

## May 25, 2010 HITOC Privacy & Security Forum Stakeholder Feedback Summary

The following questions were posed to the 150+ participants at the May 25, 2010 Privacy & Security Forum, in structured, facilitated table discussion sessions. The feedback from each table was noted and collected, and is summarized here. Individual input forms are being compiled and will be appended to this summary at a later date.

### **Question: Is the Plan directionally correct?**

There was general and widespread support and agreement that the Plan is directionally correct, including support for the phased approach. However, a few concerns were expressed. The most prominent concern pertained to prioritizing patient access to their health record, and the desire to see this more heavily emphasized in the Plan. One table each (of 17 total tables) expressed the following concerns: 1) whether and how the Plan adequately addresses a strategy for involving small care providers who are not currently using an EHR, 2) concern about having a non-governmental (the non-profit) entity running the statewide HIO, 3) concern that if we wait too long for Phase 2, the local HIOs may have developed too far in divergent directions, and 4) a concern that the Plan does not adequately protect patient privacy.

### **Question: Is the consent model the right choice for Oregon at this time (Opt Out w/Exceptions, excluding Specially Protected Health Information (SPHI), with an Opt In option for SPHI)?**

There was general support for the consent model, with most people viewing it as the best option given existing Oregon state legislation for SPHI. Interestingly, many participants saw the potential value of a No Consent model, to both providers and the public, but believed it was not politically feasible at this time. There was also strong support for the move to a full Opt Out system, if and when that becomes legally possible, and similarly, concerns expressed about the difficulty/complexity of understanding and implementing the recommended consent model. Furthermore, there were several comments and concerns about consent in general, such as 1) concerns about consent for other purposes, such as for the use/disclosure of de-identified data and for emergency situations, 2) questions about how consent will be managed, 3) opposition to the null response to a query after a patient has opted out, and the right of providers to know if the record is incomplete, 4) a concern that some information that is not legally SPHI should also be excluded because of its sensitive nature (i.e. reproductive health), 5) concerns about the negative consequences of opting out for receiving treatment, 6) the opinion that consent should be managed and applied centrally, rather than by individual providers, and 7) liability concerns surrounding the exclusion of SPHI.

**Question: What are the best tools for engaging and education consumers?**

There was general consensus that consumer education is paramount, and must happen from the beginning. Most participants felt that education should take place at the provider's office at the point of service, particularly education about opting out. Several other ideas about consumer engagement and education strategies were offered, such as that the state should help prepare and provide educational materials to providers, and that education should be mandatory. The following is a list of the suggestions given for potential sources and channels of education: public forums (such as at the local library), universities and community colleges, mass media (such as YouTube, social networking sites, and commercials), a website, provider licensing boards, health plans, employers, religious organizations, and government provided public service announcements. It was also noted that consumer education should balance information about the risks and benefits of HIE, must use simple language, and must educate consumers about relevant aspects of federal health reform, such as the prohibition on exclusion for pre-existing conditions.

**Question: Which Workgroups would you recommend going forward?**

A broad range of specialized workgroups was recommended, including: Health Equity, Financing, Standards, Audit/Quality Assurance, Privacy & Security, Consumer Outreach and Education, Provider Outreach and Education, Technology, Data Integrity, Participant Feedback, Business Agreements, Mental Health and Substance Abuse, and Patient Access.

**Question: Is there anything that's missing from the Plan or needs to be added?**

Most participants did not note that anything was missing or needed to be added to the Plan. The few comments that were noted here suggested the following: 1) there should be more culturally diverse stakeholder representation, 2) in terms of security, it should be specified who determines HIE access levels and assigns the access roles within an organization (i.e. is it up to the provider, or will HITOC make policies/requirements surrounding these issues?), and 3) there needs to be more information about timing.

**Question: Do you have any other comments or questions?**

Again, the majority of participants did not add any additional comments, concerns, or questions here. However, of those that did, liability was a prominent concern, expressed in questions such as: 1) What will be the responsibility/liability of a doctor (in the ED for example) to look for, look at, and reconcile ALL the data that might be available? , and 2) If a doctor acts on incomplete information, are they liable? There was also a concern about how the accuracy of data will be maintained and who will be responsible for this, with so many additional sources of information.