



THE NATIONAL GYPSY AND TRAVELLER HEALTH
INCLUSION PROJECT 2012 - 2015

The National Gypsy and Traveller Health Inclusion Project 2012-15

a report compiled by

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FOREWORD

I am delighted to introduce this report prepared by Friends, Families and Travellers and Leeds GATE as the culmination of their joint National Gypsy and Traveller Health Inclusion Project, funded by the Department of Health's Innovation, Excellence and Strategic Development Grant programme.

The project builds upon the work of Professor Sir Michael Marmot and his seminal report 'Fair Society, Healthy Lives' and the recognition of Gypsies and Travellers as a chronically excluded group within the Inclusion Health agenda.

The report highlights the extent to which the health inequalities experienced by Gypsies and Travellers are firmly entrenched, and that while the production of policies, guidelines and good practice frameworks are important, they are not necessarily sufficient to achieve the change needed to improve the health and wellbeing of these communities. Crucially, this report adds practical recommendations which set out the mechanisms through which positive and sustainable change may be achieved.

I hope that the report will be read and discussed by policy makers and commissioners at all levels and shared within health & Wellbeing Boards, Clinical Commissioning Groups and local Healthwatch groups. These bodies all have a part to play in reducing the health inequalities that exist within our society and this report provides some valuable insights as to how to go about the task.

Dr Ray Earwicker

Senior Policy Manager (Health Inequalities and Inclusion Health)
Department of Health





EXECUTIVE SUMMARY

This project was funded by the Department of Health and was aimed at addressing the chronic exclusion of Gypsies and Travellers across the health economy, supporting the Inclusion Health agenda and leading to improvements in the health of Gypsy and Traveller people in England. Two leading organisations in this field worked to provide a package of commissioning and implementation support to all levels of the new NHS architecture.

The project commenced shortly after the Health and Social Care Act (2012) was published, which for the first time placed an ‘equality duty’ on the Secretary of State for Health. It also came on the heels of publication of The Marmot Report - Fair Society, Healthy Lives. Critically the Marmot Report outlined the significant costs to the public purse generated by health inequities. Subsequent statements by Professor Sir Michael Marmot have indicated his view that whilst investment across the health gradient is required, investment should be targeted proportionally to reduce health inequity where it is most extreme. What data we have tells us that Gypsy and Traveller people are amongst the most vulnerable to health inequity.

The National Gypsy and Traveller Health Inclusion project was never a ‘soft’ project, we were not specifically attempting to generate local good practice (although we have). FFT and Leeds GATE were seeking to observe, and perhaps positively influence, how the new ‘commissioning’ environment would impact on improving Gypsy and Traveller health. As well as providing support, the organisations were able to utilise emerging guidance and commissioning tools to implement changes on the ground and at a local level. This has meant that we have been able to see first-hand how policy has translated into action for vulnerable and marginalised communities, and also where and why it is failing.

Gypsy and Traveller people’s health is important on its own account but we might also view the inclusion of Gypsy and Traveller people’s health, or not, as an exemplar of how the system deals with extremes of health inequity. Our conclusion must be that the new health commissioning system deals with such extremes very badly, often reinforcing, rather than addressing them, with all of the ongoing costs (human, social and financial) thereby generated.

Marketisation and the NHS

We are not convinced that there are market solutions to health inequalities. Structural and cultural change is needed within NHS organisations and beyond to tackle the root causes of avoidable health inequalities.

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The move from Primary Care Trusts to CCGs means there is a less direct route to influence NHS services as commissioners buy services from ‘any qualified provider.’ There is a problematic culture of compliance in that the risk management role of commissioners can cause NHS organisations to act evasively rather than co-operatively when challenged regarding what action they are taking to address health inequalities.

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Investment in ensuring equitable access to primary care for Gypsies and Travellers and other Inclusion Health groups is an ethical imperative that makes financial sense in the long term. A market for ‘innovative solutions’ that improve health outcomes and save CCGs money in the short term will not get to the root of the problem.

The New Economics Foundation (nef) report The wrong medicine: a review of the impacts of NHS reforms in England found that ‘market mechanisms and privatisation in healthcare systems have largely inconclusive or negative effects on quality and equity in healthcare.’¹

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¹ New Economics Foundation, The wrong medicine: a review of the impacts of NHS reforms in England - http://b.3cdn.net/nefoundation/295a135f8d05864461_87m6iyt2s.pdf



Marketisation of the voluntary sector

Simon Stevens' aspiration in NHS England's Five Year Forward Review for 'stronger partnerships with charitable and voluntary sector organisations' recognises that the voluntary sector are often 'better able to reach underserved groups, and are a source of advice for commissioners on particular needs.'² However, in the current climate small voluntary sector organisations who are close to the ground and connected to local communities are struggling to survive, competing against each other for scarce funding against national charities with bid-writers, policy, campaigning and fundraising teams.

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Generic providers who do not have relationships with Gypsy Traveller communities can find themselves unable to fulfil contract requirements to engage with these communities. Organisations must build their capacity to provide services that are accessible to all communities and where necessary 'buy in' the time and expertise of Gypsy Traveller organisations who are trusted by community members.

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Where is the capacity in the voluntary sector to hold local CCGs and HWBs to account?

Public Health in local authorities is accountable to the public. However, health inequalities do not garner much public interest and Gypsy Traveller health issues specifically even less so. National direction and oversight is needed as democratic processes do not necessarily promote equality and inclusion. Localism within the NHS is supposed to improve accountability and legitimacy; but a lack of political will risks impeding critical work to address health inequalities experienced by socially excluded communities.

