

# Trend Analysis of the National Program of Cancer Registries (NPCR) Program Evaluation Instrument (PEI) for the Years 2007-2015

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## INTRODUCTION

The NPCR PEI is a biennial survey of the NPCR-funded central cancer registries (CCR). It is designed to measure CCR functions and evaluate them against program standards. All funded programs are evaluated in the following areas for program compliance: Legislative Authority, Administration, Data Collection, Content, and Format, Electronic Data Exchange, Data Completeness/Timeliness/Quality, Linkages, Data Quality Assurance and Education, Data Use and Data Monitoring, Data Submission, Collaborative Relationships. Although this survey was first administered in its current form in 2007, no comprehensive trend analysis of the results has ever been performed.

The purpose of this analysis is to assess the progress of the NPCR program. The impact of such an analysis will offer CDC and other public health agencies the necessary guidance to make decisions for technical assistance and other resource allocation to the CCRs.

## METHODS

All NPCR-funded central cancer registries electronically submitted a PEI for all survey years (2007-2015). The analysis was conducted on a group of 45 state registries and the District of Columbia (Puerto Rico and Pacific Island registries were excluded). The data throughout the analysis are presented in terms of a response percentage: with the numerator being the number of registries that shared a particular response and the denominator being 46 (note that this was adjusted for follow-up questions, where only a subset of registries providing a response). The analysis only considered PEI questions that were present in all survey years. Responses that were either added or removed from a particular question over the course of the survey years were excluded from the analysis, but the question itself and the consistent responses **were** allowed to remain.

## RESULTS

For all survey years, over 95% of the registries:

- Had legislation or regulation in support of all 8 criteria of the Public Law authorizing NPCR.
- Maintained an operational manual that includes sections on: reporting laws, list of reportable diagnosis, list of data items, receipt of data, conducting death certificate clearance, and conducting record consolidation
- Required hospital reports to use CDC-recommended data format for electronic exchange of cancer data.
- Collected data on all patients diagnosed and/or receiving their first course of treatment in their state regardless of residency.
- Submitted NPCR core data items in datasets submitted to other states.
- Used a standardized NPCR-recommended data exchange format to transmit data reports.
- Collected and derived all required data items using NPCR prescribed codes.
- Conducted QA with multiple, designated CTRs.
- Matched all causes of death against registry data to identify a reportable cancer.
- Updated their database following death certificate matching.
- Actively collaborated with the comprehensive cancer prevention and control efforts (CCC) in their state.
- Provided data for CCC planning.
- Conducted record linkages to the state's vital statistics for follow-up purposes.

### Pathology Reports

- Registries receiving electronic pathology reports in the NAACCR, HL7 Format (Volume V), Version 2.x format grew from 23.9% in 2007 to 82.6% in 2015.
- Registries using and requiring the NAACCR Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting grew from 34.8% in 2007 to 76.1% in 2015.

