



Healthwatch Leicestershire

Annual Report 2016/17



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Rick Moore, Chair, Healthwatch Leicestershire
Vandna Gohil, Director, Healthwatch Leicestershire

The past twelve months has in many ways flown by too quick. It was very busy and a successful time for Healthwatch Leicestershire. We are pleased that so many people spoke to us about their experiences of care. We would like to thank patients, carers, family members and the public who have been in touch as it is only when people speak out, that we can speak up on their behalf, achieving improvements that will benefit the public of Leicestershire.



Message from our Chair and Director

We fulfil our statutory role as a critical friend and our relationships with service providers and commissioners remain good. All of the stakeholders have acknowledged that Healthwatch Leicestershire presents evidence-based and insightful reports and that our findings are based on what we have heard, seen and that the patient voice is respected and listened to.

All of our partners respect our independence, and value the critical insights and perspective we bring to evaluating their services.

In the past year Healthwatch Leicestershire has undertaken work in a number of areas. These have included helping the Clinical Commissioning Groups with making recommendations and reaching a decision on paracetamol and gluten free prescribing (page 24), provided patient and service user insights and intelligence to the Care Quality Commission for their inspection at University Hospitals of Leicester and Leicestershire Partnership NHS Trust (page 25), gathered the experiences of cancer patients and carers working with Coping with Cancer Leicester (page 13) and capturing the experiences of Fibromyalgia sufferers to improve local service provision (page 32). The findings from the summer tour are shaping the plans described on page 30 as part of the wider changes under the STP. We also highlight our findings from responses gathered from three separate surveys of patients, carers and staff into hospital discharge (page 22).

There is a report published for each of these areas, with responses from service providers and commissioners to address the recommendations made. We have presented to the Health and Wellbeing Board, the Adult Care Board, the Council Overview and Scrutiny Committees, and to the Clinical Commissioning Groups for Leicestershire. Our membership of these various Boards, in particular the County's Health and Wellbeing Board, remain pivotal to achieving cross-agency awareness and improvement in service provision.

As stated last year, the size of the task we have been given is immense. Healthwatch Leicestershire has a small executive team of 4, covering health and social care services for the whole of the county with a budget that equates to 28 pence per head of population. The progress and achievements this year are due to the hard work and commitment of this staff team, the dedicated Enter & View volunteers and highly engaged and active Board members.

In a short space of time we have been pleased at the progress made and the respect we have earned from our partners.

The Board of Healthwatch Leicestershire remains strong, with a wide range of experience supported by Voluntary Action LeicesterShire, who were awarded the Healthwatch contract back in April 2013.

We look forward to our fifth year of operation and to making improvements in the way in which health and social care is delivered. We also await with anticipation processes led by the Commissioners for re-tendering Healthwatch functions and aim to ensure that county residents continue to receive an efficient, effective and value for money service.

We hope you find this report informative.

Rick Moore

Chair, Healthwatch Leicestershire

Vandna Gohil

Director, Healthwatch Leicestershire

Highlights from 2016-17

The year at a glance

This year we have reached **3453** members, subscribers and twitter followers



Our board members represented local voices at **94** different health and care meetings and committees



Our signposting and information service has helped **242** individuals



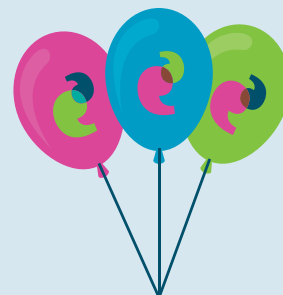
We've undertaken **6** Enter and View visits to local health and care services



We published **5** insight reports on issues ranging from access to GPs and mental health



We've met **3017** local people at **202** community events and activities



Calendar of the year

2016 April/May/June	2016 July/Aug/Sept	2016 Oct/Nov/Dec	2017 Jan/Feb/Mar
Enter & View- Hinckley & Bosworth Community Hospital 24 May 2016	Summer Tour and Engagement in the Districts	Summer Tour Report - November 2016	'Where should I go?' - Experiences of cancer patients and their carers - January 2017
Listen to Me #YoungVoicesMatter - June 2016		Enter & View - Urgent Care Centre visits 28 Oct - 4 Nov 2016	The Lived Experience of Hospital Discharge - February 2017
Quick Poll Survey: Parents views on health services - June 2016	Fibromyalgia Survey Launch	Fibromyalgia Survey End	
Enter & View - Station View Health Centre 20 June 2016			



Who we are

We exist to make health and care services work for the people who use them.

Everything we say and do is informed by our connections to local people. Our sole focus is on understanding the needs, experiences and concerns of people of all ages who use services and to speak out on their behalf.

We are uniquely placed as a national network, with a local Healthwatch in every local authority area in England.

Our role is to ensure that local decision makers and health and care services put the experiences of people at the heart of their work.

We believe that asking people more about their experiences can identify issues that, if addressed, will make services better.

Our Vision

Higher quality and more accessible health and social care services in Leicestershire through public involvement.

Our Mission and Objective

To be an independent, influential consumer champion of health and social care services in Leicestershire, ensuring that consumer rights and responsibilities in health and social care are understood and delivered. We achieve this by:

Understanding what matters most to consumers, especially those most vulnerable, by always starting with their needs and rights.

Developing evidence-based local insights to share with local partners, and Healthwatch England to inform a national picture.

Influencing those who have the power to change design and delivery of services so they better meet the needs and rights of users.





Easy Read Summary

Healthwatch Leicestershire exists to help the public get the best out of their local health and social care services. We do this by:

- **Listening to local people and health and social care providers**
- **Providing information to help people find local services to meet their needs**
- **Seeking peoples views and experiences of local services**
- **Influencing the people that make the decision and in charge of appointing and running and service**
- **Challenging and examining existing service providers**

**In 2016 - 2017
we were in
contact with
3017 individuals
across 202
different
activities and
events**

**This year we
have gained 234
more twitter
followers
and 5223 new
people have
visited our
website**

**Our information
and advice
service listened
to 242 people
about their
experiences
of health and
social care.**



The issues and concerns that people spoke to us about informs our work this includes questions for the quarterly meetings with Chief Executives of University Hospitals of Leicester (UHL) and Leicestershire Partnership NHS Trust. We have created a new section on our website where health leaders provide answers to issues and themes raised by patient questions.



Our board members have represented local peoples voices at 94 different health and social care meetings. Their time, effort and enthusiasm has helped make a difference and influence change for the better.



We currently have over have 23 volunteers helping us with our Enter & View Visits. The aim of the visits is to observe how health and social care service are being run and talk to patients, carers as well as members of staff. This year we have published 6 Enter and View reports.



Our report 'Where do I go?' details the results of our survey of cancer patients and their carers. We visited 8 Coping with Cancer groups and received 57 completed surveys.

Many patients told us they did not receive information about support groups in their local area. Over half said they were satisfied or very satisfied with the care and treatment they received overall.



The 'Local People, Local Experiences' Report details the findings from our Summer Tour. The tour saw us attend 19 events across Leicestershire and we listened to 389 local people's most recent experience of using a health or social care service. The most common theme to emerge from the findings was a call to improve waiting times to access services and receive treatment.



In October 2016, we launched our Fibromyalgia Survey to find out patients' experience of the long-term condition and to help us understand what is important to them.

950 people completed the survey with 291 of them living locally. We worked with Leicestershire Fibromyalgia Friends Together Group and we helped with a meeting between the group and University Hospitals of Leicester (UHL).

During the meeting members of the group shared their experiences directly with UHL. We were able to discuss some of the initial findings from the survey.

A Ten Top Tips leaflet has also been designed.

Our annual report shows how we are structured, where we focus our resources and how we are bringing the voice and influence of Leicestershire people to the development and delivery of services, on a local level and as part of the bigger Healthwatch network.



Your views on health and care



Your views on health and care

Listening to local peoples views

We have used a number of different ways this year to engage with local people to hear about their experiences of health and social care.

Summer Tour - 'Local People, Local Experiences Report'

The 'Local People, Local Experiences Campaign and Report' details the findings from our Summer Tour. As part of the tour we listened to 389 local residents and visited 19 locations across Leicestershire asking local people to speak out on their most recent experiences of using a health or social care service and raising awareness of how people can choose better when it comes to urgent care.

This is the third consecutive summer tour we have undertaken and it was encouraging to hear that the majority of people that we spoke to had positive experiences of their health & social care services.

