

NHS Immunisation and Screening in Lincolnshire



**Report produced by
Healthwatch Lincolnshire
*Date: February 2017***

Acronyms

Commissioner:	Organisation that has the money to pay for health or care services.
CCG:	(Clinical Commissioning Group). There are 4 of these in Lincolnshire - one in the East, South, South West and West. CCGs include GPs who know a lot about the needs of patients in their area.
DNA:	Did Not Attend refers to a patient not attending a health appointment.
HWL:	Healthwatch Lincolnshire.
LCC:	Lincolnshire County Council.
AAA:	Abdominal Aortic Aneurysm.

Navigating Flags



Red flag - the recommendation or text in the report requires action or noting.

Amber flag - the recommendation or text in the report is important or provides some key facts.

Green flag - the recommendation or text in the report is best practice or provides some interesting content.

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Acknowledgements

In order to carry out a countywide project of this size, we recognised that HWL needed to engage with specialist organisations (for advice) and enlist the help of our fantastic team of volunteers to enable us to reach across the county to promote the survey linked to this project. We would like to thank the following for their support:

Lincolnshire Public Health

NHS England - Dr Tim Davies and the NHS Regional Immunisation and Screening Team

HWL Volunteer and Employee Teams

People and Organisations that helped to electronically circulate the survey

Most importantly, we would like to thank the 785 Lincolnshire people who completed either our electronic survey or paper questionnaire. Their responses formed the basis of our findings which have been included in this report.

Executive Summary

This report provides important evidence of the experiences of Lincolnshire people when receiving NHS immunisations and screenings.

The work involved included gathering information from 785 people across Lincolnshire during the period September to December 2016. Their experiences have enabled us to highlight that:

- 1 in 4 families who choose not to immunise their child(ren) are doing this because of concerns about safety.
- 42% of responding individuals told us they had not been invited to attend pneumococcal immunisation (who felt they met eligibility criteria).
- In Lincolnshire there are potentially 14,000 women choosing not to attend cervical screening (within the eligible criteria age range).
- Where a woman misses her cervical screening appointment, our data told us they were 3 times more likely not to reschedule the appointment.
- 23% of eligible adults told us they have not been offered bowel screening.
- 13.7% of 50+ aged women told us they are not being offered breast screening.
- A staggering 59% of male respondents told us they have not been offered AAA screening (who felt they were eligible within the criteria).
- 43% of respondents (potentially 146,000 eligible adults) told us they are not being offered NHS Health Checks.

There is now more emphasis on 'self-care' which in its simplest terms means what steps patients (the public) are taking to help look after themselves, whether this is maintaining a healthy weight, eating better or attending important health appointments, being offered timely appointments for screening and immunisation is vital if we are to become more involved in our own health.

This report highlights many of the concerns and barriers people face when accessing NHS immunisations and screenings. Some of these barriers are self-generated such as fear or simply forgetting to attend appointments, whilst others are organisational barriers such as administration errors or inflexible clinics.



Summary of observations, Suggestions and Recommendations

The following 10 points have been summarised as a result of the analysis we have drawn from this project.

Child

- 1. Safety Information.** It is clear there is an issue relating to some parents feeling that information available to them, especially concerning immunisation risks to children, does not provide them with sufficient evidence to make an informed decision whether or not to have their child immunised. This is evidenced by 33% of respondents in our survey specifically indicating this fact. It also appears there may be some inconsistencies across the county in the approach by GP Surgeries etc when contacting families.
- 2. Interaction with Medical Staff.** We noted where experiences were positive in preparing the parent and child in advance of receiving immunisations, where questions and discussion were able to occur, that this approach worked really well for all concerned. We would recommend all medical staff adopt such an approach where practical.
- 3. Increasing Number of Children Immunised.** HWL feels that more work should be carried out to better understand the reasons for lack of 'take up' in the households that choose not to have their child(ren) immunised. For instance, a lack of balanced information, scaremongering, knowledge about alternatives, confusion about gaining and accessing an appointment, were all reasons given for not giving immunisations to children.
- 4. Accessing Appointments for Working Parents.** Whilst we recognise that the majority of parents are able to arrange time off work to take their child to health appointments, it was noted that for some, getting time off work was an issue. HWL feel there should be greater emphasis with employers to reinforce parents' rights in relation to unpaid leave in these circumstances.
- 5. Ongoing Resources for Parents.** Parents indicated they would like more help with reminders of when their child(ren) should be immunised. Implementing personal immunisation record cards or linking all families to the electronic tool (see Page 14) would give families the necessary information at any time. This would also transfer some of the responsibility to the family to ensure immunisations are completed when required.
- 6. HWL Summary of Points 1 - 5.** HWL believe that Lincolnshire Children Services, the 4 Lincolnshire CCGs, Lincolnshire Public Health and Lincolnshire Health Protection must work together to establish what the current differing approaches are across the county in relation to child immunisation, particularly at point of access. Following this, consider the adoption of one approach along with clear methods and messages being produced, including the focus on ensuring parents assume some responsibility for ensuring immunisations are carried out over the required timeline, (eg given a childhood immunisation planner at birth). An approach such as this would look to providing a more equal and better understanding across the county.

Adults

7. **Invitation to Attend.** Due to the high number of respondents that indicated they had not been invited to receive adult immunisation, particularly for pneumococcal immunisation, **we would recommend NHS England and the 4 Lincolnshire CCGs investigate whether there are any problems at point of invitation.** HWL is supporting this recommendation by contacting survey respondents who indicated they had not been invited, to ask if they would give permission to be part of a pilot study to check their individual health record.

8. **Self-care.** If the NHS is serious about the need for more self-care, then patients will need to have the right information to encourage this to happen. **HWL considers a collaborative approach between NHS organisations and local community and patient groups would provide opportunities to develop the right messages, in formats that the public will be able to understand.**

- Once the self-care messages have been finalised successful campaigns to encourage more self-care will require:
 - A more proactive approach to patient engagement, avoidance to working in isolation of other public messages.
 - A more consistent approach to patients from all services, for instance mixed messages are confusing and lead to personal interpretations.
 - Ensuring information is clear, easy to understand, avoiding jargon and that meets the NHS Accessible Information Standards.
 - Employer cooperation and taking a view that health and care is as relevant to its business as it is to the individuals it employs.

