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Research paper

Consent process for US-based family reference DNA samples

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ABSTRACT

DNA collection from family members of the missing is a tenet for missing persons' and mass fatality investigations. Procedures for consenting family members are disparate, depending on the context supporting the reason for sample collection. While guidelines and best practices have been developed for handling mass fatalities and for identification of the missing, these guidelines do not address standard consent practices for living family members of potential victims. We examined the relevant U.S. laws, international guidelines and best practices, sampled consent forms currently used for DNA collection of family members, and drafted model language for a consent form to communicate the required and recommended information. We modeled the consent form on biobank consenting practices and tested the consent language among students and the general population for constructive feedback and readability. We also asked respondents to consider the options for DNA collection and either hypothetically agree or disagree. The model language presented here highlights information important to relay in consent processes and can serve as a foundation for future consent practices in mass fatalities and missing persons' investigations.

1. Introduction

DNA is the most reliable method for demonstrating biological kinship for identification of deceased persons. In times of mass disaster, conflict or for individual missing person cases, DNA samples from families of the missing may be collected to identify the deceased. Over the past couple decades, disaster victim identification (DVI) operations have led to development of international DNA collection standards and recommendations, including best practices for processing DNA and the need for written consent for collection of family reference samples [1]. Still, the consent procedures differ greatly depending on the context of the incident and the scope of involvement of government and law enforcement. Moreover, the international nature of many contexts for family reference sample (FRS) collection necessitates clear guidance on processes and parameters for protection of data to be shared across borders. The U.S.-based DNA collection programs are some of the earliest models for DVI and missing persons' investigations, and hence a good starting place for examination of consent processes for FRS collection.

Collection of DNA for forensic purposes is governed under jurisdiction-specific protections. In most contexts, DNA collection to investigate missing persons' cases is entrusted to authorities under the assumption that the case may be a homicide, human rights violation or other crime. Law enforcement and medicolegal personnel adhere to the standard chain of custody as part of any criminal, missing person or disaster investigation. To maintain legal authority of what could become a criminal case, U.S.-based missing persons' cases are entered into the National Missing and Unidentified System (NamUs) and DNA profiles are funneled toward the national missing persons database operated through the COmbined DNA Index System (CODIS), which is managed by U.S. Federal Bureau of Investigation and subject to specific legal standards [2]. Some nongovernmental organizations (NGOs) have argued that the criminal justice system for missing persons' investigations excludes certain populations, such as missing migrants [3]. Continuing migration crises across the Mediterranean Sea [4] and at the U.S.-Mexico border [3,5] require ongoing collection of DNA from families of the missing. In these cases, the family members may be fearful of government authorities and even non-governmental representatives. Conversely, while historic cases of missing persons, like disappearances due to conflict, usually follow similar practices as law enforcement, they may be managed in cooperation with academic or private organizations as discrete projects.

Whether a victim is missing due to conflict or disaster, identification of their remains often depends on DNA comparisons with related family members. The voluntary provision of DNA samples from living biological relatives involves some form of donor consent. Standardization of an informed consent process has not been developed since most of the scenarios are case-based (e.g., a particular missing person), jurisdiction-

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based, and/or context specific (e.g., an airplane crash). The disparate practices for consenting donors involve varying degrees of information provision and little two-way communication between investigators and the participants. In some cases, consent involves mere willingness of a participant to be swabbed, and in other cases, consent is a part of a multi-hour intake process for a case report. Documentation during consent processes also vary in level of detail and content of information collected from donors, ranging from name and relationship with victim, to full family pedigrees drafted by individuals trained in genetics. The disparity in documentation may reflect whether DNA samples are collected solely by law enforcement or in conjunction with other types of personnel [6].

The American Bar Association (ABA) Standards on DNA Evidence describe the need for obtaining consent from the person who is the source of the sample, stating that law enforcement would not have access to or otherwise be able to obtain the collection without the persons' consent. These standards also apply in law enforcement contexts, noting the right to be informed on the reason for the request and the right to refuse the request [7]. Internationally, multiple organizations' involvement in efforts to identify victims of conflict, military war dead [8], and mass fatalities [9] has resulted in the collection of thousands of DNA samples from relatives of the missing. Best practice recommendations emerged following major incidents that relied upon DNA collection for victim identification, noting common themes regarding important processes such as chain of custody, integrity of samples, and commonality of DNA markers. Mass fatality identification processes were enhanced following the identification efforts of the World Trade Center attacks [10], with the immediate aim to improve accuracy and transparency [11–13], including development of an informed consent process for family members [14]. Practices now incorporate inclusion of genetics professionals in the identification processes [15] and provision of family support services [16]. Acquiring consent from WTC victim family members for identifications, in particular, were challenging given the lack of advanced coordination in place and the magnitude of the disaster [17]. The innovative work of the Kinship and Data Analysis Panel (KADAP), an advisory team assembled following the disaster to develop consistent guidelines, eventually improved the processes tremendously [11]. Nevertheless, the lessons learned in one context – the WTC disaster – were challenging to translate to later events including Hurricane Katrina and the Southeast Asian tsunami [18]. Some recommendations are specific to the organization responsible for identifications. INTERPOL for example, notes that the consent form should specify the possibility of international data sharing [19]. International Committee of the Red Cross (ICRC) includes exceptions in their best practices that personal data may be disclosed if "required by a substantial public interest or for the protection of the vital interests of the person concerned" [20]. The ICRC also notes in their recommendations that the person collecting consent should do so in layman's terms and in an understandable manner [21].

