

# **Dietary Approaches for Metabolic Syndrome, Obesity and improved Nutrition. The DAMSON project. Final Evaluation Report**

**Lynette Harper, Robert Stanley, Laura Cheek, Maria Lakin,  
Celayne Heaton-Shrestha and Ann Ooms.**

**Kingston University and St Georges University of London.**

**Date: 28<sup>th</sup> April 2020**

## Contents

<b>1. Project Team.....</b>	<b>4</b>
<b>2. Acknowledgements.....</b>	<b>4</b>
<b>3. Glossary .....</b>	<b>5</b>
<b>4. Introduction .....</b>	<b>5</b>
<b>4.1. Reduced health status of people with a learning disability.....</b>	<b>6</b>
<b>4.2. Interventions addressing Metabolic Syndrome among people with a Learning Disability .....</b>	<b>7</b>
<b>4.3. Existing resources to support healthy eating among people with a learning disability .....</b>	<b>8</b>
<b>4.4. Training for staff working in General Practices to support people with a learning disability who have MetS.....</b>	<b>9</b>
<b>4.5. Conclusion.....</b>	<b>9</b>
<b>5. Initial Project Aim .....</b>	<b>9</b>
<b>6. Revised Project Aims.....</b>	<b>10</b>
<b>7. The development and procurement of resources.....</b>	<b>11</b>
<b>8. Structure of the training programme .....</b>	<b>12</b>
<b>9. Study 1: The Evaluation of the workshop .....</b>	<b>14</b>
<b>9.1. Ethical approval.....</b>	<b>14</b>
<b>9.2. Overall aim of the evaluation .....</b>	<b>14</b>
<b>9.3. Evaluation Design.....</b>	<b>14</b>
<b>9.4. Data collection tools.....</b>	<b>14</b>
<b>9.5. Data collection processes.....</b>	<b>15</b>
<b>9.6. Data analyses .....</b>	<b>15</b>
<b>9.7. Results.....</b>	<b>15</b>
<b>9.8. Summary and conclusions .....</b>	<b>17</b>
<b>10. Study 2: Evaluation of training and resources on individuals with a learning disability. ....</b>	<b>18</b>
<b>10.1. Ethical approval.....</b>	<b>18</b>

<b>10.2. Overall aim of the evaluation .....</b>	<b>18</b>
<b>10.3. Evaluation Design.....</b>	<b>18</b>
<b>10.4. Data Analysis .....</b>	<b>19</b>
<b>10.5. Results .....</b>	<b>19</b>
<b>10.6 Summary and conclusions.....</b>	<b>25</b>
<b>11. Provision of training for medical staff.....</b>	<b>25</b>
<b>12. Conclusions.....</b>	<b>26</b>
<b>13. References.....</b>	<b>28</b>
<b>14. Appendix.....</b>	<b>32</b>

## 1. Project Team

Lynette Harper – Principle Investigator. Senior Lecturer in Learning Disability Nursing, Faculty of Health, Social Care and Education at Kingston University and St Georges University, London.

Contact email: Lynette.Harper@sgul.kingston.ac.uk

Dr Ann Ooms – Professor of Higher Education Research and Director of Research, School of Nursing, Faculty of Health, Social Care and Education, Kingston University and St George's, University of London

Robert Stanley - Senior Lecturer in Learning Disability Nursing, Faculty of Health, Social Care and Education at Kingston University and St Georges University, London.

Laura Cheek – Manager of the complex care team, Sweet Tree Home Care Services, London.

Maria Lakin – Learning Disability Nurse. Epsom and St Helier University Hospital, NHS Trust.

Dr Celayne Heaton-Shrestha – Researcher, School of Nursing, Faculty of Health, Social Care and Education, Kingston University and St George's, University of London

## 2. Acknowledgements

The project team would like to give a special thank you to Health Education England working across Kent, Surrey and Sussex who funded the project. Rhona and George, your support and advice was valued and appreciated by the team.

Thank you to Becky Hankin (Kent Community Health NHS Trust), all the participants and their support staff, and the Baked Bean Theatre Company who agreed to give up their time to help with the project. Your collaboration was greatly appreciated.

### 3. Glossary

#### Metabolic Syndrome

The World Health Organisation (Alberti and Zimmet, 1998) and the International Diabetes Foundation (2005) agree that the definition for metabolic syndrome (MetS) includes the presence of obesity as measured by waist – hip ratio, dyslipidaemia as shown by increased consumption of trans and saturated fats (impacting triglycerides and a reduction in high density lipoproteins), insulin resistance (fasting blood glucose >5.6mmol/ L or taking medication to lower glucose levels), and hypertension (systolic >130mm/Hg).

#### Nudge behavioural science approach

Nudges are aimed at changing people's behaviour in a certain direction, while maintaining their freedom to make choices. Nudge behavioural science theory acknowledges that many decisions are not made consciously or planned in advance but are impulsive and occur in response to our sensory input. Therefore, decisions about what and when we eat are often a response to what we see and smell rather than based on what is healthy and good for us. Increasing convenience, proximity and availability alongside an increase in perceptions of the hedonic and sensory appeal of foods, can thus encourage consumption of these healthier foods and beverages.

#### Food culture

This refers to the attitudes, beliefs and norms of a group of people regarding the production, distribution and consumption of specific food and drinks. For the purpose of this report 'food culture' is defined as the attitudes, beliefs and norms within a specific residential home, learning disability service or family home.

### 4. Introduction

#### *4.1. Reduced health status of people with a learning disability*

Health inequalities are known to be prevalent in people with learning disabilities. Recent epidemiological evidence shows that the difference in age of death is 29 years earlier in females and 23 years earlier in males with a learning disability compared to the general population (LeDeR Programme, annual report, 2017). In part, this is thought to be due to increased lifestyle risk factors in people with a learning disability, and health determinants such as poor healthcare literacy, polypharmacy and the use of atypical antipsychotic medication, physical and mental health comorbidities such as anxiety, as well as a poor diet and increased sedentary behaviours compared to the general population (Room et al, 2016; de Winter et al, 2015; Teeluckdharry et al, 2013).

Research on MetS in people with a learning disability is limited. The MetS prevalence rates are reportedly as high as 46% in this population (Room et al, 2016), while prevalence rates are around 20-25% in the general adult population (Stern et al, 2004). This increased prevalence of metabolic symptoms is supported by a study conducted in the Netherlands by the Healthy Aging and Intellectual Disability (HA-ID) (n=980). Indeed, in their sample of 980 individuals, 53% had hypertension, 14% had diabetes, 23% had hypercholesterolemia, and 45% met the criteria for MetS with this increasing to nearly 55% in women and those that live independently (de Winter et al, 2012).

