

Gypsy & Traveller Engagement
Engagement dates: 10 and 25 November 2014

Patient feedback report
Final Report



Published February 2015

Executive summary

Gypsies and Travellers are known to have poorer health outcomes and have the lowest life expectancy of any seldom heard group. Following a Community Health Needs Assessment in Leeds in 2013 it was identified that poor access to, and uptake of health services, especially to primary care is a major factor in these health inequalities.

In order to understand why this community is struggling to access health services we visited the local authority Gypsy and Traveller site called Cottingley Springs. We spoke to residents and they told us that access to primary care services was of particular concern.

We developed a project group to look at how we could improve access to primary care for Gypsies and Travellers in Leeds. The group consists of NHS Leeds West CCG, Public Health and the third sector agency Leeds Gypsy and Traveller Exchange (GATE), a local Gypsy and Traveller community member's organisation.

The engagement seeks the views of residents, their thoughts and experiences of using primary care services. This report outlines the findings of the engagement.

We used patient surveys and events to understand the views of staff and residents. Surveys were used to understand the challenges facing staff in local GP surgeries. We held a series of events at Cottingley Springs to understand residents experience of using local primary care services.

We asked people what worked well and what could be improved. They told us that the majority of people wanted it to be easier to register with a GP practice and that they would also like to be able to choose a practice of their choice. Residents felt that appointments should be available outside of traditional working hours and that there should be enough time in appointments to discuss issues. Residents told us that they would like a more accessible prescription service.

This report makes a series of recommendations to the project team who will use the findings of the engagement to improve healthcare and health outcomes for the residents. These recommendations include providing clear information on which GP practices are available, making it easier for people from the Gypsy and Traveller community to register with a GP of their choice and to look at ways to; provide clear information on the appointment process, support local GP practices and pharmacies to work together to provide a convenient prescription service.

A regular briefing will be produced once the project has begun to show to what extent the engagement recommendations have been implemented.

The patient feedback will also be used to inform a wider strategy for enhancing communication, access and the quality of services.

The report will be shared with those involved in the engagement and the report will also be available on the NHS Leeds West CCG website.

1. Background information

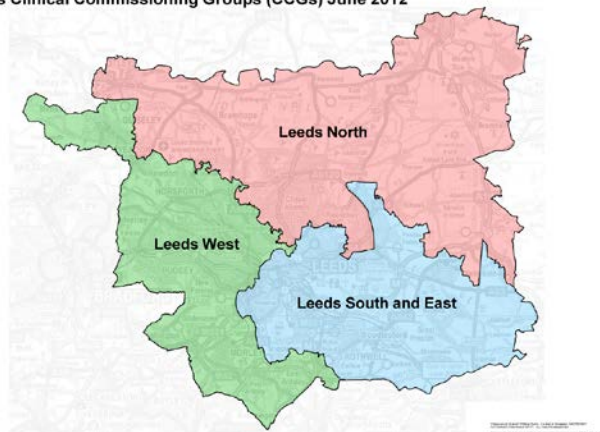
a. NHS Leeds West Clinical Commissioning Group

There are three clinical commissioning groups (CCGs) in Leeds; NHS Leeds West CCG, NHS Leeds North CCG and NHS Leeds South and East CCG. These organisations are responsible for planning and buying (commissioning) local healthcare services.

The CCG is very different from previous NHS organisations. For the first time, healthcare services will be commissioned by organisations that are led by locally based doctors and nurses, supported by experienced managers.

This means we can have a real, detailed understanding of the health and social care issues there are in our neighbourhoods, and a genuine opportunity to shape health services at a much more local level as well as across the city of Leeds.

Leeds Clinical Commissioning Groups (CCGs) June 2012



NHS Leeds CCG is made up of 38 GP practices in the west and parts of outer north west and south west Leeds. We are one of three CCGs in Leeds and are the largest, covering a population of around 350,000 people. Our population extends from some of the most affluent neighbourhoods of Leeds to some of the most deprived.

Involving people and the public in developing and evaluating health services is essential if we want to have excellent services that meet local people's needs. It is our responsibility, and one that we take very seriously, to ensure that our local communities have the opportunity to be fully engaged in the decisions we take.

b. Gypsy and Traveller Community

Gypsy and Travellers are known to have poorer health outcomes and have the lowest life expectancy of any seldom heard groups. Following a recent Community Health Needs Assessment in Leeds it has been identified that poor access to, and uptake of health services is a major factor in these health inequalities.

