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#### Education:

Master of Health Research Ethics (Universiti Malaya) BMBS, BMedSci (Universiti of Nottingham, UK)

Position:

Deputy Head Clinical Research Centre Hospital Tengku Ampuan Afzan, Pahang

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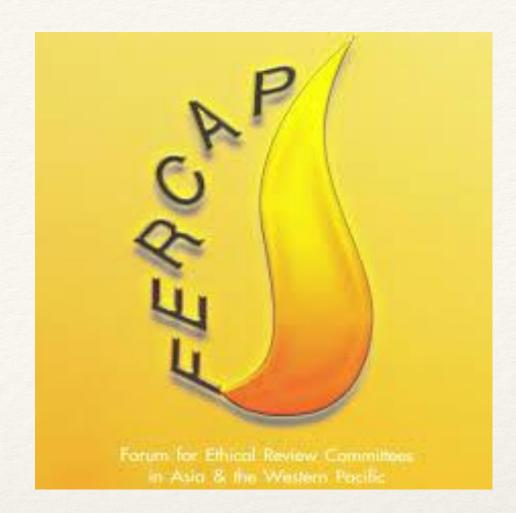
Medical officer in internal medicine for over 5 years before embarking on clinical research in 2021. GCP Malaysian Certification Programme trainer Certified in Clinical Trial Project Management Health Research Governance in Pahang

Special interests:

Community Health & Research

Research Ethics

Research in Special Populations



FERCAP Presentation 2024

# Recruitment Strategies in Health Research in Prison





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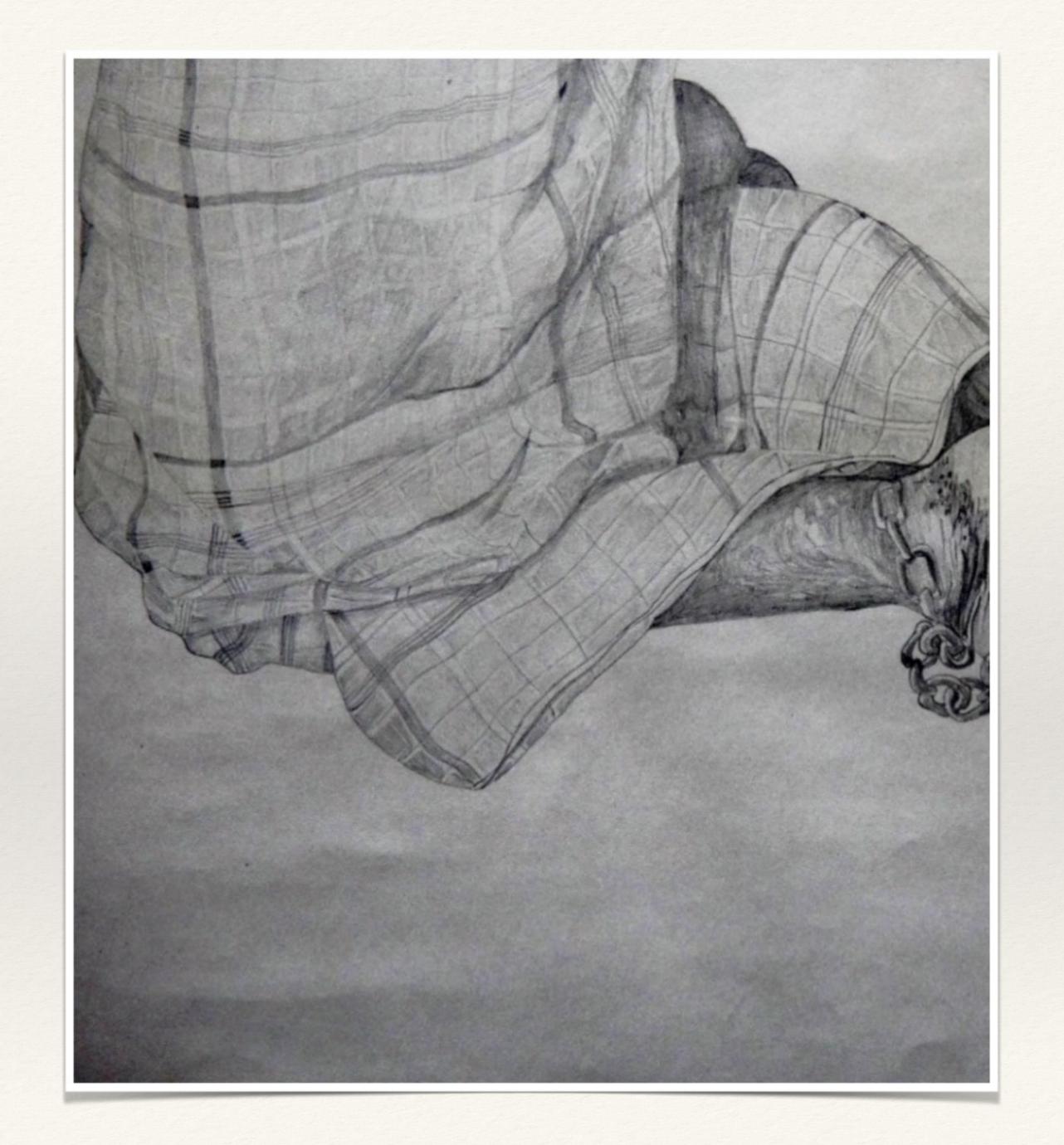
## Presentation Outline

