Discussion and conclusions

10.1 Findings discussion

10.1.1 Direct costs: food consumption

Overall, the results from the online survey comparing costs between FHS households and non-FHS households align with what people living with FHS were reporting during the qualitative interviews earlier in the study.

Households with people living with CD spend more on food consumption than non-FHS households (11.9% more on weekly groceries costs and 14.1% more on weekly eating out / takeaway costs). Households with people living with FA also spend more on food consumption than non-FHS households (14.4% more on weekly groceries costs and 26.7% more on weekly eating out / takeaway costs). Meanwhile, households with those in the FIO category also spend more on food consumption than non-FHS households (15.8% more on weekly groceries costs and 15.0% more on weekly eating out / takeaway costs (footnote 1)).

These results align with the REA findings. The literature found that gluten-free products in the UK are 100% - 500% more expensive than non-gluten-free products (Capacci, Leucci, & Mazzocchi, 2018; Fry, Madden, & Fallaize, 2018; Allen & Orfila, 2018; Singh & Whelan, 2011). We show that those with coeliac disease, who require a gluten-free diet, have statistically significant higher spending of 112% - 117% [$p = 0.03$ to < 0.001] of the cost of those without FHS. There is no comparison with the FA group as most of the literature focused on gluten-free products.
When looking at literature where differences in combined direct costs (food, medical treatment, travel, leisure activities etc) are analysed, those studies showed no significant difference between adults with FHS and those without (Jansson et al., 2014; Voordouw et al., 2010; Voordouw et al., 2016). However, this study shows that when examining food costs specifically, there are significant differences in food costs between adults with FHS and the control group, with those in the FA and FIO groups facing the highest burdens. This is a key finding, which should be taken into account in the FSA's cost of illness model to show a fuller picture of the economic burden for adults with FHS. Additionally, this study did not combine direct costs (food costs added with medical and additional kitchen equipment costs) for the FHS group as medical costs and additional kitchen equipment costs were not asked of the non-FHS group.

All the results stated above are statistically significant except for the comparison of weekly eating out / takeaway costs between those in the FIO category with non-FHS households (15.0%, p-value = 0.07). This borderline result could be statistically insignificant due to lack of power, residual confounding or heterogeneity in the FIO category. Without further research on those in the FIO category, we are unable to provide a definite explanation as to why the comparison is not statistically significant.

However, it should be noted again that FIO is not a medically recognised category and was created for the purposes of analysis by the study team. It is made up of those with food intolerances or individuals with an undiagnosed but suspected food allergy or suspected coeliac disease. Thus, any comparison made with this category must be done with caution as it includes more than just individuals with food Intolerances.

10.1.2 Discrepancy in mean food consumption costs between summary statistics and multivariate regression analysis

Discrepancies were observed in the cost differentials of food spending between those reported in the summary statistics (see Chapter 5.2) and those reported in the multivariate regression analysis for weekly groceries costs (see Chapter 5.3). The group differences reported in the multivariate regression analysis are almost 2 – 2.5 times less than those reported in the summary statistics when comparing the three FHS groups vs non-FHS. Table 10.1 below summarises the differences between groups in the summary statistics, univariate regression analysis, and multivariate regression analysis. The findings that do not have big discrepancies between the summary statistics and multivariate regressions (as in eating out / takeaway costs) or those that are not statistically insignificant, have been excluded from the table.

Table 10.1 Table showing the differences in the data and modelling for summary statistics, univariate regression, and multivariate regression across the different groups for weekly groceries costs

Summary statistics:

- outliers are removed
- data has not undergone regression
- no confounding factors adjusted for
- missing data not imputed

Univariate regression:

- outliers are removed
- data underwent Gamma with log link regression
- no confounding factors adjusted for
- matching has been done
- missing data imputed

Multivariate regression:

- outliers are removed
- data underwent Gamma with log link regression
- confounding factors adjusted for
- matching has been done
- missing data imputed

Comparison: How much more FHS types spend compared to non-FHS	Summary statistics	Univariate regression	Multivariate regression
FOI versus non-FHS	24%	21.7%	15.8%
CD versus non-FHS	19.3%	With matching and Multiple Imputation: 11.1%. Without matching and Multiple Imputation: 23.9%	11.9%

Comparison: How much more FHS types spend compared to non-FHS	Summary statistics	Univariate regression	Multivariate regression
FA versus non-FHS	25.6%	With matching and Multiple Imputation: 15.7% Without matching and Multiple Imputation: 33.9%	14.4%

Table 10.1 shows the results with summary statistics, univariate regression models (with and without propensity score matching together with multiple imputation (footnote 2)), and multivariate regression models. The costs difference between those in the FIO group with the non-FHS group (in row 1) drops from 24% with summary statistics to 15.8% with the multivariate regression model which included all the confounding factors listed in Chapter 5.3. Part of this discrepancy can be explained by the addition of confounding factors in the multivariate regression model as the univariate regression (with propensity score matching and multiple imputation) model without confounding factors results in a difference of 21.7%, which is closer to the 24% difference from summary statistics. The difference also gradually drops from 21.7% with the univariate regression model to 15.8% with the multivariate regression model as more confounding factors are gradually added. Thus, the discrepancy from 24% with summary statistics to 15.8% with the multivariate regression model can be jointly explained by the adoption of a more rigorous methodological approach including the use of propensity score matching, adjustment for confounding factors in the regression (doubly robust control for confounding) and multiple imputation to address sources of missing data.

