

Survey of motivation to participate
in a birth cohort

(出生コホート参加へのモチベーションに
関する研究)

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ABSTRACT

For longitudinal prospective cohort studies to be successful, participants' motivation to provide information must be maintained. The aim of this study was to identify factors that influence motivation to participate in a birth cohort, with a focus on the participants' understanding of the study and their concerns about potential risks and burdens.

Questionnaires were mailed to 4,541 mothers and expectant mothers who participate in a nationwide birth cohort study from which 2,387 responses (52.6%) were received. The primary motivations for participation in the study were benefits to the participants' children, monetary compensation, and contributing to making a better environment.

More than 30% of the respondents felt they lacked understanding of the study purpose and requirements for participation. Fourteen percent were concerned about leakage of personal information and 13% felt burdened by a long-term commitment to the study.

Respondents who had low initial motivation and/or were motivated by money or gifts (goods) tended to have a poorer understanding of the study and more concerns about its risks and burdens. To address these issues, more information about the study should be provided in an easy-to-understand manner not only at the initial explanation for informed consent, but also during the follow-up period.

INTRODUCTION

To address the influence of unfavorable environmental exposure on children's health,^{1,2} large-scale birth cohort studies have been conducted in a number of countries.³ In Japan, the Japan Environment and Children's Study (JECS), a nationwide government-funded birth cohort study, began in January 2011 with the objective of evaluating the impact of environmental factors on children's health and development.^{4,5} The predetermined recruitment goal of 100,000 pregnant women was achieved in March 2014 through the cooperative efforts of 15 medical university-based regional centers. The default follow-up setting was to continue monitoring the participating children until they reached age 13 years. In this birth cohort, mainly healthy pregnant women were recruited, and participants were asked to provide biological samples and information about their living environment, lifestyle, and health as well as their child's development over time.

The success of longitudinal cohort studies largely depends on whether a sufficient number of participants can be recruited and whether their motivation to provide information can be maintained over the course of the study. To that end, it is important to understand the tendencies of participants and the factors that influence their motivation. The tendencies of participants in birth cohort studies and clinical research on newborn infants have been previously reported.⁶⁻¹¹ Some studies examining tendencies in hypothetical settings found that the willingness to participate depended greatly on maternal characteristics⁷ and degree of risk.⁹ In an actual setting, Brumatti et al. found that major reasons to participate in a newborn cohort study were contributing to the research as well as willingness to benefit future mothers and children.¹⁰ Most of the participants in that study also expressed trust in the host institutions. Daniels et al.

reported that many participants were motivated not only by making potential contributions to science, but also by receiving information about their pregnancy.¹¹ On the other hand, a lack of understanding of the research¹²⁻¹⁶ and concerns about leakage of personal information¹⁷⁻¹⁹ have been noted in a number of cohort and genomic studies.

Here, we hypothesized that a lack of understanding and concerns about the JECS may result in low motivation to participate. To address this issue and identify factors that could promote the success of longitudinal prospective cohort studies, we analyzed the tendencies of participants in a large birth cohort. To our knowledge, this is the first investigation of this kind.

MATERIALS AND METHODS

The Japan Environment and Children's Study

The JECS is a birth cohort study conducted to evaluate the impact of various environmental and genetic factors on the health of children up to 13 years of age. A total of 103,106 pregnant women were enrolled in the study. Recruitment was conducted at 15 regional centers nationwide from January 2011 to May 2014. These regional centers conducted recruitment in cooperation with maternity hospitals and local health centers. Biological samples (mother's blood, urine, hair, and breast milk, cord blood, and baby's dried blood spots and hair) and medical records continue to be collected, and information about lifestyle, living environment, and child development is gathered periodically by questionnaire. Portions of the biological samples are stored for genetic analysis, and the plans are being designed to convert the biological sample repository into a biobank for further scientific research.

The Center of Chiba Unit is one of the regional units carrying out the study and it covers a total of 14 cities and towns in Chiba Prefecture, Japan. Recruitment was conducted in consecutive steps: (1) a face-to-face explanation with accompanying briefing materials by trained recruiters; (2) delivery of an explanatory booklet; and (3) receipt of a signed consent form (on the same day or within several days). If prospective participants wanted additional information, it was provided by telephone, e-mail, or the study website. As a prerequisite for enrollment, participants were required to have basic literacy so that they could complete the periodic questionnaires.

Questionnaire survey

The questionnaire used in this study was designed to ascertain the following: 1) the participants' initial motivation to participate, 2) the items for which they felt they had insufficient understanding, and 3) their concerns. Respondents were classified according to the type and level of their motivation, and then the level of understanding and/or concern was compared between the groups.

For this study, anonymous questionnaires were mailed to 4,541 mothers and expectant mothers who were participating in the JECS at the Center of Chiba Unit on August 28th, 2013; 2,387 responses had been collected by April 30th, 2014 (response rate, 52.6%). The questionnaire items are shown in Supplementary file S1. Categorical data on the age of mothers, month and year of delivery, and residential area were also collected, and a query regarding whether their participation was voluntary was included. Motivation for participation (11 items, Figure 1), self-reported understanding of the study (21 items, Figure 2), and concerns about the study (5 items, Figure 3) at the time of enrollment were measured using a 3-point Likert scale. Two motivation items that were found not to be applicable to all participants were excluded from the analysis.

This study was approved by the Research Ethics Committee of the Graduate School of Medicine, Chiba University.

