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**Developing a new Respiratory Service for adults in Barnsley**

**Engagement Feedback Report**

**September 2020**

1. **Developing a new Respiratory Service for adults in Barnsley**

**Overview**

The NHS has set out plans for the next 10 years, identifying respiratory conditions as a key priority. Respiratory conditions affect the set of organs that allows a person to breathe and we will be investing to improve treatment and support for people with respiratory conditions in Barnsley

We are now developing local respiratory services for adults and we want to use the feedback from people who have used local respiratory services over the past three years and family members and carers to help us do this as well as from the professionals who work in and refer into local respiratory services.

During August and September 2020, we have been asking for feedback from the people mentioned above about what they like about local services and how it has made a difference to their health and wellbeing (or the person they care for), what things they'd like to change and what else they think might make a difference to their health and wellbeing. We also wanted to hear what people thought of our plans outlined below.

**Why we were asking for feedback?**

We want to change the way we provide care for adults with respiratory conditions.

We want more people to be seen, treated and supported to manage their respiratory conditions either at home or in clinics locally to where they live within the community, rather than in a hospital.

**What is the current service like?**

The respiratory services in Barnsley are run by Barnsley Hospital and people requiring support will generally be seen by the team at the hospital. You might have heard it called the BREATHE service.

The current BREATHE service is for people with chronic obstructive pulmonary disease (COPD) as well as people who need oxygen at home.

**What are the plans for the new service and who is it for?**

The plan is for the BREATHE team to come to people’s home, or for them to visit the team at a clinic which is near to where they live. It would be called BREATHE in the Community.

This service will be for:

* People with Chronic obstructive pulmonary disease (COPD).
* People who need oxygen at home, nebuliser assessment and early supported discharge from hospital.
* People who experience breathlessness due to pneumonia, asthma, bronchitis, Lower Respiratory Tract Infection (LRTI), long term chronic respiratory illness, cancer where you need support at the end of life).
* People who are receiving respiratory rehabilitation.

The BREATHE in the Community service is not for people who have heart failure, an acute chest infection, or those receiving pulmonary rehabilitation (which will remain unaffected). There are other services in place to support these people.

We are expanding the service for people in the community so that more people can benefit from specialist care in their own home or local to where they live. If people need a stay in hospital due to the nature or complexity of their condition this would still be available.

The current service is coming to the end of its contract and we are using this as an opportunity to review and make any necessary changes to it.

We are proposing that BREATHE in the Community will be delivered by the specialist team in a clinic local to where people live, or in most cases in their home. The specialist team will include nurses, doctors and other healthcare professionals. This approach will mean fewer people need to travel to, or stay, in hospital.

We want the service to work alongside people so they feel confident in managing their condition to stay well. The team will identify those who might need additional support at an early stage. They will work with other health and care workers and co-ordinate the right care and support.

There is likely to be more than one health or care specialist involved in an individual’s care. To make sure they all talk to each other the team will meet regularly and to discuss individual care plans.  This care plan is developed in partnership with patients and anyone in their support network they choose to be involved. Individual care plans will also be regularly reviewed to make sure it is working the best for the person they belong to.

**What feedback have we had from local people so far to shape our plans for the new service?**

We have received feedback from people living in Barnsley about their experience of using services and what they would like to see offered in the future. From this we understand that:

* People prefer to be seen in, or locally to, their own homes where possible. In healthcare this is called “in the community”. Local clinics may be in a GP practice or other local healthcare building.
* People feel that healthcare services should work together in a joined up way (as one team) - care and support should be seamless and without barriers, with the person at the centre.
* People want to be supported and motivated to manage their long-term conditions (self-care).

**2. Summary of findings**

**What people told us about our proposals for the development of a new Respiratory Service for adults in Barnsley?**

During August and September 2020, we asked people to feedback their views and comments on our proposals for the development of a new service model for respiratory services for adults in Barnsley and any recommendations for changes. People fed back on the proposals, provided direct feedback on their own experiences or posed questions for consideration.

Over the course of the past few weeks we have heard from over 50 people who have fed back to us either in person at one of the meetings or focus session that we have held, via one of the two surveys that we have hosted online and provided paper copies of (upon request) or via email or telephone call directly to the CCG.

The emerging themes from the conversations and feedback that we have received as part of this brief engagement period has helped to reinforce our direction of travel in relation to our proposals for the development of a new Respiratory Service for adults in Barnsley and to further inform the service specification.

This will at a later date also help to shape the development of the new service and we hope to continue the dialogue that we have established with the range of stakeholders highlighted below.

Here’s a summary of who responded, what people told us about what works well, the things that need improving and what we need to consider and emphasise both in terms of our new service specification and the future way of working:

**Respondents (Patient, Carer and Member of Public Survey)**

* Majority of responses from current patients and carers/family members of current patients of local respiratory services = Over 70%
* Mainly female respondents = 64%
* Over ¾ of respondents aged between 45 and 74 years old = 77%
* Over 90% of respondents highlighted their ethnicity as White British
* Over 35% of respondents highlighted that they are unpaid carers for family members or friends
* Good coverage achieved of responses received from people living across the whole of the borough
* The majority of respondents found out about the engagement from social media.
* The majority of respondents had contacted their GP when they had experienced a sudden worsening of their condition = 24% followed by calling 999 = 18% and then attending A&E = 16%
* In relation to an ongoing worsening of their condition, the majority of respondents highlighted that they have been supported by a carer/ family member = 27% followed by their GP and/or Practice Nurse = 19%

**What works well about the current BREATHE service**

* The BREATHE Team based at the Hospital.
* The support and advice provided for patients, carers and family members.
* Communication from the service.
* Getting into the service and the specialist support provided.
* Receiving support at home and home visits.
* Nothing – struggled to access support from the service.

**What could be improved about the current BREATHE service**

* Nothing – great service as it is
* Lack of joined up communication between services.
* Perceived lack of awareness of the service from both a public perspective and with other healthcare professionals e.g. with GPs
* More capacity and staff members as the team are stretched
* Better integration with other services
* More support for people suffering with anxiety and/ or confusion as a result of their respiratory condition
* Build on working in partnership with family members and carers to support the patient at the centre.

