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IN THE SOCIAL SCIENCES

Deliverable Number: D6.11

Deliverable Title: Biomarker Consent Analyses

Work Package: WP6

Deliverable Type: Report

Dissemination Status: Public

Submitted by: MEA (MPG) – SHARE-ERIC

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Submission Date: June 2017

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 654221.





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Please cite this deliverable as: Weiss, LM (2017) *Biomarker consent analyses*. Deliverable 6.11 of the SERISS project funded under the *European Union's Horizon 2020 research and innovation programme* GA No: 654221. Available at: www.seriss.eu/resources/deliverables

Biomarker Consent Analyses

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Summary

In recent years, there has been an upsurge in the use of biological specimens as objective health measurements in socio-economic surveys. High participation rates in the collection of biomarkers are desirable to enhance the statistical power by increasing the number of observations available for statistical analyses. Consent rates may depend on many factors. This report looks at the consent rates for the collection of dried blood spots (DBS) samples in the context of the sixth Wave of the Survey of Health, Ageing and Retirement in Europe (SHARE) and focusses on two of them: different legal or ethical requirements in the participating countries and the expectations of SHARE interviewers regarding the success of the DBS collection. The analyses of these factors in correlation with actual consent rates suggest that the interviewers' expectations have been more important for the success of the blood collection in terms of higher consent rates than specific deviations regarding the collection process based on legal and ethical requirements. This is an interesting result for survey practitioners who are concerned with the integration of the collection of biomarkers in socio-economic surveys: whereas legal or ethical requirements cannot be changed easily, the expectations of the interviewers can be influenced by good interviewer training.

1 Introduction

In times of population ageing, health inequalities are of major concern to researchers and lawmakers. The process of aging will continue in countries all over the world. Because health (care) is a major factor in the economy of societies, it is important to their policy makers to understand the kind of living circumstances that lead to healthy ageing.

The Survey of Health, Ageing and Retirement in Europe (SHARE) provides a large dataset suitable to facilitate this understanding. SHARE contains data on socioeconomic factors, as well as information on the respondents' health status. By exploring correlations between the two areas, researchers of different disciplines may shed light on the pathways that lead from general life circumstances to individual health in later life.

In many socioeconomic studies, the health of the participants is assessed by self-reported health information. Such subjective measurements, however, might be affected by bias due to differing reporting styles between respondent groups (Jürges 2007) or simply due to lack of a proper medical evaluation. Objective health measurements can overcome these shortcomings. Over the past years, an increasing number of socioeconomic studies implemented the collection of such objective health data. One example is the collection of biomarkers, assessed in dried blood spots (DBS) samples.

In SHARE, the collection of DBS samples was implemented in Wave 6 of the panel study in 2015. The collection of DBS is a minimally invasive method where drops of blood are collected from the fingertip and are dried on a special filter paper. The collection, i.e., the prick into the fingertip with a small lancet, can be conducted by trained lay interviewers in most countries.

Two central aspects separate the DBS collection from the rest of the SHARE interview: first, a specific approval of the responsible ethics committees had to be obtained prior to the DBS collection in all participating countries. To obtain the approval, the collection protocol had to

be adapted to country-specific ethical and legal requirements. Second, for most interviewers, blood taking was an unusual challenge, not only because the (minimally) invasive task differed from their usual task of asking questions, but also because a separate written informed consent from the respondents had to be obtained by them before the blood could be collected.

The eventually gained rate of consent is important, because low rates bear the risk of bias caused by systematic differences between consenting and refusing respondents. A high consent rate can reduce this bias and additionally increases the statistical power by increasing the absolute number of observations available for data analysis. In this regard, several studies have shown, that interviewers have a remarkable influence on the respondents' decision to consent or to refuse (Sakshaug, Couper, and Ofstedal 2010; Korbmacher 2014). Therefore, this deliverable aims to learn more about the mechanisms behind consent decisions by using information about the legal and ethical framework conditions, respondents and the interviewers.

The report analyses the consent rates of the DBS collection conducted during SHARE Wave 6 and correlates them to the above-mentioned aspects of such a collection, i.e. specific ethical or legal requirements¹ as well as characteristics and attitudes that may influence the interviewer's success in obtaining the respondents' consent with regard to the blood collection.

2 Methods

2.1 Consent Rates

The DBS collection in SHARE Wave 6 was conducted in 12 countries: Belgium, Denmark, Estonia, France, Germany, Greece, Italy, Israel, Slovenia, Spain, Sweden, and Switzerland. In all countries, only members of panel households were asked for consent, i.e. respondents that participated at least once in the survey before, and their partners, independently of a previous participation. No blood was taken from proxy respondents (i.e., persons who answered the questions of the survey in lieu of respondents, because they were not able to respond themselves) or from respondents who were not able to give consent themselves. Respondents meeting these criteria were defined as "DBS eligible".

Since the SHARE interviews are conducted in CAPI mode², interviewers did not have to apply these criteria, but the SHARE questionnaire was routed accordingly by the software. There was only one exception: in France, not all panel households were asked for DBS

¹ This report is part of Task 6.4 "Consent and biomarkers" in Work Package 6 "New forms of data: legal, ethical and quality matters" of the Synergies for Europe's Research Infrastructures in the Social Sciences (SERISS) project. In Deliverable 6.10 "Synopsis of Policy-Rules for Collecting Biomarkers in Social Surveys" (cf. Schmidutz 2016), the experiences when implementing the collection of biological samples in various European countries and Israel as part of the SHARE study have been described. While D6.10 addresses central legal requirements and ethical issues related to the collection of DBS samples the current deliverable (D6.11) draws on these experiences and puts them in the context of quality related analyses of consent rates.

