



# Consent in escrow

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## ABSTRACT

Disasters such as flash flooding, mass shootings, and train and airplane accidents involving large numbers of victims produce significant opportunity for research in the biosciences. This opportunity exists in the extreme tails of life events, however, during which decisions about life and death, valuing

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and foregoing, speed and patience, trust and distrust, are tested simultaneously and abundantly. The press and urgency of these scenarios may also challenge the ability of researchers to comprehensively deliver information about the purposes of a study, risks, benefits, and alternatives. Under these circumstances, we argue that acquiring consent for the immediate use of data that are not time sensitive represents a gap in the protection of human study participants. In response, we offer a two-tiered model of consent that allows for data collected in real-time to be held in escrow until the acute post-disaster window has closed. Such a model not only respects the fundamental tenet of consent in research, but also enables such research to take place in an ethically defensible manner.

**KEYWORDS:** informed consent, disaster research, disaster ethics, research ethics, consent in escrow, neuroethics

### DISASTER RESEARCH: DEFINITIONS, AND ETHICAL AND REGULATORY CONSIDERATIONS

A considerable number of natural and public disasters such as mass shootings, earthquakes, floods and hurricanes, and catastrophic accidents in the air and on the ground have occurred in recent years. Notwithstanding the deep tragedy of these events, they offer opportunities for important research in the biosciences to better understand, prevent, and respond to such disasters in the future in a manner that minimizes human suffering. However, research in this area is rife with inevitable ethical, legal, and policy challenges and implications.

Fritz defines a disaster as ‘an event concentrated in time and space, in which a society or one of its subdivisions undergoes physical harm and social disruption, such that all or some essential functions of the society or subdivision are impaired’.<sup>1</sup> As such, disasters provide real-world laboratories for the effects of harmful, irreversible loss, and damage requiring long-term recovery from their social, political, and economic repercussions.<sup>2,3,4,5,6</sup> Agents of destruction vary, but in most traditional definitions of disaster research they fall into the category of natural forces.<sup>7</sup> A basic framework categorizes disaster effects into three impact conditions: hazard exposure, physical vulnerability, and social vulnerability. Research involving any of these conditions has, as at least one of its endpoints, the goal of reducing future risk.

<sup>1</sup> Charles E. Fritz, *Disaster*, in CONTEMPORARY SOCIAL PROBLEMS 655 (Robert K. Merton & Robert A. Nisbet eds., 1961).

<sup>2</sup> Denis Smith, *Through A Glass Darkly: A Response to Stallings*, in WHAT IS A DISASTER?: NEW ANSWERS TO OLD QUESTIONS 292, 307 (Ronald D. Perry & Enrico L. Quarantelli eds., 2005).

<sup>3</sup> Gideon Sjöberg, *Disasters and Social Change*, in MAN AND SOCIETY IN DISASTER 357, 384 (George W. Baker, Dwight W. Chapman eds., 1962).

<sup>4</sup> ENRICO L. QUARANTELLI, *DISASTER PLANNING, EMERGENCY MANAGEMENT AND CIVIL PROTECTION: THE HISTORICAL DEVELOPMENT OF ORGANIZED EFFORTS TO PLAN FOR AND TO RESPOND TO DISASTERS* (2000).

<sup>5</sup> RONALD W. PERRY & ENRICO L. QUARANTELLI, *WHAT IS A DISASTER?: NEW ANSWERS TO OLD QUESTIONS* (2005).

<sup>6</sup> Arjen Boin & Paul ‘T Hart, *The Crisis Approach*, in HANDBOOKS OF SOCIOLOGY AND SOCIAL RESEARCH: HANDBOOK OF DISASTER RESEARCH 42, 54 (Howard B. Kaplan, Havidán Rodríguez, Enrico L. Quarantelli eds., 2006).

<sup>7</sup> Robert A. Stallings, *Methodological Issues*, in HANDBOOKS OF SOCIOLOGY AND SOCIAL RESEARCH: HANDBOOK OF DISASTER RESEARCH 55, 82 (Howard B. Kaplan, Havidán Rodríguez, Enrico L. Quarantelli eds., 2006).