**What people like about the plans**

* Care closer to home – either in clinics in the community or at home
* Increased integration with other respiratory services and other healthcare services
* Expanded range of conditions covered
* Seems like the service already works like this – work with the current Team and services to develop the new service.
* Nothing – keep services as they are
* Anything that keeps people out of hospital is a positive
* Seems like the service will be more accessible for local people by being out in the community and will involve less travel

**What could we perhaps do differently?**

* Be proactive not reactive – learn from and work with the current service and BREATHE Team to develop the new service.
* Nothing – think the plans seem a good way forward
* Have both a hospital and community based service that works together
* Ensure that the service is fully integrated with other services and the specification acknowledges the amount of hospital activity
* Include severe asthma in the plans and learn from the Rotherham Breathing Space model
* Ensure you raise awareness of this service – with patients and other healthcare professionals
* Resource the service appropriately – the current Team work well but are stretched and need more support/ capacity.

# ****3. Overview of engagement activity****

**We set out with the aim to carry out engagement activity that would:**

* Build on any existing patient, carer, clinical and public feedback.
* Obtain further views from a range of stakeholders and help to shape and refine the draft new service specification and provide opportunity to reflect any proposals or suggestions for future ways of working.
* Work within the agreed parameters set for safe working during the Coronavirus pandemic. Working in partnership to address the key challenges that social distancing presented to us and rules about infection prevention and control about the widespread use of paper surveys.
* Act in accordance with the National Health Service Act 2006 (as amended by the Health and Social Care Act 2012), in which CCGs and NHS England have duties to involve the public in commissioning, (under sections 14Z2 and 13Q respectively).

Based on our assessment of the level of service change envisaged as part of this work, the Overview and Scrutiny Committee supported the engagement approach outlined in this report. Should any of the circumstances change in the future this will be reviewed and assessed again.

**Who got involved?**

Over 50 people got involved in this work either through completing the relevant online survey, feeding back via telephone call, taking part in the online focus session/ meetings or by emailing us. Some provided their details and asked to be kept informed and involved in the next phase of this work.

In partnership:

* The engagement activity was coordinated in partnership primarily with Barnsley Hospitals NHS Foundation Trust (BHNFT) and South West Yorkshire Partnership NHS Foundation Trust (SWYPFT) as providers of respiratory services to adults in Barnsley.

In person (via Zoom):

* Online meetings and a dedicated focus session were held throughout the duration of the engagement period and took place with the following organisations and people;

* + Online meetings held with Yorkshire Ambulance Service, Barnsley Hospice, Barnsley Healthcare Federation, Barnsley Hospital NHS Foundation Trust and South West Yorkshire Partnership NHS Foundation Trust.
	+ Focus session with current patients and carers of the BREATHE service held on Monday 14th September.
	+ Meeting with Chris Skidmore, Chair of the Yorkshire Area National Union of Mineworkers (NUM) and Chris Kitchen, General Secretary for Barnsley and Yorkshire Area National Union of Mineworkers (NUM) held on Thursday 17th September.

Online:

* Online on the ‘Get Involved’ section of the NHS Barnsley CCG website where the links to the two surveys – one for Patient/ Carers/ Members of Public and one for Professionals were made available.
* Social media posts via the CCG Facebook and Twitter pages. Posts that were shared by the CCG on our dedicated social media pages.. A wide number of partner organisations and local groups also shared posts on social media helping promote the surveys to a wider audience.

Sent directly to stakeholders:

* Sent to members of OPEN (Our Public Engagement Network) database.
* Sent to members of the NHS Barnsley CCG Patient Council.
* Circulated by local partners working across the health and social care economy.
* Promoted directly with colleagues and partner organisations working within respiratory services and we asked for them to share with their wider networks. Leaflets provided for distribution to patients with details of the different ways in how they could have their say.
* Sent directly to a wide list of stakeholders. This list was compiled in partnership with local service leads.

**What did we ask people?**

Two different surveys; one for patients, carers and members of public and another for professionals were made available to people online at [**www.barnsleyccg.nhs.uk/haveyoursay**](http://www.barnsleyccg.nhs.uk/haveyoursay), on request via paper copy or could be completed over the phone.

The survey questions we asked were as follows;

* Are you aware of the BREATHE service that is provided at Barnsley Hospital?
* Have you, or one of your family members or friends, ever used the BREATHE service? **(Patient and Carer Survey only)**
* Have you ever made a referral to the BREATHE service? **(Professionals Survey only)**
* Can you advise the approximate number of people that you have referred to the BREATHE service in the last year? **(Professionals Survey only)**
* From your experience of using/ referring into the BREATHE service, please tell us what worked well, what you liked and why?
* From your experience of using/referring into the BREATHE service, what would you change and why?
* If you have experienced a sudden worsening of your respiratory condition e.g. breathlessness, what action have you taken (please tick as many as apply from the options provided)? **(Patient and Carer Survey only)**
* If you have experienced an ongoing worsening of your respiratory condition e.g. breathlessness, who has supported you with this (please tick as many as apply from the options provided)? (**Patient and Carer Survey only)**
* Is there anything that you think is good about our plans for the BREATHE service in the Community?
* Is there anything that you think we could do differently as part of our plans for the BREATHE service in the Community?
* What would give you confidence that the new service is working for patients living with respiratory conditions, their families and carers? **(Professionals Survey only)**

# ****4. Overview of the feedback we received during this engagement phase****

As previously stated above, over the course of the past few weeks we have heard from over 50 people who have fed back to us either in person at one of the virtual meetings/ focus groups that we have held, via one of the two surveys that we have hosted online and provided paper copies of (upon request) or via email or telephone call directly to the CCG.

Below is an overview of all the feedback that we received and the demographic information we were able to capture where possible. We would like to thank everyone who has taken the time to provide us with their valuable comments, questions and feedback to inform this work.

**Survey Feedback**

**Service User and Parent/ Carer Survey**

36 responses received in total by the deadline of Sunday 13 September 2020

**I am responding to the survey as…**

A current patient of respiratory services – 40%

A former patient of respiratory services – 6%

A carer/ family member of a current patient of respiratory services –31%

A carer/ family member of a former patient of respiratory services - 6%

A member of public – 14%

Other – 3%

* + - 1. **Are you aware of the BREATHE service that is provided at Barnsley Hospital?**

|  |  |
| --- | --- |
| **Yes** | 28 (78%) |
| **No**  | 1. (22%)
 |

* + - 1. **Have you, or one of your family members or friends, ever used the BREATHE service?**

|  |  |
| --- | --- |
| **Yes** | 20 (56%) |
| **No**  | 9 (25%) |
| **No response**  | 1. (19%)
 |

* + - 1. **From your experience of using the BREATHE service, please tell us what worked well, what you liked and why?**

21 people provided a response to this question. Where possible, comments have been included in their entirety in each respondents own words below.

