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## Older Adolescents' Understanding of Participant Rights in the BlackBerry Project, a Longitudinal Ambulatory Assessment Study

DR. Diana J. Meter<sup>1</sup>, DR. Samuel E. Ehrenreich<sup>2</sup>, Christopher Carker<sup>3</sup>, Elinor Flynn<sup>4</sup>, Marion K. Underwood<sup>5</sup>

<sup>1</sup>Correspondence may be directed to Diana J. Meter, Emma Eccles Jones College of Education and Human Services, Utah State University, 2905 Old Main Hill, Logan, UT, 84322. Phone (435-797-4141), (diana.meter@usu.edu). <sup>2</sup>Samuel E. Ehrenreich, College of Education, University of Nevada, Reno, 1664 N Virginia St., MS 140, Reno, NV, 89557. Phone (775-682-5506), (sam@unr.edu). <sup>3</sup>Christopher Carker, School of Behavioral and Brain Sciences, The University of Texas at Dallas, 800 W. Campbell Road, GR 41, Richardson, TX, 75080. Phone (NA), FAX (982-883-2491), (carkerc@garlandtx.gov). <sup>4</sup>Elinor Flynn, Stern School of Business, New York University, 44 West 4th St. New York, NY 10012. Phone (214-918-1781) (eflynn@stern.nyu.edu). <sup>5</sup>Marion K. Underwood, College of Health and Human Sciences, Purdue University, Stone Hall Room 110, 700 W. State Street, West Lafayette, IN, 47907. Phone (765-494-8210), or (underwood@purdue.edu).

### Abstract

For a long-term, longitudinal study that used BlackBerry smart phones for passive ambulatory assessment among older adolescents, this study focused on three areas of ethical concern: 1) adolescents' competence to give assent; 2) understanding of confidentiality, the protection of information, and project goals, and 3) awareness of procedures and benefits, and comfort with the research design. Participants were 178 17- and 18-year-olds (84 girls). Results suggested that participants freely gave consent and understood most, but not all of the informed consent information. Participants reported a high level of satisfaction. Participants showed less understanding of when their confidentiality would be broken and how data would be protected.

### Keywords

ethics; research satisfaction; research rights

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The increasing popularity of smartphones among adolescents has provided researchers with a unique opportunity to capture detailed information about individuals' activities, location, and interpersonal communication. Indeed smartphones allow researchers to engage in ambulatory assessment of research participants using technology that is already familiar and readily available, particularly to adolescent populations. Previous research has leveraged the ubiquity of smartphones to conduct ecological momentary assessments (Cohn, Hunter-Reel, Hagman & Mitchell, 2011) and monitor participants' physical location using GPS (Odgers,

2016). However this technology also allows researchers to assess adolescents' complex social interactions *in situ*, through direct observation of text message communication.

This method of ambulatory assessment allows researchers to passively observe the naturalistic conversations of adolescents and their peer network for a period of weeks, months or even years. This technological advancement is a powerful observational tool for understanding adolescents' social development. Following the successful use of BlackBerry smartphones to collect real-time digital communication data from adolescents due to their engagement with the devices (Underwood, Rosen, More, Ehrenreich, & Gentsch, 2012), researchers are increasingly using handheld smartphones to collect data from youth. However, if researchers enter the private realm of digital communication, it is important to understand participants' awareness of informed consent procedures. Previous research has assessed participants' comfort and experiences with participation in peer relations survey research with ethnically diverse U.S. 3<sup>rd</sup> graders (Mayeux, Underwood, & Risser, 2007) and 12–17-year old Western Australians (Shaw, Runions, Johnston, & Cross, 2017), but to our knowledge, others have not investigated adolescents' understanding of their rights as research participants in a study utilizing ambulatory assessment methods. As part of a project in which participants were given BlackBerry devices configured to capture the content of their text messaging, this study focused on three areas of ethical concern that arise when employing ambulatory assessment techniques designed to capture large quantities of data over an extended period of time: 1) participants' competence to give their assent, 2) their understanding of confidentiality, the protection of information, and understanding of project goals, and 3) their awareness of procedures and benefits, and comfort with the project.

## Assent and Consent

Consent describes a person's ability to choose participation autonomously (Miller, Drotar & Kodish, 2004). When consenting to participate in research, individuals should know what participation will entail, enabling them to make an informed decision. The consentor should be competent to decide to participate, understand risks and benefits, and choose to participate voluntarily (Scherer, Annett & Brody, 2007), without the coercive influence of parents, researchers, or incentives. Before children reach the age of 18, their parents or legal guardians provide consent on their behalf, but child participants might still be asked to provide their assent, their own autonomous decision whether or not to participate in research after being provided information about the study and their rights as participants. When individuals consent or assent to participate in research, they expect that researchers will be honest and fair, will take steps to ensure no harm, and protect participants' privacy and autonomy (Fisher, 2004). This is especially true of children and adolescents due to their status as a vulnerable population.

