

# My Voice Counts Tour



**Consumer champion for health and social care services**

September 2014 - February 2015

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# Introduction

## **The 'My Voice Counts Tour' was a two-part initiative that allowed Healthwatch Leicestershire (HWL) the flexibility to engage a wide spectrum of people across Leicestershire.**

Firstly, our 'My Voice Counts Summer Tour' period saw HWL talk to over 350 people at nine events across Leicestershire. The issues and experiences gathered started discussions with stakeholders and were grouped into the priority themes of:

- Access to services
- Coordination of services
- Information
- Voice and Advocacy

Our 'My Voice Counts Winter Tour' provides HWL with a real opportunity to reach below the surface of general engagement. We were able to talk to vulnerable people in a group setting, young people in colleges, residents on the street and those that are more involved in the health and care system.

The 'My Voice Counts Winter Tour' aimed to:

- Raise the profile of Healthwatch Leicestershire
- Gather valuable experiences of local people

The geographical dynamics of each district/ borough of Leicestershire are very different from one another and face a separate set of issues. We listened to 609 residents across Leicestershire as part of our Winter Tour, and gathered valuable insights of experiences and a better understanding of how people feel about the services they receive from health and social care providers.

During the tour we asked what people would change or improve about their services and asked about their experiences.

The issues raised have been grouped into the following three key themes:

- Primary and Acute Care
- Patient Care
- Social Care

Many of the issues within these themes cut across all stakeholders, making initiatives such as the Better Care Together Programme vitally important for improvements to the local health and social care system.

This report provides an overview of what we heard and presents emerging themes by groups. We have provided a commentary of patient stories and experiences, which demonstrates the human side to services. We then move on to summarise what people told us within the different aspects of the tour. Finally we provide a conclusion and talk about potential next steps.



# Methodology

**The Winter Tour encompassed different approaches to engage various members of the public across the County. We attended events and venues across Leicestershire that included different audiences, groups and the general public as follows:**

- **Engagement with Social Groups & User Groups (200 people)** - that allowed Healthwatch to access groups in an environment that was comfortable to them, including vulnerable service users and seldom heard groups. 
- **Engagement with Colleges (171 people)** - that saw Healthwatch directly visit places of education in order to gather the youth voice. 
- **Two Wellbeing events (80 people)** - in Loughborough and Market Harborough where individuals could share their concerns to providers and Healthwatch about services that they receive. 
- **New Start, New You Campaign (158 people)** - a partnership initiative that was devised for the West Leicestershire region and the campaign centred around travelling across West Leicestershire with a health bus which offered health information. 

This approach offered various opportunities to a wide section of Leicestershire residents to tell us their views and raise awareness about HWL and our watchdog role.

We listened to  **609** people

# Overall Emerging Themes

**This report reflects the comments received at various events during the Winter Tour. We asked the public what they would change or improve about health and social care services. The following issues were most common:**

## 1. Acute and Primary Care

Patients that suffered from poor mental health told us that they would prefer to be treated holistically rather than separately for related issues. Patients also spoke about their frustration regarding lengthy waiting times for hospital clinic appointments.

Patients told us they are finding it increasingly difficult to gain a timely GP appointment especially on the same day. Inconsistencies in appointment-making processes between GP surgeries were also noted.

## 2. Patient Care

Patients told us that the emotional support they needed when being treated was underestimated. Often, if the patient felt cared for personally and not just treated medically, it could increase their overall perception of the treatment and willingness to be treated. Increasingly,

patients are noticing that customer service is an important aspect to their all-round experience of services.

Students expressed concerns that they were not taken seriously by doctors and not being treated with care, feeling, compassion and respect.

## 3. Social Care

We were told about domiciliary care and discharge processes. Patients told us that when receiving home care services, they were prone to unpredictable time management of carers, leading to missed or late meals and untimely medication.

The joint coordination of hospital discharge and care planning from a patient perspective was also raised as a growing concern. Patients told us that the time they were due to be discharged was far from the actual time of discharge. Once at home, patients spoke about poor planning regarding their care package.



# What we heard from Social & User Groups

## What we did

We visited a variety of community groups throughout Leicestershire and spoke to 200 people; including under-represented groups and individuals, vulnerable adults, Black Minority Ethnic (BME) groups and those that are rurally isolated.