9. **Failure to Attend.** Where patients are not attending appointments HWL believes much more should be done to understand what their barriers are. Attending vital health screenings should be something that everyone is able to easily do. Where patients are choosing not to attend, there needs to be a much better understanding of what concerns are driving this, whether it is transport issues, fear of what is going to happen during the screening or what results of tests mean. Learning what the main barriers are will enable those delivering the service to introduce ways in which to alleviate the problems.

10. **Failure to Receive an Appointment.** Most worryingly from our data, we are able to calculate that potentially 240,000 adults are not being invited to attend health screenings (this figure is focusing on breast, AAA and NHS Health Checks). As we know, early detection is vital for the patient. However, if patients are not even being given an opportunity to access screening in the first place, this then suggests there may be serious health inequalities occurring in our county. Even if we factor into the equation those people who choose to ignore invitation letters (maybe even throwing them away as junk mail), those who have moved house and failed to inform their health providers of this fact or it may be administration errors, this still indicates there may be a significant number of people involved.

About Healthwatch Lincolnshire

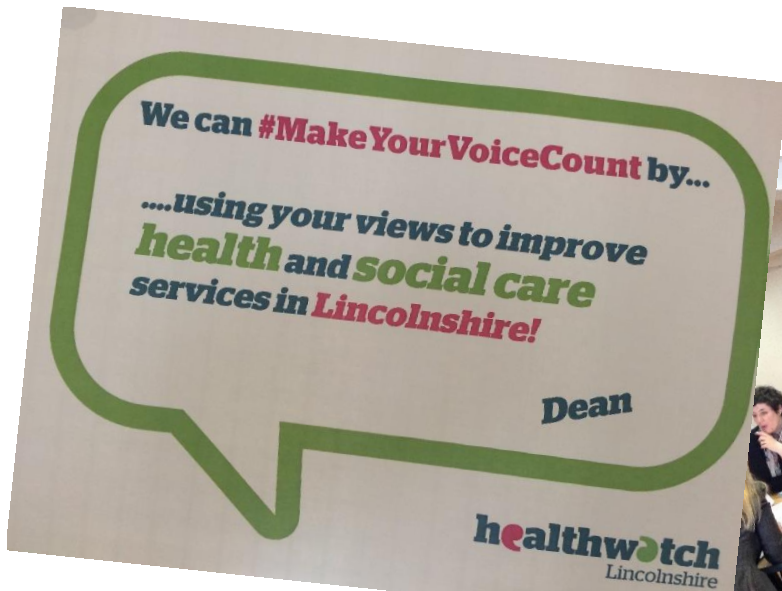
HWL came into effect on 1st April 2013 as the independent consumer champion for statutory health and social care services. HWL is a registered charity and Company Limited by Guarantee.

Healthwatch as a network is included in the Health and Social Care Act 2012. It was prior to this Act that it was nationally recognised there was a need for a public independent consumer champion for health and social care services to cover each of the 152 England county councils or boroughs, with one overarching body, Healthwatch England. The Health and Social Care Act 2012 provided each Healthwatch with the following statutory powers:

1. Promoting and supporting the involvement of local people in the commissioning, provision and scrutiny of local care services.
2. Enabling local people to monitor the standard of provision of local care services and whether and how local care services could and ought to be improved.
3. Obtaining the views of local people regarding their needs for, and experiences of, local care services and, importantly, to make these views known.
4. Making reports and recommendations about how local care services could or ought to be improved. These should be directed to commissioners and providers of care services and people responsible for managing or scrutinising local care services and shared with Healthwatch England.
5. Providing advice and information about access to local care services so choices can be made about local care services.
6. Formulating views on the standard of provision and whether and how the local care services could and ought to be improved; and sharing these views with Healthwatch England.
7. Making recommendations to Healthwatch England to advise the Care Quality Commission (CQC) to conduct special reviews or investigations (or, where the circumstances justify doing so, making such recommendations direct to the CQC); and to make recommendations to Healthwatch England to publish reports about particular issues.
8. Providing Healthwatch England with the intelligence and insight it needs to enable it to perform effectively.

- Healthwatch Lincolnshire activities can be broken down into 3 core functions:
 - **Influencing.** We are here to listen to people's views and personal experiences of their health and social care services and share the key messages we hear in order to help influence improvements in services.
 - **Signposting.** Signposting people to help them access advice, choice and information about their local health and social care services.
 - **Watchdog.** To ensure change is happening.

You can find out more about the work of Healthwatch Lincolnshire by visiting our website at www.healthwatchlincolnshire.co.uk or contact us where a member of our team will be happy to discuss further.



Background Information

For the past 3 years, HWL has been hearing from health providers and commissioners as to their concerns that a number of patients are not attending when invited to important NHS screenings. These screenings help to detect whether there might be a health problem that needs further investigation and includes areas such as breast, cervical and bowel screening. Also, at some of the meetings HWL attend eg Lincolnshire Health Protection Board, there is an indication that more patients need to keep their immunisations up to date. Doing this helps to avoid both them personally getting very ill and them potentially spreading infectious diseases to other people, eg measles and flu.

In addition to this, we are hearing more and more the phrase 'self-care', which in its simplest terms means what steps patients (the public) are taking to help look after themselves. Whether this self-care is maintaining a healthy weight, eating better or attending important health appointments, it's all about how we are looking after our own health.

To help our health colleagues in Lincolnshire better understand why people are not attending some of these important services, HWL decided to carry out a project that focused on gathering relevant patient experiences. The project was broken down into three main areas - 1 & 2: child and adult immunisations and 3: adult screening.

Child and Adult Immunisations

What is immunisation?

Immunisation is a way of protecting against serious diseases. Once we have been immunised our bodies are better able to fight those diseases if we come into contact with them.

How do vaccines work?

Vaccines contain a small part of the bacterium or virus that causes a disease, or tiny amounts of the chemicals that the bacterium produces. Vaccines work by causing the body's immune system to make antibodies (substances that fight off infection and disease).

Childhood immunisations.

Immunisation is a way of protecting ourselves from serious diseases. There are some diseases that can kill children or cause lasting damage to their health. Immunisations are given to prepare your child's immune system (its natural defence system) to fight off those diseases when your child comes into contact with them. If your child comes into contact with the infection, the antibodies will recognise it and be ready to protect him or her. As vaccines have been used so successfully in the UK, diseases such as diphtheria have almost disappeared from this country.