² CAPI: Computer-Assisted Personal Interviewing. SHARE is conducted as a face-to-face interview. The survey questionnaire is installed on a laptop; the interviewer reads out the questions appearing on the screen and enters the answers into the CAPI instrument. Whether certain questions appear or not is conditional on the answers given before (routing).

consent, but only households in four French districts. In all other households, the DBS part of the interview had to be skipped manually by the interviewer during the conduct of the interview.

For the exact wording and routing of the DBS part in the CAPI instrument, see Appendix 1 “SHARE DBS CAPI questionnaire (excerpt)”. After an introduction to the DBS collection part of the interview, eligible respondents first were asked whether any medical reasons would prevent them from participating in the blood collection. Only if there were no such reasons, they were asked for written consent. The according CAPI item had the following two answering options: “yes, the respondent signed the consent form” or “no, the respondent did not sign the consent form”.

All following measures were calculated on the base of DBS eligible respondents and the answer given to the above mentioned consent item (bs006, see Appendix 1): the generated variable *consent* is a dummy variable assuming the value 1 if the consent question was answered by “yes”; it assumes the value 0 if the question was *not* answered by yes, i.e. was answered by “no” or the answer is missing, *and* the respondent is DBS eligible.

The DBS consent rate per country (*consent_ctr*) was calculated dividing the number of respondents in this country with *consent=1* by the number of DBS eligible respondents (with a valid interview) in this country. The DBS consent rate for interviewers (*consent_IWER*) was calculated accordingly – the number of respondents having signed the consent form (*consent=1*) and that were interviewed by a certain interviewer divided by the number of DBS eligible respondents interviewed by this interviewer.

2.2 Interviewer Survey

Information on the interviewers’ characteristics, attitudes, and especially their expectations regarding the success of the DBS collection was collected in a special interviewer survey (Blom and Korbmacher 2013); for the exact wording of the questions used for this report, see Appendix 2 “SHARE Interviewer Survey (excerpt)”. The survey was conducted as an online survey. Invitations and personal login data were distributed during the SHARE interviewer training sessions; the questionnaire had to be answered after training and before the beginning of the fieldwork. Interviewers of eight countries of those SHARE countries which implemented the DBS collection participated in the SHARE interviewer survey: Estonia, Germany, Greece, Italy, Slovenia, Spain, and Sweden.

Expectations were measured with two questions: a first one asking for the interviewer’s expectations on the overall consent rate to the DBS collection (*exp_overall*), and a second question (following immediately) on the interviewer’s own consent rate (*exp_own*). *exp_overall* and *exp_own* are measured in percent and can assume values from 0 to 100 or can be missing if not answered.

2.3 Ethical and legal requirements

As mentioned in the introduction, the DBS collection protocol had to be adapted to country-specific ethical and legal requirements. This resulted in certain differences between countries. Regarding this, it has to be noted that, in general, country specific deviations regarding the DBS collection, as e.g. required by the national ethics committees (see Schmidutz 2016) could only influence the consent gaining process and thus the level of the consent rates if these deviations were perceptible by the interviewer or the respondent.

A total of five such differences have been identified. They mostly concern the information given to respondents in the form of an information leaflet and, thus, being part of the facts presented to the participants as part of the consent procedure:

- whether or not the analyses of DNA was explicitly excluded a priori (The planned analyses were mentioned in the information leaflet. Even though DNA analysis is not planned, further kinds of analyses might be considered in future from the same samples. Variable name: *eth_DNA*)
- whether or not the national ethics committee (please note: not the respondent) would have to be contacted again before conducting such further analyses (*eth_further*)
- whether or not feedback on the individual analyses results was offered to the respondents (*eth_feedback*)
- whether or not the respondents had been informed about the DBS collection in the general advance letter announcing the new wave of SHARE (*eth_advance*)
- whether or not only self-pricking was allowed (the respondent pricked his/her own finger, instead of being pricked by the interviewer; *eth_selfprick*)

All of these concepts have been operationalised via a dummy variable assuming the value 1 for countries where the requirement applied and 0 otherwise (see Table 1).

Obviously, there is only variation *between* countries (not within a country), because ethical and legal requirements were always valid for the entire country. Differences in country specific consent rates, thus, may also result from other country specific characteristics. As a “control” characteristic that was not imposed by ethics committees, an additional variable (*compass*) specifies the geographic location of the country in relation to Europe:

- **North:** Sweden, Denmark
- **Middle:** France, Germany, Switzerland, Belgium
- **South:** Greece, Italy, Israel, Spain
- **East:** Estonia, Slovenia

	eth_DNA	eth_further	eth_advance	eth_feedback	eth_selfprick
Belgium	1	1	0	0	0
Denmark	0	1	1	1	0
Estonia	0	1	0	0	0
France	1	1	0	0	1
Germany	1	0	0	0	0
Greece	1	1	0	0	0
Italy	1	1	1	0	0
Israel	1	0	0	0	0
Slovenia	1	0	0	0	0
Spain	0	1	0	0	0
Sweden	1	1	1	0	0
Switzerland	0	1	1	0	0

Table 1: Values of dummy variables for ethical or legal requirements per country

3 Results

The overall consent rate to taking blood across all participating countries in SHARE Wave 6 was high at more than 72%. However, the country specific consent rates vary and exceed 80% in Belgium, Denmark, and Slovenia (see Table 2). However, country specific consent rates varied considerably from 34,4% in Greece to more than 80% in Belgium, Denmark, and Slovenia.

Belgium	80,8
Denmark	83,5
Estonia	79,1
France	68,1
Germany	73,2
Greece	34,4
Israel	59,5
Italy	58,3
Slovenia	81,1
Spain	66,4
Sweden	80,0
Switzerland	76,9
Total	72,3

Table 2: Country specific consent rates to the DBS collection in SHARE Wave 6

3.1 Country specific consent rates and ethical/legal requirements

Figure 1–5 show the obtained consent rates with regard to the DBS collection per country. To illustrate the influence (or not) of the above mentioned ethical or legal requirements, the countries in each figure are sorted according to their value on one of the dummy variables regarding these requirements: *eth_DNA*, *eth_further*, *eth_feedback*, *eth_advance*, and *eth_selfprick*, respectively.

