EQUALLY Connected

EDINBURGH AND THE LOTHIANS

FINAL REPORT

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EQUALLY Connected

Invisible Minorities

We don't know how to reach them
so they can't be there

But when they're here
we don't know what to do with them

Might as well ignore them,
then they'll go away

When they're gone
we'll say they didn't want to be here

so they've disappeared

and because we don't know how to reach them
well, it's clear they're nowhere to be seen

Jo McFarlane

CONTENTS

1 EXECUTIVE SUMMARY

Equally Connected was a two year action research project working with a wide range of Black and minority ethnic (BME) communities across Edinburgh and the Lothians on issues relating to mental health and wellbeing. Using community development approaches we sought to learn from BME communities about their attitudes to, and experiences of, mental health, what helps maintain wellbeing and effective ways of challenging stigma and discrimination.

The key aim of the Equally Connected project was *"to ensure that the Lothian Integrated Care Pathway for people with low mood, anxiety and depression meets the needs of people from all communities across Lothian"*. To achieve this aim we set out to challenge the assumptions underpinning NHS Lothian's Integrated Care Pathway (ICP) for depression - namely, that when feeling anxious or depressed:

- people attend their GP
- people feel comfortable, and able, to articulate their concerns and symptoms
- the GP listens, understands and agrees with the person an appropriate response

Our approach was multi-dimensional - using a broad range of creative research methodologies, including group work, the arts, training and semi-structured interviews. We worked with seven groups of BME people, including a mix of age, gender, ethnicities and location. Our research focused on the issues important to the people we worked with and we made extensive use of participatory appraisal tools. We also worked closely with partner agencies from the voluntary and statutory sectors across Edinburgh and the Lothians

A number of cross-cutting themes emerged across the diverse range of BME groups which have significant implications for the ICP. Across all the groups we worked with:

- there was a distinct reluctance to go to the GP if feeling depressed or stressed
- there was very limited awareness and a lack of knowledge about the wide range of primary care mental health services, particularly those targeted at mild to moderate mental health problems
- the experience of prejudice, or the fear of encountering racism or other types of discrimination, had a significant impact on the lives of those we worked with and a knock on effect on feelings of isolation, help-seeking behaviour, coping strategies and general awareness of existing services

- shame and stigma around mental health, whether perceived or real, was raised as an issue within all the communities we worked with, often leading to increased anxiety, regularly creating barriers to accessing help to deal with negative mental wellbeing and a desire to keep problems hidden from the wider community
- resilience factors varied from community to community, and individual to individual. However, there were common themes such as the importance of faith, friendship, culturally sensitive support, using the arts and more individual approaches

In addition to these cross-cutting themes, there were a number of factors specific to certain groups:

- there is strong evidence to suggest many Gypsy/Travellers experience significant levels of mental distress often linked to 'living in a house' and feeling you have to 'hide your identity' for fear of racism
- in Midlothian, a semi-rural area, isolation was a key factor raised by many research participants and there was a distinct absence of a sense of 'belonging' within the local community
- with international students, misconceptions about the Scottish health system and a lack of knowledge about how to navigate the system were contributory factors in deciding whether or not to seek help before reaching crisis stage. Additional pressures relating to immigration, funding and expectations from home also added to the burdens experienced by some
- BME carers expressed concerns about differing cultural understandings of illness and caring and how that can negatively impact on their lives and the lives of those they care for. The stress experienced by carers was acute at times and it was felt that there was a lack of cultural competency in relation to health and support services

From the Equally Connected research it is clear that all three ICP assumptions can be challenged. The majority of those we worked with did not think of going to the GP first when experiencing depression. Secondly, many did not feel able to clearly articulate their difficulties, not only because of language but also because of a perceived lack of a shared conceptualisation of mental health. Furthermore, for some there was a reluctance to fully share their beliefs and/or disclose their ethnic identity for fear of racism. Finally, in relation to assumption three, there was a distinct lack of knowledge, amongst participants but also

some BME support organisations, about the wide range of social-prescribing initiatives and interventions – this, combined with widely held perceptions about GPs and medication, means that certain individuals are not in a position to successfully negotiate a pathway forward.

Evaluation was an integral part of the Equally Connected project - we found that using community development approaches, starting from where the person is at (not going in as a mental health project per se) and participatory tools were highly effective and engaging ways of working with BME communities. Using the arts to remove barriers was very successful, and the potential to act as an enabler in future work is enormous. Whilst some of our findings are specific to the BME communities we worked with, other issues have significance for other groups in society such as older people, people with disabilities, LGBT people, young people and others. All of the methods and approaches used by Equally Connected could easily be adapted for use with other communities of interest and we would argue that much of our learning is transferable.

The work of Equally Connected has already contributed to some service change in a variety of ways. The recommendations set out in section 11 will be taken forward within a wider context of radical change and redesign in line with the ethos and aspirations of Lothian's joint mental health and well-being strategy 2011-2016 – A Sense of Belonging. In particular, a pan-Lothian Addressing Inequalities Action Group will be established by September 2011 with responsibility for further developing the learning from Equally Connected and taking forward recommendations, across various communities of interest.

A revised ICP for depression, informed by Equally Connected learning, will be produced by NHS Lothian in 2011.

2 INTRODUCTION

"We don't need to repeat 'focus groups' – just ask things differently around people's mental health or inequalities" [1]

This quote summarises what the Equally Connected team tried to do in Edinburgh and the Lothians between July 2009 and June 2011. Our final report is a summary of the main learning from Equally Connected, an innovative action research project, based at Health in Mind, and funded by the Scottish Government and NHS Lothian. Throughout the life of the project we produced a number of reports which give greater detail about individual pieces of work,[2] this report is a summary of some of the key findings.

The Equally Connected team used community development approaches to learn from Black and minority ethnic (BME) communities about:

•   attitudes to, and experiences of, mental health
•   what helps maintain wellbeing
•   effective ways of challenging stigma and discrimination

Our evidence will be used to improve understanding and help ensure that primary care mental health services and NHS Lothian systems of care (such as the Integrated Care Pathway (ICP) for depression) are better designed to meet the needs of the diverse BME communities living in the Lothians.

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[1]   NHS Health Scotland and Outside the Box (2007). *Mind the Difference. Mental Health: Focus on Equality and Diversity*, page 22. NHS Health Scotland

[2]   For further details visit http://www.health-in-mind.org.uk/services/equally-connected.html

3 CONTEXT

3.1 National

Even before figures from the 2011 census are published, it is abundantly clear that Scotland is fast becoming increasingly ethnically diverse. In 2001, Fair for All highlighted the difficulties, such as cultural insensitivity and racism, often faced by people from BME backgrounds in accessing health services.[3] Over the last decade, a number of Scottish policy initiatives, including Towards a Mentally Flourishing Scotland and Equally Well, have sought to support and promote the mental health and wellbeing of everyone, as well as targeting health inequalities.

In relation to mental health and wellbeing among BME communities, there is only limited published information.[4] There is, however, some evidence to suggest there may be different cultural understandings of mental illness and mental health and a number of barriers have been identified by BME people trying to access mental health support services.[5] Furthermore, Grant and Jackson highlighted in 2005 that Scottish Health Boards were not routinely collecting ethnicity data, nor monitoring the uptake of mental health services by people from a BME background, to determine needs or problems in accessing appropriate services.[6]

With this in mind, between 2006 and 2011 NHS Health Scotland's Mental Health and Race Equality Programme has been working to ensure that people from BME communities secure an equal chance of enjoying the best possible mental health and wellbeing. Recognising the existence of the barriers sometimes faced by BME people in trying to access mental health support services, in 2007 the Programme proposed the need for a range of local projects focusing on Black and minority ethnic communities and primary care mental health services.

Scottish Government funding was secured from 2008 until 2011 for the *Equally Connected* programme. Following an assessment and selection process, three projects were successful – Equally Connected (Edinburgh and the Lothians), Wah Kin in Glasgow and a project in the NHS Highland area which did not subsequently proceed.[7]

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[3]   The Scottish Executive (2001). *Fair For All: Improving the Health of Ethnic Minority Groups and the Wider Community in Scotland*. Scottish Executive Health Department

[4]   Gordon, D.S., Graham, L., Robinson, M., and Taulbut, M. (2010). *Dimensions of Diversity: Population Differences and Health Improvement Opportunities*

[5]   Newbigging, K., Bola, M., and Shah, A. (2008). *Scoping Exercise with Black and Minority Ethnic Groups on Perceptions of Mental Wellbeing in Scotland* NHS Health Scotland and Glasgow Anti Stigma Partnership (2007). *Mosaics of Meaning: Exploring Stigma and Discrimination Towards Mental Health Problems with Black and Minority Ethnic Communities in Glasgow*

[6]   Grant, S. and Jackson, J. (2005). *Equal Services?* National Resource Centre for Ethnic Minority Health

[7]   For further details see Linehan, L. (2008). *'Equally Connected' Race Equality Mental Health Project:* NHS Highland Review. Report commissioned by NHS Health Scotland

3.2 Equally Connected in Lothian

By working with BME communities, our key aim was

"to ensure that the Lothian Integrated Care Pathway (ICP) for people with low mood, anxiety and depression meets the needs of people from all communities across Lothian".

With a small staff team,[8] the project was managed by a Management Group, consisting of the Project Manager and senior staff from NHS Lothian, NHS Health Scotland and Health in Mind, who met approximately every 6 - 8 weeks. In October 2009 a Steering Group was formed, comprising of a range of partner organisations,[9] and chaired by a City of Edinburgh Council representative (Health and Social Care). The Steering Group met on eight occasions over the life of the project.

Action research can be fun!

[8]   The team was made up of a full-time Project Manager, two part-time Community Development Workers (male and female), a part-time Administrative Assistant and four volunteers.

[9]   Membership of the Steering Group included representatives from: MEHIS, 'see me', a GP, Health in Mind, MECOPP, Saheliya, ELREC, CAPS, Depression Alliance Scotland, City of Edinburgh Council, Men in Mind, Health all Round, Midlothian Council, the Africa Centre, NHS Lothian and NHS Health Scotland.

4 PURPOSE

4.1 The Integrated Care Pathway

In order to assess whether or not the ICP did in fact *"meet the needs of all communities"*, NHS Lothian was keen to go 'back to basics' by testing the three underlying assumptions behind the Lothian Integrated Care Pathway (ICP) for people with low mood, anxiety and depression - namely, that when feeling anxious or depressed:

• people attend their GP
• people feel comfortable, and able, to articulate their concerns and symptoms
• the GP listens, understands and agrees with the person an appropriate response

By working with a range of BME communities, including a mix of age, gender, ethnicities and location, we wanted to find out if the ICP is accessible to all. Is the current ICP responsive to needs? If, for example, you have a particular cultural understanding of 'depression',[10] your GP may not be the first person you'd go to for help, or even if you do go to your GP you might describe the symptoms in a specific way. If that is the case, would the symptoms be recognised as 'depression'? And would the ICP meet your needs? We used a range of participatory and creative methodologies to explore these types of questions and more.

4.2 Logic Model

In order to ensure that the work of Equally Connected was focused on the key purpose identified above, a project logic model was developed in September 2010 as part of the NHS Health Scotland Learning Review (see Appendix 1).[11] The logic model is an outcome-focused planning tool which describes our 'theory of change' in a transparent and structured way, linking available inputs, planned activities, timescales and intended results. The logic model also made explicit short-term outcomes at a local level, and ensured synergy with the national outcomes identified by NHS Health Scotland, specifically that they would have more information on:

• methods that primary care mental health services can use to learn about BME needs
• how primary care mental health services can improve access to these services for BME people
• how to engage with BME communities to improve their mental health and wellbeing
• how to engage with primary care mental health services in order that these services improve BME mental health and wellbeing

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[10] See for example, http://www.mentalhelp.net/poc/view_doc.php?type=doc&id=13009&cn=5

[11] Gordon, J. and Griesbach, D. (2011). *Equally Connected Learning Review: final report* NHS Health Scotland

Within this context, the term primary care mental health (PCMH) denotes a wide range of services, run by the statutory and voluntary sectors, where individuals with mild to moderate mental health problems like stress, anxiety and depression may be referred, for example, exercise referral, Guided Self Help, stress control classes, talking therapies, complementary therapies, and so on.

As knowledge and relationships developed it became clear that the challenges around mental health and ethnicity as well as the journey/pathway that someone might follow into PCMH services are complex and not easily resolved with a single approach. With this in mind, and being aware of the limited time available, Equally Connected felt it was important that its outcomes should try to benefit individuals from BME communities, as well as provide information for service providers on accessibility. Accordingly, five short-term outcomes were identified:

1. Increased engagement with target BME groups through participatory action research methods

2. BME individuals would become more:
   • comfortable talking about their mental health and wellbeing
   • aware of sources of support and how to access them

3. Matched Care Leads (in the voluntary and statutory sectors)[12] and GPs would have a:
   • better understanding of the range and diversity of BME communities in the Lothians
   • better understanding of the mental health and wellbeing of target BME groups
   • increased awareness of the barriers and enablers to access

4. The project team would have a better understanding of the levers and barriers to accessing PCMH services

5. It was anticipated that achievement of these four outcomes would result in a revised Integrated Care Pathway by NHS Lothian

[12] The ICP for depression follows the matched care approach with the initial recommendation of low intensity treatments, and systematic monitoring of outcomes and "stepping up" to more intensive forms of treatment where required. The NHS Lothian Matched Care Leads group is made up of staff, from across the Lothians, who are involved in the delivery of the matched care approach.

5 WHO DID WE WORK WITH?

In the early stages of the project we became cognisant of the Mosaics of Meaning work being carried out in Glasgow with the four largest BME communities (Pakistani, Indian, Chinese, and African & Caribbean).[13] Given the relative dearth of information about BME communities and mental health in Scotland we were keen to use resources wisely and not simply duplicate this work in the Lothians.

The early months of the project were spent mapping existing local literature, services and identifying potential partners. All the major BME organisations, throughout Edinburgh and the Lothians, were visited and asked where they felt the gaps were, in terms of knowledge and services. From this initial scoping, and follow up discussions with the Equally Connected Management and Steering Groups, it was decided that we would focus on smaller, more marginalised BME communities and/or specific sub-sections (according to gender, age, or location) within communities. A list of possible target BME groups was drawn up and approaches were made to partner agencies and, where such agencies or representative groups did not exist, individuals within the communities. At all times we were very clear that we would not be able to provide a service but, rather, would seek to engage with communities using action research methods.

After considerable discussion the following groups were identified as key target groups:

5.1 International Students

Working primarily with Heriot Watt University as part of the 12S initiative.[14] Staff from Heriot Watt Student Support Services were concerned that international students often presented at 'crisis stage' rather than accessing preventative services. We worked with around thirty male and female students from a range of countries including Nigeria, Egypt, India, Poland, Saudi Arabia, Syria, Libya, China, and many more.

5.2 Midlothian Active Women

We were aware that much of the work carried out with BME communities in the UK (in terms of research and service provision) has tended to focus on urban areas and we were keen to include the experiences of those living in more rural or semi-rural locations. During initial scoping, a member of the team was informed by a service provider in Midlothian *"there's no point in coming here, there are no BME people really here"*. Knowing this to be

[13] Glasgow Anti Stigma Partnership (2007). *ibid*

[14] 12S is an NHS Lothian initiative, funded by the Charlie Waller Memorial Trust and NHS Lothian, working with the 12 further and higher education institutions across Edinburgh and the Lothians. See also Equally Connected (2011). *Report 5*

untrue the EC team were particularly keen to work in this geographical area. Over the course of the project we engaged with over fifty-five BME (predominantly Muslim) women living in Midlothian.

5.3 Gypsy/Travellers

From previous experience the Project Manager was aware of the high levels of mental distress often experienced by Gypsy/Travellers, but also the dearth of research with regard to this BME community. The Equally Connected project seemed an ideal opportunity to build on existing work and gather information with a specific focus on mental health and wellbeing. Gypsies and Travellers have been described as one of the most marginalised minorities in society. Research in England has shown that the health needs of Gypsies and Travellers are not being met through existing health plans and provision.[15] We worked with over forty Gypsy/Traveller women living in housing, on council sites and on roadside camps in Edinburgh, West, East and Midlothian.

5.4 BME Men

We were also keen to ensure the views of men were captured in our research and worked directly with approximately thirty BME men during group work, events and interviews. The men came from a mix of backgrounds but the majority were of African origin and lived in Edinburgh.[16]

Photography workshop with BME men in Edinburgh

[15] Parry, G. et al (2004). *The Health Status of Gypsies & Travellers in England* The University of Sheffield

[16] See Equally Connected (2011). *Report 10*

5.5 Arabic-speaking Women

During discussions with partner agencies particular concerns were raised about the mental health of the growing population of Arabic-speaking women, the majority of whom were thought to be accompanying spouses who were studying or working, in Edinburgh. There was minimal information available and many were thought to be physically and socially isolated, with limited knowledge of the English language. Project events were attended by over eighty Arabic-speaking women, from across the Middle East and North Africa, and the regular weekly programme had an average attendance of 10 – 12 women.

5.6 BME Carers

There is growing evidence to suggest carers often experience poor mental health and wellbeing as a result of their caring circumstances.[17] We were keen to work with the Minority Ethnic Carers of Older People Project (MECOPP) to explore these issues in more detail and therefore worked with over forty BME carers living in East Lothian and Edinburgh.