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Inclusive health services cannot be achieved through inclusive documentation alone, although this is an important first step. It is relatively easy to write a visionary document making an organisational commitment to equality, diversity and human rights but delivering services that are rights-respecting and fully inclusive of all communities takes time and sustained investment.

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It is in this context that we have produced the following recommendations.

² NHS England, Five Year Forward Review, <http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

RECOMMENDATIONS

Government Ministers and Departments, including but not exclusive to the Dept of Health, the Dept of Communities and Local Government and the Department of Work and Pensions.

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The social and economic conditions in which we live lead to avoidable health inequity, increasing risk of illness and preventing access to treatment. The root causes of these inequalities need to be addressed in terms of secure homes, access to education, good employment, financial inclusion and citizenship. A healthy society requires a living wage and a welfare state which provides an effective safety net. It would appear that currently the cost of health inequity is either misunderstood or disregarded, especially where budgets are allocated within departmental silos. Difficult and potentially unpopular choices require more than courageous leadership to resolve. The impacts of localism, austerity and the marketisation of public services damage the principle of universal access, which in turn is likely to reinforce inequalities.

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The responsibilities to address wider determinants of health would be made more explicit through the actioning of a UK Roma Integration Strategy as required by the European Union Framework for Roma Integration. Roma civil society groups recently called for evidence of progress on this agenda. See *Gypsy Traveller, and Roma: Experts By Experience: Reviewing UK progress on European Union Framework Roma Integration Strategies*³

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The costs of failing to address health needs should be understood and the profile of the issues raised. Health inequities created by departmental policies other than those of DH should be mapped and addressed (for example in the under-provision of sites nationally and the disproportionate refusal of planning permission for Gypsy Traveller applicants)

3 http://ww2.anglia.ac.uk/ruskin/en/home/news/roma_report.Maincontent.0007.file.tmp/Experts%20by%20Experience.pdf



NHS England / Public Health England

Much good work has taken place since the Health and Social Care Act 2012. Despite obvious challenges we have seen senior leaders speaking directly to community members and championing the needs of people experiencing inequality in accessing healthcare. We need to remain optimistic and build on progress made:

Promote and fund opportunities for effective means for dialogue between communities and NHS England/PHE leadership developing 'system leaders' to drive forward action on health inequalities and community based action.

Promote and invest in collaborative partnership work between communities, civil society groups, local public health and CCGs using advocacy, co-production and asset based approaches to reducing health inequity 'at the margins', i.e. Gypsies and Travellers, vulnerable migrants, sex workers and homeless people

Publicise the business case for addressing health inequality and for 'People Powered Health', supporting local providers to 'improve the health of the poorest fastest' and encouraging investment in community based action and supporting sustainability of 'trusted organisations'.

Promote and professionalise care navigation and health mediation roles in healthcare settings to improve registration, access and health literacy, as well as generally developing routes into employment in healthcare for Gypsy and Traveller people.

Instruct the Health and Social Care Information Centre to include 'Gypsy Traveller' in NHS data dictionary in line with 2011 census.⁴

Clarify GP duties of care with reference to registering Gypsy, Traveller and Roma patients, especially for those who have no fixed abode. NHS entitlement is based on residency in the UK, rather than nationality, and a lack of permanent postal address should not be a barrier to accessing permanent GP registration.

Update the Primary Care Service Framework for Gypsies and Travellers 2009

Health & Wellbeing boards and CCGs

Much has been invested in local health economies. There are excellent illustrations of emerging best practice, where the voice of community members is being genuinely sought and heard. We need to find ways to incentivise investment in reducing health inequality at the local level.

Health and Wellbeing Boards should have a named Inclusion Health lead responsible and accountable for coordinating action to improve the health of marginalised communities, including Gypsy/Traveller people, in the work of the Board.

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Transparent processes for engaging with the voluntary sector in producing JSNAs should be developed with timelines for planned refreshes published and accessible to the public

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Ensure that local assessment work (JSNA refresh etc.) provides information which is sufficiently robust, engages with Gypsy Traveller communities and enables progress to be measured.

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Targeted patient and public engagement work funded by CCGs and local authorities to engage with Gypsy Traveller communities, inform commissioning and improve access to primary care

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CCGs and local authorities to ensure their equalities monitoring for all services includes 'Gypsy/Traveller'

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⁴ See Traveller movement Note on Inclusion of Gypsy Traveller in NHS Data Dictionary, March 2014, <http://www.travellermovement.org.uk/wp-content/uploads/2014/11/Traveller-Movement-note-on-inclusion-of-Gypsies-and-Irish-Travellers-in-the-NHS-data-dictionary-March-2014.pdf>





Communities and Civil Society

Excellent work is being done by Gypsy and Traveller (and Roma) people and their civil society organisations, leading and supporting examples of national best practice. As with everyone in wider society austerity is having a negative impact on the growth and sustainability of community based action. Whilst making the case for investment in ‘improving health of the poorest fastest’, it is important that we express solidarity with others and a desire for self-help and accountability.

Promote sustainable, resilient, community based action in partnership with statutory and other services

Be courageous in engaging with, and developing innovative asset based responses to community wide challenges.

Identify common ground between groups of marginalised individuals, promoting ways that solutions for one group can be solutions for all.

