



## INTRODUCTION

As part of our continuous listening and ongoing commitment to meaningful engagement with local people, Lincolnshire East Clinical Commissioning Group and United Lincolnshire Hospitals NHS Trust were delighted to host their second “Hearing Lincolnshire’s Hidden Voices” engagement event which was held on Thursday, 10 January 2019 at 12.00 noon – 3.45 pm in the Lecture Theatre at Lincoln County Hospital.

The focus of the event was around mental health and well-being and the event was a fantastic opportunity to bring together representatives from various local groups who were invited to share their personal experiences of accessing health services and to share their views on local NHS plans. Through this, this will ensure that we are able to meet the diverse health needs of our local population and further strengthen the patient voice from different communities and protected characteristics.

Appendix 1 details the event agenda for the day.

Appendix 2 provides information regarding social media reach.

Appendix 3 provides a copy of the invited organisations to the event.

Appendix 4 provides a copy of actions to be addressed.

## AIMS OF THE DAY

The aims of the engagement event were to:-

- Recognise diversity, promote equality and encourage engagement between the NHS and different communities especially those related to Mental Health, Autism and Neurological conditions.

## OBJECTIVES OF THE DAY

The objectives of the day were to:-

- Gain updated information about equality, diversity and human rights provision especially in relation to Disability, including Mental Health (including Armed Forces Veterans), Autism and Neurological conditions.
- Enable community groups and NHS staff to listen and learn from each other through the exchange and sharing of information around these areas.

- Make suggestions on how to move forward to support Mental Health issues, Autism and Neurological conditions through ongoing planning and engagement.

As part of our continued Lincolnshire wide working, a range of staff across all four Lincolnshire Clinical Commissioning Groups, Lincolnshire Community Health Services NHS Trust and Lincolnshire Partnership NHS Trust were invited to the event.

This report provides you with a summary and the key findings from the day.

Through listening to the first hand powerful and inspiring patient stories and patient experiences of accessing health services, this provides us with clear actions to be taken going forward and is an opportunity to improve access to services for different patient groups and improve the quality and the patient experience.

## OUR VISION

Our vision is for equality, diversity and inclusion to be a 'golden thread' running through, and central to how we work together to provide sustainable high quality patient-centred care for all people living in Lincolnshire.



## ATTENDANCE

Attendance at the event included a range of service users and stakeholders. An explanation of the organisations who attended are described in **Appendix 3**.

## SOCIAL MEDIA

During, and after the event, social media accounts were utilised to promote the event and videos were taken of some of the key speakers. Posting live from the event and sharing Lincolnshire's Hidden Voices on social media enabled us to reach a much wider audience, to NHS staff, patients and the public. An explanation regarding social media posts is included at **Appendix 2**.

## FORMAT OF THE EVENT

The event was opened with a warm welcome by the event chair, Jennie Negus, Deputy Chief Nurse at United Lincolnshire Hospitals NHS Trust. Jennie provided an overview around the purpose of the event and highlighted that this was the second "Lincolnshire Hidden Voices" Equality and Diversity Inclusion engagement event, with the first engagement event having been positively welcomed and well evaluated. Jennie explained the importance of communication and listening to one another.

A copy of all of the presentations can be viewed via the following link:-

<https://lincolnshireeastccg.nhs.uk/about-us/key-documents/equality-diversity-1/lincolnshire-diversity-and-inclusion-listening-events/hearing-lincolnshire-s-hidden-voices-lincolnshire-diversity-and-inclusion-listening-event-10-january-2019>

## SETTING THE SCENE

In the opening presentation, Kamljit Obhi, Assurance Manager - Optum (Equality and Diversity lead for Lincolnshire East CCG and South Lincolnshire CCG) and Tim Couchman, Equality and Diversity Lead at United Lincolnshire Hospitals NHS Trust, set the scene by focusing on four key contextual factors that drive our work around equality, diversity and engagement:-

### Legal compliance

Information on the CCG and ULHT responsibilities under the Equality Act 2010 Public Sector Duty and the Health and Social Care Act 2012 was provided. They explained how jointly the two organisations exercise their functions to ensure that health services are provided in an integrated way. The work to reduce inequalities in access to services and in the outcomes achieved ensures that no one is disadvantaged through service provision, especially in line with how we:-

- Act as an employer.
- Develop, review and evaluate our policies.
- Design, deliver and review services.
- Undertake procurement and commissioning and
- How we provide equitable access to services.

## **NHS Constitution**

Driven by the legal compliance is our duty under the NHS constitution to respect the human rights of each and every individual regardless of background and circumstances, we design our services to improve, prevent, diagnose and treat both physical and mental health problems with equal regard, ensuring fair opportunities for all.

## **Organisational vision and aims**

Our organisation vision, works effectively in line with our aims:-

- Quality.
- Clinical Leadership.
- Patient Focus.
- Integration and Partnership.
- Fairness.
- Equality.
- Good value.

All of these are integral to our current functions, policies and practices and in the development of new initiatives and activities.

