

The California Parkinson's Disease Registry

Accomplishments and Updates, October 2019



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Presentation Overview

1. CA Senate Bill (SB) 97

- Objectives of the California Parkinson's Disease Registry (CPDR)

2. Operational Highlights

- What CDPH has accomplished to date

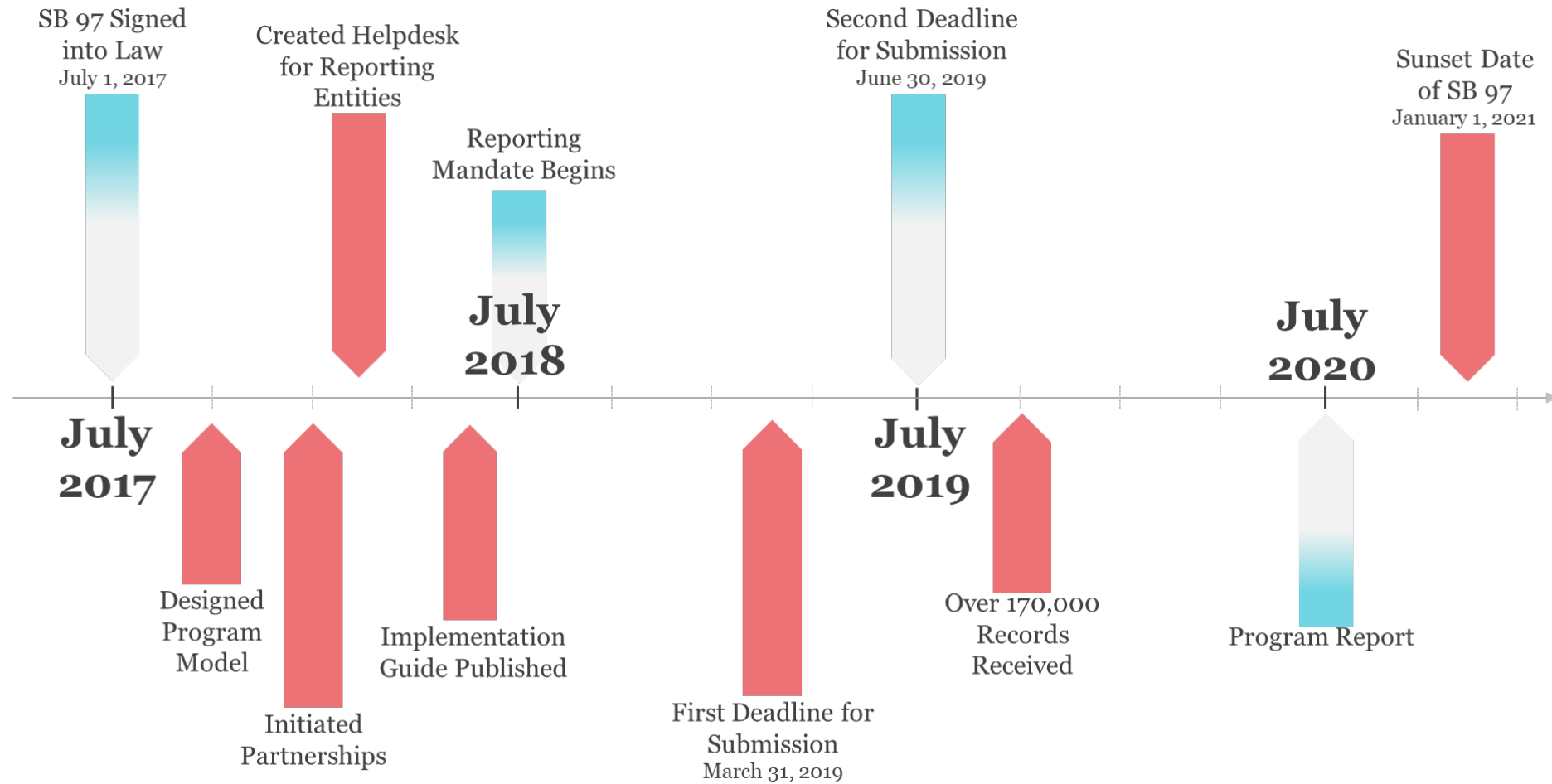
3. Data Submitted

- Data deadlines and facility reporting

4. Next Steps and Future Aims

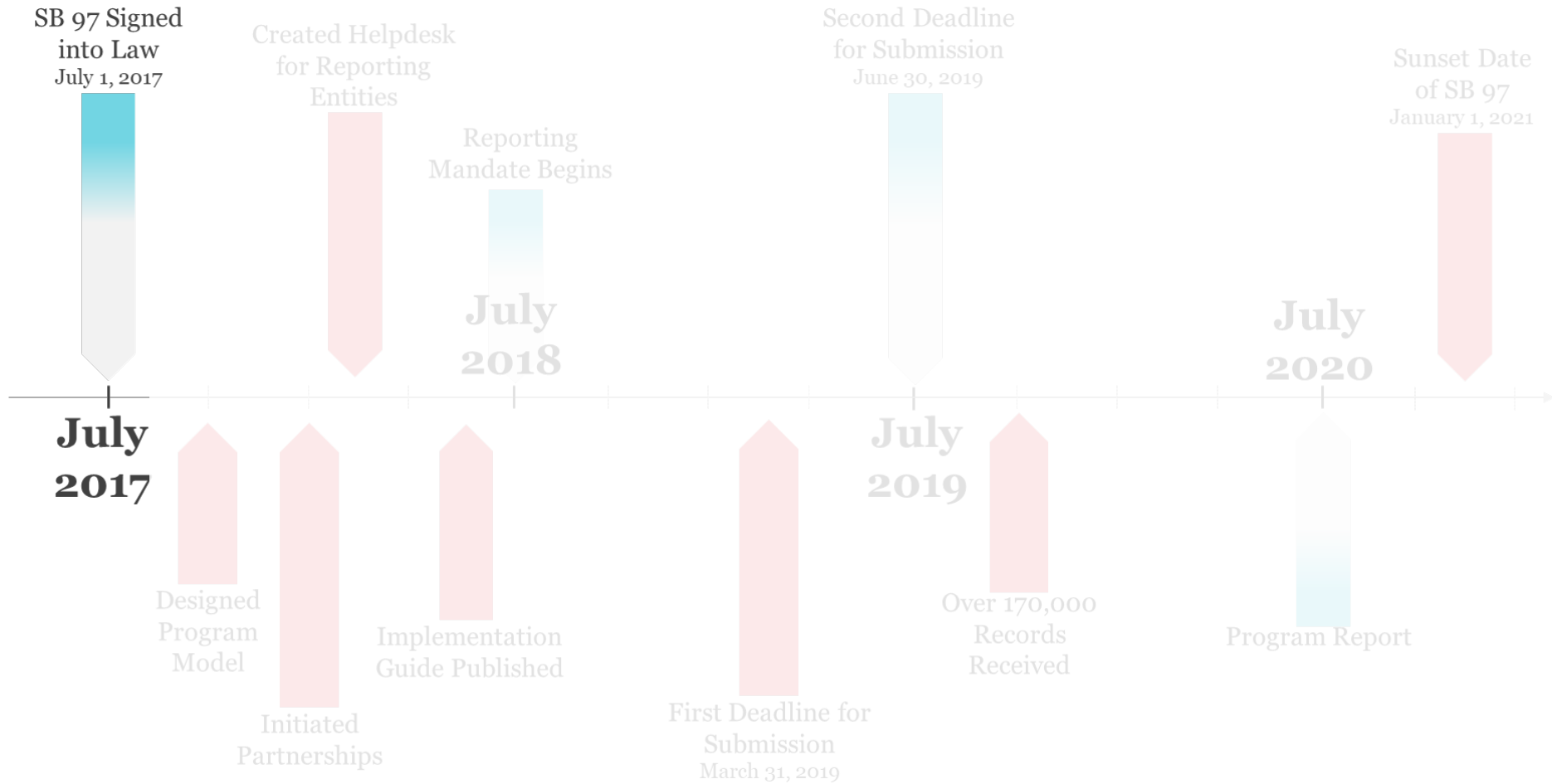
- Estimating incidence & prevalence of PD in CA
- Provide data to qualified researchers

