The Governance of Pediatric Research in Japan

NAGAMIZU Yuko
Contents

1. Introduction
2. Two pediatric research cases in the 1950s
3. Issues of consent in pediatric research
4. Conclusion

Keywords: research involving children, mature minor, interests of the child, informed assent
I’d like to introduce two scandals in 1950s concerning pediatric research in Japan first and indicate some points for policy-making concerning minors from an academic lawyer’s perspective. They are the importance of keeping the balance between the protection of minors and respect for their autonomy, categorizing minors to mature minors/ minors without consent capacity and reflecting their opinions in accordance with their understanding and capacity, categorizing research (e.g. invasiveness, with direct benefit or not), importance of listening to children’s voices, and establishing a governance system to keep transparency and accountability of research in order to protect the research subjects properly. Lastly, I’d argue that we’ve accomplished establishing the research governance system, but still have our weakness in trying to listen to children’s voices, such as referring to young people’s advisory groups in the UK, and we still have miles to go.

2. Two pediatric research cases in the 1950s

（1）The case of Nagoya City Infant Protection Institution（1952）

The head of Nagoya City Infant Protection Institution who was also the professor of pediatrics of Nagoya City Medical School was conducting a research about “special E. coli” at the time and he instructed nurses through medical doctors under him to give this type of E. coli to infants in his institution since 1952. In mid-November of that year, the infants who took it and who were infected from other infants had severe diarrhea and some of them fell into critical condition. On the 25th of that month, one infant died. According to the record, the cause of death was pneumonia, however the result of anatomy and statements of parties involved suggested that the cause of death was the infection
of the E. coli at issue from other infants. The Human Rights Committee of the Japan Federation of Bar Associations harshly denounced the professor for using infants as guinea pigs. This E. coli is widely acknowledged as toxic now.

The professor didn’t explain anything about this research to the parents of the infants, so no parental consent was taken. He regretted later on this point and tried to defend himself by saying “It’s natural to get parental consent for these kinds of experiments, but many infants in our institution either don’t have parents or their whereabouts are unknown to us, so it’s deplorable that we couldn’t do that.” The whistleblower of this case criticized this experiment not only from the standpoint of lacking parental consent, but he also insisted that the institutionalized infants should have been given the same treatment with ones from ordinary families, which probably means that he knew the experiment would be more severe on subjects without outside supervision or inspection.

It seems strange that the head of the child protection facility was also a pediatric professor who was keen to experiment on pediatric population in this case which would easily lead to conflicts of interest. Also, the Infant Protection Institution was located in the hospital affiliated with Nagoya City Medical School, so it was easily accessed by researchers as they wanted. We must look into the social environment of the time to know the reasons for this. Infant Protection Institutions or Infant Houses were established by Child Welfare Act “because infants need special attention all the time from medical perspective as their daily care tends to directly affect their lives” compared to older children. Accordingly, they were able to be taken care of in the Infant Protection Institution up to 2 years old as it was necessary for their care. Also, the mortality rate of infants in 1950 was 59.8 in 1000, compared to average population (10.9 in 1000), so the infant protection institutions needed to gear up with doctors of many years of experience in pediatrics, nurses and dietician. It was a time soon after the war and human and financial resources were scarce, so it is
understandable to locate the institution inside a university hospital where the pediatricians were available to attend to the infants’ illness. However, the professor as a researcher gave priority to research over his duty as the head to protect infants from harm, which led to the human rights violation. Also, these kinds of institutions are insulated from outside world, so it is easy to control and make observations for researchers. Furthermore, it is difficult to notice human rights violation when insiders are accustomed to inside rules and mores and have no question about them.

This case was investigated by the Human Rights Committee of the Japan Federation of Bar Associations and it filed a report and suggested the stakeholders such as the Minister of Health, the Minister of Justice, the Mayor of Nagoya City and so on to take appropriate actions. The prefectural police headquarters initiated an investigation on a charge of professional negligence resulting in injuries, but it didn’t lead to a criminal prosecution.

