"From Birth to Death, From Beginning to End": Participant Experience and the Meaning of Research Participation in a Longitudinal Birth Cohort Study

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Abstract
Research participants are vital for the success of a birth cohort study. Despite their scientific importance and large participant numbers, research on participant experience in birth cohort studies is scarce. This study explores participant experience, its different dimensions and meaning of the experience for the participants’ lives. The data comes from the Northern Finland Birth Cohort 1966. In total, 49 semi-structured interviews were conducted with participants having full participation records and then subjected to qualitative content and thematic analysis. According to the findings, the participant experience is multidimensional, consisting of four dimensions: personal, relational, societal, and scientific. The experience evoked both positive and negative feelings and a sense of belongingness. Motivations to continue, perceived benefits of the study, consequences of participation, and the theme of trust were grouped under the four dimensions. The meaning of the study participation, and the level of personal investment and involvement in the study varied a lot among active study participants, forming a continuum from a very strong to a weak. The findings of this study contribute to the theoretical conceptualization of the participant experience. They help to better understand the participant’s perspective, and the different aspects that participating in a longitudinal research project may entail as a subjective and a relational experience. The results may contribute to research design and aid in enhancing participant satisfaction. That is important, as conducting high-quality research depends on motivated and committed research participants.

Keywords
participant experience, research participation, birth cohort, meaning, qualitative content analysis

Introduction
In many fields, for instance medicine, psychology, epidemiology, health, and human sciences, research participants are vital to the success of scientific endeavors. This is especially true for studies based on longitudinal designs. The conduct of high-quality research depends on motivated and committed research participants, who trust the research project and the research process in which they are involved (Kost et al., 2011). Participants invest their time—sometimes over many years or decades—in the studies in which they are involved. They respond to surveys and questionnaires. During clinical examinations, they may experience some inconvenience and compromise their bodily integrity, for instance, when donating different types of biological samples and taking medications in pharmaceutical studies (Barnett et al., 2016). However, a surprisingly small body of work has focused on the participant experience as a research topic. The present study focuses on participant experience and its meaning for participant’s lives in a prospective longitudinal birth cohort study (BCS) design.

In a BCS, the study interval commonly begins with the recruitment of pregnant mothers, who enroll in the study and consent to their child becoming a cohort member prior to or soon after birth. The study ends at some predetermined point, with the passing away of the cohort member, or for external reasons such as lack of funding (Lucas et al., 2013). A BCS typically focuses on the possible long-term health consequences of the maternal lifestyle, genetic factors, and early exposure to environmental factors such as contaminants (Lawlor et al., 2009; Ri et al., 2018). There are also
Regardless of the study type, the extant participation experience studies mostly focus on attitudes, views, and perceptions rather than the participation experience and its meaning for participants lives, in itself. Moreover, most qualitative studies on the topic tend to take a rather limited view, focusing, for instance, on participation motivations (Almeida et al., 2007; Daniels et al., 2006; Locock & Smith 2011; Parsons, 2010), reasons for continued participation (Kost et al., 2011), or on the pros and cons, benefits and costs, and facilitating and obstructing factors (Daly et al., 2019; Horwood et al., 2016; Lawton et al., 2003). According to many studies, the common motivation for participation is altruism entangled with hope for personal benefits. The participants want to help others with health problems but also gain health benefits for themselves (Horwood et al., 2016). In addition, Yandisa Sikweyiya and others have pointed out research participation that might involve negative or harmful experiences. If a study deals with traumatic issues such as experienced violence, participants may find themselves reliving their earlier violent experiences, making the participation a potentially traumatic experience (Sikweyiya et al., 2021; Sikweyiya & Jewkes, 2012). There is some research on participant experience among BCS participants (see Barnett et al., 2016; Dahlin-Ivanoff et al., 2019; Garg et al., 2017; Park et al., 2016; Parsons 2010). Most of this research has been conducted among the mothers enrolled in newly established cohorts with their infants (Gammelgaard et al., 2006; Garg et al., 2017), rather than among the “index children,” who have been in the cohort for a longer period of time. An extensive study conducted by the UK National Child Development Study (NCDS) 1958 (Parsons, 2010) is one of the few qualitative studies that have focused on the participation experiences of long-term BCS participants. In this study, 170 interviews (86 men, 84 women) were conducted with a sample of 50-year-old participants with complete participation records. The study aimed to improve the experience of being a study participant in the NCDS and to secure future participation also in younger birth cohorts (Parsons, 2010). Among other things, the cohort members were asked how they felt about participating in the NCDS. The findings of the study were grouped under four main themes: participants’ memories of their involvement in the study as a child; reasons for continued participation (for instance personal fulfillment, feeling of pride, feeling special, regarding the study as interesting, sense of excitement, sense that opinions are valued, greater good, obligation, and understanding the longitudinal aspect of the study); reasons why they had not participated at times and thoughts on what may lead to nonparticipation in future; and finally, what the participants would like to be changed to improve their own participant experience. The findings encompassed multiple aspects of the participation experience, including...
the emotional aspect. Even so, the study largely focused on the motives and participation barriers of the participants.

**The Concept of Experience**

The concept of *experience* is frequently used both in everyday language and in research. Its familiarity makes it difficult to define, and the term is often under-defined in research articles (Kukkola, 2018). Instead of the commonly used phenomenological or phenomenological-hermeneutical discussions based on Husserl’s or Heidegger’s writings (see Kukkola, 2018; Smith et al., 2009), the present study relied on social-scientific or postmodern understanding of the concept of experience (Kukkola, 2018). The latter defines experience as something that is subjectively felt and described but has central intersubjective aspects. Once an experience is described to another person, for instance in an interview situation, it becomes collectively shared (see Gadamer, 2004; Kukkola, 2018). Although individual subjective experiences are not at the forefront of scientific explorations of experience, the study of multiple individual descriptions of a certain experience, such as the participation experience studied here, makes it possible to grasp interconnections among different subjective experiences and to explore their differences and similarities (see Derrida, 1988). In addition to viewing experience as verbally assigned, intersubjective, situational, and historical, it is here also viewed as having emotional and corporeal aspects.

