



VIRTUAL  
**2020 NATIONAL**  
**RYAN WHITE**  
**CONFERENCE ON**  
HIV CARE & TREATMENT

# Actuating Care in Iowa, Dallas, TX, and Paterson, NJ Using Multilingual, Audio-Assisted, Evidence-Based Needs Assessments.

Session ID #16211

*Milagros Izquierdo, Division Director, Ryan White Part A, MAI, SPNS, and HOPWA, City of Paterson, NJ*

*Justin Henry, Ryan White Planning Council Health Planner, Dallas County Department of Health & Human Services*

*Katie Herting, Ryan White Quality Coordinator, Iowa Department of Public Health*

*Jesse Thomas, Project Director, RDE Systems, LLC*

#RyanWhite2020

# Learning Objectives



- At the conclusion of this activity, the participant will be able to:
  1. Recognize how a paradigm of **improved data collection** strengthens **grant applications**, provides answers to community planning bodies, illuminates **counterintuitive insights** important for the description of barriers and helps positively to influence health planning and policy recommendations
  2. Describe how to **adopt and adapt strategies and tools** to deliver web-based technology to the community and planning bodies while overcoming digital divides and perceptions of digital divides.
  3. Identify, analyze and evaluate the **challenges and benefits** of an innovative program for mobile / web-based, audio-assisted, multilingual Needs Assessments and Client Satisfaction Surveys.

# Disclosures



- Paterson-Bergen-Passaic TGA, Dallas, TX Ryan White Planning Council and Iowa Department of Public Health have no financial interest to disclose.
- Jesse Thomas works as Project Director for RDE System Support Group, LLC.

This continuing education activity is managed and accredited by Professional Education Services Group in cooperation with HSRA and LRG. PESG, HSRA, LRG and all accrediting organization do not support or endorse any product or service mentioned in this activity.

PESG, HRSA, and LRG staff has no financial interest to disclose.



# Welcome and Introductions

# Introductions



Jesse Thomas, Project Director, RDE Systems

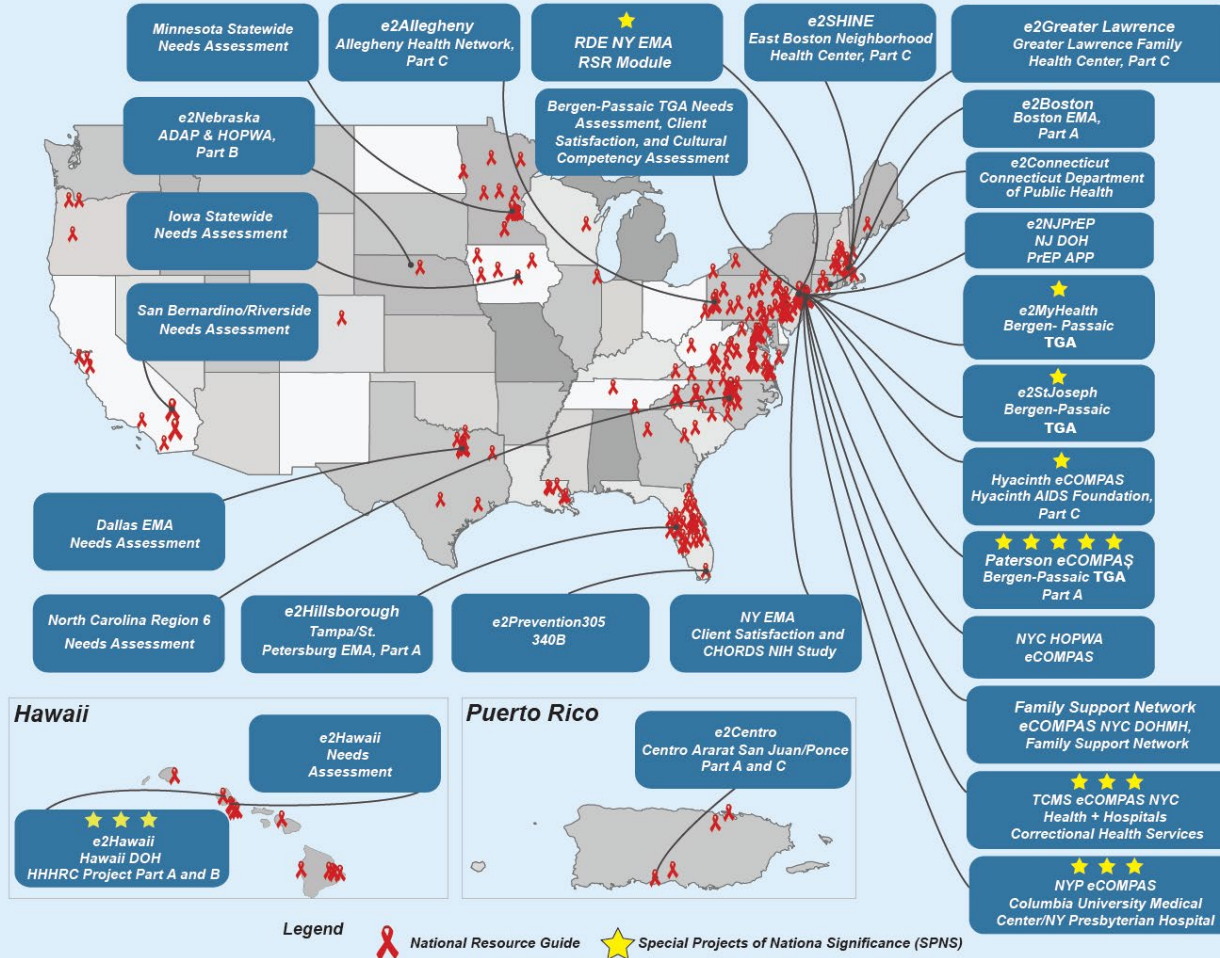
Serving public health for over 20 years, HIV/AIDS programs 15+ years (HRSA, CDC, HUD, NIH)

RDE Systems: First team to build custom web-based consumer needs assessment surveys for PLWH.

Technical Manager for over 18 HRSA Special Projects of National Significance

# Synthesizing National Lessons Learned

## eCOMPAS and e2Community Success Stories



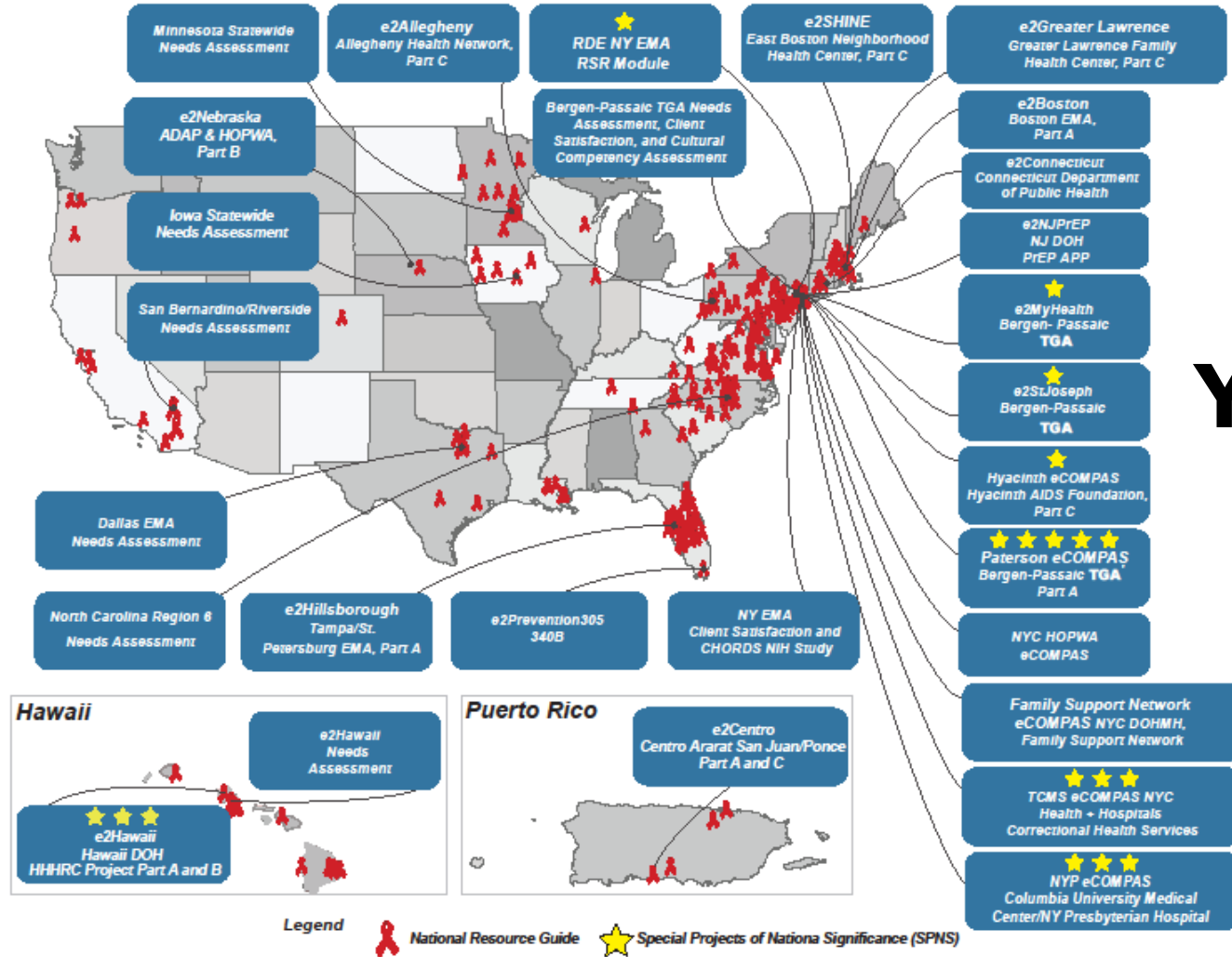
## Users

- ✓ Recipients
- ✓ Sub-Recipients
- ✓ Public Health
- ✓ Human Services
- ✓ Health Networks
- ✓ Hard Reduction
- ✓ Clinics
- ✓ CBOs
- ✓ Planning Commissions
- ✓ Clients & Patients

## Programs

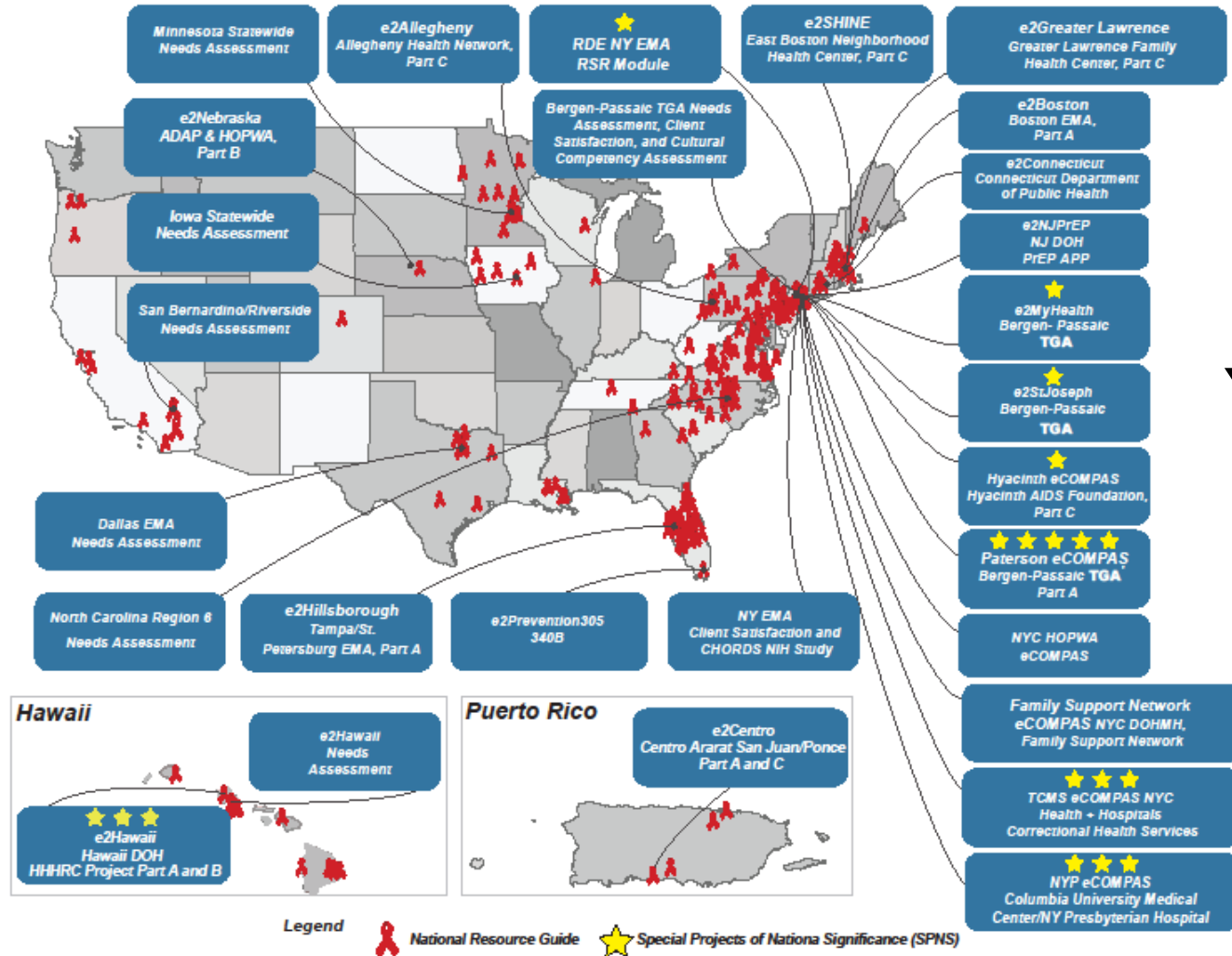
- ✓ CDC Prevention
- ✓ HRSA A,B,C,D
- ✓ HRSA ADAP
- ✓ HRSA SPNS
- ✓ HRSA AETC
- ✓ HUD HOPWA
- ✓ NIH
- ✓ ONC

