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An International Comparison of the Instigation and Design of Health Registers in the Epidemiological Response to Major Environmental Health Incidents

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ABSTRACT

Context: Epidemiological preparedness is vital in providing relevant, transparent, and timely intelligence for the management, mitigation, and prevention of public health impacts following major environmental health incidents. A register is a set of records containing systematically collected, standardized data about individual people. Planning for a register of people affected by or exposed to an incident is one of the evolving tools in the public health preparedness and response arsenal.

Objective: We compared and contrasted the instigation and design of health registers in the epidemiological response to major environmental health incidents in England, France, Italy, the Netherlands, and the United States.

Design: Consultation with experts from the 5 nations, supplemented with a review of gray and peer-reviewed scientific literature to identify examples where registers have been used.

Setting: Populations affected by or at risk from major environmental health incidents in England, France, Italy, the Netherlands, and the United States.

Methods: Nations were compared with respect to the (1) types of major incidents in their remit for considering a register; (2) arrangements for triggering a register; (3) approaches to design of register; (4) arrangements for register implementation; (5) uses of registers; and (6) examples of follow-up studies.

Results: Health registers have played a key role in the effective public health response to major environmental incidents, including sudden chemical, biological, radiological, or nuclear, as well as natural, more prolonged incidents. Value has been demonstrated in the early and rapid deployment of health registers, enabling the capture of a representative population.

Conclusion: The decision to establish a health register must ideally be confirmed immediately or soon after the incident using a set of agreed criteria. The establishment of protocols for the instigation, design, and implementation of health registers is recommended as part of preparedness activities. Key stakeholders must be aware of the importance of, and protocols for, establishing a register.

Agencies will find value in preparing and implementing registers as part of an effective public health response to major environmental incidents, including sudden chemical, biological, radiological, or nuclear incidents, as well as natural, more prolonged incidents.

Epidemiological preparedness is vital in providing transparent and timely intelligence for managing, mitigating, and preventing public health impacts of major environmental health incidents. Factors driving the need to assess the health impact of an incident include (1) incident nature and scale; (2) exposure (eg, type, degree,

duration, route); (3) physical and mental health effects; and (4) social, political, and media drivers.

Established response tools include, but are not limited to, (1) rapid health needs assessments (eg, the United States Centers for Disease Control and Prevention [CDC] Community Assessment for Public Health Emergency Response [CASPER], and the United States Agency for Toxic Substances and Disease Registry [ATSDR] Assessment of Chemical Exposures [ACE] Program)^{1,2}; (2) cross-sectional and longitudinal epidemiological studies of representative samples of the affected population; and (3) routine sources of data (eg, early warning or disease [active, passive, or syndromic] surveillance systems, health care service utilization or payment systems, and mortality records).^{3–5}

Planning for a register of people exposed to an incident is an evolving tool in preparedness.⁶ A register (also known as a “registry”) is a set of records containing systematically collected, standardized data about individual people, ranging from listings of exposed individuals with associated contact information to a full repository of information that includes demographics, exposure data, and health information.^{7,8}

Registers can be helpful to the affected population, health care professionals, and the scientific community, and particularly useful when there is (1) uncertainty about exposures or health outcomes, (2) long or unknown period between exposure and health outcome, (3) need to provide additional or specialized health or social care, or (4) need to reassure about the absence of disease.^{6,9}

We compared and contrasted the instigation and design of registers in England, France, Italy, the Netherlands, and the United States. Nations were chosen for demonstrative purposes due to their experience in responding to the major incidents, rather than aimed at being inclusive of all major incidents and registers.

METHODS

Through expert consultation, supplemented with a review of gray and peer-reviewed scientific literature, we identified the current systems and structures in place for registers in the 5 nations, presenting illustrations of historical case studies. We used PubMed and Google to search literature between January 1, 1990, and August 17, 2015, with the key words “register,” “registers,” “registry,” “registries,” “incident,” or “disaster.”

Nations were compared with respect to (1) types of incidents in remit for a register, (2) arrangements for triggering a register, (3) design of register, (4) arrangements in place for register implementation, (5) uses of registers, and (6) examples of follow-up studies. No human participants were involved in this commentary and therefore approval by an institutional review board was not required.

RESULTS

Types of major incidents in the remit for considering a health register

In England, Italy, the Netherlands, and the United States, no restrictions are placed on the incident type (eg, natural, anthropogenic); any incident of public health significance causing trauma (psychological trauma or physical exposure to chemical, biological, radiological, or nuclear [CBRN] incidents) may trigger a register. However, the responsible authorities may differ on the basis of incident type.

