

ANTHC Diabetes Registry

September 18 2020

Objectives

- ANTHC Diabetes Registry:
 - Why start a registry?
 - How was the registry started?
 - What did the initial data show?
 - What resulted from the registry data?
 - How is the registry maintained?
 - Continuing use of registry data





Initial support

- AK Chief Medical officer supportive
- Diabetes Steering committee formed



Initial Resistance

- DM not a priority among other health problems seen in AK region
- Preliminary search retrieved several hundred people with DM visits
- Skepticism - tourists, coast guard, etc.
- Chart review and data repository needed
- No funding

Initial Resistance

" I wouldn't touch that project with a ten foot pole.
If, in 30 years, everybody has diabetes, people will say:
See, you wasted all that time and money.
Everybody knew you couldn't stop diabetes.

If, in 30 years, diabetes is rare people will say :
See, you wasted all that time and money.
Everybody knew Alaska Natives didn't get diabetes."











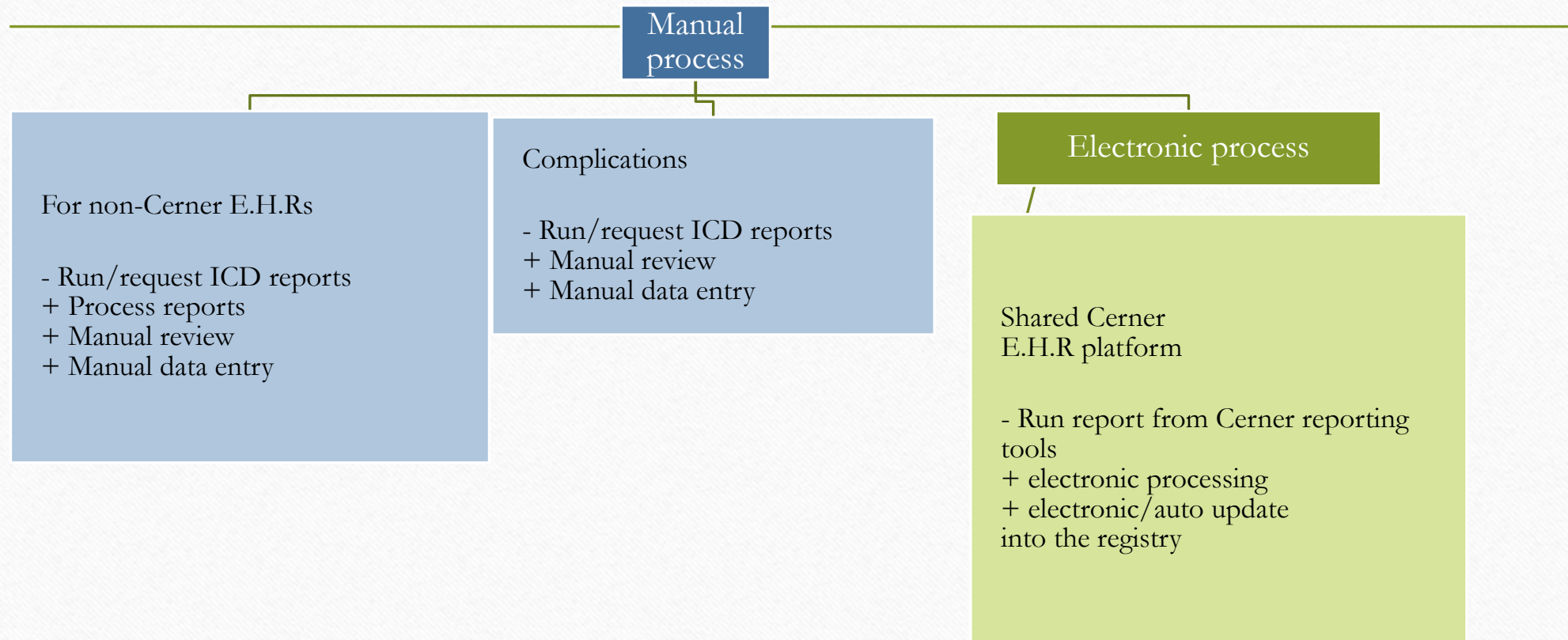
Registry Case Ascertainment

Finding people with diabetes, pre-diabetes, GDM and complications

Manual process

ICD reports run for DM, manual review, manual data entry

Registry Case Ascertainment – E-updates



LIVING IN WELLNESS

Special Diabetes Program for Indians
THE ALASKA STORY



Grant Programs

Funded greater than \$1,000,000

- 1 Southcentral Foundation
- 2 SouthEast Alaska Regional Health Consortium
- 3 Tanana Chiefs Conference
- 4 Yukon-Kuskokwim Health Corporation

