



**Gypsy, Roma and Traveller
Health: making a difference
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Background

- Diverse 'Roma' population in UK – main ethnic groups categorised as 'Romani/Gypsy'; 'Irish/Scottish Travellers' and Roma (migrants from A2 & A8 countries). Collectively identified in policy documents as 'Gypsy, Traveller and Roma' (GTR).
- Estimated 250,000-300,000 Gypsies and Travellers in Britain equivalent in size to the Sikh community (CRE 2006; EHRC/Cemlyn et. al 2009) nb: 3-4% p.a compound natural population growth = 380,000-410,000 in 2015. (Figures exclude estimates of Roma migrant populations).
- Claims of migrant Roma figures vary from between 50,000-200,000 (2008-2013 reports - e.g. Salford University RomaMATRIX; 2013; Craig, 2011; MigRom, 2014).
- First reports of Roma migration occurred in the mid-1990s largely driven by a desire to escape racism/economic exclusion with a substantial number of early arrivals claiming (and achieving) asylum. Post 2004 Roma migrants are EC citizens exercising their freedom of movement.

- 2011 UK Census records a significant undercount in G/T population enumerating 58,600 persons with a head of household from these populations. <5% of such respondents were aged >65 years (compared with 9% of the overall population)
- 39% of the G/T population were aged below 40 years of age. Median age: 26 years.
- Roma populations were not consistently captured by Census data, but would have been included as 'White Other' European born respondents.
- Average life expectancy of G/T populations in the UK has been estimated variously as 10-12 years below that of 'other' White British citizens (Parry et al, 2004). Baker/LeedsREC (2006) estimated an average life expectancy of 50 years, Bedfordshire NHS Health Trust (2010) around 65 years.
- No such data exists on Roma populations in the UK although based on European reports e.g EPHA, 2014; FRA, 2012 it is anticipated that higher morbidity and early morbidity exist and that significant variations in health status may be found when Roma are compared to other 'mainstream' populations.
- It is likely that health status and life-expectancy of Roma in the UK resemble those of G/T communities about whom more is known (e.g. Parry et. al. 2004; Cemlyn, Greenfields et. al., 2009; Ryder & Cemlyn/Federation of Gypsy Liaison Groups, 2014; Greenfields & Brindley, 2016).

Summary Literature Review – Roma health status in Europe

- Background literature and field-based case studies on access to health and associated services for Roma in their country of origin and migrant Roma populations across Europe evidence remarkable similarities in two key areas:

- **Firstly:** practical and administrative challenges which impact on SDOH as experienced by Roma e.g. lack of appropriate documentation or entitlement to services following recent migration; insufficient contribution-related welfare entitlement; limited access to, or awareness of, health insurance; poor quality/non-existent translation services/low literacy compounding existing barriers to treatment compliance; and the overarching impacts of poor quality or insecure accommodation and frequent movement on household wellbeing or treatment regimes.
- **Secondly:** all pervasive impact of misrecognition and at times institutional racism/discrimination on service delivery. In turn this impacts relationships with health and social care providers, minimising Roma clients' ability to utilise services appropriately and efficiently.

- Quality of data varies significantly across MS.
- However, policy documents and research have consistently highlighted disproportionality in Roma morbidity and mortality throughout the EU with widest discrepancies reported in Central and East European MS. (OSCE, 2003; FRA, 2011; WPHA, 2014)
- nb: emerging evidence of decreasing life expectancy in some former Socialist states (WHO/Szilard in Greenfields et. al., 2015)

- ERRRC 'Hidden Health Crisis' (2013): mortality rate Roma >10yrs old x 3 compared to non-Roma
- Average time first diagnosis of a terminal condition - 3.9 years (Roma) 6.8 years (non-Roma)
- FRA (2011) Condition of Roma in 11 member states – x 5 over-representation of Roma without health insurance compared to non-Roma; significantly greater chance of reporting 'limiting condition' (x7 in Italy)
- Reanalysis of FRA 2011 data by gender (FRA, 2013): morbidity amongst women 50yrs + twice the rate for Roma women compared to non-Roma (61%)
- FRA 2013 (Multiple Discrimination in access to health care) Czech Republic data significant evidence of refusal of medics to treat Roma patients.

