



*The NHS in Darlington,  
Durham and Tees*



# NHS Better Health Programme

## Maternity & Paediatric Services

### Voluntary and Community Group Conversations Feedback Report



ACE's Internet Café Mother and Toddler Group

April 2017



## NHS Better Health Programme

### Engagement with Voluntary and Community Sector Groups

#### 1. Background:

The NHS Better Health Programme (BHP) committed to having conversations with over 100 voluntary and community sector groups and organisations across County Durham, Darlington and Tees Valley.

NHS Better Health Programme particularly wanted to encourage smaller community-based groups and organisations to engage in conversations about the NHS Better Health Programme representing the following: .

- Groups whose members identified themselves as having 'protected characteristics,' as defined in current equalities legislation (sex, disability, race, age, religion & belief, sexual orientation, gender reassignment, pregnancy & maternity)
- Groups that may meet regularly but do not normally choose, or have the opportunity, to engage in discussions around this type of health issue.

VONNE as a regional infrastructure organisation representing and supporting the voluntary sector with significant reach over the BHP area acted as the lead body working with other CVS/ LDA (Local development agencies), Healthwatch and key special interest group organisations to support delivery of the 100 conversations across County Durham and Tees Valley between August and December 2016 as part of the BHP Engagement plan. This work enabled NHS Better Health Programme to build a full picture of the needs of all parts of the community, particularly groups that experience health and wellbeing inequalities and enable members of those groups and communities to influence the health services they use.

Following these conversations North East Commissioning Support Unit (NECS) commissioned VONNE to lead on co-ordinating delivery of a further 50 conversations with smaller voluntary groups around their views on maternity and paediatric services

## 2. The structure for voluntary and community sector engagement

. The delivery partners for the maternity and paediatric conversations were as follows:

	<b>Partner Organisation</b>	<b>Area delivered</b>	<b>Interest group</b>
1.	Redcar & Cleveland Voluntary Development Agency (RCVDA)	Redcar & Cleveland	Mixed
2.	Catalyst Stockton	Stockton & Hartlepool	Mixed
3.	Playgroup Network	Tees Valley	Parents of Young children
4.	East Durham Trust	East Durham	Mixed
5.	Healthwatch Darlington	Darlington	Mixed
6.	Middleborough Voluntary Development Agency (MVDA)	Middlesbrough	Mixed
7.	Durham Community Action (DCA)	Co. Durham	Mixed
8.	Darlington Association on Disability (DAD)	Darlington	Disabled children and young people

Each delivery partner identified smaller community and voluntary sector groups within the target communities and approached those groups about having a discussion with their members/participants. The final list of groups was agreed with VONNE and the NHS North of England Commissioning Support Communications and Engagement Team. (See full list at Appendix A).

Groups participating in a discussion were offered a 'supported' conversation facilitated by the local delivery partner organisation.

A facilitators engagement pack including information about the NHS Better Health Programme, advice on how to facilitate the discussion and information on how to feedback the responses from the discussion group was developed with input from VONNE and key representatives of delivery partners. Information was produced in other languages as requested. Standard feedback templates were agreed to ensure the format of feedback was standard across all partners.

The facilitated discussions with groups took place during March and April 2017 and each delivery partner organisation provided VONNE with numbers of the people who were involved in the discussion and the key feedback from the discussion on the feedback template provided by NECS.

46 group conversations had taken place by mid April 2017 with 421 participants providing their feedback.

Gender Specific (Women) **6%**    Disabled People **7%**    General Public **13%**    Parent Carers **7 %**    Parents **19%**  
Parents of Babies **8%**    Parents of Young Children **36%**    People of a particular ethnic/racial origin **11%**    Young People **9%**

*NB. Some groups came under two beneficiary categories therefore have been accounted for twice.*

VONNE has managed the collation of the conversation feedback notes via delivery partners and produced this feedback report summarising and analysing the feedback from the conversations so far. Appendix A sets out the full list and profile of groups engaged and Appendix B contains each individual feedback from for each group.

### **3. NHS Better Health Programme – Maternity & Paediatric Conversations Overview of questions**

a) The National Maternity Review (Cumberlege Report) recommendations were highlighted to the groups which recommends that every woman:

“...should develop a personalised care plan, with their midwife and other health professionals, which sets out her decision about her care reflecting her wider health needs”

“...should have a midwife, who is part of a small team of 4 to 6 midwives, based in the community who knows the women and family, and can provide continuity throughout the pregnancy, birth and postnatally”

“Community hubs should enable women and families to access care close to home, in the community from their midwife and from a range of other services, particularly for antenatal and postnatal care.”

b) Current and forthcoming issues for maternity, paediatrics and neonatal were highlighted:

Increasing specialisation leading to better care for:

- More mothers to be with risk factors
- More premature babies, born earlier needing care for longer
- Children with long term conditions
- Specialisation and staffing pressures means we need to change how we provide care

c) A video with clinicians setting out the current challenges in maternity & paediatrics was shown where facilities allowed

d) The different options for maternity care were explained as follows:

<b>Choice in maternity</b>	
<b>Home Birth</b>	Midwife led care Can hire birthing pool Limited pain relief available, e.g. gas and air Transferred by ambulance to consultant-led unit if your midwife has concerns about you or your baby.

<b>Standalone midwifery-led unit</b>	Midwife leads care Some have a birthing pool Limited pain relief available, e.g. gas and air No doctors available on site Transferred by ambulance to consultant-led unit if your midwife has concerns about you or your baby.
<b>Alongside midwifery-led unit</b>	Midwife leads care Some have a birthing pool Limited pain relief available, e.g. gas and air Situated next to or on the same hospital site as a consultant –led unit Transferred to consultant-led unit on site if your midwife has concerns about you or your baby.
<b>Consultant-led unit</b>	Midwife leads care with consultants also available Birthing pool available Full range of pain relief available, e.g. epidural Doctors and specialist consultant on-hand in the same building should complication occur, e.g. emergency caesarean, baby needs special care
<b>Community hub</b>	Ante and post-natal clinics Ultrasound tests Smoking cessation Voluntary sector support Quick referral to the right expert

e) Paediatric Services - The different types of paediatric care were explained as follows:

What children's health services have your family used?	
Outpatient clinics	Appointment or series of appointments with a doctor or nurse
Paediatric A&E	Children only area of an A&E department
Day assessment units	An assessment and observation ward for children with less severe episodes of illness

Inpatient ward	For children who are seriously unwell, sometimes as a result of a long term condition
Regional centres at Newcastle and Leeds ( No changes to Regional Centres are being considered as part of this process)	The most specialised care – this will not change

f) Questions put to the groups:

**Maternity**

1. What is important to you about the maternity care you and your family receives?
2. What influences your choice about where you would have your baby? e.g. (prompts) Midwife led care? Consultant presence? Pain relief? Safety? Distance to travel? Car parking? Facilities, e.g. birthing pool? Homely surroundings? Continuity of care (same team of midwives)? Other?
3. Which would you choose:
  - a. Home birth – midwife-led (low risk only)
  - b. Standalone midwife-led unit (low risk only)
  - c. Alongside midwife-led unit (low risk only)
  - d. Consultant led unit (low and high risk)
4. How we can make it better?

