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1. How do we learn more from what we know to problem solve more effectively for patients where stakes are high?
2. The value of breaking problems down into the challenges related to technology, social strategies, political will and the resources/ legal/ policy climate that having political will/leadership on our side can foster?
3. Unknowns as they relate to challenges we face in rare diseases in particular and the role of cross disease learning (I will only touch on cross disease learning...)
4. Investing in 2 related areas where technology/ social and political will related challenges are intertwined:
 - a. models for effective collaboration among all stakeholders
 - b. investment in an ecosystem of enabling technology that lowers barriers to entry and costs for all stakeholders and incentivizes broad participation (this includes registries, biospecimen data, clinical data, genomic data,...)
 - i. govt role in helping to pave way for novel research collaboration models (privacy, security, deidentification, consent, data sharing to modernize the IRB process, facilitate greater access to patient data among stakeholders; facilitate hypothesis generation, faster experiments without undermining IP and tenure concerns while maintaining ethical standards.
 - ii. Help us make significant shift in the transparency of research community efforts...sort out patient protections issues from these to maximize transparency
 - iii. Help ensure that insights "from the wild" don't get lost.
 - iv. Reevaluate the role of patients
5. For these projects, essential to define values and goals; anticipate parallel efforts; work towards integrated solutions by encouraging interoperability and modularity -
6. Signs that timing is right for collaborative solutions/ projects to succeed: true for registries in particular
7. Why registries? (list 15 reasons... Mostly focus on within diseases but some applicable to across diseases)
8. Despite timing seeming right, and imperative being there, challenges that this meeting brings to the fore:
 1. unclear if there is any one solution – need more info from stakeholders to round out the needs assessment
 2. spaces where consensus would genuinely be useful
 3. stakeholder interest alignment; defining value what's in it for each?
 - patients
 - patient organizations
 - researchers
 - research institutions
 - pharma/biotech
 - government funding institutions (NIH/DOD)
 - government regulatory bodies/ protections (FDA, NIH-OHRP...)

- clinicians
- insurance carriers