



Acknowledgements

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Aim and learning outcomes

Aim

To provide community pharmacists and their teams with the necessary information and understanding to enable them to deliver the Gluten-Free Food service and provide support to patients with Coeliac Disease (CD) and Dermatitis Herpetiformis (DH).

Learning Outcomes

After completing this support pack, you will:

- Understand the conditions which require a gluten-free diet and what the complications are when a gluten-free diet and lifestyle are not strictly adhered to.
- Know what the role of the community pharmacist is within the service.
- Understand the actions needed by community pharmacy to ensure the delivery of the service.
- Understand what is required of the community pharmacy in the Adult Coeliac Disease Pharmacy Annual Health Check on Pharmacy Care Record (PCR).

Introduction to National Gluten-Free Food Service

This support pack has been designed to assist community pharmacists gain a general understanding of conditions requiring a gluten-free diet and provide them with the necessary information they need to deliver the Scottish Gluten-Free Food service (GFFS). Pharmacists are also encouraged to undertake other national training on this topic available from NES.

The legal framework and service specification for the GFFS are detailed in Circular PCA(P)(2013) 29¹ available at [http://www.sehd.scot.nhs.uk/pca/PCA2013\(P\)29.pdf](http://www.sehd.scot.nhs.uk/pca/PCA2013(P)29.pdf)

What Is Coeliac Disease (CD)?

Coeliac Disease is an autoimmune disorder that involves a heightened immunological response to ingested gluten in genetically susceptible people. Gluten is a protein found in wheat, barley and rye and therefore treatment is the avoidance of foods containing gluten. Population based studies show that Coeliac Disease has a prevalence of 1 in 100 of the population.²

Coeliac Disease is often unrecognised and is consequently under-diagnosed. Only about 27% of people in Scotland with the condition are clinically diagnosed, and diagnosis can take many years.³ A significant number of people with undiagnosed Coeliac Disease undergo extensive medical investigation without a definite diagnosis, and the symptoms of Coeliac Disease will remain untreated. A delayed diagnosis or undiagnosed Coeliac Disease or failure to adhere to treatment, can result in growth failure, delayed puberty, nutritional deficiencies (iron, folate, vitamin B12 and vitamin D) and dental problems in children. It can also lead to long-term complications such as osteoporosis, unfavourable pregnancy outcomes and a small increased risk of intestinal cancer.^{4,5,6}

Coeliac Disease can be treated by following a strict gluten-free diet and lifestyle and it is important to identify people with the condition so that they can obtain individual treatment. To improve the recognition and increase the number of people diagnosed with Coeliac Disease, the National Institute for Health and Care Excellence (NICE) developed a clinical guideline on Coeliac Disease (CG86).⁶ This guideline was updated and replaced in 2015 by NICE Guideline (NG20) which covers the recognition, assessment and management of Coeliac Disease in children, young people and adults.² (<https://www.nice.org.uk/guidance/ng20>)

The most common signs and symptoms of Coeliac Disease include: chronic or intermittent diarrhoea, sudden or unexpected weight loss, unexplained iron-deficiency anaemia, prolonged

fatigue (‘tired all the time’), recurrent abdominal pain, cramping or distension, constipation, bloating and persistent or unexplained gastrointestinal symptoms including nausea and vomiting. Children may also present with features such as faltering growth, static weight or progressive weight loss. Some people present with typical symptoms, others will initially experience few or no symptoms.² A community pharmacist may wish to refer patients presenting with these symptoms to an appropriate healthcare professional for investigative tests for Coeliac Disease.

The Coeliac UK site is a source of good information about symptoms. The link is <https://www.coeliac.org.uk/coeliac-disease/about-coeliac-disease-and-dermatitis-herpetiformis/symptoms/>

The diagnosis of Coeliac Disease will include serological tests and an upper gastrointestinal endoscopy with intestinal biopsy. Dietary considerations are required before serological testing and clinicians are required to inform people (and their parents or carers as appropriate) that testing is accurate only if they follow a gluten-containing diet. A gluten-containing diet requires them to eat gluten in more than one meal every day for at least 6 weeks prior to testing. It is important that they do not start a gluten-free diet until diagnosis is confirmed by intestinal biopsy (even if the serological test is positive).

The NICE NG20 guideline² states that serological testing should be offered to people with any of the following:

- Persistent unexplained abdominal or gastrointestinal symptoms
- Faltering growth
- Prolonged fatigue
- Unexpected weight loss
- Severe or persistent mouth ulcers
- Unexplained iron, vitamin B12 or folate deficiency
- Type 1 diabetes, at diagnosis
- Autoimmune thyroid disease, at diagnosis
- Irritable bowel syndrome in adults
- First-degree relatives (parents, siblings or children) with Coeliac Disease.

In addition, NICE recommends that serological testing for Coeliac Disease should be considered in people with any of the following:

metabolic bone disorder (reduced bone mineral density or osteomalacia)

unexplained neurological symptoms (particularly peripheral neuropathy or ataxia)

unexplained subfertility or recurrent miscarriage

persistently raised liver enzymes with unknown cause

dental enamel defects

Down's syndrome

Turner syndrome.

For information, when healthcare professionals request serological tests to investigate suspected Coeliac Disease in young people and adults, NICE recommends testing for total immunoglobulin A and IgA tissue transglutaminase (IgA tTG) as the first choice, and the use of use IgA endomysial antibodies (EMA) if IgA tTG is weakly positive. Please note, however, that different Health Boards may have slightly different strategies of testing.

People with positive results (or negative results but with ongoing clinical suspicion) require referral to a gastrointestinal specialist for intestinal biopsy to confirm or exclude Coeliac Disease. The NICE standard is that endoscopic intestinal biopsy is carried out within 6 weeks of referral.

