

Heart Improvement Programme

A pilot study using the Discovery Interview Process, with the Vietnamese and Punjabi population of Greenwich, to facilitate patient inspired improvements

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Introduction

This report presents the findings of a six month pilot study investigating the feasibility of using the Discovery Interview technique among patients not fluent in English¹ with coronary heart disease (CHD). Developed by the CHD Collaborative, now the NHS Heart Improvement Programme, the Discovery Interview technique has thus far only been applied to fluent English speakers. A sample of 12 patients who were not fluent in English from the Punjabi community living in the Greenwich area were recruited to take part in the pilot.

The original intention had been to also carry out interviews with the Vietnamese community but methodological problems meant that these interviews did not take place (see [Section three - Research Design](#) for further explanation). The research commissioned by the CHD Collaborative, a national programme now known as the NHS Heart Improvement Programme², was carried out through the South East London Cardiac Network³ (formerly the South East London CHD Collaborative). Patients were recruited to the study from Queen Elizabeth Hospital NHS Trust in Woolwich, three purposefully selected local general practices and from the community cluster clinic within Greenwich Primary Care Trust. The fieldwork for the research was carried out between June and July 2005. A project lead from the national CHD Collaborative team advised and supported the researcher, interviewer and members of the South East London Cardiac Network on practical, intellectual and ethical issues that may have arisen during the study. Members from the South East London Cardiac Network assisted in the project set up and recruitment of patients.

¹The Discovery Interview Process was developed by the Coronary Heart Disease Collaborative in 2001, and is now used as a patient involvement and service improvement tool by the 32 cardiac networks across England. There has also been substantial interest from the wider community in the application of the technique in a number of health domains outside of the cardiac arena e.g. as a feasibility study across three care groups in mental health. Further information about Discovery Interviews can be found in *A guide to using Discovery Interviews to improve care* (2004).

²The NHS Heart Improvement Programme builds on the successful work of its predecessors, the Coronary Heart Disease Collaborative established in 2000, one of the first major NHS modernisation initiatives working across England to accelerate the achievement of the National Service Framework for Coronary Heart Disease. Twenty eight local collaborative teams covered every health economy in England and are now integrated within the structure of cardiac networks.

³At the time of this research the local CHD Collaborative service improvement teams were in a process of transformation to become integrated within the cardiac network. For the sake of consistency they are referred to as cardiac networks throughout this document.

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This report is organised into the following sections and should be read in conjunction with the [CHD Collaborative Evaluation of Discovery Interviews \(2005\)](#):

- **Section one** presents the background to CHD and ethnicity with specific reference to the Vietnamese and Punjabi community at both a national and local level.
- **Section two** presents the importance of ideas of fluency on language and communication.
- **Section three** discusses the research design. Throughout section three a number of [effective practice points](#) are highlighted to outline the learning from this study.
- **Section four** presents a discussion on the use of the Discovery Interview process with a sample of Punjabi patients who were not fluent in English.

This research pilot has been significantly delayed due to circumstances beyond the control of the sponsors which has also resulted in a delay in the full interview transcripts being made available to the South East London Cardiac Network. The intention was to have completed the project within the lifetime of the CHD Collaborative Programmes but as the work over ran it became caught up within the development of the Collaborative Programmes into the Heart Improvement Programme and cardiac networks.

SECTION 1: CHD and Ethnicity

1.1 Background

Government publications have left little doubt that services should be planned with the patient at the centre of care (Department of Health 1997, Department of Health 1998a, Department of Health 1998b, Department of Health 1999, Department of Health 2005a, Department of Health 2005b). The Department of Health set out the agenda for coronary heart disease in the national service framework, (Department of Health 2000) which reported that CHD is one of the biggest killers in the UK. 1.4 million people suffer from angina, 300,000 people have heart attacks each year and approximately 110,000 die each year of heart problems. Greenwich, in South East London, has a population of 214,403 people and deaths from heart disease are higher than the national average for England (Office of National Statistics). It acknowledges that the effects of heart disease are unequal. It is well documented that ethnic minorities suffer marginalisation and exclusion within mainstream health services due to poor socio-economic status, institutional racism, knowledge of and access to healthcare services and poor communication, including language difficulties (Madood et al. 1997b, Nazroo 1997, Balarajan 1991, Atkin et al. 1989). They also suffer marginalisation and exclusion due to limitations of the health services itself, for example, stereotyping of ethnic minority cultural and religious beliefs (Atkin 2006, Randhawa et al. 2006). This has a number of important implications for the delivery of services and securing positive healthcare outcomes for ethnic minority communities. Ethnic minority patients therefore need to be central to any discussion of appropriate and equal access to service provision. The NSF for coronary heart disease confirmed the value of involving 'patients, users and carers [for their] unique and indispensable perspectives' (Department of Health 2000).

The Kennedy Report of the Bristol Royal Infirmary Inquiry specifically recommended that the NHS Modernisation Agency should

'advise the NHS on how to achieve the widest possible involvement of patients and the public in the NHS at a local level'(Department of Health 2001b). The CHD Collaborative was firmly set within the NHS Modernisation Agency and was committed to incorporating the patient voice into service planning. The CHD Collaborative was made up of 28 programmes, broadly based around each health authority with the aim of facilitating patient-centred service developments in cardiac care in the NHS. The population profile of many of the programmes was characterised by a diverse mix of communities, cultures, religious and faith groups.

As a percentage of the UK population, ethnic minorities have grown in the last 40 years. Currently they make up 7% of the total population and this figure is likely to increase over time given the more youthful profile of ethnic minorities. However, in some urban areas the numbers are significantly higher. It is estimated that half of the populations of London, Leicester and Birmingham will, in the next few years, be of ethnic minority heritage if current trends continue. South Asians represent the largest group among Britain's ethnic minorities (Office of National Statistics 2001). An increasing number of South Asians have been born and socialised in Britain. The South Asian community who have migrated to Britain comprise mainly of Indians, Pakistanis and Bangladeshis.

An NHS report on heart disease suggested that the South Asian population were 50% more likely to die prematurely from coronary heart disease than the general population and that the death rate was 46% higher for men and 51% higher for women (Department of Health 2004). Research has indicated that a number of factors may play a part in the high incidence of CHD among the South Asian group. A study by Lowy et al (1991) found that, despite similar patterns of disease between the Asian and white sample, coronary artery disease was more severe amongst the Asian sample. Whilst they acknowledge different risk factors related to

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ethnic and cultural differences, e.g. diet, they concluded that differences in incidence may be due to delays in diagnosis. Delays in diagnosis resulted in patients presenting at advanced stages at diagnosis and therefore also having poorer survival rates. Other differences have been attributed to conditions related with CHD, such as metabolic disorders associated with insulin resistance and central obesity amongst South Asians (Forouhi et al. 2006, Kooner et al. 2003). Lifestyle has also been identified as a contributory factor to rates of CHD among the South Asian population, e.g. smoking and alcohol. Bhopal (2003) highlighted a paradox that exists within the South Asian community as high rates of CHD exist despite the lower prevalence of smoking and other risk factors.

Research to date suggests that South Asian patients have limited knowledge of services and the interaction with health professionals varies compared to white patients due to cultural and linguistic differences, e.g. limited language support and information (Ali et al. 2006b, Jacobs et al. 2001). A study by Farooqi et al (2000) identified barriers to improving lifestyle with respect to CHD as lack of information about diet (how to cook traditional Indian food more healthily) and exercise (women-only exercise facilities). Stress directly related to ethnic minority status and language was also identified as a barrier to accessing health services (Farooqi et al. 2000).

