

**diabetes is  
different for  
children**

It is time for change



# The DAWN Youth *MIND* Initiative

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**DAWN**  
Diabetes Attitudes Wishes & Needs  
**YOUTH**

  
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# Introduction

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- Guidelines (ISPAD, ADA, NICE)
  - The importance of psychosocial issues is generally acknowledged
  - None of the examined countries have detailed recommendations to help translate intentions into clinical practice (who, what, how and for whom)



# Introduction

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- DAWN Youth Web Survey
  - 20% of healthcare professionals (HCPs) use structured assessment tools regularly to assess psychosocial needs
  - >90% of HCPs, who never/rarely assess psychosocial needs, want to
  - <50% of HCPs take the initiative to discuss emotional well-being or family functioning



# Evidence from previous research

## Multicentre RCT in four paediatric outpatient diabetes centres

- The effect of monitoring and discussing the HRQoL of adolescents with type 1 diabetes in routine care on:
  - Psychosocial well-being
  - Satisfaction with care
  - Glycaemic control

de Wit *et al.* *Diabetes Care* 2008;31(8)

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# Methods - intervention

## Monitoring and discussing HRQoL: PedsQL generic and diabetes

5–7 minutes

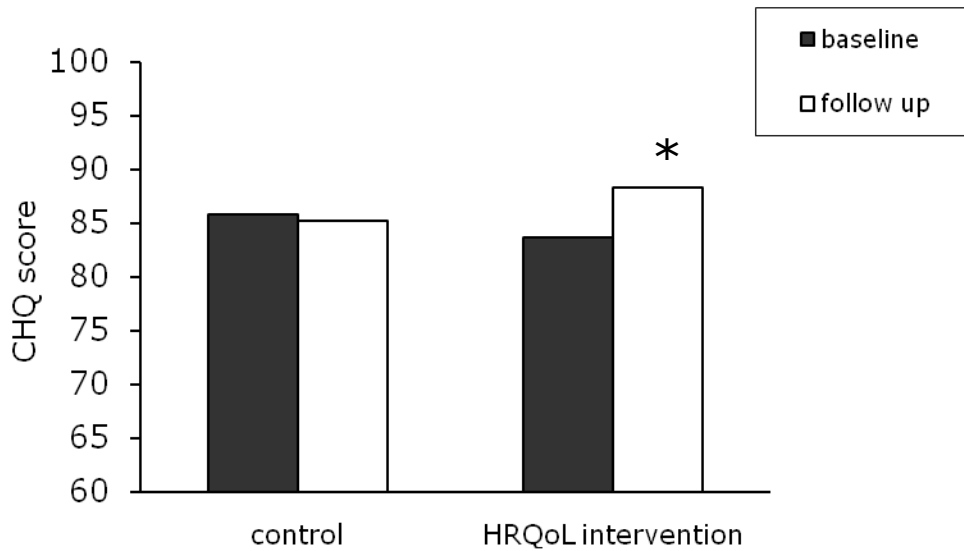


Consultation  
30 minutes

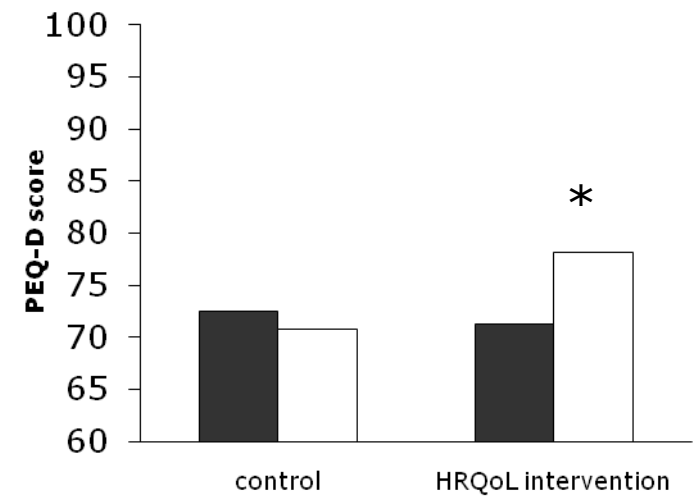


# Results

## Psychosocial health



## Satisfaction with care



de Wit et al. *Diabetes Care* 2008;31(8)



# Conclusion

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## **Monitoring and discussing the HRQoL of adolescents with diabetes**

- Improves psychosocial well-being
  - Less behavioural problems and better self-esteem
- Improves satisfaction with care
- Is well appreciated by the adolescents
- Does not alter glycaemic control



# In the press: Reuters Health News



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## Diabetic teens benefit from discussing problems

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Mon Aug 11, 2008 12:45pm EDT

By Amy Norton

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# DAWN MIND in adults

- Multicentre study in nine countries
  - Coordination: VU University medical center
  - Over 1200 patients
- Monitoring and feedback of well-being
- Two measurements
  - Baseline
  - 1-year follow up: ongoing
- Presentations at ADA, EASD, FEND



# Study proposal

## DAWN Youth *MIND* initiative

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- International project
- Longitudinal, minimum of two measurements
- Coordinated by VU University medical center Amsterdam (M. de Wit, F.J. Snoek)
- HRQoL of children:
  - Aged 8–12 years
  - Aged 13–18 years
- Well-being of parents:
  - Of children up to 18 years



# Study proposal

## Domains for monitoring

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### Previous DAWN Youth meetings

- Domains
  - Generic and diabetes-specific HRQoL
  - Family functioning
  - Emotional well-being
  - Self-management
- How should this be implemented in 'real life'?
  - Annual review
  - Time: a one-page questionnaire is not necessary
  - Mode of administration: computerised



# Study proposal

## Questionnaires for monitoring

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- Review of measures
  - 100 generic and 42 diabetes-specific
- Criteria for questionnaires
  - Psychometrically sound
  - Short
  - Relevant and acceptable



# Study proposal

## Domains and questionnaires for monitoring

- Children
  - Generic HRQoL
    - **PedsQL** / KINDL-R / KIDSCREEN
  - Diabetes HRQoL
    - **DQOL Youth-SF** / PedsQL-DM / KINDL-R-DM
  - Family functioning / responsibility
    - DFCS / DFRS (SF)
  - Self-management
    - One question
- Parents
  - Generic: WHO-5
  - Diabetes: PAID-Parents



# Study proposal

## DAWN Youth *MIND*

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- HRQoL assessment once a year
- Computerised/web-based
- Feedback and discussion of outcomes
- Support and training teams
  - Interpretation of HRQoL outcomes
  - Feedback and discussion of HRQoL outcomes
  - Communication and actions



# Study proposal

## Outcomes

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- Centralised data analysis (Vumc)
- Feasibility
- HRQoL data from multiple centres across countries in two age groups
- Impact of monitoring on psychological and glycaemic outcomes
- Publications, presentations
- Further refinement of measurement and feedback procedures

