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MEETING:	South Yorkshire, Derbyshire and Nottinghamshire Joint Health Overview and Scrutiny Committee
DATE:	Tuesday, 24 March 2020
TIME:	1.00 pm
VENUE:	Sheffield Town Hall, S1 2HH

AGENDA

1 South Yorkshire, Derbyshire and Nottinghamshire Joint Health Overview and Scrutiny Committee (Pages 3 - 62)

Please use the link below to access the papers for the South Yorkshire, Derbyshire and Nottinghamshire Joint Health Overview and Scrutiny Committee to be held on Tuesday 24th March, 2020 at 1.00pm in Sheffield Town Hall, S1 2HH.

https://sheffieldcc.moderngov.co.uk/ieListDocuments.aspx?MId=7568&x=1

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South Yorkshire, Derbyshire and Nottinghamshire Joint Health Overview and Scrutiny Committee Meeting	Tuesday 24 March 2020 1.00 pm Town Hall, Sheffield S1 2HH

1. Welcome and Housekeeping Arrangements

2. Apologies for Absence

3. Exclusion of Public and Press

To identify items where resolutions may be moved to exclude the press and public

4. Declarations of Interest

Members to declare any interests they have in the business to be considered at the meeting

5. Minutes of Previous Meeting (Pages 1 - 6)

To approve the minutes of the meeting of the Committee held on 7th November, 2019.

6. Public Questions and Petitions

To receive any questions or petitions from members of the public.

7. Proposed Standardisation of Gluten Free Prescribing (Pages 7 - 38)

Report of Idris Griffiths, Chief Officer Bassetlaw CCG and South Yorkshire and Bassetlaw Lead for Medicines Management.

8. Children's Surgery and Anaesthesia (Pages 39 - 44)

Joint Report of James Scott (SYB Programme Manager for Children, Young People and Maternity) and Anna Clack (Children's Network Manager).

9. Amendments to the Joint Health Overview and Scrutiny Committee Terms of Reference (Pages 45 - 50)

Report of the Policy and Improvement Officer, Sheffield City Council.

10. Hyper Acute Stroke Unit Update (Pages 51 - 58)

To note update.

11. Date of Next Meeting

To agree a date and arrangements for the next meeting of the Joint Health Overview and Scrutiny Committee.

SHEFFIELD CITY COUNCIL

South Yorkshire, Derbyshire, Nottinghamshire and Wakefield Joint Health Overview and Scrutiny Committee

Meeting held 7 November 2019

PRESENT: Councillors Mick Rooney (Chair), Jeff Ennis, Eve Keenan and David Taylor (Derbyshire CC).

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1. APOLOGIES FOR ABSENCE

1.1 An apology for absence was received from Councillor Andrea Robinson, Doncaster MBC.

2. DECLARATIONS OF INTEREST

2.1 Councillor Jeff Ennis declared an interest as a Non-Executive Director of Barnsley Healthcare Trust

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3. PUBLIC QUESTIONS

3.1 Councillor Mick Rooney, Chair of the Committee, referred to two questions he had received from Nora Everitt, the first of which could not be taken due to Purdah (the pre-election period before an election), and the second question would be included within Item 7 on the agenda "Hospital Services Review".

3.2 *Nora Everitt*

3.2.1 Ms Everitt raised concerns that there may be a loophole in scrutiny arrangements, if issues cannot be considered by local scrutiny committees because they fall under the remit of the Joint Health Overview and Scrutiny Committee.

3.2.2 Emily Standbrook-Shaw, Policy and Improvement Officer, Sheffield City Council, stated that under the Terms of Reference of the Joint Health Overview and Scrutiny Committee, each authority reserves the right to consider issues at a local level. A refresh of the Terms of Reference was planned, and would consider this issue.

3.3 *Pete Deakin*

3.3.1 Pete Deakin said that he had asked three questions at the previous meeting of the Committee and was not satisfied with the responses. He had concerns about the transparency and accountability of the Integrated Care System/Joint Committee of Clinical Commissioning Groups (ICS/JCCCG). Mr. Deakin asked when would the South Yorkshire and Bassetlaw Response to the Five Year Plan become available to view.

3.3.2 Councillor Mick Rooney asked Mr. Deakin to send in his written questions and he would provide a response to him. Helen Stevens, Associate Director of

Communication and Engagement South Yorkshire and Bassetlaw Integrated Care System (SYB ICS) stated that all questions and responses were recorded in the minutes of the previous meeting and published on the website of the hosting Local Authority. In addition, a supplementary document was also published onto the website. Helen Stevens added that, due to Purdah, the response to the Five Year Plan will be published after the General Election and also when national guidance on the Plan has been received.

3.4 *Doug Wright*

3.4.1 Doug Wright asked questions regarding progress made on delivering the savings targets that were identified when the Sustainability and Transformation Plan was initially published.

3.4.2 Helen Stevens stated that due to the forthcoming General Election, she was unable to provide an answer to this, but after the Election and national guidance has been received, the Five Year Plan would be a good starting point to consider financial issues.

3.5 *Alistair Tice*

3.5.1 Alistair Tice referred to an item on the agenda – Hospital Services Review – and felt that the recommendations contained in the report would enable individual CCGs to close units within their own areas without consultation, which was a contradiction to the South Yorkshire and Bassetlaw Plan

3.5.2 In response, Councillor Mick Rooney stated that discussions on this had been held during the pre-meeting to this meeting and would be dealt with under the Hospital Services Review item on the agenda.

3.6 *Louisa Fletcher*

3.6.1 Louisa Fletcher asked about Workforce Planning and its role in transformation.

3.6.2 Lisa Kell, Director of Commissioning, SYB ICS, said that nursing staff shortfall across the NHS was very concerning, so there was a need in the Five Year Plan to focus on strong workforce planning across the area. Councillor Mick Rooney stated that it was hoped that an item on Workforce Planning would be included on the agenda of a future meeting.

4. MINUTES OF PREVIOUS MEETING

4.1 RESOLVED: That the minutes of the meeting of the Joint Committee held on 18th March, 2019, were approved as a correct record.

4.2 *Matters Arising*

4.2.1 Page 7 of the printed minutes, there was some confusion around how the ICS, CCGs and JCCCGs would all work together. Councillor Mick Rooney requested that a flow chart and/or diagrams be produced to show how the SYB ICS works,

including points of access for members of the public.

4.2.2 Page 10 of the printed minutes, at bullet point three in the resolution, Councillor Mick Rooney asked that a link to a report relating to patient and public engagement in shaping health services, which had been submitted to the Collaborative Partnership Board and Executive Steering Group, be provided. With regard to Part iii. of the resolution, which asked the Joint Committee to hold a session on the ICS approach to the prevention agenda, he suggested that each Council should hold individual sessions on this and included the role of the voluntary, community and faith sector.

5. PRE CONSULTATION ON GLUTEN FREE PRESCRIBING

5.1 Due to the contents of the report and pre-election rules, this item was withdrawn from consideration and will be brought to a future meeting of the Committee.

6. HOSPITAL SERVICES REVIEW

6.1 Alexandra Norrish, Programme Director for Hospital Services, South Yorkshire and Bassetlaw Integrated Care System (SYB ICS) presented the report and stated that over the last two years, the South Yorkshire and Bassetlaw (SYB) health and care system has been considering how best to support the long term sustainability of acute hospital services in the South Yorkshire and Bassetlaw (SYB), Mid Yorkshire and North Derbyshire area. Regular reports on the development of the Hospital Services Review have been provided to the Joint Scrutiny Committee and updates on the recommendations are set out in the report. Alexandra Norrish said that the recommendations had been submitted to all CCG Governing Bodies within the area, for their consideration, which had subsequently been agreed and would be published at a later date. The report recommends that the system should take forward shared working between the Trusts, with the focus on developing Hosted Networks as an important vehicle for transformation going forward. Hosted Networks will work in three ways: Level 1 will focus on shared approaches to workforce, clinical standardisation and innovation; Level 2 will involve a higher level of sharing resources across the system; and Level 3 will consist of a closer relationship with one Trust providing or supporting services on another Trust's site.

6.2 Members of the Committee made various comments and asked a number of questions, to which responses were given as follows:-

- It was difficult to predict until after the General Election any potential savings that might be made and what the implications of Brexit might have, but these could be addressed at the next meeting.

- With regard to public engagement, a number of large open events have been held throughout the two years of the Review with individual events within each Place, run by Clinical Commissioning Groups. There has also been targeted activity focused on seldom heard groups, such as BME communities, asylum seekers, the traveller community, the LGBT community and people with disabilities.

- Committee members requested that future reports contain sufficient evidence for the Committee to be able to effectively scrutinise issues.

- Feedback and data on the consultation is available on the Integrated Care System website, however, as was pointed out, not everyone was able to access the internet and it was acknowledged that there was a need to find the right balance in providing information to all members of the public.

- The aim of the review was to reduce barriers between the Trusts and use the Hosted Networks to agree standardised transfer protocols between Trusts, so that patients can be transferred more easily, and to standardise care pathways, based on best practice, so that patients receive similar care whichever hospital they are in.

6.3 A written question was received from the South Yorkshire and Bassetlaw NHS Action Group as follows:-

"Will the JCCCG recommend the reinstatement of the Transport Patient and Public Panel, that was disbanded last month because the Hospital Services Programme had not found "reconfiguration" necessary, now that it has been agreed to reintroduce the possibility pf "reconfiguration" into the Hospital Services Programme with regular monitoring and reviewing of the success of implementing "transformation"?

6.4 Helen Stevens, Associate Director of Communication and Engagement SYB ICS, responded that the Transport Patient and Public Panel were no longer meeting because the Hospital Services Review had not resulted in any reconfiguration and therefore there was no business for the Panel to consider. If that position changes in the future, Ms Stevens assured the Committee that the Panel would be re-established.

6.5 RESOLVED: That the Committee:-

(a) notes the report;

(b) requests that future reports contain sufficient evidence for the Committee to be able to effectively scrutinise issues; and

(c) requests that a report on the development of the hosted networks is brought back to a future meeting of the Committee, including feedback from staff and clinicians.

7. HYPER ACUTE STROKE SERVICES - REVIEW

7.1 Marianna Hargreaves, Transformation Programme Lead, South Yorkshire and Bassetlaw Integrated Care System (SYB ICS), gave an update on the implementation of the new South Yorkshire and Bassetlaw model of hyper acute stroke care (HASU). She said that after a comprehensive review of stroke services across the area, a strong clinical case for change underpinned the development of a new model to improve access to high quality urgent specialist

stroke care. It was acknowledged that if changes were made, there would be improved outcomes to those being diagnosed as having had a stroke. A HASU Implementation Group was established in December 2018, with representation from all providers, the Yorkshire Ambulance Service, Sheffield CCG and the Stroke Association and the Group agreed implementation dates for a phased delivery of the new model during 2019. The HASU in Rotherham Hospital ceased in July 2019, and, as was anticipated, those suffering from a stroke who resided in Rotherham, have been taken to the Sheffield HASU for their urgent stroke care. Following such care, they have been either discharged directly home, home with early supported discharge and/or community stroke services or transferred back to Rotherham hospital for ongoing acute stroke care and inpatient rehabilitation. After successful implementation in Rotherham in July, the changes were then carried out in Barnsley from 1st October, 2019 with patients going to Pinderfields, Doncaster or Sheffield and again timely transfer after their urgent care back to Barnsley Hospital for ongoing care and support. Early feedback from patients and their families and staff has been very positive.