Guidance for diagnosis and management of Coeliac Disease in children has been published by the British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN) (<http://bspghan.org.uk/documents/Static/Coeliac%20Guidelines%202013.pdf>).⁴ This guidance aims to simplify and shorten the diagnostic process for many children. The main difference from the NICE guideline is that some children may not need to undergo intestinal biopsy. Patients will be under the guidance of the local paediatric team who deal with the condition and who would decide on how to confirm the diagnosis in each patient.

The British Society of Gastroenterology (BSG) published recommendations in 2014 regarding the diagnosis and management of adult coeliac disease.⁵ (<http://gut.bmj.com/content/early/2014/06/10/gutjnl-2013-306578>)

Treatment

The Coeliac Disease guidelines of BSPGHAN and the BSG both state that patients require to start a gluten-free diet AFTER confirmed diagnosis and that the diet is lifelong and will require dietetic support.^{4,5} BSPGHAN guidelines indicate that children will require paediatric dietetic support within 1-2 weeks of diagnosis and then regular follow up at 3-6 month intervals in the first year and annually thereafter.⁴

A gluten-free diet requires specific education, which should be provided by a dietitian who has a specialist knowledge of Coeliac Disease. This should involve a simple explanation of the principles of a gluten-free diet and provision of written information on which foods contain gluten, how to obtain gluten-free products (prescribable and non-prescribable products), how to follow a gluten-free lifestyle and how to access and use relevant sources of support information. Emphasis should be given to encouraging adherence with a gluten-free diet and the use of alternative products. Following this, patients should ideally have access to a dietitian, independently where possible or via their primary or secondary care physician. Boards vary in how to access dietetics. Within the national GFFS, the community pharmacist in some areas will also be able to provide access to a dietitian when necessary.

Adherence to a gluten-free diet requires a proactive approach by all professionals involved. Support and information is available for both patients and healthcare professionals by Coeliac UK (please see resource section). A wide range of information leaflets for professionals and patients, as well as a very useful sheet detailing gluten-free foods is available from <https://www.coeliac.org.uk/home/>. Members of the Charity receive an annually produced Food & Drink Directory which is also included in their app Gluten Free on the Move.

The sensitivity to ingested gluten varies greatly between patients. For some, small amounts of gluten ingestion on a regular basis can cause mucosal changes even when the patient feels asymptomatic.

From 2012, only foods that contain 20 parts per million (ppm) or less can be labelled as gluten-free. This applies to both substitute gluten-free products and naturally gluten-free food items. Specialist substitute foods (e.g. breads and pasta containing Codex wheat starch) containing between 21 and 100 ppm gluten may be labelled as 'very low gluten' (The Codex Alimentarius Commission develops harmonised international food standards to protect the health of consumers). These guidelines are more stringent than previous UK definitions of gluten-free as <200 ppm and are covered by law.

A very small proportion of Coeliac patients will be sensitive to oats. Due to the production process, oats can be contaminated by gluten from other milled products such as wheat, barley and rye. Therefore, it is essential that patients use only uncontaminated oats and these are labelled as

gluten-free. However, a very small proportion of Coeliac patients will be sensitive to even uncontaminated oats.

Monitoring

NICE NG 20 indicates that an annual review should be offered to people with Coeliac Disease so that adherence to a gluten-free diet and symptoms can be reviewed, information and advice about the condition and diet can be refreshed, and any further support needs can be identified. Annual reviews for children with Coeliac Disease also allow any impact on development to be assessed.²

Annual reviews provide the opportunity to measure patients weight (and height if BMI is required), review for symptoms of poorly controlled Coeliac Disease, consider the need for assessment of diet and adherence to the gluten free diet and if any concerns referral on to the dietitian or GP for further advice.

The BSPGHAN (2013) guideline states that the majority of paediatric patients/parents are well motivated but ongoing monitoring, by an experienced paediatric dietitian and paediatric gastroenterologist or paediatrician with a special interest, is still necessary to ensure long-term adherence.⁴ In Scotland, paediatric patients are reviewed by the appropriate health care professional within the paediatric team. Paediatric patients therefore do not require annual review by community pharmacy as part of the GFFS.

Within the new Coeliac Disease Patient Pathway for Scotland, the NHS is working towards adult patients over 16 years old being reviewed by GI services until clinically stable (12 months post diagnosis) and thereafter patients on the GFFS will be assessed annually by community pharmacists using the health check. Any issues identified within the health check should be highlighted in the PCR and the patient referred to the appropriate health care professional for ongoing review.

Conditions associated with Coeliac Disease include Dermatitis Herpetiformis.

What is Dermatitis Herpetiformis (DH)?

The BSG (2014) guidance describes Dermatitis Herpetiformis as a cutaneous manifestation of Coeliac Disease. It manifests as an intensely itchy, blistering rash on the trunk and extensor surfaces of the limbs. The rash can precede any evidence of enteropathy and only 20% have gastrointestinal symptoms. Diagnosis is confirmed by skin biopsy of an adjacent non-blistered area. Nearly 100% of patients have an abnormal duodenal biopsy. A gluten-free diet is advised but

improvement will often take 6-12 months to be seen. Some patients with this condition may also require additional medication to control their symptoms.

Due to rash and itch, dapsons is often initiated. More than 70% of patients on a strict gluten-free diet are however able to slowly wean off dapsons over a period of 24 months.

If a patient is taking dapsons for treatment of Dermatitis Herpetiformis they need to be monitored for blood dyscrasias. Thus, the pharmacist should ask to ensure that the patient is aware of the symptoms that they need to recognise. Symptoms are fever, sore throat, rash, mouth ulcers, purpura, bruising or bleeding. If a patient experiences any of these symptoms they should be advised to seek prompt medical review.

