

Mary Nielsen
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Dear Committee,

I'm Mary Nielsen, a member of the Oregon Psilocybin Services Collaborative Community, an education and advocacy group for the equitable access to psilocybin services in Oregon.

I'm concerned about the data privacy and health equity risks of SB 303 as currently written. I urge you to seriously consider the sound reasoning behind the submitted amendment to protect the safety of Oregon citizens' personal data & to offer equitable access to our hurting communities who would benefit from the healing power of psilocybin.

Research & data can be powerful forces for good when carried out with voluntary participation, appropriate resources, & strong privacy protections. Further changes are necessary beyond -2 Amendment. The current language threatens citizens' privacy and would create obstacles for members of marginalized communities from seeking psilocybin services, including working in this new opportunity.

The OPSCC's Data Privacy Amendment addresses 5 concerns. Please consider the following changes to language:

1. Opt-in to ensure informed consent: The current language collects clients' data unless they specifically request to be excluded. This makes it more likely that clients, who might be in a vulnerable condition, are inadvertently included without understanding the risks & their rights. **Informed consent in research requires clients to affirmatively consent to participation, & this program should follow that protocol, particularly given SB 303's goal of promoting equity, & the history of government research abuses, which disproportionately impacted marginalized communities.**
2. Clearly define & limit data: The bill purports to mandate only aggregated data be sent to OHA, but its language is far too vague and would allow various interpretations that jeopardize client privacy & decrease the security & usefulness of the data. This amendment precisely defines the dataset that may be transmitted to OHA, & ensures it contains no individual or personally identifiable data.
3. Limit the data program to what is expressly described in the bill: The current version of SB 303 gives OHA unlimited discretion to add by rule any additional data collection requirements. Psilocybin services data are far too sensitive to give an agency a blank check subject to various unknown pressures in the future. OPSCC's amendment removes this discretion so that **only legislators, directly accountable to their constituents, would determine and define the need for any future expansion of the scope of data collection.**
4. Provide data equity: Under the current version of SB303, OHA would be required to publish only a fraction of the data it collects to the public, while the remainder is shared with just one university, **excluding** other researchers & the public. **Why?** Our amendment requires OHA to publicly publish all of the aggregated data to ensure equitable access for researchers and citizens from every community.

5. Ensure OHA fully aggregates data before sharing or publishing: Even without individual client information, data transmitted to OHA will be associated with particular service centers & their owners, operators, and workers, decreasing privacy & increasing risk for these individuals. Our amendment requires OHA to only share or publish state-wide data that have been deidentified with respect to service centers & their personnel, & aggregated across service centers & geographic locations.

Thank you for the opportunity to present my concerns. I know you will take this responsibility to protect Oregonians seriously.

Sincerely,

Mary Nielsen

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