



SIDCER
Globalizing Ethics for Health Research

Protection of privacy and confidentiality in research: The arduous journey of researchers - A questionnaire-based study

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 1. Shet, V. B., Palan, A. M., Rao, S. U., Varun, C., Aishwarya, U., Raja, S., Goveas, L. C., Vaman Rao, C., & Ujwal, P. (2018). Comparison of response surface methodology and artificial neural network to enhance the release of reducing sugars from non-edible seed cake by autoclave assisted HCl hydrolysis. *3 Biotech*, 8(2), 127. <https://doi.org/10.1007/s13205-018-1163-9>
 2. Shet, V. B., Varun, C., Aishwarya, U., Palan, A. M., Rao, S. U., Goveas, L. C., Raja, S., Rao, C. V., & Puttur, U. (2018). Optimization of reducing sugars production from agro-residue coconut leaflets using autoclave-assisted HCl hydrolysis with response surface methodology. *Agriculture and Natural Resources*, 52(3), 280-284. <https://doi.org/10.1016/j.anres.2018.09.015>



PRIVACY

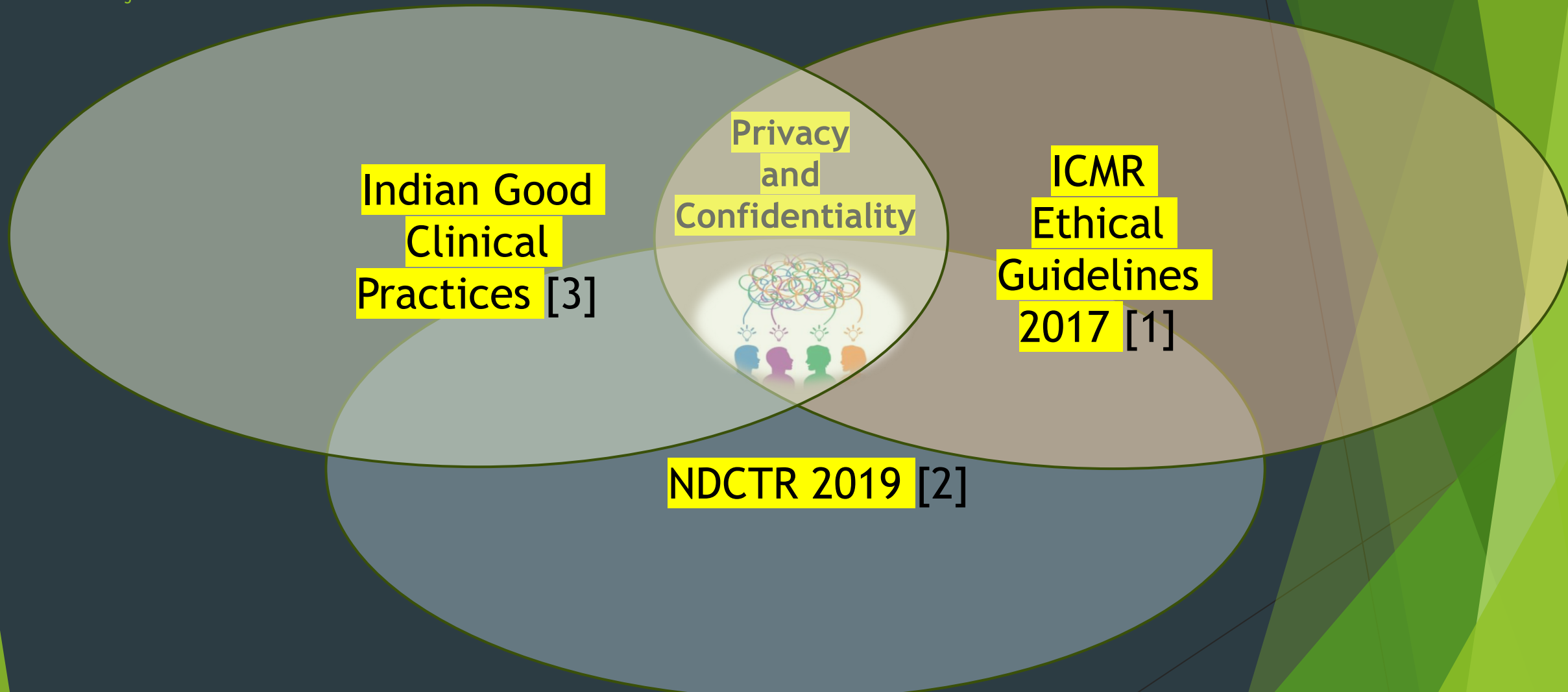
Privacy and Confidentiality



- ▶ **Privacy and confidentiality (P&C)** are a fundamental part of biomedical research. [1, 2, 3]
- ▶ Right of individual(s) to protect themselves from unwanted intrusions. [4]
- ▶ Keeping information about someone or something private. [4]

Indian scenario

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What are the **possible gaps** in policies and practices?
How are researchers maintaining confidentiality in the context of research?

Objectives

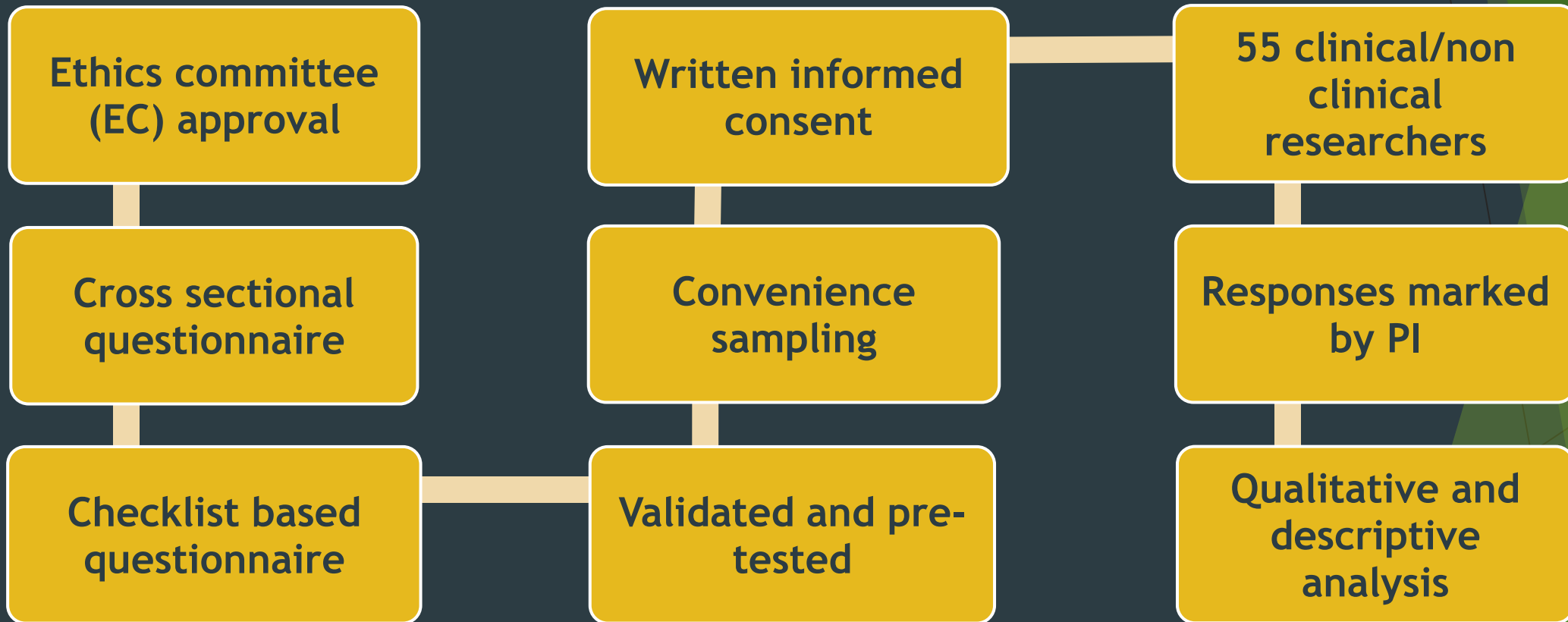
To explore the methods employed by the researchers to maintain P&C of the participants

