FEASIBILITY OF INTERNET-BASED DATA COLLECTION WITH
PEOPLE WHO HAVE KIDNEY DISEASE

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Traditional methods of data collection can be costly when large
samples are required. Internet use is similar for people on dialysis and
those with disabilities (Schattel et al., 2006), but little is known about
Internet-based data collection for survey research. As part of a broader
initiative to develop a computerized adaptive assessment of health
status for use in chronic kidney disease (CKD), we collected health-
related quality of life data via the Internet for a large-scale item
calibration study.

A survey was launched on the National Kidney Foundation's (NKF)
website in July, 2007. After pilot testing (N=100) to ensure adequate
representation by CKD stage, 31,000 recruitment letters were mailed to
NKF's Patient & Family Council, People Like Us Patient Advocates,
and Kidney Early Evaluation Program participants with eGFRs < 60
mL/min/1.73m^2, and e-mailed to NKF ListServes (e.g., Patient &
Family Council, People Like Us Patient Advocates, Transaction).
Also, a recruitment ad was published in *Kidney Beginnings*.

As of November 2007, 1,653 people consented to participate in the
study. Of those, 521 were screened or dropped out prior to beginning
the survey. Seventy-five percent (N=849) of those remaining
completed the entire survey. This CKD sample was diverse [ages 18-
90 ($\underline{M}$=50); 30% dialysis, 27% transplant]; however, men (37%) and
African-Americans (12%) were underrepresented and those of higher
SES (29% >$75,000) and educational attainment (49% college or
graduate degree) were overrepresented.

Data collection via the Internet is feasible, yet targeted recruitment
efforts are needed to ensure adequate representation of particular sub-
groups. Final sample results and lessons learned will be presented.