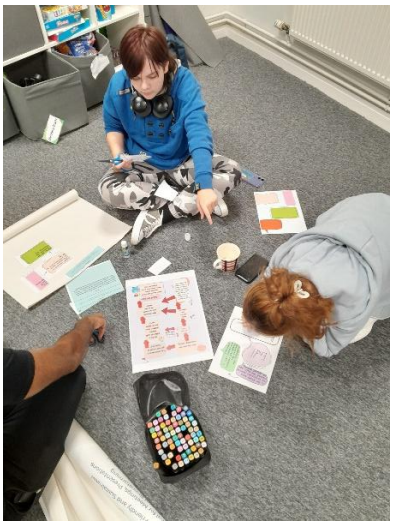
Chilypep Report -Pilot Consultation with Young People for Martha's Rule

March 2026



Introduction

This report summarises consultation findings with young people about Martha's Rule, a new NHS patient safety policy that allows patients, families, and carers to request an urgent clinical review if they believe a patient's condition is getting worse. The creative consultation was co-produced by Chilypep and their Young Health Champions participation group alongside the Yorkshire and Humber Paediatric Critical Care Operational Delivery Network. The aim of the consultation was to seek the views of young people to support the creation of a set of agreed principles around the use of Martha's Rule.

Chilypep were asked to collate the findings of the consultation in two parts according to age. This will be responses from 11- to 15-year-olds and the responses from 16–25-year-olds.

Creation of the Consultation

The creative consultation booklet and resources were coproduced with two Chilypep participation groups. This process involved 'youth-proofing' the initial consultation questions from Yorkshire and Humber Paediatric Critical Care Operational Delivery Network with the STAMP Group. The Barnsley Health Champions group co-produced youth friendly resources, to support young people to be comfortable in sharing their opinions about how Martha's Rule would work best for them. Each resource and activity was piloted by the Health Champions group to ensure that the resources were appropriate. Each stage of the process was checked with Staff working as part of the Yorkshire and Humber Paediatric Critical Care Operational Delivery Network. The booklet also included a creatively constructed story, theme, images and information to explain what Martha's Rule is and why it is important.

Method of Carrying out Consultation

Participant Distribution and Consultation Overview

A total of 23 young people took part in the consultation. This included:

- 6 participants aged 11–15 years
- 17 participants aged 16–25 years

Participants came from several groups, including the Sheffield STAMP Group, Barnsley Young Commissioners, and South Yorkshire Health Champion participation groups. These young people helped co-produce the consultation resources, pilot activities, and provide example responses that were included in the consultation booklet.

Note on percentages: Percentages reported throughout this section relate to the number of respondents to each specific question, which may differ slightly from the total number of participants in each age group.

Four separate approaches were made to groups and organisations to ask if the consultation could be carried out. This included a creative focus group with the Health Champions group in Doncaster which includes young people from Rotherham and Doncaster, Rotherham Hospital, the STAMP participation Group in Sheffield and Sheffield Young Carers. Due to time constraints two consultations were carried out and the results recorded.

Two consultation sessions were conducted with different age groups. This includes young people from Sheffield, Rotherham and Doncaster. 8 members of the Barnsley Health Champions group also responded to the consultation questions through the suggested example responses they created that were added into the consultation booklet during face-to-face creative co-production sessions, their feedback has also been included in the report.

Participant Distribution

Age Group	Participants
11 to 15 years	6
16 to 25 years	17

Both age groups completed the same consultation booklets. Within the booklets, the following questions were asked:

- 'Would you talk to a nurse or a doctor if you had a worry?'
- 'What might make it easier for you to share worries with a nurse or doctor?'
- 'What might make it harder for you to share worries with a nurse or doctor?'
- 'Have you ever felt like your worries weren't listened to by doctors or nurses when you weren't in hospital?'
- 'Design a "Super Listener" Badge for doctors/nurses. What qualities should they have to make you feel safe sharing worries?'
- 'Would you feel able to start Martha's Rule?'
- 'What would make it hard to do?'
- 'What would help you to feel confident or supported?'
- 'What could hospitals do to make it easier to know about and use Martha's Rule?'
- 'From looking at the draft examples, what do you think about using a Web of Feelings?'
- 'Circle the option you prefer.' (of the two Web of Feelings templates)
- 'What would be the best way for you to make the Martha's Rule call?'
- 'If you were a patient in hospital, how could we let you know about Martha's Rule?'
- 'How could we let you know about Martha's Rule before you go to hospital?'

These questions have been grouped into themes in order to summarise the findings of the consultation. Each theme will be addressed for both age groups.

Key Themes from Consultation with 11–15-year-olds

Trust in Healthcare Professionals

11–15-year-olds:

- **All six participants (100%) said they would talk to a nurse or doctor if they had a worry.**
- **All six (100%) also said they would feel confident starting Martha's Rule if needed.**
- **When asked about past experiences of not being listened to, five out of six respondents (83%) answered the question. Of these, three (60%) said they had not experienced being ignored by healthcare staff.**
- **One participant highlighted a distinction between physical and mental health concerns, noting they would feel more confident sharing worries about physical health than emotional wellbeing.**

100% of the young people gave a positive response saying that they would talk to a nurse or a doctor in hospital if they were worried about their condition. However, one younger person (aged 11) shared that they would be more confident to share concerns about their physical rather than their mental health.

'Yes, about my health, no about my feelings. I don't feel like a doctor is there to help me with worries about my feelings, but then I don't know who else is there to help with that. And sometimes my feelings will be sad because of my health, but I don't think doctors or nurses are there to be bothered about that, they are there to help with pain in my body, not pain inside my brain.'

Alongside this, in a later question in the consultation, 100% of the respondents said that they would feel able to start the Martha's Rule process if they felt it was needed now that they had the information about what Martha's Rule was and how it works.

