Review of the Gluten-free Food Additional Pharmaceutical Service

September 2015

The Scottish Government
Riaghaltas na h-Alba

CONTENTS

Executive Summary

Background

Coeliac disease is a lifelong autoimmune disease caused by intolerance to gluten, a protein in wheat, barley and rye. Prevalence of coeliac disease is up to 1 in 100 of the population[1] although only about 10–15% with the condition is clinically diagnosed[2]. Dermatitis herpetiformis (DH) is the skin manifestation of coeliac disease. Once diagnosed with coeliac disease, or DH, the treatment is adherence to a lifelong gluten-free diet. Potential long-term complications of coeliac disease include osteoporosis, ulcerative jejunitis, reproductive issues, vitamin D deficiency and iron deficiency.

Many food ingredients are naturally free from gluten such as rice, corn, potatoes, fruits, eggs, cheese, vegetables, meat and fish. The Western diet, however, usually has bread, pasta and wheat flour products as staple ingredients which contain gluten.

A range of gluten-free substitute products such as bread, flour and pasta are available which if Advisory Committee of Borderline Substances[3] (ACBS) approved can be prescribed on the NHS. Guidance recommends the minimum monthly prescription of gluten-free foods (GFF) on the basis, that approximately 15% of energy intake, is derived from these products[4]. The traditional model has been that gluten-free items are prescribed for patients in primary care by their GP then dispensed by community pharmacies.

Situation

On 28 November 2013, the Scottish Government published Circular PCA(P)(2013)29[5], announcing the introduction of the new Gluten-free Food Service (GFFS) to the Community Pharmacy Contract as an Additional Pharmaceutical Service on a trial basis for a period of 12 months from April 2014 which has subsequently been extended to 30th September 2015 to allow evaluation of the service.

The trial GFFS introduced a new model replacing the need for eligible and qualifying patients to request individual prescriptions for gluten-free food items from their GP. Instead, the model enabled patients to register their condition with a community pharmacy of their choice, provided that the contractor concerned had opted into providing the GFFS. The service aimed to build on a scheme already successfully initiated by NHS Tayside since 2010.

[1] NICE guidelines Coeliac disease: Recognition and assessment of coeliac disease[CG86] May 2009 [2] Ravikumara, M. Nootigattu, V.K.T & Sandhu B.K. (2007) Ninety percent of coeliac disease is being missed. J Pediatr. Gastroenterol. Nutr. 45, 497-499

[3] https://www.gov.uk/government/groups/Advisory-Committee-on-Borderline-Substances

[4] Gluten-free foods: a revised prescribing guide Coeliac UK 2013

[5] http://www.sehd.scot.nhs.uk/pca/PCA2013(P)29.pdf

Patients to be eligible for the new service must:

- have a clinically confirmed diagnosis of coeliac disease or dermatitis herpetiformis;
- live in Scotland and whose main or usual residence is not a care home; and
- be registered as an NHS patient with a GP practice

The objectives for the trial GFFS were set out to:

- Support the provision of direct NHS pharmaceutical care to patients with coeliac disease or DH by providing a pharmacy led nationally consistent service;
- Make optimum use of clinicians' skills and empower the patients to actively manage their own condition;
- Improve the patient experience of obtaining GFFs on prescription by reducing the number of visits needed to GP surgeries;
- Provide appropriate clinical monitoring for patients directly affected including dietetic intervention and annual pharmacy health check;
- Provide more systematic nationally consistent management of patient needs;
- Allow eligible and qualifying patients access to staple gluten-free food to access a convenient service customised to their needs which is also cost effective for NHS Scotland
- Assist through collaborative working the better management of the demand on the time of all members of the primary care team involved in providing this service to patients
- Remove the need for a GP to be involved in issuing multiple gluten-free prescriptions once he/she has determined the unit allocation and the patient has registered with a pharmacy
- Reduce the incidence of out of pocket expenses incurred as a consequence of community pharmacy dispensing of individual prescriptions for gluten-free foods written by GPs.

Service Outcomes

The trial service was reviewed in 2015 using a range of methods to collect stakeholder views (surveys, letters to stakeholders and meetings with stakeholders) and prescribing information. The main observed outcomes from the review were:

- There was strong support from all stakeholders for the GFFS, with all supporting its continuation and integration into NHS services.
- Stakeholders universally indicated that the provision of direct NHS pharmaceutical care to patients with coeliac disease or DH had been improved
- There was universal agreement that the patient experience of obtaining GFFs on prescription was improved with reduced number of visits needed to GP surgeries and that GP time was released.
- The majority opinion across the stakeholders was that the service allowed clinicians from different professions to utilise their skills better. Community pharmacists found that the service allowed improved interaction with patients and occasions to provide opportunistic healthcare advice.
- The general impression from respondents across the three surveyed populations was the impact, effect and value of the annual health check by community pharmacy for adult coeliac disease patients was as yet not evidenced. Further assessment of the health check to assess its value would be beneficial if GFFS continues.

- There was strong agreement from all stakeholders that the service empowered patients to actively manage their own condition. One example of this was the association found between the ease that patients can change their order and how often they do so. Both patients and community pharmacists noted that GFF orders had altered more frequently since the introduction of the GFFS.
- The service was considered to improve national consistency in the management of patient needs but that further improvements could be delivered. At present there is a Scotland wide national GFF list which contains all ACBS approved GFF. This list is used to develop local Health Board formularies which account for local population needs. There is however, nearly a tenfold variation in the number of formulary choices across Health Boards available for patients, the necessity of which requires review. The current situation has raised equity issues for patients and community pharmacies especially if they border the boundaries of two Health Boards affecting engagement with the service.
- There was a general agreement across all stakeholders that GFFS allowed eligible patients who could access a community pharmacy to access a convenient service customised to their needs. Concerns were raised why care home patients were excluded from the service and rural areas highlighted that some of their population were unable to access the service.
- The prescribing information indicates that although there has been a 31.6% increase in prescribing volume the cost increase has only been 4.6%. This reflects patients increasing the variation of their food order within their GFF unit allocation. The majority of prescribing is for bread then secondly pasta. Since the GFFS introduction, all GFF main categories had seen increased prescribing. The highest increase was in the GFF cereals and secondly crackers/crispbreads.
- There was agreement that the service supported better demand management on members of the healthcare team. There was recognition that work had shifted from GPs to community pharmacists. The main issue highlighted was the administration time required to complete the handwriting of the Community Pharmacy Urgent Supply (CPUS) forms. It was universally stated that electronic prescribing was required. The Pharmacy Care Record (PCR) was also highlighted as difficult to use and needed review plus presently not linked with the pharmacy Patient Medication Record (PMR).
- There was a unanimous response that this service had freed up GP time as they no longer were required to prescribe GFF. One proposal from GPs and dietitian stakeholders was for dietitians and not GPs to decide on unit allocation and commence patients on the GFFS with referral straight to the community pharmacist. This move to remove GPs from the GFF process has already been undertaken in collaboration with GPs in NHS Tayside.
- The incidence of out of pocket expenses (OOPE) incurred as a consequence of community pharmacy dispensing individual prescriptions for gluten-free foods reduced significantly when the four main manufacturers stopped charging in the year before the GFFS trial started. During the trial there has been little change in OOPE with one suggestion is that this was the result of local GFFS formularies in general excluding items with OOPE. This would be a general ongoing matter to ensure Health Board formularies obtain best value for the taxpayer balanced along with maximum choice for patients.

Recommendations
The results from the evaluation of the Gluten-free Food Service (GFFS) trial indicate the following recommendations

1. The GFFS should be continued and embedded into NHS Pharmaceutical services

2. Improved alignment of Health Board gluten-free food formulary choices, while still accounting for variations in local population need

3. Establish regular updates to the National Gluten-free Food NHS Prescribable List which include sufficient information to support Health Boards in local formulary development minimising resource duplication

4. Completion of the development and rollout of electronic prescribing forms for community pharmacy to undertake the service

5. Rollout of Pre-printed GFF Order Forms with standardised data set and Gluten-free Online Service for patients

6. Monitoring and further evaluation of the annual pharmacy coeliac health check to assess value to the patient

7. Annual re-registration for the service should be discontinued as coeliac disease is life long

8. Consider inclusion of patients resident in care homes within the GFFS

9. Further develop the pharmacy and dietetic processes and communication links to optimise use of professional skills including their prescribing roles

10. Consideration of other potential areas of prescribing where a similar service could improve patient access, improve skill utilisation, reduce GP workload and improve cost effectiveness.

REVIEW OF THE GLUTEN-FREE FOOD ADDITIONAL PHARMACEUTICAL SERVICE

1 Chapter 1: Introduction

A review of the trial Gluten-free Food Service (GFFS) being provided as an Additional Pharmaceutical Service was conducted on behalf of the Scottish Government by Margaret Ryan within NHS Scotland. This report sets out the findings and provides recommendations.

The review focussed on the service delivery model i.e. providing the service through NHS community pharmacies rather than the traditional model through general practice, and was undertaken to assess if the new model should continue after the trial period concludes at end September 2015.

1.1 Context

1.1.1 Coeliac disease is a lifelong autoimmune disease caused by intolerance to gluten, a protein found in wheat, barley and rye. Prevalence of coeliac disease is up to 1 in 100 of the population although only about 10–15% with the condition are clinically diagnosed. Many of the remainder may be well, but a significant minority will have chronic problems which result in chronic ill health[1]. Individuals may go undetected for many years despite multiple presentations to both primary and secondary care. This may reflect the fact that affected individuals have subtle or no gastrointestinal symptoms[6].

1.1.2 Dermatitis herpetiformis (DH) is the skin manifestation of coeliac disease and it affects around 1 in 3300 people[7]. In 2014, research from the University of Nottingham revealed a fourfold increase in the rate of diagnosed cases of coeliac disease in the UK over the past two decades[8]. In the UK, however, there is an estimated three-quarters of people with the disease who remain undiagnosed.

1.1.3 Once diagnosed with coeliac disease, or DH, the treatment is a lifelong gluten-free diet. 'Gluten' is used here as a generic term to encompass all the proteins derived from wheat, rye and barley. Following a gluten-free diet requires specific education, which should be provided by a dietitian with experience in coeliac disease[1]. It is important that coeliac patients are advised on alternative foods to include in their diet to maintain a healthy and varied intake and to increase the likelihood of adherence. Many ingredients are naturally gluten-free such as rice, potatoes, corn, fruits, eggs, cheese, vegetables, meat and fish. The modern Western diet, however, commonly includes bread, breakfast cereals and pasta made from wheat, barley and rye as staple ingredients and is therefore high in gluten. In order to replace these foods and to maintain variety and palatability, manufacturers produce a range

[6] British Society of Gastroenterology. The Management of Adults with Coeliac Disease 2010
[7] https://www.coeliac.org.uk/coeliac-disease/about-coeliac-disease-and-dermatitis-herpetiformis/
[8] *Am J Gastroenterol* 2014; 109:757–768; doi:10.1038/ajg.2014.55; published online 25 March 2014

of gluten-free substitute products such as bread, pasta, pizza and breakfast cereals[6].

1.1.4 Patients can help to minimise the potential for negative clinical outcomes by maintaining a gluten-free diet for life. Potential long-term complications of coeliac disease include osteoporosis, malnutrition, ulcerative jejunitis and vitamin D and iron deficiency. Some research has suggested that having undiagnosed or untreated coeliac disease may increase the risk of developing certain types of cancer including lymphoma[6].

1.1.5 Gluten-free products are generally more expensive than conventional ingredients and this potentially may adversely affect adherence to a gluten-free diet. Gluten-free staple foods are a category of product identified by the UK Advisory Committee of Borderline Substances (ACBS) as falling within the definition of Borderline Substances[3]. As such, they can be prescribed on the NHS for example by General Practitioners (GPs), using a standard GP10 prescription form. Guidance recommends the minimum monthly prescription of gluten-free foods, on the basis that approximately 15% of energy intake is derived from these products[4].

1.1.6 The traditional model has been that gluten-free items are prescribed for patients in primary care by their GP then dispensed by community pharmacies. Few GPs would have been able to fully implement the gluten-free food prescribing guide recommendations as in-depth knowledge around the products available on prescription would have been required. This results in some instances in patients being provided with either not enough[9] or too many gluten-free products.

1.1.7 During 2010, the NHS Tayside Nutrition Managed Clinical Network (TN MCN) tested a new local model of gluten-free food prescribing as part of coeliac disease service improvement programme which re-aligned the patient pathway with clinical guidelines[10]. The prescribing model developed was based on gluten-free food schemes in England. In the re-design, patients were involved alongside other stakeholders including general practice, dietetics, gastroenterology and community pharmacy. Patients ordered their gluten-free prescribable products direct with community pharmacy rather than going via the GP for a GP10 prescription. Annual coeliac disease health checks for adults in community pharmacy were developed in the Tayside model as many coeliac patients were identified as not being offered reviews as indicated by coeliac disease clinical guidelines[4]. The Tayside model was found to be cost effective, efficient and liked by patients, GPs and community pharmacy.

[9] Martin U. & Mercer S.W. (2014) A comparison of general practitioners prescribing of gluten-free foods for the treatment of coeliac disease with national prescribing guidelines

[10] Walker J, (2011), Coeliac Disease Improvement Project, Direct Gluten-free Food Scheme Pilot Interim Report. July 2011. (Unpublished)

1.2 **Background**

1.2.1 On 28 November 2013, the Scottish Government published Circular PCA(P)(2013)29[5], announcing the introduction of the new Gluten-free Food Additional Pharmaceutical Service (GFFS) to the Community Pharmacy Contract on a trial basis for a period of 12 months from April 2014.

1.2.2 The trial GFFS introduced a new model replacing the need for eligible and qualifying patients to request individual prescriptions for gluten-free items from their GP. Instead the model enables them to register their condition with a community pharmacy of their choice, provided that the contractor concerned had opted into providing the GFFS. The service aimed to build on the scheme already successfully initiated by NHS Tayside in 2010.

1.2.3 The objectives for GFFS were to:

- Support the provision of direct NHS pharmaceutical care to patients with coeliac disease or DH by providing a pharmacy led nationally consistent service;
- Make optimum use of clinicians' skills and empower the patients to actively manage their own condition;
- Improve the patient experience of obtaining GFFs on prescription by reducing the number of visits needed to GP surgeries;
- Provide appropriate clinical monitoring for patients directly affected including dietetic intervention and annual pharmacy health check;
- Provide more systematic nationally consistent management of patient needs;
- Allow eligible and qualifying patients access to staple gluten-free Food to access a convenient service customised to their needs which is also cost effective for NHS Scotland;
- Assist through collaborative working the better management of the demand on the time of all members of the primary care team involved in providing this service to patients;
- Remove the need for a GP to be involved in issuing multiple gluten-free prescriptions once he/she has determined the unit allocation and the patient has registered with a pharmacy;
- Reduce the incidence of out of pocket expenses incurred as a consequence of community pharmacy dispensing of individual prescriptions for gluten-free foods written by GPs.

1.2.4 To be eligible to use the new Scottish Gluten-free Food Service, patients must:

- have a clinically confirmed diagnosis of coeliac disease or DH;
- live in Scotland and whose main or usual residence is not a care home; and
- be registered as an NHS patient with a GP practice.

1.2.5 The quantity of GFF items a patient has been recommended is based on a personalised clinical assessment, and the supply of GFF items in accordance with those GFF items that are covered within the formulary published by their

local Health Board. The terms and conditions for the GFFS were provided in Circular PCA(P)(2013)29[5].

1.2.6 In December 2014, Circular PCA(P)(2014)30[11] advised that the trial service was extended until 30 September 2015. It also stated that a review of the service would be conducted to assess how successful the trial has been in terms of improving clinical benefit for appropriately diagnosed patients, cost effectively by comparison with the previous arrangements plus any other impact on participating parties.

1.3 **Implementation**

1.3.1 National food list and local GFF formularies

Prior to the introduction of the GFFS in April 2014, prescribing practice for GFF varied across Health Boards. Across Scotland, the existence of individual Health Board formularies for NHS prescribed GFF was not consistent. Where formularies did exist there were inconsistencies in the approach used to develop the formulary including no stated unit allocation and the same product having a different unit allocation. The British National Formulary (BNF) listed GFFs available for NHS prescribing do not necessarily have designated gluten-free units with the potential result of patients are prescribed either above or below the optimum units required for their needs.

In 2011, Coeliac UK produced "Gluten-free Foods: a prescribing guide" which defines a unit of prescribable GFF and the maximum number of units an individual can receive on prescription based on their sex and age per month. This was updated in 2012 after the Advisory Committee on Borderline Substances (ACBS) decision to include breakfast cereals and oats on prescription. The National Prescribing Guidelines[12] were endorsed by the Primary Care Society for Gastroenterology (PCSG) and the British Dietetic Association (BDA) and British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN)

This has been used to support the development of a Scotland wide gluten-free food (GFF) prescribable product list. A small working group of dietitians and a pharmacist collated a list of all ACBS approved gluten-free foods from all manufacturers for prescribing on a NHS prescription to minimise the variation in unit allocation for GFFs across Scotland. Where manufacturers asked to be excluded from the list, this has been done.

The gluten-free food prescribable product list lists practical information on units per item, PIP codes, minimum order numbers, costs, and days of delivery for fresh GFF foods, distributor and manufacturer details. The unit allocation used within this listing is based on the Coeliac UK guidelines. As

[11] http://www.sehd.scot.nhs.uk/pca/PCA2014(P)30.pdf
[12]https://www.coeliac.org.uk/gluten-free-diet-and-lifestyle/prescriptions/national-prescribing-guidelines/ https://www.coeliac.org.uk/document-library/378-gluten-free-foods-a-revised-prescribing-guide/?return=/gluten-free-diet-and-lifestyle/prescriptions/national-prescribing-guidelines/

the current Coeliac UK guidelines do not provide unit allocation for every pack size the unit allocation was expanded to cover all sizes of gluten-free products.

The gluten-free food prescribable product list is the starting point for Health Boards when developing a GFF prescribable product formulary and aids standardised practice across Scotland in unit allocation. The GFFS relies on each Health Board having an up-to-date and accurate GFF NHS prescribable product local formulary list which provides patients, prescribers and community pharmacy with the information they need for delivery of this service.

The final resource which was circulated by Scottish Government contained guidance on:

- the Coeliac UK prescribing guidelines which stipulate how many units of gluten-free foods and individual dependant on sex and age may receive on prescription
- the name and PIP code which is required by community pharmacy to order the product
- the number of units each product contains
- manufacturer information on minimum orders and delivery information for each product
- cost of each item and the range of carriage costs associated with each item between August 2012 – January 2013

This resource was shared with all NHS Scotland Health Boards to allow them to develop local formularies for gluten-free products prior to the commencement of the GFFS trial. The listing was subsequently updated in May 2015 with the addition of new products, new manufacturer information and deletion of discontinued products.

1.3.2 Gluten-free Food Service Implementation and Support Pack

The GFFS implementation and support pack was developed by National Education for Scotland (NES) with input from Scottish Government, ATOS, pharmacists, consultant paediatric gastroenterologist and dietitians. The training pack was developed to assist community pharmacists gain a general understanding of coeliac disease and DH and provide them with the necessary information to deliver the GFFS.

In addition to education material on coeliac disease and DH, the pack explained in detail the process for patients accessing prescribable gluten-free foods through community pharmacies. Copies of the nationally agreed GFFS patient registration form, gluten-free food requirement form and sample letters for community pharmacy communication with the GP after a patient's annual review were included in the pack.

1.3.3 Training of Community Pharmacists on the Gluten-free Food Service

To support the implementation of the GFFS, NES developed a webinar for community pharmacists. This training provided by dietitians and pharmacists delivered education on coeliac disease and DH, their treatment and how the new GFFS would be implemented as part of the management of these conditions. The webinar training has remained available for pharmacists on the NES website to refresh their knowledge and for new pharmacists preparing to provide the service.

NES organised other training events across the country where community pharmacists could attend in the evening which provided similar training and allowed attendees the opportunity to ask questions on the service provision.

1.3.4 Communication prior to commencement of the Gluten-free Food Service

In addition to the activities above, NES, using the same contributors as the community pharmacy pack, also developed an information pack for GPs on the new GFFS with the materials they required to implement the transfer of patients to the community pharmacy service.

A section on the GFFS was developed for the NHS Inform website http://www.nhsinform.co.uk and included all the necessary patient information needed for patients to transfer to the new service, seamlessly. NHS Inform also updated the coeliac disease and DH information on the patient information website. The development was undertaken with contributions from a group of dietitians, pharmacists and gastroenterologists.

The Scottish Government provided master copies of the patient registration form and gluten-free food order form to aid uniform implementation of the GFFS. Information was also provided by Scottish Government to Health Boards to aid development of local gluten-free food formularies to support the trial GFFS.

2 Chapter 2: Review Methodology

A wide range of techniques was used to gather information and views on the GFFS trial. This included:

2.1 Surveys

2.1.1 Three online survey questionnaires were prepared - for General Practitioners [Annex 1], community pharmacists [Annex 2] and patients [Annex 3]. The surveys were developed and then piloted in a group of people who represented the stakeholders that we were intending to participate in the surveys. This was to ensure validity of the questions asked and the ease to which stakeholders were likely to be able to respond. It was recognised that all questionnaires had to be short and concise to obtain engagement with stakeholders to respond.

In order to increase patient engagement with the process the patient questionnaire was also made available as a postal survey with community pharmacies providing the survey to patients when they came for their Gluten-free Food prescription. The GP and community pharmacy surveys were publicised through Health Boards and the patient survey through online sources, community pharmacy and Coeliac UK.

The response dates for the surveys were:

- GP Survey 3rd April 2015 to 30th April 2015
- Patients 1st March 2015 to 31st March 2015
- Community Pharmacists 1st March 2015 to 31st March 2015

2.2 Stakeholder Letters

2.2.1 A letter to Health Boards and stakeholder organisations [Annex 4] was sent inviting them to submit views in writing to specific questions on the GFFS trial. The letters focused on the stakeholder views on whether the aims of the trial service had been achieved, if the service should be made permanent and any improvements that should be considered if the service became permanent. Boards and stakeholder organisations were asked to return their responses by the 31st March 2015 providing them with 4 weeks to respond.

2.2.2 A letter to manufacturers of Gluten-free products along with the GFFS service aims was sent inviting any comments on the GFFS [Annex 5]. This was sent in May with a response deadline of 4 weeks to feedback their views on the trial service.

2.3 Face to face meetings with key stakeholder groups

2.3.1 A number of meetings were held with a number of individual stakeholders who were representative of a cross section of the key stakeholders. These included Coeliac UK, Scottish Dietetic Leadership Network, Community Pharmacy Scotland, National Services Scotland (NSS) and the Scottish General Practitioners Committee of BMA Scotland.

2.3.2 The intention was to gain a more in depth understanding of stakeholder views and any issues in respect to the GFFS trial that would not be captured within a questionnaire or letter with focussed questions. These discussions occurred during April to June and were found helpful in forming this report.

2.4 **Pharmacy and Prescribing Information Analysis**

2.4.1 An analysis of the NHS dispensed GFF in Scotland from 1st April 2013 to 31st March 2015 has been undertaken using information supplied by Information Services Division (ISD) of NSS plus information supplied through a specific analysis request for the evaluation. The analysis provides information on the number and cost of GFF dispensed information before and after the introduction of the GFFS. An analysis of the change in GFF dispensing through GP prescribing and through the new GFFS service including the change in patient choice of GFF food was also completed. In addition there was an analysis of the number of GFF included within local Health Board formularies.

2.4.2 Practitioner Services Division (PSD) of NSS made available information relating to the PCR held within Community Pharmacies. This information provides intelligence on the GFFS service conducted within Community Pharmacy including uptake of the service.

3 Chapter 3: Survey Analysis

Three individual questionnaire surveys [Annexes 1-3] for the GFFS trial evaluation were distributed to the three stakeholder groups of patients, community pharmacists and GPs. A good response was provided from all three stakeholder groups. The complete analysis of the three surveys is available in Annex 6.

Summary

- There were 1571 patient, 357 community pharmacy and 516 GP responses to the surveys with a geographical spread across all Health Boards in Scotland.
- There is strong support from patients, community pharmacists and GPs for the GFFS. The vast majority like the service and support its continuation.
- Both patients and community pharmacists noted that GFF orders had altered more frequently since the introduction of the GFFS. An association was found between the ease that patients can change their order and how often they do so.
- The general impression from respondents across the three surveyed populations was the impact, effect and value of the annual coeliac pharmacy health check by was as yet unknown. The survey indicated that only 44% of respondents were offered an annual coeliac disease health check post service introduction similar to the 47% prior to the service introduction. Only 23% of respondents had received an annual pharmacy check.
- Patients raised some general issues and provided a range of practical suggestions for changes to the service. The majority of comments were in relation to administration processes, food choices, and the variation between Health Board formularies, unit allocation and cost of GFF.
- Community pharmacist respondents raised the need for more training and IT enhancements to improve the service. Specifically electronic prescribing would make the prescription process more effective and the PCR should interface with the pharmacy PMR.
- Other general comments queried why GFF was available on the NHS from a cost and equity perspective.

3.1 Analysis and Results of Patient Survey

A total of 1571 survey responses were obtained from the patient questionnaire with 95% of respondents using the new GFFS and nearly all previously receiving GFF prescriptions from their GP. There were responses from across all Health Boards but not evenly distributed. Twice the number of women as men responded and 72% of responses were from people aged 50 or over.

3.1.1 Patient Survey Main Results

- There is strong support from patients for the Gluten-free Food Service (GFFS), with the vast majority liking the service and supporting its continuation.
- There is an association between the ease that patients can change their order and how often they do so. In the majority of cases this has increased since the introduction of the GFFS.
- Just under half of respondents had been offered a pharmacy coeliac disease health check which is similar to that offered by GPs prior to GFFS

implementation. Less than one third of respondents had received a pharmacy check since starting the GFFS. A point to note is that this aspect of the service is only for adults.

3.1.2 Analysis of patients comments

The majority of the respondents were positive about the GFFS with comments and suggested improvements corresponding to main themes of:

- Administration Processes
  Most respondents reported a good service which was generally easy to use, efficient and worthwhile plus they appreciated the service freed up GP time. Comments indicated patients felt they were in more control of their diet and the flexibility in ordering offered by pharmacies to try different GFF with reduced waste resulting. Main process negatives were a lack of online services, the need to write out an order each month and large bulky orders of GFF for pick up and storage. One other issue was the difficult process if wishing to change pharmacy.

- Health Board Formulary Choices
  The limited range of food available was found to be an issue but there was no clear consensus on any particular GFFs with varied personal preferences expressed. The variation between number and choice of GFF on Health Board formularies was questioned. Several respondents also noted a lack of cakes and biscuits on some formularies. There was also a call for better nutritional information.

- Food Costs, Unit Allocation and Affordability
  A number of respondents noted that receiving basic GFF food on prescription was important due to costs and the difficulties to stick to a diet if all food had to be purchased. Views were split on types of GFF that should be available.
  There were also mixed views on the number of units allocated per person with some people considering them adequate, others excessive while others insufficient. There were also calls from a few for a voucher or a card for GFF that could be used at supermarkets instead of GFFS. This had been assessed in NHS Tayside before the initial concept of a GFF Service was developed but was found to be unworkable especially in rural areas.
  There were several complaints about multiple pack sizes requiring orders of 8 loaves at a time and the resulting waste. Pack sizes are at the discretion of the manufacturers and many are now realising the burden these large packs have on patients and are moving to mixed packs.

3.2 **Analysis and Results of Community Pharmacist Survey**

The online survey comprised of 40 questions on the service covering: their experience; views on patients' experience; the impact of the service; views on the Adult Coeliac Disease Health Check and core factual information. There were 367 responses from 1250 community pharmacies sent the questionnaire.

3.2.1 Main Results

The main findings from the survey of community pharmacists were:

- The majority of community pharmacists reported a positive experience with GFFS and supported its continuation. It is an easier and more efficient system.
- Community pharmacists reported the service to patients had improved.
- Almost half of the community pharmacists had carried out health checks and whilst this was beneficial in patient engagement, it was found both time consuming and could involve raising sensitive issues.
- The PCR system appears not to operate as smoothly as it could.
- Only a minority found the service had improved relations with the wider healthcare team.
- Some respondents questioned whether the NHS should be giving food on prescription and whether it was a good use of time for a healthcare professional. Where this was accepted, there were some suggestions to issue vouchers that could be used at supermarkets instead.

3.3 **Analysis and Results of GP Survey**

The GP online questionnaire survey comprised of 19 closed questions sent to all GP practices across Scotland with 516 responses. Around one quarter of respondents gave additional comments in the free text box.

3.3.1 Main Results

The main findings from the survey of GPs were:

- The majority of GPs who responded supported the GFFS service and found it to have benefits including a positive impact on their workload.
- There was overwhelming support for the GFFS to continue.
- Although most GPs agree with the statements on the positive impact of the service for patients, a minority responded “Don’t Know”.
- Respondents generally were of the opinion that GFFS provided a better service and that patients had reported it supported self management.
- Monitoring of GFF units was more effective, equitable and fair.
- The majority of GPs did not know the impact, effect or value of the Adult Coeliac Disease Health Check. Further research was suggested to identify the impact and outcomes for patients of the service.
- Several respondents queried if GPs required being in the process at all. The prescribing of GFF could be undertaken by a dietitian once diagnosis confirmed.
- There were views expressed about whether GPs should be involved in prescribing food at all. The provision of GFF on prescription was raised in some instances where the view was the NHS should not be responsible for providing such food, and that this was ineffective use of funds.