Disaster research began in the 1950s primarily in the USA, and has become increasingly international over time.<sup>8</sup> Results have highlighted the importance of disaster research to society. Lindell's studies of the aftermath of 2005 Hurricane Katrina, for example, revealed invaluable knowledge about the impact of failed management and care of affected persons forced to disperse from the epicenter of an event, and remedies for future disaster planning. Prior to Katrina, research on the 2004 tsunami in Asia demonstrated the value of effective organizational response.<sup>9</sup> Disaster research on the 1979 Three Mile Island incident and 1996 catastrophe in Chernobyl led to policy decisions about nuclear power accidents.<sup>10,11</sup> Other research on disasters have also revealed important insights into coping strategies among emergency workers,<sup>12</sup> impact of disasters on collective memory,<sup>13</sup> the importance of culture and humor in recovery,<sup>14</sup> and the cultural impact of terrorist attacks and religion in responsiveness.<sup>15,16,17,18</sup>

The fundamental difference in doing disaster research compared to other forms of human subjects research is the context in which it is carried out.<sup>19,20,21</sup> Indeed, studies have illustrated the ethical complexities of conducting disaster research for both participants as well as researchers. Separating disaster research from other forms of research and regulatory responses is the critical nature of timing of research, access to people, documents or other materials, and ultimately generalizability to other settings. Timing is especially key where arriving late to the disaster scene may yield poor or incorrect research results or be a missed opportunity to take advantage of unfolding events—data

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- <sup>8</sup> Russell R. Dynes & Thomas E. Drabek, *The Structure of Disaster Research: Its Policy and Disciplinary Implications*, 12 INT'L J. MASS EMER. DISASTERS 5, 23 (1994).
- <sup>9</sup> Mikio Ishiwatari, *Institution and Governance Related Learning From the East Japan Earthquake and Tsunami*, in DISASTER RECOVERY: USED OR MISUSED DEVELOPMENT OPPORTUNITY 77, 88 (Robert Shaw ed., 2014).
- <sup>10</sup> CHARLES K. DODD, INDUSTRIAL DECISION-MAKING AND HIGH-RISK TECHNOLOGY: SITING NUCLEAR POWER FACILITIES IN THE USSR (1994).
- <sup>11</sup> THE PRESIDENT'S COMMISSION, THE ACCIDENT AT THREE MILE ISLAND: THE NEED FOR CHANGE (1979).
- <sup>12</sup> Carmen Moran, *Does the Use of Humour as a Coping Strategy Affect Stresses Associated with Emergency Work?*, 8 INT'L J. MASS EMER. DISASTERS 361, 377 (1990).
- <sup>13</sup> Kofamn Bos & Susann Ullberg, *The Long Shadow of Disaster: Memory and Politics in Holland and Sweden*, 23 INT'L J. MASS EMER. DISASTERS 5, 26 (2005).
- <sup>14</sup> Stephen R. Couch & Barbara A. Wade, *'I Want to Barbecue Bin Laden': Humor After 9/11*, 21 INT'L J. MASS EMER. DISASTERS 67, 86 (2003).
- <sup>15</sup> Courtney B. Abrams, Karen Albright & Aaron Panofsky, *Contesting the New York Community: From Liminality to the 'New Normal' in the Wake of September 11*, 3 CITY AND COMMUNITY 189, 220 (2004).
- <sup>16</sup> Howard F. Stein, *A Bombing in April: Culture and Disaster in the Oklahoma City Bombing*, 7 ILLNESS, CRISIS LOSS 17, 36 (1999).
- <sup>17</sup> Gerald Turkel, *Sudden Solidarity and the Rush to Normalization: Toward an Alternative Approach*, 35 SOCIOLOGICAL FOCUS 73, 79 (2002).
- <sup>18</sup> Hannah Schmuck, *'An Act of Allah' Religions Explanations for Floods in Bangladesh as Survival Strategy*, 18 INT'L J. MASS EMER. AND DISASTERS 18, 95 (2000).
- <sup>19</sup> Robert Stallings, *Disaster, Crisis, Collective Stress and Mass Deprivation*, in WHAT IS A DISASTER?: NEW ANSWERS TO OLD QUESTIONS 237, 274 (Ronald D. Perry & Enrico L. Quarantelli eds., 2005).
- <sup>20</sup> Dennis S. Mileti & Lori Peek, *The Social Psychology of Public Response to Warnings of a Nuclear Power Plant Accident*, 75 J. HAZARDOUS MAT'L 181, 194 (2000).
- <sup>21</sup> Verta Taylor, *Future Directions for Study*, in DISASTER: THEORY AND METHODS 251, 280 (Enrico L. Quarantelli ed., 1978).

