

Constructing Informed Consent in ICT4D Research

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Abstract—The field of Information and Communication Technology for Development includes participatory and action research pilots with a research and change agenda. Such ICT4D research does not fit traditional models for evaluating community risk and benefit. Looking at the history of informed consent and international development, uses of informed consent in development scenarios, and at efforts specific to ICTD research, we present how informed consent is currently addressed, as well as the inadequacy of adapting present academic informed consent models to development. Informed consent in ICT4D research provides academic rigor to the field, helps establish a fair, moral and candid relationship with the community to set expectations, and standards for other intervention-based research efforts. We suggest practical recommendations for models that contribute to community involvement and trust, while offering the target community an opportunity to negotiate their level of participation.

Index Terms—Information and Communication Technology for Development (ICTD), Informed Consent, Institutional Review Board

I. INTRODUCTION

Informed consent protocols are rooted in post-World War II concepts of social justice to ensure past egregious medical and scientific exploitations of individuals and marginalized groups do not happen again¹. In the academy, the administration of informed consent has evolved into a set of

¹ The current understanding of informed consent comes from several efforts to curtail bodily and mental harm in research, including the Nuremberg War Crime Trials (1945-46) and Tuskegee Syphilis Study (1932 to 1972). Informed consent as a principle for medical research was first coined in the 1972 Supreme Court case *Canterbury v. Spence* [1], and the National Research Act of 1974 developed and defined in the Code of Federal Regulations that Institutional Review Boards would serve to govern informed consent protocols [2, 3]. In 1978, the Belmont Report (formally titled "Ethical Principles and Guidelines for the Protection of Human Subjects of Research"), overseen by the Department of Health and Human Services, explicitly stated three fundamental ethical principles for human subject use in biomedical and behavioral research: (1) respect for persons: protecting the autonomy of all people and treating them with courtesy and respect and allowing for informed consent; (2) beneficence: maximizing benefits for the research project while minimizing risks to the research subjects; and (3) justice: ensuring reasonable, non-exploitative, and well-considered procedures are administered fairly [4]. In 1990, The International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH) established the Good Clinical Practice (GCP) standards, providing the first unified ethical standard for the United States, the European Union, Japan, Australia, Canada, the Nordic countries, and the World Health Organization [5]. The CGP is based on the Belmont

principles designed to protect human subjects by explaining the potential benefits and risks of research to the target community. The concept of informed consent originated from medical research, but now encompasses the social sciences.

While informed consent operates under the adage “do no harm,” international development agencies and practitioners have evolved in a similar timeline to “do good.” These two models are not synonymous, although they share a goal of accurately setting community expectations. Development professionals, seeking to improve the quality of the lives of others, often act under implicit good intention; ICTD researchers who attempt to employ existing academic informed consent protocols find them a poor fit. In this paper, we argue this mismatch is due to a variety of cultural factors and underlying motivations, while contending that the principles of informed consent are of critical importance to ICTD research with interventionist aims. Appropriate consent in such ICTD research ensures academic rigor, integrity and viability of the research, and helps establish a fair and just relationship with the target community. We describe the need and basis for such a model, and demonstrate how this model can contribute to the overall success of ICTD research efforts.

II. THE CASE FOR ICT4D-SPECIFIC INFORMED CONSENT

ICTD research is unique in that it is forged with practice, application and action research methods – usually separate entities in other academic disciplines. In addition, ICTD research spans and affects multiple disciplines, advancing both the fields of computer science and international development efforts. Thus, we have a complex but growing environment that attempts to bridge human need with technological innovation. ICTD as a research field now claims eleven journals and several hundred researchers [6]. Journals and conferences highlight early results from research pilots, attracting additional attention from formerly-disparate research communities. This may benefit the research corpus, but does it positively impact target research communities as intended? The emphasis on conducting short-term research pilots, due to funding cycles and time constraints, (including product development and academic deadlines), demands greater responsibility on the part of the researcher to set target community expectations about ICTD projects, especially those with an intervention agenda. The draw of ICTD research is

Report, and states that IRBs can only approve research when a bona fide informed consent process for participants is followed [5].

twofold: research that espouses an ICT *for* Development (ICT4D) philosophy towards the transformational capacity of technology to assist individuals and communities to achieve development goals; and research that espouses the ICT *and* Development approach, advancing long-term technical and theoretical contributions to the field of development