We asked respondents which health or social care service they last visited. The top 5 most visited services were:

1. GPs **41%**
2. Hospitals **25%**
3. Dentist **13%**
4. Opticians **6%**
5. Pharmacy **4%**

Over 50% of people who spoke to us rated their overall experience of health or social care as being 5 out of 5, with less than 10% rating their experience below average.

When asked what was good about their experiences, the most common themes were - helpful and friendly staff. Many people felt that they had received a good level of professionalism when using services and that many doctors and nurses demonstrated real concern for their wellbeing.

Leicestershire residents also spoke up about what could be improved, the most common theme to emerge from the findings was a desire to improve waiting times to access services and receive treatment.

Patients told us that the length of time they had to wait to see a hospital consultant is too long. Patients felt that the GP could have referred them to a specialist at an earlier stage. However once referred by the GP, the length of time that a patient would wait to see a consultant could be months. During which time their condition may deteriorate and their worry and concern for their wellbeing increases.





Young People Under 21

The Healthwatch remit covers the breadth of health and social care services children and young people might use, including Child and Adolescent Mental Health Services (CAMHS).

We are mindful of the Government's ambition over the next five years (by 2020) to support improvements in Children and Young People's mental health and wellbeing services. There was also an interest in the CAMHS Service from people across Leicestershire following the relocation to Coalville Hospital from Oakham House.

We had a two pronged approach to focus on young people as follows:-

- 'Listen to Me: #YoungVoicesMatter' Report
- Enter & View CAMHS Unit visit



Listen To Me

We asked a group of young people what mattered most to them concerning their health and social care.

The 'Listen to Me' #YoungVoicesMatter survey was designed to find out young people's attitudes and experiences of local mental health and sexual health services with input from the Student Council at South Leicestershire College to help shape and inform our work. We ran an interactive

session to capture themes and issues of 40 students aged 16 to 19 and asked them what mattered most to them concerning their health and social care.

We also invited feedback and shared the draft survey with Children and Families Services at Leicestershire County Council and officers working in Child and Adolescent Mental Health Services (CAMHS) and Sexual Health services. Their feedback provided a level of assurance that we were asking relevant questions.

To incentivise young people to respond to the survey we offered them the opportunity to win £50 or £25 worth of high street vouchers. We also approached the Chair of the Health and Wellbeing Board (HWB) who encouraged all partners, i.e. Leicester Partnership NHS Trust, the local Clinical Commissioning Groups and others, to proactively support the process and distribution of the survey.

We sent all the young people that had participated in the survey an electronic copy of the full report for taking part. The final report included a list of support services and contact numbers for local mental health and sexual health services.

The 'Listen to Me' report reflects the views and experiences of **429 young people aged between 13-25 years** and found that embarrassment and confidence are barriers for young people wanting to access mental health and sexual health services.

Some of the key findings to emerge from the report demonstrated how young people feel about services:

- The School Nurse is seen as the most trusted professional from whom young people would seek information about mental and sexual health
- Almost half of the young people surveyed would not know or were unsure who to talk to about their mental health concerns.
- Accessibility, stigma and confidentiality are the main barriers to accessing sexual health services.



- Young people are telling us that there needs to be more awareness and support for individuals suffering from mental health issues.
- Young people recognised that they need more emotional support to deal with their self-harming.
- Young women access sexual health services mainly for contraception. Young men mainly access sexual health services for STI testing and advice before having sex for the first time.

We made seven recommendations to the Health and Wellbeing Board (HWB), to help improve awareness and access to mental and sexual health services for young people.

The Director of Public Health at Leicestershire County Council, said: "What young people say is vitally important as it helps to shape future policies and we'll certainly be looking at the highlighted areas so we can ensure they are receiving the support they need."

The Chair West Leicestershire CCG - report provides a perspective and that HWBB should test how the recommendations are being used/ progressed.

The HWB Board recommended that the findings of the report be presented to the Children in Care Council, the County Youth Council for Leicestershire (CYCLE) and the LPT's "Evolving Minds" Group. Also, that the Director of Health and Care Integration was asked to take further actions to address the Healthwatch findings relating to young people's self-esteem and anxieties around their personal appearance and report back.

429

views and experiences
of young people aged
13-25 years

Child and Adolescent Mental Health Services (CAMHS) Unit

We undertook an Enter & View visit to the Child and Adolescent Mental Health Services (CAMHS) Unit at Coalville Community Hospital on 23 February 2016 (the findings presented in May), with the aim of observing the delivery of care and support given to young people, and capturing the experience of young people and staff at the unit A.

At the time of our visit, the evidence is that the Unit provides a very good standard of care. Summary of our findings:

Relationships between young people and staff

Young people told us that there is a positive relationship between them and the staff. The young people told us that the staff were supportive and we got a strong view from the young people that we spoke with that they liked the Unit and the feeling of home it provides.

Schooling arrangements

There is an onsite school (provided by the Children's Hospital School) and the Education Co-ordinator told us that there is limited space, which has meant that not all the young people can be taught together.

Activities

We saw evidence of a well developed programme of activities (therapeutic and social) for young people. We saw two timetables in the Unit, one for education and one for activities. The weekly activities include; pool tournament, baking group, quiz, young people meeting, DVD evening and swingball or games.

Carers' Assessments

We were told that there had been training for staff about support for carers, however we noted that Carers' Assessments are not routinely offered. We recommended that this is an area of practice that needs to be reviewed. In light of the Care Act (2014), Carers' Assessments should be offered and implemented as good working practice.



On 23 May 2016, Leicestershire Partnership NHS Trust (LPT) published a media release welcoming our report of the CAMHS Unit. LPT response to our report,

Firstly, the Healthwatch team asked LPT to refresh the decoration in the corridors, something which is already being taken forward by the ward's occupational therapists and activity co-ordinators in consultation with the young people. The occupational therapists and activity coordinators are also exploring the possibility of offering indoor gym activities in the multi-activity room, another point identified in the report.

Healthwatch suggested that the area allocated to the school be expanded (while recognising that space is limited), as currently it is not possible to accommodate all the students being taught together. This is an issue that has already been acknowledged by LPT, and the occupational therapy room is always made available to the school, with a window having been installed between the two rooms to facilitate this.

Finally, the team recommended that carer's assessments be routinely offered, and that LPT explore the possibility of commissioning a crisis team attached to the Coalville facility. LPT agreed to take action in relation to carers' assessments, and work continues to progress the development of a business case for a crisis team in order to secure local funding.

Head of Service, Children and Families, said:

"I am delighted that the Healthwatch team were able to see first-hand the high-quality care provided at the unit, and I'm very proud that the young people they spoke to praised the relationships they are able to build with our staff. We will continue to take steps to address the recommendations made in the report."

The report was presented to the West Leicestershire Clinical Commissioning Group Quality & Performance Committee in July 2016 and the Health and Wellbeing Board in July 2016, both meetings gave a positive feedback to the report.





'Where do I go?' Experiences of Cancer patients and their carers

The idea for this project was as a result of us meeting with Coping with Cancer Leicester, Leicestershire and Rutland (CwC) who told us that they had access to episodic information of patients and carers regarding experiences of services they used. The idea of the project then evolved where we could use our expertise of gathering patient experiences and insights with the shared aims to assess:

- the holistic care received by cancer patients and their carers
- any barriers that prevent people getting the treatment, care or service they need
- gaps in services



We spoke to
54
people at the
groups

The 'Where do I go?' survey was designed to gather the experiences of cancer patients and their carers who attended the Coping with Cancer (CwC) Leicester, Leicestershire and Rutland support groups. The focus of the survey was on individual's experiences of waiting times for referrals (before treatment) and the care and support available to patients after their treatments.

We visited 8 CwC 'Time Out' complementary therapy groups and spoke to 54 people.

The survey was made available online and cascaded to all HWL contacts, Cancer Support Groups and other networks. The survey was also promoted via social media. 57 service users

completed our survey both at the group and online.

We sought to engage with patients and carers through the support groups and we wanted to look at the patient's experience. What we found was that:

- A significant number of patients visited their GP three times or more before being referred to a specialist and were later diagnosed with cancer.
- Just over a third of patients waited over 14 days to a month before being seen by a specialist.
- The majority of patients said that they did not receive any information about how to access support groups and if there are any groups in their local area.
- There appears to be a general lack of support available for patients following treatment.

Based on our findings we made recommendations for Clinical Commissioning Groups (CCGs), service providers and other stakeholders in Leicestershire.

