



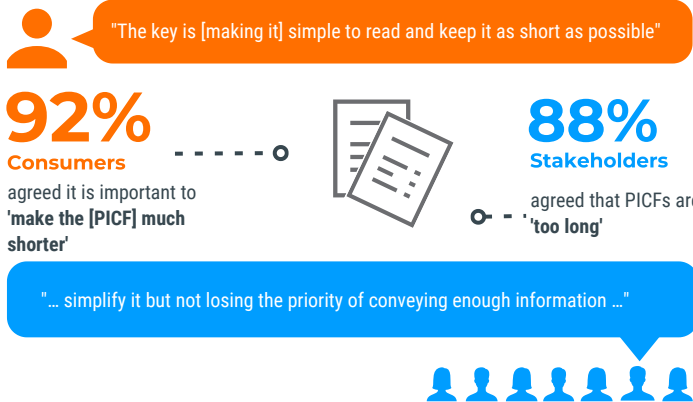
# InFORMed

Redesigning Consent to Research

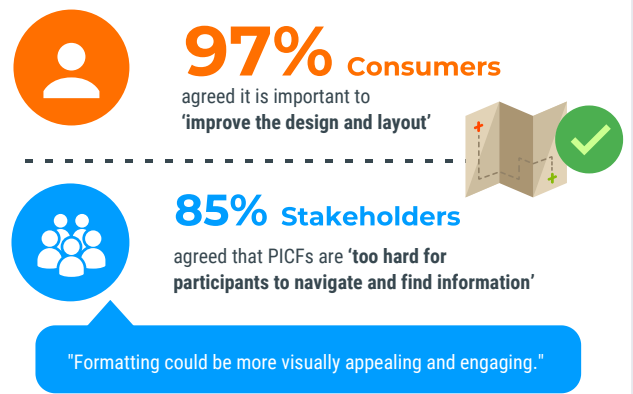
## Consumer & Stakeholder Survey Findings on Participant Information and Consent Forms (PICFs)

CT:IQ initiated the InFORMed project, working with consumers and other stakeholders to redesign and simplify PICFs in order to help consumers make more informed decisions about participating in research. Two separate surveys were administered to consumers and stakeholders exploring similar themes. The survey insights below support the need for change.

### LENGTH



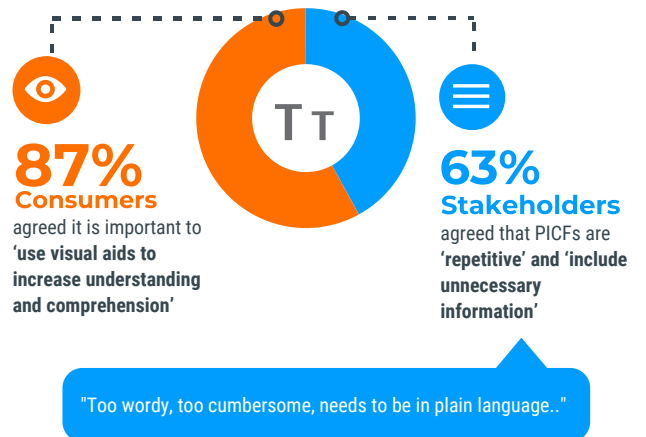
### LAYOUT & NAVIGATION



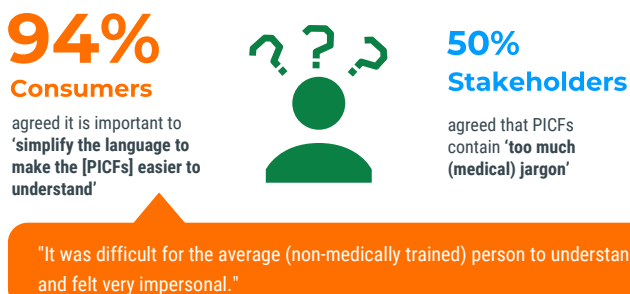
### CONTRACTUAL



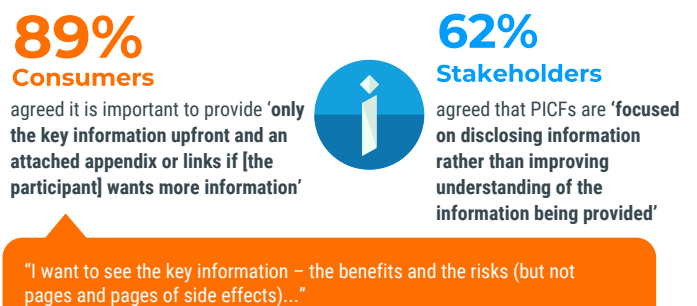
### TEXT DENSITY



### LANGUAGE



### UNDERSTANDABLE INFORMATION





# InFORMed

Redesigning Consent to Research

## Project Summary

- ✓ Participant Information & Consent Forms (PICFs) are often long, complex and not consumer focused.
- ✓ Nine out of 10 consumers agreed these forms need a significant overhaul to be simple, straightforward, and more consumer friendly.
- ✓ The CT:IQ initiated InFORMed project is working with consumers and other stakeholders to develop a new national PICF to support consumers to make more informed decisions about participating in research.
- ✓ In October 2021, two national surveys were conducted, one with consumers and one with other stakeholders, to identify the issues with current PICFs and explore areas for improvement.

## Survey Respondents



### Consumers: 157 complete responses

93 had participated in research (56% clinical trials, 39% in social science/ behavioural research), most aged 35-70 years, English speaking, located across Australia, in metro and regional areas



### Other Stakeholders: 558 complete responses

275 researchers/sites, 110 investigator initiated/academic researchers, 95 ethics and governance, 62 sponsors/contract research organisations, 16 other

**All respondents agreed that the consumer voice is the most important in this conversation about PICFs.**

The surveys received ethics approval from Swinburne University Human Research Ethics Committee in accordance with the National Statement on Ethical Conduct in Human Research (2007, updated 2018).

Check out the project:



CT:IQ  
Clinical Trials:  
Thinking Smarter