

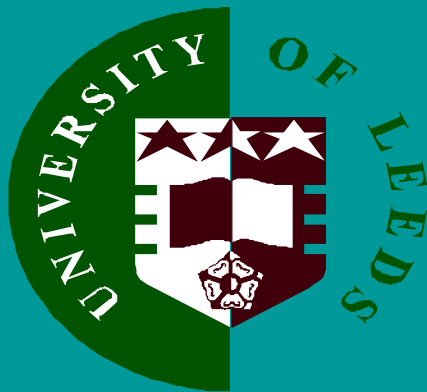
Grant Holders and Researchers

Wilson: Psychology of Health Care
Green: Physiological Reproductive Health
Luckle: Reproductive Epidemiology
Lyon: Obstetrics and Gynaecology
Wright: Clinical Genetics

Senior Research Fellow
Research Fellow
Research Officer
Grant: Genetic Downstream, Susan Arhes



Social & Ethnic Differences in Attitudes & Consent to Prenatal Testing



ESRC Project Number: L218252013



Grant Holders and Researchers

➤ Grant holders:

Prof Jenny Hewison: Psychology of Health Care

Prof Josephine Green: Psychosocial Reproductive Health

Prof Howard Cuckle: Reproductive Epidemiology

Prof Jim Thornton: Obstetrics and Gynaecology

Prof Bob Mueller: Clinical Genetics

➤ Research Staff:

Dr Janet Hirst: Senior Research Fellow

Dr Shenaz Ahmed: Research Fellow

Mrs Clare Hucknall: Research Officer

Mr Ayman Alsulaiman: Genetic Counsellor, Saudi Arabia



Background to the study (1)

- Advances in DNA technology make it possible to offer parents prenatal testing for a large number of different genetic disorders.
- Tests have been offered to date are available because the technology is there, not because of prevalence or burden of the condition.
- Obtaining separate informed consent for each disorder is not practical.

Background to the study (2)

- Could consent be obtained for *groups* of disorders?
- Groupings would need to be based on parents' attitudes to testing. Would these differ across social/cultural boundaries?
- Little is known about how people's attitudes to testing for one disorder relate to their views on testing for other disorders.



Aims of the study

- Compare attitudes towards testing and termination for different disorders of parents from different social and ethnic groups
- Describe and compare reasons for attitudes between social and ethnic groups
- Investigate clusterings of attitudes as a basis for a classification system



Study design

Study 1a:

Quantitative questionnaire (target n=400)

Study 1b:

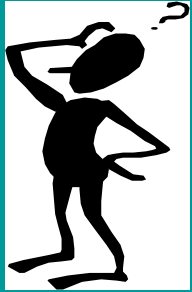
Qualitative semi-structured interviews with a sub-sample from study 1a (target n=60)

Plus interviews with women who had used Genetic services (n=19)



The questionnaire

Please tick either 'No', 'Yes', or 'Not sure'.



Main features of the condition

Would you want a prenatal test?

Would you consider termination if the test showed the baby had this condition?

<p>Child would be a very short female who might have some medical problems, a normal lifespan and would not be able to have children.</p>	<p>No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/></p>	<p>No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/></p>
<p>Child would have a blood condition, require blood transfusions and medical treatment throughout life and have a shortened lifespan.</p>	<p>No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/></p>	<p>No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/></p>
<p>Child would have problems with lungs and digestive systems, require a lot of medical care throughout life and have a shortened lifespan (death probably before 40 years of age).</p>	<p>No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/></p>	<p>No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/></p>



Hypothetical scenario...

... please assume for the purpose of this questionnaire that the result from the prenatal test would tell you whether the baby definitely does or does not have the condition. Please also assume that the prenatal test would be carried out early in pregnancy, it carries no risk to you or the pregnancy, and it is carried out using routinely collected blood.



