ASSESSMENT OF PRIVACY AND CONFIDENTIALITY IN DISTRICT HOSPITAL VARANASI, UTTAR PRADESH

Presented by
Priyanka Sharma
0328
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Introduction

The right to privacy and confidentiality is a basic human right that is guaranteed by international standards.

It is legally protected, cannot be waived or taken away, and is universally applicable (WHO 2002).

The **Universal Declaration of Human Rights** (Article 12, 1948) states that no one shall be subjected to arbitrary interference with his/her privacy, family, home, or correspondence, nor to attacks on his/her honor and reputation.

Privacy and confidentiality is a core concept in delivering quality care and maintaining patients' dignity is critical to their recovery.

In India lacks a uniform statute specifically protecting medical privacy

- The World Health Organization (WHO) defines **privacy as a personal right** and **confidentiality as a duty**, in this case, on the part of providers.

- **Privacy** is “the right and power to control the information (about oneself) that others possess”. Privacy also commonly refers to the privacy of a person and the rights of individuals not to be physically exposed against their will.

- **Confidentiality** is “the duty of those who receive private information not to disclose it without the patient’s consent”. Confidentiality is the mechanism through which the client’s right to privacy is protected.

- Interpreted as an **Extension of the Fundamental Right to Life and Liberty as guaranteed under Article 21 as well as the freedom of expression and movement under Articles 19(1) (a) and (b) of the Constitution of India (**The deliberation leading to the construction of a universally applicable Right to Privacy)**.**
- Valid interpretation, but narrows the ambit of the right as one that can only be exercised against the State.

- Impending need to create an efficient and durable structure of Law and policy that regulates the protection of privacy in Institutions that may not always be agents of the State.

Research question

What is the current status of privacy and confidentiality in District Hospital, Varanasi?

Objectives

- To review norms and/or guidelines (if any) related to privacy and confidentiality in healthcare setting.
- To assess knowledge, attitudes and practices of service providers and users of facility-based public health services on privacy and confidentiality in public health facilities.

METHODOLOGY

STUDY DESIGN

Descriptive study was conducted to review and assess the present status of privacy and confidentiality in district hospital.

STUDY AREA

Pt. Deen Dyal Upadhyay District Hospital Varanasi which also caters the need for the adjoining districts

DURATION OF STUDY

Study was conducted over a period of three months starting in February 2017.

Data collection (March-April 2017)

STUDY RESPONDENTS

Doctors/ Medical officers (n=30)

Nursing staff (n=60)

Users (Both men and women) of Public health facility services (n=106)

DATA COLLECTION TOOLS

Interview schedule for providers –general information, knowledge and training received on privacy and confidentiality, attitude towards auditory and visual privacy, health centre design and policies and procedures regarding privacy and confidentiality.

Interview schedule for patients– Knowledge and perception of the service users of privacy and confidentiality were recorded. Patients perceptions regarding informational, physical and psychological privacy were ascertained.

Checklist - observations of inputs and processes at health facility for privacy and confidentiality.

Informed Consent form was used before interview were conducted.

DISCUSSION

Provisions related to Privacy and Confidentiality in Various Health Legislations

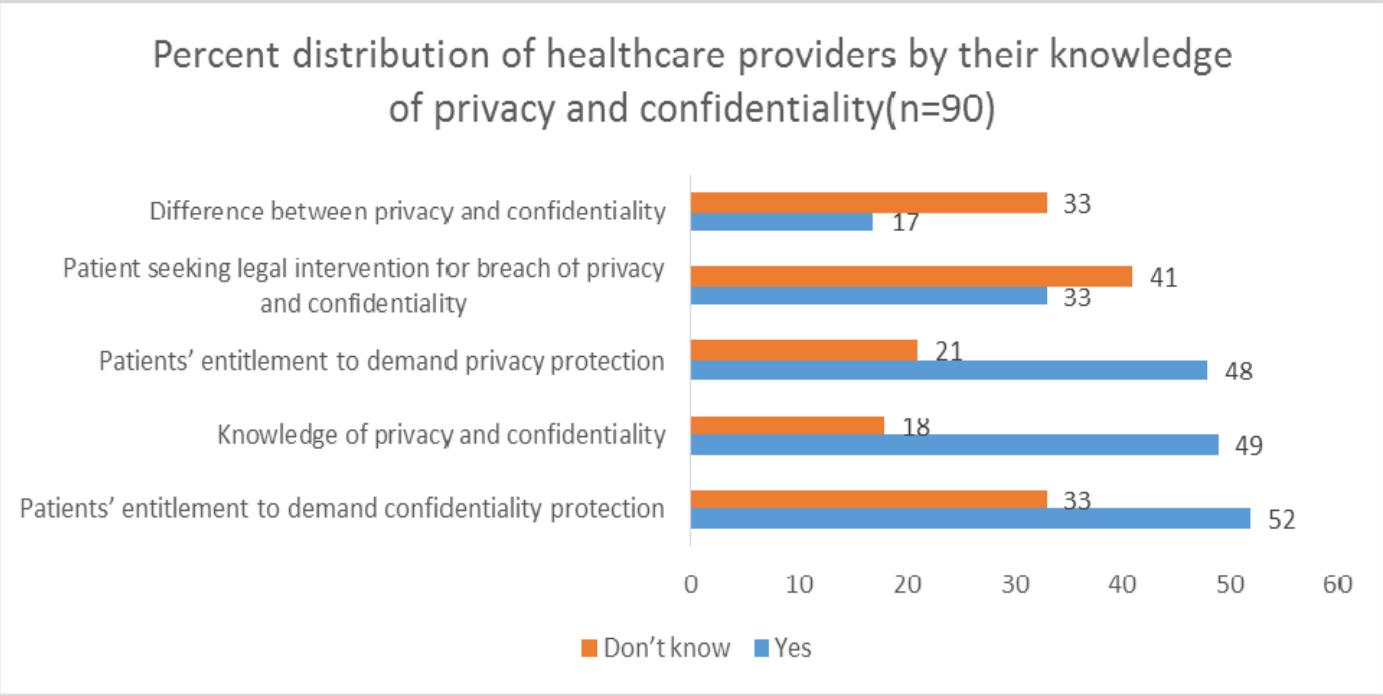
Legislation	Privacy and Confidentiality
Mental Health Act, 1987	• Inspection of records in psychiatric hospitals and nursing homes only by officers authorized by the State Government • A psychiatrist and two social workers analyze the living condition of every patient and the administrative processes of the psychiatric hospital on a monthly basis. • The disclosure of personal records of any facility by inspecting officers is prohibited
Pre-Conception and Pre-Natal Diagnostic Techniques (Prohibition of Sex Selection) Act (1994)	• Data of women undergone ultrasonography must be preserved for 2 years • To avail pre- natal diagnostic testing woman has to reveal sensitive information, which requires exercising special concern for privacy and confidentiality.