The third question asked if young people had previously had an experience where they felt like their worries were not listened to by a nurse or doctor. It is not possible to know the medical history of the respondents, i.e. how many of the young people in this age group had ever been in hospital. 83% of the respondents answered the question. 60% of the young people who answered the question said that they had not experienced feeling like their worries hadn't been listened to by a nurse or a doctor.

Factors that Help Young People Speak Up

Several parts of the consultation asked young people to share what factors could help them if they were in the situation in hospital of wanting to start the Martha's Rule process. The young people in this age group highlighted that the way medical professionals were with them was important to give them confidence for Martha's Rule. This is also reflected in the answers about what qualities the young people felt doctors or nurses needed to have.

This is a compilation of the qualities that the young people suggested for the "Super Listener" question:

Many of the young people who answered this question shared multiple qualities each. Therefore, in the 11-15 years group, there were 37 separate suggestions for the qualities in nurses and doctors which would give young people confidence to share worries if they were in hospital.

• Approachable • Honesty • Kindness • Patience • Bringing language and understanding • Not occupied • Good eye contact • Good listening • Having relaxed body language • Neutral/understanding facial expressions • Be confident with the information given • Having confidentiality	• Make the patient feel comfortable • Be less patronising to teens • Reassuring the patients • Good attitude • Able to relate • Good knowledge to reassure me • Have respect/not undermining you • give space and time • Be nice • Takes time to talk to me and says hello • Has a friendly tone of voice and is good at talking to younger kids like me.

• A choice of how much you want to share • Bring someone I want for support – family/ friends • Visual aids • Privacy • Clear ways to give feedback • Access to your health records • Pamphlet for information on how your details are handled and other worries • Safety/ comfort	• Understanding the processes in a hospital • Having patience and understanding of people who have communication difficulties • Safe space • Having the ability to have a parent there for you • A choice of who you want to tell (fav doctor/nurse)

The importance of professionals being understanding and approachable in the hospital is also highlighted in the response to the second question in the 11-15 age group.

83% of the young people answered the question 'What might make it easier for you to share worries with a nurse or doctor?' There were 11 separate written responses to this question, 72% of which related to the approaches taken by nurses and doctors, including honesty, showing they care about the patients and having patience and understanding being factors which would make it easier for young people to speak up about their worries.

As already outlined, the majority of positive factors that would support young people to have the confidence to share worries with nurses and doctors, relate to the approach of the professionals in hospital and how they interact with the young people. Some young people did share some other factors as well as behaviour and approach of the nurses and doctors would help them have the confidence to speak up.

Factors to support young people to feel confident to share worries (that don't relate to the behaviour/interactions of nurses and doctors
• -option to draw and write down their worries if they don't feel able to speak to nurses/doctors • -visual aids available to support communication • -being able to have a trusted adult present when sharing worries with a nurse or doctor • -having a clear understanding of Martha's Rule and how it works • -trusted adults in their lives having a clear understanding of Martha's Rule

Barriers to Raising Concerns

The fourth and seventh questions, supported the young people to consider and share anything that they felt may be a barrier to raising worries with a nurse or doctor.

The fourth question asked young people what would make it harder for them to have the confidence to share worries with a nurse or doctor. 100% of the young people answered this question and there were 31 written responses. 8 responses referred to how a young person may feel or the personal situation of the young person, e.g. a language barrier between them and the nurse or doctor or negative past experiences of a young person. 11 of the responses related to

how an interaction with or response from the nurse or doctor could be a negative experience for the young person:

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- ‘disrespectfulness’
- ‘In a rush’
- ‘Them thinking I’m crazy or attention seeking’
- ‘Staring me down’
- ‘Being rude’
- ‘Acting like I’m wasting their time’
- ‘Them not understanding why you’re stressed’
- ‘If they aren’t comfortable or rude’
- ‘If they talk over me’
- ‘If they look at my mum to speak for me instead of talking to me so I can speak for myself.’
- ‘If they are rude’
- Clinical – ‘might feel awkward if it is my first time with that doctor/ nurse’
- ‘Option to discuss concerns with or without parents present, depending on the individual.’
- ‘Doctors not explaining’
- ‘Multiple patients hearing’
- ‘No rooms available’
- ‘Clingy parents’
- ‘Being treated differently.’
- ‘People are generally unsettled in hospitals anyway – visitor or patient – aren’t going to be easily open to talking.
- ‘Depends on what the worry is – potentially difference between male and female nurses/ doctors.’
- ‘Disregard of patients concerns and not answering their questions.’
- ‘Stereotyping’ (e.g., too young)
- ‘Not giving support’ (e.g., websites or activities)

Later in the consultation booklet, the young people were asked what would make it difficult to start the Martha’s Rule process. 100% of the young people in this age group answered this question with 11 written responses. These responses referred to a mix of personal feelings of the young people, how much the Martha’s Rule process needed to be understood by patients and potential negative interactions with nurses or doctors. Concerns about being judged by nurses or doctors appeared in 27% of the written responses.

Written responses to the question: ‘What would make it hard to do?’ (to start Martha’s Rule)
• ‘Might feel embarrassed.’ • ‘Don’t want to feel like a burden.’ • ‘Scared of being judged.’ • ‘Anxiety, fear of being shouted at, judged.’ • ‘Judgemental.’ • ‘Anxiety-not speaking up.’ • ‘It’s hard for kids to speak against adults, especially professionals, so they would forget about it.’ • ‘If they are unaware of the rule.’

- ‘If the doctor/nurse is intimidating or not kind.’
- ‘Not being judged.’
- ‘Not understanding it or how to use it.’

Awareness of Martha’s Rule Processes and Visibility and Accessibility

The following questions in the consultation were designed to enable the participants to share how they felt it would be best to share information about Martha’s Rule with young people.

