A Better Life through Education and Empowerment

The Leicester ABLE Project to raise awareness of renal disease in the South Asian community
A Better Life through Education and Empowerment – the Leicester ABLE project to raise awareness of renal disease in the South Asian community

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Elements of the ABLE programme have been supported by
The Department of Health
Kidney disease is common, harmful and treatable but it is often silent until kidney damage and dysfunction are far advanced. Early detection, changes in lifestyle to control increased vascular risk, interventions to reduce blood pressure and in people with diabetes, to improve blood sugar control can delay or prevent the progression of kidney disease. This requires a partnership between health and social care agencies, professionals, the communities that they serve and, most importantly, the at-risk individuals themselves if the ‘preventative dividend’ prize is to be realised.

The ABLE (A Better Life through Education and Empowerment), programme of Kidney Research UK is addressing this challenge in high risk groups and has received funding from the Department of Health. We have known for over a decade that people from black and minority ethnic (BME) communities have a risk of heart disease, kidney failure and diabetes 3-5 times that of the Caucasian population. Most BME families will have relatives with one or more of these vascular problems and increasingly many individuals have all 3 conditions. The underlying molecular and genetic causes, the interactions between these 3 overlapping disease processes and the links between social deprivation and poor outcomes are complex. One constant however is the need to engage with the individual in the context of their environment, culture and aspirations to encourage lifestyle change and to support self care.

The Leicester ABLE project focussed on the needs of the local people from various south Asian backgrounds. The project was co-produced with members of the Sikh, Muslim and Hindu communities and developed innovative methods of promoting awareness, supporting lifestyle change and reducing the risk of kidney disease. It took an inclusive approach, building on the success of project Dil (Dil is the Urdu/Hindi word for ‘heart’) and the SALAD study (Schools Action in Leicester Against Diabetes and heart disease). It identifies different needs in the different communities, variations in what is a good cultural fit and that individuals have different knowledge management and learning styles. All this diversity adds up to a simple message that is almost certainly transferrable to other settings and communities – make kidney health promotion relevant to the local community and provide encouragement personalised to individual needs and aspirations.

Managing chronic diseases or long term conditions as we now often call them, requires a systematic biomedical approach to early identification and an integrated approach to service delivery. But the NHS as a system of care needs to go further to identify the missing millions, engage with the hard to reach and to encourage the individual. A Better Life through Education and Empowerment, ABLE, is a step in that direction for kidney care.

Dr Donal O’Donoghue, Consultant Renal Physician
National Clinical Director for Kidney Care
Executive Summary

The ABLE programme of Kidney Research UK seeks to address the challenges posed by the high prevalence of established renal failure (ERF) amongst groups known to be particularly at risk; these include people in black and minority ethnic (BME) communities. The Leicester ABLE project, an important component of this initiative, describes a programme of work aimed at addressing specific issues amongst people of South Asian background, who make up more than a third of the city’s population.

The project involved both interventions encouraging lifestyle change (to reduce the risk of developing kidney disease) and the early detection and treatment of renal impairment (and its risk factors).

It has been recognised that BME communities can be hard-to-reach groups in terms of health education. The reasons for this are complex and relate to cultural, language and socio-economic factors. Interventions therefore have to address these barriers if they are to have a chance of any positive impact. The Leicester ABLE project initially used focus groups to identify such barriers for the Asian community. The researchers found that there was a lack of knowledge regarding renal disease amongst even the highest-risk groups (such as people with diabetes), and that information available to them was scarce. Concerns were commonly expressed about poor communication with, and a perceived lack of time given by, health professionals (in particularly doctors), as were sentiments indicating cultural difficulties in making lifestyle changes and a fatalistic attitude in some. The research also showed that people would prefer audio-visual and group-discussion type formats for health promotion messages. The focus group evaluation stressed the importance of delivering health promotion in a way that recognised the cultural and language background of the target population.

As a consequence, the Leicester ABLE project developed several programmes of work to address renal health promotion amongst the South Asian community of Leicester. This included a Peer Educator programme, innovative education materials, including a multilingual DVD ‘Preventing Kidney Disease: the silent killer affecting you’, disease-specific leaflets, and a general media campaign. The Peer Educator programme, involving four specially trained individuals, was particularly successful in reaching large numbers of the community. Crucially the Peer Educators incorporated strategies and practical suggestions for lifestyle change that were relevant to those attending events. Qualitative assessment of their work demonstrated real impact in terms of enhanced knowledge and the initiation of lifestyle change. The DVD was also rated very highly, particularly as it enabled large numbers of the public to access the messages in a variety of settings.

The Leicester ABLE project acknowledged the importance of screening and reducing risk factors (e.g. hypertension and poorly controlled diabetes) for renal disease amongst South Asians in Leicester. It therefore sought to support local primary care health professionals in their determination to improve early detection and treatment of the risk factors for renal disease in general practice. Indeed, the project actually piloted work in setting standards – for the audit of individual care plans and for practice-provision of education programmes – before this became a recognised part of the Quality and Outcomes Framework (QOF) of the new general practice contract and was acknowledged as important in part two of the National Service Framework for Renal Services (Renal NSF). Specific lessons from the work by ABLE include confirmation of the relatively low priority assigned to renal disease prevention in general practice and the poor documentation of risk for renal disease – although the latter has possibly been improved by the QOF. The study demonstrated the limited value of a single education session as a method to encourage change in practice but pointed to the need for further work in quality improvement for renal disease in primary care. The ABLE findings and experience have supported the launch of a much more detailed and comprehensive quality improvement project funded by the Health Foundation.

Overall, despite the limited nature of the funding and remit of the Leicester ABLE project, important lessons have been learnt. This work suggests that the methods developed for providing information to minority ethnic communities are very powerful, and worthy of further development and evaluation with a view to wider implementation.
# Contents

1 Introduction and background 6

2 Development of the Educational Programme 10

3 The ABLE Community Education Programme 14
   Peer Education programme 14
   Educational materials and campaigns 18
   The ABLE DVD: Preventing kidney disease – the silent killer affecting you 19
   Written information 20
   Website and Kidney Health Information Line 21
   The ABLE Media campaign 21

4 Work with GP practices 22

5 Evaluation of the impact of the project 26
   Post-intervention focus groups 26
   Case Studies of individuals who attended educational events 29
   Impact of the Peer Educators’ work 30
   Impact of the educational materials produced 31

6 Conclusions and lessons for the future 32

7 Acknowledgements 34

8 References 35
1 Introduction and background

In the UK the prevalence of established renal failure (ERF) is at least three times greater amongst people of South Asian background than in the Caucasian population\(^{(1)}\).

This is due to many factors, in particular diabetes. Amongst South Asians Type 2 diabetes is four times more common\(^{(2)}\), and kidney failure as a complication of diabetes ten times more common\(^{(3)}\), than in the Caucasian population.

Furthermore, as the UK South Asian population is relatively young and ERF has a strong association with ageing, it is reasonable to predict that in the future this community will have an increasing burden of ERF\(^{(4)}\).

In order to minimise this there need to be interventions to prevent renal disease, and to slow its progression when it does occur. As such interventions are based on lifestyle change and the early detection and treatment of renal impairment (and its risk factors), it is important to raise public awareness of renal disease. Such awareness raising should also actively promote appropriate lifestyle changes and encourage the adoption of screening for early diagnosis of renal impairment and the presence of relevant risk factors. These health promotion activities, including early medical interventions to treat risk factors, are likely to be implemented in community and primary care settings.

The key clinical conditions requiring intervention are diabetes, hypertension and early renal impairment; these are often asymptomatic in the early stages, hence the need for screening. There is now evidence that once detected the progression of renal disease can be delayed or prevented by tight blood-pressure control, with interruption of the renal-angiotensive pathway\(^{(5)}\). Similarly, tight glycaemia control in diabetes reduces micro-vascular complications, including renal disease\(^{(6)}\).

In order to ensure the success of any early detection and prevention interventions there are two prerequisites; firstly, the ‘at-risk’ population need to be aware of the importance of screening for renal disease and the benefit of early management and treatment, and secondly, health professionals (especially in primary care) need to make such screening available, and be aware of the relevant interventions for the risk factors.

The ‘at-risk’ South Asian population is a particularly difficult target group in terms of health education. This is due to cultural and language barriers. Lifestyle changes may also be difficult for various socio-economic and cultural reasons. As an example, consumption of foods high in fat and sugar is part of the normal social and visiting structure of Asian families and refusal of food offered may cause offence. Similarly, for reasons of modesty Asian women may be restricted in their access to various forms of exercise. It is therefore important for any intervention programme to be tailored to these communities and address such specific barriers.