## **Successful first event – May 2018**

Tim and Kamlijit then went on to explain that on 16 May 2018, as part of Equality, Diversity and Human Rights Week 2018, United Lincolnshire Hospitals NHS Trust and Lincolnshire East CCG worked together to host the first Lincolnshire Diversity and Inclusion Listening event at Pilgrim Hospital to celebrate diversity and ensure meaningful engagement and raise awareness of the diversity of patient experience. An action plan has been developed in consideration of the key issues that were raised by the groups that attended and feedback shared to improve local services through '**You said we did (are doing)**':-

- County-wide BSL translation are now available ✓
- Introduced font size choices for letters ✓
- Deaf Awareness Training scheduled ✓
- Scope for Trans awareness training ✓
- Delivering ongoing Dementia training ✓
- Join up local / regional trans services ✓
- Be responsive to local population changes ✓

## SERVICE USER STORIES

As part of our wider work to promote equality, we were delighted to welcome patients, carers and staff from a range of groups and organisations to share their personal stories and experiences with staff so that we could listen, learn and plan effective and responsive NHS services for the future.

When telling personal stories, we asked our participants to consider the following questions:-

- What is your experience of accessing local NHS services?
- What does the NHS do well?
- What does the NHS not do well?
- What would an excellent service look like for you?
- If we could change just one thing from today, what would that be?

The next section of this report details a summary of each patient story shared during the event. It also highlights the key action points for consideration for improvement across the NHS as a whole.

**Please note that personal stories have been approved by individuals and consent was obtained to use patient's names. These have been anonymised when requested.**

### SESSION 1

#### HEADWAY LINCOLNSHIRE AND LINCOLNSHIRE NEUROLOGICAL ALLIANCE

#### ANN-MARIE SMITH – INFORMATION AND SIGNPOSTING SUPPORT WORKER, HEADWAY LINCOLNSHIRE

Ann-Marie Smith provided an overview around the work of Headway Lincolnshire and the important role that Headway Lincolnshire plays in supporting patients, as well as families. Headway Lincolnshire was formed in 1987 and it is a small registered charity which was formed by a group of carers. It provides support for families and patients with brain injuries ages 18 years plus.

Lincolnshire has one of the highest levels of brain injuries, including strokes, and between 2016/17, there were a total of 3,800 people in the Lincolnshire area that were admitted to hospital with a brain injury. This is due to Lincolnshire being a rural county with high levels of people retiring in the county and a growing aging population.

Brain injury is often classed as a hidden disability as people are not aware of how someone may be suffering on a day to day basis. Your brain controls everything about you and how you are as a person and it can be extremely challenging and socially isolating.

## WHAT DO HEADWAY LINCOLNSHIRE DO?

Headway Lincolnshire is able to provide the following support:-

- Home visits.
- Drop in clinics.
- Hospital visits.
- Telephone support and counselling service.
- Provide presentations.
- Social activities eg, Ten pin bowling.
- Social days, evening and activities.
- Brain injury education courses and training.
- Work with Lincolnshire Partnership NHS Trust and the Community Outreach service.
- Web-site management, support and promotion.
- Volunteers are the key to Headway.

We were able to listen to individual patient stories from Headway Lincolnshire:-

## PETER MANLEY – HEADWAY LINCOLNSHIRE

Peter worked in the Air Force field for over 30 years. Peter started experiencing headaches and went to see his General Practitioner who prescribed medication.

The headaches did not subside and one morning, Peter collapsed and through his wife's quick response, was taken to Accident and Emergency at Lincoln. Peter was transferred immediately to Nottingham.

After a 7 hour operation, Peter was informed that he had suffered an aneurysm which had burst on one side of his brain and that he also had an aneurysm on the other side.

After being discharged from Nottingham Hospital, Peter has been cared for by his wife at home. Peter has suffered memory problems and has received constant MRI's.

Peter was provided with the details of Headway Lincolnshire by Neurologists and attends monthly support meetings. It provides an opportunity to meet with other people who have experienced similar experiences and also people with different head injuries.



The help of Headway Lincolnshire has been invaluable.

### **MARLENE CAMPBELL – HEADWAY LINCOLNSHIRE**

Marlene shared her personal story about her daughter, Claire.

Claire worked as a Staff Nurse at Grimsby and survived a very serious car crash nearly 18 years ago. Claire's injuries were so serious that she wasn't expected to survive.

Since then, Marlene explained that it has been a constant battle to get the help that Claire needs from professional services. Headway Lincolnshire have been a constant help and advised Marlene and the family where to go and who to contact for support. 18 years later, Marlene feels that the family are still battling for help.

Last year in desperation, after Claire having her CPN withdrawn, Marlene contacted the local MP, Karen Lee. Since then, a new CPN has been assigned and things are beginning to improve.

### **MARY READ – HEADWAY LINCOLNSHIRE**

Mary explained that she became involved with Headway Lincolnshire in 1983 after her son suffered a traumatic brain injury 26 years ago.

Mary initially went to Headway Lincolnshire for advice but has since become involved with Headway Lincolnshire and the Lincolnshire Neurological Alliance for many years in order to help identify the gaps and campaign for better services and provide advice for those patients with all types of neurological conditions.