Problems of access to services are further exacerbated as a result of cultural stereotyping. For example, levels of smoking are reported to be lower among South Asian women but this does not necessarily mean that they do not smoke so they should be offered appropriate services. South Asian patients' own awareness of health issues and beliefs also affect their take up of services (Department of Health 2004, Bhopal 2003). Poverty, stress and racism are also being recognised as contributory factors in CHD for the South Asian population (Williams et al. 2003, Farooqi et al. 2000).

The South Asian community is made up of several national groupings - Indians, Pakistanis

and Bangladeshis. These national groupings can be further divided into various smaller national and ethnic groupings, e.g. Bengalis, Gujaratis and Punjabis etc. The statistics available on CHD are presented by national origin rather than regional and/or linguistic identifiers. They show that the South Asian group as a whole suffers disproportionate rates of CHD and has higher rates of premature mortality from CHD when compared to the UK population as a whole. CHD varies between the South Asian sub groups based on differences in risk factors, e.g. smoking, diet and exercise, levels of blood pressure, high cholesterol and genetic factors (Ahmad et al. 1989, McKeigue et al. 1994).

1.2 The Punjabi Community

The Punjabis form one of the largest groups within the South Asian population of Britain. Punjabis came from Punjab and surrounding areas. Punjab literally means land of rivers and most of the Punjab is an alluvial plain with mountains to the North. It is a rich agricultural land due to the natural river systems which make irrigation possible. The Punjab came under British rule during Imperial expansion in the late nineteenth century and in 1947 (the end of colonial rule in India) the Punjab was split between Pakistan and India.

At Partition many Punjabis were encouraged by the British to settle in the 'canal colonies' in Western Punjab which had been developed for the Muslim and Sikh peasantry during colonial rule. There was already a long tradition of Punjabi migration but the partition of Punjab between Pakistan and India in 1947 resulted in pressure on the land resources. Thus the main impetus for migration from the Punjab in the 1950s was the dislocation and the associated shortage of work in a post partition Punjab. Punjabis arrived in the UK as part of general post colonial migration from South Asia. They settled in major conurbations, finding employment in the textile mills in North England or in the service sector. The Punjabi community is normally identified by its religious and ethnic designations rather than a linguistic one, for example, Sikhs from Indian Punjab and Muslims from Pakistani Punjab.

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1.3 The Vietnamese Community

In contrast, the Vietnamese community is one of the smallest ethnic groups in the country. Over 27,000 Vietnamese people are estimated to live in Britain and more than half live in the London area (The Vietnam News 1999). Early Vietnamese migrants arrived in the 1880s. They worked for the shipping companies and were fleeing cramped conditions and settled in the East End of London. The majority of the Vietnamese however settled in Britain following the fall of Saigon in 1975. The unification of North and South Vietnam following the victory of Hanoi led to many people from South Vietnam, including Chinese minorities, to flee the country as part of 'the boat people refugees'. The United States sought its allies help in settling many of these groups. Nearly 10,000 refugees were accepted into Britain and Europe under the terms of the 1979 meeting in Geneva (the Orderly Departure Programme). Vietnamese refugees were dispersed across Europe from Hong Kong.

The Vietnamese community does not form part of a larger cultural cluster in the same way as the South Asian community. Partly this is a reflection of the different historical and political traditions prevailing in East Asia and partly it is due to the way that the Vietnamese entered the UK, which was fairly specific to them. Unlike South Asians (and Caribbean's) who had long historical associations with Britain and whose relationship with the UK has a direct post colonial dimension to it, traditionally the Vietnamese have been part of the French Empire and had a Franco-phone and subsequently American orientation. Hence the Vietnamese do not share with South Asians either the timing, reason or prior history of associations and networks which brought them to these islands.

This study focused on the Punjabi and Vietnamese population in Greenwich, South East London to identify the needs and concerns of ethnic minority patients with CHD. The Punjabi and Vietnamese groups were selected for this study as they form the largest group of ethnic minorities in Greenwich where one in five residents is from the ethnic minorities (Office of National Statistics 2001). The choice of Punjabis and Vietnamese would appear odd since one is an ethno-national (Vietnamese) group while the other is rather complicated. Punjabis could be split using religious criteria (Muslim, Sikh and Hindu) national criteria (Pakistani and Indian), or linguistic criteria (Siraiki, Pahari, Lahnda). So while the global population of Vietnamese is probably around 80 million, the population of Punjabis is over 100 million, however this population is divided in a variety of polities, cultures, languages (dialects) and religions. Thus this is a study of contrasts since the Punjabi and the Vietnamese experience was similar at a superficial level because they belong to the wider ethnic minorities of the UK and they live in Greenwich, but they are distinct at many other levels of experience.

Greenwich was chosen as the research site because, as well as the local demographics explained above, the South East London Cardiac Network had established links into the Greenwich health economy through the local health services in both primary and secondary care. It was anticipated that these links would ease access to the local community, set up recruitment processes, and support the fieldwork and project administration. The South East London Cardiac Network also had a history of using Discovery Interviews to improve services for CHD patients and their carers and thus a pilot study using the Discovery Interview process with Punjabi and Vietnamese CHD patients was well placed under the auspices of the South East London Cardiac Network.

SECTION 2: Language and Communication

Effective communication between patient and health professionals is a necessary ingredient in the provision of high quality care. Effective communication depends on both the content of what is to be communicated and the context in which the communication takes place. It is possible to consider five main barriers to effective communication (Quill 1995). These barriers can include the following:

1. environmental factors - the environment in which the consultation takes place
2. physical barriers - whether the patient is physically able to communicate effectively or is being affected by pain or fatigue or is disabled
3. psychological - including both the personality of the patient and the ability of the physician to adapt to the personality of the patient
4. socio-cultural - including the involvement of economic, linguistic and sartorial
5. transactional factors due to the expectations and exchanges that go on within the consultation process.

With the possible exception of physical barriers, all other barriers are likely to be heavily influenced by ethnicity. A study by Naqvi looking at the access to primary health care for South Asian cardiovascular disease patients highlighted that health professionals identified communication (a patient's ability to speak and/or understand English) as the most significant barrier affecting access to the relevant health care (Naqvi 2003).

At the heart of issues of ethnicity, are assumptions about cultural differences. This is in keeping with the way in which biologically determined ideas of race have given way to notions of culturally derived ethnicity (Hall 1992). A lot of this material is based on extrapolating from culturally specific perceptions of ethnic minorities and then applying these to the context of the health care setting. This includes, for example, assumptions about Asian women and their

preference to see a female doctor or their inability to talk about intimate material. Take for instance the research carried out by Ahmad, Kernohan and Baker (1989) which looked at patients' choice of general practitioner. They found that sharing language and culture with the GP was more important in their choice than the sex of the doctor. This has important implications for any Discovery Interview process with ethnic minority patients in which attempts to get information and guidance from patients regarding patients' experience of health care means engaging with some of the difficulties associated with conducting effective communication. Apart from the ethnic/cultural factors, another issue arises when the patients who are part of the Discovery Interview process do not speak English with sufficient or any fluency. Lack of fluency in English is often distressing for some ethnic minority patients when accessing relevant health services as they are unable to report their history, explain their symptoms or understand the medical regime prescribed to them (Ali et al. 2006b). In an edition of 'Cardiac Care Update', Watkins (2003) is quoted as suggesting that in one third of London homes, English is not the first language and overall nearly 300 different languages are spoken all over London. He suggests that in 14% of these homes the South Asian languages of Bengali, Punjabi, Gujarati, Hindi or Urdu are the first language which leaves considerable room for misunderstandings arising from poor communication between patients and health professionals. There is an added problem where some dialects are spoken but not written, e.g. Syhleti, which has implications for providing accessible and culturally sensitive information (see [Section 3.2.2](#) for methods utilised in this study).