that Quarantelli<sup>22</sup> describes as ephemeral or Bourque et al.<sup>23</sup> as perishable. The pressure of time for rapid interventions required of research teams may also preclude the usual formal institutional ethics board review. While some scholars have questioned whether reduced research ethics scrutiny may justifiably apply in disaster research settings, minimal risk standards which still require oversight by an external research ethics body are expected. For example, Wendler considers whether the standard of minimal risk can be applied in these rapid response situations, and proposes a charitable participation standard where ‘individuals should be enrolled in research only when the risks do not exceed the risks of charitable activities deemed acceptable for these individuals’.<sup>24</sup> Similarly, Jesus et al. address the minimal risk question by advancing the need for flexible study designs that can be used across a wide variety of disasters but reviewed prior to implementation.<sup>25</sup>

Disaster researchers, sometimes described as action researchers,<sup>26</sup> come to a crisis setting seeking access to a purposive sample of respondents or informants. They bring courage to a scene, but often do so alongside other researchers who bring their own disciplinary methodologies, perspectives, and biases.<sup>27</sup> Whether researchers are operating in collision or convergence with others, their presence can challenge the fundamental principle of non-maleficence by intruding on participants’ lives at a critical time.<sup>28</sup> Risk of exploitation, therefore, is an especially acute challenge. Sumathipala et al., for example, reviewed research carried out on survivors of the Bangladesh tsunami in 2004, and found that numerous studies were conducted without proper approval or standards.<sup>29</sup> They attributed the sources of this lapse to the leniency of local standards, the vulnerability of victims, and the collapse of infrastructure that occurred after this mass natural disaster. Even in the face of a stable infrastructure for research, however, confidentiality and privacy may be difficult to maintain. While anonymity may be preserved in data aggregated from large pools of respondents, the identity of sole or small numbers of informants, such as first responders or community leaders, may be difficult to conceal without jeopardizing the integrity of the data or attribution to such experts. The price of knowledge accumulation in any of these scenarios is borne disproportionately by subjects.

In 2004, the New York Academy of Medicine and the US National Institute of Mental Health identified four critical areas of importance to research protocols in disaster settings: (1) decision-making capacity of potential participants, (2) vulnerability,

<sup>22</sup> Enrico L. Quarantelli, *The Disaster Research Center Field Studies of Organized Behavior in the Crisis Period of Disasters*, in *METHODS OF DISASTER RESEARCH* 94, 126 (Robert Stallings ed., 2002).

<sup>23</sup> Linda B. Bourque, Judith M. Siegel & Kimberley I. Shoaf, *Psychological Distress Following Urban Earthquakes in California*, 17 *PREHOSPITAL DISASTER MED.* 81, 90 (2002).

<sup>24</sup> David Wendler, *Protecting Subjects Who Cannot Give Consent: Toward a Better Standard for ‘Minimal’ Risks*, 35 *THE HASTINGS CTR. REP.* 37, 40 (2005).

<sup>25</sup> John E. Jesus & Glen E. Michael, *Ethical Considerations of Research in Disaster-Stricken Populations*, 24 *PREHOSPITAL DISASTER MED.* 109, 1 (2009).

