

# Moving Forward with the NHS Long Term Plan No-one Left Behind

Co-produced by NHS England and Working with Everyone



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IMPROVING OUTCOMES FOR ALL

## Executive Summary

Given the number of different communities represented, there were significant overlaps in community and individual experience of using health services.

For many of the communities represented there was significant overlap and the likelihood of an individual self-identifying as being part of more than one community was highlighted. For example, an individual who had lived experience of being street homeless could have experience of childhood sexual abuse or sexual exploitation, domestic violence, substance use, sex working, the criminal justice system and sexual assault as an adult. No attempt has been made in this report to look at the correlation or causes of this, but it should be noted that Adverse Childhood Events (ACEs) were mentioned more than once.

In general, the communities and individuals represented at the event felt that they did not receive the same service as other communities and all highlighted similar barriers. It should be highlighted that many felt a poor initial engagement with a healthcare provider, was a significant barrier to further engagement with services. It was felt that even if community members did not have a poor experience personally, that they would know someone else who did and that this was a barrier to accessing services. This highlights the need for initial contact to be positive.

As well as many of the barriers to engagement being similar across communities, there were a large number of suggested solutions that were the same regardless of the community or the topic under discussion. The need for involving community members in the co-design and co-delivery of staff training was considered essential. The use of community members as health champions and peer supporters was repeatedly mentioned and the use of targeted accurate co-produced information for each community was highlighted.

## Rationale

In taking forward the NHS Long Term Plan we wanted to engage with representatives of seldom heard and marginalised communities. These communities often present with the most significant health inequalities, with poorer access to services and poorer outcomes, and if we can get it right for them, we will get it right for everyone.

Topics for themed discussion were chosen, partially on availability of NHS colleagues (it was felt that it would be a waste of everyone's time to spend the whole day discussing dentistry, if no colleagues from primary care were present) and partially on community interest, using themes identified at the previous workshop in September 2018.

The areas chosen to focus on for this event were

- Mental Health – including prevention of mental ill-health, self-management and access to specialist care
- Digitalisation
- Personalisation – Social Prescribing for prevention of ill-health and the self-management of long-term health conditions
- Prevention of ill-health A – Maternal health, ante-natal care and the first five years of life
- Prevention of ill-health B – adult health, including access to universal health checks and screening and access to targeted prevention for specific communities at increased risk, such as TB screening, HIV and/or Hepatitis prevention and testing, and targeted vaccinations for high risk communities, such as flu or Hepatitis B.

## Delivery

The event convened individuals with lived experience and professionals from support and advocacy organisations in attendance. Some individuals had lived experience and are also employed by advocacy or voluntary sector organisations, there were a proportion of individuals who were attending in a professional capacity, who also had lived experience.

The communities represented were: people who are homeless; people who use drugs; sex-workers; veterans; survivors of domestic abuse; victims and survivors of sexual violence and abuse; people who had been contact with the criminal justice system, including prisoners; migrant and refugee communities; Gypsy, Roma and Traveller Communities; Asylum seekers, refugees and vulnerable migrants. With some of these communities there was a significant overlap in membership.

The event was held in Central London on 18<sup>th</sup> March 2019. Twenty-one community members attended, along with NHS England colleagues, from the PPV, digitalisation, mental health and prevention teams.

The event was co-produced by WE and NHS England. The day was facilitated by five members of the Working with Everyone team, all of whom have lived experience of substance use. All of the team also self- identify as being from one or more of the other communities.

The themes for targeted discussion took place using the carousel format, where each participant identified the topic that they felt was most important to their community and had the opportunity to spend a longer, initial session discussing the topic in small groups. Followed by shorter small group sessions to “reality check” and refine the discussions that the previous groups had had about the other topics. There were three questions asked for each theme these were:

1. Are some communities not engaging with this service / these services? If so, which communities? Are members of your community accessing this service?
2. If not, why not? What are the main barriers to access for your community / some communities? For example, lack of awareness, life circumstances, lack of equipment, stigma, the way the service is provided, lack of confidence.
3. How would you address that? What support do people need to engage?

During the final session there was a round table discussion, using the following questions and sample answer:

Participants were asked to name one part of the Long-Term Plan that they are most worried that their community may be “left behind” from, and to propose a potential solution (or potential solutions). These could be actions which could be taken by NHS England / NHS Improvement, by local health systems (Sustainability and Transformation Partnerships (STPs) / Integrated Care Systems (ICS’), and / or by voluntary and community groups.

