

Consultation on NHS funded Gluten Free Prescribing Across Cheshire and Merseyside

Date of meeting:	07 January 2025
Report to:	Overview and Scrutiny Committee (Adult Social Care and Health)
Report of:	NHS Cheshire and Merseyside ICB
Wards affected:	All
Exempt/confidential report:	No
Contact Officer:	Deborah Butcher
Tel:	
Email:	

1.0 Why is this item before the Committee?

- 1.1 The purpose of this report is to inform the Committee that the Board of NHS Cheshire and Merseyside Integrated Care Board (ICB), at its meeting on 28 November 2024,¹ approved the recommendation that the ICB commences a period of public consultation regarding the proposal to cease NHS funded gluten free prescribing (bread and bread mixes) across Cheshire and Merseyside.
- 1.2 The ICB has duty to engage with Local Authority Health and Overview Scrutiny Committees (HOSC) to seek confirmation as to whether the HOSC believes this proposal is a substantial change to NHS services. If this is confirmed by HOSC then this triggers the requirement for the ICB to formally consult with the HOSC, in line with the [s.244 Regulations](#)² of the NHS Act 2006 (as amended by the Health and Care Act 2022).

2.0 What is Scrutiny being asked to do?

- 2.1 The Committee is asked to:
- consider and determine whether the proposal represents a substantial development or variation.

3.0 EXECUTIVE SUMMARY

- 3.1 The Board of NHS Cheshire and Merseyside Integrated Care Board (ICB), at its meeting on 28 November 2024, has approved the recommendation that the ICB commences a period of public consultation regarding its proposal to cease NHS funded gluten free prescribing (bread and bread mixes) across Cheshire and Merseyside. The paper outlining the proposal and rationale is appended to this paper (Appendix One) and is available at www.cheshireandmerseyside.nhs.uk. Contained within this Appendix is the following that was considered by the Board:
- Cover paper

- Gluten Free Prescribing Options Appraisal document
- Communications and Engagement Plan
- Equality, Diversity and Inclusion Impact Assessment
- Quality Impact Assessment.

- 3.2 Currently across Cheshire and Merseyside there are differences in the prescribing availability of gluten free products for patients due to previous arrangements of the individual predecessor Clinical Commissioning Group (CCG) organisations. GP Practices within eight Places currently offer gluten free prescribing in line with the 2018 national Department of Health and Social Care (DHSC) consultation outcome, which was to reduce prescribing to bread and bread mixes only. It is of note that St Helens CCG and NHS Cheshire West CCG opted to withdraw prescribing completely (noting this was prior to the national Department of Health and Social Care (DHSC) consultation as detailed above). For Cheshire West Place, the area that was covered by the former NHS Vale Royal CCG did not opt to withdraw gluten free prescribing, and as such there are still parts of Cheshire West where gluten free prescribing (for bread and bread mixes) can be undertaken (Winsford, Northwich and surrounding area). As the ICB has commissioning responsibilities for all of Cheshire and Merseyside patients, work has been undertaken to rectify this position and recommend a harmonised approach to gluten free prescribing.
- 3.3 In Cheshire and Merseyside, c13,000 patients have a diagnosis of coeliac disease or other conditions which requires management through a gluten free diet. Most people choose to purchase their gluten free foods at supermarkets or other retailers however 2,314 Cheshire and Merseyside patients receive gluten free bread and bread mixes via prescription. Of the gluten free prescriptions issued, 99% are exempt from prescription charges, with 73% being due to age (under 16 or 18 if in full time education, or over 60 years old) and over 60% of these being over the age of 60. Further data can be seen in Tables One, Two and Three.
- 3.4 Under the ICBs Reducing Unwarranted Variation Recovery programme, a number of options were considered in order to address the variation in gluten free prescribing. The option to maintain the current arrangements was not considered, due to the current unharmonised position, and the need to ensure equity across Cheshire and Merseyside. In order to achieve this, the two main options considered were to either fully prescribe across Cheshire and Merseyside at an estimated additional cost of £130k per year (increase annual spend on the service of c.£655k) or to withdraw prescribing completely, offering an estimated annual saving of £525k. The full options appraisal can be found in Appendix One of this report.
- 3.5 In the context of NHS Cheshire and Merseyside needing to consider how and where to allocate the fixed resources allocated by NHS England to best meet the healthcare needs of the population they serve, the Unwarranted Variation programme proposed to the Board of NHS Cheshire and Merseyside that gluten free prescribing is stopped across Cheshire and Merseyside due to the following rationale:
- availability of gluten free foods is much greater than it was when the original policies were implemented, and in the six years since the DHSC consultation. It should also be noted that bread is not classed as an essential food item and people can maintain a healthy diet without bread through choosing naturally gluten free foods
 - whilst the cost of gluten free bread is still more expensive than non-gluten free there are other gluten free products (e.g. pasta) which are the same price. In addition, improved food labelling and increased awareness enables people to make informed and healthy choices
 - Coeliac UK now say that 40% of ICBs have stopped or reduced gluten free prescribing. Our research shows that 32% have stopped completely, 61% prescribe bread and bread mixes and 6% offer to under 18s only

