NHS Birmingham and Solihull and NHS Sandwell and West Birmingham Clinical Commissioning Groups

Clinical Treatment Policies – Phase 2

Patient, Public, Stakeholder and Clinical Engagement Report

June 2018
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1.0 Background

In July 2017 the three Birmingham and Solihull Clinical Commissioning Groups (now NHS Birmingham and Solihull CCG) established a Treatment Policies Clinical Development Group. Membership includes clinical and management stakeholders who have met monthly to discuss and assess Evidence Reviews and related draft policies. Membership has included representation from NHS Sandwell and West Birmingham Clinical Commissioning Group.

This clinical and multi-disciplinary group has built on the initial Phase 1 Treatment Policy work, which includes the introduction of 45 new treatment policies. The Phase 1 work was completed in early 2017 but several of the policies have been revised in 2018 taking in to account further evidence, guidance and feedback.

Full details of Phase 1 Harmonised Treatment Policies can be found here - https://www.birminghamandsolihullccg.nhs.uk/your-health/treatment-policies

The Treatment Policies Clinical Development Group provides the required governance and oversight of the programme by:

- Providing direct clinical input and examination of nationally and, where appropriate, internationally available historic and more contemporary evidence research.
- Monitoring project planning, timelines and progress of all treatment policy areas.
- Initial engagement with a range of relevant stakeholders including local provider clinical subject matter experts, local politician members of the Birmingham and Solihull Councils’ Joint Health and Oversight Committee and the Sandwell Council equivalent, and patient and public representatives.
- Ensuring the appropriate input, endorsement and sign off of the updated policies.
- Interconnecting with existing Birmingham and Solihull CCG Governance frameworks by submitting updated policies to the Clinical Policies Advisory Group (CPAG) and the Clinical Policies Quality Sub Committee.

2.0 Introduction

As of the end of April 2018 the Treatment Policies Clinical Development Group initiated Phase 2 of the Harmonisation Policies Programme

Preparation for Phase 2 included the following high level process steps:

- Review and evaluation of Evidence Reviews for each draft treatment policy (prepared and presented by clinical colleagues from NHS Solutions for Public Health, Arden & GEM Commissioning Support Unit or by clinical colleagues in Birmingham and Solihull Local Authorities’ Public Health services).
- Assessment and evaluation of expert clinical stakeholder feedback and commentary on both the Evidence Reviews and the ensuing draft policies.
Input was sought from multiple clinical stakeholders, including clinical directorates/departments located in local providers (such as University Hospital Birmingham FT – QEH or HGS, Birmingham Women’s and Children’s FT and Royal Orthopaedic Hospital FT).

- Evaluation and consideration of NICE Guidance and other regulatory and clinical guidance papers (including relevant Royal College documents) when deliberating and drafting the policies.
- Full review and drafting of the initial policies in preparation for the broader clinical and public engagement detailed in this report.
- Interim implementation of four policies (orthopaedic policies) based on the strength of evidence presented.
- Communication updates to local Members of Parliament and in January 2018 presentation at the Birmingham Joint Health Oversight Committee (JHOSC).

Twenty-two policies were agreed to be looked at during a six-week patient, public and clinical engagement period. The list of policies, approach and sample patient facing materials were supported by Birmingham Joint Health Oversight Committee.

For the clinical engagement it was agreed that primary care clinical and managerial colleagues would have an opportunity, with other key stakeholders, to have an opportunity to review and comment on the draft policies.

For the broader public engagement it was agreed that a series of public events, facilitated meetings, promotional activities, website articles, social media and questionnaires would be used to approach and engage with members of the public, patients and key patient support groups or charities.

### 3.0 Summary of clinical and public engagement

The six week period of broad clinical and public engagement ran from Monday 14 May until Friday 22 June 2018. This engagement covered the areas covered by both NHS Birmingham and Solihull and NHS Sandwell and West Birmingham Clinical Commission Group.

The public and patient engagement consisted of:

- A patient and public questionnaire, a clinical engagement questionnaire
- Targeted outreach engagement events
- General engagement events
- Media, social media and marketing materials, including posters sent to all GP surgeries.

- Targeted outreach engagement resulted in over 100 conversations across 12 engagement opportunities at leisure centres, community groups and events.
A total of 189 patient and public questionnaire responses were obtained, the majority of which (103), were obtained during the outreach engagement. The total of online responses was 86. The survey covered the following topics:

- The principles underpinning the proposals for the harmonisation of policies
- People’s experiences of the treatments considered in the proposed policies
- To what extent people agreed with the proposed policies

**Stakeholder engagement consisted of:**

- A thorough briefing sent to over 500 stakeholder organisations. All organisations were asked to both feedback on the harmonisation of policies and encourage their staff, members or communities to attend one of the engagement events.
- Direct correspondence and feedback from organisations was encouraged through the stakeholder briefing. (See Appendix 10)

**Clinical and health staff engagement consisted of:**

- Briefing video [https://youtu.be/FTCU_4b4sh0](https://youtu.be/FTCU_4b4sh0) sent to all primary care/GPs, featuring two key members of the Treatment Policies Clinical Development Group. This video explained the principles of the harmonised treatment policies, highlighted some of the proposed changes and invited feedback.
- Targeted correspondence to specialist clinicians across the West Midlands in secondary and tertiary care locations asking for their feedback on the policies relating to their clinical speciality.
- Clinicians were invited to circulate the request for policy review to colleagues and asked to provide evidence based clinical feedback by email on the policy pertaining to their specialist clinical area.
- Reminders were sent at regular intervals throughout the engagement period to remind clinicians of the closing date for feedback.

**Key points for consideration**

- Most respondents strongly agreed with the principles that underpinned the development of the proposed policies, however, the highest number of respondents (4.32%) strongly disagreed with principle six - to stop offering cosmetic treatments - followed by (3.23%) strongly disagreeing with principle five - to prioritise treatments which provide the greatest benefits to patients (see section 7)

- All the findings from the questionnaire are key and need to be considered (see section 7)

- The largest response to the engagement process is in relation to the proposed cough assist policy. The proposed cough assist machine policy is not supported by the majority response to the engagement. There has been a detailed response to express this from clinicians, organisations and charities, an MP and members of the public who state the reasons for their opposition.
  - Reasons for opposing the proposed policy include the need to consider more clinical evidence, the creation of a postcode lottery as other nearby CCGs
commission cough assist machines. The cost of hospital-stay when a cough assist machine cannot be commissioned for the patient at home is referenced as a financial consequence of the proposed policy. Quality of life is a major concern and the detrimental effect that non-commissioning of cough assist machines would have on the patients, both for adults and children, the family, and carers. The lack of an alternative solution to cough assisted machines is also discussed as they are only prescribed as a final clinical response when all alternatives have been tried. There are also implications for workforce planning if cough assist machines are not commissioned as most physiotherapists do not have the competencies to train carers in alternatives to the cough assist machine therapy. Patient safety is also raised as an issue as not enough pressure exerted leads to ineffective expectoration and too much pressure applied may cause trauma. All further reasons are detailed in the report in section 5.4 to section 5.4.2 and section 6.2 to 6.8).

- Most people agreed that the assisted conception proposed policy in terms of age for treatment should be the same across the CCG geographical areas; some even felt it should be applied nationally to prevent a postcode lottery. However, some people fed back their concern on access to treatment being based on age, it was felt that the policy was unfair to same sex couples and feedback on future relationships when those bearing children had failed, other aspects of the proposed policy were discussed and comments made for consideration when final decisions were made, see section 5.3 to 5.6 and sections 6.1.1 and 6.1.2

- Feedback on the draft proposal for complementary and alternative therapy policy asked for the benefits of such therapies to be further considered, for example in cases of mental health illness, children's diseases such as Potts syndrome, neck and back pain and Parkinson's diseases. It is asked in the documents submitted and the verbal comments received that all feedback provided both in terms of patient anecdotal evidence and information described as evidence that benefits to patients are considered (sections 5.7 and 5.7, sections 6.3 to 6.3.6).

- The musculoskeletal policy reviewed during the engagement by stakeholders, patients and members of the public was commented on. Comments included the request that knee arthroscopy should still be considered if pain control was unsuccessful and that further alternative treatments for knee arthroscopy in degenerative knee disease be explored. Concerns were voiced about the proposal to limit availability of hip arthroscopy to provider trusts able to fully support patients with a multidisciplinary team due to the ability of some patients to then access such services. The preferred choice of arthroscopic surgery over open surgery is perceived as limiting patient choice (sections 5.2, 5.6, 6.1.1,6.12)
• Comments received on the draft policy for port wine birthmark raised concerns on the psychological impact of not having laser treatment. It was felt that particularly for children, bullying could result and that offering only camouflage makeup when laser treatment could reduce the birthmark was inappropriate (sections 5.2 and 5.7). Social prescribing and information on self-care were discussed and seen to be important for patients to be able to manage their condition if proposed policy changes were made and as an alternative for GPs when explaining to patients changed treatment options.

4.0 The engagement approach and methodology

To enable wide and inclusive engagement, a questionnaire was developed as an engagement tool to allow people to feedback their views (section 11.10). All stakeholders (over 500 stakeholder organisations across Birmingham, Solihull and Sandwell) were emailed and informed of the engagement opportunity, the time period for the engagement, and how to access the questionnaire online or by hardcopy on request. People were also informed about how to get involved via press releases and social media. Clinical and staff engagement were also part of the engagement process.

As the content of the engagement is complex, information to allow understanding and therefore meaningful engagement was prepared and shared on the Sandwell and West Birmingham and Birmingham and Solihull websites. This included a table to explain the content of current policies and the proposed changes:

https://sandwellandwestbhamccg.nhs.uk/harmonised-treatment-policies


Outreach engagement was also undertaken to allow people to have face to face conversations on the proposed policy changes. The outreach engagement included five events, where people were asked to book online or call to register their attendance at locations across Birmingham and Solihull, Sandwell and West Birmingham. Further events on the proposed changes to the assisted conception policy and the cough assist policy were also arranged. To target parents of young children, young people, and as wide an age range and demographic as possible visits to leisure centres were also organised.

4.1 Communication Channels:

Both Twitter and Facebook were used for public and patient engagement to both promote the online survey and encourage attendance at the engagement event. Twitter impressions through the two CCG accounts reached almost 17,000 through over 60 tweets. 235 clicks through to the websites were recorded and 46 likes were received on the tweets. Five key posts were published on Facebook, resulting in a reach on over 6000 people.
Example posts and tweets can be view in appendices 12.8.

Two press releases were sent to the media in the Birmingham, Solihull and Sandwell area (Appendices 12.2 and 12.3). Coverage was obtained in a number of publications and websites including The Express and Star newspaper and the Healthwatch Birmingham website (see extract and links below.)

**Have a say on health policy changes 29/05/2018 Express and Star (Page 15)**

Patients are being asked to share their views on proposed changes to a variety of health treatment policies in Sandwell. Policy changes include those relating to musculoskeletal treatments, assisted conception, breast implant revision surgery, assisted cough machines, acupuncture and treatment for snoring.

Health Watch Birmingham Website:  
https://healthwatchbirmingham.co.uk/consultation/harmonised-treatment-policies/

SCVO website:--  

**4.2 CCG Staff engagement:**

Information on the engagement events and activity was sent out in the BSOL CCG staff newsletter and in SWB CCG’s weekly Nick’s News several times during the engagement period.

**4.3 Clinical engagement approach:**

Clinicians who worked within the specialist areas covered by the draft policies were identified across Birmingham, Solihull, Sandwell and West Birmingham. Specialist teams which treated patients from the above mentioned areas but were outside of these areas, for example the Specialist Respiratory Team at University Hospitals of North Midlands were contacted regarding the draft cough assist policy.

Medical Directors and Chief Nurses of the NHS Provider Trusts within Birmingham, Solihull, Sandwell and West Birmingham were also made aware of the clinical engagement phase and asked to encourage their clinicians to respond.

Clinicians working at private hospitals undertaking specific procedures covered by the draft treatment policies were also emailed and asked to provide comments or feedback.

Contract managers at both Birmingham and Solihull and Sandwell and West Birmingham CCGs were also asked to contact the provider trust for which they were responsible, to raise awareness of the clinical engagement with mangers and to encourage clinicians to engage.
If a clinician or stakeholder had specific clinical questions or wanted to provide direct clinical feedback, then this was provided primarily through email, though if a discussion was required then this was facilitated by the Clinical Nurse Lead for the harmonisation programme, to ensure that all clinicians and stakeholders were given equal opportunity to discuss their review of the draft policy with a clinician whom had been involved in the policy development.

Throughout the engagement period, clinicians were sent reminder emails of the closing date of the engagement period encouraging review of the policy they had been sent and requesting feedback to give clinicians the opportunity to respond within the specified timeframe.

Clinical feedback was recorded against the specific policy and can be found in section 9.0.

177 GP practices in the Birmingham and Solihull area and 85 GP Practices in the Sandwell and West Birmingham area were contacted to both help promote the events to their patients and give feedback themselves. A letter and poster was sent to every practice, updates were included in the CCG GP newsletters

5.0 Outreach engagement

- Over 100 conversations took place with patients at over 12 identified engagement opportunities comprising of leisure centres, community groups and meetings. Please see the table in section 5.1.

- Events were planned to enable stakeholders, patients and the public to attend and give their feedback on the proposed policies. These were arranged at locations across Birmingham, Solihull, West Birmingham and Sandwell. The events were advertised on the website, in the information sent out to stakeholders, the media and via social media. There was low interest in attending the events and some of the events had to be cancelled as no one had registered. However, when people did attend, even in small numbers the feedback given was rich and insightful and led to one of the case studies detailed later in the report (see page 13.)

- Further events were organised so that people could feedback in person on the proposed assisted conception policy and the proposed cough assist policy. An assisted conception event was held in Solihull. No one attended. However, the opportunity was taken to talk to three mothers attending a baby massage class in the building where the meeting had been arranged and questionnaires were completed. A group of patients attending the Birmingham Women's Hospital assisted conception clinic were individually interviewed. Please see their feedback on pages 18-21.

- Most of the feedback was gathered when visiting places where people were already in attendance, for example, at the leisure centres, at patient outpatient appointments and organised patient group meetings. In total, 103 questionnaires
were completed during these engagement opportunities along with face to face interviews and information was provided for case studies.

- Working in partnership with a lead clinician at the Heartlands Hospital in Birmingham and the Muscular Dystrophy Society UK a patient meeting took place at the hospital on Tuesday 19 June; please see the feedback from this meeting on pages 15-17.

- At two of the general engagement events feedback was given on the draft patient leaflets. Attendees selected a number of draft policy leaflets and commented on the language and content. A sample policy leaflet can be found in appendices, section 11.6.
## 5.1 Engagement event summary:

<table>
<thead>
<tr>
<th>Location</th>
<th>Date</th>
<th>Target audience</th>
<th>Method</th>
<th>Completed surveys</th>
</tr>
</thead>
<tbody>
<tr>
<td>Happy Faces Stay and Play, Rowley Hall, Windsor Road, Rowley Regis</td>
<td>15/05/18</td>
<td>To speak to parents</td>
<td>1-to-1 chats with the public</td>
<td>CANCELLED due to short notice following launch being delayed</td>
</tr>
<tr>
<td>North Solihull Sports Centre</td>
<td>21/05/18</td>
<td>To speak to parents waiting for their children at swimming lessons</td>
<td>1-to-1 chats with the public</td>
<td>25</td>
</tr>
<tr>
<td>Gynaecology Outpatients Birmingham Women's Hospital</td>
<td>24/05/18</td>
<td>Patients who might need or have an interest in assisted conception</td>
<td>1-to-1 chats with public</td>
<td>8</td>
</tr>
<tr>
<td>Bartholomew House, 142 Hagley Road, Birmingham</td>
<td>25/05/18</td>
<td>General engagement on all policies</td>
<td>1-to-1 chats with public</td>
<td>CANCELLED no attendees</td>
</tr>
<tr>
<td>Brushstrokes Community Centre, St Philips Parish Centre, Messenger Road, Smethwick</td>
<td>30/05/18</td>
<td>General engagement on all policies</td>
<td>1-to-1 chats with public</td>
<td>CANCELLED due to school holidays rescheduled to Brasshouse 14/6</td>
</tr>
<tr>
<td>Erdington Leisure Centre</td>
<td>31/05/18</td>
<td>--General engagement on all policies</td>
<td>1-to-1 chats with public</td>
<td>21</td>
</tr>
<tr>
<td>Location</td>
<td>Date</td>
<td>Activity Description</td>
<td>Type of Chats with Public</td>
<td>Attendees</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>------------</td>
<td>---------------------------------------------------------------------------------------</td>
<td>---------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>BSOL Solihull Women’s Institute</td>
<td>04/06/18</td>
<td>Patients who might need or have an interest in assisted conception</td>
<td>1-to-1 chats with public</td>
<td>3</td>
</tr>
<tr>
<td>Washwood Heath Health &amp; Wellbeing</td>
<td>06/06/2018</td>
<td>General engagement on all policies</td>
<td>Group chat with public and patients</td>
<td>8</td>
</tr>
<tr>
<td>YMCA Sandwell</td>
<td>11/06/2018</td>
<td>General engagement on all policies. Feedback on cough assist patient leaflet given.</td>
<td>1-to-1 chats with public and patients</td>
<td>1</td>
</tr>
<tr>
<td>Highfield Hall Community Centre, 127-129 Highfield Road, Birmingham</td>
<td>13/06/2018</td>
<td>Patients who might need or have an interest in assisted conception</td>
<td>CANCELLED – no attendees</td>
<td></td>
</tr>
<tr>
<td>Stechford Leisure Centre</td>
<td>14/06/2018</td>
<td>To speak to parents waiting for their children at swimming lessons</td>
<td>1-to-1 chats with public</td>
<td>8</td>
</tr>
<tr>
<td>YMCA, 38 Carters Green, West Bromwich</td>
<td>14/06/2018</td>
<td>Patients who might need or have an interest in assisted</td>
<td>1-to-1 chat</td>
<td></td>
</tr>
<tr>
<td>Location</td>
<td>Date</td>
<td>Description</td>
<td>Engagement</td>
<td>Notes</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------------</td>
<td>--------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Brasshouse Community Centre, Brasshouse Lane, Smethwick</td>
<td>14/06/2018</td>
<td>General engagement on all policies. Feedback on the draft patient leaflets given.</td>
<td>1-2-1 chats with public</td>
<td>3 &amp; 1 case study Representative from Healthwatch in attendance</td>
</tr>
<tr>
<td>Saffron Centre, Moseley Road, Birmingham</td>
<td>18/06/18</td>
<td>General engagement on all policies</td>
<td>Group chats with public and patients</td>
<td>CANCELLED No attendees</td>
</tr>
<tr>
<td>Smethwick Swimming Centre</td>
<td>18/06/18</td>
<td>General engagement on all policies</td>
<td>1-to-1 chats with the public</td>
<td>21</td>
</tr>
<tr>
<td>Heartlands Hospital</td>
<td>19/06/18</td>
<td>Patients, clinicians and support organisations who might need/use or have an interest in cough assist machines</td>
<td>Group chats with patients, clinicians and stakeholders</td>
<td>0 – case study driven</td>
</tr>
<tr>
<td>Friar’s Gate public forum</td>
<td>20/06/2018</td>
<td>General engagement on all policies</td>
<td>Group chat with public and patients. Feedback on the draft patient</td>
<td>4, including a representative from Healthwatch</td>
</tr>
</tbody>
</table>
5.2 Sentiment analysis from the outreach engagement

During the outreach engagement conversations, and as people completed the questionnaire, additional comments were recorded to inform sentiment analysis:

- People felt that all policies should be the same; some said across the CCG areas involved in this review, others felt nationally.

- Many people believe the policies should be more on a case by case basis and that education is needed for patients to understand the complexities of surgical procedures and post-operative recovery for example and the need for physiotherapy.

- Some treatments such as port wine stain removal shouldn’t be treated as cosmetic as it has a massive impact on the mental health and wellbeing of an individual, especially if they are young and in school therefore more likely to be teased or bullied for how they look.

- Many felt more rationale or reasons why the changes were needed should be shared with the public.

