



# Social & Ethnic Differences in Attitudes & Consent to Prenatal Testing

**University of Leeds**

ESRC Project Number: L218252013

# Grant Holders and Researchers

- **Grant holders:**

  - Prof Jenny Hewison:** Psychology of Health Care

  - Dr Josephine Green:** Psychological Aspects Childbearing

  - Prof Howard Cuckle:** Reproductive Epidemiology

  - Prof Jim Thornton:** Obstetrics and Gynaecology

  - Prof Bob Mueller:** Clinical Genetics

- **Research Staff:**

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# Background to the study

- **Advances in DNA technology = increase in the range of conditions where prenatal tests will be available**
- **Obtaining separate informed consent to each... require system of obtaining broad classes of consent**
- **Such a system needs to be build on parents' attitudes to testing**
- **No adequate classification system available**



# Aims of the studies

- **Compare attitudes of different social and ethnic groups to different conditions**
- **Describe and compare reasons for these attitudes between conditions and between social and ethnic groups**
- **Devise a classification system??**



# The studies: Design

## Study 1a:

Quantitative questionnaire (target n=400)

## Study 1b:

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

Data from study 1a & 1b was supplemented with data from a sub-sample of women who had used genetic services (n=19)



# The studies: Methodology

## Sample:

**Pregnant Pakistani & white indigenous women attending community antenatal clinics, over 30 weeks gestation**

## Outcome measures:

- **Postnatal attitude towards prenatal diagnosis**
- **Postnatal attitude towards termination of pregnancy**



# The questionnaire... hypothetical scenario

When answering the questions, assume  
that the test would be carried out:

- using routinely collected blood
- early in pregnancy
- with no risk to you or the pregnancy
- to tell you whether the baby **definitely**  
does or does not have the condition



# 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?

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).	No <input type="checkbox"/>	Yes <input type="checkbox"/>	Not sure <input type="checkbox"/>	No <input type="checkbox"/>	Yes <input type="checkbox"/>	Not sure <input type="checkbox"/>
A male child would have a progressive muscle-wasting disease, be wheelchair-bound by 11 or 12 years and have a much-shortened lifespan (death probably before 20 years of age).	No <input type="checkbox"/>	Yes <input type="checkbox"/>	Not sure <input type="checkbox"/>	No <input type="checkbox"/>	Yes <input type="checkbox"/>	Not sure <input type="checkbox"/>
Child would have severe learning disabilities/mental handicap, unable to speak or understand, require a lot of looking after and have a nearly normal lifespan.	No <input type="checkbox"/>	Yes <input type="checkbox"/>	Not sure <input type="checkbox"/>	No <input type="checkbox"/>	Yes <input type="checkbox"/>	Not sure <input type="checkbox"/>
Child would have severe learning disabilities/mental handicap, requires a lot of looking after and die within first few months of life.	No <input type="checkbox"/>	Yes <input type="checkbox"/>	Not sure <input type="checkbox"/>	No <input type="checkbox"/>	Yes <input type="checkbox"/>	Not sure <input type="checkbox"/>



