Integrated Data Management Systems Accelerate HCV Elimination: Evidence from a US-based Patient Re-engagement Program

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(on behalf of the US Hepatitis Relink Collaborator Network)

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Faculty Disclosures

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Has no relevant financial relationships to disclose.

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CDA Foundation

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Disclosures - US Hepatitis Relink Collaborator Network

- The US Hepatitis Relink Collaborator Network comprises recipients of the Relink grant which funds efforts to reconnect US-based diagnosed but untreated HCV and HBV patients to care.
- Participants include health departments, non-profit organizations and healthcare institutions.

Scan the QR code for a complete list of authors, their affiliations and disclosures.

US Hepatitis Relink Collaborator Network

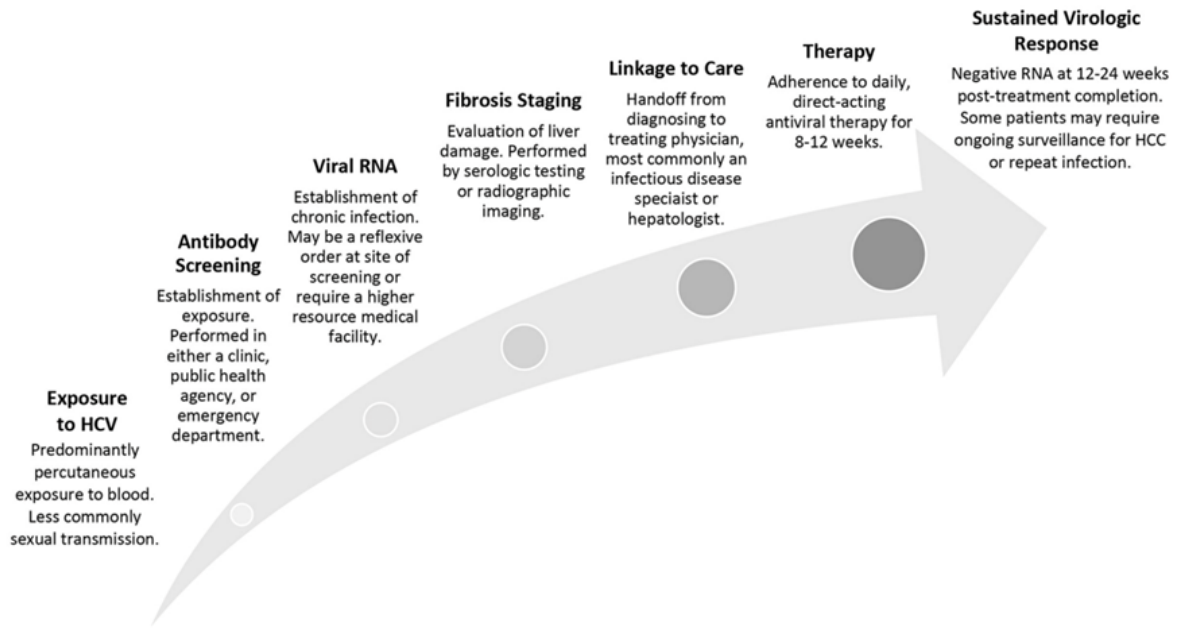
- AIDS Leadership Foothills-area Alliance, NC
- Arizona Department of Health Services, AZ
- Asian Health Services, CA
- Bluestone Health Association, Inc., WV
- Boston Health Care for the Homeless Program, MA
- Carilion Clinic, VA
- Central City Concern, OR
- Community HealthNet, IN
- Cooperman Barnabas Medical Center, NJ
- Denver Health Medical Center, CO
- Family Health Centers of San Diego, CA
- First Choice Primary Care, Inc., GA
- Health Betterment Initiative of D.C., VA/MD
- Iowa Department of Health and Human Services, IA
- Kansas Department of Health and Environment, KS
- Montefiore Medical Center, NY
- Mount Sinai, Icahn School of Medicine, NY
- Norton Healthcare, KY
- Philadelphia FIGHT, PA
- Prisma Health, SC
- Sentara Martha Jefferson Hospital, VA
- TruReach, Inc., PA
- University of Colorado, Denver CHIP Prevention, CO
- University of Florida College of Medicine, Jacksonville, FL
- University of Kentucky Research Foundation, KY
- University of Maryland – Baltimore, MD
- University of Miami Health System, FL
- University of North Carolina - Chapel Hill, NC
- University of Southern California, CA

Learning Objectives

- Assess the accuracy of Hepatitis C (HCV) patient tracking systems.
- List the reasons for ineligibility for follow up among HCV patients presumed lost to follow up (LTFU).
- Determine optimal workflows for successful HCV patient re-engagement.