**Paediatrics**

1. What children's health services have your family used?
2. What is important to you about paediatric care?
3. How can we make it better?

#### 4. Executive Summary Feedback:

##### Maternity Conversations – Key Summary Issues

###### Question 1

**What is important to you about the maternity care you and your family receives?**

###### **Travel/Access:**

‘Ease of access to services throughout pregnancy’

Access particularly from rural areas for women in labour, especially those with higher risk and pregnant women attending appointments who do not have access to a car. Cost and availability of transport was an issue. Women needing to get back to attend to other children after appointments so not having to travel long distances

Access for family/carers visiting by public transport was also a key issue.

Sufficient ambulances available to transfer to hospitals.

‘Most important factors for maternity care were locality’.

Specialist/consultant/midwifery care all being centralised and available close to home

‘Pregnancy plans can change quickly from a low risk home birth to a high risk C-section, so proximity to a consultant led unit or accident & emergency department is crucial’

Neo Natal: Until the model is rolled out not sure about distance and cost especially if it is neo-natal unit where you want to visit daily. Juggling other commitments/children/work. Cost of parking.

## **Quality of Care**

Experienced, knowledgeable staff, professionalism and staff attitude were important to many in addition to having sufficient staffing at right level.

A significant number of participants felt continuity of care from midwives, doctors and health visitors and having the same midwife throughout labour was important.

'One to one relationship with designated midwife or midwifery teams.'

'Seeing the same person all the way through pregnancy, a person who knows me.'

Having a plan, well talked through with the midwife was also felt to be valuable.

Midwife led care within specialist centres was felt to be ideal by many in addition to having midwives in the community, going out to the pregnant women at home.

Specialist care availability / Specialist care there when needed 'Consultant presence brings re-assurance'

Regular check ups & scans through pregnancy. Having plenty of support while pregnant and after baby is born.

More support with breast feeding.

## **Hospital:**

The neo-natal care at North Tees is 'fantastic'

Hartlepool General is on 'its last legs.'

Excellent service at Sunderland (5 comments)

Reputation is very important and lots of mums have heard horror stories about James Cook

## **Equality & Diversity**

Understanding of cultural backgrounds: 'when told baby's gender midwife stereotyped me thinking I must want a boy as I am Muslim'.

Language barriers – access to interpreters- must be able to communicate.

Transport to maternity services is very important as the members of the group are visually impaired and did not have access to other transport options

### **Dignity & Choice**

A number of participants felt they wanted to be listened to and respected by medical professionals. Want to feel in control of birth of baby and birth plans being followed where possible. One woman said that she would never have another baby as she felt that none of her views were taken on board.

The attitude of staff was important, being treated with care and compassion and not being patronised by professionals. There was some particular negative experiences around staff attitude fed back by a teenage mother and a single parent.

Mental Health training for staff in maternity units and neonatal units. 'If someone is visibly upset following a loss, it is not good for them or for other worried parents, very worrying to observe'.

Privacy when in labour, not pressured to have trainee doctors present. Privacy when feeding baby.

Having your partner with you as much as you can throughout my stay

Understanding and sensitivity - Separate space for miscarriage scans as sitting alongside pregnant women for scan is insensitive.

Confidentiality was important – 'don't base ante-natal clinics in open access places like Sure Start centres especially if only just pregnant'

Options for home delivery & water birth to be readily available

## **Communication & Information**

Communication between professionals and parents or parents to be, felt to be of prime importance- explaining what tests were for, what was happening and what to expect.

Getting good advice as a new mum. 'More advice about how to look after a new baby, felt a bit lost going home on my own'.

Knowing where to go and who to contact in an emergency and being given correct information or signposting.

More information about the choices pregnant women have regarding their baby's birth.

Advice about diet, routines and feeding.

## **Question 2:**

**What influences your choice about where you would have your baby?**

**Key factors influencing choice:**

### **Midwife led care/consultant presence**

The level of care available was an important factor for many participants 'Level of care would be important to me not so bothered about the travel'

Proximity of specialist services was important for many.

A number of participants said access to consultant led care 'Having a consultant present should anything go wrong as I needed the support quickly when I went from low risk to high risk because of complications'

'Women who have had babies already seem to prefer midwife or consultant led care as they are fearful of being too far away from very pressured units'

A number of participants wanted midwife led care and to have the most natural birth possible

Staff with expertise in dealing with downs syndrome

### **Quality**

The quality of service - checked out reviews of service

### **Pain relief**

Some participants mentioned pain relief availability

### **Safety**

Safety was identified by a number of participants and was often associated with consultant presence

### **Distance to travel**

Distance to travel was an important consideration for some particularly as a number of participants did not have access to a car and ease of visiting for family members was a consideration.

'First time mothers are concerned about "long waits" and travelling time if there is an emergency during pregnancy/birth'.

### **Continuity of care (same team of midwives)**

A number of people wanted to have continuity of care particularly if possible the same midwife.

'Preferences for births - especially second pregnancies - is for home delivery. There is a recognition that this may not be possible for a number of reasons, but continuity of having the same midwife all through the pregnancy is on mother's wish lists'.

### **Professional or Family/friends Advice**

Recommendations from friends, family and other mothers

Many identified advice from healthcare professionals/ Midwife

### **Pre-existing conditions.**

Existing conditions, preeclampsia etc. dictate where is appropriate

Proximity of specialist support 'I have had a heart condition since birth, mine is a high-risk pregnancy'.

### **Family Needs**

A number of participants identified the needs of the family at home as being a priority for them in considering options

'Closer the better- other children to think about'

### **Other**

Own research, on line (mums net) & reading (multiple).

Own previous experience of maternity care for subsequent pregnancies

### **Question 3. What would make it better?**

#### **Key summary factors:**

##### **Access**

Need to consider the needs of rural areas and ease of accessibility

Need to increase the amount of support in the community if there are going to be reductions to services in some hospitals

Anti-natal services including scans to be in GP or community centres so that they are local.

Free parking for pregnant mums, especially in later pregnancy as hard to walk.

Cheaper or free parking especially if baby is in special care

Provide transport for classes for those who do not have any

Put in better transport provision that compliments visiting times

More car parking spaces

Better signage - road and hospital.

### **Midwives & Community Support**

A significant number of participants identified a need for more midwives & health visitors and consistent midwifery contact:

'Mothers benefit from contact with same individual midwife but often promises can't be kept due to staff shortages or workload'.

'All would like a first contact midwife service available 24/7 via the phone.'

'Increased numbers of health visitors - many of the group had not seen a Health Visitor after a few weeks. There provide a great support especially for those who do not have family support'.

