Data Sources for the At-Risk Community-Dwelling Patient Population

Prepared for:
Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
540 Gaither Road
Rockville, MD 20850

Contract No. 290-20-0600-011

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AHRQ Publication No. 11-MO21-EF
March 2011

Funding to support *Data Sources for the At-Risk Community-Dwelling Patient Population* was provided by an Agency for Healthcare Research and Quality contract to Abt Associates (contract no. 290-02-0600-011).

Suggested Citation: Zane R, Biddinger P. Data Sources for the At-Risk Community-Dwelling Patient Population. Prepared by Abt Associates under Contract No. 290-02-0600-011. AHRQ Publication No. 11-M021-EF. Rockville, MD: Agency for Healthcare Research and Quality; March 2011.

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1. Introduction

Many patients who live in the community and need some degree of medical assistance may be unable to manage if their resources or services are depleted during a mass casualty event (MCE). Patients who are not directly affected by an MCE but who have daily medical needs, those who cannot manage their medical needs in a shelter, and those who do not have family caregivers are likely to seek care at hospitals that will already be burdened by caring for people directly affected by the MCE. This study investigates data sources to enumerate and estimate the number of people who, though not directly affected by an MCE, might seek hospital care during an MCE.

The report summarizes findings about the availability of data to quantify the at-risk community population. The city of Worcester, Massachusetts, was selected as the test area for determining how many residents in a geographic area fall into one of the major at-risk categories. Worcester is located in central Massachusetts, 45 miles west of Boston, with a population close to 175,500. It is the second largest city in New England.

Patients were grouped according to their functional, medical, and psychosocial needs. Table 1 shows the types of care needs that were included in each of the major categories.

Table 1. Patient Care Needs in the Event that Services are Disrupted During a Mass Casualty Event

Patient Needs	Patient Groups
Functional Needs	Mobility limitations (wheelchair or bedbound) Activities of daily life limitations (bathing, dressing, feeding, toileting)
Medical Needs	Dialysis Intravenous infusions/enteral nutrition Complex wound care Insulin injections Urinary catheter/colostomy Severe respiratory problems Specialized medical equipment (ventilators, ventricular assist devices) Schedule II controlled substances HIV/AIDS Terminal illness Early discharge
Psychosocial Needs	Mental illness, cognitive impairment, or developmental delay

A variety of data sources were studied for how well they capture the care needs of the at-risk population, ease of use, availability, and time of most recent update. Table 2 shows the data sources that were reviewed, their geographic specificity, and the dates of the most recent data available.

Table 2. Data Sources for Patients At Risk of Hospitalization

Data Source	Geographic Detail	Date of Most Recent Update
Outcome and Assessment Information Set (OASIS)	Zip code	Within approximately 2 months. Providers have 30 days to submit assessments to the State. It takes several weeks for assessments to be integrated into the national repository
United States Renal Data System (USRDS)	County	June 2008
National Health Interview Survey (NHIS)	No geographic detail in public use files	2007
National Health Interview Survey–Disability (NHIS–D)	No geographic detail in public use files	1995
Longitudinal Study of Aging (LSOA)	No geographic detail in public use files	1984 baseline; three follow-up interviews (1986, 1988, and 1990)
Massachusetts Community Health Information Profile (MassCHIP)	City and town	2007
National Home and Hospice Care Survey (NHHCS)	U.S. Census regions and metropolitan statistical area indicators	2007
Substance Abuse and Mental Health Data Archive (SAMHDA)	Zip code	2007
American Community Survey (ACS)	City and town	2005 to 2007
Medicare claims	Zip code	Continuous
Medicaid claims	Zip code	Continuous

2. Summary of Data Availability

For each at-risk population subgroup, the available data sources were examined and the strengths and limitations of each were evaluated.

2.1. Functional Needs

The focus of this report is those patients who are non-ambulatory and who totally depend on others for feeding, bathing, dressing, and toileting. Non-ambulatory patients may be confined to a wheelchair or bedbound. The following data sources were examined:

- Outcome and Assessment Information Set
- American Community Survey
- National Health Interview Survey
- Longitudinal Study of Aging
- National Health Interview Survey–Disability
- National Home and Hospice Care Survey
- Massachusetts Community Health Information Profile (including the Behavioral Risk Factor Surveillance System for Massachusetts)
- Medicare and Medicaid claims

Outcome and Assessment Information Set (*OASIS*). This database contains information about adults who receive home care services and specifies the activities of daily living (ADLs) with which these patients require assistance, such as bathing, dressing, toileting, transfers, ambulation/locomotion, and feeding. OASIS enrollment is completed upon admission/readmission (and every 60 days thereafter) for all patients older than 18 (excluding maternity patients) who receive skilled care from a Medicare- or Medicaid-certified home health agency. OASIS enrollment is not required for patients whose care is reimbursed by payers other than Medicare and Medicaid. OASIS data can be obtained by zip code to target a specific urban area for further study, and current data are only several months old. Data on ADL limitations can be paired with data on supportive assistance to target those individuals who have functional dependence and receive paid assistance or no assistance at all. A data user agreement (DUA) with the Centers for Medicare and Medicaid Services (CMS) is needed to use OASIS data. In addition, OASIS is limited to Medicare and Medicaid patients who currently receive home care from a certified home health agency. In that sense, OASIS could be considered as a source for incidence rather than prevalence estimates.

American Community Survey. Information on a physical disability (a condition that substantially limits one or more basic physical activities, such as walking, climbing stairs, reaching, lifting, or carrying) is collected from U.S. households through a survey administered by the U.S. Census Bureau. Each month, the survey is administered by mail, telephone, or personal visit to a sample of roughly 250,000 addresses in the United States and Puerto Rico, or 3 million addresses per year. Data are available annually for communities with a minimum population of 65,000, and for less populated areas the data is collected over 3 to 5 years. Data are publically available on the Census Bureau Web site (http://www.census.gov/acs/www/). Survey questions do not address the severity of the disability, but the data may be paired with data from supplemental security income (SSI) and disability pensions to provide an estimate of the number of individuals who have a severe physical disability.