CPDR History & Progress



CA Senate Bill 97

- Objectives of the CPDR



CA Senate Bill 97

Richard Paul Hemann Parkinson's Disease Program

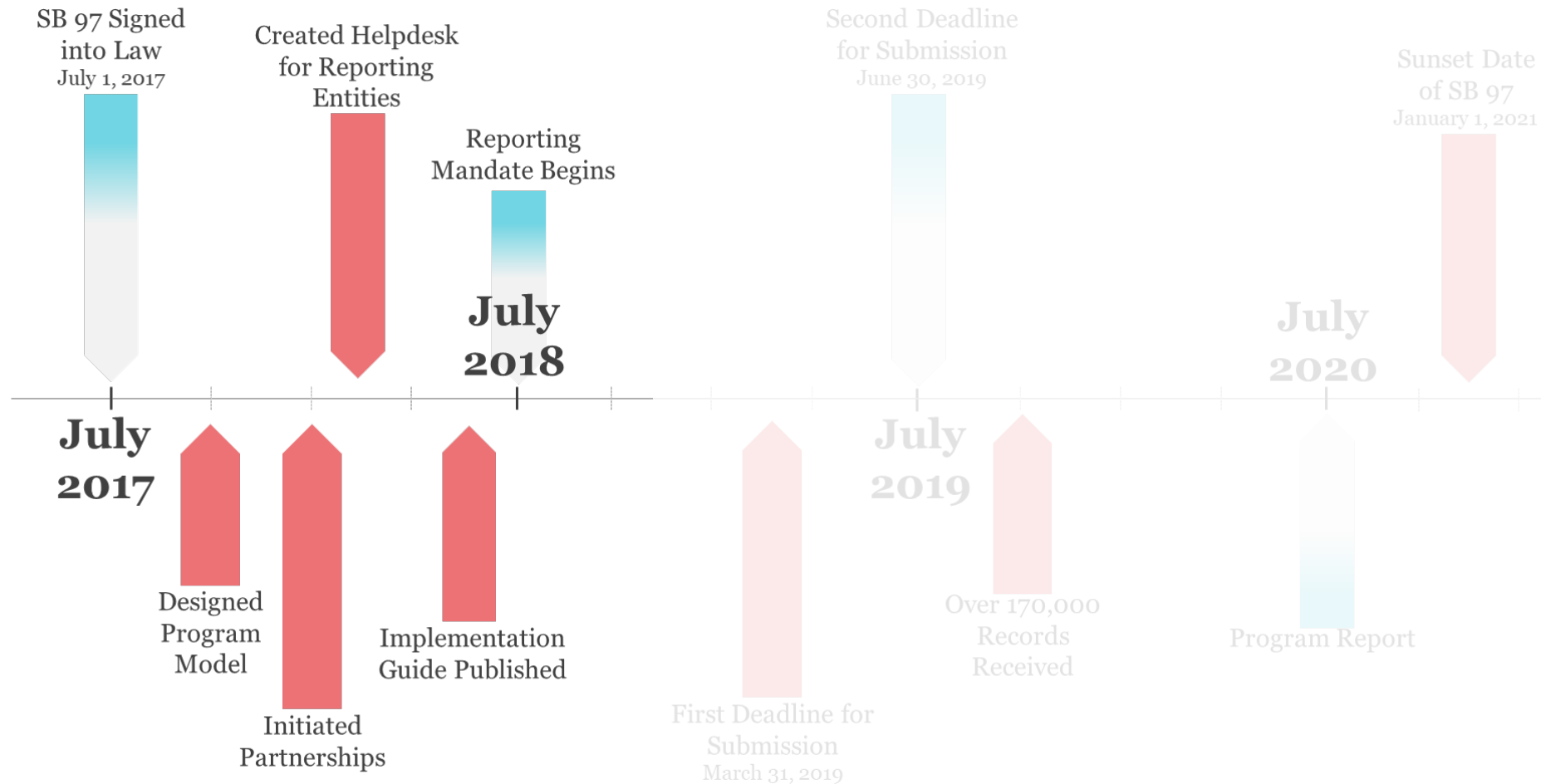
Beginning on July 1, 2018:

1. All physicians, hospitals, clinics, and other entities providing diagnosis or treatment to PD patients are required to report to CPDR within 90 days
2. CDPH must establish a system for the statewide collection of information to determine the incidence and prevalence of PD
3. CDPH must develop a data disclosure protocol to provide confidential information to qualified researchers with a valid scientific interest



