

OCTO - TWIN

INSTRUCTIONS AND CRITERIA

FOR PROTOCOLS 1, 2A, 2B, 3, 4, 5A, 5B

Wave 1 - 5

2009-08-15

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(*) **NOTE!** In the attached **Wave 1-4 file** all the above files are merged into one major double entry file.

In Wave 1 all variables are called **v** for the twin and **tv** for the partner
 In Wave 2 the same variables are called **b** for the twin and **tb** for the partner.
 In Wave 3 "-" **c** "-" **tc** "-"
 In Wave 4 "-" **d** "-" **td** "-"
 In Wave 5 "-" **e** "-" **te**

In the below text, however, v is used for defining and describing the variables and the principles for their coding.

General principles for sequencing the data collection

How to choose/select twins at Wave 1.

Some basic requirements

- The period of time between the investigations of the two twins must not be more than one month.
- The same technician investigates only one member in the twin pair.
- For practical and economic reasons the travelling lengths should be minimized.
- If one twin in the pair is unable/declines to participate the entire pair is excluded.
- Investigations should be planned for at least one week ahead.

Through computerised randomization the *twin no. 1* in each pair is given a "queue" number. The country has been divided into 37 districts, based on post number codes.

Then the following principles for selecting the twins are used:

1. Begin with the place (Place A), where the twin with the lowest queue number lives.
2. If the twin partner lives in the same district choose this twin too. If there is not enough time during the week to investigate both twins in the pair, both twins in that pair shall have to wait for the time being. In stead the next twin is chosen according to #4.
3. If the other twin (*no. 2*) in the pair lives in another district he/she is placed on a "queue list".
4. The twin with the next queue number at Place A is chosen and his/her twin partner - if any - (according to #2) until there are a number of twins enough for one week's investigation or until all twins *no. 1* at Place A have been chosen.
5. If more twins are needed for this week, proceed to those districts to which the twins on the queue list belong. If there is a *twin no. 2* from Place A, then choose him/her and put *twin no. 1* in this pair on the queue list.
6. If more twins are needed to cover the week's work choose the *twin no. 1* with the lowest queue number within the district, and go on according to ## 1 - 6.
7. Start next week with the place, where the twin lives, who is first on the queue list, and go on according to ## 1 - 6. If the queue list is empty choose the place, where the twin lives, who has the lowest queue number among the twins not yet investigated.
8. A twin who has accepted, but cannot participate according to the technicians' plans will be investigated as soon as the technicians can fit her/him into the schedule.

How to choose the next twin at Wave II and in subsequent Waves.

Some basic requirements

- Consider - as at Wave 1- the length of the travels!
- If, for some reason, one of the twins is unable/declines to participate, the other twin is asked about participation.

Order of investigation

1. Investigation II should be performed 2 years after investigation I (date on list). The ideal time is **2 years minus 1 month or 2 years plus 3 months**. If an investigation can only take place e.g., six months after the first investigation, the twin's participation should be put to question. Assessment from case to case.
2. If the time interval between *twin 1* and *twin 2* is **more than 1 month**, investigation II is planned so as to make the interval shorter this time. This must not lead to the time difference between investigation I and II for one twin, being bigger than what is acceptable according to # 1.
3. First, the week should be filled up with twins from list II ("Upp") within the same district. If the number of twins are insufficient, twins from list I within the same district are chosen.
4. Then, the queue list is checked for *twins no. 1s* in the district, which will be visited.

At Wave II twins are investigated independently of each other, i.e. if one twin is unable/declines to participate, yet the twin partner is asked about participation.

I. BACKGROUND INFORMATION

(Protocol Twin 1)

B1 Non - participation, type

This variable is always registered on this file with 1.

V111 Living, type

If it is not possible to get clear and distinct information this variable is registered with a point (.). (Go to V111A.)

V112 Living together

Required

"Do you (Subject) live alone or with someone?" means number of persons (one or several - 1 -). With = the same household.

V113-115 Orientation

Required

Orientation questions (name, year of birth, age) are controlled/corrected according to the register.