Funded between \$500,000–\$1,000,000

- ★ Alaska Native Tribal Health Consortium
- 5 Bristol Bay Area Health Corporation
- 6 Manillaq Association
- 7 Norton Sound Health Corporation

Funded between \$150,000–\$500,000

- 8 Arctic Slope Native Association
- 9 Chugachmlut
- 10 Council of Athabaskan Tribal Governments
- 11 Ketchikan Indian Corporation
- 12 Kodiak Area Native Association

Funded less than \$150,000

- 13 Aleutian / Pribilof Islands Association
- 14 Copper River Native Association
- 15 Eastern Aleutian Tribe
- 16 Kenaitze Indian Tribe
- 17 Mt. Sanford Tribal Consortium
- 18 Seldovia Village Tribe

Registry Functions

- Laboratory and ICD codes for

based on

Lab and clinical details verification

Patient Care

ANTHC
Diabetes
Registry

Communication and education

Support for quality of care reviews

Challenges and Solutions

- Challenge: Staffing for data entry
 - Difficult to find and keep clinical staff willing/able to methodically assess and enter data
- Solution: Diabetes staff, dedicated data entry person, intermittent team of research nurses

Challenges and Solutions

- Volume of people with diabetes ICD codes
- Solution: E-updates using HbA1c reports

Current Registry Location

ANTHC Diabetes Program

ANTHC Diabetes Registry

Multidisciplinary
clinical team

Community Outreach

Continuing Education
and technical assistance

Advanced Community
Health
Aide/Practitioner
Training

Clinical support

- Patient lists by community/facility
- Data support for SDPI programs
- Continuing education on diabetes diagnostic criteria
- E.H.R documentation and reporting support
- CHA/P advanced training

Epidemiologic Monitoring

- Prevalence and incidence by region, ethnicity and age
- Trends in End Stage Renal Disease and amputations
- Special data requests from tribal and I.H.S. partners
 - for new grant proposals
 - priority planning
 - presentations to tribal leaders
- Data supporting allocation of federal funding for diabetes care and prevention

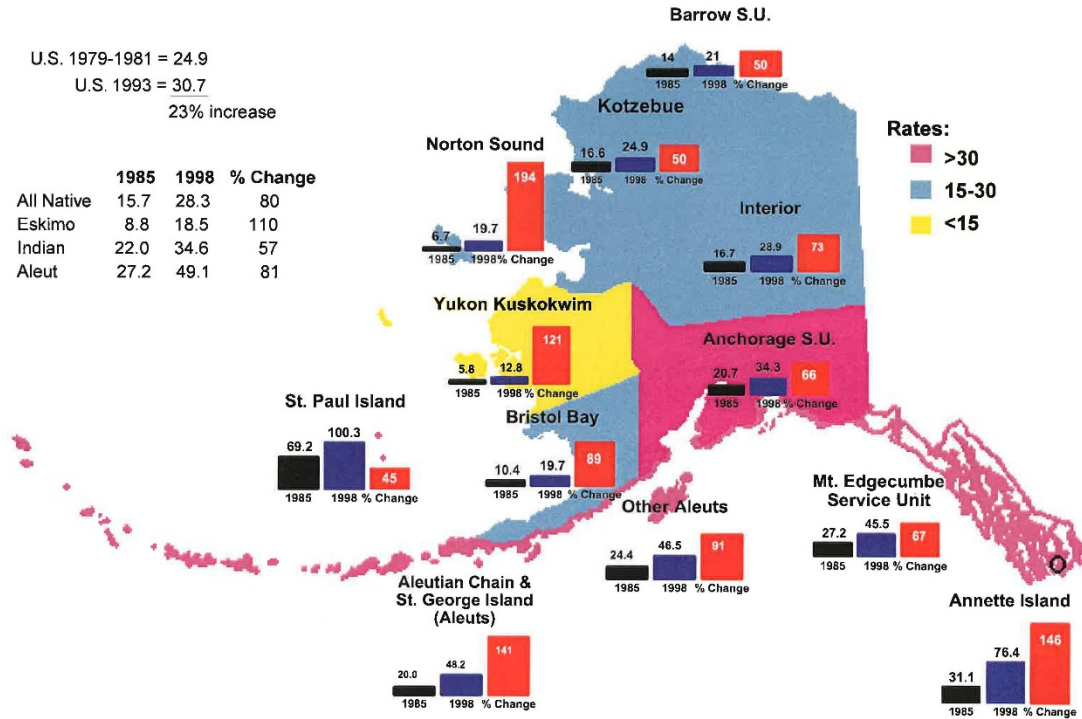
Cross-matching (with appropriate clearance)



