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Sharing human samples and patient data: opening Pandora's Box

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HIGHLIGHTS

- Sharing of clinical data and samples still happens mostly on a voluntary basis
- Moral, societal, scientific, and economic reasons are drivers to share patient data and samples
- Concerns of losing control, the impact on incentives to invest, privacy and data protection considerations, pragmatic impediments, and samples' finite nature impede sharing
- Unified, controlled access systems are preferred over full open access models
- A distinction should be made between 'primary' patient data and samples, both of which should be shared as soon as possible, and 'derived' data, created by an intellectual effort of the sponsor.

ABSTRACT

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