- When the draft patient leaflets were looked at comments were received about the appropriateness of language, the need to have more reasons why decisions had been made and links to support or self-care advice as appropriate.

5.3 Assisted conception sentiment analysis

- The discrepancy in the age limit for assisted conception across the Birmingham and Solihull was an example of how people felt the same policy should apply to all, no matter where they lived.
• Eligibility for assisted conception for same sex couples was raised as being unfair. Fairness and equality, particularly with regard to sexual orientation was raised several times.

• The considered proposal for assisted conception was felt by some not to have considered modern lifestyles where women have children later in life

• Comments were made that the proposed assisted conception policy was unfair to same sex couples

• The proposed restricted age limit for assisted conception was unfair to women who had suffered illnesses such as cancer, meaning they were unable to have children until they had recovered and subsequently received assisted conception treatment.

5.4 Cough assist policy sentiment analysis

• Cough assisted machines proved a controversial issue. One individual would like everyone who has been part of the clinical assessment team to take into consideration all of the clinical evidence.

5.4.1 Feedback from Heartlands Hospital Birmingham – Cough Assist Machines Discussion, Tuesday 19 June 2018

This event was organised in partnership with the lead specialist adult physiotherapist at Birmingham Heartlands Hospital and Muscular Dystrophy UK. Five people attended included two patient representatives, the engagement and involvement lead from Muscular Dystrophy UK, the specialist paediatric physiotherapist from Heartlands Hospital and a Muscular Care Advisor also from the Birmingham Heartlands Hospital.

Clinical Evidence

The group began by voicing their concerns that the clinical evidence recently considered by the CCGs when drafting the proposed policy on cough assist was incomplete and that further evidence should be considered before any final decisions were made.

A Postcode Lottery

Concerns were voiced over what appeared to the attendees to be a postcode lottery. The group informed that patients living in CCG areas nearby such as Dudley, Walsall, Wolverhampton and Staffordshire were able to access cough assist machines due to their local CCG policy which enabled cough assist machines to be commissioned for those who need them. The group also explained that provision of cough assist machines was also random, not only down to postcode but by disease pathway and that those suffering from certain conditions referred to a specialist centre out of area may also have access to cough assist machines. An example given was where patients with motor neurone disease are accessing cough assist machines no matter what their address as they are being
treated at a centre of excellence in Stoke, where cough assist machines are commissioned.

**Funding or clinical decisions**

There was concern expressed by the group that funding decisions over-ruled clinical decisions. The point was made that the Heartlands Hospital respiratory clinicians will only use cough assist machine when it is the only option left to help a patient to stay well. They talked about costly lengths of stay in hospital, often in intensive care or special care units for patients needing cough assist machines in comparison to patients where cough assist machines were commissioned in the community. They felt the commissioning of cough machines resulted in less frequent admissions to hospital and compared the cost of hospital stays, the quality of life experienced for the patient, the emotional and financial costs to the family to the cost of commissioning cough assisted machines. It was emphasised by the clinician present that the cough assist machine is part of a cough augmentation strategy and is often the last thing to try but is often the only thing that makes a difference.

**Individual Funding Requests**

The group discussed independent funding requests. They shared concern that clinicians on the independent funding requests panels did not have the clinical knowledge and experience to make decisions on cases such as those where hospital clinical specialists had recommended the need for cough assist machines. They felt this was an example of funding over-ruling clinical expert decisions. It was therefore felt that the route of independent funding requests was inappropriate for their patients but currently the only option open to them to have cough assisted machines commissioned. They talked about the unfairness to patients being cared for in the same ward being offered a different care pathway eg those who lived in a CCG area where cough assist machines were commissioned and those who did not. The group gave the following examples:

**Example cases shared by the group**

The group particularly wanted to feedback into the engagement process on a recent individual funding request that had been refused. Clinicians have been told to use an IFR application as an alternative route to apply for funds for a home-based cough assist machine. The Specialist Paediatric Physiotherapist spent 14 hours gathering evidence, writing and chasing a recent IFR request for a two year old girl. This little girl has had 68 days in intensive care in the two years of her life, seven courses of antibiotics from her GP and ten hospital admissions with pneumonia. Her clinical team have tried all alternative treatments and the only treatment that helps her is to use a cough assist machine whilst in hospital.

The child is a twin, from a family with five children. Every time the child has a hospital stay it has a massive impact on the whole family. A cough assist machine at home would help to avoid hospital stays, making it better for the patient but also her parents, brothers and sisters.
The patient’s hospital stays equate to a cost of over £40,000. The cost of a cough assist machine is £4000 (approx.), plus an annual maintenance cost of £500 (approx.).

Other cases were referred to in the group discussion to illustrate the group’s belief in the need for commissioned cough assist machines, for example, of children who have been given a cough assist machine to use at home and have not had an emergency admission since. A case of two brothers was highlighted where one machine was given between two children. Unfortunately, one brother lost his life and his family felt that this would not have been the case if the boys could have had a machine each.

Another family has fundraised £4000 to buy their own machine but now feel concerned that they will still have to find approximately £500 a month to service the machine.

A 39 year old woman from a neighbouring area was given a cough assist machine after several hospital stays due to pneumonia. All alternative treatments had been tried but only a cough assist machine worked. She has responded well to her home based cough assist machine and has not had a hospital stay since.

5.4.2 Interview with Muscular Dystrophy Patient

A patient attended one of the events to tell us his story so that it could be fed into the engagement process. For the purpose of this account real names have been changed:

Bob (patient with Musculo Dystrophy whose late sister also suffered from Musculo Dystrophy):
"My sister would have benefitted from a cough assist machine but unfortunately she lived in an area where they were not commissioned. She had very poor respiratory function, issues with swallowing and associated problems. She had multiple respiratory and chest infections resulting in pneumonia. She had three very severe bouts of pneumonia where she needed an emergency hospital admission. The last time this occurred she spent seven months in hospital. She was able to use a cough assist machine when in hospital. A cough assist machine would have helped with my sister's acute episodes as manual techniques didn't work for her. There are only 70000 people in the UK with MD and only a small number of these have such severe respiratory problems that they would need a cough assist machine. NHS England has given advice that commissioners should fund these machines. Why then did my sister not get one? The cost of 7 months in hospital is massively more than the cost of a cough assist machine, which is less than £5000."

5.5 Feedback from visit to Gynaecology Outpatients Department, Birmingham Women’s Hospital – Assisted Conception Discussion

Five in depth conversations with eight patients (three couples and two individuals) visiting the assisted conception outpatients clinic at Birmingham Women’s hospital were interviewed to find out their views on the proposed policy on assisted conception. Interview with IVF Patients.
Couple A: Two women in a same sex relationship (White British, 30-35 years) referred to as patient one and two for confidentiality:

- Patient 1: “I don’t agree that the age should be lowered to 40. Why wouldn’t you just put the age up to 42 for everyone? Some people even have kids up until 44 or 45 – it shouldn’t be based on age, we should look at criteria in terms of your health. It seems wrong to discriminate against age when you never know what age you’ll be when you meet the person that you want to have kids with.”
- Patient 2: “We’re a same sex couple and we want to have IUI but we’ve been told that we have to pay for it ourselves. They’ve told us that we’d only be funded by the NHS if there was something wrong with one of us. How do we even know if we can or can’t get pregnant? Everyone should be treated fairly and equally and I don’t think we have been. Why should we have to pay? Single sex couples shouldn’t be treated differently. It’s not right that you get funding if you’re heterosexual. We’re lucky that we both have good jobs and we can afford to pay but not everyone can.
- Childlessness: I think people should be treated fairly no matter if one half of the couple has had a baby before. If they’re in a new relationship then it’s not right to say that you can’t have a baby.
- Previous treatment: It’s wrong that the treatment is not available to a couple if one of them has already had fertility treatment.
- Sterilisations: I think that counselling should be in place before somebody has a vasectomy because things and people change in the future. If people are healthy then they should be considered for IVF.
- Smoking: should be a lifestyle choice. I think as long as the mum stops during pregnancy then that’s fine.

Individual B

- I think that 40 is too young to say that you can’t have any more treatment. Women are having children later in life and doing their career first. Two people need to be breadwinners these days. It’s so much harder to rely on one half of the couple to be the main breadwinner. I think you need to take more things into consideration than just age. Health and lifestyle should be looked at – it’s not all about age.
- I worked and became financially secure before I thought about having children. I wanted to buy a house by the time I was 40. I’ve done that. I’m 41 now, married and financially very secure so I’m ready to have a baby. I’ve done everything to prepare myself for the moment and now we’re ready. However, we’ve been having problems trying to have a baby and we’ve now discovered that we are not covered on the NHS for IVF treatment. I’m 41 and will be 42 in a few weeks, so I’m already too old to be covered – although I might be if I was in the other area where it’s currently up to 42 now.
- It’s really disappointing to know that even though I’ve worked hard and done everything I can to create a stable home and life for a baby, I now have to pay for the treatment to try to have a baby.
- IVF isn’t just about getting pregnant, it would also help ensure that you have a healthy baby and screen for any problems. My brother has a disability and my mum really struggled. For me the family history is really important too when thinking
about having a baby.

Policy specifics:
- Childlessness – It should be a decision between the couple whether or not to have a child. It’s not up to the state to decide who can have a baby or not. Children should be brought together through love. Nobody knows what will happen in the future and whether or not you will want to have a baby with a different partner.
- Previous fertility treatment – If it has not worked for one half of the couple in the past then I think that they should be allowed to try again if they’re in a new relationship. Sometimes it’s just about compatibility of the couple and it might be successful this time with a different partner.
- Body Mass – I think that this should be up to the individual. It should be whether they feel well and healthy, not what their body mass is saying. I’m 41 and go to the gym regularly and keep myself healthy. I’ve always looked after myself but I’ve no idea what my body mass index is or whether I’d be too high.
- Smoking – I totally agree with the suggestion that women who smoke should not be offered IVF. It’s harming them and their potential to have a baby.

Individual C
- Everyone should be given a chance if they meet the criteria. 40 is not that old these days and lots of people don’t start thinking about kids until they’re 40. I think it’s more important to check that somebody is healthy. If they’re healthy then they should be given a shot.
- If they’re healthy then why not allow them to have IVF? Up to 45 would be ok but I suppose that would only be ok if you had some evidence that there was a chance of success at that age. But I suppose if you showed that you could prioritise to help younger people have a baby, if they had a better chance, then maybe that’s a better thing.
- So, actually, I agree that it would be better to be equal across the whole area and that would give more women more of a chance. I’m still under 40 so hopefully it will be successful for me.

Couple D
- I think that IVF should be fair across the whole country. I have a friend who has relocated in order to be offered three cycles of IVF. It doesn’t seem fair that in some areas you are offered none at all.
- The age should be 40 across the whole county. Why should we have to pay when we have been paying our national insurance and working full time? It just doesn’t seem fair.
- Childlessness – Every relationship should be sacred. We should all have the choice as humans to have the chance to have a child. If you could still have a child naturally then why can’t you have a child through IVF? I totally disagree with the idea that if you’ve already had a child in a previous relationship you can’t try for a child in a new relationship. If you’re in love and you have a bright future then why shouldn’t you be offered the treatment?
• Previous sterilisation – I think this is really bad. It may have been a choice at the time in a previous relationship because you didn’t want any children. But if you’re in a new relationship and you really want to have a child, why should that choice be taken away? Some people could have multiple children from different relationships and there are others that would love to have them or love to have more but are being refused treatment.

• BMI – I think this is sensible and good. We would do anything to have a baby and I think you should show that you’re willing to be as healthy as possible before you start a cycle of IVF.

• Smoking – We both totally agree that you shouldn’t smoke if you’re trying to get pregnant. I’m a pharmacist and have seen even drug addicts come off their methadone when they

We don’t fit into the normal criteria for IVF. I have had nine miscarriages, so I can get pregnant but I can’t stay pregnant. Screening and IVF may help us stay pregnant. We have to pay for this though. If I had a different condition or even if I’d had cancer, then the IVF would be funded. Infertility is a serious condition, just like any kind of medical condition. It affects our societies, communities and countries. We’re all happier when we’ve got a happy community and being part of family, and having your own family give us all a sense of wellbeing, happiness and belonging. We all should have the basic human right to have a baby at any age if we can still conceive.

Couple E

• We’ve had two rounds of IVF previously paid for by the NHS. We’re now on our third and have to pay for it ourselves. I think that there should be no age at all. People want to get their homes and education first. They want to be fit and healthy, so they’re leaving it later to have a child. Even though the evidence is there about age it should be based on health rather that how old you are. Some people may be 40 but have a body age of 30.

• Childlessness – Everyone should be given a chance to have a child, no matter whether they have had a child before. Many people are struggling but we should all have the right to try to have a baby.

• Previous sterilisation – I think this is quite shocking and very unfair that you can’t have IVF if you have been sterilised and it’s then been reversed.

• Previous treatment – This also seems unfair. Everyone should have the same opportunity to have a child. Somebody who has had IVF previously in another relationship would actually be ahead of other people because they would have already had the tests so it would actually cost less.

• Smoking – I would agree with this because you’d be more at risk of the pregnancy not being successful if you smoke.
5.6 Feedback from General Engagement Event - Brasshouse Community Centre, 14 June 2018 (Healthwatch and patients/public in attendance)

Comments on draft Complementary and Alternative Therapies (Acupuncture)
- If alternative pain relief has been tried and hasn’t worked then if the patient prefers they should be allowed to go with Acupuncture
- Electrical impulse is also used, if in-effective then patient should be offered alternatives such as acupuncture
- There should be evidence that shows this procedure is clinically proven to work. The leaflet should explain why these therapies are not offered as some of them definitely have benefits to patients
- Hypnotherapy/Yoga; at least one person felt that it was positive so they should still be considered. If you are a practitioner can you offer this; can there be clarity? Also, is there evidence that Yoga/Hypnotherapy works for mental health patients – will this still be offered in special cases?
- The CCG is funding for dance therapy to help elderly eg: Parkinson. What evidence was done to stop this funding?
- Tai Chi is very good and is not on the list; is this still being supported. It’s great for balance for older people. More clarity required as to why these have been stopped.

Comments on draft Assisted Conception/ IVF
- The policy seems unfair and there should not be variation across the West Midlands. This should be evened out nationally not just regionally.

Comments on draft policy
- Patient experience of having problems with bunions. He went for an x-ray and then then had to wait for next steps. Told to self-care first before going through with any type of operation but was in pain in the meantime.

Comments on draft ear wax policy
- The group listed variation between their practices on the removal of ear wax. Some patients had been offered this and other hadn’t.
- There are some GPs that did not know of a policy and sends them to a specialist therefore more money is spent – this needs to stop
- How do you make sure that GPs offer these services to patients in a consistent manner?

Comments on draft hernia policy and leaflet
- Post-operative advice would be helpful. Needs to be on the flyer, for example; will symptoms come back, what to do if it does and how do they avoid return illness?
- Doctors’ communication is quite vague in surgeries and they have scored low. This needs to be addressed immediately to regain confidence with the patients.

Comments on draft knee and hips arthroscopy policy
• If pain killers cannot limit the pain then this procedure of washing out joints eg: knees should be considered.
• What is the cost and if inexpensive, why not still consider the procedure? If it even gives short term benefit then it should be considered.
• Clinical evidence shows that it is not best practice as it does not always relieve for long periods of time but group still thinks it should be considered for some cases
• Hip waiting list for Dudley is 4 weeks whereas Sandwell is 20-30 week, this needs reviewing.
• Need to know how long it would last once a washout is done could determine whether it should still be considered.

Reversal of Sterilisation
• As this was an individual decision it may not be easy to be reverse with the NHS if you have a new partner.
• If you were sterilised you cannot get IVF on the NHS even if your partner cannot conceive on their own.

Health watch feedback
• When the discussion starts with the patient, how do they match with NHS symptoms to ensure they diagnose properly and give the patient the correct advice on whether a procedure is commissioned or not?
• The leaflets need matching to symptoms. The principles of harmonising these policies are good but more advice on self-care and preventative actions are needed. Patients have to be encouraged to do constant checking and take responsibility for their own health.
• Awareness raising campaign is needed once the new policies become ratified. We need to push out the news to clinical teams as well as patients. Could PPGs help with regards to getting them involved in raising awareness?

Suggestions on draft patient leaflets
• Every leaflet should contain messages for the patient on what they can do to help themselves
• Self-care and local suggestions to keep well and active would be useful. For example, Age Well do line dancing for movement which helps with mobility and social interaction.
• Social prescribing should be considered by all GPs; no treatment or medicine needed but encouraging patients to get involved in social activities eg: dance, tai chi classes
5.7 Feedback from General Engagement Event - Friars Gate, Solihull, 20 June 2018 (Healthwatch and patients/public in attendance)

Thoughts on guiding principles of the policies and policy changes

- Patients should be looked at on a case by case basis. There needs to be education for patients to know all the details that go into having a procedure or surgery, including post-op surgery requirements from patients i.e. physio
- Overall, there should be guidance. There needs to be money saved, but there shouldn’t be a blanket policy that means some are excluded and others aren’t

Equality across Sandwell, Birmingham and Solihull

- Contentious (regarding IVF) but where does it stop? Might be cruel and heartless but there needs to be rules behind it.
- What is the reasoning behind bringing the age for IVF down? Why not raise it? Especially if it relates to the female patient when it’s the male who can’t conceive.
- Some of the statistics behind IVF treatment are misleading. The difference between a 30 year old conceiving through IVF and a 43 year old is very narrow.
- GPs have different approaches which sometimes doesn’t fit the blanket policies. Everyone’s body is different also so the blanket policy doesn’t fit.
- Understand the rationale but it feels like it’s penalising people for lifestyle choices they have made. People are waiting longer to have children so people are finding out if they can have kids later. Doesn’t fit with how patients are treated also, a 39 year old might be told to wait 2 years but then they’ll be over the age limit.
- The pathway for treating patients needs to be more effective.
- The policy doesn’t seem to fit the modern lifestyle choices.

Thoughts on Assisted Conception draft policy and patient leaflet

- Why is the age for women 40 and it under 55 for men? It is not clear in the leaflet why.
- Why there is a difference in age between sperm donor age and partner age? Perhaps due to genetic deterioration but why is it different?
- Agreement on some elements of the policy, including BMI. If someone can show they are willing to lower BMI then that shows their commitment and that should be taken into account.
- Feeling with all that group attendees that 40 is too young to be a cut off age. Minimal difference in physiology between 40 and 42. Shouldn’t the age be raised to 42 rather than everyone lowered to 40.
- Same sex couple with a donor womb? What is the policy then? Unfair that the policy would potentially exclude homosexual fathers.
- It’s a difficult to make a rule and say that’s it because there will always be somebody that doesn’t fit the blanket policy. It realistic that you have to draw the line somewhere, as long as everyone has equal access to services – particularly no matter what their sexual orientation.
• How will these policies be disseminated so the public are aware of the policies? Important that the public are made aware of the services that can impact on them. Especially on the fact that homosexual couples have to contribute funds to their treatment which a few of the attendees are shocked by and feel that it is very unfair.

Feedback on Port wine stain policy
• What if a child that looks differently is bullied? The social stigma that comes with it and the long term effects of bullying might cost the NHS more than the actual treatment to reduce the birthmark.
• This isn’t a cosmetic treatment due to the potentially social stigma that comes with it.
• Is the laser treatment not funded because it’s generally linked to underlying treatments? It’s not clear in the leaflet
• What if it’s a little boy? Men and boys don’t like wearing make-up so the psychological effect could be huge. If laser can reduce how obvious the birthmark is then surely it should be used.

Feedback on Complementary and alternative therapies
• Art therapy being stopped is contentious due to the positive outcomes that there has been seen in social prescribing, particularly with mental health patients and maybe palliative care.
• Acupuncture worked extremely well for one patient. Her operation scar hasn’t hurt since she had the acupuncture treatment.
• What is the clinical effectiveness of these treatments? Might not be great but from a holistic and wellbeing point of view, might not be the right way to look at these policies. Don’t just look at policies through a hard clinical point of view.
• Interventions are just as important as policies. Is there evidence that shows that some of these therapies prevent others?