We presented our findings to the NHSE Quality Surveillance Group on 3 March 2017. Below is an extract of the information presented:

Patient Experience Cont.



➤ Healthwatch Leicestershire 'Where should I go?' - Experiences of Cancer patients and their carers (Jan-17)

- Significant number of patients visited their GP 3 or more times before being referred - later diagnosed with cancer

We visited:



8

CwC 'Time Out' Complementary Therapy Groups

- Just over 1/3 of patients waited over 14 days to a month before being seen by a specialist
- Majority of patients said that they did not receive any information about how to access local support groups

We spoke to:



54

people at the groups

- Appears to be a general lack of support available for patients following treatment

57

service users completed a survey



What we've learnt from visiting services

We conducted 6 Enter & view visits involving our small team of trained volunteers, with Healthwatch staff, who are prepared as 'Authorised Representatives' to undertake visits to health and social care premises to find out how they are being run and make recommendations where there are areas for improvements.

This year we identified three areas of the county where we have not undertaken a visit and chose to visit the following health care providers within those areas.

- **Hinckley & Bosworth Community Hospital**
- **Station View Health Centre, Hinckley and surrounding area**
- **Enter & View - 4 Urgent Care Centres across Leicestershire**



Hinckley & Bosworth Community Hospital

As part of our Enter & View Programme for 2016/17, we wanted to visit a number of community hospitals across the county to observe the delivery of hospital care to patients and capture the experience of patients, their families or carers and staff at a community hospital.

A key strategic driver for the visit was also to inform the local Clinical Commissioning Group's review of community services in Hinckley and Bosworth.

The hospital has 42 beds, providing medical, rehabilitation and palliative care. The hospital offers patient centred care, working in partnership with patients and other disciplines, to provide treatment, care and emotional support of a high standard. On 24 May 2016, we undertook a visit to Hinckley & Bosworth Community Hospital. At the time of our visit, the evidence is that the hospital was operating to a good standard of care with regard to Dignity and Respect.

Summary of Findings

- We saw evidence of rehabilitation activities throughout the wards
- There were positive comments made by patients about the high standards of hygiene and cleanliness of the wards
- Staff told us that visiting times were more flexible although some patients were unaware of the changes
- The majority of patients were aware of their discharge plans and the process for discharge
- Staff raised concerns about shortages of commodes and some broken equipment

The Enter & View Team made six recommendations and the service provider responded positively by developing an action plan to address each action point with a lead and timescale for completing.



Station View Health Centre

There are 12,703 registered patients and the practice covers the following wards in Hinckley; Burbage, Barwell, Castle, Clarendon, De Montfort and Trinity.

On 20 June 2016, we undertook a visit to Station View Health Centre with the aim to gather patient views of the service provided and to capture any ideas they may have for change.

Summary of Findings

- The layout of the waiting room made it difficult for patients to navigate to and from the reception desk
- Some patients used the electronic check-in screen for their appointments
- There were several information noticeboards and leaflets available to patients
- Information to carers was not up-to-date
- The majority of patients did not know that the practice has a Patient Participation Group There is a Health Awareness Room that patients used to support self-care Patients reported that making appointments is difficult especially via the telephone
- The clinical team was highly praised by the survey respondents and the non-clinical team was not rated as highly

The Enter & View Team has made ten recommendations and a number of changes were being implemented to improve the service to patients as a result of our visit.

We presented the findings from - Hinckley & Bosworth Community Hospital and Station View Health Centre visits to the WLCCG Quality & Performance Committee. Our findings for the Hinckley & Bosworth Community Hospital were comparable to the Experience Led Commissioning work and we received positive feedback on the accessibility of the report and that it was patient friendly.

Our reports will be used as for the triangulation of practice appraisal data whilst noting the context of our visit provides a snapshot. The Clinical Commissioning Groups (CCGs) will be sharing the reports with the appropriate teams within the CCGs for any further actions.

E&V Visit to Urgent Care Centres (UCC) across Leicestershire

We have a focus on promoting pathways of access to pharmacies, Urgent Care Centres, Out of Hours availability and NHS 111 service. During our Summer Tour¹ last year, we found 40% of people were unsure where to find their nearest Urgent Care Centre (UCC).

We have used that insight to design a new leaflet '#YourVoiceCounts'² to raise awareness about how to access these vital services which was distributed during our Summer Tour 2016. (see page 20)

The E&V Visits of UCC was an opportunity to see the centres working first hand and to find out if local people visiting them are choosing the right service for their treatment. The four UCCs visited were, Loughborough UCC on Friday 28 October 2016 and Oadby UCC, Market Harborough UCC and Melton Mowbray UCC on Friday 4 November 2016. Over the four visits we spoke to 45 patients and 10 staff members.

Following the visits, we collated the findings that emerged across all four UCCs so that these can be considered and taken forward by all the providers across Leicestershire. These are as follows:

- (a) From the data captured, patients were unsure what illnesses and injuries can be treated at an UCC.
- (b) The majority of patients had not heard of the NHS Now App.

¹ Summer Tour Report <https://tinyurl.com/lzro38q>

² #YourVoicesMatter booklet <https://tinyurl.com/y948fvbh>



- (c) Patients did not know the process for triage or have a good understanding of the NHS 111 service. Information about services were not displayed prominently in all of the UCCs.
- (d) Patients were unaware of the opening hours for the UCCs and whether x-ray facilities were provided.
- (e) From the data captured, patients had either been unsuccessful in getting a GP appointment that day or at short notice and had therefore made the decision to visit the UCC for immediate treatment.
- (f) Although local late night pharmacy information was available on asking, this was not displayed in the waiting areas.

The report was presented at the Leicestershire County Council Health and Wellbeing Board in March 2016 and to the West Leicestershire Clinical Committee Group Quality and Performance group in April 2017.

The providers for each UCC have provided a response to each recommendation, which can be found in the full report.

Making a difference at Barrow Health Centre

Following our E&V visit of Barrow Health Centre on 7 July 2016 we received feedback from the new Patient Participation Group (PPG) Chair. She reported that she could already see some things that have made a difference. There is a new Practice Manager, Reception Staff have had training and the phone system is about to be changed over to a new provider at the end of the month.

We also spoke to a patient from the Health Centre who feedback that improvements have been made at the practice following our visit. Some of the receptionists have left and appointment times have improved.

**Read the report -
Barrow Health Centre E&V report:
<https://tinyurl.com/yc8aro77>**





**Helping you find
the answers**

Helping you find the answers

How we have helped the community to access the care they need

Signposting

This year our Signposting and Information Service handled 242 enquires. In comparison to quarter 1, there was a noticeable decrease in the number of enquiries we had for rest of the year. We believe this is due to the introduction of a voicemail message which signposts to neighbouring Healthwatch.

The service was open Monday to Friday, via telephone with voicemail services 24/7. Emails and communications through the website were responded to within 24 hours where possible. We aim to respond to queries within 24 hours (notwithstanding weekends and bank holidays).

242 total enquiries

☎	159	TELEPHONE
@	39	EMAIL
✍	27	INTERNET FORM
✉	5	OTHER (POST/DROP IN)
💬	5	VOICEMAIL

Top issues received through Signposting

- Lack of NHS dental appointments
- Complaints about NHS services (e.g. GPs, Dentists, Hospitals)
- Social Care issues and concerns (e.g. Social worker complaint, concerns regarding care packages)

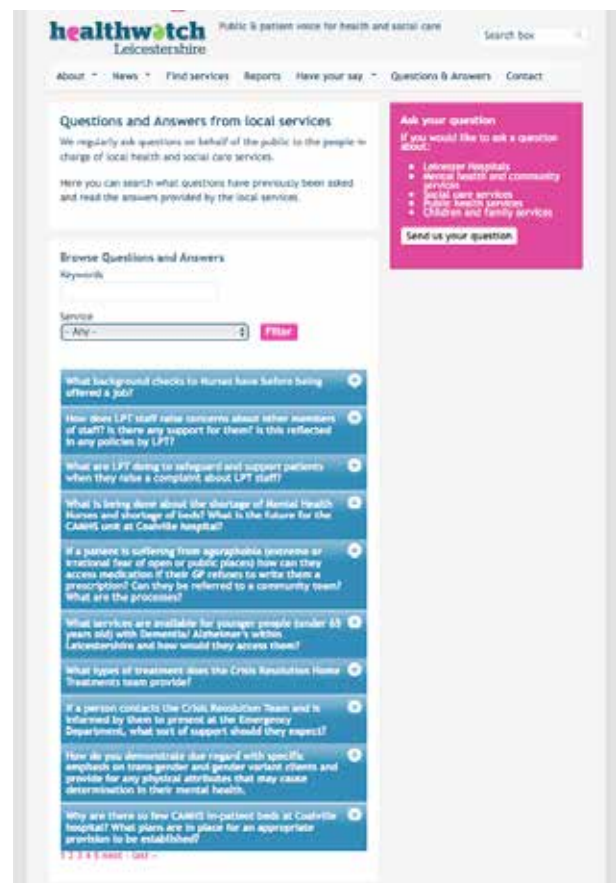
The majority of enquiries (56%) to the signposting service were made by telephone and were from individuals seeking information about NHS dentists. The insights we gain from the helpline and information service contributes to our evidence base so that our voice is authentic where changes are needed to health and social care services.