<sup>26</sup> JEAN MCNIFF, *ACTION RESEARCH: PRINCIPLES AND PRACTICE* (2013).

<sup>27</sup> CHARLES E. FITZ & JOHN H. MATHEWSON, *CONVERGENCE BEHAVIOR IN DISASTERS: A PROBLEM IN SOCIAL CONTROL* (1957).

<sup>28</sup> EARL R. BABBIE, *THE PRACTICE OF SOCIAL RESEARCH* (1995).

<sup>29</sup> Athula Sumathipala et al., *Ethical Issues in Post-Disaster Clinical Interventions and Research: A Developing World Perspective. Key Findings from a Drafting and Consensus Generation Meeting of the Working Group on Disaster Research and Ethics (WGDRE) 2007*, 2 *ASIAN BIOETHICS REV.* 124, 142 (2010).

(3) risks and benefits of participation, and (4) informed consent.<sup>30</sup> Their conclusions highlight that existing guidelines and norms pertaining to research on human participants may not be sufficient to address all situations that arise during disasters, and that ‘real vigilance is necessary [...] to ensure that general ethical principles are adhered to and participants are protected’.<sup>31</sup> Extreme life circumstances simultaneously and abundantly challenge decisions about life and death, valuing and foregoing, speed and patience, trust and distrust. Given the press and urgency of these situations, the ability of researchers to obtain informed consent by fully delivering information about the purpose of a study, risks, benefits, and alternatives may be compromised. As such, we offer a new model of consent, in complement to existing methodologies,<sup>32,33</sup> for the disaster research setting.

### THE CONCEPT OF CONSENT IN ESCROW

The basic tenet of the consent in escrow model is that data collection takes place under the time course of conventional procedures (Table 1),<sup>34,35,36,37,38,39</sup> but consent for data use is held in escrow until the acute post-disaster window has closed. This two-tiered model places opt-in at the core of the research ethics process unlike, for example, the single-tier approach articulated by the American Psychological Association and US Federal Code 45CFR46.116 that assert and protect participants’ right to withdraw at any time,<sup>40,41</sup> but according to which, consent allows for immediate data utilization. By holding data that are not time sensitive in escrow for later use, the model provides a layer of protection for individuals without compromising initial stage of data collection. The model also supports the ethical concept that consent should not be a single point in time event, but rather be viewed as an ongoing process throughout the course of a research study.

In Canada, the USA, and in other developed states, policies for protecting human subjects acknowledge that there are times when modification to standard research ethics board processes is justified, provided that ‘exceptions and the means to implement them are not unduly broad, overreaching, or unjustifiably invasive’.<sup>42</sup> This

<sup>30</sup> Dean G. Kilpatrick, *The Ethics of Disaster Research: A Special Section*, 17 J. TRAUMATIC STRESS 361, 362 (2004).

<sup>31</sup> Sumathipala et al., *supra* note 29, at 131.

<sup>32</sup> Jacquelyn Ann K. Kegley, *Challenges to Informed Consent*, 5 SCI. SOC’Y, 832 (2004).

<sup>33</sup> Jody Platt et al., *Public Preferences Regarding Informed Consent Models for Participation in Population-Based Genomic Research*, 16 GENET. MED. 11 (2014).

<sup>34</sup> TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* (2001).

<sup>35</sup> RUTH R. FADEN & TOM L. BEAUCHAMP, *A HISTORY AND THEORY OF INFORMED CONSENT* (1986).

<sup>36</sup> Wendler, *supra* note 24, at 41.

<sup>37</sup> U.S. Department of Health & Human Services, *Code of Federal Regulations*, <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html> (accessed Oct. 3, 2014).

<sup>38</sup> Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, December 2010.

<sup>39</sup> Michael Burgess, *Proposing Modesty for Informed Consent*, 65 SOC. SCI. MED. 2284 (2007).

<sup>40</sup> BRUCE D. SALES & SUSAN FOLKMAN (eds.), *ETHICS IN RESEARCH WITH HUMAN PARTICIPANTS* (2000).