All types of neurological conditions need lifelong support for each person and without this, can lead to a failure to access care which can lead to poorer outcomes and puts pressure on other parts of the health and care system. Each person needs their own individual care plan.

Mary explained that accessing services in Lincolnshire can be difficult. This is due to a lack of services and gaps in the system. Mary explained in detail the gaps and recommendations of what excellent would look like and these have been captured as part of the wider recommendations from Session 1.



## LINCOLNSHIRE NEUROLOGICAL ALLIANCE

### KAREN MISSENDEN AND KARL SMITH, PARKINSON'S DISEASE

Karen and Karl provided their personal stories in relation to caring for people with Parkinson's Disease.

There are estimated to be approximately 1,650 people living with Parkinson's in Lincolnshire.

It was explained that the diagnosis from patients first consulting their GP to a formal diagnosis takes from between 6 months to 2 years. This period of uncertainty is very stressful and could be improved if there is better awareness and a quicker follow up from the hospital. Counselling should be offered, which is rarely the case at the moment. Karen explained that she is stage 4 Parkinson's. As she was diagnosed early after 3 months, she is able to undertake deep brain stimulation treatment and is now medication free.

There is presently a lack of specialist knowledge and practice within the Lincolnshire area. Resources are stretched and there is no community specialist in Lincolnshire as there are in other areas of the country. Regular appointment times are extended and patients see a general neurologist and not a specialist.

A specialist nurse is a preferred option. Elderly patients find it difficult to travel. Community based care would address many of these issues and help patients to stay independent for longer.

Parkinson's also requires precise dosage of medication in order to help food intake. Patient experience can be problematic as patients are not allowed to administer their own medication.

There is also evidence that recognising the multi-symptom nature of Parkinson's via a multi-team approach would be most beneficial for patients to help slow progression and keep patients living independently for longer.

## DAVID STUBLEY - ATAXIA

David provided his personal story regarding Ataxia. Ataxia affects your speech and also your balance and co-ordination and is a generative condition.

David explained that he was an electrician and is now unable to walk and has been unable to work for 25 years.

David attends Sheffield for his treatment every 6 months. David lives in Boston and explains that there is no service in Lincolnshire and that there needs to be a continuous service for patients. David feels that there needs to be a specialist centre with a specialist neurological nurse in Lincolnshire which would be able to help all neurological conditions. This would save costs and would help patients tremendously.

## RECOMMENDATIONS SESSION 1

- The present triage system is thought to be scary.
- There is no step down step up inpatient/outpatient facility for neuro or trauma patients in Lincolnshire and no step down rehabilitation services.
- There is little co-ordination when transferred back to the county.
- Ashby Ward is very good if you have complex needs.
- Care plans are missing.
- Integrated care pathways are missing.
- Multi-disciplinary therapists are in short supply.
- There is a lack of speech and language therapists and there are long waiting lists.
- There is a lack of neurologists and this leads to long waits.
- Assessments are undertaken but there is a shortage of therapists to carry out recommendations and therefore treatment is often rationed.
- Patients need continuing therapies to maintain recovery reached.

## WHAT WOULD BE AN EXCELLENT SERVICE?

- Better co-ordination from acute centres to inpatient care, community care or home with individual care plans and integrated pathways.
- Access to step up/step down rehabilitation for multi-disciplinary therapies, speech and language therapists and neuropsychology.
- Community services for continuing therapies. It is imperative that the recovery reached needs to be maintained.
- Neuro specialist nurses for help and guidance.
- Care and support when returning home for independent living.
- Shorter waiting times to see neurologists.
- Information services for help with advice for carers, benefits, return to work, education etc.
- Re-assessment and respite for those who need it.
- Community hubs, as suggested in the STP plans.
- It is important to raise awareness and dispel myths about brain injuries.
- Respite for carers is extremely important.
- A brain injury is a life long condition and requires life-long support.
- Accessing neurological conditions in Lincolnshire is not good and requires improvement in many areas.
- Employ specialist nurses both in the hospital and community setting.
- Start small and then introduce services year in year to improve the situation.
- Include neurology when commissioning services.
- Take on board the recommendations in the Health Needs Assessment Report for people living in Lincolnshire with Neurological conditions.

- It is important for health professionals to realise the impact on patients of not having their medication on time. A reminder buzzer was suggested and Jennie Negus agreed to feed back to Nursing Teams at United Lincolnshire Hospitals NHS Trust. This needs to be personalised and staff need to listen to patients so that it does not just fit in with the hospital timetable.

**SESSION 2  
CHILDREN AND YOUNGER PEOPLE – AUTISM  
ROB, JO, KR, ALEX, HAYLEY**

**ROB BARBER, COMMISSIONING OFFICER – ADULT CARE  
LINCOLNSHIRE COUNTY COUNCIL AND VICE CHAIR OF AUTISM PARTNERSHIP  
BOARD**

Rob explained that nationally there are just over 1% of people diagnosed with autism which equates to approximately 8,000 people in Lincolnshire. It is predicted that there are also many people who will not have been formally diagnosed. It is a life-long condition and is a hidden disability, a spectrum disorder and will be different for every single person.