Register protocols exist in case of nuclear accidents in France, which have been tested with French nationals in Japan during the 2011 Fukushima Daiichi disaster.^{10,11} While there are currently no plans to include other types of disasters (eg, natural) in the remit for considering a register in France, other incidents can potentially be included on the proposition of a stakeholder.

Arrangements for triggering a health register

The Table compares the advance arrangements for triggering a register across the nations. There is variation in who decides to trigger and the criteria for triggering a register, as well as the need for gaining consent. In all countries, the decision may be at the local, regional, or national level, dependent on the nature of the incident. For example, in England, a decision framework for establishing a register has been developed.¹²

[TABLE].

In the Netherlands, the Coordinated Regional Incident Response Procedure (Gecoördineerde Regionale Incidentbestrijdings Procedure, GRIP) is a tiered procedure defining which authority level would be in charge, given the nature of the incident. GRIP recognizes 6 levels of response ¹³:

1. Response at the source, small-scale incident;
2. Source and effect response, incident with clear spread to surroundings;
3. Threat to well-being of large community within municipality;
4. Spread across municipality boundaries and/or possible scarcity of vital necessities/vital needs;
5. Spread across different regions;
6. National coordination when threat of national security.

Approaches to design and implementation of health register

In all nations, the design of the register, including the exposure definition and types of population considered, is dependent on the nature of the incident and is agreed following register activation. Registers can be of variable size, which will, in turn, inform planning and practice, such as data collection methods and the choice of database.

In England, the creation of a register epidemiology protocol has been published.¹⁴ The process for reaching agreement on register design is led by the Implementation Group, which reports to the Incident Director, who consults with other senior colleagues and considers register resource implications. A Major Incident Health Register plan was first established in 2012 and is presently being revised and updated by Public Health England.¹⁵ The plan provides for a flexible epidemiological response and may be used for environmental, infectious, or other incidents of public health importance. The plan includes an epidemiological protocol that considers the following requirements:

- Define the nature, scale, and extent of the hazard;
- Identify the population affected;
- Recruit the population affected and gather information on exposure and outcomes;
- Consider how the information should be used, including
 - Offer appropriate advice on relevant interventions;
 - Facilitate access to appropriate services;
- Consider the need for epidemiological studies, methodological approaches, and collection of data from the affected population.

In France, a register protocol for radiological accidents has been developed by CODIRPA (Comité directeur pour la gestion de la phase post-accidentelle d'une urgence radiologique; Steering Committee for the Management of the Postaccident Phase of a Nuclear or Radiological Accident).¹⁶ This action is listed in the French nuclear response plan. Registers are dependent on considering the exposed populations, the type of people supporting public health actions, and the specific incident circumstances. This registry contains contact information, time of record entry, registrant's location, and compliance with protective actions (eg, intake of iodine pills, sheltering). Local government representatives are responsible for register coordination. The target population is anyone potentially affected by the incident and those in the postincident protection zones. A planned working group under the coordination of the French Interior Ministry is awaiting activation to determine the logistics involved in register implementation. Application of register preparedness to other kinds of disasters beyond nuclear is being considered.

In the Netherlands, the register design is based on advice from a national expert committee to the director of the local authority or minister. Since 2000, for larger-scale incidents, the procedure is to establish an Integrated Information and Advisory Centre, where affected people can register and receive information and advice on all incident-related information.¹⁷ This may include alternative housing, clothing, and

vital necessities in the case of evacuation, financial support or compensation, or referral to medical care. Where appropriate, this may form the nucleus of a register combined with general practitioner (GP) patient lists (every citizen is obliged to be listed in 1 general practice). The register may involve registrant's location and symptoms, or it may involve a wider (cross-sectional or repeated) survey, a systematic collection and analysis of data from primary health care registries (GPs, psychologists, pharmacists), a biomarker study collecting information on pertinent exposures, or combinations thereof.

No registers have been activated following major incidents in Italy. However, a register would have been helpful following a severe earthquake that occurred in L'Aquila on April 6, 2009. Two surveys were deployed (once immediately after the incident, and again after 14-19 months) using the same instrument to measure health-related quality of life, with data collected according to the Italian Behavioural Risk Factor Surveillance System.¹⁸ Comparison of these 2 surveys is a part of CoMeTeS (Conseguenze a Medio Termine del Sisma; Medium-term Consequences of the Earthquake), which investigated the prevalence of posttraumatic stress disorder and major depression among adult survivors.¹⁹ Other relevant public health investigations have been carried out, including the well-known Seveso industrial accident.^{20,21}