*Example answer from Working with Everyone: I feel that the shift towards personalised care: asking “what matters to you?” rather than “what is the matter with you?” could be really amazing for more marginalised/stigmatised groups, particularly those with multiple overlapping vulnerabilities. I am concerned that the current attitude amongst some professionals over “but these people are too vulnerable, we have to protect them” will prevail and some more marginalised/stigmatised people will be left out. Potential solutions: specific content about working with marginalised/stigmatised communities. Specific targets to ensure that personalised care approaches are offered to these communities and appropriate follow-up and data collection to monitor uptake.*

## Findings

We discovered that while the group was drawn from very diverse communities and that although there were significant issues that affected some communities and not others, the commonality of shared experience was high.

There was also significant overlap in theme between Mental Health, Social Prescribing and Prevention. Although each focus area described above was discussed individually with the groups taking part, it is worth noting that the frequent overlap between the different focus areas reflected concerns about the overall systemic operation of the NHS. It also highlighted the similarity of the barriers faced by the communities when accessing services, regardless of the type of service involved. It is also worth noting that the solutions and examples of good practice were often similar, regardless of the particular community or type of service and centred around the idea of seeing people as whole people who were part of a community, rather than a series of disconnected health needs.

The report has been structured to reflect this overlap.

All invitees, whether present at the event or not had the opportunity to comment on the draft report.

As would maybe be expected, a large part of the round table discussion centred around topics that had been discussed during the day and have therefore been integrated into the report.

It is recognised that, obviously, some individuals may identify as being part of more than one community and that many individuals from marginalised communities have multiple overlapping needs

Quotes and stories from individuals are anonymised.

## Digitalisation

As digitalisation was (mostly) very new or in the pilot stage, the first question was not considered relevant.

Across all of the marginalised communities represented there was an acceptance of the inevitability of digitalisation of healthcare services. There was an appreciation that the implementation of digitalised services offered both significant risks and rewards.

It was felt that Increasing digital services could lead to more rapid access to services and a better connection between the user and multiple services, this would potentially improve person-centred treatment

It was felt that digitalisation could improve both access to care and continuity of care for transient individuals and that it could improve transfer between services.

It was felt that digitalization also offered a less painful way of disclosing traumatic or personal information and could limit the need to repeat painful information. However, some victims/survivors of sexual violence and abuse would prefer to be able to control who has access to this information.

### **The significant areas of concern were:**

#### Accessibility:

Universally accessibility was a concern.

- Access to appropriate hardware
- Access to an internet connection
- Cost of using data or limited data allowance
- The use of language; language needs to be clear, unambiguous, concise, modern English that is easily translated to other languages.
- There is some evidence to suggest that mental health issues affect the ability to use I.T. effectively.
- There is some evidence to suggest communities who are otherwise excluded are often digitally excluded

#### Privacy and confidentiality:

- Many members of marginalised communities are often subjects of social stigma and were significantly concerned about who might have access to their information and under what circumstances.
- It was felt that all data must be well protected
- It was felt that health data should not be passed on to third parties, including other statutory bodies or government departments.
- A concern was expressed that health apps could be used for direct marketing.

## Functionality

- Ease of use was considered to be important
- It was considered to be essential that all digital systems were kept up to date and operational. In such a sensitive area technical faults that disrupt service could be extremely damaging and it would be very easy for public trust in the digital system to be destroyed, particularly amongst marginalised communities.

Last and most importantly, everyone present insisted that digital services should be an adjunct to existing services NOT a replacement and that current options for people to engage in healthcare should remain available.

## **Potential solutions:**

- Good community consultation, particularly with those from marginalised communities
- Good communication with marginalised communities, utilising peers who may have more trust
- Training for staff working with marginalised communities, who may have more trust
- Giving individuals control of their own data

It must be remembered that not just the reality of digitalisation must be addressed, but also the individual and community perception, which may be inaccurate, and based on fear. These may also be well-founded. This will take a concerted effort. If this is done incorrectly marginalised communities may well miss out on an approach to services that could benefit them.



### Prevention of ill-health, mental health and social prescribing

In general, it was felt that the represented communities were either not accessing the services under discussion at all, or were not accessing them fully and therefore were not deriving the full benefits.