4 Chapter 4: Views of Stakeholder Organisations

Summary

- All stakeholder organisations and individual respondents were in favour of the trial GFFS and for the service to become embedded in NHS Scotland.
- The unanimous view was that GFFS should be continued with a general agreement that the service improved patient care and facilitated better use of clinician skills.
- There was general agreement that all the service aims were met.
- The annual health check due to the short time since the introduction of the service requires further assessment to confirm success.
- A number of improvements were suggested and particularly the urgent need for an IT solution to the current paper based ordering system within community pharmacy.
- The GFF manufacturers who responded suggested a number of criteria for consideration when reviewing prescription ACBS approved GFF for local Health Board formulary inclusion.

Introduction

To gain the views of the major stakeholders involved in the trial service, Scottish Health Boards, gluten-free food manufacturers and a number of stakeholders who would be affected by the GFFS were asked for their views. The questions asked mainly focussed on their opinion of the GFFS attaining the aims outlined in Appendix B of the NHS Scotland Circular: PCA (P) (2013) 29[5]. We were also interested in their thoughts on retaining the GFFS, possible service improvements as well as any other issues the stakeholder group considered relevant.

Health Board responses were received from 7 of the 14 Health Boards and included NHS Ayrshire and Arran, NHS Fife, NHS Tayside, NHS Greater Glasgow and Clyde, NHS Highland, NHS Dumfries and Galloway and NHS Shetland. A response was also provided from NHS National Services Scotland (NSS).

Other stakeholders who responded included the National Pharmacy Association, British Dietetic Association, Coeliac UK, British Medical Association (BMA), National Services Scotland (NSS) and Community Pharmacy Scotland (CPS). We also had 5 responses from interested individuals.

Responses were also received from three gluten-free food manufacturers from the nineteen who were contacted by letter.

In order to obtain some further views from a cross section of the main stakeholders meetings were arranged with the Scottish General Practitioners' Committee (SGPC) of BMA Scotland, Coeliac UK, CPS, NSS and the Scottish Dietetic Network which represents dietitians across the Scottish Health Boards.

4.1 **NHS Organisations**

a. **Support the provision of direct NHS pharmaceutical care to patients with coeliac disease or dermatitis herpetiformis by providing a pharmacy led nationally consistent service**;

All Health Boards which responded indicated that the provision of direct NHS pharmaceutical care has been improved to this patient group. The service supporting patient care by the provision of a pharmaceutical care record, a patient assessment as part of the electronic registration process and an annual pharmacy health check. The responses indicated three specific issues which affected the consistency of the service provision:

- GFF formulary choices available across the different Health Boards vary significantly. This was illustrated by one Health Board where the geographic location created issues as neighbouring Health Boards have either a wider or narrower range of formulary products. The general consensus indicated a need for reduced variation in gluten-free food (GFF) formularies between Health Boards to improve consistency of the service across Scotland.
- Requirement for an electronic solution to handwriting CPUS to save valuable community pharmacy time, increase accuracy of prescriptions and improve CHI capture for monitoring and payment verification purposes.
- Inequity of service in rural areas where for example a sizeable proportion of NHS Highland's patients have their prescriptions supplied to them by dispensing GP practices due to geographic location as there is no local community pharmacy.

b. **Make optimum use of clinicians' skills and empower the patients to actively manage their own condition**;

There was unanimous agreement that improved patient empowerment had been achieved. The service empowering patients to take more control of their diet and manage their condition better. A stakeholder in one Health Board found the service had resulted in reduced dietetic appointment times and length of clinic letters.
All except one response agreed that the service allowed clinicians from different professions to use their skills better. Another positive noted was improved multidisciplinary working relationships between dietetics and pharmacy in developing the service to improve patient care.

c. **Improve the patient experience of obtaining GFFs on prescription by reducing the number of visits needed to GP surgeries**;

Experience within all Health Boards indicated there was a reduction in GP surgery visits where the service was used. The access and flexibility of the service provided through community pharmacies had definitely improved the patient experience. Responses indicated that the majority of patients appear satisfied with the service, particularly the opportunity to try different products more easily. One Health Board pointed out that where the service was not

available the prescription burden on dispensing practices and their patients' experiences were unaltered.

One issue raised in a number of responses reflected on why some patients would not participate in GFFS. The reasons generally were certain patients were unhappy with the maximum number of units allocated as per national guidelines or the range of GFF on their local Health Board formulary. Two examples given were number of packets of biscuits a month or loaves of bread a week.
The recommendation from Health Boards to support resolution of this issue would be that no matter the prescribing point the maximum number of units was standard across all prescribers (GP and community pharmacist) and all Health Boards. A caveat would be that dietitians had the discretion to request additional units to support underweight patients especially children. The other was to have closer alignment of GFF Health Board formularies

d. **Provide appropriate clinical monitoring for patients directly affected including dietetic intervention and annual pharmacy health check;**

The Health Board experience to date suggests that although the service provides an annual pharmacy health check this has not yet been generally evidenced. One Health Board noted that the clinical monitoring through the annual health check had been useful for compliance with diet and identification of clinical signs of complications. It was also highlighted that the effectiveness of the previous system of GP annual reviews was never assessed.
The majority view was that the new GFFS provides every adult coeliac disease patient registered with the opportunity of an annual health check and therefore an improvement. NHS Tayside where this service has been available for a number of years noted that the annual pharmacy health check was valued by community pharmacists as a useful and effective tool. Another response noted that patients were reassured that they were to have an annual health check from the Community Pharmacist. Issues highlighted in responses included:

- Potential additional workload for undertaking annual blood tests as recommended by guidance from the British Society of Gastroenterology for patients recruited to the scheme.
- Request to add a generally accepted measure of bone health such as FRAX or Qfracture as part of the annual health check to distinguish patients who may benefit from DEXA scanning as these services have limited capacity.
- Lack of awareness in medical practices, that community pharmacists were providing a health check and should receive a standard letter back on the outcome.
- Further work nationally was required to ascertain if the annual health check is effective.

e. **Provide more systematic nationally consistent management of patient needs**;

The majority of responses were in agreement that the service improved consistency across Scotland but that there was more to be achieved. The main inconsistencies highlighted were some patients opting to stay with the GP prescribing due to ability to receive different quantities and items than from the

GFFS. The other was the differences in Health Board GFF formularies. Each Health Board presently devises their own formulary from the National GFF List of prescribable items. The differences can present practical problems for cross-boundary patients who are registered with GPs and pharmacies in different Health Boards.
The possible resolution if appropriate would be a Scotland wide formulary and consistency in approach to GFF unit allocation no matter where the prescribing took place. Another point noted was to have a more systematic approach to the management of the entire coeliac disease / dermatitis herpetiformis (CD/DH) patient pathway. There was a suggestion that an NHS HIS CD/DH clinical standard may be required but that is far wider than the remit of the GFFS evaluation.

f. **Allow eligible and qualifying patients access to staple Gluten-free Food to access a convenient service customised to their needs which is also cost effective for NHS Scotland**

There was general agreement that this allowed patients who could access a pharmacy a customised service for their GFF needs. The Health Boards generally noted that although the number and range of prescribed items have increased overall, prescribing costs have not risen sharply. This appears to reflect the greater flexibility now available to patients to change the products on request at the pharmacy each month. One request from a number of Health Boards was to have a pathway to allow a patient to change community pharmacy for reasons other than moving home so that they do not need to re-register via the GP unless moving GP surgery. A possible solution would be to mimic the pathway used in the minor ailment service (MAS) to change community pharmacy.
It was observed that it was as yet too soon to determine the cost effectiveness as this would require knowledge of the service clinical effectiveness e.g. episodes of illness and associated costs averted that can be attributed to the service.

g. **Assist through collaborative working the better management of the demand on the time of all members of the primary care team involved in providing this service to patients**

There was general agreement that this has supported better demand management on members of the healthcare team. It was recognised that the majority of the work shifted from GP practice to community pharmacy staff. The main issue reported was the excessive time pharmacists spent in the manual completion of CPUS forms when recording patient orders. It was universally stated that in order for the service to progress electronic prescribing was essential.

Potential opportunities, to expand the existing system, to other nutrition areas such as low protein foods were noted. Another avenue of collaborative working between dietetics, GPs and community pharmacy was provision of oral nutritional supplements. Provided robust nutritional screening and pathways were in place community pharmacy prescribing of oral nutritional supplements could reduce patient journey and improve patient care as well as cost effectiveness.

h. **Remove the need for a GP to be involved in issuing multiple gluten-free prescriptions once he/she has determined the unit allocation and the patient has registered with a pharmacy**

There was a unanimous response that this service had freed up GP time. One service proposal for the future was for dietitians and not GPs to decide on unit allocation and commence patients on the GFFS with direct referral to the community pharmacist. This move to remove GP from the GFFS has been done in collaboration with GPs in NHS Tayside.

i. **Reduce the incidence of out of pocket expenses incurred as a consequence of community pharmacy dispensing of individual prescriptions for gluten-free foods written by GPs**.

Health Boards observed that the out of pocket expenses (OOPE) reduced significantly when the four main manufacturers stopped charging in the year before the GFFS trial started. During the trial there has been little change in OOPE. One contributor suggested that this was likely due to local GFF formularies that in general do not include items with OOPE. This would be a general ongoing recommendation to ensure best value formularies are provided along with maximum choice for patients.

j. **Should the new GFFS be retained on an ongoing basis?**

There was unanimous agreement that this trial service should be retained and expanded to improve patient access and care where appropriate.

k. **Are there improvements or changes required to the trial GFFS should the service be retained?**

A number of areas for improvement were raised by Health Boards for consideration:

- A regularly updated national GFF ACBS approved food list for prescribing applicable across all primary care clinicians. This would inform and improve consistency across Health Board formularies.
- Increased utilisation of dietitians when initiating treatment to provide a recommendation of the required number of GFF units directly to community pharmacy with a copy to the GP for their records.
- Clarity of the medical monitoring role and annual blood tests including which parameters should be monitored.
- An electronic means of generating CPUS forms was essential rather than the current paper copy when recording products for patients. The development would help address the current issues regarding CHI completion / accuracy and consistency in item selection and description.
- Influence manufacturers to supply smaller minimum quantities e.g. ‘outers’ of fresh bread etc. This limits some patients’ options with their unit allocations while there was awareness that currently the majority of the fresh bread companies bake the bread to order.

- Access to a GFF Online Service across Scotland which will improve access to people with health literacy issues.

l. **Are there any specific issues you would like to raise relevant to the evaluation of the trial GFFS?**

One Heath Board questioned the requirement of GFFS as a pharmacy service as GFF products are not medicines, although as Borderline Substances they are regarded as having the characteristics of drugs in certain circumstances.

Certain issues were raised concerning prescription processing including

- A lack of standardisation of prescribing items, with often no standardised dm+d code.
- Payment Verification is significantly affected by incomplete or missing CHI mainly as a result of the handwriting of GFF prescriptions on the CPUS forms. A number of stakeholders recognised that with around 19% of the CPUS forms paid do not have a complete/accurate CHI which significantly impacts on the ability to undertake any patient level analysis.
- Health analysis using a low CHI capture rate means using patient numbers produces inaccurate results. It was also noted that the assignment of patient to the host GP may at this time also be not 100% successful.
- Patients receiving GFF prescriptions from their GP were highlighted. Although small numbers anecdotally, the perception is that the patient choice to stay with the GP was due to ineligibility as had effectively "self-diagnosed" or may not have had formal diagnosis to be eligible for the GFFS scheme. Another perception was some patients may have remained with their GP to receive non formulary GFF items on prescription.

4.2 Other Stakeholder Organisations

Stakeholder organisations external to the NHS that provided views on the trial included the British Medical Association (BMA), British Dietetic Association (BDA), Coeliac UK, Community Pharmacy Scotland (CPS) and National Pharmacy Association (NPA).
All respondents supported the trial service with one respondent stating it had been very well received by general practice and was consistent with the aims of both the Scottish GP Committee and the Scottish Government to ensure GP practices are focused on appropriate activity. Another respondent noted that their membership appreciated the opportunity the service provided to significantly contribute to the care of this patient group.

a. **Support the provision of direct NHS pharmaceutical care to patients with coeliac disease or dermatitis herpetiformis by providing a pharmacy led nationally consistent service**

All stakeholders agreed that this aim was met while also noting inconsistencies between NHS Health Boards in the interpretation on some aspects of the guidance. A consistent message from the stakeholders was that the GFFS provides a service with the potential to improve patient experience and adherence to a GFF diet.

One stakeholder highlighted that the service builds upon the fundamental strengths of prescribing in Scotland enabling GFF to be available, accessible and affordable for people with coeliac disease. Another stakeholder noting the service meant pharmaceutical care was provided when necessary.

b. **Make optimum use of clinicians' skills and empower the patients to actively manage their own condition**

The consensus was that this aim was met with patients now able to self- manage their diet and condition better as can change their prescription without going through a GP. There was also the perception that the calculation of food allowance should lie with the professionals who diagnose or initiate treatment rather than the GP.
One respondent noted that previously many patients had unchanging prescriptions which may suggest inappropriate dietary management of their condition. They also often missed appropriate clinical monitoring and professional dietetic advice. Another stakeholder noted that patients through the service recognised the pharmacist as a useful source of clinical advice and also observed that a strong clinician-patient relationship was built through the registration process and the frequent patient pharmacist encounters due to ordering GFF products. This enables the pharmacist to monitor the patient's wellbeing and refer where appropriate. The annual adult pharmacy coeliac disease health check empowered pharmacists to have significant patient care interventions, collate patient data and formalised the ability to refer patients directly. The PCR information was considered useful to support developing improvements in patient care.

c. **Improve the patient experience of obtaining GFFs on prescription by reducing the number of visits needed to GP surgeries**

The experience across all the stakeholders was that there had been a reduction in the number of visits to GP surgeries which by inference indicated an improvement in the patient experience.

d. **Provide appropriate clinical monitoring for patients directly affected including dietetic intervention and annual pharmacy health check**

The view of the stakeholders was that the introduction of the annual check in principle, was supported but they were not yet able to comment if the annual health check has provided any positive impact. One reason was it may be too early in the programme to determine the impact with GPs, as not yet routinely receiving information on the annual pharmacy checks.

e. **Provide more systematic nationally consistent management of patient needs;**

All the respondents agreed this was a positive development in the provision of a national standardised service from pharmacies available to patients across Scotland. It was noted was this service improvement was only for patients

diagnosed with Coeliac Disease or DH but not patients ineligible by living in care homes or patients previously prescribed GFF but with no formal diagnosis.
The service also only provides a more nationally consistent management for patients registered with a pharmacy for the service. Patients who are unaware of the service, in dispensing GP practices or decide to remain receiving GFF prescriptions from their GP do not receive the benefits of the service.

f. **Allow eligible and qualifying patients access to staple Gluten-free Food to access a convenient service customised to their needs which is also cost effective for NHS Scotland**

There was a general recognition in the value of the service provision to patients with an acknowledgement of possible variation across Scotland in the definition of eligible and qualifying patients. The additional work undertaken to provide the service by community pharmacy was also highlighted.
The service was perceived as cost effective to the NHS by reducing GP practice appointments, prescription waste and maintaining clinical monitoring which according to one stakeholder decreases acute hospital and clinic referral admissions. The service potential was for a more customised service resulting in a more varied diet using fresher products, increased promptness of supply resulting in a reduction in wasted foods.
Another stakeholder noted, the experience of similar schemes in individual Clinical Commissioning Groups in England, showed that a pharmacy led scheme offers improved product control. Pharmacists are in a better position than GPs to identify and source products without incurring out of pocket expenses. In addition, the service enables pharmacists and people with coeliac disease the opportunity to work together to ensure only those items and quantities that are required are ordered, leading to further product control over supply and costs.

g. **Assist through collaborative working the better management of the demand on the time of all members of the primary care team involved in providing this service to patients**

The consensus was that collaborative working was supported as improves efficiency and provides for a much greater patient experience. One example provided was the ability for direct referral from the pharmacist to the patient's GP which provided the assurance that the clinical issue would be followed up. One stakeholder noting that the introduction of this guidance followed the production of the evidenced-based Coeliac Disease pathway which was designed by a wide range of practitioners in primary care.

h. **Remove the need for a GP to be involved in issuing multiple gluten-free prescriptions once he/she has determined the unit allocation and the patient has registered with a pharmacy**

There was general agreement that this aim had been achieved with GP time overall reduced. Issues raised which require review included why the need for a signed pharmacy referral form from their GP as a repeated GP appointment was required, if the correct paperwork was unsigned. The second issue was the need

for a patient to return to the GP if they decide to change their registered community pharmacy.

i. **Reduce the incidence of out of pocket expenses incurred as a consequence of community pharmacy dispensing of individual prescriptions for gluten-free foods written by GPs.**

Overall there was agreement that these expenses appear to be reduced but required evaluation. One stakeholder noted that owing to some distribution companies altering practices, there has been evidence of an increase. There was agreement that ongoing work was needed to ensure that best value is possible for NHS boards while maintaining sufficient GFF variety for patients.

j. **Should the GFFS be retained on an ongoing basis?**

All respondents supported the retention of GFFS and its establishment on a permanent basis for the benefits to patient care and NHS Scotland efficiencies. One stakeholder response stated '*Feedback indicates that everyone involved with the service likes it'*. Another from a stakeholder constituent summed it up in the comment:

"Yes, it's a very easy Service to use. Simply fill in the form with the items and codes, take to your pharmacy and pick up when ready. There is now no putting in prescriptions, no waiting days, no taking it to the pharmacy, and also no GP appointments just to change items. It has better flexibility when working nine to five as you do not need to visit the GP."

k. **Are there improvements or changes required to the trial GFFS should the service be retained?**

A number of possible improvements were suggested:

- Minimise GP involvement
  One stakeholder indicated in their view, there was no need for GP practice involvement after a patient's referral to gastroenterology with dietitians rather than GPs determining the amounts of GFF required. The patient could take a copy of the completed form to the community pharmacist with the practice separately electronically receiving this information. A copy of the annual health checks report should go to GP practice and if a pharmacist believes a patient requires further investigations then the GP practice should be contacted.
- Service provision
  - Consideration to extend the service to care home patients
  - Ensure all CD/DH patients are referred to the pharmacy service
- GFF prescribing
  - Provide a national GFF formulary, to improve consistency of service provision particularly where a patient's pharmacy and their GP practice reside in different Health Boards
  - NHS Scotland to work with GFF manufacturers to develop patient convenient pack sizes of products

- Electronic enhancements
    - Provide electronic solutions to prescription provision, claims and reporting
    - Linking the Patient Care Record electronic system to the pharmacy Patient Medication Record with appropriate authorisation safeguards
    - Providing an electronic solution to registration that can be transferred with the patient, for example in the case of patient relocation
    - Develop a national electronic online service
- Provide an NHS public awareness campaign of the GFFS
- Specify regular audit and review of the service
- Analyse patient and prescription data with regard to improved patient outcomes, sustained community pharmacy workload and NHS efficiencies. Suggestion was these factors should influence future service settlements within the Scottish Pharmacy Contract.

l. **Are there any specific issues you would like to raise relevant to the evaluation of the trial GFFS?**

The specific issues mentioned by the respondents are a reiteration of some specific concerns highlighted earlier. These included:

- GPs are not best placed to determine the unit allocation.
- Support for the National Prescribing Guidelines and for Health Boards to continue making decisions on prescribed items based on these Guidelines noting restrictions on items prescribed would impact most on vulnerable patients due to low income and/or poor mobility.
- A request for a national formulary, to support the aim to 'provide more systematic nationally consistent management of patient needs'. This would avoid regional variations between local formularies and therefore patient choice and an issue consistently coming in feedback from one Stakeholder.
- Requirement for better communication between Health Boards and in Health Boards around their prescribing policies. This includes consultation of those using the service should be undertaken prior to changes in items prescribed.
- Two stakeholders emphasized the high priority need for an electronic solution to writing and claiming GFF prescription.
- Request that all patients have ability to choose to access the pharmacy service rather than retain prescription ordering with GPs.
- The GFFS provides improved patient management and efficiency for NHS Scotland. It necessitates however increased pharmacist time for patient care and electronic and paper bureaucracy which should be remunerated appropriately.

4.3 **Gluten-free Food Manufacturers**

Three of the 19 gluten-free food prescription manufacturers contacted to ask their views on the trial service responded. Below are the views of these three manufacturers:
Two expressed a welcome of the service however the third did not. This manufacturer expressed specific concern about the lack of direct communication about the GFFS prior to launch. The same manufacturer considered there was restrictive practices in terms of the inclusion on National GFF ACBS approved list due to non inclusion of their products. In their opinion this was detrimental to patient care, well-being and choices. However, the National GFF ACBS approved list contains all GFF approved by ACBS for prescribing.

Another of the other manufacturers noted anecdotally they had received positive support from patients regarding the trial service. They also welcomed the collaborative approach from the implementation team in checking with manufacturers in order to finalise overall national GFF list. All three manufacturers expressed their preparedness to move forward positively with the national GFF list reviews. They all expressed criteria for consideration when reviewing a product for inclusion into the national GFF prescribable list:

- Differences in ingredients e.g. sugar content between different pasta.
- Ensure any key new lines can be considered for incorporation within reasonable time periods.
- Price review should compare the cost of any item based on 100g including carriage and handling costs to allow accurate comparison. The need to be aware of price maintenance variation between manufacturers was also highlighted.
- Minimum pack sizes require attention due to potential for waste. It was noted that mixed outers are potentially available to maximise cost effectiveness and minimise waste.
- Shelf Life of Products was an issue as a long shelf life provides a longer period for consumption helping to eliminate potential waste and supporting cost effectiveness.
- Delivery times required noting particularly timescales in remote areas.

4.4 **Individual Responses**

There were responses from two GPs as individuals, one dietitian and one pharmacist. All four were positive about the trial and favoured continuation in the longer term. The positives highlighted by one or more of the respondents included the quote, ‘positive change in service for patients with coeliac disease’. Another observed an improved consistency in the amount prescribed to individual patients and that the single access point prevented duplication of work including the ‘unnecessary inconvenience of a prescription for both patient and GP surgery’. A question on GFF prescribable units, their calculation and the value of an electronic ordering system was also noted.

One respondent had a query about the necessity of a tissue diagnosis particularly for those with a diagnosis for a long time but where they lacked tissue diagnosis as some patients were infirm. The respondent proposed there should be exceptions to

the eligibility criteria if for medical reasons a return to a gluten containing diet for a period followed by endoscopy was contraindicated.

Another issue was the need for clarity on responsibilities and funding around the annual review requirement with blood tests and consideration of DXA scan. More national guidance on when and why review should be offered may assist and prevent or reduce variations in care was suggested.

The dietitian also raised concerns that to date localised referral/review pathways were being established which might lead to variations in care offered to adult coeliac patients throughout Scotland.

4.5 **Stakeholder Meetings**

4.5.1 **Coeliac UK**

As a key stakeholder representing patients with coeliac disease a meeting was convened to provide an opportunity to communicate directly into the review. This was additional to the response Coeliac UK provided to the survey.
The following is a list of points which Coeliac UK were interested to find answers for within the evaluation:

- Improved ease to order and change GFF orders due to the importance of identifying if patients were changing and varying their diet.
- Adherence to a GFF diet is important and analysis on adherence before and after the GFFS trial would support the evaluation.
- Analysis to indicate whether GP time was saved as a result of the scheme.
- Consider any clinical benefits of the scheme in terms of nutrition, by looking at the consistency and variation between the Health Board formularies and their relationship with the national food list from which local formularies are taken Review of delivery charges and identify any distribution issues particularly in relation to more rural areas.
- Analyse the costs and volume including changes since GFFS was introduced, looking at per patient cost.
- Consider improving awareness amongst users and explore what further analysis can be undertaken on trends in GFF dispensed.
- Identify why there is variation in GFFS uptake across different Health Boards.

Additionally Coeliac UK asked to be given reassurance that the annual health check element of GFFS is equivalent in standard and quality to that already offered by dietitians, plus assurance that pharmacists had appropriate skills and knowledge to know when, and who, to refer a patient for follow-up.

4.5.2 **Community Pharmacy Scotland (CPS)**

The positive meeting provided CPS a direct opportunity to feed into the review specific points, concerns and issues raised by community pharmacists. Overall CPS was encouraging about the GFFS and its continuation with issues centred on three main aspects:

- No electronic system for generating prescriptions which significantly increased community pharmacy contractor workload which was in addition to increased number of prescriptions generated.
- GFF formulary aspects contributed significant concerns. This ranged from formulary variation across Health Boards, concerns about distribution, ordering quantities and availability of the formulary items particularly in relation to fresh bread. Other formulary issues included out-of-pocket expenses if contractors were not ordering from the same supplier
- Administration issues such as need to refer patients back to their GP if moving community pharmacy. CPS also highlighted that some contractors and pharmacists found it easier to navigate and populate the PCR than others. It was noted that generating reports at individual patient level was easier than generating management information.

4.5.3 **Scottish General Practitioners' Committee (SGPC) of BMA Scotland**

The SGPC welcomed the GFFS particularly as in their opinion it had reduced GP workloads. The discussion ranged on a number of issues noted below.

The SGPC discussed the current process and queried if the GP was the correct person to determine the number of units for a patient rather than a dietitian and noted that more complex patients tend to stay with gastroenterologist. In general the preference would be that dietitians would determine patients' needs in terms of number of units they are entitled to rather than GPs. For instance, the gastroenterologist confirms the diagnosis and writes to the GP while the dietitian determines patient's needs and gives them the referral form to take to their pharmacy of choice. The discussion then led on to the GFFS annual re-registration. The SGPC view is that this is unnecessary as once diagnosed with coeliac disease it is a lifelong condition. It was also noted that the pharmacy health check had not resulted in concerns about requests for investigations.

SGPC raised their concerns that anecdotally GPs were being asked to prescribe 'around' a gluten-free food local Health Board formulary due to the restrictive choices available within the Health Board formulary.

In terms of future developments the SGPC raised the possibility of other oral nutritional prescribing following a similar service was mentioned e.g. low protein foods as the GP is only mandating for a condition that patient is not going to recover from. The ineligibility of care home patients was raised and SGPC enquired if this would be reconsidered. Other developments would be around process such as information transfer electronically rather than paper e.g. information from a pharmacy annual health check.

4.5.4 **Scottish Dietetic Leadership Network**

The meeting with this network was very supportive of the trial service and strongly supported its continuation. The discussion covered a range of the GFFS aspects and future development suggestions.

- GFFS Trial Points
  It had been expected that referrals to dietetics as a result of pharmacy service would have increased but this had not occurred suggesting no large increase in diagnosis. NHS Tayside, however, had seen a doubling of diagnosis of new patients over last year in part due to a local awareness campaign and improvement in the patient pathway which ensured that dietitians always treated newly diagnosed patients.
    - It was noted that the new service had identified patients not diagnosed or those wrongly receiving GFF.
    - The dietitians were looking forward to a GFF online service. It was highlighted that patients would like to add product reviews and also information regarding storage instructions on the online service.
    - Communication between dietitian and community pharmacist was an area where electronic connection would be very helpful.

- Gatekeeping Role
  There was a discussion on the possibility of dietitians rather than GPs taking on the gatekeeping role due to their skills and knowledge in this area of practice which had already occurred in NHS Tayside. This would however have resource implications for the dietetic service as further roles would be introduced such as communication with other healthcare professionals etc. Questions such as would the pharmacy annual health check still send issues back to GP or to dietitian instead if they became the gatekeeper would require to be thought through. The introduction of supplementary prescribing for dietitians will fit with the gate keeping role allowing dietitians to work at the top of their competency. Overall agreement was that dietitians would welcome this development.

- Dietetic Pathways.
  The group all agreed that there was a need for Health Boards to facilitate the establishment of clear, appropriate pathways for all patients to follow as currently not evident in all Health Board areas with appropriate stakeholder involvement e.g. gastroenterologist. The need for standard operating procedures was noted and an acknowledgement that the autumn publication of NICE guidelines would inform pathways.

- Formulary
  The variation between Health Board formularies was raised due to resultant issues for patients on the border between Health Boards. Stock delivery issues were also highlighted. For consideration, was the suggestion of national criteria to help Health Boards prepare their local formulary.

4.5.6 **National Services Scotland (NSS)**

The discussion focussed principally on specific prescription processing and payment issues with one positive concerning the observation of reduced “on-cost”. The issues were due to the lack of standardisation of prescribing items as what is written on a prescription can be tricky to track in dm+d (unique code for the prescribed item) and eVADIS.

- This was the result of the handwritten prescription forms, no dm+d code support plus incomplete or missing CHI (patient identifier). The effect of handwriting the CPUS forms (pharmacy prescription forms) had resulted in governance issues within payment verification, as a fifth of the CPUS forms paid did not have a complete/accurate CHI which affected ability of patient level reporting.
- The low CHI capture rate also added to imperfect assignment of patient to the host GP and impacted on ability to undertake health analysis.
- Another observation was the retention of some prescribing by GPs other than care home patients who were ineligible. The probable reasons were considered to include non formulary prescribing, as well as patients who had not been formally diagnosed which allowed patients eligibility for the GFFS.

NSS highlighted two developments which would resolve most of the above issues

- Electronic support for pharmacy-led services is being actively progressed which would help address the current issues in GFFS regarding CHI completion / accuracy and consistency in item selection and description.
- Changes have also been raised to allow report on patient use of the service for those managed through this service although this reporting is impacted by the CHI completion and item selection as noted above.

5 Chapter 5: Prescribing Information and Analysis

Summary

- There is a wide variation in the number of prescribable GFF products across the different Health Boards and closer alignment of Health Board formularies is strongly recommended.
- Prescribing volume of GFF prescribed has increased by 31.6% and prescribing cost by only 4.6%.
- Prescribing volume increased across all GFF prescribed food categories. The greatest increase was in cereals then grains/ flours with growth over the last two consecutive years.
- Analysis suggests patients are ordering a wider variation within their GFF allocation across the food categories compared to the previous year.
- Prescribing cost per item decreased overall by 20% with cereals the main GFF category where cost per item increased.
- CHI capture rate has reduced from 99% to 81% since the introduction of the GFFS due to handwriting of prescription orders. The implementation of an electronic prescription form for the service would resolve this issue.
- Patient care records were created in 87% of pharmacies.

