The meaning and consequences of hypertension for individuals of African Caribbean origin: Perceptions of Primary Health Care Services

Volume 2

An ethnographic study of hypertension in England

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Appendix 1
Glossary of terms

African Caribbean
The term 'African-Caribbean' is an artificially constructed category that has been imposed on the various black nationalities and ethnic groups who have migrated to Britain in the post war era. I have selected to utilise the term 'African Caribbean' as representing individuals who have an ancestral link to the continent of Africa or the Caribbean. The term also embraces those individuals who were born in the United Kingdom as first or second-generation migrants. The ancestral connection may be extremely significant as there is a growing body of evidence that is attempting to explain genetic components that may cause hypertension in some African Caribbean communities for example sodium sensitivity.

However, I would like to acknowledge the huge diversity in terms of culture and tradition in a heterogeneous group of individuals who might be broadly referred to as African Caribbean. The approach does have validity for this particular study as Senior and Bhopal (1994) have pointed out in health related research it may be necessary to study broadly heterogeneous groups such as African Caribbean populations as a first step to a deeper understanding of the health experience of some ethnic groups. However this approach can only be a precursor to a more detailed explanation of the phenomena investigated.

African Diaspora
"The African Diaspora concept subsumes the following: the global dispersion (voluntary and involuntary) of Africans throughout history; the emergence of a cultural identity abroad based on origin and social condition; and the psychological or physical return to the homeland, Africa. Thus viewed, the African Diaspora assumes the character of a dynamic, continuous and complex phenomenon stretching across time, geography, class and gender" (Harris 1993 p.3)

Afrocentric
Provides an alternative worldview to the Eurocentric view. It is often associated for example with primary and secondary education with the exposure of children to the historical accomplishments of people of African descent (Sheile 1995) e.g. you may be familiar with the work of Florence Nightingale, however an equally eminent nurse of the same era, Mary Seacole remains relatively unknown. Mary Seacole was a Jamaican nurse of mixed race parentage who like her contemporary received the Crimean Medal.

Black
This word will be used interchangeably with the term 'African Caribbean'. The terms may be viewed as denoting homogeneity in the sense of a shared experience of oppression and racism (Higginbottom 2000). Brah (1994 p.27) has postulated that the African Caribbean and South Asian activists in the U.K. borrowed the term from the 'Black Power' movement to foster a rejection of a chromatism amongst peoples who were defined as 'coloured' in the U.K., hence the adoption of the term black.

Cultural Competence
"Cultural competence denotes a set of skills and knowledge that have at their base the acceptance of the legitimate values, beliefs and behaviours patterns of people who are from another ethnic group." (D.O.H. 1999 P.21)

Cultural Congruent Services (Health Care)
Refers to the appropriateness of services usually developed, operationalised and usually delivered though not exclusively by individuals from a different ethnic background than those receiving the service. Requires culturally competent professionals who recognise and acknowledge variations in the appropriateness of different models of heath care. Development of culturally congruent services is dependent on the integration into the health care service of appropriate research, strategic policy development, training and education, professional development, advocacy and active listening to the consumer's perspectives.

Ethnic Minority
' Relates to all subgroups of the population not indigenous to the U.K who hold cultural traditions and values derived at least in part, from their countries of origin (or their parents or grandparents). This therefore excludes national minorities such as the Scottish, Northern Irish and Welsh, but they equally have the right to have their distinctive traditions and values respected in the way they are offered services' (Adapted from *'They look after their own don't they'* Social Services Inspectorate/DOH 1998)

Ethnicity
Ethnicity is a fluid and dynamic concept. It is a term that is separate and distinct from 'race', nationality, religion, language or migrant status. In this sense it is not possible to use the terms mentioned synonymously with ethnicity. Ethnicity is not synonymous with phenotypes or skin colour. Self-assignation and the formation of a personal identity are important dimensions to the concept (Nazroo 1997). Furthermore the fluidity of the concept is demonstrated in notions of internal definition and external definition (Jenkins 1996), referring to ethnic identity the individual constructs for themselves and external definition in respect of ethnicity relating to the societal or structural viewpoint. Jenkins states that these two dimensions are separate but interacting. He makes a particular salient point in that oppressive racist structures can impact upon the development of the internal definition. The concept is complex but embraces shared origins, traditions, culture, norms, language and religion. The boundaries of ethnicity may be especially changeable, for individuals who have migrated and subsequent generation, as the process of acculturation is likely to result in a reification of both the internal and external definition. All individuals in the world belong to an ethnic group. Increasingly in the U.K., I have heard the term 'ethnic' articulated as a pejorative concept, albeit meaningless.

Ethnocentrism
In this view the dominant majority view has primacy; inappropriate assumptions are made concerning the needs of individuals from minority groups on the basis of the majority experience (Smaje 1995)

Equality
"Condition of being equal between two or more" (Concise Oxford Dictionary 1964)

Eurocentrism
A perspective that gives the European perspective prominence and universal global application. For example *William Shakespeare was the greatest writer that ever lived.* There are clearly other eminent writers from other cultures and continents e.g. China, Asia, Africa.

Institutional Racism
"The collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping that disadvantages ethnic minority people.

[Racism] persists because of the failure of the organisation openly and adequately to recognise and address it existence and causes by policy, example, and leadership. Without recognition and action to eliminate such racism it can prevail as part of the ethos or culture of the organisation. It is a corrosive disease" (Macpherson 1999)

Race
This term is largely discredited in academic research (see Bhopal 1997, Ahmad 1993). The legitimacy of the term in the post 2nd World War era was extensively researched, resulting in the Declaration of Helsinki. The term has strong associations with 'scientific racism; that is the conduct of research to justify the racial superiority of one group of people over another. This has usually involved white and not white populations. Moreover the concept has been used to control various aspects of everyday life, such as the control of the fertility of some groups of people – Eugenics. The Jewish Holocaust was the result of ideological notions of the superiority of the German people. Bhopal (1997) points out that 'Humans are one species: races are not biologically distinct, there is little variation in genetic composition between geographically separated groups and the physical characteristics distinguishing races result from a small number of genes that do not relate to either behaviours or disease" (Bhopal 1997 p314). The term 'race' in this sense is negative, meaningless and is very emotive. However, as we move in to the third millennium one of the most important domains of health related research is that which is focused on genetics and the human geno. This domain is likely to bring about huge health gains in the future. The dilemma is that we do not have another term that will convey meaning related to those characteristics of the human species that are determined genetically.

Racialisation
"Racialisation consists of the idea that race is a primary, natural and neutral means of grouping humans and that racial groups are distinct in other ways such as their behaviours" (Bhopal 1997 p 314)

Racialism
The notion and belief that some groups of people are superiority, based on the flawed premise of the concept of race, therefore one race is inferior to another.

Appendix 2

Defining hypertension

The current definition of high blood pressure changed in 1998 from a systolic blood pressure (SBP) of 160mmHg or more or a diastolic blood pressure (DBP) of 95 mmHg or more to a definition based on a SBP of 140mmHg or more or a DBP of 90 mmHg (DO.H. 1998). Utilising the current definition the D.O.H. (1998) state that high blood pressure is prevalent in 40.8% of men and 32.9% of women. Whilst the criteria presented that defines hypertension is broadly accepted within the British health care community (Ramsay *et al.* 1999), a concern in the conduct of this research is the extent to which conclusions concerning what constitutes high blood pressure by the British Hypertension Society are based on measurements or observations of the indigenous white populations. In other words does the criteria for hypertension in the U.K. apply to all groups within multi-ethnic Britain and have validity in the diagnosis of hypertension in PHC. It is worthy of note that presently there is ongoing debate (Woodman 1999, Psaty & Furberg 1999) and discussion regarding the evidence that has informed the recommendations espousing the WHO guidelines.

Measuring blood pressure

There is ongoing concern regarding the use of a single measure of blood pressure with a traditional mercury sphygmomanometer, known as the 'Riva-Rocci/Korotkoff' method (O'Brien 2001). Aside, from the obvious of hazards of using a mercury based instrument in a clinical setting, it is recognised that this technique which may have in the past provided the best available measurement of blood pressure (O'Brien *et al.* 2001), is associated with extraordinary and unusually elevated measurements for some individuals. 'White coat hypertension' has been recognised for some time (WHO 2000) and this recognition has provided the impetus for a move towards 24-hour ambulatory blood pressure (ABPM) measurement (O'Brien *et al.* 2000, O'Brien 2001,). Twenty-four hour ABPM measurement provides the opportunity for continuous assessment of an individual's blood pressure in his or her own environment. The move towards ABPM has in the past been hindered by the reliability of the electronic blood pressure measuring equipment. However, it is likely that in the future the traditional measurement of blood pressure the sphygmomanometer will disappear. This may of course impact upon the number of individuals who were previously diagnosed has hypertension.

White coat hypertension

It is possible in situations where the patient and doctor are from different cultural groups, that the patient may experience greater apprehension and anxiety. What is not known at present is the extent to which different ethnic groups experience 'white coat hypertension' and indeed whether this is greater or less than the white population. The existence of 'whitecoat hypertension' has been known for some time (Muscholl *et al.* 1998). However, the phenomenon is not benign and may result in changes in left ventricular structure and function in-patients who experience this phenomenon (Muscholl *et al.* 1998). Indeed populations of African Caribbean descent experience greater levels of left ventricular hypertrophy (Middeke & Schrader 1994, Muscholl *et al.* 1998).

The resultant left ventricular change has serious implications in terms of the consequences and sequelae of hypertension in individuals experiencing 'white coat hypertension' On the basis of all that is known about patient/health professional interactions it is possible that individuals of African Caribbean origin or indeed any other minority ethnic group may suffer greater levels of white coat hypertension. Muscholl *et al.* (1998) state that 10% of the general population suffer from white coat hypertension; the figure for African Caribbean populations could be well in excess in of this. Ambulatory blood pressure monitoring is said to be an excellent way of detecting 'white coat hypertension' (Pras & Isles 1996). Although presently there is no way of assessing how many African Caribbean patients with hypertension are offered 24 hour ambulatory blood pressure measurement. The extent to which individuals from different ethnic groups experience 'white coat hypertension' is an important research question for the future.

