

# CONCEPTS

## Personal Derived Health Information: A Foundation to Preparing the United States for Disasters and Public Health Emergencies

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### ABSTRACT

**Background:** In the days following a disaster/public health emergency, there is great effort to ensure that everyone receives appropriate care and lives are saved. However, evacuees following a disaster/public health emergency often lack access to personal health information that is vital to receive or maintain quality care. Delayed treatment and interruptions of medication regimens often contribute to excess morbidity and mortality following a disaster/public health emergency. This study sought to define a set of minimum health information elements that can be maintained in a personal health record (PHR) and given to first responders/receivers within the first 96 hours of a disaster/public health response to improve clinical health outcomes.

**Methods:** A mixed methods approach of qualitative and quantitative data gathering and analyses was completed. Expert panel members (n=116) and existing health information elements were sampled for this study; 55% (n=64) of expert panel members had clinical credentials and determined the health information. From an initial set of 6 sources, a step-wise process using a Likert scale survey and thematic data analyses, including interrater reliability and validity checks, produced a set of minimum health information elements.

**Results:** The results identified 30 essential elements from 676 existing health information elements, a reduction of approximately 95%. The elements were grouped into 7 domains: identification, emergency contact, health care contact, health profile—past medical history, medication, major allergies/diet restrictions, and family information.

**Conclusions:** Leading experts in clinical disaster preparedness identified a set of minimum health information elements that first responders/receivers must have to ensure appropriate and timely care. If this set of elements is used as the fundamental information for a PHR, and automatically updated and validated during clinical encounters and medication changes, it is conceivable that following large-scale disasters clinical outcomes may be improved and more lives may be saved.

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**Key Words:** disasters, public health emergency, health information, personal health records

In all disasters and public health emergencies, health professionals must respond to a surge of displaced individuals and handle a variety of met or unmet health care needs. In such situations, first responders are frequently challenged in their ability to provide essential health care due to incomplete knowledge of patient health history and lack of time or resources to access it. Research results and reports from Hurricane Katrina showcased that evacuees did not carry their health information, and this lack of information ultimately resulted in a loss of lives or a delay in receiving essential health care services.<sup>1-3</sup> About one-half of the 1000 Hurricane Katrina evacuees surveyed did not carry their regular medications, and one-fifth reported a disruption in treatment of at least one chronic condition.<sup>1</sup> Moreover, in the six months following the disaster, a 47% increase was noted in crude mortality in the New Orleans metropolitan area.<sup>2</sup> Given that 125 mil-

lion Americans have at least one chronic illness, and those with chronic conditions tend to suffer the most adverse health outcomes after a disaster, there is a need for better disaster preparedness planning and improved access to care strategies, including essential health information.<sup>3,4</sup>

The Affordable Care Act (ACA)<sup>5</sup> and research suggest that timely access to personal health information, specifically following a disaster, may improve continuity of care, reduce disaster casualties, and decrease the cost of health care.<sup>2,3,6,7</sup> Personal health records (PHRs) that electronically validate information provided by primary care providers and pharmacies have been proposed as a possible method to improve timely access to more complete and accurate health information in the aftermath of disaster.<sup>8</sup> The establishment of a standard set of “minimum” health information elements (eg, pa-

