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► **To cite this version:**

Janet C. Read, Matthew Horton, Daniel Fitton, Gavin Sim. Empowered and Informed: Participation of Children in HCI. 16th IFIP Conference on Human-Computer Interaction (INTERACT), Sep 2017, Bombay, India. pp.431-446, 10.1007/978-3-319-67684-5_27 . hal-01678479

HAL Id: hal-01678479

<https://inria.hal.science/hal-01678479>

Submitted on 9 Jan 2018

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Empowered and Informed: Participation of Children in HCI

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Abstract

The participation of end users in design, research and evaluation has long been a feature of HCI. Traditionally these end users consent to participate in the general belief that they are contributing some knowledge that will eventually improve things for themselves or others. The involvement of children in research in HCI creates new challenges for ethical participation. This paper brings together current research on ethical participation and models of participation, and presents three tools, CHECK, ActiveInfo and PICO- Art, as well as a set of practical ideas, for researchers to adapt and use in their work with children. The paper explores how effective different aspects of the different tools are, and offers a set of practical suggestions based on observational assessments. The main contribution is a culturally adaptable ethical toolkit and a protocol for ethical working with children in HCI.

Keywords. Children: Ethics: Participation; Impact: Empowerment:

1 Introduction

The HCI community is a reflective community that has actively sought to explore several key themes around its practices and its methods. One area of interest is the ethical participation of individuals in research studies. When research is being done with children, there is a pressing need to examine what participation in research means. Several papers have individually explored the involvement of children in research, design and evaluation studies but these tend to be relatively pragmatic considering the happiness of children, the means by which they can participate, and the design of tools and techniques to make their participation possible. The ethics around the participation of children, in terms of being able to justify their inclusion, explain their roles and determine their influence has not been so well studied nor has there been to date any attempt to improve the practices of gaining informed consent and working openly in research with children in HCI. This paper therefore brings to the surface the key issues around children participating in HCI research and proposes some solutions that can help researchers work in more ethically appropriate ways with children.

2 Related Work

In this section previous work is presented on ethics and their role in HCI, the participation of children in HCI research, and then the ethics of children's participation.

2.1 Ethics and Values

Ethical values are concerned with what is right and what is wrong [1] and it is common for research to be governed by ethical codes. Typically, these are determined by ethical boards within institutions that examine research and determine if it is ethical. Codes of ethics tend to focus on several key themes:

- Beneficence (that work does good)
- Avoidance of harm
- Truthfulness
- Not discriminating
- Appropriately acknowledging rights of property
- Respecting privacy and confidentiality

Central to ethics in terms of research is consent. Consent is where a human participant agrees to be included in a research study. The principle of informed consent is where an individual agrees to participate based on being fully informed about the research that is being done. Consent is related to risk. The higher the risk associated with research the more severe are the requirements for informed consent. Thus medicine and psychology typically have more tightly defined consent processes than design and ethnography where the risk associated with participation is much reduced.

Informed consent has been much discussed in the literature. Of interest in this debate is:

- Who should give it
- When is it needed
- How is it gathered
- How is it tested
- How is it receded

In terms of who should give consent, the generally accepted view is that to give consent one has to be 'legally competent' as well as physically and mentally capable of giving consent [2]. Aspects of this definition have been challenged with regard to competence to consent especially highlighted in the famous 'Gillick competence'¹ which resulted in the understanding that 'A competent child is one who has sufficient understanding and intelligence to enable him or her to fully understand what is proposed and also sufficient discretion to enable him or her to make a wise choice in his or her own interests.'

In HCI work, consent is always considered to be needed when images and data are being gathered from participants. Less clear is the extent to which consent should be sought when a researcher is gathering ideas or, as is the case in some HCI work and

¹ Gillick v West Norfolk and Wisbech Area Health Authority and another [1985] 2 BMLR 11

ethnographic work, working undercover in some way such as by passively observing individuals. Sometimes referred to as deep cover research in HCI, such work certainly requires consent at the 'reveal' moment [3], this being the traditional way of gaining consent in many Wizard of Oz studies [4].