The above information was taken from www.immunisationscotland.org.uk and gov.uk websites.

NHS Screening

What is Adult NHS Screening Services?

Screening is a way of identifying apparently healthy people who may have an increased risk of a particular condition. The NHS offers a range of screening tests to different sections of the population. (NHS Choices, 2015)

Screening is different from diagnostic tests as it is used to identify potential increased risk of future illness within given populations. Sometimes, following screening, people can then be offered information, further tests and treatment to reduce their risk and/or any complications arising from the disease or condition.

“Screening is designed to reduce the risk or impact of disease in a defined population. Screening programmes aim to identify the individuals most at risk of a disease so that they can be offered early treatment. Screening programmes are based on careful calculation, including who will benefit, the scope for treatment and the level of accuracy of the tests.” (Sense about Science-Making Sense of Screening, 2015)

The NHS screening programmes currently offered in England are listed below (information taken from NHS Choices).

Screening in Pregnancy.

Expectant mothers will be offered some screening tests during pregnancy to try to find any health problems that could affect you or your baby, such as infectious diseases, Down's Syndrome, or physical abnormalities. HWL did not include this type of screening.

Screening for New-born Babies.

*Every baby is offered a thorough physical examination soon after birth to check their eyes, heart, hips and, in boys, the testicles (testes). In addition, tests for hearing and a blood test to check for serious illnesses is carried out. HWL did **not** include this type of screening.*

Diabetic Eye Screening.

From the age of 12, all people with diabetes are offered an annual diabetic eye test to check for early signs of diabetic retinopathy. Healthwatch did include this type of screening.

Cervical Screening.

Cervical screening is offered to women aged 25 to 64 to check the health of cells in the cervix. It is offered every 3 years for those aged 26 to 49, and every 5 years from the ages of 50 to 64. HWL did include this type of screening.

Breast Screening.

Breast screening is offered to women aged 50 to 70 to detect early signs of breast cancer. Women over 70 can self-refer. HWL did include this type of screening.

Bowel Cancer Screening.

There are 2 types of screening for bowel cancer. A home testing kit is offered to men and women aged 60 to 74. Bowel scope screening uses a thin, flexible tube with a tiny camera on the end to look at the large bowel. It is offered to men and women at the age of 55 in some parts of England. HWL did include this type of screening.

Abdominal Aortic Aneurysm (AAA) Screening.

AAA screening is offered to men in their 65th year to detect abdominal aortic aneurysms (a dangerous swelling in the aorta). Men over 65 can self-refer. HWL did include this type of screening.

Different types of screening have different benefits and risks. Some of these are listed below.

The benefits of having a screening test include:

- Screening can detect a problem early, before you have any symptoms.
- Finding out about a problem early can mean that treatment is more effective.
- Finding out you have a health problem or an increased risk of a health problem can help people make better informed decisions about their health.
- Screening can reduce the risk of developing a condition or its complications.
- Screening can save lives.



The risks and limitations of screening include:

- Screening tests are not 100% accurate. You could be told you have a problem when you don't - this is called a "false positive" and may lead to some people having unnecessary further tests or treatment as a result of screening. A screening test could also miss a problem - this is called a "false negative" and could lead to people ignoring symptoms in the future.
- Some screening tests can lead to difficult decisions. For example, if a pregnancy screening test tells you your baby has a higher risk of a particular condition, you may then be faced with a decision about having further diagnostic tests that involve a risk to your pregnancy. If the diagnostic test is positive, you may then need to decide whether to continue with your pregnancy.
- Finding out you may have a health problem can cause considerable anxiety.
- Even if you're screening test result is normal or negative (ie you are not at high risk), you could still go on to develop the condition.

Methodology

Our background investigation work focused on gathering the views of local people's experiences of accessing and receiving NHS Immunisation and Screening services.

HWL conducted an independent study over the period September 2016 to December 2016. Project planning work commenced in July 2016 with publication of this final report in February 2017.

Participation involved Lincolnshire residents completing a survey which was accessed via Survey Monkey (461 were completed online) and provided as a paper based version (324 were hand written). By HWL offering different methods of survey completion, this ensured people who are not confident with IT or don't have easy access to computers could be involved. The questionnaire was distributed via our website, Facebook, and Twitter, our own engagement and volunteer teams, as well as other relevant stakeholders and organisations including the 4 Lincolnshire CCGs, Lincs County Council and voluntary and community sector organisations.

The survey design work included liaison with Lincolnshire Public Health and NHS England - their expertise was extremely important in helping us include the right questions. The survey was split into the following 3 sections:

- **Section One.** Child NHS Immunisations - for families where they have a child/children that is under 6 years of age.
- **Section Two.** Adult NHS Screening Services.
- **Section Three.** Adult NHS Immunisations.

We agreed a target of 1,000 completed surveys was required, although our final total of completed surveys was in fact 785. Factors that attributed to us not quite making target was perhaps the length and detail of the questions and an individual's perception of relevance to this work. If you would like to receive a copy of the survey questions please contact HWL office on 01205 820892.

It should be noted that any personal comments included in this report are from members of the public who contributed and, therefore, will not always be the opinions of HWL. HWL acknowledge that some of the recommendations and requests from the public may not adhere to medical opinions and research. However, it is important to note that shared experiences provide essential learning opportunities for providers and commissioners of health and social care services.



This map shows where in Lincolnshire the people who responded to our survey live. Reassuringly it confirms that our project covered countywide experiences.

Results

Section One - Childhood Immunisation.

From the 785 respondents who completed the survey, 23% (179) of these related to the child immunisation section of the survey. The following information provides a breakdown of results of the significant questions asked:

Questions 2 and 3 - How up to date is your child(ren's) immunisations?

- 85% of respondents knew their child's immunisations were completely up to date, with a further 11% responding that they were 'somewhat up to date' and only 1.7% indicated they were not up to date; 1.7% were not sure (1.6% did not respond).
- Of those parents whose child(ren) had not received their immunisations:
 - 1 in 4 (25%) had concerns about safety;
 - 21% admitted to forgetting;
 - 12.5% had difficulty in getting an appointment.
 - 12.5% didn't feel their child(ren's) current health would cope.



Question 4 - is there enough information provided about child immunisations?