Background – HCV in the United States

- Between two to four million individuals in the US live with chronic HCV.[1]
- In a 2022 analysis of data from insured individuals, the US CDC found only 23%-35% DAA treatment initiation within 360 days of the first positive HCV RNA test result.[2]
- Loss to follow up remains a significant barrier to optimal HCV care given the numerous steps and protracted time of the care cascade.[3]

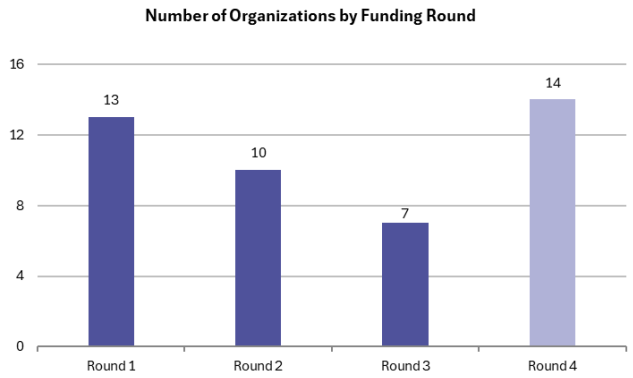


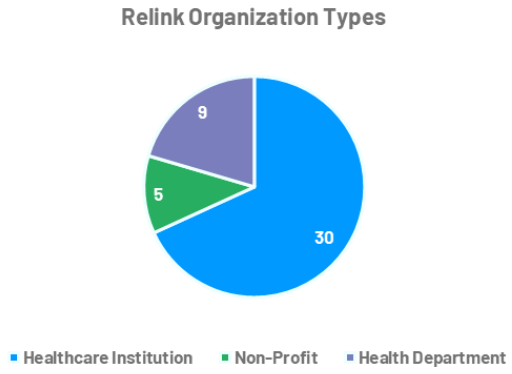
Re-engaging individuals who are lost to follow-up is needed to achieve HCV elimination in the United States.

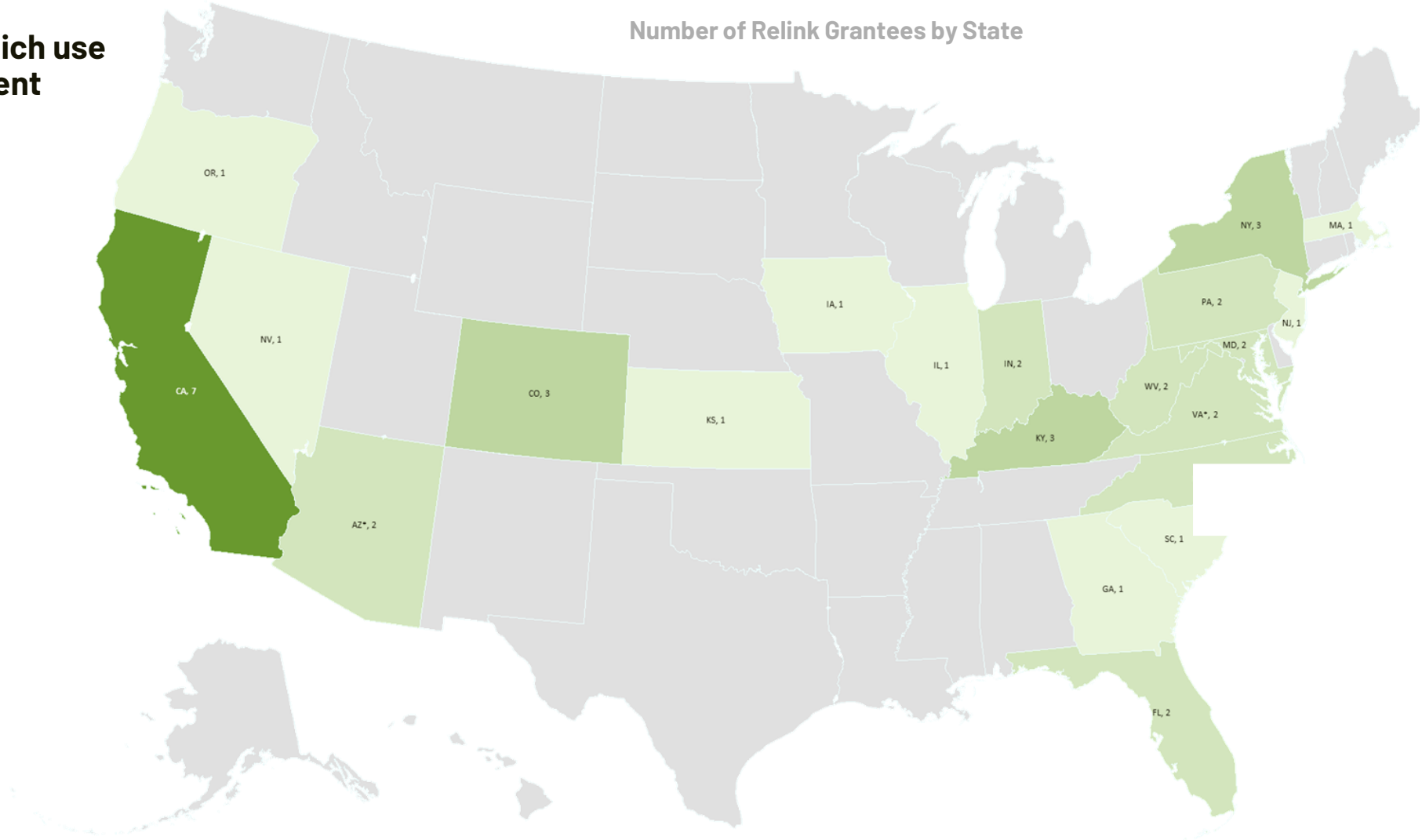
[1]Hall EW, Bradley H, Barker LK, Lewis KC, Shealey J, Valverde E, Sullivan P, Gupta N, Hofmeister MG. Estimating hepatitis C prevalence in the United States, 2017–2020. Hepatology. 2025 Feb 1;81(2):625-36.
[2]Thompson WW. Vital signs: hepatitis C treatment among insured adults—United States, 2019–2020. MMWR. Morbidity and mortality weekly report. 2022;71.
[3]Jones AT, Briones C, Tran T, Moreno-Walton L, Kissinger PJ. Closing the hepatitis C treatment gap: United States strategies to improve retention in care. Journal of viral hepatitis. 2022 Aug;29(8):588-95.

