

PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

Title (Provisional)

Cohort profile: The Understanding America Study (UAS)

Authors

Kapteyn, Arie; Angrisani, Marco; Darling, Jill; Gutsche, Tania

VERSION 1 - REVIEW

Reviewer	1
Name	Richter, David
Affiliation	Survey of Health Ageing and Retirement in Europe
Date	18-Jul-2024
COI	None

Thank you for the possibility to review this well written paper on the Understanding America Study. I have only some minor remarks and questions that I listed below:

- it is mentioned on different occasions throughout the manuscript that the data is made available with minimal delay. What is meant by that? Hours, days, or weeks? Would it be possible to maybe report the mean delay across the last years?
- Related to that, researchers contributing outside funding are granted a breif embargo. How long is this embargo ususally?
- The respondents answer surveys once or twice a month. I think that this is a really high frequency! I would like to have some more information related to this. How is the mean attendance rate for those surveys? How high is the panel stability from survey to survey? How many surveys are done per participant per year?
- I would also like to know more about the attendance rates for the special projects, i.e. the wearables, record linkage, etc.
- Generally, the attrition rates are impressively low for an online survey. I would like to learn more about the "tricks" that are used by the team to archive this.

- It was mentioned that the recruiting response rate is much lower than PSID. What this mean specifically? UAS hovers around 10%, how are the numbers for PSIS looking? Also, are you checking for possible bias and how are you doing that?

- A final question on self-interviewing: how are you making sure that the correct respondent is doing the interview? They could outsource the task to their partner or children, right?

Again, thank you very much for the interesting read, it's really an impressive study.

- One

Reviewer	2
Name	Nißen, Marcia
Affiliation	University of St Gallen, School of Medicine
Date	23-Jul-2024
COI	none

Dear Authors,

Thank you for the opportunity to review your manuscript, "Cohort Profile: The Understanding America Study (UAS)."

The manuscript presents a comprehensive overview of the UAS, a probability-based Internet panel aimed at understanding socio-economic and health disparities in the U.S. The infrastructure's scale and scope are commendable, providing valuable insights into the daily lives of U.S. families and individuals. I found the manuscript impressive for several reasons, including how long the study has been running, the comprehensive sampling method, the variety of data sources linked, and the number of publications and media reports generated. The fact that the data is made available just-in-time is extremely fascinating and valuable. I am intrigued and plan to explore how I might utilize it for my research.

Overall, this manuscript was a very interesting read and an unusual piece of work for me to review (I have never reviewed a "cohort profile" manuscript before). However, in the following, I will express my observations and questions regarding the manuscript's clarity and depth in certain areas in more detail following the structure/sections of the manuscript:

1. Abstract

1.1. The abstract states: "The information collected focuses on a defining challenge of our time – identifying factors explaining racial, ethnic, geographic, and socio-economic disparities over the life course, including racial discrimination, inequalities in access to education and healthcare, differences in physical, economic, and social environments, and,

more generally, the various opportunities and obstacles one encounters over the life course." While this is a crucial and timely topic, I expected to learn more about the rationale behind these objectives. Are there any theoretical frameworks or models, such as the Social Determinants of Health (SoDH), that underlie the study's approach? Furthermore, are any frameworks being developed based on this cohort? Understanding the foundational basis for the cohort's setup would add depth to the discussion.

2. Why was the cohort set up?

2.1. The manuscript mentions, "The substantive focus of the UAS is to understand how health disparities and economic inequality develop over the life course." Again, while this is an important focus, the manuscript would benefit from a more detailed explanation of why this cohort was established and how it links to current equity and disparity research. I would also like to draw the authors' intentions to a shift in both language and research emphasis from health disparities (focus on problem identification) to health equity (focus on solutions) around the year 2010 (cf.: Srinivasan S, Williams SD. Transitioning from health disparities to a health equity research agenda: the time is now. *Public Health Rep* 2014; 129 Suppl 2: 71–76. <https://doi.org/10.1177/003335491412915213>)

2.2. There seems to be a lack of clarity regarding the timeline: When did data collection actually start? When was the first participant included?

2.3. There also seems to lack of clarity with regards to terms like "R01s," which should be explained for readers who may not be familiar with that, and many abbreviations, such as "HRS", "USC," "PSDI", which are used without prior introduction. //edit: Some of them are introduced later in the manuscript (e.g., only on Page 12, in Section "Strengths and Weaknesses"), which suggests that the order of the sections might have been changed at some point. However, please systematically check that abbreviations are introduced properly ...