The US ATSDR has developed a Rapid Response Registry (RRR), a survey instrument that state and local entities can voluntarily adopt to register responders and other individuals exposed to natural and human-induced disasters.⁹ The RRR was developed following experience gained after the Oklahoma City bombing, the World Trade Center response, the Three-mile Island nuclear accident, and the Chernobyl nuclear accident. It is currently used by at least 22 state health departments in their statewide disaster preparedness plans.²² While data are usually collected and maintained by state or local health departments, the ATSDR provides technical assistance upon request (eg, attempting to identify individuals who left the disaster area before being enrolled and helping establish and maintain relevant databases). The type and extent of tracking efforts varied among past registries but commonly included hospital emergency and medical records departments, medical examiner records, and surveys of area physicians, building occupants, and survivors.²³ When attempting to identify individuals who have left the incident area, secondary data such as insurance or benefit claim records may be helpful. The information gathered is listed in Supplemental Digital Content Table 1 (available at: <http://links.lww.com/JPHMP/A255>), comparing register implementation arrangements between nations.

Uses of health registers

While uses of registers may vary on the basis of the type of incident and purpose of activation, the general uses across all nations include:

1. Supporting real-time needs assessment during an emergency;

2. Assessing future needs for medical assistance, health interventions, and health education;
3. Allowing appropriate advice to be given to those exposed to a major incident;
4. Facilitating access to appropriate services, including relocation management, social assistance, medical services, and compensation;
5. Assessing the baseline health status of victims before disaster (using medical records);
6. Enabling epidemiological assessment of exposure and the health impact of the incident, including the identification of short- and long-term health outcomes;
7. Initiating follow-up studies targeting the impacted population.

1. Follow-up studies based on health register

In all nations:

- The types of follow-up studies depend on the incident and study objectives but may include epidemiological investigations such as surveys, cohort, or case-control studies, time-series analyses, modeling studies, or other bespoke investigations.
- The technical and ethical process for approval of later studies involves written protocols to be submitted to the appropriate research ethics committee and the incident management team or expert committee.
- Written informed consent may be required if further studies are required. The collection of personal data is frequently required to undertake the public health response to an incident or outbreak. There are certain provisions in law to allow this without consent when it is used in this context. Such uses of data would not require ethics committee approval. Research ethics committee approval and associated research governance procedures would be appropriate for future epidemiological studies not directly supporting the public health response to the affected or exposed persons (eg, they seek to develop the evidence base for future public health action).
- Studies must comply with legislative and organizational data protection and information governance requirements. These govern the processes around collection, storage, security, access, reporting, and archiving or destruction of data including identifiable information.

Examples of incidents when a register was or could have been used for later study include:

- England:
 - A register was activated as part of the public health response to terrorist bombing events in London on July 7, 2005.²⁴ Establishing a health register was considered during the public health response after flooding in England over the winter of 2013-2014.²⁵ However, this event was not considered to have met criteria for triggering a register. A study group was established in 2014 that developed objectives of public health importance and subsequently commenced an individual-level research study.
- France:
 - A register coordinated by Santé publique France (the French National Public Health Agency), with the authorization of the Ministry of Health and the French Nuclear Safety Authority, supported French nationals in Japan during the Fukushima Daiichi disaster on March 11, 2011.¹¹ The register was launched to facilitate further epidemiological studies and the contact of people if medical follow-up was needed.²⁶
 - A register would have been useful but was not planned following the AZote Fertilisant factory explosion in 2001. A legal register was ruled by the Ministry of Justice a few months after the event, and an ad hoc representative sample was done 6 months after the event for future epidemiological studies on workers, schoolchildren, and residents.²⁷
- Italy
 - The CoMeTeS study (mid-term consequences of the earthquake) assessed population health after the 2009 earthquake in Abruzzi, although a register may have been useful.²⁸
- The Netherlands
 - Enschede Firework Disaster in 2000, where a survey and a GP registry were established, collecting blood and urine samples to assess exposures to trace elements of firework on a voluntary basis within 3 weeks of the disaster. A 10-year follow-up program with repeated surveys and registry was set up.^{29–31}
 - Volendam New Year's Eve discotheque fire 2001, where a register was compiled using electronic medical records.³²
 - Avian Flu Epidemic 2003, where a register of cases with symptoms suggestive of avian influenza was compiled.³³
- The United States

- A recent publication presents examples of environmental health registries codeveloped by the ATSDR,⁸ including the World Trade Center (9/11) Health Registry (in partnership with the New York City Department of Health and Mental Hygiene).^{34,35}

DISCUSSION

A feasible, acceptable, and valuable tool

Registers have been shown to be a feasible and acceptable tool in the public health response to major environmental incidents. Registers can be of value to all “5 Rs” in response efforts: rescue, recovery, reentry, reconstruction, and rehabilitation.³⁶

Registers are of particular value in the early stages following an incident, enabling the identification of potentially affected population to ³⁷:

1. Inform appropriate public health and management response actions;
2. Facilitate environmental exposure assessment;
3. Initiate follow-up epidemiological studies.