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| Works OK but sometimes not kept up to date i.e. individual cannot come, for various reasons, but they fail to tell us, so we are left waiting at home |
| I have twice been discharged from hospital in 2019 (following admission for a chest infection) into the care of the BREATHE team. I have severe COPD and whilst I do not need oxygen at home I found home use of a nebuliser very helpful, albeit short term. The team who visited me at home were very helpful, knowledgeable and friendly. I much appreciated being given the option of home treatment rather than an extended hospital stay. A good, professional service that is very much tailored to patient needs.  |
| Good services and short waiting time once at the appointment. Good feedback from medical staff. |
| In the current climate nothing works well, my mum cannot get anyone to come see her and when she rings BREATHE they tell her to ring her GP and when we ring the GP they won’t see her because she has shortness of breath and refer her to the blue COVID-19 clinic which makes her panic and her breathing worsen, she had a constant chest infection and keeps getting fobbed off with antibiotics when she needs an x-ray and the correct treatment.  |
| The service has worked well for me the advice given is very helpful also it’s reassuring to know there is help at the end of the phone when I need it.  |
| The BREATHE service has been a big help to my wife |
| Whenever I have called for my Mother the nurses have always been out to visit her the same day. I find it so much easier getting through to the BREATHE Team than her GP. The BREATHE nurses and Dr Longshaw also have time to sit and listen and understand my Mum’s condition where I don’t feel my Mum’s GP does. |
| Excellent service - better to be treated at home and the nurse who visited my Nan was helpful, cheerful and knew what she was doing |
| They saw my Grandad in hospital and managed to earn his trust enough to get him home sooner. They came to see him at home and stepped up his treatment when he deteriorated. Not only did they give him support, but gave us peace of mind too. They had to give him a nebuliser then took it away when he improved. They taught him and us how to use his inhalers properly. We now phone them instead of the GP as nothing is too much trouble, and he gets seen quickly.  |
| They are amazing!!! They not only cared for my Nanan in and out of the hospital, but also our family! From medical advice to a shoulder to cry on when the going got tough with my Nanan’s COPD journey! I really don’t know what we would have done without the BREATHE Team!! The home visits worked really well as this decreased the number of possible times we needed to call 999 due to complications! They had already sorted out an ICE and tests for my Nanan, they told us straight what the next steps would be at each stage as we asked them to and they were there every step of the way supporting us all! |
| Being visited by professional staff with expertise of my condition in my own home. |
| Local to the hospital & therefore easy to access |
| Nebuliser help  |
| Concerns expressed over care received by a deceased relative. The feedback received is currently being investigated as part of the NHS Complaints process and therefore has not been included.  |
| I have C.O.P.D. Emphysema and I am classed as gold. I cannot have a general anaesthetic due to severe breathing problems. The BREATHE Team have been brilliant with me. I am on home oxygen as and when I need it. I was introduced to BREATHE team as I’ve had many admissions into hospital. I also now have severe anxiety which doesn’t help my lungs. I cannot praise these people enough. |
| Sorry wasn’t aware that this service existed |
| I’ve only had two meetings with a team member from breathe, both meetings went well, they asked questions, listened and understood my condition and oxygen requirements |
| The home visit was highly commendable. The staff attending were supportive but after about 3 home visits it was felt by the Team that the condition could be managed by the patient. There were no further visits or follow up arranged by the home visiting team. Other than not having to travel to Barnsley Hospital, I would say that the services being offered by Penistone Group Practice were on a par with those currently being offered by the BREATHE team located at Dodworth apart of course from the home visits. |
| Good service provided to my husband who has COPD and Cancer. Lovely staff but just not enough of them. As a Carer I feel supported by the team. We have been working alongside the team to provide support as I am also a professional Carer and this has worked well. Family member support has also been key factor.  |

* + - 1. **From your experience of using the BREATHE service, what would you change and why?**

18 people provided a response to this question. Where possible, comments have been included in their entirety in each respondents own words below.

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| Better communication  |
| The only slight criticism I have is that I would have preferred advance notice of the time of the home visit. A phone call, text or email would have been appreciated rather than waiting, wondering what time the nurse would call. If Amazon can do it, so can the BREATHE Team |
| Difficulty getting my family member to the hospital so a local clinic or better still home visit would be preferred. |
| Back to Face to Face appointments and not the continuous fobbing of to the GPs  |
| I would not change anything. |
| I would have it combined with the Rehab Service.  |
| Nothing excellent team and service. All nurses very supportive and knowledgeable. |
| Not many people seem to know about it.  |
| The only thing I would change is to expand! The more staff they can get on their team the more people and families they can support as they did with my Nanan and my family! Barnsley needs this team! |
| An excellent service. I wouldn’t change anything. I have received excellent support and care. |
| Expand services so waiting appointment times are reduced  |
| Prescribe nebuliser salbutamol on a rolling prescription service from Barnsley Hospital in the current climate. Your hospital Dr puts you on a nebuliser then you go to your own GP surgery nurse who is hell bent on taking you off nebulisers and replacing this with rubbish inhalers.  |
| It may help if you had staff to deliver your service. |
| Before lock down I would have said that I wouldn’t change anything but THIS is my fault not theirs I have had 4 rescue packs of steroids and antibiotics over a 6 week period after having telephone calls from my GP I would after taking my prescription feel bit better for few days but then breathing wasn’t good. I am on my own and anxiety started as I was scared after the 4 rescue packs I thought I’d been on steroids two long I contacted the BREATHE Team they sorted me out. I never thought about contacting the BREATHE team as I assumed that they would be busy on the wards as my community nurse has stopped due to virus. When you have bad breathing issues they are sometimes worst at night and anxiety kicks in you don’t think properly.  |
| To have the same BREATHE team member as a constant would help build a relationship and a more informed understanding and recognition of any change in my condition and requirements. |
| The provision offered at Barnsley Hospital is first rate and my choice would be to stay with the team at the Respiratory Unit at Barnsley. They have state of the art equipment easily accessible and first rate Consultants/Clinicians. A lot of monies have been invested in the equipment at Barnsley and all other supporting services are available should they be needed for use arise. Why change something that isn't broken. I classify services at Barnsley as Primary care and other supporting services at GP Practices as SECONDARY. I feel it would be a retrograde step to tinker with a service that is fully functioning only mainly to provide a home service which brings little benefit |
| The team are stretched so we have been working alongside them to support my husband who has been admitted 9 times since March. It feels like a constant cycle of admissions and discharge and the cycle needs to be broken. If he had the right equipment (Bipap machine) he could be at home but we have difficulty in getting to this stage. It's a real balancing act getting everything in place in terms of the right equipment and support. Due to the amount of oxygen he is often confused and frustrated and this is distressing to see as it leads to him being scared about what is happening to him. My husband wants to be at home not in hospital and would be good to have the support there to enable this |