(2) Kobe Medical School Case (1956-58)
The stage of the other case is the pediatric department of the affiliated hospital of Kobe Medical School and it was concerned with the development of synthetic milk formula which had the equivalent quality to breast milk. The purpose of the research was to cultivate the benign lactic acid which is only found in the bowels of breast-fed babies and also to investigate on the appropriate density of the formula. The researchers experimented on the infants who were admitted to the hospital without telling their parents and let some of them to suffer diarrhea, high fever and infection. They used the Kobe-tubing method for the research, which was to insert a thin (1mm diameter) plastic tube from the infants’ nose to anal hole and took out the contents of the bowels from small openings of the tube to check the digestion and assimilation of the different density of milk formula. Even though they were considered as severe human rights violation and investigated by the Japan Federation of Bar
Associations and Kobe District Legal Affairs Bureau respectively, neither criminal prosecution nor civil lawsuit followed.

(3) Child Protection Laws at the time
Child Welfare Act took effect on January 1, 1948 and the major responsibilities of the head of the Infant Protection Institution then were the same as today. According to article 47, the head of the Infant Protection Institution has a responsibility to perform parental rights/duties on infants in the institution who don’t have parents nor legal guardians with good faith. So, the head had a duty to protect infants from harm and he/she must act “for the welfare of the infant” in 1950s as well. The abuse of this power was strictly prohibited.

As for infants in the institution who had parents or legal guardians, the head is able to take necessary measures concerning the infant’s custody, education and punishment for the welfare of the infant (article 47). Since the head was entrusted by the municipal government to protect children, he/she had the duty of care to the custody of infants in 1950s, too.

It is apparent that the head of Nagoya Infant Protection Institution not only breached the duty of care to the protection of infants, but far worse than that, he abused his power by deliberately putting them to peril, which may have led to legal responsibility such as administrative sanction, civil damages, and criminal responsibility such as assault and battery.

However, as mentioned above, he was not criminally prosecuted nor no civil lawsuit followed. We must make one point clear here. What he did at the time was legally wrong and it was due to the power imbalance between medical doctors, especially professors and unprotected infants that his misdeed was condoned at the time. There were too many infants who needed protection then, so there was a priority policy, and the infants who could actually be protected in the institutions were “people who don’t have someone to care for them or whose parents are unfit to care for them”. So, you can easily imagine that even
though there existed laws to protect infants or at least punish or prosecute someone who caused them harm, there were only few people who tried to advocate for them when there was a lack of social interests toward the vulnerable which was a real grave concern.

(4) Lessons learned from these cases
What we learned from these incidents are as follows. First, the importance of getting parental consent for the research is highlighted. However, we must be careful that a consent gained from duress, misunderstanding and/or threat is not a genuine consent. Also, we must be careful of the possibilities when parents might abuse their power and act against the child’s interests. Secondly, the research subjects in the pediatric field must not be someone in the institution without parental care because this would lead to the abuse of power and the grave violation of basic human rights. As the Nagoya case suggested, those institutionalized infants were vulnerable because they were not only dependent but also institutionalized without someone to watch out for them, so they must be the last candidates to become research subjects. It is strongly suggested by the Belmont report as well that the principle of justice gives rise to moral requirements that there be fair procedures and outcomes in the selection of research subjects. Thirdly, if it should be absolutely necessary to research on institutionalized infants, they would have to be protected by someone legally responsible for their care such as the head of the institution. And the research needs observation from outside as well, such as research ethics review board because we have already witnessed the abuse of power cases. Fourthly, when we compared the above two cases, the Nagoya case drew much public attention and outcry compared to the Kobe case as the latter is necessary for infants, especially institutionalized ones to develop a better milk formula, but it can be pointed out that even though the research purpose itself had a good meaning, the research design and the method had problems
as the method was heavily invasive and there was no plan to stop the experiment in case of health-related incidents. We can point out the importance of research design and method. Lastly, the most important thing is to have respect for research subjects/participants, and not to think of them as a means for the progress/advancement of medicine.

### 3. Issues of consent in pediatric research

(1) Ethical Guidelines for Medical and Health Research Involving Human Subjects

Even though we saw such horrible cases in the 1950s, it was not until 2001 that sets of ethical guidelines were issued by the government. First, genetic research (which is defined as genetic analysis of genes derived from reproductive cells, so it is outside the scope to analyse mutations in somatic cells) was regulated under government guidelines issued by the Ministry of Health, Labour and Welfare (MHLW), the Ministry of Education, Culture, Sports, Science and Technology (MEXT) and the Ministry of Trade, based on the uniqueness of the human genes. Later, guidelines on epidemiological research were issued by the MHLW and the MEXT in 2002, based on the difficulty of obtaining consent in the epidemiological research. Finally, all medical research became subject to regulation by guidelines for clinical research issued by the MHLW in 2003. Before turning to the Unification of the Ethical Guidelines in 2014, let us look at the standpoints of law and ethics on pediatric research.

