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Barriers and strategies to participation in tissue research among African-American men

Bettina F. Drake, PhD, MPH,
Division of Public Health Sciences, Department of Surgery, Washington University in St. Louis School of Medicine, St. Louis, MO 63110 United States, Alvin J. Siteman Cancer Center, St. Louis, MO 63110, drakeb@wustl.edu, phone: 314-747-4534, fax: 314454-7941

Danielle Boyd, MPH,
Division of Public Health Sciences, Department of Surgery, Washington University in St. Louis School of Medicine, St. Louis, MO 63110 United States, boydd@wudosis.wustl.edu

Kimberly Carter, PhD, MSW,
Department of Social Work, Southern Illinois University-Edwardsville, Edwardsville, IL 62026 United States, kimcart@siue.edu

Sarah Gehlert, PhD, and
Division of Public Health Sciences, Department of Surgery, Washington University in St. Louis School of Medicine, St. Louis, MO 63110 United States, Alvin J. Siteman Cancer Center, St. Louis, MO 63110 United States, sgehlert@gwbmail.wustl.edu

Vetta Sanders Thompson, PhD
Brown School of Social Work, Washington University in St. Louis, St. Louis, MO 63110 United States, vthompson@gwbmail.wustl.edu

Abstract

Before the burgeoning field of biospecimen collection can advance prevention and treatment methods, researchers must access diverse molecular data samples. However minorities, especially African American men, remain reticent to join these studies. This study, using theory based approaches, investigated African American men's barriers to participating in biorepository research. Fourteen focus groups were conducted among 70 African American men (ages 40 to 80). The groups were stratified by prostate cancer history and educational attainment background. Participants identified perceived factors that promoted or hindered study participation when questioned about their knowledge and attitudes about biospecimen research. Ninety-four percent of participants indicated never participating in a study that collected biological samples. Barriers to their participation included lack of knowledge and understanding regarding biospecimen research practices and uses. In addition they extensively cited a prevalent mistrust of the medical community and discomfort with study recruitment practices. African American males were more willing to participate in biorepository studies with physician endorsement or if they understood that participation could benefit future generations. Men also wanted more recruitment and advertising done in familiar places.

Correspondence to: Bettina F. Drake.

INTRODUCTION

Collecting biological specimens for future research is becoming a common practice. Growing evidence in support of this research advocates that collecting these biospecimens holds great promise for disease recognition, diagnosis, and prevention, particularly as it relates to cancer [1, 2]. Over the past several years, the National Cancer Institute has undertaken an intensive process to identify salient guiding principles that define state-of-the-science biospecimen resource practices [1]. Despite growing interest in this emerging area of medical research, investigators consistently report difficulty engaging minority research participants [2–5]. A number of studies have been conducted looking at minority engagement and recruitment. We must understand reasons for non-enrollment of minorities in biorepositories in order to establish biorepositories that will support research projects representative of the whole population.

Clinical trial data and the general health research literature consistently show that African American men are less likely to participate in biorepository studies. In addition, previous research has found that white men are more likely to participate in biorepository studies compared to minority men [6, 7]. Investigators continue to experience challenges in engaging these men in general health studies, as well as biorepository studies. African American men's nominal presence in existing research studies has created a limited understanding of their perceptions of and willingness to participate in biorepository studies. [8, 9] In addition, previous research has shown that recruitment of African American men into health research studies may vary by socioeconomic status [10, 11] This study contributes to our knowledge base by increasing understanding of barriers and posing strategies to increase research participation, specifically among African American men.

Our objective was to understand barriers and strategies to increase participation in biorepository studies. Therefore, we utilized a Community-Based Participatory Research (CBPR) approach to engage African American men in the process of identifying barriers and strategies to specifically improve biorepository participation. The Prostate Cancer Community Partnership (PCCP), an existing group of community members, prostate cancer survivors, and academics who help shape research, education and outreach opportunities in the region, collaborated in the effort.[12]

METHOD

Recruitment

Members of the PCCP, worked with local community and faith-based groups, fraternal organizations, prostate cancer survivor groups, university-affiliated urology clinics, and healthcare organizations, to identify prospective participants. Advertising via specially designed flyers and project correspondence was posted in community settings. Critical feedback was solicited on layout, language, and cultural appropriateness from members of the PCCP. All flyers and posters included simple, non-medical language and racially matched images of men. Focus group venues were community-based and located in places known to have positive relationships with local African American men.