# 30+ Years of Public Health



**30+**  
**Years Public Health**

# Years of RW, CDC, HOPWA



**15**

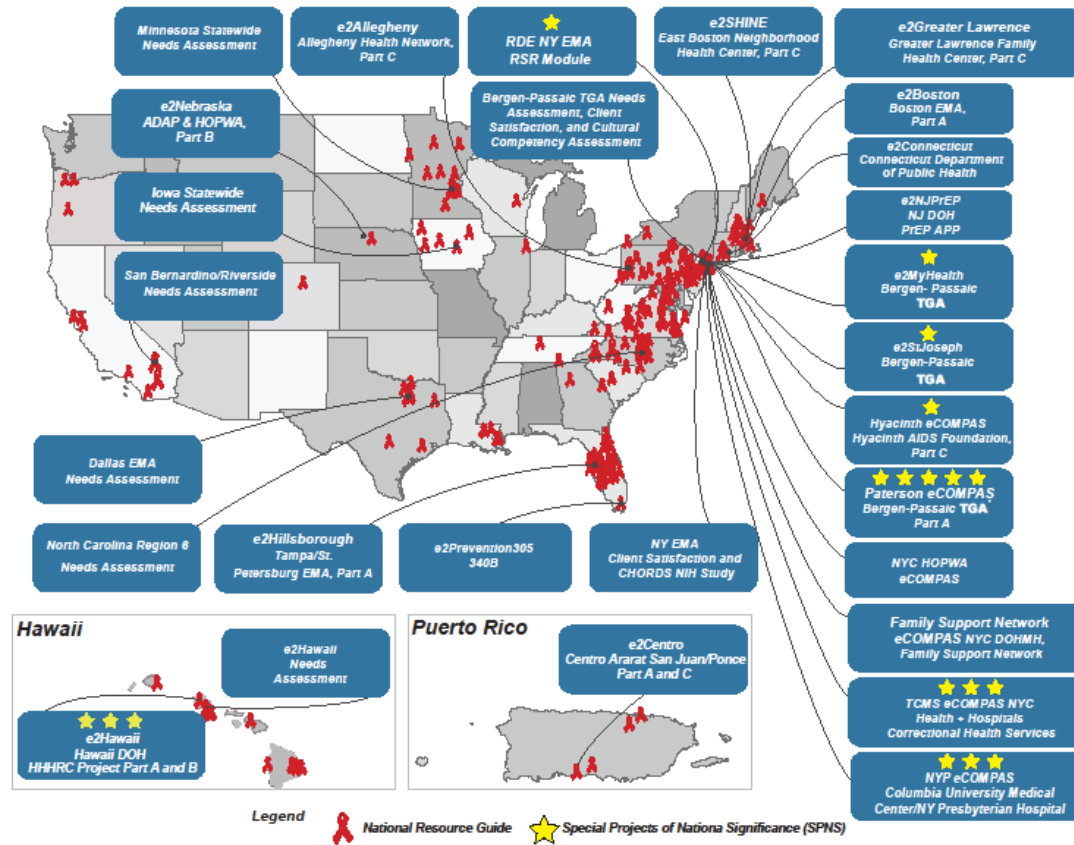
**Years Ryan White, CDC, HOPWA**



# Agencies

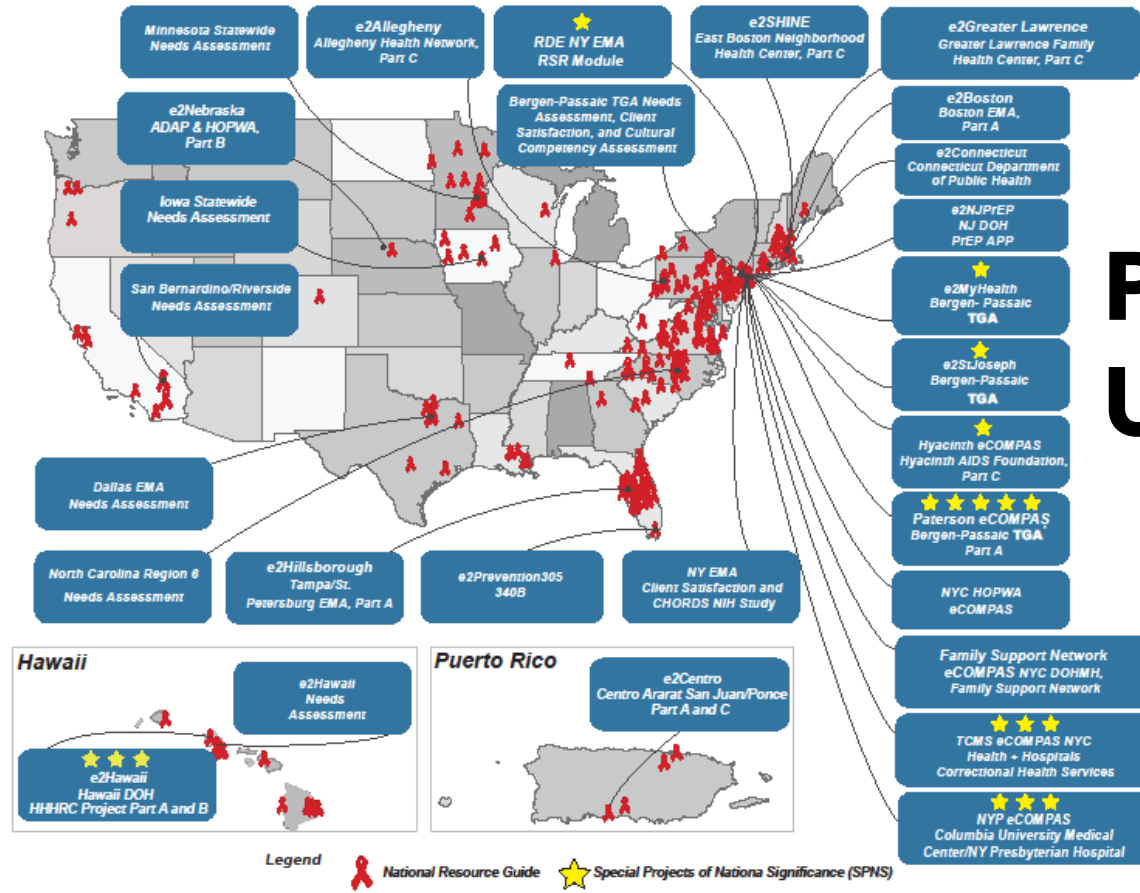


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**700+**  
**Agencies**

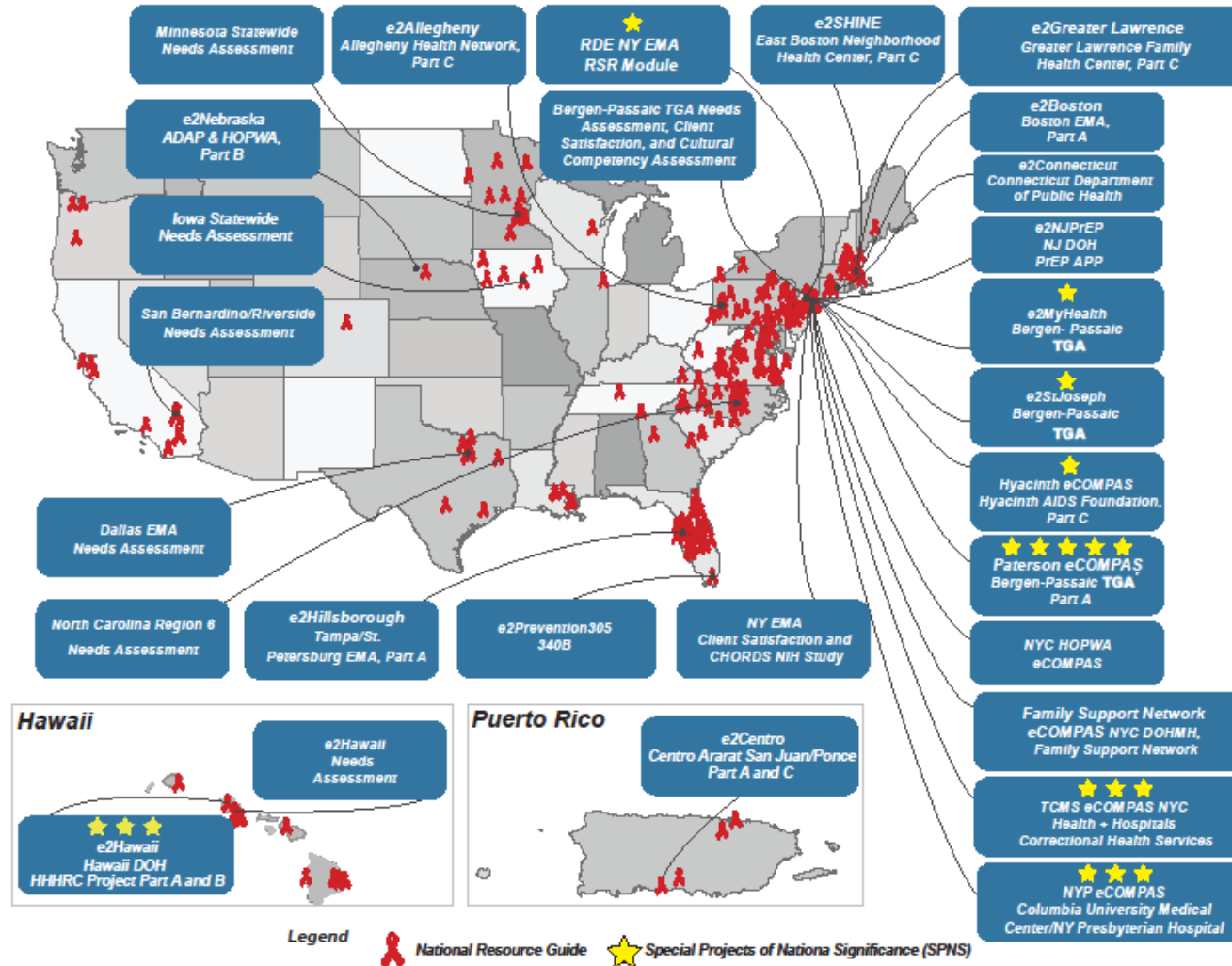
# 20,000+ Provider



# 20,000+

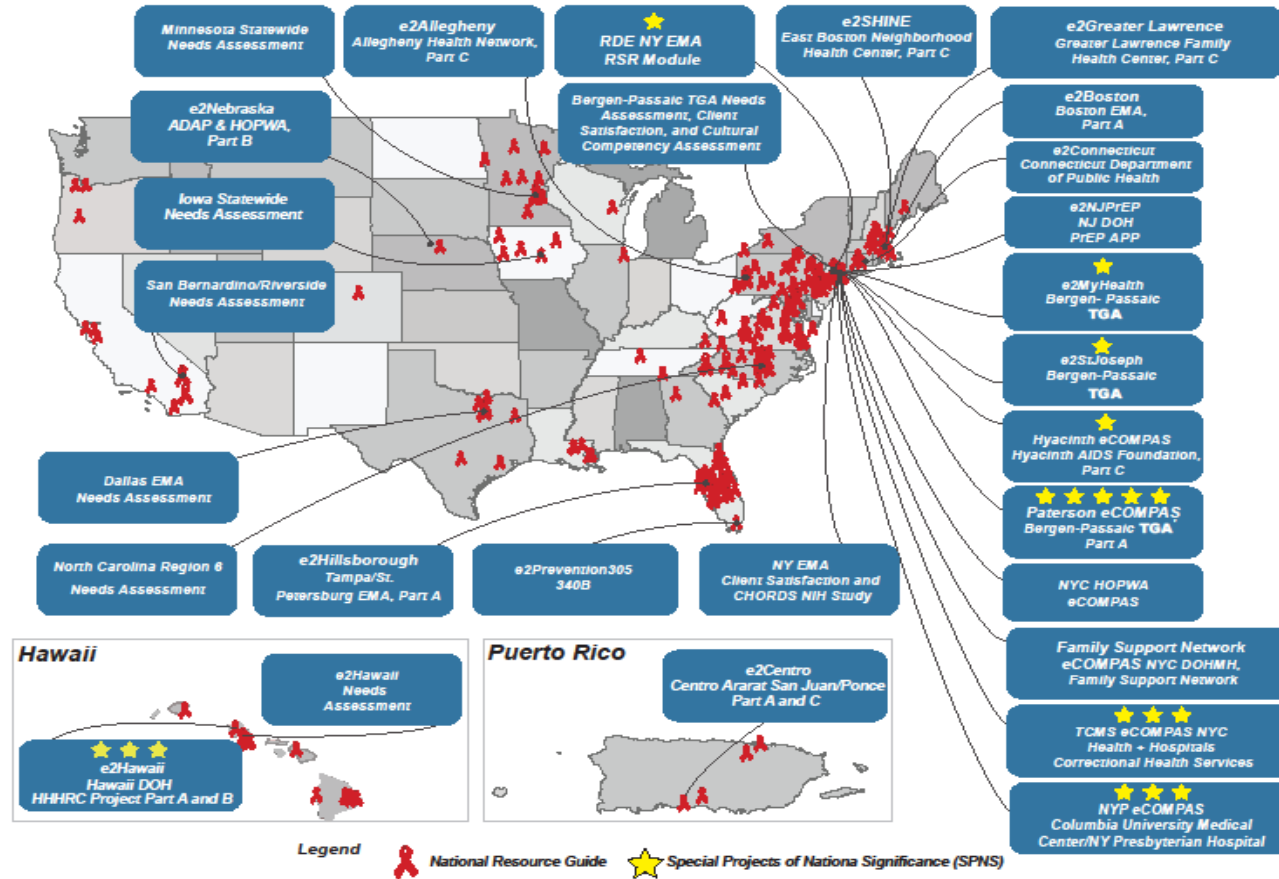
# PROVIDER, CBO, DOH USERS

# Consumer Patient Users



**13,000+**  
**CONSUMER / PATIENT USERS**

# Our Patients



**250,000+**  
**PATIENTS**

# Security and Privacy are #1

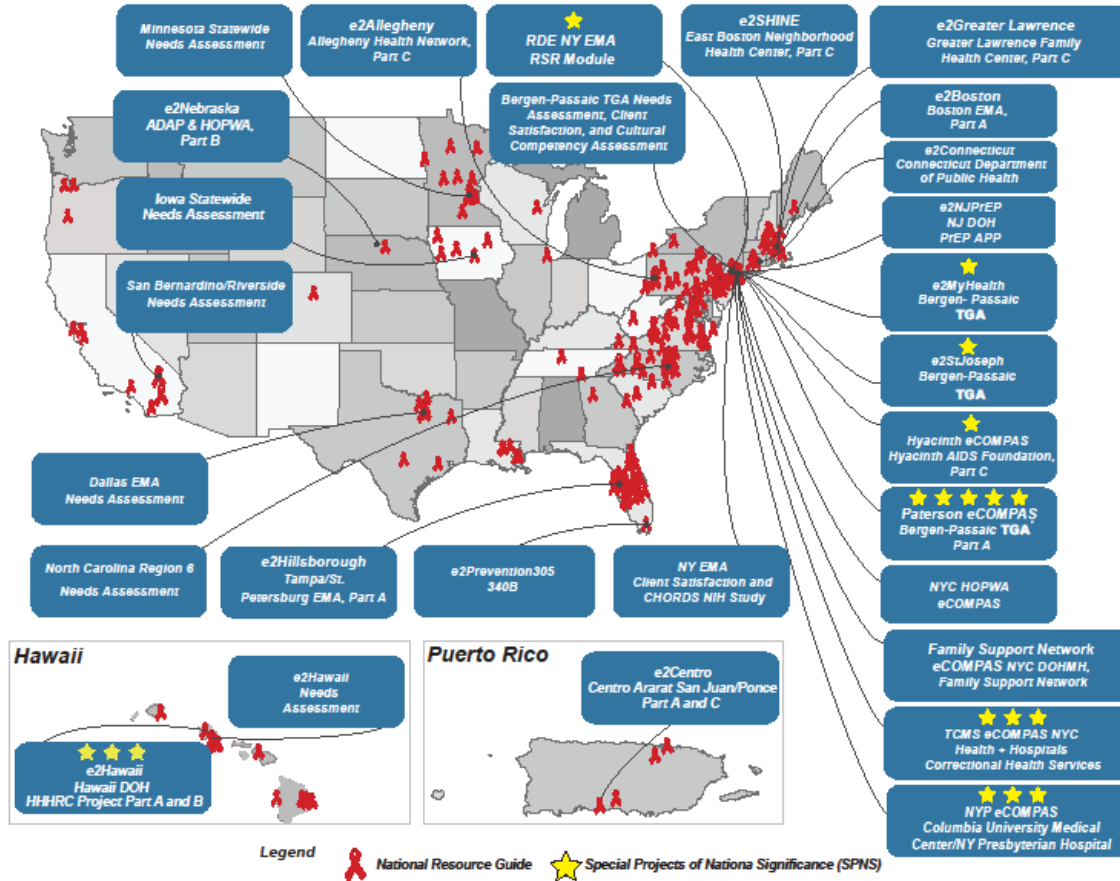


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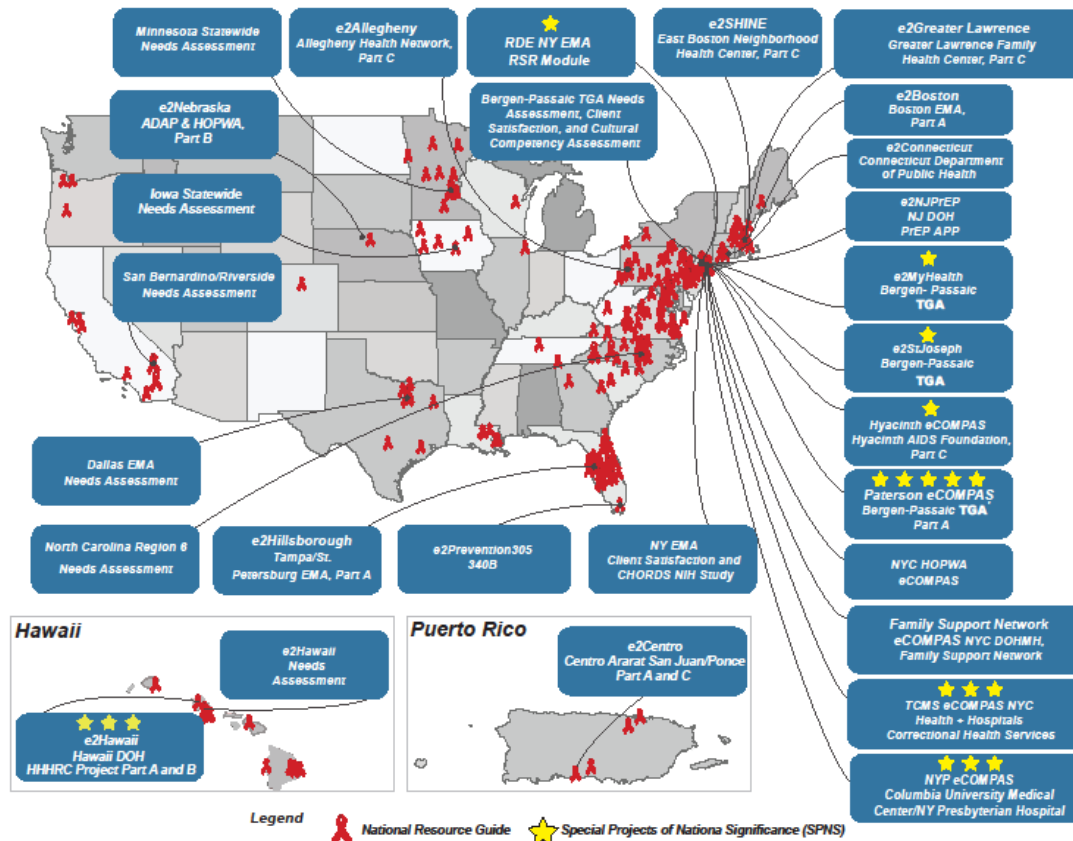
## AWS Assurance Programs



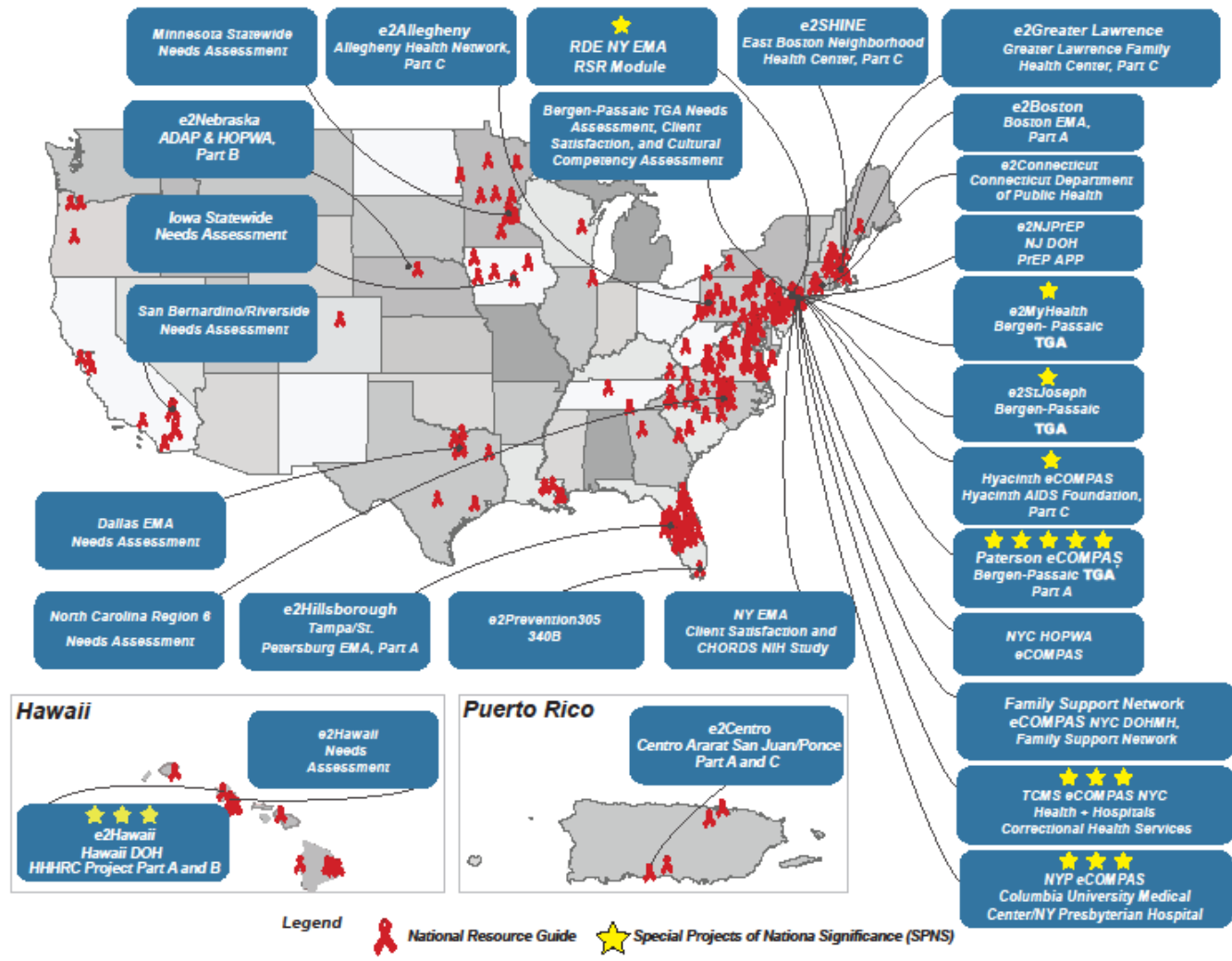
eCOMPAS  
Advanced  
Encryption



**\$1 Billion**  
**FUNDING MANAGED**

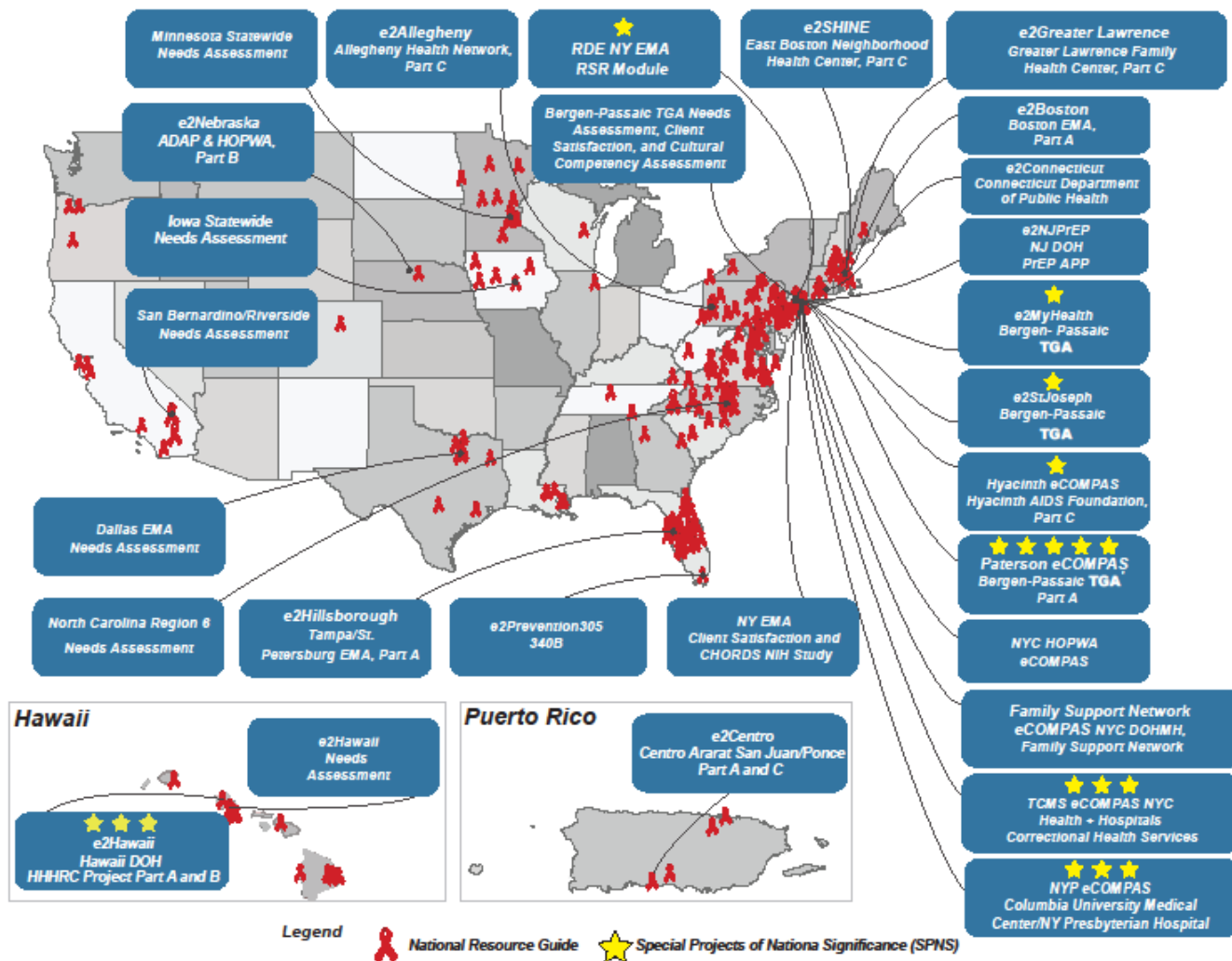


**300+ Million**  
**Provider Data Points Exchanged**



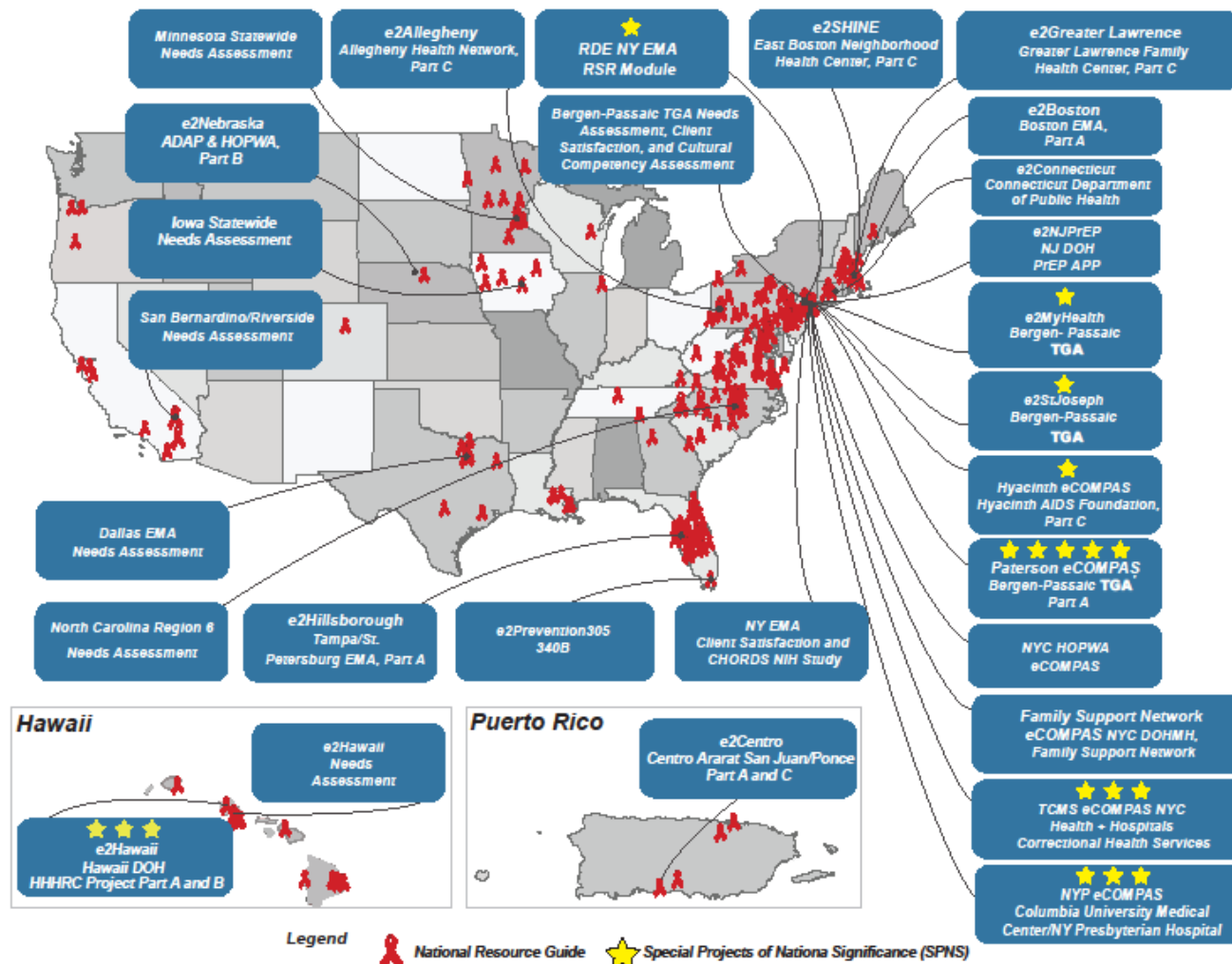
805,000+ HOURS SAVED



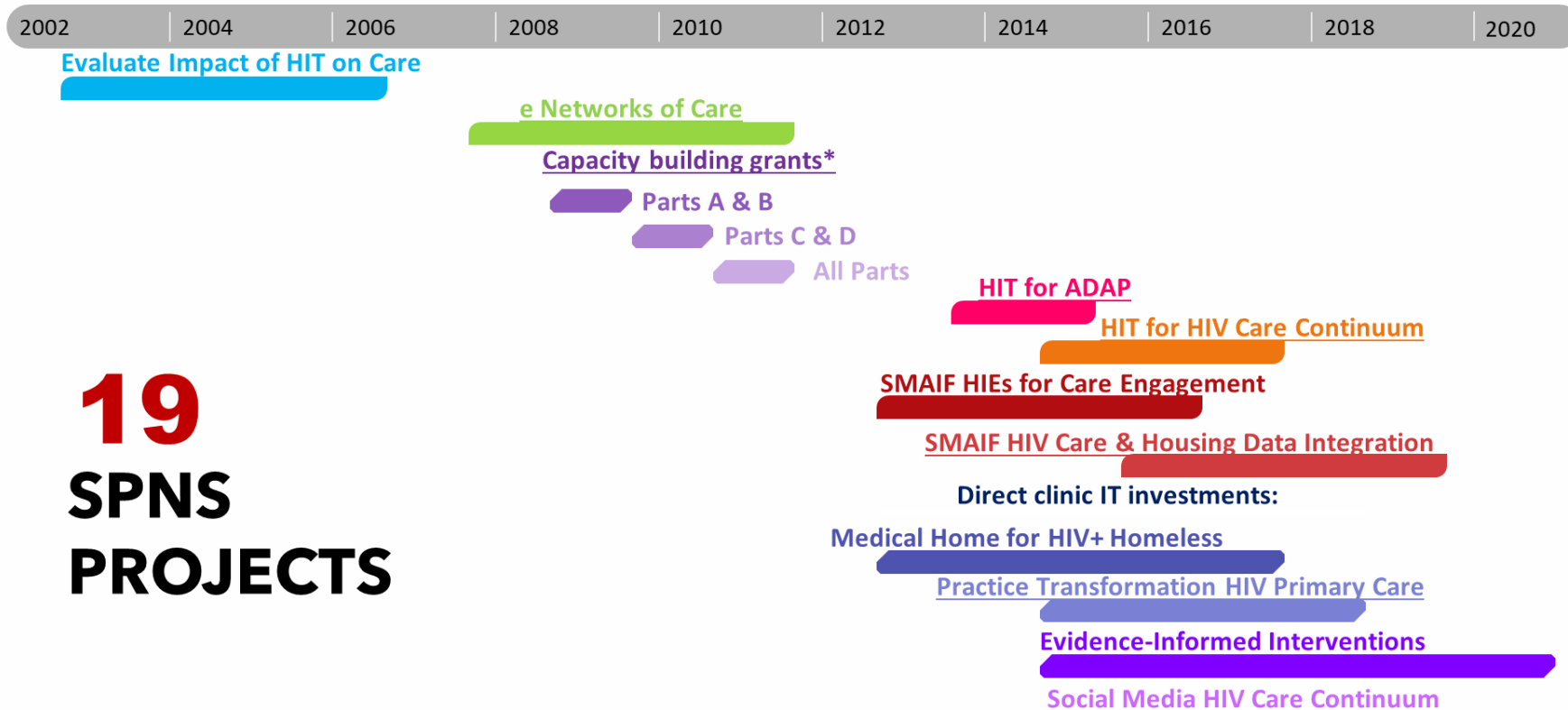


# 400+ FTEs

**\$15+ Million**  
**GRANT FUNDING ASSISTANCE**



# SPNS Projects



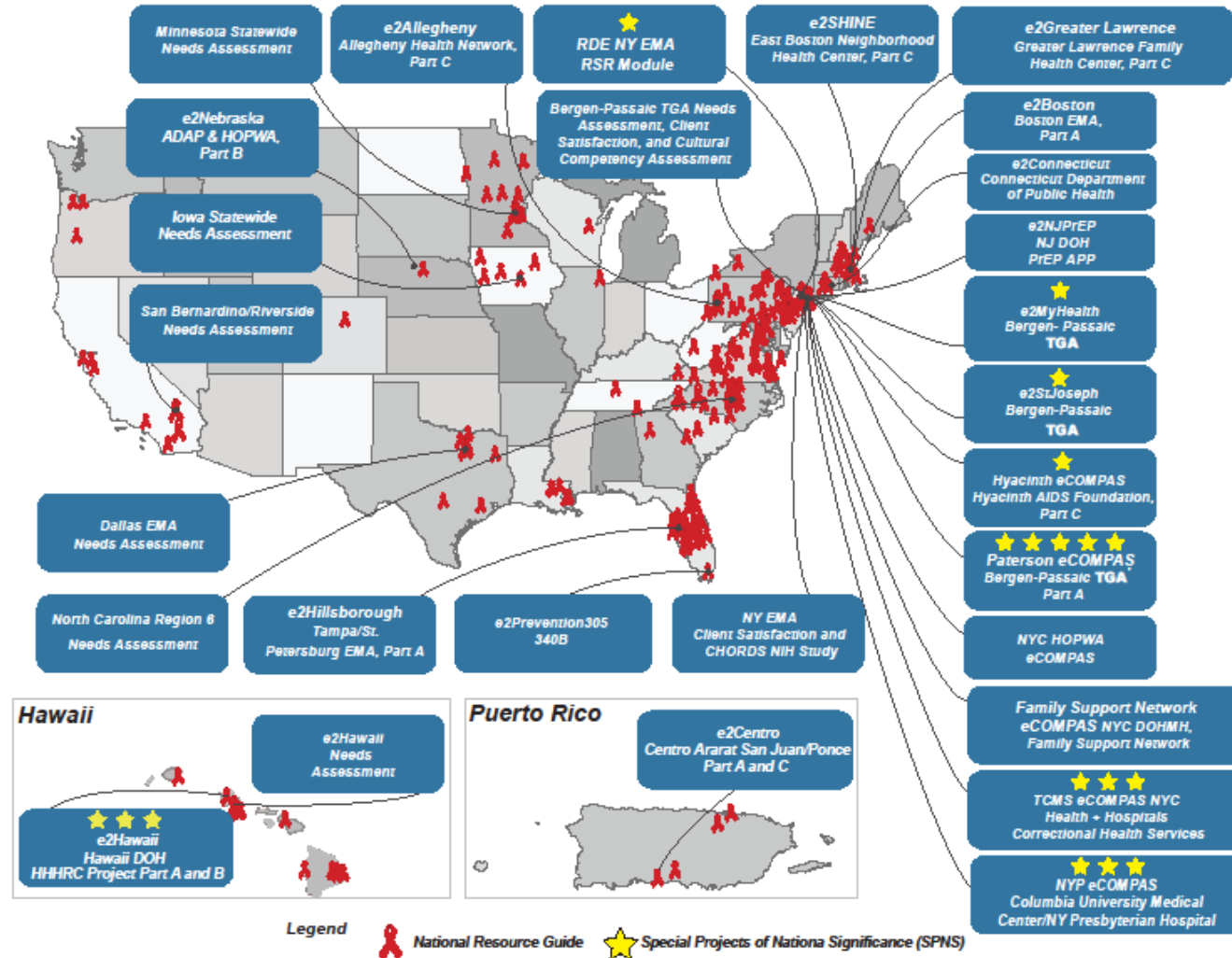
**19**  
**SPNS**  
**PROJECTS**

# Publications Disseminated



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**75+**  
**PUBLICATIONS  
DISSEMINATED**



