ARIC Cohort Stroke Form Instructions
STR VERSION D: 07/20/05
QxQ prepared: 06/24/08

General Instructions for Field Center Abstractor/Surveillance Director:

1. Before going to the hospital to photocopy the medical record for this admission, record on the STR the Event ID number from the Cohort Eligibility Form, and complete Items 1a (hospital number) and 3 (name or Soundex).

2. Photocopy complete hospital record for the appropriate admission. Complete Items 1.b, 2, 4-15. Review records of previous admissions.

3. Complete Items 23 - 29.a, and 55.a based on review of both the record of the present admission and earlier records. If there is a history of TIA, stroke, or MI apparent, a record of a previous hospitalization, or if there has been an admission for any reason within the four weeks prior to the present admission, photocopy the discharge summary and pertinent parts of the record. If you are unsure of the history status pertaining to TIA, stroke or MI, treat as if a positive history. If unsure of the timing of other hospitalizations, treat as if they were within 4 weeks.

4. Complete Items 58 - 61 (Additional Forms Needed), and note forms needed on Cohort Event Investigation Form (CEI).

5. If a cohort case is CEL eligible only on the basis of a 438 Code, review the chart and determine whether there is any evidence there may be an acute stroke process or new neurological symptoms/signs* leading to admission or developing during admission. If there is evidence or you are unsure, copy the full chart.

6. If upon review of the chart there appears to be no evidence of an acute stroke process, or new neurological symptoms/signs, then send to the Central Abstractor only the discharge codes, history and physical, discharge summary, CT scan, cerebral angiogram, carotid ultrasound, MRI reports, consult reports and any other items you think relevant. Do not change the way you fill out the CEL form.

7. As a general rule, if the size of the chart is very large and you are not sure what to do, call the Central Abstractor to discuss ways to avoid copying it all. Generally the following parts of a medical record are not required for completing the STR Form by the Central Abstractor: intake and output sheets, respiratory therapy sheets, nutrition department and social worker forms. Pages of chest x-ray reports are usually not of use.

8. All stroke transfers are eligible for abstraction regardless of ICD code.

9. Send STR Form and medical record(s) to:

    Gina Tritle, RN
    University of Minnesota School of Public Health
    1300 South Second Street, Suite 300
    Minneapolis, MN 55454-1015

    Retain a copy of the medical record in your files.

* The STROKE Q x Q's indicate that neurological systems include: weakness, paralysis, numbness, tingling, visual disturbance, speech abnormality, difficulty swallowing, difficulty chewing, difficulty hearing, dizziness, vertigo, gait difficulty, incoordination, severe headache, seizures or decreased level of consciousness. Neurologic signs include: coma, paralysis, Babinski, syncope (unless clearly of cardiac origin), etc.

Preparing Records for Shipping

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- **Use a grease pencil and thoroughly blind the following before sending to Minnesota:**

1. Name and initials: patient (participant), physicians, nurses, relatives, and other names.
2. Patient address
3. Addresses other than the patient (participant)
4. Telephone numbers: patient (participant), spouse, etc.
5. Place of employment: name, address, phone number
6. Name of insurance company: address, phone number, policy number, all information about insurance.
7. Social security # of the patient (participant)
8. Medicaid/Medicare number
9. Hospital name and address
10. Batch # that transcriptionists use.
11. Medical record numbers
12. Birth month and day

- **Do not blind:**

1. Birth year
2. Race
3. Sex
4. Age
5. Marital Status
6. Admission date
7. Discharge date
8. Room number

- **Procedures for Sending Stroke Records to Minnesota**

1. Please send the Stroke Forms and the Hospital Medical Records to Minnesota in separate packages. Please include a Packing List in each package.
2. Please send all mailings to Minnesota using Federal Express.

This will further protect the confidentiality of the participants and because the federal express packages seem to be the most efficient way to ship

Receipt of Shipment

* Minneapolis will contact sender upon receipt of stroke shipment. If word is not received in a timely manner, first contact Minneapolis abstractors to see if shipment were received. If shipment were not received then use appropriate "tracing" strategies employed by the shipping agency.

General Instructions for Central Abstractor Completing Stroke Form:

1. Items 1-15 and several items concerning history will have been completed

by Surveillance Staff at originating Field Center. Review the entire record carefully, and begin with Item 16. Item 29.a. will be completed at the Field Center; 29.b.-j. and 30.a.-f. must be confirmed by the MD advisor.

2. The abstractor should be familiar with the ARIC Instructions for Completion of Paper Forms.

3. Write legibly. Use black or blue erasable pens. Press hard when filling in blanks or circling numbers, letters, or Xs. Pen will not photocopy if too light and will fade with time.

4. Several types of responses are used:

   Fill in the blank.

   Fill in the number, such as a date, time or medical record number.

   To answer most questions you will have several choices, the simplest of all being Yes, No, Unknown or Undetermined. For this type of response, "Yes" or "No" will be checked only if there is no doubt that the response is positive or negative based on information in the hospital record. If nothing is written down that definitely answers the question, "Unknown or Undetermined" should be checked if offered as a response category. For many questions, Undetermined (U) is treated as a "No". Be sure to check the response categories and objectives for each question.

   Sometimes a clear "Yes" or "No" is not indicated for symptoms or signs. In general, the following are synonyms:

No	Yes
Rule out	Likely
Suggestive	Apparent
Equivocal	Consistent with
Suspicious	Probable
Questionable	Definite
Possible	Compatible with
Uncertain	Presumably
Reportedly	Highly suspicious
Could be	Borderline
Perhaps	Slight/mild
Could represent	Representing
May (well) represent	
May be	
Minimal	

In Question 29.d. (referring to valve disease) mild = No.

5. Complete only the appropriate questions.

   For discrepant historical items, use the hierarchy of information credibility as defined in the HRA instructions.

6. Be sure to follow correct skip patterns, *i.e.*, follow form logic.

7. To record dates, fill in 2 digit numbers for month/day/year. Zero fill the left box for any single digit numbers (*e.g.*, 03 = March and 06/08/45 = June 8, 1945). If part of the date is missing, record = for that part. For example, if the only information regarding date is June 1945, record 06/==/45.

8. To record times, use the 24-hour clock. If the time given in the chart

is from the 12-hour clock, it should be converted to the 24-hour clock before being recorded. Explanation for conversion:

1 AM = 01:00 12 NOON = 12:00
1 PM = 13:00 12 MIDNIGHT = 24:00

If an exact time cannot be recorded (*i.e.*, is not given in the chart), the best estimate should be given. If a time cannot be clearly estimated, the following guidelines for estimating times may be used in conjunction with the admission time. For no mention of the time of day, please see xii.

i) The middle of the night = 03:00
ii) Early morning = 08:00
iii) Morning = 09:00
iv) Late morning = 10:00
v) Midday = 12 Noon = 12:00
vi) Early afternoon = 14:00
vii) Afternoon or midafternoon = 15:00
viii) Late afternoon = 16:00
ix) Early evening = 19:00
x) Evening = 21:00
xi) Late evening = 22:00
xii) No mention of time of day = 12:00 Noon = 12:00
xiii) Earlier today = 12:00 Noon = 12:00

9. After completing the STR Form, *enter the form into the Data Entry System (see APPENDIX G).* Send the form, discharge summary, and test results to:

ARIC Central Receiving
Collaborative Studies Coordinating Center
NationsBank Plaza, Suite 203
137 E. Franklin Street
Chapel Hill, NC 27514-4145

Retain a copy of the STR Form and the medical record in your files.

Instructions for Items 1 - 61:

1.a. Hospital Number: Prior to going to the hospital, enter the code number assigned to the hospital for its identification. (APPENDIX C) If outside the study community, use the appropriate code (96-99) and write in name and address.

b. Hospital Record Number: This number will be found stamped or typed on almost every page of the hospital record. The easiest place to find it is both on the medical record folder and in the upper right/left hand corner of the face sheet.

List the number from left to right. Do not add zeroes to the right of the number. If the number changes with each admission, use the appropriate number for the one (admission) being abstracted.

2. Record "Yes" if chart has been obtained. Record "No" if record cannot be obtained.

3. **Enter on CFDB Form** Name and Soundex: If the hospital does not allow abstraction of names code last, first, middle name by Soundex code.

4. **Enter on CFDB Form** Social Security Number: Record Social Security Number (enter 9 digit number only)(See Appendix G) If the hospital does not

allow full abstraction of Social Security Number, record every other digit, beginning with the first, and record = in the remaining positions.

5. **Enter on CFDB Form** Address: Record the patient's address. This should include: the house number, the street name, and the apartment, box or lot number. The last line is designated for the names of the city, county and state.

6. Discharge Diagnosis and Procedure Codes: Fill in the codes as listed on the face sheet, preferably, or discharge summary, as a second choice (up to 21 codes). Pick the source which is most complete. *If codes are not found in chart, use hospital index if available.* If digit(s) to the right of the decimal are missing from the ICD code, leave the box(es) blank on the form. Do not enter zero there unless it appears in the chart.

7. Transcribe discharge diagnoses as they appear on face sheet or discharge summary. Diagnosis listed should correspond with codes in Item 6. If not, ask field center to consult with medical records department.

8. **Enter on CFDB Form** Date of Birth: Birth date is usually found on the face sheet of each medical record. Do not use the age given by the physician on the history and physical since it may be incorrect.

9.,10. Sex and Race: Check either male or female. The following definitions should be used for determining race:

White (Caucasian). A person having origins in any of the original peoples of Europe, North Africa, or Middle East.