National Health Interview Survey (*NHIS*). This interview-based survey covers functional status, such as the ability to walk, climb stairs, sit or stand for several hours, stoop, bend or kneel, reach up or grasp, and lift or carry 10 pounds). Census Bureau staff conducts interviews with a representative sample of households and non-institutional group quarters, covering the U.S. civilian non-institutional population. Interviews are conducted continuously throughout the year. The Household component collects demographic information on all of the individuals living in a particular sample house (dwelling). The Family component verifies and collects additional demographic information on each member of each family residing in the house. From each family, one sample adult and one sample child are randomly selected, and information on health topics is collected. The NHIS contains questions about members of the household who need help with personal care (such as eating, bathing, dressing, or getting around the house). The survey also includes a list of conditions that affect an individual's ability to perform certain activities. For example, NHIS data can identify the number of individuals who cannot walk, need assistance with personal care, or who have multiple sclerosis, muscular dystrophy, polio, quadriplegia, Parkinson's disease, or an amputation. There are no geographic indicators in the NHIS public use data files. A more complete data set that does include geographic indicators can be obtained from the Centers for Disease Control and Prevention (CDC), but the CDC requires the submission (and CDC approval) of a research proposal for using the data and payment of applicable fees. NHIS data can be used to generate prevalence estimates.

National Health Interview Survey Longitudinal Study of Aging. This NHIS-associated survey includes questions on functional ability similar to the standard NHIS, as well as questions about the frequency with which the respondent needs help with personal care, the amount of time the respondent stays in bed or a chair, or if the respondent is incontinent. There are also questions about community and social support, such as Meals on Wheels programs, and how often these services are used. Unfortunately, this study was originally conducted in 1984, with three follow-up interviews in 1986, 1988, and 1990, making the most recent data nearly 20 years old. The data are available on CD-ROM.

National Health Interview Survey–Disability (*NHIS–D*). This NHIS-associated survey contains the same information on ADLs as the NHIS, with additional information on ADLs that cannot be performed without help or special equipment. The survey covers the use of a special bed, hospital bed, wheelchair, or oxygen or special breathing equipment. It includes information on how often helpers are utilized and for how many hours per day, including services such as Meals on Wheels, in the past 12 months. The survey specifically asks respondents if there is someone who could take care of them for a few days or weeks if necessary. The most recent data available are from 1995. Like the other National Health Interview Surveys, no geographic information is available in the public use files. Accessing the files through the CDC requires the submission and approval of a research proposal and payment of applicable fees.

National Home and Hospice Care Survey. This survey is designed to collect descriptive information on home health and hospice agencies and their staff, services, and patients. It is conducted on a nationally representative sample of U.S. home health and hospice agencies that are Medicare- and/or Medicaid-certified or licensed by the State. The survey sample consists of about 1,800 agencies throughout the United States, with detailed data on up to 10 patients from each agency. The patient data, which are collected through in-person interviews with agency staff, include information on demographic characteristics, functional and health status, diagnoses, pain management, medical devices, services received, medications, cost, and sources of payment. Functional assistance information includes help with bathing, dressing, eating, transferring, walking, and toileting, as well as using a hospital bed, wheelchair (manual or motorized), and Meals on Wheels. The most recent

public use data files are from 2007, and data are reported by U.S. Census regions and metropolitan statistical area (MSA) indicators.

Massachusetts Community Health Information Profile (*MassCHIP*) This online information service provides access to 36 data sources, with information on vital statistics, communicable diseases, sociodemographic indicators, public health program usage, and other health, education, and social services indicators. It contains information on general disability among Massachusetts adults who have been disabled for at least one year and whose disability limited activities, caused cognitive difficulties, or required the use of special equipment or help from others. The data are specific to the city of Worcester (the model urban area for this study), and the most current data are from 2007. The data, however, are not specific to particular areas of personal care (e.g., bathing, dressing, toileting, eating), but apply to disability in general. This is an unusual data set, and comparable data have probably not been assembled in this way in other States.

Medicare claims. Medicare claims contain information on the equipment, services, and medications provided to Medicare beneficiaries by suppliers of durable medical equipment (DME). Medicare beneficiaries are generally older than 65, have a disability, or have end-stage renal disease (ESRD), and the claims database contains information for this entire population (a sample can be drawn for research purposes). DME claims can be combined with hospital and outpatient claims or prescription drug plan claims that contain diagnostic codes to identify individuals who have disabling conditions and also use equipment such as wheelchairs, hospitals beds, or oxygen. DME claims are considered incidence rather than prevalence data, because after 12 to 36 months of rental (during which claims are submitted to Medicare) the equipment becomes the property of the patient and additional claims are not submitted. Data are person-specific but limited to the Medicare population. A DUA with CMS is required to access claims data. Analyzing Medicare claims over several years could yield both incidence and prevalence estimates.

Medicaid claims. Medicaid claims contain similar information about the equipment, services, and medications provided to low-income State residents who are eligible for Medicaid benefits, regardless of age. Individuals who are covered by Medicaid and the specific services and equipment that are covered will vary by State. Data are person-specific, but cannot easily be compared among States because of the substantial differences in Medicaid eligibility and benefits. DUAs with each State may be required to access claims data. Arrangements can be made to obtain claims data for research purposes. Analyzing Medicaid claims over several years could yield both incidence and prevalence estimates.