5.1 NHS Health Board GFF Formularies

All Health Boards across Scotland use the National Gluten-free Food Prescribable Product List as the starting point to develop a local GFF product formulary. The national list is the collation of all gluten-free foods which are ACBS approved, from all manufacturers for prescribable GFF on a NHS prescription and aids standardised practice in unit allocation across Scotland.

The range of GFF products in each food category for the Health Board formularies is noted in Table 1 overleaf. All GFF Health Board formularies are available on NHS Inform[13].
Table 1 indicates the GFF formulary product range between Health Boards with NHS Lothian having the narrowest product range and NHS Grampian the widest product range. All except one Health Board have a single formulary that covers all coeliac patients, children and adults. In each Health Board, the formulary product choices are greatest for bread and rolls with the range of pasta choices second. External to the GFFS some patients require a low protein diet and these are usually gluten-free as well however these prescriptions are completed by the GP at present.

Seven of the 14 Health Boards have sweet biscuits currently on their formulary. ACBS however, no longer approve any sweet biscuits for prescription and all of these products are historic. It is understood that in many of those Health Boards, there is prescribing guidance on a maximum quantity limit for sweet biscuits as part of the GFF allowance.

[13] http://www.nhsinform.co.uk/common-health-questions/a/am-i-eligible-for-the-new-scottish-nhs-gluten-free-food-service/

It is notable that each Health Board formulary although derived from the one national food list is very different in the number of GFF products available. The questionnaire responses and stakeholder responses highlight the equity of access and concerns from patients and community pharmacists due to the variation. It is recommended that although some variation may reflect differences in local population demographics, the reasons for the variation should be assessed and greater alignment between Health Board formularies achieved.

Table 1: Number of GFF products within the main GFF categories listed in Health Board Formularies

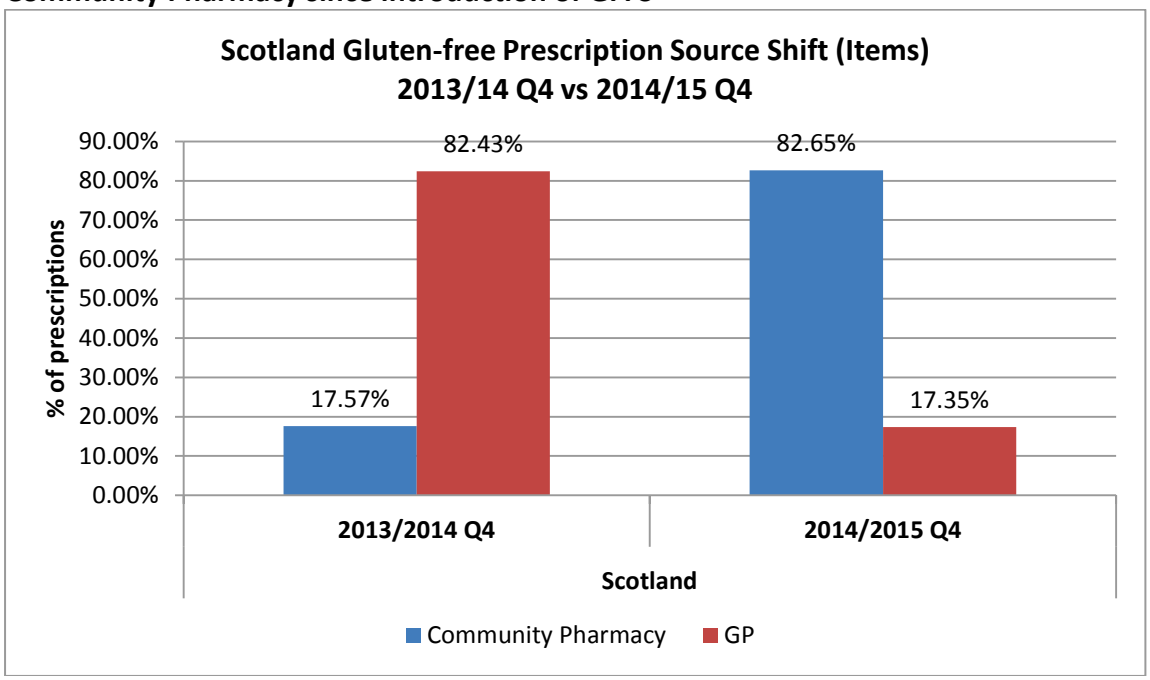
NHS Health Board	Bread & Rolls	Home Baking	Pizza Bases	Pasta	Crackers & Crispbread	Baking Aids	Breakfast Cereal	Sweet Biscuits	Total
Ayrshire & Arran	51	12	4	18	6	1	4	0	96
Borders	52	13	4	22	9	1	4	0	105
Dumfries & Galloway	49	11	2	12	5	2	6	0	87
Fife	36	7	3	10	5	1	3	0	65
Forth Valley	45	14	2	19	9	1	7	9	106
Greater Glasgow and Clyde	50	37	2	43	8	2	7	8	157
Grampian	87	37	7	46	12	2	7	11	209
Highland	71	18	3	18	9	2	5	2	128
Lanarkshire	52	14	3	12	4	2	5	0	92
Lothian	10	3	2	2	2	0	2	0	21
Lothian Children	10	3	2	3	2	0	2	0	22
Orkney	60	22	4	15	8	2	6	8	125
Shetland	60	22	4	15	8	2	6	8	125
Tayside	72	24	5	43	12	1	9	10	176
Average	50	17	3	20	7	1	5	4	108.1
Minimum	10	3	2	2	2	0	2	0	
Maximum	87	37	7	46	12	2	9	11	

5.2 **GFFS Implementation**

Since the introduction of the GFFS there has been a switch in number of GFF prescribing through GP10 prescriptions written by the GP to the community pharmacy prescribed items via CPUS form. The implementation of the trial service has resulted in a change from 82% of prescribing by GPs in January to March 2014 to 82% by community pharmacy in January to March 2015 (Graph 1). NHS Tayside started supplying GFF through community pharmacy in 2010 with other Health Boards starting to implement GFFS from March 2014. Graph 2 shows the high rate

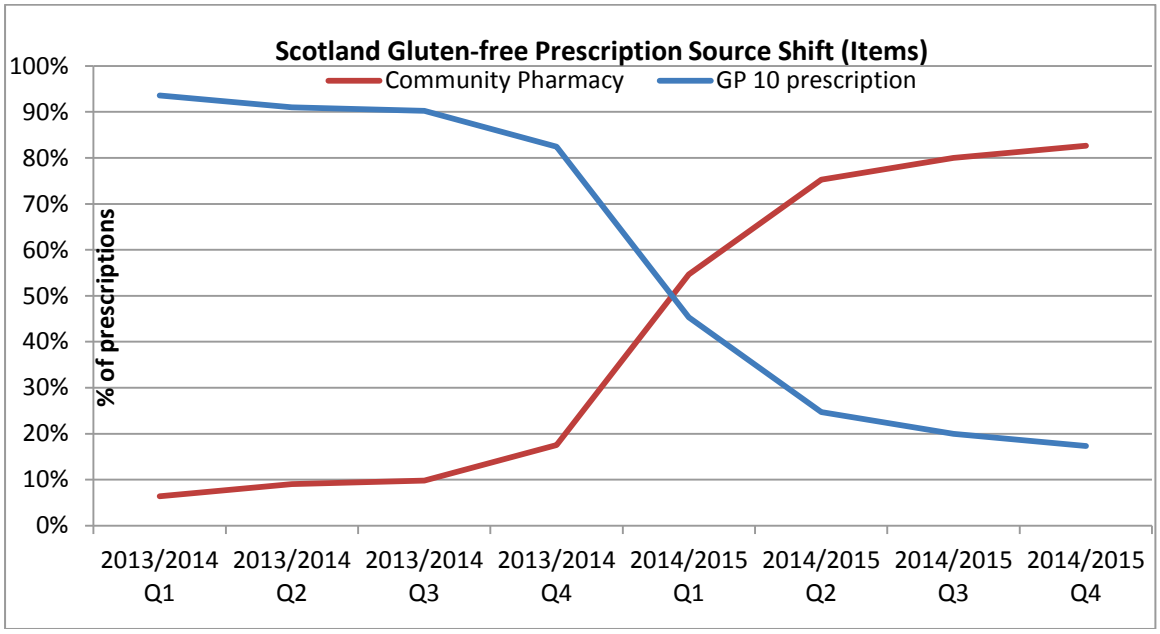
of transfer from GP to community pharmacy prescribing particularly over the first six months of the GFFS implementation.

Graph 1: Change in percentage GFF items prescribed via GP prescribing (GP) and by Community Pharmacy since introduction of GFFS



*Information supplied by iSD special request

Graph 2: Change over the four quarters as the GFFS was implemented is seen in the graph below

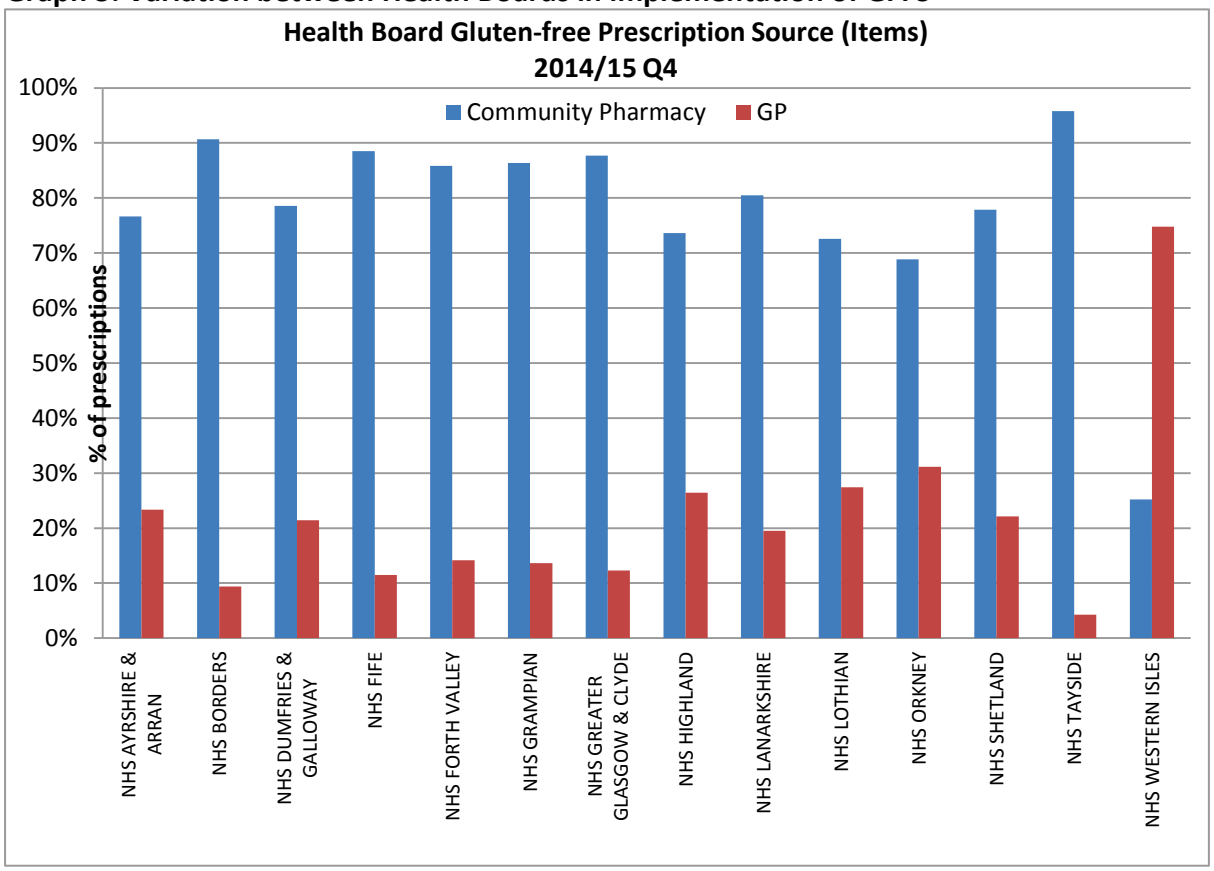


*Information supplied by iSD special request

Graph 3 below shows the different percentage uptake of the GFF service across the different Health Boards. The graph indicates the percentage of GFF prescribed in the January to March 2015 for GP prescribing (GP10) and community pharmacy prescribing.

NHS Tayside has the highest implementation with 96% and the lowest is the Western Isles with 25%. Rurality was a factor in the uptake of GFFS as seen by the island Health Boards and NHS Highland. The lowest uptake across all the mainland Health Boards however was NHS Lothian. The figures do indicate a successful implementation of the GFFS.

Graph 3: Variation between Health Boards in implementation of GFFS



*Information supplied by iSD special request

5.3 GFF Prescribing Volume and Costs

Over the last year there has been a significant change in the prescribing of GFF costs and volume. Information Services Division (iSD) publish in June each year the prescribing statistics for the last financial year[14]. The tables and graphs below utilise the information provided.

[14] http://www.isdscotland.org/Health-Topics/Prescribing-and-Medicines/Publications/

Prescribing Cost and Volume change for the first 12 months of the trial service

A review of the prescribing information indicates that the number of dispensed GFF items in the year prior to the new service to March 2014 was 2.2% with a small cost reduction of 2.1% compared to the previous year. In the year since the introduction of GFFS trial from April 2014 there has been a 31.6% increase in the number of dispensed GFF items. In terms of total GFF prescribing costs (GIC), however, only an increase of 4.6% has been observed since the introduction of the GFFS.

Table 2: Prescribing costs, number of GFF items dispensed and the average GFF item cost over the last three years

Total GFF Prescribing for Scotland	Total Dispensed Items	Total Gross Ingredient Cost (GIC)	Cost per Item (£)
April 2012 to March 2013	243,416	£3,969,770	£16.31
April 2013 to March 2014	248,811	£3,885,110	£15.61
April 2014 to March 2015	327,474	£4,062,863	£12.41
Prescribing change between the financial years 2014/15 and 2013/14	78,663	£177,753	-£3.21
Percentage of Prescribing Change between 2013/14 and 2012/13	2.22%	-2.13%	-4.25%
Percentage of Prescribing Change between 2014/15 and 2013/14	**31.6%**	**4.6%**	**-20.5%**

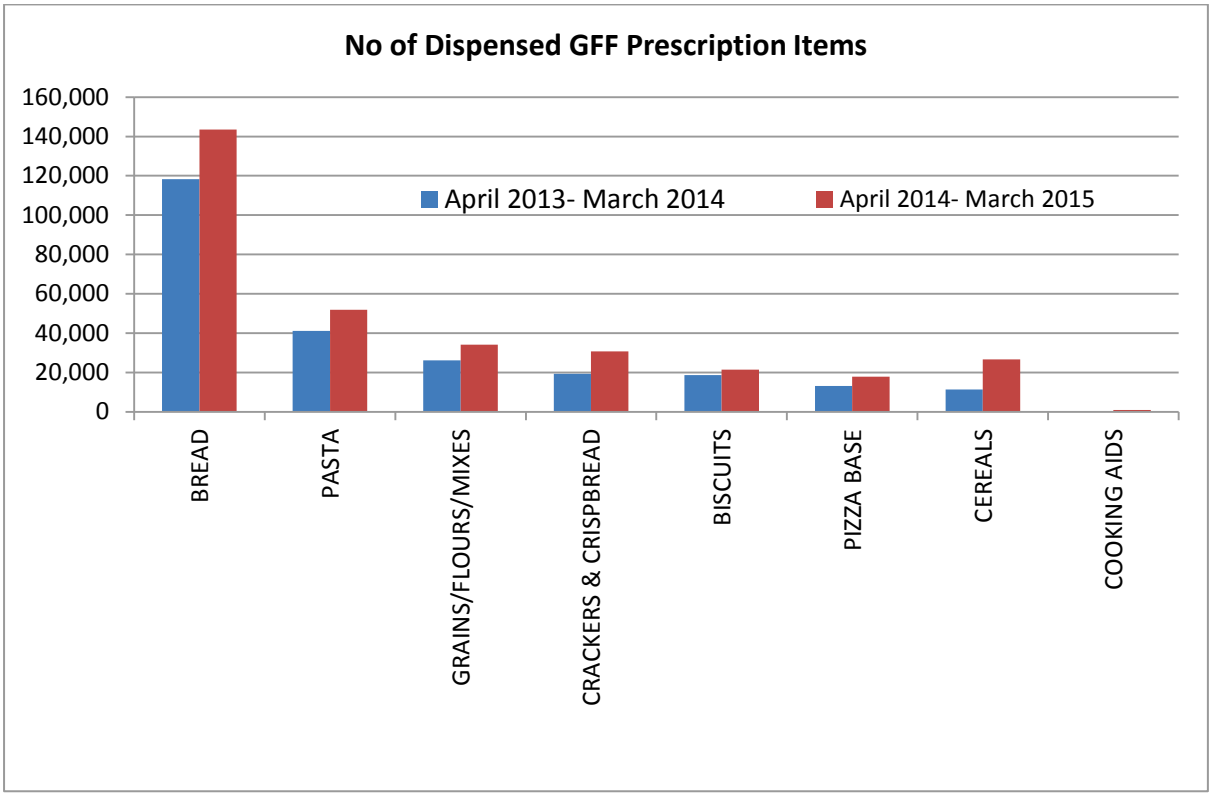
The prescribing information since the introduction of the trial service indicates that despite the total number of prescription items increasing significantly, the overall costs did not. A more technical economic analysis confirmed that changes in the number of items dispensed and the quantity prescribed per patient were statistically significant, but that there was no statistically significant change in the cost per patient. However, the analysis also flagged up that one year of data since the start of the new service might not be enough to give an adequate picture and that more data over a longer time-span is needed to make a final assessment.

Another observation was that the average cost of a GFF prescription item declined in the year prior to the GFFS trial. The cost per prescription item however has declined by 20.5% since implementation of GFFS. The cost of individual GFF products from manufacturers has not declined significantly over this period. This suggests patients were choosing to order smaller quantities of individual items per prescription, plus increasing the variety of products chosen within their allocated GFF allowance. The effect of this would be a reduced cost per prescription and an increase in the number of prescription items. This also corresponds with the information provided by patients and pharmacists in the questionnaire responses. Compliance with Health Board formularies which promote cost effective prescribing is also likely to be a factor in minimising any cost increases. This finding indicates achievement in part of the GFFS aim to allow eligible and qualifying patients' access to staple GFF through a convenient service customised to their needs which is also cost effective for NHS Scotland.

5.4 Gluten-free Food Prescribing Choices

The number of prescribed GFF items has increased across all food categories (Graph 4). The largest change in the prescribed GFF categories was a doubling in the cereals. Grains / flour prescribed along with the cooking aids also increased as necessary to utilise the flour. Both food categories had also seen a large increase in the financial year to March 2014 in comparison with other GFF categories. This particular GFF category increase also reflects the significant increase in the choices of gluten-free cereal available over the last 2 years.

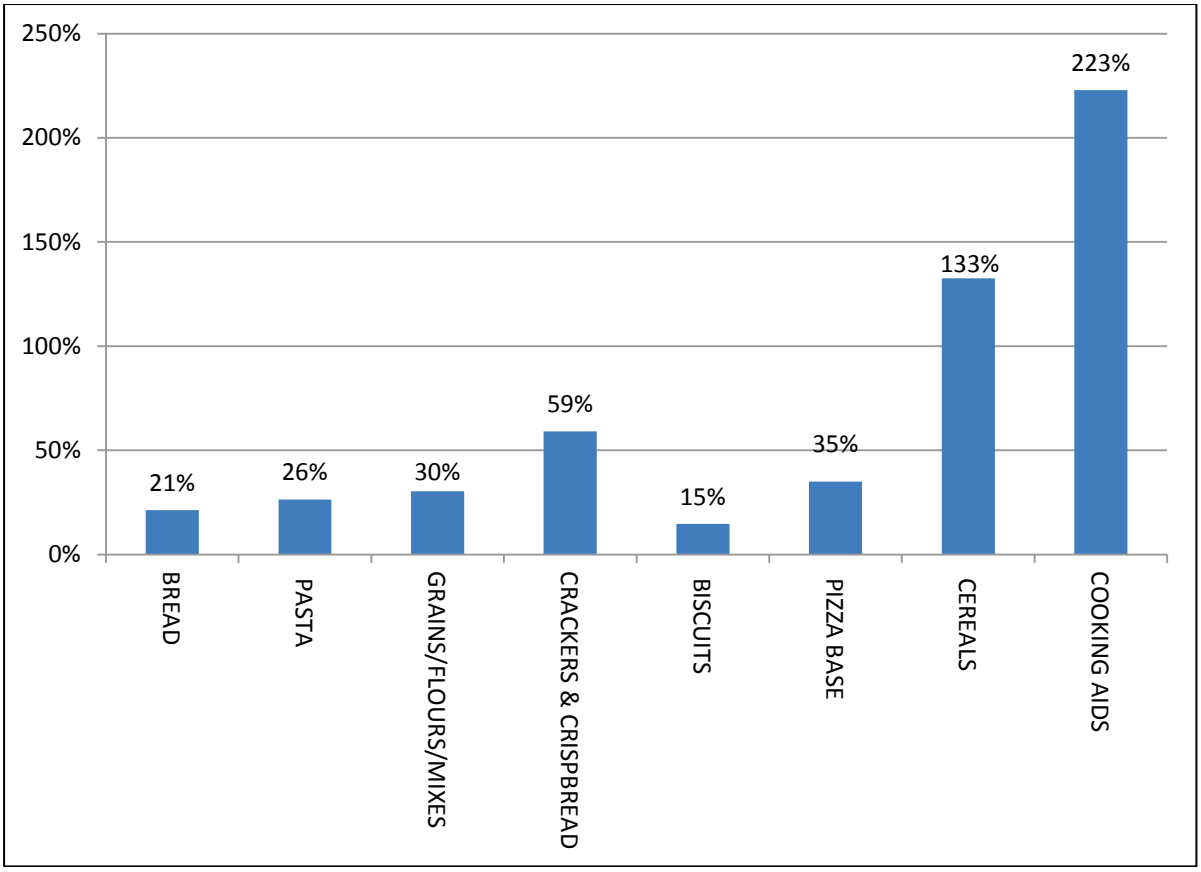
Graph 4: Number of GFF items Dispensed per food category in the year before and after the GFFS Trial Service was introduced



Graph 5 overleaf shows the percentage increase in the number of dispensed items across all the GFF food categories from April 2014 to March 2015 compared to the year prior to the implementation of the GFFS trial. All GFF food categories had increased prescribed items with the lowest increase biscuits which were only on the formularies of half the Health Boards. Bread increased by 21% but is already by far the highest prescribed category.

The highest increase is in cooking aids which were previously prescribed minimally but are required for the mixes and flour which has increased by 30%. Cereals as a category had next highest growth of 133% but this is from a low prescribed volume previously. A 59% increase for crackers and crispbreads was also observed. The graph generally illustrates the increase in variety of GFF choices made by patients.

Graph 5: Percentage change in number of dispensed items in the year 2013/ 2014 and the year 2014 /2015 after the introduction of the GFFS Trial for the range of GFF categories

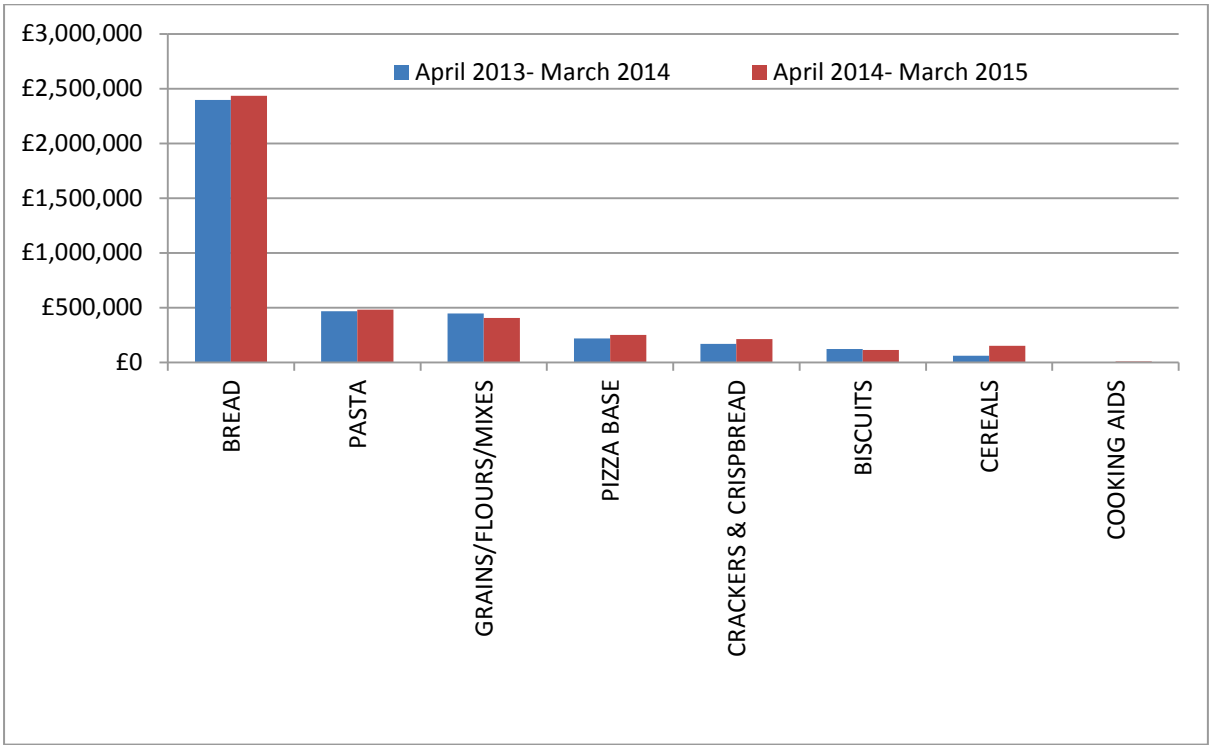


5.5 Prescribing Cost for Gluten-free Food Choices

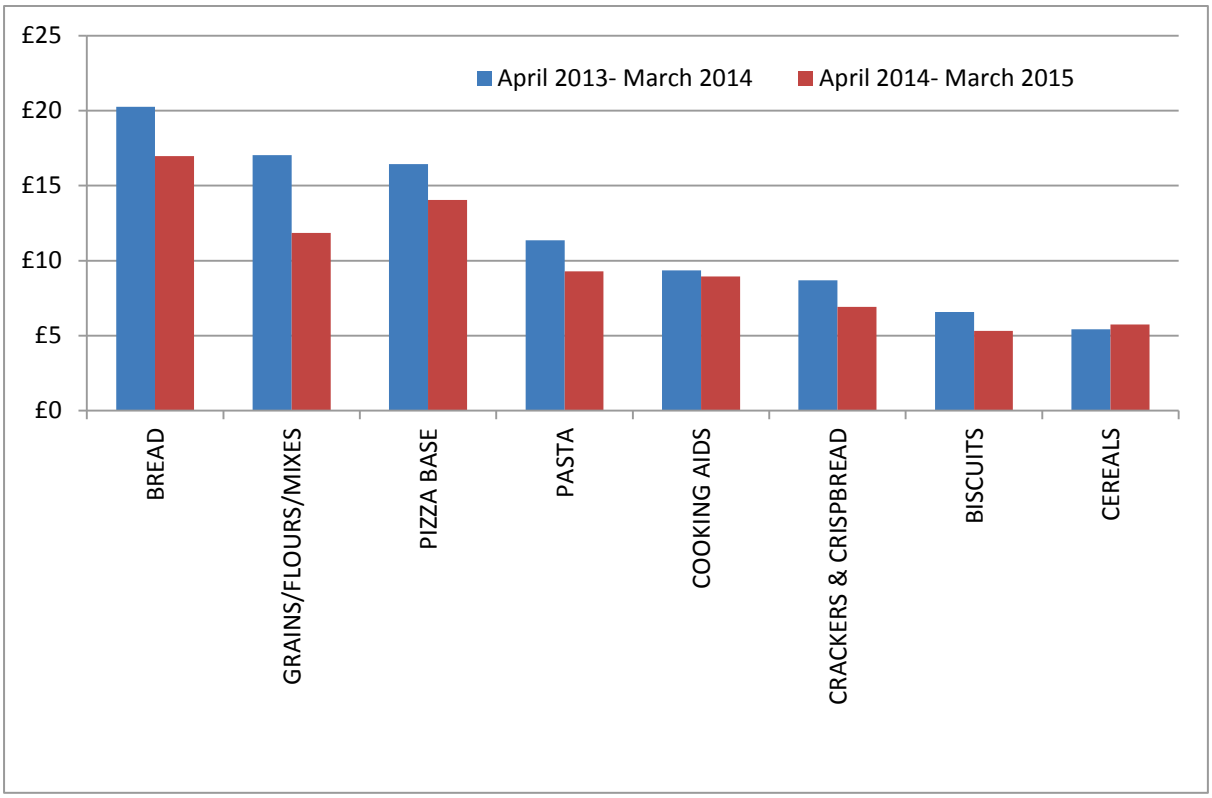
The prescribing cost change in each category (Graph 6) reflects the increase in number of dispensed items. The largest effect was observed in cereals, unsurprising due to doubling of the prescribing volume. Although GFF cereals volume prescribed has doubled the largest dispensing cost category is bread at a gross ingredient cost of £2.4 million per annum. Local Health Board formulary choices reflect the variation in prescribing cost of gluten-free bread available with cost effective formulary choices made. The prescribing cost, manufacturer dependent, can be significantly higher than supermarket retail price. One supermarket 'own' brand of gluten-free bread costs £1.50 with another well known brand £2.50 with some others significantly higher.