Black (Negro). A person having origins in any of the black racial groups of Africa.

Asian or Pacific Islander (A person having origins in any of the original peoples of the Far East, Southeast Asia, the Indian subcontinent, or the Pacific Islands. This area includes, for example, China, India, Japan, Korea, the Philippine Islands and Samoa; American Indian or Alaskan Native (A person having origins in the original peoples of North America, who maintains cultural identification through tribal affiliation).

11. Transfer From or to Another Hospital: If the patient were transferred from or to another acute care hospital, check "Yes", *fill in hospital code, as assigned in APPENDIX C,* and write the name of the hospital from or to which the patient was transferred, and the city and state in which it is located. Record the date of admission to the transfer hospital. If the patient was not transferred (*i.e.*, admit note states patient first experienced symptoms at home, work, etc.), check "No". This information can be found on the face sheet of the chart and in admitting notes. *All transfers involving acute care hospitals are eligible regardless of ICD Code.*

Transfers to rehabilitation units, rehabilitation hospitals, or chronic and extended care facilities generally are answered "No". Only if there are likely new events or diagnoses would these rehabilitation admissions be useful.
The purpose of this question is to identify recent hospitalization(s) of this patient, possibly to be reviewed at a later date.

12. Date of Arrival at this Hospital: Fill in the date the patient was admitted according to the guidelines specified in General Instructions.

13. Time of Arrival: If an exact time is not given in the chart, the best estimate should be given. See General Instructions for guidelines regarding recording times. Ambulance arrival time may be used. *If an admission time is not provided on the face sheet, search for the earliest noted time following admission on such sources as lab sheets, ECG, initial progress notes, for example. If no documentation of time whatsoever is found for admission day, follow the General Instructions for completing the STR Form and use 12:00.*

14. Date of Discharge (for nonfatal case) or Death: This information will be found on the face sheet or on the ER sheet. If there is a discrepancy in time between the two, take the later time. If the patient died, then record the date of death.

15. Discharged: Indicate vital status.

16. Timing of Death: If dead, estimate or calculate the length of time between new symptom onset and death. Chronic symptoms should not be considered here.

17.,18. The purpose of this question is to eliminate patients who did not have strokes, but who had focal neurologic deficits that were transient. If referred in Questions 17 or 18; proceed with abstraction. If you skip out of this question, it is unnecessary to complete the rest of the form. To answer Question 18, see description of neurologic symptoms below under question 19. If symptoms come and go, but no symptom lasts at least 24 hours, then answer "No". ICD 9 Code 438 is an old stroke. If there are residual symptoms circle Question 18 "Yes" and Question 19 "No", then go on to Question 20. Exactly 24 hours is taken as greater than 24 hours.

19.a. Neurologic symptoms or signs on admission: Symptoms are complaints expressed by the patient or relayed by the patient's family or friends. Signs are physical exam findings observed by a physician.

Neurological symptoms include: weakness, paralysis, numbness, tingling, visual disturbance, speech abnormality, difficulty swallowing, difficulty chewing, difficulty hearing, dizziness, vertigo, gait difficulty, incoordination, severe headache, seizures (convulsion), or decreased level of consciousness.

Neurologic signs include: coma, paralysis, Babinski, syncope (unless clearly of cardiac origin), *etc.* Do not consider carotid bruit as Yes here.

For our purpose, we are interested in new or acute findings (that is, not previously evaluated). Thus, for instance, a diabetic with long standing peripheral neuropathy who has had tingling in his feet for years would not have the same significance as someone who suddenly developed numbness in one leg.

If a patient is presenting for evaluation of neurologic symptoms that have not been previously evaluated and have occurred in the past two months, mark "Yes", even if the symptoms have resolved. If you are uncertain, describe in the summary (Question 19) and flag for field center physician review. If the patient had an old stroke with no new or recent symptoms, mark "No".

If in doubt about whether the finding is new, answer "Yes" and continue to Question 21.

b. If there are not new symptoms or signs present on admission or occurring in the recent past indicate the admission diagnosis.

20. New neurologic symptoms in hospital: The purpose of this question is to identify new symptoms that began in the hospital. Refer to neurological symptoms described above (Question 19). If the patient did not have new neurologic symptoms when admitted, and did not develop them in the hospital, it is unnecessary to continue filling out this form.

21. When did the above new symptoms begin?

Fill in boxes with month, day, and year. Treat month, day, year as separate items, *e.g.*, fill in year even if month and day are not given, enter = for the month and day. If the year is also missing, enter =. If there are multiple new symptoms, indicate the beginning of the first of the new symptoms. Within reason, fill in a date. For example, if it says "two weeks ago," subtract 14 days from the admit date.

22. Was the onset of symptoms sudden or rapid?

Mark "No" if symptoms were progressive in nature over a period longer than 24 hours. The following are examples of when to mark "Yes" response, and which description to specify. If symptoms occurred rapidly or suddenly, it should be pretty obvious from the history that patient was doing something (*i.e.*, drinking coffee) when he suddenly became symptomatic (dropped his cup and noticed he couldn't move his right hand). This would also include someone who awoke from sleep with a deficit. If a patient drops his cup of coffee and notices something wrong with his right hand which felt tingly and then over the next few minutes he realized he could no longer move it, mark "Yes". Stepwise progression is a little harder to document and may involve either stepwise worsening ("stuttering onset") of a simple symptom or several symptoms. This usually occurs over several hours to a day. For example, a patient may have a "funny sensation" on the right side of is body or feel dizzy prior to retiring in the evening. When awakening in the morning he may be weak and have some speech difficulty. Then a couple of hours later he may suddenly be a lot worse. If symptoms begin or progress over weeks to months, mark "No". If onset is not described, mark "Unknown". If you are not sure, copy pertinent parts of patient history and flag for physician review.

23. Is there a history of previous stroke?
This refers to events preceding the present acute illness and hospitalization. Synonyms for "stroke" may include some of the following: cortical infarction, intracranial hemorrhage, cerebral thrombosis, cerebral artery occlusion, cerebral infarction, subarachnoid hemorrhage, apoplexy, cerebrovascular accident (CVA), intracerebral hemorrhage. Answer "Yes" if one or more of the sources listed above makes explicit mention of previous "stroke" or states: a history of "probable stroke", a history "consistent with stroke", a diagnosis of "CVA vs. TIA", reversible ischemic neurological deficit, or partially reversible ischemic neurological deficit lasting > 24 hours. Answer "No" if absence of stroke is explicitly mentioned, if symptoms lasted less than 24 hours, if stroke was "possible" or "questionable" only, or if patient had "TIA" only with no documented residual findings. "No previous cerebrovascular disease" = no. (This means patient was normal within 24 hours after onset of symptoms and therefore did not have a stroke.) Answer "U", otherwise, or if the only information about old stroke is from a CT scan. *If a physician states history of old stroke based on a MRI/CT scan of head, answer "Yes" to history of stroke. Do not say "Yes" on the basis of a MRI/CT scan report alone.* This information is needed to distinguish first events from recurrent events

in subsequent data analysis. (See APPENDIX A for additional clarification.)

24.,25. Date and Time: Enter month and year for first event and most recent *one*. If there was only one previous event, complete Items 24 and 25 with the same date (*i.e.*, the first and most recent event were the same). If specific dates are not given, use information available to calculate date. For instance, if stroke *were* "eight years ago" subtract eight from current year. If "month" is not available, fill in "=". If dates not available, enter "=".

26. Is there a history of previous TIA (Transient ischemic attack)?
This refers to events preceding this acute illness. If admitted for first TIA, answer "No". If TIA preceded current event, answer "Yes". Synonyms for "TIA" may include: acute cerebrovascular insufficiency, spasm of cerebral arteries, insufficiency of basilar, carotid, or vertebral arteries, or neurological deficit lasting less than 24 hours. If TIA is not mentioned, only that symptoms lasted less than 24 hours, answer "Yes" to TIA, Amaurosis fugax (or transient monocular blindness) = TIA. (See APPENDIX A). Reported (by patient or family) but unevaluated TIAs should be answered "No".

27. Date and Time: Enter month and year for first event and most recent. If there was only one previous event, complete parts (a) and (b) with the same date (*i.e.*, the first and most recent event were the same). If specific dates are not given, use information available to calculate date. For instance, if TIA were "eight years ago" subtract eight from current year. If "month" is not available, fill in "=". If date not available, enter "=".

28. Is there a history of previous MI?
This information may be found in the history and physical exam done by the admitting physician or in the nurses admitting interview. This question refers to events that occurred prior to this hospitalization. Take information from the history of the resident or intern, if any, the attending physician, the cardiovascular consultant, the ER physician, nursing notes, or medical student, in that order. "History" refers to information from the patient and his family. Answer "Yes" or "No" only if mentioned, otherwise check "Undetermined". If information states silent MI, record that as a "Yes" to previous MI. An abnormal ECG, alone, stating "old MI" cannot be used for positive previous history, unless the physician verifies it. If conflicting information is recorded in two or more sources, choose the information from the most reliable source. If "No cardiac problems" or information indicates "No heart disease", "No history of cardiovascular disease", "No adult illness", "No medical history", or "Previously well", you may check "No" instead of "Undetermined". (*i.e.*, APPENDIX A).