Guidelines on the Management of Hypertension

The British Hypertension Society (1999) provides comprehensive guidelines in relation to the management of hypertension in PHC. The objectives of the guidelines are:

- "To promote the primary prevention of hypertension and cardiovascular disease by encouraging changes in diet and lifestyle of the whole population
- To increase detection and treatment of undiagnosed hypertension (particularly among those at high risk) by routine screening and increasing awareness of hypertension among the public
- To increase the proportion of patients on antihypertensive treatment who have optimal blood pressure levels
- To reduce the cardiovascular risk of treated hypertensive patients by non-pharmacological measure and appropriate use of aspirin and Statin treatment

- To promote continuation of and compliance with treatment by optimising the choice and use of drugs, minimising side effects and increasing information and choice for patients" (Ramsay *et al.* 1999 p630)

The guidelines focus on a comprehensive range of prevention, diagnostic and management intervention, much of which is conducted in Primary Health Care settings. However, the guidelines are contested by Pstay & Furberg (1999) and Wilding and Williams (2000). The guidelines (WHO 2000) on the management of hypertension similarly criticised (Woodman 1999). Criticisms of the WHO guideline focus on concerns that their recommendations will result in a greater use of anti-hypertensive drugs.

An interesting observation is that the British Hypertensive Society (2000) provides a number of flow charts for assessing the risk of individuals with and without diabetes in relation to CHD. No reference is made in these flow charts to ethnicity and how this increases the risk of stroke mortality. In reviewing the guidelines, however some reference is made in the text to ethnicity and hypertension. This is important as black and white populations respond differently to anti-hypertensive therapy and treatment may be further complicated by potential cultural clash, miscommunication and misunderstanding between patient and the health professional.

Appendix 3
Explanation of study population

I am seeking participants of 'African Caribbean' origin, by this I mean individuals who have an ancestral link to the continent of African via the Caribbean. The term also embraces those individuals who were born in the UK or are second-generation migrants. Individuals may have origins in a number of Caribbean Islands e.g. Jamaica, Barbados, St.Kitts, Nevis, Antigua or St.Lucia.

Appendix 4

Summary of studies – Access to Primary Health Care Services by minority ethnic populations

Study	Population	Methods	Main Themes
Bhatti & Sinclair 1999	B.E.M. pops 4 surgeries	Qualitative Interviews 5 stage audit	Access to PHC Language/Communication Inequality Practitioners Knowledge GP reluctance to take part
Chapple & Gattrell 1998	Total Pop Morecambe & E.Lancs	Qualitative Semi-structured Interviews	Language/communication. inequalities -geographical location Cultural Clash Discrimination
Carr-Hill *et al.* 1996	Survey of GP's	Survey	Access to PHC Variation by ethnicity
Chaturvedi *et al.* 1997 1998	South Asian	Survey	Access to PHC Communication may be more complex than just Spoken language Cultural clash exists in relation Socialisation in different forms Of medicines Consultation lengths differ in ethnic groups
Commander *et al.* 1997	Total pop in an inner city area	Survey & General Health Questionnaire	Third did not consult GP GP failed to recognise symptoms half Access to inpatient care restricted Ethnicity had a marked Influence on use of specialist services Inequality Cultural Clash Practitioners' knowledge of services
Commander *et al.* 1999	Total pop in an inner city	Survey	Case recognition of alcohol problems poor for Asians Poor access to specialist services for people from ethnic minorities Inequality Pt knowledge of services Mental Health Referral to Specialist

Cooper *et al.* 1998	Children & Young people	Secondary Analysis of GHS 1991-1994 Survey	Ethnicity influences use of services Socio-economic status does not Black Caribbean, Indian, Pakistani & Bangladeshi less likely to use Outpatients and be in patients Implications for quality of health c are Discrimination GP Utilisation Referral to Specialist
Cooper *et al.* 1999	Children	Secondary Analysis GHS 1991-1994	ditto
Farooqi *et al.*	South Asian	Focus Groups	Language barriers Influences access to services Access to PHC Language
Free *et al.* 2000	S.Vietnamese	Focus groups	Lack of knowledge of services Communication/language Interpreting services lack of Service provision Access to PHC inequality Practitioner knowledge
Goddard & Smith 1998	Total Pop	Systematic Review	Minority ethnic groups Experience inequity Inequality No systematic inequity in terms of socio-economic status – exists in some specialities elderly people do experience some inequity Those living further away from Care location have less utilisation Geographical location Communication Consultation Referral
Li *et al.* 1999	Chinese	Survey – Chinese Health Questionnaire (CHQ)	Participants delayed contact with GP when ill GP was first port of call for 27% only 74% encountered difficulties in seeking professional help inequality Language barriers effective Communication main determinant Lack of knowledge of services Lack of access to bi-lingual Health professionals Cultural clash Mental health

			Service provision Social exclusion
Modood *et al.* 1997	Minority Communities	Fourth National Survey	Chinese pop less likely to consultant GP All other groups' consultation Increased with perceived ill Health, especially Pakistani & Bangladeshi Quality of care poorer than white Population Under referral to 2° Language/Communication Access to PHC Inequality
Nazroo, J 1997	Minority Communities	Fourth National Survey	ditto
Rao & Stewart	Asians	Retrospective Cohort Study	Wide variation in Diabetes Care 2000 but not statistically significant GP Reluctance to take part Equity of Care
Smaje, C 1998	Total Pop	2° Analysis of GHS	Access to PHC Language Discrimination Inequality Service Provision Equity/fairness Social Capital Geographical location
Smaje & Le Grand 1997	Total Pop	2° Analysis of GHS	GP consultation as higher or higher in ethnic groups then white population Important ethnic differences Access to PHC Utilisation/need
Stewart & Rao 2000	Asian	Retrospective Cohort Study	Inequality GP reluctance to participate

Appendix 5

Review of Department of Health – Policy Directives & Initiatives

Date	Document	Comments
15.11.2001	Personal Social Services User Experience Survey 2000-2001	Survey identifies the acknowledge of cultural, race or religious factors within the delivery of social care services – 148 councils participated
19.7.2001	Improving working Lives Standards	Commits all NHS Employers to improve all aspects of working lives and meet their obligations under Race Relations (Amendment) Act
8.2.2001	Detained	Social Services Inspectorate inspection report gives a detailed account of the effectiveness of care for people detained in psychiatric hospitals including anti-discriminatory practice
24.1.2001	The 1999 Health Survey for England	Focuses on Black Caribbean, Indian, Pakistani, Bangladeshi, Chinese and Irish communities both adults and children
13.6.2000	Strategy - £1 million announced for projects to reduce smoking among ethnic groups	Specifically Bangladeshi men, Irish and Black Caribbean men
April 2000	The Vital Connection	Equalities Framework
2000	Positively Diverse	Promoting change in the culture of the NHS in managing diversity
18.4.2000	Sick of being excluded	Partnership working to tackle health inequalities that black and minority ethnic groups in London face
27.1.2000	Tackling Race Inequalities in the Health and Social Care Services	Measure to ensure that the needs of people and minority ethnic communities are given full consideration by health and social care services
Dec 2000	Race Relations Amendment Act	The Act imposes a statutory duty on all NHS employers to promote race equality, also puts the onus on NHS employers to show they are taking determined action to combat racial harassment in their organisations
12.5.1999	The Mental Health Act Commission – 2nd National visit	Unique snapshot of care and treatment of people from black and minority ethnic groups
March 1999	Tackling Racial Harassment – A plan for actions	NHS Directive – HSC1999/060
October 1998	Health Directories	A series of directories detailing health imitative for black and minority ethnic groups

Appendix 6
Letter to potential participants

HEADED NOT PAPER OF PRACTICE

Dear

Re: Research project investigating how having high blood pressure affects and influences African Caribbean patients' lives and the health services provided.

The GP's and practice nurses at your surgery have agreed to assist a researcher Gina Higginbottom from the University of Sheffield, to conduct the above mentioned research project. Gina is seeking individuals who would like to participate in the research. She has a particular interest in Black and Minority health issues. Participating in the research will mean that you will be interviewed or take part in a discussion group on one occasion. Travel expenses will be reimbursed. The interview or discussion group will be entirely focused on your experience of having a high blood pressure. It is important this type of research is conduced to enable African Caribbean communities to have their health needs met by the National Health Service. The NHS Executive is funding and supporting the research.

If you would be willing to meet Gina to find out more about the research please will you complete the slip below and return to the surgery in the free post envelope with this letter (no stamp required). Gina will then arrange a convenient time and place to give you more information. You can withdraw from the research at any stage and participation in the research will not affect in anyway the health services or treatment you are receiving at present. The information Gina collects will not be shared with you GP or practice nurse and no one be able to identify you. You are not obliged to take part in the research. Many thanks.
Yours sincerely,

Dr.

I would/would not like to discuss with the researcher Gina Higginbottom participating in the research project on high blood pressure.
Please contact me by telephone.....................................between the hours of..
by letter please provide
address...
....
....
Please delete as appropriate and return in the freepost envelope

Appendix 7
Examples of community groups contacted

<table>
<tr><td>'Anna Revill
Black Community Forum
Unit 114
SYAC Centre
120 The Wicker
Sheffield. S3 8JD</td><td>Arthur Bennett
All Saints Church
All Saints Street/Raleigh Street
Radford
Nottingham
NG7 4DP</td></tr>
<tr><td>Barry Lomas
North Radford Residents Group
C/o High Cross Community Room
Highcross Court
Radford
Nottingham</td><td>Bev Brown
Vice Chairperson
Sojourner Black Womens Group
The Hub
Sitwell Road
Sheffield. S7 1BG</td></tr>
<tr><td>Constance Davies
Castle Black Womens Group
The Space
Park Library
Duke Street
Sheffield. S2 5QP</td><td>David Jones
All Souls Church
All Souls Church & Community Centre
Ilkeston Road
Nottingham.
NG7 3HF</td></tr>
<tr><td>Rev Delroy Hall
Duke Street African-Caribbean Community Centre
Duke Street
Sheffield.
S2 5QL</td><td>Gill Dennis, Team Leader
Hub African-Caribbean Youth Project
Sitwell Road
Sheffield.
S7 1BG</td></tr>
<tr><td>Isadora Aiken
Sadacca Black Womens Group
Sadacca
48 The Wicker
Sheffield
S3 8JB</td><td>Joan Williams
Co-ordinator
204 Verdon St
Sheffield.
S3 9QS</td></tr>
<tr><td>Keith Levy
Sadacca Mens Group
48 The Wicker
Sheffield
S3 8JB</td><td>Mr M Atkins, Chairperson
Caribbean Sports Club - Black People and Ethnic Minorities
The Common
Ecclesfield
Sheffield.
S35 9WL</td></tr>
</table>