This was demonstrated during the French response to the Fukushima Daiichi disaster in March 2011.^{10,11} Given Santé publique France had established the legal and logistic capacity for register implementation, Santé publique France was able to launch a Web-based register within 1 week of the incident for French nationals in Japan at the time of and following the disaster. More than 1000 French nationals registered, providing the opportunity to understand and address the affected population's needs, as well as to provide useful information for external radiation exposure assessments during the short- and middle-term phases. While register establishment also offered the possibility of further studies, these were deemed unnecessary for the purpose of analyzing radiation-related health effects. The questionnaire offered a space for expression of people's concerns; individual answers or recommendations were given. Furthermore, a qualitative study on exposure to the stress and psychosocial impact of the Great East Japan Earthquake on French Nationals in Japan in March 2011 was launched among people who registered.³⁸ This study delivered valuable information on the mental stress and needs of populations exposed to industrial disasters, particularly useful as a positive initiative in the context of an apparent perception of abandonment by the authorities. The development of the French nuclear response plan revealed that registers were of value to management stakeholders, in addition to public health authorities.

The value of registers may be strengthened through the inclusion of occupationally exposed groups (ie, acute emergency, clinical, and public health responders).³⁹ This was seen in the aftermath of the World Trade Center disaster, when respiratory symptoms in firefighters signaled the possibility of health problems among residents.⁴⁰ With the potential for rescue and recovery efforts leading to harmful exposures, analyses of registers may detect any detrimental impact on health.³⁵

Moreover, concerns about reentry of the population may warrant monitoring and surveillance through registers.

Assuring quality and validity

For epidemiological purposes and appropriate public health response, the quality and validity of registers depend on the extent to which the population captured is representative of the exposed community. The identification of this population and enrollment onto a register must be established early to minimize (1) loss to enrollment and subsequent follow-up associated with population dispersal after the incident and (2) recall bias associated with increasing time following the incident.^{6,12,15,41}

The risk of inaction

The After Action Report following Hurricane Katrina described how the lack of a registry by the management support team compounded the tracking and location of patients treated in the medical unit.⁴² The societal unrest following the Tianjin explosion in China in August 2015 highlights the importance of timely identification of the affected population to develop an effective communication strategy that addresses the community's concerns.⁴³ Registers, as part of centrally organized outreach programs that do not depend on referral pathways, may reduce delays and barriers to access to services, as experienced following the London terrorist bombings.⁴⁴

Hallmark disasters in the Netherlands during the 20th and 21st centuries have greatly affected the thinking about Dutch disaster response. The 1953 flood, with more than 1800 deaths and tens of thousands of displaced people, led to the "Delta Works" elaborate defense system against high waters.⁴⁵ At the time, response efforts focused on restoration and the prevention of future events rather than health care after incidents. The 1992 Bijlmermeer airplane crash near Amsterdam was another "game changer." While the initial response and follow-up were exemplary, the manifestation of "medically unexplained physical symptoms" several years after the event and the attribution to possible exposure to the fire of the plane and its cargo led to social upheaval. Eventually, a Parliamentary Inquiry and a delayed health investigation 7 to 11 years after the event were established. The "secondary disaster" concept came to the forefront, with a need to implement integrated health and psychosocial care and epidemiological studies.⁴⁶ The lessons learned from the Bijlmermeer disaster led to an "integrated psychosocial aftercare approach" that is now the typical response to larger-scale incidents.¹⁷ This is a 3-pronged approach:

1. To set up an Information and Advice Centre (IAC) and maintain it for several years;
2. To adopt an integrated approach to psychosocial care provision;
3. To consider conducting a health study as well as health monitoring.

This integrated approach was first applied following the Enschede Firework Disaster in 2000.^{29–31} Relief workers from the Netherlands, Belgium, and Germany were at the scene within hours. An IAC, survey, and GP registry were established, with blood and urine samples collected voluntarily to assess potential exposures to trace elements of firework within 3 weeks of the disaster. The health survey assessed where people were, what they experienced, and what their first health symptoms were. The goal was to collect relevant information that otherwise would be lost over time.

Natural and prolonged disasters

In addition to sudden, major CBRN incidents or acts of terrorism, registers may be useful for natural or more prolonged incidents. Potential examples of when health register protocols may be helpful include floods, chronic exposure to mold, and secondary stressors such as displacement after the floodwater has receded.²³ In the United States, the GuLF prospective study is assessing the long-term health of cleanup workers and volunteers who responded to the 2010 Deepwater Horizon oil spill in the Gulf of Mexico.⁴⁷

In the context of a nuclear disaster, the possibility for the registered population to return for a follow-up surveys allows for completion of the duration of prolonged or intermittent exposures. Registers may also allow the follow-up of all public health actions.