* + - 1. **If you have experienced a sudden worsening of your respiratory condition e.g. breathlessness, what action have you taken (please tick as many as apply)?**

|  |  |
| --- | --- |
| Called the BREATHE Service  | 8 (13%) |
| Called my GP  | 15 (24%) |
| Called NHS 111 | 9 (15%)  |
| Called 999 for an ambulance  | 11 (18%)  |
| Attended Accident and Emergency  | 10 (16%)  |
| All of the above  | 1 (1%) |
| Other  | 3 (5%) |
| Not applicable  | 5 (8%) |

* + - 1. **If you have experienced an ongoing worsening of your respiratory condition e.g. breathlessness, who has supported you with this (please tick as many as apply)?**

|  |  |
| --- | --- |
| Self – care without additional support  | 10 (17%) |
| Carer/ Family Member  | 16 (27%)  |
| Consultant  | 7 (12%)  |
| Specialist Respiratory Nurse  | 9 (15%)  |
| GP and/or Practice Nurse  | 11 (19%)  |
| Community Nurse  | 0  |
| All of the above  | 3 (5%) |
| None of the above  | 1 (2%) |
| Other  | 1 (2%) |
| Not applicable  | 1. (2%)
 |

* + - 1. **Is there anything that you think is good about our plans for the BREATHE service in the Community?**

24 people provided a response to this question. Where possible, comments have been included in their entirety in each respondents own words below.

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| Thank goodness it is there, but like most things it could be better. Clinicians tend to go their own way without actually thinking about the knock on effect, of time and inconvenience. |
| Clinic based BREATHE team sounds good but please ensure there is adequate car parking on level ground adjacent. Walking and inclines are no go areas for COPD sufferers. |
| The fact that is local or home visit. My family member is elderly and it is a struggle to get to transport to hospital appointments |
| People not needing to attend hospital but use GP surgeries. Service expanding to other illnesses |
| It’s a fantastic idea as stated before someone at the end of a phone call with help and reassurance who have training and expertise in lung conditions |
| I know it is there for support when my wife has an infection. |
| My mother has already been seen at home by the BREATHE Team and has been seen in a clinic at her GP practice |
| I think it’s a good idea having nurses in the community |
| It appears this is how the BREATHE Team already work. My grandad has been seen in a clinic at a local GP surgery by the consultant. The consultant spent a long time listening, and again nothing was too much trouble. |
| I really hope you can develop the team and allow them to grow! |
| Although a local clinic would mean less travelling, I would still find it difficult and would prefer to continue to receive care at home. |
| I think any help would be a godsend, husband left six month with one inhaler has been horrendous, I know out of all the departments respiratory has been the busiest. Due to being left like this (needs an appointment at the sleep clinic for oxygen nothing happening during lockdown) he has developed PTSD and a full mental breakdown. We have been lucky enough to have psychiatric nurses in weekly but it’s got that bad the there is a psychiatrist coming tomorrow, anything that helps the community with respiratory conditions has my vote.  |
| Nothing good about it because eventually the staffing numbers will be reduced … Other services that have become community based are eventually run down … Clinics or health settings are not suitable in all area so travel would still be required be patients.  |
| Any extra support that frees bed space on the wards is going to help for frequent admissions such as myself. Being on AMU with such difficult asthma is never ideal. |
| Not sure, as dealing with my local Practice nurse when needed has worked fine for me so far |
| Maybe accessible to more people, but would depend on locality of service |
| Please provide a boxing gloves and punch bag budget to use at home to use as a respiratory aid |
| It is excellent that this service plans to cover additional chronic respiratory conditions, other than COPD and home O2 users. My family member has Idiopathic Pulmonary Fibrosis and has been seeing a consultant in the chest clinic for several years. Although she is considered stable at the moment, she has persistent breathlessness and worsening physical weakness. She has never been offered any help on how to manage or improve her breathing technique. She does a lot of shallow breathing which leads to 'panic breathing' sometimes, and consequent negative emotions. Her breathlessness has led to a marked decrease in physical activity which is leading to frailty and falls. She also is finding it harder to take in written information, so handouts that we've provided from the British Lung Foundation or similar, now go unheeded. So if the new BREATHE service provided a more joined-up support of breathing issues and the consequent effects on physical mobility and mental health that would be very valuable. |
| Care in the community will be more useful to myself if it means less time travelling to hospital |
| Providing services more locally is the best option for patients as long as quality is not compromised |
| Only to save travel/parking |
| I think this would benefit severe asthmas sufferers like myself as I would possibly prevent me going into hospital with exacerbations on a frequent basis and stop me taking up hospital beds when it could be dealt in the community possibly I think this is a very good idea |
| Will be good to be able to stay at home and receive support required to do so. |
| I agree with everything you are trying to achieve and would like to be able to access this service myself |

* + - 1. **Is there anything that you think we could do differently as part of our plans for the BREATHE service in the Community?**

20 people provided a response to this question. Where possible, comments have been included in their entirety in each respondents own words below.

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| Listen to the end user. Be proactive, not reactive |
| Maintain the home visit facility for patients too sick to travel ...If it isn’t bust don't change it |
| No at the minute  |
| Include severe asthma  |
| Be in the community!!  |
| No |
| You could look at Breathing Space in Rotherham and take the good points from them |
| There doesn’t seem to be anything different in the plans to how the BREATHE Service works now |
| More information for patients and family. The hospital knows about the team but my grandads GP had never heard of them |
| Although having a team based in the local community is a good idea, it might stretch and limit resources. It would also depend upon what is classed as ‘local’ and whether or not a team was based there permanently or on a part time basis. Local could still mean significant travelling to an area not necessarily on a bus route, unlike the hospital. |
| You could tell GPs to actually tell patients about this service I've had 14 COPD for years and never even heard of this service from anyone let alone my GP! |
| No.......... can’t wait for my husband to get the help he needs, 12 years in the Mining Industry has left him like this, never smoked in his life. Help in the community is a brilliant idea. |
| Keep out of the community  |
| Make it more known to people like myself |
| Flexibility to see patients at home if appropriate |
| All asthma sufferers like me should be able to attend exercise sessions designed to help improve lung condition. I would like to have my condition checked by a sports nurse then be given targets. I would like to be monitored and encouraged in my exercise plan so that I could see improvements. I walk for 3 miles most mornings alone, I would like to join others in a group. I attended Dorothy Hyman cardio rehabilitation classes after my heart bypass and it was very good. |
| Leave things as they are I cannot anticipate any major benefits emerging. |
| Make it into a rapid response team then if patient need to go to hospital we can go directly to a ward instead of waiting 4 hours in A+E as with me I suffer with anxiety and sometime if I can’t breathe I struggle more when over thinking I can’t breathe if that make sense.  |
| Need to ensure that the right equipment and levels of support are available to support patients and their families. |
| No apart from when would the likes of me be approached to be part of the scheme and how would I go about this. |

* + - 1. **Any other comments**

8 people provided a response to this question. Where possible, comments have been included in their entirety in each respondents own words below.

