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Determinants of the uptake of prenatal aneuploidy screening among pregnant women at The Aga Khan University Hospital, Nairobi, Kenya

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DETERMINANTS OF THE UPTAKE OF PRENATAL ANEUPLOIDY SCREENING AMONG PREGNANT WOMEN AT THE AGA KHAN UNIVERSITY HOSPITAL, NAIROBI, KENYA.

By

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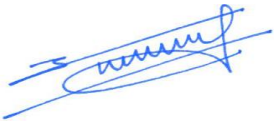

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DEDICATION

This dissertation is dedicated to my dear wife and daughter for being the inspiration for this work and for their invaluable never ending support.

ABSTRACT

INTRODUCTION

Aneuploidies present with an abnormal copy number of chromosomes. Majority are lethal with only a handful carrying on to term and beyond in pregnancy. Its currently recommended that all pregnant women be offered screening for aneuploidies. This is to facilitate pregnant women make informed choices regarding their pregnancies. At present the current uptake rate of aneuploidy screening in Kenya is unknown. The purpose of this study this study was to determine whether pregnant women are aware of aneuploidy screening, the uptake rate of screening and the determinants of screening at a tertiary private healthcare facility in Nairobi, Kenya.

METHODS

A cross-sectional study was conducted between August to December 2021 that involved 325 pregnant women attending their antenatal clinics at the Aga Khan University Hospital, Nairobi, Kenya. A self-administered questionnaire was used to collect data on demographics, pregnancy follow up information, knowledge and attitude towards aneuploidy screening and uptake of screening.

RESULTS

Three hundred and twenty-five (325) pregnant women were enrolled over a period of 6 months. Of the 325 only 186 were aware of aneuploidy screening. Uptake rate of aneuploidy screening was found to be at 39.2% (95%CI: 32.2% - 46.7%) and the only statistically significant factor associated with increased uptake of aneuploidy screening was a positive attitude towards screening (AOR: 4.36; 95%CI: 1.95-10.81, p=0.001.

CONCLUSION

The level of awareness of aneuploidy screening among pregnant women is low. Of those aware of the screening methods, less than half of them underwent screening and the concept of informed choice was lacking in a majority. Increased uptake rate of screening was associated with having a positive attitude towards aneuploidy screening.

LIST OF ABBREVIATIONS

ACOG	American College of Obstetricians and Gynaecologists
AFP	Alpha-feto protein
AKUHN	Aga Khan University Hospital, Nairobi
CFFDNA	Cell free fetal deoxyribonucleic acid
DSS	Down syndrome screening
HCG	Human chorionic gonadotropin
IQR	Inter-quartile range
KAP	Knowledge, attitude and perception
N/A	Not applicable
NACOSTI	National Commission for Science, Technology and Innovation
NIPT	Noninvasive prenatal testing
NT	Nuchal translucency
OR	Odds Ratio
AOR	Adjusted Odds Ratio
PAPPA	Pregnancy associated plasma protein A
RCOG	Royal College of Obstetricians and Gynaecologists
TOP	Termination of pregnancy
UE3	Unconjugated estriol

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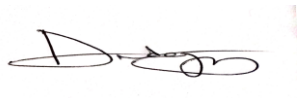
DECLARATION

I declare this dissertation does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university and that to the best of my knowledge it does not contain any material previously published or written by another person except where due reference has been made in the text.

The editorial assistance provided to me has in no way added to the substance of my dissertation which is the product of my own research endeavours.



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CHAPTER ONE: INTRODUCTION

Aneuploidies present with either additional chromosomes or loss of chromosomes. Common aneuplodies include Down Syndrome (trisomy 21), Edwards's syndrome (trisomy 18) and Patau's syndrome (trisomy) 13. Others include Sex-linked aneuploidies, which are compatible with life; Turner syndrome (monosomy X) with a prevalence of 1 in 2,500 live births and Klinefelter syndrome (47 XXY) which is the most common sex chromosome aneuploidy with prevalence rate of 1:500 males (1). Trisomy 21 stands out as it is the most common chromosomal abnormality among live born infants. It is characterized by a range of clinical manifestations that include cognitive impairment, congenital malformations, dysmorphic features and other medical conditions (1). Individuals with trisomy 18 and 13 will also present with similar clinical manifestations but have a shorter life span as compared to those with Trisomy 21. Having a child with the above syndromes places a huge burden on the parents with far reaching psychological, emotional and financial implications, greatly affecting the quality of life of both the child and the parent (2). The prevalence of Trisomy 21 globally is estimated to be 1 in700 live births, prevalence of Trisomy 18 is 1 in 3000 live births and prevalence of Trisomy 13 is 1 per 6,000 live births (3) (4). The prevalence of Aneuploidies among African populations is unknown(5). In Kenya the prevalence of congenital anomalies at birth is estimated to be 3% of all live births (6).

The World Health Organization through its report on community genetics services in low and middle income countries recommended measures to reduce the incidence and burden of congenital anomalies and genetic diseases to communities. Among the recommendations was noninvasive prenatal screening for aneuploidies. Globally the trend is towards adopting routine prenatal screening for genetic disorders for all women presenting for antenatal clinics. For instance, the American college of Obstetricians and Gynecologists and the Society for Maternal Fetal Medicine recommend that all pregnant women regardless of age should be offered routine prenatal screening for aneuploidies with pre and posttest counselling(3). This preferably should be early in pregnancy during the first prenatal visit. The choice of screening test depends on the patient's age, gestational age, number of fetuses, obstetric history, family history, test availability, test sensitivity and limitations, risk of invasive diagnostic procedures, desire for early test results, and options for early pregnancy termination (3). Some of the screening modalities available include ultrasonography to measure the nuchal translucency (NT) of the foetus done between 11 weeks and 13+6 weeks. This can be done as a standalone screening test or in combination with maternal serum analytes. On its own NT screening has a detection rate of 70% For Trisomy 21. For first trimester screening, NT screening can be combined with maternal serum beta human chorionic gonadotrophin (HCG) and

pregnancy associated plasma protein A levels (PAPP-A), better known as the double test. Its offered between 11 and 13+6 weeks and has a detection rate of 82-87% for Trisomy 21. In the second trimester (15-22 weeks) main stay of screening involves maternal serum analytes assessment. The triple screen involves measurement of beta HCG, Alpha feto protein and unconjugated estriol with a detection rate of 73% for Trisomy 21. The Quadruple screen test involves the measurements of serum analytes similar to those in the triple test with inclusion of dimeric inhibin A. It has a detection rate of 81% for Trisomy 21. In order to increase detection rates these tests can be combined or done sequentially. Serum integrated test involves measurement of PAPP-A followed by the quadruple screen with a detection rate of 88%. The integrated test involves NT measurement, PAPP-A and the quadruple screen with a detection rate of 96%. Stepwise sequential involves measuring NT, beta HCG and PAPP-A followed by the quad screen with detection rate of 95% (1, 7-9). The most recent noninvasive prenatal test to be employed is screening for circulating free fetal DNA in the maternal circulation. Its highly sensitive and specific for the common trisomies (99.7% for trisomy 21, 98.2% for trisomy 18, and 99.0% for trisomy 13) and sex chromosome aneuploidies (3) (10-13).

Women found to be at high risk for aneuploidies following screening are offered genetic counselling, detailed anatomic survey ultrasonography scans plus invasive diagnostic tests which include Chorionic Villus Sampling, offered between 10-13 weeks and Amniocentesis, offered between 15-20 weeks (3) (11). Pregnant women whose screening results are deemed low risk for aneuploidies are counselled that there is a small risk of their pregnancy being affected by genetic and chromosomal anomalies not detected by the screening test. There is room for offering such women invasive diagnostic tests at a later date especially if anomalies are noted during subsequent ultrasound scans (3).

The rationale behind prenatal screening for genetic disorders is to offer women an opportunity to make timely and informed decisions regarding their pregnancy. Currently in Kenya we do not have a national policy regarding prenatal aneuploidy screening and the few facilities offering the tests are mostly in the private sector.

The screening protocol at the Aga Khan University Hospital in Nairobi includes offering all pregnant women attended to at all its antenatal clinics the opportunity to undergo aneuploidy screening and further testing if necessary. Tests offered include the double (combined) test, triple and quadruple screen tests. Patients who desire Non Invasive Prenatal Testing (NIPT) or cell free fetal DNA are referred to private laboratories that can facilitate the test. Between January 2017 to December 2019 the estimated total number of women who delivered at AKUHN was 10,000. During the same period a total of 620 aneuploidy tests were performed. This number represents only 6.2% of the eligible women during that period of time. As

such it is prudent to establish the level of awareness of the existence of aneuploidy screening and the uptake rate of aneuploidy screening among women who deliver at AKUHN, and furthermore, to evaluate the factors that influence uptake of screening tests. In addition, it will be important to establish whether pregnant women are making informed choices regarding undergoing prenatal screening for aneuploidies.

This study therefore aims to evaluate the factors that influence uptake of aneuploidy screening among pregnant women on follow up at The Aga Khan University hospital in Nairobi, Kenya.

1.1 LITERATURE REVIEW

1.1.1 Awareness of aneuploidy screening

Assessment of risk for aneuploidy screening has been done since the 1930's where maternal age was used as a screening tool and over time evolved to include amniocentesis in the 1970s, assessment of maternal serum analyses in the 1980s to the most recent highly sensitive screening modality, the non-invasive prenatal test or cell free fetal DNA assessment(14). Currently the recommendation is that all pregnant women should be offered aneuploidy screening during their pregnancies and additional diagnostic testing if found to be at high risk (1, 3).

From the various studies done on aneuploidy screening, varying rates of awareness of aneuploidy screening have been reported. These include an awareness rate of 59.1% in a study done in Romania, 74.3% in Jordan, 76% in Australia and 45% in Thailand (15-17).

Aneuploidy screening has been available in Kenya for a number of years. However, the country does not have any national or regional protocols guiding aneuploidy screening and diagnosis. It is also unknown whether obstetrician gynaecologists in the country are offering pregnant women information on aneuploidy screening and the opportunity to undergo these crucial tests. Therefore, at present, awareness of aneuploidy screening amongst pregnant women in Kenya is unknown.

