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NorthPoint Domain Inc.
One Joy Street
Boston, MA
02108-1403 USA

(800) 603-1420

www.northpointdomain.com
memberservices@npdinc.com

Most Consumers Willing to Share Personal Data

Privacy and safety must be respected, however

Consumers are generally willing to share information from their personal health records so long as they have the power to select the conditions, according to a study published in the June issue of the *Journal of Medical Internet Research*.

Access to personal health records could benefit public health research greatly in part by fostering improved understanding of health outcomes, barriers to care and adherence, follow-up, and follow-through. The recently established Health Information Technology for Economic and Clinical Health (HITECH) Act has as its goal harnessing digital technology to “prevent and treat illnesses and to improve health” and to aid in the collection and analysis of health information.

However, little was known about individuals’ attitudes toward sharing. The authors of the current study thus surveyed a group of people in an urban area of the northeastern United States.

Using self-report survey, qualitative questionnaire, semi-structured focus group, and one-on-one interview, the authors asked 181 early adopters of a personally controlled health

Participants used the health record and also sat in on a demonstration session in which they interacted with a live system that was not populated with their own data.

record about their willingness and interest in sharing personal information. Participants used the health record and also sat in on a demonstration session in which they interacted with a live system that was not populated with their own data. There were three subject groups: an employee and student population, a community-based health maintenance organization popu-

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lation, and a retiree and health advocacy mailing list population. Most participants reported their health as good to excellent, high levels of education, moderately high levels of income, female gender, and white race.

Analyses revealed high levels of willingness to share personal health information for disease monitoring, evaluation, and needs assessment, but also a strong concern for privacy and safety issues. Ninety percent of subjects reported that strict anonymity would increase the likelihood that they would share; 71 percent said guaranteeing privacy but not anonymity would encourage them to share; and 79 percent said a way to view who accessed their information would increase their willingness. Restricting the

use of their information to health research and to trusted intermediaries were also expressed as important prerequisites to sharing. Greater preference for an “opt-in” versus “opt-out” default mode was observed.

The authors concluded that more research in diverse populations is necessary, but that “allowing users to select their preferred conditions for sharing may be vital to supporting sharing and fostering trust as may be safety monitoring mechanisms.”

Source: Weitzman ER, Kaci L, Mandl KD. 2010. Sharing medical data for health research: the early personal health record experience. *Journal of Medical Internet Research* 12(2):e14.

Beyond 4.5 Hours, Alteplase Not Beneficial for Ischemic Stroke

Early therapy is best

Every effort should be made to treat ischemic stroke patients as soon as possible because the risk-benefit ratio of intravenous alteplase is not desirable beyond 4.5 hours, according to a study published recently in *The Lancet*.

Although it is well-established that early treatment with intravenous recombinant tissue plasminogen activator is ideal, less conclusive data existed regarding effects after 3 hours. The authors of the current study pooled data from 2 important clinical trials (the National Institute of Neurological Disorders and Stroke 2 and the European Cooperative Acute Stroke Study III) with data from 6 newer trials to re-examine the relationship between time-to-

treatment and outcome.

A total of 3,670 participants – 1,850 randomly assigned to receive alteplase and 1,820 randomly assigned to receive placebo – were studied. Median age was 68 years. Patients who were rapidly improving, who had seizure associated with stroke onset, or serum glucose concentration below 2.8

mmol/L or above 22.2 mmol/L were excluded. Intravenous alteplase doses were 0.9 mg/kg or 1.1 mg/kg with the first 10 percent given as a bolus in the first minute and the rest infused over 1 hour. Oral or intravenous anticoagulants or antiplatelet agents were not allowed in the first 24 hours after treatment.

Investigators in all studies used NIHSS score, modified Rankin scale, and Barthel Index up to 3 months post-treatment, to

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assess mortality, hemorrhage, and other outcomes.

The authors found significant benefit for alteplase treatment in each interval up to 4.5 hours, but none between 4.5 and 6 hours. Mortality rates increased as time-to-treatment increased. Although alteplase is effective, about 1 in 3 patients treated within 3 hours and 1 in 6 patients treated within 4.5 hours did not achieve significant benefit. Hemorrhage rates were independent of time-to-treatment. The authors concluded that “the stroke community is expending [too] much effort to identify

patients who might benefit from treatment given at the end of the therapeutic time window” and that “mortality increases with [time-to-treatment] longer than 4.5 hours.”

Source: Lees KR, Bluhmki E, von Kummer R, et al. 2010. Time to treatment with intravenous alteplase and outcome in stroke: an updated pooled analysis of ECASS, ATLANTIS, NINDS, and EPITHET trials. *The Lancet* 375:1695-1703.

Hot Topic Highlights

Neuroscience Domain recently posted the following Hot Topics to your website:

Depression Frequent After Traumatic Brain Injury

More than half of people who experience a traumatic brain injury (TBI) develop major depression in the year following the incident, according to a study published in the *Journal of the American Medical Association*. Less than half of the patients who experienced depression during the study received treatment. A total of 297 of 559 people developed depression in the year following a TBI, and only 44 percent received treatment of medication or counseling.

Source:

Bombardier CH, Fann JR, Temkin NR, et al. 2010. Rates of major depressive disorder and clinical outcomes following traumatic brain injury. *Journal of the American Medical Association* 303(19):1938-1945.

Common Parkinson's Drug May Cause Impulse Control Problems

People with Parkinson's disease (PD) who take dopamine-replacement therapy may be putting themselves at risk for impulse control disorders, according to a study published recently in the *Archives of Neurology*. The analysis of 3,090 PD patients revealed that patients taking dopamine agonists had a 2.0- to 3.5-times greater likelihood of having an impulse control disorder than patients taking other medications. Taking levodopa as well as a dopamine agonist increased impulse problems by another 50 percent.

Source:

Weintraub D, Koester J, Potenza MN, et al. 2010. Impulse control disorders in Parkinson disease. *Archives of Neurology* 67(5):589-595.