- ‘What could hospitals do to make it easier to know about and use Martha’s Rule?’
- ‘What would be the best way for you to make the Martha’s Rule call?’
- ‘If you were a patient in hospital, how could we let you know about Martha’s Rule?’
- ‘How could we let you know about Martha’s Rule before you go to hospital?'

66% of the young people answered the question about hospitals sharing information about Martha’s Rule. 83% of the young people in this age range answered the question about how young people, who are patients in hospital can be informed about Martha’s Rule. Across both of these questions there were 13 different written suggestions. Visibility and accessibility of information about Martha’s Rule was highlighted in most of the young people’s responses.

Written responses from questions:
‘What could hospitals do to make it easier to know about and use Martha’s Rule?’
‘If you were a patient in hospital, how could we let you know about Martha’s Rule?’

- ‘Attentiveness from professionals’
- ‘Someone professional who counsels patients’
- ‘Posters- make it stand out’
- ‘Have an information board in the room which is legible’
- ‘a story with pictures on or something I can watch’
- ‘Explaining how I can tell you anything is wrong’
- ‘Online classes’
- ‘posters’
- ‘a poster with not too much information so you’re not overwhelmed’
- ‘Nurses talking to me about it’
- ‘Having a nice welcome pack if I’m going to be in hospital for a long time with other things inside that will help me’
- ‘Posters in my room about it and a short story on YouTube’
- ‘a friendly short story along with some web-themed colouring pages’

50% of the respondents in this age group answered the question; ‘What would be the best way for you to make the Martha’s Rule call?’. The four written responses for this question highlighted that none of these young people felt that a phone call or sending a phone message would be the best. Their suggestions were:

- ‘One on one’
- ‘a Blooket game’

- ‘My mum won’t let me have a phone so I wouldn’t be able to text unless I used my mum’s phone. I like the Worry Webs because it will show a journey and if this was a book of webs, I’d be able to look back on my journey, and it would help me see if things was better or worse for me.’
- ‘A form/quiz like the worry web templates, that are fun and creative to do.’

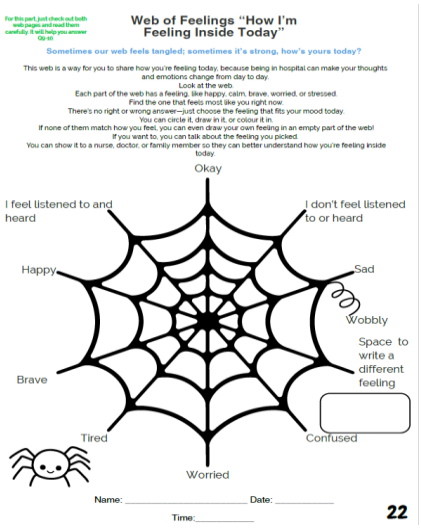
83% of the respondents answered the question ‘How could we let you know about Martha’s Rule before you go to hospital. The importance of visibility and accessibility also came out in the 9 written responses to this question.

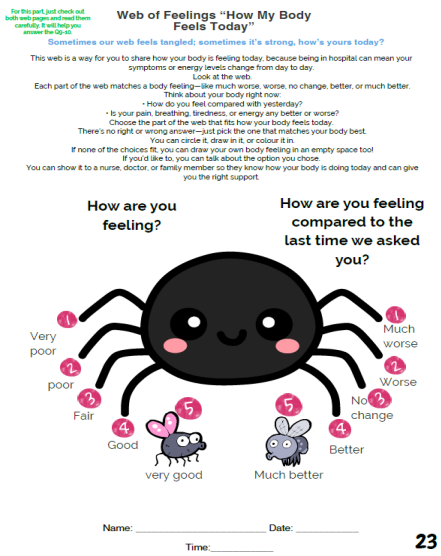
‘How could we let you know about Martha’s Rule before you go to hospital?
• ‘School make it compulsory for kids to talk about this’ • ‘Assemblies in schools to inform kids’ • ‘Posters in communal areas with families’ • ‘Going into schools for PSHE lessons’ • ‘Letter sent out nationally to parents’ • ‘On the radio in the morning when my mum drives me into school as we always listen to it’ • ‘Tell my mum so she can explain it to me’ • ‘a video or a letter to me’ • ‘a QR code and poster with signposting to the story and web colouring pages’

Sharing feelings with doctors or nurses in hospital- “Web of Feelings”

The consultation booklet shared two templates that could be used by young people in hospital to support them to record and share their feelings with doctors or nurses. This record could then support the young people to be able to start the Martha’s Rule process if it became necessary during their time in hospital.

Two different DRAFT template ideas were shared with the respondents, and the young people were asked their thoughts about recording their feelings in this way and which template they preferred.





50% of young people in the 11-15 age group shared their thoughts about using a "Web of Feelings" template in hospital. 100% of young people shared which of the two template designs they preferred with 83% preferring the second template with the spider at the centre of the design.

'What do you think about using a Web of Feelings if you were in hospital?
'The cobweb is great, but some kids might hate spiders, so try to make the spiders something kids really love like a cake.' 'Feels overwhelming due to not knowing where to write the answers.' 'Make the web more colourful because one colour makes it feel sad; we should try to promote positivity.' 'I like the flies they are funny, the spider is okay if they have a cute, friendly story about it so I know it's not a creepy spider. I do like how the spider fits with the web idea.'

Overall Findings

In summary, there were six respondents to the consultation in the 11–15 years age group. This group of young people shared that they would feel confident initiating Martha's Rule if they were in hospital and believed their condition was not improving. They highlighted several factors that would support them to raise concerns, with most suggestions focusing on how healthcare professionals communicate, particularly the importance of being listened to, spoken to directly, and treated with respect in ways that feel age-appropriate and reassuring.