1.1.2 Uptake of aneuploidy screening

The current incidence of aneuploidies in Kenya and Africa by extension is unknown (5). A study in south Africa looking at Down syndrome in the African population noted that a majority of women with a child with Down syndrome would have accepted prenatal diagnosis if it had been offered to them during their pregnancies. About half of the respondents also expressed that they would have acted on the information provided, and, among the considerations would have been termination of an affected pregnancy (18). Since the introduction of aneuploidy screening, no studies have been done on the African continent looking at the uptake rate of screening among this population. A few studies have been done across the world looking at uptake of aneuploidy screening with varying rates of uptake. In Romania uptake rate was noted to be at 80.36% (16), in the United States of America the uptake rate was 84.8% and 88.2% for women aged less than 35 years and those aged above 35 years respectively (19), in Australia an uptake rate of 79% (20), in Canada an uptake rate of 62.2% (21),in China an uptake rate of 35.8% (22) and in the Netherlands an uptake rate of 25.7% (23). There is a therefore need to determine the uptake rate of aneuploidy screening in Kenya and Africa in general.

1.1.3 Determinants of Aneuploidy screening

Various factors have been identified as likely to be associated with the uptake of aneuploidy screening. Factors associated with higher rates of aneuploidy screening include, greater level of income/social economic status, greater educational attainments, inclination towards termination of pregnancy for an affected fetus, higher perceived value of testing information, higher levels of knowledge about screening, having regular prenatal/antenatal checkups, taking maternal preparation classes, being followed up at a tertiary healthcare facility, advanced maternal age and age less than 35 have both been associated with higher screening rates, nulliparity, women from highly urbanized areas and pregnancies following artificial reproductive techniques (19, 22, 23).

Factors associated with reduced rates of aneuploidy screening include, multiparity, living in rural/non-urban settings, pregnancy follow up by a midwife or family physician, reduced levels of income, age below and above 35 years, race (African American), increased perceived risk of procedure related miscarriage, distrust of the healthcare system, higher levels of faith and fatalism, and the belief that modern medicine interferes with pregnancy (19, 21-23).

Among the notable factors associated with uptake of aneuploidy screening is knowledge and attitude towards screening. Higher levels of knowledge on screening has been associated with a higher level of education, higher income levels, having private insurance or civil servant insurance schemes, living in metropolitan areas, family history of genetic diseases, follow up by an obstetrician gynaecologist, increase in time allocated for discussion of aneuploidy screening, age and positive attitude towards screening. Higher levels of knowledge on screening and age less than 35 have been associated with positive attitudes towards screening (15-17, 20, 24).

As noted there are numerous factors both positively and negatively associated with uptake of aneuploidy screening. What is unknown is whether these same factors hold true for pregnant women in Kenya and Africa in general.

1.1.4 Informed choice

An important aspect of the process of making a decision to undergo aneuploidy screening is the issue of informed choice. Informed choice has been defined as a reasoned choice which is made by a reasonable individual using relevant information about the advantages and disadvantages of all possible courses of action, in accordance with the individuals' belief. An informed choice to accept antenatal screening for aneuploidies occurs when a woman has relevant knowledge about the screening test, has a positive attitude

towards screening and undertakes the test. On the other hand, women who make an uninformed choice to accept the screening test have a poor level of knowledge, have a negative attitude towards screening and yet still undertake the test. Women who have inconsistent attitude and behavior, or do not have relevant knowledge, make uninformed choices (25-27). Notable studies looking at informed choice in the context of aneuploidy screening have reported different rates, 89% in the United Kingdom, 44% in Greece and 14.2% in Romania (16, 24, 28).

1.2 JUSTIFICATION

Current guidelines recommend offering aneuploidy screening to all pregnant women. Data are lacking on the awareness of the availability of aneuploidy screening, the uptake rate of aneuploidy screening and the potential factors that influence uptake of aneuploidy screening among pregnant women in Kenya. Additionally, it is unknown whether pregnant women in Kenya are making informed decisions regarding the choice to undergo aneuploidy screening. From statistics obtained from the laboratory and records departments at AKUHN it is evident that most pregnant patients attended to at AKUHN are not screened for aneuploidies. This study aims to determine the factors associated with the uptake of aneuploidy screening, awareness levels of aneuploidy screening, the uptake rate of aneuploidy screening and to determine if pregnant women are making informed choices as regards aneuploidy screening at AKUHN.

1.3 RESEARCH QUESTION

What are the determinants of the uptake of aneuploidy screening among pregnant women at the Aga Khan University Hospital Nairobi?

1.3.1 Primary objective

1. To assess the determinants of the uptake of aneuploidy screening among pregnant women at the Aga Khan University Hospital Nairobi.

1.3.2 Secondary objective

1. To determine whether pregnant women are aware about aneuploidy screening at the Aga Khan university Hospital Nairobi.
2. To determine the uptake rare of aneuploidy screening among pregnant women at the Aga Khan University Hospital Nairobi.
3. To determine whether pregnant women are making informed choices regarding undergoing aneuploidy screening at the Aga Khan University Hospital Nairobi.

CHAPTER TWO: MATERIALS AND METHODS

2.1 Overview of research design

A cross sectional analytical quantitative study was conducted at the main hospital of the Aga Khan University hospital in Nairobi, Kenya. Participants were pregnant women above 10 weeks gestation on follow up at the antenatal clinic. Consenting participants were provided with a self-administered closed ended questionnaire with sections on demographic data, pregnancy follow up information, knowledge on aneuploidy screening and attitude towards aneuploidy screening.

2.2 Study setting

This study was conducted at the antenatal clinics in the Aga Khan University Hospital Nairobi, Kenya.

2.3 Study population

Pregnant women whose gestation was 10 weeks and above on follow up at the main antenatal clinic of the Aga Khan University Hospital, Nairobi, Kenya. The cut off of 10 weeks was chosen as above this gestation the patient is eligible for the common tests usually offered at AKUHN for aneuploidy screening. The assumption was above this gestation the patient would have been counselled on aneuploidy screening and offered the same. The patient will then have made a decision whether to have the test done or not.

2.4 Eligibility criteria

2.4.1 Inclusion criteria

- Pregnant women aged 18 years and above.
- Gestational age of 10 weeks and above.
- Conversant with spoken and written English and Swahili.

2.4.2 Exclusion criteria

- Pregnant women with cognitive deficits.

2.5 Sample size calculation

Outcome of interest in this study will be uptake of prenatal aneuploidy screening measured on a binary scale. The sample size was determined using a sample size formula for simple logistic regression model using women with history of miscarriage as a predictor of the outcome as illustrated in Hsieh et al (29) defined as:

$$n = \left(Z_{1-\frac{\alpha}{2}} \left[\frac{p(1-p)}{B} \right]^{\frac{1}{2}} + Z_{power} \left[p_1(1-p_1) + \frac{p_2(1-p_2)(1-B)}{B} \right]^{\frac{1}{2}} \right)^2 /[(p_1 - p_2)^2(1-B)]$$

Where n is the required sample size, p= (1-B)p_1+Bp_2 is the overall event rate defined as uptake of the screening test, B is the assumed proportion of women with history of miscarriage in the general population X=1; p_1 and p_2 are the event rates at X=0 and X=1 respectively, and X is history of miscarriage. The sample size assumed B=0.2, p_1=0.622, p_2=0.627 80% power and 95% level of significance. Some of these assumptions were based on literature from a similar study conducted by Hayeems et al(21) in Canada and suggested values by Hsieh et al. We calculated different samples at different powers based on these assumptions. A minimum sample size of 300 was sufficient to give a power of 80%, while adjusting for 5% non-response rate, the final minimum sample size was estimated to be 315 participants for the study.

2.6 Sampling

Consecutive sampling was used in selecting study participants from the study population. This method was chosen as it presented the most pragmatic means of ensuring we included as many women as possible in the study. Women attending the antenatal clinics were approached to participate in the study by a study assistant. Those who accepted were assessed for eligibility and those who met the criteria were enrolled into the study.

2.7 Research tool

A Self-administered closed ended structured questionnaire was adapted from a similar study conducted by Melania et al in Romania(16) who had themselves adapted it from related studies in Thailand(15) and Australia(20) where the questionnaire had been validated. The questionnaire was modified to suit the present study's objectives.

The questionnaire consisted of sections looking at demographics (9 items), knowledge (24 items), attitude (18 items), and sources of information and pregnancy follow up (10 items). Knowledge score was assessed depending on the responses given. A "yes" or "no" response was awarded 1 point depending on whether the response given is correct. A response of "do not know" was awarded 0 points. Women with a total score of equal or less than 8 were classified as having a low level of knowledge, women with a score of between 9 and 16 were classified as having an average level of knowledge and the women with a score of between 17 and 24 were classified as having a high level of knowledge. Attitude was assessed based on a Likert scale and based on the responses given the women were placed in three categories, positive attitude (agreement), Neutral attitude and lastly negative attitude (disagreement).

A pilot study was done on 15 women during their antenatal clinic visits. Reliability of the knowledge and attitude sections was assessed using Cronbach's alpha coefficient. Scores for knowledge and attitude were 0.819 and 0.78 respectively.

2.8 Operational definitions

Table 1: Operational definitions

VARIABLE	OPERATIONAL DEFINITION	SCALE OF MEASUREMENT
AWARENESS OF ANEUPLOIDY SCREENING	Being cognizant of the existence of screening tests for aneuploidies during pregnancy.	Yes/No
UPTAKE OF SCREENING	State of having undergone aneuploidy screening.	Yes/No
KNOWLEDGE OF PRENATAL SCREENING	Total score obtained by a participant based on how conversant they are with aneuploidies and the available tests for them.	Low/Moderate/High
ATTITUDE TOWARDS PRENATAL SCREENING	Total score obtained by a participant based on their thoughts and feelings about aneuploidy screening and testing.	Negative/Neutral/Positive

2.9 Data collection procedure

A research assistant was employed and trained on the intended research project, sampling technique and recruitment procedure for participants. A total of 350 participants were identified and recruited for the study between August to December 2021 at the antenatal clinic of AKUHN. They proceeded to fill in the self-administered questionnaire which comprised of closed ended questions. After completion the questionnaires were collected for safe keeping.

2.10 Data management

Once filled the questionnaires were collected and assigned a unique identifying number before being archived and safely stored awaiting analysis. Access to the stored questionnaires was restricted to the principal investigator and research assistant only. A standard Microsoft Excel data sheet was used to capture data from the questionnaires. This database was password protected and a copy was made and saved on a portable storage device. All study materials will be handed over to the research office for storage and will

be discarded later as per the Aga Khan University's research office rules and regulations for discarding of research materials.