The individual cost of other GFF categories is less than one fifth of the total cost of bread. The prescribing cost per item in general indicated a cost reduction (Graph 7).

Graph 6: Total prescribing cost (GIC) of GFF categories before and after the introduction of the GFFS Trial

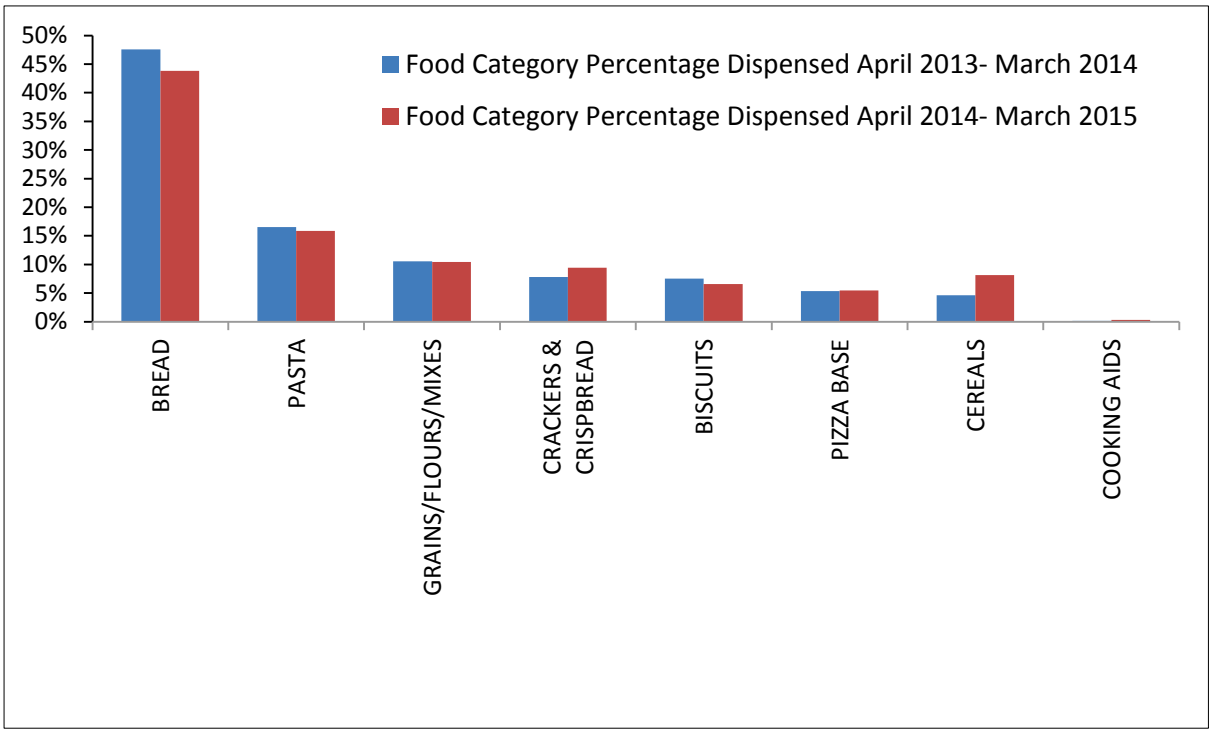


Graph 7: Comparison of the cost per prescription item before and after the introduction of the GFFS Service



5.6 GFF Allowance Distribution across Food Categories

Graph 8: Percentage of the total prescribing for each GFF category before and since implementation of GFFS



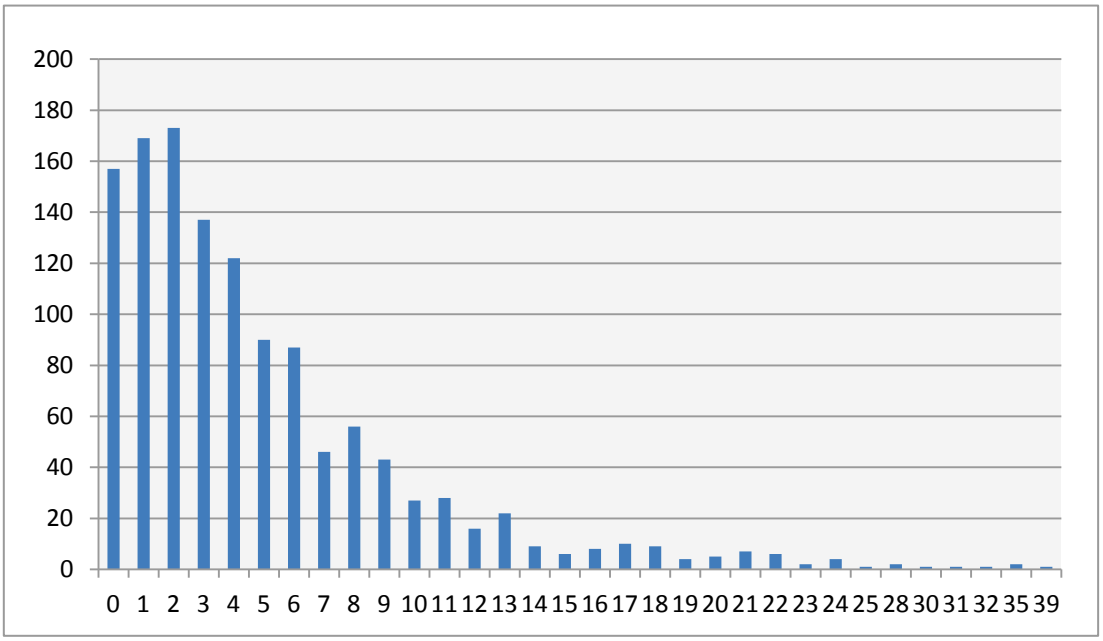
The changes observed in Graph 8 illustrate the change in GFF allocation use by patients. The variation in food choices made by patients in using their GFF allocations is of interest. The significant change was a switch to more cereals and crackers /crispbread dispensed. As previously mentioned, the effect of an improved range of cereals available will be one factor in the growth. The only other category to have an increased share was crackers and crispbreads. Biscuits accounted for approximately 6.5% of the total GFF prescribed items a reduction from 7.5% previously.

5.7 Gluten-free food service (GFFS) support

Pharmacy Care Record (PCR) information

The Practitioner Services Division (PSD) of NSS provided information for the purposes of the review on the open and closed records created in support of the GFFS. It identified that 87.5% of the community pharmacies across Scotland had created at least one PCR with a maximum of 39 records in one pharmacy. It would be expected that Health Boards would seek to identify if a community pharmacy had not used the PCR that the pharmacy also did not have any patients receiving the GFFS. Graph 9 indicates the number of community pharmacies who opened at least one PCR record.

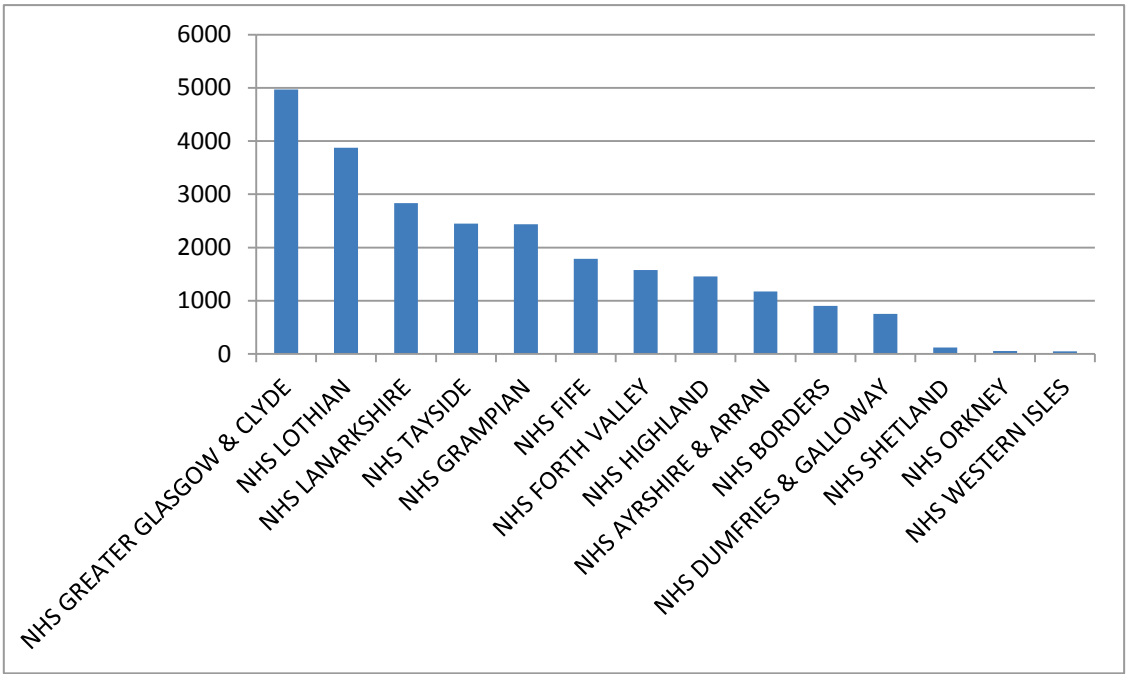
Graph 9: Total number of Community Pharmacies and the number of PCRs opened or closed for patients prescribed GFF as part of the trial service



5.8 GFFS Prescription Form information

PSD also provided for the review the number of GFF prescription forms submitted for March 2015 (Graph 10). There were 24,428 GFF prescription items in Scotland with 4719 patients identified using their CHI number, however as the average CHI completion for the submission was only 81% the patient numbers as an accurate reflection of number of patients within the GFFS require to be treated with great caution.

Graph 10: Number of GFF prescription items submitted per Health Board for March 2015

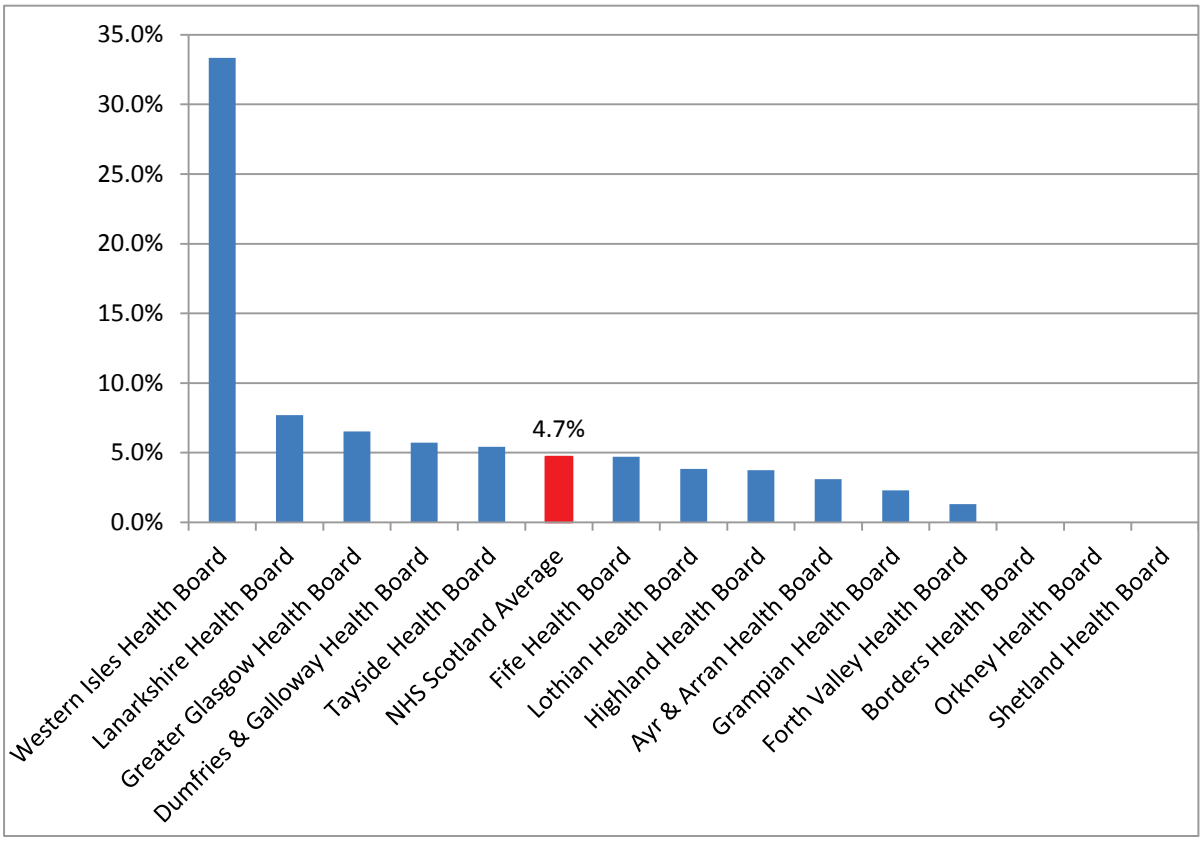


The number of contractors in each Health Board where no patient CHI number was captured is shown below in Table 3. The average percentage of community pharmacy contractors with no patient CHI number recorded is 4.7% presented in Graph 11. The effect is a current inability to accurately determine the number of patients receiving GFF prescriptions through community pharmacies including linking prescribing to GP practice for prescribing governance and cost allocation. This is also important from a payment verification perspective. The solution is electronic prescribing for the GFFS.

Table 3: Number of Pharmacy Contractors where no Patient has been recorded for GFFS

NHS Board	Total	NHS Board	Total
NHS Ayrshire & Arran	3	NHS Highland	3
NHS Dumfries & Galloway	2	NHS Lanarkshire	11
NHS Fife	4	NHS Lothian	7
NHS Forth Valley	1	NHS Tayside	5
NHS Grampian	3	NHS Western Isles	1
NHS Greater Glasgow and Clyde	19	NHS Scotland Total	59

Graph 11: Percentage of Health Board Community Pharmacies where no CHI was captured for the GFFS



6 Chapter 6: Discussion

The review used a range of methods to engage stakeholders and provide sufficient opportunity to feed in comments and experiences of the GFFS. The effect was a good response from a wide range of stakeholders with the unanimous agreement that the GFFS trial should be continued and embedded in NHS services. There was also agreement that in general the service objectives set out largely had been achieved. Comments indicate that a degree of effort is still required for full achievement of some aims. Due to the short time since GFFS implementation, the short and long term value of the annual pharmacy coeliac disease health check would benefit from an assessment of its usefulness at a future date.

Experience of the Service

On average 90% of patients agreed that they liked the GFFS service although there was some variation (82%-100%) between Health Boards. Also 93% agreed that the GFF order was easy to place and 90% stated there was enough information provided on how to use the service.

"It is excellent and makes ordering food very easy without bothering the GP."

For 82% of community pharmacists the GFFS had been a positive experience and they agreed it was easy to implement and use. The additional work associated with the service was highlighted within the questionnaire response, stakeholder letters and meetings. The necessity of handwriting all the GFF prescriptions rather than using electronic technology was frustrating for the respondents. This also affected the accuracy of the data collected for payment verification including determining the number of people utilising the service.

From the GPs who responded 83% agreed that the service was easy to implement within their practice noting that over 10% of patients receiving GFF items on the NHS still have their GP writing the prescriptions. A proportion will be patients resident in care homes who are currently ineligible; a number will relate to rural location and for others preference to stay with their GP.

Impact of the Service

For 89% of patient respondents the impact of the service was an improved ease of ordering with 71% of patients acknowledging that they change their food orders more often. This was borne out by pharmacist responses and prescribing information indicating a 29% increase in the number of GFF prescribed items since implementation of the service while costs only risen by 4.6%.

There was agreement by 85% of community pharmacists who responded that the GFFS provided a better interaction with their patients and led to wider identification of healthcare issues. GPs also found that the service had a positive impact on their workload for this area and enabled them to spend time on other responsibilities better using their skills. This is illustrated in a number of quotes set out in the survey analysis [Annex 6] for example.

"This is one of the best patient care systems invented! Streamlines their gluten-prescription service, more efficient for patient & professionals. Allows GPs to get on with treating illness rather than 'conditions'."

There were also positive comments on the flexibility of the pharmacy service and the fact the pharmacy staff were around to provide advice. Disappointingly, in general the opinion was the new service had not yet led to improved communication with the wider healthcare team.

"Ability to use community Pharmacist is easier and less time consuming. It provides greater flexibility to allow me to try alternative products."

Both individuals and stakeholder organisations in general observed that the service supported self management. Due to the short time since introduction the evaluation cannot clearly state the size of contribution the national GFFS brings to improving patient quality of care.

Adult Coeliac Disease Health Check

Positive and negative preferences were expressed by patients and some organisations on the annual pharmacy health check. Questions were raised on its value, pharmacists' skills and community pharmacy as an appropriate venue particularly if bloods were to be taken, however, this was never an expectation within the service provision.

Prior to the GFFS service implementation however, only 47% of patients were offered an annual health check and 44% since implementation.

"The annual check the pharmacist provided was identical to the annual check my GP provides except that the GP also requests the bloods. It doesn't make sense for the pharmacist to complete 95% of the review, only for the GP to replicate it a week later."

There is no significant information on outcomes when GPs undertook the check. Patients did generally report the lack of an annual check being offered since GFFS implementation. Only 23% of respondents had received a check by a pharmacist. The survey also indicated that only 49% of respondents had undertaken the annual pharmacy health check. This aspect of the service requires future evaluation to assess the value.

One concern prior to GFFS implementation was the potential for increased number of investigation requests, however, stakeholders indicated that this had not materialised. Similarly, referrals to dietitians had not increased significantly. A few pharmacists did question the value of the health check, however, pharmacists in general found the adult coeliac health check a useful opportunity for positive patient engagement. The main issue was the time commitment to undertake the health check within a busy community pharmacy.

GP comments indicated a lack of knowledge on this part of the service and noted that receipt of a patient health check report from the community pharmacist would increase awareness. Already available within the NES training packs is a standard template for community pharmacists to send to GPs.

Given, the interest in this new development and concerns regarding implementation and perceived value, it would be beneficial to monitor the implementation of the annual health check and evaluate its worth in one to two years.

Service Processes

The process for an eligible patient to change from GP prescribing to the GFFS has been successful with 82% of GFF now prescribed by community pharmacy. The training and support including the NES resources to support the service and its processes were generally viewed positively. Going forward, ongoing training was considered required by 43% of pharmacist respondents with online training materials (68%) the favoured delivery method.

Although there were many positive comments that the GFFS was an easier to use and more flexible service, there were specific processes that caused issues for patients, GPs and pharmacists.

Community pharmacists highlighted the amount of time it took to prescribe a patient's GFF order and the issues with the PCR as neither interfaces with the PMR or is easy to use. Patients also commented on the time it took for them to complete the blank order form. A number of improvements were suggested including greater use of email and a pre-printed order form with GFF details including order codes already printed for patients to use. This pre-printed order form suggestion has already been taken up within some Health Boards. Another suggestion was a GFF online prescribing service which has already been developed in NHS Tayside with patients and pharmacists and could be rolled out to all Health Boards. Patients and the community pharmacies liked the simplicity of the online service, speed of creating an order, how GFF units were calculated and created a clear order form. Additionally some community pharmacies have accepted an emailed order which was also found beneficial. NES webinars have been developed to support community pharmacy and Health Boards with the online service.

A number of current pharmacy processes do require review and these include:

- The fixed monthly order cycle has been found too inflexible as necessitated patients having to plan orders for a month then collect and store bulky quantities of GFF plus issues for patients if going on holiday.
- Process when transferring between community pharmacies, this presently requires a GP appointment and a reauthorisation with sign up to a different pharmacy. In some instances, this process had resulted in time delays especially if moving GP and Health Board area. This also was a problem for students returning to their home from university for the summer or people working away from home for a couple of months. One solution provided was to mimic the process currently operating with the pharmacy minor ailment service when patients change between community pharmacies.
- Annual reauthorisation was also considered unnecessary as coeliac disease once diagnosed is a lifelong condition.

Gluten-free Food Choice
There were many comments on the range of GFF available and the variation in the number of GFF products across Scotland. A number of patients commented that receiving GFF on prescription was important due to the cost premium compared to general food as supported compliance with a GFF diet.
"So grateful for this service as our food is so expensive in the shops. Now I can have the basics on prescription and it allows me a bit more variety."

"This type of food is somewhat restricted - no biscuits or fruit loaf or cakes but I can understand the logistics must be pretty horrific. The choice is adequate and from a financial point of view it is great. I purchased GF Food until I was informed about GFFAPS and the savings are considerable."

For patients, availability and cost of GFF has improved significantly in the last decade with supermarkets now stocking a range of GFF. One area of improvement suggested by stakeholders was to improve nutritional information provided to patients on what general food groups were gluten-free e.g. rice, potatoes, corn, meat, cheese, vegetables and fruit etc.

The present NHS prescribing choices for patients are based on local Health Board formularies. These are created using as a baseline a nationally composed GFF prescribable list which contains all GFF products that are ACBS approved for prescribing. The intention of the constructed national list was to assist Health Boards, in their local formulary development reducing replication of work, with the outcome of a greater consistency in approach and content of local formularies. A comparison of Health Board formularies (Table 1) indicates a high variation in the number of GFF choices across the food categories available for patients. The degree of variation was a source of a large number of comments from patients, GPs and community pharmacists in terms of consistency of service and was likened to postcode prescribing. Many problems were described and anecdotally GPs in one Health Board cited that patients would ask for GFF prescription due to the narrow prescribing choices on the formulary. It is strongly recommended that there is greater alignment of Health Board formularies and for patient representation in formulary development. The formulary should also apply to all prescribers.

A large number of comments focused on patient and pharmacist issues with fresh GFF items e.g. fresh bread with large minimum order sizes, short expiry dates, delivery times and bulky. All of which are issues which can lead to high GFF waste. Pack sizes are at the discretion of the manufactures and working with suppliers was one suggestion. Already many manufacturers are realising the burden these large packs have on patients and are moving to mixed packs. Gluten-free food manufacturers that responded also provided some specific points that should be considered within the development of a Health Board formulary. There were many mirrored comments from patients and other stakeholders on the above including a method of comparing costs and GFF units.

Types of food categories prescribed were also a focus for comment from all stakeholders. Prescribing information indicates bread and pasta are the most often prescribed. The largest GFF category growth over the last two years was cereals

although still a low prescribing volume. The percentage prescribing between the categories has not changed significantly since the implementation of GFFS except for cereals and crackers/crispbreads. Patient views were split on the types of food available with some happy with basics and others wanting biscuits and cakes available. Although half of the Health Boards chose not to have biscuits within their GFF formulary, biscuits constitute 6.5% of the GFF items prescribed a slight reduction from the previous year. It is worth noting that ACBS will now only approve items considered to be "dietary staples" which does not include biscuits or cakes.

Although not part of the review, there were a number of comments across various stakeholders on the fact that GFF was prescribable. Financial cost of prescribing which is £4.06m per annum and inequity of access were both cited. Specifically, observed was a lack of equity for other patient groups with long term conditions such as diabetes, allergies (e.g. nut, egg and lactose intolerant) particularly as GFF was increasingly available in supermarkets. The following quote illustrates many of the negative points made:

"The NHS should not be funding food for coeliacs. Other patients with allergies have to buy their own goods (e.g. lactose intolerant patients)…….If the NHS insists on paying for people's shopping, perhaps a more cost-effective solution would just be giving a voucher for a supermarket for gluten-free goods, with an annual check done in pharmacy…."

Service Developments

A number of service improvements and developments were mentioned by the stakeholders. Some are noted above which support streamlining of the existing service. GPs highlighted other areas particularly non drug prescribing to consider a similar type of service to improve patient access, skill utilisation, cost effectiveness and reduce GP workload. Dietitians and pharmacists were also interested in developing services for other prescribing within oral nutrition such as foods for special diets e.g. phenylketonuria (PKU) and low protein diets or patients requiring oral nutritional supplements.

7 Chapter 7: Recommendations

The evaluation of the GFFS trial using questionnaires, surveys and meetings of stakeholders produced results from which the following recommendations were produced:

7.1 The GFFS should be continued and embedded into NHS Pharmaceutical Services

Stakeholder groups were unanimous in their agreement that the GFFS should be continued as had generally delivered the objectives which had been set out to achieve.

7.2 Improved alignment of Health Board gluten-free food formulary choices, while still accounting for variations in local population need

At present, there is up to a ten-fold variation in the number of GFF product choices available for patients across the 14 Health Board GFF formularies. Stakeholders highlighted this variation, as an equity of access issue. Although local Health Board formularies differ to allow for local population needs, the reasons why the degree of present variation requires review. Patient participation in formulary development is recommended.

7.3 Establish regular updates to the National Gluten-free Food NHS Prescribable List which include sufficient information to support Health Boards in local formulary development minimising resource duplication

The regular update of the National Gluten-free Food NHS Prescribable List was highlighted as important by patients, GFF manufacturer respondents and dietitians. The list supports and informs the regular updating of all Health Board formularies. The inclusion of a range of information on the GFF products would assist standardisation of variables to be considered by a Health Board in deciding on formulary GFF product choices. There is also a need for a clear central point of contact for maintaining the list so that manufacturers know who to notify regarding new products. Suggested information for inclusion from stakeholders to support patient choice and cost effectiveness includes:

- Number of GFF units per item
- Shelf life of products to support minimisation of waste
- Minimum orders required particularly for fresh items with short expiry dates
- Delivery times required noting particularly timescales in remote areas.
- Cost of item based on 100g plus any carriage costs and handling charges
- Availability of mixed ‘outers’ to maximise cost effectiveness and minimise waste
- Differences in ingredients e.g. some GFF are fortified with vitamins/ minerals where others are not

7.4 Completion of the development and rollout of electronic prescribing forms for community pharmacy to undertake the service

The GFFS service use of the CPUS forms which require to be handwritten was highlighted as a significant problem. The prescribing of the various GFF choices takes considerable time and causes frustration for community pharmacists and patients. A further outcome has been the significant reduction in the patient CHI capture rate to 81% which impacts on payment verification and the need to manually process some prescriptions.

Practitioner Services Division of NHS National Services Scotland has a single electronic form in development for community pharmacy services. This is considered an important priority for completion and implementation in GFFS.

7.5 Rollout of Pre-printed GFF Order Forms with standardised data set and Gluten-free Online Service for patients

Patients highlighted frustration in the need to write out their GFF choices and then go to their community pharmacy to order their GFF. Some community pharmacies already provide an email service option. One suggested improvement is a standardised pre-printed order form with all relevant GFF ordering information criteria already provided and aligned with the local Health Board formulary. In at least two Health Boards a standardised pre-printed order form with check boxes has been introduced with patients and pharmacists declaring benefit. A lack of knowledge on the GFF available was also noted as a problem. To support greater access to information and help with the ordering process a gluten-free food online service has been in development within NHS Tayside and could be rolled out across Scotland.

7.6 Monitoring and further evaluation of the annual pharmacy coeliac health check to assess value to the patient

The evaluation highlighted a number of issues. These included concerns from a range of stakeholders on the value of the pharmacy annual health check. The results of the questionnaires also indicated that only 23% of the patient respondents had received an annual health check although 44% had been offered an annual health check which was similar to the offer rate prior to the introduction of the service.

GFFS has only been implemented since April 2014 with few patients transferred to GFFS for 12 months or more. A review of this aspect of the GFFS in one to two years would be of value to appropriately assess the benefits of the annual pharmacy adult coeliac disease health check and if any further refinement was required.

7.7 Annual re-registration for the service should be discontinued as coeliac disease is life long

Once a patient is assessed as having coeliac disease or DH, as a life-long condition, no annual re-registration is necessary to assess need for continued inclusion in the service. GPs will continue to be notified of new diagnosis or GFF unit changes

through the dietetic services and provided with a record of the annual health check undertaken by the pharmacist at the designated community pharmacy.

7.8 Consider inclusion of patients resident in care homes within the GFFS

Stakeholders generally agreed that care home patients should be able to participate in the service as not to do so sanctioned inequity of service provision for care home patients. Non participation means GP have to continue to prescribe for care home patients which reduces the GFFS benefits. One service offered by community pharmacy makes monitoring and review of prescribing more efficient.

7.9 Further develop the pharmacy and dietetic processes and communication links to optimise use of professional skills including their prescribing roles

Views from the various stakeholders indicated that aspects of the service required development and improvement. Specific aspects highlighted varied between stakeholders but included:

- The formation of a standardised dietetic led patient pathway to support health Boards
- Improved communication pathways between community pharmacists and dietitians. Improved communication links would potentially allow dietitians to directly refer the patient to the community pharmacy of their choice. A copy of the dietetic assessment of the patient's GFF allowance requirements would also be sent to the GP practice. This would reduce the patient journey and GP workload plus increase dietitian and pharmacy communication which has not changed significantly since introduction of the GFFS in some areas
- Improve the Pharmacy Care Record (PCR) operational use as stakeholders highlighted problems in its functional capability and requested its linkage to the PMR
- When changing to another community pharmacy for any reason a system similar to the Minor Ailment Service (MAS) registration should be considered instead of the patient needing to return to the GP.

7.10 Consideration of other potential areas of prescribing where a similar service could improve patient access, improve skill utilisation reduce GP workload and improve cost effectiveness.

The prescribing areas identified for consideration were foods for special diets such as patients with phenylketonuria (PKU) and patients with metabolic conditions on low protein diets or patients requiring oral nutrition support. Also suggested for consideration were other areas of non-drug prescribing.

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for General Practice

Introduction

The Gluten-free Food Additional Pharmaceutical Service (GFF APS) was introduced as a trial in April 2014. An evaluation of the Service is being undertaken to ascertain if it is an improvement compared to traditional gluten-free prescribing for patients by general practice and dispensed in community pharmacy.

This questionnaire forms part of the evaluation and your views as a General Practitioner are vital to help identify how successful the service has been, and importantly, whether it continues or not. Also, if the service continues are any further improvements required?