Alongside this, young people identified a range of perceived challenges to implementing Martha's Rule. These included individual factors such as previous negative healthcare experiences, as well as concerns about how medical staff might respond. Notably, respondents also raised the role of parents and caregivers as an important influence. Some young people described situations where parental involvement, such as needing access to a parent's phone or navigating parental attitudes, could either enable or create barriers to initiating Martha's Rule. This highlights that young people may need to navigate not only interactions with professionals but also the dynamics of caregiver involvement when seeking to escalate concerns.

Overall, these findings suggest that successful implementation of Martha's Rule for this age group should consider not only communication between staff and young people, but also the practical and relational role of caregivers in supporting or potentially limiting access.

Key Themes from Consultation with 16–25-year-olds

Trust in Healthcare Professionals

16–25-year-olds:

- **Responses were more mixed: 8 of 17 participants (47%) said they would talk to a nurse or doctor, 6 (35%) gave mixed responses, and 3 (18%) said they would not.**
- **Regarding starting Martha's Rule, 44% responded positively, while the remainder were unsure or felt hesitant due to confidence or concerns about whether their worries would be taken seriously.**
- **Most participants (77%) reported that they had previously felt their concerns were not listened to in hospital, highlighting the need for processes like Martha's Rule to improve patient confidence.**

In order for young people to feel able to use Martha's Rule, it is important that there is trust between the young people and healthcare professionals.

There were mixed responses to the question. Out of 17 young people, 8 gave positive responses, 6 gave mixed responses, and 3 gave negative responses. The question, "Would you talk to a nurse or doctor if you had a worry?", is an indicator of trust in healthcare professionals. Approximately 47% of young people in this age group responded positively.

Written responses to- 'Would you talk to a nurse or doctor if you had a worry?		
Positive response	Mixed response	Negative response
'I would talk to my doctors if I was worried or tense.' 'Yes x5' 'Yes, I would describe the worry.' 'They know best, I'd ask for advice.'	'Depends on the worry/situation x2' 'Maybe- you've got a 1/4 chance it'll be taken seriously or not blamed on something unrelated.' 'I'd be cautious.' 'Not sure'	'Probably not, at least not directly. I would probably ask my mum to pass the worry on.' 'Probably not unless I feel its life or death.' 'I'd wait till it's bad as I'm not good at putting me first.'

All respondents answered the question, "Would you feel able to start Martha's Rule?" Of these, 44% of young people responded positively. Those who gave mixed or negative responses explained that they might feel unsure about starting Martha's Rule due to a lack of personal confidence or uncertainty about whether their concerns about their physical health would be considered serious enough to raise.

During the consultation, the concept of the hospital's existing support systems as a web of safety nets was explored. Young people recognised that hospitals already have several processes in place to help patients raise concerns. However, it would be better for them to understand this visually through something like the web to further raise awareness. Within this framework, Martha's Rule was understood as an additional layer of protection, strengthening the existing network and providing a clear route for patients or families to escalate concerns if they feel they are not being heard.

The third question explored trust in healthcare professionals: “Have you ever felt like your worries weren’t listened to by doctors or nurses when you were in hospital?” All young people answered this question, with 77% sharing that they had experienced a time when they felt their worries were not listened to. While this highlights the importance of ensuring young people feel heard within healthcare settings, it also reinforces the value of initiatives such as Martha’s Rule and other supportive processes already in place.

Young people also shared constructive suggestions about how awareness of Martha’s Rule and the wider safety-net processes could be strengthened. These included ensuring that awareness materials clearly explain when and how Martha’s Rule can be used, what will happen after it is activated, and reassurance that raising concerns is encouraged and welcomed. Young people suggested that information should be presented in accessible and engaging ways, such as short creative stories or scenarios that help illustrate real-life situations where someone might use Martha’s Rule. These approaches could help young people better understand the purpose of the rule, build confidence in using it, and reinforce the message that their voices and concerns are important within healthcare settings.

Overall, the findings highlight a valuable opportunity to build on the existing web of safety nets within hospitals by increasing awareness of Martha’s Rule alongside other established support processes. By using young-person-friendly information and creative storytelling approaches, healthcare organisations can help ensure that young people feel informed, confident, and supported to speak up about their health concerns.

Additional factors that Help Young People Speak Up

A common theme in the consultation responses is young people feeling that the way nurses and doctors would speak and interact with them would be a significant factor in helping young people speak up. The question asking young people for qualities nurses or doctors should have to support patients to be able to share worries gave 34 written suggestions for how to be a “Super Listener”. Below is a visual summary of those written responses:

Full written responses to the question asking for qualities of a "Super Listener":

• 'We as individuals know our body the best.' • 'knowledge' • 'welcoming' • 'understanding' • 'Don't interrupt when we are speaking about what we think is wrong.' • 'Ready to listen' • 'Look interested' • 'Good under pressure' • 'Experienced with emotions' • 'respectful' • 'Have a welcoming smile/attitude' • 'Friendly and welcoming' • 'Treat us like adults in terms of the terminology used.' • 'They should be patient enough to explain things to us fully.' • 'Good facial expressions' • 'Good eye contact'	• 'Good communication skills, i.e. knowing when to speak out' • 'Active communication through body language' • 'Make notes about anything that makes us feel unsafe.' • 'Having patience' • 'Ask more questions about symptoms and issues they cause' • 'Name badge and job title' • 'Not being held up on diagnoses that are unrelated.' • 'don't blame everything on anxiety' • 'friendly' • 'Be specific in questions. Don't ask does it hurt?' • 'Professional yet kind' • 'Inclusivity trained' • 'Asking related questions to make it feel like they care.' • 'Do not ask too many questions if they are already overwhelmed.' • 'listen' • 'don't undermine due to age' • 'Offer solutions/advice' • 'Communicate confidentially'

88% of young people in the 16–25-year-old age range answered the question 'What might make it easier for you to share worries with a nurse or doctor?'. As with the younger age group, the responses to this question for the 16-25 age group largely referred to the way nurses and doctors could interact with patients to ensure patients felt comfortable to share worries. Some of the responses also related to contextual factors such as the patient feeling more comfortable with a nurse or doctor of a specific gender or ensuring that there was no language barrier between the patient and medical professional.

