

**Report from the ACD Participant and Data
Protection (PDP) Working Group for
GAIN/GWAS**

**Presentation by
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to the
Advisory Committee to the Director, NIH
June 6, 2008**

Report from the ACD PDP Working Group

ACD PDP Working Group Meetings in 2008:

- Conference Calls
 - January 29, 2008
 - April 25, 2008
- Planned in-person meeting
 - October 29 – 30, 2008

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- Briefed about inadvertent data releases:
 - Discussed nature of the releases, the level of risk associated with various types of disclosures and the terminology used to describe them;
 - Discussed timing of notifications;
 - Concluded that NIH's response was careful and appropriate in both cases.

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- Received reports on:
 - COPR's interest in and support of the GWAS policy
 - GWAS oversight
 - NIH progress towards implementing the ACD recommendations on GWAS

- Identified need for:
 - additional education of health care providers about the genetics of common and complex disorders, the sensitivity of GWAS data and attendant privacy issues

- Discussed the importance and complexity of issues related to the return of research results
 - Established a small subgroup to define the parameters of concern on this topic

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- Topics for discussion at the next meeting, October 29 – 30, 2008:
 - Policy implementation issues for IRBs
 - Group harms
 - Return of research results
 - Others?