To reduce attrition between recruitment and focus groups, men received a reminder call one to three days prior to their scheduled group. Additionally, the team over-recruited for all groups to circumvent problems of non-attendance.

Participants

Participant recruitment occurred between February and July 2011. Seventy African American men between the ages of 40 and 80 were recruited to the study and assigned to one of fifteen focus groups that comprised four categories. These categories classified participants based on their history of prostate cancer (yes/no) and educational attainment (high school diploma or lower vs. greater than high school diploma). See Table 1. Direct SES information was not collected. Resultantly, education did not serve as a fair or accurate marker for SES in this study.

Procedures

The appropriate Institutional Review Board approved this study and consent procedures.

To ensure ease of accessibility and convenience, focus groups were conducted at community venues. The choice of community venues was based on feedback from community partners who knew this population of interest. Focus groups were also conducted on a Neighborhood Voice Mobile Unit (NVMU), a shuttle-type vehicle customized for research purposes. The unit, which resembles a large conversion van, serves as an 8-person focus group facility with perimeter seating around a conference style table [12]. It allowed the team to conduct its research activities in accessible community locations and overcome common participation barriers related to convenience and accessibility.

Two team members facilitated focus groups of 6–8 men. An experienced African American male served as the primary facilitator who asked most of the questions. A secondary facilitator largely engaged in note-taking and provided additional facilitation support. Focus groups lasted approximately 90 minutes.

Upon arrival, the research team reviewed the informed consent individually with each participant and obtained written consent. Participants completed a pre-focus group survey including information on demographics, health, age, marital status, insurance status, educational background, and past experience with research studies.

Prior to the start of the focus group, participants received the NCI-developed brochure, “Providing Your Tissue for Research: What You Need to Know”.

Facilitators explained the points in the brochure before beginning each focus group. In particular, the literature was used to both generally define a biorepository study and to describe the nature of the biospecimens to provide baseline knowledge of the concepts discussed in the focus group.

Focus groups were audio taped and the research team periodically reviewed audiotapes to assess fidelity to the protocol and interview guide. The focus group used a semi-structured questioning route (interview guide) that included open-ended questions and related conceptual probes. The initial questions addressed participants' pre-existing knowledge, past experience, and general attitude around health research studies. The later questions delved more specifically into biospecimen research. Participants were asked about their general knowledge of biospecimen research, about barriers to participation, particularly for African American men, and about factors that promote participation. All participants were reimbursed with a $25 retail gift card for their time.

Framework

The framework for this study was informed by the work of Swanson and Ward that encompasses barriers related to the recruitment of members of minority groups to clinical trials [13]. This framework categorizes barriers to participation in health research into four areas: sociocultural, economic, individual, and barriers inherent in the study design [13].

Data Analysis

Focus groups were recorded and professionally transcribed verbatim. Nonverbal cues (e.g., hesitation in answering, etc,) were included in transcripts. The team checked the transcripts against the audio to verify accuracy of the data and corrected any detected errors. Two researchers and one of four community reviewers coded each focus group to identify key themes and develop the codebook. Research team members coded transcripts using Atlas-ti, qualitative analysis software. Community members coded the transcripts by hand which were added into Atlas-ti before analyses. All final codes and themes were entered into Atlas-ti to facilitate organization of codes and final analysis.

Four community members from the PCCP reviewed this work. Professional transcriptionists transcribed the focus group audio verbatim. Nonverbal cues (e.g., hesitation in answering, etc.) were included in transcripts. The team checked the transcripts against the audio to verify accuracy of the data. Any detected errors were corrected. Emerging themes were discussed at monthly PCCP meetings. The list of themes from the community reviewers was compared against the list compiled by the research team in an iterative process until there was satisfaction among all reviewers that a comprehensive list of codes and themes had been developed.

RESULTS

Seventy men completed 14 focus groups. The mean age was 57, 46% were employed, and 66% had some college or greater education. Additional demographics are shown in table 2.

