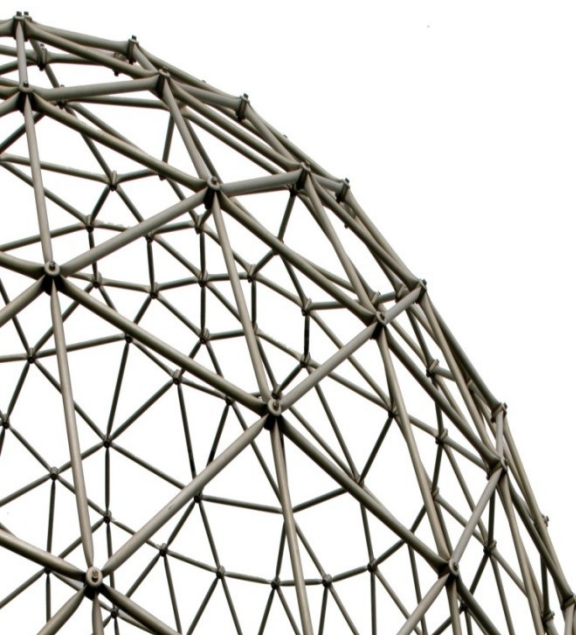


# PROMS: What can they do for us?



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# PROMS

Standardised, validated questionnaires completed by patients to assess different health constructs



# PROMS

....any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else

*FDA Guidance for Industry on PROMS, 2009*

# Constructs that PROMS capture

Functional status

Well-being

Quality of life

Impact of condition or its treatment

Symptoms

Distress

# Why are PROMS important?

- Unique patient perspective
- Capture information that is not observable
- PROMS information may be more important than clinically observable information

# Why are PROMS important?

- PROMS often better prognostic indicators than standard, clinical measures
- Lots of evidence that clinicians poor at detecting emotional distress and depression; tend to underestimate symptoms, particularly those that are harder to observe clinically

# Predicting mortality: Questionnaires beat physical tests

UK Biobank study (Ganna &  
Ingleson, 2015; Lancet)

# Applications

- Clinical trials: clinical and cost-effectiveness
- Monitoring symptoms
- Facilitating communication between patients and clinicians
- Commissioning services
- Drug/treatment approval



# Quality of PROMS

Benchmarks re psychometric properties of  
PROMS

Federal Drug Administration (FDA)  
European Medicines Agency

# Psychometric Properties

- Internal reliability (consistency)
- Test-retest reliability
- Content validity
- Sensitivity or responsiveness to change (minimally important difference)

# Generic or disease-specific?

## Quality of life; Depression or distress

Generic	Disease-specific
SF-36, SF12, SF6	DSQOLS; ADDQoL; QoLQ
Hospital Anxiety & Depression Scale	Problem Areas in Diabetes Scale; Diabetes Distress Scale

# ePROMS

## Benefits

- Rapid data collection
- Less missing data
- Easier and quicker input and storage of data
- Reduced cost

## Limitations

- Cost may be too high for small healthcare systems
- Data security

**Table 3** The EUBIROD framework of diabetes indicators (ToD = type of diabetes, Cage = age classes, R = region)

Section/subsection			Ref.	Indicator
1 Demographic characteristics	1.1 Basic demographics		1.1.1	Age (classes) * Gender [adult, pediatric]
2 Clinical characteristics	2.1 Diabetes status		2.1.1	Type of diabetes [adult, pediatric]
			2.1.2	Duration of diabetes (classes) [adult, pediatric]
	2.2 Risk factors for diabetes complications	2.2.1 Obesity and Growth (most recent value in the last 12 months)	2.2.1.1	Weight (classes and continuous)
			2.2.1.2	BMI (classes and continuous) [adult, pediatric]
			2.2.1.3	Height (classes) [pediatric]
		2.2.2 Lifestyle	2.2.2.1	Smoking status
		2.2.3 Clinical measurements (most recent value in the last 12 months)	2.2.3.1	Systolic blood pressure (classes and continuous)
			2.2.3.2	Diastolic blood pressure (classes and continuous)
			2.2.3.3	Total cholesterol (classes and continuous)
			2.2.3.4	HDL-cholesterol (classes and continuous)
			2.2.3.5	Creatinine (classes and continuous)
			2.2.3.6	HbA1c (classes and continuous) [adult, pediatric]
	2.3 Diabetes complications		2.3.1	Retinopathy
			2.3.2	End stage renal failure
			2.3.3	Foot ulcer



## Quality and Outcomes of Person-Centred Care

The Quality and Outcomes of Person-centred Care Policy Research Unit (QORU) is a collaboration involving researchers in health and social care from the Universities of Kent, Oxford and the London School of Economics and Political Science (LSE), and has been funded by the Department of Health in England (from January 2011 for seven years) to support current government policy in health and social care on achieving outcomes.

[Read more >>](#)



## Research Themes



## Type 1 diabetes: Less guesswork, more freedom, better health





## DAFNE Database Study

to enable the development of an existing web-based DAFNE audit database to include a research database which can be used to answer research questions and support prospective studies.

Includes biomedical, psychological and health economic data





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