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Evaluation of Health Questions in HRS

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I have reviewed the health questions in the HRS. I concentrated particularly on Section C (Health) and Section N (Health Services and Insurance) [all references to sections and questions are to Preliminary Version 2 of the 2002 questionnaire, dated 8/13/2002, unless otherwise noted]. I did not focus on the questions on cognition. This is in part because there is a separate assessment of cognition being conducted as part of this HRS review, and in part because it is not my area of expertise.

In the course of my review, I have consulted with other researchers who have used the health questions. This list of people includes: Amy Finkelstein, Dana Goldman, Ellen Meara, Frank Sloan, and Elizabeth Richardson Vigdor. I also spoke with David Weir about some issues. I have tried to represent everyone's comments as faithfully as I can, but the views in this document should not be attributed to anyone but me.

I divide my review into an overall assessment, a discussion of areas needing improvement, and a discussion of areas that could be condensed.

Overall Assessment

Health questions are essential to any survey of the elderly. They need to be asked as well as possible, and integrated into other decisions people make. The track record of HRS on the health questions is mixed. The self-assessment of health has been enormously valuable. Researchers have related self-assessed health to wealth, retirement, savings, and a host of other issues. We understand much more about how health changes affect – and are affected by – other aging processes than we did before the HRS. This is a great credit of the HRS. My suggestions for this aspect of the HRS are largely to do more – more complete health assessments, adding questions about health knowledge, etc.

The survey has been much weaker on objective measures of medical care and its impact on the elderly. Researchers have not been able to relate retirement and savings decisions to specific medical interventions. Nor have researchers been able to examine how medical interventions affect the trajectory of self-reported health. This is in large part because the medical claims information that was a goal of the HRS has been delayed and is difficult to access. Solving this problem is a major issue in the expanding the value of the survey.

In the remainder of this document, I spell out the changes I would make in the HRS health modules.

Areas Needing Improvement

1. Use of Medical Services

The area of the HRS that is most in need of smoothing out/elaboration is the information on medical care utilization. For many purposes, we want to know exactly what services people received and from whom. Examples of research questions that can be addressed with this information include:

- How does the change in use of surgical procedures affect the rate of disability among the elderly?
- Are the near elderly who receive treatment for mental illness more likely to return to work than those who do not receive such treatment?
- What will happen to Medicare costs in the future as people age with their existing set of medical conditions?

Integrating this information was a key design issue in the HRS. The survey has tried hard on this issue, but the results are not as useful as they could be.

The 'gold standard' in the medical literature is medical claims records. Most clinical researchers in health policy will not accept self-reports of treatments as valid. Thus, obtaining useable and timely claims records is a central issue for the HRS.

For people enrolled in Medicare or Medicaid, the HRS asks for beneficiary information and attempts to link that to administrative claims records. The idea is to make that information available to researchers as widely as possible. That principle has not been met in practice,

however. This issue concerns me greatly, and was the number one item raised by many of the researchers I spoke with. I also discussed the situation with David Weir. The linkage is behind schedule, and the linked data are difficult to access.

There seem to be two problems. The first is the participation with NBER West, esp. Mark McClellan, that is suffering while Mark is away. NBER West prepares abbreviated versions of the claims data, but this takes a long time. The second problem is that CMS wants to approve all proposals to use the Medicare data. The CMS process is slow and cumbersome. As a result, most researchers simply cannot use the claims data in a reasonable period of time.

Solving the first problem is relatively straightforward: the work that was done at NBER West can be transported and picked up elsewhere. The HRS staff appears happy with the work and eager to continue where it has left off. The second issue is more problematic, and some discussions with CMS are necessary. It is imperative to speed up the approval process. The HRS medical records will never be widely used unless the approval time for those data falls to at most one or two months. The NLTCS has worked with CMS to make approval of their data requests far less time consuming. HRS should explore what can done in this case.

Enabling wider use of the Medicare claims records is not the entire problem. There are also issues in the non-elderly population. Currently, the HRS asks people (elderly and non-elderly) about use of a few medical services. This list is reasonably small, and one possibility is to expand it. The cancer area is particularly weak. Suggested additions: the site of the cancer [this was not asked for many years]; whether treatment involved chemotherapy, radiation, surgery, or a combination. The cardiovascular area could also use work. Diagnostic catheterization should be separated from therapeutic angioplasty. In addition, revascularization

such be asked about for heart disease patients. Finally, there are additional areas of screening to inquire about, including colorectal screening.