The questionnaire will take approximately 10 minutes to complete and your response will be anonymous.

The deadline for completing this questionnaire is 1st May 2015. All responses will be analysed and used to help evaluate and improve the service. A final report on the evaluation is anticipated in Summer 2015. Thank you for your participation.

If you would like further information on this survey or the GFF APS, please contact

Elaine Muirhead
Scottish Government
Pharmacy & Medicines Division
St Andrews House
Edinburgh
EH1 3DG

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for General Practice

The Scottish Gluten-free Food Additional Pharmaceutical Service

1. What Health Board area does your GP practice reside?

- ○ Ayrshire & Arran
- ○ Borders
- ○ Dunfries & Galloway
- ○ Fife
- ○ Forth Valley
- ○ Grampian
- ○ Greater Glasgow & Clyde
- ○ Highland
- ○ Lanarkshire
- ○ Lothian
- ○ Orkney
- ○ Shetland
- ○ Tayside
- ○ Western Isles

2. Are you a dispensing GP practice?

- ○ Yes
- ○ No

* 3. Does your GP practice use the Gluten Free Food Service (GFF APS)?

- ◯ Yes
- ◯ No

If Yes, Please skip to the next page, by clicking on the next button

4. If No, Please tell us why not (tick all that apply)

- ☐ Not available in my area
- ☐ Unaware of the Gluten Free Food Additional Pharmaceutical Service
- ☐ Patients do not want to use the Gluten Free Food Additional Pharmaceutical Service

Other (please specify)

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for General Practice

Your experience of the GFF APS

5. The GFF APS was easy to implement in my practice

◯ Agree ◯ Disagree ◯ Don't Know

6. My workload in gluten-free prescribing has reduced as a result of the GFF APS

◯ Agree ◯ Disagree ◯ Don't Know

7. Signing a re-registration form for GFF APS each year would improve patient care

◯ Agree ◯ Disagree ◯ Don't Know

8. I prefer patients to use the new GFF APS

◯ Agree ◯ Disagree ◯ Don't Know

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for General Practice

Your experience of the GFF APS

9. It is often difficult to get patients to opt in to the service

◯ Agree ◯ Disagree ◯ Don't Know

10. In my experience, the GFF Service is working well

Agree Disagree Don't Know

11. The GFF APS has contributed to the improvement in the quality of care of patients

Agree Disagree Don't Know

12. The GFF APS contributes to supportive patient self-management

Agree Disagree Don't Know

13. I have fewer disputes with patients over obtaining gluten free food since the introduction of the GFF APS service

Agree Disagree Don't Know

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for General Practice

The Adult Coeliac Disease Health Check

14. The Community Pharmacy adult coeliac disease health check contributes to improved patient care

Agree Disagree Don't Know

15. The system of referring patients for investigations after Community Pharmacy adult coeliac disease health check is a real benefit

Agree Disagree Don't Know

16. The implementation of an adult coeliac disease health check by Community Pharmacy as part of the GFF APS, has increased the number of investigation requests

Agree Disagree Don't Know

17. I am concerned that there may be negative health consequences because patients who receive GFF have less contact with a GP

Agree Disagree Don't Know

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for General Practice

The Scottish Gluten-free Food Additional Pharmaceutical Service

18. Would you like a similar service for other ACBS food?

Yes

No

19. In your opinion should the trial GFF APS continue as an ongoing service?

- Yes
- No

20. Do you have any other comments on the GFF APS or the Adult Coeliac Disease Health Check?

Thank you for participating in this survey.

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for Community Pharmacists

Introduction

The Gluten-free Food Service Additional Pharmaceutical Service (GFF APS) was introduced as a 12 month trial in April 2014. An evaluation of the Service is being undertaken to ascertain if it is an improvement compared to traditional gluten-free prescribing for patients through GP prescribing and community pharmacy dispensing.

This questionnaire forms part of the evaluation and your individual views as community pharmacists are vital to help identify how successful the service has been, if any improvements are necessary and, importantly, if it should continue.

All responses will be analysed and will be used to support the evaluation and incorporated in the evaluation report of the service. The evaluation report of the GFF APS is anticipated to be completed in Summer 2015.

The questionnaire should take no more than 10 minutes to complete. Your response will be anonymous. Please spend a few moments to complete this questionnaire and contribute to the assessment of the service.

This questionnaire will run from 3rd March to the 31st March 2015. Thank you for participating.

If you would like further information on this survey or the GFF APS, please contact:

Elaine Muirhead
Scottish Government
Pharmacy & Medicines Division
1ER
St Andrews House
Edinburgh
EH1 3DG
Email: elaine.muirhead@scotland.gsi.gov.uk

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for Community Pharmacists

The Gluten-free Food Additional Pharmaceutical Service (GFF APS)

1. Do you provide the Gluten Free Food (GFF) Additional Pharmaceutical Service in your Community Pharmacy?

- ○ Yes
- ○ No

If you answered No to this question, Go straight to the Training & Information Support page, by clicking on the next button

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for Community Pharmacists

The Gluten-free Food Additional Pharmaceutical Service (GFF APS)

In relation to the new GFF APS, how much do you agree or disagree with each of the following:

2. The GFF APS was easy to implement within my pharmacy

Agree Disagree Don't Know

3. It is easy for my pharmacy staff to place patients' orders for GFF

Agree Disagree Don't Know

4. Patients using the GFF APS are trying out different gluten free foods

Agree Disagree Don't Know

5. I prefer patients to order their GFF via GP prescription

Agree Disagree Don't Know

6. My overall experience of the new GFF APS has been positive

Agree Disagree Don't Know

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for Community Pharmacists

The Gluten-free Food Additional Pharmaceutical Service (GFF APS)

The new GFF APS has many aims.
Please tell us how much you agree or disagree with the following statements on the impact of the service:

7. The GFF APS has helped my pharmacy improve the service it gives to patients

Agree Disagree Don't Know

8. Community Pharmacy is contributing positively to healthcare

Agree Disagree Don't Know

9. I have better interaction with patients

Agree | Disagree | Don't Know

10. Identification of wider health issues has improved patient care

Agree | Disagree | Don't Know

11. Use of the Patient Care Record (PCR) means better patient care

Agree | Disagree | Don't Know

12. GFF APS supports patient self-management

Agree | Disagree | Don't Know

13. Relations with the wider healthcare team (e.g. dieticians) has been improved as a result of the service

Agree | Disagree | Don't Know

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for Community Pharmacists

The Gluten-free Food Additional Pharmaceutical Service (GFF APS)

14. There has been a reduction in inappropriate prescribing

Agree | Disagree | Don't Know

15. The new service gives better value for the NHS

Agree | Disagree | Don't Know

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for Community Pharmacists

The Gluten-free Food Additional Pharmaceutical Service (GFF APS)

16. It is easier for patients to change their GFF order

Agree | Disagree | Don't Know

17. It is faster for patients to receive their monthly order of GFF with the pharmacy

Agree | Disagree | Don't Know

18. Patients using the GFF APS are changing their GFF orders more often since the service began

Agree Disagree Don't Know

19. It is easy for patients to receive their monthly order of GFF with the pharmacy

Agree Disagree Don't Know

20. The variation in HB food lists affects my service to patients

Agree Disagree Don't Know

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for Community Pharmacists

The Gluten-free Food Additional Pharmaceutical Service (GFF APS)

In your opinion, how can we make the provision of GFF APS easier for Community Pharmacies?

21. IT solution for handwriting CPUS

Agree Disagree Don't Know

22. Community Pharmacy rather than GP practice manage annual re-registration

Agree Disagree Don't Know

23. Community Pharmacy manage patients transfer if they move to another Community Pharmacy

Agree Disagree Don't Know

24. A single food list across Scotland

Agree Disagree Don't Know

25. No items should require out of pocket expenses (OPE)

Agree Disagree Don't Know

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for Community Pharmacists

The Adult Coeliac Disease Health Check

26. Have you undertaken any adult coeliac disease health checks?

Yes

No

If you answered No to this question, Go straight to the Training & Information Support page, by clicking on the next button

If you answered Yes to the above, please answer the following:-

27. What was positive about the checks? (Tick ALL that apply)

- [ ] Positive patient engagement
- [ ] Chance to discuss healthcare issues with patients
- [ ] Identify need for onward referral to another health professional
- [ ] PCR helpful
- [ ] Other (please specify)

28. What was negative about the checks? (Tick ALL that apply)

- [ ] Negative patient engagement
- [ ] Time consuming
- [ ] PCR not helpful
- [ ] Felt out of my depth
- [ ] Of little value
- [ ] Other (please specify)

29. How could it be made better? (Tick ALL that apply)

- [ ] More training needed
- [ ] Update of PCR required
- [ ] Other (please specify)

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for Community Pharmacists

Training and Information Support

30. NES resources were important to my learning and delivery of the service e.g. (training pack, local events, webinar)

- ( ) Agree
- ( ) Disagree
- ( ) Don't Know

31. There was adequate training prior to the GFF Service starting

Agree | Disagree | Don't Know

If you disagree, what more could be done to meet your needs?

32. In your opinion is ongoing training needed?

Agree | Disagree | Don't Know

If you agree, What additional training is needed?

33. If you feel additional training is nedded, how would you want this delivered? (Tick ALL that apply)

Meetings | Webinar | Online Training Material

Podcast | Written Material

34. The online support information on the GFF APS was useful

Agree | Disagree | Don't Know

35. CPS resources are important to my understanding and delivery of the service (e.g. podcast, key facts sheet)

Agree | Disagree | Don't Know

36. There is adequate support for you to run the service?

Agree | Disagree | Don't Know

If disagree, what more could be done to meet your needs?

37. In your opinion should the trial GFF APS continue as an ongoing service?

Yes

No

Any other comments?

Scottish Gluten-free Food Service Improvement Measures - Survey Questions for Community Pharmacists

About you

38. Which NHS Board do you usually work in?

- ○ Ayrshire & Arran
- ○ Borders
- ○ Dunfries & Galloway
- ○ Fife
- ○ Forth Valley
- ○ Grampian
- ○ Greater Glasgow & Clyde
- ○ Highland
- ○ Lanarkshire
- ○ Lothian
- ○ Orkney
- ○ Shetland
- ○ Tayside
- ○ Western Isles

39. Are you a:

- ○ Community Pharmacist
- ○ Pharmacy Technician

Other (please specify)

40. Do you usually work in a:

- ○ Independent Community Pharmacy
- ○ Larger chain of Community Pharmacies
- ○ Small chain of less than 7 Community Pharmacy premises

Thank you for participating in this survey.

Scottish Gluten-free Food Service - Survey Questions for Patients

Introduction

In April 2014, patients eligible to access Gluten-free food on prescription in Scotland were given the opportunity to register for the new pilot Scottish Gluten-free Food Additional Pharmaceutical Service (GFF APS). This service enables patients to receive their prescription Gluten-free Food directly from the community pharmacy without going to their GP for a prescription.

If you are eligible for this new service then we would be grateful if you would take 10 minutes to answer the following questions to help evaluate the service. The feedback will help us understand if the service meets your needs, could the service be improved and most importantly should this service continue.

Responses are invited by 31 March 2015. Please be assured your response is anonymous and cannot be traced back to you.

Thank you for taking part in this survey. Your views will be collated and help form the report on evaluating the service. The report is anticipated to be completed by summer 2015 for submission to the Scottish Government.

If you would like further information on this survey or the Community Pharmacy Gluten-free Food Service, please contact:

Elaine Muirhead
Scottish Government
Pharmacy & Medicines Division
St Andrews House
Edinburgh
EH1 3DG
Email: elaine.muirhead@scotland.gsi.gov.uk
Telephone: 0131 244 3433

Scottish Gluten-free Food Service - Survey Questions for Patients

The Scottish Gluten-free Food Service

1. Did you receive Gluten-free Food prescriptions from your GP prior to April 2014?

- ○ Yes
- ○ No

2. Do you receive Gluten-free Food prescriptions using the new Community Pharmacy Gluten-free Food Service?

- ○ Yes
- ○ No

Scottish Gluten-free Food Service - Survey Questions for Patients

If you are using the new Community Pharmacy Gluten-free Food Service, please answer the following:-

3. I like the new Gluten-free Food Service

Agree | Neither Agree nor Disagree | Disagree | Not Applicable

4. It is easy to place my Gluten-free Food monthly order with my Community Pharmacy

Agree | Neither Agree nor Disagree | Disagree | Not Applicable

5. I prefer to obtain a prescription from the GP practice for Gluten-free Food

Agree | Neither Agree nor Disagree | Disagree | Not Applicable

6. I am provided with enough information to use the Gluten-free Food Service

Agree | Neither Agree nor Disagree | Disagree | Not Applicable

Scottish Gluten-free Food Service - Survey Questions for Patients

7. I have changed my Gluten-free Food order more often since using the new Gluten-free Food Service

Agree | Neither Agree nor Disagree | Disagree | Not Applicable

8. I make changes to my Gluten-free Food choices at least once every 3 months

Agree | Neither Agree nor Disagree | Disagree | Not Applicable

9. I would like this new Gluten-free Food Service to continue

Agree | Neither Agree nor Disagree | Disagree | Not Applicable

10. Where have you obtained useful information on the new Community Pharmacy Gluten-free Food Service?

- [ ] GP Practice
- [ ] Community Pharmacy
- [ ] Health Board
- [ ] NHS Inform

Other (please specify)

Scottish Gluten-free Food Service - Survey Questions for Patients

The Adult Coeliac Disease Health Check

In this section we would like feedback from adults who have been diagnosed with Coeliac Disease. If you are not an adult with Coeliac Disease, please skip to Question 15. :-

11. Before the introduction of the Gluten-free Food Service were you offered an annual Coeliac Disease health check?

- ( ) Yes
- ( ) No

If Yes, by whom?

12. Since the introduction of the Gluten-free Food Service have you been offered an annual Coeliac Disease health check?

- ( ) Yes
- ( ) No

If Yes, by whom?

13. Have you had a pharmacy health check since starting the Gluten-free Food Service?

- ( ) Yes
- ( ) No

14. Did you require onward referral to another health professional?

- Yes
- No

If Yes, whom were you referred to?

Scottish Gluten-free Food Service - Survey Questions for Patients

The Scottish Gluten-free Food Service

15. Do you have any other comments on the new Gluten-free Food Service?

Scottish Gluten-free Food Service - Survey Questions for Patients

About you

16. In which Health Board area do you live?

- Ayrshire & Arran
- Borders
- Dumfries & Galloway
- Fife
- Forth Valley
- Grampian
- Greater Glasgow & Clyde
- Highland
- Lanarkshire
- Lothian
- Orkney
- Shetland
- Tayside
- Western Isles
- Don't know

17. Are you male or female?

- Male
- Female

18. What was your age on your last birthday?

Thank you for participating in this survey.

Letter to Health Boards and stakeholder organisations

Finance, EHealth and Pharmaceuticals Directorate
Pharmacy and Medicines Division

T: 0131-244 3433 F: 0131-244 2326
E: Elaine.Muirhead@scotland.gsi.gov.uk

3 March 2015

Dear Colleague

REVIEW OF GLUTEN FREE FOOD ADDITIONAL PHARMACEUTICAL SERVICE

As you may be aware, the Scottish Government commenced the national Gluten-free Food Service (GFF) as an Additional Pharmaceutical Service (APS) on a 12 month trial basis from April 2014. This trial has been extended to 18 months, ending on 30 September 2015 to allow an evaluation of a full year implementation of GFF APS.

I have agreed to lead a review of the trial service, to assess its success in meeting the aims, objectives and desired outcomes, and recommend if the service should continue following the trial period. A report will be submitted to the Scottish Government on the review outcomes by summer 2015.

It is intended to look at whether the new GFF APS has improved clinical benefit for appropriately diagnosed patients, is cost effective by comparison with the previous arrangements, plus the impact on participating parties, principally patients, General Practice and Community Pharmacy. Questionnaires for patients, pharmacists and GPs have been developed to gather the views of those major stakeholders involved in the GFFS APS. In addition, views will be gathered from a wide range of stakeholders on the trial service.

To help inform the review, I am writing to invite you to submit your views on the new GFFS by Tuesday 31 March 2015. A list of questions is attached as an Annex overleaf. All responses received will be considered for incorporation into the service evaluation report to the Scottish Government. If you have any questions about the review process, please do not hesitate to contact me on the email address: margaret.ryan@ggc.scot.nhs.uk

Yours sincerely

Margaret Ryan

MARGARET RYAN

REVIEW OF GLUTEN FREE FOOD ADDITIONAL PHARMACEUTICAL SERVICE

Questions for stakeholder organisations

1. In your opinion, does the GFF APS meet the aims outlined in Appendix B of the NHS Scotland Circular: PCA (P) (2013) 29 to:

- **a.** Support the provision of direct NHS pharmaceutical care to patients with coeliac disease or dermatitis herpetiformis by providing a pharmacy led nationally consistent service;
- **b.** Make optimum use of clinicians' skills and empower the patients to actively manage their own condition;
- **c.** Improve the patient experience of obtaining GFFs on prescription by reducing the number of visits needed to GP surgeries;
- **d.** Provide appropriate clinical monitoring for patients directly affected including dietetic intervention and annual pharmacy health check;
- **e.** Provide more systematic nationally consistent management of patient needs;
- **f.** Allow eligible and qualifying patients access to staple Gluten Free Food to access a convenient service customised to their needs which is also cost effective for NHS Scotland
- **g.** Assist through collaborative working the better management of the demand on the time of all members of the primary care team involved in providing this service to patients
- **h.** Remove the need for a GP to be involved in issuing multiple gluten free prescriptions once he/she has determined the unit allocation and the patient has registered with a pharmacy
- **i.** Reduce the incidence of out of pocket expenses incurred as a consequence of community pharmacy dispensing of individual prescriptions for gluten free foods written by GPs.

2. Should the new GFF APS be retained on an ongoing basis?

3. Are there improvements or changes required to the trial GFF APS should the service be retained?

4. Are there any specific issues you would like to raise relevant to the evaluation of the trial GFF APS?

Responses are invited to be submitted by either post or email by **31 March 2015** to:

Margaret Ryan
Lead Clinician Prescribing Services
Queens Park House
Victoria Infirmary
Langside Road
Glasgow
G42 9TW
Telephone: 0141 201 5639
Email: margaret.ryan@ggc.scot.nhs.uk

Letter to manufacturers of Gluten-free products

Healthcare Quality and Strategy Directorate
Pharmacy and Medicines Division

T: 0131-244 3433 F: 0131-244 2326
E: elaine.muirhead@scotland.gsi.gov.uk

TO MANUFACTURERS

5 May 2015

Dear Colleague

REVIEW OF GLUTEN FREE FOOD ADDITIONAL PHARMACEUTICAL SERVICE

As you may be aware, the Scottish Government commenced the national Gluten-free Food Service (GFF) as an Additional Pharmaceutical Service (APS) to be delivered through NHS community pharmacies throughout Scotland, on a 12 month trial basis from April 2014. I enclose a copy of the Circular which announced its introduction and set out the aims and objectives. This trial has been extended to 18 months, ending on 30 September 2015 to allow an evaluation of a full year implementation of GFF APS.

I have agreed to lead a review of the trial pharmacy service, to assess its success in meeting the aims, objectives and desired outcomes, and recommend if the service should continue following the trial period. I am currently gathering views from a wide range of stakeholders, including patients who use the trial service and pharmacists involved in delivering it. A report will be submitted to the Scottish Government on the review outcomes by summer 2015.

If your company has any specific comments that you would like to considered as part of the review, please send them in writing to me by 1st June 2015 to my email address: margaret.ryan@ggc.scot.nhs.uk

If you have any questions about the review process, please do not hesitate to contact me.

Yours sincerely

Margaret Ryan

MARGARET RYAN

Annex 6

Evaluation of Gluten Free Food Service
Survey of Patients, Community Pharmacists and GPs

1. Introduction and Methods

The views and experience of patients, Community Pharmacists and GPs were gathered to inform the Evaluation of the Gluten Free Food Service (GFFS) being provided as an Additional Pharmaceutical Service in NHS community pharmacies.. An on-line questionnaire comprising mainly closed questions was developed for each group (Annexes 1-3). GPs and Community Pharmacists were sent links to the relevant questionnaire and asked to complete and submit it. The patients' questionnaire was made available on-line and in hard copy and advertised through relevant bodies, i.e. Coeliac UK. Community Pharmacists were also provided with flyers to pass onto patients in receipt of gluten free food. These gave information on completing the questionnaire on-line or obtaining a paper copy of the survey from the Pharmacist. The patients and Community Pharmacists were surveyed in March 2015 and GPs in May 2015.

2. Survey of Patients – Analysis and Findings

2.1 Patient Responses

Patients completed a questionnaire comprising 14 questions on; their experience of the service; the impact of the service on their food selection; the Adult Coeliac Disease Health Check; and an invitation to give comments. A total of 1571 patients completed and returned the survey, and of these 1494 (95%) were using the new Gluten Free Food Service (GFFS). Practically all (95%; n=1570) respondents had previously received gluten-free food prescriptions from their GP.

2.2 Main Findings

- There is strong support from patients responding to the survey for the GFFS, with the vast majority liking the service and supporting its continuation.
- There is an association between ease in changing their order and how often patients do so. In the majority of cases patient reported changing their order more often increased since the introduction of the GFFS.
- Just under half of respondents had received a coeliac health check but less than one third had received a pharmacy check since starting the GFFS.

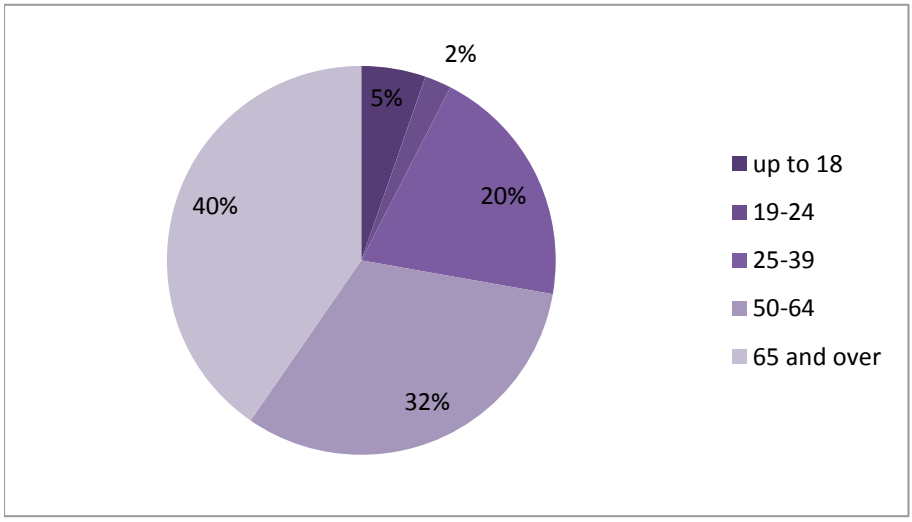
2.3 Profile of Respondents

There were responses from: individuals living in all the Health Board areas in Scotland; men and women; a range of ages but the distribution was not even. Over twice as many responses were from women (65%; n=1016) as men (29%; n=463) (6%; n=92 did not indicate their gender) (Table 2-1). The respondent age profile was towards older age groups, with 40% (n= 603) aged 65 and over and 32% (n=476) aged between 50-64 (Figure 2-1). There were fewest respondents in the 19-24 age category (2%; n=33) and 5% (n=80) were aged under 18, of which just over one third (n=28) were under 10 and their parents had completed the survey.

Table 2-1 Gender of respondents

	Number of responses	Percentage
Male	463	29%
Female	1016	65%
Not Answered	92	6%
	1571	100%

Figure 2-1 Age of Respondents



Responses were broadly in line with population proportions in Health Board areas. Fife, Forth Valley, Tayside, Dumfries and Galloway and Borders had the highest proportion of responses and Grampian, Lothian and Lanarkshire the lowest (Table 2-2).

Table 2-2 Population and Survey Respondents by Health Board

Health Board	Pop	% of pop	Response Count	Response %
Ayrshire & Arran	372,210	7%	115	7.7%
Borders	113,870	2.1%	69	4.6%
Dumfries & Galloway	150,270	2.8%	77	5.2%
Fife	366,910	6.9%	126	8.4%
Forth Valley	299,680	5.6%	125	8.4%
Grampian	579,220	10.9%	118	7.9%
Greater Glasgow & Clyde	1,137,930	21.4%	337	22.6%
Highland	321,000	6.0%	108	7.2%
Lanarkshire	652,580	12.2%	137	9.2%
Lothian	849,700	15.9%	99	6.6%
Orkney	21,570	0.4%	4	0.3%
Shetland	23,200	0.4%	12	0.8%
Tayside	412,160	7.7%	163	10.9%
Western Isles	27,400	0.5%	4	0.3%
	5,327,700	100%	1494	100%

2.4 Patients' Views of Service

The vast majority of respondents liked the service (90% n=1284) and want it to continue (93%; n=1318) (Table 2-3). Indeed very few respondents disagreed with this (4%; n=52 and 2% n=34) and only a few more neither agreed nor disagreed (6% n=87 and 5% n=64 respectively).

Table 2-3 Views on the GFFS and its continuation

	I would like this new Gluten Free Food Service to continue		I like the new Gluten Free Food Service	
	Number of responses	Percentage	Number of responses	Percentage
Agree	1318	93%	1284	90%
Disagree	34	2%	52	4%
Neither Agree nor Disagree	64	5%	87	6%
		100%		100%

One question asked if respondents would prefer their prescription to be from the GP. In a further indication of support for the GFFS, 78% (n= 1093) disagreed and only 5% agreed (n=70) with this suggestion (Table 2-4).

Table 2-4 Prefer to Obtain Prescription from GP

	Number of responses	Percent
Agree	70	5%
Neither Agree nor Disagree	170	12%
Disagree	1093	78%
Not Applicable	61	4%

Whether respondents liked the GFFS was analysed according to health board in which they reside. In all Health Board areas the majority of respondents liked the service (Table 2-5). This was highest in Orkney and Western Isles (100% n=3) (but the low response numbers should be noted). There were high levels of support in Borders (94% n=63) Forth Valley and Lanarkshire (93% n=108 and n=120 respectively). This fell to 82% in Fife, and 85% in Ayrshire and Arran. The areas that had the most, although still a small number and proportion, people disagreeing with statement "I like the Gluten Free Food Service" were; Fife (8% n=9); Dumfries and Galloway (7% n=5) and Highland (6% n=6).

Table 2-5 Response to Statement "I like the new Gluten Free Food Service" by Health Board

	Ayrshire & Arran	Borders	Dumfries & Galloway	Fife	Forth Valley	Grampian	Greater Glasgow & Clyde	Highland	Lanarkshire	Lothian	Orkney	Shetland	Tayside	Western Isles	Total
Agree	85%	94%	89%	82%	93%	89%	91%	90%	93%	92%	100%	91%	92%	100%	90%
Disagree	4%	1%	7%	8%	4%	4%	3%	6%	2%	3%	%	%	2%	%	4%
Neither Agree nor Disagree	12%	4%	4%	10%	3%	7%	6%	3%	5%	4%	%	9%	6%	%	6%
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

2.5 Patients' Experience of service

The majority of respondents, 93% (n=1320) agreed with the statement, "It is easy to place a gluten-free monthly order with my community pharmacy" (Table 2-6). 90% (n=1281) agreed that they are provided with enough information to use the service.

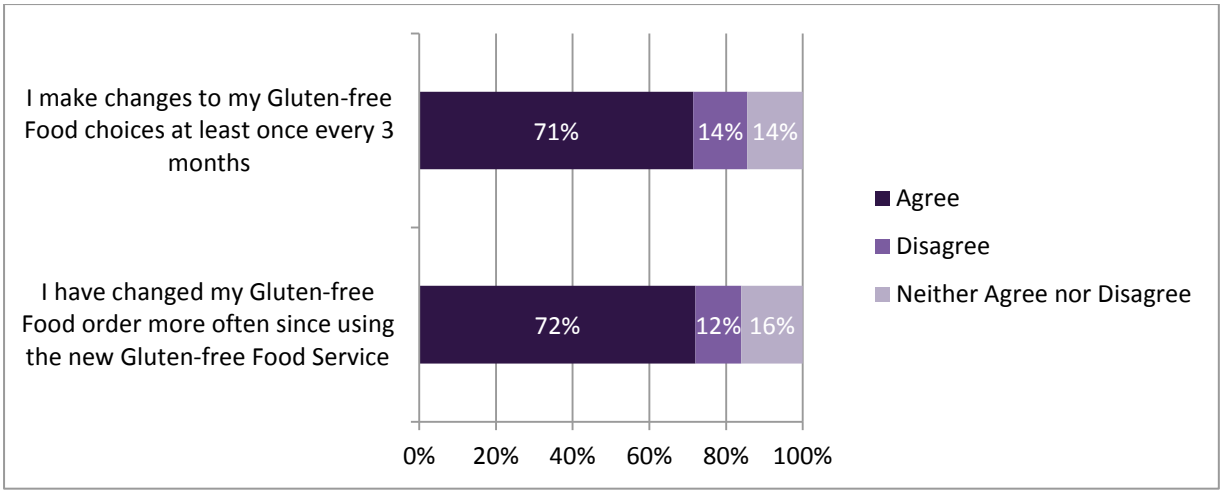
Table 2-6 GFFS Service Ease

	Easy to place my Gluten Free Food order		I am provided with enough information	
	Number	%	Number	%
Agree	1320	93%	1281	90%
Disagree	51	4%	50	4%
Neither Agree nor Disagree	52	4%	93	7%

2.6 Impact of Service

The service seemed to facilitate patients changing their order more often. 72% (n=982) altered their order more often than prior to the service introduction and 71% (n=995) had made changes at least once in three months (Figure 2-2).