7.2 Marianna Hargreaves circulated a leaflet which had been developed to help explain the regional model and outline what patients and their families could expect. She said further work was continuing to develop an accessible, easy to read patient leaflet. She stated that the information on many leaflets was in the form of pictures and diagrams to assist patients, particularly those with aphasia, and the aim was to develop an accessible, easy read patient leaflet. Helen Stevens, Associate Director of Communication and Engagement, SYB ICS, said that every hospital has a substantial amount of leaflets, covering all aspects of health care, and every leaflet needed to be checked every two years to refresh the information as necessary.

7.3 A regional patient flow policy has also been developed jointly by all partners setting out clear expectations to enable smooth and timely patient flow through the regional service. The policy includes a daily teleconference call for all providers to participate in, to enable joint oversight of the patient flow. Initial feedback is that patient flow is working out as anticipated.

7.4 Workforce planning and recruitment had been progressed in a phased way during 2019, with each HASU successfully recruiting additional nursing and therapy staff, through staff movement and career development. Each HASU has reviewed their internal medical cover arrangements to consider how best to put in place increased cover for the new model. However, workforce planning and recruitment for the future continues to be an area that requires further work, for both HASU and the whole stroke pathway.

7.5 In response to a number of questions from Members, Marianna Hargreaves stated that it was too early to provide evidence of improvement, but that data is being collected and will be brought to a future meeting of this Joint Committee. She reported that it was also too early to tell whether there were any unintended consequences of the changes, but so far the changes had gone smoothly. With regard to the closure of the Units in Rotherham and Barnsley, she stated that planning for any additional capacity that would be required at the other Units had been anticipated, and repatriation is happening within 48-72 hours.

7.6 NHS England has concluded that there is sufficient evidence to support the routine commissioning of Mechanical Thrombectomy for acute ischaemic strokes and Sheffield has a neuroscience centre which was crucial to the provision of complex, highly specialised neurological and neurosurgical quality care. The centre is open Monday to Friday but it is planned to increase coverage following the development of the highly specialised skills necessary.

7.7 RESOLVED: That the Committee:-

(a) notes the report; and

(b) requests that a report is brought to a future meeting of the Committee, including evidence to demonstrate that the new model is working as planned; information on patient flows; feedback from patients and families and feedback from the hospitals providing the additional services.

8. JOINT COMMITTEE OF CLINICAL COMMISSIONING GROUPS - FORWARD WORK PROGRAMME

8.1 The Committee received a report from Lisa Kell, Director of Commissioning, South Yorkshire and Bassetlaw Integrated Care System (SYB ICS), which set out the current and future work of the Joint Committee of Clinical Commissioning Groups (JCCCGs). Lisa Kell stated that in July, 2019, the JCCCG had updated its Terms of Reference which resulted in a number of changes, including a change in membership due to NHS Wakefield CCG withdrawing as an associated member. A new work programme was implemented and as work progresses the JCCCG will identify any areas where this Joint Committee would need to be consulted. Two areas identified were the continued implementation of the Hospital Services Programme and Gluten Free prescribing.

8.2 RESOLVED: That the Committee notes the forward work programme and requests that it is brought back to a future meeting.

9. DATE OF NEXT MEETING

9.1 The Policy and Improvement Officer stated that, as Wakefield had officially withdrawn from the Joint Committee, the name of the Committee would need to be amended, along with the Terms of Reference.

9.2 It was agreed that the next meeting the Joint Committee would be held on a date and time to be agreed late January/early February, 2020, at Sheffield Town Hall.

Report to Joint Health Overview and Scrutiny Committee for South Yorkshire, Nottinghamshire and Derbyshire
24th March, 2020

Report of: Report on proposals to standardise the prescribing of Gluten Free products across South Yorkshire and Bassetlaw

Subject: Proposed standardisation of Gluten Free prescribing

Author of Report: Idris Griffiths, Chief Officer Bassetlaw CCG and South Yorkshire and Bassetlaw lead for medicines management

Summary:

Information relating to Gluten Free prescribing, including the differences between CCGs in terms of prescribing guidelines and cost differences, were presented to the South Yorkshire and Bassetlaw Joint Committee of Clinical Commissioning Groups (JCCCG) for consideration of whether all 5 CCGs should adopt the same prescribing recommendations.

To get an initial public viewpoint on this the JCCCG instructed that focused engagement take place. This paper sets out the relevant issues relating to Gluten Free prescribing and seeks the views of the Joint Scrutiny Committee regarding next steps.

Type of item: The report author should tick the appropriate box

Reviewing of existing policy	**Yes**
Informing the development of new policy	
Statutory consultation	**Yes**
Performance / budget monitoring report	
Cabinet request for scrutiny	
Full Council request for scrutiny	
Call-in of Cabinet decision	
Briefing paper for the Scrutiny Committee	
Other	

The Scrutiny Committee is being asked to:

Discuss the views from the engagement exercise on a potential standardisation of the NHS policy on prescribing Gluten Free products across South Yorkshire and

Bassetlaw and provide the Joint Committee of CCGs with any views and comments.

To provide their views on whether any changes to the prescribing of Gluten Free bread and mixes in South Yorkshire and Bassetlaw would be considered a substantial development or variation, and accordingly if they recommend that there is a formal duty to consult with the Local Authority under the s244 regulations.

Category of Report: OPEN

Report of the South Yorkshire and Bassetlaw Chief Officer Lead for Medicines Management

1. Introduction/Context

1.1 Information relating to gluten free prescribing, including the differences between CCGs in terms of prescribing guidelines and cost differences were presented to the South Yorkshire and Bassetlaw Joint Committee of Clinical Commissioning Groups (JCCCG) for consideration of whether all 5 CCGs should adopt the same prescribing recommendations.

1.2 To get an initial public viewpoint on this the South Yorkshire and Bassetlaw Citizens Panel members were asked for their thoughts. They felt that all 5 CCGs should adopt the same prescribing recommendations, i.e. that there should be equity of access across the CCGs. The Panel felt that the consideration should be one of equity rather than cost saving.

1.3 The JCCCG then instructed that engagement should take place with targeted members of the population, including those who might be most affected by any proposed changes (Low income groups; Mother and baby groups; Mental health patients; Young people; Older people; People with long term conditions; Coeliac and Gluten Free patients; Groups with other dietary needs). The report of this engagement is appended to this report.

1.4 This paper sets out the relevant issues relating to Gluten Free prescribing and seeks the views of the Joint Scrutiny Committee.

2. Background

2.1 Coeliac disease is a lifelong autoimmune disease caused by a reaction to gluten. When someone has coeliac disease their small intestine becomes inflamed if they eat food containing gluten. This reaction to gluten makes it difficult for them to digest food and nutrients. Symptoms include diarrhoea, constipation, vomiting, stomach cramps, mouth ulcers, fatigue and anaemia.

2.2 Once diagnosed, coeliac disease is treated by following a Gluten Free diet for life. A Gluten Free diet can be achieved without the need for specific manufactured products as many food items are naturally Gluten Free, e.g. meat, fish, fruit and vegetables, rice & potatoes.

2.3 Gluten Free (GF) foods are available on prescription to patients diagnosed with gluten sensitivity enteropathies, and have been since the late 1960s when the availability of GF foods was very limited. GF foods are now readily available in most supermarkets and a wider range of naturally GF food types are also available, so the ability of patients to obtain these foods without a prescription has greatly increased.

2.4 In March 2017, the Department of Health launched a consultation on the availability of Gluten Free Foods on Prescription. The outcome of the

consultation was reported in January 2018 and the overall statement was as follows:

"Following its consultation on the availability of GF foods on NHS prescription, the government has decided to restrict GF prescribing to bread and mixes only. The majority of consultation responses were in favour of this."

https://www.gov.uk/government/consultations/availability-of-gluten-free-foods-on-nhs-prescription

2.5 In August 2018 the Department of Health published a consultation on the changes to be made to the drug tariff for Gluten Free Items. The consultation closed on 1st October 2018; then, following amendments to the Prescribing Regulations, the Drug Tariff was amended in December 2018. NHS prescriptions issued in England from December 2018 can only be for specific GF bread or GF mixes as listed in the Drug Tariff.

2.6 Whilst GPs can only now prescribe GF bread and mixes CCGs can adopt local policies that may go further than the changes implemented in December 2018. There are differences across South Yorkshire and Bassetlaw between the CCGs in the prescribing of Gluten Free Products to coeliac patients.

3.0 Current Policies

3.1 Prescribing of Gluten Free foods to adults (over the age of 18) are not recommended in Sheffield. Prescribers can however apply discretion in exceptional circumstances where they are sufficiently convinced that there is a genuine risk that a vulnerable individual is, or will become, undernourished if they do not prescribe Gluten Free products. A full public consultation with people in Sheffield was undertaken before this policy was adopted in Sheffield.

3.2 Barnsley CCG has restricted prescribing of bread and mixes to a volume of 8 units per month per individual.

3.3 Bassetlaw and Doncaster CCGs recommend to clinicians that Gluten Free bread and mixes should be prescribed to the Coeliac Society recommendations.

3.4 Rotherham is slightly different to Bassetlaw and Doncaster recommending that the quantity to prescribe is 2 units less than the Coeliac Society recommendations.

3.5 Across South Yorkshire and Bassetlaw in 2018/19 over £400,000 was spent on prescribing Gluten Free food.

3.6 Standardising policies on Gluten Free products would have significantly different financial impacts depending on the approach taken with a potential range of an investment of £200,000 to a saving of up to £290,000

4.0 What does this mean for the people of South Yorkshire and Bassetlaw?

4.1 There are approximately 1,400 adults who request prescriptions for Gluten Free bread and mixes in South Yorkshire and Bassetlaw. This is approximately 0.11% of the population – a figure which has reduced significantly in recent years, largely due to the wide availability of Gluten Free products in shops.

4.2 Approximately 1% of the population have coeliac disease.

4.3 Approximately 90% of those with coeliac disease do not use prescriptions. Where prescriptions are used the volumes requested by individual patients vary from infrequent to regular.

4.4 Any change in policy is therefore likely to have no, or very little, impact on 99.9% of the population.

4.5 If any future policy recommended further removal of access to Gluten Free prescriptions the impact on some of the 0.1%, particularly those living in poverty, could be significant.

