

# Recommendations issued to counter patent, proprietary barriers to sharing stem cell data

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An international group of stem cell scientists, bioethicists and experts in law and public policy called urgently today for specific measures designed to counter secrecy and self interest. The recommended measures focus on the sharing of data, materials and collective management of intellectual property related to stem cells.

In a consensus statement, the Hinxton Group—so named for the British city where members first met in 2006—lists five recommendations about data and materials sharing in a field in which patenting and other proprietary claims threaten to slow progress and steer the focus toward big profits rather than advancing public health.

"Progress in human pluripotent stem cell science has been incredibly rapid over the last 12 to 13 years," says Debra Mathews Ph.D., assistant director for science programs at the Johns Hopkins Berman Institute of Bioethics and a member of the Hinxton Group's steering committee.

"The science has moved so fast that there hasn't been much opportunity for the field to develop or reflect on norms or standards for sharing data and materials," Mathews adds, "or to engage in the sorts of collective action now needed in the field to allow both basic and translational science to move forward, and for society to see benefits in the form of new therapies and treatments."

The Hinxton Group—formed by the Berman Institute's Stem Cell Policy and Ethics Program—issued its recommendations today at a panel

discussion about obstacles to openness in stem cell science. The event, held at the headquarters for the American Association for the Advancement of Science, was co-hosted by the bioethics institute and AAAS.

Mathews says the "concrete and actionable" steps called for in the statement require the concerted effort of researchers and their institutions, funders, members of industry and government agencies.

The group's recommendations are to:

1. Establish two central, publicly available databases that would ease the sharing of information vital to scientific progress. One database would include information on all stem cell lines being used in research worldwide. The other would be a central hub for accessing information about stem cell intellectual property rights. Both resources would link to and build on similar registries already in existence.
2. Encourage, support and coordinate an international network of stem cell banks and human tissue and cell repositories. The network would catalyze standardization, coordination and expansion of what is now a patchwork of inconsistent bio-banking and sharing practices.
3. Develop and institute incentives for data and materials sharing through publication, participation in information hubs and other mechanisms. Under this guideline, funders, research institutions and scientific journals would insist researchers submit their data to these "hubs," and that enough information—and materials, where appropriate—would be shared to allow other researchers to evaluate and replicate published work.

Funders and journals would also request that researchers share useful negative data generated in the course of a project, with scientists and clinicians advising journals and funders on appropriate standards for data completeness.

4. Explore options for formal collaborative networks and mechanisms such as patent pools and patent brokering. When collective management of intellectual property can move the field forward, such arrangements could ease growing fears of patent infringement and crippling lawsuits.
5. Adopt licensing practices and patent policies that promote fair, reasonable and non-discriminatory (equitable) access to knowledge and health-care applications. Licensing should follow recommendations endorsed by other professional societies, such as the recommendation to reserve research rights for non-profit institutions and promote access to novel technologies that can help meet critical health needs in both developing and developed nations.

The statement calls on technology-transfer offices at government-funded research institutions to make public their stem cell intellectual property rights. The group also urges [patent](#) offices and key policymakers to reassess whether current standards for granting stem cell patents are appropriate.

Members of the Hinxton Group met in Manchester last November to develop the recommendations, focusing primarily on human embryonic [stem cells](#) and induced pluripotent stem [cells](#).

While acknowledging that [intellectual property](#) rights can help ensure financial return on the much-needed private investments that fund much

translational research, the Hinxton Group says its recommendations aim to uphold overriding societal goals at the same time. "We believe that licensing practices in the biological sciences should reflect the goal of global justice," the group states in the document, "borne out of a human dignity common to all and a universal commitment to reduce suffering."

**More information:** Johns Hopkins Berman Institute of Bioethics:  
[www.bioethicsinstitute.org](http://www.bioethicsinstitute.org)

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