Background – The Relink Program

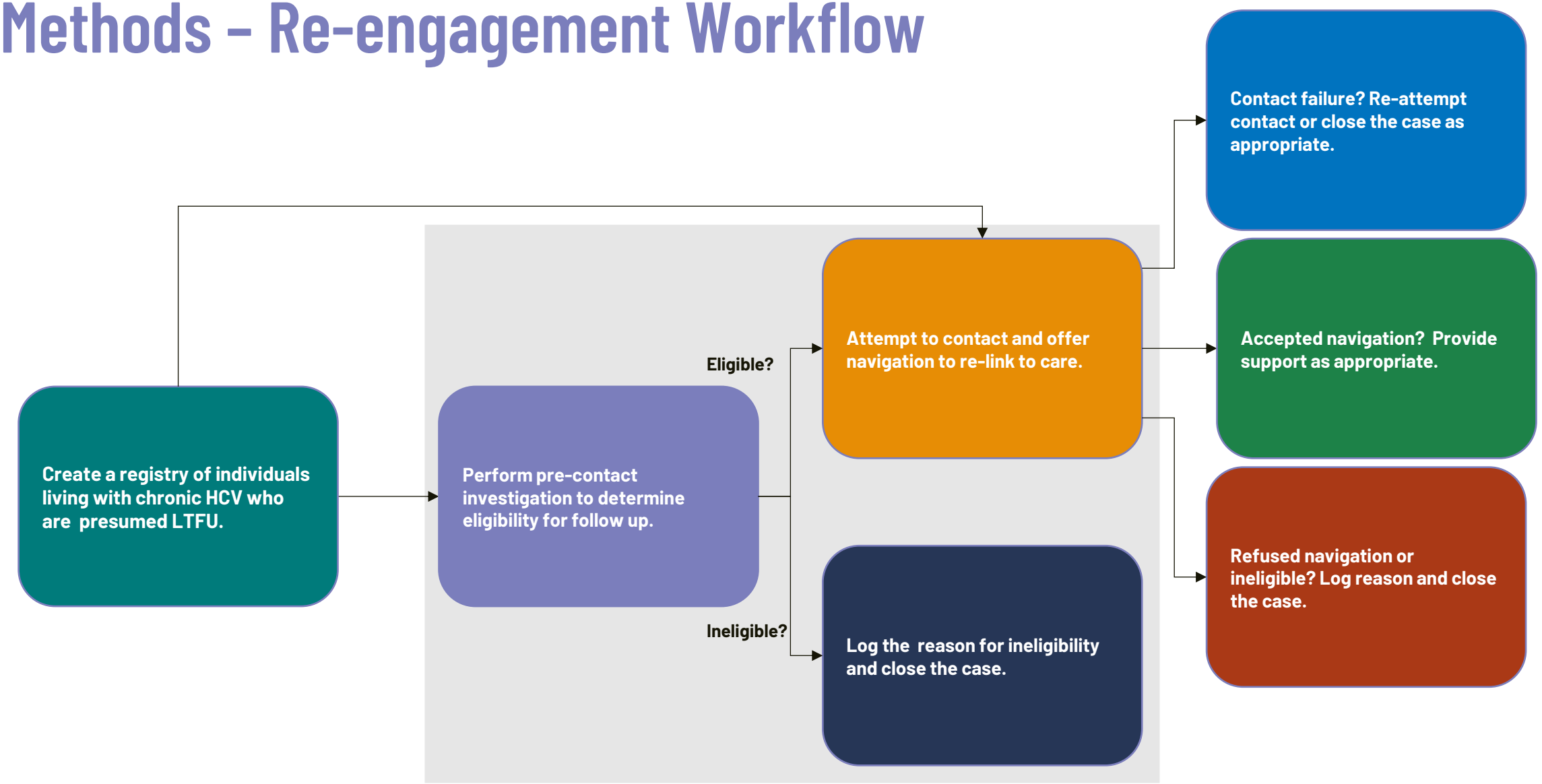
The Relink grant funds programs which use data management systems like patient registries to identify and re-engage individuals with HCV who are LTFU.







