MRC CFAS additional data information

The following document details some key information regarding the MRC CFAS datasets, measurements, biological resource data and the bolt on studies.

1) MRC CFAS variables in need of explanation

The following contains information on some of the key variables used across the datasets:

CENTRE   `01'=Cambridgeshire
              `02'=Gwynedd
              `03'=Liverpool
              `04'=Newcastle
              `05'=Nottingham
              `06'=Oxford

IDENT   - project number (unique within centre)

INT_CODE   - interview code

INT_NUM   - interview number
               The combination of the first 4 variables above gives a unique code for each interview.

INTV   Interviewer number (unique within centre)

DATE   - (ddmmyyyy) day, month and year of interview
               (e.g. 10/02/1992 - see additional information below).

STRT   - time (hh:mm) - start of interview

LEN   - length of interview in minutes

DOB   - (ddmmyyyy) day, month and year of birth
               (e.g. 10/02/1902 - see additional information below).

AGE   - age at screen (calculated from date of birth and date of interview).

SEX   male=1, female=2

POSTCODE   - subject's postal code (blanked out in data file)

LANG_1ST   - subject's first language. This variable has not been used (blanked out in data file)

GP   - general practice code

OBSERVER   - quality control variable. This has not been used in the screening interview as quality control
               has been monitored with taped interviews (blanked out in data file).

CONTACT   - this variable is redundant in the prevalence screening interview (blanked out in data file).

HEAD - indicates the variable at which the contact sheet has been edited. (i.e. that it has been edited).

PRIOR - this indicates the variable at which priority mode is instigated. The priority questions are the cognitive section (to obtain an MMSE score) some medication questions and observer ratings. `v10' indicates automatic priority mode at screen.

END - this indicates the variable at which the interviewer quits and goes straight to the observer ratings.
END may be initiated at any time during the interview.

EMG - this indicates the variable at which the interviewer quits the interview. Again this can be used at any time during the interview. EMG will bring interviewer straight out of the interview without being directed to any priority questions.

OUT - this indicates whether interview was successfully completed. It relates to the question after Q207 in the screening interview.

V0A - this variable will indicate whether a proxy has been used from the beginning of the interview without subject involvement. Orientation section is skipped.

V158B - this variable placed just before the cognitive section indicates whether questions are currently being answered by a proxy, and if so, cognitive items are skipped.

PROXY - indicates whether proxy has been interviewed. A proxy interview is so called if a proxy has been used for any of the interview sections (i.e. v30a, v39a, v107a, v116a, 120a, 194b).

ELIG - this indicates whether the subject is eligible for assessment. (0=no, 1=yes)

ACCT - this indicates whether the subject is willing to be interviewed at assessment stage. (0=no, 1=yes)

RELIG - this indicates whether a subject is eligible for RIS (no=0, 1=yes)

RACCT - this variable indicates whether the subject is willing to be interviewed as a part of RIS. (0=no, 1=yes)

ACATI - AGECAT score. If one or more agecat questions are missing then AGECAT = 0. This variable is the laptop definition of AGECAT. The laptop AGECAT has been used for sampling.

ACAT - AGECAT (organicity) score as originally defined by Liverpool.

XTRA - this variable is redundant in the screening interview.

V6A - this variable is a record of subject's age if different from interviewers' record of the age.

V7A - this variable once recorded the subject's date of birth if different from interviewer's record of the date of birth. In later interviews it is coded: 1 if age difference is <= 2 years; 2 if >2 years.

V8A   - calculated variable used by AGECAT (if age/dob difference is inconsistent by 2 years then V8A =1, if age/dob difference is inconsistent by 3 or more years then V8A = 2. If age and dob are not as recorded originally, but consistent AGE/DOB are altered.

V15B   - ethnicity variable. (added at version 6.)

V15C   - related to ethnicity question - for `other' ethnic origin in version 6.

V105A   - women only, menstruation.

V120B   - variable indicating whether or not permission is given by subject to pass on any relevant information to GP.
            (centres 01 and 06 only).

V157   - replaced with157aa in version 6.

V158   - replaced with158aa in version 6.

V179f   - total score on serial seven item (v179). This is used in computing an MMSE score.

V193Y   - this variable indicates whether subject took more drugs than could be entered.

BLOC   - this indicates whether an interview has been unblocked and edited.
            (1 = not edited, 0 = edited)

RIS   - this indicates whether a subject agrees to go forward to RIS after interviewer has explained in some detail the nature and involvement of RIS.

INTDATED - SAS date. This variable stores the date of interview as the number of days between Jan. 1, 1960 and the interview date. This is useful for calculating differences between dates and sorting in date order.

VER   - interview version number. A value of `5b' distinguishes those idents whose interview was version 6, but whose data was transmitted via version 5.

DOBD   - SAS date. This variable stores the date of birth as the number of days between Jan. 1, 1960 and the birth date. This is useful for calculating differences between dates and sorting in date order.

PPROX   - Paper Proxy (1 = yes)

CLASS90   - social class based on occupation
            (class 10, 20, 31(non-manual), 32(manual), 40, 50, 60 (60 = army personnel) 00 (missing)

AGEG   - age has been grouped where:- 65-69 =1, 70-74 =2 75-79 =3, 80-84 =4, 85-89 =5, 90+ =6

DX   full agecat algorithm (0=normal,1=dement, 2=depression, 3=anxiety etc.) - not got at screen interviews

ORG   indicates organicity level within DX

DEP   indicates depression level within DX

ANX   indicates anxiety level within DX

The following variable names are all prefixed by ED. These variables were added to Version 3 data and provide values to previously missing data. The information was not known at the time of interview and has therefore been separated from original interview values.

ED_V11, ED_V12, ED_V14, ED_V16, ED_V31 (prevalence screen)
ED_V7, ED_RELN (prevalence assessment informant)
ED_V2, ED_V25 (annual follow up (1))
ED_V11, ED_V11A, ED_V12, ED_V11E, ED_V11I, ED_V17, ED_V106B-I (incidence screen)

*V2a is unreliable when used with accommodation variable and its edits. i.e. V2a does not reflect the edits made to other variables.

Details of these edited variables follow:

Prevalence screen

ED_V11   indicates that marital status information has been added subsequent to interview.

ED_V12   indicates that accommodation information has been added subsequent to interview.

ED_V14   indicates that `who lives with you' information has been added subsequent to interview.

ED_V16   indicates that education information has been added subsequent to interview.

ED_V31   indicates that `any children?' information has been added subsequent to interview.

ED_CLASS indicates social class given subsequent to interview.

Prevalence assessment and informant

ED_V7   indicates that relationship to subject has been added subsequent to the interview (informant interview).

Annual follow up 1

ED_V2   indicates that type of accommodation information has been added subsequent to the interview

ED_V25   indicates that information about children has been added subsequent to the interview

Incidence screen

ED_V11   indicates that information about marital status if it has not been changed since last interview has been added subsequent to the interview.

ED_V11A indicates that information about marital status has been added subsequent to interview.

ED_V12   indicates that information about type of accommodation has been added subsequent to interview.

ED_V106B indicates that information about illnesses in the family has been added subsequent to interview.

<u>Missing values</u>

A missing value in the data file is shown as a `.' or `-1' if a numeric variable.

In some cases the variable `out' will be missing - this is due to the machine having been switched off prematurely during interview, or due to an incomplete interview where interviewer observations (and possibly other questions) were not answered.

The following list are variables that have been added after the initial screening interview was sent to centres, and can be found towards the end of the variable list. These are new or replacement variables which were incorporated into the interview by version 6. The variables are:

DISC_NO, V15A, V15B, V15C, V105A, V158AA, V158BB, V157AA, V157BB, V157CC, V193Z.