- Introduction & background
  - Research involving prisoners: a historical perspective
  - Prison population
- Review objectives
- Review methodology
- Results and discussion
- Review strengths and limitations
- Conclusion



## Introduction

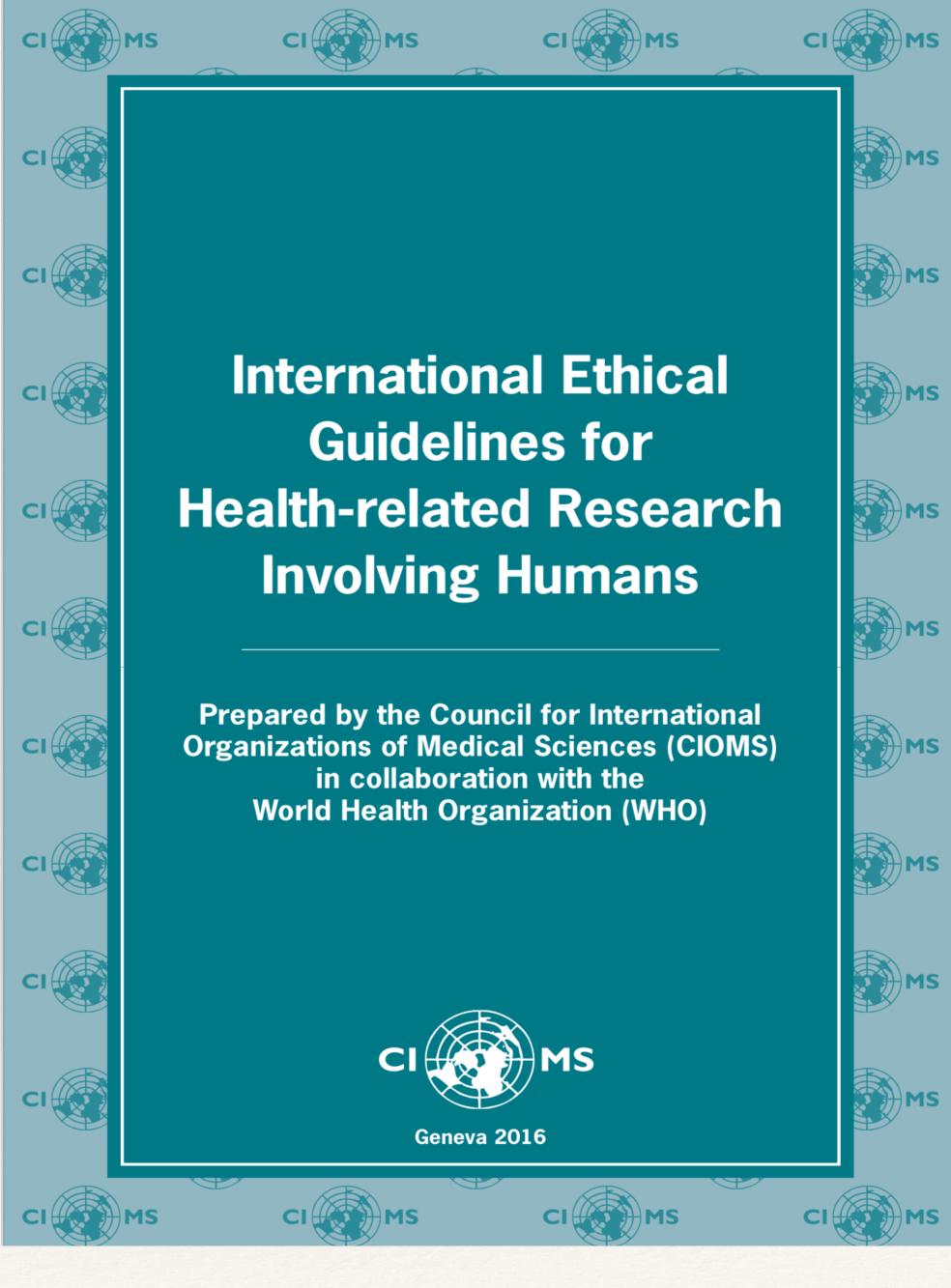
Chronological Development of Guidelines for Conducting Research