5.7 Younger BME Women

Many partner agencies raised concerns, confirmed by one of the project volunteers, about specific issues facing younger women within various BME communities, many of whom had been born in the UK or migrated to the UK at a very young age. Within the *Fashion Talks* project we worked with twenty-five young women aged 11 – 21 from a range of cultural backgrounds.[18]

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[17] Gordon, D.S., Graham, L., Robinson, M., and Taulbut, M. (2010). *ibid* and Minority Ethnic Carers of Older People Project (2010). *Needs Must* MECOPP

[18] Combining art and fashion, *Fashion Talks*, was a collaborative project between Equally Connected, Health all Round, MECOPP and Saheliya. Working with a community artist, the young women created a design and logo which promoted a strong message of positive mental health. The design was then printed onto T-shirts. See Equally Connected (2011). *Report 11* for more details.

Creating the *Fashion Talks* T-shirt

Working with such a diverse range of groups, from a wide range of BME communities living in Edinburgh and the Lothians, was not without challenges and our approach required to be tailored to meet the needs of each group, there is *'no one size fits all'.*

6 RESEARCH METHODOLOGIES

Equally Connected was an action research project, using community development approaches, to learn from these seven groups about their understanding, and experiences, of mental health and wellbeing. We worked with both people who were accessing PCMH services as well as taking a more generic approach to gather the views of those who, for whatever reason, were not accessing services.

In addition, we were keen not to impose our views, or present ourselves as a 'mental health project', but rather we aimed to start from where the individual was at in terms of their own understanding of mental health and wellbeing. During initial conversations with research participants and partner agencies it quickly became clear that there was a very strong sense of research fatigue – BME community members, in particular, were tired of being asked questions or being consulted, often with little or no feedback and it was felt there was a lot of asking but rarely any resultant action or change.

Several partner agencies were also somewhat sceptical at the outset and initially reluctant to participate in further research, feeling that resources could be better utilised in providing more services. Similarly, along with participants, there was a limited, rather traditional, view of research, most fearing it would simply consist of questionnaires and focus groups which would be of limited benefit, with few outcomes and simply reveal *'more of the same'* or *'what we already know'.*

In addition, simply asking about mental health is a difficult and complex area - in 2009 ELREC carried out a needs assessment survey, covering a wide range of topics, with over 100 BME people living in East, West and Midlothian. They asked 'what is your understanding of the term mental health?' - in their report the interviewers describe the difficulties they experienced: *"... this area of the questionnaire focused particularly on mental health and wellbeing and was undoubtedly the least understood area. Hence we had the least comment from people on this section...we got a definite sense that this topic was not one people were comfortable discussing".*[19]

Given the initial responses, and for the above reasons, the project decided it was even more important to use community development approaches which are generally considered to be more sustainable and empowering. Community-led research can empower not only community

members, but also provides opportunities to improve knowledge more generally which can be utilised to improve service provision, whilst challenging discrimination and promoting equality.[20]

Building on the critical pedagogy of Paulo Freire, we were keen to utilise a range of Participatory Appraisal (PA) methods and tools, feeling that they would be particularly useful in working with individuals who feel 'over-researched' or 'dis-empowered'.[21] Chalmers has described PA *"as a growing family of approaches and methods to enable local people to share, enhance and analyze their knowledge of life and conditions, to plan and to act"*.[22] In addition, we were keen to work in a creative way by utilising the visual arts with individuals, who may not speak English as their first language or have limited literacy skills, to enable them to express their views and experiences, again hoping that this would be not only an enjoyable and engaging process but also empowering.

Decision-making with a BME carers group in East Lothian

Participatory Action Research is 'client-centred' and composed of the cyclical process of planning, acting and reflecting. Throughout our work, regardless of the methodology employed, we tried to incorporate these core elements. In practical terms, this brought many challenges and struggles but also transparency; our learning is composed of what went well, as well as what didn't go so well.

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[20] See work by the University of Central Lancashire on community engagement models http://www.uclan.ac.uk/schools/school_of_social_work/community_engagement.php and Minkler, M. and Wallerstein, N. (2008). *Community-based Participatory Research for Health: From Process to Outcomes*

[21] Freire, P. (1996). *Pedagogy of the Oppressed* Penguin

[22] Chalmers, R. (1994). The Origins and Practice of Participatory Rural Appraisal. *In World Development*, 22 (7)

There is insufficient space in this report to detail all the research methodologies employed by the project and further information can be found in the individual reports.[23] For the purpose of this report we will summarise the key ways in which we engaged with BME communities, along with some examples of each approach. In each case we used a wide range of PA tools including Issue Trees, Body Maps, Impact Ranking, Relationship Mapping, Poster and Dot Questions, Mind Maps, and many more. We used these tools because we found them to be fun, accessible, engaging, adaptable and visual.

Impact-ranking exercise

Using an Issue Tree in West Lothian

6.1 Methods of Engagement

Poster to advertise Midlothian
Active Women's Group

Group work – regular group work was carried out with Muslim women in Midlothian, mainly focusing on exercise and confidence-building in a women-only setting, and with Arabic-speaking women in Edinburgh.

In each case, participants were involved in drawing up the programme which best met their needs. Our challenge in each case was then to incorporate our research agenda in a transparent and non-threatening manner. Group work was also carried out with BME men through a reflective photography project and Ubuntu.[24]

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[23] Equally Connected *Reports 1 - 14*

[24] For more details see Equally Connected (2011). *Report 10*

Events – a series of Health and Wellbeing events were held to bring community members together with their peers, or in particular locations, in a safe and non-threatening environment. For some very isolated individuals, for example Arabic-speaking women and Gypsy/Travellers, these were important occasions to make friends and connections, share experiences and take part in a range of health and wellbeing-related activities. They were also vital opportunities for partner agencies to engage with community members and pass on information about service provision.

Community wellbeing event in Midlothian

First aid workshop at Health Fayre in Edinburgh

Training – at an early stage in the project it became clear there was a lack of awareness and understanding about both our methodologies and the issues facing specific BME groups. During the course of the project we hosted a training day, focusing on using PA tools in group work, and two training seminars which sought to raise awareness of issues faced by Gypsy/ Travellers; both sessions were led by community trainers. Each training event was evaluated at the time.[25]

In-depth interviews – whilst recognising the benefits of group work, particularly for those who are isolated, we were also aware of the limitations of this approach in terms of gathering robust research data. With this in mind, we carried out 29 semi-structured interviews, and collected nine Case Studies, with individuals from all the groups we had worked with. In collecting Case Studies, individuals focused on the issues, relating to mental health and wellbeing, which were of most importance to them. In contrast, in the interviews we used a short vignette and topic guide to focus the discussion on the three assumptions underpinning the ICP.

Community Conversation – with carers, Arabic-speaking women and Gypsy/Travellers we held Community Conversations to encourage discussions and raise awareness about mental health.[26] In both cases we adapted the Community Conversation model to suit the needs of the group.[27]

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[25] See Equally Connected (2010). *Report 2* and Equally Connected (2011). *Report 4*

[26] Sanctuary (2008). *Community Conversation, Peer Educators' Manua*l. Glasgow Anti Stigma Partnership

[27] Equally Connected (2011). *Report 12*

Using the arts – recognising the likely stigma associated with talking about mental health in some communities, and being aware of the immense benefits of using the creative arts to raise issues about sensitive topics, we were keen to use the arts as a means of engaging with individuals and communities at an early stage in the project. Arguably, creativity can be regarded as a pathway in itself which cuts across language, literacy and culture. Some examples of the different ways we used the arts include:

- Story-telling was used with older Polish and Ukrainian women[28] and BME carers in East Lothian
- Photography with BME men and BME community members in North Edinburgh
- Film-making with international students and a BME carer
- *Fashion Talks* – young BME women worked with a community artist to create a design and logo to promote positive mental health which was then printed onto T-shirts[29]
- Poetry with Gypsy/Travellers

Fashion Talks workshop with young BME women

Much of the artwork produced was displayed for two weeks as part of Lothian's programme for the 2010 Scottish Mental Health Arts and Film Festival (SMHAFF) at the Out of the Blue Gallery in Edinburgh. It was also exhibited as part of the Happy Souls Festival in London in June 2011.

From the quality and diversity of the displayed work, it was clear that many complex issues had been tackled and explored during the making of these art pieces. For many people it was the first time that they had openly shared their experiences of, and thoughts on, mental health and wellbeing. As one participant said, after attending the exhibition opening party:

Research participant with his artwork at SMHAFF exhibition

"… had a nice time last night talking to the folk ... But what was really nice was hearing how other folk express themselves and their problems, knowing we have been going through the same really helped. I was so scared of coming but so proud on the night. Wish I'd talked more about it [my depression] years ago. Thanks so much!" (Text from Gypsy/Traveller female)

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[28] Unfortunately due to funding cuts within our partner organisation, Alzheimer Scotland, this project was closed and we were unable to continue working with this community group

[29] Equally Connected (2011). *Report 11*

Wellbeing Mela – following the success of the Equally Connected stall at the Edinburgh Mela in August 2010, we co-organised two Wellbeing Melas in Edinburgh and Midlothian. A Mela is traditionally a time to come together with friends and family to watch, and participate in, diverse artistic performances and workshops. Working with partners, we sought to challenge the stigma often surrounding mental health by using the concept of a Mela and adding a new dimension of promoting positive mental health and wellbeing. To our knowledge this is the first time this approach has been used in Edinburgh and the Lothians. The two Melas followed a similar structure and were promoted as a daytime community event for the whole family. The two Wellbeing Melas were attended by approximately 500 people, the majority from BME backgrounds.[30]

One specific tool we used to impart information on PCMH services, as well as gather views, was a 'Stress Buster Quiz' – a fun, non-threatening, easy-to-complete exercise which was completed by 333 people, the majority from BME backgrounds, and produced many interesting results (see Appendix 2).

Rhythm Sticks at Edinburgh Wellbeing Mela

Henna-painting at Wellbeing Mela

Tibetan dance at Wellbeing Mela

Living Life to the Full – it quickly became apparent to Equally Connected staff that many of the possible ICP interventions available to GPs, via Refhelp,[31] were based on self-help materials and/or Cognitive Behaviour Therapy (CBT) approaches, in line with the SIGN recommendations for depression. With this in mind, in conjunction with partners, we ran the Living Life to the Full (LLTTF) course with a group of eight BME women in order to 'test out' whether such materials and approaches are accessible to all members of our community.[32]

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[30] See Equally Connected (2011). *Report 14* for more details

[31] For more details see http://www.refhelp.scot.nhs.uk/

[32] Equally Connected (2011). *Report 13*

6.2 Evaluation

Using a variety of approaches, evaluation has been an integral part of the Equally Connected project. At a national level we were a key element of the Equally Connected Programme Learning Review commissioned by NHS Health Scotland.[33]

At a local level, there were three main areas of evaluation, depending on the kind of information required, methodology used and the circumstances of the groups:

- event or group work evaluation - recognising language or literacy difficulties, and sometimes a reluctance to write things down, we used a range of visual, easy-to-use PA evaluation tools to assess and record practical issues (venue, activities, accessibility), key learning, future priorities and suggested changes

Event evaluation chart

- research participants – using the Kirkpatrick model,[34] to assess outcomes at four levels (reaction, learning, behaviour and results), we interviewed a range of BME individuals towards the end of the project. To limit the potential for bias, in most cases this took the form of a telephone call by a member of staff not involved in the delivery of the piece of work
- to ascertain the views of service providers and partner agencies we used a web-based survey to ask about the impact and any service changes to arise from Equally Connected

The findings from the different kinds of evaluation are detailed in section 9.

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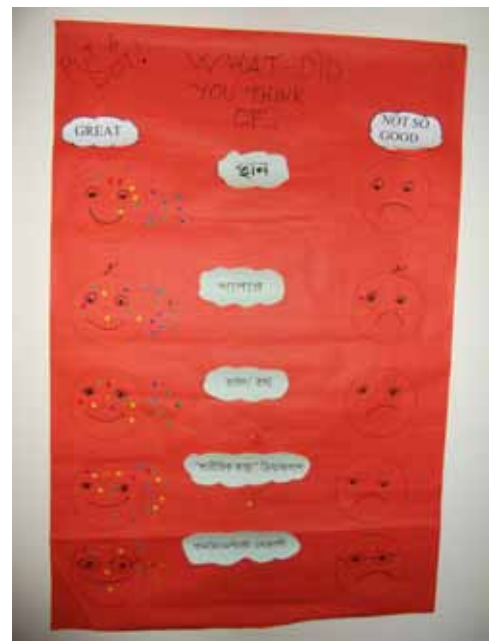
[33] Gordon, J. and Griesbach, D. (2011). *ibid*

[34] Kirkpatrick, D.L. (1959). Techniques for evaluating training programmes, *Journal of American Society of Training Directors*, 13.

7 KEY LEARNING - CROSS-CUTTING THEMES

Despite working with a diverse range of BME groups, using a wide variety of research methodologies, there were a number of cross-cutting themes which emerged across all communities. These themes have significant implications for successful implementation of the ICP.

7.1 GPs and Primary Care Mental Health Interventions

Central to the effective implementation of systems of care such as the ICP is: firstly, the perception of GPs and related interventions; and, secondly, having sufficient knowledge and awareness of the system (both how to access it and the range of available treatments) amongst the target populations.

Consideration of these issues is a complex process and we used a variety of methods to explore these matters. From the outset, we were aware that many of those we worked with might have differing perceptions of mental health and wellbeing, for example, culturally rooted ideas about mental illness which could prevent them from seeking medical advice. For example, for some participants a mild to moderate mental health problem is regarded as part of life, rather than something about which to seek professional help:

"…it's usually seen as a Western disease among foreign people, to be depressed. We don't believe we get depressed. We believe life gets hard and you move on, but we don't believe that there's time to wallow enough to have time to be depressed. You may be depressed but you still get up and go and do it. So you apparently seem fine" (LLTTF female)

Across all the groups we worked with there was a distinct reluctance to go to the GP if feeling depressed or stressed. This was especially evident from the Poster Questions and interviews. The Poster Question 'where would you seek support if feeling depressed?' was used with 115 women (Arabic-speaking, Gypsy/Traveller and in Midlothian), and we were surprised to find not one woman said they would go to their GP. Instead, the most popular answer was friends and family.

Poster Question at Arabic-speaking women's event

Similarly, in the interviews, very few interviewees, male or female, said that they would first go to their GP. Reasons cited were: the restricted time available; the perception that you would just be prescribed medication; the GP was viewed as being there for physical illnesses; concerns about cultural competency and a lack of trust, shared understanding or conceptualisation of mental health. Clearly this has significant implications for ICP assumption one.

"Why would I go to the GP? When you go to the GP they do not even look at you or listen to you, they do not have time for you. Why should I then go with my most personal problem to them?" (Arabic-speaking female)

"Sometimes the doctor is quite serious or firm I would find that difficult because I interpret body language to be negative ..." (Chinese male)

"... it isn't always something you can put into words, if the doctor came from my culture he would know the honour stuff, understand where I am coming from but instead they don't. The shame/honour thing is so hard to explain most wouldn't bother but an Arab doctor would know straight away" (Arabic-speaking female)

"I feel the Eastern approach is to see you as a whole person and to make your cure like a healing or something. But the Westernised, they see you as the disease and they want to cure the disease" (Chinese female student)

"I told my doctor all this and said I didn't want to keep popping pills, they didn't help in the past and I don't want to become a junkie, but that's all he gave me ... I tried to tell the Dr once but I don't think he really listened, they just want you in and out in 5 minutes these days" (Gypsy/Traveller female)

"No, not really. I never thought about going to a doctor really … we don't have this … If I would talk a lot, take a lot of his time, I don't think so. Well, he'll listen to a certain time, for a limited time but not for a long time" (Arabic-speaking female)

"Because I don't think GPs are always so sensitive to these kinds of issues of isolation, maybe not understanding the big picture ... I see the GP as someone to go to for a medical condition" (LLTTF female)

"The GP will not understand his experience. If he knows somebody from the community that would be better. The GP just times you, tried to diagnose you, so I don't think the GP would be the best thing" (African male)

"You only go to them when you're ill or need medicine. I don't know if they're appropriate for things related to jobs or family life. I don't know. I don't think I would go to a doctor ... I would never go to a doctor. I see them as people who help you with illnesses and medicine. I don't see them as someone who can help me with my personal life. It's just too personal. I don't know them. They could be writing it down for someone else. I just don't trust them" (young BME female)

"What I've found in the UK is that everything is timed ... But it shouldn't be so for health situations because health doesn't give time. When a bad condition wants to happen it doesn't give time. So treatment should not be timed" (African male)

There were, however, a few examples of good practice:

"It was a young man who understood I was a Gypsy/Traveller and wasn't judgemental towards me and was very calm, there was no pressure towards me at all. We could sit in silence for 5 minutes, and because I'd seen him the 2 or 3 times it was learning to trust. After that if I needed to see a doctor I'd only call for him" (Gypsy/Traveller female)

"... doctors would help you and they would really want to know what's going on with you ... even in the countryside. And personally I would also say from my own experience, when I met my first GP, this person was so friendly. He looked at me and the first thing he said, "you look so stressed, what's happening to you?" And I was quite scared even, talking to this person, but he said, "you don't have to be scared, I'm a doctor. Anything we discuss will remain in this room, so we are bound by confidentiality rules" (Midlothian BME female)

"Doctor is someone you should consider he is on your side. He is not your enemy. He is on your side if you tell him everything you feel about. Then he can help you. Doctors actually primary responsibility is health, but then we will say health, in my point of view, that's not only physical health, that is mental health as well" (South Asian male)

"Yes I found my GP luckily very understanding and very sympathetic with my particular situation and my background and experiences, bad and good" (Arabic-speaking female)

Across all the groups we worked with there was very limited awareness and a lack of knowledge about the wide range of PCMH services, particularly those targeted at mild to moderate mental health problems. In the majority of cases, there was still a widespread expectation that treatment involved medication:

"I just thought it was tablets, that's all I have ever heard about and that's why I wouldn't go to the GP. I have seen what tablets do to others. I didn't know about any of these things you are mentioning" (BME carer)

"So the way I view a GP is probably they are the first to prescribe you medication rather than you know helping you in different ways so yes and no. Maybe the doctors should at least give you the opportunity to try something else, maybe prescribe you not medication but prescribe you physical activities or something" (African male)

"... I just kept taking them, feeling worse but I couldnae tell the doctor that, he knew best that's the way we thought. He never offered me anything else just tablets and more tablets" (Gypsy/Traveller female)

"I feel alone, no one to talk to, don't want tablets, want other things but don't know what, for me tablets no good but what else is there ... medicine is what is keeping me depressed, having to take medicine, but no other choice" (BME carer)

"A lot of people don't know there are services there to help; some people just don't want it. They just like living like me in private. But a lot of them just don't know the service is out there because they move up and down that much. Like my brothers move up and down an awful lot so that's probably a lot to do with it" (Gypsy/Traveller female)

The Stress Buster quiz (see Appendix 2), used at Melas and events, also produced some interesting findings about awareness of interventions and the links between exercise and mental health. When asked if 'Guided Self Help involves using a guide dog' – 49% of respondents said true and 2% gave no answer. Similarly, 47% thought exercise only had a positive impact on physical health. Interestingly, one of the women involved in Midlothian Active Women commented during the evaluation that she had learned *"that exercise is a necessity not just for the body but mind also"*.