Appendix 7
Examples of community groups contacted

Clinton McCoy Sadacca Elderly Daycare Centre 4 Willey Street The Wicker Sheffield. S3 8JU	Mr Milton Samuels Sadacca Elderly Daycare Centre 4 Willey Street The Wicker Sheffield. S3 8JU
Mrs Pam Sumner, President Sadacca Elderly Daycare Centre 4 Willey Street The Wicker Sheffield. S3 8JU	Muna Deria/Ramchand Samachetty Black Health Forum Room 3/4 SYAC Centre 120 The Wicker Sheffield. S3 8JD
New Deal for Communities Provident Works Newdigate Street Radford Nottingham. NG7 4FD	Raphael Richards, Programme Co-ordinator Black Palm (Partnerships, Advocacy, Learning and Mentoring) The Hub Sitwell Road Sheffield. S7 1BG
Ricky Bennett Lets Face It C/o Sadacca 48 The Wicker Sheffield S3 8JB	Rosemary Jarrett St Pauls Avenue Residents Association C/o Hyson Green Community Centre St Pauls Avenue Hyson Green Nottingham NG7 5EB
Miss S Brown Childcare Co-ordinator Black Womens Resource Centre Children's Project 72b Burngreave Road Sheffield S3 9DD	Samantha Beeby ACFF Education Centre 28 Beaconsfield Street Hyson Green Nottingham NG7 6FD
Sharon Brown Childcare Co-ordinator Black Womens Resource Centre 72a Burngreave Road Sheffield. S3 9DD	Stephen Brown LARNA (Lenton & Radford Neighbourhood Association) All Souls Community Centre Ilkeston Road Nottingham. NG7 3HF
Trenton Wiggan/Satish Sachdeva Co-ordinator/Amineh Salehi, Enrolments Sheffield Positive Action Training Consortium (SPAT-C) C/o SYAC Centre 110-120 The Wicker Sheffield. S3 8JD	Vaness James Health Promotion Office/ Outreach Worker (Caribbean Communities). Linden House 261 Beechdale Road Nottingham. NG8 3EY

Appendix 8
Example of letter to community groups and associations

Community Sciences Centre
Northern General Hospital
Herries Road
Sheffield S5 7AU
Fax: 0114 242 2136

Direct Dial Inward: (0114) 271 5733
Email: G.Higginbottom@sheffield.ac.uk

Ref. GH/DW/17.09.01

Black Community Forum
Unit 114
SYAC Centre
120 The Wicker
Sheffield. S3 8JD

17th September 01

Dear

Re: The Meaning and Consequences of Hypertension for Individuals of African Caribbean Origin: Perceptions of Primary Health Care Services.

I am writing to ask if there are members of your association who will be willing to participate in the above mentioned research project.

You may know that high blood pressure (hypertension) is a major health problem for the African Caribbean community in the United Kingdom. The National Health Service are very keen to seek out ways of improving the prevalence of high blood pressure within the African Caribbean community and they have funded the above mentioned study via a National Primary Care Researcher Development Award.

Participation in the study will mean that individuals would take part in either an interview or a small discussion group. All travel expenses will be re-imbursed however; there is no payment for taking part. All the information that is collected in the study will be entirely confidential and no-one will be able to identify participants by name.

I would be very grateful indeed if you would ask members of your association who have hypertension if they would be willing to participate in the study.

I enclose pre-paid envelopes for your replies.

Please do not hesitate to contact me if you require further information about the study or indeed if you would wish me to come to your group to give a brief presentation, I will be very happy to do so.

Many thanks in anticipation.

Yours sincerely

Gina Higginbottom,
Lecturer/National Primary Care Research Fellow

Appendix 9

Focus group interview: topic Guide

Informal Introductions

Diagnosis of hypertension

- When was this
- What alerted you to the possibility you may have hypertension/symptoms/illness/how manifested
- Professional v lay help – opinions, view of friends/relatives/colleagues/GP/practice nurse/NHS Direct/walk in clinic
- What prompted help seeking behaviour – attitudes and behaviours/judgements and decision making
- Feelings when given diagnosis of hypertension

Lived experience of hypertension – mapping out nature and form of the experience

- Do you worry about your high blood pressure/what are the consequences of having high blood pressure
- If so who did you share your worries with professionals/friends/relatives
- How does having high blood pressure effect your life – impact on life experiences
- Does the fact that you have high blood pressure effect other family members of friends
- What modifications have you made to your life style
- Mapping out/explore language and terms African Caribbean people use to describe this experience
- Differences and association between experiences

Knowledge of condition

- What do you understand by high blood pressure – sources of information/professionals/books/TV/friends/relatives
- Is high blood pressure the same as hypertension
- To what extend do you think is could be prevented/explanations for explicit and implicit
- What can you do to prevent/manage/control your high blood pressure barriers/obstacles/mitigating factors/enhancing factors/ cultural socio-economic factors
- Why do you think that African Caribbean people in the UK suffer from high blood pressure – explore reasons

- Is the experience of high blood pressure the same in the UK as the Caribbean

Current treatment

- How often do you see your GP/Practice nurse/what treatment are you receiving
- How does what GP/Practice nurse say influence what you do?
- Medication – number and types/changes – knowledge of reasons for/concordance
- Do you always take note of what the GP/practice nurse say – how does this influence your life
- Explore other forms of treatment, exercise, diet, relaxation
- Do you take any other remedies e.g. traditional herbal remedies/if so which do you think is more effective/do you share this information with health professionals
- Are you able to obtain traditional remedies if you need them/ how did you find about traditional remedies
- Do you think the current PHC services meet your needs/how can they be improved

In the future

- High blood pressure is difficult to detect – how do you think we could improve detection
- Explore mechanisms TV/radio/media/PHC services/schools/occupational health
- In the future do you think you own hypertension can be resolved/improved/views on future health status

Invite further involvement in project

Appendix 10
Semi-structured interview topic-guide

Diagnosis of hypertension

- When was this
- What alerted you to the possibility you may have hypertension/symptoms/illness/how manifested
- Reflecting how long do you think you had high b/p – symptom recognition
- Why participant did not seek help earlier
- Professional v lay help – opinions, view of friends/relatives/colleagues/GP/practice nurse/NHS Direct/walk in clinic
- Decisions to seek help
- What prompted help seeking behaviour – attitudes and behaviours/judgements and decision making
- Feelings when given diagnosis of hypertension
- Reception from gp/practice nurse

Lived experience of hypertension – mapping out nature and form of the experience

- Do you worry about your high blood pressure/what are the consequences of having high blood pressure
- If so who did you share your worries with professionals/friends/relatives
- How does having high blood pressure effect your life – impact on life experiences
- Does the fact that you have high blood pressure effect other family members of friends
- What modifications have you made to your life style
- Mapping out/explore language and terms African Caribbean people use to describe this experience
- Differences and association between experiences

Knowledge of condition

- What do you understand by high blood pressure – sources of information/professionals/books/TV/friends/relatives
- Is high blood pressure the same as hypertension
- To what extend do you think is could be prevented/explanations for explicit and implicit
- What can you do to prevent/manage/control your high blood pressure barriers/obstacles/mitigating factors/enhancing factors/ cultural socio-economic factors
- Why do you think that African Caribbean people in the UK suffer from high blood pressure – explore reasons

- Is the experience of high blood pressure the same in the UK as the Caribbean

Current treatment

- How often do you see your GP/Practice nurse/what treatment are you receiving
- How does what GP/Practice nurse say influence what you do?
- Medication – number and types/changes – knowledge of reasons for/concordance
- **Concordance**
- Do you always take note of what the GP/practice nurse say – how does this influence your life
- Explore other forms of treatment, exercise, diet, relaxation
- Do you take any other remedies e.g. traditional herbal remedies/if so which do you think is more effective/do you share this information with health professionals
- Are you able to obtain traditional remedies if you need them/ how did you find about traditional remedies
- Do you think the current PHC services meet your needs/how can they be improved

In the future

- High blood pressure is difficult to detect – how do you think we could improve detection
- Explore mechanisms TV/radio/media/PHC services/schools/occupational health
- In the future do you think you own hypertension can be resolved/improved/views on future health status

Invite further involvement in project

Appendix 11
Vignettes

Vignette 1

Mrs Pearl Campbell is 60 years of age; she came to England 40 years ago from Jamaica. At the time her aunt and cousin were in Sheffield, as she wanted to travel and find a better way of life, she decided to join them. Pearl had ambitions to become a nurse, however soon after she arrived in Sheffield she met and married her husband George and very soon afterwards became pregnant with her first child.

To begin with Pearl was extremely homesick as the place was so grey, wet and not everyone was as friendly as she hoped. The family had to move house once because of racist neighbours. Although she had five children Pearl has always worked in Bassets sweet factory, the work was quite tough as it involved lifting trays of heavy sweets. During her employment she worked the 'twightlight' shift 6pm – 10 pm, this meant she could be at home with the children until George returned in the evening. Life was pretty tough with not much money to spare with five children to feed and clothe, however Pearl was a thrifty and resourceful housewife, something she put down to her upbringing in the Caribbean. Pearl baked every other day so the children would have plenty to fill up on and George was not keen on English food, so the family rarely ate English food at home.

During her third pregnancy Pearl developed high blood pressure. Pearl was not unduly worried about this, as she knew her Mum and Sister also suffered from high blood pressure, and it was not really a very serious condition. When Pearl returned for her 6-week post-natal check her blood pressure was still high, so the doctor gave her a course of tablets to take her blood pressure down. Pearl was not too happy about this; she did not like taking tablets and believed they could be addictive. She was angry and cross that she had been given these pills, so she put the tablets in away in a plastic lunch box but she knew she had not intention of taking the tablets. She wasn't convinced that the hospital doctor knew what is talking about or could read the blood pressure machine. Pearl had heard from friends doing nursing how hard it was to read the machine. Pearl talked to her aunt about this and her aunt recommended Singer Bible as being very good for high blood pressure. Her aunt knew a man who treated for high blood pressure in England, but his blood pressure was still high. He went home to Jamaica on holiday and tried Singer Bible and it came right down and he felt much better. Pearl decided to stick to the traditional Caribbean remedies, as she knew they worked and were also more wholesome and natural.