Feedback on Chronic fatigue syndrome
• Is it being put under the umbrella of a mental health condition? Is it wasted money if someone is on a CBT programme when it’s a mental health related condition?
• Pathways need to be made more clear in the leaflet.

Comments on other policies and the draft patient leaflets
• One patient is glad that the carpal tunnel hasn’t changed. She feels it is a really positive change.
• Some people aren’t suitable to have hip arthroscopy, some patients should have physio instead of arthroscopies. Anything that aids the patient’s movement and it would help with patient isolation issues.
• Patients need to be made aware of the seriousness of operations including everything that follows the actual surgery.
• There needs to be a look at the limiting of providers trusts. How can people who live further, who might not be so mobile, be helped. The knock-on effect on health and social care, ambulance call outs etc could be huge if a patient is isolated.
• In some areas such as Solihull you can self-refer to physios which many don’t know about.
• More social prescribing needs to be taken into account by GPs. Need to direct patients to healthy alternatives, especially for mental health patients or those with social anxiety. Health trainers can maybe help with this, encouraging people to get out and socialise more while exercising.
• The leaflets are more useful for patients to take home and read instead of waiting in the waiting area of a surgery. Helps inform patients what to actually expect instead of expecting a miracle cure.

6.0 Feedback from charities, statutory bodies, officials, concerned individuals and other organisations

Feedback and correspondence was received from a number of organisations and individuals.

Please see below all feedback received by email or letter:

6.1 Feedback on multiple policies

6.1.1 Letter received from Healthwatch Birmingham

Harmonised Treatment Policies - Phase 2

Healthwatch Birmingham welcomes the opportunity to respond to Birmingham and Solihull’s consultation on ‘Harmonised Treatment Policies – Phase 2’. Our key role is to make sure that patients, the public, service users, and carers (PPSuC) are at the heart of service improvement in health and social care. In line with our role, we have focused our comments on:

• whether the proposals will improve the quality of care and lead to services that are responsive to the needs of patients and service users
• Whether proposed changes may address or lead to health inequality

We welcome the CCGs plan to ensure that policies incorporate the most up-to-date published clinical evidence, stop variation in accessing NHS-funded services across Birmingham and ensure that access is equal and fair. The premise that underpins Harmonised treatment policies is good as it ensures that there is an evaluation of the effectiveness of treatments and assessment of what works or does not work for patients. However, the effectiveness of these policies in meeting the needs of Birmingham residents will depend on how they are implemented and the principles that govern their implementation. In particular, should financial considerations become the overriding principle, then there is the potential for patient’s wellbeing being considered second best. As such it is important to consider the following issues:
For the policies that will no longer be funded, are there alternative treatments that should be considered. For instance the ‘Knee Arthroscopy for Degenerative Knee Disease’, are there other arthroscopy techniques that might be useful and be of benefit than arthroscopic debridement?[1]

For restricted procedures – what processes will be put in place to ensure that assessments are timely, that it is easy to access services, and people have choice.

- For instance, the hip arthroscopy policy aims to limit availability to provider trusts able to fully support patients with a multidisciplinary team. If services are then limited to particular locations, what plans are in place to ensure that all Birmingham residents regardless of location are able to access these services. Especially taking into consideration transport, parking, age of users and other issues that might affect those with lesser economic means or those that would have to rely on public transport.

- One of the eligibility criteria for hip arthroscopy is that patients are offered choice of modality of surgery. However, the consultation document states that ‘where surgery is considered appropriate following an assessment, an arthroscopic surgery should be promoted as the treatment of choice over open surgery’. It is difficult to see whether patients will be offered real choice when one method is being promoted over another.

The CCG needs to consider the potential impact of these policies on health inequality. As stated by NHS England, CCGs must have regard to the need to reduce inequalities between patients with respect to their ability to access health services and outcomes achieved for them by the provision of health services[2]. We are concerned that changes to some policies might affect some groups more than others. For instance:

- We note that assisted conception is now only limited to those under 40 years of age and that only one cycle of IVF will be funded. Although the age limit is in line with NICE guidelines, we note that the CCG has failed to adhere to NICE Guidance that recommends that up to three IVF cycles should be available on the NHS. According to NICE, the cumulative effect of three full cycles of IVF increases the chances of a successful pregnancy to 45-53%. Three IVF cycles are the most cost effective and clinically effective number for women under the age of 40.

As a result of the CCGs plans, this will mean that only those who can afford to continue treatment privately will be able to do so. Thus the outcome for those from poorer backgrounds will be worse off as they might not be able to afford private treatment.

- In addition to the above, we note that IVF treatment will not be offered to women over the age of 40 contrary to NICE guidance that recommends that women between 40 and 42 should have at least one IVF cycle.

- It is not clear from the documents provided whether the change of eligibility age from 42 to 40 will be the same for patients under Birmingham South Central and Solihull CCG. As it seems from the document that the change
only applies to patients under Cross City CCG. Unless this has been brought in line with the other two CCGs, having different eligibility ages under the same CCGs will lead to inequality in access to services and health outcomes.

- As regards ‘Gamete retrieval and cryopreservation’ policy, we note that whilst female same-sex couples or single women are eligible for IVF, male same-sex couples or single men who have surrogate arrangements are not eligible. It is not clear in the document the reasons for this and is contrary to the CCGs duty towards inequality as well as the CCGs needs to ensure equal and fair access to services.

- We also note with concern that the individuals family circumstances, such as having adopted or biological children, precludes them from accessing Gamete retrieval and cryopreservation treatment. NICE Quality Standard on fertility states that previous children, sexual orientation and relationship status should not be a factor in determining eligibility for treatment[3]

We believe that these issues need to be considered as plans, to roll out these policies, take shape. The CCG needs to take the diversity of Birmingham and the deprivation prevalent in the city, into consideration. In particular the potential impact it will have on some communities who might not be able to access private services to be able to travel to locations further to them etc. It is important that medical needs of service users and the public in Birmingham remain central in commissioning decisions.

 Yours Sincerely,

Chipiliro Kalebe-Nyamongo Andy Cave  
Policy Officer Chief Executive Officer  


6.1.2 An email received from Steve McCabe MP Birmingham Selly Oak

RE: Proposed changes to health policies

I am getting in touch in response to the email myself and other Birmingham MP’s received regarding changes to health policies. I am writing on behalf of my Birmingham Labour MP colleagues.
Can you outline how many patients would be affected by the proposed changes to each policy? For example, you propose to limit the availability of knee arthroscopy for degenerative knee disease. How many people have received a knee arthroscopy in the last year and how many of these patients would no longer be eligible under your proposed policy change? Is this in line with NICE guidelines?

In the breakdown some of the proposed policy changes are bringing commissioning policy in line with NICE guidelines. Can you explain why in some cases the CCG has decided to adhere to the NICE guidelines but in other areas they are ignored? How are these judgments made?

I want to specifically address the policy regarding IVF treatment. I am very concerned that you are proposing to decrease the upper age eligibility for IVF treatment from 42 to 40 years for patients previously covered by Birmingham Cross City CCG. I am aware that South Central CCG already set the upper age eligibility at 40 year old. You will know that this is not in line with NICE guidelines which states women aged 40-42 years should be offered 1 full cycle of IVF if they satisfy certain medical criteria. It is not right that Birmingham and Solihull CCG are seeking to further reduce access to IVF and I cannot not support this proposal.

When do the CCG propose to implement these changes? I’d be grateful if you could provide further information on these proposals.

Yours sincerely
Steve McCabe MP
Birmingham Selly Oak

6.2 Feedback on draft cough assist policy

6.2.1 Email from Spinal Muscular Atrophy Support UK

To the Commissioning Group

Thank you for the information about the NHS Birmingham and Solihull Clinical Commissioning Group: engagement on proposed changes to health policies.

We had a look at your questionnaire on the proposed changes to health policies but found that it would not give us the opportunity to give the feedback we think necessary, hence the email.

Use of cough assist machines

We have read in your ‘What is coughing?’ advice that ‘due to the lack of robust clinical evidence to support the use of cough assist machines as clinically effective intervention, cough assist machines are not routinely commissioned’ unless patients meet criteria you have listed.
We are concerned to ensure that your criteria include routine funding of cough assist treatment for patients with spinal muscular atrophy (SMA) who are ‘non-sitters’ or ‘sitters’.

The references you have do not appear to include the new 2017 international standards of care for SMA that have been established by an international group of experts. These standards are described in Part 1, page 101 as ‘assessments or interventions that constitute the minimal care that families should expect to find in any neuromuscular centre’

The summary of these minimal care interventions in terms of pulmonary care is outlined on Part 2, page 32.

Where you will see that cough insufflator/exsufflator is very clearly a recommended intervention for anyone with SMA who is either a non-sitter or sitter – this includes those with SMA Type 1 or SMA Type 2.

We are concerned that these patients should have routine access to cough assist machines and that this should be explicit. Their consultation should not have to prove exceptional clinical need.

We hope that you can reassure us that this clearly routine need will be reflected in your future policy.

Eugenio Mercuri, et al., Diagnosis and management of spinal muscular atrophy Part 1 Recommendations for diagnosis, rehabilitation, orthopaedic and nutritional care


Richard S. Finkel, et al., Diagnosis and management of spinal muscular Atrophy: Part 2: Pulmonary and acute care; medications, supplements and immunisations; other organs systems; and ethics, Neuromuscular Disorders (2017), doi:10.1016/l.nmd.2017.11.004


With thanks

Yours sincerely

6.2.2 Statement also received from Spinal Muscular Atrophy Support UK

NHS Birmingham and Solihull Clinical Commissioning Group: engagement on proposed changes to health policies
Policy Harmonisation Programme:
Treatment using Cough Assist Equipment: Mechanical Insufflator/Exsufflator (MI-E)
Statement for consultation;
SMA Support UK is a national charity with over 30 years’ experience of supporting families and adults affected by Spinal Muscular Atrophy (SMA). We disagree with the proposed draft policy which recommends not to provide cough assist equipment for people with neuromuscular conditions, including SMA.

We are not medically qualified, nor researchers – the views and points expressed here reflect the questions and experiences of those with SMA who contact us for support and information and who share their views and experiences with us. Many of the points may well apply to other neuromuscular conditions.

We are concerned that your final policy should include routine commissioning of cough assist equipment for infants, children and adults with SMA who are ‘non-sitters’ or ‘sitters’.

We ask for the points made below to be considered as part of your consultation.

- We appreciate that robust study evidence is the standard by which your harmonised CCG policies are measured and appreciate the process already undertaken to review the evidence as widely as possible and to further consider the new references recently submitted to you by the Birmingham clinicians.
- We understand that the decision not to recommend commissioning of cough assist equipment was reached because of lack of robust study evidence. We are concerned that the study evidence available is judged not robust enough to meet your threshold required - and that it would not be realistically possible to collect such evidence in any future study since:
  - SMA is a rare condition - it is difficult to find the numbers of comparable individuals needed to provide a large sample with control groups.
  - Cough Assist is currently being used by many with SMA in UK so it would be difficult to set a clinical trial baseline.
  - The first drug treatment (nusinersen) has recently become available to eligible infants who have SMA Type 1 (non-sitters) through an Expanded Access Programme (EAP). This group are included in the recommendation by experts for proactive use of cough assist. It would be difficult to recruit to a trial for cough assist from this significant group, where key inclusion criteria for the EAP require ‘patients whose care in the opinion of the treating physician meets, and is expected to continue to meet, the guidelines set out in the 2007 Consensus Statement for Standard of Care in SMA’.
  - If a control arm was required, it would be difficult to justify and recruit to a trial for use of equipment which is already recommended by a group of international experts in SMA.
- In your summary policy statement, the initial paragraph states; “Most coughs clear up within three weeks and do not require any treatment”. This is not the case for people with SMA who, due to muscle weakness, are unable to cough effectively and can experience very rapid progression to severe chest infection leading to severe breathing difficulties and hospitalisation.
- In our experience, across the UK more children and adults have had access to cough assist equipment since initial research by Chatwin and Simonds in 2003. Indeed, the British Thoracic Society acknowledges lack of robust evidence but still
recommends use of cough assist equipment for children\textsuperscript{5} and adults\textsuperscript{6} with neuromuscular weakness. The 2007 Standards of Care for SMA\textsuperscript{1} recommended daily use of cough assist in most severely affected children and adults, and proactively before surgery. The 2017 Standards of Care\textsuperscript{2} clearly recommends that use of a cough assist should be proactively prescribed for ‘sitters’ and ‘non-sitters’, based on respiratory assessment.

- SMA support UK has recently collected experiential evidence from the families we support through a UK survey about the impact of SMA, taken in January 2018. This included a question about equipment used. From 128 respondents:

  Type 1 – 2 (0 – 17yrs) – 53% currently use cough assist
  Type 1 – 2 (18+ yrs) – 92% currently use cough assist

The above statistics highlight the extent to which cough assist is currently used by infants, children and adults and shows a clear need for this piece of equipment to support those with SMA. These numbers do not include those people who need/have been recommended to use cough assist by their specialist respiratory team, but have been unable to access the equipment.

- Proactive and regular use of the cough assist, in our families’ experience, has a positive role in:
  - Maintaining optimum chest physio routines
  - Reducing time spent on effective chest physio (also see Chatwin and Simonds 2009\textsuperscript{7})
  - Increasing strength and capacity of lungs
  - More effectively moving secretions from lungs on a regular basis
  - Increasing ability to fight a chest infection if one does occur
  - Increasing feelings of wellbeing and confidence when respiratory function is maintained at a stable level
  - Decreasing severity of chest infections if they do occur

- We suggest that the evidence for the use of cough assist for infants, children and adults with SMA is outlined in the Standards of Care document (2017)\textsuperscript{2}. This is the consensus of highly respected international clinical experts and they outline minimum care provision for individuals with SMA. Their working groups identified the aspects that constitute optimal care but considering that some of the recommendations may not be easily applicable in centres or countries with less resources, an effort was made to identify assessments or interventions that constitute the minimal care that families should expect to find in any neuromuscular centre.” In our view, this is the appropriate clinical evidence needed to recommend the use of cough assist to infants, children and adults with SMA, including recommendations that:
  - All children and adults with SMA should be seen by a specialist neuromuscular multi-disciplinary team, including respiratory specialists.
- Assessment and monitoring by the respiratory specialist, experienced in SMA should be regular and ongoing.
- Where indicated by clinical assessment, proactive introduction of cough assist is recommended for ‘non-sitters’ and ‘sitters’

- We believe that the use of cough assist equipment is a cost-effective way of meeting need. We agree with the “Right to breathe” report (2015)\(^8\) which concluded that not providing cough assist is a false economy. The cost of the equipment compared to one week’s stay in ICU is minimal.

- With clinicians needing to submit an Individual Funding Request application for every infant, child or adult they assess as needing cough assist equipment, we would be concerned about;
  - The time and resources this will take
  - The focus and effort that already overstretched clinicians and families will need to put towards any application
  - The waiting time increase which could be detrimental to individuals
  - The risk of developing a severe chest infection that means hospitalisation and threatens life
  - The burden on the clinician to prove exceptional clinical need, when Standards of Care 2017 recommend cough assist is a minimal intervention for those with SMA (sitters/non-sitters)
  - Family already juggling 24-hour care and emotional stress of caring together with an ever-present prospect of life threatening chest infections
  - Families feeling that they must fight for a piece of equipment that has already been agreed by SMA experts as essential and which have been seen to improve individuals’ and families’ quality of life.
  - Individuals potentially missing out on eligibility for, or experiencing delayed access to, newly emerging drug treatments and clinical trials which require as inclusion criteria that they adhere to standards of care.

In summary, we understand that equity of process is important and that robust study evidence is required by the CCGs before they can recommend the routine commissioning of cough assist equipment. However, we would emphasise that;
- for SMA such evidence is extremely difficult to obtain from standard research methods and that the recommendations of the BTS\(^5,6\), the 2017 SoC\(^2\) and from the expert clinicians working in the field should, in this case, instruct the CCG commissioning body to recommend the routine commissioning of cough assist where the respiratory specialist team have recommended its use.

We believe that this action would;
- reduce the risk to the individual
- offer a better quality of life
- reduce cost for the CCG by decreasing the time spent in hospital and undergoing treatment by those with a neuromuscular condition who, through a lack of preventative equipment, develop life threatening respiratory infection.
Support Services SMA Support UK

SMA support services UK who submitted the above statement also emailed in with the addition below to be received as part of their feedback:

_The only reference we would submit in addition (and which we have cited in our statement) is_


6.2.3 Letter from Musculo Dystrophy UK to BSOL and SWB CCGs

**Re: Birmingham and Solihull CCG & Sandwell and West Birmingham CCG, treatment Policy Harmonisation Programme, Phase 2 – Clinical Engagement Cough Assist Machine**

As a team of clinicians working across the West Midlands specialising in patients with neurological and neuromuscular conditions, we write to express our disappointment and frustration at Sandwell and West Birmingham CCG’s proposed mechanical insufflation-exsufflation (MI-E – Cough Assist machine) policy. The CCG’s current position is that there is a "lack of robust clinical evidence to support the cough assist machine as a clinically effective intervention for this cohort of patients". This is despite evidence and clinical opinion supporting the use of MI-E for patients with neuromuscular conditions including neuromuscular disease (NMD).

There are multiple flaws in the evidence policy written by Solutions of Public Health in January 2018. Notably, it fails to take into consideration past policies on MI-E which were co-written by respiratory clinicians working with people with muscle-wasting conditions in the West Midlands.

Our key concerns are:

- There appears to be a lack of understanding of the phases of cough and the treatment techniques available. This is demonstrated by the recommendation that Lung Volume Recruitment (LVR) can be utilised instead of an MI-E.
- Cost savings have been identified by suggesting LVR is equal to MI-E. Again, this demonstrates a lack of understanding that LVR can be used in all patient groups. It cannot be used in patients with severe disease progression and reduced bulbar function.
- Item 4.1.1. discusses the results of a randomised control trial (RCT) (Rafiq. et al., 2015) on the use of MI-E to affect survival rates of adults with motor neurone disease (MND). Within this paper there is a clear bias in the randomisation of patients in each cohort, which reduces the credibility of the results. The MI-E group’s patients had ineffective peak cough flow (PCF) values to start and more bulbar dysfunction, indicating a more severe group of patients than the non-MI-E
group with higher PCF values and less bulbar dysfunction. As the study looked at survival, the MI-E group baseline was always going to progress more quickly and have poorer survival. However, again this is MND not NMD, and therefore not a reflection on cough effectiveness with MI-E in the NMD population.

- National guidelines such as: MND NICE Guidelines (2016), NHS Neuroscience Service Specification (2013/14), and British Thoracic Society Guidelines (2012), which support the use of MI-E, have been disregarded.
- The evidence review listed studies (Mahede et al 2015, Rafiq et al 2015, and Moran et al 2013) that discussed size concerns and lack of data availability to show compliance. However, machines are now smaller and portable with back-up batteries and capacity for data storage. Morrow et al (2013) also states that appropriate devices should be available.
- A recent European Consortium (Toussaint et al 2018) which reviewed expert opinions of treatments and was supportive of MI-E was recorded in your reference list. However, neither that, nor the paper by (Toussaint et al 2009), were included in the main document.

Despite the current public engagement process and the discussion of evidence, Sandwell and West Birmingham CCG is set to decide not to fund MI-E devices. Vital evidence has been ignored and clinical opinion has not been considered. Muscle-wasting conditions are rare and it can be difficult to gather research on efficacy, therefore clinical consensus should be sufficient. It is also the case that provision of these devices is supported by international consensus (Chatwin et al 2018, Toussaint et al 2018, Finkel et al 2017). Furthermore, the review fails to take into account ethical concerns about undertaking a large-scale study on MI-E. For example, the implications of comparing patients who have benefited from this equipment, compared with a group who have been denied it.

We request that you meet with our network’s representatives to discuss the policy Sandwell and West Birmingham CCG plans to implement. A full reference list identifying the missed evidence has recently been shared with your colleagues for consideration. We urge your organisation to review this evidence and follow the example of other CCGs in the West Midlands by implementing a best-practice policy on the commissioning of MI-E devices. These are the CCGs we are forced to refer our patients to, at a cost to your organisation and to patients who struggle to access this vital treatment.

Thank you for your taking the time to consider this letter.