How many gluten-free units should be prescribed for a patient?

National recommendations exist for the number of gluten-free units a patient should receive through the NHS service. These recommendations vary by age and gender. The number of gluten-free units' patients are given should meet their individual dietary needs.

Below are the national recommendations of gluten-free units per month based on age and sex:

Age and Sex	Units per Month
1-3 years	10
4-6 years	11
7-10 years	13
11-14 years	15
15-18 years	18
Male 19-59 years	18
Male 60-74 years	16
Male 75+ years	14
Female 19-74 years	14
Female 75+ years	12
Breastfeeding	+4
3 rd trimester of pregnancy	+1

If a patient feels they need more than these recommendations, the pharmacist should issue as per the above and then refer the patient to their GP or dietitian as per local Health Board policy for reassessment of their unit requirement.

How much is a gluten-free unit worth?

Each prescribable gluten-free food item has been valued on the following basis:

Food Item	Units
400g bread/rolls/baguette	1
500g flour/bread mix	2
200g biscuits/crackers/crispbreads	1
250g pasta	1
2 pizza bases	1
300g breakfast cereal/500g gluten free pure oats	1½

Is there an electronic web application?

There is the national GFF On-line service which is being rolled out to all Health Boards. It has been developed to make ordering easier for patients and is available at www.scotlandglutenfree.org.uk. The On-line service will assist patients with identifying the foods they want to order and calculate the units for them and works from the local Health Board food list. It can be used on a PC, smart phone or tablet.

Examples of common foods that are gluten-free, not gluten-free and products you may need to check for gluten

Gluten-free foods

- Fresh meat and poultry
- Cured pure meats, plain cooked meats and smoked meats
- Fish
- Cheese and eggs
- Milk, all cream and plain yoghurt
- Butter, margarine and cooking oils
- Fruit and vegetables
- Rice and potatoes
- Plain nuts, seeds and all pulses (peas, beans, lentils)
- Almonds and corn/maize flour
- Jam, conserves, syrup, honey and marmalade
- All vinegars (including barley malt vinegar), ground pepper, herbs and spices
- Cocoa, coffee, tea and fresh fruit juice
- Ciders, liqueurs, port, sherry, spirits and wine.

Not gluten-free foods

- Products made from wheat, barley or rye
- Bread and rolls
- Cakes, biscuits, crackers and muffins
- Flours made from wheat, rye or barley e.g. plain flour, self-raising flour
- Porridge oats and oat based snacks not labelled gluten-free
- Wheat pasta and noodles
- Pizza bases
- Ice cream cones/wafers and puddings made using semolina or wheat flour

- Meat, poultry or fish cooked in breadcrumbs, breaded ham and haggis
- Muesli and wheat-based breakfast cereals
- Couscous and semolina
- Batter mixes, breadcrumbs and stuffing mix
- Barley soft drinks
- Ales, beers, lagers and stouts.

Foods you may need to check for gluten

- Burgers, sausages and pates
- Breakfast cereals
- Rice noodles
- Flavoured yoghurts
- Oven, deep fried, microwave and frozen chips, instant mash and roasted potatoes
- Tomato sauce, stock cubes, dressings, mayonnaise, gravy granules and salad cream
- Chocolates, ice cream, mousses, sweets and crisps
- Macaroons, meringues and drinking chocolate
- Oats – these are often contaminated with gluten so only special, uncontaminated oats are recommended. Check with the patient that the dietitian has said they can eat pure uncontaminated oats.
- Some flours made from naturally gluten-free grains may be milled with wheat, barley or rye so can be contaminated. Flours labelled 'gluten-free' will be guaranteed to be free from contamination.

Information taken from the Coeliac UK Website – www.coeliac.org.uk

How the Gluten-Free Food Service works

Patient Identification

Patients are currently eligible to register for the service if they are registered with a Scottish GP practice. Patients will be identified and informed of GFFS by their General Practitioner (GP) or dietitian. They will inform the patient how many units they can order using the nationally agreed allocation or information from a dietitian. They will also provide the patient with the Patient Registration Form to take to a community pharmacy.

Registration

The patient will bring their partially completed Patient Registration Form (see Appendix 1) from the GP or dietitian to the pharmacy of their choice. At this point they will need further explanation of the service, which the pharmacist will be required to give. A PCR should be initiated at this point if there is not already one available for the patient. Ensure the patient's CHI number is entered accurately (refer to PCR user guide). The Gluten-Free section on the Patient Profile on PCR also requires to be completed, detailing the diagnosis and the number of units that the patient is to receive.

A patient does not need to be registered for the Chronic Medication Service (CMS) to receive the GFFS but must have a confirmed diagnosis of either Coeliac Disease or Dermatitis Herpetiformis. Qualifying patients who do NOT wish to opt into the service and ineligible patients will continue to access prescriptions from their GP. Pharmacists should always check with any newly registered patient that they are not already registered with another community pharmacy for the GFFS.

For community pharmacists, best practice may be to complete the first annual health check at the point of registration.

Patients are encouraged to retain registration at the same pharmacy for the duration of the service. This provides continuity of care and completeness of PCR annual health checks. If the patient chooses to move their registration to a different pharmacy, the new pharmacy must repeat the process above as per new patient requirements. A new registration form will also be required for the new pharmacy.

The patient registration form should be retained in the pharmacy for 7 years.

Ordering

Products will be chosen from the local Health Board Formulary of Prescribable Gluten-Free Foods. This is available from their community pharmacist, via NHS Inform website or on the GFF On-line service. The patient can write down their choices up to their maximum allocated units on a Gluten-Free Food Requirement Order Form (Appendix 2). They may need some assistance from the pharmacist with their first order. Alternatively, if available, they could choose to use the GFF On-line service which will assist them to create their order electronically. Emailed orders should only be accepted if this has been agreed between patient and pharmacy.

