

Improving Migrant Health: A critical evaluation of the impacts of the East Sussex

Bilingual Health Advocacy Service

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DECLARATION

The dissertation/project is the product of my own work and has not been presented for any other award. I declare also the dissertation “Improving Migrant Health: A critical evaluation of the East Sussex bilingual advocacy service” is available for photocopying, reference purposes and Inter-library loan.

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Abstract

There has been extensive research into the inequalities migrants experience in health outcomes and access to health services. Statutory organisations in the UK have a legal responsibility to work to reduce these inequalities. One intervention designed to address this in East Sussex is the Bilingual Health Advocacy Service (BHAS). This service has been piloted for a 2 year period and demand from migrant residents has grown steadily during that period.

This study critically evaluates the effectiveness of the East Sussex Bilingual Health Advocacy Service during the pilot period. Utilising existing data captured throughout the pilot and new information collected for the purposes of this study, the evaluation measures the impacts of the BHAS against a range of indicators identified through an extensive review of literature in order to identify whether there is:

1. Evidence that this model of advocacy has improved migrant access to health services?
2. Evidence that this model of advocacy has improved migrant health?
3. Evidence that service recipients are more empowered to manage their health following advocacy intervention than before?

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-

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CHAPTER I - Introduction

The purpose of this study is to critically evaluate the impacts of the pilot phase of the East Sussex Bilingual Health Advocacy Service (BHAS).

1.1 Background

In the report “How health systems can address health inequities linked to migration and ethnicity” (2010), the World Health Organisation (Europe) describes that:

“There is substantial evidence of inequities in both the state of health of these groups [migrant communities] and the accessibility and quality of health services available to them.” (Page V)

There is significant evidence that migrant communities experience inequality of health outcomes, the way in which services are organised and delivered is one of the factors that can impede good health.

“Health services do, of course, have an impact on levels of health and illness, and there is evidence that migrants and members of ethnic minorities are often poorly served by existing services... The services offered may not be well-adapted to their particular needs by, for example, making too little allowance for linguistic, social and cultural differences.” (WHO, 2010, Page 15)

NHS organisations not only have a moral duty of care to meet the needs of migrant residents and reduce health inequalities, they also have a legal obligation.

The Equality Act 2010 places a legal duty on all statutory organisations to, in the exercise of its functions, have due regard to the need to—

*“(a) eliminate discrimination, harassment, victimisation
(b) advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it;
(c) foster good relations between persons who share a relevant protected characteristic and persons who do not share it.”*

It goes on to state that having due regard involves the need to -

*(a) remove or minimise disadvantages suffered by persons who share a relevant protected characteristic that are connected to that characteristic;
(b) take steps to meet the needs of persons who share a relevant protected characteristic that are different from the needs of persons who do not share it;
(c) encourage persons who share a relevant protected characteristic to participate in public life or in any other activity in which participation by such persons is disproportionately low.”(HM Government, 2010, page 96)*

In 2009, the East Sussex Primary Care Trusts (PCT), alongside partners from the Local Authority, police and district councils, received funding from the Migration Impact Fund to deliver a partnership project aimed at developing support services for migrants in East Sussex.

Following a review of interventions operating in other parts of the UK, it was decided that the health element of the project would focus on providing specialist advocacy targeted at the migrant population. The rationale given in the funding bid was that advocacy would address a number of existing problems:

“Migrants often access secondary care (A&E) when they should be accessing primary care (GPs), as they have no experience of the local health system.

Registering with a GP is also a common difficulty, due to the language barrier. This can be costly for health services as treatment is sought once the patient’s condition becomes serious.” (Czepil, 2009, Page 3)

This view is supported by recent statistical evidence for East Sussex compiled by the South East Health Observatory (2012), which demonstrated that in 2010 – 2011 people from ethnic minority groups were more likely to be admitted to hospital through emergency access routes when compared to the majority population.

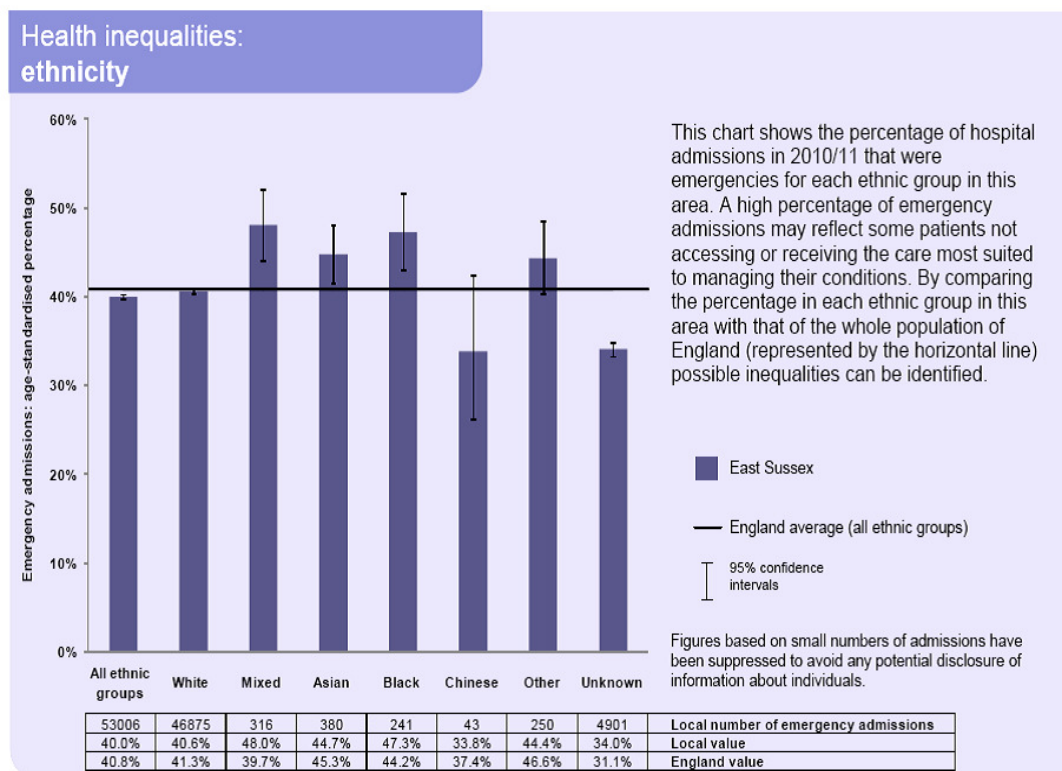


FIGURE 1: Emergency hospital admissions in East Sussex by ethnic group

South East Public Health Observatory, 2012, found at [http://www.apho.org.uk/default.aspx?QN=P HEALTH PROFILES](http://www.apho.org.uk/default.aspx?QN=P_HEALTH_PROFILES)

Advocacy is a recognised strategy for providing support to migrants to build understanding of health services (how and when to access them) and to tackle some of the specific public health issues that a growing migrant population brings. There is evidence of bilingual health advocacy services operating successfully in other parts of the UK (for example, Newham, and Tower Hamlets)

Initially, the idea was to develop a service based around employing two full-time advocates to work across East Sussex. This model was based on best practice developed elsewhere e.g. Hackney. (Geater, 2010, page 2) However, the geography and migrant profile of East Sussex differs significantly from many of the areas where advocacy services for migrant communities had been established. Most of the existing examples are in London boroughs and therefore working in a small geographical area where there are one or two sizable minority communities, for example the Bangladeshi population in Tower Hamlets. East Sussex covers a relatively large geography (200 miles²) with a mixture of urban and rural communities. Additionally, the make-up of the migrant population is diverse both in terms of status (asylum seekers, economic migrants etc) and ethnic and cultural background (ref. section 3.1).

A study conducted by the Supported Voices Project (2009) identified that

“A good practice model is to build the capacity of BME communities to represent themselves as advocates, either within advocacy organisations or as advocacy schemes within wider voluntary sector organisations in the BME community.”(Page 56)

This view was tested with representatives of local migrant communities in East Sussex prior to establishing the East Sussex advocacy model. A number of features were identified as important if the service was to be utilised effectively by members of their communities.

