

New principles for patient data use balance research benefits, individual privacy

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In an ever-evolving world of big data, more powerful analytics, and the

application of artificial intelligence fueled in part by consumer, research and patient data, the American Heart Association has released new policy guidance for the collection, storage, ethical use and sharing of patient data.

While consumers and patients may be aware of social media companies' health information [collection](#) strategies and practices, many are unaware that health data collection and sharing can be tremendously valuable to advance [health research](#), leading to [new discoveries](#) and enabling more informed health decision-making.

The new AHA policy statement, "Principles for Health Information Collection, Sharing, and Use," has been published in the journal, *Circulation*.

With these advances come concerns about privacy regarding the handling of sensitive health information, ensuring that research is also designed for or generalizable to historically excluded and underrepresented communities, and the network of complex laws attempting to govern this space.

"These new principles regarding health information collection, sharing and use will inform the Association's public policy work and commitment to life-saving research, and underscore the need for transparency, privacy, education and a commitment to health equity across the data sharing spectrum," said Kayte Spector-Bagdady, J.D., M.Be., Co-Director of the Center for Bioethics and Social Sciences in Medicine at the University of Michigan Medical School.

As outlined in the statement, the following guiding principles will help to protect the privacy of patients and bring much needed clarity and regulation to a vast sector of a growing industry.

- Funders of medical and [scientific research](#) should prioritize and support research generalizable to or designed for historically underrepresented communities.
- Entities that collect health information and researchers who use it should be held to high standards of behavior, including respecting the people from whom the data are derived and responsible stewards of this valuable common resource.
- Entities that collect health information and researchers who use it should be transparent about potential and actual future uses with patients and other data contributors.
- Awareness, education and involvement of patients in low-risk research is encouraged to enable important future discoveries.
- Medical and scientific researchers, [research institutions](#) and publishers should commit to making health information that is derived from research findings and innovations widely accessible, along with access to supporting data of sufficient quality to validate and replicate research findings and data documentation that permits reuse and interoperability of the data.
- Federal law should provide a consistent baseline of protection and enforcement for individuals whose [health information](#) is collected and used.

More information: Kayte Spector-Bagdady et al, Principles for Health Information Collection, Sharing, and Use: A Policy Statement From the American Heart Association, *Circulation* (2023). [DOI: 10.1161/CIR.0000000000001173](#)

Provided by American Heart Association

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