



## Common Terminology and Definitions

### CONSENT

**No consent:** *Health information of patients is automatically included—patients cannot opt out*

- Typically found in states that require no additional provisions beyond the federal floor set by HIPAA privacy regulations
- Exchange can take place irrespective of and without obtaining patient preferences for participation (within the bounds of applicable federal and state laws)
- Options
  - Notify patients of their participation in the exchange and educate them as to what the exchange does, how the information is used, and what purpose(s) it serves
  - Give patients the opportunity to exercise consent for making the information available for any purpose not already permitted by law (e.g., public health surveillance) - no ability to constrain the flow of their information into the system, but some authority to determine how (e.g., by whom, under what circumstances) it can be used

**Opt-out:** *Health information of patients is automatically included, but the patient can opt out completely*

- Default is for all or some pre-defined set of data (e.g., labs, summary record information) to be eligible automatically for exchange, with a provision that patients must be given the opportunity to opt out in full
- Patient's information is either all in or all out
- Options
  - Patient information is collected through the exchange (and used only for legally permitted purposes, such as public health reporting), but never shared with other providers for clinical care
  - Patient's preferences are captured and propagated such that his / her clinical information never even enters the exchange

**Opt-out with exceptions:** *Health information of patients is automatically included, but the patient can opt out completely or allow only select data to be included*

- All or some pre-defined set of data types are eligible for exchange
- Options:
  - Opt out in full
  - Selectively exclude categories of data / specific data elements from the exchange
  - Limit exchange of patient information to specific providers / provider organizations
  - Limit exchange of patient information for specific purposes

**Opt-in:** *No patient health information is made available by default*

- Patients must actively express consent to be included, but if they do so then their information must be all in or all out - no control over what information is shared, how, with whom, or for what purpose
  - Exceptions: 1) permission is later revoked by the patient; 2) other protections extend to the data (e.g., marketing provisions in the HIPAA privacy regulations)

**Opt-in with restrictions:** *No patient health information is made available by default, but the patient may allow a subset of select data to be included*

- Patients wishing to make all, or a pre-defined set, of their information available for exchange must actively grant their consent to participate
- Options
  - Make all patient information eligible for exchange
  - Include only specific categories of data or data elements
  - Enable information to flow only to specific providers
  - Allow patient information to be exchanged only for specific purposes

## **GRANULARITY**

**Granularity by Data Type:** Block specific data elements (e.g., a recent lab test) or categories of data (e.g., all medications) from being exchanged electronically

**Granularity by Provider:** Restrict information access to only those providers approved by the patient

- Options
  - Permit access to only specific individual providers
  - Permit access to only specific provider or staff types (e.g., all MDs and RNs could be granted access, but not office staff)
  - Restrict access at the provider entity level (e.g., primary care and cardiology practices are granted access, but the allergist is not)

**Granularity by Time Range:** Inclusion or exclusion of information based on the time / date associated with an element of clinical data

**Granularity by Purpose:** Segmentation according to the intended use or specified purpose for which data can be accessed via electronic exchange

Definitions from: [Consumer Consent Options for Electronic Health Information Exchange: Policy Considerations and Analysis](#) by Melissa Goldstein and Alison Rein for the Office of the National Coordinator for Health IT