(2) Obtaining parental consent is not a panacea

Even though medical treatment and medical research are difficult to distinguish sometimes such as the cases of innovative therapies, the biggest difference between them is that the purpose of medical treatment is to pursue the best interests of the patients while the purpose of medical research is to gain
new medical knowledge from analyzing the data of the research subjects. So, while the patients may expect some direct benefits for their best interests from treatment, the research subjects/participants may not because they are the means to gain useful medical knowledge in the research. That is why one of the justifications for competent adults to participate in a research is obtaining voluntary informed consent from them. 

But children are legally incompetent to make a decision to do that, so the parents or the legally acceptable representatives must do it on their behalf. Parents have a duty to exercise parental rights for the “interests of the child” (The Civil Law article 820; not “the best interests of the child”) in Japan, but what is for the “interests of the child” in the context of medical research poses a very difficult question. From the point of view of protecting children from harm, it might be best not to let children participate in any research when no direct benefit is expected. However, medical research in the pediatric field is necessary to understand pediatric diseases and to provide the best evidenced medicine for children as possible. Also, it has been strongly argued that it’d not be fair to ignore the wishes of minor patients of rare diseases to participate in a research which has a possibility of gaining important medical knowledge or treatment for that group of patients just because they should be protected from harm. From the latter half of 1990s, the public consciousness has shifted from protecting children “from” medical research to protecting children “through” medical research. That is why the staunch research governance to protect research participants has been established and one of the requirements is to obtain parental consent which must be in the interests of the child. Generally speaking, we are able to judge whether something is for the interests of the child or not by balancing the risks and benefits and analyzing the extent of the burdens.

We must be careful that parental consent is not a panacea, as the consent might have been gained from duress, misunderstanding and/or threat which is
not deemed as a genuine consent. The following is a strong argument from the lessons of the past experiences in Japan, some of which I mentioned above. “It is dangerous to think obtaining parental consent is enough. Even parents do not necessarily respect human rights of their children the same as theirs. Especially, when the patients have mental disability or severe physical handicap, the parents might more or less think of them as an obstacle with or without realizing it.” The ethical integrity of the principal investigators/researchers and the research community are necessary to protect the interests of the child and also each research ethics review board must consciously review this point.

(3) Categorization of children

Furthermore, as the word “children” covers a wide range of group from babies to adolescents in its scope, I’d argue that they need to be categorized and treated differently not only from the ethical perspective but also from the legal perspective because Japan signed and ratified the Convention on the Rights of the Child in 1994. From the legal standpoint, children are categorized as “minors” and incapable of decision-making and “minors” but capable of decision-making. However, from the ethical perspective, the former category is divided into 2 groups depending on the capacity to form their opinion or not.

So, I’d like to categorize them into 3 groups: ① those who are incapable of decision-making such as babies, ② those who are incapable of decision-making, but have an understanding to some extent about the medical research to be carried out, and ③ those who are “minors” but capable of decision-making.

As for the first category, parents must decide whether to let their child participate in the research based on the “interests of the child” by balancing the risks and benefits and analyzing the extent of the burdens. According to the Nuffield Council on Bioethics report, “Children and Clinical Research: Ethical Issues” published in 2015, the ethical considerations that parents should take into account in deciding whether to let their children participate in the medical
research are: (a) to respect children as individuals regardless of their age and capacity, (b) to recognize that they are capable of developing into autonomous agencies and that each parent has a supportive and educational role in helping them develop and practice decision-making skills and confidence; and (c) to have concern for the immediate and longer-term welfare of the child. Because the duty of parents is to promote not only the immediate but also the longer-term welfare and interests of their child, there should be a spectrum of acceptable decision-making. This longer-term welfare includes the possibility to contribute to the social good or the community as they grow up, as it’s one of the functions of parents to influence on their child to realize their responsibility to others as a member of the society. Of course, the principal investigator/researcher must make sure that the protocol does not place undue burdens or risks to children and research ethics review board must review the research carefully before recruiting children.

In the second category, these children are able to understand about the research to some extent, so it’s preferable from the ethical standpoint that they participate in the process of decision-making and researchers obtain their “assent” other than consent from their parents. Even though their assent is not legally required, it’s necessary to try to communicate with children in accordance with the spirits of the Convention on the Rights of the Child.