Kidney Research UK is the leading national charity dedicated to research that will lead to better treatment and cures for kidney disease. Founded in 1961, the organisation has been at the forefront of pioneering kidney research for many years, as well as caring for patients and raising vital public awareness.

In 2001 the charity launched the ABLE programme to highlight and reduce the high incidence of ERF in at-risk groups such as BME communities. ABLE is an acronym for A Better Life through Education and Empowerment and this ethos is embedded in the work with patients and health care professionals. ABLE is now the awareness programme seeking to address such issues for anyone at risk of CKD and ERF.

As well as the project in Leicester, there are six other projects under the ABLE programme:
The Birmingham project has been an awareness initiative among the local African Caribbean community. Working with a local steering group, we produced advertisements and targeted leaflets and gave presentations in community settings via local Peer Educators. Working with Boots the Chemists, we provided information on CKD to the general public and undertook blood-pressure testing. Many people were receptive to the information, giving positive documented feedback, and at one event 15% of those tested were referred to their GP. Collaborative work with GPs also took place.

The West London project, involving the screening of over 20,000 people to elicit prevalence rates of CKD and risk factors, led to an important finding: that in Black and South Asian people there appears to be a faster progression rate through CKD stages 3 to 5. Kidney Research UK is now funding a follow-up longitudinal study - the latest ABLE project.

The other three projects are still in early phases but two are clinical research projects. One focuses on the pathway of the diabetes patient in Leicester, Luton and West London, comparing South Asian and white patients. Another project is on attitudes to organ donation in West London. A third, the Community ABLE Toolkit (CAT) project, considers the dissemination of the initial findings of the first ABLE projects to the wider community – the public and health professionals.

These projects are helping to identify a large unmet need, enabling the renal health of BME communities and the development of innovative methods of promoting awareness that are being sought by other organisations within and beyond the UK. The key messages include reduction of lifestyle risk and encouragement for patients and primary care to work together – an approach transferable to any group.

Supporting the effective management and treatment of diabetes and hypertension while allowing patients to share the responsibility with health care professionals is an important balance to aim for. These projects appear to have begun to affect attitudes and levels of knowledge, and to enable lifestyle modification.

In particular the Leicester ABLE initiative aims to investigate and develop methods to:

- increase awareness of the importance of screening for and reducing risk factors for renal disease amongst South Asians in Leicester;
- support local primary care health professionals in improving early detection and treatment of the risk factors for renal disease in general practice.

In order to achieve these objectives ABLE aims to build on previous experience in health awareness with this community. Successful initiatives, such as Project Dil (7) (dil is the Urdu and Hindi word for heart) and the SALAD study (8) (Schools Acting in Leicester Against Diabetes and heart disease), which used methods such as peer education and development of tailored educational materials, and media dissemination are used as starting points for the development of the methodology for ABLE.

The approach of the ABLE project is aligned to the national aspirations in managing and reducing renal disease as described in the Renal NSF (9).
Methods

The ABLE project in Leicester ran for three years, commencing in June 2003 and was formally completed in June 2006. A project manager and co-researcher, Neerja Jain (NJ), was appointed by Kidney Research UK. An increasing proportion of her time was dedicated to the running of this project, whilst she project-managed the other ABLE projects. A steering group was established, comprising a mix of various local healthcare professionals and lay representatives of local Asian communities. The steering group met approximately every 12 weeks (see ABLE Project: steering group opposite). A project-management team consisting of the project manager and two local clinicians, (Dr Azhar Farooqi (AF) from primary care and Professor John Feehally (JF) from secondary care), undertook the day-to-day running of the project. This team met as required, usually on a monthly basis.

Following the formal project launch, the main elements of the Leicester ABLE project were

- A baseline focus-group study to establish current knowledge and awareness of issues relating to renal disease. This was undertaken as a previous study – relating to coronary heart disease (CHD) – had revealed significant lack of knowledge on an important chronic disease in these communities (10);
- A public education programme, including the training of Peer Educators, development of audio-visual materials and involvement of the media;
- A healthcare professional audit and education programme;
- Project evaluation, including the use of further focus groups;
- Dissemination of findings.

These will be described in detail in subsequent sections of this report.

A steering group was established, comprising a mix of various local healthcare professionals and lay representatives of local Asian communities.
ABLE Project: steering group

Terms of reference

The group will have a maximum of 16 members, including the following:

the ABLE RENAL Operational Group, Professor John Feehally, Dr Azhar Farooqi, Ms Neerja Jain (Kidney Research UK, Project Manager) and PA support, two representatives from patient groups with renal disease and/or diabetes, community representatives, including one member each from the Sikh, Muslim and Hindu communities, a Community Health Development worker with expertise in working with Peer Educators, and a PCT representative.

The Group will meet quarterly (or as necessary) to discuss issues and provide suggestions for action.

Aims and objectives of the steering group:

- to ensure a multi-professional contribution to steering the ABLE RENAL Project;
- to ensure all major South Asian faith communities are represented on the steering group and are involved in implementation and delivery of the project;
- to ensure user participation by including a patient with diabetes and renal disease ensuring that they are involved in planning, implementation and delivery of the project;
- to steer, monitor progress and have overall control of the strategic development of the ABLE RENAL programme;
- to ensure relevant milestones are being achieved;
- to report progress to Kidney Research UK.
2 Development of the Educational Programme

Baseline focus group study
The ABLE project used an action-research methodology to develop educational interventions, tailored to the needs of the South Asian communities of Leicester, to raise awareness of renal disease. Action research in this context involves using feedback and commentary from the community on the development and the ongoing modification of a community education programme.

Focus groups were felt to be a useful way to obtain rich and detailed information on what community members understood about renal disease and how they felt the community could best be given information (11). The focus groups comprised volunteers from diabetes clinics, hypertensive clinics (primary care), renal clinics (hospital) and local community centres serving South Asian communities (general public). Individuals were recruited from the clinics either by being asked by the consulting doctor or from response to a general invitation. 8 to 12 participants were invited to each group. The groups were held in local venues and participants were provided with lunch and a £5 gift voucher as nominal recompense for their time and expenses.

Using this methodology we sought to identify levels of knowledge regarding renal disease, factors likely to influence relevant health-related behaviour and the most effective methods of informing the local community.

A focus group study to investigate knowledge and attitudes to renal disease amongst South Asians in Leicester, in order to inform a renal disease education programme - the ABLE project.

Aim
The purpose of this qualitative study was to explore knowledge and attitudes regarding renal disease amongst South Asians (from a range of backgrounds). We aimed to obtain information which would help to develop a community education programme for the ABLE project. We then went on to investigate the impact of the programme on participants who attended.

Methods
Design
The study was based on focus groups held before and after the interventions, in both cases using purposive sampling for recruitment and a topic guide for facilitation of discussion.

Focus groups were felt to be a useful way to obtain rich and detailed information on what community members understood about renal disease
Recruitment of participants

In order to reflect views from a range of South Asian communities and to reflect those at standard and increased risk of renal disease, participants were recruited from the following environments:

- hospital renal outpatient clinics - i.e., patients with established renal disease;
- GP hypertension and diabetes clinics (from the East Leicester Medical Practice - a large inner city practice with a mixed ethnic population);
- community centres – various community centres in central Leicester, serving a range of South Asian communities, including Sikh, Hindu and Muslim groups.

Potential participants were invited through poster advertisements and invitation from consultants and GPs to contact the research team or speak to a researcher who was available at the appropriate venue. Participants were given written information about the focus groups and asked to consent to the study. Individuals who were too ill to attend or participate in the focus group exercise were excluded. Language was not a specific exclusion criterion as multilingual researchers were used. Initial agreement to participate was followed up by a formal invitation to attend a group.

Data Collection

Between January 2005 and July 2005 focus groups took place as shown in Table 1. They were held at the Leicester General Hospital, the East Leicester Medical Practice or a community venue (depending on the place of initial recruitment). The focus groups were facilitated by two members of the research team, Neerja Jain and another bilingual qualitative researcher, Davinder Nagra.

A topic guide for the focus groups was developed by discussion between the key researchers with the aim of providing a feasible framework for facilitating discussion. The discussion sought to find out how much participants knew about causes of renal disease, risk factors, and signs and symptoms, and how renal disease could be prevented. Issues concerning lifestyle risk and how to reduce such risk factors were also discussed.

Sessions commenced with introductions and a brief explanation of the study. Participants were asked for views on the language to be used during the focus group, and a consensus was reached on the main language to be used. Whenever necessary, however, the multilingual researcher used appropriate languages to explain and obtain clarification according to her judgement. An open and facilitative style of questioning was used in order to promote open discussion. Each session lasted for about 60 minutes and was audio-taped, and then translated and transcribed by the multilingual researcher. A small selection of tapes was back-translated by a second researcher to ensure accuracy of the translation process.

