



Diabetes Federation of Ireland

Annual Report 2009

Supported by



Foreword

Looking back on 2009, there were many significant milestones. The most important one yet to be finalised is the announcement of a new Health Service Executive Clinical Lead in Diabetes with the official naming of the individual eagerly awaited.

Other new milestones for the Federation include setting up the Diabetes Ireland Research Alliance, bringing teenagers from all over Ireland together to voice their views, training professionals to deliver structured diabetes education and establishing a tri-partite consortium to advocate professionally for people with diabetes. In addition to those activities, we were delighted to be awarded the Guaranteed Irish symbol.

Alongside these milestones, we continue to host the lo-call telephone helpline and website; publish new, and reprint, educational literature; fund two high quality research projects; produce Diabetes Ireland and Diabetes Professional four times a year; hold public education meetings throughout the country; host a healthcare professional study day; continue to educate people with diabetes and their carers through the CODE programme and support people with diabetes and families affected by diabetes.

On the financial side 2009 has been a tough year as a result of the sharp change in the economic climate and in trying to maintain our many services. In June, the National Council had to take a hard look at the balance sheet and to reduce our expenditure asked all employees to reduce their working hours whilst maintaining our many services. This was not entered into lightly but fortunately, employees accepted the need to do this and since July despite working fewer hours have continued to maintain our many services.

We gratefully acknowledge our thousands of generous supporters and fundraisers who are helping us to support people with diabetes and fund diabetes research. With your continued support, we are confident that we can maintain the current level of services we provide and continue to extend them to meet your needs.

Jim Byrne
Chairperson

Table of Contents

Chapter 1	2
Diabetes Federation of Ireland	2
Overview of Services	2
Diabetes Support and Education	3
Local Branch Support.....	3
Helpline Support.....	4
Website Support	4
Literature Support.....	5
Diabetes Ireland & Diabetes Professional	6
Chapter 2	7
Patient Education:.....	7
CODET2 2009 Evaluation	7
Demographic Details	9
Physical Characteristics and Biomedical Markers	10
Empowerment	11
Wellbeing	12
Knowledge.....	13
Post attendance Evaluation.....	14
Well being	14
Knowledge.....	15
Biomedical Measurements	15
Training Professionals to Deliver CODET2.....	16
Conclusion.....	17
Parents’ Support Group	19
Family Events.....	19
National Teen Activity Day.....	19
Sweetpea Kidz Club	20
Time to Talk Teen Support Group	20
National Teen Conference.....	21
Chapter 3	23
Health Promotion	23
Workplace	23
Community Screening	24
Community Talks and Presentations	25
Schools	26
Professional Services.....	27
Media Reach.....	28
Volunteer of the Year	28
Diabetes Expert Advisory Group First Report	29
Diabetes Research	29
Finance	30
Conclusion.....	30
Appendix 1	32
CODE 2009 Lay Summary	32
Appendix 2	34
Geographical locations of CODET2 2009	34
Appendix 3	35
Acknowledgements	35
Corporate partners	36

Chapter 1

Diabetes Federation of Ireland

The Diabetes Federation of Ireland (formerly Irish Diabetic Association) has been established since 1967 as a registered charitable organisation. It is dependent mainly on voluntary donations, contributions from our corporate partners and grants from the Health Service Executive to fund the delivery of its health promotion initiatives, diabetes education programmes and other services.

All activities of the Federation stem from its' mission which is:

To provide a quality service in improving the lives of people affected by diabetes and working with others to prevent and cure diabetes.

The organisation has three aims and they are:

- To provide support, education and motivation to people with diabetes, their families, and friends;
- To raise awareness of diabetes in the community and foster programs for early detection and prevention of diabetes;
- To support and encourage advances in diabetes care and research.

Overview of Services

The Federation supports all people with diabetes and those at risk of developing diabetes, through

- Providing objective, reliable and evidence based information via its helpline, website, magazine, journal and leaflets;
- Delivering direct diabetes education services to professionals and communities;
- Increasing awareness of diabetes and its symptoms in the wider community;
- Giving voice to those denied their rights because of diabetes;
- Funding research to prevent, cure and manage diabetes.

These services are streamlined as Support and Education, Health Promotion, Awareness, Research and Discrimination.

Diabetes Support and Education

Support

With increasing prevalence of diabetes and pre-diabetes, the Federation has actively looked to improve access to peer support, education and information.

The Diabetes Federation of Ireland support people with diabetes through a wide range of services including face-to-face contact, literature provision, helpline and website support. Inherent in any supportive interaction is promotion of health and for many people with diabetes; this means the provision of diabetes education.

Local Branch Support

There are 23 branches of the Diabetes Federation situated around the country. Their role is to promote the aims of the Federation and provide a local support network for people of all ages with diabetes and their families. The Regional Development Officers (RDOs) of the Federation work closely with the local branches calling on their local knowledge to promote events and work with them in organising public meetings and other similar events. Branches are run on a voluntary basis and are always seeking people willing to help with local events.

One of the key activities of a branch is to provide opportunities for its local community to come together to share their experiences and hear from a range of diabetes healthcare professionals on all aspects of effectively living with diabetes on a daily basis.

In 2009, 17 public education meetings were held which a combined audience of 900 attendees. The breakdown of the meetings were:

Area:	HSE North East	HSE Mid Leinster	HSE South	HSE West
Number:	2	7	2	6

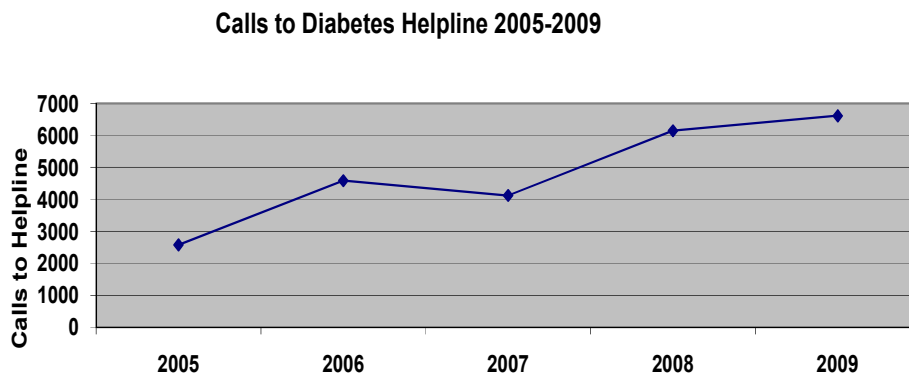
Evaluation of each meeting is undertaken in order to ascertain the best vehicle for promoting each meeting locally and identifying topics of particular interest for future meetings. Overall, evaluations of these meetings are extremely positive and will be maintained for 2010.