FIGURE 1

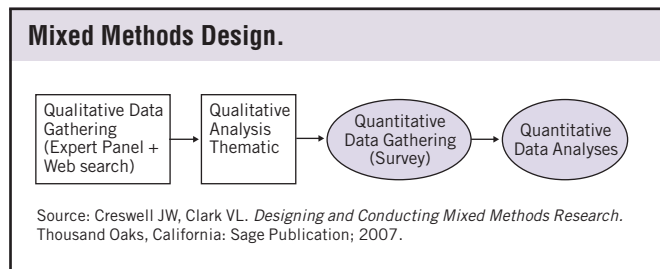
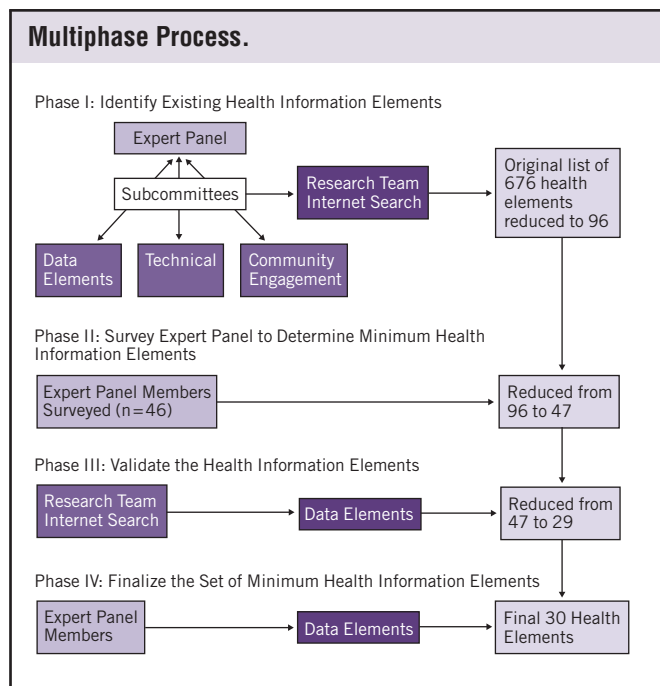


FIGURE 2



tient identification and personal health history) could reduce barriers to timely and appropriate postdisaster health care and mitigate excess morbidity and mortality by providing only the essential information needed by a first responder (eg, first-response personnel including emergency medical personnel, firefighters, police, or volunteers) in a postdisaster setting.

The present investigation identifies the minimum health information on existing PHRs and establishes a new data set using input from subject matter experts in the field of disaster health. This investigation is part of a larger translational research project to evaluate existing and potential health security devices that individuals could carry and use to share their personal health information with health care providers in the first 96 hours of a disaster.

**METHODS**

A multiphased, mixed methods approach, which combined expert panels, surveys of experts, and examinations of existing/past efforts, was employed to arrive at a set of minimum health

information elements. The set was reconfirmed through various weighting procedures, as described here (Figure 1).<sup>9,10</sup>

**Expert Panel**

A 116-member panel representing federal organizations, public health associations, health information technology organizations, emergency preparedness officials, and content experts in the fields of aging, chronic diseases, and disparities (Table 1) served as subject matter experts for the broader grant project.\* Each member of the expert panel participated in at least one of three workgroups (community engagement, data elements, or technical) that informed the direction and goals of the larger research project. More than one-half (n=64, 55%) of the expert panel had clinical credentials and served as content experts for the literature review and as raters for reliability and validity tasks. The final set of health information elements were validated by the 13 members of the data elements workgroup and the clinician content experts of the research team.

**Health Information Elements**

A purposive sample of existing health information elements was compiled by the expert panel and used as the initial source to derive the set of minimum health information elements for this project. The inclusion criteria used to determine the health information stipulated that the document or product of origin must be established by research, existing literature, and expert reviews recommended by our expert panel and through snowball sampling of leaders in the field. The research team conducted two separate Internet searches. The first was to ensure that the expert panel’s recommendations for health information adhered to the inclusion criteria, and the second was to ensure no additional products/forms were available in the peer-reviewed literature.

**Procedure to Establish the Minimum Health Information Elements**

A four-phase process was used to establish the set of minimum or essential health information elements (Figure 2).

**Phase I—Existing Health Information Data Elements Are Identified**

The first phase identified all health information elements contained in existing instruments. An Internet search was conducted using the following search engines: MEDLINE-PUBMED, PubMed Central, Free Medical Journals, and the Directory of Open Access Journals. The following key terms were searched: personal health record and emergency preparedness.

From the collection of national health information instruments, the research team completed a thematic analysis to gather an exhaustive list of all health information data elements.<sup>10</sup> The frequency of occurrence of each data element was then calculated to identify the health information elements that appeared in multiple instruments. Given the need to ensure commonality and uniformity, the identified health information elements were further analyzed for their use in medicine by first responders and their

alignment with electronic record requirements in both the ambulatory and inpatient settings of care.<sup>11</sup> Health information elements that were identified in at least one-half of the forms were presented to the expert panel and data elements workgroup for further review. If a particular element was identified in fewer than half of the forms, but was also a subcategory of a data element that did meet the inclusion criteria, that particular element was also included. For example, “allergies” (data element) appeared in three of the six instruments, but “reason for allergy” (subcategory) was only in two. “Reason for allergy” and “allergies” were both kept for the next phase of evaluations.