Our Website - Q&A Repository

A new section on our website was launched in February 2017 where we have posted all 'Questions and Answers' we've received from the public and health care providers. This database is a resource for patients and the public to search as part of our signposting service. <http://www.healthwatchleicestershire.co.uk/questions>

The repository contains past questions submitted either University Hospitals of Leicester or Leicestershire Partnership NHS Trust with the responses that were provided. A search can be made by key word.

See a screenshot from the website:





Case Study:

Communication in Braille

A patient contacted us as she wanted to discuss two issues she had with regards to the NHS Nail Cutting Service and the Ophthalmology clinic at Leicester Royal Infirmary.

The patient is registered blind and explained that her doctor suggested she use the NHS Nail Cutting Service at the Oadby Walk-in Centre. The patient later received a letter which stated that the service will no longer accept patients who do not have significant risk factor or possibility for further health problems and that those individuals who had been using the service but do not fall under the new criteria should self-care.

The patient said she felt as though it was discriminatory towards blind people as they are unable to see and there is a potential for injury. She felt that a blind person's feet are their eyes and it is essential that their care be maintained.

The patient also explained that she has been using the Ophthalmology clinic at LRI for the past 5 years. She said they know she is a braille user and she has received appointment letters in braille before, however letters, which are sent to the doctor, are always in print. She had made a complaint about this already and they have written back to say it will not happen again, but it happens every time. She does not mind having somebody read to her what the letters say but anything medical she wants to be confidential and personal.

What we did

The patient wanted help to make a complaint and as she is blind she said she would struggle with writing letters. We explained the role of POHWER Advocacy to her and offered to make a referral if she was happy for us to share her information, which she agreed to.

We used this case study to formulate a question, which was sent to University Hospitals of Leicester in September 2016.

We received a response which outlined that

'UHL has the facility to arrange the translation of all their information into different formats languages etc. however they do not have the ability to record a patient's information requirements on their patient information system. This would enable UHL to automatically generate the information in the patients chosen format. UHL are hoping to have new systems put in place to enable this but until they are not replaced they are implementing a flagging system against patients to specify their preferences.'



Health and Social Care Signposting Directory

In partnership with Health Care Publications we produced two Health and Social Care Signposting Directory's one for residents in East Leicestershire CCG and the other residents in West Leicestershire CCG.

Twelve thousand copies of the directories were dispatched to GP surgeries, pharmacies, hospitals, domiciliary care providers, residential/nursing homes, various local authority departments, Meals on Wheels and other health care providers.

A link to the to download the directories was sent to all County Councillors

East Leicestershire Directory

https://issuu.com/healthwatch/docs/leicestershire__east_brochure_for_w

West Leicestershire Directory

https://issuu.com/healthwatch/docs/leicestershire__west_brochure_for_w

Covers services within the areas:

- ✓ Baby
- ✓ Harborough
- ✓ Melton
- ✓ Oadby & Wigston



Health & Social Care Signposting Directory

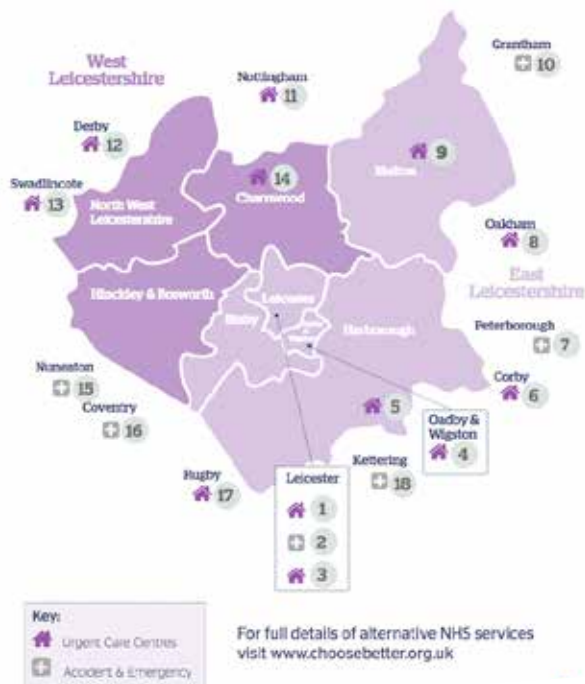
East Leicestershire



Your Voice Counts Leaflet

As part of our 2016 summer roadshow we wanted to raise awareness of how people can choose better when it comes to urgent care. This was in response to the previous year's tour where 40% of people we spoke to told us they were unsure where to find their nearest Urgent Care Centre (UCC).

Find your local Urgent Care Centre (UCC)



To raise awareness we produced a leaflet which included a map of where to find your local UCC and information on the types of injuries and illness that can be treated at UCCs.

The leaflet named, #YourVoiceCounts, was distributed to 97 local GP surgeries and electronically circulated to members of the Clinical Commissioning Groups (CCG). This was in addition to the leaflet being handed to members of the public during the summer tour events.

This formed part of our ongoing work to signpost members of the public to appropriate services and where possible, reduce the amount of people presenting at A&E.

The leaflet can also be downloaded from our website: #YourVoicesMatter booklet -
<https://tinyurl.com/y948fvbh>



**Making a difference
together**



Making a difference together

Helping to influence change

The Lived Experience of Hospital Discharge

In January 2016, we surveyed our members and the general public to find out what areas of health, wellbeing and social care they considered a priority to help shape our campaigns, activities and programmes.

A number of priorities emerged including: Hospitals and Care in the Community; care and treatment, waiting times, safe discharge into community, accessible care in the home, domiciliary services and care packages.

Building on our previous work on 'Unsafe Discharge for Vulnerable People' - (bit.ly/hwdischargereport) we wanted to conduct further research in the area to gather experiences from a wider group of patients. The discharge partnership project focused on older people's experiences of discharge from care settings.

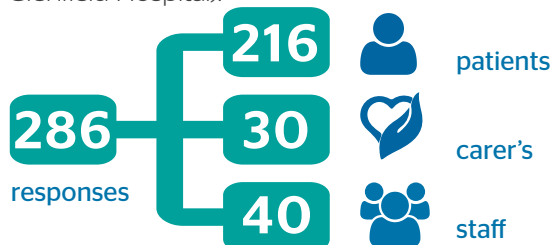
We took a consultative approach with stakeholders by sharing our emerging findings, priorities, and working together on the discharge project.

We spoke to

- WL CCG - Communications, Engagement and Involvement Manager
- ELR CCG - Head of Communications and Public Affairs
- Leicestershire County Council - Strategic Planning & Commissioning Team Adult Social Care
- Leicestershire Partnership Trust (LPT) Patient Experience and Involvement Officer
- University Hospitals for Leicester (UHL) - Patient & Public Involvement/ Membership Manager

The Lived Experience of Hospital Discharge report provides an independent insight into some of the issues of hospital discharge that remain important to local patients, carers and staff. It was important to capture the different perspectives of the target groups, and so we developed three separate questionnaires specifically targeted to each group.

The surveys were open from September to December 2016 and we heard from 286 people (216 patients) 30 carers and 40 staff (responded from across three main hospitals - Leicester Royal Infirmary, Leicester General Hospital and the Glenfield Hospital).



The report found that just over a third (36%) of patients had experienced a delay in their discharge from hospital and that almost a third (30%) of patients had previously been discharged from hospital for the same condition.