European Commission (2009 & 2014) in-depth analysis of the health status of Roma in 31 member states (2014 study).

Consistent inequity in morbidity and mortality when Roma and non-Roma are compared, most starkly in relation to life expectancy.

”a body of evidence demonstrates, among other things, that the Roma population has considerably shorter life expectancy compared to the non-Roma population and face a range of barriers in accessing health” (EC, 2014 pp31-32).

Review of data from MS led to the conclusion that the gap in life expectancy is between 5-20 years for Roma across the EU. (EC, 2014). Nb: gaps in datasets noted in many MSs.

Why is the European background Relevant?

- Roma migrant populations as well as Gypsies/Travellers are included in 'Inclusion Health' categories of priority communities/groups.
- Not only are many Roma “vulnerable migrants” but they are potentially likely to be found within the other categories including 'homeless' people and on occasion 'sex workers' or categorised as 'Gypsies/Travellers'.
- Poor pre-migration health impacts on current health status and household functioning as does on-going marginalisation and poverty in the UK.

Environmental and Living Conditions

- G/T households predominantly live in residential housing (estimated 2/3rds of the population often as 'forced settlement' in response to lack of adequate pitch numbers) (Cemlyn et, al 2009; Clark & Greenfields, 2006; Greenfields and Smith, 2010-11; ONS, 2013)
- Roma overwhelming living in housing – anecdotally often severely overcrowded and poorly maintained (Craig, 2011; Greenfields et. al., 2016 - forthcoming).
- Approximately 20% of G/T caravans are not stationed 'lawfully' (estimated 3,400 households) with their residents being technically homeless (CLG, 2015; Travellers Times, 2016).
- Impacts of poor quality sites and statutory homeless having a profound and long-term effect on physical and mental health of G/T respondents (Parry et. al., 2004; Smith & Greenfields, 2013; Greenfields and Brindley: Dept Health commissioned report, TM: 2016)

General Health Status – GTR populations

- 2011 Census analysis (ONS, 2013) found that in England and Wales, Gypsy or Irish Travellers had the lowest proportion of people rating their general health as 'good' or 'very good' at 70 per cent compared to 81 per cent overall
- Parry et. al. 2004; Cemlyn et. al., 2009; Greenfields, (various dates) have all found abundant evidence of premature morbidity; high rates of cardio-vascular disease; over-representation in Type II diabetes; arthritis; asthma and obesity; increasing reports of problematic substance misuse and high rates of anxiety and depression.
- Craig, 2011 suggests that the limited research findings pertaining to Roma migrants offer a similar picture. See too NFGLG, 2014 – report on NRIS in the UK, health review and recommendations.

Mental Health and Wellbeing

Mental health issues (particularly depression and anxiety) among housed Gypsies/Travellers identified in a number of studies (Parry et al, 2004; Van Cleemput, 2008; Greenfields, 2007). Smith & Greenfields, 2013 found particularly gendered dimensions to experiences of MH. Research Summarised by Cemlyn et.al., (2009) and Lau & Ridge (2011)

Recognition of untreated/undiagnosed MH amongst community but stigma of acknowledging conditions and concerns over access to treatment and cultural competence of health professionals: *“most of the women I know they are on the pills – but the doctor and nurses do just want to get rid of us – handful of pills and go away – and they don’t understand what it is like for us losing your family, losing your culture”*

- *“Mental illness is big in the housed Gypsies. I’ve seen it. It’s massive and I see it all through the country. They put them [us] in substandard housing because they think that’s what they [we] are substandard people.”* Woman interviewed for Smith & Greenfields study 2013.
- *“I think that the hostility [towards GTR people] is so great and so accepted that there is a tendency to just join in – have you heard the term a “self-hating Traveller”? – to differentiate yourself and the people you know and your family from “those Travellers” the ones who commit crimes or do bad things and then if you tell yourself often enough that you aren’t like them [the ‘bad’ Travellers], then you can go along with it ... but when you stop and think you know that this isn’t happening for other communities. It’s horrible really it’s a sort of schizophrenia.* (Interview with a Professional of GTR ethnicity)

