

# Virtual Pooled Registry (VPR): Gateway to Increased Access & Use of Registry Data



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# Polling Question #1

Are you familiar with the Virtual Pooled Registry?

- A. Yes
- B. No

# Background

- Population based cancer registries offer broad capacity and foundation for research support
- Multistate engagement of registries:
  - Increase statistical power
  - Improve representativeness
  - Expand geographical coverage
- But linkage studies needing identifiers must apply to each state for access to data
  - Long, arduous, costly, frustrating process
  - Sometimes reveal very few cases





# Virtual Pooled Registry (VPR)

- Goal is to streamline the process for research cohort linkages with multiple cancer registries
  - One research application process
  - One research file submission
  - One standardized linkage process occurring simultaneously at multiple registries, with plans to automate
  - Registry data remains behind separate security firewalls at each participating registry and only counts of linked cases release initially
  - Registry data release of identifiable data controlled by registry
  - Identify ways to streamline IRB application and review process

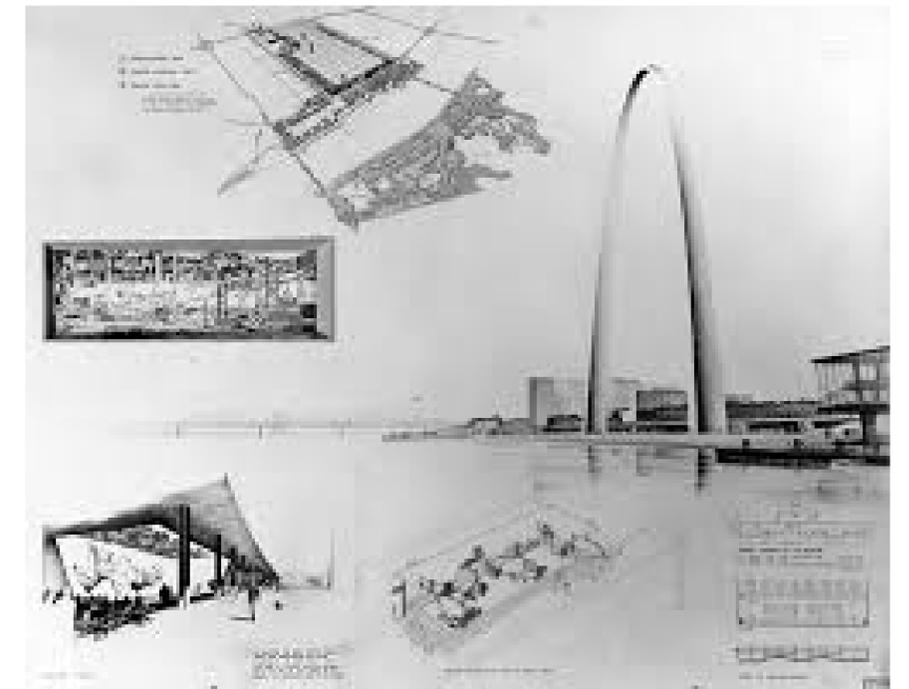


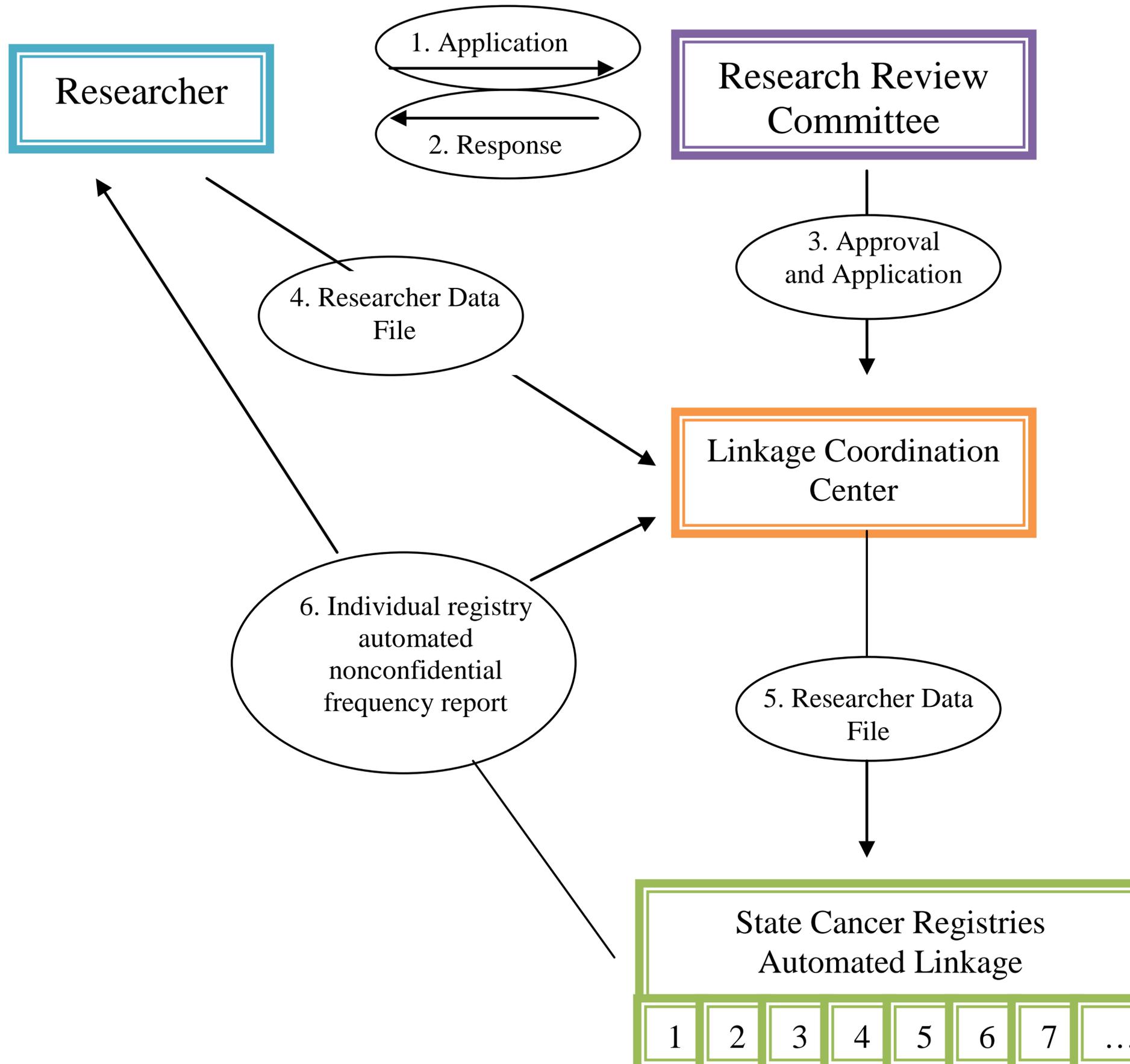
# Virtual Pooled Registry: Benefits

- Save years of time and save taxpayer dollars
- Utilize standardized linkage methodology for more rigorous and comparable scientific research
- Automate the process to allow registries with fewer resources to participate in linkage and research
- No negotiated data release/IRBs if no matches

# NEW FUNDING: NCI/NAACCR 9/15-8/16

- Recruit volunteer registries for pilot linkages
  - ~25 states = 67% US population
- Recruit one or more research cohorts for linkage
- Establish VPR Working/Advisory Group
- Establish Research Review Committee
- Create Linkage Coordination Center (IMS)
- Explore Central IRB and ways to facilitate IRB process







## Polling Question #2

How many cohort linkages does your registry perform annually?

- A. None, we don't have the resources
- B. 1-9
- C. 10-15
- D. More than 15