The needs assessment identified that people from the Gypsy and Traveller community felt they were often treated poorly by health professionals. The assessment also identified that there is a need to improve the cultural awareness of staff so that they can work more effectively with this community.

This engagement seeks to understand the experience of Gypsy and Travellers who use primary care services in Leeds. It will also look at the experience of GP staff who work with this community. Feedback from this engagement will help us support staff and improve access to primary care for the Gypsy and Traveller community of Leeds.

This report outlines the findings of the engagement.

2. How did we identify and engage with stakeholders?

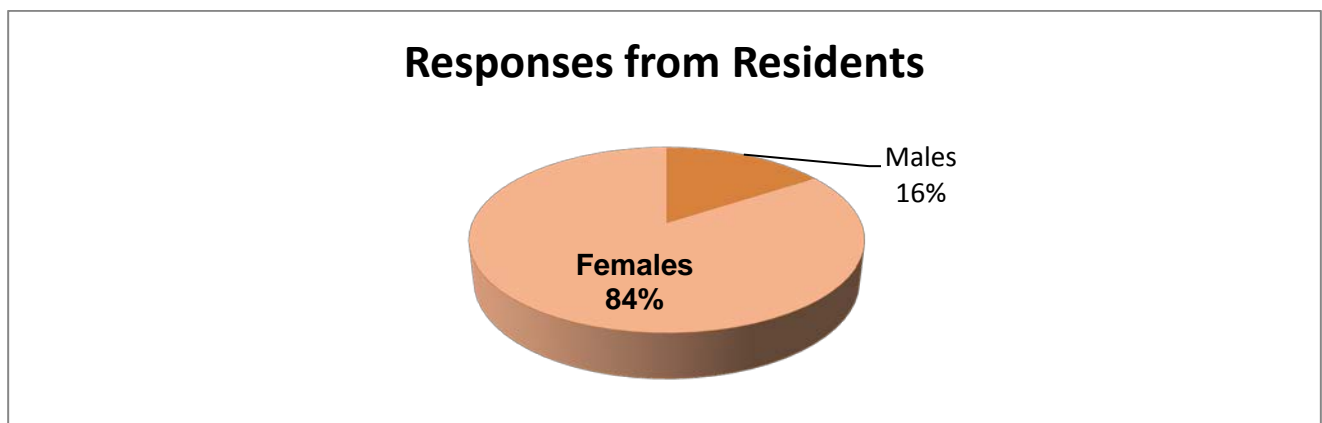
In order to access residents at Cottingley Springs we worked closely with Leeds GATE and Public Health. Leeds GATE have developed strong relationships with these communities over the last few years and were able to facilitate access to the site and the communities.

We worked with our colleagues at NHS Leeds South and East CCG to access staff in local GP practices.

Group	Who	How
Patients	People who live at Cottingley Springs	<ul style="list-style-type: none"> Held a fun event where residents could share their thoughts and experiences Focus groups
Providers	7 GP practices	<ul style="list-style-type: none"> Survey which was available online

3. Who replied?

In total 19 residents at Cottingley Springs contributed to the engagement. Feedback was received from the following groups;



4. What did people tell us?

Cottingley Springs Residents

What are the things you want from your GP?

- All the residents felt that GPs and staff did not listen to what they had to say
*A resident recalled visiting the GP and telling him of her allergy to a medication. It was only when she refused the medication that the GP recognised she had an allergy.
 'I have had a lump on my forehead for 3 years. I have shown it to different GPs several times and been told it was nothing to worry about. (one doctor has now sent me for tests)*
- All the residents felt that clinicians sometimes did not explain treatment in a way they could understand