Analysis of focus groups revealed that men's thoughts on tissue research addressed two major themes; *barriers to participation in tissue research* and *strategies to increase tissue research participation*. Barriers to participation in tissue research encompassed the following themes: 1) understanding tissue research, 2) mistrust of medical community, and 3) unwillingness to participate in tissue research. This section's additional quotes can be found in Table 3. Strategies to increase participation contained the following themes: 1) addressing knowledge deficits, 2) mistrust of research recruitment, and 3) willingness to participate in tissue research. See Table 4 for this section's additional quotes.

Four categories of focus groups were analyzed, however the statements provided by the participants throughout all fifteen focus groups were similar regardless of their educational attainment or prostate cancer status.

Barriers to participation in tissue research

Understanding tissue research—Participants showed awareness for other types of research concerning family relationships, drug or alcohol abuse, but they did not know about the existence of tissue research. Their initial impressions reflected uncertainties about the nature of these studies. More specifically, the participants noted how the words “tissue research” in the research description could confuse people into “thinking that it's coming from your skin or something… There could be blood or urine or something like that.”

Few individuals expressed general knowledge of research studies in their area which derived through personal connections to the research institution. The participants voiced concerns about lack of information on research studies in the community. Some participants stated the African American community did not fully understand that in research studies “we need more black donations” in order for research “to help the black community.”

Lastly, a few participants stated some people in their community avoided studies because they did not want the research process to uncover unknown medical conditions. Participants recalled conversations with persons “30 and under” who explicitly stated that, “if I got it, I don't want to know about it, see just thinking about that's scaring me."

Mistrust of medical community and research practices

Mistrust of medical community: Discussions revealed a general theme of mistrust for both the medical community and the intentions of researchers. The majority of participants justified their mistrust of the medical community and research intentions by citing historic failings of the medical field toward African Americans. Most notably, participants repeatedly alluded to the United States Public Health Service Syphilis Study at Tuskegee to frame their mistrust of the medical community. Some participants admitted that they limited their interactions with healthcare due to their mistrust.

Mistrust of research practices: The overwhelming majority of participants stated they generally didn’t trust the researcher’s intentions to fairly present their study objectives to participants. Instead, they felt like researchers would lie and tell them they were “researching for one thing but I’m actually using the stuff for something else.” Similarly they felt researchers would not prioritize their individual well-being above research objectives or future profits. To this effect they also feared that researchers would downplay the harms associated with a study:

> “If I’m going to be taking medication how threatening is the medication going to be. And are they going to give me all of the information I need to know while taking the specific medication.”

The perceived incentive for researchers to value research outcomes over participant well-being was further illustrated in the following conversation about the news stories highlighting the profit derived from minority medical specimens (i.e. Henrietta Lacks' research story):

> Participant 3: {Medical researchers} discovered this medicine that helped cure something. And that family lived in poverty for years.
>
> Participant 13: And they sued the medical company because had it not been for the research that their grandfather or father participated in, they would have never have made that cure that they got real wealthy off of…

Some participants expressed uncertainty that researchers would notify individuals if "they find something that's wrong with me." Furthermore, the participants did not feel that they would experience the benefits of the research outcomes.

<u>**Concern for Personal Privacy:**</u> Many participants voiced concern for researchers divulging their personal information or health outcomes to other medical entities.

> "What you do here should stay here and it shouldn't be revealed to any other person, any other medical facility or anything like that."

Some participants did express slightly more trust in the current system. They presumed an increase in privacy and believed, *"It's not like it was then. The world knows how to handle situations better…"*

Unwillingness to participate in tissue research—A few men acknowledged their unwillingness to participate in tissue research if it involved pain, preferring "no bloodwork, no needles, no cuts." Compensation was repeatedly mentioned as another deterrent for participation. Participants noted that they expected any study requiring a substantial time commitment to include compensation like food and travel reimbursements to account for their time and transportation expenditures. Participants noted that community members would be unwilling to participate in studies without the assurance of some form of compensation.

Strategies to improve tissue research participation

Addressing knowledge deficits—Participants felt the African American community lacked knowledge about tissue research studies and was often not approached. Participants believed researchers were missing "a huge conglomerate of young intellectuals that are available who probably would participate if they knew it was available." Participants who did know about tissue research studies, stated they found the research materials difficult to understand. Some participants suggested researchers "simplified" research materials or "put it so I can understand it." Most participants expressed that "education is a real key." They strongly supported actively engaging their community in educational opportunities like free "study classes" or "group sessions" where people could learn about tissue research. While the participants reiterated the need for research education in their community, they also acknowledged that these sessions need to be strategically placed in convenient locations and places of prominence in the community.

