



Healthwatch Northamptonshire activity on sensory impairment in 2018



Contents

Introduction)
1. Addressing the needs of deaf and hard of hearing people in accessing healthcare services	
2. Supporting the case for an Eye Clinic Liaison Officer	3
3. Raising concerns about capacity issues at NGH Opthalmology Department	3
4. Responding to consultation on cutting prevention services for people with sight and hearing loss	1
Thanks and acknowledgements	1
Appendix 1 - Notes from training course 'Involving the Deaf Community Masterclass', EMAHSN 27 September 2018	5
Appendix 2 - Patient Story	5
Appendix 3 - Evidence presented as part of business case for an ECLO at NGH 9)
Appendix 4 - Email correspondence re NGH eye clinic issues)
Appendix 5 - Healthwatch Northamptonshire responses to NCC consultations 14	1
About Healthwatch Northamptonshire17	7
Contact us	3

2



Introduction

Healthwatch Northamptonshire (HWN) identified sensory impairment as one of its priorities for work in the year April 2018 to March 2019. This short report provides an update on Healthwatch Northamptonshire activity on sensory impairment issues in Northamptonshire during 2018. In September 2018 Healthwatch Officer Dr Becky Calcraft attended a masterclass 'Involving with the Deaf Community', hosted by the East Midlands Academic Health Sciences Network (EMAHSN). Notes from this class, which was run by a consultant from the British Deaf Association, were shared with Healthwatch Northamptonshire colleagues (see Appendix 1).

1. Addressing the needs of deaf and hard of hearing people in accessing healthcare services

In October 2018 HWN volunteer Sandra Bell gained recognition through a national award at the Healthwatch Network Conference for her work in drawing attention to the issues deaf and hard of hearing people can face in accessing healthcare services, including sharing a powerful 'patient story' from August 2017 (see Appendix 2). As a result of her efforts, including the involvement of NHS England, the local Clinical Commissioning Group (CCG) has committed to improve the training of staff and provide online or face to face British Sign Language (BSL) translators when requested. However, we are aware that the issues are ongoing and patients who are deaf or hard of hearing are still experiencing difficulties. HWN has asked Nene and Corby CCGs for assurances that BSL interpreting services are provided for deaf patients who require them. The CCG Deputy Director of Quality has asked the county's three NHS trusts for details about their BSL interpretation services at their quality monitoring meetings and will be updating us on their responses.



Sandra Bell receiving her award certificate from Dr David Jones, HWN Chair



2. Supporting the case for an Eye Clinic Liaison Officer

In October 2018 the Partnerships and Development Manager at Royal National Institute of Blind People (RNIB) and CEO of Northamptonshire Association for the Blind (NAB) attended the HWN Board meeting and presented their case for an Eye Clinic Liaison Officer (ECLO) at Northampton General Hospital (NGH). This included results of a survey of local people with recent experience of sight loss, reflecting the patient voice. Case studies of Eye Clinic Liaison Officers elsewhere in England demonstrate how such a role can provide emotional and practical support at the point of diagnosis, easing pressure on clinical staff and resources. An extract of this business case is included as Appendix 3 of this report.

The HWN Board voted unanimously to lend their support for the proposal, which was considered by Nene CCG in November 2018. At that meeting the CCG expressed support of the ECLO proposal but did not commit to any investment in the service. RNIB and NAB continue to lobby NGH Trust and discussions with divisional managers there are ongoing and positive. RNIB told us:

"The NGH ophthalmology department has, according to published data, seen an increase of over 60% in footfall over the last two years and clearly this will be reflected in experience in the eye clinic for patients and clinicians alike. The role of an ECLO in supporting patients, helping the department to manage risk, and adding to the overall capacity has been recognised in a recent Patient Standards document from the UK Ophthalmic Alliance, and the issue of capacity in ophthalmology has been recognised this year by both NHSE and an All Party Parliamentary Group who have written to all STPs about the matter" (email correspondence, December 2018).

3. Raising concerns about capacity issues at NGH Ophthalmology Department

In November 2018 a HWN volunteer reported experiencing problems at various parts of the eye clinic at NGH, including long waiting times, lack of coordinated appointments and difficulties getting through on the phone. HWN raised these concerns with the Head of Patient Experience at NGH, who forwarded the concerns to the directorate manager of Ophthalmology. HWN received a prompt response, which acknowledged problems with capacity. The manager explained remedial actions being taken by NGH to address the issues, including additional clinics at weekends and increased staffing (clinicians, nurses and admin staff). Reassurances were given that those who are high risk or have particular travel needs or other personal circumstances were prioritised within the clinic and were not kept waiting (see email correspondence in Appendix 4). HWN continues to keep a watching brief on this matter.