- All residents felt that they were not given enough time in the appointment to discuss their issues
- All of the residents who attended wanted to be able to choose which doctor they saw so that they could build up a trustful relationship
- The majority of residents wanted it to be easier to register with a GP practice
 - 'We feel that once we tell the surgery our postcode, we are then told that the list is full (and we are unable to register)'*
 - 'A resident shared her experience, she had physically presented at a GP surgery and asked to be registered. She was told that the surgery was not taking new patients. Her friend (not a Traveller woman) rang from outside the surgery and was told that they were registering new patients'*
- The majority of residents wanted it to be easier to register with a GP practice of their choice. Some residents told us that they were told by practices that their postcode was outside the boundary for the practice. Some practices which are further away from Cottingley Springs are actually easier to get to or are preferable in other ways.
- The majority of residents said that they wanted a more accessible prescription service. Currently they have to attend the surgery to order the prescription in person, wait two days for the prescription to be prepared and then return to the surgery to pick up the prescription.
 - 'Ease of getting a prescription some surgeries deliver prescriptions by car to Cottingley Springs site-like that (Windsor House Surgery)'*
 - 'Middleton Surgery won't let patients order prescriptions over phone-need to go to surgery to order, would be easier if could order over phone and also don't deliver to site'*
 - 'Need to collect prescription (from GP) and take to a pharmacy'*
- The majority of residents did not want to be kept on hold when making an appointment. This is because it uses up credit on their mobile phone.
- The majority of residents wanted it to be easier to make on the day appointments. They told us that by the time they spoke to the receptionist all the appointment for that day had often been taken.
- Most of the residents felt that appointments should be available outside of traditional working hours
- Some of the residents gave examples of accessing health information on site from Healthy Living Network and Leeds GATE
- Some residents expressed a need for better follow up care
 - 'A resident told us that she had never received follow up appointments after surviving cancer'*

What are the things that stop residents visiting a GP?

- All of the residents feel that they are not always able to get an appointment quickly enough, sometimes having to wait up to a week (it is unclear from the data where this refers to an urgent or routine appointment)
- The majority of residents were limited to how many times they could call the surgery for an appointment by the credit balances on their mobile phone
- The majority of residents felt that they should be able to ring the surgery anytime to make an appointment and not be made to ring back the next morning which impacts on the working day
- All the residents said that the location of all the GP surgeries made it difficult to get to their appointments. This is due to cost, time and transport difficulties.
- Most of the residents registered at Middleton Park Surgery said that the cost of public

transport and the time it took to catch two buses stopped them making appointments.

The residents were asked if they were aware of advertising campaigns and national screening programmes relating to breast, bowel and cervical cancer?

- The residents told us that cancer research was respected on the site. One of their community members, who was a Youth Worker for Leeds GATE, passed away from cancer at 33 and that had a big impact on residents.
- The majority of residents told us that if they were to get cancer they would not survive
- Some of the residents said that they would be happy to attend screening if this was arranged either on or off site
- Some of the residents said that they were not aware of the bowel screening programme
- Some residents asked if they would receive a screening letter when they were not registered with a GP practice
- A female resident told us that she attended cervical screening but had not responded to breast screening letters.

Other residents told us that they had not attended breast screening because:

'fear of unknown'

'heard sometimes picking up and operating on breast cancer is not always the best'

'may have lived longer if not operated on'

'operation could have spread it'

The residents were asked to share why they might attend A&E?

- All the residents told us that they would take their children to A&E if they were very concerned about them and unable to obtain an appointment at the GP surgery
- Some of the residents they told us that they use A&E as it offers immediate access
 - 'severe asthma and couldn't get in at GPs'*
 - 'Severe illness unable to get in at GP'*
- Falls that resulted in fractures and broken bones
- If they were bitten by a dog.
- Some residents said that they would either ask their mum or go to the chemist for advice before attending A&E
- The registered residents told us that they would attend A&E if they were unable to access a primary care appointment and felt that they needed to be seen by a clinician

During the course of the day a number of lifestyle observations were made:

- The men were active, enjoying boxing, football, gym.
- Some people felt that their diet was not good and that their traditional cooking had been replaced by fast food and takeaways
- However, some of the residents gave examples of healthy diets and that they made traditional foods using fresh ingredients
- The residents didn't feel that obesity was a big issue generally
- There were a large number of residents who smoked and it was stated that this was mostly stress related
- Drinking. Less so for women
- Cannabis becoming a big issue, particularly for younger people
- Other recreational drugs like cocaine becoming more prevalent too
- 'Pass it on,' good way of connecting things because of close knit nature of community
- To link in with social navigation aspects GATE are trying to develop
- Risk taking behaviour a real concern

- Accidents – people driving without seatbelts / children getting run over / quad bike accidents

5. What did GP Staff tell us?

What are some of the most important health needs for the Gypsy and Traveller community?