29. This question is designed to ascertain non-atherosclerotic etiologies (causes) for stroke or diseases that may mimic or present as stroke. Parts (a) through (f) specifically are an attempt to establish the presence of an "non-carotid embolic source", a mechanism where blood clots could form in the heart and travel through blood vessels to the brain, causing a specific type of stroke. To be documented the item must have been present within four weeks prior to or during this hospitalization. Any "Yes" response must be verified by MD advisor.

a. Was there any evidence of MI?
To check "Yes" here there must be a history of severe chest pain, diagnostic or evolving ECG, or positive isoenzyme CPK-MB either four weeks before or during this admission. We need strong evidence of

MI, chest pain, an evolving or diagnostic ECG, and/or positive enzymes. If there is an MI code, but not evidence of MI, this can be checked "Unknown". Do not take admitting diagnosis of "R/O MI" alone, as we need more evidence.

b. Intracardiac Thrombus
This refers to a blood clot seen within the heart. It may also be called "intraventricular thrombus" (or clot) or "ventricular aneurysm with clot". Check to see if an echocardiogram, autopsy or cardiac CT was done. These should specify if intracardiac thrombus was present. Echocardiogram is the most frequently used clinical study to evaluate the heart for this problem. Rarely cardiac CT has been used for the same purpose. If an autopsy was performed, read the section that pertains specifically to the heart on gross examination. Coronary artery thrombosis or coronary thrombotic occlusion is not intracardiac thrombus.

Intracardiac tumor. This is also called atrial myxoma and should be reported on echocardiogram, cardiac CT, or autopsy, if present (see above).

c. Atrial fibrillation or flutter. This may also be called paroxysmal atrial fibrillation. This does not include paroxysmal tachycardia, supraventricular tachycardia, sinus tachycardia, SVT, or PAT. Check all ECGs interpretations for atrial fibrillation or flutter. It may be abbreviated as A.F., A.fib or At.fib. If present on any ECG, check "Yes".

Atrial fibrillation/flutter has important implications for stroke, regardless of the "timing" issue. Therefore, if any ECGs have atrial fibrillation/flutter, answer "Yes", even if the atrial fibrillation/flutter became apparent after the stroke occurred. The only exception to this would be if AF occurred as part of a terminal process, *i.e.*, minutes before death in a patient who previously had no record of cardiac arrhythmias.

d. Valvular heart disease. Other descriptions include:

Rheumatic heart disease - abbreviated RHD, R.Ht. dis; this includes rheumatic valvular disease of mitral, aortic, tricuspid or pulmonary valves.

Mitral valve disease - Mitral Stenosis, MS, calcified mitral valve or mitral regurgitation. Isolated mitral valve prolapse, without regurgitation = "No".

Artificial - artificial heart or prosthetic heart valve (*i.e.*, Starr Edwards Valve, Bjork Shiley valve). Do not include porcine heart valves here.

Answer "Yes" to history of any valve disease but if described as mild, the response is usually "No".

e. Subacute bacterial endocarditis (infective endocarditis). This is an infection of the heart, abbreviated as SBE, which may predispose to emboli. The patient likely would be treated with IV antibiotics. This must be specifically diagnosed by a physician to answer "Yes". If patient has acute bacterial endocarditis (abbreviated ABE) or maurantic endocarditis, a "Yes" response is also indicated.

f. Systemic Emboli are emboli to the systemic arterial circulation, *i.e.* limbs, brain, kidney. They are to be distinguished from pulmonary

emboli, which got to the pulmonary circulation, *i.e.* lungs only. A renal embolus or a femoral artery embolus is a systemic embolus. Although a cerebral embolus is technically a systemic embolus, we are looking for evidence to support the diagnosis of cerebral embolism (the presence of other systemic emboli). However, if cerebral embolus is the only type of embolus documented by angiography, this is sufficient evidence to answer "Yes". The origin of a systemic embolus may be the heart. If a "paradoxical embolus" (a systemic embolus arising "paradoxically" from the systemic veins and travelling through a septal defect in the heart) is noted in the chart, check "Yes". Also, check "Yes" if a blood clot is documented blocking a blood vessel by angiography. Read any non-cerebral or non-pulmonary angiograms for documentation of embolus. "Rule out or possible embolus" only should be coded as "No". "Consistent with" or "probable embolus" should be coded as "Yes". Thromboembolus = systemic embolus.

g.1. Hematologic Abnormality

Hypercoagulable states include promyelocytic leukemia, *protein S deficiency, protein C deficiency, antithrombin III deficiency, Factor V leiden, resistance to activated protein C,* polycythemia vera, dysproteinemias, or other blood conditions specifically termed hypercoagulable or described as causing hyperviscosity by a physician. Include Disseminated Intravascular Coagulability (DIC) if it resulted in a hypercoagulable state.

g.2. Hematologic Abnormality

Hemorrhagic conditions include blood diseases that lead to defects clotting, such as thrombocytopenia, leukemia, aplastic anemia, liver disease, vitamin K deficiency and anticoagulation therapy.* Hemorrhagic conditions may also be side effects from use of anticancer drugs which destroy the bone marrow. You may also see the term "hemorrhagic diathesis" which means a tendency to bleed. Include DIC if it resulted in a hemorrhagic state.

* Although anticoagulant drugs such as Heparin and Coumadin may cause a hemorrhagic condition, these are asked about specifically in Question 30. If they are the only reason for hematologic abnormality, answer this question "No". All other conditions listed above would be recorded as "Yes".

h. Brain tumor. Synonyms include neoplasm of brain, glioma, meningioma, astrocytoma, oligodendroglioma, pituitary adenoma, metastasis to brain, neuroma or subarachnoid cyst. Answer "Yes" if any of these are mentioned as being present by physician or in CT report. "Rule out brain tumor" with no evidence should be coded as "No". "Probable" or "consistent with brain tumor" should be coded as "Yes".

i. Trauma is described as blunt trauma to the head with LOC (loss of consciousness), contusion (brain), or concussion. Check the admitting history for mention of trauma.

Trauma may cause a basilar skull fracture (with or without cerebrospinal fluid leak or rhinorrhea), a subdural hematoma (also called subdural hemorrhage - abbreviated SDH), or less commonly an epidural hematoma.

Note: Subarachnoid blood is also commonly seen in association with trauma. This type of SAH (subarachnoid hemorrhage) should be distinguished from primary SAH which results not from trauma, but from aneurysm rupture that occurs spontaneously. If SAH occurs in the presence of trauma, answer "Yes" on this question. If SAH is

present and there is no history or evidence of trauma answer "No". If trauma followed a stroke answer "No" (*e.g.*, a fall after the onset of neurological symptoms).

j.,k. Record other nonstroke disease processes that cause:

i) Focal Neuro Deficit

a) Central nervous system:
multiple sclerosis
hyper- or hypo-glycemia
vasculitis, systemic lupus erythematosis
giant cell arteritis
tertiary syphillis
CNS abscess
radiation to head

b) Peripheral nervous system:
peripheral neuropathy
diabetic neuropathy
myopathy/muscular dystrophies
Guillain Barre Syndrome
polyneuropathy
entrapment neuropathy
i.e., carpal tunnel
radicular problems
i.e., cervical or lumbar radiculopathy

ii) Coma

severe metabolic conditions as
end stage renal disease
end stage liver disease
acute intoxications from drugs or alcohol
hypoxia or anoxia - *e.g.*, following cardiac arrest
electrolyte disturbances of sodium, calcium, magnesium, or phosphorous
encephalitis

If other conditions are present and not listed above, or you are unsure of the significance record the disease, to be checked later with the surveillance director. Each listed condition should be verified by a physician during final editing.

30. Procedures: The indicated procedures or treatments may lead to stroke in or out of the hospital. The first four procedures are invasive tests that could lead to clot formation or dislodgement of plaque, both of which may result in stroke. Answer "Yes" only if these procedures occurred prior to the neurologic event. If the neurologic symptoms had multiple onsets, answer in relation to the most important.

The same logic applies to treatment with anticoagulants such as Heparin and Warfarin. These are anticoagulant medications which may lead to a hemorrhagic complication, such as cerebral (brain) hemorrhage. If anticoagulants are being used to treat something other than the acute neurologic syndrome that this form is evaluating, answer "Yes". If the patient presents with acute neurologic syndrome, and is placed on Heparin or Coumadin as treatment for this condition, answer "No". The same logic applies to treatment with thrombolytic agents. Any answer of "Yes" must be validated by MD advisor.

Synonyms and definitions of these medications are summarized below:

a. Cardiac catheterization. Catheter is placed in the heart chambers or coronary arteries for visualization. Also called coronary angiogram, coronary angiography.

b. Open heart surgery. Includes coronary artery bypass grafts (CAB or CABG), valve replacements or commisurotomy (mitral or aortic), repair of septal defect (ASD, patent foramen ovale).

c. Cerebral angiography. Also called cerebral angiogram, carotid angiography/angiogram, or 4 vessel angio. If only the carotids are visualized, this may be referred to as a 2 vessel angio. Also include vertebrobasilar angiograms.

d. Carotid endarterectomy. Surgical revascularization of a carotid artery obstruction.

e. Therapy with Heparin or Warfarin. This is "full dose" therapy, and does not include subcutaneous (SQ) Heparin.

f. Therapy with thrombolytic agents. Intravenous or intracardiac lysing (clot dissolving) agents used in the early stages of acute MI: TPA (tissue plasminogen activator, streptokinase, urokinase, APSAC (anisoylated plasminogen streptokinase activator complex), alteplase. Other similar products which enter the market after the date of writing should be included.