- *Community Interpreters welcomed the idea of training to be an advocate as this is a role they are sometimes pulled into inappropriately. Several people have identified that they would be interested in the advocacy role.*
- *Migrant communities felt it was important that the migrant advocates were culturally aware and spoke the language of the service user.*
- *The migrant communities spoken to considered it more important to have access to a range of advocates meeting different language and cultural needs than it was to have continuity in terms of the individual delivering the advocacy or a physical access point for the advocates.”*

(Geater, 2010, page 2)

Taking this learning on board, the East Sussex Bilingual Health Advocacy Service (BHAS) was established by working with two local interpreting and translation service providers. The capacity of the providers to deliver bilingual advocacy was developed by up-skilling some of the existing pool of community interpreters who were proven to be fluent in English and at least one other language. These community Interpreters, themselves from diverse ethnic and cultural backgrounds, received an intensive, 12 week accredited course in advocacy skills with a particular focus on health services. These new skills built on the experience gained through

their work as interpreters and was viewed as career progression by course participants.

“The bilingual advocacy training course took place from December 2010 to May 2011... This training was a rare and much welcomed career opportunity for suitable candidates residing in Sussex.” (Vandu, 2012, page 3)

A service pilot was commissioned with the stated aim to:

“Improve the health and well-being of migrant communities within East Sussex by improving access to health and well-being services.” (NHS Hastings and Rother, 2010, page 1)

The objectives of the service, described in the service specification (appendix 1)

were:

- Improve access to health services for migrant communities
- Improve the health outcomes of migrant communities
- Encourage more appropriate use of health services and compliance with treatment
- Increase knowledge and understanding of barriers to good health for migrant communities
- Increase trust between health services and migrant communities
- Improve engagement with migrant communities with the aim of better meeting their needs” (NHS Hastings and Rother, 2010, page 2)

The service pilot began in March 2011 and demand for the service has increased steadily since that time. By the end of year 1 (March 2012), over 400 sessions had been delivered, working with 96 service users. This exceeded the minimum contractual requirement of 350 sessions.

In order to align the service with commissioning cycles for other migrant support services, notably interpretation and translation provision, the pilot period was extended until September 2012.

1.2 Aim of the research

The World Health Organisation - Europe (WHO) report asserts that:

“Inequities in health service delivery should be systematically investigated, “good practices” should be developed to tackle them, and the effectiveness of these interventions should be critically evaluated.” (WHO, 2010, Page VI)

Within East Sussex, research has been conducted (Lodge, 2010 & Sikora et al., 2010) to identify the health needs of local migrant communities. Learning from this research led to the development and piloting of the Bilingual Health Advocacy Service. This research paper aims to complete the process by critically evaluating the impacts of that intervention.

The researcher holds organisational (NHS East Sussex) responsibility for ensuring that resources allocated to support the equality agenda are utilised to greatest effect. With a relatively small budget available to address health inequalities, and a number of competing priorities within the groups affected, it is essential that any investment made delivers demonstrable benefits. As such, the findings from this

evaluation will inform future commissioning of services to support the migrant communities of East Sussex and will help determine whether to continue investment in bilingual advocacy.

A range of other statutory service providers have expressed an interest in the findings of the evaluation which may inform decisions about whether this model may help to support their service users. The main audiences for this research will be:

- NHS commissioners
- Partner organisation commissioners
- Advocacy service providers

1.3 Research questions

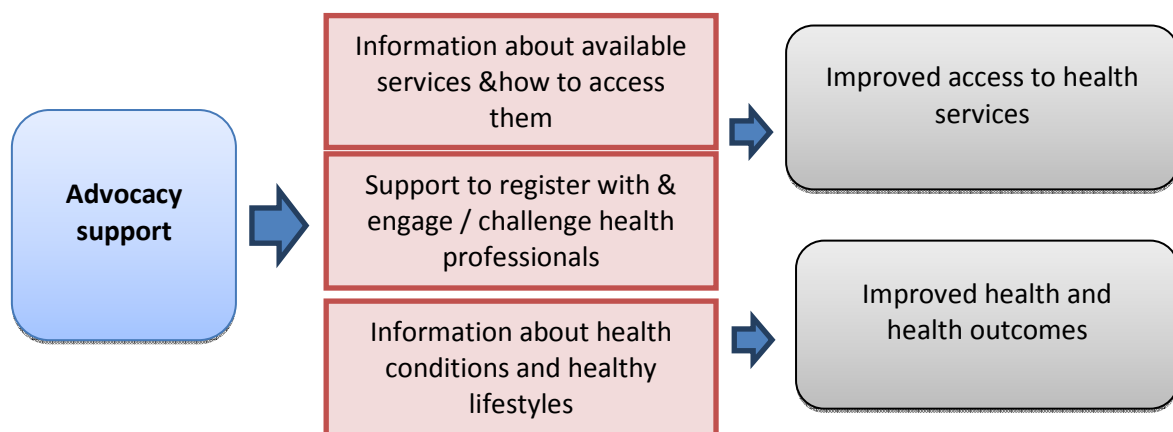
The aim of the research is to evaluate the impacts of the pilot phase of the Bilingual Health Advocacy Service. The research questions that will be considered are:

1. Is there evidence that this model of advocacy has improved migrant access to health services?
2. Is there evidence that this model of advocacy has improved migrant health?
3. Is there evidence that service recipients are more empowered to manage their health following advocacy intervention than before?

The researcher is lead commissioner for the service and had direct involvement in designing and developing the service model. It should therefore be acknowledged that there is an underlying assumption that the investment in bilingual advocacy has had a demonstrable impact and a bias to anticipate that the impacts are largely positive.

1.4 Theoretical framework

The basic premise that underpins the Bilingual Health Advocacy Service is that if people feel supported and informed their sense of empowerment improves and as a result their ability to access health services appropriately and their capacity to make informed choices about their healthcare, and lifestyle choices affecting their health, will also improve. This is depicted in the diagram below.



1.4.1 Definition of key terms

Migrant

A migrant is someone who has moved from one place to live in another. In the context of this study, the term migrant relates to individuals who have moved to the UK, and specifically East Sussex, from their country of birth.

“The term “migrant” conceals great diversity and a number of different types can be distinguished; refugees and asylum seekers, labour or economic migrants, family members of existing migrants, victims of trafficking, irregular (undocumented) migrants.” (WHO (Europe), 2010, Page 5)

Advocacy

One of the difficulties encountered in establishing this service was to translate the term ‘advocacy’ into other languages while maintaining the meaning as intended by the service. There is no universally accepted definition of the term, indeed understanding of advocacy varies significantly depending on the context in which it is used. In many cultures the term advocacy denotes legal counsel rather than the less formal source of support offered by the East Sussex service. This could be a hindrance when trying to describe the service to speakers of different languages and encourage potential service users to engage.

“Evidence has found that many different communities have no word in their language that translates the word ‘advocacy’ or how it can help them. This lack of awareness may contribute to the low uptake of services. It will also reflect on the

way advocacy has to be delivered to different ethnic minority communities.”
(Supported Voices Project, 2009, page 20)

When establishing the BHAS, consideration was given to describing advocacy in a way that was true to the ambitions of the service. The following definition, produced by Action for Advocacy, has been used throughout the service pilot:

“Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain service they need.” (Action for Advocacy, 2006 found at www.actionforadvocacy.org.uk)

Empowerment

Empowerment, like advocacy has no agreed definition.

“Rappoport (1984), has noted that it is easy to define empowerment by its absence but difficult to define in action as it takes on different forms in different people and contexts.” (Cited in Page, 1999, found at: www.joe.org)

However, for the purpose of the BHAS evaluation it is necessary to provide a definition of empowerment that best relates to the subject matter. In order to settle on an agreed definition, the researcher explored the subject at a focus group with bilingual advocates (ref. section 2.2.4).

