



Preparedness for a major incident: Creation of an epidemiology protocol for a health protection register in England



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ABSTRACT

Large incidents and natural disasters are on the increase globally. They can have a major impact lasting many years or decades; and can affect large groups of people including those that are more susceptible to adverse consequences. Following a major incident, it may be considered necessary to establish a register of those people affected by the incident to provide appropriate advice on relevant immediate and longer-term public health interventions that may be required, provide reassurance to the public that their care is paramount, to reassure the worried well to avoid them inappropriately overwhelming local services, and to facilitate epidemiological investigations.

Arrangements for the prompt follow-up of populations after large incidents or disasters have been agreed in England and a protocol for establishing a register of individuals potentially affected by a large incident has been developed. It is important for countries to have a protocol for implementing a health register if the circumstances require one to be in place, and are supported by Public Health Authorities. Health registers facilitate the initial descriptive epidemiology of exposure and provide the opportunity of carrying out long term analytical studies on the affected population. Such epidemiological studies provide a greater understanding of the impact that a large incident can have on health, which in turn helps in the planning of health care provision. Registers can also assist more directly in providing access to individuals in need of physical and mental health interventions. The challenge that still remains is to formally pilot the register in the field and refine it based on that experience.

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1. Introduction

Large incidents involving chemical, biological, radiation and nuclear (CBRN) agents as well as natural disasters are on the increase globally (WHO, 2009). Such incidents, as well as transportation accidents and mass attacks on the general population can have a major impact on physical and mental health lasting many years or decades; and can affect large groups of people including those that are more susceptible to adverse consequences such as children, the elderly and pregnant

women. There is also a growing public interest in the impact of major incidents on health (Palmer et al., 2000).

There are many examples of natural and manmade disasters with major impacts; some of these led to a health register being established whilst others did not. In 1986 a chemical factory in Schweizerhalle, Switzerland caught fire and burned down. The factory contained 1300 tonnes of chemicals which were mostly agrochemicals; a large cloud developed and was driven by winds to Basel. A toxic stream from fire water run off flowed into the river Rhine and had international consequences (WHO, 1997). Environmental sampling was undertaken and a health register was established and the population was followed over time; the main health effects observed were an increase in respiratory symptoms and a considerable psychological strain on the population.

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In 1988 in the UK, 20 tonnes of aluminium sulphate solution was discharged into the wrong tank at Lowermoor Water Treatment Works, Camelford. Contaminated water entered the distribution network, causing mains water to have increased concentrations of aluminium sulphate (COT Lowermoor Subgroup, 2005). A health register was not established following this incident, but due to the on-going nature of public concern regarding water contamination following this event, a health register and health follow-up would likely have been beneficial to alleviate concerns over public health.

An explosion and fire at a fireworks depot occurred in the Netherlands in May 2000, completely destroying the surrounding residential area and injuring almost 1000 people and killing 22. Following this incident a health register was established and implemented effectively, allowing follow-up surveys of those directly affected and ongoing health monitoring by healthcare professionals to take place (Rorda et al., 2004).

In Japan in 2011, the Tōhoku earthquake and tsunami caused massive human distress, with over 100,000 people being evacuated from their homes and 19,000 deaths (World Nuclear Association, 2012). It also led to a series of equipment failures, nuclear meltdowns and releases of radioactive materials at the Fukushima Nuclear Power Plant, although there is no evidence of any deaths occurring as a result of radiation exposure following the Fukushima accident (WHO, 2013). Due to the nature of the accident, authorities acted quickly in setting up a health register and several follow-up surveys and studies on populations are on-going.

In June 2013, the North Indian states of Uttarakhand and Himachal Pradesh experienced heavy rainfall causing devastating floods and landslides which led to a huge population evacuation and caused the loss of 120 lives as of 11th July 2013 (DNA, 2013).

Following a major incident, it is important that public health agencies are able to respond in a coordinated manner. Central to the public health response is the ability to provide appropriate advice, information, and treatment to people affected both in the short- and long-term. In London on 7th July 2005, a series of bombs struck across the public transport system during morning rush hour resulting in injuries to over 770 and 52 fatalities (BBC News, 2005). Collaboration between the Health Protection Agency (HPA; now part of Public Health England; PHE) and National Health Service (NHS) providers in organising the response by mental health services staff to the London bombings in 2005 pinpointed difficulties in identifying affected individuals (Brewin et al., 2009). The need to consider epidemiology follow-up of those involved or affected by an incident prompted the development of a new protocol (Leonardi and Aus, 2006). On 26 May 2006 a workshop was held on population registries following incidents, reviewing data protection, legal and public health issues arising from the possible need to follow up members of the public affected by events such as the London bombings, natural disasters, chemical and radiation incidents. This encouraged the development of epidemiological protocols for establishing registers of affected people following large incidents.