The following variables that were thought to be useful have been added by BSU. Details of the variables are given above. The variables are:

AGEGRP, INT_DATED, DOBD OPTIMA, PPROX, WAVE

The interview date and date of birth are provided in 2 forms. At the beginning of the variable list, date of interview and date of birth have been formatted to provide date as day, month and year (e.g. 10/02/92) whereas INT_DATED and DOBD at the end of the variable list are given in SAS form as described above.

The OPTIMA variable applies only to the Oxford data. CFAS has only limited data on those idents from Oxford who show OPTIMA = 1. Prevalence assessment - There may be 5 missing dates of interview - it was decided to include 5 idents from the OPTIMA study in the assessment phase, (these idents had been included in the prevalence screen phase) but data is very minimal.

The variable PPROX denotes whether ident was a paper proxy. If, having been a paper proxy at prevalence screen (pprox=1) the ident is does not carry on through the study. Only limited information is available where PPROX=1.

The WAVE variable at prevalence screen has values 1 and 2 and corresponds to the year (year 1, year 2) in which an ident was sampled.

The following variables (at prevalence screen) are character variables and should be treated as such for analysis:

STRT, GP, HEAD, PRIOR, END, EMG, V7A, V34, V68, V84A, V84B, V84C, V132, V134A, V134B, V134C, V137, V139A, V139B, V139C, V141, V143A, V143B, V143C, V146, V148A, V148B, V148C, DISC_NO, V15B.

The following variables have been taken out of the interview at version 6, being deemed too easy/demeaning.

V165, (point to the window), V187 (wave goodbye), V188 (brush your teeth).

2) MRC CFAS measurements

Mini Mental State Examination (MMSE)

There are several variables to do with MMSE (Folstein, 1975) in each interview for the 5 centres (**mmse**, **mmsg4**, **mms01**-**mms26**). In the screen interviews there is also **mmsei**. Below is some further information on these variables:

mmsei_s0 and **mmsei_s2**
- Missing values 7, 8 and 9 are recoded to the value 0. This MMSE variable is the original laptop MMSE and has been used for deciding the sample at assessment.

mmse
- MMSE in CFAS publications has been coded up so that items that could not be answered due to sensory or mobility problems ('physical items' in the table below) were recoded to zero whenever the question was not asked (interviewer recorded 9). If the interviewer recorded 7 (interviewee didn't know) or 8 (no answer) these were also recoded to zero. If a non-physical item was not asked or any question was skipped, then a person's MMSE score was declared invalid and they are given an impossible score of -1 to show this.

mms01 – mms26
- These are the appropriate questions recoded so that they are ready to be added together (if not equal to -1) to make up the MMSE score (**mmse**). All are worth 1 point with the exception of **mms16** which is worth a maximum of 5 points. The table below shows how these relate to the MMSE questions and where the questions are found in each MRC CFAS interview.

VARIABLE	QUESTION	SCREEN	ASSESSMENT	CSA
mms01	Name of city/town/village	Q4	Q183	Q10
mms02	Day of week today?	Q159	Q179	Q14
mms03	Date today – day	Q160a	Q180a	Q15a
mms04	Date today – month	Q160b	Q180b	Q15b
mms05	Date today – year	Q160c	Q180c	Q15c
mms06	Season	Q161	Q181	Q186
mms07	County	Q162	Q182	Q187
mms08	Name two main streets nearby	Q163	Q184	Q188
mms09	On what floor of building?	Q164	Q185	Q189
mms10*	What is this called? (pencil)	Q166	Q193	Q197
mms11*	What is this called? (wristwatch)	Q167	Q194	Q198
mms12*	Repeat: 'No ifs, ands or buts'	Q171	Q207	Q211
mms13-15	Repeat 3 words: apple table penny	Q178a-c		
	Repeat 3 words: tree clock boat		Q221a-c	Q223a-c
mms16	Sevens	Q179f	Q224f	Q226f
mms17-19	Recall 3 words: apple table penny	Q180a-c		
	Recall 3 words: tree clock boat		Q225a-c	Q227a-c
mms20*	Read and do: Close your eyes	Q181	Q226	Q228
mms21*	Copy this diagram (pentagon)	Q182	Q228	Q230
mms22*	Write a sentence	Q183	Q233	Q235
mms23*	Paper – take in right hand	Q184a	Q234a	Q236a
mms24*	Paper – fold in half	Q184b	Q234b	Q236b
mms25*	Paper – place on lap	Q184c	Q234c	Q236c
mms26	Address of this place?	Q3/Q5	Q7/Q8	Q9/Q11

Key: * Physical items

mmsg4

- MMSE has been grouped at every interview such that:

mmse	mmsg4
26 – 30	4
22 – 25	3
18 – 21	2
0 – 17	1
Cannot be certain of above groups MMSE falls	-1

The following derived measurements can be found within the extra variables dataset.

Angina

In MRC CFAS (5 centres), the questions relating to angina across all interviews up to year 8 were:

Prevalence screen (s0)

Q41 Have you ever suffered from angina?
Q42 Have you ever had any pain or discomfort in your chest?
Q43 Have you ever had any pressure or heaviness in your chest?
Q44 Do you get it when you walk uphill or hurry?
Q45 Do you get it when you walk at an ordinary pace on the level?
Q46 What do you do if you get it while you are walking?
Q47 If you stand still what happens to it?
Q48 How soon?
Q49 Will you show me where it was?

Incidence screen (s2)

Q41 Have you ever been diagnosed as having angina? (If yes, was that in the last two years?)
Q42 Have you, in the last two years, had any pain or discomfort in your chest?
Q43 Have you, in the last two years, had any pressure or heaviness in your chest?
Q44 – Q49 *same as in prevalence screen listed above*

First and second annual follow up interviews (f1, f3); CSA at year 2, 6 and 8 (c2, c6, s6, c8)

Q257 Since we last saw you have you been diagnosed as suffering from angina?
Q258 Have you had any pain or discomfort in the centre of your chest when walking uphill or hurrying, that is relieved quite quickly when you rest (since we last saw you)? *Possible answers: Yes, No or never walks uphill/hurries.*

All informant interviews (h0, h2, ch2, h6, h8)

Q193 Has there ever been pain or discomfort in the chest that goes away with rest? *Possible answers: No, probable angina or certain angina*.

CODING AND INTERPRETATION OF THE COMBINED ANGINA VARIABLES:

Rose (1962) produced a questionnaire from which a diagnosis of angina can be made. The questions in the questionnaire, and relevant for diagnosing angina, were questions that featured in MRC CFAS interviews: s0 and s2. For the people in these interviews who had not previously been diagnosed with angina by a doctor, the criteria of Rose (1962) were used to diagnose angina or not angina. Only when neither a positive diagnosis could be made (not all questions were answered) nor a negative diagnoses (not answering any question in such a way as to rule out angina) was a missing value assigned. The combined angina variables that have been coded up can be interpreted as follows:

Has angina been reported or diagnosed for the first time in a MRC CFAS interview?
If an individual has reported or been diagnosed with angina at one interview, then in all subsequent interviews they, by definition do not report or get diagnosed for the first time in a MRC CFAS interview. The variable definitions in full are:

angin_s0: 'ever had angina according to Rose (1962) or diagnosed by a doctor'
angin_s2: 'first report of having previously been diagnosed with angina, or had angina according to Rose (1962), *where* did not report or get diagnosed with angina at screen'
angin_f1, angin_c2, angin_f3, angin_c6, angin_s6, angin_c8: 'since last seen, had angina (roughly according to Rose (1962)) or reported having previously been diagnosed, *where* in all previous interviews did not report or get diagnosed with angina'

Table of newly reported/diagnosed angina incidents up to year 8:

Frequencies	angin_s0	angin_f1	angin_s2	angin_c2	angin_f3	angin_c6	angin_s6	angin_c8	angin_cx
Yes	2,127	42	319	64	22	81	48	18	227
No	10,447	676	6,737	1,174	472	1,330	557	307	2,445
Missing	430	202	119	413	96	322	114	65	473
Total	13,004	920	7,715	1,651	590	1,733	719	390	3,145

Missing values

Some people have missing values in the above table because they did not answer some questions or were not asked them in the first place, and had not previously reported or been diagnosed with angina. Some people have missing angina diagnoses because they never walk uphill or hurry (for angin_f1, angin_c2, angin_f3, angin_c6, angin_s6 and angin_c8) and had not previously reported or been diagnosed with angina. In s0 and s2, people who never walk uphill or hurry could receive a positive angina diagnosis but only if they could walk on the level.