Table 3. Data Availability for Functional Dependence

Data Availability	Functional Dependence Data	Advantage	Disadvantage
Public use data files	MassCHIP	• Available online • Free • Specific to Worcester • 2002–2007	• General disability definition is broad; could include persons who are not target subjects. No information specific to personal care needs

Table 3. Data Availability for Functional Dependence

	National Home and Hospice Care Survey	• 2007 • Descriptive data on services provided by home health agencies and hospices • Could be requested from CDC	• Reported by U.S. Census regions and MSA indicators • Does not adjust the patient sample based on agency size • Cannot be used to estimate number of functionally dependent individuals in the general population
	American Community Survey	• 2005–2007 • Available for Worcester metro area • Reports on individuals who have physical and self-care disabilities	• No indication of the severity of the disability
CMS approval/ DUA required	OASIS	• Good ADL descriptors • Available by zip code • Available within several months	• Population covered is limited to those receiving home health services from a Medicare/Medicaid-certified agency
	Medicare claims	• Captures the use of hospital beds, wheelchairs, and lifts by persons who live in the Worcester zip code	• Data capture ends after one year, when equipment is no longer considered “rental” • Data are limited to a segment of the population that is older than 65, has a disability, or has ESRD
	Medicaid claims	• Captures the use of hospital beds, wheelchairs, and lifts by persons who live in the Worcester zip code	• Data are limited to eligible low-income individuals, which varies from State to State and year to year
Submission of proposal and fee	NHIS and NHIS–D	• Good ADL descriptors	• Requires proposal development and fee payment and possible separate submissions for each survey

2.2. Medical Needs

This category includes patients who have complex medical needs and depend on health care staff to administer treatments and/or medications or depend on various types of medical equipment and supplies. This category also includes those patients who would be discharged early from acute care hospitals in the case of an MCE to make room for those affected. These latter patients will likely need a cadre of services, such as frequent assessments of vital signs, lung and heart sounds, and wounds, as well as dressing changes, laboratory tests, and medication adjustments.

Specifically, patients with medical needs are those who require the following services:

- Dialysis (peritoneal or hemodialysis)
- Intravenous (IV) infusions (includes enteral feedings,TPN, chemotherapy infusions, IV antibiotics)
- Complex wound care (sterile dressing changes, wound vacuum assisted closure (VAC), chest tube, pleurovac)
- Insulin-dependent diabetics unable to self injections and have no trained caregiver
- Urinary catheter or colostomy – patients dependent on others for assistance
- Severe respiratory problems – individuals with COPD and/or asthma requiring the use of oxygen, nebulization, or other respiratory equipment (e.g., continuous positive airway pressure (CPAP))
- Specialized Medical Equipment (e.g., Ventilator or Ventricular Assist Device (VAD))
- Schedule II controlled substances (drug dependent)
- HIV/AIDS care patients
- Terminal ill
- Early discharges from acute care hospitals

The following data sources were consulted:

- United States Renal Data System
- OASIS
- National Home and Hospice Care Survey
- MassCHIP
- NHIS
- NHIS–D
- SAMHDA
- Medicare claims
- Medicaid claims

2.2.1. Medical Needs Subgroups and Data Sources

Dialysis

The United States Renal Data System (USRDS) collects incidence and prevalence data about all persons with ESRD who use peritoneal dialysis and hemodialysis, regardless of insurance type; data are available at the county level and online. Analyzing USRDS data over several years would yield both incidence and prevalence estimates.

Medicare and Medicaid claims could provide the same information for people eligible for these public insurance programs, but would require DUAs with CMS and each State, as well as analytic file construction.

Table 4. Data Availability for Dialysis

Data Availability	Dialysis Data	Advantage	Disadvantage
Public use data files	United States Renal Data System	• Provides number of patients on hemodialysis and peritoneal dialysis by county • Free • Available online	• Not available at the city level
CMS approval/ DUA required	Medicare claims	• Captures number of patients on dialysis in the Worcester zip code	• Data are limited to a segment of the population that is older than 65, has a disability, or has ESRD
	Medicaid claims	• Captures number of patients on dialysis in the Worcester zip code	• Data are limited to eligible low-income individuals, which varies from State to State and year to year

IVs and Infusions

OASIS collects data on therapies provided to adults in the home setting, including IV or infusion therapy, parenteral nutrition (e.g., total parenteral nutrition [TPN] or lipids), and enteral nutrition (e.g., nasogastric, gastrostomy, jejunostomy, or any other artificial entry into the alimentary canal), as well as the level of assistance that the patient requires. Patients who are coded as a "4" completely depend on someone else to manage all equipment. OASIS identifies patients who require IVs, but does not specify the purpose of the IV. To determine if the IV is for antibiotics or chemotherapy, data could be paired with OASIS items that capture diagnoses using ICD-9 codes.

The National Home and Hospice Care Survey identifies people who live alone (in a non-institutional setting) and use enteral feeding or IV therapy equipment or who receive IV therapy. Like OASIS, the survey does not specify the purpose of the IV (antibiotics or chemotherapy).

Medicare claims contain information about IV equipment and supplies and medications/infusions provided to all Medicare beneficiaries who are older than 65 or have a disability or ESRD.

Medicaid claims also contain information on IV equipment and supplies and medications provided to eligible low-income State residents, regardless of age. Individuals who are covered, as well as the specific services and equipment that is covered, varies by State. Data are person-specific, but cannot easily be compared among States.

Table 5. Data Availability for IVs and Infusions

Data Availability	IVs/Infusion Data	Advantage	Disadvantage
CMS approval/ DUA required	OASIS	• Captures IVs, TPN, enteral feedings, and level of assistance required • Data are current (within several months) and available by zip code	• Unable to tell purpose of IV unless paired with diagnosis codes • Requires application for DUA
	Medicare claims	• Captures the use of IV equipment, enteral supplies, and medications by persons living in the Worcester zip code	• No detail on the level of assistance required • Data are limited to a segment of the population that is older than 65, has a disability, or has ESRD
	Medicaid claims	• Captures the use of IV equipment, enteral supplies, and medications by persons living in the Worcester zip code	• No detail on the level of assistance required • Data are limited to low-income individuals, which varies from State to State and year to year
Public use files	National Home and Hospice Care Survey	• Identifies people who live alone (not in an institution) and receive enteral feedings or IVs • Last updated in 2007	• Unable to tell purpose of IV unless paired with diagnosis codes

Complex Wound Care

OASIS specifies the presence of a surgical wound and the status of the wound, but does not provide details about the care or equipment required.