# Other Sessions To View

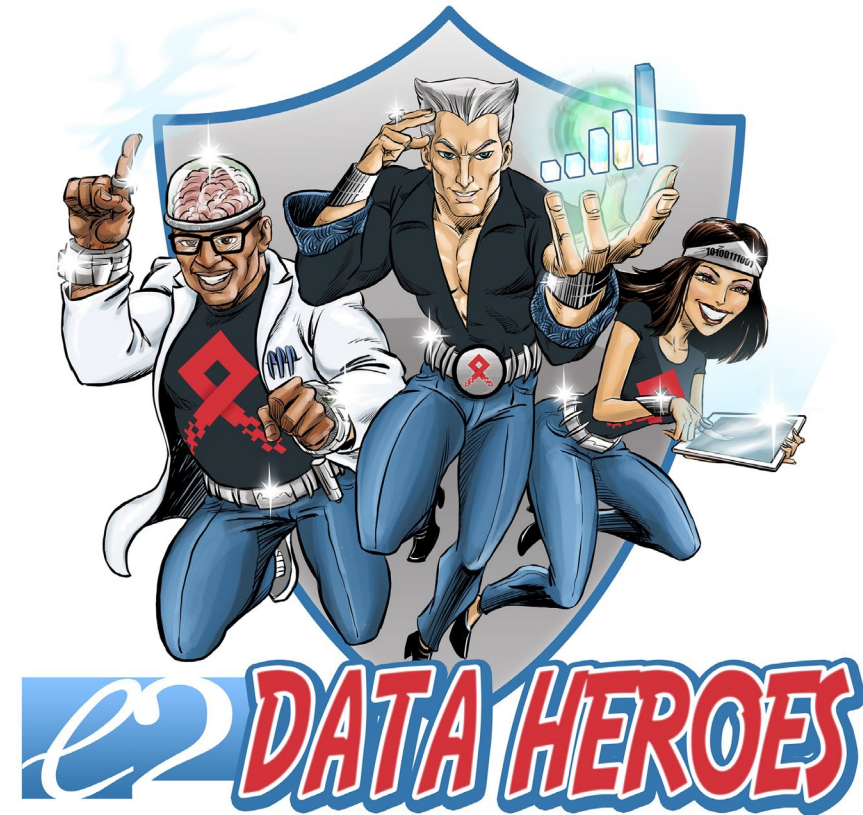


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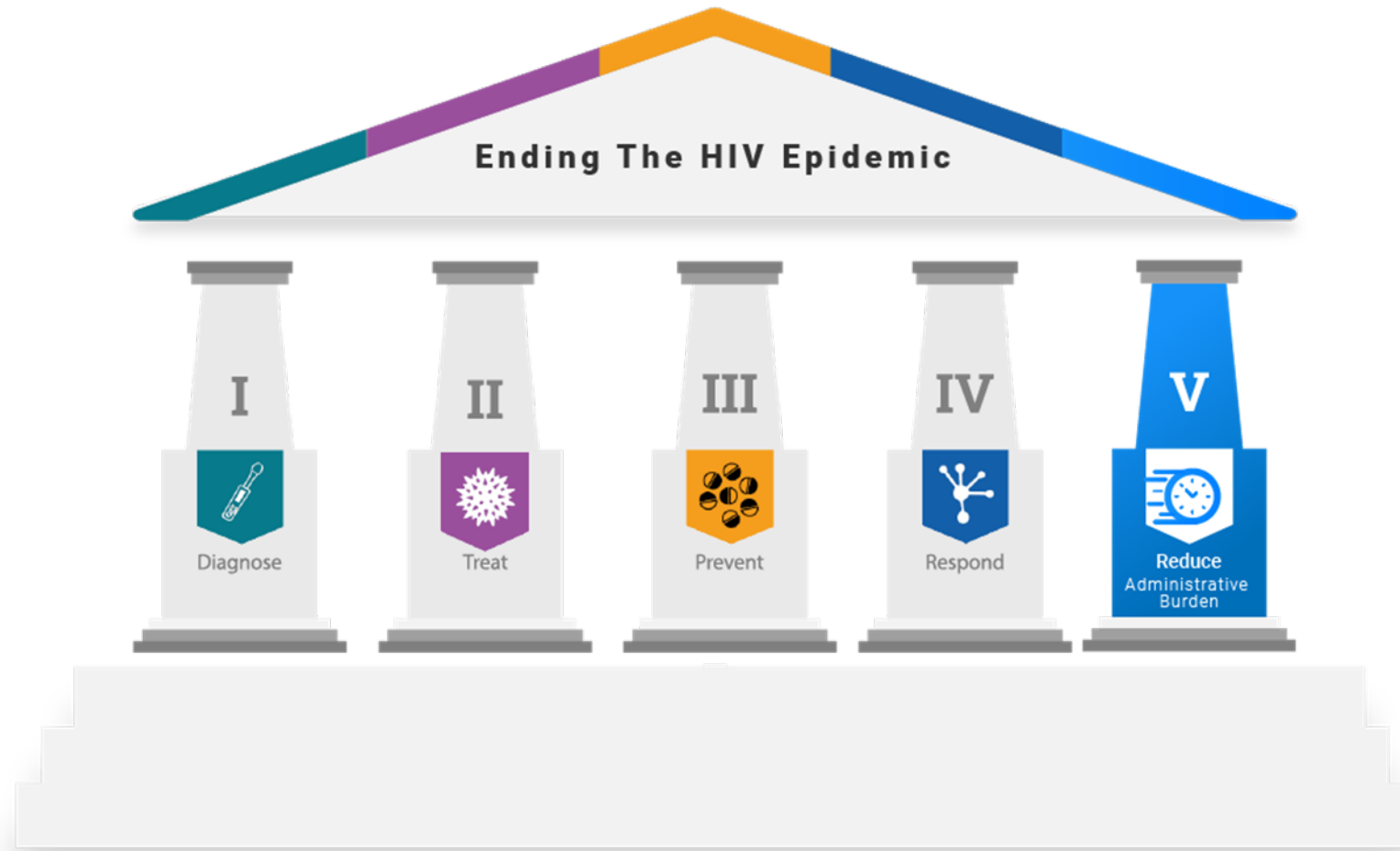
#	Title	Presenters/Panelists	Presenters	Date and Time
1	<b>Innovative Automation in data management, claims processing and electronic billing which saves time and costs!</b> (Session #15910)	Tampa-St. Petersburg EMA; RDE Systems	Aubrey Arnold; Onelia Pineda; Jesse Thomas	Wednesday, August 12:45pm - 2:15pm (Subject to change)
2	<b>Housing, Employment, and Quality Improvement for Incarcerated Populations - Paterson, NJ, and Puerto Rico.</b> (Session #16238)	Bergen-Passaic NJ TGA; Puerto Rico One Stop Career Center; RDE Systems	Millie Izquierdo; Carmen Cosme Pitre; Alison Jordan; Jesse Thomas	Wednesday, August 2:30pm - 4:00pm (Subject to change)
3	<b>How to Share and Leverage Data: Learn from Three Diverse Clinics: Puerto Rico, Boston and Pennsylvania.</b> (Session #16252)	Centro-Ararat, Puerto Rico; East Boston Neighborhood Health Center, Boston; Allegheny Health Network, Pennsylvania; RDE Systems	Marianela De La Cruz Fraticelli; Elisa Sosa; Jesse Thomas	Wednesday, August 2:30pm - 4:00pm (Subject to change)
4	<b>Avoiding the Data System Black Holes: Stakeholder-driven design to increase data integration and reduce administrative burden.</b> (Session #16205)	Connecticut Department of Public Health; RDE Systems	Mukhtar Mohamed; Michael Ostapoff; Daniel Hulton; Jesse Thomas	Thursday, August 13 2:30pm - 4:00pm (Subject to change)
5	<b>Practice transformation, data analytics, and quality improvement: Addressing HIV/HCV and opioid use disorder in NYC.</b> (Poster Presentation #15892)	Columbia Presbyterian University / New York Presbyterian; RDE Systems	Mila Gonzalez Davila; Susan Olender; Megan Urry; Kenneth Ruperto; Jesse Thomas	Thursday, August 13 4pm - 4:25pm (Subject to change)
6	<b>Actuating Care in Iowa, Dallas, TX, and NJ Using Multilingual, Evidence-Based Needs Assessments.</b> (Session #16211)	Dallas EMA; Bergen-Passaic NJ TGA; Iowa State AIDS Program; RDE Systems	Justin Henry; Millie Izquierdo; Katie Herting; Jesse Thomas	Friday, August 14 11:00am - 12:30pm (Subject to change)

## Worth Checking Out – Additional Presentations by Our Partners

	<b>Incidence of Syphilis Among Persons With Recent HIV Diagnoses – Connecticut, 2016</b> (Poster Presentation #16205)	Connecticut Department of Public Health	Mukhtar Mohamed	Thursday, August 13 4pm - 4:25pm (Subject to change)
	<b>Using Data Tools and Partnerships to Provide Innovative Disruption.</b> (Session #16164)	Atlanta EMA Planning Council	Sandra Vincent	Thursday, August 13 4:30pm - 5:30pm (Subject to change)



# 30 Years of Innovating Care, Optimizing Public Health, Ending the HIV Epidemic



## Reducing Administrative Burden

- Time is our finite resource
- Reduce staff stress, burnout, and turnover
- Burden → empowerment

## Right Data & Right Tools

- Quality
- Actionable
- Useful + Usable

Source: Four Pillars: [Ending the HIV Epidemic: A Plan for America](#), HIV.gov

# Who are you?

An interactive poll

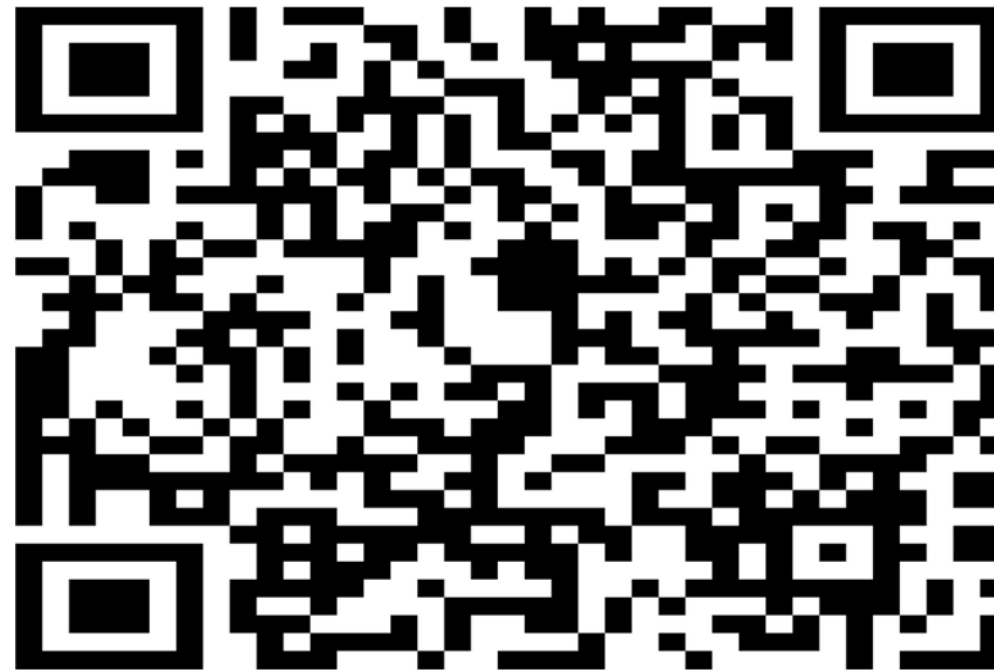
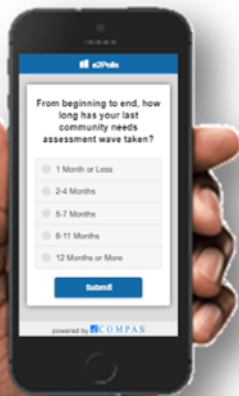
# Interactive Poll

 e2Polls.com

Code: **CNA**

Join us on [e2Polls.com/CNA](https://e2Polls.com/CNA)

Access Code: **CNA**



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free by  **RDE Red**

powered by  **COMPAS**

[RDE.org/Red](https://RDE.org/Red)

## Acknowledgments

City of Paterson, NJ

Dallas County  
Department of Health  
& Human Services

Iowa Department of  
Public Health

RDE Systems

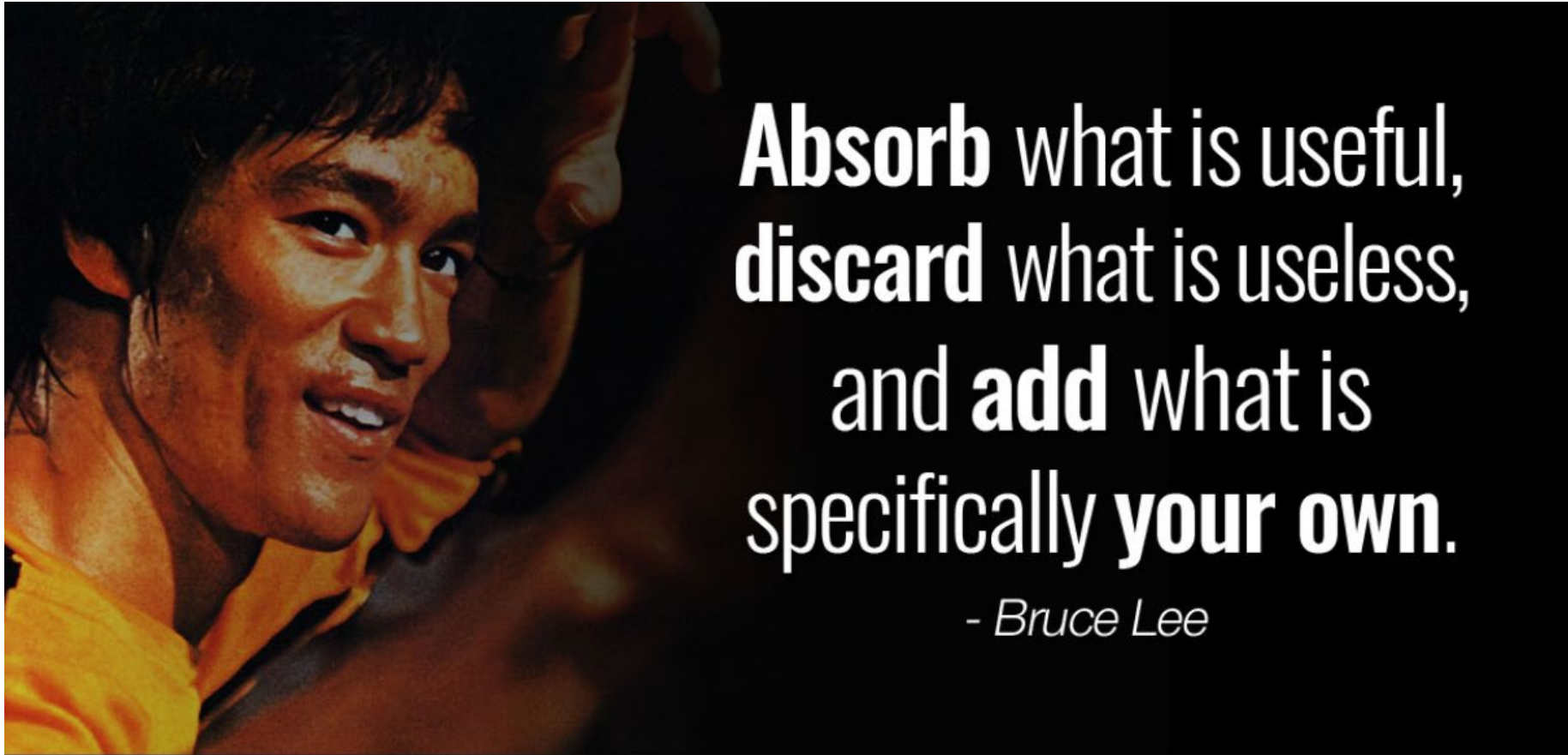
HRSA



# Bruce Lee Quote



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# National HIV/AIDS Strategy



## Goals:

- 1. Reducing new HIV infections*
- 2. Increasing access to care and improving health outcomes for people living with HIV*
- 3. Reducing HIV related disparities*

*(Implementation Plan: Achieving a more coordinated National response to the HIV/AIDS epidemic in the U.S.)*

# How Do We Know What Services to Provide?

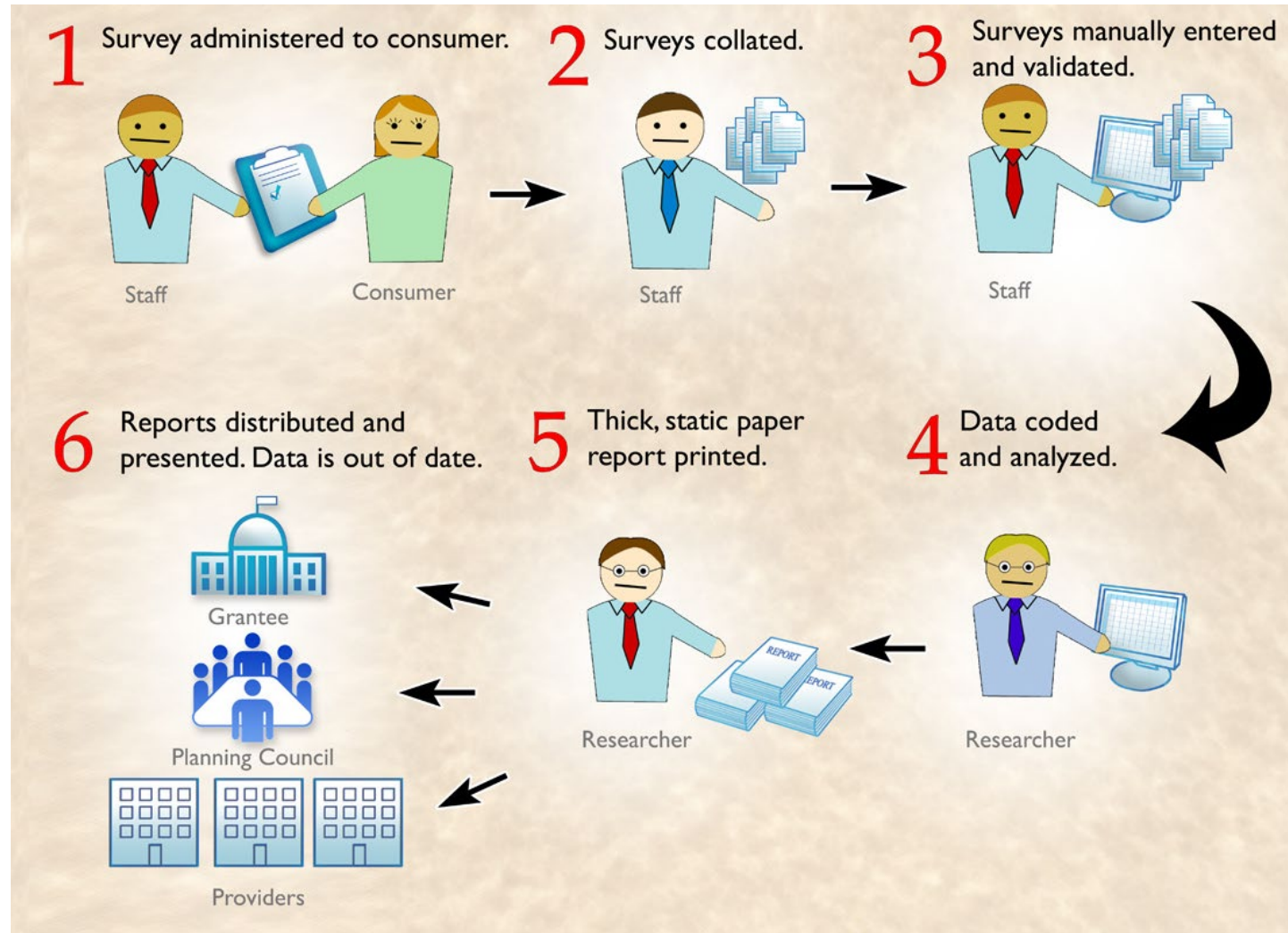


- Evidence-based planning for HIV prevention and care services begins with:

## **DATA-DRIVEN NEEDS ASSESSMENT**

- The “Justification of Need” is included in every grant application that you write.
- Developing an effective needs assessment process is vital to organizational sustainability and delivering high quality, effective programs.

# Traditional Needs Assessment Process

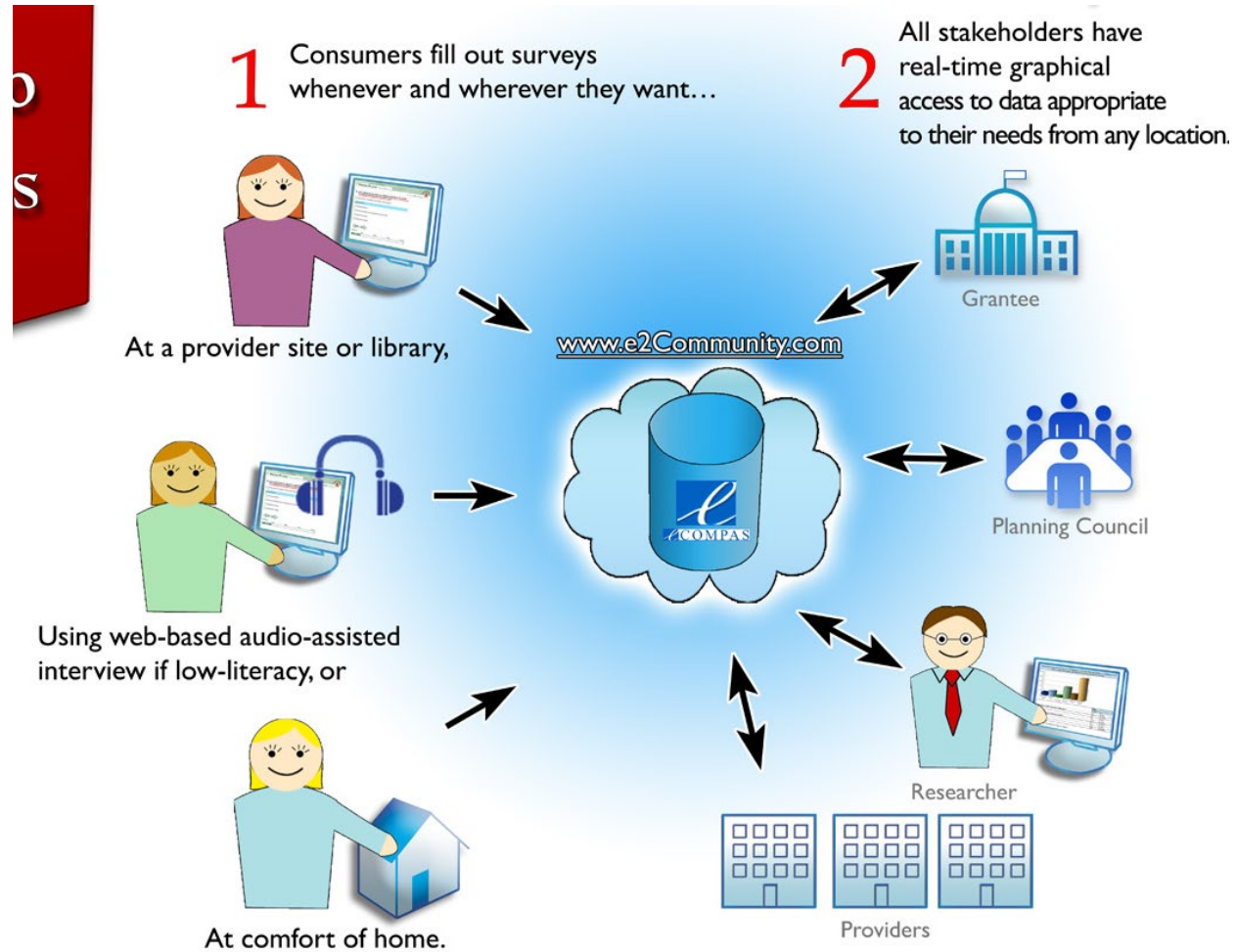


# Problem Statement



1. Too much time spent managing paperwork
2. Delay from data collection to action
3. Validating surveys a challenge
4. Too costly and inefficient
5. Paper reports are not interactive
  - Questions people have about the data result in health planners having to manually re-analyze the data