31.-46. The next series of questions is to determine the specific neurologic signs or symptoms of stroke. These symptoms may have occurred prior to hospitalization, and prompted the patient to seek medical care, or may have occurred while the patient was in the hospital for a different illness. If a symptom is present, additional questions may be asked regarding duration or affected body part. See each instruction below.

SEVERAL OF THE QUESTIONS, IF ANSWERED "Yes", REQUIRE THAT ADDITIONAL INFORMATION MUST BE SPECIFIED. FOR MOST QUESTIONS, DISTINGUISH WHETHER THE DURATION OF SYMPTOMS FROM ONSET LASTED < 24 HOURS OR GREATER THAN OR EQUAL TO 24 HOURS. IF THE PATIENT DIED, THE DURATION IS FROM ONSET TO DEATH. IF THE SAME SYMPTOM BECAME MORE SEVERE (*E.G.*, MARKED WEAKNESS PROGRESSING TO PARALYSIS), DO NOT JUDGE THE "WORSENING" TO BE A NEW SYMPTOM: DURATION STILL SHOULD BE FROM ONSET OF ORIGINAL COMPLAINT. IF THE PATIENT'S SYMPTOMS RESOLVED, DURATION IS FROM ONSET UNTIL COMPLETE RESOLUTION. PARTIAL RESOLUTION SHOULD BE DISREGARDED FOR CALCULATING DURATION. IF THE SYMPTOMS COME AND GO, BUT NO SYMPTOM LASTS AT LEAST 24 HOURS, THEN ANSWER "No".

31. Headache. The occurrence headache should be described as part of the history. We are interested in headaches that are acute in onset or different in character, as opposed to a long standing history of headache with no change in pattern. If the patient had a new or an acute headache mark "Yes" and indicate whether "Severe" or "Mild/Moderate".

32. Vertigo is a sense of dizziness where the patient feels a spinning sensation like they are on a merry-go-round. This is different from a sense of light headedness or a sensation of passing out. Answer "No" if patient is said to have syncope, presyncope or dizziness.

33. Convulsions = Seizures. These may be described as generalized tonic clonic (abbreviated "GTC sz") or "partial complex" (PCS) with or without "secondary generalization" (2^{O} gen).

34. Stiff neck/nuchal rigidity. Synonyms = meningismus, (+) meningeal signs. A complaint of "stiff neck" is insufficient to count as "Yes" unless there is also stiffness to flexion demonstrated. "Neck supple" or "full ROM" count as "No". Pain on chin to chest flexion generally = Yes.

    Limitation on leg extension. This would be mentioned in the physical exam and refers to a test for meningeal irritation. A positive Brudzinski or Kernig sign occurs if a patient has pain along his spinal column that results from either neck flexion or leg extension. These may simply be referred to as "meningeal signs". If present, mark "Yes" response.

35. Coma, unconsciousness, stupor. These refer to altered states of consciousness and may also be referred to as "depressed level of consciousness", "decreased LOC", "patient unarousable" "patient obtunded" or "patient unresponsive". Syncopal episode generally = No.

    This does not include altered states of cognition such as dementia, Alzheimers disease, mental confusion, or persistent vegetative state. The question does not refer to the quality of conscious behavior but to the quantity of consciousness.

36. Aphasia. This refers to language difficulty where the patient either has difficulty producing speech and can't get the words out (Broca's aphasia) or the wrong words come out (Wernicke's aphasia). These are different from dysarthria (see Question 40 below) which is slurred speech. This is tested by tasks of repetition, comprehension, reading, writing, and naming. If paraphrasic errors are noted, answer "Yes".

37. Pre-retinal/subhyaloid hemorrhage. These would be noted on admitting physical exam or neurology/ophthalmology consultants' physical exam as part of the funduscopic exam of the eyes.

38. Hemianopia. This refers to inability to see in a particular visual field. For instance, a patient can't see to the right. This is different from being blind in the right eye. Other descriptions would include visual field cut, homonymous hemianopia (or hemianopsia) (abbreviated HH). Absent corneal reflex, nystagmus, decreased extraocular muscle strength, or abnormal pupils are "No".

    This would be noted under physical exam for eyes or cranial nerve II. If it states visual fields (V.F.), are full or full to confrontation, answer "No".

39. Diplopia. This means double vision, seeing "two" of something. Do not include blurred vision or a visual field cut (Question 38). If patient is alert, and double vision or diplopia are not specifically mentioned, record "No".

40. Dysphagia, dysarthria, dysphonia, tongue deviation. All of these are cranial nerve (CN) findings and should be noted under CN IX, X, XI or XII of the neurologic exam. If the chart says CN II to XII intact, check "No" to this question.

    Dysphagia = difficulty swallowing

    Dysarthria = slurred speech occurs when patient is actually able to talk, but sounds drunk; this is different from aphasia (see Question 36 above and APPENDIX F).

    Dysphonia = change in quality of voice.

Tongue deviation = deviation to one side when patient is asked to protrude tongue.

Under CN XII it may say "tongue to (R) (or (L))". This would be considered a positive; check "Yes" response.

41. Facial weakness may be noted under cranial nerve exam for CN VII, under general appearance or under motor exam. Frequently facial weakness is described as a decrease in the nasolabial fold on the side of the weakness. Right facial weakness may be noted as CN VII, decreased on (R) or abbreviated as decreased NLF (nasolabial fold) on (R). Ptosis is not adequate for this question. It should be recorded in Question 46.a.

Record the side involved.

42. Weakness. The symptoms should be acute in onset. Generally, the entire limb is involved, worse distally (fingers and toes) than proximally (shoulder and hips). "Drift" or "pronator drift of arm" = weakness.

Other synonyms include: hemiparesis, hemiplegia, monoparesis/monoplegia, UE = upper extremity, LE = lower extremity, (R) = right, (L) = left. If chart says "weak R side", assume body not face.

If there is weakness, paresis, or paralysis, record the affected limb and duration. "Arm" refers to any part of the extremity, including fingers or hand. Similarly "leg" includes any part of the lower extremity such as toes and/or foot.

Most grading systems for strength are on a scale of 0 - 5, where 5 is normal. Asymmetric differences in extremity strength or anything < 5 is abnormal.

43. Facial numbness. May involve one whole side of face or just the cheek and chin. Perioral numbness means numbness around the mouth and would be considered a positive response, unless there was evidence that the patient was hyperventilating. For periorac numbness, unless it is reported that one side is affected, choose answer B (both sides).

Record the side affected.

44. Loss of sensation. This may be described as numbness, marked tingling, or abnormal sensation. We are interested in acute, not chronic, unchanged sensations. Generally, the entire limb is involved, worse distally (fingers and toes) than proximally (hips and shoulder).

Other synonyms include: hemianesthesia, parasthesias, analgesia.

UE = upper extremity, LE = lower extremity, (R) = right, (L) = left

If there is a sensation deficit, record the affected limb and duration.

45. Gait disturbance. Here we are looking primarily for ataxic or staggering gait. This would be described under cerebellar or coordination portion of neurologic exam. We are interested in acute changes that have occurred in gait, not chronic problems.

Answer "No" for patients with: Parkinson's Disease and shuffling gait, hemiparetic gait (but answer "Yes" for weakness), foot drop, or "unsteady" gait.

If not tested, check "No".

46. a. Cranial Nerve III Palsy. May be written: CNIII(3), 3rd Cranial Nerve. Synonym for palsy is paralysis. Paralysis of the 3rd Cranial Nerve affects muscles of the face used in raising eyebrows, eyelids (i.e., ptosis), eyeball movements, grinning, etc.

b. Other neurologic signs/symptoms: apraxia, acalculia; agnosias - prosopagnosia, topographnosia, finger agnosia; acalculia; agraphia; neglect syndrome; bulbar or pseudobular palsy; dysconjugate gaze; decerebrate/decorticate posturing; hyperreflexia, *absent* corneal reflex, photophobia, syncope. Record *positive* or equivocal Babinski, papilledema, Horner's, *nystagmus. Consult physician if questions arise.*

The following would not be included: dizziness; blurred vision; pain syndromes; delirium; frontal release signs, confusion, dementia, carotid bruits.

c. Neuro signs and symptoms lasting > 24 hours or death in < 24 hours. This is a global question which can be answered by reviewing responses to question 16 or questions 31-45. If any sign or symptom lasts > 24 hours or if the patient died within 24 hours of the onset of new symptoms answer “Yes”. Exactly 24 hours is taken as greater than 24 hours.

47. Lumbar puncture (L.P.) Also called "spinal tap", "spinal" or "tap". Check physician progress notes for procedure note, as well as laboratory results, for first nontraumatic LP after onset of symptoms. Use results of first LP, if all traumatic. If a report is available, check "Yes"; if none, check "No". Record date. (A traumatic tap is when the needle hits a blood vessel on route to spinal cord. First tube might be bloody and the next, clearer.)

If physician states LP was traumatic, check "Yes". Check the appropriate box for appearance and RBCs. If two tubes were sent for cell counts, please record results of both. Record the results of the first tube sent under Tube 1 (even if Tube #2 was actually sent first), and the results from the last tube sent under Tube 2. For example, frequently tubes 1 and 4 are sent for cell counts. Record this under Tube 1 and Tube 2, respectively. If only one tube was counted, record the results under Tube 1 regardless of what number the tube was. Note: These results apply to only one spinal tap. If more than one LP was performed, choose the first nontraumatic tap only.

47. g. Record L.P. (Lumbar Puncture) diagnosis. Refer to APPENDIX B.

