

**Title: Separated after a Disaster: Trust and Privacy Issues in Sharing
Children's Personal Information**

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Background: After disasters, unaccompanied children may present to an emergency department (ED) requiring reunification. An effective reunification system depends on willingness of guardians to utilize it.

Objective: Assess guardian willingness to share children's personal information for reunification after a disaster, perceived concerns and beliefs, and trust in reunification agencies.

Design/Methods: Guardians of children presenting to two pediatric EDs were approached to participate in a survey-based study. Willingness to share their children's personal information was scored on a scale of 1-19 (1 point per item). Perceived concerns and importance about sharing information, level of trust in reunification agencies, and guardian's demographics were collected. Chi-square was used to compare trust and attitudes/beliefs. Multivariate linear regression was conducted to determine factors associated with willingness to share information.

Results: 363 surveys were completed (response rate 80%). Most guardians (95.6%) were willing to share at least some information (mean 16 items; range: 1–19). Half were concerned about protection (55.4%) or abuse (52.3%) of their child's information. Hospitals were trusted more than other reunification agencies ($p < .001$). Perception of reunification importance was associated with willingness to share ($p < .001$).

Conclusion(s): Guardians are willing to share their children's information to facilitate reunification after disasters, but have privacy concerns.

Introduction

Over the past few decades, millions of people worldwide have been affected by natural, manmade, and technological disasters as well as complex humanitarian emergencies.¹ Disasters can disproportionately affect children with consequences of being separated from their families and caregivers during the event. In addition, unaccompanied children may face secondary injuries, such as abduction, neglect, physical and sexual abuse, and long term psychological distress.¹⁻³ In order to minimize the potential for harm and protect displaced children in disaster situations, identification and reunification of these children with their families should be considered a top priority.^{1,2}

During past disasters, reunification has been found to be very challenging, especially when the event involved a large number of displaced children.² After Hurricane Katrina in 2009, 5,068 children were separated from their families, many of whom were transported to different shelters across the country from their parents without an adequate way to track their location. With the assistance of a nongovernmental organization, the National Center for Missing and Exploited Children (NCMEC), the final child was reunited with their families six months later.^{2,3} Reunification is a complex process that requires organization and coordination, communication, and sharing of information between public and private local, regional and national agencies.^{1,2,4} Various reunification approaches have been attempted to collect information and track displaced individuals during disasters, including national programs such as the Red Cross's program Safe and Well and the NCMEC's reunification program. However, as of 2018, a standardized community reunification system does not exist in the United States.

Having a standardized community reunification system would help shorten the time to reunification. Such a system would need a centralized database able to combine information on unidentified children with information provided by guardians seeking lost children. However, use of a centralized database would require support from parents and legal guardians, as only they are legally able to share their child's personal information. A general increase in concern for protecting private health and personal information has arisen in recent years, as cyber attacks have become more frequent and publicly reported.⁷⁻⁹ Past studies have found that parents/guardians are reluctant to share their child's information, depending on the content as well as the entity with which the information would be shared.⁵

The primary purpose of this study is to determine legal guardians' willingness to share their children's personal information in a centralized reunification software system. Secondary aims are to identify guardians' attitudes and beliefs regarding the sharing of their children's personal information to determine possible obstacles to development of a shared reunification system, identify perceived trust in agencies that might manage a reunification system, and ascertain perceived ability to use and trust various reunification system formats.

Methods

An anonymous online survey administered via RedCap® was offered to a convenience sample of adults presenting with a child to the emergency department (ED) at Boston Children's Hospital, Boston, MA, and Cardinal Glennon Children's Hospital, St. Louis, MO during October, 2017 through April, 2018.⁶ Adults were excluded if they

were not able to read or speak English or if they did not have at least one child aged 14 years or younger.