In the case of social prescribing some of those present did not know of anyone in their identified community who accessed social prescribing which may be considered to be evidence of the lack of social prescribing in marginalised communities.

### Cross-cutting themes when discussing access to services

There were a number of themes that came up repeatedly in all of the discussion groups, to save on repetition these have been discussed separately below.

#### *Access to GP*

Although Primary Care was not a topic for discussion, in its own right, access to a GP was consistently identified as essential for communities and individuals to be able to access the services under discussion. Recognition that GP's are gatekeepers to the wider NHS cannot be overstated.

Many of the communities had difficulty registering with a GP. This may be due to a lack of photographic ID and/or permanent address. Whilst it was acknowledged that this should not be a problem, as it is not a legal requirement for GP registration, it was mentioned frequently. There was significant confusion amongst community members about what exactly was needed to register with a GP, the majority present had either had problems themselves or knew someone who had had problems. The main barrier was considered to be reception staff, who often were unaware of policy or misinterpreted it, along with a misunderstanding among GP's that an individual did not need identification to register with a practice.

Some people do not understand the confidential nature of a discussion with a GP, especially if they are not from this country, nor do they understand they are under no obligation to reveal their immigration status.

Potential solutions:

- Accurate information for community members. The cards produced by NHS England in partnership with London Pathway for people who are homeless were cited as an example. It was acknowledged that this was useful but had limited success, as it was the smaller part of the problem.
- NHS England have produced award winning leaflets for asylum seekers and refugees, homeless people and the travelling community about registering with a GP. They have the NHS England logo on them and state clearly that people do not need any form of ID to register with a GP. They give a phone number people can ring if they are refused registration and GP practices are meant to fill in the back and give a reason for not registering a person. They are an

extremely powerful leaflet which have evaluated well. It is suggested these are distributed far and wide.

- Good information and training for Primary Care staff. Particularly those who were the first point of contact, such as reception and other support staff.
- GP's to be aware that people not from the UK might need the patient/doctor relationship explained during the first appointment.

Pre-existing mental health conditions, such as anxiety and trauma were cited as reasons why individuals did not access GP services and therefore, social prescribing or prevention services.

Lack of secure accommodation, uncertainty about the future (not knowing if you might need to move or long-term immigration status), or concerns about safety (being in an abusive or exploitative relationship) meant that individuals weren't in a position to prioritise their long-term health because their basic needs for safety and shelter weren't being met.

For some, travelling to a GP was a problem, either because of their mental or physical health. For others the issue was cost.

#### *Charging for health care in migrant communities*

There was significant confusion amongst those present about who could be charged for healthcare and under what circumstances. If this confusion occurred amongst a fairly well-informed group of community members, community advocates and NHS England staff, it is reasonable to conclude that the confusion amongst community members and frontline healthcare staff is equal or larger.

Obviously, as far as the community was concerned, it would make sense to drop all charges for health care for everyone. It was felt that any saving would be offset by preventing acute health emergencies and the need for additional support in the future. This is not current government policy. As policy currently stands, these suggestions were made:

- Good accurate information for staff, including reception staff as they were often the first point of contact. This should be delivered alongside training.
- Good, appropriate, information for communities, delivered in a format that makes sense to them. This could vary amongst different groups and it was considered important that information was co-produced with community members.
- The use of trusted intermediaries, such as known health professionals, to deliver information.
- The use of community groups and/or peer supporters/community health champions and specialist voluntary sector providers to deliver messages.

### *Domestic Violence*

For a number of the communities present, there was a need for community education about what constituted a violent or abusive relationship. The example “but they only pushed me, not actually hit me” was given.

There was significant stigma associated with being a victim/survivor of domestic abuse. This made disclosure difficult. Some community members feared being judged or even ostracised from their community.

There was a problem around disclosure of domestic abuse when a family or community member was used to translate.

There was a fear that asking for help could mean loss of custody of children.

Concern was expressed that an increasing reliance on informal carers to fill the gaps between health care and social care, meant that more people may be trapped in an abusive relationship/situation.

There is little understanding that sexual violence is often experienced in a domestic violence setting, this leads to added stigma for victims and survivors, making disclosure difficult.