The groups we visited to gather experiences were:

GROUP	DISTRICT/BOROUGH	ENGAGED WITH
Sileby & District Wellbeing Group	Charnwood	 8
The People's Forum	Leicester	 10
Thursday Club at All Saints Church	Charnwood	 26
Over 50's Day	Hinckley & Bosworth	 80
Oadby Muslim Women's Centre coffee morning	Oadby & Wigston	 8
Earl Shilton Open Day Age UK	Hinckley & Bosworth	 10
Melton Seniors Club	Melton	 16
Bottesford Carers Support Group	Melton	 8
Melton Mowbray Carers Support Group	Melton	 15
Alzheimer's Society Carers and User Group	Oadby & Wigston	 19

We spoke to



**200**  
people

We visited



**10**  
groups

## What patients told us

### The following themes emerged when talking with groups about health and social care services:

#### Acute and Primary Care

**Access to health services** - People tended to have awareness that there were various options to choose from when they were not well. However, overall they were not as aware about which specific service to use. For example, when to use the pharmacy and when to use NHS 111 services.

**Accessing GP appointments including opening hours** - When attempting to access services, patients told us about their experiences of using patient transport, which in many cases was frustrating. This referred mainly to waiting times for the return journey from the health setting to their home. Patients told us that they would personally pay for private transport to avoid waiting for the free transport. Those that could not afford private transport would often spend the best part of the day out of their homes, despite swift appointments/ consultations.

**Opening hours of GP surgeries** - patients would like to see longer opening hours to better accommodate those who work. This may include a weekend option, for example Saturday or even a seven-day week.

Often the first comment that people make is about being able to ring their GP Practice and obtain an appointment on the same day. This is a major concern for the people that spoke to us. Some patients have taken it upon themselves to change surgeries as they found it almost impossible to get a timely appointment. People told us that some surgeries offer on the day appointments only; others

offered appointments two weeks in advance and in some cases six weeks in advance.

**Access and Parking at health settings** - Where locations charged, people told us that a pay on exit service would be much more beneficial to the customer. There is also the issue of increased wheelchair and scooter use and access. Many facilities are often difficult to navigate larger scooters.

#### Patient Care

**Receptionist** - At the point of contact, patients' experiences with receptionists have often left them with a negative impression of their surgeries. Patients commented that receptionists acted like gatekeepers when patients were attempting to access their GP. Better customer service on the front desk is something that patients often spoke about.

Patients told us about the lack of privacy when discussing personal information with the receptionist. In addition there were patients that told us how they felt uncomfortable discussing particular issues with the receptionist.



**Mental Health-** One group of service users told us that many people they know that suffer from poor mental health also suffer from diabetes and depression<sup>1</sup>. They told us that they would prefer to be treated holistically rather than separately for related issues.

Patients that suffer from poor mental health can feel disrupted if they are moved from bed to bed, ward to ward. As patients start to gain confidence and build relationships with the person delivering their care, it can cause anxiety and confusion if this consistency is interrupted.

There is a common theme around care, compassion and coordination of care. Patients told us about drugs and medication not being available in hospital when needed and GPs prescribing medication that is extremely difficult to obtain. People also had a desire to be cared for as opposed to just being treated. Patients mentioned that compassion around their wellbeing would help them to better cope with their physical treatment.

Patients told us that they would like better communication around the side effects of medication.

People thought that there should be more support for the emotional effects of having treatment.

<sup>1</sup> According to NICE, people who are diagnosed with a chronic physical health problem such as diabetes are three times more likely to be diagnosed with depression than people without it.

**“It would be very beneficial to see the same person of the crisis resolution team when you need that service”.**

**“It is more difficult to get carers in rural areas. It would be great to have a community based carer who could be someone who lives locally and knows the area”.**

Patients commented that it was easy to lose hope when they felt that their voices are not being heard and acted upon. Patients felt as if they could not complain about a service or professionals because they were fearful of how it would affect their treatment.

## Social Care

**Discharge-** Patients told us of being discharged from hospital and not receiving care at home in a timely manner, even though it should have been agreed and in place. This has led to incidents when themselves or family members were readmitted due to poor processes and a lack of joined up services.

Other issues around discharge were about the waiting time between patients being told that they would be going home, to actually being discharged. Some of this was due to transport, medication and capacity.

Patients also told us that they felt abandoned and likely to need support or medication if care at home did not materialise.