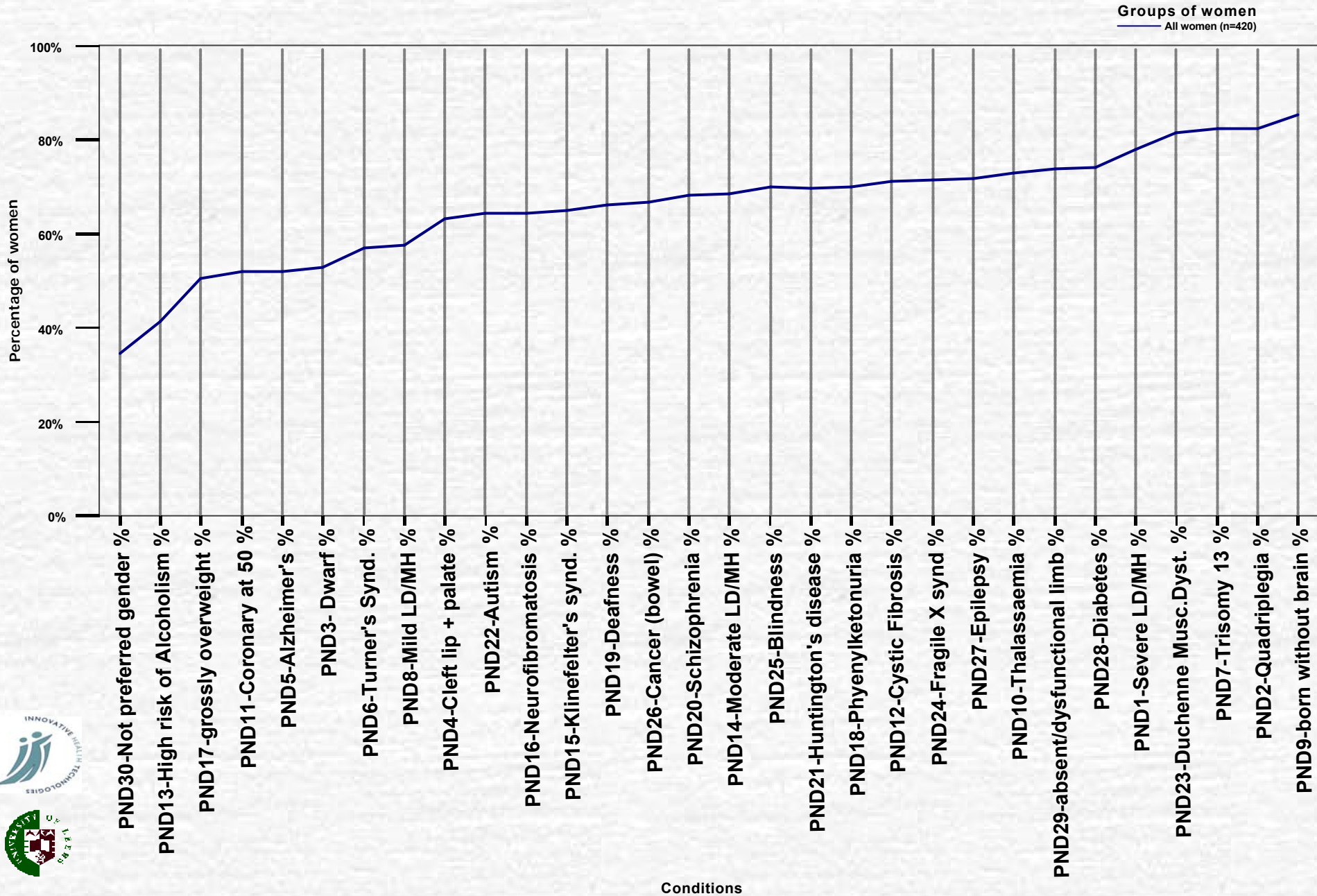


# Completed Questionnaires: Ethnic origin x Education

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

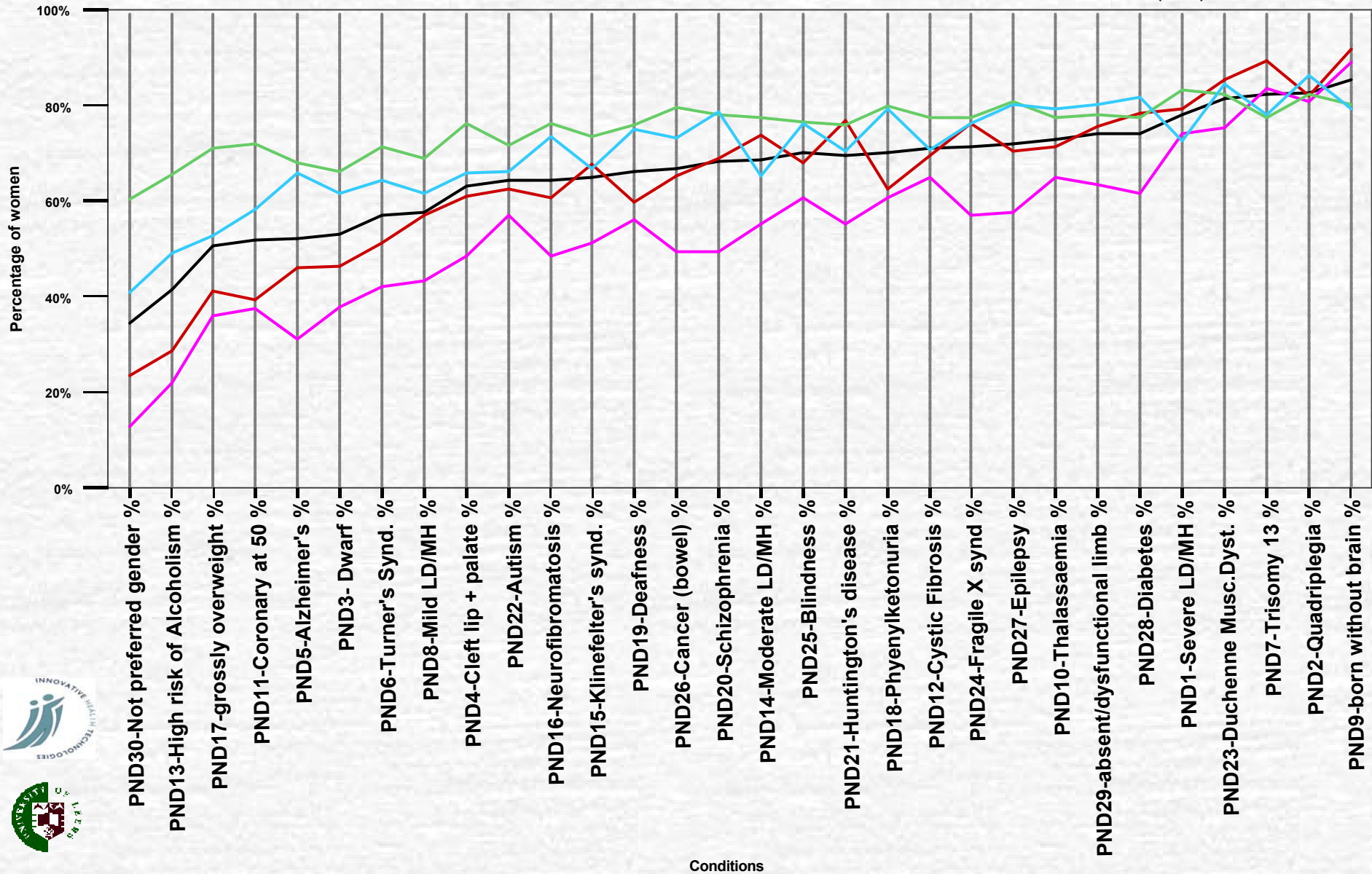