Yours sincerely,

West Midlands Neuromuscular Network and colleagues across England
6.2.4 Email from The Motor Neurone Disease Association

Re: The use of mechanical cough assist devices (MI-E) with MND cases
Please find below some case examples describing the effective use of mechanical cough assist devices (MI-E) with MND cases.

Section 20: Cough effectiveness – NICE guideline in NG42 Motor neurone disease: Assessment and management, gives recommendations for the management of cough effectiveness and a link to the evidence.

In addition, here is a link to information on the MND Association’s website regarding cough management, which in turn has a link through to the above NICE guideline:


As MND cases are predominantly managed in the community, provision of a mechanical cough assist device gives immediate access in the home to assistance with the clearance of bronchopulmonary secretions in those patients with an ineffective cough. Manual techniques to assist expectoration, either directly from a physiotherapist or by the carer, are unlikely to be as accessible to patients in the home setting.

The quality statement ‘Tailoring healthcare services to the individual’ which comes under the NICE quality standard regarding ‘Patient experience in adult NHS services’ is relevant here:

Patients experience care that is tailored to their needs and personal preferences, taking into account their circumstances, their ability to access services and the coexisting conditions:


The following was also emailed in as an addition to the above email:

In addition to the information I sent earlier, I would be grateful if you could also consider these comments which I just received from a physiotherapist:

You have to be skilled and trained to use manual techniques to assist expectoration. Cough assist is controlled and delivers a set pressure. If you don’t exert enough pressure manually or exert too much pressure, it can be damaging. There are also contraindications for the use of manual techniques, such as PEG (percutaneous endoscopic gastrostomy). Other comorbidities may have to be considered’

The above considerations do have implications for MND cases, particularly as many are elderly and have elderly carers.
Please see below the patient case studies referred to in the email above:

Patient stories to support the provision of MI-E Cough Assist Machines to MND patients

Case A
“Regarding Cough Assist, here are my thoughts as A’s carer.

A. was diagnosed with ALS in November 2017. By April his breathing was faltering but he passed flight assessments and had CO2 level recordings at 5.5%. From April A. started having difficulty clearing his chest, due to his cough action getting weak. Since early May 2018 A. has used a Nippv breathing machine to aid his shallow breathing but this alone did not help with expelling secretions. By 1st June his CO2 levels had gone to 7.9% - acceptable high is 6%. The nurse from the ventilation unit who looks after us visited us on 11th June and brought a cough assist machine with her. Within just a few attempts, and after weeks of not being about to cough anything up, A. was able to expel phlegm. I was shown how to operate the equipment. Within 2 days, A. was bringing up green phlegm alerting us to the need for antibiotics. We were lucky to have the cough assist machine to help us see things were going wrong. We use the machine 4 or 5 times a day, without the need for nurses. A. is still producing secretions which he cannot get up without mechanical assistance. He would be in serious difficulty without the cough assist. We have not used a lung volume recruitment bag or any other system.”

Case B
“…More recently it [the Cough Assist] has been helpful in getting rid of sticky mucous. I have got used to using it. Without it I would be thoroughly exhausted coughing and spluttering for hours on end.”

Case C
“It [Cough Assist] won’t bring anything up, but it loosens [secretions]. Occasionally, like now, I have to wipe my tongue, because it [secretions] gathers at the top. Before I had that [Cough Assist] it was getting terrible. Carbocisteine didn’t seem to do much at all. The nebuliser loosens me up, but Cough Assist is the best. It clears my chest. It makes it easier to breathe and speak. It makes it easier to eat. As the day goes on it tends to build up in your throat. I use it when I get up before I have breakfast…. I use it several times a day.”

Regional Care Development Adviser (West Midlands North)
MND Association
22 June 2018

6.2.5 Telephone conversations to receive feedback and answer questions

Organisation representatives and a member of the public requested the opportunity to talk to someone involved in the process of considering the proposed changes in when
developing the proposed policies under consideration during the harmonisation of policies engagement period. This led to several telephone conversations with a senior clinician who had been part of this process:

6.2.6 Summary of telephone call with Spinal Muscular Atrophy Support UK

Dear M & J,

Many thanks for taking the time to speak with me today. Please find attached and below the references which have been submitted to us for further review regarding the cough assist policy. Apologies they are a little piecemeal, they have come from a number of sources.

- Airway clearance techniques in neuromuscular disorders: A state of the art review Michelle Chatwina,* Michel Toussaintb, Miguel R. Gonçalvesc, Nicole Sheersd, Uwe Mellies, Jesus Gonzales-Bermejof, Jesus Sanchog, Brigitte Faurouxh, Tiina Anderseni, Brit Hovj, Malin Nygren-Bonnerik, Matthieu Lacombel, Kurt Pernetb, Mike Kampelmacherm, Christian Devauxn, Kathy Kinnettop, Daniel Sheehanp, Fabrizio Raoq, Marcello Villanovar, David Berlowitzd, Brenda M. Morrow
Respiratory Medicine 136 (2018) 98–110


- Special Considerations in the Respiratory Management of Spinal Muscular Atrophy
Mary K. Schroth, Pediatrics 2009;123;S245-S249


- Richard S. Finkel, et al., Diagnosis and management of spinal muscular atrophy: Part 2: Pulmonary and acute care; medications, supplements and immunizations; other organs systems; and ethics, Neuromuscular Disorders (2017), doi: 10.1016/j.nmd.2017.11.004

If there is any further evidence which you would like to submit, then I would be grateful if you could do this by the close of the engagement phase which is 5pm on Friday 22nd June 2018.
Regarding our conversation today:

We, KD and MP Information support co-ordinators SMA Support UK. and Senior IFR Nurse AGEM CSU) discussed the following:

Engagement process:

- Website and questionnaire were confusing particularly regarding the postcode lottery and harmonisation – this was explained to be a local harmonisation between Birmingham and Solihull CCG (which have recently merged) and Sandwell & West Birmingham CCG – however SMA Support UK covers a national population where a ‘postcode lottery’ is evident and so this was deemed to be confusing for members
- KD confirmed no current policy for Birmingham and Solihull CCG or Sandwell and West Birmingham CCG, current applications are made through the IFR process as required. KD confirmed that the phrase “for patients who do not meet the above criteria”, should not have been included in the draft patient document and acknowledged that this typing error was confusing / potentially misleading and should have been removed.
- Current number of cough assist machines approved for funding – this information can be gained through a Freedom of Information Request
- KD advised of the policy harmonisation and review process:
  - Solutions for Public Health (https://www.sph.nhs.uk/) undertook a clinical evidence review for the use of cough assist machines in late 2017,
  - the evidence review was presented to the Treatment Policy Clinical Development Group and clinicians from the respiratory speciality were invited to attend the meeting and to provide their clinical expertise
  - on the basis of the evidence review and the specialist clinical input, a DRAFT policy was written
  - the DRAFT policy was submitted to the CCG Clinical Priorities Advisory Group, where another public health review was undertaken of the clinical evidence before the draft policy recommendation was made
  - DRAFT policy released for public and clinical engagement
  - Further clinical evidence has been submitted by specialist respiratory clinicians
  - This further clinical evidence has been submitted to SPH for review against the original evidence review
  - Once the engagement phase has been completed then the new evidence, SPH review and all feedback received will be re-reviewed by the Treatment Policy Clinical Development Group (TPCDG) and assessed by the CCG Clinical Priorities Advisory Group.
- JG/MP – particular evidence not included: Standard of Care Guidelines for SMA.
- JG/MP will submit written support statement for the use of cough assist machines based on their clarified understanding of the process and questions and concerns raised during the discussion.
- KD to circulate the list of additional evidence to JG/MP as attached above.
Please do not hesitate to contact me if you require any further information or there are amendments you would like made to the notes above. I would like to thank you for the time taken to respond to the request for further information and feedback, your time is greatly appreciated.

6.2.7 Telephone conversation with a member of the public

A member of the public attended one of the engagement events on harmonised policies. Insightful information gained at the event has been fed back as a case study into this report. The person asked to speak to a clinician who had been involved in the development of the proposed policies including the policy on cough assist. A telephone meeting was planned and went ahead to enable feedback to be heard and questions to be answered. The email below details the response to the member of the public following the telephone meeting.

Many thanks for your email. I have responded to your questions below. I hope that these responses are helpful.

I would like feedback on the IFR (Individual Funding Request) process both for BSOL CCG and Sandwell and West Birmingham CCG.

– The West Midlands CCGs (Birmingham and Solihull CCG; Sandwell and West Birmingham CCG; Dudley CCG; Walsall CCG; & Wolverhampton CCG) have a harmonised IFR Policy and so the IFR process for all of these CCGs is harmonised.

What formal stages do IFRs for both CCGs go through –

Once an IFR Application is received, it is initially screened by the IFR Case manager to determine the following questions:

• Has the application been full completed?
• Which CCG is the responsible commissioner for the patient?
• Is the application urgent?

Once the above has been determined the case is then sent to the relevant CCG's IFR Screening panel for review.

The Screening Panel reviews the case to determine if the case can proceed to an IFR Full panel on the basis of:

• Is there clinical evidence of exceptionality demonstrated within the application?
• Is there clinical evidence to support the clinical effectiveness of the intervention?

If the screening panel determine that there is evidence of clinical exceptionality within the application then the case will be sent to an IFR Full panel for review.

• The Full IFR Panel will then determine if there is evidence of exceptionality / evidence of clinical effectiveness to support the intervention
• If these are deemed to be present, a recommendation will be made to the CCG that the case has demonstrated clinical exceptionality and clinical effectiveness of the intervention.
The CCG will then decide based on their fiscal responsibilities whether they are able to fund the intervention for the individual patient.

**How many individuals sit on each IFR Panel -**

I am led to believe there may be separate screening and formal panels as part of the process. The IFR Case Manager will Chair and present the case to the IFR Screening Panel.

The membership of the IFR Screening Panel at a minimum will be:

- Head of the IFR Team or the IFR Case Manager
  - This is usually the IFR Case Manager who Chairs the IFR Screening Panel and presents the case to the other panel members.
- A Public Health Consultant
- A Senior Pharmacist

The membership of the IFR Full Panel will be at a minimum:

- One member or employee from the responsible CCG.
- A Public Health Consultant
- Head of Individual Funding Requests (Chair)
- Individual Funding Request Manager (Deputy Chair)

There should be at least one medicine management representative and one general practitioner at each meeting of the IFR Full Panel.

**What are the qualifications of the individuals who sit on the panels and which professions and departments are represented**

The IFR Panels are CCGs panels and have clinical representation from a variety of backgrounds: Medicines Management; a CCG GP Clinical Lead and Public Health. Other CCG representatives can attend but all who sit on the panels must have undertaken the annual IFR Training.

**At which meetings and how frequently are IFRs reviewed**

There are specific IFR Screening Panel and IFR Full Panels for each CCG scheduled weekly, these will run or cancelled depending on whether an IFR has been submitted and is required for that particular CCG.

A request will normally be screened within 7 working days of the date of receipt of the IFR, unless there is a delay with further information being sought, an IFR decision will be determined within 20 working days.

**Are IFRs sent to the IFR Panel members in advance for pre-reading or are they presented only when the IFR Panel meet**

IFR case packs for each case are circulated to panel members prior to the panel, if the clinician submits further information following the original application, then this is circulated to the panel at the earliest opportunity by the IFR Team.
What is the process for requesting and capturing additional detail / evidence
It is the clinician's responsibility to include within the application all of the clinical information to enable the panel to determine exceptionality. If the panel would like further information then they can request this from the referring clinician, from public health colleagues and from medicine management colleagues.

If there is no response from the requesting Clinician, the IFR team will chase him or her after two weeks and notify them that the application for treatment will be closed after one month if no response is received. The patient’s GP and the Clinician will be informed if the application is closed.

What is the Appeal Process for IFRs and does this allow for personal representation
The IFR Appeal Panel may review an IFR case to ensure that the IFR process was correctly followed, this may only be used following an IFR Full Panel, NOT an IFR Screening Panel. If the IFR Appeals Panel feels that the IFR process has not been followed, then they can ask the IFR Full panel to reconsider their decision in light of the incorrect process being followed, the IFR Appeals panel cannot overturn the decision of the IFR Full Panel.

If an IFR is rejected is the individual or organisation who submitted given a full and thorough explanation with appropriate evidence of why the IFR has been rejected
Yes, the referring clinician will receive a letter within 5 working days of the IFR Screening / Full Panel decision outlining the decision and the rationale for the decision. If IFR evidence includes financial cost detail which can be substantiated can we formally expect the CCGs to acknowledge the NHS cost impact.

What options are available to the individual or organisation to work with the CCG to review the cost impact and reach consensus on the way forward to avoid future episodes
If it is determined by the IFR Screening/ IFR Full Panel that there are a cohort of patients to whom the requested intervention would give equal benefit, then the CCG has a responsibility to adhere to the ethical framework and strive, as far as practicable, to provide equal treatment to individuals in the same clinical circumstance, therefore the clinician would be invited to submit a business case which would be considered as part of the next phase of work in the policy harmonisation process.

Is data recorded on the number of IFRs received and the number accepted / rejected including the number of IFRs received for a specific item or concern. Is this data available to the public and / or the organisation / clinicians / individuals who may have raised.
Yes, records are kept regarding this information and reported to the CCGs named above on a monthly basis. This information can be obtained through a Freedom of Information Request.

I would like to know what both CCGs consider as Specialised Commissioning and therefore not the responsibility of either CCG This in relation to both services and equipment commissioning
• Specialised Commissioning is determined by NHS England, not by the CCGs.
• Each year NHS England updates its manual for prescribed specialised services and any changes to specialised commissioning can be detected through its manual – the 2017/2018 manual is attached for your reference.

If you require any further information or clarification please do not hesitate to contact me.

Other such conversations took place with the Motor Neurone Disease Association and others; please see appendix 11, pages 45-51.

6.2.8 A further email from The Motor Neurone Disease Association

You’re right that there is little clinical evidence pointing towards the efficacy of the MI-E devices but the concluding remarks of this paper are worth noting:

https://www.ncbi.nlm.nih.gov/books/NBK367737/

‘There is consensus that secretion encumbrance resulting from an ineffective cough is a contributor to morbidity and mortality in MND. However, this has not been established in a clinical study.

Cough assist machines are loaned to BSOL patients from Stoke. I have liaised with all physio colleagues across the region and bar one, none of them have the competencies to deliver training on manual cough assist techniques. In Birmingham respiratory physios can deliver this training but they’re not commissioned to see MND patients. The one specialist palliative physio says she does try breath stacking with patients but this is only ever as a short term measure and then all patients move on to cough assist machines. There is a generalised concern that even if they had the competencies to try manual cough assist techniques they wouldn’t have the capacity to do this as these techniques require more time to educate, and then monitor for efficacy.

There is concern that the use of a LVR bag requires dexterity of the patient and the carer. It has been commented that breath stacking can be effective in a calm environment, but not useful in a crisis if the patient is anxious, short of breath, or struggling with secretions. All patients comment that the cough assist machine has helped during a crisis, and they have avoided a hospital admission.

It’s well recognised that there is a high degree of carer burden in MND and it has been noted that the cough assist machine reduces some of this burden.

There has been some research completed at Preston which points in favour of the use of a cough assist machine with MND patients but unfortunately, it’s not ready for publication so I’m not able to share this.

As you know, MND patients can deteriorate rapidly so need to have prompt access to equipment, so I am guessing that completing an IFR for every patient is going to be
burdensome to Stoke who provide the machines and will delay the provision of the equipment.

Regional Care Development Adviser for West Midlands and South

6.3 Feedback from patients regarding the proposal for complementary and alternative therapies

Testimonies from patients had been collected to feedback views on the benefits of cupping (which is part of the complementary and alternative therapies proposed policy):

6.3.1 Email from Patient A

I’m emailing you my testimony of the benefits of cupping as requested. After having ACDF and fusion surgery of C3/4 on my spine in October 2016 I was referred for physiotherapy. After several sessions my physiotherapist suggested trying cupping on my neck as I have suffered severe pain and stiffness to my neck area since the surgery. Following the cupping sessions, I have experienced some relief in the stiffness of the neck and a reduction of the intensity of the headaches. During the sessions I experience relaxation of the muscles in my neck and shoulders. The cupping used alongside my medication has made a marked difference in the intensity of my symptoms and gives me some relief from the pain and stiffness.

6.3.2 Email from Patient B

I am currently undergoing a course of cupping at Good Hope Hospital NHS Trust. When it was first suggested as a treatment option, I said no as I didn’t realise that cupping was under the acupuncture umbrella. As I am needle phobic, I know that I wouldn’t be able to tolerate needles and it was not an option I could consider. Luckily my physiotherapist has been trained in cupping and as I know it’s non-invasive I said yes. On my second session I had woken with a cricked neck and after having my cupping session I had immediate relief and the tight muscles had reduced significantly afterwards. I am now half way through my treatment plan and would highly recommend cupping to anyone as it’s not painful, non-invasive, cost effective and very effective. I have worked in the NHS for 17 years and I know that costing is a major factor in developing and implementing packages of care, this ancient art of cupping stands alone as once you have the cupping equipment you don’t need extra supplies, such as single use only equipment, thus reducing storage requirements, by not ordering equipment and using cupping more within the physiotherapy department you are reducing your carbon foot print, thus making it cost effective. However, as a patient myself I much prefer a holistic approach to patient care which is very important to me. Overall, I feel extremely luckily that I was paired with the right physiotherapist who was trained in cupping enabling me to gain more movement in my neck and reduce pins and needles in my hands after being told I could have surgery but there was not a guarantee it would work, so for me cupping has been very beneficial.
6.3.3 Email from parent on behalf of daughter

My daughter suffers from severe scoliosis and as a result she attends fortnightly physiotherapy appointments at Good Hope. Her treatment involves the use of cupping for which she finds relief for her pain and tightness in her back

6.3.4 Email from patient C

I just wanted to write a testimony about the cupping therapy L is having with you. As you know L has pots syndrome & suffers with chronic pain in the back, shoulders & neck.
L is definitely feeling the benefits of the cupping therapy, her shoulders, back & neck feel lighter & less knotted up & tight after a session.
I really hope L can carry on with these cupping therapy sessions.
Any relief from pain for a period, is helpful as there is nothing worse than being in chronic pain as well as all L’s Pots symptoms especially for a child it’s heart-breaking to see L suffering so much.

6.3.5 Email from patient D

I have been seeing my physiotherapist since March 2018 to help manage my pain in my neck & shoulders. My physiotherapist has been using an acupuncture technique named cupping to help manage and reduce the pain. After my physiotherapy sessions with my physiotherapist my neck pain is lighter and the pain is reduced by 30/40%.

I am a holistic being who believes in traditional natural remedies. I am person centred and believe this cupping technique is really aiding me.

6.3.6 Literature to support cupping

As part of the engagement process, a Hydrotherapy Clinical lead and Senior Physiotherapist sent in the following links to evidence which supports the benefits of cupping for consideration:
Hopwood, V, Lovesey, M, Mokone, S, Acupuncture and Related Techniques in physical Therapy, chapter 8 in section 2, P101-110.

References from this chapter for physiological effects:


Dear All,

In case this has missed you I thought I would share for your perusing, see attached document.

We’ve got some NICE news for you, the National Institute for Health and Care Excellence (NICE) has published a new guideline on the assessment and management of hearing loss in adults for the first time!

In 2015, we lobbied for the publication of this guideline and we were a key stakeholder in its initial development. We also responded to NICE’s consultation when they release a draft version in January. Now they’ve released the final version of the guideline ‘Hearing Loss: Assessment and Management’ has now been released.

The guideline is intended for health and social care professionals, commissioners, patients and carers to help them make informed decisions about treatment and care. It is a vitally important and will further strengthen the case for the prevention and management of hearing loss. It includes key recommendations which contradict proposals to restrict hearing aid provision, made by several CCGs across the country in recent years.

Kind regards
Roger Thompson, Service Development Manager (South England)
7.0 Analysis and feedback from the patient and public questionnaire

Question1- Draft policies for a number of treatments that are available in Sandwell, Birmingham and Solihull have been created and reviewed to meet the principles below. To what extent do you agree with these principles?