Helpline Support

One of the main support mechanisms for people with diabetes is immediate access to up to date quality information. The Diabetes Helpline is a national lo-call helpline which can be accessed from anywhere in Ireland and for any duration for €0.25 cent.

In 2009, there were 6,613 callers to the helpline, an increase of 468 from 2008, reflecting increased awareness of the helpline. The helpline team are kept abreast of breaking news issues by healthcare professional staff and are advised on appropriate responses to the wider public.

The annual number of callers to the helpline is increasing year on year highlighting the continuing need for this service. Seventy-seven per cent of callers in 2009 were seeking general information about the management of diabetes. Most callers received written information (66%) following initial contact.



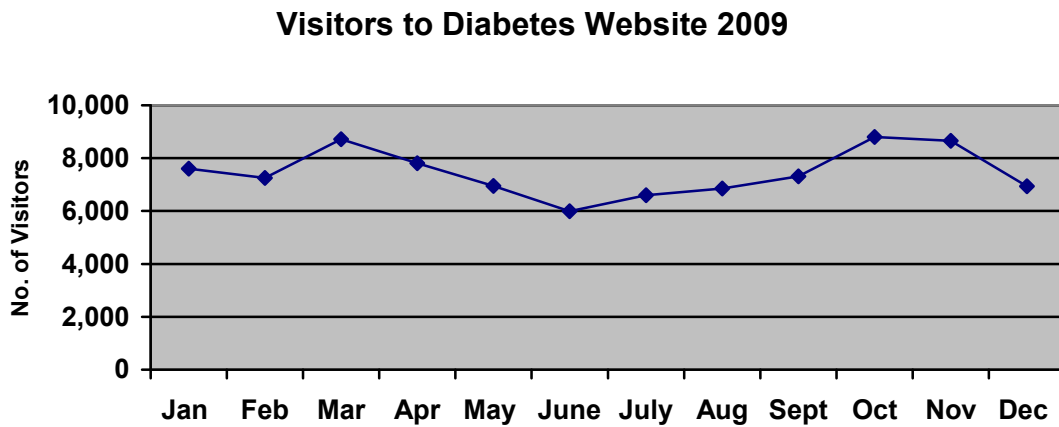
Graph 1 – Calls to helpline 2005-2009

Website Support

Electronic support continues to become more common and the Diabetes Federation of Ireland has responded by updating their website www.diabetes.ie with more user friendly links.

In 2009, 84,501 (61,109 in 2008) people visited the website spending on average 8.25 minutes (5.9 minutes in 2008) on the site which most likely reflects the increased use of the web as an

information source. Monthly increases in visitor numbers was notable at times of the year that the Federation had increased national coverage on radio and through public events (see Graph 2)



Graph 2 – Visitors to www.diabetes.ie 2009

Literature Support

People with diabetes require access to information that is easily accessible and appropriate to their needs. The Federation acknowledge that literature is time specific and due to the evolving nature of diabetes management and changing technologies, all literature needs to be updated regularly and new written information leaflets/booklets need to be developed as funding permits.

In 2009, in conjunction with the Diabetes Interest Group of the Irish Nutrition and Dietetic Institute and supported by the Health Service Executive, the Federation developed and launched the “Healthy Eating for People with Type 2 diabetes” booklet. Proving extremely popular, stocks of the booklet were depleted within 6 months of being launched. The Federation plan to re-print the booklet in 2010. In addition, during spring 2009, a diabetes leaflet was produced with the Cork Travellers’ Women’s Network and the Health Service Executive to promote the health and wellbeing of the travelling community.

The Federation has an extensive range of information leaflets about diabetes and related areas. In order to facilitate people and professional healthcare workers accessing these publications in a timely fashion, pdf copies of a range of them are available on www.diabetes.ie.

To aid people who require background information about diabetes, diabetes services and management in Ireland, a section of www.diabetes.ie is also devoted to publish downloadable reports. With this facility, it is now possible to download a variety of national publications related to diabetes from a central point.

With the increasing media profile of diabetes, the Federation regularly assist journalists of national media organisations with background information on their articles, programmes and help clarify technical issues related to diabetes. In addition, some publications have commissioned articles from the Federation and publish these with details of how to access further information /support.

Diabetes Ireland & Diabetes Professional

In 2009, four issues of both Diabetes Ireland and Diabetes Professional were issued. Diabetes Ireland is distributed to all members while Diabetes Professional is distributed to all healthcare professional members plus a range of allied healthcare professionals interested in diabetes. Diabetes Ireland has 8,000 readers and Diabetes Professional 5,000 readers per issue respectively.

Chapter 2

Patient Education:

In 2007, the Diabetes Federation of Ireland launched its patient education programme, Community Orientated Diabetes Education (CODE). Part funded by the HSE, the programme is delivered at local level throughout Ireland by trained healthcare professionals.

CODE is a structured diabetes education programme for people with type 2 diabetes (CODET2) and for families living with type 1 diabetes (CODET1). CODE supports and supplements care from the individual's own diabetes team so that knowledge and skills are reinforced and the taking of responsibility for personal self-management of diabetes is gradually strengthened.

The CODE programme for people with Type 2 diabetes (CODET2) is delivered over three successive weeks with a telephone support session at 10 weeks and a follow-up support/appraisal session at 26 weeks. While initially developed for delivery by Federation professional staff at primary care level, demand was so great that it became necessary to train other professionals to become CODE educators for delivery of the programme at both primary and secondary care level.

See Appendix 1 for a lay summary of the 2009 CODET2 programme results.

CODET2 2009 Evaluation

During 2008, the evaluation of CODET2 showed that CODET2 was well received by people with diabetes and their primary care teams and that the demand for course delivery rose considerably. With the support of an education grant from Merck Sharpe Dohme, the focus of the CODET2 programme shifted for 2009 from an increase in number of courses delivery to training healthcare professionals with an academic diabetes qualification to train as CODE educators. Thus during 2009, 31 CODET2 programmes were delivered throughout Ireland to which 427 people attended (See Table 1).

Table 1 Code Attendance in each HSE region.

HSE Region	Number of participants	Number of programmes
Mid-Leinster	118	9
NorthEast	49	5
Southern	62	5
West	198	12
Total	427	31

See Appendix 2 for actual geographical locations.

The areas with notable low participation were the opposite of that for 2008 e.g. the Southern region had 16 CODET2 programmes with 186 participants and the North East had 7 programmes with 90 participants in 2008 compared to 5 programmes each in 2009 (See table 1).