Figure 1: Manual-only Review of Pathology Reports

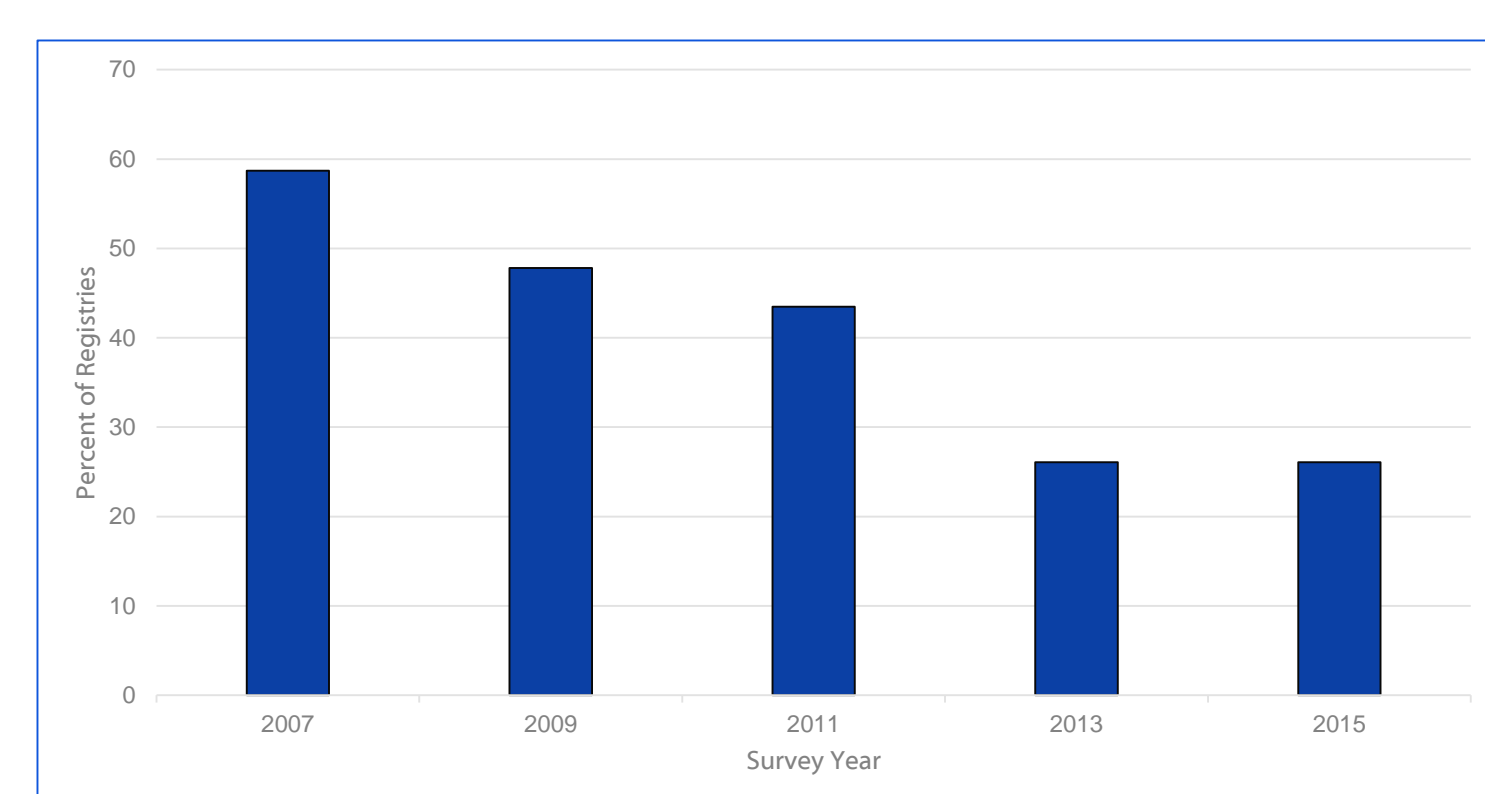
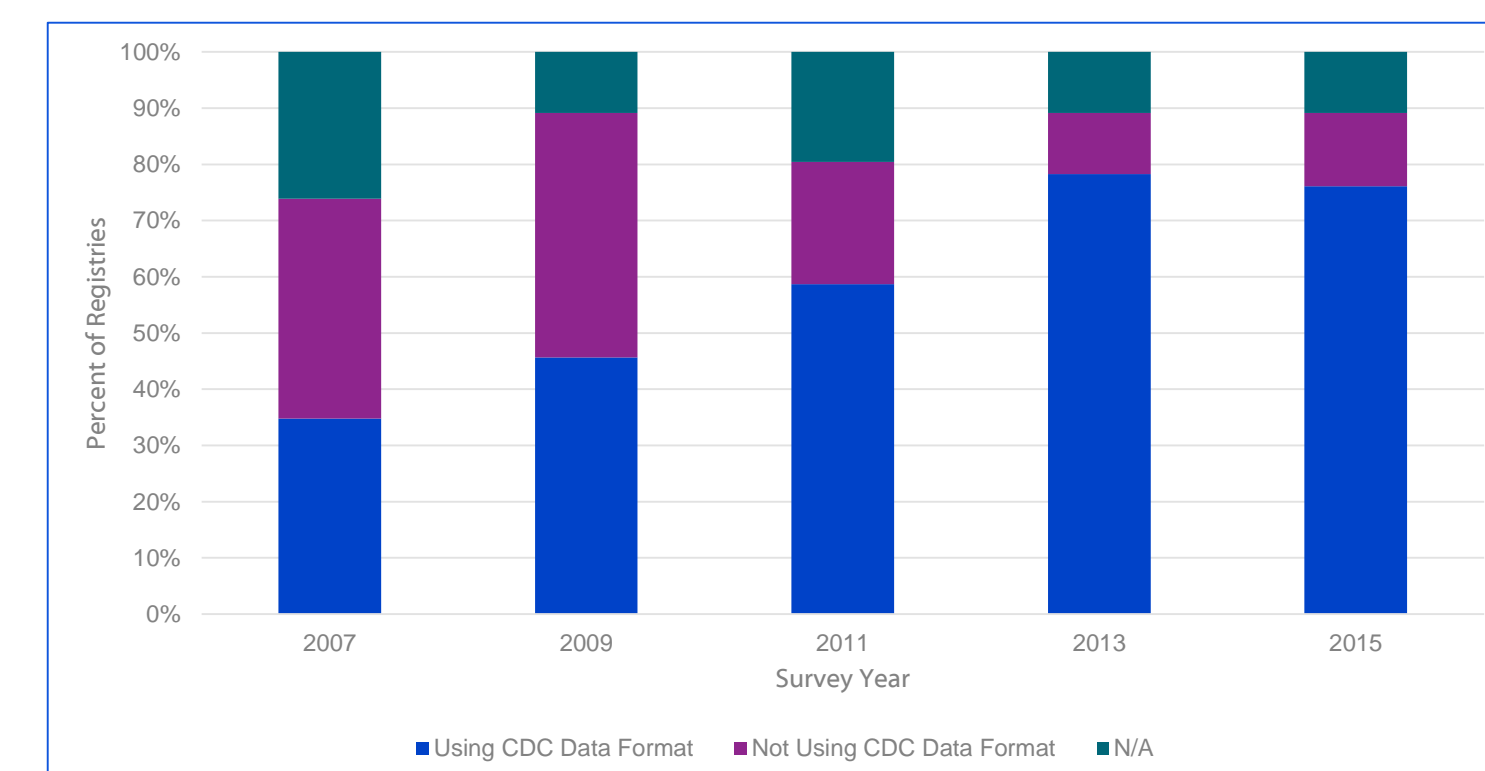