- **V113** If Subject gives the wrong name "incorrect/does not know" is registered (1). If Subject does not understand the question at all "does not know" is registered (0).

Parish/county of birth (Only in Wave 1)

Required

Can later be registered according to a special code of figure only. 99 = does not know.

V116 Marital status

Required

Subject's present (last) status is registered.

V118-121 How long did your father and mother live?

(Only in Wave 1)

- **V118** and **V120** = the exact age (the age given by Subject) is registered. 9 = does not know.

- **V 119** and **121**, registration according to interval list:

03 19=19	60 - 64=60	Does not know = 9
20 - 24=20	65 - 69=65	
25 - 29=25	70 - 74=70	
30 - 34=30	75 - 79=75	
35 - 39=35	80 - 84=80	
40 - 44=40	85 - 89=85	
45 - 49=45	90 - 94=90	
50 - 54=50	95 - 99=95	
55 - 59=55	100 - =00	

V126-V127 Father's and mother's cause of death

(Only in Wave 1)

Registering according to list:

99=does not know

01=accident

02=infirmary, unspecified

03=heart attack or other heart disease

04=cerebral hemorrhage/stroke

05=cancer

06=pneumonia or other respiration diseases

07=gastro-intestinal diseases

08=urinary tract diseases

09=infection diseases (Tuberculosis)

10=childbirth complications

11=worn out from work ("the nerves")

12=diabetes

13=uremi, "kidney failure"

14=childbirth

15=after-effect of the Spanish flu

16=blood poisoning

17=fistula on the back

18=the throat "suffocated"

19=shock after accident

20=died from alcoholism - periodical drinker

21=ate him/herself to death

22=suicide

23=poisoning (at work)

24=mononucleosis

25=shot wound

26=sorrow

27=intestinal haemorrhage

28=rheumatic pain

29=clot of blood, unspecified

30=senile

31=water in the lungs

32=anaemia

33=blood diseases
34=Spanish flu
35=hardening of the arteris
36=albuminuria towards the end
37=gangrene
38=after-effect of surgery

39=hard work
40=appendix
41=liver disease
42=goitre
43=neurological disease

V128-v129 Household economy in childhood

(Only in Wave 1)

v130 Years at school

(Only in Wave 1)

"Years at school" means school education. Less than a 1/2 (a half) year does not count, a 1/2 year or more is equivalent to 1 year.

V131 School education, type and level

(Only in Wave 1)

Several alternatives may be noted - only the highest level is registered.

EDU = NEW Education variable

(NEW!)

This variable is based on data from the Swedish Twin Registry. The variable contains less missing data on education than those from Wave 1. However, we do not have edu for all subjects.

- 0 = Less than elementary
- 1 = elementary (and more than elementary but short of secondary)
- 2 = secondary (Swedish = realskola)
- 3 = yrkesskola, folkhögskola (Swedish =
- 4 = high school (Swedish = gymnasium)
- 5 = university

V132-V138 Siblings

- **V132-136:** Number of siblings with whom Subject has **grown up**.

(In Wave 2 and subsequent Waves only questions about siblings alive)

- **V137-138:** Number of siblings before, resp. after the twin pair, with the same biological mother, with whom Subject has **grown up**.

(Only in Wave 1)

V139 First born in the pair

(Only in Wave 1)

V140-V141 Frequency of contacts in pairs

V142-152 Children, grandchildren, etc.

If the answer to **V142** is "no" points are registered at **V143 - V150**. For grandchildren, great grandchildren and the children of great grandchildren, approximative answers are accepted.

- **V145 & V146** Adopted children are registered as foster children.

- **V151 & V152** (miscarriages resp. stillbirths): 0 means that the female Subject was asked and gave a negative answer. A point (.) means "does not know", i.e. Subject was not asked or gave no answer. (Abortion is registered as misscarriage.)

V153-154 Work/professional background*(Only in Wave 1)*

Try to get as thorough information as possible, e.g. farmer: how many hectares? The social group which has been dominant during most part of Subject's life is registered. It is the family's (own or spouse's) social group, which should be registered.