<sup>41</sup> U.S. Department of Health & Human Services, *The Belmont Report*, <http://www.hhs.gov/ohrp/policy/belmont.html/> (accessed Aug. 13, 2013).

<sup>42</sup> Panel on Research Ethics, *TCP2—2nd Edition of Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, <http://www.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default/> (accessed Aug. 13, 2013).

**Table 1. Summary of traditional models of informed consent and limitations for the disaster context.**

Model	Description	Limitation(s) for disaster context
Informed consent	Free, informed, ongoing, or broad voluntary consent with competent adults.	Reasonably questionable ability to provide informed consent due to stress associated with the acute situation.
Assent	Agreement to participate by individuals (including children) who are able to express their wishes, but lack legal capacity to consent.	See informed consent.
Broad and blanket consent	Consent for all and any future uses of information or materials (e.g., in the case of biobanking).	Not appropriate for disaster research. Broad consent assumes that future uses of information are unknown. In the case of disaster research, future uses are in fact known, making the approach disingenuous in this context.
Presumed consent	Consent assumed; withdrawal required for opt-out.	Consent could be assumed in a disaster setting, however, the decision whether or not to opt-out is an unreasonable burden in the acute setting.
Proxy consent	Consent on behalf of an individual who lacks capacity.	Identifying a suitable proxy for consent in the midst of a disaster places unrealistic expectations on researchers conducting real-time studies.
Consent for future use	Expressed preference for future uses of data or for recontact.	Does not protect subjects who later regret contribution of data.
Community consent	Consent from legitimate community leaders or representatives acquired prior to individual consent.	The requirement for community consent should not be circumvented by the consent in escrow approach.
Alternations and waivers to consent	Exceptions and waivers for studies involving medical emergencies, publicly declared emergencies, or when acquiring consent compromises a protocol as in deception studies.	Standard research ethics guidance already acknowledges the need to modify the consent process in certain cases such as emergencies, so the consent in escrow approach is supported in principle.

guidance applies specifically to and enables research in the disaster setting. These policies also widely acknowledge that research participants in the midst of a disaster or an emergency are vulnerable, and that pre-existing vulnerabilities are potentially exacerbated under these extreme circumstances.<sup>43</sup> Gender, race, and class are all factors

<sup>43</sup> Jesus & Michael, *supra* note 25, at 109.

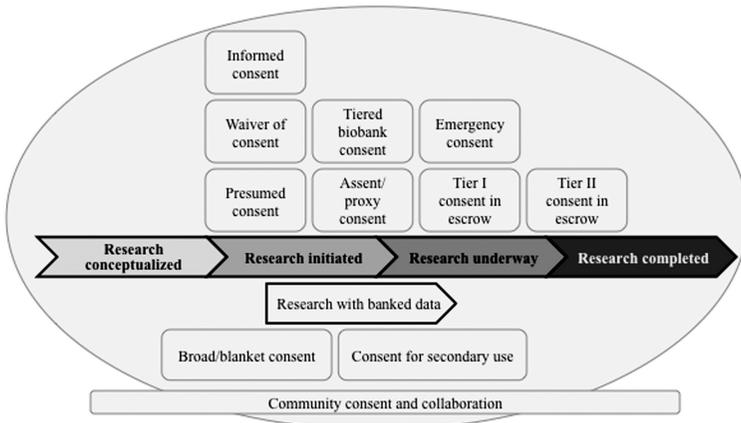


Figure 1. Temporal dimensions of traditional models for informed consent and new model for consent in escrow.

correlated with vulnerability during disaster events, including those such as Hurricane Katrina.<sup>44,45</sup>

While traditional notions of informed consent make allowances for the exposure of research participants or groups through mechanisms such as assent for children or community consent in the case of indigenous peoples, a model that enables individuals to opt out of participating in a study to which they contributed data under acute circumstances has not been broached. In this way, consent in escrow builds on the two-stage model for retrospective clinical research proposed by Norris et al.,<sup>46</sup> that provides the opportunity for subsequent research and is sensitive to participant recovery with a lengthened timeline, but that is not a prerequisite to release of data for analysis and utilization.