Typically, a signature attached to a consent form assumes consent. The general principle is that an information sheet is produced that outlines the research and then signatures are gathered. The readability of such forms has been studied in some detail and is often considered to be a problem [5].

The understandability of such information, and the test of whether or not the participants really are informed is associated with both the readability of consent documents but also with the general understanding of the participants as to the extent of, and possible impact of, what the research aims to do. This is the very essence of informed consent. That the consenting individual has to know what the research is about. It is argued that this understanding should be tested [6] in some way otherwise it is wrong to assume it.

In most cases individuals consent to participate in research before they start a study and a core principle is that there should be a 'right to withdraw'. How consent is withdrawn rather depends on what is being consented to. Actioning the removal of consent after the surgical removal of a limb for instance is impossible, but data from a HCI study should be withdrawable.

2.2 Children and Participation

The participation of children in research is highlighted as especially problematic in terms of consent. Much of the debate in this has come from medicine where the right of a child to consent (or not) to a medical procedure has been widely debated. This was indeed the case in which *Gillick competence* was derived. Traditionally, research ethics boards refer to all adults under the age of 18 as minors and demand special considerations in terms of informed consent. This focus on age as opposed to activity is historic and is rooted in legal argument. Age based lineation has been widely challenged as research consent has moved beyond the operating theatre to consent to participate in research across a multitude of disciplines.

Concern about the child as a participant in research has been brought to the fore as thinking has changed from seeing a child as an object or subject to seeing the child as a social actor. Ethically, this move in position leads to new considerations including what Hill et al [7] refer to as 'negotiation not imposition' in terms of what is being done with the child in research. In 2002, Christensen [8] introduced the idea of ethical symmetry in research work where the concern is to be ethically appropriate to 'the other' and where children are treated no differently from adults in terms of being informed and included in research work. This requires a move towards more personalized ethics where responsibilities are shared, embracing the philosophy of Jean Paul Sartre that the 'primacy of system over individual' does not remove responsibility of the individual to take ethics onboard. In [8] Christensen further refers to cultures of communication where practices in research should be in line with children's experiences, values and everyday routines.

This move towards individual responsibility is a theme for our own work. Believing in the three principles from Thomas in regard to participatory research with children [9] that a) their inclusion depends on their active agreement, b) that they should be able to withdraw and c) they should have some choice in terms of the research methodology, our approach is based on going beyond the ethics review board and seeking ways to make HCI research work with children in mutually beneficial ways.

Our long term objective is to develop means to make research meaningful and fun for children, acknowledging the pressures of time and attention, [10] whilst promoting a move from ‘research on’ through ‘research with’ to ‘research by’ children as provoked by Kellet in 2005 [11].

2.3 Children’s Participation in HCI Research

Models of participation in research exist in the literature both within HCI and beyond. The earliest studies of participation were less about children and more about adults and many of the papers in this area come from the fields of sociology where the participation of different actors in society is studied and categorized. Participation can be described in many ways but one useful definition is that it is “*the social process of taking part (voluntarily) in formal or informal activities, programs and/or discussions to bring about a planned change or improvement in community life, services and/or resources*” [12]. This definition is especially useful for HCI as it stresses the voluntary aspect of participation which can be a point of tension. In many situations, when working with children in schools and clubs, children are not always empowered to decline participation if they do not wish to take part. Bracht [12] refers to participation as being something that results in a ‘change’ outcome. This is also pertinent to the HCI debate and it raises the question, if children are participating without there being an expectation that something changes, can they be assumed to have participated at all?

Participation is generally regarded as being something that occurs at different levels; one can participate in a superficial way, or in a deep way and for those seeking to promote participation as an ideal, the aim is generally to maximize participation in order to maximize both individual and collective potential [13].

Modeling the effect and depth of participation has been a theme of considerable research. One of the most useful models for the HCI community comes from Hart [14] who conceptualized youth participation aligning to rungs on a ladder, (see Fig. 1), showing increasing autonomy, increasing knowledge and increasing influence as the participant moves up the rungs.

