

Appendix E Informal patient reported outcome measures

Table E.1 Recommended patient reported outcome measures (informal)

Informal diabetes specific PROMs used or recommended in included studies.

Patient reported outcome	Patient reported outcome measures (informal)
PSYCHOLOGICAL: Diabetes specific psychological well-being	
Diabetes distress	Developed for DAWN study
PSYCHOLOGICAL: Diabetes self-management behaviours: Am I doing it? (Performance)	
Physical activity	Active Australia Survey and National Physical Activity Guidelines for Australians; Developed for DAWN study; Questionnaire on leisure-time physical activity; 'How successful have you been in following the exercise recommendations given by your doctor or nurse for managing your diabetes?'; Authors own distance survey ⁱ
Diet	Dietary Guidelines for Australian Adults; Developed for DAWN study; 'How successful have you been in following the diet recommendations given by your doctor or nurse for managing your diabetes?' (1 item); Authors own distance survey ⁱ
Self-monitoring blood glucose	Developed for DAWN study; Self-monitoring of blood glucose frequency; 'How successful have you been in following the self-monitoring of blood glucose recommendations given by your doctor or nurse for managing your diabetes?' (1 item); Authors own distance survey ⁱ
Foot care	Authors own distance survey ⁱ
Medication taking (including oral and injectable)	Developed for DAWN study; Adherence to scheduled insulin injections; 'How successful have you been in following the medication recommendations given by your doctor or nurse for managing your diabetes?' (1 item); Authors own distance survey ⁱ
Engaging with health services	'How successful have you been in following the appointment keeping recommendations given by your doctor or nurse for managing your diabetes?' (1 item); Developed for DAWN study; Frequency of forgetting and skipping injections/bolus/medication dose, reasons for forgetting/skipping
Oral health	Authors own distance survey ⁱ
PSYCHOLOGICAL: Diabetes self-management behaviours: Do I want to do it? (Perceived importance)	
Diet	Modified Importance and Burden items (for diet) from the Summary of Diabetes Self-Care Inventory – Revised SDSCI-R (unpublished)
Physical activity	Modified Importance and Burden items (for physical activity) from the SDSCI-R (unpublished)
Self-monitoring blood glucose	Modified Importance and Burden items (for blood glucose monitoring) from the SDSCI-R (unpublished)
PSYCHOLOGICAL: Diabetes specific health beliefs	
Perceived control over diabetes	Developed for DAWN study
Diabetes specific health beliefs (theoretical model)	Questionnaire on diabetes treatment beliefs and health behaviour
PSYCHOLOGICAL: Diabetes knowledge	
Diabetes knowledge	Questionnaire on understanding of diabetes
PSYCHOLOGICAL: Attitude to insulin	

Attitude to (initiating) insulin treatment (including psychological insulin resistance)	Willingness to begin insulin' single item: Perceived efficacy ('Taking insulin will help me manage diabetes better') and self-blame ('Starting insulin means not having followed treatment recommendations properly') (single items)
PSYCHOLOGICAL: Diabetes related avoidance behaviour	
Hyperglycemia avoidance behaviours	Two items adapted from the Hyperglycaemia Avoidance Scale
PHYSICAL AND FUNCTIONAL: Hypoglycemia unawareness	
Hypoglycemia unawareness	Study-specific items - some based on the Hypoglycaemia Awareness Questionnaire
PHYSICAL AND FUNCTIONAL: Diabetes symptoms (including symptoms of complications)	
Diabetes symptoms (presence and/or burden) (multi-dimensional)	Authors own distance survey ⁱ Study specific items
Female urinary incontinence (presence)	Authors own distance survey ⁱ
Hyperglycemia (presence)	Developed for the DAWN study
SOCIAL: Diabetes-specific social support	
Diabetes specific social support	DAWN Family Support Scale (DFSS); DAWN Support for Diabetes Self-management Profile (DSDP); Study-specific items on peer support
SOCIAL: Diabetes related stigma	
Diabetes related stigma	6 study-specific items about portrayal of diabetes in the media; 'I have been discriminated against because of diabetes' (1 item)
PSYCHOLOGICAL, PHYSICAL/FUNCTIONAL AND SOCIAL: Diabetes burdens and restrictions	
Diabetes and treatment burdens and restrictions	Modified Importance and Burden items (for diet, physical activity, blood glucose monitoring) from the SDSCI-R (unpublished)

ⁱ Based on National Health Interview Survey (NHIS), and National Assessment of Adult Literacy (NAALS), Summary of Diabetes Self-Care Activities (SDSCA), International physical activity questionnaire (IPAQ); National Health and Nutrition Examination Survey (NHANES) Questionnaire; Behavioral Risk Factor Surveillance System (BRFSS), 12 item Short-Form Health Survey (SF-12), 8 item Short-Form Health Survey (SF-8), Patient Health Questionnaire-9 (PHQ-9), Consumer Assessment of Health Plans Study (CAHPS 2.0) Questionnaires; Consumer Assessment of Health Plans Study (CAHPS 1.0) Survey Measures, Trust in Physician Scale, and multiple studies in the field.