Participants who took part in the CODET2 programme were requested to complete a pre and post survey of their demographic details, empowerment and well being. Data was also collected from each individual with diabetes on their recent blood results for A1c and Cholesterol. Anthropology measurements of Body Mass Index and waist circumference (if the Body Mass Index indicated being overweight but not obese) was recorded on validated equipment by the healthcare facilitator. A number of participants had partners /carers in attendance with them. Therefore, data analysis was only available for the 402 participants of which there were 9 booklets excluded leaving data from 393 participants for analysis.

Demographic Details

The average age of participants was 64 years ($m = 63.91$, $SD = 4.90$, range 32-86 years) of which 10% were less than 50 years of age, 19 % in their 50's, 38 % in their 60's, 27 % in their 70's, and 4% were greater than 79 years of age (see Table 2).

Table 2 Characteristics of participants.

Characteristic	N	% of sample
Gender		
Male	232	59%
Female	161	41%
Age group		
25-49	43	10%
50-59	72	19%
60-69	148	38%
70 -79	106	27%
>80	15	4%
Not stated	9	2%
Diabetes treatment		
Diet and Exercise	58	15%
+ medication	283	72%
Insulin therapy	43	11%
Not Known	9	2%

Duration of type 2 diabetes ranged from newly diagnosed to 38 years. The average duration was 6.5 years ($SD=5.98$) but the majority of people (75%) had diabetes for 9 years or less with 16% (21) having diabetes for one year or less.

Physical Characteristics and Biomedical Markers

In general, the blood results collected for patients indicated that their cardiac risk markers were only controlled for half of the participants. The high standard deviation and maximum levels recorded raises concern for the level of medication adherence /medical management of these factors (see Table 3)

Table 3 Biomedical Markers of Participants.

	N	Minimum	Maximum	Mean	Std. Deviation
Cholesterol	259	2.1	8.0	4.24	0.97
LDL	219	.40	4.80	2.36	0.82
HDL	217	.47	3.30	1.21	0.38
Triglycerides	226	.26	7.60	1.75	1.15
A1c	262	4.4	11.3	7.03	1.17

However, 12% (45) continued to smoke contrary to medical recommendations. Only 9% (37) had a weight appropriate for their height, 30% (116) were overweight and the remainder were obese. Twenty -seven (7%) participants had a body mass index of greater than 40. there was a tendency for men to be overweight ($p= 0.57$) whereas women were more likely to be very obese (See Table 4).

Table 4 Cross reference of Body Mass Index and gender

Category		Gender		Total
		Men	Women	
Body Mass Index Group Week 1	Normal BMI	21 (9%)	16 (10%)	37 (10%)
	Overweight	78 (36%)	38 (25%)	116 (32%)
	Obese	105 (50%)	81 (54%)	186 (51%)
	Very Obese BMI>40	11 (5%)	16 (11%)	27 (7%)
Total		215	151	366

Diabetes Care

Over half of participants (54%, 211) reported attending a GP only for their diabetes care while a further 33% (144) reported attending hospital while 8% (29) reported attending both their GP and hospital.

For the majority of people (72%, 283), their diabetes was treated with tablets while 15% (58) were using diet and exercise alone to manage their diabetes and 11% (43) were on insulin therapy. Those attending their GP was most often (83%) treated with diet and exercise alone or with medications while those attending hospital were more often on insulin treatment ($p=.000$). there was no association gender or body mass index and method of treatment.

Individuals were asked if they had another medically diagnosed illness and if yes to name the most serious. Thirty per cent (30%, 115) reported not having another illness. Of those who stated they had another illness, 47% (120) reported it to be cardiac related.

Empowerment

Empowerment relates to participants' belief in their role as chief decision maker for their own diabetes self-management and indicates how much control of their diabetes, a person perceives themselves to have. CODE supports people to be empowered by helping them to recognise their own problem areas/barriers to effective diabetes self-management, problem solve and achieve their goal through internal resources. In CODET2, the Diabetes Empowerment Short Form Scale allows for a brief overall assessment of diabetes-related psychosocial self-efficacy. It is composed of 8 simple statements which the participant indicates their level of agreement to, (range 5, most positive to 1, most negative) and assesses need for change, coping with feelings, asking for support, motivating oneself, supporting oneself, developing a plan, overcoming barriers, and making diabetes related decisions appropriate for individual self-care.

Generally, people were empowered ($M= 4.03$, $SD=0.61$) but not strongly about managing their diabetes. The highest score possible was 5 and in this study, 95% of participants scored between 3.32 and 4.64. They perceived themselves to be most empowered ($M= 4.22$, $SD= 0.74$) in asking

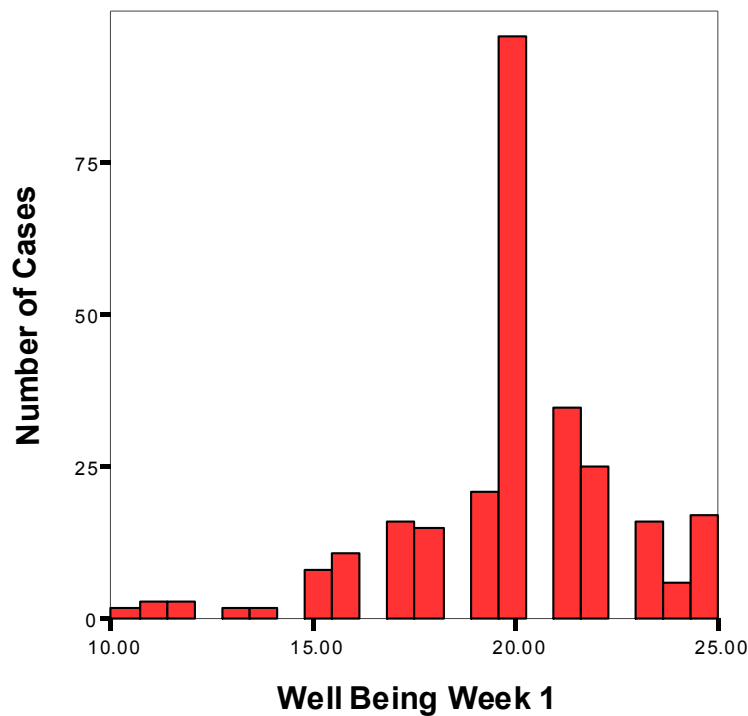
for support for their diabetes and least in describing positive action they take to reduce the stress of having diabetes ($M=3.87$, $SD=0.87$). Only 30 (8%) reported being strongly empowered to manage their diabetes. Older people living in the West of Ireland appeared to be more disempowered but this proved not to be statistically significant. Likewise there was an association between attending GP care only and being disempowered but also did not prove significant.