### *Trauma Informed Care*

Trauma was mentioned consistently by all present as a significant barrier to accessing services. This was true of mental health services and social prescribing as well as some of the prevention (screening) services.

The high prevalence of trauma amongst those from the refugee community was highlighted, alongside a lack of awareness amongst health professionals and a lack of, or long waiting list for, specialist services.

Sexual trauma was mentioned as a significant barrier to accessing antenatal and maternity services. It was also identified as a significant barrier to accessing some screening services, particularly those where an intimate physical examination may be necessary, such as cervical cancer screening. Even in those screening processes where the initial screening did not involve an initial physical examination, such as bowel cancer screening, fear of follow-up testing or treatment, such as colonoscopy or gastroscopy was a significant barrier.

Whilst it was agreed that specialist trauma services were essential, it was felt that all health professionals, non-medical staff, such as drugs workers and hostel staff and support staff, such as receptionists, should be able to deliver trauma informed care and know where to make referrals

It should be noted that when staff work in a trauma informed way their own need for support and supervision may increase since it is likely that more disclosures will be received. There also need to be clear processes and guidance for staff relating to responding sensitively to disclosures rather than automatically going down a safeguarding route.

Trauma informed care is not about becoming a trauma specialist, nor is it about forcing disclosure. It is about being aware of the effects that trauma may have on an individual or community and how it may present. It is about asking the individual what may help, rather than assigning a solution, such as medication. Some individuals found that medication such as Valium made them worse, as they then felt out of control. Suggestions for questions included: where would you like treatment? When would you like treatment? Would you prefer a clinician who is of a particular gender? Would you like to bring someone with you? There are the specialist services in your community would you like some information or would you like help in contacting them?

### *Cost of travel*

The cost of travel to primary care appointments was mentioned as difficult for some community members.

The cost of travel to social prescribing activities was mentioned as a potential barrier

Paying out the up-front cost for travel to secondary care was mentioned as a barrier by some. Some community members were unaware that they could claim travel costs back. The difficulty of claiming travel costs back was mentioned by some.

Many more vulnerable individuals would want to ask a friend to go with them to appointments (particularly mentioned by victims/survivors of sexual assault, those with mental health problems, victims/survivors of domestic abuse and those who do not speak English as a first language – although it is probably a fairly universal preference across the whole population – wouldn't many people want to take a friend to a scary appointment?). For many communities represented at this event the extra cost of someone else attending an appointment with them was a significant barrier.

### *Good translation services*

There was a tendency for medical professionals to rely on family members, including children, to translate which is not appropriate. There should be access to good independent translation services, for example to be sure informed consent was given.

The fact that the person translating is known to the individual could be a barrier to an honest discussion with a health professional: examples given, a mother discussing gynaecological problems in front of a teenage or adult son. There was a risk that the family member may not translate properly (often, but not always, from stigma or shame) for things like problems with mental health). There was also concern that relying on family members or informal community relationships may inhibit disclosure of domestic abuse or sexual trauma: someone would be unlikely to disclose abuse in front of the perpetrator.

## Summary of Topic Specific Discussions

### Social Prescribing

One of the most important points to come out of the discussion about social prescribing, was the importance of the social aspect. Examples were given of how isolating it could be to go somewhere that is totally outside of someone's ordinary experience (like a gym), but that it was much easier to attend if it was a social gathering that was held in a gym with the opportunity to take part in activities.

- Individuals from marginalised communities were unlikely to seek help, so the link worker needs to take a proactive approach. Link workers involved in social prescribing need to be proactive in reaching the marginalised communities.
- It was felt that large parts of the population are likely to contact a GP, so why would a link worker need to be present there? It could be considered a less effective use of time and resource to locate the link worker in a GP surgery when they could be used more effectively in proactive outreach.
- When social prescribing for an individual has been arranged, there may be barriers for the person to turn up (could be travel costs or practicalities, fear, stigma).
- There was a suggestion to overcome the barrier of fear and anxiety in attending social prescribing.
- Following on from above point it would be beneficial if the link worker attended group or community meetings within their areas (drug and alcohol group meetings, religious meetings etc). This would enable the link worker to further understand their local marginalised community and build trust with individuals and communities.
- Direct cost of social prescribing activities, such as subscription apps or gym membership were a significant barrier.
- Indirect costs of social prescribing activities, such as equipment (trainers, swimming costume etc) and travel costs were a significant barrier.
- Other potential indirect costs, such as all other group members going for a coffee after a session were mentioned. There was a concern that being unable to afford to participate in the "additional" social aspect of the activity could increase isolation and limit potential benefits.
- Concern was expressed about link workers knowledge and skills of the particular needs of those from marginalised communities, including background, history, culture. Lack of knowledge can translate into barriers.
- Concern was expressed about how link workers would initially engage with marginalised communities.