33% of respondents did not think (or were not sure if) there is enough information provided about child immunisations. Many comments we received relate to a lack of information available which provides a 'rounded view of vaccines'. There were also comments made about the scaremongering online which some parents felt influenced their decisions.



Carer (respondent) comments.

Is it safe for my child to be immunised? 25% of those responding felt it was not safe to allow their child(ren) to be immunised. When we extrapolate these figures we are then looking at a possible 5,300 children in Lincolnshire who have not been immunised. Below provides a few of the comments made with further respondent comments included at Appendix 2.

“Information not completely balanced - only reflects the benefits and short term side effects, rather than any longer term potential effects”.

“I think that it would be useful for reminders to book in for, then should be sent inclusive of the information relating to the diseases which are to be immunised against. How many injections to expect etc”.

“When I take my child for immunisation I don't know what it is for and they don't tell us what the immunisation or vaccinations for. Not enough information about the reasons or the risk effects”.

“There's a lot of scaremongering online, in popular chat forums”.

Question 6 - How easy was it to get an appointment?

- 81% of respondents found getting an appointment for their child to be immunised was easy. Where comments were made in the negative, they did relate to inflexible clinics (particularly difficult for working parents) and lack of help for patients with a disabled child (this does differ from surgery to surgery).
- 57% of families were able to get an appointment within a week (or less).

Carer (respondent) comments.

Below provides a few of the comments made. Further respondent feedback is included at Appendix 2.

“Appointments not at convenient times, inflexible clinics. Often have to ring back because only one clinic is available and if you can't do that day then there are no others available to book till that one is fully booked. It often feels it is very difficult to get your child immunised.”

“I would like my appointments with more advance notification please as it was beyond the milestone that the services wrote to me with the clinic appointment.”

“We have an excellent GP practice and they send letters reminding you. They had even sent a letter with registration documents to our house before I got out of hospital with new baby”.
Comment regarding patients at Beechfield Medical Centre, Spalding”.

“Work and childcare arrangements make it difficult for a clinic one day per week.”

Question 8 - Where do children go to receive immunisation?

We note from the responses that the vast majority of immunisation is completed within the GP setting.

Service Type	% of Responses*
GP	95.86
Health clinic	2.37
School	2.96
Other	2.96

*Please note, the total number of responses calculates 101.19% - this was due to the fact that recipients ticked more than one option.

Useful Information for Parents



The following link provides a very useful resource for families as it enables an electronic record of child immunisations to be stored by the family which includes due dates www.nhs.uk/Tools/Pages/NHsvaccinationplanner.aspx

Observations, Suggestions and Recommendations - Child Immunisation

- 1. Safety Information.** It is clear there is an issue relating to some parents feeling that information available to them, especially concerning immunisation risks to children, does not provide them with sufficient evidence to make an informed decision whether or not to have their child immunised. This is evidenced by 33% of respondents in our survey specifically indicating this fact. It also appears there may be some inconsistencies across the county in the approach by GP Surgery's etc. when contacting parents with children.
- 2. Interaction with Medical Staff.** We noted that where experiences were positive in pre-preparing the parent and child in advance of receiving immunisations, where questions and discussion were able to occur, this approach worked really well for all concerned. We would recommend all medical staff adopt such an approach where practical.
- 3. Increasing Number of Children Immunised.** Healthwatch feels that more work should be done to better understand the reasons for lack of 'take up' in the households that choose not to have their child(ren) immunised. For instance, lack of balanced information, scare mongering, knowledge about alternatives, confusion about gaining and accessing an appointment, were all reasons given for not giving immunisations to children.
- 4. Accessing Appointments for Working Parents.** Whilst we recognise that the majority of parents are able to arrange time off to take their child to health appointments, it was noted that for some getting time off work was an issue. HWL feel there should be greater emphasis within employer sector to reinforce parents' rights in relation to unpaid leave in these circumstances.
- 5. Ongoing Resources for Parents.** Parents indicated they would like more help with reminders as to when their child(ren) should be immunised. Implementing personal immunisation record cards or linking all families to the electronic tool above would give families the necessary information at any time, this would also transfer some of the responsibility to ensure immunisations are completed when required with the family.
- 6. HWL Summary of Points 1 - 5.** For Lincolnshire Children Services, 4 Lincolnshire CCGs, Lincolnshire Public Health and Lincolnshire Health Protection to work together to establish what the current differing approaches are across the county in relation to child immunisation, particularly at point of access. Following this, consider the adoption of one approach, along with clear methods and messages being produced, including the focus on ensuring parents assume some responsibility for ensuring immunisations are carried out over the required timeline (eg given a childhood immunisation planner at birth). An approach such as this would look to providing more equal and better understanding across the county.

Section Two - Adult Immunisation

Question 16 - Have you been invited to receive any of the listed immunisations?

From the Respondents that had been invited to attend immunisations:

- Flu - 10% fell within criteria but hadn't been invited, with 11% having been invited but then 'did not attend'.
- Pneumococcal - 42% fell within criteria but indicated they hadn't been invited.
- There are 167,671 adults in Lincolnshire over the age 65 years (*Office of National statistics, 2015*). Therefore, we can assume that if 42% (based on the number of respondents in our survey) of adults fall within the criteria are not being invited to pneumococcal immunisation this potentially equals 70,400 patients.



The high rate of this statistic is concerning and we feel does require further investigation to ascertain why so many people are not being invited to receive a pneumococcal injection.

- Shingles - 34% of respondents fell within the criteria but indicated they hadn't been invited (there is no requirement to be invited for shingles vaccine). There is also some confusion around understanding of the criteria, which is that a patient must be 70 at a specific date rather than on their birthday.

Flu - A number of comments were provided which relate to fear of the side effects of flu injections. Comments also suggest there is possibly a certain amount of apathy or misunderstanding by patients, all resulting in the patient refusing to have the flu injection.

Question 18 - How easy was it to make an appointment to receive your immunisation?

Reassuringly, the response rate to this question was over 90% positive that it was easy to arrange an appointment to receive immunisation. This contradicts the daily feedback HWL receives with regards to access to GP appointments but may reflect that such injections are most likely administered by the practice nurse and within a pre-arranged flu clinic setting.