In relation to ICP assumption three, this lack of awareness is likely to also affect treatment, even if they do consult the GP, as people would be unable to discuss the options and agree with the GP on an appropriate response.

7.1.1 Recovery

Within the field of mental health, amongst service users and providers alike, there appears to be a great deal of discussion about the concept of recovery. In working with BME people the project was keen to follow up on some of the work started with Finding Strength from Within by exploring these issues further, albeit in a limited way.[35] This is undoubtedly a complex area, which links to the aforementioned notions about cultural perceptions of mental health and wellbeing and it clearly has implications for all three ICP assumptions. As noted earlier, depression and stress for many are seen as part of life and not needing specific action or treatment. This can be interpreted as having either a positive or negative impact, as this type of attitude or view may help the coping process; therefore, it may in itself be a subtle form of recovery. For others, it is an acceptance of circumstances and a need to move on rather than identifying it as 'recovery':

"I'm sure there are elements of deep depression amongst the immigrant community. But they plod on, you know, money has to be made and sent home, that kind of thing" (LLTTF female)

We also encountered some quite fatalistic attitudes towards mental illness - as being something that one cannot recover from. During the Community Conversation with carers, for example, it emerged that there was little awareness of the concept of recovery in relation to mental health and wellbeing. Several members asked the facilitators what was meant by recovery in this context. Comments about their situation included: *"you are helpless when you are caring for someone"* and *"frustration, nothing I can do so learn to live with it"*.

As one Arabic-speaking woman said:

"... there is so much that needs to be done in communities from ethnic backgrounds, so much worse for women, most still think mental illness is a disease like something you can catch from someone. They don't know you can, only with support, live with it. No idea about all this recovery stuff, not talked about. I have but it is very hard, very, very hard".

7.2 Impact of Racism

Another strong theme across all groups, either directly or indirectly, was the impact that racism seemed to have on the mental health of the research participants. Across all engagement methods used by Equally Connected, the experience of prejudice, or the fear of encountering racism or other types of discrimination, appeared to have a significant impact on

[35] NHS Health Scotland (2008). *Finding Strength from Within* NHS Health Scotland

the lives of those we worked with and a knock on effect on feelings of isolation, help-seeking behaviour, coping strategies and general awareness of existing services.

Although not commonly found in the ethnicity and mental health discourse in the UK, some work from the US on 'minority stress theory' may be of interest. Meyer, researching mental health and same sex relationships, has argued that since stress is related to social structures, individuals from minority backgrounds are subject to excess stress as a result of their social circumstances, that is being a minority, within a majority, position.[36] He argued that stigma, prejudice, and discrimination create a hostile and stressful social environment that can cause mental health problems, including the experience of discriminatory events and media reporting, expectations of rejection, hiding and concealing. Of course, minority status is not the only source of stress and in utilising this deficit model one must be wary not to overlook the resilience and positive coping strategies used by many.

The Mosaics of Meanings research in Glasgow also found that racism is a common source of mental distress, especially amongst the African and Caribbean communities.[37] Our evidence suggests it is also a source of distress in several other communities. For example, at the Gypsy/Traveller Health Fayre, when asked, on a Poster Question, 'What affects your mental health?' the response with most votes was 'How others see us', followed by 'alcohol', and there could well be connections between the two.

Using Poster Questions at the Gypsy/Traveller Health Fayre

Defaced poster

Interestingly, the poster advertising this event was also defaced with 'dirty gypo' scrawled across it whilst the event was going on.

The Gypsy/Traveller interviewees made frequent reference to racism, or the fear of being treated differently, often shaping their lives in such ways as to avoid situations that might place them at risk. Similarly, interviewees often made reference to hiding their identity in case it placed them in danger, for some it had almost become a way of life. One woman who attended the Health Fayre said

"you grow up knowing to keep who you are to yourself it is just safer that way, I know it isn't right but I tell the kids that too".

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[36] Meyer, I.H. (2003). Prejudice, Social Stress, and Mental Health in Lesbian, Gay, and Bisexual Populations: Conceptual Issues and Research Evidence, in *Psychological Bulletin* 129(5): 674–697.

[37] Glasgow Anti Stigma Partnership (2007) *ibid*

Another woman described her concerns about possible repercussions:

"It's very negative. I can go in and say I'm a Gypsy/Traveller, I taught my children to say that, although I've got the confidence to say that and so do my children, my child went into school and never declared it. If push came to shove, if she was backed into a corner I still don't know if she'd declare it. It's not that we're not proud of it, it's everything that comes with it, the backlash that comes with it. Of course it makes you fed up, we're very proud people".

Similarly, for Gypsy/Travellers in particular, community isolation is an additional barrier for those who have experienced long-term misunderstanding and prejudice which has led to an increasing distancing from services, including health services. During the awareness-raising training, Gypsy/Traveller trainers said it is not uncommon for community members to travel hundreds of miles to see a known GP or Health Visitor, rather than risk rejection at a local surgery. The following extract from an interview illustrates this practice:

X: "... my sister has problems [mental health] and I had her child for quite a while because I was frightened in case the authorities intervened.
Y: Do you think that is common in the community?
X: Most definitely, especially when a child is concerned. I'd go 100 miles to be with my nephew and thinking that a Health Visitor was maybe going to come and see my wee sister in 2 hours because she was very unwell I'd be there in an hour and have my nephew away from there before she even came.
Y: And that fear…
X: It's a genuine fear, I've always had that fear. I've had that fear since I was a baby, and it was confirmed when I was a young mother on a camp site when the police actually visited and threatened to take my husband away and put my children in care. That was where my confirmation came from".

Under such circumstances, it is perhaps hardly surprising that there was little, or no, understanding of the availability of PCMH services.
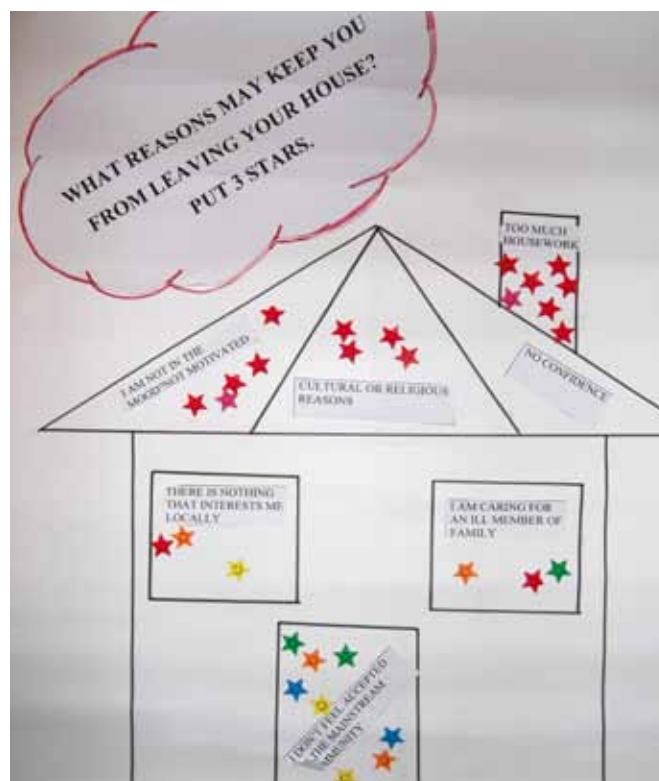
In project group work, we found that the impact of racism and discrimination was a consistent theme emerging across the different groups. During our engagement with BME residents in North Edinburgh, racism, stress and isolation were identified as the key factors

impacting on mental wellbeing and it was argued that racism could very well be the cause of participants' stress and isolation.[38]

Photography workshop – a visual representation of stress and isolation

In Midlothian the women's group was asked to vote on the things that kept them from leaving their homes, since many had said they felt isolated. The top score was: *"I don't feel accepted in the mainstream community";* further discussion revealed this was based on previous discriminatory experiences such as name-calling, 'dirty' looks and body language, and feeling patronised by the way that some people communicated with them. Importantly, it was also based upon stories of what had happened to other people within their community. The fear of rejection, based on discrimination, seemed just as problematic as the actual rejection.

Using Participatory Appraisal tools in Midlothian

[38] Equally Connected (2010). *Report 1*

Whilst piloting Living Life to the Full with a group of BME women, it became clear from a very early stage that the materials failed to include societal issues such as racism, and this was mentioned immediately as an issue with a large impact on mental wellbeing. It became increasingly difficult to fit racism into the coping methodologies taught in the course, without blaming the person for the racist incident. This together with some language used in the course DVD, for example, referring to black as a constant negative, was poorly received by the group, making them react negatively towards the remaining learning within the DVD.

In the interviews and case studies it was even more apparent how much distress racism can cause - there was also reference to the way some communities are portrayed in the media, leading to a greater fear of racism and increasing the false information and myths in the public domain about some peoples and cultures:

"Also when people look at me, bas [meaning that's it, enough] I think it is because of my dress and then I feel like … bad, and sad, because I think my faith is not good. Here all things about Islam are bad in the papers, on TV, everywhere. This makes me sad. At home I feel proud and find hope and direction but not here" (Libyan female student)

Many Gypsy/Travellers also felt media reporting of their community was primarily negative. As one woman commented,

"…it's all bad publicity, and they've nothing nice to say about Travellers. Actually we had a convention … last year and there were thousands of caravans there … you never hear the good stuff. Thousands of Travellers in the one place praising the Lord but no they couldn't say this is Traveller people, because they are clean and they are tidy".

Some interviewees also described being referred to a service/therapy which, from their perspective, had been unable to tackle the root cause of their depression:

"I was then referred to a confidence-building group, but I think that was a wrong referral. And I just went with it, thinking that might be the right thing. She thought, the circumstances when I was low, at that point, were related to professional career … but I think I needed to speak to someone more about what I was going through. Because I had experienced discrimination and that was the cause of my low point" (Arabic-speaking female)

One African man describes what he feels was his psychologist's inability to spot the cause of his depression:

"My perception or the way I viewed it, whether I was discriminated or I experienced some racism, so I was a little bit hesitant to start talking to him because even though he is a psychologist, still I had my, you know closed doors, yet I did leave a lot of things open, that's how I concluded to say this guy's useless, because he didn't dig deep to open those doors. I closed the doors purposely, to see whether I can, make my expectations, can he come to where I think he should be, so I closed some doors to leave a challenge whether he would be able to open those doors or at least try. He did not".

Similarly, for those who look different to the majority population, either because of dress or colour, participants often questioned whether people acted or reacted in specific ways because of the difference,

"... it came as a surprise for her because they rarely see dark skinned people around those areas, so she was quite surprised. And she asked me what am I doing here and I told her that I live here, I'm just going for a walk. And she was really shocked to hear that. Just from the expression on her face, it was strange and shocked" (Midlothian BME female)

Others mentioned the perceived inability of GPs and service providers to understand the importance of this issue:

"Anyway the doctor is too quick in handing people anti-depressants things ... they didnae understand the name-calling and the eggs and other stuff, no really knowing how that made me feel and being apart from my ain folk. Think they just thought I should be happy I was in a house, but those four walls were crawling in on me think that's why I went to the park so often, fresh air" (Gypsy/Traveller female)

Another participant noted the need for service providers to simply not make assumptions and be more aware:

"What might those additional needs be? Awareness of the fact this person might face racism, they might be more isolated, this person may be coming from different cultural contexts from your cultural contexts and taking that on board or trying to understand or even try to be empathetic if they don't have the lived experience" (BME carer)

As the quotes above illustrate, many BME people we worked with did not feel service providers made, or fully understood, the links between racism and mental health.

7.3 Stigma and Shame

Throughout our research, shame and stigma around mental health, whether perceived or real, was raised as an issue within all the communities we worked with. Such concerns often led to increased anxiety, created barriers in terms of accessing help to deal with negative mental wellbeing and a desire to keep problems hidden from the wider community. The complex issues surrounding stigma within BME communities have been explored by other work in Scotland including "Are you really listening"[39] and Mosaics of Meaning.[40] Our research confirmed many of these findings and we managed to capture the sentiments around shame and stigma and what it means to individuals in relation to their mental wellbeing.

During community events Poster Questions were used to gather opinions in an anonymous and non-threatening way. In terms of shame and stigma, the most useful question was 'what affects our mental health?' More specifically the option 'the way people see us', seemed to hint at the complexities around shame and stigma. These findings were backed up by staff observations and informal conversations with participants.

What could be seen as slight indications of shame and stigma from the Poster Questions were reinforced by information gathered during group sessions. Where some groups, such as the carers' group, the international students and Arabic-speaking women were happy to speak about stress and other anxieties connected to mental wellbeing from the very beginning, others, such as, Midlothian Active Women remained reluctant to speak openly about the issue over a long period of engagement. This alone indicates some of the strength of beliefs about stigma and shame.

Sometimes group participants, for example in Midlothian, would happily speak to a project worker about mental wellbeing whilst on their own, but never whilst in a group setting. From the very beginning this group of women was happy to speak about other aspects of their physical wellbeing within the group setting, but when asked about their "happiness" or wellbeing they would claim to not have any concerns or problems whatsoever. However, when an imaginary woman of the same origin, and similar situation was used as a discussion prompt, a number of issues relating to mental health emerged and the women were able to discuss them passionately. This is perhaps an indication of the issues surrounding shame and stigma, especially where numbers are small in a semi-rural setting, making it hard to remain anonymous.

[39] NHS Health Scotland (2008). *Are You Really Listening* NHS Health Scotland

[40] Glasgow Anti Stigma Partnership (2007). *ibid*

Stigma, and the accompanying sense of shame, was also well-captured during the Community Conversations conducted with Arabic-speaking women and carers. This tool made it easier to explore issues such as stigma and approach them in a non-threatening manner. With the carers' group, some of the complexities around stigma and shame were immediately evident when participants were asked to agree or disagree with seven statements. In response to *'I would be happy for someone with a mental health problem to marry into my family',* seven out of nine disagreed, of whom five strongly disagreed. For the statement *'if I had a mental health problem, I wouldn't tell anyone about it'*, six out of nine agreed, four of those strongly agreeing.

These responses could be linked to some of views expressed earlier about recovery. During the same Conversation, participants also mentioned factors like upbringing, family status and the importance of marriage as the causes of much of the stigma related to mental health, in turn causing shame for carers and those experiencing mental health problems as this stigma is internalised. In small communities, with close-knit families it is more difficult to remain anonymous and avoid gossip.

When it came to discussing stigma, the carers were very vocal about the stigma surrounding mental health which negatively affects people within the various BME communities. In the second session, several participants also vocalised their concerns about one of the anti-stigma campaigns (posters and other visual materials), suggesting that they were inappropriate and ineffective for those from a BME background.

Similarly, the Community Conversations held with the Gypsy/Traveller and Arabic-speaking groups also included discussions about a general lack of understanding from the community about what mental health is and the suggestion was made that the Community Conversation provided a good opportunity to inform people. Furthermore, participants agreed that mental health problems within their communities were usually looked upon as a serious illness that could be potentially contagious. For the Arabic group issues of marriage were also keenly debated, with examples given where a husband, as the main provider, with perceived mental health problems, would immediately be rejected by the woman's family. Some added that for women, as mothers and principal homemakers, there would also be a fear that mental health difficulties would be inherited by children.

In talking about the fear that mental health problems can be inherited within the Gypsy/Traveller community one woman remarked it can be

"... shaming for the whole family, like 'look at them'. But basically if you've got it, it comes down to shame ... do you know what I mean? Like it would run in families or that, you hear it all the time but naebody will actually say that tae your face" (Gypsy/Traveller female)

As with racism, throughout the Gypsy/Traveller interviews and case studies, regardless of age, there is frequent reference to stigma and sense of shame, in particular losing pride if you admit you suffer from mental health problems both within the community and if you have to ask for help outside of the community. As two women said:

"I'm shamed to death to say anything to my own folks, not even my sister it would be like saying I am crazy or mad".

"It's shame, innit? It's more shaming … people would look at you as if you are mental, do you know what I mean? Other Travellers, most, they don't want to know ... But it is no just about money, anyone can get it, but they like to keep it hidden, keep you away from folk, like it is catching, a disease or that".

