



PANDEMIC PLANNING AND PATIENT- AND FAMILY-CENTERED CARE

BACKGROUND

With the arrival of H1N1 influenza hospitals and clinics began making decisions about policies and practices to aid in efforts to prevent disease transmission. In October 2009, a working group was convened during the Institute's *Hospitals and Communities Moving Forward with Patient- and Family-Centered Care Intensive Training Seminar* in Minneapolis, MN to create a set of guidelines that reflect the core concepts of patient- and family-centered care when developing a pandemic plan.

During any outbreak of infectious disease, it is important to take steps to contain the illness **and** to remember that family members are stewards of patient safety and integral to the healing of loved ones. The continued presence of a family member with a patient, during a pandemic has both safety and psychological components.

CORE CONCEPTS OF PATIENT- AND FAMILY-CENTERED CARE

Dignity and Respect. Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.

Information Sharing. Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

Participation. Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

Collaboration. Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation, and evaluation; in facility design; and in professional education, as well as in the delivery of care.

GUIDELINES FOR PANDEMIC PLANNING

- ▼ Educate infection prevention staff and leaders about the overall safety and health benefits of patient- and family-centered care. As part of this training, outline the potential risks and costs – psychological, developmental, physical and financial – if patient- and family-centered care is not fully embraced.
- ▼ Involve patients and families with health experts who understand the science of disease transmission in both pandemic planning and in communicating any pandemic response plan to patients, families, and the general public. Consider including patient and family representatives on the hospital’s safety committee to ensure that all appropriate perspectives are considered.
- ▼ Ensure that decisions made are based on available scientific evidence and the unique community epidemiology of each geographic area. In any pandemic, the incidence of disease will typically differ by geographic location and, therefore, organizations will need to respond accordingly. In 2009 and 2010, the response to H1N1, the scientific guidance from CDC and Health Canada changed frequently. It is important that publications and all types of communication tools be reviewed and updated frequently to reflect these new clinical practice guidelines.
- ▼ Build in mechanisms to loosen or tighten restrictions as circumstances change and ensure that the public understands the rationale for such decisions. As an example, it is important to have patient and family advisor input on messages about vaccine limitations to high-risk populations during vaccine shortages.
- ▼ As any restrictions are considered in the context of infection control, ask the following:
 - Have the proposed restrictions proven to be effective for the current infection? For example, is there any scientific data to support the age under which children will be limited in their access to the patient?
 - Will the proposed restrictions have the desired effect in terms of preventing the spread of infection?
 - Are there alternative approaches, especially ones that would be considered to reflect patient- and family-centered care? For example, could healthy children be welcomed on units if they wash their hands and wear a mask?
 - For every proposed action, might there be unanticipated reactions and/or unintended negative consequences?
 - Will there be a mechanism for making exceptions on “compassionate grounds”?
- ▼ Consider exploring the experiences and advice from other regions that have already experienced pandemics.
- ▼ In making plans for a pandemic, consider not only aspects of infection control and the implications for patients and families, but also the potential stresses on staff. Ensure that there is a workable implementation plan that does not add more burden to staff who may already be stretched to capacity. Also identify what psychological supports and infection protections need to be in place for staff.

- ▼ Develop clear criteria for children and/or adults who have been immunized (differentiating between live and killed viruses) and/or have already had the particular infectious disease so that they know when they can have regular access to patients and family members who are hospitalized.
- ▼ In all pandemic planning, hospitals should include a mechanism to continuously review restrictions on family presence policies with a clear intention to return policies to normal as soon as is safely possible.

GUIDELINES FOR IMPLEMENTATION

- ▼ Consider limiting groups in public areas (such as entrances, waiting rooms, cafeteria).
- ▼ Include public health education for patients and families that will help them understand the symptoms of the particular pandemic and what to do if they suspect a child or family member has those symptoms. Hospitals and clinics also should provide a brief description of infection prevention precautions they are undertaking to ensure safety. In many communities, hospitals and clinics set up “assessment centers” separate from hospitals to assess who needs hospital attention and who does not.
- ▼ Public health education for patients and families should also explain what people can do to protect themselves and their children:
 - Hand washing
 - Wearing of masks, covering nose and mouth
 - Avoiding facial contact, especially around the mouth and nose
- ▼ Give patients the right to determine and define their family and who is most important to be present with him/her if there must be limitations to the number of people at the bedside.
- ▼ If an outbreak requires severe access restrictions to hospitals, consider ways selected family members can still have access. This may include some limitations on their movement within the hospital and an understanding of any risks they may be subject to by choosing to stay with their family member in the hospital.

GUIDELINES FOR COMMUNICATION

- ▼ Hospitals should have a clear communication strategy and should ensure that special signage is written as positively as possible and in appropriate languages for the community. Patient and family advisors should be part of the planning for communication strategies. Any materials and messages for patients and families related to a pandemic response plan and its prevention should be:
 - Made available in a variety of media (e.g., written, audiovisual);
 - Communicated in the primary languages spoken by communities served by the hospital;
 - Reviewed by patient and family representatives before they are finalized; and
 - Marked with the date.

- ▼ In a pandemic plan with tiered stages of restrictions, communicate clearly the triggers for each level of restriction and how the triggers were determined. Common triggers include overall incidence of the pandemic in the community, especially in schools; number of cases presenting in screening clinics and in Emergency Departments; number of admissions to hospital and number of cases that are in intensive care; and number of staff absences due to the pandemic.
- ▼ In a full pandemic, with severe access restrictions, hospitals and clinics should have a designated 24/7 manned phone line for responding to questions, concerns, and special requests. Recorded messages may aggravate levels of high anxiety.
- ▼ If families are separated, use available communication infrastructure to enable family members to stay in touch and be informed of a patient's condition and progress. Creative use can be made of cameras, telephones, fax machines, computers, and video conferencing software (e.g., Skype™).

For additional references related to this topic, please see the *Patient Safety* and the *Changing the Concept of Families as Visitors: Family Presence and Participation* bibliographies in the Institute's Compendium of Bibliographies at <http://www.ipfcc.org/advance/supporting.html>. For additional guidance, see *Changing the Concept of Families as Visitors: Supporting Family Presence and Participation* available from the Institute at <http://www.ipfcc.org/resources/pinwheel/index.html>