48. Cerebral angiogram. Indicate if done **after** neurologic event. If this procedure was performed more than once, use the report you judge to be most pertinent for this case (*i.e.*, the one most helpful to arrive at a diagnosis). If cerebral angiography preceded symptom onset record "No".

48. c. Record angiography diagnosis. Refer to APPENDIX B.

48.d.e. Record maximum stenosis for right and left internal carotid.

48.d.1.,e.1. Record the exact stenosis for right and left internal carotid. If the exact stenosis is not clear enter "==" and the existing categorical question should be specified in 48.d. and 48.e. *If spread is less than 5% take the lower figure. If a range of stenosis overlaps two categories choose the one where most of the range falls.*

Do not count MRI angiograms as "Yes" here on angiogram unless it is an invasive procedure. However, if a description of brain tissue is included record findings in Question 52. If MRA of neck were done and provided information on the carotid arteries, record this in Question 53.

49., 50. CT Scan (first) and CT Scan (last). This would include ACTA, EMI, CT, CAT scans, but not brain scans of the nuclear imaging (radionuclide) type. Indicate if done. If so, mark appropriate time sequence on form to relate CT to onset of symptoms.

49.d., 50.d. Record first and last CT diagnosis. Pick only one diagnosis: focus on the acute event and look for the strongest evidence if there is more than one finding indicated in the report. Refer to APPENDIX B.

51. Prehospital CTs/MRIs. There may be evidence of other CT(s)/MRI(s) performed prior to this admission but after the onset of the neurologic event. The interpretation might be recorded in the physician's or consultant's progress notes, or a formal report of that CT/MRI may be in the chart. Frequently, outside CT/MRI Scans will be officially read by the radiologist at the second hospital and dictated as if it were done there. Identify this report by comparing the date of scan to the date of admission. If "Yes", complete Questions b - d.

51. d. Record Pre-admission CT diagnosis or MRI. Refer to APPENDIX B.

52. Magnetic Resonance Imaging. Again, if done at any time and reported in the chart, it is important to note the interval between symptom onset and MRI. If this procedure was performed more than once use the report you judge to be most helpful to arrive at a diagnosis (*i.e.* look for the strongest evidence). *If MR angiography provides a description of brain tissue, record information here.*

52. d. Record MRI diagnosis. Refer to APPENDIX B.

53. B-Mode/Doppler. Also frequently referred to as "non-evasive studies" (of carotids). If done at any time and reported in the chart, indicate the test performed. If this procedure was performed more than once, use the report you judge to be most pertinent for this case (*i.e.*, the one most helpful to arrive at a diagnosis). Another term for B-mode is "real time" scan. *If MRI angiography of the neck were done and it provides information on the carotid arteries, record this here. If both ultrasound and MRA provide measurements of carotid stenosis, pick the more informative test. Consult physician as needed.*

53.c.,d. Record Ultrasound diagnosis for left and right internal carotid. Refer to APPENDIX B. Make use of ultrasound done at anytime during this admission and reported in the chart. *See instructions given for Questions 48 above.*

53.c.1.,d.1. Record the exact stenosis for right and left internal carotid. If the exact stenosis is not clear enter "==" and the existing categorical question should be specified in Questions 53.c and 53.d.

54. Craniotomy. This is any operation performed post event by a neurosurgeon that involves opening the skull. This might be done to evacuate/remove a hematoma, clip an aneurysm, or relieve intracranial pressure, etc. If this procedure was performed more than once, post event, use the report you judge to be most pertinent for this case (*i.e.*, the one most helpful to arrive at a diagnosis). A burr hole is a craniotomy.

54. c. Record Craniotomy diagnosis.

55. Autopsy. May be referred to as "post-mortem exam" or "post". First check to see if patient died. If so, in Death Note (last progress note in chart), it should state if permission for autopsy was granted. If autopsy available, photocopy and include in materials for review.

55.b-f. Record Autopsy diagnosis.

56. Abstractor Number: This is the code number assigned to you *at the Field Center*. It should be filled in each time a chart is abstracted, even one that is ineligible. Double check that your code number has been written in for all the ineligibles since this is a common error.

57. Date Abstracted: Fill in the date that the medical record was abstracted *at the Field Center*. Follow the procedure indicated in the General Instructions.

58.-62 Record additional forms required by circling "Yes" corresponding to each form required, and "No" for forms not required.

APPENDIX A

TABLE OF RESPONSE

BY TYPE OF PAST HISTORY

	Question 23 Stroke	Question 26 TIA	Question 28 MI
No prior IHD/CHD	NA	NA	NO
Previous well	NO	NO	NO
No heart disease	NA	NA	NO
No adult illness	NO	NO	NO
Negative medical history	NO	NO	NO
No cardiovascular disease	NO	NO	NO
No cardiac problems	NA	NA	NO
No neurological problems	NO	NO	NA
PRIND < 24 hours	NO	YES	NA
PRIND > 24 hours	YES	NO	NA

NA = Not applicable

APPENDIX B

DETAILED INSTRUCTIONS FOR QUESTIONS 47 - 54

Physician review is required for coding of procedures performed to assist in making the diagnosis of stroke and cerebral hemorrhage. You will record results of specific tests and diagnoses into the space provided on Questions 47-54. Review the available data and enter the appropriate diagnostic code in Items 47.g, 48.c, *48.d, 48.e*, 49.d, 50.d, 51.d, 52.d, 53.c-d., and 54.c. A complete list of diagnostic definitions is attached. In addition, there are specific examples and instructions for each code on the following pages.

Some similarities exist for all procedure codes except autopsy. For instance, any "normal study" will be coded as A (except for a normal CT done within 24 hours of symptom onset). In addition, there will be two possible responses for "nonstroke" pathology for each procedure. The first will include "exclusionary findings". These refer to specific diagnoses, whose presence would eliminate a possible stroke case from analysis. These include disease processes such as CNS tumor, infection, vasculitis and head trauma which may mimic stroke by producing focal neurologic signs and symptoms. These exclusions are described on the last page of the stroke criteria and mentioned specifically under each procedure below. Exclusionary diagnoses are coded as B for all procedures. The second type of nonstroke pathology includes all other types of unrelated findings and should only be coded if none of the other categories apply. This category is called "unrelated pathology" and coded C for all procedures with the exception of autopsy.

<u>L.P. (Lumbar Puncture)</u>

A. Normal study. All of the following must be true, if the specified test was performed:

spinal fluid is clear and colorless

WBC < 10, at least 90% mononuclear unless traumatic, then expect 1 WBC:700 RBC

protein normal

glucose normal

RBC should be < 100; unless traumatic; then must decrease between 1st and last tube. Clotted blood indicates traumatic tap as well.

Other studies done, should be normal. This includes cultures, AFB, cryptoantigen, myelin basic protein, oligoclonal bands, protein electrophoresis.

B. Exclusionary criteria include:

infection - increased WBC without evidence of old hemorrhage; (+) cultures; (+) AFB, (+) VDRL, or (+) crypto antigen
Neoplasm - (+) cytology with or without increased protein

Only use this response if it appears likely that the stroke was caused by this pathology.

C. Unrelated pathology includes:

traumatic tap - grossly bloody or pinked tinged fluid that clears by final tube. Associated with proportionate increased WBC (1:700 CBC) and increased protein

D. Bloody, Nontraumatic; xanthochromia

Angiography

A. Normal study - no abnormalities identified

B. Exclusionary pathology

Neoplasm - may be described as tumor blush or displacement of vessels due to "avascular mass"

Vasculitis - including moya moya

Subdural hematoma

Ruptured AVM

C. Unrelated pathology:

Unruptured aneurysm or AVM

Carotid artery stenosis/ulceration

Vertebrobasilar artery disease - including stenosis/tortuousity

D. Aneurysm - this should be described in vicinity of recent hemorrhage or associated with clot.

E. Avascular mass without evidence ruptured aneurysm/AVM

Stenosis: Fill in appropriate code for both right and left internal carotids. If more than one lesion, select most stenotic plaque within internal carotid. The following qualitative terms should be answered as follows:

Term	Answer
Slight/Mild/Minimal	0 - 29%
Moderate	30 - 69%
Subtotal/high grade/tight/significant	70 - 89%
Severe (occluded = 100%)	> or equal to 90%

Computerized Tomography (CT)

A. Normal study - must check timing to determine when study was done in relation to symptom onset. If $\leq$ 48 hours and normal, code D.

B. Exclusionary pathology includes:

tumor; evidence of trauma such as fractured bones, coup and contrecoup injuries, soft tissue swelling over area of hematoma; subdural hematoma, epidural hematoma, and abscess or granuloma.

C. Unrelated pathology or findings include:

old stroke

old surgery

unruptured aneurysm

generalized atrophy, encephomalacia

description of old surgery

hydrocephalus

normal variants - cavum septum pellucidum, calcification of falx/tentorim

D. Normal study, but done within 48 hours of symptom onset.

E. Subarachnoid hemorrhage - blood seen in Fissure of Sylvius, between the frontal lobes, in basal cisterns or within a ventricle with no associated intraparenchymal hematoma

F. Intracerebral hematoma - blood clot within the brain parenchyma. Occasionally these occur within secondary rupture into the ventricle or subarachnoid space. "Hypertensive" or "spontaneous hemorrhage" would be included. Typical locations include basal ganglia, cerebellum, thalamus and pons. Traumatic = "No".

