

# **Diabetes Minority Ethnic Group (DMEG) Progress Report**

**November 2012**

The DMEG sub-group of the Scottish Diabetes Group (SDG) was tasked to collate and report on best practice across NHS Health Boards on working cross-culturally, including quality patient education and self management support and the training and support provided to healthcare professionals.

Based on the report on best practice, DMEG was to report to the SDG with recommendations on taking this work forward and its value in supporting NHS Health Boards.

## ***Best Practice Report***

We used the mechanism of case studies to identify, compile and share good practice across NHS Health Boards. The rationale underpinning this choice was to learn from current and planned work with minority ethnic communities which would inform our recommendations on delivering change.

Case studies were invited for management of people with diabetes, coronary heart disease (CHD) and stroke due to the areas of clinical overlap in care. Case studies were invited from all Health Boards, Local Authorities, Voluntary Sector, Minority ethnic groups and other interested parties. Invitations were sent by email after a telephone call with a key individual, via groups such as the SDG Managed Clinical Network (MCN) group, member's personal and professional contacts and networks as well as attending meetings and encouraging professionals and managers to contribute.

A case study pro-forma with a broad range of relevant criteria was developed to assist and encourage individuals to identify initiatives involving minority ethnic communities. It was hoped that individuals would broadly follow the pro-forma template. Information however, arrived in a number of different formats including reports, research papers, emails, summaries and briefings. The deadline for submission had to be extended several times. Some contributors were not able to submit a written case study due to time constraints so Smita Grant, chair DMEG, and Joan McDowell, National Education Co-Coordinator, used telephone conversations as a method of gleaning the relevant information.

A total of 33 case studies were submitted. They were analysed according to three parameters although there was overlap between these parameters: ethnic group; clinical aspects of care; structure and organization of care. A draft report with recommendations was produced and submitted to staff in the Scottish Government Long Term Conditions Unit.

There were many examples of short term and piecemeal work with some ethnic groups. Other ethnic groups, though at high risk of diabetes, received very limited attention, if any.

Groups with special needs such as refugees and asylum seekers and gypsy travellers also received little attention. Minority ethnic issues in women with gestational diabetes; work with children and young people; and psychological support still need consideration.

On the whole, there was no evidence of any strategic direction to integrate diabetes care for minority ethnic groups within organisational vision, planning or sustainable service delivery framework.

Given that Scotland's ethnic diversity is continuously changing and increasing, it is important to consider how culturally appropriate care can be sustained and delivered by mainstreamed services appropriately adjusted and supported.

Language and communication issues pose a major barrier in providing culturally competent holistic care. Further exploration and evaluation is required on bridging communication via interpreters, Link workers or Health care support workers.

All aspects of clinical care need to be culturally specific and integrated within mainstream services as far as possible for sustainability. In order to achieve this, culturally competent practitioners need to be equipped and supported to working cross culturally.

### ***MCN Needs Analysis***

The Scottish Diabetes Action Plan (page 32) notes the need for MCNs to 'revise and update their needs analysis and review of services for minority ethnic communities'.

This has proved difficult for many MCNs. The small percentage of minority ethnic groups widely dispersed geographically adds to the complexity of finding suitable and effective analytical tools.

The 2011 Census will provide robust data at local level on Health Board demographics. New questions on ethnicity, long term limiting illness, language proficiency in English spoken language at home and detailed geographical data will be particularly useful. However this information is not expected to be released until summer 2013.

Improving quality in service provision and patient outcomes could progress via the Health Inequalities Impact Assessment (HIIA) process. The assessment considers impacts on equalities groups, other potentially affected populations and disadvantaged groups, who already suffer poorer health.

The equalities team in NHS Health Scotland have agreed in principle, to provide support to Diabetes MCNs in co-ordinating the HIA process, with support from the Health Board Equality Leads at a local level. Health Boards who have carried out HIA have found the process helpful. This will be discussed at the MCN Managers group.

### ***Ethnicity recording***

Recording of ethnicity on SCI-DC has been improving. Accurate ethnicity data would assist Health Boards to develop and target their services more effectively. The diabetes retinal screening service (DRS) is in an ideal position to improve ethnicity recording since all diabetes patients are invited to an annual review. Discussions have taken place with staff in the DRS and Scott Cunningham from SCI-DC to improve ethnicity recording.