The presence of biochemical markers of inflammation are also observed and together these metabolic symptoms have been shown to increase the risk of cardiovascular disease (such as atherosclerosis and stroke), Type 2 diabetes, depression and associated health conditions in people with a learning disability as well as in the general population (Chang et al 2012; de Winter et al, 2015).

Data from primary care has shown that 37.2% of individuals with a learning disability are obese and a further 28.1% are overweight, with these figures increasing with age and in females (Public Health England Learning disability Conference, 2016). Thus the prevalence of obesity among people with a learning disability is significantly higher than the 26% reported in the general population (Health Survey for England, 2014). This has been corroborated by a recent study on the anthropometric status of 131 adults with learning disabilities. The study found that that 28% were overweight and 47% obese, and that waist circumference in this sample was correlated to severity of learning disability (Hoey et al, 2016). In addition, the examination of 4-day food diaries revealed that intakes of sugar and saturated fat were above recommendations, while the intake of micronutrients was clearly below daily recommended amounts. (Hoey et al,

2016). Flygare-Wallen et al (2018) also found that men and women with a learning disability and / or autism had an increased prevalence of obesity, type 2 diabetes, and an increased prevalence of hypertension in men with a learning disability and / or autism.

Metabolic syndrome has been shown in the general population to increase twofold the risk of morbidity from coronary heart disease and stroke. Metabolic syndrome also increases the risk of developing Type 2 diabetes fivefold (Stern et al, 2004). This is significant given that coronary heart disease is the second leading cause of death, and that an inquiry into the premature death of people with a learning disability found that cardiovascular disease was recorded in 39% of cases (Heslop et al, 2013). Additional findings from the inquiry showed that 9% of people with a learning disability were diagnosed with Type 2 diabetes, and 22% had hypertension (Heslop et al, 2013).

Van de Louw et al (2009) found an increase in glucose concentrations in 28% of participants with a learning disability, and cholesterol concentrations above normal levels in 23% of the sample. The increased prevalence is also evident among 15-18 year olds: a study on adolescents with a learning disability in Taiwan reported that 11.7% of cases suffered from hypertension, 9.1% had high triglyceride levels, 1.1% elevated cholesterol and 0.3% had a fasting plasma glucose above >126 mg/dl (Lin et al, 2010). This reflects results in Britain with Emerson et al (2016) reporting that children with a learning disability are more likely to be obese at ages five (Odds Ratio compared to children without a learning disability 1.32), seven (O.R. 1.39) and eleven (O.R. 1.68) with obesity likely to increase into adolescence and adulthood. Thus it is vital that interventions be tailored at young children and consecutive years through to adulthood.

Therefore, further insights into MetS are imperative to enable effective screening and interventions to support people with a learning disability, who are known to have a reduced health status compared to the general population.

#### *4.2. Interventions addressing Metabolic Syndrome among people with a Learning Disability*

The National Institute of Health and Care Excellence endorse the view that lifestyle interventions are the best treatment for metabolic syndrome reversal, with diet combined with exercise being the best choice (Dunkley et al, 2012). Despite evidence from NICE (2012) physical exercise and healthy eating in people with a learning disability rarely meet the national standards of healthy lifestyles (Crawley

et al, 2007). In addition, evidence on the effectiveness of weight management and interventions to increase healthy dietary habits is lacking in the literature (Hsu et al, 2012).

Dietary interventions using multi-tiered approaches have been shown as more effective to promote healthy eating habits in children. Thus influencing the organisation, the staff and the service users / children. One example of this is the Food Dudes Program that combines positive reinforcement and role modelling with repeated exposure (Lowe and Horne, 2009) which has been successfully used in two Welsh schools for children with disabilities (Roberts-Mitchell, 2014). In addition the Nudge approach which uses a combination of food availability, positive reinforcement and indirect suggestions to influence decision making, is gaining support within the literature to improve lifestyle behaviours within both institutional work and school settings (Williamson et al., 2013).

Various authors have emphasised that staff supporting people with a learning disability would benefit from additional training to manage non-communicable diseases related to obesity. Cardol et al (2012), for instance, express that staff need to develop the skills and knowledge to communicate how to lead a healthy life. DiMaria-Ghalili et al. (2014) argue that healthcare professionals need further training in relation to basic and applied nutrition. This training, moreover, would need to be inter-disciplinary and consider the different health conditions that staff are likely to experience in their working life, enabling them to educate and support their service users.

#### *4.3. Existing resources to support healthy eating among people with a learning disability*

A number of resources are already available for people with learning disabilities to encourage healthy eating. The British Heart Foundation and Bromley Mencap's range of materials relies on easy-read formats which are only accessible to 10% of people with an intellectual disability and who are able to read.

The videos that the DAMSON project team have viewed are accelerated in order to show the process of cooking a healthy meal over a few minutes. People with intellectual disabilities and/ or Autism have difficulties with sequencing and recalling large chunks of information making this difficult and potentially frustrating for them to follow. Real-time videos that explain step by step what is required using easy to follow instructions are preferable. These resources also need to consider individual skill level when asked to weigh out or measure different amounts (grams / millilitres) and the cook's ability to tell the time.

#### *4.4. Training for staff working in General Practices to support people with a learning disability who have MetS.*

Individuals with learning disabilities have greater primary care use than individuals without a diagnosed learning disability (Carey et al., 2016). Despite this fact, Boon et al. (2017) found that 1 in 5 medical schools taught students about learning disabilities. More recently, the GMC's Outcome for Graduates (2018) stipulates that newly trained graduates should be competent in communicating with and assessing the needs of individuals with learning disabilities. Therefore, it is expected that an improvement in the percentage of medical schools delivering training regarding supporting patients with learning disabilities has recently occurred. This training should involve individuals and their family / carers. Co-facilitating sessions with individuals with learning disabilities and those with lived experiences of supporting them has been shown to improve communication skills (Coret et al., 2018).

#### *4.5. Conclusion.*

People with a learning disability have poorer health than people who do not have a learning disability. Interventions for MetS in people with Learning Disabilities has been under researched. Further support for staff working with individuals with a learning disability, who either have MetS or are at increased risk of developing MetS, is warranted.

