

### Multiethnic populations and trial recruitment

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### Overview

- Ethnicity health & research
- Qualitative studies
- Diabetes prevention trial (PODOSA)
- Recommendations & Conclusions

### Ethnic variations in health in the UK

- Pakistani population at significantly increased risk of angina (rate ratio 189.3 in men, 159.7 in women)
- Chinese population much reduced risk of angina (rate ratio 60.5 men, 67.4 women)

(European Journal of Cardiovascular Prevention & Rehabilitation published online 5 October 2011 Raj S Bhopal et al)

#### Prevalence of diabetes 4 to 5 times higher in UK South Asians

2005 data – Diabetes registers linked to hospital admission records (Dr Sarah Wild 2008)

# Research by ethnic group: studies showing the gap

- 39% of RCTs in US reported results by ethnicity vs 7% in Europe (Sheikh et al BMJ 2004: 329 87-88)
- 15 of 31 North American cardiovascular cohort studies provided data by ethnic group, the corresponding figures in Europe were zero out of 41 (Ranganathan and Bhopal PLoS Jan 3 2006)
- SEHRS working group in 2009, reported sparse evidence for prevention trials in UK ethnic minority groups

# Inclusion and exclusion in research: why should we have data by ethnicity?

- address existing health inequalities
- legal and policy developments (eg demonstrate response to RRA 2000, Equality Act 2010 etc)
- unethical to bypass ethnic groups in trials
  Increasingly diverse population

# Summary of key issues identified - UK asthma researchers

- Unconvinced about the importance of the subject
- Practical difficulties
  - Lack of knowledge
  - Language barriers
  - Costs
  - Problems obtaining meaningful consent
- Overall, considerable hassle not recognised by funders

(Facilitating the Recruitment of Minority Ethnic People into Research: Qualitative Case Study of South Asians and Asthma- Sheikh et al, PLOS Medicine, October 2009)

## Key issues from community leaders & patients

- Most have no experience of being approached to participate in asthma studies, but would, if asked, be interested
- Factors that would heighten interest include:
  - Research question that they can relate to
  - Being approached in an 'appropriate' way
    - By someone they trust preferably GP or researcher
    - Personalised contact rather than impersonal approaches such as written invitations

### PODOSA (Prevention of Diabetes & Obesity in South Asians)

#### National Prevention Research Initiative: funders



Additional support from NHS Lothian and NHS Greater Glasgow & Clyde R&D, Chief Scientist Office, NHS Health Scotland, NHS National Services for Scotland

### **Trial adaptations**

- Materials translated
- Cultural adaptations
- Bilingual research staff
- Multi-pronged recruitment strategy
  - NHS/Community/media



### **Recruitment to screening: Results**

_	Initial target (%)	% of total screened
NHS		
Direct referrals		1
Written invitations via	50	
GPs		11
Community		
Snowball effect		47
Community groups	50	26
Research team		14
recruitment		

Douglas et al Trials 2011, 12:220

### **Promotion & retention**



### Recommendations

- Personal, face-to-face contact most successful strategy
- Involve link workers for recruitment
- Fully estimate cost of face to face recruitment & of translations
- Bilingual research staff if possible

### **Conclusions 1**

- Trials in the diseases & populations where boosted and ethnic specific recruitment is important -so additional resources are likely to be seen as justifiable
- Seek advice from teams who have experience in studying the populations of interest & proven track record of recruiting

### **Conclusions 2**

- Ethics committees have a role to play
- Funders need to recognise additional costs may be required
- Studies in general populations should include ethnic minority participants