Data Analysis

The relationships between motivation and understanding and concerns were examined using data from 2,106 returned questionnaires with complete answers for age, motivation, understanding, and concerns. Maximum likelihood factor analyses (promax rotation with Kaiser normalization) were conducted on 11 items for motivation, 21 items for understanding, and 5 items for concerns, and items with factor loadings ≥ 0.35 were summarized in four, six, and two factors, respectively. All factors were named in reference to the factor loadings of each item. Factor scores were calculated for each respondent on each factor. To classify the respondents based on their motivation, cluster analysis of standardized factor scores for each motivation factor was performed using Ward's linkage to conceptualize cluster locations and squared Euclidean distance to measure distances between respondents and clusters; this yielded four groups. Group comparisons were conducted for continuous and categorical variables using the Mann-Whitney U test and chi-square test with Bonferroni correction, respectively. A p -value < 0.05 was considered statistically significant. Data analysis was performed using SPSS statistics ver. 22 (IBM corporation, Armonk, NY).

RESULTS

Among the 4,541 mothers and expectant mothers who received the questionnaire, responses were received from 2,387 (response rate, 52.6%). Respondents were more representative of mothers in their 30s and 40s and those who had recently given birth than other JECS participant groups (Table 1).

Motivation, understanding, and concerns of respondents

Figure 1 shows a list of motivation factors and levels of respondents' motivation to participate in the JECS at the Chiba unit. The most frequent motivation factor at the time of enrollment was "benefit my children or grandchildren", followed by "monetary compensation" and "contributing to making a better environment". Less than half of the respondents considered the credibility of the research institute or the fact that it was a national research study to be a motivating factor.

Figure 2 shows the level of the respondents' self-rated understanding about information to be disclosed before their decision to participate. Ninety percent of respondents answered that they had a good understanding of the voluntary nature of participation. Regarding confidentiality of personal information, requirements for participation, study duration, and the purpose, 59–69% of respondents understood the study well, which rose to more than 90% when including respondents who partially understood. Concerning study procedures such as obtaining assent from their child in the future, how medical records would be accessed, and the use of data collected, less than half of the respondents understood well, which rose to 68–85% when including respondents who partially understood.

Figure 3 shows the level of respondents' concerns about the study at the time of

enrollment. About 14% and 13% of the respondents were concerned about leakage of personal information and the burden of a long-term commitment to the study, respectively. Significantly more participants concerned about leakage of personal information were unclear whether their name would be disclosed to anyone other than the institutions involved in the JECS compared with those who were less concerned or not concerned at all (14% vs. 8%, respectively) ($p < 0.001$).

Factor analyses and classification of respondents

Results of factor analyses identified four motivation factors, six understanding factors, and two concern factors. The factor loadings are shown in Supplementary tables S1–S3. From the factor loadings obtained, the motivation factors were named 1) credibility, 2) helpful information, 3) money or gifts, and 4) contribution. The understanding factors were named 1) implementation of the study, 2) handling of personal data, 3) voluntary nature of participation, 4) outline of the study, 5) contact information (including withdrawal procedure), and 6) analysis of data. The concern factors were 1) risks and benefits and 2) mental burden. The cumulative contribution ratios before rotation were 54.1% for the four motivation factors, 53.1% for the six understanding factors, and 41.8% for the two concern factors.

Respondents were classified into four groups based on cluster analysis using standardized motivation factor scores for each item. A comparison of standardized motivation factor scores between the four groups is shown in Figure 4. Based on the results, the groups were named 1) high overall motivation, 2) not motivated by money or gifts, 3) motivated by money or gifts, and 4) low overall motivation.

Group comparisons of age, understanding, and concerns

A comparison of age, scores for the six understanding factors, and scores for the two concern factors between group 1 (high overall motivation) and the other three groups is shown in Table 2. The largest number of respondents were categorized into group 3 (motivated by money or gifts), followed by group 1 (high overall motivation).

Factor scores for understanding, except for “voluntary nature of participation”, were highest in group 1 (high overall motivation), followed by group 2 (not motivated by money or gifts), group 3 (motivated by money or gifts), and group 4 (low overall motivation). Meanwhile, factor scores for concern increased in the reverse order. Respondents in group 2 (not motivated by money or gifts) were significantly older than those in group 1 (high overall motivation). More than 90% of the respondents in every group answered that they made the decision to participate in the study on their own.

DISCUSSION

In this study, a substantial number of participants were found to have low overall motivation or to be motivated by money or gifts. These respondents tended to have more concerns and a poorer understanding of the cohort study than the other respondents. This may indicate that these types of participants are at an increased risk of dropping out from this long-term cohort study. If this is in fact the case, appropriate measures need to be taken to maintain their commitment and motivation to continue, such as providing additional explanations of the study content to deal with their level of understanding and concerns.

Comprehending fully the content of a study and the measures that will be taken to protect personal information through the initial informed consent procedures is almost impossible for participants.^{12-16,20-22} In fact, in our cohort, only 59% of the respondents felt that they had sufficient understanding of the purpose of the study, and even fewer felt that they had enough information on data collection methods, the data that would be analyzed, assent from their child in the future, and other study procedures. To improve participants' understanding of the study, more information about the study should be provided in an easy-to-understand manner not only at the initial explanation for informed consent, but also periodically throughout the duration of the study.

Although most of the participants were not concerned about the study content or procedures, 14% were concerned about the risk of personal information leakage, and 13% were concerned about the burden of a long-term commitment. A previous study showed that some people showed willingness to participate in a hypothetical biobank while being concerned about privacy.¹⁸ In our study, there were significantly more respondents who did not know whether their name would be disclosed to anyone other

than participating institutes in the group with concerns about privacy protection compared with those with no or less concern. This result indicates that a limited understanding about privacy protection may increase participants' concerns. To address this issue, more explanations about privacy protection and data management should be provided.