**The Present Study: Aims and Research Questions**

The BCS design is a unique setting for exploring research participant experience. The interviewees in the present study were recruited from the Northern Finland Birth Cohort 1966 (NFBC1966). It was launched in Finland in 1965 with more than 12,000 participants and is now among the longest-lasting birth cohorts in the world (Wadsworth, 2010). *The present study aims* to explore participant experience and its different aspects/dimensions, including the emotional aspect, and what meaning the experience may have for the participants and their lives. The aim is to offer a nuanced and multidimensional description of the participant experiences of a set of cohort members who have been actively involved in the study for more than 50 years. The study also contributes to the more theoretical question of the conceptualization of the participant experience. This type of knowledge may help researchers engaged in designing and executing longitudinal and birth cohort studies to better understand study participants’ perspectives and experiences, enhance the participation experience, and through that, to improve the quality and usability of longitudinal birth cohort data.

*The research questions are as follows:*

1. What kind of experience is it to participate in a BCS, as described by BCS participants?
2. What are the different dimensions the experience may consist of?
3. What kind of meaning the participation may have for participants and their lives?

**Data and Methods**

**Data**

NFBC1966 is a prospective BCS based in Oulu. The cohort comprises people who were born in the provinces of Lapland and Oulu, the two northernmost provinces of Finland. Data-collection started when the mothers were on their 24th gestational week. The cohort initially included 12,055 mothers who had 12,068 deliveries (13 women delivered twice). The data comprises health care records, questionnaires, biological samples and clinical measurements as well as data on cohort participants’ parents and offspring (total \(n=70,000\)).

Another comprehensive BCS on newborns in Northern Finland was launched in 1986 \((n=9,432)\). Together, the two cohort studies explore the life-course determinants and pathways to health and disease, aiming to understand the role of social, genetic, and environmental factors influencing the life of two generations. (https://www.oulu.fi/nfbc/nfbc1966_1986).

The first set of data in NFBC1966 was collected before birth (16th, 24th, and 28th gestational weeks), and the main follow-ups took place at ages 1, 14, 31, and 46. In the first follow-ups before age 14, areas associated with motor, social, psychological, and mental development were examined with questionnaires. At age 14, a survey regarding participant’s health and physical condition was conducted. In the 31-year follow-up somatic and mental health as well as work ability were studied, and the follow-up included postal questionnaires and a clinical examination. The 46-year follow-up included several questionnaires with questions about social background, lifestyle, medical history, occupational health, economy, personal traits, functioning, quality of life, and use of health services (Nordström et al., 2021). It also included a versatile clinical examination. The participation rate in different childhood follow-ups was high. While 91.2% of the children participated in the 1-year follow-up, as many as 93.6% participated in the 14-year follow-up. The adult follow-ups had lower participation rates, yet 75.3% answered to the 31-year postal questionnaire, and 70.7% participated in the clinical examinations. These numbers were 69.2% and 56.5% in the 46-year follow-up. In addition to comprehensive data-gathering on the whole cohort, about 25 sub-studies have been conducted with smaller research populations (https://www.oulu.fi/nfbc/nfbc1966_1986).

Altogether, over 1,600 publications has been published that make use of the data. One influential early finding was, when for the first time in a prospective study, the association between maternal smoking in pregnancy and the risk of low birthweight was established (Rantakallio, 1988).
follow-up study with data at 46 years of age has resulted in novel findings showing, that low-grade inflammation is associated with several skin diseases such as atopic eczema and onychomycosis (Sinikumpu et al., 2018).

**Participant Selection for the Interview Study**

A purposeful sampling strategy was used to select the study participants for the semi-structured interviews. The target population consisted of NFBC1966 cohort members with full participation records, that is, the selected participants were required to have responded to the main data-collection phases at ages 14 (survey), 31 (surveys and clinical examination(s)), and 46 (surveys and clinical examination(s)).

Gender and socioeconomic status are known to influence participation and commitment. Hawkes and Plewis (2006) found nonresponse in BCSs to be more common among male cohort members and among those with less education, less stable employment patterns, and more disadvantaged living circumstances. Thus, socioeconomic background, gender, and geographical location were included as selection criteria to ensure the selection of diverse interviewees and the inclusion of participants representing a large population of NFBC1966. The interviewees came from three regions in Northern Finland: Lappi, Kainuu, and Northern Ostrobothnia. In addition, the southern Finnish region of Uusimaa, where the capital is located, was selected because many cohort members have relocated there. Altogether, 3,458 participants met these criteria. Among them, the data specialist extracted the addresses of 160 cohort participants (80 women and 80 men) who fulfilled the selection criteria, after which an interview invitation was mailed to them. Forty-nine cohort members (30% of those invited) responded to the invitation and were interviewed by the author. Among them, 21 (43%) were women and 28 (57%) men. Interviewees were either 53 or 54 years old at the time of the interview.

**Semi-Structured Interviews**

This study relies on the constructivist approach with relativist and postmodern epistemology (Guba & Lincoln, 1994), when semi-structured interviews are considered a suitable method for knowledge production. Interviews are considered as a form of social interaction and the interviewer and the interviewees co-constructors of knowledge (Holstein & Gubrium, 1995). A semi-structured interview is conducted to obtain descriptions of the experiences of the interviewee, and to interpret the meaning of the described phenomena or experiences from the interview data (Kvale, 2007). A semi-structured interview is designed to address specific topics related to the phenomenon under study, but it also allows participants to offer new concepts and meanings to the study focus (Galletta & Gross, 2013). The interview guide (see Supplemental Appendix 1) was formulated based on earlier empirical research of the topic of research participation experience (e.g., Parsons, 2010; Dahlin-Ivanoff et al., 2019; Garg et al., 2017; Park et al., 2016), the birth cohort webpages describing the contents of the clinical study days (https://www.oulu.fi/nfbc/nfbc1966_1986), and previous knowledge and practical experiences of the author with NFBC data and participants. Before the actual interviews, two pilot interviews were conducted with the NFBC1966 participants (both women) who did not receive interview invitations for the present study. One was an acquaintance of a member of the research team, while the other was working at the same faculty in the author’s University.

