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Contextualising, Identifying and Meeting the Health Needs of Gypsy, Traveller and Roma Communities

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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).

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.

Comparing the UK to Wider Europe

- Quality of data varies significantly across member states re health status of Roma.
- 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)
- Emergent data (Greenfields et. al., 2016) forthcoming suggests that Roma in UK may over time experience improved health status re access to NHS but at present problematic barriers to care exist e.g. social work interventions in relation to malnourished migrant Roma children.

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 Gypsies, Travellers and Roma and non-GTR peoples 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.

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.

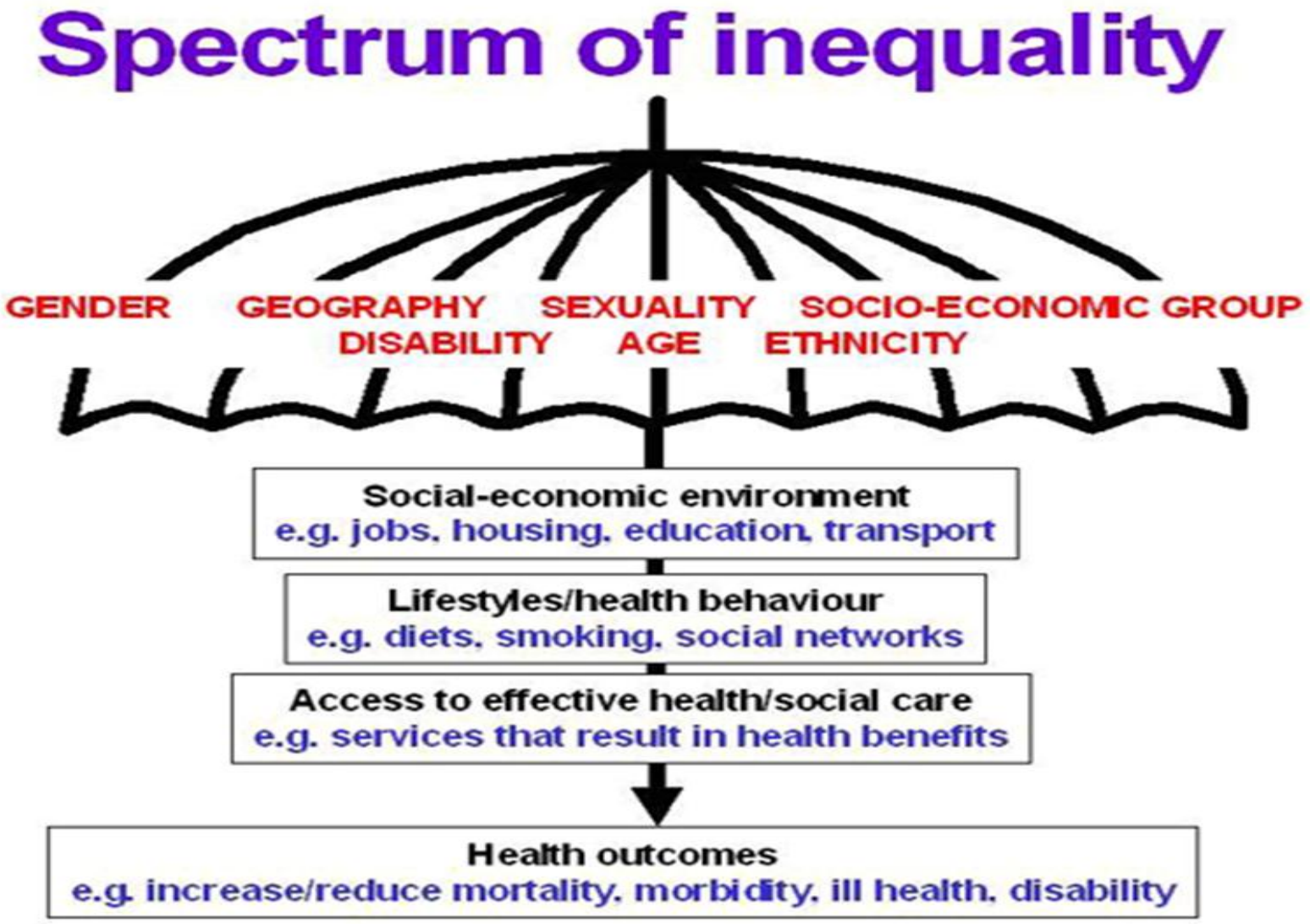

Image courtesy of London Health Observatory
http://www.lho.org.uk/LHO_Topics/National_Lead_Areas/HealthInequalitiesOverview.aspx

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 NFGLG/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/
- 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

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.

QUESTIONS??

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