We focus on the researcher's responsibility in ICT4D research in this paper, considering ICT4D a subset of the larger ICTD research field. ICT4D research is often complex: it is motivated by socioeconomic equity, informed by a breadth of interdisciplinary methods and theories, and loaded with interpersonal dynamics between the researcher and the community and within the community itself. This research invokes risk as interventions do not follow a script; thus, formative methods like Participatory Action Research are used to generate unbounded outcomes and "new" knowledge [7, 8]. Given its interventionist nature, results of ICT4D research can, and often aim to, manipulate social structures and affect power relations in a community. These may result in diverse outcomes, including negative ones, such as exacerbating local tensions or adversely affecting community dynamics. Institutional Review Boards (IRB) and Informed Consent protocols in research were designed to mitigate community and individual risk, and are better aligned to the experimental and empirical nature of more established research disciplines. ICT4D research challenges these conventions by adopting participatory and action research methods. The charged context of ICT4D research (with its political, economic and emancipatory goals) discounts scientific objectivity, another hallmark of traditional models. Given the mismatch between IRB and the ICT4D research goals, researchers often have chosen to circumvent the IRB process.

There is much merit to ICT4D research. Outcomes *can* transform social and economic structures to better empower communities, leading to additional research and policy attention. However, without a formal review process of ICT4D research design, opportunities to legitimize ICT4D -- struggling for a definitive academic status -- are lost. More importantly, ICT4D researchers have a responsibility to inform the target community about the very unknowns inherent in ICT4D research, in order for the community to consider the implications of consent. We argue that, while ICT4D research does not easily fit current IRB procedures and informed consent protocols, it is necessary to implement transparent processes to ensure responsibility to the target community and maintain integrity of the intervention.

A. Structural limitations of ICT4D research and ethics

In addition to a broad research base, ICT4D has both an active research and practice community. In our definition, ICT4D researchers are those professionals who explore a set of research questions through a research pilot that determine the nature and strength of commitment to continue the pilot or work with the target community. ICT4D practitioners are not limited to an academic structure or timeline, but are motivated to change community social structures to allow for sustainable development (and often have a longer-term vision of engagement). ICT4D researchers fill gaps in ICTD/Development studies by doing new and novel work;

practitioners employ practical techniques and strategies to address societal needs and gaps. In ICT4D research, research pilots can look like "real" projects, and are often deemed successful when research questions are answered. In ICT4D practice, success hinges on recognized community benefit. Having research and practice efforts occur in the same community or time frame can introduce confusion at the community level. It is difficult to position research versus practice, especially to a target community unfamiliar with academic terminology, and a probable history of past development initiatives and discourses.

Explaining the legitimate aims of research to a community that has no prior concept of academic or industrial research remains a critical factor in supporting and legitimizing ICT4D research. The ICT4D researcher has the responsibility to articulate the *unknowns* of research, as well as the unknown consequences likely to affect the community. Explanations of ICT4D research need to be made explicit in order to gain community trust. Non-governmental organizations (NGOs), with their history of activism and involvement in the local development programs, are often the most trustworthy citizens to broker ICT4D research, but rarely incorporate formal informed consent processes into their interactions with communities. However, by leveraging the transitive rapport established with the NGO, researchers may better engage in discussions about the iterative, formative nature of ICT4D research with the target community. As part of this process, the researcher can thus facilitate discussions about the range of potential positive and negative outcomes, both proximal and liminal, as the core of the informed consent process. The community enters into a consensual relationship with the researcher only in the aftermath of these discussions. Should the researcher not be able to represent the community's hypotheses in the IRB approval process, then s/he cannot move forward. This process demands due diligence of both the researcher and the approval entity, while initiating a model for other participatory and action research-based development outside of ICTD.

B. The need for an ICT4D research protocol

The principles of informed consent include respect for autonomy, beneficence, and justice [9]. Explaining the concept and scope of ICT4D research attempts to level the power relations between researcher and researched, and encourages negotiation of consent between the community and the researcher. We contend that the target community involvement is little more than conscription if we deny their ability to critically examine the costs and benefits of the research pilot. Moreover, existing informed consent protocols put in place by Institutional Review Boards (IRB) are ill-acquainted to address risks and benefits of ICT4D research process and the inherent socio-cultural complexities involved. Standard medical and social science use of informed consent do not preclude emancipatory or equity-based goals of ICT4D research. IRBs struggle with the kinds of research that ICT4D often involves, such as Participatory Action Research or approaches that aim to address social inequities. Additionally, research often takes place in geographies and cultures far removed from those that set standards for IRBs.