Participants were supplied with six definitions of empowerment offered by different scholars and were asked to select the definition that resonated most with them in relation to the BHAS. One of the definitions was selected by the advocates

significantly more often than the others. Therefore, for the purpose of this research study the definition is:

“Empowerment is a process of internal and external change. The internal process is the person’s sense of belief in her [or his] ability to make decisions and solve her [his] own problems. The external change finds expression in the ability to act and implement the practical knowledge, the information, the skills, the capabilities and the other new resources acquired in the course of the process.”

(Parsons 1988, cited in Sadan, 1997, Page 76)

CHAPTER II - Research methodology

2.1 Research paradigm

A mixed methods approach has been taken to this research study combining phenomenological and positivistic methodologies. This approach seemed most appropriate for a number of reasons:

1. The BHAS pilot adopted an outcome based approach to advocacy designed to capture information about the impact advocacy intervention has had on service users. This included a requirement to capture case study information and service user perspectives alongside qualitative activity data. This rich source of existing data has helped to define the approach to this research study.
2. The study is concerned with defining the problems experienced by migrants and the impacts of the chosen intervention based in a wider social context with a range of different variables. It is not attempting to test a hypothesis for which a purely positivistic approach may have been more appropriate.
3. The study is time-limited which restricts the methodology that could be utilised to collect data.

Rapid Appraisal (RA) techniques have been used to collect qualitative data providing insight into migrant communities and their needs. Rapid Appraisal is:

“A participative method that has been proven to yield a rapid overview of a community and its health... It involves collecting data about the assets, needs and resources in the community from interviews [with community representatives], documents and observations.” (Pallant, 2002, page 13)

A literature review has provided contextual information for the study and has facilitated the identification of indicators that will be used to evaluate the service impacts.

Quantitative data about service activity and service user profiles is contained in performance reports which the service providers are contractually required to produce each quarter. Additional quantitative data was generated by undertaking service user surveys and advocate questionnaires.

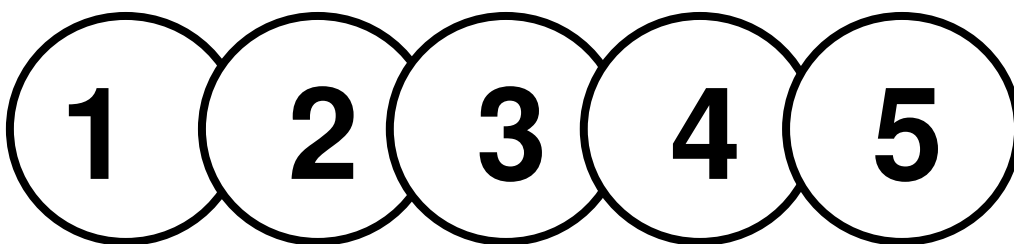
Qualitative data was gathered through service case studies and focus groups. The questionnaires also yielded qualitative information via free-text comments. The quantitative data has been cross-referenced against the qualitative information to provide greater insight into the perceptions of the research participants and whether their perceptions are supported by evidence drawn from client case studies.

2.2 Data collection methods and data handling

2.2.1 Service user surveys

During the design phase of the BHAS, the commissioner and providers worked to develop a method to systematically capture information about the impact advocacy has had on the service users and hence the overall effectiveness of the service for individuals and the wider community. The decision was made to utilise a service user survey (appendix 2) adapted from a tool generated by Action for Advocacy. The aim of the survey was to collect evidence to demonstrate whether there is a link between advocacy and improved levels of confidence and empowerment of service users to deal with issues unsupported.

The tool has been used to measure the 'distance travelled' by the service user against a number of outcomes. A test-retest approach was employed by asking a series of questions at the first and last advocacy session. Each question had a selection of possible responses represented within a series of circles and each answer choice was assigned a numerical equivalent (1-5). Circles overlapped to allow the possibility to capture a half-way point and therefore a half score was permitted e.g. 1.5



Questions were arranged to test different service outcomes with one question asked for each of the themes:

- Independence
- Access and information
- Rights
- Voice
- Control
- Physical health and wellbeing
- Mental health and emotional wellbeing

The survey also captured details of whether the service user was registered with primary care services and where they were most likely to access services. Again, this was conducted at the first and last sessions:

	1st session		Last session	
Are you registered with an NHS dentist? (Delete as applicable)	Yes	No	Yes	No
Are you registered with an NHS dentist? (Delete as applicable)	Yes	No	Yes	No
Where are you most likely to go to access health services? (Delete as applicable)	Hospital A&E Pharmacy GP practice Walk-in centre		Hospital A&E Pharmacy GP practice Walk-in centre	

Prior to implementation, the survey was tested by a group of advocates to ensure that it served its intended purpose and could be accurately translated into the different community languages. This exercise identified that it would be difficult to

accurately and consistently translate the survey into the necessary range of community languages in written format in order to allow self-completion. Therefore advocates supported service users to complete the survey at the initial session and the final session working with the client. While this may have led to a degree of positive bias in responses, as a result of service users wanting to please the advocate, incorporating the tool as part of the advocacy process potentially reduced the interview bias that could have been a feature had the researcher conducted the survey with the service users directly (Oppenheim, 1992, page 103).

Data from the client surveys were entered into an Excel spread sheet. Scores were then plotted on a radar graph to form an “empowerment web”. This web provides a visual representation of changes service users experience as a result of advocacy.

An average score for each question (at first and again at last session) was identified by adding the relevant scores for all clients and dividing by the number of individual scores. When plotted on a radar graph, this demonstrates the average empowerment journey clients of the BHAS experience. Scores across all clients for individual questions / outcomes were plotted using a comparison line graph to show the trend in changes for clients between first and last sessions.

2.2.2 Advocate questionnaire

Perceptions of the advocates working for the BHAS were captured using a questionnaire (appendix 3) divided into sections entitled

1. Working as an advocate

2. About the advocacy role
3. About the advocacy clients
4. About the impacts of advocacy
5. Working with healthcare professionals
6. About the bilingual health advocacy model
7. About you

The questionnaire was designed using SNAP survey software which ensured a consistent approach was taken to the questioning. Respondents were asked to rate the extent to which they agreed with a series of statements using a five point Likert scale with a choice of:

- Strongly disagree
- Disagree
- Neither agree or disagree
- Agree
- Strongly agree

A free-text box was included at the end of each section to capture any additional comments and observations the advocates wished to provide.

Each question was asked using positive phrasing, for example “Advocacy is an effective way of reducing health inequalities for migrants” or “My clients’ physical health has improved as a result of advocacy”.

At the beginning of the questionnaire, respondents were asked:

“Have you undertaken active case work for the Bilingual Health Advocacy Service?”

This allowed the researcher to eliminate results from those who had no experience of working as an advocate and ensure that the findings represented the informed views of active advocates.

The questionnaire was piloted by the directors of the service provider organisations and also by a colleague of the researcher who had no previous involvement with the BHAS. This was to test the clarity of the questions and instructions for completion, identify if there was any important information that would not be captured by the questionnaire, and to understand how long the questionnaire would take to complete. The questionnaire was then reviewed and the researcher identified which aspect of the research each question related to. This was done to ensure that all data collected was relevant to and usable in this study.

The questionnaire was self-administered to remove interview bias as far as possible. It was distributed in hard copy to those advocates attending the focus groups (see section 2.2.4) and those participants were given time to complete it on that day in an attempt to maximise response rates. For advocates not attending the focus groups, the questionnaire was sent out in hard copy or completed electronically via a web-link which was emailed to advocates by the service providers. In all cases the

questionnaire was accompanied by a covering letter which explained the purpose of the research and how the results would be utilised.

Due to the small sample size it was important that a high proportion of active advocates completed the questionnaire. To assist in gathering as many perspectives as possible, service providers contacted the advocates prior to its distribution to explain the questionnaire's purpose and encourage them to complete it.