## Patient Comments

**Members of the public are aware of the enormous challenge to deliver health and social care services that meet the needs of every individual and are sympathetic to that challenge. Below are some of the patient experiences that were captured throughout the tour:**

“My cancer treatment was second to none”

“I had two new hips and received excellent care at the Glenfield Hospital both times”

“I have been with my GP for years and I am totally satisfied with Severn Surgery in Oadby”

“I would like to see more affordable care homes that include nursing”

“I was taken to hospital after a fall and the paramedics arrived within eight minutes. They stayed with me whilst I was being treated at the hospital to make sure I was okay”

“I would like more local accessible services as I often use a wheelchair”

“Why can the system not be fixed? It has been like this for the past 20 years or even longer”.

“The Loughborough Urgent Care Centre is very good and the care is excellent. Although it would be better if it was still in the centre of town”

Barwell Medical Centre is very good, to improve they would need a bigger premises”

“My experience of Sunnyside Hospital (Hinckley & Bosworth Community Hospital) was excellent, although it does need refurbishing”

“People to be mindful that many elderly patients or dementia carers cannot easily leave their partners alone to get to appointments”.

# Patient Stories

- “I suffer from poor mental health and upon a visit to the hospital I realised they had run out of the drugs needed to continue my care effectively. I went for hours without medication until the hospital could locate the drugs needed”. **Leicestershire resident**
- “There is not enough help for the hard of hearing. Everything is based around computers. I told my GPs that I would come in and make an appointment but they told me that the procedure is to ring on the morning. I told them that I couldn’t hear on the phone. So now I text my sister who lives in Scotland and she rings up for me, then text’s me back with the time of my appointment. If there are other options, they have not been explained to me”. **Hinckley & Bosworth resident**
- One service user told us that due to the scanning machine not being available to scan for suspected cancer, that they had to wait for two and a half days. The patient felt that there was no compassion when they were advised of the possible diagnosis. After the scan results ruled out cancer, the doctors reviewed the patient’s history and realised that they had a history of Irritable Bowl Syndrome (IBS) and that it was an inflammation in the bowel. The patient felt that their history should have been reviewed earlier, which would have helped to investigate the issue without the scare of cancer. **Oadby & Wigston resident**
- “My son was sent down for a gall bladder operation and was then bought back up and told that there was no one to do his operation. This is very poor practice and left my son and family feeling even more anxious than we were before the mix up”. **Hinckley & Bosworth resident**
- “I was released from hospital at 9pm and my care was not in place in time for me when I arrived home. Hours later I needed help and luckily the warden managed to call social services as my carer never turned up. Unfortunately for me no one could come out to me and at 2am we had to call the paramedics, who were very nice. I was returned to hospital and readmitted”. **Hinckley & Bosworth resident**
- “I suffer from diabetes and have to make sure that I eat regularly and at specific times. Yet when the hospital makes me an appointment, they schedule them around the same time that was specified I should eat and take my medication. Even though I have mentioned this to the doctor and they know my condition, it still happens repeatedly. I would like the hospital, if not the doctor to understand and take my condition in to account”. **Hinckley & Bosworth resident**
- “I have Parkinson’s Disease and arranged for Arriva to pick me up after my appointment at the hospital. I waited for 4 hours and then spoke to the receptionist to see if they could help but they had no idea who to contact. I ended up calling a private taxi company to take me home”. **Charnwood resident**
- “My elderly mother was admitted to Leicester Royal Infirmary. She needed to be taken to the bathroom and I asked nine nurses to assist and help her. She was not helped and she messed herself. They then had to wash and deep clean everything. The same thing happened again later on. Not one of the nurses was willing to help – they were all chatting to each other. This was very upsetting for my mother. Where was her dignity and care?” **Charnwood resident**
- “I am 80 years old and my husband had an appointment at the hospital. I am not able to push him in the wheelchair so my daughter had to come from Nottingham to take us. I am not aware of support staff that could help me, but I would like to know if they are available”. **Oadby & Wigston resident**

# What we heard from Colleges

## What we did

We spoke to over 170 people including students, students with a learning disability, teachers, teaching support workers and practitioners.