If the patient wishes to get a copy of their order form, pharmacy staff can photocopy it for them or the patient can be encouraged to keep a duplicate copy on a spare form.

The prescription should then be processed and the patient informed when their order is ready for collection. When patients have ordered fresh products, it is essential that they are contacted by telephone as soon as possible and advised their order is ready.

When the patient's order is complete, the Gluten-Free Food Requirement Order Form should be retained in the pharmacy for 12 months.

Please ensure that the patient has spare order forms for future ordering. These forms can be sourced from your local Health Board or the patient can download themselves from the NHS Inform Website www.nhsinform.co.uk/coeliacdisease

Currently to receive payment, the pharmacist should complete a Community Pharmacy Urgent Supply (CPUS) form detailing the CHI number of the patient concerned and the items supplied. This should be included with other prescription forms in the pharmacy form submissions to Practitioner Services. Once the pharmacy PMR system has support for the Universal Claim Framework, claims should be made electronically with no requirement to print or submit a paper form. The patient's CHI number will be required to submit the claim for payment.

Changes in Unit Requirement

If the patient moves into the next age bracket, or is pregnant or breastfeeding, the pharmacist should amend the unit allocation using the list provided on page 11. Any other changes in unit requirements, e.g. for someone undertaking a high level of physical activity, should be discussed with the GP or dietitian to ensure that the unit allocation is correct for the individual's needs.

Pharmacy Annual Health Check on PCR

As part of the GFFS, pharmacists are required to undertake and record an annual health check with Coeliac Disease patients over 16 years old. Adult Coeliac Disease patients should be discharged (if stable) from the GI service/dietitian at 12 months after diagnosis. The Community Pharmacy health check would then be undertaken 12 months after this date (around 24 months, post diagnosis) and then annually thereafter using the PCR. The format of the annual health check is guided by a series of prompt questions in the support tool in the PCR. More details about the PCR are found in Appendix 3.

Activity Point 1

1. Download and make copies of your local Health Board Formulary of Prescribable Gluten-Free Foods for reference purposes for the patient. This information will need to be checked for accuracy on a monthly basis as the list will constantly be updated with new products added or items removed.
2. Go to NHS Inform and download the Gluten-Free Food Service Patient Information Pack for reference purposes. <https://www.nhsinform.scot/publications/gluten-free-food-service-patient-information-pack>

National Gluten-Free Food Service Flowchart

Registration

Patient brings in Patient Registration Form initiated by their GP/Dietitian (Appendix 1). This service is available to adult and paediatric patients.

- Service explained to patient.
- Patient Registration Form completed and signed by pharmacist and patient/carer.
- Refer patient/carer to local Health Board Formulary of Prescribable Gluten-Free Foods.
- Create a PCR for this patient. Best practice recommendation is that the Pharmacy Annual Health Check is carried out at this point if appropriate for this patient.

Ordering

- Patient/carer brings in Gluten-Free Food Requirement Order Form (Appendix 2) or emails an electronic order via GFFS On-line. Provide a copy if requested by patient. Check units do not exceed patient's allocation and uses up to date food list.
- Contact patient/carer to collect goods - phone patient on the day that the 'fresh bread' is received.
- Supply patient/carer with new Gluten-Free Food Requirement Order Form if required.
- To receive re-imburement for the supplied items, a claim should be made to Practitioner Services detailing the CHI number of the patient concerned and the items supplied endorsing as required. Currently the claim is made using the CPUS form. Once the pharmacy PMR system has support for the Universal Claim Framework claims should be made electronically.

Pharmacy Annual Coeliac Disease Health Check

- Arrange appointment with the adult Coeliac Disease patient to complete a Pharmacy Annual Coeliac Disease Health Check on PCR every 12 months (Appendix 3). The health check should be carried out by completing the support tool. Complete the responses and identify any pharmaceutical care issues that require to be actioned.
- N.B. To be completed only if patient is over 16 years and has Coeliac Disease. Paediatric assessments are not carried out by community pharmacists.
- Complete appropriate SBAR for the GP once a health check has been completed or if it has been declined (Appendix 4).

Changes to Registration

A new Patient Registration Form (Appendix 1) should be completed by the GP or dietitian if:

- A patient moves house and requires to change their community pharmacy
- A patient chooses to move pharmacy.

Activity Point 2

Go to the web application site – www.scotlandglutenfree.org.uk and create an appropriate monthly gluten-free order using these forms as if you were the patient suffering from Coeliac Disease. Create a monthly order for yourself on the paper copy of the Gluten-Free Food Requirement Order Form (Appendix 2)

Pharmacy Annual Health Check (on PCR)

The annual health check is an opportunity for patients to be signposted or referred to relevant health professionals where there is a clinical need. This process also ensures that the evidence-based Coeliac Disease guidelines are being met, which recommend that Coeliac Disease patients have an annual review. The health check is only for adults with Coeliac Disease and should be conducted in private (See Appendix 3).

It should be explained that the annual health check is part of the GFFS. Some patients may not wish to have an annual health check or take part in some parts of the assessment. If this is the case, please record this on the PCR and inform their GP using the standard SBAR tool (Appendix 4). A patient may be under the review of GI services or dietitian and therefore a health check is not required. If this is the case, please record this within the PCR.

