Bissell Centre

Participant Perspectives on Privacy, Consent and Data Governance

Please note that this project is ongoing, and results will be updated.
For future updates, please contact

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Bissell Centre

- 100+ years old
- Down Town Edmonton
- Range of poverty elimination programs

Reason for this project

- Approached to share
- Leverage external capacity
- Lack of legislation
- Conflicting advice
- Bissell Centre's philosophy – person centred work

Key Questions

- What do participants think of data collection?
- What do participants think about operational data being put to other uses?
- What do participants think of data being shared to learn more about the sector?
- What type of consent process would participants prefer?
- How would participants like data to be used?

Methods

- Vignette – animated video
- Focus Group s
- Background materials
  (e.g. of reports)

Ethics

- ARECCI tools
- External informal review
- Internal feedback

Participant recruitment

- Active in ETO (last 2 months)
- In our Community Space
- Attending parenting program
- Staff referral

Participants

	One	Two	Three
	Parenting Program	Community Space	Community Space
Female	4	3	1
Male	2	4	8
Total	**6**	**7**	**9**
Kept in the loop	**3**	**1**	**5**

Information Journey

Information Journey

0:24 / 1:58

Information Journey

John's files are password protected

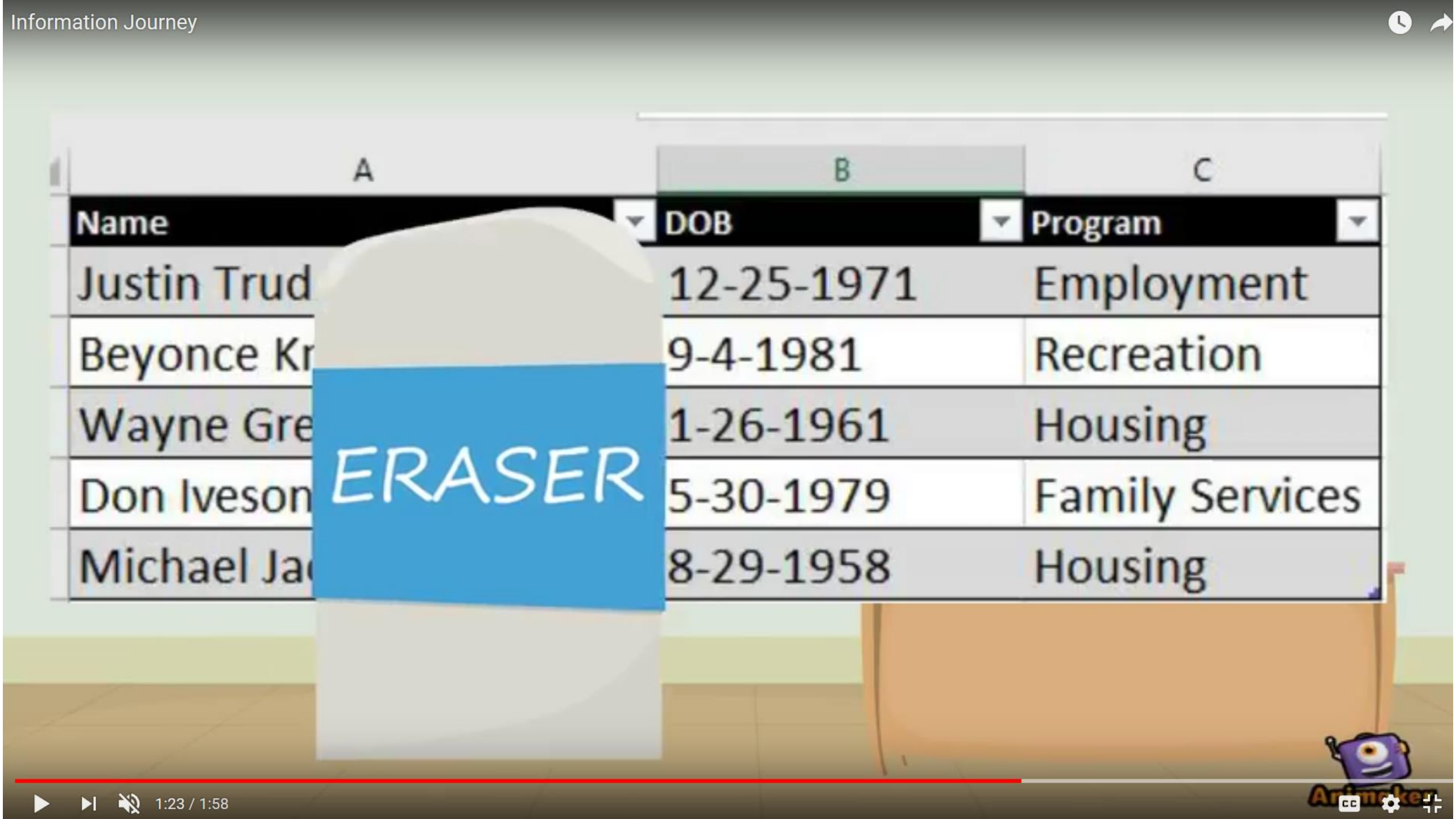
0:33 / 1:58

Information Journey

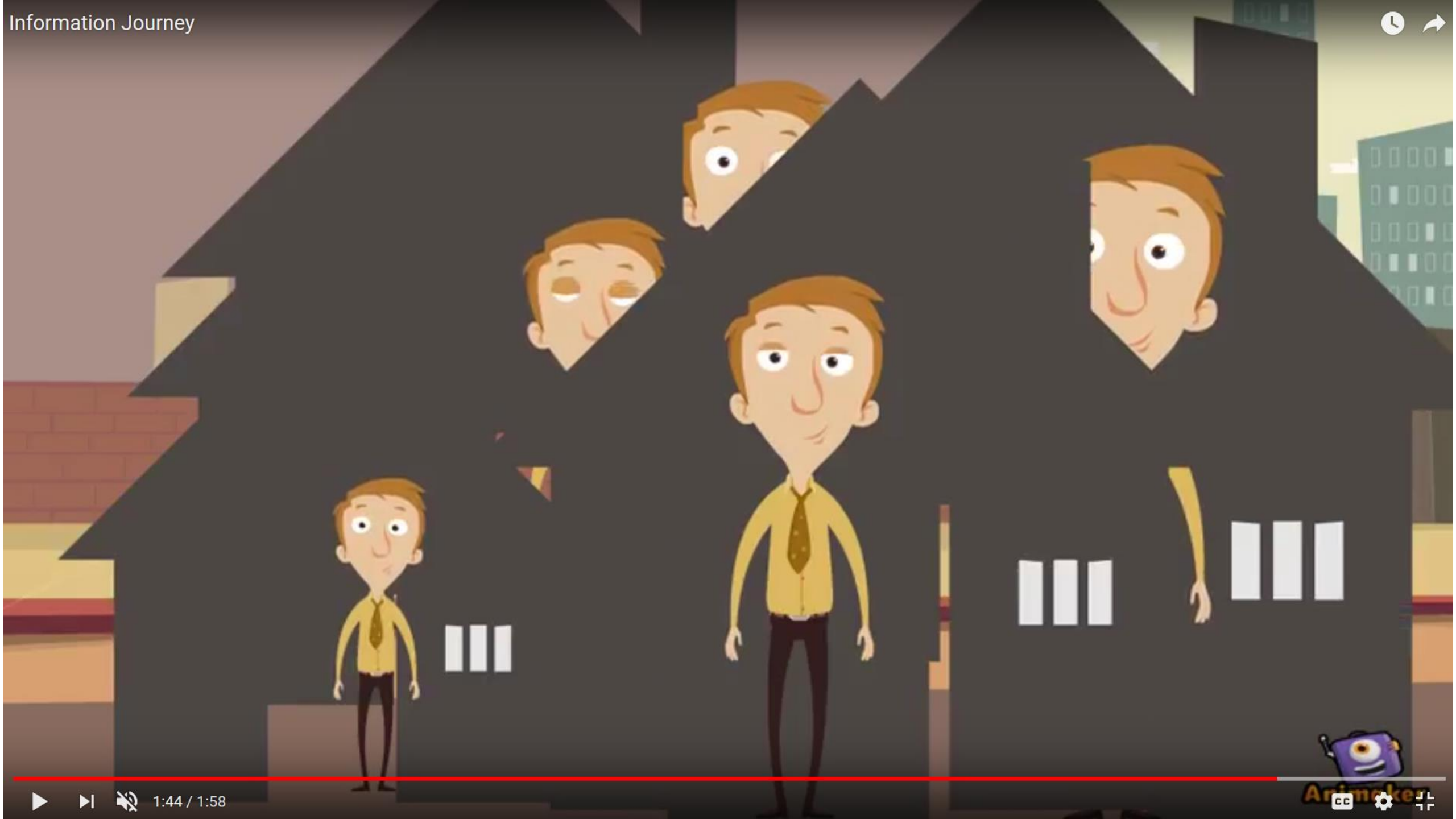
I need to find the numbers!