The colleges we visited were:

DISTRICT	COLLEGE	ACTIVITY
North West Leicestershire	Stephenson College, Coalville - 38 people	Stand in the main college foyer
Oadby and Wigston	South Leicestershire College - 88 people	Freshers' Fair
Hinckley and Bosworth	Groby Community College - 30 people	Practitioners Network meeting
Oadby and Wigston	South Leicestershire College - 15 people	Equality & Diversity Fair

Engaged with



**171**  
people

Spoke directly to 38 students and Staff Members



**38**

Stephenson College, Coalville

Engaged with 30 people at the Practitioners Network Meeting



**30**

Engaged directly with 103 students and staff members



**103**

South Leicestershire College

## What patients told us

The following themes emerged when talking with groups about health and social care services:

### Acute and Primary Care

**Accessing GP Services** - Students and teachers said that it was difficult to obtain an appointment with their doctor, many saying that they had to book weeks in advance. People told us that they often had to wait up to an hour after their appointment time to be seen by the doctor. Students and teachers shared their increased frustrations with the doctors not being helpful and compassionate and felt they were prescribed medication without any care for them as a person.

**Accessing Dentists** - Some students expressed concerns about finding an NHS Dentist. Issues were raised about how long it takes to obtain an appointment and the cost of the dentist was expressed as worry. Some students who had been treated by a NHS Dentist were unhappy with the service and treatment they had received.

“I was discharged from LRI and then had to wait for a prescription for my medication. This took hours and I was waiting around the hospital. Why can patients not be given a prescription and take it to a pharmacy of their choice? Why does it have to be dispensed at the hospital?”

“Finding a good NHS Dentist is a nightmare. I felt let down by my dentist, as the treatment I received was not good. I'm now with a private dentist because I do not trust the NHS but I don't want to worry about the cost of my dentist bill every time I go”



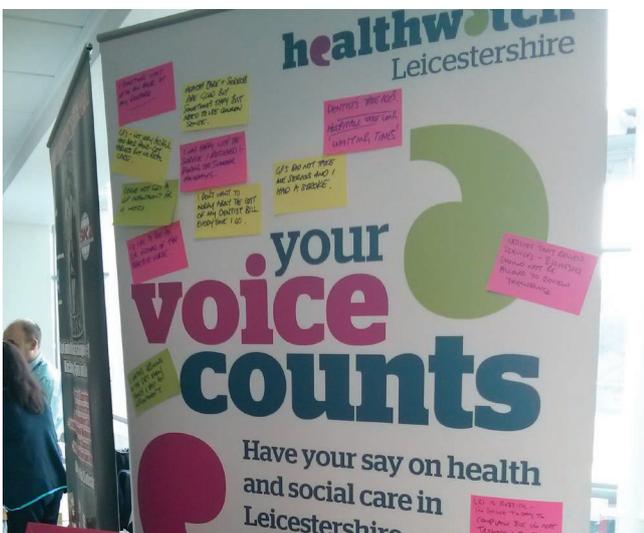
## Patient Care

**Communication** - Students said that they did not feel listened to by their doctor. Students told us that GPs talk to their parents and not directly to them about their illnesses. Students expressed concerns that they were not taken seriously by the doctors and often made to feel that they were making things up and not being treated with care, feeling, compassion and respect.

**Young Mothers** - A number of female students at South Leicestershire College said that they were being judged because they were a teenage parent. A number of them had experiences where their child had been ill and the healthcare professionals did not take their concerns seriously and they felt undermined as a parent. They would like to have more time for appointments with their midwives and health visitors so that they did not feel rushed.

“I went to see my doctor regarding the pill I was taking as I wanted to change as I was unwell on this brand. The doctor would not change my medication. I was not listened to. I have decided that I am not going to take the pill now, as I know that this one is not for me”

“I struggle to get an appointment at my doctor. When I do take my children to see the doctor, they are always prescribed calpol when they are ill”



# What we heard from the Winter Wellbeing Fairs

## What we did

Winter Wellbeing Fairs were held in December 2014 for Leicestershire residents to share their experience of local services with us. The Fairs took place in Loughborough on Thursday 4 December and Market Harborough on Thursday 11 December 2014.

Local people had an opportunity to get free health checks for hearing and blood pressure as well as talk to staff from Leicestershire's health and social care services such as Ambulances, Social Services, GPs and Dentist.