- consideration was given to prescribing to under 18s only, however, Cheshire and Merseyside data shows that over 60% of gluten free prescriptions are for patients 60 years old, and therefore could be seen as discriminatory against the older population
- gluten free prescriptions are in the main received by patients who have exemptions from payment, with the majority of this being due to age (73%). Because age exemption does not take into account financial capacity, it is difficult to evidence the individual financial impact on the impacted patients.
- withdrawing prescribing has already been implemented fully in St Helens and part of Cheshire West and to date we are not aware of any unforeseen health consequences
- ceasing ICB funded gluten free prescribing across Cheshire and Merseyside would enable achievement of a harmonised policy and remove existing unwarranted variation in access to these products based on the rationale set out in this document. In addition, it would harmonise the approach to prescribing other foods for conditions impacted by “standard” products e.g. lactose intolerance, as NHS Cheshire and Merseyside does not currently prescribe food alternatives for other food allergies / intolerances
- a number of neighbouring ICBs including Lancashire and South Cumbria and Shropshire, Telford and Wrekin have already stopped prescribing.

3.6 NHS Cheshire and Merseyside will commence its public consultation on 28 January 2025 for a 6-week period, with the closing date being the 11 March 2025. It is anticipated that the outcome of the consultation and the recommendation for the Board to consider and decide upon will be undertaken at the meeting of the Board on 29 May 2025. The Board will receive the results of the consultation and any feedback report/opinion of Local Authority Health Scrutiny at this meeting to help inform its deliberations and decision. Any formal response to the proposal/consultation by Local Authority HOSC would be requested to be provided prior to the start of May 2025 so as to help inform in a timely manner the final report to the Board of NHS Cheshire and Merseyside, however the exact date will need to be agreed with the HOSC.

3.7 As outlined within the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny)³ regulations, and covered within the Cheshire and Merseyside protocol (Appendix Two) for the establishment of joint health scrutiny arrangements, where a proposal on changes to NHS services impact on more than one Local Authority area, it is for each individual authority to reach a view on whether the proposal is deemed to be a substantial development or variation for that Local Authority area, and where more than one Local Authority agrees that it does (for the same proposal) then regulations place a requirement on those local authorities to establish a joint overview and scrutiny committee for the purposes of considering it (the proposal). The Cheshire and Merseyside protocol deals with the proposed operation of such arrangements for the Local Authorities of Cheshire and Merseyside.

3.8 Subject to the decision of the Sefton HOSC, and that of the other Local Authority HOSCs in Cheshire and Merseyside, NHS Cheshire and Merseyside will make the necessary preparations to formally consult with the agreed scrutiny arrangements. The ICB is attending Local Authority HOSC meetings across Cheshire and Merseyside throughout December 2024, January 2025 and early February 2025 with regards these proposals.