Children and adolescents are considered to be a vulnerable population because there is doubt in their capacity to understand all research procedures and to be able to fully consent to their participation in research (Chu, DePrince, & Weinzierl, 2008). Challenges to understanding could include the language used in the consent documents and the complexity of the purpose, risks, benefits, and level of confidentiality of the study. Parents have the right to

give consent for their child or adolescent, but children and adolescents should also have the right to autonomously speak for themselves and choose to participate or not even if their parents wish for them to, and without undue coercion from their parents or researchers (Miller et al., 2004). In other words, even after gaining parental permission, minors should be given the opportunity to assent, or give affirmative agreement (Tait, Voepel-Lewis, & Malviya, 2003) to their participation under the same standards of knowledge, competence, and voluntariness. Providing detailed and accurate information, ensuring that participants and parents understand the information, and evaluating consenters' and assenters' capacity to make the decision to voluntarily participate have been listed as "critical components" of the informed consent process (Vitiello, 2008).

Although research on youths' ability to consent or assent in social science research is limited, there is an informative body of literature on individuals' ability to consent to medical procedures or research. In assessing individuals' capacity to consent to medical treatment, Applebaum and Grisso (1988) describe the legal standards of competence including communicating choice, understanding the information relevant to making a decision about treatment, appreciating the situation and consequences of the situation, and rational consideration of the information. The different standards of competence can be tested to see whether individuals in different situations or at different ages seem able to competently consent or assent. In our review of the literature, we will refer to social science and medical studies of children and adolescents' understanding of their rights as research participants and recipients of medical treatment.

As observed in mostly White sample of 4<sup>th</sup>, 7<sup>th</sup>, 10<sup>th</sup> graders and college students in the U.S. in social science research, youths' understanding of information provided during informed consent procedures was high, especially among older adolescents (Bruzzese & Fisher, 2003). Children seem to be aware that they can stop participating (mostly White 2<sup>nd</sup>, 4<sup>th</sup>, and 6<sup>th</sup> graders, Hurley & Underwood, 2002; 12–17-year-old mostly White depressed sample, Vitiello, Kratochvil & Silva, 2007), that no one will be mad at them if they decline participation (Hurley & Underwood, 2002; Miller et al., 2004) that participation is voluntary, and that they can ask questions. In a review study of typically developing children and to young adults and individuals with medical and psychological problems ages 4–21-years-old, the authors reported there was less understanding of the purpose of the study, risks and benefits, and alternatives to participation in comparison to other informed consent topics (Miller et al., 2004). In a study of informed consent in clinical research among HIV and cancer patients 8–18-years-old, participants had less understanding of topics such as the duration of participation, their right to withdraw, and voluntary participation than topics such as the study objectives, risks, and benefits (Chappuy, Doz, Blanche, Gentet, & Tréluyer, 2008). Among an ethnically diverse younger U.S. sample of children (ages 7–12 years) in social science research, 98% of youth were aware that they could stop at any time, and were also aware of their right to skip questions and take a break (Chu et al., 2008). In an observational study that involved child deception and peer provocation, most 2<sup>nd</sup>, 4<sup>th</sup>, and 6<sup>th</sup> graders (78%) understood what they would be doing in the project, and knew that they did not have to be in the project (90%) and that they could stop participating (92%, Hurley & Underwood, 2002). Comprehension of some of these informed consent concepts was significantly higher among older youth, but overall understanding tended to be high (over

80% for most concepts, even among 2<sup>nd</sup> graders). Most participants were also aware of who would know what they did in the project (83%), although these percentages tended to be slightly lower than for concepts about stopping participation (92%), not answering questions (95%), or not participating (90%) (Hurley & Underwood, 2002).

It is important that participants do not feel coerced to participate by their parents or researchers. Although parents have been cited as the main influence on children or adolescents' decision to participate, none of the youth in a medical research study involving 7–18-year-olds who were asked to participate in a study about anesthesia or surgery reported that they thought their parents would be upset if they did not participate and few believed the researcher would be upset either (Tait et al., 2003). However, an important factor we have learned from the medical field is that if parents and adolescents (11–17-years old) diagnosed with asthma disagree about participation in treatment, parents' opinions may take precedence. In the case that an adolescent wants to participate but their parent does not want them to, a relationship with the physician who suggests the treatment may reduce parent concerns and allow adolescents to have autonomy in the decision-making process about their treatment (Brody, Annett, Scherer, Turner, & Dalen, 2009). Whether parent opinions or a relationship with the individual suggesting treatment are deemed coercive is a question worth considering. However, evidence from the Tait et al. (2003) study suggests that although youth look to their parents for guidance about whether to participate, they do not report undue influence from their parents, reflected in their reports that their parents would not be upset with them. In a social science study previously mentioned, over 90% of 2<sup>nd</sup>, 4<sup>th</sup>, and 6<sup>th</sup> graders understood that nothing bad would happen to them if they decided to stop participation. Over 90% of 2<sup>nd</sup> and 4<sup>th</sup> graders, and over 80% of 6<sup>th</sup> graders understood that the experimenter would not have been mad, upset, or disappointed if the participant wanted to stop (Hurley & Underwood, 2002). This evidence shows that most youth are aware that there will be no unwanted consequences if they stop participating, suggesting again that when children have agreed to participate, there is not undue influence of them wanting to please researchers or others.