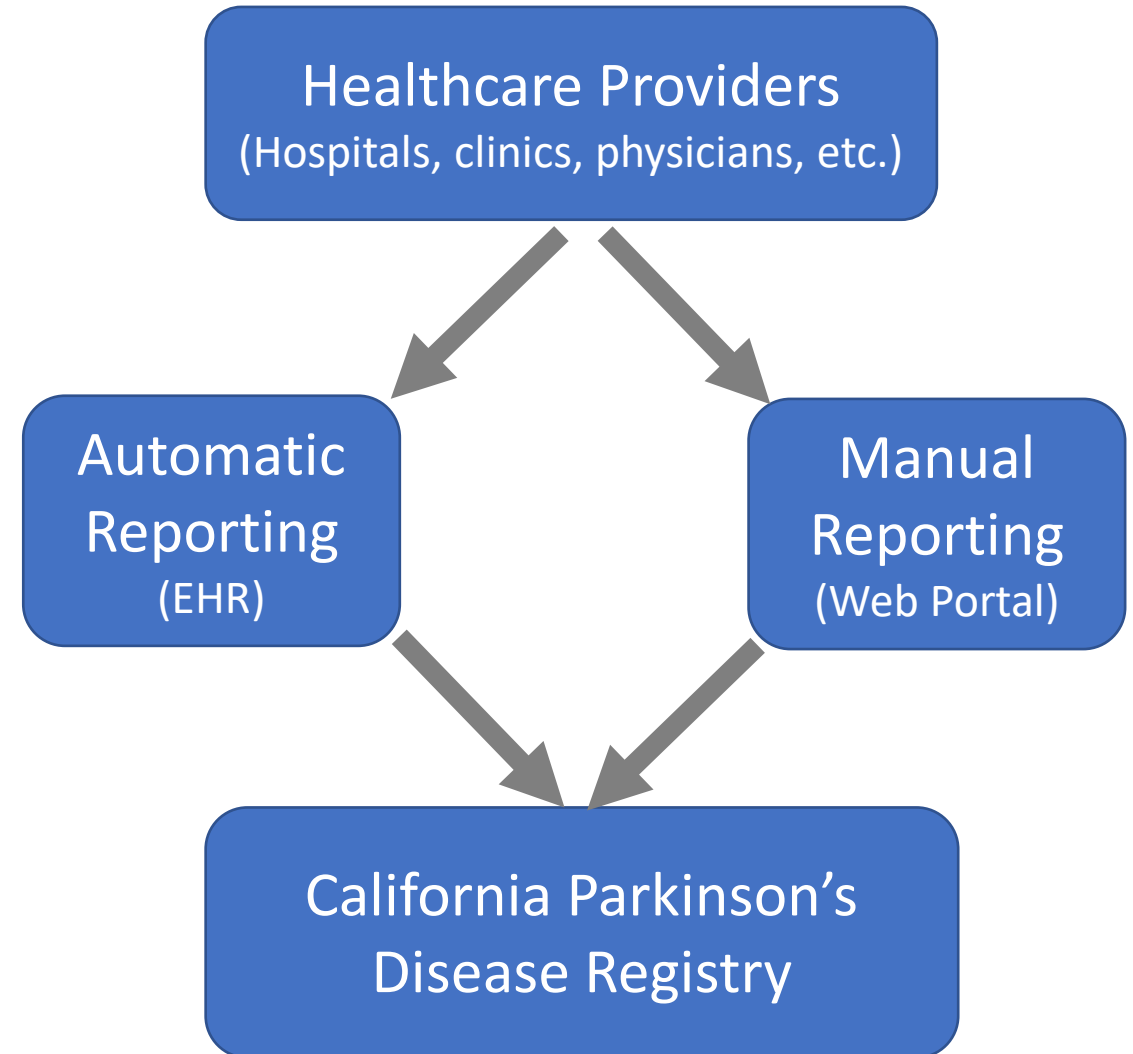
Operational Highlights

- What CDPH has accomplished to date



CPDR Development and Data Collection

1. Established and implemented IT system for data capture
2. Developed program model
3. Created help desk and technical support for reporting entities
4. Formed partnerships with external entities
5. Assured patient confidentiality protections