G. Ischemic infarction - these are described as areas of low density (attenuation) in a typical vascular distribution. There should be no evidence of hemorrhage or subarachnoid hemorrhage. If "possible" infarction, use your best judgment of the quality of evidence and radiogist's language. Hemorrhagic infarction should be recorded as "Infarction" if it is clear infarction preceded. If unclear, use best judgment.

MRI - see CT. Also exclusionary pathology includes M.S. plaques.

U.S. - The following qualitative terms should be answered as follows:

Term	Answer
Slight/Mild/minimal	0 - 29%
Moderate	30 - 69%
Subtotal/high grade/tight/significant	70 - 89%
Severe (occluded = 100%)	> or equal to 90%

Craniotomy

A. Normal

B. Exclusionary pathology includes

tumor, subdural hematoma, epidural hematoma, trauma, abscess, AVM

C. Unrelated pathology - includes incidental aneurysm/AVM

D. Ruptured aneurysm - should describe evidence for recent bleed, or clot

E. Intracerebral hematoma - if source is related to ruptured aneurysm, code D. If there is no apparent source and blood is primarily intraparenchymal, code E.

APPENDIX C

HOSPITAL CODES (7.22.03)

	Name	Hospital Type	Notes
Forsyth County			
11	North Carolina Baptist	Teaching	
12	Forsyth County Memorial	Non teaching	
13	Medical Park	Non teaching	
96	Hospital outside study area		
Jackson			
21	University of Mississippi Med Center	Teaching	
22	Veterans Administration Hospital	Teaching	
23	St. Dominic's Hospital	Non teaching	
24	Central Mississippi Med Center	Non teaching	
25	Mississippi Baptist Hospital	Non teaching	
26	River Oaks Hospital	Non teaching	
27	Madison County Med Center	Non teaching	JHS only
28	Rankin Medical Center	Non teaching	JHS only
97	Hospital out of study area		
Minneapolis			
30	Abbott-Northwestern	Teaching	
31	Riverside Medical Center	Teaching	
32	Fairview-Southdale	Non teaching	
33	Fairview- Ridges	Non-teaching	Closed
34	Hennepin County Med. Center	Teaching	
35	Mercy Hospital	Non teaching	
36	Methodist Hospital	Teaching	
37	Metropolitan	Non teaching	Closed
38	Midway	Non teaching	Closed
39	Mt. Sinai	Non teaching	Closed
40	North Memorial	Teaching	
41	St. Paul Ramsey	Non teaching	Closed
42	St. John's Northeast	Non teaching	Closed
43	St. Mary's	Non teaching	Closed
44	Unity	Non teaching	
45	University of Minnesota Hospital	Teaching	
46	VA Hospital	Teaching	
47	Fairview	Non teaching	
48	Phillips Eye Institute	Non Teaching	
98	Hospital out of study area		
Washington Co.			
51	Washington County Hospital	Non teaching	
52	Western Maryland Center	Non Teaching	
53	VA Medical Center, WV	Non Teaching	

54	University of Maryland	Teaching
55	Frederick Memorial	Non teaching
56	Johns Hopkins Hospital	Teaching
57	Washington Hospital Center	Non Teaching
58	George Washington University	Teaching
59	Georgetown University	Teaching
60	Saint Joseph Medical Center	Non teaching
61	Washington Adventist	Non teaching
62	Sinai Hospital	Non teaching
63	Union Memorial	Non Teaching
99	Hospital out of study area	

APPENDIX D

COMA

In general, the coma exam is very simple. Most neurologists will comment on five things:

1) Level of consciousness - (stupor, lethargy, coma: *i.e.*, Question 35).

2) Pupillary position and reactivity -- (not on STR Form - can put under Question 46 "Other")

3) Extraocular response -- to either Doll's maneuver or ice water (not on stroke form may list under Question 46 as "Other")

4) Tone and posturing (list under Question 46)

5) Breathing pattern (list under Question 46)

Only one of these five points are considered in the stroke form.

What is more important when coma is present is how to interpret the other symptoms requested by the stroke form. As a general rule, a person in a coma in unable to experience symptoms. This includes headache, vertigo and double vision, etc. Most signs are unable to be elicited because of the comatose state. For instance, if someone is in a coma, he/she cannot talk. An examiner, (physician, etc.) therefore cannot assess whether or not a comatose patient is aphasic. Therefore, the correct response for aphasia during coma is unknown, which is recorded as "No".

On some occasions, focal signs are obvious -- even in coma. If a patient is spontaneously moving one side of his body, or withdraws to stimuli on one side but not the other; this asymmetry would constitute hemiparesis, or weakness on one side. On a Q by Q basis, the following principles apply when coma is present:

31) HA at onset - may be present prior to coma onset.

32) Vertigo - may be present prior to coma.

33) Seizures - these may occur at any time in association with CNS injury. Please note, however, that deceases LOC is normal following a seizure and is called a "postictal" state. If the "coma" under consideration refers only to the postictal state mark "No" under coma.

34) Meningeal Signs - these can be tested and determined despite the presence of coma. If present, mark "Yes".

36) Aphasia - in the setting of coma this cannot be assessed. Always mark "No" unless there is evidence of aphasia prior to or following coma. In all other circumstances mark "No".

38) Hemianopia - cannot be tested if patient is comatose. In stupor or lethargy, if there is asymmetry in response to visual threat, mark "Yes".

39) Diplopia - it is common for semi-comatose patients to have "dysconjugate gaze". Do not consider this "Yes" unless the patient, prior to or following coma, was able to complain of double vision.

40) Dysphagia/Dysarthria/Dysphonia - cannot test in coma. Ignore absent gag reflex when there is coma.

41) Weakness of face - Central VII may be mentioned and can be recorded. Otherwise mark "No" when there is coma.

42) Weakness of limbs - mark "Yes" in coma only if there is asymmetry in response to painful stimuli and spontaneous movements.

43) Facial sensation - probably not testable when there is coma unless specifically established by clinician.

44) Sensory loss of limbs - answer "Yes" in coma only if there is obvious asymmetry between sides. This may be difficult to distinguish from weakness. If the patient grimaces to pain on one side and withdraws on that side, but has no response to pain on the other side (no withdrawal and no grimaces) mark "Yes."

45) Gait - obviously cannot be tested in comatose patient - mark "No".

APPENDIX E

STROKE

3.3.2. Stroke

This section describes the ARIC diagnostic criteria used to define strokes. Stroke is broadly defined as a clinical syndrome consisting of a constellation of neurological findings, sudden or rapid in onset, which persist for more than 24 hours or lead to death. This definition excludes *events* whose neurologic findings are due to traumatic, metabolic, toxic, vasculitic, neoplastic, or infectious processes of the central nervous system. Based upon objective diagnostic or pathologic findings, strokes are subcategorized into five major categories: (1) Subarachnoid hemorrhage, (2) Brain hemorrhage, (3) Brain infarction, thrombotic, (4) Brain infarction, non-carotid embolic, and (5) Stroke of undetermined type.

3.3.2.1. Definite Subarachnoid Hemorrhage (SAH)

Evidence in the patient's clinical record of sudden or rapid onset of neurologic symptoms lasting for more than 24 hours or leading to death, plus must meet the criteria specified under at least one of the four paragraphs below:

1. Meets criteria (a) and (b) below:

   a) Angiographic identification of a saccular aneurysm as the source of bleeding (*e.g.*, demonstration of a clot adjacent to aneurysm or reduced caliber of otherwise normal vessels), or

   b) Blood (not traumatic) tap or xanthochromic spinal fluid, or

2. Demonstration by computerized tomography or magnetic resonance imaging of a blood clot in Fissure of Sylvius, between the frontal lobes, in basal cisterns, or within a ventricle, with no associated intraparaenchymal hematoma, or

3. Demonstration at surgery of a bleeding saccular aneurysm, or

4. Demonstration at autopsy of recent bleeding of a saccular aneurysm.

3.3.2.2. Probable Subarachnoid Hemorrhage

Evidence in the patient's clinical record of sudden or rapid onset of neurologic symptoms lasting for more than 24 hours or leading to death, plus must meet either criteria (1.) or criteria (2.) and (3.) below:

1. a) Angiographic identification of a saccular aneurysm as the source of the bleeding (*e.g.*, demonstration of a clot adjacent to aneurysm or reduced caliber of otherwise normal vessels) and

   b) Spinal tap was either not done or was traumatic, or missing or

2. One or more of the following symptoms or signs occurred within minutes or a few hours after onset:
   a) Severe headache at onset, or severe headache when first conscious after hospital admission;
   b) Depression of state of consciousness;
   c) Evidence of meningeal irritation;
   d) Retinal (subhyaloid) hemorrhages and

3. Bloody (not traumatic) tap or xanthochromic spinal fluid.

3.3.2.3 Definite Brain Hemorrhage (IPH)

Evidence in the patient's clinical record of sudden or rapid onset of neurologic symptoms lasting for more than 24 hours or leading to death, plus must meet the criteria specified under at least one of the three paragraphs below:

1. Demonstration of definite intracerebral hematoma by computerized tomography, or magnetic resonance imaging *e.g.*, an area of increased density, such as seen with blood, or

2. Demonstration at autopsy or surgery of intracerebral hemorrhage, or

3. Evidence in the patient's clinical record that meet criteria (a), (b), (c), and (d) below:

   a) One major or two minor neurological signs or symptoms from the following list that lasted at least 24 hours or until the patient died:

      Major
      Hemiparesis involving two or more body parts
      Homonymous hemianopia
      Aphasia

      Minor
      Diplopia
      Vertigo or gain disturbance
      Dysarthia or dysphagia or dysphonia
      Unilateral numbness involving two or more body parts

   and

   b) Bloody (not traumatic tap) or xanthochromic spinal fluid, and

   c) Cerebral angiography demonstrates an avascular mass effect and no evidence of aneurysm or arteriovenous malformation, and

   d) No computerized tomography/magnetic resonance imaging was performed or the CT/MRI was technically inadequate.