Observations, Suggestions and Recommendations - Adult Immunisation

Invitation to attend. Due to the high number of respondents that indicated they had not been invited to receive adult immunisation, particularly for pneumococcal immunisation, we would recommend NHS England and the 4 Lincolnshire CCGs investigate whether there are any problems within the system at point of invitation.

Section Three - Adult Screening

Q11 - Have you been invited to attend cervical, breast, bowel, Abdominal Aortic Aneurism (AAA) or NHS Health Check?

- **Cervical screening is offered to women aged 25 - 64 every 3 to 5 years.** 7.7% (33) out of 431 women who responded to our survey have been invited to cervical screening but chose not to go 'DNA'. Lincolnshire has low rates of cervical screening take up which is in line with national data for cervical screening.
- According to the *Office of National Statistics (2015 data)* there are 188,000 eligible women for cervical screening between the ages of 25 - 64 years of age in Lincolnshire, our data suggests there could be as many as 14,476 women in Lincolnshire not attending cervical screening when invited.



We received a significant number of comments from respondent telling us that embarrassment and pain from previous cervical screenings resulting in them not attending again.

Respondent Comments

"In common with many women I had a very painful experience with cervical screening and consequently have not attended again since. Obviously this has put my health at risk, and that of many other women too. Unfortunately, publicity about the changes to the service and attitudes/patience of practitioners and changes to the equipment used have not been publicised. I had a screening done by a consultant recently and I just could not believe the difference in the experience!"

"Accessing cervical screening is very difficult at my surgery. You are informed in a timely manner that you are due to call to make an appointment. In my experience I call and they are full as they only book 6 weeks in advance, they give me a date to call back and when I do they are again full and tell me to call back in the future. This happened to me before making my screen one year late last time; currently going through the same situation."



Lincolnshire Health Screening and Immunisation services report Lincolnshire is not achieving its required targets for cervical screening. However, it is worth noting that the published data we used is relatively old being 2014/15. More recent data is indicating that the age group between **25-49 years of age is the cohort of population who are less likely to receive cervical screening**, with 50-64 years of age patients achieving targets.



Our data told us that where a respondent misses an appointment for cervical screening they were 3 times more likely than any other screening not to re-schedule the appointment.

Other reasons for not attending cervical screening appointments were, not being able to organise childcare, and not being able not get time off work.



Patients need to better understand the importance of all screening. Cervical cancer in particular is a cancer that is known as a silent killer due to the fact that symptoms do not always become obvious until the cancer has taken hold. *Every year in the UK, over 3,000 women will be diagnosed with cervical cancer. Cervical cancer is the most common cancer in women aged 35 and under.* <https://www.jostrust.org.uk/about-us>

Bowel screening is offered to adults aged 60 to 71 years of age every 2 years

- 10.1% of those invited to complete bowel screening chose not to complete the testing kit.
- 23% of respondents indicated they were within the criteria range but had not been offered the screening.



According to the *Office of National Statistics (2015 data)* there are 140,000 eligible people for bowel screening between the ages of 60 to 71 years of age in Lincolnshire, our data suggests there could be as many as 32,200 adults in Lincolnshire not being offered bowel screening.

Other issues why people chose not to complete bowel screening include comments such as “*I was worried about what the results might mean*” and “*I didn’t understand what the procedure was for*”.


SPOTTING BOWEL CANCER EARLY CAN MAKE A DIFFERENCE

 When bowel cancer is diagnosed at the earliest stage, more than **9 in 10 people** will survive the disease for 5 years or more...

 ...But fewer than **2 in 10 people** are diagnosed at the earliest stage.



When cancer's detected at an earlier stage, there's a better chance of surviving it.

 **Get to know your body.** Tell your GP about any unusual or persistent changes. **Register with a GP so you will receive bowel screening kits when eligible.** That's people aged 50-74 in Scotland and people aged 60-74 in the rest of the UK.

Breast screening is offered to women aged 47 to 73 years of age every 3 years.

- 13.7% of respondents told us that they had not been invited to this screening but indicated they fell within the criteria.



According to the *Office of National Statistics (2015 data)* there are 137,696 eligible females for breast screening between the ages of 47 - 73 years of age in Lincolnshire. Our data suggests there could be as many as 18,864 women in Lincolnshire not being offered breast screening.

Respondent Comment

"I live in Billingham. Ladies in the village and surrounding villages, have to travel to Sleaford for breast screening. For ladies requiring public transport, this 9 mile journey involves catching 2 buses there and 2 home!! Very limited public transport makes this journey almost impossible, especially for those who are less mobile. Secondly, the mobile mammography unit is based at Hockmeyer Motors - no woman should have to attend a garage for screening of any kind. For both these reasons, I am aware that Billingham ladies do not attend for breast screening. I am currently investigating the possibility of the mobile mammography unit coming to Billingham (possibly the village hall). Any info on the necessary requirements would be gratefully received. Many thanks"

Lincolnshire Health Screening and Immunisation services report that Lincolnshire is generally achieving their required targets for breast screening with the exception of Lincolnshire East and to a lesser degree, Lincolnshire West.

Abdominal Aortic Aneurysm (AAA) is offered to men in their 65th year.

- 59% of respondents told us they had not been offered this screening despite being within the criteria range.



According to the *Office of National Statistics (2015 data)* there are 4,900 eligible males 65 years of age in Lincolnshire. Our data suggests there could be as many as 2,891 men in Lincolnshire not being offered AAA screening each year. It is also worth noting that again, according to the *Office of National Statistics* there are 78,525 men in Lincolnshire over 65 years of age (any man 65 or over can self-refer for AAA screening) meaning a possible 46,340 men have not accessed AAA screening.

AAA screening detects any dangerous swelling (aneurysm) of the aorta - the main blood vessel that runs from the heart, down through the abdomen to the rest of the body. Early detection is important because once identified AAAs can be monitored or treated, greatly reducing the chances of the aneurysm causing serious problems in the future. (Public Health matters gov.uk).



Lincolnshire Health Screening and Immunisation services report Lincolnshire is not achieving its required targets for this screening. HWL believes much more should be done to address this problem due to the high levels of stroke and cardio-vascular incidents in Lincolnshire being higher than regional or national averages <http://www.research-lincs.org.uk/UI/Documents/cardiovascular-disease-in-lincolnshire.PDF>

NHS Health Checks are offered to all adults between 40 and 74 every 5 years

- 43% of respondents indicated that they had not been offered a check but felt they were entitled within the criteria.