Figure 1 shows the country specific consent rates with the countries ordered according to whether any future DNA analysis was explicitly excluded a priori or not. There is no clear correlation between the level of the consent rate and this exclusion. If any, there is a tendency to higher consent rates in countries without the explicit exclusion of further DNA analysis: Spain, Switzerland, Estonia, and Denmark.

Most countries need to re-contact the national ethics committee if they want to analyse the collected DBS samples for biomarkers that are not mentioned in the information leaflet before (*eth-further*=1). Only three countries do not need such a further approval (*eth_further*=0): Israel, Germany, and Slovenia. Regarding the obtained consent rates in these two groups of countries, no tendency can be observed (see Fig. 2).

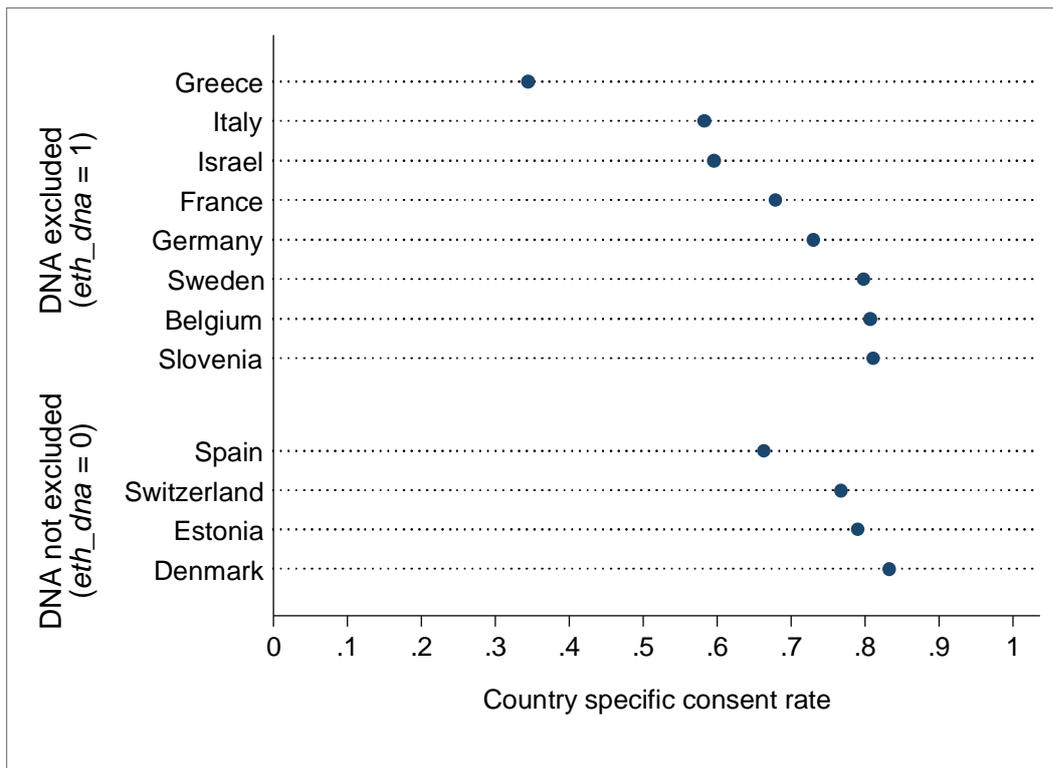


Figure 1: Country specific consent rates and exclusion of DNA analysis (*eth_DNA*)

Denmark was the only country offering individual feedback on the analyses results of certain biomarkers to their respondents (*eth_feedback=1*). It obtained the highest country specific consent rate of all participating countries. But because it is only one country out of 12 (see Fig. 3), no reliable statement can be made on the correlation of the feedback offer with the success of consent gaining.

In all countries of SHARE, advance letters had been sent to the respondents to announce the upcoming survey fieldwork of Wave 6 (see Fig. 4). In four countries these letters contained explicit information about the DBS collection taking place in this wave (*eth_advance=01*): Denmark, Italy, Sweden, and Switzerland. Respondents in all other participating countries learned about the blood collection during the SHARE interview only. Figure 4 does not show a clear correlation between this pre-announcement and the obtained consent rates.

France is the only country where interviewers were not allowed to prick the respondents' fingers (*eth_selfprick=1*). Here, consenting respondents had to prick themselves. Figure 5 shows that the French consent rate is in the middle of the other countries' rates. Being France the only country with the self-pricking restriction, no conclusion on the correlation of this restriction with the obtained consent rate can be drawn.

