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South Yorkshire, Derbyshire and Nottinghamshire Joint Health Overview and Scrutiny Committee Meeting	Tuesday 20 October 2020 11.45 am To be held as an online video conference

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 3 - 14)

To approve the minutes of the meeting of the Committee held on 28th July, 2020.

6. South Yorkshire, Derbyshire and Nottinghamshire Joint Health Overview and Scrutiny Committee - Terms of Reference (Pages 15 - 20)

Report of Emily Standbrook-Shaw, Policy and Improvement Officer, Sheffield City Council.

7. Proposals to Standardise the prescribing of Gluten Free Products across South Yorkshire and Bassetlaw (Pages 21 - 52)

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

8. Date of Next Meeting

The next meeting of the Committee will be held on a date to be arranged.

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SHEFFIELD CITY COUNCIL

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

Meeting held 28 July 2020

(NOTE: This meeting was held as a remote meeting in accordance with the provisions of The Local Authorities and Police and Crime Panels (Coronavirus) (Flexibility of Local Authority and Police and Crime Panel Meetings) (England and Wales) Regulations 2020.)

PRESENT: Councillors Jeff Ennis, Eve Keenan, Mick Rooney and David Taylor

In attendance:-

Des Breen, Anna Clack, Lesley Smith, James Scott, Jaimie Shepherd Lesley Smith and Helen Stevens - South Yorkshire and Bassetlaw Integrated Care System (SYB ICS)

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1. APOLOGIES FOR ABSENCE

1.1 There were no apologies for absence.

2. EXCLUSION OF PUBLIC AND PRESS

2.1 No items were identified where resolutions may be moved to exclude the public and press.

3. DECLARATIONS OF INTEREST

3.1 Councillor Jeff Ennis declared a personal interest as a Non-Executive Director of Barnsley Healthcare Federation.

4. MINUTES OF PREVIOUS MEETING

4.1 The minutes of the meeting held on 7th November 2019, were approved as a correct record.

4.2 *Matters Arising*

4.2.1 It was noted that a number of questions from members of the public were still outstanding and the Chair, Councillor Mick Rooney, together with Emily Standbrook-Shaw, Policy and Improvement Officer, would obtain answers to those questions and circulate them to Members within the next two weeks.

5. PUBLIC QUESTIONS

5.1 *Nora Everitt, on behalf South Yorkshire and Bassetlaw NHS Action Group*

SYBNHSAG) asked the following questions on behalf Peter Deakin:

5.1.1 (a) What protocol is there regarding national emergencies for not informing Scrutiny or the public about:
- how you will keep health and care services accessible and safe
- any changes to services you will be making?

(b) How, in this national emergency and possible second wave of virus infections, are you going to inform and involve the public to be sure you are transparent and accountable? Concerned that there were no public information on the website and no Joint Meetings of the CCG.

5.1.2 Lesley Smith and Helen Stevens, South Yorkshire and Bassetlaw Integrated Care System (SYB ICS) responded by saying that each NHS body had a duty to ensure services were safe and report on the latest position of the pandemic to the public. When the national emergency was declared, the NHS took national command and control but the ICS could make changes regionally if it was considered that there was a risk to public safety. She added that the Integrated Care Service was not responsible for managing the effects of the pandemic, the pandemic was a public health issue the ICS served to provide updates and, where necessary, seek advice from NHS England on service changes. Helen Stevens stated that NHS bodies have a duty to continue to keep the public informed and Clinical Commissioning Groups and NHS Foundation Trust Groups were there to oversee that this was done. She referred to examples of information that had been given through social media, in particular Facebook, and also wrap-around reports in local newspapers as well as interviews on television and local radio stations. Also, the Clinical Commissioning Group (CCG) had been involved in carrying out online and telephone surveys and all NHS partners had been keeping the public well informed throughout the national campaign. Councillor Rooney considered that a verbal report, rather than a written report on this would be more effective as the pandemic was ongoing and changed daily, and whilst it was right and proper to provide regular updates, he said a written report might give an element of finality and, he felt, the pandemic was far from over. At a later date, there would be an in-depth analysis into the effects of the virus. Emily Standbrook-Shaw stated that here had been a significant response to the pandemic from local authorities and their respective Scrutiny Committees were looking into the how the virus had affected their local communities.