Following the introduction of the Autism Act in 2009, in 2010, Lincolnshire developed its own Autism Partnership Board which comprises the local authority, health and social care, Education, mainstream public services, the voluntary sector, autistic people and their family members and carers. A re-launch occurred in 2015 in order to develop an all age Lincolnshire Autism Strategy.

Together, this helps to inform what is required to be undertaken, improve support, training and to ensure families get the appropriate care and support they need.

Rob introduced Jo Minchin, who works as an Autism Expert by Experience Worker hosted at South West Lincolnshire Clinical Commissioning and Jo explained about her role and her personal experiences and perspective of being autistic.

**JO MINCHIN – EXPERT BY EXPERIENCE - AUTISM**

Jo is autistic and two of her three children have also been diagnosed with autism.

Autism is a lifelong developmental condition, you are born with it.

Jo explained some of the key points in relation to living with autism:-

- You can have good and bad days, depending on the interplay of one's autism and the social barriers in your surroundings.
- Autism is a hidden disability. Just because you do not see it, it does not mean that people are not disabled. It is an invisible condition.
- You can experience sensory differences e.g., lighting. Jo explained that she wears green glasses which help her cope with harsh fluorescent lighting.
- The majority of people diagnosed with autism are men, but that is because we are not so good at diagnosing girls. There is a strong gender bias in the diagnostic process.
- Rates of depression and anxiety are much higher in autistic people than the general population. This is because the disability is not generally recognised or understood, and every day living is more of a struggle for them.
- There is a higher population LGBT people in the autistic population.
- There are no specialist counselling services in Lincolnshire. Jo explained that she attended counselling in Sheffield. We desperately need those services, or something like them in Lincolnshire.
- Recovery and group therapy models are the norm in Mental Health services. However, autistic people have a chronic condition which means needs are life-long, services have to accommodate for that. Autistic people can find working in groups difficult, so there needs to be one to one options available.
- There are higher incidents of homelessness, drug and alcohol abuse in autistic populations compared to the general population.
- Autistic people can have co-occurring conditions. Most people think that because you are autistic that everything relates to that, but individuals need treating for the condition (eg, depression) and not assume that it is a natural consequence of being autistic, or that nothing can be done about it. Autism must not be used as a criterion for exclusion from services.
- The National Autistic Society figures show that less than 20% of the known autistic population are in full time employment.
- Jo explained that her autistic daughter was unsuccessful in finishing her degree due not having the right support at university and has experienced severe mental health problems as a consequence.
- Most autistic people do not have a co-occurring Learning Disability. Autistic people fall through the gaps between services and it can be difficult to get any help at all, especially if you do not have a learning disability.

- As a professional, Jo sees a number of gaps in provision and it is evident when Jo undertakes care and treatment reviews for individuals, that services have failed them.
- If you have someone in hospital in distress, Jo feels that there should be someone trained to undertake sensory profiling so that their hospital stay can be made comfortable.
- Once someone is admitted to hospital, it can be difficult to ascertain if it is mental health, sensory or autism issues that have brought them there. It can take time to tease it out.
- There are no read codes/tick boxes on medical records, so patients need to alert health professionals about their autism in advance, which can sometimes be very difficult for the individual to do.
- There is a need for lower level support interventions such as mentoring, housing support, employment coaching, and so on, which would prevent people going in to crisis.
- Jo said that she is very aware of the level of self destruction that is allowed to occur before people take notice that autistic people need help.
- There is national work taking place and autism features as a clinical priority in the NHSE 10 year long term plan.
- Jo explained that she is really looking forward to building on the Autism Strategy over the next year to make services happen for autistic people in Lincolnshire.

**FAMILY MEMBER: HAYLEY  
PARENTS AND AUTISTIC CHILDREN TOGETHER (PAACT)**

Hayley explained that Parents and Autistic Children Together (PAACT) is a family support group which has been running for over 20 years and provides support to 150 families across Lincoln, Gainsborough and the surrounding areas.

After engaging with parents, PAACT would like to see the following improvements for autism services:-

- Improve waiting times for diagnosis. Long waiting times are not helpful for families and it also means that schools will not put in any extra support for a child until a formal diagnosis has been made.

- There needs to be more support after diagnosis.
- Once a child has been seen by a paediatrician and has been diagnosed, if a child is not medicated there is no further input and the child is often discharged.
- There are no follow up appointments with diagnosis and there needs to be better joined up working with services eg CAMHS, Occupational Therapists, Speech and Language services.
- On the diagnostic pathway, if you are using outside agencies to diagnose eg, SALT, once you receive a diagnosis, SALT does not continue to support children and younger people.

### **WHAT WOULD PARENTS LIKE TO SEE?**

- Families would like to see a single point of access for parents and carers before and after diagnosis.
- Having someone to talk to about their concerns other than support groups, like a counselling service.
- More volunteer groups, similar to Macmillan, who can provide support in home, support for coffee mornings so that all parents can meet up.
- Provide up-to-date training for all NHS and outreach staff so that staff are fully trained to work effectively and appropriately with people with autism.