The purpose of establishing a register is to identify the population affected by or exposed to the incident so that 1) appropriate advice on relevant immediate interventions can be provided, 2) access can be facilitated to the appropriate services, 3) reassurance can be provided to the public, 4) assessment of the health impact of the incident can be initiated, and 5) the longer-term health implications of the incident can be investigated. Those affected by or exposed to an incident can often disperse quite quickly following an incident and the rapid establishment of mechanisms to activate a register will help to ensure that the register is as complete as possible.

Epidemiology can be a useful tool to assess the health burden associated with a major incident even when the nature of the exposure is not known. The goal of the epidemiological investigation is to identify subgroups of the population who are at higher risk of disease and who will benefit the most from specific interventions. Epidemiological information can also be used to develop prevention strategies and should inform management actions (HPA, 2012).

Routine data is often insufficient to adequately capture health impacts of an incident and a health register may be the only way to capture the range of potential exposures and outcomes and follow up exposed populations over time.

Basic epidemiological information (i.e. name and address) may be collected by questionnaire or other methods (e.g. electronic data capture) and stored in a database which then constitutes a basic health register (Morgan and Odams, 2012). Health registers are key to facilitating communication between relevant services and to affected individuals, as well as enabling emergency and health services to better assess the health impact and identify longer-term health implications of an incident. In England, prior to 2012, there was not a standardised procedure or protocol for establishing a Health Register to systematically collate data in the immediate aftermath of a major incident (London Emergency Services Liaison Panel, 2012) so HPA (now part of PHE) agreed to develop an epidemiological procedure to generate a health register to address this gap.

2. Methods

A working group for the study was established for the Health Register Project (HRP), which included Delivery and Operational sub-groups. The Delivery Group (DG) was responsible for determining the requirements for triggering the establishment of a health register. Members were experts from many fields, including Infectious Disease Surveillance and Control, Emergency Response and other specialist in radiation, chemical and Environmental Hazards. It also included representatives from Department of Health (DH), Home Office and NHS London.

The Operational Group (OG) included subgroups for (i) epidemiology; (ii) data sharing and; (iii) communications with representation from across HPA and a number of Hospital Trusts and the Police National CBRN Centre. The OG and DG determined that a key requirement for a health register is to be able to establish rapidly following a variety of major incidents or sudden events resulting in casualties (or their likelihood).

The epidemiology subgroup was responsible for developing the epidemiology protocol and was chaired by one of the authors (HM). Members included experts in public health, environmental and field epidemiology, health response to disasters, radiation dose assessment, clinical psychology, and Accident and Emergency medicine.

A literature review was undertaken of incidents or events when a health register was used, or should have been considered, and included; UK events such as the incident affecting drinking water supplies at Camelford (UK) in 1988 (COT Lowermoor Subgroup, 2005), the London bombings of 7th July 2005 (Brewin et al., 2009; Brewin et al., 2010), the Buncefield oil depot fire in December 2005 (Hoek et al., 2007; HPA, 2006), and the alleged poisoning of a Russian dissident with polonium-210 in 2006 (Maguire et al., 2010). Other events from a number of countries included the large aircraft crash, in Amsterdam, in 1992 (Slotje et al., 2005), an explosion at a fireworks depot in Enschede, the Netherlands, 2000 (Rorda et al., 2004), the explosion at the AZF fertiliser factory in Toulouse, France in 2001 (Lang et al., 2007) and the collapse of the World Trade Centre (World Trade Centre Registry, 2004).

Unpublished literature were also included in the review including internal HPA reports covering incidents such as the polonium-210 incident, the Wigan coal tip fire follow-up, a diesel spillage in drinking water in Cornwall, as well as student dissertations from various countries such as Soler et al. (2010). In addition, views about methodological and practical aspects were obtained from a broad range of experts and stakeholders (Police, Ambulance, NHS Emergency Departments, Hospital Managers, Communication specialists).

The study group proposed four key objectives for a protocol: (1) how to identify the population affected; (2) how to recruit the population affected onto the health register; (3) how the information gathered

would be used, including: to offer appropriate advice on relevant interventions, and to facilitate access to appropriate services; and (4) what follow-up and epidemiological studies might be done and what the implications are for the methodological approaches to data collection and analysis.

