Seldom Heard Voices
August 2015

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Contents

Acknowledgements

For Healthwatch Lincolnshire to complete a project of this size, we rely heavily on Lincolnshire residents to get involved and share their experiences. We would firstly like to thank the 886 people who have completed surveys and taken part in focus groups - we recognise that sharing your personal experiences can sometimes be very difficult and scary.

Support for this project has also come many sources. Lead organisations were:

- CentrePoint.

- Framework.

- Grantham Polish Club.

- Lincolnshire LGBT Plus Patient User Group.

- MIND, Peterborough & Fenland.

- Rethink.

- Salvation Army, Boston.

- SHINE.

- South Lincs Blind Society.

The above leads also worked with other organisations, voluntary and community groups and charities to support our work with seldom heard groups. This provided a wider engagement across the county. We would like to thank all the organisations that supported our Seldom Heard Voices work.

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Executive Summary

Access to primary and secondary health services or social care should be equal for all of us, but Healthwatch Lincolnshire recognise this is not always the case. We often hear that people are treated differently when they are accessing health or care services due to the nature of their illness, disability or personal barrier.

To help us understand what, if any, inequalities are occurring we needed to engage with people from specifically identified communities. To enable us to do this during 2014/15 we focused some of our resources on a 'Seldom Heard Voices' programme of activities.

These 'Seldom Heard Voices' activities included:

Identifying - 6 focus areas including people from Eastern European countries now living and working in Lincolnshire; people who are homeless; people from the lesbian, gay, bi-sexual and transgender community; have mental ill health; live in rural communities or are socially isolated and people with a range of sensory impairments.

Connecting - with charitable and community organisations who are already working with the above communities. We contracted our lead organisations from local charities. We recognise their role in our engagement as they have already built up trust and understanding with individuals and communities.

Collating - responses from all the questionnaires and focus groups and assess final reports from each of our lead organisations.

From all the groups we heard common themes emerging such as:

- Need for tailored communication methods.

- Better understanding by front line staff for individual health, disability or care needs.

- Concern for staff shortages. This was often linked to the patient's ability to get an appointment or to receive an appropriate level of service.

- Need for more emotional and mental health support. This was particularly important for people whose illness or disability led to isolation or mental health problems eg being diagnosed as going blind.

- Enhanced need for supporting carers. The cared-for recognised the amount of lifeline support their carers provide for them on a daily basis but also recognised the needs of the carers and the gaps in access and availability.

To support this report, each of the 6 areas identified have produced individual responses or reports. These provide more detailed results and also include some of the personal views and comments shared by the people responding to questionnaires and received from focus groups.

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Healthwatch Lincolnshire

Healthwatch Lincolnshire came into effect on 1st April 2013 as an independent organisation and formed as a registered charity and Company Limited by Guarantee.

Part of the Health and Social Care Act 2012 recognised the need for a local independent consumer champion for health and social care services to cover each of the 152 county councils or boroughs, with one overarching body Healthwatch England. The Health and Social Care Act 2012 provided each Healthwatch with the following statutory powers:

- A duty on service providers and commissioners to respond to requests for information within 20 working days.

- A duty on service providers and commissioners to respond to recommendations within 20 working days.

- Make reports and recommendations about services known to commissioners, providers and regulators of health and social care services.

- A duty to allow entry to authorised statutory health and care facilities known as 'Enter and View' visits.

- A seat on the Health and Wellbeing Board to promote health improvements and tackle health inequalities.

- A process where recommendations to Healthwatch England about which special reviews or investigations may be required and where relevant, to the Care Quality Commission.

Healthwatch Lincolnshire activities can be broken down into 3 core functions:

Influencing - We are here to listen to people's views and personal experiences of their health and care services and share the key messages we hear in order to help influence improvements in services.

Signposting - Signposting people to help them access advice, choice and information about their local health and care services.

Watchdog - To ensure change is happening.

You can find out more about the work of Healthwatch Lincolnshire by visiting our website www.healthwatchlincolnshire.co.uk or by contacting us and a member of our team who will be happy to discuss further.

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What is our Seldom Heard Voices Project?

Healthwatch Lincolnshire has a duty to listen to all people and communities across our county. Everyone should have an equal right to NHS or social care services, but due to personal or other barriers some people may feel, this is not always the case.

The key theme running throughout all of our Seldom Heard Voices work looks at access to and treatment from health and care services. The work across all 6 Seldom Heard Voices themed areas was carried out between the period of December 2014 and July 2015.

We have always recognised there are groups of people who are classed as 'seldom heard', but for Healthwatch Lincolnshire and the purpose of this work we concluded there are 2 categories of people that apply:

❖ People, who due to the nature of their illness, disability or personal circumstances may not always receive the same level of NHS or care services.