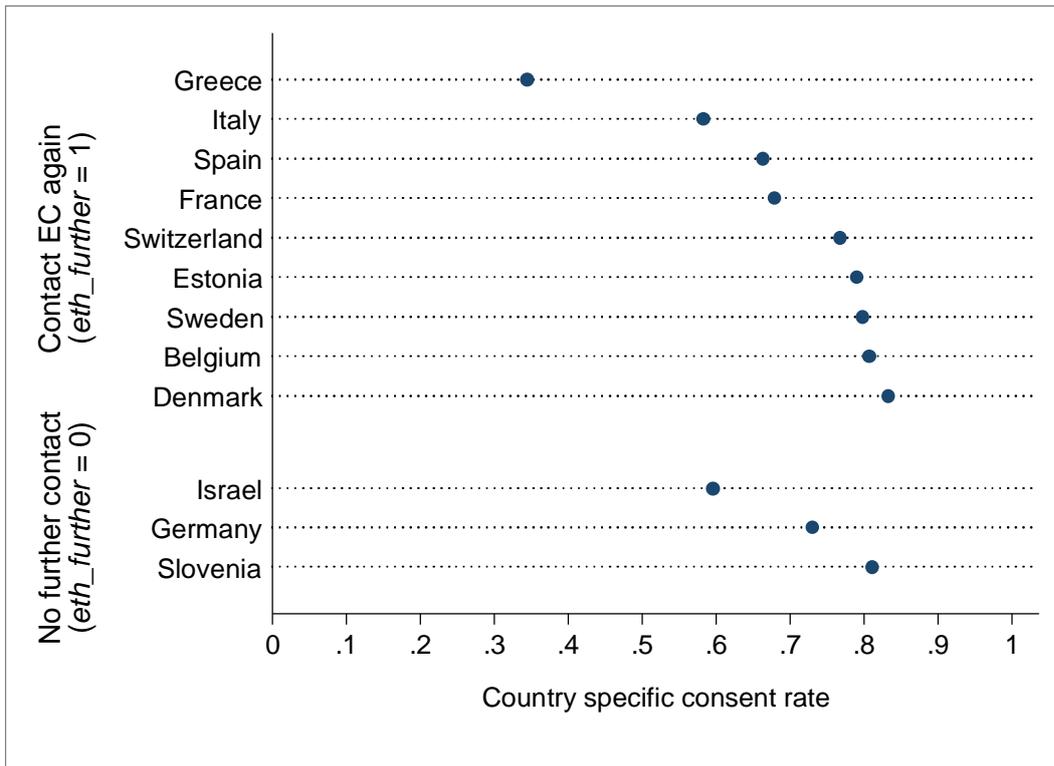


Figure 2: Country specific consent rates and the need to re-contact the national ethics committee if analyses should be made that are not mentioned in the respondents' information leaflet (*eth_further*); EC=ethics committee