According to the *Office of National Statistics (2015 data)* there are 340,000 eligible adults between the ages of 40 - 74 years of age in Lincolnshire. Our data suggests there could be as many as 146,200 people in Lincolnshire not being offered an NHS Health Check.

Respondents raised additional comments with regards to NHS Health checks including:

- being worried about the results and what they might mean.
- not feeling the check was relevant.
- not understanding what the screening was for.
- forgetting to make the appointment or rescheduling and
- not being able to have the time off work.

The NHS Health Check is offered to everyone aged 40-74 to prevent premature death from heart disease, stroke, kidney disease and diabetes. It does this by picking up warning signs that your risk of these health conditions are maybe higher than average. You can then be given lifestyle advice and possibly medical treatment to bring your risk down. Some warning signs of cardiovascular disease, such as high blood pressure and high cholesterol, are "silent", which means they have no symptoms. So you can feel well even though your risk is raised. With more emphasis being placed on the patient to keep as healthy and well as possible, NHS Health Checks will become a very important part of your self-care regime.

Question 12 - How easy was it to get a screening appointment?

Responses to this question indicated there was (generally) no difficulty for patients organising an appointment for screening once they had been invited.

Question 15 -Additional information shared?

We received a significant number of text comments with regards to all NHS screenings some key messages include:

- not being sent screening appointments.
- patients having to take the initiative.
- didn't know about health checks.

Respondent comment



A full list of respondent comments to NHS screening and immunisations can be read in Appendix 2.

Observations/Suggestion/Recommendations - NHS Adult Screenings

7. **Invitation to Attend.** Due to the high number of respondents that indicated they had not been invited to receive adult immunisation, particularly for pneumococcal immunisation, **we would recommend NHS England and the 4 Lincolnshire CCGs investigate whether there are any problems at point of invitation.** HWL is supporting this recommendation by contacting survey respondents who indicated they had not been invited to ask if they would give permission to be part of a pilot study to check their individual health record.

8. **Self-care.** If the NHS is serious about the need for more self-care, then patients will need to have the right information to encourage this to happen. **HWL considers a collaborative approach between NHS organisations and local community and patient groups would provide opportunities to develop the right messages, in formats that the public will be able to understand.**

Once the self-care messages have been finalised successful campaigns to encourage more self-care will require:

- A more proactive approach to patient engagement, avoidance to working in isolation of other public messages.

- A more consistent approach to patients from all services, for instance mixed messages are confusing and lead to personal interpretations.
- Avoidance of information shared being done in a way that is too formal, full of jargon and with an approach that meets the NHS Accessible Information Standards.
- Employer cooperation and taking a view that health and care is as relevant to its business as it is to the individuals it employs.

9. **Failure to Attend.** Where patients are not attending appointments HWL believes much more should be done to understand what the barriers are. Attending vital health screenings should be something that everyone is able to do easily. Where patients are choosing not to attend, there needs to be a much better understanding of what concerns are driving this, whether it is transport issues, fear of what is going to happen during the screening or what results of tests mean. Learning what the main barriers are will enable those delivering the service to introduce ways in which to alleviate the problems.

10. **Failure to receive an Appointment.** Most worryingly from our data, we are able to calculate that potentially 240,000 adults are not being invited to attend health screenings (this figure is focusing on breast, AAA and NHS Health Checks). As we know, early detection is vital for the patient, nonetheless, if patients are not even being given an opportunity to access screening in the first place then this suggests there may be serious health inequalities occurring in our county. Even if we factor into the equation those people who choose to ignore invitation letters (maybe even throwing them away as junk mail); have moved house and failed to inform their health providers of this fact; or it may be administration errors, this still indicates there may be a significant number of people involved.

March 2017 - update

This report was presented to the Lincolnshire health and Wellbeing Board on 7th March 2017.

Whilst the report and its contents were noted and generally well received there were concerns raised as to the viability of patient's comments in relation to whether they were eligible for NHS screenings. It was noted during the meeting that Healthwatch Lincolnshire is currently working with NHS England with regards liaising with a checking exercise which should help to determine whether there is a gap in NHS screening invitations for patient's in Lincolnshire.

In addition, two of the Clinical Commissioning Groups chairs who were present at the meeting, raised concerns with regards to NHS Health Checks. They highlighted that many patients who have long-term conditions will receive regular health related checks as part of the GP support to manage their conditions and therefore will not require NHS Health Checks under the current criteria. Healthwatch Lincolnshire suggested that informing patients of this fact may help to address any patient confusion as to whether they have received an NHS Health Check.

Conclusion and Next Steps

At this end of this project HWL was able to identify 10 areas of observation/suggestion and recommendations. From these 10 areas we would conclude they can be summarised into the following:

- **Information** - it appears there needs to be an increase in the amount of public (patient) information and messages that are clear and consistent. This will help to provide better understanding of the importance and risks to patients (both in non-attendance and with regards to safety).
- **Attitudes** - this includes the public treating medical appointments as very important (reducing DNA) and to help alleviate any personal barriers that are at times preventing people from attending eg fear. Also, where positive attitudes from medical staff have been experienced, this was raised as very important to how patients will commit to their future attitude towards attending. We believe such approaches should be replicated across the county.
- **System** - we were concerned with the number of people who indicated they had not been offered an appointment to attend screening - breast, AAA, NHS Health Checks and bowel in particular. From our data we have calculated this potentially could be 240,000 Lincolnshire residents who have not been invited to take part in screening. As a matter of urgency, we believe this needs investigating and have already been in contact with NHS England to support some test cases into this

This report will be shared with Lincolnshire Public Health, Lincolnshire County Council, 4 Lincolnshire Clinical Commissioning Groups; Lincolnshire Health Protection Board, NHS England and Healthwatch England for information and consideration.

Once the above organisations have had an opportunity to consider the contents of this report, we will be asking them to provide responses to our observations, suggestions and recommendations. In addition, we will be asking that they provide an update of any actions being implemented updated to HWL at their earliest opportunity.