'More staff - as they must be under pressure as well, one midwife was working a ten hour shift due to lack of capacity which will affect their demeanour'

'All would like the same midwife throughout pregnancy during delivery and after care – all feel this is very important to them. '

Promotion of home births as an option especially for 2nd or 3rd babies

Aftercare needs to be improved: 'Better after care for first time mothers as I never really felt I got very much support'

Have a consultant on call to attend Midwife led units as and when required - mums to be would be more confident to have babies in the unit.

More help with breast feeding especially for first time mothers: 'Breast feeding support – some were encouraged some were not, with little or no after care'

More education to allow for better self-care, better use of voluntary sector as support mechanism

Milk/nappies/sanitary protection etc. being provided in first 24 hours

### **Quality of Care**

High quality care, friendly approachable staff.

Consistency of care across all hospitals and GP surgeries - as group talked about their experiences it was clear that they had not all had the same level of care

Discharge was a bit quick, you made to feel as if you need to move out right away

There was a concern expressed that there should be sufficient numbers of beds on Consultant led units as delays in admittance will lead to birth complications.

### **Information & Communication**

Improved communication- better explanations of what is happening by medical professionals to pregnant woman and new parents was identified by a number of participants including better education/information especially for first time parents. 'There needs to be better communication about what is happening during labour'

Have a person based at GP surgery or community centre who could provide advice and support to new parents. Not everyone has family they can ask.

'Would like to be given more information about what to expect in pregnancy and once the baby is first born. For first time mums it can be a scary time and it is not always possible to speak to family, having the opportunity to attend groups and classes along with having discussions with the midwife helps'

Provide information and communications in different languages or if not even a diagram, for those who cannot read written English.

Improve communication between hospitals and midwives especially if the baby is born out of area.

### **Dignity & Choice**

A number of participants had not had a have birth plan in place and felt this was important.

Want to visit the maternity facilities in order to choose the right option for them

There is a need for a more flexible approach to engagement and interaction for those with additional barriers e.g. mental ill health, poor parental health, caring responsibilities etc.

Midwives need to listen and communicate better - parents didn't feel they were important; 'Listening to me and talking to me would have been good as opposed to talking to my mum' and they should be less judgemental - 'one mother felt she was stigmatised because she was in a women's refuge. She was not given any information on classes or support available'

Comments were made about not stigmatising mothers who do not want to breast feed or find it hard to do so. Help and support needs to be given regardless of what feeding method is used.

Somewhere for partner or family member to stay with you, even if it is after hours

Chairs for visitors (People should be comfortable, especially partners who are there for hours)

More birthing pools

### **Equality & Diversity**

These are examples from women from Bangladeshi communities -

DO NOT MAKE ASSUMPTIONS - e.g.:

- Assume women want to be fully covered (They might be extremely hot and this just makes them even more uncomfortable)
- Not letting partner in
- Assume you MUST see a female health professional, which sometimes means you wait longer for appointment.

The women would like to be ASKED and not have these assumptions made.

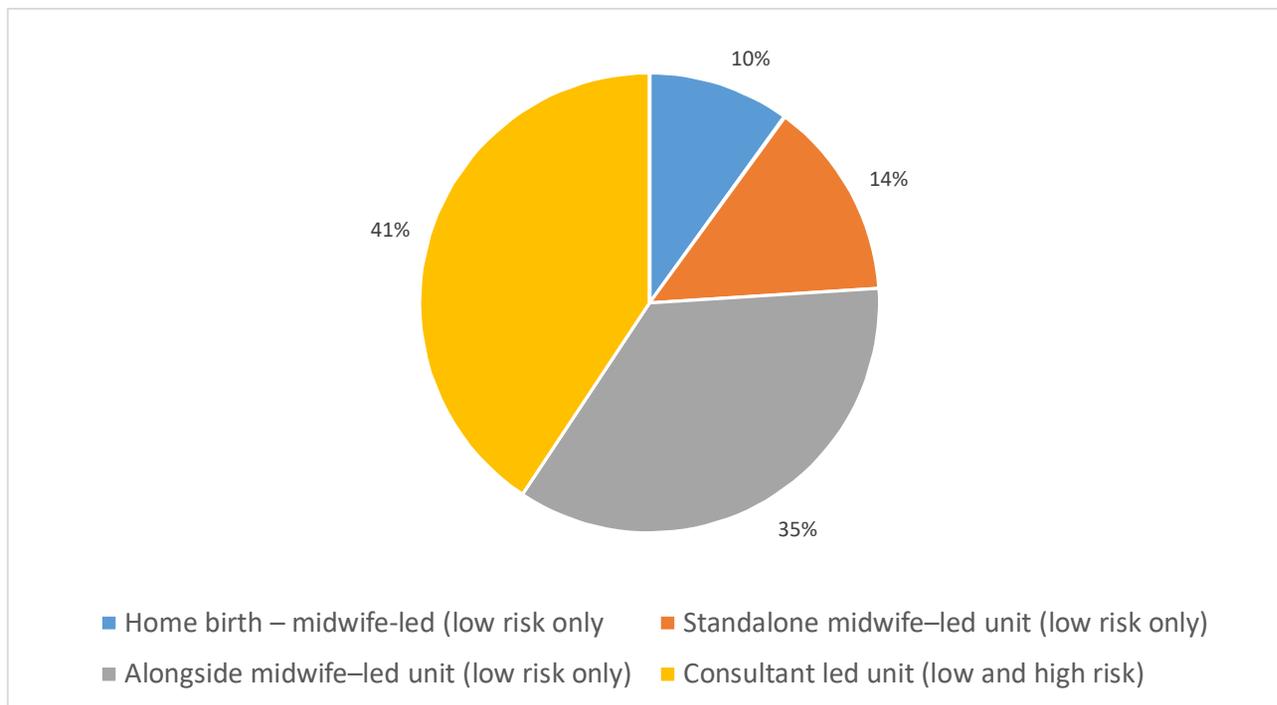
Ethnic communities only receive 1-2 visits, post birth/discharge - used to be more. Need more help with first baby - often Mothers do not have the family support they would have in their old country - pushed to do things for themselves, but may not even know what temperature the babies' bath should be.

'Babies born to women with little English speaking ability who may have been subject to domestic violence should not just be discharged with no support'.

'Refugees need to be thought about, they have come from war torn countries and don't know how to use household goods, let alone navigate the NHS service. They must be given lots of help when they need it, they are not used to getting medical help'.

'If you have to use a machine in reception to book in for appointments, it needs to be voice activated as well for those who have a visual impairment.'