3. Who is in the cohort?

3.1. Why does the cohort only include participants older than 18 years, especially for a study examining life course effects? Childhood experiences would be highly relevant. I understand that some aspects may be covered via questionnaires, but an explanation would be helpful. //edit: It is later explained that childhood experiences are surveyed ...

3.2. Are the data primarily self-reported, or are there also "other reports" included? For instance, by caregivers, romantic partners, etc.?

3.3. The manuscript assumes a level of prior knowledge about protocols like "HRS" and "PSID" that may not be shared by all readers. A brief overview or explanation of these protocols might be beneficial.

4. Measurements and Findings

4.1. It would be interesting to include more comprehensive sex- and gender-specific health questionnaires, for instance, requiring women's health history, menstrual health status, current menstrual cycle phase while filling out surveys (cf: "A life-course approach to women's health": <https://www.nature.com/articles/s41591-023-02777-8>; "A life course approach to reproductive health: Theory and methods", <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3504662/>)

5. Publications:

5.1. While there is an impressive compilation of various publications, I was surprised to only see few studies mentioned that actually investigate life course effects of health disparities. I would appreciate a clearer distinction or visualization between "target" publications (i.e., investigating life course effects of or on health disparities), and those using the UAS data beyond the cohort's core purpose.

6. What are the main strengths and weaknesses?

6.1. Strengths

6.1.1. Terms like compliance, attrition, adherence, churn, and response rate, etc. should be defined clearly first to avoid any ambiguity.

6.2. Weaknesses

6.2.1. The manuscript could mention other potential at-home test kits, such as pregnancy and ovulation test kits or CGM data that could be used for self-sampled biomarker data?

7. Collaboration

7.1. This surprised me a lot too: Why are there no more health or medical experts involved except from psychology? An even more interdisciplinary approach involving various health disciplines could enhance the study's comprehensiveness and understanding of health disparities. How are health status and health data otherwise eventually evaluated without a broader range of health expertise? How do you decide on relevant conditions to be included in surveys?

8. Table 1

8.1. Additional measurements that could enhance the study with regard to studying health disparities could encompass women's health literacy and/or digital (health) literacy

VERSION 1 - AUTHOR RESPONSE

Dear Dr. Bennet,

We have revised the manuscript following your guidance and in response to the reviewer comments. We have responded to each of the reviewers' comments. We have included the

original Table 2 as a text box. The original Figure 1 is now Figure 2 and is uploaded separately. We have included a consort diagram of the recruiting process as Figure 1, which also has been uploaded separately.

I hope these changes meet your approval.

I am looking forward to your response.

Arie Kapteyn

Response to reviewer 1

Thank you for these very helpful comments, which serve to improve the clarity and information of the cohort profile. Below are the reviewer's comments in italics and the authors' responses in regular font.

- it is mentioned on different occasions throughout the manuscript that the data is made available with minimal delay. What is meant by that? Hours, days, or weeks? Would it be possible to maybe report the mean delay across the last years?

We have now clarified that in principle data are made available immediately after the end of a field period, with possible limited embargo periods in cases where outside researchers contribute their own funds.

- Related to that, researchers contributing outside funding are granted a brief embargo. How long is this embargo usually?

Six months, in exceptional cases one year. We have now included this information in the paper.

- The respondents answer surveys once or twice a month. I think that this is a really high frequency! I would like to have some more information related to this. How is the mean attendance rate for those surveys? How high is the panel stability from survey to survey? How many surveys are done per participant per year?

We have clarified that the median number of surveys per year taken by a respondent equals 28. We also note that the average response rate to surveys is about 75%, but may reach 90, if a survey is kept in the field long enough.

- I would also like to know more about the attendance rates for the special projects, i.e. the wearables, record linkage, etc.

We now report that these are on the order of 65%, with some differentiation by age.

- Generally, the attrition rates are impressively low for an online survey. I would like to learn more about the "tricks" that are used by the team to archive this.

We cite a paper by Jin and Kapteyn (2021), showing very little relation between survey burden (defined by either questionnaire length or number of survey invitations) and response rates. The authors conclude that the financial incentive appears sufficient to compensate for the effort of answering the questionnaire. We have implemented a “sleeper protocol”, whereby different actions are undertaken to contact UAS participants who have failed to respond to survey invitation for several months. [The protocol](#) is described on the UAS website. For reasons of space, we could not include this in the profile. We send respondents a quarterly newsletter. Beginning in October 2023, we have provided a random sub-sample of UAS participants with regular feedback on how UAS survey data are used for research purposes. This feedback experiment will continue until September 2025. Preliminary analysis indicates no significant difference in survey response rates between the control (no feedback) and treatment (feedback) groups. As part of a continuous program of quality improvement, we experiment with a sequence of approaches to possibly improve recruiting rates and reduce attrition (a detailed document about these experiments is available at this [link](#)). It turns out that most of the experiments have no significant effect on response rates or attrition.

