

PA Chapter American Academy of Pediatrics – All Provider Survey

Form Approved

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Dear Colleague,

Families with children who have special health care needs have unique risks during major disasters. Providing these families with clear and targeted communication from trusted sources can be critical to their survival. The Centers for Disease Control and Prevention (CDC) is sponsoring this study to understand the disaster communication needs of families with special health care needs, and the capacity of medical and other professionals to meet those needs.

CDC is working with the Pennsylvania Chapter of the American Academy of Pediatrics and Drexel University to survey pediatricians in Pennsylvania. The information you provide will be used by emergency response agencies, health care and other professionals to improve their ability to communicate with families during emergencies that threaten their health and safety.

Please complete this survey which should take no more than 15 minutes of your time. We thank you for your input.

Part 1. General Practice Questions

1. Type of practice: Primary care Specialty Both

2. How would you characterize your practice?
 - Independently owned and managed, non-profit
 - Independently owned and managed, for-profit
 - Owned and managed by a health care system
 - Government agency or organization
 - Academic medical practice in a university or academic health system
 - Community health center
 - Other (please specify): _____

3. What is the age range of patients in your organization? (Check all that apply)
 < 5 years 5-10 years 10-18 years > 18 years

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4. How many patients are currently in your practice?
 < 500 500-1,000 1,000 – 5,000 > 5,000 – 10,000 >10,000
5. How many physicians/providers (e.g., include physician assistants, nurse practitioners) work in your practice? ____ (please estimate number of full-time providers)
6. Does your practice have more than one clinical site? Y or N
- a. If yes, how many? _____
7. In what county (or counties, if multiple sites) is your practice located? _____
8. Does your practice use an electronic medical record? Y or N
9. Approximately, what percentage of your practice consists of children and youth with special health care needs (CYSHCN)? An estimate is sufficient.
(CYSHCN defined as “children who have or are at increased risk for a chronic physical, developmental, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”)
- <10% 10-24% 25-50% >50%
10. What types of special health care needs do your patients have? Check all that apply:
- Require daily medication
 - Chronic respiratory illness
 - Require technology for respiratory support (e.g., oxygen, apnea monitor, tracheostomy, ventilator)
 - Chronic GI diagnosis/nutritional support
 - Requirement of technology for feeding (e.g., G-tube, NG tube)
 - Visual or hearing impairment (even when wearing glasses or using hearing aid)
 - Developmental delay
 - Intellectual disability
 - Access/mobility challenges (e.g., requires wheelchair or other equipment)
 - Depend on assistive technology for communication
 - Immune suppression (e.g., either congenital or acquired, including malignancy or chemotherapy-related)
 - Autism spectrum disorders
 - Behavioral conditions such as ADHD
 - Other (please specify) _____
11. Does your practice participate in the PA American Academy of Pediatrics’ Medical Home Initiative for children and youth with special health care needs? Y or N

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12. Does your practice participate in another patient-centered medical home model to provide care for children with special health care needs? Y or N

a. If yes, specify _____)

Part 2 – Practice Communication Procedures

13. How do individual patients contact the practice if they have health-related questions? (Check all that apply)

- Telephone
- Portal messaging
- Email
- Fax
- Text message
- Facebook message
- Twitter
- Come into practice (face-to face)
- Other (please specify) _____
- Patients do not contact the practice for questions outside of patient visits or encounters.

14. Does your practice have a fast way to communicate with ALL of your patients in an emergency?
Y or N

If No, skip to 17

15. If yes, what mechanisms or channels do you use (check all that apply):

- Post information on your website
- Patient Portal
- Email
- Automated phone calls
- Text messaging (group)
- Twitter
- Facebook
- Add message to practice telephone voice mail
- Other (specify) - _____

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16. If you have the ability to communicate with large numbers of your patients during emergencies, what types of information would you convey? (Select all that apply)

- Changes in hours or location (e.g., open or closed, limited hours, alternative location, etc.)
- Answering service number for patients to reach providers
- Alternative number if answering service is not available
- Information about how to access prescription refills, medical equipment orders
- Availability of a vaccine or medication
- Recommendations for protective measures appropriate for the emergency (e.g., stay at home; go to a shelter, avoid exposure to a type of food if during a foodborne disease outbreak)
- Availability of resources (e.g., more information, supplies) for patients, either through practice or in community
- Other (please specify): _____

