



# Health on the Margins – commissioning to tackle health inequalities in Gypsy and Traveller communities

Thursday 26th February 2015

Conference Report

#healthonthemargins

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## Introduction

The conference, *Health on the Margins – commissioning to tackle health inequalities in Gypsy and Traveller communities*, shared learning from [Leeds GATE](#) and [Friends, Families and Travellers'](#) joint Department of Health Inclusion Health project to map and influence commissioning structures in the new health architecture.

English Gypsy and Irish Traveller people are among those experiencing the most significant inequality in healthcare access and outcomes in the UK, including low life expectancy, high co-morbidity, poor mental health, poor infant and maternal outcomes.

Health inequalities are estimated to cost the UK economy £70 billion every year according to The Institute of Health Equity at University College London. In seeking to address this, the Health and Social Care Act (2012) put in place legal duties on Clinical Commissioning Groups to reduce health inequality.

The conference focused on commissioning outcomes for Gypsy and Traveller people, exploring ways that improved health and wellbeing outcomes, and reduction of costs associated with health inequality, can be secured via integrated and culturally sensitive commissioning and service provision based in effective local relationships.



## Welcome

**Tom McCready - Conference Chair**

**"If I had a magic wand... I would get people to walk a mile in each other's shoes"**

Tom described his experience as a Health Development worker and how this had taught him to try to understand his own difficulties as a Gypsy man, but also to recognise the difficulties faced by those attempting to deliver health care.

You can see all the slides from the conference [here](#)

## Addressing the cost of health inequalities

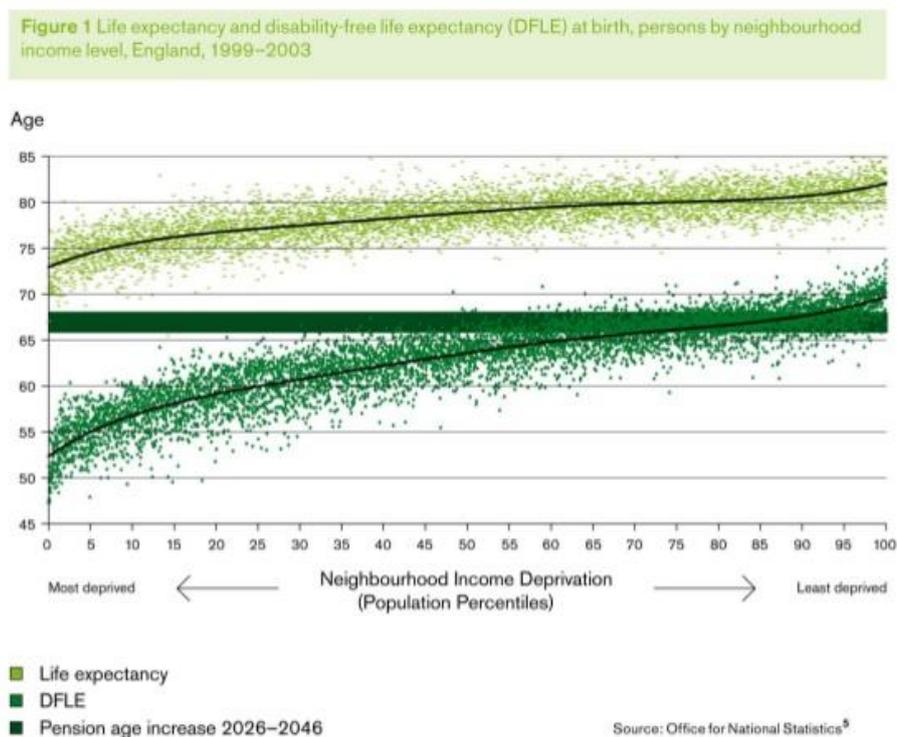
Dr Jessica Allen, Deputy Director, Institute of Health Equity,  
University College London

**“If I had a magic wand... I would invest in prevention and delivering the Marmot principles”**



### Key points

- Dr Jessica Allen presented research from the [Marmot Review, 'Fair Society Healthy Lives' \(2010\)](#) that demonstrates how there are significant avoidable health inequalities across the social gradient. For the health of those 'at the margins' these inequalities are most severe.



- Income inequality leads to health inequality; we need to create fair employment and good work for all.
- £70 billion a year is the total cost of health inequality in England.
- Whilst there are economic benefits to addressing health inequalities, action is a matter of social justice that goes beyond economics. Health inequality is the worst inequality of all and the economic costs are to individuals, communities and society.
- Having control over your life promotes mental and physical health.
- We need more evidence of cost-effectiveness but costing the efficacy of health interventions costs money too.