Methods – Re-engagement Workflow



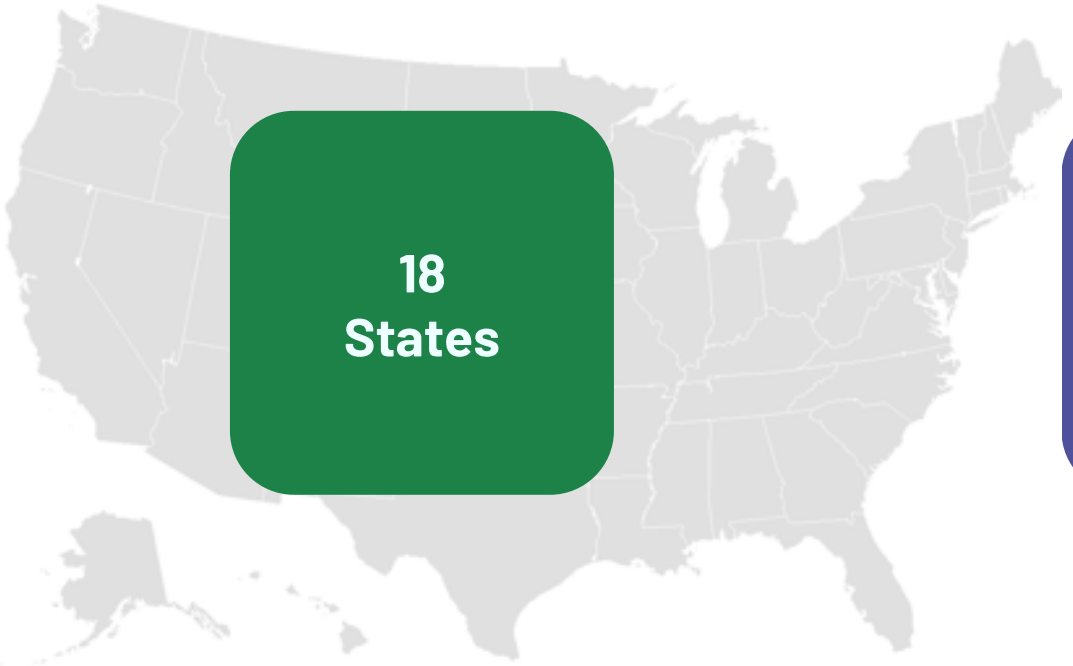
Methods – Pre-Contact Investigations (PCI)

- Pre-contact investigations are in-depth patient record audits to:
  - Confirm LTFU status.
  - Determine eligibility for follow up.

- Combines information from sources beyond what is typically available in a patient's record:
  - Vital records
  - Incarceration records
  - DMV records
  - Partner organizations
  - People finder sites
  - Investigative platforms
  - Social media
  - Obituaries

Methods – Data Sources

- Patient registries of 29 out of 30 Round 1-3 grant-funded organizations, n = 35,542 records.