- Concern was expressed that this lack of understanding of marginalised communities also extends to those who run social prescribing groups. This could cause an individual to not want to attend initially and could subsequently cause them to drop out.
- There was concern that link workers and leaders of social prescribing groups did not have sufficient awareness of the impact of trauma.
- There was a concern that link workers and leaders of social prescribing groups may not be able to offer services in a language other than English. This was a particular barrier for refugee and migrant communities when accessing social prescribing services and interacting with link workers.

#### Potential solutions:

- Link workers being partially based in places other than GP surgeries.
- Work in partnership with the non-NHS providers who are already delivering services
- Co-designed and co-delivered training for link workers from community groups, about the particular needs and culture of marginalised communities
- Link workers contacting trusted intermediaries (specialist health and community workers) for an “introduction” to community members
- Training for link workers in the potential impacts of trauma and in the delivery of trauma informed care
- Training for non-specialist community groups in the potential impacts of trauma and in the delivery of trauma informed care and referral pathways
- Joint local initiatives (joint funding bids, fundraising) to fund equipment and travel for individuals to be able to participate in social prescribing activities.
- Good data collection and appropriate data sets, to ensure those from marginalised communities are offered social prescribing
- An emphasis evaluating the experience of engaging with link workers and social prescribing activities for those from marginalised communities so that what worked well and what did not work so well can be used to improve services.
- Access to appropriate translation services (see comments on page 11)
- A suggestion was made that for many individuals access to volunteering opportunities and/or employment training could improve outcomes from social prescribing
- One suggestion was to group people up with people of similar marginalised communities or similar people with lived experience so there is a sense of identity. Although it was acknowledged this may not always be practical.

- One suggestion was to have a buddy system, so someone went along with the individual and helped them integrate into the group and feel comfortable attending. Overall buddy system to help people 'walk through the door'.
- It was suggested that link workers could train community members in outreach and social prescribing to facilitate engagement within their own communities. This would have the added benefit of increasing skills and confidence for the volunteers.
- A local database of community groups

## Mental Health

Potential barriers to access:

- For many in the refugee/migrant community mental health problems are not recognised. They are often regarded not as an illness but a decision. Fear that an acknowledgement of a mental health problem will lead to them being labelled crazy and locked up.
- In the same community post-partum depression is not admitted. There is a fear that it will lead to their kids being taken away.
- Many people, either because English is not their first language, or because of poor educational skills do not have the vocabulary to discuss their problems in a way that is easily understood or clearly articulate what they are feeling.
- There is often a lack of understanding as to the terms used by medical professionals and there are misunderstandings about what they actually mean. For example, assessment is often seen as equivalent to judgement.
- Terms such as self-medication are often used in respect of substance use, often by the service users themselves, but there can be little awareness as to what they are self-medicating against, and it is easy to assume if they know the term they also understand the driver behind their substance use.
- Services provide generic services and there is often a real lack of understanding of the cultural and social background, norms of behaviour and cultural and social differences of many marginalised communities that lead to them either not accessing services, or not attending follow up appointments. The easy wins were felt to take precedent.
- Stressed and pressured systems lose the people who find them hard to access first and this is exacerbated the loss of community and outreach workers.
- A lack of translators, or the tendency to use members of the family or local community as translators either stop people coming because they can't speak the language, or not discussing certain problems because of the relationship with the translator in the wider community.
- Many people with complex needs are referred to counselling sessions or group work unprepared for what will happen next, and do not attend after the first appointment through fear, confusion or embarrassment.
- Lack of knowledge about or community groups in the wider community within local health service providers.
- Referral pathways between health providers often means that those with complex needs are passed from service to service, with everyone marking the job done on referral and the patient eventually disappearing having never been seen.



