

**AMIA Invitational Conference on Secondary Use of Health Data
June 14-15, 2007**

**DRAFT: Policies and Practices to Look for from Organizations that Collect
Your Personal Health Information: A Consumer Checklist**

- ✓ Does the organization prominently post a privacy policy with an effective date?
- ✓ Is the privacy policy written in clear and understandable language with definitions of terms?
- ✓ Will you be notified in advance of any changes to the privacy policy, and can you terminate any agreements, without penalty, if you do not agree to the change?
- ✓ Does the privacy policy describe how your data are handled if the organization is sold, merges with another organization, or files for bankruptcy?
- ✓ Does the privacy policy clearly list any and all uses of your data, whether or not you can be identified?
- ✓ Does the privacy policy describe how your data are protected?
- ✓ Does the privacy policy clearly list any and all sharing of your data with other organizations, whether or not they are affiliates or business partners, and whether or not you can be identified?
- ✓ Does the privacy policy describe whether your permission is required to share your data and, if so, how your permission is obtained?
- ✓ Does the privacy policy describe how you can contact a privacy official with questions or complaints about the organization's privacy policy or behaviors, and receive a timely response?
- ✓ Does your decision to deny permission result in any adverse actions against you (for example, denial of services)?
- ✓ Can you obtain a free report at any time of who has accessed your data and when?
- ✓ If you terminate an agreement, will the organization remove (and no longer use or disclose) your data, whether identifiable as yours or as part of a group?