5.2 *Steve Merriman (questions asked by Nora Everitt)*

5.2.1 (a) Given the overwhelming gravity of C19, the gigantic effort put into fighting it and the fact that the last JHOSC meeting was last November, why is there no written report for the JHOSC members to consider?

(b) In accordance with the JHOSC Terms of Reference, can JHOSC request and consider a written report in order to form a view on the extent to which the pandemic has been successfully managed showing:

- comparative data for :

- SYBICS against other ICS's (re. Hospitals, Care Homes and Community)
- The 6 Committee Member Authorities in the SYBICS (re. Hospitals, Care Homes, Community)

- comparative data over time to do with :
  - Deaths per 100,000
  - C19 infections per 100,000

Deaths and infections by profession in NHS, Care Homes, and Community?

5.2.2 Councillor Mick Rooney stated that, as was mentioned earlier, each constituent local authority was carrying out its own analysis of the situation, and indicated he would be happy to discuss whether there should be joint analysis with colleagues on this Scrutiny Committee to avoid duplicity. It was reiterated again that the ICS was not responsible for the management of the pandemic.

5.3 *Luisa Fletcher (questions asked by Councillor Mick Rooney)*

Q1. What arrangements have been made in the plans being discussed under agenda items 8 and 9 to address the likelihood of a second wave of the COVID-19 pandemic?

5.3.1 There had been a huge amount of emergency planning at the beginning of lockdown, however the majority of services had remained intact and many lessons had been learnt and continuously updated. As there was improvement in dealing with the first wave of the crisis, protocols had been put in place to be able to effectively manage a second wave. With regard to the treatment of serious medical conditions such as cancer and heart attacks and also elective surgery, all which had been put on hold throughout the pandemic, Des Breen stated that the public had been afraid to go to hospitals due to fear of being infected with the virus and also not wanting to place extra burden on NHS staff working in the hospitals. When this became apparent, the NHS published a statement saying they were "still open for business". Although appointments initially would be held virtually, every effort would be made to encourage people to attend for treatment. It was also stated the Derbyshire Health Services were working as well as they possibly can.

Q2. P12. Point 3.8 The Equality Impact Assessment (presented to the SY&B JCCCG Feb'20) identified that the changes would have an impact on some children and families. (Carers, Lone Parents, Low Income families and Employment implications). The impact was considered low despite four categories affected. The paper intended for the cancelled Mar'20 meeting acknowledged there were identified groups affected by these changes.

- *Why is there no reference to these groups identified in the EIA as*

affected by the changes in today's update?

- *Why has there been no commitment to attempt to reduce any such an impact the changes will have on these families?*

5.3.2 Anna Clack stated that whilst additional protocols had been put in place during the pandemic, overall the EIA would ensure that no family would struggle to travel between hospitals should that situation arise. The position was fully explained to parents should a child require an appendectomy. Only those requiring surgery were transferred.

5.3.3 With regard to the financial impact on parents, a child that had had an appendectomy would be required to stay in hospital overnight, and only in very rare cases would a child be required to stay in hospital any longer, which would then mean a parent or carer would have to take time off work. In cases where children had been transferred to Leeds, reasonable costs in line with local hospital policy would be covered to ensure parents were able stay with their child.

5.3.4 An evaluation of the situation between parents and the Liaison Service based at Sheffield Children's Hospital, had taken place to ensure safe emergency transfer of patients during Covid. A significant amount of patient feedback had been received and this feedback had been very positive, one of the main points that had been picked up was that the whole experience was very smooth, there had been good communication between staff and families. However, the majority of questions from parents were where could they get a cup of tea and the best way to enter and leave the hospital.