Written responses to: 'What might make it easier for you to share worries with a nurse or doctor?'
• 'Same gender as me- female doctor.' • 'If the nurse/doctor was approachable in their appearance and if they are nice and understanding.' • 'Having patience to listen.' • 'Understanding people despite language barrier.' • 'Soft tone when speaking.'

- ‘Having patience to listen to concerns.’
- ‘Holding good eye contact.’
- ‘Being able to see a Dr for more than 5 minutes a day.’
- ‘Having the ability to look past current/prior diagnoses. They can often cause bias.’
- ‘Constantly asked if I have any questions.’
- ‘In detail explanations of treatment.’
- ‘Notes on treatment written down.’
- ‘Constantly asked if I have any questions.’
- ‘Showing interest in what I say.’
- ‘Ask me what they can do to help.’
- ‘Judge free zone.’
- ‘Specific gender’
- ‘Different forms of communication- e.g. talk/write it.
- ‘Posters about the process.’
- ‘Time to talk- struggle to find the right words.’

The final part of the consultation asked young people: *“What would make you feel confident or supported?”* (to start Martha’s Rule). This question was answered by 100% of the respondents in this age group, with 10 written responses received. Some of the responses overlapped or reflected the same idea, which is why the total number of responses was 10 even though multiple young people may have expressed similar thoughts.

The key themes from the answers included:

- **Positive relationships with medical staff** – feeling supported by nurses and doctors encourages young people to speak up.
- **Openness of the Martha’s Rule process** – ensuring that using the process doesn’t feel like “making trouble” for anyone.
- **Validation of opinions** – young people want to feel that their thoughts and concerns are respected and taken seriously by the nurses and doctors caring for them.

These responses highlight that young people are more likely to feel confident to use Martha’s Rule when they have trusting relationships with medical professionals, understand that the process is safe and open, and feel that their opinions are valued.

‘What would make you feel confident or supported?’ (to start Martha’s Rule)
• ‘All staff knowing what it is.’ • ‘Having social support and mental support.’ • ‘Seeing posters in the hospital ward.’ • ‘Good energy’ • ‘Being informed about the rule when I go.’ • ‘If the person you go to is a 3rd party, not staff treating you.’ • ‘An anonymous way or a way to start it without directly having to speak to them.’ • ‘The staff wouldn’t “get in trouble” if they were wrong and the “trouble” wouldn’t be directed from me if they were being neglectful.’ • ‘That they care for me as a human, not another number.’

• Checking in often.’

Barriers to Raising Concerns

The consultation questions asked young people to share what challenges young people could face in hospital that may make it harder for them to share worries with a nurse or doctor or harder to start the Martha’s Rule process. 100% of the respondents in this age group gave answers to the questions ‘What might make it harder for you to share worries with a nurse or doctor?’ and ‘What would make it hard to do?’ (to start the Martha’s Rule process). For these two questions there were 41 written suggestions from the young people, which gives valuable information about what can be avoided to ensure young people can be supported to feel comfortable in hospital to share worries or start the process of Martha’s Rule.

Written responses to questions: ‘What might make it harder for you to share worries with a nurse or doctor?’ ‘What would make it hard to do?’ (to start the Martha’s Rule process).	
• ‘Doctors not speaking English, not understanding.’ • ‘Student doctors being present.’ • ‘Communication problems’ • ‘Language barrier’ • ‘Overthinking, anxiety’ • ‘Trust issues’ • ‘Maybe a very personal issue’ • ‘Coming too quick to conclusion easily.’ • ‘When they make you feel rushed.’ • ‘Language barrier.’ • ‘Fear of seeming stupid.’ • ‘I will take up space others need more than me.’ • ‘I will not be listened to.’ • ‘Not understanding what the words or meaning are.’ • ‘Anxiety, staff not knowing and them thinking it’s not true.’ • ‘Not being heard and anxiety’ • ‘Not having confidence to raise the Martha’s Rule or you may not have been trained yet on Martha’s Rule.’ • ‘I would feel rude disagreeing with a professional’s opinion. No matter how bad it was I would feel so horrid.’ • ‘Judgement from the professionals currently involved.’ • ‘Staff not listening.’	• ‘When they consider me a child, so they don’t know what I’m saying.’ • ‘When they try to guess my concern.’ • ‘Going non-verbal.’ • ‘Waiting time.’ • ‘Lights’ • ‘Noise’ • ‘Anxiety’ • ‘Pain or discomfort during any treatment.’ • ‘Side effects of any treatment.’ • ‘Length of hospital stay.’ • ‘Not wanting to hold the nurse or doctor up.’ • ‘Bad experiences’ • ‘How serious the topic is.’ • ‘Embarrassment’ • ‘White coat syndrome’ • ‘Safeguarding’ • ‘If the concerns are being ignored and are seen as small, so the patient may be overreacting, which would make it hard to use.’ • ‘Arrogance or annoyance’ • ‘Unsupportive staff, not trustworthy.’ • ‘Judgement from professionals if it isn’t needed.’ • ‘No information available to access Martha’s Rule.’

Awareness of Martha's Rule Processes and Visibility and Accessibility

An important part of ensuring that Martha's Rule is successful for young people is to ensure that there is maximum awareness of the process of Martha's Rule. This was explored in several parts of the consultation, where the young people were asked to suggest ways of informing young people about Martha's Rule in and outside the hospital environment. As with the younger age group earlier in this report, visibility and accessibility were fundamental aspects of the suggestions from young people. The questions that covered this theme of the consultation were:

- 'What could hospitals do to make it easier to know about and use Martha's Rule?'
- 'What would be the best way for you to make the Martha's Rule call?'
- 'If you were a patient in hospital, how could we let you know about Martha's Rule?'
- 'How could we let you know about Martha's Rule before you go to hospital?'