1:08 / 1:58

Information Journey



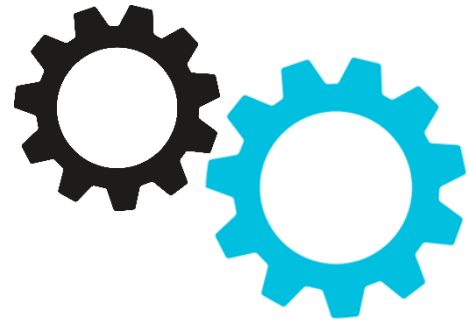
1:23 / 1:58


Information Journey
1:44 / 1:58

Preliminary Results - Overarching Themes

- Service Impacts
- Control and Trust
- Accountability
- Personhood

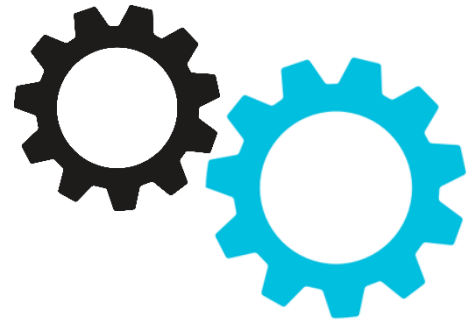
Service Impacts



"If that [data linkage] *happens, why did my services get passed over?" – Group 2*

"If it helps me get services faster or better then I want to know that it happens" – Group 2