Although the first step is to define the population at risk, in other words the exposure definition, in practice the term “affected population” was used to convey the notion that the risk of a health impact needs to be addressed even when not yet confirmed.

There are likely to be legal and practical issues raised by health care and other agencies when a public health authority requires individual level confidential information for the purpose of building a health register. This apparent conflict between the UK Data Protection Act and the UK Public Health Act could result in a potential reluctance to share information relevant to a register, especially in the possible absence of informed consent; therefore, a data sharing subgroup was formed to identify the approach required.

Following previous efforts to compile health registers in the aftermath of an incident, the lack of communication between agencies and the public has been highlighted as one of the most common issues. Therefore, a communication subgroup was established and prepared a communication plan.

3. Results

A major incident health register protocol was developed comprising of an implementation plan, epidemiology protocol, data protection and sharing guidance and communications strategy. The four stages for the epidemiology protocol included:

- (i) Trigger;
- (ii) Phase 1: Recruitment to a health register (establish register);
- (iii) Phase 2: Early studies (more detailed early analyses and uses);
- (iv) Phase 3: Later studies (later analyses and uses).

In general it is useful to recognise the sequence of activities as described in phases 1, 2 and 3; however, in practice the health register arrangements will have to be made to address each event in an appropriate way resulting in activities that may not follow this sequence of events precisely. The DG deemed that the initial decision or trigger to establish a health register following an event would be taken by an Incident Director (ID) in consultation with a number of specified health protection specialists and the Chief Medical Officer or appropriate deputy from the Department of Health (HPA, 2012). Given the need to get into the field very quickly, it is desirable to involve local stakeholders as soon as possible so they can be involved in discussions regarding setting up a register. Criteria that should be considered when deciding whether a health register should be established include the nature and scale of the incident (including incidents with novel characteristics or unknown health impacts), poor prior knowledge of the type and latency of health outcomes and the possibility of short or long term health impacts, access to appropriate health services for those affected by, or exposed to, the incident including specific vulnerable groups, improved understanding of the epidemiology of the incident and the resultant health outcomes (leading to improved health interventions in the future) (HPA, 2012). A good degree of consensus on the criteria was reached between health protection specialists and external experts consulted (Paranthaman et al., 2012).

The arrangements formulated require that, following the decision to establish a health register, the ID will nominate a Responsible Officer (RO) for the task, who then immediately convenes a Health Register Implementation Group (HRIG). The membership of this group would normally comprise the following: the RO (chair), a medical director, a senior epidemiologist, a chemical or radiation specialist (depending on the nature of the incident), a coordinator, an emergency medicine specialist, an emergency planner for the local area, a local director of

health protection, a communications manager and administrative support staff. Further members can be co-opted for later meetings.

3.1. Identification and recruitment of population affected (Phase 1)

A number of possible scenarios or situations and corresponding affected populations or case definitions were identified as part of the study; these were as follows: explosion (Bombings, London 2005); chemical (Sarin gas, Tokyo 1995); biological (hypothetical bioterrorist release of anthrax in a sports complex); radiation (polonium 210 poisoning, London 2006); and rising tide (hypothetical major flood in three regions).

Exposure is the quantity of a substance (or distribution of a factor) in the environment that may adversely or beneficially affect human health, usually by direct contact with the human body through media such as water, air, soil, or food (Nieuwenhuijsen, 2003). In the context of health registers, the above definition needs to be applied to the geographical distribution of the hazard initially in Phase 1 to direct the selection of the population affected, and to collect initial information, and later in Phases 2 and 3 for more detailed assessment that might include modelling, questionnaires on individuals, and biomonitoring. As exposure assessment is an essential aspect to consider during an incident, it should adopt a simple approach. In the aftermath, it should be developed further to adequately capture characteristics of the exposure, as these assessments will provide estimates to inform epidemiological studies identifying associations between the exposure and subsequent health effects, if appropriate as well as to aid in the evaluation of the effectiveness of interventions taken to reduce exposure (WHO, 1997) (Bongers et al., 2008). The Health Register Implementation Group (HRIG) would need to consider at least two key questions: first, the type of exposure and how a relevant model of population exposure could be developed; second, the type of population affected and the appropriate methods of recruitment (Bongers et al., 2008).

In general, classification of the affected population by several levels of exposure is desirable for possible internal comparisons but in addition an external comparison could be studied as well.