Traveller Movement ("Tell Someone" DVD – mental health support for GRT populations)

<https://www.youtube.com/watch?v=WcDK9ZLZg-k>

The Situation of Older GTR populations

- As identified above limited information on life-expectancy of populations HOWEVER population pyramids appear similar to the UK in the late 19th Century.
- Cemlyn, et. al., 2009 *“Inequalities Experienced by Gypsy & Traveller communities”* EHRC - chapter on older G/T populations. Literature review and survey of professionals revealed remarkably little data which referred to older G/T population – what exists has had to be extrapolated from GTAAs.
- Existing papers: Scharf et al (2006) noted ‘very modest expectations’ of older G/T populations emphasising high levels of poverty and difficulties in accessing pensions as a result of literacy issues and limited documentary evidence concerning birth etc.

- Lane et. al. 2012 research for JRF: consisted of small samples of older G/T populations reflecting on 'perspectives on aging' and changing life-styles & family support provided.
- Hodges & Cemlyn, 2013 reviewed potential and barriers to personalisation of services for older G&T populations and the role of 'supporting people' services.
- ONS 2014, census data on family care provided; Greenfields with Ryder, 2010, leisure, wellbeing and older G/T populations
- GTAA evidence re site conditions/caring responsibilities/untreated conditions/high levels of premature morbidity: inevitable negative impacts on older people. Whilst clear evidence of high levels of resilience and family support the conditions/stress experienced by older GRT populations likely to reduce quality of life at an earlier age.

- Anecdotal evidence of suicides and increased rates of depression for isolated G/T older people moving into housing re lack of sites/suitable accommodation
- Poor quality sites – GTAAs significant evidence of injuries/falls resulting from badly maintained locations outwith environmental health legislation and isolated older people without family support re: site shortages
- ‘Hidden Needs’ (Aspinall, 2014, DH Health Inclusion Board) referred to ‘yawning gaps’ in information on GRT populations and health.

Maternal and Child Health

- GRT Women's health severely impacted by intersectional exclusion (CoE, 2003; FRA, 2011)
- Greatly increased levels of perinatal mortality and stillbirth as well as complications of pregnancy (Hajioff and McKee, 2000; Sheffield Health Study, 2004; Matthews, 2008). The Confidential Enquiry into Maternal Deaths 1997-99 (Lewis and Drife, 2001), found that Gypsies and Travellers have "*possibly the highest maternal death rate among all ethnic groups*", suggesting that this related to late booking, and disrupted ante-natal care.
- High childhood accident rate (Beach, 1999) and death from preventable diseases (i.e Measles outbreak 2007). The All-Ireland Traveller Health report (2012) found 4x childhood death rate amongst Travellers than other populations. G/T populations (particularly children) experience 100x greater disease burden (preventable infectious diseases than surrounding populations (Maduma-Butshe & McCarthy, 2012).
- Low rates of child-hood immunisation. NHS England consider that GRT Traveller children are particularly prone to risk as failing to achieve herd immunity (Greenfields et al 2015).

- Large family size, early child-bearing and disrupted health care or pre-existing health complication may have particularly dramatic impacts on child/maternal health (5.9 whole life fertility rate, IT, 3.5 RG – Cemlyn et al 2009)
- Significant variants found by faith-group, country of origin and migration status of Roma populations but average number of children – where data exists by country - suggest around 4 living children per woman. (FRA 2011/European Commission 2014) and for women from Romania/East Europe relatively high number of abortions (as substitute for contraception in country of origin). Overall generally higher birth rate than surrounding populations.
- 29% of Gypsy and Traveller women (UK) had experienced one or more miscarriages compared with 16% of age matched comparators from other ethnic groups. 22% had undergone Caesarean sections compared to 14% of women in the comparator group.
- Similarly 17.6% of Gypsy and Traveller women (UK) reported having experienced the death of a child (of any age and excluding miscarriage) compared with <1% of comparators (Parry et. al., 2004)

Diabetes

- Anecdotally very high rates of Type 2 Diabetes amongst GRT population associated with evidence from small scale studies of increased rates of obesity and inactivity.
- V. limited published evidence that differentiates between type 1 and type 2 diabetes amongst Gypsy and Traveller communities
- Saunders (2007) reported a high prevalence of diabetes amongst Gypsies and Travellers, and extremely limited knowledge of risk factors or implications
- Greenfields (2009/2014) analysis of secondary data from GTAAs reported found that in some localities, up to 14.6% of Gypsy/Traveller respondents reported that they had diabetes, compared with a range of 5.3–6.7% of the mainstream population in the UK.
- (Greenfields and Lowe, 2013) found that 17–20% of Gypsy and Traveller respondents (varying by specific ethnic groups) reported having diabetes.