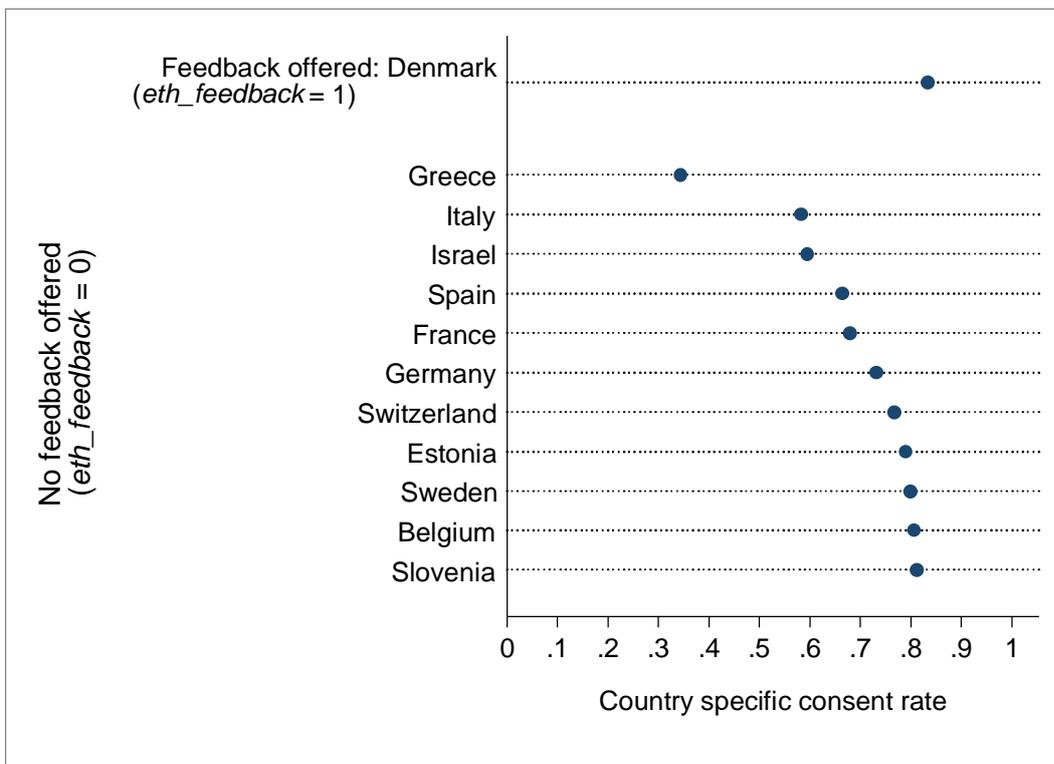


Figure 3: Country specific consent rates and feedback of individual results

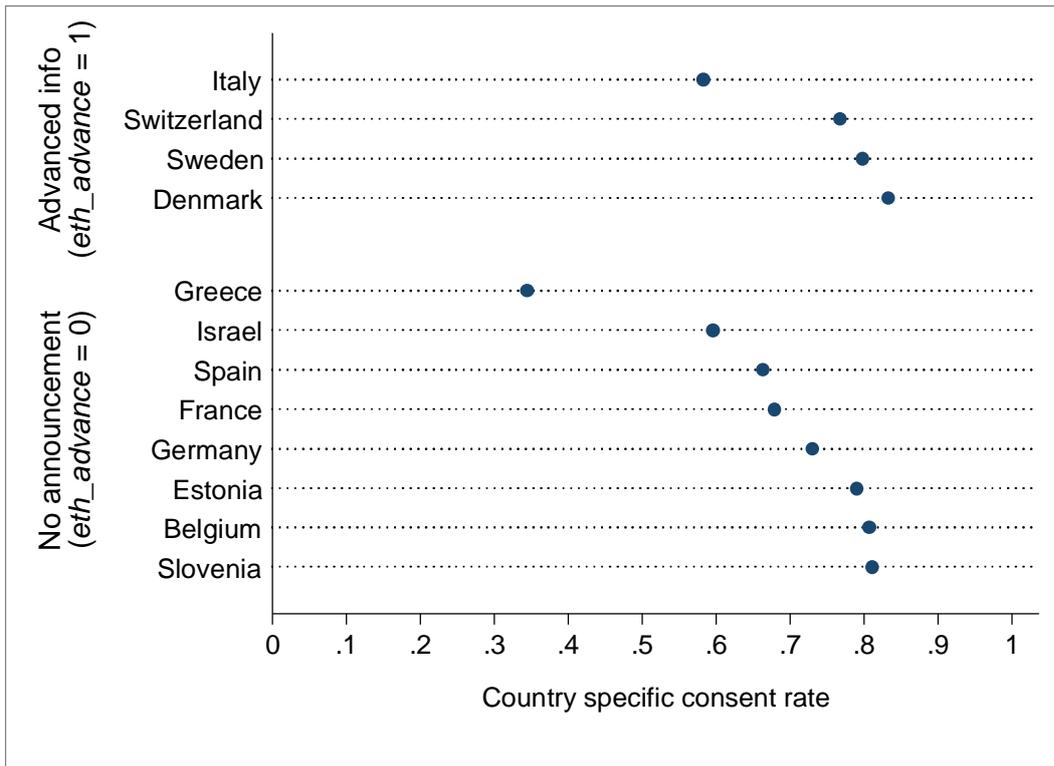


Figure 4: Country specific consent rates and the advanced announcement of the DBS collection