2.11 Data analysis

Participants characteristics were analyzed descriptively using frequencies and percentages for categorical data and median and inter-quartile range for continuous data.

Tests of association between (independent) variables and outcome (dependent variable – uptake of screening) were performed using Chi square and Fisher's exact test for categorical data. Mann Whitney U (Wilcoxon Rank-Sum) test was applied for continuous data.

Variables whose P value was <0.2 in the bivariate analysis were included in the multivariable analysis using the logistic regression model. Statistical significance was set at 5% ($p<0.05$). All data Analysis were performed using SPSS version 23.

Informed choice was assessed by comparing the concordance between knowledge, attitude and uptake of aneuploidy screening tests. The participants with a high level of knowledge and positive attitudes towards aneuploidy screening who underwent the screening process were deemed to have made an informed choice.

2.12 Ethical considerations

Permission was sought to adapt the questionnaire used by Melania et al in their study. The study obtained ethical approval from The Aga Khan University's Institutional Scientific, Ethics and Research Committee and from the National Commission of Science Technology and Innovation (NACOSTI). Participation was voluntary and written consent was obtained from all participants. Patients' details were handled with utmost confidentiality and all identifying information remained anonymous. Each questionnaire was assigned a unique identifying number. Participants were not exposed to any risk or harm. No financial incentives or rewards of any type were offered to the participants.

CHAPTER THREE: RESULTS

A total of 350 participants were eligible for the study. Twenty-five of the participants had incomplete questionnaires leaving a final sample size of 325. A hundred and eighty-six (186) participants out of the 325 (57.2%) were aware of aneuploidy screening, while 139 (42.8%) participants were naïve of aneuploidy screening. Those naïve of aneuploidy screening only provided demographic and clinical follow up data and were excluded from completing the knowledge and attitude sections of the questionnaire. Determination of the uptake rate of screening, analysis of the factors associated with aneuploidy screening and assessment of informed choice was limited to the participants aware of aneuploidy screening (n=186).

Table 2 and 3 summarise the demographic and clinical follow up characteristics of the participants. Notably, the prevalence of chronic illness was 5.9% (n=11), history of a pregnancy or child with congenital anomalies was 2.7% (n=5) and those who had ever had an abortion or miscarriage was 25.3% (n=47).

A large proportion of participants were being followed up by an obstetrician gynaecologist (83.3%) in private institutions (96.8%). Of those aware of aneuploidy screening, 46.2% were aware of one test, 26.9% were aware of two tests, 22% were aware of three tests and 4.8% were not aware of any specific tests. The median time spent on discussion of aneuploidy screening with their physicians was 10 minutes (IQR;5-20), and the uptake rate of aneuploidy screening was 39.2% (95%CI: 32.2% - 46.7%) (Table 3).

Table 2: Participants socio-demographic and clinical Characteristics

Characteristic	**N = 186[1]** **Number (%)**
Age in years	33 (30, 36)
Age-group in years	
18-24	3 (1.6%)
25-34	114 (61.3%)
35-45	69 (37.1%)
Parity	
Nulliparous	49 (26.3%)
Parous	137 (73.7%)
Median (IQR) gestation (weeks)	30 (22, 36)
Complete gestation (weeks)	
11-14 weeks	10 (5.4%)
15-28 weeks	69 (37.1%)
Above 28 weeks	107 (57.5%)
Residence	
Urban area	176 (94.6%)
Rural area	10 (5.4%)
Current occupation	
Employed	125 (67.2%)
Self-employed	51 (27.4%)
Unemployed	10 (5.4%)
Religion	
Christian	173 (93.0%)
Other	13 (7.0%)
Race	
African	180 (96.8%)
Other	6 (3.2%)

Characteristic	**N = 186[1]** **Number (%)**
Marital status	
Married	170 (91.4%)
Single	16 (8.6%)
Level of education	
Primary	1 (0.5%)
Secondary	5 (2.7%)
Tertiary	180 (96.8%)
Presence of chronic illness	
No	175 (94.1%)
Yes	11 (5.9%)
Ever had pregnancy or child with congenital anomalies	
No	181 (97.3%)
Yes	5 (2.7%)
Ever experience abortion/miscarriages	
No	139 (74.7%)
Yes	47 (25.3%)

[1]Wilcoxon rank sum test; Fisher's exact test; Pearson's Chi-squared test

[1]n (%); Median (IQR)

Table 3: Participants pregnancy follow-up information

Pregnancy follow up characteristics	**N = 186[1] Number (%)**
Who follow-up your pregnancy	
Medical doctor	29 (15.6%)
Obstetrician	155 (83.3%)
Midwife	2 (1.1%)
None	0 (0.0%)
Other	0 (0.0%)
Place of follow-up	
Public Institution	6 (3.2%)
Private Institution	180 (96.8%)
Number of tests aware of	
0	9 (4.8%)
1	86 (46.2%)
2	50 (26.9%)
3	41 (22.0%)
Unknown	0
Time allocated by the specialist for aneuploidy discussion	10 (5, 20)
Time allocated by the specialist for aneuploidy discussion	
0 min	21 (11.3%)
<= 10 min	82 (44.1%)
15-20 min	67 (36.0%)
>=30 min	16 (8.6%)
Screened for aneuploidies	
No	113 (60.8%)
Yes	73 (39.2%)

[1]Median (IQR); n (%)

3.1 Factors Associated with the uptake of aneuploidy screening

The bivariate analysis showed that attitude towards aneuploidy screening was the only variable associated with uptake of screening ($p<0.001$). It is also notable that the prevalence of screening increased with increasing levels of knowledge on screening (Table 4).

The multivariable analysis included all variables with p-value <0.2 in the bivariate analysis. This included occupation, religion, knowledge on aneuploidy screening and attitude towards aneuploidy screening. Apart from positive attitude towards aneuploidy screening, none of the other variables were significantly associated with screening of aneuploidies in the multivariable analysis. Controlling for other variables in the model, women who had positive attitude towards aneuploidy screening were 4.36 times more likely to be screened compared to those with negative attitude (AOR: 4.36; 95%CI: 1.95-10.81, p=0.001) (Table 5).

Table 4: Bivariate analysis of aneuploidy screening and demographic and clinical characteristics

	Screened for Aneuploidies		
Variable	**Not screened, N = 113[1] Number (%)**	**Screened, N = 73[1] Number (%)**	**p-value[2]**
Age in years	33 (30, 36)	33 (31, 36)	0.548
Age-group in years			0.614
18-24	1 (33.3%)	2 (66.7%)	
25-34	71 (62.3%)	43 (37.7%)	
35-45	41 (59.4%)	28 (40.6%)	
Parity			0.865
Nulliparous	29 (59.2%)	20 (40.8%)	
Parous	84 (61.3%)	53 (38.7%)	
Median (IQR) gestation (weeks)	30 (22, 34)	31 (26, 36)	0.056
Complete gestation (weeks)			0.230
11-14 weeks	8 (80.0%)	2 (20.0%)	
15-28 weeks	45 (65.2%)	24 (34.8%)	
Above 28 weeks	60 (56.1%)	47 (43.9%)	
Residence			0.999
Urban area	107 (60.8%)	69 (39.2%)	
Rural area	6 (60.0%)	4 (40.0%)	
Current occupation			0.123
Employed	72 (57.6%)	53 (42.4%)	
Self-employed	32 (62.7%)	19 (37.3%)	
Unemployed	9 (90.0%)	1 (10.0%)	
Religion			0.138
Christian	108 (62.4%)	65 (37.6%)	
Other	5 (38.5%)	8 (61.5%)	
Race			0.999

	Screened for Aneuploidies		
Variable	**Not screened, N = 113[1] Number (%)**	**Screened, N = 73[1] Number (%)**	**p-value[2]**
African	109 (60.6%)	71 (39.4%)	
Other	4 (66.7%)	2 (33.3%)	
Marital status			0.889
Married	103 (60.6%)	67 (39.4%)	
Single	10 (62.5%)	6 (37.5%)	
Level of education			0.787
Primary	1 (100.0%)	0 (0.0%)	
Secondary	4 (80.0%)	1 (20.0%)	
Tertiary	108 (60.0%)	72 (40.0%)	
Presence of chronic illness			0.999
No	106 (60.6%)	69 (39.4%)	
Yes	7 (63.6%)	4 (36.4%)	
Ever had a pregnancy or child with congenital anomalies			0.382
No	111 (61.3%)	70 (38.7%)	
Yes	2 (40.0%)	3 (60.0%)	
Ever experienced an abortion or miscarriage			0.889
No	84 (60.4%)	55 (39.6%)	
Yes	29 (61.7%)	18 (38.3%)	
Sum of knowledge scores	11 (8, 15)	13 (10, 17)	0.020
Knowledge on Aneuploidy screening			0.072
Low	29 (74.4%)	10 (25.6%)	
Average	66 (60.0%)	44 (40.0%)	

	Screened for Aneuploidies		
Variable	**Not screened, N = 113[1] Number (%)**	**Screened, N = 73[1] Number (%)**	**p-value[2]**
High	18 (48.6%)	19 (51.4%)	
Attitude			<0.001
Negative	42 (84.0%)	8 (16.0%)	
Positive	71 (52.2%)	65 (47.8%)	

[1]Median (IQR) or Frequency (%)

[2]Wilcoxon rank sum test; Fisher's exact test; Pearson's Chi-squared test

Table 5: Logistic regression parameter estimates for the factors associated with the uptake of aneuploidy screening, N=186

Variable		Not screened (%)	Screened (%)	Odds Ratio (OR) (univariable)	P value	Adjusted Odds Ratio (AOR) (multivariable)	P value
Occupation	Employed	72 (57.6)	53 (42.4)	-		-	
	Unemployed	41 (67.2)	20 (32.8)	0.66 (0.34-1.25)	0.209	0.68 (0.34-1.34)	0.268
Religion	Christian	108 (62.4)	65 (37.6)	-		-	
	Other	5 (38.5)	8 (61.5)	2.66 (0.85-9.12)	0.098	2.91 (0.85-11.16)	0.098
Knowledge on aneuploidy screening	Low	29 (74.4)	10 (25.6)	-		-	
	Average	66 (60.0)	44 (40.0)	1.93 (0.88-4.54)	0.112	2.08 (0.89-5.22)	0.101
	High	18 (48.6)	19 (51.4)	3.06 (1.19-8.29)	0.023	2.44 (0.89-6.99)	0.088
Attitude	Negative	42 (84.0)	8 (16.0)	-		-	
	Positive	71 (52.2)	65 (47.8)	4.81 (2.20-11.73)	<0.001	4.36 (1.95-10.81)	0.001

3.2 Women's attitude

The median attitude score among the tested was 74 (70-79), 26 (35.6%) had negative attitude, 27 (37%) were neutral and 20 (27.4%) had positive attitude. In the non-tested group, the median score was 58 (52-63), 54 (47.8%) had negative attitude, 40 (35.4%) were neutral, and 19 (16.8%) had positive attitudes (Table 6).