But people wont always know what they received. Thus, we might also ask people for permission to contact their insurer and/or medical providers to get their medical records. This is the strategy followed by the Medical Expenditure Panel Study (MEPS). The MEPS contacts providers and gets medical records for people. I would try insurers first, but providers are a reasonable substitute. This path would be more costly, but would result in much higher quality data.

In addition to issues of data quality and integrity, there is a major advantage to the survey of obtaining timely and complete medical records: many questions about service use could be eliminated, and the overall survey could be shortened substantially. Even if the linkage is only expedited for Medicare, the survey could be shortened for the elderly. Since the elderly need additional time on other areas (nursing homes, home care, etc.), that is a big saving.

Particular attention needs to be paid to the issue of medication use. Since Medicare does not cover prescription drugs, a separate assessment is needed of prescription drugs. Further, there are issues of compliance with prescription medications. Compliance with many medications is known to be poor. Only half of people who are taking anti-hypertensives, for example, have controlled blood pressure. Incomplete compliance is surely part of the explanation. The HRS should ask much more about medications prescribed and compliance with those recommendations. I recommend two paths:

1. A complete assessment of prescription and non-prescription medications. The individual would bring out their pill bottles. The information would either be

copied down, or (better) a digital photo taken. People will naturally think about prescription medications. Special attention would be needed to remind people about use of non-prescription medications such as aspirin and non-steroidal anti-inflammatories.

2. Questions should be asked about medication compliance. People might be asked how frequently they are supposed to take the medications and how frequently they actually take them. Reasons for non-compliance might also be assessed (price, convenience, side effects, perceived need).

2. Health Assessment

A second major area that is lacking is the self-assessment of health. The HRS has a few questions about self-assessed health, but they are not coherent. In the 2002 survey, the health assessment questions include C001-C004 (self-assessment of health), C104-C106 (pain), C150-C182 (depression screen – asked only some years). This is not a very comprehensive health assessment. A more comprehensive measure would help to evaluate quality of life as people age, and allow researchers to determine the value of medical interventions.

My recommendation is to use one of the existing self-assessment questionnaires that have been developed. The best known of these in the US is the SF-12 (abbreviation for short-form 12). A copy of the SF-12 is attached at the end of this document. The SF-12 asks about a number of domains of health. At the broadest level, the survey asks about physical and mental health. Within these broad domains, there are questions about physical and mental functioning,

interference with role playing resulting from physical or mental functioning, pain, and so on. The SF-12 is supposed to take only a short time. Thus, the time cost of adding the SF-12 to HRS is not great.

The SF-12 has assessments of some health domains, but not all. In particular, the SF-12 is relatively weak on cognitive functioning. I would thus continue to ask the CES-D depression screen. In addition, there are other cognitive issues in the older population that would need to be asked about separately – dementia, memory failure, etc. I am not certain what the state of the art is here.

The SF-12 is also not ideal for measuring health of people with a particular medical condition. For example, there are scales for measurement of functioning for people with coronary heart disease, arthritis, and other diseases. My suspicion is that there are not enough such people to justify disease-based health assessments, and that HRS should stick with an overall assessment of health. But the sample sizes should be investigated more to see if any of these make sense.

A related topic to self-rated health is perceptions of future health. The questions about probability of being alive at various points in the future have been very successful. These might be expanded to ask about future health and disability. For example, people might be asked:

- What is the probability that you will get {cancer/heart disease} in the next 10 years?
- What is the probability you will be disabled enough to need a nursing home in the next 10 years?

3. Common Assessments (Vignettes)

Health assessments may differ across people because true health differs, or because norms about what constitute good health differ. For example, two people may each rate their overall health as fair, one because he has recurrent pain, and the other because he feels in good condition but is more pessimistic or stoic. It is important in making health assessments to differentiate between these cases. It would also be good for other reasons to have a measure of optimism/ stoicism. With such information, one could ask whether optimistic people are healthier than less optimistic people, whether they recover from disease more rapidly, whether they work to later ages, and so on.

The HRS should ask people general questions getting at their optimism. In order to norm self-reported measures of health, however, the HRS should go further. In particular, it would be valuable to ask people to rate the health of someone in their demographic group but with a particular impairment. The ratings of the hypothetical people could then be compared to self-assessmnents. This strategy is termed the use of vignettes. The vignette idea has been developed by Gary King at Harvard, along with Chris Murray and Josh Salomon of the World Health Organization.