5.0 Findings from the recent engagement

5.1 Following a stakeholder mapping exercise, a range of groups was identified and engaged throughout February and early March across Barnsley, Bassetlaw, Doncaster, Rotherham and Sheffield. These included:

- Low income groups
- Mother and baby groups
- Mental health patients
- Young people
- Older people
- People with long term conditions
- Coeliac and GF patients
- Groups with other dietary needs

5.2 In total 88 people took part in the engagement through focus groups, attendance at existing groups and meetings and in-depth interviews—either face-to-face or over the telephone.

5.3 It was felt that this targeted approach to engagement would ensure the views of different communities who could be impacted by any proposed changes were heard in an equitable way that didn't favour one viewpoint over another. It was also felt that this would build on and not duplicate the national and Sheffield full public consultations into GF prescribing which have already taken place.

5.4 The engagement was independently analysed.

5.5 The vast majority of participants felt that access to health and care services and medication prescribing should be the same regardless of location, not only within South Yorkshire and Bassetlaw but also nationally.

5.6 Overall, the vast majority of participants felt that the NHS should not be funding products that are readily available in supermarkets and that funding for clinical decisions should be the priority.

5.7 Overall, the vast majority of participants felt that an increase in Gluten Free prescribing was not needed, especially not at the expense of other NHS services.

5.8 Almost all participants stated that they would be happy with a reduced level of Gluten Free prescribing in their area as long as those in need of support were protected and that it should be looked at on an affordability basis.

5.9 Overall, it was felt that whatever happens next with regards to Gluten Free prescribing the changes made should make the system fairer for all and reduce waste within the NHS. The most common themes emerging from participants were that there needs to be support to access Gluten Free foods in place for those most in need and a wider package of support for recently diagnosed people.

6.0 Recommendation

6.1 The Committee is asked to discuss and provide the Joint Committee of CCGs with any views and comments on the proposals to standardise the NHS policy on prescribing Gluten Free bread and mixes across South Yorkshire and Bassetlaw.

6.2 The Committee is asked for their views on whether any changes to the prescribing of Gluten Free bread and mixes in South Yorkshire and Bassetlaw would be considered a substantial development or variation, and accordingly if they would recommend that that there is a formal duty to consult with the Local Authority under the s244 regulations.

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Gluten Free Prescribing in South Yorkshire and Bassetlaw Engagement analysis

An independent report from The Campaign Company for South Yorkshire and Bassetlaw ICS

The Campaign Company

March 2020

Contents

1 Background

South Yorkshire and Bassetlaw Integrated Care System (ICS) is a partnership of 23 organisations – from the NHS and local authorities to the voluntary sector and independent partners – responsible for looking after the health and care of the 1.5 million people living in Barnsley, Bassetlaw, Doncaster, Rotherham and Sheffield. Working together, the ICS's ambition is to ensure local health and care services are the best they can possibly be and give patients the seamless care they have said they want.

As part of this partnership approach, the Joint Committee of Clinical Commissioning Groups (JCCCG) is considering making changes to the way in which gluten free (GF) products are prescribed across South Yorkshire and Bassetlaw (SYB).

The JCCCG has agreed to look at gluten free prescribing because currently it is different depending upon where you live in South Yorkshire and Bassetlaw and many people feel that there should be equity in the way gluten free products are prescribed.

Across England, gluten free bread and flour mixes are available on prescription. Currently, the level of gluten free prescribing in South Yorkshire and Bassetlaw varies as follows:

- Bassetlaw and Doncaster recommend to their clinicians that they prescribe the level of gluten free bread and mixes recommended by the Coeliac Society[1].
- Rotherham recommend to their clinicians that they prescribe that they prescribe two units less than the level of gluten free bread and mixes recommended by the Coeliac Society.
- Barnsley recommend to their clinicians that they prescribe eight units of gluten free bread and mixes.
- Sheffield recommend to their clinicians that they do not prescribe gluten free bread and mixes to adults (over the age of 18). Prescribers can apply discretion in exceptional circumstances where there is genuine risk that a vulnerable adult is, or will become, undernourished if they do not prescribe gluten free products.

Gluten free foods have been available on prescription since the late 1960s when the availability of gluten free foods was limited. Gluten free foods are now more readily available and accessible in supermarkets along with a wider range of naturally gluten free foods.

Gluten free foods in the supermarket are typically more expensive than gluten containing foods. For example, a gluten free sliced loaf of bread typically costs £1.80 whereas a gluten containing sliced loaf of bread typically costs £1.

Coeliac UK believes that despite gluten free staple foods being more widely available today than ever before, they are still not readily accessible across the country and that in many budget or convenience stores gluten free staples are virtually absent. They believe that

[1] https://www.coeliac.org.uk/information-and-support/coeliac-disease/once-diagnosed/prescriptions/national-prescribing-guidelines/

when prescribing is restricted solely to those on a limited income, the elderly or those living in remote rural areas can be left struggling to maintain a gluten free diet.

Approximately 1% of the population have coeliac disease and 10% of them use prescriptions for gluten free products. There are currently 1,400 adults in South Yorkshire and Bassetlaw who request prescriptions for gluten free bread and flour mixes.

The prescribing of gluten free foods costs the NHS £15.7 million nationally. In Sheffield since they recommended that gluten free products are not prescribed to adults, £250,000 has been saved to be reinvested in other areas of healthcare. If Barnsley, Bassetlaw, Doncaster and Rotherham recommended the same approach as Sheffield in 2018/19 more than £100,000 would be have been available to be reinvested in other areas of healthcare.

To help inform the decision-making process, the JCCCG has been seeking the views of a range of stakeholder groups to better understand the range views on this issue.

This report is an independent analysis of the responses gathered from the groups identified throughout February and early March.

2 Approach to engagement and analysis

2.1 Engagement

Following a stakeholder mapping exercise, a range of groups were identified and engaged throughout February and early March across Barnsley, Bassetlaw, Doncaster, Rotherham and Sheffield. These included:

- Low income groups
- Mother and baby groups
- Mental health patients
- Young people
- Older people
- People with long term conditions
- Coeliac and gluten free patients
- Groups with other dietary needs

In total 89 people have taken part in the engagement through focus groups, attendance at existing groups and meetings and in-depth interviews—either face-to-face or over the telephone. A breakdown of the engagement by place can be found below:

- Barnsley: Fareshare (foodbank users, staff and volunteers) and Patient Participation Group (PPG) members (13 participants)
- Doncaster: Safe Space (people with mental health and learning disabilities) and Young Advisors (9 participants)
- Rotherham: PPG network and parent carer forum (including families with children with disabilities) (38 participants)
- Sheffield: Chinese community centre members, Darnall Wellbeing staff and Refugee Council (10 participants)
- South Yorkshire and Bassetlaw: people with coeliac disease from Doncaster and Bassetlaw (9 participants) and people with other dietary needs and coeliac disease from Barnsley (10 participants)

Participants were asked to complete an equalities form to help South Yorkshire and Bassetlaw ICS understand who had taken part in the engagement. 48 people completed these and a breakdown of the equalities profile can be found in Appendix 1.

Before taking part, participants were given the opportunity to read a briefing paper and a gluten free facts sheet, which can be found in Appendix 2.

The core questions asked throughout the engagement were:

- Do you think the availability of health and care services and medication prescribing in SYB should all be the same? Why?
- Do you think the NHS should be funding supermarket available foods?
- Would you be happy for more GF prescribing to be provided in your area meaning disinvestment in other health services?

- Would you be happy for less GF prescribing to be provided in your area?
- What do you think are the main things we should think about?

2.2 Analysis

The Campaign Company (TCC) was commissioned to provide an independent analysis of the feedback from the engagement. Responses have been collated by South Yorkshire and Bassetlaw ICS. All data has remained anonymous and was shared with TCC for the purpose of this analysis.

The data has been analysed using a qualitative data analysis approach, identifying common themes among responses and highlighting any differences by demography or geography.

The aim of this qualitative analysis is to accurately capture and assess the range of points put forward rather than to quantify the number of times specific themes or comments were mentioned. Where appropriate, we have described the strength of feeling expressed for certain points, stating whether a view was expressed by, for example, a large or small number of responses. If a specific issue was raised by a relatively large number of participants, the report uses the phrase ‘many participants’; the phrases ‘several’, ‘some’, or ‘a few’ participants are used to reflect smaller numbers.

3 Findings

3.1 Introduction

This section reports on the analysis of the feedback received through the engagement exercise. The feedback is reported as received to each of the questions discussed and where there are differences by geography or stakeholder group these are referenced within the analysis.

3.2 Do you think the availability of health and care services and medication prescribing in SYB should all be the same? Why?

The vast majority of participants felt that access to health and care services and medication prescribing should be the same regardless of location, not only within South Yorkshire and Bassetlaw but also nationally. Many felt that this universality was part of a deep sense of fairness and equality at the point of treatment that should run through the NHS, and the need to avoid a 'postcode lottery' was also referred to by many participants.

"Yes. It should be fair to all as we pay the same level of tax." (Chinese Community Centre, Sheffield)

"What the NHS was built on was a foundation of providing everyone with a standard of care which was fair to all and that is how it should still be." – (Doncaster Safe Space group)

"It can't be a postcode lottery. I know some places they've completely stopped." (Elderly Coeliac)

'It's a postcode lottery and it just feeds into why some areas have longer life spans than others. It should be equal across the country.' (Other dietary needs)

Concern was also expressed for the most vulnerable people in society by some participants, in particular in relation to the cost of following a gluten free diet – with examples described of elderly people who have struggled to eat enough due to the cost of gluten free products and also those who struggle due to low income, reliance on foodbanks and in-work poverty.

Some also noted that a diagnosis is required before gluten free prescriptions can be accessed and that there may need to be better pathways for diagnosis, particularly for those with multiple allergies, or complex, or additional needs.

Other themes emerged from some specific stakeholder groups, including:

- Older groups in Rotherham suggested taking the best practices from each area
- For some universal access is not an issue as gluten free products are affordable and accessible
- Surprise that it isn't unified already following national consultation

3.3 Do you think the NHS should be funding supermarket available foods?

Overall, the vast majority of participants felt that the NHS should not be funding products that are readily available in supermarkets and that funding for clinical decisions should be the priority. The additional cost of following a gluten free diet was noted – and the price difference quoted in the briefing materials was contested - by many participants, in particular those managing a gluten free diet themselves.

'On balance, I think it's manageable but we both work. You can survive not having it but my concern would be children in vulnerable families.'

'I'll be going to university and I'll need to budget carefully. The bread I eat is at least £2, not the 60p for a loaf.'

'Bread usually costs at least £2.50 for a small loaf. I only eat 2 or 3 slices but a younger adult would manage at least double that…basic food costs do add up.'