Diabetes Prevalence, Alaska Natives 1985, 1998 and Percent Change Age-Adjusted Rates Per 1,000 Population

U.S. 1979-1981 = 24.9
U.S. 1993 = 30.7
23% increase

	1985	1998	% Change
All Native	15.7	28.3	80
Eskimo	8.8	18.5	110
Indian	22.0	34.6	57
Aleut	27.2	49.1	81

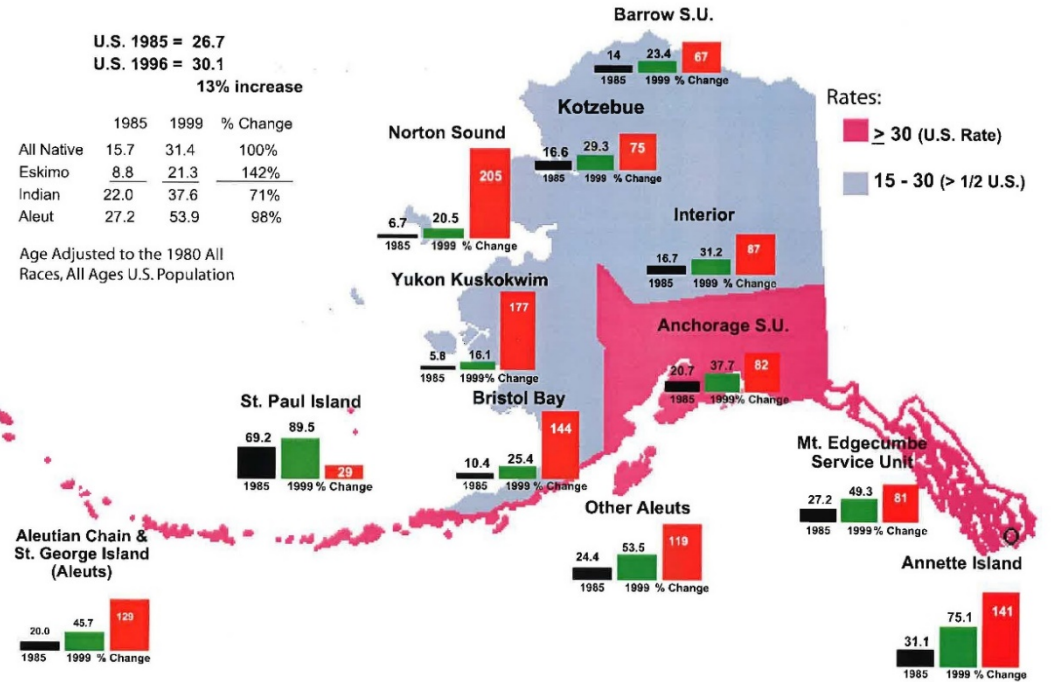


Diabetes Prevalence, Alaska Natives 1985 & 1999 and Percent Change Age-Adjusted Rates Per 1,000 Population

U.S. 1985 = 26.7
U.S. 1996 = 30.1
13% increase

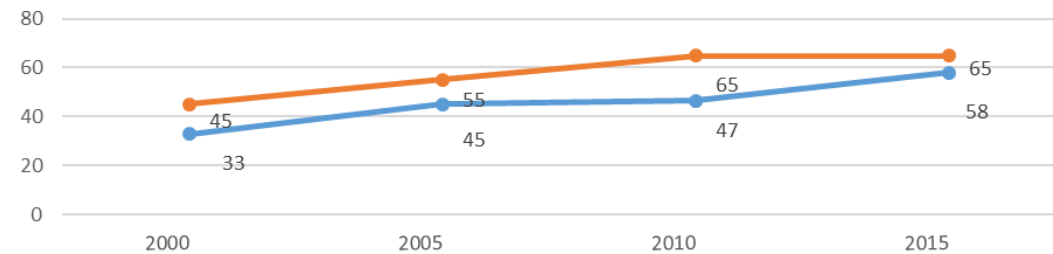
	1985	1999	% Change
All Native	15.7	31.4	100%
Eskimo	8.8	21.3	142%
Indian	22.0	37.6	71%
Aleut	27.2	53.9	98%