In this study, we identified major motivating factors for participation in a large-scale birth cohort study. We found that many respondents had self-interest motivations (e.g., benefit my children or grandchildren, monetary compensation, individual test results, and helpful information about childrearing) as well as altruistic motivation factors (e.g., contributing to making a better environment). Previous studies also reported that most participants of birth cohort surveys had altruistic motivation.^{10,11} Although altruism is a principal factor in participation, it would be difficult to maintain participants' willingness to take part in a long-term study based on altruistic motivation alone. A review reported a decreased tendency of volunteerism as a factor in recent uncooperativeness in epidemiologic studies with little immediate benefit to participants themselves.²³ Offering incentives to serve participants' self-interests may improve their disposition. Given that studies found that participants expected their individual data to be returned and that this was one of their key motivating factors for participating in a study, highlighting the return of individual test results could be an effective strategy for encouraging long-term participation.^{24,25} The effect of monetary compensation on encouraging participation has, however, been inconsistent among studies.^{8,17,25-27} In our study, although monetary compensation seemed to be a major motivating factor, it is a difficult strategy to employ due to financial limitations and potential ethical concerns.²⁸

Unexpectedly, compared with an Italian hospital-based birth cohort in which 78% of the participants cited the credibility of the research institute as the reason for their

participation,¹⁰ in our study this was a relatively minor factor. Similarly, another study found that the credibility of the research institution was low in terms of motivation to participate in a Japanese population-based genomic epidemiological study.²⁹ The discrepancy could be due to differences in study design—whether the study is hospital- or population-based—and/or cultural differences.

Our study has several limitations. First, we assumed that a lack of understanding and numerous concerns would cause low levels of motivation; however, due to the nature of the cross-sectional study design, the opposite causal relationship cannot be excluded. It is possible that participants did not try to understand and had numerous concerns because of their low overall motivation to participate. Second, to avoid false descriptions due to participants worrying that their answers would be identifiable to researchers, this survey was conducted anonymously. Therefore, it was not possible to investigate whether the group with weak overall motivation actually had a tendency to drop out. Further study is required to address this issue. Third, information about social and educational situations was not available in this survey. Younger JECS participants tend to have lower household income and lower educational attainment. In this study, the group that was not motivated by monetary compensation had a larger number of older participants than younger ones, which may be associated with their higher household income and educational attainment. Finally, this survey was conducted with participants who enrolled in the Center of Chiba Unit and it is unclear whether the results would apply to all participants of the JECS. The participants in the Chiba unit are estimated to cover about 40% of all pregnant women in the research area, which is comparable to estimates in the other JECS units (47%).

In conclusion, we found for the first time that participants with low overall motivation and participants motivated by money or gifts alone had limited

understanding and numerous concerns about the study. These results suggest a need to address these issues by providing further explanations about the study not only at the time of enrollment, but also periodically throughout the duration of the study.

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Notes: The findings and conclusions of this article are solely the responsibility of the authors and do not represent the official views of the Japanese government.

The authors declare that they have no competing interests.

Supplementary tables S1 – S3 and Supplementary file S1 containing the feedback questionnaire form are available at the website of *the Journal of Human Genetics*: http://www.nature.com/jhg/index.html?WT.mc_id=SPG_JHG_society.

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Table 1 Comparison of survey respondents to total participants

	Survey respondents (N=2,358)		Total participants (N=4,541)	
<i>Age (years)</i>				
<20	5	(0.2%)	32	(0.7%)
20–29	665	(27.9%)	1,609	(35.4%)
30–39	1,530	(64.1%)	2,654	(58.4%)
≥40	176	(7.4%)	246	(5.4%)
No answer	11	(0.5%)	0	(0%)
<i>Birth month of child</i>				
Jul 2011–Jun 2012	680	(28.5%)	1,396	(30.7%)
Jul 2012–Jun 2013	1,086	(45.5%)	2,214	(48.8%)
Jul 2013–Jun 2014	600	(25.1%)	923	(20.3%)
No answer	21	(0.9%)	8	(0.2%)
<i>Residence at enrollment</i>				
Chiba (Midori-ku)	382	(16.0%)	713	(15.7%)
Kimitsu	1,133	(47.5%)	2,199	(48.4%)
Awa	540	(22.6%)	998	(22.0%)
Isumi	286	(12.0%)	527	(11.6%)
Others, No Answer	46	(1.9%)	104	(2.3%)

^a In the case of multiple participation, the first delivery date was used.