Main Study participants

- Setting: North of England
- Stratified sample of Pakistani & white indigenous women, two levels of education
- Recruited from community antenatal clinics, over 30 weeks gestation
- Data collected postnatally

+19 women recruited through Genetics clinics

Main sample: Ethnic origin x Education

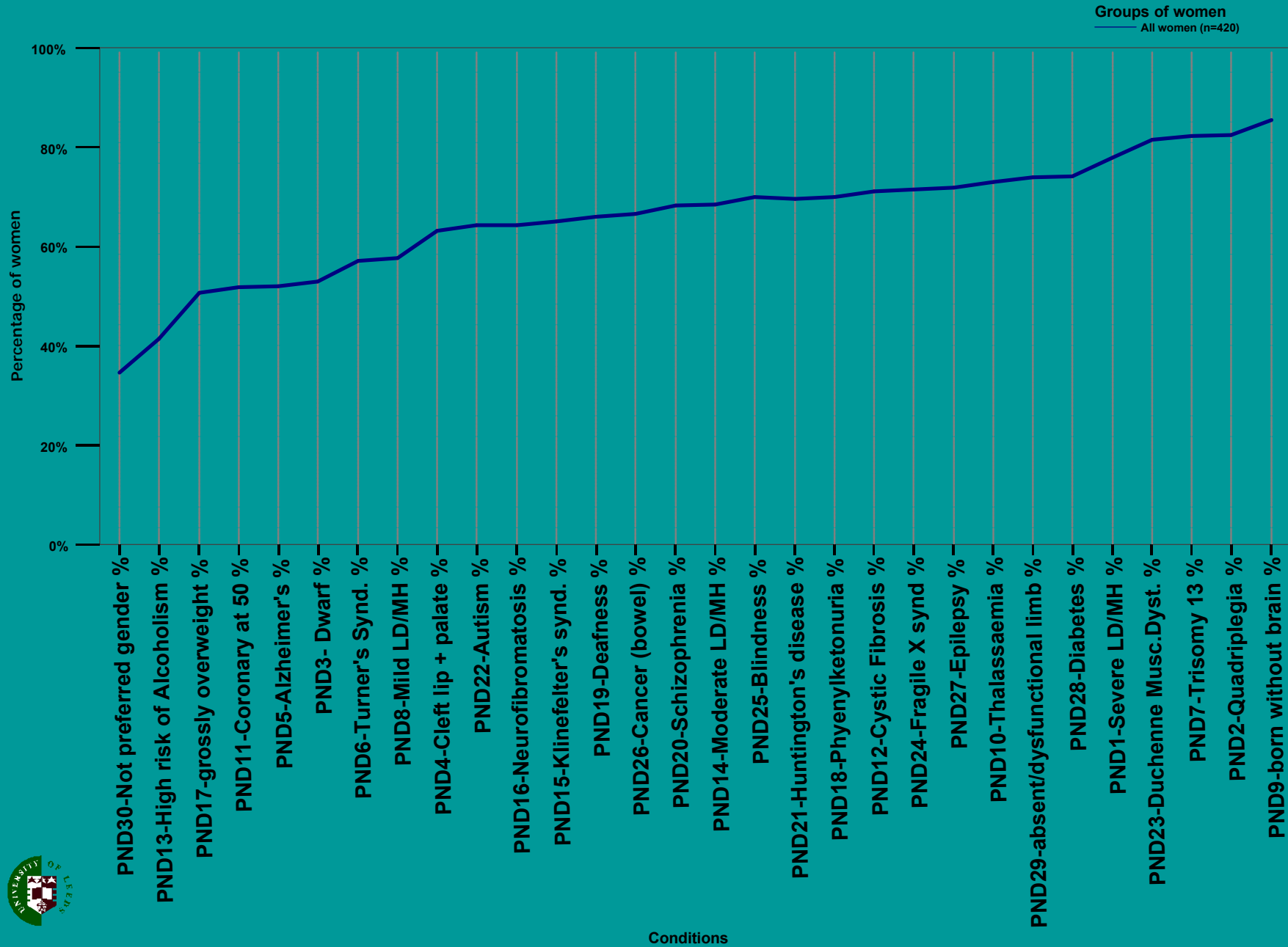
	ETHNIC ORIGIN		Total
	UK White	Pakistani	
GCSE or less	113	125	238
beyond GCSE	109	73	182
Total	222	198	420