The costs difference between those in the CD group with the non-FHS group (in row 2) drops from 19.3% with summary statistics to 11.9% with the multivariate regression model which included confounding factors. However, this discrepancy cannot be explained by the addition of confounding factors (footnote 3) as the univariate regression (with propensity score matching and multiple imputation) model without confounding factors results in a difference of 11.1%, which is even further from the 19.3% difference with summary statistics. Thus, the univariate regression (without propensity score matching and multiple imputation) model with log-transformation was run to check if the propensity score matching and multiple imputation could have caused the difference. The results from this model showed a difference of 23.9%, which is closer to the 19.3% difference with summary statistics. Thus, the discrepancy from 19.3% with summary statistics to 11.9% with the multivariate regression model can be mainly explained by the use of propensity score matching together with multiple imputation.

The costs difference between those in the FA group with the non-FHS group (in row 3) drops from 25.6% with summary statistics to 14.4% with the multivariate regression model which included confounding factors. However, this discrepancy cannot be explained by the addition of confounding factors as the univariate regression (with propensity score matching and multiple imputation) model without confounding factors results in a difference of 15.7%, which is still far from the 25.6% difference with summary statistics. Thus, the univariate regression (without propensity score matching and multiple imputation) model with log-transformation was run to check if the propensity score matching and multiple imputation could have caused the difference. The results from this model showed a difference of 33.9%, which is slightly closer to the 25.6% difference from summary statistics. Thus, the discrepancy from 25.6% with summary statistics to 14.4% with the multivariate regression model can also be mainly explained by the use of propensity score matching together with multiple imputation.

Propensity Score Matching was clearly necessary for the last two cases with the comparison of FA and CD with the non-FHS group. It performs well as it ensures better balanced samples in terms of socioeconomic characteristics (such as household income, gender, and geography) as demonstrated by balance statistics in Appendix 10. This means there is a “like for like” comparison between the FHS groups and the non-FHS group.

10.1.3 Other direct costs and indirect costs

The results show that the average one-off costs for additional kitchen equipment to an FHS household is £21.05 (those with FA spend £16.12, those with CD spend £26.26, and those with FIO spend £13.59). Meanwhile, the figure for average monthly medical costs to people living with FHS is £16.89 (those with FA spend £27.98, those with CD spend £11.08, and those with FIO spend £17.60). The average number of paid days lost per year due to FHS for people living with FHS is 2.67 days and the costs of these days (using the annual national median income of £29.900) is £307.05 per year (those with FA lose £433.52, those with CD lose £199.64, and those with FIO lose £438.89). Meanwhile, the average number of unpaid days lost per year due to FHS for people living with FHS is 3.87 days. Depending on the range of national minimum / living wage used for different wage groups, the monetary costs range from £133.13 to £276.85 per year (those with FA lose £208.78 – £432.62, those with CD lose £66.76 - £138.34, and those with FIO lose £213.52 - £442.44). Adults with FHS also spend an average of 6.21 hours per week on FHS related activities. Using the hourly national living wage of £8.91, this amounts to £55.33 lost per week (those with FA lose £61.48, those with CD lose £51.58, and those with FIO lose £56.93).

The literature on lost productivity (lost work time, household task time etc) showed mean productivity level valued at $1,038 (£778.60 (footnote 4)) across worldwide studies (Bilaver et al., 2019). If we add up the paid and unpaid days lost, from our study for people living with FHS, the total indirect costs ranges from £440.18 - £583.90 per year, which is a slightly more conservative estimate compared with studies conducted across the globe. However, once cost of time spent on FHS-related activities are included, the indirect costs rise to £3,317.40 - £3,461.12. This suggests that extra time spent on FHS-related activities represent a large chunk of productivity lost to adults with FHS.

There are other studies which combined indirect costs (lost productivity, lost time to healthcare) and compared these to a control group. The evidence was mixed with some finding no significant difference (Voordouw et al., 2016) and others finding significant differences in the range of EUR 2,578 - EUR6,424 (Jansson et al., 2014; Voordouw et al., 2010). As our study did not ask for control group costs, we cannot determine the difference in costs for those with FHS compared to the control group; however the study finding of an indirect cost of £3,317.40 - £3,461.12 does fall within this previously reported range.