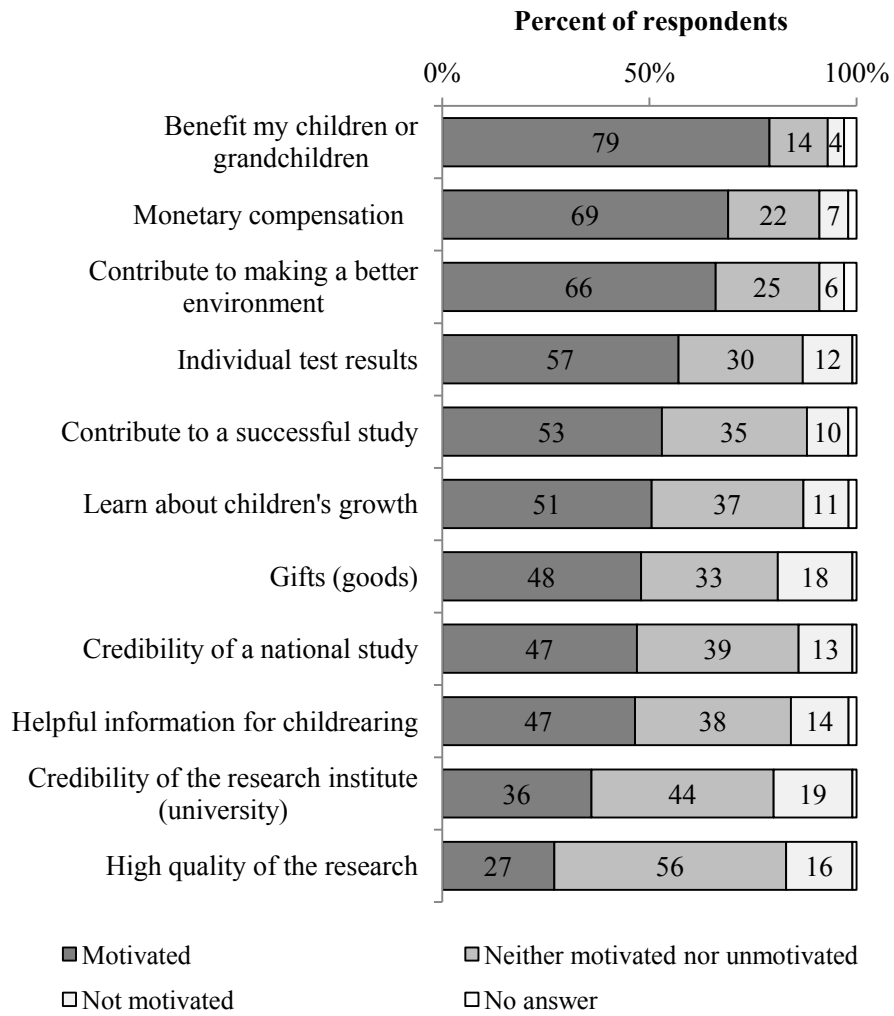


Figure 1 Motivation to participate in the study (N=2,358)

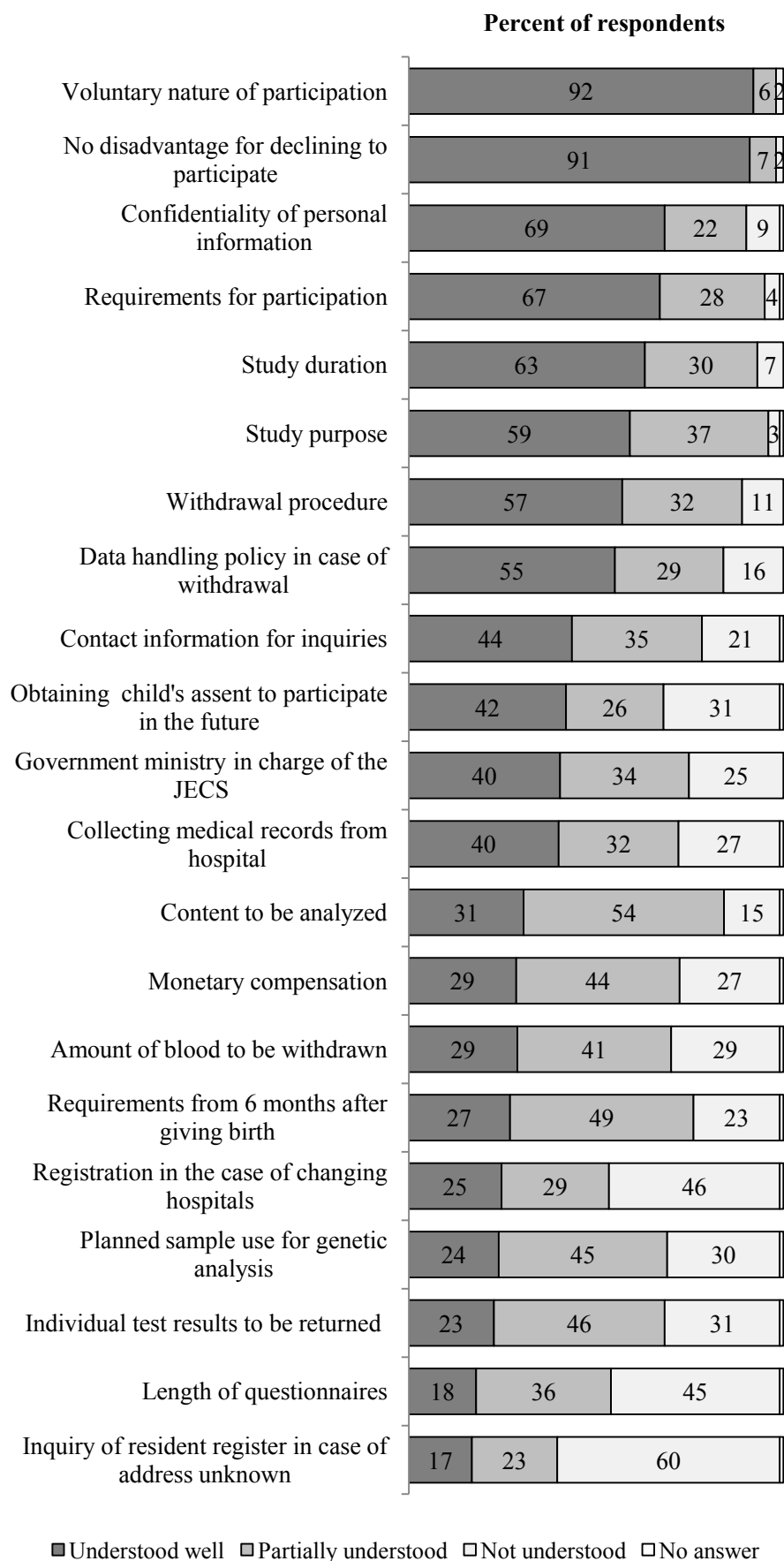


Figure 2 Participants' self-perceived understanding of study aspects at the time of enrollment (N=2,358)