17. From whom does your practice receive current information (e.g., “situational awareness”) about emergencies that will impact practice operations or the health of your patients? Check all that apply:

- Pennsylvania Emergency Management Agency (PEMA)
- Local (county or township) emergency management agency
- Pennsylvania Department of Health
- Local health department
- Center for Disease Control and Prevention (CDC)
- American Academy of Pediatrics (AAP) or other professional society
- Television news local
- Television news national
- Newspaper
- Internet/websites (Please specify: _____)
- Health system central office
- Colleagues (informal networks)
- Facebook
- Twitter
- Radio
- Other (please specify) _____

If Facebook or Twitter selected:

18. If your practice gets information during emergencies from Facebook or Twitter, what sources are most helpful to you?

- Media outlets
- Government agencies
- Health systems
- Other (please specify): _____

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19. Does your practice receive alerts from CDC's Health Alert Network (HAN)? Y or N
20. Do you or your practice receive alerts from your state/local public health department Health Alert Network (HAN)? Y or N
21. Does your practice receive alerts or other information from your state/local emergency management agency alert system? (e.g., Ready PA, or local/county equivalent such as Ready Philadelphia, Ready Erie, or Ready Chesco)
- Yes
 - No
 - Don't Know
22. Does your practice have a back-up generator?
- Yes
 - No
 - Don't Know

Part 3: Emergencies and Children with Special Health Care Needs

While we recognize the need to support all patients during disasters, the next few questions ask about how your practice might assist patients with special health care needs.

23. Does your practice encourage families with children/youth who have special health care needs to have plans for emergencies? Y or N
24. How would you get information about how the emergency is affecting the health of your patients with special health care needs? Check all that apply:
- Contact individual families directly by telephone
 - Go to family's home
 - Home health agency/visiting nurses
 - Social service providers
 - Durable Medical Equipment (DME) providers
 - Community or faith-based organizations
 - Other _____

25. Does your practice have a fast way to communicate during an emergency specifically with multiple families of children with special health care needs? Y or N

26. If yes, what mechanisms or channels do you use to communicate (check all that apply):

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- Patient Portal
- Email
- Automated phone calls
- Text messaging (group)
- Post information on your organization's website
- Facebook
- Twitter

Other (specify) - _____

27. Which of the following would be most useful to provide information during disasters to the families in your practice with special health care needs?

	5 Very Useful	4 Useful	3 Neutral	2 Not very useful	1 No need for this
List or registry of patients in the practice who have special health care needs that place them at risk for poor outcomes during disasters					
Technology that gives the practice the capacity to reach patients urgently (assuming electricity not disrupted)					
Education and training in the health impacts of specific threats and how to mitigate or treat them					
Real-time situational awareness and information from government agencies to share with patients					
Other (please specify):					

28. In the event of a **major storm or weather event** that disrupts power for several days and interferes with transportation routes, would you try to communicate with the families in your practice to provide them with information to help them get through the storm and minimize the impact to their health?

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Check all that apply:

- Yes – would contact all families in the practice
- Yes - would contact the families with special health care needs specifically (with information tailored to their needs)
- No, would not do this

29. In this type of scenario (major storm), which of the following applies to your practice and its plans for communicating with your patients: (Check all that apply)

- I need more information to advise families in a weather emergency
- I don't believe that it is the practice's responsibility to provide information to patients about how to survive a weather emergency
- I don't believe that patients expect me (the practice) to provide information to them during a weather emergency
- I am concerned that communicating health recommendations to large numbers of patients in an emergency might violate HIPAA and the privacy of protected health information
- The practice lacks the technological capacity to do this
- Other (please specify): _____
- None of these apply

30. In the event of a major infectious disease outbreak like an influenza pandemic, would your practice try to communicate with patients with special health care needs to help them minimize the impact to their health?