Topic guide used in focus groups

The following themes were addressed:

- What do the kidneys do and what is kidney disease?
- What are the risk factors for and causes of kidney disease?
- Why are South Asians more prone than other people to kidney problems?
- How can kidney disease be prevented in South Asian communities?
- What are the barriers to changing lifestyle risk factors?
- What sources of information on renal disease are there currently and what is needed?
- What do you think about the general provision of health services to the community?
- What associated diseases can lead to kidney disease?
- You have high blood pressure/diabetes. Do you know what the relationship is between this and kidney disease?
- What tests are used for kidney disease? What can be learnt from monitoring blood pressure and blood glucose levels (HbA1C ) and the results of other tests?
- What do you know about dialysis and transplantation?

Table 1: Pre-intervention focus groups and numbers participating

<table>
<thead>
<tr>
<th>Group number</th>
<th>Focus group (initial)</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Female hypertension group</td>
<td>8</td>
</tr>
<tr>
<td>2</td>
<td>Female diabetes group</td>
<td>10</td>
</tr>
<tr>
<td>3</td>
<td>Mixed-sex renal disease group</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>Mixed-gender community group</td>
<td>7</td>
</tr>
<tr>
<td>5</td>
<td>Male diabetes group</td>
<td>9</td>
</tr>
<tr>
<td>6</td>
<td>Male hypertension group</td>
<td>7</td>
</tr>
</tbody>
</table>
Ethical Considerations
Ethics committee and local research governance approval was obtained. Before they took part in a focus group participants were given information sheets and asked to sign consent forms. Strict confidentiality was assured regarding audio-taping, analysis and reporting of data. Participants also agreed, by consent, to maintain confidentiality of the views of fellow participants.

Data analysis
The data was first analysed independently by each of the two researchers (AF, NJ) who identified themes. The researchers then met to agree the therapeutic framework. After this the two researchers again worked independently, manually coding the data. The data was then checked, first using major themes and then dividing into sub-themes. The researchers then discussed the results and explored core concepts and models to explain the findings.

Results
Typical quotes from key themes
Lack of basic knowledge/confusion
Researcher: ‘Do you know what tests are available for kidney disease?’
‘No’ [the entire group] (Male hypertension group)
‘No’ (Female hypertension group)

Researcher: ‘Do you know what your blood pressure numbers are?’
‘The drugs say it’s all right’ (Male hypertension group)
‘You know sometimes with other things you take medicine and it’s sorted ... Can it happen with blood pressure?’ (Male hypertension group)

Researcher: ‘What causes kidney disease?’
‘It could be due to liver problems.’ (Female diabetes group)

‘It’s not to do with blood pressure but the sugar’ (Female hypertension group)

‘South Asians suffer a lot from kidney disease. Why is that?’ (Male hypertension group)

Researcher: ‘What should your blood pressure be?’
[Different voices saying different figures]
‘131-30,’ ‘150/90,’ ‘120/90’ (Male diabetes group)

Sources of knowledge
‘I don’t have kidney disease. How do I find out?’ (Male diabetes group)

‘I think a little more information would be brilliant. I know we can go on the internet but not everybody is comfortable going on it or has a computer, and loads and loads of people don’t like reading.’ (Mixed-gender general renal group)

‘In hospital you get little booklets but we Asian people we don’t like looking at them.’ (Female hypertension group)

‘You get a lot of information from the telly.’ (Female hypertension group)

‘I think if it’s visual more people will take note of it.’ (Mixed-sex renal group)

‘Approach the temples, mosques etc … believe the people will bend over backwards to help.’ (Male hypertension group)

‘… to have Gujarati speakers, Hindi speakers, Punjabi speakers … it makes a big difference.’ (Male diabetes group)

‘... literature [helps] as well … As individuals we learn differently. Some people learn by speaking, some people by reading and some people by watching a TV, or programmes.’ (Female diabetes group)

Difficulties in changing lifestyle
‘In our Asian community you will see a lot suffering from disease -- arthritis, heart ... why? We never had this kind of problem in Africa or India. It must be related to quality of life.’ (Mixed-gender renal group)
If I want boiled food at a wedding, I might as well stay at home.' (Mixed-gender renal group)

'The quality of life in this country ... people are so stressed. They haven't got time, too expensive.' (Mixed-gender renal group)

[On children] 'They go to college and get a meal for £3.00 – to get pop, crisps and a burger.'

Cultural issues

[On kidney disease] 'Religion has nothing to do with this as culture ... it's up to you.' (Female hypertension group)

'Whatever you eat it makes no difference - it's God that decides.' (Female hypertension group)

'The poor elderly who don’t know ... they don’t listen, won’t watch what they eat.' (Female hypertension group)

'When a person gets to 65, they think well that’s it.' (Male diabetes group)

'There are some people who leave it in the hands of God ... whatever is to happen, let it happen.' (Male hypertension group)

[On fast foods] 'So many shops are opening … at our weddings they serve these foods. It’s put in front of you.' (Female diabetes group)

View of health profession

'They are saying everything is fine, and this, that and the other, but what is fine?' (Mixed-gender renal group)

'I will only find the results if I go to my GP and knock on his door ... he's too busy anyway to give me his time or to ring.' (Mixed-gender renal group)

'I've known people who have been to the doctors here and they didn't like their diagnosis, so they fly back to India, spend money and the doctor there tells them a different story – whom do they believe?' (Mixed-gender renal group)

'Information from consultants – is blunt. They tell me and say this is it ... but I'm left in limbo.' (Mixed-gender renal group)

'They never give you enough time.' (Female hypertension group)

Summary

Five main themes emerged from the analysis relating to attitudes to and knowledge about renal disease amongst the focus group participants. As we undertook several focus groups, with different types of participants, we feel these represent a reasonable cross section of views from the community in general and those at risk from renal disease.

The key themes were:

• the lack of knowledge and available information regarding the cause of renal disease and confusion amongst even the highest at-risk groups (i.e. those with diabetes and hypertension) about the causes of or risk factors for renal impairment;

• a preference for audio-visual and discussion-group type approaches to health education;

• an acknowledgement that the 'Asian' lifestyle in the UK makes lifestyle changes very difficult and a worry regarding the dietary habits particularly of children;

• the negative impact of a fatalistic attitude amongst particularly elderly South Asians;

• concerns about poor communication with and a perceived lack of time given by health professionals, particularly doctors.

This data was used to further develop and fine-tune educational and awareness initiatives, including peer education (the use of trained lay people to disseminate health messages), development and use of audio-visual (as well as some written) materials and the use of the media.
3 The ABLE Community Education Programme

Peer Education programme
The use of peer education is an established methodology for promoting awareness in groups who are otherwise difficult to access. Such educators have previously been used successfully for sexual health education in young people and for in coronary heart disease (CHD) in minority ethnic communities (7); the national ‘Expert Patient’ programme shares some of the concepts of the peer education model.

ABLE project Peer Educators
A considerable part of the project work and development of educational resources revolves round the use of the unique Peer Educator concept and model. Peer Educators are active representative lay members of their community who are trained in health promotion matters. With supervision and guidance from the project team, they deliver vital messages in a culturally sensitive manner; having a good knowledge of the needs, attitudes and experiences of their audience, their peers, they have a natural empathy.

Leicester is fortunate in having a cohort of accredited Peer Educators employed by Eastern Leicester PCT to help reduce CHD amongst the local South Asian community. The focus-group study results supported the use of peer education in delivering the educational messages of the ABLE project, in particular via face-to-face health-promotion activity delivered in an appropriate cultural framework and language.

Although it was not part of the methodology as initially planned, it was therefore decided to provide further training to four Peer Educators (three existing and one new) to enable them to carry out peer education on renal disease. The project manager felt that the success gained with Project Dil could easily be replicated in this renal project and the local team agreed. It was therefore discussed with the operational team at Kidney Research UK, who were wholly supportive of the initiative.

A renal health promotion course was developed and delivered, building on a previous course developed locally by Project Dil (6). This included education on associated risk factors, such as those of coronary heart disease, which is a parallel and potentially more life-threatening co-morbidity for most renal patients with even early kidney impairment. The training modules consisted of advice on diet, exercise and smoking, as well as information on kidney disease and its prevention, particularly emphasising the relevance of timely and robust management of diabetes and hypertension.

Table 2 outlines the modules that were part of the initial CHD peer education programme and the further modules for renal disease that were undertaken by the educators.