Table 6: Attitude towards having aneuploidy screening

Attitude	Screened (N=73)	Not screened (N=113)
Negative	26 (35.6)	54 (47.8)
Neutral	27 (37.0)	40 (35.4)
Positive	20 (27.4)	19 (16.8)
Total	73 (39.2)	113 (60.8)
Median (IQR)	74 (70-79)	58 (52-63)
Mean (SD)	74.0 (7.2)	57.4 (7.6)

3.3 Women's knowledge

The median knowledge score was 12 (IQR: 9-15). The knowledge scores were stratified into three levels based on whether the scores were high, average or low. Majority had an average level of knowledge (n=110; 59.1%) about aneuploidy screening, 39 (21.0%) had low levels of knowledge, and 37 (19.9%) had high levels of knowledge (Figure 1).

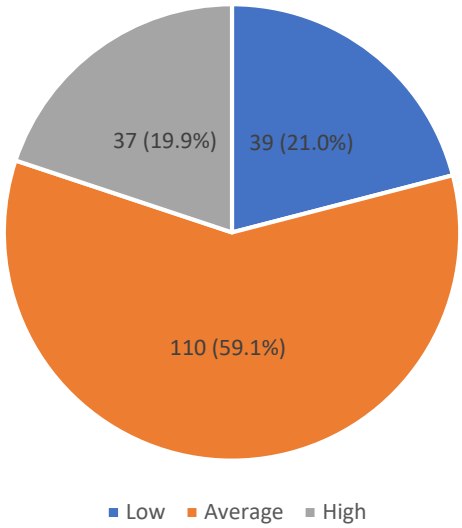

Figure 1: Level of knowledge about aneuploidy screening

3.4 Knowledge and attitude

Of those who had low level of knowledge, 23 (59.0%) had negative attitude towards the test, 10 (25.6%) had neutral attitude, only 6 (15.4%) of them had positive attitudes. Among those who had average levels of knowledge, 50 (45.5%) had negative attitudes towards screening, 39 (35.5%) were neutral and 21 (19.1%) had positive attitude. For those who had a high level of knowledge, 7 (18.9%) had negative attitude, 18 (48.6%) had neutral attitude and 12 (32.4%) had positive attitude (Table 7).

Table 7: Knowledge and attitude of those who were aware of screening

	Attitude			
Knowledge	Negative n (%)	Neutral n (%)	Positive n (%)	Total
Low	23 (59.0)	10 (25.6)	6 (15.4)	39
Average	50 (45.5)	39 (35.5)	21 (19.1)	110
High	7 (18.9)	18 (48.6)	12 (32.4)	37
Total	80 (43.0)	67 (36.0)	39 (21.0)	186

3.5 Informed choice

The study also assessed the relationship between level of knowledge on aneuploidies, attitude towards aneuploidies and uptake of screening. Uptake was noted to increase with increasing level of knowledge from 31.0% of women with low level of knowledge to 42.1% among those with high level of knowledge. The rate of uptake was observed to be higher among women with positive attitude and average to high levels of knowledge than those with negative attitude (Table 8). Only 7 (3.76%, n=186) participants who were screened had a high enough level of knowledge on aneuploidies and a corresponding positive attitude towards screening to be judged to have made an informed decision as regards screening.

Table 8: Knowledge, attitude and screening for aneuploidies

	Knowledge					
Attitude	Low		Average		High	
	Not screened n (%)	Screened n (%)	Not screened n (%)	Screened n (%)	Not screened n (%)	Screened n (%)
Negative	16 (69.6)	7 (30.4)	32 (64.0)	18 (36.0)	6 (85.7)	1 (14.3)
Positive	4 (66.7)	2 (33.3)	10 (47.6)	11 (52.4)	5 (41.7)	7 (58.3)
Total	20 (69.0)	9 (31.0)	42 (59.2)	29 (40.8)	11 (57.9)	8 (42.1)

CHAPTER FOUR: DISCUSSION

Slightly more than half of the participants in the study (57.2%, n=186) were aware of aneuploidy screening and only 39.2% of them underwent screening. The only statistically significant factor associated with an increased uptake rate of screening was a positive attitude towards aneuploidy screening (AOR 4.36; 95%CI: 1.95-10.81, p=0.001).

4.1 Factors associated with the uptake of aneuploidy screening

A positive attitude towards aneuploidy screening was the only statistically significant factor associated with an increased uptake rate of aneuploidy screening (AOR: 4.36; 95%CI: 1.95-10.81, p=0.001). Other significant factors associated with either an increased or decreased rate of uptake have been reported. Crombag et al identified advanced maternal age, residing in urban areas and higher social economic status as being associated with increased rates of aneuploidy screening. Grand multiparity was noted to be associated with reduced rates of screening(23). A population based retrospective study done in Ontario Canada looking at aneuploidy screening across different regions noted uptake to be lower in women residing in rural areas, those being followed up by midwives or family physicians and among those women within the lower income quartile (21). A hospital based cross-sectional study done in China identified low levels of education and maternal age above 35 years as significant factors towards underutilization of aneuploidy screening. Factors identified to be associated with increased screening rates in that study included attending maternal preparation classes, regular prenatal checkups and follow up at a tertiary health facility (22). Kuppermann et al also noted that women with higher levels of income and education levels, and those more inclined towards termination of an affected pregnancy, have higher uptake rates of aneuploidy screening. Women of African American descent and those with advanced maternal age were less likely to undergo screening as well (19). Studies looking specifically at factors associated with uptake of NIPT or CFFDNA have identified higher levels of income, higher education levels and insurance coverage as being significant factors (30). Increased interest in NIPT has also been noted in women with advanced maternal age, women of Asian or Caucasian ethnicity and in those women with a likelihood to terminate pregnancy(31). Though not investigated in this present study, cost of aneuploidy screening has been identified as a significant factor in the decision-making process to undergo NIPT(30, 32-34).

4.2 Awareness of aneuploidy screening

Only 186 (57.2%) participants out of 325 had heard or knew about aneuploidy screening. This was an unexpected finding especially in a tertiary private health facility frequented mostly by patients from middle to high social- economic backgrounds with high literacy levels as noted in this study. The study noted that a history of chronic illness and being of non-African race was associated with higher rates of awareness of aneuploidy screening. Similar studies have reported awareness rates ranging from 45% to 76%. Factors associated with low levels of unawareness include low levels of education, residing in rural areas and inadequate follow up during pregnancy. (15, 16, 20)

4.3 Uptake of aneuploidy screening

The uptake rate of screening in this study was found to be 39.2%. In comparison, Melania et al reported an uptake rate of 80.36% in Romania (16) , while Kuppermann et al reported an uptake rate of 84.8% and 88.2% for women aged less than 35 years and those aged above 35 years respectively in the United States of America (19). Additionally, Rostant et al in Australia reported an uptake rate of 79% (20), while in Canada, China and the Netherlands uptake rates of 62.2%, 35.8% and 25.7% have been reported respectively (21-23).

4.4 Knowledge and attitude towards aneuploidy screening and informed choice

A majority of the participants who were aware of aneuploidy screening had an average to high level of knowledge regarding aneuploidy screening, at 59.1% and 19.9 % respectively. These findings were similar to those reported by Melania et al where 57.1% of the participants had an average level of knowledge and 12% had a high level of knowledge(16). In the study done by Gourounti et al, 45% of the participants were found to have a good level of knowledge on aneuploidy screening (24). Some of the factors noted to be associated with a high level of knowledge in this study were a positive attitude towards screening and undergoing the screening process. Other notable factors in similar studies done include average to high levels of education, being followed up by a specialist in a private facility, use of handouts and teaching aids, time allocated to discussing aneuploidy screening and living in an urban setting. Surprisingly, undergoing the screening process and positive attitude towards screening have also been negatively associated with knowledge (16, 20, 24).

Most of the participants in the study agreed with the opinion that aneuploidy screening was valuable and beneficial to pregnant women, and should be available to all regardless of cost. This was similar to the findings made by Pruksanusak et al(15). Screening was also perceived to reduce anxiety during pregnancy. A majority of the participants also thought that it would be difficult for them if they were to have a child with an aneuploidy. Studies have also noted that many pregnant women were uncertain about accepting a

child with an aneuploidy(15). Additionally, most of those who underwent screening felt that the results were clear and they were provided with enough information and they felt confident about them.

Among the participants screened for aneuploidies, 35.6 % had negative attitudes, 37.6% were neutral and only 27.4% had positive attitude. For those who did not undergo screening, majority at 47.8 % had negative attitude, 35.4% were neutral and 16.8% had positive attitude. As noted very few participants in this current study had positive attitude towards screening. This is contrary to similar studies done which reported a majority of respondents having positive attitudes (15, 20, 24). Melania et al noted that 78.95% of participants in their study had positive attitude towards screening. In their study, participants who underwent screening and were on follow up by a specialist in private facilities were more inclined towards having a positive attitude(16). When compared with different levels of knowledge on aneuploidies, majority of those with low levels of knowledge on aneuploidies had negative attitude (59.6%) while among those with high levels of knowledge on aneuploidies, 48.6% were neutral and only 32.4 % had a positive attitude.

Only 3.76% (n=186) of the participants in this study were found to have made an informed choice based on their level of knowledge, attitude towards screening and test behavior. Similar studies looking at informed choice regarding aneuploidy screening reported rates of 14.2% and 44% respectively (16, 24). In these studies, the lack of informed choice was attributed to low levels of knowledge and poor attitudes towards screening.