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Communication between patients and professionals has been largely through the medium of patient satisfaction surveys (Cleary et al. 1991, Charles et al. 1994, Bruster et al. 1994, Ali 2003). Patients who lack fluency in English are likely to find it difficult to access relevant services because of their difficulty in communicating and thus likely to have a lower level of patient satisfaction. A vicious circle emerges in relation to such patients whose difficulty in communicating leads to being marginalised from healthcare provisions, which then reinforces that marginalisation by their experience of poor health care outcomes.

The Discovery Interview process, which is reliant on patients being able to articulate their experiences, needs to cope with a situation in which its interviewees do not command English. This absence of English speakers requires the intervention of translators either in the form of multilingual interviewers or the assistance of professional interpreters. The first option seems to be better than the second, its main difficulty arising from the problem of getting interviewers with the requisite language skill. The difficulty with the second option is that interpreting for the Discovery Interview process is a specialised activity and not necessarily one that general interpreting skills would be adequate for (see [Section 3.2.4](#) for discussion on this point). The meaning of normal conversation also comes from non verbal communication. Non verbal communication is often likely to be lost when there is a great cultural distance between interviewer, interviewee and/or interpreter. In addition to non verbal communication there are also para-verbal aspects of communication. These refer to the culturally embedded conventions of how speech is conducted reflecting age, gender and class. To understand the para-verbal requires not only fluency with the content of the language but literacy in its cultural conventions. The reliance on

professional interpreters means that the interviewer is once removed from his or her interviewee, further complicating the Discovery Interview process.

Any study attempting to use the Discovery Interview process with non English speaking ethnic minority patients⁴ needs to be cognisant of the difficulties of the communication process in these settings. Without this awareness, the Discovery Interview process may not be able to deliver the kind of information which healthcare practitioners may be able to use effectively and thus the experience of non English speaking patients from ethnic minority communities may remain outside the remit of the patient experiences that are used to design and test healthcare provision packages in CHD. In keeping with the aims of the NSF on CHD, it is essential that the needs of the Punjabi and Vietnamese community CHD are heard along with those of other minority ethnic groups.

⁴ In this report we use non English speakers and people not fluent in English interchangeably.

SECTION 3: The Research Design

3.1 Aims and objectives

The aim of this pilot research study was to target Punjabi and Vietnamese CHD patients and test the extent to which the Discovery Interview process is transferable to individuals not fluent in English. The Discovery Interview process offers the possibility of ethnic minority voices to be heard. The following objectives were explored to meet this aim:

- Test the use of the Discovery Interview technique with non English speaking CHD patients to discover whether the process is transferable to the Vietnamese and Punjabi populations.
- Explore how the interviews translate into English to identify the extent to which the meaning of conversation is lost in translation.
- How to use the narratives to enable clinical teams to make improvements based on patient's narratives.
- Gain greater understanding of the experience of heart disease and its care and treatment for patients who are not fluent in English.
- Contribute to the body of knowledge on the needs and experiences of ethnic minority populations with CHD.

3.2 The Discovery Interview Process

The Discovery Interview process has been successfully applied to English speaking CHD patients and carers. Transcripts from the interviews have been used to inform clinical teams about patient's and carer's experiences as a way of improving services. It is important to incorporate ethnic minority accounts however, this is often made difficult due to many patients not speaking English and interviewers not sharing the patient's vernacular. The complexities of carrying out Discovery Interviews with non English speakers warranted a more detailed pilot which could identify the feasibility of using the Discovery Interview process with non English speaking CHD patients.

The Discovery Interview process encourages individuals to tell the story of their experience rather than answer questions. The key issue here is whether the interviewer or the patient are in control of the interview i.e. where the perceived power lies. The more the interviewer asks questions the more they are perceived to be in control and the answers are likely to be limited to public accounts. Story telling gives the narrator more control as their attention is more focused on the story than the audience and, since they are less self-conscious, they provide information that is closer to their private accounts. For many non English speakers this may be the first time they have been given the opportunity to tell their story in their own language. In addition being able to communicate allows the patient to express the context of their experience i.e. their experience will be located within their religious and cultural belief systems.

Effective practice point 1

Ethnic and linguistic matching of the researcher to patients will allow patients to feel that the cultural and religious context and beliefs of health and illness are being understood (language is more than words).

The essence of the Discovery Interview process is about understanding the experience of the person (or carer) with a health problem and the impact this has on their everyday life, as opposed to the interviewer asking the patient (or carer) to make value judgements about the services or care they received although, as they tell the story of their journey, they weave these accounts into their narrative. They do this in their own way and by using their own language. The focus is on the patient's (or carer's) experience of their illness rather than the care they received. This is what adds to the strength and richness of the Discovery Interview method and the narrative gleaned from the process. In the case of Discovery Interviews the term interview is used in the loosest sense of the word; interviewers are

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trained to be empathic listeners, able to hear the patient's (or carer's) testimonials of their experience using a limited amount of questioning.

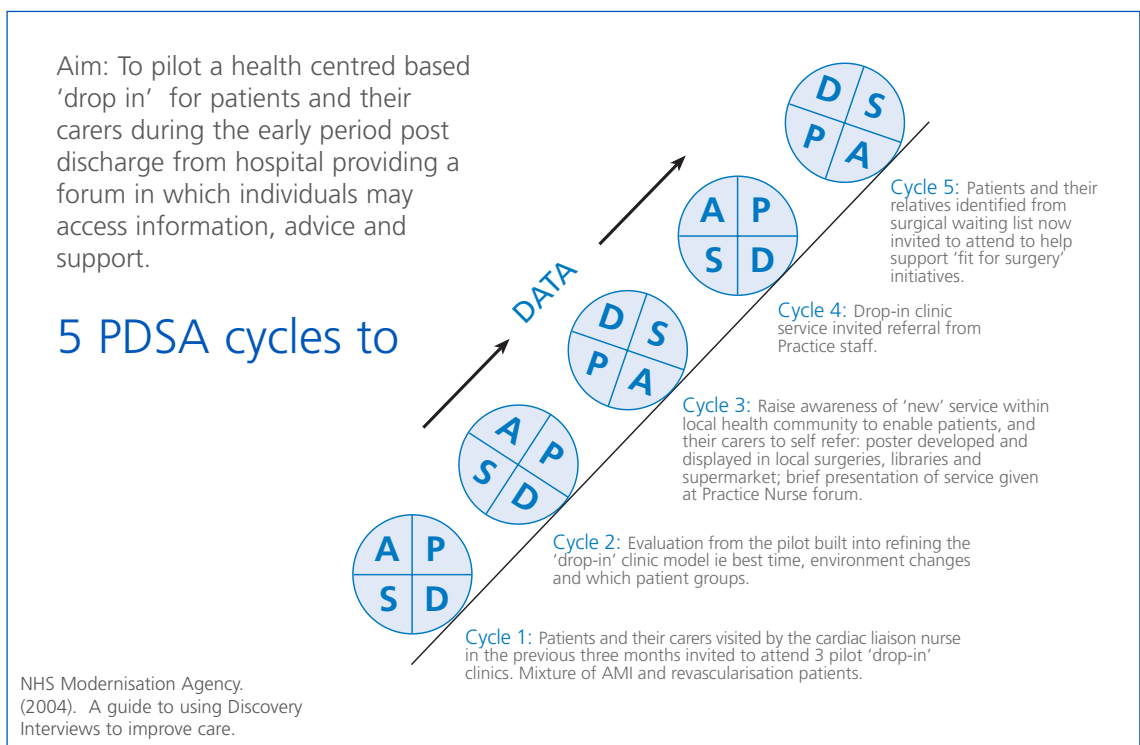
Hearing the patient's story can have a significant impact upon health care practice in a number of ways:

- Touching hearts and minds**
 Hearing whole transcripts allows a healthcare team to experience the impact of the illness journey by stepping into the shoes of the patient (or carer). This enables them to gain an insight into parts of the service both before and after the part they play in the system. This is often the first time a healthcare team will have heard the impact of the illness on the patients (and carers) in their own words.
- Seeing quality through the patient's eyes**
 Patients (and carers) know things that doctors and health professionals cannot know which can in turn help them to improve healthcare services. Staff are able to identify issues and concerns of

significance to patients (and carers) they may previously have considered to be of little importance.