## **5. Initial Project Aim**

Kingston University obtained funding from Health Education England for a project running from July 2018 to December 2019 that aimed to improve knowledge and resources available to support people with intellectual disabilities. To this end, we aimed to:

- Develop a cookbook designed to support people with a learning disability who may not be able to read, to gain knowledge and skills in preparing food and in making educated choices about healthy eating.

- Deliver training regarding metabolic syndrome to staff working in the NHS and who support individuals with learning disabilities as part of their role.
- Evaluate the impact on service user's dietary habits and health of staff training and the provision of resources that have been developed to promote healthy eating and dietary practices.
- Approach the course directors of medical students, including those running the Physicians Associates programs within the Surrey, Sussex and Kent regions, to invite them to training events tailored to those students' needs.

## 6. Revised Project Aims

Course directors or module leaders from Universities across Kent, Surrey and Sussex and South West London were contacted. As Physician Associate programs already included sessions on supporting individuals with learning disabilities, it was felt that additional training involving individuals with learning disabilities would be difficult to include in the program.

The aims of the programme were therefore revised to the following:

- To develop an electronic cookbook designed for people with learning disabilities to promote healthy eating.
- To offer training, namely
  - Three full-day workshops for staff working in the NHS across Kent, Surrey and Sussex.
  - Two full-day training workshops with provision of resources to staff working in services that support individuals with learning disabilities.
- To evaluate the impact of training and resources on service users.
- To provide training through the Primary Healthcare Partnership Event commissioned by the local CCG, for students and practicing primary and community care staff. The training was to involve individuals with learning disabilities.

## 7. The development and procurement of resources

An online resource has been produced which explains to people with a learning disability how to prepare healthy meals. This online cookbook prototyping consumption of a healthy diet is freely available to participants.

A number of organisations local to the project's lead place of work were contacted. These were a special educational needs school, a learning disability adult service and a collaborative initiative involving nursing students and individuals with learning disabilities. Meetings were arranged to observe cooking sessions, discuss and review resources currently being used, liaise with staff and service users about their needs and preferences, discuss the design of the cookbook, trial the cookbook, and support future engagement with the cookbook.

Individuals with learning disabilities and their support staff made suggestions regarding:

- Meals they would like to be included in the book
- The importance of hygiene and reducing risk of cross-contamination. Staff felt it was important to highlight in the cookbook how we should wash our hands prior to any cooking session.
- Portion control - what a healthy portion looks like.

In addition, observations highlighted the complexity of ensuring correct timings for cooking and the misleading nature of photographs. This was illustrated by one individual, who, when verbally asked and shown a photograph of grating a bit of the skin of the orange, went on to attempt to grate the entire orange. However, when staff role-modelled the process of zesting an orange she was able to follow this process easily. This underscored the point that the use of videos to explain steps of the food preparation process is preferable to photographs.

Staff were also able to feedback following the training about what information they would find beneficial in the training section of the website.

It was agreed that an outward facing webpage, from Kingston University's virtual learning environment, could be used to hold the contents of the cookbook. A web-based cookbook was developed. This can be accessed through <https://canvas.kingston.ac.uk/courses/12067>.

Individuals with learning disabilities from the Baked Bean Company agreed to participate in cooking sessions, and for these sessions to be recorded and used in the cookbook. Service users were informed that the cookbook would be online and people from around the world would be able to access this. All confidential information was removed using sound-over equipment and the faces of service users were not visible within the screenshots in order to protect their anonymity.

Resources procured for training included plates that displayed the eatwell guide, seeds, shopping bags and food timers (see picture below). The shopping bags in the shape of fruit were intended to remind and encourage service users to purchase more fruit and vegetables when shopping. The timers were altered to support people who cannot read the time, enabling them to gauge if foods had been cooking for an appropriate length of time (thus reducing the risk of foodborne illnesses). A colour system was employed to ascertain different lengths of times. Recipes in the cookbook indicated the appropriate colour to turn the timer to. Positive feedback was obtained from staff during the training days, about how they would use the timer with service users in other planned activity sessions. Staff had previously experienced difficulties with explaining timings to people that had difficulty recalling number sequences.

## 8. Structure of the training programme

The training provided to staff who work in the NHS supporting people with a learning disability focusses on the following approaches being applied to dietary choices

- Nudge behavioural science theory (cognitive, affective and behavioural nudges that can guide people choices towards a healthier option)
- Social learning theory (role modelling and reinforcement)
- Mere exposure theory (Repeated exposure, stimulus recognition, convenience and availability / accessibility).

The programme was implemented across Kent, Surrey and Sussex and ran over three days as presented in table 8.1.

*Table 8.1: Workshop on metabolic syndrome, obesity and improved nutrition.*

Location of workshop	Date	Delegates registered to attend	Number of people who attended
----------------------	------	--------------------------------	-------------------------------

Location of workshop	Date	Delegates registered to attend	Number of people who attended
Reigate	10 <sup>th</sup> Jan 2019	24	17
Crawley	4 <sup>th</sup> Feb 2019	22	14
Tonbridge	1 <sup>st</sup> March 2019	17	9
Total		63	40

The workshop included information and activities to support learning. The day covered:

- How to recognise metabolic syndrome
- Prevalence of metabolic syndrome in people with a learning disability
- Risks associated with metabolic syndrome
- How to explain metabolic syndrome and risks associated with it, to people with a learning disability.
- Strategies to reduce metabolic syndrome.
- What is a healthy diet?
- Service users' perspective of cooking healthy meals and being involved in making the cookbook.
- Approaches to support behaviour change
- Food swaps and changing the way that we cook
- Nudges and changing the food culture
- Barriers to changing the food culture in practice.

In addition, delegates were encouraged to state what additional training or information they felt would be useful, which was added to the web-based cook book as appropriate.

The sessions were held in an off-site venue with full catering provided. Delegates were released from their usual work to attend the day. Conference workshops were advertised on social media platforms, such as twitter and websites, including HEE workforce development for Kent, Surrey and Sussex. In addition, liaison with the training departments for each of the NHS Trusts enabled the conference workshops to be advertised within organisations.

Delegates included community nurses, a community matron, a clinical lead for physiotherapy, psychiatrists, physiotherapists, a teacher at a specialist school, health facilitators, a clinical lead for speech and language therapy, diabetes nurse educators, activity and residential support staff, community support staff, staff

working for local CCGs, home managers, nurses working in 24/7 care provision, and day service providers.