- \* All prisoners shall be treated with the respect due to their inherent dignity and value as human beings.
- \* There shall be no discrimination on the grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.
- \* Prisoners shall have access to the health services available in the country without discrimination on the grounds of their legal situation.

- \* Institutionalized persons including prisoners are considered vulnerable because, in a confined setting, they have few options and are denied certain freedoms that non-institutionalised persons enjoy.
- \* "And inherently coercive environment"
- \* Dependent relationship between prisoners and prison guards which may compromise the voluntariness of informed consent.



Guideline 15: Research Involving Vulnerable Persons and Groups - Institutionalized Persons (2016)

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# Prison Population Background

Prison population statistics Reality of health in prison



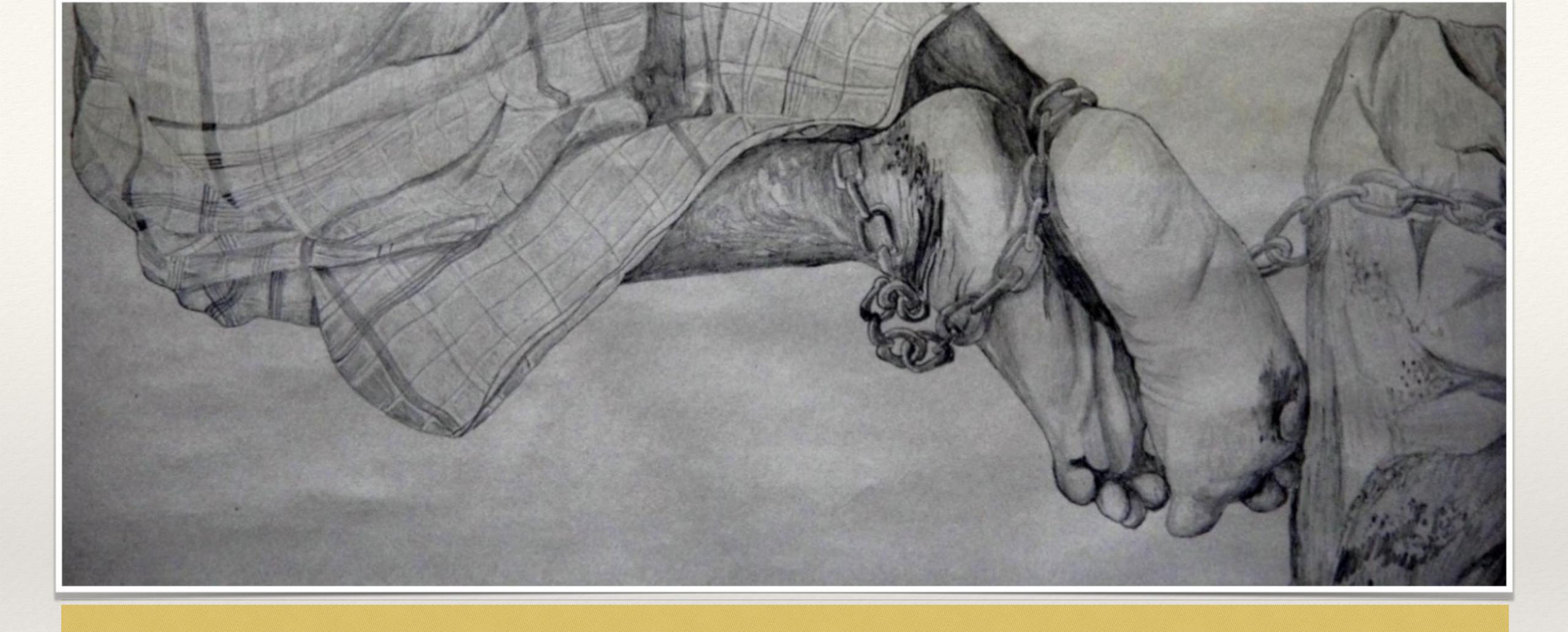
#### Prison population

World Prison Population List, 13th Edition (December 2021)

- \* More than 10.77 million people are held in penal institution globally
- \* Total number of prisoners has increased worlwide Oceania by 82%, Americas by 43%, Asia by 38% and Africa by 32%
- \* Overcrowding of prisons
- \* Unmatched investment in capacity and resources

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4400	Malaysia		Female prisoners (percentage of	5.9% (mid-2021)		
inistry responsible	Ministry of Home Affairs		prison population)	Further Information		
Prison administration	Malaysia Prison Department		Juveniles / minors / young prisoners incl. definition	2.2%		
Contact address	Prison Headquarters, Bukit W Darul Ehsan, Malaysia	Vira, 43000 Kajang, Selangor	(percentage of prison population)	(30.9.2002)		
Telephone	+60 3 8732 8000		Foreign prisoners (percentage of prison population)	18.3% (mid-2021)		
Fax	+60 3 8739 9205		Number of establishments / institutions	52		
Website	http://www.prison.gov.my			(2019) 61 242		
Email	pro@prison.gov.my		Official capacity of prison system	(25.8.2021)		