Over three quarters of staff (33 out of 40) said they are involved in the care planning and discharge of patients on a weekly basis. However, almost half of the staff told us that they have never had discharge training. Training staff is identified as a recommendation.

From the survey responses of patients, carers and staff, the following themes were identified as common:

Waiting times

Featuring alongside all the feedback surrounding hospital discharge, patients, carers and staff talked about their lived experience of delayed discharge. For example, having to wait for test results, medication or discharge letter so that patients could be discharged with their care plans involving their family/carer.

Coordination

Patients and service users assume that all health care professionals act as 'one team' working together and sharing relevant information. Therefore, it is bewildering to them as to why joined up working does not happen at staff handovers between nurses and doctors, when getting medications from the pharmacy and arranging transport.



Communication

Keeping patients and their carers up to date with timings for discharge can often place the patient more at ease. On many occasions, patients were not given any clear information as to why their discharge was delayed or when issues would be resolved.

The report highlights experiences and insights into how patients, carers and staff feel about hospital discharge services and from which our recommendations were derived:

1. Timely medication

The issue of timings for medication to take out (TTOs) should be addressed with some urgency, including more immediate practical steps to examine how the overall discharge process can be speeded up and improved.

2. Training

The experience of hospital discharge should be the same whichever hospital setting the patient is coming from. **There should be an improved schedule and a consistent approach to staff training relating to discharge. This training should have an element of multi-disciplinary and multi-agency focus.**

3. Cultural change

There are many processes, people and procedures that are intertwined with hospital discharge. **There needs to be a cultural shift that leads to greater communication between staff teams, departments and partners working toward an effective pathway and process for discharge.**

4. Inclusive approach

Carers and family members often feel on the margins and left out when it comes to the care of the patient. **Better information for carers and family members, in terms of processes, timings and care should be made accessible and explained.**

5. Feedback loop

Hospital discharge affects people's lives in many different ways. **There should be a timely follow up survey specifically around hospital discharge so that the system can continually be improved to benefit patient and carer's experiences.**

In response to our report and recommendations, the following outcomes were achieved:

The Chief Executive of University Hospitals of Leicester NHS Trust responded by saying,

"We welcome this report as a very helpful insight into the discharge process within our hospitals from the viewpoint of patients, carers and our own staff. It is quite clear that there is much that we can do to improve the experience of patients in this area and we are already working hard on this."

We presented the report to the Leicestershire County Council Health Overview and Scrutiny Committee (HOSC) on 1 March 2017 and received the following feedback from elected members:

"Thank you Healthwatch, this is a brilliant report".

"The report is beautifully presented and very easy to read".

In response to the report, HOSC have is scheduled to invite the Chief Nurse to discuss discharge.

The report was also presented at the Leicestershire County Council Health and Wellbeing Board in March 2016.

In response to the report, UHL prepared an action plan to the specific recommendations that are included in our report as our findings highlighted key issues that the Trust was going to take forward.

UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST	
REPORT TO:	Leicestershire Health and Wellbeing Board
DATE:	16 th March 2017
REPORT BY:	Gill Staton, Head of Nursing/ Clinical lead Red2Green, UHL
SUBJECT:	The Lived Experience of Hospital Discharge Report
1. Introduction	
1.1	The purpose of this paper is to provide the Health and Wellbeing Board with a summary of the actions that the University Hospitals of Leicester NHS Trust and our partners are taking in response to the five key recommendations outlined within 'The Lived Experience of Hospital Discharge' report.

Our research identified a significant frustration from all parties around consistent delays in hospital discharge. Although at times there appears to be a lack of internal ownership as to who is responsible for improving the system of discharge, we found that there is a desire from staff to tackle the issues and move forward.

Making a difference together

Working with other organisations

Changes to prescribing

In June 2016, we launched a survey in collaboration with the three local Clinical Commissioning Groups (CCGs) in Leicester, Leicestershire and Rutland (LLR). The survey focused on the current prescription of paracetamol, over the counter medicines and gluten free foods and proposed changes. A total of 821 surveys were completed and respondents left over 2,300 qualitative comments.



HWL provided a findings report from the survey as a source to help the CCGs with making recommendations and reaching a decision on prescribing. HWL also provided the CCGs with all anonymised qualitative comments in order to carry out any further analysis.

There was a strong response to the survey from individuals who may be impacted by the proposed changes and from the wider public whose opinions needed to be heard.

Our desk research highlighted that other localities have adopted different strategies to address the challenges of choice, access and cost. We outlined them in the report and noted that learning from these would be useful to help overcome barriers as well as ensuring patient and public have been listened to e.g. dispensing GP's particularly in rural areas.

Our report concluded that more exploration with different cohorts of the population may be required before formal consultation on ways in which CCGs can potentially reduce the amount spent on prescriptions.

The Head of Prescribing at West Leicestershire Clinical Commissioning Group (WLCCG), presented an update from the findings of this survey at the Leicestershire County Council Health Overview and Scrutiny Committee on 14 September 2016

in advance of any discussion at CCG level. At that time, the CCGs were due to reach a decision regarding the future prescribing of paracetamol and gluten free foods across LLR.

At the end of September 2016, East Leicestershire & Rutland CCG announced that from 31 October 2016 they would no longer prescribe medicines that are available over the counter at pharmacies and supermarkets. These medicines include painkillers, cough medicines, hay fever tablets and cold sore treatments. Patients with particular conditions who use paracetamol to manage chronic pain are exempt from this change. It was later announced that the same changes would come into effect in West Leicestershire from 1 December 2016.

The CCGs also discussed the impact on people if any changes were made to the prescriptions of gluten-free foods. It was decided that from 1 December 2016 the CCGs would make the following changes to the prescription of gluten free products across Leicestershire and Rutland:

- Patients who have been diagnosed with Coeliac Disease and/or Dermatitis Herpetiformis will receive up to 8 units per month of gluten free bread and flour.
- Prescribing of pasta, pizza bases, cereals and crisp breads is no longer recommended as these foods are available from supermarkets at a similar cost to their gluten containing equivalents and therefore the patient is not unfairly disadvantaged by having to purchase these goods

The Chief Executive of Coeliac UK wrote the following to HWL:

“We are pleased that the decision has been made and that patients with coeliac disease in Leicestershire will continue to be supported in the management of the gluten free diet. We hope you will join us in reiterating the needs of patients diagnosed with coeliac disease when the CCGs review this policy in 6-12 month's time”.



Working with HWE

HWE Dentist Review

In November 2016, Healthwatch England published an evidence review, sharing what local Healthwatch's are hearing from patients to help dental professionals, better understand people's experiences, inform the development of the new dental contract and help ensure that user feedback plays a key role in the future regulation of the dental sector.

People's concerns around dental services have been one of our most common issues raised with national champion Healthwatch England (HWE). We found that those struggling to access care include - care home residents, those who only go to the dentist when something is wrong and people living in areas where commissioning has not adapted to meet changes in demand.

Prior to the national review by HWE, we had released a report in October 2015³ and sent the report to the Chair of the Local Professional Network to help make positive change in the NHS locally and nationally.

Our research was selected with 31 other local Healthwatch to contribute to the HWE evidence review, Access to NHS Dental Services: What people told local Healthwatch, that pulled together people's experiences over the last two years. The review identified three groups of people in particular struggling to get the dental care they need:

- People who may find it difficult to access high street dentists, such as care home residents.
- People who don't think they need to go to the dentist or only go when they have a problem - often because they are nervous about seeing the dentist, find it too expensive, or just don't see the need to.
- People living in areas where commissioning of NHS treatment has not kept up with changes in demand - e.g. as a result of rapid population growth or demographic change.

Working with the Care Quality Commission

During this year we have provided insights and intelligence to the Care Quality Commission (CQC) for their inspection at University Hospitals of Leicester (UHL) and Leicestershire Partnership NHS Trust (LPT). We also get regular requests for information on their visits.

Patient views on Leicester Hospitals

The CQC inspected UHL NHS Trust between 20-23 June 2016. To ensure the voices of people who use UHL services were heard and their views and experiences were taken into account, the following outreach activities were undertaken:

- Analysis of information captured via our database and helpline, those included previous outreach and engagement reports/ surveys.
- Evidence gathered from people who use the service by putting out targeted callouts to Healthwatch membership.
- Targeted Tweets via @HWLeicShire accounts.
- Launched a short survey online on Thursday 12 May and closed on Monday 6 June 2016.
- Promotion of the survey on our website and twitter.