The interviews were conducted between January and March 2020 in a variety of locations, chosen on the basis of the interviewees’ preferences. About 14 interviews were conducted at the home of the interviewee, 7 in public libraries, 1 at the home of a relative, 3 at workplaces, and 1 in a hotel breakfast room. The COVID-19 pandemic started to affect life in Finland after March 13, 2020, and several scheduled face-to-face interviews had to be conducted over the telephone or online. Moreover, many participants preferred telephone interviews even before COVID-19 emerged as an imminent threat. Furthermore, due to conflicting schedules and logistical issues, the interviewer proposed, that some interviews be conducted over the telephone. Altogether, 20 interviews were conducted over the phone, 2 in Skype, and 1 over a WhatsApp call. In total, 31 hours of interview data were collected, and the interview lengths varied between 26 and 56 minutes, with the mean interview length being 42 minutes. The interviews were recorded using a professional recording device, after which a research assistant transcribed them verbatim and anonymized them. The author analyzed the interview data using the NVivo12 program.

For the purpose of the present interview study, an ethical statement was requested from the Ethics committee of human sciences of University of Oulu. The committee reviewed the statement request and ruled that no separate ethical statement was needed because the participants were volunteer adults, and sensitive issues that would disrupt the participants’ daily lives were not discussed. Before the interviews, the participants signed written informed consent forms.

**Qualitative Content Analysis**

Firstly, the data were subjected to qualitative content analysis (QCA). QCA summarizes what the qualitative data contains and focuses on how the constructed categories from the data relate to each other. QCA is a method for describing the topic of the study and the meaning of the material, and it is commonly used for the analysis of personal experiences (Schreier, 2012). Author (ARR) first read the material several times to get a sense of the whole and then created a coding frame for the analysis. She drew from the interview guide to select already known central categories for the coding frame (e.g., “Study days” and “Consequences of participation”) and added newly arriving topics/categories from
the data (e.g., “Northern Finland as a Research context” and “Theme of trust”). Simultaneously, she added a few subcategories under the central categories to capture more specific descriptions and meanings.

Thereafter, the author processed the first 13 interviews with NVivo12 to complete the coding frame. She divided the material into smaller units of coding so that each piece was small enough to thematically fit into one of the categories comprising the coding frame (see Schreier, 2012). She also added new central categories and subcategories to the coding frame based on newly arrived ideas from the data. After this, a pilot coding phase was conducted. During this phase, four interview transcripts (two women and two men) were double-coded with another postdoctoral researcher from the research team. Firstly, one interview transcript was coded together. The relevant passages to be included in the analysis and assigned predetermined numerical codes of the relevant categories to these passages were marked. Unclear codes or related questions were marked, and discrepancies were discussed and solved page by page. If needed, new subcategories (such as “Feelings attached with study participation”) were added. The remaining three interviews were then coded independently and another meeting was set up to check whether the assigned codes were agreed upon. Any discrepancies were again discussed and solved.

After the pilot phase, ARR modified the coding frame and then conducted the main analysis/coding with all of the interview data, following a procedure similar to that in the pilot phase, except that she conducted the analysis by using NVivo12. Then, another double-coding was conducted with the Principal investigator (professor) of the research project. The process was similar as that followed for the pilot coding. Then, ARR started to construct the main findings from the coding frame, that is, the four dimensions of the participant experience (see Figure 1; Schreier, 2012). A detailed example of the analysis process can be found in Supplemental Appendix 2.

**Thematic Analysis**

The third aim of the study was to detect the meaning that the participation had for participants. After the qualitative content analysis was conducted and the multidimensionality of the experience was constructed from the data, it seemed that even the active participant had somewhat different levels of personal involvement and investment in the study and that the meaning of the study for the participants and their lives varied. The second phase of the analysis was conducted in the form of thematic analysis (Guest et al., 2012), which provided a way to organize and interpret data
by bringing together the similarities and differences in the participants’ descriptions of their participant experience (see Crowe et al., 2015). The analysis was primarily conducted by the author, while the Principal investigator also reviewed the process.

Each interview transcript was read once again to evaluate the level and “strength” of investment, involvement, and the meaning of the participation for the participants. The evaluation was based on the ways in which the individual interviewees discussed, described, reminisced, and recalled their participation. That is, the involvement/investment/meaning was poor for those participants who had little recollection of the study days and did not consider that the participation had influenced their lives or that the study had benefited neither them nor science or the society. The study had a stronger meaning for those participants who discussed their participant experience in great detail, recalled their results, listed personal consequences and benefits, mentioned motives for continued participation, were enthusiastic about study, had given it considerable thought and discussed it with other people, and had attended additional event(s) for cohort members. Based on the thematic analysis, it is proposed, that the meaning and the level of investment and involvement of the study formed a continuum among the 49 research participants, comprising of four separate participant groups ranging from a group with a very strong involvement and investment and thus meaning of the study, to a group with weak meaning and relative indifference. The Figure 2 illustrates this continuum. The darker blue color depicts the intensity and “strength” of the meaning of the study to the four participant groups with number of participants in each of them.

The findings of the study respond to three research questions: (1) what kind of experience is it to participate in a BCS as described by BCS participants; (2) what are the different dimensions the experience may consists of; and (3) what kind of meaning the participation may have for participants and their lives? Next, the findings for research questions 1 and 2 will be presented.

### Four Dimensions of Participant Experience Among Birth Cohort Participants

Based on a QCA of the semi-structured interviews, participant experience was constructed as being multidimensional, and having four different dimensions: Personal, Relational, Societal, and Scientific (Figure 1). These dimensions consist of several subcategories including motivations, benefits, consequences of participation, and trust. Together, these dimensions and categories depicts the multidimensional nature of the birth cohort study participant experience (see Figure 1).

#### Personal Dimension of Research Participation

The *Personal* dimension was very central among the four dimensions of participant experience. The study participation as an experience was linked with different, mostly but not exclusively positive feelings. Motivations to participate were commonly at the personal level, as were the perceived benefits. The consequences of the participation were described in solely personal terms.

**Emotions and feelings.** All the interviewees expressed positive sentiments about and attitudes toward the study and about their own role in it. In 88 responses, positive feelings were associated with being a birth cohort participant. Being a part of the cohort study made the participants feel happy, good, great, and nice, as described by P45 (the letter P refers to participant/interviewee and number refers to the code of each interviewee):

> Well, it feels great. I think it is wonderful that I am involved in this. Only positive. P45, woman

Some participants mentioned that they felt lucky, flattered, and valuable because they had been selected as participants in the longitudinal study together with other people from their age group.