Attitudes towards testing

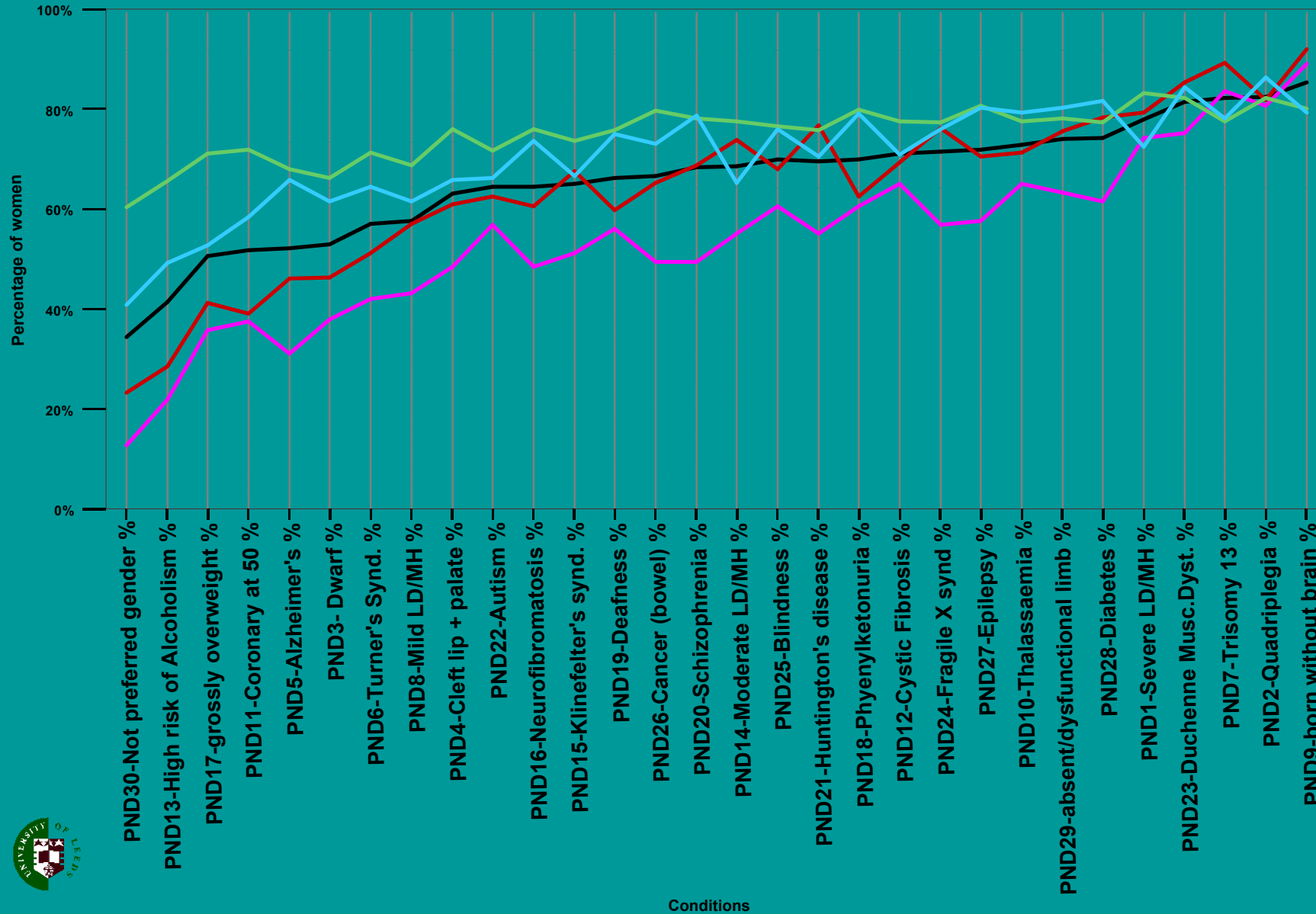


All women who said "Yes" to PND: conditions ordered by "Yes" to Prenatal Diagnosis