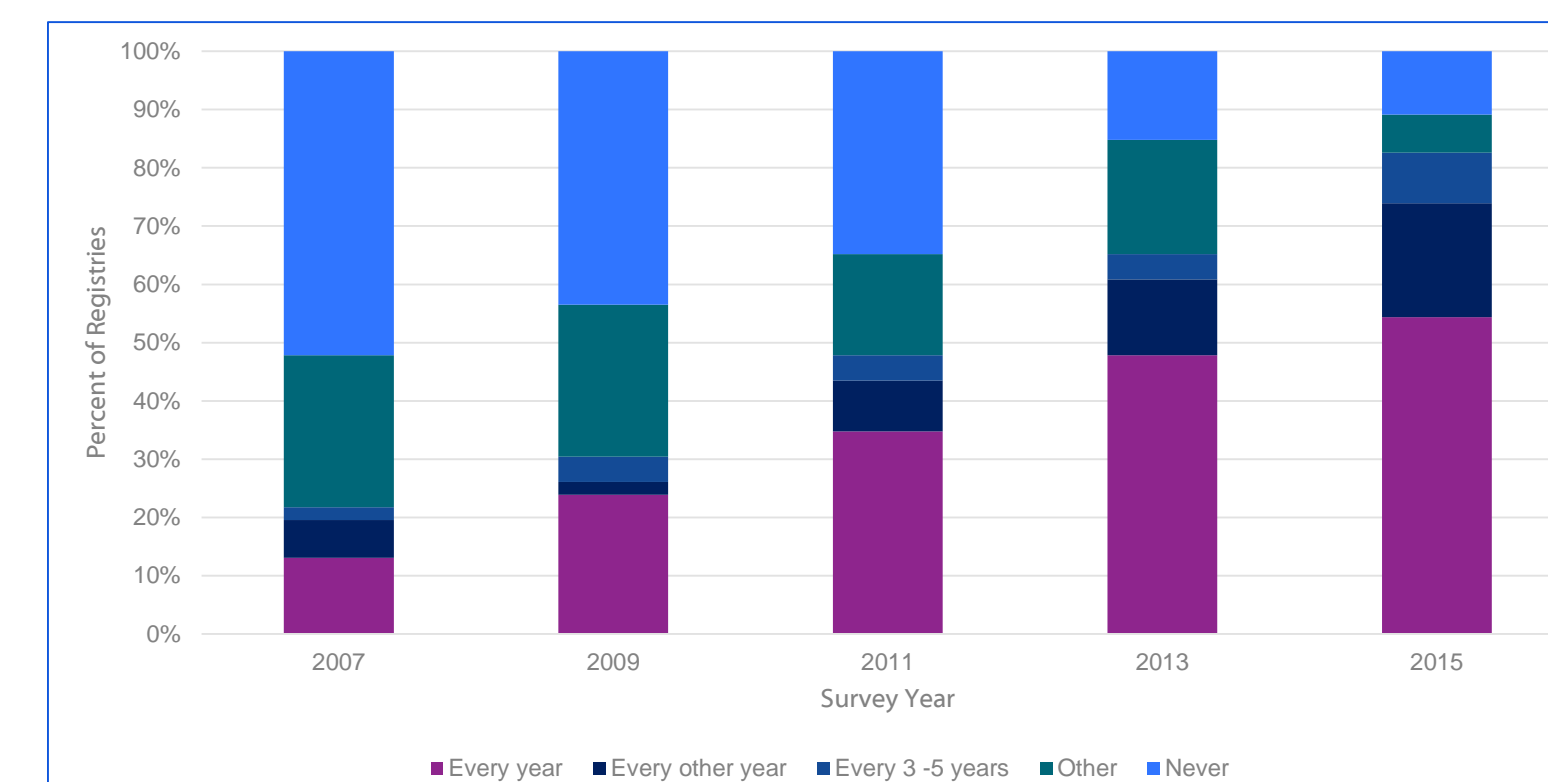


