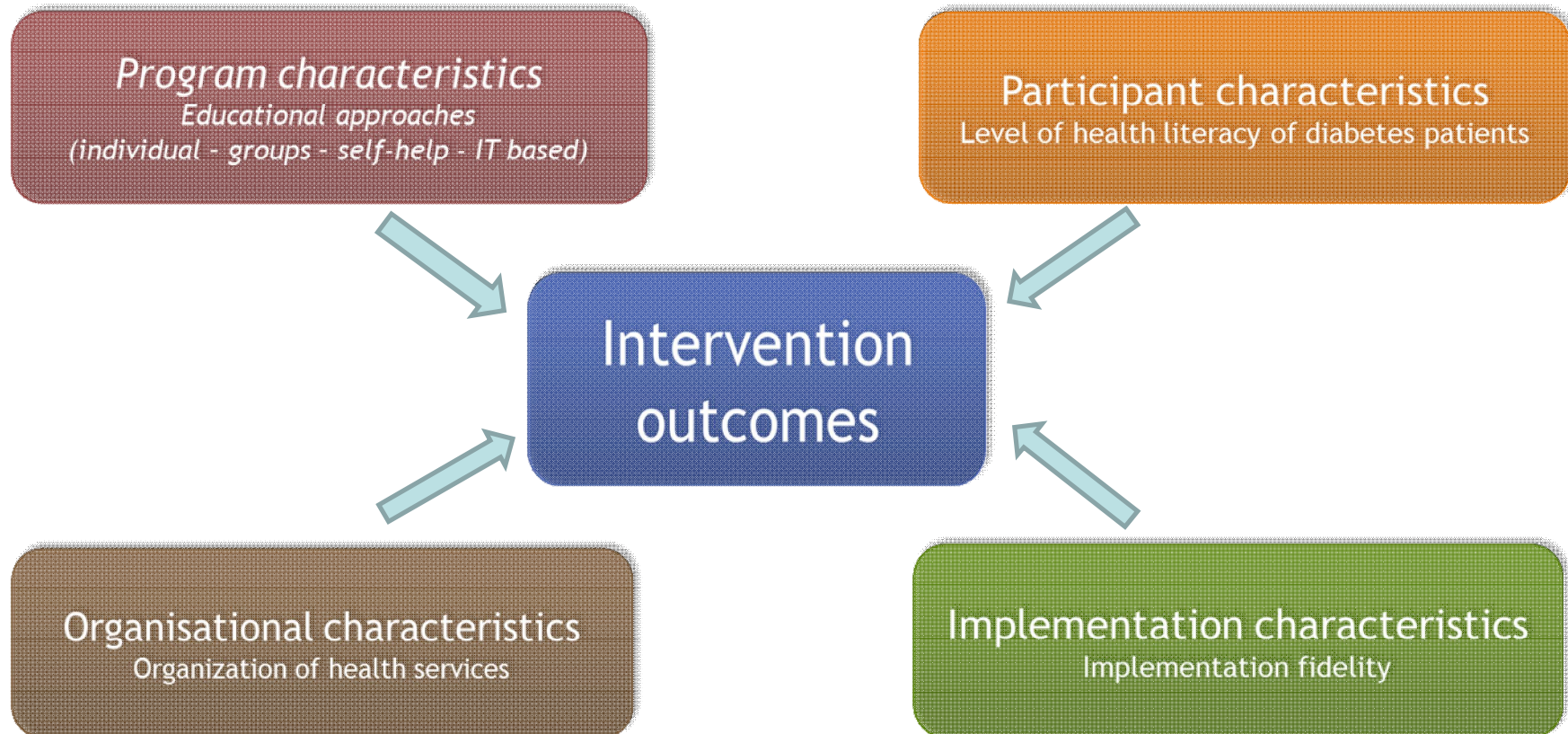- No studies on conditions for effective implementation of diabetes education

The Diabetes Literacy project

- A European project, funded by the EU through the 7th Framework Programme for Research
- A consortium of organizations from 6 EU Member States (B, D, IRL, NL, A, UK) + Israel, USA and Taiwan
- Aims to provide empirical evidence that can be used to increase the effectiveness of self-management education for diabetes type 2 in adults

Aims of the Diabetes Literacy project

- Perform a content analysis of national diabetes strategies across the EU. assess
- Assess the (cost-) effectiveness of different formats of diabetes self-management education
- Investigate the mediating role of implementation fidelity on program effectiveness
- Investigate the moderating role of organization characteristics and of the participants' health literacy on program effectiveness
- Develop and pilot-test low literacy-appropriate materials for diabetes self-management education

Health literacy as a moderator of diabetes education effectiveness

« People's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course»

Skills and abilities → **Health literacy** ← Demands and complexity

Health literacy as a moderator of diabetes education effectiveness

- Supporting health literacy of people with diabetes and their families to successfully self-manage disease means
  - providing opportunities and an environment to develop skills, confidence and knowledge in addition to relevant health information
  - reducing the complexity of health-related information

- The effectiveness of diabetes education is enhanced by creating environments that encourage service providers to
  - combine traditional care with peer-led self-management support
  - incorporate new roles for service users

Source: Kickbush et al. Health literacy :The solid facts. WHO, 2013.

Methodology: Inventory

In each participating country

- Apply the European Diabetes Survey
  - Standardized questionnaire to assess the nature of the National Diabetes Education Strategies
- Comprehensive document review + Semi-structured interviews with stakeholders and experts on diabetes
- Provide an overview of Diabetes Self-management education strategies in each country

Across countries

- Comparative qualitative analysis to identify best practices
- Develop an annotated compendium of diabetes self-management education strategies offering an overview of existing programs

Methodology: Comparative study

Program characteristics → Select different types of educational programmes (individual, groups, self-help, IT based)

Recipient characteristics → Assess the level of health literacy (using the HLS-EU-Q)

Implementation characteristics → Assess implementation fidelity (using a generic questionnaire)

Contextual characteristics → Assess characteristics of the health services (ease of access, multidisciplinary staff, patient monitoring system) using questionnaire for key staff + case-studies

Intervention outcomes → Asses the intervention outcomes through self-reported behavioural measures and medical data

di·a·be·tes
lit·er·a·cy

7
SEVENTH FRAMEWORK
PROGRAMME

Methodology: Development of low literacy materials

In a subsample of participating countries

- Select the core components of web-based patient self-management support
- Identify key user needs for self-management support   through research and stakeholder views
- Develop web-based materials using the LifeGuide software

In all participating countries

- Qualitative study of web-based materials and tools (n = 50-60)
    - Observational 'think-aloud' studies
    - Interviews with users
- Quantitative trials of web-based materials and tools (n > 676)
- Randomized two-arm trials comparing the web-based material with standard written materials

Exepected outcomes of the Diabetes Literacy project

Results will inform practices and policy
decisions to improve the quality of
care for the growing number of people
with diabetes

Visit us at

http://www.diabetesliteracy.eu/