Legislation	Privacy and confidentiality
Medical Termination of Pregnancy Act, 1971	• Right to an abortion is afforded to a woman within the construct of her inherent right to bodily privacy, decisional privacy(not for sex determination) • The Act mandates *Written Consent* of the patient and prohibits the disclosure of matters relating to treatment for termination of pregnancy to anyone other than the Chief Medical Officer of the State • Medical practitioner assigns a serial number for the woman terminating her pregnancy • Records maintained at hospital must be destroyed after expiry period of 5 years.
Indian Medical Council (Professional conduct, Etiquette and Ethics) Regulations, 2002 (Code of Ethics Regulations, 2002	• Physicians are obliged to protect the confidentiality of patients during all stages of the procedure and information provided by the patient, including information relating to their personal and domestic lives

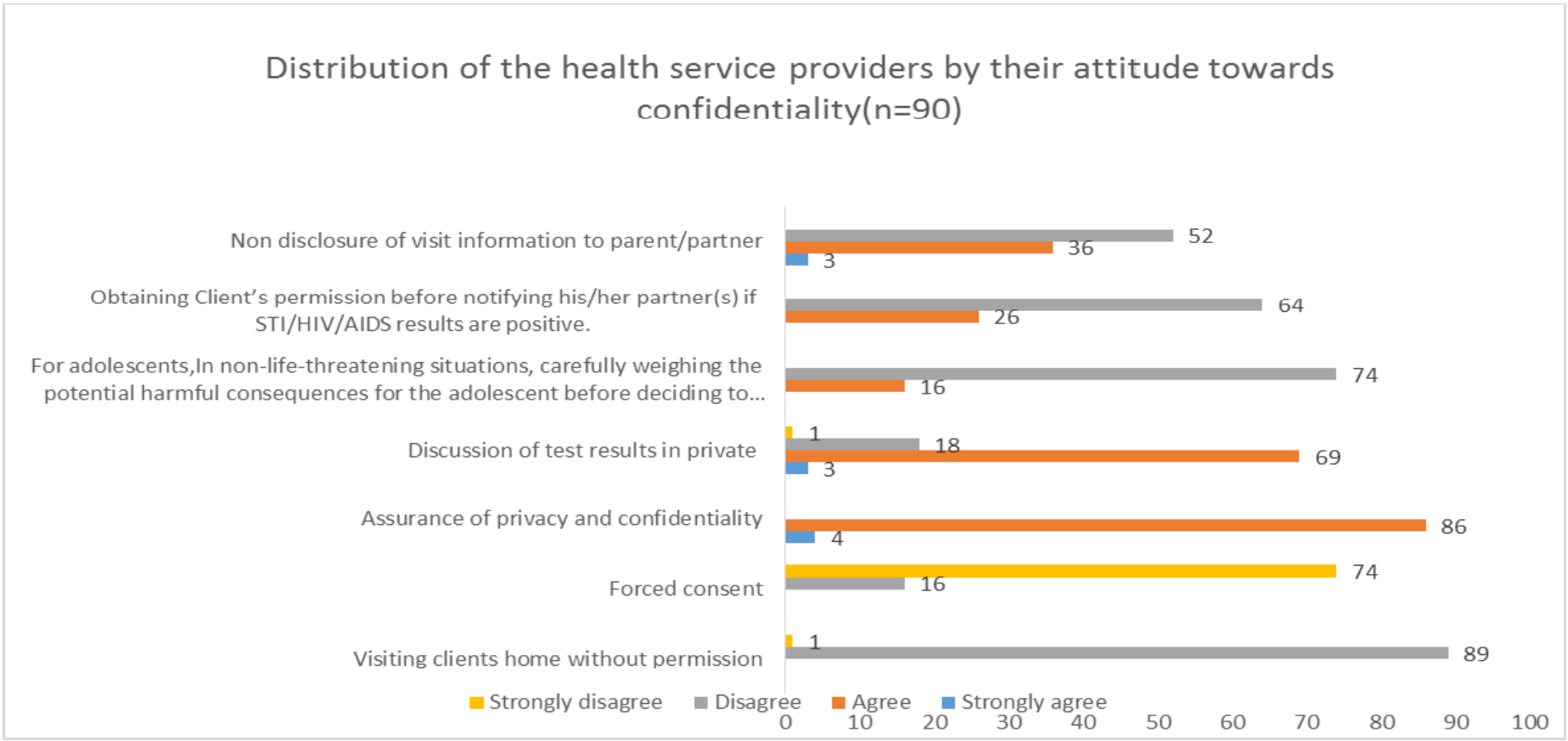
Legislation	Privacy and confidentiality
National Policy for Persons with Disabilities, 2006	• NSSO collects information and there is a limit on the amount of information collected • Access to such data is limited to any person who is authorized by the Special Employment Exchange/Government, to access, inspect, question and copy any relevant record, document or information in the possession of any establishment • For conducting research on persons with disabilities consent is required from the individual or their family members
Insurance Regulatory and Development Authority (Third Party Administrators) Health Services Regulations, 2001	• TPAs must maintain the confidentiality of the data collected and proper records of all transactions carried out by it on behalf of an insurance company • They are also required to refrain from trading information and the records of its business. • They must keep records for a period of not less than three years

Legislation	Privacy and confidentiality
Ethical Guidelines for Biomedical Research on Human Subjects	• *Informed consent is an integral part of this set of guidelines* • *Protection of privacy and confidentiality, specifically of the identity and records, is maintained when using the information or genetic material provided by participants for research purposes*
HIV Interventions Guidelines	• *Lack of a limitation and subsequent confidentiality in the amount of Information collected.* • *Proof of address and identity documents are required to get enrolled in government ART programs.* • *Peer-educators operate under a system known as line-listing for referrals and follow-ups. They have to follow-up with those who have not gone at regular intervals for testing.* • *It can result in peer-educators noticing and concluding that the names missing are those who have tested positive*