Figure 2-2 Changes to gluten-free food order



The ease with which a patient could place their gluten-free food monthly order was associated with changing the order more often. Therefore 89% of respondents (n=935) who agreed it was easy to place their order also agreed that they had changed it more often (Table 2-7). This was supported in the reverse with a majority (59% n=23) who disagreed it was easy to change the order were not changing it more often. Ease of changing was not essential and 41% (n=16) who didn't find it easier were still altering their order more often. There was a little variation with age, with older people a little less likely to change their order.

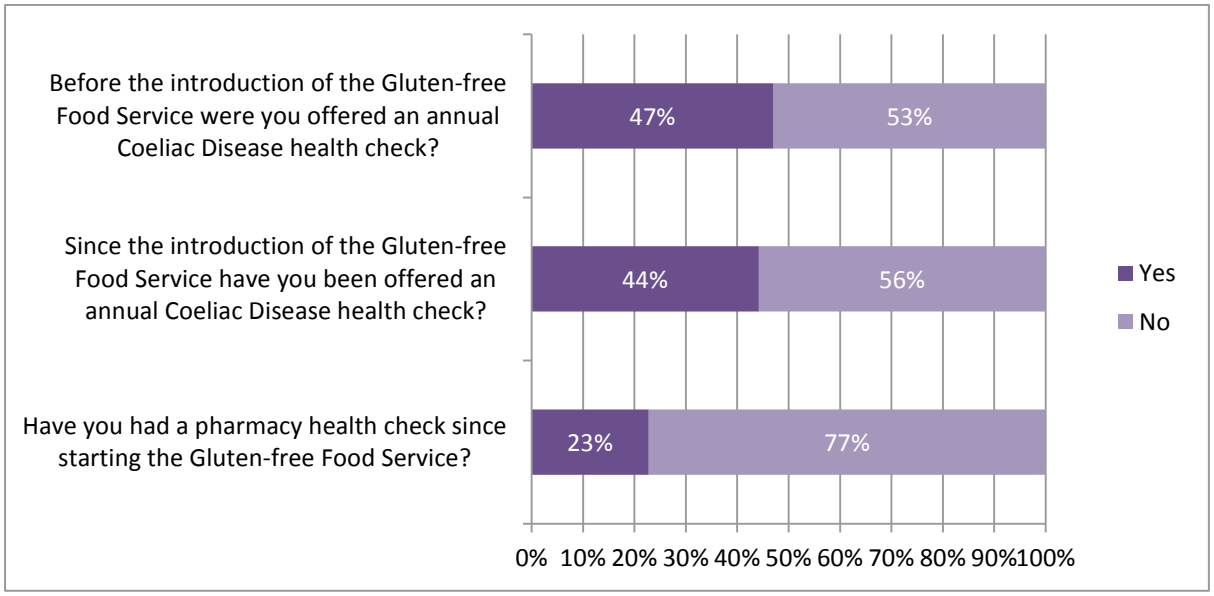
Table 2-7 Ease of Changing Order with Increased Changes

It is easy to place my Gluten Free Food monthly order with my Community Pharmacy				
Changed order more often	Agree		Disagree	
Agree	935	89%	16	41%
Disagree	121	11%	23	59%

2.7 Adult Coeliac Disease Health Check

The survey contained a section on health checks for people with coeliac disease and there were 1398 responses to these questions. There was a fairly even split as to whether respondents had a health check. 47% (n=658) were offered an annual Coeliac Disease Health check prior to the GFFS and 44% (n=618) since the introduction (Figure 2-3). This fell to 23% (n=325) that had actually had a pharmacy health check since commencing the GFFS. There were 10% (n=126) that reported needing onward referral to another health professional. These numbers suggest that this question was answered by more than those who had received a pharmacy health check.

Figure 2-3 Coeliac Disease Health Checks



2.8 Analysis of patients comments

This section reports analysis of 962 respondents' additional comments made in the survey. These were primarily on the GFFS system, and most of the remainder were on six overlapping themes:

- Frontline services
- Administration and other process
- Choice of food
- Formulary lists – differences between health boards
- Costs and affordability of gluten-free food
- Units awarded

Respondents also raised general issues and provided a range of practical suggestions for the service.

2.9 GFFS system generally

Over 330 respondents who provided comments supported the new services. Some were very enthusiastic and wholly positive, others liked the arrangement overall but suggested potential improvements that are outlined below. Fewer than 30 respondents who gave written comments, disliked the new service, the primary reasons for this were; they found it less convenient or disputed their unit allocation.

2.10 Frontline services

Most respondents reported a good service from their pharmacy and were happy with the new arrangements. They received help and support from the pharmacist and though it was an efficient and worthwhile service. It was generally described as easy to use.

The vast majority that gave comments were very positive about the Community Pharmacy service. Respondents generally found it was easier to visit their local pharmacy since they could go at a time that suited them without needing an appointment as with the GP. Choose which pharmacy to use which was particularly convenient for working persons, although for others the "office" opening hours were not convenient.

Some commented that they felt more in control of their diet and lifestyle as a result of the new service. They were more inclined to try a variety of products since it was easier to change monthly orders. In addition several noted that they had been given helpful advice from pharmacy staff on products. There were positive comments about the flexibility offered by pharmacies and staff readily available to answer questions and provide advice.

"Ability to use community Pharmacist is easier and less time consuming. It provides greater flexibility to allow me to try alternative products."

Respondents also appreciated that the service freed up their GP's time. There were a number to the effect that their view was providing repeat prescriptions for gluten-free products was not best use of GP's time and resources. Indeed under the previous arrangements, they had not made appointments with their GP because they thought it was not good use of GPs time. Therefore they did not change their prescription or seeks advice on products. The GFFS was seen as a better use of local health services and allowed GPs to spend more time with other patients. The comments illustrate there is no desire to have the service transferred back to GP practices.

"This is a service that does not need to be undertaken by the GP so should free up some of their time."

"It is excellent and makes ordering food very easy without bothering the GP."

There were difficulties in practice reported. A small number of respondents had encountered problems in trying to change the pharmacy they used for GFFS. Some experienced slow transfer when they had moved area and one respondent case reported a month without food on prescription as a result. Moving from the GP to the GFFS could be problematic and there were reports of patients needing to negotiate between the GP and pharmacist. One respondent was told that they were required to remain with the pharmacist they had registered with although they were dissatisfied with the service. A few respondents reported communication difficulties between their GP and pharmacist or some lack of GP awareness of GFFS.

Some mentioned inconvenience getting to the pharmacy to hand in order forms due to their work hours. A solution proposed was introduction of a drop box or other out of hours box. Others to mentioned previously they use one system, it now involves two contacts; (i) GP for repeat prescriptions for medicines and; (ii) Pharmacist for gluten-free foods. Those with more complex food allergies and intolerances had also found the new service difficult to use. Finally, there was mention of the difficulty in discussing issues in confidence in a busy pharmacy.

2.11 Administrative and other processes

A wide range of comments were given on administrative and the service process, but the positive comments clustered under three themes; easier and more flexible system; more straightforward way to change the content of orders and reduced use of GP time.

Many respondents reported they found the GFFS easy to use. The reasons given included that access to a pharmacy was straightforward, the forms are simple to complete and the order can be collected within a couple of days. Being able to complete the order form at home was seen as beneficial. Others noted the GFFS was clear, flexible and a quicker in comparison to previous system.

Largely as a result of the ease of the arrangements, respondents noted that it was simpler to change the order in the GFFS. In part this was due to the administrative arrangements, for example the list of the products available attached to order forms was reported as helpful. For many the removal of the GP from the process was the other main reason for finding the system easier i.e. changes could be made through dropping off a form at the pharmacist and no longer necessitated an appointment with a GP or speaking to the surgery. Many recognised and supported the mutual benefits in being able to obtain gluten-free food without taking up GP time and GP time not used for prescribing foodstuffs.

"I would very much like for this service to continue as it is so much easier to place my order with the pharmacy using the forms and it saves me involving my GP whose time would be better spent seeing patients."

It was common for respondents to report they tried more new foods because it was easier to change their order, and because they knew there were not then committed for a period. This gave flexibility to try products to find which they liked best. Consequently people were using a greater variety of new foods. The information given on the products available also supported people trying new foods and generally more variety in products ordered.

Many believed that there were also indirect improvements resulting from the GFFS. More effective use of resources was mentioned, such as reduced food waste, as a result of the flexibility in ordering. For some the GFFS had reduced the number and length of trips for ordering and collecting food that produced environmental benefits. This could be the case in rural areas, where the pharmacy was nearer than a GP. The following quote below illustrates many of the points made on these themes:

"I think it is a very useful and easy to use service. I hardly ordered anything before as I felt it was a burden on the doctor to be constantly changing prescriptions based on what I need and doctors are overworked as it is. With the new service, I have been able to try different things at my leisure and decide what works for me. I vary what I order from month to month and don't waste food by working out what I need and when. It is simple to complete the form and hand into the pharmacy. Having the list with the pip codes makes the choices available much clearer, and possibly if I had had this list when ordering prescriptions prior to the new service, it would have been an easier process. Not knowing what points were allocated to each time, meant I would have to pester doctor to put a simple order in. I think the new system is far superior, but would be interesting to know if it costs the NHS more or saves money. Thank you."

There were also respondents who were not entirely content. For some people the

new system was more cumbersome due to various reasons. The requirement to complete a monthly order form even when no changes were made was questioned. The necessity of completing a hard copy form in person, with no on-line option was a source of complaint, although some respondents did seem to be able to email orders to their pharmacist. In one example, under the previous system individuals had been able to telephone or email the GP for a repeat prescription. Now a trip to the pharmacist in person to submit an order in hard copy was required. It was suggested that an email or online ordering system would be useful for GFFS.

"The service would be much easier to use online. As it is I have to fill in a blank template paper form each time I want to make an order and physically take it to the local chemist's. Then I have to go again to pick up the GF items (which I would have to do using an electronic ordering system). I also need regular medical repeat prescriptions from my Dr so that requires another, separate, trip to the Chemist's to collect. An online ordering system would cut out one monthly trip to the chemist and make monitoring much easier. I'd also be able to select favourite items, instead of handwriting out all the information every time."

In some cases, forms were completed in the pharmacy and some patients felt pressure to make the selection quickly. These irritations were compounded by the style of the form that required the order and PIP codes to be completed each time. One proposal was for a pre-printed form with the core items. This could avoid the necessity of looking up PIP codes and points values and make calculation easier. Another proposal to improve the order system was inclusion of pictures of the goods with the order form. This could also help deal with a problem for some people that arose from the lack of information on the product list on the weight and amount of food. This was confusing and the source of waste. Finally the need to plan in advance the food that was wanted/required was disliked by a few respondents.

One recurring theme was the minimum order size, primarily for fresh bread where a single bread order was often a pack of eight loaves. Those without freezers, or small freezers, in particular found this problematic and bread would go off and be wasted. If they were not alerted the order was available, the bread and other fresh food could be near or past its use by date by the time it was collected. Proposed solutions were to be able to order less bread more often and sharing orders of fresh food.

"It is good because you have a chance to try any gf products available. It is not so good because you need a freezer to store the months supply of bread, or more to the point enough room available which is rarely the case in the household one. Also the supplies of fresh items when they arrive often have very short use by dates maybe just 2-3 days and I have had supplies past there date which the pharmacy would not take back because they said it was in date when they received it."

Storage of many bulky items was an issue for both pharmacists and patients. Transporting large and heavy items was very difficult for people without cars and the possibility of a delivery service was raised. There was differing experiences in the delivery of food as some arrived as one order and could be collected in one journey, while for others collection took several trips. One suggestion was a text message service from pharmacists when orders were ready for collection.

The fixed monthly ordering cycle did not suit all; for some this is too infrequent for the changes for others it seemed unnecessary to order so frequently. The inflexibility could be problematic, for example additional items could not be ordered to cover a holiday period.

Having accurate, up to date information on availability of products was a theme in the comments. There was some concern about how frequently the list of products was updated and whether new products would be added to the list. It was proposed that new food be added more regularly to the list. There were also a number of comments about supply difficulties where the pharmacy could not order, or did not receive, requested products. Several respondents reported supply problems, missing items or a lengthy wait for products to arrive or incorrect orders.

"It was a nightmare to set up, no one knew what they have to do. The forms weren't easy. The pharmacy doesn't update the list of products available free. Not really set up as it should."

Whilst there was not a problem with this service, some expressed a preference for obtaining food form a supermarket and wondered if a vouchers system could be introduced.

2.12 Choice of food

A number of respondents were very positive about the range of gluten-free food and thought there were more products available on the NHS; others thought the range of choice too limited. There was a view from many that there was more limited choice that they had experienced when previously receiving gluten-free food via a GP prescription. Many respondents stated the names of particular brands or products that they would like to see available through the GFFS. There was no clear consensus with this and a very wide range of different products were mentioned as personal preferences.

"Good range of products though inevitably there are a few things I like which are not available."

"The choice is fairly limited and I am not keen on a lot of the products on offer."

There was some potential for confusion with information about new products that were available through the GFFS. Some stated that they were unsure if new items would be added to the list of prescribable products and how they would find out about any additions or changes.

"I wish they would introduce new items to the list and update it every so often as it gets a bit repetitive."

There were some comments that the products available through the GFFS were less palatable than gluten-free food available in supermarkets. Several respondents noted that biscuits and cakes were not available and were of the view that they should be included. Those with other food allergies found it particularly difficult to find suitable products and there were calls for better nutritional information about each product to help inform choices. There was also a suggestion that there should be a wider choice that would appeal to children.

2.13 Formulary lists – differences between health boards

There were comments on the variation between Health Boards on the gluten-free products permitted and this overlapped with feedback on the produce choice more generally. Some respondents wondered why it was that some products were available on some health boards' lists but not others. There was questioning of the variation in the availability of types of items, e.g. biscuits; or a brand of a food. There was an example where the respondent's experience was differing units allocated for the same item in two areas, meaning they received less food. Solutions proposed

were; to have a Scotland-wide list or the full Coeliac list and/or include all foods with a PIP number. A perceived lack of user involvement in drawing up the list was raised and it was felt this should be improved in the future. The quote illustrates the points outlined:

"Although I like the new service, I am not very happy with the choices available. Some reason NHS X have drastically reduces the choices of gluten-free foods, in comparison with other regions. I have checked out the choices available to other regions. NHS X have 2 pages of choices, whereas other regions have 5 or 6 pages, and some with even more (9/10 pages for one region). I feel this is very unfair, and some foods that I was able to have through my doctor are now no longer allowed. Is there any way to find out why NHS X have done this?"

Respondents reported both more and less choice than under the previous system, but these did not prevent support for the new system overall.

2.14 Cost and affordability of gluten-free food

Given gluten-free food can be expensive a number of respondents noted that receiving the food on prescription was important. If all food had to be purchased diet adherence would be difficult and trying new foods would be less likely. Some respondents found their supply adequate. For many, there was a need to supplement items provided by GFFS by purchasing additional food from supermarkets. Given gluten-free food is higher in price, several respondents stated that the GFFS was important in providing them with the basic foods. Another suggestion was to increase units on the GFF system or restrict the price of gluten-free food.

"So grateful for this service as our food is so expensive in the shops. Now I can have the basics on prescription and it allows me a bit more variety."

Views seemed split on the type of products that should be available. For some, non-basic food such as biscuits and cakes should be on prescription because these are expensive; prohibitively so for some respondents. For others basic food such as bread, pasta and flour were the priority for prescription.

"This type of food is somewhat restricted - no biscuits or fruit loaf or cakes but I can understand the logistics must be pretty horrific. The choice is adequate and from a financial point of view it is great. I purchased GF Food until I was informed about GFFAPS and the savings are considerable."

2.15 Units awarded

Respondents had differing opinions on the points allocated. For some it was adequate, indeed one reported they were sufficient to feed a family and was concerned the system is open to abuse. For others the unit allocation was insufficient. Some made specific cases; such as an individual who worked on a building site and was really restricted to taking sandwiches so most of their units were used on bread. One proposal was to be able to rollover unused units to the next month since some people did not use their allocation every month. Some also proposed that there are transferred to cash to spend on commercial gluten-free products.

2.16 General Issues

There were more specific issues raised, generally by one or a few respondents. A group of respondents reported that GFFS played a part in them managing their

condition. One parent pointed out their 13 year old child could now choose their own food and this supported their learning for future self-management of the condition.

The issue of diagnosis was raised, both being diagnosed and the length of time this could take. Whilst there was support for the service and consequential reduction in GP time, a note of caution was sounded to ensure that this did not impact on diagnosis. It was also queried as to whether the service should be expanded to people who are wheat intolerant.

One respondent found an NHS list reassuring of quality and had negotiated with their pharmacist to supply other additional items not readily available that the patient then paid for.

There were respondents who only first heard of the service through the survey and one who had checked with their pharmacist who was also unaware. Another asked why the service was limited to adults, although this is not the case.

2.17 Health Checks

Respondents expressed differing views on who should carry out a health check; pharmacist; GP, coeliac nurse specialist or a dietician. Some respondents had doubts as to whether the Pharmacist had the skills or suitable venue to take blood and thought that this needed to be done as an individual service by a dietician or GP. Others thought it sensible, and that pharmacists are well able to deal with standard blood tests for people with coeliac disease. Indeed one comment proposed this would reduce much duplication in the current system:

"The annual check the pharmacist provided was identical to the annual check my GP provides except that the GP also requests the bloods. It doesn't make sense for the pharmacist to complete 95% of the review, only for the GP to replicate it a week later."

Comments indicated that patients often had not been offered an annual coeliac health check. Some were aware that this existed but others had not heard of it. In one case, the Pharmacist had advised an individual to contact their GP if they had any problems, and this left the individual with the responsibility of booking a regular health check. Some confusion was apparent around who would now conduct blood and bone density tests, and when these tests would occur. There was also mention of lack of contact with hospital nurses.

2.18 Practical Suggestions

There were a number of suggestions about how the GFFS might be improved. The most common suggestion was that the order form should be made electronic so that it could be completed online and emailed direct to the community pharmacy. There were also calls from a few respondents for the GFFS to be replaced by vouchers or a card for gluten-free food that could be used at supermarkets. There were several complaints about multiple pack sizes requiring orders of 8 loaves at a time and the resulting waste.

Other suggestions included:-

<u>Order form</u>

- A simpler text only order form without bold headings so that it uses less printer ink
- More space on order form for writing in PIP codes

- Pre-printed form with details previous order to save writing out item name, PIP codes etc each month
- Add tick boxes to order form

Order process

- Email confirmation/ text message from pharmacy to advise order is ready for collection
- Ability to place phone order with pharmacy to save two visits
- Ability to order a two month supply at one time – more convenient for holidays and also for freezer/storage space
- Enable rollover of unused units to the next month – this would enable less frequent ordering e.g. a larger order every three months
- Patients to retain own copy of list of products available so can decide orders at home
- Provide patients with updated list of products when new items are added
- Quicker delivery times to pharmacy, particularly for fresh bread
- Home delivery

Food

- More choice and variety
- Add seasonal items such as at Christmas
- Suggestions to add specific named products to the list of available foods.
- Smaller samples to try different products without a lot of waste
- Better information about the products available e.g. nutritional information, weight – in advance of ordering them
- Pictures of the foods available to assist decision making
- Make it a national service instead of a service that varies by Health Board.

3. Survey of Community Pharmacists – Analysis and Findings

3.1 Main findings

The three main findings from the survey of community pharmacists are:

- The majority of community pharmacists reported a positive experience with GFFS and support its continuation. It is an easier system and can bring savings.
- Community pharmacists reported the GFFS had improved service to patients.
- Practically all agreed there should be an IT solution to replace writing Community Pharmacy Urgent Supply (CPUS) Forms by hand.
- Almost half had carried out health checks and this was beneficial in patient engagement, it can be time consuming and can involve raising sensitive issues.
- A minority found the service had improved relations with wider healthcare team.

3.2 Introduction and Respondents Profile

Community pharmacists' views and experience of the Gluten Free Food Service provided as an Additional Pharmaceutical Service (GFF APS) were gathered via on-line survey. This comprised 40 questions on the service covering: experience; views on patients' experience; the impact of the service; views on the Adult Coeliac Disease Health Check and core factual information. This section reports the findings from the analysis of the 367 responses from the survey electronically via Health Boards and Community Pharmacy Scotland to approximately 1250 community pharmacies.

A total of 358 (98%) of the respondents provide the GFFS service. The spread of responses are generally in line with the populations covered by the health boards, with most responses returned from Community pharmacies in Greater Glasgow; Lothian, Grampian and Lanarkshire (Table 3-1).

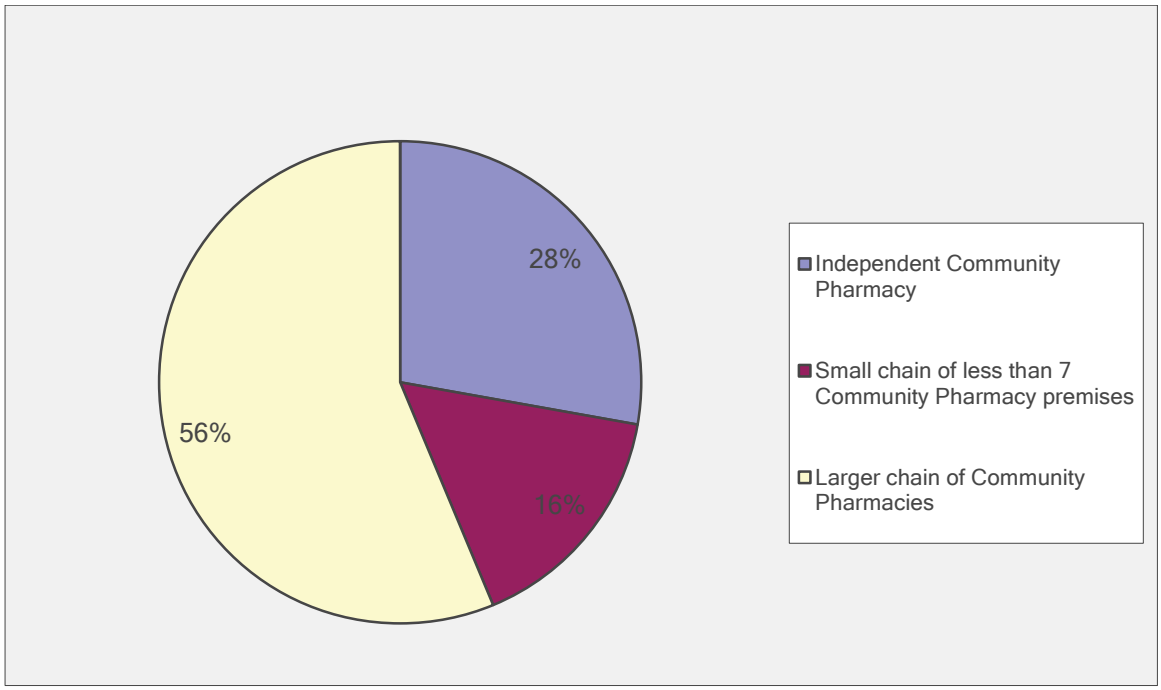
Table 3-1 Which NHS Board do you usually work in?

Health Board	Population	% of pop	Response %	Response n
Ayrshire & Arran	372,210	7.0%	5.5%	18
Borders	113,870	2.1%	3.4%	11
Dumfries & Galloway	150,270	2.8%	0.9%	3
Fife	366,910	6.9%	7.0%	23
Forth Valley	299,680	5.6%	9.2%	30
Grampian	579,220	10.9%	12.8%	42
Greater Glasgow & Clyde	1,137,930	21.4%	18.3%	60
Highland	321,000	6.0%	5.2%	17
Lanarkshire	652,580	12.2%	11.6%	38
Lothian	849,700	15.9%	15.0%	49
Orkney	21,570	0.4%	0.0%	0
Shetland	23,200	0.4%	0.3%	1
Tayside	412,160	7.7%	10.7%	35
Western Isles	27,400	0.5%	0.0%	0
	5,327,700	100%	100%	327

Most of the respondents were from community pharmacists (97%; n=315) and the remaining 3% pharmacy technicians (n=9), although 43 respondents (12% of the total) did not answer this question. In this report the term "community pharmacist" is used for all respondents. The largest group (56%; n=184) worked in larger chains of

pharmacies, followed by independent community pharmacies (28%; n=91) and the fewest respondents worked in small chains, of fewer than seven, pharmacies (16%; n=52) (Figure 3-1).

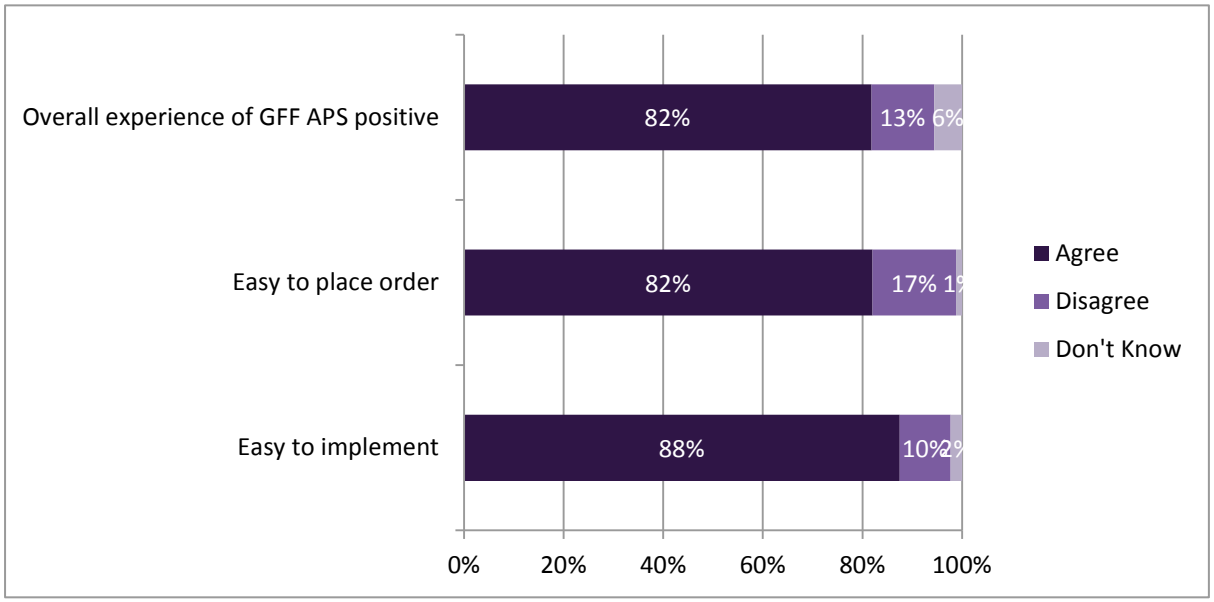
Figure 3-1 Usual Place of Work



3.3 Community Pharmacist Experience

The majority of community pharmacists reported a favourable experience of the GFFS. A total of 82% (n=279) agreed that their overall experience of GFFS had been positive. 88% (n= 301) agreed it was "easy to implement" and 82% (n=283) it was "easy for my pharmacy staff to place patients' orders for GFF" (Figure 3-2).

Figure 3-2 Experience of GFFS



GFFS was preferred to the previous service; most respondents, 76% (n=262) disagreed with the statement: "I prefer patients to order their GFF via GP

prescription" (Table 3-2). There were 17% who agreed (n=59) and 6% responded "Don't Know" to the statement.

Table 3-2 Response to statement "I prefer patient to order their GFF via GP prescription"

Agree	17.2%	59
Disagree	76.4%	262
Don't Know	6.4%	22

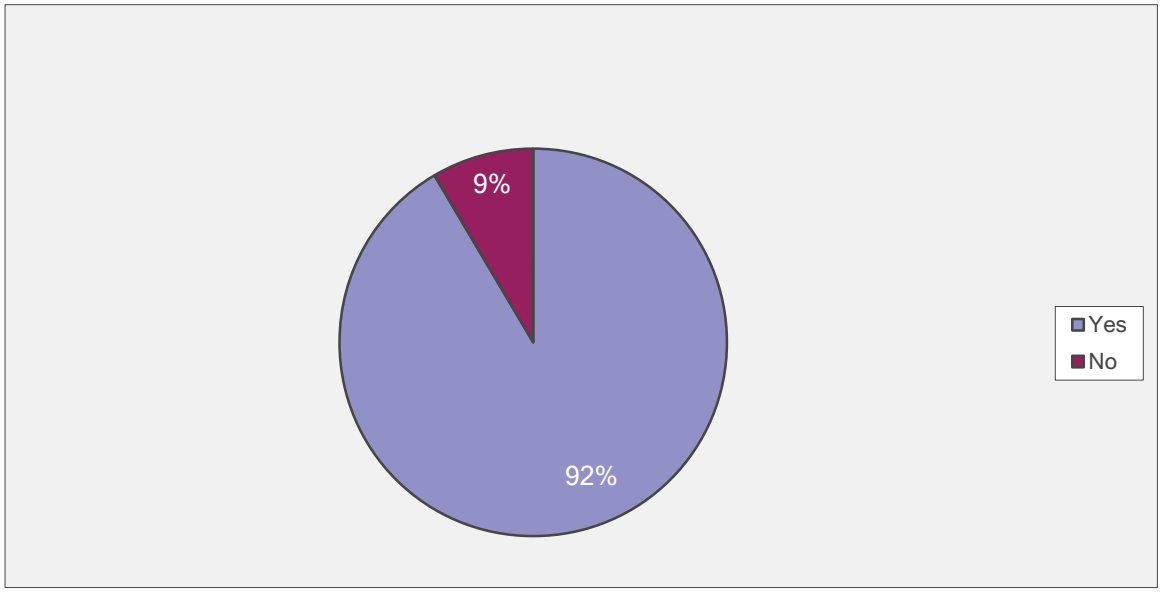
The following illustrates the positive aspects of the service for community pharmacists:

"very good service, patients have given a very positive response and are finding it easier to order and change their GFF orders than with GPs"

In the opinion of the majority of respondents, 92% (n=300), GFFS should continue as an ongoing service (Figure 3-3). In all Health Board areas the majority wanted the service to continue. The responses from the following Health Boards had the most, although still a minority, respondents who did not want the service to continue; Lanarkshire 25% (n=7) and 18% (n=5) in Greater Glasgow & Clyde and Tayside. Where reasons were offered, these questioned whether the NHS should be giving food on prescription and whether it was a good use of time for a healthcare professional. Where this was accepted, there were suggestions to issue vouchers that could be used at supermarkets instead. The following quote illustrates the points made:

"The NHS should not be funding food for coeliacs. Other patients with allergies have to buy their own goods (eg lactose intolerant patients."

