How to Build Consumer Support in the Development of RHIOs

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Consumer Support of RHIOs

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In RHIO development, it is 20% about the technology and 80% about the *personal* and *political* exchange.

The biggest failing in these emerging organizations is the lack of involvement of the patient/consumer at the beginning.
The personal health record can be the biggest benefit or the biggest problem in building consumer confidence.

The consumer has the opportunity to be a part of his/her own health care decisions in a way never before possible.

The PHR has the potential to bring consumer –provider- payer together around one common technology.
Management of the expectations of what we will do with the data is key.

Is it de-identified?

How will we treat people who don’t want to be a part?

What is a data warehouse/

What is data mining?
Opt in / out can have profound economic, liability, and value impact

- Automatic opt in with opt out on exception basis, or the reverse? Automatic opt out with burden to opt in is a significant barrier to establishing functional system.
- Opt out be at the entity, patient, or visit level?
- How to manage opt out, i.e. local entity, RHIO, or?
- How to instill trust in data exchange if opt-out is not known and clinical decisions are made based upon what is believed to be complete information?
Concern that there will be “discrimination” if opt out known to query request

- Will clinicians or entities refuse to treat patient?

Notice of opt-out provides patient choice and control and fulfills the purposes of establishing an RLS

- Saving lives and decreasing healthcare costs through efficient and timely exchange of information—this is what data exchange is all about
There are no absolute answers

Technology and business practices must be able to handle opt-out at:

- Local entity (data is not sent to the RHIO)
- RHIO (data is sent to RHIO, but flagged as not available)
- Encounter level (perhaps)
Get ready for patient requests that will include:

- Who has accessed my data?
- When they accessed it?
- What they saw?
- Were they authorized?

Therefore a RHIO must ask itself:

- Do my software and business practices support this type of request?
- How will I present the answer to the patient?
- What timeframe and process will my business practices support?

ONCHIT use cases will have to demonstrate this?
PROVIDER

- Accountability
- Value
- Sustainability
CONSUMER

- RHIO Components
- Clinical Integration
- Patient Experience
Questions of the Panel

Can we / should we guarantee privacy?
What is the value proposition to offset the risk of loss of privacy?
How do we convey the value in terms of the six aims identified in the IOM Report?
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