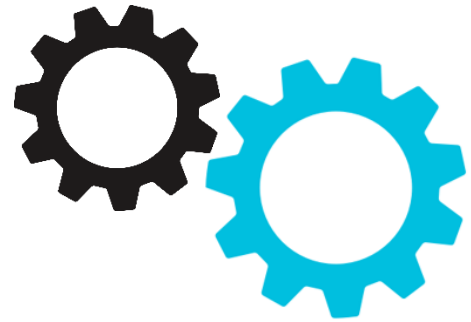
Service Impacts



"The more information you give, the more help you get" – Group 2

"There'd be less double dipping" – Group 2

Service Impacts



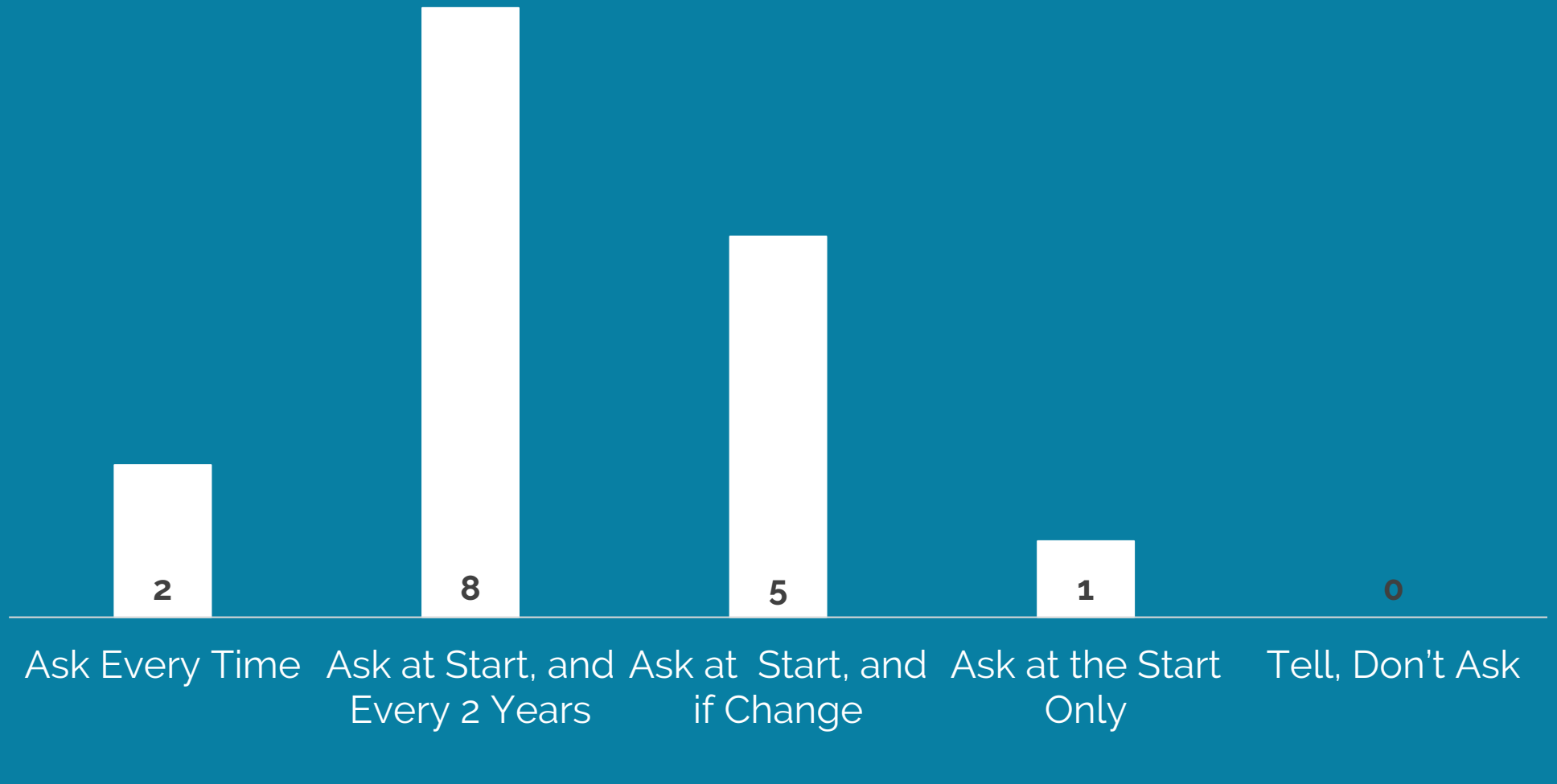
"Not if it's going to be used against them" – Group 3

"Some information should be shared, but for instance, the food bank, they won't be able to last the whole month if only accessing one food bank but have a large family" – Group 3