# VPR PROGRESS

# Virtual Pooled Registry- Cancer Linkage System (VPR-CLS)



Star Trek: The Viper Class fighters are *fast, smart, and more maneuverable*



**Responsive & efficient. Lots of boat for the money!**

“The viper striking is a sign of strong direction and intentions... to create good”



**Fast, sleek, & powerful!**



“The viper spirit is a strong totem [that] will lead you down a difficult path in your life, but one that will be blessed with rewards” 😊

# VPR Pilot Linkages

- ATSDR Camp Lejeune Study (~340K records)
  - Linkage with 45 central cancer registries around the nation
  - Identified 17,412 high quality matches
  - 15 Registries performed manual review of potential matches
  - ATSDR contacting registries for official linkage in 2018, including IRB
- NCI Radiation Technician Study (~140K records)
  - Alternative to resource intensive medical record review
  - Anticipated July 2016



# ●●●● VPR Linkage Testing and Development

- Tested and compared various linkage software systems
- Selected and fine-tuned a standard software for linkage and match count report generation
- Developed data standardization and edits tool for researcher and registry
- Created protocol for linkage



# ●●●● Linkage Coordination Center

- Single location for researcher to submit linkage application, for review and approval to occur, and files to be securely exchanged between researchers and registries
  - Beta site developed
  - Draft researcher application created
  - Workflow and automated notifications determined





## VPR Working Group

- External group of 10 members representing key stakeholders
- Provide overall scientific direction, technical expertise, guidance, and input in the development of the VPR system
  - Develop best practice recommendations for registry data research use, release, and protection, including high-quality, streamlined IRB review
  - Champion the use and benefits of the VPR

# VPR FUTURE INITIATIVES

# ●●●● Research Review Committee

- Review applications for technical feasibility and scientific merit
- Up to 8 individuals with experience in cancer surveillance, research, data linkage, and population-based cancer registries