### IMPLEMENTING CONSENT IN ESCROW

Using the consent in escrow approach, initial informed consent from participants for the collection of data is obtained in the acute setting, but the data are held unexamined in escrow by a data steward until contributors can be recontacted and the second tier of informed consent is obtained for data release (Figure 1). Respect for the autonomy of research participants is promoted through the opportunities afforded by the passage of time and the post-acute setting, and upheld by enabling them to re-evaluate their contribution. These benefits exceed the risk of potentially unwanted secondary contact. Multiple attempts for recontact are built into the protocol *ex ante* following other established ethics procedures where future attempts at recontact must be justified. Limits to repeated attempts must be factored into any protocol to preserve the benefit-risk balance with respect to autonomy and the right to refuse recontact. As with the model proposed by Norris et al., researchers using the consent in escrow model may invite

<sup>44</sup> HAVIDÁN RODRÍGUEZ et al., *HANDBOOK OF DISASTER RESEARCH*, Springer (2009).

<sup>45</sup> Alice Fothergill & Lori A. Peek, *Poverty and Disasters in the United States: A Review of Recent Sociological Findings*, 32 *NAT. HAZARDS* 89, 110 (2004).

<sup>46</sup> FRAN NORRIS et al., *METHODS FOR DISASTER MENTAL HEALTH RESEARCH* 98 (2012).

participants to provide information for kin through whom recontact is pursued secondary to primary contact at the future timepoint.<sup>47</sup> The significance and effectiveness of the kinship resource depends on the proximity of the kin to the affected person, the closeness of the tie, and the extent to which the kin is also affected.<sup>48</sup> Nonetheless, it is common for study teams to collect information about relatives and friends of participants during the informed consent process for clinical trials when longer term follow-up is desired.<sup>49</sup> This option is explicitly stipulated and agreed upon during the initial consent process.<sup>50</sup>

The timing of the second stage of consent for release of data held in escrow will vary by context, but we anchor it in the period of time when the lives of research participants can reasonably be expected or observed to have stabilized such as when social, economic, and political routines have been restored.<sup>51</sup> New data may be collected under conventional procedures to compare or augment data collected at the acute timepoint, but originally collected data may not be modified *post hoc*. Should a recontacted participant desire the latter, the conditions for release of data under the consent in escrow model are not satisfied and the data are destroyed. The requirement to obtain community consent such as research with indigenous populations should not be circumvented in the first tier, and must be explicitly respected in the second.<sup>52</sup>

Under conditions when assenting youth attain age of majority during the data holding period, consent in the second tier is not required from the originally consenting surrogate. Under conditions in which competence of the participant is compromised over time after first-tier consent, proxy consent must be invoked at the second tier. In the case of participant's death, an advanced directive for research or the instructions of the executor of the estate to which data may become property prevail. Alternatively, the data are destroyed.

A limited version of this model is currently being applied successfully in a pediatric emergency research setting in British Columbia, Canada. Here, verbal consent for research is acquired at the time of tissue biopsy by a treating physician, and then confirmed at a later time when the research study can be explained in greater detail and at time of reduced stress by an arm's length researcher to avoid potential coercion.<sup>53</sup> Situating consent in escrow in broader world events, the model would apply, for example, to a comparative study of emotional differences and long-term psychological changes between the families of those who vanished in flight MH370, which disappeared presumably off the western coast of Australia, and flight MH17, which was shot down over Ukraine. While the location of the former flight and, most significantly, the victims'

<sup>47</sup> Russell Dynes & Thomas E. Drabek, *The Structure of Disaster Research: Its Policy and Disciplinary Implications*, 12 INT'L J. MASS EMER. AND DISASTERS 5, 23 (1994).

<sup>48</sup> Michael K. Lindell, *Disaster Studies*, 61 CURR. SOCIOLOGY 797, 811 (2013).