It is important to note that the results of this study cannot be generalised to the entire pregnant population of women in Kenya, as it was conducted at a single, tertiary, private health facility, with majority of patients with similar socio-demographic and economic backgrounds. However, based on the findings from other studies on the influence of the socio-economic status on awareness and knowledge of aneuploidy screening (15, 16, 20, 24); one can infer that the levels of awareness and knowledge would be lower in the general population. In addition, the fact that quite a large number of pregnant women were unaware of aneuploidy screening, could have influenced the results.

This study is the first of its kind in Kenya and Sub Saharan Africa looking at aneuploidy screening and the factors that influence its uptake. It forms a basis towards which further research on aneuploidy screening in Africa can be conducted on a larger, more diverse scale.

CHAPTER FIVE: CONCLUSION

The level of awareness of aneuploidy screening among pregnant women is low. Of those aware of the screening methods, less than half of them underwent screening and the concept of informed choice was lacking in a majority. Increased uptake rate of screening was associated with having a positive attitude towards aneuploidy screening.

CHAPTER SIX: RECOMMENDATIONS

Care providers should place emphasis on educating pregnant women on aneuploidy screening. This could be supplemented by providing information leaflets and links to audio visual content focusing on aneuploidy screening and testing.

Protocols should be developed in line with the current recommendation of offering all pregnant women aneuploidy screening across all healthcare facilities nationwide.

Additionally, comparative studies should be done in different settings such as public hospitals, in order to obtain a deeper perspective as to the factors associated with aneuploidy screening.

CHAPTER SEVEN: STRENGTHS AND LIMITATIONS

The study used a validated tool that had been applied in similar studies in other jurisdictions and this gave the investigators confidence with the data and results obtained. The tool also had good reliability scores across different sections.

The study is the first in Sub Saharan Africa to provide information on the uptake and the determinants of uptake of aneuploidy screening.

A large proportion of the participants were unaware of aneuploidy screening thereby limiting analysis of the determinants of uptake to only those aware of screening. This could have introduced bias thereby rendering the results non generalisable to all pregnant women.

In addition, this study was conducted in a single, tertiary, private health institution, with majority of the participants sharing the same social, demographic and economic backgrounds. Due to this fact, there is potential for selection bias based on the study setting and the nature of the sampling technique employed.

CHAPTER EIGHT: DISSEMINATION

Results of this study will be presented at the weekly faculty and residents academic rounds at the Aga Khan University Hospital, Nairobi. Additionally, the results will be published in a peer-reviewed journal. Finally, a copy of the study will be availed at the AKUHN library.

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APPENDICES

1.1 Consent form

1.1.1 English version

Principal investigator: Dr. Sikolia Wanyonyi

Co-investigator: Prof. Marleen Temmerman

Co-investigator: Dr. Ngugi Duncan Ndegwa

ETHICS ID	

STUDY TITLE: Determinants of uptake of prenatal aneuploidy screening among pregnant women at the Aga Khan University Hospital Nairobi, Kenya.

OBJECTIVES: To assess the determinants of uptake of aneuploidy screening among pregnant women at the Aga Khan University Hospital Nairobi and to determine the uptake of aneuploidy screening at the Aga Khan university Hospital, Nairobi.

BACKGROUND: Aneuploidy refers to an abnormal number of chromosomes. The common aneuploidies include Down syndrome, Edward Syndrome, Patau Syndrome and Turner syndrome. These conditions present with significant congenital abnormalities and majority are not compatible with life. Currently its recommended that all pregnant women be screened for aneuploidies regardless of age. This is to enable pregnant women to make informed choices regarding their pregnancies. This study aims to find out the factors that influence pregnant women's decisions to either have, or, not have aneuploidy screening performed during their pregnancies. Additionally, the study also aims to find out the overall uptake of the tests.

PARTICIPATION: You are being invited to be among the participants in this study. Your participation will be purely voluntary. If at any point during the study you no longer wish to be part of the study you will be free to withdraw from it without the need to offer any justification. Withdrawing or deciding not to participate in the study will not affect the quality of health care that you receive within this medical institution.

CONFIDENTIALITY: This questionnaire does not require your name or address and the required demographic data will not disclose your identity as a participant. Rest assured that the study will be conducted guided by the principle of anonymity. and it will not expose you to any risk whatsoever. This means that your replies will be used to achieve the intended purpose, and the data obtained may be published or presented at conferences, however the identity of all participants will remain anonymous.

BENEFITS: There are no direct benefits that will be derived by the participant for taking part in this study. however, the information you provide will assist in the formulation of policies that will improve the health of all pregnant women in our country.

RISKS: Participation in this study will not expose you or your pregnancy to any risk.

Before proceeding kindly confirm that

a) You have understood the information provided
b) You understand your role in this study
c) You understand that you can withdraw from the study at any time without compromising your care

IF YOU AGREE WITH THE ABOVE WISH TO PARTICIPATE IN THE STUDY KINDLY APPEND YOUR SIGNATURE BELOW AND PROCEED TO FILL IN THE QUESTIONNAIRE.

PARTICIPANT: **INVESTIGATOR:**

DATE: **DATE:**

In case of any questions or clarifications kindly feel free to get in touch with the investigators.

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The following questionnaire relates to prenatal screening tests which are carried out during pregnancy to detect aneuploidies such as Down Syndrome, Edward's Syndrome and Patau's Syndrome just to mention a few.

1. **Have you heard of ANY of these prenatal tests?**

Yes ☐ ⇒ Please continue

No ☐ ⇒ Please go to Question 5,6 on page 3 and Questions 54 to 64 on pages 7&8

2. **Which of the following tests have you heard of?**

(Please tick either the "Yes", No" or „Unsure" box for each of the following options below):

Prenatal screening tests	**Tick as appropriate**
Ultrasound and blood test before 11-13^{+6}weeks (3rd month) of pregnancy	Yes ☐ No ☐ Unsure ☐
Second trimester maternal serum screening (MSS)(Triple/Quadruple tests at 5months gestation)	Yes ☐ No ☐ Unsure ☐

Non-Invasive Prenatal Testing (NIPT)(Cell Free Fetal DNA)	Yes ☐ No ☐ Unsure ☐

3. Where did you first find out about the tests? (Please tick ONE box Only)

Family doctor	☐	Previous pregnancies	☐
Obstetrician	☐	Internet	☐
Midwife	☐	Media	☐
Family/Friends	☐	Pamphlets/resources	☐

Other (Please specify) .....

4. Who/what provided you with most information about prenatal screening tests?

(Please rate your top 3)

Family doctor	☐	Previous pregnancies	☐
Obstetrician	☐	Internet	☐
Midwife	☐	Media	☐
Family/Friends	☐	Pamphlets	☐

Other (Please specify) .....

5. **Who follows-up your pregnancy?**

Medical doctor	☐	Midwife	☐
Obstetrician	☐	None	☐

Other (Please specify) …….....

6. **Where?** Public Institution ☐ Private Institution ☐

7. **Have you seen/received materials about Down Syndrome and prenatal testing from them?** (Please tick ONE box Only)

Yes	☐
No	☐
Unsure	☐

8. **Have you been screened for Down Syndrome during this pregnancy**? Y ☐ N ☐

For the next questions please read and indicate the extent to which you agree or disagree with the statement by circling the relevant number for each question (follow the example).

	Example	Strongly Disagree	Disagree	Neutral	Agree	Strongly agree
	Christmas is the best time of year.	1	2	(3)	4	5
	Your Answer(s):					
9.	Prenatal screening tests for down syndrome are valuable	1	2	3	4	5
10.	Prenatal screening tests for down syndrome benefit all pregnant women	1	2	3	4	5
11.	All pregnant women should have prenatal screening tests for down syndrome	1	2	3	4	5
12.	The cost of prenatal screening tests for down syndrome should not influence whether they are done or not	1	2	3	4	5
13.	If I were to have another pregnancy I would have prenatal screening tests for down syndrome	1	2	3	4	5
14.	During my pregnancy I was worried about my baby's health	1	2	3	4	5
15.	Prenatal screening tests for down syndrome help reduce anxiety during pregnancy	1	2	3	4	5
16.	It would be very difficult for me if I had a child with Down Syndrome	1	2	3	4	5
17.	During this pregnancy I am certain that my baby is healthy	1	2	3	4	5

	Example	Strongly Disagree	Disagree	Neutral	Agree	Strongly agree
18.	The information found on the internet or other unofficial sources made me worry about my baby	1	2	3	4	5
19.	I had enough time to make a decision whether to have the test for down syndrome or not	1	2	3	4	5
20.	I was provided with enough information about prenatal screening tests for Down syndrome	1	2	3	4	5
21.	The information I was given was clear	1	2	3	4	5
22.	My doctor/midwife knew enough about the tests that were available for down syndrome	1	2	3	4	5
23.	I was given enough information to help me make the decision to have the test.	1	2	3	4	5
24.	The results of my tests were explained clearly	1	2	3	4	5
25.	I felt confident about the results of my tests	1	2	3	4	5
26.	I was given enough information about the test results	1	2	3	4	5

	For each next statement please tick whether in your opinion the statement is "true", "false" or you "don't know".	**True**	**False**	**Don't Know**
27.	Down syndrome (DS) is one of the most common birth defects, affecting about one in every 600 live births			

28.	Down syndrome is a genetic defect that occurs during conception of the baby			
29.	All Down syndrome children have mental retardation			
30.	Down syndrome children may have congenital structural abnormalities such as heart disease, gastrointestinal disease, etc.			
31.	Down syndrome children need someone to take special care of them			
32.	Down syndrome children could be trained to improve daily functioning			
33.	Down syndrome fetuses have a higher chance of abortion than normal ones.			
34.	All pregnant women have a chance of having a Down syndrome fetus			
35.	Risk of having Down syndrome fetus is higher as maternal age advances			
36.	If there is no case of Down syndrome in the woman's and her partner's family means that her risk of giving birth to a child with this syndrome is zero			
37.	First trimester screening involves ultrasound and maternal blood test			
38.	The Down syndrome screening tests only tell us whether the fetus has a higher or less chance of having Down syndrome.			
39.	Tests can be done as early as 11-13 weeks/approximately 3 months gestation to identify pregnancies at risk of Down Syndrome			
40.	Second trimester maternal serum screening can be done at 14-22 weeks/approximately 5 months to identify pregnancies at risk of Down Syndrome			
41.	Following a screen test, 5% (1 in 20) of women receive an "**at increased risk"** result			
42.	Most women (98%) who receive an "at increased risk" result have healthy babies			

