Ethical issues in the conduct of longitudinal studies

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Abstract

Many complex ethical and legal issues arise in the day-to-day conduct of longitudinal studies of addiction treatment. These issues are rooted, in part, in (a) the sustained and potentially ambiguous relationship between research staff and study participants, (b) the frequently changing clinical and legal status of the participants, (c) the assertive methods required to sustain contact with participants, and (d) the numerous systems of care and control in which participants are involved. To identify common ethical and legal issues that arise in such studies, the authors conducted individual and group interviews with staff (case trackers, field trackers and interviewers) from a research team that has completed more than 12,700 treatment follow-up interviews.

The ethical issues identified through these interviews fell into seven broad arenas: 1) informed consent for research participation, 2) confidentiality and information disclosure, 3) relationship boundaries between study participants and research staff, 4) duty to warn/report responsibilities, 5) questions of autonomy and privacy, 6) compensation for research participation, and 7) data integrity. Case studies are presented and discussed that illustrate common ethical dilemmas within each of these seven areas. The ethical dilemmas described can be effectively managed via ethically-informed research protocol; staff training in ethical decision-making; monitoring and supervision; and collective debriefing of critical events.

Key words: research, follow-up, ethics, informed consent, confidentiality, relationship boundaries, duty to warn