❖ People who do not readily share their experiences of health and care services with Healthwatch Lincolnshire.

To support people from category one, we identified the need to allocate financial and organisational resources to set up a Seldom Heard Voices programme. There are a large number of communities that have been identified within this category, however, for 2014/15 we selected 6 diverse groups of people to focus on, these were:

- People Living in Lincolnshire who are from a Black Minority Ethnic BME (Eastern European) community.

- People who are homeless.

- People who are Lesbian, Gay, Bi-sexual, Transgender, LGBT.

- People who have mental health illnesses.

- People living in rural communities and are socially isolated.

- People who have sensory impairments.

There is often a strong correlation between category 1 and 2. For instance being gay may not cause a barrier to accessing mainstream health services, but often where people do not feel confident or able to share their health and care experiences means that inequalities in services may not highlighted. To address the voices of people in category 2, in 2014 we also completed work on 2 projects covering men's health and children and young people.

Healthwatch England's Consumer Principles
Working with local Healthwatch organisations and the general public Healthwatch England have developed 8 consumer principles. Whilst all 8 consumer principles are important, we believe 2 of the consumer principles that concern access to and delivery of safe and dignified services, directly supports our Seldom Heard Voices project work. Below is the outline of what these 2 principles mean to patients and users of services. You can read more about the 8 consumer principles by visiting the Healthwatch England website http://www.healthwatch.co.uk/rights
Healthwatch England, Consumer Principles 2 and 3

ACCESS
"I want the right to access services on an equal basis with others,
without fear of prejudice or discrimination, when I need them
and in a way that works for me and my family."

People should be able to access the treatment and services they need, irrespective of where they live or who they are and have a clear sense of what they are entitled to. People felt that easy and timely access to GPs is particularly important as they are often the gatekeeper for access to other medical services.

What this could mean in practice

If you need to see a GP you should be able to choose and register with a local practice and ask to see a particular GP, especially if you want to see one of the same gender. If you need to use a health service the health professional should not deny you access, provide you with a lower quality service or discriminate against you because you are disabled or because of your age, religion, ethnicity, sexuality or gender.

If you need social care and are moving from one council area to another, the councils should ensure you have a continuity of support before, during and after you move. If you are homeless you are still entitled to register with a GP. You can do so using a temporary address, such as a friend's place or a day centre. You cannot be refused access to GP services just because you are homeless.

DELIVERY
Safe, Dignified and High Quality Service
"I want the right to high quality, safe, confidential services
that treat me with dignity, compassion and respect."

This right is about how services are delivered. When people are ill or need care they should expect high quality services that are safe, will help make them better or make their lives easier. They should also expect to be treated like a human being, being looked after by people who are compassionate. Those we spoke to felt very strongly about this, pointing out the good and the bad.

What this could mean in practice

If you are in a care home and can't go the toilet alone, staff should offer *support in a timely fashion* and *give you the privacy you want*. You should not be left to soil yourself or leave you in a compromising or potentially harmful situation.

If you have a learning disability and are undergoing surgery you should expect the specialist to talk to you (if you want them to) about the surgery - what it will feel like, what the benefits might be and any possible side effects. They should do this *using language you will understand*. They should not withhold any information if you want to know more.

How Healthwatch Lincolnshire has engaged with communities.

Many seldom heard groups of people are supported with daily living by voluntary and community organisations. Because these organisations have taken time to build confidence and respect locally, we recognised they would be the best way for us to engage with the people we need to hear from. We decided to set up a formal contract process which would reimburse them for the work they conducted on this project. The sub-contracted work was delivered through focus groups, surveys, one-to-one discussions and other events. Our role was not necessarily to deliver the work but to provide the funds to enable other groups to engage with their own members or service users.

What do we mean when we refer to mainstream health and care services?

What do we mean by primary care services? This is treatment delivered by a doctor, dentist, optician, walk-in centre or NHS Pharmacy service and is most often the first or 'primary' place they visit when a day-to-day health concern arises. Access to these services should be the same for everyone. Our concern is that for some people eg homeless or who are blind or deaf, this is not always the case. For instance, telephoning to make an appointment can be a challenge.

What do we mean by secondary (or acute) health services? This is usually delivered in a hospital or clinic setting. This may be unplanned emergency care or surgery or planned specialist medical care or surgery. Our concern is that for some people they don't always feel they are listened to, for instance someone who has English as a second language may not always understand what a consultant is telling them and so cannot speak out if they are concerned or confused and the consequences of this might be they don't take essential medication properly.