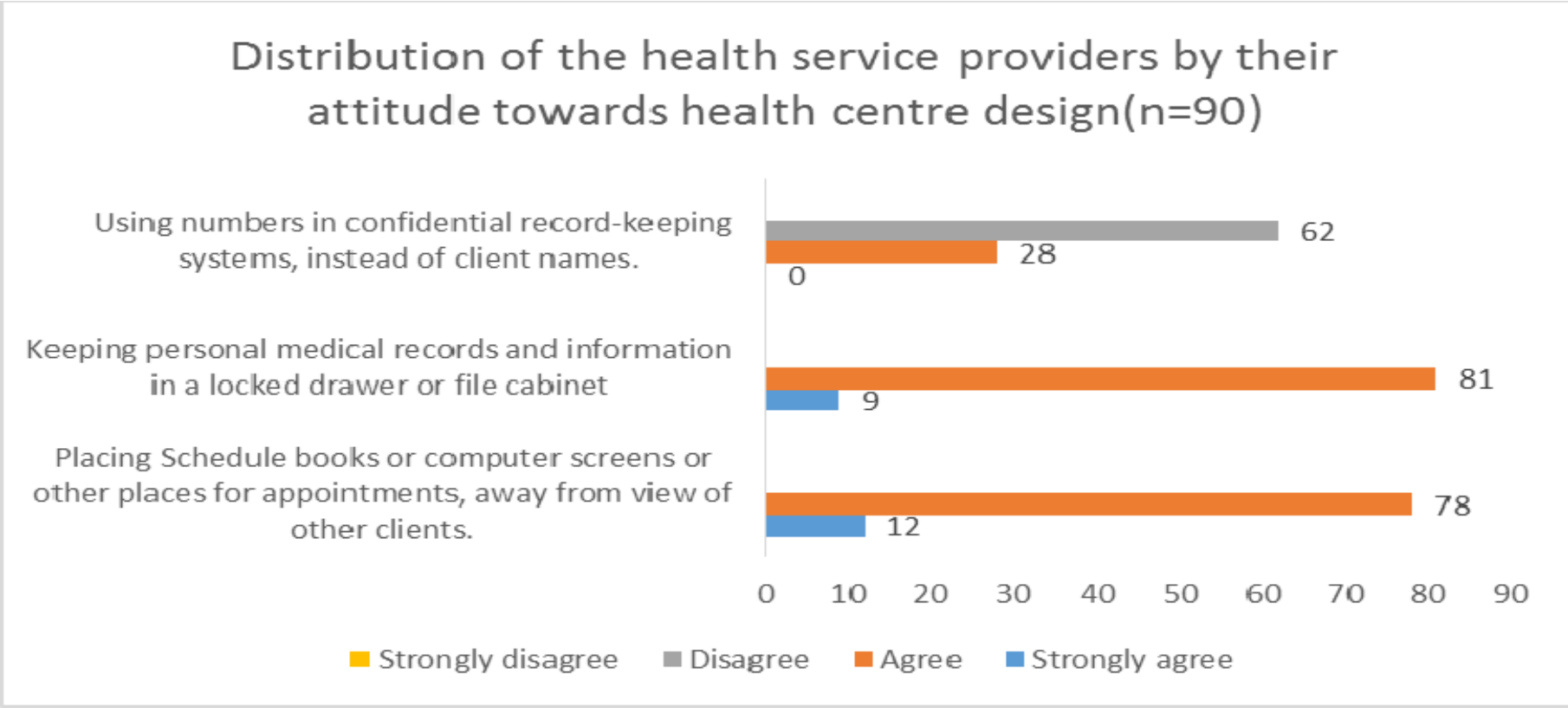
RESULTS



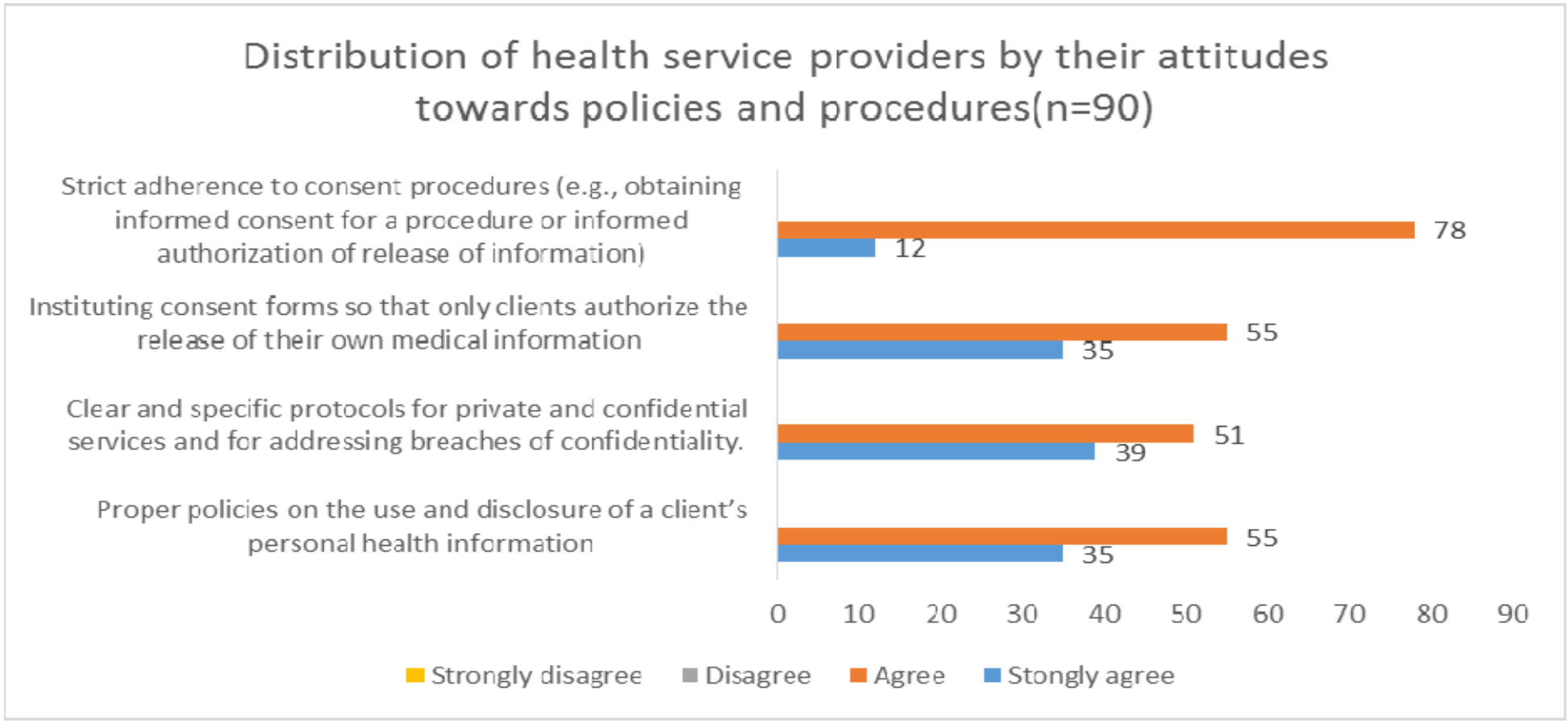
- Forty nine percent knew about privacy and confidentiality, only 17 percent could correctly point out the difference
- Approximately half of them knew about patients entitlement to demand privacy and confidentiality protection whereas patients entitlement to legal intervention was known to only 33 percent.



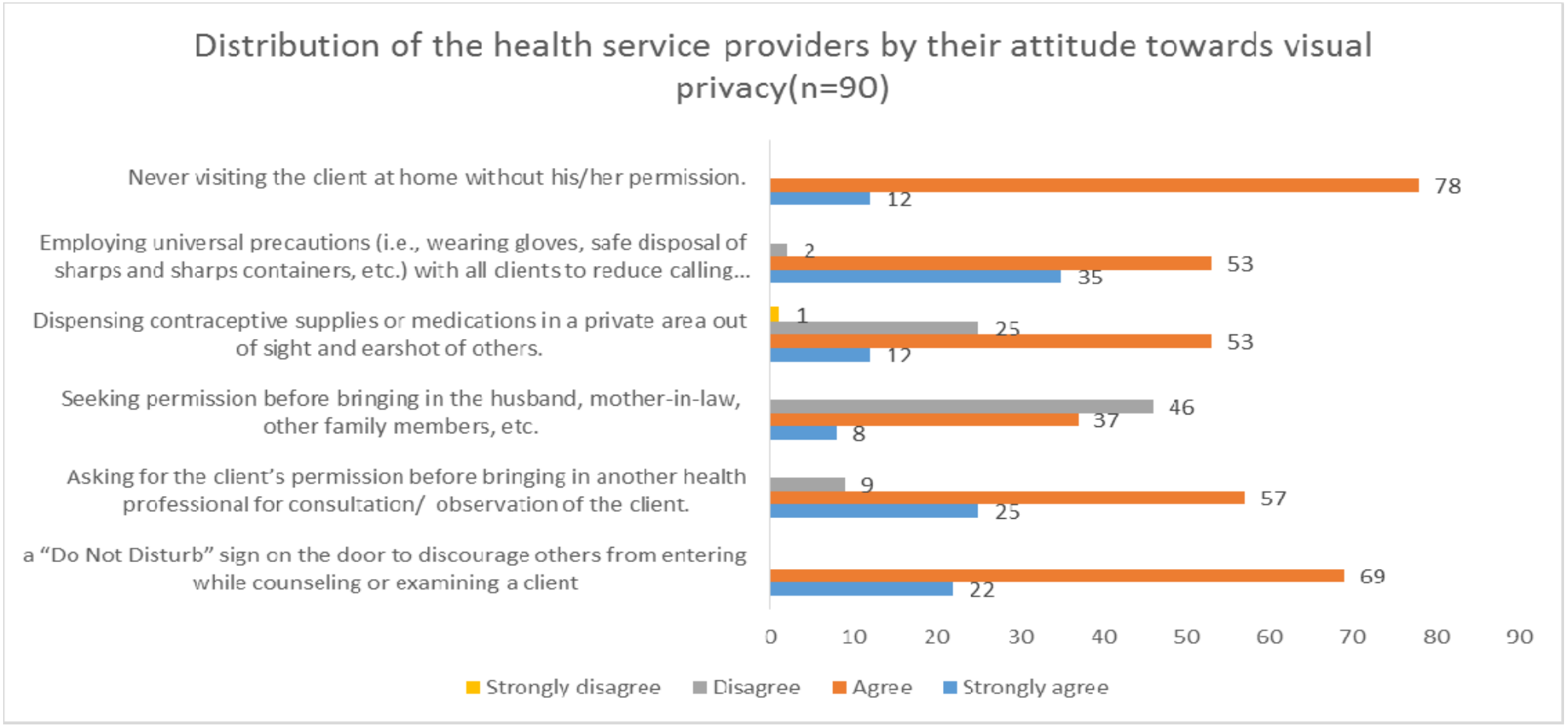
- A majority agreed to informed consent, assurance of confidentiality and discussion of test results in private.
- However, their views wavered when asked about adolescents confidentiality and obtaining clients permission before notifying partners about tests results.