A sense of shame, and similar sentiments, were expressed by others, across all the groups with whom we worked. A woman of African origin said

"... there's awareness but there's stigma of being associated with those services because you don't really want people to think that you can't manage, or you're not managing, so these people, more people who should be coming for those services are not because of the stigma of being seen as mentally unable to cope by yourself" (LLTTF female)

"If you have a pain keep it close to your heart, don't show it to other people. It's disgraceful thing, it's a shameful thing if other people see you are looking miserable or you are having these scratches on your arms – it's not what I want to be seen" (Chinese female student)

Amongst international students the fear of stigma also acted as a definite barrier to seeking help, particularly in case a record was kept which could then be passed to funders, employers or families:

"... like in China every department is connected but here there is the divisions and maybe she's scared that if she talks about something, some other people – the school will intervene or you know, in a bad way, suspend her study or something" (Chinese female student)

Within several groups, there was also a sense that mental health problems are a sign of weakness, displaying a lack of strength to deal with life,

"you can't say, my weakness, I feel weakness, I feel bad, you know? It's like failure if you say it" (Arabic-speaking female)

This notion is backed up by results from the Stress Buster quiz where 38% of respondents thought that depression was a sign of weakness (see Appendix 2 for details).

There also appeared to be a gender difference in dealing with stigma. Where women may, when necessary, seek support from each other or the wider community when dealing with depression, men would often act differently. Similarly, in the interviews women seemed to find it easier to raise problems about stigma and shame, whereas men seemed to speak about helping themselves via other means – often related to different ways of coping by themselves rather than admitting to the wider community or professionals that they were experiencing mental distress. Is this perhaps linked to issues raised in the Arabic group relating to the expectation that men will be 'the provider', perhaps making the sense of shame even greater? A Gypsy/Traveller woman raised a similar issue about the men in her community:

"It is there within Traveller men, but within Traveller men nobody knows about it ... a women would tell another women, there is no way a man would tell another man he was depressed. I think probably it's harder for men, they can't express how he feels to another man, never mind a doctor. They never go to a doctor, they just go to a chemist and bring back the whole chemist when they're not well. Under no circumstances would they go to a doctors and say I feel mentally unfit to care for my family, it's a no go area, because the man is the provider and the stronghold of the family".

In terms of stigma, for some, there are also signs of change:

"Yeah they're not too bad at that. Years ago they were but nowadays, they're not too bad on that. Like my friend's father with senile dementia, they probably wouldn't have shared it and said he was just getting on in life, just changing or being silly today, but now they will admit that" (Gypsy/ Traveller female)

And within the carers' group there was a willingness to try and work with 'see me' to develop materials more relevant to their communities to challenge stigma.

7.4 Ways of Coping and Resilience

Historically, those working in mental health services have often focused on vulnerability, or risk factors, which can sometimes be at the expense of acknowledging the capacity for positive coping and resilience.[41] How do people thrive despite adversity? What are their coping mechanisms (positive and negative)? Although more commonly discussed in relation to young people, Daniels and Wassel have described resilience as *"the ability to: resist adversity, cope with uncertainty and recover more successfully from traumatic events or episodes".* [42]

Factors influencing one's resilience levels can be intrinsic (personality traits, qualities, confidence) or extrinsic, located outwith the individual (close attachment to family, peer support, feeling accepted). In seeking to 'learn from BME communities about their mental health and wellbeing', we sought to gather data about resilience, information about the factors that assist people to thrive, and adapt, in the face of adversity. As could be expected, resilience factors varied from community to community, and individual to individual. However, there were a few cross-cutting themes such as faith, friendship, culturally sensitive support, using the arts and more individual approaches.

7.4.1 Importance of family/friends

As stated earlier, there was a distinct reluctance to attend the GP when experiencing anxiety or depression. Instead, when answering the Poster Question *'who would you go to for support when feeling depressed'?'* the majority in the BME groups we worked with, stated they would seek help from family and friends. During follow up discussions at events, participants often added comments like: *"they know your situation", "would trust my friends first, they'd know what I was going through"* and *"would try to get help or advice from them first".*

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[41] See Scottish Recovery Network (http://www.scottishrecovery.net/What-is-Recovery/what-is-recovery.html) and The Patients' Council (Royal Edinburgh Hospital) (2010). *Stories of Changing Lives*

[42] Daniels, B. and Wassel, S. (2002). *Assessing and Promoting Resilience in Vulnerable Children (Early Years)* London: Jessica Kingsley

This finding was confirmed in interviews with women, young and old, and across cultures, as the following quotes reveal:

"I talk to my friends, because they understand, we're from the same culture. You just have to get on with it really. You can't have it keeping you down. I have friends, thank God! It's really difficult if you don't have friends. Especially if you need help, cause they can be the ones who sort you out. Get out and meet some friends" (young BME female)

"If you're in a trailer [caravan] and there's someone beside you, their problems are your problems, there's a bonding…" (Gypsy/Traveller female)

"I think you have to be amongst your community to sort of get all the relevant help you can source" (LLTTF female)

"... it was just like self-help, you just spoke to your sisters or your family or your mother-in-law about what the problem it was then and at that time families rallied round if there were any family problems and helped you out of it and that. And I think that culturally that goes across the board for all Asian cultures" (BME carer)

"I find that for example I come from Africa, it's a bit about, I think we have less mental health issues because someone will spot it and pull you up on it because it's all very community based, whereas here it can be so isolated and people can go downhill without people noticing it" (BME carer)

Interestingly, as noted above, men were more likely to suggest other options such as doing sports activities or joining societies,

"... he can improve his situation … do exercises, sports, and maybe clubbing, perhaps, he can meet people of different orientation, so that he can at sometime divert from his particular problem, divert his mind this way, and who knows maybe he can just get his mind off this trap and get happiness somewhere else" (African male student)

Although for some individuals, particularly women, in speaking to friends and family in the UK or 'at home' there was also an element of caution and a pressure to 'keep up appearances' and, in turn this could lead to, further isolation or loneliness (see comments about shame/ stigma in section 7.3).

"Well I think speak to friends and family first but then again ... may not want to as it is difficult when you are here, alone without your auntie or sister. Some people might choose to share with those back home on the phone but that can be hard too and they can be hard on you. There is this attitude 'oh what are you complaining about you have water and electricity and there is no fighting where you are what can be wrong in your life?' From the third world this is the view and you are made to feel you should feel grateful you live in the West, but it isn't always like that, here you can feel so alone" (Arabic-speaking female)

As the same woman went on to explain,

"... as I said speaking to friends or family but that can be a double-edged sword, for women it is much worse. Especially as a mother you are expected to 'cradle' everyone, your husband, your children, your family and there is an expression as a mother you give and receive last".

However, it was also acknowledged that there can be disadvantages too in speaking to someone in your own community and concerns, as one woman explained:

"... there is a lot of controversy about confidentiality. Sometimes people don't want to come to someone who is from a same country for support and guidance because it might get out into the community" (LLTTF female)

"... [go to] somebody you can confide in you, it depends how close you are with them. If it's a relative or a sister-in-law but you'll find that a lot of women keep it to themselves … me personally, if I had a problem like I'll not go to my mother, I'll not go to my sisters. I'd have more confidence speaking to a stranger sometimes than I would coz I still feel shame discussing things with my mother and my sisters, that's it amongst Travellers, keeping up appearances. But I think it all depends just basically who it is. But sometimes you can tell, I think because I've suffered it, I've suffered depression" (Gypsy/Traveller female)

"The first thing is I went to talk to some of my close friends about my situation but actually I did some wrong thing, I really, really regret about this because during that time, in my second year... But actually I found that, probably I suddenly realised that I talked too much about myself and sometimes people are not really good in nature ... so they might look down on you or they might talk you secret or your difficulties to other people which makes the situation worse ... or keep my confidence and just try to treat my difficulty as a kind of joke to others" (Taiwanese female student)

"Well, it would be better somebody different outwith the family that she could talk to ... especially if her family's not here, and they are abroad and obviously the distance makes it that she'll be telling them and they'll be worried about her, wondering how she's coping, what's she doing. So this way she's getting help first hand without passing on any anxiety to the rest of her family" (BME carer)

On the basis of learning from Equally Connected's events, interviews and group work, it is clear that family and friends are the primary source of support and sometimes the only source.

7.4.2 Faith

The importance of religion or spirituality, both as causal factors, and potential treatments for mental illness, has been well-documented elsewhere.[43] Our small scale research was not an attempt to investigate this issue in depth, nor are we in a position to suggest religion or spirituality is more/less important within the BME communities we worked with than within other communities. However, it is a factor that was raised by participants on a regular basis at health events, during the LLTTF course and in interviews. Comments were not restricted to any one religion. Some examples of where religion or spirituality were mentioned are noted below.

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[43] Glasgow Anti Stigma Partnership (2007). *ibid*

Arabic Poster Question – when depressed how do you make yourself feel better?

At the Arabic-speaking women's event, when asked *"When you are unhappy/depressed how do you make yourself feel better?"* the top-scorer was 'prayer' followed by 'speaking on the phone' and 'exercise'. The use of religion for guidance or support when feeling depressed was also confirmed on the Poster Question used at the Gypsy/Traveller women's Health Fayre and in interviews with several individuals from a range of ethnicities and faiths.

One Arabic-speaking woman described the importance of her faith:

"Islam is not something you do once a week or whatever, it is all encompassing, all around you, it is what you wear, what you eat, how you stand, how you talk, how you look and communicate. Often people don't understand that they think it is just going along to the place of worship once a week but it isn't, and it needs to be part of my recovery".

When asked how she had improved her wellbeing and built up her confidence another woman said,

"... at the mosque, they [flyers] would go on the bulletin board or someone would hand them out after prayers. So after so often, you see people you recognise but they don't know you; you say "I keep seeing you but I don't know your name". So then I slowly started to bond" (LLTTF female)

One Gypsy/Traveller woman described the role religion had played in treating her depression,

"I do gain my strength from the Lord ... twice a week I went to my church, I've got commitments, I clean it, I sing and through the Lord, I'm not saying I've never lost my temper or never been angry, but God has sustained me in it. If I didn't have God to turn to I probably would be in a straight jacket".

Another Gypsy/Traveller suggested the first place someone with depression should seek help should be,

"if she belongs to a church or chapel, if she's been on first name terms with the priest or minister, go and speak to them".

Similarly, in a South Yorkshire study, Marr found that Gypsy/Travellers often stated that faith played a significant part in their overall feeling of wellbeing.[44]

Another Gypsy/Traveller woman acknowledged the importance of Christianity for some in her community,

"... now, for some of us they go to the church, but that's not for me. I don't like the way they tell you what to do, taking the control away. I know it helps them that is grieving or sad but you don't know where you'll end, it's the way the promise you I don't like. Nope, not for me. Even if I have to stick to the tablets"

and another said

"see well when they're dealing with mental health, they think like sometimes a lot of them are Christians and they think that helps a lot and this is what they believe. This is their way of dealing with it".

A young carer, looking after a terminally ill partner, spoke of the importance of being able to speak to someone who understood her faith:

"Two weeks ago I heard that my husband was going to die. Two weeks ago I saw a Muslim doctor ... as soon as he heard it he said "Mrs … I understand, because I am a Muslim myself". You know, it's Allah, and then doctors come after that. As soon as he said it I had a comfortable level straight away. I don't know how, but I had it. Because I thought this man understands. I wanted to make another interview, appointment with him, to

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[44] Marr, C. et al (2008). *Community Engagement Project: Gypsy Traveller Community Research in Mental Health*, University of Central Lancashire

find out what the procedure is after someone dies, if I want to send back home. Straight away it was in my mind that I could talk to him, basically. He would understand my feelings" (BME carer)

When asked how mental health support services could be improved, one LLTTF participant suggested using her place of worship:

"They could have some kind of programme with the mosque for people who are newly arriving. We have this thing where I'm from for new Muslims or people who have relocated to the city, they have a big breakfast for them, it's like welcoming them and to introduce them to other people, they don't feel alone. I'm new here but you're new too, so we have something in common".

In trying to use CBT approaches, during the Living Life to the Full course, some participants said they sometimes struggled to also accommodate their own deep rooted beliefs in 'fate' , 'God's will', tests and punishments, and so on. At times they felt the way their faith had taught, or expected, them to perceive certain situations, including overcoming them, were completely different from and at odds with the CBT-based suggestions. For example, in week 3 of the LLTTF course participants are told *"bad thoughts are like bullies. They sound strong but really they're weak underneath. And they tell lies".*[45]

A BME carer also talked about the influence of her religion:

"Well, see in the Sikh culture, it's [taking medication] quite frowned upon, but then now when you look around, the people are taking them because they think that that's helping them and it might be keeping them calm for a few hours or something or helping them to sleep. But it's not the answer".

It should also be mentioned that some research participants felt that religion, or particular interpretations of their faith, had also been used against them:

"It is not something some women [Muslim] know they just seem to think they have to live with it or it is his upstairs [Allah's] way. It is in the book and part of life and sometimes men make you think this and make it worse. Islam has become a kind of girdle, clasp for women. But it shouldn't be there that isn't what the real faith says" (Arabic-speaking female)

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[45] C. Williams (2007). *Why does everything ALWAYS go wrong – and other bad thoughts you can beat*, pp13

Similarly, one young Gypsy/Traveller woman described her father's attempts to deal with her self-harming:

"He [her father] knew he couldn't sort it on his own so he sent me to the Church (it was really big around X at that time) but they just made me feel worse like it was my fault again because I wasn't a good person or something. I know some people think the Church is good but not for me, I think it is like brainwashing – I know people will get mad when they see that but for me that is what it is, they take away your brain so you can't think for yourself. They also don't want you to mix with others. I used to get dragged along to their meetings but it was awful".

In the film, Facing Life's Challenges,[46] a carer expressed more mixed views about his faith, "according to the religious point of view, whatever they are in this life it's because of what we done in the previous life ... some people think, you know, if he got that sort of disability he done something wrong in the previous life. First of all, that person is suffering because of some kind of disability. Secondly, that person gets discriminated by the society. So there is some sort of taboo that in a way you deserve. That sort of attitude hurts to some people, probably more than me ... it hurts I think".

Spirituality, and faith in general, was not an area that the Equally Connected project intended to investigate, nevertheless this issue was raised by many research participants, especially when talking about coping strategies or ways to overcome isolation.

7.4.3 Using the arts

Our success in using the arts as a means to raise awareness of, and de-stigmatise, mental health has been mentioned above. It is perhaps not surprising then to note the number of individuals who, at a personal level, mentioned using the arts, including dance and story-telling, as coping strategies:

"Listen to music. Sometimes, you wouldn't believe it, I would just, I wear a scarf, but sometimes when my daughter is sleeping and my son, I would actually just close the door and just dance away. I know it's very weird but I've done that. Sometimes I would think "I'm so stupid, what did I just

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46 Two films were produced by Equally Connected, *Facing Life's Challenges* by a BME carer and *Breaking Isolation* by international students

do?", but it makes me feel better in some way or other. Sometimes in the bathroom I would just sing. So that's a small thing. Sometimes my son would come running to me and say "what are you doing Mum?" and I'm like What?... it's something you're doing for yourself ... this is the way you are soothing yourself" (BME carer)

"Creative activities, like just walk down the road and watch the faces of people around, thinking, what are they thinking, do they have problems or something like that" (Arabic-speaking female)

"Yeah, since then I have joined some groups for drama, for dance. And I think that has really helped me enormously. You can't imagine how much, you just need to be able to listen to music and move with it, is such a healthy way to deal with what is going on. Because movement, being creative, it's just very healthy. ... I think a lot of people use it to offload their issues and I just find the energy that it gives very beneficial" (Arabic-speaking female)

Similarly, when asked about the importance of fashion in a focus group, young BME women said:

"people can't always express how they're feeling by words so sometimes they do it with fashion and how they look and that".

Scottish Mental Health Arts and Film Festival exhibition October 2010

And, during the Scottish Mental Health Arts and Film Festival exhibition, a Gypsy/Traveller woman described how she had used poetry to share her personal experience of living with, and overcoming, depression. Her insightful poetry described for us what it feels like to hide your cultural identity and the impact this can have on your sense of wellbeing.

7.4.4 Other Coping Mechanisms

Many of those we spoke to felt that coping had almost become part of their personality –
"and my personal trait is, especially growing up away from home, away from my family; has taught me to be self-reliant and coping with a lot of things on my own" (Arabic-speaking female)

Whilst other individuals described actions they took 'just to reduce the isolation' or 'be on their own',
"sometimes I just go and sit in the shopping centre just to see folk but even then I don't know them, I can't tell them" (Gypsy/Traveller female)

And another older member of the same community suggested,
"they need to mix with people and take an interest in life again, because if you let that go, you've nothing. It's not looking at televisions and looking at books, you've got to get out there, go for a good brisk walk and get a wee animal or something"

"I would never go down the anti-depressant route even if it was forced down my throat. I'd rather look at other holistic therapies" (LLTTF female)

Others embarked on further study:

"I had never been to the centres before, I mean Travellers didnae dae that kinda thing, we'd never go there, too long we are used to getting turned back from those kinda places. I was fascinated, as soon as I walked in and all these courses that could maybe help me, improve my reading and my writing a bit, and there were a de-stress buster course, what was that? I had nae idea about stuff like that. People think I'm mental, eh, going to these courses" (Gypsy/Traveller female)

"....to study some courses, to study English course because I have to find my way and that means I have to know English, first of all. So now I am studying English course. I feel more confidence about myself, about my life" (Arabic-speaking female)

The same woman has now gone on to set up a support group for women like herself, "actually I'm established now in [X] women's group, especially to discuss these things, like "why you don't get out to take over, take control, to lead your life", so I say to them "if you want to keep your life healthy and happy you have to get some knowledge about the area you live, you know. Because that will be good for your mind, for your relation with your children, for your relation with your husband, for yourself because the human have to have some friends, some communication with other, something I want to do just myself, not to other people and maybe I can't explain that in English very well but that's something I already said to them when I meet them every two weeks in my group".