## Bringing a Gypsy and Traveller voice into the NHS



Olivia Butterworth, Head of Patient and Public Voice, NHS England

“If I had a magic wand... I’d invest in community level support”

### Key points

- Olivia reminded us that the NHS is a social movement founded on a set of principles and values to serve patients and the public
- NHS England is working to support CCGs to get patient participation and involvement right and has produced the [Transforming Participation in Health and Care toolkit](#).
- NHS England and CCGs have legal duties to reduce health inequalities in access and outcome. The NHS England board also have a legal duty to involve patients.
- [NHS Five Year Forward View](#) makes a commitment to providing patients with greater control over their health and social care, supporting community volunteering, carers and forming stronger partnerships with the voluntary sector.
- [NHS Citizen](#) is a platform that is being developed to gather patient views via the internet in order to inform NHS decisions and promote culture change.



- Olivia made a plea to go to where people are, where they are comfortable and feel safe to talk, don't expect communities to come to you.
- Olivia acknowledged the value of grants rather than contracts that leave the voluntary sector free to get on with what it does best. NHS England has just published [Guidance on the use of the grant funding agreement](#) for CCGs.

## Applying learning from commissioning for marginalised groups

Dr Ann Marie Connolly, Director of Health Equity and Place for Public Health England

**“If I had a magic wand... I’d wish for parity of esteem so that talking about mental health was as easy as talking about diabetes or heart disease but I’d also invest in prevention”**



### Key points

- Dr Ann Marie Connolly outlined the main health inequalities Gypsies and Travellers face – lower rates of GP registration, poor general health, higher rates of long term illness, higher smoking prevalence, poor birth outcomes and maternal health and low child immunisation rates.
- Joint Strategic Needs Assessments and Health and Wellbeing Strategies are key to keeping health inequalities at the top of the agenda. These documents should include all the community, including Gypsy Travellers.
- Dr Ann Marie Connolly drew our attention to the following reports -
  - [Standards for commissioners and service providers Version 2.0](#) – this includes standards for providing services to Gypsy Traveller communities
  - [Hidden Needs Identifying Key Vulnerable Groups in Data Collections: Vulnerable Migrants, Gypsies and Travellers, Homeless People, and Sex Workers](#) – this includes suggestions for overcoming the problem of identifying ‘hidden’ communities
  - [Promising Practice: Enabling better access to primary care for vulnerable populations – examples of good local practice](#) – this includes an example of the Market Harborough practice in Leicestershire that built
- There is a need for an integrated approach to universal and specialist services
- A new Public Health England report offers guidance on '[community centred approaches](#)'

## The National Gypsy and Traveller Health Inclusion Project



Helen Jones, Leeds GATE

**“If I had a magic wand rather than having access to only one generalist ‘gateway to care’, I wish I could have been directed to people, be that lay people or clinicians, who had specific experience of my particular problem and to who I could chat regularly and easily”**

### Key points

- Gypsy Traveller organisations need longer term sustainable funding to continue their work. Localism within the new health architecture threatens the sustainability of our work.
- Vulnerable groups are excluded in many ways but they are not helpless, we need to work in a way that respects and supports the assets that people have.

- Investment must be made in improving health at the 'furthest margins', rather than in the 'comfort zone' where people are already engaged. Helen points out that investment in health for the most marginalised does not 'trickle out' from investment in those less marginalised.

For more information read the final report [The National Gypsy and Traveller Inclusion Health Project 2012-2015](#) and [Gypsy and Traveller Health: Who Pays? A cost-benefits analysis report, Leeds GATE, May 2013](#) and you can read Helen's speech to the conference [here](#).