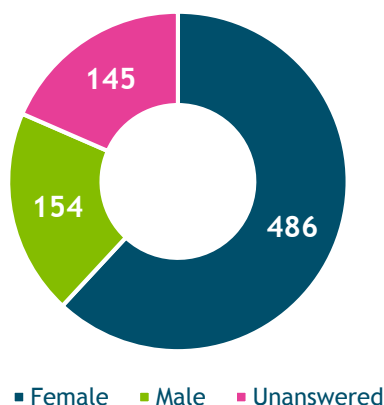
Lincolnshire Joint Strategic Needs Assessment and Immunisation

Lincolnshire Joint Strategic Needs Assessment (JSNA) is currently updating their datasets, this includes child and adult immunisation. We are pleased to have supported this work and have noted the contents of the refresh documents as part of our background research. More information about the JSNA can be found using this link <http://www.research-lincs.org.uk/Joint-Strategic-Needs-Assessment.aspx>

Please note, if you would like a copy of our project survey for Immunisation and Screening please contact our Swineshead office (details in back cover).

Demographics

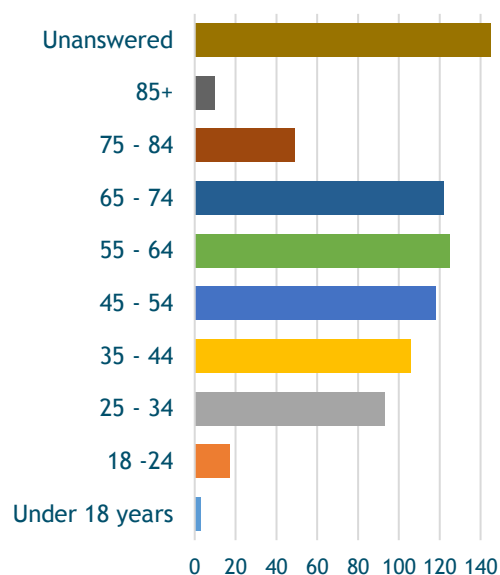
Gender



Gender	Percentage	Number
Female	61.9%	486
Male	19.6%	154
Unanswered	18.5%	145
Total		785

Age	Percentage	Number
Under 18 years	0.4%	3
18 - 24	2.2%	17
25 - 34	11.8%	93
35 - 44	13.5%	106
45 - 54	15.0%	118
55 - 64	15.9%	125
65 - 74	15.5%	122
75 - 84	6.2%	49
85+	1.3%	10
Unanswered	18.5%	145
Total		785

Age



The above tables provide information as to the demographics of the people who completed our immunisation and screening survey. We are pleased to record that we have received responses from all age ranges but note that the largest number of responses were from people aged 25 - 74. The number of men and women responding reflects normal trends in that more women than men tend to complete surveys.

Text Comments

HWL received a significant number of comments with regards to child and adult immunisations and adult screening, below gives examples of the comments from each category. If anyone is interested in receiving a full copy of all comments we received please contact our Swineshead office.

Child Immunisation

It is worth noting that we received many comments in the positive with regards to how wonderful nurses are with children - not all are listed below.

All Good. But I would like my son to have his TB and there is not much information about this. Also as he is now entering Secondary School, we have not been offered any other information or vaccinations for age group 11 - 18 years.
Appointments very good for children.
At the 3rd lot we got told she had not had 2nd lot (which she had) due to error on system as both 1st and 2 and had been in same month (was a long month) and it listed by month, so if we had not been on top of it she would have had extra 2nd lot. Thankfully the red book proved us correct. Also at GP surgery the automatic booking does not work for triple appointments, as baby did not get signed in for last one (even though screen confirmed it) so nearly missed his first lot of vaccinations - computer system needs to be sorted to fix this error as ended up waiting 1 hour and 30 mins with a 2 year old and new born, which was needless stressful for us all.
Good service. Dr's surgery automatically sends a letter when an immunisation is due.
I believe strongly in immunisation but feel that access is difficult. As a working parent the services are not readily accessible even though I make every effort to ensure that my child doesn't miss any.
I dislike the NHS culture of giving parents the impression that immunisations are compulsory. The language used is loaded and emotive. HCP are also dismissive of any parents who question the NHS literature and present with other evidence-based studies.
I had to wait for flu vaccine and all available appointments I could not go to due to work (I only work 3 days) for a couple of weeks. Luckily my mother took her although I would have much rather preferred to take her myself.
I have always been kept well informed and been given my appointments when necessary. I am happy with the service my GP provides.
I hope all these immunisations do not produce any long term effects in my children.

I think the immunisations is useful and also if at the beginning I was not sure about it, my previous GP in Kent told me very clear the reason of this important step in the life of a new little person, when I moved with my family in Stamford (Lincolnshire) my little girl has had the other immunisation last Year but after that I didn't have other information about other kind of vaccinations useful to know. My little girl is very delicate and often with cold and cough and she already had few Paediatrician appointment, she has some medication with Salamol inhaler and I think I need to know more about the possible vaccination for flu because every time she has a normal cold for her never end...because she is more delicate the other kids.

My son is severely autistic and refuses to attend Dr's appointments. He is not up to date on his jabs. He also refused the flu vaccine at school so that wasn't done either. There are no alternative methods offered to help parents in my situation which ultimately leaves him vulnerable to these illnesses.

Not enough information about what is on the immunisations and the possible side effects

Nurses have always been brilliant with my daughter, the surgery staff generally are really helpful, positive and friendly about all appointments for my child and immunisations have been no exception.

Please supply full ingredients and side effects I need to know what they are putting into my child regardless of how they will help the child. Parents should be fully informed.

Reminders that immunisation are due would be a good thing.

Since moving to Lincolnshire I have had no contact even though I have registered at GP surgery.

The nurse was awesome. I saw her in advance of the appointment and we chatted about the preparation of my son who was 3.5 at the time so unlike his previous immunisations, he would now be more aware of what was going on. Maybe a social story could be distributed to all parents prior to the 3 years immunisations as without me talking to her how to prepare him I was totally in the dark as to let him know what to expect or not.

The system should be more flexible according to patients as people who move into the country with kids find it difficult to understand the different vaccination schedule of the new country.

Doctors and hospitals may need to send out more information about appointments to avoid missing opportunities to be immunised.

I am concerned because so many immunisations are required over such a short period.

I didn't receive any information about the immunisations the kids have had to have, and nothing to address the concerns that people scaremonger about.