Both Medicare and Medicaid claims contain information about the use of wound dressing supplies and equipment.

Table 6. Data Availability for Complex Wound Care

Data Availability	Complex Wound Care Data	Advantage	Disadvantage
CMS approval/ DUA required	OASIS	• Captures presence of a surgical wound • Data are current (within several months) and available at zip code level	• No details on care or equipment required • Requires application for DUA • Captures only patients in the care of Medicare/Medicaid-certified home health agencies
	Medicare claims	• Captures the use of dressing supplies and equipment by persons living in the Worcester zip code	• No details on the level of assistance required • Data are limited to a segment of the population that is older than 65, has a disability, or has ESRD
	Medicaid claims	• Captures the use of dressing supplies and equipment by persons living in the Worcester zip code	• No details on the level of assistance required • Data are limited to low-income individuals, which varies from State to State and year to year

Insulin Injections

OASIS captures the need for injectable medications and indicates which adult patients totally depend on others (caregivers). Pairing this data with items containing the ICD-9 code for insulin-dependent diabetes could identify patients who have diabetes and who receive care from a certified home health agency.

NHIS captures information about respondents who are currently taking insulin, but does not determine the level of assistance required.

Medicare and Medicaid claims contain information on insulin syringes and insulin, but not whether individuals require assistance in using the insulin.

No other data sources provide information on this subgroup. MassCHIP data include the number of hospitalizations and emergency room (ER) visits related to diabetes in Massachusetts, which might be an indication of likelihood of future ER visits/hospitalization, especially during an MCE.

Table 7. Data Availability for Insulin-Dependent Diabetes

Data Availability	Diabetes Data	Advantage	Disadvantage
CMS approval/ DUA required	OASIS	• Captures need for injectable medication and level of dependence; could be paired with diagnosis of insulin-dependent diabetes • Data are current (within several months) and available at zip code level	• Requires application for DUA • Captures only patients in the care of Medicare/Medicaid-certified home health agencies
Submission of proposal and fee	NHIS	• Information on individuals currently taking insulin • Data from 2007	• No information on level of assistance required • Requires submission of proposal and fee

Urinary Catheter/Colostomy

OASIS collects information on the presence of a urinary catheter or colostomy for bowel elimination, and the level of assistance required for ADLs (which includes bowel/bladder along with bathing, dressing, toileting, eating/feeding, and other ADLs).

Both the NHIS–D and the National Home and Hospice Care Survey include information about indwelling catheters and colostomies and the need for help in caring for these devices.

Medicare and Medicaid claims contain information about catheters and colostomy equipment and supplies, but not the degree of assistance needed to manage this care.

Table 8. Data Availability for Urinary Catheter/Colostomy

Data Availability	Urinary Catheter/ Colostomy Data	Advantage	Disadvantage
CMS	OASIS	• Captures the presence of	• Level of assistance for ADLs is not

Table 8. Data Availability for Urinary Catheter/Colostomy

approval/ DUA required		urinary catheters and colostomies • Captures level of assistance needed for ADLs • Data are current (within several months) and available at zip code level	specific to only bowel/bladder • Requires application for DUA • Captures only patients in the care of Medicare/Medicaid-certified home health agencies
	Medicare claims	• Captures the use of catheter and colostomy supplies and equipment by persons living in the Worcester zip code	• Cannot determine the level of assistance required • Data are limited to a segment of the population that is older than 65, has a disability, or has ESRD
	Medicaid claims	• Captures the use of catheter and colostomy supplies by persons living in the Worcester zip code	• Cannot determine the level of assistance required • Data are limited to low-income individuals, which varies from State to State and year to year
Submission of proposal and fee	NHIS–D	• Captures the presence of urinary catheters and colostomies • Captures level of assistance needed to care for devices	• Requires submission of proposal and fee • Data are old (1995)
Public use files	National Home and Hospice Care Survey	• Captures the presence of urinary catheters and colostomies • Captures level of assistance needed to care for devices • Last updated in 2007	• Geographic detail for U.S. Census regions and MSA indicators–county level

Severe Respiratory Problems

This category includes individuals who depend on oxygen and/or require nebulization or use of other respiratory equipment.

OASIS collects information about adults in the care of home health agencies who use oxygen (continuous or intermittent), how well patients manage their inhalant/mist medications, and how well patients manage oxygen and other equipment. Patients may be rated in OASIS as unable to take medication or manage equipment unless assisted by someone else. ICD-9 diagnosis codes could be paired with data on the use of oxygen and equipment to identify individuals who have chronic obstructive pulmonary disease, asthma, or other related pulmonary conditions.

NHIS collects information on emphysema, asthma, and lung and breathing problems that interfere with ADLs.

The National Hospice and Home Care Survey identifies people who live alone (in an non-institutional setting) and use oxygen or other respiratory equipment.

MassCHIP contains data about asthma incidence among adults and asthma-related hospitalizations and ER visits.

Medicare and Medicaid claims contain information on oxygen and respiratory equipment supplies and inhalant medications, but do not capture the level of assistance that the individual needs.