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| COPD is a life threatening condition, but I have heard on many occasions, oh, you have COPD. It is not a bad headache it is a real, frightening experience, not dissimilar to drowning. Terrifying |
| Current services have totally failed my mum for the last 5 months, constantly being fobbed off as having corona symptoms from every angle.  |
| Thank you for the wonderful service |
| Fantastic Team  |
| Never heard of BREATHE and go to A&E at least once a year with severe asthma. In A&E it just takes too long - often all you need is a nebuliser/ steroids. It seems to takes forever and I have been left more than once breathless. Once in A&E, I was moved out of my cubicle to make way for a patient being brought in by the police and forgotten about. I had to go and tell the staff that I still hadn’t being treated. |
| Why are GPs failing to tell patients with respiratory issues about this service? |
| There is no doubt that people like me with chronic asthma are in a mind-set placed on us by the medical model. We need to turn away from medicine and medical establishments and get out into the fresh air. That way we will improve our mental health and that will give us the strength to keep trying to improve our health. As I say above I get out on my own but it would be so much better to be with others like me. We would be able to empathise and encourage others in our groups. In Locke park where I do my walks there’s a multi gym which I use. If I met others there it would be much better. But we would need someone to guide and support us.  |
| I think this will be a positive development of local services for local people |

**Equality Monitoring Questions**

**Age Range**

|  |  |
| --- | --- |
| **Under 18**  | 1 (3%)  |
| **18 - 24**  | 0 |
| **25 - 34**  | 3 (8%) |
| **35 - 44**  | 2 (6%) |
| **45 - 54**  | 11 (30%) |
| **55 - 64**  | 5 (14%) |
| **65 - 74**  | 12 (33%) |
| **75+** | 1 (3%) |
| **Prefer not to say**  | 1 (3%) |

**Gender**

|  |  |
| --- | --- |
| **Male**  | 13 (36%) |
| **Female** | 23 (64%) |

**Transgender - Do you live and work permanently in a gender other than the one you were born into?**

|  |  |
| --- | --- |
| **No**  | 33 (92%) |
| **Yes** | 3 (8%) |

**Ethnicity - How would you describe your ethnicity?**

|  |  |
| --- | --- |
| **White British**  | 34 (94%) |
| **Prefer not to say** | 2 (6%) |

**Sexual Orientation - How would you describe your sexual orientation?**

|  |  |
| --- | --- |
| **Heterosexual**  | 31 (86%) |
| **Gay** | 1 (3%) |
| **Bisexual**  | 1 (3%) |
| **Prefer not to say** | 3 (8%) |

**Religion - How would you describe your religion?**

|  |  |
| --- | --- |
| **No religion**  | 16 (44%) |
| **Christian**  | 15 (42%) |
| **Prefer not to say**  | 3 (8%) |
| **Other (Catholic)** | 2 (6%) |

**Disability - Do you have any of the following disabilities?**

|  |  |
| --- | --- |
| **I do not have a disability**  | 14 (30%) |
| **Mental Health Condition**  | 8 (17%) |
| **Physical Impairment**  | 3 (8%) |
| **Cognitive Impairment**  | 2 (4%) |
| **Long Standing Illness** | 12 (26%) |
| **Sensory Impairment**  | 4 (9%) |
| **Learning Difficulty**  | 2 (4%) |
| **Prefer not to say**  | 1 (2%) |

**Carer - Do you provide unpaid care for someone (friend/family member)?**

|  |  |
| --- | --- |
| **Yes**  | 10 (29%) |
| **No**  | 22 (65%) |
| **Prefer not to say** | 2 (6%) |

**Postcodes**

We received feedback from the following post code areas

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| S36 | S63 | S70 | S71 | S72 | S73 | S74 | S75 |



**Did we provide enough information for you to be able to comment on the questions we asked?**

|  |  |
| --- | --- |
| Yes  | 29 (80%) |
| No  | 1 (3%) |
| Unsure | 6 (17%) |

**Where did you find out about this survey?**

|  |  |
| --- | --- |
| Social Media  | 15 |
| Family Member/ Friend  | 2 |
| Email from CCG  | 7 |
| Partner Organisation | 6 |
| CCG Website  | 2 |
| Barnsley Chronicle  | 4 |

**8 people gave us their contact details and asked to be kept updated.**

**Professionals Survey**

10 responses received in total by the deadline of Sunday 13 September 2020

**Job role of respondents**

|  |
| --- |
| Advanced Nurse Practitioner  |
| GP x 2 |
| Community Matron  |
| Respiratory Nurse x 4  |
| Public Health Officer  |
| Air Quality Officer  |

1. **Are you aware of the Barnsley BREATHE Service?**

|  |  |
| --- | --- |
| **Yes** | 10 (100%) |
| **No**  | 0 |

1. **Have you ever made a referral to the Barnsley CAMHS service?**

|  |  |
| --- | --- |
| **Yes** | 5 (50%) |
| **No**  | 5 (50%) |

1. **Can you advise the approximate number of people that you have referred to the BREATHE service in the last year?**

|  |  |
| --- | --- |
| **0**  | 2 (40%) |
| **1 - 5**  | 2 (40%) |
| **6 – 10**  | 1 (20%) |
| **10 +** | 0 |

1. **From your personal experience of referring into the BREATHE service, please can you share with us what you felt worked well and the reasons why in the space provided below?**

4 people provided a response to this question.

|  |
| --- |
| The service was able to prevent admission in some cases and has been able to support many of my colleagues with optimising medication to improve patient quality of life. Patients generally prefer not to travel far for treatment and almost without exception would prefer to be cared for at home where this is possible, this is something the BREATHE team have been able to facilitate. Patients have felt they have good support and access to the team and seemed more confident managing their conditions following contact. |
| Referral process was simple, team were easily accessible via the phone |
| I have not made a referral but utilised contacting the team for updates or answers to queries from patients |
| An excellent avenue to use for patients with acute exacerbations of COPD which are difficult to control. Easy referral process. The form is not too lengthy. Response seems timely. Also useful for a patients with diagnostic uncertainty. |