# Inter-Registry Deduplication

- Encrypted linkage to identify cases that are captured in multiple registries and counted as incident in each
  - More accurate estimates of state and national incidence rates
  - Identification of multiple primaries and improved estimates of multiple primary rates
  - Exchange of information on shared cases, thereby increasing the quality, completeness, and accuracy of treatment, follow-up, and recurrence data
  - Potential resolution of death clearance only cases

# ●●●● Templated IRB Form and Central IRB

- Review IRB application forms from all registries
  - Common data elements will be identified
- Develop templated IRB interface
  - Researchers would complete one form with common elements
  - Individual state forms would be pre-populated,
  - Researchers would only need to enter any additional information required by the specific IRB.
- Create a Central IRB for linkage studies





## Polling Question #3

What is the most recent data your registry uses for cohort linkages?

- A. Everything that has been loaded to date
- B. Cases through 2014 diagnosis year
- C. Cases through 2013 diagnosis year
- D. It varies by cohort



## Other Interesting Tidbits

- Determining instructions for annual creation of VPR linkage file at time of NAACCR call for data
- Developing funding mechanism for registries engaged in VPR
- Exploring VPR linkages between cohorts the central VA and DoD registries



- Increase data use
- Minimize resources
- Facilitate communication
  - Streamline processes
- Ensure completeness & quality