### Results

Table 1 summarizes the background characteristics of the interviewees. More men ($n=28, 57\%$) than women ($n=21, 43\%$) participated. There were participants from all the four major geographical areas included in the study. Most of the participants had graduated from university or university of applied sciences/polytechnic, and most were either upper-level employees with administrative, managerial, professional or related occupations, or lower-level employees with administrative and clerical occupations. The interviewees family situations varied considerably, but the majority were married and had children.
Well, it feels quite prestigious that I have been included in this study, because I think this is a rather expensive and extensive longitudinal study, and for me, it feels like I have specially been selected to this (laughs). P1, woman

The “clinical days” (clinical examinations) in which the interviewees participated were intensive, but not frequent, because they had been conducted only twice, at ages 31 and 46. The clinical days required that the participants visit a medical center of about 1 to 3 days for clinical examinations. The medical center was typically located in their home town or in the closest large town. The clinical tests included rest-ECG, skin allergy tests, spirometry, physical activity tests, eye examinations, dental examinations, and cognitive tests. Moreover, biological samples (blood, saliva, hair, urine, and feces) were harvested from the participants, and they were administered multiple questionnaires about their health, occupational history, and lifestyle. Most of the participants described the clinical days positively. Most commonly, they were described as “versatile” (n=20), “interesting” (n=18), and “nice” (n=14). The participants stated that they looked forward to the clinical days, and many would have liked to have attended more of them. The majority of the participants did not consider the overall NFBC1966 program as being too intensive (n=39, 78%).

A few participants expressed negative feelings (21 responses). Some were irritated because they did not receive adequate information about the overall findings of the cohort study, and others were disappointed because of their poor tests results. Many participants experienced physical discomfort and nervousness due to and during the clinical days.

### Table 1. Background Variables of the Interviewees.

| Background variables                        | Women          | Men      | Total  |
|--------------------------------------------|----------------|----------|--------|
| **Living area**                            |                |          |        |
| Uusimaa                                    | 8 (38%)        | 7 (25%)  | 15 (30.6%) |
| Northern Ostrobothnia                      | 4 (19%)        | 7 (21%)  | 10 (20.4%) |
| Lapland                                    | 6 (29%)        | 8 (32%)  | 15 (30.6%) |
| Kainuu                                     | 3 (14%)        | 6 (21%)  | 9 (18.3%)  |
| **Total**                                  | 21 (100%)      | 28 (100%)| 49 (100%) |
| **Education**                              |                |          |        |
| Vocational school                          | 8 (38%)        | 12 (43%) | 20 (41%) |
| Specialist vocational qualifications       | 0 (0%)         | 1 (4%)   | 1 (2%)  |
| Applied sciences                           | 0 (0%)         | 1 (4%)   | 1 (2%)  |
| University                                 | 8 (38%)        | 9 (32%)  | 17 (35%) |
| Comprehensive school (9 years)             | 0 (0%)         | 1 (4%)   | 1 (2%)  |
| Comprehensive school (12 years)            | 0 (0%)         | 1 (4%)   | 1 (2%)  |
| **Total**                                  | 21 (100%)      | 28 (100%)| 49 (100%) |
| **Socioeconomic status**                   |                |          |        |
| Entrepreneur                               | 0 (0%)         | 1 (4%)   | 1 (2%)  |
| Upper-level employees with administrative, managerial, professional, and related occupations | 8 (38%) | 11 (40%) | 19 (39%) |
| **Lower-level employees with administrative and clerical occupations** | 4 (19%) | 6 (21%) | 10 (20%) |
| Manual worker                              | 6 (29%)        | 6 (21%)  | 12 (24%) |
| Full time student                          | 1 (5%)         | 0 (0%)   | 1 (2%)  |
| Disability pension                         | 0 (0%)         | 2 (7%)   | 2 (4%)  |
| Sick leave                                 | 1 (5%)         | 0 (0%)   | 1 (2%)  |
| Training/work-try-out                      | 1 (5%)         | 1 (4%)   | 2 (4%)  |
| Unemployed                                 | 0 (0%)         | 1 (4%)   | 1 (2%)  |
| **Total**                                  | 21 (100%)      | 28 (100%)| 49 (100%) |
| **Family situation**                       |                |          |        |
| Married, have children                     | 13 (62%)       | 14 (50%) | 27 (55%) |
| Cohabiting, have children                  | 1 (5%)         | 2 (7%)   | 3 (6%)  |
| Divorced/separated, have children          | 3 (14%)        | 4 (14%)  | 7 (14%) |
| Married couple without children            | 0 (0%)         | 1 (4%)   | 1 (2%)  |
| Cohabitating/living with partner, have children | 0 (0%) | 2 (7%)  | 2 (4%)  |
| Reconstituted family, were married/cohabiting, had children | 2 (10%) | 4 (14%) | 6 (12%) |
| Living alone, no children, not dating      | 1 (5%)         | 1 (4%)   | 2 (4%)  |
| Living alone, dating, no children          | 1(5%)          | 0 (0%)   | 1 (2%)  |
| **Total**                                  | 21 (100%)      | 28 (100%)| 49 (100%) |
The tests did not go very well, and I am a nervous type of a person. In such test situations, I feel terribly nervous, so the situation was somewhat uncomfortable for me. P36, woman

Some participants considered the clinical days heavy and tightly scheduled. Three mentioned that they had suffered from a headaches because they were required to fast before the first tests. A quote from P31 exemplifies these feelings and bodily sensations:

But then, I remember still very vividly, how the fasting, not having a morning coffee and breakfast on the first day, and there was no opportunity to get coffee after the blood tests. Then, there was a physical test after that before noon, and still no food or drink was allowed so that the heartbeat won’t be affected. But my coffee withdrawal symptoms were so bad that they may have raised my heartbeat. (—). Then I just lay there, and I had such a headache, I couldn’t sit. Then I got the permission to have some coffee. P31, woman

**Personal motivations and benefits affecting the continued participation in the study.** When the participants were asked for their motives to continue in the study, they most often mentioned personal reasons. In total, 14 (67%) of the 21 different motivations expressed were personal, and the rest were societal or scientific. Many participants stated that they wanted to participate and continue in the study because they were interested in their health and wellbeing. A few mentioned that they were the kind of people who would participate in any survey or study if asked. Others mentioned curiosity as their main motivation. Moreover, many participants described that because they were selected as subjects of study decades ago, they were motivated to continue because of a sense of privilege, obligation, and responsibility.

I feel that it is my responsibility to be involved here because I can, and data have been collected for over 50 years. P37, woman.