## 9. Study 1: The Evaluation of the workshop

### 9.1. Ethical approval

Ethical approval was gained from the Faculty of Health, Social Care and Education Research Ethics Committee at Kingston University prior to data collection.

### 9.2. Overall aim of the evaluation

The aim of the evaluation was to measure the participants' perceptions of the value and the impact of the workshop.

### 9.3. Evaluation Design

The longitudinal evaluation was conducted in three phases, pre-workshop, post-workshop and follow-up. The questionnaire covered the following four domains:

1. Participants' perceptions of the workshop and resources
2. A description of current behaviours and practices of the staff teams and service users
3. Perceived motivation of the staff member and their perceived capacity to enable change
4. Expected impact of the workshop and resources

### 9.4. Data collection tools

All questionnaires were developed and administered according to the principles of the Tailored Design Method (Dillman, 2014). This method minimizes the burden on the participants and increases the response rates and validity of the questionnaires. Concurrent triangulation design was used where the questionnaires include both quantitative and qualitative questions, aiming to expand the quantitative results with qualitative data. The quantitative and qualitative data were merged into one overall interpretation.

The pre-programme and post-programme questionnaires were administered online using Survey Monkey.

#### 9.5. *Data collection processes*

Invitations for completing the online questionnaires were sent by email. The data collection tools and invitations were developed by the project team, the project team was responsible for forwarding the online questionnaire invitations to the participants.

#### 9.6. *Data analyses*

SPSS was used to analyse the quantitative data from the pre-programme and post-programme questionnaires. Descriptive and inferential statistical analyses were conducted, reporting on frequencies of responses and means and measuring statistical significant differences between the pre- and post-data. The analyses were used to identify strengths and areas for improvement of the programme and to identify and measure the magnitude of impact.

Thematic analysis was used to analyse the qualitative data collected through the open-ended questions on the questionnaires.

### 9.7. Results

This section presents the results from the pre-post programme participants' questionnaires.

Seventeen participants (out of 40 delegates) completed the pre- and post- online questionnaire, resulting in a response rate of 42.5%.

Respondents expressed that the main motivation to attend the training was the need to support service users who were overweight and / or had obesity-related health concerns, or having a personal interest in the topic. Seventy-five percent of respondents stated that they supported service users who would like to lose weight or eat more healthily.

Unhealthy food choices appear to be related to snacks rather than main meals, snacks choice were reported to be influenced by taste, habits, convenience and availability.

Confidence to implement changes improved following the workshop. On a 4-point Likert Scale (disagree – somewhat disagree – somewhat agree – agree), the majority of respondents agreed that they were confident to offer support and influence dietary choices of their colleagues and/or service users or both? See table 9.7.

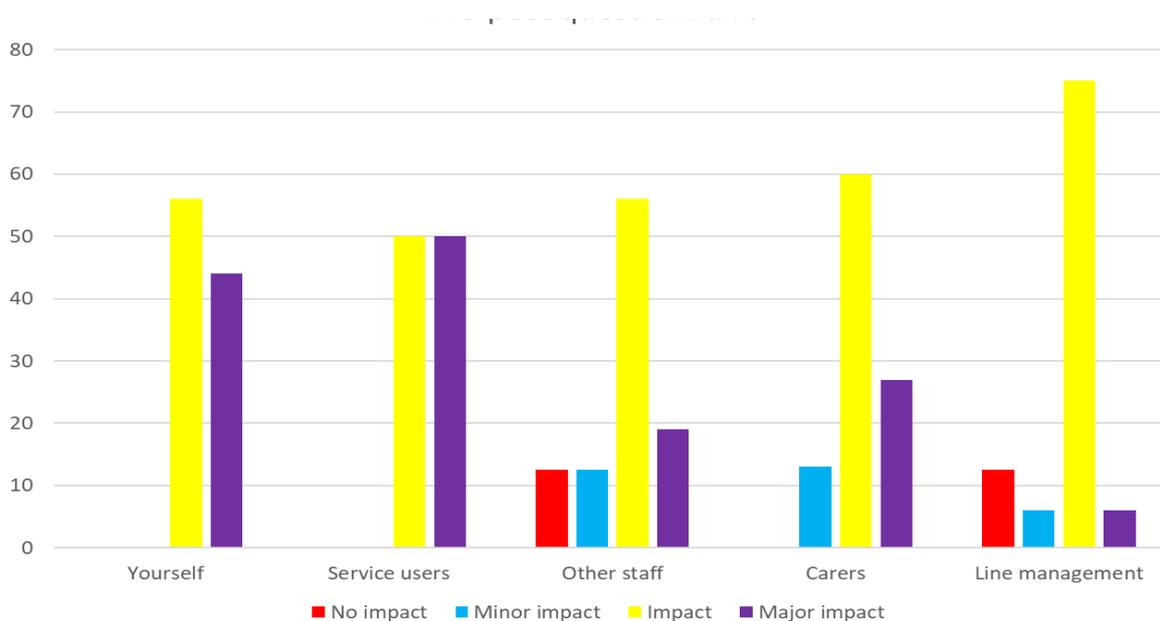
*Table 9.7: Motivation and confidence to offer and influence other people's dietary choices.*

	<i>n</i>	Pre-programme (Mean)	Post -programme (Mean)
Motivation to support others	16	3.94	3.94
Confident to offer support and advise about diet	16	3.44	3.75
Confident to influence service users to make good dietary choices	16	3.31	3.67
Confident to influence other members of the team	16	3.31	3.63
Coding: 1=disagree, 2=somewhat disagree, 3=somewhat agree, 4= agree			

Comparison of pre and post scores from respondents also showed that they felt an increase in access to resources following the training, to support service users with making healthy food choices, preparing nutritious meals, learning about diet and learning about obesity related health conditions.

All respondents reported that the workshop would have a positive impact on themselves and the service users they supported (see figure 9.7). Some impact on other staff, carers and line management was also expected but to a lesser extent. However, in the responses on the follow-up questionnaire, none of the respondents felt that the workshop had had an impact on other staff / managers (n=2), although respondents still felt the workshop had impacted themselves and service users.

Figure 9.7: Perceived impact of workshop on the work environment.



## 9.8. Summary and conclusions

Prior to and following the workshop NHS staff rated their perceptions of working with people with learning disabilities who had MetS or obesity. Respondents rated that their confidence, knowledge and motivation had improved, however, they felt that the workshop would have less impact on other team members or carers who they work with.

