

HRA 2019 Fall Meeting

Patient Registry Breakout Session

As we all get situated with our lunches, please note the “Hello my name is” stickers on your table.

Please take a moment and a marker to indicate if you are a:

- Registry – User
- Registry – Planner
- Or just
- Registry – Curious

HRA 2019 Fall Meeting

Survey questions & results bit.ly/HRAregistry

Working Group Members:

- Angela Dobes, Crohn's & Colitis Foundation
- Shannon Gallagher, AACR
- Jenna Koschnitzky, Hydrocephalus Association
- Erik Lontok, Barth Syndrome Foundation
- Kristen Mueller, Melanoma Research Alliance
- Krissa Smith, Susan G. Komen

Contact:

adobes@crohnscolitisfoundation.org

erik.lontok@barthsyndrome.org

HRA membership and external org. Registry Survey

18 total respondents

- 12 with registries
- 6 are planning registries

Registry Users & Platforms

- 3 use Proprietary
 - Google Docs, RexDB, IBD Plexus
- 8 use Commercial platforms
 - Qualtrics, D-Chip, StudyTRAX, Velos, Patient Crossroads/Invitae, FigMD, REDCap Cloud
- 1 uses Academic
 - REDCap

Platform INPUTS	Patient-input	Clinic or site-input	EMR/EHR	Res & Clin -omics data	Pharmacy Data	Wearables & mhealth apps	Genetic testing results	Medical Claims
Proprietary – Google Docs	X	X	X	X	X			
Proprietary – RexDB			X					
Proprietary – IBD Plexus	X	X	X	X		X		
Patient Crossroads/ Invitae - FFB	X	X					X	
Qualtrics	X							
FigMD		X	X					X
StudyTRAX		X						
Velos	X							
D-Chip	X	X						
REDCap	X	X				bit.ly/HRAreistry		

Platform USES	Linked to Biorepository	Study/trial recruit	Recontact for ext. partners	Data-sharing external	Industry partners	Org-specific CancerLinQ
Proprietary – Google Docs		X	X	X		
Proprietary – RexDB		X			X	
Proprietary – IBD Plexus	X	X	X	X	X	
Patient Crossroads/ Invitae		X	X	X	X	X
Qualtrics & FigMD (just begun)						
<u>StudyTRAX</u>	X	X			X	
Velos		X		X		
D-Chip	X		X			
REDCap		X	X		bit.ly/HRAregistry	