Affordability

Linked to this, one of the key themes emerging from this question was affordability. Affordability was commonly mentioned as a reason for the NHS to support people who would otherwise struggle to access readily available gluten free products. Some felt that the introduction of means testing – looking at vulnerability, age, complex needs - would be worthwhile.

'I see people living out of food banks and gluten free products won't be donated. It really needs to be thought through who needs these prescriptions when that is the only way some people will access those products.' (Other dietary needs)

'On a low budget everything is three times more expensive and it's not fair.' (Coeliac patient)

'I will struggle to feed my children without it. When you have to rifle through the reduced section to feed your family, it feels like a tax on being ill.' (Mother of son with Coeliac disease)

Review of the prescribing system

Further to this, some people felt that the system for gluten free prescribing should be reviewed to allow better choice and flexibility for individuals. While a few did prefer the products available on prescription, many had stopped requesting prescriptions due to the limited items available following previous changes in their area and also being given a whole month of bread and flour at one time, which proved wasteful.

'I get the flour on prescription and I used to get the bread but the trouble was they would send you eight loaves! I've nowhere to put it. You should have been able to get what you wanted. We get the flour and make the bread now.'

'We used to get cereal, pizza bases, crackers and it changed two years ago. I don't like bread when it's been in the freezer so I don't order anything now.'

'When they stopped doing pasta, that was a big deal. It was one of the meals I could offer the whole family, with a rich vegetable-based sauce.'

The possibility of introducing a voucher system, rather than prescriptions, so that individuals could select the brands and products that suited them and that they would use was also discussed by some participants.

Accessibility

Many participants who follow a gluten free diet, or care for someone who does, also mentioned that while availability had improved, this had not necessarily improved the diet of those with coeliac disease. This is because many of the newer products were snacks rather than staple foods allowing you to make balanced gluten free meals.

'When I was diagnosed there was nothing – you had fruit, vegetables, salads, fresh meat. It was a brilliant diet. Now I find it more difficult because so many products are full of fat, sugar, you name it. As coeliacs we have to be a lot more careful now than we did 30 years ago.'

It was also noted by others that more affordable supermarkets, for example Aldi and Lidl, tend to have a much more limited choice and that those with limited mobility may have to make do with corner shop produce where options may be limited or non-existent.

Funding other types of support

Many participants commented that, alongside being aware of gluten free produce, education and resources could help to further guide people to exclude gluten from their diet and that this could be something that the NHS might provide more support for moving forwards.

However, parents of children with coeliac disease raised the point that gluten free equivalents of every day food – pizza bases, pasta and cake for example - were important in helping young people being able to feel like they belong and could be socially the same as their peers.

'Naturally gluten free food is not always inclusive. It's important that children can be socially the same as their friends. They need to experience life as a child.'

Further views from specific stakeholder groups included:

- Those with other dietary requirements felt that there were not enough options available, particularly for lactose intolerance in children.

- Young Advisors were all opposed to NHS-provided food, anticipating the additional pressure to provide food for people with different conditions. Most allergies are not provided for by the NHS, for example.
- For some, particularly people with coeliac disease and other dietary needs, they not only felt that gluten free products should not be routinely offered by the NHS but also everyday health related items such as paracetamol and antihistamines where the cost to the NHS providing these things was felt to be disproportionate.
- Several people argued that supermarkets and restaurants should take up their social corporate responsibilities, raising awareness, having offers and not charging more for gluten free options. Young Advisors felt the supermarkets should be pressured by the government to provide gluten free food at a cheaper price.

3.4 Would you be happy for more gluten free prescribing to be provided in your area if it meant disinvestment in other health services?

Overall, the vast majority of participants felt that an increase in gluten free prescribing was not needed, especially not at the expense of other NHS services.

For those who can afford to buy the gluten free products themselves, many felt that prescriptions could be removed. However, most also felt that those who needed the support should receive prescriptions – or some equivalent assistance - and support should be prioritised taking into account multiple conditions that affect diet as well as vulnerability.

Some also questioned how much money would be saved and where that money would go, suggesting that the money should stay within the system to support those with autoimmune conditions – through research and early diagnosis - and others felt the money could be targeted to better support those who need it, eliminating waste from the current system and providing better education.

'I've gone onto half pay now and I'm struggling to buy. I applied for bread on 24th January and I'm still waiting (6 weeks later). I'm buying things that I don't always like at the moment.'

'*I don't think prescription is the answer. There needs to be more education. We've all had to become cooks and changed the way we eat as a family…'*

'If you can afford it, you shouldn't be getting the prescriptions but that money should be ringfenced for research, community and family support for people with autoimmune or allergy conditions.'

'Families who are struggling should get the gluten free pasta, rice and other items available to support a gluten free diet.'

Other views from specific stakeholder groups included:

- The Young Advisors expressed a preference for money to be invested in prescribing medications which you cannot buy.
- The Rotherham PPG group felt that the current Sheffield model should be adopted across South Yorkshire.

3.5 Would you be happy for less gluten free prescribing to be provided in your area?

Almost all participants stated that they would be happy with a reduced level of gluten free prescribing in their area as long as those in need of support were protected and that it should be looked at on an affordability basis.

Many also suggested that the money saved should be reinvested as part of a wider package of support for the same group of patients, whether that be through: better access to appointments to help early diagnosis; education, advice and follow-up support; community dietitians; or mental health support following a diagnosis.

'Both my children have allergies and autoimmune conditions and I spent a long time feeling guilt ridden with their late diagnosis. I have allergies and I think families should be looked at holistically. More money should be available for early diagnosis.'

'How do people with less understanding cope following a diagnosis? The money needs to be redirected to training and providing any cooking equipment.'

''If it's decided that there are no prescriptions available, there has to be something else in its place. They can't just take it away. '

Participants from almost all areas of South Yorkshire commented on the support of dietitians and that it had been essential following their or a family member's diagnosis.

Many participants with coeliac disease also expressed the following points:

- They often felt that being gluten free was treated as a lifestyle choice, by restaurants, schools, wider social networks and even by the NHS, rather than a lifelong condition which needed support.

  'We did not become coeliac because of a lifestyle choice and should be treated more sympathetically.'

  'A lot of money is put into smoking and obesity, so why not gluten free? It's self-inflicted versus ongoing health needs.'

  'I often feel belittled. I want to shout from the rooftops that they should walk a mile in my shoes.'

- They also felt that there was a lack of equity in the idea of providing less for gluten free patients when other groups of patients already received far more in terms of free prescriptions (for example, thyroid patients).

  'People who have thyroid get everything free on prescription and I think that is wrong. Get your thyroid free, yep, but you should pay for others. My daughter

has to pay for her inhalers, how is that right? The whole of the prescribing system – that's where it goes wrong. We're talking about a tiny proportion of the NHS budget here – think about all those people receiving all their prescriptions free, for life. Millions. It needs to be looked at to make it fair.'

'I feel we're at the bottom of the pile. If I hadn't been diagnosed, I wouldn't even know about it. It isn't very well discussed. It feels a little bit discriminatory. We're not a priority.'

- They also referred to the consequences of not following a gluten free diet and the health and cost impact to the NHS; the availability of certain products outside of accessing them on prescription; and the cost of following a gluten free diet without prescriptions.

'Diet is so important to coeliacs, otherwise you'll end up in a hospital bed seriously ill and that will cost far more money.'

'It would affect my diet quite a bit if I didn't have the prescription. I get the part-baked rolls and eat them every day. I'm quite a fussy eater and eat sandwiches every day at school.'

'The NHS is shooting itself in the foot here, increasing the health risks for people at a later date.'

'I can't afford a gluten free diet, I'll be eating egg and beans every day.'

3.6 What do you think are the main things that we should think about in relation to taking this work forwards and any future decision making?

Overall, it was felt that whatever happens next with regards to gluten free prescribing the changes made should make the system fairer for all and reduce waste within the NHS. The most common themes emerging from participants were that there needs to be support to access gluten free foods in place for those most in need and a wider package of support for recently diagnosed people.

Support for those most in need

Many participants considered that changes could be made to reduce gluten free prescribing overall as long as those most in need were still provided for in some way by the NHS - for example, those on low incomes or benefits; multiple health conditions; mobility issues; children and elderly people – and that some work would need to be undertaken to identify these vulnerable groups to ensure consistency of access.

Participants from Barnsley Foodbank added that some people do not readily identify they are in need and Safe Space in Doncaster, which hosts a foodbank, has had to turn people away as they had no gluten free products. These participants, and some others, felt if gluten

free prescribing is stopped there needs to be more of an effort on local authorities/job centres to collect dietary requirements before signposting to a foodbank.

Support for those recently diagnosed

Many participants also felt that a better package of support should be in place for people who are recently diagnosed and require a gluten free diet, including: support to manage their diet with education about labels and cross-contamination; planning and cooking meals; mental health support; budgeting; access to peer support; and, where appropriate, support for the whole family not just the individual.

Some also felt that better access to ongoing support from dietitians and GPs was important, especially for those unable to access the prescriptions or those struggling to know what to eat and cook either for themselves of their family.

A range of other points to consider were raised by stakeholder groups including:

- Those with other dietary needs felt that there should be more understanding about access to and availability of gluten free products in different areas of South Yorkshire and Bassetlaw
- Coeliac patients and those with other dietary needs also raised the issue of equity within prescribing for different conditions and suggested that this should be looked at more broadly. For example, people have to pay for epi-pens and inhalers but those with a thyroid condition receive all their prescriptions free, regardless of the link to the condition and their ability to pay
- The concept of a voucher system to allow more individual choice was raised by participants at Barnsley Foodbank
- Young Advisors suggested that developing an app, similar to the NHS Fitness for Life App, could help manage the condition

Appendix 1: Equalities Profile

Introduction

As part of the survey, participants were asked a number of equalities questions to see whether the views of all relevant groups of opinion, including those with protected characteristics, had been captured as part of the research.

While not every respondent answered every question, in total 48 participants answered at least one of the equalities questions.

Dietary needs

Whilst not a protected characteristic, due to the nature of the research it was important to hear from those who either suffered from a medical condition affecting their diet, or cared for someone who affected their diet. In this case, two-thirds of respondents had such a condition. This is unsurprising given the topic.

Do you or someone who you care for have a medical condition that affects your diet?	No.	%
Yes	30	67%
No	16	36%
Total	46	102%

Despite two-thirds of respondents having a medical condition affecting their diet or that of someone that they care for, less than a sixth of respondents use prescriptions for food to manage that condition.

Do you or someone you care for currently use prescriptions for food to manage your condition?	No.	%
No	40	89%
Yes	6	13%
Total	46	102%

Gender identity

Women made up the majority of respondents to the survey, potentially reflecting the greater likelihood of women to have caring roles or to suffer from coeliac disease.