43.	Ultrasound can detect all cases of Down Syndrome			
44.	If a positive or at increased risk result is given this mean the fetus definitely has Down Syndrome			
45.	Women who had normal screening results can be certain that they will have a healthy baby			
46.	If the screening test shows at increased risk, further tests can be done to clarify a diagnosis			
47.	NIPT or Cell free fetal DNA is a maternal blood test			
48.	NIPT or Cell free fetal DNA can be done early in pregnancy, beginning with 9-10 weeks			
49.	NIPT or Cell free fetal DNA has a detection rate of over 99% for Down syndrome			
50.	A positive NIPT or Cell free fetal DNA result should always be confirmed with invasive testing			

*Non-Invasive Prenatal Testing (**NIPT**)

51. Would you consider pregnancy termination if down syndrome is confirmed during pregnancy? **Yes** ☐ **No** ☐ **Don't know** ☐

52. Please, approximate the time (in minutes) spent with your doctor or midwife talking about prenatal screening ☐

53. What is your age?

54. How many deliveries have you had (Born alive and deceased)?

55. How many miscarriages/abortions have you had?

56. Have you ever had a pregnancy or child with congenital anomalies?

Yes ☐ **No** ☐

57. Do you have any chronic/long standing illness?

Yes ☐ **No** ☐

58. What is the highest level of education you have completed? (Please tick ONE box only)

Primary (class 1 to 8) ☐

Secondary (form 1-4) ☐

Tertiary (College/university) ☐

59. What race do you belong to?

African ☐

Caucasian ☐

Hindu ☐

Asian ☐

Other……..(Please specify)

60. Which religious group do you belong to?

Christian ☐

Jew ☐

Muslim ☐

Hindu ☐

Other……. (Please specify)

61. What is your current occupation ?

Employed ☐

Self employed ☐

Unemployed ☐

62. Where do you live?

City ☐

Rural area ☐

63. How many weeks/months pregnant are you?

☐

64. Marital status

Married ☐

Single ☐

1.1.2 Swahili version

Mchunguzi/Mtafiti mkuu: Dr. Sikolia Wanyonyi

Mchunguzi/Mtafiti mwenza: Prof. Marleen Temmerman

Mchunguzi/Mtafiti mwenza: Dr. Ngugi Duncan Ndegwa

KITAMBULISHO CHA MAADILI MEMA YA UTAFITI	

KICHWA CHA UTAFITI: Viamuzi vya kufanyiwa uchunguzi wa aneuploidy kabla ya kujifungua miongoni mwa akina mama wajawazito katika Hospitali ya Chuo Kikuu cha Aga Khan Nairobi, Kenya.

MALENGO: Ni kutathmini viamua vya kuchukua uchunguzi wa aneuploidy miongoni mwa akina mama wajawazito katika Hospitali ya Chuo Kikuu cha Aga Khan Nairobi na kutathmini uchukuaji wa uchunguzi wa aneuploidy katika Chuo Kikuu cha Aga Khan, Nairobi**.**

HISTORIA: Aneuplody inahusu idadi isiyo ya kawaida ya kromosomu. Aneuploidies za kawaida zinajumuisha Down Syndrome, Edward Syndrome, Patau Syndrome, and Turner Syndrome. Hali hizi hujionyesha na kasoro/ukiukwaji mkubwa wa kuzaliwa na wengi wao hawaendani sawa na maisha. Kwa sasa inapendekezwa kwamba mama wote wajawazito wafanyiwe uchunguzi wa aneuploidies bila kujali umri wao. Hii ni kuwawezesha akina mama wajawazito kufanya maamuzi sahihi kuhusu ujauzito wao. Utafiti huu unalenga kutafuta sababu zinazoshawishi maamuzi ya akina mama wajawazito iwapo watafanyiwa uchunguzi wa aneuploidy wakati wa ujauzito au la. Kwa kuongezea, utafiti pia unalenga kuangalia kwa ujumla kiwango cha watu wanaofanyiwa vipimo.

KUSHIRIKI. Unaalikwa uwe miongoni mwa washiriki katika utafiti huu. Kushiriki kwako ni hiari yako kabisa. Uko huru kujitoa kwenye utafiti huu wakati wowote

hata bila kutoa sababu zozote za kujitoa kama hutaki kuendelea kushiriki kwenye utafiti huu. Ukijitoa ama ukiamua kutoshiriki kwenye utafiti huu hakutaathiri ubora wa huduma za afya unazopata katika kituo hiki cha afya.

USIRI. Orodha hii ya maswali haihitaji jina lako au anwani yako na data ya idadi ya watu inayohitajika haitakutambilisha kama mshiriki. Tunakuhakikishia kwamba utafiti huu utafanywa kwa kuzingatia kanuni ya kutokujulikana na hautakuweka kwenye hatari ya aina yoyote vyovyote vile. Hii inamaanisha kwamba majibu yako yatatumika kufikia malengo yaliyonuiwa, na data itakayopatikana huenda ikachapishwa au kuwasilishwa kwenye mikutano, hata hivyo washiriki hawatajulishwa/hawatatambulishwa kwa watu wengine.

FAIDA. Hakutakuwa na faida za moja kwa moja zinazotokana na mshiriki kwa kushiriki kwenye utafiti huu. Hata hivyo, maelezo utakayopeana yatasaidia katika kutengeneza sera ambazo zitaboresha hali ya afya kwa akina mama wote wajawazito katika inchi yetu.

HATARI. Kushiriki kwenye utafiti huu hakutakuweka wewe au ujauzito wako kwenye hatari yoyote.

Kabla ya kuendelea tafadhali thibitisha kwamba

d) Umeelewa maelezo yaliyopeanwa
e) Unaelewa jukumu lako kwenye utafiti huu
f) Unaelewa kwamba unaweza kujitoa kwenye utafiti huu wakati wowote bila ya kuhatarisha uangalizi wako

KAMA UMEKUBALI KUSHIRIKI KWENYE UTAFITI HUU TAFADHALI WEKA SAHIHI YAKO HAPO CHINI NA UENDELEE KUJAZA ORODHA YA MASWALI.

MSHIRIKI: **MCHUNGUZI/MTAFITI:**

TAREHE: **TAREHE:**

Ukiwa una maswali ama unahitaji ufafanuzi zaidi jisikie huru kuwasiliana na wachunguzi/watafiti.

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Orodha ya maswali inayofuata inahusiana na vipimo vya uchunguzi wa kabla ya kujifungua/kuzaa vinavyofanywa wakati wa ujauzito ili kugundua magonjwa ya aneuploidies kama vile Down Syndrome, Edwards Syndrome na Patau Syndrome nikitaja tu baadhi ya magonjwa machache.

9. Je ushawahi kusikia kuhusu vipimo hivi vyovyote vya ujauzito?

Ndio ☐ ⇒ Tafadhali endelea

La ☐ ⇒ Tafadhali nenda kwa maswali ya 5, 6 katika ukurasa wa 3 na maswali ya 54 hadi 64 katika ukurasa wa 7 na 8

10. Ni vipimo vipi kati ya hivi vifuatavyo umewahi kuvisikia?

(Tafadhali weka alama eidha kwenye kisanduku cha ‘’Ndiyo’’ au ‘’La’’ kwa kila chaguzi zifuatazo hapo chini):

Vipimo vya uchunguzi wakati wa ujauzito	**Weka alama ipasavyo**
Kufanyiwa ultrasound na kupimwa damu (Double test) kati ya wiki 11 hadi 13^{+6} (au mwezi wa 3) wa ujauzito	Ndio ☐ La ☐ Sina hakika ☐
Kufanyiwa uchunguzi wa damu ya mama katika trimester ya pili ya	Ndio ☐

ujauzito (Triple/Quadruple tests kati ya wiki 14 na 22 ya ujauzito)	La ☐ Sina hakika ☐
Non-Invasive Prenatal Testing (NIPT)(Cell Free Fetal DNA)	Ndio ☐ La ☐ Sina hakika ☐

11. Vipimo hivi ulivijulia wapi? (**Tafadhali weka alama kwenye kisanduku kimoja tu**)

Daktari wa familia	☐	Ujauzito uliopita	☐
Daktari wa uzazi	☐	Mtandao	☐
Mkunga	☐	Vyombo vya habari	☐
Wanafamilia/Marafiki	☐	Vipeperushi/Rasilimali	☐

Zingine (tafadhali fafanua).....

12. Ni nani/ni nini kilichokupatia maelezo zaidi kuhusu vipimo vya uchunguzi wa kabla ya kuzaa(prenatal screening tests)?

(**Tafadhali taja zako 3 zenye kiwango cha juu zaidi**)

Daktari wa familia	☐	Ujauzito uliopita	☐
Daktari wa uzazi	☐	Mtandao	☐

Mkunga ☐ Vyombo vya habari ☐

Wanafamilia/Marafiki ☐ Vipeperushi/Rasilimali ☐

Zingine (tafadhali fafanua).....

13. Ni nani ambaye anafuatilia ujauzito wako?

Daktari wa matibabu ☐ Mkunga ☐

Daktari wa uzazi ☐ Hakuna ☐

Mwingine (Tafadhali fafanua) …….....

14. Wapi? Taasisi ya umma ☐ Taasisi ya kibinafsi ☐

15. Je ushawahi kuona/ushawahi kupokea vifaa kuhusu ugonjwa wa Down Syndrome na vipimo vya uchunguzi (prenatal testing) kutoka kwao? (t**afadhali weka alama kwenye kisanduku kimoja pekee**)

Ndio ☐

La ☐

Sina hakika ☐

16. Je umefanyiwa uchunguzi wa Down Syndrome wakati wa ujauzito huu?

Ndiyo ☐

La ☐

Kwa maswali yanayofuata, tafadhali soma na uonyeshe kiwango unachokubaliana au kiwango ambacho haukubaliani na kauli kwa kuweka mduara kwenye nambari inayostahili kwa kila swali (fuata mfano).