A typical vignette for mobility, developed by King, Murray, and Salomon, is attached at the end of this document. The respondent self-rates his/her own mobility, and then rates a number of hypothetical people. Ideally, the HRS would use one, or perhaps two vignettes. The most important vignette would be about overall health state. It is difficult to design such vignettes, however, because the person in the vignette needs to be specified in some detail. Thus,

it might be necessary to choose one or two domains of health (for example, mental health and mobility) to ask about.

Determining the appropriate vignettes would require some experimentation. King, Murray, and Salomon have indicated their willingness to work with the HRS to design appropriate questions, and HRS investigators have already met with them. Thus, this is an issue that could be readily addressed.

4. Health Insurance

The health insurance questions are generally good. Indeed, I suspect the time devoted to them could be cut back. For example, the interviewer could take down the information about the insurance plan and checking could be done later to determine if it is an indemnity plan, HMO, PPO, POS, or other plan. Digital photographs of insurance cards would be helpful.

Still, some more information would be useful in the insurance section. The most important problem is that the HRS asks about prescription drug coverage for people in traditional Medicare but not people in Medicare HMOs. There are related problems with dental insurance. In the 1996 survey, dental insurance is asked about for people with employer-provided health insurance (R28), people with Medicare (R46f), and people without public or employer-provided insurance (R56). But the question about dental insurance is missing in 1998 and 2000.

In addition, more overall assessments of health insurance should be asked. People who report no coverage should be asked explicitly "So, you are uninsured?" The CPS now does this, and found that asking a summary question reduced the number of uninsured by a significant

amount. The HRS did this in 1996 [I couldn't find it in 2002], but at that point didn't ask people what the policy covered if they first reported having coverage at this stage.

The long-term care insurance questions seem generally good. There are two issues to flag, though. First, the survey doesn't ask whether the policy is through an employer or purchased separately. This is important as employer-provided long-term care insurance is now tax subsidized. The question about what the plan covers is also somewhat outdated. Apparently, there are no longer any nursing-home facility only policies. At a minimum, policies cover all facilities, including assisted living facilities as well as nursing homes. Amy Finkelstein has looked into what the policies cover and would be pleased to help design appropriate questions.

Beyond the issue of what coverage people have, more information could also be obtained on why people do not take up coverage. The HRS asks whether people are offered insurance, and whether they have it. Thus, take-up is a residual. But that residual is important: over time, the increase in the share of workers not covered by insurance is due almost entirely to lower take-up rates, not lower rates of employers offering coverage. A few questions could help us understand this a lot more:

- "So, you chose not to take up coverage [for you/spouse/both]?" (To be sure)
- "Why?" (Price, convenience, didn't cover enough)
- (If answer price): "How much would you be able to pay for this insurance?"

5. Health Information/Knowledge

Another area in which the HRS is weak is in understanding how people get health information and make health decisions. People learn about health information in many ways: from physicians, from the news, from peers, from the internet, and so on. As health information diffuses more widely, it is vital to track how people acquire this information, and what information they want. There are several important research questions that could be addressed with such knowledge. Here is a small sampling:

- Are blacks less healthy than whites because they do not know as much about appropriate health practices?
- Do people in HMOs believe that doctors are less trustworthy than people in indemnity insurance plans?
- Do people feel they can distinguish good from bad information on the internet?

To address these questions, I suggest adding questions on several aspects of information acquisition:

- How much attention do people pay to health information from:
  - newspapers; TV/radio; peers; internet; physicians/medical professionals
- How much do people trust that information?
- How comfortable are people in knowing what they should be doing to improve their health?

In addition to asking about sources of health information, it would be useful to give people a brief health knowledge quiz. Such quizzes have been administered before. In the

1980s, the National Health Interview Survey asked people about the causes of cardiovascular disease and what they could do to prevent it. There were big differences in answers between blacks and whites, and between more and less educated people. The table at the end of this report shows such differences. Four or five questions would be sufficient here. The questions could be topical to what policymakers were interested in that year: cardiovascular disease; the best way to lose weight; diabetes; etc.

6. Access and Overall Satisfaction

The HRS might get an overall assessment of how happy people are with their medical care, and how easy it is to use the system. This is important in gauging the perceptions of the elderly and near elderly for medical care reform, and to design policies to make the system work better. Question N235 asks something about this. I would add just a few more questions:

- Do you have a primary care physician who you can speak to as needed?
- Generally, how long do you have to wait to get a doctor's appointment?
- How satisfied are you with your current health insurance plan?

Areas to Cut

Any researcher who proposes adding to a survey must indicate where to cut [within his own section, if possible]. There are several areas that could be reduced.

