# Questions for HEART in profiling Sensitive Data

This document begins by describing the problem. Based on that, I am offering a proposal to reflect the current state of the industry.

## Background:

“Data segmentation” is the term often used to describe the electronic labeling or tagging of a patient’s health information in a way that allows patients or providers to electronically share parts, but not all, of a patient record.”

Some clinical data repositories have sensitive data tagged, while others do not. Many of the EMRs do not currently, but if they support behavioral health, etc, they may have the data tagged already. Some organizations are considering adding a tagging function to their RS. This could also be provided as a service. I don’t think that HEART needs to address how the data gets tagged (clearly out of scope). Rather we can assume that data must be tagged to support this functionality.

To date we have discussed registering resources and providing a mechanism for the patient to determine which resources they want to share. Some clinical implementations offer options to the patient to share based on sensitive data types instead of by resources. (The Resource Type option would be share all.) We have a very real need for the patient to indicate the type of ‘Sensitive’ or ‘Confidential’ information they wish to share or not share. This requirement is cross-cutting against the resource definition.

Example: For a problem list, we have a FHIR resource –‘Condition’. A given patient has conditions A, B and C. The patient does not wish to share condition C because it relates to substance abuse. When the resource ‘Condition’ is sent to the client, the condition C would be redacted from the data sent.  
 A likely consent signed by our patient may indicate:

* Share all resources
* But don’t share any resources that have the ETH (Substance Abuse) label

We need to profile where/how this would be handled in HEART.

Note that there are many policies that impact this as we heard from the workgroup. HEART should not try to address all the policies, but instead provide a mechanism to support the patient desires within policies supported.

My sense is that some policies may have default sharing based on Confidentiality Classification. When the patient is allowed to specify sharing options they could do so by Sensitivity categories. For the later, they may support the option of either ‘share’ specified category, or ‘deny’ specified category.

## Proposal:

1. Profile how HEART will support these two types of codes.

It seems that the list of sensitivity data codes is still evolving. Further, policies differ, and can change from state to state or country to country.

The recommendation is that the HEART profiles AVOID listing the sensitive data list as part of the profile. Instead use several examples:

For Sensitivity data codes, the following could be used as examples:

* ETH – Substance Abuse
* PSY – Psychiatry Related

For Confidentiality Codes use these examples

* Normal – code “N”
* Restricted - code “R”
* Very Restricted – code “V”

Note: Most clinical data would be coded as ‘Normal’. Most sensitive data would be coded as ‘Restricted’. The code ‘Very Restricted’ tends to be used for a different purpose, such as VIP. My sense if that the Confidentiality Codes are typically determined by an over-arching policy. The sensitivity codes would be more likely to be authorized in a patient consent policy. Policy enforcement engines need to support both. (Out of scope for HEART.)  
  
From my perspective, if we stopped here, that may be adequate for this phase. What do others think?

1. For Resource Registration add new options

Background: Currently we have the RS registering resources available for each patient. We don’t want to have the RS register the types of restricted data available for a given patient as that is disclosing PSI. Instead, have the RS register the types of sensitive data it supports for all patients. (An RS that does not support this function, would not register this feature with the AS.)

For an RS that supports this feature:

It may register that is supports the following Confidentiality Codes and if appropriate will support both Include and deny for each.

* Normal – code “N”
* Restricted - code “R”
* Very Restricted – code “V”

It may also register that it supports the following Sensitivity Data Codes, and include/deny.

* ETH – Substance Abuse
* PSY - Psychiatry Related
* Others that it may support

The AS would only make options available to the patient if the RS supports them. This would help to address Luis’ concern regarding backwards compatibility.

1. The second part of this proposal will require some evaluation about how to handle within UMA, per Eve:
   1. Registering scopes that are "pan-resource" in their nature may take some thought on our part because in UMA all scopes are *associated with specific resources*.
   2. Do we need to support ‘special cross-cutting scopes”?