### Phase II—Survey Expert Panel Determines Minimum Health Information Elements

The list of health information elements obtained from phase I was presented to the expert panel through a Web-based survey.† Respondents ranked each health information element on a three-point Likert scale as either “Do not include,” “Should include,” or “Must include.” To test for content criteria and face validity,<sup>12</sup> the survey was reviewed by the research team and expert consultants, and then pilot tested with experienced clinical health care providers who were not associated with the project before being administered to the expert panel.

Survey results were analyzed using descriptive statistics in a stepwise process, which included the following:

Step 1: Frequency test. Any element that had at least one “Must include” was kept for consideration. Elements that ranked only “Should include” or “Do not include” were omitted.

Step 2: Mean test. Remaining elements were compared after they were weighted and averaged. For individual health information data elements, each response of “Must be included” was weighted at 100% (1 point), “Should include” scored 50% (0.5 point), and “Do not include” scored 0% (0 point). An average was calculated based on the weights, and each survey element received an overall percentage.

Step 3: Range. Elements were kept if the weighted average was above 70%.

### Phase III—Data Elements Workgroup Validates the Minimum Data Elements

The results from phase II were checked for reliability and validated by the data elements workgroup.‡ The workgroup used an interrater reliability process in which a group leader moderated a discussion and provided information to support, refute, or analyze discussants’ concerns.<sup>10</sup> This process was done for each health information element. The final list of data elements was approved by all members of the workgroup.

### Phase IV—The Set of Minimum Health Information Elements Are Finalized

Using a performance management methodology, a final vetting process of the phase III list of data elements took place at a face-to-face expert panel meeting. All data element work-

## TABLE 1

### Expert Panel Member Organizations

American Medical Association <sup>a</sup>
Agency for Healthcare Research and Quality
American Academy of Pediatrics <sup>a,b</sup>
American Association of Motor Vehicle Administrators (Real ID, Organ Donation)
American Association of Retired Persons
American College of Surgeons
American Health Information Management Association <sup>a,b</sup>
American Hospital Association
American Nurses Association
American Public Health Association
American Red Cross
American Society of Consultant Pharmacists
ANSER/Analytic Services Inc
Association of State and Territorial Health Organizations
Bureau of Public Health Preparedness and Emergency Response—Chicago Department of Health
Cabarrus Health Alliance—North Carolina
Department of Defense—Office of Health Affairs
Department of Homeland Security
DHHS—Office for At-Risk Individuals
DHHS—Office of Public Health Preparedness and Response <sup>b</sup>
DHHS—Specialized Information Services, National Institutes of Health, National Library of Medicine
DHHS—Office of the Assistant Secretary for Preparedness and Response
DHHS—Office of the National Coordinator for Health Information Technology <sup>b</sup>
eHealth Initiative
Environmental Systems Research Institute—Geographical Information Systems (Hospitals and Healthcare) <sup>b</sup>
inVentiv Health & Global Emergency Resources
Johns Hopkins Bloomberg School of Public Health <sup>b</sup>
Kaiser Permanente <sup>a</sup>
LexisNexis Risk Solutions
LifeGuard30 (Emergency Personal Health Record System)
Medical Group Management Association—Project SwipeIT
Microsoft HealthVault
MITRE—Information Systems Engineer (FFRDC—HHS APSR Support)
National Association of Chronic Disease Directors
National Association of Community Health Centers
National Association of County and City Health Officials
National Council for Prescription Drug Programs <sup>b</sup>
National Disaster Life Support Foundation, Inc
National Hispanic Medical Association
National Medical Association/W. Montague Cobb Health Institute
National Native American EMS Association <sup>b</sup>
National Sheriffs’ Association <sup>b</sup>
Office of the Assistant Secretary of Defense for Health Affairs OASD(HA)
Office of the Surgeon General—Civilian Volunteer Medical Reserve Corps
Project HealthDesign—Robert Wood Johnson Foundation
Public Health Law and Policy—Sandra Day O’Connor College of Law <sup>b</sup>
RAND Corporation
Robert Wood Johnson Foundation Health Group
Smart Card Alliance
Strategic Health Innovation—Center for Disaster Medical Response
The PHR Project—University of North Carolina
The Smart Card Alliance
VHA—Office of Health Information
VHA, Veterans and Consumer Health Informatics Office <sup>b</sup>
Workgroup for Electronic Data Interchange <sup>b</sup>