Response data were then entered into the SNAP data management programme allowing analysis of responses. The findings were corrected for standard deviation. Graphs representing the findings were created in the SNAP programme and exported into word format for inclusion in this report. The qualitative feedback was included in the analysis of other qualitative data gathered through case studies and focus groups.

2.2.3 Case studies

As part of the performance monitoring of the service, providers were required to present a range of case studies summarising the work undertaken with clients. Case studies were recorded on a template designed by the researcher so that they provided consistent and comparable information. Case studies were produced by the advocates using client case notes. It should be noted that the case studies

provided a summary of the intervention and therefore not all indicators of service impact will be recorded.

Case studies recorded:

- A client needs assessment – recording the goals set with the advocate at the first session
- Additional needs identified that lay outside the scope of the BHAS e.g. immigration queries
- Summary of intervention outcomes
- Client feedback

The researcher reviewed each case study and coded the data using key words and phrases which had been identified, through the literature review, as indicators of BHAS impacts (see chapter 3). A constant comparative method was used to analyse the information for trends and patterns. Throughout this process, the researcher identified particular examples of the impacts experienced which supported, or challenged, the themes that were emerging from the different sources of research. Qualitative information generated through the advocate questionnaire were analysed in the same way.

2.2.4 Workshop / Focus groups

A workshop was held with BHAS bilingual advocates and directors of the service providers in July 2012. Participants were split into small groups and were asked to discuss a series of questions designed to explore their perceptions of the impacts

that the service has had on their clients and on the NHS. This methodology was selected as *'the most appropriate way of exploring the perspectives of participants who are involved in a common situation.'* (Collis & Hussey, 2003, Page 166)

"The explicit use of the group interaction to produce data and insights that would be less accessible without the interaction found in a group" (Morgan, 1998, Page 12) *provides the researcher with rich data."* (Collis & Hussey, 2003, Page 167)

The researcher reminded participants of the service objectives and explained the purpose and approach of this evaluation. Working in small focus groups of between 4 and 6 people, participants were supplied with a workbook containing structured activities and templates to capture their responses in a consistent way. The activities were designed to capture:

- Perspectives of the advocates about the impacts of the BHAS – by providing time and space to complete the advocate questionnaire (conducted as an individual activity and not group work).
- Views on what “empowerment” looks like – to help design indicators of empowerment against which the impacts of the BHAS could be measured.
- Perspectives about how “empowerment” should be defined – to identify an agreed definition that was relevant to the BHAS.
- Advocates’ experiences about whether and how the BHAS has improved access to healthcare.
- Achievements and challenges that the BHAS has presented.
- Views on how the challenges could be addressed in future.

The data collected through this activity was written up to provide collective set of qualitative data. Trends in the data were analysed using a constant comparative approach (see section 2.2.3).

2.3 Response levels

- 24 advocate questionnaires were completed of which 21 responders had undertaken at least one advocacy case for the BHAS (this represents 95% of advocates that had undertaken case work). The three questionnaires that were completed and indicated that the respondent had not undertaken any casework under the BHAS were excluded from the analysis contained within this study.
- 40 client surveys were analysed (test –retest data). A number of surveys (additional to the forty stated) had to be excluded from the research for incomplete data (i.e. the survey was only completed at a first or last session and therefore no change as a result of advocacy could be measured).
- 70 case studies were reviewed. Each case study relates to a separate client. Where work with a single client was recorded over more than one case study (as a result of an advocacy extension being granted) these were considered as a single case to eliminate double-counting.

- 19 people participated in the workshop (these were either BHAS advocates or representatives from the provider organisations). Participants were split into 4 focus groups.

2.4 Ethical considerations

The researcher sought advice about whether this study required NHS Research Ethics Committee (RES) approval. Guidance produced by the RES (2011) confirmed that the data sources utilised in this study were subject to the following exemptions from requiring NHS ethics approval:

“1. Research involving previously collected, non-identifiable information

Research limited to secondary use of information previously collected in the course of normal care (without an intention to use it for research at the time of collection) is generally excluded from REC review, provided that the patients or service users are not identifiable to the research team in carrying out the research.

4. Research involving staff

REC review is not normally required for research involving NHS or social care staff recruited as research participants by virtue of their professional role.”

(NHS Research Ethics Service, 2011, pages 8 & 10)

The data relating to service users (service user survey and case studies) was collected as a contractual requirement of the service and was not for the specific purpose of this research study. All case studies and service user surveys were anonymous so that service users could not be identified.

Advice was given that exemption 4 also relates to Staff contracted to work for the NHS via a provider organisation. All advocates completing the survey and / or taking part in the focus group were provided with a participant information sheet and asked to complete a consent form (appendix 4). No data from these sources was utilised without a signed consent form having been completed. These forms were submitted with the questionnaires but removed prior to data entry so that responses could not be attributed to any individual.

CHAPTER III - Literature review

This research draws on local, regional, national and international studies into population profiles of migrants and the health inequalities they face. It considers examples and evaluations of advocacy services and explores different theories and concepts of empowerment. The literature review will be used to identify indicators against which the impacts of the Bilingual Health Advocacy Service can be measured.

3.1 Migrant profile

“In the last decade, statisticians estimate that between 150,000 and 200,000 more people have arrived to live in the UK each year than have left to live abroad, but this figure is likely to be substantially revised once the 2011 census is published.

38% of new migrants in 2008 arrived to work, 30% to study, and 17% to join family members already settled here. The numbers now coming to seek asylum have decreased substantially to under 20,000 in the last year, and the UK ranks 14th out of all European countries in terms of numbers of asylum applications per head of population.” (Hastings Borough Council, 2012 found at www.hastings.gov.uk)

It is difficult to put an accurate figure on the number of migrants living in East Sussex at any one time. While there are a number of measures to count migrants entering an area (for example National Insurance Registration, Asylum Seeker dispersal notifications, children registering at schools etc.) there are not such accurate measures to record people leaving the area.

There are more accurate figures relating to the ethnic profile of the population as a whole. However, due to the UK's long history of receiving migrants, these do not give an accurate view of migrant population figures at any one time as they include people of different ethnicities who were born in the UK.

The Joint Strategic Needs Assessment, compiled by the Public Health Department of East Sussex County Council (2012) provides a number of indicators for the migrant population. However, these generally relate to recorded in-coming migrants and do not always reflect settled communities, nor do they capture figures for asylum seekers. This is particularly notable since Hastings (the second largest town in East Sussex) is an official asylum seeker dispersal area.

'Figures from 2011 place the population of East Sussex at 517, 040. The population is predicted to increase by 3% by 2014 and 4% by 2016.' (Public Health Department, 2012, page 2)

The following graphs are compiled from data contained on East Sussex in Figures web resource (www.eastsussexinfigures.org.uk)