Additionally, our results showed that those with FHS lose £55.33 per week from FHS-related activities (planning for food shopping etc). This aligns with numerous studies that report the amount of time needed for these activities are a major burden on people living with FHS (Bilaver et al., 2016; Broome, Lutz, & Cook, 2015; DunnGalvin et al., 2020a; Komulainen, 2010; MacKenzie, Grundy, Glasbey, Dean, & Venter, 2015; Neil, 2012; Peniamina, 2014; Peniamina, Bremer, Conner, & Mirosa, 2014; Peters, Crocker, Jenkinson, & Violato, 2020; Sommer, MacKenzie, Venter, & Dean, 2012; Stjerna, Vetander, Wickman, & Lauritzen, 2014).

There is no direct comparison with the non-FHS households for these costs as these are all expenditure incurred due to FHS. For example, if future studies were to attempt to compare these costs with non-FHS households, it must be ensured that the non-FHS households respondents and FHS household respondents are matched based on similar medical histories. A non-FHS respondent could have a chronic medical condition which drives up their medical costs so that when their medical costs are compared with people living with FHS, it would obscure the effect of having FHS on the medical costs.

10.2 Conclusions

The online surveys conducted with adults living with and without FHS in England, Northern Ireland, and Wales indicates that adults with an FHS condition face an increased financial burden due to food costs compared to non-FHS households.

Those in the FIO group face the highest burdens for weekly groceries costs whilst those in the FA group face the highest-burden for weekly eating out / takeaway costs.

However, food is not the only cost. Adults with FHS also experience additional direct costs (such as kitchen equipment and medical costs) and indirect costs (lost work days, lost unpaid days, and time spent on FHS-related activities). Overall, those in the FA group and FIO groups generally experience a higher financial burden compared to those in the CD group (except for additional kitchen equipment costs). The average additional costs for adults with FHS and the specific FHS groups are summarised in Table 10.3 below.

Table 10.3: Key findings on non-food direct and indirect costs from the multivariate regression analysis of the online survey of FHS adults in England, Northern Ireland, and Wales (n = 1,225)

Type of costs	Costs to people living with FHS (aggregate of FIO, CD and FA)	Costs to those in the FIO group	Costs to those in the CD group	Costs to those in the FA group
Average one-off additional kitchen equipment costs due to FHS	£21.05	£13.59	£26.26	£16.12
Monthly medical costs due to FHS	£16.89	£17.60	£11.08	£27.98
Annual medical costs due to FHS	£202.68	£211.20	£132.96	£335.76
Average number of paid days lost per year due to FHS (costs in £) (footnote 5)	2.67 (£307.05)	3.81 (£438.89)	1.74 (£199.64)	3.77 (£433.52)

Type of costs	Costs topeople livingwith FHS (aggregate of FIO, CD and FA)	Costs to those in the FIO group	Costs to those in the CD group	Costs to those in the FA group
Average number of unpaid days lost per year due to FHS (costs in £) (footnote 6)	3.87 (£275.85)	6.07 (£432.62)	1.94 (£138.34)	6.21 (£442.44)
Average hours on FHS related activities per year due to FHS (costs in £)	322.92 (£2,877.22)	332.28 (£2,960.62)	301.08 (£2,682.62)	35.8 (£3,196.91)

This study importantly highlights the specific cost elements affecting people living with an FHS condition, in particular demonstrating that not only does food cost more, but so do a range of other direct and indirect costs. The literature on lost productivity showed mean productivity level valued at $1,038 (£778.60) across worldwide studies (Bilaver et al., 2019). From our study, the total indirect costs (from paid and unpaid days lost) ranges from £440.18 - £583.90 per year, which is a slightly more conservative estimate compared with the literature. However, once cost of time spent on FHS-related activities are included, the indirect costs rise to £3,317.40 - £3,461.12. This not only has significant financial implications for the individuals concerned but also their health and wellbeing.

This study is unique in its focus on the people living with FHS but it would also be beneficial to collect and analyse data on actual consumer transactions in order to allow for more accurate cost comparisons at a granular level. However, this approach would require consumer consent to share their personal details and expenditure data. Additionally, a longitudinal study on financial burdens of adults with FHS conducted across multiple time periods would capture the impact of changing attitudes and food environment across time.
Overall, the study shows that those living with FHS, regardless of their FHS condition, face increased financial and economic burdens due to their condition. As such, policy actions are needed from the FSA and other government departments to help alleviate the burden felt by those with FHS and aid in managing the stress that arises from their condition.

1. This result is not statistically significant.

2. In order for propensity score matching to be performed, multiple imputation needed to be performed before that as propensity score cannot be done with the presence of missing data

3. It is important to note that once propensity score matching has been conducted, it is not expected that regression adjustment will make much of a difference to estimates

4. Calculated using 2018 average exchange rate of 1USD = 0.7501 GBP (Exchange Rates.org.uk)

5. Monetised using the annual national median income of £29,900.

6. Monetised using a National Living Wage of £8.91.