	Mfano	Sikubaliani kabisa	Sikubaliani	Upande wowote	Nakubaliana	Nakubaliana kabisa
	Krismasi ndio wakati mzuri zaidi wa mwaka.	1	2	(3)	4	5
	Jibu/Majibu Yako:					
9.	Vipimo vya uchunguzi vya Down Syndrome kabla ya kujifungua ni muhimu.	1	2	3	4	5
10.	Vipimo vya uchunguzi vya Down Syndrome kabla ya kujifungua hufaidisha kina mama wote wajawazito.	1	2	3	4	5
11.	Kina mama wote wajawazito wapaswa wafanyiwe vipimo vya uchunguzi vya Down Syndrome kabla ya kujifungua.	1	2	3	4	5
12.	Gharama ya vipimo vya uchunguzi vya Down Syndrome kabla ya kujifungua haipaswi kushawishi ikiwa vipimo vitafanywa au havitafanywa.	1	2	3	4	5
13.	Nikipata ujauzito mwingine nitafanyiwa vipimo vya kuchunguza Down Syndrome kabla ya kujifungua.	1	2	3	4	5
14.	Wakati wa ujauzito huu wangu nilikuwa/nimekuwa na wasiwasi kuhusu afya ya mtoto wangu.	1	2	3	4	5
15.	Vipimo vya uchunguzi vya Down Syndrome kabla ya kujifungua husaidia kupunguza wasiwasi wakati wa ujauzito.	1	2	3	4	5

	Mfano	Sikubaliani kabisa	Sikubaliani	Upande wowote	Nakubaliana	Nakubaliana kabisa
16.	Itakuwa vigumu sana kwangu nikipata mtoto mwenye ugonjwa wa Down Syndrome.	1	2	3	4	5
17.	Kwa ujauzito huu, ninahakika kwamba mtoto wangu yuko na afya nzuri.	1	2	3	4	5
18.	Maelezo yanayopatikana kwenye mitandao ama vyanzo vingine visivyokuwa rasmi yalinifanya niwe na wasiwasi kuhusu mtoto wangu.	1	2	3	4	5
19.	Nilikuwa na mda/wakati wa kutosha ili kuamua iwapo nitafanyiwa vipimo vya kuchunguza Down Syndrome.	1	2	3	4	5
20.	Nilipewa maelezo ya kutosha kuhusu vipimo vya kuchunguza Down Syndrome kabla ya kujifungua.	1	2	3	4	5
21.	Maelezo niliyopewa yalikuwa wazi.	1	2	3	4	5
22.	Daktari wangu/Mkunga wangu alijua vya kutosha kuhusu vipimo vya Down Syndrome vilivyokuwepo.	1	2	3	4	5
23.	Nilipewa maelezo ya kutosha yaliyonisaidia katika kufanya uamuzi wa kufanyiwa vipimo.	1	2	3	4	5
24.	Matokeo/Majibu ya vipimo vyangu yalifafanuliwa wazi.	1	2	3	4	5
25.	Nilikuwa na amani na matokeo ya vipimo vyangu.	1	2	3	4	5
26.	Nilipewa maelezo ya kutosha kuhusu matokeo ya vipimo.	1	2	3	4	5

	Kwa kila taarifa weka alama ya kuonyesha iwapo kwa maoni yako hiyo taarifa ni ''Kweli'', ''Uongo'' au ''Sijui''	**Kweli**	**Uongo**	**Sijui**
27.	Down Syndrome ni miongoni mwa kasoro za kawaida za kuzaliwa, huathiri karibu mtoto mmoja (1) kati ya kila watoto mia sita (600) wanaozaliwa.			
28.	Down Syndrome ni kasoro ya maumbile ambayo hutokea wakati wa kutunga mimba.			
29.	Watoto wote wenye ugonjwa wa Down Syndrome wako na upungufu wa akili.			
30.	Watoto wenye ugonjwa wa Down Syndrome huenda wakapata upungufu wa miundo ya kuzaliwa kwa mfano ugonjwa wa moyo, ugonjwa wa utumbo na magonjwa mengineyo.			
31.	Watoto wenye ugonjwa wa Down Syndrome wanahitaji mtu atakayewapatia huduma maalum.			
32.	Watoto wenye ugonjwa wa Down Syndrome wanaweza kupata mafunzo ili kuboresha utendaji wao wa kila siku.			
33.	Mimba ambazo vijusi vyake vina ugonjwa wa Down Syndrome ziko na nafasi kubwa ya kutoka kuliko mimba ambazo vijusi vyake viko katika hali ya kawaida.			
34.	Wanawake wote wajawazito wako na nafasi/uwezo wa kupata kijusi kilicho na ugonjwa wa Down Syndrome.			
35.	Hatari ya kuwa na kijusi chenye ugonjwa wa Down syndrome ni kubwa zaidi kadri umri wa uzazi unavyoendelea.			

36.	Kama hakuna mtu mwenye ugonjwa wa Down Syndrome katika familia ya mama na bwanaake inamaanisha hakuna hatari ya mama kujifungua mtoto mwenye Down Syndrome.			
37.	Uchunguzi wa trimester ya kwanza hujumuisha ultrasound na uchunguzi wa damu ya mama.			
38.	Vipimo vya uchunguzi vya ugonjwa wa Down Syndrome hutueleza tu ikiwa kuna uwezekano wa juu au wa chini kwa kijusi kupata Down Syndrome.			
39.	Uchunguzi unaweza kufanywa mapema kuanzia wiki ya 11 hadi 13(takriban miezi 3) ya ujauzito ili kutambua mimba zilizo katika hatari ya kuwa na ugonjwa wa Down Syndrome.			
40.	Uchunguzi wa seramu ya mama katika trimester ya pili unaweza kufanywa kuanzia wiki ya 14 hadi 22^{+6}/takribani miezi 5 ya ujauzito ili kutambua mimba katika hatari ya kuwa na ugonjwa wa Down Syndrome.			
41.	Kutokana na vipimo vya uchunguzi, asilimia 5 (yaani mama 1 kati ya wamama 20) hupata matokeo ya **''kuwa katika hatari kubwa''.**			
42.	Wanawake wengi (asilimia 98) ambao hupata matokeo ya **''kuwa katika hatari kumbwa''** hupata watoto wenye afya nzuri.			
43.	Ultrasound inaweza kugundua visa vyote vya Down Syndrome.			
44.	Kama matokeo yataonyesha kuwepo na hatari kuu hii dhahiri inaonyesha kijusi kina ugonjwa wa Down Syndrome.			
45.	Wanawake ambao hupata matokeo ya kawaida ya uchunguzi wanaweza kuwa na uhakika kwamba watazaa mtoto mwenye afya.			
46.	Kama matokeo ya uchunguzi yataonyesha kuwepo na hatari kuu, vipimo zaidi vinaweza kufanywa ili kufafanua utambuzi (kufafanua matokeo ya awali).			

47.	NIPT au Cell free fetal DNA ni kipimo cha damu ya mama.			
48.	NIPT au Cell free fetal DNA inaweza kufanywa mapema katika ujauzito, kuanzia wiki ya 10.			
49.	NIPT au Cell free fetal DNA ina kiwango cha kudundulika kwa Down Syndrome cha asilimia 99.			
50.	Matokeo ya NIPT au Cell free fetal DNA yakionyesha uwezekano wa kijusi kuwa na aneuploidy/Down Syndrome ni lazima ya thibitishwe na upimaji vamizi?			

*Non-Invasive Prenatal Testing (**NIPT**)

51. Je, unafikiria kwamba unaweza kuamua kutoa mimba iwapo ugonjwa wa Down Syndrome utathibitishwa wakati wa ujauzito?

Ndiyo ☐

La ☐

Sina hakika ☐

52 Tafadhali kadiria ni takriban muda gani (kwa dakika) mliochukua wewe na daktari au mkunga wako mkizungumza kuhusu uchunguzi wa Down Syndrome

.

53. Wewe una umri gani/miaka mingapi?

.

54. Umejifungua Watoto wangapi (walio hai na wale waliokufa)?

.

55. Je ushawahi toa mimba/umemwaga mimba mara ngapi?

56. Je ushawahi kupata ujauzito au mtoto aliye na kasoro za kuzaliwa?

Ndiyo ☐ **La** ☐

57. Je uko na ugonjwa wowote sugu/ugonjwa ambao umekuwa nao kwa muda mrefu?

Ndiyo ☐ **La** ☐

58. Je umesoma mpaka kiwango gani? (tafadhali weka alama kwenye kisanduku kimoja pekee)

Shule ya msingi (darasa 1 to 8) ☐

Shule ya upili (kidato 1-4/6) ☐

Elimu ya juu (College/chou kikuu) ☐

59. Wewe ni wa taifa(race) lipi?

Mwafrika ☐

Mzungu ☐

Mwarabu ☐

Mhindi ☐

Masia ☐

60. Wewe ni wa dini gani ? (tafadhali weka alama kwenye kisanduku kimoja pekee)

Ukristo ☐

☐

Uyahudi

Uislamu ☐

Uhindi ☐

Sina dini ☐

Nyinginezo …….. (Fafanua zaidi)

61. Kwa sasa kazi yako ni nini/gani ?

Nimeajiriwa ☐

Nimejiajiri mwenyewe ☐

Sina ajira ☐

62. Wewe unaishi wapi ?

Mjini ☐

Sehemu za mashambani ☐

63. Je ujauzito wako ni wa wiki/miezi ngapi?

☐

64. Umeolewa?

Ndio ☐

La ☐

1.2 Study variables

VARIABLE	OPERATIONAL DEFINITION	SCALE OF MEASUREMENT
AGE	Total number of completed years since birth	Years
AWARENESS OF ANEUPLOIDY SCREENING	Knowledge of the existence of aneuploidy screening	Yes/No
PARITY	Total number of deliveries both live and still birth above 24 weeks gestation	Numerical
RACE	Distinct societal group sharing similar physical and social qualities	African vs Asian Vs Caucasian
RELIGION	Belief in a particular system of faith and worship	Christian vs Muslim vs Hindu vs Atheist Vs Other (Traditional)
LEVEL OF EDUCATION	Highest attained level of formal schooling	Tertiary/Secondary/Primary
OCCUPATION	Income generating activity	Employed/Self Employed/Unemployed
GESTATIONAL AGE	Total number of weeks since conception	weeks
PREGNANCY FOLLOW UP(CLINICIAN)	Primary health care worker who followed up the pregnancy in the antenatal period	Obstetrician/Midwife/Medical Doctor/Family physician
PLACE OF FOLLOW UP	Primary health center where patient attended antenatal clinics	Public vs Private facility
RESIDENCE	Place of permanent abode	Urban vs Rural
MISCARRIAGES	History of pregnancy loss at less than 24 weeks gestation	Yes/No
AWARENESS OF ANEUPLOIDY SCREENING	Assessment of whether the participant is cognizant of the	Yes/No

	existence of screening tests for aneuploidies during pregnancy	
UPTAKE OF SCREENING	Assessment of whether the participant took up the aneuploidy screening tests or not	Yes/No
KNOWLEDGE OF PRENATAL SCREENING	Assessment of how conversant the patient is with aneuploidies and the available tests for them	True/False/Do not know
ATTITUDE TOWARDS PRENATAL SCREENING	Assessment of the patients' thoughts and feelings about aneuploidy screening	Likert scale numbered 1-5 representing strongly disagree, disagree, neutral, agree and strongly agree respectively
TIME SPENT DISCUSSING PRENATAL SCREENING	Approximate time spent by the primary clinician discussing prenatal screening	Minutes
INFORMED CHOICE	Assessment of whether the decision made by the patient to undergo the tests or not was made from a point of knowledge and understanding	Inferred from concordance of knowledge and attitude and test uptake
PREGNANCY TERMINATION AFTER ANEUPLOIDY CONFIRMATION	Audit of whether the patient may consider pregnancy termination if an aneuploidy is confirmed	Yes/No/Unsure