Q3. The report (point 4.2) says the Hosted Network will be "monitoring the delivery of the new HASU model" listed some aspects they will look at. What have they learned from this and how have they been consulting with patients about their experience of the new model?

5.3.6 Jaimie Shepherd stated that the Network Team had been working across all services within the pathway. The Team had been participating in setting up a number of sub-groups and working with the Stroke Association. All clinicians were working well together, and close relationships have been developed. Patients have moved into the system as anticipated, but we are keeping eye on the national audit, patients entered onto this audit to monitor that HASU services were offering a high quality service and consistency in the services received. It was acknowledged that there was a need to increase Thrombolysis and Thrombectomy rates across the region. Patient experience which had been monitored through the Friends and Family Test and had shown that in February 2020 (the last published results) 100% of families were happy to recommend the services in Doncaster and Sheffield and 96% in Wakefield. The HASU performance dashboard had been suspended during Covid, but it was anticipated that an evaluation report would be published after October, 2020 allowing the service to gather a full year of data. Focus Groups (and/or surveys) would be developed to ask patients and families for their views.

Q4. "Repatriation" (points 3.9 and 3.10) is a very emotive word for many people, particularly those in ethnic minority communities. Why is the ICS not more sensitive in its use of language when other words, or phrases, can be used to describe a transfer from one hospital to another?

5.3.7 It was acknowledged that the word "repatriation" was a very emotive word, and an apology was given for any offence caused by this. It was explained that when staff speak to patients they use the word "transfer" not "repatriation" and that repatriation was a NHS technical term.

5.3.8 The final question asked by Luisa Fletcher re the Workforce Plan, would be dealt with in the mop up questions to be circulated at a later date.

6. UPDATE - COVID 19 AND THE INTEGRATED CARE SYSTEM

6.1 Lesley Smith gave a verbal update on Covid 19 and the Integrated Care System (ICS). She reiterated the point made earlier that the ICS was not a statutory body but linked in to the Joint Scrutiny Committee through transformation work. She said that during the Covid crisis, the ICS had adapted to be able to support local organisations and enable them to respond to the Covid crisis and facilitate mutual aid. She said that a group had been established to hold weekly meetings across the area. There had been a collective approach towards cancer patients to ensure that their treatment continued in line with clinical priority. Due to the decline in new cases of coronavirus in the South Yorkshire and Bassetlaw area, the ICS was in a position to implement Phase 3 in the recovery from the crisis, and that between August 2020 and August 2021, it would be looking into treatments that had been postponed and tackle lengthening waiting lists. One of the challenges had been the supply of Personal Protective Equipment (PPE) and it should be noted that 50 local companies had adapted their businesses to produce PPE. Lesley Smith stated that hospital staff and patients had been swabbed for the virus, and referred to the sites which had been set up at Doncaster and Meadowhall to carry out tests on all key workers and members of the public, and also the mobile testing units in Barnsley, Rotherham and the Dearne Valley that had been set up within communities to enable them to test, track and trace so that staff would be able to respond to local outbreaks or clusters. There had been a need to increase the intensive care capacity for the treatment of infectious diseases, which was based at Sheffield Hallamshire Hospital, but had been developed across all sites, however, as the number of coronavirus infections decrease, care was being returned to the Sheffield site to free up intensive care at District Hospitals. Community support was being given to survivors of Covid 19, particularly those who required longer term rehabilitation. Each member organisation with theICS was working closely with its local authority to develop robust plans in tackling future spikes in the virus.

The ICS had also been involved in the Nightingale Scheme. More than 600 final year nursing and allied health students from Sheffield Hallam University had volunteered to join NHS and support the frontline. Local Authorities were working with care homes and local resilience forums to offer support in care homes, which included education, training, development, tutorial on the safe use of PPE and safe disposal of contaminated items. There had been the deployment of specialist

hospital equipment to help with deep cleaning inside care homes.