Still today, the numerous DVI guidelines [9] thoroughly address the science and practicalities of identification, but ethical aspects related to the family members providing genetic information are largely unaccounted for. One un-reconciled difference among current recommendations is whether or not to disclose genetic information (e.g., misattributed parentage) revealed through testing, either to the donor or the potentially affected kin. The ICRC argues that "access to personal data should be granted to the individual to whom the data relate" [21]. This policy resonates with the principle right to access personal information held by government authorities in order to question the accuracy of the information. Yet academics have argued that some genetic information about biological relationships can be dangerous and that the right to not know information should supersede this right to access data, particularly when that data could be damaging to family dynamics, or put a person at risk of violence [22]. For instance, misattributed paternity may put a woman or child at risk of abuse when the fact of non-paternity brings supposed shame upon a family, even in cases of rape or incest.

Protection of genetic information has long been a priority in medicine and law enforcement. Bioethical guidelines for participation of research subjects were developed following the release of the Belmont Report in 1978 [23]. The protection policies and guidelines, developed since the report's publication, encompass many aspects of research risks including but not limited to protection of biological and genetic information. One of the mandates following the report's release implemented the process of informed consent to ensure a person's participation in research is with full knowledge and understanding, freely and without coercion or duress [24]. Provision of biological specimens for research is included as research. United Nations Educational, Scientific and Cultural Organization (UNESCO) proposed additional measures to protect genetic data collected for research from misuse, including data from governmental authorities [25]. The use of, sharing of, and access to voluntarily provide genetic information is a topic of much discussion since the completion of the human genome sequence in health applications [26,27].

Samples collected for forensic purposes in the U.S. are not ordinarily considered research, but are instead protected from misuse by the various state laws, and sharing of data at the federal level is governed under the Privacy Act of 1974 (5 U.S.C. §552) [28]. The Privacy Act is limited in its scope, excluding non-residents and with no provisions for persons who may be considered belonging to a vulnerable population. The Privacy Act does require that the agencies collecting information inform each individual of the intended uses, the authority under which it is collected, and what the effects may be on the person (See §3(e)(3)). In the context of DNA collection, the Privacy Act notice for the National DNA Index System (NDIS) from 1996 (61 FR 37495) requires consent for retention and disposal of DNA records outside of judicial or criminal justice authority [29]. In the missing persons context in particular, the NDIS protocol requires consent to document the voluntariness of the collected FRS [2]. The mechanism of consent, however, is not proscribed.

While FRS collection for missing persons is not research per se, the families of the missing may be of populations considered "vulnerable" under research contexts governed under the Common Rule (45 CFR 46) [30,31], which typically encompasses groups that are perceived to lack the capacity to consent fully and/or that are at risk of exploitation (e.g., children, pregnant women, and prisoners) [32,33]. Recent updates to the Common Rule have expanded this definition to include individuals with impaired decision-making capacity, or economically or educationally disadvantaged persons [34]. Not covered under this definition are populations that have been historically excluded and socially disadvantaged persons [35].

In the contexts of FRS collection, the vulnerability of a person may include these definitions, and indeed the missing person may be from a socially excluded population (e.g., homeless, immigrants, refugees, sex workers, youth) [33]. But also importantly, collecting FRS from a person who has a missing loved one places the donor at risk of coercion. In an emergency scenario, like the loss of a loved one, the comprehension of risk is secondary to the urgency to do whatever is possible to locate the family member. With that mindset, a person under duress at the time the agreement is presented may not fully comprehend informed consent. In this way, the family members of a missing person should be considered a group vulnerable to coercion by authorities. Standard practices in FRS collection acknowledge this coercion risk and recognize that trust between the agent collecting the sample and the family member is vital [9]. Moreover, the criminal justice purpose of FRS collection in mass fatalities and missing persons' cases overlaps with the humanitarian nature of the identification of the deceased, necessitating an examination of the privacy protections of the family members. Therefore, we argue that the bioethical principles of informed consent in research contexts ought to be applied in FRS provision.

One best practices analysis for missing migrants' investigations