Registration according to two systems:

- Social group codes according to the Swedish Election Statistics, Socialforskningsinstitutet: Social group 1, 2 & 3 (where 1 is the highest level).
- Socio-economical classification (SEI), SCB. (11-87 + housewife 95). The SES-code is (unlike the social group code) Subject's "personal", unique code.

11 - 22 workers, all kinds - all levels
 33 - 57 employees, all kinds - all levels
 60 - 87 farmers, all kinds - all levels

V155 Economy at the time of work*(Only in Wave 1)*

Work = work or corresponding.

V157-V158 Stopped working/Retirement

- **V157** = Age (e.g. 22 for Subject who became a housewife at that age). For a person who never worked a point is registered at this variable. Work = work which is paid (cash or perks).
- **V158** = Cause for Subject to stop work. Early retirement/sick pension is registered only if there was no other cause for stopping work.

V159-V161 Current finances

II. HEALTH**(Protocol Twin 2A and 2B)****V201-V204 Self-rated health****V205 Healthy living***(Only in Wave 1)***V206-V207 Measures to preserve health**

(v206 only in Wave 1)

V208-V242 Sensory functions (see protocol)**V243 State of teeth***UNRELIABLE! DON'T USE! (Data available in Wave 1-3)*

Required

Number of fixed teeth, also crowns.

V252-V362 Diseases and Disorders -checklist (see protocol)**V363-V398 Other**

If Subject states that he/she has got no diseases except those listed in the protocol, points (.) are registered. If Subject, on the other hand, refers to diseases/disorders which are not listed, mark "Other" and note additional diseases/disorders. Note also in what degree these might bring about difficulties to his/her daily life. Registration of additional diseases/disorders should not be done with yes/no. Instead every new disease/disorder is given a code (01-99) according to list (which is refilled as the diseases/disorders come up):

- | | |
|---|---|
| 01=lung disorders/pleuritis | (Meniere`s disease?) |
| 02=circulation disorders | 35="tits"? syndrom (inflammation of the breastbone) |
| 03=blood diseases | 36=erysipelas ("the Rose") |
| 04=gastric catarrh | 37=fatty bump on the back of the head/lipom |
| 05=constipation | 38=diphtheria |
| 06=spleen | 39=amputation of leg |
| 07=wound on the toe (because of circulation disorder) | 40=streptococcus infection/infection post op |
| 08=lymphatic stasis (post op.)/arm | 41=heart burn |
| 09=headache | 42=Asiatic influenza |
| 10=breast pain/hart disorder/nervous heart | 43=restless legs |
| 11=lack of B12 | 44=buzzing in the head |
| 12=boils on head, arms and the back of the head | 45=pernicious anaemia |
| 13=stiffness in left elbow after fracture, arm feels funny" | 46=fractured rib |
| 14=fungus | 47=thrombosis - lung |
| 15=plug of wax | 48=headache several years (from car accident)/unconsiosness |
| 16=diaphragm hernia | 49=concussion |
| 17=encephalitis | 50=erythema nodosum |
| 18=rheumatic fever | 51=weak legs |
| 19=broken thigh | 52=genetic disease in scalp |
| 20=groin hernia | 53=strained vocal cord/hoarseness |
| 21=cramp in legs/leg pain | 54="red-swollen" aching scrotum |
| 22=decubitus ulcer (heel and seat) | 55=shunt operation - skull injury |
| 23=embolus after car accident ("air embolus") | 56=skull injury with haematoma/skull injury |
| 24=jaundice | 57=the flu - "Beijing"/Asian flu |
| 25=tinnitus (the devil's music) | 58=faints easily |
| 26=contraction after fractured arm | 59=ischaemia |
| 27=fracture of legs | 60=caries |
| 28=fracture of left wrist/arm/sprain | 61=pacemaker |
| 29=heavy breathing/breathlessness | 62=pancreas/pancreatitis |
| 30=meniscus damage/knee damage | 63=sclerodermia |
| 31=the Spanish flu | 64=muscle pain/muscle inflammation |
| 32=nervous stomach disorders (no catarrh) | 65=torticollis |
| 33=tooth surgery/tooth problem | 66=lipoma - arms |
| 34=unusual disease, dizziness for 3 years | 67=contusion - left leg |
| | 68=trigeminus neuralgia |