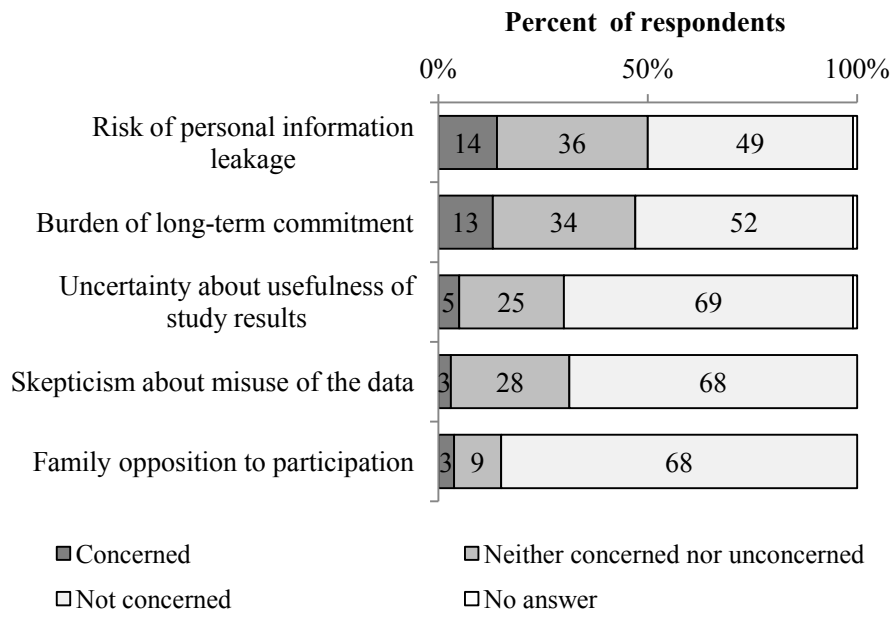


Figure 3 Participants' concerns about the study (N=2,358)

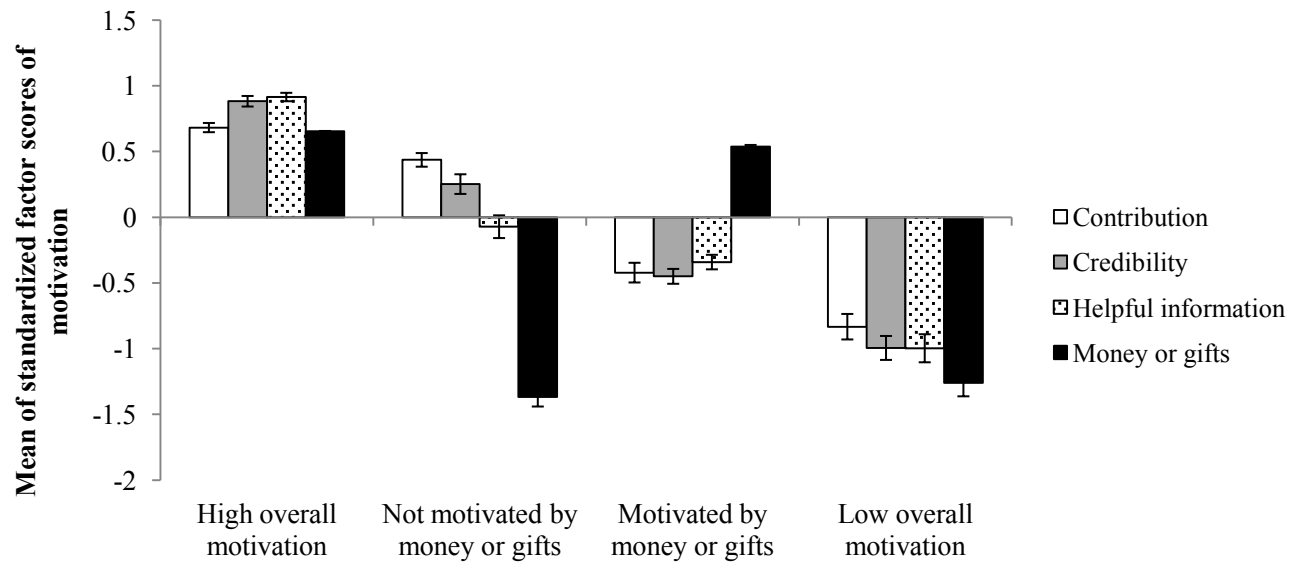


Figure 4 Feature of respondents groups classified by motivation factors

Data are shown as standardized factor scores of motivation. Error bars indicate 95% confidence intervals.

Table 2 Comparison of groups classified by motivation with age, self-perceived understanding of study aspects, and concerns (N=2,106)

