E-mail Remarks from Tiger Team members Larry Garber and John Houston:

Question posed: What policy issues arise (and need to be resolved) to enable access by friends and family members, and legal representatives (called personal representatives under HIPAA) to a patient's information via View/Download/Transmit functionalities of Certified EHR Technology.

(Answers relevant to minors data have been shaded; we are reserving these for when we take up the issue of minors data later this year)

Larry:

I don’t believe that data segmentation will be reliable in our lifetime. Our approach at Reliant Medical Group is largely everything being available to those that have access on behalf of the patient. The one exception is adolescents (age 13-17, inclusive) where the parent only has access to Demographics, Family Hx, Surgical Hx, Allergies, Immunizations, and Growth Chart.  The Allergies is still controversial because it may point to treatments that are sensitive in nature.

John:

UPMC also limits access to parents of adolescents.  However, our approach is slightly different.  We also limit access to the types of information that Larry described at the age of 13.  However, we can extend access to the entire record if (1) the child agrees (with such agreement being "witnessed" by the physician ,with the physician believing that the child's agreement is without duress); or (2) the physician believes that such access is necessary due to the child's chronic illness or lack of mental capacity.  However, in either case, if the child receives treatment where such treatment does not require parental consent, then full access to the record by the parent is turned off.  In such cases, the parent would need to make a request to our Medical Records Department to receive a copy of the record.  The Medical Records Department would review the information to be released to ensure that only appropriate information is provided to the parent.  This scheme was the result of many meetings involving representatives from the physician community (both in general practice and pediatricians at our children's hospital), legal, HIM and IT.

Larry:

We’re firm believers in face-to-face authentication of patients and their proxies or family members when setting up online access.  We are aware of other organizations where online access using online authentication services failed to prevent a mother pretending to be her 18 year old daughter.  I suspect spouses could do the same thing in many cases.  We have started to allow authentication for patients over age 25 via the telephone, thinking that we’ll have cleared the riskiest age and can tell a wife faking being a husband…

John:

We do use commercial tools to perform remote identity proofing.  In such cases, the identity can be confirmed for approximately 75% of the request for an account.  Where the patient's identity cannot be confirmed, the patient can "prove" his/her identity in person.  We can also send correspondence to the patient at his/her address of record, so that the patient can complete the registration process remotely.

Larry:

Our EHR (Epic) allows for automatic change in proxy access as the patient ages (<13 = full parent access.  13-17 = partial parent access. At age 18, access is withdrawn).  Not sure if other EHRs do this automatically.

John:

We do as well.

Larry:

The adolescents are tricky as well in that the parent signs a form acknowledging that they are getting limited access, and the adolescent is signing a non-legal document acknowledging that they will use their online PHR appropriately.  (See attached our education to parents about proxy access

John:

See above regarding our process.

Larry:

We don’t routinely get Healthcare Proxies (or Alternates) to get set up for online proxy access in advance.  But when the Proxy is activated, we no longer have a competent patient to grant access to their Healthcare Proxy.  But if you set it up in advance, you’d be giving the proxy access when they aren’t actually allowed to have access.  Sort of a Catch-22 that requires EHR functionality to grant access with the ability access nothing, and then change the security when the Healthcare Proxy is activated (which our EHR can indeed do).

John:

We set up accounts for the proxy and then allow the patient to turn on/off proxy through the portal.  In the vast majority of cases, the patient is competent (however, the patient wants someone else to assist them in their care).   In the case of incompetent patients, we typically allow the care team to decide how to engage those individuals who are authorized to make decisions on behalf of the patient.  It is typically a judgment call, and rarely do we need to get the courts to intervene.  As an aside, we also have a class of individuals who are call "personal representatives".  These individuals are in a position to aid the patient in their care (whether it be to help explain treatment, pick up prescriptions, etc.), but are not intended to make medical decisions for the patient.  We have the patient sign a form to designate someone to be a personal representative.  Regardless, a proxy can use or portal to ask medical questions on behalf of the patient.

Larry:

Our EHR allows access by other patients who have online accounts, as well as people who are not our patients.  Unclear if this is the case for all EHRs.

John:

We provide this as well as a part of the proxy process.  By example, a child who is in another part of the country would get an account so that he/she could then have proxy access to his/her elderly parent's record.

Larry:

Our EHR allows us to know whether it’s the patient or their proxy sending a message.  Unclear if all EHRs have this capability.

John:

We do as well.

Larry:

Our experience with adult children of elderly parents is that even though we offer a formal proxy-access process, they just give their user ID and password to their kids.  Same thing for spouses.  So we certainly can’t make a policy that says this isn’t acceptable because the reality won’t change…  But it does make it harder for us physicians if the author doesn’t clearly say that they are the child or spouse.

John:

While a patient can always do this, all we can do is put the tools in place to allow a patient "to do it the right way".

Larry:

We have lots of problems regarding forgotten passwords, so password recovery processes are important.  This will be most prominent when you set up a Healthcare Proxy who may not actually get real access for years.

John:

This has not been a significant issue for us.  If a patient forgets his/her password, our staff can reset it.

Larry:

Related to this is that spouses occasionally share email accounts.  So it makes password recovery even trickier.  Not sure if any organization is giving patients a choice for which password-recovery option they prefer…

John:

Infrequently, this is an issue.  But, this is ultimately a patient decision. In any case, our portal contains a secure messaging function, so a patient always receives treatment related correspondence in his/her account.