Pearl went to see her GP he took her blood pressure and found that it was still high, he asked if she was taking the tablets she said yes even though she was not. She thought he might be angry if she told the truth, even though Pearl liked her GP and knew he was trying his best. The GP decided to change the tablets as the first lot did not appear to be working. Pearl collected the new tablets when she got home she read the drug information leaflet and noticed the tablets could cause liver and kidney damage. Pearl thought – '*that is there is no way I am taking those pills*'.

The next two times Pearl's blood pressure was more stable, her GP seemed pleased with the effects of the new tablets (which Pearl had not taken). During this time Pearl had taken many natural remedies as she could to maintain her general health and well-being. She was taking cerasee every day in addition to the bush tea Singer Bible. Her friend Eunice was going to Jamaica, so Pearl give her list of 'bush' she wanted her to bring back to last her a least a year.

Pearl had a good circle of friends at the Church of God of Prophecy, she started to wonder, because one of the sisters who used to work in a hospital had mentioned that blood pressure was a 'silent disease' meaning it could cause damage without the person knowing. Pearl felt quite well; she did know another of the elders who had high blood pressure who had a stroke. Pearl wondered what all this meant for her.

Vignette 2

Lincoln was in his late forties, he came to England from Jamaica when he was 9 years of age to join his parents, who migrated a few years earlier to establish themselves. He found it hard at first when they left him behind in Jamaica, although he lived with his Grandmother, he felt slightly abandoned by his parents. Although, his parents provided well for him and his Grandmother sending money and a barrel at least twice a year.

Lincoln could still remember his first day at school in St Anne's Nottingham, a lot of the kids made fun of his accent. Also he arrived in winter and could not seem to get warm. As he was growing up in the 60's and 70's he and his friends did put up with quite a bit of abuse from the local skinheads and they had to learn to stick up for themselves. Some of his own personal experiences motivated his decision to train as a social worker. At times the job was a strain, this was not just related to the young people he was working with, Lincoln believed the organisation had some racist workers and policies. He felt it his duty to challenge racism in a professional context. He felt bitter because although he had a good track record a number of younger white colleagues had gone on to senior positions, whilst he seemed to be working twice as hard as everyone else, without recognition.

He worried a lot about some of the kids and how they would end up. Sometimes on an evening he find it hard to relax, so he liked to have a drink sometimes rum or barley wine. Often he woke up in the morning with headaches and did not feel too good. He began to feel annoyed if he could not manage to call in the pub on his on way home from work.

The headaches he experienced became more frequent, but he thought no point in '*running to the doctor*' best wait a while and see how things progress. After about 6 months things were getting no better, so he decided to visit his GP. Lincoln got on well with his GP he had changed because he believed his previous GP was not giving him and his family they service they deserved. His GP decided to take his blood pressure. Lincoln was shocked to find his blood pressure was high, he thought only old people had high blood pressure. How could a person as young as him have high blood pressure. The GP mentioned that heavy drinking was not good for your blood pressure, so Lincoln decided to cut out alcohol. Lincoln wondered also if his diet contributed, although he came to England as a child he did prefer to eat Caribbean food, which he thought, could have too much carbohydrate and fat.

Lincoln took the tablets as directed and he began to feel better, however he did notice he became impotent and could not have sex with his wife. When he read the information leaflet he found this was side effect, so he stopped taking the tablets. He was annoyed as he thought the doctor should have told him this. A couple of months later he was not feeling so well, he returned to the doctor and explained his situation. The GP gave him new tablets, which seemed to work well, however he also developed a stomach ulcer and had to take medication. Lincoln was concerned he was taking too many tablets, so he decided to take control of the issues, by adjusting both his blood pressure and ulcer tablets according to how he was feeling. If he felt ok he did not take the tablets and if he felt bad he did.

Vignette 3

Mr Henry is 72 year of age he came to England from Jamaica 47 years ago, he hoped to improve himself and find a good job in a trade. At the time workers were in short supply in England, so he was sure he was making the right decision, in any event he only planned to stay for five years and save enough money to secure his future in Jamaica. He found a job at British Steel, Sheffield there he met his wife Marva who worked in the canteen. Although they had up and downs in life in England, he had the satisfaction of knowing that his three children all had done well, all had gone on to University. The eldest was a teacher, the second an architect and the youngest worked in banking in London, and was already earning more then the first two.

When he was in Jamaica he had never visited a doctor he had heard of one in the Montego Bay but only the rich were able to visit a doctor as it cost quite bit. One of the good things about England was the National Health Service, although during the 60's he was perturbed to find that every time he visited the doctor no matter what the complaint he was given a bottle of white medicine. Mr. Henry was convinced that this white mixture was a waste of time; it just did not appear to have any effect whatsoever. A friend of his also told him that all black people had their hospital notes marked with a black circle, he did not think this was quite right. Down at the domino club a few of the men were talking about organising a trip to Derby to see Dr.Ali a private doctor who could give far better medicine then on the NHS. Also as Dr.Ali was Indian and he seemed to treat Jamaican people who visited him with far more respect then the NHS doctors. Mr. Henry decided to visit him also and he was extremely impressed with the treatment, although it was expensive and the medication costly he could not believe the quality of care he received. Some of his friends were sceptical about the private GP and made a joke of it, he thought perhaps they were a bit jealous as they could not afford a private GP.

Shortly following this on a routine visit to his GP Mr Henry was diagnosed with high blood pressure. Mr. Henry thought his was just part of getting older, he was not unduly concerned as he did not have any symptoms. The thing that caused him more anxiety was his 'sugar' as his levels were so up and down, he thought the blood pressure was a very minor complaint. However, he thought he had better visit Dr.Ali the private GP, as he was not convinced that he was getting the best blood pressure tablets from his NHS GP. The consultation with Dr.Ali as usual was excellent, Mr Henry could not believe a person of such standing a doctor would treat him so well. He obtained a new prescription that cost £14.00 however when his youngest son visited from London he looked at the tablets and said – *"Dad these are the same as the tablets you already have from your NHS GP!"* Mr Henry started to question his decision to visit a private GP.

Appendix 12
List of codes from a single interview

|HU: AFCH Interview 10
File: [c:\program files\scientific software\atlasti\HPRB393]
Edited by: Super
Date/Time: 2003/08/19 - 07:53:48

Code-Filter: PT
---------------------------------------!

alcohol
consequences
consultations
diagnosis
diagonsis - significant events
duration of hypertension
Explanations - socio-economic
explantions for hypertension
family members
Feelings on diagnosis
help seeking behaviour
herbal remedies
hypertension knowledge
in frequent use of PHC
information sources
lack of insight
lay explanations
lifestyle modifications
maintaining lifestyle
medication - knoweldge
medication - number
no symptoms
non- concordance
nurse consultation
other illnesses
PHC - improvements
Private GP
professional advice
rationalising illness
risk factors
satisfaction with PHC
smoking
support networks
symptoms now

Appendix 13
Atlas/ti. code list: total data set

HU: AFCH
File: [c:\program files\scientific software\atlasti\HPRB393]
Edited by: Super
Date/Time: 2003/06/24 - 12:30:03

Codes-Primary-Documents-Table

Code-Filter: All
PD-Filter: All
* software does not allows text in the available space

	PRIMARY DOCS																								
CODES	1	2	3	4	5	6	7	8	10	11	12	13	14	16	17	19	22	23	27	29	30	32	39	40	41	Totals
acceptance *	1	0	0	0	0	0	0	2	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	0	0	5
Acting on advice	0	0	0	0	2	0	0	0	1	1	1	1	0	1	1	0	0	0	0	0	0	0	0	0	0	8
Adaption	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	1
AFC experience of hy	1	7	1	0	0	0	1	1	4	0	2	1	0	1	1	0	0	0	0	0	0	0	0	0	1	21
alcohol	0	2	3	0	4	2	1	1	0	0	1	1	0	0	1	0	0	0	0	0	0	0	0	0	2	18
anger	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3	0	0	0	0	0	3
Aspirations	2	0	1	0	0	0	1	2	1	0	1	0	1	0	2	0	0	0	0	0	0	0	0	0	0	11
awareness of body fu	0	0	0	0	0	0	0	0	0	1	0	0	2	2	0	0	0	0	0	0	0	0	1	0	0	6
b/p under control	0	1	0	0	0	0	0	0	0	0	0	1	0	2	0	0	0	0	0	0	0	0	0	0	0	4
belonging	0	0	0	0	0	0	0	0	0	0	0	0	3	0	0	0	0	0	0	3	0	0	0	0	0	6
bereavement	0	0	0	0	0	0	0	0	0	0	0	0	3	0	0	0	0	0	0	0	0	0	0	0	0	3
biomedical perspecti	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	1
blood,liver and kidn	0	0	0	0	0	0	0	0	0	0	0	0	0	22	0	0	0	0	0	0	0	0	0	0	0	22
Bounds of profession	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Caribbean family tra	2	0	0	0	0	0	0	0	0	2	4	0	0	1	2	0	0	0	0	0	0	0	0	0	0	11
cause of high blood	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	7	0	0	0	0	0	
caution in using her	0	0	0	0	0	0	0	0	0	0	0	0	0	3	0	0	0	0	0	0	0	0	0	1	0	4
concordance	0	0	0	0	0	0	0	0	2	4	0	1	3	4	1	0	0	0	2	0	0	0	0	0	0	17
consequences	4	3	3	2	2	1	2	1	4	0	3	2	1	2	2	0	0	0	0	1	0	0	0	5	0	38
consultations	3	5	1	0	5	1	1	3	1	1	1	1	1	1	2	0	0	0	1	0	0	0	0	0	0	28
Consultations -secon	0	0	1	0	2	0	0	5	0	0	0	0	0	3	0	0	0	0	0	0	0	0	0	0	0	11
denial	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1