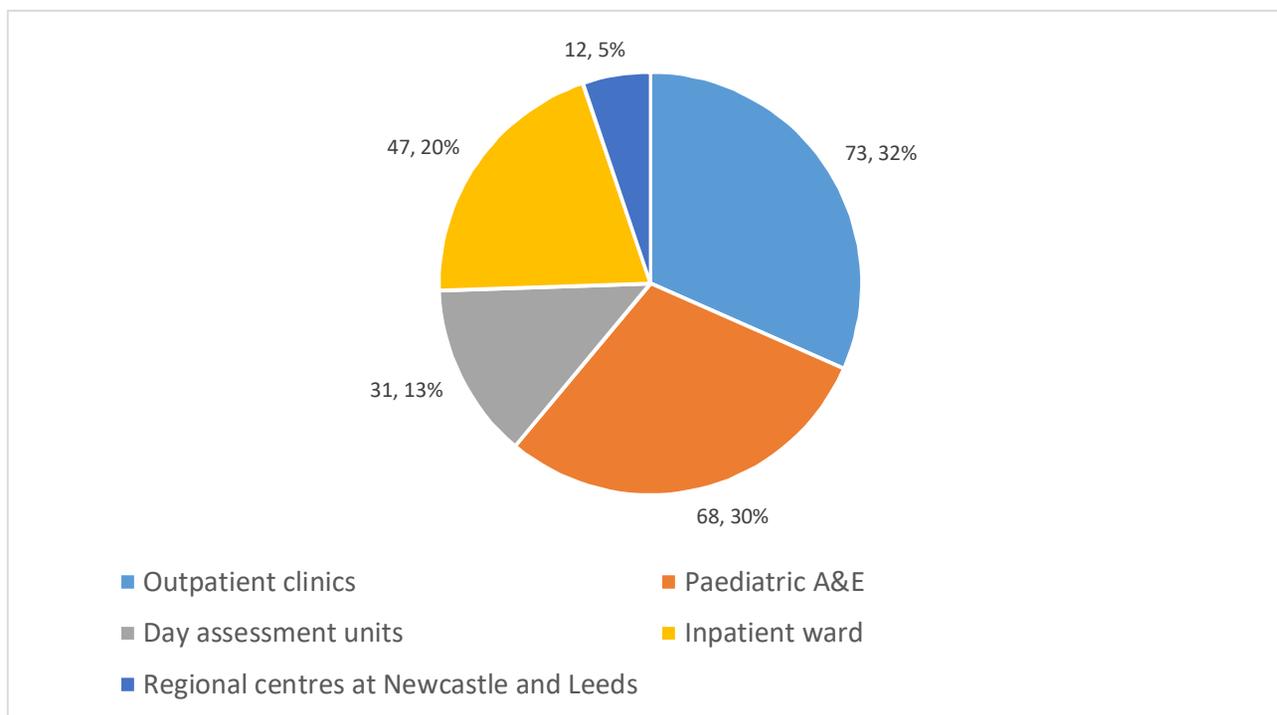
**Question 4: Which would you choose?**



## **Paediatrics: Key Summary issues**

### **1. What children's health services have your family used?**

N.B Not all participants responded to this question as not all had used paediatric services



## 2. What is important to you about paediatric care?

### Quality Care

The quality of care in terms of experienced paediatric nurses and doctors/consultants was important but staff being helpful, reassuring, supportive and caring in their approach to the child was of significant importance to the majority of participants and 'staff who appear to really care about the child'.

The quality of care was important but also continuity of care.

Parents and children being kept informed was also a key priority for many.

Making children feel safe and taking the child's feelings into account was also important to many.

**Environment** was felt to be very important and the need for comfortable homely surroundings, somewhere for parents to stay when children are kept in hospital for prolonged periods.

Clean & tidy surroundings, friendly welcoming, non-judgemental staff.

'Ability to stay with your child - not just a chair - Shower, food/drink etc.'

Play facilities, toys and games, internet access – age appropriate activities. Access to kitchen facilities, refreshments etc.

Access to separate A & E area for children was also highlighted by a number of groups

### **Communication**

Being kept informed was felt to be of key importance to many and explaining things in plain English. Understanding the need for reassurance and regular feedback. There was also feedback about the need to recognise the needs of people whose first language was not English.

### **Responsiveness**

Speed of response to children was felt to be important as children can deteriorate quickly.

Reductions in waiting times and time waiting between testing and results was felt to be important

**Location** was important particularly as speed of response was felt to be important and access from rural areas was a concern.

Some feedback was about closeness to home because of demands of rest of family/ other children in school etc.

### **a. What would make it Better?**

#### **Location**

Better access from rural areas and support for transport cost for families on low income and/or without access to a car.  
'Specialist centres good if they improve results but need to be balanced with need to keep services as local as possible'.  
Local Hubs /clinics felt to be a good idea by many and more health delivery from Sure Start/Children's centres was suggested.

#### **Environment**

Access to separate A & E area for children was also highlighted by a number of groups  
Access to a separate quiet room for children with particular needs i.e. children on Autistic spectrum.

Better facilities for parents/carers to be able to stay with their child overnight. Access to shower, refreshments and bed.

Clean, tidy & homely environments (non clinical) with friendly welcoming staff.

Play facilities, toys and games, internet access – age appropriate activities.

Need more privacy (comment from a 16yr old)

#### **Appointments**

Reductions in waiting times for speech and therapy - referrals are very slow  
Not having to wait long for appointments as this causes anxiety  
Reminders about appointments - especially when they are booked 6 months in advance  
If appointments need to be cancelled they should be rearrange in a timely manner.

#### **Quality of care**

A significant number of participants felt there should be more trained staff, particularly nursing staff and better staffing levels on overnight shifts .Also that there was a need for GP's to have great knowledge of paediatrics.  
Improved continuity of care was felt to be important and a need for more respect and compassion from staff.

#### **Communication**

Communication was identified as a key area for improvement with many identifying the need for better and more communication between staff, parents and children/young people.

'Medics need to treat the parents and children as individuals because each case is different'  
The need for more sensitivity and to be aware of parents emotional needs when given bad news about their child.  
'Would be good to have someone that parents could talk to when they first receive the diagnosis of their child condition.'  
The need for professionals to respect and communicate more effectively with children/young people with learning disabilities was also highlighted: 'Give me more time to talk' 'Talk to me as well as my parents'  
'Use more simple language and pictures to help me understand written information'  
'More information in Easy Read so that we are able to read our own letters and information without having someone needing to explain.'  
Challenges for people in need of interpreters were raised and that this can cause delays.  
Improved communication between departments and health and care services was also highlighted as in need of improvement by many:  
'There should be co-ordination between departments to ensure that parents do not have to repeat giving the information.'  
'Information sharing with other services should be encouraged to be improved'

## 5. Feedback from conversations:

**Below is a selection of the majority of the feedback from the conversations including a selection of representative quotes.**

The full feedback can be found at Appendix B (click on relevant question links at bottom of excel spreadsheet to access all responses to a particular question).

### **Maternity Conversations**

#### **Question 1**

**What is important to you about the maternity care you and your family receives?**

#### **Travel:**

Regional specialist centres ok but consideration needs to be taken of the time required to travel rather than the distance, 50 miles up the A1 isn't the same as 50 miles starting in rural East Cleveland.

