Balancing benefit and risk

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Clinical benefits of NHIN

- Patient gets test from another MD, or Rx from another MD
- Patient hospitalized, outpatient records not available
 - Compare previous EKG
 - What medications were previously tried?

Clinical benefits of NHIN

- Sensitive conditions like depression
 - What other medications were tried?
 - What doses?

Clinical benefits of NHIN

- Greater if
 - More information included
 - Timely access by providers
 - More providers participate
 - More patients participate
- Electronic records often a condition of care

Risk to privacy and confidentiality

Greater if

- More information included
- Timely access by providers
- More providers participate
- More patients participate
- No control over information

Balancing benefit and risk

- As scope of NHIN increases
 - Usefulness for patients greater
 - Risk of breaches of confidentiality greater

Limits on access to PHI

- Limit what is placed in NHIN
 - Needs to be informed choice
 - Benefits are poorly understood?
 - Giving information does not ensure comprehension

Limits on access to PHI

- Limit what is placed in NHIN
 - Different viewpoint when consumer or patient
 - Cannot quickly include information when needed clinically

Limits on access to PHI

- Limit who has access to NHIN
 - Access be easily changed
 - Allow surrogate to expand access

Protection of privacy and confidentiality

- Strengthen penalties, to provide incentives for security
 - Responsibility for subcontractors
- Opt-in for advertising
 - Currently not even opt outs
 - Broaden definition of advertising/marketing

Protection of privacy and confidentiality

First focus on uses for treatment

- Other uses are secondary to patients
- Need to demonstrate both effectiveness and safety