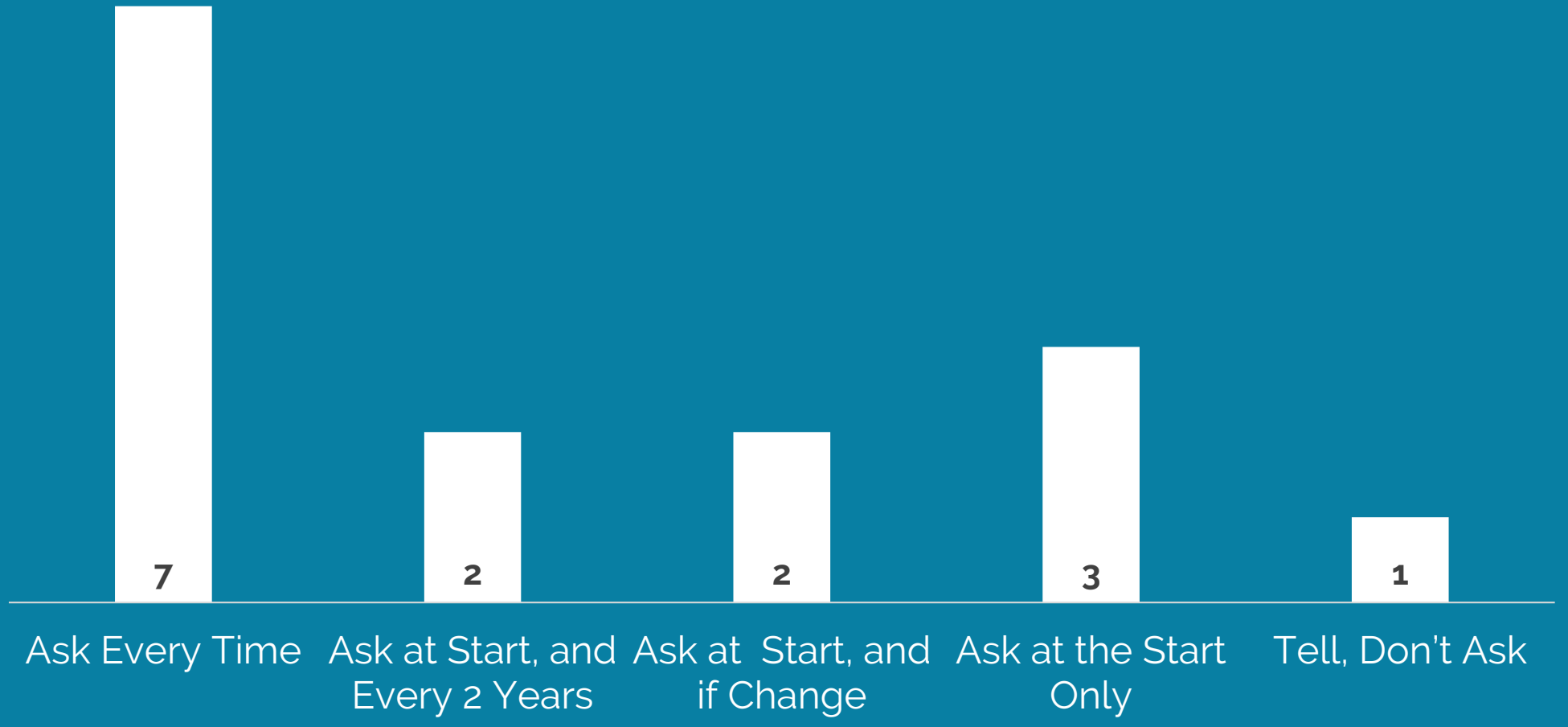
Control and Trust

"If the person didn't sign a consent for their information to be shared, then don't share their information" – Group 1