## Confidentiality and protection of information

Prior to adolescence, some children have difficulty defining the term confidential. In one social science study, 69% of 6<sup>th</sup> graders correctly defined the term (compared to 41% for 4<sup>th</sup> graders and 9% for 2<sup>nd</sup> graders). Despite this finding, the majority of youth understood that no one would find out about what they did including their family or school, even if the family or school requested that information (Hurley & Underwood, 2002). When asking adolescents to use a BlackBerry smart phone for research purposes in which all of their communication will be captured, it is vitally important to investigate exactly what they believe about how their text messaging communication will be kept confidential.

## Procedures and benefits

Institutional review boards require participants to be informed of the risks to participation in a research study, but also the benefits. One of those benefits is the enjoyment of serving as a study participant, in that participants might enjoy sharing information about themselves,

their families, and their peers, or they might feel good about contributing to science and potentially other adolescents' wellbeing (Singer & Bossarte, 2006). In many studies, benefits to participants may include the opportunity to access treatments, services, or compensation for time. In the case of ambulatory assessment, access to the equipment being used for data collection (e.g. a FitBit, smartphone, or tablet) may be viewed as a benefit for adolescents who may be particularly enthusiastic about technology. When compensation or incentives are given to participants, it raises the ethical question of whether participants voluntarily participate, or whether their willingness to participate is influenced by monetary compensation or other benefits (Grant & Sugarman, 2004). The use of incentives in research with child or adolescent participants is controversial, but is used to "maximize participation and minimize attrition" (Rice & Broome, 2004, p. 167). Incentives may be especially important when participants need to be retained for many years. Under these circumstances, incentives may be justifiable because finding and retaining these participants is mandatory for study success (Rice & Broome, 2004).

## Current study

The BlackBerry Project, a multi-year, longitudinal study of adolescents' sent and received text messages (Underwood et al., 2012), the earliest study of naturalistic, digital communication among youth and their communication partners using mobile technology, provided a unique observational look into the everyday conversations between adolescents in one of their most commonly used forms of communication—text messaging (Lenhart & Page, 2015). The BlackBerry Project data are valuable in that they go beyond typically-used self-report surveys to study adolescent development and peer influence (Mishna, Underwood & Milne, 2013). This form of ambulatory assessment allowed researchers to capture actual interactions between youth and their peers, passively and in the context in which these interactions naturally occur. However, ethical challenges arise when investigators use technology to passively observe participants for an extended period of time (Mishna et al., 2013). Although previous evidence suggests that children and adolescents have a general understanding of their rights as research participants (Bruzzese & Fisher, 2003; Hurley & Underwood, 2002), these studies have usually focused on paper-and-pencil data collection techniques (e.g. Bruzzese & Fisher, 2003; Chu et al., 2008) or observational methods that are highly salient to a participant (such as physically coming into a laboratory and engaging in a research procedure for a one-hour period; Hurley & Underwood, 2002). In contrast, ambulatory assessment techniques—such as the observational methods of the BlackBerry Project—operate "in the background," when the participant may not be as cognizant that the procedure remains ongoing.

Although the BlackBerry Project procedures were reviewed and approved annually by the National Institutes of Health and the university Institutional Review Board (IRB), because of the novelty and sensitivity of Smartphones used in passive ambulatory assessment, we examined participants' understanding of the study, the procedures to which they consented, and their evaluation of the project. To answer our research questions, we coded participants' verbal responses to interview questions regarding their understanding of the assent and consent process. In addition to descriptive analysis of the frequency of responses to the interview questions, we present illustrative quotations from the interviews and from the

ambulatory assessment text message data. As the investigation of older adolescents' understanding of informed consent/assent procedures and contemporary ambulatory assessment data are both rare in the study of adolescent development, we chose to present illustrative descriptive statistics and examples to orient readers toward this important area of inquiry. We hypothesized that, by the end of the BlackBerry Project, older adolescents would understand the meaning of confidentiality and their right to withdraw, but be less clear about the limits of confidentiality. We hypothesized that adolescents would report a high level of satisfaction with participation, primarily because they were provided with a smartphone and free unlimited texting plan, and youth in this age range are highly engaged with text messaging (Lenhart & Page, 2015). This study extends previous research by assessing older adolescents' understanding of their research rights after a long-term longitudinal study with a unique research design, and is the first to examine these concepts in a study that recorded digital communication.