18 States

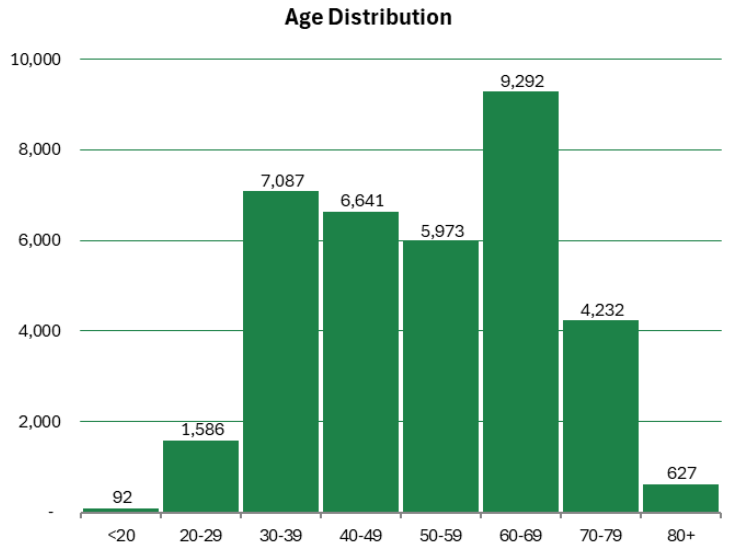
21 Healthcare Institutions

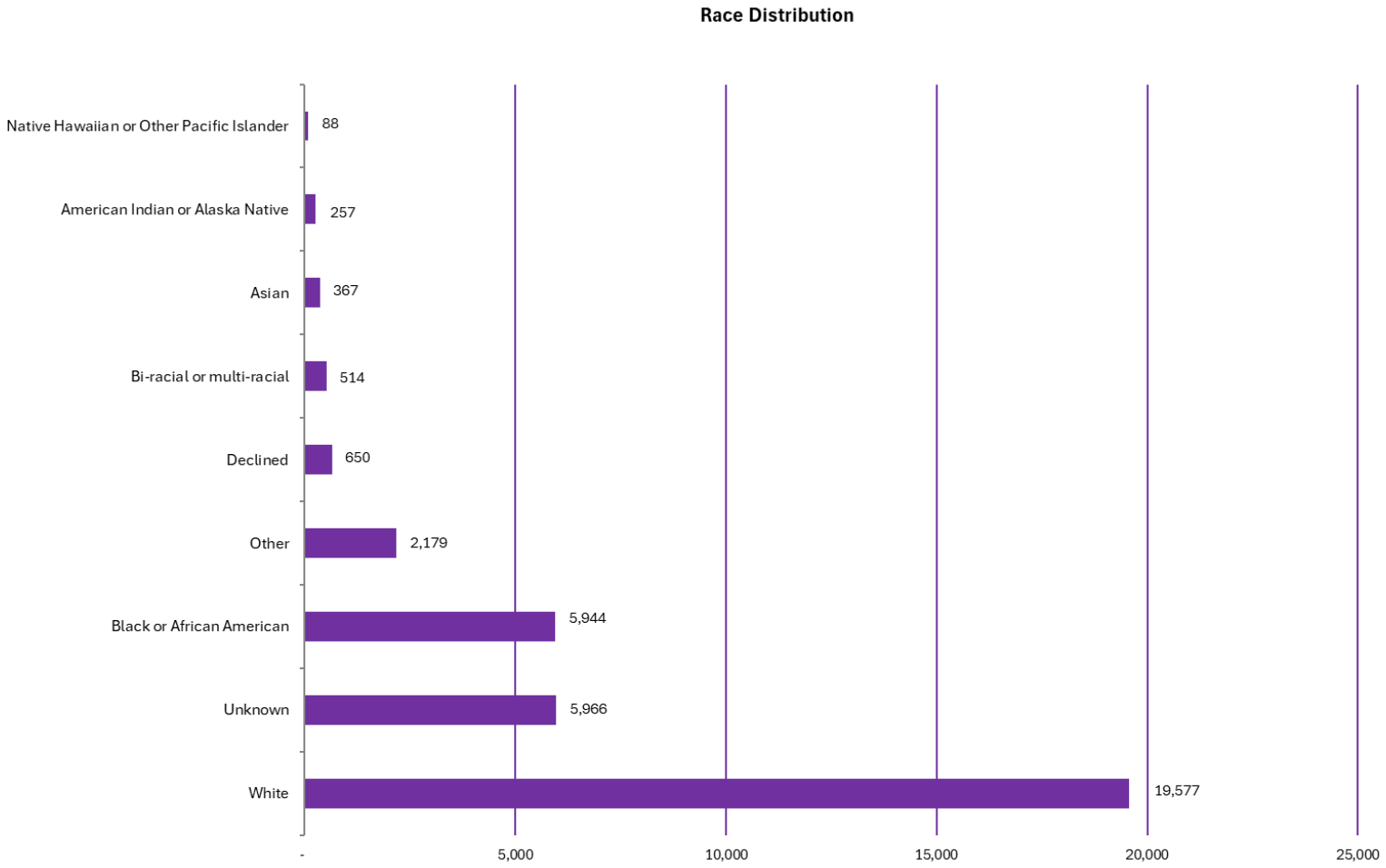
5 Non- profits

3 Health Departments

Results - Demographics

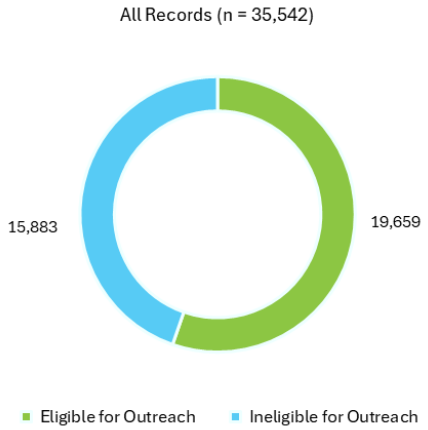
Overall Mean: 54
Men: 53
Women:52