- 69=weakened muscle - throat
 70=operation - arm
 71=depression
 72=itch
 73=quincies
 74=poisoning/food, paint/amalgam etc.
 75=operation, ganglion - hand/no op
 76=amputation - right hand/finger/toe/injury left ringfinger
 77=testectomy
 78=otitis
 79="gravel in hands" - nerve injury
 80=tapeworm
 81=cystectomy - throat
 82=polycythemia vera
 83=fractured thumb
 84=fractures collar bone
 85=tonsillectomy
 86=hallux valgus
 87=nose bleedings
 88=benign tumour of the brain
 89=sinusitis
 90=slipped disc
 91=fracture - foot/ligament/toe
 92=scoliosis
 93="fluid in knee"/pain in knee
 94=fracture - pelvis
 95=polymyalgia reumatica
 96=vitiligo
 97=benign tumour - nose/forehead/cheek/jaw
 98=tick bite - complications
 100=sicca syndrom
 101=rachitis
 102=aneurysma
 103=concussion
 104=fracture - right arm
 105=aching knot - throat
 106=abscess behind the ear
 107=abscess in the jaw
 108=fainting fit - low blood pressure
 109=surgery, benign tumour, breast op
 110=sleeping sickness
 111=temporalis arteria
 112=the metabolism
 113=tremor, hands/numbness hands/feet/arms
 114=fracture, shoulder/ pain shoulder/ crack
 115=surgery, carpal tunnel syndrom
 116=prepuce stricture
 117=nightmares
 118=Quincke's oedema
 119=the ears - infection/ disease
 120=infection - arm
 121=epiglottis inflammation
 122=buzzing in one's ears/disturbance of balance/ not dizziness
 123=herpes-sore on the lips
 124=burn injury
 125=hallocinations/drug side-effects
 126=dysarthri
 127= ingrown toenails/calcanoeapophysitis
 128=sepsis
 129=febris undulans
 130=TIA-attacks
 131=hear voices
 132=senile spots (op) - benign
 133=tumour,bladder, urostomi
 134=wound
 135=cyst,hemorroids rectum/analfistel
 136=lack of apetite
 137=hormonchanges, struma
 138=ratbite
 139=clot of blood,eye
 140=grointumour

Make sure to use updated list.

V401-V460 Medication NOTE! Changes in the FASS-coding system. Check before using!

Required

Medication at present. For longitudinal analyses make sure that codes are consistent across waves. (Changes have been made in the FASS-classification.)

V401, 406, 411, 416, 421, 426, 431, 436, 441, 446, 451 och V456

Medicine "Registered" (= in the FASS) medicines/drugs are registered according to the ATC-system, Anatomical Therapeutic Chemical classification system (=the FASS-code). (A correct FASS-code contains: **letter-figure-figure-letter-letter-figure-figure**.

Naprosyn =**M01AE02**).

V402, 407, 412, 417, 422, 427, 432, 437, 442, 447, 452 samt V457

Concentration given on the package is registered.

V402A, 407A, 412A, 417A, 422A, 427A, 432A, 437A, 442A, 447A, 452A samt V457A

Unit is registered according to list below:

1=mg	5=ml/dosage	9=mcg	13=
2=ml	6=g	10=mcg/dosage	
3=mg/ml	7=IE	11=mcg/ml	
4=mg/dosage	8=IE/ml	12=%	

V403, 408, 413, 418, 423, 428, 433, 438, 443, 448, 453 samt V458

Dosage/day is converted into days according to list below:

daily, for the night, etc. = 1

1 per day for 6 days/2 one day per week = 1.14

1/2 daily = .5

1 per day for 5 days/2 two days per week = 1.29

1 every other day = .5

1 per day for 5 days/.5 two days per week = .64

2 three times per day = 6

1 per week = .14

2 per week = .28

3 per week = .42

4 per week = .56

5 per week = .71

10 per week = .43

1 per month = .03

5 per month = .15

When needed = 99.97

Individual need (recommended by doctor) e.g. T. Waran, Cortison =99.97

1 every fourth hour = 6

1 every 6th hour = 4

1 every 8th hour = 3

1 every 12th hour = 2

1 every other week = .7

1/2 three times per week = .21

1/2 four times per week = .28

5 for two days = 2.5

Etc.