4. Responding to consultation on cutting prevention services for people with sight and hearing loss

Northamptonshire County Council (NCC) conducted a consultation in October 2018 on proposals to cease commissioning prevention services for adults with hearing or sight loss from Deafconnect and NAB respectively. We met with the CEO of Deafconnect, to discuss the potential impact of such proposed cuts to funding. HWN responded to the consultations (see letters in Appendix 5) emphasising that Deafconnect and NAB provide vital support services that NCC does not offer, and that to cut such services would be counter to the important duty of prevention under the Care Act 2014.

HWN also raised concerns about how the NCC consultation was carried out, which demonstrated a lack of understanding of the particular communication needs of deaf and blind people and the need to adjust consultation meetings accordingly.

HWN welcomed the subsequent decision by NCC in December 2018 not to end their contracts for prevention services with Deafconnect and NAB, acknowledging the negative equalities impact that cuts to these services would have and the lack of alternative services locally.

Thanks and acknowledgements

Healthwatch Northamptonshire would like to thank the volunteers and voluntary organisations that have highlighted issues and raised concerns.



Appendix 1 - Notes from training course 'Involving the Deaf Community Masterclass', EMAHSN 27 September 2018

There are broadly four different groups of people who are deaf and hard of hearing:

- 1. Deaf people who are confident in articulating their own needs and are able to use BSL
- 2. Deaf people who don't identify as deaf, who may lack confidence, may have had a negative family or education experience in relation to their deafness, are consistently facing barriers and feel excluded in their own local areas
- 3. People who are hard of hearing mostly elderly people but also some younger people, who may or may not use hearing aids
- 4. People who are deaf and blind

There is some shared experience but these groups are quite different and have different needs. The cultural norms between deaf and hearing people can differ.

What are the barriers to deaf people in health and social care services?

- If you rely on telephone contact and do not offer an alternative way of contacting people
- If you have an intercom system to enter a ward, building or car park
- Lack of reception staff is a significant barrier to deaf people accessing services

If a deaf person has difficulties in accessing a service, when they finally get through they may arrive in a frustrated state - staff should be aware of this and make reasonable adjustments.

The best question to ask a deaf person is, "How would you like to communicate?" Let the deaf person say what they need.

Not all deaf people can lip read. Do not expect deaf people to lip read - this is very tiring and is up to 80% guess work for the deaf person. If a person can lip read, then be aware that the environment needs to be quiet and free of distractions.

We should not rely on deaf people using written information/writing everything down for them - many deaf people have poor English or a lower level of reading ability, so may find it hard to take in complex information in written form.

Text phones or minicom have limitations; not all deaf people have a mobile phone. 'Sign Live' is an online BSL interpreting service via video link but it cannot always be relied on - it does not work if signal/bandwidth is poor. Interpretation services should only use qualified BSL interpreters - using a staff member or a family member who can 'sign a little' can lead to confusion or catastrophic consequences (e.g. in abusive situations).



Using language such as 'speak out', 'have your say' in consultations deaf people may not feel it includes them and so will not respond or take part.

Appendix 2 - Patient Story presented to CCG Joint Quality Committee, 8 August 2017

What occurred?

The profoundly deaf patient, Sally^{*} (name has been changed) was admitted to Knightley Ward at Northampton General Hospital (NGH) in April 2017.

Sally is a BSL using older lady who had been in hospital for a week with not one interpreter booked for appointments with Doctors. Deafconnect Northamptonshire (DCN) became aware of this (Sally is one of their users). They contacted the hospital immediately and told them that they needed to book interpreters for all doctors' visits. The Learning Disability Liaison Nurse from NGH phoned and confirmed that this would happen.

The next day the ward phoned DCN and said they needed an interpreter NOW! Clearly they had no knowledge of the correct procedure to book BSL interpreters. NGH usually use the Big Word for interpreters. However just by chance the CEO of DCN had arranged to visit Sally that afternoon, so she agreed to interpret, but made it very clear that although she has level 3, she is not a qualified interpreter. The ETA was given and the doctor waited until the CEO arrived to assess Sally.