4. BACKGROUND

4.1 Coeliac disease is an autoimmune condition associated with chronic inflammation of the small intestine, which can lead to malabsorption of nutrients. The complications of coeliac disease (which may or may not be present at diagnosis) can include osteoporosis, ulcerative jejunitis, malignancy (intestinal lymphoma), functional hyposplenism, vitamin D deficiency and iron deficiency. Other key information about coeliac disease includes:

- population screening studies suggest that in the UK 1 in 100 people are affected.

- according to Coeliac UK, most people are diagnosed from 50 years old and coeliac disease is most common in people aged between 50-69 years old
- people with conditions such as type 1 diabetes, autoimmune thyroid disease, Down's syndrome and Turner syndrome are at a higher risk than the general population of having coeliac disease.
- first-degree relatives of a person with coeliac disease also have an increased likelihood of having coeliac disease.
- according to NICE the prevalence in females is higher than in males (0.6% compared to 0.4%). Cheshire and Merseyside data reflects this with 65% of patients diagnosed with coeliac disease being female.

4.2 Across Cheshire and Merseyside, we have the following data available.

Table One: Total number of patients, registered with a GP Practice, diagnosed with coeliac disease by Place and by age

Place	Age Range										Grand Total
	0-9	10-19	20-29	30-39	40-49	50-59	60-69	70-79	80-89	90+	
Liverpool	44	196	314	280	227	293	391	305	200	18	2268
Cheshire East	52	200	216	293	231	293	351	304	216	45	2201
Wirral	43	163	193	267	200	288	317	258	157	35	1921
Cheshire West	45	171	199	219	231	235	331	273	161	31	1896
Sefton	22	113	101	162	102	224	258	187	126	26	1321
Warrington	31	108	97	117	106	178	173	126	68	15	1019
Knowsley	12	83	79	87	87	132	151	100	61	12	804
St Helens	14	65	84	100	86	120	137	121	61	14	802
Halton	14	72	77	91	78	95	108	100	42	7	684
Grand Total	277	1171	1360	1616	1348	1858	2217	1774	1092	203	12916

Source: EMIS, November 2024

Table Two: Total number of patients, registered with a GP Practice, currently receiving gluten free bread and/or bread mix prescriptions

Place	Age Range										Grand Total	% of total coeliac patients in Place
	0-9	10-19	20-29	30-39	40-49	50-59	60-69	70-79	80-89	90+		
Liverpool	16	61	28	20	34	67	120	104	66	5	521	23%
Cheshire East	19	64	18	23	22	38	97	98	67	6	452	21%
Wirral	13	42	20	27	28	48	81	75	55	7	396	21%
Sefton	9	34	13	19	10	53	69	74	49	6	336	18%
Warrington	11	24	8	8	8	19	37	35	23	8	181	14%
Knowsley	5	22	11	11	9	21	32	35	24	2	172	17%
Halton	4	17	3	14	10	22	28	31	9	3	141	18%
Cheshire West	2	8	5	3	11	10	18	19	11	2	89	11%
St Helens	0	0	0	0	0	0	0	1	1	0	2	0%
Grand Total	79	272	106	125	132	278	482	472	305	39	2290	

Source: EMIS, November 2024

Table Three: Total Number of Prescriptions issued (September 2023 – September 2024)

Area	Number of prescriptions issued
Sefton Place Total	3202
South Sefton Primary Care Network	1420
PC24	303
Southport and Formby Primary Care Network	1476
Netherton Surgery	2
South Sefton GP Extra Service	1

Source: EMIS

4.3 Management of coeliac disease is a lifelong gluten free diet. Historically, availability of gluten free foods was limited and expensive, so patients obtained these products via prescribing, however, all major supermarkets now commonly stock a wide range of gluten free foods, and the price differential is reducing as demand grows.

4.4 It is difficult to evidence the impact of stopping gluten free prescriptions for bread and bread mixes and understanding the impact on affected patients. Whilst there are known risks to not adhering to a gluten free diet, which could have long term health impacts and lead to greater demand on wider health services, there is now greater availability of gluten free foods in supermarkets and other retailers (both in store and on-line), improved food labelling and greater awareness of the impact of non-adherence, which all support the patient to make good food choices for a healthy diet.