1. The first area is specific health events and treatments. These could be cut for the Medicare population if the linkage to administrative data were more timely (except for the pharmaceuticals questions), and for the non-Medicare population if physician or insurance records were obtained for that group.

2. Major savings are possible in the "services and insurance coverage" sections (N099-N248).

   - If access to medical claims is known, all of the utilization questions could be eliminated (how many hospital stays, nights in hospital, did insurance cover anything, would insurance cover anything, etc.). Even if claims data are not available, I would eliminate most of these questions. I would ask only summary information about any use of hospital, nursing home, home health, and outpatient surgery; about how many physician visits the person made; and about whether the person saw the dentist. Knowledge of what insurance would pay for can be inferred from the nature of the policy.
   - The questions about whether people were admitted to a hospital, whether they had outpatient surgery, and whether they used nursing homes or home health should be integrated into the health conditions section. At the end of that section, people should be asked if they used one or more of these services. If they respond yes,

they should be asked what the condition was and what treatments they received.

- Other utilization areas (other health services, etc.) can be eliminated as can the specific details of the number of hospital and nursing home days (as noted above). These questions add a lot to time and don't yield much.
- At the end, I would keep the summary question about overall individual payments for medical care and total payments including insurance (assuming no access to claims records).

3. Some of the specific health assessment areas might be eliminated, including urinary incontinence (C087-C094) and insomnia (C083-C086).

SF-12® Health Survey Scoring Demonstration

This survey asks for your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities.

Answer every question by selecting the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

	Excellent	**Very good**	**Good**	**Fair**	**Poor**
	☐	☐	☐	☐	☐

The following questions are about activities you might do during a typical day. Does your health *now* limit you in these activities? If so, how much?

	Yes, limited a lot	**Yes, limited a little**	**No, not limited at all**
2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐	☐	☐
3. Climbing **several** flights of stairs	☐	☐	☐

During the *past 4 weeks*, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	**No**
4. Accomplished less than you would like	☐	☐
5. Were limited in the **kind** of work or other activities	☐	☐

During the *past 4 weeks*, have you had any of the following problems with your work or other regular daily activities *as a result of any emotional problems* (such as feeling depressed or anxious)?

	Yes	**No**
6. Accomplished less than you would like	☐	☐
7. Didn't do work or other activities as **carefully** as usual	☐	☐

8. During the *past 4 weeks*, how much did pain interfere with your normal work (including both work outside the home and housework)?

	Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
	☐	☐	☐	☐	☐

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the *past 4 weeks*...

	All of the time	Most of the time	A Good Bit of the Time	Some of the time	A little of the time	None of the time
9. Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
10. Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
11. Have you felt downhearted and blue?	☐	☐	☐	☐	☐	☐

12. During the *past 4 weeks*, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	☐	☐	☐	☐	☐

Anchoring Vignettes for Mobility

Self-Rating:

Overall in the last 30 days, how much of a problem did [name of person/you] have with moving around?

In the last 30 days, how much difficulty did [name of person/you] have in vigorous activities, such as running 3 km (or equivalent) or cycling?

Response categories:

None Mild Moderate Severe Extreme/Cannot Do

Vignettes (rate each of the following people on the same scale):

[Paul] is an active athlete who runs long distance races of 20 kilometres twice a week and engages in soccer with no problems.

[Mary] has no problems with walking, running or using her hands, arms and legs. She jogs 4 kilometres twice a week.

[Adriana] is quite active and does sports twice a week, such as tennis or swimming. Once a month, however, she is too tired for sports so takes a three kilometre walk instead.

[Philip] goes walking every day for half an hour, one or two kilometres. He does not practice any strenuous sports as he feels out of breath when he walks very quickly or runs.

[Rob] is able to walk distances of up to 200 metres without any problems but feels tired after walking one kilometre or climbing up more than one flight of stairs. He has no problems with day-to-day physical activities, such as carrying food from the market.

[Anton] does not exercise. He cannot climb stairs or do other physical activities because he is obese. He is able to carry the groceries and do some light household work.

[Vincent] has a lot of swelling in his legs due to his health condition. He has to make an effort to walk around his home as his legs feel heavy.

[Margaret] feels chest pain and gets breathless after walking distances of up to 200 metres, but is able to do so without assistance. Bending and lifting objects such as groceries also causes chest pain.

[Rina] has had a stiff neck for the last 10 days and it makes her move around slowly as any sudden movement causes pain.

[Jenny] is an adult with an intellectual impairment and she is also obese. She struggles to get out of a chair, and moves very slowly.