Age Adjusted to the 1980 All Races, All Ages U.S. Population



Diabetes Prevalence

Diagnosed Diabetes Prevalence* among Alaska Native People is lower than in U.S. population

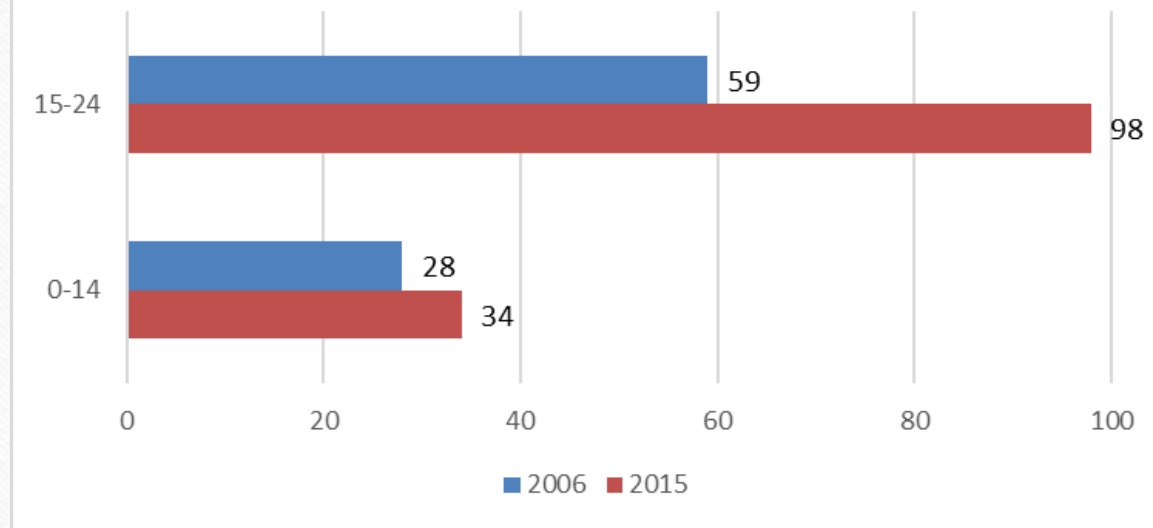


*age-adjusted rate/1000

—●— Alaska Native People —●— National data

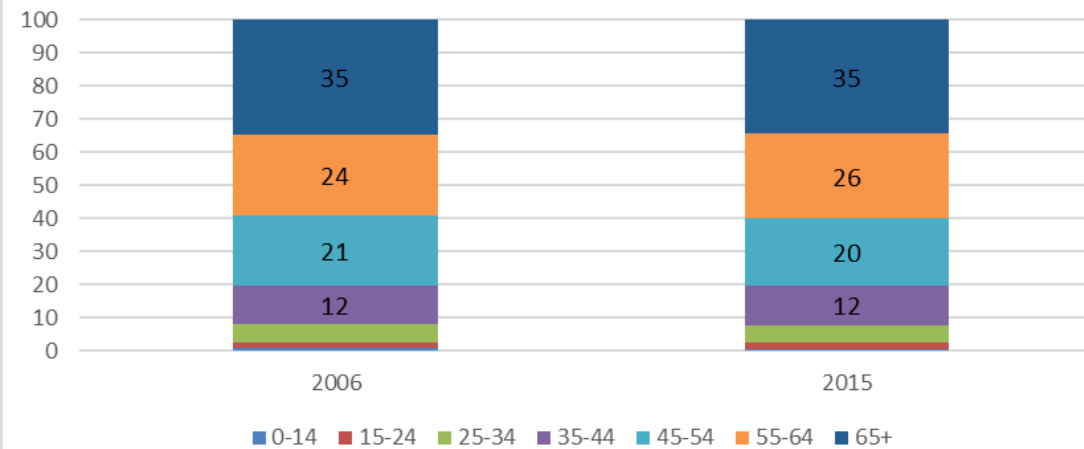
Young People with DM

The **number** of Alaska Native young people (<25) with diagnosed diabetes has increased.