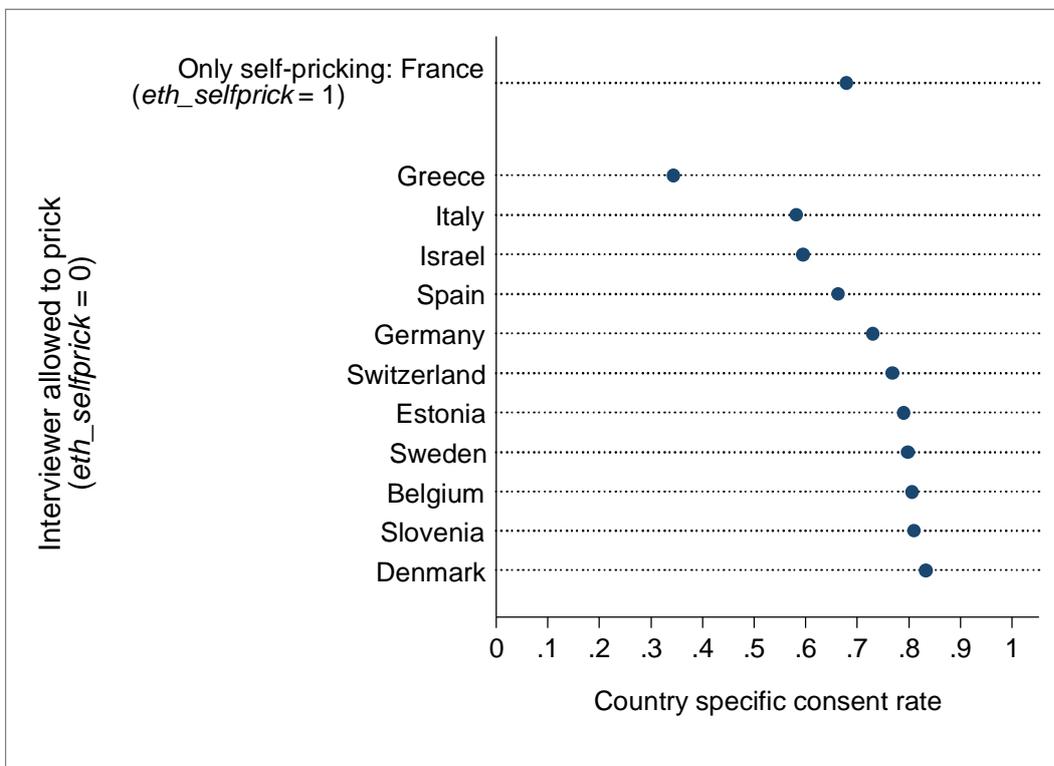


Figure 5: Country specific consent rates and the restriction to self-pricking

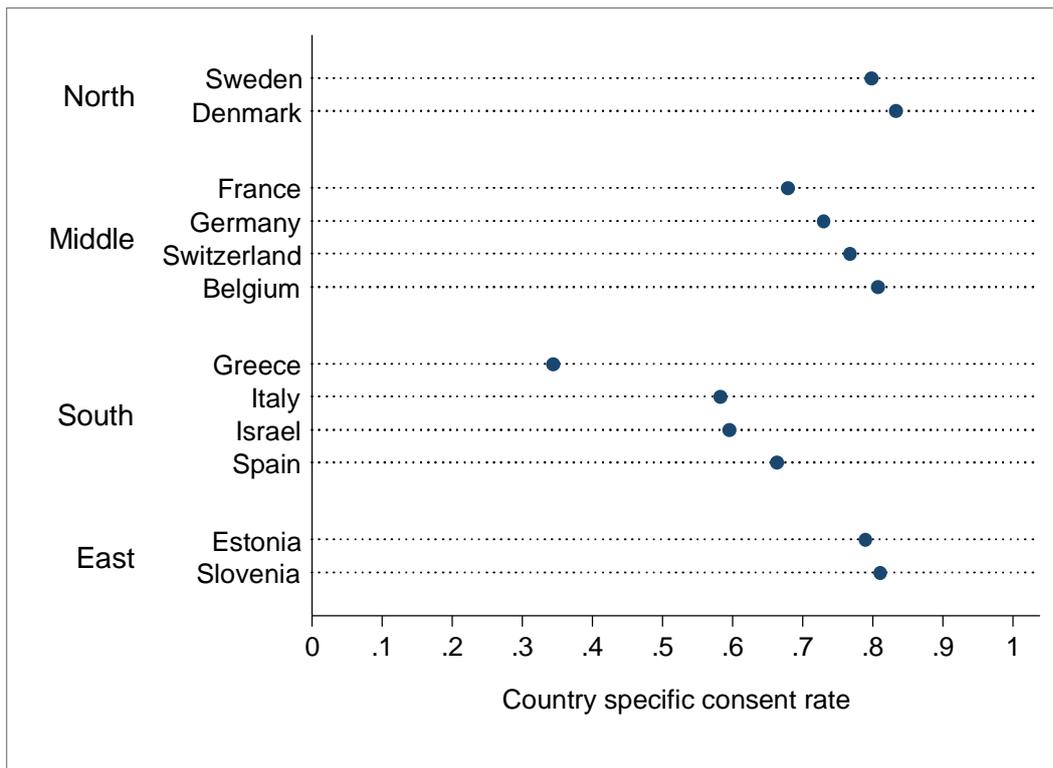


Figure 6: Country specific consent rates and the geographic location of the country regarding to Europe

3.2 Country specific consent rates and geographic country location

Figure 6 shows constantly lower consent rates for the countries located in the south of Europe. This group of countries includes Greece, Italy, Spain, and Israel, which is not European, but also located in the south.

The geographic location of a country is unlikely to directly influence the success in consent gaining to a blood collection. More substantial differences between the countries or their respective geographic regions have to be responsible for the lower consent rates in the southern countries.

3.3 Interviewer attitudes depending on the geographic location of origin

Such substantial characteristics have been observed in the SHARE interviewer survey. In the countries participating in both—the DBS collection and the interviewer survey—570 interviewers participated in the survey. The interviews of 464 of them have been included in the analysis of the correlation between expectations and actually obtained consent rates (shown in Fig. 8). The remaining 106 interviewers did not respond the expectation questions of the interviewer survey and, hence, could not be used for the analysis.

Figure 7 shows the expectations of the interviewers regarding the average success in their countries and their own success in DBS consent gaining. Compared to the other European regions, interviewers located in the south on average reported the lowest expectations, regarding the expected overall consent rates (orange bars, *exp_average*) as well as regarding the consent rates they expected to obtain themselves (grey bars, *exp_own*). Both kinds of expectations were highest in the Northern countries. All expectation means were significantly different from each other.

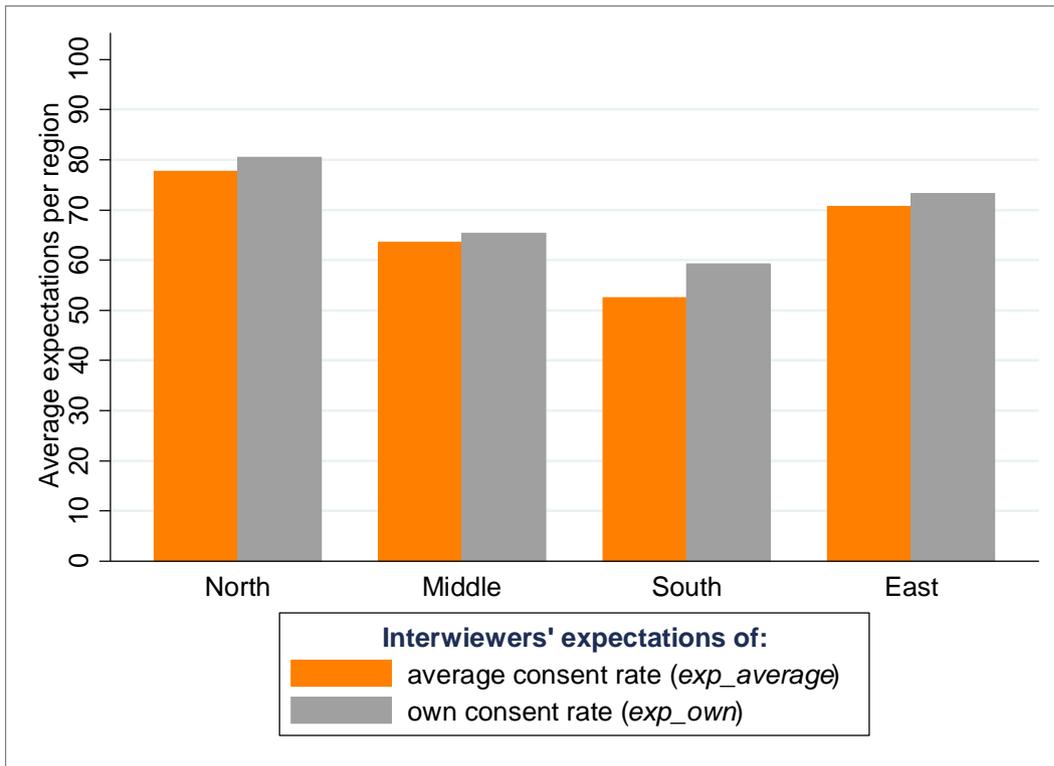


Figure 7: Interviewers' expectations of DBS consent rates depending on geographical region; Number N of included interviewers per region: N(North)=66, N(Middle)=204, N(South)=126, N(East)=68