Extra points

1) Angina was not graded by severity using the answer to Q45 as in Rose (1962). This was because angina could not be graded for people who skipped Q42-Q49 because they had previously been diagnosed with angina by a doctor (i.e. answered yes to Q41).
2) Whilst Q43 appears in Rose (1962) and also Rose et al. (1968), it does not appear in Rose et al. (1982) where the questionnaire is 'reproduced' and nor does it appear in the self-administered version of the questionnaire (Rose et al. 1977). There were 62 people in s0 and 25 people in s2, who according to Rose (1962) had angina, answered no to Q42 but yes to Q43. These people would not have angina according to Rose et al. (1982) or Rose et al. (1977). According to Rose et al. (1968), these may be categorised as having 'doubtful angina'. The self-administered questionnaire is slightly different in other ways including

that it is not possible to answer 'never hurries/walks uphill' to Q44. You presumably answer 'no' instead and get a diagnosis of no angina. Also, there is no recoding of 'continue at same pace' to Q46 if on nitroglycerine.

References:

Rose, G. A. (1962). The diagnosis of ischaemic heart pain and intermittent claudication in field surveys. *Bulletin of the World Health Organization*, *27*(6), 645.

Rose G, Blackburn H, Gillum RF, Prineas RJ 1982 Cardiovascular Survey Methods. Monograph Series, No.56 2nd edition Geneva: WHO

Rose, G., McCartney, P., & Reid, D. D. (1977). Self-administration of a questionnaire on chest pain and intermittent claudication. *British journal of preventive & social medicine*, *31*(1), 42-48.

Rose GA, Blackburn H, 1968 Cardiovascular Survey Methods. Monograph Series, No.56 Geneva: WHO

Intermittent Claudication (equivalently Peripheral Vascular Disease)

In MRC CFAS (5 centres), the questions related to intermittent claudication across all interviews up to year 8 were:

Prevalence screen (s0)

Q51 Have you ever suffered from intermittent claudication?
Q52 Do you get pain in either leg on walking?
Q53 Does this pain ever begin when you are standing still or sitting?
Q54 In what part of your leg do you feel it?
Q55 Do you get it if you walk uphill or hurry?
Q56 Do you get it if you walk at an ordinary pace on the level?
Q57 Does the pain ever disappear while you are walking?
Q58 What do you do if you get it when you are walking?
Q59 What happens to it if you stand still?
Q60 How soon?

Incidence screen (s2)

Q51 Have you ever been diagnosed as having intermittent claudication? (If yes, was that in the last two years?)
Q52 Have you, in the last two years, had any pain in either leg on walking?
Q53 – Q60 *same as in prevalence screen listed above*

First and second annual follow up interviews (f1, f3); CSA at year 2, 6 and 8 (c2, c6, s6, c8)

Q259 Since we last saw you have you been diagnosed as suffering from intermittent claudication?
Q260 Have you had pain in either calf on walking uphill or hurrying that only goes away with rest?
Possible answers: Yes, No, chair/bedfast or never walks uphill/hurries.

All informant interviews (h0, h2, ch2, h6, h8)

Q187 Has there ever been pain or discomfort in the legs on walking that goes away with rest? *Possible answers: No, probable intermittent claudication or certain intermittent claudication*.

CODING AND INTERPRETATION OF THE COMBINED INTERMITTENT CLAUDICATION VARIABLES:

Rose (1962) produced a questionnaire from which a diagnosis of intermittent claudication (IC) can be made. The questions relevant for diagnosing IC were questions that featured in MRC CFAS interviews: s0 and s2. For the people in these interviews who had not previously been diagnosed with IC by a doctor, the criteria of Rose (1962) were used to diagnose IC or no IC. Only when neither a positive diagnosis could be made (not all questions were answered) nor a negative diagnoses (not answering any question in such a way as to rule out IC) was a missing value assigned. The combined IC variables that have been coded up can be interpreted as follows:

Has intermittent claudication been reported or diagnosed for the first time in a MRC CFAS interview?
If an individual has reported or been diagnosed with IC at one interview, then in all subsequent interviews they, by definition do not report or get diagnosed for the first time in a MRC CFAS interview. The variable definitions in full are:

intcl_s0: 'ever had IC according to Rose (1962) or diagnosed by a doctor'
intcl_s2: 'first report of having previously been diagnosed with IC, or had IC according to Rose (1962), *where* did not report or get diagnosed with IC at screen'
intcl_f1, intcl_c2, intcl_f3, intcl_c6, intcl_s6, intcl_c8: 'since last seen, had IC (roughly according to Rose (1962)) or reported having previously been diagnosed, *where* in all previous interviews did not report or get diagnosed with IC'

Table of newly reported/diagnosed angina incidents up to year 8:

Frequencies	intcl_s0	intcl_f1	intcl_s2	intcl_c2	intcl_f3	intcl_c6	intcl_s6	intcl_c8	intcl_cx
Yes	503	67	135	106	44	99	49	15	267
No	12,004	632	6,852	1,055	416	1,252	528	286	2,234
Missing	391	216	134	484	128	371	142	85	629
Chair/bedfast	106	5	54	6	2	11	0	4	15
Total	13,004	920	7,175	1,651	590	1,733	719	390	3,145

<u>Missing values</u>

Some people have missing values in the above table because they did not answer some questions or were not asked, and had not previously reported or been diagnosed with IC.
Some people have missing IC diagnoses (for intcl_f1, intcl_c2, intcl_f3, intcl_c6, intcl_s6, intcl_c8) because they never walk uphill or hurry or were chair/bedfast, and had not previously reported or been diagnosed with IC. In s0 and s2, people who never walk uphill or hurry could receive a positive IC diagnosis but only if they could walk on the level.
People who were chair/bedfast (intcl_?#=9) could not be diagnosed by Rose (1962) and these people, if they had not reported having previously been diagnosed with IC, were separated from the missing category (intcl_?#=-1).

<u>Extra points</u>

1) Intermittent claudication was not graded by severity (using the answer to Q56) as in Rose (1962). This was because IC could not be graded for people who skipped Q52-Q60 because they had previously been diagnosed with IC by a doctor (i.e. answered yes to Q51).

2) In the self-administered version of the Rose questionnaire (Rose et al. 1977) you cannot answer 'never hurries/walks uphill' to Q55. You presumably answer 'no' instead and get a diagnosis of no IC. This is the only difference between the interviewer administered and the self-administered version of the questionnaire.

References:

Rose, G. A. (1962). The diagnosis of ischaemic heart pain and intermittent claudication in field surveys. *Bulletin of the World Health Organization*, *27*(6), 645.

Rose, G., McCartney, P., & Reid, D. D. (1977). Self-administration of a questionnaire on chest pain and intermittent claudication. *British journal of preventive & social medicine*, *31*(1), 42-48.

Extended Mental State Exam (EMSE)

At the 2 screening interviews, subjects were asked a range of questions relating to cognitive function. These include the Mini-Mental State Exam (MMSE, Folstein et al., 1975 – see above) which has a maximum score of 30, and a selection of additional questions from the MRC Alzheimer's Disease Workshop (1987), also with an additional maximum score of 30. The additional items combined with the MMSE comprise the Extended Mental State Exam (EMSE).