Appendix 13

Atlas/ti. code list: total data set

Depression	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1
detection of hyperte	0	0	0	0	0	0	1	3	3	0	0	4	0	1	2	0	0	0	0	0	0	0	0	0	0	14
diagnosis	0	1	1	2	0	2	3	1	1	0	2	4	0	0	0	0	0	0	1	0	0	0	0	0	0	18
diagnosis - medicati	1	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	2
diagonsis - signific	2	3	1	1	0	1	0	0	0	4	2	1	1	2	0	0	0	0	0	0	0	0	2	0	2	22
diet	0	5	1	1	0	0	1	2	2	0	1	4	1	2	4	0	0	0	0	0	0	0	1	1	0	26
disappointment	0	0	0	0	0	0	0	0	0	0	4	0	0	0	0	0	0	0	0	1	0	0	0	0	0	5
Don't believe in doc	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Don't discuss	0	0	0	0	0	0	0	0	0	0	2	0	2	0	0	0	0	0	0	0	0	0	0	0	0	4
don't use private gp	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	1
duration of hyperten	0	1	1	0	2	1	1	1	1	1	1	1	1	1	1	0	0	0	0	0	0	0	1	0	0	15
effects of migration	0	0	0	0	0	0	0	0	0	0	1	0	1	0	1	0	0	0	0	0	0	0	0	0	0	3
elevated blood press	1	1	0	0	0	0	0	0	0	1	4	0	2	3	3	0	0	0	0	0	0	0	0	0	1	16
empowerment	0	0	0	0	1	0	0	0	0	0	0	1	1	1	1	3	0	0	0	0	0	0	0	1	1	10
enviroment	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3	0	0	0	1	0	4
event pre-diagnosis	0	3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3
exercise	0	0	0	0	0	0	1	1	1	0	0	0	0	0	1	0	0	0	0	0	0	0	0	1	0	5
exhaustion	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1
Explanations - socio	0	0	0	0	1	2	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	4
explantions for hype	0	22	4	4	2	2	0	0	0	0	3	3	2	2	1	0	0	0	0	0	0	0	0	3	1	49
Faith & Religion	0	0	0	0	1	0	0	0	0	0	4	0	0	6	0	0	0	0	0	0	0	0	0	0	0	11
family discussions	0	0	0	0	0	0	0	5	0	0	0	1	0	3	0	0	0	0	0	0	0	0	0	0	0	9
Family medical histo	0	0	0	0	0	0	0	0	0	0	0	0	2	1	4	0	0	0	0	0	0	0	0	0	0	7
family members	4	0	1	0	0	1	0	3	0	1	3	0	1	0	0	0	0	0	0	0	0	0	0	0	1	15
Family relationships	4	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	5
Fatalistic views	0	0	0	0	0	0	1	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3
fear	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	2
Feelings on diagnosi	1	1	0	0	0	1	1	3	3	1	1	1	1	1	1	0	0	0	0	0	0	0	0	1	0	17
GP - risk perception	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
GP - veracity	1	0	0	0	1	0	0	0	0	6	0	0	0	1	0	0	0	0	0	2	0	0	0	0	0	11
GP relationship	0	0	0	0	0	0	0	0	0	0	0	2	1	0	2	0	0	0	0	0	0	0	0	0	0	5
Health professionals	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
help seeking behavio	2	1	0	0	0	1	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	5
herbal - generationa	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3	0	3
herbal - sources of	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	2	0	4
herbal remedies	4	13	0	1	3	1	4	13	1	6	11	1	11	9	4	0	0	0	5	0	0	0	4	5	0	96
herbal remedies - in	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1
herbal remedies + pr	0	2	0	0	1	0	0	0	0	0	0	2	0	0	0	0	0	0	0	1	0	0	1	1	0	8
hereditary	0	0	0	0	0	0	0	1	0	0	0	0	2	0	1	0	0	0	0	0	0	0	0	0	0	4
high blood pressure	0	0	0	0	0	0	0	5	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	5

Appendix 13
Atlas/ti. code list: total data set

historical anteceden	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2
holidays	0	0	0	0	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	0	0	0	1	0	0	3
Hypertension - detec	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
hypertension knowled	11	2	2	9	0	6	5	3	2	0	4	3	2	1	4	1	0	0	1	1	0	0	0	0	0	57
hypertensive types	0	1	0	3	0	0	0	0	0	0	0	0	0	2	2	0	0	0	0	1	0	0	0	0	0	9
I never think about.	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	2
Impotence	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1
in frequent use of P	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
inequalities	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
information sources	3	2	1	0	3	4	3	1	3	0	1	1	3	1	2	0	0	0	0	1	0	0	0	0	0	29
knowledge of family	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2
lack of information	0	2	1	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	3	0	0	0	0	0	8
lack of insight	0	0	2	3	0	3	0	2	0	0	2	0	1	6	1	0	0	0	0	0	0	0	0	0	0	20
lack of recognition	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1
lack of stigma	0	0	0	0	2	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	3
language	1	2	0	0	0	0	0	1	1	0	1	0	1	0	2	0	0	0	0	0	0	0	0	0	0	9
lay diagnosis	0	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2
lay explanations	8	16	2	2	2	2	2	8	1	0	0	0	1	3	1	0	0	0	0	3	0	0	2	10	0	63
Level of attention	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
lifestyle modificati	2	3	1	0	3	4	1	3	0	0	2	1	5	1	2	0	0	0	0	2	0	0	0	0	0	30
limitations of herba	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2
loss of control	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	1
Love life	0	0	0	0	0	0	0	0	0	0	1	0	0	1	1	0	0	0	0	0	0	0	0	0	0	3
Maintaining educatio	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
maintaining lifestyl	2	5	0	0	0	1	0	4	0	0	1	0	0	2	2	0	0	0	0	1	0	0	0	0	0	18
Managing blood press	2	2	0	0	0	0	0	3	4	0	3	1	2	1	2	0	0	0	0	0	0	0	0	0	0	20
med- wrong precripti	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
medicatiion - wrong	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	1
medication	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	1
medication - changes	0	0	1	0	1	0	1	1	0	0	3	0	0	4	0	0	0	0	0	1	0	0	0	0	0	12
medication - dislike	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1	0	0	1	1	0	4
medication - knoweld	2	0	2	0	0	1	0	0	0	2	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	8
medication - limitat	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
medication - number	1	3	0	1	2	1	1	1	1	2	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	15
medication - side ef	2	0	0	0	1	0	0	1	0	0	2	0	5	5	3	0	0	0	1	4	0	0	0	0	0	24
medication - type	3	0	0	0	0	0	0	0	1	0	0	1	0	0	1	0	0	0	0	1	0	0	0	0	0	7
medication efficacy	0	0	0	0	0	0	0	0	0	0	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	2
medication fear	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	2
more damage then goo	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1
n fact you have too	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1

Appendix 13
Atlas/ti. code list: total data set

new forms of PHC	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
no side effects	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
no symptoms	0	0	0	0	0	3	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	5
no worry	0	0	0	0	0	0	0	0	0	0	0	1	0	1	3	0	0	0	0	0	0	0	0	0	0	5
non- concordance	3	4	2	0	0	2	0	10	0	0	6	0	5	0	2	0	0	0	0	0	0	0	4	0	5	43
non-use of herbal re	1	0	2	0	1	0	1	0	1	0	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	8
non-verbal communica	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
nose bleeds	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
nurse consultation	1	1	1	0	2	1	0	0	0	0	1	0	0	3	0	0	0	0	1	0	0	0	0	0	0	11
obesity	0	0	0	0	0	0	1	0	1	0	0	0	2	0	0	0	0	0	0	1	0	0	0	0	0	5
Older AFC people	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2
opression	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	2
other illnesses	1	0	2	0	2	1	1	2	0	4	0	2	0	2	0	0	0	0	0	0	0	0	0	0	0	17
Patient - veracity	1	0	0	0	0	0	2	0	0	2	1	0	0	0	1	0	0	0	2	1	0	0	2	0	2	14
Perceived racism	0	0	0	0	2	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3
perservation mechani	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
PHC - changes	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	2
PHC - dissatisfactio	0	2	3	0	3	0	0	8	0	1	2	9	0	0	8	3	0	0	0	2	0	0	2	3	3	49
PHC - improvements	0	2	0	3	0	5	1	5	3	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	20
PHC - new forms	0	0	0	0	0	0	1	1	0	0	0	1	1	0	1	0	0	0	0	0	0	0	0	0	0	5
PHC - Strategic view	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	2
PHC -use	0	0	0	0	0	0	0	0	0	0	3	0	0	2	1	0	0	0	0	0	0	0	1	2	0	9
PHC in the Caribbea	0	0	0	2	4	0	0	0	0	0	4	1	0	0	0	0	0	0	0	0	0	0	2	2	0	15
Pressure of life	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	2
Prevention of high b	0	3	0	0	1	0	0	1	3	0	3	3	3	0	3	0	0	0	0	0	0	0	0	0	0	20
Private - GP ethnic	0	0	0	0	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3	5
Private GP	0	0	0	0	9	1	0	1	0	3	2	0	0	2	2	0	0	0	1	0	0	0	3	1	4	29
Private GP - other t	0	0	0	0	2	0	0	1	0	1	1	0	0	0	0	0	0	0	0	0	0	0	2	0	1	8
professional advice	0	2	0	1	2	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	7
racism	0	0	0	0	0	0	0	14	0	0	0	0	4	0	1	0	0	0	0	0	0	0	0	0	0	19
raising awareness of	0	3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3
rationalising illnes	0	1	0	3	2	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	7
Relationship with GP	1	1	0	0	0	0	1	2	0	0	0	0	2	0	1	0	0	0	0	0	0	0	0	0	0	8
relaxation	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	2
rest	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	2	0	4
Returning home	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	2
risk factors	0	2	1	0	0	1	0	2	0	0	1	2	0	1	0	0	0	0	0	0	0	0	0	0	0	10
risk perception	5	0	0	0	1	0	0	0	0	0	0	0	2	1	0	0	0	0	0	0	0	0	0	0	0	9
satisfaction with PH	1	1	1	1	4	2	2	3	2	2	1	3	3	2	3	2	0	0	1	0	0	0	1	0	2	37
secondary care	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3	0	0	0	0	0	3