- Mental health professionals refusing to work with individuals until their substance use is dealt with, not understanding that the substance use is the armour that allows them to make it through the day.
- Criteria for accessing services set at a benchmark people can't meet. Appointments made for times people will be unable to make.
- Overstretched services setting thresholds as a means of denying access to services or passing clients on.
- Short term care (IAPT 6 – 12 week sessions) and crisis care (sectioning) were felt to be effective but there was felt to be a massive gap in the middle where very long waiting lists or a complete absence of services meant that many people effectively received no treatment.
- Still too many disagreements between service professionals that was a barrier to effective treatment. The debate between capacity and lifestyle choice often meant that treatment was withheld on the assumption that the client has a responsibility to change their behaviour first.
- Talking therapies only work for some in the community. Poor language skills, a lack of emotional intelligence, cultural barriers or inarticulacy meant that it was ineffective for many.
- Better partnership working at a local level to widen communication with other stakeholders in the community.
- Trauma was not understood well enough.
- Small community services and organisations that were effective in dealing with specific marginalised communities often disappeared due to a lack of funding.
- Some health services, mental health services being an example, tend not to work in partnership and do not include effective specialist (non-generic) community organisations in their overall treatment. Health services have a tendency to favour generic provision.
- Social prescribing was felt to be a good idea, but was often badly done, with people being given a flyer or a form for a gym discount and nothing else.
- Not enough time in the therapeutic relationship to build genuine trust and open communication. Specialist community-based organisations are often able to offer more time to build trust and establish effective relationships.
- Waiting lists too long and thresholds too high. People give up on accessing services because they feel they are not worthy enough or are unwanted. Community based specialist services could help to support individuals in the interim while they await specialist appointments,
- Expert knowledge in voluntary sector often ignored.
- People being taken out of the community, medicated and set back adds to trauma.

- People can be traumatized by receiving a complex diagnosis (HIV+) for example without the proper support being put into place to look after them afterwards.
- There was mention of a significant gap between IAPT and inpatient treatment that wasn't currently being filled, particularly for those with complex/multiple needs or underlying trauma.

#### Potential solutions.

- Supporting people from marginalised communities to give talks to health professionals about the own communities and its culture and belief systems.
- More investment in independent translators and clear communication around the confidentiality of what is being said.
- Better communication that poor mental health is a common experience and nothing to be ashamed of. It's ok not to be ok.
- Pre-treatment sessions for vulnerable people who might struggle with the therapeutic relationship, explaining what will happen, why it will happen, how it might help and what they can expect.
- A national programme to support an awareness of wider service provision within the local community among NHS providers.
- Flexibility around mental health workers working with individuals who have substance use issues. Capacity to be measured on their capability to take an active part in the session.
- Appointments to be made with life circumstances taken in account – childcare, substance use, distance to travel.
- Better investment in medium term therapeutic services and a recognition that IAPT could be a valuable service but did not meet the needs of everyone referred to it. It appears that too often IAPT is the only modality available to individuals.
- Mutual aid groups based around specific conditions and facilitated by a therapist may be more effective than 1-1 work with certain marginalised communities.
- Training around the recognition that other stakeholders could often help individuals where the NHS could not. A reluctance to use non-medical stakeholders was a barrier to effective care.
- Better training and awareness around recognising and dealing with underlying trauma.
- Investment from CCG's in effective local community and voluntary sector organisations

- Recognition that for social prescribing to work, some vulnerable people might need a buddy to take them to the first gym session or appointment with a new organisation or community group.
- Investment in training to help recognise/support individuals liable to not attend the first appointment or fail to return for a second because they feel they are unwanted by a service, or that people do not want to help them.
- Learning from other fields. Peer support/mutual aid has an evidence base for being effective in drug and alcohol treatment, Can this be transferred to specific marginalised communities in mental health?
- Mental health assessment for refugees on first contact.
- Investment in the time to get to know an individual and what they think their needs are would save money in the long run, rather than prescribing medication people do not take or want, causing them to come back into services over and over.
- More provision of “mid-range” treatment, for those whose needs are not currently being met by IAPT, but who do not meet the threshold for in-patient care. This could be provided by, or in partnership with, specialist community groups