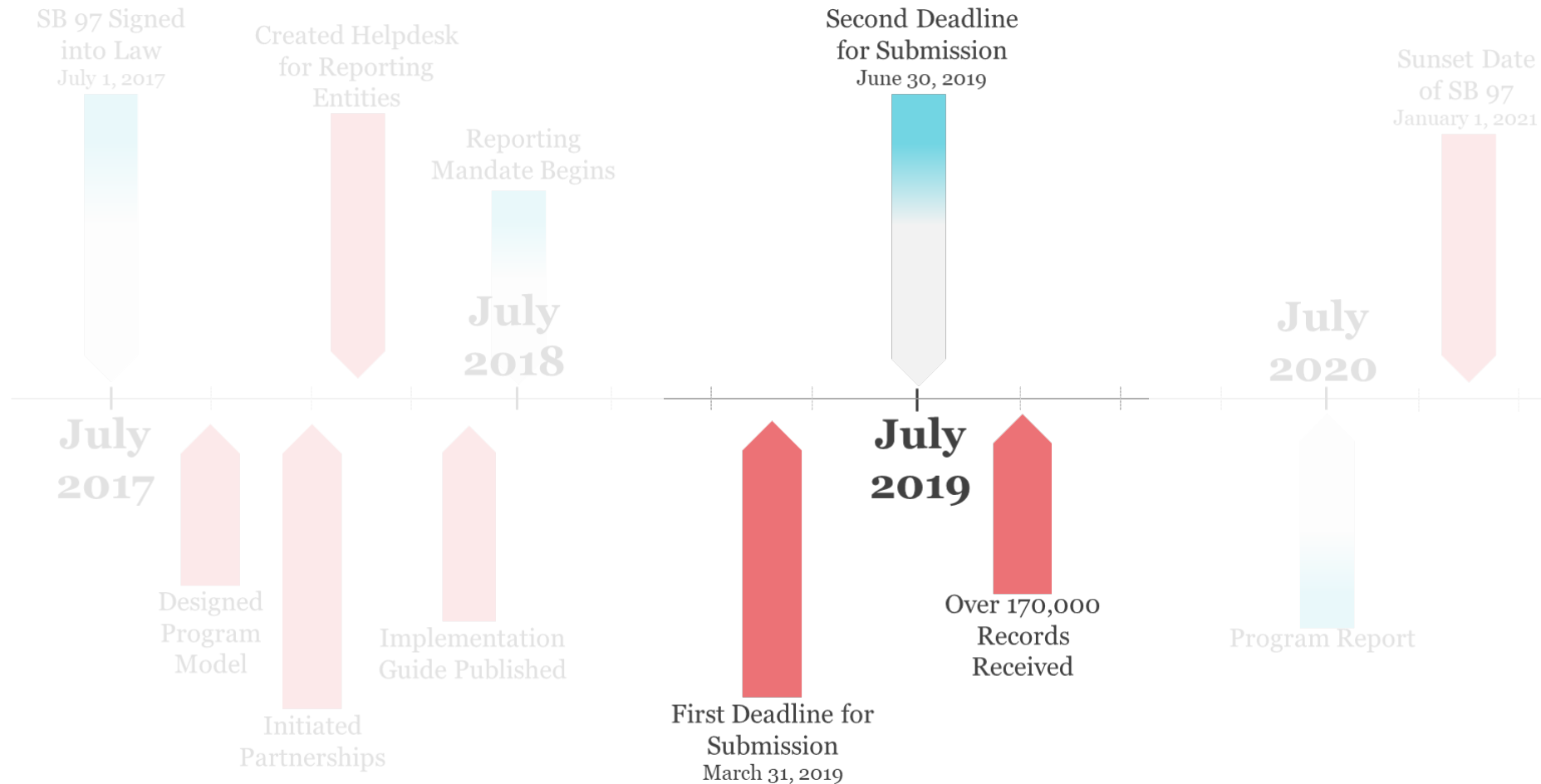


CPDR Development and Data Collection

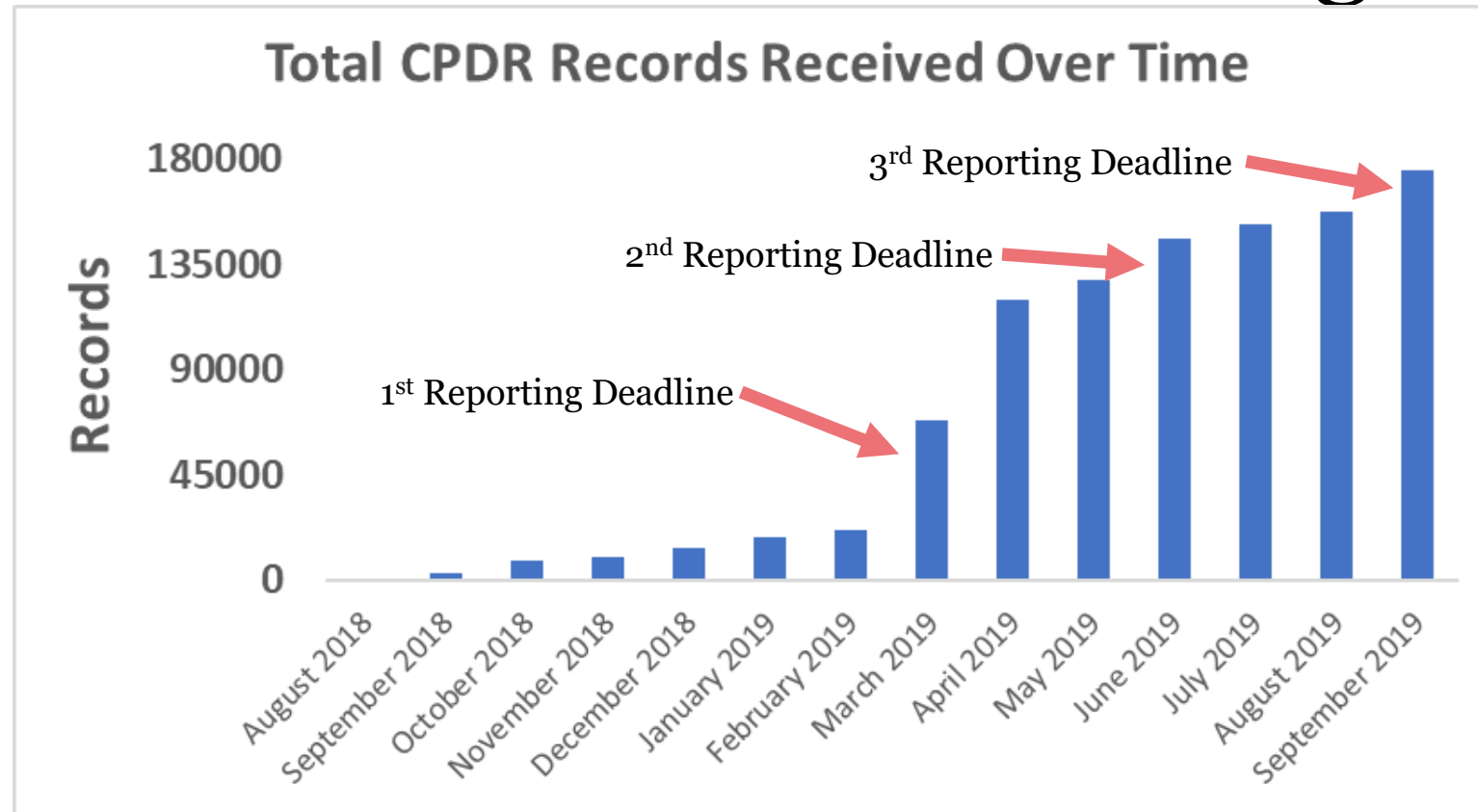
Requirement	Variable
Required	Name (Last, First, MI)
Required	Date of Birth
Required	Sex (Gender)
Required	Patient Address
Optional	Social Security Number
Required	Medical Record Number
Required	Race & Ethnicity
Optional	Date Last Contact/Death
Required	Physician Name (Last, First)
Required	Author NPI – Physician ID
Required	ICD-10/Diagnostic Term
Required	Date of Diagnosis
Optional	Onset Date