Practicalities: 6.5 hr round trip to and from Middlesbrough by bus from Middleton in Teesdale which takes 3 buses.

Rural location - some people have got to get to Middleton in Teesdale - may be totally car dependant and no car available.

Having to go any further than Darlington could cause many problems. (Upper Teesdale)

Lack of discharge support due to distance from hospital, no mobile connection.

Limit to what GP can provide, not as many choice in rural area.

Local - scared about getting to hospital on time

Distance/Transport issues of visiting/picking up other children from school etc.

I don't want to be travelling back and forth for hours for clinic appointments that last 10 minutes.

Ambulances available to transfer from hospitals.

Upper dales (all rural areas) are at risk, if there's a 'risky' birth.

That it is accessible by public transport.

Travel/distance

Travel /transport

Women cannot drive in labour

Travel issues and costs

A woman with experience of a premature baby said that the baby had stopped in hospital until the gestation date (40 weeks) and if she had had to travel distances this would've made it much harder to cope.

Travel is a huge issue. I could not travel far as do not drive, have no family here and husband works long hours. Rely on friends for support. It would be a massive worry if had to travel far. It would cost money.

Close - nearby - hard to travel if you are from another country, especially if your husband isn't home. Hard to get other children looked after. - Sometimes you might need to go back 2-3 times a night - difficult to do if further away. Some people may decide not to go and end up in a much worse state

Getting there quickly - Really good signage - road on route and in Hospital itself. No signs on roads until you get close to Hospital.

Local as possible, transport an issue for visitors (time, cost, public transport)

North Tees is difficult for travel and transport from Hartlepool but Consultant was at North Tees

Closer to home would be preferable and would feel scared if they had to travel further than Durham

High risk - more appointments - cost, travel time etc. if have to see them 2-3 times a week

Family members also have to travel - sometimes 3 - 4 times per day.

What about if low risk becomes high risk - suddenly needs C section etc.

Parents will travel to the best place for treatment of their children and feel that services are excellent at present.

Being moved in an ambulance when you're having contractions is awful - being strapped down when you want to move, can't get comfortable

Ambulance staff will need extra training - it will be extra pressure on them

'Three-quarters of people would rather go to James Cook than North Tees. Hartlepool is closer, it's a big town but the hospital is practically non-existent. Hartlepool General is only out patients, it does not have the services, not just lacking maternity.

Costs incurred due to centralised services (travel, parking etc.), people in this position should not even think about parking

The cost of car parking at James Cook was highlighted.

You can NOT rely on ambulance transfers or that they will even get to you within a given time slot. Xxx is a paramedic and is afraid it will take a pregnant mother or baby to die before this is re-evaluated.

## **Access**

Closing any units down is completely wrong, some of the units are already some distance away, travelling and having to leave babies in units is distressing and impacts on the whole family.

Ease of access to services throughout pregnancy

Shutting North Tees would be detrimental to the whole Teesside area.

Need to have easy access to GP and midwives and longer opening times

High risk pregnancies and complicated births need appropriate services available

Difficult situations - wouldn't want to be far away from home if you had lost a baby - again, other children to be looked after

Home birth classed as high risk due to rural nature and not allowed.

Most important factors for maternity care were locality. Previously women were transported back to their local hospitals from James Cook Hospital once their babies were born, but this will not occur with these proposals.

That the services are local so do not have to take too much time out from work for appointments and easy to get to if you have a toddler in tow

The visiting hours at North Tees are restricted and don't coincide with public transport

Flexible approach to appointment times.

No waiting, if they need help/care they should get it.

Access to health visitors.

Specialist/consultant/midwifery care all being centralised and available close to home

Having support in my local community, I don't like driving.

Neo Natal: Until the model is rolled out not sure about distance and cost especially if it is neo-natal unit where you want to visit daily. Juggling other commitments/children/work. Cost of parking. Was offered to stay over- night at James Cook on a put up bed as there was only 1 member of staff per 3 babies

Experiences of intensive baby care units was that they were cramped for space and full. Often parents have to watch upsetting things happening to their own child or other people's babies.

Pregnancy plans can change quickly from a low risk home birth to a high risk C-section, so proximity to a consultant led unit or accident and emergency department is crucial

### **Quality of Care**

Highest quality available

Appropriately qualified people to deal with individual needs.

When appropriate to be midwife led.

Good, friendly midwives

More midwives. Midwife led care within specialist centres the ideal. Bring in the high tech when it is required not before.

5/17 in the group had the same midwife throughout.

Want to see the same midwife throughout whole pregnancy and when you have had your baby to build up rapport and confidence.

Same midwife and consultant throughout with involvement from family GP

Continuity-many of the group did not see the same midwife during the whole of their pregnancy. This can be a problem in not being able to build up trust and confidence

I had a plan which was very well talked through by my midwife but then we needed the consultant

Same person all the way through pregnancy and labour.

Same midwife all through, not going at end of shift and new one not knowing how the labour has been.

Prefer to see same midwife

Seeing the same person all the way through pregnancy, a person who knows me.

Having midwives available 24/7.

Having the same midwife all the way through pregnancy and labour.

Midwives who know what to do if things go wrong, 14 hour labour then another 6 hours before emergency surgery.

Having midwives in the community, going out to the pregnant mums home.

Regular check-ups all the way through pregnancy.

Regular scans to give reassurance everything is ok.

Having plenty of support while pregnant and after baby is born, especially 2nd baby as didn't get much support 2nd time around.

Check-ups to see if baby and mum are healthy.

Improved support from GP around health of mother during pregnancy, optimum health should be the ideal not lack of illness.

More support with breast feeding.

One to one relationship with designated midwife or midwifery teams.

Older ladies being supported

Obese and diabetic pregnancies being supported

Continuity of care

Continuity of care, same health professional.

Continuity of care from midwives, health visitors and doctors.

Pain relief

Being prepared for complications because of previous risks making second pregnancy high risk

Having high risk care available as there isn't any at Hartlepool

The best care for you and your baby - consultant led

Specialist care availability / Specialist care there when needed

Quality of care - the right levels of staffing

Staffing - have the right staff available

Want to know that there are enough staff who are competent and equipped to deal with any problems

Comforting staff - scary times

Experienced, knowledgeable staff

Want the best care so wouldn't bother me if I had to travel, you do it for your child

Having everything in place ready for delivery especially if a premature baby labour

Consultant presence brings re-assurance

See same midwife and doctor so as not to have to explain things over and over again and are able to build confidence

Consistent approach to care and feeling safe

Continuity-many of the group did not see the same midwife during the whole of their pregnancy. This can be a problem in being to be able to build up

Complicated pregnancies and pleased that expertise was on hand to deal with situations

Managing pain during labour.

Staff Training

Professionalism and staff attitude

Want to feel confident that staff have the expertise to deal with all and any problems that might occur

To have enough staff on duty. One mother was left with just a student midwife who she felt did not know what she was doing

### **Hospital:**

The neo-natal care at North Tees is 'fantastic'

Hartlepool General is on 'its last legs.'