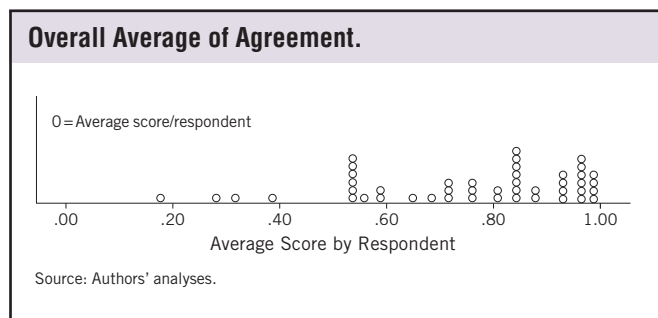
Abbreviations: APSR, annual project and services report; DHHS, US Department of Health and Human Services; EMS, emergency medical services; FFRDC, federally funded research and development centers; VHA, Veterans Health Administration.

<sup>a</sup>Snowball sample for personal health records.

<sup>b</sup>Data elements workgroup.

Source: Authors’ data.

FIGURE 3



group members approved the final list. The elements were then clustered according to category or theme, and domain titles were decided.

## RESULTS

### Overall Results

The overarching goal of the multiphase process was to delineate a set of minimum health information elements to be included on a portable person-owned health record for use by displaced individuals and first responders within the first 96 hours of an emergency. From the initial cache of personal health information products/forms, a total of 676 health information elements were identified. Through the multiphase process, these were reduced to a set of 30 health information elements (Table 2) deemed necessary and essential to providing timely, quality health care in the aftermath of disaster or public health emergency. Of these 30 elements, 25 were selected by the expert panel and data elements workgroup. Another five health information elements (biomarker, universal identification,<sup>§</sup> alternative language, communicable disease, and mental illness) were identified, based on their importance to health care retrieval, the high risk of individual nondisclosure of health information, and their importance in ensuring timely and appropriate postdisaster care. The results from the iterative phases are described here.

### Phase I—Existing Health Information Data Elements Are Identified

The phase I content expert inquiry and literature search identified and validated six distinct national health information forms (Table 3). From these six forms, 676 mutually exclusive health information elements were identified. A total of 96 data elements occurred in at least one-half of the personal health information forms and were kept for further review.

### Phase II—Survey Expert Panel Determines the Set of Minimum Health Information Elements

Step 1: Frequency test. A total of 72% (n = 46) of the expert panel members\*\* responded to the Web-based survey and rated the 96 health information elements from phase I (Table 2).

Step 2: Mean test. The overall average response rating was 75.1% on a scale from 0 to 100%. Many respondents ranked

most items “Must be” or “Should be” included, with the majority of respondents reporting the items “Must be” included (Figure 3).

Step 3: Range. By retaining the elements that scored above a 70% weighted average, the list of minimum health information elements was reduced from 96 to 47. Of these 47 elements, 28 were discrete health information elements and 19 were subcategory elements of these discrete items.

### Phase III—The Health Information Elements Are Validated

Data elements workgroup members came to consensus on 25 of the 47 phase II elements. The workgroup additionally identified four new elements (biomarker, universal identification, alternative language, and communicable disease) for further exploration with the public, bringing the minimum data elements list to a total of 29.

### Phase IV—The Set of Minimum Health Information Elements Are Finalized

The workgroup members agreed that the 29 (25 plus 4) health information elements from phase III met the defined “minimum and essential” criteria established in phase I. They also identified “mental illness information” as a fifth element to be explored with the public.†† These five additional elements were introduced and accepted by panel members as important, sensitive information that might not be disclosed or provided but would be essential for appropriate care within the first 96 hours of a disaster or public health emergency. The final set of 30 health information elements were then clustered into seven domains, reduced from eight domains. The seven domains include: identification, health profile—past medical history, emergency contact, health care contact, medication, major allergies/diet restrictions, and family information (Table 4).

