

PATIENT PUBLIC INVOLVEMENT
DIABETES SERVICE
REVIEW

Lucy Hall
Health Development Service
2005

PATIENT PUBLIC INVOLVEMENT – DIABETES SERVICE

REVIEW

INFORMATION FROM PREVIOUS COUSULTATION

Access to Information and Services

Information from Diabetes focus groups and other Patient Public Involvement groups has shown that people from South Asian and Chinese communities have greater difficulty accessing information and services than people in the general community.

People with Diabetes from these communities generally have a limited understanding of diabetes in relation to its causes, implications for lifestyle and longer term effects' (Mori 2000). Macaden 2005 in a presentation of initial finding found a lack of risk perception and hence management of diabetes amongst older South Asian men and women.

Over the last few years Black and Minority Ethnic communities have identified a gap in practical support to access health provision (Access report 2003). Barriers to accessing services and information include lack of awareness of services, language and cultural barriers which effect people's ability to contact and communicate with services. Literacy levels, appointment letters in English referral letters not indicating whether an interpreter is required, getting to appointments because of language barriers and racism, negotiating hospital buildings, lack of familiarity with

NHS systems and procedures, getting feedback from tests and result.

People from South Asian communities are also more likely to live in socially deprived communities, impacting on rates of diabetes and access to services.

People from the Chinese community have been described as the invisible community. This is partly because they do not live in small geographical areas within towns and cities, and partly because there is so little information available on their health needs. (Diabetes in Chinese people living in the UK 2005).

Out of 70 Chinese and South Asian participants in the 'What do People Really Think Report 1998':

- No one could explain what diabetes or cardiovascular disease was
- Patients and their families did not seem to enjoy access to information about the management of their disease or relevant services. Many did not understand instructions for their drugs
- Participants were concerned about messages on diet – they needed culturally sensitive messages
- Health information did not relate to peoples cultural belief
- In hospital participants felt ignored because 'you cannot make yourself understood.'

What Local People from Black and Minority Ethnic Communities Wanted from Services

In local focus groups people said they needed:

- Access to information through a range of languages and formats
- Access for everyone to education about diabetes
- Access to interpreters (being offered not having to ask)
- Opportunity to get together
- Review of appointment systems
- Feedback on results and meanings of tests
- Disability awareness and racial equality awareness for service providers
- Support to overcome difficulties in accessing services

Diabetes Focus Groups

2000 and 2001

Consultation Reports

Summary of key issues from consultation reports over the past five years included:

- **Planning Ahead**

When agencies prepare any service development; a service review, developing a new service, expanding an existing service, they need to think in advance about issues of access to Black and Minority Ethnic communities and develop appropriate plans.

Making the Message Accessible

Information needs to be accessible, both in language and in clarity. Rather than getting information separately from agencies, they should work together and share tools and resources. Similarly, information about patients should be more streamlined.

- **Letting Black and Minority Ethnic Communities Know**
There are established trusted and effective ways of communicating with Black and Minority Ethnic communities in addition to simply providing information in other languages. For example, there are established community networks or trusted workers or activist. Giving time within appointments for interpreting.
- **Making Access Work**
Developing an effective and accurate ethnic monitoring system is the key to monitoring practice, to improve targeting of services and measure effectiveness, eg: access to and uptake of flu vaccines.

Common themes that cut across services in relation to the needs of people from Black and Minority Ethnic community were identified in the 'Listening and Learning together report 2002'.

They are summarised these as follows:

Messages to older people and carers:

“Try to become aware of the services available and request services from your GPs. Use interpreters for visits to GPs and other health professionals. Do not just manage. You are important.”

“There is a need for a change of attitude in the wider community and for more cultural awareness. A shift of attitude is needed. This is equally important from the ethnic minority community perspective who equally need to make a shift and effect a coming together.”

“There is some good support and information services out there who are trying to make contact with you – sometimes we need you to be more open to hearing about them.”

“Get involved!