Roger Hart's Ladder of Young People's Participation

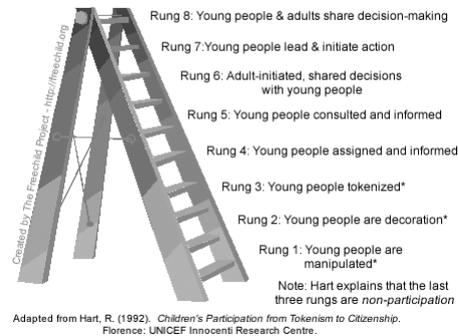


Fig. 1. Hart's model of participation

In Hart's model, the lower three rungs are considered to be 'not participation'. These refer to children as decoration, as having a token involvement and as being manipulated. These are strong words and they need to be considered by the HCI community when justifying inclusion of children in studies. Others model participation in terms of the depth, as opposed to the autonomy of the involvement; an example can be seen in the literature review by Nielsen et al [15] where studies of participation were categorized against what was being done in terms of the 'mass' or density of participation. In HCI a depth style model is proposed by Druin [16], who modeled the participation of children in HCI design activities in terms of the roles the children take on (Fig. 2).

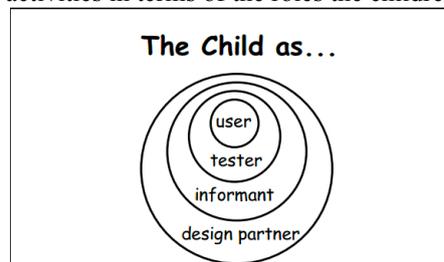


Fig. 2. Participation according to roles

In this model the emphasis is on the perceived increasing influence of the child as the circles expand. The design partner is also, in this view, an informant and the informant a tester and so on. This model has been heavily used in HCI to allow researchers to distinguish between the roles of children. It was the main model used in a review of Interaction Design and Children design research found in [17].

The involvement of children within participatory research in HCI is known to be beneficial as it allows children to gain knowledge in social action and helps them to prepare for active participation in democratic society. Participation is believed to

strengthen social development and is, to varying extents, a right of the modern child [18].

In HCI, children typically participate as evaluators of a product, as contributors to a research study, or as designers of ideas and products [19]. In considering these three roles, it is pertinent to consider to what end the child is contributing, to what extent that child understands his or her contribution, and what, if anything, is the value of the contribution made.

It is recognized in other fields that conflict can occur in ‘adult’ participation when the ‘agenda’ is set by a third party rather than it being set by the participants [20]. In the HCI community, the sort of activity being promoted will determine the agenda. In some design sessions the child might have a lot of freedom to do as he or she likes whereas in a controlled experiment there may be very little freedom.

From the point of view of the child, understanding participation is central to the act of informed consent. It is not possible for a child to consent to participate unless the extent of, and the effect of, participation is understood. Whilst not directly associated to participation per se. the works by [21] and [22] could be useful in the ongoing study of the effect of participation by children within HCI as both are concerned with identifying the contributions made by children in participatory activities.

3 Ethical Participation in Action

HCI research can take many guises, it can be design and it can be experimentation, it can be about the effect of technology on people, or it can be all about the performance of the technology. Given that it can have many guises, the process of completing a University ethics application to carry out research in HCI can be fraught with difficulties. With others in the HCI field [23] we have suffered at the hands of ethical review boards in the process of making understood what it is that we are doing but this tension has enthused us to make application for ethics approval easy by creating products and processes that can be validated and be shown to be useful across a wide range of research scenarios. That said, we also maintain that every study is different and are keen to not suggest a one-size fits all approach to ethics. Whilst there may be a set of forms that can approximate to most scenarios in terms of getting through a review board, our own view is that when working with children in HCI the ethical principles used should transcend any variance in institutional ethics boards, especially as they may not appreciate the more sophisticated issues of consent and participation considered here

In the following sub heading, our own work towards ethical participation is presented in three sections. The first section is concerned with how we communicate to children what we are doing and how we set up research studies. The next section describes how we challenge ourselves in terms of why we are doing what we are doing by exposing the values of the research team. In the third section we describe how we start to understand how children feel at the end of the research activity in terms of how they have participated.