What is your sex / gender?	No.	%
Female	31	69%
Male	14	31%
Total	45	100%

One participant indicated that they had gone through part of a process to bring their physical sex appearance and/or gender role more into line with their gender identity.

Have you gone through any part of a process, to bring your physical sex appearance, and/or your gender role, more in line with your gender identity?	No.	%
No	42	95%
Yes	1	2%
Prefer not to say	1	2%
Total	44	100%

Sexual orientation

93% oi those responding to the survey identified as heterosexual or straight.

Which of the following options best describes your sexual orientation?	No.	%
Heterosexual / Straight	42	93%
Bisexual	1	2%
Gay	1	2%
Lesbian	1	2%
Total	45	100%

Ethnic identity

45 out of 48 respondents selected 'White British' as their ethnic identity.

What is your ethnic group?	No.	%
White British	45	94%
Other White	1	2%
Mixed White and Asian	1	2%
Other Asian / Asian British	1	2%
Total	48	100%

Despite 94% of respondents selecting 'White British' as their ethnic identity, only 23% would select 'British' as their national identity with almost three quarters of respondents indicating that they were 'English'.

How would you describe your national identity?	No.	%
English	35	74%
British	11	23%
Scottish	1	2%
Total	47	100%

Only one participant indicated that they preferred not to say whether they were a UK citizen.

Are you a UK citizen?	No.	%
Yes	47	98%
Prefer not to say	1	2%
Total	48	100%

Following this question participants were asked 'If you are a national of another country are you?' and give the opportunity to provide a free text response. Two respondents clarified their response, with one stating 'Prefer not to say' and a second stating that they were 'An EU national.'

Religious identity

Over half of respondents either identified as 'Christian' or 'Roman Catholic', with over a third stating they were of 'No religion' and the remaining participant indicating that they were 'Muslim.'

Do you have a religion?	No.	%
Christian	25	53%
No religion	18	38%
Roman Catholic	3	6%
Muslim	1	2%
Total	47	100%

Age

58% of respondents were aged over 55, indicating that respondents in general tended to be older than the general public.

What age are you?	No.	%
0-15	1	2%
16-24	4	8%
25-34	4	8%
35-44	6	13%
45-54	5	10%
55-64	10	21%
65-74	8	17%
75-84	9	19%
85+	1	2%
Total	48	100%

Employment Status

When asked about their employment status, 40% of respondents indicated that they were 'Not currently employed.' Given that average age of those participating in the survey it is likely that the vast majority of those giving this answer are in fact retired. This question had the lowest response rate of the equalities questions applicable to every respondent, potentially due to individuals failing to identify with the categories.

Are you currently in employment	No.	%
Not currently employed	19	40%
Yes - either self-employed, part-time or full employment	15	32%
Prefer not to say	3	6%
Student	2	4%
Total	39	83%

While no respondent indicated that they were a serving member of the military, two participants did state that they were military veterans.

Are you serving military personnel or a military veteran?	No.	%
No	38	95%
Yes – veteran	2	5%
Total	40	100%

Domestic arrangements

Over two-thirds of respondents were either married or co-habiting, with just under a third indicating that they were either single, divorced/separated, or widowed.

What is your marital status?	No.	%
Married	20	47%
Co-habiting	9	21%
Single	7	16%
Divorced / separated	4	9%
Widowed	2	5%
Prefer not to say	1	2%
Total	43	100%

No respondents indicated that they were either currently pregnant or expecting a baby. This is perhaps unsurprising given the average age of participants.

Are you currently pregnant, or expecting a baby?	No.	%
No	41	98%
Prefer not to say	1	2%
Total	42	100%

Participants were given the opportunity to give multiple responses to the question as to the ages of their children and the percentages and total figures given represents the total number of responses given as opposed to the total number of participants answering the question. In total, 35 individuals answered this question, with 33 out of 38 participants indicating that they had children. The majority of respondents indicated that they had children aged over 21, with the next most common answer age that they had children aged at, or less than, three years old.

Please specify the number of children that you have, in the following age ranges	No.	%
0-3	8	23%
4-10	4	11%
11-16	2	6%
17-21	2	6%
Over 21	20	57%
Prefer not to say	2	6%
Total	38	100%

20% of respondents indicated that they had caring responsibilities.

Do you have caring responsibilities? Do you provide paid or unpaid care for a family member who is ill, elderly or frail?	No.	%
No	33	73%
Yes	9	20%
Total	42	93%

Domestic arrangements

Almost half of survey-takers indicated that they considered themselves to have a disability.

Do you consider yourself to have a disability	No.	%
No	23	51%
Yes	21	47%
Prefer not to say	1	2%
Total	45	100%

As with the question on the age of participants' children, this question enabled respondents to select multiple answers with the total figures and percentages relating to the numbers of responses given rather than the number of participants answering the question. Almost two-thirds of respondents indicated that they had a long standing health condition which was not covered on the list. The most frequently selected option specified on the list was that they had a 'Long standing psychological or mental health condition' with over a third of participants selecting that answer. The most common physical disability selected was a 'Condition which severely limits physical activity for example climbing the stairs, walking.'

Please can you tell us the nature of your disability	No.	%
Blindness or severe visual impairment	0	0%
Condition which severely limits physical activity for example climbing the stairs, walking	6	26%
Deafness or severe hearing impairment	4	17%
Learning disability	2	9%
Long standing psychological or mental health condition	9	39%
Other long standing health condition	15	65%
Total	23	100%

Those respondents who had indicated that they considered themselves to have a disability were they asked ‘does your disability affect your ability to access services? If so, please tell us briefly how,’ with the survey then enabling a free text response to the question. Different answers from respondents indicated that participants with disabilities struggled to move effectively, that they needed transport, that they suffered from deafness, that their autism impacted upon the time needed to process information and created sensory overload, that they felt anxiety in accessing services—particularly from form-filling, and that it did not impact upon their access to services significantly.

Appendix 2: Briefing for participants

Gluten Free Prescribing in South Yorkshire and Bassetlaw

Issues Paper

Broad overview of the issues that are prompting this work to take place:

- Gluten free prescribing in South Yorkshire and Bassetlaw is different depending on whether you live in Barnsley, Bassetlaw, Doncaster, Rotherham or Sheffield. Many feel that this should not be the case and that there should be equity across the sub-region.
- Gluten free prescribing started in the 1960s when the availability of gluten free foods was limited. Gluten free foods are now more readily available in supermarkets and a wider range of naturally gluten free foods are now available.
- The NHS has a limited budget and there is some thinking that spending money on products that are available in supermarkets is not a good use of NHS budgets.
- Coeliac disease is a lifelong autoimmune disease caused by a reaction to gluten. Coeliac disease is treated by following a gluten free diet for life. Coeliac UK feel strongly that the prescribing of gluten free foods is an essential NHS service that should be available to all people diagnosed with coeliac disease.

This paper:

The Joint Committee of Clinical Commissioning Groups has agreed to look at gluten free prescribing and gather some initial views from people in South Yorkshire and Bassetlaw to help inform next steps.

This paper has been put together for discussion with focus groups who have been identified by stakeholder mapping to ensure a cross section of view points.

This paper, and an accompanying infographic, set out the facts about gluten free prescribing and some of the challenges we face in trying to decide whether to take this work forwards or not.

The discussions with focus groups will help inform the JCCCG who will use them to decide:

- If we want to change the prescribing of gluten free bread and mixes in some parts of South Yorkshire and Bassetlaw so that it's all the same or not

- If we do decide to change it your answers will help us decide which options we should consider in more detail

Detail to help inform your thinking:

Coeliac disease is a lifelong autoimmune disease caused by a reaction to gluten. When someone has coeliac disease their small intestine becomes inflamed if they eat food containing gluten. Symptoms include diarrhoea, constipation, vomiting, stomach cramps, mouth ulcers, fatigue and anemia. In diagnosed, untreated coeliac disease there is a greater risk of complications including anemia, osteoporosis, neurological conditions such as gluten ataxia and neuropathy. Coeliac disease is treated by following a gluten free diet for life.
A gluten free diet can be achieved without the need for specific manufactured products as many foods are gluten free. Meat, fish, fruit, vegetables, rice and potatoes are all gluten free.

Across the UK it is possible to receive gluten free bread and mixes on prescription. No other gluten free products are available on prescription. The amount of gluten free bread and mixes that patients can receive on prescription varies depending where you live. In South Yorkshire and Bassetlaw:

- Bassetlaw and Doncaster recommend to their clinicians that they prescribe the level of gluten free bread and mixes that is recommended by the Coeliac Society
- Rotherham recommend to their clinicians that they prescribe two units less than the level of gluten free bread and mixes that is recommended by the Coeliac Society
- Barnsley recommend to their clinicians that they prescribe eight units of gluten free bread and mixes
- Sheffield recommend to their clinicians that they do not prescribe gluten free bread and mixes to adults (over the age of 18). Prescribers can apply discretion in exceptional circumstances where there is genuine risk that a vulnerable adult is, or will become, undernourished if they do not prescribe gluten free products.

Gluten free foods have been available on prescription in the UK since the late 1960s when the availability of gluten free foods was limited. Gluten free foods are now readily available in supermarkets and a wider range of naturally gluten free food types are now available.

Gluten free foods in the supermarket are typically more expensive than gluten containing foods. A gluten free sliced loaf of bread typically costs £1.80, where a gluten containing sliced load of bread typically costs £1.

Coeliac UK believes that despite gluten free staple foods being more widely available today than ever before, they are still not readily accessible across the country and that in many budget or convenience stores gluten free staples are virtually absent. They believe that when prescribing is restricted those on a limited income, the elderly or those living in remote rural areas can be left struggling to maintain a gluten free diet.

There are currently 1400 adults in South Yorkshire and Bassetlaw who request prescriptions for gluten free bread and mixes.

Approx 1% of the population have coeliac disease, only 10% of them use prescriptions for gluten free products.

The prescribing of gluten free foods costs the NHS £15.7million nationally. In Sheffield since they recommended that gluten free products are not prescribed to adults £250,000 has been saved to be reinvested in other areas of healthcare. If Barnsley, Bassetlaw, Doncaster and Rotherham recommended the same as Sheffield in 2018/19 over £100,000 would have been available to be reinvested in other areas of healthcare.

The challenges we face in tackling these issues:

- Should health and care services and prescribing in South Yorkshire and Bassetlaw be the same whether you live in Barnsley, Bassetlaw, Doncaster, Rotherham or Sheffield, or is it okay for them all to be different?
- The NHS has a limited budget. Should we spend some of that budget on prescribing gluten free bread and mixes given all we know about availability/ cost?
- Would it significantly disadvantage coeliac patients if the future recommendation was to reduce the amount of gluten free bread and mixes available on prescription?
- How would people in Sheffield feel about £250,000 per year being disinvested in other services to be re-invested back into larger amounts of gluten free prescribing if the future recommendation was a higher level than the current Sheffield recommendation?