Survey Questionnaire

This questionnaire was based on research related to reunification of unaccompanied minors during a disaster, the American Academy of Pediatrics Disaster Preparedness Advisory Council Reunification subcommittee's developing toolkit, "Family Reunification Following Disasters: A Planning Tool for Health Care Facilities", and existing programs used to reunite families in disasters, such as NCMEC.⁷ The primary outcome was willingness to share elements of their children's personal information, such as the child's name, physical description (hair, eye, and skin color), language, distinguishing physical characteristics (e.g., birthmarks, scars, tattoos, or piercings), photographs, and videos. A secondary outcome includes identification of parents' and/or legal guardians' attitudes and beliefs regarding the sharing of their children's personal information that may influence their willingness to share such information, such as perceived concern about data security breaches, perceived importance of having a shared community reunification system, and perceived trustworthiness of various agencies. Willingness to share, attitude/belief questions, and perceived trust in agencies were measured on a five-point Likert type scale (very willing to very unwilling, strongly disagree to strongly agree, and very untrustworthy to very trustworthy, respectively). Perceived ability to use and trust in the three reunification system formats (telephone call, smartphone/tablet app, and internet site) were measured as yes/no.

The questionnaire was pilot tested using a group of 10 guardians of children at each site. The study was approved by the Saint Louis University Institutional Review Board and Boston Children's Hospital Institutional Review Board.

Data Analysis

An *a priori* power analysis was conducted to determine an appropriate sample size. Both a multivariate linear regression (outcome variable= sharing information score that can range from 0 - 19) and a multivariate logistic regression (outcome variable= willing to share even a single item of information versus unwilling to share anything) were planned, with possible stratification by hospital. Using G*Power, the desired sample size was calculated to be 323 subjects (about 162 per site), assuming a 95% confidence interval and a margin of error of +/- 5%.⁸ The study aimed to include a total sample of 350 subjects; 175 from each of the two participating hospitals. The Statistical Package for the Social Sciences (SPSS®) 24.0 and R 3.5.0 were used for all analyses.⁹ Attitude/belief Likert-scale questions were dichotomized (agree somewhat and agree strongly = 1; neutral, disagree somewhat, and disagree strongly =0). An overall *sharing information* score was calculated by assigning 1 point for each piece of personal information that the parent/guardian reported they would be willing to share about their children for reunification purposes (i.e., indicated they were somewhat willing or very willing to share). The highest possible *sharing information* score was 19 (i.e., 1 point for each of the 19 personal information items). The full list of items is available in Table 2.

Descriptive statistics were used to describe the percentage of parents/guardians who were willing to share each item of their children's personal information, their attitudes/beliefs about the safety of sharing such information, perceived trustworthiness of agencies, and preferred formats for reunification systems. Proportions tests were used

to evaluate differences in agreement between attitudes/beliefs, perceived trustworthiness of agencies, and preferred formats for reunification systems. Chi squares were used to assess racial differences and attitudes/beliefs and perceived trustworthiness of agencies. Multivariate linear regression was used to determine factors associated with parents'/guardians' willingness to share more pieces of their children's personal information for reunification purposes. The Hosmer and Lemeshow goodness-of-fit test was used to assess overall model fit for the regression. Univariate analyses consisting of independent samples t-tests and analysis of variance were conducted prior to the regression analysis, using all demographic variables and attitude/belief items as possible predictors. Only variables that were significant in univariate analysis (with a critical p-value of .05) were included in the multivariate analysis. Variables that were significant on univariate analysis, but non-significant on multivariate analysis were dropped from the model. Only the final model is reported.

Results

In all, 363 individuals participated (response rate=80.3%); 51.8% (n=188) were from Boston and 48.2% (n=175) from St. Louis. Most were female (78.0%, n = 276; Table 1). A little more than half (57.4%, n=193) were Caucasian, about a third (34.6%, n=116) were African American. A full list of participant demographics is provided in Table 1. Participants in Boston were older, had received more education, had higher income, and a larger percentage were male and white compared to the St. Louis participants (Table 1).

Fewer than 1% of parents/guardians (0.8%, n=3) reported having ever been physically separated from children during a past disaster. Almost a quarter (19.0%, n=69) reported having been separated from their children when out in public, such as at a sports

stadium, fair, the mall, or amusement park. About a third of parents/guardians (32.0%, n=116) reported that they have at least one child under the age of 15 years whose medical history would be necessary for medical providers to know in order to prevent harm to the child if separated during a disaster. Of the parents/guardians who have a child with a critical medical history (n=116), 62.1% (n=72) reported that this makes them more willing to share their child's personal information for reunification purposes and another third (31.9%, n=37) indicated that it does not affect their willingness to share personal information; only 6.0% (n=7) reported that their child's medical history makes them less willing to share their child's personal information for reunification purposes.