Figure 2: Electronic Pathology Report Data Format



### NDI Linkage

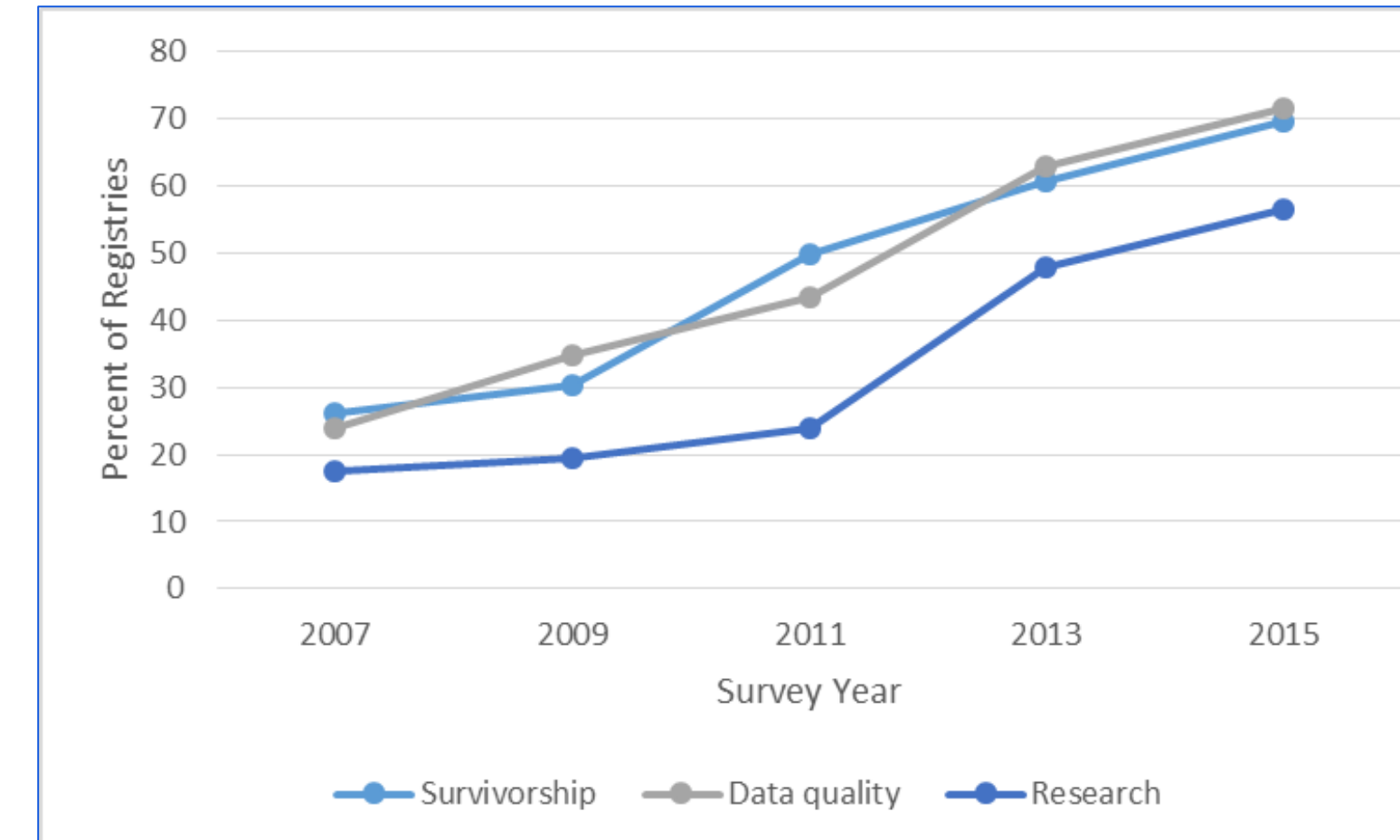
Figure 3: Frequency of Linkage to NDI



Additionally, from 2007 to 2015 registries

- linking to NDI for follow-up or some other purpose grew from 19.6% to 67.4%.
- updating their database following the linkage grew from 57.1% to 91.3%.

Figure 4: Benefits of NDI Linkage



- Survivorship, data quality and research have more than tripled from 2007 to 2015.