DRS Managers are receptive to the suggestion that improved ethnicity recording can be achieved by their staff when appropriate. However not all screening episodes are carried out in a fixed base and many staff are under extreme pressure to complete screening clinics. To facilitate with recording of ethnicity, a training package will need to be developed for staff. Coupled with this, there would need to be a change to the policy and procedure for DRS staff that would need to be drafted and agreed by DRS Managers and management groups. This will be coordinated by the DRS coordinator, Mike Black, in conjunction with Smita Grant, Chair of DMEG.

Any update to the Soarian system carried out by DRS staff will appear on the SCI-DC database. It should also be noted that at present if data on ethnicity is input from a GP using SCI-DC this has a higher precedence than DRS data. When SCI-Diabetes is fully implemented then the latest data (from whatever source) is given the highest precedence.

### ***Diabetes Retinopathy Screening***

*The Scottish Diabetes Retinopathy screening collaborative (SDRSC) will report to SDG through the annual Scottish Diabetes Survey with information on DRS uptake across different ethnic groups in Board areas (responsibility SDRSC/SDSG)*

DRS reports do not currently monitor trends in retinal screening uptake by ethnic group. SDRSC have agreed to provide DRS uptake reports by ethnic group for each Health Board using the Soarian Key Performance Indicator (KPI) reporting system. Several standard reports classified by ethnic grouping can be produced. This can be done locally by service managers or centrally by the DRS coordinator. Pre and post pilot trends could therefore be noted for improvements.

## **NHS Lothian South Asian DRS pilot**

The DRS uptake report for NHS Lothian by ethnicity showed that all minority ethnic groups apart from the Chinese had lower uptake than the majority white population.

A small pilot is underway in NHS Lothian to improve DRS in serial Indian/Pakistani non attendees. The Minority Ethnic Health Improvement Service (MEHIS) Indian / Pakistani Linkworker will invite and encourage identified individuals to attend DRS appointments. It is hoped that this will inform us why some Indian/Pakistani patients decide not to attend DRS appointments. If successful, this will be rolled out to other ethnic groups in Lothian and if could be developed to be rolled out nationally.

### ***Clinical Outcomes for people from minority ethnic groups***

*The Scottish Diabetes Survey will produce report on clinical outcomes for people from minority ethnic groups (responsibility: Scottish Diabetes Survey Group).*

Meetings have taken place with Tom Pilcher, in the Scottish Government, Prof John McKnight as Chair of the Scottish Diabetes Survey Group, and Scott Cunningham, from SCI-DC to progress this action.

The Scottish Government Long Term Conditions Unit have agreed to provide extra funding for an administrator's time so SCI-DC can report on clinical outcomes by ethnicity. The MCN Managers group have informed us that Health Boards will want to comment on their data before they are shared more widely.

Prof McKnight has suggested that a reporting template should be sent to each Health Board to provide a base line. Health Boards will report on key clinical indicators, ethnic recording, patient education, and DRS uptake by ethnicity and any adjustments to improve access or appropriateness of services for minority ethnic groups.

### ***Professional Education***

The National Education Co-Coordinator for Diabetes, Joan McDowell, has been actively involved with DMEG to integrate minority ethnic issues in patient and professional education.

### ***Patient education***

Minority ethnic uptake of structured patient education is low. This is an area of concern as self-management is a new concept for many minority ethnic

groups. Patient education packages need to be adapted and delivered in an accessible way.

Conversation Maps <sup>TM</sup> delivered by a trained diabetes educator and co-facilitated by a bi-lingual worker could be effective for people with low literacy and those from an oral tradition. NHS Lothian plan to pilot Conversation Maps <sup>TM</sup> with bi-lingual Linkworkers co-facilitating with a Diabetes educator. Joan McDowell is confident that Conversation Maps <sup>TM</sup> will meet the criteria for structured patient education and it will then be possible to record uptake on SCI-Diabetes.

The current Minority Ethnic Patient education resource on the Diabetes in Scotland website will be updated and amended in 2013.