The academic researcher has few options, all sub-optimal: write the informed consent protocol in such generic terms as to avoid scrutiny and time-consuming reviews (and subsequently follow or ignore the protocol), or by-pass the informed consent process entirely². What is needed is an informed consent protocol modified to constructively challenge the formative approach in much of ICT4D research. Potential impacts need to be articulated prior to receiving approval to conduct the ICT4D research pilot. Such general impacts include gendered barriers to ICTD access and use [10], the physical placement of technology in the community (to what degree is the location considered safe/private/welcoming), the hidden costs in terms of productivity lost, and the expectation that the very presence of technology will better lives need to be understood by both the community and the researcher.

This places the onus on the researcher and institution to ensure, to the best of their ability, that the involvement of a target community is willingly and knowingly engaging in light of the potential outcomes of ICT4D research pilots. There have been efforts to modify academic informed consent protocols for use in industrial ICTD research, but the efforts have not made the distinction between sub-categories of ICTD research and the myriad complexities involved in conducting participatory and action research. As a starting point, we discuss one such effort attempted at Microsoft Research Labs, India (MSRI) in 2007, offering feedback from the researchers who incorporated informed consent protocols into fieldwork to abide by IRB standards for international research and publication. However, the scope of the 2007 effort was focused on obtaining consent in low-literacy and socially-marginalized populations, rather than focusing on unknown impacts and the community's threshold for such unknowns. This shift in focus from understanding the ICT4D research pilot to understanding the *potential impacts* of the research pilot surfaced in our study of the MRSI effort, and further underscores the opportunity we have, as ICT4D researchers, to improve how we conduct ethical, participatory and action research within diverse cultural environments.

III. ISSUES WITH INFORMED CONSENT IN INTERNATIONAL DEVELOPMENT

“By itself, the doctrine of informed consent does not do full justice to the complexity of the ethical judgments fieldworkers confront [12].”

² There is a precedent for avoiding the IRB process – many engineering departments directly engage in community development pilots (water, sanitation, energy), and Journalism students are traditionally exempt from having to obtain informed consent. The case could be made that engineering-for-development pilots are not research but practice; likewise, journalists have a standard of objectivity and ethics that we hope are applied in ICT4D-type interventions, such as development communications. We argue that many such projects are indeed participatory and action research-oriented, and thus should undergo the same scrutiny and consideration that is missing from current IRB processes. Otherwise, like ICT4D research, such circumvention defeats the purpose of informed consent and ignores the moral imperative to explain research accurately and to distinguish it from practice.

“Informed consent” is defined as “the knowing consent of an individual, or a legally authorized representative, able to exercise free power of choice without undue inducement or any element of force, fraud, deceit, duress, or other form of constraint or coercion” [2]. Sobel further defines both *informed* and *consent*, stating that consent is the act of participating voluntarily; informed requires the subjects understand the scope, duration, risks and goals of the research [11]. Freedman expands upon this definition, stating that the requirement of informed consent is grounded in a “substantial requirement of morality,” where all people have the right to be treated as persons, not research subjects [12].

The social sciences have been regulated by this collection of acts and standards, although tensions between social scientists and IRBs are many, due to the medical and laboratory science basis of IRBs. There are several hundred IRB entities in the United States alone, including all research universities, medical and pharmaceutical research companies and institutions, and national labs such as the National Institutes of Health (NIH)³. The National Science Foundation (NSF) has attempted to assure academic and institutional IRBs that flexibility is required and understood in social science research, noting that IRBs should focus on limiting risk while maximizing informed consent [13]. Some researchers call for more research on IRBs and alternative IRB structure to fit the changing research landscape, into which ICT4D research certainly falls [3, 14].

International development initiatives have tried to incorporate formal informed consent protocols into their work, to limited degrees of success. There is the shared notion that informed consent is a “bedrock moral issue” that should be practiced globally [15]. Informed consent in development is discussed primarily in regards to the rights of indigenous people [16, 17]. Since the 1980's, the World Bank has adopted a number of policies to “safeguard” indigenous populations in large development projects in response to several public campaigns by indigenous people demanding, at the minimum, “free, prior and informed consent,” or FPIC [18,19]. FPIC is not a Bank mandate, but a non-binding guiding principle. In 2000, most World Bank Group member countries either abstained from comment (United States) or opposed requiring FPIC in large development projects (United Kingdom, joint statements from the African, Central American and Latin American blocks) [20]. Likewise, the proposal to include FPIC in the 2001 revision of the World Bank Group's policy on involuntary resettlement was summarily rejected [20]. The OECD and UN systems recognize, and in some cases, require FPIC; however, it is unclear to what degree the FPIC policies are actually implemented.

