



The Path To Becoming a Survival Central Cancer Registry*



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Background

MCR-ARC sent surveys to 60 central and regional cancer registries located in the U.S. to learn more about becoming a survival registry. We defined a survival registry as one that *performs active follow-up to document a patient's vital status and quality of life.*

For incidence registries, the focus was on finding out if the registries were planning to become survival registries; the challenges and barriers registries face; anticipated costs; and perceived benefits. Questions for survival registries focused on how registries moved from incidence to survival (or were they always a survival registry); barriers and challenges; methods registries use to keep data current; costs involved in starting and maintaining a survival registry; and how registries perceived the quality and completeness of their data.

Survey Results – General Registry Information:

Of the 36 responding registries, only five were affiliated with academic institutions. Annual caseloads ranged from 2,500 to more than 150,000. The number of CTRs on staff ranged from two to 30; number of other staff ranged from one to 31. Ten registries classified themselves as survival registries.

Discussion:

It is clear confusion exists about the definition of a “survival registry.” For MCR-ARC, it meant performing annual active follow-up; however, several respondents indicated they felt they were survival registries due to their ability to calculate survival rates through passive follow-up. Survey comments strongly urged NAACCR, NPCR, SEER and others to define “survival.”

According to a 2010 article “when death ascertainment was complete, there were only minor differences between survival estimates for complete follow-up and no follow-up of live patients.” Johnson CJ et al. The impact of patient follow-up on population-based survival rates. J Registry Manag 2010; 37(3)86-1-3.

Survey Results – Incidence-only Registries:

Nearly three-fourths of incidence-only registries stated they had no plans to become a survival registry; 23 percent were not sure while the remaining registries plan to become survival registries.

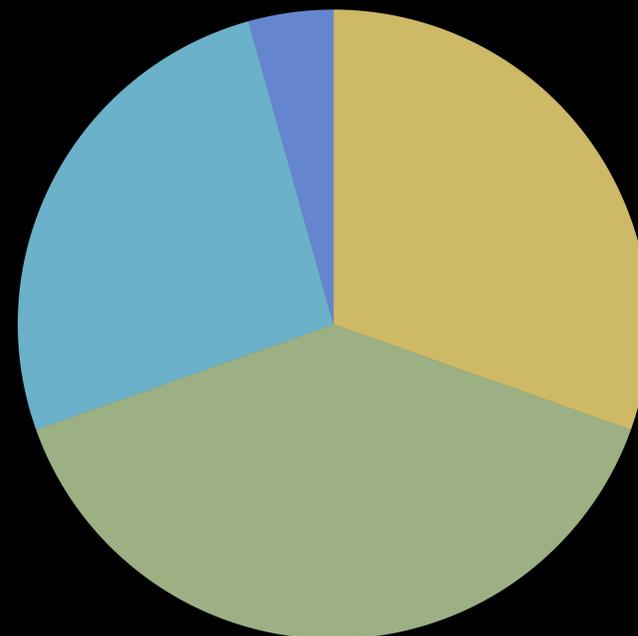
Anticipated barriers, ranked in order of importance, were:

- #1 – inadequate funding
- #2 – inadequate resources (staff, staff expertise, etc.)
- #3 – difficulties updating non-hospital cases
- #4 – inadequate software and legislation (tied)
- #5 – inadequate linkage resources

“Other” barriers included:

- “Expense of active follow-up not justifiable, passive follow-up is sufficient for reliable survival data”
- Previously performed follow-up to physicians but registry can no longer afford this activity
- Inadequate life tables for the state’s population.

Survival Registry Follow-up Methods



- Hospitals send follow-up
- Linkages
- Follow-back to reporting sources
- Contact patients

Survey Results – Survival Registries:

- Of the ten survival registries, six were SEER. Most have been in existence for 20-30 years, with one being created in 1935 and only one recently (2010). The three that collect recurrence information also capture treatment information.
- Registries were not clearly able to state whether their incidence data quality had changed; many have no analysis on the completeness/accuracy of their survival data.
- Follow-up sources included linkages (100%), hospital-provided follow-up (78%) and active follow-back to reporting sources (67%). Registries use both free and fee-based linkages.
- It is not easy to ascertain start-up costs although several said they expend up to 15% of their annual budget to maintain a survival registry.
- Difficulty updating cases reported by non-hospital sources is the #1 challenge reported, followed by inadequate sources for linkage. “Other” barriers included lack of patient identifiers such as social security number from reporting sources as well as in certain linkage sets.

Solutions to challenges included:

- Moving to Registry Plus software
- Cleaning data to have high-quality linkage identifiers (SSN & DOB)
- Changing active follow-up by contacting hospitals rather than individual physicians: this decreased costs by about \$30,000 annually
- Identifying additional linkage sources
- Have not yet overcome it!

Conclusion:

All registries agree the most important benefit to being a survival registry is the ability to provide outcomes data, which would in turn attract researchers and produce more studies.

Next Steps:

MCR-ARC will perform a gap analysis and use information learned from the survey to decide if it is possible to shift resources and determine if passive follow-up will be sufficient to meet the needs of researchers and public health agencies.

*Based on preliminary results