All women who said "Yes" to PND: data subdivided by women who said "Yes" to Prenatal Diagnosis from each group: conditions ordered by "Yes" to PND

Groups of women
 — All women "YES" to PND (n=420)
 — Ind White-Low ed (n=113)
 — Ind White-Hi ed (n=109)
 — Pakistani-Low ed (n=125)
 — Pakistani-Hi ed (n=73)



Attitudes to testing: summary (1)

- Pakistani women wanted testing for more conditions than did white women.
- Independent of ethnicity, less educated women wanted testing for more conditions than those with more education.
- The less educated Pakistani sample differentiated least between conditions, and the more educated white sample differentiated the most.



Attitudes to testing: summary (2)

- Only 3% of women said that they would not want testing for any of the conditions and 25% would want testing for everything.
- The remaining 72% said that they would want testing for some conditions but not others, i.e. they did not have an attitude to prenatal testing that was independent of the condition being referred to.



Attitudes to testing: summary (3)

The great majority of women in all four subgroups favoured prenatal testing for:

- born without a brain, early death (anencephaly)
- severe learning difficulties with early death (trisomy 13 and 18)
- being unable to move from the neck down, normal lifespan (quadriplegia)
- progressive muscle-wasting with death probably before age 20 (Duchenne muscular dystrophy).