The last category is so-called mature minors and they basically have the decision-making capacity to their medical treatment and research in general, so we need to balance the autonomy and the protection of children. The essence of parental rights and duties is the protection and nurture of the child, so parents are able to influence on the child physically and mentally. On the other hand, as children develop and grow, parental rights and duties for child protection decrease according to their maturity and development and the rights and duties shift toward respecting their autonomy. Balancing the respect for the child’s autonomy and his/her protection is not easy, but if the decision by the
When the invasiveness and risks of the medical research are very high, parents must play the role to protect the child’s longer-term welfare and interests, so even though it may seem like a contradiction on the surface, researchers need to obtain consent from both the mature minor and parents. It is because parental duties and rights do not only stem from complementing the incapacity of the child but also from respecting the autonomy of the child according to their age and maturity and the protection of the child’s life and limb. So, it is too simplistic to think that parental duties would perish when the child attained the capacity to make decisions.

(4) Unification of the two ethical guidelines

The requirements of consent in pediatric research were different between the guidelines for epidemiological research and clinical research. In epidemiological research, even a minor (16 years old or more) might give consent, whereas in clinical research, the consent of the parent(s) was needed (and the minor’s assent, if he/she was 16 years old or more). These two sets of guidelines were unified into a single set of guidelines in 2014, as the Ethical Guidelines for Medical and Health Research Involving Human Subjects. As a committee member to revise and unify the ethical guidelines, I suggested that we must take into account: (1) the importance of keeping the balance between the protection of minors and the respect for their autonomy; (2) categorizing minors according to their capacities into mature minors/ minors without consent capacity; (3) categorizing research (e.g. invasiveness, with direct benefit or not); (4) importance of listening to their voices (which leads to the importance of obtaining their informed assent); and (5) establishing a governance system to keep the transparency and the accountability of research in order to protect the research subjects properly.

As for the (1) to (3) points, the quality of risks (i.e. risk to the body or to
private medical information) and the invasiveness to the body are quite different in typical epidemiological studies and clinical research, so categorizing research (e.g. invasiveness, with direct benefit or not) and considering what is at stake in each category is quite important. In that sense, it would put children at risk of life and limb if we simply provide that ‘16 years or older’ minors are able to participate in any research only with their consent. I believe, children need more protection and parents’ advice in the case of the invasive clinical research than the epidemiological research, and it would be reasonable to treat them differently.

The essence of above points was included in the unified guidelines and the consent policy under the 2014 guidelines has been made as follows which is the same on specified clinical research under the Clinical Research Act of 2017 and its regulations (Article 47):

“Chapter 5 Informed Consent, etc.
Part 13 Procedures, etc. for Obtaining Informed Consent from Legally Acceptable Representatives, etc.
1. Requirements for obtaining informed consent from legally acceptable representatives, etc.
   (1) When the investigator, etc. or the individual providing existing specimens or information obtains informed consent from a legally acceptable representative, etc. pursuant to the provisions in Part 12 above, all requirements as defined below shall be met.
   A. The research protocol has description on the following matters:
      (i) Criteria for selection of legally acceptable representatives, etc.;
      (ii) Information to be provided to the legally acceptable representative, etc. (including information on (iii) below, when research subjects are those who correspond to either (a) or (b) in B. below); and
      (iii) When the research subject is an individual who corresponds to either (a)
or (b) in B. below, the reason why such an individual shall be the research subject.

B. The research subject shall correspond to any of the following:
(a) The research subject is a minor. When the research subject has completed junior high school or other relevant schooling, or is 16 years or older, and is considered to have enough judgment concerning the research to be implemented on him/herself, as well as the following matters are prescribed in the research protocol and the chief executive of the research implementing entity approves to carry out the research after relevant ethical review committee deliberation, informed consent shall be obtained not from representative but from the said research subject.

   (i) The research to be implemented does not involve any invasiveness; and
   (ii) Information concerning implementation of the research, including purpose of the research and how specimens or information will be handled, is made public, and opportunities to refuse that the research is commenced or continued on the research subject are ensured for persons who exercise parental authority over the said research subject and guardians of the minor.

(2) omitted

(3) When having obtained informed consent from legally acceptable representative, etc., and the research subject has completed junior high school or other relevant schooling, or is 16 years or older, and is considered to have enough judgment concerning the research to be implemented on him/herself, the investigator, etc., or the individual providing existing specimens or information shall obtain informed consent also from the said research subject.”