## Influencing local commissioning

**Dr Peter Ilves, GP Principal, Clinical Lead for West Wandsworth Locality Commissioning Group, and Lead Primary Care Consultant for Big White Wall**

**“If I had a magic wand I would create an environment where we could be honest and open about our mental health”**

### Key points

- 90% of medical consultations occurring in primary care settings. The pressures on primary care are increasing with people presenting with more complex needs.
- The elements of the health system continue to be isolated from communities, especially from 'seldom-heard' communities
- To influence commissioning now your commissioners priorities and demonstrate the value and mutual benefits of your work

## Monitoring and evidence based commissioning for Gypsy Traveller health

**Zoe Matthews, Strategic Health Manager, Rachel Wemyss, Policy Officer & Michelle Gavin, CCG engagement worker from Friends and Families of Travellers**

### Key points

- Evidence-based commissioning is a sound principle but problems arise when there is a lack of ethnic monitoring for Gypsy Traveller people using health services and an under-developed evidence base for health intervention.
- Whilst there are pockets of good practice, the inclusion of Gypsy Traveller health and social care needs in Joint Strategic Needs Assessments (JSNAs) is currently patchy nationally. See [Inclusion of Gypsy Traveller health needs in Joint Strategic needs assesments: a review, February 2015](#) for more details.
- The NHS data dictionary must be updated to include 'Gypsy/Traveller' in line with the 2011 Census. But, inclusive practice takes more than just boxes on forms, an environment in which Gypsies and Travellers have the confidence to declare their ethnicity, free from fear of prejudice, must be fostered.
- Health & Wellbeing boards, CCGs and public health teams should refer to [RCGP guidance on improving access to health care for Gypsies and Travellers, homeless people and sex workers and homeless people](#) and [Inclusion Health guidance on Commissioning Inclusive Services when producing JSNAs](#).

- A data and ethnic monitoring gap need not be a justification for inaction. Data on health and social care needs can be gathered whilst meeting the current, basic needs of community members. The model of Brighton & Hove CCG who fund an FFT community engagement worker is an example of this.
- A help card was produced with the Gypsy Traveller community in Brighton to address the barriers to accessing primary care the community had identified. You can download a [printable version of the FFT Literacy Help Card](#) to use and share with Gypsy Traveller patients and clients.



- I need help filling in forms
- I need help reading and understanding
- I would like a GP who is the same gender as me
- I would like to speak to someone confidentially

## Gypsy Traveller community speakers

Throughout the morning we heard the personal testimonies of Gypsy Traveller community members.

- Elizabeth Elliot talked about her worry that she would develop arthritis as she knew that this was a condition Gypsy women developed at a younger age. She called for better and more accessible information about the condition so she would be aware of the warning signs of the condition and what treatment was available.
- Mandy Lowther spoke of the inaccessibility of health for young men like himself and asked for health services nearer to Gypsy Traveller people's homes.
- Eileen Lowther spoke of the fear of cancer in Gypsy Traveller communities and the need to help people have confidence to access help sooner. Doctors need to be welcoming.
- Valerie Elliot described how her Mother died and her Father was badly injured when she was a child. She spoke of the need for continuity of care and better support for carers where-ever they live.

## Questions, comments and responses

What about the role local authorities play in addressing health inequalities? Are we letting them off the hook too easily?

What can Public Health England do to support the needs of over 25,000 Gypsies and Travellers with no legal place to stop due to a national shortage of transit sites? These people have no access to toilet facilities with long term health implications in terms of bowel and bladder problems.

Why can't the NHS include 'Gypsy/Traveller' on ethnic monitoring forms?

## Workshops

### 1 – Using Asset Based thinking to engage with Gypsies and Travellers

Ellie Rogers, Claire Graham, Eileen Lowther, Leeds GATE

#### Key learning

- Gypsy and Traveller communities have many assets which we can draw on in delivering solutions to intractable problems which these communities face, often people are incredibly resourceful as they have had to be to survive in the face of discrimination and a lack of access to services.
- Communities should not have to present themselves as helpless in order to garner attention and funding, this narrative is dangerous, backing up stereotypes and not providing effective challenge to systems.
- Change will be most effective when community assets are recognised
- Adhering to the principle of nothing about me without me communities need to be involved at the level of decision making and service design
- Involving all stakeholders in a process of design is co-production, leading to better service provision and saving money as culturally appropriate services best deliver preventative care. See Cost Benefit Analysis <http://www.leedsgate.co.uk/wp-content/uploads/2013/06/Cost-Benefit-Analysis-report-Gypsy-and-Traveller-Health-Pathways.pdf>
- Co-production can't happen without all stakeholder staking an Asset Based approach, examining internal value systems and facilitation of spaces where these process can happen

#### Discussion

We explored the meaning of Asset Based Community Development, coming to our own definition and sharing definitions we had made at Leeds GATE. We looked at a variety of case studies and explored how services could approach them in an asset based way, who they needed to involve and what solutions might look like. We discussed how asset based thinking is an approach which needs to be fostered in a range of stakeholders to make progress and that solutions look different depending on the particulars of a situation.