The HRIG would also need to request advice of appropriate experts on exposure to specific agent(s) or factor(s) relevant to the event (i.e. population demographics, agent involved and source–exposure pathway). It is expected that the choice of an appropriate external expert, probably an employee of an academic institution, would often be necessary for inclusion in the initial consultation. Based on an initial understanding of the type, extent, location and time of the incident, combined with local knowledge about location of population and man-made structures, the population at risk can be defined, identified, and recruited into a register. For example, following a flood, the location of individuals potentially affected depends on the distribution of the flood water in the area, and the time of year of occurrence, as well as the general pattern of flood-related factors that could represent a hazard for population health. Also in terms of accounting for health and psychological impact of a flood, secondary stressors or indirect impacts such as bereavement, loss or financial difficulties could be considered as outcomes of the flood, they may also be precursors to mental health difficulties.

The protocol developed identified a range of possible groups of population affected along with suggested options on approaching and recruiting individuals for inclusion in a health register (Table 1).

Members of the public who seek medical care after an event would experience a range of symptoms with different degrees of severity. There are many potential health effects of flooding such as drowning, infectious diseases, drinking water contamination or shortages or mental health problems (Stanke, 2012). Therefore the recruitment of the affected population would need to be undertaken using a variety of methods.

Table 1
Groups of 'population affected' and appropriate methods of recruitment.

Group	Potential methods for recruitment
A. First responders in emergency service or health care settings	<ul style="list-style-type: none"> Emergency responders will mostly be members of the fire, police and ambulance services. However, a large number of other organisations may have also deployed staff in response to an incident, including local authorities, utility companies, private industry, military, civil defence and voluntary organisations. Individuals from these groups can usually be traced from work records after an incident and recruitment could take place in collaboration with occupational health departments.
B. Occupational or other groups	<ul style="list-style-type: none"> Some individuals affected by the incident may have been working at the time of the incident, such as train drivers or security guards. Individuals from these groups can usually be traced from work records after an incident and recruitment could take place in collaboration with occupational health departments. This group would also include children and staff at schools and other similar institutions.
C. Members of the public who seek medical care	<ul style="list-style-type: none"> Individuals who seek medical care after an incident, at primary or secondary facilities, or those contacting the health service helplines by telephone, for example via NHS 111 (formerly NHS Direct), are likely to be the worst affected proportion of the population exposed and represent the 'tip of the iceberg' of all those exposed. For this group, there is a clear opportunity to recruit individuals onto the health register at first contact, at a very early stage.
D. Other members of the public	<ul style="list-style-type: none"> The individuals most difficult to identify are those not occupationally deployed and who do not seek medical treatment or advice. This may include individuals who suffer the psychological, rather than physical effects of an exposure. Depending on the type of incident, 'other members of the public' may be the largest of the four groups. To minimise selection and enrolment bias and to get a true picture of the health impact, recruitment of these individuals is equally important. Dedicated help lines could be set up to provide medical advice, or existing telephone services such as NHS 111 (formerly NHS Direct) or poisons information services might become involved. Callers to these services could be recruited onto the health register. A more detailed operational protocol will be developed jointly between NHS 111 (formerly NHS Direct) and PHE describing the process. In some cases people could be identified through routine records such as immigration records, hotel guest registers, sales lists, credit cards, and so on. Direct media campaigns using social, local or national media may encourage individuals to self-report and web based and recruitment options should be explored.
E. Foreign Nationals	<ul style="list-style-type: none"> Recruitment and follow-up may prove difficult if interpreters are needed, or if potentially affected persons quickly return to their home countries. If many foreign nationals are involved, an Overseas Advice Team (OAT) may be set up at PHE from which advice may be taken. Close liaison with the public health authorities in persons' home countries may be needed, as follow-up may happen in a persons' home country. Representatives from each relevant country may have to be briefed and details of individuals affected passed on to ensure that follow-up takes place. A briefing pack may be useful in this case. This could be done through the OAT. A dedicated e-mail address could be set up so that affected overseas nationals or UK nationals outside the UK can make contact. It should be noted that previous incidents have highlighted issues regarding differing legislation and approaches to confidentiality in other countries.

Table 2
Possible methods of recruitment of individuals in Group C: Members of the public who seek medical care.