## **10. Study 2: Evaluation of training and resources on individuals with a learning disability.**

### *10.1. Ethical approval*

Ethical approval was gained from the Health Research Authority prior to the recruitment of participants. Information sheets and consent forms were presented in easy-read format. A video was also developed and provided to potential participants to explain what the study entailed and their rights as participants within the study.

### *10.2. Overall aim of the evaluation*

The aim of the pilot study was to assess the impact of the training and resources on individuals with a learning disability.

### *10.3. Evaluation Design*

A pilot study, using a prospective cohort design, involving individuals with a learning disability (n=10).

Baseline measures were collected after gaining consent from participants and their service managers. Individuals had their weight, height, blood pressure, and waist circumference measured. Participants also completed a short pictorial food-frequency questionnaire and completed diary sheets for their food and drink intake. Selected members of staff supporting the service users were provided with access to resources and attended the training. The community nurse working with service users residing in the service was also present at the training, and able to offer further individualised support to the staff teams and service users.

To enable participants the time to make changes to their lifestyle, data collection was repeated after eight weeks. The measures indicated above were repeated at this point. In addition, qualitative data was collected from participants through semi-structured interviews.

#### 10.4. Data Analysis

Quantitative data was analysed using SPSS. Inferential statistics were applied using a paired t-test.

Interviews were digitally recorded with the consent of the interviewee and were transcribed in full by the PI and a researcher. The transcripts were then coded manually line by line following a thematic analysis approach (e.g. Braun and Clarke 2006) by the researcher. Given the small number of interviews and the short duration of each interview (from around 2 minutes to around 11 minutes), it was decided that manual coding was appropriate and the use of qualitative data analysis software was not needed.

The researcher developed initial categories (themes) from a sample of interviews to develop a basic coding tree. The researcher then coded the entire set of interview transcripts using the basic coding tree and developed further codes as required until the entire contents of the interviews had been coded. This was then presented in table form with frequencies for each type of response or theme

#### 10.5. Results

##### Quantitative data

The descriptive data found that weight decreased by 0.48kg across the group, thus the average weight loss was 0.05kg. This was not statistically significant and is unlikely to be clinically significant given that the average weight of participants was 102kg.

Only two measures resulted in statistically significant results, namely participants' systolic blood pressure and the variety of vegetables consumed in the previous week. A reduction in mean systolic blood pressure from 131 at baseline to 121 post-intervention reached a statistical significance of  $p > 0.023$ . Consumption of vegetables increased from an average of 7.4 different vegetables consumed in a week to 10.9 different types of vegetables ( $p > 0.028$ ).

Other trends in the data were noted but were not significant, some of these trends indicated healthier lifestyle choices (e.g. reduction in take-away meals and sugary

fizzy drinks) and others were noted to be in the opposite direction (e.g. reduction in the variety of fruit eaten).

### Qualitative data

The responses from the interviews are presented in Table 10.1. A frequency is given for the number of times any given response is given across the interviews. Not all interviewees responded to all the questions and, on occasion, responses were ambivalent. In such cases responses were omitted from the table.

Table 10.1: Analysis of qualitative data

Theme	Sub-theme	Frequency	Example (verbatim quotation)
<b>Feelings about own eating habits</b>	Interviewee is happy with their eating habits	10	- 'Yeah'  - 'Yes I am' (in answer to question about whether they are happy with their eating habits)
	Interviewee would like to change their eating habits further	1	- 'A bit further.... have a little bit smaller portions for dinner.' [in response to the question: 'So are you happy with your eating habits as they are now? Or do you think you'd like to change them a little bit further? ... what would you like to change?']
<b>Changes in eating habits</b>	Interviewee has not changed their eating habits	4	- 'About the same'  - 'No, there hasn't been a change'
	Interviewee has become more mindful of their eating habits	1	- 'I've been more mindful of what I've been eating'
	Interviewee controls frequency of treats or snacks	2	- 'Trying not to have chocolate or chocolate once in a while'  - 'Not snacking as much as I used to.'
	Interviewee tries to reduce portion size or evaluates positively staff	2	- 'Trying to watch my portion size.... I ask the staff about smaller plates to make it look bigger than it actually is'

	reduction in portion size		- 'Oh yeah, that is a good thing.' (in response to staff saying that portion size has been reduced by staff)
	Interviewee has been eating more fruits and veg	5	- 'How have they changed? Been eating nice things... like vegetables, peas, carrots not cauliflower because cauliflower doesn't agree with my stomach.'  - 'Yes, eating more Fruit and veg'  - 'Yes, I've had bananas, oranges yesterday so I do, like, eat fruit. Cos they are more healthier, so trying to do it'
	Interviewee reports eating less now	1	'I eat less'
	Interviewee has cut down on sugar	1	'I've cut down on the sugar. I used to have about three, you know, now I've cut that down to two. Yeah so I've cut down a little bit.'
<b>Perception of impact of changing in eating habits on self</b>	Interviewee feels lighter / more mobile	2	- 'Slowly getting lighter'  - 'A lot more mobile'
	Interviewee feels they have lost weight	1	- 'It makes me feel, a little bit lose weight. That's what supposed to be doing'
	Interviewee feels positive / happier	2	- 'It just makes me feel positive'  - 'I feel happier'
	Interviewee is proud of herself	1	- 'Yeah. And I want to keep that off me.' [in response to question: 'so you're saying you're really proud of yourself for losing some weight?']
	Interviewee feels healthier	2	- 'Feel a bit healthier.'  - 'I do yeah' [in response to question 'do you feel more healthy?']
	Interviewee does not feel there has been a change	1	- 'The same.'