The modules were delivered by local health care professionals with expertise in the relevant topics. As well as attending the sessions students had to undertake further reading, role play and prepare ‘mock’ educational sessions as well as evaluate themselves and their colleagues, all as part of the training. They themselves were evaluated by the supervisors and Project Manager.
Table 2: Peer education for renal disease

<table>
<thead>
<tr>
<th>Module</th>
<th>CHD training programme (already completed) accredited by Open College Network</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Introduction: heart disease and South Asian communities</td>
</tr>
<tr>
<td>2</td>
<td>Smoking and alcohol: prevention, intervention and access points</td>
</tr>
<tr>
<td>3</td>
<td>Physical activity and stress: prevention, intervention and access points</td>
</tr>
<tr>
<td>4</td>
<td>Diet, obesity and diabetes: prevention, intervention and access points</td>
</tr>
<tr>
<td>5-10</td>
<td>Peer education skills, project development, group discussion</td>
</tr>
<tr>
<td>11</td>
<td>Media and presentation skills</td>
</tr>
<tr>
<td>12</td>
<td>Presentation of projects</td>
</tr>
<tr>
<td>13-14</td>
<td>Campaigns and display skills</td>
</tr>
<tr>
<td>15</td>
<td>Delivering heart-health initiatives in the community</td>
</tr>
<tr>
<td>16</td>
<td>Evaluation</td>
</tr>
<tr>
<td>17</td>
<td>'Mop-up' study day (voluntary attendance)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Module</th>
<th>Further Renal Disease Modules (each of these between 2 and 5 hours)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Introduction: diabetes, CHD and renal disease in the South Asian community</td>
</tr>
<tr>
<td>2</td>
<td>Basic anatomy and physiology of the kidney, Renal disease and risk factors</td>
</tr>
<tr>
<td>3</td>
<td>Peer education methodologies for renal disease</td>
</tr>
<tr>
<td>4</td>
<td>The ABLE project</td>
</tr>
<tr>
<td>5</td>
<td>Living with renal disease: patient perspectives and treatment, dietary advice to reduce risk factors</td>
</tr>
<tr>
<td>6</td>
<td>Diabetes and hypertension: links to renal disease</td>
</tr>
<tr>
<td>7 (revision)</td>
<td>Smoking and alcohol: prevention, intervention and access points</td>
</tr>
<tr>
<td>8 (revision)</td>
<td>Physical activity and stress: prevention, intervention and access points</td>
</tr>
<tr>
<td>9 (revision)</td>
<td>Media and presentation skills</td>
</tr>
</tbody>
</table>

Four Peer Educators were trained in Leicester. Each focused on one of the main religious communities in the area, Hindu, Muslim and Sikh, and, as we wanted to facilitate better access to both gender groups in the Muslim community, we were advised to have two Muslim Peer Educators, one male and one female. As no existing Peer Educator from Project Dil was available for the Sikh community, one was specifically recruited and trained for the ABLE project. She had some prior experience and training in related disease areas and was recommended by one of the community development workers, herself a Sikh.
Examples of the type of venue used included places of worship and meetings of religious organisations, schools and colleges, and health fairs at community centres, as well as the general public arena.

**Table 3: Examples of community groups receiving kidney health information from Peer Educators, according to religion**

Audience size varied from small groups to over two-hundred-and-fifty; approach was either one-to-one or en masse.

<table>
<thead>
<tr>
<th>HINDU</th>
<th>MUSLIM</th>
<th>SIKH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crown Hills Community Centre</td>
<td>Parent and toddler group</td>
<td>Ashfordby Sikh Group</td>
</tr>
<tr>
<td>St Saviour’s Neighbourhood Centre</td>
<td>PYCA (Pakistani Youth &amp; Community Assoc.) ESOL</td>
<td>Clarendon Park Road, Gurdwara</td>
</tr>
<tr>
<td>Shama Women’s Centre</td>
<td>ESOL group</td>
<td>Holy Bones</td>
</tr>
<tr>
<td></td>
<td>St Barnabas Library</td>
<td>Gurdwara</td>
</tr>
<tr>
<td>Gayatri Pariwar</td>
<td>MKA</td>
<td>East Park Gurdwara</td>
</tr>
<tr>
<td>Savera Centre</td>
<td>Sparkenho School</td>
<td>Elderly &amp; youngsters group, Clarendon Park Road</td>
</tr>
<tr>
<td>Yagna Event, Gayatri Pariwar</td>
<td>St Barnabas Poetry group</td>
<td>Vista</td>
</tr>
<tr>
<td>VD</td>
<td>Hussaini Mosque</td>
<td></td>
</tr>
<tr>
<td>Panahghar Shantighar</td>
<td>Mother and toddler group</td>
<td></td>
</tr>
<tr>
<td></td>
<td>St Barnabas Library</td>
<td></td>
</tr>
<tr>
<td>Hindu Temple, St Barnabas Road</td>
<td>Halal lunch club, Age Concern</td>
<td></td>
</tr>
<tr>
<td>Shree Sarvoyda Samaj</td>
<td>Catherine House, mixed Asian elders group</td>
<td></td>
</tr>
<tr>
<td>Jalaram Mandir (Temple)</td>
<td>Khidmah Muslim male event</td>
<td></td>
</tr>
<tr>
<td>Peepul Centre health weekend</td>
<td>Peepul Centre health weekend</td>
<td>Peepul Centre health weekend</td>
</tr>
<tr>
<td>Dinner and dance</td>
<td>Dinner and dance</td>
<td>Dinner and dance</td>
</tr>
<tr>
<td>Shree Prajapati Association health fair event</td>
<td>Khidmah Muslim female event</td>
<td></td>
</tr>
<tr>
<td>Morarji Bapu Katha event</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peepul Centre – Navratri celebrations event</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Members of the public at an ABLE Kidney Health Information Day, with Peer Educator, Sarjit Gill, seated on extreme left.
Summary

The Peer Educator programme enabled several of the key issues raised by the focus groups to be addressed. In particular, they were able to deliver the key messages to a large audience using very graphic displays and materials and do this in a way that recognised the cultural and language background of the target population. Crucially the programme incorporated strategies and practical suggestions for lifestyle change that were relevant to the attendees at events. Overall evaluation suggests that this method of providing information to ethnic communities is very powerful.

It appears from analysis of our pre-intervention qualitative focus-group research that people often prefer this kind of direct approach, which enables them to get health information in their mother tongue and involves the opportunity for discussion. This is not surprising as Peer Educators have the requisite language skills and the natural cultural empathy to engage with these patients and provide the favoured discussion-type forum.

The Hindu Gujarati community benefited most from the programme, as they appeared to be more enthusiastic than the other two communities about taking advantage of the sessions, with level of uptake in the Muslim and the Sikh groups being about the same, but all the Peer Educators reached many individuals with no previous knowledge about CKD and its impact. Between them, they are known to have passed on life-saving messages to over four thousand individuals in Leicester, but the total number of people reached is likely to be several thousand more because we cannot begin to estimate the impact there would be from the sharing and cascading of information to friends, relatives, work colleagues and other contacts – even if this were to have been done by only one direct beneficiary.
Educational materials and campaigns

The educational steering group

It has been recognised that it is particularly important for educational materials to be appropriate for target audiences when cultural and language barriers exist (13). There was also a need for a multidisciplinary team approach, patient and public involvement being a necessary part of the consultative process and as recommended by recent Department of Health initiatives and strategies. The ABLE project established an educational steering group in order to review currently available patient literature and other material in relation to kidney disease and, where necessary, to produce appropriate and accessible educational materials.

The educational steering group consisted of the following:

- a community development worker;
- Peer Educators from Muslim, Sikh and Hindu communities;
- a youth worker;
- a patient with diabetes;
- a patient with diabetes;
- a public health development specialist;
- the ABLE project manager;
- two lead researchers on the project, a GP and a professor of renal medicine.

Meetings were held every 6 to 12 weeks as required, at hospital, community venue or GP’s practice; e-mail and telephone correspondence facilitated communication and decision-making.

A search was conducted for information on kidney disease and its prevention available on the internet, through library services, in health promotion departments at the PCT, from patient support groups, from charities and from personal knowledge. A literature search on the same subjects was conducted by the ABLE research administrator, reviewed by the lead researchers and the project manager and presented to the steering group.

The searches revealed that

- Negligible information was available for access by speakers of languages other than English;
- Information on the kidney was often contained within information for patients with diabetes;
- There was insufficient detail;
- There was not enough variety in type of resources;
- Language was over-formal and not culturally sensitive in terms of accessibility of language and format of presentation.

These findings and those from the focus groups led the steering group to the following recommendations:

- A multilingual DVD should be produced;
- Some written information should be produced;
- A personalised approach should be adopted in the campaign, as in the Peer Educator model.