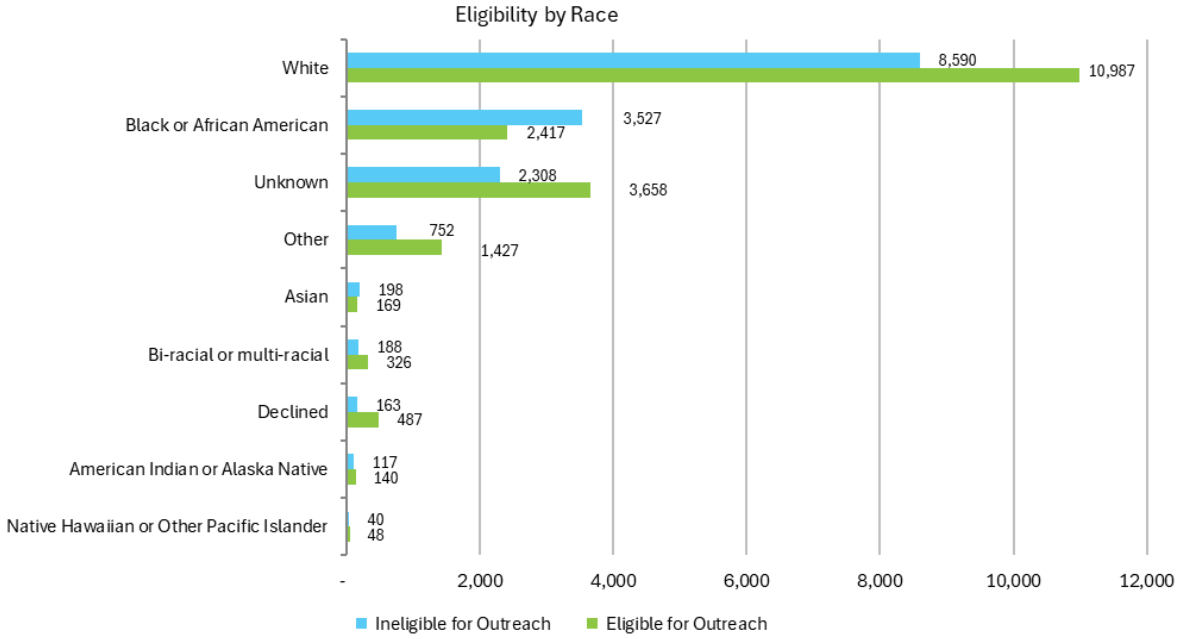


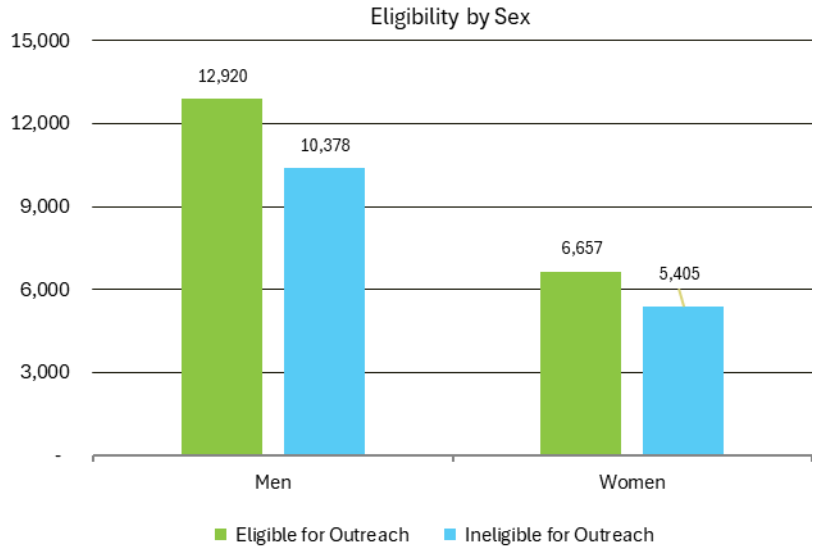


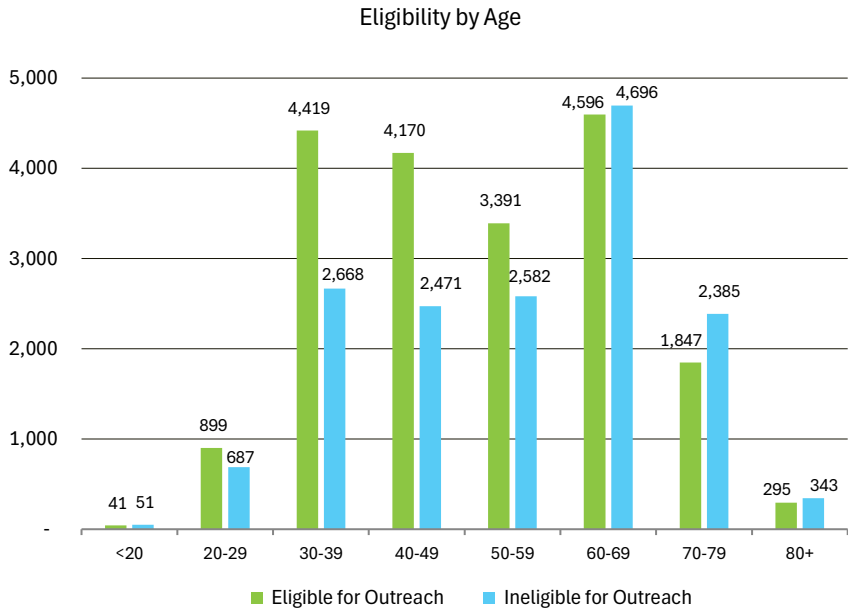
Gender	n
Male	23,298
Female	12,062
Unknown	123
Non-Binary	27
Trans Male-to-Female	20
Other	7
Trans Female-to-Male	3
Declined	2