The doctor then in passing announced Sally was going to be given antidepressants that evening. That was challenged by the CEO who has known Sally for 7 years and stated that she is the most positive person you could ever meet. The doctor explained that she had been assessed earlier that day by a psychologist. The CEO asked Sally about this and she didn't know who any of the people who had visited her were. She had been visited earlier that day by someone new, but hadn't understood a word, signing that they had wittered on verbally but she didn't know what about.

The CEO eventually managed to get hold of one of the psychologist team who said that Sally was suicidal! So they had prescribed antidepressants. When asked how they had communicated with her, he waxed lyrical about how important communication was for them but did not grasp that his patient had not understood anything that was said to her, so how could they diagnose anything? Finally he asked to meet Sally with the DCN CEO (again it was explained that she was not a qualified BSL interpreter) but as luck would have it a retired interpreter was visiting Sally so agreed to interpret the short meeting. The doctor questioned her as though she was blind - virtually sat on her lap! Until he was told, she could see well enough but needed him to sit down so Sally could see the interpreter.

After a few questions about her wellbeing all of which were answered positively, in answer to the question, "Do you have suicidal thoughts?"



(translated as do you want to kill yourself) she told him that God wouldn't want her to kill herself (in no uncertain terms) and that yes she was old and didn't understand why God hadn't taken her yet. Sally made it clear she didn't need or want antidepressants, the doctor realised then she was not at risk.

Sally was then moved the Angela Grace Centre, where she stayed for 10 days. The CEO visited her on day two and discovered that they were calling her Diana* (name has been changed), which is her true first name but she goes by Sally. It was on her door and on the register in reception. The senior nurse was challenged about it and discovered that it was indeed highlighted on her report that she went by Sally, but no one had checked and Sally couldn't hear. Unless her visitors had known that her first name was Diana they would have been sent away.

Whilst there Sally asked the CEO to explain all her medication to her as she was on so many tablets, and she didn't know why. The senior nurse used the CEO again to interpret this to Sally. The CEO made it clear when leaving that they must start booking interpreters.

No interpreter was booked when the occupational therapists (OTs) went to assess Sally on her ability to look after herself. Then another separate complaint was made to PALS from a deaf member of staff from DCN who had visited Sally with her Access to Work (ATW) interpreter whereby the OT took the opportunity to discuss issues with Sally using the DCN ATW interpreter.

Interpreters were then used for some of the meetings with Sally.

Sally was sent home with a care package put in place but again a full explanation was not given to Sally with an interpreter she could understand, so Sally was completely taken by surprise when one of the carers stayed overnight to look after her.

Impact on the patient, family, staff

The final outcome for Sally is that she states she will never use her Carelink (emergency call) button again as she never wants to be admitted to hospital ever again. The frustration as far as DCN is concerned (putting it mildly) is that Sally's file clearly states she is deaf and needs a BSL interpreter. This has been ignored, or nurses have to go to Managers to authorise it, so doesn't end up getting done. This is not a one-off instance, it happens regularly. As service providers, not using or providing BSL interpreters is purely and simply discrimination. There is an assumption that all Deaf people can lipread. Sally has a very Deaf Voice so is not always clearly understood. Due to her advanced years her eyesight is failing and she finds it difficult to concentrate for more than five minutes lipreading, therefore using a BSL interpreter is vital.

As for the staff, a catastrophe caused by a wrong diagnosis and administration of incorrect medication was narrowly avoided thanks to the swift actions of the CEO of DCN.

2

What has changed as a consequence?

Extremely slow process. A meeting was arranged between DCN and the Equality Lead at NGH. Using an online interpreting service, in some circumstances, maybe worth investigating.

But above anything else a timely reminder - see below:

The Accessible Information Standard - What you can expect from services 31/07/17

It's now been a year since the Accessible Information Standard came into force. It requires any organisation providing NHS or social care to communicate in a way that everybody can understand, regardless of their circumstances. Here's a reminder of what you should expect.

The standard aims to make sure that people who have a disability, impairment or sensory loss are communicated with in a way that meets their needs. Organisations are required to provide alternative formats where required, such as braille, large print, and easy read. They must also support people to communicate, for example by arranging a British Sign Language (BSL) interpreter, deafblind manual interpreter or an advocate.