Messages to Managers and Staff:

“Don’t assume that you and your services are geared up to meeting the needs of people from Black and Minority Ethnic groups.”

“In allocating time for such services it is crucial that consideration be given to communication and cultural issues so that a more realistic time slot is allowed.”

Messages to PCT and Social Services:

“We need to invest in individuals (staff in services and those in the community) to ensure that training, understanding and problem solving are joint priorities.”

INFORMATION FROM CONSULTATION IN 2005

This involvement has been undertaken in partnership between the Health Development Service, Community Action on Health, The Strategic Health Authority, and community groups.

Discussion has taken place with the following groups:

- Chinese Community
- Pakistani and Indian Women
- Bangladeshi Men
- Other groups will take place in October / November 2005

GROUPS FOR DIABETES DISCUSSION

Chinese Community

Twenty people, including four with diabetes, four carers

1	<i>What would you have liked from diabetes services when you were first diagnosed?</i>
	<p>Someone to explain about how to care for yourself and your diabetes.</p> <p>Information about diet so I can be more in control of my diabetes.</p> <p>For services to involve my family more so that they could support me.</p> <p>To know more about complications – tests to tell me how my organs are now.</p>
2	<i>What support has been most helpful in managing your diabetes?</i>
	<p>Regular contact with the GP.</p> <p>Information in my first language.</p> <p>Health Development Workers having time to explain about diabetes.</p> <p>Groups where others can share my experience.</p>
3	<i>If you were able to choose one thing that could change in diabetes services what would it be?</i>
	<p>To run more regular workshops.</p> <p>To see GP every 6 / 12 instead of each year.</p> <p>To know more about results of tests.</p>

GROUPS FOR DIABETES DISCUSSION

Pakistani and Indian Women

Six women

1	<i>What would you have liked from diabetes services when you were first diagnosed?</i>
	<p>To explain more about diabetes. Some women diagnosed for a couple of years, but didn't understand until information given in first language.</p> <p>Information in first language.</p> <p>Time for older people.</p> <p>Support to get appointments and at appointments.</p>
2	<i>What support has been most helpful in managing your diabetes?</i>
	<p>Diabetes Centre – you get all the check-ups you need.</p> <p>Health Development Service – listen to your problems and the information is in your first language.</p> <p>Group Work - especially exercising together.</p>
3	<i>If you were able to choose one thing that could change in diabetes services what would it be?</i>
	<p>The Diabetes Centre to remind us of appointments.</p> <p>More help at home, for older people – shopping, home care.</p>

GROUPS FOR DIABETES DISCUSSION

Bangladeshi Men Ten men

1	<i>What would you have liked from diabetes services when you were first diagnosed?</i>
	Information in first language. Explanation about why it happens (some people think you can catch it off other people). Understanding about how dangerous it can be. Only took it seriously when I went on insulin. Help with worries about diabetes.
2	<i>What support has been most helpful in managing your diabetes?</i>
	District Nurse – good rapport with nurse. GP – good service, but I already know about diabetes. Health Development Service – information and groups in first language, better understanding. Retinal Screening – I know something is okay.
3	<i>If you were able to choose one thing that could change in diabetes services what would it be?</i>
	More Black Minority Ethnic workers – they understand the issues faced by people and also cultural issues. More listening to what clients want to talk about – not just information about what we should do. Time – more explanation about why. More lifestyle sessions in first language. Appointment systems – evening appointments.

GROUPS FOR DIABETES DISCUSSION

What would you have liked from diabetes services when you were first diagnosed?

To tell us what Diabetes is, what are the symptoms.

What we can do to prevent it, is it a life long illness, do we have to be on regular medication.

How big is this illness, is it like any other illness or not, can we live a normal life.

What support has been most helpful in managing your diabetes?

From the Doctors surgery, nothing, apart from prescribing medication, dietician yes they are helpful, Doctors are not. They do not listen to you. They do not have the time.

How has the Health Development Service been helpful?