- It was mentioned that the recruiting response rate is much lower than PSID. What this mean specifically? UAS hovers around 10%, how are the numbers for PSIS looking? Also, are you checking for possible bias and how are you doing that?

The original recruiting response rate of the PSID is not available¹, but in view of long term downward trends of survey response rates, it seems safe to assume the recruiting response rate in 1968 was not lower than the HRS recruiting response rate in 1992, which was over 80% (Sonnegga, Faul et al. 2014). We have compared population estimates of outcome variables across UAS, HRS, and CPS and found little to no bias (Angrisani, Finley et al. 2019). An unpublished comparison of UAS estimates of covid vaccination rates with CDC administrative data found a close fit.

- A final question on self-interviewing: how are you making sure that the correct respondent is doing the interview? They could outsource the task to their partner or children, right?

This is a problem common to any form of self-interviewing for which we have no satisfactory solution. We do monitor consistency in self-reported demographics and sometimes find inconsistencies and then take action.

¹ “Panel Study of Income Dynamics (PSID) 1968-2015 Cumulative Response Rates for 1968 Sample Persons”, Steven Heeringa, Wen Chang, David Johnson
SRC Statistical Design Group and Panel Study of Income Dynamics Survey Research Center University of Michigan, Technical Series Paper #18-01

Response to reviewer 2

Thank you for these very helpful comments, which serve to improve the clarity and information of the cohort profile. Below are the reviewer's comments in italics and the authors' responses in regular font.

1.1. The abstract states: "The information collected focuses on a defining challenge of our time – identifying factors explaining racial, ethnic, geographic, and socio-economic disparities over the life course, including racial discrimination, inequalities in access to education and healthcare, differences in physical, economic, and social environments, and, more generally, the various opportunities and obstacles one encounters over the life course." While this is a crucial and timely topic, I expected to learn more about the rationale behind these objectives. Are there any theoretical frameworks or models, such as the Social Determinants of Health (SoDH), that underlie the study's approach? Furthermore, are any frameworks being developed based on this cohort? Understanding the foundational basis or the cohort's setup would add depth to the discussion.

The UAS is an effort by a multidisciplinary group of researchers. Although we have certainly taken our inspiration from various theoretical frameworks, the data we collect are meant to be broad enough to serve as an empirical basis for investigations following different paradigms. More importantly, by collecting data covering such a broad spectrum, we create conditions for multidisciplinary integration of frameworks into a more comprehensive understanding of inequality and disparities.

2.1. The manuscript mentions, "The substantive focus of the UAS is to understand how health disparities and economic inequality develop over the life course." Again, while this is an important focus, the manuscript would benefit from a more detailed explanation of why this cohort was established and how it links to current equity and disparity research. I would also like to draw the authors' intentions to a shift in both language and research emphasis from health disparities (focus on problem identification) to health equity (focus on solutions) around the year 2010 (cf.: Srinivasan S, Williams SD. Transitioning from health disparities to a health equity research agenda: the time is now. Public Health Rep 2014; 129 Suppl 2: 71–76. <https://doi.org/10.1177/00333549141291S213>)

We appreciate the difference in perspective. Although the motivation for concentrating on inequality and disparities certainly is based on equity concerns, we believe it to be more productive to concentrate on analysis of causes of inequality and disparities than to start advocating for particular solutions. Of course, the data we collect and the analyses we and others conduct based on the data can very well serve to propose solutions.

2.2. There seems to be a lack of clarity regarding the timeline: When did data collection actually start? When was the first participant included?

Thank you for pointing this out. We have now made clear that data collection started in 2014.

2.3. There also seems to lack of clarity with regards to terms like "R01s," which should be explained for readers who may not be familiar with that, and many abbreviations, such as "HRS", "USC," "PSDI", which are used without prior introduction. //edit: Some of them are introduced later in the manuscript (e.g., only on Page 12, in Section "Strengths and Weaknesses"), which suggests that the order of the sections might have been changed at some point. However, please systematically check that abbreviations are introduced properly ...

Thank you for this observation. We have now made sure that whenever an abbreviation occurs it has defined previously. We have dropped the term R01, as indeed it does not add information for those readers who are not familiar with NIH (National Institutes of Health) parlance.