The timeframe

The JCCCG on February 26th will decide, utilising the feedback gathered from these focus groups to help inform their thinking, whether or not to take forward work to make gluten free prescribing in South Yorkshire and Bassetlaw equitable across the patch.

Please give us your views.

GLUTEN FREE FACTS

We are considering if we should change the way we prescribe gluten free products in South Yorkshire and Bassetlaw. Here are some facts about gluten free.

1 COELIAC DISEASE

Coeliac disease is a lifelong autoimmune disease caused by a reaction to gluten. When someone has coeliac disease their small intestine becomes inflamed if they eat food containing gluten. Symptoms include diarrhoea, constipation, vomiting, stomach cramps, mouth ulcers, fatigue and anemia. In diagnosed, untreated coeliac disease there is a greater risk of complications including anemia, osteoporosis, neurological conditions such as gluten ataxia and neuropathy. Coeliac disease is treated by following a gluten free diet for life

2 A GLUTEN FREE DIET

A gluten free diet can be achieved without the need for specific manufactured products as many food items are naturally gluten free. Meat, fish, fruit, vegetables, rice and potatoes are all gluten free.

3 THE COST OF GLUTEN FREE

From the supermarket gluten free sliced bread loaves cost: approx £1.80.
From the supermarket gluten containing sliced bread loaves cost approx £1
It costs the NHS £15.7 million nationally to prescribe gluten free food

4 AVAILABILITY OF GLUTEN FREE FOODS

Gluten free foods have been available on prescription since the late 1960s when the availability of GF foods was limited. GF foods are now readily available in supermarkets and a wider range of naturally GF food types are now available.
For some patients, e.g vulnerable or less mobile patients there may be some issue with access if they are living in an area where there is no supermarket and they are unable to use online shopping.

GLUTEN FREE FACTS

5 GLUTEN FREE PRESCRIPTIONS

In the UK it is possible to receive gluten free products such as bread and mixes on prescription. No other gluten free products are available on prescription.

6 SHEFFIELD PRESCRIBING

Prescribing of Gluten Free foods to adults (over the age of 18) is not recommended in Sheffield. Prescribers can apply discretion in exceptional circumstances where there is genuine risk that a vulnerable individual is, or will become undernourished if they do not prescribe gluten free products. This has allowed over £250,000 to be re-invested in other areas of healthcare.

7 BARNSLEY, BASSETLAW AND DONCASTER PRESCRIBING

Barnsley has restricted prescribing of bread and mixes to a volume of 8 units per month per individual. Bassetlaw and Doncaster have similar recommendations to clinicians regarding prescribing of gluten free products and prescribe bread and mixes to the Coeliac Society recommendations.

8 ROTHERHAM PRESCRIBING

Rotherham is slightly different to Bassetlaw and Doncaster in that the quantity recommended to prescribe is 2 units less than the Coeliac Society recommendations.

9 GLUTEN FREE IN SOUTH YORKSHIRE AND BASSETLAW

There are approx 1,400 adults who request prescriptions for gluten free mixes in South Yorkshire and Bassetlaw . This is approx 0.11% of the populations, this figure has reduced significantly in recent years.
Approx 1% of the population have coeliac disease, around 90% who suffer from the disease don't use prescriptions.
Across South Yorkshire and Bassetlaw in 2018/19 over £400,000 was spent on prescribing gluten free food. If every region prescribed similar to Sheffield over £100,000 would have been available to be re-invested in other areas of healthcare.

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Report to Joint Health Overview and Scrutiny Committee for South Yorkshire, Nottinghamshire and Derbyshire 24th March, 2020

Report of: Report on update on the children's surgery and anaesthesia work and recommendations to change the appendicectomy pathway

Subject: **Update:** Children's Surgery and Anaesthesia

Author of Report: James Scott (SYB Programme Manager for Children, Young People and Maternity) and Anna Clack (Children's Network Manager)

Summary:

In June 2017 the Joint Committee for Clinical Commissioning Groups (JCCCG) for South Yorkshire and Bassetlaw took a decision to change the way some children's surgery and anaesthesia services are provided in South and Mid Yorkshire, Bassetlaw and North Derbyshire. At that time, the JCCCG agreed to clinical recommendations that children needing an emergency operation for a small number of conditions, at night or at a weekend, would not be treated in hospitals in Barnsley, Chesterfield and Rotherham, and would instead have their surgery at Doncaster Royal Infirmary, Sheffield Children's Hospital or Pinderfields General Hospital in Wakefield.

Since that decision, a number of factors have changed (as detailed in this report) which mean that a new recommendation has been put forward by local clinical experts. The new recommendation is for surgery for three of the four conditions covered by the previous decision (post-tonsillectomy bleeding, foreign body in the airway, torsion of the testes) to continue being provided in the local District General Hospitals, with no change. The recommendation for the fourth condition – suspected appendicitis – is that for children aged under 8, and for children with complex needs, appendicectomies should be conducted at Sheffield Children's Hospital. This would affect around 45 children a year from across South Yorkshire and Bassetlaw.

We are currently seeking the views of parents and carers from across South Yorkshire and Bassetlaw on this potential change.

Type of item: The report author should tick the appropriate box

Reviewing of existing policy	
Informing the development of new policy	
Statutory consultation	
Performance / budget monitoring report	
Cabinet request for scrutiny	
Full Council request for scrutiny	
Call-in of Cabinet decision	
Briefing paper for the Scrutiny Committee	**X**
Other	

The Scrutiny Committee is being asked to:
Consider the recommendations of the report and provide the JCCCG with any views or comments.

To provide their views on whether any changes to the appendicectomy pathway in South Yorkshire and Bassetlaw for children under 8 and those with complex needs would be considered a substantial development or variation, and accordingly if they recommend that there is a formal duty to consult with the Local Authority under the s244 regulations.

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Category of Report: OPEN

Report to update on the children's surgery and anaesthesia work and recommendations to change the appendicectomy pathway

1. Introduction/Context

1.1 The purpose of this paper is to provide an update to the Joint Health Overview and Scrutiny Committee on proposed changes since the Committee were last updated on the South Yorkshire and Bassetlaw Children's Surgery and Anaesthesia work (February 2019).

1.2 This paper sets out details of a new proposal for a revised service model, and the implementation of an associated pathway for paediatric appendicectomy surgery. The proposal has been put forward by Clinicians working in South Yorkshire and Bassetlaw and has been supported in principle by the Joint Committee of Clinical Commissioning Groups (JCCCG).

1.3 The JHOSC is being asked to consider the recommendations of the report and to provide their views on whether any changes to the appendicectomy pathway in South Yorkshire and Bassetlaw for children under 8 and those with complex needs would be considered a substantial development or variation, and accordingly if they recommend that there is a formal duty to consult with the Local Authority under the s244 regulations.

2. Background

2.1 In June 2017 the Joint Committee for Clinical Commissioning Groups (JCCCG) for South Yorkshire and Bassetlaw took a decision to change the way some children's surgery and anaesthesia services are provided in South and Mid Yorkshire, Bassetlaw and North Derbyshire.

2.2 At the time, the JCCCG agreed to clinical recommendations that children needing an emergency operation for a small number of conditions, at night or at a weekend, would not be treated in hospitals in Barnsley, Chesterfield and Rotherham, and would instead have their surgery at Doncaster Royal Infirmary, Sheffield Children's Hospital or Pinderfields General Hospital in Wakefield.

2.3 Since the decision:

- Strengthened partnerships across the region and even closer ways of working have been formed across the patch
- Closer joint working across the NHS Hospitals has strengthened Ear, Nose and Throat (ENT) services and made them more stable and sustainable

- The more detailed investigation that happens before any proposed change takes place (known as the designation process) has shown reality to be more complex than the original business case assumed
- There is evidence that the torsions pathways are appropriate and should be retained
- The introduction of Integrated Care System geographical footprints has changed previous joint working arrangements. In South Yorkshire and Bassetlaw this has impacted on working arrangements with Mid Yorkshire Hospitals

2.4 These changes of circumstance therefore led the Children's Surgery and Anaesthesia Managed Clinical Network (which is a regular meeting of working clinicians from South Yorkshire, Bassetlaw and North Derbyshire) to develop revised recommendations, which meet the principles from the original work of:

- Commitment to a model where children are guaranteed to be seen by surgeons and anaesthetists who have current training in, and / or who regularly work on, the care of children
- Commitment to no unnecessary transfers of patients, and that care close to home, where this able to be delivered in line with standards, is the preferred outcome

2.5 The revised recommendations do not support the three hub geographical model proposed in 2017.

2.6 A new paper, which was received by the Joint Committee of Clinical Commissioning Groups (JCCCG) in February, instead recommended that clinical models should be different depending on the type of surgery.

2.7 All of the information about the original proposal and consultation can be found here: https://smybndccgs.nhs.uk/what-we-do/childrens-surgery

3 Proposal

3.1 A new paper, which was received by the Joint Committee of Clinical Commissioning Groups (JCCCG) in February, and which was put forward by local clinicians, recommended that clinical models should be different depending on the type of surgery.

3.2 The new proposal suggests all district general hospitals maintain the provision of these pathways where there is evidence that they are able to provide a safe, quality and sustainable service. Only in a small number of cases would activity be transferred from district general hospitals to the Sheffield Children's Hospital which will be supported by clear clinical protocols.

3.3 Anaesthetic skills across South Yorkshire and Bassetlaw, including within district general hospitals, are deemed to be effective and safe in managing paediatric cases.

3.4 The Ear Nose and Throat (ENT) pathways currently in place, developed through the previous Working Together collaborative programme are clinically appropriate and should be retained.

3.5 Torsions pathways should be retained. Further work is required within Doncaster and Bassetlaw Teaching Hospitals to recruit the workforce to secure a long term torsion service comparable to the torsion service provided in other district general hospitals.

3.6 Abdomens are the most complex pathway. Issues include:

- An inconsistency of approach, particularly with regards to the age ranges covered by district general hospitals.
- The number of appendicectomies (surgery to remove the appendix) undertaken in South Yorkshire and Bassetlaw each year on children under 8 is very small. The numbers are so small that some surgeons in some of the district general hospitals had only been exposed to one or two in the past 5 years.
- Children under 8 are not 'small adults' and if they need an appendicectomy, it is better and safer for them to be seen by a surgeon who is trained to and regularly operates on children their size.
- Appendices do not have the time criticality of testicular torsions. All Trusts, including Sheffield Children's Hospital, already operate a policy of not operating on children after midnight, except in extremis.

A clinical pathway model was developed by senior local clinicians to address this, and would involve the movement of children under 8 years or with significant complexities or comorbidities from district general hospitals to Sheffield Children's Hospital. This would affect about 45 children a year and arrangements would be put in place to ensure safe transfers.