Data Submitted

- Data deadlines and facility reporting



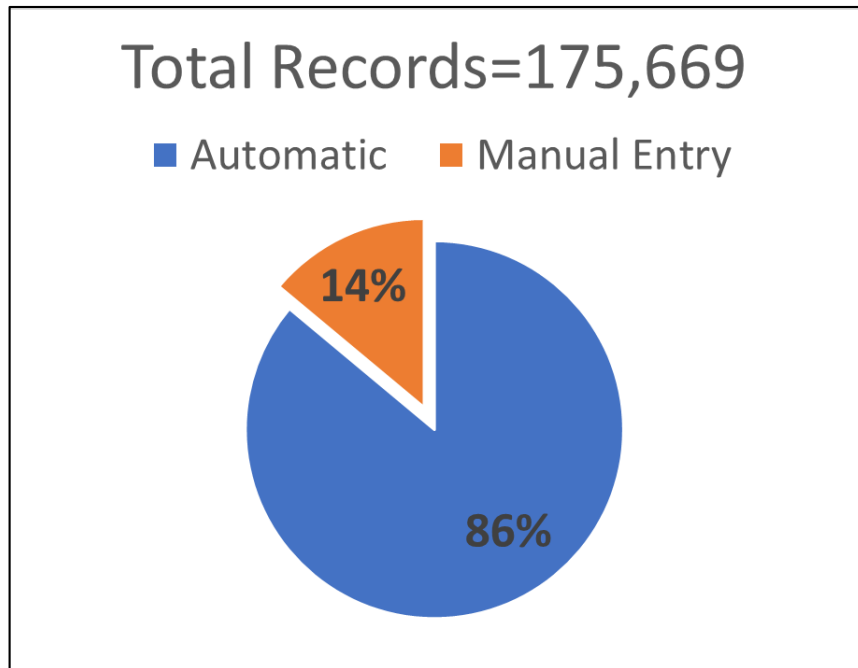
CPDR Data Submission Progress



1. 175,669 records collected through the first five quarters of mandated reporting (July 1, 2018-September 30, 2019)

*The information presented reflects the *total records received* and not the consolidated, deduplicated dataset used to calculate incidence or prevalence

CPDR Data Update



Unique Case Estimate

35% of total records

Unique Reporting Entities

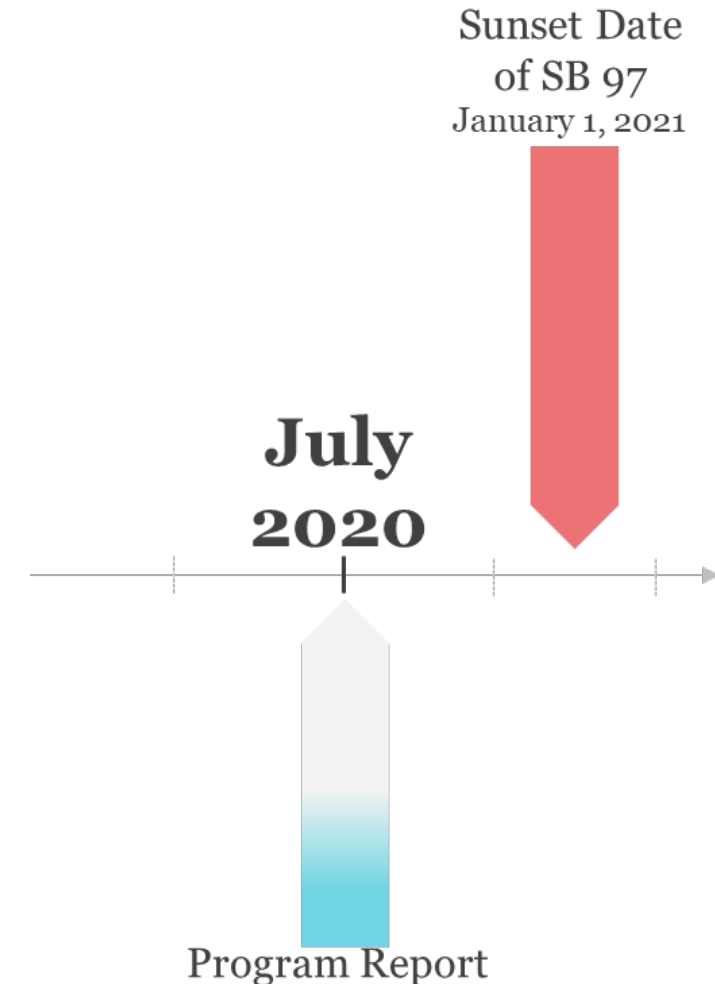
497

1. As of October 1, 2019, CPDR has received about 175,000 records* from approximately 500 reporting entities
2. CPDR is identifying and onboarding facilities and providers that are not reporting to CPDR

*The information presented reflects the *total records received* and not the consolidated, deduplicated dataset used to calculate incidence or prevalence

Next Steps and Future Aims

1. Continue working with facilities and providers
2. Determine incidence and prevalence of PD in California
3. Use of CPDR data
 - Research (qualified applicants)
 - Surveillance
 - With data security and patient protections



CPDR Impact

1. Data collected about PD patients is invaluable for CA and beyond
2. Research will accelerate our understanding about the causes of PD
3. Reporting will raise awareness and contribute to earlier diagnosis of PD



Acknowledgements

- Patients
- Facilities, providers, and health system administrators
- Academic institutions
- PD organizations
 - Michael J. Fox Foundation
 - Parkinson's Association of Northern California