Table 9. Data Availability for Severe Respiratory Problems

Data Availability	Respiratory Problems Data	Advantage	Disadvantage
CMS approval/ DUA required	OASIS	• Captures use of oxygen • Captures how patients manage inhalant/mist medications • Captures how well patients manage equipment • Data are current (within several months) and available at zip code level	• Level of assistance category covers oxygen and respiratory equipment • Requires application for DUA • Captures only patients in the care of Medicare/Medicaid-certified home health agencies
	Medicare claims	• Captures the use of oxygen and respiratory equipment and supplies and inhalant medications by persons living in the Worcester zip code	• Cannot determine the level of assistance required • Data are limited to a segment of the population that is older than 65, has a disability, or has ESRD
	Medicaid claims	• Captures the use of oxygen and respiratory equipment and supplies and inhalant medications by persons living in the Worcester zip code	• Cannot determine the level of assistance required • Data are limited to low-income individuals, which varies from State to State and year to year
Public use files	National Home and Hospice Care Survey	• Includes information on people who live alone (not in an institution) and use oxygen • Includes information on other respiratory equipment • Last updated in 2007	• "Other respiratory equipment" is not specific to type of equipment • Geographic detail for U.S. Census regions and MSA indicators–county level
	MassCHIP	• Shows asthma among adults and asthma-related hospitalizations and ER visits • Data available for Worcester	• Does not provide detail on use of oxygen/nebulization equipment
Submission of proposal and fee	NHIS	• Includes information on emphysema, asthma, and lung and breathing problems that interfere with ADLs • Data from 2007	• Does not provide detail on use of oxygen/nebulization equipment • Requires submission of proposal and fee • No geographic information available in public use files

Specialized Medical Equipment

Some community-dwelling patients require specialized medical equipment, such as ventilators and ventricular assist devices (VADs).

OASIS contains one data element about adult use of a ventilator, either continually or at night.

NHIS–D includes items on the use of a ventilator and/or tracheostomy tube in the last 12 months and in the last 2 weeks.

Medicare and Medicaid claims contain information about DME, such as ventilators and VADs, that are currently being rented by the beneficiary.

Table 10. Data Availability for Specialized Medical Equipment

Data Availability	Specialized Medical Equipment Data	Advantage	Disadvantage
CMS approval/ DUA required	OASIS	• Captures the use of ventilators • Data are current (within several months) and available at zip code level	• No information on VADs • Requires application for DUA • Captures only patients in the care of Medicare/Medicaid-certified home health agencies
	Medicare claims	• Captures the use of ventilators and VADs and supplies and equipment by persons living in the Worcester zip code	• Not captured after one year, when equipment is no longer considered "rental" • Data are limited to a segment of the population that is older than 65, has a disability, or has ESRD
	Medicaid claims	• Captures the use of ventilators and VADs and supplies and equipment by persons living in the Worcester zip code	• Data are limited to low-income individuals, which varies from State to State and year to year
Submission of proposal and fee	NHIS–D	• Captures the use of ventilators and tracheostomy tube	• No information on VADs • Require a proposal and fee • Data are old (1995)

Schedule II Controlled Substances

Many community-dwelling individuals depend on narcotics, such as methadone, or pain relievers. Schedule II drugs (e.g., oxycodone, methadone, amphetamine, dextroamphetamine, and methylphenidate) have stricter prescribing rules. For a full list of Schedule II drugs, see http://www.usdoj.gov/dea/pubs/scheduling.html.

Medications used for treating drug addiction withdrawal, such as buprenorphine, may be difficult to access during a disaster or emergency. For a description of these drugs, see http://www.nida.nih.gov/PODAT/Evidence.html#Pharm.

Similarly, some antipsychotics and other psychiatric medications could be critical for individuals who are displaced during an MCE and depend on their medications (e.g., benzodiazepines).

Medicare and Medicaid claims contain information about medications, including Schedule II controlled substances.

Table 11. Data Availability for Schedule II Controlled Substances

Data Availability	Scheduled II Controlled Substances Data	Advantage	Disadvantage

Table 11. Data Availability for Schedule II Controlled Substances

Public use files	SAMHDA	• Counts patients receiving methadone or buprenorphine as inpatients, outpatients, and residential • Data from 2005	• County-level data
CMS approval/ DUA required	Medicare claims	• Captures the use of Schedule II controlled substances by persons living in the Worcester zip code	• Data are limited to a segment of the population that is older than 65, has a disability, or has ESRD
	Medicaid claims	• Captures the use of Schedule II controlled substances by persons living in the Worcester zip code	• Data are limited to low-income individuals, which varies from State to State and year to year

HIV/AIDS

Most HIV/AIDS patients who are stable and on medication will not likely present any special needs in the event of an MCE. Those who are ill will likely be captured in other categories (i.e., terminal illness or functional dependence). However, ready access to complex and costly medications is critical for these patients, and many community pharmacies do not stock these particular medications. In the event that these patients need to be relocated to a shelter, they may be concerned about delay in getting their medications and seek help in the ER.

MassCHIP is one data source that provides data on new and existing HIV/AIDS cases. Medicare and Medicaid claims could be used to capture HIV/AIDS medications.

Table 12. Data Availability for HIV/AIDS

Data Availability	HIV/AIDS Data	Advantage	Disadvantage
Public use files	MassCHIP	• Prevalence and incidence data • Data from 1999–2006 • Data available for Worcester	• Does not specify patient status in terms of the disease process
CMS approval/ DUA required	Medicare claims	• Captures the use of HIV/AIDS medications by persons living in the Worcester zip code	• Does not specify patient status in terms of the disease process • Data are limited to a segment of the population that is older than 65 or has a disability
	Medicaid claims	• Captures the use of HIV/AIDS medications by persons living in the Worcester zip code	• Does not specify patient status in terms of the disease process • Data are limited to low-income individuals, which varies from State to State and year to year

Terminal Illness

Patients who receive hospice care or who have less than 6 months to live may have medication needs (especially pain medications) and require assistance with ADLs. These patients may not be able to continue living at home during an MCE if their hospice services and/or medications are delayed or

disrupted. If these patients are displaced from their homes, they will not likely be appropriate candidates for a general shelter or even a special needs shelter.