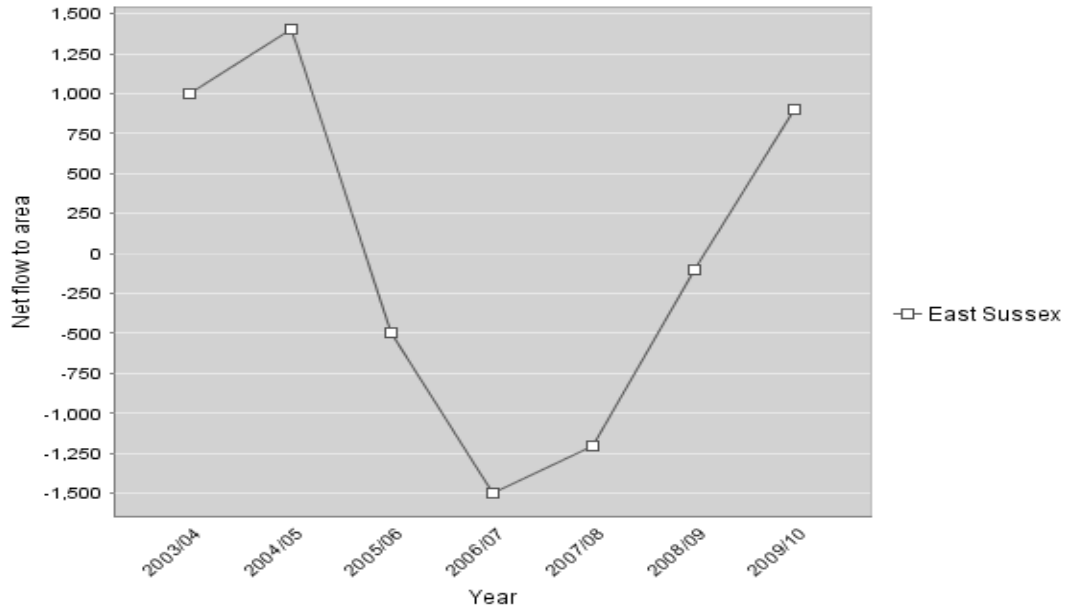


FIGURE 2: Recorded international in-migration between 2003 – 2010

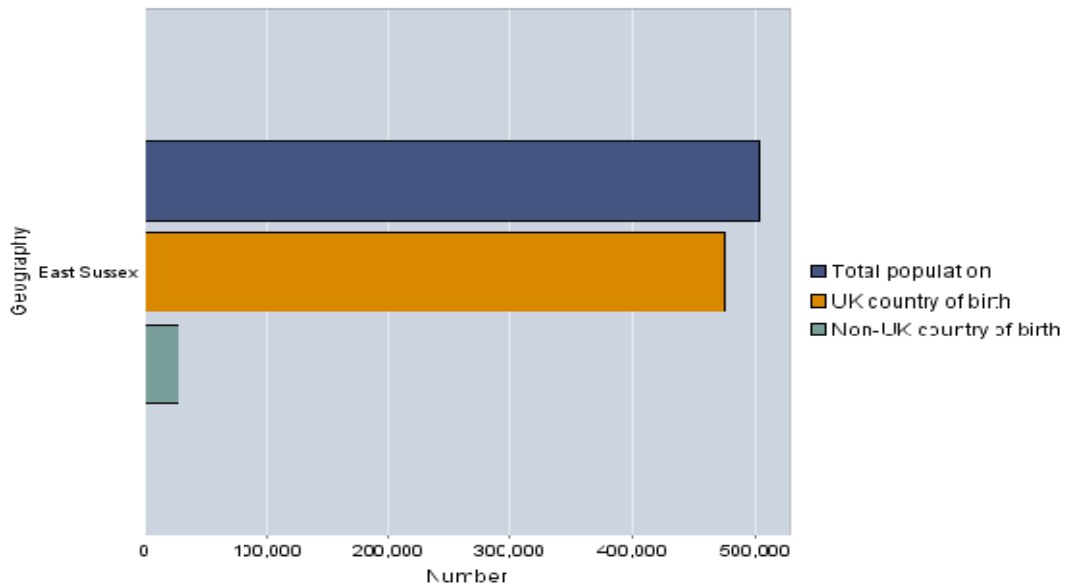


FIGURE 3: 2010 figures of recorded population in terms of UK birth (476,000) and non-UK birth (27,000).

Around 2200 in-migrants in East Sussex apply for a National Insurance Number (NINo) each year. Around one third of these are applications from in-migrants from EU accession countries.

The top six nationalities for NINo registration in East Sussex (by district) 2004 – 2008 were:

Rank	Eastbourne	Hastings	Rother
1	Poland (1210)	Poland (560)	Poland (250)
2	Portugal (240)	Latvia (210)	Philippines (90)
3	Spain (190)	Latvia (210)	Slovakia (70)
4	Philippeans (180)	Czech Republic (140)	India (70)
5	India (150)	Lithuania (120)	South Africa (70)
6	Germany (140)	India (120)	Czech republic (60)

(Hastings Borough Council (2012) found at www.hastings.gov.uk)

In 2009/10, 3416 international in-migrants registered with a GP. This figure declined slightly in 2010/11 but registrations have been relatively consistent each year since 2002/03 standing at between 3250 and 3500 per year. (East Sussex County Council 2012, found at www.eastsussexinfigures.org.uk)

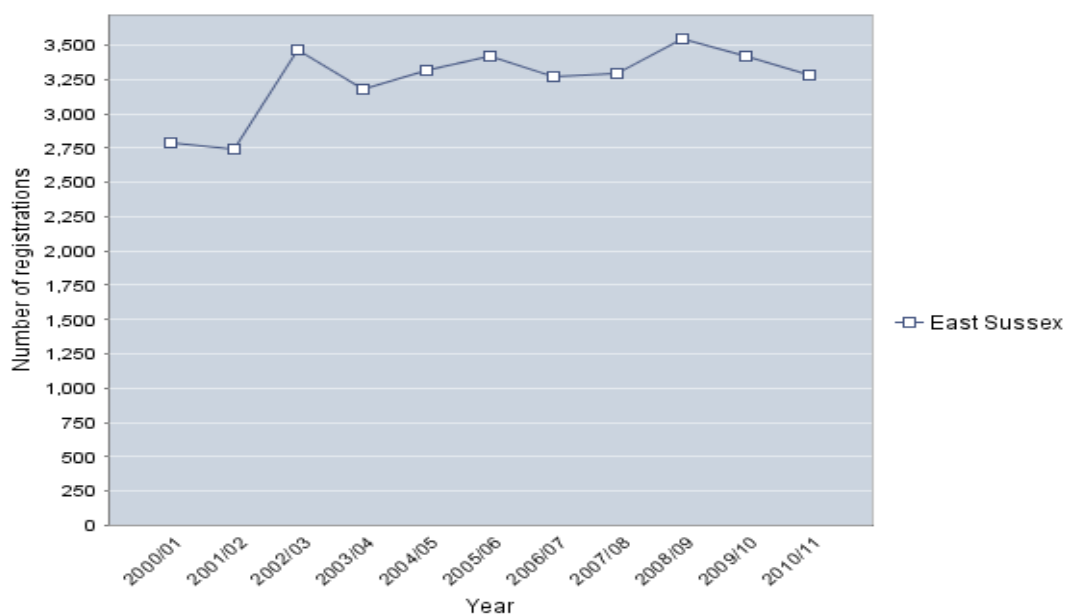


FIGURE 3: International in-migrants registering with GPs in East Sussex, by year

Reviewing the most commonly requested languages for interpretation reflects the range of different nationalities residing in East Sussex that are perhaps not captured through other methods of recording.

According to reports from the two main interpretation and translation providers serving the NHS in East Sussex the top twelve languages requested for interpretation were:

Polish	Cantonese
Kurdish	Russian
Bengali	Portuguese
Farsi	Arabic
Mandarin	Turkish
Pashto	Spanish

(Vandu, 2012, page 2 & SIS, 2012, page 6)

Only two of the most requested languages for interpreting in 2011-2012 are widely spoken in EU member states. This may be due to higher levels of English among European-born migrants or reflect differences in the demographic profile of migrant groups, with most EU-born migrants entering the UK for economic reasons having better health and access to services.

The barriers, and health needs of these groups will vary and not all migrants will need support to access mainstream services.

“Economic and educational migrants tend to be drawn from healthier and wealthier populations in any country, whereas those arriving as asylum seekers or refugees may have experienced deprivation, disease and disaster, often arriving in the UK with greater and more immediate health needs.”

(Raphaely & O’Moore, 2010, page 9)

Research into the health needs of migrants is sometimes incorporated into studies of ethnic minority needs generally. While this study will draw on learning from this wider research, the target client group for the BHAS is newly arrived migrants (majority living in the UK for 5 years or less). Some health considerations apply to all ethnic minority groups, including those born in the UK, however, there are specific issues that migrants may experience which this more widely defined group do not.