All campaign materials were assessed using the following criteria:

- Is it kidney focused?
- Is there sufficient information on kidney disease and the impact of co-morbidities diabetes and hypertension?
- Does it give particular emphasis to the high risk of ERF in South Asians and the importance of robust and timely management?
- Is the information culturally sensitive?
- Can it be accessed in a multilingual format?
- Is the language/terminology pitched at an appropriate level?
The group met to discuss findings, establish gaps in current availability and devise a way forward for the development of new materials if these were deemed necessary.

In view of the paucity of educational material currently available it was decided that there was a need for specially developed written and audiovisual materials specifically for the South Asian community. It was decided to produce a DVD as it could be made available in several languages and would then be accessible to a large number of people; this format was also shown by the focus group results to be what the community preferred. Additionally the group decided to produce a simple information card in several languages to be distributed particularly in healthcare settings.

The ABLE DVD: Preventing kidney disease – the silent killer affecting you

An innovative DVD outlines overarching risk factors and uses real life case studies, including one from a member of the steering group who is also a trained diabetes ‘expert patient’. This DVD has been produced to raise awareness of kidney disease in the South Asian population and of how individuals can take action to avert their risk, for example, through lifestyle changes and correct management of their diabetes or high blood pressure and other risk factors.

It provides practical advice as to how to manage risk factors – diet, exercise, screening and monitoring tests; positive health messages as well as real case studies of what can happen if renal failure develops, and a light-hearted interactive component to assess levels of understanding and knowledge gain. The languages available are: Bengali, English, Gujarati, Hindi, Punjabi and Urdu and, working with representatives from these communities within the educational steering group, we have been at pains to make it culturally sensitive and accurate.

During the pre-intervention focus groups, patients told us that they preferred audiovisual materials in the appropriate language for communication regarding health matters, and this resource was developed as part of our intention to tailor the presentation of health information to the target audience. Furthermore, the Centre for Evidence in Ethnicity, Health and Diversity (CEEHD) points to the following evidence: ‘Three major national surveys have collected data in recent years which provide the opportunity to make some estimates of adult language capacity and literacy in the UK. In all cases, these show that among older people, and especially within the population of Bangladeshi origin, there is limited ability either to understand (spoken) English or to read (any language), more especially among women. Even in the ‘middle-age’ group there are significant numbers who cannot be expected to read English (14). Hence the vital need is to ensure that, irrespective of the language, resources other than just written material are available.

The DVD has been welcomed by the Renal Policy Team at the Department of Health and we have recently been awarded further funding from their Section 64 grants scheme in order to share findings from the first phase of ABLE on a national level.

The DVD can help all such patients around the country and not just in the Leicester area, where this DVD was produced as part of the project outputs.

Requests for copies have been received from around the country as well as from overseas. To obtain a copy, please contact kidneyhealth@kidneyresearchuk.org.

DVD Cover. Clips streamed at www.kidneyresearchuk/able
Written information

During the focus groups, participants informed us of the need for some limited written information, their preference being for other types of resources. We believe that patients do need some written information and advice to take away in order to supplement that given by their doctor or practice nurse; especially if they received that information at a time of stress, they are unlikely to have remembered much.

An information card has been produced in a concertina-style format in order to hold a significant amount of information in a readable format; it is the width and length of a business card so that it can be readily stored in a purse or wallet for easy reference as required. There is a lot of information in the card relating to daily lifestyle, e.g. diet, exercise, salt and water intake, correct levels of blood pressure and blood sugar (for those with diabetes) and people may need to refer to the card frequently. So this format has been used instead of a standard size leaflet so that it can be carried around easily and consulted as and when needed. There are also useful telephone numbers and website addresses, allowing the patient/member of the public to access further information.

Again, the educational steering group (with others co-opted) consisting of patients, community and professionals, were instrumental in the development of this resource. We have also kept the language simple, with minimal medical terminology. These cards are available in the following languages: Bengali, English, Gujarati, Hindi, Punjabi and Urdu.

The rationale for good quality health information

From our literature search, it was evident that communication between patients speaking languages other than English and their doctors needed to be improved. This is particularly relevant where patients require education and guidance on self-care and lifestyle change. We also believe that an individual’s ability to look after themselves and be compliant with their treatment (e.g. blood pressure medication; special diet) is more likely if they are better informed. By involving patients and carers in the diagnosis and treatment of their condition, the overall experience is improved and can reduce patient anxiety. We espouse this ethos, which informs the work outlined here.

Health literacy is a major issue for many patients. We hope to have improved some of the skills necessary by providing basic health knowledge in an accessible format that patients can understand and that enables them to communicate verbally with doctors.

We believe that we have produced good quality information, as it is:

• accessible – different languages, novel design, widely available, portable (in the case of the information cards), personal and non-threatening (in the approach of the Peer Educators), the DVD is available at community centers and other organisations;
• usable - answers many questions relating to how people can look after their kidneys (whether they have the main causative conditions, diabetes and high blood pressure, or not); provides details of further sources of help;
• reliable and evidence-based, drawing on the expert advice of general practitioners, individual kidney specialists – The Renal Association – and whole organisations involved in this area – East Midlands Renal Network (www.emrn.org.uk) and Kidney Research UK (www.kidneycure.org.uk). All these resources have been widely distributed and promoted (and in the case of the DVD screened), in community centres, religious organisations and places of worship, businesses, public places, outpatient clinics and GP practices. Formal and informal presentations have been held with groups of all sizes, and health fairs have

An information card has been produced in a concertina style format in order to hold a significant amount of information in a readable format.

It is the width and length of a business card so can be readily stored in a purse or wallet for an easy reference as required. These cards are available in the following languages: Bengali, English, Gujarati, Hindi, Punjabi and Urdu.
been put on, with stands by organisations promoting awareness of related health areas, such as diabetes and coronary heart disease, as well as by Kidney Research UK, order to ensure as far-reaching an effect as possible, so that the maximum number of people benefit and thus communication is improved between them and their doctors.

We believe that knowledge about kidney disease has increased and some change in attitudes and lifestyles has begun. This is a highly significant step forward from the previous position, where these issues were not being addressed at all and so the medium and long term consequence of this intervention is very likely to be a reduction in CKD.

Website and Kidney Health Information Line

As a result of all this community activity the charity has further developed the ABLE pages on its website and the Kidney Health Information Line has been prepared for enquiries. Details of activity in Leicester and links from other sites, such as the East Midlands Renal Network, have been made available on the website. Clips of the DVD have also been streamed onto the website (www.kidneyresearchuk.org/able).

The ABLE Media campaign

There has been widespread and targeted media coverage on all aspects of the ABLE project: local, Asian and mainstream national media have focused on the work, for example on ITN News, BBC Radio 4, the Leicester Mercury newspaper, and BBC Asian Network.

This included the following:

- Clips of the DVD and a piece on the project on ITN News (national news);
- Clips of the DVD and a piece on the project on ITN Central (regional news);
- BBC Radio Leicester – pre and post coverage of DVD Launch;
- BBC Asian Network – post event coverage in Gujarati;
- Leicester Mercury newspaper – interviews and photographer at DVD Launch, with write-up on 26th November 2005. Also other stories covered on two other occasions;
- Article on the project and work of Peer Educators in several Hindu organisations’ newsletters 2006;
- BBC Radio 4 programme on CKD, ABLE and Peer Educators
- Article in Daily Mail and interview with ABLE supporter, actress Nina Wadia;
- Two articles in Gujarat Samachar, Gujarati-language newspaper
- BBC cameraman filming at awareness event targeting the younger generation in April 2006;
- BBC Asian Network covering of awareness event targeting the younger generation in April 2006;
- Sabras Radio advertising awareness event targeting the younger generation in April 2006;
- MATV (Leicester-based popular Asian TV channel) covering key ABLE supporter, Asian pop artist Raghav, and work in Leicester;
- Raaj Radio (Punjabi radio station based in Leicester) – interview about ABLE and issues;
- BBC Asian Network advertising an ABLE health fair event in Leicester in May 2006;
- ITV Central News May 2006;
- BBC East Midlands News May 2006;
- Leicester Mail (Loughborough edition);
- Sunrise Radio (digital Asian radio station with wide coverage and listenership);

The effect of media coverage cannot be quantified but it is likely to be considerable, in the short, medium and long term.