<b>Perception of factors contributing to weight loss</b>	Cutting out foods considered unhealthy	1	- 'Cutting out more naughties like cheese savouries, as like those, so say cut it out now.'
	Exercise/doing more exercise	2	- 'I did it myself, lots of steps, walking on the stairs, I do that sometimes. Walking back and forwards sometimes.'  - 'I'd say a little bit more walking, because sometimes, I mean I'm walking quite a bit because I love walking. Like yesterday we went from here to the doctors .. yeah a lot of walking.'
	Not sure of the cause of weight loss	1	'I am not sure to be honest.'
<b>Interviewee involvement in cooking</b>	Yes	9	- 'Yeah, every Monday I cook for the lads.'  - 'Yeah, Saturday.'  - 'Yeah sometimes...[staff: you help cut veggies] yeah potatoes.'
	Not at the moment	1	'I used to.... But I don't do cooking anymore.'
	no	1	
<b>Reported usage of cooking guidelines and perceptions of usefulness</b>	No	4	- 'Just wing it.'  - 'No, I choose what to cook.'
	No personally but a member of staff does	1	- 'That lady, [named her]...she has a recipe on the table or wall.'
	Not sure	1	- 'Hmm I don't know.'
	Yes and the recipes are easy to follow	2	- 'Yes,...from a book... staff team help.'
	Yes, and sometimes the recipes are hard	1	- 'Sometimes... sometimes hard.'

	to follow		
<b>Perceptions of other factors that help respondent eat well</b>	Interviewee setting themselves goals	1	- 'Setting myself goals. like next Christmas I'd like to go to China to see my niece, I'd like to lose the weight, that's a major incentive to lose the weight.'
	A diversity of food offerings	1	'Like lots of different foods.'
	Availability of specific foods liked by interviewee	3	- 'Fruit, pears, peaches.' - 'Salad' 'Yes' [in response to question: having salad available?] - 'Fruit ...pizza.'
	Staff picking the healthy option on outings	1	'Yeah we do.' [in response to staff suggestion that staff help pick healthy options when on outings]
	Staff cooking healthy meals	1	'Yes' [in response to the question: does that help you eat well when staff cook good meals?]
	The use of colour-coded plates for each of the food groups	1	'Yeah, yeah.' [in response to the question "those plates, do you think that helped you to eat more of the vegetables?"]
	The use of smaller plates	1	'Yeah that's helped.'
	Including veg in the main meal (e.g. spaghetti sauce)	1	'I think so.' [in response to the question: "does that help you eat more vegetables when they're in the main meal?"]
	Playing football	1	'It's football.' [in response to question 'what's helped you eat more fruit?']
<b>Perceptions of other factors that make it hard for</b>	Interviewee unsure	4	- 'Not sure.' - 'Don't know.'

<b>respondent eat well</b>	Seeing sweet treats in shops	1	'Yeah it does.' [in response to staff suggestion that seeing chocolate bars in shops when on outings makes it difficult to eat healthily]
	Past eating habits	1	'It's from your childhood from your family.'
	Dislike of fruit that is on offer	1	'Yeah.' [in response to the question 'the fruits and vegetables are too hard? Some of them are, aren't they? So you like your fruit and vegetables to be softer? ...so you like your fruit to be cooked?']
	Feeling sad	1	'When you feel sad.... [then I eat] junk food.'
<b>Perception of extent of staff support in eating well</b>	Staff help in various ways	5	<ul style="list-style-type: none"> <li>- 'Sometimes they suggest they help, perhaps reminding about small portion size, watching sugar.'</li> <li>- 'They try...they do help when you want help.'</li> <li>- 'They do help...on the Sunday they do a menu plan and then each of us pick what they want and yeah most of the time they actually pick really good ones and then they just cook it. So yeah, I think the staff do a really good job.'</li> </ul>
	Staff make it hard	4	<ul style="list-style-type: none"> <li>- 'Make it hard.'</li> <li>- 'Harder.'</li> <li>- 'Maybe a little bit.'</li> <li>- 'Sometimes hard.'</li> </ul>
<b>Other forms of support for eating well</b>	none	2	'Not really.'
	unsure	4	<ul style="list-style-type: none"> <li>- 'Er I don't have an answer to that one.'</li> <li>- 'I don't know.'</li> </ul>

	Being recognised for successes	1	'Yeah! I'm going to make the chart now.' [interviewee becomes very enthusiastic after interviewer suggests that by making a chart tracking her weight loss others would come and congratulate her]
--	--------------------------------	---	--

## 10.6 Summary and conclusions.

Limitations of the study need to be acknowledged. The small sample size and short duration of the intervention phase means that anthropometric measurements may not have had the opportunity to change significantly.

Participants' responses to questions about factors that have helped them to eat well during the study indicate that staff have implemented a number of techniques and resources discussed in the training. This included using smaller plates and providing colour-coded plates to indicate the ratio of vegetables, protein and carbs for a balanced meal. The availability and diversity of healthy snacks in close proximity also appeared to have improved. In addition, the research team was able to observe that staff within one home had created an easy-to-read presentation on the dining room wall to pass on information they had learnt to service users and other staff. However, the majority of service users were not aware of the online resources that had been produced for them. Further research is required in order to investigate the most effective approaches for delivering training and resources in a way that will positively impact the health of individuals with learning disabilities using health and social care services.

## 11. Provision of training for medical staff.

The organisers of the Healthcare Partnership Event agreed that the project team could facilitate two training sessions in June 2019, and a further session in December 2019.

Due to last minute changes in timetabling, the individuals with learning disabilities who were scheduled to co-facilitate the session were unable to accommodate for these changes. Therefore, one of the sessions in June had to be cancelled.

Nineteen delegates were registered to attend the session, but changes to the schedule meant that many were no longer able to attend, leaving five delegates to complete the session.

Feedback after the June session regarding GPs' remit in supporting an individual with metabolic syndrome led to the contents of session being revised. The session was changed to focus on communication and how individuals with learning disabilities would like to be treated in healthcare settings. This included captions of individuals with learning disabilities own words to ensure authenticity to open up dialogue with the delegates.

In December, the actors with learning disabilities were not able to support the event due to service closures over the winter period. The winter event was thus to be facilitated by a member of the DAMSON project team. Due to a miscommunication between the different event organisers on the day, delegates were wrongly informed that the session had been cancelled. Therefore, only one individual (a practice nurse) completed the session.

## 12. Conclusions

The development of the cookbook with individuals with learning disabilities has produced a sustainable resource, which was well received by those attending the workshop. Delegates who attended the workshop were able to request what information needed to be added to the training section of this resource, to ensure that their needs were met. The evaluation of the impact on service users had mixed results, which is due to a number of challenges, including how it is best to support staff to engage with and apply research in the practice. Secondly, how we can change snacking behaviour of service users when they are independent in accessing local facilities. Thirdly, as one participant stated "it's from your childhood, from your family" showing that training and resources to encourage healthy eating should be available early in life and available across the lifespan.

Engaging staff in non-mandatory training, is likely to result in a selection bias, where staff who are already interested in nutrition and lifestyle health promotion initiatives, are more likely to register for additional training opportunities on nutrition. A consistent message for service users is required, therefore, greater impact is expected if there is engagement from all individuals involved in the persons care. Further to this, other professional including primary care staff, need opportunities to develop skills around communication and how to tailor support for individuals with learning disabilities, who are at increased of developing MetS.