Explore how social media can be used to connect Gypsy Travellers and build solidarity between communities

Cross-cutting

Maintain momentum of dialogue sustained by the National Gypsy and Traveller Health Inclusion project steering group by re-grouping as a national Stakeholder Liaison Group

Reward and Recognition policies for valuing and enabling the contribution, whether voluntary, sessional or fully employed, of Gypsy Traveller community members should be adequate and standardised wherever possible

POLICY CONTEXT

The Health & Social Care Act 2012 places a duty on the Secretary of State for health and CCGs to reduce inequalities in access to health services and health outcomes. A commitment to reducing health inequalities exists as an underlying ethos within every element of the health system from NHS England and Public Health England to individual Health & Wellbeing boards and CCGs.

In this context FFT and Leeds GATE have worked strategically and locally to embed provision for Gypsy Traveller health needs into the health system. We have contributed significantly to guidelines intended to support effective commissioning, we have reviewed joint strategic needs assessments, health & wellbeing board strategies, equality and diversity strategies and commissioning plans. Progress has been made in some local areas; however, piecemeal efforts are not appropriate given the severity of entrenched health inequities. It is yet to be seen how the aim of reducing inequities will be achieved without co-ordinated and resourced efforts to target the inequalities faced by Gypsies and Travellers, other Inclusion Health groups – sex workers, vulnerable migrants and homeless people – and other people for whom a ‘one size fits all’ health service is not appropriate or accessible.

The Equality Act 2010 places a duty on all public bodies to have ‘due regard’ for the need to eliminate discrimination, foster good relations and promote equality of opportunity. When commissioning services CCGs and HWBs must be aware that providers must be compliant with the Equality Act when carrying out services on behalf of public bodies. There is a requirement to ensure the robustness of organisations’ equality and diversity policies and their commitment to providing a non-judgemental service to all communities, including Gypsies and Travellers, when awarding contracts.





THE INCLUSION HEALTH BOARD

The National Inclusion Health Board has played a critical role in leading the Inclusion Health programme by providing expertise, focus and momentum to the agenda, and championing the needs of those most vulnerable to poor health outcomes. There were four working groups with the aim of driving forward inclusive practice in the following areas – data and research, leadership and workforce, provision, prevention and promotion, and accountability (which met only once).

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We have worked with the Inclusion Health board and the Royal College of General Practitioners to produce guidance on producing inclusive JSNAs and commissioning inclusive services.

Inclusion Health guidance Commissioning Inclusive Services: Practical steps towards inclusive JSNAs, JHWSs and commissioning for Gypsies, Travellers and Roma, homeless people, sex workers and vulnerable Migrants⁵

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Royal College General Practitioners guidance Improving Access to Healthcare for Gypsies and Travellers, sex workers and homeless people⁶

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⁵ <https://www.gov.uk/government/publications/commissioning-inclusive-health-services-practical-steps-2>

⁶ <http://www.rcgp.org.uk/news/2013/december/~~/media/Files/Policy/A-Z-policy/RCGP-Social-Inclusion-Commissioning-Guide.ashx>

⁷ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/287805/vulnerable_groups_data_collections.pdf

⁸ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/307376/Promising_Practice.pdf

These practical documents should be used by public health teams, CCGs and HWBS to inform needs assessments and commissioning. The guidance has been well received but it is early days to see its impact on commissioning.

Other Inclusion Health publications include -

Hidden Needs: identifying key vulnerable groups in data⁷

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Promising Practice Enabling better access to primary care for vulnerable populations - examples of good local practice⁸

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Impact of Insecure Accommodation on Gypsy Traveller Health, a study conducted by Traveller Movement to be published soon

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STRUCTURAL CHANGES

Communities and civil society organisations have had to keep pace with extensive changes to NHS structure, although for community members much of this may have been ‘behind the scenes’. In the face of reducing available budgets the necessity to keep abreast of these changes, often simple changes of individuals and processes at a local level, has placed a strain on the capacity of civil society organisations. Additionally in areas where contact with isolated Gypsy or Traveller families had been developed by individual healthcare workers (such as health visitors, public health development workers etc.), changes of staff and process can lead to loss of vital knowledge and relationships.

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We know that leadership is vital to driving forward the health inequalities agenda in a time of austerity and where there is a focus on localism and democratic involvement. Localism presents a practical challenge for civil society organisations looking to influence commissioning decisions and when necessary to hold institutions to account. It is evidently difficult to contact and keep track of developments in 212 CCGs and 130 HWBs.

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We have observed the effect of Health & Wellbeing boards operating in a political environment, usually led by a local authority elected member.⁹ This presents a problem in working to ensure the needs of Gypsy Traveller and other marginalised communities are recognised. Chronic exclusion, stereotyping and structural marginalisation is more difficult to overcome when politicians are attempting to make difficult budgetary decisions, particularly when the issues are viewed as not being popular with the electorate.

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⁹ The Kings Fund, Health and Wellbeing Boards One Year On, http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/health-wellbeing-boards-one-year-on-oct13.pdf

Public health grants to local authorities are calculated based on geographical inequalities. Geographical inequalities are more apparent in data but the need to tackle social inequalities between communities is no less pressing. In allocating resources HWBs and CCGs are in danger of seeking 'quick wins' to show progress against the public health and NHS outcomes framework indicators. However we know that entrenched health inequalities and chronic social exclusion faced by Gypsies and Travellers will take a long term commitment and investment to address.