The Health Development Workers come to see you at home. They give you time. They talk to you in your own language and identify your needs. They refer you to their service and help you to access the other services. They find out information for you, they take us to their exercise groups and we can contact them if we have any problems. If we think the GP is not listening to us, they support us to solve the problem. If we don't understand something about medication they will ring the GP surgery and obtain a full explanation.

If you were able to choose one thing that could change in diabetes services what would it be?

Spend more time with a patient.

If you were able to choose one thing that could change in the Health Development Service what would it be?

Hold a focus group / run a small drop-in session run by Black and Minority Ethnic Workers.

What would you like health workers to know about your faith and culture?

Respect people, culture and their belief. Avoid prayer time on Friday. These are usually in the afternoon. Be aware that you may need to take off your shoes. Be aware of fasting and festivals especially during Ramadan – find out dates each year.

With younger women try to avoid cooking times. Cooking is done from scratch and is usually from 11.00 am – 1.00 pm.

Men often work in restaurants, taxi business and arrive home in the early hours of the morning. Therefore early appointments are not usually good.

- Gender – Women mainly prefer to have a female worker
- Dress – Modestly when visiting peoples homes
- Faith – Be aware and open to the fact that people have a holistic approach to health. This includes faith and prayer impacting on their health and health behaviour.

Offering hospitality is an important part of culture accept it if you can, or refuse gracefully.

GROUPS FOR DIABETES DISCUSSION

Pakistani men
Twelve men

1.	<i>What would you have liked from the diabetes service when you were first diagnosed?</i>
	<ul style="list-style-type: none">• More information given by hospital• More information from GPs• To be informed that I had diabetes as soon as I was diagnosed• Information in other languages• Information on diet and precautions to take• To be referred to a dietician• To be referred to specialist services e.g.<ul style="list-style-type: none">○ Health Development Team○ Diabetes UK

	<ul style="list-style-type: none"> ○ BME group ○ Diabetes Centre ● Separate service for men and women ● Eye tests on diagnosis rather than waiting for first yearly screening
2.	<i>If you care for someone with diabetes, what would you like from diabetes services</i>
	<ul style="list-style-type: none"> ● Training for carers ● For those who care for someone with insulin treated diabetes – how to prepare insulin injections ● How to help the patient in case of an emergency ● Knowledge about diets ● What to do if the patient has a hypo ● Provision of glucose meters ● Advice on travelling ● More information in patient's first language
3.	<i>What support has been most helpful in managing your diabetes?</i>
	<ul style="list-style-type: none"> ● Quick referral to diabetes centre ● Follow up by Health Development Service ● Free prescriptions ● Free retinal screening ● Advice from practice nurse ● Some advice available in other languages ● Some advice given by friends
4.	<i>If you care for someone with diabetes, what support has been most helpful?</i>
	<ul style="list-style-type: none"> ● Respite care ● Education and information received ● Help from Health Development Service workers ● Support from practice nurse ● Friends and family ● Advice from Diabetes UK
5.	<i>How has the Health Development Service been helpful?</i>
	<ul style="list-style-type: none"> ● Good information in BME first languages ● Has raised awareness in many venues ● Friendly staff

	<ul style="list-style-type: none"> • Easily accessible • More staff with language skills • Sometimes staff are not from the same region and may not be aware of some religious or cultural issues. It is not always possible to find staff who speak the same dialect • Overall do a good job. All GPs in Newcastle should refer patients to the service
6.	<i>If you were able to choose one thing that could change in diabetes services what would it be?</i>
	<ul style="list-style-type: none"> • More staff to reach out at a “grass roots” level to raise awareness • More preventative work and advice • Information on CD, video, Braille etc. • More staff in proportion to number of people who have diabetes – 5:1 (!)
7.	<i>If you care for someone with diabetes, what one thing would you change in support services for you?</i>
	<ul style="list-style-type: none"> • Carers should be informed of their rights, that is: • To know about carers’ entitlements e.g. <ul style="list-style-type: none"> ○ Benefit entitlements • To know about services for carers e.g. <ul style="list-style-type: none"> ○ Respite care ○ Carers’ project • More advice from GP and practice nurses • Waiting times should be improved at the Diabetes Centre • More resources • Quicker referral • To be seen by Health Development Service within one month of diagnosis
8.	<i>If you were able to choose one thing that could change in the Health Development Service, what would it be?</i>
	<ul style="list-style-type: none"> • More aware of race/cultural issues (if patient and Health Development Worker are not from same background/region/religion) • More services available in the afternoon or full time • More flexible services, covering unsocial hours/weekends • For the Health Development Service to work more closely