Questions that may have been missed due to sensory or motor impairment were recoded to 0 (i.e. treated as not able to answer the question correctly). Such questions include those involving writing or drawing, or those involving picture or object recognition. Furthermore, in the MRC additional items, subjects are asked to recall an address that they have previously been asked to write. If the subject was physically unable to write the address, it should have been repeated twice by the interviewer and then the subject would be asked to recall the address. However, as evidenced by the large number of missing values for these items, it is suspected that some interviewers may have skipped eliciting this recall because of the subject's physical limitations. Therefore, the recall of the written address was categorized as a physical item and missing values were recoded to 0. For those questions that were not physical, missing items were left coded as missing. A small number of people were just missing 1 or 2 items and these have been recoded to 0 so that they may have an EMSE score.

The items making up the EMSE were the MMSE questions (listed above) plus the following:

Q No	Question		Q No	Question
Q168	Naming – keys		Q185	Write address (score 2 if correct; 1 if poor but acceptable)
Q169	Naming – envelope		Q189	Similar – fruit (score 2 if abstract response, 1 if a concrete response)
Q170	Number of animals named (score 0 if name 0; 1 if name 1-9; 2 if name 10-14; 3 if name 15-19; 4 if name 20-24; 5 if name 25+)		Q190	Similar – transport (score 2 if abstract response, 1 if a concrete response)
Q172a	Recent recall – pencil		Q191a	Recall – first name
Q172b	Recent recall – wristwatch		Q191b	Recall – surname
Q172c	Recent recall – keys		Q191c	Recall – no. of street
Q172d	Recent recall – envelope		Q191d	Recall – street
Q173	Prime Minister		Q191e	Recall – county
Q174	US President		Q192a	Picture recognition – shoe
Q175	Union Jack colours		Q192b	Picture recognition – glasses
Q176	Neville Chamberlain		Q192c	Picture recognition – pipe
Q177	Guy Burgess			

References:

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician.*Journal of psychiatric research*, *12*(3), 189-198.

Report from the MRC Alzheimer's Disease Workshop (1987), Medical Research Council

The Cambridge Cognitive Examination (CAMCOG) and subscales (Roth, 1988)

CAMCOG and its subscales has been coded up at prevalence and incidence assessments (ccog_a0, ccog_a2), annual follow ups 1 and 2 (ccog_f1, ccog_f3), combined screen and assessments at years 2, 6, 8 and 10 (ccog_c2, ccog_c6, ccog_s6, ccog_c8, ccog_cx). It has not been possible to do this at the prevalence and incidence screen interviews (s0, s2) because the questions involved were not asked then.

Cognitive function	Subscale	Variable	Description	Assessment	CSA	Points	Total
Orientation		scgor	Day*	Q179	Q14	1	10
			Date*	Q180a	Q15a	1	
			Month*	Q180b	Q15b	1	
			Year*	Q180c	Q15c	1	
			Season*	Q181	Q186	1	
			County*	Q182	Q187	1	
			Town	Q183	Q10	1	
			Streets*	Q184	Q188	1	
			Floor*	Q185	Q189	1	
			Place*	Q7/Q8	Q9/Q11	1	
Language	Comprehension	scglc	.Nod	Q186	Q193	1	9
			.Touch	Q187	Q192	1	
			.Ceiling	Q188	Q190	1	
			.Tap	Q189	Q191	1	
			Hotel	Q190	Q196	1	
			Village	Q191	Q194	1	
			Radio	Q192	Q195	1	
			.Read1	Q226	Q228	1	
			.Read2	Q227	Q229	1	
Language	Expression	scgle	Hammer	Q203	Q210	1	21
			Chemist	Q204	Q209	1	
			Bridge	Q205	Q207	2	
			Opinion	Q206	Q208	2	
			.Name obj.	Q195-200	Q199-204	6	
			Fluency	Q202	Q206	6	
			.Ifs*	Q207	Q211	1	
			.Address	Q236	Q238	2	
Memory	Remote	scgmm	WW1	Q210	Q214	1	6
			WW2	Q211	Q215	1	
			German	Q212	Q216	1	
			Russian	Q213	Q217	1	
			Mae	Q214	Q218	1	
			Kidnap	Q215	Q219	1	
Memory	Recent	scgcm	Queen	Q216	Q220	1	4
			Heir	Q217	Q221	1	
			PM	Q218	Q75	1	
			News	Q220	Q222	1	
Memory	Learning	scglm	.Recall pics	Q208a-f	Q212a-f	6	17
			.Recog. pics	Q209a-f	Q213a-f	6	
			.Recall addr.	Q243a-e	Q245a-e	5	

Attention/ Calculation		scgac	Count	Q223	Q225	2	8
			Sevens*	Q224f	Q226f	5	
			Calculation	Q242	Q244	1	
Praxis		scgpr	.Pentagon*	Q228	Q230	1	12
			.Spiral	Q229	Q231	1	
			.Cube	Q230	Q232	1	
			.Clock	Q231-2	Q233-4	3	
			.Envelope	Q235	Q237	1	
			.Wave	Q237	Q242	1	
			.Cut	Q238	Q240	2	
			.Teeth	Q239	Q241	2	
Abstract thinking		scgat	Similarities	Q244-7	Q246-9	8	8
Perception		scgpc	.Faces	Q248a-b	Q250a-b	2	8
			.Views	Q249a-f	Q251a-f	6	
TOTAL							103

Key: * Items in MMSE also   /   . physical items

Three items were not asked from the standard CAMCOG interview (Roth, 1988). The omitted items were the tactile recognition of coins (which is omitted in the revised CAMCOG-R (Roth, 1998)) and calculating their sum (omitted because UK coins had just changed), and recognition of two people in the room. These items counted for 4 points and hence the maximum score that could be achieved was 103 rather than 107. The subscales are defined as in CAMCOG-R (Roth, 1998) except the attention/calculation and the perception subscales which are worth one point less due to an item missing.

Questions that may have been missed due to sensory or motor impairment (the 'physical items' identified above by a dot before the description) were recoded to 0 (i.e. treated as not able to answer the questions).

Some questions (i.e. nod, hotel, hammer, chemist, teeth, wave) were skipped in the combined screen and assessments. These were recoded to correct if previous questions were answered correctly for all interviews.

When just one item was missing, 0 was imputed so that the whole scale would not be missing. The various subscales were calculated before this final stage.

Number of people with complete CAMCOG score by interview:

Interview	s0	a0	f1	c2	s2	a2	f3	c6	s6	c8	cx
n	0	2,162	714	1,224	0	1,238	493	1,489	698	335	2,954
N	13,004	2,640	920	1,651	7,175	1,463	590	1,733	719	390	3,145
%	0	82	78	74	0	85	84	86	97	86	94

See Williams et al. (2003) for psychometric properties and normative values based on a first attempt at coding ccog_a0 and its subscales.

References:

Williams, J. G., Huppert, F. A., Matthews, F. E., & Nickson, J. (2003). Performance and normative values of a concise neuropsychological test (CAMCOG) in an elderly population sample. *International journal of geriatric psychiatry*, *18*(7), 631-644.

Roth, M., Huppert, F. A., Tym, E., & Mountjoy, C. Q. (1988). The Cambridge examination for mental disorders of the elderly (CAMDEX). *The Cambridge Examination for Mental Disorders of the Elderly (CAMDEX)*.

Roth, M., Huppert, F. A., Mountjoy, C. Q., & Tym, E. (1998). The Cambridge examination for mental disorders of the elderly–revised. *The Cambridge Examination for Mental Disorder of the Elderly-revised*.