Outside of the multilateral development agencies, there are few examples of informed consent research in development. Two examples from the medical community in Africa offer case studies of uses of informed consent in public health. These cases illustrate important issues that are not adequately addressed by standard informed consent protocols, offering specific data to consider in creating a development-specific

³ For example, NIH itself has fourteen IRBs with over 200 people [23].

protocol. In one Kenyan study, Western medical terminology, even when translated into local languages, consistently failed to elucidate the aims of the health initiative. Community members were not familiar with the definitions of “research,” “investigation” and “project,” leading to confusion about the actual tasks and goals of the medical initiative [21]. Molyneux et al posit that community members conceptualize such terminology based on individual understanding or development history – “projects” were indicative of aid projects in this setting, thus double meanings can complicate both the study and the informed consent process. Thus, such initiatives must be “exceptionally carefully worded” [21].

Another health study in The Gambia investigated the possibility and desirability of a universal standard of informed consent, given cultural and educational differences across communities. The study investigated the informed consent process in a vaccine trial, and analyzed people’s attitudes towards consent. 137 people consented to giving the vaccine to their children; 51 refused. Those who refused did not trust the vaccine because of rumors of resulting sterilization, or were not able to obtain consent from the male head of the household [22]. While the individual is at the core of informed consent protocols in a Western context, community involvement trumps individualism in many developing, especially rural, areas, where male (or chief/elder) consent is often required and must be considered [22]. Following the vaccine pilot, community members suggested that future initiatives be introduced with ample time to consider new information and to involve husbands/other family members; likewise, the research team should widely educate the community and tackle rumors and anxieties inevitable in foreign-led research projects [22].

Similar issues were uncovered in a 1998 qualitative and quantitative study sponsored by the United States National Bioethics Advisory Commission. Medical, academic, military and industry researchers were surveyed about their views on conducting informed consent in research in developing countries. While 82% of the researchers believed that informed consent was important, 52% stated that the legal language on consent forms was meaningless, compounded by the local lack of research terminology in some languages [24]. Researchers reported that using signed forms was problematic for a variety of reasons, including the technical content, the length of many informed consent forms, and community distrust of signing paperwork they didn’t understand – oral consent, community meetings and question and answer sessions were preferable to community members [24]. This study demonstrated the difficulty in obtaining consent from women, who in turn had to attain permission from their husbands or community leaders. Finally, 87% of the researchers reported that IRBs needed to offer more flexibility in terms of explaining, obtaining and documenting consent, as standard procedures were inadequate to establishing mutual respect and rapport between researcher and community [24]. Building on this study, Weijer posited that “respect for communities” should be included in research ethics, which requires a deeper level of understanding of the culture, and which is not explicitly part of informed consent protocols [25].

Anthropologists have cataloged similar arguments against informed consent in social science research: informed consent is difficult to obtain, impedes subjects acting naturally, is obtrusive, cannot be explained adequately, and closes the door to the researcher [1]. Anthropologists have also stated that “informed consent is not suitable to the nature of anthropological research and is contrary to the flexibility required in fieldwork”. They argue that notions of informed consent nurtured in the developed context of the west misconceive the contexts in which informed consent is sought. There exists not only a fundamental cultural gap between the world of the researcher and his subjects but also in understanding what is informed consent and ways of obtaining them.

While these issues are valid and familiar to ICT4D researchers, we argue there remains a need to *interpret* informed consent as a professional and ethical responsibility, while integrating the process into the larger research design and community context.

IV. INFORMED CONSENT AND ICTD – A PILOT STUDY

A. *Creating a protocol – The MSRI model*

In the summer of 2007, the Technology for Emerging Markets division at Microsoft Research Labs, India (MSRI) instituted a protocol for acquiring informed consent for ICTD research projects conducted with low-income, low-literacy and socially-marginalized populations. The MSRI informed consent protocol was concerned with three goals: setting the expectations of the target community, holding industrial research labs to the standards of academic research, and creating a protocol that was appropriate for a corporate research entity conducting human-centered research with unique populations. Prior to mandating an informed consent procedure, many of the researchers had integrated informed consent language *ad hoc* into their design and implementation. The degree to which the concepts of informed consent were explained varied from project to project, as did the methodologies used to obtain “consent.”