OASIS contains a data item on life expectancy and another item that indicates intractable pain.

The National Hospice and Home Care Survey collects data on hospice services provided by an outside agency. These data could be paired with data on the primary caregiver to show whether or not someone in the home is able to provide care.

Medicare and Medicaid claims could be used to capture the use of hospital beds, medications, and any other equipment or supplies, but it is not possible to determine if these medications and supplies are being used by people who are terminally ill. Medicare data indicate whether a beneficiary receives hospice services, but most people who use hospice care do so only in the last days or weeks of life.

Table 13. Data Availability for Terminal Illness

Data Availability	Terminal Illness Data	Advantage	Disadvantage
CMS approval/ DUA required	OASIS	• Captures life expectancy of less than 6 months • Data are current (within several months) and available at zip code level	• Requires application for DUA • Captures only patients in the care of Medicare/Medicaid-certified home health agencies
	Medicare claims	• Captures use of equipment (hospital beds and medications) and hospice services by persons living in the Worcester zip code	• Data are limited to a segment of the population that is older than 65, has a disability, or has ESRD
	Medicaid claims	• Captures use of equipment (hospital beds and medications) and hospice services by persons living in the Worcester zip code	• Data are limited to low-income individuals, which varies from State to State and year to year
Public use files	National Hospice and Home Care Survey	• Captures hospice services provided by an agency Data from 2007	• Geographic detail for U.S. Census regions and MSA indicators– county level

Early Discharge

During a disaster, hospitals may try to discharge patients who can manage at home or in other levels of care in order to make room for patients who require tertiary care related to the MCE. It is difficult to evaluate a data set for its ability to provide data on a hypothetical situation. Using literature on "reverse triage," investigators formulated a description of the type of patient who is a candidate for early discharge. Kelon et al., (2006) describes a classification system that consists of five categories, in which patients are evaluated on the basis of their risk of a consequential medical event. Patients in low-risk categories are discharged home or to a low-acuity alternate facility; moderate-risk patients are not deemed safe to return home, but can be discharged to a moderate-acuity facility. Patients in high-risk categories can be discharged only to another high-acuity facility or not moved at all. Patients who have little hope of recovery can also be discharged in order to make beds available for those more likely to survive.

In evaluating data sources, investigators considered the needs of a "typical" post-operative patient; that is, someone who would likely require IV antibiotics and pain medication, have a wound with or without drains and tubes, and require monitoring and dressing changes, frequent vital sign assessment, daily laboratory tests, and frequent medication adjustments.

OASIS is the only data set that can provide a portion of the data elements required to identify such patients, and its data only apply to adults who receive services from a Medicare/Medicaid-certified home health agency and whose care is paid for by Medicare or Medicaid. OASIS contains data elements about recent hospital discharge, severity ratings for diagnoses, and changes in medical or treatment regimens in the past 14 days. It does not capture the frequency of nursing assessments, changes to medications, or other procedures based on nurse assessments or laboratory test results.

Medicare and Medicaid claims could be used to identify patients who require IVs, medications, dressing supplies, oxygen equipment, or laboratory tests. Many of these items, however, will be captured in other categories as well. Only laboratory tests are likely be captured only by Medicare and Medicaid claims.

Table 14. Data Availability for Early Discharge

Data Availability	Early Discharge Data	Advantage	Disadvantage
CMS approval/ DUA required	OASIS	• Captures recent hospital discharge, severity ratings for diagnoses, and changes in medical or treatment regimens in past 14 days • Data are current (within several months) and available at zip code level	• Does not indicate frequency of nursing assessment, changes to medications, or other procedures based on nursing assessment or laboratory test results • Requires application for DUA • Captures only patients in the care of Medicare/Medicaid-certified home health agencies
	Medicare claims	• Captures the use of equipment, supplies, medications, and laboratory tests by persons living in the Worcester zip code	• Data are limited to a segment of the population that is older than 65, has a disability, or has ESRD
	Medicaid claims	• Captures the use of equipment, supplies, medications, and laboratory tests by persons living in the Worcester zip code	• Data are limited to low-income individuals, which varies from State to State and year to year

2.3. Psychosocial Needs

This group includes those individuals who have mental illness, cognitive impairment, or developmental delays and live independently in the community with the support of a treatment or day/mental health program or (nearly) full-time caretaker.

NHIS–D includes data about people who receive services from adult day care or day activity centers. Services include meals, counseling, nursing, monitoring of medications, and personal care. There are also items about outpatient mental health services, the number of months that outpatient mental health

services were received, the number of visits that were made on an emergency basis, and any support provided by a community mental health program.

The American Community Survey includes information on individuals in households who have difficulty learning, remembering, or concentrating. When combined with the receipt of SSI, this information may be an indication of the severity of the condition.

MassCHIP does not capture information on services utilized, but does collect information about the number of days of poor mental health in the past 30 days and the number of days of sad, blue, or depressed mood in the past 30 days. These items are probably too broad to be good indicators of severe mental illness.

Medicaid claims may contain information about programs in the community that support individuals who have psychosocial needs, if such services are covered by a given State's Medicaid program.

Table 15. Data Availability for Psychosocial Needs

Data Availability	Psychosocial Needs Data	Advantage	Disadvantage
Proposal and fee required	NHIS–D	• Information on use of adult day care or day activity centers, outpatient mental health services, mental health ER visits, and community mental health programs	• Data are old (1995)
Public use files	MassCHIP	• Number of days of poor mental health in past 30 days • Number of days of sad, blue, or depressed mood in past 30 days	• No information on mental health services utilized
	American Community Survey	• Available for Worcester metro area • Information on individuals who have difficulty learning, remembering, or concentrating	• No information on mental health services utilized • May indicate severity of condition when combined with receipt of SSI
CMS approval/ DUA required	Medicaid claims	• May contain information on programs in the community attended by individuals in the Worcester area	• Data are limited to low-income individuals, which varies from State to State and year to year

2.4. Children

Children who have significant functional deficits or complex medical care and/or psychosocial needs present a slightly different situation during an MCE. These children would most certainly be under the care and supervision of a parent or adult at all times; thus, they are not as vulnerable to lack of a caregiver. However, those children who depend on equipment or medical supplies and electricity would be subject to some of the same issues as their adult counterparts. Investigators sought databases or surveys that would show the number of children who depend on medical equipment or supplies.

