

CONSENT, PRIVACY & DATA GOVERNANCE

A summary of what Bissell Centre participants have to say

There is a need for an expanded understanding of ethics and consent in working with data in the social services sector. It makes sense for our data handling philosophies and policies to be informed by those whose information makes up our datasets.

As such, we decided to talk with our participants to understand what they think about the collection, storage and use of their information.

Conversations from 5 community workshops were transcribed and analyzed and the emerging themes were:

1. We (participants) feel **ownership** of our data, and care about maintaining **control** of it via consent
2. We're concerned about the **security** of our information, and want to protect our **safety**
3. We share our information to get access to **services** but we want to see the information used **for learning** to make those services better

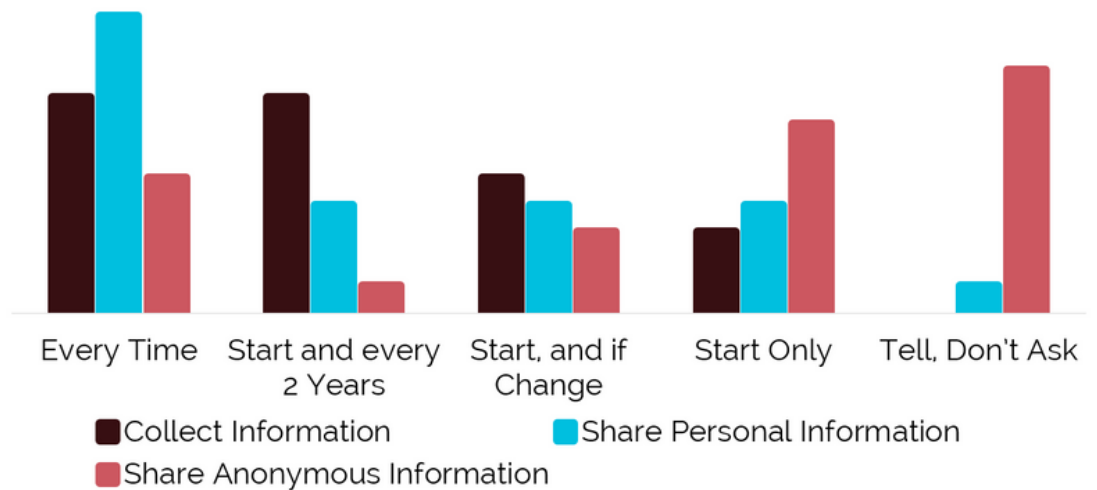


"I have this anonymous person, yes, but this anonymous person is a real human being" [Workshop 5]

"I would love to help somebody else, take my info, as long as you're not using it to slander me, put me down" [Workshop 2]

We did a poll about consent in the workshops. The results indicate that consent is more important the more personal the information is, and less important once the information is aggregated.

When Do You Expect To Give Consent?



In summary, participants typically are okay with the collection of their information providing there's transparency around the process, and most importantly that consent has been sought. They think that their information should be used for operational purposes in a private and efficient way. Participants feel that their information should be used for evaluation and research. Transparency and consent are considered necessities once again. Some are interested in being kept informed, or even contributing to the process. Participants desire consent processes that find a balance between keeping them informed, allows control, yet isn't too taxing.