4.5 It should be noted that although gluten free bread and bread mixes are still more expensive, the cost of these products has been reducing. It is also worth noting that bread is not an essential food item and there are many naturally occurring gluten free foods. Additionally, gluten intolerance individuals do not need to eat wheat based products to maintain good health.

5.0 CONSULTATION AND ENGAGEMENT

5.1 The ICB is now engaging with Local Authority HOSCs across Cheshire and Merseyside to seek confirmation from each individual HOSC as to whether the HOSC believes this proposal triggers the requirement for the ICB to formally consult with them.

5.2 Subject to the decision of the Sefton HOSC, and that of the other Local Authority HOSCs in Cheshire and Merseyside, NHS Cheshire and Merseyside will make the necessary preparations to formally consult with the agreed scrutiny arrangements, and attend meetings on the date(s) arranged.

5.3 NHS Cheshire and Merseyside intends to begin a 6-week public consultation period from 28 January 2025, with the closing date being the 11 March 2025. The public consultation will present a single option – the cessation of NHS funded gluten free prescribing across Cheshire and Merseyside. The objectives of the consultation are:

- to inform patients, carers/family members, key stakeholders, and the public of proposed changes to gluten free prescribing.
- to engage with people who currently receiving gluten free bread and bread mixes on prescription, organisations which support them (where applicable), their carers/family members, and the wider public, to gather people's views about the proposed changes, including how individuals might be impacted.
- to use these responses to inform final decision-making around the proposal.

- 5.4 A clear consultation communication plan is being finalised, with the draft plan being available within Appendix One to this report. NHS Cheshire and Merseyside will produce clear and accessible public-facing information about the proposal, details of who is likely to be impacted and how, setting out the background to the issue and explaining why NHS Cheshire and Merseyside is proposing to make a change. This information will be accompanied by a questionnaire containing both qualitative and quantitative questions, designed to gather people's views and perspectives on the proposals. Both the information and questionnaire will be available in Easy Read format. All materials will be made available on the NHS Cheshire and Merseyside website, with printed versions and alternative formats/languages available on request (via email or telephone). People who are unable to complete the questionnaire will be able to provide their feedback over the telephone.
- 5.5 The consultation will be promoted across NHS Cheshire and Merseyside's internal and external communication channels. Wider partners and stakeholders, including providers of NHS services (hospitals, community and mental health providers and primary care), local authorities, Healthwatch, and voluntary, community, faith and social enterprise (VCFSE) organisations, will be asked to share information using their own channels, utilising a toolkit produced for this purpose.
- 5.6 To ensure that those who would be most impacted by any potential change have an opportunity to share their views, NHS Cheshire and Merseyside will seek to work with colleagues in general practice and local pharmacies, to ensure that those who currently receive gluten free bread and bread mixes on prescription are made aware that the consultation is underway.
- 5.7 While specific standalone events will not be organised as part of the consultation, if individual groups/networks request further information, NHS Cheshire and Merseyside will offer to attend meetings to provide additional briefings if required/appropriate.
- 5.8 NHS Cheshire and Merseyside recognise that it is important to understand the effectiveness of different routes for reaching people, so that this can be utilised for future activity, and the questionnaire will ask people to state where they heard about the engagement. We will summarise this information – along with other measures such as number of enquiries received and visits to the website page – in the final consultation report.
- 5.9 When the consultation closes, the findings will be analysed and compiled into a report by an independent external organisation. The feedback report will be used to inform final decision-making about the proposal, and will therefore be received by the Board of NHS Cheshire and Merseyside at its meeting on 29 May 2025. The outcome of this will be communicated using the same routes used to promote the consultation.
- 5.10 Any formal response to the proposal/consultation by Local Authority HOSC would be requested to be provided prior to the start May 2025 so as to help inform in a timely manner the final report to the Board of NHS Cheshire and Merseyside, however the exact date will need to be agreed with the HOSC.
- 6.0 FINANCIAL IMPLICATIONS**
- 6.1 There are no financial implications for Warrington Council. If the ICB was to cease funding Gluten Free prescriptions, then this would result in an estimated annual saving of £525k.