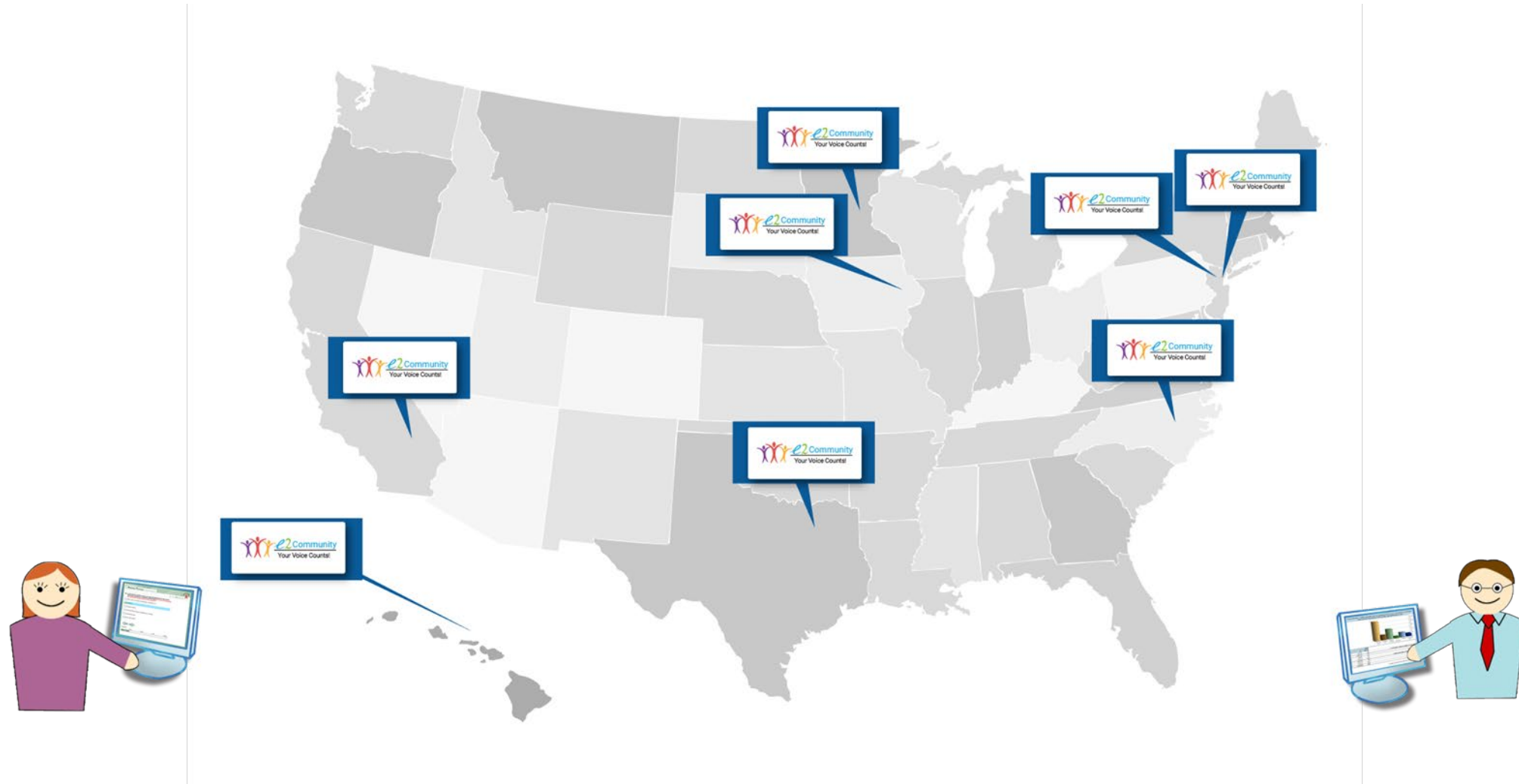
# Our Vision



# National Context



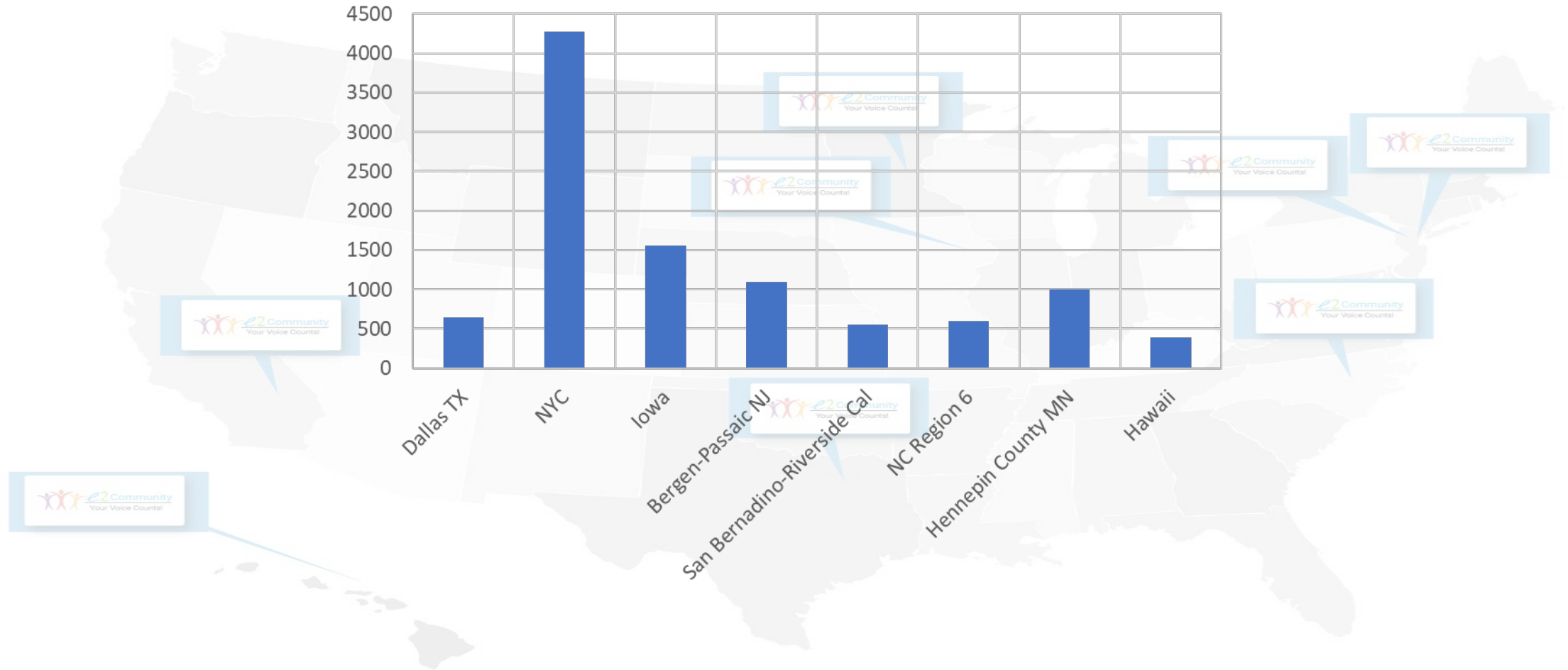
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# Over 9,500 Total Consumers



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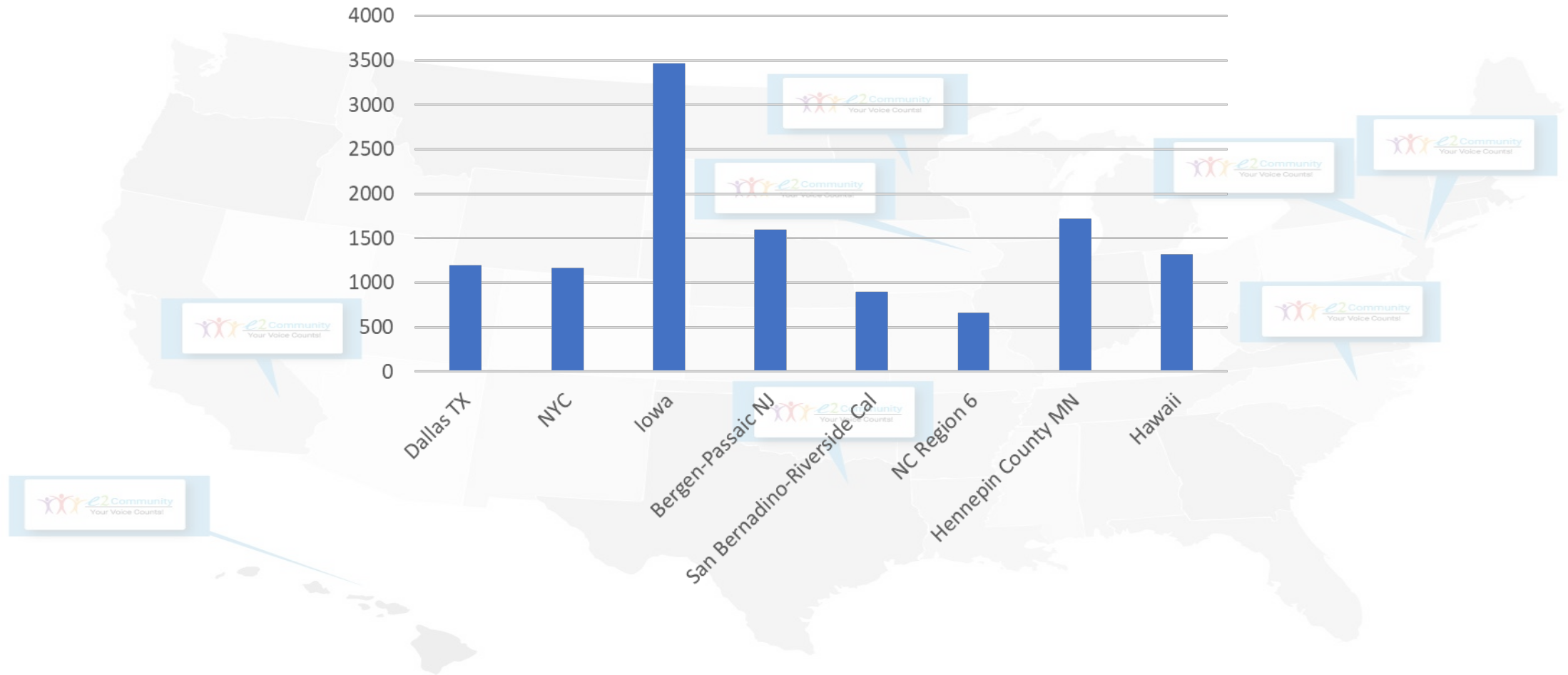


Covering Urban, Suburban, and Rural Regions.

# Survey Complexity: Over 12,000 Q & A Fields



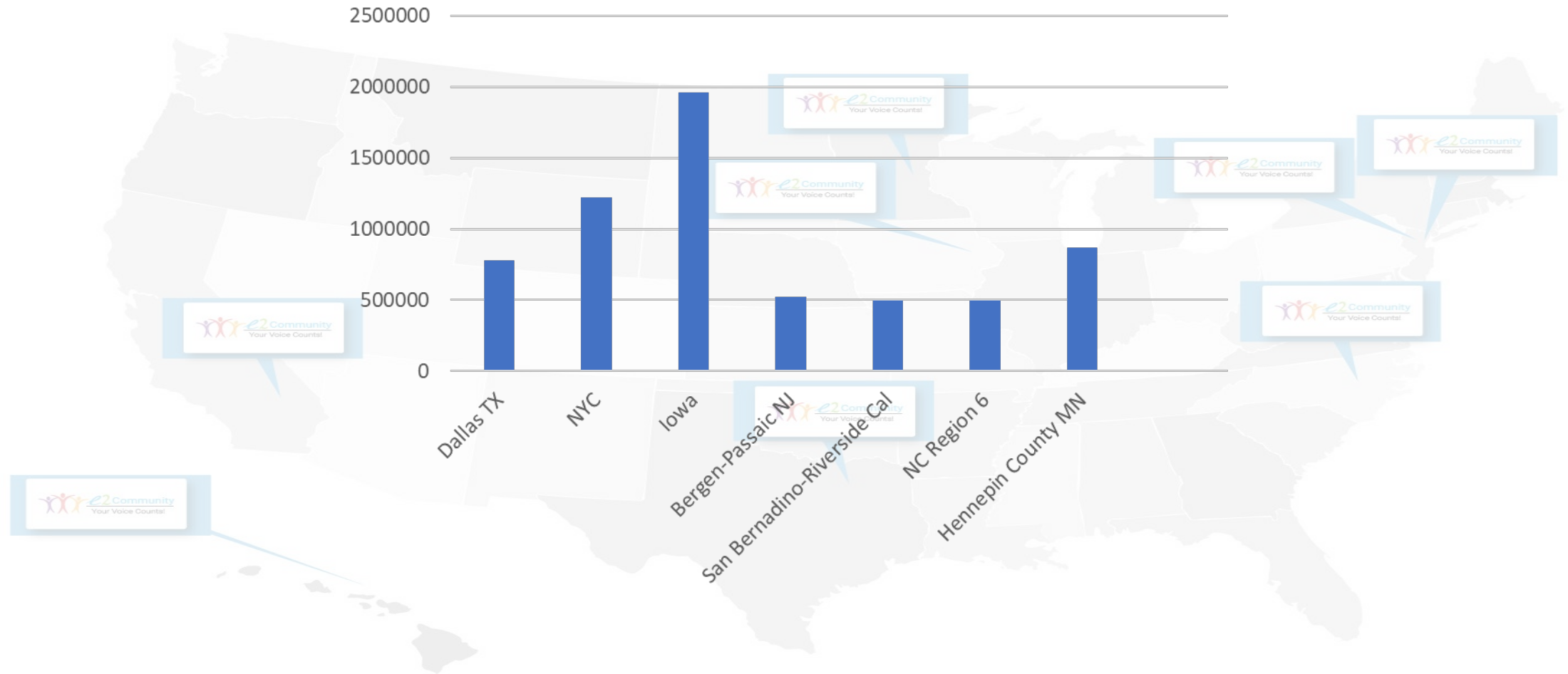
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# Over 7 Million Data Points



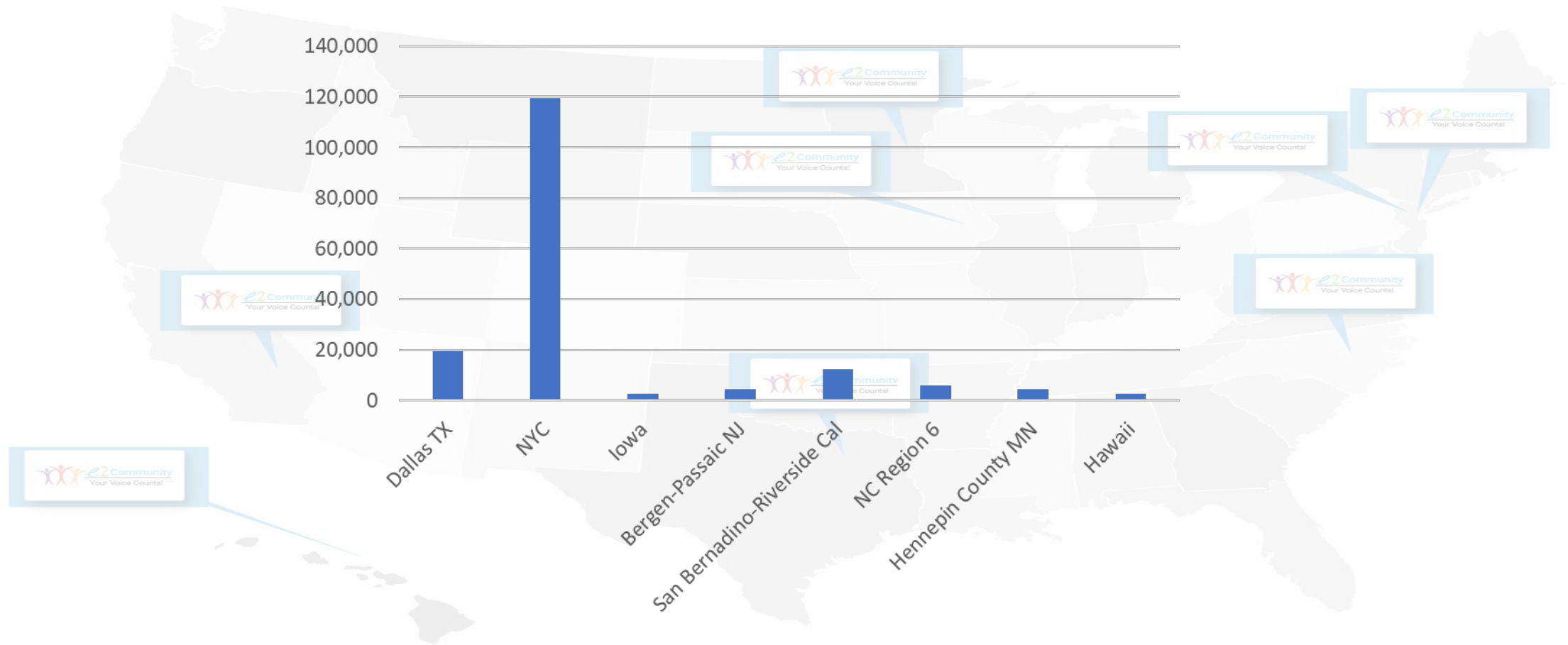
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# Diversity of Size of Regions: PLHWA



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Over \$69,000 in Client Incentives Distributed



**Over 19,000 Staff Hours Saved!**

# Hennepin County/Minnesota

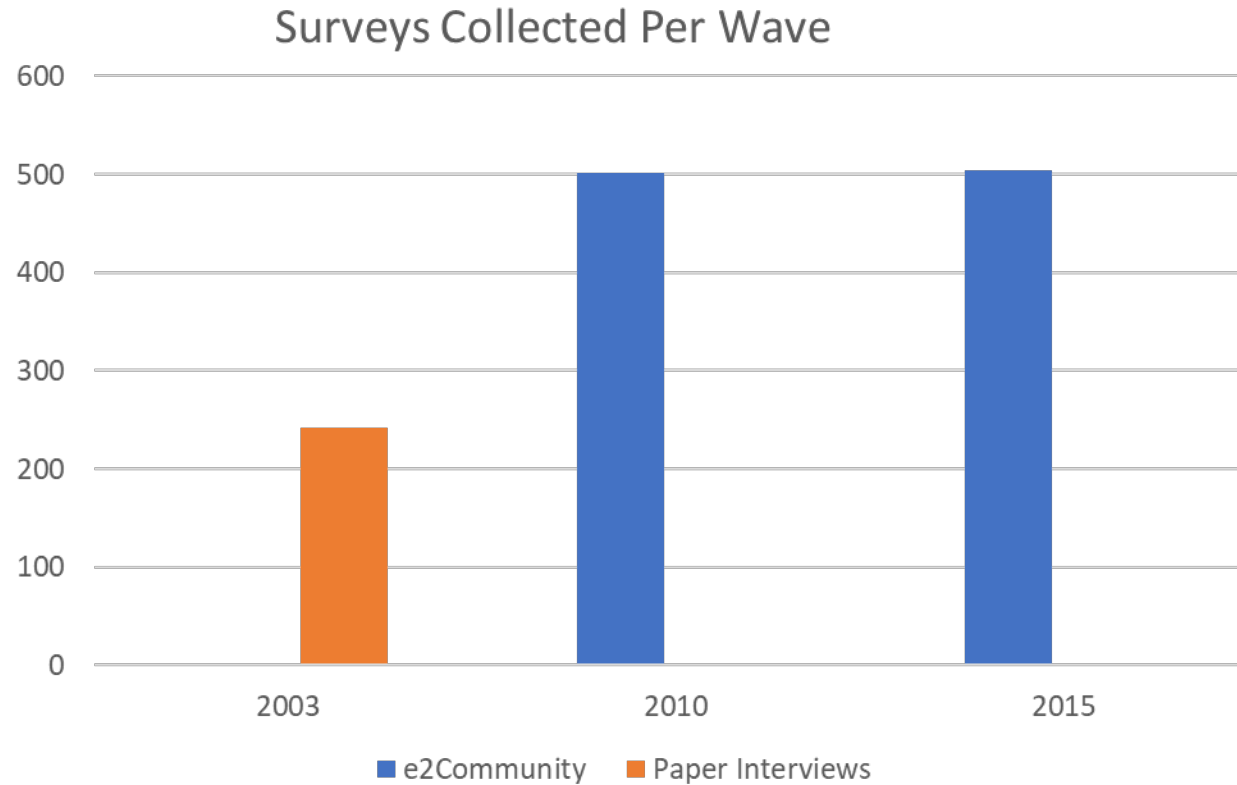


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*Hennepin County / Minnesota's  
Comprehensive Needs Assessment Web-  
Audio Surveys*



# Double the Response Rate







# Innovative Use of Inexpensive Netbooks

## Before Netbooks and eCOMPAS



2003: Survey required  
6 interviewers to conduct  
face-to-face interviews

## After Netbooks and eCOMPAS



2010: Majority of respondents (69%) did  
so from a private/public computer.

The remaining 31% participated in a  
session led by one of six volunteer  
consumer ambassadors

# Unanticipated Benefit

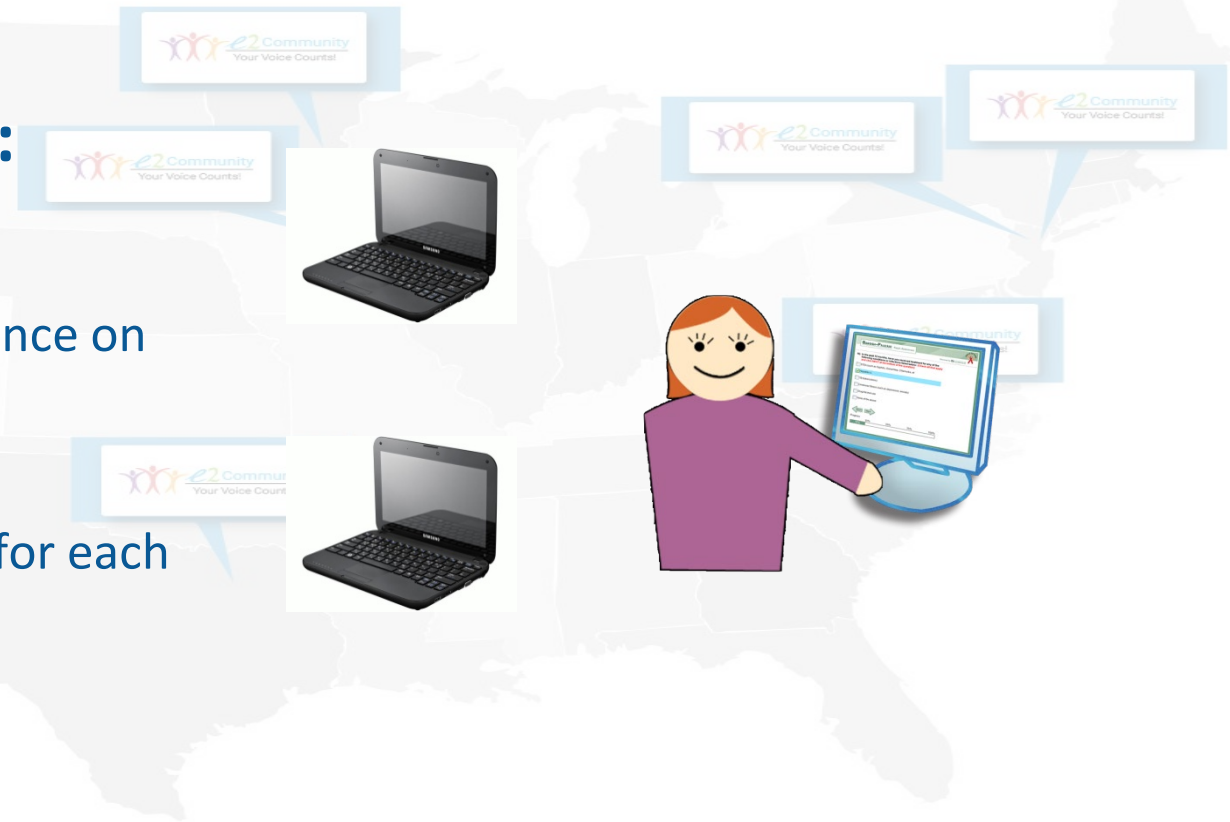


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## Unanticipated Benefit:

Needed to do translation only once on the web.

Instead of needing a translator for each consumer who needed it.



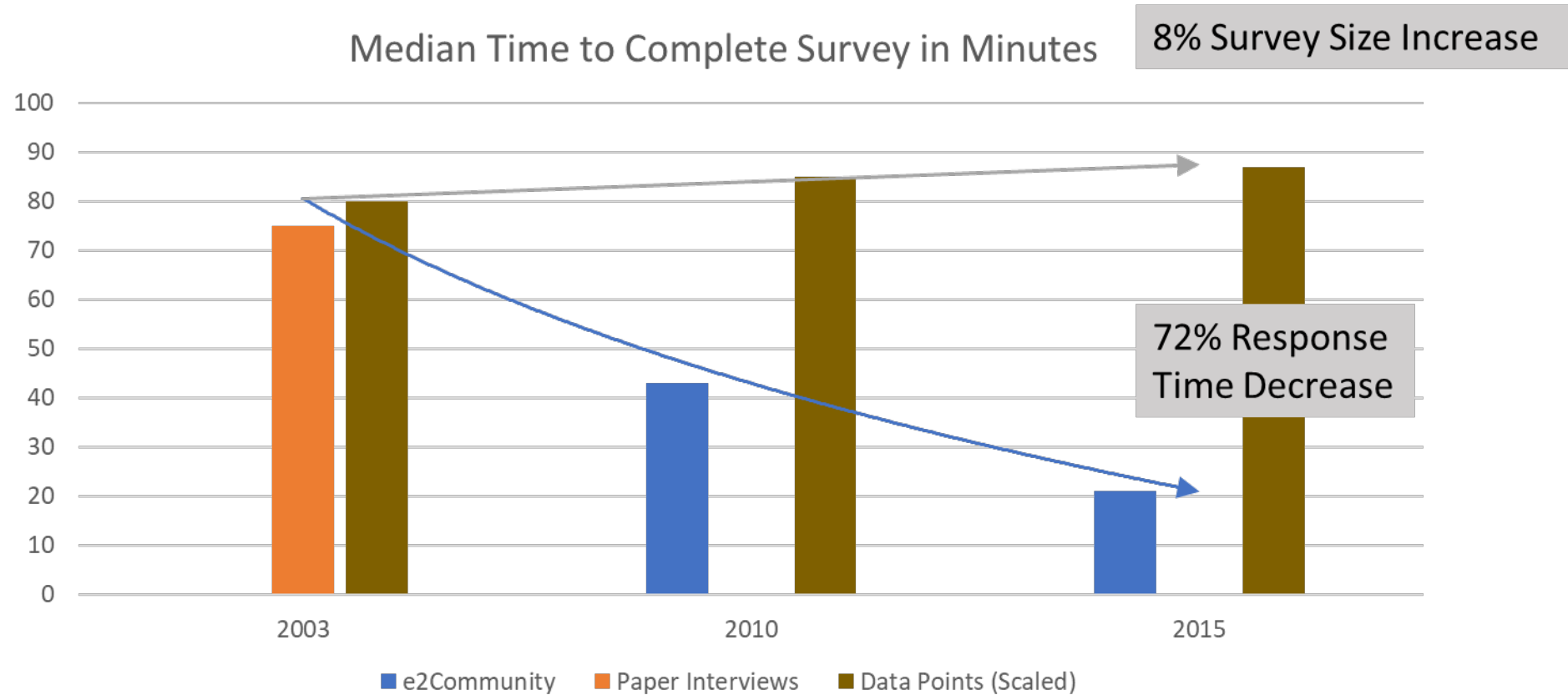
# How are Interpreters Seen by Clients?