### **ALEX ASPERGER'S SYNDROME**

Alex shared his personal story. Alex has Asperger's Syndrome (diagnosed at the age of 3), Type 1 diabetes (diagnosed at age 18) and epilepsy (diagnosed at age 25).

### **WHAT DOES THE NHS DO WELL?**

Alex feels that the hospital look after him well. They are very good at managing his diabetes condition and provide him with the appropriate equipment and medication. Staff are very good and friendly and provide him with good clinical care.



## WHAT WOULD ALEX LIKE TO SEE IMPROVED?

Alex feels that all staff should receive adequate training around all autistic spectrum disorders and that situations should be adjusted for each individual and that staff should always be open and provide clear instructions.

Alex would also like to see an improvement in services for transgender and LGBT.

## WHAT WOULD AN EXCELLENT SERVICE BE?

Alex feels that the automated text system could be improved and provide further information so that, as well as providing dates, it states clinic number, what samples are required etc.

## KR

KR shared her story regarding her son, AR. AR is 33 years old and lives at home. AR is autistic, has attention deficit hyperactivity disorder (ADHD), learning difficulties, challenging behaviour, suffers from social anxiety and has a blood pressure machine and needle phobia. KR and her husband are AR's prime carer.

KR explained that AR has complex needs and is looked after at home.

KR says that they do not see any one for care now and they telephone a social worker when they require support.

KR wished to share her personal story and raise awareness around the "All about Me" book and the importance on health professionals reading this prior to meeting with patients.

KR shared AR's personal story about the difficulties and anxiety experienced when attending a hospital appointment, which should have lasted 30 minutes, but due to not reading the book took all day and the effects that followed the following day. The book detailed information regarding AR and his condition and phobia's which would have made the experience better for the patient, family and members of staff. KR highlighted that the patient is not asking for special treatment but for people to be tolerant of the condition.

KR wished to highlight that the book is wonderful but only if it is read. KR feels that the system has to change to accommodate the patient in order that it is easier for everyone.

## RECOMMENDATIONS SESSION 2

- Improve the diagnostic pathway and timescales both in terms of children and adult diagnosis.
- Improve support that is available after diagnosis.
- There is a lot of reliance on the voluntary sector.
- There are no autism specific health services in Lincolnshire.
- Timeframes for diagnosis is too long.
- Learning disabled and autism are often linked together but they are not the same.
- There are a high percentage of people who are autistic and transgender/gay – there are a multiple of support needs, however there is a lack of specialist knowledge and experienced staff, including carers, to support families.
- There is no clear pathway from childhood to adult hood. Often people are lost in this transition as services are not linked up.
- Single diagnostic pathway questionnaire is often filled in by parents/carers, however it is not always read by the clinical staff due to lack of time/resources, so care/treatment is often not followed up.
- Too long a waiting time for patients – no on-going support when diagnosed (just given leaflet). Often patients are just discharged with no medication given.
- Up-to-date training for NHS is required.
- Varies with different people in terms of how well NHS staff deal with them.
- It is good that there is an automated text system for appointments, but information is vague. Clearer instructions on automated texts are needed.
- Autistic conditions vary. There is a need for one service to support a variety of autistic conditions and have trained specialists.

- Provide support to autistic people who are trans or are transitioning and/or gay.
- Specialist support/nurses for autism and other related conditions required in Lincolnshire.
- The transition from child to adult is extremely important to ensure that patients do not slip through the net.
- Jenny agreed to discuss within United Lincolnshire Hospitals NHS Trust about how important it is for patients to ensure that staff are reading the “All About Me” book prior to appointments.
- It was acknowledged that there is a lot of work taking place around services for autism, including engagement listening clinics, and multi-agency working is key to improving services.
- Penny Snowden agreed to contact PAACT to ensure that service users and patient views are feeding in to the wider children and younger people work that is being undertaken in Lincolnshire.

**SESSION 3**

**PAULA JELLY - REGIONAL LEAD FOR THE VETERANS SERVICE, LINCOLNSHIRE PARTNERSHIP NHS TRUST**

**LYNDSAY KHAN, SENIOR VETERAN LIAISON NURSE, LINCOLNSHIRE PARTNERSHIP NHS TRUST**

**KAREN SALTER, VETERAN LIAISON NURSE, LINCOLNSHIRE PARTNERSHIP NHS TRUST**

**RAF SERGEANT  
SP AND SP**

Paula and Lyndsay provided an introduction around the Veterans Mental Health Transition Intervention and Liaison Service (TILS).

It is anticipated that there are 2.5 million veterans identified in the country at the current time and following an engagement exercise undertaken by NHS England to look at armed forces commissioning and what services are available to veterans, the TILS service was commissioned by NHS England and has been running for 18 months.

One of the key themes when undertaking the engagement was that veterans felt that they needed better support from staff who had a real understanding of living or working in the armed forces community.

The entry criteria to receiving support from the service is if you have 1 days' paid service within the armed forces and you are experiencing a mental health difficulty, a diagnosis is not required.

There is a single point of enquiry where you dial in to one number and the referral goes directly in to the team who will undertake a specialist mental health assessment.

Paula indicated that whilst the service is still at its infancy, they have already seen an increase in referrals of 213%.