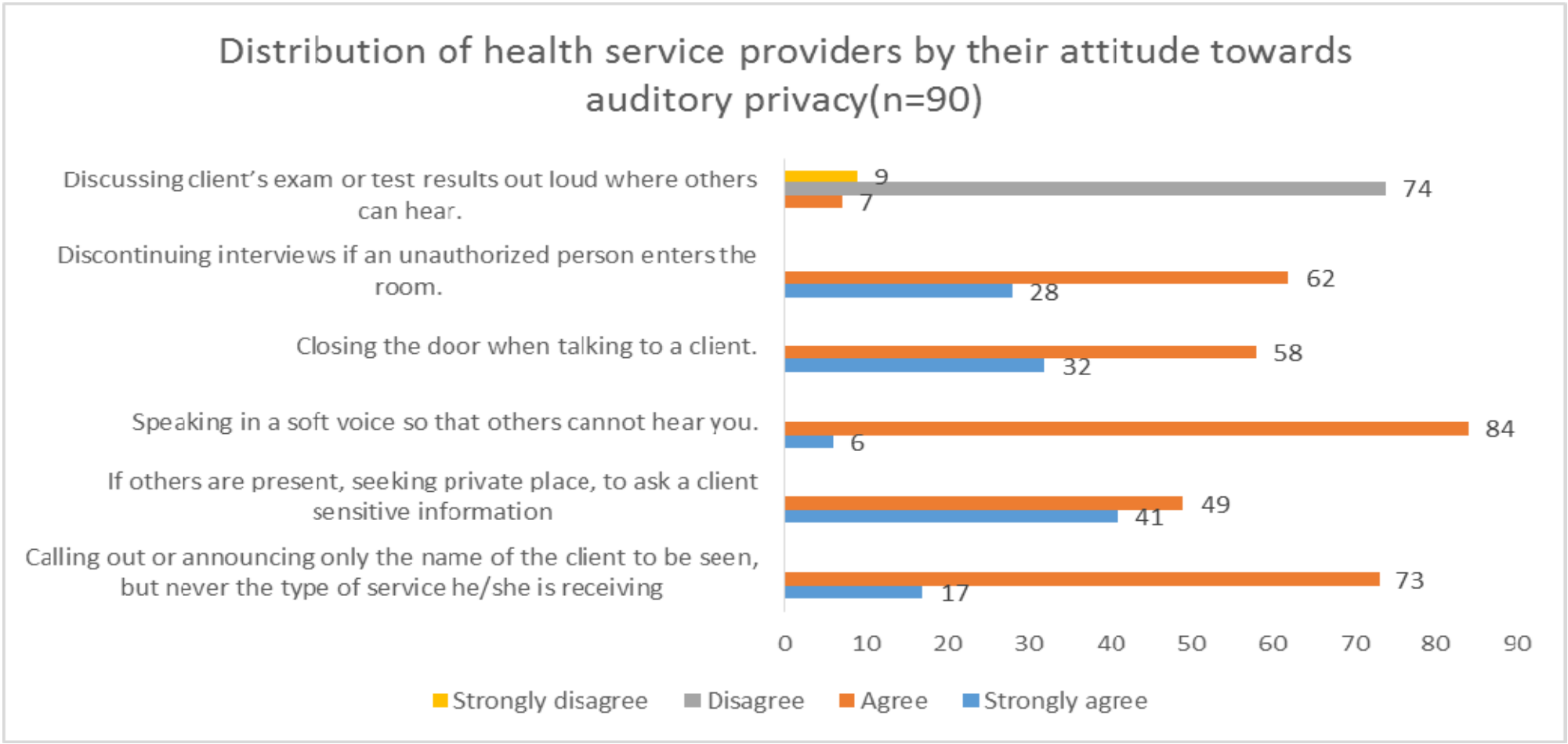
- Service providers attitude was overall positive regarding maintenance of confidentiality through health centre design
- Disagreement was seen when they were asked about using numbers instead of client name, for confidential record keeping