To start, the MSRI leads on this effort (also the authors) initiated internal debates about the value and necessity of informed consent. We conducted a literature review of informed consent while analyzing protocols introduced by research interns and partners from academic institutions. The product of these efforts was a document outlining the research charter and practice of MSRI, and its rationale of compliance with international standards of ethical research. The document was intended to outline the conditions necessary to obtain informed consent, the ethical considerations underlying ICTD research studies, and the standpoint of research participants within the context of socioeconomic, historic and cultural differences.

The final document followed a standard academic model, while allowing for a range of appropriate confirmations – signatures, symbols, audio-video capture, and proxy confirmations. According to the MSRI protocol, “obtaining informed consent consists of disclosing the details of the

research project to research participants, and receiving explicit confirmation that the research participant understands and accepts the conditions of participation.” While the protocol included standard IRB language describing research goals, risks and benefits, privacy, use of data, access to results, compensation information, termination policies and contact information, the tone and word choices were stripped of much of the standard formality. The protocol mandated that datasheets describing the research be given widely to the community. Special review was required for ICTD research that intended to use children and illiterate populations, aware of the legal work age for children in different locales, with instructions for obtaining additional degrees of approval.

The lifespan of the MSRI informed consent protocol was short, and researchers once again returned to the practice of integrating the spirit of informed consent *ad hoc* into their fieldwork. While ongoing efforts to integrate informed consent into research demonstrate its seriousness, the MSRI effort and subsequent interviews revealed key findings -- informed consent is critical in participatory and action research scenarios, distinguishing ICTD and ICT4D research. The inherently “unbounded” nature of ICT4D research required a much different protocol design.

B. Researcher response to the MSRI protocol

Fifteen researchers and research interns who used the MSRI informed consent protocol were contacted for this study. Researcher demographics include researchers from India, United Kingdom, North America, and South America. All responses pertain to research projects conducted at MSRI, although some researchers applied the MSRI protocol to non-Microsoft research as a model. These interviews were semi-structured open interviews based on fieldwork experiences; no distinction between ICTD and ICT4D was made at the time of the interviews.

In the interviews, we focused on how researchers used the MSRI protocol to inform individuals and communities about the nature and purpose of research, and how communities responded to the letter and spirit of the protocol. Many researcher-respondents felt that the scripted language mandated by the protocol needed to be significantly simplified. As one researcher from the United States said,

“Informed consent is of course very important from an ethical standpoint, but in my experience, the ‘informed’ part can often be problematic, since the very notion of research often seems incomprehensible to some disadvantaged respondents. The substance of consent then usually falls to reliance upon social ties—the trusting of whoever has introduced the respondent to the researcher. In such cases, the informed consent document and process might as well be in Chinese, and probably do more to remind the researcher of his or her obligations and ethical responsibilities than to reassure the respondent...I don’t view it as my job to explain the general concept of research to respondents. In any case, it should be clear from the above that I’d view that

as a futile undertaking in many cases, given time restrictions.”

Another researcher, having first used the MSRI protocol in India and then in the Peruvian Amazon and Southeast Kenya, experienced distrust from communities where she had spent considerable and positive rapport-building efforts. In her words,

“I felt like I had to read the Informed Consent Agreement – it’s the right thing. But in every instance, it created a wall that hadn’t been there, and I ended up apologizing to the community, saying that I had to do this for legal/institutional reasons, and that I was sorry I had to sound so official. I downplayed the consent form that I had championed, because the negativity was so strong.”

This embarrassment was experienced by another researcher, who found that assuming different roles could assuage this discomfort, based on the type of research being conducted. When collecting financial data, he stated, “Some of the people noted my address and contact details to check me out. I had to wear my student hat and show vulnerability to induce people to talk to me... I would say that I might fail to pass my grades if there is no data!” He continues, “On the contrary, when I did a survey on entertainment choices and consumption, still wearing my student hat, there was no such anxiety or restraint to share data.” The target community was clearly hesitant to talk about their financial practices and quick to note the potentially unintended and unknown consequences of sharing such information; there was not the same level of resistance when discussing movies. Issues of content and context point to the need for ICT4D-specific informed consent processes.