As for informed assent, the ideal of the article 12 of the Convention on the Rights of the Child is reflected in the guidelines as follows:

“Chapter 5 Informed Consent, etc.
Part 13 Procedures, etc. for Obtaining Informed Consent from Legally Acceptable Representatives, etc.

2. Procedures, etc. for obtaining informed assent

(1) Even when having obtained informed consent from legally acceptable representative but when the research subject is considered to be able to express his/her will concerning the research is to be implemented on him/herself, the investigator, etc. or the individual providing existing specimens or information shall endeavor to obtain informed assent from the said research subject. The same shall not apply to cases in which informed consent is obtained from the research subject pursuant to the provisions of Section 1 (3) above.

(2) When carrying out the research for which procedures for obtaining informed assent will be predicted pursuant to the provisions of (1) above, the principal investigator shall, in advance, prescribe information to be provided and the means to provide to research subjects, in the research protocol.

(3) When a research subject expresses his/her will of refusal all or part of the research to be commenced or continued, in the course of the procedures for obtaining informed assent pursuant to the provisions of (1) above, the investigator, etc. or the individual providing existing specimens or information shall endeavor to respect such will. This, however, shall not apply when direct benefits to the research subjects’ health are expected if the research is commenced or continued and when the legally acceptable representative gives consent to it.”

4. Conclusion

We’ve advanced from making children just as means in the 1950s to the subject of protection and finally to someone who may be able to decide for their own when they are mature enough to do that, but I’d argue we have our weakness in trying to listen to children’s voices, such as referring to young
people’s advisory groups in the research design stage in the UK practice.

According to “the Guidance on clinical research involving infants, children and young people: an update for researchers and research ethics committees” issued in 2014, the Royal College of Paediatrics and Child Health (RCPCH) acknowledged a greater focus on involving children and their parents more actively in the design, review and conduct of clinical research and they included them in the discussion of amending the guidance. The view of the NIHR MCRN Young Persons Advisory Group is “that children should be offered the opportunity to participate in research, and have their care ‘assured by research’”. There are 5 Young Persons Advisory Groups in the UK and they consist of children and young people who are interested in improving health research and their main interests are in advising on, and providing input to all stages of research, although most frequently they are asked to review participant information sheets for readability, language, acceptability to young people, and overall comprehension.

Compared to the UK practice, we are able to say that we’ve come so far, but we still have a long way to go.

The study was supported by JSPS KAKENHI Grant Number JP19H01083 (the Grants-in-Aid for Scientific Research (A) #19H01083 from Japan Society for the Promotion of Science).

[Notes]
(1) This article is partly based on my previous article “KODOMO WO TAISHOU TO SURU KENKYU (RESEARCH INVOLVING CHILDREN)” in “IGAKU KENKYU RINSHOU SHIKEN NO RINRI-WAGA KUNI NO JIREI NI MANABU (LEARNING FROM EXPERIENCE: ETHICS IN MEDICAL RESEARCH AND CLINICAL TRIALS)” (Yusuke Inoue & Tsunakuni Ikka eds.) (chapter 7, Japanese) and also based on my oral presentation “The change of governance on pediatric research in Japan: From 1950s to date” at the 25th World Medical Law Congress on 7th August 2019 at Waseda University, Tokyo.
(2) The description of this incident is based on the Japan Federation of Bar Associations’ “JINKEN HAKUSHO (WHITEPAPER ON HUMAN RIGHTS)” (1968 fiscal year), at 134–136 except some parts especially indicated (Japanese).

(3) It is said that this deceased infant was institutionalized temporarily due to its mother’s hospitalization for the operation of kidney disease, and became diarrhea soon after that. (SHINGO TAKASUGI, 731 BUTAI SAIKINSEN NO ISHI WO OE (CHASE THE DOCTORS OF 731 UNIT), 1982, chapter 4 (Japanese).)


(5) Takeshi Okuda, Nyujiinji Hoiku no Gaiyou (Outline of Care in an Infant Protection Institution), Nagoya City University Medical Association Journal (now Nagoya Medical Journal) 5(4), at 204 (1955) (Japanese).

(6) MASAMI TAKADA, JIDOU FUKUSHI HOUN no KAISETSU TO UNYOU (ANNOTATION ON CHILD WELFARE ACT AND ITS OPERATION) (1951), now reprinted as “JIDOU FUKUSHI KIHON HOUSEI (CHILD WELFARE LAWS) vol. 8” at 272 (2005) (Japanese).