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Public Health's location within local authorities should make it better placed to improve provision, quality and equality of access to: accommodation, education and employment opportunities. We would hope that Health and Wellbeing Boards could aspire to play a co-ordinating role in action to reduce health inequalities, for example through a 'health in every policy' approach where the health impact of local authority policies is assessed. This approach ensures that local authority policies and procedures are not having a negative impact on health for example through poor conditions on local authority sites or lack of funding for Traveller education services that support access to education. We would support and echo the call from the Homeless Health Matters¹⁰ campaign to extend the legal duty to reduce health inequalities to include local authorities.

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¹⁰ See Mungos Broadway, Homeless Health Matters, Campaign Briefing, <http://www.mungosbroadway.org.uk/documents/5390/5390.pdf>



REVIEWING JSNAs/HWBs

JSNAs are intended to build understanding of local needs, identifying health inequalities to inform commissioning plans made by HWBs, LAs, CCGs and NHS England, and to support individual services to target their resources appropriately.

FFT contacted public health teams and CCGs across the South East, South West, London and East of England to share commissioning guidelines and offer bespoke support with producing inclusive JSNAs. Broadly we have found that the inclusion of Gypsy Traveller health needs in JSNAs is patchy across the country. Without robust and inclusive JSNAs that detail the health and social care needs of Gypsies and Travellers and identify key barriers to accessing services locally, Gypsy Traveller health needs are unlikely to be prioritised by commissioners. Lack of inclusion in JSNAs will lead to the further exclusion of Gypsies and Travellers. See FFT’s full report *Inclusion of Gypsy Traveller health needs in Joint Strategic Needs Assessments: a review* for more information.

Leeds GATE conducted a community health needs assessment using community interviewers. The CHNA was intended to influence the Leeds JSNA and the Health and Wellbeing Strategy and has been included as an example of best practice in updated NICE guidelines about community engagement.

See Appendix 3 for a case study example of Leeds GATE’s CHNA. Asset based approaches to JSNAs are becoming more popular and Leeds GATE are currently piloting the effectiveness of this approach with Gypsy Traveller communities. See Appendix 4 and Leeds GATE website for details.

NHS EQUALITY DELIVERY SYSTEM 2 (EDS2)

EDS2 is a generic toolkit for NHS commissioners and providers to improve services and patient experience whilst fulfilling equalities duties. As refreshed in November 2013, the toolkit stipulates that socially excluded groups should be included in the process along with considerations of how services meet the needs of people and communities in relation to the nine protected characteristics – age, disability, gender reassignment, marriage or civil partnership, pregnancy and maternity, religion or belief, sex and sexual orientation.¹¹

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In engaging with CCGs across the South East and South West FFT found that very few CCGs included Gypsies and Travellers in the EDS or identified Gypsies and Travellers as a community with poor access to services that face prejudice and discrimination. The structure of the Equality Act with its focus on the ‘protected characteristics’, of which race is one of nine, can draw focus away from the reality of lived experience. Gypsies and Travellers may face multiple discrimination or disadvantage as women, as people with disabilities and as members of sexual or gender minorities.

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EDS2 suggests the following outcomes should be worked towards

Better health outcomes for all

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Improved patient access and experience

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Empowered, engaged and well supported staff

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Inclusive leadership at all levels

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¹¹ <http://www.england.nhs.uk/wp-content/uploads/2013/11/eds-nov131.pdf>



We have found it to be crucial that targets sitting under suggested overarching outcomes are sufficiently specific in order to identify priority areas for action. We are concerned that EDS2 may be weak as a tool for prioritising needs; there is a danger that the grading process can reduce the equalities agenda to a 'tick box exercise' to demonstrate apparent compliance with equalities legislation.

Overall the effectiveness of the EDS2 as a tool to address health inequalities appears to be dependent on the commitment of individuals at a local level. Our observations suggest that Commissioners may need to be reminded that equality duties cannot be delegated. This is especially relevant where Commissioning Support Units (CSUs) are producing equality & diversity strategies on behalf of the CCG.



PATIENT PARTICIPATION

Within the re-organised structures of the NHS there is a new focus on patient and public participation with the aspiration of ‘no decision about me, without me.’ As such, Health & Wellbeing boards and CCGs have a duty to engage with the public in developing their needs assessments and commissioning plans.

Whilst the focus on patient participation is a very positive development that is widely supported, in practice it can be a challenge. Patient participation is not a level field and we have seen a strong temptation for officers to rely on tried and tested methodologies, even when it can be seen to be ineffective with some groups, for example via surveys. There would also appear to be a structural reluctance to invest in participation which might ensure engagement of those with ‘the poorest health fastest’. The CCG structures in place for patient & public participation often rely on GP surgery patient participation groups. The people with the time and inclination to engage with these forums are less often those from socially excluded communities. We know that people from socially excluded groups face considerable barriers to participation in forums which rely on traditional structures and procedures. However, rather than employing creative or innovative strategies, there is a danger that marginalised groups like Gypsies and Travellers, who continue to be referred to as ‘hard to reach’ or ‘seldom heard,’ can be regarded as ‘difficult.’

We have seen that pro-active engagement with Gypsy Traveller communities is needed to establish trust and credibility. CCGs need to recognise the role of patient participation in reducing health inequalities when allocating funds and a commitment to sufficiently resourcing engagement is necessary. The longevity and sustainability of targeted projects is key to ensuring relationships are maintained. While the role of trusted organisations can be critical to reaching communities, representation from Gypsy Traveller organisations cannot replace genuine engagement with Gypsy Traveller community members themselves.