- Access to practices
- Continuity of care
- Maternity Care
- Managing long term conditions i.e diabetes, cardiovascular
- Mental Health
- Vaccinations and Immunisations

What are the specific challenges to providing care to this Community?

- Allowing access
- Understanding the cultural beliefs of the communities
- Gaining respect from the community
- Missed appointments due to a number of factors; poor literacy, unsuitability of appointment times
- Lack of continuity of care
- Educating the community on how they can influence their health
- Offer support to encourage these health changes

Along with not being registered at a practice, what are the main reasons that the Gypsy and Traveller community do not attend/use your practice?

- Lack of knowledge about opening times
- Lack of knowledge about the appointment system and how it works
- Distance to surgeries from the Cottingley Springs site
- Lack of transport links
- Health services not promoted on the site
- Lack of information on services available in accessible formats
- Distrust of surgery approaches versus their own beliefs and remedies

If we offered training on the needs of the Gypsy and Traveller community, what topics would you want to cover and what additional support do you think you would need?

- Understanding the culture of the Gypsy and Traveller communities
- Specific health issues
- How public health is delivered successfully
- More funding
- Look at how the communication from secondary care can be tailored to meet the specific needs of the residents of Cottingley Springs

Any other comments?

‘As a children’s lead, I would consider working for the children, delivering health education via schools they attend’

‘It is crucial we understand the needs of the community, respecting their needs when delivering guidance’

'When we agreed to register residents from the Gypsy and Traveller community, it was with the assistance of GATE and the Healthbus which went on site on a weekly basis with a dedicated Health Visitor'

6. What are the key themes from the feedback?

A number of themes can be identified through the engagement process:

Cottingley Springs Residents

Residents want it to be easier to register with a local GP practice

Residents are often told that the list is full.

Residents want to be able to register with a practice of their choice

All of the people who attended told us that it is important that they can choose the location of their GP surgery.

The GP practices that Cottingley Springs residents are able to register with are difficult to get to

Generally people felt that the GP surgeries they are able to register with are were too far to travel and would impact on people accessing primary care.

The majority of residents want to be able to see the GP of their choice when they book an appointment

The majority of residents who attended the group felt that it was important to build up relationships with the clinicians they see

It's hard for residents to make a telephone appointment

Using mobile phones makes it difficult to make an appointment, especially in the morning when residents are kept on hold for long periods of time.

Waiting times to see a GP are too long

Some of the people felt it took too long to make an appointment to see a GP. Some of these people ended up in A&E (it is unclear whether these appointments were urgent or routine)

Better follow up care

Some residents wanted better follow up care for long term conditions.

A number of people felt that they were not always listened to

Some people felt that they were not listened to and there were concerns about the lack of clear communication

Hard to make an appointment outside traditional working hours

A lack of appointments in the evening and at weekends make it difficult for people who work during the day.

Information from clinicians about their health was not always clearly explained

Generally it was felt that inadequate information regarding their health made it difficult for patients to make decisions

The process for obtaining prescriptions is too difficult

The majority of people felt that the prescription process was very difficult to use and involved far too much travelling

Some of the residents attend A&E because they struggle to access primary care

As some of the residents struggle to access primary care appointments they then find that they must attend A&E

Many people were aware of campaigns and national screening programmes

Many of the people were aware of the campaigns but did not feel that they were relevant to them

GP Staff

Health needs

Generally GP staff tell us that it is difficult to provide continuity of care

Understanding the cultural beliefs of the community of Cottingley Springs

Some GP staff told us that they would like to receive training to achieve this

Education on health changes

Staff tell us that they would like to support the residents in making health changes

Access

Generally staff tell us that access to surgeries near to the Cottingley Springs site is a problem

Missed appointments

GP staff told us that some residents from Cottingley Springs miss appointments for primary care and secondary care due to communication problems

7. Recommendations

Following the engagement the project team are asked to consider ways to:

- Make it easier for people from the gypsy and Traveller community to register with a GP of their choice
- Provide clear information on which GP practices are available and clarity around the registration process
- Provide people from the Gypsy and Traveller communities with clear information on the appointment process, this may include how to make an appointment and how to see a preferred GP
- Increase the length of appointments to allow better communication between GPs and community members
- Look at ways to increase flexibility of practices with regard to family members or children attending with an individual to make them a more welcoming environment
- Provide appointments outside of traditional working hours
- Support local GP practices and pharmacies to work together to provide a convenient prescription service to residents.
- Issue prescriptions in a way suitable for those with low literacy such as using medication dispensers
- Ensure that residents are aware of all the services a pharmacy can offer
- Provide residents from the Gypsy and Traveller communities with the relevant information to allow them to make informed choices before attending A&E
- Give patients an opportunity to routinely feedback about their service experience

- Provide training for GP staff to enable them to understand the culture of the residents of Cottingley Springs
- Look at ways in which all of the above key messages can be shared with the residents of Cottingley Springs including the implementation of a Service Navigators model, whereby community members are trained and employed to navigate services and spread public health messages

Appendix A

Case Studies: Accessing health care as a Gypsy or Traveller in Leeds

Communities Manager, Leeds GATE

Case Study 1: Literacy and Technology

Many of the Gypsy and Irish Traveller members of GATE are 'not too good at reading or writing', what this means in reality is very varied. Some people are quite good but struggle with low confidence around spelling for example, others may not be able to write more than their name.

This confidence certainly transfers to the use of computers; many of the younger generations are 'hooked up' to social media on their phones, but in our experience a lower than average number of households have laptops or PC's with internet access.

Combine both of the above points and access to a GP surgery with touch screen check in can pose problems to a disproportionate number of members of the Gypsy and Traveller communities.

Example: A woman living on Cottingley Springs wanted to go to the family planning clinic. On arrival she was told to book in on the touch screen, she explained that she could not do this. The receptionist stood with her in a waiting room full of people, she explained that she was very embarrassed to have to answer many of the personal questions it asked in front of a room of both men and women. Especially the equality question about her sexuality; she explained that she did not, at first, understand the question and the receptionist laughed.

When she described this experience to me, together we rang the practice and asked if this situation could be avoided, we were told that this is the process everyone must go through to use the service. Unfortunately the woman in this example has not returned to the clinic even though GATE offered to attend with her. The initial experience of the service has put her off.

Case Study 2: Language and Communication

The use of language needs to be considered when working with communities that often don't have a lot of technical vocabulary or awareness of 'academic terms'. Leeds GATE knows that this does not reflect intelligence rather someone's access to formal education. In the same way that Gypsy and Traveller people may not understand some 'gorgier' words they also use a vocabulary (originating in Sanskrit and Ancient Gaelic respectively) that perhaps we would not understand. The best way to meet is in the middle, with easy language understood by everyone and making sure that information has been understood.

Example: A woman, 24, is having her second child, she had complications with her first child (prematurely born) so is familiar with medical processes around pregnancy. She is told after her first scan that there are problems with the baby and is advised to have a termination. She agrees to this.