3.1 Basic Information - ActiveInfo

Early in our work we chose to go beyond just gathering parental consent to actively seek consent from children. Active consent requires the children to be informed and to be engaging with the process of being informed. An early attempt was the production of information packs for children, built as three page booklets. These packs started with the creation of usernames (Fig.3) as well as activities that could be either done at the start of the research study while things were being handed out, or could be used as filler activities for children completing a research task early etc.

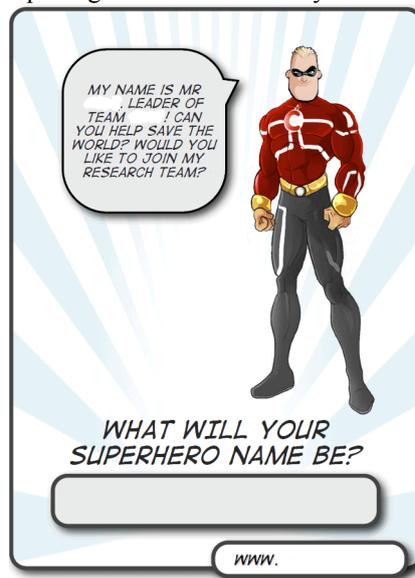


Fig. 3. Choosing a secret username

Activities in the booklets, which were designed differently for three different age groups, included coloring, word games and collecting researcher autographs (Fig. 4). These side-activities are also helpful to have in the cases where a child may want to withdraw from the research activity. They provide something for the child to do without creating a problem for the research study and without drawing attention to themselves. The children can also take these booklets home and talk to their parents about what they did at school. Each booklet has a contact number and the group website so parents can find out more if they want to.

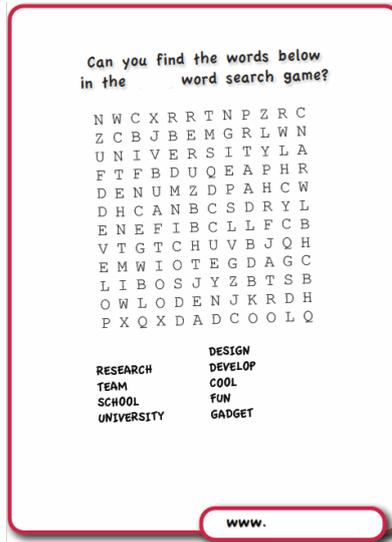


Fig. 4. Fun activities like word searches

In addition, these information booklets sought to explain something about data and research, as well as providing information about what we would be doing with the research outputs (Fig. 5).



Fig. 5. Explaining what research is

These information booklets were designed for the children we were working with so were aligned to their abilities and their cultures. We have not stuck only with these designs, we have incorporated secret names and filler activities into many information booklets but we have always sought to make the booklet suit the activity and the children.

3.2 Examining our values – the CHECK tools

Value centered design explains itself as ‘frontloaded ethics’ [24, 25] and promotes an early look at the values that are incorporated in design. As written by Friedman [26], ‘*Human values and ethical considerations no longer stand apart from the HCI community but are fundamentally part of our practice. This shift reflects, at least in part, the increasing impact and visibility that computer technologies have had on human lives*’. Whilst accepting that technology conveys and supports values, researchers and designers are also called to be ‘value conscious’ [27] and to deliberately clarify their ethical objectives in design by considering who’s values are being considered. Central to value conscious and value centered design is the need to examine our own values; as adults enabling research practices with children. To that end we have developed two *values checklists* to assist in this process [28].

CHECK1

CHECK1 is a value checklist for use prior to a research study. Six questions ask:

1. What are we aiming to research or design?
2. Why are we *concerned* with this?
3. What platform / technologies or methods are we planning to use with the children?
4. Why are we using *these*?
5. Which children will we work with?
6. Why are we working with *these* children?