The National Survey of Children's Health (2007) provides information on children who need/use more medical care or mental health or educational services, or are limited in activities compared with other children of the same age. It identifies the underlying condition in general terms (e.g., bone, joint or muscle problems or brain injury or concussion), but does not indicate the types of equipment/supplies the child may need.

The National Survey of Children with Special Health Care Needs (2005-2006) provides information on the demographic characteristics of children who have special health care needs and the types of health and support services needed. The survey is conducted through telephone interviews in all 50 States and the District of Columbia. Telephone numbers are dialed at random to identify households with children and then the households are screened for children who have special health care needs (at least 3,000 households per State are screened). Data are available through an online Data Resource Center. Information on the child's condition and need for DME (e.g., wheelchair, hospital bed, oxygen tank, and pressure machine), medical supplies, mobility aids, and substance abuse treatment or counseling is supplied. Information on the type of medical equipment is not specific to those children who depend on medical technology, but includes children who used any of the listed medical equipment/supplies at any point in the past 12 months.

In 1987 and 1990, a statewide census of children who depend on medical technology was conducted in Massachusetts to determine the size, pattern of distribution, and trends in the population of children who are assisted by medical technology (Palfrey et al., 1991 and 1994). An unduplicated count of children ages 3 months to 18 years who used one or more of the following devices was obtained from medical and educational sources: tracheostomy, respirator, oxygen, suctioning, gastrostomy, jejunal or nasogastric feedings, colostomies, urethral catheterization, ureteral diversion, intravenous access, or dialysis. Using the 1990 U.S. Census figures, the researchers were able to estimate the prevalence rate of technological dependency for children in this age range and apply this rate to the entire U.S. child population.

2.5. Summary

The information from this report is summarized in the table below. For each of the at-risk population groups, the data sources were reviewed to determine which contain the needed information, are most current, and are most readily available. The table below shows the various data sources and the groups in the at-risk population that they adequately cover.

In some cases, more than one data source is highlighted. In these cases, there would likely be a problem with "double counting" if multiple data sources were used to create community-level estimates. For example, Medicare claims and OASIS have a considerable degree of overlap; we could not simply add the results obtained from these two data sources. For some data sets the degree of overlap can be estimated, but this is not always the case. For example, it may be difficult to estimate the overlap between NHIS data and OASIS data.

Table 16. Data Sources for At-Risk Population Groups

Data Source	Most Recent Data	Geographic Detail	Availability	At-Risk Population Covered	Limitations
MassCHIP	1999–2006	City	Online	HIV/AIDS patients*	No information on severity of disease
SAMHDA	2005	County level	Online	Methadone patients*	Data at the county level

Table 16. Data Sources for At-Risk Population Groups

United States Renal Data System	2008	County level	Online	Dialysis patients*	Data at the county level
NHIS	2007	States are grouped in 4 U.S. Census regions: NE, MW, S, and W	Requires submission and approval of proposal, fee payment	None	N/A
National Home and Hospice Care Survey	Last conducted in 2007; public use data files released in 2009	County level	Available on CD from CDC	Functional dependence* IV/Infusions* Catheter/colostomy Oxygen/other respiratory equipment Hospice care*	Limited to a nationally representative sample of home health agencies, but not a representative sample of patients
OASIS	Data available within several months of submission	Zip code	CMS approval/ DUA required	Functional dependence* IV/Infusions* Insulin-dependent diabetes Oxygen/nebulizer use Ventilator Hospice care*	Captures only those patients in the care of a certified home health agency
American Community Survey	2005–2007	City and town	Public use data files	Functional dependence Cognitive impairment	No information on severity of condition
Medicare claims	Check data availability	Zip code	CMS approval/ DUA required	Functional dependence* Dialysis* Catheter/colostomy* Schedule II controlled substances HIV/AIDS* IV/Infusions* Insulin-dependent diabetes* Oxygen/nebulizer use Ventilator* Hospice care* Complex wound care Early discharge Specialized medical equipment	Captures only the elderly, and those who have a disability or ESRD
Medicaid claims	Check data availability	Zip code	CMS approval/ DUA required	Functional dependence* Dialysis* Catheter/colostomy* Schedule II controlled substances HIV/AIDS* IV/Infusions* Insulin-dependent diabetes* Oxygen/nebulizer use* Ventilator* Hospice care* Complex wound care Early discharge Specialized medical equipment Community programs for mental illness,	Captures only low–income individuals; covered services not consistent from State to State or year to year

Table 16. Data Sources for At-Risk Population Groups

				developmental delays, and cognitive impairment	

* More than one data source available.

2.6. Discussion

After reviewing all the data sources, investigators were able to locate one or more for each of the at-risk population groups of concern. However, there does not appear to be one ideal data source for the information the investigators were seeking, and some of the better data sources omit children. Neither the public use files nor those that require a DUA with CMS (as well as analytic file construction and/or payment of a fee) could provide information on the at-risk population across all provider and patient types.

The public use files (i.e., MassCHIP, SAMHDA, United States Renal Data System, American Community Survey), although sufficient for certain narrow categories (e.g., dialysis, methadone use, HIV/AIDS patients), do not contain a broad enough picture of the other subgroups. OASIS provides comparable information on many of the at-risk categories of interest, but the population is limited to only those patients who currently receive home care—an incidence rather than prevalence measure. The National Home and Hospice Care Survey focuses on the services that home health agencies and hospice agencies provide and could not be used as a reliable source for information on the population of patients receiving home care services.