1. Recruitment through agencies present at site of incident:	London Ambulance Service	Some individuals will receive medical attention at the scene of an incident but do not go to hospital. Unless their details are recorded on-site by paramedics, these people will have to be traced along with other members of the public and an opportunity would be lost. In the case of other agencies collecting, or holding, a register of individuals who were at or affected by an incident, there are legal provisions of sharing data with PHE as a Category 1 Responder, if this information is needed for the efficient response and recovery from a major incident.
	Other services: e.g. metropolitan police	
2. Recruitment through primary care services:	General practice	In the days following a disaster, some affected people may seek medical attention from their family doctor who may be outside the disaster area. It may therefore be necessary to alert all medical facilities in the local area of the need to notify such individuals to PHE. Protocols may be developed and implemented through syndromic and other GP surveillance systems that allow recognition of increased numbers of people presenting with specified symptoms (e.g. nausea and vomiting in the case of potential exposures to very high radiation levels). Individuals with minor injuries may present at local Walk-in Centres. It may therefore be necessary to alert all medical facilities in the local area of the need to notify such individuals to PHE.
	Walk-in centres	
	NHS 111 (Formerly NHS Direct)	
3. Recruitment through secondary care services:	Minor Injuries units	Individuals with minor injuries may present at Minor Injuries units. It may therefore be necessary to alert all medical facilities in the local area of the need to notify such individuals to PHE.
	Hospital Accident and Emergency Departments and Admissions	

Table 3
Minimum dataset.

General Details	
Incident _____	Date: ___/___/___
Location of incident _____	
Personal Details	
Unique ID Number _____	
Surname _____	Forename _____
Next of kin (name/contact details): _____	
Date of Birth: ___/___/___	Male: Y/N Female: Y/N
Country of birth/nationality: _____	Country of residence: _____
Address in UK: _____	
Address abroad: _____	
Telephone number: _____	Mobile number: _____
Passport number (if not resident in UK): _____	
Email address: _____	
GP name: _____	GP practice (+address): _____
NHS number: _____	
Hospital Number: _____	A+E number: _____
Member of public: Y/N	Emergency responder: Y/N
Specify role and agency: _____	
Exposure Details	
Location at Incident: _____	Assisting at incident _____
Injured: Y/N	Nature of injury _____ (* See full list in Appendix 4)
Smelt fumes: Y/N	Inhaled fumes: Y/N
Smoke: Y/N	Blood splash: Y/N
Chemical splash: Y/N	Noise: Y/N
Other: Y/N (please specify) _____	
Medical Services contacted after incident	
GP: Y/N	Walk in clinic: Y/N
If yes which one? _____	
A+ E: Y/N	If yes which one? _____
Outpatient: Y/N	If yes which one? _____
Hospitalised: Y/N	If yes which hospital? _____
Ward? _____	

It is crucial to make a distinction between the phase of the incident when recruiting individuals to the health register (Phase 1), and later phases for developing specific follow-ups (Phases 2 and 3), delivering public health interventions (if required) or communicating information to members of the public or media appropriate to the event of interest.

3.2. Information to be collected (Phases 1 and 2)

Depending on the specific incident, a decision can be reached about what information is needed for inclusion in a register. A standardised questionnaire or proforma could be used to assess the exposure(s) and outcome(s). It should be emphasised that the nature and content of these questions will be dictated by the incident in question and population(s) affected (HPA, 2012).

The HRIG will attempt to ensure the completion of a minimum set of data for phase 1. The information collected in phase 2 is broad and depends on the specific scenario. A minimum dataset would include information on general details on the incident, personal, exposure details and medical services contacted after the incident (Table 3). Additional information should be considered to be collected in an early phase (Table 4), such as: bereavement or loss, access to healthcare and treatment, consent to follow-up, tertiary referral and psychological effects. Depending on the nature of the incident there are further questions that could be asked, for example if it is a radiation exposure there are specific questions to ask around what instructions were provided, the contaminated area and blood cell counts. The choice of fields for initial data collection needs to be flexible and appropriate to the specific

event, as well as being restricted to what is essential and cannot be obtained by other means, or at a later phase.

The HRIG will need to decide if more detailed information in the form of an early assessment of exposure and immediate health outcomes is important to estimate early effects and inform public health action. If HRIG decide more detailed information may be important for example in order to prevent further exposure, identify casualties and provide medical treatment to them (WHO, 1997). This early assessment could take the form of a cross sectional survey of all the individuals recruited onto the health register. It should be initiated as soon as possible with rapid completion as people's recollection of symptoms and whereabouts can become diminished and/or confused over time (partly through memory loss, and partly through messages being communicated in the media relating to the incident). Lack of clarity about the nature of the exposure, and hence what information to collect, may hamper rapid data collection efforts (HPA, 2012).