## RAF SERGEANT

RAF Sergeant shared his personal story about his experiences serving as a veteran and how the TILS service has played such an important role in his recovery and being able to help with his transition back to work as an Instructor at RAF Cranwell.

RAF Sergeant worked as a Sergeant and spent 15 years service working in combat search and rescue, which involved going in to active war zones.

RAF Sergeant served in Afghanistan and saw and dealt with some horrific experiences, which involved seeing his best friend killed in action. When RAF Sergeant returned home, he took on a ground role at RAF Waddington.

One day on his way home from work, RAF Sergeant was involved in a serious accident on his motorbike which left him with spinal and brain injuries, which caused memory and cognitive defects and chest injuries. For the last 4 years, RAF Sergeant has had to learn how to walk again, how to talk and eat, recognise his family again and dress himself.

Through this accident, it brought to the forefront his Post Traumatic Stress Disorder, depression and anxiety experienced through serving as a veteran and for the past 4 years RAF Sergeant has attended Headley Court, the military rehabilitation centre in London and has received psychiatry, psychology, rehabilitation, physiotherapy and cognitive therapy.

RAF Sergeant explained that he met with Karen from the TILS team and following the interview with Karen, was referred to a psychiatrist who was a specialist in the field.

RAF Sergeant explained that the TILS Service enables you to meet with ex military staff and people that understand the armed forces. RAF Sergeant also attends a focus group which means he can talk and share his experiences with other veterans.

RAF Sergeant has now returned back to work and said that it feels amazing to be back in his uniform which is all thanks to the help of the TILS service.

## SP

SP joined the Army at the age of 16 and spent time serving his country in Northern Ireland, Afghanistan and Bosnia. SP worked as a dog trainer and suffered an injury whilst out in Afghanistan which has left him with deafness in one ear and psychological issues. He now runs his own business and is a Mental Health First Aid Instructor.

SP attended an appointment with his PRO and through this, was given the number for the TILS Service.

The TILS Service and Focus Group have been an immense support to SP and he hopes that the service is able to continue running. He said that he has had to understand himself before he could understand and support others.

## SP

SP cares for her husband JP, her mum and daughter.

SP explained that JP suffers from Post Traumatic Stress Disorder, Crohn's Disease, Osteoarthritis and is in the early stages of Pancreatic Cancer.

The British Legion were able to put SP and JP in touch with the TILS Team who have provided significant support.

SP didn't know where to go for help with Post Traumatic Stress Disorder and Karen has been SP's "lifesaver" to provide her and other families with her support.

JP has now been transferred to a complex treatment service where he is getting help through mental health nurses and will continue his journey.

### SESSION 3 RECOMMENDATIONS

- The main issue concerning service men/women are that the majority of services eg, GP, clinics, hospitals do not understand their mental health issues and cannot respond appropriately as they do not always understand what it is like to live as a veteran.
- Veterans like to speak to others who have been through a similar situation.
- The NHS should look to extend the TILS type service.
- Most service men/women find it difficult to talk about their experiences.
- When veterans return, they are expected to get on with life as normal, however they experience a lot of pain and hurt. Images of what they have seen are still in their heads, which they find difficult to talk about so often sit on the problem and end up suffering in silence and from depression.
- Through the TILS service, GP's are more aware. The TILS service rings GP's at their practices, but there needs to be more awareness of the TILS Service.
- Transition is a key area in terms of service provision and transition in to NHS services is a key priority for the TILS Team.
- There is so much that we can all do that does not cost anything that can make a difference– be kind, phone someone, sharing and educating.

## DEAN EALES ACCESSABLE (FORMALLY DISABLED GO)

Dean provided an up-date in respect of AccessAble, formally Disabled Go.

Dean explained that through AccessAble you are able to:-

- Create detailed accessibility information to enable people with a disability to check locations, organisations and areas for accessibility.
- Factual information has been collected and published live, so that people can check facilities first, before they go anywhere.
- Organisations AccessAble have supported include:-
  - 110 Local Authorities.
  - 110 Educational establishments.
  - 75 private sector organisations.
  - 55 NHS services.
- Different assessment criteria is used to identify access needs of different organisations/sectors e.g. health prospective strands include:-
  - Patient experience
  - Better care
  - EDI
  - Lower risks
  - Improve Estates.

You are able to access this information on an app. You can search for AccessAble on the App Store on iPhone or Goggle Play on Android. It is free to download and use.

## RECOMMENDATIONS ACCESSABLE

- Lincolnshire East Clinical Commissioning Group to invite AccessAble to assess its own premises.





### **'I will support the NHS by...'**

- Continuing to work in the NHS to promote the issues autistic people face in Lincolnshire.
- Pledging to continue to fight for the help my daughter needs.
- Allowing the patient (and/or carer/family) to be central to their care and treatment.
- Continuing to treat people as individuals and not just another patient.
- Thinking of the small things – they all add up!
- Making my voice and experience heard. Sharing, supporting, and continuing as a peer supporter.
- Listening more to what people have to say.
- Continuing to raise the profile of veteran mental health issues and access to services.
- Taking small steps to move forward and make a difference.
- Listening to support groups and including them in decisions.
- Engaging in service improvement to achieve the vision of neurological rehabilitation.
- Helping to keep our staff healthy.
- Continuing to work with Lincoln University's Medical School to teach them about Parkinson's Disease.
- Reading the Joint Strategic Needs Assessment Topic in Neurology and supporting it.