6.2 Helen Stevens stated that a Citizens Panel was in development, however the company that had been commissioned to deliver this work across the NHS, usually built membership databases face to face, but due to the current situation, recruitment had had to be carried out online and was doing all it could to reach across different demographics. There were plans to work with voluntary organisations and to start an online campaign initially through Facebook, and then look at where the gaps were.

6.3 Recent discussions had focused PPE supplies, recognised the impact of Covid within the region and looked at the local economy and what was required to stimulate employment within the area, and felt that it was important to connect with Sheffield City Region to recognise the economic challenges in the area.

6.4 The Chair thanked Lesley and Helen for the update.

7. CHILDREN'S SURGERY AND ANAESTHETIC SERVICES

7.1 The Committee received a report which provided an update on proposed changes on the South Yorkshire and Bassetlaw Children's Surgery and Anaesthesia Work. The report set out details of a new proposal for a revised service model and the implementation of an associated pathway for paediatric appendectomy surgery. The proposal had been put forward by Clinicians working within South Yorkshire and Bassetlaw and had been supported, in principle, by the Joint Committee of Clinical Commissioning Groups.

7.2 Des Breen introduced the report and stated that the proposal would ensure that children presenting with acute abdominal pain would be seen by surgeons and anaesthetists who were trained in the care of children. District General Hospitals carried out a lot of paediatric care but there was a need to target surgeons who currently carried out surgery on adults but had no formal paediatric training and encourage to them train and carry out surgery on children. The Royal College of Surgeons considered that a child was someone who was 16 years and under. The reduction in hours in recent years for junior doctors had led to limited training. When asked how far down the age range can an adult surgeon carry out general surgery on children it was considered that the cut off age was around eight. He said the numbers of appendectomies on children were very small and that some surgeons in District General Hospitals only carried the procedure once or twice over a five year period. Appendectomies were not time critical so patients could be safely transferred. Clinicians have developed a pathway which monitors abdominal pain through a scoring system that decided which patients should be transferred for local district hospitals to Sheffield Children's Hospital. He said it was safer and better for children under the age of eight to be seen by someone trained to operate on size appropriate. Des Breen said that the clinical pathway to be developed to transfer children under eight years old from local hospitals to Sheffield Children's Hospital would only affect about 45 children a year with appropriate arrangements being put in place to ensure their safe transfer. The acute response to Covid had meant that all emergency operations were carried out in Sheffield, but it was now possible for those services to be returned to district

hospitals. Des Breen asked for the Scrutiny Committee's views and whether this matter needed further consultation.

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

- Across South Yorkshire and Bassetlaw, children under the age of six were already transferred from District Hospitals to Sheffield Children's Hospital and this was seen as an extension of this. Processes were in place to transfer a child with a parent or guardian and parents were reassured that their child would receive the highest quality of care and that the proposed pathway was seamless.

- Children who presented at District Hospitals with abdominal pain were assessed first and not necessarily transferred straight away, it was found that three out of four cases often don't require surgery. There was a period of observation and children were given pain relief and if necessary, transferred to Sheffield Children's Hospital by ambulance under close observation.

- Operating on children under the age of eight was all about the confidence of an adult surgeon and their ability to carry out such operations.

- During the Covid 19 pandemic it had been agreed that throughout April and May, all non-time critical emergency surgery for children should be carried out at Sheffield Children's Hospital to ensure the continuation of safe services for children during the pandemic and this had applied to all children under the age of 16. This had been a temporary pathway and surgery was being handed back to District Hospitals but it had been agreed that emergency surgery stay at Sheffield Children's Hospital.

- It was felt that anaesthetic skills and ear, nose and throat pathways be retained at District Hospitals and there was no need to diminish the level of paediatric care at those hospitals.

- Whilst taking account of parents' concerns, children under the age of five were always transferred to Sheffield. There was a process to follow when transferring children with a parent or guardian and support processes were in place. Parents were reassured that their child would be treated in the safest place which often mitigated their anxieties and transfers were often seamless.

- During the pandemic, all children were transferred to Sheffield at the rate of one per week for under 16s and much less for under 8s. Robust data was available as to what had happened during that time, however the landscape changed all the time, so it was felt only right and proper that this matter was revisited and brought back for discussion.