- Recognising that patients (and carers) can contribute as co-producers of health care**

Traditionally providers of care have a tendency to focus on the technical aspects that patients (and carers) take for granted while patients (and carers) focus on their needs. They have the experience and the expertise to judge for example, the impact of the illness/condition on their daily lives - waiting times, quality and timing of information. Through listening to stories about the impact of the illness and the experiences, healthcare teams link this new knowledge to their professional knowledge and experience. Bringing these two bodies of knowledge together has a catalytic effect on stimulating improvement. When teams have heard a story they will decide on areas for improvement and develop systems of change to improve healthcare provision.



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The diagram above shows how a team approached building improvements to their service using the improvement model described as the PDSA (plan, do study act) cycle (NHS Modernisation Agency 2004). This methodology (Langley et al. 1996) has been used by healthcare teams to provide rapid feedback for learning when building improvements. There are a number of ways in which healthcare teams can use the PDSA cycle to develop change based on information gathered through the Discovery Interview process:

- **Turning reflection into action**
Healthcare teams need to think in terms of a patient's needs as this helps them to delve into the patient's mind and see what is not currently available. Experience so far demonstrates that this is an activity where healthcare teams require support and time to work through issues they identify from patient (and carer) stories as there is a tendency to jump straight into identifying the solution to the issue at the expense of exploring the underlying patient need.
- **Not realising the real issues/needs**
Healthcare teams need to focus on the things patients (and carers) know when trying to understand their needs.
- **Only one person's perspective**
The argument often levelled at the Discovery Interview technique is that it centres around the concern for advocating improvements in healthcare based on the subjective experience of what one person says. This leads to a questioning of the value in emphasising outcome measures that direct attention to the individual over groups and the interests of unique patients over those of society. There are at least two key factors of importance here. First, stories are memorable and are self propagating. Second, a story that describes direct experience changes listeners' understanding through the opportunity to learn from tacit knowledge. Writing reports loses this impact and can inhibit learning.

3.2.1 Employing interpreters

A tri-lingual (Punjabi-Urdu-English) researcher was employed to lead the field research. Part of the researcher's role was to carry out interviews with the South Asian respondents. The researcher did not speak Vietnamese so it was essential to recruit a Vietnamese interpreter to support the researcher with the interviews. As the principal researcher was not local to the Greenwich area it was essential that other Punjabi and Vietnamese interviewers were trained in the Discovery Interview process to ensure consistency and the long term sustainability of the Discovery Interview process within the local cardiac network work once the pilot was completed.

The original intention was to employ interpreters from the local Punjabi and Vietnamese interpreting services. During the preliminary stages of the research, recruiting interpreters to the project proved very difficult. Identifying and co-ordinating the release of interpreters from the local Punjabi and Vietnamese interpreting services involved ongoing negotiation but was unsuccessful. Work commitments and time constraints for the interpreters impacted upon their release for essential training in the Discovery Interview process and interpreting. Other options were considered to ensure continuity after the pilot was completed so a Punjabi speaking practice nurse was approached. After consideration she felt that, although she spoke the relevant language, the time constraints within her job as a practice nurse meant that she was unable to carry out the interviews. She also felt that she might be known to some of the patients in the study, which may impact on the quality of the interviews since patients may present her with public accounts of their experience. In other words, say what they feel she wants to hear rather than the private accounts of their experience because of her role as a practice nurse. There was also a possibility that subjects might seek to use the interview for discussion about their condition as the practice nurse would be seen as a clinical expert.

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After further consultation with members of the project team a Punjabi/Sikh bi-lingual member of staff from a neighbouring primary care trust was recruited to the project. Care was taken to ensure that the language she spoke was cognisant of regional, socio-economic inflections.

A female member of staff from the local commission for racial equality (CRE) was identified as a potential Vietnamese interviewer however, despite several communications and a one to one meeting, the project team were unable to recruit this person. All prospective interpreters were offered payments above the standard rate for interpreting. Although a considerable degree of interest was expressed in taking up a position as an interviewer on the project, existing work commitments led to the CRE staff member declining the position and consequently the Vietnamese interviews were abandoned.

These problems reflect some of the infrastructural problems of carrying out this type research despite the CHD Collaborative having good links within the local health economy. Potential interviewers held junior level positions within their organisations which meant that, although they showed interest and enthusiasm for carrying out the work, they did not have the authority to make decisions around their release from work.

Effective practice point 2

To achieve successful implementation of Discovery Interviews it is important to gain the support of senior managers regarding staff recruitment to the role of Discovery Interviewer, as this has implications for any service on release of its staff to carry out interviews. Protected time for the Discovery Interviewers needs to be secured when they undertake this role as part of their substantive post.

One of the consequences of a poor recruitment strategy was the impact on the sustainability of conducting Discovery Interviews with the Punjabi and Vietnamese patients in the local health economy.

Effective practice point 3

A more formal structure for employing interpreters may help to secure arrangements for training in the Discovery Interview technique, interpretation and translation.

As a result of these recruitment issues and time constraints the research team decided that the Punjabi community would become the focus of the pilot. The researcher was invited to attend a training event to introduce, explain and train in the technique of Discovery Interviewing. A further training session was arranged for the interviewer, also attended by the researcher. Both sessions were delivered by the project lead. This also provided the opportunity for the research team to meet and alleviate any anxieties about the research fieldwork. Interviewers were required to submit a practice tape for assessment purposes as part of the accreditation process as a Discovery Interviewer which were then reviewed by the project lead. Further training was delivered to support competency development in the Discovery Interview technique for both researcher and interviewer.

Effective practice point 4

Conducting Discovery Interviews requires an enhancement of the skills set used to gather data from questionnaires, surveys or by clinical practitioners in their assessment of patients. Staff should be specially trained in the Discovery Interview technique and able to gain access to ongoing support to develop competence.

3.2.2 Recruiting Punjabi CHD patients

A service improvement facilitator from the South East London Cardiac Network was involved in the research to ascertain the support of health care staff as local recruiters (senior nurses and general practitioners) and of the local health community. Patients were to be recruited from both primary and secondary care: Queen Elizabeth Hospital NHS Trust, Greenwich and three general practices within Greenwich Primary Care Trust.

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The intention was to purposefully recruit patients who reflected the use of services in primary and secondary care, who had suffered a cardiac event in the preceding three months of the study commencing and who were receiving support from a health care professional. The three month period was seen to be an appropriate length of time for patient recovery thus insuring that the interviewers were not carrying out Discovery Interviews with clinically fragile patients. Patient data was obtained from the hospital Patient Administration System (PAS) and the nurse's own records, for example, the heart failure specialist service.

Effective practice point 5

Significant effort in promoting the approach to clinical teams can be beneficial in gaining support from clinicians, which is essential to the identification and recruitment of potential Discovery Interviewees.