Similarly, the outsider/insider relationships in ICT4D research require a level of self-reflexivity that should be integrated into research project design and approval⁴. A researcher from the United Kingdom working in a village telecenter project near Bangalore had to mediate four tiers of contact between herself and the community, including different NGOs, introducing a significant handicap to transparency and rapport-building. The researcher also came face to face with the complexities of development history and culture. The community had been over-researched, and was more interested in why a British Asian woman with roots in Karnataka could not speak Kannada and was not married. In addition, while she bore physical resemblance to women in the region, her position as someone living abroad further cemented her as an outsider with money, thus in a position to give financially to the community, but still not be trusted. In addition, her affiliation with Microsoft meant that she could “open doors” to opportunity. It was when she adopted the persona of a student that she made inroads and fostered interest, trust and a desire to participate. While we cannot make generalizations about

⁴ Persona adoption and researcher self-reflexivity, which come up in these accounts, remain a larger discussion. There is a fine line between leveraging one’s role as a student or woman or tourist or expert and engaging in deceptive practices to gain access and trust. We do not explore this issue in this paper, but encourage such discussions among the ICT4D research community.

community responses to both the researcher and how s/he positions it, what we can posit is that ICTD research, especially ICT4D research, is necessarily and universally complex. It makes mandatory a process to better “unpack” research complexities to be able to articulate the otherwise obscured community concerns, research motivations, perceptions and expectations of outcomes between the researcher and the researched.

A majority of the researchers interviewed chose to bypass the informed consent process entirely, and gave the responsibility of explaining the research to a partnering NGO who was “better able to bridge the research and resident community.” Researchers stated that it was easier to delegate consent to the NGO who could make a comprehensible yet simplified “pitch,” rather than a formal statement that “goes completely over the heads (despite the polite nodding) of respondents.” NGOs are a convincing intermediary, as their reputation and familiarity may influence community participation in ICTD research more than other factors. For one researcher, working with an NGO made her ICTD research possible -- “they took me around the community... this established my presence as a benevolent outsider who would do no harm.” However, it should be noted that this researcher was an Indian female who had previous experience working with Indian women’s self-help groups; the same helpful NGO did not prove as helpful to a Caucasian American female researcher, and whose attempts to self-employ the informed consent protocol failed to connect her respondents to research concerns. The researcher’s gender, race, age and experience should not be overlooked in research design.

Abdicating informed consent to an NGO is one strategy, but does not guarantee that the guiding principles of informed consent are upheld. A researcher working with a state-aided school near Bangalore obtained consent from teachers of a class of students participating in a research pilot. He reported,

“We received a signature (on the consent form) from a teacher...When we suggested sending a statement home with students (as per the MSRI protocol), she said it was unnecessary and would confuse or needlessly worry parents. Since our intervention is just a single class period, we decided to let this go... For my previous work in schools here, I must admit that we left the burden on the NGO to establish informed consent. Since we were modifying an aspect of the NGO's intervention in schools where the NGO was already working, we looked at ourselves as collaborating with the NGO (and the existing population they served) rather than as experimenting on the participants.”

Such positioning of the NGO-community-researcher triangle may make research “easier,” but does not apply equally across ICT4D research interventions. In the case above, the researcher did not categorize the research as interventionist or “actionable;” thus, it was unnecessary to hold conversations about unintended outcomes. Nonetheless, the researcher should address issues of securing data and participant identity, and not leave this to the sponsoring NGO or agency. This

ensures mandatory confidentiality even in cases where a community expresses difficulty in comprehending confidentiality or is concerned about the state and other powerful political actors accessing data.

One researcher had little difficulty in obtaining consent using the Agreement as in her study of technical micro-entrepreneurs -- mobile phone repairers, PC assemblers and cyber café owners -- in the urban slums of Mumbai. Many subjects were high school-educated, tech-savvy, and were regarded as community spokespersons. Most were more interested in what Microsoft stood to gain in this research, while concerned that they themselves would not benefit financially. All, minus one cybercafé owner, signed the Informed Consent Agreement. The subject who refused to participate was concerned that he would face punishment for using pirated software. Others, who did consent to participate, needed assurance that they would not face repercussions for having pirated copies of Microsoft Windows. This illustrates a perceived risk that would rarely surface in a standard informed consent process; these are the kinds of potential outcomes and concerns that require a different and more thoughtful informed consent framework.

