Responding to ethnic diversity within health systems: what is the role of research evidence?

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Some ideas to share today

- A largely English perspective
- Healthcare policy, design & delivery
- Ethnic diversity and inequality
- Own research, experience and that of others
- “Evidence-informed” healthcare for diverse contexts
Strong legal & policy framework
Persistent ethnic inequality

- Lower levels of service satisfaction
- Poor communication
- Repeated primary care visits; lower rates of referral (e.g. IAPT; cancer follow-up)
- Lower uptake of preventive interventions
- Unmet needs
- Inappropriate and oppressive care
- Higher levels of DNA
Frequently Raised Objections

- Race equality is not an issue nowadays; this is political correctness gone mad.
- We just don’t have the evidence to act.
- BME is such a diverse and difficult area.
- We can’t privilege ethnicity without considering other groups and issues.
- This is important but it’s not my job.
- We’d like to do more, but we need to prioritise quality and efficiency.
Deeply embedded structures & processes

Marginalisation

Ambivalence

Lack of clarity & confidence
What role is research playing?
Low demand for evidence

Lack of fit between research and evidence needs

Limited skills and confidence

What should we be doing differently?

Why is research evidence not shifting policy and practice?
What are we researching?
Exclusion: data and agendas

- National surveys and datasets e.g. HSE 2004
- Routine data collection systems
- Local evidence products e.g. JSNAs
- NIHR funding streams
Partial/adverse inclusion

Describe
Understand
Explore & pilot solutions
Refine & test
Implement & sustain

Fewer studies that embed attention to ethnic diversity and inequality
### Partial/adverse inclusion

<table>
<thead>
<tr>
<th>Level</th>
<th>Definition and Example</th>
<th>Instances</th>
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<tbody>
<tr>
<td>Patient</td>
<td>Change knowledge and/or behaviours of patients and/or family members (e.g., self-management and goal setting)</td>
<td>50%</td>
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<tr>
<td>Community</td>
<td>Work with community organizations and/or community members (e.g., health education outreach)</td>
<td>32%</td>
</tr>
<tr>
<td>Provider</td>
<td>Change the knowledge and/or behaviour of providers (e.g., cultural competence training)</td>
<td>7%</td>
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<tr>
<td>Microsystem</td>
<td>Add new members to, or shift responsibilities among, the immediate care team, such as the primary care provider, nurse, and staff (e.g., integrate peer educators into team)</td>
<td>9%</td>
</tr>
<tr>
<td>Organization</td>
<td>Change organization operations involving, but not limited to, clinic flow, information technology, and/or human resources (e.g., Electronic Medical Records; open appointment system)</td>
<td>3%</td>
</tr>
<tr>
<td>Policy</td>
<td>Influence laws, regulations, and/or resource allocation on a regional or national basis (e.g. legislative advocacy; professional standards)</td>
<td>&lt;1%</td>
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Clarke et al. 2013; US, 391 intervention studies, 2,420 strategies/approaches
Partial/adverse inclusion

- Insufficient research focus on racism
- Subtle; normalised; unspoken
- Few studies of institutional racism or racial/ethnic variation in the impact of regulations, policies, and practices

“Better instrumentation, innovative methodology, and strategies are needed for identifying and tracking racial/ethnic discrimination in health care settings” Shavers et al. (2012)
Missed opportunities

Missed opportunities
How are we researching?

- Expert opinions
  - "Experts are of the opinion that ..."
- Cross-sectional studies and case studies
  - "There are signs that ..."
- Uncontrolled longitudinal studies
  - "It is likely that ..."
- Controlled longitudinal studies
  - "It is shown that ..."
- Randomised controlled studies
- Establish causality (bias --)
  - Generate hypotheses (bias ++)
“...we knew that NICE doesn’t tell us anything about outpatient care. I mean NICE tends to give us clinical guidance ..., it almost certainly doesn’t tell you much about how many nurse specialists you really need to look after a population of half a million people or, you know, or how they’re best organised or whatever.”

(Service commissioner, Salway et al. 2013)
Interviewer: So, *tell me a bit about how you go about getting the evidence and information you need to improve services*

Respondent: *Well, there's the information you need to work out what needs to be done; and then of course there's the information you need to convince people to let you get on and do it*

(Service commissioner, Salway et al. 2013)
Slow and costly

Unheard voices
Excluded knowledge
- patients
- public
- practitioners
Why are we researching?

• Academic acclaim
  - 3* and 4* publications?
  - Impact Stories?

  “direct, short-term, surrogate” Greenhalgh, 2015

• Definitive impact
  - better access, experiences and outcomes
  - messy, convoluted, long-term, multi-layered, uncertain
Promising ways forward?
Increasing demand for evidence

Improving fit between research and evidence needs

Enhancing skills and confidence

Promising shifts in research practice

New ways of working
Increasing evidence demand

• Direct, instrumental use of evidence is rare

• Recognise that evidence into action is:
  - dynamic, interactive, messy, plural
  - political and contested when focus on ethnicity

• Need to mobilise in influential ways; “circulation of ideas”; “front stage and back stage”

→ shifting understanding and motivation
Example from Canada

Bowen et al. (2010) From 'multicultural health' to 'knowledge translation'—rethinking strategies to promote language access within a risk management framework

- Getting the issue on the agenda – “risk”
- Close partnership with end users of evidence
- Informing the response – synthesise evidence in context
- Informing implementation – culture, values, priorities
- Changing and sustaining behaviours - drivers
Improving the fit

- Co-production
- Participatory methods
- Action research

- Improvement science
- Implementation science
- Theory-driven process evaluations
- Mixed methods
Increasing clarity & confidence

• PHE and NHSE – joint units that integrate health inequalities and equalities

• eeic.org.uk; associated workshops and NIHR Knowledge Mobilisation Fellow (Lynne Carter)

• Sustained relationships – “researchers-in-residence”; community-based participatory research (CBPR)
Conclusions
• Current role of research in tackling ethnic healthcare inequalities is disappointing

• Embedded obstacles – marginalisation; ambivalence; lack of clarity and confidence – characterise both research and practice arenas

• Current research practices, including measures of success, act against progress on complex and contentious issues

• Some promising developments, but concerted effort will be needed to make them work for diversity and equality
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Thank you

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