Appendix A. Recommendations for Ideal Consumer Reporting Systems

A 2010 report by Research Triangle Institute (RTI) and Consumers Advancing Patient Safety, Designing Consumer Reporting Systems for Patient Safety Events, outlined recommendations for an ideal reporting system that consumers could use to report experiences with patient safety events. The recommendations are summarized here.

Recommendations for Key Features of an Ideal Consumer Reporting System

1. What types of information can consumers provide concerning their health care experience with patient safety events that may be useful and/or actionable in a patient safety event reporting system?

Recommendation 1.1. Types of Information. The system should collect information on all types of events, ranging from near-miss and no-harm events to adverse events. The system should capture both objective information about what occurred and more-subjective information based on the consumer's unique perspective. Information collected from consumers should include where a patient safety event occurred; what contributed to the event; whether or to whom the event was reported; what happened when the event was reported; and the impacts or consequences of the event.

Recommendation 1.2. Sources of Reports. The system should allow for reporting by any individual, but the emphasis should be on obtaining the consumer perspective.

2. What are the scope and range of options for consumer reporting mechanisms? How would these options differ at the international, national, regional, state, and local levels?

Recommendation 2.1. Purpose and Goals. The dual purposes of a consumer reporting system are to learn and to be accountable to consumers providing reports. *To learn* means obtaining the consumer perspective and experience to identify, mitigate, and prevent risks, hazards, and harms; improve outcomes; and advance patient safety. *To be accountable to consumers providing reports* means that reported information will be actively used to design meaningful improvements in patient safety.

Recommendation 2.2. Level of Operation. Reports should be collected locally and communicated to a centralized (national) level that can aggregate and analyze data and triage or distribute information to state and local levels for action. The reporting system will need to be flexible regarding analysis and other activities occurring at local levels, based on needs, capabilities, and funding/resources for them.

3. What type of infrastructure is needed to enable effective, actionable consumer reporting of patient safety events?

Recommendation 3.1. Linkages. The system should have linkages to a broad range of

organizations that can change health care practices and demonstrate that reported information was used. Linkages should be formed to encourage consumer reporting, improve analysis, share results, and change delivery for quality improvement. Linkages will also ensure timely information sharing. Because linkages are dynamic and rapidly changing, their exact nature and specifications should be more fully specified at implementation.

Recommendation 3.2. Analytic Functionality. The system will need decision rules for the levels or types of analysis performed for different kinds of events. The system should collect information and conduct aggregate causal analyses. It should also gather responses of organizations and evaluate their feedback.

4. What is the most effective operational approach for consumers to report patient safety event information?

Recommendation 4.1. Type of Organization. Guiding principles and characteristics that should be sought for organizations that own or operate consumer reporting systems include being an independent entity with a steady stream of sustainable funding, where "independent" is defined as being completely separate in ownership, governance, and affiliation from entities that provide health care and whose members, employees, or affiliate entities may be the subjects of reports about adverse events; governing body members having a fiduciary responsibility to represent the public; being a neutral oversight body with consumer representation; transparency of goals, process, and results; having consumer involvement in organizational governance and operations; and being dedicated to analyzing incoming information to identify threats to patient safety and feeding it back to systems that may be able to act on it.

Recommendation 4.2. Access at Different Points in Time. The system should allow reporting at any point in time.

Recommendation 4.3: Reporting Modalities. To maximize reporting, the system should include multiple routes or modalities for reporting.

Recommendation 4.4. Reporting Format. The system should enable a mix of structured and unstructured reporting.

Recommendation 4.5. Anonymity. The system should allow anonymous reporting, but it should be designed to discourage such reporting by ensuring and providing well-designed confidentiality safeguards. The system should allow reporters to opt out of confidentiality to increase the report's efficacy in certain situations.

5. How would consumer reporting of patient safety events be linked to quality and/or patient safety improvement efforts?

Recommendation 5.1. Linking to Quality and Patient Safety Improvement Efforts. The system should be linked to efforts to improve quality and patient safety. If the reporter allows his or her reports to be shared, the consumer reporting system will automatically forward them to appropriate reporting systems at the local or facility level.

Recommendation 5.2. Public Reporting. Public reporting should be used to hold the system accountable to its own goals. The system should:

• Publish information such as how much the system is used.

- Publish information on what has been learned.
- Publish information about recommendations and changes that were made as a result of patient and caregiver reports.
- To the extent determinable, information about the responsiveness of institutions to patient safety issues should be published.
- Because this is an evolving and dynamic issue, the exact specifications will be developed at implementation and will be determined over time.

6. How can a reporting system maximize the willingness and ability of consumers to report on patient safety events?

Recommendation 6.1. Maximizing Reporting. The system design should facilitate reporting to ensure maximum use; that is, it should maximize the ease of submitting reports and the ability of consumers to do so. This will include public awareness campaigns or other outreach/marketing activities and getting buy-in from appropriate individuals and organizations as part of implementation.

Recommendation 6.2. Accessibility. The system should be designed to facilitate access for diverse populations (e.g., persons of different age, race/ethnicity, education, language, disability).

Recommendation 6.3. Feedback. The system should provide meaningful and timely feedback to reporters. Feedback includes a report to the public, awareness campaigns, and meaningful acknowledgment of receipt of a report. However, the system will not be able to assure reporters that they will receive meaningful and timely feedback from the health care facility where a patient safety event took place.