## All women who said "Yes" to PND: conditions ordered by "Yes" to Prenatal Diagnosis



**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**

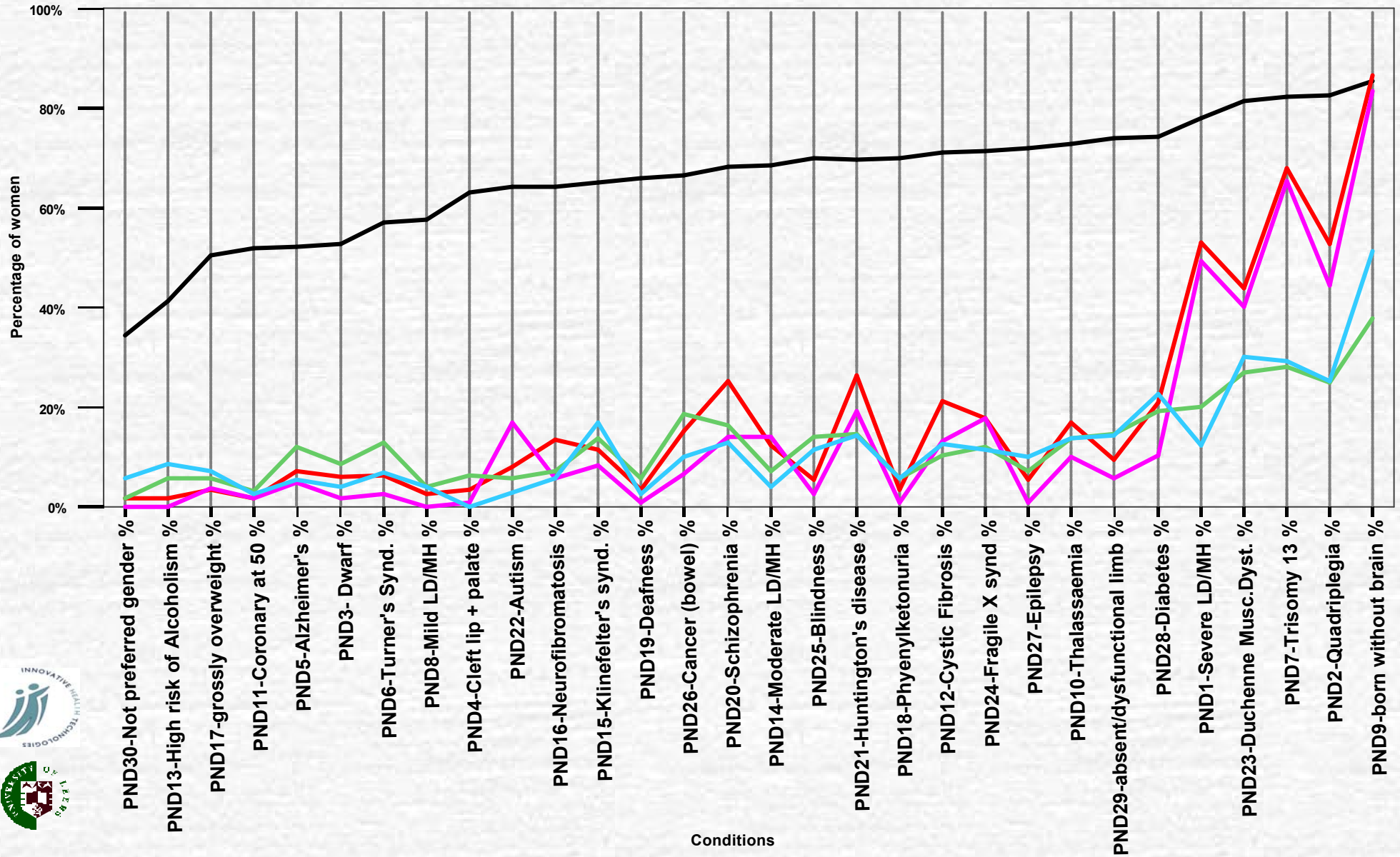
**Groups of women**  
 — All women "YES" to PND (n=420)  
 — Ind White-Low ed (n=113)  
 — Ind White-Hi ed (n=109)  
 — Pakistani-Low ed (n=125)  
 — Pakistani-Hi ed (n=73)