Appendix 13
Atlas/ti. code list: total data set

self-medication	3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3
self determination	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2
shame/stigma	0	0	0	0	0	0	0	4	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	6
Sickness is not part	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
silence on blood pre	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
smoking	1	3	1	1	0	3	0	1	0	0	0	1	0	0	2	0	0	0	0	0	0	0	0	0	0	13
social life	0	0	0	0	1	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	2
socio-economic facto	0	0	0	0	0	0	1	0	1	0	0	1	2	1	1	0	0	0	0	0	0	0	0	0	0	7
Sometimes things can	1	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	2
stress	6	0	1	6	0	0	1	4	0	0	5	3	4	0	21	0	0	0	0	1	0	0	0	2	2	56
struggle in Britain	0	0	0	0	0	0	0	2	0	0	1	0	5	1	2	0	0	0	0	3	0	0	3	2	1	20
Support	0	2	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	3
support networks	1	1	2	0	1	2	0	1	0	0	3	0	1	1	2	0	0	0	0	0	0	0	0	0	0	15
symptoms - pre-diagn	6	2	1	0	0	0	1	5	0	1	2	6	2	3	3	0	0	0	0	1	0	0	1	4	0	38
symptoms now	0	1	2	0	0	1	0	2	0	0	4	1	2	3	0	0	0	0	3	6	0	0	0	0	1	26
treatment choices	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1
treatment stopped	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Trust/belief in GP	0	0	0	0	0	0	0	3	0	0	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	5
types of herbal reme	3	0	0	0	0	0	0	0	0	2	0	1	1	7	2	0	0	0	2	0	0	0	3	4	0	25
unanswered questions	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1
variation in blood p	0	3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3
washouts & purges	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	5	0	5
weight loss	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	2
weight loss obsessio	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1
which is playing up	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
work/occupation	0	0	0	0	0	0	0	6	0	0	2	2	6	1	6	0	0	0	0	7	0	0	0	0	0	30
worry	2	19	4	11	2	0	8	1	2	0	1	0	2	4	1	0	0	0	0	2	0	0	0	1	0	60
Totals	115	169	54	58	88	63	53	171	53	50	119	81	119	146	136	9	0	0	22	84	0	0	46	64	37	1737

Appendix 14

Graphic representation of codes illustrating Interviewee 19's explanatory model of high blood

Legend: Co = associated with

Appendix 15
List of memos created during analysis

HU: AFCH
File: [c:\program files\scientific software\atlasti\HPRB393]
Edited by: Super
Date/Time: 2003/06/24 - 14:10:20

Memo-Filter: All

"be careful, don't let me have a stroke.->5:70 {1/Co} - Super
5 minutes {1/Co} - Super
Adrenalin rush {0/Co} - Super
AFC experience of hypertension->2:68 {1/Co} - Super
Ageism {1/Co} - Super
alcohol {1/Co} - Super
anxiety->1:60 {0/Co-F} - Super
b/p mechanism not working smoothly {0/Co} - Super
Black on black {1/Co} - Super
blood,liver and kidneys->16:34 {1/Co} - Super
Bounds of professional conduct->5:18 {1/Co} - Super
by chance {1/Co} - Super
Can't read {1/Co} - Super
cannabis {1/Co} - Super
causes of high b/p {1/Co} - Super
causes pressure in the head {0/Co} - Super
Change of GP {1/Co} - Super
Changes in the Caribbean {1/Co} - Super
childcare {1/Co} - Super
Chronic nature {1/Co} - Super
Complimenting NHS phc {1/Co} - Super
conk out->3:15 {1/Co} - Super
contracdictions {1/Co} - Super
Contradiction {1/Co} - Super
Contradictions {1/Co} - Super
Crazy people {1/Co} - Super
danger of too much blood {0/Co} - Super
Death of mother {0/Co} - Super
denial or reality {1/Co} - Super
diagnosis {1/Co} - Super
disappointment {1/Co} - Super
Dismissive {1/Co} - Super
distinction {1/Co} - Super
doesn't bother me {0/Co-F} - Super
Door to door sales {1/Co} - Super
early on {1/Co} - Super
effect on live {1/Co} - Super
effects of migration->17:16 {1/Co} - Super
Elevated Blood Pressure {0/Co} - Super
Emotional response {1/Co} - Super
eradicate thought processes {0/Co} - Super
Everyone has a story {1/Co} - Super
Everything happen to us {1/Co} - Super
Exhaustion {0/Co} - Super

explantions for hypertension->2:15 {1/Co} - Super
family history {0/Co} - Super
Family members {1/Co} - Super
family members->1:31 {0/Co-F} - Super
feel the pressure {1/Co} - Super
Feelings on diagnosis {1/Co} - Super
For life or not {1/Co} - Super
forms of non-concordance {1/Co} - Super
friends advice {0/Co-F} - Super
gave up work {0/Co-F} - Super
Gestalt {1/Co} - Super
Get lost {1/Co} - Super
GP - risk perception->1:14 {1/Co} - Super
had high blood pressure {1/Co} - Super
haemorrhage {0/Co} - Super
health {0/Co} - Super
Heart attack {0/Co} - Super
herbal {1/Co} - Super
herbal remedies {1/Co} - Super
herbal remedies - limits {1/Co} - Super
herbal remedies + prescribed medication {1/Co} - Super
high and low {1/Co} - Super
high blood pressure {0/Co} - Super
high blood pressure v hypetension {1/Co} - Super
hypertensive types->2:28 {0/Co-F} - Super
I can't fanthom out this notion of private gp's in other towns {1/Co} - Super
I don't keep friends {1/Co} - Super
I don't really bother {1/Co} - Super
I don't talk about it {1/Co} - Super
I don't think she understand it herself {0/Co-F} - Super
I don't think she understands it {1/Co} - Super
I feel comfortable then {0/Co-F} - Super
I got a release {1/Co} - Super
I HAVEN'T BEEN IN AGES YOU KNOW {1/Co} - Super
I never think about.->4:9 {1/Co} - Super
I was lucky {1/Co} - Super
impotence {1/Co} - Super
information sources {1/Co} - Super
It's better then some {1/Co} - Super
It just creep up anyway {0/Co-F} - Super
keeping busy {1/Co} - Super
Kidneys {0/Co} - Super
lack of insight {1/Co} - Super
lack of stigma->5:40 {1/Co} - Super
Language {1/Co} - Super
lay explanations {1/Co} - Super
lay explanations->1:26 {1/Co} - Super
lay explanations->2:44 {1/Co} - Super
Level of attention {1/Co} - Super
License loss {1/Co} - Super
lifestyle changes {1/Co} - Super
lifestyle modifications {1/Co} - Super
Liver {0/Co} - Super
Looking after yourself {1/Co} - Super
Love life->17:17 {1/Co} - Super

low blood pressure {0/Co} - Super
Main factor {1/Co} - Super
Managing stress {0/Co} - Super
medication - type->1:18 {1/Co} - Super
migration {0/Co} - Super
mind feel unsettled {0/Co-F} - Super
miss checks {1/Co} - Super
mixing of blood {0/Co} - Super
morbidty/mortality {0/Co} - Super
more chemicals in the body should not be there {0/Co} - Super
more time {1/Co} - Super
multiple medication {1/Co} - Super
New culture {0/Co} - Super
new medication {1/Co} - Super
Nice people {1/Co} - Super
no balance {0/Co} - Super
no interest in medication {1/Co} - Super
no pain {1/Co} - Super
no problem {1/Co} - Super
no stigma {1/Co} - Super
no stress {1/Co} - Super
no treatment {1/Co} - Super
non-concordance {1/Co} - Super
nose bleeds {0/Co-F} - Super
nostril bleeding {0/Co} - Super
Not belonging {0/Co} - Super
not happy {1/Co} - Super
obesity {1/Co} - Super
other illness {1/Co} - Super
out there {1/Co} - Super
own Gp {1/Co} - Super
Poison my body {1/Co} - Super
Powerful statments {1/Co} - Super
Pressure (of life) {0/Co} - Super
Pressure of life {1/Co} - Super
Pressure on brain {2/Co} - Super
Pressure up {0/Co} - Super
pressure v high blood pressure {1/Co} - Super
Prevent me {1/Co} - Super
Private GP {1/Co} - Super
Private GP - ethnic origin {1/Co} - Super
Private GP - other towns {1/Co} - Super
Private GP - other towns->5:22 {1/Co} - Super
Racism {0/Co} - Super
rationalisation of illness {1/Co} - Super
refusal {1/Co} - Super
release of blood {0/Co} - Super
Reticence {1/Co} - Super
riotous life {0/Co} - Super
role of elders {0/Co} - Super
running to the dr {1/Co} - Super
Runs in families {1/Co} - Super
Searching for explanations {2/Co} - Super
self determination->2:105 {1/Co} - Super
self determination->2:106 {1/Co} - Super

Separating out illness/health experience {1/Co} - Super
Sickness is not partial {1/Co} - Super
silence on blood pressure->1:54 {1/Co} - Super
Smoking rosemary {1/Co} - Super
Something in the blood {0/Co} - Super
Sometimes things can creep {1/Co} - Super
steady head {0/Co} - Super
steady life {0/Co} - Super
Stress {0/Co} - Super
stress v worry {1/Co} - Super
stroke {1/Co} - Super
Stupid traiditions {1/Co} - Super
Subjective experience {1/Co} - Super
support {1/Co} - Super
support networks->1:24 {1/Co} - Super
Synergy {1/Co} - Super
Tha't what families are for {1/Co} - Super
Thinking {1/Co} - Super
Told GP {0/Co-F} - Super
too busy {1/Co} - Super
Too much blood {0/Co} - Super
too much worry results in crazy people {0/Co} - Super
Too young can't have it {0/Co} - Super
transfusion {0/Co} - Super
Trust/belief in GP {1/Co} - Super
under control {1/Co} - Super
weight increase {0/Co} - Super
what I eat {0/Co-F} - Super
which illness {1/Co} - Super
which is playing up->16:46 {1/Co} - Super
Work {0/Co} - Super
worried and depressed {1/Co} - Super
worry {0/Co} - Super

Appendix 16

Example of post-interview analysis notes

Interview Analysis notes – Interview 16

This interview is one of the longest conducted, with one of the youngest participants in the study, who was born in the UK. The interview produced some extremely rich and interesting data. 14 new codes emerged, therefore clearly theoretical saturation is not reached. See reflective comment on interview process. The data elicited is markedly different from that which is elicited with older participants and C is much more forthright on issues where older participants were reticent and reluctant to comment.