<table>
<thead>
<tr>
<th>Principle</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>To offer procedures and treatments consistently and fairly to patients</td>
<td>64.86%</td>
<td>120</td>
<td>29.73%</td>
<td>55</td>
<td>1.62%</td>
<td>185</td>
</tr>
<tr>
<td>To end the ‘postcode lottery’ by having the same eligibility criteria for treatments regardless of where patients live</td>
<td>65.96%</td>
<td>124</td>
<td>23.40%</td>
<td>44</td>
<td>6.91%</td>
<td>188</td>
</tr>
<tr>
<td>To ensure that policies meet the latest national clinical guidance and are supported by robust clinical evidence</td>
<td>53.48%</td>
<td>100</td>
<td>36.36%</td>
<td>68</td>
<td>6.95%</td>
<td>187</td>
</tr>
<tr>
<td>To stop using treatments that do not have any benefits for patients, or have very limited clinical evidence base</td>
<td>40.76%</td>
<td>75</td>
<td>28.26%</td>
<td>52</td>
<td>17.39%</td>
<td>184</td>
</tr>
<tr>
<td>To prioritise treatments which provide the greatest benefits to patients</td>
<td>55.38%</td>
<td>103</td>
<td>32.26%</td>
<td>60</td>
<td>6.45%</td>
<td>186</td>
</tr>
<tr>
<td>To stop offering cosmetic treatments</td>
<td>34.05%</td>
<td>63</td>
<td>28.11%</td>
<td>52</td>
<td>21.62%</td>
<td>185</td>
</tr>
</tbody>
</table>

This question was answered by the majority of respondents (189) with two skipping this question. Overall the majority strongly agreed or agreed with the principles detailed above. The highest number of respondents of (4.32%) strongly disagreed with principle six- To stop offering cosmetic treatments followed by (3.23%) strongly disagreeing with principle five- To prioritise treatments which provide the greatest benefits to patients.
Question 2- Do you have any other comments you would like to make about this approach to harmonising the policies for all patients across the area?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Answered</td>
<td>87</td>
</tr>
<tr>
<td>Skipped</td>
<td>104</td>
</tr>
</tbody>
</table>

From the 191 respondents that completed this survey 87 answered this question and left comments on what approach should be taken to harmonise policies for patients across the area, these include:

- Each patient should be assessed on their individual needs case by case
- Consider what alternative treatment could help patients
- Mental health and wellbeing of patients is key and should be taken into account before making any decisions
- Harmonising those policies with clinical evidence and not based on cost savings
- Priority should be given to the elderly and babies
- To understand what cosmetic surgery is and why it is needed.
Question 3 - Have you or a loved one had any experience of the procedures currently being proposed in the new draft harmonised treatment policies as NOT NORMALLYFUNDED? (Tick all that apply)

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cough assisted machines</td>
<td>11.76%</td>
<td>6</td>
</tr>
<tr>
<td>Female sterilisation</td>
<td>19.61%</td>
<td>10</td>
</tr>
<tr>
<td>Removal of kidney stones</td>
<td>39.22%</td>
<td>20</td>
</tr>
<tr>
<td>Knee arthroscopy</td>
<td>33.33%</td>
<td>17</td>
</tr>
<tr>
<td>Male sterilisation</td>
<td>27.45%</td>
<td>14</td>
</tr>
<tr>
<td>Management of port wines stains</td>
<td>3.92%</td>
<td>2</td>
</tr>
<tr>
<td>Treatment for snoring</td>
<td>5.88%</td>
<td>3</td>
</tr>
<tr>
<td>Use of complimentary or alternative medicines</td>
<td>19.61%</td>
<td>10</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td>12</td>
</tr>
</tbody>
</table>

Answered 51
Skipped 140

This question was answered by 51 respondents who had experienced at least one of the procedures being proposed. It was confirmed that 10 respondents had not experienced any of the procedures. The majority of respondents (39.22%) had experienced procedures relating to Removal of kidney stones followed by the second highest with (33.33%) choosing Knee arthroscopy.
Question 4- Have you or a loved one had any experience of the procedures currently being proposed in the new draft harmonised treatment policies with RESTRICTED CRITERIA?

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hip arthroscopy</td>
<td>11.32%</td>
<td>6</td>
</tr>
<tr>
<td>Surgery for Carpal Tunnel Compression</td>
<td>32.08%</td>
<td>17</td>
</tr>
<tr>
<td>Dupuytren's Contracture treatment</td>
<td>3.77%</td>
<td>2</td>
</tr>
<tr>
<td>Assisted Conception</td>
<td>13.21%</td>
<td>7</td>
</tr>
<tr>
<td>Gamete Retrieval and Cryopreservation</td>
<td>3.77%</td>
<td>2</td>
</tr>
<tr>
<td>Bunion Surgery</td>
<td>24.53%</td>
<td>13</td>
</tr>
<tr>
<td>Treatment for Ear Wax</td>
<td>43.40%</td>
<td>23</td>
</tr>
<tr>
<td>Management of Hernias</td>
<td>24.53%</td>
<td>13</td>
</tr>
<tr>
<td>Breast Implant Revision</td>
<td>1.89%</td>
<td>1</td>
</tr>
<tr>
<td>Acupuncture for Indications other than Back Pain</td>
<td>15.09%</td>
<td>8</td>
</tr>
<tr>
<td>Standing Upright MRI</td>
<td>7.55%</td>
<td>4</td>
</tr>
<tr>
<td>Treatment for Chronic Fatigue Syndrome</td>
<td>1.89%</td>
<td>1</td>
</tr>
<tr>
<td>Policy for Vasectomy</td>
<td>15.09%</td>
<td>8</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td>8</td>
</tr>
</tbody>
</table>

Answered 53
Skipped 138

This question was answered by 53 respondents and skipped by 138 respondents. The majority of those that answered (43.40%) had experienced procedures relating to Treatment for ear wax followed by the second highest (32.08%) choosing Surgery for carpal tunnel compression. In total eight respondents confirmed that they have not experienced treatment for any of these procedures.
Question 5- Do you agree with the list of procedures that are proposed to be not normally funded?

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>35.29%</td>
<td>42</td>
</tr>
<tr>
<td>No</td>
<td>21.85%</td>
<td>26</td>
</tr>
<tr>
<td>Please let us know your views or any additional comments:</td>
<td>42.86%</td>
<td>51</td>
</tr>
</tbody>
</table>

**Answered** 119  
**Skipped** 72

The majority of respondents (35.29%) agreed to the list of procedures that are proposed not to be normally funded and (21.85%) disagreed. Additional comments were also sought to capture views on this to include:

- Each procedure should be considered case by case
- In some instances the procedures would be seen as prevention and so should be available
- There should be flexibility to decide whether the treatment would be beneficial and improve an individual’s quality of life.

To see the all comments to this question see section 11.1.2 in the Appendices.
Question 6- Do you think any of the proposed changes would have a negative impact on your care/ the care of your family/ any particular group of patients within the community?

This question was answered by 74 respondents and skipped by 117 people. Of those that did answer also left comments on how this proposed change could impact on patients including:

- Elderly and Vulnerable people would suffer
- It would impact patients with hearing problems
- Would mean having less access to places for treatment
- This could increase the use of mental health services
- Social care would be effected
- Inequality to those that cannot afford the procedures privately

To see all comments to this question see section 11.1.2 in the Appendices
Question 7- Do you agree with the list of procedures that are proposed to have restricted criteria?

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>40.71%</td>
<td>46</td>
</tr>
<tr>
<td>No</td>
<td>31.86%</td>
<td>36</td>
</tr>
<tr>
<td>Please let us know your views or any additional comments:</td>
<td>27.43%</td>
<td>31</td>
</tr>
</tbody>
</table>

Answered | 113
Skipped | 78

The majority of respondents (40.71%) agreed with the list of procedures that should have restricted criteria and (31.86%) disagreed. Of those that did respond to this question also left additional comments to include:

- Agree with some of the restrictions but not all
- There should be a checklist in place to assess if treatment is required
- Age of patients should be considered

To view all comments for this question see section 11.1.4 in the Appendices.
Equality data

What is your ethnic group?

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>White English, Welsh, Scottish, Northern Irish, British</td>
<td>68.51%</td>
<td>124</td>
</tr>
<tr>
<td>White Irish</td>
<td>2.21%</td>
<td>4</td>
</tr>
<tr>
<td>White Gypsy/Irish Traveller</td>
<td>0.00%</td>
<td>0</td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td>0.55%</td>
<td>1</td>
</tr>
<tr>
<td>White and Black African</td>
<td>1.10%</td>
<td>2</td>
</tr>
<tr>
<td>White and Asian</td>
<td>0.55%</td>
<td>1</td>
</tr>
<tr>
<td>Indian</td>
<td>4.97%</td>
<td>9</td>
</tr>
<tr>
<td>Pakistani</td>
<td>6.08%</td>
<td>11</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>0.00%</td>
<td>0</td>
</tr>
<tr>
<td>Chinese</td>
<td>0.00%</td>
<td>0</td>
</tr>
<tr>
<td>African</td>
<td>2.76%</td>
<td>5</td>
</tr>
<tr>
<td>Caribbean</td>
<td>4.42%</td>
<td>8</td>
</tr>
<tr>
<td>Arab</td>
<td>0.00%</td>
<td>0</td>
</tr>
<tr>
<td>Any other ethnic group, please describe</td>
<td>8.84%</td>
<td>16</td>
</tr>
<tr>
<td><strong>Answered</strong></td>
<td>181</td>
<td></td>
</tr>
<tr>
<td><strong>Skipped</strong></td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

What is your ethnic group?
What is your gender?

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>30.56%</td>
<td>55</td>
</tr>
<tr>
<td>Female</td>
<td>68.33%</td>
<td>123</td>
</tr>
<tr>
<td>Transgender</td>
<td>0.00%</td>
<td>0</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>0.56%</td>
<td>1</td>
</tr>
<tr>
<td>Other (please state)</td>
<td>0.56%</td>
<td>1</td>
</tr>
</tbody>
</table>

Answered 180  
Skipped 11
Are your day to day activities limited by a health problem or disability which has lasted or is expected to last over 12 months?

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, limited a lot</td>
<td>12.85%</td>
<td>23</td>
</tr>
<tr>
<td>Yes, limited a little</td>
<td>19.55%</td>
<td>35</td>
</tr>
<tr>
<td>No</td>
<td>67.60%</td>
<td>121</td>
</tr>
</tbody>
</table>

Answered: 179  
Skipped: 12
Which of the following ages categories do you fit into?

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Up to 17</td>
<td>0.00%</td>
<td>0</td>
</tr>
<tr>
<td>18-24</td>
<td>3.33%</td>
<td>6</td>
</tr>
<tr>
<td>25-34</td>
<td>30.56%</td>
<td>55</td>
</tr>
<tr>
<td>35-44</td>
<td>15.00%</td>
<td>27</td>
</tr>
<tr>
<td>45-54</td>
<td>12.78%</td>
<td>23</td>
</tr>
<tr>
<td>55-64</td>
<td>13.33%</td>
<td>24</td>
</tr>
<tr>
<td>65-74</td>
<td>13.89%</td>
<td>25</td>
</tr>
<tr>
<td>75+</td>
<td>11.11%</td>
<td>20</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>0.00%</td>
<td>0</td>
</tr>
</tbody>
</table>

Answered 180  
Skipped 11
What is your religion?

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>No religion</td>
<td>30.11%</td>
<td>53</td>
</tr>
<tr>
<td>Christian</td>
<td>48.86%</td>
<td>86</td>
</tr>
<tr>
<td>Buddhist</td>
<td>0.57%</td>
<td>1</td>
</tr>
<tr>
<td>Hindu</td>
<td>3.41%</td>
<td>6</td>
</tr>
<tr>
<td>Jewish</td>
<td>0.57%</td>
<td>1</td>
</tr>
<tr>
<td>Muslim</td>
<td>6.82%</td>
<td>12</td>
</tr>
<tr>
<td>Sikh</td>
<td>1.70%</td>
<td>3</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>2.27%</td>
<td>4</td>
</tr>
<tr>
<td>Other (please state)</td>
<td>5.68%</td>
<td>10</td>
</tr>
</tbody>
</table>

Answered 176, Skipped 15
8.0 Key points for consideration based on patient, public and stakeholder engagement

- Most respondents strongly agreed with the principles that underpinned the development of the proposed policies, however, the highest number of respondents of (4.32%) strongly disagreed with principle six - To stop offering cosmetic treatments followed by (3.23%) strongly disagreeing with principle five - To prioritise treatments which provide the greatest benefits to patients.
- All the findings from the questionnaire are key and need to be considered (see section 7.0)
- The largest response to the engagement process is in relation to the proposed cough assist policy. The proposed cough assist machine policy is not supported by the majority response to the engagement. There has been a detailed response to express this from clinicians, organisations and charities, an MP and members of the public who state the reasons for their opposition. Reasons for opposing the proposed policy include the need to consider more clinical evidence, the creation of a postcode lottery as other nearby CCGs commission cough assist machines. The cost of hospital-stay when a cough assist machine cannot be commissioned for the patient at home is also referenced as a financial consequence of the proposed policy. Quality of life is a major concern and the detrimental effect that non-commissioning of cough assist machines would have on the patients, both for adult and child patients, the family, and carers. The lack of an alternative solution to cough assisted machines is also discussed as they are only prescribed as a final clinical response when all alternatives have been tried. All further reasons are detailed in the report in section 6.0
- Most people agreed that the assisted conception proposed policy agreed that the age for treatment is the same across the CCG geographical areas, some even felt it should be applied nationally to prevent a postcode lottery. However, some people feedback their concern on access to treatment being based on age, it was felt that the policy was unfair to same sex couples and feedback on future relationships when those bearing children had failed and other aspects of the proposed policy, see section 6.0
- Feedback on cupping both in terms of patient anecdotal evidence and information described as evidence of the benefits to patients is reported for consideration, also in section 6.
9.0 Clinical and stakeholder engagement

9.1 Clinical engagement and feedback on specific policies

9.1.1 Rationale

Clinical engagement was undertaken with specialist clinicians from provider trusts to enable the CCGs to gain a specialist clinical review of the proposed policies from the clinicians who are directly treating patients. The review was devised following feedback from clinicians following the Treatment Policy Harmonisation Programme Phase 1, as clinicians submitted feedback following ratification of the final policies and commented that the approach used during the Phase 1 engagement phase to enable them to provide feedback on the draft policies had not reached the treating clinicians.

9.1.2 Methodology

The clinical engagement for Treatment Policy Harmonisation Programme Phase 2 was undertaken in a targeted approach, with a database compiled of specialist clinicians being asked to review each of the policies which fell within their area of expertise.

Commissioners and service managers were also asked to review the draft policies where this had been highlighted by the clinical team as an avenue for review, with clinical leaders from the provider trusts being asked to support and encourage their clinical team members to respond.

Contract managers from Birmingham and Solihull CCG & Sandwell and West Birmingham CCG were asked to raise awareness of the engagement period with the provider trusts for whom they were responsible to ensure the profile of the engagement with clinicians was sufficient to support the clinical review.

In total 207 clinicians were contacted across the region during the engagement phase to ask for their specialist review of the policy documents relevant to their specialist clinical area.

The engagement was undertaken with clinicians from the following provider trusts:

- University Hospitals Birmingham NHS Foundation Trust
- Sandwell and West Birmingham Hospitals NHS Trust
- University Hospitals of North Midlands NHS Trust
- BMI Healthcare
- Spire Healthcare
- Birmingham Community Healthcare NHS Foundation Trust
- Birmingham and Solihull Mental Health NHS Foundation Trust.
Clinicians were sent policy packs for policies specific to their clinical area which included:

- DRAFT Policy Document
- Evidence Review Paper or Supporting Guidelines
- Equality Impact Analysis
- DRAFT Patient Leaflet.

The policy packs pertaining to each clinician’s specialist area were sent by email on the 14 May 2018, reminders of the closing date of the engagement period were then sent out to clinicians on the following dates:
- 29 May 2018
- 11 June 2018
- 20 June 2018.

9.2 Results of clinical engagement

Prior to the engagement phase contact had been made with the various clinical specialities to gain specialist clinical knowledge in drafting the proposed 22 policies. Specialist clinical input was received in preparing 6 of the policy drafts.

Of the 22 DRAFT policies released during the engagement period, direct clinical feedback was received regarding the following 10 DRAFT policies:

1. DRAFT Policy for the use of Mechanical Insufflator/exsufflator (MI-E) – Cough Assist Machines
2. DRAFT Policy for Carpal Tunnel Syndrome (CTS)
3. DRAFT Policy for Arthroscopic Hip Surgery for Femoral Acetabular Impingement (FAI)
4. DRAFT Policy for the Management of Ear Wax
5. DRAFT Policy for Dupuytren’s Contracture
6. DRAFT Policy for the Management of Umbilical, Para-Umbilical and Incisional Hernias
7. DRAFT Policy Complementary and Alternative Therapies
8. DRAFT Policy for the treatment of Chronic Fatigue Syndrome (CFS) / Myalgic Encephalomyelitis (ME)
9. DRAFT Policy for Vasectomy
10. DRAFT Policy for the Management of Port Wine Stain.

The clinical engagement responses are summarised in the table below:
<table>
<thead>
<tr>
<th>DRAFT Policy</th>
<th>Clinical Expertise provided to the TPCDG (during DRAFT policy formulation phase)</th>
<th>Clinical Feedback received during the engagement phase</th>
<th>Further Clinical Evidence Submitted</th>
<th>Clinical Support for DRAFT policy received</th>
</tr>
</thead>
<tbody>
<tr>
<td>DRAFT Policy for Assisted Conception</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No comments received</td>
</tr>
<tr>
<td>DRAFT Policy for the Provision of NHS funded Gamete Retrieval and Cryopreservation for the Preservation of Fertility</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No comments received</td>
</tr>
<tr>
<td>DRAFT Policy for Carpal Tunnel Syndrome (CTS)</td>
<td>No</td>
<td>Revision surgery is not included in the draft – please include this. Should NCS be undertaken in primary care prior to referral? Blueteq deemed unnecessary by clinicians</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>DRAFT Policy for Arthroscopic Hip Surgery for Femoral Acetabular Impingement (FAI)</td>
<td>Yes</td>
<td>Clarity around the requirements for a quorate MDT Requirement to input patients into: non-arthroplasty hip registry <a href="https://www.britishhipsociety.com/main?page=NAHR">https://www.britishhipsociety.com/main?page=NAHR</a> GP engagement ref: referral pathways in line with the policies</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>DRAFT Policy for Knee</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arthroscopy for Degenerative Knee Disease</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>-----------------------------------------</td>
<td>-----</td>
<td>----</td>
<td>----</td>
<td>-----</td>
</tr>
</tbody>
</table>
| DRAFT Policy for the use of Mechanical Insufflator/exsufflator (MI-E) – Cough Assist Machines | Yes | • Key papers are missing from the evidence review (see Appendix Clinical 2 for clinical evidence submission)  
• Clinical opinion appears to have been disregarded.  
• There appears to be a lack of understanding of the clinical phases of cough and the treatment techniques available. This is demonstrated by the recommendation that Lung Volume Recruitment (LVR) can be utilised instead of an MI-E.  
• Cost savings have been identified by suggesting LVR is equal to MI-E. Again, this demonstrates a lack of understanding that LVR can be used in all patient groups. It cannot be used in patients with severe disease progression and reduced bulbar function.  
• The evidence review listed studies (Mahede et al 2015, Rafiq et al 2015, and Moran et al 2013) that discussed size concerns and lack of data availability to show compliance. However, machines are now smaller and portable with back-up batteries and capacity for data storage.  
• The review fails to take into account ethical concerns about undertaking a large-scale study on MI-E. For example, the implications of comparing patients who have benefited from this equipment, compared with a group who have been denied it.  
• Issues with respiratory physiotherapists within Birmingham being trained to deliver training on manual cough assist techniques and the commissioning pathways not enabling them to see MND patients.  
• National guidelines such as: MND NICE Guidelines (2016), NHS Neuroscience Service Specification (2013/14), and British Thoracic Society Guidelines (2012), which support the use of MI-E, have been disregarded.  
• The results of a randomised control trial (RCT) (Rafiq. et al., 2015) on the use of MI-E to affect survival rates | Yes – Please see Appendix Clinical 2 | No – Clinicians requested review of the DRAFT policy in light of submitted clinical evidence and clinical opinion. |
of adults with motor neurone disease (MND). Within this paper there is clear bias in the randomisation of patients in each cohort, which reduces the credibility of the results. The MI-E group’s patients had ineffective peak cough flow (PCF) values to start and more bulbar dysfunction, indicating a more severe group of patients than the non-MI-E group with higher PCF values and less bulbar dysfunction. As the study looked at survival, the MI-E group baseline was always going to progress more quickly and have poorer survival. However, again this is MND not NMD, and therefore not a reflection on cough effectiveness with MI-E in the NMD population.