So if you're speaking to a dentist, doctor, care home manager or any other provider of health and social care, here's what you can expect:

- You should be asked if you have any communication needs, and asked how these needs can be met.
- Your needs should be recorded in a clear and set way.
- Your file or notes should highlight these communication needs so people are aware and know how to meet them.
- Information about your communication needs should be shared with other providers of NHS and adult social care, when they have consent or permission to do so.
- Information should be delivered to you in a way you can access and understand, with the option for communication support if needed.

Sandra Bell Vice Chair Healthwatch Northamptonshire July 2017



Appendix 3 - Evidence presented by RNIB as part of business case for an ECLO at NGH

Incidence of sight loss in Northamptonshire and other health indicators

2 million people live with sight loss in the UK and, due to the aging population, by 2034 the number of people living with sight loss will be 3.1 million.

Here in Northamptonshire we have a particularly rapidly ageing population which means that the proposed investment in an ECLO service (with sight loss incidence associated with age) at NGH at this time is particularly required in order to enhance efficiency and effectiveness of patient care in the eye department and support the growing numbers of patients with sight loss to live with their diagnoses, preventing or delaying greater need for hospital services. Outpatient appointments in the ophthalmology department at NGH went up by over 60% from 2015/16 to 2016/17.

	Total No.	Aged 65+	Proportion aged 65+
Registered Blind (Severely Sight Impaired)	2056	u/k	u/k
Registered Partially Sighted (Sight Impaired)	1489	u/k	u/k
Total	3545	2675	75%

Registrations (2013/14)

Of the 3545 total registered **560 people are also deaf or hard of hearing** (as recorded on the Register).

Certificates of Visual Impairment (CVI)

	No. of CVIs (2014/15)	Rate per 100,000 Population	Change in rate since 2012/13
Northamptonshire	161	22.5*	
England	23,017	42.4	-1%

* Note - the rate of CVI issues in the County is significantly lower than the national rate suggesting a difference in local practice re: issuing CVIs. This could be affecting the help that local people with sight loss are receiving (pathway from CVI to registration by NCC and associated support) since the level of resource deployed to help people with sight loss is influenced by those numbers. An ECLO at NGH would assist in processing CVIs and would advocate for appropriate CVI and registration issues where patients would benefit.

Sight Threatening Conditions

Sight Threatening Conditions	Estimated No. of People Living with this Condition in Northants 2016	Estimated increase in Northants by 2030	Estimated increase across England by 2030
Early stage AMD	28,900	44%*	35%
Late stage dry AMD	2,090	64%*	48%
Late stage wet AMD	4,300	67%*	50%
Cataract	6,720	65%*	51%
Glaucoma	6,860	13%	14%
Diabetic Retinopathy	14,280	10%	11%
Severe Diabetic Retinopathy	1,310	11%	11%

*Denotes significantly higher than expected England-wide increase

Other Health Indicators

No. of people 65+ with sight loss who have experienced a fall	2630 (2015 estimate)
No. of people who have experienced a fall which is directly attributable to sight loss	1,243
No. of people 65+ with sight loss who have experienced a severe fall (i.e. resulting in hospital admission through A&E)	197
No. of people 65+ who have experienced a severe fall which is directly attributable to sight loss	93
Estimated no. of people with dementia and severe sight loss	1,333
Estimated no. of people with dual sensory impairment	4,155

Outpatient throughput at Northampton General Hospital NHS Trust was recorded at **66,098 patients** during 2016/17. This was **an increase of 60.6% on the previous year.**



The Northamptonshire JSNA 2017 (Adults with Disabilities)

The JSNA does not specifically address the needs of those in the County with sensory impairments but its recommendations for all adults with disabilities include, in particular, the following:

- Prevention programmes to avoid development of physical disabilities in older age
- Develop a targeted self-care/empowerment programme to increase independence in Adult Social Care clients.
- Develop support to facilitate more people who receive Adult Social Care services, and those in contact with Mental Health services to live independently

The established relationships between sight loss and poorer mental wellbeing (anxiety/depression, isolation, reduced physical activity) and the higher likelihood of falls, including serious falls, makes these recommendations particularly applicable to those with sight loss. The establishment of an ECLO service would be in line with these recommendations.