Conditions

**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)



# A classification system??

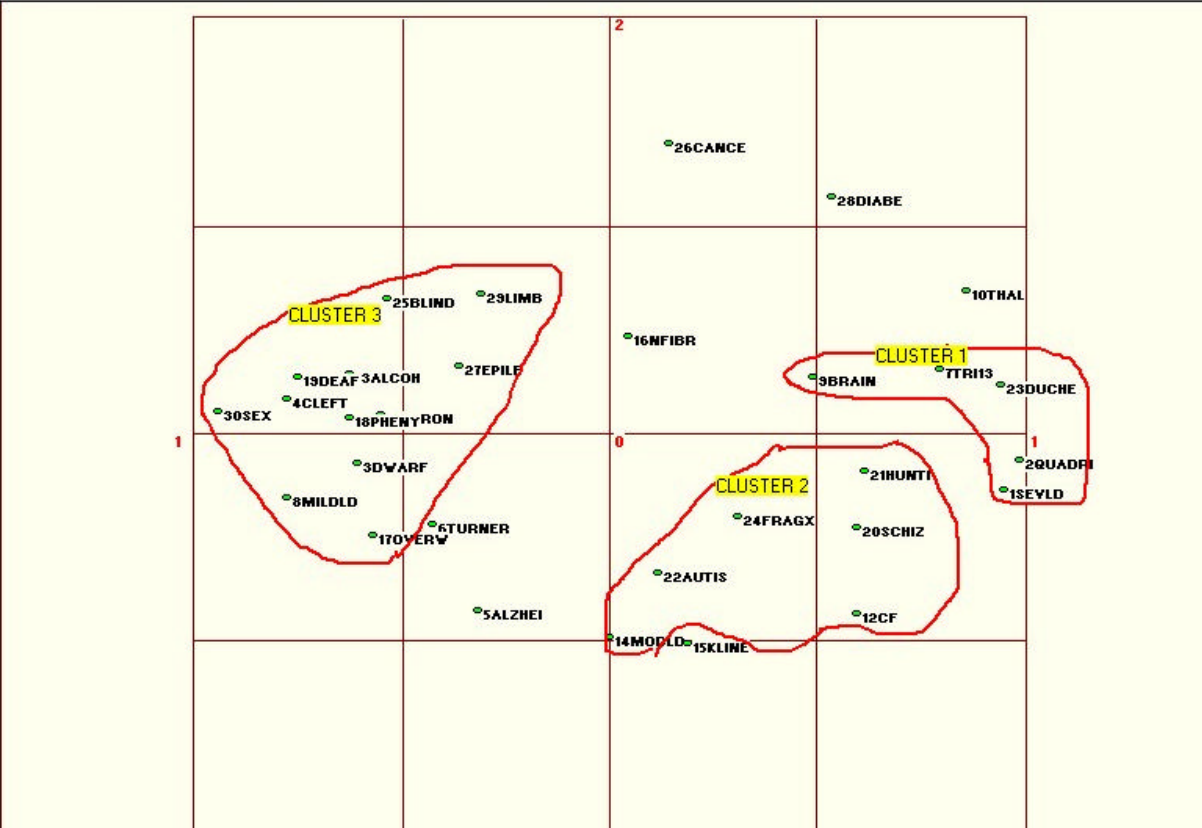
Do individuals hold similar attitudes to different conditions?

- Multivariate analysis conducted by Prof Tony Coxon of Edinburgh University
- Two techniques:
  - Multidimensional scaling
  - Hierarchical cluster analysis