ADL-IADL disability / IADL disability / No ADL or IADL disability

Our classification splits people into one of four groups. The first is those who have ADL-IADL disability and is based on activities of daily living (ADL) and instrumental activities of daily living (IADL). This group require help at least several times per week. The second is those who have IADL disability and are not in the first group, and this is based on two IADLs. This group require help regularly. The third group is those that have no ADL or IADL disability, and the fourth group is those who were unclassifiable due to their pattern of missing data.

ADL-IADL disability requiring help at least several times per week (disab = 2)

Questions which determine ADL-IADL disability in screen/combined screen and assessment interviews are:

Q122/Q299 Are you able to wash all over or bath?
Q127/Q304 Are you able to prepare and cook a hot meal? [This is an IADL]
Q130/Q307 Are you able to put on your shoes and socks or stockings?

Possible answers to questions above:

0 = (No), needs help
1 = (Yes), some difficulty   *(Use of special aids: Code 1)*
2 = (Yes), no difficulty

Q149/Q313 Mobility of subject *(possible answers:)*

1 = Usually ambulant non-housebound
2 = Usually ambulant housebound
3 = Chairfast permanently
4 = Bedfast permanently

A person has ADL-IADL disability if they need help with washing or hot meals or shoes and socks (any of the first three questions answered 0) or if they cannot get around outside (last question answered as 2, 3 or 4).

It is inferred that if a person answered the first few questions showing they were unfocussed in time (at Q10/Q15c), they have ADL-IADL disability. These people were asked a select subset of questions (i.e. went into priority mode) which did not include the above questions with 10% of those at prevalence screen that had ADL-IADL disability classified on this basis.

If a person did not need help with washing or hot meals or shoes and socks (i.e. all of first three questions answered 1 or 2) and they could get around outside (i.e. last question rated 1) then they were divided into IADL disability or no ADL or IADL disability.

IADL disability (disab = 1)

A person has IADL disability if they need help with heavy housework or shopping and carrying heavy bags.

Q125/Q302 Are you able to do the heavy housework?
Q126/Q303 Are you able to shop and carry heavy bags?

No ADL or IADL disability (disab = 0)

A person has no ADL or IADL disability if they do not need help with washing, hot meals, shoes and socks, heavy housework or shopping and carrying heavy bags, and they can get around outside. If a person did not need help with the two IADLS* and had some missing data on the ADLs then they were coded as having no ADL or IADL disability (by the hierarchical nature of ADL and IADL). Also a person could be recoded to no ADL or IADL disability if they had one IADL missing and ADL disability had been ruled out. These ways of dealing with missing data affected a very small number of people
* For this paragraph, preparing a hot meal is treated as an ADL

Unclassifiable (disab = -1)

This only affects people who did not answer all of the questions above. This includes a lot of cognitively frail people who went into priority mode but not immediately after the first few questions.

disab	s0	f1	c2	s2	f3	c6	s6	c8	cx
0	8,819	423	763	4,744	296	819	505	188	1,575
1	1,763	115	202	1,273	78	305	90	72	761
2	2,259	286	460	1,063	154	500	106	106	700
-1	163	96	226	95	62	109	18	24	109
Total	13,004	921	1,652	7,175	590	1,734	719	391	3,145

Modified Townsend Disability Scale

This scale consists of 9 activities: cutting own toenails, washing all over or bath, getting on a bus (replaced running to catch a bus in Townsend (1979)), going up and down stairs, heavy housework, shopping and carrying heavy bags, preparing and cooking a hot meal, reaching an overhead shelf and tying a good know in string (Bond, 1982).

For each activity, a person was assigned a score of 2 if they needed help; 1 if they had some difficulty or used aids in order to complete the activity; and 0 if they had no difficulty and did not need any use of aids.

The scores (town_?#) from these activities are added up to form a score from 0 – 18 where 0 is no functional incapacity and 18 is very severe functional incapacity.

The relevant questions are Q121-9 in the screen interview and Q298-306 in the combined screen and assessment interviews. At assessment interviews, these questions were not all asked.

Getting on a bus, and to a lesser extent, going up and down stairs were quite often missing, and so a score of 2 was imputed if a person's mobility as assessed by interviewer (Q149/Q313) was poor. If these activities were still missing then if not asked, a score of 2 was given, and if no answer or the interviewee didn't know, a score of 1 was given.

A person had an unclassifiable score (town_?# = -1) if they were missing an answer to any questions other than getting on a bus and going up and down stairs. This mostly happened to people who went into priority mode due to being disorientated in time and space.

This scale of functional incapacity has also been dichotomized (towng_?#) where a score of 1 is given if the scale was 11-18, and 0 if the scale was 0-10. If someone did not have a modified Townsend Disability score, but they were likely (or certainly) going to fall one side of 10/11, they were coded.

Percentage of people with town_?# and town_?# scores at each interview:

Interview	s0	f1	c2	s2	f3	c6	s6	c8	cx
town_?#	96.2	78.7	74.4	97.2	83.4	83.8	95.0	82.6	92.0
towng_?#	97.0	81.3	76.0	97.9	84.4	86.8	97.1	86.7	94.2
Total	13,004	920	1,651	7,175	590	1,733	719	390	3,145

References:

Bond, J., & Carstairs, V. D. (1982). *Services for the elderly*. Edinburgh: Scottish Home and Health Department.

Townsend, P. (1979). Poverty in the United Kingdom. Harmondsworth, UK; Pelican

Dementia Scale of Blessed (1968)

As has been done by other researchers (e.g. Roth, 1998), the section on personality, interests and drive has been discarded and a score from 0-17 has been produced. The score has been composed for individuals where an informant was interviewed at prevalence assessment (bless_h0); incidence assessment (bless_h2); and at combined screen and assessment at years 2 (bless_ch2); 6 (bless_h6); 8 (bless_h8) and 10 (bless_hx).

The items of the scale, their corresponding questions, ways of dealing with missingness and maximum points are outline below. The comment 'go to other interviews' means go to the same question(s) on earlier or later informant interviews. Earlier interviews are used if they were unable to perform the task. Later interviews are used if they were able to perform the task.

1) <u>Inability to perform household tasks (max score = 1)</u>
Q41 Does s/he have difficulty performing common household tasks, for example, can s/he make a cup of tea? (Recode 9 ('due to disability') to 0 ('no difficulty'))
If missing:
Q16d (new after h0) Is s/he less able to take care of her/himself without help?
If still missing: go to other interviews.

2) <u>Inability to cope with small sums of money (max score = 1)</u>
Q42 Does s/he have difficulty managing small amounts of money?
If missing: go to other interviews. *If still missing:* assume can't use money if Q42 not asked, recode to 0.

3) Inability to remember short lists of items, e.g. in shopping (max score = 1)
Q17 Can s/he remember short lists of items when shopping? (For example if s/he went to buy 3 things would s/he remember them or be able to tell someone else what s/he needs?)
If missing: go to other interviews.
If still missing: Q15 Has s/he had any difficulty with her/his memory? (If yes: Have you noticed any change over the last year or two?)

4) Inability to find way about indoors (max score = 1)
Q27 Does s/he have difficulty finding the way around the home (or ward), or finding the toilet?
If missing: go to other interviews.
If still missing: and few or no problems with Q28 (see below), assume fine on this question.

5) Inability to find way about familiar streets (max score = 1)
Q28 Has s/he had difficulty finding the way around the neighbourhood, for example, to the shops or post office near home? (If yes, Has there been any change in the last year or two?)
If missing: Q20 Has s/he had difficulty finding her/his direction or has lost the way when you have been out together or s/he has been out alone? Have you noticed any change over the last year or two?
If still missing: and few or many problems with Q27 (see above), assume difficulty with this question.
If still missing: go to other interviews.