The workforce of the NHS itself is understood to be an important link to all the communities it serves. There are Gypsies and Travellers working in the NHS. However, it is common for people to conceal their ethnic identity at work to avoid opening themselves up to prejudice and discrimination. Whilst there is a critical need for formal training to raise cultural competence and effectiveness, Gypsy and Traveller people, who are confident to declare their ethnicity, can make a significant contribution to changing practice. Whilst generic care navigator roles are beginning to appear, as yet we can find no evidence of these roles being developed to target specific marginalised groups except for the Pathways service for homeless people leaving hospital which has been trialled by the University College London Hospitals.¹² As above, there is a danger that generic navigators will not reach Gypsy Traveller communities.

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In addition to influencing service access and delivery, patient voice is vital in ensuring patient safety. There is currently a greater recognition that improved patient involvement can lead to higher quality care and patient safety, with patients more engaged and in control of their treatment. Nevertheless, the potential of patient participation to tackle social exclusion, reduce health inequalities and increase patient safety and satisfaction needs to be developed.

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¹² University College London Hospital Trust: Homeless Care, http://www.pathway.org.uk/wp-content/uploads/2013/02/UCLH_Homeless_Care_FINAL1.pdf

HEALTHWATCH

Healthwatch has been established as an external body aimed at enabling the public to influence the effectiveness and accessibility of their local healthcare services.

However local Healthwatch organisations often have little expertise in directly working with isolated 'seldom heard' communities and as such rely on the strength of the local voluntary sector. In common with many of the structures aimed at increasing patient voice or identifying and addressing health inequality, Healthwatch rely on the knowledge, commitment of interest or individuals locally. There is a danger that those with voice direct the work of this watchdog, given that information that directs its priorities is less likely to highlight issues for those already without voice in the system. For example, if monitoring is not being effectively collected trends will not highlight issues for Gypsy Traveller communities and if work is directed by complaints procedures that are already inaccessible to seldom heard groups, these voices won't be heard.





WHAT WE HAVE DONE

The National Gypsy and Traveller Health Inclusion project identified a number of themes we wished to explore. We were concerned to both capture a ‘big picture’ of how the changing health architecture influences improving Gypsy and Traveller people’s health, at the same time as seeing how changes affected provision at the local community level. This report attempts to capture these themes.

The separate case studies and appendices detail the work that this project has accomplished:

FFT Influencing Work

FFT Case Study examples

Appendix 1: Brighton & Hove CCG Community Engagement Project, Friends, Families and Travellers

Appendix 2: Bath North East Somerset CCG Gypsy Traveller Outreach pilot, Friends, Families and Travellers

Leeds GATE Case Study examples

Appendix 3: Community Health Needs Assessment

Appendix 4: Cottingley Springs Health Improvement Group

We have also produced the following reports -

FFT report Inclusion of Gypsy Traveller health needs in Joint Strategic Needs Assessments: a review

Leeds GATE Cost Benefit Analysis - “Gypsy and Traveller Health - Who pays?”

Health Pathways: Cost-Benefits Analysis Report

CONCLUSIONS

The conclusion of our three year Gypsy and Traveller Health Inclusion project is that significant progress to ensure Gypsy and Traveller health equity has been difficult to find. Despite instances of good practice, using Gypsy and Traveller people's experiences, the status quo will not deliver significant improvement to the health of the poorest fastest. We have to be brave enough to be frank about this, whilst remaining optimistic and continuing to identify and use the levers available to us. We know that there is extensive commitment to increasing health equity amongst leaders, opinion formers and ground level practitioners.

Austerity measures may be the single most significant threat to progress made and particularly the sustainability of 'trusted intermediaries' including civil society groups like ours presents a pressing challenge which must be recognised. The new health architecture presents both opportunities and threats. Perhaps the main threat that we perceive is that structural chronic exclusion remains entrenched and that not enough leverage is being brought to bear to enable significant advances, despite excellent work to produce guidance and to promote best practice.

The opportunities that the 2012 Act presents are real. The new equality duties placed upon the Secretary of State for Health and other bodies are significant although they could be further strengthened. There is still an urgent need for clarity, accountability and investment in improving access to primary care for Gypsies and Travellers. It is clear however that it requires sustained effort at all levels, including by community members themselves, to really capitalise on the opportunities that we have made. It would be a tragedy if the progress made so far could not be maintained and pursued. The potential financial and human costs of inaction are grave.





FRIENDS FAMILIES AND TRAVELLERS

National Influencing

FFT has acted as an advisor on the following groups –

Former Ministerial Advisory Group on Equalities and Mental Health, chaired by Rt Hon Paul Burstow and Rt Hon Norman Lamb

National Equalities Advisory Group on Personal Health Budgets

National Equalities Advisory Group on Improving Access to Psychological Therapies (IAPT)

One meeting of the Assurance and accountability Working Group on Inclusion Health

NHS England

FFT supported Citizens Assembly development

FFT raised concerns about the care.data programme about the disproportionate risk of damage of trust relationship between the NHS and Gypsies and Travellers and the importance of ensuring people with no fixed abode are informed of changes to the way their data is collected and shared.