In addition to community education, they stated research advertisements needed to be featured in schools, businesses and workplaces. They repeatedly suggested using varied methods of advertisement to target all groups of the community, specifically citing the use of social media to target younger African American participants.

Mistrust of research recruitment—The time, placement, and presentation of the first encounter concerning a research study proved essential. Many participants said they felt the first conversation with a research recruiter was so important, its outcome could determine the participant's willingness to participate. The participants agreed that the recruitment "presentation is everything", however the preferred method varied. Some participants wanted the recruiters to clearly disclose the study's collection methods. Others did not want the researchers to say anything in the first encounter. One participant explicitly stated that he wanted researchers to "just give {material} to me. I can read." Likewise, a consensus for the ideal time or location was not agreed upon. Most agreed that research approaches done while waiting in the emergency room is "not the appropriate time". Some felt very comfortable having recruitment take place in their physician's office. They believed "if you trust your doctor then you're more apt to say okay and go along with those things. You'll be more apt to go along with it." However, other participants did not like recruitment in physician offices. They noted that many distractions may be present like a man may have "other things on {his} mind" or be in pain at that time.

> "That might seem like a good time for the researchers to approach somebody because they're incoming, but you're not even in that frame of mind then."

Participant familiarity with researcher/institution: Participants weighed the reputability of the researcher, physician or research institution when deciding which research to trust. Some expressed concerns about who approached them. One participant stated "I also think about who's asking for {my recruitment}? How do they qualify themselves?" Participants stated that they were more likely to trust, and subsequently enroll in a study if the person who initially told them about the study was familiar or "already trusted." These persons included family and friends. Participants strongly supported receiving study information from medical personnel, especially doctors or nurses, even if they merely reinforced what a prior researcher said.

Willingness to participate in tissue research—The participants expressed a genuine desire to participate in tissue research in order to "help someone down the line." Most men held a common perception that the study would allow them to use their health experiences to improve health experiences for close relatives and future generations. Additionally, some participants noted that they previously held negative attitudes toward joining a research study and only changed their mind as they aged or if they were diagnosed with cancer in particular.

DISCUSSION

Biorepository research has the potential to improve treatment and therapies for a variety of conditions, many of which disproportionately affect minorities. However, minority groups are least represented in biorepository research and have proven a challenge to recruit. This study used Swanson and Ward's[13] evidence-based framework concerning the involvement of minority populations in clinical trials to further explore some of the underlying factors driving the lower level of research participation in African American men. Swanson and Ward[13] suggest that the poor accrual of minority populations into clinical trials results from a multi-faceted breakdown of cosiocultural, economic, individual and study design considerations. The insight provided by our participants showcased ways in which study recruitment fails to alleviate African American men's concerns across this four-part framework.

African American males have proven particularly difficult to recruit and less likely to allow their tissue to be used for research purposes in comparison to women [10, 11]. The utilization of CBPR principles in this study helped generate candid data from a traditionally hard to reach population of participants. The partnership between community members and researchers was made more equitable by including community members in both the planning and analysis portions of this research further strengthening the depth of research data. Having an African American male serve as primary facilitator for the focus groups also added a level of familiarity between participants and researchers. The participants candidly discussed African American men's thoughts on participating in biorepository research in the fifteen focus groups. Their sentiments addressed two major concepts: barriers to participation in tissue research and strategies to increase participation in tissue research.

Researchers have suggested different levels of understanding of what a biorepository is and the purpose of storing tissue samples may lead to the differences in participation in tissue research between minorities and non-Hispanic whites [12]. Participants reiterated these individual level discrepancies regarding their own understanding of biorepository research. They noted African American men lacked knowledge about the nature of tissue research and noted that the materials used in studies were very hard to understand.

All focus group participants agreed that African American men were largely unaware of local tissue research studies because the advertising was not made readily available outside of research institutions. They wanted to see study advertisements in locations where they frequented, specifically, in key venues such as high school or at work. All participants recognized that reaching their community would require more responsibility from invested men and researchers educating men in the community. They suggested increasing research advertisements in the community as well as holding meetings or educational sessions to help community members learn about ongoing research topics. However, some of the PCCP members did not feel that work-place teaching opportunities, specifically on prostate cancer tissue donation, would be received well given the potential sensitivity of the topic of cancer and its impact on quality of life. Work-place teaching on general tissue research studies were viewed as positive by PCCP members.