### ***Patient information and resources***

First generation minority ethnic groups require information in their language and usually in an oral and visual format. It is desirable that second and third generation minority ethnic groups have acquired some spoken English and literacy although there is still the need for educational materials to be produced in their original language, but maybe available as web-based resources.

Minority ethnic patient resources in English and other community languages are on many different websites and many diverse sources. It has been agreed that a minority ethnic Hub would be much more accessible for both patients and professionals. Discussions are ongoing on where the Hub should be sited. A subgroup led by Brian Forbes, representative from the Industry group on DMEG, is collating patient and professional resources. Some Voluntary Sector agencies have already agreed to link access to minority ethnic resources from their websites.

### ***People's Voices on Healthy Lifestyles***

This audio-visual resource was funded by the SDG and features minority ethnic people who have been diagnosed with diabetes sharing how they cope and how they have changed their lifestyles.

Three video sections have been developed on:

- Living with Diabetes
- Diet
- Physical activity

It was developed in English and translated into Urdu. It is on a temporary website and can be viewed using the link:

<http://www.cmactest.co.uk>

This audiovisual resource is ready to be uploaded and discussions are ongoing with Scott Cunningham, from SCI-DC and Joan McDowell, National Education Co-Coordinator for Diabetes, on the appropriate web site.

A draft copy of the resource was placed on a temporary website for comment from a wide range of stakeholders both during its development and also after translation. Draft DVDs were also circulated to those who could not view the resource online.

Several focus groups were held with bi-lingual minority ethnic people on the English version and with Urdu speakers with limited English proficiency on the Urdu version. The resource has been positively received by both professionals and minority ethnic communities; the latter resulted in requests for more input to understand the prevention and management of diabetes.

Health professionals who commented on the resource requested more supporting material for practitioners to understand cultural issues and also for handouts / resources to motivate and support goal setting on each the three video sections.

Two work streams to address these concerns have been set up: one on diet and the other on physical activity.

### ***Patient experience***

Voluntary Sector agencies, represented on DMEG, currently have initiatives to capture Patient Experiences and a Voices Programme to provide training and mentoring to enable patients to influence policies / services.

The need to be more inclusive of minority ethnic patients and carers, especially those who have low health literacy and limited English proficiency, is acknowledged and several Voluntary Sector agencies have prepared funding bids to improve inclusion from minority ethnic groups. Chest, Heart and Stroke Scotland (CHSS) and MEHIS in NHS Lothian are currently planning a Voices programme in Lothian.

### ***Group membership***

The membership of DMEG has been reviewed and new members have been invited onto the group to achieve a more strategic focus and to progress some of the priorities highlighted from the case studies. The Voluntary Sector agencies represented are British Heart Foundation (BHF), CHSS, Diabetes UK, The Alliance, Scottish Refugee Council and Frae Fife.

The group was renamed Scottish Minority Ethnic Long term Conditions Group as it addresses care of people with diabetes, CHD and Stroke. To avoid confusion, we will continue to report to SDG as DMEG. Other Voluntary Sector groups will report to their relevant Scottish Government National committees.

Partnership working between the NHS, Community Health Partnerships, Local Authorities, Voluntary Sector including minority ethnic, faith and cultural groups, is essential to provide an integrated system of culturally appropriate care and to support self management in local communities.

At the last meeting the group discussed how to mobilise and empower minority ethnic communities at high risk of developing diabetes, CHD and stroke to improve their health and reduce their risk of developing complications. The group agreed that working in partnership was crucial in planning any community development initiatives and campaigns. Dr. Pauline Craig from Health Scotland's Equality Unit has agreed to assist us in exploring how best to do this.

### ***Way Ahead***

To progress the work, it is important that robust working relationships are developed and maintained within DMEG, especially with the Voluntary Sector agencies. Stronger working relationships could be developed with the Diabetes Care Focus group and the Foot action group to progress the work.

Strategic direction of future work must be in tandem with NHS Health Boards where there is identified need, as a result of MCN's Health Inequalities Impact Assessments. Sustainable solutions need to be identified. Where possible, care should be integrated into main stream care provision with staff prepared to provide culturally specific care. Due to the transitory nature of some people from minority ethnic groups, there remains a need to provide care that is culturally and language specific for population groups.

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Chair of Diabetes Minority Ethnic Group  
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