What do we mean by social care services? Social care covers a wide range of services that support people either in their own home or in a residential or nursing home setting. This might be if you have mobility issues you may simply require some equipment to help you remain mobile and independent, but if you develop a condition that seriously affects your mental capacity or your ability to move and look after yourself, you are likely to need a much wider range of social care services. Care and support services might typically include equipment, help in your home, community support and activities, day centres, home adaptations, residential care, financial support, information and advisory services and advocacy. Our concern is that for some people they may not be able to express concerns and wishes effectively or indeed may not be listened to.

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Specific Project Theme 1:
Black Minority Ethnic BME (Eastern European)

Key organisations contracted with to support this theme: Grantham Polish Club, Salvation Army (Boston) and CentrePoint are organisations that all provide support to the migrant communities in Lincolnshire.

Other organisations supporting and engaged with the Migrant Communities included St Barnabas and Bakkavor (large local employer in the south of the county) also participated in this work.

Number of people formally responded: 53

- 53 people responded to the questionnaire translated into 3 languages.
- Average age of individuals was 30 years and ages ranged from 20 – 63 years.
- 30 Polish, 19 Lithuanian and 4 Latvian .
- Gender: 30 male, 16 female and 7 did not declare.

Methods of Engagement

A questionnaire was designed by Healthwatch Lincolnshire to explore the views of predominantly migrant residents to find out exactly how accessible health and care services were to them and their families. The questionnaire was translated into 3 languages and distributed among groups who we knew had integrated access to the BME communities. We also put the questionnaires online and produced local media releases to support the work for the wider community. The focus of the work is to identify some of the real-time challenges facing local communities and share them with commissioners and providers to inform the development of health, care and wider support for these communities where there is a real or perceived need.

Key Findings

88% of respondents said that when they arrived in the UK they registered with a doctor which was encouraging. Of the respondents that didn't register with a doctor the 3 main reasons why include:

- they did not have the language skills to communicate.
- they did not know they were able to and
- they were not sure how to register.

Nearly 60% have accessed A&E departments in Lincolnshire with 39% attending on one occasion, 11% attending on 2 occasions and 9% frequently visiting Lincolnshire A&E services. This is a concerning response and possibly confirms the belief there is a misunderstanding by the migrant community as to of the role of A&E services.

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23 of the 53 respondents (41%) go back to their originating countries to receive healthcare services. They said they went back for 3 main reasons:

- because they felt the quality of services were better.
- because it was convenient as they were visiting anyway and
- because there are no language barriers making the whole process easier.

The response to respondent awareness and access to social care services was interesting with 82% stating that they knew what social care services were. However, a supplementary question showed that 33% said they didn't know what help was available and they didn't know where to seek support and advice - so conflicting responses may suggest confusion about the social care system and how it can support communities.

Only a small percentage of those asked currently accessed social care services. The main areas where communities knew where to ask for help showed substantial but not complete awareness. 80% knew where to go for employment support, 78% for health services, 64% knew where to access help for housing, 63% for social care, 61% for language education, 56% for language services and 55% were aware of where and how to seek benefits.

Around three quarters of the community find out about health and care services through their family and community rather than being made aware of services either on arrival or through a more formal route. Over half of the population responding said they believe the additional help of 'community-based team' for translated support for migrant communities would help them access services better and more appropriately. 25% said they felt there needed to be better access to translated documents that supported communities through health and care systems. In addition, improved access to English classes and more support for the development of social groups specific to the community was needed.

It is cheaper and easier for me to travel back to my home country for dental care, particularly for more difficult procedures like root canal treatment which is so expensive in the UK".

As a health and care community do we know where migrant communities access services and where they don't? Only 44% told us they were registered with a dentist.

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Conclusion

The lead organisations commented that whilst a significant number of questionnaires were distributed, completing surveys is not something Eastern Europeans are familiar with, resulting in only 53 responses. However, from the small sample size spoken to across the 3 main migrant communities, the themes were the same. This may prompt an opportunity to undertake some synergistic developments in supporting these communities integrate more effectively.

Enabling communities to be informed and educated in living and working in Lincolnshire focussed on providing community hubs offering holistic services which helped people navigate the UK health, care, education, economic and welfare systems. The communities suggested a single point of access to help people throughout their stay in Lincolnshire in the hope that communities would access services appropriately rather than reactively. The relevance of specific and targeted help to set up 'support and social groups' for the communities was interesting as reference has been made to the increasing isolation of the elderly migrant population, which in turn has a whole health and wellbeing impact on the individual and family.

Specific Project Theme 2: Homeless

Key Organisation contracted with to support this theme. Framework Street Outreach Team engages with and helps rough sleepers and works in partnership with other agencies to understand the extent of street homelessness in Lincolnshire.