3.3. How the information gathered will be used (Phases 1 and 2)

Information gathered might be used for different purposes in different circumstances (Morgan and Odams, 2012). There are many situations where health registries are particularly useful, for example registries are able to identify the health and social care needs of the affected population which can then be used to target evidence-based and needs-based services, as was the case after the Enshede firework disaster (Rorda et al., 2004). An early identification of exposure as required by a register might prevent or reduce exposure in some groups. Data collected from environmental sampling may be used to measure exposure which can inform the risk assessment and environmental modelling if required (Bongers et al., 2008). Any evidence generated can then be used to reassure the public about the absence of disease, as for example after the Buncefield oil depot fire (Palmer et al., 2006). If there is a long period of time between exposure and health outcomes, a register would support identification of those that might need help later. If outcomes are anticipated but the extent or timing of these is uncertain, studies following a cohort of individuals over time might allow the assessment of various health outcomes, for example it will allow the identification of initial outcomes as well as those with long latency period. Consideration should also be given regarding the psychological aspects of any incident and how these are present whether or not a toxic agent is also present; both could be analysed following the same event (Page et al., 2010). Screening could be valuable to identify individuals who may be in need of intervention and should be followed up with a more detailed clinical assessment (as after London bombings). Data are helpful if the exposure and health outcomes are uncertain, or if exposures are identified (i.e. chemical plume) but health outcomes are unknown.

3.4. Later studies and their methods (Phase 3)

Once the earlier phases of identifying and recruiting affected individuals into a health register have been managed, the HRIG can use information to consider if further epidemiological studies to explore the relationship between exposure and health outcomes in the population recruited to the health register are warranted on public health grounds. If this is thought to be the case then Phase 3 of the protocol would be initiated.

Depending on the incident, the type of study set up could involve a cross-sectional study, cohort or case control study, or reviewing of patients that attended Emergency Departments (HPA, 2012).

In some cases diseases with long latency periods may be of concern. This would require careful consideration in view of the cost of long term follow-up. However, in some cases a subclinical measure (biomarker of effect) could be identified and measured within a shorter timeframe.

Any studies based on a register could also be used to support NHS outreach programmes to identify and treat individuals with persistent

Table 4
Checklist of possible questions to be included in the early assessment in Phase 2.

<i>Demographic details:</i>
Name
Age
Sex
Date of Birth
<i>Contact details:</i>
Home address
Telephone numbers (including mobile number)
Email address
GP: Name, address, telephone number
<i>Exposure variables:</i>
Location during the incident
Brief description of exposure:
- exposure time (time of day and duration)
- exposure pathway (i.e. air, soil, or water)
<i>Bereavement or loss</i>
- loss of close other
- loss of home or other asset
<i>Access to health care and treatment</i>
- already accessed or planned
<i>Consent to follow-up</i>
Tertiary referral—planned or done
<i>Psychological effects</i>
- panic response at the time or since
- fear of serious injury or death at the time or since
<i>Explosion: screening questions</i>
<u>Questions to ask persons affected:</u>
- Was the person within the cordon zone at the time of the incident?
- Was the person within a defined geographic area or present at a specified set of locations at the time of the explosion?
- Did the person report a defined set of related symptoms (e.g. blast injuries) at health centres, hospitals, NHS Direct.
<i>Radiation exposure: screening questions</i>
<u>Questions to ask persons affected:</u>
- Was the person within the cordon zone?
- Was the person instructed to evacuate from their location at the time of the incident?
- Was the person instructed to shelter within a building at the time of the incident?
- Was the person advised by a competent authority to take stable iodine tablets after the incident?
- Was the person within a defined geographic area or present at one of a specified set of locations at the time of the incident?
- Did the person report symptoms of nausea, vomiting & diarrhoea to a GP, at a health centre, at a hospital, or to NHS Direct since the time of the incident?
<u>Questions to ask relevant HPA, SCG or Senior NHS Staff:</u>
- Has the person been identified as a member of the affected population by a competent authority (e.g. the Strategic Coordination Group)?
- Was the person within a contaminated area defined by environmental contamination monitoring?
- Was the person within an area of elevated radiation doses defined by radiation dose rate monitoring?
- Was the person identified by screening measurements for individual external and internal contamination?
- Was the person identified as showing depletion of blood cell counts on the basis of full blood counts?

mental health problems. Data gathered from the studies following the 2007 floods was used to consider the psychosocial and mental health impact of flooding (Paranjothy et al., 2011), following this public health guidance on dealing with the aftermath of flooding has been prepared.

3.5. General arrangements

Detailed communication plans are required; these include templates for presentations and statements to inform meetings with health care facility management, staff of public agencies, and other collaborators in the formation of a health register.