- These proposals would decrease the numbers of children being transferred, the only increase would be in abdominal cases transferring to

Sheffield. District Hospitals provide excellent services and would continue to do so, and parents should feel confident in the services they provide. Intrinsically it doesn't seem right that a surgeon would possibly only operate once or twice during a three to five year period.

- When looking at other surgical pathways, there was great assurance of what was happening in district hospitals and it was felt that there was a strong basis for maintaining work in district hospitals. The proposed change would not negatively impact on this.

RESOLVED: That the Scrutiny Committee does not consider the proposed change to be a 'substantial variation' to the service and therefore does not require further consultation on this matter.

8. UPDATE ON HYPER ACUTE STROKE SERVICES

8.1 The Committee received a report giving an update on the ongoing delivery of the new South Yorkshire and Bassetlaw model of hyper acute stroke services. The report also set out how the pathway had been sustained and delivered in line with the hyper acute stroke unit (HASU) service specification throughout the Covid-19 pandemic.

8.2 Jaimie Shepherd presented the report giving an update on the HASU. She said that changes to the Service were approved in 2017 and enacted in 2019. HASU services were now provided in Doncaster, Sheffield and Wakefield for South Yorkshire and Bassetlaw patients (SYB). HASU care was usually offered for up to 72 hours. Mechanical Thrombectomy surgery (a clot retrieval treatment) was carried out in Neuroscience Centres and SYB patients can receive this treatment in either Sheffield or Leeds. Work was ongoing to monitor HASU patient flow and patient activity numbers. The Stroke Hosted Network has been monitoring the quality of care and feedback on the HASU model has been positive. A dashboard had been developed which would will monitor the model and allow for patient activity and flow through the pathway to be reported. Full implementation of the dashboard had been delayed due to Covid-19.

8.3 Jaimie Shepherd stated that Stroke Services nationally participated in the Sentinel Stroke National Audit Programme (SSNAP) where every patient was entered onto a clinical audit web tool. Each quarter, results are collated and services receive level scores to indicate the quality of their services. The South Yorkshire and Bassetlaw services area have scored very highly in the most recent report. The SYB Stroke Hosted Network Steering Group which has representation from all providers, and including the Yorkshire Ambulance Service, Clinical Commissioning Group and the Stroke Association meet regularly to oversee the work of the Network and monitor progress with HASU. Patients are moving through the HASU pathway generally as expected. There have been a small number of delays in patients transferring between Sheffield and Rotherham. However, providers were working together to resolve this and it was being managed by the daily calls between the Services where joint actions were agreed. The SYB Stroke Hosted Network consists of Senior Clinical and Managerial multi-disciplinary leaders and has support from a Workforce Lead, Data Analyst and

Administrator, the focus of the Network is to reduce unwarranted variation in care through the development and application of consistent clinical guidelines, to take a strategic and collaborative approach to workforce planning and explore the opportunities to take an innovative approach to improving 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 a stroke.

8.4 Nora Everitt was invited to ask her questions on this item which were as follows:-

The report (point 2.7) mentions the new Mechanical Thrombectomy service offered in Sheffield. This is a relatively new procedure with only a few thousand people a year in England considered suitable to receive it.

- *How long has this been offered in Sheffield?*
- *How many thrombectomies have been carried out since it was first offered?*
- *How do you ensure the person carrying out the procedure does it often enough to maintain the necessary skills?*
- *Will Barnsley people be assessed for thrombectomy before transferred to Wakefield?*
- *Before the pandemic lockdown in March, there was an average of 22 cases transferred each month from both Rotherham and Barnsley to a HASU. Since March, the number transferred per month appears to have increased to 32 cases for each town. (Numbers based on the two reports Mar'20 and Jul'20)*
- *Why do you think this is, given that nationally people going to A&E with strokes reduced dramatically after the lockdown?*

Before a response was given, it was agreed that Councillor Eve Keenan be invited to ask a question on this matter, as follows:-

I understand that there is a link between certain strains of Covid 19 and increase in strokes, have you seen increase in cases? I have also heard that detailed research into patients in Doncaster and Barnsley, as well as other areas. Do you intend to roll out this treatment would be rolled out in Rotherham?

