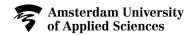


Minimum Data Set example for Urban Vitality – 'Gezond ouder worden / Mensen in Beweging'

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This document provides an example for the development of a potential Minimum Data Set (MDS) within the Urban Vitality (UV) themes 'Gezond ouder worden / Mensen in Beweging'. The goal is to ensure more uniform collection of outcome measures, based on FAIR principles (1), and to facilitate reuse of data and analyses spanning multiple studies. This prototype MDS is based on *The Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS)* (2), the project *FAIR: geen woorden maar data* (3) in which we examined 14 UV-studies about ageing and frailty of elderly, and the set of common data elements for rare disease registration (4). This prototype MDS is open for discussion in terms of feasibility (is it worth the effort), relevant candidate outcome measures and values, and whether it should be obligatory or more facultative.

Group	Data	Description	Coding	Remarks / For discussion
Pseudonym	<u>Pseudonym</u>	Participant's pseudonym (random PIN)	String	
Study	Study name	Name of study	String	Date of start study relevant?
Demographics	Age	Age at start study	Number	Date of birth or age at start study? Age in years is less identifying than date of birth
	<u>Gender</u>	Participant's gender identity	 Masculine Feminine Unknown Unspecified Surgically transgendered transsexual 	What is more relevant in the context of UV research, sex assigned at birth or an individual's personal sense of being a man, woman, or other gender? And what are the best corresponding values? See here and here
	Marital status	Participant's marital status at start study	 Married Widowed Divorced Separated Never married Living with partner 	
	Living situation	Participant's living situation at start study	 Lives alone Lives with family Lives with roommate Home care Lives in nursing home 	



Body composition	<u>Weight</u>	Value	Participant's weight in kg	Float	
		Measuring method	Measured by investigator or stated/self-reported by participant	Measured Self-reported	
		Clothes	Clothing worn during weight measurement	• With clothes • Without clothes	
		<u>Device</u>	Device used for weight measurement	Weighing scale Bodpod	
	<u>Height</u>	Value	Participant's height in cm	Float	
		Measuring method	Measured by investigator or stated/self-reported by participant	• <u>Measured</u> • <u>Self-reported</u>	
		Shoes	Shoes worn during height measurement	• Yes • No	
		<u>Device</u>	Device used for height measurement	• Stadiometer • Measuring tape	Define difference between digital and mechanical stadiometer?
	<u>BMI</u>		Participant's Body Mass Index calculated with weight and height value	Float	
Physical performance &	SPPB_score		Physical performance/mobility	Number (score)	
functioning	Hand grip strength value		Strength using a hand dynamometer	Number (different units)	What is important to specify, e.g. hand used, how grip strength was measured, how many times, etc.?
	2MST_Number of steps		Exercise capacity	Number (amount of steps)	Different versions of the 2MST with different outcome measures exist. Which one do we use?
Behavioral & psychosocial functioning	EQ-5D Score		General health status	Number (score)	
	MMSE_Score		Cognitive impairment	Number (score)	
	SF-36 Score		Quality of life measures/care outcomes for adult patients/measuring patient health	Number (score)	In some studies RAND-36 was used. What is preferred?

^{*}The underlined words in the Data and Coding column below link to (candidate) ontology terms.