Wellbeing

Wellbeing refers to person's state of mind of being happy and feeling good about life in general. The term quality of life is used to evaluate the general well-being of people and is a measurement of their satisfaction with life specifically taking into consideration the effect a health issue may have on it. In CODET2, the World Health Organisation Well-Being Questionnaire (WHO-5) is used to permit the participant to describe their own emotional wellbeing over the previous two week period and thereby indicate their quality of life. Measurement is by indicating their level of agreement to 5 key statements regarding life satisfaction (range 5 – present all of the time to 0 – none of the time). The WHO-5 measures (the absence of) positive affect rather than the presence of negative emotions i.e. the statements are stated in a manner that promotes positivity rather than introducing negative thoughts.

Over a quarter of people (27.5%) had negative wellbeing i.e. did not feel good about their life. Dissatisfaction was most profound for activity related areas such as feeling active, vigorous and rested. A small number (8 participants) reported poor wellbeing sufficient to indicate they should be assessed for depression (See Table 5).

Table 5 Self-reported Wellbeing of participants.



Knowledge

The purpose of any education programme is to promote understanding and knowledge to bring about a change in attitudes and beliefs. In view of current best practice guidelines, assessment of the effectiveness of group education is essential and should include some element of knowledge retention and understanding examination. In addition, it is vital that any education programme meets the needs of participants based on their initial knowledge level. In CODET2, knowledge of the participants and their understanding of diabetes management were assessed using 12 statements which the participants indicated as true / false with each correct answer getting a point and wrong answer deducting a point to prevent guessing responses. The maximum possible score was 12 indicating good knowledge and understanding to minus 12 (no knowledge = 12 wrong responses). The initial knowledge base of each individual group allowed for tailoring of the programme contents to meet those needs.

Pre-attendance at CODET2, over half the participants (55%) were unable to answer half the questions correctly with 7% (27) scoring one or less (down to minus 3). Only 5% (19) responded correctly to all statements. The overall average score was 6 (SD= 3.15) with 6 as the median.

Post attendance Evaluation.

Attendance at a CODET2 programme resulted in participants feeling more empowered to manage their diabetes ($p=.0005$). The average score had increased (increase showing more empowerment) from pre-attendance ($M= 4.07$ $SD=0.564$) to post-attendance ($M=4.16$, $SD=0.51$) ($p=.047$) with most noticeable improvement in knowing oneself well enough to know the best ways to manage diabetes and finding ways to feel better about having diabetes (See Table 6).

Table 6 – Empowerment scores before and after attendance.

	Mean	Std. Deviation	Std. Error Mean	t	Significance
I know which parts of my managing my diabetes I am unhappy with.	-0.141	.874	.68	-2.061	.041*
I can find ways to feel better about having diabetes	-0.205	.946	.071	-2.868	.005**
I can describe the positive action I take to handle the stress of having diabetes	-0.094	.953	.073	-1.283	.20
I can ask for support for my diabetes when I need it	-0.128	.813	.059	-2.159	.032*
I can describe what helps me stay motivated to care for my diabetes	-0.077	.866	.067	-1.155	.250
I know myself well enough to know the best way to manage my diabetes	-0.210	.903	.066	-3.167	.002*
I can use my diabetes goals to create a plan to manage my diabetes	-0.175	.792	.061	-2.895	.004**
I am able to try different things to overcome barriers to achieving my diabetes goals	-.142	.840	.063	-2.244	.026*
Total empowerment Score	-.13382	.57186	.04298	-3.113	.002**

*significant at $P \leq .05$ **significant at $P \leq .01$

Well being

Post attendance at CODET2, people reported feeling happier and better about life in general (See table 7). The average score had increased (increase showing better satisfaction with life) from pre-attendance ($M= 17.28$, $SD= 4.86$) to post-attendance ($M= 18.57$, $SD=4.29$) ($p=.000$). Almost 20% (26) of participants who completed all five parts of the well being questionnaire before and

after attendance (135) showed a significant change in their self-reported well being using World Health Organisation criteria.

Table 7 –Wellbeing scores before and after attendance.

	Mean	Std. Deviation	Std. Error Mean	t	Significance
I have felt cheerful and in good spirits	-0.169	1.06	.075	-2.55	.025
I have felt calm and relaxed	-0.179	1.16	.083	-2.16	.032*
I have felt active and vigorous	-0.288	1.27	.092	-3.13	.002**
I have woke up feeling fresh and relaxed	-0.320	1.29	.092	-3.46	.001**
My daily life has been filled with things that interest me.	-0.254	1.03	.074	-3.417	.001**
Total Well being Score	-1.291	4.29	.318	-4.060	.000**

*significant at $P \leq .05$ **significant at $P \leq .01$

Knowledge

At six months knowledge had increased (increase showing more understanding and knowledge) from average score pre-attendance (M= 6.09 SD= 3.18) to post-attendance (M= 7.84, SD=2.68) (p=.000).

Biomedical Measurements

People had lost weight from pre-attendance (M= 87.30 kgs SD=15.79) to post-attendance (M= 86.79 kgs, SD=15.81) (p=.015) with a similar reduction in body mass index (M= 31.52, SD= 5.09) pre-attendance and (M=31.28, SD= 4.93) post attendance (p=.006) (see Table 8).

There was a trend towards positive change in the blood result. (see Table 8).

Table 8 –Biomedical Measurements before and after attendance.

	Mean	Std. Deviation	Std. Error Mean	t	Significance
Weight	0.508	2.93	.207	2.46	.015*
Total Cholesterol	0.239	0.958	.085	2.79	.006**
LDL	0.121	0.776	0.078	1.55	.125
HDL	0.0434	0.395	0.041	1.08	.282
Total Triglyceride	0.192	1.130	.114	1.69	.95

In summary, people who attended CODET2 in 2009, gained better understanding of their diabetes and put this into practice by setting targets for their diabetes management resulting in feeling happier and about their diabetes and general well being

Training Professionals to Deliver CODET2

In early 2009, a two day training programme CODET2 for Health Professionals was developed to allow for other health professionals, at present, clinical nurse specialists, practice nurses and dieticians, with the relevant diabetes qualifications, to deliver CODE in their own practice setting. Facilitation skills are now recognised as the key criteria that practitioners require to educate people with chronic illness. Therefore, the starting point for any CODET2 educator training is attendance at a compulsory two day facilitation skills programme provided by an accredited institute - Empower Training. The development of this programme was supported by Merck Sharp & Dohme. During 2009, two facilitation skills programmes were held (Dublin and Killkenny) and four CODE educator training programmes were delivered (Cork, Cahir, Sligo and Dublin) resulting in 18 professionals training as CODET2 educators during 2009.