## COMMENT

To our knowledge, this is the first national effort to derive a set of minimum health information elements for use in disasters and public health emergencies. This established set of elements is defined by national experts to address the perceived need of first responders to more efficiently and effectively communicate with individuals displaced by a disaster.<sup>13</sup> Moreover, because the elements were derived from health information for both adults and children, this set may meet the government’s initiative (ie, US Health and Human Services [HHS] and Department of Homeland Security) to address the function-based approach for health-related acute and ongoing care across continuums.<sup>8,14</sup> This set of health information elements will allow first responders and receivers to be prepared to aid *all individuals* in an emergency disaster or public health emergency by ensuring clear and accurate communication about the individual’s health care needs.

Accurate identification and emergency contact information have proved to be challenging issues following disasters/public health

TABLE 2

**Health Information Elements by Phases**

Phase II Final Domain	Phases III & IV Health Information Elements	
	(n = 47)	(n=25; additional=5)
<b>Identification</b>		
Name: first, last, middle	x	x
Address: street #, city, state, zip	x	x
Primary phone	x	x
Primary e-mail address		x
Date of birth	x	x
Gender	x	x
Biometric ID (fingerprint/thumbprint, photo for facial recognition, retina scan, etc) <sup>a</sup>	x	x <sup>a</sup>
Blood/RH type <sup>a</sup>	x	
Unique ID number <sup>a</sup>	x	x <sup>a</sup>
Preferred language spoken <sup>a</sup>	x	
Do you understand spoken English? (Y/N, if no please list an emergency contact who understands English and specify your primary language) <sup>a</sup>		x <sup>a</sup>
Are you oxygen dependent? (Y, N)	x	x
Do you have a major medical condition? (Y/N, if yes select from the pull-down menu - critical chronic disease list)		x
Do you have another condition not listed? (Y/N, specify)		x
Do you have a major physical injury/impairment? (Y/N, specify)		x
Do you have a major cognitive injury/impairment (Y/N, specify)		x
Are there additional health concerns? (specify)		x
Please list any communicable disease (HIV, tuberculosis [TB], etc) <sup>a</sup>		x <sup>a</sup>
Do you have a mental illness? (Y, N) <sup>a</sup>		x <sup>a</sup>
<b>Emergency Contact</b>		
Emergency contact 1 name/phone #/e-mail	x	x
Emergency contact 1 phone #	x	x
Emergency contact e-mail address		x
Emergency contact 1 alternate phone	x	
<b>Family Information</b>		
Would you like to complete this information for your dependents or other family members? (Y/N, If yes, prompt to additional records)		x
<b>Health Care Contact</b>		
Primary health care provider/physician (PCP) name	x	x
PCP phone #	x	x
PCP e-mail address if known		x
Health insurer name/Type	x	x
Member # and group ID	x	x
Insurance phone #	x	
<b>Medications</b>		
Are you taking any medications? (Y/N)		x
If you are taking medication, please specify the name(s) and indicate your dose & frequency if you know them (with don't know [DK] options)		x
<b>Major Allergies/Diet Restrictions</b>		
Dialysis regimen (renal failure) (medication list is a mix of things to indicate medical conditions– move to treatment/medication)	x	
Are you allergic to any medication(s)? (Y/N/DK, if so, to what?)	x (specific)	x
Specific medical allergy (what?)	x	
Do you have any other major allergies or dietary restrictions? (Y/N/DK, if so, to what?)	x	x
<b>Other</b>		
Penicillin	x	
Codeine	x	
Phenytoin sodium	x	
Latex	x	
Other major allergy (what?)	x	
Tetanus-Diphtheria-Pertussis (Y/N/DK & year if known)	x	
Major medical conditions (pull-down menu)	x	
Asthma	x	
Cancer (in treatment Y/N)	x	
Diabetes	x	
Deep venous thrombosis/pulmonary embolus	x	
Chronic obstructive pulmonary disease/emphysema	x	
Epilepsy/seizure disorder	x	
Revised to coronary artery disease (cardiac arrest)	x	
Hepatitis: this information may be sensitive	x	
High cholesterol: not clinically useful	x	
High blood pressure/hypertension	x	
HIV+/AIDS	x	
Stroke (history of)	x	
Active TB/TB	x	
Additional medical condition (specify)	x	
Major physical injury/impairment (Y/N, specify)	x	
Neurological damage/trauma (Y/N, cause)	x	
Major cognitive impairment (Y/N, specify)	x	
Significant surgery (Y/N, please specify procedure, date if known)	x	

Source: Authors' analyses.