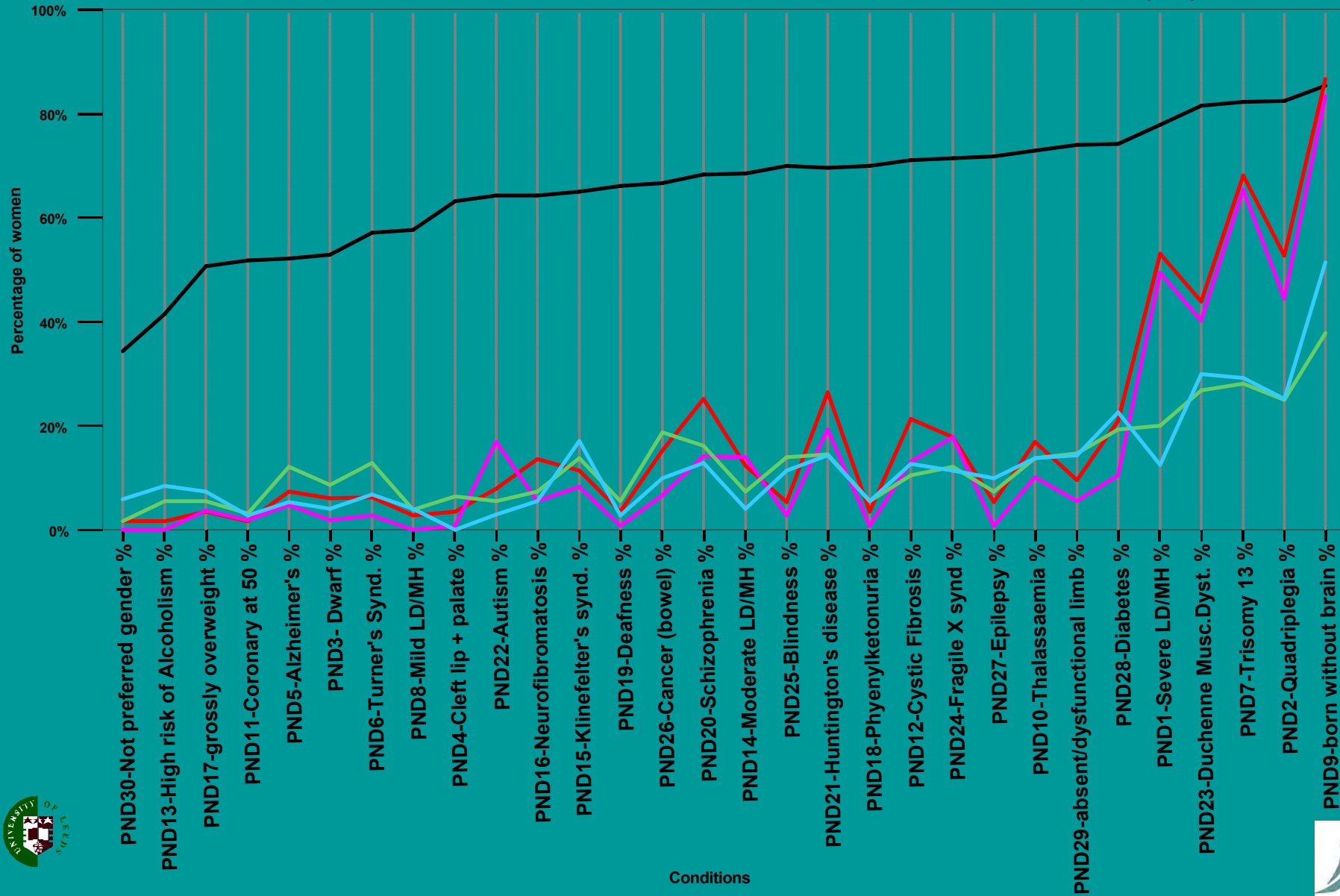


Attitudes towards termination of an affected pregnancy



**All women who said "Yes" to Prenatal Diagnosis:
data subdivided by women who said "Yes" to
Termination of Pregnancy from each group:
conditions ordered by "Yes" to PND**

Groups of women
 — All women "YES" to PND (n=420)
 — Ind White-Low ed (n=113)
 — Ind White-Hi ed (n=109)
 — Pakistani-Low ed (n=125)
 — Pakistani-Hi ed (n=73)



Attitudes to termination: summary (1)

- Pakistani women said they would consider termination for fewer conditions than would white women.
- Education was not related to attitudes to termination of pregnancy in either white or Pakistani women.



Attitudes to termination: summary (2)

- Most women did not have an attitude to termination of pregnancy that was independent of the condition being referred to. Most women said that they would consider termination for at least one of the conditions on the list.
- For most of the conditions, less than a quarter of participants said that they would want a termination of pregnancy.



Attitudes to termination: summary (3)

- Attitudes between subgroups diverged at the more severe end of the spectrum.
- Despite the divergence, women from all four subgroups were most likely to favour termination for the same four conditions: anencephaly; trisomy 13 and 18; quadriplegia, and Duchenne muscular dystrophy.



Attitudes to termination: summary (4)

- The groups diverged most re “severe learning difficulties with a normal lifespan”: white women were much more likely to favour termination than were Pakistani women.
- Many women did not see prenatal testing as necessarily leading to termination in the circumstances of an affected pregnancy.