To support Framework with distribution of the questionnaire they liaised with Lincoln YMCA, The Nomad Trust, The Corner House, The Pathways Centre, Lincoln Young Persons Service, Boston Young Persons Service, Be Attitude Day Centre, CentrePoint Outreach, the Street Outreach Team and SEA Participation.

Number of people formally responded: 107

- 101 completed questionnaires received (41 of the people classed themselves as having a disability).
- One Service User Forum; 6 attendees with an independent facilitator.

Methods of Engagement

Framework designed a questionnaire (copy can be viewed in their full report) which covered both demographic data and subject specific entitled 'Accessing Mainstream Health and Care'. SEA Participation (Independent Facilitator) hosted a service user forum in which current service users were asked their opinion on health services without the presence of support staff.

Key Findings

Overall the view of homeless people when accessing health and care services were broadly positive. There were some issues raised such as difficulties of not having a fixed address - "I was not allowed to collect my asthma inhaler from a walk in centre", lack of understanding of using legal highs and alcohol - "Health care staff need to be more aware of the consequences of legal highs", lack of access to information and need to access medication quickly - "it took a week to get my mental health tablets".

When needing primary care appointments or social services homeless people who are in more secure accommodation settings responded as having a better experience (average 74% yes response) than those with 'no fixed abode' (average 61% yes response). The 2 services that homeless people could best access was a doctor or pharmacist, with the pharmacist being rated as best when understanding their needs. The service that received the most negative response was social services with only 44% of respondents considering the service did not support their needs. There were a number of comments about time delays in getting an appointment particularly with a GP.

Support from staff (understanding their needs) was on the whole positive, but again it was felt social service staff were not as helpful. There were a few comments about staffing levels impacting on the individual's ability to receive support when they needed it.

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Mental health concerns were raised on a significant number of occasions. The concerns raised ranged from a better understanding from GP's and other health workers about mental health illnesses, referrals, treatments and medication needs.

Communication was a consistent theme. This included services listening better to patient needs - "I tell them how I feel, they tell me how they think I feel – and they're 2 different things" or "in some way I feel cared for but not listened to". It was also felt that better communication across agencies would provide a much better experience - "better communication between services" and "services need to speak to each other more" was a consistent theme.

"Accessing healthcare is not easy when you're homeless. The likelihood is unless you have a doctor already, you have to access the church or nomad to get a doctor, so it is a very grey area."

Do all front line staff recognise the many challenges faced by homeless people ever

Conclusion

Whilst the overall responses were positive for homeless people needing to access mainstream health and care services, understanding patients' needs through better communication methods was a significant issue. Support for people with a mental health problem is a concern for many and this is an ongoing issue for the wider Lincolnshire population. For homeless people, there is often a need to have easier and timelier access to services. For instance, if they require essential medication to help manage their mental health illness, they do not always have the ability to wait for an appointment or prescription.

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Specific Project Theme 3:
Lesbian, Gay, Bi-sexual, Transgender LGBT

Key organisations contracted with to support this theme. The key group who supported this work was the Lincolnshire LGBT Plus Patient User Group. The University of Lincoln and Lincolnshire Community Health Services (LCHS) helped the group with this work.

The organisations and, in particular, the Lincolnshire LGBT Patient User Group were instrumental in the delivery and dissemination of the survey.

Number of people formally responded: 101

- Gender: Male (39%), female (32%), Non-Binary (6%) and Transgender (3%).
- 21% did not disclose their gender.
- 20% of respondents stated their gender identity did not match the sex they were assigned at birth.

Methods of Engagement

A questionnaire was designed by the Lincolnshire LGBT Plus Patient User Group along with researchers at the University of Lincoln with some input from Healthwatch Lincolnshire. The purpose of the work was to explore lesbian, gay, bisexual and transgender experiences about accessing healthcare services across Lincolnshire. In order to achieve this the user group needed to be targeted and as such, the support of the Lincolnshire LGBT Plus Patient User Group website, their networks and social media was vital.

Key Findings

It was found (from all the respondents) that:

- 34% of respondents said they had a long standing illness, health problem or disability.
- 16% had a mental health problem.
- 10% had a physical/mobility impairment.
- 4% with a learning disability and
- 3% had visual or hearing impairments.

We asked people whether they had used some of the more common and general services like GPs, Dentists, and A&E etc. Perhaps the most striking statistic to come from this analysis was the relatively low numbers accessing dental services (around 66%). However, when comparing this data with the commentary made alongside the responses it would appear that this was related to access to NHS dental services generally rather than access for the LGBT community specifically.