Parents'/Guardians' Willingness to Share Their Children's Personal Information for Reunification

Overall, 4.4% (n=16) of parents/guardians were unwilling to share any of their children's personal information for reunification purposes. The remainder (95.6%, n=347) were willing to share an average of 16 items (SD +/- 5.4; range: 1 – 19). The only significant predictor of willingness to share one's child's personal information was perceiving that having a community reunification system is important ($p < .001$); all other demographics, such as age, gender, income, or child's age, and all other attitude and belief questions were non-significant.

Most parents/guardians were willing to share every personal information item assessed. Agreement to share each piece of personal information ranged from 72.3% (video) to 88.6% (birthmarks). Table 2 outlines the percentages of parents/guardians who were willing to share each piece of their children's personal information for reunification purposes. Parents/guardians were significantly more willing to share information about their children's birthmarks, piercings, tattoos, hair color/description, and eye color

compared to their willingness to share their children's school name ($p < .02$), home address ($p < .01$), photo of child's identifying marks ($p < .01$), video of child ($p < .01$), or DNA ($p < .001$).

Parents'/Guardians' Attitudes and Beliefs About Sharing Their Children's Personal Information for Reunification

Most parents/guardians believed it is important to have a community reunification system (87.9%, $n=319$), though significantly fewer believed it would be necessary to share their own child's data (80.4%, $n=292$, $p < .01$; Table 3). Approximately half were concerned about the protection or misuse of their child's information to either claim their child or for another purpose (55.4%, 53.2%, and 52.3%, respectively; Table 3). Just under half (46.6%, $n=169$) were concerned that if they shared their child's information, it would stay in the database permanently (Table 3). About a quarter (24.0%, $n=87$) were concerned that their child's personal information would be shared with child protective services (Table 3). Non-Caucasian parents/guardians were significantly more concerned than Caucasian parents/guardians about the protection or misuse of their child's information (Table 3).

Perceived Trust in Agencies to Manage Reunification Information

Parents/guardians were asked whether they would trust ten different agencies to manage a reunification system/program. Table 4 outlines the percentages of parents/guardians who trust each agency with their children's personal information for reunification purposes. Hospitals and the NCMEC were the two most trusted agencies to manage reunification information (86.0% and 78.8%, respectively; Table 4). Universities and a state government other than the state in which the parent/guardian lives were the least trusted (57.3% and 47.9%, respectively; Table 4). Significantly more

parents/guardians reported trusting hospitals than any other agency ($p < .001$ for all comparisons). Significantly fewer non-Caucasian parents/guardians reported trusting local ($p < .01$), state ($p < .05$), and federal governments ($p < .01$), and public health ($p < .05$) compared to the percentage of Caucasian parents/guardians who trusted those agencies.

Parents'/Guardians' Perceived Ability to Use and Trust in Telephone, Smartphone, Tablet, or Internet Reunification System Formats

Parents/guardians were asked about their perceived ability to use and their trust in a reunification system implemented through a smartphone or tablet app, an internet site, or a telephone call. Most parents/guardians reported that they would be able to use a telephone call, smartphone/tablet, or internet site for reunification (96.4%, 94.5%, and 93.4%, respectively). Although most parents/guardians reported trusting a telephone call, smartphone/tablet, or internet site (80.7%, 77.7%, and 69.7%, respectively) for relaying reunification data, they were significantly more likely to report being able to use these systems than trusting in those systems ($p < .05$ for all comparisons). Significantly more parents/guardians reported trusting a telephone call for reunification than a smartphone/tablet or internet site ($p < .001$ for both comparisons).