Does not know = 99.98

V404, 409, 414, 419, 424, 429, 434, 439, 444 and V449:

Cause Subject's own statement why he/she takes the medicine. Registration according to list below: (if Subject can not answer a point is registered).

- | | |
|--|--|
| 99 = Does not know | 55 = Potassium deficiency/calcium dif |
| 01 = Insomnia /hormone-deficiency | 56 = Stomach pain |
| 02 = Gastric catarrh/ulcer | 57 = "Something is lacking" |
| 03 = Goitre | 58 = Lack of food |
| 04 = Diuretic | 59 = Palpitation |
| 05 = Thrombosis/TIA attacks | 60 = Muscle pain |
| 06 = Breast pain | 61 = Claudication |
| 07 = Blood pressure | 62 = Cold |
| 08 = Gout | 63 = The circulation |
| 09 = Nervous disorders | 64 = "Spirit raising" |
| 10 = Dizziness | 65 = Pernicious anemia |
| 11 = Pain | 66 = Psoriasis |
| 12 = Pressure in the eye/eyes | 67 = Fungus disease |
| 13 = Asthma/bronchitis | 68 = Vitamin and mineral additonate |
| 14 = The stomach/winds | 69 = Phlegm in cervix |
| 15 = Glaucoma | 70 = Shortness of breath |
| 16 = Angina pectoris | 71 = Colic |
| 17 = Frequent need to urinate/incontince | 72 = Pancreas, prevents belches |
| 18 = Varicose ulcer | 73 = The throat, the gullet |
| 19 = The heart | 74 = Rheumatic pain/rheumatic disease |
| 20 = The blood | 75 = Fungus - legs |
| 21 = Thrombosis in the eye | 76 = The nose is stopped |
| 22 = Cataract surgery/cataract | 77 = Urinary infection |
| 23 = Eczema wounds/wounds | 78 = The sleep - the pain |
| 24 = Bronchitis | 79 = Well-being in general |
| 25 = Pneumonia | 80 = Rash, dry skin/eczema |
| 26 = Restless legs/leg cramps | 81 = Mucous membranes - lower abdomen |
| 27 = Strengthening | 82 = Insect bite/tick bite |
| 28 = Lack of B12 vitamin | 83 = Muscle cramp/spasm |
| 29 = Anxiety | 84 = Ulcerous colitis |
| 30 = Sedating | 85 = Eczema in auditory meatus |
| 31 = "Because I take Furix"
(diuretic medicine) | 86 = Eczema in hair/itch in hair |
| 32 = Parkinson's | 87 = Eczema in skin |
| 33 = Winds, constipation | 88 = Removal of stomach |
| 34 = Thyroid gland/metabolic disturbance | 89 = "For the brain" |
| 35 = Diabetes | 90 = Caries/teeth/before dentist visit |
| 36 = Preventing heart attack | 91 = Side effects - neuroleptica |
| 37 = Hernia | 92 = Hormones |
| 38 = Prolapse | 93 = Varicose veins |
| 39 = Decalcification | 94 = Haemorrhoids |
| 40 = Heart burn | 95 = Osteoporosis |
| 41 = "Sand in the eyes" (allergy)/running
eyes | 96 = Swollen legs |
| 42 = Saliva restrainer | 97 = Inflammation - joints |
| 43 = Cough | 98 = Gall-bladder |
| 44 = Blood thinner | 100= Tremor - hands |
| 45 = Breathlessness | 101= The metabolism |
| 46 = Eye inflammation | 102= Rakitis |
| 47 = Vitamin addition | 103= Iron addition |
| 48 = Zinc deficiency | 104= Migraine |
| 49 = Cleaning of the urinary tract | 105= Dry mouth |
| 50 = Allergy | 106= Prostrate |
| 51 = Expectorant | 107= Erysipelas |
| 52 = Respiration | 108= Headache |
| 53 = Cancer restrainer | 109= Weak hearing |
| 54 = Diarrhoea | 110= Calcium addition |
| | 111= Numbness - legs |
| | 112= Leukemia |
| | 113= "Lung problems" |

