4/2/12:
American Psychoanalytic Association Response to NTIA RFI

1. **What issues should be addressed through the privacy multi-stakeholder process?**

   NTIA should explicitly include issues involving the sharing of personal health information through Health Insurance Exchanges, hospital system data systems, etc. We suggest NTIA consider how these systems interact with consumer devices. It is important to ensure that the security technology used for consumer devices and sites is compatible with security technology used by doctors' offices and hospitals. Additionally, consumers could potentially share health information via mobile applications and cloud computing, and security and privacy issues should be of utmost importance.

2. **What factors should be considered in selecting issues for the privacy multi-stakeholder process?**

   NTIA should consider accountability and readiness as key factors in selecting and prioritizing issues for the privacy multi-stakeholder process. The public must trust their health information privacy is protected under federal law in order to seek out to engage in commerce, to participate in the political process, and to seek needed health care.

3. **How can NTIA promote participation by a broad range of stakeholders?**

4. **Which stakeholders should participate? And what expertise should participants have?**

   NTIA should consider the populations affected by previous breaches of security systems and include them in their stakeholders who participate. NTIA should also reach out to stakeholders that have the most to lose from breaches of electronic health information (ie, patients with sensitive mental health issues and the providers that serve them).

   NTIA should reach out to experts on privacy, security and technology to ensure adequate and possible measures are developed in this process. It is important to include experts in the field of security, such as American National Standards Institute (ANSI) who recently reported on the costs of security breaches involving health information and the difficulty of complying with incoherent health information laws

5. **How can NTIA best ensure the process is inclusive, given that participants will have access to different levels of resources?**

6. **What impact would a requirement to submit a brief position paper in advance of a stakeholder meeting have on participation? Are pre-requisites for participation consistent with the principle of openness?**

   We recommend encouraging, but not requiring, participants to submit a brief position paper in advance of a stakeholder meeting.

7. **What balance is needed between in-person and virtual meetings?**

8. **What technologies could facilitate discussions among stakeholders before, during, and after in-person meetings?**

9. **How should discussions during meetings be published? Is it necessary to have verbatim transcripts or recordings, or is an abbreviated recording more appropriate?**

10. **How can NTIA facilitate broad public review of codes of conduct during their development?**

    Preserving public trust and certainty with respect to the privacy of electronic data generally is missing from the electronic health information privacy laws and regulations even though health information is likely to be far more sensitive and damaging to the individual if improperly disclosed. The HIPAA/HITECH Act ignore standards of professional ethics, do not recognize that individuals have a right to health information privacy, do not adopt a clear and understandable framework of privacy principles, and instead, provide for health information technology policy and standards to be developed by committees of "stakeholders" in which consumers are a small minority.[1] Any broad public review of codes of conduct needs to involve consumers, and we recommend this be facilitated by advance publication of draft codes, a public comment process and public hearings at which stakeholders can provide testimony.

11. **What procedures should stakeholders follow to explain their decisions on issues discussed within the privacy multi-stakeholder process?**

12. **What procedures should stakeholders follow to explain decisions they reach in concert with other stakeholders?**

13. **Are there lessons from existing consensus-based, multistakeholder processes in the realms of Internet policy or technical standard-setting that could be applied to the privacy multistakeholder process? If so, what are they? How do they apply?**

    To date, health information privacy standards have been developed by committees of "stakeholders" in which consumers are a small minority.[2] The result has been electronic health information privacy laws that Americans do not believe are effective in protecting their right to health information privacy and regulated entities find difficult to implement. Further, the limited privacy protections under the HIPAA/HITECH Act only apply to covered entities and their business associates rather than to the rapidly expanding group of entities that handle personal health information.

14. **How did those groups define consensus? What factors were important in bringing such groups to consensus?**

15. **Are there multistakeholder efforts that have failed to achieve consensus? What did those efforts fail to reach consensus? What policies or standards, if any, resulted from these efforts?**

16. **In what ways could NTIA encourage stakeholders to reach consensus? Under what circumstances should NTIA facilitate discussions among sub-groups of stakeholders to**

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[1] HITECH Act, sections 3002.
[2] HITECH Act, sections 3002.

help them reach consensus? In these cases, what measures would be necessary to keep the overall process transparent?