Head of prison administration (and	Datuk Nordin Muhamad		Occupancy level (based on official capacity)	113.5% (25.8.2021)		
title)	Commissioner General			2000	27,358	116
Prison population total (including	76 336			2002	28,804	118
pre-trial detainees / remand	at 5.10.2022 (national prison ac	odministration)		2004	43,424	171
prisoners)	at 5.15.2522 (national prison at	arminocite along		2006	42,389	161
Prison population rate (per	229		Prison population trend	2008	39,440	145
100,000 of national population)	based on an estimated national population of 33.27 million at	(year, prison population total, prison population rate)	2010	38,387	137	
	beginning of October 2022 (from	m United Nations figures)	process proposed trace,	2012	36,608	126
Pre-trial detainees / remand	41.7%					
	F1.7 70					
prisoners (percentage of prison	(mid-2021)	60,000 ——			47 986	5
prisoners (percentage of prison population)		60,000	43,42442,389	1-4.0	47,986	5
prisoners (percentage of prison population)	(mid-2021) Further Information 5.9%		43,42442,38939,4	14038,387 <sub>36</sub>	47,986	55,490 <sup>5</sup>
prisoners (percentage of prison population)  Female prisoners (percentage of	(mid-2021) Further Information  5.9% (mid-2021)	10.000	43,42442,389 <sub>39,4</sub> 5828,804	14038,387 <sub>36</sub>	47,986	55,490 <sup>5</sup>
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prisoners (percentage of prison population)  Female prisoners (percentage of prison population)  Juveniles / minors / young	(mid-2021) Further Information  5.9% (mid-2021) Further Information  2.2%	40,000 27,3	43,42442,38939,4	14038,38736	47,986	55,490
prisoners (percentage of prison population)  Female prisoners (percentage of prison population)  Juveniles / minors / young prisoners incl. definition (percentage of prison population)  Foreign prisoners (percentage of	(mid-2021) Further Information  5.9% (mid-2021) Further Information  2.2% (30.9.2002)	40,000 27,3	43,42442,389 <sub>39,4</sub> 5828,804	14038,38736	47,986	55,490
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Prisoners as research participants: ethical challenges in low- and middle-income countries - a scoping review