The survey asked whether they as patients would recommend a variety of services to other LGBT people. In response they could select from recommend, not recommend, neither or don't know - the latter 2 were not included in the percentages. Patients in this category either have not used or they do not have an opinion one way or another relating to this service. In terms of those not recommending a service, mental health services came out as the highest with 20.5% of the total respondents not recommending Lincolnshire services, whilst only 45% of those using the service would recommend. Where patients felt they would recommend a service GP, Dentist and Sexual Health clinics came out highest.

Where patients had requested a gender change on their medical records 100% reported that this had happened. Six out of the 7 respondents said that when they had been admitted to hospital they had been put onto the single sex ward that best suited their gender identity.

Some very clear themes came through that were not unique to the LGBT community and these were primarily around the patient view that their medical concern was not being treated with the level of seriousness that the patient thought it should. There was a perception that GPs, consultants etc could appear judgemental, dismissive and had a lack of understanding and education on a particular condition or lifestyle when it impacted on their health. In addition, patients didn't always feel that their request for mental health support was acted upon leading to delays or no treatment. However, we also heard patients praise the 'general health' rather 'mental health' services for their understanding of LGBT patient's needs. Other areas highlighted included not being able to get a GP appointment and the lack of access to carers support services.

It was felt there is a lack of printed material for the LGBT community relating to health and care and a suggestion that this should be given consideration in terms of patient, clinician and wider community education.

Whilst the majority of patients felt they experienced no barriers to their care, it was acknowledged that social stereotyping sometimes does occur. One example given was when a lesbian patient was asked for next of kin details, she gave her partner's name - the clinician automatically assumed it was a mother or sister rather than partner which caused embarrassment for the patient.

Conclusion

The LGBT Report covers many different aspects of the community's broader health needs. For the purpose of our work we extracted a smaller sample which specifically looked at primary and secondary care and a sample which would be comparable with our other areas of seldom heard work.

As a result we concluded that many of the LGBT community's thoughts, feelings and experiences echoed what we already know about Lincolnshire communities in general ie not being able to get a GP appointment, poor access to mental health assessment and treatment services. Limited access to NHS dental services are key concerns for the community as a whole.

However, what was also clear was the need to be visible and understood. The community identified that deliberate or undeliberate stereotyping of the LGBT community as a challenge in managing their health and care needs. They also felt that there wasn't enough health and care information readily available to support and educate patients and clinicians about the needs of LGBT community patients.

Specific Project Theme 4: Mental Health

Key organisations contracted with to support this theme: Our 3 lead organisations were:

- SHINE is a mental health support network with a membership of over 800 people and organisations across Lincolnshire. SHINE worked with 11 of their member organisations from around the county.

- Peterborough & Fenland MIND is a mental health charity that supports people with mental health conditions. They run the South Lincolnshire Wellbeing and Recovery Programme and offers a service in Stamford, Bourne, Spalding and Boston.

- Rethink every year help millions of people affected by mental illness by challenging attitudes and changing lives. This includes carers who play a vital role in supporting their loved ones who are suffering with a mental health condition.

Number of people formally responded: 196

- 11 organisations returned 65 completed surveys via SHINE.
- Peterborough & Fenland MIND interviewed 30 people.
- Rethink surveyed 101 carers, with responses received from people across Lincolnshire. Responses related to services accessed from January until April 2015.

Methods of Engagement

Shine produced a very detailed survey which was designed over 2 parts. Part 1 related to primary care services and part 2 regarding secondary care.

Mind worked differently by engaging with 30 clients in private one-to- one interviews. Rethink distributed a survey to the people identified as carers that access their support services.

Key findings:

It was found that:

- The overall responses concerning accessing 'mainstream' health and care services eg booking appointments was very positive. It was generally felt that doctors were supportive, however, there were concerns raised about specific doctors who the respondents felt didn't understand their mental health needs and as a result led to a patient's condition worsening. "The doctor did not seem 'clued up' and was an old fashioned doctor who focused on medication and increased the dosage but did not give any coping strategies" and "GPs do not have time to see 'the person', just see the diagnosis".

- Waiting times for specific treatment was a concern and did cause distress for some. For instance 3 of the respondents had been waiting nearly 4 months to receive counselling. One person commented that "waiting times for treatment has proven to be ridiculously long before treatment (currently 10 months)".

- Lack of understanding of the needs of mental health patients was identified regularly as an issue. It was suggested that "more training in mental health conditions would improve the quality of care for patients". Also, it would help to have identified a 'go-to' member of staff for mental health support - perhaps even a mental health champion on each site.