Feature of group	High overall motivation	Not motivated by money or gifts		Motivated by money or gifts		Low overall motivation	
			p value ^a		p value ^a		p value ^a
<i>Number (%)</i>	674 (32%)	325 (15%)		778 (37%)		329 (16%)	
<i>Age^b</i>							
<30	29%	19%	<0.001	32%	N.S.	26%	N.S.
30–39	64%	69%		62%		70%	
≥40	7%	13%		7%		4%	
<i>Factor scores^c</i>							
<u>Understanding</u>							
Implementation of the study	0.293 [-0.358 , 1.003]	-0.084 [-0.765 , 0.577]	<0.001	-0.174 [-0.758 , 0.460]	<0.001	-0.312 [-0.927 , 0.388]	<0.001
Handling of personal data	0.331 [-0.435 , 0.984]	0.037 [-0.518 , 0.693]	<0.01	-0.141 [-0.677 , 0.526]	<0.001	-0.261 [-0.737 , 0.505]	<0.001
Voluntary nature	0.296 [0.230 , 0.334]	0.287 [0.228 , 0.335]	N.S.	0.290 [0.206 , 0.338]	N.S.	0.281 [0.185 , 0.329]	<0.01
Outline of the study	0.472 [-0.275 , 0.789]	0.188 [-0.402 , 0.673]	<0.01	0.159 [-0.553 , 0.668]	<0.001	0.050 [-0.792 , 0.617]	<0.001
Contact information	0.564 [-0.503 , 0.892]	0.368 [-0.602 , 0.769]	<0.01	0.204 [-0.686 , 0.718]	<0.001	-0.034 [-0.790 , 0.657]	<0.001
Data analysis	-0.006 [-0.297 , 1.147]	-0.148 [-0.475 , 0.823]	<0.001	-0.212 [-0.509 , 0.753]	<0.001	-0.225 [-0.511 , 0.748]	<0.001
<u>Concerns</u>							
Risks and benefits	-0.651 [-0.725 , -0.313]	-0.482 [-0.725 , 0.814]	<0.001	-0.408 [-0.651 , 0.983]	<0.001	-0.239 [-0.627 , 1.057]	<0.001
Mental burden	-0.358 [-0.768 , 0.101]	-0.130 [-0.768 , 0.512]	<0.001	0.010 [-0.449 , 0.561]	<0.001	0.193 [-0.449 , 0.561]	<0.001

^a P values for comparison with the "high overall motivation" group were calculated by chi-square test for age and Mann-Whitney U test for standardized factor scores, with Bonferroni correction.

^b Values represent percentage of respondents in groups.

^c Values represent median, 25th percentile and 75th percentile.

Supplementary Table 1 Results of maximum likelihood factor analysis for motivation to participate

Motivation factors and items	Factor 1	Factor 2	Factor 3	Factor 4
	Credibility	Helpful information	Money or gifts	Contribution
Credibility of research institute (university)	.89	-.04	-.02	-.06
Credibility of a national study	.82	-.11	.06	.03
High quality of the research	.46	.32	-.05	.08
Learn about children's growth	-.04	.75	-.07	.00
Helpful information for childrearing	.00	.69	.05	.03
Individual test results	-.07	.67	.08	-.04
Monetary compensation	-.04	-.07	1.03	.02
Gifts (goods)	.09	.21	.54	-.04
Contribute to making a better environment	-.02	-.09	.00	.78
Benefit my children or grandchildren	-.05	.05	-.02	.63
Contribute to a successful study	.12	.07	.03	.40

Number represents factor loading of each item after promax rotation with Kaiser normalization. Factor loadings ≥ 0.35 are indicated in bold.

Supplementary Table 2 Results of maximum likelihood factor analysis for self-perceived understanding of study aspects

Factors and items of self-perceived understanding	Factor 1 Implementation of the study	Factor 2 Handling of personal data	Factor 3 Voluntary nature	Factor 4 Outline of the study	Factor 5 Contact information	Factor 6 Data analysis
Amount of blood to be withdrawn	.77	-.03	.04	.04	-.07	-.05
Length of questionnaires	.74	.00	.01	-.04	-.05	-.03
Requirements from 6 months after giving birth	.55	-.06	-.04	.24	.02	.11
Monetary compensation	.48	.15	.03	-.04	.11	.04
Collecting medical records from hospital	.00	.73	-.06	-.02	-.02	.01
Data handling policy in case of withdrawal	-.03	.67	.06	.11	-.06	-.06
Confidentiality of personal information	-.14	.51	.14	.17	-.02	.02
Inquiry of resident register in case of address unknown	.24	.48	-.10	-.17	.06	-.03
Obtaining child's assent to participate in the future	.05	.38	-.01	.02	.05	.02
No disadvantage for declining to participate	.02	.01	.97	-.06	-.01	.00
Voluntary nature of participation	.02	-.04	.86	.01	.03	.00
Study duration	.05	.01	-.07	.79	.05	-.11
Study purpose	-.14	.04	-.01	.56	-.02	.27
Requirements for participation	.23	.00	.08	.55	.01	-.03
Withdrawal procedure	-.08	-.06	.01	.05	.93	-.02
Contact information for inquiries	.05	.11	.01	-.01	.59	.02
Content to be analyzed	.01	-.04	.01	.03	-.02	.90
Individual test results to be returned	.27	.11	.00	-.09	.03	.44

Number represents the factor loading of each item after promax rotation with Kaiser normalization. Factor loadings ≥ 0.35 are indicated in bold. Other items with factor loadings < 0.35 are not shown.

Supplementary Table 3 Results of maximum likelihood factor analysis for concerns about the study

Factors and item of concerns	Factor 1 Risks and benefits	Factor 2 Mental burden
Skepticism about misuse of the data	.97	-.12
Risk of personal information leakage	.59	.17
Uncertainty about usefulness of study results	.36	.25
Burden of long-term commitment	-.01	.57
Family opposition to participation	.06	.37

Number represents the factor loading of each item after promax rotation with Kaiser normalization. Factor loadings ≥ 0.35 are indicated in bold.

Supplementary File 1 Feedback questionnaire on participating in the Japan Environment & Child Study (JECS) at the Center of Chiba Unit

Date (yyyy/mm/dd) _____ / _____ / _____

A) Personal information

1) Age

<input type="checkbox"/> 1 10—19	<input type="checkbox"/> 2 20—29	<input type="checkbox"/> 3 30—39	<input type="checkbox"/> 4 40—49
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2) Birth month (or expected month of birth) of your child participating in the JECS

(If you enrolled in the study more than once, please answer for each of your children.)