- Researchers & registries
- Cohort studies

- Registries
- Cancer data and outcomes



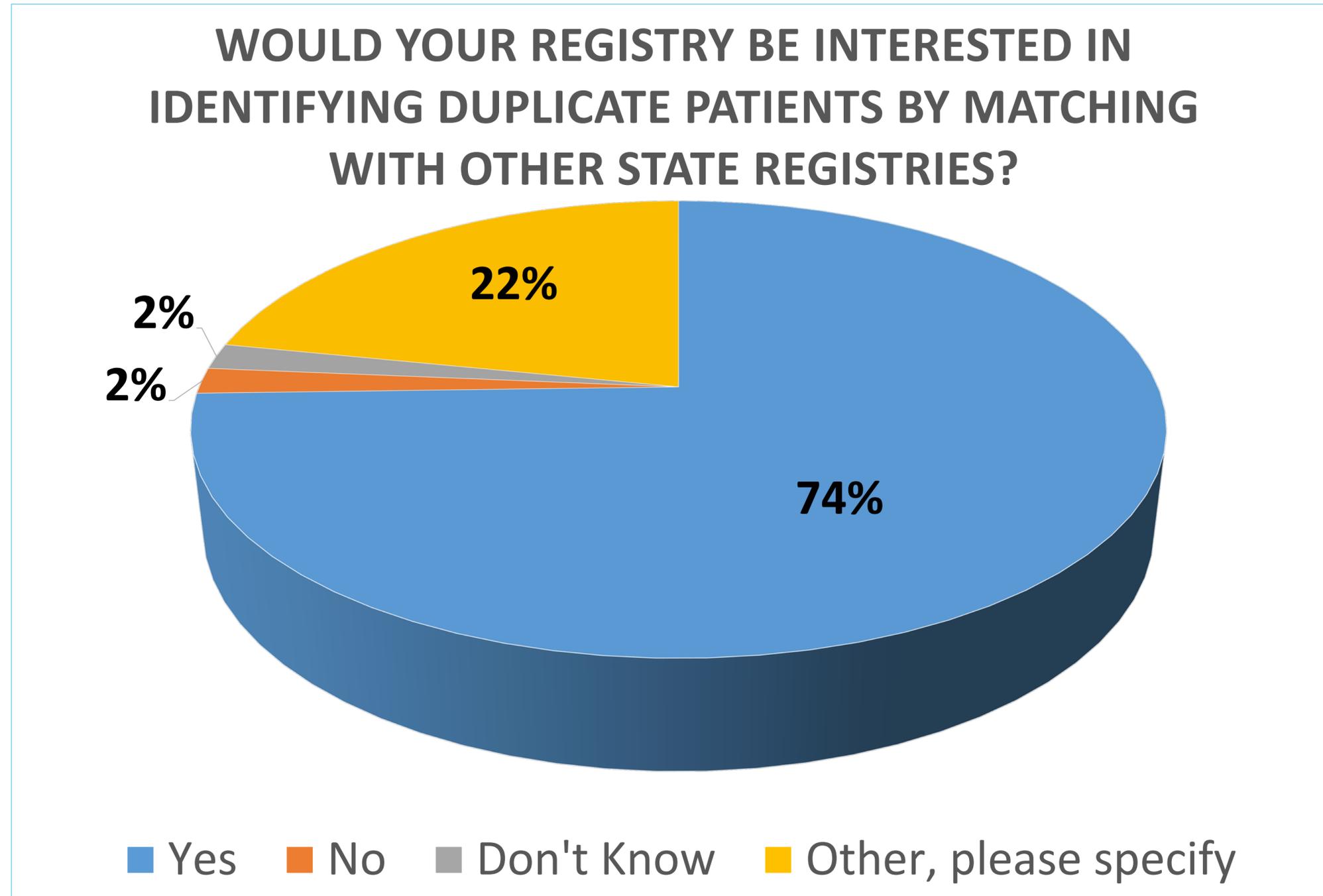
## More Information

- Breakout Session: Wednesday, June 15<sup>th</sup>, from 10:15-11:45
- Castine Clerkin: [cclerkin@naaccr.org](mailto:cclerkin@naaccr.org)

## Special Thanks!

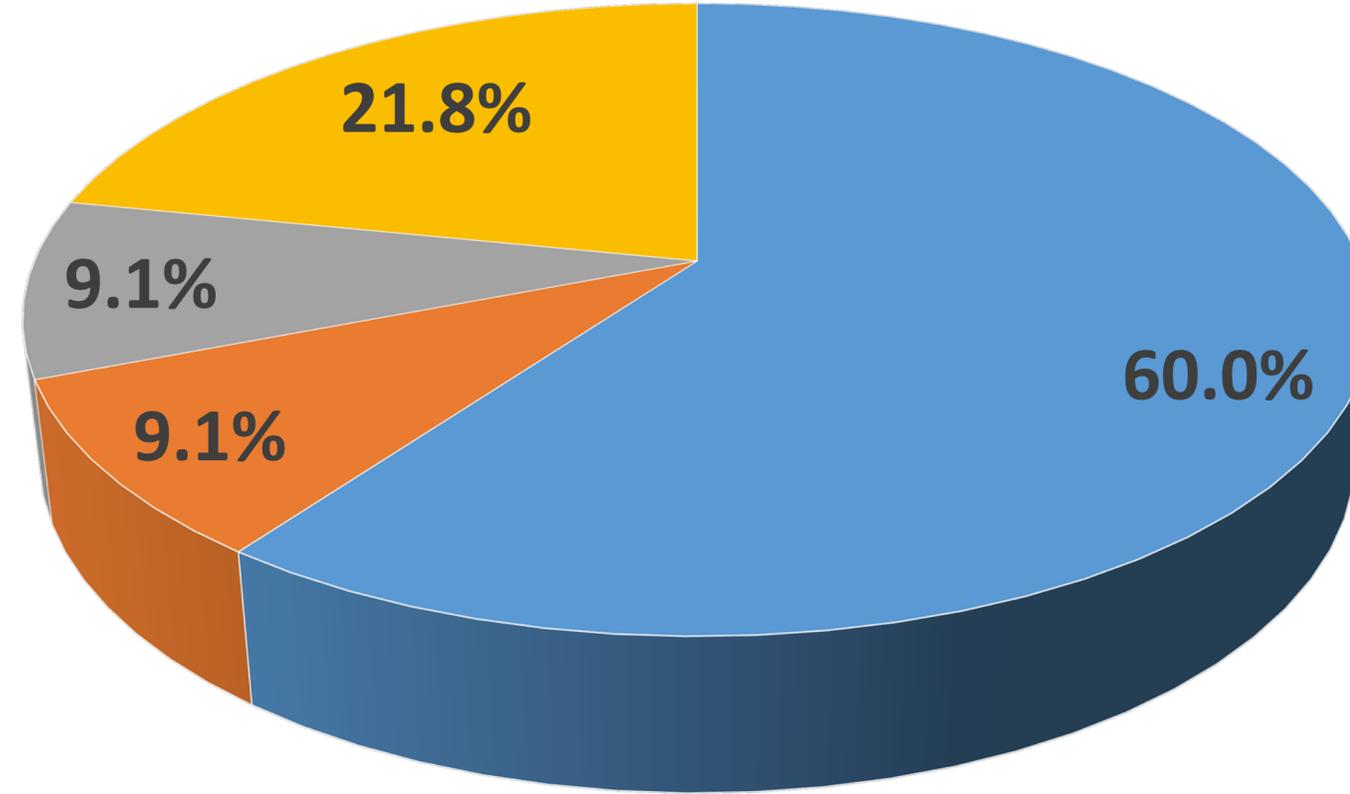
- Betsy Kohler & Recinda Sherman
- Lynne Penberthy
- Dennis Deapen
- IMS, Inc.
- Central and regional registries

# Additional Survey Results



# Survey Results (55 of 60 registries)

**Would your registry consider performing a cohort match and releasing the number of matches?**



■ Yes   
 ■ No   
 ■ Don't Know   
 ■ Other, please specify