Source of data: RNIB's Sight Loss Data Tool

https://www.rnib.org.uk/professionals/knowledge-and-research-hub/keyinformation-and-statistics/sight-loss-data-tool



Appendix 4 - Email correspondence re NGH eye clinic issues, November 2018

Email from HWN to NGH:

"One of our volunteers has reported difficulties with appointments at the eye clinic at NGH - he has struggled to get through on the phone and only managed it after four days. He also says that the appointment system is very poorly organised and if a patient needs to attend two appointments for different procesess/assessments, then they are given on different days, causing additional travel and time costs - he's particularly concerned of the impact of this on older people in rural areas. He was told at the start of the month that it is no longer possible to co-ordinate appointments to fall on the same day, and that the department reports that they are 'two months behind with appointments' due to persistent lack of capacity. He's concerned that additional delays in assessment and treatment can exacerbate eye problems where prompt treatment is needed. We also heard at our last board meeting from RNIB that the growth in the elderly population locally is adding to increased demand for ophthalmology services.

Our volunteer said that the eye clinic staff are aware of the issues and are trying to address them, but that they still say their capacity is stretched. He is complimentary about the staff though!

Is this an issue you are already aware of and do you know more about what is being done to improve the situation?"

Reply from NGH Ophthalmology Directorate Manager:

"Thank you for your email below, I will try to answer the queries posed in turn. Our Ophthalmology department sees approximately 65,000 patients per year in outpatients, 11,000 via Eye Casualty and 3,000 day case admissions. Being a high volume service capacity is an issue and I suspect is for every Ophthalmology department in the country. We do carefully monitor our patient waits and this is reviewed on a weekly basis. All high risk patients are seen on time and it is only the lower risk patients that are affected by delays, which at present are seen approximately 8 weeks after their to be seen by date. We regularly hold additional weekend clinics and are looking to standardise these sessions and extra by moving to a 3 session a day week. This as I am sure you will appreciate is not an easy task to implement due to requirement of additional Clinicians, Nurses and admin staff and funding to facilitate this change.

The phone line is currently managed by one member of staff per day for the main follow up appointment line, if the line is busy then unfortunately patients will encounter a wait. We have however recently submitted a business case for additional admin staff and if approved would enable us to have two members of staff answering calls for our follow up patients. We are awaiting the outcome of whether this has been approved or not.



Patients who require two appointments, one to see the Orthoptics department and one to see the clinician will sometimes experience difficulties in having those two appointments arranged on the same day. Whilst we always try and combine them for the convenience of the patients, trying to organise this for over 40,000 of our patients just isn't possible for every patient. Whilst we do appreciate that this can cause an inconvenience to the patient if not seen on the same day for both appointments we will only do so when there is no other option, currently combining them for every patient would mean the patient encounters a delay in them being seen. It's a tough one to marry up the capacity required in Orthoptics to the Clinician clinics to guarantee patients could be seen on the day, when we have looked at it before, again we would require a bigger Orthoptics department, it would require a major overall of the clinic structure and when analysed our work suggested it would actually lead to clinics being under booked/utilised thus increasing waiting times even further. This isn't to say we cannot revisit it in the future and it will certainly form part of the work we are doing to move to a 3 session day.

I hope the above is somewhat helpful in answering the queries/concerns below but please feel free to contact me directly should you need to."



Appendix 5 - Healthwatch Northamptonshire responses to NCC consultations

Letter 1

8th November 2018

Consultation, Equalities and Accessibility Team BIPM Northamptonshire County Council One Angel Square Northampton, NN1 1ED

Dear Sir or Madam

Healthwatch Northamptonshire response to the consultation on decommissioning prevention service for adult social care service - Hearing Impaired Services

We are writing to you in response to Northamptonshire County Council's (NCC) current consultation on decommissioning adult social care prevention services from Deafconnect.

Healthwatch Northamptonshire (HWN) holds the view that the services provided by Deafconnect are essential for people affected by hearing loss and deafness to enable them to access adult care services. The diagnosis of hearing loss can have a major impact on a person's mental health and often leads to social isolation. Early support is essential to prevent further deterioration of a deaf person's wellbeing. Prevention is a key duty under the Care Act 2014; the local authority has a duty to make sure that people who live in their area receive services that prevent their care needs from becoming more serious, or delay the impact of their needs. If prevention services are withdrawn it is false economy for NCC, because many of those who are elderly in the population will call on the council's funds in greater numbers as they lose their independence.

We are aware that there are no longer any specialist NCC staff to support people who are deaf or hard of hearing and that Deafconnect's services are extremely well-attended. HWN, on behalf of deaf and hard of hearing people locally, must be informed of what alternatives services will be offered if services by Deafconnect are decommissioned.