Discussion:

This study found that the vast majority of parents are willing to share at least some personal information on their child in order to rapidly reunify with them during a disaster. This indicates that parents/guardians are open to interacting with a reunification system that utilizes personal information. While parents/guardians are willing to share information to enable faster reunification, privacy concerns pervade.

While rapid and effective reunification is universally acknowledged as an integral part of disaster management and recovery, reunification planning remains underdeveloped, with plans often existing in silos. Hospitals, which will be site for family reunifications if there are injuries, are lagging in preparing for this scenario; a recent survey shows only 47% of US emergency departments have disaster plans that involve children.¹⁰ The 2010 National Commission of Children and Disasters recommended that the Department of Homeland Security lead the way in developing technology capable of tracking and reunifying children in a disaster.¹¹ While there are multiple systems capable of performing some aspects of disaster preparedness, including those of NCMEC, the Red Cross, and even systems developed by social media sites such as Twitter and Facebook, a complete dual portal system able to match information submitted by parents/guardians with information submitted by those in custody of an unidentified child does not yet exist on a national level. A parent seeking their missing child may need to access various systems to find their child.¹²

The development of a broader community reunification system would also relieve the burden of reunification from already overwhelmed first responders and guardians. To best utilize such a system, combining information gathered about the child from both the guardian as well as those with an unaccompanied minor in their custody is essential. However, guardians may be reluctant to share their child's personal information due to potential privacy concerns, especially if the data is collected electronically.⁵ This extends to seemingly irrelevant but unique and useful information, such as a school or pet name. This survey sought to identify guardians' concerns regarding the sharing of their child's personal information in a disaster setting. Identifying information guardians are unwilling to share allows a reunification system to be designed that will address and minimize such

concerns. Additionally, though gathering more information on children would potentially allow easier and faster identification, it is critical to restrict information gathering to only those variables guardians are comfortable sharing, as this will increase trust and the likelihood of the system being utilized during a disaster.

After Hurricane Katrina, the use of children's photographs was found to be the most effective means of reunification.^{2,13} Chung and Shannon proposed a system where digital images of children separated from their parents could be uploaded into a centralized system. Using advanced imaging and feature extraction algorithms, the system would automatically index facial features, such as skin or eye color. Parents trying to find their children could enter their child's facial features into the system and receive a reduced set of images for identification, allowing for rapid reunification of the family.¹⁴ In a survey of emergency management professionals, Chung et al found that participants preferred a system that displayed unedited photographs of missing children and over 50% were willing to adopt a photo-based reunification system, if the system could only reunite 10% of the families in a large scale disaster.¹⁵ In their pilot prototype, Chung et al showed that such an image-based reunification system reduced the number of images reviewed before parents identified their child. Our study shows that requesting photos or videos of children, or collecting DNA samples is more likely to cause discomfort in guardians, although most (72-83%) are still willing to share this information.¹⁶ While some of this information may be extremely useful, such as utilizing facial recognition software with photographs, special framing for these requests may be helpful to encourage guardians to share this particular data.^{17,18}

Findings from this study indicate that a reunification system needs to clearly delineate with whom the child's personal information will be shared, have clear

parameters for the removal of information, and outline the steps used to protect information. Half of the respondents expressed concerns about these topics. Events where information is hacked, such as the 2017 *WannaCry* ransomware attack to the U.K. National Health Service or the September 2018 breach of over 40,000 patient records in Hawaii, generate distrust among guardians.¹⁹ Advanced security measures are necessary to protect the personal information of such a vulnerable population.¹⁰ These concerns were particularly prominent in the minority population responding to this survey. In particular, prevention or detection of privacy leaks and security breaches on any aspect of a healthcare system are active areas of research in computer security. Effective measures to guarantee privacy of children's information in database entries exist. For example, confidentiality and live authentication can be achieved with the latest encryption technologies, access control rules can be changed dynamically, or differential privacy techniques can be implemented on database records.²⁰ However, even when adopting the most effective security and privacy mechanisms, it is critical to educate those who will have access to this sensitive data to ensure the safety of the information.