- (Saunders, 2007; Roberts et al, 2007) noted regardless of their accommodation type, or ethnicity, members of the travelling community experienced disproportionate diagnoses of diabetes and other preventable conditions.
- G/T Respondents to a variety of studies/health assessments commonly regarded Type 2 diabetes as a natural process on reaching middle age.
- Roberts et al (2007), in an outreach project in Wrexham, noted that when compared to a control group of residents from a deprived local area, the Gypsy and Traveller respondents had a significantly poorer diet, particularly in relation to consumption of fresh fruit/vegetables and lower use of exercise regimes (see similar findings from case study also NICE guidance on diabetes, 2011).
- Parry et al (2004), supported by findings from Saunders (2007), Matthews (2008), Dion (2008), Cemlyn et al (2009) and Greenfields and Lowe (2013) all stress that Gypsies and Travellers experience significant institutional barriers to accessing preventive screening services or primary care including diabetes screening.

Cardio-vascular conditions

- European Roma Health Report (2014) EC and Dobranici et al. (2012 review of 75 European studies) have found that Roma populations experience roughly double the risk factors and occurrence of of cardio-vascular incidents leading to mortality when compared to main-stream populations; typically associated with life-style factors as well as suggestions of genetic pre-disposition and metabolic syndrome.
- Mangaloiu et. al. (2015) found 48% of Romanian Roma had hypertension in a random sample of 200 Roma patients.
- Limited but persistent reports from small scale studies in the UK and anecdotal 'community evidence' suggest similar patterns amongst British Gypsies and Travellers with factors detailed above re: poor access to screening and fatalistic attitude to health (Parry et al, 2004; Dion, 2008) exacerbating risk factors.
- Distance from hospitals/poor levels of GP registration for mobile Travellers and a reluctance of health care professionals and ambulance crews (Cemlyn et al 2009; Greenfields with Lowe, 2013) increase the risk of poor outcomes in emergency situations.