### 'I wish the NHS would...'

- Mean it when they say they respect their staff.
- Have more awareness of veterans issues.
- Ensure Individual Patient-Centred Care.
- Share information more readily between services and adapt to individual's needs.
- Find the balance between the medical model and person-centred care.
- Listen and communicate.
- Take on board NHS England's statement that rehabilitation is everyone's business and start to improve in Lincolnshire.
- Have a dedicated hospital appointment co-ordinator to ensure that places are given and a person-centred approach is taken.
- Have an autism specialist team and one stop shop hub in Lincolnshire.
- Use microphones as a lot of people may be deaf or hard of hearing.
- Produce a mini version of the "All About Me" handbook for all people with disabilities (or even everyone).
- Treat people for their individual needs, not as a whole.
- Have better discharge links with Adult Social Care.
- Recognise the value of Occupational Therapists in supporting neurological rehabilitation.
- Improve neurology services and take this branch of medicine more seriously.

## EVENT FEEDBACK AND EVALUATION

Feedback from the event was extremely positive.

47 attendees attended the event.

Of these, 19 people completed a feedback form and a synopsis of feedback is below from the answers detailed on the form:-

- 94% (17/18) were either satisfied or very satisfied with the event organisation.
- 82% (14/17) were either satisfied or very satisfied with the time allocated to discussions.
- 100% (17/17) were either satisfied or very satisfied with the opportunities for participation.
- 100% (14/14) felt that their views were fully or partially valued.
- 94% (17/18) felt that the level of engagement fully or partially met their expectations.
- 72% (13/18) were very confident or confident that the outcomes from this engagement will help to shape future plans.
- 100% (17/17) felt that the range of stakeholders and organisations involved was fully or partially valuable.

Further detailed analysis, including comments, has been undertaken by the Engagement Manager and circulated to Equality and Diversity Leads.

## CONFERENCE CHAIR

Jennie Negus, Event Chair, thanked everyone for sharing their experiences and for contributing to an excellent second listening event.

## NEXT STEPS

The event presented an occasion for all involved to make a considerable contribution to that will shape the future of services in our area for many years to come.

Lincolnshire East Clinical Commissioning Group and United Lincolnshire Hospitals NHS Trust has produced a list of actions (**Appendix 4**) in consideration of the key feedback shared to improve local services.

## CONTACT INFORMATION

To contact the event team about any aspect of this report, or if you are interested in getting involved in this work further, please contact:-

- Tim Couchman, Equality, Diversity and Inclusion Lead, United Lincolnshire Hospitals NHS Trust. [Tim.Couchman@ulh.nhs.uk](mailto:Tim.Couchman@ulh.nhs.uk)  
Telephone: 01522 512512
- Kamljit Obhi, Assurance Manager, OPTUM Commissioning Support Services  
[kamljit.obhi@nhs.net](mailto:kamljit.obhi@nhs.net)  
Telephone: 01476 406368
- Nikki Pepper, Engagement Manager, Lincolnshire East Clinical Commissioning Group: [nikki.pepper@lincolnshireeastccg.nhs.uk](mailto:nikki.pepper@lincolnshireeastccg.nhs.uk)  
Telephone: 01522 515305

**APPENDIX 1**  
**AGENDA FOR THE DAY**

**LINCOLNSHIRE DIVERSITY AND INCLUSION LISTENING EVENT**

**Thursday, 10 January 2019**

**12.00 noon – 3.45 pm (registration and sandwiches will be available from 11.30 am)**  
**Lecture Theatre, Lincoln County Hospital, Lincoln, LN2 5QY**

**A G E N D A**

11.30 am – 12.00 noon Sandwiches and Refreshments.

12.00 noon – 12.15 pm	Welcome and Introductions.	<b>Jennie Negus, Deputy Chief Nurse, United Lincolnshire Hospitals NHS Trust</b>
12.15 pm – 12.30 pm	Setting the Scene.	<b>Tim Couchman, Equality and Diversity Lead, ULHT Kamljt Obhi, Assurance Manager, Optum</b>
12.30 pm – 1.15 pm	Session 1 – Lincolnshire Neurological Alliance and Headway.	<b>Mary Read - Headway, Ann Marie Smith – Headway, David Stubley, Lincolnshire Neurological Alliance. Additional Representatives from Lincolnshire Neurological Alliance and Headway to be confirmed</b>
	Discussion and Questions.	<b>All</b>
1.15 pm – 2.00 pm	Session 2 - Children and Young People - Autism Partnership	<b>Rob Barber, Commissioning Officer – Specialist Adult Services, Lincolnshire County Council, Jo</b>

**Minchin – Autism  
Expert by Experience,  
South West Lincolnshire  
CCG, Parents and  
Autistic Children Together  
(PAACT), Alex and  
and KR  
All**

Discussion and Questions.