7.0 EQUALITY IMPACT ASSESSMENT

7.1 Within Appendix One there is a link to the Equality and Quality Impact Assessments undertaken by NHS Cheshire and Merseyside ICB. There are no equality implications in relation to the ask contained / request outlined within the report to the Committee.

8.0 REASONS FOR RECOMMENDATIONS

8.1 For NHS Cheshire and Merseyside to understand better and plan accordingly how to inform and/or consult Local Authority HOSC across Cheshire and Merseyside, a decision is required by each Local Authority regarding whether:

- they determine that the proposal to cease NHS funded gluten free prescribing is to be classed as a substantial development or variation, and
- whether this triggers the need to establish a Joint HOSC in line with the Cheshire and Merseyside protocol.

9.0 RECOMMENDATIONS

9.1 The Committee is asked to:

- consider and determine whether the proposal represents a substantial development or variation
- note that, subject to the decision of the Sefton HOSC and that of the other seven Local Authority HOSCs that NHS Cheshire and Merseyside will need to inform and/or consult with the relevant health scrutiny arrangements on the consultation and its outcome

10.0 IMPLICATIONS AND COMMENTS

10.1 A substantial development or variation is not defined in legislation. Guidance has suggested that the key feature is that it should involve a major impact on the services experienced by patients and/or future patients. Paragraph 5.2.3 of the Cheshire and Merseyside Protocol outlines the following criteria that Local Authorities should consider to help them with their determination:

- *Changes in accessibility of services:* any proposal which involves the withdrawal or change of patient or diagnostic facilities for one or more speciality from the same location.
- *Impact on the wider community and other services:* this could include economic impact, transport, regeneration issues.
- *Patients affected:* changes may affect the whole population, or a small group. If changes affect a small group, the proposal may still be regarded as substantial, particularly if patients need to continue accessing that service for many years.
- *Methods of service delivery:* altering the way a service is delivered may be a substantial change, for example moving a particular service into community settings rather than being entirely hospital based.
- *Potential level of public interest:* proposals that are likely to generate a significant level of public interest in view of their likely impact

10.2 Where a substantial development or variation impacts on the residents within one local authority area boundary, only the relevant local authority health scrutiny function shall be consulted on the proposal. Where a proposal impacts on residents across more than one local authority boundary, the NHS body/health service provider is obliged to consult all those authorities whose residents are affected by the proposals in order to determine whether the proposal represents a substantial development or variation.

- 10.3 Those authorities that agree that any such proposal does constitute a substantial development or variation are obliged to form a joint HOSC for the purpose of formal consultation by the proposer of the development or variation. Whilst each local authority must decide individually whether a proposal represents a substantial development/variation, it is only the statutory joint health scrutiny committee which can formally comment on the proposals if more than one authority agrees that the proposed change is “substantial”.
- 10.4 Determining that a proposal is not a substantial development/variation removes the ability of an individual local authority to comment formally on the proposal. Once such decisions are made, the ongoing obligation on the proposer to consult formally on a proposal relates only to those authorities that have deemed the proposed change to be “substantial” and this must be done through the vehicle of the joint committee. Furthermore, the proposer will not be obliged to provide updates or report back on proposals to individual authorities that have not deemed them to be “substantial”

References:

1. Papers for the 28 November 2024 meeting of the Board of NHS Cheshire and Merseyside ICB
<https://www.cheshireandmerseyside.nhs.uk/get-involved/meeting-and-event-archive/nhs-cheshire-and-merseyside-integrated-care-board/2024/28-november-2024/>
2. National Health Service Act 2006, Section 244
<https://www.legislation.gov.uk/ukpga/2006/41/section/244>
3. Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013, <https://www.legislation.gov.uk/uksi/2013/218/contents/made>

Appendices:

Appendix One: Gluten Free prescribing Paper to the Board of NHS Cheshire and Merseyside ICB, 28 November 2024

Appendix Two: Cheshire and Merseyside Protocol for the establishment of Joint Health Scrutiny Arrangements in Cheshire and Merseyside