Medicaid and Medicare claims cover a large population and are not limited to those who receive home care services. They are, however, limited to low-income individuals or the elderly/disabled populations, and do not contain information about most children, or about those whose care is paid for by private insurance, self-pay, or is uncompensated.

To understand the size of the populations of concern, and how estimates could be assembled from the data sources described above, estimates of the at-risk population for one sample city, Worcester, Massachusetts, is constructed in Table 17.

Table 17. Estimates of the At-Risk Population in Worcester, Massachusetts

Patient Need	Estimate	Source
Functional Needs	646*	ACS (2005–2007)
Medical Needs		
• Dialysis	469**	USRDS (2006)
• IVs/infusions/enteral nutrition	Not available	
• Complex wound care	Not available	
• Insulin injections	Not available	
• Urinary catheter/colostomy	Not available	
• Severe respiratory problems	Not available	
• Specialized medical equipment	Not available	
• Schedule II controlled substances	Not available	
o Methadone outpatients	1496**	SAMHDA (2005)
o Buprenorphine outpatients	70**	SAMHDA (2005)
• HIV/AIDS	910	MassCHIP (2006)
• Terminal illness	Not available	

Table 17. Estimates of the At-Risk Population in Worcester, Massachusetts

Psychosocial Needs		
• Mental illness, cognitive impairment, developmental delay	414***	ACS (2005–2007)

* Reported on the ACS as difficulty with ADLs (e.g., dressing, bathing, ambulation inside home) and a condition that substantially limits one or more basic physical activities, such as walking, climbing stairs, reaching, lifting, or carrying. Number of these individuals reporting receipt of SSI = 109.

**Worcester county.

***Reported on the ACS as having problems with learning, remembering, or concentrating, having difficulty going outside alone to shop or visit a doctor's office because of physical, mental, or emotional problems, and difficulty working at a job or business. Number of these individuals reporting receipt of SSI = 126.

3. An Alternative Method for Estimating the At-Risk Population

Given the difficulty of identifying data sources that contain the necessary level of detail, the investigators attempted to take a grassroots approach by going directly to one community (Worcester, Massachusetts) and asking local health care and social service providers to estimate the number of at-risk individuals. A global list of home health agencies, hospice care organizations, oxygen suppliers, home infusion providers, medical supply companies, substance abuse and methadone clinics, Meals on Wheels providers, and adult day care centers was compiled through an Internet search and the Department of Health and Human Services' Medicare Supplier Directory. These organizations were contacted by phone during May and June 2009. When an appropriate contact person was located, which was not possible in all cases, the contact was asked a list of questions related to emergency preparedness. The table below shows the number of entities on the original contact list, the number of entities for which a contact person was found, and the number of entities that provided information about at least one of the questions, either by phone or E-mail. Although investigators were able to reach 87 percent of the original contacts, only slightly more than 25 percent were willing to share information, and of those only a handful could provide estimates of the number of clients/patients they considered to be in the highest risk category for hospitalization if services were disrupted during a disaster.

The home care agencies were better able to estimate the number of patients in the highest risk category; in contrast, only one oxygen supplier could provide an estimate of their patients at highest risk.

Table 18. Worcester Area Providers Who Responded to Requests for Information

Type of Provider	Number of Entities in the Worcester Area	Number of Entities Contacted	Number of Entities That Shared Information
Home Health/Hospice	22	17	4
Home Infusion/Medical Supply/Oxygen	10	10	3
Substance Abuse/Methadone Clinics	5	5	2
Meals on Wheels Providers	1	1	1
Total	38	33	10

This attempt at gathering estimates from the "ground up" was labor intensive and did not appear to yield any better information than that available from the national surveys. The investigators were not completely confident that they had reached every possible supplier/provider in the area and found it took multiple attempts to establish contact with the entities identified. In some cases, the supplier/provider identified did not service the group of patients/clients pertinent to this study. Even when contact was made with an appropriate individual, some supplier/providers were not particularly forthcoming with information they may consider proprietary. For these reasons, local emergency planners are not likely to be able to estimate the at-risk population in this way.

4. Recommendations

The objective of this study was to determine how easy or difficult it would be to quantify the population of individuals who depend on medical assistance and who, if their services and/or support were disrupted during an MCE, would potentially seek those services in their local hospital emergency department. The investigators began by exploring a variety of databases containing information on the medical needs of these individuals, but found that no one data source could provide the level of detail they were seeking. Information was available, but no corresponding information, such as caregiver availability, presence of a medical condition, or the level of disability, was provided. Furthermore, there is considerable overlap of information in these databases, making any combination of groups prone to overestimation.

The investigators attempted an alternative approach to developing population estimates, "from the ground up," which involved contacting local agencies in one city that have regular interactions with at-risk individuals and soliciting their estimates. Identifying the agencies and the most appropriate contact within the agency, as well as overcoming their hesitation to provide information, was quite labor intensive, and the investigators were not confident that the estimates they were able to derive are accurate.

Although neither approach yielded reliable estimates of the at-risk population, further exploration of these databases has the potential to provide the level of detail needed. The searches in this study were limited to only those databases that are publically available (i.e., that did not require a DUA or submission of a proposal and fee). Data on medical/clinical needs (e.g., IVs, enteral nutrition, complex wound care, insulin injections, urinary catheters/colostomies, ventilators, VADs, and hospice care) are the areas in which data are most lacking. This type of information could, however, readily be obtained from Medicare and Medicaid claims. Although each has its limitations (Medicare covers only the elderly and disabled; Medicaid covers only the poor and each State's eligibility and benefits vary), the population covered by these public payers is substantial.

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