3.1. Why does the cohort only include participants older than 18 years, especially for a study examining life course effects? Childhood experiences would be highly relevant. I understand that some aspects may be covered via questionnaires, but an explanation would be helpful. //edit: It is later explained that childhood experiences are surveyed ...

We have now clarified that at least until now information on children is obtained from parents. Moreover, the life history surveys cover childhood of the respondents themselves. Nevertheless, we do not exclude the possibility that we will interview individuals below 18 going forward.

3.2. Are the data primarily self-reported, or are there also "other reports" included? For instance, by caregivers, romantic partners, etc.?

Data are primarily self-reported (apart from passive data collection through biomarkers, wearables and contextual data), as we now state explicitly in the paper.

3.3. The manuscript assumes a level of prior knowledge about protocols like "HRS" and "PSID" that may not be shared by all readers. A brief overview or explanation of these protocols might be beneficial.

We have now explained briefly that both studies collect core information at a biannual frequency. We have also avoided the word "protocol", as that may suggest more intricate similarities than just the frequency at which information is collected.

4.1. It would be interesting to include more comprehensive sex- and gender-specific health questionnaires, for instance, requiring women's health history, menstrual health status, current menstrual cycle phase while filling out surveys (cf: "A life-course approach to women's health": <https://www.nature.com/articles/s41591-023-02777-8>; "A life course approach to reproductive health: Theory and methods",

Currently information about sex- and gender-specific health is taken directly from the core HRS survey. We are certainly open to further expansion of that information in keeping with the open nature of the UAS as a research platform for the whole research community.

5.1. While there is an impressive compilation of various publications, I was surprised to only see few studies mentioned that actually investigate life course effects of health disparities. I would appreciate a clearer distinction or visualization between "target" publications (i.e., investigating life course effects of or on health disparities), and those using the UAS data beyond the cohort's core purpose.

It is important to note that the past years have been devoted to building a research infrastructure, an effort that is still going on. Publications taking advantage of the new information we are collecting on life-course disparities and inequality naturally lag the availability of the new data. The limited selection of published papers, on the other hand, reflects the breadth of the collected data and how these can serve research in a wide variety of areas. We certainly anticipate a strong growth of UAS based publications taking advantage of the new data. Indeed, one reason to publish a cohort profile is to make researchers aware of the potential of the UAS for doing research in this area.

6.1.1. Terms like compliance, attrition, adherence, churn, and response rate, etc. should be defined clearly first to avoid any ambiguity.

We don't believe most of these terms actually appear in the paper. We have clarified that the Initial Response Rate to our recruitment invite is based on AAPOR RR1.

6.2.1. The manuscript could mention other potential at-home test kits, such as pregnancy and ovulation test kits or CGM data that could be used for self-sampled biomarker data?

We have changed the text to clarify that beyond the current genotyping project, other self-administered tests are feasible and may be implemented in the future.

7.1. This surprised me a lot too: Why are there no more health or medical experts involved except from psychology? An even more interdisciplinary approach involving various health disciplines could enhance the study's comprehensiveness and understanding of health disparities. How are health status and health data otherwise eventually evaluated without a broader range of health expertise? How do you decide on relevant conditions to be included in surveys?

This is partly an omission; the team does include epidemiologists and health experts. We have now added that information. As mentioned in the paper, the DMC has added expertise in these areas. Furthermore, by including the full HRS instrument, we are indirectly benefitting from the expertise of the HRS investigators. The HRS principal investigator is part of the UAS team.

8.1. Additional measurements that could enhance the study with regard to studying health

disparities could encompass women's health literacy and/or digital (health) literacy

Thank you for the suggestion. The power of the UAS infrastructure includes easy incorporation of new data elements when called for.

Angrisani, M., B. Finley and A. Kapteyn (2019). Can Internet Match High-quality Traditional Surveys? Comparing the Health and Retirement Study and its Online Version. The Econometrics of Complex Survey Data: Theory and Applications, Emerald Publishing Limited: 3-33.

Sonnega, A., J. D. Faul, M. B. Ofstedal, K. M. Langa, J. W. Phillips and D. R. Weir (2014). "Cohort profile: the health and retirement study (HRS)." International journal of epidemiology **43**(2): 576-585.

VERSION 2 - REVIEW

Reviewer	1
Name	Richter, David
Affiliation	Survey of Health Ageing and Retirement in Europe
Date	02-Sep-2024
COI	None

The authors did a great job with the revision. I have no further remarks.