“Ethnic groups are not homogenous. They differ in respect of:

- *History, culture, and religion*
- *Health and disease patterns*
- *Exposure to risk factors relating to health*
- *Perceptions of health and illness*
- *Expectations of health and social services”* (Lodge, 2010, Page 10)

3.2 Advocacy as an effective intervention

The literature review has highlighted evidence of advocacy being used successfully to address barriers to migrant access to health services.

"Because of the barriers to changing the way in which health and social care practitioners' work, practices such as advocacy have been developed to strengthen service users' voices in their individual encounters with service providers. Advocacy is designed to enable service users to have their voice represented in service decision making, even in situations where they are unable to speak directly for themselves or need help to do so." (Barnes & Cotterell, 2012, Page 75)

The World Health Organisation (Europe) (2010) refers to "cultural mediators" and suggests that:

"Cultural mediators can fulfil a very important role in reducing barriers to access and bridging the gap between migrant and minority communities and the health system... Cultural mediators, chosen for their familiarity with the culture and "life-world" of the service user, participate in health interventions to bridge the social and cultural gap between service providers and users." (Pages 19& 22)

'There is a spectrum or continuum of advocacy, which ranges from legal advocacy through to the informal support and encouragement of a friend.' (Advocacy Rights Hub, 2009 found at www.advocacyrightshub.co.uk)

The model of advocacy delivered through the East Sussex BHAS is short term advocacy.

“This recognises that some people may require support of an independent advocate during a major change in their life e.g. death of a carer, or with a particular issue e.g. accessing housing advice or making a complaint. The short-term advocate is somebody who is not involved in the person’s issues and offers them person-centred independent support. The relationship would usually only last until the issue has been dealt with by the appropriate body.” (Advocacy Rights Hub, 2009, found at www.advocacyrightshub.co.uk)

In developing an advocacy service targeted at migrants, it is essential that the service is accessible and sensitive to the client group they are working with.

Research conducted for the Joseph Rowntree Foundation (2002) has shown that:

“Where mainstream advocacy services existed, they were inaccessible and often inappropriate to the specific needs of black service users and carers” (page 1)

Guidance produced for health professionals working with refugees and asylum seekers states that:

“Health related behaviour and healthcare are both affected by culture. How, when and what people present to health workers will be influenced by culture and beliefs...Interpreters, health advocates and health workers from displaced backgrounds can assist with details of cultural background”(Burnett & Fassil, 2000, page 14).

This study quotes a nurse team leader from London who asserts

“Advocacy services seem to be more appropriate than basic interpreting services.”
(Burnett & Fassil, 2000, page 15)

The Bilingual Advocacy Service has worked with qualified community interpreters to capacity build and train them to become accredited advocates. This model means that not only can the advocate speak the clients' language (removing one of the barriers to healthcare) in many instances they share the same or similar cultural beliefs.

Research among the Bangladeshi community in London undertaken by Kelleher & Hillier (1996) found that being supported or treated by a professional who shared or understood the language and cultural needs and assumptions of the client improved the trust and value placed in the service received. One of the research participants said:

"If I could have used my own language I would have felt at ease. It would have been better for me to have a Bangladeshi professional; a Bangladeshi would have understood me. I could have expressed myself and the professional would have listened." (Page 41)

3.3 Indicators of improved access to health services

'Accessibility of services refers to the ease of which people can make use of them when they need them.' (WHO, 2010, Page 17)

There is a wealth of recent research into barriers that migrant communities may experience when trying to access health services. Some migrants (irregular migrants) may not be entitled to the full range of NHS care and these individuals may face financial barriers to access to healthcare in the UK. However, Raphaely & O'Moore's research (2010) shows that, at the time of writing, the majority of migrants living in East Sussex are entitled to access health services but may experience difficulty in doing so.

"Many migrants will clearly understand their entitlement to care in the UK and will access both primary and secondary care services effectively within the south East. However, for some, access problems can arise due to:

- *Lack of understanding of UK health systems*
- *Lack of knowledge around entitlement to care*
- *Language barriers*
- *Cultural barriers"* (Page 76)

Research into the needs and experiences of migrants in East Sussex was undertaken for a "Comprehensive Needs Assessment for Black and Minority Ethnic Groups (including Gypsies and Travellers) in East Sussex" (Lodge, 2010)

“The comprehensive needs assessment identified a number of key issues affecting health, as perceived by community leaders and members of the public:

- *Language barriers*
- *Lack of interpreters / not using existing interpreting services*
- *Difficulties in getting to appointments*
- *Transport issues*
- *Fear of being judged*
- *Overt and covert prejudice*
- *Lack of understanding of how the system works*
- *Time to ask questions of “why” rather than just “what”*
- *Lack of understanding of how the UK system fits with advice from birth country e.g. how to make decisions about immunisations, how to live with recurring conditions like malaria” (Page 46)*

3.3.1 Access to primary care

Anecdotal evidence gathered through the Link asylum seeker and refugee drop-in service operating in St Leonards-on-Sea, East Sussex suggested that many of the clients engaging with that service had difficulty registering with primary care services. This local insight is echoed in National research by the Health Protection Agency which found that;

“Migrants might inappropriately use A&E services when their needs would be better served by GPs. But because they do not register with primary care, they may find walk-in services offering immediate care without the need for registration more easily available to them.” (Raphaely & O’Moore, 2010 page 10).

Indicator A1: Evidence of registration with primary care practitioners (GP / Dentist / Optician).

Indicator A2: Evidence of changing behaviours in terms of point of access from urgent care access points (A+E, Walk in Centres) to managed care access points (primary care and self-management services)

The difficulties in accessing primary care services also means that migrants may leave health problems untreated for long periods.

“Another indication that a particular group is experiencing problems of access may be that its members more often access care when problems are more advanced and symptoms more severe.”(WHO, 2010 page 17)

Indicator A3: Evidence of service users residing in the UK for a long time accessing treatment for a long-standing condition with support from an advocate.

Even if migrants are able to register with primary care services, sometimes the systems and processes operating at the GP or dental practice can be a barrier to access.

“An appointment system (in Hastings) where one is required to phone on the day of the appointment in the morning did not suit some people; and prevented some from accessing their GPs.” (Sikora et al. 2011, page 34)

Indicator A4: Evidence of advocates assisting with making Primary Care appointments.

3.3.2 Access to specialist services and diagnostics

The NHS relies on the majority of healthcare to be managed within primary care (by a GP) and referrals to a specialist are made when primary care solutions have been exhausted.

Local research shows that migrants sometimes feel that they are blocked from accessing diagnostic services and specialist care:

“Some hospital staff and GPs were seen to be ignoring migrants’ health issues and being reluctant to refer people for examinations and tests.” (Sikora et. al, 2010, Page 5)

Whilst it may be possible to attribute some of this feeling to different approaches to healthcare in the UK compared to their country of origin, whether this is perception or reality, if people believe they are facing discrimination they may be reluctant to seek medical help and onward referral.

Indicator A5: Evidence of referral for diagnostic tests and specialist treatment.

3.3.3 Understanding health systems

A lack of understanding of how the NHS system works is a barrier that has been identified in several research studies;

“Second and third generation residents from different community groups may all have a different understanding of the health and social care system and of information delivered by groups within these systems...For recent arrivals into the UK, or families who have experienced other health care and education systems, their perceptions may be based on criteria and definitions that do not match those operating in the UK”. (Supported Voices Project, 2009, pages 20 - 21)

Guidance produced to support health workers to meet the needs of refugees and asylum seekers (Burnett & Fassil, 2000), quotes a male doctor with refugee status as saying:

“Health workers know the system; refugees are blinded to the system. They need help to access the system.” (Page 21)

Indicator A6: Evidence of improved knowledge and understanding of health services and systems.

3.3.4 Language & Cultural Barriers

Local people contributing to research exploring access to services for migrant communities in East Sussex cited language difficulties as a significant barrier to accessing services. This is a problem in terms of registration, booking appointments and then communicating health issues during appointments with health professionals and can make migrants reluctant to seek medical attention.