### 2 – Advice and advocacy: tools to reduce health inequalities

Zoe Matthews and Rachel Wemyss, Friends, Families and Travellers

#### Key learning

- The professional perspectives of workers impacts on the support that they are able to offer doctors, advice workers, health improvement workers and mental health support worker all come to people with their own agendas. The workshop explored how different professionals would aim to meet the needs of a Gypsy Traveller woman on an authorised site.
- Basic needs must be met before behavioural change can be made. The priorities of Gypsy Traveller people are likely to differ from those of professionals. Smoking cessation may not be the most relevant priority for a woman living on an unauthorised encampment, suffering with 'bad nerves', domestic abuse and trying to raise a family.

- A greater level of flexibility is needed to allow health and social care professionals to meet the needs of Gypsy Traveller communities.
- FFT works with an empowerment model supporting Gypsy Traveller people and taking a whole-family approach

### 3 – Culturally competent dementia care –

Dr Mary Tilki/Charlotte Curran, Irish in Britain Cuimnhe Project

#### Key learning

- Suspicion and past negative experiences with insensitive services can cause Gypsy Traveller people to be unwilling to engage with dementia care.
- Lack of knowledge and evidence on Gypsy Traveller communities and dementia leads to poor commissioning
- Mainstream services do not cater for cultural diversity in terms of catering for gender difference, language and dietary needs.
- Person centred dementia care and culturally sensitive dementia care is the way forward – every person is worth of being valued and respected.

### 4 –The role of trust in promoting health

Dr Alison McFadden, Research Fellow, School of Nursing and Midwifery, Dundee University

#### Key learning

- The more you can build up trust the better the outcomes in terms of better access to and use of health services, satisfaction with doctors etc.
- There are two types of trust – ‘Social Trust’ which is based on people’s intentions and values, and ‘confidence’ which is based on experience and current performance. Social Trust can be resilient but confidence is quite a fragile thing and can easily be damaged by poor performance.
- We develop trust by –
  - Understanding that it is a two way street
  - Working through trusted mediators
  - Recognising that it takes time to develop
  - Delivering on promises

#### Discussion

There was discussion of the pros and cons of specialised services versus mainstream services. Yvonne MacNamara, Traveller Movement, said she was in favour of mainstreaming services and didn’t like an ‘apartheid’ system of separate services. Chris Whitwell, Friends, Families and Travellers agreed that there must be a distinction between specialised services and specialised agencies. A specialised agency such as FFT or TM plays an important role in acting as a conduit between the community and the mainstream services. At the same time there is a need to build the capacity of the mainstream services to deliver more accessible, culturally appropriate services.

## 5 – MECOPP

Staff and Volunteers from MECOPP (Minority Ethnic Carers of People Project), based in Edinburgh, described some of the creative ways they have worked with Gypsy/Travellers across Scotland on mental health. This has included using Community Conversation tools, creating Storyboards, running drama workshops and producing the the Moving Minds exhibition and book. There was a film and discussion about how to tackle the stigma in talking about mental health and using drama to bring people together to discuss sensitive issues, and support each other to resolve problems.

### Key learning

- \* Drama can be a very effective tool and builds confidence.
- \* Take risks - workers should not be afraid to try innovative or unfamiliar techniques with their clients.
- \* Many tools are transferable
- \* The all-important need for trust
- \* Community members described their pleasure at participating with the project and the improvements this had brought in their lives.

## Feedback from the Conference

Overall delegates who gave feedback rated the conference 67% Excellent and 33% Good.

Delegates commented that the conference was useful and informative, providing information and ideas that they could take back to their own localities.

“The conference created a positive atmosphere where people felt they could share experiences, there was levelling out between the different people attending, there was opportunity to speak to senior people about your ideas. It felt like fertile ground for making change happen”

“Attending the Leeds GATE ABCD workshop has changed my working practice. I’m now trying to take an asset based approach my work”

From Twitter.. “Excellent conference today, food for thought about JSNAs & HWB reflecting Gypsy and Traveller local need”

We will continue to tweet using #healthonthemargins please join us.

**Many thanks to everyone who attended, and joined us on Twitter, and helped to make the event such a success.**

Check out the project report [here](#) and the conference slides [here](#)

**And finally, once again many thanks to Jane and her team at [Central Conference Consultants](#) for their excellent work behind the scenes which made the whole day such as success.**