Innovation Health and Wealth consultation response

Equalities and Health Inequalities Draft Strategy consultation responses

NHS Accessible Information Standard consultation response, February 2014

Call to Action consultation on improving dental & oral health consultation response, April 2014

Call to Action consultation on Eye Health consultation response September 2014

Working Group on NHS Commissioning Assembly Toolkit: Working to reduce health inequalities, August 2014

Public Health England

FFT attended PHE Healthy People, Healthy Places launch event, November 2013

NHS Health Check priorities for research consultation November 2014

Department of Health

Migrant Access to the NHS, August 2013 – FFT raised concerns about the impact of proposals to charge migrants for accessing NHS services. Further complication of GP registration would impact on resident Gypsy Traveller communities and newly arrived Roma disproportionately as these communities already face significant barriers to registering with GPs, especially if no fixed abode or do not have I.D documentation.

CQC consultation fundamental standards, April 2014

Draft Guide for Patients for making complaints and giving feedback, August 2014

FFT are an Information Standard registered organisation

National Voices

FFT Strategic Health Manager, Zoe Matthews is a trustee of National Voices advising on Equalities and Inclusion (2nd Term)

FFT fed into the following consultations through National Voices

Addressing inequalities in the NHS Outcomes Framework / Aug 2014

Health Premium Incentive Scheme and public health allocations, September 2014



NICE

Public Health Quality standards library, December 2013

Public Health Guidance on community engagement: approaches to improve health and reduce health inequalities, February 2014

Oral health promotion approaches for dental health practitioners, April 2014

Oral health promotion approaches for local authorities, May 2014

Other Influencing work

Institute Health Equity UCL consultation 'Implementing the Marmot Review Locally', February 2014

Healthwatch England consultation on vision, mission and strategic priorities, February 2014

Welsh Government consultation 'Travelling to better health: Guidance for Health Practitioners on working effectively with Gypsies and Travellers, October 2014

FFT presented at the General Medical Council Patients at Risk panel event sharing good practice on improving access to primary care for Gypsies and Travellers, September 2014



FFT supported researchers from Northumbria University to evidence the value of outreach services in improving Gypsy Traveller health. The final project report 'Outreach programmes for health improvement of Traveller Communities: a synthesis of evidence'¹³ has now been published. The research highlights that Traveller engagement with services and health improvement work is more likely if the service is provided by outreach workers who have experience of working with Traveller communities. Evidence also suggested that the greater the level of trust between the outreach worker and Traveller the more likely health promotion interventions will be successful and lead to behaviour change such as smoking cessation.

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FFT presented at the London Voluntary Sector Council 'Health Inequalities in London event: developing joint solutions to achieve better health outcomes for all' in October 2014. Creative approaches to addressing health inequalities were explored through the example of Crystal's Vardo, a Gypsy Traveller history play. Challenging the widespread prejudice and discrimination against Gypsies and Travellers in order to improve relationships between health professionals and Travellers is a critical first step towards inclusivity. FFT also presented at LVSC seminar on 'Supporting Influence - Supporting VCS reps on the health & Wellbeing Boards: Using data to influence HWBs and JSNAs' - 4th December

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Queens Institute Nursing FFT wrote an article on supporting Gypsy Traveller carers for Homeless Health newsletter December 2014.

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13 See – <http://www.journalslibrary.nihr.ac.uk/phr/volume-2/issue-3#abstract>



APPENDIX 1: CASE STUDY EXAMPLE

Brighton & Hove CCG Community Engagement Project, Friends, Families and Travellers

Background

Brighton & Hove CCG community engagement worker have funded a community engagement worker from Friends, Families and Travellers for 2½ days a week to engage Gypsies and Travellers with the CCG and inform commissioning plans. This funding is part of several other CCG funded voluntary sector engagement projects with 'hard to reach' communities and protected characteristic groups including adults with learning disabilities, young men aged 16 and LGBT communities.

Key Actions

In the first year of the project 101 people participated in interviews from Irish Traveller, New Traveller, Gypsy and Welsh communities living on unauthorised encampments, site and bricks & mortar accommodation, residing and resorting in Brighton & Hove. The project provides insight into the needs of Gypsy Traveller communities with actionable recommendations for commissioners.

Focused engagement work has been conducted in the following areas with reports of community feedback produced on -

- Use of urgent care services
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- Breastfeeding uptake and continuation
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- Mental health and wellbeing
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- Personalisation and integrated care
.....
- Record sharing and informatics
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All reports include actionable recommendations for the CCG that have led to genuine action to improve access to health care services. For example, following a survey into the use of urgent care services the recommendations were made and actioned -

3 GP surgeries and the walk-in centre were given cultural awareness training facilitated by FFT with a Gypsy Traveller trainer to promote greater understanding

.....
Information regarding duties to register patients with no fixed abode and lack of utilities bill was provided to GP surgeries

.....
A discreet help card was produced and distributed to help overcome the barriers to accessing services that had been identified in the survey

.....
The recommendations in other research reports have led to action to ensure Gypsy Traveller communities are included in provision of personal health budgets, developing peer support approaches to supporting wellbeing, consideration of the need to make appointment booking accessible for people who cannot access online facilities

Key Learning

The role of a trusted individual who has high levels of cultural competency and familiarity with the community is invaluable in uncovering health needs. For example, FFT community research has drawn attention to the disproportionate instances of bowel and bladder problems experienced by Gypsies and Travellers on unauthorised encampment.

There is an ethical imperative to be able to offer immediate assistance whilst doing engagement works that uncovers high levels of unmet need. FFT outreach workers support access to suitable accommodation, education and benefit entitlements concurrently with engagement work.

Barriers to accessing health services sometimes occur begin before people have entered the building. The need for improved parking for van users at Sussex County hospital was acknowledged

In depth local intelligence is vital for pin-pointing specific barriers to accessing healthcare and informing commissioning.