For over one-third of the participants, (n=17, 35%), the up-to-date, varied health information they received after the study days was the key motivation. Moreover, this was also the most commonly cited benefit of participation in the study (46% responded so). Only a couple of interviewees mentioned that they derived other types of personal benefits from the study, mainly the ways in which their participation made them reflect on their health and lifestyle.

**Personal consequences of participation.** The perceived consequences of participation were solely on the personal level – the interviewees did not mention any relational, societal, or scientific consequences of the study. On the other hand, almost half (42%, n=21) stated that the participation had no consequences for their lives. Four participants had received new health information from the tests, which they would not have received at that time without participation.

Actually, because of this study, it was discovered that I have diabetes. At times, I was like, I do not feel good. But then it was found out that it is diabetes. (—) So that is a positive experience related to this study, that it was discovered. P22, man

Conversely, not receiving alarming results from the tests was perceived as a positive personal consequence of participation. Some participants felt that their participation in the study influenced their eating and exercise habits and encouraged them to live healthier lives. Yet, most of the responses related to personal consequences were less specific: The participants stated that they thought about the tests results and reflected upon their health from time to time and considered lifestyle changes, but these reflections did not necessarily translate into actions. P2 described how the cohort study did not have direct consequences for her but nevertheless acted as an external authority, reminding her about the importance of health issues and how she should be more active and take better care of herself:

Well, I do not think that it has consequences, but I always get a feeling that when I’m invited to the studies, I must get a grip on myself. I start to ask myself, have I lived healthy and well, can I let other people examine me (laughs)? In this sense, this study is sort of an authority, which sees deeper inside me than I see myself even. P2, woman

**Relational Dimension**

Participation as an experience included different types of relationships and embarked the sense of belongingness.

**Relationships with personnel.** The relationships formed between the participants and the personnel (researchers and study nurses) came across as a central aspect of the research participation when clinical research days were discussed. The majority of the participants provided positive feedback about the research personnel. They were described as being professional and friendly and that they ensured that everything went very well during the clinical days. P48 felt that the participants were like “objects in an assembly line,” which can also be interpreted as a metaphor for the lack of “personal touch” or warmth on the behalf of the personnel, but this did not bother him.

ARR: How would you describe the actions of the personnel during the clinical days?

P48, man: Nice. They were businesslike and nice, and I had no grievances against them. And if you have to wait for a minute. . . it is obvious that you always have to wait a minute. So, I have no, no negative feelings. They were very professional. It was sort of like an assembly line there. But everyone knows that it was not a place for chit chat. We were involved in research. I have a positive recollection about everything.

Interaction between the participants and the cohort personnel outside of the clinical days was scarce. The interviewees
expressed dissatisfaction about the inadequate amounts of feedback and information received from the overall findings from the study. They expressed keenness to know about the overall health of the 1966 cohort and their own health in comparison. Surprisingly, however, only a few participants had looked for more information on about the study from the Internet. Many were unaware about the existence of the cohort webpage. Some participants expressed their wish to receive some recognition for their participation, even a modest token such as a lapel pin was acceptable. Other types of communication problems arose occasionally. For instance, most participants learned only during the interview that a 50th birthday party had been organized for the cohort members, and some were sorry and disappointed for not having been informed about the event.

Belongingness and “we-talk” among research participants. One-fourth of the interviewees linked the participation experience to a sense of belongingness, as described by P46:

I feel like I belong to a group. I am important. P46, woman.

The cohort included all people born in Northern Finland during, or, with the expected delivery date in year 1966, which means that for instance, all of the participants’ schoolmates were also cohort members. Many interviewees mentioned discussing NFBC1966 with people of the same age over the years. Moreover, the participants sense of belongingness was apparent in the way they often talked about “we-talk”, about “us,” and “we.”

Well, actually yes, with one peer, I have discussed it, and he has positive sentiments toward the study, and we have often times talked about this as “our cohort.” P9, man

Media coverage of the study could also have bolstered this sense of belongingness. Occasionally, there are news items and media stories about NFBCs, especially in Oulu-based media outlets, and most (n = 30, 61%) of the interviewees had read or seen news about the cohort in newspapers or on television. P46, for instance, felt uplifted after reading a newspaper article about the cohort:

Sometimes there is a news story about the cohort, and I am like, wohoo, I am part of that! Nice, I belong to something! (Laughs). I feel proud. P46, man

Many interviewees described surprise, yet pleasant, encounters with their former schoolmates and other people from their childhood and youth during the clinical days.

Societal Dimension of the Participant Experience

The study participation as an experience also had a societal dimension. Context of Northern Finland came across strongly and many mentioned how they perceived the benefits of the study as being societal.

Context of Northern Finland and societal benefits of the study. Participation in the study was justified by local Northern considerations. More than half of the participants (n = 25, 51%) brought up regional concerns in the interviews. They valued the NFBC because it targeted issues that they thought were prominent in Northern Finland, such as social exclusion, mental health issues, and suicide. Moreover, the participants regarded some aspects of Northern Finnish culture as inimical to health. For instance, they noted the adverse effects of poor dietary habits and socioeconomic factors on the health of the people of the North. One interviewee, a Sámi person herself, brought up the role of the indigenous Sámi people in the NFBC. She regretted that Sámi people and their health had not been singled out in the cohort data and had not been compared with the health of the Finnish people living in the same areas. The study covered the entire Sámi homeland area. Ethnicity was not directly queried in the surveys, but mother language and occupation of the parents were queried and could have served as indicators of ethnic background. The participants assigned many societal benefits to the BCS. Moreover, future generations of Finns, especially those living in Northern Finland, were repeatedly mentioned. At this rather general level, the participants’ motivations can be characterized as altruistic.

For the future generations specifically, this does not necessarily influence us. If they now find that something was not right, was not going well, then we would know to act or do differently for the next generation. (—) For example, if there is something that we (author: as a society) should have reacted to differently in certain situations, such as in relation to mental health. P46, man

Scientific Dimension of the Participant Experience

The scientific aspects of the participation were discussed a lot. The interviews unraveled the participants’ deep trust in the Finnish scientific community, and the local university and scientific motivations for participation were repeatedly mentioned.

Trust toward Finnish higher educational institutes. The theme of trust emerged strongly, especially when interviewees were asked whether the participants had any worries about their research participation. Almost all (n = 40, 81%) stated that they had absolutely no concerns about the study and justified this statement with their trust in the Finnish university system.