1. **From your personal experience of referring into the BREATHE service, please can you share with us what you feel could be improved upon and the reasons why in the space provided below?**

4 people provided a response to this question.

|  |
| --- |
| As you will be aware asthma and COPD often co-exist and where a person has both the service has been less helpful. It is difficult to make care seamless at present as if a patient has received telephone advice we may not be updated and a care plan shared between us and BREATHE would be very helpful, particularly for those with frequent exacerbations and rescue packs. Contacting the BREATHE team has been difficult on occasion and if a person needs seeing quickly to avoid deterioration and admission being able to contact BREATHE and know that contact is planned and when is important for the confidence of the patient and the practitioner when referring. |
| I feel the current provision of only seeing patients with COPD is quite limiting and opening up the service to patients with other respiratory illnesses is a positive step forwards |
| I feel that it would be better utilised in the Community. Many individuals with a respiratory condition cannot make it to hospital for a review and management of their condition. The service needs to be integrated to the Neighbourhoods in which the individual lives and have direct contact with their GPs so that their management plan is endorsed by all involved in their care. Plans for EOL care also need to be discussed early in their diagnosis so that it is in a timely manner and that they know that the condition may be life limiting. |
| It is difficult to sell to patients a BREATHE clinic that is a fair distance from where they live. The cohort of patients that I tend to need to refer tends to be frail and elderly who often don't have access to a car. It can be difficult to know when to make a respiratory or a BREATHE team referral as there is some overlap in the service offered |

1. **Is there anything that you think is particularly good about our plans for the new BREATHE Service in the Community?**

9 people provided a response to this question.

|  |
| --- |
| I think patients will like the ease of access and I hope that this change might mean better working links with the BREATHE team for general practice in Barnsley. Wide range of respiratory conditions supported for breathlessness, this will be really helpful for management of conditions outside of COPD. |
| Wider range of conditions covered is good |
| I feel that the plans set out will better meet the needs of the individuals living with these conditions. I would wholeheartedly endorse the fact that patients only go into hospital when necessary and that their discharge is timely so that they do not contract any other infection. They are best cared for in their own home and the Clinical expertise which facilitates this service and also those who practice in Community are more than able to care for these patients in surroundings which the patient feels most comfortable |
| Improving access will be good |
| I like the name ‘Breathe in the Community’. This informs other services (especially within the hospital) that the service is a community service. The hospital currently uses the BREATHE service for advice and support meaning that we are often providing that support for acute patients who are not medically fit for discharge. I think the role of the BREATHE service within the hospital is not clear to other health care professionals and the new name makes it clear that it is a community service. I like the idea of being based within a neighbourhood and having a caseload of patients within that neighbourhood. This would allow for better continuity for patients and the nurses. It would also allow the service to build professional, working relationships with GP practices and other health professionals within that neighbourhood. We can then encourage referrals from primary care for patients who require support to help manage their condition and those at risk of admission to hospital. I like the idea of clinics for patients who are not housebound in their own neighbourhood. This could include new referrals, ongoing condition management, patients in an exacerbation, post discharge follow up and oxygen reviews. Housebound patients would still need to be reviewed at home. |
| A service delivered in the patient's own home sounds great as advice and support can be given that's specific and relevant to the patient's typical environment. |
| Currently, the biggest workload for team is in-hospital inpatient work, which I don’t think the current specification outlines. The current spec wants respiratory nurses visible in the community, seeing patients in their own homes. Ideally the respiratory nurses should be embedded within the community services and be present in GPs surgeries. Currently (and pre-Covid) the bulk of the workload is in-patient assessments and these are not always assessments for Early Supported Discharge, they’re general respiratory assessments or inpatient Long Term Oxygen Assessments and these take a substantial amount of time. This often means we cannot always review patients who are referred in for support in the community as quickly as we would like to. |
| Positive that there will be more of a community focus |

1. **Is there anything that you think we could do differently as part of our plans for the new BREATHE Service in the Community**

9 people provided a response to this question.

|  |
| --- |
| I am a little concerned about diagnostics, if the service is moving from site to site it will not be practical to have large amounts of equipment and I wonder if patients may still have to travel quite a bit for investigations. I am a little concerned that breathlessness treatment isn't really explained in the description, I wonder if perhaps a physiotherapist might be involved for dysfunctional breathlessness for example as this often accompanies other diagnoses (I would really like to see this as up to present it is very difficult to manage/refer these patients). |
| I would hope that the new service might cover those patients recovering from Covid-19 with long-term respiratory symptoms |
| To ensure that there are strong links to the End of Life (EOL) team and that decisions are made by clinicians in a timely manner and that the individuals future wishes are listened to and documented for all involved in their care. |
| Formalise a diagnostic uncertainty pathway |
| A separate hospital and community team would allow staff and patients to have greater continuity of care. At the moment staff work within both areas. Staff may typically work one week in the hospital a month and three weeks in the community. This can be difficult for new staff to be confident in both sides of the service. Hospital oxygen reviews can be complicated and it is difficult to build confidence when not routinely performing them. At the moment the hospital (in-reach nurse) performs the hospital oxygen reviews. This may be better performed by the oxygen team who have confidence completing oxygen assessments as it is part of their daily work.  |
| I have always felt the team is unique and dynamic. Most of our patients are picked up in hospital or self- referral from our past patients. When patients call us we see them at home within 24 hours. Having a consultant working with us means we can get prescriptions quickly if GP is unable to see them, and if we are particularly concerned about a patient’s worsening or continued condition, we are able to get them seen by the consultant quite quickly in clinics. Sometimes the clinics are on the hospital grounds, but that is often easier for the patient due to transport issues or location of the planned community clinic. We have a good rapport with patients, and they do seem to like the support of the team. I feel that there are a number of ways our team could be improved to be more diverse and multidisciplinary. We currently receive no referrals from GPs. We would welcome GP referrals so that we can get to patients to support them before they get to hospital. This would greatly reduce the work load on the one in-reach nurse. We have often discussed the value a physiotherapist could bring to our team, to work with patients who appear to have frequent non infective exacerbations and anxiety. Although we make many referrals to other services, patients with anxiety often won’t reach out. Working together at the point of recovery, within the patient’s own home where they feel safe and comfortable, may greatly improve their overall outcome and management. We have discussed the possibility of some teaching sessions with patients. Many are given a diagnosis and never fully explained what their disease is and what it means for them. I personally feel that, teaching them about their own illness, and given the right tools, as well as ensuring they are using the right medications and devices for them, patients would feel more empowered to manage their disease better. We enjoy working with the Community Matron team, and would happily work with practice nurses to provide support and advice. |
| Alongside colleagues from Pollution Control, I lead on the air quality work programme across Barnsley. Given the strong links between respiratory conditions and air quality, I hope that this is included as the BREATHE service. Air pollution is the biggest environmental risk to health. A recent report from The Lancet Commission on pollution and health (2017), estimates that within the UK, air pollution is linked to 50,000 deaths each year and causes more harm than passive smoking. Air pollution contributes to an increased chance of developing lung cancer, increased risk of heart disease and increases in asthma, coughs and bronchitis. Indoor and outdoor air quality should be key considerations for someone with a respiratory condition, but often this is overlooked. For instance, keeping the engine running while stuck in traffic or waiting to collect someone significantly contributes to an increase of air pollutant levels. Schools, hospitals and bus stops in particular are hotspots, as firstly, idling is more likely to happen at those locations and secondly, such areas are populated by vulnerable groups such as children, older people, and those that are unwell, particularly those with respiratory conditions. Please consider including advice (simple tips and pointer) about air quality. This can start with the patient's home environment - keeping rooms well ventilated, being careful when using cleaning products, domestic fires etc. There is a range of resources and information available on the Clean Air Hub that may be of interest: https://www.cleanairhub.org.uk/  |
| The team have just appointed a wonderful leader and changes are already in the making. The team is evolving into a really good, dynamic team. Talk to the people who have experienced what does and doesn’t work over the last few years- we could all work together to develop a much better service for our patients.  |
| Base a hospital team at Barnsley Hospital to concentrate on in-reach, ESD and home oxygen referrals. Have a community base for BREATHE staff in individual localities |

