

# NHII – Privacy Track

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# **NHII – Privacy Track**

## **Current Status**

- **NHII is a new concept to many and needs to be understood.**
- **Most of healthcare is coming off of the HIPAA Privacy implementation and there are misconceptions that need to be addressed and understood before we can move on to NHII. Education – Education – Education geared to different groups.**

# **NHII – Privacy Track**

## **Current Status**

- **Many people do not trust the system/government. Trust has to be rebuilt.**
- **Some systems are being built on a local basis and working – how do we get from there (including public/individual confidence) to an NHII.**

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## **Current Status**

- **We [our group?] need to have a better understanding of the potential solutions that applied to the NHII could address privacy questions including:**
  - **Architecture – alternatives, structures, and uses.**
  - **Need for and use of individual identifiers – how used/when are they really needed or not needed – do we need unique identifiers?**
  - **Security technology.**

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## **Current Status**

- **We still have a myriad of state laws, regulations, and practices and HIPAA only gave us a floor:**
  - **We need to know what these laws et al. are**
  - **We need to know what changes are needed – individual or preemption?**

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## **Current Status**

- **What are the intended uses of NHII? There is a concern/fear that some healthcare data can be used against the individual – until this is addressed information will not be allowed to flow in an appropriate manner.**

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## **Desired State**

**An effective and efficient NHII that balances the individual's interest in privacy and fair information practices with society's need for health information to serve the public.**

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## **Short Term Recommendation 1**

**Privacy has to be a key consideration in the development of architecture and standards – look at privacy questions related to use, disclosure, control, access, identifiers, accountability, etc.**



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## **Short Term Recommendation 2**

**Evaluate [funding] state and federal laws that could affect the architecture, development, and implementation of an NHII.**

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## **Short Term Recommendation 3**

**Educate [funding] individuals/groups on existing healthcare privacy laws/rules, for better understanding.**

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## **Short Term Recommendation 4**

**Evaluate [funding] existing studies on privacy. If needed, evaluate individuals' perspectives on privacy of healthcare data/information in an NHII.**

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## **Short Term Recommendation 5**

**Identify existing infrastructure projects that are being developed and the privacy aspects of such information exchange [trust concept—scalability].**

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## **Short Term Recommendation 6**

**Evaluate [funding] the role of the individual in controlling/managing his/her PHI, in the context of an NHII.**

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## **Short Term Recommendation 7**

**Establish [funding] an ELSI group to address ethical, legal and social issues of NHII, similar to Genome project – ensure that we evaluate and incorporate views of various stakeholders, vulnerable populations, etc.**

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## **Short Term Recommendation 8**

**Establish a permanent independent entity to oversee/advise with respect to the privacy considerations associated with the NHII.**

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## **Medium Term Recommendation**

### **1**

**Inform the public on an on-going basis of the NHII concept and implementation including the privacy impacts.**



# **NHII – Privacy Track Other Observations**

*Cryptic notes available – not written by a physician.*