Repeated words and phrases

Because they never explain the illness.
G Right.
C I don't know why. They never explain the illness.

Genuine (in the context of friendships x 3)

Headaches x10

Calm x 3

Stress x 3

Mentions herbs, bush teas, aloe vera, single bible, cerrasay several times

Repeatedly mentions her non-concordance also that GP's do not understand the condition ***I don't have time for pills***

Waving the red flag

They <u>never</u> spend time with them. (GP's with black patients)

I don't know why. They (Doctors) <u>never</u> explain the illness.

those tablets was <u>never</u> helping

I will chat rubbish in the doctors just to stay in there a bit longer.

G Hmm.

Appendix 16

Example of post-interview analysis notes

C Because I think 'I've got a right to be here.
How dare you fob me off so quickly, to get me
out, so your own people can come in and sit down
longer?' I always do it. You've got the odd ones
who will sit down and spend time with you

What is going on here

This participant is very angry, upset and frustrated. She is angry with health services in particular secondary care, angry with doctors lack of veracity, respect and feels unfairly treated and discriminated against. C is angry that discrimination and racism affect her working environment in the workplace and her aspirations and wish to be successful. C changes her mind on quite a few viewpoints, not sure if initial resignation, acceptance of aspects of health experience is denial. This is an interesting interview to consider reflexive dimensions, for example would C share views on racism and discrimination with a white researcher.

C also states she is ashamed of having high blood pressure because she is so young, seems resentful about this. Would not have told anyone only medical people. You don't want people constantly commenting on this. Does not discuss her blood pressure with other family members who have high blood pressure. Mum and Dad have high blood pressure, what does C feel about this genetic/heredity component?

C acknowledges the affects her condition has on her children

Also speaks quite a lot about her non-concordance, and her idea thay she would not be taking the tablets from the outset/diagnosis. In fact she appeared to be determined not to take the tablets under any circumstances. The usefulness of the medication was further undermined, as C blood pressure seemed to lower without the medication, further compounding C's view that tablets are useless. ***When I was taking them my blood pressure was still high***

Also C's view is interesting that GP's do not really know the cause, e.g. your blood pressure is up so tablets are prescribed, does this mean that C knows that this is not the root cause of the condition. Seems to locate high blood pressure as being a consequence of arduous, stressful life and wider societal influences e.g. racism and discrimination. - what can your GP do about this!!!! High blood pressure is caused by ***Pressure of Life***

Reflective Comment

Not sure if the quality of the interview is influenced by the fact that I was similar in age to this participant and have a professional background in health and social care. I was

Appendix 16

Example of post-interview analysis notes

able to establish a rapport very quickly with this participant, which I think has clearly influenced the quality of the interview and depth of disclosure.

At the end of the interview, although I do not have hypertension, I was struck by the similarity in our experiences and view points I held with this participant. Especially in our working lives, a commonality of experience existed. I was upset at the end of the interview, because C was obviously struggling with a lot in life which seemed to me very unfair. Although I am not struggling in the same way, C views on her working environment held resonance for me. I was so busy reflecting on this, that I did not concentrate on driving and crashed my car near to the participant's home. Conducting research can be dangerous physically & psychologically, especially if the participant holds up a mirror and you see yourself!!!

Appendix 17
Atlas/ti: Code family

HU: AFCH
File: [c:\program files\scientific software\atlasti\HPRB393]
Edited by: Super
Date/Time: 2003/06/24 - 14:25:05

Code Family: Participant's experience of PHC
Created: 03/06/24 14:19 (Super)

Comment:

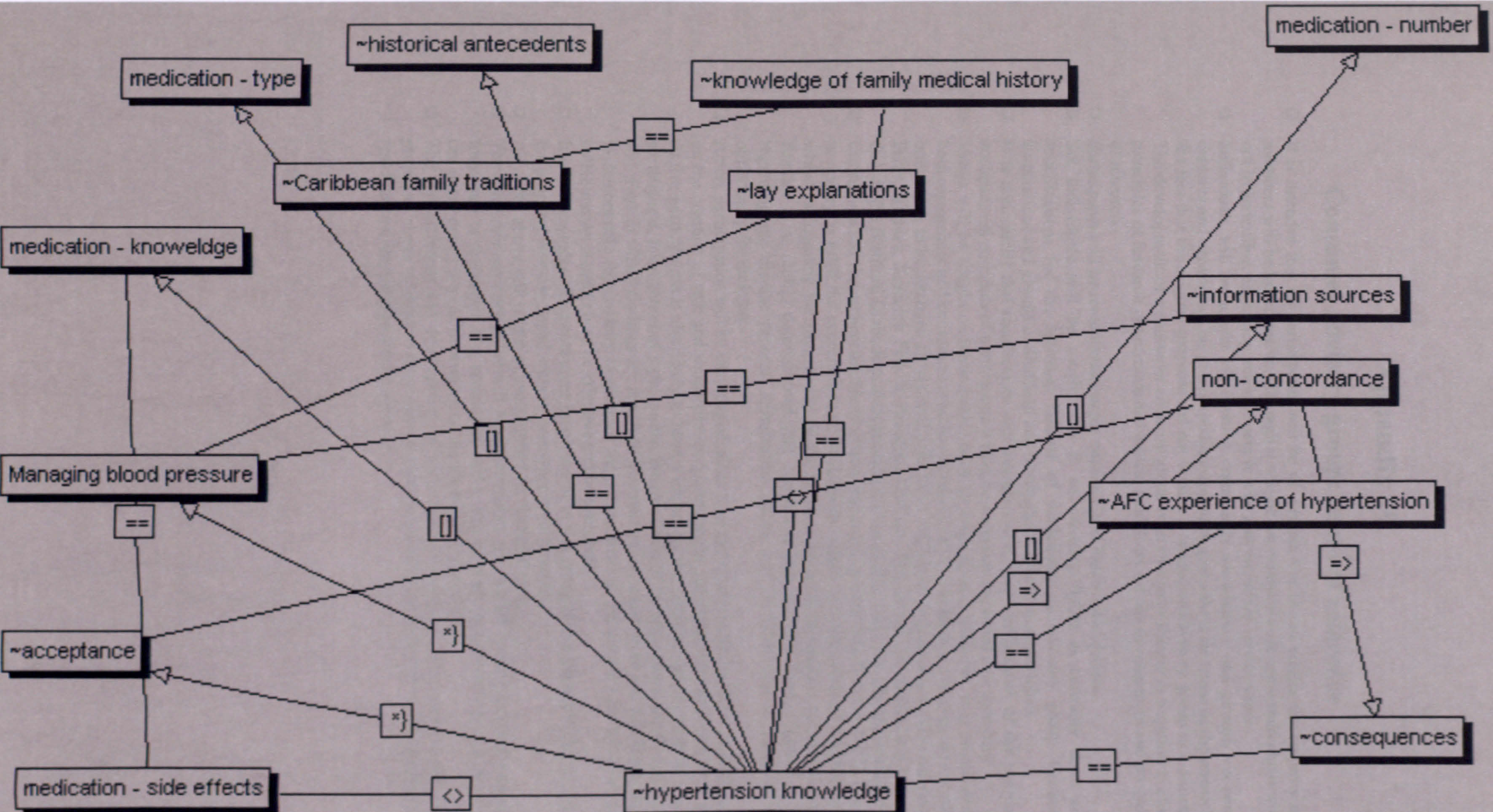
Codes (26)
[Acting on advice] [Bounds of professional conduct] [consultations] [elevated blood pressure] [empowerment] [GP - risk perception] [GP - veracity] [GP relationship] [Health professionals lay explanations] [in frequent use of PHC] [new forms of PHC] [nurse consultation] [PHC - dissatisfaction] [PHC - new forms] [PHC -use] [PHC in the Caribbea] [Private - GP ethnic origin] [Private GP] [Private GP - other towns] [professional advice] [Relationship with GP] [satisfaction with PHC] [secondary care] [treatment choices] [treatment stopped] [Trust/belief in GP]

Quotation(s): 267

Appendix 18

Atlas/ti: code family graphic representation

Legend: R= associated with, N= a cause of, G=part of, P=a property of,A=contradicts



Appendix 19

Consumer advisory group: terms of reference

- It is intended that all participants will be of African Caribbean origin; the majority of the members will be hypertensive, although it will be necessary to seek some individuals who are not hypertensive, especially younger people who may be future service users.
- Individuals will be sought via existing community associations and groups, via personal contacts and networks. This is an expedient approach given the time frame of the research and the fact that the original proposal did not outline a consumer advisory group as a dimension. The development of a consumer advisory group is an emergent feature in response to changed principles of research governance and ethical guidelines for the development and progression of research.
- Participants will be remunerated as per current Good Practice Guidelines
- Six individuals will be sought; this is an arbitrary figure as currently there are no specifications for the optimum number of participants in advisory group. Community associations and groups in Sheffield and Nottingham have been approached.
- It is anticipated that membership will remain static, however because of the personal or occupational demands of participants it may be necessary to recruit new members.
- Views will be sought on participants' need for training and induction, it is anticipated that both researchers and consumers who have experience in this domain will provide a workshop orientation to be arranged provisional date 27.11.2001 prior to joint supervision meeting. Dr. Penny Rhodes, Research Fellow, Bradford Diabetes Project will be approached concerning this, as the Bradford Diabetic project specifically focused on minority ethnic populations.
- Consumers and researchers are likely to have different agendas (Rhodes et al 2001). It may be necessary to fulfil the expectations of participants within the parameters of the research and whilst maintaining the progression of the research in order to create a reciprocal process. Rhodes et al (2001) demonstrated that consumers are likely to have educational needs regarding the disease process. Information packs will be developed in addition to the opportunity for dialogue.
- Active participation will be encouraged rather than consultation; this is likely to be dependent on the creation of safe and supportive environment for participants to articulate their views. Active participation is also likely to have a impact on the research design, ways of accessing participants, formulation of topic guides, interpretation of findings, dissemination of findings and ways in which findings are reported. The researcher, supervisors and funding body need to demonstrate the capacity to embrace the perspectives of the advisory group otherwise the collaboration is unlikely to be effective and be tokenistic.
- It is acknowledged that consumer involvement in this research has been less than optimal as the proposal was developed without consumer involvement.
- All of the above will create an unaccounted for financial cost.
- The consumer advisory group will meet three times per year (financial constraints dictate the frequency of meetings). It is anticipated that a joint or overlapping meeting with supervisors can occur once per year, depending on the views of all concerned.
- The establishment and development of the consumer advisory group mapped out for this project as above is likely to be challenging and not without difficulty, this will result in a time and financial implication for the research.