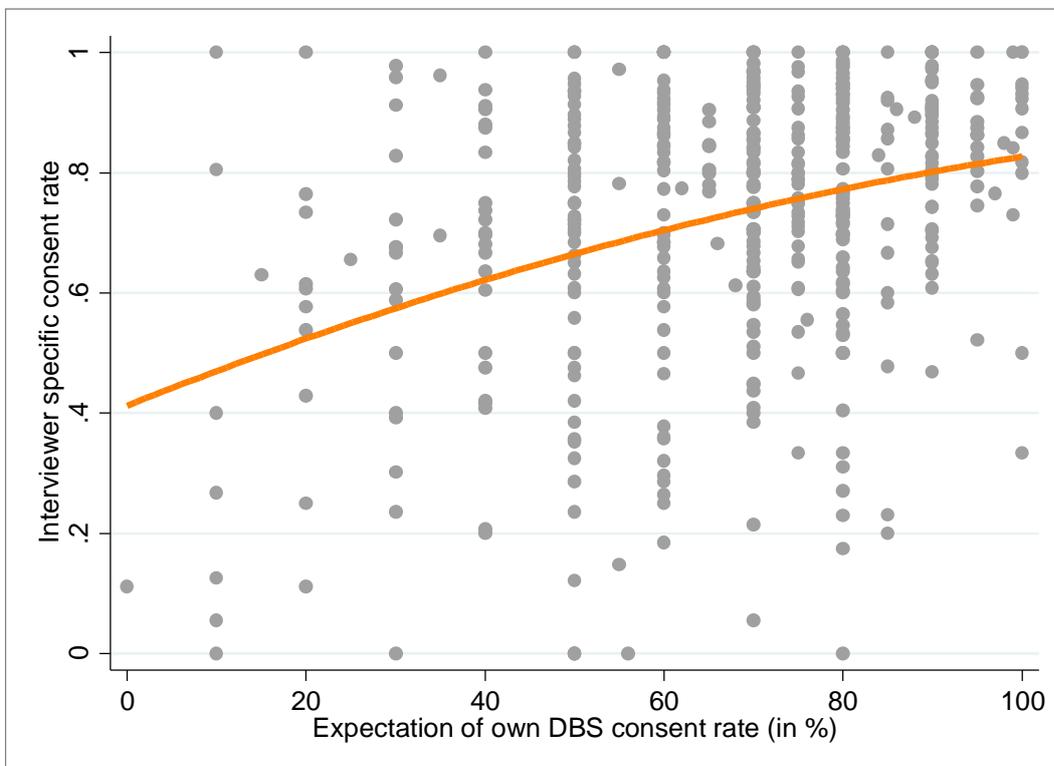


Figure 8: Achieved DBS consent rates depending on expectation of own consent rate (exp_own)

3.4 Interviewers' consent gaining success depending on expectations

Figure 8 compares the actually obtained interviewer specific DBS consent rates to the consent rates they expected to achieve before fieldwork started (*exp_own*). Each dot stands for one observation (interviewer). The orange line shows the fitted values (quadratic prediction) for the observations. The dots appear arranged in vertical columns, because interviewers tended to report round numbers and only very rarely mentioned expectation values that are not multiples of five. As can be seen in Figure 8, interviewers reporting higher expectations of their own success, in fact subsequently tended to achieve higher consent rates. The variance of the actual consent rates is high, but the tendency is clear.

4 Conclusions

The collection of biomarkers (obtained from blood, collected in form of DBS) differed from the other parts of SHARE for two reasons: first, specific approvals from the responsible ethics committees in all participating countries were needed beforehand (only in some countries the conduction of the whole survey had to be approved). This had implications for the collection process in some countries and resulted in country specific deviations regarding the collection process, the information given to the respondents, the content of the consent to be given, and the handling of the samples. Such deviations, if perceptible by the respondents, might have influenced their consent decision and, hence, the overall consent rate in the respective country. Second, the collection of blood was an unfamiliar task for most interviewers conducting SHARE since they are the ones asking for consent and conducting the measure.

It was shown before that, in general, interviewers characteristics—mainly their expectations—correlate with the consent decision of survey participants (Sakshaug, Couper, and Ofstedal 2010; Korbmacher 2014).

High consent rates are preferable, because they reduce the risk of bias that might arise if consenting respondents differ systematically from non-consenting respondents. Furthermore, higher consent rates lead to more blood samples available for laboratory analysis. Thus, a larger number of observations is available for statistical analyses—a fact that increases their statistical power.

A total of five country specific deviations resulting from the demands of national ethics committees have been identified, that potentially could have influenced the DBS consent decision of the respondents: the a priori exclusion of future DNA analyses in the collected blood samples, the requirement to go back to the national ethics committee for an approval of the analysis of further biomarkers, the offer of individual feedback on the laboratory results to the participants, the announcement of the upcoming DBS collection already in the general advanced letter, and the interdiction of interviewers pricking the finger of a respondent. In this report, however, no clear influence of any of these country specific differences based on legal/ethical requirements could be shown (see Fig. 1–5).

As these deviations were always valid for entire countries, their influence cannot be disentangled from—or might be masked by—other country specific characteristics affecting the consent decision of the respondents. This report, therefore, includes a consent rate comparison of countries located in the north, east, west, and south of Europe (the last group of countries including Israel), as shown in Figure 6. The geographic location of the country

serves as a “control” characteristic that is not imposed by an ethics committee requirement. Furthermore, the country-specific deviations treated in this report did not show any systematic pattern regarding the geographic location of the countries where they apply (or not). Figure 6 shows constantly lower consent rates for the southern countries (Greece, Israel, Italy, and Spain) than for the other countries.

The geographic location itself is very unlikely to influence the consent decision. Other differences have to exist between the countries/regions which affect the process of obtaining consent. Interviewers’ attitudes (mainly expectations on the success in obtaining consent) were shown to correlate with the actually gained consent rates (Korbmacher 2014). Hence, country specific differences in these characteristics may also correlate with differences in consent rates.

Information about the interviewers’ expectations was derived from the SHARE interviewer survey. In Wave 6, the interviewer survey included two questions on interviewers’ expectations of the consent rates regarding the subsequent DBS collection: interviewers were asked to state (i) which percentage of *all* SHARE respondents in their country they expect to consent to the blood collection and (ii) which percentage of *their own* respondents they expect to give consent.