3.7 For those children who will remain at their local DGH for appendix surgery, the proposal also suggests additional ways to strengthen the service – these are that all children will be jointly managed between the paediatrics and surgical teams to ensure that the child's holistic needs are met; surgery will be undertaken (or directly supervised) only by consultant surgeons. There is a view from our clinical experts that this would put our area ahead of most other parts of the UK in assuring a quality service.

3.8 An Equality Impact Assessment (EIA) was completed to identify whether the proposed changes to the appendicectomy pathway are likely to result in any adverse or negative impacts in the promotion of equality and diversity. The proposed changes to the pathway are aimed at assuring equitable access to high quality surgical capability for all children and young people in South Yorkshire and Bassetlaw. While there are some key areas in the EIA identified for consideration, the proposed changes to the pathway are not considered to hinder the promotion of equality and diversity.

3.9 The JCCCG supported the changed proposal, subject to the outcomes of the discussion at the JHOSC and the outcomes of a current engagement exercise, which is asking the public in South Yorkshire and Bassetlaw, in particular parents and carers of children aged under 8, about the appendicitis element of the proposal. If the JHOSC and the

engagement exercises show support for the proposal, work would take place to change the appendectomy pathway during 2020.

3.10 It was felt that the proposal outlined within this document addresses the issues in an appropriate and proportionate way given the changing context, whilst meeting the spirit and intent of the 2017 work in terms of ensuring all children area treated by professionals who have access to appropriate skills, and wherever possible close to their homes.

4. What does this mean for people in South Yorkshire, Bassetlaw and North Derbyshire?

4.1 More care will be retained closer to home than was originally agreed in 2017. Children with three of the conditions that were looked at during this work - post-tonsillectomy bleeding, foreign body in the airway, torsion of the testes - will now have their surgery provided in their local district general hospitals, as it is currently, and patients will not have to travel to one of the three out of hours hubs as had previously been agreed in 2017.

4.2 The proposal is for children aged under 8, and for children with complex needs, appendicectomies should be conducted at Sheffield Children's Hospital, this would affect about 45 children a year and arrangements would be put in place to ensure safe transfers.

5. Recommendations

5.1 The JHOSC is asked to consider the proposal within this report and provide the JCCCG with any views and comments.

5.2 The JHOSC is asked to provide their views on whether any changes to the appendicectomy pathway in South Yorkshire and Bassetlaw for children under 8 and those with complex needs would be considered a substantial development or variation, and accordingly if they recommend that there is a formal duty to consult with the Local Authority under the s244 regulations.

Report to South Yorkshire, Derbyshire and Nottinghamshire Joint Health Overview & Scrutiny Committee
24th March 2020

Report of: Policy & Improvement Officer

Subject: Amendments to the Joint Health Overview and Scrutiny Committee Terms of Reference

Author of Report: Emily Standbrook-Shaw
Policy & Improvement Officer
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Summary:

The Terms of Reference for the South Yorkshire, Derbyshire, Nottinghamshire and Wakefield Joint Health Overview and Scrutiny Committee have been amended following changes to the membership and operation of the Committee. The revised Terms of Reference are attached for the Committee's approval.

It is also proposed that the Committee carries out a more detailed review of its role and remit in the new municipal year, given the changes to the regional health system since the Committee was established in 2016.

Type of item:

Reviewing of existing policy	**x**

The Scrutiny Committee is being asked to:

- Agree the amended Terms of Reference
- Agree to carry out a more detailed review of the role and remit of the committee in the new municipal year

Category of Report: OPEN

Amendments to the Joint Health Overview and Scrutiny Committee Terms of Reference

1. Introduction

1.1 The South Yorkshire, Derbyshire, Nottinghamshire and Wakefield Joint Health Overview and Scrutiny Committee was established in 2016 to consider changes to health services over the 'Commissioners Working Together' footprint. Since then the health and social care system in South Yorkshire and Bassetlaw has evolved into an Integrated Care System; there have been changes to the membership of the commissioning and scrutiny arrangements, and the operating model of the Joint Health Overview and Scrutiny Committee has changed. This report sets out the proposed changes to the terms of reference, which are attached at appendix 1.

2. Changes to the Terms of Reference

2.1 Wakefield

The Commissioners Working Together Programme included Wakefield CCG in its commissioning arrangements, and therefore Wakefield MBC was a member of the Joint Health Overview and Scrutiny Committee. As the South Yorkshire and Bassetlaw Integrated Care System has developed over a slightly different geographical footprint, Wakefield CCG is no longer a part of the commissioning arrangements. Wakefield MBC has therefore withdrawn from the scrutiny arrangements. The terms of reference, including the name of the committee have been amended to reflect this.

2.2 CCG Mergers

The original terms of reference stated that the Joint Health Overview and Scrutiny Committee covered Hardwick CCG and North Derbyshire CCG. Since then, these CCGs have merged to become Derby and Derbyshire CCG. The amended terms of reference reflect this.

2.3 Committee Working Arrangements

When the Joint Health Overview and Scrutiny Committee was established, the hosting and chairing of the meetings rotated between participating local authorities. Since then, the Committee has decided that to provide continuity and consistency, one local authority should chair and host. This is currently Sheffield. The terms of reference have been amended to reflect this.

3 Further review

3.1 Recognising that there have been significant changes to the health and social care system since the JHOSC was established in 2016, the JHOSC is asked to consider a more detailed review of its role and remit in the new municipal year. This would ensure that there is clarity over the committee's purpose, a shared understanding of where decisions are

being made in the health service and who is responsible for scrutinising them, and that scrutiny arrangements are in line with national best practice.

4. Recommendation

4.1 The Committee is being asked to

- Agree the amended Terms of Reference
- Agree to carry out a more detailed review of the role and remit of the committee in the new municipal year

Terms of Reference for the South Yorkshire, Derbyshire and Nottinghamshire Joint Health Overview and Scrutiny Committee

The South Yorkshire, Derbyshire and Nottinghamshire Joint Health Overview and Scrutiny Committee is a joint committee appointed under Regulation 30 of the Local Authority (Public Health, Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013/218 and is authorised to discharge the following health overview and scrutiny functions of the authority (in accordance with regulations issued under Section 244 National Health Service Act 2006) in relation to health service reconfigurations or any health service related issues covering this geographical footprint:

a) To review and scrutinise any matter relating to the planning, provision and operation of the health service in its area, pursuant to Regulation 21 of the Local Authority (Public Health, Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013.

b) To make reports and recommendations on any matter it has reviewed or scrutinised, and request responses to the same pursuant to Regulation 22 of the Local Authority (Public Health, Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013.

c) To comment on, make recommendations about, or report to the Secretary of State in writing about proposals in respect of which a relevant NHS body or a relevant health service provider is required to consult, pursuant to Regulation 23 of the Local Authority (Public Health, Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013.

d) To require a relevant NHS body or relevant health service provider to provide such information about the planning, provision and operation of the health service in its area as may be reasonably required in order to discharge its relevant functions, pursuant to Regulation 26 of the Local Authority (Public Health, Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2014.

e) To require any member or employee of a relevant NHS body or relevant health service provider to attend meetings to answer such questions as appear to be necessary for discharging its relevant functions, pursuant to Regulation 27 of the Local Authority (Public Health, Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013.

Principles

- The purpose of the committee is to ensure that the needs of local people are an integral part of the delivery and development of health services across this geographical footprint.
- The committee's aim is to ensure service configuration achieves better clinical outcomes and patient experience.
- As new NHS work streams and potential service reconfigurations emerge, the JHOSC will determine whether it is appropriate for the committee to jointly scrutinise the proposals under development. Each local authority reserves the right to consider issues at a local level.
- All Members, officers, members of the public and patient representatives involved in improving health and health services through this scrutiny committee will be treated with courtesy and respect at all times.

Membership

- The Joint Committee shall be made up of six (non-executive) members, one from each of the constituent authorities.
- A constituent authority may appoint a substitute to attend in the place of the named member on the Joint Committee who will have voting rights in place of the absent member.
- Quorum for meetings of the Joint Committee will be three members from local authorities directly affected by the proposals under consideration.

The 6 Committee Member Authorities are:

Barnsley MBC
Derbyshire County Council
Doncaster MBC
Nottinghamshire County Council
Rotherham MBC
Sheffield City Council

Covering NHS England and the following 6 NHS Clinical Commissioning Groups (CCGs):

Barnsley CCG
Bassetlaw CCG
Doncaster CCG
Derby and Derbyshire CCG
Rotherham CCG
Sheffield CCG

Working Arrangements:

- The Committee will meet on an ad-hoc basis as topics require scrutiny.
- The Committee will agreed the hosting and chairing arrangements. Meetings will take place in the Town Hall of the local authority hosting the meeting.
- Agenda, minutes and committee papers will be published on the websites of all the local authorities 5 working days before the meeting.
- There is a standing agenda item for public questions at every meeting. Time allocated for this will be at the discretion of the Chair.
- Members of the public are encouraged to submit their questions 3 working days in advance of the meeting to enable Committee Members time to consider issues raised and provide an appropriate response at the meeting.
- The Committee will identify and invite the appropriate NHS witnesses to attend meetings.

Last updated March 2020

Report to Joint Health Overview and Scrutiny Committee for South Yorkshire, Nottinghamshire and Derbyshire
16th March 2020

Report of: Jaimie Shepherd

Subject: **Update:** Hyper Acute Stroke Services

Author of Report: Jaimie Shepherd
Network Manager - South Yorkshire and Bassetlaw Stroke Hosted network
South Yorkshire and Bassetlaw Shadow Integrated Care System / Sheffield Teaching Hospitals NHS Foundation Trust

Summary:

- The South Yorkshire and Bassetlaw (SYB) model of hyper acute stroke unit (HASU) care was successfully enacted in 2019
- The model is being delivered in accordance with the HASU service specification and providers are working to meet all expectations of this within agreed timescales
- The pathway is being monitored closely by all partners with support from the newly established South Yorkshire and Bassetlaw Stroke Hosted Network
- Since enacting the changes, a total of 333 Rotherham and Barnsley stroke patients have received their HASU care in Sheffield, Wakefield and Doncaster. Work is ongoing to monitor patient flow and patient activity numbers.
- Patients are moving through the agreed pathway as expected and all partners are working together to support seamless transfer of care
- Feedback from patients and their families to staff on the ground continues to be positive. All partners remain committed to realising the full benefits for patients
- The SYB Stroke Hosted Network was launched in January 2020. It will continue to support and monitor the HASU Pathway as part of its work programme

Type of item: The report author should tick the appropriate box

Reviewing of existing policy	
Informing the development of new policy	
Statutory consultation	
Performance / budget monitoring report	
Cabinet request for scrutiny	
Full Council request for scrutiny	
Call-in of Cabinet decision	
Briefing paper for the Scrutiny Committee	**X**
Other	

The Scrutiny Committee is being asked to:
Consider the recommendations of the report.