All participants shared an understanding that increasing the number of minority men in tissue research would greatly improve the health outcomes of future generations. They used this stark knowledge as the impetus for their willingness to assume more responsibility in educating their community. In spite of this expressed commitment to increase minority representation in these research studies, many obstacles prevent this from occurring. Potential participants' inability to link research to personal benefits represents one such research barrier. Researchers suggest that a lack of personal relevance to the research purpose could explain low participation rates among individuals [14]. Additionally, other research has attributed lack of time to dedicate to a topic of low personal priority to individuals not participating in randomized controlled trials [15].

Study participants expressed how African American men can derive personal relevance for research participation. They derived personal relevance from their study participation when they could see a benefit to those closely related to them. Furthermore, they expressed a willingness to participate in biorepository research when they understood that their participation could help a family member in the future. Specifically, the prostate cancer survivors were interested in protecting younger male family members from a diagnosis of prostate cancer. This sociocultural factor has not been well understood or adequately addressed in biorepository recruitment efforts and subsequently represents a missed opportunity in research recruitment designs.

Additional sociocultural concerns expressed by African Americans regarding biorepository research studies include mistrust [16, 17]. In fact, a recent study has demonstrated that African Americans consistently show less trust and are therefore less likely to provide biospecimen samples [18]. Our participants also expressed their negative views toward the research community and noted the presence of medical mistrust within their community. They cited the discrimination faced by African American's during the USPHS Syphilis Study at Tuskegee. They also discussed the use of Henrietta Lacks' tissue samples [19] asan instance when medical research did not adequately compensate or protect its participants. For the purpose of our topic, history still has a profound impact on the present as the participants describe an accepted culture of mistrust for the medical community and a general unwillingness to participate in medical research studies.

Further research has shown that participants tend to withdraw their tissue from a biorepository as a result of a breach of security or some sort of scandal [20]. Our findings also indicate that privacy was an utmost concern for all participants. However, those with less than high school education and no history of prostate cancer showed more leniency toward researchers, asserting that current research practices employ more security measures than previous studies. Concerns about privacy in research have been well documented throughout previous literature [14, 21]. Without the guarantee of privacy, men may be hesitant and even unwilling to participate in biorepository research.

We also found that some African American men fear tissue research and associate it with pain. However, if researchers assured participants that tissue collection is not necessarily an invasive or painful process, they were more receptive to the idea of participating. These reassurances highlight a very important idea of researcher rapport, raised by all of our participants. Participants adamantly agreed that their first encounter with a researcher was vital to their agreement to be in a study. If the potential participant did not know the researcher or felt like the researcher was misrepresenting his or herself or their study, then that man would not agree to participate in the study. Further research could examine research study recruitment methods.

We must consider several limitations in this study when reviewing these results. Although our goal was to specifically understand barriers to participation among African American men, this focus group limits the generalizability of our results to other ethnic minorities. In addition, it is possible that some barriers we uncovered could have been gender specific. Future research is needed to assess differences between perceived barriers among minority men and women. This study is also subject to other common limitations of qualitative research, such as the inability to make causal inferences.

These study findings highlight crucial practice gaps in clinical research recruitment that systematically exclude minority populations. The participants voiced equal concerns about trusting those who approached them for recruitment as well as clearly understanding how the research study would benefit others most like them. Current research recruitment strategies emphasize the benefits of participation in terms of broadly improving research rather than how individual lives may benefit from the research findings. This shift in recruitment may clarify the direct and indirect benefits of research and may ultimately increase their likelihood to participate in a biorepository study. The findings from this study can direct future research efforts to explore barriers for African American men's participation in biorepository studies. In particular, the concerns about the pain or nature of biospecimen samples taken when participating in these studies may be explored with a larger more diverse sample of people. In addition, further research could test various study recruitment interventions that address some of the concerns raised by these participants.

