

Healthwatch Lincolnshire

Statement regarding:	Access to neurology, autism, dyspraxia services and cervical screening results for patients in Lincolnshire
In response to:	Patient feedback Healthwatch Lincolnshire representative internal feedback
Date prepared:	15 th October 2018
Statement circulation for response	Lincolnshire East, South, South West and West Clinical Commissioning Groups

Why is Healthwatch Lincolnshire bringing this to your attention?

Healthwatch Lincolnshire has become increasingly concerned about the lack of access, both in and out of Lincolnshire, to adult Neurology, Autism Spectrum Disorder (ASD), Tourette’s Syndrome, Dyslexia, Dyspraxia and other neurodevelopmental disorders of childhood services, our concern has been recognised by the number of comments raised with us by patients and their carers.

In addition, we have more recently been aware of the delays in cervical screening test results for Lincolnshire women.

To add to our main concern, we believe if no pressure is put on our health and care services to address the growing list of services that our patients are experiencing, both in and out of county, this list will escalate further to the detriment of our resident’s health.

Examples of patient and carer feedback:

***Autism** - “Our GP has tried everywhere to refer the child but to no avail. Even tried out of county but they will not take ‘out of county’. How does a child get the diagnosis as it will help with the EHC plan and they cannot go forward with the EHC plan until the diagnosis has been given?”*

***Adult neurology** - “My partner has recently had a heart attack, is being treated for cancer and just received notification that they need to be urgently referred to neurologist as they most likely have a degenerative neurological condition. Only problem is we have been told by our doctor that we are not able to get an appointment anywhere to see a consultant neurologist, we are so concerned about any delays and I am concerned the stress of waiting caused their heart attack”*

***Cervical screening** - “I was told this morning the wait it now 20 weeks!!!”; “Already waited 13 weeks” “Our surgery have been as helpful as they can (but still no results)”*

What has Healthwatch Lincolnshire already done?

Escalation papers have been written and sent to relevant organisations for:

- **Autism Spectrum Disorder (ASD), Tourette's Syndrome, Dyslexia, Dyspraxia and other neurodevelopmental disorders of childhood service - September 2018** - We have received a response from the Federated Team which identified the work in progress for changes in services to be completed by 2020. However whilst we welcome this news we are concerned about what happens between now and 2020 for those families needing to access assessment and diagnosis. We have already shared this the CCG lay members and we understand there will be some further dialogue, we will also be raising this directly with Chair of Health Scrutiny and Health and Wellbeing Board.
- **Cervical screening test results - October 2018**
We have received a response from NHSE and the response did provide reassurance that patients were not being put at risk, but what it did highlight was 3 areas:
 1. At what point does a screening sample become unviable.
 2. Practices were not routinely sharing the messages around screening with patients.
 3. Patients are not aware of the purpose and risk factors built into the screening programme and this would helpful to share more widely, the response from NHSE provided we felt more context than any other public facing information we have seen.
- **Adult neurology - March 2017** - we feel that this has not really been addressed to the satisfaction of the patient population of Lincolnshire who have a neurological condition, family and carers. There does not appear to be any changes to patient experience or proposals related to e-consult or any other opportunities for bringing in 'some kind' of service into the county.

How does Healthwatch Lincolnshire feel this affects patients?

Healthwatch Lincolnshire is extremely concerned that patients in Lincolnshire are being treated unequally to patients from others areas of England, and most importantly where they are not able to access these services their health and wellbeing will significantly deteriorate.

Questions for CCGs

Healthwatch Lincolnshire on behalf of Lincolnshire residents are asking East, South, South West and West CCG to answer the following questions:

- Does the CCG have the same concerns about the above services as Healthwatch Lincolnshire, and if yes we are keen to know what you are doing to ensure patients do not continue to experience such delays?
- What assurance do we have that no one has been impacted adversely by delays in requiring further diagnostics, results and treatment?
- What messages are you giving GPs and other organisations (like Healthwatch) to help them support patients

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