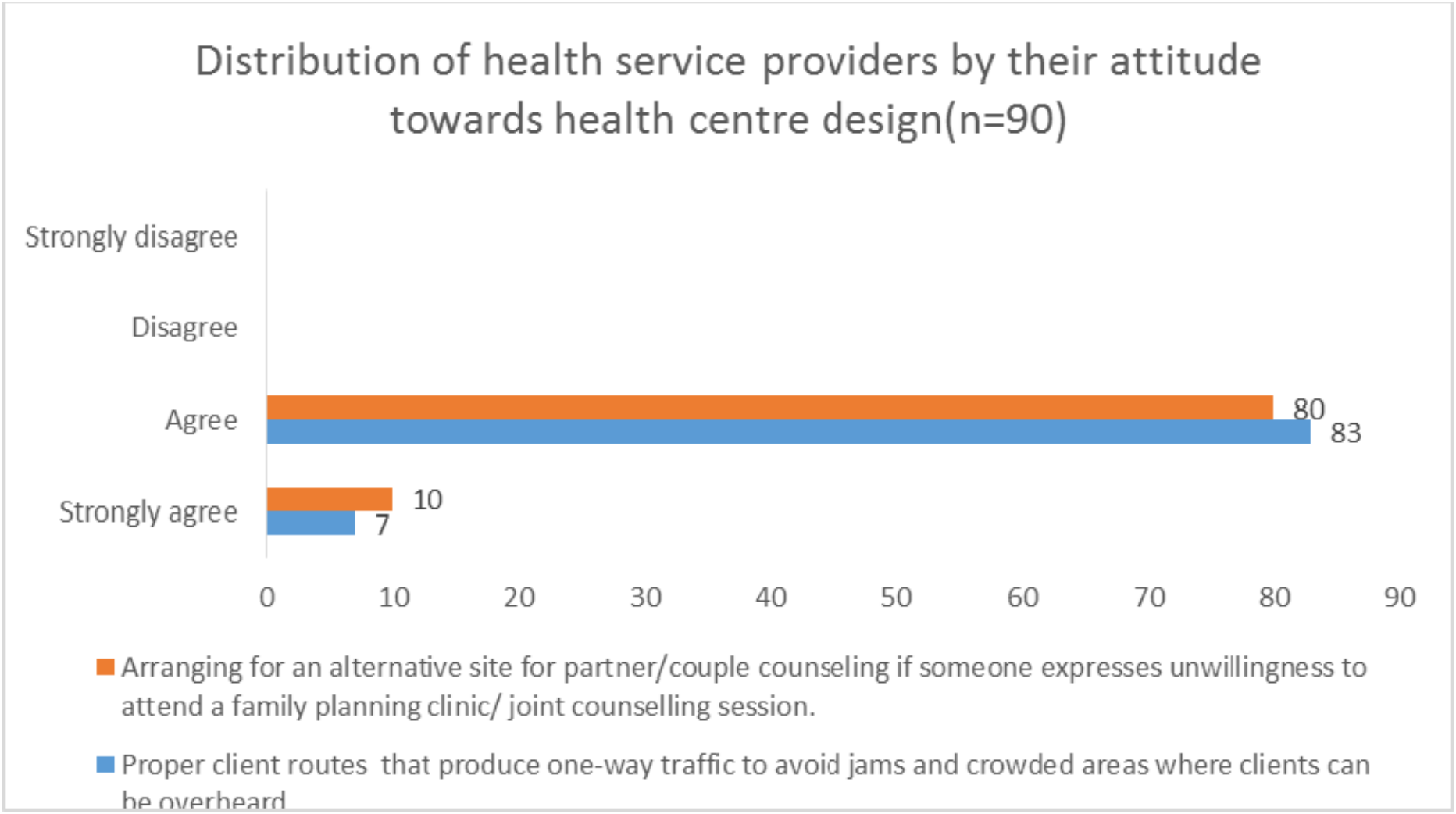
- Generalized positive attitude was observed regarding appropriate policies and procedure in place and strict adherence to protocols.