## Registry Operations

### Data Quality Assurance

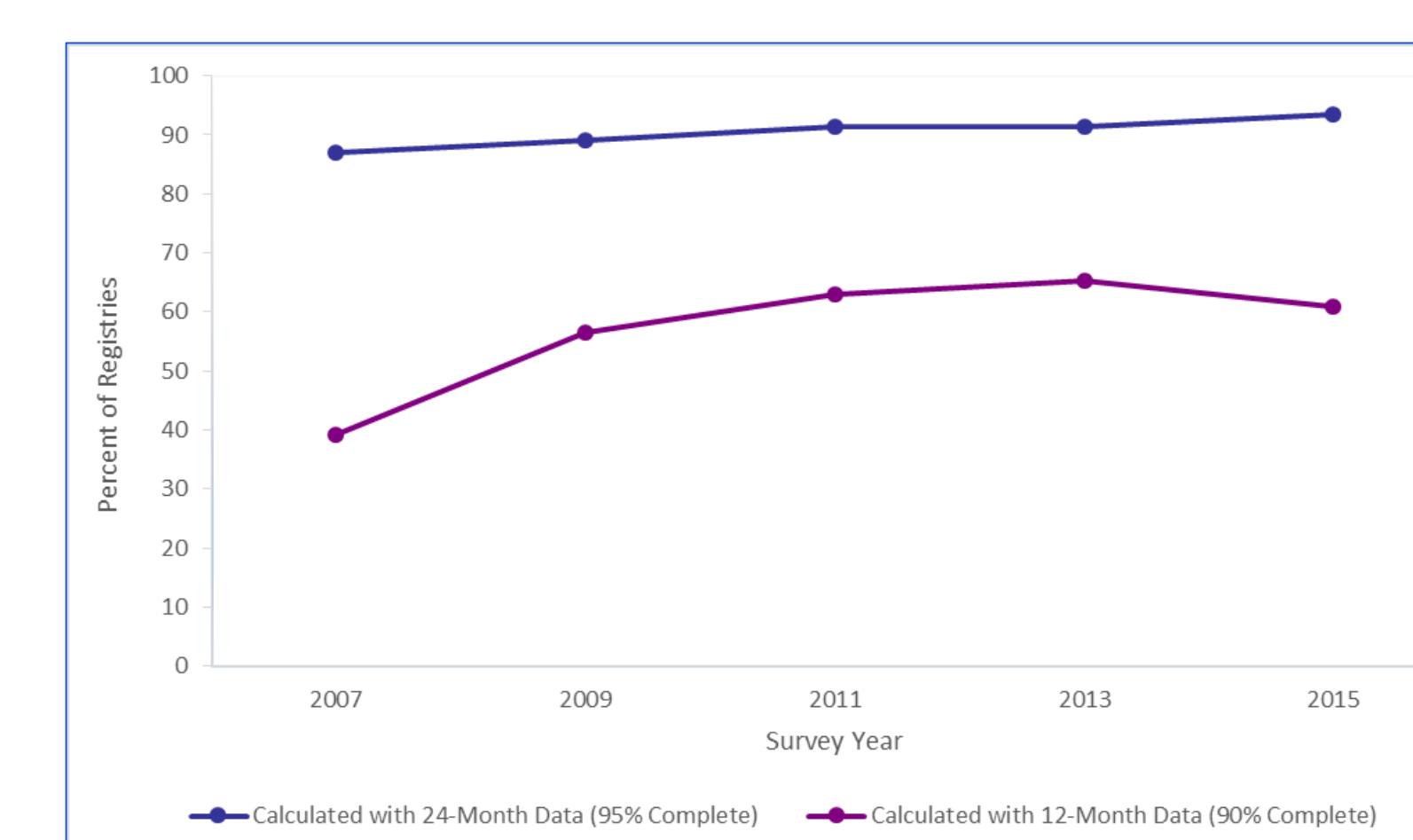
Table 1: Percentage of CCRs that perform record consolidations by year

	2007	2009	2011	2013	2015
Patient data group	97.8	97.8	100.0	100.0	100.0
Treatment data group	91.3	93.5	97.8	100.0	100.0
Follow-up data group	87.0	84.8	84.8	82.6	80.4

- Records consolidation improved for patient and treatment groups and remained steady for the follow-up data group.