Similarly, a carer described the benefits of culturally specific befriending and self-help services that she had used,

"because all the women there, they speak my own language and we can sit and chat. You can just drop in at any time. There's always somebody there to listen to you".

With the exception of Gypsy/Travellers, many participants acknowledged the significant support they had received from BME specific, and community health, organisations such as Saheliya, MECOPP, Health all Round and Sikh Sanjog. Several international students also mentioned support they had received from the Chaplaincy, regardless of whether they had a faith or not.

Some people also brought up coping mechanisms which might have a more negative impact. We were unable to interview any Gypsy/Traveller men in person specifically about mental health issues, although early in the project one man did comment to the Project Manager: *"Come on, you know Traveller men just don't do health".* Nevertheless, several Gypsy/Traveller women did comment on how they felt their brothers, husbands and fathers coped, adding that they thought men were under an enormous amount of pressure, often using alcohol as a coping mechanism:

"... the only way a man will cope with it is taking his frustration out on his wife, that in itself is a man's escape from depression. Either that or drinking alcohol"

"Well, you ken what its like Traveller men just don't go to the Doctor…there is an even bigger problem for Traveller men, they do get depressed, of course they do, I saw it in my own father but no-one talks about it. Why do so many turn to alcohol? That's probably their way of coping"

"Thinking back he [her ex-husband] was depressed too but reacted in a different way, with temper and I couldn't live like that, I'm no like that, I wasn't brought up that way"

8 KEY LEARNING – SPECIFIC THEMES

Throughout our research it quickly became clear that in addition to the cross-cutting themes presented in section 7, there were a number of factors specific to particular BME groups.

8.1 Gypsy/Travellers

There is limited information available in Scotland with regard to Gypsy/Travellers' health status, but increasing evidence from elsewhere that Gypsy/Travellers experience significant health inequalities, high infant mortality rates, premature deaths and higher than average rates of major long-term conditions such as diabetes and cardiovascular disease.[47] In Parry's matched-subject study, researchers found that overall Gypsy/Travellers reported poorer health status than both white British residents and other minority ethnic groups. In comparison, Gypsy/Travellers were much more likely to have a long-term illness, health problem or disability. A recent report by the Keep Well team in Lothian has confirmed similar findings.[48]

Similarly, there is very little published research on Gypsy/Travellers and mental health in the UK. According to Parry's research Gypsy/Travellers have amongst the highest levels of mental distress in the UK, which results partly from the forced evictions, constant harassment and the physical health problems many individuals face. Similarly, a community-led research project in South Yorkshire highlighted a distinct lack of awareness about a range of mental health issues and a number of gaps in provision.[49]

In addition, anecdotal evidence suggests a high rate of mortality through suicide although no accurate figures are available. A recent research report commissioned by the Equality and Human Rights Commission recommended *"that urgent research is undertaken into the prevalence of suicide and self harm amongst Gypsy, Traveller and Showpeople communities in Britain, as no adequate statistics exist on the true extent of the problem, or on the numbers of families affected by premature death by suicide".*[50]

In discussing mental health and wellbeing, two major issues were raised by almost all the Gypsy/Travellers we spoke to, at events and during interviews – the pressures of living in a house and having to hide your identity.[51]

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[47] Parry et al (2004). *ibid* and University College Dublin (2010). *All Ireland Traveller Health Study; Summary of Findings*

[48] Lambie, J. (2010). *Report of Keep Well Gypsy and Traveller Outreach Service* NHS Lothian

[49] Marr et al (2008). *ibid*

[50] Cemyln, S. et al (2009). *Inequalities Experienced by Gypsy and Traveller Communities – A Review.* Research Report 12 EHRC

[51] Equally Connected (2011). *Report 7*

In relation to accommodation, for many, regardless of where they were living at the time, there was a strong feeling that there is now a lack of choice or options and many felt they were being forced to live in 'bricks and mortar'. Respondents clearly regarded living in a house as having a major impact on mental health, as the following quotes illustrate:

"It was the loneliness that was the worst; just sitting looking at four walls, what kind of a life was that"

"Staying in a house is the depression itself that is what starts the road to depression is staying in the house. Especially in the summer months, and nobody listens to you"

"How did I feel? It's hard to say, just like the house had something to do with it too, we'd never been in a house before and those walls. Oh I remember being in my room and just sobbing, there was no air, just closing in around me ... it's these walls – how can I explain it. You'll think I'm daft, you can't put it into words but they are coming in on me"

The Parry research also found that depression and anxiety, especially amongst housed Travellers, were much higher than the national average.

However, a few women did acknowledge some benefits of living in a house, particularly if suffering from long-term health complaints:

"Well some things were better for me – like showers with having X problem, they were better for me. But other things like just coming out the door I used to see people all the time, whereas in the house I didn't know anybody and I found that everybody kept to themselves. Whereas in the trailer, everyone says 'good morning' and that's what it's like on the camps".

The same woman described her own coping strategy when she first moved into a house,
"... when I first went into the house, the thing was I wasn't too far away from a caravan site where my parents and brothers were. So ... when my husband went to work I just jumped in the car and that's where I went every day. Near enough every day I went down there, when I shouldn't have been going down every day, but I was at first. I went down there an awful lot".

Another woman, who had recently separated from her husband, something she thought others might view as 'shameful', also acknowledged that she had more privacy in her house,

"... but I also couldn't go back into the trailer. Everyone would have known. At least in the house I had some kind of a private life but it was hell, I cried so much, not just cried, sobbed".

For most, it was not only the impact of living within 'four walls' but also the physical isolation from other community members and a fear about how this could affect you:

"In amongst Travelling People I believe there would always be somebody by that person, unless they were in a house. In a house it would be very dangerous as they'd be very isolated from their own people"

"But when you're in a house its different coz you've not got that same closeness, you're isolated. Do you know what I mean, the next person to you might be miles away so, you know what I mean, so they cannae come and help you".

The words 'depression' and 'stress' were often used interchangeably and there were strong links to environmental factors – the absence of a safe place to stay and discriminatory attitudes were felt to be contributory factors to poor wellbeing. As one woman said

"instead of using the word depressed we'd more use the word distressed, we would more use that... I don't know if you would find depressed and distressed different".

There was also a strong sense that 'being down' or depressed has almost become 'part of life', something you have to get on with; this was often combined with believing in fatalism and stoicism.

One woman identified a main cause of stress as:

"Things that get you down as a Traveller is maybe travelling 100 miles to a site and you can't get on, that's a really distressful thing. Then maybe having to pull into a lay-by for a night, with no electricity, no nothing, till the man goes out and finds you a site the next day. A lot of sites you think you can get on them but you just can't get on them, which is ridiculous because you're going and paying rents just the same, that's a stressful thing! It's mainly because they're Travellers that they can't get on; they don't

let them on because of that. Or they're there for a couple of hours, then people from round about just phone and then they're getting told to move in the middle of the night, with kids – so they're stressful things ... That's the most stressful thing is not getting on the sites and getting moved off sites if they've only been there for a couple of hours, which then causes arguments. That's definitely the most stressful thing".

However, those who had suffered stress or depression did not necessarily identify as having a 'mental health problem'. Instead, when asked during the Community Conversation what mental health meant to them, responses included: *"Do you mean if someone's not well in the mind?"*; *"schizo like"*; *"crazy, completely lost it, I know I probably shouldn't say this but some do need to be locked up they can't help themselves".*

Along similar lines, one older interviewee said:
"I'll tell you what I was told by my dad. Anyone who gets a mental illness, it's an evil that comes over them, like an evil spirit that comes over them because they've done something in their life that must be banished before the light comes into their mind and body".

Marr also found that respondents who experienced symptoms such as cutting, extreme tiredness, lethargy, inability to cope and so on did not regard these as mental health problems, leading the authors to conclude: *"This could be a reflection of the lack of awareness and understanding of mental illness; the respondents not considering their symptoms to be a mental illness, or a fear or unwillingness to recognise symptoms because of the stigma attached to mental illness".[52]*

Although most said they would not go to a GP if they felt depressed, there were others who felt they had had no choice. If the person had visited the doctor for depression most had not disclosed their identity even when they did think it was important,
"... it is relevant because the depression itself could be, most probably is, because of your ethnic status, and whether it be a relationship, housing, health, ... I don't think you feel any more depressed but there's different ways of dealing with it and different reasons for it being there in the first place".

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[52] Marr et al (2008). *ibid*

Amongst all those we interviewed there was a consensus that the GP would simply prescribe medication and many did not want to go down that route (see also section 7.1). There was virtually no awareness of other kinds of interventions. At the Health Fayres we included taster sessions of zumba and massage, feedback comments included

"... why does the doctor just give you pills when you could be getting this", "the doctor should have that massage on prescription"
and
"I've seen that exercise but never thought I'd get to try it, Traveller women don't get to do stuff like that".

As confirmed in other studies, whether GP, Health Visitor or simply a non-Traveller, it is vital that there is a relationship of trust and respect. Sometimes this can take months or years to build up, as one woman describes,

"... with country folk [non-Travellers] it is hard, you need to know a person, trust them like, know they'll treat you normal like, I can't explain that feeling when you think they might know who you are. It is like a churning inside, you see it in their eyes even before they say anything".

Fortunately, a few women did describe positive experiences with their GP, particularly when there was trust and understanding:

"The house was part of the problem for me, that must sound stupid to you but it was, I hated it. My doctor, he's been the family doctor for years. When I eventually went to him, about the flu actually, not about depression, he knew straight away, he'd worked with Travellers, he knew our ways. He made it easier for me. He said to me it's the house isn't it? I cried then, boy did I cry. I just let it all out. I still struggle with these four walls even after, what is it 10 years".

Another noted
"it will be easier... he would be aware she was a Traveller and she wouldn't have to go through all the details telling him that she is a Traveller before she tells him what's wrong ... for her to go in and say she's depressed and that she's cut off from her family. Being a Traveller is so family-orientated that the doctor needs to be clued up".

8.2 Location and Isolation

A common theme that kept emerging in Midlothian was the effects of living in a semi-rural area and the levels of isolation in the local communities. This is also evident from scoping and small scale research carried out by other organisations.[53] Sometimes these issues were expressed as disappointment or resentment, especially in relation to the limited services targeted at BME communities. Although at other times this point was made in a more proactive manner in the hope of change though usually led by, given the small numbers and busy lives led by most, a handful of passionate and confident individuals.

8.2.1 Location

One of the reasons Equally Connected was keen to work outside the City of Edinburgh, in particular Midlothian, was to look at the impact of living in a rural or semi-rural area. During regular group sessions with Midlothian Active Women there was much reference to not feeling part of the local community. While men may work locally or in the city, the situation seemed to be different for women where there was a greater risk of isolation as many remained in the home doing domestic chores, and/or looking after other family members, and rarely participating in local public activities.

In group sessions, often using an imaginary person to raise issues, problems such as the lack of places to go locally for socialising, depression, housework, domestic relations came up often. Also traditions and religious reasons were thought to prevent some women from engaging in local activities. For example, in the city there are various options for women-only activities and several culturally sensitive services, whereas there are very limited, if any, options elsewhere in the Lothians.[54] Many women said they had to travel to Edinburgh for services, especially for one-off events such as the Mela during the summer, or to join in activities at the Central Mosque, but for others this was not always possible due to cost or mobility difficulties:

"... it's quite easy for you, especially when you are living in town, but when you are living out here; you need to look for a close, something first hand. If you want to come to town, you have to think of, "where am I going to get my bus fare from?" (Midlothian BME female)

For the sake of their children some Muslim women do gather at a local school to provide religious instruction and language classes in their mother tongue. For many, this is their only chance to meet up and socialise.

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[53] ELREC (2009). *ibid* and MECOPP (2010). *ibid*

[54] Equally Connected (2010). *Report 1*

These views, and the absence of a sense of belonging in the local community, were also expressed in other interviews,

"I was really stressed. To me, in my perception of the UK was, you come and you meet people, just the same way you used to back home. But when I came here and I could not even see, for the first six or seven months I did not even make contact with a dark, coloured skin, so that really made me feel like, "oh, gosh, where are these people? Are they only found in London?" Because the only faces I could see were white, white faces. And that really got me stressed out a bit ... contacted one of the minority and ethnic groups in Edinburgh and made an appointment for me to go and talk to those people ... It was a big help to me. And that was how I started seeing people of my own colour, which was quite a relief to me, because it was like, say for six months you are coming to a country ... I could see somebody, like the same person as me. That was a relief to me, I would say. So I made friends and I'm still making friends" (Midlothian BME female)

Racism is not confined to the city as one woman described her first experience of volunteering:
"I had a very bad experience one time. There was this thing in the church and people were being asked "Who is free to help?" And then I raised up my hand. I heard a very funny comment from another lady who was just seated behind me, saying, "What can a black person do?" So I was really shocked, and the guy at the front said, "What would you like to do?" and I said, since this is a party, serving out plates and serving food and just cleaning the tables and all that. He said, "okay, fine" and he asked me for my name and he wrote it down. And then this lady, she was still talking to another, she is an old lady, and she was talking to a lot of friends, saying, "I don't trust something that a dark person does". And I just turned and I looked at her and she just get quiet. But I did not gain courage to turn and ask her why she said that or anything" (Midlothian BME female)

8.2.2 Isolation

Isolation was a key issue raised by many individuals and is a key factor in depression, but it was of particular concern to those living outside the city.

In response to the request from the Midlothian women we set up a regular programme of women-only exercise taster classes, but the sessions also acted as a way of addressing, and speaking about, isolation within the community. Interestingly, Midlothian Active Choices, an exercise referral service accessible via your GP, referred six women of South Asian origin to our group as they found that isolation was the major factor affecting their wellbeing. Language barriers and caring responsibilities for family members also limited the women's ability to leave the home, in turn increasing their isolation.
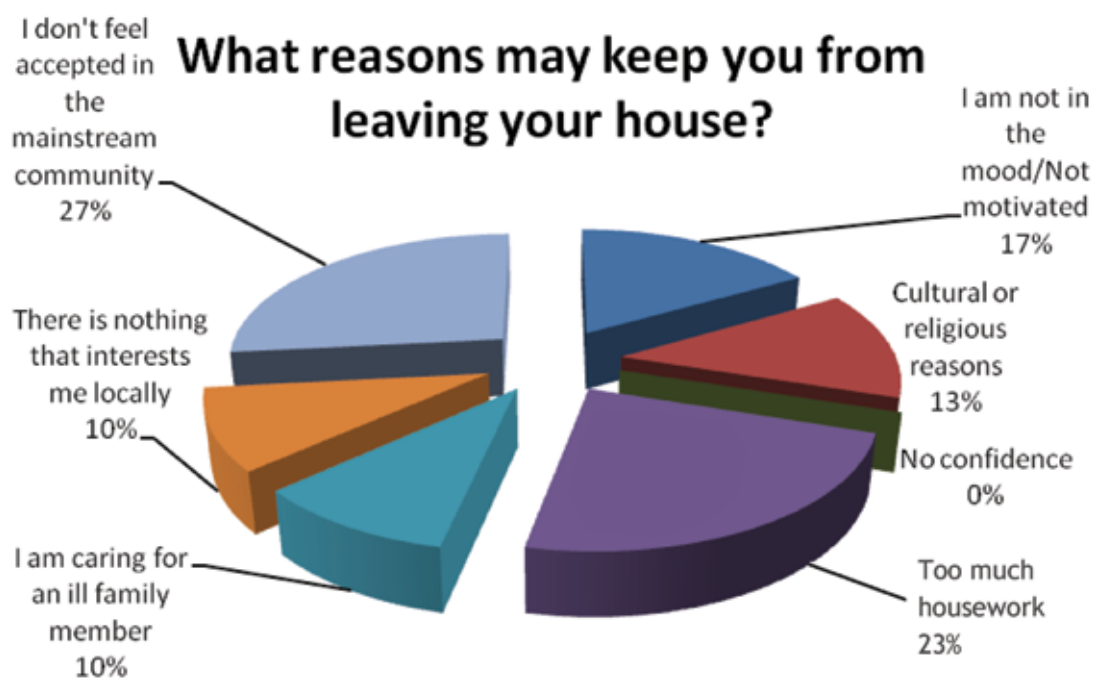

Figure 1 Causes of isolation

Interviewees all referred to the loneliness - many times the women said it was a relief to join the sessions as it gave them a reason to socialise with other women, this is also evidenced by some women who came to sessions even when they couldn't exercise due to illness, but they came just to watch and have a chat or laugh with their peers. While this might be expected with some older or married women, over the course of the programme we also witnessed an increased interest from teenagers and young unmarried women.

Workshop at Dalkeith Country Park

The sessions Equally Connected ran, in collaboration with Midlothian Council, were aimed at decreasing isolation whilst at the same time increasing awareness of local services and possibilities. Assisting the women to use local premises such as the leisure centres and country parks, has given some women more confidence to use them independently. Also, the first intercultural Wellbeing Mela in Midlothian, in March 2011, came about largely in response to the women being dissatisfied that such events only take place in Edinburgh. At the time of writing, a second event is being planned for the winter of 2011 and we are hopeful that Midlothian Council will manage to continue to support the women's group.

8.3 International Students

There is growing concern about the mental health status of students; NUS Scotland's Silently Stressed report highlights the main factors which can affect mental wellbeing whilst studying. The study did not collect data on ethnicity, nor does it specify home or international students but it does reveal some worrying statistics, for example, *"80% reported the stigma attached to mental illness would act as a barrier in approaching someone for support"*.[55] Similarly, over a third of the referrals to the Guided Self Help service at Health in Mind have come from students.