Findings from this and previous studies indicate that one significant way to improve guardians' trust and hence utilization of a reunification system would be to have a hospital manage the system. One study showed baseline trust in confidentiality with personal health information to be highest with hospitals (85%), followed by universities (73%), and local government (39%).²¹ A UK study suggested that universities were the most highly trusted with health information (after the National Health Service), and private organizations were least trusted.²² Guardians were significantly more likely to trust a hospital with their child's personal information. Interestingly, in this current study, universities, while often affiliated with hospitals through medical schools (including both

hospitals used as sites for this study), were amongst the groups least trusted. Academic hospitals implementing a reunification system may find it more successful to emphasize the hospital name as being the managing agency.

A final factor to consider when planning how to develop a successful reunification system is how users will access the system. Though guardians in this study reported being capable of using multiple modalities, telephone calls were perceived as most trustworthy compared to using an app or internet site to enter their child's information. This has significant implications for development and implementation of a reunification system, as the resources needed to depoly a phone line(s) are much higher than using a passive app. Further research is needed to determine if guardians would tolerate a reunification system that either minimized or did not use a telephone line. It is likely that a reunification system used in a future disaster would need to use a mix of modalities to ensure flexibility and comprehensive coverage. For example, a successful system may need to encourage guardians to use an app or another Internet-based service, but also have a backup phone system that would take calls.

This study has some limitations. It was conducted in two hospitals in two different geographical regions of the United States to gain opinions from diverse populations. However, the sample may be biased towards those who live in urban and suburban areas that have access to a pediatric hospital. Those who are rural and/or live somewhere other than St Louis or Boston may not share the same opinions as those in this study. This study also excluded non English speakers, and their willingness to share their child's personal information may differ from this sample. Additionally, it is possible that trust in hospitals was biased by the recruitment approach used in this study (i.e., approaching

families seeking care in a hospital ER). Recreating this survey in a non-hospital setting would be helpful to determine the reproducibility of these findings.

Conclusion

There is near universal willingness of guardians to share their child's personal information to facilitate reunification after a disaster. The potential for misuse of a database of children's information is of concern, so selection of the managing agency, appropriate handling of sensitive information, and clear guidelines on how and when information is purged from the system are critical to ensure parental trust. Findings from this study indicate that hospitals would be the ideal agency to manage a reunification system. In addition, a multi-method approach involving an app, internet-based system, and/or telephone line, to collect data for the reunification system would be best to ensure successful. To be most effective, a reunification system will need to take all of these factors into account in its design and implementation.

Table 1 Demographics of Respondents

	All Respondents N = 363*		Boston N=188*		St. Louis N=175*		Boston vs St. Louis
	%	n	%	n	%	n	p value**
Gender - Female	78.0%	276	71.2%	131	85.3%	145	= .001
Age							< .001
18 – 25 years	11.5%	41	4.3%	8	19.2%	33	
26 – 35 years	40.4%	144	34.6%	64	46.5%	80	
36 – 45 years	33.3%	119	40.0%	74	26.2%	45	
≥ 46 years	14.8%	53	21.1%	39	8.1%	14	
Race							< .001
Caucasian	57.4%	193	72.7%	128	40.6%	65	
African American	34.6%	116	15.9%	28	55.0%	88	
Asian	1.5%	5	2.8%	5	0	0	
Other	6.5%	22	8.5%	15	4.4%	7	
Ethnicity - Hispanic	9.2%	30	13.1%	23	4.7%	7	< .01
Income							< .001
≤ \$20,000	22.0%	63	9.6%	14	34.8%	49	
\$20,001 - \$75,000	32.8%	94	19.2%	28	46.8%	66	
\$75,001 - \$150,000	22.6%	65	30.8%	45	14.2%	20	
≥ \$150,001	22.6%	65	40.4%	59	4.3%	6	
Education Level							< .001
High school or less	25.8%	89	16.0%	29	36.6%	60	
Some college	33.3%	115	23.2%	42	44.5%	73	
Bachelors degree or higher	40.9%	141	60.8%	110	18.9%	31	
Employment Status							NS
Unemployed or retired	28.1%	94	24.7%	44	32.1%	50	
Part-time	15.6%	52	15.7%	28	15.4%	24	
Full-time	56.3%	188	59.6%	106	52.6%	82	
Have At Least One Child in the Following Age Group							NS
< 2 years	28.9%	105	22.9%	43	35.4%	62	
2 – 4 years	41.6%	151	41.0%	77	42.3%	74	
5 – 11 years	59.5%	216	62.2%	117	56.6%	99	
12 – 17 years	36.4%	132	35.1%	66	37.7%	66	