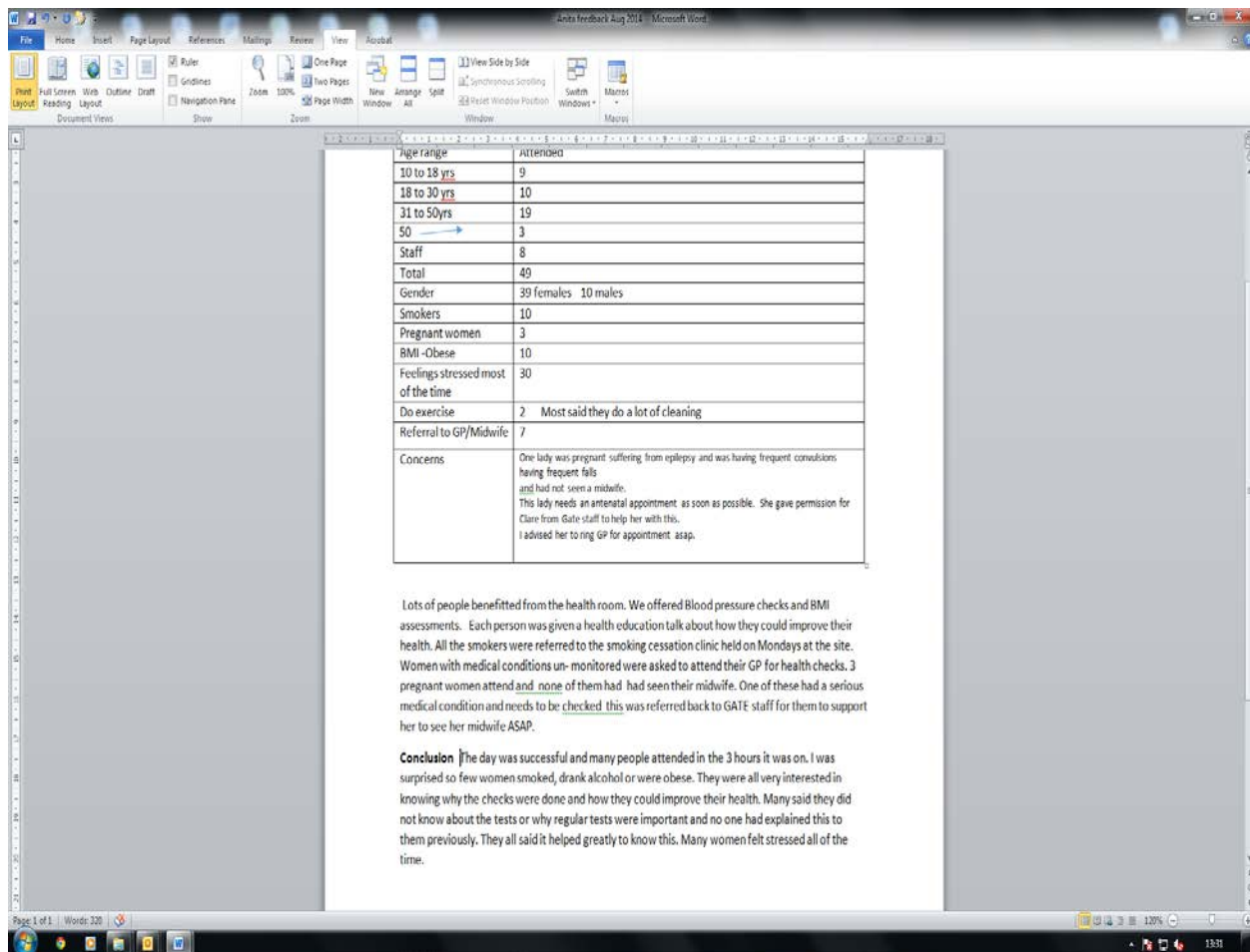
It is not until the point that she is about to be put to sleep that the nurse says to her 'you look happy for someone who is just about to have an abortion'. 'An abortion!' she says, 'I'm going to have an examination not an abortion'. She had confused the term termination with examination. Because the procedure had not been properly explained to her, she is in this distressing situation.

She told me this story many years later, although her second child was also born prematurely he is now a fit and healthy young man.

Appendix B

Appendix B - Report for GATE Fun Day 1st August Cottingley Springs

by Anita Jones RN/RM/Health Improvement Specialist



8. What will we do with the information?

The report will be shared with all the people involved in the project. The report will also be included in our next e-newsletter which is sent out to patients, carers, the public and voluntary, community and faith sector services. The report will also be available on the NHS Leeds West CCG website.

The project team will use the report to under pin the project going forward. A briefing will be produced once the project has begun, to show to what extend the recommendations have been implemented. This briefing will be shared with the people involved in the project.

The patient feedback will also be used be used to inform a wider strategy for enhancing communication, access and the quality of services.

Appendices

Appendix C – Glossary of terms

GLOSSARY

Commissioning	Commissioning is the planning and purchasing of services. The Clinical Commissioning Groups are responsible for commissioning most healthcare services.
Procurement	The acquisition of goods or services.
Provider	Providers are the organisations who deliver healthcare services. GP practices and hospitals are providers of healthcare services.

NHS
Leeds West
Clinical Commissioning Group

Alternative formats

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If you need this information in another language or format please contact us by telephone: **0113 84 35470** or by email: commsleedswestccg@nhs.net

'Jeśli w celu zrozumienia tych informacji potrzebuje Pan(i) pomocy w innym języku lub innej formie, prosimy o kontakt pod numerem tel.: **0113 84 35470** lub poprzez email na adres: commsleedswestccg@nhs.net

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Further information

If you would like any more information about this project or NHS Leeds West Clinical Commissioning Group, or have any questions or comments, please write to:

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