The text boxes on the annual health check provide prompts for discussion with patients dependent on how they answer the questions. It also provides guidance for the pharmacist conducting the assessment. Some further guidance on how to use the annual health check can be found in the PCR User Guide.

http://www.communitypharmacy.scot.nhs.uk/core_services/pcr/user_guide.html

Initial Assessment

The pharmacist is required to create a PCR for a new patient, or edit the patient profile screen for an existing PCR when the patient registers for GFFS. The patient profile screen contains some basic information which is used in the reporting function in the Home page and will help the pharmacist to plan when health checks may be due.

Pharmacists are required to add a diagnosis and number of expected units onto the patient profile page.

Annual Health Check

This is accessed via the Support Tools tab. The check covers key areas such as concordance, interactions and precautions, adverse effects and monitoring.

Each section has a list of agreed outcomes and should be completed depending on any care issues raised during the annual health check. The outcome is a drop-down list and the pharmacist should select the most appropriate option.

Concordance: Given that following a gluten-free diet is complex and difficult, some people may not be following a strict gluten-free diet. This can be for various reasons – such as willing to take the risk, not enough information and/or lack of support. The risks associated with non-compliance include osteoporosis, anaemia and gut lymphoma. Some patients are quite happy to take this risk and therefore have no desire to discuss their diet further. Others, however, may not be fully aware of the long-term risks of continuing to include gluten in their diets and have become used to low grade symptoms, for example, lethargy. The role of the community pharmacist is to help these patients to adhere to their gluten-free diet and seek appropriate support. Further detail is available in NICE Guideline (NG20)(<https://www.nice.org.uk/guidance/ng20>),² and also from the BSG guidelines at http://www.bsg.org.uk/images/stories/docs/clinical/guidelines/sbn/bsg_coeliac_14.pdf.⁵

Interactions and Precautions: Health risks associated with non-compliance with a gluten-free diet include osteoporosis, chronic malabsorption, and gut lymphoma. However, not all patients will require supplementation with vitamins or minerals, and the pharmacist should be mindful of this when discussing this with the patient to avoid raising expectation that there is a requirement when there is no clinical need to prescribe this sort of medication.

Coeliac Disease patients have an increased requirement for calcium due to malabsorption and, as a consequence, are at greater risk of osteoporosis. This is also the reason for enquiring about a bone density scan. SBAR tools are provided for GP referral if patients need to see another healthcare professional (Appendix 4).

Adverse effects: Patients who do not adhere strictly to their diet may experience symptoms such as decreased appetite, weight loss, pain, diarrhoea, anaemia, mouth ulcers, abdominal bloating, lethargy, nausea. Blood in stools is not a common symptom of non-adherence to a gluten-free diet and should be investigated further.

Monitoring: Patients should be monitored periodically to ensure that they maintain a healthy weight. Some patients may have a blood test at intervals by their GP or healthcare professional to ensure that the patient is not showing signs of malabsorption, or dietary deficiencies (e.g. iron, calcium, folate and B12) or complications (e.g. thyroid disease, diabetes). The pharmacist needs to ascertain if the patient is having blood checks without raising any anxiety or unnecessary expectations as regular blood tests will be at the clinical decision of the patient's GP or other member of the primary care team.

If the pharmacist weighs and checks the height of each patient using calibrated equipment, this information can then be used to calculate Body Mass Index (BMI) (Appendix 5). Where this is not possible the patient may be able to provide these details. Body Mass Index (BMI) is measured as patients can be under or overweight and require appropriate intervention. Unexplained or unintentional weight loss, no matter what their present BMI is (patient could be overweight) should be discussed and the patient referred to their GP using the appropriate SBAR tool (Appendix 4).

N.B. For newly diagnosed patients, symptoms can take up to two years to fully resolve. On-going significant symptoms may need to be flagged up to the GP.

The outcome of the annual health check should be shared with the patient's GP or other healthcare professionals involved in the patient's care. SBAR's are available for this purpose. (See Appendix 4).

Frequently Asked Questions

What are the benefits to patients of the Gluten-Free Food service?

Patients can have more variation in their diet as the service will enable them to make changes to their order, on a monthly basis, if they wish.

Patients can ensure they are receiving the appropriate number of units.

Patients will have regular contact with their community pharmacist who will be a point of contact to other health professionals who they may wish to talk to about aspects of their disease management from time to time.

Can a patient go to any community pharmacy for gluten-free foods?

Yes. A patient can choose which community pharmacy in Scotland they wish to use for their gluten-free foods. Once they register however they must always visit this specific pharmacy for their orders and annual health check, if appropriate.

How does a patient register with the service?

Patients take their Patient Registration Form, partially completed by their GP or dietitian, to the pharmacy from which they wish to receive their gluten-free foods, and the pharmacist will set up the service for them.

What does the patient and pharmacist need to do?

The pharmacist will explain to the patient how the service will work and answer any questions they may have. The pharmacist will also complete their part of the Patient Registration Form and get the patient to sign the form.

The pharmacist will provide Gluten-Free Food Requirement Order Forms. The pharmacist will inform them about the GFF On-line Service (if available) and agree or not to accept e-mail orders from the patient. The patient should look through the local Health Board Food List provided by the pharmacist and choose the products they would like to order. These might be the same products they previously had on repeat prescription, or something different.

Patients need to ensure they do not go over the total number of units they are allowed for the month.

Patients fill in the food order form with their details and the gluten-free product(s) they have chosen and then give the completed food order form to the pharmacist or use the GFF On-line service to print off or e-mail. If they are ordering fresh products, patients need to allow sufficient time for their order to be processed and be prepared to collect on day of delivery.

If patients would like a copy of the order for their records, they can either copy it onto a spare form or ask the pharmacist if they will photocopy it.

The pharmacist will arrange with patients when their order can be collected. Patients can ask their pharmacist for more order forms, or visit the NHS Inform Website www.nhsinform.co.uk

Patients need to complete a new food order form each month – they can change the foods they order if they want to.