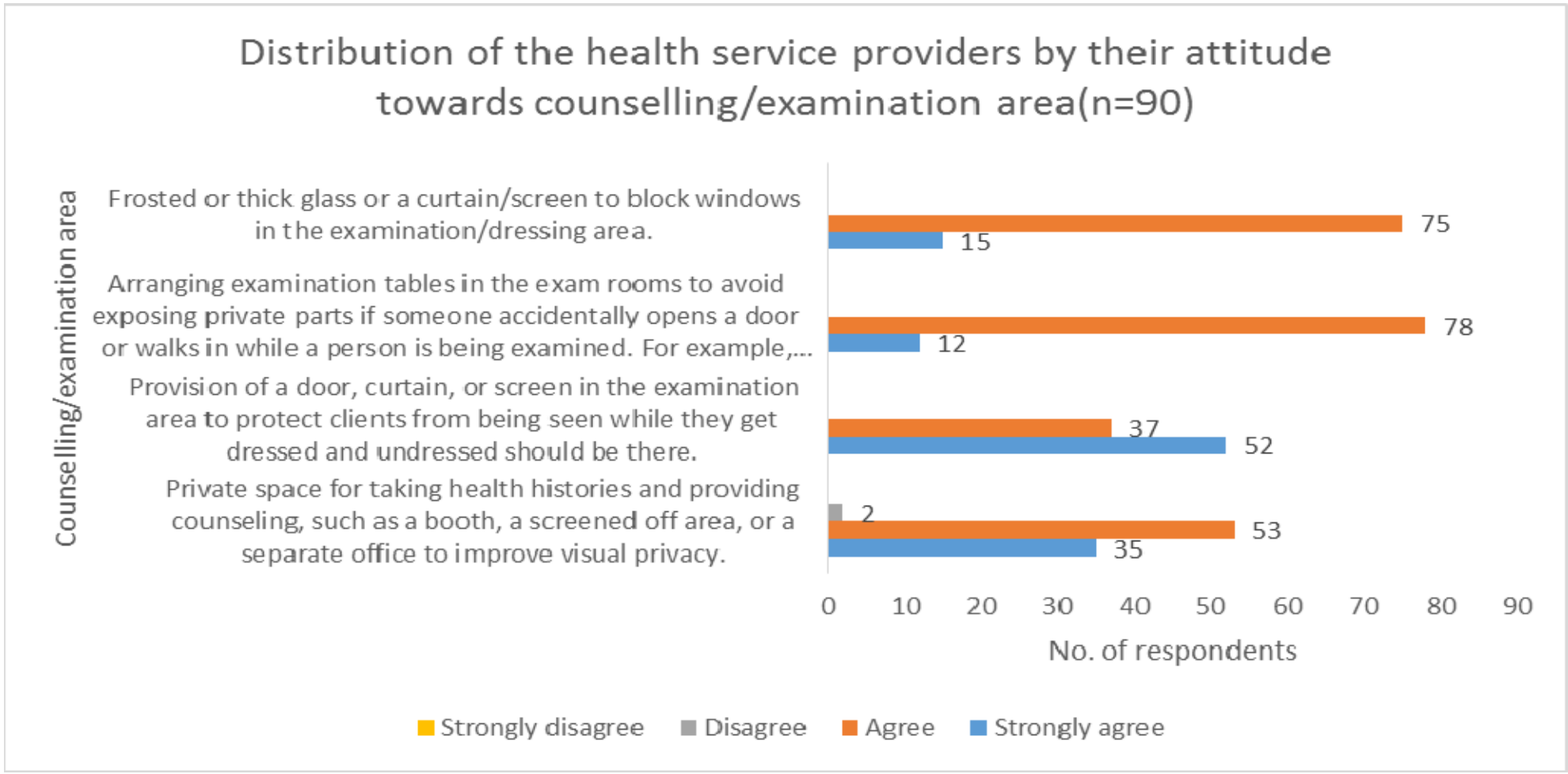


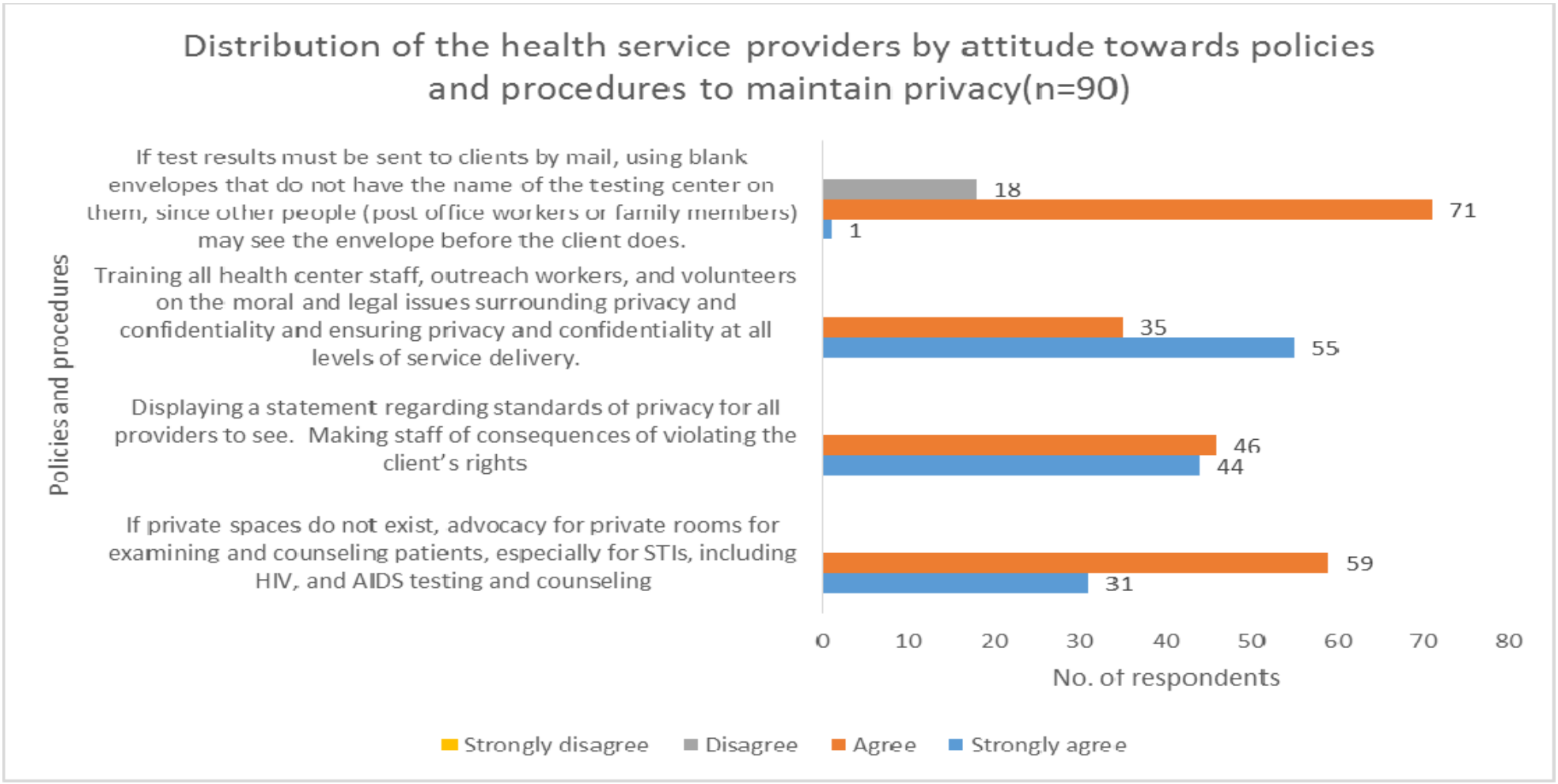
- Majority of them displayed positive attitude towards maintenance of visual privacy.
- Regarding seeking permission before bringing relative/partner and dispensation of medications in private, few of them disagreed



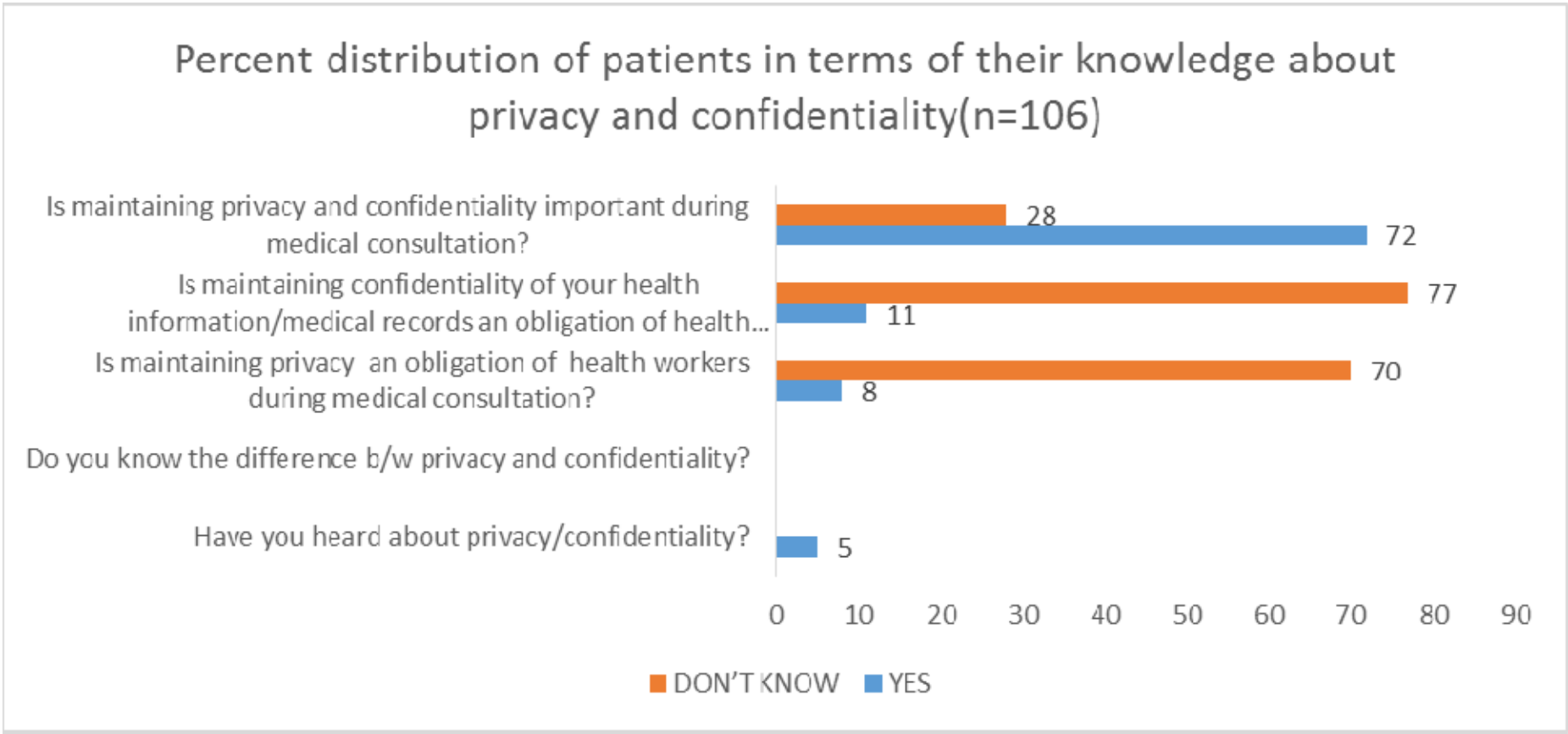
Majority of them agreed or strongly agreed when asked about maintenance of auditory privacy


Distribution of health service providers by their attitude towards health centre design(n=90)
Strongly disagree
Disagree
Agree
Strongly agree
80
83
10
7
0
10
20
30
40
50
60
70
80
90
Arranging for an alternative site for partner/couple counseling if someone expresses unwillingness to attend a family planning clinic/ joint counselling session.
Proper client routes that produce one-way traffic to avoid jams and crowded areas where clients can be overheard