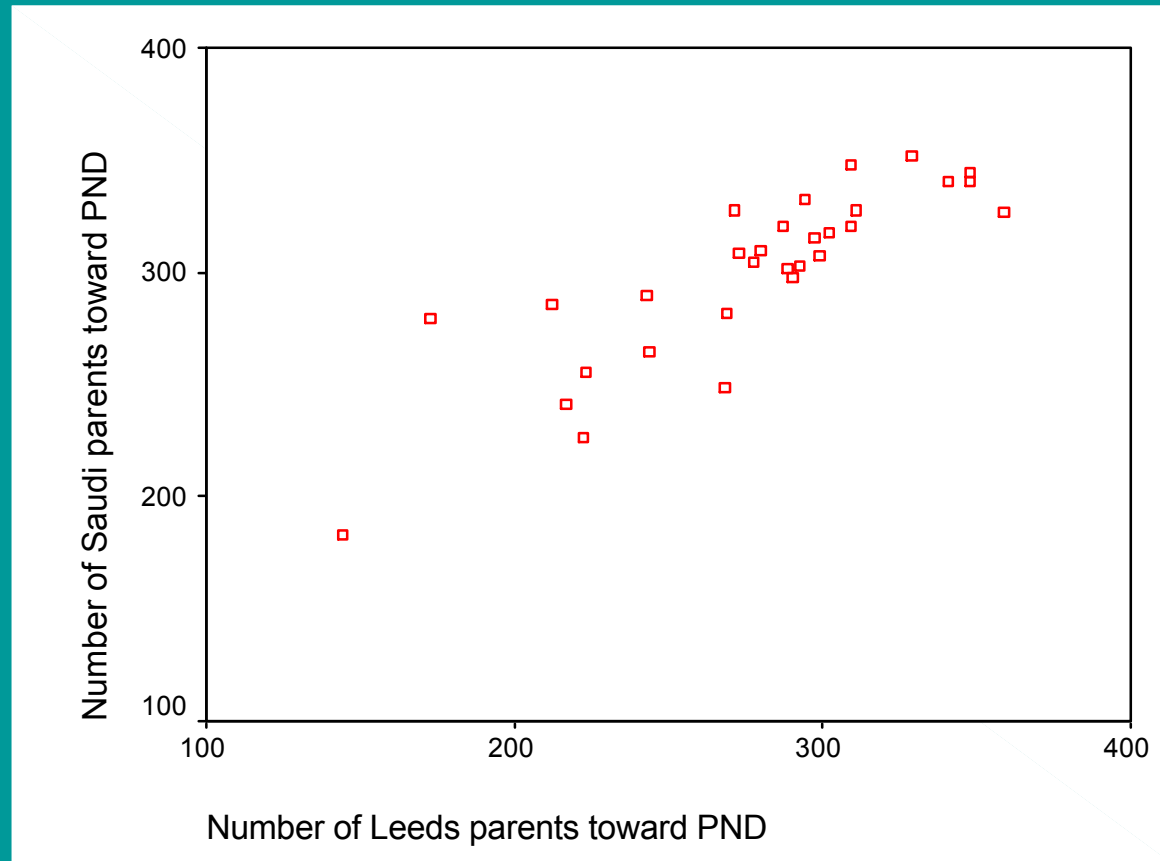


The Saudi sample

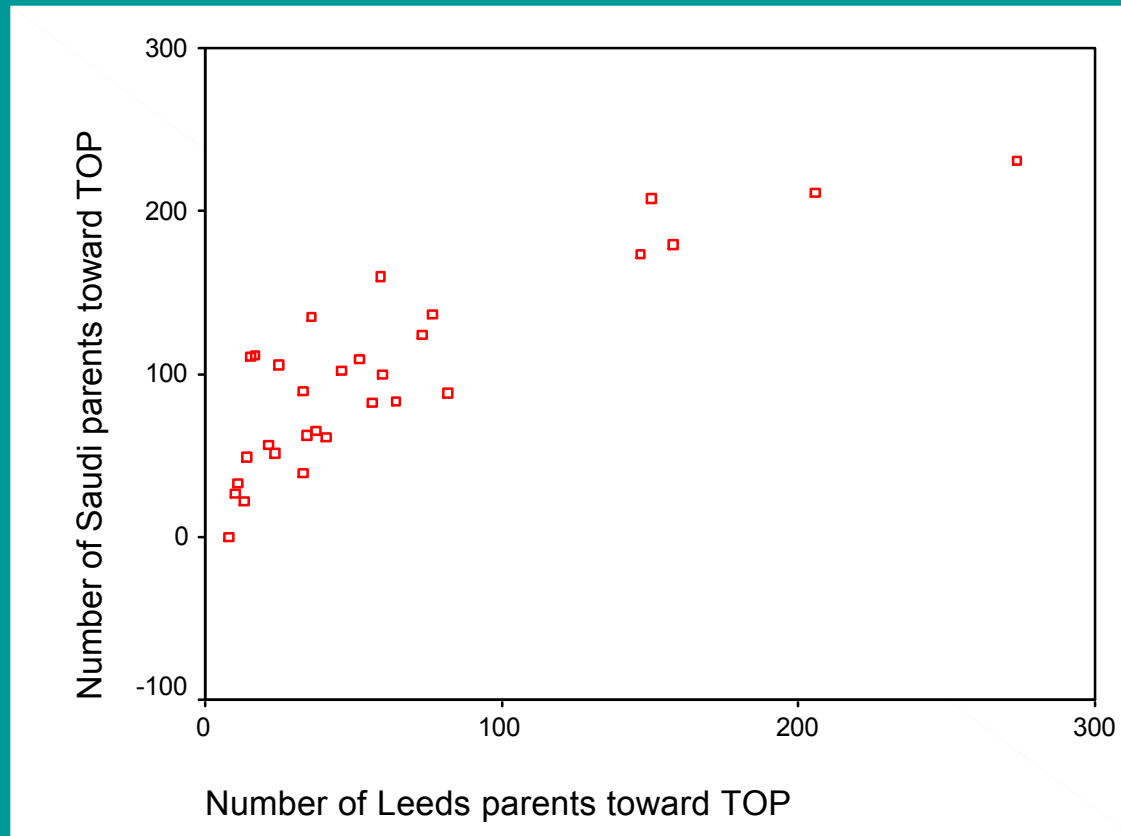
- replicated methodology, including sampling from genetics clinics
- similar sample size
- inclusion of fathers