The US CDC CASPER methodology is another complementary epidemiological tool that has been used extensively in response to natural and chronic disasters such as Hurricane Katrina, the Haiti earthquake, and the Gulf of Mexico Deepwater Horizon oil spill.^{2,3,48} The CASPER rapid health needs assessment uses 2-stage cluster sampling to capture a representative population from a line listing of addresses in the potentially affected community. The information on the representative population may be used to develop a register.

In addition, the US ATSDR developed the ACE Program to assist state and local health departments to perform a rapid epidemiological assessment after toxic substance spills and chemical emergencies.¹ The ACE Program has been successfully used during the chemical contamination of a municipal water supply for approximately 300 000 people and during an ammonia release affecting cleanup workers in the Gulf of Mexico Deepwater Horizon oil spill, among other incidents.

The benefits of preparedness and planning

Because of the infrequent nature of major incidents, key stakeholders must be aware of the importance of and protocols for establishing a register following such incidents.¹⁴ A preestablished register protocol will help ensure the capture of a representative population.^{16,41}

Implications for Policy & Practice

The decision to establish registers must be confirmed immediately or soon after the incident using set criteria. While specific criteria may be unique to each country, Paranthaman et al 12 present a decision framework that includes several criteria. Given the infrequent nature of major incidents, key stakeholders must be aware of the importance of, and protocols for, establishing registers. The establishment of protocols for the instigation, design, and implementation of registers is recommended, together with preparedness activities, and establishing a register in pilot or exercise circumstances. We recommend that the register protocol be aligned with the entire response effort, and not in silos, risking duplication of efforts during a time when resources are limited. Finally, it is worth exploring an international standardized approach to the design and implementation of a registry.

In France, a factsheet presents the principles of implementing a register after a nuclear accident. A Ministry of Interior working group is planned to manage the sharing of information between authorities. The 2015 Paris terrorist attacks illustrated once again how much a coordinated and standardized registering process would help all stakeholders. Currently, a tool for centralizing registers is being implemented by the Ministry of Health. For environmental disasters, Santé publique France has established a protocol and computing capacity for the launch registers without delay.

Limitations

This was neither a systematic review of the literature nor a comprehensive study of every incident where a register has or could have been used. Moreover, our report is limited to 5 nations. However, the consultation with experts has demonstrated the value of using registers in the public health response to major environmental incidents.

CONCLUSION

Our review demonstrates that local, regional, national, and international agencies will find value in preparing and implementing registers as part of an effective public health response to major environmental incidents, including sudden chemical, biological, radiological, or nuclear incidents, as well as natural, more prolonged incidents.

Author Contribution:

1. Behrooz Behbod wrote the first draft and edited the subsequent and final versions.
2. Giovanni Leonardi cogenerated the idea and structure for the manuscript and reviewed and contributed to all drafts.
3. Yvon Motreff cowrote the French results and discussion and reviewed the manuscript.
4. Charles Beck wrote the English contribution and reviewed the manuscript.
5. Joris Yzermans cowrote the Dutch results and discussion and reviewed the manuscript.
6. Erik Lebre cowrote the Dutch results and discussion and reviewed the manuscript.
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8. Tesfaye Bayleyegn cowrote the US

results and reviewed the manuscript. 9. Amy Funk Wolkin cowrote the US results and reviewed the manuscript. 10. Paolo Lauriola cowrote the Italian results and reviewed the manuscript. 11. Rebecca Close reviewed and contributed to all drafts. 12. Helen Crabbe reviewed and contributed to all drafts. 13. Philippe Pirard, senior author, cogenerated the idea for the manuscript, cowrote the French results and discussion, and reviewed and contributed to all drafts.