- Staffing levels was also an issue with a feeling there is insufficient mental health professionals available leading to long waiting lists. "CMHT's staffing levels need to be drastically increased without delay. Keeping staff numbers low is a false economy as it results in many more costly hospital admissions, as well as patients suffering more than they would if more staff were available".

- A small number of people commented on problems post discharge with a feeling of being lost or "they wash their hands of you"; "treatment was for 6 weeks then everything stopped".

- Communication with patients was raised by a small number of respondent; a plea for "clearer language with shorter words and less medical terminology in both face-to-face conversations and in letters would be very useful".

I have had to wait a long time for mental health support. It was 6 months before I had an initial appointment".

This client has terminal cancer and feels this should be taken into consideration. We agree and feel it is important that every patient is recognised for their individual health and care needs. Patient records should enable all services to recognise this.

Conclusion

For people with mental health conditions coping mechanisms with everyday situations can be problematic. Functions like telephoning for an appointment, challenging decisions about their health or care needs, having to wait long times for an appointment with a professional when they need that help immediately; feeling suicidal and not knowing where or who to go to because "*I can't get through to the crisis team*" exacerbates their illness. Some services were rated as excellent, others not so. This rating was also linked to geographical delivery meaning there is a gap or inequality in mental health support services across our county. This service postcode lottery could result in life or death situations.

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Specific Project Theme 5: Rural and Social Isolation

Organisations who supported this theme. We had a number of organisations support us in the distribution of 331 questionnaires across Lincolnshire, 10 in total. Questionnaires in the main were delivered direct to the residences of people who received some kind of care in their own home. The organisations involved included Age UK, food delivery service providers, GP surgery patients and care and support agency recipients.

Number of people formally responded: 98

- 77 people responded to the questionnaire. (23% response rate).
- 21 individuals took part in 4 focus group activities.

Methods of Engagement

A questionnaire was designed by Healthwatch Lincolnshire which sought the views of local residents to find out exactly how easy it is for them to access health and care services whether that be carers in the home, getting to a doctor's appointment or even finding out information that can support people to live independently in their own homes. In addition, Healthwatch Lincolnshire met with a local community group and asked those Lincolnshire residents about their opinions and experiences of health and care services when living in a rural location.

We had anticipated there would be significant challenges in accessing the rurally isolated or more vulnerable members of our communities hence our method of using existing providers to reach people in their own homes.
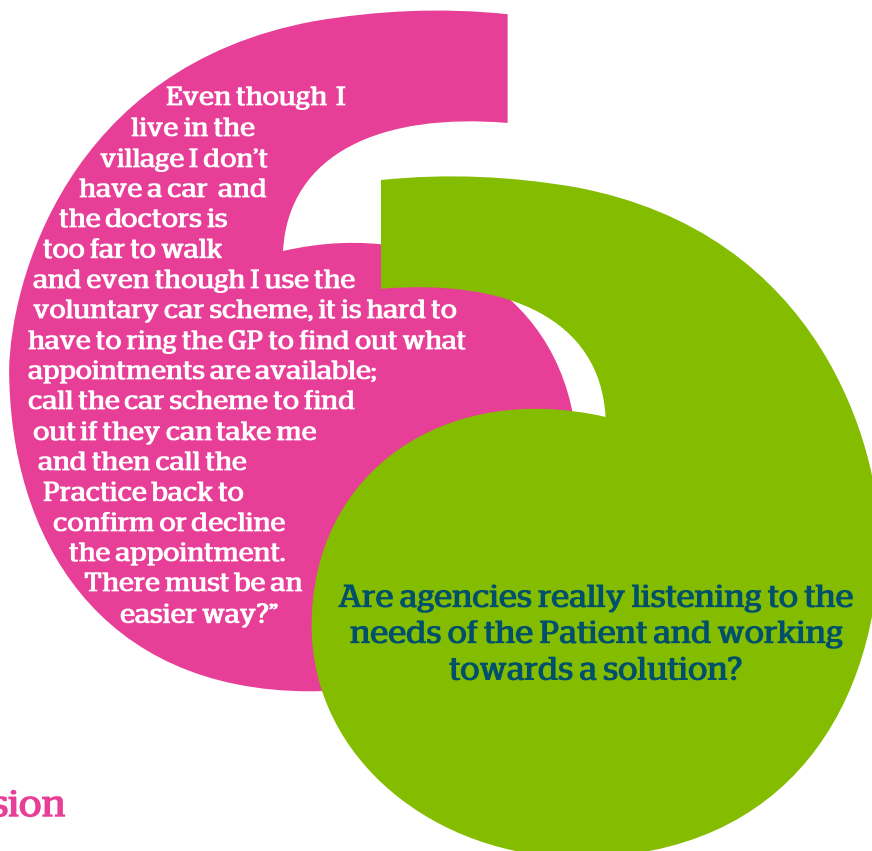
Key Findings

Transport was highlighted as a key trend throughout with access and cost of transport a consistent challenge. In particular, access to transport which supported wheelchair users appeared to be one of the key areas where people struggled to get support. Respondents also stated that mobility vehicles and the use of specialist taxis was very expensive. There was a heavy reliance on family members to transport to appointments and undertake day-to-day living tasks such as shopping.