114= Muscle inflammation
 115=Aging
 116=Temporalis arterit
 117=Cramps
 118=Plug of wax/buzzing in one's ears
 119=Because of the legs
 120="Acid blood"
 121=Night mares
 122=Otitis
 123=Mouth sore

124=Indisposition
 125=Dysatri
 126=Infection
 127=Rash
 128=Increased uric acid
 129=Epilepsy
 130=Shingles
 131=Kidney

Make sure to use most updated list!

V405, 410, 415, 420, 425, 430, 435, 440, 445, 450, 455 samt V460

Time Subject's own statement of for how long he/she has taken the medicine. Time is converted into months, as below:

1 month = 1	1 year = 12
1/2 month = .5	2 years = 24
1 week = .2	10 years = 120
2 weeks = .4	Etc.
Several years = 99	

Does not know = 999

V461-V469 Not registered medicine

"Not registered" (=not in the FASS) medicines are registered according to the diary number in Läkemedelsverket's "Reported Nature Cure Medicines".

- **V469** Number of "not registered" (=not in the FASS) medicines, which are not listed in the "Reported Nature Cure Medicines" are registered 0 if Subject is asked and (.) if not asked.

V470-V472 Medication and compliance

V473-V483 Tobacco use

- In Wave 2 and subsequent waves only variables V476-V479, V483, V484-V487, V492-V493, and V496-V497.

V484 - V491 Alcohol consumption

- In Wave 2 and subsequent Waves only V484-V487

V492-V497 Tea and coffee consumption

- In Wave 2 and subsequent Waves only V492-V493, and V496-V497

III. MEMORY AND COGNITIVE ABILITY (Protocol Twin 3)

(also Orientation items V113 - v115)

V501-V504 Self-rated memory and cognition

N504 Self-rated change in memory and cognition

(Only in Wave 2 & 3)

V505-V506 Measures to preserve memory and cognition

- v505 "earlier in life", only in Wave1

V507-V512 Cognitively demanding activities

V513-543 MMSE-Mini Mental State Examination

Note, memory items should be recoded before calculating

- Compute summary score = MMSE (30 p=max).

V546-V547 Information Test

- Compute = Part 1 + Part 2 = Inf. Test.

V549-V553 SRB2/Figure Logic/Inductive Reasoning

- Compute = Part 1 + Part 2 = Test Reasoning.

V554 - V563 SRB3/ Block Design

- v562 = sum score

V565-V569 SRB1/Verbal meaning/Synonyms

- Compute = Part 1 + Part 2 = Verbal meaning/Synonyms

V572-.. Symbol Digit

- Compute v573+575+577+579+581 (Part 1/Page1: 45 sec.)

- Compute v583+585+587+589+591 (Part 2/Page2: 45 sec.)

- (These two computes can be added)

V595 - V595 Digit Span

- V594 Digit Forward

- V595 Digit Backward

V598 Perceptual speed -Psif

V602 Thurstone's picture memory

V605 Prose Recall

V608-V615 MIR Memory Test

- V609 MIR free recall

- V610 MIR recognition = V609+V610 (max 10 p.)

V616-621 The Clock Test

- Compute v617+619+ 621 (Sum score, max = 15p).

V623 The Coin Test

IV. FUNCTIONAL CAPACITY (*Protocol Twin 4*)

V701- V750 Balance and gait

- Scoring and registering according to SATSA procedure.