REFERENCES

1. Agency for Toxic Substances and Disease Registry. Assessment of Chemical Exposures (ACE) Program. <http://www.atsdr.cdc.gov/ntsip/ace.html> . Published 2015. Accessed September 1, 2015.
2. Centers for Disease Control and Prevention. Health Studies Branch—Preparedness and response for public health disasters. <http://www.cdc.gov/nceh/hsb/disaster/publications.htm> . Published 2015. Accessed September 1, 2015.
3. Centers for Disease Control and Prevention. Community Assessment for Public Health Emergency Response (CASPER) Toolkit. 2nd ed. Atlanta, GA: Centers for Disease Control and Prevention; 2012.
http://emergency.cdc.gov/disasters/surveillance/pdf/casper_toolkit_version_2_0_508_compliant.pdf . Accessed April 27, 2015.
4. van den Berg B, Grievink L, Gutschmidt K, et al. The public health dimension of disasters—health outcome assessment of disasters. *Prehosp Disaster Med*. 2008;23(4):s55–s59. Bibliographic Links
5. Orford R, Crabbe H, Hague C, Schaper A, Duarte-Davidson R. EU alerting and reporting systems for potential chemical public health threats and hazards. *Environ Int*. 2014;72:15–25.
6. Morgan O, Odams S. Health registers as a tool for disaster epidemiology. In: Kreis IA, et al., eds. *Essentials of Environmental Epidemiology for Health Protection. A Handbook for Field Professionals*. Oxford, England: Oxford University Press; 2012:46–55.
7. Brooke EM. *The Current and Future Use of Registers in Health Information Systems*. Geneva, Switzerland: World Health Organization; 1974.
8. Antao VC, Muravov OI, Sapp J II, et al. Considerations before establishing an environmental health registry. *Am J Public Health*. 2015;105(8):1543–1551.
9. Agency for Toxic Substances and Disease Registry. Rapid Response Registry. <http://www.atsdr.cdc.gov/rapidresponse> . Published 2015. Accessed September 1, 2015.
10. General Secretariat for Defence and National Security. National response plan—major nuclear or radiological accident. No. 200/SGDSN/PSE/PSN. http://www.sgdsn.gouv.fr/IMG/pdf/N_Plan.pdf . Published February 2014. Accessed September 1, 2015.
11. InVS (Institut de Veille Sanitaire). Séisme Japon: enregistrement des ressortissants français présents au Japon dans les suites du séisme du 11 mars 2011. <http://www.invs.sante.fr/%20fr/Dossiers-thematiques/Environnement-et-sante/Catastrophes-naturelles-et-industrielles/Etudes-autour-de-catastrophes/Seisme-Japon-enregistrement-des-ressortissants-francais-presents-au-Japon-dans-les-suites-du-seisme-du-11-mars-2011> . Published 2011. Accessed September 1, 2015.
12. Paranthaman K, Catchpole M, Simpson J, Morris J, Muirhead CR, Leonardi GS. Development of a decision framework for establishing a health register following a major incident. *Prehosp Disaster Med*. 2012;27(6):1–7.
13. GRIP (Gecoördineerde Regionale Incidentbestrijdings Procedure). <http://www.infopuntveiligheid.nl/Publicatie/DossierItem/12/5678/kennispublicatie-grip-regeling-1-tm-5-en-grip-rijk.html> . Published 2014. Accessed October 5, 2015.
14. Close RM, Maguire H, Etherington G, et al. Preparedness for a major incident: creation of an epidemiology protocol for a health protection register in England. *Environ Int*. 2014;72:75–82.