Two of these questions relate to how the young people felt hospitals should put in place to inform and support young people to use Martha's Rule if needed. 100% of the 16–25-year-olds answered the question 'What could hospitals do to make it easier to know about and use Martha's Rule?' 66% of the respondents answered the question, 'If you were a patient in hospital, how could we let you know about Martha's Rule?'. The answers from both these questions are combined below. The suggestions show the importance for young people of highly visible information in hospital to explain what Martha's Rule is and clear explanations of the process.

Responses to the questions: 'What could hospitals do to make it easier to know about and use Martha's Rule?' 'If you were a patient in hospital, how could we let you know about Martha's Rule?'
• 'Posters in waiting areas' • 'Badges on staff lanyards' • 'Advertise on social media and put Martha's Rule posters around the hospital.' • 'Create posters' • 'Inform patients' • 'Providing leaflets or videos and explaining information about Martha's Rule including scenarios of how and when it should/can be used.' • 'Signs and nurses telling you' • 'Big posters on screens, waiting rooms' • 'Reception staff giving leaflets out' • 'TV and radio ads' • 'Posters and giving leaflets out' • 'Numbers and leaflets available to access Martha's Rule' • 'Staff offer to start Martha's Rule if they are concerned or at least tell you that it's an option.' • 'Talking about it, leaflets, social media, poster.' • 'Posters' • Pamphlet/booklet etc.' • 'Inform me or my loved ones every month.' • 'When getting treatment, remind the patient of their rights.' • 'After getting treatment, nurses/doctors should inform you about Martha's Rule.' • 'A fun game that can be played in hospitals.' • 'Posters in bathrooms or on walls.'

- ‘A kind professional that tells you what it is.’
- ‘There is a leaflet’
- ‘There’s a webpage shown, on a QR code, on walls, that tells you if it is applicable and what it is.’

Of the young people in this age group, 55% responded to the question: *“What would be the best way for you to make the Martha’s Rule call?”*. There were 17 young people in total, so around 9–10 provided responses. Some young people suggested the same approach, which is why the total number of unique ideas is smaller than the number of responses.

Six distinct suggestions were recorded, all proposing alternatives to making a phone call:

1. **Form** – filling out a form instead of calling.
2. **Quiz** – using a short interactive quiz.
3. **Eye-catching sign** – a sign that shows the information clearly.
4. **Posters/leaflets with QR codes** – allowing access to information digitally.
5. **Receptionist or nurse** – speaking to someone in person.
6. **Texting a number or filling out a form** – another written/digital option.

In some cases, multiple young people suggested the same idea (for example, several mentioned forms or texting), which explains why the percentage responding to the question (55%) is higher than the number of unique suggestions.

These responses are similar to those from the younger age group. This indicates that young people would be more comfortable to start the Martha’s Rule process in a written method rather than an in-person conversation or a phone call.

The final consultation question that fits within the theme of ‘Awareness of Martha’s Rule Processes and Visibility and Accessibility’, was ‘How could we let you know about Martha’s Rule before you go to hospital?'. 33% of the respondents answered this question:

- ‘posters’

- ‘Social media posts’

- ‘Information on the NHS website’

- ‘Posters and billboards’

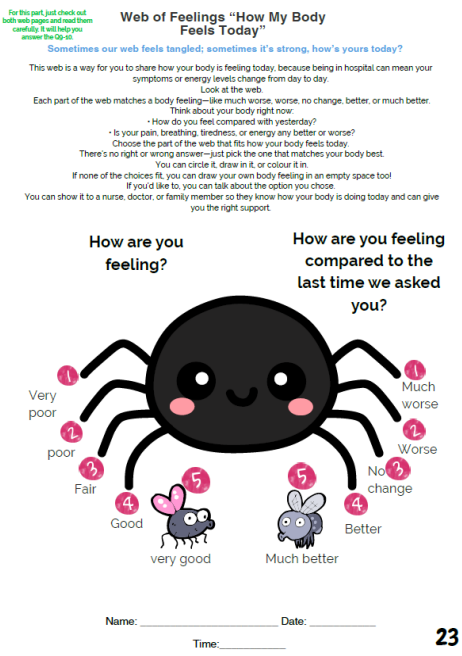
- ‘Letters with being admitted’

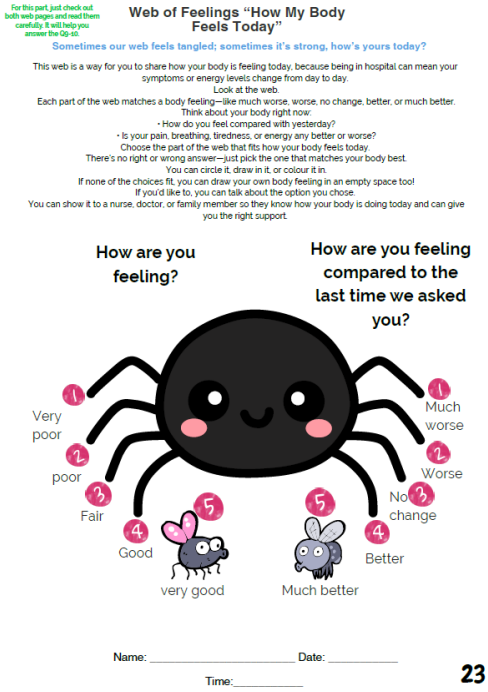
The answers to this question are themes similar to the other answers in this theme, showing the importance of visible and accessible information for young people to inform them of Martha’s Rule.

Sharing feelings with doctors or nurses in hospital- “Web of Feelings”

Two “Web of Feelings" templates were coproduced by the Young Commissioners Group and included in the consultation as potential formats for young people to record their feelings whilst

in hospital. 66% of the young people in this age group shared their feelings about using a template to record their feelings whilst in hospital. 77% of the group voted on which of the two “Web of Feelings” templates they preferred.