## Prevention of ill-health – pregnancy and the early years

### Potential barriers to engagement

- Poor previous experience of services
- Norms are different in different countries and cultures and individuals don't necessarily understand the benefits of pre-natal care. For example, they may not understand what a mid-wife is, or their role.
- Lack of information about and fear of bills for secondary health care.
- Fear that engaging in services will result in judgement coupled with shame and guilt about behaviours or not engaging earlier
- Fear that asking for help will result in the baby being removed from the parent's care
- Bad relationships with professionals in the past, if this did not apply to the individual it usually applied to someone that they knew within their own community
- Victims/survivors of sexual assault may suffer additional trauma with care or intimate physical examination, during and immediately after giving birth. Or the fear of what might happen during an examination may make them unlikely to engage
- Domestic Violence: there was a lack of knowledge amongst some communities around what exactly constituted a violent or abusive relationship – "it was only a push...". for some communities there was a significant stigma, a fear of being judged and even the fear of being ostracised from the community associated with being a victim/survivor of domestic violence. Amongst some communities there was a significant fear of children being removed from the parent's care if domestic abuse was disclosed.
- Sexual Violence and Abuse: there is a lack of understanding about the trauma experienced by victims and survivors. NHS services including IAPT tend to focus on a diagnosed single symptom not the cause of the trauma that often results in complex needs that cannot be met by one service alone.

### Potential solutions.

- Clarity about which services are potentially chargeable and for whom
- Explanation of the role of a midwife and why antenatal appointments are important.
- Trauma informed care
- Use of appropriate interpreters

- There is a role for school nurses in identifying children who may need safeguarding, or have other additional needs
- It would be of benefit to community members if Practice Nurses were able to immunise school children, in addition to school nurses.
- More multiagency working about the care of vulnerable children of a certain age whose parents are in abusive or violent relationships.
- More knowledge about drinking in pregnancy and funding for creches for the parents to access support
- Dental care for children
- Mindfulness in schools
- Sharing of commissioning best practice
- More awareness of the multiple needs of women such as: mental health, history of offending, housing status, immigration status, sexual violence and abuse etc
- Co-producing services using a lived experience team
- To consider non-generic needs led provision of midwifery services.
- Awareness raising amongst community members, delivered by trusted intermediaries and/or peer supporters
- Clear and consistent advertising messages
- Training for professionals from community groups, specialist service providers and those with lived experience

### Prevention of ill-health – adult screening services

Both whole population prevention, such as cancer screening and over 40s health checks and targeted screening, such as HIV or Hepatitis testing were discussed. As were universal and targeted immunisation programmes.

It was felt that some communities were missing out on both targeted and universal immunisation programmes, such as flu vaccine or meningitis.

#### Potential barriers

- Not having English as a first language (see above).
- Lower levels of literacy – not understanding the letter, or not understanding the importance of screening.
- Not seeing screening as a current priority, when immediate needs, such as shelter, or safety weren't being met
- Pre-existing trauma, particularly sexual trauma
- Lack of address or frequent change of phone number, so that appointment letters and reminders weren't being received
- Difficulty in requesting screening outside of the national screening programmes. The example given was difficulty accessing cervical screening by actually requesting a smear test, without a "referral" letter.
- The assumption by healthcare professionals that prevention wasn't a priority for individuals "they have bigger things to worry about" or an assumption that individuals were "too vulnerable" to attend follow-up care

#### Potential solutions

- Targeted education about the importance of screening – co-produced by community members and delivered by community groups, trusted intermediaries, such as nurses working in specialist drugs services and peers (community health champions).
- Education for professionals
- Targeted immunisation campaigns
- Using the new patient check, when registering with a GP to promote the benefits of immunisation and screening
- Opportunistic provision of screening and immunisation, such as in drug treatment services and by using health buses that were already visiting some communities.

- The use of pharmacies and other community health care settings (such as antenatal and new mother groups and sexual health services) to deliver immunisation.
- The ability to access screening “on-demand”, without the need for the letter from the screening programme

### Cross-cutting solutions

During the event, the same potential solutions came up over and over again, regardless of the topic or community. Although some of these have been mentioned above, it was felt to be value in listing them all below.

#### *Delivering Messages and services to where people actually are*

A cross-cutting concern was that members of marginalised communities weren't necessarily being reached by existing awareness raising campaigns. It was suggested that targeted campaigns were needed at that a format that reached one community wouldn't necessarily be appropriate for another.

Examples: using digital media, such as Grindr and other geosocial networking apps to target MSM who are using chemicals as part of the sexual experience

Using trusted intermediaries (specialist health professionals), assertive outreach, and/or peer education and support may be a way to deliver various health messages and increase access to all of the services discussed.