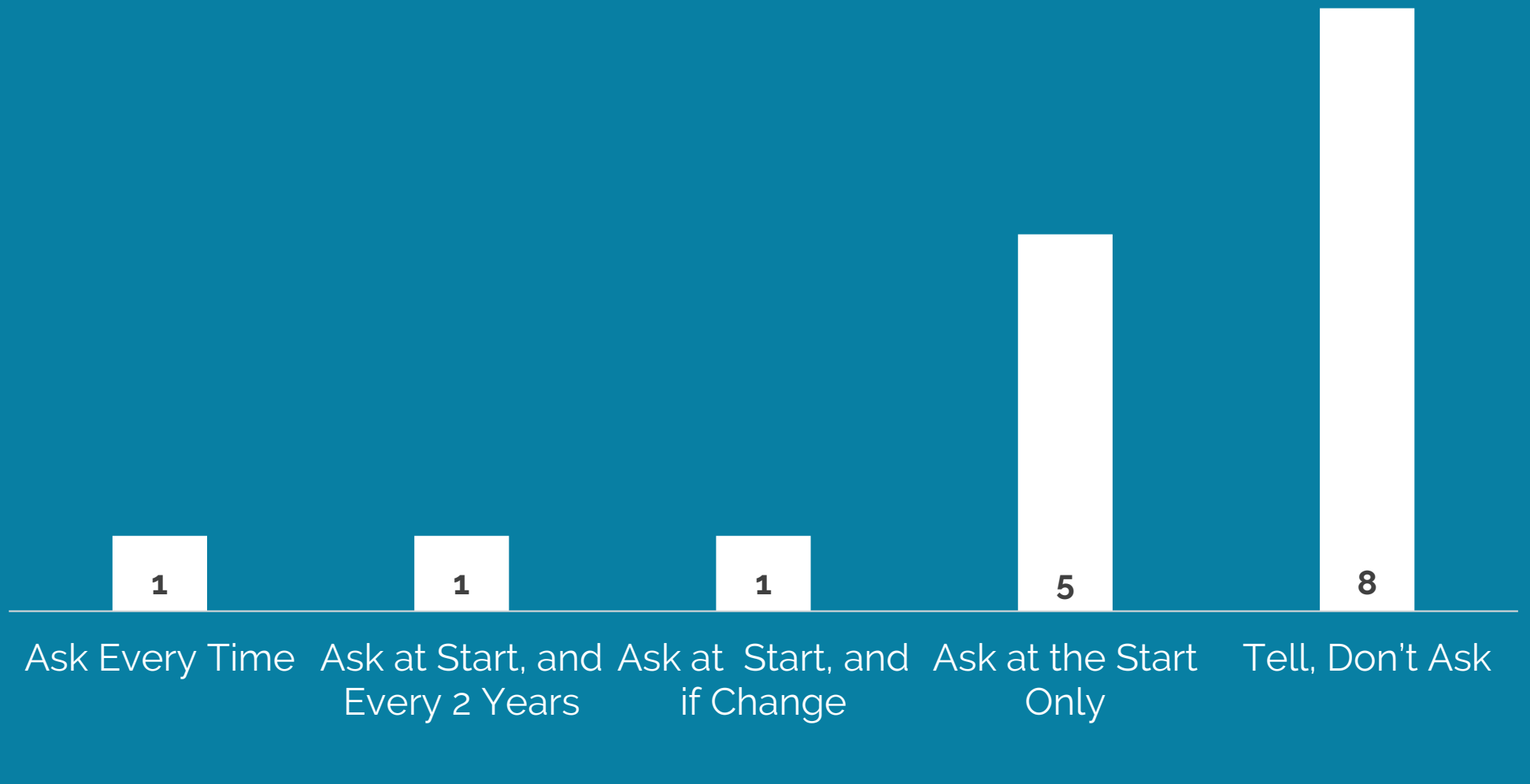
When should John be asked permission to **COLLECT** his information



When should John be asked permission to **SHARE** his **PERSONAL** information



When should John be asked permission to **SHARE** his **ANONYMOUS** information



Control and Trust

- Access procedures:

  "No volunteers, they don't care as much, they're only temporary… and not as experienced" - Group 2

  "There should be a screening process so we know why they are requesting it and what their platform is. That would be very important" – Group 3

  "Needs to minimize the harm to the individual" – Group 3

Accountability

- If…then…

  “If it helps someone else, take my info, as long as you don’t slander me, don’t call me a crackhead” – Group 2

  “I think it’s okay because everyone deserves help if they want it” – Group 1

Accountability

“I knew they had a physical folder, not an electronic one” – Group 3

“Transparency is important” – Group 3

Accountability

“It would be good for participants to find out if their anonymous information was used” - Group 1

“The information could help us figure out if housing in Edmonton even works!” – Group 2

Personhood

"I was one of the 769 families helped by family support. I ate some of those meals" – Group 1

"A lot of places I go to, I am a number. I don't like it, it's not personal." – Group 1

Surprises and Observations

- High level of engagement
  - (surveys are typically not well responded to)
  - 9/22 elected to be kept in the loop

- More interested in data sharing (with control) than anticipated

- Difficult to keep on topic – salience of service access and quality often took precedence despite keen interest

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Next Steps

- Two more workshops planned
- More comprehensive analysis of all data
- Work to integrate findings into consent processes and organisational policies
- Keep in touch if you're interested in the outcomes from this project!

Bissell Centre

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