Excellent service at Sunderland (5 comments)

Breast feeding team were very understanding at Sunderland - didn't feel pressured at all or made to feel as if I was doing something wrong

Regular check-ups and support was well rounded at Sunderland

Reputation is very important and lots of mums have heard horror stories about James Cook

### **Equality & Diversity**

Understanding of cultural backgrounds, when told baby's gender midwife stereotyped me thinking I must want a boy as I am Muslim.

No language barrier - must be able to communicate

Cultural issues - Elders tell women to, 'sit it out' as they do not want to make 2 trips - sometimes women get into trouble for not waiting long enough before going to hospital, if they are sent home in early labour. Health visitors need to have more training to spot issues in the home. - A lot of women who know the area/service, know they can get there by foot or by ordering a local taxi, if it is out of town, they may not have any idea how to get there. Need one single point of contact.

Must make use of BME Health Connectors in Darlington - involve them in the transition process, use them to help with communication and putting people at ease, sharing information, give them peace of mind. Help to reduce extra appointments by ensuring they understand what's happening.

Polish speaking midwife/ doctor

Someone to translate for us if we had to ring for an emergency.

Transport to maternity services is very important as the members of the group are visually impaired and did not have access to other transport options

### **Dignity & Choice**

Being treated like an individual

Being listened to as mother's instinct is usually correct and consultants believe that they are always right

Being treated well, older mums get treated differently

Attitude of staff, my midwives were very condescending and patronising particularly as I was only 16

I didn't like being patronised because I was a young single mum - midwife was very judgemental and asked very personal questions

NEED somebody Mental Health trained at maternity units and neonatal units. If someone is visibly upset following a loss, it is not good for them or for other worried parents, very worrying to observe. It is a massive state of distress.

Not being patronised and treated like I'm useless

Privacy when in labour, not pressured to have trainee doctors present.

Want to feel in control of birth of baby. One woman said that she would never have another baby as she felt that none of her views were taken on board.

Having your partner with you as much as you can throughout my stay

Care and compassion.

To feel that health staff care

Midwives and consultants to be open to different options such as Daisy Class which is about natural active labour.

Understanding and sensitivity

Confidentiality - don't base ante-natal clinics in open access places like Sure Start centres especially if only just pregnant.

Separate space for miscarriage scans as sitting alongside pregnant women for scan is insensitive.

Privacy when feeding baby.

Knowing about different options in time to make choice.

Birth plan being followed

Right for us, not just what is available

Option for home delivery

Be listened to - felt not listened to

Water birth availability

Being able to have more scans if worried.

### **Communication & Information**

Information sharing between trusts

Trusting the staff that are looking after you, one consultant had me worried the whole time, running all sorts of tests but not explaining what was happening.

Communication is also important especially in early stages

Getting good advice as a new mum.

Knowing where to go and who to contact in an emergency.

Being given correct information.

Good signposting and information/knowledge/training

Knowing the options about where and how to deliver your baby.

More information about the choices mums have regarding their baby's birth.

Info on different types of birth and where could have baby.

More information about the choices mums have regarding their baby's birth.

More advice about how to look after a new baby, felt a bit lost going home on my own.

Health promotion leaflets are useful.

Advice about diet, routines and feeding.

**Question 2:**

**What influences your choice about where you would have your baby?**

**Midwife led care/Consultant presence**

Proximity of specialist services.

Consultant led care (multiple)

For birth I wanted a consultant as you don't know what's going to happen, particularly if you're constantly in pain

Knowing there was somebody there, a consultant needed to be there. For my daughter's first two children no consultant was available when she went into distress

Level of care but what is really worrying is if there are specialist units and there is no more expertise in the local area - we need to make sure that things are picked up correctly so we can access the specialist support

Level of care and attitude

Level of care would be important to me not so bothered about the travel

Having a consultant present should anything go wrong as I needed the support quickly when I went from low risk to high risk because of complications

Midwife led care.

Want to be where specialist care is

Women who have had babies already seem to prefer midwife or consultant led care as they are fearful of being too far away from very pressured units.

Wanted midwife led care to have the most natural birth possible

All the parents had wanted to have midwife led care but when problems developed in their pregnancy they were transferred to consultant led care.

The majority of the group wanted consultant led care as they have the expertise and parents felt safer

Staff to have expertise in dealing with downs syndrome

### **Quality**

The quality of service - checked out reviews of service

### **Pain relief**

Pain relief availability

Pain relief - epidural.

Wanted full range of pain relief

### **Safety**

Safety

Safest place if anything went wrong

Survival rates for babies.

Consultant presence – safety x 3

Want to feel secure that they can deal with any problem

### **Distance to travel**

Close by as possible - no-one wants to give birth in the car

Distance x 3, ease of visiting.

Most people drive but those who don't may have issues getting to places that are further away

Travel would be a major issue for those who don't drive

Travel still affects those who have no car

First time mothers are concerned about "long waits" and travelling time if there is an emergency during pregnancy/birth.

The distance to the hospital is important as some of the group do not have cars

Family can't drive so need to be close to hospital

### **Car parking**

Bigger parking area

### **Facilities**

Availability of modern equipment

### **Continuity of care (same team of midwives)**

Continuity of care (multiple)

Preferences for births - especially second pregnancies - is for home delivery. There is a recognition that this may not be possible for a number of reasons, but continuity of having the same midwife all through the pregnancy is on mother's wish lists.

### **Professional or Family/friends Advice**

Ease of visiting, recommendations from friends, advice from health care professionals.

Recommendations from mothers at school (new to area)

Advice from healthcare professionals/ Midwife (multiple)

Advice from my mother

Talking to other Mams

### **Pre-existing conditions.**

Existing conditions, preeclampsia etc. dictate where is appropriate

Proximity of specialist support, I have had a heart condition since birth, mine is a high-risk pregnancy.

### **Family Needs**

Need to support family.

The needs of the rest of my family.

Friends and family feedback (multiple).

What is available locally.

Requirements of the rest of the family and work commitments.

Closer the better- other children to think about

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### **Other**

Own research, on line (mums net) & reading (multiple).

Own previous experience of maternity care for subsequent pregnancies

How well you have been during pregnancy.

Previous experiences

### **Question 3. What would make it better?**

#### **Access**

Need to consider the needs of rural areas and ease of accessibility

Need to increase the amount of support in the community if there are going to be reductions to services in some hospitals

Anti-natal services including scans to be in GP or community centres so that they are local.

Do ultra sounds at GP surgeries

There is a lack of health visitors - many of the group had not seen a Health Visitor after a few weeks. There provide a great support especially for those who do not have family support.

Accessibility is key. Members of the group felt that decision makers do not recognise the significant differences between the needs of rural and urban areas. There needs to be more services in the rural areas not less because of the lack of transport. Services should be based on local need.

Within reasonable travelling distance.