### Data Use

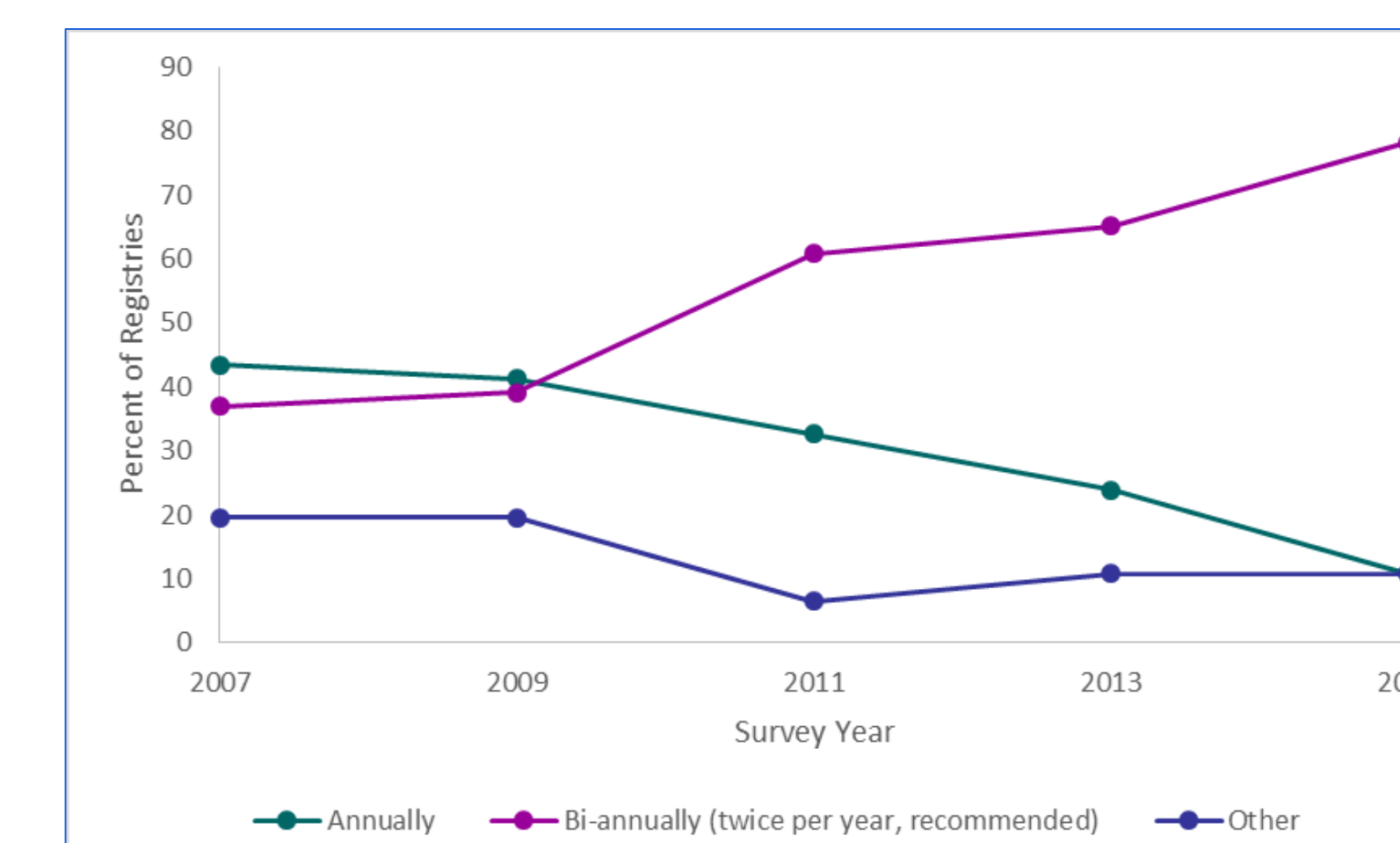
Figure 5: Reporting of Incidence Data



- Incidence data are reported in terms of Surveillance Epidemiology and End Result (SEER) standardized site groups. The 12-month data are used as a preliminary monitor of top cancer sites.

### Data Exchange

Figure 6: Interstate Data Exchange Frequency



From 2007 to 2015, registries also increased their online data exchange.

- Registries able to receive secure, encrypted cancer abstract data from reporting sources via the internet grew from 69.6% to 95.7%.
- Registries exchanging data transmitted via a secure encrypted internet-based system grew from 56.5% to 97.8%.

## CONCLUSIONS

This trend analysis evaluates progress toward and compliance with program standards. It allows for better resource allocation by identifying areas of need among all CCRs as well as CCRs within a particular group.

Over the period that the PEI has been administered, central registries have consistently reached the NPCR evaluation standards and greatly expanded their use of technology and data linkage to improve the efficiency of their operations.

For a more complete picture of follow-up and other linkage activities, subsequent PEI surveys should include questions about the frequency with which registries link to the Social Security Administration's Death Master File.

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