The attitudes towards carers and the home care support agencies received mixed feedback with the majority feeling that carers were not given the support or time from their employers that was needed to complete tasks with the cared for. However, 33 out of 39 did say that the carer did come at a time that suited the individual. Other feedback praised care staff for high levels of support and care - there was a correlation between this point and those carers that were with the patient full-time rather than those carers delivering specific home care needs at allotted times during the day.

One third of the respondents felt that carers didn't spend enough time with them and that this contributed to the isolation they felt. Nevertheless, two thirds felt that the services still adequately met their needs.

One third felt that 'choice' in finding and obtaining home care was challenging. Not knowing where to look or who to ask was common and it was the same when the care wasn't suitable or satisfactory with one third not knowing how to change provider.

Patients and family members felt continuity of care was essential where a trusting and reliable relationship could be developed between those providing and receiving the care. This continuity was available for some whilst others said that they never knew who would be caring for them and how long they would last.

Even though I live in the village I don't have a car and the doctors is too far to walk and even though I use the voluntary car scheme, it is hard to have to ring the GP to find out what appointments are available; call the car scheme to find out if they can take me and then call the Practice back to confirm or decline the appointment. There must be an easier way?"

Are agencies really listening to the needs of the Patient and working towards a solution?

Conclusion

Notable from this piece of work was the wish and desire for rurally isolated and/or the vulnerable to remain independent, but also the heavy reliance on so many unpaid carers, whether they be family members, friends or neighbours. In addition to the use of family and friends for day-to-day living tasks, the impact of lacking, limited or costly transport options was an obvious issue.

It appeared from the feedback that many were not aware of choices and possible support mechanisms available to them - simple things like knowing which providers offered which services in their area right through to not being aware that hearing aid batteries could be replaced by post rather than having to pay for expensive taxis or be reliant on family to take the aid back to the hospital.

Others felt too much was being spent on signposting and advice services and that a single point of access should be in place.

It was clear that when people were in the home care system they felt the services met their needs but there was also a clear message about people not having enough time to spend with those who found themselves housebound or in a rurally isolated areas which has the potential to impact on other services.

Communication. Access via our transport infrastructure and continuity of care were all key themes which emanated from this piece of work and impacted on people's health and general wellbeing.

Specific Project Theme 6: Sensory Impairment

Key Organisation contracted to support this theme: South Lincolnshire Blind Society (SLBS) is a key provider of services for blind and partially sighted people and their carers living in the Districts of North and South Kesteven, Boston Borough and South Holland. Their aim is to work with blind and partially sighted people, to provide services so that they lead fuller, more independent lives. SLBS had support with this project from Lincoln & Lindsey Blind Society and Spalding Deaf Club.

Number of people formally responded: 331

Methods of Engagement:

SLBS and supporting agencies ran the questionnaire over several weeks which focused on access to the services available and was distributed via the following methods:

- Talking through the questions as part of a group discussion within a setting familiar to those taking part.

- Telephone consultation which enabled people who could not access a group meeting to take part.

- Circulating the written questionnaire to over 2,000 people.

The most difficult group for SLBS to interact with was people who are deaf or hard of hearing. Some of this was due to the lack of support groups across the county and the need for interpreters which are not readily available. However, deaf and hard of hearing people were invited to complete the paper based questionnaire but none chose to.

Key Findings

Disappointingly, the responses to all of the questions that specifically concerned access to and treatment by health and care services suggest more people felt the support offered did not meet their needs. 56% of people with sensory impairments did not feel confident to make their own appointment with comments such as "telephone options given out over the phone are hard to follow if you are blind" and "I cannot write down any information given to me over the phone when making appointments". With regards to systems or facilities, adaptions and alterations that are in place to support their needs, the responses were again slightly higher towards 'no, they did not believe these met their needs'. Comments such as "glass sliding doors, signage, self-check in, A-Boards are all useless for a blind person so better communication is needed", "corridors and pathways to be kept clear of clutter" and "better sound systems in GP practices" demonstrate the problems.