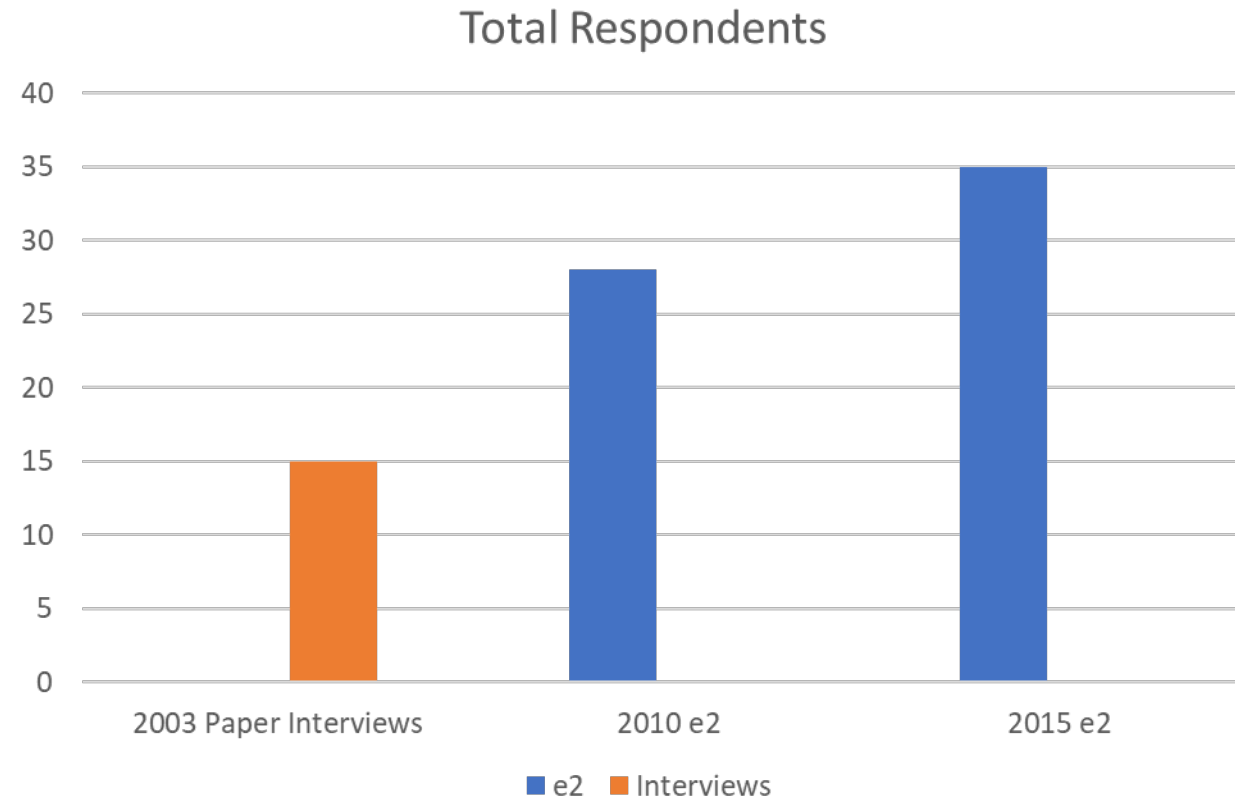
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# Quarter the Time Per Response

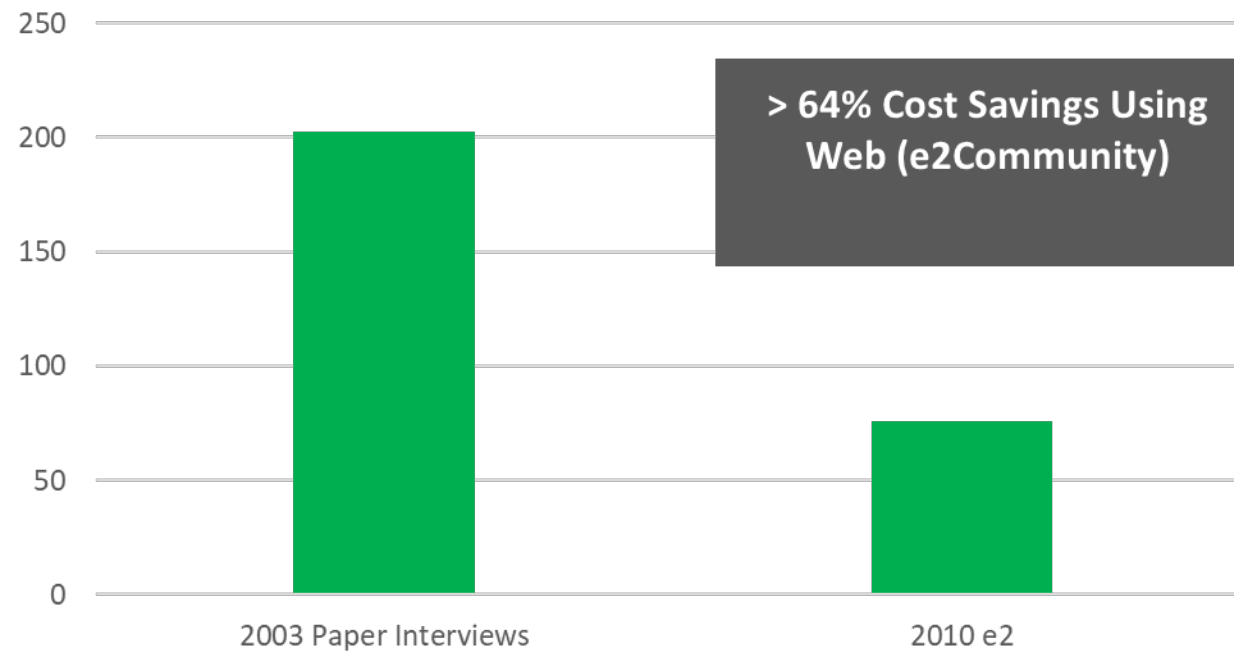


# Case Study: African-Born Population



# MHSPC Cost Savings Analysis

Paper Vs. e2: Cost per Survey in Dollars



# New York City



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# Case Study: NYC Client Satisfaction & IRB Surveys

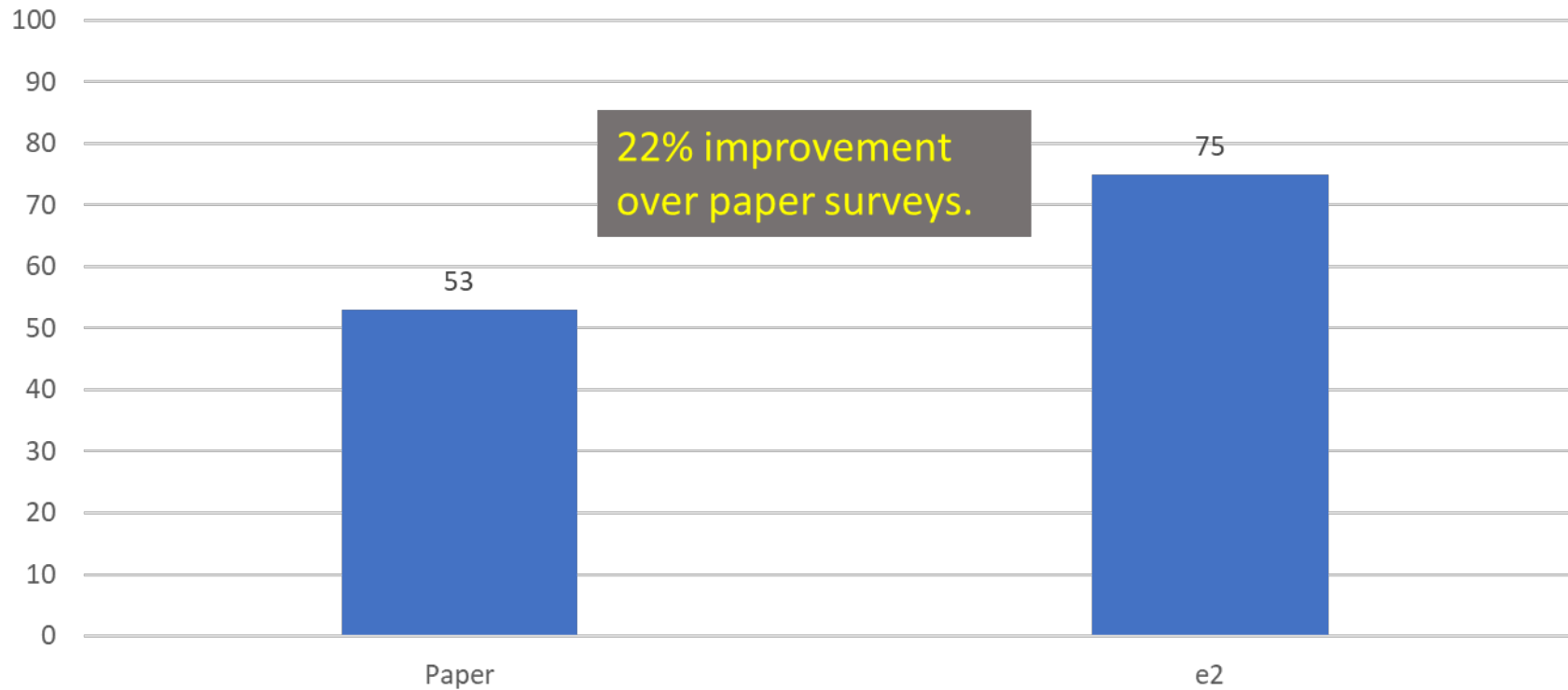


- **Better Consumer Experience:** “We have found, anecdotally, that many clients enjoy the experience of taking the survey as well as the ability to provide feedback on different aspects of the Care Coordination program. Clients have reported that the survey platform is easy to use, with many clients having taken it on smartphones, tablets, and computers.”
- **Proactive TA:** “Because of the way survey IDs were set up, even for anonymous surveys, we could figure out which service category and agency a person was being surveyed about. This allowed us to look at the types of responses received by service category and agency and to use that information to provide technical assistance to agencies regarding particular problem areas, and to identify particular facilitators and barriers to receiving services by agency and service category.”
- **Real-time Analysis:** “Electronic extract of survey data made real-time analysis of survey data possible and could be used to regularly track survey’s progress and any survey issues.”

# More qualitative data with web (e2)



Percent of Responses With Qualitative Feedback



# Region 6, NC



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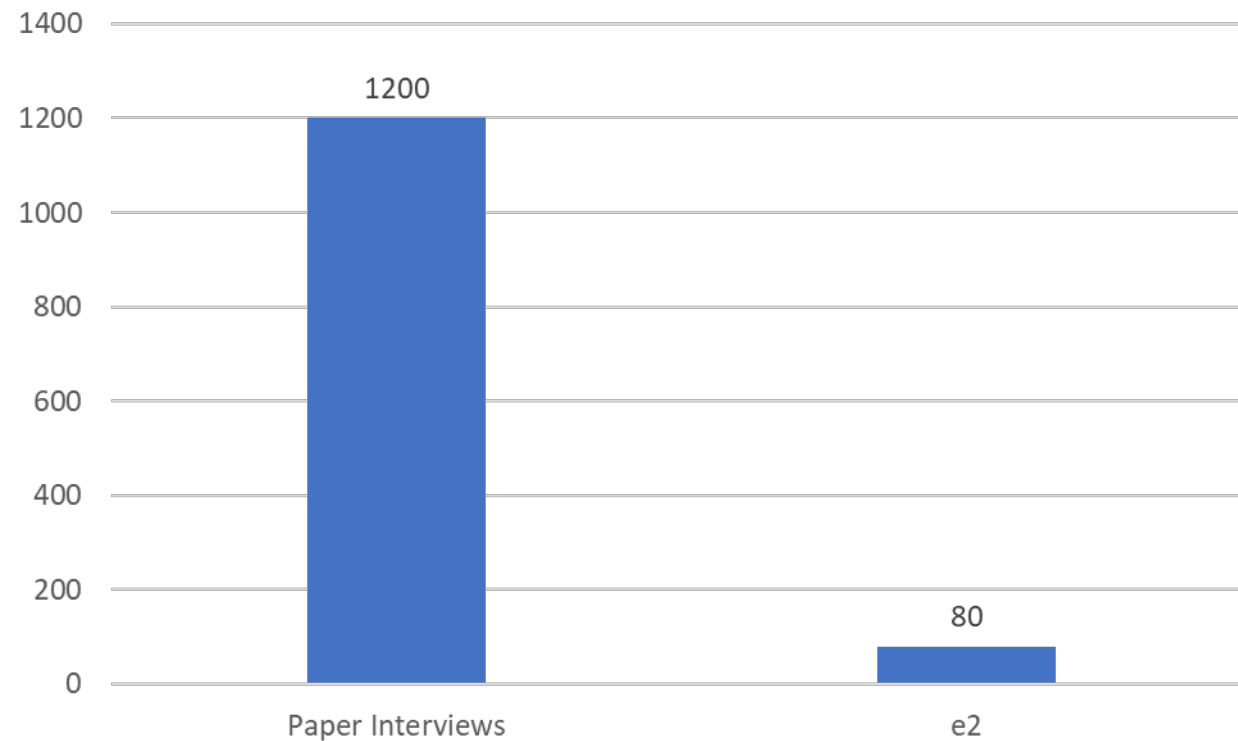
## Region 6, North Carolina



# Wake County Results



### Staff Hours Spent in Outreach



# Summary of Three Regions In-Depth Today



Number of consumers surveyed:	2,686
Languages used:	English, Spanish
Number of municipalities covered:	1,079
Number of Q&A fields in real-time:	5,357
Number of staff hours saved:	3,910
Grants written using needs assessment data:	3



**Bergen-Passaic TGA:**  
Pioneer in Web Tools for Health Planning

# Introduction



- Milagros Izquierdo, Program Director, Paterson-Bergen-Passaic TGA
- Jesse Thomas, Project Director, RDE Systems

# A Long Partnership



- Partnered with RDE in needs assessment & client satisfaction surveying cycles since 2005.
- Impact of digital surveying vs paper-based processes immediate.
- The Story of Consumer Accessibility and the Voices Committee



# The Old Way



26. Answer each of the following questions, following directions listed under the headings.

The Old Way	A During the past 12 months, did you get:				B If YES, how easy was it for you to get this service?				C If NO, during the past 12 months, did you need?				D If YES, what is the main reason you were not able to get this service?
	1	2	3	4	1	2	3	4	1	2	3	4	See Code List
Visits with a doctor, nurse, or assistant to take care of your HIV outpatient medical care.													
Visit to a medical specialist based on a referral from your doctor.													
Visit with a doctor, nurse, or assistant to examine or treat non-HIV health conditions.													
Education or counseling about HIV, HIV transmission, and how to reduce the risk of HIV transmission.													
Treatment adherence services to provide you with education and counseling on ways to help you routinely take HIV/AIDS medications and follow through on HIV/AIDS treatments.													
Case management session(s) with a case manager to help you coordinate your HIV/AIDS care and help access other services and benefits.													
Client advocacy where a counselor assists you to work through a particular problem in obtaining a service, obtaining benefits or in a complaint against a service provider.													

25a) During the past 12 months, did you get HIV outpatient medical care visits?

- Yes
- No
- Don't know



25a) How easy was it for you to get HIV outpatient medical care visits?

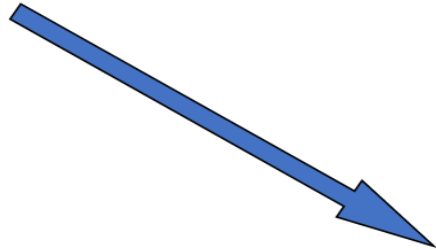
- Easy
- Somewhat hard
- Hard

Next Question

25b) During the past 12 months, did you Visit a medical specialist based on a referral from your doctor?

- Yes
- No
- Don't know

Next Question



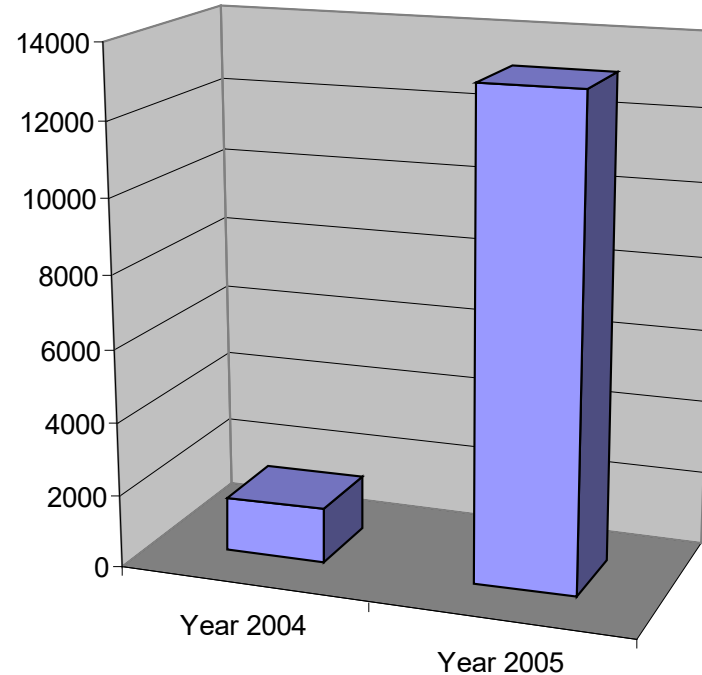
25a) What is the main reason it was hard to get HIV outpatient medical care visits?

- Information - Where to get it, how to qualify
- Personal or cultural - You weren't comfortable with the agency staff or language barrier
- Service delivery - No agency available, you didn't qualify to get it
- Access/availability - Too far away, not open when you could get there, long waits
- Not applicable/no barriers

The New Way  
The System  
does all the  
work behind  
the scenes.

# A Long Partnership – Immediate Impact

Client Satisfaction Observations

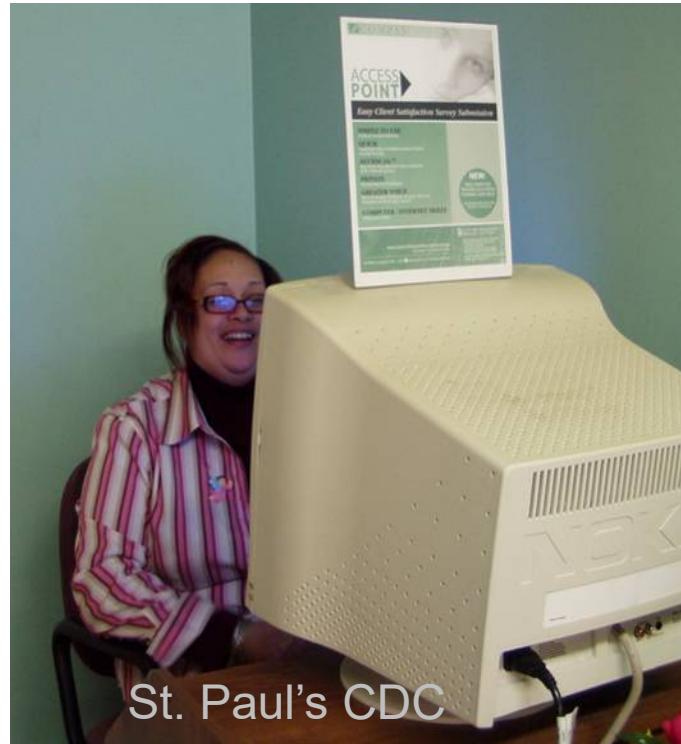


**We were expecting response rates to drop in moving from paper-based to web-based surveys. Instead going web-based produced a surprising increase in response rates for a primarily urban, disadvantaged population, making internet access barriers a myth.**

# 2005 Consumer Access Points



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**COMPAS**

**ACCESS POINT**

*Easy Client Satisfaction Survey Submission*

**SIMPLE TO USE**  
*Click on-screen buttons.*

**QUICK**  
*Automatically completes parts of each survey for you.*

**ACCESS 24/7**  
*Any time, any day from any computer with Internet access.*

**PRIVATE**  
*No surveys in envelopes.*

**GREATER VOICE**  
*More frequent feedback of your views to Providers and Planning Council.*

**COMPUTER / INTERNET SKILLS**  
*Helps you learn.*

[www.ryanwhitegrantee.com/ecompas](http://www.ryanwhitegrantee.com/ecompas)

**CITY OF PATERSON**  
Mayor José "Joey" Torres  
Department of Human Services  
Ryan White Title I Services  
226 Ellison Street  
Paterson, New Jersey 07505  
Bergen/Passaic County EMA  
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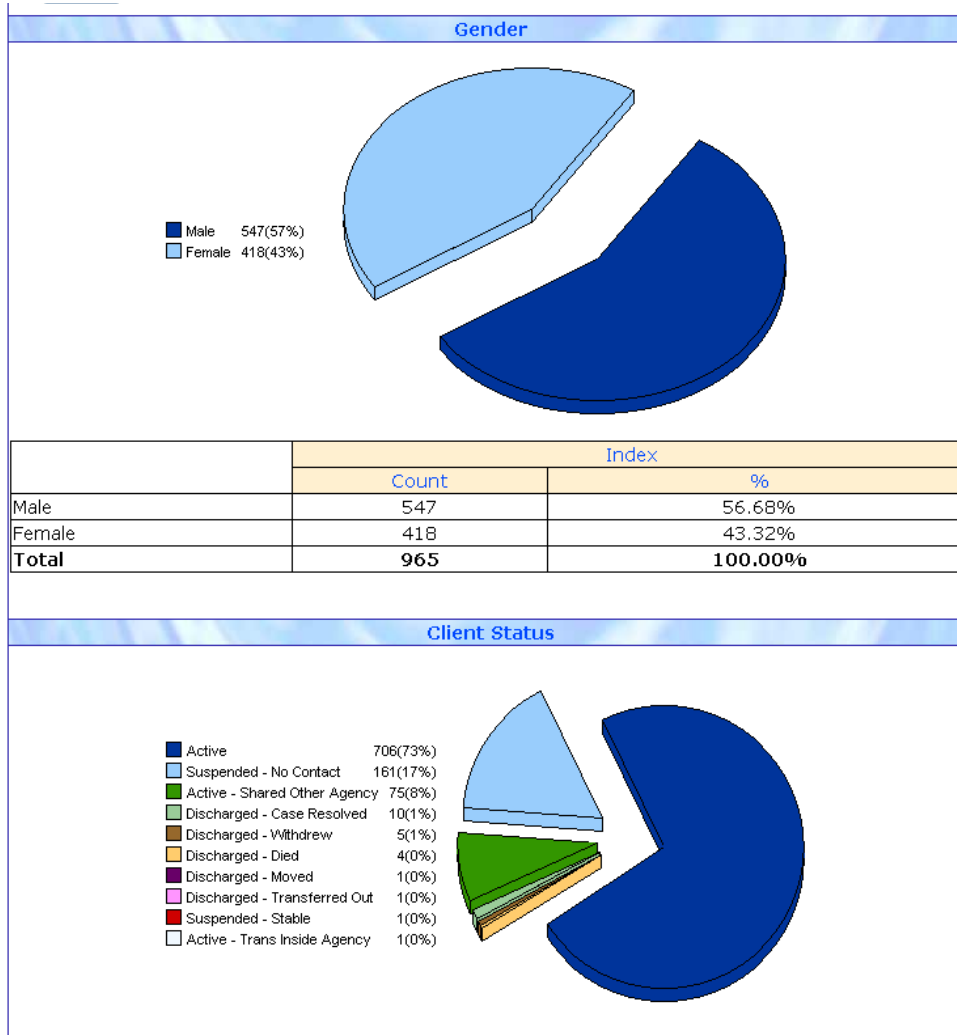
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# Planning Council Interface



The screenshot shows a Microsoft Internet Explorer browser window displaying the e-COMPAS website. The browser's address bar shows the URL: [https://www.e-compas.com/OutcomesView/a\\_index.cfm?CFID=600&CFTOKEN=22910094](https://www.e-compas.com/OutcomesView/a_index.cfm?CFID=600&CFTOKEN=22910094). The website header features the e-COMPAS logo with the tagline "The smart alternative to paper-based outcomes management" and three small portraits of healthcare professionals. A navigation menu includes links for Main, Reports, Help, My Account, Comments, About Us, and Logout. The main content area is titled "Planning Council Interface" and contains several interactive elements: two buttons labeled "Demographics [beta]" and "Indicators [beta]", a link for "View My Favorite Reports", two dropdown menus for "Select service category" (one set to "Provider Outcomes" and the other to "Client Satisfaction"), and a "CITY OF PATERSON" logo at the bottom.

# Demographics & Utilization



# Building the Big Picture



- Long-term goal of partnership is to integrate CLD and other client data in order to build a big picture about PLWHA and the HIV/AIDS Epidemic in the TGA.
- Combining CLD with needs assessment responses.
- Interlinking data from disparate medical providers and funding sources through Special Project of National Significance.
- Recording and comparing outcomes across the TGA's 3 major medical service providers.

# Building the Big Picture - Timeline



First needs client  
satisfaction  
survey wave.

2005

2008

Implement  
eCOMPAS  
Client Level  
Data (CLD)  
system.

Begin SPNS HIT Electronic  
Networks of Care Project

2014

2016

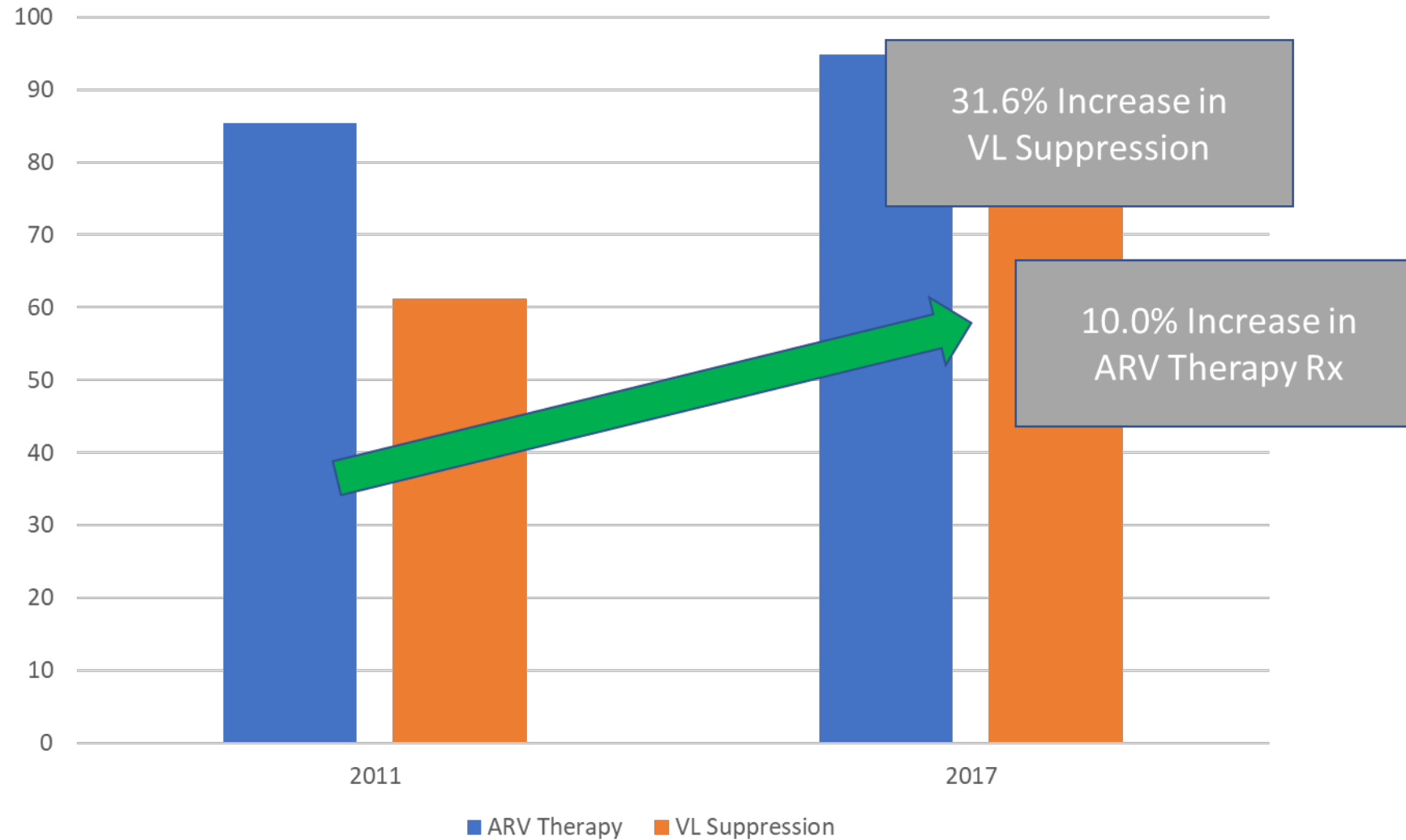
Second needs assessment  
wave.

