

## Online obituaries are a reliable and valid source of mortality data



Loss-to-follow-up may result in loss of statistical power by reduction of effective sample size; may introduce bias which compromises the study's validity [1]; result in different patient distribution between study arms [2]; and underestimate mortality data [3]. Reasons for loss-to-follow-up include deterioration in the medical condition, socioeconomic factors, and mortality [4,5]. Tracking the survival status of patients who are lost-to-follow-up is limited by restricted access to death certificate data and patients moving. One strategy to obtain mortality data is to use online obituaries. Chronic disease clinics and studies have used online obituaries to track patients lost-to-follow-up [6–10]. It is uncertain if this is appropriate for research. Our objectives were to evaluate the reliability and validity of online obituaries as a source of mortality data in two chronic diseases: systemic sclerosis (SSc) and idiopathic pulmonary arterial hypertension (IPAH).

Subjects whose survival status was known were randomly selected from the Toronto Scleroderma Program and the University Health Network Pulmonary Hypertension Program. Five online obituary web sites were evaluated [11–15]. Two investigators, blinded to survival status, independently entered the first and last name of each subject in each web site. If the subject was identified as deceased, other matching variables (date of birth, location, diagnosis) were used to verify the patient. Intrarater and interrater reliability was evaluated using the intraclass correlation coefficient (ICC). Pearson's correlation coefficient ( $r$ ) was used to evaluate the correlation between the web site and actual survival status.

We studied 365 (219 SSc, 146 IPAH) subjects (Table 1). The ICC for the intrarater reliability was [Legacy.com](#) 0.95 (95% CI 0.93–0.96); [Yourlifemoments.ca](#) 0.96 (95% CI 0.95–0.97); [Inmemoriam.ca](#) 0.77 (95% CI 0.72–0.80), [Lifeneews.ca](#) 0.75 (95% CI 0.71–0.80), and [Lenecrologue.com](#) 0.21 (95% CI 0.11–0.31). The ICC for interrater reliability using [Legacy.com](#) was 0.82 (95% CI 0.78–0.85). Because the intrarater reliability was lower for the other web sites, the ICC for interrater reliability for these web sites was not evaluated.

[Legacy.com](#) correctly identified the most deceased subjects ( $r = 0.36$  [95% CI 0.27–0.45]). This positive correlation was

**Table 1**  
Patient characteristics

| Characteristics | Cohort, N = 365 | SSc, N = 219 | IPAH, N = 146 |
|-----------------|-----------------|--------------|---------------|
| Female sex      | 273 (74.7%)     | 171 (78.0%)  | 102 (69.8%)   |
| Deceased        | 206 (56.4%)     | 112 (51.1%)  | 94 (64.3%)    |

Abbreviations: SSc, systemic sclerosis; IPAH, idiopathic pulmonary arterial hypertension.

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**Table 2**

Correlation of web site findings and known survival status

| Web site                  | Correlation coefficient, $r$ (95% CI) |
|---------------------------|---------------------------------------|
| <b>Legacy.com</b>         |                                       |
| Total cohort              | 0.36 (0.27, 0.45)                     |
| SSc                       | 0.34 (0.21, 0.45)                     |
| IPAH                      | 0.41 (0.26, 0.53)                     |
| <b>Inmemoriam.ca</b>      |                                       |
| Total cohort              | 0.06 (−0.04, 0.16)                    |
| SSc                       | 0.08 (−0.05, 0.21)                    |
| IPAH                      | 0.01 (−0.15, 0.18)                    |
| <b>Yourlifemoments.ca</b> |                                       |
| Total cohort              | 0.09 (−0.01, 0.19)                    |
| SSc                       | 0.07 (−0.05, 0.21)                    |
| IPAH                      | 0.11 (−0.05, 0.27)                    |
| <b>Lifeneews.ca</b>       |                                       |
| Total cohort              | 0.08 (−0.02, 0.18)                    |
| SSc                       | 0.02 (−0.11, 0.15)                    |
| IPAH                      | 0.16 (−0.01, 0.32)                    |
| <b>Lenecrologue.com</b>   |                                       |
| Total cohort              | 0.12 (−0.02, 0.18)                    |
| SSc                       | 0.09 (−0.04, 0.22)                    |
| IPAH                      | 0.19 (0.03, 0.34)                     |

Abbreviations: CI, confidence interval; SSc, systemic sclerosis; IPAH, idiopathic pulmonary arterial hypertension.

similar across diseases (SSc  $r = 0.34$  [95% CI 0.21–0.45]), IPAH ( $r = 0.41$  [95% CI 0.26–0.53]) (Table 2).

We found that selected obituary web sites were reliable and valid sources of survival data. Traditional sources of survival data include clinic charts, hospital medical records, or death certificates. However, these sources have critical limitations [16]. Outpatient charts are dependent on notification that the patient is deceased or has moved. Hospital records are only useful if the terminal event occurred as an inpatient. Most investigators do not have access to death certificates. Furthermore, death certificates have been shown to be an inaccurate source of cause of death data as individuals unaware of the full medical details, or insufficiently trained in accurately indicating the required information, frequently complete them [16,17]. The inaccuracy of death certificates is particularly true in older patients that have a greater number of comorbidities [18].

In summary, use of selected online obituaries is a reliable and valid method to collect mortality data. This approach may be used to track the vital status of some patients who are lost-to-follow-up.

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## New insights into smoking cessation question the effectiveness of nicotine replacement therapy



Stanley and Massey’s [1] recent analysis of a Cochrane systematic review on smoking cessation is an important addition to the ongoing debate around the efficacy of nicotine replacement therapy (NRT) and other pharmaceutical interventions in helping smokers to quit. Proponents of NRT, including leading clinical and professional bodies in the United States [2], the United Kingdom [3], and Australia [4] base their position on randomized clinical

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