## TESTING: HIERARCHICAL CLUSTERING (CONNECTEDNESS METHOD)

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1 1 1 0 0 0 0 1 2 1 2 2 1 2 1 0 0 0 0 1 2 1 2 2 2 1 2 2 3
3 7 1 5 6 3 4 8 6 0 5 1 2 4 4 2 1 2 9 7 0 3 9 5 8 6 8 7 9 0
1.00000000 . . . . . XXX . . . . .
8.06200027 . . . . . XXXXX . . . . .
8.42599964 . . . . . XXX XXXXX . . . . .
8.48499966 . . . . . XXX XXXXXXX . . . . .
8.94400024 . . . . . XXXXXXXXXXX . . . . .
9.22000027 . . . . . XXXXXXXXXXX . . . . . XXX . .
9.38099957 . . . . . XXXXXXXXXXX . . . . . XXXXX .
9.43400002 . . . . . XXXXXXXXXXX . . . . . XXXXXXX .
9.64400005 . . . . . XXX . XXXXXXXXXXX . . . . . XXXXXXX .
9.74699974 . . . . . XXX . XXXXXXXXXXX . . . . . XXXXXXX .
9.79800034 . . . . . XXXXX . XXXXXXXXXXX . . . . . XXXXXXX .
9.84899998 . . . . . XXXXX . XXXXXXXXXXX XXX XXXXXXX .
9.89900017 . . . . . XXXXXXX . XXXXXXXXXXX XXX XXXXXXX .
9.94999981 . . . . . XXXXXXX XXXXXXXXXXXXXX XXX XXXXXXX .
10.10000040 . . . . . XXXXXXX XXXXXXXXXXXXXXX XXXXXXXXXXX .
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10.43999960 . . . . . XXXXXXXXXXX XXXXXXXXXXXXXXXXXXXXXXXXXXX .
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10.53600030 . . . . . XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX .
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11.18000030 . . . . . XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX .
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12.12399960 . . . . . XXX XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX .
12.36900040 . . . . . XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX .
12.48999980 . . . . . XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX .
12.56999970 . . . . . XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX .
13.00000000 XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX .
14.42199990 XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX .
```

FINAL CONFIGURATION - STRESS D'HAT = 0.147685 : dimensions 1 and 2




## Reasons?

- Women often considered it self evident that a termination would not be justified.
- In Barbara's words, a condition such as blindness, *"wouldn't bother me"*.
- Problems were acknowledged, but regarded as insignificant or manageable in the overall scheme of things – there was plastic surgery, prostheses, Braille and sign language, therapy, parental reserves of understanding and patience.




## Reasons why "yes" ?

- Nadira: *If anything happened to me, or I died, or their dad's not around..who's going to look after them? Because the way a mother looks after you, nobody else does.. they're not other people's problems and you know what people can be like out there. You gonna regret it yourself that it's suffering 'cos of me..you might as well just put an end to it before you knew it was gonna go through all that and die slowly, and that kid's gonna blame you as well.*




Heather: *One child can live to be one, the other can live to be 30 - you never know, and you're living with that every day, not knowing whether you're going to bury them next year, or whether they're going to carry on and grow up into adulthood. She went on: ..even though you work full time, you still sort out the physio, the medicine, the hospital visit.*




## Different conditions?

- ☛ Rebecca thought she probably would have a termination for thalassaemia: *They're going to know that they're gonna die, and they're not going to have much of a life in and out of hospital.*
- ☛ For her, facial disfigurement was not a reason for termination: *Their life is just the same really.*



☛ Lareb disagreed: *His parents will not look at him with hatred but friends, brothers and sisters will say, “you stay away from us, your face is not good, don’t come near our friends”...they will say “don’t sit with my friends, you go out – go to your room” .*



# Summary

## 1. Attitudes to testing


- A high level of interest in testing
- 6% of UK Pakistani women and 4% of white indigenous women wanted no prenatal testing at all

## 2. Attitudes to termination

- For the great majority of conditions, fewer than a quarter of participants would consider a termination of pregnancy
- 25% of UK Pakistani women and 6% of white indigenous women would consider a termination for none of the conditions on the list

### 3. Conditions?

- A small group of conditions, anencephaly, trisomy 13 or 18, quadriplegia, Duchenne muscular dystrophy, and to a lesser extent, severe learning difficulties, stand out from the rest.

- 
- The great majority of women would like prenatal tests for these conditions, and even women who on the whole rejected testing tended to make exceptions for these conditions.



- Interest in termination was lower, but again, if a woman who was essentially against termination was prepared to make exceptions to that rule, these were the conditions seen to justify an exception being made

## 4. "Clustering" of conditions?

- ☛ Women's views of "less serious" were much more variable than their views of "more serious".
- ☛ In focus groups, cluster approach acceptable, but only for "more serious" conditions.
- ☛ Otherwise, most participants wanted to make their own choices.

# Risk, anxiety and information

- Literature – and policy makers? -preoccupied with risk (of condition, and of miscarriage), and attendant anxiety
- Women want information about conditions for which they are not at increased risk
- In future? Non-invasive diagnostic tests?
- And today? Miscarriage risk is the same for information on one condition or 30