V. A FRAMEWORK FOR INFORMED CONSENT IN ICTD RESEARCH

A. Discussion of findings

The findings from the MSRI informed consent pilot demonstrate the need to design and test new protocols that differentiate ICT4D research from the larger field of ICTD research. They also demand that new protocols account for perceived and potential impacts and consequences of ICT4D research. The target community needs to have the authority to articulate their concerns and aspirations connected to the research, and negotiate their participation prior to the ICT4D research intervention. The researcher, then, must create opportunities for these conversations with (and within) the community to take place, as in the example of the Mumbai kiosk owner who was given the option to discuss his fear of repercussion for using pirated software. Such a concern would not have surfaced in standard informed consent protocols, where the researcher is the presumed expert who can enumerate research risks and benefits.

We suggest that informed consent in ICT4D research becomes a mediated process, whereby instead of explaining risks and benefits, researchers *ask* about perceived risks and benefits to negotiate the terms of involvement entrusting a fair share of mediatory power with the respondent. The process of explaining research and obtaining informed consent needs to move from being an ill-communicated and dislocated process in the research lifecycle to one that engages discussion across several layers of social and psychosocial understanding. From the pilot study, it is evident that perceived risks and benefits can be closely related – a research subject may hope to gain social status by being affiliated with an institution with international cachet; the risk, then, is to not experience increased status. A research subject may worry about

possessing illegally-obtained software, and needs to be reassured that the researcher is not from the anti-piracy team and that the interviewee's name will be masked in any reports. Certainly this becomes more important in other ICT4D research scenarios, where the aim of the research is to manipulate power relations and social structures "for good." The community as research subject needs to be able to voice their concerns in the research design process -- have past gender equality efforts lead to backlash and increased domestic violence? Has the introduction of a new technology or technology-mediated service in the past pulled people away from their jobs or led to inequities in the community due to access and use issues? Has an NGO in the past turned out to be an agent of the government? What are the community discourses about technology, development, "outsiders?" and how will this affect the pilots?

There are opportunities to forge trust in these encounters between researcher and target community in the process of creating new models of informed consent. Active research and experimentation is required to understand effective practices in trust-building. The case studies and examples in this paper underscore four requirements for negotiation strategies to obtain meaningful informed consent. The first involves a community-led disclosure of perceived risks and benefits. The second is a discussion and disclosure of the scope of the proposed research even at the risk of refusal to participate. This candor will better set community expectations while indentifying participant motivations and concerns. Third, the community must be given time for deliberation and thought, (as research deadlines may likely side step to avert higher opt-out ratio). This can avoid greater proliferation of rumors and distrust resulting from a lack of - community reflection to digest the information. Finally, researchers need to consider the choice of terminology – how have terms been encountered and used before, and what do they signify? Are there analogs in local languages and practices better suited to use? All four of these requirements demand a level of openness that reduces the power gradients between the researcher and the community (and within the community), one of the primary tenets of action research [7, 8].

B. Moving towards a new model

We suggest the following strategies to create and negotiate informed consent in ICT4D research. Prior to developing the research pilot design, researchers should meet with the community (and by community, this includes the various, and often less-empowered, sub-communities within a larger community, as described in *The Myth Of Community* [26]. In these interactions, researchers should explain their ideas, solicit feedback from the community in terms of costs and benefits through the use of such methods as problem trees, and give the community a few to several weeks to deliberate their interest in participating in the pilot. Problem trees are one mechanism used by NGOs to catalyze participatory discussions of potential primary and subsequent impacts. The tree metaphor is nearly universal, and offers discussants a model for analyzing the intervention in a visual root, trunk and

branch representation. Some of the otherwise "unknowns" in ICT4D research pilots are thus brought to the forefront.

Figure 1 offers an example of a Problem Tree created by the community, facilitated by one of the authors, in the Peruvian Amazon. The initial research pilot involved creating a closed wireless phone system to report malaria outbreaks – this was the directive of the funders and Principle Investigator. The communities, during "search conferences" (essentially a meeting of all project stakeholders, or more realistically as many as can be reasonably involved and accommodated) [27, 28, 29, 8] stated their top development priority was in fact not malaria reporting, but a distance learning system that would support both formal and informal learning in order to increase vocational expertise and job placement opportunities. The community, as a group facilitated by one of the authors, identified "root" causes and high-level (branch) opportunities and challenges. Further conversations were held at the "branch" level about potential subsequent secondary and tertiary outcomes and impacts. The resulting "leaf nodes" (not shown due to scale) can then be addressed both as important standalone issues and as part of the larger tree ecosystem.