**Privacy
and
Confidentiality**



To explore the barriers and enablers encountered while maintaining P&C

Methodology



Results - Maintaining P&C

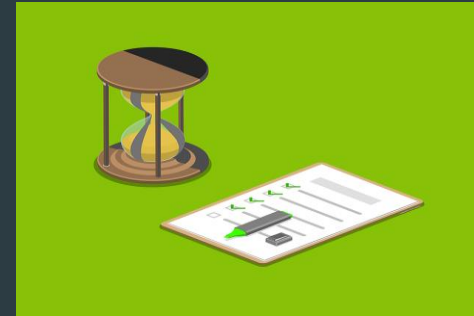
Informed consent	OPD	54.4%	Anonymization measures	Code	72.7%
	Ward	43.3%		Remove/mask identifiers	38.2%
Sensitive data collection	OPD	9.1%	Storage measures for data and samples	Cabinet	72.7%
	Consultation room	9.1%		Password	68.2%
Personal identifiers collected	MRD number	50.0%		Logbook	45.5%
	Address	32.7%		Biometric	36.4%

Results - Breach of confidentiality

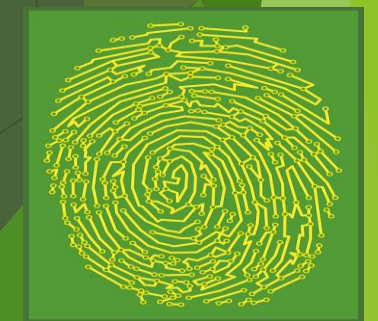


- ▶ Only **one researcher** reported experiencing data breach.
- ▶ However, this was minor and was quickly resolved with the help of the IT department.
- ▶ While the EC was made aware of this, the **participants were not informed.**

Results - Barriers



- ▶ Barriers were reported to be;
 1. Time and space constraints
 2. Utilizing crowded areas for informed consent and data collection
 3. Poor participant comprehension
 4. Documentation
 5. Sharing work space with others
 6. Cost
 7. Memory and technical issues



Results - Enablers



- ▶ Enablers mentioned by the researchers were;
 1. **Ethics training**
 2. **Convenience** and **accessibility** to participants
 3. **Anonymization** of participants samples/data
 4. **Protection of P&C** of participants



Discussion

- ▶ Many challenges like technical issues lack of understanding from researchers and participants etc., were observed as found by Noroozi M *et al* (2018). [8]
- ▶ **Strict measures** were taken to protect confidentiality by **psychiatry department** and this was also reflected by Karasneh R *et al* (2021). [9]
- ▶ As seen other studies by Adarmouch L *et al* (2020), Mac-Seing M *et al* (2021), Karasneh R *et al* (2019), Noroozi M *et al* (2018) and Karasneh R *et al* (2021) our study indicates many researchers seem to have a **lack of understanding** of various aspects of P&C. [5, 6, 7, 8, 9]

Conclusion

- ▶ Our study reveals several weak points about protecting P&C in research like **utilization of crowded places for collecting data** and **easy access to medical records**, thereby increasing the vulnerability of participants to breach of P&C.
- ▶ Possibilities of breach of P&C include **informed consent process**, **data collection** specifically related to sensitive information, **storage** and **sharing of data/samples** and **anonymization**.
- ▶ Researchers require **more robust mechanisms** to protect P&C in research.

Limitations of the study

1. An **in-depth interview study** would be a better study design to explore barriers and enablers.
2. Participants **hesitated** to speak freely.
3. Due to **busy schedule** of researchers, there was **lack of interview time**.
4. Responses are **self reported** and **not directly observed**.

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Thank you



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