3.3.2.4 Probable Brain Hemorrhage

Evidence in the patient's clinical record of sudden or rapid onset of neurologic symptoms lasting for more than 24 hours or leading to death, plus must meet all criteria (1.), (2.), (3.), and (4.) below:

1. One major or two minor neurological signs or symptoms listed in Section 3.3.2.3, Number 3 above that lasted at least 24 hours or until the patient died, and

2. Decreased level of consciousness or coma that lasted at least 24 hours or until the patient died, and

3. Blood (not traumatic tap) or xanthochromic spinal fluid, and

4. No computerized tomography/magnetic resonance imaging was performed or the CT/MRI was technically inadequate.

3.3.2.5 Definite Brain Infarction, Thrombotic (TIB)

Evidence in the patient's clinical record of sudden or rapid onset of neurologic symptoms lasting for more than 24 hours or leading to death, plus must meet the criteria specified under at least one of the two paragraphs below:

1. Demonstration at autopsy of nonhemorrhagic infarct in brain, or

2. Evidence in the patient's clinical record that meet criteria (a) and (b) below:

   a) One major or two minor neurological signs and symptoms that lasted at least 24 hours or until the patient died:

      Major
      Hemiparesis involving two or more body parts
      Homonymous hemianopia
      Aphasia

      Minor
      Diplopia
      Vertigo or gait disturbance
      Dysarthria or dysphagia or dysphonia
      Unilateral numbness involving two or more body parts and

   b) Computerized tomography or MRI shows "infarct" or an area of decreased density which may indicate edema or ischema, with no evidence of hemorrhage.

3.3.2.6 Probable Brain Infarction, Thrombotic

Evidence in the patient's clinical record of sudden or rapid onset of neurologic symptoms lasting for more than 24 hours or leading to death, plus must meet al criteria (1.), (2.), and (3.) below:

1. One major or two minor neurological signs or symptoms listed in Section 3.3.2.5 (a) above that lasted at least 24 hours or until the patient died, and
2. Demonstration of negative or nonspecific findings and no evidence of hemorrhage by computerized tomography or MRI performed in the first 48 hours after the onset of symptoms or signs, and

3. A spinal tap was either not done, or was a traumatic tap, or yielded clear, colorless spinal fluid.

3.3.2.7 Definite Brain Infarction, Non-carotid Embolic (EIB)

Evidence in the patient's clinical record of sudden or rapid onset of neurologic symptoms lasting for more than 24 hours or leading to death, plus must meet the criteria specified under at least one of the two paragraphs below:

1. Demonstration at autopsy of:

   a) An infarcted area (bland or hemorrhagic) in the brain, and

   b) A source of emboli in a vessel of any organ, or an embolus in the brain, and

2. Evidence in the patient's clinical record that meet criteria (a), (b), and (c) below:

   a) One major or two minor neurological signs and symptoms that lasted at least 24 hours or until the patient died:

Major
Hemiparesis involving two or more body parts
Homonymous hemianopia
Aphasia

Minor
Diplopia
Vertigo or gait disturbance
Dysarthria or dysphagia or dysphonia
Unilateral numbness involving two or more body parts and

b) Establishment of a likely source for cerebral embolus, *e.g.*:

Valvular heart disease (including prosthetic heart valve)
Atrial fibrillation or flutter
Myocardial infarction
Cardiac or arterial operation or procedure
Cardiac myxoma
Bacterial endocarditis and

c) Computerized tomography or magnetic resonance imaging shows an area of decreased density which may indicate edema or ischemia, with no evidence of hemorrhage.

3.3.2.8 Probable Brain Infarction, Non-carotid Embolic

Evidence in the patient's clinical record of sudden or rapid onset of neurologic symptoms lasting for more than 24 hours or leading to death, plus must meet all criteria (1.), (2.), (3.), and (4.) below:

1. One major or two minor neurological signs or symptoms listed in Section 3.3.2.7 (a) above that lasted at least 24 hours or until the patient died and

2. An identifiable source for the cerebral embolus as specified in Section 3.3.2.7 (b), and

3. Demonstration of negative or nonspecific findings and no evidence of hemorrhage by computerized tomography or MRI performed in the first 48 hours after the onset of symptoms or signs, and

4. A spinal tap was either not done, or was a traumatic tap, or yielded clear, colorless spinal fluid.

3.3.2.9 Possible Stroke of Undetermined Type

Evidence in the patient's clinical record of sudden or rapid onset of at least one major or two minor signs and symptoms that lasted more than 24 hours or until the patient died:

Major
Hemiparesis involving two or more body parts
Homonymous hemianopia
Aphasia

Minor
Diplopia

Vertigo or gait disturbance
Dysarthria or dysphagia or dysphonia
Unilateral numbness involving two or more body parts
Severe headache at onset, or severe headache when first conscious after hospital admission
Depression of state of consciousness
Evidence of meningeal irritation
Retinal (subhyaloid) hemorrhages
Palsy of the iii cranial nerve and

Clinical history, signs, symptoms and findings from diagnostic tests and/or autopsy are not sufficient to meet the criteria for classifying the case as a "Definite" or "Probable" case of one of the four specific diagnostic categories of stroke.

3.3.2.10 Undocumented Fatal Stroke

Must meet the following criteria:

1. Does not meet criteria for definite, probable, or possible stroke noted above and
2. Underlying cause of death consistent with stroke (*i.e.*, ICD 9: 430 - 438), but death occurred without hospitalization or hospital chart cannot be located.

3.3.2.11 Exclusionary Conditions for Diagnostic Criteria for Stroke

Cases are not considered a stroke if there is evidence in the patient's clinical record that the neurologic symptoms were the result of any of the following:

1. Major head (brain) trauma; *e.g.*, epidural hematoma, subdural hematoma, skull fracture

2. Neoplasm; *e.g.*, primary or metastatic brain/CNS neoplasia (malignant or benign)

3. Coma due to metabolic disorders or disorders of fluid or electrolyte balance; *e.g.*, due to diabetes, hypoglycemia, epilepsy, hypovolemia, poisoning, drug overdose, uremia, or liver disease

4. Vasculitis involving the brain; *e.g.*, SLE, radiation, *etc*.

5. Peripheral neuropathy

6. Hematologic abnormalities (considered exclusionary if present prior to event under consideration); *e.g.*, thrombogenic conditions (*e.g.*, DIC) are exclusionary for thrombotic or non-carotid embolic strokes, hemorrhagic conditions (*e.g.* anticoagulant or thrombolytic therapy, thrombocytopenia) are exclusionary for brain hemorrhage or subarachnoid hemorrhage

7. CNS infection: brain abscess, granulomas, meningitis, encephalitis, or any specific infection involving the brain or meninges.

Table 3.2 Stroke Diagnosis Summary for ARIC Cohort Study[1]

Category		Specific Symptoms	NC Embolic Source	CT Scan	Angiogram	Lumbar Puncture	Pathology
Subarachnoid Hemorrhage							
Definite	a.				+	+	
	or b.			S			
	or c.				+		+
Probable	a.	(+)				+	
	b.				+	+	
Brain Hemorrhage							
Definite	a.			H			
	or b.						+
	or c.	+		0	+	+	
Probable		+		0		+	
Brain Infarction, Thrombotic							
Definite	a.					+	
	or b.	+		I			
Probable		+		N		-	
Brain Infarction, Non-Carotid Embolic							
Definite	a.		+				+
	or b.	+	+	I			
Probable		+	+	N		-	
Stroke of Undetermined Type							
Possible		+					
Undocumented Fatal Stroke							

+ = present/positive
- = absent
() = either one must be present
H = CT or MRI shows hemorrhage
S = CT or MRI shows SAH
I = CT or MRI shows infarction
O = CT or MRI not helpful
N = CT or MRI w/in 48 hours is negative

[1]All strokes must have neurologic finding(s) lasting at least 24 hours or until death, and no nonvascular cause.

APPENDIX F

GLOSSARY

Acalculia: loss of ability to do math reckoning.

Adiadochokinesia: inability to perform rapidly alternating movements.

Agraphia: inability to write.

Alexia or Visual Aphasia: loss of ability to understand written word.

- auditory: lack of comprehension of spoken word
- jargon or pharaphasia: words may be fluent but inappropriate
- amnesic: loss of memory of special words with hesitant and fragmentary speech
- nominal aphasia: (anomia, dysnomia) - loss of ability to name objects
- semantic aphasia: loss of meaning of words

Amaurosis fugax: monoculer (one eye) transient blindness.

Analgesia: loss of pain sensation.

Aneurysm: saccular dilation of blood vessel. If it ruptures, it causes SAH.

Anisocoria: inequality of the diameter of pupils.

Anosmia: loss of smell.

Anoxia: lack of oxygen which can cause tissue damage if prolonged.

Aphasia: inability to express oneself properly through speech or loss of verbral comprehension

Apraxia: inability to perform certain movements without loss of motor power, sensation or coordination; loss of learned behavior, *e.g.*, dressing (inability to dress oneself).