6) Inability to interpret surroundings (max score = 1)
Q26 Does s/he have difficulty in telling the difference between people such as visitors, relatives and doctors?
If missing: Q26a (new after h0) Does s/he ever mistake you (or (other) family members or friends) for someone else?
If still missing: go to other interviews.

7) Inability to recall recent events (max score = 1)
Q19 Is there difficulty remembering what happened yesterday?
If missing: go to other interviews.
If still missing: Q25 Does s/he have difficulty remembering when s/he last saw you?

8) Tendency to dwell in the past (max score = 1)
Q23 Does s/he tend to talk about what happened long ago rather than in the present?
If missing: go to other interviews.

9) Eating (max score = 3)
Q44 Does s/he have difficulty feeding her/himself?
If missing: go to other interviews.

10) Dressing (max score = 3)
Q43 Does s/he have difficulty dressing? In what way? (Is help needed?) (Recode 9 ('due to disability') to 0 ('no difficulty'))
If missing: go to other interviews.

11) Complete sphincter control (max score = 3)
Q45 Does s/he ever wet or soil her/himself by mistake? (How often?)
If missing: go to other interviews.

Questions from items 4, 5, 9 and 11 featured in skip sections and hence persons not entering the skip section have no difficulties.

Many people did not have an answer to item 5 (inability to find way about familiar streets). It was fairly common for people to have up to 2 answers missing for the first 8 items (often items 4 and 5). As none of these questions dominate the scale, 0 was imputed for up to 2 of these questions, and a score given.

There is a bias in that cognitively frail people were more likely to have HAS interviews than cognitively intact people.

bless_	h0	h2	ch2	h6	h8	hx
n with score	2,115	1,130	1,317	351	89	331
N	2,197	1,162	1,356	382	96	352
% no score	3.7%	2.8%	2.9%	8.1%	7.3%	6.0%

References:

Blessed, G. T. B. E., Tomlinson, B. E., & Roth, M. (1968). The association between quantitative measures of dementia and of senile change in the cerebral grey matter of elderly subjects. *The British Journal of Psychiatry*.

Roth, M., Huppert, F. A., Mountjoy, C. Q., & Tym, E. (1998). The Cambridge examination for mental disorders of the elderly–revised. *The Cambridge Examination for Mental Disorder of the Elderly-revised*.

Hachinski Ischaemic Score (HIS)

The HIS (Hachinski et al. 1975) has been coded up on all those who we classified as demented and for whom we had informant interviews. The notes of Wade et al. 1987 were particularly helpful. The HIS is coded up at prevalence assessment (h0); incidence assessment (h2), combined screen and assessments [CSA] at years 2 (ch2), 6 (h6), 8 (h8) and 10 (hx).

The questions and points for each component are given below. All questions are from informant (HAS) interviews unless stated otherwise. Answers to questions are given in brackets like this (first answer that would score positively / second answer that would score positively … : first answer that would score negatively / second answer that would score negatively).

With the exception of components D (Nocturnal confusion) and E (Relative preservation of personality), just one piece of evidence was enough to get the whole component positively scored. For D, both questions had to be answered 'Yes'. For E, one piece of evidence in favour of a change in personality was enough to score it negatively. Components were missing if there was no evidence in favour or against the component. When appropriate, answers from backup questions were used to reduce the number of missing components and missing HIS scores. With the exception of component A (abrupt onset), this affected very few individuals and so these questions are not mentioned.

A) Abrupt onset (max score = 2)

Q79 Did (the problems/symptoms/illness) happen suddenly, in a matter of hours or over   days, or did it happen slowly over weeks or months? (>=0.5 months: <0.5 months)

Backup questions - any evidence from:
Q31 Did these problems with memory begin rapidly or gradually? (Rapid onset 1-3 days probable/certain /Rapid onset 4-21 days probable/certain: Gradual onset probable/certain)
Q36 Have these difficulties with thinking and making decisions developed in a gradual manner or have they come on suddenly? (Sudden : Gradual)
Q47 Have these (aphasia/apraxia) difficulties developed gradually or did they come on suddenly? (Sudden : Gradual)

B) Stepwise deterioration (max score = 1)
Q37 Have these difficulties (with thinking and making decisions) developed in steps and stages? (Yes : No)

C) Fluctuating course (max score = 2)
Q57 Are there periods lasting days or weeks when his/her thinking seems quite clear and then muddled? (Yes : No)
Q81 Has the (present illness) tended to vary a lot, day to day, week to week, becoming worse and then perhaps improving for a while - up and down? (If yes, how much did it vary? How long did these periods last?)
(Mild/Moderate or marked fluctuation : No fluctuations)

D) Nocturnal confusion (max score = 1)
Q59 Are there long periods during the day when s/he is lucid and not confused (that is, knows where s/he is and knows what s/he is doing and saying)? (Yes : No) AND
Q60 Does s/he get confused at night, wander about or talk nonsense? (Yes : No)

E) Relative preservation of personality (max score = 1) - includes preservation of insight

Q48 Have you noticed any changes in his/her personality such as the way s/he behaves socially (with other people)? (No : Yes)
Q52 How does s/he treat you (his/her relatives, friends) now. Is there a tendency to show a lack of interest, concern or affection? (No : Mild/Severe)
Q302 (Assessment) / [Q364 CSA] Observer: Lack of insight into present disability (No : Yes)

F) Depression (max score = 1)

dep_?# [Assessment/CSA] from the AGECAT algorithm (dp3/dp4/dp5/dn3/dn4/dn5 : d0/d1/d2)
Q63 Has there been any indication that s/he may be depressed, for example, is there a loss of interest or enjoyment in things in general? (Yes : No)
Q68 Do you think s/he is depressed? (Yes : No)

G) Somatic complaints (max score = 1)

Q276 (Assessment)[Q334 CSA] Observer: Gait normal, just unsteady (Mild/Severe : Absent)
Q94 (Screen) [Q290 CSA] Do you suffer from regular headaches? (Yes, non-specific : No/Yes, migraine)
Q74 (Assessment)[Q104 CSA] Do you often feel dizzy? (More than once per week : No or rarely)
Q203 Does s/he have a tendency to fall? (Yes : No)

H) Emotional incontinence (max score = 1)

Q202 If something happens to make subject laugh or feel sad or cry, is it sometimes difficult to control? (Fairly certain/Unsure but probably : No)

I) History of hypertension (max score = 1)

Q194 & Q195 Has s/he ever had high blood pressure? How was it treated? (Hypertension probable/Certain and Medication Probable/Certain: No/ Yes but not treated)

J) History of strokes (max score = 2)

Q201 Has there ever been a stroke or a time when part of the body became paralysed? (If YES when was that? Did it happen suddenly? (Probably/Certainly after age 40 : No history of stroke or sudden paralysis)

K) Evidence of associated atherosclerosis (max score = 1)

Q192 Has a heart attack ever been diagnosed by a doctor when several weeks rest was advised? (Probable/Certain : No)
Q187 Has there ever been pain or discomfort in the legs on walking that goes away with rest? (Intermittent Claudication Probable/Certain : No)
Q193 Has there ever been pain or discomfort in the chest that goes away with rest? (Angina pectoris Probable/Certain : No)
angin_?# / intcl_?# at all interviews up to and including current interview. First reported having angina/intermittent claudication respectively according to Rose (1962) or diagnosed by doctor? (Yes : No)

L) Focal neurological symptoms (max score = 2)

Q197 Has s/he ever had sudden blindness in one eye? (Probable/Certain : No)
Q198 Has s/he ever had weakness or difficulty with speech, memory or vision which got better after a day? (Yes : No)
Q199 Has there been a weakness in one arm or one leg, or an arm and a leg on the same side of the body? (Probably lasted <24hrs/Certainly lasted <24 hrs/ Probably lasted 24+hrs/Certainly lasted 24+hrs : No)
Q288 (Assessment) / [Q348 CSA] Observer: Dysarthria due to brain damage (Yes : No)

M) Focal neurological signs (max score = 2)

Q274 (Assessment) / [Q332 CSA] Observer: Obvious evidence of paralysis or stroke (mild/severe : no)
Q78 (Assessment) / [Q107 CSA] Observer: One or more limbs appear to be wholly or partially paralysed, or one side of the face (yes left sided/yes right sided/other : no)

The score has also been grouped (hisg_?#) such that:
1 = score 0-4
2 = score 5-6
3 = score 7-18

There are fewer missing here because often the scores of people, who had just a few missing components, would fall into one group irrespective of the missing values had they been observed.