Figure 3-3 In your opinion should the trial GFF APS continue as an ongoing service?



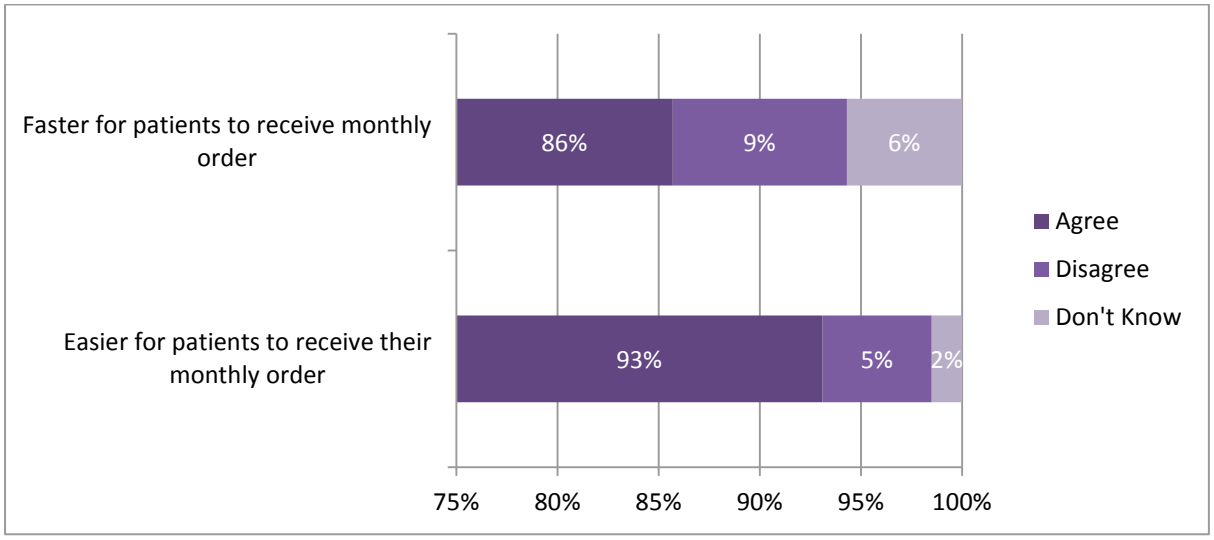
Other comments indicated that the providing the service was additional work; time consuming, although it alleviated GPs time, and the storage of goods could be problematic.

3.4 Community Pharmacist View on GFFS Impact for Patients

There had been an improvement in the services for patients in the view of the vast majority of pharmacists. Around 9 in 10 agreed "it is easy for patients to receive their

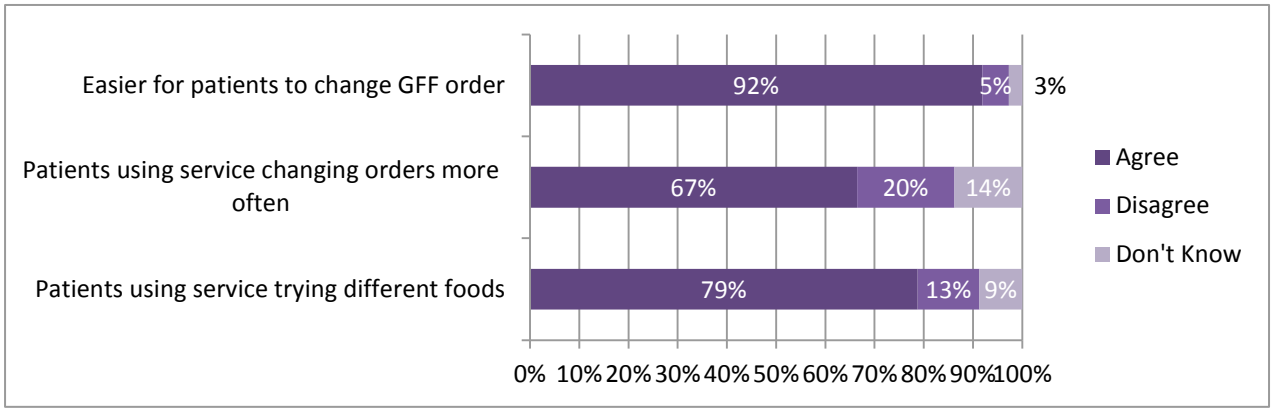
monthly order of GFF with the pharmacy" (93%; n=313) and that order receipts are faster (86%.; n=288) (Figure 3-4).

Figure 3-4 Pharmacist View of Service for Patients



Over 9 in 10 respondents thought that the service made it easier for patients to change their GFF order (Figure 3-5). A majority, albeit fewer, 67% (n=222) agreed that patients were changing their orders more often and 79% (n=270) reported that *"patients using the GFF APS are trying out different gluten-free foods"*. However 20% (n=66) disagreed that patients were changing their order more frequently and 13% (n=43) did not agree that they were trying different foods (Figure 3-5).

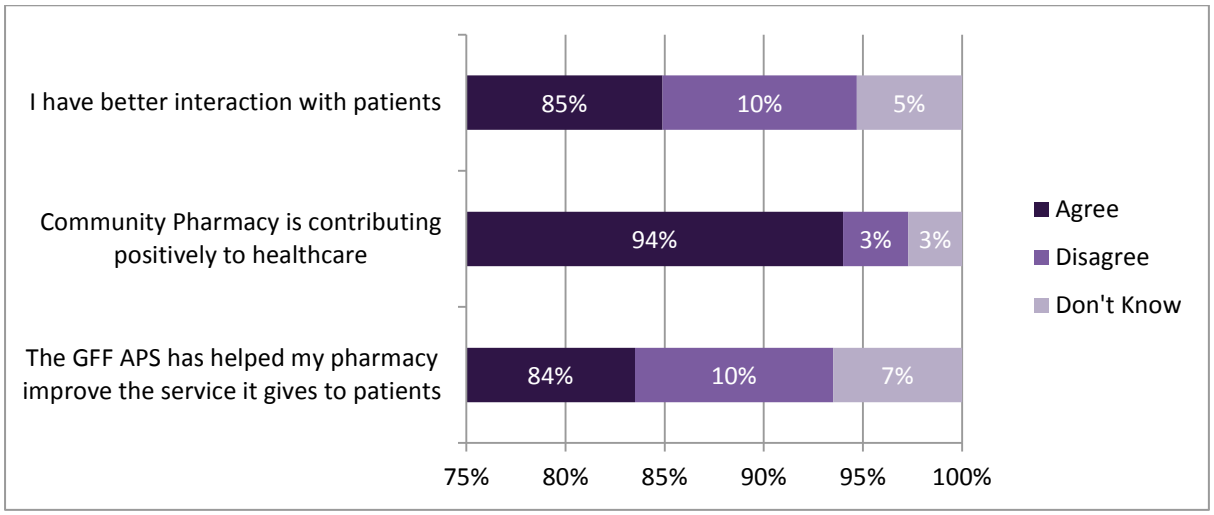
Figure 3-5 Pharmacist View on Changing Order



The survey had a series of questions on the impact of the GFFS service. A large majority (94%; n=316) agreed the community pharmacy is contributing to healthcare through this service (Figure 3-6). There were 84% (n=283) who agreed that the GFFS helped the pharmacy improve service to patients and 85% (n=287) that "I have better interaction with patients". In response to both 10% of respondents (n=34 and n=33 respectively) disagreed (Figure 3-6). The following comment illustrates the broader benefits reported:

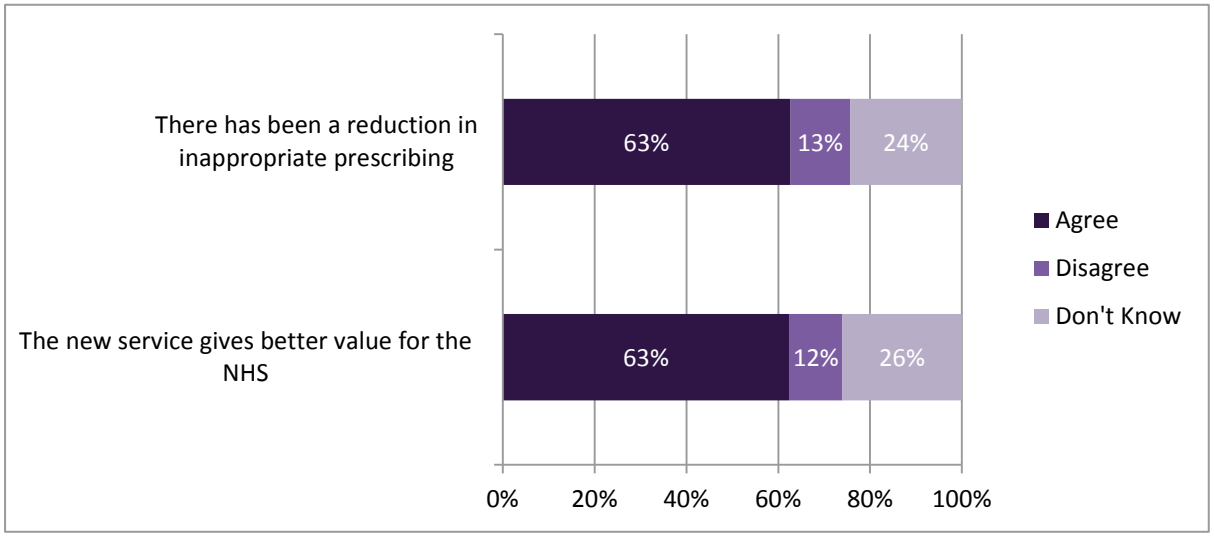
"I think the GFF service is a very good concept as it takes a workload off the GP, allows customers to have more control on what they want to order and pharmacists have more opportunities to interact with patients."

Figure 3-6 Impact of GFF on Service



Two questions invited pharmacists' views on the effect GFFS had on reducing costs and providing value. A majority, 63% (n=212) agreed that "there had been a reduction in inappropriate prescribing" and the same percentage that the "the new service gives better value for the NHS" (Figure 3-7). Nearly one quarter (24% n=82; 26% n=88 respectively) responded "Don't Know" to these questions and only just over 10% disagreed (13% n=44; 12%, n=39).

Figure 3-7 GFFS Impact on cost effectiveness



The following comment illustrates many points:

"I am totally in favour of this service continuing. I have found an increase in patient confidence, reduction in waste and an increase in my confidence in being able to care for my patients. I have produced my own GF order forms and a CPUS template to print prescriptions. My main concern is how best to record what I am supplying, points wise, to my patients to prove I am remaining within the constraints of the system. The GP practices I serve, are very happy with pharmacy doing the GF service as more often than not, the wrong items were prescribed leading to GF foods being wasted, new prescriptions issued and delays in supply to my patients."

Community pharmacists (83% n=281) agreed with the statement that the service supports patient self-management; and only 9% (n=29) disagreed (Table 3-3).

Table 3-3 GFFS supports patient self-management

Answer Options	Response Percent	Response Count
Agree	83%	281
Disagree	9%	29
Don't Know	8%	27

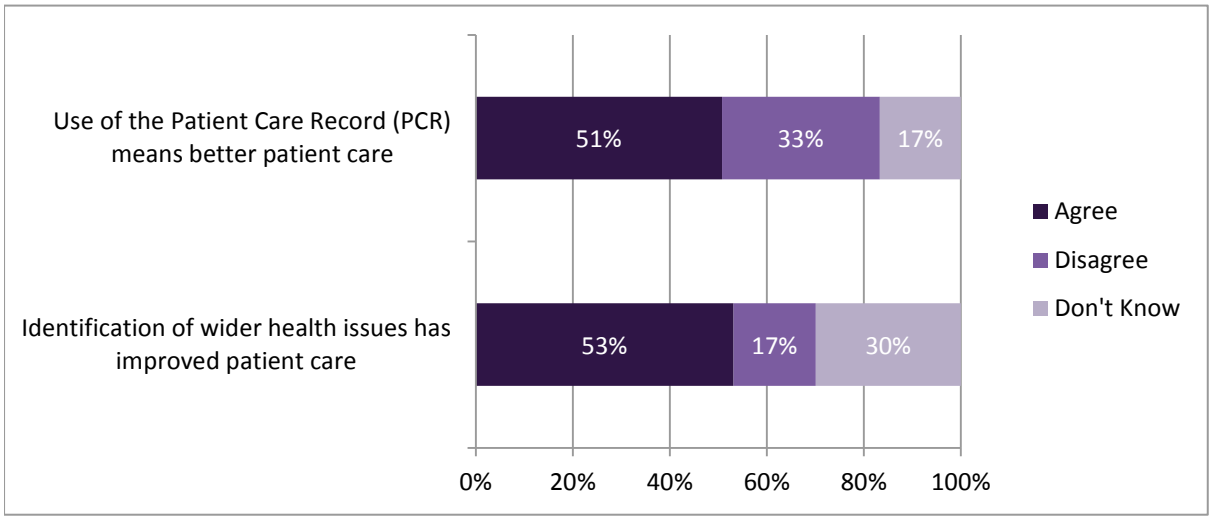
One aim of the service is to support improved collaborative working, and the survey asked if "relations with the wider healthcare team (e.g. dieticians) had been improved as a result of the service". Just over half, 54% (n=182) disagreed with the statement; 30% replied "Don't Know" (n=99) and only 16% agreed (n=55) (Table 3-4).

Table 3-4 Relations with the wider healthcare team improved as result of the service

Answer Options	Response Percent	Response Count
Agree	16.4%	55
Disagree	54.2%	182
Don't Know	29.5%	99

Views were more divided as to whether the service had contributed to holistic care. There were 51% (n=170) of community pharmacists that agreed "use of Patient Care Record (PCR) means better care" but 33% (n=109) disagreed (Figure 3-8). Similarly 53% (n=178) agreed that "Identification of wider health issues has improved patient care" and whilst only 17% (n=57) disagreed; 30% (n=100) "Don't Know".

Figure 3-8 Improved Care: Patient Care Record & Identification Wider Health Issues



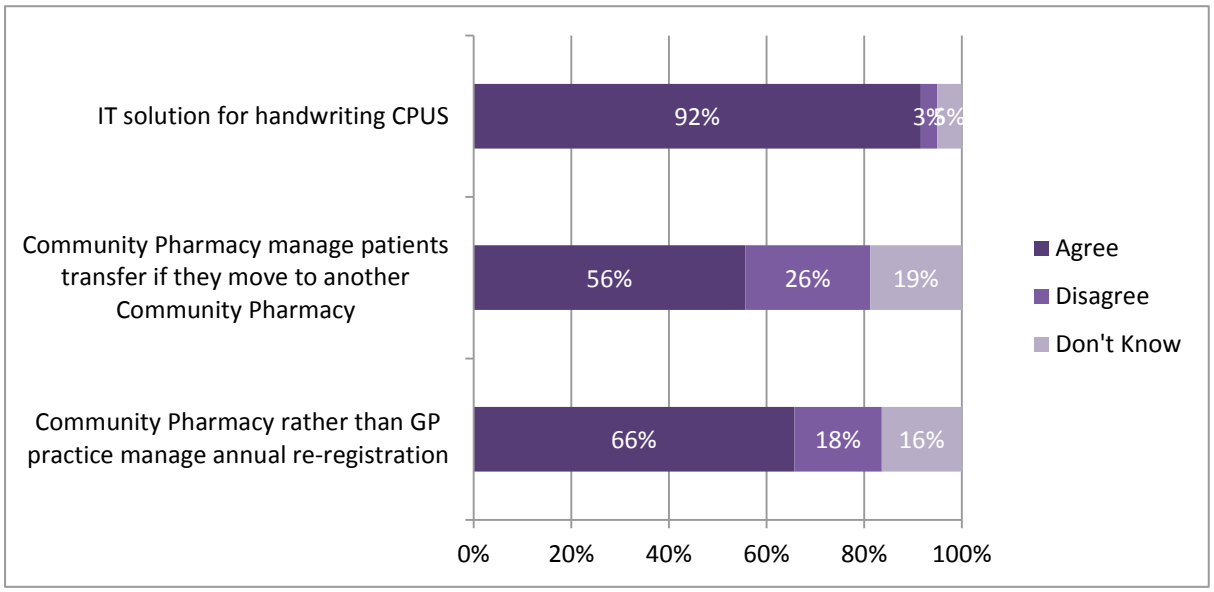
3.5 Improving Provision and Process

One set of questions probed how the provision of GFFS could be made easier for community pharmacies. There were a series of statements that asked about IT and patient transfer; and two questions on a single food list and whether items should receive out of pocket expenses.

A majority agreed with the statements that community pharmacy rather than a GP practice should manage annual re-registration (66%; n=220) and transfer from another community pharmacy (56%; n=187) (Figure 3-9). The overwhelming majority agreed that there should be an IT solution for CPUS (92%; n=308). Respondents' comments supported this and many proposed an IT solution was a requirement for the service. Without it the process was very time consuming, and that was time that could be spent with patients.

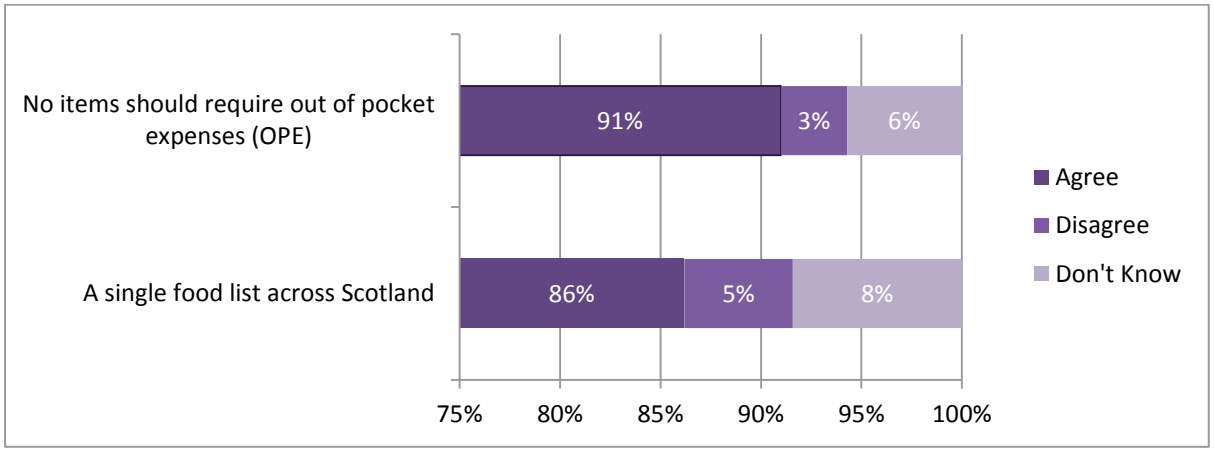
"Paperwork extremely time consuming, writing up order forms as most patients don't, then writing and copying CPUS, as well as labelling in PMR"

Figure 3-9 Make Provision of GFFS easier



A large majority of respondents agreed there should be a single Scottish food list (86%; n=286) and an even higher number agreed that no items should require out of pocket expenses (OPE). (91%; n=305) (Figure 3-10).

Figure 3-10 Make Provision of GFFS easier: Single Food List and No OPE



Views were more divided as to whether the variation between health board lists affected service to patients. The largest group (43%; n- 144) disagreed this was the case but almost one third agreed (32%; n=107) and one quarter (n=85) didn't know (Table 3-5).

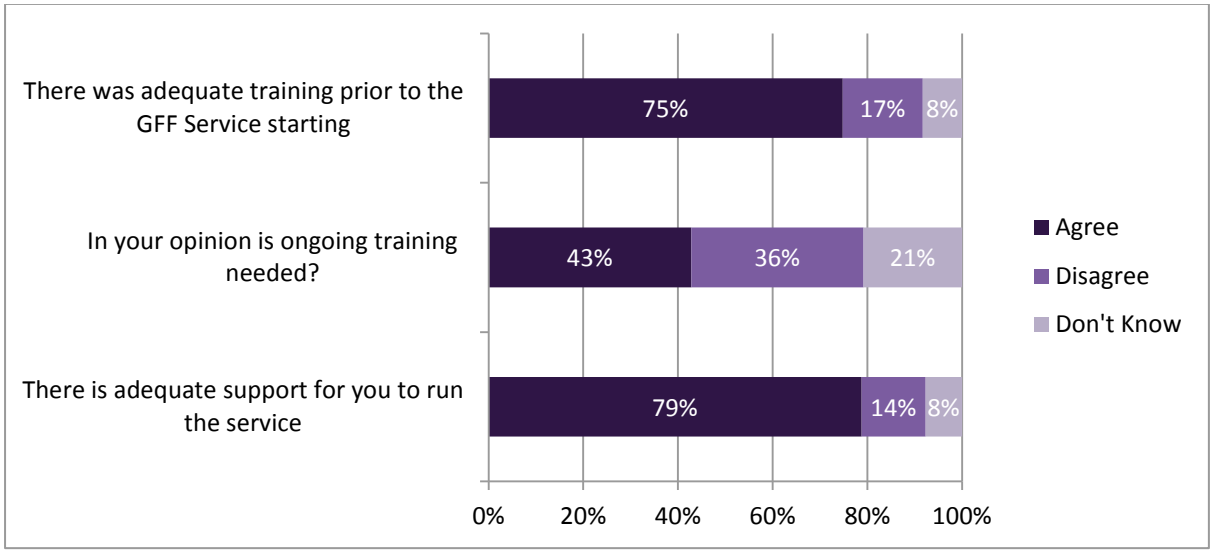
Table 3-5 The variation in HB food lists affects my service to patients

Answer	Response Percent	Response Count
Agree	31.8%	107
Disagree	42.9%	144
Don't Know	25.3%	85

3.6 Training and Support for GFFS

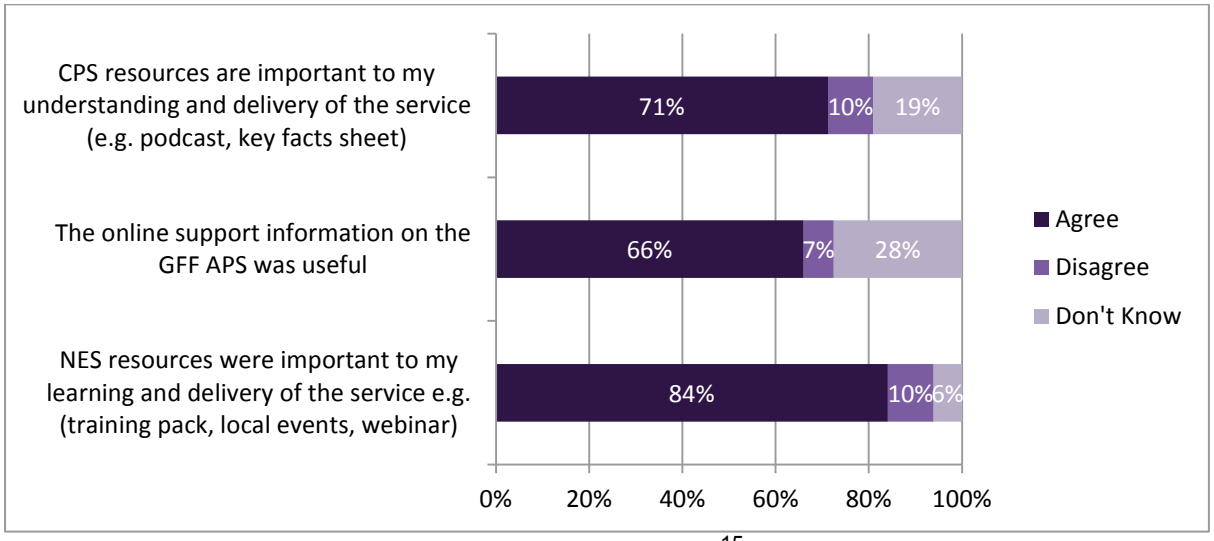
There was a generally positive view on training and feedback from community pharmacists for the GFFS. 75% (n=243) agreed that prior to the service commencing, there was adequate support and 79% (n=256) there is adequate support to run the service (Figure 3-11). On whether ongoing training is needed, opinion was more split; 43% (n=140) agreed and 36% (n=119) disagreed and 21% (n=68) replied "Don't Know" (Figure 3-11).

Figure 3-11 Service Implementation – Training and Support



84% (n=274) agreed that NES resources were important to community pharmacists' learning and delivery of the service. 71% (n=233) agreed CPS resources "are important to my understanding and delivery of the service"; although 10% (n=32) disagreed and 19% (n=62) replied Don't Know (Figure 3-12). In a similar pattern 66% (n=214) agreed the online support information for GFFS was useful; 7% (n=21) disagreed and 28% (n=89) replied Don't Know (Figure 3-12). This may be because they were not sure of the impact of the training or it may be that they are indicating they are unaware of the training and support.

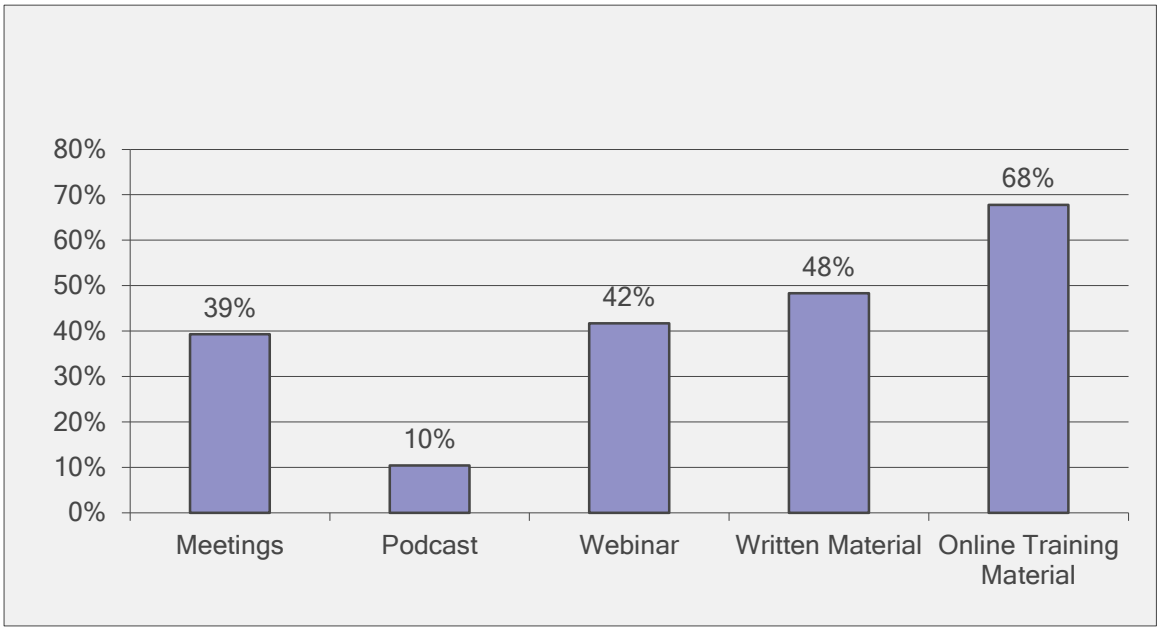
Figure 3-12 Training and Learning Resources



Those who thought additional training was needed[15] were asked how they would want this delivered and given five options. The single highest group preferred online training material (68%; n=143) followed by written material (48%; n=102) and webinars (42%; n=88) (Figure 3-13).

[15] There were more respondents to this question than had indicated they thought ongoing training was needed from the previous question

Figure 3-13 If additional training is needed, how should it be delivered?

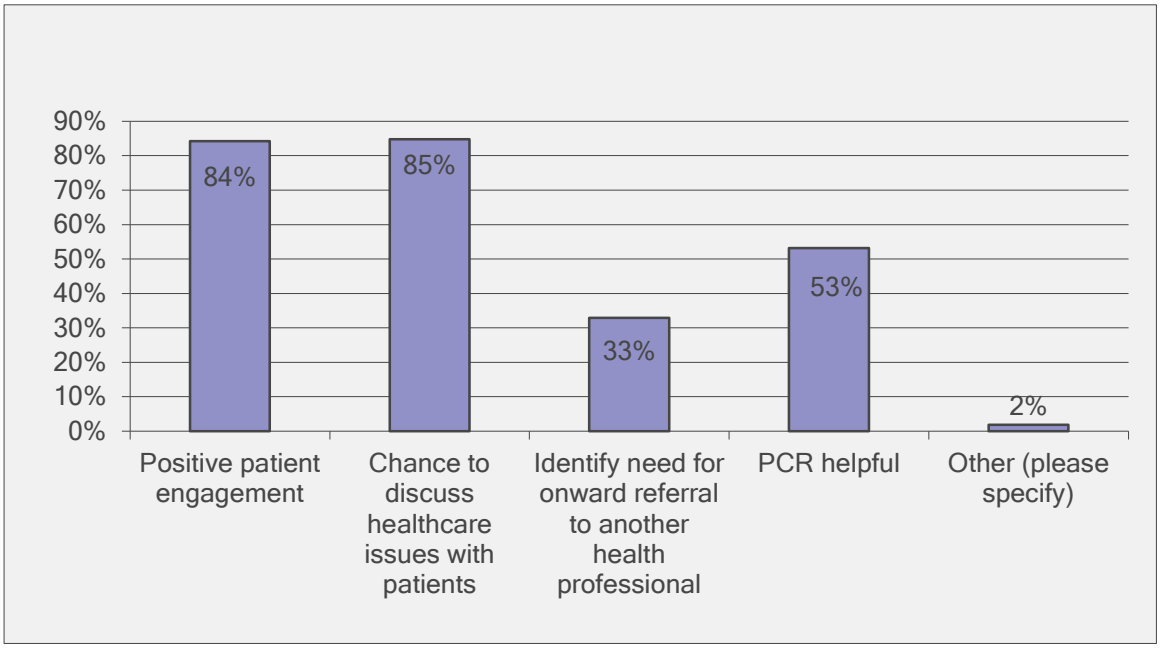


3.7 Adult Coeliac Disease Health Check

There was a fairly even split between community pharmacists who had undertaken any adult coeliac disease health checks; 49%; (n=160) had and 51% (n=169) not.