## METHOD

### Participants

Participants provided ambulatory assessment data during the last five years of the 10 year longitudinal project. Two hundred fourteen adolescents participated in at least one of the five waves of ambulatory text message data collection. The sample presented here represent the participants who completed visits during the final year of data collection ( $n = 178$ , 84 girls, 17–18 years old). The Ambulatory Assessment took place during years 6–10 of the project (approximately 2008 to 2013); 77% of participants included in the current study actively participated in all five waves of ambulatory assessment, 20% in four waves, and 3% in three waves. Parents reported the following income: 14% < \$25,000, 23% between \$26,000 and \$50,000, 14% between \$51,000 and \$75,000, 18% between \$76,000 and \$100,000, and 30% more than \$101,000. The participants were 51% White, 24% Black or African American, 18% Hispanic, and 7% other races/ethnicities; data were collected in the United States. More details about the BlackBerry Project are available in Underwood et al., 2012.

### Procedure

Participants received a new BlackBerry smartphone with text and data each year in grades 9, 10, 11, and 12. Each parent and child received \$50 for their participation in the annual survey component of the study. This study evaluated responses to the Research Rights and Satisfaction interview, which took place during the final in-person visit of the BlackBerry project.

At every yearly visit as part of the BlackBerry data collection, research assistants (RAs) explained participant rights to children and parents. Parents and participants were given an orienting description of the study procedure while together, then proceeded to separate rooms of the laboratory for a more detailed review of the consent documents. When describing the study, the RA highlighted the following points: 1) Everything said in surveys and texts is completely confidential with two exceptions: a) discussion of child abuse or b) seriously harming yourself or another. 2) You can stop at any point. 3) You can skip questions that you do not feel comfortable answering or that are not relevant to you. The

assent/consent documents included who investigators would contact in the event that a participant reported abuse (Child Protective Services) or intent to harm oneself (authorities if the threat of harm was imminent, and a family referral to appropriate psychological/psychiatric services). Participants and parents provided assent/consent every year. After the RA's verbally described the study, parents and participants were given time to read and sign the consent document. RA's remained present in each room to answer questions as the parent and adolescent reviewed the documents. When visits were conducted at the participants' home, they were separated to the extent that the layout of the home allowed. Although minor changes were made to the consent forms over the years, the general meaning of the information did not change.

## Measures

The Research Rights and Satisfaction interview, created by the last author, included 13 interview questions used by a trained RA. Answers were recorded and coded by two RAs.

*Could you have stopped participating in this project if you had wanted to?* Responses were coded as "Yes," "No," and "I don't know" ( $\kappa = 1.00$ ).

*Would anything bad have happened to you if you wanted to stop participating?* Responses were coded as "Yes," "No," and "I don't know" ( $\kappa = 1.00$ ).

*Would your parents have been disappointed or upset with you?* Responses were coded as "Yes," "No," and "I don't know" ( $\kappa = .84$ ).

*Would the BlackBerry Project people have been disappointed or upset with you?* Responses were coded as "Yes," "No," and "I don't know" ( $\kappa = .90$ ).

*In your own words, what does "confidential" mean?* Responses to this item were coded "Accurate," "Incorrect," and "I don't know" if the participant stated they did not know ( $\kappa = .67$ ).

*Who will have access to the information you have provided us in this study?* The correct response to this question was coded "BlackBerry project people." Incorrect responses included "Parents," "Anybody," and "No one." Some participants stated they did not know. Two participants stated the name of the university, but not the BlackBerry project people specifically. These responses were coded as "BlackBerry project" people because the participants' primary exposure to the university was through the project ( $\kappa = .83$ ).

*Throughout this study, we promised all participants that all information would be kept private, everyone's answers to questionnaires and everyone's text messaging. Would there have been any circumstances where we would have told anyone's parents or other adults about questionnaire responses or text messages?* The investigators obtained a Certificate of Confidentiality from the Department of Health and Human Services precluding them from being forced to disclose information that could be used in legal proceedings. Fully accurate responses were coded "Accurate" when participants correctly identified the caveats to confidentiality: When they mentioned abuse and harm to self or others. If they noted one of the caveats, this was coded as a partially correct response. Responses could also be coded

“No one,” if the participant said the BlackBerry researchers would never tell anyone; other inaccurate responses were coded “Incorrect.” Other participants responded “I don’t know” ( $\kappa = .81$ ).

*How will your privacy be protected?* Correct answers included ID numbers being used instead of names and data stored in a locked cabinet. Responses were also coded “Incorrect” or “I don’t know” ( $\kappa = .88$ ).

*Did anything about this project ever upset or worry you? Please tell us what it was, and why.* Response options were “Yes,” “No,” and “I don’t know” ( $\kappa = 1.00$ ).

*Did the fact that your text messages were being recorded ever change anything you said or did not say in your text messaging?* Participants coded answers included “Yes,” “Only at first, then I forgot [about being monitored],” “Maybe,” and “No” ( $\kappa = .90$ ).

On a scale of 1 – 10, how much did you enjoy participating in the BlackBerry Project (1 = not at all, 10 = very much)?

*What was your favorite thing about the BlackBerry Project?* Responses included “Getting a free phone,” “Getting to come to the university,” “I don’t know,” “No response,” and “Other” ( $\kappa = .94$ ).