Table of HIS scores:

Interview	h0	h2	ch2	h6	h8	hx
# demented with HAS	511	176	322	234	48	201
HIS 0-4	54%	54%	61%	59%	48%	51%
HIS 5-6	15%	19%	17%	18%	17%	17%
HIS 7-18	26%	24%	20%	18%	21%	19%
hisg_?# missing	5%	3%	2%	6%	15%	12%
	100%	100%	100%	100%	100%	100%
(his_?# missing)	16%	11%	11%	14%	23%	23%

References:

Hachinski, V. C., Iliff, L. D., Zilhka, E., Du Boulay, G. H., McAllister, V. L., Marshall, J., ... & Symon, L. (1975). Cerebral blood flow in dementia. *Archives of neurology*, *32*(9), 632-637.

Wade, J. P. H., & Hachinski, V. C. (1987). Multi-infarct dementia. *Dementia*, London: Churchill Livingstone, 209-28.

Rose, G. A. (1962). The diagnosis of ischaemic heart pain and intermittent claudication in field surveys. *Bulletin of the World Health Organization*, *27*(6), 645.

Social class / Employment

Occupations were coded according to the Registrar General's occupation-based social class divisions using Computer Assisted Standard Occupational Classification software (HMSO Publications Centre, London). For social class based on occupation (class90), women were categorised based on their partner's occupation unless they were divorced or single, in which case they were assigned a social class based on their own occupation. Social class I denotes professions; II managerial and technical workers; III Non-Manual which is separated into non-manual skilled workers (IIINM) and manual skilled workers (IIIM); IV partly skilled workers and V unskilled manual workers. These are coded 00, 10, 20, 31, 32, 40, 50 and respectively 60 for armed forces and 00 for missing.

We also have socio-economic group (seg90), standard occupational classification (soc) and employment status (estatus) which ranges from 1-7 with 0 meaning missing.

All the above scores were calculated using data collected at baseline.

References:

Office of Population Censuses and Surveys (1990). Standard Occupational Classification Volumes 1 and 2. London : HMSO.

Townsend Deprivation Index

The Townsend deprivation score is a measure of area-based socio-economic status. It does not include a component that overlaps with the individual indicators of socio-economic status. It is a composite measure that takes into account the proportion of unemployed, yet economically active, individuals aged 16-59/64, the proportion of households who do not possess a car, the proportion of households with more than one person per room, and the proportion of households that are not owner-occupied. The higher the score, the more deprived the area. Complete postcodes from 1991 for most participants were determined from either the initial interview or by entering the address into the Royal Mail Postcode Finder website (www.royalmail.com).

Postcodes were mapped to the appropriate enumeration district, which is the smallest geographic division in the UK, containing about 200 households and 400 individuals, using the Manchester Information & Associated Services (MIMAS) website conversion feature. There were 1,746 enumeration districts represented in this data set, with, at most, 60 individuals from the same enumeration district. Once the enumeration district for each individual was identified, the corresponding score was then identified using the MIMAS conversion feature.

Source of postcode (postcdfr) is coded: S0_0 Prevalence screen (if we still had their postcode); S0_1 Admin database of 1996 - for those not moved after 2 years; S0_2 Admin database of 1996 - for those who refused or died by wave 2; SC_0 Admin database of 1996 - for those that moved after 2 years - so this won't be their original postcodes; SC_1 Admin database of 1996 - for those where we don't have enough information on if they moved after 2 years.

References:

Townsend, P., Phillimore, P., & Beattie, A. (1988). *Health and deprivation: inequality and the North*. Routledge.

Education, Accommodation and Marital status at baseline with edits incorporated:

educ_s0 is v16_s0 unless ed16_s0 had a value
accom_s0 is v12_s0 unless ed12_s0 had a value
marst_s0 is v11_s0 unless ed11_s0 had a value

Weights

Design sampling fractions (and modifications) – what fraction of people from the prevalence and incidence screen interviews were to be selected for assessment at that wave:

3) Additional information on biological resources in MRC CFAS

Saliva

i) Saliva - neurological examination bolt on studies
In Cambridge and Nottingham, salivas were taken as part of the neurological examination bolt on studies. The Cambridge samples have been analysed as a pilot for the total study. The Nottingham samples were handled and stored separately. This resource was mostly exhausted in the original DNA work.

ii) Saliva – as fall back during 1996-1998 phase
In the 1996-1998 fieldwork phase, in which all assessed individuals were contacted for approach, where it was not possible to take a blood sample from an individuals, a saliva sample was obtained. This is stored with the blood DNA resource.

Bloods

i) Old Bloods
Bloods have been taken in the past in Cambridge and Nottingham (500 each), funded by a different grant stored in freezer facilities in the Department of Psychiatry, Cambridge. 10mls of whole blood, with serum from earlier endocrine analyses on 1000 bloods have been stored in freezers at -20 degrees. The Nottingham bloods have been retrieved but despite extensive searching the Cambridge bloods have not been found.

ii) DNA from 1996 – 1998
Blood was taken in the third wave of the study on assessed individuals. EDTA tubes were sent directly to the Clinical Genetics laboratory at Cambridge where DNA was extracted and stored in the diagnostic laboratory. The samples arrived in the laboratory and were logged onto the database with a unique identifier and DNA bank number. A back-up hard copy of the sample details was also made. The DNA bank number allows efficient retrieval from the -80 freezer. DNA is extracted from blood or saliva using standardised procedures. Quality control procedures were routine. The samples are stored under the usual rigorous confidential and secure manner integral to Clinical Genetics. These have been transferred to Sheffield and are at present in Exeter for collaboration with Professor Melzer (NIA grant).

iii) Serum from 1996 – 1998
Blood samples collected at the third wave of interviews were sent to the EPIC laboratory where they were handled according to the EPIC protocol. Labelled straws were filled with specific samples and are stored in clearly marked containers in liquid nitrogen Dewars. These are stored in Cambridge within the MRC Genetic Cooperative.

iv) Oxford bloods
At Oxford, independent funding was obtained to enable collection of blood samples at the second wave of interviews. These may be available for collaborative purposes on request to Oxford PI's, but are not available within the CFAS collaboration. The CFAS Study and BRAC have no role in the use of these bloods. The Oxford investigators use the phenotype data provided by the CFAS collaboration but operate under different REC understandings. MREC do, however, expect to be approached for approval of single centre work in CFAS which may require Advisory Committee approval. DNA was extracted on these samples by Dr Rubinsztein and is stored in Exeter at present. Part of the DNA has been taken to the US in an Oxford-specific genetic collaboration.