*Denominator varies due to missing data (i.e., those who chose not to identify their gender, race, or other demographics)

**Determined by the Chi Square test

NS = non-significant

Table 2 Percentage of Parents/Guardians Willing to Share Each Piece of Their Child(ren)’s Personal Information for Reunification Purposes

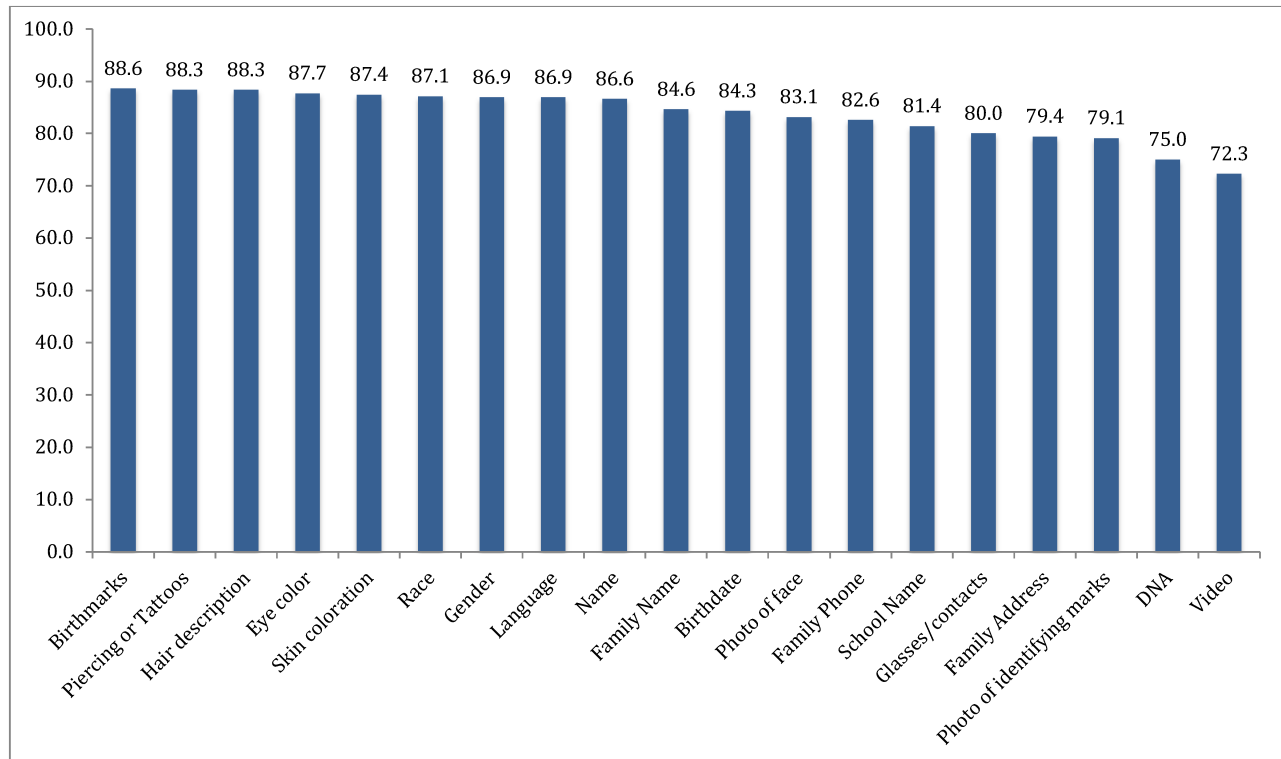


Table 3 Parents/Guardians' Attitudes and Beliefs Regarding Sharing Their Child(ren)'s Personal Information for Reunification Purposes