A review of the numbers of Punjabi patients attending the rapid access chest pain clinic (RACPC), post myocardial infarction (MI) clinic and heart failure nurse led service in secondary care revealed very low figures during the recruitment time frame. In response to these findings, the recruitment time frame was extended to allow for the recruitment of Punjabi patients who had used these services up to six months before the research. This also failed to generate sufficient numbers of Punjabi patients. In addition, the research team initially approached two local general practices known to have a large concentration of Punjabi patients registered at the surgeries. The practice nurse at these surgeries reviewed the practice's CHD register to identify Punjabi patients via the use of the clinical coding system and by their names. These were easily identifiable to the practice nurse who was herself Punjabi and therefore spoke and understood Punjabi. It was anticipated that the recruitment of patients from this domain would provide learning about the patient's experience of longer term care and living in the community with a cardiac condition.

Once patients had been identified either through the rapid access chest pain clinic (RACPC), post myocardial infarction (MI) clinic, heart failure nurse specialist, community cluster clinic or from general practice, a process of incremental consent was to have been initiated. Initially, a health professional would talk to patients with whom they had direct clinical contact to introduce the research. For patients recruited through hospitals, the initial intention was to identify patients using the ethnicity identifier on the hospital PAS system. The research team found gaps in the recording of ethnicity data and thus patients were identified using their surnames and by the recruiters questioning patients directly about their ethnicity and their fluency in English. There were problems in purposefully recruiting patients not fluent in English as patient administration systems recorded a limited number of data items in relation to ethnicity monitoring. This makes it important for team members to make efforts to gather appropriate information on ethnicity on admission.

Effective practice point 6

Identifying patients from specific minority ethnic groups is a complicated process as many of the dimensions that determine these groupings are not routinely recorded as part of patient data sets. For example, recording of a persons ethnicity is largely focused on national group i.e. Indian, Asian and faith group Sikh, Muslim, Hindu. Data concerning specific group i.e. Punjabi, Bangladeshi or linguistic criteria i.e. Siraiki, Pahari, Lahnda is not required.

Staff members with a familiarity of ethnic minority names can help with the purposeful recruitment of patients from specific ethnic backgrounds as can efforts to gather appropriate information on ethnicity on admission.

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The recruiters were provided with patient information packs used to support the discussions with patients considering taking part in the interviews. The research team were aware of the need to ensure patients were supported by their health professionals. Involving the clinical team from the onset of the study helped to facilitate an improved understanding of patient narratives.

The recruitment of patients via general practice involved the practice nurse identifying South Asian patients with CHD from the practice CHD register who were then sent a recruitment letter. This was followed up by an information pack to those individuals interested in taking part in the research.

There were significant delays in the recruitment process in both primary and secondary care due to;

- low numbers of patients attending hospital services during the study period
- enlisting the support of the general practice surgeries
- poor patient response in returning the reply slips attached to the recruitment letter indicating interest in taking part in the research.

The fieldwork dates had been arranged whilst patient recruitment had not been completed. The first round of letters sent out by the nurse only generated three potential interviewees and thus a further recruitment drive was needed. The second phase of recruitment yielded a further 11 potential interviewees to the study and involved a third general practice. A total of 14 patients were recruited: eight patients were recruited from practice A, one from practice C, one from practice D, two from the heart failure service and two from the community cluster clinic. Patients were provided with information packs. Some of these were mailed to patients but to speed up the process, some of the information packs were hand delivered.

All the information in the patient packs was translated using written and audio media. As discussed above, the Punjabi community of Greenwich is made up of people from the Pakistani and Indian side of Punjab and thus there are differences (albeit subtle) in the spoken and the written forms of Punjabi. There is no written text for the Punjabi spoken in Pakistan and thus interview material had to be translated into Urdu, which is the formal written language of Pakistan and Guramuki, for the Punjabis of Indian heritage. One of the main problems the research team encountered when trying to translate material was the knowledge, availability and cost of local translating services in the Greenwich area. Those services that were interested in supporting the research felt unable to meet our request for translation and transcription, despite appropriate payment, due to existing pressures and small teams. As well as written material, the research team felt it was important to provide the consent form and patient information sheet in audio form to account for those patients who were unable to read their vernacular. These tapes were included in the patient information packs. Every measure was taken to ensure that everyday Punjabi/Urdu was used in the written and verbal translations.

Effective practice point 7

The provision of information used to recruit patients (and carers) not fluent in English for Discovery Interviews should be provided in languages other than English and in a variety of media other than written text to support informed decisions about participation for the following reasons:

- there may be no written text for some languages;
- differences in the spoken dialect and written forms of text within a single community;
- low levels of literacy within native and host country language.

Audio tapes were reported as the most useful medium by interviewees participating in the study.

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Although research participants were asked for their consent by the recruiters and the information packs were sent out accordingly as mentioned above, no reply slips were returned. The research team decided that a follow up phone call was necessary to explain the research and then consent patients. During the conversations with patients, every effort was made by the researcher to ensure that patients were not coerced into consent. Three patients were recruited using this method. All patients were then called to explain the Discovery Interview procedure verbally and to arrange the interview. At this stage patients were informed of their right to withdraw from the research without giving any reason. The researcher also explained that the transcripts of the interviews would be shared with the local CHD teams following removal of patient identifiers. Special attention was also given to explaining the meaning of the confidentiality clause.

Effective practice point 8

To maximise the recruitment response of participants not fluent in English, different strategies to those of the more traditional methods used in recruitment are needed. Elements that appear to be of significance are:

- the personalised contacts and follow up by a person known to the community with whom the patient is familiar;
- discussion with a family member about what taking part entails.

NB it is important to take account of the potential influence the individual may exert regarding the decision to participate.

Patient recruitment proved very difficult during this research. In the case of patients recruited from the GP surgeries, the interviewer had to hand deliver and consent patients to the study. Delays in obtaining lists of potential patients from the GP surgeries often meant recruitment happened only a few days before the interview. This was a far from ideal situation as patients should be allowed adequate time to

consent to taking part in research and consequently some patients may have consented reluctantly. It is important however to note that the interviewer was known in the local Punjabi community which, together with a personal visit, may have contributed to patients consenting to take part in the Discovery Interview process more quickly than traditional recruitment methods.

3.2.3 The Sample

Eight patients from the 14 recruited to the study consented to taking part in the Discovery Interviews. There were several reasons for low interview numbers at this stage of the research. One patient was suffering memory loss and his son declined the interview on his behalf. The researcher and interviewer were unable to get through to some potential interviewees because patient's telephone numbers were not available or out of order. One patient wanted the researcher to speak with her son and ascertain his consent and two declined to be interviewed.

3.2.4 Data Collection

It has been documented that there is a distinction between people's public accounts (things they say that they think will be acceptable to others) and their 'hidden transcripts' (Scott 1990). Hidden transcripts refer to the stories people tell about themselves and their experiences in settings where they do not feel threatened or subordinate. In other words, hidden transcripts consist of stories people tell away from the gaze of the health care professionals (the researcher and the interviewer were not part of the clinical team).

Effective practice point 9

Interviews should be carried out by staff who have not been directly involved in the patients care as this may influence the accounts of experience shared.

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These are the accounts that people share with close peers and that spring directly from personal experiences and from the thoughts and feelings that accompany them (Cornwell 1984). Language and an understanding of the patient's cultural context are essential to access such hidden accounts. For the purpose of this initiative it was the patients' stories of their experience of illness that was the focus of inquiry.

Effective practice point 10

A qualitative methodology which underpins the Discovery Interview method is particularly effective for obtaining in-depth information in under-researched areas such as the experience of patients not fluent in English. It is a useful method for gaining insight into attitudes and experiences including those that occur through marginalisation and exclusion and the way in which people perceive their identity has shaped those experiences. Discovery Interviews allow services to be evaluated on the basis of the experience of users rather than the process of how and what it provided reflecting the diversity that exists among people and their needs.