*If we were going to start another research project like this, what would you want us to change, to make it a really great experience?* The participants’ responses were coded as follows: “iPhones or better devices,” “Fewer questionnaires,” “Nothing,” “I don’t know,” and “Other” ( $\kappa = .90$ ).

## RESULTS

To examine possible dosage effects of exposure to the consent/assent process during the years of ambulatory assessment, we used multiple regression and chi square analyses to test for possible differences between these groups in their responses to the interview questions and found no significant differences for any of the questions, however the chi square analysis results may have been incorrect due to low frequencies in some cells. The coded responses to the Research Rights and Satisfaction Survey are presented in Table 1.

### Assent

The results generally suggest that participants knowingly and independently consented to participate. The majority of participants understood that they could withdraw without negative consequences. Furthermore, 83% felt free to do so without their parents’ disapproval, and most participants felt that the researchers would not be disappointed if they withdrew (69%). There was no difference in thinking that parents would approve, disapprove, or did not know between participants from different income groups,  $\chi^2(8) = 11.29, ns$ .



### Confidentiality and protection of information

Participants generally provided accurate definitions of “confidential” (90%). Almost 80% of participants understood that only the researchers could access their data, however some participants believed no one could, their parents could, or “anybody” could.

Few participants correctly identified both circumstances when confidentiality would be broken; 34% identified at least one exception or were aware of exceptions. Sixty percent of adolescents provided incorrect responses, the most common being that there were no circumstances when confidentiality would be broken (57%). The participants also had poor understanding of how their data would be protected. Incorrect responses to this question were given by 64% of participants, 14% gave a correct response, and 22% said they did not know.

### Perception of procedures and benefits

Ninety-six percent of participants reported not feeling upset or worried about the project, and 90% of respondents said that they did not adjust their behavior due to being monitored. Of the 12 adolescents who reported that they adjusted their behavior, three claimed they only did so at the beginning. Four participants said they “maybe” changed what they texted because they were recorded.

Almost all participants reported enjoying the BlackBerry Project, ( $M = 9.34$ ,  $SD = 1.00$ , range = 6–10). Sixty-four percent rated their enjoyment a “10.” The BlackBerry device was the participants’ favorite thing about the study (83%). In a post hoc  $\chi^2$  analysis, we tested whether participants who were lower in income may have appreciated the free device and data plan more than higher income participants. There was no significant difference in terms of income between participants who said their favorite thing about the project was the device and participants who gave a different response,  $\chi^2(4) = 4.11$ , *ns*, although the cell frequency for some cells was so low the chi square approximation may not be correct. When asked what they would change about the project, the participants reported that they would not change anything (59%), they would have preferred fewer surveys (17%), or they favored different devices (9%). Fifteen percent reported something else, or that they did not know what they would change.

Next we present results of how many participants understood multiple components of the informed consent procedure. Only four individuals out of 178 who answered all four questions in the Understanding Confidentiality and Project Goals section (Table 1) answered all four questions correctly. One hundred seven of 178 participants (60%) understood that neither their parents nor the BlackBerry Project staff would be upset if they dropped out of the project; only four participants thought that both their parents *and* the Blackberry Project people would be upset if they dropped out of the study.

## DISCUSSION

The results suggest that in most respects participants competently and autonomously participated in the BlackBerry Project. However, adolescents were unsure of the circumstances when confidentiality would be broken.

## Assent

Most participants understood that no one would be upset with them and nothing bad would happen to them if they withdrew. This may indicate that the consenting process was successful in highlighting participants' ability to choose to participate independent of their parent. Participants' awareness of their right to decline to participate was highlighted in a text message exchange between two participants (17–18 years old):

(11:28:23am) Participant A says to Participant B:

Did you let the <BlackBerry Project> link up with your Facebook?

(11:28:32am) Participant B says to Participant A:

Yes

(11:41:10am) Participant A says to Participant B:

Ehh I didn't

(11:41:30am) Participant B says to Participant A:

Haha that is like the whole point for theprojec

(11:41:34am) Participant A says to Participant B:

They already have my phone..I don't want them on my fb too

(11:41:41am) Participant B says to Participant A:

Haha ok

In this case, the participant opted to continue allowing the BlackBerry Project to monitor her text messaging, but did not consent to her Facebook communication being monitored (a separate portion of this study). This exchange supports the empirical results, highlighting the participant's awareness of her ability to withdraw assent or to only participate in parts of the project with which she was comfortable.

Features of the study that may have promoted adolescents' autonomy included emphasizing their right to decline participation, conducting parent and child surveys in separate rooms to emphasize their independent roles in the study, and the longitudinal nature of the study, which resulted in repeated exposures to the consent process. It is also possible that participants' confidence in their autonomy to choose for themselves is evidence of a natural developmental process that led to participants feeling comfortable asserting their decision.