Conclusion

The key educational messages of the ABLE methodology with respect to lifestyle modification and vital management of diabetes and hypertension are entirely applicable to anyone at risk of kidney disease, irrespective of ethnic background. We believe that the innovative and extensive awareness and education achieved during this project will be of enormous benefit in ultimately reducing CKD in all those at risk of this terminal illness.
4 Work with GP practices

Over 90% of interactions between NHS healthcare professionals and patients occur in general practice. The GP practice is therefore uniquely placed both to provide patients with information on prevention of disease and to carry out screening and treatment for early kidney disease. The ABLE project felt it important to engage local practices and to undertake preliminary and pilot work to see how general practices can best support patient education and prevention.

Audit

General practices with a high proportion of South Asian patients (i.e. at least 75% of the practice list) were invited to participate in the project. (Practices were identified as likely to be eligible on the basis of the wards in which they were located using local authority demographic information.) These first audits took place before the renal points were introduced to the Quality and Outcomes Framework (QOF) and before the publication of part two of the Renal National Service Framework (NSF).

Twelve practices (out of 21 who were approached by way of a single written invitation) agreed to participate, and were paired according to practice size. All had the following assessment and intervention:

- Baseline audit of detection and management of risk factors for renal disease (using GP computer database)
- Baseline audit of management of patients with existing renal disease (using GP computer database)

Six of the twelve practices (one in each pair) were randomly selected as the ‘intervention practices’ and these received the following:

- Feedback of audit data (after the first data collection) and an educational session on screening and prevention of renal disease. This combined intervention resulted in a two hour session to the primary health care team.
- Re-audit of the practice 12 months after initial data collection and feedback.

Methodology and results of practice audit and educational meetings

The audit consisted of an EMIS search of practice computer systems using the criteria shown below. The criteria were chosen on the basis of the (then) current Quality and Outcomes Framework (QOF) for general practice and other information it was reasonable to assume the practices to have collected on the basis of the best current evidence (5, 6, 16, 17, 18). The audit was performed at the time of the recruitment of the practices and again after a period of 12 months. Within the first three months of this period the intervention practices received feedback of their first data collection and a educational session on the risk factors for and prevention of renal disease. An unvalidated questionnaire was administered to doctors and nurses in the practices to determine level of knowledge regarding renal disease and its prevention. Unfortunately the return rate was too low for it to be possible to form any firm conclusions (<20%). However it seemed that levels of factual knowledge were good among those who did respond. As an example, a GP, Dr S, from Leicester said, ‘The ABLE project has been an eye opener for me as it helped me to recognise the importance of preventing kidney disease. It’s also highlighted my awareness about the available patient information.’
Table 4: Practice educational meeting on preventing renal disease

1. Renal disease and the South Asian community
2. Risk factors for renal disease
3. Feedback of audit data
4. The ABLE project
5. Issues for the practice

Table 5: The audit data-collection tool

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>% of patients with diabetes with a recorded blood pressure reading in last 15/12</td>
</tr>
<tr>
<td>2</td>
<td>% of diabetes with a recorded microalbuminuria test in the last 15/12</td>
</tr>
<tr>
<td>3</td>
<td>% of patients with diabetes with a record of serum creatinine in the last 15/12</td>
</tr>
<tr>
<td>4</td>
<td>% of patients with diabetes who have proteinuria/microalbuminuria who are treated with an ACE/ARB</td>
</tr>
<tr>
<td>5</td>
<td>% of diabetes patients with BP 145/85 or less</td>
</tr>
<tr>
<td>6</td>
<td>% of patients with hypertension for whom there is a blood pressure recorded in the last 9/12</td>
</tr>
<tr>
<td>7</td>
<td>% of patients with hypertension whose last BP was 150/90 or less</td>
</tr>
<tr>
<td>8</td>
<td>% of patients with hypertension who have a serum creatinine measurement in the last 15/12</td>
</tr>
<tr>
<td>9</td>
<td>% of patients with serum creatinine &gt; 150mmol/L</td>
</tr>
<tr>
<td>10</td>
<td>% of patients with serum creatinine &gt; 150mmol/L referred to a renal specialist</td>
</tr>
<tr>
<td>11</td>
<td>% of patients over the age of 45 who have had a BP recording in the last 5 years</td>
</tr>
<tr>
<td>12</td>
<td>Number of patients with renal calculi/stones</td>
</tr>
</tbody>
</table>

Knowledge questionnaire on renal disease (for doctors and practice nurses)

- What do you feel are the main causes of renal failure?
- Which groups or ethnic groups are at highest risk?
- How do you feel renal disease is best detected?
- Which group of patients do you prioritise for screening?
- Do you have a written policy for screening renal disease?
- Do you have a register for renal disease patients?
- Which patients do you refer for a specialist opinion?
- How many patients with real impairment do you have in your practice?
- What is your target BP for people with renal disease?
- Which drugs would you avoid in renal disease? (List up to three.)
- Are you aware of any guidelines for renal disease?
Table 6: Audit results

<table>
<thead>
<tr>
<th>AUDIT CRITERIA</th>
<th>1st data collection (%)</th>
<th>2nd data collection (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of patients with diabetes with a recorded blood pressure reading in last 15/12</td>
<td>85</td>
<td>92</td>
</tr>
<tr>
<td>% of diabetes with a recorded microalbuminuria test in the last 15/12</td>
<td>56</td>
<td>75</td>
</tr>
<tr>
<td>% of patients with diabetes with a record of serum creatinine in the last 15/12</td>
<td>79</td>
<td>86</td>
</tr>
<tr>
<td>% of patients with diabetes who have proteinuria/microalbuminuria who are treated with ACE/ARB</td>
<td>52</td>
<td>86</td>
</tr>
<tr>
<td>% of diabetes patients with BP 145/85 or less</td>
<td>76</td>
<td>84</td>
</tr>
<tr>
<td>% of patients with hypertension in which there is a blood pressure recorded in the last 9/12</td>
<td>92</td>
<td>96</td>
</tr>
<tr>
<td>% of patients with hypertension whose last BP was 150/90 or less</td>
<td>56</td>
<td>66</td>
</tr>
<tr>
<td>% of patients with hypertension who have a serum creatinine measurement in the last 15/12</td>
<td>82</td>
<td>84</td>
</tr>
<tr>
<td>% of patients with serum creatinine &gt; 150mmol/L</td>
<td>Poorly recorded</td>
<td>Poorly recorded</td>
</tr>
<tr>
<td>% of patients with serum creatinine &gt; 150mmol/L referred to a renal specialist</td>
<td>Not recorded</td>
<td>Not recorded</td>
</tr>
<tr>
<td>% of patients over the age of 45 who have had a BP recording in the last 5 years</td>
<td>83</td>
<td>84</td>
</tr>
<tr>
<td>Number of patients with renal calculi/stones</td>
<td>Poorly recorded</td>
<td>Poorly recorded</td>
</tr>
</tbody>
</table>

More research needs to be done on overall quality-improvement intervention to ensure wider improvement.
Discussion

The audit carried out in the volunteer practices demonstrated that practices are generally doing well in terms of recording information relevant to the QOF, and for most QOF parameters were scoring highly. The audit did not seem to affect this performance whether or not the practice received feedback on its audit performance and whether or not it had a practice education session. However, for non-QOF items (such as % of patients with serum creatinine above 150 mmol/L or number of patients with renal calculi) recording was generally poor. This probably demonstrates the influence of QOF (which has associated performance-related income for the practice) on recording of data and quality assurance activity in general practice.

Other possible reasons for the apparent poor impact of the feedback and educational session for practices was that this was a very limited intervention with no sustained support for quality improvement work. It may be that follow-up of the educational session with further support for the practice might have had a greater impact on performance. The practices did not receive any support in change management or in quality assurance techniques. Again, such interventions might have had greater impact but require further research in the context of improving prevention and management of renal disease.

Part way through the audit the local pathology service decided to provide estimated glomerular filtration rate (eGFR) results to general practices. It is likely that this led to many practices deciding that this new service, which provided improved information regarding renal impairment, should supersede any other plans they may have had regarding practice recording of information.

The more recent introduction of CKD grading (modified QOF for 2006) (19) in primary care may also have had a positive effect in the management of renal impairment in primary care but this needs further evaluation.

In summary our limited intervention with practices has demonstrated that practices need to improve some aspects of renal disease prevention and management and that the General Practice Quality and Outcomes Framework has been useful in improving quality. However more research needs to be done on overall quality-improvement intervention to ensure wider improvement, particularly in parameters not addressed by performance-related income.
5 Evaluation of the impact of the project

Action research and community action projects are not always easy to evaluate. Some of the outcomes desired are not apparent for many years and often are difficult to interpret due to other social and societal changes.

The Leicester ABLE project was evaluated in a number of ways: individuals who attended ABLE education events were invited to ‘post-intervention’ focus groups, simple feedback was elicited at events and questionnaires were also administered to attendees at some health fairs. We also report case studies of individuals who have reported significant lifestyle change as a result of the project.