Most of the young people in this age group preferred the second template, with the two separate questions on. This matches the votes in the younger age group who also preferred the second template therefore this is the preferred template overall for the whole consultation. There were several suggestions in this group however, to separate the second template into two separate pages, one for each question on the template.

This understanding of the relationship between physical and mental health was strongly reinforced by Young Commissioners during the pilot sessions. Drawing on their own experiences of hospital care, they emphasised that physical illness and mental wellbeing are deeply interconnected, and that one often has a direct impact on the other. They highlighted that existing hospital check-in approaches, such as the question within the National Paediatric Early Warning Score (NPEWS) and the Patient Wellness Questionnaire (PWQ) are primarily focused on physical health and do not fully capture this relationship.

Young Commissioners explained that when they are physically unwell, in pain, or undergoing treatment, it can significantly affect their mood, anxiety levels, and sense of safety. At the same time, they noted that their mental health can influence how they experience physical symptoms, their ability to cope, and their engagement with care. This two-way relationship was described as a routine part of their experience, yet not something that is consistently explored through current hospital check-in questions.

Feedback from the pilot sessions highlighted that this gap could lead to important aspects of a young person’s wellbeing being overlooked, particularly when their primary needs may at times relate to mental health. As a result, Young Commissioners strongly advocated for check-in

questions that reflect both physical and emotional wellbeing, rather than exploring only the physical concerns of their illness.

This feedback directly informs the need to further develop the PWQ-style check-in used as an example during the consultation to consist as two sperate check ins on both their current physical illness/injury/health issue alongside their mental health. By retaining a familiar hospital format, aligned with approaches such as NPEWS and PWQ, while expanding the content to include mood, emotional wellbeing, and feelings of safety, the tool better reflects the lived experiences of young people. It ensures that the interconnected nature of physical and mental health is recognised in daily check-ins, supporting a more holistic and responsive approach to care.

Written answers for the question- 'What do you think about using a "Web of Feelings"?'
- 'People might have a phobia of spiders.' - 'Okay I guess, not much difference.' - '2 separate webs of feelings' - 'Separate ones, they should be different, two separate ones to spotlight the different aspects, both important.' - 'It may help some people, but I don't think it'd help me express myself as it's too simple so I'd feel I can't express complex feelings.' - 'I like the room to explain it on the web.'

Overall Findings

In summary, there were 17 respondents to the consultation in the 16-25 years age group. There were mixed responses to questions relating to young people's confidence around sharing worries with nurses and doctors and being able to start Martha's Rule. Concerns and barriers around speaking to doctors and nurses about concerns included contextual worries such as potential language barriers, previous bad experiences and worries about nurses or doctors reacting in a negative way to worries being brought up. This group of young people shared that high visibility of Martha's Rule information was essential for as many young people as possible to know about the process. There were a range of suggestions about how to share the information about Martha's Rule in and out of hospital settings with young people.

Additionally, members of the Barnsley Health Champions Group, as already mentioned took part in the consultation as part of the face-to-face creative co-production of the consultation booklet. Young people shared a range of ideas for increasing awareness and accessibility of Martha's Rule. They suggested promoting it through schools and colleges using posters, lessons, and leaflets, as well as through media outlets such as social media platforms, newspapers, and television or online advertisements. An accessible website or app was also suggested to provide clear information and guidance.

They highlighted that awareness materials should clearly explain what Martha's Rule is, when it can be used, who to speak to when raising a concern, what happens after it is activated, and what steps can be taken if no action follows.

Suggestions for posters included developing a recognisable Martha's Rule logo and tagline, ensuring materials are accessible (for example, using multiple languages, dyslexia-friendly formats, and Braille), and including QR codes linking to further information such as Martha's

story and patient testimonies. Young people also recommended that posters clearly explain the hospital escalation process and identify how they respond to Martha's Rule requests.

In addition, technology-based solutions were proposed, including a text line, the NHS website, Healthier Together website, or an online questionnaire to help individuals understand whether Martha's Rule may apply to their situation. QR codes placed around hospitals could link directly to these tools, making it easier for patients and families to access support and guidance.

The **Sheffield University Digital Health Charter** provides principles for designing digital health tools that are safe, accessible, and responsive to young adults needs. The older SY Health Champions at Chilypep contributed to developing the charter, helping ensure that it reflects the perspectives of young people themselves. Applying these principles can support feedback from Martha's Rule for 18–25-year-olds by creating systems that allow young adults to raise concerns in a way that feels safe, confidential, and age appropriate. For example, digital tools guided by the charter could make it easier for young people to communicate worries directly with healthcare staff, and ensure staff respond appropriately. Using digital forms or QR codes to raise concerns safely, as suggested by older participants, which aligns with the charter's principles.

Young Adults' Digital Health Charter Launch Webinar | SYDHH | The University of Sheffield

Overall Findings from all age groups

Young people strongly support systems that ensure patient voices are heard. Martha's Rule was viewed as a positive step that could improve patient safety and give patients and families confidence that their concerns will be acted upon.

Recommendations

Area	Recommendation
Communication and Language	Ensure that information about Martha's Rule is explained using simple, clear and age-appropriate language. Materials should clearly explain what Martha's Rule is, when it can be used, who to speak to, and what will happen after it is activated so that young people feel confident in understanding the process.
Visibility in Hospitals	Increase the visibility of Martha's Rule through posters, information boards, leaflets, and digital screens in wards, waiting areas, and communal hospital spaces. Posters should be visually engaging, not overly text-heavy, and include QR codes linking to further information.
Accessible Information	Ensure awareness materials are accessible to a wide range of young people by providing information in multiple languages and formats such as dyslexia-friendly text, Braille, visual aids, and short videos or stories explaining Martha's Rule.