1. **What would give you confidence that the new service is working for patients living with respiratory conditions, their families and carers?**

8 people provided a response to this question.

|  |
| --- |
| Hearing good feedback from patients and carers, who will tend to feedback about recent experiences naturally when spoken too. Seeing evidence that less people are requiring treatment in hospital. Good numbers of people being seen by the new service. Easy referral and quick action when required even if initially this is more advice. |
| Prompt assessment either remotely or F2F, good communication between the GPs the BREATHE service, knowing that the BREATHE service can tie in/refer onwards to other community teams such as the community matrons |
| For the service to be visible in the Community, to work collaboratively with all community practitioners and not be seen as a Hospital based service but a Respiratory service which covers all care environments. To have a focus not just on COPD but also ILD as a great deal of patients who have fibrosis feel they are left to manage alone. |
| Continued good quality and timely letters from clinics |
| Having the capacity for same day appointments for patients in an exacerbation of their condition. Patients ringing into the service, rather than presenting at ED or ringing 999 wherever possible. Reducing hospital admissions and length of hospital stay. GPs and other health care professionals referring into the service. |
| A lot of our patients call into the service before calling GP or 999. I have always felt proud of the fact that we have a good rapport with them, and that they feel they can do this. We also have a lot of relatives who call into the service to refer or just for advice. I would hope that this would continue in the future with a different or new team if this is how the service would be moving forward. What currently works well is that patients are visited by different members of the team rather than one ‘key worker’. Patients seem to prefer this. More referrals into the service should mean less hospital admissions. I feel that if patients are referred into the service sooner, they may be less likely to end in a hospital admission. If GPs commence treatment for infective exacerbations and refer to the service, the team may be able to manage them at home before the point of admission. This would be a great success, along with early education. |
| A faster response time when patients are referred, or self- refer into the service. We should have the capacity to go out and assess the patients in their own homes- that day. We do receive positive feedback from our patients and their families- they really do appreciate the service. The majority of the caseload comes from referrals in from the community from other healthcare practitioners, or self -referrals in from the patients or their families. The in-reach/hospital early supported discharge just doesn’t work |
| Patients and carers contacting the Service sooner for advice and guidance before getting to crisis point and requiring admission to hospital. Evidence that GPs are being proactive and encouraging patients to look at self-management when reducing re-admissions. Improved communication between the Team and other services such as Matrons, GPs and practice nurses. |

1. **Any Other Comments**

|  |
| --- |
| On the whole I am excited to see the new service develop and feel it will benefit patients. Looking at other similar approaches of integrated care outcomes seems positive and I hope this works well in our area. I am certainly keen to support it. |
| As a member of the current BREATHE team I am excited at the description of the new service and hopeful that I will be part of it. |
| The current BREATHE service has been through many changes since the beginning... We have all tried various ways of working, and have found what works well and what does not work very well. We have worked hard to provide presence in all areas asked, which has also meant working hard with other teams within the hospital or in the community. We have struggled at times, but as a team we have overcome difficulties together and always kept the patients as our main priority…We have been flexible in all areas and will continue to do so. Please work with the current team to discuss and agree any changes**.**  |
| In my opinion the team have done a great job since COVID 19 started, supporting patients with COPD remotely, feedback from patients has been positive and they have valued the support and reassurance they have received |
| Barnsley MBC has a duty to monitor ambient air pollution across the Borough. The links between ambient air pollution and respiratory disease are now well known. The monitoring undertaken by the Council is compared against the Government's daily air quality index, where air pollution forecasts and health advice are also provided. Further information can be found at https://www.barnsley.gov.uk/services/polution/air-polution/air-quality/. This information may be of use to BREATHE service users in planning their daily activities, particularly during in high air pollution episodes, so they can limit their exposure and take necessary action (e.g. ensure inhalers are with service users when outside during such episodes etc.) Is there scope for this air pollution information and forecasts to be made available BREATHE service users? I am happy to discuss this further should the CCG wish (my contact details are given later) |

1. **Did we provide enough information for you to be able to comment on the questions we asked?**

|  |  |
| --- | --- |
| **Yes**  | 8 (80%) |
| **Unsure** | 1 (10%) |
| **No answer** | 1 (10%) |

1. **Where did you find out about this survey?**

|  |  |
| --- | --- |
| **Social Media**  | **2** |
| **Colleague**  | **2** |
| **Email**  | **5** |
| **Partner Organisation** | **1** |

**3 people gave us their contact details and asked to be kept updated.**

**Feedback from virtual focus session held with two current patients and one carer of a patient (who have all accessed the BREATHE Service) via Zoom on 14 September 2020**

* Overview provided by CCG of engagement that had been carried out to date: Completed a four week engagement period. Explained challenges of socially distanced engagement exercise.
* Overall people so far were supportive of the proposed changes and developments and were complimentary of the support they have received from the BREATHE Team based at Barnsley Hospital.
* Patient story utilised to illustrate what happens in the service now from a patient perspective and what this will look like in the proposed new service prior to discussing the following questions. The feedback received is below.
* **Topic 1** - People will receive healthcare closer to home: the new respiratory service will be provided locally in the community and delivered to people in their own homes. What are your thoughts on this?

