Thinking outside the Box: Experience of Delivery

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Assumptions / Challenges

Study Design teams

• Hard to reach communities??!! = expensive, time delays, no large numbers, problematic interpretations of illness / disorders

• Concern around Data integrity: ensuring measures are filled accurately – no real sensitivity to language or subtleties of understanding cultural variations and definitions of illness - recovery

• Limits data/study credibility - wealth of knowledge we miss out

• Feels like too much hard work better to just exclude client groups who don’t conform to norms

Communities/individuals:

• Services unaware of needs – they don’t ask

• Don’t understand our subjective idiosyncratic perspectives

• Lack of trust – “Don’t trust services / research – don’t want to be a lab rat”

• Fear of leading to other issues and challenges – interference in way of life - Fear of being judged

• No time – not a priority

• Hassle of going to clinics or having to travel to meetings.
Case study

**Care Giving Hope:** Dementia study focusing particularly upon the carer needs of those from an Asian background. (University of Bradford)

Interview / questionnaire based study – wanting to ascertain the nature of carer responsibility and willingness of carers to look after family relatives and map service interaction.

- Assumptions from service and client perspectives:
  - Asian clients don’t engage with services - They look after their own through extended family
  - Merely just want medication
  - (client); Services cant be trusted – don’t understand our culture, religious or practical needs. – fear of being judged,
  - Social, cultural, religious stigma – language and idiosyncratic understanding of illness
  - Service users hard to reach as they don’t attend services / clinics that often / DNA.
• Local target of 30 - Doubled actual recruitment to study alongside invaluable links to range of community groups and individuals who have since been used as a medium to distribute and support further research studies:-

• Identified partners to national to local organisations
  – Health watch, Local Voluntary sector partnership
  – Statutory bodies,

• Key community groups - mosques, churches, interfaith organisations – building trust – explaining rationale – lead to community radio, TV and local publicity

• All very open happy for individuals to engage – to ask questions and support ideas – to listen to them – plug them in to other contacts – working with peoples passions

• Being realistic of objectives, not going to bring additional finances but can barter support – offer to undertake mental health awareness, training sessions etc.
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Method to the madness

• Being creative and identifying links and partners across the spectrum – not reinventing the wheel but utilising networks and contacts across areas.

• Getting out there – but being realistic with expectations

• Looking at all our ‘assets’ inside & outside of the network - Using internal and external data sources
  – Internally within the network/CRN:
    • NIHR Research Targeting Tool - ODP

• Host / statutory partners - organisations engagement teams
• External data observatories: breakdown of populations stats and other details
• Geographical mapping of issues JSNA
• Takes a bit of time but results in stronger and vibrant research portfolios
Example of cross boundary working
Local data Sources

Welcome to the Kirklees Observatory. This new facility is for anyone looking to find out more about communities and geographies in Kirklees. So whether you’re a professional or just curious, your information needs are just a few clicks away.

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