For international students, concerns about mental health can be even more acute. Our engagement with students at Heriot Watt University whilst making the Breaking Isolation film, and interviews with students across Edinburgh, further proved that misconceptions about the Scottish health system and a lack of knowledge about how to navigate the system were contributory factors in deciding whether or not to seek help before reaching crisis stage. Additional pressures relating to immigration, funding and expectations from home also added to the burdens experienced by some.

[55] National Union of Students (2010). *Silently Stressed*, p4

8.3.1 Navigating the Scottish health system

From the outset it was clear that international students, regardless of their country of origin, found the health system complex and *"very complicated"* – the main barrier was said to be *"not even knowing where to start"*–

"Friends I met, years after, they weren't registered in any GPs or anything and I told them, because they needed something ... they didn't know" (Iranian female student).

Another student described his first few months:

"I have a lot of queries about the system. When we came here, they don't really provide any information. It's a form or one e-mail telling us what they can offer and what to expect of them. For instance I visited the clinic here for the first time after about 1 or 2 months, they told me how come you didn't come to us at the start of the year and the insurance stuff I entered was wrong but, I don't know, nobody sent me an e-mail telling me I should do that. They should send information; try to communicate with people from the start because for people they don't think about their health unless they lose it ... you feel shy to ask people or you maybe don't want to ask, you maybe don't know how to go and ask properly about what services are provided" (Syrian male student)

In response to this kind of comment, Heriot Watt has now developed an easy-to-use Z card with a clear flowchart giving details about who and how to access support services. Similarly, the Breaking Isolation film has already been shown to over 3000 new students.

From a participatory session at Heriot Watt, the process of referral from one practitioner or service to another was especially confusing and presented a further barrier to seeking help. Many could not understand why they could not go straight to a specialist. As one Iranian female student explained,

"... he can't really define "I'm feeling blue and sad today". I think it's a bit difficult, some people might think it's not relevant when

Heriot Watt University Z card

they go to a GP to discuss that sort of stuff ... it's that much more difficult to open up to two people than one, cause you have to go to the GP and tell them what's going on with you and then after that you have to go and find another person to tell all that stuff to. So it's much easier specially for people who might be a bit more reserved, to only have to go through that once and not find different places to get help".

The language barrier, especially when using the telephone, was also frequently cited as a barrier to accessing services. Although most students have a good command of the English language they are often not prepared for the difference it makes when trying to understand the Scottish accent.

Generally, in relation to mental health, students did not have much awareness of what services were available or how to find them, this was particularly the case for those living off campus or joining after Fresher's Week. As one student said:

"... but these things, exercise and cognitive and things, but they don't probably know. Actually being part of the University I've never been in Teviot or the Health Service and I've never heard anything about that you see a lot of posters in the waiting room but I've never seen related to mental health or alternatives or things like that" (Taiwanese female student)

Even when living on campus, many were fearful of trying something new or engaging with psychological therapies they knew nothing about or didn't understand,

"...they don't have something to compare to with the service back home, they don't know what this is ... I told her this is the counselling office.... and this was the first time she'd ever come across this term of vocabulary" (Chinese female student)

Other difficulties arose when students tried to compare to services 'back home', not knowing if a payment was expected or where to access more spiritual therapies. Similarly, even when made aware of a service, many were reluctant to use them due to concerns about how the service operated, particularly issues about confidentiality. There was a very real fear that information about their mental health would affect their visa status, their eligibility as students and funding,

"... so a part of me felt like, by giving him information about what I think about the immigration and where my mind is with immigration, I thought

that maybe he would definitely call them and say, "oh, I have such and such a patient and she is saying this and this and this about the immigration office" (Kenyan female student)

8.3.2 Other triggers of distress

Aside from study-related stress, the complexities around visa regulations, and for some seemingly ever-changing regulations, can cause tremendous distress for international students. We heard several stories like this one:

"I was thinking of coming here to study, but then what I did not know was how long the visa was going to take, they were going to process the visa for me ... I talked to somebody, and somebody told me usually it doesn't take long, it takes like two to six months. So I waited for the six months to elapse, at the moment it's almost two years now and I've heard nothing from these people" (Kenyan female student)

Another persistent issue was pressure from families and/or funders 'back home'. Knowing the financial sacrifices sometimes made by families, many students feared failure and worried greatly about disappointing their families, even when they faced huge problems in the middle of their studies,

"... at the start for days I lock myself away, my brother he always phone me, he knows I am not okay but I can't tell him, I am the oldest girl and I am the first time going out of my country. Everyone is so proud and it took so long for my father to agree, how could I go home or not succeed. I think many students feel like me" (Libyan female student)

On top of that, some are either expected to, or feel obliged to, send back money, meaning that they also have to work, either legally or illegally:

"My visa runs out 2 months after, like. And then, it was student visa, because I had a first challenge visa, the process that it works for 2 years, then I had to switch back to student because I couldn't find an employer willing to do the work permit for me. But the problem was that I wasn't studying when I had the student visa. I enrolled in tuition but then I quit, I wanted to save some money [to send home] and I was working excessive hours - this was a breach of the visa conditions. So I was very worried and didn't know what to do, so this was the trigger point" (Chinese female student)

"Especially my parents are quite shocked, because the kind of mentality that people have back home is the UK is like heaven, yeah, it's like heaven ... they think that since I am here, I am working, I am getting good money and all that, I need to send that money back home. And they don't understand it...they say, 'oh, you don't want to send us money or you don't want us to come there, and all that'. You know, that also makes me a bit stressed" (Kenyan female student)

8.4 Carers

"The physical and mental health of those providing high levels of care is worse than that of non-carers. This is seen in higher reported rates of stress, anxiety, depression and sleeplessness". [56]

For BME carers, the impact on mental health can be particularly acute, many of those we worked with felt their mental health is often overlooked because of the focus on those being cared for. The following themes are interrelated and they have significant implications for the lives of carers, those they care for, and the way that services are structured and delivered:

1. Cultural understandings of illness and caring
2. Carer stress
3. Lack of time for themselves/lack of support

During interviews and the Community Conversation, several participants voiced concerns about cultural understandings of illness and caring and how that can negatively impact on their lives and the lives of those they care for. Some were keen to highlight that illnesses such as dementia are often still seen as part of life within some communities, as one person said

"... in Asian culture, they just think it is growing old, there really is a need for public education in our communities".

Similarly, in an earlier event, participants expressed strong views that caring should be done within the family - *"it's in our culture, to stay together"*. But this can also lead to tensions. One carer, who also requires care himself, said guilt was a factor that created pressure in his life, *"if a younger person sacrifices their job to look after you, they're not appreciated".* Adding that the state did not financially reward carers, or in his case, the individual who cared for him. Even though the participant had a number of physical difficulties he still emphasised *"it's more psychological than physical".*

56 Quoted in Gordon, D.S. et al (2010). *ibid*

Carers were concerned that there was a lack of cultural competency in relation to health and support services. One participant expressed concern about how the person she cares for is viewed by the doctor and the Asian community:

"I look after my mother, in my opinion she takes too many tablets, the doctor doesn't really listen to her or offer other treatments, just seeing her as an old Asian lady who doesn't speak English good. But I can see how low she is and how much she has gradually just cut herself off, she needs to get out and be with others in her age group, but in our culture you tend to keep such problems hidden, people act like it is a disease you can catch. I know it is awful but feel what can I do?".

The stress that the mother's self-imposed isolation is having on this participant is implicit; however, it is also expressed that there is a lack of understanding and support from the Asian community.

There was also recognition of changes within their own communities; during the Community Conversation, South Asian carers talked about the changing role of women within their community, noting that in the past they would have stayed at home to look after the elderly but now it was suggested women had to work too. Concerns about ageing and isolation were expressed by another carer

"I've heard people thinking oh I'm turning 50, I'm going into a nursing home, you know that sort of thing ... I'm getting old and that might be causing depression. Getting old and thinking you're going into a home".

Carers also said they often felt there was a lack of time for themselves, or if they did have time they felt guilty, which in itself can lead to stress, and this is often hidden from others. Some comments from the Community Conversation were: *"no time for yourself, relax yourself"*; *"caring brings depression"*; *"always thinking how you can make them happy"*.

One participant said:

"Most of the time I just feel very lonely, my family are around but it is me that is there all the time. Even when I am not I am still caring. Nobody in the community wants to know you, they slowly start to stay away. When we do go out they shun us and it is as if I am a nobody too, they don't see the person any more".

This participant's stress is apparent as he feels they are regarded as outcasts by others in the community.

During a follow up session to the Community Conversation, the story of an imaginary carer was used to encourage the group to open up and speak about their own experiences. One participant became visibly upset as he shared his own experience as a carer for his wife:

"I am one of those unhappy people, get up 7 every morning, get prayer, then read book, 7-9 (14 hours) everyday all the same … how many hours I am alone, she's mentally too much trouble, everything I do is wrong to her".

These comments evoked much sympathy from the others. In relation to caring, one person said *"sometimes you can't deal with it anymore"*. The carers' frustrations and feelings of helplessness also showed in comments such as *"only way for him to feel better is if wife feels better"; "family in our community is important, always has been, always will be for us"*.

There was also clear evidence of how stigma/shame affects, or even exacerbates distress, particularly when caring for a family member with mental health difficulties, creating almost a double burden:

"My careless X, causes my problems, no support and shame for my people, I know they judge me and blame me. I know X has an illness but they don't see that, only blame me as the carer…it is all in my head, my headaches, my shame. I tell X makes me headache and tense and then I have to tell X to leave, but I feel the shame, the guilt for me like it is my fault".

9 EVALUATION FINDINGS

Throughout the project we used a variety of approaches and methods to evaluate our work and assess whether or not we were meeting our short-term outcomes with both BME community members and service providers.

	Outcome	Comments	Extent to which outcome met
1	Increased engagement with target BME groups through participatory action research methods	Significant engagement with all target groups throughout the project, including so-called 'hard to reach' groups	met
2	Project target groups: • More comfortable talking about their mental health and wellbeing • More awareness of: - how to look after their mental health - appropriate sources of support and how to access these	The project has demonstrated a range of methods which can be used to encourage people to talk about their mental health and wellbeing. Many participants also detailed changes in behaviour and awareness	met
3	Matched Care Leads and GPs: • Better understanding of range/diversity of BME communities in Lothian • Better understanding of mental health and wellbeing of target BME groups • Increased awareness of barriers and enablers to access	The on-line survey with service providers provides significant evidence that the project met these outcomes and there is evidence of changed practice. Further engagement with GPs is required and should be taken forward by NHS Lothian	Partially met

4	Project team have better understanding of barriers/levers to accessing services	The team has a much improved understanding of barriers and enablers. This learning has been shared at various opportunities in the Lothians and nationally	met
5	Revised ICP by NHS Lothian in 2011	NHS Lothian has already agreed to revise the ICP by late 2011	met

9.1 Participant Evaluation

In relation to individuals in the target BME community group, our outcomes were: increased engagement with target BME groups through participatory action research methods. In turn, we hoped individuals would become more:

- comfortable talking about their mental health and wellbeing
- aware of sources of support and how to access them

9.1.1 Events

All the events that we organised were evaluated at the time using a variety of PA tools including, Poster Questions (often using happy/sad faces), graffiti boards and feedback forms. There is insufficient space to detail feedback from all group work or events so we have focused on feedback from the Wellbeing Melas and SMHAFF exhibition.

It is clear from the comments below that the Wellbeing Melas provided opportunities to promote wellbeing, cultural diversity and community cohesion, as well as vital opportunities to learn about local services:

• "very wide range of activities both therapeutic and entertaining; it brought a diverse group of people together in a unique celebration of mental wellbeing"

• "I have been reminded of the importance of keeping fit and whole, of relaxing and making social connections"

• "I had an interesting encounter with a volunteer telling me about men's mental health support in Edinburgh"

Giving feedback on the Graffiti Board at the Wellbeing Mela

Similarly, Graffiti Board comments collected during the SMHAFF exhibition, illustrate the effectiveness of using the arts to raise sensitive issues:

• "Amazing, touching exhibition that opens the too long locked doors to living with mental illness. Beautiful"

• "In my culture we don't talk about mental problems, you hide it so this is SO important"

- "It's lovely when people can express their emotions about mental health, years ago you'd be put in a padded cell and they'd throw away the key. If any Travelling People had mental health problems they'd keep the person hidden, even amongst Travellers"
- "Very informative and wholly user led – excellent – needs to be more!"
- "Wow, so good to see BME people having this platform it has been kept hidden for too long"
- "Shows the experiences across communities, and the shared stigma – powerful work indeed!"

9.1.2 Group work

In addition to the evaluation carried out at specific events, a member of the Equally Connected team (not directly involved in the delivery of activities) carried out a phone interview with a selection of participants, thereby enabling us to gather more detailed evaluation data. Twenty participants were asked what they had learned at events or during group work, whether they had made any changes to their daily lives, how they thought about mental health and wellbeing and their awareness of possible sources of support.

A short question guide was used covering the key headings in the Kirkpatrick evaluation model noted in section 6.2. It was designed to be flexible and adaptable to suit the needs of the different participants. Participants were drawn from the following groups: BME men, carers, Midlothian Active Women and Gypsy/Travellers. This part of the evaluation took place towards the end of the project. It was not possible to interview any international students as many of those who had participated in the early work, including making the film, had now completed their studies. In addition, due to the ongoing political crisis in the Middle East, our partner agency felt this was not an appropriate time to interview any Arabic-speaking women.

A summary of the responses from each group can be found in Appendix 3. Aside from enjoying the social aspect, which in itself reduced isolation and improved confidence, the majority of participants gave positive feedback, detailing changes in their behaviour and awareness. Although this is only a snapshot, when combined with the levels of participation and feedback from events, there is evidence to suggest that participants did feel more comfortable talking about their mental health and wellbeing and were more aware of sources of support and how to access them. As one carer said, he now had a

"better understanding and insight, knowing you're not alone in experiencing mental health and wellbeing problems".

9.1.3 Living Life to the Full

Initial evaluation of this pilot was carried out using Depression Alliance Scotland mental health literacy forms. This did not fully capture the views of participants so we also held a separate evaluation session, led by an independent facilitator. The full results of this pilot can be found in the LLTTF report.[57]

In brief, participants felt the course had taught them several useful skills which could help them manage their low mood and anxiety. However, to be fully accessible the women felt the course materials required adaptation to ensure that the examples used are relevant to as wide an audience as possible and do not offend or present barriers to those from a BME background. In addition, many of the women had identified racism as the cause of their depression and they felt it should be made clear at the outset that, as an individualized self-help programme, the course is not designed to tackle societal issues such as racism or prejudice. With this in mind, the titles of some course booklets, or the approach taken in sessions, suggesting that 'everything' can be resolved, is in reality untrue and potentially counter-productive. We concluded that there is real danger in trying to put such life situations into the LLTTF approach which could end up 'blaming the victim' or implying that the individual needs to change their behaviour or thinking. Further recommendations are listed in the LLTTF final report.

9.2 Service Provider Evaluation

Short-term outcome 3 stated that service providers (in the voluntary and statutory sectors) and GPs would have a:

- better understanding of the range and diversity of BME communities in the Lothians
- better understanding of the mental health and wellbeing of target BME groups
- increased awareness of the barriers and enablers to access

In order to assess our effectiveness in meeting this outcome we emailed over eighty service providers, asking them to complete a web-based survey during a two week period in May 2011. Survey Monkey was used as it was deemed to be the most efficient method in terms of time, resources and ease of analysis.

[57] For more details see Equally Connected (2011). *Report 13*

9.2.1 Summary of survey results

1. 59 completed the survey (63% statutory 37% voluntary)

2. Respondents described their role as: 50% delivery of mental health services, 31% caseload (including 1 GP), 21% community work, 23% planning of mental health services, 19% mental health policy development (some ticked more than one box)

3. Only 20% did the majority of their work with BME communities

4. When asked if there had been any change in knowledge which they would attribute to Equally Connected:

- 73% said they felt more informed about what affects the mental health and wellbeing of BME people
- 75% said they felt more informed about the barriers faced by BME people in accessing mental health services
- 64% said they felt more informed about the types of support/services that BME people would like in relation to their health and wellbeing

5. Service providers were also asked about other ways in which their knowledge/understanding has changed besides those detailed above. Comments reflect a positive impact and, amongst other things, the transferability of approaches and methods used by EC:

- *"There has been more knowledge about certain groups like the Gypsy travellers groups and also adapting more inclusive methods of evaluating work with BME"*
- *"How the findings also relate to other population groups"*
- *"Mental health issues are being more openly discussed in Pakistani, Nepalese and Indian communities for varying reasons including as a result of Equally Connected's activity. This is still in infancy with regards to the Bangladeshi community…will consider the implications of the work of Equally Connected when addressing these issues within practical partnerships continuing in particular with the Bangladeshi community but also in general community health and wellbeing events particularly in the Lothians"*

6. When asked what (if anything) they had learned from working with Equally Connected, comments mentioned both the methods used as well as increased knowledge:

- *"Community development approach is useful and empowering if carried out well"*

- *"I have learned a lot about engagement, barriers, wrong assumptions and the challenge of hardly reached communities rather than hard to reach. I have also learned the need to be creative, open and patient to find the right way to engage others"*

- *"That considerable progress can be made in overcoming BME mental health stigma and dealing with mental health issues if it is approached in an intelligent, flexible thoughtful and sensitive way. This kind of organisation that combines research with action partnership, evaluation and training is a very effective model and could be utilized in other fields…a neutral well-informed and skills based organisation can draw together an effective and practical exchange of information and partnership…a range of creative and interesting ways of working with BME communities around mental health issues"*

7. Finally, when asked what they regarded as the major achievements of EC, comments included recognition of awareness-raising, methodologies and creative partnership working:

- *"Equally Connected used some innovative participatory techniques in their work and facilitated participants in developing the projects and events they were involved in"*

- *"1) Opened up new methods of work to raise mental health in non-threatening ways*

  2) Achieved diminishment of mental health stigma and resulting repressed and hidden situations in BME communities

  3) Creation and enhancement of some successful partnership initiatives"

- *"Raise awareness of different perspectives/ways of conceptualising mental health and wellbeing. And how each should be respected and regarded as equally valid. Challenges many assumptions behind things like ICPs, etc. Hopefully in time this will address power imbalances within MH system, lead to greater flexibility of approach, people feeling that more appropriate services are available (and that they feel comfortable using them), and that people feel more in control of their own MH and wellbeing"*

10 REMOVING BARRIERS – THE TRANSFERABILITY OF LEARNING

All individuals may face potential barriers in accessing mental health services but, as we have found through our research, people from BME communities often face additional barriers involving ethnicity, racism, culture, language and stigma.