IMPACT WHO BENEFITS WHAT CHANGES FOR THEM

Community

Gypsy Travellers in Brighton have a direct route of influence to the CCG

.....

Gypsy Traveller communities have their voices heard

.....

Increased knowledge of health services

Increased awareness of CCG future plans and how they will be affected by changes

.....

FFT

Stronger connections with the CCG able to influence commissioning to ensure Gypsy Traveller health needs are met.

Additional funding has been secured for a for a wellbeing project with Traveller men to participate in a local Forest Garden project learning bush craft skills.

.....

Commissioners

Stronger intelligence to inform commissioning broken down by age, accommodation status, ethnicity (Irish Traveller, Romany Gypsy, Irish Traveller, Welsh)

Current identification of key issues being experienced by communities to facilitate intelligent commissioning

.....

GP practices

GP practices are better able to meet the needs of Gypsy Traveller communities due to increased liaison with FFT engagement worker.

GPs are able to deliver a more culturally competent service

.....

Better able to co-ordinate action to address Gypsy Traveller health needs and provide an inclusive service. For example the issue of home visits for communities on unauthorised sites has been raised and arrangements are being considered to address this gap in provision.

.....

APPENDIX 2: CASE STUDY EXAMPLE

Bath North East Somerset CCG Gypsy Traveller Outreach pilot, Friends, Families and Travellers

Background

Bath & North East Somerset CCG have commissioned a Gypsy Traveller outreach worker pilot project. The pilot was commissioned following Dr Margaret Greenfields extensive study on the health and social Gypsy, Traveller, Boater, Showman and Roma Health Survey 2012-2012.

This project is through Quality, Innovation, Productivity and Prevention (QIPP) based on the potential for reduced A&E attendances. The Gypsy Traveller Outreach & Engagement worker pilot will run for two years with a total budget of £50,000. The pilot will be used to scope the needs of the communities, build trust and shape the specification for future procurement.

The aim of the pilot is to engage with Gypsy and Traveller communities, identify what outcomes the communities want from the services and how they want that service to be delivered whilst delivering limited health interventions, health promotion and social support such as accommodation and welfare advice.

Julian House, a homelessness charity local to Bath have been awarded the contract and the project began in January 2015.

Key Actions

FFT have sat on the steering group of this project offering advice and support throughout the commissioning process.

.....
FFT offered advice drawing on our experience of delivering health outreach to Gypsies and Travellers for over 15 years.

.....
FFT supported the development of key performance indicators and measures suggesting case studies are an effective way of showing the journey of the impact outreach workers make.

.....
FFT gave feedback on job specification to ensure that the role was accessible to Gypsy Travellers



Key Learning

The service was not commissioned through the standard process as the CCG recognised the need to explore how to creatively commission a service that would reach Gypsy Traveller communities.

.....

Evaluation of the service was considered from the start to demonstrate impact and ensure the sustainability of the service.

.....

Focus on engaging with communities and developing relationships, support to accessing primary care and signposting to other support services where necessary.

.....

IMPACT

WHO BENEFITS WHAT CHANGES FOR THEM

Community

Basic First Aid course offered to community to improve health literacy and skills

.....

Gypsy Traveller community members have the opportunity to become Community Champions who can help lead the service within their own community.

.....

Improved awareness of health services and better access

.....

CCG

Improved engagement with Gypsy Traveller communities

.....

Improved intelligence into the needs of Gypsy Traveller communities

.....

Projected savings from reduced A&E admissions due to increased accessibility

.....

APPENDIX 3 : CASE STUDY EXAMPLE

Community Health Needs Assessment, Leeds GATE

Background

Leeds GATE led a Community Health Needs Assessment (CHNA) to help improve the health and well-being of Gypsies and Travellers in Leeds. The primary aim of the CHNA was to understand the health needs of the Leeds' Gypsy and Irish Traveller population from their own perspective. The scope of the health needs assessment was to provide a means of understanding the Gypsy and Traveller health status including the impact of wider determinants of health such as accommodation, financial inclusion and environment. The purpose of conducting the CHNA was to provide enhanced local evidence to influence service commissioning, design and delivery, leading to improved health outcomes, reducing morbidity and mortality, and increasing health and wellbeing for these communities.

The local authority is required to produce a Joint Strategic Needs Assessment on the health of its population, the initial findings for the JSNA in Leeds indicated that whilst we had worrying indicators that the health status of Gypsies and Travellers was very poor we didn't have sufficient and robust evidence to support work around this. The JSNA recommended a CHNA be produced to highlight the health needs of the community.





Key Actions

CHNA was led on by a trusted and embedded civil society organisation

Community members were involved throughout the CHNA from designing the questionnaires to delivering the surveying work. Training was delivered to support community members to participate. This enabled rich data to be collected as the interviewers were trusted. The report was written up by a Public Health Specialist giving it currency in influencing commissioning

The role of Leeds GATE in maintaining momentum following the CHNA has been key to resultant action

Key Learning

Strong buy in from statutory partners would have strengthened the work - allowing wider dissemination and learning from best practice elsewhere

Funding to support the work would have enabled a wider range of creative engagement activities

Producing a report that demonstrates the lived experience of community members meant research covered traumatic events in people's lives. It is important this information is captured to influence change but it must be recognised that this can be emotionally draining experience for a community.

It was important that the CHNA was community led and fully engaged the community but also that it translated into an academically robust report that could influence services, practice and policy.