Conclusion

The demand for CODE had risen beyond available resource capacity in 2008 so that for 2009 the focus for CODE delivery was on training up other professionals to deliver CODE. This was achieved through three CODE training programmes with a resultant additional 18 qualified CODET2 educators being available by December 2009. These educators will all be delivering their CODE programmes with support of the Federation's Regional Development Officers in 2010, thus expanding the spread and reach of the CODE programme. Further professionals will be trained during 2010 with the target being for the Federation development officers eventually supporting 40 local CODET2 educators.

The outcome evaluation of the CODE programme 2009 show that at a group level, participants become more empowered and improved their general wellbeing. The majority of participants continue to attend three of the four sessions with most of the attrition being excused by phone messages (most commonly, illness, scheduled appointments and funerals), further reflecting the positivity of participants for this initiative.

CODET1 - CODE Type 1 Parents Interactive Workshop

During 2009, seven (7) type 1 parents' interactive workshops were held with 132 parents attending. As in previous years, the response to the workshops was extremely positive as they are deemed to be a great way for parents to openly discuss with other parents their trials and joys of managing diabetes.

The format for 2009, mirrored other years but with more use of case studies in the Carbohydrate Counting workshop so that the session was practical as well as educational. In 2008, the workshop was held over one day but due to parents requesting evening events to facilitate baby sitting, the workshops are now held on two consecutive weeks. One evening is devoted to the impact of having diabetes and is facilitated by a psychologist, counsellor or social worker. Most usual topics discussed include how meal time difficulties could be addressed, how to think "outside the box", looking at "things" from the child's point of view, and an opportunity to look at parents views versus the child's view. The other evening is an overview of dietary aspects of managing type 1 diabetes in the young and aims to increase food choices for this group by giving reassurance regarding carbohydrate counting, refreshing knowledge regarding exchanges, food choices, meal times and food weighing. At the end of the workshop parents are invited to sign up for further local support meetings through a circulation list so they could stay in contact with each other. The aim being to set up a local parents support group that meets regularly and when a need for information on a specific topic is identified, the Federation Development Officer can organise suitable speakers for the group.

An issue that was identified during the workshops was the desire for parents to know more about pump therapy even if that facility was not available locally. This was addressed by inclusion of pump therapy as a topic for public meetings and holding specific pump information evenings.

Evaluation of the evenings showed that parents loved to share their experiences and concerns with other parents in similar circumstances and found this informative and supportive. They were also asked what were their most pressing needs which elicited a range of comments from financial support to ongoing school problems. Because of the diversity of reported pressing needs, there were no core themes. However, the desire to meet in such open groups was well identified and therefore, a parent's conference should be held and use focus groups to explore

individual needs that parents believe the Federation could address. Subject to funding, a parent's conference will be held in 2010.

Parents' Support Group

Parents of children living with diabetes continue to receive support from the Federation through the helpline and website and in particular, from other families living with diabetes in the form of peer support. The most active parents support groups are in Cork, Galway, Drogheda who meet up regularly for informal chats and organise events as required by local need.

Family Events

The Donegal Branch also had a family weekend for branch members and their families on 15th - 17th May 2009 (32 families with 47 children attended). Families of young children with type 1 diabetes and families living with type 2 diabetes came together on the Friday night for fun, networking, some work but most of all to support one another. Dr Maeve Durkan, Consultant Endocrinologist, Portlincula Hospital gave an outstanding talk on diabetes and made herself available for informal questions throughout the weekend, which was greatly appreciated. Ms. Anne Mullan (Western HSE Federation RDO) ran a practical session on "Reading Food Labels". While parents attended the educational component of the weekend, children attended workshops with the diabetes nurses from Letterkenny Hospital who did an interactive session with the children before joining their families for fun activities.

National Teen Activity Day

On Friday 17th July 2009, the Federation held its first ever National Teen Activity Day. The event, held simultaneously in 6 outdoor adventure centres country wide, was attended by over 80 teens from 10 to 16 years of age. Feedback from the event was extremely positive with participants getting the opportunity to meet their peers in an informal and fun setting. This event will be held again on Friday 16th July 2010.

Sweetpea Kidz Club

The Sweetpea Kidz Club/Cork Parent's Support Group family weekend took place in April with over 125 people (29 families) attending. The club also had its annual Summer Family picnic in July and Christmas parties in Dublin and Cork in December 2009.

Time to Talk Teen Support Group

The Time to Talk Teen Support Group has been running in Cork and is now in its fourth year. The group is co-facilitated by Ms. Margarita Quinn, Senior Social Worker at Cork University Hospital, Ms. Siobhan Madden, Senior Social Worker at Cork University Hospital and Ms. Pauline Lynch, Southern HSE Federation Regional Development Officer. The group meets regularly at the Southern Regional Office and is attended by approximately 10/12 teens at any one time.

The group works both on a therapeutic and social level, where through discussion in small groups, the focus is on attitudes and approaches to diabetes. The social group continues with activities such as, bowling, soccer, horse riding, canoeing and other physical activities. One of the activities in particular, helps the teens to make good food choices. They are encouraged to buy lunch and then discuss with a dietician the choice they have made. It is believed that the mix of social and therapeutic interaction is the best forum to reach the teens on a level that suits them. This has been initiated as a result of experience and constant evaluation methods that elicit the view of parents and teens.

Candidates for the program are formally referred through the Paediatric Department of Cork University Hospital (CUH) and Ms. Pauline Lynch states that 'without doubt, the reason the group has been so successful is that it has been run with the cooperation of the hospital. This co-working of the Federation and CUH Social Work Department has proved very beneficial to all concerned'.

National Teen Conference

In February 2009, the Diabetes Federation of Ireland in conjunction with a range of hospital based healthcare professionals hosted a national conference for 70 adolescents between the ages of 13-18 years of age in Croke Park.

The conference covered a range of issues of concern to adolescents and provided an opportunity for them to share their views on managing their condition. Topics covered ranged from identifying optimal diabetes services for adolescents to fostering stronger relationships between adolescents with diabetes, their parents, siblings and friends.

A report which set out the findings of the various group discussions was produced to inform diabetes healthcare professionals on how to effectively organise their clinics to optimise their service to this age cohort and remove potential barriers to clinical support and help foster stronger relationships between adolescent with diabetes, their parents, siblings and friends.