Complete SPNS  
SPNS HIT  
Electronic  
Networks of Care  
Project

2017



# Cumulative Gains – 2017 3-Clinic Statistics





# How We Did It

**Visual Analytics**

**Real-Time Feedback**

**Broad Access to Data**

**Linkage to CLD Systems**

**Goal-Attainment Tracking**

**SPNS and Capacity Development Grants**

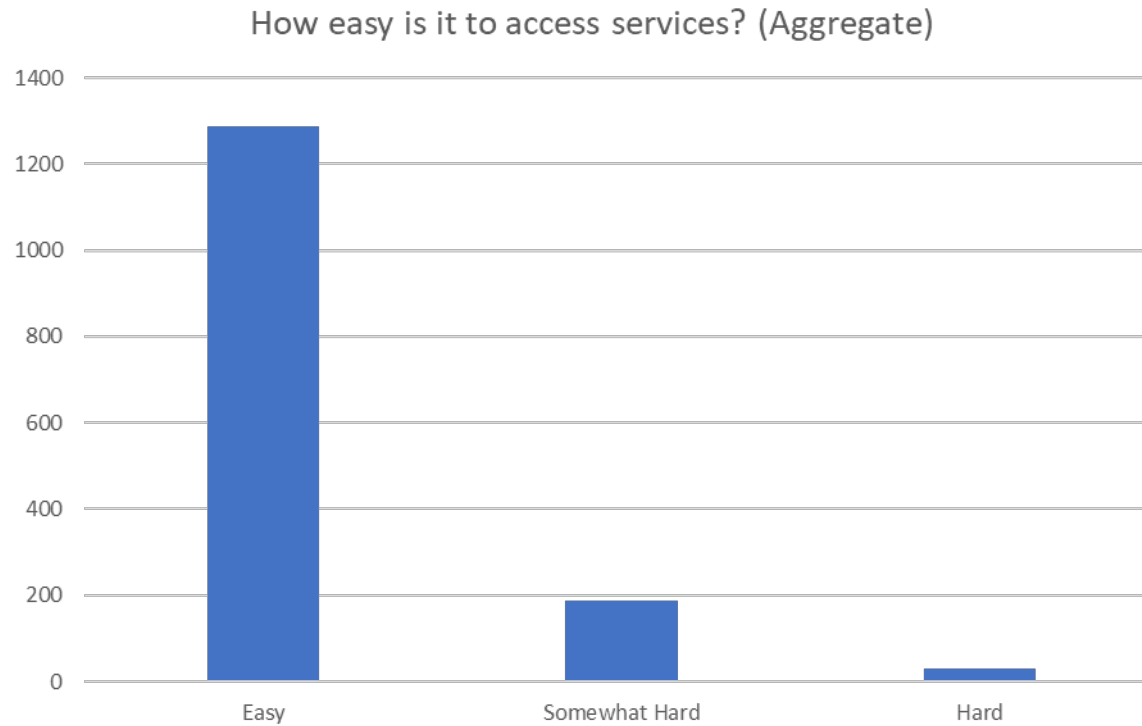
**Tight Integration with QM**

# How We Did It (cont....)

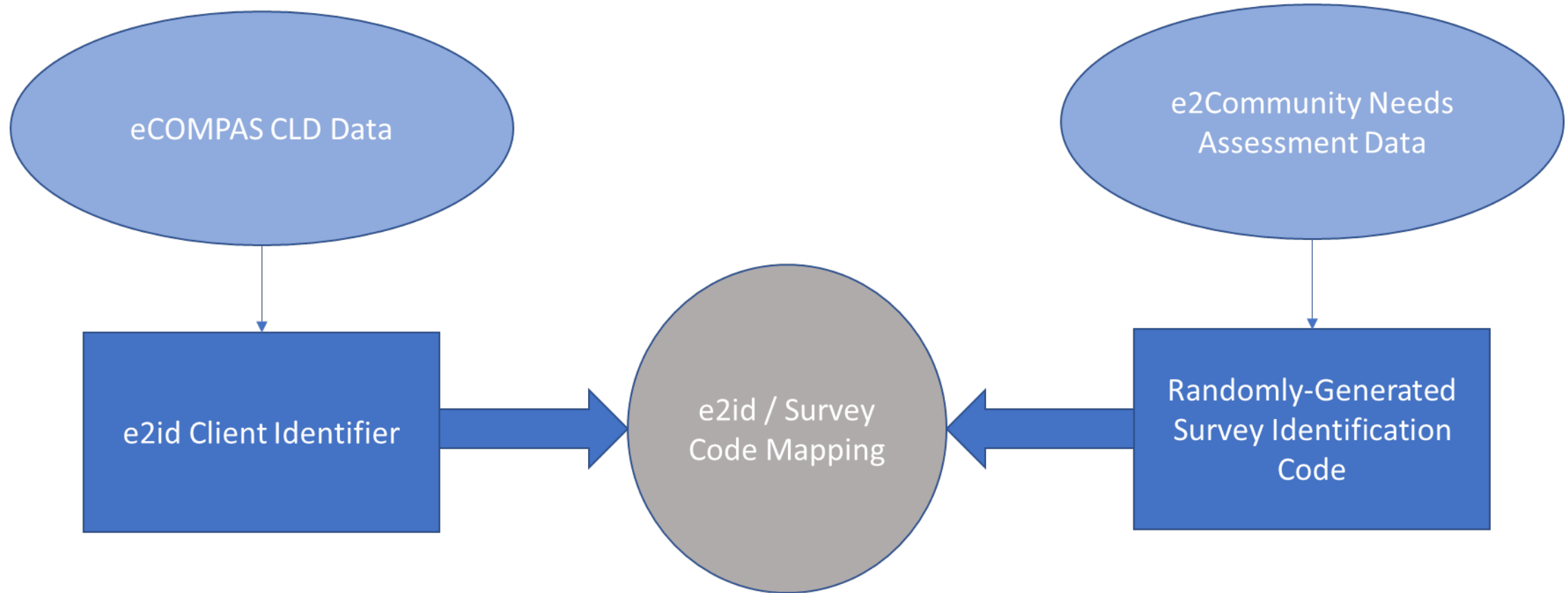


- Make sure your client base's service needs are met.
- 15+ years of working with digital client satisfaction & needs assessment data simplifies this process.
- According to 2016 needs assessment, majority of PLWHA in the TGA can easily get services that they need.

# How We Did It (Cont...)



# How We Did It – Record Linkage

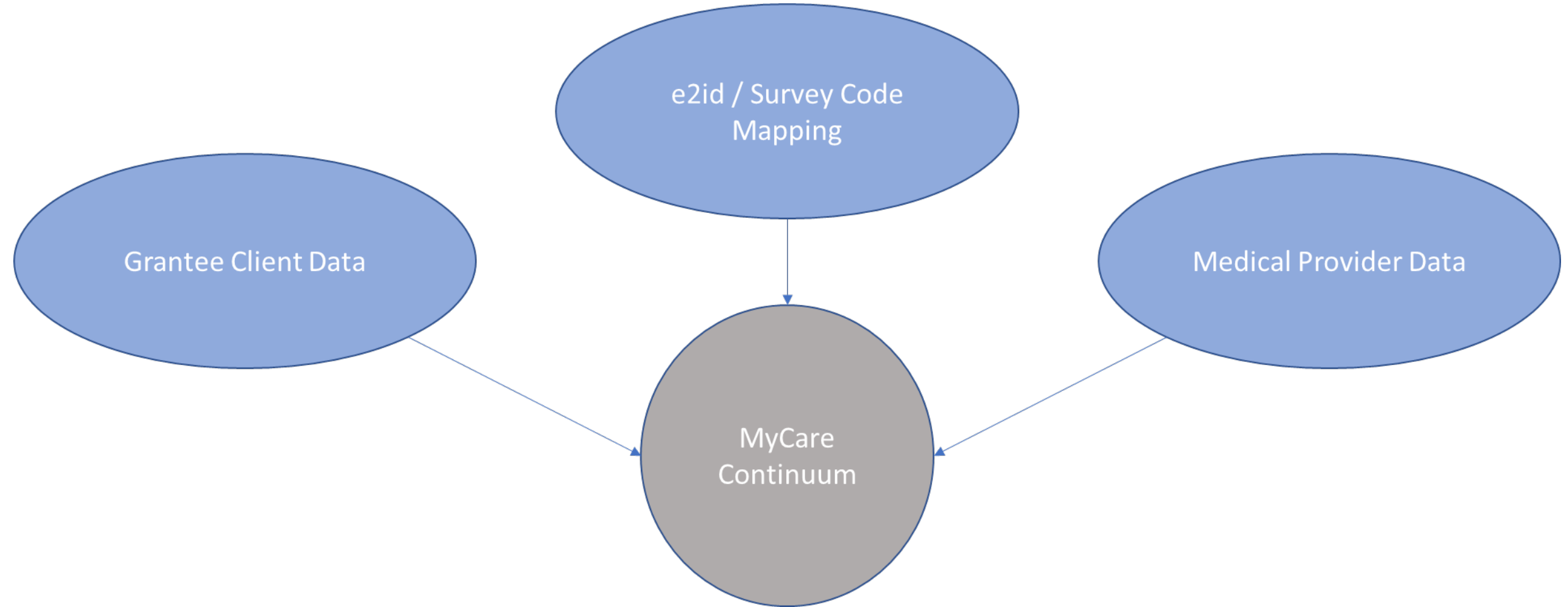


# How We Did It – Record Linkage (cont...)



- CD4 values
- Viral load counts
- Services received
  - Medications
  - Screenings
- Medical Care

# How We Did It – MyCareContinuum





# Bergen Passaic e2MyHealth



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2020 NATIONAL  
RYAN WHITE  
CONFERENCE ON  
HIV CARE & TREATMENT

e2MyHealth Bergen Passaic

Email Address Password Log in Register Forgot your password?

THIS IS AN RDE DEMO SITE. DO NOT INCLUDE ANY PERSONAL HEALTH INFORMATION IN THIS SITE. USE ONLY DUMMY DATA.

Your Health. Simplified.

A photograph of three runners (two men and one woman) running along a grassy cliff edge overlooking the ocean at sunset. The runners are in silhouette against the bright sky and water.

This is a secured web connection. All data is protected by the highest level of Internet encryption (SSL).

eCOMPAS © 2017 RDE Systems, LLC. All rights reserved.

# Features of e2MyHealth



- Easy and secure login
- Care team information displayed
- Upcoming appointment reminders
- View medical and lab results
- View prescribed medications
- Ability for consumers to grant secure temporary access to others
- Audit Log
- Integration with MedLine Plus for plain English explanations
- Mobile / tablet and cross-browser compatible



e2MyHealth
Care Information
Access Management
Help
My Account
Sign Out
18 : 45

---

General
Labs
Services
Satisfaction Survey

### Satisfaction Survey

A satisfaction survey is awaiting your response. [Click here to answer it.](#)

### My Care Team

<b>Case Manager (Non-Medical)</b>	None	<b>HIV Specialty Care</b>	
<b>Case Manager (Medical)</b>	None	<b>Clinic Last Serviced</b>	ABCD Healthcare
<b>Private Doctor</b>	None		

### Demographics

<b>Name</b>	J*** S***	<b>HRSA Insurance Category</b>	
<b>e2MyHealth ID</b>	JCLHV4A6	<b>Primary Insurance</b>	
<b>Ethnicity</b>	Non-Hispanic	<b>Payment Source</b>	
<b>Race</b>	White		

### HIV & AIDS

<b>Most Recent CD4</b>	350	11/05/2019	<b>HIV Status</b>	HIV Positive, AIDS Status Unknown
<b>Lowest CD4</b>	350	11/05/2019	<b>HIV Year of Diagnosis</b>	2007
<b>Most Recent Viral Load</b>	255	11/05/2019	<b>AIDS Year of Diagnosis</b>	0
<b>Highest Viral Load</b>	255	11/05/2019	<b>Transmission Mode</b>	

General Labs Services Satisfaction Survey

### Satisfaction Survey

1.) Please tell us how satisfied you were with the SUBSTANCE ABUSE TREATMENT AND COUNSELING services you received.

Very satisfied

Satisfied

Neutral

Unsatisfied

Very unsatisfied

2.) Are there any services that **YOU NEEDED** and were unable to get?

3.) Overall, how satisfied are you with the Ryan White Part A Program?

Very satisfied

Satisfied

Neutral

Unsatisfied

Very unsatisfied

General Labs Services Satisfaction Survey

## Satisfaction Survey

1.) Please tell us how satisfied you were with the staff during your service visit.



# CSS Survey – Future Vision (cont..)

General Labs Services Satisfaction Survey

## Satisfaction Survey

1.) Please tell us how satisfied you were with the staff during your service visit.



2.) Would you like to leave a compliment for a staff member?

Submit

# CSS Survey Client Emails



Hello,

You have been invited to participate in the Client Satisfaction Survey because you have recently received the following services from your Ryan White Part A provider:

- Case Management Community
- Treatment Adherence
- Non-Medical Case Management

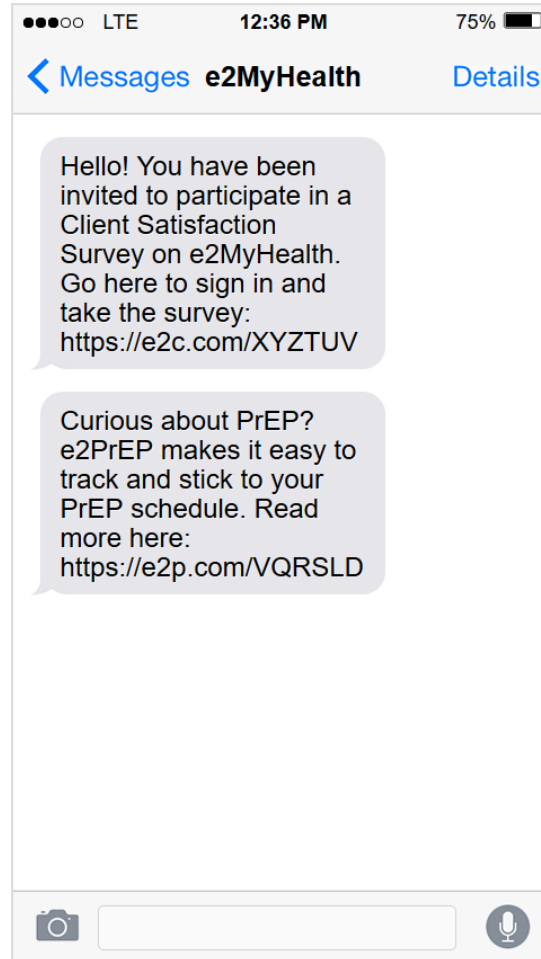
Please complete the survey by following the link below and logging into your My Health Profile account. The survey will only take about 5 minutes to complete and all survey responses are confidential.

[Go to My Health Profile →](#)

If you have any questions, please email [support@e-compas.com](mailto:support@e-compas.com) and we will be happy to help.

— The eCOMPAS Team at RDE Systems.

# CSS Survey – Future Vision (cont...)





# Future Vision – Geospatial Visual Analytics

e2community - Needs Assessment Survey

Main Reports Help 19 : 59

## Visual Demographics Report

### 1. Select Reporting Period

Start: 01/01/2020 End: 06/01/2020

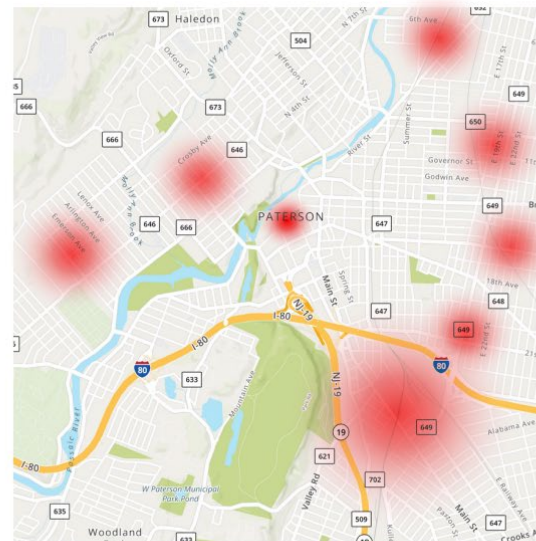
### 2. Custom Filters

Question: 20 0. Have you ever experienced homelessness? (St Answer: Yes

Add New Filter

Run Report

## Results



# Future Planning – Using Assessment Data



- Goal: Bridge gaps of knowledge about client base.
- Problem: Current data shows that majority of new clients in TGA were not diagnosed there. It is unknown where they came from.
- Solution: Add place of diagnosis as a needs assessment question for the next survey wave.

# Future Planning – Using Assessment Data (cont.)



- Goal: Identify and better serve populations of need.
- Focus: The needs assessment helped identify three populations of need across the PLWHA in the TGA: African American females, heterosexual Hispanic males, and gay/bi-sexual male youth.
- Plan: Further study and planning is needed to address these issues.

# Future Planning



- Further integration of digital needs assessment tool e2Community with eCOMPAS CLD platform and MyCareContinuum.
- Outreach to and study of identified under-served populations.
- Using MyCareContinuum to identify under-served populations.

# Future Planning (cont.)



- Continue using an integrated, collaborative process to study needs assessment data, derive useful findings from said data, and plan for future needs assessment processes.
- Increase collaboration between:
  - Planning council
  - Providers
  - Consumers
  - Quality management team
  - Health policy experts

# Contact Us!



Milagros Izquierdo  
[mizquierdo@patersonnj.gov](mailto:mizquierdo@patersonnj.gov)

Jesse Thomas  
[Jesse@rde.org](mailto:Jesse@rde.org)

# Des Moines, Iowa

Katie Herting

Ryan White Quality Coordinator

Iowa Department of Public Health

# Des Moines, Iowa 2

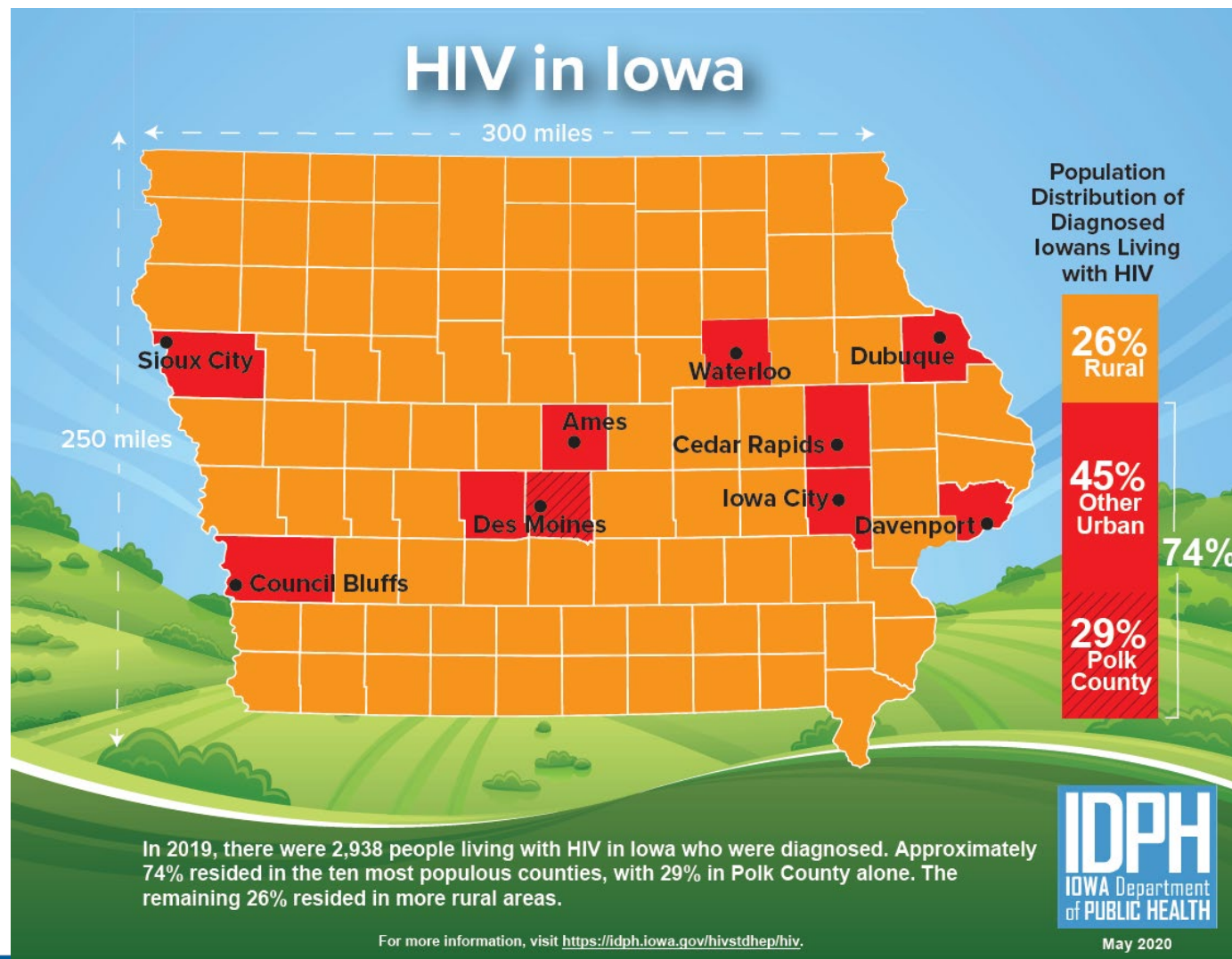


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HIV CARE & TREATMENT**





# HIV in Iowa



# Iowa CNA History



## 2005 – Paper survey

- Original survey developed
- Managed by program manager
- Hired consulting agency to enter raw data – took 4 weeks to receive
- Data analysis conducted in Excel by program staff

## 2011 – Paper and online survey

- Managed by temp
- Paper survey data entered into Survey Monkey (110 hours)
- Paper and online results displayed in Survey Monkey (separately)
- Other data analysis conducted in Excel by contractor

## 2019 – Online survey

- Managed by RDE Systems and Consumer Needs Assessment coordinator (hired through contractor)
- New CAREWare integration
- Added Prevention Needs Assessment for people not living with HIV or who do not know their HIV status

## 2008 – Paper survey

- Managed by intern/temp
- Hired consulting agency to enter raw data – took 4 weeks to receive
- Data analysis conducted in Excel by contractor

## 2016 – Online survey

- Managed by RDE Systems and long-term contract employee
- Data available in real-time
- Data analyses conducted by RDE Systems
- Other data analysis conducted by program staff

# Differences Between Paper and Online Surveys



## Data Collection & Analysis

	Paper Survey	Paper & Online Survey	Online Survey
Survey Distribution	Received surveys in the mail from participants	Received surveys in the mail from participants	Responses received in real time
Data Analysis	Hired staff to enter the data into Excel	Hired staff to enter the data into Survey Monkey	Data displayed online and available to review in real time
Report	No formal report	No formal report	Formal report published

# 2019 CNA Timeline



JULY

AUGUST

SEPTEMBER

OCTOBER

NOVEMBER

DECEMBER

CNA planning meeting with programmatic staff

8/16/2019: CNA & PNA specification complete

9/17/2019: Release of initial survey prototype

9/24/2019: Testing complete

10/1/2019: Survey opened

11/25/2019: Survey closed

# CAREWare Data Integration



- Imported data from CAREWare into the survey for clients who:
  - Were actively enrolled at an agency, and;
  - Had the required fields completed in CAREWare
- Eligible respondents were pre-determined prior to assigning Survey IDs
- Respondents were able to choose whether they wanted to link their CAREWare data to their survey responses
  - Either way, anonymity was maintained
- Eligible respondents were able to skip 12 questions in the survey
- Able to use data for crosstab analysis

# CAREWare Data Integration (cont.)



- **2,227** respondent records imported from CAREWare
- **500** completed surveys from imported records
  - Accounts for 90% of all completed surveys
- **48,994** total data points imported from CAREWare

# Outreach Strategy



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HIV CARE & TREATMENT



WE'D LOVE TO HEAR  
FROM YOU!

The Iowa HIV and Hepatitis C Community Planning Group and the Iowa Department of Public Health would like to invite you to participate in a **survey** to learn about how HIV has affected you, what your living circumstances are, and what services you may need. The information we collect will help provide better care and prevention services for people living with HIV in Iowa.

**Your responses are CONFIDENTIAL!**

We will ask personal questions about your background so that we can better understand the current concerns and issues you may be facing. Your name will **never** be linked to your answers.

As a thank you for completing the survey, we would like to give you a **\$25 gift card** to HyVee or Walmart. Surveys are coded to protect your confidentiality and so you can confidentially receive your gift card upon completion of the survey.