## 13. References

Alberti K.G., Zimmet P.Z. (1998). Definition, diagnosis and classification of diabetes mellitus and its complications. Part 1: diagnosis and classification of diabetes mellitus provisional report of a WHO consultation. *Diabet Med.* 15, 539–553

Boon, V., Ridd, M. and Blythe, A. (2017). Medical undergraduate primary care teaching across the UK: what is being taught? *Education for Primary Care*, 28(1), 23-28.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2). pp. 77-101.

British Heart Foundation (n.d.). Recipes. Accessed at <https://www.bhf.org.uk/information-support/support/healthy-living/healthy-eating/recipe-finder>. Last accessed 30.01.2020.

Bromley Mencap (2017). Dinners and Puddings: Easy read Recipes for people with Learning Disabilities. Accessed at <https://www.bromleymencap.org.uk/wp-content/uploads/2011/02/Easy-read-recipes-version-May-2017-emailable.pdf>. Last accessed 30.01.2020

Cardol M, Rijken M, van Schrojenstein Lantman-de Valk H. (2012). Attitudes and dilemmas of caregivers supporting people with intellectual disabilities who have diabetes. *Patient Educ Couns.* 2012 Jun; 87(3):383-8.

Chang YW, Lin JD, Chen WL, Yen CF, Loh CH, Fang WH, Wu LW. (2012). Metabolic syndrome and short-term heart rate variability in adults with intellectual disabilities. *Res Dev Disabil.* 2012 Nov-Dec; 33(6):1701-7.

Coret A, Boyd K, Hobbs K, Zazulak J, McConnell M. (2018). Patient Narratives as a Teaching Tool: A Pilot Study of First-Year Medical Students and Patient Educators Affected by Intellectual/Developmental Disabilities. *Teaching and Learning in Medicine.* 2018 Jul-Sep; 30(3):317-327.

Crawley, H. (2007). Eating well: children and adults with learning disabilities Nutritional and practical guidelines. Caroline Walker Trust: Hertfordshire Uk.

de Winter CF, Hermans H, Evenhuis HM, Echteld MA. (2015). Associations of symptoms of anxiety and depression with diabetes and cardiovascular risk factors in older people with intellectual disability. *J Intellect Disabil Res.* 2015 Feb; 59(2):176-85.

de Winter CF, Bastiaanse LP, Hilgenkamp TI, Evenhuis HM, Echteld MA. (2012). Cardiovascular risk factors (diabetes, hypertension, hypercholesterolemia and metabolic syndrome) in older people with intellectual disability: results of the HA-ID study. *Research in Developmental Disabilities.* 2012 Nov-Dec; 33(6):1722-31.

DiMaria-Ghalili RA, Mirtallo JM, Tobin BW, Hark L, Van Horn L, Palmer CA. (2014). Challenges and opportunities for nutrition education and training in the health care professions: intraprofessional and interprofessional call to action. *Am J Clin Nutr.* 2014 May; 99(5 Suppl):1184S-93S.

Dunkley, A., Charles, K., Gray, L., Carnosso-Stefinovic, J., Davies, M. and Khunti, K. (2012). Effectiveness of interventions for reducing diabetes and cardiovascular disease risk in people with metabolic syndrome: systematic review and mixed treatment comparison meta-analysis. *Diabetes, obesity and metabolism.* July 2012: 14(7).

Emerson E, Robertson J, Baines S, Hatton C. (2016). Obesity in British children with and without intellectual disability: cohort study. *BMC Public Health.* 2016 Jul 27; 16:644.

Fragher, r. and Clarke, B. (2013). *Educating Learners with Down Syndrome: Research, theory, and practice with children and adolescents.* London, Uk. Routledge.

Flygare Wallén E, Ljunggren G, Carlsson AC, Pettersson D, Wändell P. (2018). High prevalence of diabetes mellitus, hypertension and obesity among persons with a recorded diagnosis of intellectual disability or autism spectrum disorder. *J Intellect Disabil Res.* 2018 Apr; 62(4):269-280.

Health Survey for England (2016). Found at <https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england/health-survey-for-england-2016#key-facts>. Accessed on 18.7.2018

Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A. and Russ, L. (2013). The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet.* Volume 383, No. 9920, p889–895, 8 March 2014

Hoey E, Staines A, Walsh D, Corby D, Bowers K, Belton S, Meegan S, McVeigh T, McKeon M, Trépel D, Griffin P, Sweeney MR. (2017). An examination of the nutritional intake and anthropometric status of individuals with intellectual disabilities: Results from the SOPHIE study. *J Intellect Disabil.* 2017 Dec; 21(4):346-365.

Horne PJ, Hardman CA, Lowe CF, Tapper K, Le Noury J, Madden P, Patel P, Doody M. (2009). Increasing parental provision and children's consumption of lunchbox fruit and vegetables in Ireland: the Food Dudes intervention. *Eur J Clin Nutr.* 2009 May; 63(5):613-8.

Hsu SW, Yen CF, Hung WJ, Lin LP, Wu CL, Lin JD. (2012). The risk of metabolic syndrome among institutionalized adults with intellectual disabilities. *Research in Developmental Disabilities.* 2012 Mar-Apr; 33(2):615-20.

International Diabetes Federation (2006). The IDF consensus worldwide definition of the METABOLIC SYNDROME. IDF communications: Belgium.

Learning Disability Mortality Review Programme (2018) LeDer annual report 2016-17. Available at <http://www.bristol.ac.uk/university/media/press/2018/leder-annual-report-final.pdf>. Accessed on 18.7.18

Lin P, Lin L, Lin J. (2010). Hypertension, hyperglycemia, and hyperlipemia among adolescents with intellectual disabilities. *Res Dev Disabil.* 2010 Mar-Apr; 31(2):545-50.

Public Health England (2016). Learning Disabilities Conference 2016: Using primary care data to plan better services for people with learning disabilities. London.

Public Health England (2018). The Eatwell Guide. Available at <https://www.gov.uk/government/publications/the-eatwell-guide>. Last accessed 03.03.2020.

Roberts-Mitchell, A. (2014). Accessed at <https://www.bangor.ac.uk/research-innovation-and-impact-office/news/healthy-eating-for-denbighshire-special-schools-19865>. On the 1.11.2018.

Room B, Timmermans O, Roodbol P. (2016). The prevalence and risk factors of the metabolic syndrome in inpatients with intellectual disability. *J Intellect Disabil Res.* 2016 Jun; 60(6):594-605.