2.00 pm – 2.15 pm	Refreshments.	
2.15 pm – 3.00 pm	Session 3 – Armed Forces Veterans.	<b>Paula Jelly - Regional Lead Veterans Service – Lincolnshire Partnership NHS Trust, Lindsay Khan - Veteran Liaison Nurse, Lincolnshire Partnership NHS Trust, Karen Salter – Veteran Liaison Nurse - Lincolnshire Partnership NHS Trust, Veterans and Carers All</b>
	Discussion and Questions.	
3.00 pm – 3.30 pm	AccessAble.	<b>Dean Eales, Senior Partnerships Manager, AccessAble All</b>
	Discussion and Questions.	
3.30 pm – 3.45 pm	Pledges and conference close.	<b>Jennie Negus, Deputy Chief Nurse, United Lincolnshire Hospitals NHS Trust</b>
3.45 pm	Close.	



## APPENDIX 2

### SOCIAL MEDIA

We received the following interest:- (as at 15 January 2019):-

### FACEBOOK

#### Lincolnshire East CCG Facebook page

<https://www.facebook.com/LincsEastCCG>

Total posts	5
Total reach	8,076 accounts
Total likes	72
Total shares	25
Total comments	13

Our most popular Facebook post was the video posted of Tim Couchman, setting the scene just before the event started.

The video has reached 2,350 people, received 939 video views, 17 likes, 2 comments and 8 shares to date. You can view the video and comments received here:-

<https://www.facebook.com/LincsEastCCG/posts/622243098196129>

### TWITTER

**Twitter Twitter:** @NHSLincsEast <https://twitter.com/NHSLincsEast>

Posting live from the event and sharing Lincolnshire's Hidden Voices on social media enabled us to reach a much wider audience to NHS staff, patients and the public.

Here's a snapshot of how our Twitter event hashtag #LincsVoices performed on the day leading up to the event and on the day. You can view all the #LincsVoices tweets and contributors here >>

<https://twitter.com/hashtag/lincsvoices?f=tweets&vertical=default&src=hash>

## SUMMARY

Estimated reach	56,736
Impressions	137,670
Tweets	100
Contributors	33

100 tweets were published using the event hashtag #LincsVoices resulting in 88 retweets with an estimated reach of 56,736 accounts and 137,670 impressions (the number of times a tweet has been seen) 33 contributors engaged with hashtag and helped us share Lincolnshire's Hidden Voices.

### Lincs East Twitter

<https://twitter.com/NHSLincsEast>

Tweets	18
Impressions	11,990
Engagements (including retweets,, replies, likes, profile click, hashtag clicks, media engagements)	407

Our most popular and engaging tweet was “Here's @TimJPCouchman Equality & Diversity Lead @ULHT\_News setting the scene for our #LincsVoices listening event. We're looking forward to meeting and hearing from a range of community groups affected by #Mentalhealth #Autism and Neurological conditions to share, listen & learn”

This tweet has received 12 retweets, 19 likes and 2,212 impressions. View the tweet here >> <https://twitter.com/NHSLincsEast/status/1083330139843371008>

### APPENDIX 3

#### LIST OF GROUPS THAT ATTENDED THE EVENT

- United Lincolnshire Hospitals NHS Trust.
- Lincolnshire East Clinical Commissioning Group.
- South West Lincolnshire Clinical Commissioning Group.
- Lincolnshire West Clinical Commissioning Group.
- Lincolnshire Community Health Services NHS Trust.
- Lincolnshire Partnership NHS Trust.
- Optum Commissioning Support Services
- Headway Lincolnshire.
- Lincolnshire Neurological Alliance.
- Ataxia.
- The Autism Partnership.
- PAACT (Parents and Autistic Children Together).
- Healthwatch Lincolnshire.
- Lincolnshire County Council.
- TILS Service, including Armed Forces Veterans
- Royal Air Force.
- AccessAble.

## APPENDIX 4

### ACTIONS FOR UNITED LINCOLNSHIRE HOSPITALS NHS TRUST AND LINCOLNSHIRE EAST CLINICAL COMMISSIONING GROUP

- United Lincolnshire Hospitals NHS Trust will be presenting this report to the Patient Experience Group in May 2019 with a request that United Lincolnshire Hospitals NHS Trust related issues are addressed.
- Lincolnshire East Clinical Commissioning Group will be taking this report to the Equality Forum in March 2019 in order to discuss the issues identified and decide on key work priorities.
- Both organisations will do our utmost to work with the relevant departments and ensure that patient feedback and experiences are shared and we will work on implementation of the work priorities.
- United Lincolnshire Hospitals NHS Trust and Lincolnshire East Clinical Commissioning Group will continue to communicate developments.
- The report will be circulated to all attendees, staff at the four Lincolnshire Clinical Commissioning Group's, United Lincolnshire Hospitals NHS Trust, Lincolnshire Partnership NHS Trust, Lincolnshire Community Health Services and Lincolnshire Sustainability and Transformation Partnership. Equality Leads from relevant organisations to ensure distribution to all department's highlighted within the report to ensure that awareness and actions are undertaken within departments.