**Your assigned Survey ID is:**

**AC983759**



*Do not lose your Survey ID! You will need it to complete the survey and receive your gift card.*

For more information, or to take the survey, go to: <http://iowa.e2community.com>

**We appreciate your time! Thank you!**

# Survey Completion

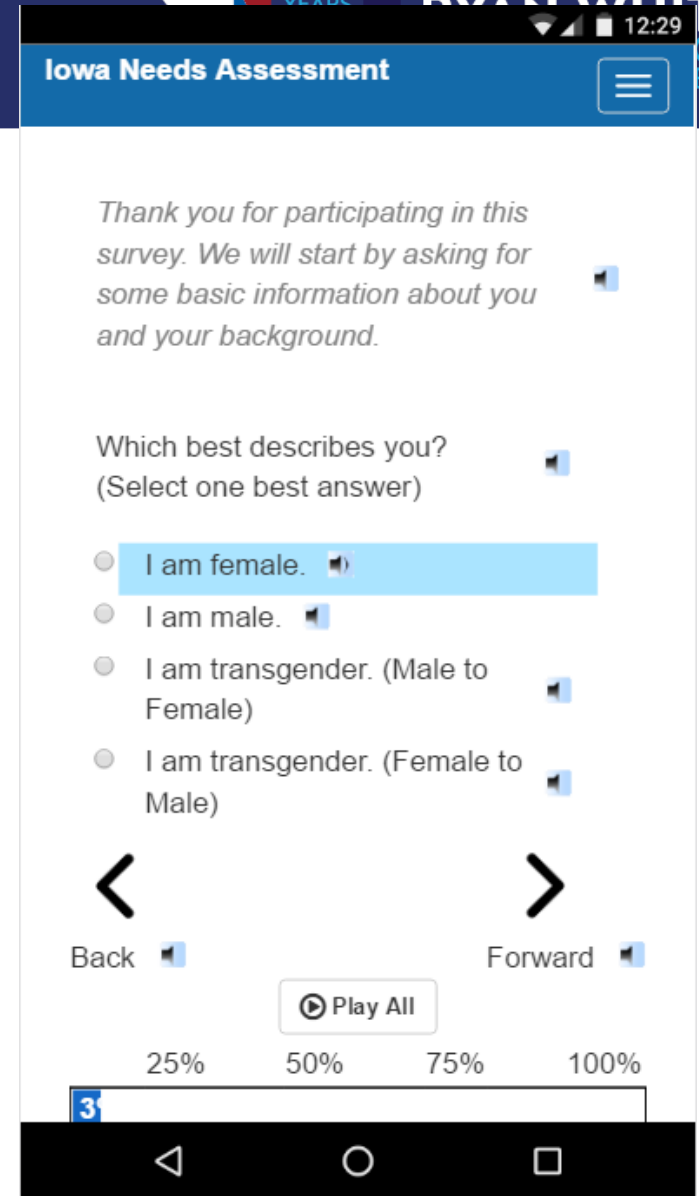


- Respondents were able to complete the survey:
  - At their Ryan White agency using agency computers or tablets
  - On their own devices, including smartphones
  - Over the phone with the Consumer Needs Assessment Coordinator
- Survey took 20-30 minutes to complete
- Up to 83 questions (survey included skip logic)
- Goal of 500 respondents
  - Met goal after 4 weeks



# Using RDE Systems

- Survey accessibility features:
  - Mobile and tablet compatibility
  - Multi-language compatibility
  - Audio playback for all text
  - Fully translatable
  - Survey progress saving
- Real time data analysis
  - Able to see results in real time and track trends



# Incentive Module



- Respondents received a \$25 gift card
- Clients eligible to link CAREWare data to their survey were also eligible to pick up their gift card at their Ryan White agency
  - Otherwise, gift cards were mailed to respondents
    - Required respondents to provide a mailing address, names were optional
    - Confidential client info kept secure using LKM encryption technology
- Case Managers had access to the Incentive Module online to mark gift cards as distributed

# Incentive Management – The *OLD* Way



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Upon completing survey, respondent receives unique incentive code

Respondent contacts staff at IDPH & provides their survey ID and incentive code

IDPH staff confirms respondent completed survey using survey ID

Respondent provides name and mailing address to IDPH staff

IDPH staff mails gift card to respondent

# Incentive Management – The *NEW* Way



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CONFERENCE ON  
HIV CARE & TREATMENT

Upon completing survey, respondent indicates how they would like to receive their gift card

IDPH or agency staff confirm respondent completed survey in the Incentive Module

IDPH staff mails gift card to respondent OR agency staff provides gift card on site

# Thank You Cards



**Thank you** for completing the 2019 Consumer Needs Assessment. The information provided will help develop better care and prevention services for people living with HIV in Iowa.

**Please enjoy your \$25 gift card!**

The gift card you received is based on your specified preference and the gift cards in stock.

**Thank you,**  
**Annie Rodruck**  
**Consumer Needs Assessment Coordinator**

- Start early - Know that the process will probably take much longer than you anticipate
  - Factor contract procurement into timetable
- Early in the process:
  - Consider modifications needed to translate a paper survey to an online tool
  - Identify staff capacity for data analysis
- Review real-time analytics to adjust population outreach effort

# Conclusions about Online Survey



- Maximized staff time and efficiency
- Reduced potential for human error
- Reduced burden for clients
- Allowed for:
  - Real-time analysis of data
  - Greater in-depth analysis of data
  - Faster dissemination of data

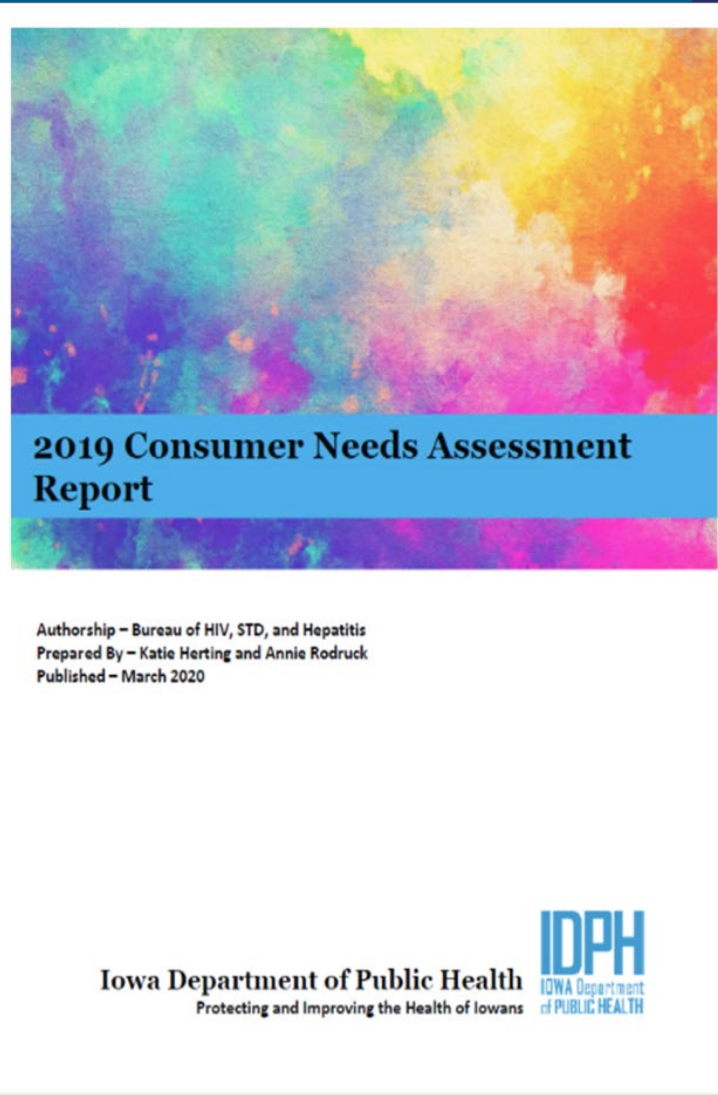
- Survey sections:
  - Demographics
  - Perceived impact of racism
  - Housing & homelessness
  - Incarceration
  - Transportation
  - Alcohol and substance use
  - Serious mental illness
  - Intimate partner violence
  - HIV stigma
  - Service gaps and needs
  - Medical care
  - Interest in new HIV injectable medication
  - STIs
  - Hepatitis C
  - Sexual partners and practices
  - Adverse childhood experiences
  - Resilience
  - Brand awareness



# CNA Report



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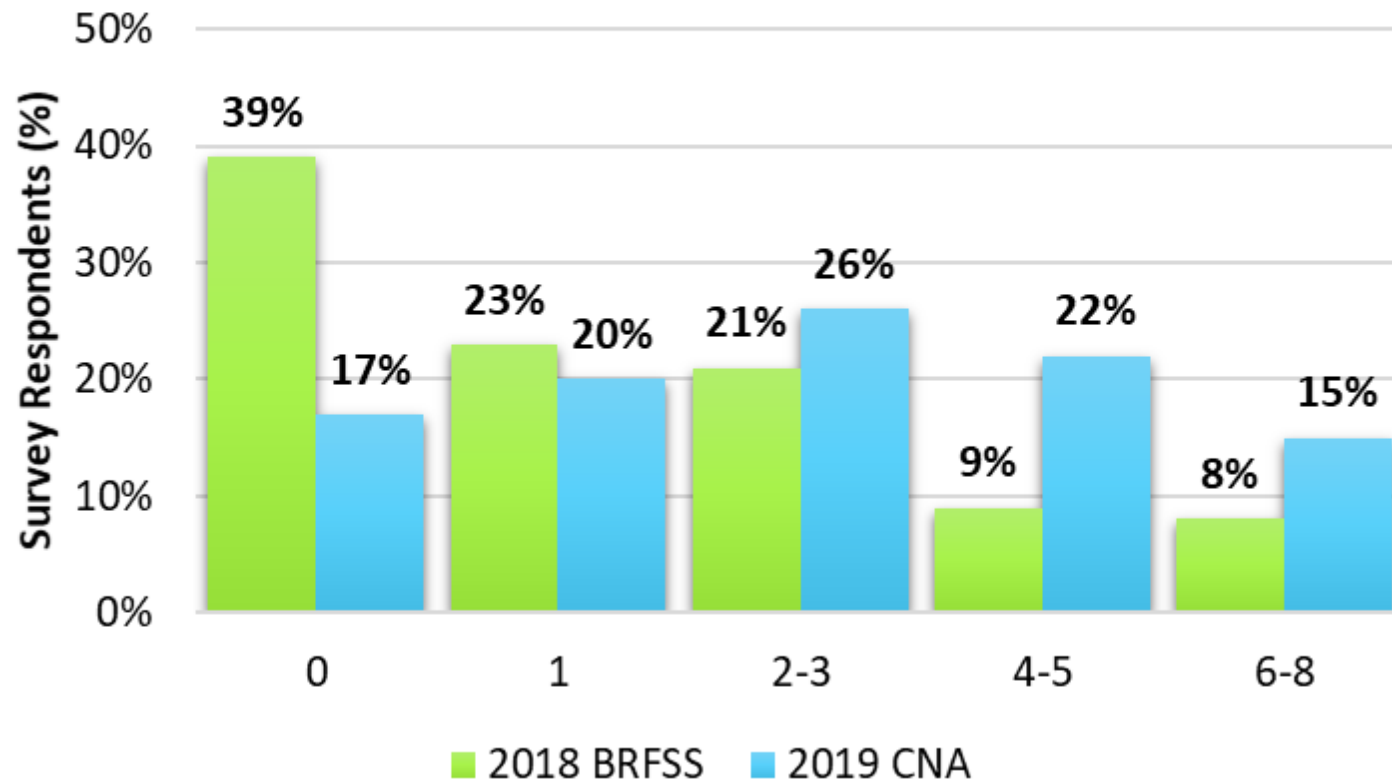


# Content of Report



# Adverse Childhood Experiences (ACEs)

ACE Scores Among 2018 BRFSS (n=9,127) and 2019 CNA (n=555) Respondents

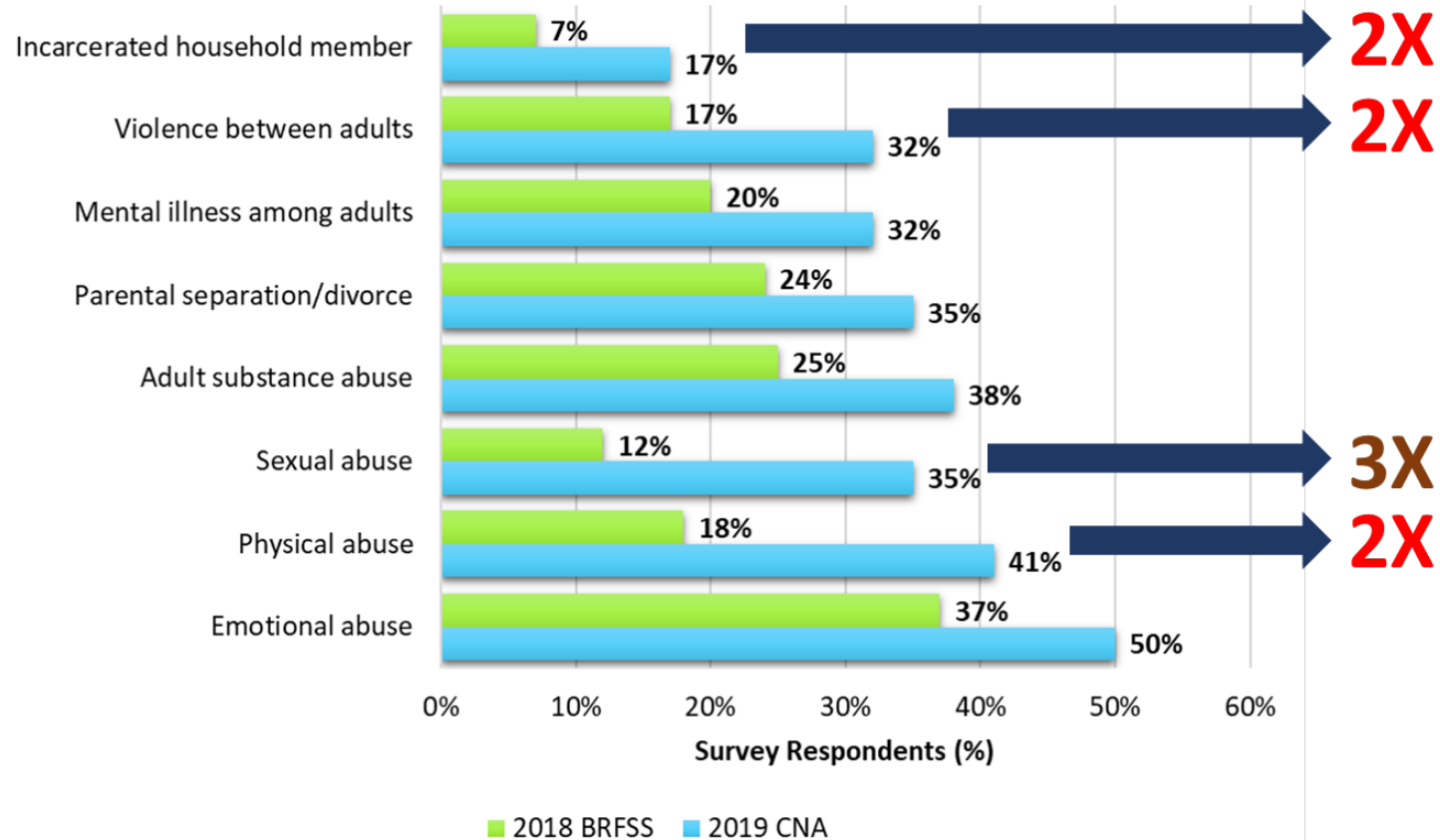


BRFSS = Iowa Behavioral Risk Factor Surveillance System

# Adverse Childhood Experiences (ACEs) (Cont...)



ACEs Experienced by 2018 BRFSS (n=9,127) and 2019 CNA (n=555) Respondents



# Prevention Needs Assessment (PNA)



- Similar to the CNA but for people not living with HIV, or who do not know their HIV status
- Evaluated HIV, STI and Hepatitis C testing and treatment (when applicable), along with PrEP, nPEP, and condom use
- Used the same RDE platform to deploy survey and track incentives

# Prevention Needs Assessment (PNA) (Cont...)







- **572** completed surveys
- Ability to direct respondents to proper survey based on survey ID and response to initial question


# Prevention Needs Assessment (PNA) (Cont..)




Thank you for participating in this survey. The first section asks for some basic information about you and your background. 

Are you living with HIV? (Select one best answer) 

- Yes 
- No, I am not living with HIV 
- I don't know if I am living with HIV 

Back 




Next 


Turn On Autoplay Play All




Prevention Needs Assessment. All responses are confidential.

# Prevention Needs Assessment (PNA) (cont....)



Thank you for participating in this survey. The first section asks for some basic information about you and your background. 

You were assigned a survey for people who are unsure of their HIV status or are HIV-negative, but you selected that you are HIV-positive. Please confirm your HIV status below to continue to the survey: 

- I am living with HIV 
- I am HIV-negative 
- I don't know my HIV status 

Back 

2%

Next 

Turn On Autoplay

Play All

Prevention Needs Assessment. All responses are confidential.



# PNA Marketing Materials



The Iowa HIV and Hepatitis C Community Planning Group and the Iowa Department of Public Health would like to invite you to participate in a **survey** to learn about your HIV and STD prevention services. The information that we collect will help provide better HIV and STD prevention services in Iowa. **Your responses are CONFIDENTIAL! Your name will never be linked to your answers.**

We will ask personal questions about your background so that we can better understand the current concerns and issues you may be facing.

As a thank you for completing the survey, we would like to give you a **\$25 dollar gift card**. Surveys are coded to protect your confidentiality, and so you can receive your gift card after taking the survey.

**Your assigned Survey ID is:**

*Do not lose your Survey ID! You will need it to complete the survey and receive your gift card.*

For more information, or to take the survey go to: <http://iowa.a2:community.com>

**For Questions or assistance, please contact:**

Annie Rodruck  
Consumer Needs Assessment Coordinator  
515-204-8773





# Future Vision



- Increased utilization of client data import
  - Service information
  - Increased availability of medical data
  - Increased survey instrument response pre-population
- Management of automatic electronic incentive distribution through the platform
- Client satisfaction survey

# Thank You!

Katie Herting  
[Katie.Herting@idph.iowa.gov](mailto:Katie.Herting@idph.iowa.gov)

Jesse Thomas  
[Jesse@rde.org](mailto:Jesse@rde.org)

## Dallas County, Texas



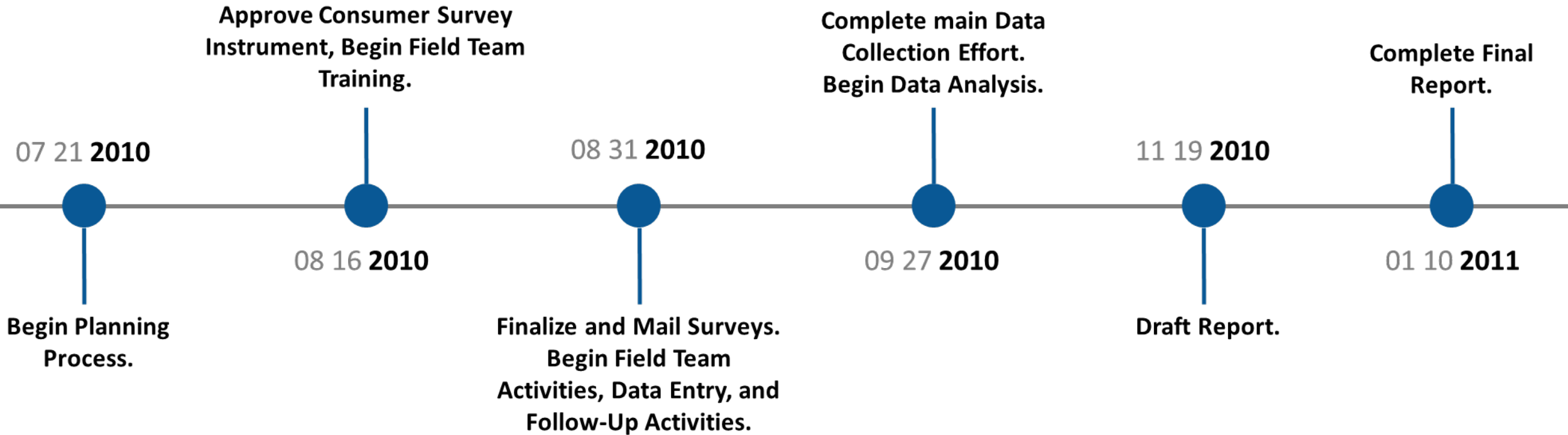
# Introduction, Dallas



Justin Henry, Health Planner, Ryan White Planning Council Dallas, TX

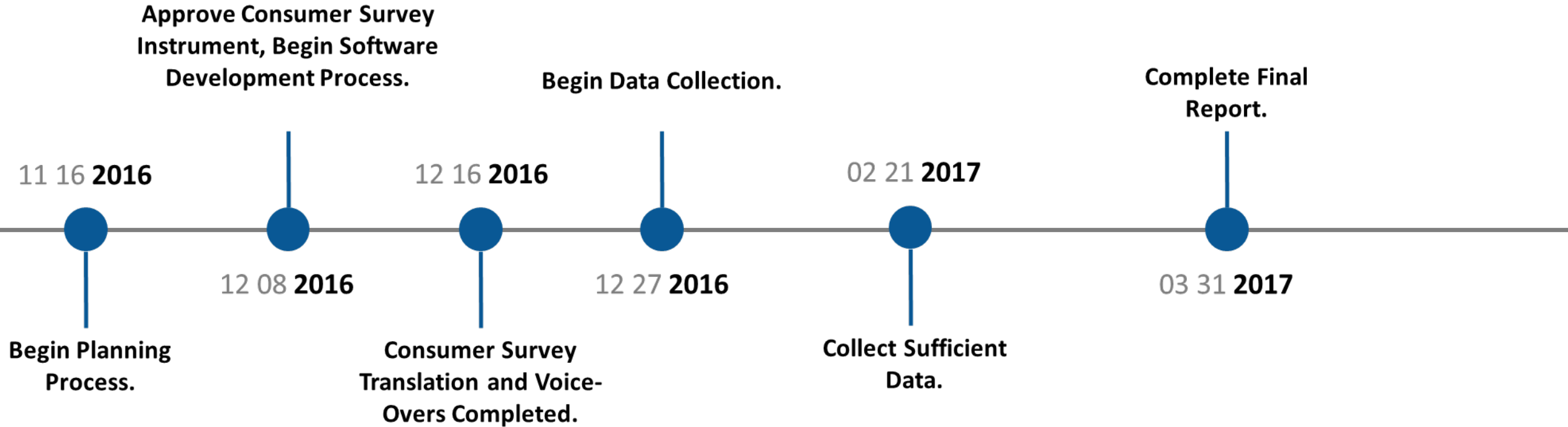
## 2010 Paper-Based Survey vs. 2016 Digital Survey

# Timeline – Paper-Based Process (2010)

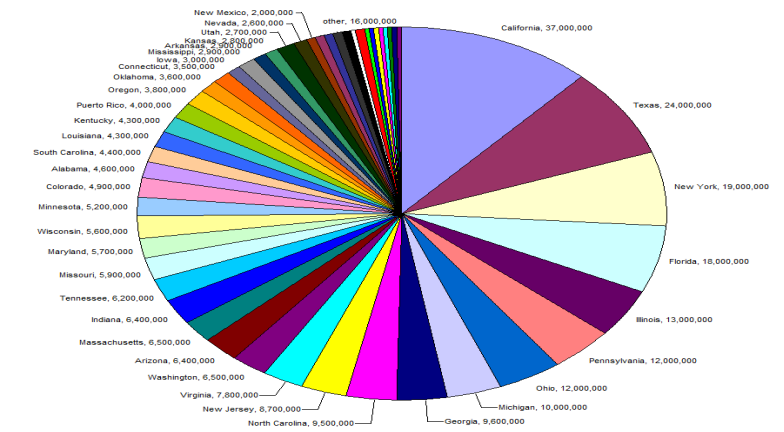
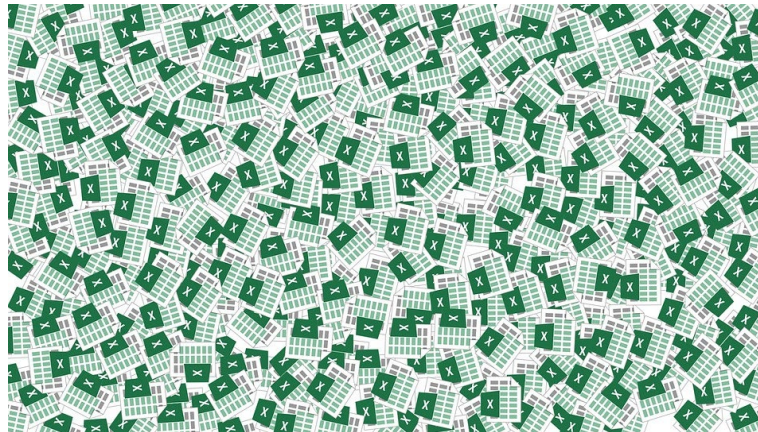




# Timeline – Digital Process (2016)



# Additional Work



# Time Savings from Digital Process



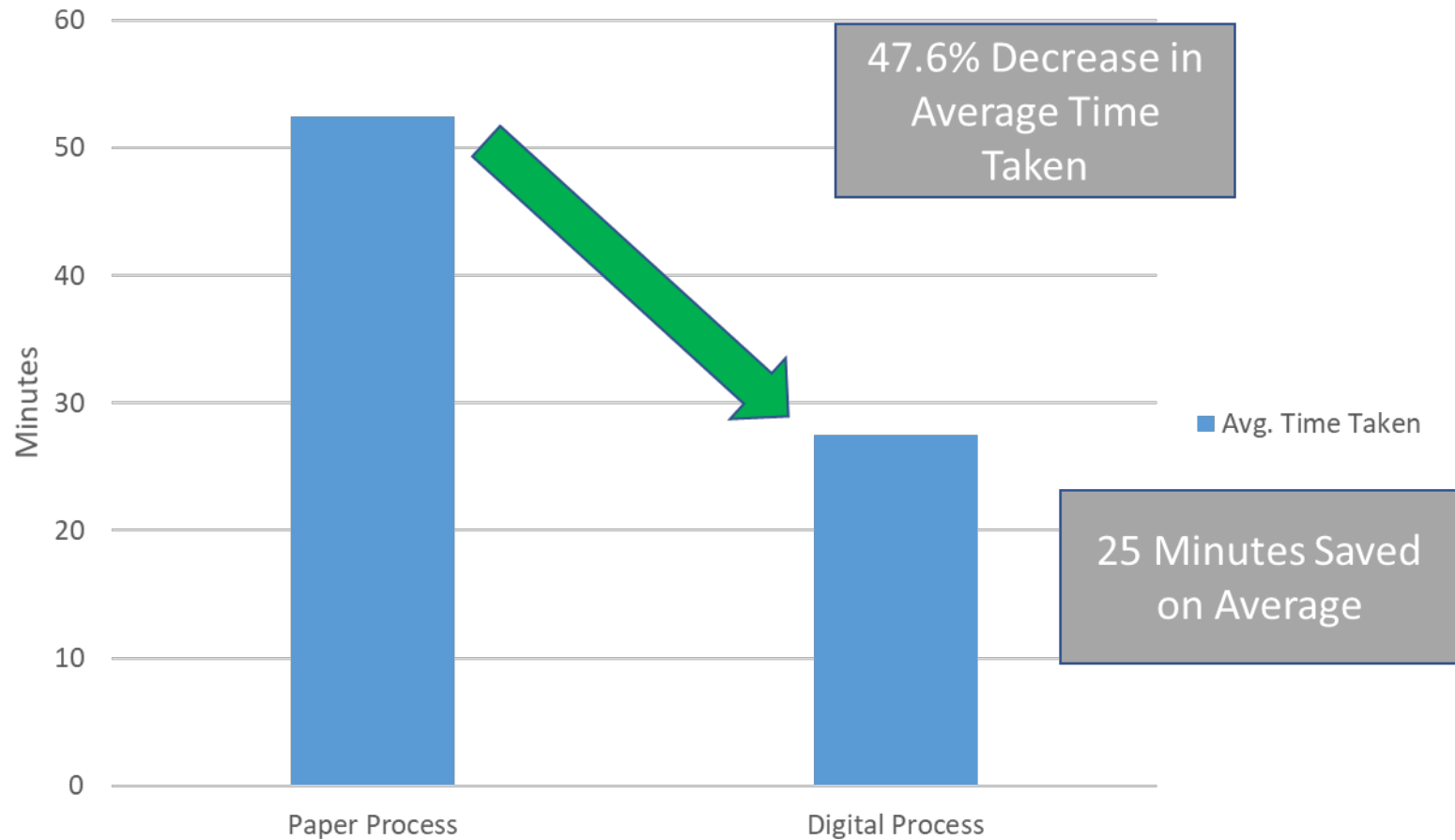
- Total time savings in 2016: 38 days
- Time savings from report writing: 67 days

- Voice assistance utilization- 69% of Completed Surveys
- Usage on mobile device- 35% usage on mobile device

# Consumer Time Savings from Digital Process



Time to Complete Survey: Paper vs. Digital



# 2016 Needs Assessment



On the 2016 Needs Assessment:

*“We did this down to the hour, it wouldn’t have been possible without New Solutions and RDE Systems.”*

# Goal Reached



Goal reached, over **600** complete surveys collected!