Can patients order whatever they want?

No. Some foods such as gluten-free biscuits and cake mixes are luxury items containing little nutritional value and should not be staple foods in their diet. For this reason, patients must adhere to the local Health Board Formulary of Prescribable Gluten-Free Foods and Health Board guidance. Always ensure the patient is using the most up to date formulary. Boards should update their formularies once a year.

Can units be carried over to the next month?

No.

Can more than one order form be submitted in a month?

Generally, patients will be encouraged to submit only one form per month. However, some may experience storage problems or may forget to order an essential item. In these circumstances a second order form can be accepted, as long as the total number of units does not exceed their monthly allocation.

Can patients e-mail their forms?

If the pharmacy is able to accommodate this as part of the service, please advise the patient. The GFF On-line service offers the function of creating the order in PDF format and can be e-mailed but only if this has been agreed by the pharmacy.

Where can the patient get additional copies of order forms and more information?

The pharmacist should signpost the patient to the NHS Inform website for more patient information – www.nhsinform.co.uk/coeliacdisease

Pharmacists will be able to obtain extra copies of the order forms from their local Health Board. Patients can ask their pharmacist for more order forms, or visit the NHS Inform Website - www.nhsinform.co.uk/coeliacdisease.

What else is the pharmacist required to do?

Each year the pharmacist must carry out a Pharmacy Annual Health Check with each ADULT Coeliac Disease patient using this service and record outcomes on the PCR. This will help to identify whether or not patients are managing their disease and if they would benefit from being referred to another healthcare professional. The outcome of the health check should be shared with the patient's GP or other healthcare professional involved in their care. SBAR tools are available to do this.

What if a patient asks about bloods being taken as part of their routine follow up?

It should be explained to patients that routine blood tests are not seen as a regular part of Coeliac Disease follow up and are only performed on the clinical decision of the patients GP or other member of the Primary Care team.

Can patients transfer to a different community pharmacy?

If the patient moves home and requires to register with a new pharmacy, then the GP or dietitian (depending on local arrangements in your Health Board area) must complete a second registration form for the new pharmacy providing the service. The first pharmacy should be notified of the change.

Ideally, for all other reasons, patients would be encouraged to remain with their chosen pharmacy for continuity of care but if they do wish to move, the same process as above will apply.

What if a patient doesn't need any gluten-free foods this month?

They do not need to place an order if they do not need anything. Patients simply put in an order form the next time they need gluten-free products.

If a patient is moving house, what do they need to do?

If the patient is moving house but is still able to go to the same pharmacy, they should simply inform the pharmacist of their change of address. If the patient is moving further away (please note that this service is only available within Scotland), the (new) GP or dietitian would then partially complete a new Patient Registration Form for the patient which they would take to their new pharmacy.

Is it necessary for patients to have a Pharmacy Annual Health Check?

All patients over 16 years with Coeliac Disease should have an annual health check with the pharmacist, if not under the care of the GI service/dietitian. This brief check will give them the opportunity to discuss any concerns and the pharmacist can signpost them to other health

professionals if appropriate. If a patient does not want to have their annual checks undertaken by the pharmacist, they should not register for the GFFS and should be under the care of their GP for their Coeliac Disease.

For how long can fresh bread rolls be frozen?

The products have all been tested for one month in the freezer. Ensure patients follow the manufacturer's instructions on how to store the product.

What should patients do if they have a problem with the quality of any of the products they have ordered?

Inform patients to bring the product back to the pharmacy and the staff will arrange for it to be returned. If patients ask, the pharmacist should contact the manufacturer on their behalf.

How do patients try different gluten-free products?

Inform patients that many manufacturers will send out samples of their products if they contact them. Ensure the patient checks these new products are listed on the local Health Board Formulary for Gluten-Free Prescribable Foods.

Crossed Grain the magazine published by Coeliac UK will often have details of new products <http://www.coeliac.org.uk>. Please note that the magazine is only available to members of Coeliac UK.

Details of Coeliac UK

Coeliac UK is a major source of support and information for people following a gluten-free diet, it is worthwhile encouraging patients to join or re-join. The address is:

Coeliac UK,
1 St. Colme Street,
Edinburgh, EH3 6AA.
Telephone: 0131 220 8342

Coeliac UK,
3rd Floor,
Apollo Centre,
Desborough Road,
High Wycombe,
Buckinghamshire, HP11 2QW
Helpline 0333 332 2033

www.coeliac.org.uk

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3. West J, Fleming KM, Tata LJ, Card TR & Crooks CJ. Incidence and Prevalence of Coeliac Disease and Dermatitis Herpetiformis in the UK Over Two Decades: Population-Based Study. *Am J Gastro*. 2014; 109: 757-768
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Gluten-Free Food Service Patient Registration Form



GPs/Dietitians please complete and sign this part of the form and allow patients to take it to the pharmacy of their choice.

Patient's full name			
Patient's CHI number			
Date of Birth		Male	Female
Address			
Postcode			
Patient's GP/Surgery and Practice Code			
Patient's contact telephone no. and/or e-mail address			
Condition	Coeliac Disease		Dermatitis Herpetiformis
Carer Details (if appropriate)			

The above patient should receive the following GFFS units per month (in figures)
 (in words). Please see Coeliac UK recommended allocated units (www.coeliac.org.uk).
 I have/have not (please delete) given prescriptions for one month's supply of products.
 I will no longer supply GFF for this patient from ____ / ____ / ____ (date).

Signature		Date	
Name		GMC No or Dietitian No	

.....
Pharmacists please complete and sign this part of the form.