I don't feel we are given a balanced opinion therefore it's very difficult to make an informed choice.
I had to constantly remind the GP for my appointment for vaccination
I have no idea when the next ones are due, I rely on my doctors surgery telling me
I think that it would be useful for reminders to book in for them should be sent inclusive of the information relating to the diseases which are to be immunised against. How many injections to expect etc.
I think the information is heavily biased towards pushing parents to have them. I would like to see more balanced information readily available.
I would like a full list of ingredients and side effects before I take my child for them. With normal medication you get the leaflet with all information, you get nothing with injections, why? It's wrong.
Just didn't feel that well informed and was all a bit of a 'new baby blur'!
Leaflets could be sent out prior to immunisations so you could get the facts prior to the event.
We get letters for immunisation but don't know what is due at what age, I am assuming our GP could answer this when attending a routine appointment.

Adult Immunisation and Screening

I am responsible for my own health and so I eat well and walk plenty. If I want advice I will not be going to a fat nurse who smokes just to contribute to the surgery's cash box. I do not wish to take statins or worry about my cholesterol. No wonder all this costs so much. We should all be encouraged to be far more responsible and get on with our lives rather than using the NHS as a nannyng service.
As I have a family history of bowel cancer - I believe screening is relevant to me even though I'm not 60 years old - I haven't been given this option.
Because of heart problems and related medication I attend a review every year.
Bowel screening was by post from Nottingham University. I declined a health check for several reasons. I look after my own health. I am active and only slightly overweight. I eat a good diet. The person who would do the check was not medically qualified and would refer you to a medical person. Nettleham Surgery. That's what the letter said. They have a very overweight pharmacist, at least one overweight doctor, at least one overweight nurse, an overweight assistant manager. Why are they giving other people advice? When you go to visit in hospital some of the staff are obese. The phrase 'Physician heal thyself' comes to mind. I do not have chest problems so have never had a flu vaccination. I have also refused a shingles vaccination. The doctors' usual remedy is to hand out pills instead of referring you to a dietician. The scales and blood pressure machine are in a shabby corner behind a screen in the reception area. That is a good reflection of their perspective.

Breast screening is a concern for me but I am ineligible due to age.
Concerns I have not been called for an NHS screening and note I will soon be too old to go anyway.
Didn't know about NHS Health check! Simple as that! Needs to be advertised a lot more!
Difficult to arrange appointment as had moved from a different area. Made more tricky as needed check prior to three year interval.
Disappointing to have to apply for breast screening after 73 and bowel cancer screening after 69.
Early stage breast cancer detected and treated accordingly bowel Cancer Screening was one of the kits sent in the post I had an AAA screening as my mother has been diagnosed with this condition and it was suggested that this would be prudent.
Had abnormal cervical cells from the age of 20 years was treated and monitored regularly until having hysterectomy. I had a lump in breast and was given a mammogram at Pilgrim within 8 weeks.
Had bowel cancer at 45 so too early for screening.
Have always been on bowel cancer screening done the test 3 times now. But have never been invited to others. I do see my GP twice a year for a review of my heart medication and maybe this covers the other items.
I am a cardiac pacing patient and on changing GP practice my annual blood test for cardiac patients has been stopped. I received annual cardiac blood testing and monitoring for 7 years at my previous practice. I was also not offered a flu jab last year despite being offered one annually at my last practice for 7 years. Have the criteria for these two checks changed or have I simply been missed out? I have a pacemaker for sinus node disease.
I attended the NHS Health Check and it was noted I have high blood pressure. Blood tests were taken and medication prescribed in 2015. I have never been asked to attend a hyper tension clinic nor have I had a medication review although my prescription states I should have had one in January 2015.
I failed to make an appointment for NHS screening when invited, my reason was I knew my employer would not be happy with me asking for two appointments one week apart.
I had to make my own appointment for NHS Health check. Never received an invitation from GP.
I have attended some invitations to screening but not others. As a survivor of rape I find intimate examinations extremely difficult and there is absolutely no understanding or provision for this scenario. More needs to be done!

I have been invited for NHS Health check but have been too busy to respond - I will do though. It would be easier if the tests could be done on a Saturday.
I have had breast cancer so am being screened through that route. A scan at 47 might have found the cancer earlier and saved me a lot of treatment.
I have never been asked to attend an NHS health check. I am 51 years of age and female.
I have not attended for the most recent NHS Health Check as the delay in appointments discouraged me. My last Cervical screening was some years ago.
I like this proactive approach to health, much better than waiting until people are ill and then treating them too late.
I moved house and changed GPs around the time of my 40th birthday, so it is possible that an invitation to health check screening was missed, but it is now over five years so I should be due for another invitation - not received anything as yet.
My last Cervical Screening appointment, over 2 years ago, was a complete failure. I have always found the smear a painful experience (far more than 'uncomfortable' as is claimed) and I'm now overweight which I understand makes it harder but the nurse who saw me was clumsy and insensitive while she caused me a lot of pain. She rushed off to catch the transport while I got dressed and when she came back she cheerfully said she couldn't see my cervix so she may not have scraped the right cells and the test might have to be one again. The next day I had a message from the surgery to say I needed to book another test, not because there was anything abnormal or too few cells, my sample had not even been tested, the lab sent it straight back because it wasn't identified properly and she'd not completed the paperwork correctly! I was reluctant to go through the experience again but when I saw a female GP for something else I asked her about it and she was sympathetic and suggested I book a double appointment with herself and a particularly experienced nurse for a smear. I tried to get such an appointment but the receptionist was unhelpful wanting an explanation for why I wanted to see both and I had to discuss the matter quite loudly because of the glass screen between us, in the middle of the surgery which I found very embarrassing. I did not get an appointment because of staff holidays and pre-bookings meaning she couldn't find a slot in the next 6 weeks which is as far ahead as they book. I've tried twice since without luck and am now waiting for the female doctor to come back from maternity leave, when I shall try again but surely this should be an easier process?
Neither myself nor my husband have been sent and NHS Health Check.
Over 40's check identified renal failure - and I am a health professional! Did not notice any changes in my health.
Pleased to attend 40 - 74 health check every year.
PSA test discovered Prostate cancer early on.
Screening very good the older you get.

Distribution of this Report:

This report will be available to download from the Healthwatch Lincolnshire website, copies can also be available in other formats by request.

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Lincolnshire Public Health, 4 Lincolnshire CCGs, Lincolnshire County Council, Lincolnshire Health and Wellbeing Board, NHS England and Healthwatch England

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