# Lesson Learned – Organization & Communications



- Make sure all promotion and advertising material is correct.
- Make sure that question language is tailored to the expected literacy level of population and that all translations are correct.
- Questions written to target a specific special population should be written in language that is common and acceptable to that population.
- Make sure that survey instrument is well-tested against general population and each targeted special population.



# Lesson Learned – Cont.



- Don't try to do too much in a short timeframe!
- Needs assessment is an outreach opportunity.
- Additionally, needs assessment helps the planning council reach out to clients who have fallen out-of-care.
- Leverage the knowledge of experienced partners like New Solutions, Inc. and RDE Systems.
- Use a low-literacy, mobile-friendly platform to help collect data from low-literacy populations with limited access to technological resources.

# 2019 Digital Survey Results & Findings

# Key Statistics Related to Access

<b>Racial and Ethnic Distribution</b>	Dallas County is less than 50% White Non-Hispanic. Other counties in the EMA - percent of White Non-Hispanic residents range from 52.4% (Collin) to 81.2% (Fannin).
<b>Age Distribution</b>	Dallas County, where the majority of People Living With HIV/AIDS (PLWHA) reside, is the only county where more than half of residents are age 34 or younger.
<b>Income Disparities</b>	The percent of people living in poverty ranged from 5.0% to 21.1%. The lowest poverty rates were in Rockwall, Collin, Denton, and Ellis Counties and the highest were in Henderson, Dallas, Kaufman, and Hunt Counties.
<b>Lack of Health Insurance</b>	The % individuals with no health insurance ranged from 11.1% in Denton County to 21.7% in Dallas County. The percent in all counties were higher than the U.S. average of 8.9%.
<b>Education Disparities</b>	Education level across counties varied from 5.7% of individuals in Rockwall County with less than a high school education to 20.3% in Dallas County.
<b>Transportation Access</b>	Between 1.3% (Rockwall County) and 7.0% (Hunt and Kaufman Counties) of households did not have access to a vehicle.
<b>Language Barriers</b>	The percent of people who speak English less than very well ranged from 2.8% (Collin County) to 19.7% (Dallas County).
<b>Internet Access</b>	The percent of households with Broadband Internet ranged from 70.8% in Grayson County to 96.1% in Rockwall County.

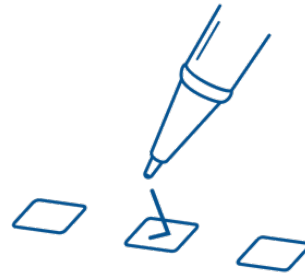
# Quantitative and Qualitative Data Collected



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**Quantitative  
epidemiologic and  
demographic data**



**Consumer survey  
392 PLWHA**



**Key informant  
interviews  
20 HIV service  
providers**

# Quantitative and Qualitative Data Collected (cont.)



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**12 consumer  
focus groups**



**RW HIV services  
provider survey  
7 of 9 providers**

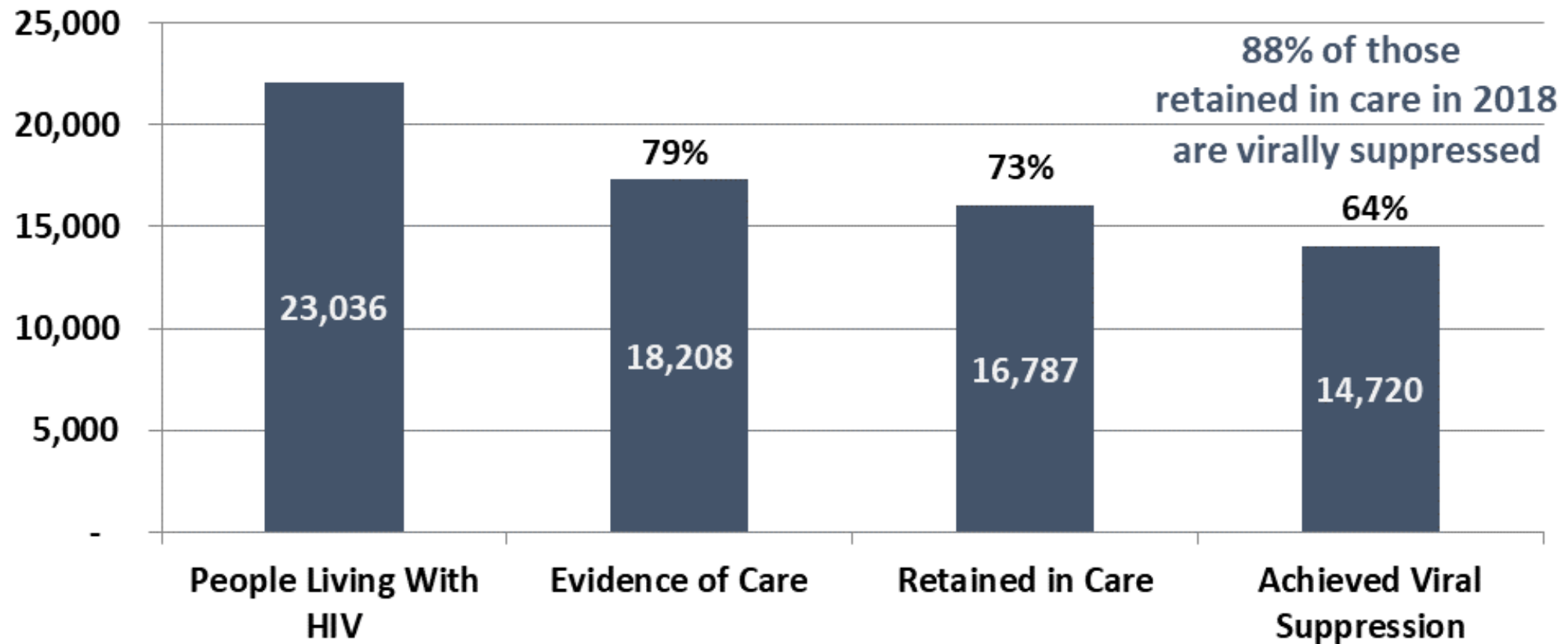


**Telephone surveys  
20 other providers**

# The HIV Care Continuum - 2018



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2020 NATIONAL  
RYAN WHITE  
CONFERENCE ON  
HIV CARE & TREATMENT



# Services Needed That Are Not Available



Medication  
Access

Affordable  
Adequate  
Housing



Transportation

Co-Pay and  
Insurance  
Assistance



# Services Needed to Improve Health and/or Access for PLWHA



**Job Training  
Job Recruitment**



**HIV Outpatient  
Centers and  
Locations – Rural  
Areas**



**Nutrition  
Resources**



**Substance  
Misuse  
Treatment**



**Mental Health**



# Services Available That Need a Different Approach or Location



**Mental Health**



**Substance  
Misuse  
Treatment**



**Part A Funding**



**Support Services  
Accessible via  
Computer/Internet**

# 2019 Dallas County RW Needs Assessment



The 2019 Dallas County Ryan White Needs Assessment Consumer Survey results identified multiple barriers to HIV care at the structural and systems, socio-economic, interpersonal, and individual levels.

## 21 Organizations serving PLWHA in the Dallas EMA

- 8 provide medical transportation support
- 6 provide language translation/interpretation
- 6 provide health education programs
- 1 provides rental assistance for long-term housing

# Structural and Systems Barriers (cont)



## Reported Barriers were:

- Time it takes to get to get an appointment or get care
- Amount of paperwork required
- Lack of weekend/evening hours
- Clinic treats only HIV and not other medical conditions
- Staff does not understand culture or language
- Past discriminatory experiences in healthcare
- Issues related to matching identification or immigration status

# Black MSM



**Peer navigation for newly diagnosed**



**Cross-generational mentorship**



**Risk reduction and prevention education**



**Tailored awareness campaigns targeting stigma and available services**



**Address paperwork burden, case management, and negative provider interactions**

# Cisgender Black Women



**Peer navigation for newly diagnosed**



**Risk reduction and prevention education**



**Increased services for mental health and  
cardiometabolic health**



**Tailored awareness campaigns targeting  
stigma, available services, medical options**



**Address housing, transportation, paperwork  
burden, negative provider interactions,  
provider education**

**Peer navigation for newly diagnosed**



**Risk reduction and prevention education**



**Increased services for cardiometabolic health**

**Tailored awareness campaigns targeting stigma, available services,**



**Address availability of Spanish-speaking staff, discrimination based on race, language and immigration status, housing and housing instability**



**Increased visibility and inclusion of Latinx, especially cisgender women**

# Transgender

**Peer navigation for newly diagnosed**

**Tailored risk reduction and prevention for pre- and post-operative transwomen, men, and non-conforming individuals, youth, and seniors**

**Increased visibility and inclusion of transwomen of color**

**Need for trans-inclusive and properly trained providers and HIV service agencies**

**Tailored awareness campaigns/interventions to reduce stigma**

**Address structural violence, affordable housing, transportation, negative provider experiences, and systemic exclusion of transpeople from medication trials**



# Youth / Millennials

**Cross-generational mentorship and navigation support**

**Risk reduction and prevention education**

**Tailored awareness campaigns targeting stigma among young people and families, availability of services, and safe sex practices**

**Increased youth-centered services and safe social environments**

**Systems issues related to provider education and training to care for youth with HIV, sex education in school systems**

# Seniors



**Increased services for specialty care for comorbidities, long-term housing, and transportation**

**Provider education/training caring for aging people living with HIV**

**Cross-generational mentorship and navigation support**

**Risk reduction and prevention education**

**More outreach for seniors who are homeless or transgender**

# Final Considerations

Focus efforts on increasing awareness of services, using peer navigation/mentorship models

**Address systemic challenges related to housing, transportation, and paperwork burden**

Education, health and prevention programs must be tailored to be socio-culturally and linguistically appropriate for the diverse consumer population

**Systematically enhance visibility and voice of Black and Latina heterosexual women, Black and Latinx trans men, youth.**

**Increased capacity for specialty care for transpeople and seniors, including post-operative trans seniors**

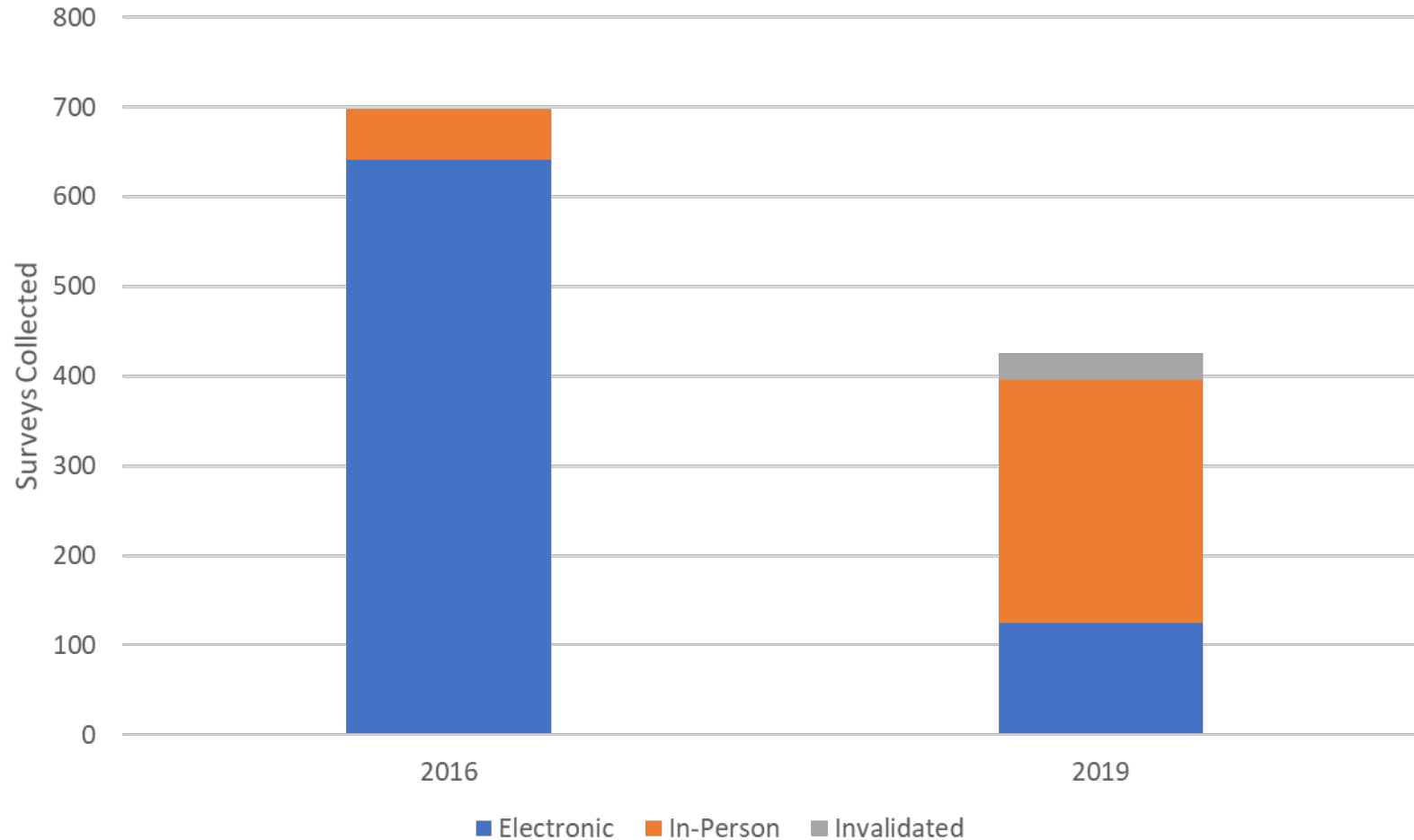
# Timeline – Digital Process (2019) (cont..)



# Comparison between 2016 & 2019 Digital Survey Waves



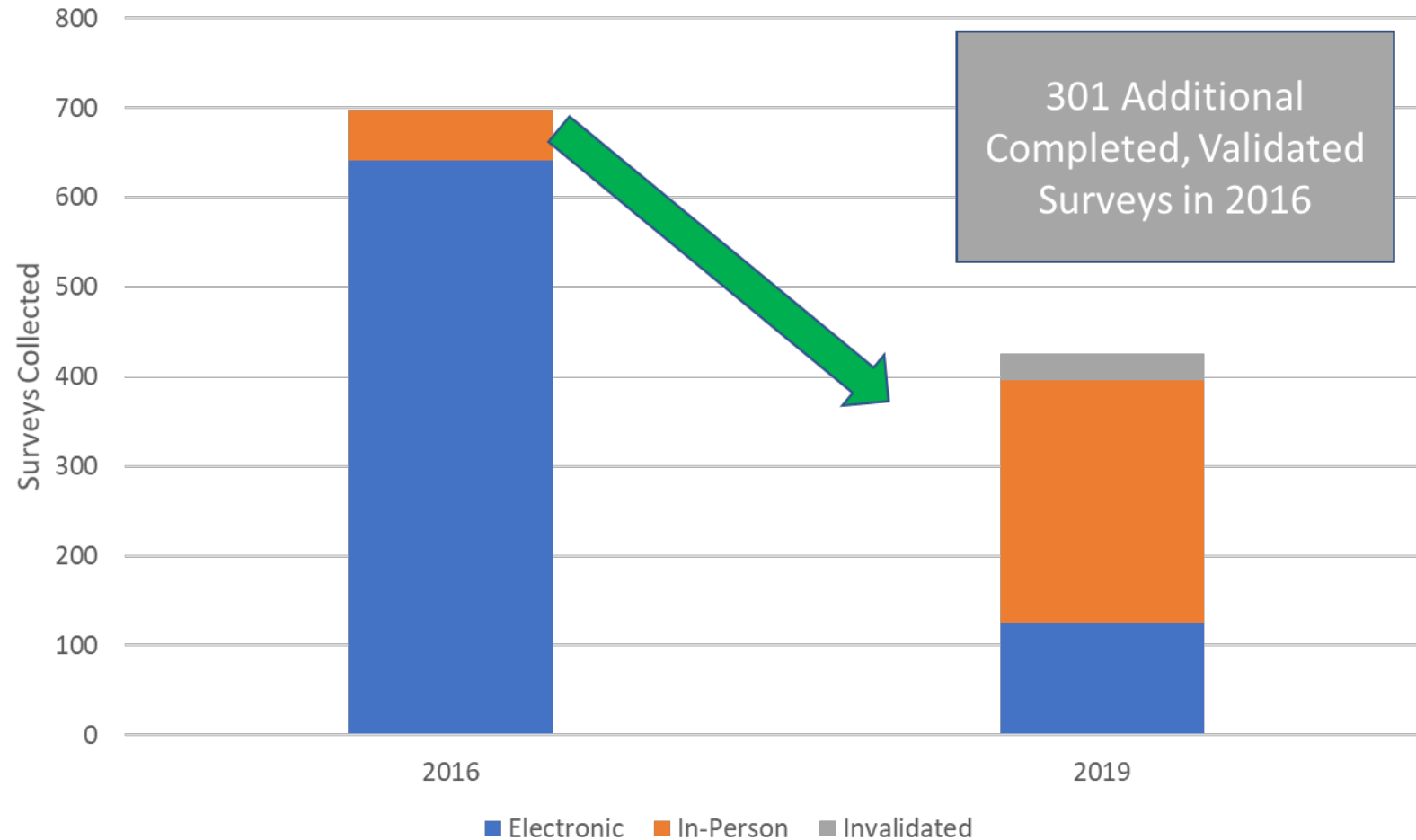
Total Validated Surveys per Wave



# Comparison between 2016 & 2019 Digital Survey Waves (pt 2)



Total Validated Surveys per Wave



# Lessons Learned!



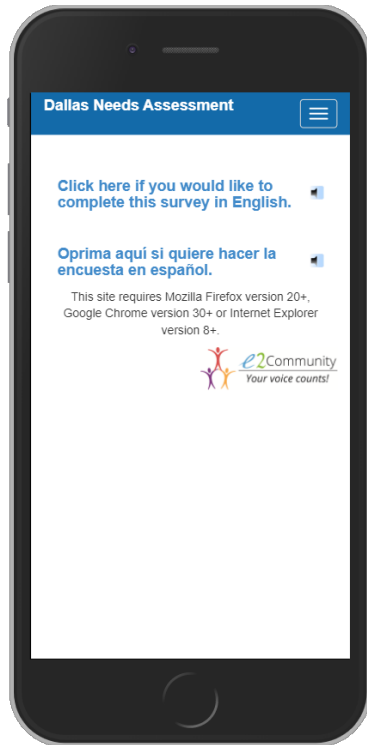
- In 2019 we fell short of our quantitative data collection goal, but exceeded it in 2016.
- One potential difference: our digital assessment tool.

# 2016 & 2019 Comparison – Spanish Language Accessibility



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## 2016



## 2019



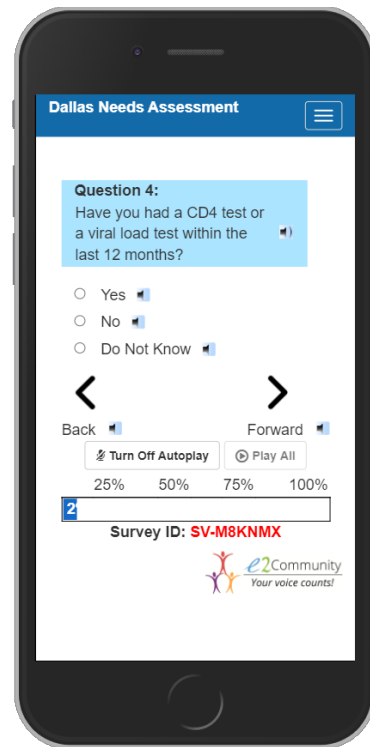


# 2016 & 2019 Comparison – Low-Literacy Accessibility



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## 2016



## 2019



# 2016 & 2019 Comparison – Reporting and Data Aggregation



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## 2016

4. Have you had a CD4 test or a viral load test within the last 12 months?



Answer	Count	Percentage
1. Yes	571	89.08%
2. No	64	9.98%
3. Do Not Know	6	0.94%
<b>Total:</b>	<b>641</b>	

## 2019



# 2019 Mobile Accessibility



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# 2016 & 2019 Comparison – Resuming an Unfinished Survey

2016



2019



# Lessons Learned..



- In 2016 we used e2, a specialty tool designed specifically for assessing the needs of Ryan White clients, low-literacy populations, and related cohorts.
- In 2019 we used a general-purpose surveying tool which lacks features tailored to our target audience.
- Features we valued in the e2 tool:
  - Low-literacy audio assistance
  - Mobile accessibility, ease of access & use for respondents
  - Reporting capabilities
  - Incentive automation & tracking

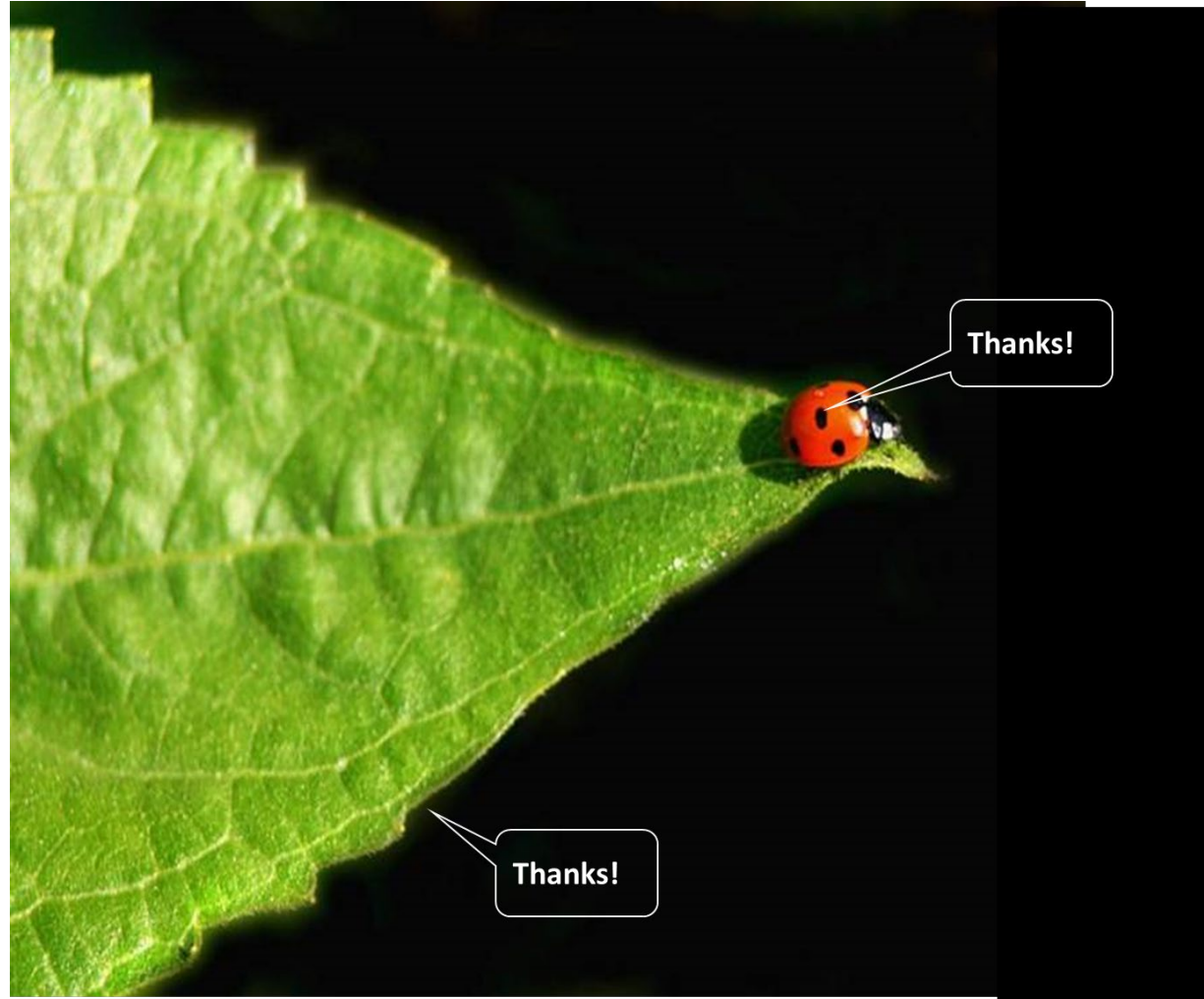


# Wrap Up

249,000 pages of paper saved  
and counting...



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# Replication and expansion



1. Client Satisfaction
2. Rolling Needs Assessment
3. Tailored Action Buttons
4. Statistical Reporting
5. Online, Interactive Resource Guide



# Feedback on e2 approach



*“Survey Monkey is an ok tool but only has canned reporting and is not helpful for low-literacy outreach.*

*E2Community has customizable analytics which are very helpful, and the audio playback feature saves many hours of staff time.”*

*– Needs Assessment Consultant*

*“Although many providers seemed to be hesitant and wary of an electronic tool at first, many of them finally opened up to the idea and saw how simple the process actually was.*

*I also anticipate that they will be glad to get reports on client satisfaction back to them sooner than they would have with a paper survey.”*

*– Field Research Assistant*

# Feedback on e2 approach (cont..)



*“We do want to commend you guys on the ease of use of your system. This part has been so remarkably easy! Thanks for making this as painless as possible!”*

*– RW Data Manager*

*“We are really starting to see the advantages of having an electronic tool for this survey process.”*

*– Research & Evaluation Director*

# Practical Tips on Replication



1. Find a few **key champions** on the planning body, recipient, and quality team.
2. Utilize a **web-based architecture** to minimize management and maintenance headaches and costs. Have automatic linkage with client level data system.
3. Choose a systems partner and consultant who operates on a **human-centered approach** (not technical approach) and has experience with surveying special populations.
4. **Just do it.** Don't be paralyzed with logistics. Evolve your approach and system based on experience. Start as early as you can to avoid time crunches.

# How can we accomplish ambitious goals?



How can we accomplish ambitious goals??



One bite at a time.

# Thanks for your time



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## Thank you for your time!



# Thank You!



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