

# **AARP Perspectives on Consumer Protections**

**Presentation to Texas Health Services Authority**

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**AARP Texas**



*The power to make it better.*

# AARP Texas Basics

- Two million+ Texas AARP members and more than 140 chapters across the state.
- 300+ volunteers that are crucial to our work.
- More than 525,000 e-advocates signed up to receive updates about our legislative efforts.
- AARP Foundation WorkSearch offices in eight Texas communities serve more than 6,000 age 50+ job seekers annually.
- More than 200,000 Tax-Aide volunteers working at more than 300 sites serve around 200,000 low- and middle-income Texans annually.
- Web at [www.aarp.org/states/tx/](http://www.aarp.org/states/tx/)
- Twitter: @AARPTx
- Facebook: facebook.com/aarptexas

# AARP HIT Policy Principles

- **Right to Privacy**
  - Federal and state governments should ensure individuals' right to privacy with respect to their personal medical information. State and federal polices should grant individuals the right to examine and copy the contents of their health care records, be notified who has examined these records, and identify who may have access to their personally identifiable health information and for what purpose.
- **Design Attributes for HIT Systems**
  - **Control and Access** - Individuals must have the ability to control who has access to their personal health information and the ability to review who has reviewed their files;
  - **Disclosure and Accountability** - Individuals should receive information that fully explains policies affecting the transfer of that information maybe used;
  - **Functionality** - Individuals must be able to move their information securely and reliably from one health care entity to another; and
  - **Governance** - Consumers must be represented on an equal footing with other parties in the governance and advisory structure of all regional and national bodies, including standard setting and operational entities.

# AARP HIT Policy Principles, Continued

## (Design Attributes for HIT Systems, continued)

- **AARP Supports *Connecting for Health* \* Policy Principles:**

- Policies and practices addressing personal health information are developed in an open and transparent manner;
- The purposes and intended uses for which personal data are collected are specified at the time of collection and subsequent uses are limited to the initially specified purpose unless otherwise disclosed;
- Personal health information is not made available or used for any purposes other than those specified;
- Individuals can control access to their personal health information and have the right to obtain data relating to them communicated in a reasonable timeframe, at an affordable charge (if any), and in a form that is readily understandable;

\*<http://www.connectingforhealth.org/aboutus/collaborators.html>

# AARP HIT Policy Principles, Continued

## (Design Attributes for HIT Systems, continued)

- If an individual's request for personal health data is denied by the entity controlling access to the data, the individual should be able to challenge such denial and have such data corrected, completed, or amended;
- All personal data collected are relevant to the purposes for which they are to be used and are accurate, complete, and current;
- Personal data are protected by reasonable security safeguards against risks such as loss, unauthorized access, destruction, use, modification, or disclosure;
- Entities controlling personal health data are held accountable for implementing effective practices to ensure adherence to these principles; and
- Legal and financial remedies exist to address security breaches or privacy violations.

# Initial Thoughts on the Texas HIE Draft Plan

- Patient and consumer focus in **Guiding Principles**
- Special consideration for consumers with special needs (e.g., long term care) in terms of privacy and security
- Legal/policy principles are a good articulation of consumer rights/concern
- Compliance with Federal/State Requirements – contract monitoring and enforcement related to privacy/unauthorized use protections
- Inclusion of consumer groups in the process on an ongoing basis

# Implementation Considerations

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- Consider lessons from problematic, large scale IT implementations
- Testing/readiness for consumer protections
- Willingness to act on readiness information and delay, if not ready
- Consumer confidence can be fleeting; need to get it right the first time

**Thanks!**

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