Spectrum of inequality

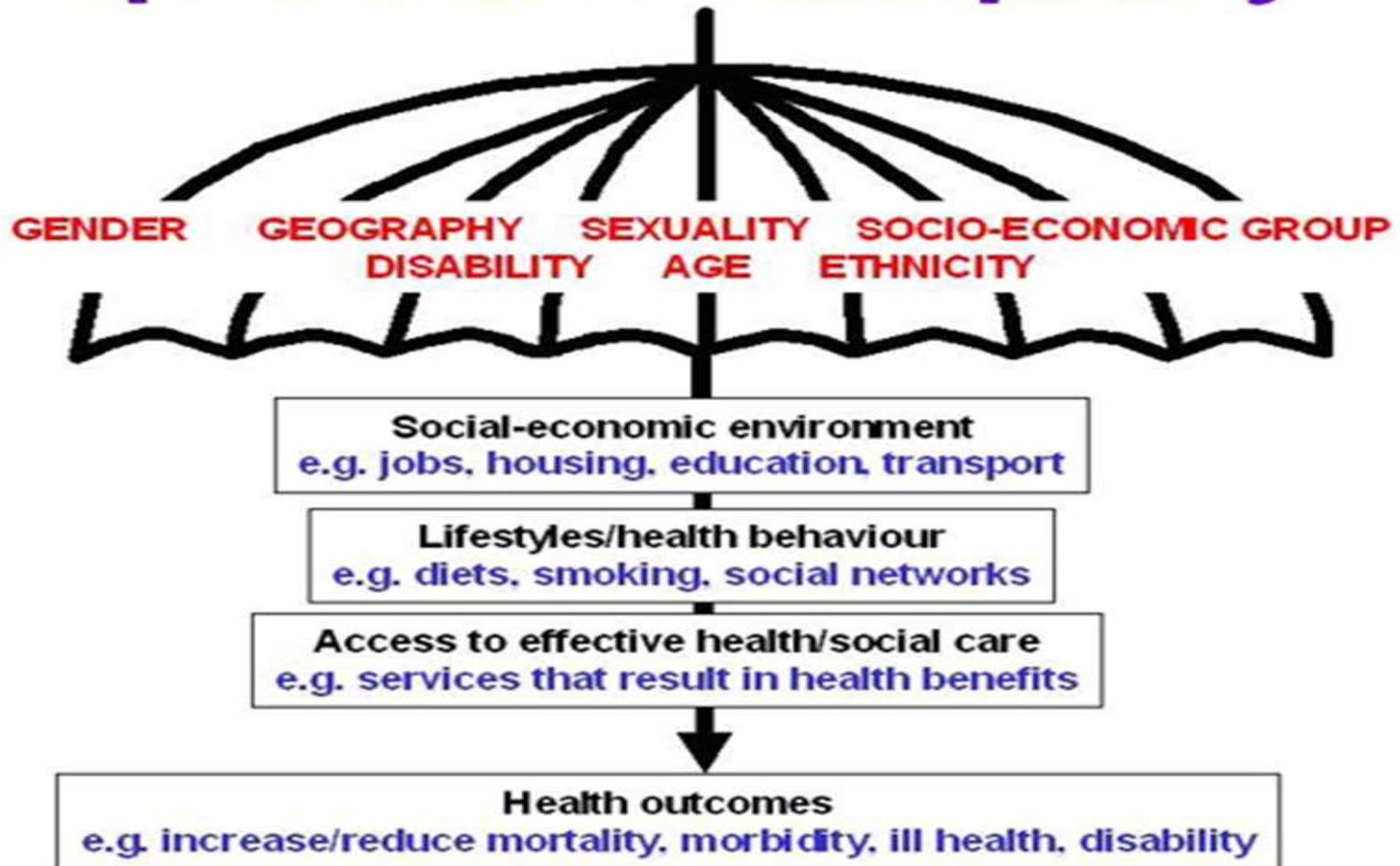


Image courtesy of London Health Observatory

http://www.lho.org.uk/LHO_Topics/National_Lead_Areas/HealthInequalitiesOverview.aspx

Barriers to Care and Support for GRT communities

- In many localities GRT not included in health statistics – optional category re use of 16+1 codes despite repeated recommendations – nb PHE indicate that NHS Data Directory codes will change in coming years..
- Training needs of staff in hospital settings – limited information on GTR culture/practice (cf: DH/Inclusion Health report 2016: Lovegrove & Davis)
- No national GRT health strategy included in the UK NRIS recommendations (see NFGGLG/Ryder/Cemlyn, 2014; TM health briefings; Greenfields & Brindley, 2016).
- Sparse individual good practice in some locations CCG-led and/or NGO driven – cf ‘Movers and Shakers’; BANES – older people’s health checks and discussion on supported ageing on boats..

Costs of Poor Quality Care

- Human cost (pain, suffering, avoidable mortality)
- Impact of diminished trust in services resulting from 'word of mouth' transmission of poor care experience
- Excess cost to the NHS resulting from late treatment of preventable condition (see further <http://www.leedsgate.co.uk/wp-content/uploads/2013/06/Cost-Benefit-Analysis-report-Gypsy-and-Traveller-Health-Pathways.pdf>) [estimated cost over 1 year – non-specialist health pathways > £20,000 per client]
- Impact on staff skills/trajectories/empathy

Good Practice Examples

- BANES – CCG commissioned follow-up outreach service to GRT/Boaters following 2013 study (Greenfields et al,) using specialist experienced staff. (Service renewed 12/2015 – report forthcoming 2016)
<http://kanda.boatingcommunity.org.uk/%EF%BB%BFnew-welfare-service-provides-advice-and-support-for-liveaboard-boaters/>
D Mangaloiu
- Doncaster practice – use of health ambassadors from Gypsy communities; longer appointments; opportunistic screening/immunisations, hand-held medical records for nomadic travellers, flexible appointments: Immunisation levels 4% in 2003 to > 70% 2014. 2004, 0% cervical smear tests, 55%, 2014. <http://www.gponline.com/gps-improve-healthcare-travellers/article/1325098>