Sixty percent of participants understood that neither their parents nor the BlackBerry Project staff would be upset if they dropped out of the project; only four participants thought that both their parents *and* the blackberry project people would be upset if they dropped out of the study. Some participants reported they did not know if their parents or the blackberry project people would be upset with them if they dropped out. The small number of people who believed that both their parents and the BlackBerry Project staff would be upset with them if they dropped out suggests that in addition to there being few participants who believed either party would be upset with them, there does not seem to be a clear pattern of fear of disapproval from authority or adults if they were to drop out. Despite this finding,

some participants did report that parents or researchers would be upset with them if they withdrew or that something bad would happen to them. For these youth, actual or perceived pressure from adults may have impacted the voluntariness of their participation. By testing whether family income was related to thinking parents would be upset if the adolescent dropped out, we were able to rule out income as a factor. We thought lower income parents may have wanted their child to have the free cell plan and compensation from the study, but found no difference in adolescents' reports about their parents being upset between different income groups.

In future studies, in addition to explaining rights, researchers may want to check in with participants during the study. When employing ambulatory assessment designs such as this, participants' initial consent can lead to an ongoing data collection procedure, making it all the more important that adolescents' truly are voluntarily assenting. Researchers should also communicate the importance of children choosing to participate autonomously to parents so that parents do not unduly pressure their child.

### **Confidentiality and protection of information**

The percent of participants who provided a correct definition of confidentiality was similar to that found in previous studies (Bruzzese & Fisher, 2003; Chu et al., 2008). Despite this, participants were not very familiar with how their data would be protected and the special circumstances that would require the researchers to break confidentiality.

Circumstances when confidentiality might be broken were shared both in writing and verbally, but few participants had complete awareness of these conditions; the majority incorrectly answered that there were no circumstances when confidentiality would be broken or only knew one circumstance. This was unexpected because this was one of the points that the research team made specific efforts to highlight. One strategy to ensure participants are aware of circumstance when confidentiality would need to be breached is to have participants relay this information back to the research assistant during the consent process.

Four out of 178 participants answered all four questions in the Understanding Confidentiality and Project Goals section correctly. This is likely due to the fact that there was not a very clear understanding of how data would be protected and the special circumstances that would lead to sharing data. One hundred thirty-one out of 178 participants (74%) understood the meaning of the term confidential and understood who would have access to the information provided by the ambulatory assessment and other means of data collection in the study. Therefore it seems as if the misunderstanding comes from specific details about data collection and privacy, not lack of understanding that in almost all cases the data is going to be private and protected. It seems as if perhaps participants are overly trustworthy of researchers, believing that under no circumstances will their data be shared. In regard to not understanding how their data would be protected, we reflect on adolescents' use of many digital platforms that collect and share data, but are not explicit about how data are stored and protected; individuals may have to purposefully have to seek out this information. In a digital culture where this is the norm, the exact way data are protected may not be of high importance to participants, so they may not attend to this information during the informed consent process.

## Procedures and Benefits

In the BlackBerry Project, 90% of the participants reflected that they did not change their texting behavior due to their text messages being recorded. Other evidence supporting participants' reports of texting "as usual" comes from the content analysis of participants' texts; text messages frequently contained highly graphic discussions and the percentage of sexual and profane texts were similar to that found among youth in chat rooms (Underwood, Ehrenreich, More, Solis, & Brinkley, 2015)).

Few participants reported ever worrying or feeling upset about the project. Of those who did, concerns included worries about cell phone talk minutes, phones breaking, or the surveys being too long or "funny." Only a few of the participants listed concerns regarding confidentiality. One participant said, "At the beginning I was weirded out by the text messaging archiving, but I am not worried by it anymore." Balancing the need for participants to be aware that they are being observed, without this observation leading to changes in their typical behavior is one of the essential challenges of any observational methodology. Our participants' comfort with the project, and reports that observation did not change their behavior is important for both ethical and scientific reasons. This sentiment was evident in numerous text message exchanges that were recorded. Participants would periodically discuss the BlackBerry project team with their peers, such as in this example exchanged between a participant (approximately 16 years old) and her boyfriend.

(12:52:43am) Participant says to Boyfriend:

I wonder what the blackberry people think of our relationship

(12:52:50am) Boyfriend says to Participant:

Hahahaha oh god

(12:53:18am) Participant says to Boyfriend:

Haha that's a funny thought. I don't think about them much haha. But they see all 0.0

haha I don't care lol

This example followed a lengthy romantic exchange. The exchange indicates that while the participants were aware their communication was being recorded, it did not interfere with their behavior. Knowledge of being observed is a requisite for ethical research, but the participants' assessment of the effect of observation on their behavior suggests that awareness of the observational component did not significantly confound the findings.

Ambulatory assessment designs may be uniquely well-suited to maintaining this balance between ethical research and naturalistic data in two ways. First, ambulatory assessment by definition provides some distance between the researcher and participant. Passive ambulatory assessment techniques, such as capturing digital communication, allow participants to go about their lives without necessarily being conscious in the moment that they are being observed. Assuming they were properly consented in the first place, this achieves the ultimate goal of naturalistic observation. A participant supported this conclusion in the exit interview by stating, "The project did a really good job [of] staying

out of my life. Even though I knew they were watching me, they did a good job of staying invisible.”