(7) Now, the age is extended to the day before the entrance of primary school based on Child Welfare Act articles 37 and 4(1) 2.

(8) SABURO KAWASHIMA, JIDOU FUKUSHI HOUN no KAISETSU (ANNOTATION ON CHILD WELFARE ACT) (1951), now reprinted as “JIDOU FUKUSHI KIHON HOUSEI (CHILD WELFARE LAWS) vol. 5”, at 133–134 (Japanese); TAKADA, supra note 6, at 272.

(9) KAWASHIMA, supra note 8, at 204–205.


(11) Circulation No. 50, Health and Welfare Ministry, October 4th, 1948, “Satooya tou Katei Youiku no Un-ei ni Kanshite (On the familial care by the foster parents and so on)” (Japanese). According to this circulation, it was desirable for the infant to be placed to the foster mother who was able to give breast milk and if it was not possible, the infants must be given appropriate milk, goat’s milk and artificial nutrients, which meant that it was urgently needed to develop an appropriate synthetic milk formula such as experimented in the Kobe case at the time.
(12) Ethically problematic cases after the two scandals continued until early 1970s, see Inoue & Ikka eds., supra note 1, part 3 (summary of cases, Japanese).

(13) Eiji Maruyama, Japanese Governmental Guidelines Concerning the Issues, in Law and Ethics of Human Tissue Uses, Matsumura, English, Sato & Utsugi eds. 2008, at 75. Manufacturing, selling etc. of pharmaceuticals and medical devices including the procedure for approval are regulated by Pharmaceuticals and Medical Devices Act and beyond the scope of this article.


(16) Nagamizu, supra note 1, at 134.


(19) Ibid.


(22) Nuffield Council on Bioethics, Children and Clinical Research:
ETHICAL ISSUES, MAY 2015, chapter 4.


(24) Ibid.

(25) NAGAMIZU, supra note 1, at 137.


(27) It is in the context of mature minor’s refusal of life-sustaining medical treatment, but some scholars allow the restriction of the minor’s right to self-determination by the interests in the preservation of life (Jennifer L. Rosato, The Ultimate Test of Autonomy: Should Minors Have a Right to Make Decisions Regarding Life-Sustaining Treatment?, 49 Rutgers L. Rev. 1, 50 (1996)) or by the interests of minor to become an adult who is able to make a decision for him/herself (ALAN BUCHANAN & DAN BROCK, DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING, 1990, at 226–32); See Yuko Nagamizu, Do Mature Minors Have a Right to Refuse Life-Saving Medical Treatment? : A Subtle Balance Between Autonomy and Protection, 15 St. Andrew’s University Law Review 153–239 (2010) for more analysis of doctrines on this topic (Japanese).

(28) NAGAMIZU, supra note 1, at 137–138.

(29) NUFFIELD COUNCIL ON BIOETHICS, supra note 22, at [4.45]–[4.47].

(30) I hadn’t thought of it much more than getting assent at the time, but later I would learn about it more in the UK when I interviewed about the NUFFIELD COUNCIL ON BIOETHICS, CHILDREN AND CLINICAL RESEARCH: ETHICAL ISSUES, MAY 2015 to Professor Bobbie Farsides at the Brighton & Sussex Medical School (chairperson of the working group) in 2016 and interviewed Ms. Lynn Molloy of ALSPAC (Children of the 90s) at the University of Bristol in 2017.

(31) Yuko Nagamizu, Miseinensha no Kenkyu Sanka eno Assent oyobi Sai-


(34) Ibid.

(35) National Institute for Health Research, Medicines for Children Research Network, which is called Clinical Research Network: Children (CRN: Children) now.

(36) For example, an article on the London Young Persons Advisory Group (YPAG) is on https://www.invo.org.uk/ypag-the-young-persons-advisory-group/ (Last visited, Nov. 29, 2019). For more information on this and ALSPAC (Avon Longitudinal Study of Parents and Children, long-term cohort studies which has the same kind of system in reflecting children’s voices called “Teenage Advisory Panel”, now called OCAP (Original Cohort Advisory Panel)), see Yuko Nagamizu, The Importance of Reflecting Children’s Voices in Pediatric Research: Analysis of the Report of the Nuffield Council on Bioethics, 26 St. Andrew’s University Law Review 313, 326-330 (2017) (Japanese) and NUFFIELD COUNCIL ON BIOETHICS, supra note 22, at chapter 3 for YPAGs.