# Presentation Objectives

To explore the extent of literature published that involved prisoners in health research in low- and middle-income countries:

To identify recruitment methods for health research involving prisoners

To discuss the ethical issues when recruiting prisoners as research participants

# Methodology

- \* Systematic scoping review
- \* PIO framework:
  - \* Population: Prisoners
  - \* Intervention: Recruitment strategies
  - \* Outcome: Protective measures
- \* PubMed, Cochrane Library, Scopus
- \* Articles published from 2018

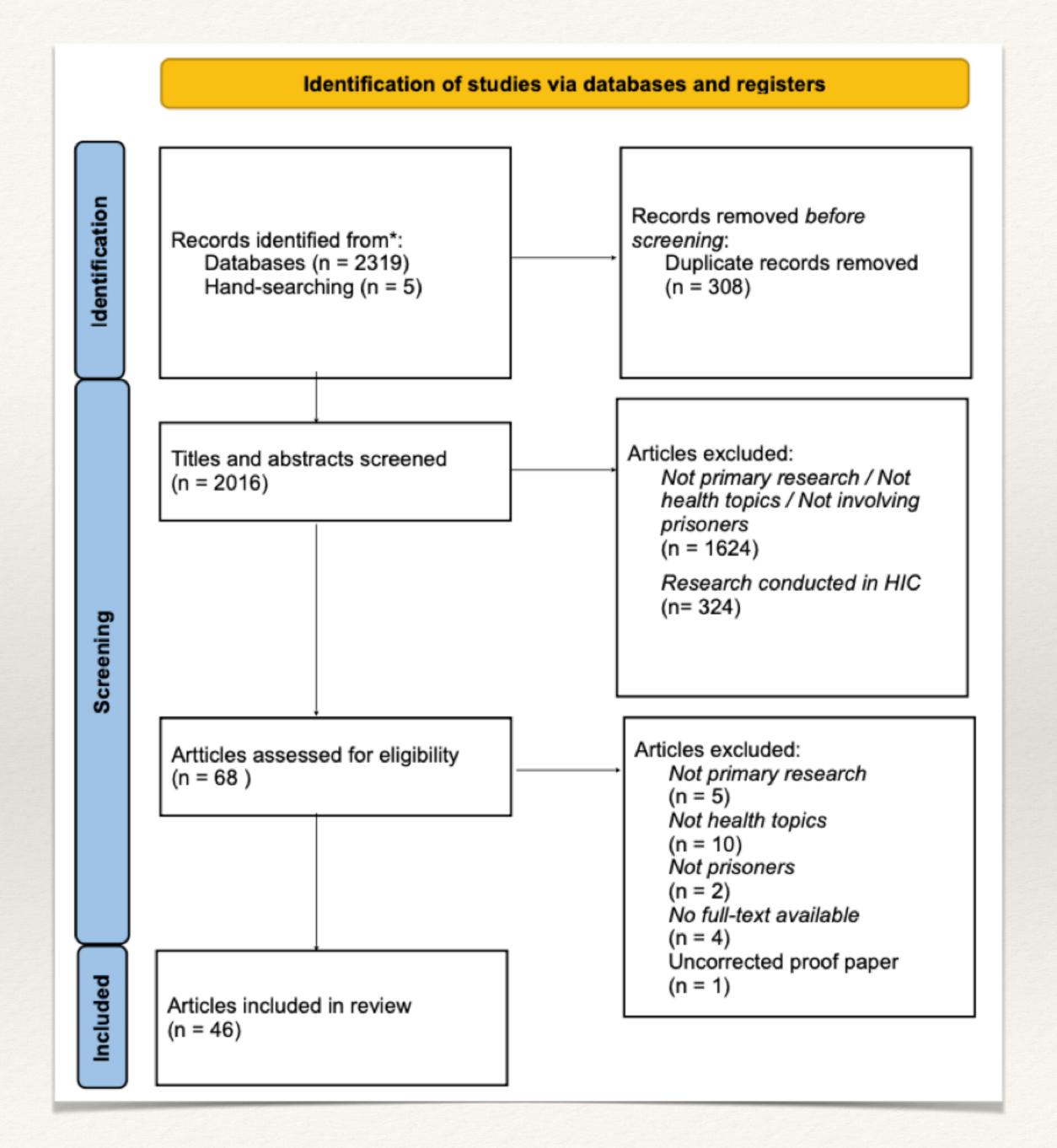
## Results

PRISMA Flowchart



### Review Results

- \* PRISMA Flowchart
- \* 46 articles were included based on the inclusion and exclusion criteria