Our fourth short-term outcome was that the project team would become more aware of levers and barriers to accessing PCMH services. Without doubt, the project team, and our many partners, did become more aware of barriers and levers - throughout this report we have detailed, at length, the barriers mentioned by the individuals we worked with. Along with other social factors, the barriers can affect one's perception and use of services, as well as the potential outcome and effectiveness of the intervention. We have also described the methods and approaches we used which acted as 'levers', enabling BME individuals to participate or share their views and experiences.

The two priority questions for the Equally Connected team, identified in our monitoring and evaluation framework, were firstly:

> 1. What approaches have Equally Connected found to be the most effective in engaging with BME groups?

We found that community development approaches, starting from where the person is at (not going in as a mental health project per se) and participatory tools were highly effective and engaging ways of working with BME communities. Using the arts to remove barriers was very successful, and their potential to act as enablers in future work is enormous. Whilst some of our findings are specific to the BME communities we worked with, other issues have significance for other groups in society such as older people, people with disabilities, LGBT people, young people and others. All of the methods and approaches used by Equally Connected could easily be adapted for use with other communities of interest and we would argue that much of our learning is transferable.

Our second priority question was:

> 2. Is there evidence of Equally Connected contributing to service change, specifically revisions to the ICP for low mood and depression?

The evaluation of service providers (section 9.2.1) suggests that the work of Equally Connected has already contributed to some service change; Figure 2 details the responses when asked if they had already made any changes to service/practice.
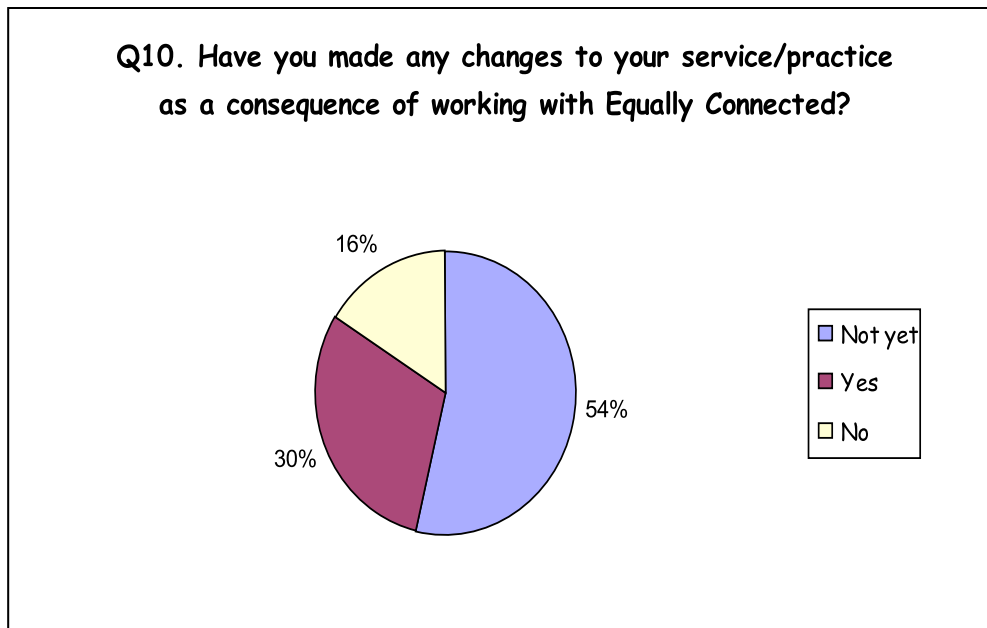
Q10. Have you made any changes to your service/practice as a consequence of working with Equally Connected?

16%

54%

30%

Not yet

Yes

No

Figure 2 Changes in services after engagement with EC

In addition, 60% of respondents said they had considered putting learning from Equally Connected into practice, 33% had considered it but not yet been able to implement.

Several other attempts to remove barriers and potentially change services are worthy of mention:

- Dr Chris Williams and Depression Alliance Scotland have indicated they are willing to take forward some of the recommendations from our pilot to make the LLTTF course more inclusive and accessible to BME community members
- Breaking Isolation, the film made by international students at Heriot Watt university, has already been shown to over 3000 new international students and there are plans to show it at the other 12 university and college settings across the Lothians
- Plans are underway to hold further Wellbeing Melas in Edinburgh and Midlothian this autumn and winter
- Further work on caring, and mental health, within the Gypsy/Traveller community will be taken forward by MECOPP and NHS Lothian
- Health all Round has noticed that some of the Arabic-speaking women now feel comfortable enough to attend their generic confidence-building classes
- Within Lothian's new mental health and wellbeing strategy - *Sense of Belonging* - a key commitment area focuses on 'addressing inequalities' and several approaches used by Equally Connected have been recommended

In relation to the final outcome, NHS Lothian has given an assurance that upon publication of this Final Report, Matched Care Leads will carefully consider the research findings and learning from Equally Connected. They have already agreed that a revised ICP will be produced by late 2011.

10.1 Perceptions

From our relatively limited contact with PCMH providers we often got the impression that many services are developed without any BME involvement, in part this is because BME groups aren't perceived to be accessing services anyway. When people do not use services, there may be a perception amongst those who design and deliver services that BME people do not want PCMH services – the Invisible Minorities poem at the start of this report raises these issues in a succinct and creative way.

Similarly, a review of UK literature on evaluated interventions that have sought to improve access and reduce barriers to PCMH services for BME people, commissioned for the Equally Connected Learning Review, backs up our findings.[58] This review identified ten characteristics which seem to reflect effective interventions, including the use of a community engagement model, self-referral and a multi-dimensional approach (for example, providing training and awareness-raising to staff as well as BME communities).

Some groups we worked with are often referred to as 'hard to reach' when in reality the project would argue that it is the services which don't try hard enough. During initial scoping, Equally Connected staff sometimes came across attitudes like *"we've offered our service but no-one came, what more can we do".* This is a dangerous argument in that it can exclude the opinions of BME people and risk further alienation and segregation of communities and services. As one service provider noted in our evaluation survey, *"I have learned a lot about engagement, barriers, wrong assumptions and the challenge of hardly reached communities rather than hard to reach. I have also learned the need to be creative, open and patient to find the right way to engage others".*

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[58] Greisbach, D. and Gordon, J. (2011). *Making primary care mental health more engaging, responsive and accessible for Black and minority ethnic groups: a literature review*. NHS Health Scotland

Similarly, comments from participants suggest they often feel excluded from service design discussions and that there is a need for greater cultural awareness, and training amongst service providers,

"there are ways to improve wellbeing – one big way is for the agency to understand the culture, need to speak to us" (BME carer)

"if there was more understanding for the culture. This will help me exactly, if I see someone [who] listens to me and knows what is my situation back in my country and also the exact problem that I feel ...Yes, definitely it will help" (Arabic-speaking female)

Participants also noted the need for good interpretation, rather than relying on family members or workers who happen to be bilingual:

"The NHS and the hospitals, there's nothing like that. There's only one Asian person that I've known and when she started with the NHS in Edinburgh and again her English wasn't very good but obviously at that time they were maybe desperate to have taken her on. She's still there. But you know at that time ... if you were ... if she was to translate ... she was to get from one Asian person across to the doctors, her translations weren't very good, but the doctors and that never ever picked up on it. Nobody ever thought that this person is not translating correctly, cause all they'd said was that there was nobody else to see it. They need somebody that can speak both languages fluently" (BME carer)

Our experience was that community members were regularly willing to engage with service providers, and keen to offer opinions, as long as the approach was made in a meaningful and appropriate way. The numbers attending events was always reasonable, sometimes exceeding expectations, and in part this was because considerable time and effort was spent beforehand considering what the potential barriers might be and how to overcome them. For example, during the Community Conversation with carers, there was a keen interest in discussing the appropriateness of 'see me' posters and further work could be done in this area.

Similarly, the women involved in the LLTTF pilot were eager to suggest improvements so that the course and materials could become less euro-centric and more inclusive of those from BME backgrounds.[59]

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[59] See Equally Connected (2011). *Report 13* for more details.

10.2 Connecting on Equality

Towards the end of the Equally Connected project we hosted a lively event - bringing over 80 research participants and service providers together to share our learning and showcase which approaches had worked for us. This participatory event included dance, poetry, quizzes and laughter as well as an opportunity to learn from each other in four workshops, focusing on overcoming barriers, which were all led by BME community members and partners. The event was also recorded graphically by an artist:

Connecting on Equality - graphic facilitator Albi Taylor ©2011 www.albitaylor.com

The key learning points from the workshops included:

Workshop 1 – Arts, Engagement & Empowerment

- Others may benefit from the creative approaches used by EC – participants had fun and felt empowered by the experience.
- National stigma campaigns learned a huge amount about engagement with diverse communities and want to do more, are open to input
- Whatever the activity, it's important to have fun!

Workshop 2 – Community-led Training

- The real power and impact of individual narratives around discrimination
- The ignorance of many service providers about the level of discrimination experienced by Gypsy/Traveller communities
- Using case-studies and materials created by community members
- This method was empowering for community members

Workshop 3 – Improving Access

- Use scenarios of 'real' situations faced by research participants a useful model for learning, need for web-based sharing
- It's not just about having people speaking different languages or translation, but also about the words we use - words which people can relate to. People are put off if services have a label attached e.g. mental health; need to use accessible words and concepts e.g. feeling 'sad' or 'down'
- Advocacy and outreach also have an important role to play and should be available i.e. LLTTF – promoting through leaflets was simply not enough, there was a lot of work to promote this due to the myths of mental health
- There needs to be an understanding that there is a fear of services amongst people who don't understand the systems
- There is a lot of worry about confidentiality, so this needs to be clear and emphasised
- Materials needs to be accessible e.g. pictorial/translated, a bilingual phone/helpline, etc

Workshop 4 – Using Participatory Appraisal Tools and Community Conversations

- there is potential to introduce or approach it from a different perspective, saying it is a mental health session could scare people off, better to focus on wellbeing
- The flexibility/adaptability of the community conversation method was well received (again stressing the importance of making materials and learning accessible for the future)
- The importance of 'tuning in' to the particular context of the group involved – not to simply deliver the awareness raising session 'by the book' but to know your audience and their priorities (e.g. Arabic-speaking women's group), as well as 'listening' and following up
- Lots of positive reasons for using PA methods – achieving a balance of evidence when you do actually need quantitative data can be challenging

Feedback from the event was very positive. As one participant said
"not only was it well-organised, but the content and delivery was creative and different which made the learning more memorable".

10.3 A Sense of Belonging

Lothian's joint mental health and wellbeing strategy 2011-2016 – A Sense of Belonging – sets out a clear vision, principles and approach for how the public, people with lived and living experience of mental illness and mental health problems, people who use services, carers, the third sector, the four local authorities and NHS Lothian will work together across Lothian to improve our mental health and wellbeing and ensure that the services delivered have an ethos of recovery embedded within them.

The strategy is based on the twin principles of social justice and social inclusion. This means that the inherent ethos of the commitments is to hold a focus on those affected by inequalities, and to address the gap between those most and least well off. This is particularly crucial in the current economic climate when staying focused on those who are most vulnerable can be a challenge. There needs to be attention and mindfulness brought to efficiencies and service redesign.

Across most population groups, there is a repeated finding of diminished mental health because of the pervasive and insidious effects upon wellbeing of experiencing personal prejudice, collective discrimination and structural exclusion from full and fair participation in Scotland's material prosperity, social life and power structures. These effects may also contribute to poorer health-related behaviours. The findings and learning from Equally Connected have resonance and implications for a number of vulnerable communities.

Specifically within mental health and wellbeing, the key risk factors identified by Rogers and Pilgrim in relation to poor mental health are: poverty; relative deprivation; inadequate housing; unemployment; poor local resources such as transport, shopping, leisure pursuits; neighbourhood violence; poor access to support networks.[60] Again the identified themes detailed in Sections 7 and 8 reaffirm these key risk factors.

The public sector duty in the Equality Act, 2010 means that public bodies will need to be particularly mindful of how the inclusion and equitable treatment of all protected groups is incorporated. Public agencies will be required to produce, monitor and report on how they have met their equality objectives.

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[60] Rogers, A. and Pilgrim, D. (2002). *Mental Health and Inequality* Palgrave and Macmillan

As disadvantage has many forms and disadvantages tend to concentrate among the same people, health problems accumulate throughout life.[61] Therefore, it is critical to understand the complex nature of inequalities, and look holistically at solutions for people and communities.

The new strategy recognises that there will be a continuing need for services to meet the needs of vulnerable communities but these services should also work closely with 'mainstream' services to ensure that the learning gained is shared and becomes a part of proactive planning in mainstream services. Crucially, it recognises that when working with vulnerable or marginalised communities it is important to recognise how essential building trust with communities is. Building trust can be a lengthy process but the longer term benefits are substantial.

It is opportune and timely that the learning from Equally Connected is being published now, as implementation planning to deliver on the agreed Mental Health and Wellbeing Strategy for Lothian commences, following the sign off in May 2011. NHS Lothian has agreed that the recommendations set out in the Reflections and Recommendations section will be taken forward within a wider context of radical change and redesign in line with the ethos and aspirations of A Sense of Belonging. Throughout the engagement and consultation process for A Sense of Belonging stakeholders signalled their willingness to think and work more creatively, in partnership, with and for all communities.[62]

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[61] Marmott, M. and Wilkinson, R.G. (2003). *Social Determinants of Health: The Solid Facts*

[62] For a summary of responses to the draft A Sense of Belonging consultation paper see *Briefing, for all with an interest in mental health and wellbeing across Lothian*, Issue 6, March 2011

11 REFLECTIONS AND RECOMMENDATIONS

Real and effective engagement with BME communities is essential if we are *"to ensure that the Lothian Integrated Care Pathway for people with low mood, anxiety and depression meets the needs of people from all communities across Lothian"*.

From the Equally Connected project's range of research it is clear that all three ICP assumptions can be challenged. The majority of those we worked with did not think of going to the GP first when experiencing depression. Secondly, many did not feel able to clearly articulate their difficulties, not only because of language but also because of a perceived lack of a shared conceptualisation of mental health. Furthermore, for some there was a reluctance to fully share their beliefs and/or disclose their ethnic identity for fear of racism. Finally, in relation to assumption three, our research showed there was a distinct lack of knowledge, amongst participants but also some BME support organisations, about the wide range of social-prescribing initiatives and interventions – this, combined with widely held perceptions about GPs and medication, means that certain individuals are not in a position to successfully find out how their needs can be met or negotiate a pathway forward.

Equally Connected research highlighted the strong links between racism and mental health which are rarely acknowledged. For research participants, the experience of prejudice, or the fear of encountering racism or other types of discrimination, had a considerable impact on the wellbeing of those we worked with. This societal problem had a considerable knock on effect on help-seeking behaviour, coping strategies and general awareness of existing services. In many cases, research participants did not feel PCMH services were able to understand the significance of this issue and were therefore unable to tackle the root cause of their depression or low mood.

There is much room for improvement, and we would certainly concur with the view of a service provider in our evaluation survey *"to a large extent issues around mental health are often hidden within BME communities ... a considerable amount of work is still to be done to address stigmatisation and discrimination".* As regards 'what next' one service provider suggested,*"... by successfully reaching out to a lot of organisations and various communities and individuals they managed to collect some valuable information about mental health which hopefully will be used to inform and influence the NHS policies in the future".*

11.1 Recommendations

11.1.1 Flexibility and engagement

Our research suggests PCMH services need to understand their local populations, challenge assumptions about BME communities and do robust monitoring of service uptake. For existing PCMH services, there needs to be an increased understanding and awareness of the needs of BME communities and a more flexible approach to providing services. Service planners need to be aware that mental health may be viewed and understood differently by people from different cultures. Service planning and delivery must reflect this. There may also be differences between different generations. Services need to be flexible in responding to these changing needs.

Our action research has clearly demonstrated a number of approaches which can be used to improve engagement with BME, and other, communities. It is imperative that the engagement process and service planning should be enabling – not disabling. At the outset planners should try to adopt an open mind, thinking of the possible barriers and trying to overcome these, rather than trying to fit BME individuals into existing services.