A range of practical suggestions aimed at enhancing relationships were made by the teenagers attending. These included:

- hospital appointments e.g. with the doctor, nurse, dietitian etc. should be on the same day as teenagers do not want to miss school. Out of hours clinics were not seen as a viable option because of the teen's involvement in extra-curricular activities which cannot be missed without repercussions.
- transition clinics should be set up between paediatric and adult diabetes services where the teenager will retain the support of the diabetes team they know while they get to know the "adult" diabetes team.
- the practice of seeing a different doctor for each visit results in repetition and wastage of professional time while contributing to a lack of trust in the healthcare system by the teenager.
- teenagers do not welcome sharing the waiting area with younger children and feel they should have designated areas where they could meet their peers on clinic day.

- the environment of clinics would be enhanced by more appropriate décor and whereas this would not improve the clinic visits, the gesture of improving décor would be much appreciated. Similarly, for healthcare professionals wearing informal dress attire.
- adults, especially those in a professional capacity, who know they will be in the company of young people with diabetes should have a reasonable knowledge of diabetes and its' management and should not rely solely on the teenager for information.
- there needs to be increased focus on differentiating between type 1 and type 2 diabetes, especially in the media, so that teenagers are not discriminated against due to lack of understanding of the difference between poor lifestyle habits contributing to the development of type 2 diabetes and the dietary and physical activity goals outlined in the management of type 1 diabetes.

Parents, teachers and sports coaches did not escape either. Parental attempts to control their teenager's diabetes can reflect a lack of trust. Teenagers are aware that trust can only be assumed gradually and that the trust is not just diabetes related. However, teenagers whose diabetes is not controlled welcomed support from parents and siblings.

Chapter 3

Health Promotion

During 2009, health promotion continues to play an important role in the Federation activities, with the focus to increase awareness that diabetes is a serious illness that can be managed effectively provided diagnosis is prompt and treatment regimes including lifestyle behaviors are implemented.

The Diabetes Federation of Ireland health promotion programme in community locations has a diabetes risk assessment and screening protocol. Assessment focuses on the preventative role people can play in delaying or preventing the onset of type 2 diabetes. The assessment tool is a pen and paper exercise to help individuals identify their own risk factors for the development of type 2 diabetes with modifiable risk factors (e.g. weight) being targeted for professional interventions. People identified at high risk of undiagnosed type 2 diabetes are screened for diabetes using a capillary blood sample.

Screening for type 2 diabetes and pre-diabetes is justified because the current epidemic of type 2 diabetes is exacting a staggering toll on individuals, families, and communities, the convincing clinical trial evidence that the incidence of type 2 diabetes can be reduced and the importance of early detection and treatment of those with undiagnosed diabetes.

The Diabetes Federation of Ireland health promotion initiatives focus on the workplace, the community and schools.

Workplace

The Health Promotion in the Workplace Initiative was developed by the Diabetes Federation of Ireland, to raise awareness that unhealthy lifestyle habits increase the risk of developing type 2 Diabetes and heart disease. The aim of this initiative is to:

- a) Alert employees to their possible risk of developing type 2 Diabetes, heart disease and other health related issues.
- b) Promote healthy behaviour to help individuals prevent, if not postpone, the development of illness.

The format of the day is flexible to meet the needs of the company but can include, presentations, assessments, screening and individual consultations (body mass index, waist circumference, blood pressure and diabetes risk assessment).

The economic climate impacted severely on this service in 2009 with only 8 companies (42 in 2008) requesting diabetes screening for its employees. However, where they were held numbers attending were high with 617 being screened and 37 of those being referred for further testing.

Each person attending received a written feedback and additional health promoting literature as required. The company hosting the day received a report on key issues important to the health of their employees.

Community Screening

Throughout the year diabetes screening days were held throughout the regions. These days are generally held in pharmacies, shopping centres, or public areas. The purpose of these screening days again are to raise awareness of diabetes and its signs and symptoms amongst the general public and also to provide an opportunity for people to have a personal diabetes risk assessment/ screening. Each person is offered

- A brief diabetes risk assessment;
- Discussion and literature on the signs and symptoms of type 2 diabetes;
- A random capillary glucose check if required with a letter of referral for formal assessment to the GP if necessary;
- Discussion and literature on healthy eating guidelines and physical activity;
- Those with queries regarding diabetes are also welcome to attend.

Noting the reduction in workplace screening requests, in mid 2009 the Federation decided to increase activity in hosting community based diabetes screening days. The breakdown of screenings days held and the results by region were:

Region	Number	Number attended
Mid Leinster	5	231 with 22 referred to GP
North East	1	40 with 6 referred to GP
Western	9	495 with 18 referred to GP
Southern	34	2,161 with 173 referred to GP
TOTAL	49	2,930 and 219 referrals

Community Talks and Presentations

Talks and presentations were held through out the regions during 2009, attended by over 950 people the majority of whom would be in the high risk category for developing type 2 diabetes or had diabetes. The breakdown of presentations by region was:

Region	No of Presentations	Number attended
Mid Leinster	5	288
North East	9	250
Western	4	100
Southern	8	320
TOTAL	27	958

Groups that availed of this free service included, secondary schools, women's groups (e.g. ICA), retirement groups, carers training, health promotion events, mental health groups and their professional staff, disability groups, staff of network groups and their service users. Each event allowed for the promotion of the Federation literature, services and availability of support if ever needed.

In addition, during February 2009, the annual National Tea 4 Diabetes Ireland (T4DI) initiative, supported by Splenda, was held. People with diabetes used their own knowledge to educate their family friends, work colleagues about diabetes and the need to move to a healthier lifestyle over a cup of tea. The Federation provided general information literature and a knowledge quiz to stimulate debate around diabetes. Despite being launched in the height of the banking collapse, more than 150 people became T4DI co-ordinators and held parties reaching 6,700 people throughout the country.

Schools

Children with diabetes require supervision to maintain their diabetes management and to remain healthy. The need for diabetes management does not end while the child is at school. Thus, while at school, each child with diabetes must be allowed to do blood sugar checks, treat hypoglycemia with emergency sugar, inject insulin when necessary, eat snacks when necessary, eat lunch at an appropriate time and have enough time to finish the meal, have free and unrestricted access to water and the bathroom and be allowed to participate fully in physical education and other extracurricular activities including field trips.

Sometimes, because of misconceptions about diabetes management, the requirements of a child with diabetes are neglected.

In 2009, the Federation was contacted on 18 occasions by parents who were experiencing problems in having their child with diabetes supervised in school. Initial contacts were seeking written guidelines on the management of diabetes in school situations or for an independent professional to provide an educational session for teachers at their in-service day. In conjunction with the parties involved in each case, the Federation worked to reassure the parties and agree a care plan for each child. For example, a case involved the school informing parents of a child with type 1 diabetes that their child was being moved to another class to ensure that the school did not lose their special needs assistant. Lengthy collaboration between the family, Federation and Board of Management resolved the issue with the child staying in their original class but not without interruption of her education as the parents removed the child from school during the conflict.