The sections above have described and explained the Discovery Interview process, experiences of employing interpreters and recruiting Punjabi patients to the research. In this section we turn our attention to some of the experiences of carrying out the Discovery Interviews with Punjabi patients in Greenwich.

3.3 The Interviews

The Discovery Interviews took place in patient's homes. Interviews were arranged by the researcher and interviewer as described above in Section 2.3.2 and logged on an interview spreadsheet. On the whole, all patients remembered their interview time. Two female participants were late arriving for the interview as they had 'forgotten' that that they were being interviewed. On one occasion, the patient arrived whilst the researcher was still on her doorstep and in the other case, the researcher was invited to wait for the patient

by her husband. The patient arrived about 20 minutes late for the interview.

Effective practice point 11

Interviewers should contact interviewees both a few days before and on the day of interview to confirm the date, time and venue.

Before the interviews began, patients were asked to confirm their consent and extra care was taken to ensure that the confidentiality clause was explained along with what taking part involved. Some patients explained that they had not read the written material that they had received but found the audio information much more accessible. There was some confusion in some cases with other letters received from the hospital relating to their CHD. One patient did not know that she was a heart patient. She explained that she had received no treatment for CHD and that she had only been told that she had high cholesterol. During the interview she was more comfortable talking about her arthritis. She found the tape very intrusive and mentioned that she was not used to giving interviews. Another patient had recently experienced a stroke and consequently had very poor communication. The researcher and interviewer were unaware of the extent of this until they arrived at the patient's home. The patient's carers controlled much of this interview. Another patient was suffering from Parkinson's disease and he had difficulty in remembering his experience. Although these respondents were suffering from CHD, they also had medical problems which affected the quality of the Discovery Interview process. Although every patient's story is important, in the last two cases their conditions made it impossible. Recruiters were briefed to look at patient history before recruiting but unfortunately this did not happen which affected the quality of interviews. In both cases discussed above the carers took over as interviewees but this was not the remit of this project and carers had not formerly consented to participate as this was outside of the remit of the project's ethical submission.

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Effective practice point 12

Key points of importance that relate to the involvement of the clinical team (GPs and practice nurses, hospital medical and nursing staff) in the recruitment of patients is:

- they are vital in ensuring that patients unsuitable on clinical or psychological grounds are excluded from participating in the interviews;
- they review the patient's clinical history/record to make an assessment of issues/problems that may cause difficulty/distress for the individual and exclude these interviewees from recruitment.

The interviews were tape-recorded with the patient's permission which formed part of the consent process. Patient's narratives were collected in the language of their choice. Where patients had some command of English, they used this interchangeably with their vernacular. Some of the interviews took place on a one-to-one basis with the researcher or with the researcher and interviewer but generally a spouse or family member/s were present during the interview. Patients were asked to talk about their experiences using an interview spine. An interview spine ([Appendix B](#)) is a number of statements based on the key stages of the CHD patient journey through their experience of illness. These key stages were referred to as the CHD spine and were presented as individual cards (in Punjabi/Urdu and English), laid out before the interview and used as a guide for the interviewers and patients during the interviews.

The aim of using the spine during the interview was to encourage a natural discussion about the patient's experience and to trigger significant memories and thoughts that would be the basis of needs identification. The focus of the interview discussion was on the impact of the illness on their daily lives rather than on making value judgments about the services they have received.

A number of issues arose around the use of the interview spine with the interview sample:

- There was a marked difference in the interview experience between those patients who had some fluency in English (reading and understanding English) and those that did not.

Those patients who could not read and understand English and could not read their vernacular did not grasp the meaning of the interview. In these cases the researcher and interviewer read out the cards at the beginning of the interview. It was very difficult for patients to remember all the cards during the interview and the researcher and interviewer had to prompt the patient throughout the interview, which resulted in the interview being more like a question and answer session rather than patients telling their stories. Translating the interview spine without giving concrete examples proved very difficult for patients to understand so there was a constant need to concretise abstract institutions, for example, instead of the NHS, the use of terms like 'doctors and nurses'. In such cases the researcher and interviewer were very aware of the value judgments associated with translating material. This was contrary to the essence of Discovery Interviews in which the principle of patient empowerment and control of agenda is central to the process.

- The Hindi speaking Punjabis in the sample were unable to read the Guramuki text. The lack of expertise regarding ethnic minority languages and the difficulty of accessing relevant interpreters created situations in which miscommunication was present during the interview process. The service improvement team had invested a great deal of resource to map out the local community but, despite these efforts, significant information gaps remained and these had a detrimental effect on the coordination of the research.

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Effective practice point 13

It is important to understand the community that the interviews are focussed on and that access to expert advice is available as required regarding, for example, the linguistic dialect and religious needs.

- All patients, despite levels of fluency in English or their vernacular, found the concept of telling their 'stories' very alien. Patients were so used to answering questions that trying to get a discussion going about their experiences of healthcare proved in some cases extremely difficult. Statements such as 'what else do you want to know' and 'why don't you ask me and I will give you an answer' and 'I hope I answered all your questions' were very common when the researcher and interviewer explained the centrality of patient 'stories' to the respondents.

Effective practice point 14

Conducting this type of interview can pose additional challenges and requires the enhancement of interviewing skills. Mastery of the Discovery Interview technique as applied to patients (and carers) not fluent in English also requires that interviewers take account of both language and cultural contexts of interviewees.

- Translation itself is inherently unstable since the semantic content of two languages cannot always find an appropriate phrase or word in common. While this difference may be insignificant in situations where patient and health care practitioner/interviewer enjoy a relatively high degree of mutual linguistic competence, it may have severe consequences for patients with weaker linguistic facilities. This was something that occurred during the interview process.

Effective practice point 15

Spines need to be reflective of the patient group interviewed and in the case of patients not fluent in English; care should be taken to ensure that once the interview spines have been translated into the patient's vernacular/dialect, they do not lose their meaning.

- Many patients looked to carers and other members of the family present to discuss their experience. This was either to recall information or due to lack of confidence in telling their 'story' rather than responding to direct questions. This may also be related to patients appearing not to know much about their illness although overall, men appeared to know more about their conditions and associated healthcare experience than women. This is linked to differences in levels of literacy between men and women in the Punjabi community, which is related to access to information about the healthcare system generally and more specifically their experience of utilising CHD services. Older generation men are also culturally more likely to be the communicators within families and therefore more familiar with locating their experiences with confidence. It may also be related to an overall confidence in the medical system. It is also important to consider the presence of others during the interview as previous experience has shown that other people present can change the dynamic of the interview, particularly when it is a family member who may have a different perspective. from the interviewee.
- Some of the terminology used on the spine cards did not resonate with the Punjabi patients, e.g. the NHS. This was far too broad for patients to conceptualise. They were more comfortable talking about GPs and nurses.

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- Using the Discovery Interview technique is a specialised task and requires significant training in the method and practice to develop competence. A larger sample of respondents combined with shorter lead in time between training and carrying out interviews would have ironed out any issues to do with interviewers' technique during the pilot.

3.4 Lost in Translation: The Transcripts

The Discovery Interview process does not lend itself to any formal analysis of transcripts. What is central to the Discovery Interview process is the 'story' rather than a thematic analysis which presents extracts of narrative. In other words, it is the power of narrative that is used to make connections of patients experience rather than a researcher summarising patient experience.

The art of translation does not depend on the exact replication of terms and phrases from one language to another, not only because of differences in grammatical structure, but also because the semantic content of similar words may vary according to language. It follows then that translation is an attempt to render a different language as close an approximation in meaning as possible. This may often require use of dissimilar words and a dissimilar grammatical structure, e.g. 'kia kurra ho' literally means 'what doing you' so would need to be changed to make grammatical sense. This means that all translations are to some extent creative recreations of meaning and not just literal replications. In the case of the Discovery Interview translations, there were no major issues of loss of meaning through translation. In part this was due to the nature of the topic covered in which technical terms predominate, as opposed to poetry which uses metaphors and idiomatic expression.