Post-intervention focus groups

Aim
The aim of the post-intervention focus groups was to obtain qualitative data to assess the impact of the ABLE educational interventions in the South Asian communities of Leicester.

Methods
Three post-intervention groups were held, with individuals who attended ABLE project events being contacted from registers of attendees. A letter was sent inviting participation in a focus group and those expressing an interest were contacted with further information. Those who eventually participated later completed consent forms. The composition of the groups is described below. The groups were held between July 2006 and August 2006 at either the East Leicester Medical Practice or a community venue. The focus groups were facilitated by two members of the research team, including NJ and a multilingual researcher.

The topic guides that had been used in the initial baseline focus groups were used; however attendees were also asked to comment on the education events they had attended. An open and facilitative style of questioning was used in order to promote open discussion.

Sessions commenced with introductions and a brief explanation of the study. Participants were asked for an agreement on the language to be used during the focus group. Each session lasted for about 60 minutes and was audio-taped and then translated and transcribed by the multilingual researcher. A small selection of tapes was back-translated by a second researcher to ensure accuracy of the translation process.

The data was first analysed independently by two researchers (AF, NJ). Themes were identified and the researchers met to agree the therapeutic framework. Detailed manual coding was then undertaken independently by the two researchers.

The data was then checked using major themes and then divided into sub-themes.

The researchers discussed their individual data and explored core concepts and models to explain the findings. In particular, the themes generated by these focus groups were considered in the light of the findings and key themes of the initial focus group study.

Table 7: Post-intervention focus groups

<table>
<thead>
<tr>
<th>Group</th>
<th>Date</th>
<th>Type of Group</th>
<th>Venue</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1</td>
<td>July 2006</td>
<td>Male diabetes group</td>
<td>East Leicester Medical Practice</td>
<td>4 participants</td>
</tr>
<tr>
<td>Group 2</td>
<td>August 2006</td>
<td>Female community group</td>
<td>Peepul Centre</td>
<td>5 participants</td>
</tr>
<tr>
<td>Group 3</td>
<td>August 2006</td>
<td>Male community group</td>
<td>Peepul Centre</td>
<td>7 participants</td>
</tr>
</tbody>
</table>
Results

Knowledge
Participants in the educational activity in general made a number of comments demonstrating awareness of some of the causes of kidney disease.

DN [interviewer] ‘Have any of you had kidney health information from anywhere … like from doctors, nurses, health fairs?’

SG: ‘Yes… yes … this ABLE programme, I saw the video … Now I know a little bit.’

‘Blood pressure and sugar increases your risk.’

‘If your general health is not good it has an effect on the kidneys; sugar levels and blood pressure has an effect on the kidneys. That is my understanding.’

Participants also seemed to have good understanding of some of the things that help prevent kidney disease.

‘Drink plenty of water, cut down on sugary foods’

‘Kebabs, somosas, bhajis, we need to encourage children and adults to cut them down.’

Some participants (in contrast to people in the initial focus groups) also seem to have an idea of how kidney disease is detected:

‘I think kidney disease is picked up with a blood and urine test.’

A response to the question ‘Do you think you have more knowledge on kidney disease compared to 6 months ago?’

‘Oh yes … very much’ – with the rest of the group agreeing with this sentiment.

Educational materials
The focus group participants had been exposed to some elements of the ABLE programme. Comments on the educational materials and methods used included:

‘We think the work of ABLE has been tremendous, not only because of the event at Prajapati but I have heard people talk about it, and found it so useful. If there were more events … it would be useful.’

‘I was looking at the DVD … the demonstration of the cooking … she made it look so appetising … I thought, I can do that!’

‘Yes the DVD is good because other family members are able to get the information; it’s just like watching a film.’

‘I watched the DVD, I didn’t know much before but now I know what a kidney is and what it does. I know a bit more.’

Mrs H M, a community member who helped organise a health fair in April 2006, said:

‘I think Purnima (a Peer Educator) was good…the language she used…quite useful talking in Gujarati. I got a lot of positive feedback…that people actually understood more…because the information was relayed in the language they spoke. I think it’s important to continue to do that.…because you’ll be reaching the public that you normally wouldn’t reach.’

Chanda did an exercise session - it was a great hit, every body talked about the exercise young and old.
All I can say is give the public more. On a Sunday we can get 7 to 800 people to come the community who want to learn.’

Lifestyle changes
Many participants reported making attempts at lifestyle change:

DN [Interviewer]: ‘But... are you keeping an eye on your diet?’

Mrs H M: ‘Absolutely... particularly since we had the kidney health day. I tend to walk a lot. I walk part way to work... before I used to catch the bus. I’ve cut down literally on all the fried foods at home and I think it’s generally helped everybody... and eat a lot more salady stuff, use wholemeal chapatti flour.’ (Female community focus group July 2006)

‘I don’t take sugar; ... even salt, when cooking I only add a little.’

‘I try and control my food.’

‘I make sure I do not add sugar to my food and have stopped putting butter on chapattis.’

‘Eat lots and lots of salads.’

‘In my house we now boil vegetables.’

‘I try to control my food ... have cut down on fried ... and less sugar.’

‘We now eat lots of fruit and salads. And exercise as well, we walk a lot ... even try not to catch the bus to town.’

‘My family is taking more exercise. Now the evenings are warmer we go cycling for 30 to 40 minutes in the park - it’s better than watching TV.’

Fatalistic attitudes
A few comments gave cause for hope:

‘Some of the older generation found the information very useful.’

‘You feel there is a need to adjust to prevent this disease.’

‘Mum now walks to the temple.’

‘The older generation were saying... we did not know you can exercise whilst sitting down, it didn’t enter their minds; that was brilliant.’

Summary
The post-intervention focus groups in general demonstrated a very positive response to the educational activities of the ABLE project; in particular, the cultural-specific information provided in appropriate languages was well received. The practical advice given (e.g. on cooking and exercise) was particularly welcome and suggests that many of the perceived extra barriers in the South Asian communities (e.g. fatalism) could be overcome by appropriate education and advice that has relevance to the particular audience. A key result appears to be that some people are beginning to make positive lifestyle changes to reduce the risk to them and their families of the related co-morbidities, the main causes of ERF. This, the difference between health promotion theory and practice is often a difficult gap to bridge.
Case Studies of individuals who attended educational events

Shree Prajapati Association (SPA) Health Fair, May 2006

Evaluation

186 people attended, of whom 85 were male and 101 were female. At the end of the event the participants were asked to complete a short evaluation form, which 87 people completed (37 male and 50 female) – an excellent response rate of 47%. A majority of participants were of the Hindu religion.

The overall outcome of this event was that the majority of the participants had found the event very helpful and informative, many saying that they would make an effort to improve their lifestyle to a healthier one. One woman in the 31 to 45 age band found the event particularly informative: ‘I think there should be more health events during the year for every age. I found this event very educational and interesting’. She also expressed her intention to improve her health, saying it was important ‘to make sure you eat healthy, drink plenty of water, walk regularly, exercise and most of all keep a regular check on your diabetic levels, blood pressure level, kidney function level and cholesterol at the doctors’.

The evaluation forms showed that the majority of individuals in the upper age bands felt there was a need to change and improve their lifestyle, either by doing regular exercise or by having a healthy diet; as one man in the 46 to 60 age band put it, ‘From now on I have decided to go for walk every day for 45 minutes and do mild exercise’.

Nearly all the participants seemed to feel that exercise plays a vital role in having a healthy lifestyle. Within the 60+ age band one woman said she would be doing ‘sitting exercise because of a mobility problem’ and a man said he had resolved ‘to eat less salt, to do exercise regularly, to visit the GP regularly’.

Overall, we had a much greater attendance than expected because of competing events on at the same time. All the organisers and participants felt it was a very worthwhile and successful event, to be repeated again.
Impact of the Peer Educators’ work

Purnima Chavda, Hindu
Peer Educator

Why I became a Peer Educator:
A friend had kidney disease and was on dialysis so I was interested; I've generally been interested in health after working as a GP’s receptionist. I was used to helping people and enjoyed it, feeling that there was a particular need to address health issues in the Asian community.

'I was quite seriously ill at one time and just wanted to give something back.'

Purnima's case studies

A regular venue, the Savera Centre – several people have commented on making lifestyle modifications since hearing Purnima’s session. They say that they are drinking more water and eating better. They are aware of what ‘5 a day’ constitutes and can give examples of how these can be taken; they are using less oil in their cooking. They are also exercising more – and finding benefits in changing their lifestyle.