#### Lorem Ipsum Dolor

### Discussion

- \* Ethical challenges of health research involving prisoners
- \* Additional safeguards for the participating prisoners



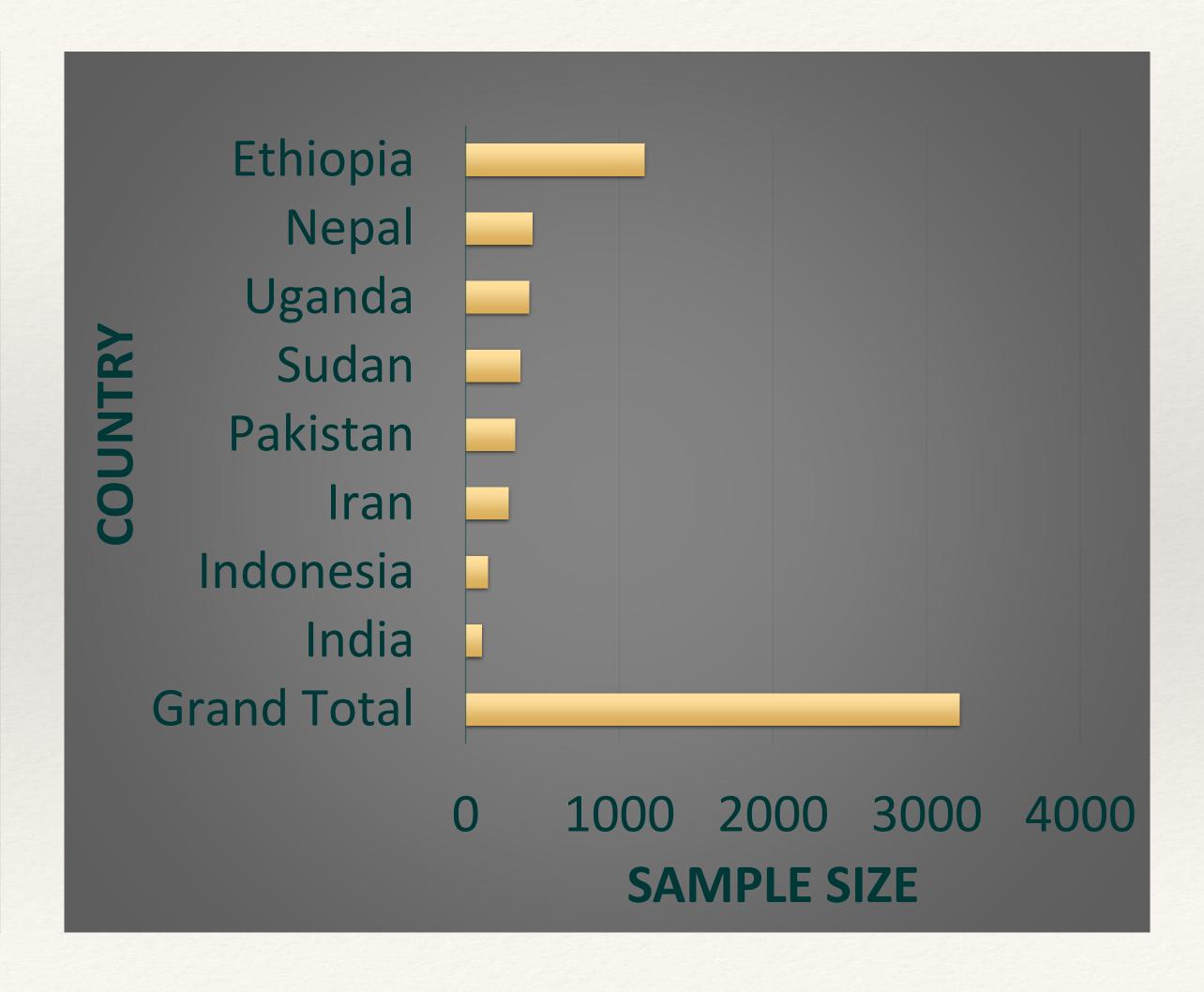
# Sampling method

- \* Snowballing to reduce the effect of selection bias from purposive sampling
- \* Delegated person in charge as the spokesperson for the project
- Delegated prisoner in-charge for the project