More than the translation, quite often mistakes arise due to a neglect of contextual factors and the impact on expression of meaning. In other words, it is the context which helps to determine the meaning of the story. The problem therefore in the field of health care arises from the way in which health care problems are often embedded with cultural understanding, so that certain types of illness are described in the context of old age or other philosophical and psychological beliefs. In other words, different cultural frameworks may have developed particular ways of talking about particular pathologies. This point is illustrated by PA/5 who comments that;

It (CHD problems) is due to household (family) problems. My husband is not with me. I am alone. I worry all the time that I have very young children and I have to bring them up. Due to these kinds of worries an ailment starts or the other. You know with worries one has heart problems. That is why I have this problem (PA/5).

As a person grows older the difficulties increase. I have had the heart problem...twice...twice, three times (PA/7).

Effective practice point 16

When sharing a story with the clinical team it is important to understand the cultural context of the storyteller.

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For translations to be effective they require not only a re-description from one language to another but also a learning of different cultural contexts. The full transcripts are available to the multidisciplinary project teams as a way of enabling teams to identify patient needs and plan improved ways to meet them. What is offered in the next section of this report is a discussion of some of the issues that arose whilst transferring the Discovery Interview process to non English speaking Punjabi patients in Greenwich.

Effective practice point 17

Prior to conducting interviews it is important to identify support services for the transcription and translation of interview tapes, this may include for example:

- Suitable skilled person –competent in audio typing in the relevant language spoken by interviewees and translation of this information into the host language used by a team.
- Suitable equipment – to support typing of text in language other than English.
- Reimbursement for transcription and translation services.

Equally important to consider is the overall project planning and the scheduling of phases concerned with the process of transcription/translation of interview tapes as it is important to minimise delays in sharing the final transcript with clinical teams.

SECTION 4: Discussion - Transferring the Discovery Interview Process to Non English Speakers

4.1 Introduction

The Discovery Interview process has been successfully applied to English speaking patients where it has proved its value in assisting clinical teams to understand what is important to CHD patients and carers. The opportunity to hear these uninterrupted patient and carer stories has allowed teams to gain new knowledge which would not necessarily have been gained using other investigative techniques (Wilcock et al. 2003, Bateson et al. 2004). The technique is used by many cardiac network teams as one of several service improvement and patient and public involvement tools. The Discovery Interview technique however poses a number of challenges since its innovative nature and its patient centred approach requires a relatively greater investment in the research process. A general discussion of the merits of the Discovery Interview process can be found in the [CHD Collaborative Evaluation of Discovery Interviews: Final Report \(2005\)](#).

To apply Discovery Interviews to ethnic minorities requires not only commitment from the commissioning organisation but recognition of the specific challenges that the use of the Discovery Interview technique entails when researching ethnic minority patients. Some of the challenges highlighted during this pilot research study are presented below.

4.2 Ethnic Minority Narratives and Reconfiguring the Discovery Interview Process

There is a widespread recognition that one of the structural conditions that determine the subordinated and excluded status of most ethnic minorities is based on difficulties with those in subordinated positions to articulate their own narratives. Therefore, a Discovery Interview process would benefit strongly by catering for those minority voices. Discovery Interviews are an innovative and powerful tool for assisting healthcare practitioners to shape services and individual practices so that they meet their statutory and moral commitments to the healthy wellbeing of all residents of this country. The innovative nature of Discovery Interviews however is one of the reasons why there needs to be a rethinking of the applicability of Discovery Interviews to ethnic minority contexts.

Discovery Interviews depend a great deal on being able to mix and match publicly available accounts of ill health and the capacity of patients to make a contestation with these overarching accounts when they tell 'their' story. In the case of ethnic minorities, such an assumption of a homogenous and taken for granted narrative which includes both ethnic and national majority communities may be problematic. Thus patient narratives of ethnicised minorities may be so far removed from public accounts that their capacity to inform health care practitioners may be limited. The Discovery Interview process may need to be reconfigured so that it can be applied to ethnic minority contexts. Such a reconfiguration would ideally include the following points:

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- Recognition that the Discovery Interview process for ethnic minorities cannot simply be an appendix to make enquiries on the national majority population. In other words, it needs to be a dedicated initiative in which the role of ethnic minorities is central. Therefore information such as recording ethnicity, language use and religious affiliation has to be easily available prior to the process of detailed research design. Given the complex nature of the NHS there is a need for 'joined up' research facilities. Information held at different locations is not always easily accessible or available.
- There is a need to recognise the specialist nature of conducting Discovery Interviews with ethnic minorities. This again requires prior project planning and investment in recruiting ethnic minority specialists. Recruitment of patients for the Discovery Interview process has to be recognised as a specialist task in which the patient has to have not only the appropriate health care profile, but also the linguistic skills and confidence to fully engage with the Discovery Interview process. Such recruitment requires the input of experienced recruiters. The recognition of the complex nature of ethnic minority research implies the need for specialist recruiters with the necessary language and cultural translation skills.
- The use of healthcare practitioners to conduct recruitment of patients to this type of research has not proved ideal in this study, thus potentially disempowering often the most vulnerable patients. This is contrary to the dictates of the Discovery Interview methodology which claims to be patient centred.
- Recognition that healthcare practitioners often have other pressing demands on their time which impacts on their capacity to recruit suitable patients with the relevant health and ethnicity profile for the research. This is often hampered by limitations of the data recording ethnicity, language use and religious affiliation.
- The actual Discovery Interview was beset by a number of difficulties. These included a perceived lack of knowledge by many patients of their illness. Several patients did not realise that they were CHD patients which may be suggestive of communication difficulties experienced between healthcare professionals and some of their patients. This problem also had an impact on the actual conduct of the Discovery Interview since the Discovery Interviews were predicated on a sample which included only CHD patients so that one could uncover the stories of these patients. Patients who did not realise that they were CHD sufferers were inclined to narrate health care experiences that were not related to CHD. This again emphasises the importance of the patient recruitment stage of the research.
- There was also a difficulty arising from issues of translation, linguistic fluency and the capacity of patients to provide a more or less coherent narrative of their CHD experience. For example, some of the terminology used on the spine cards did not resonate with the Punjabi patients and as such, the current design of the spine cards did not facilitate the production of patient narrative. Many patients could not read therefore even the translated spine cards did not assist them. This was also compounded by the difficulty many patients had in understanding the Discovery Interview method. In this small sample, all the interviewees wanted to answer specific questions and were reluctant to express themselves outside the context of question and answer situation. However, from the general experience of conducting Discovery Interviews the skill of the interviewer is commensurate to the story obtained.
- There needs to be recognition that the minority status of ethnically marked people has a massive impact on the availability of suitable interviewees. This pilot project highlighted the difficulties (even for an experienced researcher) of accessing ethnic minority patients for a sustained period of time which would allow the Discovery Interview process to be accomplished.

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- Contrary to the expectations of the oral nature of ethnic minority cultural exchanges, patients were not used to engaging in such oral traditions. As such there was not the same level of skill or expectation that one would have assumed to be the case in a largely pre-literate sample. The fact that many of the patients could not read any language did not automatically imply that they could engage in 'oral history' since they did not have the institutional ensemble in which such oral traditions are practiced. Therefore, the mechanisms which would encourage the development of oral narration were absent from the patients' lives. As such they did not develop the story telling skills that one would have expected in the absence of a literary culture. It was clear that patients were not explaining their complete story. It felt like too much information remained unsaid. Interviewees that had received treatment (rather than those that had been diagnosed with heart disease) had the most to say about their experience. The researcher and interviewer felt that many of those who had received a diagnosis of heart disease did not have very much information and understanding about their condition.