Appendix 20
Letter to General Practitioners

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Northern General Hospital
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Sheffield S5 7AU
Fax: 0114 242 2136

Direct Dial Inward: (0114) 271 5733
Email: G.Higginbottom@sheffield.ac.uk

Dear GP

Re: The Meaning and Consequences of Hypertension for Individuals of African Caribbean Origin

The above mentioned study has received ethical approval and I am writing to ask if you would be willing to participate in the research. I am seeking practices who have African Caribbean patients in the practice population.

As you know, reducing hypertension in this population is a national imperative and presently we have very little evidence which will facilitate the achievement of policy goals. In this respect the study is urgently needed. The NHS executive via the National Primary Care Research and Development Awards for this study and my research supervisor is Professor Nigel Mathers who is Director of the Institute of General Practice and Primary Care. The study is a qualitative study that will utilise focus groups, semi-structured interviews and structured vignettes (Greenhalgh et al, 1998) to elicit patients health beliefs and behaviours associated with hypertension. It is anticipated that the outcomes will influence the cultural congruence of services in Primary Health Care and aid understanding in relation to culturally specific health beliefs, decision making processes and risk perception that may mitigate against or enhance the early diagnosis and management of hypertension for African Caribbean patients in Primary Health Care.

Participation will require practices to generate a list of participants who are African Caribbean and have hypertension. This of course will not be shared with the researcher. However this activity is necessary in order to forward a prepaid letter on behalf of the researcher. The data collection is scheduled for September 2001 to the end of December 2002.

If you are willing to participate in this study I would be very grateful if you will let me know. I am happy to provide more information or to give a presentation if required. I will be telephoning the surgery over the next few weeks to elicit your willingness or otherwise to participate in the research.

Many thanks

Gina Higginbottom
Lecturer/National Primary Care Research Fellow

Appendix 21
Glossary of herbs and medicinal uses

Herb	Use
Aloe Vera	High blood pressure, healing of wounds
Bissy	Stomach upset
Bread fruit plant leaves	High blood pressure as an infusion
Cerasee (cerrasee, serasee)	General health, blood cleanser
Cho-Cho	High blood pressure
Coconut water, lime & lemon	High blood pressure
Fever grass	High blood pressure as an infusion
Hawthorn	High blood pressure
Lime juice) Garlic)	High blood pressure
Marijuana	Asthma as an infusion
Scorn the earth	High blood pressure
Singer bible (Single bible or semper viva)	High blood pressure
Tuna	High blood pressure
Cho-Cho	High blood pressure
Any bitters	Lower blood pressure

Appendix 22
General use of herbal remedies

Barbette recollects her early introduction to herbal remedies in the form of purges and laxatives:

> *"It's a rule. Every parents give, every time we have school holiday, we get a wash out before we go back to school, to prevent us from having fever and all them kind of things. Bellyache. Then we go back to school all fresh, because we have a wash out and your insides clean. You know, children eat this, that and the other.*
> *So, your inside clean to go back to school, when school re-open".* Interview 14

It is interesting that Barbette refers to this process as a rule or perhaps family or social norm; the implication is that not to engage in this activity would be a transgression of social norms. I think this is a significant statement as it may demonstrate the extent to which the use of traditional Caribbean herbal remedies is embedded within the socialisation processes an individuals who have grown up in the Caribbean. Loretta goes on to describe her own experience of receiving herbal remedies and purges as a child:

> *"Those days, those days I didn't because when they would say boil such and such a thing and give you, they have to, sort of, stand over you and watch you*
> *...to see you drink it, because you never want to drink it.*
> *But, now I realise that there was benefits from it.*
> *I'm sure it was.*
> *G Yes. You think it was helping.*
> *L Yes, because erm, there was always, sort of, little, if you had a cold. They never say 'well, go to the doctor', or 'go to the chemist'.*
> *They just buy different things.*
> *For instance, my Father, as far as I understand, has never, ever seen a doctor till*

three months before he died.
He kept good health, but any little thing, it
was always some bush [herbal remedies/plants] or other…
that was used". Interview 17

Loretta explains although she was not appreciative as a child of the remedies she was required to take looking back she can see that the herbal remedies were beneficial. The unpleasant and bitter taste of some of the remedies was further re-iterated by Carmel who remarks:

"One thing I remember, when I was younger, very
young and my Mum, I had a chest problem, cough
and she scrap that Single Bible there…
And my Mother scrap it, you see, like this,
she cut a piece off and she scrap all the…
She scrape the inside out.
And mixed it up with milk.
And give me to drink.
And when I drank it down, they had to beat me
to drink it". Interview 21

Some of the herbal remedies are referred to as bitters (Morgan 1993) this reflects the actual taste of the substance. Reflective biographical accounts of this nature provide insights into the health related actions and behaviours of the African Caribbean people in this study and how they might respond to prescribed medications and why a continued reliance on herbal remedies might exist despite the availability and access to contemporary PHC services and prescribed medications.

Amongst those participants who did use herbal remedies, Edgar, Delbert, Hyacinth and Carlene provided a narrative that formed a powerful 'significant event'. My perception of the purpose of these significant events is that participants wished to demonstrate to me and convince me as a researcher of the effectiveness of the models mentioned. Edgar provides the following insights:

"You see, because in Jamaica I know that
same Cannabis that they talk about, I know a man,
he had asthma all his life. Big man. And, erm,
he go to this doctor, and erm, and he has
a lot of land, and er, he go to his doctor and he
spent so much money and he couldn't cure him. And
this is what he says, right, I don't know. He
said he met this man and this man tell to er,
boil it, drink it.
G Cannabis?
E Hmm.
And he boil it, and he been drinking it,
being he was a big man, he knew this drink
couldn't get people [inaudible].He boil it and he been
drinking it. He say 'every time I got to the
doctor, takes a sample and says er, 'so far
you're not as bad as you were'.
He said 'no'. And he, he'd been on
with this thing for a couple of months.
And when he went back to doctor one week,
the doctor tell him 'I think you're alright now'.
Interview 6

This account is interesting as within the UK a commonly held assumption is that cannabis is a herb that is smoked, whereas in this narration cannabis is taken as an infusion or bush tea and the participant is convinced of the medicinal value in relation to relief of asthma. Delbert provides further insights regarding his powerful personal insight into the efficacy of herbal remedies and the antipyretic qualities, as he comments:

"... Once when I was about seven, I was telling someone this same story yesterday, I was at home with a fever. The fever was hot. Very hot, I was burning up. It was only me and? Arncy at home and about 8 o'clock my mother filled up the big wash pan (tin bath) with water, put it outside in the evening dew and told me to stand in it. She brought Cannymin [inaudible] I don't know if you know it? It's white. She told me to drink it. I asked her why and she said if I don't I will catch a cold. Well my dear I dried myself put my clothes on and went back into the house. Everyone was eating dinner, so I said could I have some dinner. Everyone was shocked because up till then I wasn't talking, or eating". Interview 9

Significant events regarding the use of herbal remedies and the health enhancing properties were not confined to older people who were raised in the Caribbean had and migrated to England as adults. Carlene and Hyacinth provided equally powerful accounts that they felt provided a rationale for their belief in the efficacy of traditional Caribbean herbal remedies. Carlene was born in England and spent her childhood in England, however during a holiday in Jamaica her viewpoints about herbal remedies changed, as she remarks:

> *C "I didn't before [value herbal remedies]. It's only when I went to Jamaica and I got bit. You know when you get bites.*
> *G Hmm.*
> *C What do you call them? Mosquito's and ants.*
> *G Yes.*
> *C And my Dad got the single bible and squeezed the juice and rub it on it.*
> *G Yes.*
> *C And it stopped it swelling up and scratching.*
> *G Yes.*
> *C Yes.*
> *G So, that's made you change your mind?*
> *C Yes. Because, on my arm, it really swelled up.*
> *G Right.*
> *C And my Dad says 'put some on'. I says 'oh, no. Don't put, don't be silly. I don't want a plant on my arm!'*
> *G Yes.*
> *C But it started scratching bad and swelling and it was oozing, and he put the single bible on it and sealed it and it went down.*
> *G Hmm.*
> *C Yes. So, I thought 'ooh. It must be true, then.'*
> *G Yes.*
> *C So, I started drinking it.* Interview 16

Hyacinth is a younger participant (38 years) who spent her early childhood in Jamaica she explains her own significant event:

> *H "I mean a good example is, this is nothing to do with the interview but, I've almost lost a finger, you know.*
> *G Really?*

H Yes.
G How?
H When I was a child in Jamaica.
G Okay.
H Chopping wood.
G Oh,yes. Yes. Yes.
H And it was only a little bit of skin that was hanging on.
G Ohhh.
H And there was two old people standing in the house, the garden at the time, and they went around and there was me crying and screaming like mad and they went around and they picked some bush, honestly, and beat it up with some cocoa and whatever they did, you know, from the cocoa tree.
G Yes.
B And band it around this finger and I didn't have one stitch in it.
G Fantastic!
B Honestly!!
G Fully functioning?!
H Honestly, it was just dangling by a little skin. So, I don't know whether those kind of things have anything to do with, with me and my, you know, but really, at the time, the doctor medical service was too expensive, so I suppose the old people had to manage the best way the can". Interview 19

The intensity and graphic description associated with the explanations of Edgar, Delbert, Carlene and Hyacinth, I think to some extent explains why some participants may have difficulty in forgoing a reliance on herbal remedies in favour of prescribed Western Medication. To do so would involve a salient de-construction and rejection of personal socialisation, values and belief system.

Appendix 23
Consumer advisory group recommendations for dissemination

- Black churches – leaflets and presentations
- Day care centres
- Presentations to community groups and associations e.g. lunch clubs
- Adult learning centres
- Local BBC radio
- African Caribbean Enterprise Centre
- GP's with high percentage of African Caribbean patients