Responses to these questions and questions from Members of the Scrutiny Committee were as follows:-

- Mechanical thrombectomy was a relatively new procedure which had been offered to patients in Sheffield since April 2018, and since then 57 patients had received this type of treatment. There were only three neurology surgeons trained to do it. As far as expertise was concerned, it takes two years to train a specialist to carry out the procedure, although it was not dissimilar to other procedures, it basically removes a blood clot caused by a stroke in a different way to Thrombolysis. Anyone who presented with an acute stroke, was taken to the Hyper Acute Stroke Unit where an assessment and a CT scan was carried out to determine whether the patient should be considered for the thrombectomy procedure was to be carried out. So anyone in Barnsley or Rotherham would be directed to the

HASU first, receive assessment and them be transferred to a neuro science centre if Thrombectomy is indicated.

- One of the things known about the coronavirus was that it can cause clots in the heart, the lungs and other areas around the body, it can make the blood very sticky.

- With regard to the increase in numbers and managing demand, it had been seen across South Yorkshire and Bassetlaw (SYB), that there had been a slight reduction in stroke admissions across the region with the exception of Sheffield. Numbers of Barnsley and Rotherham patients being admitted to HASU's have remained fairly stable. It was not unusual to see fluctuations in the numbers of strokes throughout the year, a slight rise in admissions had been seen in Rotherham during March this year. During the pandemic, there had been a national reduction in the number of patients presenting at hospital with a suspected stroke, and there was a national concern that patients wouldn't present with symptoms. However, stroke admissions have now begun to return to normal levels and a number of organisations have sent out clear messages to members of the public to encourage them to access stroke services. One of the Stroke Nurse Consultants based in Sheffield was interviewed on "Look North" and encouraged people with stroke symptoms to present at hospital. There had also been a reduction in cases where someone had had all the symptoms of having a stroke, but on investigation, it had been found not to be the case (stroke mimics).

- In terms of links to Covid 19, Clinicians were still working to discover whether there was a link to strokes and the virus and were studying the latest evidence. One of the SYB Stroke Hosted Clinical Leads who works at Rotherham Hospital was capturing patient experiences of experiencing a stroke during the COVID-19 incident. Some of the questions that had been asked during the telephone review were whether people had received face to face rehabilitation or remote rehabilitation using the technology that was available and what was their experience of it.

- If something was to go wrong within the Service, HASU have a number of clinicians and key leaders so if there was failure to respond within that Service, on investigation into that incident would be carried out and the results fed into a Steering Group that had been set up and the Service would be held accountable. There was a clear governance structure to deal with all aspects of the Service that was provided and its providers. Individual providers have statutory duties around patient safety and quality of care and a standards process to follow if there was serious risk to patients.

- Discussions had been held with a Clinical Lead in Wakefield with regard to the "B" rating it had received on SSNAP. On the whole, the service was very strong, the main area which that had reduced the overall SSNAP level score was speech and language therapy, linked to the level of intensity offered and whether this meets the national guidance on this. Performance on this has fluctuated. There had been a reduction in speech and language

staffing levels at the beginning of the year and currently a recruitment initiative was being carried out in an effort bring the speech and language domain scores service back up to an "A" rating. Mid Yorkshire was around four points off the overall level ratings for Doncaster and Sheffield. This is a relatively small number and there was a plan was in place to identify areas requiring improvement. Lessons learned from the "Getting It Right First Time" programme had helped to inform the Network on where to focus.

- Community teams in SYB include stroke specific specialists, offering early supported discharge. To be considered a specialist a clinician should care for stroke patients 80% of the time which was important. Patients could access generic services further down their care as their health improved.

RESOLVED: That the contents of the report be noted.