2011	<input type="checkbox"/> 1 Jul—Sep	<input type="checkbox"/> 2 Oct—Dec		
2012	<input type="checkbox"/> 3 Jan—Mar	<input type="checkbox"/> 4 Apr—Jun	<input type="checkbox"/> 5 Jul—Sep	<input type="checkbox"/> 6 Oct—Dec
2013	<input type="checkbox"/> 7 Jan—Mar	<input type="checkbox"/> 8 Apr—Jun	<input type="checkbox"/> 9 Jul—Sep	<input type="checkbox"/> 10 Oct—Dec
2014	<input type="checkbox"/> 11 Jan—Mar	<input type="checkbox"/> 12 Apr—Jun		

B) Information provided about the JECS

(If you enrolled in the study more than once, please answer in relation to the information provided the first time.)

3) Did you know about the JECS before you received an explanation at a maternity hospital or local health center?

<input type="checkbox"/> 1 Yes, I knew about it. → How did you know?	<input type="checkbox"/> 1-1 Family/acquaintances
	<input type="checkbox"/> 1-2 Posters/flyers
	<input type="checkbox"/> 1-3 TV/radio
	<input type="checkbox"/> 1-4 Other ()
<input type="checkbox"/> 2 I had heard of it, but didn't clearly understand what it was.	
<input type="checkbox"/> 3 I didn't know about it.	
<input type="checkbox"/> 4 I don't remember.	

4) Where did you receive the maternity health record book?

<input type="checkbox"/> 1 Midori-ku, Chiba	<input type="checkbox"/> 2 Sodegaura	<input type="checkbox"/> 3 Kisarazu	<input type="checkbox"/> 4 Kimitsu	<input type="checkbox"/> 5 Futtsu	<input type="checkbox"/> 6 Kyonan
<input type="checkbox"/> 7 Minamiboso	<input type="checkbox"/> 8 Tateyama	<input type="checkbox"/> 9 Kamogawa	<input type="checkbox"/> 10 Katsuura	<input type="checkbox"/> 11 Onjuku	<input type="checkbox"/> 12 Isumi
<input type="checkbox"/> 13 Otaki	<input type="checkbox"/> 14 Ichinomiya	<input type="checkbox"/> 15 Other city/town in Chiba Prefecture	<input type="checkbox"/> 16 Outside of Chiba Prefecture		

5) Did you receive an explanation about the JECS at the same time you received the maternity health record book?

<input type="checkbox"/> 1 I received a full explanation.	
<input type="checkbox"/> 2 I received a partial explanation.	
<input type="checkbox"/> 3 I didn't receive an explanation. → Why?	<input type="checkbox"/> 3-1 Nobody was available to explain
	<input type="checkbox"/> 3-2 Not enough time to receive an explanation
	<input type="checkbox"/> 3-3 My family went to the local health center
	<input type="checkbox"/> 3-4 Other ()
<input type="checkbox"/> 4 I don't remember.	

6) At which hospital did you register to participate in the JECS?

<input type="checkbox"/> 1 Kashiwagi Clinic	<input type="checkbox"/> 2 Chiba Aoba Municipal Hospital	<input type="checkbox"/> 3 Chiba University Hospital
<input type="checkbox"/> 4 Mineta Maternity Clinic	<input type="checkbox"/> 5 Miyake Women's Clinic	<input type="checkbox"/> 6 Muneta maternity Clinic
<input type="checkbox"/> 7 Iijima Mother's Clinic	<input type="checkbox"/> 8 Yushudai Clinic	<input type="checkbox"/> 9 Murata maternity Clinic
<input type="checkbox"/> 10 Jujo Clinic	<input type="checkbox"/> 11 Kato Hospital	<input type="checkbox"/> 12 Koma Clinic
<input type="checkbox"/> 13 Yakumaru Hospital	<input type="checkbox"/> 14 Kimitsu Chuo Hospital	<input type="checkbox"/> 15 Kumakiri Clinic
<input type="checkbox"/> 16 Kiyokawa Clinic	<input type="checkbox"/> 17 Famil Clinic	<input type="checkbox"/> 18 Kameda Medical Center
<input type="checkbox"/> 19 Ide Clinic	<input type="checkbox"/> 20 Morikawa Clinic	<input type="checkbox"/> 21 A hospital/clinic outside of Chiba Prefecture

7) Who explained the JECS to you?

<input type="checkbox"/> 1 Medical doctor/nurse/midwife/hospital staff	<input type="checkbox"/> 2 Staff from the Center of Chiba Unit
<input type="checkbox"/> 3 Staff from the center of a different unit	<input type="checkbox"/> 4 I don't know
<input type="checkbox"/> 5 I didn't receive an explanation at a hospital	

C) Decision to participate in the JECS

(If you enrolled in the study more than once, please answer in relation to the first enrollment.)

8) Did you decide on your own to participate in the JECS?

<input type="checkbox"/> 1 Yes (→Q9)	<input type="checkbox"/> 2 Not sure	<input type="checkbox"/> 3 No
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↓ ↓
8a) If you answered "Not sure" or "No",
Who influenced your decision?

<input type="checkbox"/> 8-1 Medical doctor/nurse/midwife/staff of hospital	<input type="checkbox"/> 8-2 Staff from the Center of Chiba Unit
<input type="checkbox"/> 8-3 Partner	<input type="checkbox"/> 8-4 Parent
<input type="checkbox"/> 8-5 Friend or acquaintance	
<input type="checkbox"/> 8-6 Other ()	

9) Did you understand everything you wanted to know about the study when you made the decision to participate?

<input type="checkbox"/> 1 No, I didn't understand well.	<input type="checkbox"/> 2 I partially understood.	<input type="checkbox"/> 3 Yes, I understood well.
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10) Did you understand the following items when you made the decision to participate?