“Several migrants were unable to get an interpreter at their GP surgery even though they chose that option when they registered.” (Sikora, 2011, page 5)

Indicator A7: Evidence of increased use of interpreters and other communications support solutions (such as language flags on patient notes or use of appointment cards to write down appointment information) following advocacy intervention.

Cultural beliefs and a person's experiences of healthcare in their country of origin, can dictate how migrants interact with health services. Local research into the needs of asylum seekers living in East Sussex found that:

"The biggest challenge with the Farsi speaking community is their isolated lifestyle behaviour, within their local community. Also their pride which hinders their approach for help and support as they are conditioned to suffer in silence, this cultural behaviour is "not to complain and agree with whatever fate puts on their destiny path"." (DRI, 2010, page 26)

Culturally insensitive services and a lack of cultural awareness on the part of professionals and volunteers can also be a barrier to health. One local resident claimed that:

"Some of these services don't have a good way....know the correct way to deal with people who have got very heavy accents, whose English isn't very good and they're not treated as well as they could be" (Sikora et al., 2010, Page 56)

Research conducted by the British Medical Association (2004) recommended that:

"GPs need training and support to develop a greater understanding of cultural, social and other issues relating to refugees and asylum seekers." (Page 17)

Indicator A8: Evidence of advocacy promoting greater cultural understanding among health professionals

3.4 Indicators of improved health

Health inequalities faced by migrants are well researched and documented.

“The physical health needs of migrants are affected by the background levels of diseases, health behaviours and health services in countries of origin, as well as the reason for migrating.”(Raphaely & O’Moore, 2010, page 9)

This study does not intend explore health inequalities in any depth, but in order to assess the impact of the BHAS on improving migrant health, it is necessary to understand some of the areas where migrants experience different health outcomes and may have higher disease prevalence rates.

Across the research explored, there is agreement that generally, the illnesses that migrants experience are the same as those suffered by the majority population. However, there are some conditions which migrants are more prone to face. Research by the Healthcare Commission (2009) states that:

“There are some marked differences in health outcomes between minority ethnic groups and the majority of the population. For example, Pakistani men and Indian women have higher rates of angina and Pakistani men and women are more prone to heart attacks. Diabetes is more common in people from Black Caribbean and many Asian communities. There is a high infant death rate in Pakistani communities. Black Caribbean people are three to five times more likely than the wider population to suffer from psychotic illnesses.” (Page 5)

Given the short-term nature of this research study it would not be possible to attribute reduced disease prevalence rates to advocacy intervention which would need to be monitored and evidenced over several years. Even then, it would be difficult to attribute the reduction in disease prevalence to any single intervention. There are however a range of indicators of improved health that may be directly attributed to advocacy intervention.

3.4.1 Health inequalities in migrant communities

Infectious diseases

Some infectious diseases, less common among the indigenous population, are more prevalent in other countries, and migrants can enter the UK already affected. The Comprehensive Needs Assessment of Black and Minority Ethnic Groups in East Sussex suggests:

“Among cases for which information was available, 70% of all TB [Tuberculosis] cases and HIV cases reported in England, Wales and Northern Ireland and 70% of malaria cases reported in the UK in 2004 had been born outside the UK. In any given year, it is also estimated that the majority of chronic hepatitis B infections newly added to the existing numbers of such infections in England and Wales are likely to be in the non-UK born.” (Lodge, 2010, page 30)

Indicator H1: Evidence of diagnosis and treatment of conditions which particularly affect migrant groups.
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Mental illness

The study “Understanding the health needs of migrants in the South East region”

(Raphaely & O’Moore, 2010) found that:

“Mental health, more than any other issue, was identified by survey respondents as ‘a significant problem’ for migrant populations, and no respondents judged it as ‘not a problem’.” (Page 83)

Asylum seekers and refugees are particularly vulnerable to suffer psychiatric problems due to the circumstances that led them to flee from their countries.

Further research undertaken for the Commission for Public and Patient Involvement in health states that:

“In terms of known factors that might predispose an individual to develop mental health issues, including serious and enduring problems, refugees are a group with high indicators of mental health need. Refugees are likely to have experienced war, persecution or inter-communal conflict, resulting in multiple losses including family, friends, home, status and income.” (Warfa, & Bhui, (2003) cited in Palmer & Ward, 2006, Page 5)

However, whilst more likely to suffer from mental ill-health, there is also evidence that these most vulnerable groups may not recognise that they need help or may be reluctant to seek professional intervention.

Burnett and Fassil (2000) describe how:

“Mental illness carries marked stigma in many cultures, which may deter people from seeking help. Culture affects interpretation of behaviour and may influence diagnosis of mental illness.” (Page 15)

In her article “Mental health of refugees and asylum seekers”, Rachael Tribe (2012) asserts that:

“The idea of talking to a psychiatrist, who is a stranger, about feelings may be an extremely alien and culturally incongruous concept, particularly given the associations with ‘madness’ and different cultural positioning around these issues.”(Page 242)

Indicator H2: Evidence of service user interaction with counselling or specialist mental health services.

Maternity care and reproductive health

Another area of healthcare where there are differences in experience and outcomes for migrants is around maternity care.

“Black African women including asylum seekers and newly arrived refugees have a maternal mortality rate 6 times higher than White women, and the rate in Black Caribbean and Middle eastern women is raised but not to this extent” (Lodge 2010, page 29).

It is not always clear why there are such significant differences in maternal mortality and perinatal mortality among ethnic minorities but it may be due to a lack of engagement with ante-natal care.

“Women of Asian origin are more likely to initiate care later and have fewer antenatal visits. The reasons for late booking amongst ethnic minority women have not been fully explored but may include barriers perceived by the women, such as language and cultural issues, or high levels of geographical mobility in some groups”(Lodge, 2010, page 29)

Indicator H3: Evidence of support for service users to access antenatal and maternity care.

Reproductive health is another area where cultural differences can have a significant impact.

“In family planning, the most sensitive and complex areas of culture come into play. How we feel about pregnancy, contraception, abortion, female circumcision, STDs and the value of female infants can divide even those within one culture.” (Bancroft, 2002, Page 3)

There may also be different levels of access and choice in the UK than is available in the service user’s country of origin which can lead to uncertainty about what services are available.

“People’s knowledge of contraception will vary according to their experience prior to arriving in the UK. Some refugees may have little knowledge of the range of contraceptives available.” (Wilson et al., 2007, Page 108)

Indicator H4: Evidence of support to access family planning and other reproductive health services

3.4.2 Lifestyle factors & health promoting activities

Smoking

Research shows that among certain migrant communities’ levels of smoking is high, particularly among men from Eastern European countries.

“A recent equality impact assessment for a new tobacco control policy for England discussed culture, religion and socio-economic factors possibly contributing to the “considerable” variation between ethnic groups and between men and women within ethnic groups” (Raphaely & O’Moore, 2010, Page 52)

Citing research conducted by the World Health Organisation, demonstrating considerable variation in smoking rates in different countries, the report suggests:

“Migrants are a diverse group, but many are young adults, living in relatively deprived circumstances, from countries with relatively high rates of smoking. Their smoking behaviour may also be influenced by cultural and religious beliefs”

(Raphaely & O’Moore, 2010, Page 52)

Obesity

Other evidence (Lodge, 2010) demonstrates that Obesity rates (waist to hips ratio) is higher among Pakistani men and Black Caribbean women and that BME groups are less likely to meet recommended daily levels of physical activity. (Page 58)

Engagement with health promotion activities, for example smoking cessation, exercise programmes, dietary advice, all contribute to healthier lifestyles and improved health. MacLachlan (2006) suggests that:

“There is strong evidence that community health promotion programmes can be effective in reducing serious diseases and mortality... and that they can specifically target minority cultural groups.” (Page 258)

Indicator H5: Evidence of service user engagement with health promotion activities.