Sampling method		Number of
		articles
Random sampling	Simple random sampling	12
(n=18)	Systematic random sampling	2
	Stratified random sampling	3
	Cluster random sampling	1
Non-random sampling	Purposive sampling	16
(n=27)	Convenience sampling	9
	Quota sampling	1
	Census	1

# Number of samples according to country

Country	Sum of Sample size	
Ethiopia	1163	
Nepal	434	
Uganda	414	
Sudan	354	
Pakistan	320	
Iran	280	
Indonesia	145	
India	105	
Grand Total	3215	



# Number of sample according to research methodology

Design	Sum of Sample size
Cross-sectional	20436
RCT	18142
Implementation research	1713
Mixed-method	857
Quasi-experimental	674
Randomised trial	606
Qualitative	295
Conjoint	160
Grand Total	42883

# Power dynamic & coercion

- \* Acknowledgement of the superiority of prison officers above prisoners and applied it in research through patronage counselling intervention (9)
- \* An informal prison hierarchy system within prison called *obschak* governed by the prisoners themselves. (20,22)
- \* However, coercion was not mentioned clearly in any of the articles although it might be implied indirectly through the involvement of prison authorities in the recruitment process.

## Informed consent

- \* Explanations were given to prisoners, allowing enquiries before agreeing and signing the informed consent.
- \* Specifically mentioned that consent was obtained **verbally** only due to cultural context (Gamble, 2020).
- \* Achieving true voluntary informed consent may not be as apparent due to the higher risk of coercion and undue influence.
- \* Even in privacy, the desperate impoverished living conditions in prison could be a significant factor that would affect their decision.

Type of informed consent	Number of articles
Written individually by participating prisoners	33
Written individually by next of kin/ LAR	1
Seid et al.; 2022; Ethiopia	
Not mentioned written or verbal	4
Chatterjee et al.; 2020; India	
Fakorede et al.; 2021; Nigeria	
Manzoor et al.; 2021; Pakistan	
Junaedi et al.; 2022; Indonesia	
Verbal	4
Topp et al.; 2018; Zambia	
Gamble et al.; 2020; Iraq	
Mohamed et al.; 2020; Sudan	
Diendéré et al.; 2022; Burkina Faso	
Not mentioned at all	4
Vildoso-Cabrera et al.; 2018; Peru	
Zajmi et al.; 2018; Kosovo	
Hechanova et al.; 2020; Philipine	
Sujianto et al.; 2021; Indonesia	

# Privacy & Confidentiality Protection

- \* Many articles mentioned that confidentiality was assured
- \* Research activities mainly interviews were conducted in private rooms
- \* No prison staff presence during research activities
- Personal information collected was anonymized by replacing them with identification numbers, masked, or not documented
- \* Digital recordings were not permitted. Data was collected by taking detailed field notes (Chatterjee et al., 2020; India).
- \* Only audio recordings were allowed
- \* Strict and limited access to data stored. Documents and files were password-protected.
- \* Identities of non-participants were not revealed to prison officials in implementation research

## Research incentives

- \* Incentives were not offered in most studies to minimise undue influence that could affect their decision to participate.
- \* Non-monetary incentives:
  - \* Snacks & gift items (Amoke, 2020, Nigeria), supplies of hygienic items (Kose et al.; 2019, Turkiye & Naidoo et al., 2022; South Africa), full meals (Hechanova et al., 2020; Phillippine)
- \* Monetary incentives:
  - \* 150 Ethiopian birr (\$5.50) for peer educators (Adane et al., 2019, Ethiopia), RM 40-130 (\$31) at different time points (Chandra et al., 2019, Malaysia)

## Conclusion

- \* Study methodologies and provision of safeguards were contextually-based and may differ across countries
- \* Research stakeholders need be sensitive and aware of the ethical challenges in conducting research in prison population and we have to continue improvising safeguards for prisoners to protect them
- \* Balancing protection and allowing prisoners' right to get benefits from participating in research.