**Summarised comments/ feedback**:

* + It would seem better / a good way forwards for patients to be seen at home where possible especially when they are so poorly.
	+ It would certainly be more convenient to have care closer to home where people can and keep hospital for those people that really need it.
* **Topic 2** - The service will be integrated: the service will combine specialist respiratory nursing and clinical skills, together with GP practices and community services to deliver co-ordinated care, with consistent response times and linked by a Single Point of Access. What are your thoughts on this?

**Summarised comments/ feedback**:

* + Can’t fault it as a sensible approach and positive way forwards.
	+ It is always good for services to be integrated wherever possible for all concerned - both from a staff and patient perspective.
	+ It will enable better communication between services and importantly with patients as sometimes can feel like you fall through the gaps between services or have to repeat your history over and over to different people.
	+ It would be great to have less but more joined up appointments and a wrap- around 24/7 service if at all possible from crisis to rehab.
* **Topic 3** - The service will provide people with confidence to manage their conditions at home, where clinically appropriate supported by the revised BREATHE team, GPs and clinicians in the community (motivation, not just medical). What are your thoughts on this?

**Summarised comments/ feedback**:

* + Would be good to have one point of access and access to ongoing support from a range of services working together.
	+ The current service has been really helpful and it would be good to see this good work being built on and the staff involved.
	+ They have given me confidence to manage my condition at home and the knowledge and tools required. I
	+ It would be good to see the Team have additional support from other services too in order to support the number of patients they have across the borough.
	+ It would be useful for the Team to work closer with Carers and Family members where possible so we can support our family member better and support the Team too.
	+ People underestimate how scary severe breathlessness can be and how it can make you make you feel and the impact that this can have on both you as an individual and those around you. The confusion that this can cause is quite far reaching for everyone.
* Additional Comments;
	+ Family support has been vital for us to be able to work alongside and support services to support our family member.
	+ Discussion about the issues for people living with COPD and severe breathing problems in wearing a mask and the lack of tolerance being shown from other people and lack of acceptance that not everyone can wear a mask or feels comfortable sharing the reasons why they can’t when challenged.

**Summary feedback from meeting held with representatives from the National Union of Mineworkers (NUM) – Yorkshire Area on 17 September 2020**

* Overview provided by CCG of engagement that had been carried out to date: Completed a four week engagement period. Explained challenges of socially distanced engagement exercise. Overall people so far were supportive of the proposed changes and developments.
* Question asked how much of the changes had been driven by Covid-19. Explained that although there was an expansion to Covid -19 rehab pathways this was not solely driven by Covid-19 but by providing care closer to home. Proposals viewed as ‘what people expect as a result of Covid -19 – to be treated in own home’ and it ‘makes sense’ to delay or negate hospital care. It was acknowledged this would be ‘better all round for everyone’ so that more complex cases could be treated in hospital.
	+ It was highlighted that the NUM have engaged with the CCG and current respiratory consultant (Dr Mark Longshaw) over a number of years as one of the greatest concerns for the NUM is the welfare of their retired members. Particularly in relation to those suffering from pneumoconiosis (lung disease caused by dust). The primary pneumoconioses are asbestosis, silicosis, and coal workers' pneumoconiosis or CWP / Black lung. See further <https://www.nhs.uk/conditions/silicosis/> . Major concerns were expressed about lack of patients receiving correct diagnosis and correct treatment due to knowledge understanding and education.
	+ A concern in many former mining areas is experience and awareness regarding the identification of pneumoconiosis. Of particular concern is the lack of understanding of this condition e.g. history and education. There is a belief that education needs to be made stronger on relationship to lung disease and airways. Particularly on achieving an accurate diagnosis in order to 1) supporting patients to claim compensation for industrial illness (disablement benefit) or claiming a lump sum / supporting dependents to claim if somebody dies from the condition and 2) in order that treatment is optimised as often pneumonconioses takes a number of years to manifest and worsens rather than remains static and patients need appropriate information e.g. these patients will benefit from CT scans to aid diagnosis and maybe incorrectly diagnosed as asthma.
	+ **Post meeting note**: this letter and article on the NUM website illustrates the importance of an accurate diagnosis / recording on death certificates (the rules were relaxed in C19): NUM and Conor McGinn MP for St Helens North and Chair of the All Party Parliamentary Group (APPG) Coalfield Communities have written to Secretary of State for Justice on this issue:  <http://num.org.uk/news/pneumoconiosis-during-the-coronavirus-pandemic/>
* It was noted that care planning and patient history should support appropriate onward signposting and previous industrial links and the role that the NUM could play within the broader Neighbourhood Team model in supporting patients to seek assistance for their condition – e.g. proposing that the NUM should link as part the voluntary and community sector to the service once patients diagnosed for support e.g. through monitoring and assisting people.
* Concerns were expressed that that Department of Work and Pensions (DWP) is not up to date with the NHS model of out of hospital care. Particularly as conditions treated in the community are not seen as meeting DWP thresholds for compensation. We discussed that under the BREATHE service patients would remain on the caseload of a service and it was a specialist service so the location should not alter this. It is important to note that good care shouldn’t prevent welfare case – on the caseload – under the care of a specialist service and on the model.

# ****5.**** Next steps

The feedback included within this engagement report will be used to support the development of the service specification. Following submission to Barnsley CCG Senior Management Team and Governing Body, further involvement activity will take place as part of the procurement and mobilisation phases during 2020/21.

A copy of this report and an update detailing the decisions taken by the Senior Management Team and the CCG Governing Body will be sent to everyone who has requested it and provided us with their direct contact details. It will also be published on the CCG website.

We would like to take this opportunity to thank all of the individuals and organisations who have taken the time to share their views and also get involved in the promotion of this engagement activity.

Report produced by NHS Barnsley Clinical Commissioning Group

This report will be available here, visit [www.barnsleyccg.nhs.uk/haveyoursay](http://www.barnsleyccg.nhs.uk/haveyoursay)

If you require this report in a different format please contact us

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