In fact, the interviewers located in the southern countries of SHARE expected fewer respondents to consent to the DBS collection than the interviewers in other countries did. They stated lower expectations for the total of all respondents in their countries as well as for the subgroup of their own respondents. Reasons might be found in cultural differences between the countries located in different geographical regions. For example, there might be a correlation of the overall and personal expectation levels with the level of institutional or social trust in the respective country. This idea should be investigated further with macro data such as those of the European Social Survey (ESS). Furthermore, parts of the differences in expectations (and outcome) might be explained by composition differences in the groups of interviewers between countries. One example is the age of the interviewer: younger interviewers tended to report lower expectations and to obtain lower consent rates. Countries with a high rate of younger interviewers, thus, on average may show lower expectations due to this reason. The same holds for the gender of the interviewer: female interviewers tended to report higher expectations and obtained slightly higher consent rates. However, none of these differences were statistically significant.

Lower expectations of interviewers’ own success correlated with lower actually achieved consent rates. The variance is large, but the tendency can be easily seen. It has to be kept in mind that the causality behind this correlation is not clarified by these descriptive figures. Nevertheless, a possible mechanism may be that interviewers with less confidence in their own success are more likely to accept the refusal of a respondent, while interviewers with a higher self-confidence (and higher expectations) try harder to convince even reluctant respondents. It, hence, is reasonable to assume that a thorough interviewer training—increasing the interviewers’ expectations of their own success—may help to increase the achieved consent rates and thereby reduce a possible bias due to systematic nonconsenting. However, this assumption is still to be investigated further.

As a conclusion of this report, it can be stated that good interviewer training is more important for the success of a blood collection than changes in the collection process or associated documents based on slightly different legal or ethical requirements in the

countries that participated in the DBS collection. Training is likely to affect interviewers' expectations, especially with regard to their own success, which in SHARE Wave 6 were positively correlated to the actually obtained consent rates. Country specific deviations in the collection process due to legal or ethical requirements, on the other hand, were not clearly correlated to differences in the consent rates.

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Appendix 1 – SHARE DBS CAPI questionnaire (excerpt)

bs023_bsnonproxy

*IWER: Start of a **non-proxy section**. No proxy allowed. If the respondent is not present or not capable to give consent to participation on her/his own, please select "5".*

1. Continue.
5. Proxy-interview

IF bs023_bsnonproxy ≠ 1. please go to next module

IF bs023_bsnonproxy =1. please continue here:

bs001_introduction

To assess the health status of the general population age 50 and above, we would like to collect a few drops of blood. This will be done *using just a finger prick as it is done daily by millions of people with diabetes*. We would be very grateful if you agreed to participate. Yet, this blood collection is absolutely voluntary.

Before we begin, I would like to have you read this information sheet.

IWER: 1. Take the „information leaflet“ and the „Dried Blood Spots Collection“ consent forms and hand them to the respondent.

2. Let respondent read the information leaflet. Allow sufficient time for reading.

1. Continue.

CONTINUE WITH *bs006_medicalreasons*

bs006_medicalreasons

From your point of view: are there any medical reasons which would prevent you from participating?

1. Yes

5. No

IF bs006_medicalreasons ≠ 5. no please go to bs003_enddbs

IF bs006_medicalreasons =5. no please continue with question bs002_consent

bs002_consent

Do you have any further questions?

IWER:

1. If respondent has any questions, please answer them

2. Let respondent sign the consent forms

3. Leave one copy of the consent form with the respondent

1.R signed the consent form

5. R did NOT sign the consent form

IF (bs002_consent = 5. R did NOT sign the consent form) OR (bs002_consent = DK/RF) continue with question bs003_enddbs

IF bs002_consent = 1. R signed the consent form go to question bs004_forbiddenanalyses

bs003_endbs

Thank you. We will continue with the next topic.

1. Continue.

bs004_forbiddenanalyses

IWER: Please copy the excluded analyses that the respondent specified on the consent form. Type "none" if respondent did not write anything down.

_____ (String)

bs008_dbsinstruction

IWER: Please be aware: if respondent takes blood thinning medication, it may take longer time to stop the bleeding. In this case make the respondent elevate his/her hand and have gauze pads available.

Take "DBS Interviewer Short Instructions" and follow the instructions 1 to 15.

1. Continue

bs009_barcodefirst

IWER: Enter barcode number from barcode label into CAPI.

_____ (soft check: 8 digits)

bs010_barcodesecond

IWER: Repeat barcode number.

_____ (soft check: 8 digits and same as bs009)

Only IF Denmark:

bs021_feedback

Do you wish to be informed [OR country-specific: Do you wish to be informed via your general practitioner] about blood results if a value lies outside the normal range? Please be aware that a lot of time may pass until these results are available, and that this information does not replace consultation with a physician.

IWER: If the respondent wants to be informed, take the “TRANSMISSION OF DBS ANALYSES RESULTS” consent form and hand it to the respondent. Let respondent read and sign the consent form. Allow sufficient time for reading.

1. Yes, R wants to be informed AND signed the consent form.
5. No, R doesn't want to be informed/did not sign the consent form.

ENDIF

bs011_thanks

Thank you for your cooperation. This completes the collection of dried blood spots. Before we continue with the interview, I need a moment to enter a few pieces of information in the computer.

1. Continue

Appendix 2 – SHARE Interviewer Survey (excerpt)

In SHARE respondents are asked to consent to the collection of blood spots. Please give your expectations for each row!

1. In general, what do you think, which percentage of all [Country specific nationality for example “German”] SHARE respondents will consent to the collection of dried blood spots?
_____ (0-100)

2. In addition, what do you think, which percentage of your respondents will consent to the collection of dried blood spots?
_____ (0-100)