- Royal Preston Hospital feedback noted the challenge in assessing the efficacy of cough assist (every case unique and complex disease process) but audit report shows good uptake of machine and self reported reduction in chest infection frequency. Importance of having clinical back up combined with machine access to optimise medications, ensure safe and competent use.
- Stoke Respiratory Consultant noted that MND patients managed between UHB/Stoke have a well-developed pathway for respiratory muscle management, including cough. Patients are assessed for possible cough assist and only those likely to benefit are issued the devices. Patients benefit from reduced chest infections and hospitalisation but also prevention of death from sputum plugs. Expecting the same level of evidence for a device in this patient group that you would for a drug and say asthma, is disingenuous, as it will never be achieved and a beneficial treatment would be denied to our patients.

<p>| DRAFT Policy for the Treatment Of Snoring with Uvulopalato, Uvulopalatopharyngoplasty, Palate Implants and | No | None received | None received | No comments received |</p>
<table>
<thead>
<tr>
<th>Policy Title</th>
<th>Recommendation</th>
<th>Comments</th>
<th>Review Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Radiofrequency Ablation of Soft Palate.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DRAFT Policy for the Management of Ear Wax</td>
<td>Yes</td>
<td>Contraindications to ear irrigation should be clearly listed</td>
<td>None received</td>
</tr>
<tr>
<td>DRAFT Policy for Asymptomatic &amp; Symptomatic Bunions</td>
<td>Yes</td>
<td>None received</td>
<td>None received</td>
</tr>
<tr>
<td>DRAFT Policy for Dupuytren’s Contracture</td>
<td>Yes</td>
<td>Review of the patient leaflet required - it was thought to be too complex for patients</td>
<td>None received</td>
</tr>
<tr>
<td>DRAFT Policy for the Management of Umbilical, Para-Umbilical and Incisional Hernias</td>
<td>No</td>
<td>The issue of wound infection after open hernia repair is complex and there is no clear guidance.</td>
<td>Yes - Please see Appendix Clinical 2</td>
</tr>
<tr>
<td>DRAFT Policy for the Investigation of Rectal Bleeding</td>
<td>No</td>
<td>None received</td>
<td>None received</td>
</tr>
<tr>
<td>DRAFT Policy for the use of Upright / Open MRI Scanning</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>DRAFT Policy Complementary and Alternative Therapies</td>
<td>No</td>
<td>A mixture of evidence and anecdotal reports suggesting support for Cupping</td>
<td>Yes - Please see Appendix Clinical 2</td>
</tr>
<tr>
<td>Policy for Treatment</td>
<td>Feedback</td>
<td>Comments</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------------</td>
<td>----------</td>
<td>--------------------------</td>
<td></td>
</tr>
<tr>
<td>Chronic Fatigue Syndrome (CFS) / Myalgic Encephalomyelitis (ME)</td>
<td>Feedback queried the impact of the policy on referrals and PACE programme.</td>
<td>Yes</td>
<td>No comments received</td>
</tr>
<tr>
<td>Reversal of Female Sterilisation</td>
<td>No</td>
<td>No comments received</td>
<td></td>
</tr>
<tr>
<td>Reversal of Male Sterilisation</td>
<td>No</td>
<td>No comments received</td>
<td></td>
</tr>
<tr>
<td>Vasectomy</td>
<td>No</td>
<td>No comments received</td>
<td></td>
</tr>
<tr>
<td>Port Wine Stain</td>
<td>No</td>
<td>No comments received</td>
<td></td>
</tr>
<tr>
<td>Acupuncture (for indications other than back pain)</td>
<td>No</td>
<td>No comments received</td>
<td></td>
</tr>
<tr>
<td>Breast Implant Revision Surgery</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Lithotripsy to treat Renal Calculi (Kidney Stones)</td>
<td>No</td>
<td>No comments received</td>
<td></td>
</tr>
</tbody>
</table>
10. Key points for consideration

10.1 Stakeholder, patient and public

Key points for consideration

Most respondents strongly agreed with the principles that underpinned the development of the proposed policies, however, the highest number of respondents of (4.32%) strongly disagreed with principle six - to stop offering cosmetic treatments - followed by (3.23%) strongly disagreeing with principle five - to prioritise treatments which provide the greatest benefits to patients (section 7)

All the findings from the questionnaire are key and need to be considered (see section 7)

The largest response to the engagement process is in relation to the proposed cough assist policy. The proposed cough assist machine policy is not supported by the majority response to the engagement. There has been a detailed response to express this from clinicians, organisations and charities, an MP and members of the public who state the reasons for their opposition.

Reasons for opposing the proposed policy include the need to consider more clinical evidence, the creation of a postcode lottery as other nearby CCGs commission cough assist machines. The cost of hospital stay when a cough assist machine cannot be commissioned for the patient at home is referenced as a financial consequence of the proposed policy. Quality of life is a major concern and the detrimental effect that non-commissioning of cough assist machines would have on the patients, both for adults and children, the family, and carers. The lack of an alternative solution to cough assisted machines is also discussed as they are only prescribed as a final clinical response when all alternatives have been tried. There are also implications for workforce planning if cough assist machines are not commissioned as most physiotherapists do not have the competencies to train carers in alternatives to the cough assist machine therapy. Patient safety is also raised as an issue as not enough pressure exerted leads to ineffective expectoration and too much pressure applied may cause trauma. All further reasons are detailed in the report in section 5.4 to section 5.4.2 and section 6.2 to 6.8).

Most people agreed that the assisted conception proposed policy in terms of age for treatment should be the same across the CCG geographical areas; some even felt it should be applied nationally to prevent a postcode lottery. However, some people fed back their concern on access to treatment being based on age, it was felt that the policy was unfair to same sex couples and feedback on future relationships when those bearing children had failed, other aspects of the proposed policy were discussed and comments made for consideration when final decisions were made, see section 5.3 to 5.6 and sections 6.1.1 and 6.1.2

Feedback on the draft proposal for complementary and alternative therapy policy asked for the benefits of such therapies to be further considered, for example in
cases of mental health illness, children's diseases such as Potts syndrome, neck and back pain and Parkinson's diseases. It is asked in the documents submitted and the verbal comments received that all feedback provided both in terms of patient anecdotal evidence and information described as evidence that benefits to patients are considered (sections 5.7 and 5.7, sections 6.3 to 6.6.6).

The musculoskeletal policy reviewed during the engagement by stakeholders, patients and members of the public was commented on. Comments included the request that knee arthroscopy should still be considered if pain control was unsuccessful and that further alternative treatments for knee arthroscopy in degenerative knee disease be explored. Concerns were voiced about the proposal to limit availability of hip arthroscopy to provider trusts able to fully support patients with a multidisciplinary team due to the ability of some patients to then access such services. The preferred choice of arthroscopic surgery over open surgery is perceived as limiting patient choice (sections 5.2, 5.6, 6.1.1, 6.12).

Comments received on the draft policy for port wine birthmark raised concerns on the psychological impact of not having laser treatment. It was felt that particularly for children, bullying could result and that offering only camouflage makeup when laser treatment could reduce the birthmark was inappropriate (sections 5.2 and 5.7). Social prescribing and information on self-care were discussed and seen to be important for patients to be able to manage their condition if proposed policy changes were made and as an alternative for GPs when explaining to patients changed treatment options.

10.2 Key points for consideration: clinical

Clinicians were generally understanding and supportive of the CCG in undertaking an evidence based review of treatment policies in order to provide equitable access to healthcare provision.

Clinicians were pleased to be given the opportunity to engage with the policy development process.

Clinicians would like further clarity and transparency regarding the process which the CCGs follow and how clinical evidence / expert clinical opinion is reviewed.

The 10 policies which received further clinical feedback will require further review by the Treatment Policy Clinical Development Group.

Clinicians were keen to continue to engage with the policy review process.

Clinicians were keen for these policies to be widely communicated to those in primary care so that the referral pathways and patient expectations could be appropriately managed.
10.3 Next Steps: Governance

- Late June – Engagement Feedback Evaluation Report prepared and submitted to the TPCDG
- July-August – Further TPCDG evaluation meetings (x3) to review all draft policies in light of the feedback.
- May-September – rolling period of communication updates – both governance related e.g. submission of policies to CPAG, and updates to MPs and JHOSC
- September – communication of ‘finalised policies’ to relevant stakeholders.
- October – provider notification of new policies
- January 2019 – new policies implemented.

- Treatment Policy Clinical Development Group (TPCDG) members will evaluate and consider the collective public and clinical feedback (July/August 2018).
- Draft policies will be divided into 3 Review Work Streams:
  - Draft Policies with no public/clinical feedback
  - Draft Policies with only positive public/clinical feedback and endorsement of the proposed draft
  - Draft Policies with public/clinical feedback that proposes amendments to the draft policy document
    - TPCDG review will determine if further evidence review or policy amendment is required depending on the evidence submitted.

- The TPCDG will review each policy in light of the CCG Clinical Priorities Advisory Group (CPAG) Report.
- The TPCDG will make their final endorsement of the reviewed policies
- The reviewed policies will then be resubmitted to CPAG as required.
- Following review by CPAG, the reviewed policies will be submitted to:
  - The Birmingham and Solihull CCG Clinical Polices Quality Sub Committee
  - The Birmingham and Solihull Quality and Safety Committee.
  - The Sandwell and West Birmingham Strategic Commissioning and Redesign Committee
## 11.0 Appendices

### 11.1 All additional comments from engagement questionnaire

#### 11.1.2 Question 5- Do you agree with the list of procedures that are proposed to be not normally funded?

<table>
<thead>
<tr>
<th>Please let us know your views or any additional comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depends on the income status.</td>
</tr>
<tr>
<td>Making cuts in wrong areas - people pay into a system so should be looked after.</td>
</tr>
<tr>
<td>Having suffered with any of these issues I don't know.</td>
</tr>
<tr>
<td>Their treatment procedure to remain in plan with good XXXX to all.</td>
</tr>
<tr>
<td>Some but not all.</td>
</tr>
<tr>
<td>It would be a case by case.</td>
</tr>
<tr>
<td>Some complementary medicine can support early probs before they need crisis treatment</td>
</tr>
<tr>
<td>Everyone deserves a chance to have a child.</td>
</tr>
<tr>
<td>Back Pain injections I believe should still be offered.</td>
</tr>
<tr>
<td>But some of the treatments are necessary.</td>
</tr>
<tr>
<td>All medical treatments should be available to all people. Not a restricted list.</td>
</tr>
<tr>
<td>Ear Wax as this may lead to more problems.</td>
</tr>
<tr>
<td>Dance therapy - hypnotherapy - good evidence here</td>
</tr>
<tr>
<td>Lots of activities that don't meet strict medical double blind criteria eg: gardening that could be recommended by NHS</td>
</tr>
<tr>
<td>*Port Wine stains should be funded if in a visible place</td>
</tr>
<tr>
<td>*Kidney stones should be funded</td>
</tr>
<tr>
<td>Some</td>
</tr>
<tr>
<td>No. Clinical stats drawn out of proportion. Person centered approach should be taken into consideration.</td>
</tr>
<tr>
<td>No. Underlying conditions should always be considered and automatic exclusion not be taken for granted.</td>
</tr>
<tr>
<td>No. Most but concerned about a blanket ban especially where there is likely to be a wider system cost if stopped.</td>
</tr>
<tr>
<td>Breast implant revision</td>
</tr>
<tr>
<td>Chronic Fatigue Syndrome</td>
</tr>
<tr>
<td>Carpal tunnell</td>
</tr>
<tr>
<td>should be on the list to stay</td>
</tr>
<tr>
<td>Does this mean vasectomy will need to be paid for by an individual?</td>
</tr>
<tr>
<td>More detail required before I would say yes or no especially around management of hernia and hip arthroscopy.</td>
</tr>
<tr>
<td>No - there needs to be a push back to NHSE to fund appropriately. With the CCGs joining together there should be savings made to the economy with efficiencies</td>
</tr>
</tbody>
</table>
across teams, delivery models and procurement.
This online explanation is too technically complex and not sufficiently simply explained for patients to comment in such a short period of time.

Female sterilisation should be funded in certain cases - I have made one referral in the last 5 years as usually the IUS is more acceptable but some women do have bleeding problems with progesterone only methods and are not suitable under UKMEC guidelines to have oestrogen containing methods. Their choice is then condoms or menorrhagia inducing copper IUCD.

It is cruel to refuse to treat all port wine stains - placement and severity should determine need.

assisted conception is difficult - but nationally we should have an agreed no of attempts and agreed eligibility criteria

See individual case

Yes, but it must be clear whether CCG or GPs would be allowed to recommend alternative procedures or none, and providers in the former case (including self-administered ones as with, for instance, snoring). Also would CCG have a policy about use of "complementary/alternative medicine" (which we must broadly define as ineffective, presumably).

However the efficiency of the surgery was very quick

Boils down to people who really need the treatment

Apart from portwine stain agree with all

Each case must be treated on own merit

IVF yes

Portwine no

Some of these procedures may have a one time cost but the cost of not offering them could be greater in the future both monetary and for the well being of patients

What if someone needs it or financially can’t afford it

Only agree to an extent

Don't know the procedures but if not beneficial they shouldn’t be

I believe sterilisation should be funded if it is a final decision, Reversal should not be

If got have empyema you need help and should receive it

Depends on if person is taking benefits, they should not pay

Should be funded to help patient have better life even if its limited

They should be funded because patient has a lot of illness + uncomfortable chronical illness

In the middle

I believe that nearly all procedures should be funded, as it can benefit patient’s variability.

But not really dear what it's all about

I believe that cough assist devices should be funded, as they are the only practical means to support chest clearance in weak patients e.g. those with neuro-muscular conditions.

There must be flexibility

In some cases the appearance of a hernia can affect daily life, it’s not just about pain, walking, sleeping. Stopping cosmetic treatments is too wide a statement. Some
cosmetic treatments will still be necessary
Also offer alternative/complimentary medicine.
not sure what this question means
I do not believe there is a clear blanket response for everyone. Treatment offered to
individuals has got to be based on their circumstances (this includes the use of
cosmetic surgery).

11.1.3 Question 6 - Do you think any of the proposed changes would have a
negative impact on your care/ the care of your family/ any particular group of
patients within the community?

<table>
<thead>
<tr>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes those with hearing problems might lose it completely.</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>No, at least trying a procedure will help the individual whether short or long term.</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes - Kidney stone removal use of.</td>
</tr>
<tr>
<td>Could be.</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Elderly patients</td>
</tr>
<tr>
<td>Elderly and disabled</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Yes!</td>
</tr>
<tr>
<td>My dad has serious back issues and would need constant care.</td>
</tr>
<tr>
<td>I do.</td>
</tr>
<tr>
<td>May lead to problems with my husband.</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Some</td>
</tr>
<tr>
<td>Always. As it leaves people with lack of access.</td>
</tr>
<tr>
<td>May have impact on social care crisis and may also increase use of mental health services</td>
</tr>
<tr>
<td>It can do to any community or family as they are livening with the impact</td>
</tr>
<tr>
<td>Only around a robust and transparent appeal process - those who are vulnerable or have mental health problems may find that more difficult. So the appeals process needs to consider how patient friendly it should be in future.</td>
</tr>
<tr>
<td>Comments as above</td>
</tr>
<tr>
<td>Not my family</td>
</tr>
<tr>
<td>If these become by payment only, there will be discrimination for those who can’t pay. This will add inequity to provision of service.</td>
</tr>
<tr>
<td>Answer</td>
</tr>
<tr>
<td>--------</td>
</tr>
<tr>
<td>yes</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td>No</td>
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<tr>
<td></td>
</tr>
<tr>
<td>Not sure</td>
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<td></td>
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<td></td>
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<tr>
<td>No</td>
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<tr>
<td>yes</td>
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<td>Yes</td>
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<td>Yes</td>
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<td></td>
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<tr>
<td>Not sure</td>
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<tr>
<td></td>
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<tr>
<td>yes</td>
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<tr>
<td>Yes</td>
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<tr>
<td>No</td>
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<tr>
<td>No</td>
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<td></td>
</tr>
</tbody>
</table>
Yes possibly could affect them, particularly elderly and vulnerable people

No

No

I need to understand the changes proposed to make an informed decision. Based on the limited knowledge I have, I think it would impact negatively in that a lot of patients will suffer pain and discomfort.

Those less able to pursue their treatment in alternative venues.

I agreed with the proposed changes. Often our patients use NHS funded treatment for aesthetic reason more than medical. I think this is going to create lots of dissatisfaction among them. This will negatively reflect on GPs' consultations and feedback.

Unable to answer as it is unknown what the overall cost would be to fund these conditions and how it would impact on existing funds.

Yes

11.1.4 – Question 7 - Do you agree with the list of procedures that are proposed to have restricted criteria?

Please let us know your views or any additional comments:

NHS new policies are ruining lives of decent tax payers.

As above

Some but not all.

But some of the treatments may be needed.

Meet but not visible marks for male or female.

Some common sense should be applied

Some

There are some inequalities especially infertility treatments for non heterosexual couples.

As above

As above, the online explanation is too technically complex and not sufficiently simply explained for patients to comment in such a short period. You also do not always point out the costs of the restricted treatments and how much you are saving. If the treatments are of little value as some of your explanations try to point out, why were they being offered in the first place? How will all this impact on the local population? What numbers of people are going to be affected? All too quick.....

I think there needs to be a much wider discussion about such things as very expensive individual treatments for a small number of people vs cheaper procedures for less serious illnesses for a much larger group of people. There are ethical questions involved but it should not be assumed that very expensive emergency procedures are more important than less serious procedures which benefit quality of life for a much larger group. Again if such things as cataracts are to be refused or not offered as soon as beneficial then this should be clearly stated and the opportunity to get private health insurance to cover such gaps should be made clear to everyone.

See each case

Yes, but as above (though with ear wax as the example).

Not sure about changing hernia as husband needed it

Should be a checklist to pass a particular standard to keep the cost low

Only if really needed

As above

Depends on age and individual
Because one thing that doesn't work for one person, no reason why it shouldn't work for someone else. Not everybody is the same

I agree women over 40 should not try to have babies due to complications and managing a child at that stage in life is challenging

Again not aware of the procedures

Others should be on it

Majority should still be funded

Because symptoms can vary and I feel that criteria is quite robust

As above

I don't disagree with this in the main however I feel cryopreservation restrictions are being made out of context. It appears IVF eligibility criteria are being proposed. Being told I have a major condition, such as cancer, is a significant life event and requires thought/consideration of an overwhelming amount of matters. Fertility is one consideration that has to be made in a very short amount of time to enable cancer treatment to commence. Oncologist have this conversation and the patient makes the decision; if it is to proceed they then have to consider funding/long-term funding themselves. All in a short space of time. I feel it is unethical to apply IVF criteria to fertility preservation.

as previously stated

Hopefully you will have more funding due to T.May realising that the NHS shouldn’t be firefighting but blossoming in its incredible service and skills. but not so strict that people couldn’t get what they need, there has to be some discretion as circumstances vary greatly

I need to understand the changes proposed to make an informed decision. Based on the limited knowledge I have, I think it would impact negatively in that a lot of patients will suffer pain and discomfort.