<sup>a</sup>Represents the health information that should be considered for data elements workgroup.

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emergences; hence, they have been identified as essential elements that the expert panel unanimously agreed must be included.<sup>1,2</sup> However, health information for the most vulnerable populations requires further evaluation and attention to ensure that appropriate information is being obtained and used as intended (eg, to advance comfort, nutrition, and the medi-

cal regimen).<sup>8,15</sup> Acceptance of this health information set by both the public and first responders is critical to moving forward with this initiative. The topics that have been identified as sensitive in nature (ie, communicable disease information such as HIV status, insurance status, primary spoken language, and biomarkers used for identification) will be further ex-

### TABLE 3

Health Information Forms		
Citation	Name of Form	Purpose
American Academy of Pediatrics (AAP). Emergency Information Forms and Emergency Preparedness for Children With Special Healthcare Needs. <i>Pediatrics</i> . 2010;125(4):829-837. <a href="http://pediatrics.aappublications.org/cgi/reprint/125/4/829.pdf">http://pediatrics.aappublications.org/cgi/reprint/125/4/829.pdf</a> . Accessed April 27, 2010	Emergency Information Form (EIF) for Children with Special Health Care Needs	Target population: Children with special needs during emergency care Goal: Inform health care providers to provide the most optimal emergency care
American Medical Association (AMA). <i>The physician's role in medication reconciliation: Issues, strategies, and safety principles; 2007</i> . <a href="http://www.ama-assn.org/ama1/pub/upload/mm/370/med-rec-monograph.pdf">http://www.ama-assn.org/ama1/pub/upload/mm/370/med-rec-monograph.pdf</a> . Accessed April 27, 2010	My Medications	Target population: Individuals with chronic conditions Goal: Patients to make sense of his or her medications, reduce medication errors, minimize harm, maximize therapeutic effect
American Health Information Management Association (AHIMA). <i>Health information form for children; 2006</i> . <a href="http://www.myphr.com/images/uploads/childform.pdf">http://www.myphr.com/images/uploads/childform.pdf</a> . Accessed April 27, 2010	Health Information Form for Children	Target population: Parents and children Goal: Inform health care
American Health Information Management Association (AHIMA). <i>Health information form for adults; 2006</i> . <a href="http://www.myphr.com/PHR_Forms/adultform.pdf">http://www.myphr.com/PHR_Forms/adultform.pdf</a> . Accessed April 27, 2010,	Health Information Form for Adults	Target population: Adults Goal: Comprehensive adult health information to inform care
American Health Information Management Association (AHIMA). <i>Emergency personal health record</i> . <a href="http://www.myphr.com/index.php/start_a_phr/choose_a_phr/">http://www.myphr.com/index.php/start_a_phr/choose_a_phr/</a> . Accessed April 27, 2010	Emergency Personal Health Record	Target population: Children, adults, in emergencies Goal: Provide personal health information
In Case of Emergency (ICERX). ICERX.Org Informed Decisions, LLC © 2007	Public-service resource developed by the health care industry	Target population: Health care providers Goal: Allows licensed doctors and pharmacists anywhere in the United States to help you get information about your prescription medicines

### TABLE 4

Domains for Health Information by Phases		
	Phases I and II	Phase III
1	Identification	Identification
2	Emergency Information	Health Profile (Past Medical History)
3	Legal Documentation/Medical Directives	Emergency Contact
4	Immunizations	Health Care Contact
5	Allergies/Drug List	Medication
6	Health Log	Major Allergies/Diet Restrictions
7	Prescription Medications	Family Information
8	Other Nonprescription Medications	

Source: Authors' analyses.

\*Source: Authors' procedure. For the larger translational protocol, the goals focused on obtaining consensus on the type(s) of device(s) best suited for holding and sharing personal health information in a disaster, and ensuring that data collection methods garnered wide-reaching public response and represented vulnerable and at-risk subpopulations.

† Source: Authors' procedure. Specific PHR forms from which the health information elements were drawn were not revealed to the core collaborator team.

‡Source: Authors' procedure. The 13 group member volunteers were from the expert panel.

