

# Plain talk: Helping consumers understand HIPAA privacy protections

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# ODPHP's interest in "plain language privacy communication"

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## # ODPHP is a

- Consumer health information provider, which includes privacy
  - Lead on Healthy People 2010 objectives on improved communication (health literacy and provider-patient communication)
  - Lead on assessing the reliability and utility of health Web sites for consumers, and privacy is a key concern
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# Why educating the public about privacy is important

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## # Public

- Strong opinions
- Unfamiliar topic
- Little direct personal experience

## # Current and likely media coverage

## # Complex regulations, concepts and vocabulary

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# Why plain language communication matters

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- # Regulation requirement
  - # Most health information is difficult for majority of public to understand
    - About 25% of U.S. population has very low literacy skills in English
    - Additional considerations of literacy in languages other than English and cultural differences
  - # People typically don't use information they don't understand
  - # Plain language contributes to people's understanding of privacy protections and rights
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# Importance of notices of information practices

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- # Part of healthcare relationships
  - # Gateway or point of entry for the public
  - # Explanation of protections and rights
  - # Physical representation of abstract concepts, such as “information practices”
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# Prior experience with notices of information practices

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- # Gramm-Leach-Bliley Act (financial services)
    - Required notices of information practices and remedies for customers
    - Notices were described as “dense,” “misleading,” “confusing,” and cumbersome”
    - Unflattering media coverage and anecdotes of consumers throwing away notices unopened and unread
    - Over one year after initial distribution, notices are still the subject of Congressional testimony
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# Notices and good communication

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- # Public education about privacy and protections for personal health information is essential to the success of the regulation
  - # Public education prior to and in conjunction with notices is necessary to help consumers read and understand notices
  - # Effective notices can contribute to public understanding
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# Why does it matter that consumers understand privacy protections?

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- # Support informed decision-making by patients and caregivers
  - # Promote trust between patients and the healthcare system
  - # Promote consumer acceptance of information exchange as part of the NHII
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# Resources on effective notice

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- # Federal Trade Commission guidance on writing effective notices
    - <http://www.ftc.gov/bcp/online/pubs/buspubs/getnoticed.htm>
  - # Federal Inter-agency Workshop on effective notice
    - <http://www.ftc.gov/bcp/workshops/glb/>
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