Opportunistic screening, assessment by link workers and immunisation could increase uptake of services. Examples given included the mobile TB screening service, co-location of services (screening offered in drug treatment services) and the use of health buses.

A number of examples of health services targeted at particular communities and built around individual need were highlighted: such as City Reach in Norwich.

#### *Use of Language*

Concern was expressed that the language in some communications wasn't understood by particular communities, this could be potentially overcome by working with communities and individual community members to ensure that any health messages are delivered in an appropriate format and via appropriate channels. Appropriate language, formats and channels may not be the same for all communities.



### *Involving Communities and Community Members in Supporting Delivery of Healthcare*

A clear and consistent message from all of the communities present was that communities and individual community members should be involved in the design and delivery of health service and in a wider supporting role.

Suggestions and examples included:

- Co-production of service design for marginalised communities
- Personalised care, that was co-produced between individuals and healthcare professionals
- The provision of staff training by community groups and Experts by Experience
- The provision and commissioning of peer support and “buddying” systems
- Provision and commissioning of community-led translation services

There was an acknowledged risk that sometimes when a community led service became commissioned that it “lost” its community connection and hence, some of its value and risked becoming “just another service”.

### *Staff Training*

Staff training was identified as a major need right across the communities and all of the topic areas discussed.

- It was felt that specialist community groups were in a good position to deliver training to staff
- It was felt that training that was co-produced and co-delivered using Experts by Experience was important
- Training was needed about specific issues such as, domestic abuse, drug use, sexual violence and abuse, including childhood abuse and sexual exploitation, mental health and trauma but also in cultural competencies in dealing with members of marginalised communities, particularly those communities which were hidden.

It was felt that training needed to be delivered not only to health workers, but to support staff as well. It was also needed for other allied professions, such as social workers, hostel workers, drugs workers and link workers. and CCG's.

## *Stigma*

Throughout the whole event, stigma was mentioned repeatedly. This took two forms: stigma from professionals and stigma from either within a community or within oneself.

It was noted that professionals made assumptions based on stigma, such as assuming an individual was too “vulnerable” or didn’t have the ability to understand – this was demonstrated by a paternalistic and directive treatment. Or even not listening at all and assuming that symptoms were caused by drugs or alcohol, an example was given of medical professionals assuming that the symptoms of carbon monoxide poisoning were in fact alcohol intoxication. Another example was given of an individual approaching a GP because they were concerned about a lump in their breast and being told “I’m not going to give you methadone”.

Examples were given of stigma within particular communities, such as the stigma of being a domestic violence survivor and/or sexual violence and abuse survivor within some parts of the traveller community or where having difficulties with mental health was seen as personal within some of the migrant communities.

There were many examples offered where individuals felt too ashamed to ask for help, whether this was self-stigma or whether this was based on prior experience of poor treatment by health professionals is a moot point. The majority of individual community members in the room had either had this happen themselves or knew someone it had happened to. It made individuals from many of the marginalised communities reluctant to ask for help.

Many of the communities were also wary of asking for help in case they were viewed as poor parents. They felt that they were less likely to be offered help and more likely to be referred for safeguarding assessments. Whether this was true or not it was a fairly universal belief and therefore a significant barrier to engagement.

### *Community Awareness*

Awareness of some of the issues under discussion was low amongst many communities. It was felt that a concerted effort was needed to raise awareness of mental health, domestic violence, sexual violence, abuse and sexual exploitation and the impact of trauma. It was felt that targeted awareness raising about the value of prevention (ante-natal care, immunisations and screening) was needed to help people see the potential of these services.

For those from migrant communities it was important that consistent and accurate information was provided about charging policies.

For those with no permanent address or no ID, it was important that they were aware of their right to register with a GP.

In all cases it was important that the information was given in an appropriate way using the right channels for the information.

The value of trusted intermediaries and competent advocates was noted. These often exist within communities, but health services are not always aware of who they are

The role of community groups and specialist service providers was considered to be vital.

The use of peer support/community health champions was mentioned consistently throughout the day.

For further information:

For further information about the NHS Long Term Plan, please see:

<https://www.longtermplan.nhs.uk/>

For further information about Working with Everyone, please contact:

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