In completing this value checklist each ‘why’ question is required to be answered twice. The first time we answer with our first excuse for the work, the second time we reflect on this and seek to really get down to the real reasons for each response. An example makes this clear. In recent work with children in a very well-funded private school in the US, the research team was working with children to design a game for children in rural Africa. In asking ‘why’ in question 2, the excuse would be that we wanted *to improve the lives of children in Africa*, the more honest answer might refer to *the need to write an Interact paper* or *the desire to study design practices*. In question 4, our excuse might be to *gain great design ideas* but in an honest view it might be that *a study of the PD process* was being couched in the research activity. Question 6 is especially important. Often researchers will ‘justify’ a group of children on the basis of their *unique position to inform research* but more realistically the inclusion of a specific group of children is probably more likely to be that that group had a headteacher who *said yes on the day of a phone call*.

As can be seen in the example, the purpose of this checklist is to expose some of the tensions that are relevant to the research space. Having completed the checklist it is then down to the researcher, or the research team, to critically consider where the honest answers conflict with the excuses and where the excuses are not defensible.

CHECK2

CHECK2 is a consent checklist that seeks to assist in the formulation and communication of research to children. Like CHECK1, CHECK2 has a series of questions; some of which directly feed from CHECK1. As with CHECK1, the questions arrive in pairs with the second question of each pair informing the researcher on how to talk to the children about the research. The questions are as follows:

1. Why are we (the research team) doing this research project?
2. What do we tell (the children)?
3. Who is funding, and /or who are the stakeholders in, this research project?
4. What do we tell (the children)?
5. What might happen to the information / data / ideas that we take away in the long term?
6. What do we tell (the children)?
7. What might we publish / share / exploit from this project and who will read it?
8. What do we tell (the children)?

In completing CHECK2 the intention is to look before and beyond the research activity in order to better frame, for the children, the landscape of the work so they can better consent to participate. In completing this second checklist, researchers find that they better understand the ethics of their own work as well as finding that the research is done in more honest ways.

The CHECK tools are designed to assist thinking. We believe these to be cross-cultural in terms of their usefulness as they are simply prompts for thinking. Having answered the two checklists, the researcher is then in a strong position to talk to the children about the work they will be doing.

3.3 Explaining HCI Research to Children

Once the research team understands what they have to tell children, the next challenge is to convey this to children in ways that they can understand.

Our experience is that the way to talk with children is to engage with them and use images and examples to explore concepts. Our narrative, on coming to a group of children is firstly to introduce ourselves, then to talk about Universities, Research, Science, Funding, Publishing and finally Consent. Each of these needs explaining in an appropriate way so children can understand. Thus, when we talk about Universities we describe how they are similar to, but a bit different from, schools. We explain that research is more than finding out about things that are already known and is about discovering new things; we use examples of scientific enquiry, like talking with children about how we could find out if playing out was better for them than sitting at a computer all day. We talk about how research is paid for and ask children to suggest who they

wouldn't want to be paying for research. We then talk to children about the possibilities for the outcomes from their research and this is possibly the hardest part of this process as it is far removed from their usual experiences.

PICO-Art

Discussion about outcomes is complicated by the different ways that children participate in research. Given that HCI research is so often multi-faceted, for example a research scientific style study with then some design ideas, we have found it complex to be able to explain to children how these different things will be used. To that end we have chosen to visualize what we consider to be the four different aspects of participation using meaningful images for children, referred to here as PICO-Art where P is for participation, I for influence, C for control and O is for outcomes. We can explore these four aspects with imagery. We do not see that there is single set of images for PICO-Art, rather that this is a way of thinking about expressing complex ideas to children and as such we would encourage all researchers to make their own culturally sensitive PICO-Art. Fig. 6 shows our UK PICO-Art that is appropriate for our location and for the children in the schools we work with. Four images describe different positions on the participation continuum as it pertains to HCI. They allow us to talk to the children about how participation affords control, influence and outcomes.