- Opportunistic screening and ‘pop-up clinics (community outreach) has been effective in identifying GRT populations at risk enabling onward referral (Wrexham health study – cardio-vascular disease and diabetes screening, Robert et. al. 2007; screening at Gypsy ‘horse fairs’ e.g Appleby, etc.). Edinburgh ‘Keep-Well’ scheme/NHS Lothian found dedicated health workers going onto sites and roadside encampments to work with local Travellers identified/reduced risk factors substantially: [http://www.parliament.scot/S4_EqualOpportunitiesCommittee/Inquiries/JamieLambieGypsyTravellerNHSLothiansummaryNovember2011\(2\).pdf](http://www.parliament.scot/S4_EqualOpportunitiesCommittee/Inquiries/JamieLambieGypsyTravellerNHSLothiansummaryNovember2011(2).pdf). Durham has funded community health advocates (from within GRT communities): <https://www.youtube.com/watch?v=et7zqedtEY0>
- Tailored and targeted maternity services (including on-site drop-ins and translator availability at Roma outreach groups) supported by Gypsy/Traveller health advocates have proved effective in improving outcomes for GRT populations. Service offered culturally-alert maternity pathways; fast-tracking for ‘at-risk’ women and longer appointments and was found to increase uptake of maternity services and engagement at an earlier stage in Leeds (Bennett, 2013) <http://www.dmu.ac.uk/documents/business-and-law-documents/research/cchr/sarahbennettintegratedcarepathwaysfortravellersinleeds.pdf>

'Public Health' policy 'toolbox'

- 'Joined Up' working: RR(A)A 2000: general duty to promote race equality + Care Act 2014 'promotion of wellbeing' duty. Health & Social Care Act 2012 duties specific groups
- Emphasis to 'change-makers and influencers' that Public Health as an over-arching concern: involving partnership across communities and between professionals see Public Health England/NHS England priorities as well as joint-commissioning
- Some fast-tracking of 'vulnerable groups' (G/T) possible without specialist commissioning e.g. 2009 guidance: https://www.pcc-cic.org.uk/sites/default/files/articles/attachments/ehrg_gypsies_and_travelle rs_pcsf_190509.pdf
- Gill et al (RGCP, 2013) have developed an evidence-based commissioning guide, which emphasises best practice in delivering services to Gypsies and Travellers and other hard-to-reach groups. https://www2.rcn.org.uk/_data/assets/pdf_file/0006/555081/RCGP-Social-Inclusion-Commissioning-Guide_ashx_2.pdf
- See further RCN publications on nurses to vulnerable groups: <http://www.rcn.org.uk/professional-development/publications/pub-004378>
- And Inclusion Health recommendations on training for professionals (2016): https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/490851/NIHB_-_Inclusion_Health_education_Executive_Summary_accs.pdf

Good Practice Recommendations

- Embed cultural competence into training of staff pre and post-qualification (e.g. CPD points as incentives)
- Ensure Key staff with specific experiences/competences are identified in within teams and across localities (community staff) + resource library
- Engage with CCGs/ in relation to joint commissioning – and across areas to save on resources
- Specialist outreach services/direct access by pt. and ‘one stop shops’ for vulnerable groups staffed by ‘experts’ with internships/rotations for other clinical staff.

Good Practice (2)

- Community trained advocates (cf: DH Pathfinders funding stream)
- Enhanced links to localised projects (e.g clinics/drop-ins within NGOs)
- Outreach workers (who may or may not be clinically trained)
- Enhanced information provision/sharing and service delivery across disciplines
- Appropriate commissioning – and input into that process by front-line staff
- Access to resources appropriate to meet needs of local communities – and information on staff with specialist contacts/knowledge/languages
- **READ AND STUDY!!!**

QUESTIONS??

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