<sup>49</sup> NORRIS et al., *supra* note 46, at 98.

<sup>50</sup> INSTITUTE OF MEDICINE AND NATIONAL RESEARCH COUNCIL, INTEGRITY IN SCIENTIFIC RESEARCH: CREATING AN ENVIRONMENT THAT PROMOTES RESPONSIBLE CONDUCT (2002).

<sup>51</sup> Lindell, *supra* note 48, at 810.

<sup>52</sup> Samuel J. Stratton, *Prehospital Pediatric Endotracheal Intubation*, 27 PREHOSPITAL DISASTER MED. 1, 2 (2012).

<sup>53</sup> Suzanne Vercauteren et al., *Verbal Consent Procedure for Acquisition of Biospecimens in an Acute Pediatric Setting*, ISBER POSTER PRESENTATION, (2013).

bodies remain a mystery, families associated with the latter tragedy have the opportunity for closure and healing.

In what disaster or emergency research settings situations will consent in escrow not be suitable? For one, it cannot be applied to research with an immediate health intervention or short-term goal. The current Ebola outbreak in West Africa is a prime example. It cannot be applied when real-time analysis is required. And, it cannot be applied to studies of war refugees, for example, where recontact would be too burdensome or simply a ludicrous requirement during times of political instability.

Pre-reviewed, minimal risk research, as conceptualized and described above by Wendler and Jesus et al., can be excluded from two-tier consent. The collection of hair samples, for example, would qualify for such an exemption. Indeed, as with all research conducted in disaster and emergency settings, the consent in escrow model should be evaluated for its appropriateness to the specific research situation and for the associated risks and benefits it offers. Other complexities in applying the model will derive from heterogeneity in methods to determine return-to-life stability by research teams, and the inherent variability in progress along this continuum among people and populations. Recontact information may be unavailable at time of disaster or later invalidated due to a change in anticipated participant location. Participants may also feel burdened by the two-stage model and not wish to be reminded of the traumatic event in question. Use of the model may compound or extend fear of retaliation experienced by disaster researchers who are confronted with pressures to reveal informants' identities, such as those reported after the 1989 Exxon Valdez oil spill.<sup>54</sup> Two-tiered consent imposes pressures on funding streams, on researchers who rely on sufficient data to be released from escrow to power their analyses, and is complicated by changes in research leadership and personnel that inevitably occur over time. Publication and dissemination of research findings may be delayed.

## CONCLUSION

Decisional capacity and the ability to provide truly informed consent rely on durable and ongoing competence of research participants, and must neither be impulsive or be made under duress. These conditions are difficult to achieve in disaster and emergency situations, and increasingly so in this era of instant messaging and social media, in which the right to privacy has been all but lost.<sup>55</sup> Still, human societies are remarkably resilient in the face of large-scale crises, and disaster victims do not become irrational, self-destructive, necessarily hopeless, or dependent.<sup>56</sup> Disaster victims may well be able to provide consent for immediate or long-term data use, but our model alleviates the extra burden of decision-making and choice *in situ*, and privileges time for participant reflection. The model still needs to be tested, but we submit that when applied judiciously, consent in escrow will mitigate an extra strain that research brings to an already challenged setting, offer a welcome extra layer of protection to participants, and foster

<sup>54</sup> Kathleen J. Tierney, *The Field Turns Fifty: Social Change and the Practice of Fieldwork*, in *METHODS OF DISASTER RESEARCH* 348, 374 (Robert Stallings ed., 2002).

<sup>55</sup> Rebecca McKee, *Ethical Issues in Using Social Media for Health and Health Care Research*, 110 *HEALTH POL'Y* 298, 301 (2013).

<sup>56</sup> Enrico L. Quarantelli, *Images of Withdrawal Behavior in Disasters: Some Basic Misconceptions*, *SOC. PROBS.* 68, 79 (1960).

the completion of the research cycle for the advancement of the health and well-being of survivors.

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