The first of these images represents the 'no control' and 'no influence' end of participation. Here, in our PICO-Art, the image shows a child being taken to the supermarket mostly against his / her will; we associate this with the child as *object* or maybe as *research subject*. A position where the child could be any child, he / she bringing little to the research and having little control. In the second image the child as an evaluator is portrayed. Here the child gets to vote on the performance of his / her teacher. If the teacher performs well maybe he or she will get to carry on in the job, if badly, then who knows. The child here has some control over what happens next to the teacher to a small extent. The child has a voice and is making a judgment that is considered to have some value.

The third image tends towards the classic research study where the child provides input towards a question that could have lasting impact. The child here is with the adult but the child is making the decision so this conveys the idea of more control than the 'you must come along because that is how it is' supermarket visit. In the fourth image the child has almost too much freedom and can do whatever he / she wants. Everything is possible and all the choices are his / hers in the shop of everything.



Fig. 6. Being taken to the shops by the parents, voting on the teacher, choosing the next direction and having a chance to do anything

A PICO-Art set can be used at the start of a study to explain what is being planned but the abstractness of research makes it more useful after a study has taken place. Recently we have used these as a means to evaluate how children have felt about their participation. In Figure 7, children voted for the participation descriptor that they most felt fitted what they had been doing in a research study. Note the use of masks so we can photograph children. All these children had been doing the same activities but given a choice, at the end of their participation, to stand by any one of the four images; twice as many thought they were solving problems (the signposts as in image 3, that coming up with great ideas and having the chance to do everything (the shop of everything as in image 4); no children see themselves as evaluators (which was encouraging as that is not something we were doing). Eight children seemed to find themselves rather un-empowered by choosing to stand by the reluctant shopper image.



Fig. 7. Using PICO-Art to gauge how children feel about research participation

The PICO-Art images can be used in different ways – as props for children to talk about as well as signposts for children to align towards. The most important thing about PICO-Art is that all the words and images used are locally meaningful.

Having actively talked to children about universities, funding, participation and science in several research studies we have had interesting discussions with children about the possibility of their research being used to make money, about where that money should go (should it materialize) and about what data is and where it is to be used. Discussions on the possible profit from design work have been inclusive and informative; groups of children have been seen to draw towards a consensus decision.

4 Discussion

Applying these processes to our work has had several consequences. The first is that we have established a protocol by which research has to be explained to children before, and after each study using, as appropriate, tools from our toolkit described here. Sometimes researchers have used only narrative to explain things to children, in other cases they have used ActiveInfo in the form of booklets and worksheets. We have also embarked on a series of studies to ‘evaluate’ the effectiveness of our tools and our protocols. In these evaluations we have discovered that some concepts are harder than others for children to understand. In particular, children find the concept of research as discovery of new knowledge to be quite difficult to understand; having a tendency to see it as a way to answer a question for which the answer is known but just needs to be unearthed. This is a subtle idea and one that we will need to work harder on as it impacts on how children consider they contribute. If children are simply helping us find an existing answer or evidence this is slightly different than helping us invent. The idea of publication, which we have framed as ‘exposing or advertising your answers’ we have found children struggled to understand, but funding from ‘good’ and ‘bad’ sources and the idea of a university being like a school are easy concepts for children to grasp.

As has been shown in Figure 7. Children may all do one activity and see it in a different way. This is perhaps a little surprising but given that an activity that we propose is designed in a certain way, that does not immediately map to the child perceiving it in that same way. This exposes that each child comes to an activity as an individual with expectations, their own understandings and then their own interpretations. We recently explored the individualization of participation with a class of twenty-seven 7 and 8-year-old children who were doing design and evaluation in two different research activities. In this work, the children were mainly engaged in a participatory design activity (Fig. 8), creating sketches of ideas, of a game to teach children about hygiene in which they were working in groups of three and four and then they were being taken out, in groups of four, to carry out an evaluation of an iPad game in which they were being asked for opinions on how to improve it.



Fig. 8. The participatory study

Children had brought bears to school that day and so, within the ActiveInfo concept we asked them to use their bears' names as their secret usernames for their research activities.

