

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

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07-07-2020, version 1, concept

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 | <u>Study_name</u> | Name of study | String | <i>Date of start study relevant?</i> |
| Demographics | <u>Age</u> | Age at start study | Number | <i>Date of birth or age at start study? Age in years is less identifying than date of birth</i> |
| | <u>Gender</u> | Participant's gender identity | <ul style="list-style-type: none"> • <u>Masculine</u> • <u>Feminine</u> • <u>Unknown</u> • <u>Unspecified</u> • <u>Surgically transgendered transsexual</u> | <i>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</i> |
| | <u>Marital status</u> | Participant's marital status at start study | <ul style="list-style-type: none"> • <u>Married</u> • <u>Widowed</u> • <u>Divorced</u> • <u>Separated</u> • <u>Never married</u> • <u>Living with partner</u> | |
| | <u>Living situation</u> | Participant's living situation at start study | <ul style="list-style-type: none"> • <u>Lives alone</u> • <u>Lives with family</u> • <u>Lives with roommate</u> • <u>Home care</u> • <u>Lives in nursing home</u> | |

| | | | | | |
|---------------------------------------|---------------------------------|-------------------------|--|---|---|
| Body composition | <u>Weight</u> | Value | Participant's weight in kg | Float | |
| | | <u>Measuring method</u> | Measured by investigator or stated/self-reported by participant | <ul style="list-style-type: none"> • <u>Measured</u> • <u>Self-reported</u> | |
| | | <u>Clothes</u> | Clothing worn during weight measurement | <ul style="list-style-type: none"> • <u>With clothes</u> • <u>Without clothes</u> | |
| | | <u>Device</u> | Device used for weight measurement | <ul style="list-style-type: none"> • <u>Weighing scale</u> • <u>Bodpod</u> | |
| | <u>Height</u> | Value | Participant's height in cm | Float | |
| | | <u>Measuring method</u> | Measured by investigator or stated/self-reported by participant | <ul style="list-style-type: none"> • <u>Measured</u> • <u>Self-reported</u> | |
| | | Shoes | Shoes worn during height measurement | <ul style="list-style-type: none"> • Yes • No | |
| | | <u>Device</u> | Device used for height measurement | <ul style="list-style-type: none"> • <u>Stadiometer</u> • <u>Measuring tape</u> | Define difference between digital and mechanical stadiometer? |
| Physical performance & functioning | <u>BMI</u> | | Participant's Body Mass Index calculated with weight and height value | Float | |
| | <u>SPPB_score</u> | | Physical performance/mobility | Number (score) | |
| | <u>Hand grip strength value</u> | | 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.? |
| | <u>2MST_Number of steps</u> | | Exercise capacity | Number (amount of steps) | Different versions of the 2MST with different outcome measures exist. Which one do we use? |
| Behavioral & psychosocial functioning | <u>EQ-5D_Score</u> | | General health status | Number (score) | |
| | <u>MMSE_Score</u> | | Cognitive impairment | Number (score) | |
| | <u>SF-36_Score</u> | | 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.