I do trust this, yes. I trust the research and everything, yes. I have 100% confidence that it is being conducted as it is supposed to. P34, woman
The study is about very personal matters and personal questions are asked. So, in principle, I would, mmm, I would be reluctant in other circumstances. I would not be happy to respond, I typically don’t. But here, it is conducted at Oulu University. So, I feel like that it is appropriate. P26, woman

When asked whether the participants had any concerns about data storage, protection, or usage, a clear majority stated that they had not thought about these issues at all and had no concerns. The common response was that they were sure that Finnish scientists and the university handle privacy issues competently. Somewhat surprisingly, many participants stated that their personal health data would not be of any interest to outsiders.

I don’t worry, no. Researchers collect the data and use it. I have given my consent, and the data are anonymous, I guess, I hope. Or maybe my name is there somewhere. But this is not secret information about my health. So, even if it were to be leaked, if someone would benefit from it, I don’t care. No, I do not waste my time thinking about it. P48, man

Scientific motivations of continuation in the study. Motivational aspects were often related to the perceived scientific value of the BCS. As many as 31 (63%) interviewees mentioned that the study benefited present and future science and researchers. Six participants underlined that they were motivated to continue in the study because they felt it was unique and important.

Well somehow, isn’t this, at the global scale, quite a rare study, so extensive? That (author: motivates me to continue). P45, woman

Well, I think collecting valuable data (author: motivates me). I do appreciate science. P38, man

The participants commonly stated that they wanted to continue in the study because they did not want to disrupt or deteriorate the findings of the longitudinal study with which they had been involved for decades. The value they set on science in general and the BCS in particular was intermingled with a personal sense of duty, commitment and obligation.

There is no way I want to quit this. I think, the more people participate, who can, the more reliable the findings will be. P16, woman

Meaning of the Participation Experience for the Interviewees: Varied Levels of Involvement and Investment

The third objective of the study was to explore the meaning of the participation for the participants and their lives, and thematic analysis was utilized to study that (see Methods section). Based on the interpretation of the thematic analysis, four distinct participant groups were formed from the data. The intensity, involvement and the meaning varied between the groups, forming the “meaning continuum” depicted in Figure 2. Next, these groups will be described with more details.

The participant experience having very strong (Group 1) or strong meaning (Group 2) in one’s life. About 11 participants (6 women and 5 men) had extremely positive attitudes and outlook toward the study, remembered and described the tests in detail, and showed strong interest and involvement in the study beyond the clinical study days. This group included members of the Facebook group for NFBC participants and had participated in additional events organized by the research center. Many of them used the terms “us” and “we” when referring to the NFBC. The people in this group were the most highly educated in comparison to those in the other four groups, which may partly explain their high degree of commitment. Possibly because of their background, they understood the value and the role of individual participants in a longitudinal study. Most of the individuals in this group lived close to the research center. Their physical proximity may have offered practical advantages, in that they were more likely to see and hear about the cohort in the media, and it was easier for them to attend besides the clinical days, also additional events. The self-reported health of this group was generally good, but there were health issues. A quote from P9 illustrates his positive attitude toward and investment in the study:

In a way, it is nice to be a part of the Finnish, global medical history. (—) For instance, once we are six feet under, like in 2066, new research will be published stating that this is an extensive study, from birth to death, so it is great to be involved. From the beginning to the end. (—) Possibly my grandchildren will say that my great grandpa was a part of that study. P9, man

Despite showing high levels of involvement and investment, four members of this group stated that being a cohort member had had no significant consequences in their personal lives. However, the other individuals in this group stated that their participation had various consequences on their lives.

The second most invested group consisted of 15 participants (5 women and 10 men). It was interpreted that they were somewhat less invested in and enthusiastic about the study than the members of the first group. They offered less detailed descriptions of the study days, had not participated in additional events, and were not members of the Facebook group. However, all of them referred to different personal consequences of the study on their lives.

Mediocre meaning and involvement (Group 3). Eight participants (five women and three men) took a neutral view on the study and could be place around the middle of the
continuum. They could remember some details of the study days, but their participation did not evoke strong feelings in them. Their self-reported health was better than that of the other groups in the continuum. Six of these participants stated that the study had had no consequences in their lives. The following quote from H13 describes well the tone of the members of this group:

Neutral. Every once in a while, the study comes to mind, but not often. P13, man

Weak meaning of the study (Group 4). For as many as 15 (6 women and 9 men) individuals, the study seemed to have a weak and insignificant meaning. They recalled the individual studies poorly or not at all. Nevertheless, they wanted to continue in the study. Five of them reported being in poor health, and only two had no health issues. Only six of the people in this group reported that being a participant had any consequences in their lives. None of them had visited the cohort website. H4’s quote illustrates well the typical short responses provided by the participants belonging to this group.

ARR: Well, if you think about the clinical days at age 31, could you please describe how did you experience that day, could you describe the day?

P4, woman: Yes (pause), my only recollection is that it went quite alright and . . .I do not remember where it even was. (—)

ARR: You have responded to many surveys over the years; do you have any recollection of those, were they alright to fill, or did you wonder something, or . . .?

P4, woman: Well I do not have many memories of those either. I just read and responded to them and then forgot about them altogether (laughs).

Discussion

This study has explored different aspects of the participation experience in a longitudinal BCS. More specifically, it asked what kind of experience it is to participate in a longitudinal BCS, what kind of dimensions the participant experience consists of, and what is the meaning of the participation for the participants. The findings underline the multidimensional nature of the participant experience in terms of four different dimensions: personal, relational, societal, and scientific. The meaning of the participant experience varied among active participants in the cohort study, forming a continuum from a very strong to weak meaning.

Participation Experience Has Strong Relational Aspects

The findings of the present study emphasize the centrality of the relational aspects of the participation, that is, social relations, trust between different actors, and a sense of belongingness among the cohort participants. Earlier studies (Dixon-Wood & Tarrant, 2009; Hallowell et al., 2010) have stressed that any form of research that includes human participants is a form of social action, where social actors exist within a network of social behaviors. A birth cohort research design has specific relational aspects: It commonly involves more than one member of the family; the participants remain in the study for long period of time; and the participants usually know at least some other cohort participants from other circumstances, too. A BCS involves a specific form of cooperation between researchers and participants, participants and other cohort members, and participants and their families.