In order to prevent this repetition of this occurrence, Diabetes Federation of Ireland staff are available to provide a teleconference call and provide a general overview of best practice

guidelines when there is a child with diabetes attending the school and healthy lifestyle recommendations for all pupils attending the school.

In 2009, the Federation brought together appropriate stakeholders to develop a “School Policy Guidelines” to help all schools develop their own guidance document to facilitate their pupils with a chronic illness. The group made excellent progress in 2009 and plan to produce a draft document in 2010.

The Federation continues its efforts to foster positive attitudes towards diabetes thereby reducing discrimination of persons with diabetes so they can have the potential to live a full and normal life. This can be best facilitated by raising awareness of the wider community that diabetes is a condition that with personal attention and proper management will not curtail the individual’s activities. This will help eradicate discrimination of individuals on the basis of having diabetes.

In 2009, the Federation worked with a number of individuals who felt they were discriminated on the basis of their condition in the workplace. The Federation will continue to work on behalf of such people in 2010.

Professional Services

The Professional study day was held in Croke Park on March 27th 2009 with 132 attendees including medical physicians, general practitioners, nurses, dietitians, pharmacists and podiatrists. The focus for the day was on genetics and preconceptional care in diabetes management with guest speaker Professor Gisela Dahlquist from Umeå University, Sweden. The day included updates on current research on the links between birth weight and development of type 1 diabetes, updates on effective management of pre-existing diabetes/gestational diabetes during pregnancy.

The Paediatric Professional study day was held in the Crowne Plaza, Dublin on April 4th 2009. The Federation presented the findings of the Teen Conference to an audience of seventy paediatric diabetes specialists.

Media Reach

Effective use of the media is imperative if the Federation is to raise awareness of diabetes and its symptoms to the wider community and raise the Federation's profile among the diabetes community both at national and local levels.

In 2009, the Federation continued efforts to increase the knowledge and awareness of diabetes and its symptoms through the media. This was achieved through a range of media activities. These included:

- as part of the T4DI initiative, the Federation ran a diabetes awareness advert on Today FM reaching 1.1m listeners.
- in November 2009, to celebrate World Diabetes Day, the Diabetes Federation of Ireland undertook diabetes screening in Leinster House. In conjunction with the Irish Endocrine Society, the Federation also made a presentation to TDs on diabetes and podiatry resulting in prime coverage in the 3 main national newspapers and a number of local newspapers. A diabetes Type 1 supplement was also included in the Irish Medical Times.
- Appearances on the RTE's Afternoon show and TV3's Ireland AM reached 550,00 viewers

Other diabetes related media stories saw journalists contact the Federation for clarification and/or further information to supplement their articles. This happened on 42 occasions throughout the year with a mixture of national and medical media seeking help on a wide range of issues.

Volunteer of the Year

There are many well deserving people who work tirelessly to ensure that people living in their locality are given the opportunity to meet, share experiences and learn from each other about living life with diabetes.

The volunteer of the year award, sponsored by Roche Diagnostics, recognises the tireless efforts of volunteers throughout Ireland in supporting, educating and motivating people with diabetes,

raising awareness of diabetes in the community and in promoting the interests of people with diabetes.

This year, there were seven nominations including three healthcare professionals nominated for their support work with children with diabetes and their families with the remainder nominated for their work with their local Federation branch. The 2009 winner was Pat Power from the Waterford Branch.

In making their decision, the judging panel were most impressed with the huge involvement by Pat at local, regional and national level as a volunteer of the Federation.

Southern Regional Development Officer, Ms Pauline Lynch, who nominated Pat said:

From the day I met Pat, he gave a commitment and has never faltered. He is always on hand to help if needed. Additionally, he is creative and is constantly seeking opportunities to promote the Federation and to support people with diabetes.

Diabetes Expert Advisory Group First Report

Following publication by the HSE's Diabetes Expert Advisory Group of its First Report setting out its vision for future diabetes services, the Federation continued to advocate for implementation of this report so that all people with diabetes regardless of where they live will receive the high quality service they deserve.

In the latter part of 2009, the Federation and the Irish Endocrine Society set up a tri-partite Diabetes Advocacy Group with pharmaceutical, healthcare professional and patient representation to advocate for implementation of the First Report and raise awareness of diabetes symptoms and risk factors among the general population. In 2010, the work of this group will be a major focus for the Federation.

Diabetes Research

2009 saw the setting up of the Diabetes Ireland Research Alliance (DIRA) to focus more on developing and funding diabetes research in Ireland.

Currently, the Federation funds two three year research studies. The “Adipocyte and Type 2 diabetes – a study of patients having bariatric surgery” overseen by Professor O’Shea, Loughlinstown Hospital which won the prestigious Niall O’Meara medal at the Irish Endocrine Annual Meeting in November 2009. The winning poster presentation by Dr. Jean O’Connell showed very promising initial results. The other Federation funded study is the Galway Diabetic Foot Study which commenced in July 2008 and already has attracted interest from other podiatry services wishing to follow the model of care under study.

The Diabetes Ireland Research Alliance has entered into a partnership agreement with the Juvenile Diabetes Research Foundation (JDRF), the leading charitable funder of type 1 diabetes research worldwide.

A first step of the partnership will be to hold three open research meetings in early 2010. The goal in 2010 is to formally publicise the partnership and raise €50,000 to be split equally for the JDRF funded D-GAP project in the UK and an Irish Type 1 diabetes project to begin in 2011.

Finance

The latest available annual audited accounts to 30th June 2009 show income of €1,514,229 for the 12 month period and expenditure for the same period of €1,563,289, giving an operating loss of €49,060 for the period. However, when bank interest was added, the loss for the period was €28,090. The balance sheet showed a reserve of €604,765 at 30th June 2009.

In July 2009, all staff agreed to reduce their working hours for an initial 12 month period. One member of staff resigned and was not replaced.

Conclusion

Despite the gloomy economic climate, the Federation continued to deliver key services in 2009. The continuing support of members and active volunteers at local community level were vital in the period, specifically as staffing resources were reduced.

With more and more people with diabetes being left to manage their own condition, the expansion in the number of CODE Trainers is a huge step forward. The value of this and many initiatives can be measured in terms of the number of people with diabetes who were supported by the Federation, the number of people detected early and the increased awareness of diabetes among the wider community.

In the current climate, the work of the Diabetes Advocacy Group may prove vital in ensuring that diabetes remains a key priority area for development by the HSE.