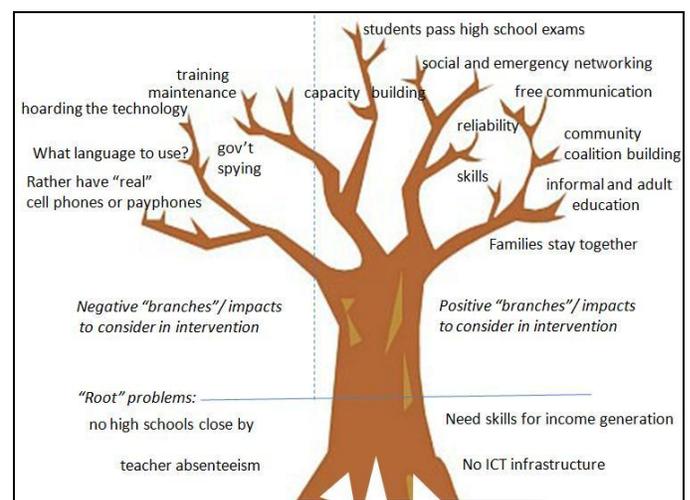


Figure 1: Problem tree as applied to an ICT4D research intervention: a closed Wi-Fi system linking primary and secondary schools in the Amazonian Basin for distance educational needs

The other practical suggestion to ICT4D researchers is to complete a framework of socioeconomic, political and external factors that demonstrate the researcher's knowledge of the target community. These help extrapolate potential impacts (even if they do not come to pass) from historical data and development theories. They suggest with reasonable conviction that the researcher is well equipped to understand nuances of socio-cultural conceptions and behaviors that are specific to the target community. Moreover, such an espousal of familiarity with community sentiments would set to rest the critique of ignorance and untoward effects of project outcomes and impacts on community social structures and customary routines. Researchers should chart the potential positive and negative impacts of their pilot across these factors, including but not limited to history with development efforts, existing

infrastructure, status of health indices, gender roles, experience with technology, community and individual goals concerning livelihoods, education and employment opportunities, and standpoint of the community in regional and country-wide socio-political environments. IRB committees can then challenge the researcher on her articulations of prospective research benefits and consequences, and recommend additional discussions with the target community.

Participatory and Action Research methods and tools enable informed consent to transpire between the researcher and the target community. The search conference example brought conversations about potential research outcomes and concerns to surface that influenced one of the author's IRB proposal. Ideally, the intention is to induce IRB processes to change their approaches to ICT4D research, and any action research being conducted under auspicious of the academy. Failing that, ICT4D researchers can and should voluntarily add findings and risk frameworks to their IRB submissions. Industrial research labs have greater flexibility in mandating review processes, from increasingly using outside IRB firms [14] to tailoring the process to fit a corporate environment. This is not meant to discourage the use of other methods and tools to expose potential impacts on communities due to ICT4D research, which is likely an exhaustive list. The important requirement is consistency and candor in assessing impact in order to set community expectation to the best of the researcher's ability while creating an on-going iterative investigation of both the ICTD research intervention and its less-obvious but crucially-important effects. These outcomes, and their significance, will spawn new research that will better inform ICT4D deployments and evaluation.

VI. CONCLUSION

We close this paper with a call to action for ICT4D researchers to drive forward a process of constructing an informed consent protocol that serves a variety of purposes, the foremost being a responsibility towards the *researched* communities. Past development and ICTD efforts to employ traditional informed consent mechanisms have not been able to adequately support discussions required to design and carry responsible and participatory action research; the unknown impacts of ICT4D research require new thinking and negotiation. Underlying this requirement is a serious obligatory practice to inform and *be* informed about these possible unknowns to obtain meaningful community consent. There is an additional benefit to this new model that extends beyond transparency and fairness: a more thoughtful approach to increasing the levels of scholarship and rigor that interdisciplinary fields such as ICTD need to gain deserved legitimacy in academic and industrial research.

It is our intention to grow a community of interest and involvement that applies and refines these recommendations, to better serve both the target and research communities. As more ICTD researchers enter into the field, and as ICT4D professionals continue to span both research and practice, academic and industrial research should develop an additional component to their research review process, be it a formal IRB

review or conversation between manager and researcher. Consistency in using an agreed-upon informed consent tool will enable the ICTD community to better understand the community concerns, opportunities and consequences of ICT4D research pilots while creating a community of ICT4D researchers to support each other's efforts in framing ICT4D research to target communities.

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