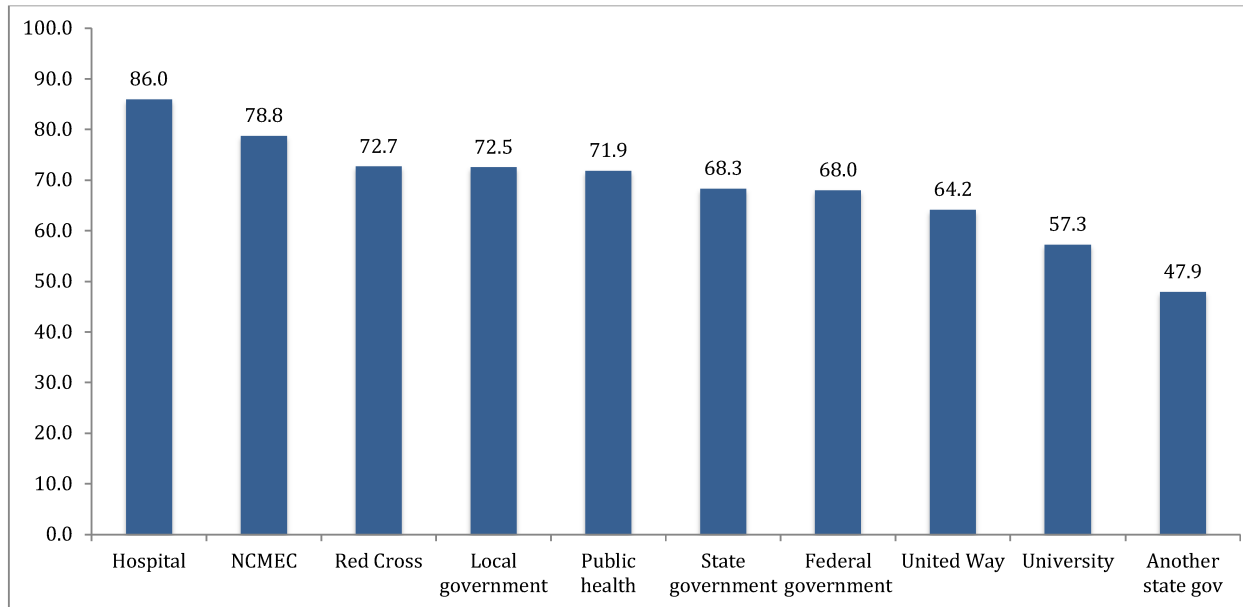
Statement	All Respondents N = 363	Caucasian vs Non-Caucasian N = 336*		
	Strongly Agreed or Agreed % (n)	Caucasian N = 193	Non-Caucasian N = 143	Caucasian vs Non- Caucasian
		Strongly Agreed or Agreed % (n)	Strongly Agreed or Agreed % (n)	p value**
It is important that my community has a rapid reunification system	87.9 (319)	91.2 (176)	86.0 (123)	NS
A reunification system that uses photos or videos would be useful	84.6 (307)	88.1 (170)	83.9 (120)	NS
I believe that sharing my child(ren)'s personal information would be necessary to reunify us	80.4 (292)	85.5 (165)	78.3 (112)	NS
I would be concerned that my child(ren)'s personal information would not be protected	55.4 (201)	48.2 (93)	63.6 (91)	< .01
I would be concerned that someone else would use my child(ren)'s personal information to claim my child(ren)	53.2 (193)	45.1 (87)	61.5 (88)	< .01
I would be concerned that my child(ren)'s personal information would be used for another purpose besides reunification	52.3 (190)	44.0 (85)	61.5 (88)	= .001
I would be concerned that my child(ren)'s personal information would stay in the database permanently	46.6 (169)	40.4 (78)	51.0 (73)	< .05
I would be concerned that my child(ren)'s personal information would be shared with protective child services	24.0 (87)	12.4 (24)	36.4 (52)	< .001

*Denominator is fewer than all respondents due to individuals who did not report their race

**Determined by the χ^2 test

NS = Non-significant

Table 4 Percentage of Parents/Guardians Who Trust the Agency with Reunification Information



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