15. Health Protection Agency. Establishing a Major Incident Health Register. London, England: Health Protection Agency; 2012.
16. Pirard P, Schmitt M, Fite J, Bernier MO. Le recensement, un acte indispensable en situation post-accidentelle, une organisation importante à prévoir. *Reflexions du GT4 du CODIRPA. Controle*. 2008;180:35–40.
17. Huijsman-Rubingh RRR. Disaster relief policy in the Netherlands, contribution to the OECD international futures project on emerging systemic risks. In: *Emerging Risks in the 21st Century: An Agenda for Action*. Paris, France: OECD; 2002.
<http://www.oecd.org/futures/globalprospects/37944611.pdf> . Accessed September 1, 2015.
18. Baldissera S, Campostrini S, Binkin N, et al. Features and initial assessment of the Italian Behavioral Risk Factor Surveillance System (PASSI), 2007-2008. *Prev Chronic Dis*. 2011;8(1):A24.
19. Gigantesco A, Mirante N, Granchelli C, et al. Psychopathological chronic sequelae of the 2009 earthquake in L'Aquila, Italy. *J Affect Disord*. 2013;148:265–271.
20. Consonni D, Pesatori AC, Zocchetti C, et al. Mortality in a population exposed to dioxin after the Seveso, Italy. Accident in 1976: 25 years of follow-up. *Am J Epidemiol*. 2008;167:847–858.
21. Pesatori AC, Consonni D, Rubagotti M, Grillo P, Bertazzi PA. Cancer incidence in the population exposed to dioxin after the “Seveso accident”: twenty years of follow-up. *Environ Health*. 2009;8:39.
22. US Government Accountability Office. HHS needs to develop a plan that incorporates lessons from the responder health programs. Report to Congressional Requestors p21-22. <http://www.gao.gov/new.items/d08610.pdf> . Published 2008. Accessed September 1, 2015.
23. Mallonee S, Shariat S, Stennies G, Waxweiler R, Hogan D, Jordan F. Physical injuries and fatalities resulting from the Oklahoma City bombing. *JAMA*. 1996;276(5):382–387.
24. Catchpole MA, Morgan O. Physical health of members of the public who experienced terrorist bombings in London on 07 July 2005. *Prehosp Disaster Med*. 2010;25(2):139–144.
25. Public Health England. Protocol for establishing a health register after a flood. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/378420/health_register_v2_CT.pdf . Published 2014. Accessed September 1, 2015.
26. Motreff Y, Pirard P, Lagrée C, Roudier C, Empereur-Bissonnet P. Voluntary health registry of French nationals after the Great East-Japan Earthquake, Tsunami, and Fukushima Daiichi nuclear power plant accident: methods, results, implications and feedback. *Prehosp Disaster Med*. 2016;31(3):326–329.
27. Lang T, Schwoebel V, Diene E, et al. Assessing post-disaster consequences for health at the population level: experience from the AZF factory explosion in Toulouse. *J Epidemiol Community Health*. 2007;61(2):103–107.
28. D'Argenio P, Carbonelli A, Cofini V, et al. Rapporti ISTISAN 13/2. Vol VIII (in Italian). Rome, Italy: Istituto Superiore di Sanità; 2013:72.
29. Yzermans CJ, Donker GA, Kerssens JJ, Dirkzwager AJE, Soeteman RJH, ten Veen PMH. Health problems of victims before and after disaster: a longitudinal study in general practice. *Int J Epidemiol*. 2005;34:820–826.
30. Dirkzwager AJE, Grievink L, van der Velden PG, Yzermans CJ. Risk factors for psychological and physical health problems after a man-made disaster. A prospective study. *Br J Psychiatry*. 2006;189:144–149.
31. van den Berg B, Grievink L, Stellato RK, Yzermans CJ, Lebre E. Symptoms and related functioning in a traumatized community. *Arch Intern Med*. 2005;165:2402–2407.
32. Dorn T, Yzermans JC, Spreuwerberg PM, van der Zee J. Physical and mental health problems in parents of adolescents with burns—a controlled, longitudinal study. *J Psychosom Res*. 2007;63:381–389.
33. Bosman A, Mulder YM, de Leeuw JRJ, et al. Avian Flu Epidemic 2003: public health consequences. Investigation of risk factors, health, well-being, health-care needs, and preventive measures with regard to poultry farmers and persons involved in controlling the AI H7N7 epidemic in the Netherlands. RIVM report 630940001/2004. <http://rivm.openrepository.com/rivm/bitstream/10029/9043/1/630940004.pdf> . Published 2004. Accessed October 5, 2015.

34. Farfel M, DiGrande L, Brackbill R, et al. An overview of 9/11 experiences and respiratory and mental health conditions among World Trade Center Health Registry enrollees. *J Urban Health*. 2008;85:880–909.
35. Antao VC, Pallos LL, Shim YK, et al. Respiratory protective equipment, mask use, and respiratory outcomes among World Trade Center rescue and recovery workers. *Am J Ind Med*. 2011;54:897–905.
36. Vallero DA, Lioy PJ. The 5 Rs: reliable postdisaster exposure assessment. *Leadersh Manage Eng*. 2012;12:247–253.
37. Bongers S, Janssen NA, Reiss B, Grievink L, Lebrete E, Kromhout H. Challenges of exposure assessment for health studies in the aftermath of chemical incidents and disasters. *J Expo Sci Environ Epidemiol*. 2008;18(4):341–359.
38. Hemdane A, Rudy H, Sturm G, et al. Exposure to Stress and Psychosocial Impact of the Great East Japan Earthquake on French Nationals Who Were in Japan in March 2011. Saint-Maurice, France: Institut de veille sanitaire; 2015:49.
<http://www.invs.sante.fr/Publications-et-outils/Rapports-et-syntheses/Environnement-et-sante/2015/Exposition-aux-facteurs-de-stress-et-impact-psychosocial-du-tremblement-de-terre-de-Tohoku-et-de-ses-consequences-sur-les-Francais-presents-au-Japon-en-mars-2011> . Published 2015. Accessed September 1, 2015.
39. Morgan O, Murray V, Snashall D. Occupational medicine, public health and disasters: a shared agenda? *Occup Environ Med*. 2008;65(6):367–368.
40. Izbicki G, Chavko R, Banauch GI, et al. World Trade Center “sarcoid-like” granulomatous pulmonary disease in New York City Fire Department rescue workers. *Chest*. 2007;131(5):1414–1423.
41. Soler MS, Pirard P, Motreff Y. Comparison of Three European Countries (UK, the Netherlands and France) in Terms of Epidemiological Response and Preparedness for a Disaster [practicum dissertation].
http://www.invs.sante.fr/en/Invs_en/Publications/Comparison-of-three-European-countries-United-Kingdom-the-Netherlands-and-France-in-terms-of-epidemiological-response-and-preparedness-for-a-disaster . Published 2015. Accessed September 1, 2015.
42. Miller H, McNamara J, Jui J. Hurricane Katrina (OR-2 DMAT) After Action Report: New Orleans Airport, August 31-September 10, 2005.
<https://www.hsdil.org/?view&did=766144> . Published 2015. Accessed July 28, 2016.
43. Traynor P. Residents demand compensation in Tianjin blasts. Associated Press. August 17, 2015. <http://bigstory.ap.org/article/85c54dbf44954367ac949f1d67684308/china-blast-zone-blocked-over-contamination-fear-112-dead> . Accessed September 1, 2015.
44. Reifels L, Pietrantonio L, Prati G, et al. Lessons learned about psychosocial responses to disaster and mass trauma: an international perspective. *Eur J Psychotraumatol*. 2013;4. doi:10.3402/ejpt.v4i0.22897.
45. Delta Works Online Foundation. Deltawerken Online.
<http://www.deltawerken.com/en/10.html?setlanguage=en> . Published 2015. Accessed September 1, 2015.
46. Yzermans J, Gersons BPR. The chaotic aftermath of an airplane crash in Amsterdam: a second disaster. In: Havenaar JM, Cwikel JG, Bromet EJ, eds. *Toxic Turmoil. Psychological and Societal Consequences of Ecological Disasters*. New York, NY: Kluwer Academic/Plenum Publishers; 2002:85–100.
47. National Institutes of Health. GuLF Study (Gulf Long Term Follow-Up Study).
<https://gulfstudy.nih.gov/en/index.html> . Published 2015. Accessed October 5, 2015.
48. Bayleyegn TM, Schnall AH, Ballou SG, et al. Use of Community Assessments for Public Health Emergency Response (CASPERs) to rapidly assess public health issues—United States, 2003-2012. *Prehosp Disaster Med*. 2015;30(4):1–8.