One of Purnima’s case studies is Mr N, who attends Vista, an organisation for the blind and partially sighted where she also volunteers. Mr N is in his 40s and lives on his own. He is known to have hypertension and his doctor has prescribed medication for this. He admitted that he tended to omit his medication when he felt he ‘didn’t need it’. Purnima advised him to take his medication as prescribed and the explained its importance for his eyesight and his kidneys. She feels he understands this now and is more compliant.

Purnima’s experience of the sessions and feedback in the field

• She recognises signs of low blood sugar level from her training with the ABLE course and has been able to assist the clients of the organisations where she helps on a volunteer basis;
• her confidence has increased;
• she enjoys delivering kidney health promotion to all groups – e.g., SPA, Savera, Peepul Centre;
• the fact that her verbal and written feedback has been excellent makes Purnima feel that she is making a difference and this is very gratifying;
• although change is slow it is happening, which is very encouraging – even the community centres are making changes, such as serving healthier food.

‘I was quite seriously ill at one time and just wanted to give something back.’
Sarjit Gill, Sikh Peer Educator

Why I became a Peer Educator:

‘I’ve always been involved with and had an interest in health in some way. I felt there was a particular need for the Asian community, and wanted to help them.’

‘I really enjoyed the training, learnt a lot from all the lecturers, especially the patients.’

Sarjit’s experience of the sessions and feedback in the field:

‘I’ve felt really good delivering the sessions. The audiences have thought I was really helpful. They know me and they know I’ll tell them the truth and they trust me. I felt they were very keen to have the knowledge.’

Verbal and written feedback from sessions has been excellent, which makes Sarjit feel that she is making a difference and this is very rewarding.

Saeed, a Muslim Peer Educator

Saeed’s case study

‘A gentleman had been feeling generally unwell and after I spoke, he visited his GP and was found to have kidney disease!’

Summary of the Impact of the Peer Educators’ work

Between them the four Peer Educators were responsible for providing over 4,000 individuals with information and general advice. The people reached were in some otherwise ‘hard-to-reach’ communities and there were reports of lifestyle modification actually taking place.

Impact of the educational materials produced

The DVD

- has been welcomed by patients, the communities, primary and secondary health professionals and the DH;
- around 200 copies have been screened and circulated;
- requests have been received from other parts of the UK and abroad;
- has been the subject of numerous positive comments, mostly verbal but some written.

Concertina information cards

- produced in five South Asian languages and English;
- 4,000 copies each of English and Gujarati distributed and 2,000 of each of the other languages.

Media

The project has had very wide coverage:

- local mainstream;
- South Asian;
- national;
- numerous examples of the project being given exposure at various points (see above).
6 Conclusions and lessons for the future

The Leicester ABLE project has been a unique initiative to help identify and implement strategies to address the problem of renal disease in South Asians. Whilst the underlying genetic factors that may lead to increased risk are difficult to address, it is now established that lifestyle change and risk-factor management are the key to reducing or even eliminating the increased risk to South Asians \(^{(1, 2, 3, 5)}\).

The National Service Framework (NSF) for Renal Services, part two \(^{(2)}\), states that ‘Lifestyle changes that reduce the risk of diabetes, cardiovascular disease and hypertension by improving diet, cutting salt intake, reducing obesity, ceasing smoking, moderating alcohol consumption and increasing physical activity are also likely to reduce CKD. Similarly, the strict control of blood pressure and blood glucose…can reduce the development of CKD’.

Raising community awareness of the importance of positive lifestyle change and increased access to risk-factor assessment are therefore fundamental to successful prevention of renal disease. However, in itself this is not enough; we need to take health promotion further and ensure that people are actually empowered to change lifestyle risk factors and healthcare professionals are trained and supported (e.g., by IT systems) to help identify and treat the known risk factors for renal disease.

The ABLE project has attempted to address these fundamentals of health promotion. Through qualitative research the project has demonstrated that knowledge of renal disease is generally poor amongst South Asians in Leicester, and many members of this community do not feel empowered to change their lifestyle even when they know this is necessary. We have demonstrated that these attitudes are based on misconceptions of what is required: a lack of knowledge of simple methods and a failure to understand that small changes (for example in diet and exercise) can lead to significant improvements. Such an approach has already been pioneered in CHD prevention \(^{(7)}\) and in diabetes management \(^{(20)}\). Now ABLE has demonstrated its potential in the context of renal disease.

The project has developed the recommended type of education materials in a way that is relevant to South Asians using methods of review and consultation that provide important lessons for those undertaking this type of project in other areas. The approach was taken in order to make provision for education materials that were not available before but were shown to be needed by the evidence of the pre-intervention focus groups. The evidence both from focus groups and individuals on the value of such materials – in particular the DVD – has been very encouraging and supportive of the approach taken by the project.

The use of Peer Educators has also been shown to be an approach favoured by the community. The educators were particularly successful in overcoming the language and cultural barriers that many healthcare professionals face in delivering the necessary messages and advice.

The project confirmed that people in the South Asian community are keen to help themselves; they wish to know more about health issues and, with support, can overcome what many have considered fatalistic attitudes to health problems.

ABLE, however, has only started to address the key issues in renal health promotion in ethnic minorities. The difficulties perceived by South Asians in accessing health services and communicating with health professionals are an issue identified by ABLE but not addressed in

Raising community awareness of the importance of positive lifestyle change and increased access to risk-factor assessment are therefore fundamental to successful prevention of renal disease.
any detail, although other studies have touched on it (21). Further investigation is required on how to improve access by South Asians to health services.

In a limited way the project identified some of the issues with respect to improving renal disease detection and prevention in primary care. However further work needs to be done, particularly with respect to quality-improvement methodology in this area. Similarly, the successful elements of ABLE, such as production of educational materials and community-specific health promotion, need to become part of the mainstream work of the NHS, and not just delivered by charities or by short term projects.

**Limitations/Weaknesses**

Ethics approval – there were very significant delays in obtaining this because of new and more rigorous guidelines at the time (2004-5). An honorary contract for one of the lead researchers, Neerja Jain (project manager) was also delayed and a protracted process. This resulted in the project being delayed by over nine months.

NSF and QOF - during the project’s lifetime, in February 2005, part two of the Department of Health’s Renal NSF (National Service Framework) came into being, focusing on early detection and prevention of CKD. In December of the same year 27 renal points were introduced in the GP’s new contract Quality and Outcomes Framework (QOF), which provides financial incentives for achieving targets. These events are likely to have had some effect on our educational interventions.

Sustained support for primary care and further research on the most appropriate quality-improvement methodology for primary care is required. So, the latest CKD project is to be welcomed:

**Quality improvements in CKD: A significant challenge for primary care**

Kidney Research UK, in collaboration with University Hospital Leicester and St George’s Hospital Trust, have developed a unique, £1.2 million partnership with support from the Health Foundation and Edith Murphy Foundation. Two complementary, three-year community research studies, commencing in summer 2007, will test and implement a range of quality improvements (QIs) for individuals with CKD with one project specifically focussing on those patients also having diabetes. The overall objective is to identify a quality improvement (QI) programme showing the best improvement in the quality of care and ultimately, to influence the next round of QOF in 2008.

**Circumstances that favoured the project**

A suitable infrastructure was in place, for example, in the Peer Educators trained in the primary prevention of coronary heart disease who were already established; this precedent enabled the recruitment of the Peer Educator required for the Sikh community. Leicester is well equipped to receive community-based health initiatives with collaborative work between health professionals and the local communities already underway.

**Summary of latest publications and dissemination: (conferences and print)**

- EDTNA (European Dialysis and Transplant Nurses Association) conferences, September and November 2006
- Royal College of Nursing (RCN) Nephrology Forum conference, October 2006
- British Journal of Renal Medicine (BJRM) – pending
- Pulse – pending
- GP – pending
- Doctor – pending
- Gujarat Samachar Healthcare Magazine, March 2007 (popular and widely distributed South Asian UK publication)
- Department of Health (Renal) Annual Report, April 2007
- British Renal Society (BRS) conference, June 2007

**Final words**

Despite significant delays with the formal start of the project due to the need to wait for ethical approval, an immense amount of work has been achieved. The objectives of the project and the resulting outputs and outcomes achieved far exceeded all expectation, especially given the total funding of £90,000 over three years. This compares extremely favourably with similarly funded projects. The principal investigators have had considerable experience in developing and delivering research projects. Dr Azhar Farooqi, OBE, in particular, has been very active with community-based primary led health research and he is surprised and delighted with the achievements from this ABLE project, especially given the level of funding. It is felt that the project achieved a great deal.
7 Acknowledgements

- Local steering group (patient, community and health professional representatives)
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- Kidney Research UK Operational Group
- East Midlands Renal Network
- The Department of Health
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