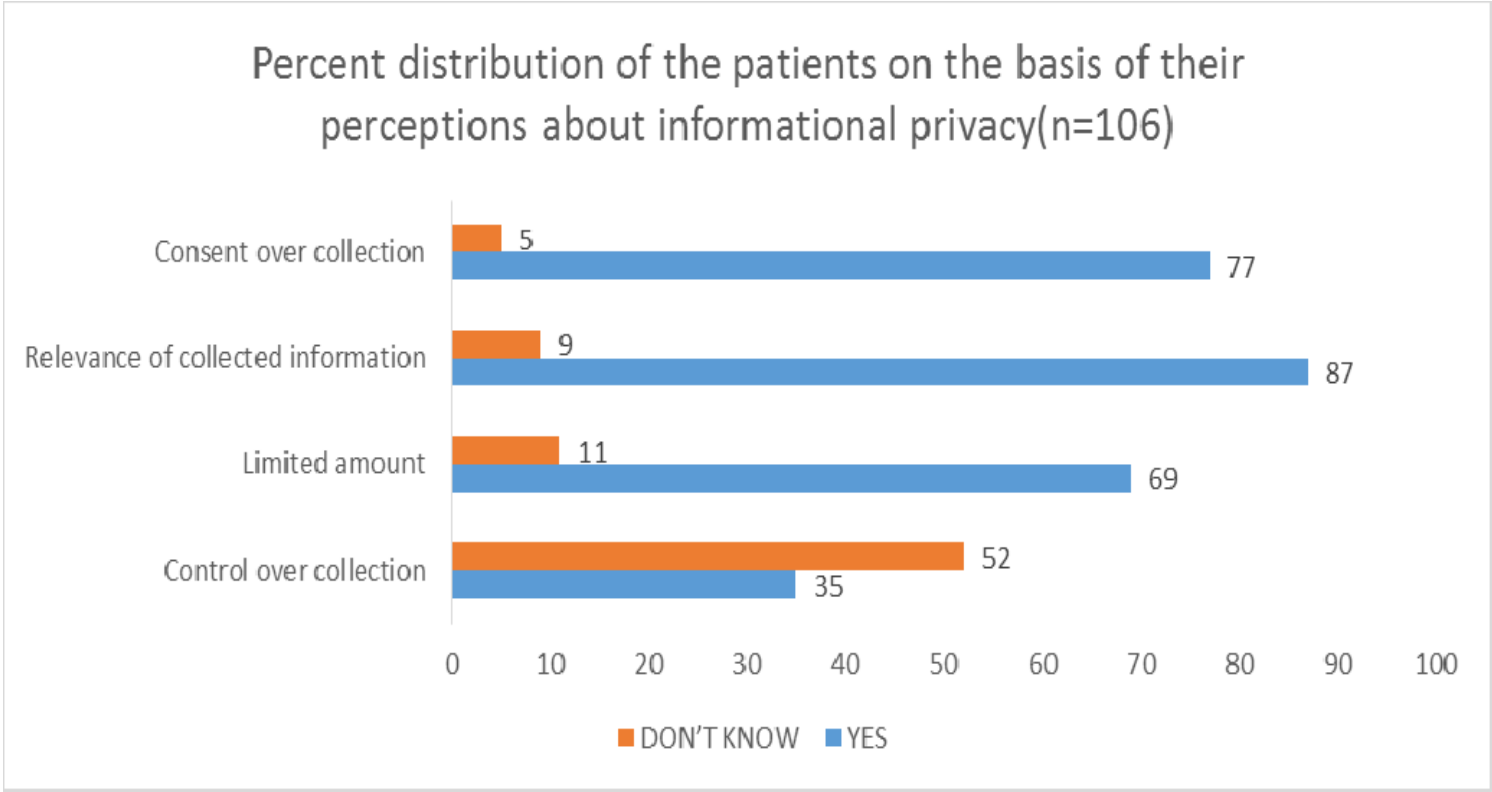

Distribution of the health service providers by their attitude towards counselling/examination area(n=90)
Counselling/examination area
Frosted or thick glass or a curtain/screen to block windows in the examination/dressing area.
Arranging examination tables in the exam rooms to avoid exposing private parts if someone accidentally opens a door or walks in while a person is being examined. For example,...
Provision of a door, curtain, or screen in the examination area to protect clients from being seen while they get dressed and undressed should be there.
Private space for taking health histories and providing counseling, such as a booth, a screened off area, or a separate office to improve visual privacy.
75
15
78
12
37
52
2
53
35
0
10
20
30
40
50
60
70
80
90
No. of respondents
Strongly disagree
Disagree
Agree
Strongly agree



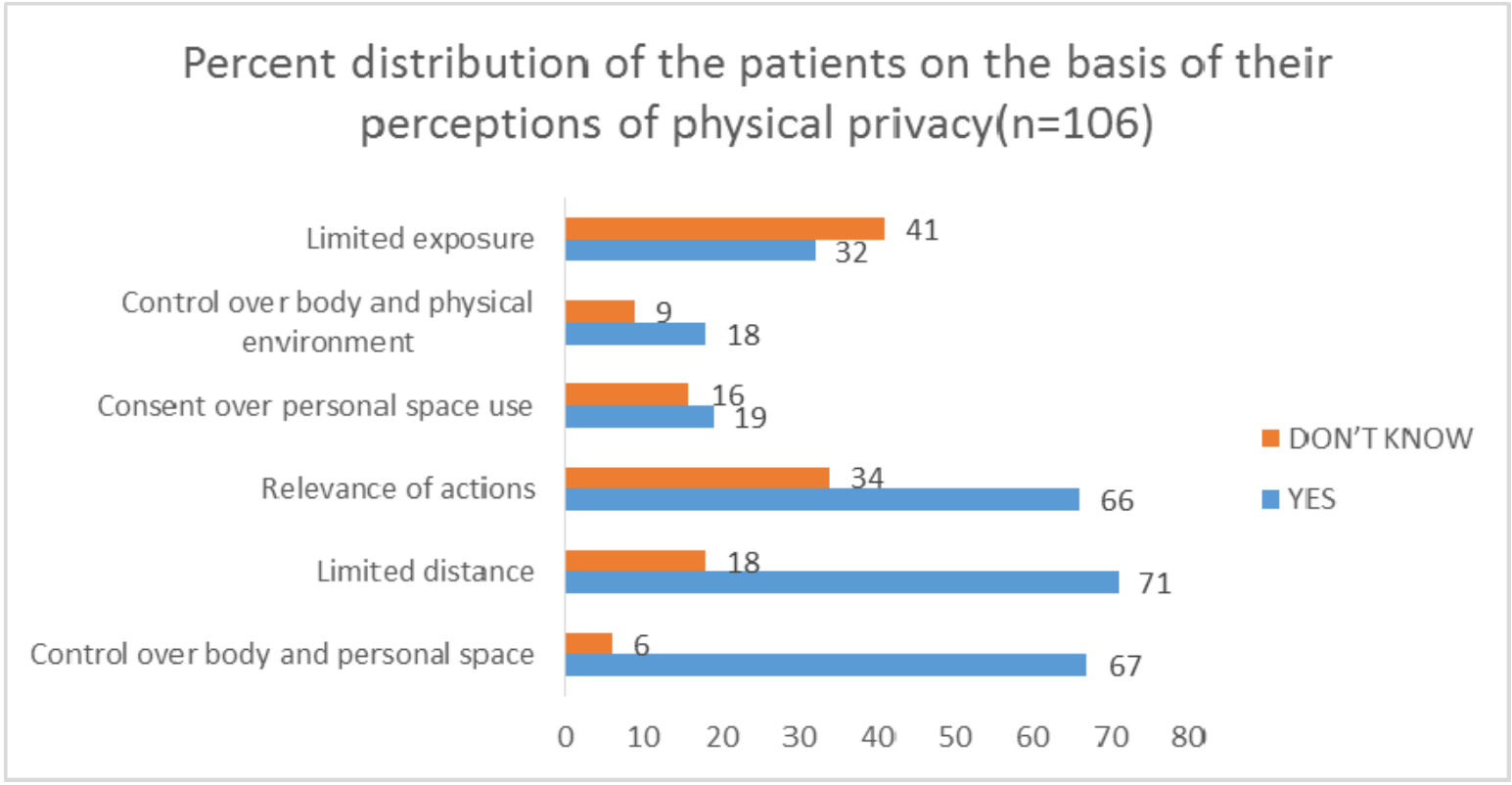
About 18 percent of the providers did not agree to the usage of blank envelopes to maintain privacy while mailing test results.