Please select your level of understanding from the choices below. Please check the box (right column) corresponding to any item for which you wanted a better explanation.

	When I made the decision to participate, I ...			I wanted to get more information
	1. didn't understand well	2. partially understood	3. understood well	
(Example)	⊕----- -----			<input checked="" type="checkbox"/>
Purpose of the study	----- -----			<input type="checkbox"/>
Total duration of the study	----- -----			<input type="checkbox"/>
Requirements for participation	----- -----			<input type="checkbox"/>
Amount of blood sampling	----- -----			<input type="checkbox"/>
Length of questionnaires	----- -----			<input type="checkbox"/>
Requirements from 6 months after giving birth	----- -----			<input type="checkbox"/>
Content to be analyzed from biological samples and questionnaires	----- -----			<input type="checkbox"/>
Test results to be returned	----- -----			<input type="checkbox"/>
Planned sample use for genetic analysis related to diseases and developmental disorders	----- -----			<input type="checkbox"/>
Registration in the case of changing hospitals	----- -----			<input type="checkbox"/>
Procedure for withdrawing from the study	----- -----			<input type="checkbox"/>
Contact information for inquiries	----- -----			<input type="checkbox"/>
Voluntary nature of participation in the study	----- -----			<input type="checkbox"/>
Being at no disadvantage for declining to participate	----- -----			<input type="checkbox"/>
Process of obtaining my child's assent in the future	----- -----			<input type="checkbox"/>
My name would not be disclosed to anyone other than institutions involved in JECS	----- -----			<input type="checkbox"/>
Data would be used even if I withdrew from the study (unless I specifically asked for data to be destroyed)	----- -----			<input type="checkbox"/>
Medical data would be collected from hospitals	----- -----			<input type="checkbox"/>
Resident's register would be accessed in the case my address was unknown	----- -----			<input type="checkbox"/>
Monetary compensation would be paid	----- -----			<input type="checkbox"/>
Name of the government ministry in charge of the JECS (Ministry of the Environment)	----- -----			<input type="checkbox"/>

11) Were you concerned about any of the following when you made your decision to participate?

Please select your level of concern for each of the items below. Please check the box (right column) corresponding to any item for which you still have concerns.

	1. Not concerned	2. Neither concerned nor unconcerned	3. Concerned	Still have concerns
Burden of making a long-term commitment to the study	----- -----			<input type="checkbox"/>
Family opposition to my participation	----- -----			<input type="checkbox"/>
Risk of personal information leakage	----- -----			<input type="checkbox"/>
Study results might not be useful	----- -----			<input type="checkbox"/>
Study results might be misused	----- -----			<input type="checkbox"/>
Effect of my lifestyle on my child	----- -----			<input type="checkbox"/>
Effect of my eating habits on my child	----- -----			<input type="checkbox"/>
Effect of living environment on my child	----- -----			<input type="checkbox"/>
My child's growth	----- -----			<input type="checkbox"/>

12) Were you motivated to participate in the JECS by any of the following when you made your decision to participate?

Please select your level of motivation for each of the items listed below. Please check the box (right column) corresponding to a reason for why you are continuing to participate.

	1. Not motivated	2. Neither motivated nor not motivated	3. Motivated	Reason for continuing participation
Contribute to making a better environment	----- -----			<input type="checkbox"/>
Benefit my children or grandchildren	----- -----			<input type="checkbox"/>
Contribute to a successful study	----- -----			<input type="checkbox"/>
Credibility of the hospital	----- -----			<input type="checkbox"/>
Credibility of the municipal government	----- -----			<input type="checkbox"/>
Credibility of Chiba University	----- -----			<input type="checkbox"/>
Credibility of the national study	----- -----			<input type="checkbox"/>
High quality of the research study	----- -----			<input type="checkbox"/>
Learn about children's growth	----- -----			<input type="checkbox"/>
Individual test results	----- -----			<input type="checkbox"/>
Helpful information for childrearing	----- -----			<input type="checkbox"/>
Monetary compensation	----- -----			<input type="checkbox"/>
Gifts (goods)	----- -----			<input type="checkbox"/>

D) After enrolling in the JECS

13) Did you feel that any of the following were burdensome?

Please select the level of burden for each of the items listed below. Please check the box (right column) corresponding to any item that you have not done and so cannot answer.

	1. Not burdensome	2. A little burdensome	3. Very burdensome	Can't answer because I haven't done it
Questionnaire (mid- to late pregnancy at the time of enrollment)	----- -----			<input type="checkbox"/>
Questionnaire (1–6 months after childbirth)	----- -----			<input type="checkbox"/>
Questionnaire (1–1.5 years after childbirth)	----- -----			<input type="checkbox"/>
Blood drawing	----- -----			<input type="checkbox"/>
Urine collection	----- -----			<input type="checkbox"/>
Hair collection	----- -----			<input type="checkbox"/>
Breast milk collection	----- -----			<input type="checkbox"/>
Other burdens, if any				

14) How do you feel about the following?

Please select your level of agreement with the items listed below.

	1. Disagree	2. Neither agree nor disagree	3. Agree
My participation will benefit children	----- -----		
I am contributing to society	----- -----		
I could look into my daily life	----- -----		
I became more interested in the environment	----- -----		
I could get helpful information on childrearing.	----- -----		
It became easy to ask others about childrearing.	----- -----		
Other positive aspects, if any			

E) Suggestions, comments, and requests

15) Do you have any suggestions about content you would like to see in newsletters?

16) Are there any topics you would like to learn about in the participants' lecture meetings?

17) Do you have any requests for events other than lecture meetings?

18) If you have any other comments, please let us know in the space below.

Thank you for your cooperation with our questionnaire.

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