Astereognosis: loss of ability to recognize common objects by touching and handling them with eyes closed.

Atrophy: loss of tissue.

Autotopagnosia: inability to recognize one's self or part of one's self.

AVM: ateriovenous malformation - abnormal collection of blood vessels - prone to cause hemorrhages. If large, may exert mass effect.

Babinski reflex: on plantar stimulation large toe extends upward on involved side.

Bolt: peripheral monitor used to measure ICP.

Brudzinski: flexion of leg when neck is flexed. This is a sign of meningeal irritation.

Bruit: blowing sound heard with a stethoscope in blood vessel; caused by

turbulent blood flow. These may occur over an aneurysm or area of stenosis.

Bulbar palsy: involvement of brain stem.

Burr hole: hole drilled through skull.

CAD: coronary artery disease.

Carotid artery: arteries that supply front and middle portion of brain. These travel on either side of neck from clavicle bone to jaw.

Carotid endarterectomy: surgical removal of clot or atherosclerosis from carotid artery.

Clonus: spasm with rapidly alternating rigidity, relaxation. May be sustained (continuous) or unsustained.

Coma: decreased level of consciousness to the point of unresponsiveness to external environment, unable to be aroused.

Computerized tomography: "CAT Scan" or CT special radiographic procedure to visualize the brain.

Conjugate movement: describes normal appearance of how the eyes move together. Dysconjugate movement is seen in certain neurologic conditions or in a "lazy eye" where eyes don't move together.

Craniotomy: surgical procedure that involves entering the cranial cavity.

CSF: cerebrospinal fluid.

CVA: cerebrovascular accident (stroke).

Decerebrate: posturing response to stimuli with extension of upper and lower extremities frequently seen in coma.

Decorticate: posturing response to stimuli with flexion of upper extremities and extension of lower extremities.

Diplopia: double vision.

Dizziness: sensation of unsteadiness with feeling of movement in head.
Dysarthria: difficult and defective speech due to impairment of the tongue or other muscles essential to speech causing slurred speech.

Dysconjugate gaze: see conjugate movement.

Dysesthesia: unpleasant cutaneous sensation (burn, tickle, etc.).

Dysphagia: difficulty in swallowing.

Dysphonia: difficulty with phonation.

Edema: swelling.

Embolism: this is a blood clot that forms in one part of the body and travels in the blood stream to another part of the body. A thrombosis of an artery may break off of the "parent" vessel (*i.e.*, carotid artery) and form an embolus that eventually lodges in a vessel of smaller size in an end organ (*i.e.*, brain).

EOM: extraocular muscles or movement.

Fasiculations: irregular, inconstant, isolated contractions of fiber bundles within a muscle.

Flaccid: describes muscle tone which is lax.

Frontal release signs: "primitive" reflexes that result from disinhibition of frontal lobe, includes snout, palmomental, suck, grasp reflexes.

Glabellar reflex: patient cannot refrain from blinking when tapped on forehead between their eyes.

Hemianopsia: see homonymous hemianopsia (below).

Hemiparesis: weakness involving half of the body.

Hemiplegia: paralysis involving half of the body.

Herniation: a process which occurs when there is swelling or mass effect from other processes (tumor, brain hemorrhage) that leads to loss of brain function and death over several hours.

Hoffman sign: finger reflex - contraction of thumb and/or fingers when distant phalanx of middle finger (hand prone and relaxed) forcibly flexed by examiner.

Holme's sign: excessive flexion rebound after muscle extension pressure released.

Homonomous hemianopsia: impairment of half of the field of vision on the side of the lesion.

Homonymous hemianopsia: impairment of half of the field of vision of each eye on the side opposite the lesion.

Hypalgesia: decreased pain, diminished sensitivity to pain.

Hypesthesia: decreased tactile sensation.

ICP: intracranial pressure.

ICP monitor: intracranial pressure monitor - may be a bolt or ventriculostomy.

IHD: ischemic heart disease.

Infarction: area of tissue (cell) death.

Ipsilateral: situation on or pertaining to same side.

Ischemia: lack of blood flow.

Kernig: inability to straighten leg when hip is flexed. This is a sign of meningeal irritation.

Locked in: lesion in basis portis that causes patient to be quadrapaetic with intact cognition and eye movements only.

LP: lumbar puncture (spinal tap)

MAE: moves all extremities.

Mass effect: results from inability of the cranial cavity (area inside of skull) to expand. Thus any mass such as blood (hematoma), tumor, or swelling, exerts a mass effect or pressure on the brain itself.

Meninges: membranes covering brain, consists of three layers.

- dura: thick outer layer.
- pia: intermost layer - wrapped around brain
- arachnoid: middle membrane - vascular layer

Meningismus: patient exhibits signs of meningeal irritation such as stiff neck, Kernig or Brudzinski.

Myoclonus: clonic spasm of muscle or group of muscles.

Neglect syndrome: occurs in nondominant hemisphere events such as stroke. Affected patients will ignore their nondominant (usually left) side.

Nystagmus: oscillating or jerking movements of the eyes.

Occlusion: refers to complete blockage of an artery or vein.

Oriented X3: oriented to person, time, place.

Ox4: oriented to person, time, place; also includes situation.

Paraplegia: paralysis of legs and lower part of body - both in motion and sensation.

Paresthesia: unpleasant cutaneous sensation, *i.e.*, numbness or tingling.

Parosmia: any disease or perversion of the sense of smell.

PERL: pupils equal, react to light.

PERRL(d+C)A: pupils equally round and reactive to light (direct and consensual) and to accommodation.

PM&R: physical medicine and rehab.

Post ictal: after an ictus or event, usually refers to period immediately following a seizure.

PRIND: partially reversible ischemic neurological deficit.

Proprioception: position sensation.

Ptosis: drooping of upper eyelid.

Quadriplegia: paralysis of all four limbs.

Reflexes:

Scale A	Scale B
N = normal reaction	2
1+ = slightly hyperactive	3
2+ = markedly increased unsustained clonus	
3+ = one that shows sustained clonus	4
1- = reflex slightly decreased	
2- = reflex markedly decreased	1
3- = reflex absent except on reinforcement	
0 = reflex cannot be obtained at all	

RIND: reversible ischemic neurologic deficit (symptoms last > 24 hours).

Romberg sign: patient unable to stand with feet placed close together and eyes closed.

SAH: subarachnoid hemorrhage, blood in space around the brain.

Scotoma: a blind or partially blind area in visual field.

Scotomata: optic nerve lesion producing impaired vision in one eye only.
SDH: subdural hematoma, blood clot outside of brain, but pressing against brain.

Seizure: convulsion; abnormal electrical activity of brain causing jerking movements, LOC.

Snout reflex: mouth puckers when chin tapped.

Spastic: muscles stiff, movements awkward (of the nature of or characterized by spasm).

Stenosis: narrowing of a blood vessel, frequently from atherosclerotic buildup.

Suck reflex: sucking occurs reflexively when something is placed in their mouth.

Syncope: faint, swoon.

Thrombosis: clot of blood that obstructs or blocks an artery or vein.

TIA: transient ischemic attack; fleeting focal.

Tinnitus: ringing sound in ear.

Todd's paralysis: focal weakness or paralysis following a seizure, usually lasting minutes to days, but resolving.

Tomography: see computerized tomography.

Trapezii: shoulder muscles.

Tremors: involuntary movements resulting in rhythmic movement of a joint.

Vasospasm: a complication of SAH where subarachnoid blood irritates blood vessels causing them to constrict. As a result, blood flow is

decreased. This can lead to ischemic infarction (strokes).

Vegetative: loss of all cognitive function. Patient appears alert and awake, but does not interact with environment.

Vertebrobasilar arteries: arteries in back of neck that supply brain stem and back of brain vessel.

Vertigo: abnormal sense of spinning-type movement.

Ventricles: fluid (CSF) filled cavities within the brain.

Ventriculostomy: catheter inserted into ventricles with the brain to relieve and or monitor ICP.

Xanthochromia: yellowish colored spinal fluid.

APPENDIX G

GUIDELINES FOR DATA ENTRY
COHORT STROKE FORM

General Instructions for Central Abstractor:

1. Data entry of STR Form will be done by the Central Abstractor. Following data entry, STR Forms and records will be filed.

2. STR Forms that require physician review will have record materials copied and sent along with a Batch Inventory Sheet for each ID Number to the Statistical Coordinating Center. STR Forms that "skipout" after abstraction will have materials retained in files, but not shipped to the Coordinating Center.

3. Follow the batch and shipping instructions for mailing Stroke Abstraction data packets to the Coordinating Center dated 10/1/93.

Specific Instructions for Questions 3-53:

3.b. Enter the initial only.

3.c. This can be blank.

4. Enter the 9 digits only. Do not enter the terminal letter.

5. Do enter address.and enter zip code.

6. Enter codes carefully. The computer does require double entry of ICD Codes.

7. Type discharge diagnoses in the screen notelog that appears after entering "Yes". Alt-S saves.

11.c. If Question 11 is answered "Yes", fill in information for Questions 11.a. and b. If there is not a second transfer, skip over Question 11.c. and 11.d.; *i.e.*, leave blank.

24.,25.,27.a.,27.b. The computer may "reject" dates prior to 1992 as not valid. Enter the date as recorded and do a Ctrl-F twice to confirm the date.

48.d.1.,48.e.1.,53.c.1.,53.d.1., If numbers are not recorded, enter the equal signs as recorded on the paper form.