§ Source: Agency for Healthcare Research and Quality. Recommendations for a National Mass Patient and Evacuee Movement, Regulating, and Tracking System. Rockville, Maryland. Social Security numbers are not recommended as a unique identifier. Current recommendations include name, gender, and date of birth; however, biomarkers or universal identification was recommended by our core collaborator group.

\*\*Volunteers specifically had clinical health care experience and were well qualified through professional accreditation.

††Source: Authors' analyses. The workgroup unanimously decided that focus groups should be held to determine if the public was comfortable sharing this type of information because of the stigma and cultural sensitivity toward communicable diseases and mental health.

plored with the public in the next stage of research, as individuals may choose not to provide the information or use the PHR because of concern for stigma and/or profiling.

As sensitive health information, such as communicable diseases or mental illness may be required so that health providers can take appropriate precautions and interventions, consideration for privacy has been an ongoing discussion throughout this initiative. For example, Social Security numbers could not be used as the unique identifier due to poor recall of numbers, fake numbers, or no number.<sup>16</sup> While a universal identification (Voluntary Universal Healthcare Identifier) has been proposed, it has not been widely adopted. The expert panel from this study recommended using a biomarker (eg, a thumbprint) as an additional identity-authentication mechanism.

Policy must ensure that use of this information is for care and not rationing of care in day-to-day situations. Education at the community and individual practice levels will be essential to promoting this concept to at-risk communities. Moreover, HHS could use this set as an agreed-upon minimum health information standard to support their many initiatives, campaigns, and programs to promote basic public health.<sup>17</sup> We believe that this set of health information elements could be used as the fundamental information for PHRs. In addition, by continually updating and validating the elements through ongoing clinical encounters and medication changes, it is conceivable that clinical outcomes may be improved and more lives may be saved following large-scale disasters and on a daily basis.

As the ACA established that more electronic and integrated health information systems should better facilitate the concept of integrating PHRs into validated health information databases, this set of minimum health information elements could serve as standardized health information that will provide consistent information and aid the public in receiving appropriate, timely, quality care. The importance of interoperability standards using common health information among electronic systems will drive appropriate access and improved care, ultimately ensuring that health care providers and organizations requiring past and current health information will have access to the same information. Moreover, it is conceived that this vital information could be used while traveling or in day-to-day emergencies, although inquiry about this opportunity was not studied in the present research.

### Limitations

The results of this study are being evaluated with the public, but further evaluation with public health, emergency health responders, pediatricians, and health care providers should be completed to validate the utilization of these elements for both adults and children. In particular, the language used to collect the health information elements should have consistent meaning between the public and health care providers and meet health literacy standards to enhance patient-provider communication, especially in times of stress.

The expert panel did not constitute an exhaustive representation of public and private health care leaders; rather it was a fundamental, cross-functional sample of those who have expertise regarding disaster preparedness and chronic disease management for their organization or representative group. While the diverse expert panel was committed to ensure that clinical and social health information was captured, further research is needed to investigate other points of view. Additional research should explore the needs of responders for the utility of these elements during everyday disasters as well as public health emergencies.

Finally, this study looked only at PHRs in the US health care system. Similar work may exist in other countries, and consideration to personal health information and disaster response processes gathered and used in international arenas should be further evaluated for their public acceptance and effectiveness in disasters/public health emergencies.

### CONCLUSIONS

The results of this study highlight how experts in various organizations or agencies recognize what is needed for individuals to be prepared with basic minimum health information to receive improved quality care following disasters and public health emergencies. This information should be strongly considered for care across the continuum in clinical and community settings. Access to this set of health information by first responders, receivers, and individuals can help promote national priorities to improve health access and care, including safer care, enhanced population health, quality care with reduced inefficiencies, and increased patient satisfaction. Next steps include conducting a series of focus groups within communities throughout the United States for the public to be introduced and asked to provide their thoughts regarding the inclusion of the following elements: biomarkers, alternate language, mental illness, and communicable diseases. In addition, they will be asked about issues such as data storing, device management issues, safety, and security of personal health data.

Finally, policymakers and decision makers at the federal, state, and local levels can use this essential health information to set standards for PHRs. The results of this study should be considered to establish fundamental health care and policy that standardize the information that individuals and health care providers need to know across a continuum of care. To have a common language with patients and readily available health information allows health care providers the potential to not only save lives, but to reduce the impact of the financial burden on our health care system.

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