

Patient Outcomes Online:

Guidance for Collection of Prevalence Data that adheres to the principals of Confidentiality and Anonymity.

Prevalence data provides an important avenue for organizations to track outcomes, monitor adverse events, and detect trends that portend important changes in clinical outcomes. JBI Patient Outcomes OnLine (POOL) is a web portal that enables the tracking and reporting of prevalence data. As data is usually entered in the system as an event or outcome occurs, users are encouraged to be mindful of the principals associated with confidentiality and anonymity and avoid using labels that may later, be used to identify a particular individual. It is expected that individual organizations will have ethics committees and requirements for data collection and entry, the guidance below is not intended to replace local ethics requirements, and should be considered a minimum standard.

- When using POOL, the data should ideally be anonymous while preserving the integrity and usefulness of the data. The best way to achieve this is to:
 - Avoid using real names at any time (pseudonyms are acceptable);
 - Avoid using medical record numbers or any number that is specific to an individual (such as bed numbers, or social security numbers);
 - Avoid printing the data entry page that lists the participants per outcome;
 - Avoid keeping multiple copies of a paper-based register (if using one keep a log of any duplicates and to whom they were given);
 - Ensure that only the project coordinator has access to the paper register, Ensure the register is kept secure (in a locked cabinet or drawer within a secure office)
 - Ensure the paper based register is destroyed or put in a “confidential waste” bin on completion of the project

Further reading

1. BMJ 2007;334:1330-1331 (30 June), doi:10.1136/bmj.39247.679329.80 BMJ 2006;333:196-198 (22 July), doi:10.1136/bmj.333.7560.196