Registration date	
Patient Care Record (PCR) completed	
Pharmacy Coeliac Annual Assessment required	
Name and address of Pharmacy	

Pharmacist's declaration I declare that the information I have given on this form is correct and complete.

Pharmacist's Signature		Date	
Contractor's Code		Pharmacy Stamp	

Gluten-Free Food Service Patient Registration Form



Patients please complete and sign this part of the form.

I agree to obtain my gluten-free foods from the above pharmacy as detailed. To enable the NHS to ensure accurate payment and for the purposes of prevention, detection and investigation of crime, I understand that my data will be shared with the Common Services Agency, NHS Business Services Authority, the Department for Work and Pensions, HM Revenue and Customs, the pharmacy contractors representative body in Scotland and Local Authorities.

Patient's Signature		Date	
---------------------	--	------	--

IMPORTANT NOTES FOR PATIENTS

The NHS may use the information on this form to:

- Assist in the provision and improvement of NHS Services; and
- Improve the health of the public.

Information which could identify you will not be used by NHS Services unless:

- You have consented.
- It is allowed or required by law.

NHS Scotland Counter Fraud Service may request access to the information on this form.

HELPFUL INFORMATION

NHS Inform is a national service providing a single source of quality assured health information and self care advice. Further information can be found at www.nhsinform.co.uk

Gluten-Free Food Requirement Order Form



Patient Name	Date of Birth
Address	Tel No.
	Date
	Units allowed for month

Please write below the items you wish to order

Manufacturer/Description	PIP Code	Unit Size	Quantity	Total Units
Glutafin Fibre Loaf Sliced	237 7356	400g	6	6
Total units				

Hand this form to your community pharmacy to place your order
 If you wish to keep a copy for your records please use a spare form or ask if your pharmacist can copy it for you.

Pharmacy Use: This form should be kept in the pharmacy for 12 months

Patient record in PCR

Please note the pharmacist should consult the PCR user guide for instructions on how to operate the PCR system for the GFFS.

http://www.communitypharmacy.scot.nhs.uk/core_services/pcr/user_guide.html

Patient Profile

Each patient on the GFFS will require a record on the PCR. A section has been added to the PCR patient profile that records the diagnosis and the number of units to be allocated, as confirmed by the form completed by the patient’s GP/dietitian. Patients should not be commenced on the GFFS until this form is received.

If the patient is pregnant or breastfeeding, the allocated units will be increased by the pharmacist for the duration of the pregnancy or breastfeeding according to national guidance. The patient will be returned to their normal allocation when this time is completed. As patients become older, their allocated units will also change and these should also be adjusted on the PCR by the pharmacist, as identified.

The patient profile should be completed to reflect the patient’s diagnosis and number of units that they require. This information is used within the PCR reporting mechanism in the Report functionality. The date added to this screen is also used with planning workload and highlighting when an annual health check will be due.

Gluten-free

Diagnosed coeliac (historical) Yes No Not Recorded

Gluten-free diet Diagnosed coeliac

Gluten-free annual health check not completed
in pharmacy

Number of units

Dietitian advised

Guideline units			
Child 1-3 years	10	Male 19-59 years	18
Child 4-6 years	11	Male 60-74 years	16
Child 7-10 years	13	Male 75+ years	14
Child 11-14 years	15		Female 19-74 years 14
Child 15-18 years	18		Female 75+ years 12
			Breastfeeding +4
			3rd trimester pregnancy +1

Patient accepted onto scheme and agreed to annual health checks

What date is the patient due to receive their gluten-free annual health check at the pharmacy?

All annual health checks are started using the Support Tool tab, and then selecting the appropriate assessment from the drop down menu. This is the case for the first and subsequent checks for an individual.

Support Tool Assessment

The structure of the health check questions and guidance has been updated (for details, please refer to the most recent PCR user guide. The guidance for the pharmacist has increased clinical input and there is an outcome box added to allow the pharmacist to record any actions that are either given or planned following the assessment.

PCR user guide: http://www.communitypharmacy.scot.nhs.uk/core_services/pcr/user_guide.html

Please note that the Pharmacy Annual Health Check is only offered to adult patients with Coeliac Disease and registered with the GFFS.

The health check contained on the PCR tool has a number of sections. These are aimed to be questions to help enable the pharmacist to undertake a conversation and identify any areas of concern with the patient about the management of their condition. Some suggested clinical outcomes are also listed to help signpost or refer the patient to the most appropriate healthcare professional depending on the outcome of the discussion. The pharmacist would tick the most appropriate box depending on the responses from the patient.

Pharmacy: 1234 - Pharmacy
 User: Testuser - Jane Smith
 Last login: Mon, Apr 24, 2017 13:16



Home Search Protocols Reports Change password Manage profile Yellow card Help Logout

FISHER, Henry (Mr)	Born 01-Jan-1988 (29y) Gender Male CHI No. 0101884052
Preferred name PH:1234 PCD:T GFD:DCH GFA:O	Patient Details Last Modified On 16-May-2016 By AppSupport
Address 82 Drury Street, ER5 8LP	Phone and email 0356384578

[Gluten-free foods annual health check](#) > [Concordance](#) > **Interactions and precautions** > [Adverse effects](#) > [Monitoring](#) > [Review](#)

Gluten-free foods annual health check

Interactions & precautions

Is the patient prescribed folic acid, iron or calcium and Vitamin D supplements? Yes No

If yes, is the patient aware of how to take these medicines properly, if indicated? Yes No N/A

Outcomes

Referral of patient to GP for a review of supplements

General advice given on taking supplements

Advice given to patient on how to take medicines properly

Health risks associated with non-compliance with a gluten-free diet include osteoporosis, chronic malabsorption, and gut lymphoma.