TABLE

TABLE					
Arrangements for Triggering Health Registers					
	England	France	Italy	Netherlands	United States
Who decides to trigger?	Incident Director	LA with regional or national authorities.			
Decision at the national or local level?	Either; will depend on the incident.				
Criteria considered ^{a,b}	a-h, (± o, p, q)	b-h, p, q	a-h, k, n, q	a-h, m	c, e, f, i-o
Clear statement about need for consent of individuals for their details to be included on the register	Developing a register is an epidemiological investigation that may form part of the public health response. Completion of the minimum data collection form to establish the register may not require consent.	Clear statement exists. However, if not possible, people have to be informed about the treatment of data and their rights. For further epidemiological investigations, informed consent is required.	Clear statement exists.	Except for biomonitoring, there is no need for consent. Privacy procedure exists for linking demographic characteristics to medical records.	Currently, no clear statement; dependent on several issues including, but not limited to, whether federal public health officials are involved or a registry is being built entirely by local or state agencies. As a general rule, collection of minimum data to establish a basic registry will, most likely, be done by local and/or state responders and will not require consent. However, consent required to collect data for further epidemiologic al studies.

Abbreviations: INVS, Institut de Veille Sanitaire (French Institute for Public Health Surveillance); LA, local authority.

^aCriteria considered

The incident relates to exposure with novel characteristics (eg, setting or mode of distribution) or a novel exposure with little prior experience and is likely to harm public health.

There is insufficient knowledge on the type and latency of health outcomes due to the exposure and there are reasonable grounds to expect adverse outcomes.

The incident is likely to lead to significant political/public/media interest and might lead to excessive societal concerns. The decision to activate on this basis is subject to consultation with relevant interested parties.

The register might be useful in the clinical management of patients, particularly in the long term.

There is a reasonable possibility of short- or long-term physical and/or psychological health effects among the exposed population.

The exposure might result in particular adverse effects in vulnerable groups such as children or pregnant women including possible teratogenic effects.

Follow-up studies on exposed persons in the register might provide new knowledge of potential benefits to improve the health of the wider population in addition to benefits for the exposed persons.

Knowledge of health outcomes due to the exposure might enable interventions to reduce the impact of such exposures in the future, although future developments in science are not predictable.

Registry purpose and expected outcomes.

Duration and scope of data collection.

Existence of other data sources.

Timeliness of creation.

Availability of funds.

Availability of scientific and administrative capacity and expertise.

^bNote that for criteria o, p, and q, the availability of complete information is not essential at the decision stage, as the most of the relevant data can be gathered at a later date based on preliminary information on exposure (Paranthaman et al¹²).

It is possible to identify the population at risk due to availability of detailed demographic data.

It is possible to measure or estimate exposure data for individual cases or groups of individuals exposed.

There are sufficient data on the spatial distribution of the contamination or exposure.