Results – PCI Outcomes





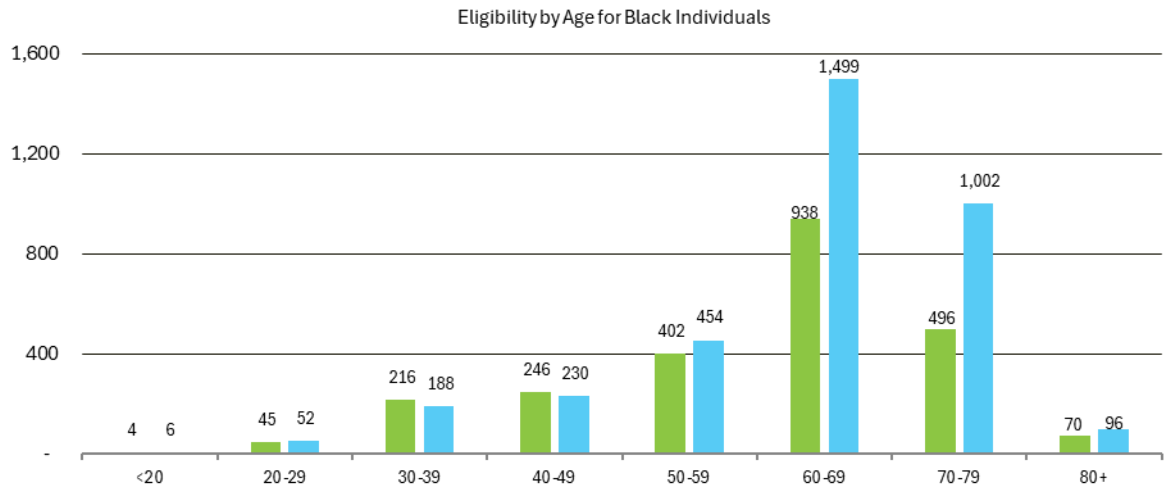


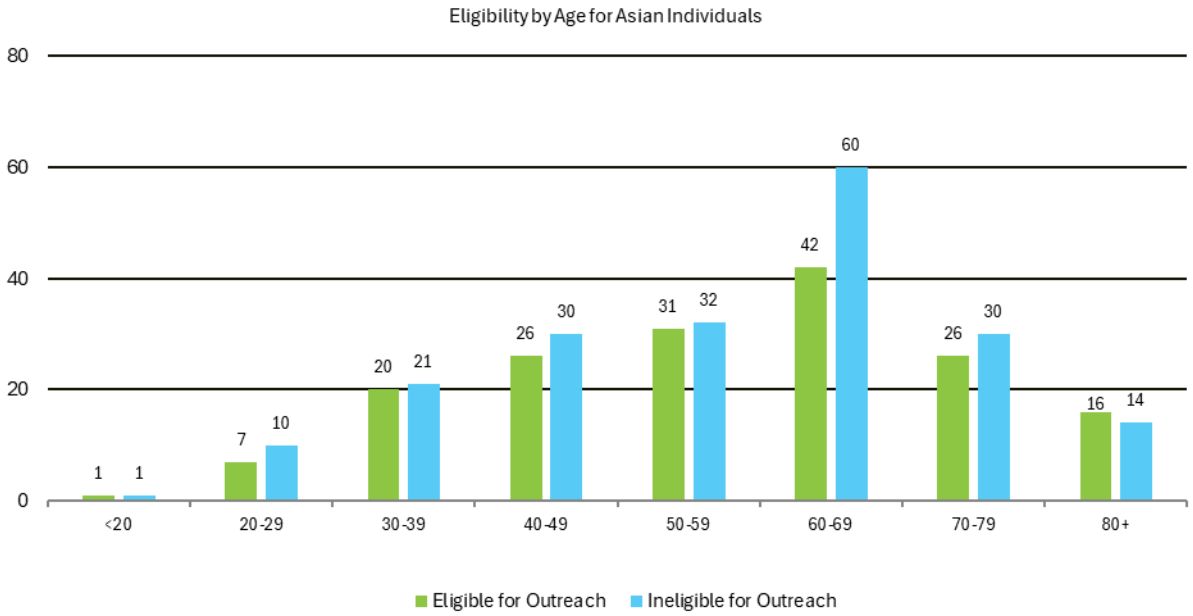


Results - PCI

Overall Ineligibility Reason	n	%
Already Receiving Care/Cured	8,344	53%
Deceased	4,098	26%
Incomplete/No Contact Information	1,645	10%
Relocated	440	3%
Incarcerated/Corrections	402	3%
Study Age Criteria Not Met	367	2%
Spontaneous Clearance/False Positive	334	2%
Too Ill	91	1%
Declined	88	1%
Other	75	0.5%
Total	**15,884**	**100%**