It was also felt that communication was a problem with the way people with a sensory impairment are treated. The respondents felt that their sensory impairment needs were not recognised sufficiently with comments such as "case notes should be clearly

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marked with a person's disability", "better trained receptionists, no sight means NO brains, to many", "audible medication packaging" and "more large print books" are all useful insights for providers to know when helping with people with sensory impairments.

Emotional support for both social and mental health needs for anyone diagnosed with a sensory impairment was highlighted as a service inequality. One person quoted her experience when diagnosed as being permanently blind was told "go home and learn to live with it" and another was told "nothing more can be done, so sorry and goodbye". In fact 67% of respondents indicated they did not feel there was sufficient social and mental health support available to them.

There was a universal feeling that much more training for all staff is needed. From receptionists, GPs, nurses, consultants to supermarket staff, the respondent's comments confirmed "training for clinical staff in visual and hearing loss awareness is essential". It was also felt that training for people diagnosed with sensory loss would also be useful "confidence building" and "job training or re-training after diagnosis" was mentioned.

"To be treated like a human being" - comment made by a person with sensory impairment.

Are agencies really listening to the needs of the Patient and working towards a solution?

Conclusion

The overall conclusions from the results of this theme highlights the need for better improvements with training of front line staff thus enabling them to have better knowledge and awareness of the needs of patients with sensory impairment. It is also clear that methods of communication need to be improved, if provider could offer a range of different communication methods and could adapt these to the individual this would help enormously. Transport to enable patients to access health and care services was also raised as a concern, as we are all aware patient transport is an issue for many communities across Lincolnshire. There was also a great deal of concern raised about the gap in emotional and mental support available for people with sensory impairments.

Cross-Theme Recommendations

The 4 themes below are those which repeatedly came through these 6 independent pieces of work. None were unique to the seldom heard groups and many affected the communities of Lincolnshire as a whole. Where community-specific themes are identified they are reported within their section but still draw on the main themes below. However, it is vital to recognise that we don't put patients into boxes as a 'particular' community group. Their needs require additional support but should be included within the infrastructure of the wider health and care environment. The purpose of this report ensures that we sought their views and have some assurance that the themes below address their need to be heard.

Communication
Adapt the methods of communication to meet the patient's or communities' needs was continuously referred to throughout the seldom heard work. Communication needs to be fit for purpose and achieve its purpose. If communication is failing our communities then this needs to be addressed at all levels and across all sectors.

Training
Better awareness of specific disabilities, conditions, personal barriers for patients needs to be a priority; also recognising that more materials and access to information for the patient and the clinician should lead to more educated choices being made.

Emotional and Mental Health support
Helping people to manage their health, mental health and disability conditions on a daily basis. Across all areas limited or poor access to mental health services was seen as having a direct impact on people's wellbeing in the county.

The Wider Community
Better use of voluntary and community services would help people manage their conditions on a daily basis. If statutory providers and commissioners invested more in voluntary and community services, it could help to alleviate pressures and save money in the long term.

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Conclusions and Next Steps

All our Seldom Heard Voices work during 2014 and 2015 represents a very rich and diverse mix of our Lincolnshire population. We are certain that one size does not fit all and that the health and care system could and does present challenges for everyone. We are also accepting that within today's world not everything can be achieved as we might like. However, what is clear and in many ways encouraging, is that no matter what the community, seldom heard or otherwise, there are some strong similarities in terms of needs, wants and desires.

Patients and carers want to be communicated with well so they understand and can use what is available to them, effectively and in the right way. Patients and carers want people to be supported to take responsibility for themselves which in turn will support our health and care infrastructure. Therefore, training and education is critical for professionals and for patients alike.

We know that the whole health and care economy recognises each other and the community and voluntary sector. However, we want to see it work together more on a micro-level, at the coal face to improve people's lives and access to care, not just in the Board rooms. Lincolnshire Health and Care (LHAC) provides the perfect platform for involvement of organisations at all levels and across all sectors. Health and care services are not solely provided by statutory organisations; the services of voluntary and community groups such as voluntary car schemes, self-help health groups, wellbeing services and befriending schemes all play a vital part in Neighbourhood Teams and local communities will benefit from a more holistic approach to health and care partnership working.

Following the publication of this combined report and publication of the supporting individual reports we will ensure that parties that require or wish to have a copy, will do so. We will then seek responses, particularly from commissioners, providers and the community and voluntary sector to ascertain where change and development can be made. Even small change can make a difference.

Perhaps most importantly, Healthwatch Lincolnshire will continue to seek and promote the views of seldom heard communities and wherever possible, we will work collaboratively with others to maximise the results and strive to improve access and quality of care for the common good no matter what walk of life you are part of.

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