- v719 Handeness (a719)

(Only in Wave 1)

V751-758 Finger agnosia

V759-v762 Perception of touch

V763-V766 Muscle strenght (+Vigorimeter below)

V767-V774 Grip strenght/Vigorimeter test

V775-V779 Lung capacity - the PEF measure

V780-V790 ADL -apparatus

For functional capacity; see also ADL-assessments below

V. CONTACTS AND FRIENDS (*Protocol Twin 5A*)

V801-V802 Feelings of loneliness

- v802 "ealier in life" Only in Wave 1

V803 - V814 Social networks: quality and frequencies

VI. ADL-CAPACITY (Protocol Twin 5A)

V815-V870 ADL/PADL - Personal ADL

- see below

V871-V898 IADL - Instrumental ADL

- see below

ADL-Scales (above) are scored in the following way:

- Each item is scored:

1. by the subject's him/herself = own rating of capacity
2. by the technician = nurse's independent rating of subject's capacity

Need of help is defined as the need of personal help to (satisfactory) manage a function.

Need of help is registered with a point (missing) if subject is unable to perform the activity even with help.

The ADL-assessment refers only to **function**. The reason(s) for compromised/ reduced functional capacity is not taken into account.

Assessment by investigating nurse:

- | | |
|---|---|
| ? | Cannot at all (=total disability) |
| ? | Big problems (below) |
| ? | Certain problems (below) |
| ? | No problems (= "normal" functioning; no limitations; no aids) |

- PADL - criteria

	<u>Big problems</u>	<u>Certain problems</u>
1. Walk indoors	Support from walls, furniture etc. Able to walk only with big difficulties (in spite of aids)	Needs sometimes Totters, walks unsteadily, slowly and carefully
2. Walk outdoors	Able to walk only with living support Uses trestles, walkers etc. with big difficulties Unable to manage curbs etc.	Manages well at good state of the road and good lighting Uses e.g. walking stick
3. Walk the stairs	Able only with living support up/not down; great effort	Demands handrail
4. Bend down and pick up something up from floor	Needs very much support; uses long time; great effort	Manages, but sluggishly and slowly
5. Get in and out of bed	Can assist him/herself, demands help by other person	Manages him/herself with effort/aids
6. Move from bed to chair	_"-	_"-

7. Rise from chair without arm rest	Help from other person; lift aids	Braces to get up; rocks
8. To stretch up over the movements	Shows much discomfort and pain	Slow and sluggish shoulders
9. Handle small things with the fingers, eg writing	Strong tremor	Tremor, fumblingness
10. Take a bath, shower	Demands living support Great risks (slipperiness)	Manages shower, not bad
11. Other personal hygiene	Manages only certain functions e.g. comb his/her hair in front, wash his/her face	Manages most things, but with some difficulty
12. Dress and undress adjusted clothes; small	Manages undressing, not dressing aids	Manages most things with
13. Toilet	Manages only handicap accessible toilet	Manages with certain difficulties
14. Eat	Needs reminders; forgets about meals	Tremor, spills. "Meal aids"
<u>- IADL - criteria</u>		
15. Housework with cleaning and laundry	Manages only a few simple, easy household duties cleaning/easy	Manages simple household duties e.g., easy laundry
16. Bedmaking	Great effort even at daily bedmaking	Manages daily bedmaking, not changing the bedclothes
17. Cooking	Manages only to heat ready made food	Manages easy cooking
18. Shopping everyday commodities	Difficulties to make plan the shopping, to pick articles, can't carry him/herself	Manages easy shopping in neighborhood store
19. Go to places out of walking distance	Manages with special vehicle short distances, few changes	Manages public transport,
20. Handle economy, bank and post business	Does not manage to keep in good order, no "general view", must have assistance	Some uncertainty; need some assistance
21. Use the telephone not disc; not the	Can answer the phone, but not make a phone call telephone book	Manages a telephone with buttons,

N870 and N898 Self-rated change in ADL performance

- Only in Wave 2 and subsequent waves

V899 Home making service

Only formal (paid for) help/home making service is allowed.