Scatter plot: N. England x Saudi in favour of testing $r=0.86$



Scatter plot: N. England x Saudi in favour of termination $r=0.78$



Reasons for attitudes (UK sample)

- consistent across groups

- perceived seriousness of the condition
(child's quality of life)
- quality of life for the family



Agreement at the 'serious' end of the spectrum

"...children who cannot do anything, can't eat or ask their parents for anything" Hafsa (P)

"It's (about) quality of life..I couldn't see what sort of life they'd have...I know it's a life, but it's just an existence" Jennifer (W)

"...a child that is going to be suffering, in pain..." Meredith (W)

"...if the baby will die soon after birth or during childhood. It's not fair on the children if they're going to be ill and then die young" Noor (P)

"...a child that couldn't enjoy their life...doesn't understand what they're living or why" Anmol (P)



Effect on mother & family

“I know I couldn’t cope, I’d go mad myself” Sameena (P)

“It’s purely selfish but I don’t know whether I could... put 24 hours care into a child for the rest of my life” Kim (W)

“...not fair on the first child... would put a strain on absolutely everybody Amber (W)

“...My other children would feel left out” Rani (P)



Same dimensions raised by the Saudi sample

Thamer (34 year old Saudi male, highly educated with three healthy children and two affected with PKU

“..I have to hide my healthy children at meal time in a locked room as a jail like criminal people, because I do not want the affected daughters to be upset by looking at their brothers and sisters eating what they want to eat....”

Hussein (49 year old Saudi male, highly educated (assistant professor) with seven healthy children and one child with sickle cell anemia)

“..Any kind of condition that makes the parents busy with the disabled child and ignore the healthy children should be terminated.”



Religion and attitude to termination

- not as influential as expected

“We believe in Allah and if he gives me a baby with thalassaemia then I have to accept his will” Yasmeen (P)

“I’d be scared to have it terminated..it's a big sin” Rabeea (P)

BUT

“I'd rather go to hell than put my child through all that.”
Aamina (P)



Religion and attitude to termination - early death

“You leave it in God’s hands..if that baby’s meant to die after it’s born..or going to be in hospital and won’t survive anyway, that’d be much easier for me”. Rabea (P)



Conclusion

- **Attitudes are very individual. Multidimensional scaling and hierarchical cluster analysis (confirmed by focus groups) showed that only the most severe conditions could be grouped for consent purposes.**
- **Most respondents would want testing for some but not all conditions. Most had at least one condition for which they would consider termination of pregnancy.**
- **Social and ethnic similarities are more striking than the differences.**
- **Other replications currently planned and ongoing in other countries.**