Staff Awareness and Behaviour	Ensure all staff are aware of Martha's Rule and are able to explain it to patients and families. Staff should demonstrate approachable, respectful, and supportive behaviours, ensuring young people feel comfortable raising concerns and confident that they will be listened to.
Young Person-Friendly Resources	Develop youth-friendly resources such as short creative stories, animations, or scenarios that explain how and when Martha's Rule might be used. These resources can help young people understand the process and build confidence to speak up. Provide clear guidance for young people on when and how to request an urgent review.
Education and Community Awareness	Increase awareness of Martha's Rule outside of hospital settings through schools, PSHE lessons, assemblies, and youth organisations. Information could also be shared through social media, radio, and community campaigns to ensure young people and families are aware of the process before attending hospital.
Alternative Ways to Raise Concerns	Provide multiple ways for patients to access Martha's Rule beyond a phone call, such as online forms, QR codes, text services, or digital and in person questionnaires. These options may help young people who feel anxious about speaking directly to staff.
Supportive Hospital Environment	Encourage environments where young people feel safe sharing concerns, including offering privacy, allowing trusted adults to be present if desired, and ensuring that young people are spoken to directly rather than only through parents or carers.
Use of Creative Tools	Consider using tools such as the "Web of Feelings" template to support young people in recording their worries and tracking how they feel during their hospital stay. **Web of Feelings** • Templates to record feelings in hospital • Preferred template: second version, could be split into 2 pages • Supports both **mental and physical wellbeing check-ins** • Offers young people ownership and a visual way to communicate worries These tools can help patients communicate concerns and may support escalation through Martha's Rule if needed. Ensure they are more visual and young people have ownership or option to complete on their own/look back on. As well as options for staff to also support asking the young person and completing on their behalf.

Demographics of Participants

11-15 years olds group

Age

11 years old	12 years old	13 years old	14 years old	15 years old
1	1	1	1	2

Where do you live?

Sheffield	Barnsley	Rotherham	Doncaster
1		2	3

Ethnic Background

Chinese		Nigerian	3	Gypsy	
Indian		Mixed- White and Black Caribbean	2	Irish	
Pakistani		Mixed- White and Black African		Irish Traveller	
Somali		Mixed- White and Asian		Polish	
African	1	Mixed Ethnic Background		Romany	
Caribbean		English/Scottish/Welsh/Northern Irish/British		Any other White Background	
Arab		Filipino		Prefer not to say	
Any other ethnic group					

Nationality:

Nigerian	West African	Lagosian	Zimbabwean	British
1	1	1	1	1

Gender Identity

Male	Female	Non-binary	Prefer not to say	Other- please specify
2	4			

Was this the gender assigned to you at birth?

Yes	No	Prefer not to say
6		

Sexuality

Heterosexual	Lesbian	Gay male	Bisexual	Prefer not to say	Other- please specify

5				1	

Religion and belief

No religion	Christian	Buddhist	Hindu	Jewish	Muslim	Sikh	Prefer not to say	Other- please specify
1	5							

Do you consider yourself to have a physical disability?

Yes	No	Prefer not to say
	5	1

Do you consider yourself to have a learning disability or Neurodivergency?

Yes	No	Prefer not to say
	4	2

Please select all of the following that apply to you:

Mental health condition, such as depression or anxiety	
Neurodivergency, such as dyslexia, dyspraxia, ADHD, autism	
Blind or have a visual impairment uncorrected by glasses	
Deaf or have a hearing impairment	
Developmental condition affecting motor, cognitive, social and emotional skills and speech and language	
Long-term illness or health condition such as cancer, HIV, diabetes, chronic heart disease or epilepsy	
Physical condition (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying)	
Social/communication conditions such as speech and language difficulties	

16-25 years olds group

Age

16 years old	17 years old	18 years old	19 years old	20 years old	21 years old	22 years old	23 years old	24 years old	25 years old
7	4	1	1	1	1	1	1		

Where do you live?

Sheffield	Barnsley	Rotherham	Doncaster
4	9		4

Ethnic Background

Chinese		Nigerian	3	Gypsy	
Indian		Mixed- White and Black Caribbean	1	Irish	
Pakistani		Mixed- White and Black African		Irish Traveller	
Somali		Mixed- White and Asian		Polish	
African	1	Mixed Ethnic Background		Romany	
Caribbean		English/Scottish/Welsh/Northern Irish/British	12	Any other White Background	
Arab		Filipino		Prefer not to say	
Any other ethnic group					

Nationality

2 Did not answer

British	English	Nigerian
12	1	2

Gender Identity

Male	Female	Non-binary	Prefer not to say	Other- please specify
3	7	5		2

Was this the gender assigned to you at birth?

2 did not answer

Yes	No	Prefer not to say
6	5	4

Sexuality

2 did not answer

Heterosexual	Lesbian	Gay male	Bisexual	Prefer not to say	Other- please specify
5	1	1	4	2	2 1-omnisexual 1-pansexual

Religion and belief

No religion	Christian	Buddhist	Hindu	Jewish	Muslim	Sikh	Prefer not to say	Other- please specify
11	4						1	1 Agnostic- 1

Do you consider yourself to have a physical disability?

Yes	No	Prefer not to say
6	8	3

Do you consider yourself to have a learning disability or Neurodivergency?

Yes	No	Prefer not to say
9	4	4

Please select all of the following that apply to you:

Mental health condition, such as depression or anxiety	6
Neurodivergency, such as dyslexia, dyspraxia, ADHD, autism	8
Blind or have a visual impairment uncorrected by glasses	
Deaf or have a hearing impairment	
Developmental condition affecting motor, cognitive, social and emotional skills and speech and language	
Long-term illness or health condition such as cancer, HIV, diabetes, chronic heart disease or epilepsy	2

Physical condition (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying)	4
Social/communication conditions such as speech and language difficulties	