V900 Technical aids

Twin resemblances:**V911-V913 Twin resemblances concerning**

- v911 physical health
- v912 memory and thinking
- v913 well-being

V914-V914 Twin resemblances concerning

- v914 appearance
- v915 personality

(Only in Wave 1)

V916 -v918 Finally - Open ended questions

- not coded

VII. PERSONALITY, PERSONAL CONTROL AND PSYCHOLOGICAL WELLBEING *(Protocol Twin 5B)*

Selfreport inventories below:

All, except CES-D, are mailed back after the in-person testing. CES-D is administered in the in-person testing and given in an interview format.

V999 Forms given/received (V1101-)

"Partly filled out" means forms where not all questions are answered or commented on, i.e. Subject has in some way stressed that he/she does not want or can not answer. **V999** does not apply to the form which is filled out by Subject, while the nurse is sitting beside (V1001-1020).

V1001-V1020 CES-D: The Center for Epidemiological Studies-Depression Scale

- The CES-D is filled out in the in-person testing session to instruct subjects how to fill in the other scales/inventories and to make sure that we get information for all subjects who are able to be interviewed with CES-D

V1101-V119 Eysenck Personality Inventory (19 items - Identical to SATSA)
(In-Waves 1-4)

V1201-v1213 Life Satisfaction Index (13 items - Identical to SATSA)
(In-Waves 1-4)

V1301-V1312 Locus of Control (12 items - Identical to SATSA)
(In-Waves 1-4)

V1401-V1418 Health Locus of Control Scale (18 items)
(In-Waves 1-4)

V1501-1510, V1511 - 1514 Season variations scale *(Only in Wave 1)*

Before using the above scales make sure to define subscales/factors, reverse items etc and consider how to treat "missingness".

VIII. RATINGS AND ASSESSMENTS (Protocols Twin 5B)

V1601 Accuracy (Validity) in self-reports

V1602 - V1606 Vision, hearing and language

V1607 The FAST - GDS scale

- Assessment of cognitive impairment/functional incapacity in different stages of dementia

- 8 Cannot be assessed due to somatic and other problems
- 7 No decrement
- 6 Subjective deficit in word finding
- 5 Deficit in demanding employment settings
- 4 Assistance required in complex tasks (handling finances, marketing, or planning dinner for guests)
- 3 Assistance required in choosing proper clothing
- 2 Assistance required in bathing properly
Assistance required with the mechanics of toileting (flushing, wiping, and so on)
Urinary incontinence, Fecal incontinence
- 1 Speech ability limited to approximately a half-dozen intelligible words, Intelligible vocabulary limited to a single word
Ambulatory ability lost, ability to sit up lost
Ability to smile lost
Consciousness lost

V1608 The Berger scale

- Severity of dementia

- 8 Cannot be assessed due to somatic and other problems
- 7 Functions normally
- 6 Can function in any surroundings, but forgetfulness is often disruptive of daily activities
- 5 Can function without direction only in familiar surroundings
- 4 Needs direction to function even in familiar surroundings
- 3 Needs assistance to function; cannot respond to direction alone
- 2 Remains ambulatory, needs assistance to function, but cannot communicate verbally in a meaningful fashion
- 1 Bedridden or confined to a chair and responds only to tactile stimuli

V1609 Cognitive Rating (CR)

- Boo makes for each case using cognitive tests

- 1 = normal memory and cognition/no evidence of impairment
- 2 = mild dysfunction, however, within normal range
- 3 = mild cognitive impairment/dementia
- 4 = moderate cognitive impairment/dementia
- 5 = severe cognitive impairment/dementia

V1610 Dementia (DSM-III-R criteria)

- Tentative dementia: All cases diagnosed as suspects (code = 2) are worked-up according to principles in the OCTO Twin Dementia component.

NEW NOTE!!! Following the diagnostic work-up new variables were created for

- Wave 1, 2 and 3, respectively.

Code = 1 on variables **W1dem**, **W2dem**, etc refers to twins who were diagnosed with dementia in wave 1, 2, 3, etc. respectively. Code = 0 for those who were found not to meet criteria at that occasion. **Tw1dem**, **Tw2dem**, etc. refers to their twin partner (with the same codes).

V1611 Severity of dementia