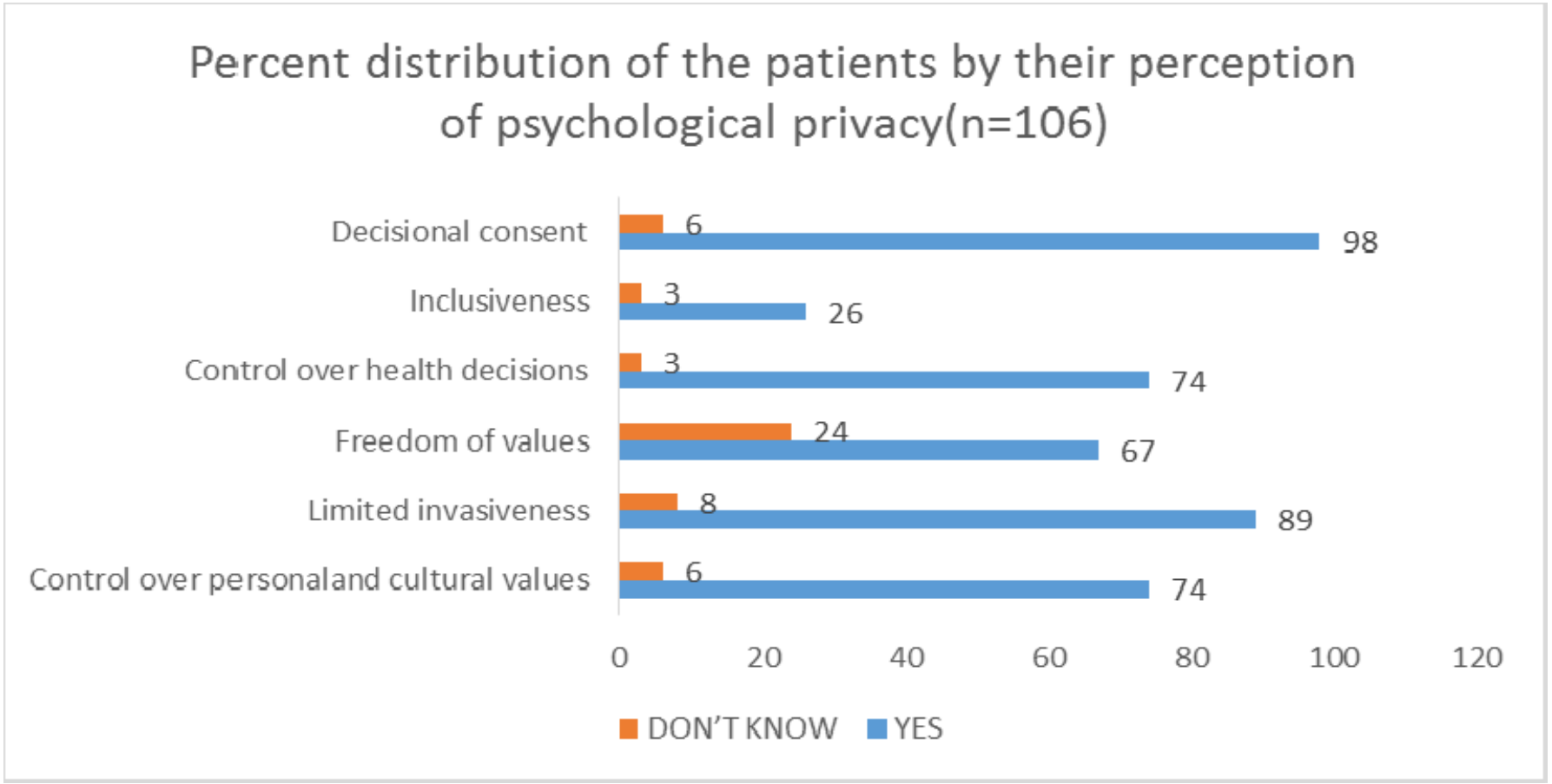
- Only a dismal percent(5%) had heard about privacy/ confidentiality.
- Majority didn't know about the service providers obligation to maintain privacy and confidentiality during medical consultation.



Only 35 percent of the patient respondents felt that they had control over the information being gathered from them, 13 percent denying and 52 percent not being sure of the same.



- Only 32 percent agreed that in doctor's office, their actions and conversations were not observed or overheard by people outside, while 27 percent answered otherwise.
- Only 18 percent agreed that the space and furniture arrangement in doctor's office created a sense of privacy, 73 percent answered otherwise.



Only 26 percent felt that their doctor considers their opinion about their health.

Observations regarding inputs available at facility to ensure privacy and confidentiality

INPUT	Present	Partially Present	Absent
One Patient is seen at a time in clinics			
Curtains have been provided at windows			
Screens provided at Emergency			
Provision of a counselling corner/designated area			
Availability of Breast feeding corner			
Separate queue for female at registration			
Demarcated male and female observation areas			
Separate toilets for male and females			
Availability of female staff if a male doctor examine a female patients			
Patients are dressed/covered while been shifted from one department to other			
Medical records room where records of the patients are kept locked in			
No two patients are treated on one bed			

CONCLUSION

- Review of the present legislature and regulations suggests that the Right to Privacy and confidentiality has been embodied in a multitude of domestic legislations pertaining to the healthcare sector but a strong foundational framework where the rights are addressed and find mention in a single document is still awaited.
- On the knowledge front, approximately half of the providers did not know about privacy and confidentiality. A dismal portion of those who knew could not tell the difference accurately. Only 15 percent knew of any existent legislation providing for privacy and confidentiality safeguards.
- Regarding patients' entitlement to privacy, confidentiality and seeking courts intervention doctors were better aware than nursing staff, none of whom could correctly respond which is again indicative of the dearth of knowledge due to missing training and adequate relevant teaching in professional courses.

- The attitudes of the providers to ensure visual and auditory privacy was satisfactorily positive. Regarding the attitudes towards maintaining confidentiality, they seemed rather unsure in agreeing to certain points (like confidentiality in case of adolescents, obtaining clients permission before notifying partner etc.) which is only indicative of their lack of training, exposure and knowledge.
- Knowledge of the patients regarding privacy and confidentiality was rather nonexistent with 95 percent of them not knowing anything about their right to privacy and confidentiality, which is the reason for their not being empowered enough to seek private and confidential health care.
- Their perception regarding informational, physical and psychological privacy were recorded, which showed gaps in consent over personal space, physical setting of the hospital to ensure privacy, inclusiveness etc., which is reflective of the way services are delivered in the facility. Also if we see the compliance to privacy and confidentiality regarding inputs at facility, it has fallen short fulfilling only 4 criteria out of 12 observed.