We collated the findings based on feedback from 77 respondents and gathered insights and evidence from patients, relatives and carers using services within Leicester Hospitals.

In presenting the findings from the survey, we summarised who we heard from, hospital visited, patient type, age and gender. We then reported on the findings by each hospital including qualitative feedback.

It was clear from the data and qualitative feedback that communication, hygiene, waiting times and care and compassion were reoccurring themes.

The findings alongside the insight and evidence reports also presented appreciative comments that value the trained staff, professionals and the care and treatment patients receive.



Working with LPT

In September 2016, we launched a survey to give patients and the public an opportunity to have their voices heard in the CQC inspection of mental health services provided by Leicestershire Partnership NHS Trust (LPT) 14-17 November 2016.

The findings from the survey were analysed in October 2016 and presented in a report. From the data and qualitative feedback received, the reoccurring themes were:

- Long waiting times for treatment
- Lack of support for patients
- No explanation of treatment options/ choices to the patient
- Better communication needed between mental health professionals and social care
- Caring and compassionate staff
- Staff shortage
- Access to out of hours' services

The findings together with the insight and evidence reports, also presented appreciative comments that valued the trained staff, professionals and the care and treatment patients received.

Alongside the findings from the survey, we compiled document of quarterly Q&As previously submitted on behalf of patients and issues emerging from our engagement and insights for the period April 2015 to November 2016 for the Inspection team.

Board member Chris Faircliffe who leads on LPT attended the LPT Quality Summit on Thursday 16 February alongside our Director. We prepared a position statement following feedback with board members on the key points of concerns and a summary of findings from our own survey which we conducted in Oct/Nov 2016.

We asked for an improvement plan to be circulated so that we could monitor pace of change going forward.

Chris will follow up on the improvement plan (circulated to stakeholders in April 2017) at the quarterly meetings with LPT.

Thinking outside the Tick - Box LPT Conference

We were invited to LPT's clinical audit for patients safety annual event on 7 March 2017 to judge the poster competition that received 11 entries from across LPT divisions that undertook clinical audits in the last 12 months. They were judged against the following criteria:

- The topic should be important and help improve patient care
- There should be a clear explanation for why the audit was carried out
- The poster was clear and understandable to a patient/service user
- That the audit measured care against clearly identified best practice,
- The results should be clear and easy to identify and carried out in the last 12 months
- Evidence that showed healthcare teams working together with service user/patient involvement with poster designs that was visually appealing.

HWL jointly agreed the top three awards with Healthcare Quality Improvement Partnership (HQIP) who gave a presentation at the conference on patient involvement in clinical audits.



Cathy Ellis, LPT Chair speaking with Sue Staples, HWL Board member 7 March 2017



Working with EMAS

Patient Handover at the Emergency Department Visit

Healthwatch Leicestershire Board wrote to the Chair and Acting CEO of East Midlands Ambulance Service (EMAS) to express concern on Performance Targets for June 2016.

EMAS Performance report for June 2016.

Year 2016 month	Red 1	Red 2
JUNE	43.44%	44.15%
MAY	54.74%	44.06%
APRIL	50.48%	44.52%
MARCH	50.34%	35.03%

We have noted that Leicestershire figures for this month are particularly poor for both Red 1 and Red 2.

We registered our strong concerns on the EMAS figures given the consistent failure to meet the eight-minute target. A comparison with our regional neighbours puts Leicestershire near to the bottom. We kept key stakeholders informed of our actions.

Following their response we met with EMAS Acting CEO and Operations Director on 23 September to better understand the issues relating to handover delays at UHL.



HWL Board members and volunteers on Monday 17 October 2016

One of the actions resulting from this meeting was an invitation to observe the handover process in place at Leicester Royal Infirmary Emergency Department on Monday 17 October from 4.45pm - 6.15pm.

The team spoke to the Senior Site Manager who was very passionate about their work and answered every question we asked. On this occasion, we did not speak with patients as we wanted to observe patient flow.

- We observed 16 Ambulances from a total of 24 (including 2 private ambulance vehicles) outside – this represented 66% of all ambulances stock for Leicestershire).
- The traffic management system appeared chaotic and it was difficult to see any traffic management system in place. We had previously made recommendations for traffic management in our Ambulance Handover Enter and View Report - March 2015 <https://goo.gl/ebXgEZ> and asked for an update with improvements traffic flow.
- We observed a congested 'check in' with EMAS staff at ED handover corridor and inflow and outflow of patients and "stacking" of ambulances that had been triaged by a senior nurse whilst waiting to physically enter the building. We observed that the 4 hour handover to UHL starts once the triage process happens. This meant that there were many patients still waiting at the back of the ambulance with EMAS staff, whilst other EMAS staff were waiting to handover to UHL staff.

A further exchange of correspondence with the Director of Urgent and Emergency Care updated us on the Recovery Action Plan which aims to improve flow through the Emergency DEpartment to the hospital to help improve handover times.

Our board has maintained a strong interest in regards to ambulance handover times and registered their concerns on patient safety. They have received assurance from the lead commissioners that their concerns regarding patient harm is being addressed. They informed us that they will be pursuing this to gather information on quality and safety risks and the mitigating actions taken by the commissioners.



Working with our community

How we have supported our rep's on The Health and Wellbeing Board

Our representation on the Health and Wellbeing Board (HWB) provides a platform for sharing formal patient, user and public insights, evidence and intelligence to inform the process of strategic commissioning and improve services for the benefit of the local population.

We have established a strong relationship with the HWB and stakeholders have come to appreciate our presence, our reports and our insights.

Below are some examples of how the HWB has helped us to raise our profile and improve outcomes for local people living in Leicestershire.

Healthwatch was also represented at the HWBB development sessions that discussed with HWBB members and stakeholders the Joint Health and Wellbeing Strategy (JHWS). We highlighted the importance of using performance data to drive learning and evaluation to prompt action. In another session at which departmental commissioning intentions were presented we highlight the importance of looking at the different departmental priorities and the opportunity to join up and make use of what is already out there in other agencies.

Rick Moore, Chair with Board members Chris Faircliffe and John Baker met with the county council's lead Policy Manager on 25 May 2016 to contribute to the priorities for inclusion in the new strategy set out for the Joint Health & Wellbeing Strategy. We were able to share the findings from our consultation on priorities with members and the public and also share details of our work plan and workstreams.

“Healthwatch Leicestershire makes a genuine contribution to the work to improve quality of care across the local health and care system. Its findings are respected by all partners on the Health and Wellbeing Board.”

Ernie White, Chair of Leicestershire County Council Health & Wellbeing Board

Healthwatch Leicestershire Annual Report 2015 - 16 September 2016

We presented our Annual Report at the September HWB meeting, they commented;



“It would be important to continue to work with Healthwatch to support public and patient involvement in key areas such as public consultation on the delivery of certain elements of the STP. Healthwatch would also have a role to play in monitoring delivery of the STP from a patient perspective, to test whether the care patients received was seamless and joined up across organisations”.

Listen To Me #YoungVoicesCounts July 2016

The HWB welcomed the report and wanted it to be sent to local GP surgeries, libraries and schools. They also requested that its findings should be



presented to youth groups; such as the County Youth Council for Leicestershire (CYCLe), the Children in Care Council and the LPT's "Evolving Minds" Group. Any actions arising from the presentations with the youth groups should be fed back to the HWB with a view to establishing

whether any further action was required.

The Lived Experiences of Hospital Discharge - March 2017

HWB noted and that health and social care partners should be urged to consider actions to improve services, systems and processes



outlined in the findings report. At the meeting the University Hospitals of Leicester NHS Trust welcomed the report and provided a response to each of the recommendations within the report. (see page 22)



Sustainability and Transformation Plan (STP)

The Sustainability and Transformation Plan (Programme) 'footprint' covers Leicester, Leicestershire and Rutland as the multi-year plan built around the health and social care needs of the local population.