Brain donation

i) Declarations of Intention to Donate Tissue (DOI)
Centres vary in their approach to DOI and retrieval of brains. Some centres rely entirely on pre-existing agreement of the respondents and their carers. Others also carry out opportunistic collection. All centres include the more intensively investigated CFAS respondents: some centres include also those who have been screened only. Documentation of centre procedures and samples is essential to appropriate choice of material later.

ii) Brain tissue
Death notification is routinely received from the Office of National Statistics, but this is inappropriate for the purposes of brain retrieval due to the time lag of notifications. An infrastructure is in place in each centre for the ongoing collection of brains, although only funded by MRC in Newcastle. There are procedures in place for brain retrieval in each centre. Each centre follows a standard protocol for extraction and handling of the tissue, and all centres fix at least one hemisphere. Those centres with appropriate facilities snap freeze material also. Storage is currently at each centre (Gwynedd brains are stored at Liverpool), with completion of the basic CERAD neuropathological forms by the local neuropathological CFAS investigator. Such data is then transferred to the CFAS database at MRC Biostatics Unit. At present, those wishing to collaborate with the group are recommended to view the CFAS website and are then directed to an appropriate CMC member who then represents their proposal to the Group.

CERAD forms include the following information: general information and gross brain findings; vascular disease gross findings; vascular disease microscopic findings; findings in Hippocampus and neocortex; findings in brainstem; neuropathological status – without knowledge of dementia status and following CERAD criteria and knowing dementia status.

iii) Documentation
Local documentation varies with feedback to the central administration about successful collection only, rather than details of the exact location and nature of tissues available. Information was co-ordinated further with the creation of a detailed database for monitoring exact uses.

Data release

The basic principal is that linked biological and clinical data are not released. Under specific conditions this may be negotiated but proposals must be approved by BRAC.

Information linking data from the CERAD forms or genotyping information is held in MRC Biostatistics Unit, Cambridge. All neuropathological data is stored separately to respondent and informant data.

4) Additional information on the bolt-on studies of MRC CFAS

The Resource Implications Study (RIS)

The RIS, a substudy of MRC CFAS produced estimates of the number of cognitively impaired and physically disabled elderly people in England and Wales. At the screening interviews for the main CFAS study (1991/1992) 1,446 people were classified as disabled by the study and were selected to be monitored for 2 years as part of the resource implication study. Service monitoring data was subsequently available for 1,391 of these people.

Several different scales were used to categorise the participants:

- A modified Townsend activities of daily living scale was used to assess the level of help the subjects required to carry out various tasks. The activities assessed vary from personal care tasks such as washing and toenail cutting to use of public transport and cooking.
- Participants were classified as cognitively impaired using the 'AGECAT' computer algorithm.
- Participants were also classified by the 'interval of need for care'. This is based on the time interval that passes between essential activities that the subject requires help with. For example, 'long interval' means needing care less often than once daily and 'critical interval' means needing care or supervision continuously.

From the study sample and using the study definitions of disability it was estimated that there are 1.3M disabled elderly people in England and Wales, which is 15.7% of those aged 65 years and over (95% CI 15.1-16.3%).

Of the estimated 1.3M disabled elderly people:

- 3% (35,576) would be independent
- 14% (171,586) would need care less often than daily (long interval)
- 62% (778,401) would need care at some point daily (short interval)
- 21% (268,863) would need care continuously (critical interval)

Key messages - Disability:

- 38% of disabled elderly people have cognitive impairment.
- People aged over 85 years and people with cognitive impairment combined with limitations in activities of daily living make up a large proportion of those needing institutional care or intensive home support.
- Formal community services were the only source of support for 29% of physically disabled elderly people and 23% of those with physical and cognitive disabilities in the community.
- 43% of disabled elderly people were admitted to acute hospitals during the 2 year follow-up period.

Key messages – Cost of informal care:

- Of the 1,127 participants living at home 7% reported no informal support; 15% had paid support only and 78% nominated a key informal supporter.
- Key supporters were spouses (38%); daughter (30%); son (9%); daughter-in-law (4%); other relatives (11%) and friends and neighbours (8%).
- Of the 317 living in institutions 55% received a main visitor at least once a week.

- A substudy of 650 of the nominated informal supporters found 43% of these supporters reported financial costs and 45% reported lost social opportunities. The vast majority reported at least one social cost (92%) and identified one positive aspect of care giving (95%).

Key messages – Cost of formal care:

- CFAS and the RIS estimated that the total costs per year associated with dementia in England and Wales in 1994 would be £0.95 billion for men and £5.35 billion for women.
- For 2031, these costs were predicted to increase to £2.34 billion and £11.20 billion respectively.
- Recalculating assuming reduced dementia prevalence rates and improvements in mental and physical functioning resulted in lower estimates: £1.01 billion (men) and £5.77 billion (women); and £1.65 billion (men) and £7.87 billion (women) respectively.

References:

Brayne, C., Johnson, T., & Bond, J. (1999). Profile of disability in elderly people: estimates from a longitudinal population study. *BMJ*, *318*, 1108-11.

RIS MRC CFAS, Bamford, C., Gregson, B., Farrow, G., Buck, D., Dowswell, T., McNamee, P., Bond, J., & Wright, K. (1998). Mental and physical frailty in older people: the costs and benefits of informal care. *Ageing and Society*, *18*(03), 317-354.

RIS MRC CFAS, Bond, J., Farrow, G., Gregson, B. A., Bamford, C., Buck, D., McNamee, P., & Wright, K. (1999). Informal caregiving for frail older people at home and in long-term care institutions: who are the key supporters? *Health & social care in the community*, *7*(6), 434-444.

RIS MRC CFAS, McNamee, P., Bond, J., & Buck, D. (2001). Costs of dementia in England and Wales in the 21st century. *The British Journal of Psychiatry*, *179*(3), 261-266.

Healthy Active Life Expectancy

Although originally designed to investigate cognition, MRC CFAS also collects data on physical functioning and health. The longitudinal design allows incidence of disability and other health transitions to be investigated. MRC CFAS can be used to calculate nationally representative health expectancies such as Health Active Life Expectancy (HALE) at ages 65 years and above.

Data collected at the screening interviews in 1991/1992 has been used to calculate healthy life expectancies. The three areas of health examined were: functional (based on ability to perform essential activities of daily living); cognitive (based on the Mini-Mental state score, MMSE) and physical health problems.

The study concluded that preventative programmes for the older population should take into account the large differences between the young old, the middle old and the oldest old.

Summary of findings:

- Women have consistently greater morbidity than men.
- Morbidity increases sharply with age, with a more dramatic rise in women.
- Life expectancy without any morbidity is short at all ages over 64.
- As a proportion of remaining life expectancy, the period of time spent with two or more areas affected rises by the age of 90 years to 30% in men and 60% in women.

References:

Brayne, C., Matthews, F. E., McGee, M. A., & Jagger, C. (2001). Health and ill-health in the older population in England and Wales. The Medical Research Council Cognitive Function and Ageing Study (MRC CFAS). *Age and Ageing*, *30*(1), 53-62.

MRC CFAS Neuropathology Group

This study looked at the brains of 209 CFAS participants who had agreed to donate their brain to the study after death. Dementia had been diagnosed before death in 100 of the participants. Study of the brains found that a substantial number of non-demented people also had changes in their brains that might have been expected to be associated with dementia. This study suggests that additional factors may need to be present before a moderate level of Alzheimer's like pathology and vascular lesions lead to cognitive decline.

References:

Brayne, C., Matthews, F. E., Xuereb, J. H., Broome, J., McKenzie, J., & Rossi, M. (2001). Pathological correlates of late onset dementia in a multicentre, community-based population in England and Wales. Neuropathology Group of the Medical Research Council Cognitive Function and Ageing Study (MRC CFAS). *Lancet*, *357*(9251), 169-75.

Young cohort 1996

A new cohort aged 65-69 in the Cambridgeshire centre were given a screen interview at year 6 – 1997 (s6). At wave 3, all those in the Cambridgeshire centre that had not previously refused or died were approached for interview. 719 of those that had taken part in two previous screen interviews but never any assessment interviews were interviewed. This interview is labelled s6, but it was not another screen interview as the label might suggest but a combined screen and assessment interview.