For the UK, data protection and sharing guidance developed need to include key principles from the Data Protection Act 1998, the Civil Contingencies Act 2004, the Human Rights Act 1998, the NHS Act 2006, and the 2007 Cabinet Office document Data Protection and Sharing—Guidance for Emergency Planners and Responders (HM Government, 2007).

In England, PHE is a category one responder in the emergency response to a major incident. Establishing a health register during or soon after an incident should be considered part of the public health response to the incident and ethical committee approval should therefore not be required. Initial baseline exposure and health data collection are not considered research and can be implemented without ethical approval. An ethical oversight group comprising of individuals with expertise and responsibility for ensuring ethical aspects are properly managed should be established at the beginning of an incident. Written consent by individuals is not always required for phase 1 and 2 of the register; however it may be required for phase 3 depending on the nature of the study or intervention planned. It is not required in support of clinically-led outreach programmes.

The ethical oversight group will also protect the public and relevant stakeholders against the misuse of the health register data (HPA, 2012). In other countries, this process may be very different, and laws in certain countries that protect individuals' privacy may limit or not allow registries to store data for health studies (Bongers et al., 2008).

4. Discussion

Arrangements for following up populations after large incidents or disasters have been agreed in England and a protocol for establishing a register of individuals potentially affected by a large incident has been developed and agreed (HPA, 2012). There is clear support from public health authorities for the establishment of the register if required.

Such registers will allow the identification of the populations affected by or exposed to the incidents so that 1) appropriate advice on relevant immediate interventions can be provided, 2) access can be facilitated to the appropriate services, 3) reassurance can be provided to the public, 4) assessment of the health impact of the incident can be initiated, and 5) the longer-term health implications of the incident can be investigated for example via an epidemiological investigation if required.

The PHE health register protocol is established and ready for deployment at any time although it has yet to be formally piloted so some aspects of the implementation are still to be tested. Plans for a pilot are in place and should include a range of appropriate settings such as Emergency Departments, Primary Care and Health Protection Teams. The criteria for a trigger decision have been identified and the next step is to finalise the actual procedure.

After the incident and trigger, it is beneficial to identify the population affected and start recruiting these individuals into the health register as early as possible, ideally within the first 24–48 h. Logistical and practical issues may also need to be considered and resolved before data collection can begin. This is because the population will disperse quickly; may potentially be lost to follow-up and the more time that passes the less likely individuals are able to recall accurate information (Morgan and Odams, 2012). Despite the broad variation in the management of different types of incidents, a number of common steps have been identified to assess its health burden.

One of the biggest challenges is to identify the nature and extent of exposure as well as the affected population. Table 1 demonstrates potential groups of people affected, some of whom will be harder to reach than others. Speed of implementation will increase chances of inclusion within the registry. For example group D—other members of the public, can be the most difficult to identify but are often the largest group and they may disperse quickly, not realising that they have been exposed. To minimise selection, enrolment and recall bias and to obtain

a true picture of the health impact, recruitment of these individuals should be a core early activity (HPA, 2012), (Paranthaman et al., 2012; Soler et al., 2010).

Careful consideration is needed of the possible methods of recruitment of individuals within the various groups in Table 2. Registries should be carefully compiled, stored and kept up to date in order to reduce bias through increasing completeness and accuracy. It is important to note that the epidemiological response does not have to be based on a register but may also incorporate data from Syndromic Surveillance to enhance the response (Soler et al., 2010).

Due to the infrequent requirement to establish a health register, it is vital that key stakeholders are aware of the need to establish a register following a major incident and what this may involve. Awareness can be raised by ensuring that the protocols are drawn to the attention of key stakeholders through local emergency preparedness and resilience meetings. In addition, it would be advantageous if the possible need to share data on those affected after an incident is included in major incident plans. It is not cost-effective to train a cadre of data collection staff; however, identified staff should be made aware of the possibility that they may be required to collect data in these circumstances and to ensure that training is provided at the time. It is useful to have pre-prepared training materials so that this process can be initiated as quickly as possible.

From the perspective of providing clinical psychology services to the affected population, excessive levels of anxiety and other psychological symptoms have to be responded to whatever their cause and a register would be helpful to identify individuals who would benefit from such health care provision in the aftermath of an event. However, from the perspective of using the register to produce new knowledge, the presence of anxiety in the population may lead to an incorrect attribution of a physical symptom to a toxic exposure. Also it should be considered if any anxiety may be triggered by the request to join a register. In view of the reporting of symptoms by individuals who are anxious or nervous about the exposure or may have received a financial incentive to take part, the design and analysis need to consider how the chance of an erroneous conclusion based on this would be minimised. For example the questionnaire could include items about anxiety concerning the environment and then the analysis could estimate the risk by separate subgroups: those that are more anxious and those that are less. If the effect is similar in both groups then it is more likely to be true, but if the effect is larger amongst the anxious the over-reporting among the anxious group is the likely explanation. Another approach is to use objective measurements such as hospital records or laboratory results wherever possible as they are not affected by this bias.