Healthwatch Leicestershire role is to ensure local people's views influence the delivery and design of local services. Not just people who use them, but anyone who might need to in future. In relation to the STP in February 2017 we agreed our position statement and shared this with local people and stakeholders :-

- 1.** We will not pass judgement on the STP, but will challenge to ensure that Leicestershire residents have their say in how services are run in the future by acting as a critical friend.
- 2.** We will work to ensure that there is a strong voice for local people in the process and that this is reflected in the decisions will be taken.
- 3.** Our role is to scrutinize and advise the organisations involved in the STP on effective communications, engagement, and consultation with local people.
- 4.** We will monitor the quality of the communications, engagement and consultation.
- 5.** We will challenge the STP process if we have any concerns about these areas.
- 6.** We will attend locality and stakeholder meetings with the public as observers to listen to the views of local people where possible.
- 7.** We will inform, promote and publicise to Healthwatch members and the public about events and activities relating to the STP using our communications channels.
- 8.** We will engage at strategic level on Programme Boards relating to the transforming services to provide independent scrutiny and assurance from a public and patient perspective taking into account patient experience, insights, choice, points of views, design of commissioned services and patient outcomes.

In the course of the year our board members who are the CCG leads (Sue Staples, John Baker, Evan Rees and Fiona Barber) have actively engaged in a number of local meetings in readiness for the formal consultation on the STP.

Rick Moore, Chair Healthwatch Leicestershire, said:

“We want to make sure patients can find out more about the proposals, have their say, be better informed, ask questions and get their views heard before options are developed for public consultation and decisions made.”



Sustainability and Transformation Plan Meeting, Lutterworth, 24 January 2017



Lutterworth Hospital meeting - 15 December 2016

We were asked by East Leicestershire and Rutland CCG to facilitate a meeting in advance of wider public engagement and consultation on proposals for Lutterworth Hospital outlined in the draft Sustainable and Transformation Plan (STP) published on 21 November 2016.

We provided the time and space for open and honest dialogue between health leaders and an invited audience of district and parish councillors, Friends of Fielding Palmer, local doctors and PPG representatives to be involved in the earliest stage to contribute effectively to the start of a consultation process to shape the Lutterworth STP offer.

There was positive engagement and constructive dialogue with suggestions on key messaging for the public consultation.

On 24 January 2017 100 local residents gathered at the Wycliffe Rooms, Lutterworth to hear about the proposed plans to close Fielding and Palmer Community Hospital

GP Commissioning Board

HWL Board have agreed to be involved in the GP commissioning board as part of our involvement in the priority areas for the STP.

Healthwatch attended the meeting (24 February 2017) to review the narrative and to comment on the General Practice Five Year Forward View Leicester, Leicestershire and Rutland Sustainability and Transformation delivery plan

We were pleased to see that the findings from our summer tour (see page 9) were used to inform the General Practice Five Year Forward View Leicester, Leicestershire and Rutland Sustainability and Transformation Plan. See extract below:

What Patients have said

.... Overall, almost everyone tells us the high regard in which primary care is held and the vital role it provides for patients and local communities. It is the part of the NHS that people have most contact, and satisfaction with the services provided by their practice – particularly doctors and other clinical staff – is high. This is evidenced, for example, through work undertaken by Healthwatch in Leicestershire and, in the city, focused activity with the local PPG network.

However, it is clear that there are also opportunities for improvement. Key themes and feedback emerging from the events and meetings held across the region have influenced our priorities for the future and can clearly be seen within this plan.

What was good about your experience?



What could be improved?



In relation to the plan in our scrutiny and challenge role we made the following the comments:

- we cannot fault the key aspirations of the plan and direction of travel.
- we note that patients concern relating access is recognised as the plan aims to 'tackle unwarranted variations' with reference to HWL summer Tour 2016 cited as evidence for this
- concerned that patients and the public need to understand 'Federations' – what they are, their governance and purpose so that they can make best use of them.
- 'Prevention' was a mentioned but the plan did not refer to resources for this?



**It starts with
you**



It starts with you

In January 2016 we received 442 completed surveys in response to our consultation 25 respondents (6%) talked about the lack of a Fibromyalgia clinic and the need for a specialist nurse in Leicestershire. Healthwatch Leicestershire board chose Fibromyalgia for an intervention as part of our approach to ensure healthcare is accessible for all.

Fibromyalgia is a long-term condition that causes pain all over the body, is not uncommon but relatively few people know about it or understand the symptoms.

We were made aware that services for local people with Fibromyalgia are not meeting their needs. Fibromyalgia Action UK have referenced research that cites there may be 1.5m / 2.9% of the population in the UK who may suffer from this condition.

In February 2016 we met with Shuttlewood Clarke Foundation and Fibromyalgia Friends Together Group (FFTG) to discuss with their members about their wish to have a service where they can receive help and advice by a local (not London) Fibromyalgia specialist.

We then met with the FFTG again in April 2016 and through discussions we agreed to co-produce a survey and promote it widely to gather the experience of local patients with Fibromyalgia. We wanted to capture the lived experience and insights to feed into local commissioners and providers to improve service provision.

The survey was designed with feedback from the FFTG and launched on Monday 26 September 2016 and was closed on Wednesday 28 December 2016.

In addition to the survey, we supported and facilitated a meeting between the FFTG and a representative from University Hospitals of Leicester (UHL). The meeting was in November 2016 and we were able to give an update on some key headlines from the findings of the survey and FFTG members shared some of their experiences with the Patient and Public Involvement Membership Manager from UHL.

The outcome from the meeting included an offer for FFTG to attend a Marvellous Medicine talk on Fibromyalgia arranged by UHL to health professionals and UHL agreed to circulate an information leaflet produced by the FFTG across the Trust.

The Support Services Manager, Shuttlewood Clarke Foundation has said that

“We are pleased Healthwatch are raising awareness of Fibromyalgia and are working to improve the services”

We received a total of 950 responses from people all over the UK with just under 300 people responding from Leicester, Leicestershire and Rutland (LLR).

Healthwatch received a number of qualitative comments from individuals across LLR stating that, doctors and medical staff in hospitals do not see fibromyalgia as a “real thing” and their symptoms are dismissed.

Our analysis showed strong similarities between the experiences of local and national respondents. We took this into account in the presentation and design of the findings report so that the Healthwatch network could use it more widely.

Our report shines a spotlight on this particularly hidden group of people suffering in silence to improve services. Fibromyalgia is largely a diagnosis of exclusion, it can take time to carry out tests and receive the results to rule out other conditions.

We have designed, with content provided by the FFTG to produce a jointly badged ‘Top 10 Tips for those living with the condition’ leaflet. This will be circulated by UHL to 28,000 people including 12,000 professionals which will help to raise greater awareness of the condition.

The report ‘It’s not in my head’ is due to be published in June 2017.



Fibromyalgia Friends Together

Fibromyalgia is a recognised illness. The main symptoms of Fibromyalgia are widespread pain, profound fatigue, headaches, depression, increased sensitivity, fibro fog and irritable bowel.

These are our **Top 10 Tips** for living with fibromyalgia.

01

Support Group -

Join a Fibromyalgia support group such as Fibromyalgia Friends Together; it is really useful to talk to people who understand what you are going through.

02

Pace Yourself -

Take time to come to terms with your diagnosis and learn to manage your symptoms. Organise and prioritise your workload as you won't be able to do as much as you used to. Be kind to yourself and accept help from wherever possible.

03

Health Professional -

Try to find a GP that understands and recognises fibromyalgia. Keep a food and pain diary and take it with you to all appointments. Ask for a referral to a rheumatologist, pain clinic, physiotherapist or dietitian and be persistent.

04

Treatment -

Fibromyalgia is different for everyone, so it's important to learn how it affects you. There is no one treatment or medication that works for all; what suits one person will not necessarily suit another.

05

New Symptoms -

Do not ignore new symptoms; it is not always fibromyalgia. If you are not sure, see your GP.

06

Complementary Therapies -

Try complementary therapies such as Acupuncture, Reflexology or Aromatherapy. Hyperbaric Oxygen Chamber Treatment, available at MS therapy centres, has shown promise in helping people with pain and insomnia. A hot bath or shower can help to ease aches and pains.

07

Relaxation -

Stress often increases symptoms, therefore it is important to relax as much as you can. Learn how to relax by joining a relaxation or mindfulness class; do whatever it takes for you to switch off, reading, painting, knitting, music, visiting family or friends.

08

Exercise -

It is better to keep moving if you can. Take gentle exercise such as walking or swimming, or join an exercise class such as Yoga, Tai Chi, Pilates etc.

09

Information -

Fibromyalgia Action UK is the registered charity for Fibromyalgia where you can get a variety of information. Seek support online, there are many sites supporting Fibromyalgia. Our Facebook group is Fibromyalgia Friends Together Leicestershire. Use the internet as a tool but recognise not all information is correct.