- Not all patients with Coeliac Disease will require supplements - Check patient's PMR to determine whether this section is applicable.
- Adults with **coeliac disease** should have at least 1000 milligrams (mg) of calcium in their diet each day. The recommended amount for the general population is 700mg.
- Iron and folic acid requirements are the same as the general population guidelines.

Actions:

- Provide advice on how to take the medicines (where appropriate) properly.
- Record any care issues in the patient's care plan and agree desired outcomes and actions.
- Seek prescribing advice on supplements from Health Board where necessary.

[return to Gluten-free Review Page](#)

Review

This section summarises the details recorded during the Pharmacy Annual Health Check. Any pharmaceutical care issues identified should be recorded and actioned. Appropriate advice should be offered or referral can be undertaken (according to local Health Board guidance). The health check should be set as ‘complete’ once the pharmacist has captured all the data they require.

Pharmacists should remember to complete the health check. This will prompt for a date for the next one to be added to the PCR.

In addition, there is a new functionality added to the Patient Profile to offer options if a patient does not have an annual health check completed in the pharmacy. This should allow pharmacy staff to reconcile health checks where the patient has been lost to follow up or no longer accessing the service.

Gluten-free foods annual health check summary

Concordance

Is the patient adhering to their gluten-free diet?	No	+ ...
Does the patient understand how to identify foods that may contain gluten?	Yes	+ ...
Does the patient have information that will support their concordance with a gluten-free diet?	Yes	+ ...

Outcomes

Patient requires support – signposted to information

Interactions and precautions

Is the patient prescribed folic acid, iron or calcium and Vitamin D supplements?	No	+ ...
If yes, is the patient aware of how to take these medicines properly, if indicated?	N/A	+ ...

Outcomes

Use + ... to add care issues for the specific question.

Adverse effects

Is the patient aware of the common symptoms that are caused by not following a gluten-free diet?	Yes	+ ...
Does the patient have any new/ongoing/recurring symptoms that may suggest that they are consuming foods that contain gluten?	Yes	+ ...
If yes, has the patient discussed these symptoms with their GP or dietician?	No	+ ...
Is the patient aware that adverse effects should be reported?	No	+ ...

Outcomes

Patient has symptoms and has been referred to GP
Patient informed that adverse reactions should be reported to their pharmacist / GP / Dietitian

Monitoring

Is the patient aware of how many gluten-free units they are able to order each month?	Yes	+ ...
Have the patient's folic acid/iron/calcium/Vitamin D supplements been reviewed in the last 12 months?	No	+ ...
Height or weight or both not available	Yes	
Height (m)	Unanswered	
Weight (kg)	Unanswered	
BMI	Unanswered	+ ...

Outcomes

Referral of patient to GP for a review of supplements

Care issues associated with this assessment

Care issue	Earliest review by	Last modified on
No records to display.		



SBAR Communication Tool – Sample for Referrals

SBAR

For the attention of :

Organisation/ GP practice :

Requested by:

Pharmacy Name:

Date Created:

ACTION REQUIRED BY:

Patient Details

Name

CHI:

Core Service Registration:

Situation

The above named patient recently attended for their annual Coeliac Disease Health Check in the pharmacy and presented with the following symptoms:

Appendix 4 Example SBAR Communication Tools

Background

The patient factors were recorded as

Weight

Date

Previous Weight

Date

Height

BMI

Assessment

The following issues were identified:

unintentional / unexplained weight loss

despite following a strict gluten-free diet they are experiencing the following symptoms (please circle symptom(s)):

Change in: appetite / nausea / vomiting / abnormally loose bowel movements

Blood in stools / abdominal pain / other, please state:

Recommendation

I have suggested that the patient contacts you for further investigation.

SPACE FOR REPLY:

Action: [YES] [NO] (If yes, please outline response. If no, please state the reason.)

Appendix 4 Example SBAR Communication Tools

SBAR Communication Tool – Sample for Referrals

SBAR



For the attention of :

Organisation/ GP practice :

Requested by:

Pharmacy Name:

Date Created:

ACTION REQUIRED BY:

Patient Details

Name

CHI:

Core Service Registration:

Situation

The above named patient recently attended for their annual Coeliac Health Check in the pharmacy

Appendix 4 Example SBAR Communication Tools

Background

Assessment

Attended for their annual Coeliac Disease Health Check on:
and no issues were identified from the assessment.

OR

Declined to attend for their annual Coeliac Disease Health Check

Recommendation

For noting

SPACE FOR REPLY:

Action: [YES] [NO] (If yes, please outline response. If no, please state the reason.)

Appendix 5 How to Calculate Body Mass Index (BMI)

The BMI will calculate automatically in the PCR support tool assessment by clicking the within the monitoring section.

$$\text{BMI (kg/m}^2\text{)} = \frac{\text{weight in kg}}{\text{Height in metres} \times \text{Height in metres}}$$

Example

Height = 1.58 m

Weight = 60 kg

$$\text{BMI (kg/m}^2\text{)} = \frac{60 \text{ kg}}{(1.58 \times 1.58)} = \frac{60}{2.50} = 24 \text{ kg/m}^2$$

Healthy Range 18.5 – 25 kg/m²
< 18.5 kg/m² is underweight
25 – 30 kg/m² is overweight
< 30 kg/m² is obese

BMI Healthy Weight On-line Calculator

<http://www.nhs.uk/Tools/Pages/Healthyweightcalculator.aspx>

Height/Weight Conversion Chart

<http://www.nhs.uk/Livewell/healthy-living/Pages/height-weight-chart.aspx>

Useful websites to assist with understanding BMI

<http://www.nhs.uk/livewell/loseweight/pages/bodymassindex.aspx#people>

http://www.bhf.org.uk/bmi/BMI_Calc.html