DISTRICT/BOROUGH	LOCATION OF EVENT	ENGAGED WITH
Charnwood	Town Hall, Loughborough	 50
Harborough	Methodist Church, Market Harborough	 30

We spoke to **80** people



We held 2 wellbeing fairs

 2

30 stakeholders came along with information stands

 30


## What patients told us

The following themes emerged when talking with groups about health and social care services:

### Acute and Primary Care

**GPs** - Patients felt that GP's could at times neglect patients and that waiting times to receive an appointment were far to long in many cases. Loughborough Hospital Urgent Care Department was said to be excellent as well as the ambulance and A&E services.

### Patient Care

#### Support for patients

The care a patient receives can impact on their whole experience of using a service. Patients told us that they had been advised to use Google for information by healthcare professionals and to go home because walk-in centre staff were too busy. People had experienced being left in hospital corridors for hours with no food or drink and family members being sent home from hospital with no support and a lack of information.

### Social Care

#### Support Services

We were told that there is a lack of consistency in support workers and information sharing from mental health home treatment and crisis resolution services. Social Services and Adult Mental Health Services worked together excellently for partners and children, to keep parents experiencing adult mental health safe.

Providers that attended the events made the following comments:

“A useful networking session plus interest from potential volunteers and clients”

“Had some good engagement with participants - also useful to network with potential partners”

“Super opportunity to network - needs more publicity to professionals in future events to promote their attendance as well as public”



# What we were told from the New Start, New You campaign

## What we did

As part of the 'New Start, New You' campaign, we travelled across West Leicestershire with a bus offering health information and giveaways. We worked with West Leicestershire Clinical Commissioning Group (WLCCG), district councils, Voluntary Action LeicesterShire (VAL), Public Health and Leicestershire County Council (LCC) in order to provide advice, support and information. Patient Participation Groups (PPGs) from across West Leicestershire also supported us on the bus.

The campaign was based upon a proactive partnership, with each organisation involved taking a lead role in their area of expertise. HWL was able to capture patient experiences and signpost people to the wealth of health information available.

The places that we visited to gather experiences were:

DISTRICT/BOROUGH	ACTIVITY	ENGAGED WITH
Charnwood	ASDA, Thurmaston, Charnwood	 50
Charnwood	Loughborough Market, Loughborough	 60
Hinckley & Bosworth	Hinckley Market, Hinckley	 10
North West Leicestershire	Morrisons, Coalville	 20
North West Leicestershire	TESCO, Ashby-de-la Zouch	 3
Hinckley & Bosworth	Woodlands Garden Centre	 15

We listened to  **158** people

Many visitors to the bus had a free mini health check including blood pressure, body mass index and more. Experts offered advice on many aspects of staying fit and well, as well as how to 'Choose Better' and get the right treatment, in the right place at the right time.

## What patients told us

The following themes emerged when talking with groups about health and social care services:

### Acute and Primary Care

**GP Services** - People spoke highly of their GP Practice and gave positive feedback. However, some patients could not always get appointments or had a long wait (up to 3 weeks) before they could see their GP.

**Pharmacy** - A number of people told us that Syston Pharmacy does not always stock medication that is needed or have repeat prescriptions ready when the patient goes to collect their medication. Members of the local PPG said that it was the pharmacy's policy to hold minimum stock, which was causing problems for patients.

**Local services** - Concerns were raised around wider NHS services and some people were not aware of all the services available to them in their local area. Once they were made aware of services such as the Urgent Care Centre in Loughborough they said they would definitely use them.

“As a young mother I felt that the aftercare at the General Hospital Maternity Ward could be improved. I did not receive any help breastfeeding and was instead given a DVD to watch and not the practical help I would have liked. I did not feel cared for and felt left to my own devices. At one point my baby was not feeding and I felt that she needed additional support and that I needed more information before being discharged”.



# Conclusion

## **We engaged with a diverse range of groups and communities as well as recruiting members and raising the awareness of HWL.**

In order for us to challenge and scrutinise providers and commissioners of services, we continually seek opportunities to listen to the patient and public voice. We will share the experiences of the public and the key issues raised in this report with those that provide services and commission services.

We will work with stakeholders to address the issues of Acute and Primary care in regards to GP appointments, waiting times and mental health services. We will also discuss the quality of care from the patient perspective and the issues surrounding discharge processes.

At a time when so many improvements are being made within the health care system, it is vital that we as local Healthwatch have a strong voice and are able to influence decision makers.





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