Bring more maternity services back to Hartlepool

Bring Bishop Auckland Hospital maternity unit back!

Free parking for those in the labour wards

Free parking for pregnant mums, especially in later pregnancy as hard to walk.

More car parking spaces

Better signage - road and hospital.

Cheaper or free parking especially if baby is in special care

Provide transport for classes for those who do not have any

Put in better transport provision that compliments visiting times

### **Midwives & Community Support**

More midwives & health visitors (multiple comments)

'Mothers benefit from contact with same individual midwife but often promises can't be kept due to staff shortages or workload'.

Better use of and an increase in the number of, Midwives and community services.

During pregnancy mums -to - be would like to see their midwife more often and not feel that the visits are rushed.

Would prefer to see the SAME midwife throughout - some see a different one every week

Keep the same midwife throughout pregnancy.

Promote home births as an option especially for 2nd or 3rd babies

Consistent midwifery team

All would like a first contact midwife service available 24/7 via the phone.

Usually can get a GP appointment but when baby has additional needs would be good if they could see same doctor

Better after care for first time mothers as I never really felt I got very much support

More help with breast feeding for first time mothers

Breast feeding team have lost funding twice in the last couple of years and now don't even have the time to visit nurseries or healthy start sessions to give advice/talks

Breast feeding support – some were encouraged some were not, with little or no after care

Breast feeding support is disgraceful - told that funding has been cut so can't access the breast feeding cafes which were great as they helped act as a support network as well

Help with keeping pregnant mother healthy, not just stop smoking advice but help with healthy eating, weight control.

More education to allow for better self-care, better use of voluntary sector as support mechanism

Milk/nappies etc. being provided in first 24 hours

Free baby milk/nappies/sanitary protection for the first few hours

## **Care**

High quality care, friendly approachable staff.

More staff - as they must be under pressure as well one midwife was working a ten hour shift due to lack of capacity which will affect their demeanour

Best available care, budgets ought to be irrelevant when discussing the health of a child

After care – all would like the same midwife throughout pregnancy during delivery and after care – all feel this is very important to them. A different midwife every time is 'dreadful...terrible'

Have more suites like the 'Martin Suite' at James Cook

Aftercare needs to be improved

There should be some consistency as I had 4 different consultants and they all conflicting opinions

Consistency of care across all hospitals and GP surgeries - as group talked about their experiences it was clear that they had not all had the same level of care

Have a consultant on call to attend Midwife led units as and when required - mums to be would be more confident to have babies in the unit.

Discharge was a bit quick, you made to feel as if you need to move out right away

There was a concern expressed that there should be sufficient numbers of beds on Consultant led units as delays in admittance will lead to birth complications.

### **Information & Communication**

Better education/information for first time parents.

Have a person based at GP surgery or community centre who could provide advice and support to new parents. Not everyone has family they can ask.

Young mothers really need to be told about what will happen when you go in to hospital - especially about having food before hand

There needs to be better communication about what is happening during labour - one of the women said her hospital experience had put her off having any more children.

Would like to be given more information about what to expect in pregnancy and once the baby is first born. For first time mums it can be a scary time and it is not always possible to speak to family, having the opportunity to attend groups and classes along with having discussions with the midwife helps

Provide information and communications in different languages or if not even a diagram, for those who cannot read written English.

Improve communication between hospitals and midwives especially if the baby is born out of area.

Feel that things were being done to the baby without explaining what or why. For example baby tested for diabetes without explain what was happening to the baby. Again communication in this area needs to be improved.

Utilise new technologies to support the care of expectant mothers

### **Dignity & Choice**

Want to have birth plan in place - the majority of the group did not have one. A member of the group is due to have baby in a week's time but still does not have a plan and does not feel sufficiently informed to put one in place.

Want to visit the maternity facilities in order to choose the right option for them

More flexible approach to engagement and interaction for those with additional barriers, mental health, poor parental health, caring responsibilities etc.

Less judgemental - mother felt she was stigmatised because she was in a women's refuge. She was not given any information on classes or support available.

Midwives need to listen and communicate better - parents didn't feel they were important.

Listening to me and talking to me would have been good as opposed to talking to my mum

Listen to mums, they usually know best and know their body.

Do not stigmatise mothers who do not want to breast feed or find it hard to do so. Help and support needs to be given regardless of what feeding method is used.

Somewhere for partner or family member to stay with you, even if it is after hours

Take care of new mothers who may be distressed - had a baby who is taken away for treatment, partner sent home, all alone with no baby, no partner

Enable partners or other family members to stay over to help out new mums during the night especially if they have had a C section

More private rooms

Chairs for visitors (People should be comfortable, especially partners who are there for hours)

More birthing pools

### **Equality & Diversity**

DO NOT MAKE ASSUMPTIONS - E.g. of assumptions made currently:

- Assume women want to be fully covered (They might be extremely hot and this just makes them even more uncomfortable)
- Not letting partner in
- Assume you MUST see a female health professional, which sometimes means you wait longer for appointment.

These are examples of what women from Bangladeshi communities have given - they would like to be ASKED and not have these assumptions made.

Ethnic communities only receive 1-2 visits, post birth/discharge - used to be more. Need more help with first baby - often Mothers do not have the family support they would have in their old country - pushed to do things for themselves, but may not even know what temperature the babies' bath should be.

Babies born to women with little English speaking ability who may have been subject to domestic violence should not just be discharged with no support.

Refugees need to be thought about, they have come from war torn countries and don't know how to use household goods, let alone navigate the NHS service. They must be given lots of help when they need it, they are not used to getting medical help.

If you have to use a machine in reception to book in for appointments, it needs to be voice activated as well for those who have a visual impairment.

## **Paediatric Services**

### **1. What is important to you about paediatric care?**

#### **Environment**

Friendly, welcoming service - personalised, knowing the children's name, making the child feel special

Clean & tidy surroundings, friendly welcoming, non-judgemental staff.

Comfortable surroundings, somewhere for parents to stay when small children are kept in for prolonged periods.

Separate A&E area

Side waiting area for children at A&E

Children only area for A&E (waiting area away from drunks etc.)

Easy visiting regime.

Modern equipment

Secure - need to know children are safe

Nice environment.

Clean environment

Games and toys for older kids - something for people of different ages

Play room - toys, can wheel a bed in - ability to transport child - change of scenery

Child needs to be able to sleep in hospital, too many checks and interruptions during the night.

Facilities for family members to stay - offered refreshments, can cost a fortune to stay and have to pay £1 for every drink, food etc.  
- £10 for TV etc.

Facilities for parents to stay with children.

Facilities to stay over with children when in hospital.

Made to feel at home - given use of kitchen facilities, showers, play room for children

Ability to stay with your child - not just a chair - Shower, food/drink etc. (Provision for carers - staying overnight for under 5's)

Specialist equipment meaning you could move child around. E.g. Spica cast buggy

Keep specialist paediatric units as small as possible, parents and children need to bond, impossible in a huge unit miles from home.