The social relations involved in a BCS may take multiple forms, as the present study has demonstrated. Many participants described their sense of belongingness with other cohort members. This sense was constructed and maintained in discussion with other participants and family members, through seen media coverage and through the short encounters in the waiting area during the clinical days. The fact that all the coeval inhabitants of the town were included in the study contributed to the sense of belongingness. This feature distinguishes NFBC1966 from many other large BCSs, where the participants are born, for instance, during a single week within a country (see Parsons, 2010). For instance, while the participants of the latter can resent being “singled out” from the rest of the class in school (Parsons, 2010), this problem did not emerge with NFBC1966, because every pupil in class was likely to be enrolled in the study. According to literature, this sense of belongingness may enhance the participants’ motivation to continue in the study. Price et al. (2016) noted that feeling part of the community formed by the study and its members was reported by 41% of the 4,216 women who participated in a longitudinal mother-child cohort study as a "very important" motive to participate.

In NFBC, personal contact between the personnel and the participants was not frequent, yet, these relationships were perceived as important. Maintaining a positive relationship with the cohort members is crucial for continued commitment. Kowal (2013) used the term “affective networks” when referring to the intersubjective arrangement of the emotions that create and sustain relationships, which in the context of research, are framed by a scientific endeavor. According to him, the personnel are mainly responsible for maintaining affective networks in a research project, and this must be done in a sustainable and ethical manner. In the present study, the interviewees were happy with the conduct of the personnel during the clinical face-to-face encounters but criticized the low frequency of the clinical days and the poor information flow between the research center and the participants. A few of them wished to receive some form of recognition for their participation, and many of them would have wanted to see general health results from the whole study population in regular intervals. Thus, the participants welcomed closer interaction and more reciprocity between them and the research center. Based on the findings, it seems that
NFBC was not fully successful in sustaining affective networks over the decades. This can also be seen as a research ethical issue, as ethical debates have concluded, that research participants should receive general or aggregated results from the studies they are participating (Clayton & Macguire, 2012). However, whether participants should receive individual or personal results is debated (Affleck, 2009; Young, 2013), and in NFBC the participants did receive personal results from the two clinical studies they were participating, which was perceived positively. A survey-based study explored the ways European BCSs engage with their young cohort members (Lucas et al., 2013). According to the review, and similarly to NFBC, direct consultation with the participants was rare (Lucas et al., 2013). There were many reasons for this. Some studies were bound by the original consent, which did not allow additional contacts. Some investigators raised concerns that any activity that might bring together study members would breach anonymity (Lucas et al., 2013). Furthermore, if participation rates remain high over time, there does not seem to be any need for more frequent contacts. Finally, some were concerned that more frequent contact with participants would compromise research quality by increasing respondent burden and thus the risk of attrition (Lucas et al., 2013).

In turn, some studies in the review were found to communicate with their participants through yearly newsletters, birthday cards, and summaries of findings. Facebook was also used for communication. (Lucas et al., 2013). Many of these means of communication were not used in NFBC, but active cohort participants established a Facebook page for cohort members. The official webpage of NFBC1966 is highly informative, and participants are encouraged to contact the study personnel if they have any questions regarding the study. Moreover, a few public events have been organized for the participants. Although the participants said they were keen to know more about the study, especially about its key findings, they were surprisingly unaware of the existence of the cohort webpage, and very few of them had searched the Internet for additional information about the study. Parsons (2010) made a similar observation regarding the participants of UK BCSs. Personalized direct information, such as e-mail newsletters, might reach participants better and, thereby, improve participation satisfaction.

The researchers working in BCSs need to carefully balance between sufficient engagement without burdening the participants too much. A good way to find ethical and sustainable procedures regarding communication would be to ask feedback about the ways the participants wish to be informed about the study. This can be done for instance in the questionnaire forms they are filling in during the follow-ups.

**Personal Dimension: Emotional Aspects and Personal Motivations for Continuing in the Study**

Besides relational, the personal dimension of the experience was central. The emotional aspects came across strongly from the findings of this study. The emotional aspect of research participation has been rarely studied. In one of the few such studies, Dahlin-Ivanoff et al. (2019) studied the experiences of the elderly cohort participants of the Swedish H70 birth cohort. The participants described their experiences as intense, exhausting, and never-ending but also as interesting, rewarding, challenging, and beneficial. The H70 is a retrospective study which started with elderly participants, and the clinical program of H70 was considerably more intense than that of NFBC1966, thus these two programs are different from each other. Nevertheless, as the cohort participants age in NFBC, too, it is important to plan the clinical days carefully to ensure that the burdens of examinations and logistics do not increase significantly. The NFBC1966 participants expressed both negative and, much more often, positive feelings toward the study. The clinical days evoked some negative feelings and physical discomfort, but the burden was not overwhelming.

As regards motives, birth cohort participants form a distinctive participant group because they do not initially volunteer for the study. As the study evolves and data sweeps are organized, they are asked for their informed consent. BCS participants are by default healthy and are not recruited because of a specific illness, which is commonly the case with clinical trials. The desire to receive health information has been identified as a significant motivating factor in previous BCSs (see Gammelgaard et al., 2006; Harcombe et al., 2011). Participants are driven by altruism, but it is also increasingly important for them to feel that they are getting something in return (Horwood et al., 2016; Locock & Smith 2011). The study of the participants of the BCS H70 found that its elderly participants felt that it was beneficial to participate in a cohort study because the healthcare system did not function in satisfactory manner (Dahlin-Ivanoff et al., 2019). In the present study, too, the opportunity to undergo free clinical tests was considered a significant benefit and was among the central motives to continue in the study. Regular health checkups are not readily offered in the Nordic countries, which underlines the value of clinical tests of BCS for preventive health. Many studies offer participants small payments in exchange for their time and effort. This may raise some ethical concerns such as undue inducement and biased enrollment (Resnik, 2015). Paying monetary incentives did not come across in the interviews either, and it is not common procedure in Finland in general. Given that some altruistic motivations were also mentioned, the NFBC participant motivation could be considered “reciprocal altruism” (Hallowell et al., 2010; Titmuss, 1971).