Those who had undertaken the health checks were asked about the positive and negative aspects. They were given stated options and asked to select all that applied and give any other reasons. On the positive side, the majority thought that this offered an opportunity for positive patient engagement (84% n=133) and a chance to discuss healthcare issues (85%; n=134). One respondent stated this contributed to patients' awareness as to what pharmacists can offer (Figure 3-14).

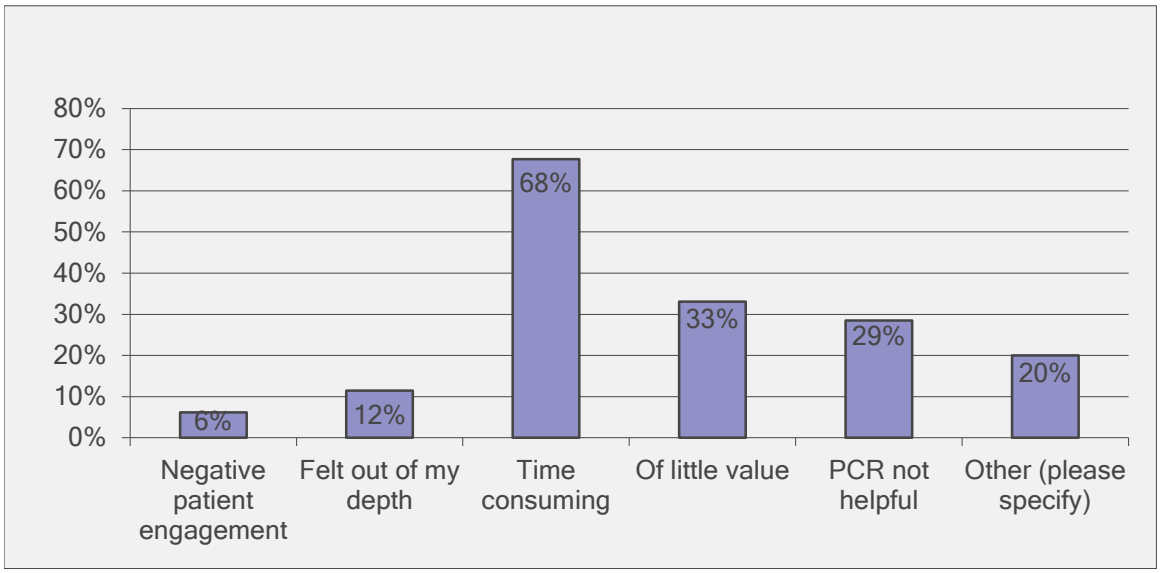
Figure 3-14 What was positive about the adult coeliac disease health checks?



For the negative aspects, the majority (68%; n=88) selected "Time consuming". Otherwise views were more spread between the following reasons; of little value

33% (n=43) and PCR not helpful (n=37) (Figure 3-15).

Figure 3-15 What was negative about the adult coeliac disease health checks?

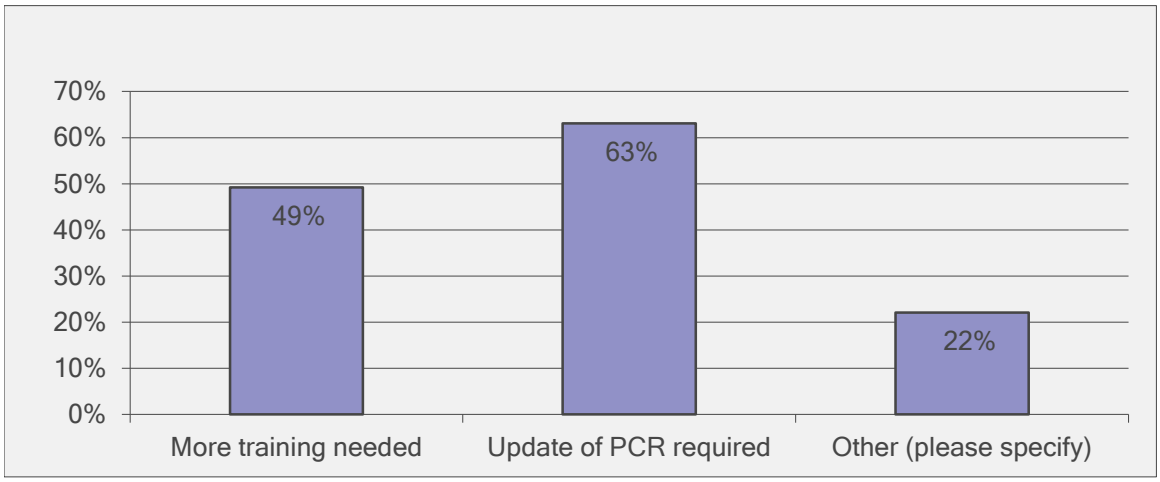


One fifth (n=26) gave other reasons that fell under the following themes.

- Too basic for patients with coeliac diagnosis for many years
- The PCR system is not efficacious and there were IT problems
- Difficulties in gaining patient participation due to: individual not collecting own prescription; reluctance to discuss weight; lack of knowledge about the service
- community pharmacists lacking knowledge on other monitoring tests, requesting a more concise "flow chart" since not doing regularly and time pressures.

One improvement that could be made to the health check seemed to be updating the PCR. A majority (63%; n=77) of those responding to this question gave this answer, and this is 21% of the total survey respondents (Figure 3-16). The open comments echoed this with many raising the issue of the operation of the PCR; specifically that it should interface with the pharmacy Patient Medication Record (PMR). 49% (n=60) agreed that more training was needed. Comments also proposed making prescription process more effective through IT. Others proposed using more specialist skills; e.g. coeliac clinic and dieticians.

Figure 3-16 How could Adult Coeliac Disease Health Check be made better?



3.8 Comments from Community Pharmacists

This section reports on the comments from community pharmacists primarily to add to or include those covered in the earlier sections.

Most pharmacists were supportive of the GFFS, although many called for the system to be streamlined particularly to transfer as much as possible to an on line system. Indeed a few commented that their support for the service was contingent on it becoming electronically based and eradicating much of the current need for manual processing. This was the case with prescriptions but was also raised in relation to the process for sourcing and ordering stock i.e.:

"The service has been a positive one but it needs to be streamlined as currently we are tripling our workload by - ordering the stock by pipcode as descriptions don't match computer - labelling the stock so it goes through PMR - handwriting the Rxs It could surely be done a lot easier by using the PCR???"

Comments were made to the effect that patients liked the service and were using the pharmacist's expertise and flexibility to change their order more often.

"Patients prefer this service. They can easily try new products/brands. They appreciate our input with suggestions about what other patients have tried and liked."

The wider and knock on effects were raised:

"I think the GFF service is a very good concept as it takes a workload off the GP, allows customers to have more control on what they want to order and pharmacists have more opportunities to interact with patients."

The supply chain was the subject of a range of comments. The availability of items was problematic as was the time delay in delivering fresh products. Dealing with a number of suppliers could be very time consuming and it was proposed that choice in core products could be reduced. One comment was critical of the delivery costs that are borne by the NHS. The formulary list updating could also be improved.

There were views that staple foods only should be supplied since biscuits, for example, were contrary to the NHS health messages. The issue of storing and wastage of fresh food was raised:

"It's good that it takes time away from gps however i do feel fresh bread should be excluded as many don't bother to pick it up even after a phonecall also many patients get bags of items making storage very difficult. I now trip over bags as

nowhere to store them. I think maybe vouchers in retail to subsidise prices or charges to prescriptions rather than it all free. Maybe then less wastage esp fresh bread"

Moving more, or even all patients into the service was a theme that emerged and there were various reasons for this. One commented that GPs should be given active encouragement to do so. There was also a proposal that this could be a template for chronic disease management, responsibly for which could lie with pharmacists.

"all ongoing chronic disease management should be carried out in the pharmacy (but will require extra resource, training and funding). However this would provide best value for money and an improved service"

One suggestion was that it should be compulsory to use the service to reconcile the different foods and quantities that people could receive via GPs.

"I think it should be mandatory for all patients to be on the service as its not fair that some patients are limited to amounts and others are not and leave with 4 times the allowance of someone else."

One community pharmacist was seeking more patients on to this service, particularly to improve value given the investment in training they had made and received to prepare to deliver it.

A couple of respondents suggested a voucher scheme with supermarkets as an alternative arrangement.

There was some difference on the basis of payment for the service with comments supporting the status quo but others suggesting it should relate to the number of patients registered. The inequity of the same payment for one or 25 patients was raised.

4. Survey of GPs – Analysis and Findings

4.1 Patient Responses

This section contains the findings from the survey of GPs. The questionnaire was issued electronically via Health Boards and the Scottish General Practitioners Committee of BMA Scotland to approximately 1000 GP practices and a total of 516 responses were received from individual GPs. The questionnaire comprised 19 closed questions on their experience and views of the GFFS service and Adult Coeliac Disease Health check and core factual information. The analysis gives the findings by those who responded to these questions. Around one quarter of respondents gave additional comments in the free text box. These are included as Illustrative examples in relevant sections and at the end of the chapter.

4.2 Main findings

The three main findings from the survey of GPs are:

- The majority of GPs who responded support the GFFS service and found it to have benefits and want it to continue
- Although most GPs agree with the statements on the positive impact for patients, a sizable minority responded "Don't Know".
- The majority did not know the effect or value of the Adult Coeliac Health Check.

4.3 Profile of Respondents

The spread of responses are generally in line with the populations covered by the health boards, with most responses returned from GPs in Greater Glasgow and Clyde; Lothian, Lanarkshire and Grampian (Table 4-1).

Table 4-1 What NHS Board area does your GP practice reside?

Answer Options	Population	Percent of population	Response %	Number of responses
Ayrshire & Arran	372,210	7.0%	6.9%	35
Borders	113,870	2.1%	5.5%	28
Dumfries & Galloway	150,270	2.8%	2.2%	11
Fife	366,910	6.9%	4.1%	21
Forth Valley	299,680	5.6%	11.0%	56
Grampian	579,220	10.9%	9.4%	48
Greater Glasgow & Clyde	1,137,930	21.4%	22.8%	116
Highland	321,000	6.0%	6.1%	31
Lanarkshire	652,580	12.2%	9.6%	49
Lothian	849,700	15.9%	14.9%	76
Orkney	21,570	0.4%	0.0%	0
Shetland	23,200	0.4%	0.8%	4
Tayside	412,160	7.7%	6.5%	33
Western Isles	27,400	0.5%	0.2%	1
	5,327,700	100%	100.0%	509

4.4 GPs experience of the GFFS

91% of GPs responding to the survey had patients who were using the GFFS (Table 4-2).

There were 47 not using the service and the reasons given were; unaware of the

service 82% (n=31); not available in their area 11% (n=4); patients do not want to use the service 13% (n=5).

Table 4-2 Does your GP practice use the Gluten Free Food Service (GFFS)?

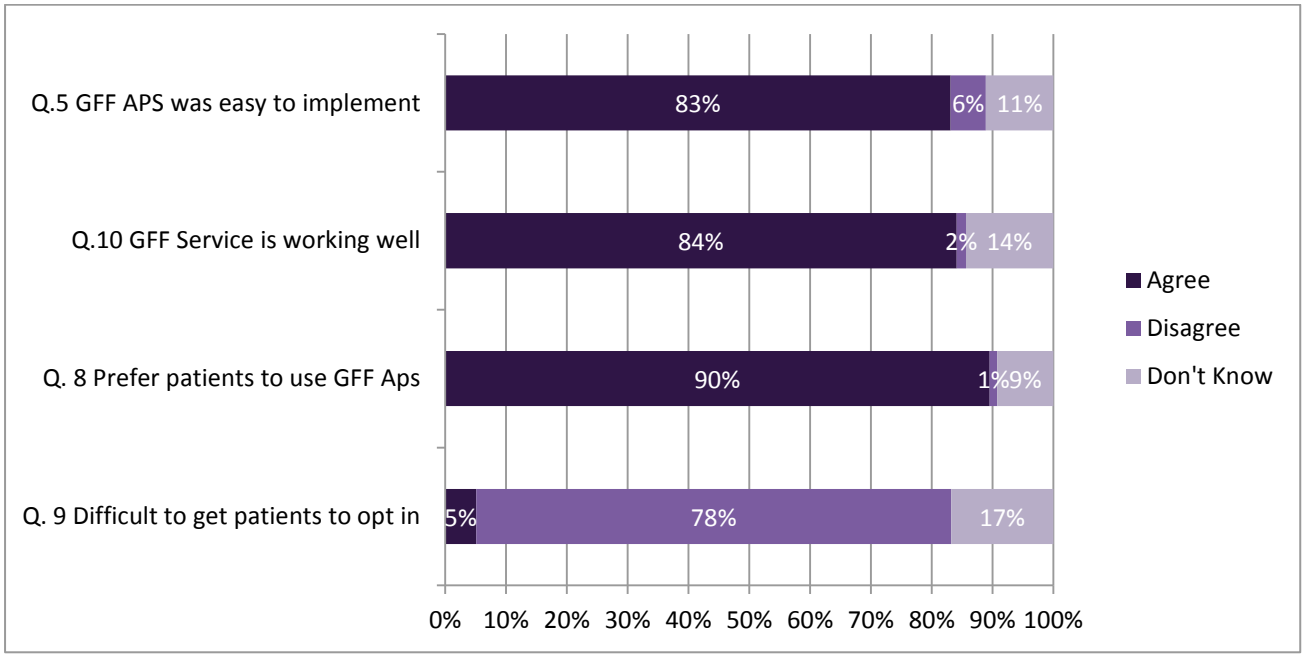
Answer Options	Response Percent	Response Count
Yes	90.9%	469
No	9.1%	47

Other reasons included increased workload, problems with the community pharmacist and believed it was only available in pilot areas. The areas with the highest non participation were also those with few respondents, so may be unrepresentative and should be treated with caution. These included Western Isles; Shetland; and Highland. Dumfries and Galloway; Fife; Grampian; Lanarkshire and Tayside all had 10% of respondents not participating in the GFFS.

4.5 Experience and Impact of GFFS

Of the GPs responding, 83% (n=398) agreed with the statement "the GFF APS was easy to implement in my practice"; only 6% (n=28) disagreed and 11% (n=53) stated Don't know. Similarly, 84% (n=390) agreed with the statement "in my experience, the GFF Service is working well" (Figure 4-1). With regard to patients, 90% (n=426) of GPs agreed they preferred patients to use GFFS. In support of this, 78% (n= 366) disagreed and only 5% (n= 24) agreed that it "is often difficult to get patient to opt into the service[16]".

Figure 4-1 GP's Experience of Service



There was overwhelming support (98% n= 442) for the trial GFFS to continue as an ongoing service. There was support for similar services for other Advisory Committee on Borderline Substances (ACBS) foods, with 89% (n= 403) stating they would like a similar service. However there was one note of caution in the comment box:

[16] For the survey, this question was asked in the negative.

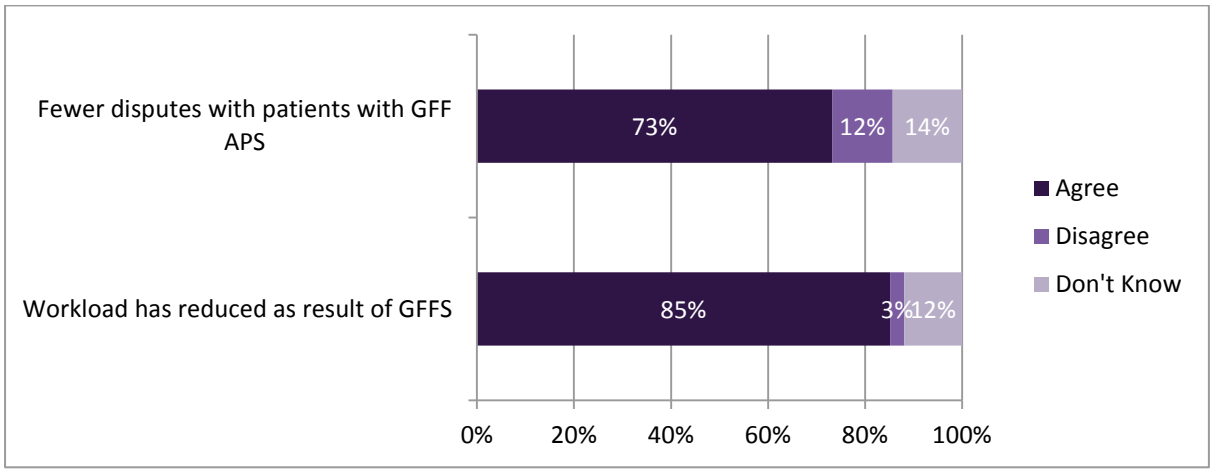
"extension to other ACBS food would need to meet rigorous criteria to avoid huge costs and possible inappropriate prescribing".

Respondents also proposed that a similar service could be extended to nursing homes and similar arrangement should *"be introduced for prescribing devices for colostomy and catheters"*. Finally one comment proposed integration with the Chronic Medication Service (CMS): "*It should be linked with CMS prescribing and should be able to register directly with the pharmacy.*"

4.6 Impact of the GFFS for GPs

Most GPs had found the GFFS to have a positive impact on their work. The majority (85%; n= 409) agreed their workload in gluten-free prescribing had reduced due to the GFFS (Figure 4-2). Almost three quarters (73%; n=343) have had fewer disputes with patients over obtaining gluten-free food since the introduction of the service.

Figure 4-2 GFFS Impact on GPs



In the additional comments, there were many were general positive views on the GFFS and strong statement of support for it to continue. GPs reported the service impact, for example, it had reduced their workload in this area and this enabled them to spend time on their other responsibilities.

"This is one of the best patient care systems invented! streamlines their gluten-prescription service, more efficient for patient & professionals. Allows GPs to get on with treating illness rather than 'conditions'."

"The GFF APS has been very welcome and allows me to concentrate in other more complex health issues and workload."

It was noted that prescriptions for gluten-free food could be time consuming and not best use of GPs time and expertise.

"I cannot praise the logical and sensible person who devised this scheme. It has had huge impact on my prescribing workload.(and sanity, to boot !!!). Withdraw it at your peril !!!"

In line with this there were suggestions for the service to be amended, from example given coeliac is a lifetime condition, removing GPs from the requirement to sign forms annually.

Some suggested that the GFFS contributed to improved quality of services for example:

"This has been a huge success. I absolutely hated doing gluten free product prescriptions before. I frequently made mistakes and certainly was very unclear about appropriate total amounts. I am sure this is far better regulated through the new system with definite cost savings to the NHS."

But for one respondent there were immediate benefits but criticism of the overall approach:

"Whilst I am happy that patients do not need prescriptions for GF foods I am unhappy that they have to do this through pharmacy. This is food we are talking about. I don't go to Boots to buy my spaghetti so why should anyone else? This is discriminatory and stigmatising."

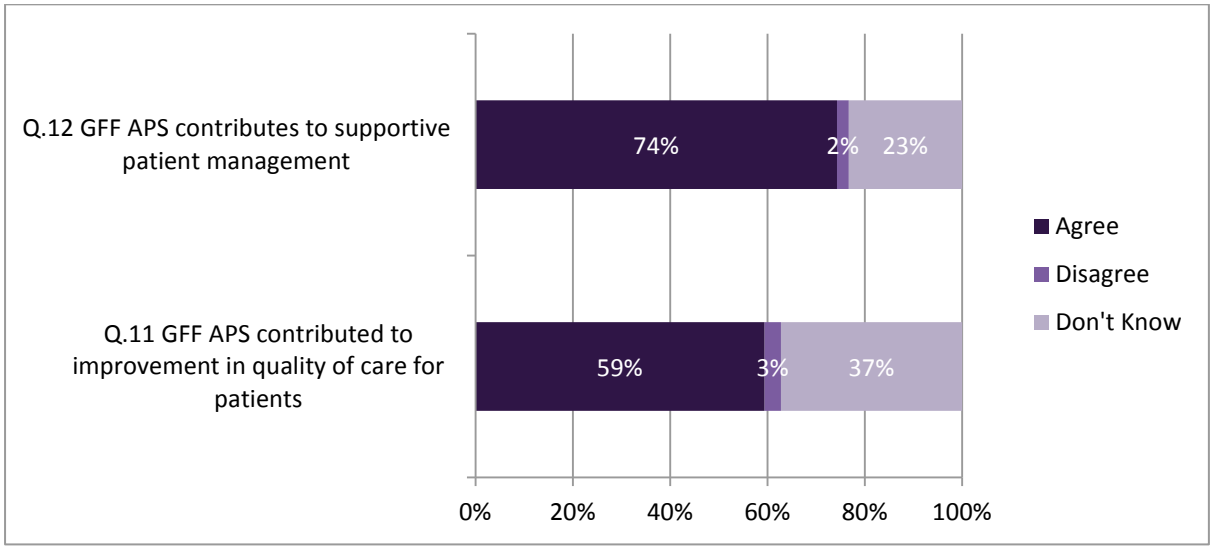
There were views that monitoring units was also more effective, since GPs could do this effectively, and this should save money but fair and equitable. This was noted as important in that patients were provided with an improved service:

"fantastic service saving GPs a huge amount of time and giving patients easier access to foods they are entitled to get on prescription."

4.7 GPs views on impact for patient

GPs responses indicate that GFFS was helpful for patients, although a sizable minority were unclear as to whether this was the case. Almost three quarters (74%; n= 345) agreed that it "contributes to supportive patient self-management" but nearly one quarter (23%; n= 108) replied "don't know" (Figure 4-3). A majority, 59% (n=278), agreed that "the GFFS contributed to the improvement in the quality of care of patients" but over one third (37%; n= 174) didn't know if this was the case (Figure 4-3). This indicates that there would be benefits in further research into the actual impact and outcomes for patient on such a service.

Figure 4-3 Contribution to Improvement for Patient



A few GPs commented that patients preferred the GFFS for the reasons such as; it increased choice; delivered the products they wanted and could support self-management of the condition. However, patients had complained about the absence of certain products from the list. For other patients the GFFS should reduce waste:

"It is much easier for the pharmacy to limit the patients requests than for GPs with GF food on repeat. I suspect this will stop patients getting inappropriate quantities. A positive patient also said it allowed her to change and try different GF foods much

more easily."

It was suggested that more flexibility would benefit the system, for example the GP could vary the number of units and range of foods.

Sourcing foodstuffs sought by patients was reported as more time consuming for GPs given this is not a field of expertise, so has been reduced by the GFFS.

That the GFFS is non-mandatory was problematic and the following quotes indicate a couple of practical problems and concerns:

"It has been hard to get patients to 'opt in', especially as not all preparations are on the pharmacy list. At the outset we were given different versions of the forms for registration, and this caused confusion for GP and pharmacy. It would be disappointing, after putting effort into registering people, for the system to be cancelled."

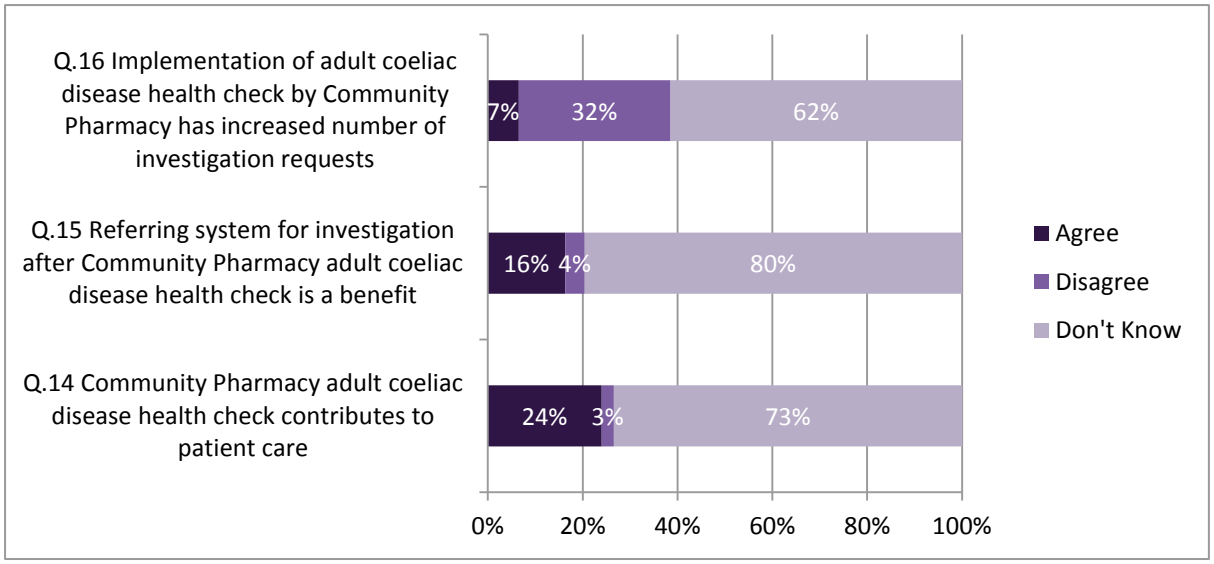
"The answers above may seem a bit confusing as we are only using the new system for new patients, so we have some using the new system but most still using the old. It was not unique in not taking GP time in transferring folks from one system to another into account, and it was a complete cop out to make it optional and leave both systems in place."

4.8 The Adult Coeliac Disease Health Check

Almost one third (32%; n=148) disagreed that the community pharmacy health check had increased the number of investigation requests, 7% (n= 30) agreed, but the majority, 62% (n=284) responded "Don't Know (Figure 4-4). In the comments there was reference to the lack of awareness of this aspect of the service. Some mentioned that they did not receive feedback from pharmacists so did not know if health checks had been carried out.

Nevertheless the majority (81% n=375) disagreed with the statement "I am concerned that there may be negative health consequences because patient who received GFF APS have less contact with a GP" and 16% (n=72) responded "Don't know" and only 4% (n=17) agreed (Figure 4-4).

Figure 4-4 Impact of the Adult Coeliac Disease Health Check



Comments in at the end of the survey indicated that GPs were unaware of the adult

coeliac disease health check generally. It was remarked that they had not received a health check report from the Community Pharmacist which would make them aware of the services and provide information on the patient.

Occasionally GPs expressed doubt as to whether community pharmacists should be carrying out health checks.

“I was not aware that pharmacists were carrying out coeliac health checks or that they had training to do so. [I do not think pharmacy training includes non-drug disease management].”

“Completely inappropriate to carry out coeliac "health checks" without doctor contact beforehand and appropriate discussion and counselling.”

4.9 Comments from GPs survey

This section is comments by GPs that relate less directly to the survey question but are relevant to the evaluation of the service.

There were views expressed that indeed GPs should not be involved in prescribing food at all. The following quotes illustrate these views, the strength in which they are expressed and where responsibility should lie:

“Would like all FOOD to be removed from medical prescribing. If a dietician wants supplementation, they can be responsible for cost effective prescribing and monitoring, working to the top of their license.”

“GPs should not be involved in this process at all - amounts required should be calculated by the Gastroenterologist diagnosing the condition or dietician and GPs should merely be copied in to the decision. We have no role to play here. Patient should not be able to opt out and expect the GP to continue to prescribe. If they do not comply they should be made to buy their products - it is a waste of scarce GP time for them to be involved.”

In some instances the view the NHS should not be responsible for providing such food, and that this was ineffective us of NHS funds was given.

“Do not think that health service should fund a food source for patients when other options available in supermarkets. No-one has to eat wheat. Diabetics don't get sugar free food on prescription.”

“There is no reason why GPs should have to prescribe food. I am not sure that food should be a prescription item in the first place given the massive strain on health budgets and the need to use resources elsewhere.”

Glossary

ACBS	Advisory Committee Borderline Substances
BDA	British Dietetic Association
BMA	British Medical Association
CD	Coeliac disease
CHI	Community Health Index
CPS	Community Pharmacy Scotland
CPUS	Community Pharmacy Urgent Supply
DH	Dermatitis herpetiformis
dm+d	Dictionary of Medicines and Devices
eVADIS	NHS NSS prescriber, practice and community pharmacy codes and payment database
GFF	Gluten-free food
GFF APS	Gluten-free Food Additional Pharmaceutical Service
GFFS	Gluten-free Food Service
GP	General Practitioner
HIS	Health Improvement Scotland
ISD	Information Services Division
MAS	Minor Ailment Service
MCN	Managed Clinical Network
NICE	National Institute for Health and Care Excellence
NES	National Education for Scotland
NPA	National Pharmacy Association
NSS	National Services Scotland
OOPE	Out of pocket expenses
PCR	Pharmacy Care Record
PKU	Phenylketonuria
PMR	Patient Medication Record
PSD	Practitioner Services Division
PV	Payment Verification
SGPC	Scottish General Practitioners' Committee
SIGN	Scottish Intercollegiate Guidelines Network

This publication is available at **www.gov.scot**

Any enquiries regarding this publication should be sent to us at
The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-78544-610-8 (web only)

Published by The Scottish Government, September 2015

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS54713 (09/15)