We asked children, before and after each activity about how much influence they felt they would have and had had on the outcomes from the two activities. In other words, they were asked to what extent they imagined their designs might be used in the eventual game and to what extent what they said about the iPad game would be included in future instances.

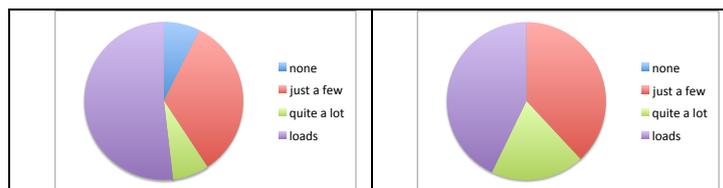


Fig.9. Children's self-report on perceived influence

As can be seen in Figure 9, the children expected to be pretty influential in both the design and the evaluation activities with over half the children expecting to contribute loads or quite a lot of ideas / comments / content. But, and this is important, quite a few of the children though did not expect to have much influence. There is a real possibility that these children see their inclusion in the research in quite a negative way and in much the same way as the children who voted in Fig. 7, to align to the 'dragged to the

supermarket image', so these children were not able to imagine their individual value to the research study.

In this instance, the children were introduced to the PICO-Art at the end of the two activities and it was used as a tool to talk to the children about what they had been doing rather than as a tool to evaluate how they had felt. Having heard what we said about the research activities, the teacher lead a fifteen minute conversation with the class about participation while one of the research team took notes.

From this discussion it was clear that the children understood about freedom and control as portrayed in the PICO-Art images and they had also identified with the idea of being able to choose or make choices.

One aspect that the teacher explored with the children, prompted by the PICO-Art, was the 'shop of everything'. The teacher took a straw poll to get a sense of the children's enthusiasm for completely open activities and it was interesting to note that almost a third of the class voted for each possibility 'yes please', 'not sure', 'no thanks'. This confirms what we have observed over many studies with children, that some are very happy with open ended work whilst others much prefer structure. In proposing more freedom for children to influence participation levels in research, and in moving their involvement higher up the Hart's ladder, we mustn't lose sight that this might be a very uncomfortable place for some children to be.

5 Empowering and Informing Children in HCI Research

This paper has reviewed literature on the ethical participation of children in HCI. A set of three culturally adaptable reflective ethical 'tools' have been described, each providing additional value to HCI research with children. Practically these tools can be used in many different ways according to the situation and context of the work. We would always encourage, in all cases, the use of the CHECK toolkits as this is done away from the children and will always provide a means for the research team to reflect on what they are doing and on what they are going to say to the children. Having understood this, researchers can then consider how that information is best given to the children in terms of ActiveInfo. Whether this is a booklet or a single sheet of paper, whether a small passport is used for the bear's secret name, that is part of the research environment design. Consideration should be given to whether there is an intention, or willingness, to evaluate the extent of understanding after the research activity. If this is the case, then some post-activity questions can be asked or some notes made of discussion with a teacher or with one of the research team. Understanding how children have felt about their participation can be done in different ways, one way is to do a short before and after survey, as we did with the study with the seven and eight year olds, another is to explore their deeper sense of what they have been doing using PICO-Art in an appropriate way.

Going forward there is a need for the HCI community to seek ways to better understand the impact of child participation on the children, on the community and on the

society and systems beyond academia. That children gain from participating in research and design activities is a commonly stated justification for participation but it may be that this has to be challenged. Whilst an activity may not be harmful to a child, it may still not be the best use of their time. Given the extent of child participation in HCI studies; the community needs to grapple with this as a matter of some urgency.

Understanding the value of children's contributions will be complex. As a community the obvious place to begin is in understanding what these children bring to our field and then we can start to look beyond what they bring to us towards what they bring to each other and to society. Tools we create to help talk about participation with children may end up being useful prompts for our own discussion.

We need to be able to explain what participation means to the children who freely give their time and talents to our endeavors. This is possibly the biggest challenge for our research community to date.

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