

The Ethics of Biobanking: Two Challenges

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Two Challenges

(Based on my experience as Chair of EGC of UK
Biobank)

Feedback

Consent

Feedback 1

- ❑ Excellent general communication essential to show enterprise worthwhile.
- ❑ Feedback of individual health results from *baseline* tests (eg. BP) seems reasonable
- ❑ But what of incidental findings and research results relevant to participants?

Feedback 2

Points against feedback of individual results later in project

- ❑ Huge volume of data on each person, genetic and phenotypic, applied to many different projects in aggregated form
- ❑ Unethical to release data which cannot be interpreted, without individual explanations and interpretations - genetic counseling?
- ❑ Most data will be meaningless until research completed
- ❑ Quality standards of testing in research setting below those of clinical laboratories

Feedback 3

Arguments for Selective Feedback

- If *analytically valid*, reveal *substantial risk* and *clinically actionable*
- If affected person wishes
- Relevance to others – offspring, relatives

Consent

- Broad? Blanket? Generic? Implied?
- Extendable and Rescindable?
- Renewable? (How often?)
- Effect on others (relatives)

Thank You