No opinion

### 11.2 Clinical Evidence

**1.** Further evidence submitted regarding Mechanical insufflation-exsufflation (MI-E) – Further evidence submitted for review

<table>
<thead>
<tr>
<th>Statements</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2.</strong> BTS (2009): MIE for bulbar patients, unable breath stack or increase PCF by other strategies</td>
<td>Guidelines for the physiotherapy management of the adult, medical, spontaneously breathing patient Thorax 2009, v64 (Suppl1), Extract Mechanical insufflation–exsufflation Recommendations • Consider mechanical insufflation–exsufflation as a treatment option in patients with bulbar muscle involvement who are unable to breathe stack. (Grade D) • Consider mechanical insufflation–exsufflation</td>
</tr>
</tbody>
</table>
for any patient who remains unable to increase peak cough flow to effective levels with other strategies. (Grade D)
- Where cough effectiveness remains inadequate with mechanical insufflation–exsufflation alone, combine it with manually assisted coughing. (Grade D)

|--------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

|-------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

|--------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

|-------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

|--------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Late non-ambulatory stage

As they progress through the non-ambulatory stage, individuals with DMD develop weak cough efforts, placing them at risk of atelectasis, pneumonia, ventilation–perfusion mismatch, and progression to respiratory failure, especially during respiratory tract infections. Treatment consists of manual and mechanically assisted coughing, which are indicated when FVC is less than 50% predicted, when peak cough flow is less than 270 L/min, or when maximum expiratory pressure is less than 60 cm H2O (figure 1).

### 3. Care Standards SMA, Finkel et al (2018): MIE must be available

|---|
| 3.3. Airway clearance
Manual chest physiotherapy combined with mechanical insufflation–exsufflation (e.g., Cough Assist® or VitalCough®) should be the primary mode of airway clearance therapy and should be made available to all non-sitters |

### Respiratory muscle weakness

1. **Primary cause morbidity and mortality**

|---|

Pulmonary manifestations of neuromuscular disease with
special reference to Duchenne muscular dystrophy and spinal muscular atrophy.
Gozal D

Airway clearance in children with neuromuscular weakness.
Panitch HB1.

Mayer et al (2017) DMD: Annual Rate of hospitalizations respiratory events bt PEF%p and FVC%p category
Mayer O H1 , Henricson E K,2 Craig M McDonald2 C M, Buyse G M ,3 on behalf of the Cooperative International Neuromuscular Research Group (CINRG) and the DELOS study group
Advances in Pulmonary Care in Duchenne Muscular Dystrophy

Respiratory interventions in DMD

Bushby et al 2010

Birnkrant et al 2018

Diagnosis and management of Duchenne muscular dystrophy, part 2: implementation of multidisciplinary care.
Bushby, K., Finkel, R., Birnkrant, D.J., Case, L.E., Clemens, P.R., Cripe, L. et al,
Abstract, Full Text, | Full Text PDF

Diagnosis and management of Duchenne muscular dystrophy, part 2: respiratory, cardiac, bone health, and orthopaedic management.
Birnkrant DJ, Bushby K, Bann CM, et al.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5889091/

NHS England (2013) MIE to be available if <PCF/techniques ineffective
SMA I/II(Finkel 2018): MIE must be available

Fig. 1. – Clinical algorithm including timing of interventions. REM: rapid eye movement; FVC: forced vital capacity; % pred: %predicted; NREM: non-REM; PEG/PEJ: percutaneous enteral gastrostomy/percutaneous jejunostomy; T-IPPV: Tracheostomy intermittent positive pressure ventilation.

Diagnosis and management of spinal muscular atrophy: Part 2: Pulmonary and acute care; medications, supplements and immunizations; other organ systems; and ethics.
Finkel et al (incl SMA Care group.)
https://www.nmd-journal.com/article/S0960-8966(17)31290-7/fulltext

3.3. Airway clearance
Manual chest physiotherapy combined with mechanical insufflation–exsufflation (e.g., Cough Assist® or VitalCough®) should be the primary mode of airway clearance therapy and should be made available to all non-sitters.
LVR Continued

1. PCF 1.8 x greater than with unassisted cough (Bach 1993, Bach et al 1993)

Mechanical insufflation-exsufflation. Comparison of peak expiratory flows with manually assisted and unassisted coughing techniques.
Abstract, | Full Text, | Full Text PDF, | PubMed

Intermittent positive pressure ventilation via the mouth as an alternative to tracheostomy for 257 ventilator users.
Abstract, | Full Text, | Full Text PDF

2. Increases MIC over time despite decrease VC (Bach et al 2008)

Lung insufflation capacity in Neuromuscular Disease.
Bach, J.R., Mahajan, K., Lipa, B., Saporito, L., Goncalves, M., Komaroff, E.
PubMed


- Improvement FVC
- But, majority pts had PCF <160l/min and only able to reach 160l/min with LVR
- <160l/min need MIE
- (2009) Need VC >558ml/min to reach PCF>160l/min
- so LVR not for severe pts

Cough Augmentation in Subjects With Duchenne Muscular Dystrophy: Comparison of Air Stacking via a Resuscitator Bag Versus Mechanical Ventilation.
http://rc.rcjournal.com/content/respcare/61/1/61.full.pdf

BUT- severe pts!!!
VC <340mls LVR + MAC insufficient therefore need MIE

Limits of Effective Cough-Augmentation Techniques in Patients With Neuromuscular Disease
Michel Toussaint, et al
Respiratory Care March 2009, 54 (3) 359-366
http://rc.rcjournal.com/content/54/3/359.short

1. MUST have MIC > VC so requires bulbar function
2. Moderate/severe glottic dysfunction MIC does not exceed/is less than IC so technique ineffective
3. As disease progresses and VC decreases LVR ineffective

(Katz et al 2015) LVR becomes

Katz S L, Barrowman N, Monsour A, Su S, Hoey L, McKim D
less effective as disease progresses, to reach PCF >180 need VC >558mls/ breath stacking and MAC need >340mls, Katz et al 2015 also found that as MIC fell, ability to reach PCF with LVR >160 also fell

Annals ATS Volume 13 Number 2 February 2016
Long-Term Effects of Lung Volume Recruitment on Maximal Inspiratory Capacity and Vital Capacity in Duchenne Muscular Dystrophy
https://www.atsjournals.org/doi/full/10.1513/AnnalsATS.201507-475BC#readcube-epdf

Manually Assisted Cough


Limits of Effective Cough-Augmentation Techniques in Patients With Neuromuscular Disease
Michel Toussaint, et al
Respiratory Care March 2009, 54 (3) 359-366
http://rc.rcjournal.com/content/54/3/359.short

Sivasothy et al (2001) MAC was not sufficient to increase PCF above 160l (84 to 144l/min reached)

Effect of manually assisted cough and mechanical insufflation on cough flow of normal subjects, patients with chronic obstructive pulmonary disease (COPD), and patients with respiratory muscle weakness.
PubMed

Benefit for non-scoliosis, MAC not >160l/min in severe pts

Benefits of MI-E

1. Mobilises and clears retained bronchopulmonary secretions (Edens et al 2005, Chatwin et al 2003) Clears more secretions and more quickly than PT (Chatwin et al 2009)

Cough augmentation with mechanical insufflation/exsufflation in patients with neuromuscular weakness.
PubMed
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Source(s)</td>
<td>Summary</td>
</tr>
<tr>
<td>-----------</td>
<td>---------</td>
</tr>
<tr>
<td>Prevention of pulmonary morbidity for patients with Duchenne Muscular</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
</tbody>
</table>
5. **Patients with FVC <50% (Tzeng and Bach 2000/2004/Birnkrant et al 2018)**

Prevention of pulmonary morbidity for patients with Neuromuscular Disease.


Abstract, | Full Text, | Full Text PDF

Birmkrant (see above)

<table>
<thead>
<tr>
<th>Maximal Expiratory Pressure &lt;60H20 (Miske et al 2004/Birnkrant et al 2018)</th>
</tr>
</thead>
</table>

Use of the mechanical in-exsufflator in pediatric patients with neuromuscular disease and impaired cough.


Birmkrant (see above)

<table>
<thead>
<tr>
<th>1. Recurrent episodes of chest infections and atelectasis (Miske et al 2004)</th>
</tr>
</thead>
</table>

Use of the mechanical in-exsufflator in pediatric patients with neuromuscular disease and impaired cough.


<table>
<thead>
<tr>
<th>Peak cough flow (PCF) in a) paediatric patients, b) paediatric controls, c) adult patients, and d) adult controls/ a, c) Maximal unassisted cough and b, d) insufflation/exsufflation cough in a, b) a control and c, d) a child with neuromuscular disease. a) represents the start of the cough and b) peak cough flow.</th>
</tr>
</thead>
</table>


Cough augmentation with mechanical insufflation/exsufflation in patients with neuromuscular weakness


European Respiratory Journal 2003 21: 502-508; DOI: 10.1183/09031936.03.00048102

[http://erj.ersjournals.com/content/21/3/502](http://erj.ersjournals.com/content/21/3/502)

Further evidence

| --- |

Mechanical ensufflation-exsufflation. Comparison of Peak Expiratory Flows With Manually Assisted and Unassisted Coughing Techniques

Bach JR

Chest 1993 v104(5) p1553-62

[https://doi.org/10.1378/chest.104.5.1553](https://doi.org/10.1378/chest.104.5.1553)


Effects of mechanical insufflation-exsufflation on respiratory parameters for patients with chronic airway secretion encumbrance. 
Winck JC1, Gonçalves MR, Lourenço C, Viana P, Almeida J, Bach JR. 
Chest. 2004 Sep;126(3):774-80. 


2. Senent et al (2011) ALS PCF improved most with MIE, use if LVR/NIV+ MAC not effective
A comparison of assisted cough techniques in stable patients with severe respiratory insufficiency due to amyotrophic lateral sclerosis. 
Senent C1, Golmard JL, Salachas F, Chiner E, Morelot-Panzini C, Meninger V, Lamouroux C, Similowski T, Gonzalez-Bermejo J. 

Mechanical insufflation/exsufflation improves vital capacity in neuromuscular disorders. 
Stehling F, Bouikidis A, Schara U, Mellies U 
http://journals.sagepub.com/doi/full/10.1177/1479972314562209

Mechanical insufflation-exsufflation improves outcomes for neuromuscular disease patients with respiratory tract infections. 
Vianello A, Corrado A, Arcaro G, Gallan F, Ori C, Minuzzo M, Bevilacqua M. 

5. Moran et al (2013) reduction in bed days post MIE
Effect of home mechanical in-exsufflation on hospitalisation and life-style in neuromuscular disease: a pilot study. 
Moran FC1, Spittle A, Delany C, Robertson CF, Massie J. 

Be aware of poor evidence!

A preliminary randomized trial of the mechanical insuffulator-exsufflator versus breath-stacking technique in patients with amyotrophic lateral sclerosis. 
Rafiq MK1, Bradburn M2, Proctor AR1, Billings CG3, Bianchi S3, McDermott CJ1, Shaw PJ1. 
| 1. | ALS (rapidly progressing pts), reviewed survival rate |
| 2. | PATIENTS NOT MATCHED IN PCF OR BULBAR SO HUGE BIAS!!!. |
| 3. | PCF >220l/min in LVR group with less severe bulbar weakness (less progressed disease and able to cough therefore survival better!) |
| 4. | PCF <120l/min MIE group and more severe bulbar weakness (severe, more progressed pts, unable to cough, so survival poorer!) |
| 5. | MND NICE GUIDELINES DISMISS THIS WORK AND RECOMMEND MIE USE |

**Sivasothy et al (2001)** sorry error in date! used only 20cmH2O pressures, not therapeutic >40cmH2O!

**Sivasothy P, Brown L, Smith IE, Shneerson JM.** Effect of manually assisted cough and mechanical insufflation on cough flow of normal subjects, patients with chronic obstructive pulmonary disease (COPD), and patients with respiratory muscle weakness. Thorax 2001;56(6):438-44

**Toussaint et al European Consensus Statement (2017)**


**Conclusion**

1. **Morrow et al (2013) and Auger et al (2017):** Pre DMD and SMA standards of care, report insufficient evidence either way to support MIE or show lack of evidence. Accept evidence greatly contrasts with clinical practice.


<table>
<thead>
<tr>
<th>Reference</th>
<th>Summary</th>
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<tr>
<td>Source</td>
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<td>---------------------------------------------------------------------------------------------</td>
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<tr>
<td>Diagnosis and management of spinal muscular atrophy: Part 2: Pulmonary and acute care;</td>
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<tr>
<td>medications, supplements and immunizations; other organ systems; and ethics.</td>
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<td>Finkel et al inc SMA Care group.</td>
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<td><a href="https://www.nmdjournal.com/article/S0960-8966(17)31290-7/fulltext">https://www.nmdjournal.com/article/S0960-8966(17)31290-7/fulltext</a></td>
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<td>Motor neurone disease: assessment and management [NG14]</td>
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<td>NICE 2016</td>
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<td>1.13.4 Consider a mechanical cough assist device if assisted breath stacking is not effective, and/or during a respiratory tract infection.</td>
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<td><a href="https://www.nice.org.uk/guidance/NG42/chapter/Recommendations#managing-symptoms">https://www.nice.org.uk/guidance/NG42/chapter/Recommendations#managing-symptoms</a></td>
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<td>reduce respiratory morbidity for children with neuromuscular disease?</td>
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<td>Chatwin et al (2018) Airway clearance techniques in neuromuscular disorders: A state of the</td>
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<tr>
<td>Airway clearance techniques in neuromuscular disorders: A state of the art review Michelle</td>
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<td>Chatwina, Michel Toussaint, Miguel R. Gonçalvesc, Nicole Sheersd, Uwe Melliese, Jesus</td>
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<td>Gonzales-Bermejof, Jesus Sanchog, Brigitte Faurouxh, Tiina Anderseni, Brit Hovj, Malin</td>
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<td>Nygren-Bonnierk, Matthieu Lacombel, Kurt Pernetb, Mike Kampelmacherm, Christian Devauxn,</td>
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<td>Kathy Kinneto, Daniel Sheehanp, Fabrizio Raoq, Marcello Villanovar, David Berlowitzd, Brenda</td>
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<td>F. Stehling, A. Bouikidis, U. Schara, U. Mellies, Mechanical insufflation/exsufflation</td>
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<td>Wang CH, Finkel RS, Bertini ES, Schroth M, Simonds A, Wong B,</td>
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<tr>
<td>Special Considerations in the Respiratory Management of Spinal Muscular</td>
<td>Schroth, Pediatrics 2009;123;S245-S249</td>
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<td>Atrophy Mary K.</td>
<td></td>
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<td>Eugenio Mercuri, et al., Diagnosis and management of spinal muscular</td>
<td>recommendations for diagnosis, rehabilitation, orthopedic and nutritional</td>
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<tr>
<td>10.1016/j.nmd.2017.11.005</td>
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<td>Richard S. Finkel, et al., Diagnosis and management of spinal muscular</td>
<td><a href="http://www.sciencedirect.com/science/article/pii/S0960896617312907?via%3Dihub">www.sciencedirect.com/science/article/pii/S0960896617312907?via%3Dihub</a></td>
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<td>and immunizations; other organs systems; and ethics, Neuromuscular</td>
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<td>Michelle Chatwin and Anita K Simonds; The Addition of Mechanical</td>
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<td>Insufflation/Exsufflation shortens airway-clearance sessions in</td>
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<td>Care 54 (11) 14731479. Available at:</td>
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<td>Wang CH, Finkel RS, Bertini ES, Schroth M, Simonds A, Wong B,</td>
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<td>Expanded Access Program (EAP) for Nusinersen in Participants With Infantile-onset (Consistent With Type 1) Spinal Muscular Atrophy(SMA) 2016, Available at: <a href="https://clinicaltrials.gov/ct2/show/NCT02865109?term=EAP&amp;cond=SMA&amp;rank=1">https://clinicaltrials.gov/ct2/show/NCT02865109?term=EAP&amp;cond=SMA&amp;rank=1</a> (Accessed 20 June 2018)</td>
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<td>Concise BTS / ACPRC guidelines Physiotherapy management of the adult, medical, spontaneously breathing patient</td>
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</table>
2. Further evidence submitted regarding: DRAFT Policy for the Management of Umbilical, Para-Umbilical and Incisional Hernias

3. Further evidence submitted regarding DRAFT Policy Complementary and Alternative Therapies
Huijuan et al. 2014. An overview of systematic reviews of clinical evidence for cupping therapy *Journal of Traditional Chinese Medical Sciences* (2015) 2, 3e10

Jin-Quan et al. 2017 Cupping therapy for treating knee osteoarthritis: The evidence from systematic review and meta-analysis *Complementary Therapies in Clinical Practice* 28 (2017) 152e160

Lowe et al (2017) Cupping therapy: An analysis of the effects of suction on skin and the


Lee-mai et al. The Effectiveness of Cupping Therapy on Relieving Chronic Neck and Shoulder Pain: A Randomized Controlled Trial. Evidence-Based Complementary and Alternative Medicine Volume 2016, Article ID 7358918, 7 pages http://dx.doi.org/10.1155/2016/7358918


11.3 Website content

https://sandwellandwestbhamccg.nhs.uk/harmonised-treatment-policies

Press releases to launch engagement

Sandwell & West Birmingham

Patients asked to share their views on proposed changes to variety of health treatment policies across Sandwell and West Birmingham

Patients and the public are being asked to share their views on proposed change to a variety of health treatment policies in Sandwell and West Birmingham. These include, for example, those relating to musculoskeletal treatments, breast implant revision surgery, assisted cough machines, acupuncture, treatment for port wine stain (birthmark), treatment for ear wax, and treatment for snoring.

In July 2017, NHS Sandwell and West Birmingham Clinical Commissioning Group (CCG) began working with clinicians and key stakeholders to discuss and assess the evidence and current clinical guidance relating to 21 treatments and procedures. As a result, draft policies have been developed. The CCG are now seeking the views of local people on the proposed changes to these policies.

To see the full list of policies, and the rationale for proposed changes please visit: https://sandwellandwestbhamccg.nhs.uk/harmonised-treatment-policies
The CCG is holding a series of public engagement events, and also targeted events, to listen to local people to ensure their views influence and help shape the proposed changes. At the events, there will be opportunities to discuss and feedback on all the proposed policy changes.

The CCG wants to hear from as many people as possible, if you are unable to attend any of the events listed below, you can still complete the online survey at: https://sandwellandwestbhamccg.nhs.uk/harmonised-treatment-policies

You can feedback views on as many, or as few, policies as you wish. Paper copies of the survey are also available on request by calling: 0121 6110 611. The survey closes on Friday 22 June.

Engagement events will be taking place in the following locations. To book your place, please click on the Eventbrite link. Book early to reserve your space. Events with no booking link are open to anyone who wishes to attend.

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<thead>
<tr>
<th>Date</th>
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<td>Erdington Leisure Centre, Orphanage Road, Birmingham B24 9HU</td>
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| Wednesday 6 June 2018 | 10am-12noon| Washwood Heath Health & Wellbeing Centre, 4 Clodeshall Rd, Saltley, Birmingham, B8 3SW [https://www.eventbrite.co.uk/e/harmonised-treatment-policies-tickets-46106637193]
| Thursday 7 June 2018  | 4-6pm      | Stechford Cascades Leisure centre, Station Rd, Birmingham B33 8QN             |
| Monday 11 June 2018   | 10am-12noon| YMCA, 38 Carters Green, West Bromwich, B70 9LG [https://www.eventbrite.co.uk/e/harmonised-treatment-policies-tickets-46107032375] |
| Thursday 14 June 2018 | 1.00pm-3.00pm | Brasshouse Community Centre, Brasshouse Lane, Smethwick, B66 1BA [https://www.eventbrite.co.uk/e/harmonised-treatment-policies-tickets-46444055420] |
| Monday 18 June 2018   | 10-12pm    | The Saffron Centre, 256 Moseley Road Highgate Birmingham B12 OBS [https://www.eventbrite.co.uk/e/harmonised-treatment-policies-tickets-46444328236] |
| Monday 18 June 2018   | 4-6pm      | Sandwell Leisure Trust, Smethwick Swimming Centre, Thumbermill Road, B67 5QT |
| Tuesday 19 June 2018  | 2-4pm      | Room 1, Education Centre, Birmingham Heartlands hospital, Bordesley Green East, Birmingham B9 5SS [the discussions on this date will focus on muscular dystrophy and cough assisted machine event] |
| Wednesday 20 June 2018| 1-3pm      | Friars Gate, 1011 Stratford Road, Shirley, Solihull B90 4BN [https://www.eventbrite.co.uk/e/harmonised-treatment-policies-tickets-46108299164] |
Patients and the public are being asked to share their views on proposed change to a variety of health treatment policies in Birmingham and Solihull. These include, for example, those relating to musculoskeletal treatments, assisted conception, breast implant revision surgery, assisted cough machines, acupuncture, treatment for port wine stain (birthmark), treatment for ear wax, and treatment for snoring.