**The Theme of Trust**

Previous research on participant motivation has stressed the significance of trust in the study and in the people responsible for it in securing the motivation and continued commitment of the study participants. Trust is even more important than receiving information about the study.
(Gammelgaard et al., 2004), although the two are interconnected. The present findings are consistent with those of previous studies. The people interviewed firmly trusted the study program even if they knew little about its length, origins, or findings. A study on the participants of a mother-child BCS in South Africa (Barnett et al., 2016) similarly found that the participants firmly trusted the personnel and believed that participating in the study would be conducive to the health of the child, which was reflected in their overall satisfaction with the study. Interestingly, interviewees in the present study saw no problem in donating bio samples and worried little about their present or future use. Ethical and privacy issues must be closely monitored even when, or perhaps especially when, participants themselves do not worry about them. Moreover, there have been signs of general trust toward science deteriorating (Huber et al., 2019), and it is encouraging that participants in the longitudinal BCS expressed strong trust toward the study. In general, studies have found that research participants trust the public sector and medical and educational research institutes but often mistrust commercial actors, such as pharmaceutical companies or biobanks (McDonald et al., 2008).

**Northern Finnish Societal Contexts and the Role of Indigenous Peoples and Minorities**

NFBC is clearly the most extensive of the few existing circumpolar birth cohorts (Bjerregaard et al., 2007; Javo et al., 2009), which was specifically acknowledged by some of the participants. The Sámi people, the only indigenous peoples of European Union area, live in the NFBC study area. The Sámi person who participated in the interviews criticized the study program for not specifically studying the health of the Sámi people. Overall, the older Nordic birth cohorts include very few minorities because there were very few immigrants in the area at the time of the establishment of the cohorts. In younger cohorts, especially in those established after the millennium, the situation is different. Unfortunately, many of the newer cohorts used language as an inclusion criterion. For instance, the Aarhus Birth Cohort Biobank excluded participants who could not speak and read Danish (Mortensen et al., 2013), thus precluding potentially important health information on non-ethnic Danes.

**Meaning of the Study in the Participants’ Lives**

Very few studies have explored the meaning of research study participation before (the exceptions include Dahlin-Ivanoff et al., 2019; Moreno-Black et al., 2004), especially in the BCS setting. Moreno-Black et al. (2004) studied what it meant for 158 HIV-positive volunteer participants to be involved in randomized controlled trials. In that study, the meaning was researched from participant’s accounts of the reasons why they continued in the study. There are some similarities between theirs and the present findings. In Moreno-Black et al. (2004) the meaning of participation was related to medical and health support and emotional support and sociability, which in turn, were related to three higher-level concepts of meaning: increased health awareness, personal enhancement, and sociability. Similarly, in the present study the relational and personal aspects were important regarding the participation experience, and more so among the highly involved group. Furthermore, in the present study the meaning of participation was also strongly related with health issues, for example when the participants stated that their participation had direct or indirect personal health consequences, and they named no other consequences.

In future studies, it would be important to explore whether participation actually has health consequences at the population/age cohort level. Are the BCS participants healthier than others close of their age group and can this be attributed to their participation in the study? In the present study the findings regarding self-reported health were mixed. Only 9 of the 49 participants stated that their health was outstanding, while the rest reported some health issues. In general, the participants in better health belonged to the more committed end of the meaning continuum, although some were also from the middle of the continuum. Self-reported health did not seem to play a central role in terms of the meaningfulness of study participation. Moreover, the group in the middle of the meaning continuum may represent a rather typical birth cohort participant: they willingly participate in the study, but it does not play a major role in their lives. Parsons (2010) found that study participation had no discernible impact on the lives of many respondents in a UK BCS, even though the participants had full participation records. Similarly, surprisingly many of the active participants in the present study had indifferent outlook toward the NFBC study and its meaning for them and their lives was weak.

**Strengths and Limitations of the Study**

The present study is one of the few to explore the different aspects of research participation among active cohort members who have been participating for several decades in a single BCS program. The interviewees were both men and women from all the main geographical locations included in NFBC and from different socioeconomic backgrounds, thus providing comprehensive insights into the participation experience. The data analysis followed the QCA protocol and thematic analysis, and the findings can be compared with those of other qualitative participation studies conducted in Northern European contexts.

The original study population was over 12,000 participants, while the number of active participants who reached the inclusion criteria of the study was 3,458. Eventually, 49 interviews were conducted, which is a small proportion of the original study population. This can be considered as a limitation, as some important aspects of the participation experience may not come across from the interviews. It should be noted that this was a qualitative interview study, and the number of interviews in this type of a study setting...
was relatively large (Savin-Baden & Howell-Major, 2013). As only active volunteers were interviewed, the overall experiences of and attitudes toward the study could be expected to be either positive, neutral, or indifferent. However, some interviewees did bring up difficult aspects of participation, and a satisfactory saturation point was reached. In the future, it would be valuable to interview people who had dropped out, as their experiences may differ considerably from those of the active participants.

Implications for Future Practice and Conclusion

Committed and active research participants exhibit a high level of trust, are emotionally involved, and discuss the study with other participants, family, and friends. As the findings of this study propose, cohorts can enhance participant satisfaction and ensure good attainment by focusing on the social aspects of the study, namely communication and continued trust between the participants and the research center. Committed participants experience a strong sense of belonging that can be further promoted, for instance, by conducting different activities outside of the clinical days and through media coverage about the study. Frequent dissemination of the general study findings through e-mail-based newsletters, means of social media, and webpage updates are important for increasing participant satisfaction.

As Hallowell et al. (2010) emphasized, it is important to move away from simple and individualized notions of research participation to more complex and dynamic accounts of the experience. The present study indicates how being a research participant in a longitudinal BCS is a multi-dimensional experience, and that its meaning can vary greatly across individual participants. The findings of this study may contribute to research design and can help the investigators involved in planning and maintaining birth cohort programs to better understand the participant perspective and enhance participant satisfaction, thus ensuring the continuation and longevity of such studies. The findings also may contribute to the theoretical conceptualization of the participant experience, and in the future studies it can be tested, whether the four dimensionalities were part of participant experience in other research contexts, too.

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Ethical Approval

For the purpose of the present interview study, the author requested an ethical statement from The Ethics Committee of Human sciences of University of Oulu Finland. The committee reviewed the statement request and ruled that no separate ethical statement was needed because the participants were volunteer adults, and sensitive issues that would disrupt the participants daily lives were not involved. Before the interviews, the participants signed written informed consent forms.

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Supplemental Material

Supplemental material for this article is available online.

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