Conclusion

The nature of the Discovery Interview technique is that the primary burden of analysis shifts from the investigator to the multidisciplinary team hearing the stories. It is hoped that the stories will provide a richer source of information that will allow a better understanding of the needs that are not met in this non English speaking sample to emerge. The integrity of the Discovery Interview process however depends on healthcare professionals using these patient narratives to inform and guide their practice. The challenge for healthcare professionals is that these narratives come without spin, i.e. there is no analysis of the data by a third party, therefore it is incumbent upon the health professional to analyse and learn from the stories patients tell about their experience. The difficulty of allowing predominantly healthcare workers unmediated access to the narratives of ethnic minority patients is that they may not have the requisite cultural literacy to make best use of these stories. There is a great need to recognise that healthcare practice has to become culturally literate in response to the diversity of the patients that are being cared for. Such cultural literacy can only be acquired by a significant commitment to making cultural literacy an intrinsic part of the training for healthcare professionals rather than a minor appendix. Thus it is essential that the reading of transcripts should be accompanied by facilitators who have cultural literacy to ensure that the transcripts are not misread or lead to the replacement of old by new stereotypes.

Recommendations

- Understanding the needs of minority ethnic groups should be the concern of any organisation involved in the delivery of health care.
- Ethnic minority research needs to be integrated into the overall process of improving health care delivery.
- There needs to be a strategic vision and commitment to the Discovery Interview process prior to undertaking any research using this technique. Discovery Interviews need to fit within the organisation's priorities and planning framework.
- Research with ethnic minority patients requires specialist skill and expertise.
- The Discovery Interview process needs to be modified to take into account the special needs of doing research with ethnic minorities from the recruitment stage through to reading the transcripts.
- The importance of providing information concerning Discovery Interviews in a variety of media as ethnic minority languages may not have a written form of words.
- Meeting the needs of minority ethnic groups requires cultural diversity training to support the whole approach to using Discovery Interviews obtained from ethnic minority patients and with assisting the reading of transcripts.
- This research needs to be repeated using a wider sample of ethnic minority patients who are not fluent in English in different geographical locations.
- The interviewers who carry out the Discovery Interviews should be culturally aware, fluent in the language they are using in the interview and have a good working knowledge of the Discovery Interview technique.
- Consideration of mechanisms for providing feedback on the outcomes of teams hearing the patient stories to patients who participated in the work.
- Services available to support the process for transcription and translation of tapes as this is a complex process.

A summary of effective practice points for implementing Discovery Interviews can be located in [Appendix A](#).

Appendix A - Effective Practice Points

Effective practice point 1

Ethnic and linguistic matching of the researcher to patients will allow patients to feel that the cultural and religious context and beliefs of health and illness are being understood (language is more than words).

Effective practice point 2

To achieve successful implementation of Discovery Interviews it is important to gain the support of senior managers regarding staff recruitment to the role of Discovery Interviewer, as this has implications for any service on release of its staff to carry out interviews. Protected time for the Discovery Interviewers needs to be secured when they undertake this role as part of their substantive post.

Effective practice point 3

A more formal structure for employing interpreters may help to secure arrangements for training in the Discovery Interview technique, interpretation and translation.

Effective practice point 4

Conducting Discovery Interviews requires an enhancement of the skills set used to gather data from questionnaires, surveys or by clinical practitioners in their assessment of patients. Staff should be specially trained in the Discovery Interview technique and able to gain access to ongoing support to develop competence.

Effective practice point 5

Significant effort in promoting the approach to clinical teams can be beneficial in gaining support from clinicians, which is essential to the identification and recruitment of potential Discovery Interviewees.

Effective practice point 6

Identifying patients from specific minority ethnic groups is a complicated process as many of the dimensions that determine these groupings are not routinely recorded as part of patient data sets. For example, recording of a persons ethnicity is largely focused on national group i.e. Indian, Asian and faith group Sikh, Muslim, Hindu. Data concerning specific group i.e. Punjabi, Bangladeshi or linguistic criteria i.e. Siraiki, Pahari, Lahnda is not required.

Staff members with a familiarity of ethnic minority names can help with the purposeful recruitment of patients from specific ethnic backgrounds as can efforts to gather appropriate information on ethnicity on admission.

Effective practice point 7

The provision of information used to recruit patients (and carers) not fluent in English for Discovery Interviews should be provided in languages other than English and in a variety of media other than written text to support informed decisions about participation for the following reasons:

- there may be no written text for some languages;
- differences in the spoken dialect and written forms of text within a single community;
- low levels of literacy within native and host country language.

Audio tapes were reported as the most useful medium by interviewees participating in the study.

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Effective practice point 8

To maximise the recruitment response of participants not fluent in English, different strategies to those of the more traditional methods used in recruitment are needed. Elements that appear to be of significance are:

- the personalised contacts and follow up by a person known to the community with whom the patient is familiar;
- discussion with a family member about what taking part entails.

NB it is important to take account of the potential influence the individual may exert regarding the decision to participate.

Effective practice point 9

Interviews should be carried out by staff who have not been directly involved in the patients care as this may influence the accounts of experience shared.

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A qualitative methodology which underpins the Discovery Interview method is particularly effective for obtaining in-depth information in under-researched areas such as the experience of patients not fluent in English. It is a useful method for gaining insight into attitudes and experiences including those that occur through marginalisation and exclusion and the way in which people perceive their identity has shaped those experiences. Discovery Interviews allow services to be evaluated on the basis of the experience of users rather than the process of how and what it provided reflecting the diversity that exists among people and their needs.

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Interviewers should contact interviewees both a few days before and on the day of interview to confirm the date, time and venue.

Effective practice point 12

Key points of importance that relate to the involvement of the clinical team (GPs and practice nurses, hospital medical and nursing staff) in the recruitment of patients is:

- they are vital in ensuring that patients unsuitable on clinical or psychological grounds are excluded from participating in the interviews;
- they review the patient's clinical history/record to make an assessment of issues/problems that may cause difficulty/distress for the individual and exclude these interviewees from recruitment.

Effective practice point 13

It is important to understand the community that the interviews are focussed on and that access to expert advice is available as required regarding, for example, the linguistic dialect and religious needs.

Effective practice point 14

Conducting this type of interview can pose additional challenges and requires the enhancement of interviewing skills. Mastery of the Discovery Interview technique as applied to patients (and carers) not fluent in English also requires that interviewers take account of both language and cultural contexts of interviewees.

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Effective practice point 15

Spines need to be reflective of the patient group interviewed and in the case of patients not fluent in English; care should be taken to ensure that once the interview spines have been translated into the patient's vernacular/dialect, they do not lose their meaning.

Effective practice point 16

When sharing a story with the clinical team it is important to understand the cultural context of the storyteller.

Effective practice point 17

Prior to conducting interviews it is important to identify support services for the transcription and translation of interview tapes, this may include for example:

- Suitable skilled person –competent in audio typing in the relevant language spoken by interviewees and translation of this information into the host language used by a team.
- Suitable equipment – to support typing of text in language other than English.
- Reimbursement for transcription and translation services.

Equally important to consider is the overall project planning and the scheduling of phases concerned with the process of transcription/translation of interview tapes as it is important to minimise delays in sharing the final transcript with clinical teams.

Appendix B - Coronary Heart Disease Interview Spine

Thinking something was wrong

Seeing someone in the NHS

Having tests to see what was wrong

Receiving treatment

Getting better

Living with the condition

Being followed up

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