In July 2017, the NHS Birmingham and Solihull Clinical Commissioning Groups (CCGs) began working with clinicians and key stakeholders to discuss and assess the evidence and current clinical guidance relating to 22 treatments and procedures. As a result, draft policies have been developed the CCGs are now seeking the views of local people on the proposed changes to these policies.

To see the full list of policies, and the rationale for proposed changes please visit: https://www.birminghamandsolihullccg.nhs.uk/get-involved/consultations-surveys-and-events/harmonised-treatment-policies-phase-2

The CCGs are holding a series of public engagement events, and also targeted events, to listen to local people to ensure their views influence and help shape the proposed changes. At the events, there will be opportunities to discuss and feedback on all the proposed policy changes.

The CCGs want to hear from as many people as possible, if you are unable to attend any of the events listed below, you can still complete the online survey at: https://www.birminghamandsolihullccg.nhs.uk/get-involved/consultations-surveys-and-events/harmonised-treatment-policies-phase-2.

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<td>1-3pm</td>
<td>Edgbaston Community Centre 40 Wood view Drive, Bham, B15 2HU</td>
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<tr>
<td>Monday 25 June</td>
<td>4-6pm</td>
<td>West Bromwich Leisure Centre, West Bromwich B70 7AJ, UK, Moor St, West Bromwich B70 7AZ, 0121 580 6430</td>
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11.5 Press releases reminder

Sandwell & West Birmingham
Last chance to share your views on proposed changes to variety of health treatment policies across Sandwell and West Birmingham

There is just over a week left to have your say and share your views on proposed changes to a variety of health treatment policies across Sandwell and West Birmingham.

NHS Sandwell and West Birmingham Clinical Commissioning Group (CCG) is reviewing 21 health policies including, for example, those relating to musculoskeletal treatments, breast implant revision surgery, assisted cough machines, acupuncture, treatment for port wine stain (birthmark), treatment for ear wax and treatment for snoring and wants to hear local views.

To see the full list of policies, and the rationale for proposed changes please visit:

https://sandwellandwestbhamccg.nhs.uk/harmonised-treatment-policies

In July 2017, NHS Sandwell and West Birmingham CCG began working with clinicians and key stakeholders to discuss and assess the evidence and current clinical guidance relating to 21 treatments and procedures. As a result draft policies have been developed and we are now seeking the views of patients and the public across the local area on the proposed changes to these policies that we are reviewing.

The CCG has held a number of public engagement events across Sandwell and West Birmingham, where we have listened to local people to ensure their views influence and help shape the proposed changes. At the events, patients were given opportunities to discuss and feedback on all the proposed policy changes.

The remaining public engagement events engagement events will be taking place in the following locations. To book your place, please click on the Eventbrite link. Book early to reserve your space. Events with no booking link are open to anyone who wishes to attend.

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<tr>
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<tr>
<td>Monday 18 June</td>
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<td><a href="https://www.eventbrite.co.uk/e/harmonised-treatment-policies-tickets-46444328236">https://www.eventbrite.co.uk/e/harmonised-treatment-policies-tickets-46444328236</a></td>
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<td>4pm – 6pm</td>
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We want to hear from as many people as possible, if you are unable to attend any of the events listed above, you can complete the survey at: https://www.surveymonkey.co.uk/r/treatmentpolicies2018.

The survey will close on Friday 22 June 2018.

You can feedback views on as many, or as few, policies as you wish.

Paper copies of the survey are also available on request by calling: 0121 6110 611. The survey closes on Friday 22 June.

Find out more on the CCG website: https://sandwellandwestbhamccg.nhs.uk/harmonised-treatment-policies

Birmingham & Solihull

Patients asked to share their views on proposed changes to variety of health treatment policies across Birmingham and Solihull

Patients and the public are being asked to share their views on proposed change to a variety of health treatment policies in Birmingham and Solihull. These include, for example, those relating to musculoskeletal treatments, assisted conception, breast implant revision surgery, assisted cough machines, acupuncture, treatment for port wine stain (birthmark), treatment for ear wax, and treatment for snoring.

In July 2017, the NHS Birmingham and Solihull Clinical Commissioning Groups (CCGs) began working with clinicians and key stakeholders to discuss and assess the evidence and current clinical guidance relating to 22 treatments and procedures. As a result, draft policies have been developed the CCGs are now seeking the views of local people on the proposed changes to these policies.

To see the full list of policies, and the rationale for proposed changes please visit: https://www.birminghamandsolihullccg.nhs.uk/get-involved/consultations-surveys-and-events/harmonised-treatment-policies-phase-2

The CCGs are holding a series of public engagement events, and also targeted events, to listen to local people to ensure their views influence and help shape the
proposed changes. At the events, there will be opportunities to discuss and feedback on all the proposed policy changes.

The CCGs want to hear from as many people as possible, if you are unable to attend any of the events listed below, you can still complete the online survey at: https://www.birminghamandsolihullccg.nhs.uk/get-involved/consultations-surveys-and-events/harmonised-treatment-policies-phase-2.

You can feedback views on as many, or as few, policies as you wish. Paper copies of the survey are also available on request by calling: 0121 6110 611. The survey closes on Friday 22 June.

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11.6 Posters sent to all GP Practices

11.7 Stakeholder briefings launch

SWB STAKEHOLDER BRIEFING – PLCV MAY 2018

Dear friends, colleagues and partner organisations,
We are emailing to make you aware that we are starting a period of engagement on proposed changes to a variety of health policies we are reviewing. These include for example, those relating to musculoskeletal treatments, breast implant revision surgery, assisted cough machines, acupuncture, treatment for port wine stain (birthmark), treatment for ear wax and treatment for snoring. To see the full list of policies, and the rationale for proposed changes please visit: https://sandwellandwestbhamccg.nhs.uk/harmonised-treatment-policies

The engagement period lasts for 8 weeks from Monday 14th May until Friday 22nd June 2018. We want to hear from as many people as possible and ask that you share this information with your colleagues, friends and family members.

People can get involved by choosing from a selection of events to attend and or by completing a questionnaire at: https://sandwellandwestbhamccg.nhs.uk/harmonised-treatment-policies

Hard copies of the questionnaire are also available on request by calling: 0121 6110611

**Engagement Events**

The following events will give people the opportunity to discuss and feedback on all of the proposed policy changes. To book your place, please click on the Eventbrite link next to the event you wish to attend:

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<td>Tuesday 19</td>
<td>4pm – 6pm</td>
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Dear friends, colleagues and partner organisations,

We are emailing to make you aware that we are starting a period of engagement on proposed changes to a variety of health policies we are reviewing. These include for example, those relating to musculoskeletal treatments, assisted conception, breast implant revision surgery, assisted cough machines, acupuncture, treatment for port wine stain (birthmark), treatment for ear wax and treatment for snoring. To see the full list of policies, and the rationale for proposed changes please visit: https://www.birminghamandsolihullccg.nhs.uk/get-involved/consultations-surveys-and-events/harmonised-treatment-policies-phase-2

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People can get involved by choosing from a selection of events to attend and or by completing a questionnaire at: https://www.birminghamandsolihullccg.nhs.uk/get-involved/consultations-surveys-and-events/harmonised-treatment-policies-phase-2

Hard copies of the questionnaire are also available on request by calling: 0121 6110611

Engagement Events

The following events will give people the opportunity to discuss and feedback on all of the proposed policy changes apart from those being considered for Assisted Conception. To book your place, please click on the Eventbrite link next to the event you wish to attend:

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<td>5pm – 7pm</td>
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</tr>
<tr>
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<td></td>
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</tbody>
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We highly value your feedback and input and we look forward to hearing your views.

Yours sincerely,

The Engagement Team
NHS Sandwell and West Birmingham Clinical Commissioning Group

BSOL STAKEHOLDER BRIEFING – PLCV MAY 2018
Specific events have also been organised to give people the opportunity to come and discuss the proposed changes to the assisted conception policy. The clinical evidence review has demonstrated that a fresh cycle of IVF in the 40-42 year old patient group has a significant reduction in producing a live birth. Therefore, the new proposed policy will offer one fresh cycle of IVF to clinically suitable women under the age of 40yrs rather than up to the age of 42yrs. The CCG is eager to hear people’s views on this proposed change. To book your place at any of the events below, please click on the Eventbrite link next to the event details.

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</tr>
<tr>
<td>Wednesday 13 June</td>
<td>TBC</td>
</tr>
<tr>
<td>Thursday 14</td>
<td>1pm- 3pm</td>
</tr>
</tbody>
</table>
June

(the discussions on this date will focus on assisted conception)
https://www.eventbrite.co.uk/e/harmonised-treatment-policies-tickets-46107128663

Thursday 21 June 1pm- 3pm

Edgbaston Community Centre, 40 Woodview Drive, Birmingham, B15 2HU (the discussions on this date will focus on assisted conception)
https://www.eventbrite.co.uk/e/harmonised-treatment-policies-tickets-46108175795

We highly value your feedback and input and we look forward to hearing your views.
Yours sincerely,

The Engagement Team
NHS Birmingham and Solihull Clinical Commissioning Group

11.8 Stakeholder briefings update

SWB STAKEHOLDER BRIEFING – PLCV JUNE 2018

Dear friends, colleagues and partner organisations,

We are emailing to update you on our period of engagement on proposed changes to a variety of health policies we are reviewing. These include for example, those relating to musculoskeletal treatments, assisted conception, breast implant revision surgery, assisted cough machines, acupuncture, treatment for port wine stain (birthmark), treatment for ear wax and treatment for snoring. To see the full list of policies, and the rationale for proposed changes please visit: https://sandwellandwestbhamccg.nhs.uk/harmonised-treatment-policies

The engagement period started on Monday 14th May and will finish on Friday 22nd June 2018, a total of eight weeks. We want to hear from as many people as possible and ask that you share this information with your colleagues, friends and family members.

People can get involved by choosing from a selection of events to attend and or by completing a questionnaire at: https://sandwellandwestbhamccg.nhs.uk/harmonised-treatment-policies

Hard copies of the questionnaire are also available on request by calling: 0121 6110611

Engagement Events

A number of public engagement events have taken place across Sandwell and West Birmingham where we have engaged with a number of groups and members of the public to ensure patient views influence and help shape the proposed changes. At the events, patients were invited to discuss and feedback on all the proposed policy changes.
The remaining public engagement events will be taking place in the following locations (see table below). The CCG is eager to hear people’s views on this proposed change.

To book your place, please click on the Eventbrite link. Book early to reserve your space. Events with no booking link are open to anyone who wishes to attend.

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<td>Stechford Cascades Leisure Centre, Station Road, Birmingham, B33 8QN</td>
</tr>
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<td>Monday 18 June</td>
<td>10am – 12pm</td>
<td>The Saffron Centre, 256 Moseley Road, Highgate, Birmingham, B12 0BS</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="https://www.eventbrite.co.uk/e/harmonised-treatment-policies-tickets-46444328236">https://www.eventbrite.co.uk/e/harmonised-treatment-policies-tickets-46444328236</a></td>
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<td>Monday 25 June</td>
<td>4pm – 6pm</td>
<td>West Bromwich Leisure Centre, West Bromwich, B70 7AZ</td>
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We highly value your feedback and input and we look forward to hearing your views.

Yours sincerely,

The Engagement Team
NHS Sandwell and West Birmingham Clinical Commissioning Group

**BSOL STAKEHOLDER BRIEFING – PLCV JUNE 2018**

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The engagement period started on Monday 14th May and will finish on Friday 22nd June 2018, a total of eight weeks. We want to hear from as many people as possible
and ask that you share this information with your colleagues, friends and family members.

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Hard copies of the questionnaire are also available on request by calling: 0121 6110611

Engagement Events

A number of public engagement events have taken place across Birmingham and Solihull where we have engaged with a number of groups and members of the public to ensure patient views influence and help shape the proposed changes. At the events, patients were invited to discuss and feedback on all the proposed policy changes.

The remaining public engagement events will be taking place in the following locations (see table below). Specific events have also being organised to give people the opportunity to come and discuss the proposed changes to the assisted conception policy. The clinical evidence review has demonstrated that a fresh cycle of IVF in the 40-42 year old patient group has a significant reduction in producing a live birth. Therefore, the new proposed policy will offer one fresh cycle of IVF to clinically suitable women under the age of 40yrs rather than up to the age of 42yrs. The CCG is eager to hear people’s views on this proposed change.

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<td>Smethwick Swimming Centre, Sandwell Leisure Trust, Thimblemill Road, Smethwick, B67 5QT</td>
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</tr>
<tr>
<td><strong>Wednesday 19 June</strong></td>
<td>2pm – 4pm</td>
<td>Room 1, Education Centre, Birmingham Heartlands Hospital, Bordesley Green East Birmingham B9 5SS</td>
<td>[focus on Muscular dystrophy]</td>
</tr>
<tr>
<td></td>
<td>1pm –</td>
<td>Friars Gate, 1011 Stratford Rd, Shirley, Solihull B90</td>
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We highly value your feedback and input and we look forward to hearing your views.

Yours sincerely,

The Engagement Team
NHS Birmingham and Solihull Clinical Commissioning Group

11.9 MP letter

BSOL STAKEHOLDER BRIEFING – PLCV MAY 2018

Dear (insert name of MP)

We are emailing to make you aware that we are starting a period of engagement on proposed changes to a variety of health policies we are reviewing. These include for example, those relating to musculoskeletal treatments, breast implant revision surgery, assisted cough machines, acupuncture, treatment for port wine stain (birthmark), treatment for ear wax and treatment for snoring. To see the full list of policies, and the rationale for proposed changes please visit: https://sandwellandwestbhamccg.nhs.uk/harmonised-treatment-policies

The engagement period lasts for 8 weeks from Monday 14th May until Friday 22nd June 2018. We want to hear from as many people as possible and ask that you share this information with your constituents.

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https://sandwellandwestbhamccg.nhs.uk/harmonised-treatment-policies

Hard copies of the questionnaire are also available on request by calling:
0121 6110611

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The Engagement Team
NHS Sandwell & West Birmingham Clinical Commissioning Group

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Hard copies of the questionnaire are also available on request by calling: 0121 6110611

**Engagement Events**

The following events will give people the opportunity to discuss and feedback on all of the proposed policy changes apart from those being considered for Assisted Conception. To book your place, please click on the Eventbrite link next to the event you wish to attend:

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<td>Venue</td>
</tr>
<tr>
<td>Wednesday 13 June</td>
<td>TBC</td>
<td>Highfield Hall Community Centre, 127-129 Highfield Road, Birmingham, B28 0HS (the discussions on this date will focus on assisted conception)</td>
</tr>
<tr>
<td>Thursday 14 June</td>
<td>1pm-3pm</td>
<td>YMCA, 38 Carters Green, West Bromwich, B70 9LG (the discussions on this date will focus on assisted conception) <a href="https://www.eventbrite.co.uk/e/harmonised-treatment-policies-tickets-46107128663">https://www.eventbrite.co.uk/e/harmonised-treatment-policies-tickets-46107128663</a></td>
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We highly value your feedback and input and we look forward to hearing your views.

11.10 Social media

Example of social media posts:
Patients are being asked to share their views on proposals on variety of health treatment policies in Sandwell and West Birmingham. These include, for example, those relating to musculoskeletal treatments, assisted conception, breast implant revision surgery, assisted cough machines, acupuncture, treatment for port wine stain (birthmark), treatment for ear wax and treatment for snoring.

We are holding a series of public engagement events to speak to local people to ensure patient views influence and help shape the proposals. At the events, patients will be invited to discuss and feedback on all the proposed policies.

For more information about the proposals, details of the engagement events or to complete the questionnaire visit: http://bit.ly/2GC57Qn
11.10 Copy of general engagement questionnaire

We would like your views on the principles we used to created draft harmonise treatment policies across the Sandwell, Birmingham and Solihull area. To request the information in alternative formats including other languages, braille, audio and easy read, please call us on 01926 252810.

Thank you in advance for taking part in the survey. We will publish the results in a report on our website within two months of the end of the listening exercise period.

1. Draft policies for a number of treatments that are available in Sandwell, Birmingham and Solihull have been created and reviewed to meet the principles below. To what extent do you agree with these principles?

<table>
<thead>
<tr>
<th>Principle</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>To offer procedures and treatments consistently and fairly to patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To end the ‘postcode lottery’ by having the same eligibility criteria for treatments regardless of where patients live</td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>To ensure that policies meet the latest national clinical guidance and are supported by robust clinical evidence</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To stop using treatments that do not have any benefits for patients, or have very limited clinical evidence base</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To prioritise treatments which provide the greatest benefits to patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>To stop offering cosmetic treatments</td>
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</tbody>
</table>

2. Do you have any other comments you would like to make about this approach to harmonising the policies for all patients across the area?

[Blank space for comments]

3. Have you or a loved one had any experience of the procedures currently being proposed in the new draft harmonised treatment policies as NOT NORMALLYFUNDED? Tick all that apply.

☐ Cough assisted machines
☐ Female sterilisation
☐ Removal of kidney stones
☐ Knee arthroscopy
☐ Male sterilisation
☐ Management of port wines stains
☐ Treatment for snoring
☐ Use of complimentary or alternative medicines

Other (please specify)

4. Have you or a loved one had any experience of the procedures currently being proposed in the new draft harmonised treatment policies with RESTRICTED CRITERIA? Tick all that apply.

☐ Hip arthroscopy
☐ Surgery for Carpal Tunnel Compression
☐ Dupuytren's Contracture treatment
☐ Assisted Conception
☐ Gamete Retrieval and Cryopreservation
☐ Bunion Surgery
☐ Treatment for Ear Wax
☐ Management of Herrnias
☐ Breast Implant Revision
☐ Acupuncture for Indications other than Back Pain
☐ Standing Upright MRI
☐ Treatment for Chronic Fatigue Syndrome
☐ Policy for Vasectomy

Other (please specify)
5. Do you agree with the list of procedures that are proposed to be not normally funded?

- Yes
- No
- Please let us know your views or any additional comments:

6. Do you think any of the proposed changes would have a negative impact on your care/ the care of your family/ any particular group of patients within the community?

7. Do you agree with the list of procedures that are proposed to have restricted criteria?

- Yes
- No
- Please let us know your views or any additional comments:
8. What is your ethnic group?
- White English, Welsh, Scottish, Northern Irish, British
- White Irish
- White Gypsy/Irish Traveller
- White and Black Caribbean
- White and Black African
- White and Asian
- Indian
- Pakistani
- Bangladeshi
- Chinese
- African
- Caribbean
- Arab
- Any other ethnic group, please describe

9. What is your gender?
- Male
- Female
- Transgender
- Prefer not to say
- Other (please state)

About you

It is important to us to listen and hear from as many people as we can. The following information will allow us to ensure that we collect the views of our diverse population.

10. Are your day to day activities limited by a health problem or disability which has lasted or is expected to last over 12 months?
- Yes, limited a lot
- Yes, limited a little
- No
11. Which of the following ages categories do you fit into?

- [ ] Up to 17
- [ ] 18-24
- [ ] 25-34
- [ ] 35-44
- [ ] 45-54
- [ ] 55-64
- [ ] 65-74
- [ ] 75+
- [ ] Prefer not to say

12. What is your religion?

- [ ] No religion
- [ ] Christian
- [ ] Buddhist
- [ ] Hindu
- [ ] Jewish
- [ ] Muslim
- [ ] Sikh
- [ ] Prefer not to say
- [ ] Other (please state)

13. Which of the following options best describes how you think of yourself?

- [ ] Heterosexual or straight
- [ ] Gay or Lesbian
- [ ] Bisexual
- [ ] Prefer not to say
- [ ] Other (please state)