	with mosques, religious centres and community centres
--	---

Participants – Pakistani men's group:

M. Choudhry

Dr Iqbal

Dr K Farook

Cl. Karamat

Tariq Mahmood

M. Akser

M. Afzal

A. Sattah

F.H. Shakir

Mumtaz Asif

HgM Azam (or Ayam?)

Qari M. Saeed

GROUPS FOR DIABETES DISCUSSION

Arabic speaking Muslim women from middle eastern community
(held at Millin Centre)
Six women

1.	<i>What would you have liked from the diabetes service when you were first diagnosed?</i>
	<ul style="list-style-type: none"> • Information about: • What is healthy food for someone with diabetes • Blood sugar monitoring – how is it done, what does it mean • Information in first language • Written • Oral – may need interpreter
2.	<i>What would you like health workers to know about your faith and culture?</i>
	<ul style="list-style-type: none"> • Knowledge of the food we eat e.g. halal diet • About fasting – people within the same religion may have different patterns of fasting. • Fasting occurs at Ramadan but also at other times – for example some people fast every Monday and Thursday, some on one Monday and Thursday per month • What periods should be avoided for appointments and visits, for example: • Prayer time especially Fridays • School time • Early morning for taxi and restaurant workers • Islam has a different calendar based on a 29/30 day month and depending on the moon – so people may be working from two calendars, which can cause confusion with appointment dates, particularly for people who don't read English • Faith is an important part of health i.e. faith may contribute to health at least as much as medical input • Herbs are often used for health, in drinks for example • Shoes should be removed when entering the house – the carpet must be kept clean for prayer • A female practitioner is preferable, and people may prefer

	<p>to wait longer to see a female practitioner than to see a male practitioner earlier</p> <ul style="list-style-type: none">• Staff's dress – there may be some aspects that need to be considered e.g. covering shoulders, although this group saw staff dress as being down to individual choice• Health beliefs that someone might hold e.g.• Fasting will help diabetes as it gives the pancreas a rest
--	--

Participants:

Lucy

Amany

Esma

Hajer

Karema

Amma

Asma

GROUPS FOR DIABETES DISCUSSION

Punjabi speaking community (Asra group) – held at the Millin Centre

1.	<i>What would you have liked from the diabetes service when you were first diagnosed?</i>
	<ul style="list-style-type: none"> • Interpreter • Counselling by someone with an understanding of diabetes • Team to work at the pace of the patient when newly diagnosed • One to one and group settings • Education and training for family members to raise awareness of diabetes • Support regarding medication, for example: • Repeat prescriptions • Help from chemist • Someone to arrange and collect medication for patient if they would have difficulty picking it up from the chemist • A social worker
5.	<i>How has the Health Development Service been helpful?</i>
	<ul style="list-style-type: none"> • Providing ongoing support; more is needed
3.	<i>If you were able to choose one thing to change about diabetes services, what would it be?</i>
	<ul style="list-style-type: none"> • More support from GP services • On going support to access services • On going support from Health Development Service • More female workers in Health Development Service especially Urdu and Punjabi speaking
4.	<i>What would you like health workers to know about your faith and culture?</i>
	<ul style="list-style-type: none"> • About Ramadan and other festivals and events – to be able to understand these and provide support at these times