Ambulatory assessment techniques often allow researchers to observe participants in a context in which adolescents are extremely comfortable sharing about themselves. Adolescents are currently living their lives online, frequently sharing pictures, updates about their current activities and whereabouts, and their innermost thoughts (Lenhart & Page, 2015; Subrahmanyam & Smahel, 2010). Indeed, adolescents often interact with technology with the expectation that their information is being monitored, if not by peers, than by the digital platforms themselves (boyd, 2014). With this in mind, technological means of data collection may not just be convenient for researchers, but may be the preferred venue through which adolescents want to participate in research. Empirical assessment of this assumption would be of value to adolescence researchers.

Although our study focused on ambulatory assessment techniques assessing digital communication, the questions in our interview addressed general concerns that would likely affect adolescents participating in a wide range of ambulatory assessment research techniques. For instance, who has access to the data? What does it mean for the data shared with researchers to be confidential? Under what circumstances will researchers need to share these private data? This can apply to any type of ambulatory data, as well as any data the adolescent reports or is reported on the adolescent more broadly. What is different in ambulatory assessment, however, is the continuous, ongoing passive data collection that may concern some participants. We believe these findings apply to multiple methods of data collection with adolescents, from traditional survey research to experience sampling and diary studies, to continuously collected ambulatory assessment methods.

The BlackBerry Project was the first study to capture text message communication between adolescents and their communication partners over the course of years. However other studies have employed direct observation of a range of other digital communication platforms, including Internet chatrooms (Subrahmanyam, Greenfield & Tynes, 2004), and various social media platforms (Moreno et al., 2012). Often these observational studies have relied on large corpuses of publically posted digital communication, without connecting this communication to the individuals’ offline experiences (Bellmore, Calvin, Xu & Zhu, 2015). However researchers are increasingly using digital communication to better understand adolescent and young adults’ social relationships, behaviors, and adjustment (D’Angelo, Kerr & Moreno, 2014; Nambisan, Luo, Kapoor, Patrick & Cisler, 2015). As technology develops, we expect ambulatory assessment methods to become increasingly common in the field of adolescent development. With that increase, we anticipate the conversation regarding ethical conduct of research using these methods to become richer and more nuanced. We do not believe the information we learned about participants’ understanding and comfort with these ambulatory assessment methods for capturing text data are different from other studies that collect geographic (Schauppenlehner, Muhar, Taczanowska, & Eder, 2011), behavioral/activity (Majeno, Tsai, Huynh, McCreath & Fuligni, 2018), and communication data (Mehl & Pennebaker, 2003). Researchers and participants engaging in research with any of these methods should have the same concerns about confidentiality, protection of data, and necessary breaches in confidentiality since a great deal of personal information is collected

continuously. This is because rather than have participants report data at particular time points, technology continuously records the data of interest.

Interestingly, historical changes have occurred in the several years between when the current study's ambulatory assessment data were collected and now. If anything, youth are *more* connected now than they were at the time the BlackBerry Project data were collected, having multiple social media accounts (Smith & Anderson, 2018) and apps that themselves constantly track and collect user data. For youth active in digital spaces, this data sharing is a normal part of their lives (e.g. "Data Policy," 2018). According to one study, forty percent of youth did not keep their Facebook profiles private; only 24% kept their Twitter accounts private with 12% of youth not even knowing whether their accounts were private. Only 40% of teens were concerned businesses and advertisers might access the information they share on social media, 9% of teens reported being very concerned about third-parties accessing their social media data, and 60% report being not too concerned, or not at all concerned (Madden et al., 2013). Our assumption is that in our connected and digital world, for many youth, data sharing is not a big concern, especially under circumstances when they are confident their data will be kept private; this is an important question for researchers and those who collect data from minors' in industry. However, given the potential risk to individuals participating in research who provide information that could put them at risk in the event of needing to breach confidentiality, it is imperative that researchers do their best to ensure participants' understanding and agreement with study procedures. We suggest that researchers continue to use best practices as recommended by institution review boards and perhaps go beyond these typical procedures to ensure the best adolescent and adult understanding of participant rights in regard to participating in a study that uses ambulatory assessment techniques.

One approach may be to provide checklists used by participants privately or in consultation with a researcher of how the data will be used and protected, and any risk that comes from participating so that participants must read and reflect on each point individually. These points can include basic informed consent concepts, but also possible specific implications of data sharing, such as the possibility of uncovering illegal behavior and having to intervene, such as in the case of a sexual relationship between an adult and a minor, or, in studies that do not have a Certificate of Confidentiality, more typical illegal behavior. Concerned researchers may also consider a friendly "quiz" to document participants' understanding of the informed consent information. This would also indicate when additional participant education is necessary.

At least in the research context, minor participants' parents are able to give informed consent and they themselves are able to give informed assent after being provided with information about what the research entails, how their data will be used, and how their data will be protected, with the opportunity to ask questions and discuss the study and implications with their adolescent. It is also likely that for youth developing in a digital context in which data sharing is the norm, unobtrusive data capture is likely a typical part of their online social networking experience.

