

Privacy of Information and the Disaster Registry

The privacy of enrollment information has been an important design consideration in the development of the Registry Program and the Internet technology that supports the program's operations. The program has set in place the following protections:

Programmatic Protections:

- ⤴ The Registry Program devised Privacy Policies that fully meet HIPAA standards. These policies have been subjected to repeated legal review and approval.
- ⤴ The Registry's Privacy Policies are publicly available and offered for review prior to enrollment to permit fully informed consent.
- ⤴ The disclosure of health information is highly recommended, but not required. At-high risk individuals who use in-home services to support their independence may choose to enroll without furnishing information regarding their health.
- ⤴ All program operations are conducted in strict compliance with the Privacy Policy and on a highly restricted need-to-know basis.

Technological Protections:

- ⤴ All enrollment information resides on City of Lincoln servers. Every defensive, technically possible, measure is in place to protect the security of the servers and data.
- ⤴ The security of the servers and data is overseen by a national award-winning staff of data processing professionals. Security is a constant concern.
- ⤴ On-line access to data is carefully limited to the leadership of sponsoring organizations and delegates with data management or emergency response responsibilities.
- ⤴ Access to information is individually password protected. Accountability for access to and the usage of information is carefully maintained.
- ⤴ Multiple local Disaster Registry programs across Nebraska store data on City's servers. Enrollment data is stored in separate, fire-walled data bases to prevent unauthorized access.

Risk and Self-Determination:

Ultimately, the decision to enroll in the Disaster Registry program is a matter of individual choice regarding risk.

Real-life experience and extensive subsequent research clearly indicates functionally and/or health impaired individuals disproportionate face the most severe consequences. Natural or man-made disasters in this population are more likely to disrupt care, cause injury and the loss of life. Emergency Managers and health professionals believe these disproportionate dangers far outweigh the highly unlikely detrimental use of Registry information.

In the end, the South Central Nebraska Disaster Registry supports self-determination. The evaluation of risk and resulting choice regarding enrollment belongs solely with the individual and/or their family.