It is clear that finances will dictate the level of services provided by the Federation. Therefore, it is important that we work together to ensure services are maintained in 2010 and beyond. If not, the potential impact of the current economic may see a reduction of services.

Appendix 1

CODE 2009 Lay Summary

In 2009, a total of 429 people attended a CODET2 programme in their local community.

More men than women attended the CODET2 programme. Most of the participants (95%) were between 59 and 69 years of age. Seventy five percent of participants managed their diabetes through dietary intake, exercise and taking tablets.

Half of the participants had raised cholesterol levels which put them at increased risk of a cardiac event and other diabetes complications. This raises concerns about their diabetes management. In addition, some participants smoked which would further increase their risk of developing diabetes complications.

Most CODET2 participants were overweight or obese. It may only be a chance finding but there was an indication that men were more often carrying 1 to 2 stone in extra weight whereas women tended to carry above 2 stone.

Over half the participants attended their GP only for their diabetes care and these were most often managing their diabetes with diet, exercise and medications regardless of their sex or weight. The participants who attended a hospital clinic were most often managing their diabetes with insulin.

Two out of every three participants who attended CODET2 had another serious illness. The most common illness reported was heart problems.

Participants attending CODET2 felt they could manage their diabetes reasonably well. They believed most strongly in the need to seek help to manage their condition. In contrast, they did not believe in looking to seek ways to reduce the stress of having diabetes. This finding may be related to peoples' age and/or where they live in Ireland. But there is no way of knowing if this just happened by chance for this particular group of people or if it could be said for all people with diabetes.

One in every four participants attending CODET2 felt badly about life in general. The areas of their life that people reported feeling worst about were related to activity, for example, feeling active or rested.

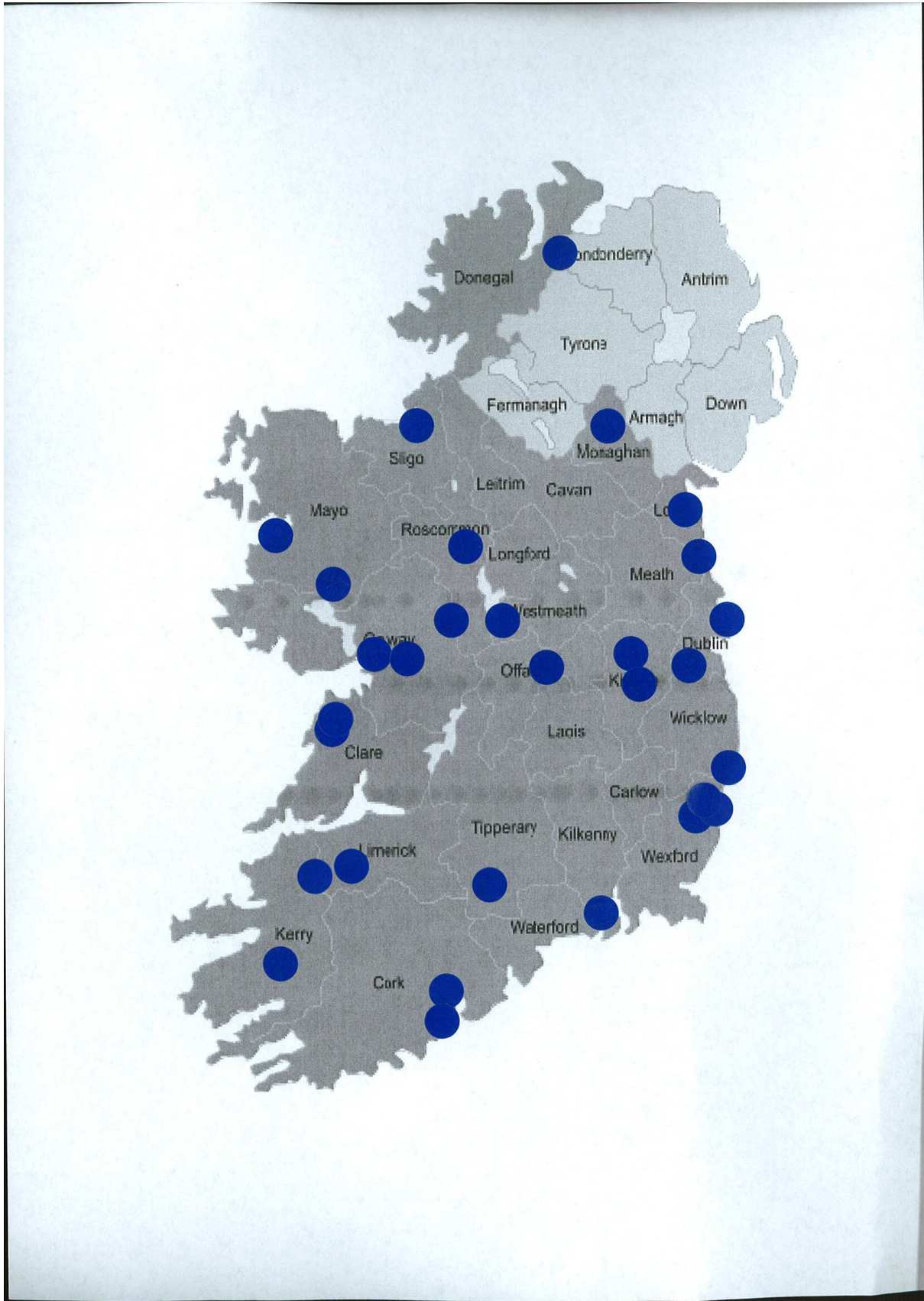
In terms of diabetes knowledge, from a total of 12 statements less than half the participants knew the correct response to six statements requiring a true or false response. Out of 12 statements, most people answered between 3 and 9 correctly with only 19 people knowing the correct response to all statements.

Outcomes from the 2009 programmes was that it was felt that:

- attending the CODET2 programme helped participants to feel more in control of their diabetes with the greatest improvement in knowing the best way to manage their diabetes and finding ways of feeling better about having diabetes.
- participants felt happier and better about their life.
- attending the CODET2 programme helped participants to know more and understand how to better manage their diabetes.
- attending the CODET2 programme helped people to lose weight i.e. people attending had lost weight at the 6 month session.
- people who attended the CODET2 programme also appeared to have an improvement in their blood results indicating a reduction in the risk of heart problems but there is no way of knowing if this was really the result of attending the CODE programme.

The outcome evaluation of the CODE programme 2009 show that at a group level, participants became more empowered and improved their general wellbeing. The majority of participants continue to attend three of the four sessions with most of the attrition being excused by phone messages (most commonly, illness, scheduled appointments and funerals), further reflecting the positivity of participants for this initiative.

Geographical locations of CODET2 2009



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