Offer parents respite - they need to wash and go to the loo, eat etc.

### **Quality Care**

For specialisms, it is important to have centres of excellence.

Care - comfortable, clean, check on temp etc., turning child etc. Always there, a comforting presence, keep families up to date

Helpful reassuring supportive staff

Staff who appear to really care about the child

Child is happy and doesn't feel patronised.

Making children feel safe.

Taking child's feelings into account.

Need to feel safe, no bullies (Disability group –children/young people)

Nurses tell me what is going to happen (Disability group –children/young people)

Consistent and informed services

Expertise in their field

Friendly caring staff.

Personalised care

Staff - numbers, caring, gentle, experienced

Staff - Who is looking after them - named nurses, child knows and is comfortable with them, consistency/continuity of care

Consistent care from all the staff dealing with child and parent.

Continuity of care so that you do not have to continually repeat everything.

Having a doctor that knows the family/child history on hand is very important

Having doctors who specialise in paediatrics.

Paediatric consultants are necessary.

To have paediatric trained nurses is very important.

Getting the best possible care including going to a specialist hospital if needed.

Learning Disability and Disabilities need quality local provision.

It needs to be high quality. That they can cope with challenging patients (autistic son)

High quality care, friendly approachable staff.

Best available care, budgets ought to be irrelevant when discussing the health of a child

Child gets the best possible start in life or most timely interventions to improve chances.

High quality, well explained interventions.

### **Responsiveness**

Speedy response.

Be seen quickly

Speed - quick as possible, reduce waiting times. - Reduce time waiting between testing and results. - Reduce waiting times between appointments

Quick access to care - children tend to get sick during out of hours and this can be very stressful

### **Communication**

Being kept informed

Good communication - appointment letters and information and regular feedback

Explain things in simple English

Level of care but being kept informed and better communication

Medical staff being as honest as possible in a caring way.

Reassurance - scary time, keep informed of what is happening, give explanations

Mental health issues need understanding (parents/carers) sometimes challenge due to lack of understanding or fear of unknown

### **Location**

Closer to home for routine interventions, visiting important for mothers and young children. More care at home an excellent idea but do we have the necessary staff trained and available to cover East Cleveland?

Within reasonable travelling distance.

Closeness to hospital

Need services close by as children can be accident prone

Timing - having to get back for the other children in time

Reliable ambulance service

Again Accessibility from rural West Durham.

## **2. What would make it Better?**

### **Location**

Better coverage for rural areas. Keep waiting times low. More support for carers. Hub idea good, will we see one in East Cleveland or are we travelling to Guisborough or Redcar. Keep Guisborough Hospital open if you believe in local care.

More support for transport - how are low income families to get to appointments out of town, daily

Specialist centres good if they improve results but need to be balanced with need to keep services as local as possible; public transport provision poor in East Cleveland, not everyone has access to a car.

Within reasonable travelling distance.

Local clinics, can we have more health delivery from Sure Start Centres?

More care at home an excellent idea, no one wants to go to hospital if they can avoid it.

Care closer to home an excellent idea.

Support services in the community

### **Environment**

Having a smaller room for child or parent with special need, better if can be away from others, children on Autistic spectrum.

Comfortable surroundings, somewhere for parents to stay when small children are kept in for prolonged periods.

Having toys for children to play with when they are in hospital, if quarantined can't leave room to go to play area.

Make environment homely.

Special areas just for children.

Places for parents to stay - put up beds.

Area for parent/carer to stay

Need more privacy (comment from a 16yr old)

The waiting rooms are dull and too small and crowded. This is not good for disabled people - they should have a quiet space for those who can't cope with noises / crowds.

Internet access

### **Appointments**

Long waiting times for speech and therapy - referrals are very slow

Making sure follow up appointments are made.

Not having to wait long for appointments as cause's anxiety

Quicker appointments

Less waiting times

Reminders about appointments - especially when they are booked 6 months in advance

If appointments need to be cancelled they should be rearrange in a timely manner. It takes a lot of energy for parents to keep track and chase appointments.

### **Staff**

Bring back school nurses and district nursing staff, they know their patients.

More trained staff, better training for GP's.

We need better local GP knowledge of paediatrics.

Train more staff

More trained staff and staff to stay in post.

Trainees to do lower level stuff - clean, paperwork, bloods etc.

Continuity of care.

High quality care, friendly approachable staff.

Improve staffing levels (multiple)

Health visitors available out of hours.

Better staffing levels on overnight shifts

Best available care, budgets ought to be irrelevant when discussing the health of a child

Health Visitor should be one to one service – privacy is needed and separation of sick/ill children during this service.

There should be more respect/compassion and support not increased 'target' levels.

Very Low staff moral

## **Communication**

More communication between staff and parents

'Give me more time to talk' (disabled young person)

'Talk to me as well as my parents' (disabled young person)

'Use more simple language and pictures to help me understand written information' (disabled young person)

'More information in Easy Read so that we are able to read our own letters and information without having someone needing to explain'

'More time to read information' (disabled young person)

There needs to be training on interpersonal skills for all medics on Downs Syndrome and how to talk to parents

Medics need to treat the parents and children as individuals because each case is different

Be aware of parent's emotional needs when given bad news about their child.

Would be good to have someone that parents could talk to when they first receive the diagnosis of their child condition.

Allowing other health care professionals to speak to patients instead of only consultants especially at outpatients appointments.

It is already excellent if you understand the system, more help for those who don't. Advocates.

Please do not be judgemental: One Doctor has allegedly made a comment stating "You're an overprotective parent. ALL Bangladeshi communities do this"

Sometimes patients are waiting at the back of the queue for an interpreter to arrive. Families and partners can be used or even a telephone service to confirm with the patient that they are happy for the other person to translate on their behalf.

Been told more about process so we understand what's going to happen. (BME group)

Giving parents results of tests by email, phone or post if they do not need to attend an appointment.

Having a way to get back into the system when a problem reoccurs rather than starting a new referral.

Improve communication between departments

There should be co-ordination between departments to ensure that parents do not have to repeat giving the information.

Improve communication between patient and consultant

A & E Communication is rubbish, people are just left guessing what is going on as staff have to prioritise and may have had to go elsewhere, but being informed would be helpful. Perhaps they do not explain to avoid conflict.

Doctors and nurses should talk to us as well as our parents, they should explain to us what is going on and what will happen

Communications between services must be improved. E.g. NHS, GP's, schools, Urgent Care etc.

Information sharing with other services should be encouraged to be improved

Share information

**Prevention**

Better support, education and training for parents to allow them to play a bigger role in caring for children.  
Better prevention information

**Other:**

Child gets the best possible start in life or most timely interventions to improve chances.

Planned discharge - not waiting until 10pm for meds etc.

Where is Young Peoples Mental health in the proposals? Current service appears to be crisis only, we need better. CAHMS poor, waiting times unacceptable.

Don't forget the needs of carers.

More resources to be put in including staff and equipment