10

Benefits -

Apply for any relevant benefits as these can make your life much easier. Keeping a diary of symptoms will help you complete the forms. Help is available at your local CAB office. If you have difficulty walking apply for a Blue badge.

Contact:

✉ kathleen@shuttlewood-clarke.org
☎ 07860 639693 or 01530 244914

Shuttlewood Clarke Foundation

Ulverscroft Grange, Whitwick Road, Ulverscroft, Leicestershire. LE67 9QB

Fibromyalgia Friends Together meet on the third Thursday of the month at Ulverscroft Manor, Priory Lane, Ulverscroft, Leicestershire. LE67 9PH



Our plans for next year



Our plans for the future

Future Priorities

Priorities and workplan 2017-18

With our funding levels remaining the same as the previous year we have reviewed our focus on where we can make the greatest impact on where we can make a difference to local people and services. The plan for 2017 therefore builds on the work that has been done over the past four years. This will include:

- Insight projects based on feedback from local people and statutory regulation to ensure we can make more difference locally through our reports and recommendations.
- Reviewing our signposting service so it is better at informing our activities and enabling us to identify and share trends in patient experiences with providers and commissioners.
- Continuing to provide data and reports to inform CQC inspections and working more closely with Scrutiny Committees.
- Sustaining our Enter & View model giving local people the opportunity to scrutinise services, particularly in residential and social care.
- Supporting University Hospitals of Leicester NHS Trust with their new Emergency Department, and other parts of the system that are failing. We will do this by attending Quality Oversight groups, promoting the involvement of patients and carers and ensuring their views are informing future planning.
- Contributing data and intelligence to the planning of services through the Joint Strategic Needs Assessment.
- Supporting our Board Members on appropriate boards and committees with their involvement in the commissioning, provision and scrutiny of services.
- Continuing to develop relationships and influence on Transformation programmes and Health and Wellbeing Board initiatives.

As reported last year, pressure on frontline health services puts Accident and Emergency (A&E), Urgent Care and GPs under tremendous and increasing. As a result, more care in the community is needed, which requires the redesign of local services and adds complexity to the delivery of community services.

Leicester, Leicestershire and Rutland (LLR) are taking on the challenges facing health and social care services head on the Sustainability Transformation Programme (STP) as the place based, multiyear plans built around the needs of local populations. The STP is delivered by local health and care systems by the organisations working together to deliver transformation and sustainability.

At Healthwatch Leicestershire we are keen to be involved in the local 'footprint' to ensure the local community and public are engaged in the development of the STP.



Our people



Our people

Our governance and decision-making

The governance arrangements include an overarching Healthwatch Leicestershire Board, (HWL Board) made up of members who are able to represent the diverse communities of our county.

The role of the HWL Board is to help determine the strategic direction and to ensure engagement with all segments of the local population in order to provide a representative voice for as many residents and health and social care service users as possible.

The HWL Board meets quarterly in public and the headlines and highlights on our activities are posted on the website. In addition the Board hold bi monthly meeting as a opportunity to review and reflect on the local health and social care economy, relationships with key stakeholders, identify and agree actions on 'hot issues' and agree appropriate actions.

Voluntary Action Leicester (VAL) is the contract holder and therefore employs the staff to support the work of HWL and has the responsibility for financial management, insurance, contract performance and compliance. To support this relationship there are working agreements between VAL Chief executive and HWL Board, to ensure clear lines of responsibility and accountability including 2 of VAL Trustees* as nominated leads who are also on the HWL Board (see below) .

Board

Rick Moore, Chair
 Mina Rodgers, Frail Older People Lead
 Sue Staples, Enter & View Safeguarding Lead
 Fiona Barber, CCG and EMAS Lead
 Christopher Faircliffe LPT and EMAS Lead
 *Narendra Waghela, Planned Care Lead
 John Baker, Urgent Care Lead
 Pat Fraser MBE, Carers and Mental Health Lead
 *Evan Rees, Hospital Lead

Resigned

Dee Nagra, resigned December 2016
 Anne Collier, resigned September 2016

Staff Lead

Vandna Gohil, Director
 Gemma Barrow, Development Officer
 Ivan Liburd, Development Officer
 Yachna Desai, Information Advisor
 Stephanie Hollis, Communications Officer (to August 2016)

We have 23 active volunteers who are involved in many activities including:

- HWL Board
- Sitting on Strategic Boards, Forums, Groups and Meetings
- Quarterly meetings held with University Hospitals of Leicestershire, Leicestershire NHS Partnership Trust, East Midlands Ambulance Services, Arriva Transport Solutions Ltd
- Engagement Activities
- Enter & View Task Group



Our finances



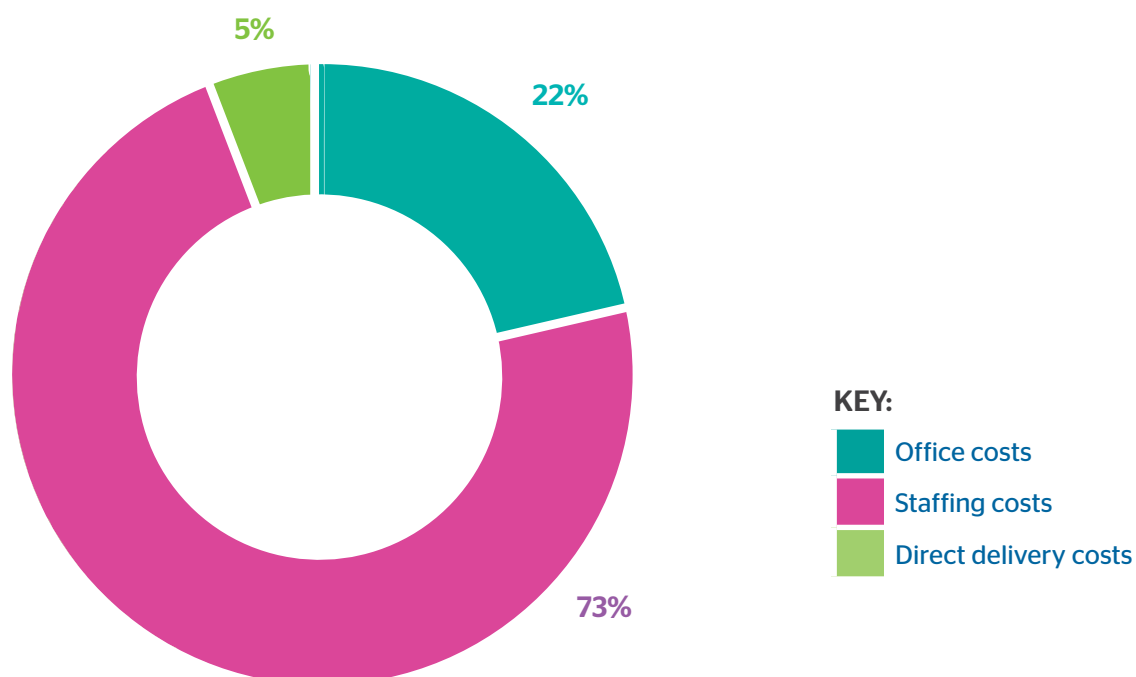
Our finances

Financial information 2016-17

INCOME		£
Funding received from local authority to deliver local Healthwatch statutory activities		187,391
Additional income		11,778
Commissioned assignments (WLCCG prescribing survey, County Council Carers Assessment and SIMTEGR8 phase 2)		
Total income		199,169

EXPENDITURE		£
Office costs		42,887
Staffing costs		144,365
Direct delivery costs		10,413
Total expenditure		197,665
Surplus/(Deficit)		1,504

The figures above are for guidance, as they are still subject to a formal audit.



Contact us

Healthwatch Leicestershire

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Address of contractors:

Strategy Business Intelligence
Chief Executives Department
County Hall,
Leicester Road, Glenfield,
Leicester, LE3 8RA

We will be making this annual report publicly available by 30th June 2017 by publishing it on our website and circulating it to Healthwatch England, CQC, NHS England, Clinical Commissioning Group/s, Overview and Scrutiny Committee/s, and our local authority. We confirm that we are using the Healthwatch Trademark (which covers the logo and Healthwatch brand) when undertaking work on our statutory activities as covered by the licence agreement.

If you require this report in an alternative format please contact Healthwatch Leicestershire on the address above.

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Voluntary Action LeicesterShire (VAL) is the contract holder for Healthwatch Leicestershire