We also have serious concerns about how the consultation process has been carried out. It was not widely publicised and the process appears rushed, with little understanding of the access and communication needs of deaf and hard of hearing people. A longer time period is needed to cater for the additional communication needs of deaf and hard of hearing people. Many people who use British Sign Language (BSL) have a lower reading ability than the general population and find the length and wording of the online questionnaire very off-putting and difficult to understand.



In addition, the questionnaire contains leading questions and factual inaccuracies. Deafconnect will not be able to continue the services it currently offers without NCC funding, and the lack of NCC funding may have a negative impact on other sources of funding, placing the viability of Deafconnect at risk.

HWN is concerned about the lack of an equality impact assessment for this consultation. We acknowledge that NCC's grounds for this is that the consultation process will provide data on the potential impact of proposed cuts. However, we expect that under the Equality Act 2010 proper consideration of the potential impact on this group of disabled people would be investigated before any final decision on cuts to services is made.

HWN understands the financial pressure under which Northamptonshire County Council is operating. However, HWN must stress that vital services should not be depleted so much that the council becomes ineffective in meeting its objectives and neglects its statutory duties.

Yours faithfully,

Dr David N. Jones Chair Healthwatch Northamptonshire CC. HWN Board and volunteers

Letter 2

8th November 2018

Consultation, Equalities and Accessibility Team BIPM Northamptonshire County Council One Angel Square Northampton, NN1 1ED

Dear Sir or Madam

Healthwatch Northamptonshire response to the consultation on decommissioning prevention service for adult social care service - Visually Impaired Services

We are writing to you in response to Northamptonshire County Council's (NCC) current consultation on decommissioning adult social care prevention services from Northamptonshire Association for the Blind (NAB).

Healthwatch Northamptonshire (HWN) holds the view that the services provided by NAB are essential for visually impaired people to enable them to access adult services. Early support at the time of diagnosis is essential to



overcome emotional and practical challenges of sight loss and to prevent further deterioration of a visually impaired person's wellbeing. Prevention is a key duty under the Care Act 2014; the local authority has a duty to make sure that people who live in their area receive services that prevent their care needs from becoming more serious, or delay the impact of their needs. If prevention services provided by NAB are withdrawn it is false economy for NCC, because many of those visually impaired people who are currently able to manage in the community with NAB support will call on the council's funds in greater numbers as they lose their independence.

HWN, on behalf of visually impaired people locally, must be informed of what alternatives services will be offered to support people with sight loss if services by NAB are decommissioned.

We also have serious concerns about how the consultation process has been carried out. It was not widely publicised and the process appears rushed, with little understanding of the access needs of people living with sight loss. HWN is concerned about the lack of an equality impact assessment for this consultation. We acknowledge that NCC's grounds for this is that the consultation process will provide data on the potential impact of the proposed cuts. However, we expect that under the Equality Act 2010 proper consideration of the potential impact on this group of disabled people would be investigated before any final decision on cuts to services is made.

HWN understands the financial pressure under which Northamptonshire County Council is operating. However, HWN must stress that vital services should not be depleted so much that the council becomes ineffective in meeting its objectives and neglects its statutory duties.

Yours faithfully,

Dr David N. Jones Chair Healthwatch Northamptonshire CC. HWN Board and volunteers



About Healthwatch Northamptonshire

Healthwatch Northamptonshire is the local independent consumer champion for health and social care. We are part of a national network of local Healthwatch organisations. Our central role is to be a voice for local people to influence better health and wellbeing and improve the quality of services to meet people's needs. This involves us visiting local services and talking to people about their views and experiences. We share our reports with the NHS and social care, and the Care Quality Commission (CQC) (the inspector and regulator for health and social care), with recommendations for improvement, where required.

Our rights and responsibilities include:

- We have the power to monitor (known as "Enter and View") health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised and delivered.
- We aim to be an effective voice rooted in the community. To be that voice, we find out what local people think about health and social care. We research patient, user and carer opinions using lots of different ways of finding out views and experiences. We do this to give local people a voice. We provide information and advice about health and social care services.
- Where we do not feel the views and voices of Healthwatch Northamptonshire and the people who we strive to speak on behalf of, are being heard, we have the option to escalate our concerns and report our evidence to national organisations including Healthwatch England, NHS England and the Care Quality Commission.









Contact us

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