Biorepository studies are generally low-cost to the participant in terms of time and medical procedures, because the biological samples are usually acquired during standard medical procedures or treatments. Diversifying the participants in these studies will require continued diligence and collaboration on the part of community and research entities. The findings from this study highlight some areas ripe for collaboration and the use of CBPR principles will greatly increase the impact and potential for sustainable community-relevant advertising and educational opportunities. We anticipate that these findings will also elucidate some areas where educational efforts concerning biorepository research can be focused; namely explaining its nature and explicit goals, its benefits and its personal relevance for all ethnic and racial groups. In addition, these findings can greatly inform future studies in their recruitment methods. By adjusting these approaches to be more mindful of the sensitivities of the target participant population, we anticipate that this study not only will increase minority enrollment in ongoing biorepository studies, but continued efforts in this area will advance our long-term goal and will result in the gain of sufficient information to increase knowledge and awareness about biorepositories. Understanding barriers to participation at this level will help us to address similar issues found with minority recruitment in more complex studies such as randomized controlled trials.

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Table 1

Stratification of Focus Group Sample

	PCa		No PCa		N (%)
	# of Groups	# Men	# of Groups	# Men	
≤ High School	2	10	4	21	31 (44.2)
>High School	4	15	4	24	39 (55.7)
Total Men N(%)	25 (35.7)		45 (64.2)		70 (100)
Total Groups	6		8		14

Table 2

Demographic of study sample

Participant Characteristics N=70	%
Age (mean)	57
Employed	
yes	46%
Education	
Some college or technical degree	66%
Marital Status	
Married	58%
Insurance	
Private	62%
Medicare/Medicaid	25%
Uninsured	13%
Participated in a Health Research Study	
Yes	28%
Participated in Tissues Research Study	
Yes	8%

Table 3

Additional Quotes for Barriers to Participation in Tissue Research

Additional Quotes for Barriers to Participation in Tissue Research
Understanding tissue research
" {Health Research} information isn't floating around maybe like {the research institution} thinks it's floating around out there in the black community."
Mistrust of medical community and research practices
" Just the word research in our community is like that's a bad apple, you know, going back to Tuskegee and all of that and not even-- you don't even really have to go back that far…that's going on right now…"
"We for years, you know, we're not meant to rely on the healthcare industry to have our best interests at heart. And that history is dying very slowly. There may be generations behind us that don't remember the Tuskegee experiments and things like that."
"Theoretically everybody's supposed to benefit, but let's be real. The ones with the money actually benefit from it."
"{I} neglected going in for even healthcare from a doctor because {I} was not able to trust."
Unwillingness to participate in tissue research
"Well how are you going to get these tissues? Are you going to cut me? What are you talking about here? If you're talking about cutting me, forget about it."

Table 4

Additional Quotes for Strategies to Improve Tissue Research Participation

Additional Quotes for Strategies to Improve Tissue Research Participation
Addressing knowledge deficits
“I don't know what you can do except go to places that they are and have it there. Like this. Go to a black man's job…or get a group of men together. See if you can do it at their lunch time…”
“Putting that information out there to them will really make them understand better what their risks are and how they can alleviate themselves.”
“So I think if you made it available on radio, TV, like where there’s social media that is available for the African American community.”
Mistrust of research recruitment
“You have to have the manners of approaching it the right way with the right words. Professionalism would mean {the difference} between me doing it and me not doing it.”
“… that’s why I asked you well, who was funding this research? Because on the surface it may look like one thing but underneath that you never know. So you don’t know if you’re doing something to help mankind or to hurt mankind.”
“Well how are you going to get these tissues? Are you going to cut me? What are you talking about here? If you’re talking about cutting me, forget about it.”
Willingness to participate in tissue research
“I don't have a problem participating in {research} especially with health problems that I done had, I see that it's beneficial to other people, hopefully, since I've been diagnosed with cancer too so I'm hoping that people participate in it to keep other people from going through what I've had to go through.”
“My first thought is if I can help somebody I wouldn’t mind helping a person if they need something that I have that they can use, I wouldn’t mind helping them. And the same process, I might need some help from somebody.”
“Before I was diagnosed with cancer I would have gave it a second thought. ‘I’m not giving you tissue, don’t even come close to me.’ But now that I’ve been personally affected by that then I see the need for it.”
“And so yeah, I’m more receptive to looking at those issues than I would have been 30 years ago. Thirty years ago I would have been saying, ‘Catch you later’. And then later finally came for me. So now I gladly participate in those kinds of studies.”