Stern MP, Williams K, González-Villalpando C, Hunt KJ, Haffner SM. (2004). Does the metabolic syndrome improve identification of individuals at risk of type 2 diabetes and/or cardiovascular disease? *Diabetes Care.* 2004 Nov; 27(11):2676-81. Erratum in: *Diabetes Care.* 2005 Jan; 28(1):238.

Teeluckdharry S, Sharma S, O'Rourke E, Tharian P, Gondalekar A, Nainar F, Roy M. (2013). Monitoring metabolic side effects of atypical antipsychotics in people with an intellectual disability. *J Intellect Disabil.* 2013 Sep; 17(3):223-35.

van de Louw J, Vorstenbosch R, Vinck L, Penning C, Evenhuis H. (2009). Prevalence of hypertension in adults with intellectual disability in the Netherlands. *J Intellect Disabil Res.* 2009 Jan; 53(1):78-84.

Williamson DA, Han H, Johnson WD, et al. (2013). Modification of the school cafeteria environment can impact childhood nutrition. Results from the Wise Mind and LA Health studies. *Appetite* 2013; 61:77–84.

## 14. Appendix.

### Lesson Plan for the workshop.

Time	Topics covered	Resources
09:00 – 09:30 arrival time to get coffee and meet other delegates	Interesting / thought-provoking nutritional facts	Cards with food facts on tables.  Half tables have sealed packet of biscuits, other tables have a plate of biscuits provided.
09:30	Why are you here?  Discussing issues from practice.	
10:00	Why are we here?  <ul style="list-style-type: none"> <li>• What is Metabolic Syndrome.</li> <li>• Why do we need to know about it, what is the risk and how can we prevent it?</li> <li>• What can we do about it?</li> </ul>	
10:30	Recognising people with MetS  <ul style="list-style-type: none"> <li>• Guessing the BMI of presenters and pictures.</li> <li>• Guessing healthy range for waist circumference</li> <li>• Discussion regarding how the group underestimated BMI for</li> </ul>	Pictures of individuals than range from a BMI of 18 to 80.  Tape to show waist and easy calculation (height halved should be more than waist)

	<p>anyone above 25. How this links to evidence regarding perceived norm of a healthy weight.</p>	
11:30	<p>How can we explain MetS to an individual with a learning disability?</p>	<p>Balloons to signify heart – pump up with 1kg bag of sugar on it.</p> <p>Draw round self for body map and then label health issues associated with obesity</p> <p>Teeth in coke</p> <p>Tube to represent arteries with sugar and fat going through</p>
12:00	<p>Discussion regarding “isn’t it just personal choice”.</p> <p>Capacity to understand long term implications of unhealthy lifestyles.</p>	<p>Refer to biscuits on table – did we give choice (only chocolate biscuits or ginger biscuits) - is this choice? Or would choice be the option of biscuits or fruit?</p>
12:15	<p>What is a healthy diet?</p> <ul style="list-style-type: none"> <li>• Variety (not same 5 everyday)</li> <li>• Moderation (a treat after every meal or once a week)</li> <li>• Adequacy and balanced nutrient density (to gain all vitamins, protein / energy requirements etc)</li> </ul>	<p>A3 Eatwell Guide</p> <p>A3 Mediterranean pyramid</p> <p>How these can be used to make a shopping list (circling foods to buy).</p>

	<ul style="list-style-type: none"> <li>Personalisation (celiac, Food sensitivity / selectivity)</li> </ul>	
12:45 – 13:30	<p>Explaining cookbook – showing a video from cookbook.</p> <p>Lunch with the chefs.</p>	Lunch provided that contained specific nutrients that evidence has linked to improving health of people with MetS.
13:30	Why did we include the foods in the buffet provided?	See sample slide below
13:45	<p>What is in your food?</p> <p>Consider drinks that we have – lattes, smoothies.</p>	To put the amount of fat and sugar on the plates that correspond the fat and sugar contained in the food / beverage.
14.45	<p>Does education change behaviour? – making this easy.</p> <p>Food swaps and hidden veg: How to change a few things to make it taste good but be healthier.</p> <p>Discussion – what would be priority (not changing too much at once), how and what we cook, motivation and skills to cook well, finances and availability / accessibility.</p>	<p>Scenario showing shopping receipt (see slide below)</p> <p>scenario of food diary</p> <p>Jollof rice with plantain recipe.</p>
15.45	<p>What is in your fridge?</p> <p>Positioning of foods and the Nudge approach</p>	Designing a buffet for a birthday celebration.

	<p>Availability and accessibility</p> <p>Exposure, role modelling and reinforcement (discussion what foods are in the nursing office).</p>	
16:15	<p>Portion control and managing Moorish foods.</p>	<p>Game on portion sizes.</p> <p>Variable sized plates / bowls / glasses.</p>
16:30	<p>Barriers to changing the culture where you work?</p> <p>Developing an action plan – what will you take from the day.</p>	<p>Flipchart and pens.</p>



## Micronutrients and phytochemicals

Carotenoids – antioxidants – carrots, apricots, cantaloupes, sweet potatoes.

Vitamin B12 – reduced oxidative stress / risk of neuropathy (beef, fortified cereals, shellfish)

Vitamin C – antioxidant (peppers, broccoli / kale, kiwi, oranges, strawberries)

Vitamin D – anti-inflammatory (fish, eggs. Mushroom, sunlight)

Vitamin E – antioxidant (almonds, sunflower seeds, wheat germ)

Selenium – antioxidant (brazil nuts)

Zinc – needed for beta cells - beef, seafood, wheat-germ, cashew nuts

Magnesium – effects insulin secretion, binding and activity – beans / lentils, spinach, brown rice.

Nitrates – nitric oxide reduces hypertension- Beetroot, walnuts.

## What food swaps could you suggest?

This is Mina's till receipt for her midweek shop.

£0.69	Basic tea bags
£0.42	Sliced white bread
£1.4	4 pack of mars bars (promotional offer)
£1	Tube of Pringles (on offer)
£1	Family size bag of crisps (on offer)
£0.80	Cheese spread
£1.20	Margarine
£1.00	6 X yoghurts
£0.55	digestives
£1.99	Sausage and mash with onion gravy ready meal X2; chicken curry ready meal (on offer 3 for £5).
£1.20	Semi-skimmed milk
£1.00	2 litres of coke (on offer)