- Yes – would contact all families in the practice
- Yes - would contact the families with special health care needs specifically (with information tailored to their needs)
- No, would not do this

31. In this type of scenario (major infectious disease outbreak), which of the following applies to your practice and plans for communicating with your patients: (Check all that apply)

- I need more information to advise families in an infectious disease outbreak
- I don't believe that it is the practice's responsibility to provide information to patients about how to survive an infectious disease outbreak
- I don't believe that patients expect me (the practice) to provide information to them during an infectious disease outbreak
- I am concerned that communicating health recommendations to large numbers of patients in an emergency might violate HIPAA and the privacy of protected health information
- The practice lacks the technological capacity to do this
- Other (please specify): _____
- None of these apply

32. If there was an **accident at one of the nuclear power plants** in Pennsylvania (or in a nearby state), would your practice try to contact patients with special health care needs to convey risks (or lack thereof) to their health and other guidance for health-protective behaviors (e.g., shelter in place, evacuate, take potassium iodide (KI) pills)?
- Yes – would contact all families in the practice
 - Yes - would contact the families with special health care needs specifically (with information tailored to their needs)
 - No, would not do this
33. **In this type of scenario (accident at a nuclear power plant), which of the following applies to your practice and plans for communicating with your patients:** (Check all that apply)
- I need more information to advise families in this type of disaster
 - I don't believe that it is the practice's responsibility to provide information to patients about how to survive this type of disaster
 - I don't believe that patients expect me (the practice) to provide information to them during this type of disaster
 - I am concerned that communicating health recommendations to large numbers of patients in an emergency might violate HIPAA and the privacy of protected health information
 - The practice lacks the technological capacity to do this
 - Other (please specify): _____
 - None of these apply

Part 4: Practice Communication Needs

34. Do you believe that your practice needs additional technology or technological support to expand its capacity for large-scale patient communication during emergencies? Y or N
If yes, which of the following would be useful to you? **(Select all that apply)**
- Text messaging capacity for multiple recipients
 - Automated phone message capacity
 - Blast email capacity
 - Use of patient portal to send messages for multiple recipients
 - Capacity to target communications to subsets of patients
 - Other (please specify): _____
35. Do you believe that **you or your practice** would benefit from trainings or guidance regarding how to communicate with families who have special health care needs before or during emergencies? Y or N
****If no, skip to end of survey***

36. If yes would training or guidance related to any of the following be useful:

	5 Very useful	4 Useful	3 Neutral	2 Not very useful	1 No need for this
Accessing up-to-date information from official sources (e.g., emergency management/public health) during emergencies					
Availability of services for patients during emergencies					
Preparing patients for emergencies					
Using social media					
Using technologies for rapid communications with patients					
Understanding disaster Information needs of families					
Addressing psychological needs during disasters					

Other educational needs? Please specify: _____

37. If yes, what formats for guidance or trainings would be useful to you? (Check all that apply)

- Webinars
- Websites with communication tools, checklists
- Conferences (in person) with didactic trainings
- Publications (available electronically) with recommendations for communicating with CYSHCNs during emergencies
- Clinical practice guidelines and toolkits to facilitate large-scale communications during emergencies with patients

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- Maintenance of certification modules (including Part IV Learning collaborative)
- On-site technical assistance to improve practice capacity for patient communications during emergencies
- Other formats? Please specify: _____

Thank you for completing this survey. The results will be shared with government emergency response agencies and used to develop communication protocols that support patients with special health care needs before, during and after disasters.

The following resources are available for pediatric medical practices who would like additional information regarding practice emergency planning, communications during emergencies and disasters, and how to prepare patients with special health care needs:

1. AAP Children and Disasters website
<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Children-and-Disasters/Pages/default.aspx>
2. Pediatric Practice communications toolkit
<http://diversitypreparedness.org/browse-resources/resources/CPHRC%20Pediatric%20Toolkit/>
3. Practice Emergency Planning Materials
<http://bit.ly/2pgEFHO>
4. Checklists for patients with SHCNs
<http://bit.ly/2pgEFHO>

Information in emergencies:

5. PA HAN registration
<https://han.pa.gov/>
6. CDC HAN registration
<https://emergency.cdc.gov/han/updates.asp>
7. Ready region/Ready PA
<http://www.pema.pa.gov/planningandpreparedness/readypa/pages/readypa.aspx>