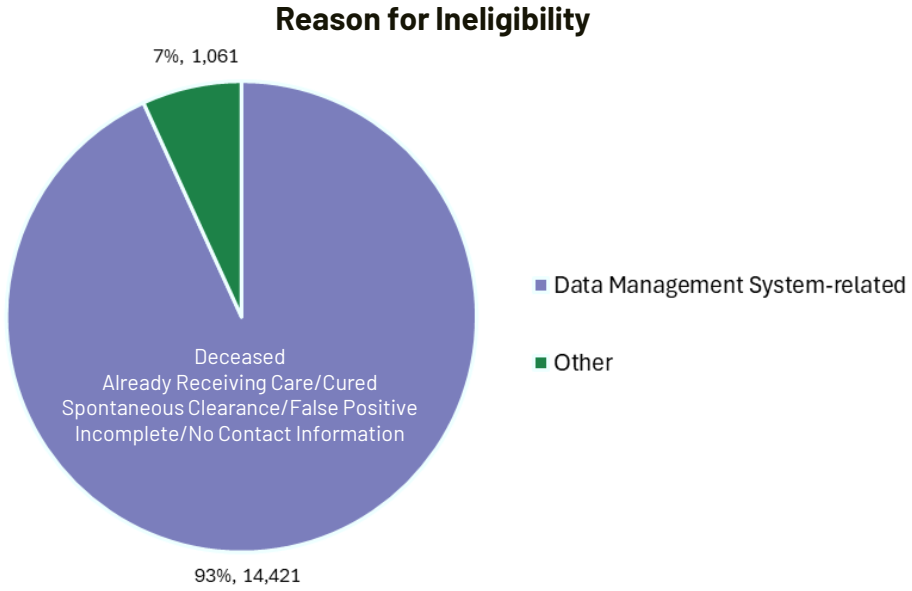
Ineligibility Reason (Baby Boomers)	n	%
Already Receiving Care/Cured	3,940	47%
Deceased	3,013	36%
Incomplete/No Contact Information	476	6%
Study Age Criteria Not Met	360	4%
Spontaneous Clearance/False Positive	190	2%
Relocated	177	2%
Incarcerated/Corrections	89	1%
Too Ill	73	1%
Declined	57	1%
Other	37	0.4%
Total	**8,412**	**100%**

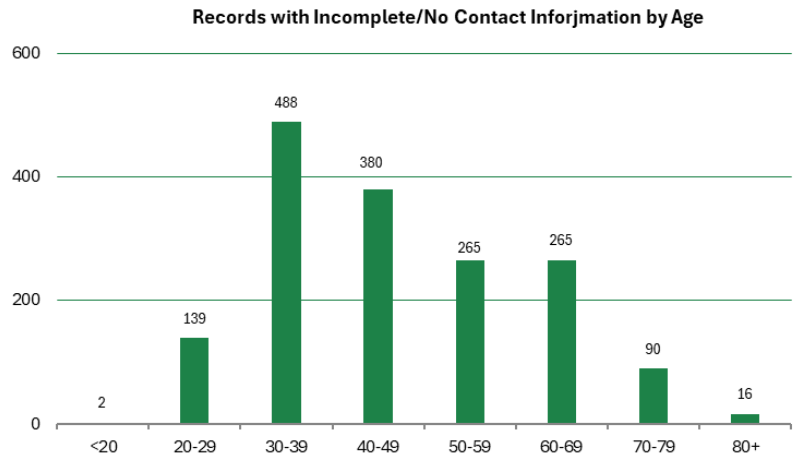




Key Findings

- >90% of reasons for outreach-ineligibility can be attributed to poorly integrated data management systems.
  - Investigation of >50% of these records revealed ongoing or completed treatment.
  - 26% of these records were for deceased individuals.
- A tenth of patient records have incomplete or missing information.
  - >50% of these records are for individuals aged 30-49 who are a key demographic experiencing rising HCV incidence.





Conclusions

Issue	Recommendations	Impact
Misclassification of "Lost to Follow-Up" patients.	• Implement mechanisms or workflows that integrate laboratory, pharmacy, and Medicaid and other data to verify real-time treatment status.	• Focus time and resources on outreach to individuals who truly need re-engagement.
Incomplete/missing patient contact information.	• Auto-update and synchronize address/phone/email fields across systems. • Flag incomplete/missing records in real time for follow-up. • Integrate trusted third-party verification tools.	• More efficient and productive re-engagement programs.
Persistent risk of loss to follow up.	• Adapt definitions of "loss to follow up" to target population. • Provide navigation support before loss.	• Pro-active rather than reactive care coordination.

Thank you! Questions?

CDA FOUNDATION | Relink

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Health HIV | National Coalition for LGBTQ Health | Health HCV