One important consideration in research that uses technology for ambulatory assessment is the role of the device itself as a possible incentive. It is important to note that the BlackBerry devices were not given to the participants in order to entice them to participate. The BlackBerry devices were the method of data collection for a novel, observational portion of the study and therefore possession and use of the device was a requirement of the procedure. Nonetheless, the recording of adolescents' text messages, while unobtrusive, does involve the collection of a great deal of information over a long period of time. To study developmental processes over time, continued and consistent participation was necessary. Experts have expressed concern as to whether compensation, or in this case a benefit, is coercive to participants, especially those from lower income families (Fisher et al., 2002). BlackBerry devices were an age-appropriate benefit to adolescents, who report communicating with friends via texting regularly (Lenhart & Page, 2015). The BlackBerries could seem overly enticing, given that participants rated them as their favorite part of participation. However, we found no evidence that the benefit of having the free phone was not enticing only to youth with fewer resources.

This study provided unique information about older adolescents' understanding of the informed consent procedure and their rights and benefits as participants. As ambulatory assessment techniques become an increasingly common method of data collection (Odgers, 2016), a comprehensive evaluation of ethical concerns is necessary. Despite the strength of this study in contributing to understanding adolescents' awareness of their rights in a study using ambulatory assessment, longitudinal data from each time point of the BlackBerry project would have allowed us to analyze developmental changes in comprehension of the informed consent procedure. It is possible that ongoing informed consent procedures with children and parents at each data collection occasion contributed to greater knowledge of informed consent concepts, but without longitudinal data, we are unable to explore whether there was an actual increase in understanding over time. Further, we cannot know from this study whether younger adolescent participants understood the informed assent procedure the first time they assented since these data were collected at the end of the project. Not all participants completed the study. Some participants dropped out over the years, and without their interview responses, the reason for their attrition is unknown. If their reason for dropping out concerned confidentiality or worries about the study, these participants' concerns could inform future research. Interviewing participants at every wave could provide clues as to whether understanding of and comfort with the study procedures was related to attrition. Last, an important direction for future research is to understand how adolescents' understand their rights as research participants at younger ages. Although older adolescents are heavily engaged in digital communication, these activities begin during earlier teenage years (Lenhart & Page, 2015), and as ambulatory assessment techniques become more common, it is likely they will be used with younger adolescent participants.

## Conclusions

No studies, to our knowledge, have found complete comprehension of informed consent across concepts for participants of any age. For this reason, it is imperative that researchers continually remind participants of their rights as participants and give participants opportunities to assert their rights if they would like to stop participation. A review of

clinical research on how to improve the consent process for research participants so that they more thoroughly understand information shared during the consent procedure concluded that spending more time explaining the study to participants one-on-one may be one effective way to improve participants' understanding (Flory & Emanuel, 2004). This was echoed by parents in another clinical study who were asked how to improve the decision-making process around treatment for their children with Leukemia (Eder, Yamokowski, Whittmann, & Kodish, 2007).

Adolescent participants seem to be capable of understanding most of their research rights and reported a high level of satisfaction as participants in a long-term, longitudinal study involving the use of technology to gather a great deal of personal information. These findings provide insight into some aspects of participants' rights that should be emphasized in future studies using observational techniques in digital spaces. As youth continue to live much of their lives online (Lenhart & Page, 2015), we hope these results will inspire future investigators to consider using ambulatory assessment to observe communication via digital communication to understand more about how adolescents' interactions in the digital world affect their relationships and adjustment.

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**Table 1.**

Participants' Responses to Research Rights and Satisfaction Exit Survey

<u>Consent</u>	N	Correct	Partially Correct	Incorrect	"I don't know"
Could you have stopped participating in this project if you had wanted to?	177	94%	-	3%	2%
Would anything bad have happened to you if you wanted to stop participating?	177	97%	-	3%	1%
Would your parents have been disappointed or upset with you?	178	83%	-	13%	3%
Would the BlackBerry Project people have been disappointed or upset with you?	177	69%	-	12%	19%
<b><u>Understanding Confidentiality and Project Goals</u></b>					
In your own words, what does "confidential" mean?	178	90%	-	7%	3%
Who will have access to the information you have provided us in this study?	178	79%	-	12%	8%
Would there have been any circumstances where we would have told anyone's parents or other adults about questionnaire responses or text messages?	175	3%	34%	60%	3%
How will your privacy be protected?	175	14%	-	64%	22%
<b><u>Procedures, Benefits and Incentives</u></b>		Yes	No	Maybe	Other
Did anything about this project ever upset or worry you?	177	4%	96%	-	-
Did the fact that you text messages were being recorded ever change anything you said or did not say in your text messaging?	158	8%	90%	3%	-
What was your favorite thing about the BlackBerry Project?	178	83%	17%		
		Nothing	Fewer Surveys	iPhones	Other/ I don't know
If we were going to start another research project like this, what would you want us to change, to make it a really great experience?	176	59%	17%	9%	15%

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