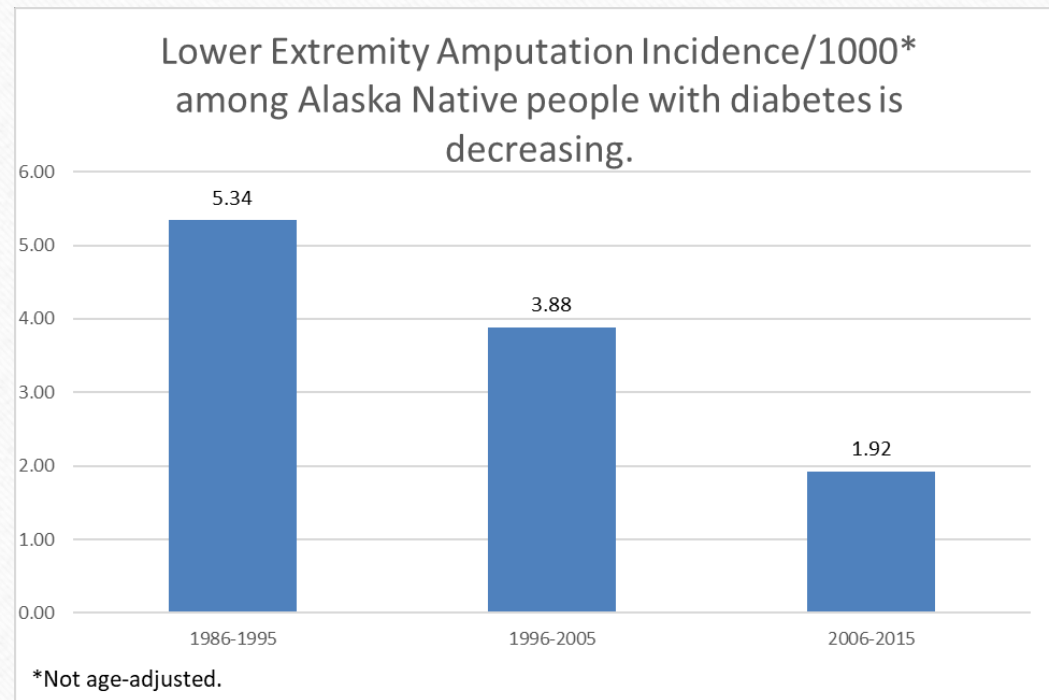


Prevalence by age group

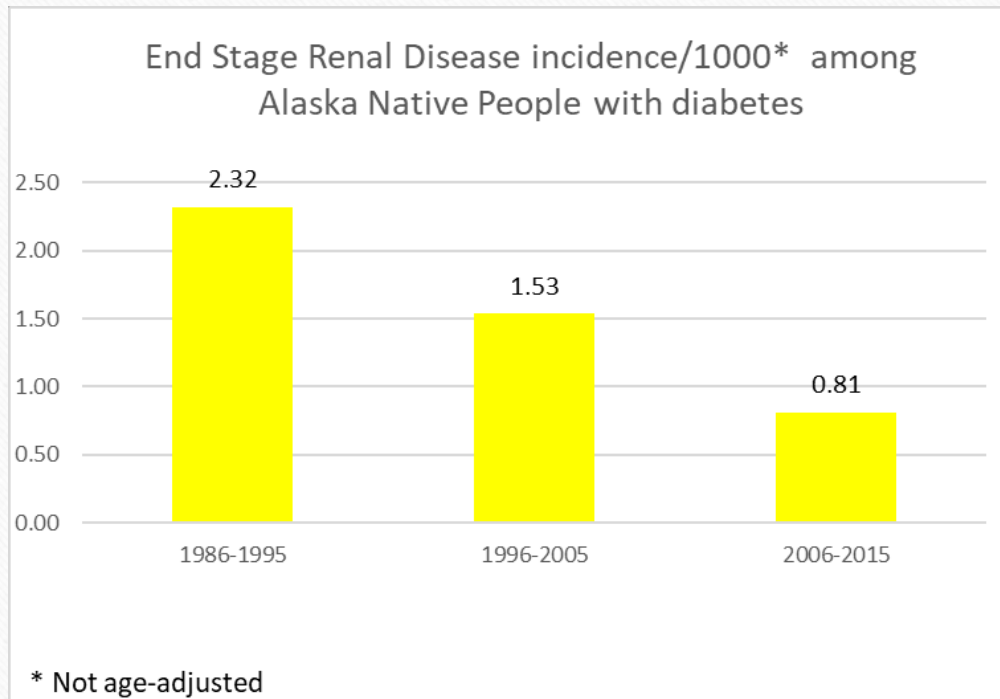
The **percent** of Alaska Native People with diagnosed diabetes (by age group) has remained **stable**.



LEAs



ESRD Trends



Conclusion

- 35 year young registry
- ATHS-wide support
- Used for patient care, regional program planning, advocate for funding
- Adapt and use new tools to handle volume



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