9. AMENDMENTS TO THE JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE TERMS OF REFERENCE

9.1 Emily Standbrook-Shaw, Policy and Improvement Officer, Sheffield City Council referred to the Terms of Reference of the Joint Scrutiny Committee and stated that (a) a change would be made showing that Wakefield had opted out of being part of the Committee, (b) there were slight changes to the operating arrangements of the Committee and (c) the Terms of Reference would be kept under review as things change.

10. DATE OF NEXT MEETING

10.1 It was agreed that the next meeting of the Joint Scrutiny Committee will be held on a date in October, 2020 yet to be agreed.

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Report to South Yorkshire, Derbyshire and Nottinghamshire Joint Health Overview & Scrutiny Committee
20th October 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 of the South Yorkshire, Derbyshire and Nottinghamshire Joint Health Overview and Scrutiny Committee have been amended to clarify that 'powers of referral' to the Secretary of State are retained by each of the participating authorities and not delegated to the Joint Committee.

This amendment does not represent a change to the way the Committee operates; it is a clarification of the existing position.

The amended terms of reference are attached for the Committee's consideration.

Type of item:

Reviewing of existing policy	**x**

The Scrutiny Committee is being asked to:

- Agree the amended Terms of Reference

Category of Report: OPEN

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

1. Introduction

1.1 Where a health scrutiny body has been consulted by a relevant NHS body or health service provider on a proposed substantial development or variation, it may refer a proposal to the Secretary of State if:

• It is not satisfied with the adequacy of content of the consultation.
• It is not satisfied that sufficient time has been allowed for consultation.
• It considers that the proposal would not be in the interests of the health service in its area.
• It has not been consulted, and it is not satisfied that the reasons given for not carrying out consultation are adequate.

1.2 In the case of Joint Health Overview and Scrutiny Committees (JHOSC), the 'power to refer' may be delegated to the joint committee, in which case only the joint committee may make a referral; or where the 'power to refer' has not been delegated to the joint committee, the individual authorities that have appointed the joint committee may make a referral.

1.3 In the case of the South Yorkshire, Derbyshire and Nottinghamshire Joint Health Overview and Scrutiny Committee, the 'power of referral' is retained by each of the participating authorities and is not delegated to the JHOSC.

2 Amendments to the terms of reference

2.1 The terms of reference have been amended to clarify this point, with the Insertion of the following wording at section c:

Each Local Authority retains the power of referral to the Secretary of State of any proposed "substantial variation" of service, unless the power has been delegated to the JHOSC by that Local Authority in accordance with their local constitution. No Local Authority has made such a delegation and so this power is not exercisable by the JHOSC.

2.2 This change does not represent a change to the way the Committee operates; it is a clarification of the existing position.

2.3 The amended terms of reference are attached for the Committee's consideration.

3. Recommendation

3.1 The Committee is being asked to

- Agree the amended Terms of Reference

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. Each Local Authority retains the power of referral to the Secretary of State of any proposed "substantial variation" of service, unless the power has been delegated to the JHOSC by that Local Authority in accordance with their local constitution. No Local Authority has made such a delegation and so this power is not exercisable by the JHOSC.

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 2013.

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 agree 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 October 2020

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Report to Joint Health Overview and Scrutiny Committee for South Yorkshire, Nottinghamshire and Derbyshire
20th October, 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 and some principles to guide future work 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 that are drawn up utilising the principles that have been garnered from this engagement exercise, 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 Proposals

6.1 The engagement has shown us that people feel:

- There should be uniformity of approach across SYB
- The NHS should not be routinely funding products available in the supermarket
- An increase in Gluten Free prescribing is not felt necessary
- They would be happy with reduced levels of GF prescribing
- But they would like to see support measures in place for those who are most vulnerable/ in need

6.2 Our proposed next step is therefore to develop a business case based on these principles.

7.0 Recommendation

7.1 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.

7.2 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 that are drawn up utilising the principles that have been garnered from this engagement exercise, 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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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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