The importance of an accurate and complete register of affected individuals in order to assess the impact and carry out short-, medium- and long-term follow-up has been demonstrated following incidents that have occurred worldwide. There have been many reports that recognise the value of registries of victims and responders. Many countries now have health registries that were set up following specific disasters or major incidents. For example, in 1992 a large aircraft crashed into two apartment blocks in Amsterdam, killing 43 people. Many individuals were exposed to hazardous materials and health authorities were worried about the health consequences of these exposures. Several years later an epidemiological study was established to monitor the long-term health effects of occupational exposure from this incident (Slotje et al., 2005). Following this plane crash a parliamentary commission made recommendations that information about exposure and possible health consequences should be assessed as soon as possible after such an incident. In May 2000 an explosion at a firework depot in Enschede, the Netherlands, occurred, the explosion and fire completely destroying the surrounding residential area, injuring almost 1000 and killing 22 people. Based on the recommendations following the Amsterdam incident a risk assessment and environmental measurements were taken immediately afterwards (Rorda et al., 2004). Two airplanes crashed into the World Trade Centre (WTC) building in

New York, in 2001, causing a large fire and subsequent collapse of the WTC (World Trade Centre Health Registry, 2004). Although a registry was not set up until some years had passed, long-term health studies are now taking place based on the data collected for it. An explosion took place at the AZF fertilizer factory in Toulouse, France, in September 2001. Following the explosion, environmental sampling and modelling took place but these did not indicate exposures high enough to cause long-term health effects. Follow-up studies took place which focused on psychological effects (Lang et al., 2007).

The HRIG ought to consider the possible value of using biomarkers of exposure and/or effect as part of the investigation, as well as possible use of genetic and or host susceptibility factors for example to identify genetic high risk subgroups of the population at risk, especially in relation to metabolism of toxic chemicals.

Many countries have learned from previous incidents and put procedures in place to establish registers. For example in the United States the Agency for Toxic Substances and Disease Registry (ATSDR) has established a Rapid Response Registry (RRR) service, which aims to recruit exposed or potentially exposed individuals to a register in a timely manner (Paranthaman et al., 2012). The RRR have a specific website containing a survey instrument which provides local, state or federal entities with a tool to register exposed individuals. The survey is a 2 page form which can be used electronically or in paper form and takes 5–10 min to complete (ATSDR, 2012).

Following several large incidents such as the Amsterdam airplane crash and the explosion at the firework depot the Dutch government established the Centre for Health Impact Assessment of Disasters (CGOR). One of the Centre's main roles is to facilitate the rapid recruitment of exposed persons in a health register (National Institute for Public Health and the Environment leaflet).

A major strength of a health register is the ability to carry out long term cohort studies on individuals within the register. Individuals can be followed up over time and their health outcomes monitored; however, there is often a long period of time between exposure and health outcomes. A major challenge in undertaking analytical epidemiology on health register data is that sample of individuals recruited to the register is likely to be highly biased; this is because those that have had the highest exposures and/or most significant health effects are more likely to be identified and recruited. Agencies should also consider the costs associated with the setup and maintenance of a register when considering the initial setup decision. Maintaining cohort studies based on individuals in health registries can be extremely costly and time consuming and individuals will drop out or become un-contactable over time also contributing to selection bias (Morgan and Odams, 2012).

In the face of increased public expectations that public health agencies will provide follow-up of individuals exposed during a major incident, agencies need to be transparent and clearly state why and how a study will take place, having considered several potential benefits and difficulties specific to the event as well as the associated costs. (Paranthaman et al., 2012).

5. Conclusion

It is important for countries to have a protocol for implementing a health register if the circumstances require one to be in place. Health registers facilitate the initial descriptive epidemiology of an exposure and provide the opportunity of carrying out long term analytical studies on the affected population. Such epidemiological studies can provide a greater understanding of the impact that a large incident can have on health, which in turn helps in the planning of health care provision. Registers can also assist more directly in providing access to individuals in need of physical and mental health interventions. The challenge that still remains is to formally pilot the register in the field and refine it based on that experience.

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