

Equality Objectives Community and LINK workshop discussion, 19th February 2013:

The discussions followed several themes as outlined below. The groups highlighted what they perceived to be key issues of concern for the communities they work with or represent.

Primary care services:

The feedback was that GP services and primary care services need improvement to meet needs of whole community. The areas repeatedly highlighted were:

- Timings of services – after hours and a Saturday morning service would help people
- Equally children who are carers would benefit from more flexible appointment times which don't take them out of education.
- Length of time of the consultations was a repeated barrier. It was reported that if a person had complex or multiple conditions they were not given the time and space to address these
- There was a positive example of the way in which services had try to address this. At an Islington GP practice: once a year each patient in the practice is given a 20/30 minute consultation (per patient) to discuss issues in more depth and ask any questions.
- Self-confidence and health literacy has a big impact on how a patient uses their appointment system.

Receptionist staff were reported across services, but in particular GP services, as lacking in front of house skills.

The areas highlighted as being of concern were:

- A lack of understanding to deal with patients who experience barriers to communicating their needs
- It was felt this could tip into a lack of empathy to deal with patients (e.g. English not as a first language, difficulties speaking, sensory disability)
- A lack of due regard to privacy and respect of patients e.g. patient files on display, asking patients to say their condition in front of the waiting room, repeating their condition back to them).
- GP services were reported as not being consistently good at involving patients in their own care.
- It was reported that patient choice is based more on socioeconomic conditions than real choice so while Choose and Book is a very good service it has hidden restrictions which aren't considered e.g. how does a patient afford to travel to their chosen location?
- On the above Dental services were used as an example - they do not assess an individual's needs instead they assess on socioeconomic level – and what they can afford. The resulting service is provided on this basis.

They felt there was a need for receptionist and wider management staff training on identifying disabilities including deafness and blindness, along with the wider patient experience.

Access to care and services:

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Language is a huge barrier, to services, for BME communities.

The points raised by the group were:

- Interpreters only work on specific days of the week. A patient will be asked to make their appointment on the day the interpreter is attending rather than when the patient can most conveniently make the appointment.
- Feedback has been there is a reliance on a spouse, relative or children to translate and interpret for a patient. This can infringe on health and wellbeing (e.g. domestic violence, cultural barriers or restrictions) and basic privacy.
- LINks research has shown that patients are unable to access language line and it is not offered consistently across GP services.

In terms of patient care, it was highlighted that it should be focused on how they can be supported to speak for themselves. Those patients that can speak up get better care. Those that can't are at risk of receiving care which does not meet their needs as successfully. There was a user experience reported of a polish-speaking man who repeat attends A&E with drugs and alcohol dependency. Each time he is not given the correct information in a format he understands.

It was felt by the group that the resources which are available within the community need to be more widely promoted. Some of the areas which were highlighted were:

- Referral systems and self-referral.
- General signposting to health and community services.

Currently it was felt GPs don't know enough about these services.

The group also felt that language used given at the point of diagnosis is often very clinical and not patient friendly. Equally they reported that information given is very clinical in language and doesn't make sense to a patient. Patients can be at risk of not understanding the diagnosis they are given or the information, or of receiving the full information.

Online resources can be really effective and are often the best for most people. However, Computer literacy and access to computers can be an issue so the group highlighted that ways to improve patient access and ability to online resources e.g. computers in GP surgeries and training should be explored.

The groups most affected by access barriers were highlighted as: complex issues, frail and elderly, carers, BME communities – particularly those with English not as a first language.

It was reported by the group that asylum and refugee communities are not aware of their rights and how to meet their needs re: health services and GP registration, so will often go to A&E. It was felt that on top of this refugees and asylum seekers do not know what are their rights and how can they make sure they access these. Currently it appears neither GPs nor patients know. This again goes back to barriers to accessing services and information, ensuring all communities have access to services and information.

The group felt that health advocacy is not used enough, and that patients often look to and use community organisations to help them.

Mental health services:

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There appear to be some identified gaps within mental health services. The group reported that changes to services had brought some real difficulties with it. They felt that prevention was becoming more difficult and they were instead crisis fighting. They feedback that from their perspective it felt as if there hasn't been communication across the system about what these changes mean to patients e.g. patients discharged back to GPs or communities from care homes or a care coordinator has changed and the patient has not been informed.

Some of the group also identified a group of people between IAPT or care planning who do need help and are not receiving it. It was felt there is a gap in provision and holistic support – members of the group expanded upon this – by explaining that the support might not be clinical but focus on whole health and wellbeing which would impact positively on health and wellbeing outcomes.

It was highlighted that if these patients fall into crisis they may attend A&E.

It was felt mental health patients are not always listened to - or the other professionals in their care – e.g. reports of Locums changing a patient's medication which makes the patient go up and down.

It was felt there is a lack of understanding around the mental health services offered to BME communities and their specific needs. One area highlighted was an overreliance on CBT – which it was felt was not appropriate for some communities who have undergone trauma.

Integrated care and Holistic care:

It was felt that health and promotion for particular groups is very poor – especially when promoting prevention. Prevention was described as looking at integrated care, housing and socioeconomic.

Health vs wellbeing: the group reported that they felt there is a struggle at the moment between the two e.g. Counselling for those with LTCs – the group reported a lapse between the time when they need it and then when they are finally offered it / if they are offered it.

The group also felt there is a disconnect between people's needs and the health service and help they are given e.g. Medications: it was reported that elderly people are not having their 6 months review, also 65 + some of their health needs not assessed - sexual health and drugs and alcohol. The group report that it does not feel like the system currently offers integrated care, but instead they felt that feedback shows the patient often feels caught between health and social care. The group elaborated that they felt health specific transitions managed well and yet social transitions not well managed.

They felt that Expert patient programme is a great example of supporting people.

They felt there was an ongoing issue of dual diagnosis. Thus, health needs are very good at being assessed but in silos. Dual diagnosis means that one condition can overshadow another. e.g. HIV overshadows other health issues or conditions a patient has.

It was highlighted that the changes to benefits – housing and immigration – are a risk to populations more at crisis.

The homeless pathway at UCLH (Pathway) was mentioned as an exemplary service. It is currently for those users who are homeless. There is a holistic checklist for patients – which takes into account their lifestyles and needs.

Carers:

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Carers were specifically highlighted as a group. It was shared that carers are the people who translate and facilitate, and yet their own needs are not addressed in the process of caring, or that their appropriateness as a carer are not assessed.

They also reported that young carers and children often support parents. The impacts this has on their lives including education is not assessed – meaning they are adversely affected in life.

There is an overall lack of awareness on available services for carers by GPs. Carers are overlooked and their needs aren't recognised. Referral services are crucial without recognition people can get lost.

Complaints and patient experience:

The group felt that although the systems are in place doesn't mean all services are good at handling complaints - and that there can be fear from patients that services will be taken away if they complain.

Specific communities were mentioned in terms of being scared or finding it difficult to make a complaint:

- Patients with HIV experience feeling bullied – and not always given a good service because of their condition.
- Elderly people find it harder to make a complaint.
- BME communities very reluctant to make any complaints which they perceive might impact on their care and service. Therefore, they can find it very difficult to complain directly to provider.

Experience from patients and communities can often be that they are passed from pillar to pillar to make a complaint, and that service providers don't always know their own complaints service process or know who is accountable.

It was raised that with the new NHS structures:

- Will it be more difficult to make complaints.
- Will everyone understanding there is a complaints process and ability to access care.



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