Background Papers:
https://www.healthandcaretogethersyb.co.uk/what-we-do/working-together-network/regional-stroke-service

Category of Report: OPEN

Report of Network Manager: Update: Hyper Acute Stroke

JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE

16th March 2020

1. Purpose

1.1 At the last meeting of the Joint Health Overview and Scrutiny Committee, the committee requested an update on the ongoing delivery of the new South Yorkshire and Bassetlaw (SYB) model of hyper acute stroke care (HASU). This paper will provide an update on the new model and provide further information on the development of the SYB Stroke Hosted Network. The committee is asked to take note of the ongoing successful implementation of the new model and the positive initiation of the network.

2. Background

2.1 After a comprehensive review of hyper acute stroke services across South Yorkshire and Bassetlaw a strong clinical case for change underpinned the development of a new model to improve access to high quality urgent specialist stroke care, informed by the evidence to improve outcomes for patients.

2.2 The model included a Stroke Managed Clinical Network to support the development of networked provision and the consolidation of hyper acute stroke care at Doncaster Royal Infirmary, Royal Hallamshire Hospital (Sheffield) and Pinderfields Hospital (Wakefield). Plus the continuation of existing provision at the Royal Chesterfield Hospital.

2.3 The Joint Committee of Clinical Commissioning Groups approved the changes to hyper acute stroke care at the end of 2017. The decision was followed by an application for a judicial review. Confirmation that the judicial review was not granted and permission to progress implementation of the new HASU model was given in the summer 2018.

2.4 Work progressed to enable us to commission, contract and agree the financial arrangements for the new model of hyper acute stroke care (HASU) in South Yorkshire and Bassetlaw. It was agreed that the new SYB HASU model

would be contracted for through existing contractual arrangements with Sheffield Clinical Commissioning Group (SCCG) acting as a contract coordinator.

2.5 The business case required additional investment through tariff and best practice tariff to secure improved quality and outcomes through the new HASU model. It was not possible for us to use the national stroke tariffs as care would be delivered across providers and so local tariffs were developed and agreed to underpin the new HASU model. The specification was finalised and commissioners worked together to develop a draft monitoring dashboard for the new HASU model, including key performance indicators, activity, patient flows and all aspects of quality.

2.6 A HASU Implementation Group with representation from all providers, the Yorkshire Ambulance Service, Sheffield CCG and the Stroke Association was established in December 2018. The group completed their work in December 2019. The HASU Implementation Group was chaired by Dr Richard Jenkins, the Chief Executive of Barnsley Hospital, in his role as Provider Development Lead for South Yorkshire and Bassetlaw Integrated Care System.

2.7 Simultaneously NHS England commissioned Mechanical Thrombectomy to be delivered at Neuroscience Centres, including Sheffield and Leeds. Work is ongoing in parallel to expand access to Mechanical Thrombectomy as we respond to the commitment to do so in the NHS Long Term Plan.

2.8 Workforce planning and recruitment progressed in a phased way during 2019, with each HASU successfully recruiting additional nursing and therapy staff. Each HASU reviewed their internal medical cover arrangements to consider how best to put in place increased cover for the new model. In addition to this a collaborative approach was taken to securing additional medical cover. A new Stroke Physician was recruited to work in Rotherham with inreach into the Sheffield HASU. Workforce planning for the future continues to be an area that requires further work, for both HASU and the whole stroke pathway.

2.9 The HASU Implementation Group agreed implementation dates in early 2019 for phased delivery of the new HASU model during 2019 and was enacted as follows:

- Rotherham HASU ceased on 1st July 2019
- Barnsley HASU to ceased on 1st October 2019

2.10 The HASU Implementation Group offered oversight and monitored the progress of implementation. This included co-ordinating all the necessary aspects, including communication and engagement, planned changes to estates, workforce planning and recruitment. The sub groups supported the

embedding of the model and focused on clinical aspects of the new model such as reviewing clinical guidelines, developing a patient leaflet and planning for onward referral pathways.

2.11 The SYB Patient Flow Policy, which aims to ensure that there is a consistent approach to patient flow through the stroke pathway, was successfully implemented. As part of the policy a series of daily conference calls were implemented for all providers to participate in to enable joint oversight of the patient flow. A weekly check in call between key partners was also put in place to monitor patient flow across the system, manage any challenges and share learning.

2.12 As anticipated most patients were taken to their closest HASU in Sheffield, Doncaster or Mid Yorkshire for their urgent stroke care, from which they were either discharged directly home, home with early supported discharge and/or community stroke services or transferred back to their local hospital of either Rotherham Hospital or Barnsley Hospital for their ongoing acute stroke care and inpatient rehabilitation.

2.13 Most Rotherham patients were either taken to Sheffield or Doncaster and most Barnsley patients were taken to either Wakefield of Doncaster as expected.

2.14 Stroke teams across SYB and Mid Yorkshire worked together closely with the Yorkshire Ambulance Service to ensure that patients were transferred back to Rotherham or Barnsley after their initial urgent specialist stroke care in a timely way, so that their ongoing care and support was closer to home in a place that best meets their needs.

3. 2020 Progress Update - HASU

3.1 The model is being delivered in accordance with the HASU service specification and providers are working to meet all expectations of this within agreed timescales.

3.2 Patient flows to HASU units in Wakefield, Doncaster and Sheffield are as expected. All units are working together closely to ensure timely transfer of patients after their urgent specialist stroke care back to Rotherham Hospital or Barnsley Hospital for ongoing care and support if required. Some Barnsley patients are being transferred to Kendray Hospital, Barnsley for rehabilitation directly from HASU as expected. Some patients are being successfully discharged directly home with local follow up for community rehabilitation and Stroke Consultant Review.

3.3 Since enacting the changes, a total of 333 Rotherham and Barnsley stroke patients have received their HASU care in Sheffield, Wakefield and Doncaster. Work is ongoing to monitor patient flow and patient activity numbers.

3.4 A dashboard has been developed which will allow patient activity and flow through the pathway to be reported. Contracting teams have been working with providers to implement use of the dashboard and this will be in place in the coming months.

3.5 Feedback from patients and their families to staff on the ground continues to be positive. All partners continue to be committed to realising the full benefits for patients. Going forward there are plans to gather feedback from patients and families and staff to enable continuous improvement. A patient engagement plan is under development by the SYB Stroke Hosted Network to gather comprehensive feedback.

3.6 There have been positive examples where patients who have accessed their HASU care at Sheffield have received Thrombectomy as a result of this and had excellent outcomes. These cases have had reduced disability as a result of their treatment and have been successfully discharged home to live independently.

3.7 There have been some challenges in the repatriation of patients from Sheffield to Rotherham. Any delays are captured and resolved by providers via the daily teleconference call.

3.8 A quarterly regional delayed repatriation report is in use which captures any delays and will support the reimbursement mechanism for Trusts. This commenced in Quarter 3 2019/20.

3.9 In Quarter 3, there were five cases where repatriation from Sheffield to Rotherham was delayed. Of these, two patients were discharged directly home and three were repatriated to Rotherham Hospital. The longest delay was 5 days and the shortest delay 1 day. The median delay was 2 days. In all cases providers worked together to resolve the delays.

3.10 In Quarter 3, there were no reported delays in repatriation for Barnsley patients.

3.11 Providers are working well together to resolve any delays and these are being discussed at both the daily and weekly check in calls where joint actions are agreed.

4. 2020 Progress Update – Stroke Hosted Network

4.1 The SYB Stroke Hosted Network was launched in January 2020 and is hosted by Sheffield Teaching Hospitals NHS Foundation Trust. The Network Team consists of Senior Clinical and Managerial multi-disciplinary leaders from across SYB and has support from a Workforce Lead, Data Analyst and Administrator.

4.2 The SYB Stroke Hosted Network is building on the work to date to bring together all key partners to embed the changes to hyper acute stroke services. Together with commissioners it is monitoring the delivery of the new HASU model, including key performance indicators, activity, patient flows and all aspects of quality to enable us to realise the full benefits for patients.

4.3 The SYB Stroke Hosted Network is focusing on reducing unwarranted variation in care through the development and application of consistent clinical guidelines, take a strategic and collaborative approach to workforce planning and explore the opportunities to take an innovative approach to improve care delivery. The Network's work programme will go beyond just hyper acute stroke services and will focus on the whole stroke pathway, from prevention through to living with stroke

4.4 The SYB Stroke Hosted Network is aligning to the Integrated Stroke Delivery Network (ISDN) Specification as described in the NHS Long Term Plan and is working to the agreed national timeframe for this.

4.5 The SYB Stroke Hosted Network Governance arrangements and infrastructure have been agreed. There is an Integrated Stroke Delivery Network (Stroke Hosted Network) Steering Group (ISDN Steering Group) now in place which is the key decision-making and oversight forum for the Network. It is accountable to the Acute Federation (AF) CEOs for its actions and is Chaired by the Director of Strategy and Planning at STH.

4.6 The ISDN Steering Group includes members from across SYB, Wakefield and Chesterfield representing the whole SYB stroke pathway. The Stroke Association are a key member of the group and will ensure that the voice of patients and their families is represented.

4.7 The first ISDN Steering Group took place on 3rd March 2020 with excellent representation from all key partners across the stroke pathway.

4.8 The ISDN Steering Group began to consider the work programme priorities for the Network and these will be shaped collaboratively with key stakeholders from across the Region. These will align with the National ISDN priorities but will be developed within the local SYB context. Learning from the recent

Getting It Right First Time and Sentinel Stroke National Audit Programme (SSNAP) was shared.

4.9 As part of the Network infrastructure a number of Regional Network Groups have been agreed and have begun to meet for the first time in March 2020. These will be critical to the development and implementation of the work programme. They will receive direction from and report progress to the ISDN Steering Group.

4.10 The easy read patient leaflet, which was developed in conjunction with patients and their families across SYB, has been developed further and was presented at the first ISDN Steering Group with group offering their approval pending a minor change.

5. Next Steps

5.1 The Network will continue to support ongoing development of the HASU pathway and monitor progress as part of its work programme.

5.2 The Network will be one of the vehicles through which we will work together in future to plan and implement the commitments in the NHS Long Term Plan for Stroke.

5.3 Patient and carer engagement will be play a key role in the Network and this will utilise / build upon existing forums that exist across the region.

5.4 There will be a SYB HASU Review Group convened in May 2020 to share learning from the new pathway, evaluate patient flows, performance and agree any further actions required to develop the HASU Pathway specifically.

5.5 Over the coming months the SYB Stroke Hosted Network will agree a new work programme in line with the NHS Long Term Plan and local priorities.

6. Recommendations

The JHOSC is asked to note:

6.1 The ongoing successful implementation of the new South Yorkshire and Bassetlaw model of hyper acute stroke care.

6.2 The positive initiation of the SYB Stroke Hosted Network.