Recommendation
- Establish a pan-Lothian Addressing Inequalities Action Group, by September 2011, who will be responsible for further developing the learning and taking forward recommendations, across various communities of interest

11.1.2 Community-based initiatives

Services should also work more closely with community organisations, and faith groups, many of whom have traditionally not been involved in the delivery of PCMH services. This is likely to require learning on all sides. One of our Steering Group members suggested that Equally Connected had acted as a catalyst, bringing sometimes disparate groups together to work in partnership. Effective partnership working is crucial, very often these community groups have extensive experience of engaging with target groups, and can offer knowledge and insight into successful ways to reach the communities they seek to represent. However, we would suggest there is also a need to build their capacity and awareness of mental health issues, addressing stigma within and providing tools to open up a dialogue about mental health and wellbeing in a non-threatening way. Our research also suggests that community groups could play a key role in raising awareness and signposting, on issues related to mental health, as well as providing valuable feedback, on an ongoing basis, to PCMH services.

In the current economic climate it is undoubtedly easier to consult with individuals and groups already known to services, but it is also important to reach out to those who are often missed

by traditional consultation processes or not represented by existing BME groups. This is a more challenging area of work, requiring greater time and investment. However, as Equally Connected has shown there are ways to engage which work and can be replicated elsewhere.

There is a pressing need for more community-based interventions to promote dialogue, improve awareness of interventions and challenge stigma. In addition to the approaches already suggested, there is enormous scope, for example, to adapt elements of Scotland's Mental Health First Aid, and other similar training courses, for delivery to community or faith groups.

Recommendations
- Establish a rolling programme of Scotland's Mental Health First Aid training delivered by community leaders, beginning with a "Training for Trainers" course.
- Ensure that the networks built up by Equally Connected continue to be supported to engage in mental health activities, including service planning and redesign

11.1.3 Resilience

With BME individuals and communities, it is important to build on what is already there - develop and nurture existing resilience, or coping skills, for people who are experiencing adversity, rather than 'assume you know the answer'. There needs to be a much greater understanding, and appreciation, of the societal model of health, including the impact of poverty and racism on mental health. There is a pressing need to engage more with organisations involved in tackling hate crimes.

Our research has also highlighted the importance of taking the cultural values of the extended family/community into consideration and a need for better, more appropriate, dissemination of mental health information into communities.

Many of the participants we worked with raised faith as a coping strategy but spirituality and religion are rarely mentioned in either mainstream or BME mental health forums. Spirituality can provide a sense of belonging and hope as well as enhancing coping strategies and a sense of control. However, the spiritual needs of people experiencing mental health problems can often be overlooked or pathologised and, in many cases, little effort is made to support this aspect of their lives.

Recommendations[63]

- Integrated Care Pathways should have a more explicit focus on spirituality with staff training to support opening up conversations or discussions about spirituality with service users
- Promote the involvement of spiritual care services in service redesign and planning
- Develop awareness-raising and training to help staff develop a language and understanding of spirituality so they can discuss these issues with service users
- Arrange further stakeholder events to explore spirituality and mental health
- Continue to promote strengths-based approaches within service delivery

11.1.4 Social-prescribing interventions

There should be a greater emphasis on, and acknowledgement of, the importance of social and holistic interventions such as befriending, complementary therapies and culturally-sensitive exercise groups, rather than a sole focus on psychological interventions. There is also a clear need for a wider choice of referral routes, not only via a GP. Within communities an outreach approach is required to improve general awareness of social-prescribing initiatives.

Recommendations

- Improve opportunities for people to self refer to social-prescribing interventions
- Work with existing exercise referral projects to ensure that culturally-sensitive exercise groups are available
- Promote stronger links between mental health services and community development and health projects

11.1.5 Training

We would suggest there is a pressing need to provide training for PCMH staff (statutory and voluntary), to address inequalities, including reflection and dialogue to overcome professional or personal bias. Following on from the popularity of the Gypsy/Traveller community-led training, and the example of WRAP training in NHS Lothian (delivered by those with lived experience), there is scope to create and develop a comprehensive programme of community-led training. This would be a long-term investment but is arguably a sustainable and empowering approach.

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[63] These five recommendations are already listed in A Sense of Belonging

At a community level, community groups and individuals could be trained to act as lay health workers, promoting understanding of, and ongoing dialogue about mental health within their communities and in their own languages.

In all training, creative methods like quizzes should be used to promote reflection and challenge underlying assumptions.

Recommendations
- Develop a general awareness-raising course for PCMH staff informed by Equally Connected learning
- Support community organisations to develop and deliver a lay health worker course, informed by Equally Connected learning

11.1.6 Resources and materials

Additional resources may be required to adapt existing therapeutic materials, and possibly create new ones, to make them more inclusive and relevant to all sectors of the community. This will include translation of self-help materials into different languages and a wide range of formats, including audiotapes, CDs and DVDs for those with literacy problems. As we found in the LLTTF pilot, this is not simply a case of translating key words, but rather of exploring concepts and understanding.

Recommendation
- Identified Matched Care Leads from Lothian should work with Dr Chris Williams to incorporate the learning from the Equally Connected pilot into the Living Life to the Full resources and educational programme

11.1.7 Location

Ensuring that mental health resources and services are language/literacy appropriate is only part of taking a more inclusive approach, they also need to be delivered in a supportive environment. Sometimes, given the fear of stigma or reluctance to use traditional PCMH services, services may need to be available in places where there can be a degree of anonymity. Could services be made available alongside hate crime services, for example?

Recommendation
- Promote the use of community venues for the delivery of PCMH services
- Explore with hate crimes services, including the Police, effective ways of working together to support the victims of hate crime

11.1.8 Culturally-sensitive services

There is a continuing need for culturally-sensitive services, including the provision of therapists from different cultures/languages and effective access to interpretation services (rather than having to rely on the key worker who may or may not be knowledgeable about mental health issues). Access to culturally-sensitive services in rural areas needs to be improved; consideration should be given to providing travel costs or a mobile service. All public bodies, in rural and urban areas, have a legal duty to promote good race relations; there is a need to ensure this duty is implemented and monitored effectively, regardless of numbers.

Recommendation
- Improve the routine recording of ethnic origin by statutory and third sector organisations, and ensure the data is shared and informs planning and redesign
- Key leads in psychological therapies to increase staff awareness of the need for cultural sensitivity in the delivery of therapies
- Produce a revised ICP for depression, informed by EC learning

11.1.9 Research

Equally Connected was a two year project and inevitably there are areas which require further research using action research methodologies. We would suggest all the themes raised by specific groups in section 8 could all benefit from further research. In addition, there is a clear need for further targeted anti-stigma work with BME communities.

Recommendation
- Work with see me to develop further specific work around stigma and discrimination. informed by EC learning
- Explore opportunities for further research through the Addressing Inequalities Action Group

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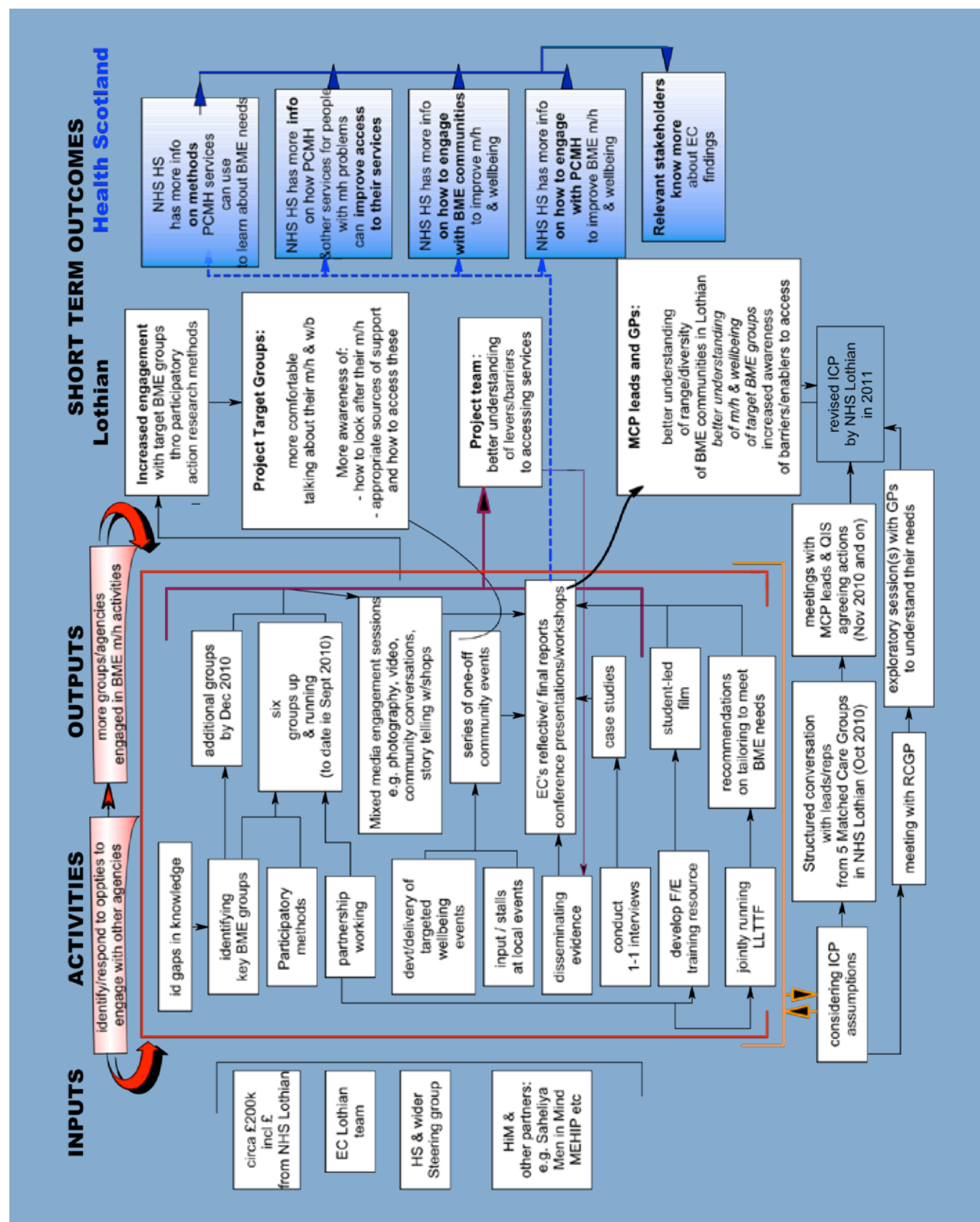
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Acknowledgements

Appendix 1

Logic Model

Appendix 2

Stress Buster Quiz Results (completed by 333 people)

1. Eating a balanced diet only improves physical health?
   True 47%   **False** 53%

2. Sleepless nights can be a sign of stress or anxiety?
   True 91%   **False** 9%

3. Gardening can have a positive effect on mental wellbeing?
   True 83%   **False** 16%   **No answer** 1%

4. One of the best places to find out about health and wellbeing in Edinburgh/Midlothian is the Yellow Pages?
   True 45%   **False** 50%   **No answer** 5%

5. Keeping in touch with friends and family can be a good way of staying healthy and happy
   True 91%   **False** 7%   **No answer** 2%

6. Treating yourself to something good/nice is just selfish and has no health benefits?
   True 19%   **False** 80%   **No answer** 1%

7. Exercise can make you happier and increase your energy levels?
   True 89%   **False** 10%   **No answer** 1%

8. During their life 1 in 5 people in Scotland will experience depression?
   True 75%   **False** 24%   **No answer** 1%

9. Guided Self-Help involves using a guide dog for the blind?
   True 49%   **False** 49%   **No answer** 2%

10. Some stress is good for you?
    True 58%   **False** 41%   **No answer** 1%

11. Depression is just a sign of weakness?
    True 38%   **False** 61%   **No answer** 1%

Appendix 3

Summary of Feedback from Research Participants

BME men and carers

- Most respondents from these two groups said they very much enjoyed the events they were involved in and that they would recommend such activities to others. Comments and reasons included: *"very creative and good first impressions"; "stimulates mental side of person…usually people lose concentration, but the way things were done here people were involved"; "very beneficial and educational…better than I expected"; "very good and I really enjoyed the photography…wanted more photography"; "I would recommend it…people get involved and you think about mental health and health in general".* One respondent felt a particular one-off event needed better organisation but was on *"the right lines"*

- Some respondents said they learned something new and others said that although they could not be specific about what they had learned; simply attending the activities had improved their confidence greatly. Most said they met new people and connected well with them but one noted that it's difficult to stay in touch with them. Comments included: *"yes, you learn a lot from these things…we are learning all the time"; "better understanding & insight, knowing you're not alone in experiencing mental health and wellbeing problems"; "getting out there and meeting other people helps"*

- Only one person said they were not more aware of sources of support and/or ways of maintaining wellbeing. Some of the comments were *"yes, thankfully"* and *"yes, more aware…what you are doing is very good, especially for people like me"*

- Most felt that the changes they made after attending activities were reflected in their attitudes towards maintaining wellbeing. Comments included: *"no dramatic changes but these things, they keep people active and they need to carry on"; "maybe, but the changes are not always obvious…not many people know about places like X… when I told my daughter, she wanted to go so I took her there"; "... it helps…gives me confidence"*

- Some people did feel the activities and events affected the way they thought about mental health and wellbeing. One person expressed that the changes were subtle but went on to reiterate the importance of having such activities: *"I really enjoyed it… subconscious changes and subtle implementation…but you learn new tricks and next time you might think differently".* Additional comments included: *"these things help automatically…the main thing is to get people out of the house and thinking about other things than their ailments"*

Midlothian Active Women

- All respondents were generally very positive about their involvement with EC. One used the words *"fun, energy and friendly"* to describe the classes and another said the *"classes were excellent, really enjoyed the taster sessions, looked forward to coming each week".* Some went on to say they enjoyed aspects such as *"the friendly atmosphere"* and *"zumba and self-defence classes"*

- All of the women said they would recommend the classes to a friend for reasons such as *"good for health"* and *"great atmosphere…a laugh…tried to get fit as well"*. They also said they *"met lots of people that were in the community that hardly ever go out"* and *"enjoyed company"*

- In terms of learning all said they had learned something. Comments included *"that exercise is a necessity not just for the body but mind also"*; *"exercise…don't do much of that on my own…meeting other people"*; *"spending time with others is good"*; *"how to exercise properly"*. Only one woman said she wasn't more aware of sources of support and/or ways of maintaining wellbeing. The others felt they were more aware but also made some constructive suggestions: *"could do with more information on community activities, college, evening classes and other events"*; *"wish more was for BME community in Midlothian and not having to go to Edinburgh for info/support"*

- Only one woman said she didn't do anything different in her daily life after attending the exercise, she felt was already active and the classes added to usual activities. The others felt they made changes such as *"going for long walks"* and *"exercised at home"*. Suggestions for improvement: the classes should also perhaps be held in the evenings and more activities such as swimming and yoga and *"more time to get to know each other"*

- All those who responded said they had made some changes in the way they think about wellbeing and behave as a result of the classes. Comments suggest they are more aware of the links between emotional health, physical health and good nutrition – *"tried to eat more healthy & exercise more"*; *"feel very fit and motivated to do more"*, *"feel more motivation and more info gained"*; *"more confident"*; *"feel more happy"*. One respondent said that it had also helped others in the community too (by word of mouth): *"classes have helped 3 or 4 ladies to be more involved in being fit"*

Gypsy/Traveller women

- Generally the women had mixed expectations and the majority of them felt that the activities and workshops on offer were different and engaging; particularly some that they had never tried before and they really enjoyed zumba and first aid. One woman stated *"they were different from what I expected, but better!"*and another feared it would be *"stuck up"* but found this wasn't the case

- All the women enjoyed the events with one commenting that they were*"brilliant"* and another saying it was *"a great day, I really enjoyed it"*. They noted the flyer had been good and easy to understand, all enjoyed the zumba session in particular along with the food and massage *"didn't know dancing and exercise could be that much fun"*. Another said *"it gave me the chance to try the gym machines, before I just looked at them, scared like"*. Others would have liked longer massage sessions and more regular events for Gypsy/Traveller women. One woman had hoped there would have been more women

- All the women said they had or would recommend the Health events to a friend. One said it *"brought women together and showed how many different options there are for a healthy living"*

- All of the women felt they learned something. Many felt they now had a better understanding of mental wellbeing and looking after yourself. One woman said she now attends a regular zumba class after trying it for the first time at the Health Fayre. Others have also attended exercise classes and one woman is now going for regular massages to maintain her wellbeing and another said that neck massages are good at relaxing you if you're *"not feeling well, particularly if you're stressed, or not stressed"*. Another participant had used some of the first aid she learned with her children and grandchildren

- Three women felt more aware of sources of support as a result of the Health Fayres

- Some women had done things differently since attending the Health Fayres with one woman stopping smoking, another regularly attending massage and the majority of them attending zumba; however one woman felt she had not changed anything. They also said they thought about mental wellbeing differently by *"trying to be more aware of looking after myself"*, now eating healthier food i.e. fruit and one said she's now more aware of *"the link between wellbeing and massage"*

- Some suggestions from the women for improvements included providing a crèche as this would have attracted more women, having longer events and one woman wanted to see these activities *"up and rolling"* in her local area. She felt that if zumba and massage were more widely available and more regular, more Gypsy/Traveller women would attend

Appendix 4

Further information about Equally Connected is available as below:

Equally Connected National Programme. Visit http://www.healthscotland.com/equalities/ mentalhealth/equally-connected.aspx or contact NHS Health Scotland on 0141 354 2900

Equally Connected Edinburgh & the Lothians. Visit http://www.health-in-mind.org.uk/ services/equally-connected.html or contact Health in Mind on 0131 225 8508

Equally Connected Wah Kin Project in Glasgow. Visit http://www.healthscotland.com/ equalities/mentalhealth/equally-connected.aspx or contact Glasgow Association for Mental Health on 0141 404 3769