Flexibility and allowing enough time to deliver is key when working with community members

IMPACT WHO BENEFITS WHAT CHANGES FOR THEM

Community Members as Volunteers

The group reported feeling valued within their community, getting respect and feeling like they had helped their community. Friendships developed within the community - "We grew closer to each other, if we had any problems we'd open up to each other." (Community member)

Community

Increased awareness of health issues and health status of the community resulting in increased uptake of services and screening.

Community ownership of the project meant transparency in delivering feedback about what happened as a result of the project was achieved.

Leeds GATE has credible and robust evidence about the health status of Gypsies and Travellers in Leeds. This confirms health status and access issues which for a long time had been informally recognised by the community and community workers.

External Stakeholders / Commissioners

The city has a much better understanding of the needs of one of its most marginalised communities.

The CHNA is a tool that can be used to effectively commission services. This is a vital resource and gives a jumping off point for a range of service to improve their practice.

To address the findings of the CHNA, a steering group has been developed with West Leeds CCG and Public Health about delivering improvements to Primary Care provision for Gypsies and Travellers in Leeds. This group will feed back to the Health and Wellbeing Board, creating avenues for accountability and helping to ensure Gypsy and Traveller health remains a strategic priority for the city.

The CHNA has been evaluated by researchers for NICE Guidelines on Community Engagement and should feature in its Best Practice guide, enabling the wider sharing of best practice and learning.



APPENDIX 4 : CASE STUDY EXAMPLE

Cottingley Springs Health Improvement Group

Please note this project is ongoing and some outcomes are projected.

Background

A Community Health Needs Assessment provided robust data on the health status of Gypsies and Travellers in Leeds. West Leeds CCG whose area covers the local authority Traveller site, convened a steering group to address some of the key issues highlighted in the report. Members of the group include Public Health, West Leeds CCG (including a GP seconded to develop the project and a GP with responsibilities for improving cancer screening and care) and Leeds GATE staff.

The group have developed an action plan and are working around a few key strands, taking a step by step approach to improving services. The group are currently looking at improving access to primary care services for residents on the local authority site at Cottingley Springs.

Whilst the project has ambitions to attract investment and deliver far reaching change in access to healthcare, practical and simple actions are also being explored to deliver improvements here and now (such as organising Breast Screening bus).

Key Actions

A literature review has been conducted, assessing best practice nationally and internationally.

.....
Contact has been made with best practice examples to enhance learning

.....
Data has been analysed regarding GP registration and A&E usage

.....
GPs have been surveyed about their work with Gypsies and Travellers Community consultation on the local authority site. This was delivered between all steering group members in partnership, drawing on the community connections of Leeds GATE to engage people. Separate engagement events were held for Women and Men, food being provided and an informal and friendly atmosphere created. the consultation drilled down on specific good and bad practice in access to services and information. Drawing on all of the above an Options Paper has been produced detailing options for improving access to primary care, which will be presented to the Senior Management Team.

.....

Key Learning

Good and equal relationships between the steering group members are fundamental to developing this work. There is genuine engagement and interest from West Leeds CCG and Leeds GATE have been able to draw down on their knowledge of research in this field to contribute to the process.

Leeds GATE's thinking about Asset Based Community Development is having a direct impact on the direction of this project. The project has an ambition to coproduce solutions between all stakeholders, including community members. Any work developed must use and value the skills and assets of community members in improving their health status.

A commitment to coproduction is essential in delivering a service that is wanted

Increasingly important to our thinking about the development of this project is the development of a Navigators / Mediators role which would employ community members to navigate services - being a bridge between services and communities. Learning has been taken from the European Roma Health Mediators Project. This role would feature public health promotion, designing appropriate information, delivering training and being a mechanism to catalyse service improvement through feeding through access issues both practically on the ground and strategically. We believe employing Gypsies and Travellers in institutions that we wish to be more inclusive is a key way to creating cultural change and increasing awareness within those institutions.

Choice is a key message from communities. This fits with our findings from a service provision perspective, that the creation of specialist services does not always lead to improvements in health equity, in fact sometimes the siloing of Gypsy and Traveller services leads to a poorer service and a lack of wider accountability. It should be possible to deliver excellent healthcare for Gypsies and Travellers in mainstream settings and the ways in which we do this do not appear to be rocket science, simple adjustments such as increasing appointment times are found to be very effective.



IMPACT

WHO BENEFITS WHAT CHANGES FOR THEM

Community Increased awareness of health services

Consultation has also provided a platform for practical tips on how to get an appointment, what screening is etc to be shared between medical professionals and community members

Community are being listened to

Projected Outcomes:

.....
Improved Access to Primary Care
.....

Improved Access to Screening
.....

Employment
.....

Utilisation of community assets and skills in delivering Public Health information
.....

Leeds GATE Have better access to and knowledge of the CCG and other commissioning structures through participation in the work
.....

Have a clear focus for strategic health work and a way of feeding in both concerns and knowledge of research and best practice
.....

Projected Outcomes:

Demand on Advocacy Service lessens as Navigator Role enables people to better understand and map services and get access to appropriate help in a timely manner

.....

There are clear structures which facilitate service improvement

.....

External Stakeholders / Commissioners

Ability to attract additional funding through voluntary sector partners

.....

Increased knowledge and expertise

.....

Fulfilling its equality responsibilities

.....

Projected outcomes:

Significant savings in delivery of appropriate healthcare (see cost benefit analysis)



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