1.3 Participants demographic, clinical and follow up information

	Awareness of aneuploidy screening	
Characteristic	**Not aware N = 139[1] Number (%)**	**Aware N = 186[1] Number (%)**
Age in years	32 (30, 35)	33 (30, 36)
Age-group in years		
18-24	6 (4.3%)	3 (1.6%)
25-34	91 (65.5%)	114 (61.3%)
35-45	42 (30.2%)	69 (37.1%)
Parity		
Nulliparous	37 (26.6%)	49 (26.3%)
Parous	102 (73.4%)	137 (73.7%)
Median (IQR) gestation (weeks)	29 (20, 35)	30 (22, 36)
Complete gestation (weeks)		
11-14 weeks	10 (7.2%)	10 (5.4%)
15-28 weeks	57 (41.0%)	69 (37.1%)
Above 28 weeks	72 (51.8%)	107 (57.5%)
Residence		
Urban area	130 (93.5%)	176 (94.6%)
Rural area	9 (6.5%)	10 (5.4%)
Current occupation		
Employed	99 (71.2%)	125 (67.2%)
Self-employed	33 (23.7%)	51 (27.4%)
Unemployed	7 (5.0%)	10 (5.4%)
Religion		
Christian	129 (92.8%)	173 (93.0%)
Other	10 (7.2%)	13 (7.0%)
Race		
African	139 (100.0%)	180 (96.8%)
Other	0 (0.0%)	6 (3.2%)

	Awareness of aneuploidy screening	
Characteristic	**Not aware N = 139[1] Number (%)**	**Aware N = 186[1] Number (%)**
Marital status		
Married	130 (93.5%)	170 (91.4%)
Single	9 (6.5%)	16 (8.6%)
Level of education		
Primary	0 (0.0%)	1 (0.5%)
Secondary	4 (2.9%)	5 (2.7%)
Tertiary	135 (97.1%)	180 (96.8%)
Presence of chronic illness		
No	137 (98.6%)	175 (94.1%)
Yes	2 (1.4%)	11 (5.9%)
Ever had pregnancy or child with congenital anomalies		
No	137 (98.6%)	181 (97.3%)
Yes	2 (1.4%)	5 (2.7%)
Ever experience abortion/miscarriages		
No	111 (79.9%)	139 (74.7%)
Yes	28 (20.1%)	47 (25.3%)
Who follow-up your pregnancy		
Medical doctor	24 (17.3%)	29 (15.6%)
Obstetrician	113 (81.3%)	155 (83.3%)
Midwife	1 (0.7%)	2 (1.1%)
None	0 (0.0%)	0 (0.0%)
Other	1 (0.7%)	0 (0.0%)
Place of follow-up		
Public Institution	1 (0.7%)	6 (3.2%)

	Awareness of aneuploidy screening	
Characteristic	**Not aware N = 139[1] Number (%)**	**Aware N = 186[1] Number (%)**
Private Institution	138 (99.3%)	180 (96.8%)

1.4 Bivariate analysis of attitude, demographic and clinical information.

	Attitude towards screening		
Characteristic	**Negative, N = 80**	**Positive, N = 39**	**p-value[1]**
Age in years, Median (IQR)	32 (30 – 35)	35 (30 – 38)	0.065
Age-group in years, n (%)			0.006
18-24	1 (1.2)	2 (5.1)	
25-34	57 (71.2)	17 (43.6)	
35-45	22 (27.5)	20 (51.3)	
Parity, n (%)			0.52
Nulliparous	24 (30.0)	9 (23.1)	
Parous	56 (70.0)	30 (76.9)	
Median (IQR) gestation (weeks), Median (IQR)	30 (22 – 36)	30 (25 – 36)	0.70
Complete gestation (weeks), n (%)			0.48
11-14 weeks	4 (5.0)	4 (10.3)	
15-28 weeks	30 (37.5)	12 (30.8)	
Above 28 weeks	46 (57.5)	23 (59.0)	
Residence, n (%)			0.47
City	75 (93.8)	35 (89.7)	
Rural area	5 (6.2)	4 (10.3)	
Current occupation, n (%)			0.89
Employed	55 (68.8)	25 (64.1)	
Self employed	21 (26.2)	12 (30.8)	

	Attitude towards screening		
Characteristic	**Negative, N = 80**	**Positive, N = 39**	**p-value[1]**
Unemployed	4 (5.0)	2 (5.1)	
Religion, n (%)			0.66
Christian	75 (93.8)	38 (97.4)	
Other	5 (6.2)	1 (2.6)	
Race, n (%)			>0.99
African	78 (97.5)	39 (100.0)	
Other	2 (2.5)	0 (0.0)	
Marital status, n (%)			0.75
Married	73 (91.2)	35 (89.7)	
Single	7 (8.8)	4 (10.3)	
Level of education, n (%)			0.17
Primary	0 (0.0)	1 (2.6)	
Secondary	4 (5.0)	0 (0.0)	
Tertiary	76 (95.0)	38 (97.4)	
Presence of chronic illness, n (%)			0.72
No	75 (93.8)	36 (92.3)	
Yes	5 (6.2)	3 (7.7)	
Ever had a pregnancy or child with congenital anomalies, n (%)			0.55
No	79 (98.8)	38 (97.4)	

	Attitude towards screening		
Characteristic	**Negative, N = 80**	**Positive, N = 39**	**p-value[1]**
Yes	1 (1.2)	1 (2.6)	
Ever experienced an abortion or miscarriages, n (%)			0.51
No	61 (76.2)	27 (69.2)	
Yes	19 (23.8)	12 (30.8)	
Knowledge score x/24, Median (IQR)	10 (8 – 13)	13 (10 – 18)	0.005
Knowledge of aneuploidy, n (%)			0.009
Low	23 (28.7)	6 (15.4)	
Average	50 (62.5)	21 (53.8)	
High	7 (8.8)	12 (30.8)	
Screened for aneuploidy, n (%)			0.070
No	54 (67.5)	19 (48.7)	
Yes	26 (32.5)	20 (51.3)	

[1]Wilcoxon rank sum test; Fisher's exact test; Pearson's Chi-squared test

n (%); median (IQR)

1.5 Bivariate analysis of knowledge, demographic and clinical information.

	Knowledge on screening		
Characteristic	**Low, N = 39**	**High, N = 37**	**p-value[1]**
Age in years, Median (IQR)	34 (31 – 35)	35 (32 – 37)	0.13
Age-group in years, n (%)			0.25
18-24	0 (0.0)	1 (2.7)	
25-34	24 (61.5)	17 (45.9)	
35-45	15 (38.5)	19 (51.4)	
Parity, n (%)			>0.99
Nulliparous	8 (20.5)	7 (18.9)	
Parous	31 (79.5)	30 (81.1)	
Median (IQR) gestation (weeks), Median (IQR)	31 (26 – 37)	30 (22 – 34)	0.20
Complete gestation (weeks), n (%)			0.79
11-14 weeks	2 (5.1)	2 (5.4)	
15-28 weeks	12 (30.8)	15 (40.5)	
Above 28 weeks	25 (64.1)	20 (54.1)	
Residence, n (%)			0.68
City	35 (89.7)	35 (94.6)	
Rural area	4 (10.3)	2 (5.4)	

	Knowledge on screening		
Characteristic	**Low, N = 39**	**High, N = 37**	**p-value[1]**
Current occupation, n (%)			0.42
Employed	24 (61.5)	27 (73.0)	
Self employed	11 (28.2)	9 (24.3)	
Unemployed	4 (10.3)	1 (2.7)	
Religion, n (%)			>0.99
Christian	34 (87.2)	33 (89.2)	
Other	5 (12.8)	4 (10.8)	
Race, n (%)			0.49
African	39 (100.0)	36 (97.3)	
Other	0 (0.0)	1 (2.7)	
Marital status, n (%)			0.68
Married	35 (89.7)	35 (94.6)	
Single	4 (10.3)	2 (5.4)	
Level of education, n (%)			0.49
Secondary	2 (5.1)	0 (0.0)	
Tertiary	37 (94.9)	37 (100.0)	
Presence of chronic illness, n (%)			0.68
No	35 (89.7)	35 (94.6)	
Yes	4 (10.3)	2 (5.4)	

	Knowledge on screening		
Characteristic	**Low, N = 39**	**High, N = 37**	**p-value[1]**
Ever had a pregnancy or child with congenital anomalies, n (%)			>0.99
No	38 (97.4)	37 (100.0)	
Yes	1 (2.6)	0 (0.0)	
Ever experienced abortion or miscarriage, n (%)			0.31
No	26 (66.7)	29 (78.4)	
Yes	13 (33.3)	8 (21.6)	
Attitude, n (%)			0.002
Negative	23 (59.0)	7 (18.9)	
Neutral	10 (25.6)	18 (48.6)	
Positive	6 (15.4)	12 (32.4)	
Screened for aneuploidy, n (%)			0.033
No	29 (74.4)	18 (48.6)	
Yes	10 (25.6)	19 (51.4)	

[1]Wilcoxon rank sum test; Fisher's exact test; Pearson's Chi-squared test

n (%); median (IQR)