[Louis] is able to move his arms and legs, but requires assistance in standing up from a chair or walking around the house. Any bending is painful and lifting is impossible.

[David] is paralyzed from the neck down. He is unable to move his arms and legs or to shift body position. He is confined to bed.

[Sid] suffers from a mental illness and spends his days rocking in a chair. He never moves out of his chair except when physically assisted by another person.

[Gemma] has a brain condition that makes her unable to move. She cannot even move her mouth to speak or smile. She can only blink her eyelids.

Subgroup Means (%) for Knowledge about Healthy Lifestyles

1985 NHIS ages 45-74

Survey Question	Non-Hispanic Black	Non-Hispanic White	Less than High School Degree	High School Degree	Some College	College Degree	Low Income	High Income
Best way to lose weight?								
-don't eat at bedtime	41	29	41	31	22	16	38	26
-eat fewer calories	**44**	**64**	**47**	**63**	**74**	**79**	**52**	**68**
-take diet pills	2	0	1	0	0	0	1	0
-increase physical activity	**3**	**3**	**3**	**3**	**2**	**3**	**4**	**3**
-eat NO fat	3	1	2	0	0	0	1	1
-eat grapefruit with each meal	0	0	0	0	0	0	0	0
-don't know	7	3	6	2	2	1	4	2
Best way to exercise to strengthen the heart and lungs: How fast should the heart rate and breathing be each time?								
-no faster than usual	9	4	7	4	3	2	6	3
-a little faster than usual	47	46	46	50	47	38	48	47
-a lot faster but talking is possible	**11**	**26**	**12**	**25**	**34**	**45**	**15**	**33**
-so fast that talking is not possible	0	1	1	1	1	1	0	1
-don't know	33	23	35	21	15	15	30	17
Which food substance most often associated with HBP?								
-sodium/salt	**46**	**62**	**47**	**63**	**70**	**72**	**52**	**65**
-cholesterol	25	24	26	24	23	20	26	24
-sugar	15	6	14	5	3	2	11	5
-don't know	14	8	14	7	4	6	11	6

Survey Question	Non-Hispanic Black	Non-Hispanic White	Less than High School Degree	High School Degree	Some College	College Degree	Low Income	High Income
Increase chances of getting heart disease?								
cigarette smoking								
-definitely increases	**49**	**66**	**54**	**66**	**71**	**74**	**58**	**70**
-probably increases	**29**	**23**	**27**	**23**	**21**	**19**	**26**	**22**
-probably does not increase	4	3	4	3	2	1	4	2
-definitely does not increase	1	1	2	1	1	1	2	1
-don't know/no opinion	17	7	13	6	4	5	10	5
high blood pressure								
-definitely increases	**60**	**69**	**59**	**70**	**77**	**75**	**63**	**72**
-probably increases	**25**	**23**	**26**	**23**	**18**	**20**	**24**	**21**
-probably does not increase	3	2	3	2	1	1	2	2
-definitely does not increase	1	1	1	1	1	0	1	1
-don't know/no opinion	11	6	11	5	3	4	9	4
diabetes								
-definitely increases	**28**	**31**	**27**	**30**	**36**	**37**	**29**	**33**
-probably increases	**29**	**26**	**25**	**27**	**28**	**27**	**25**	**27**
-probably does not increase	5	7	6	7	7	6	6	7
-definitely does not increase	3	3	3	3	2	2	3	3
-don't know/no opinion	35	33	39	33	26	28	36	30
being very overweight								
-definitely increases	**62**	**69**	**61**	**70**	**75**	**73**	**63**	**73**
-probably increases	**24**	**25**	**27**	**24**	**22**	**22**	**27**	**22**
-probably does not increase	2	1	2	1	1	1	2	1
-definitely does not increase	1	1	1	1	1	0	1	1
-don't know/no opinion	11	5	10	4	2	3	7	3
high cholesterol								
-definitely increases	**45**	**58**	**48**	**60**	**61**	**60**	**52**	**60**
-probably increases	**31**	**29**	**31**	**28**	**29**	**31**	**30**	**29**
-probably does not increase	3	3	3	2	4	2	3	3
-definitely does not increase	1	1	2	1	1	1	2	1
-don't know/no opinion	19	9	17	8	6	5	14	7
Sample Size	1631	9730	4308	4397	1616	1665	5045	5365

All figures are weighted to be nationally representative. Figures may not sum to 100 percent within categories because of rounding. Correct answers according to the 1985 NHIS survey of designers are in bold print.