Immunisations

Immunisation programmes are key to life-long health and have a population-wide impact by reducing the risk of epidemic. Families moving to the UK have not always benefitted from childhood immunisation programmes and therefore may be more exposed to preventable illnesses than their peers. Some nationalities may not have

a culture of immunisation and therefore public health programmes such as flu prevention campaigns may not resonate with those communities leaving them exposed to higher risk of infection.

Dr David Elliman (2012), a consultant in community child health advises that:

“Immunisation is one of the most important ways of improving the health of the population, not only in less developed countries, but also in the UK. People coming to take up residence here may come fully immunised, but a disproportionate number will be unimmunised or have not completed their immunisations according to the schedule for their country of origin. Even if they have completed the schedule, it may be less comprehensive than that in the UK.” (found at: www.hpa.org.uk)

Indicator H6: Evidence of service user uptake of immunisation programmes.

3.4.3 Medication compliance

Language barriers can prevent people using medications appropriately which can have a significantly detrimental impact of their health. In the worst cases, overuse of medications can lead people to be hospitalised, in less severe cases, not taking medications as directed lead the drugs to be ineffective and the condition for which they were prescribed will persist. Medication reviews can help to ensure that people are on the correct medication, that it is having the desired effect and that long-term conditions are managed effectively.

Indicator H7: Evidence of medication reviews being undertaken for service users.

3.5 Indicators of empowerment

'The process of empowerment means a transition from a state of powerlessness to a state of more control over one's life, fate, and environment.' (Sadan, 1997, Page 13)

There has been extensive scholarly discussion about the nature of empowerment and studies into the concept came to the fore during the 1970s and 1980s.

Concepts of empowerment can generally be categorised either in terms of community empowerment or individual empowerment.

In its "Scottish Community Empowerment Plan" the Scottish Government describes how

"The process of community empowerment helps to unlock the potential of communities by stimulating and harnessing the energy of local people to come up with creative and successful solutions to local challenges." (Housing and Regeneration Directorate, 2009, Page 6)

The model of advocacy in operation through the BHAS focuses on individual empowerment through the 1:1 relationship of client and advocate. While it is hoped that, having more empowered individuals within these communities it may result in a greater level of community empowerment, that is not the principle objective of the service.

“When the individual empowerment process occurs in a man’s or a woman’s life, they begin to believe that they are capable of having better control over their lives; they understand their situation, and begin to act to improve their lives and their environment” (Sadan, 1997, Page 193)

It is difficult to evidence increased levels of empowerment among service users as many of the signs are internal to the individual, for example a sense of improved confidence. Improved health and access to health services should contribute to a sense of empowerment and some indicators, for example improved knowledge and understanding of systems and processes, reflect the definition of empowerment agreed for this study. However, these indicators are viewed at a point where the service user is receiving support from the advocate and may be relying on that intervention rather than beginning to act for themselves.

In an attempt to identify indicators of increased empowerment, the researcher explored the subject with advocates. During a focus group, participants (BHAS advocates) were asked to identify some of the visible or tangible signs of increased empowerment among their clients. The insights of the advocates are depicted in the following “wordle” diagram, with most commonly used terms displayed most prominently.



3.5.1 Independence and communication

Language barriers have a significant impact on migrants' ability to effectively interact with health services. Local research has demonstrated that, whilst interpreters should always be provided by the NHS to support at health appointments, this is not always the case.

"[Language issues were] a major issue for both staff and members of the public. All were concerned about the apparent lack of use of interpreters. Very few non-professionals were aware of Language Line e.g. none of the women at the Bengali Women's Forum had heard of it. Most members of the Black and minority ethnic community reported being led to believe that they should provide their own interpreters." (Lodge, 2010, page 48)

This leads to an inability to explain their health issue or understand the treatment options available to them. One of the signs of increased empowerment identified by the advocates was that service users' had a voice and were able to interact effectively with health professionals, to be able to explain their health issues and understand the details of their condition.

Indicator E1: Evidence of improved English languages skills

Having a basic level of English not only allows the service user to book appointments independently but also can lead to better social integration with the service user able to undertake other tasks independently, for example, go shopping.

Indicator E2: Evidence of service user's ability to manage service interactions independently

3.5.2 Voice and control

Even if the service user has sufficient levels of English to communicate, they are not always confident enough to challenge health professionals and to take control of decisions regarding their health and treatment. A theme that came out strongly in the focus group exercise was that a sign of empowerment was service users being able to express their views, be listened to and to be involved in making decisions about their health and health care. Being able to act for yourself is the very essence

of empowerment and is a sign that the service user is no longer reliant on the advocate.

Indicator E3: Evidence of service user involvement in decision making about their care and treatment

3.5.3 Social Exclusion and social isolation

Social exclusion and social isolation can lead to a sense of disempowerment. They can also lead to poor health, particularly mental health and emotional wellbeing. Forming social contacts, being in employment and interacting with those around you helps to build confidence, and better cope with life generally.

“Continuing anxiety, insecurity, low self-esteem, social isolation and a lack of control over work and home life, have powerful effects on health....Long periods of anxiety and insecurity and a lack of supportive friendships are damaging in whatever area of life they arise. The lower people are in the social hierarchy of industrialized countries, the more common these problems are.” (WHO (Europe), 2003, Page12)

Indicator E4: Evidence of service users forming social connections and experiencing reduced isolation.

Migrant communities are more likely to live in deprived conditions when compared to the majority population. This is particularly the case for non EU migrants who, due to the different reasons for coming to the UK, often have complex health needs.

“The migrant population, particularly those born outside the EU tend to have a higher risk of poverty than other sections of the community, in some countries, a much higher risk.” (Lelkes & Zolyomi, 2011, page 5)

An article in the British Medical Journal (BMJ) explains that:

“No one would dispute that poverty is bad for health. In general, the lower the material standard of living (as measured by indicators like income) the worse is the level of health, whether measured by mortality, morbidity, or quality of life.”

(Kawachi & Kennedy, 1997, found at: <http://www.bmj.com/content/314/7086/1037>)

If we refer back to the agreed definition, empowerment relates to:

“...The ability to turn knowledge into practical actions which can help to improve their [the individual’s] situation” (Parsons 1988, cited in Sadan, 1997, Page 76)

Therefore, activities such as claiming benefits that they are entitled to, and seeking improved housing conditions could also be seen as indicators of empowerment among service users.

Indicator E5: Evidence of service users engaging other support services e.g. benefits advice, housing advice, carer assessment

Research conducted by Lelkes & Zolyomi (2011) into poverty and social exclusion of migrants found that:

“Migrants are more likely to be socially excluded than the local population.

The share of migrants at risk of exclusion or poverty is relatively high. On average, 26% of non-EU migrants and 19% of EU migrants are at risk of poverty, compared to 17% of the “local” population.” (Page 14)

Evidence from local research demonstrates that there is a perception from migrants that they face discrimination from some health professionals and are not treated equally.

“Some migrants in East Sussex felt discriminated against when accessing healthcare” (Sikora et. al, 2010, Page 5)

Social exclusion can be challenged when individuals know their rights and entitlements and are competent to question when these are compromised. Social exclusion can also be reduced if organisations listen and understand experiences of social exclusion and work to eradicate its causes.

“To the extent that the health problems of these groups result from (or are exacerbated by) their disadvantaged social position, measures which combat social exclusion are likely to have the most fundamental effect on health.” (WHO, 2010, page 12)

Indicator E6: Evidence that migrants perceive that they are treated better, in terms of equality and fairness, following advocacy intervention.

CHAPTER IV - Data analysis and interpretation

4.1 General findings

A number of studies (Rai-Atkins et al (2002), Supporting Voices Project (2009)) cite advocacy as a “best practice” approach to addressing some of the barriers migrant communities may face in accessing health services.

As part of the advocate questionnaire, respondents were asked a series of general questions designed to capture their perspectives on the effectiveness of East Sussex BHAS model.

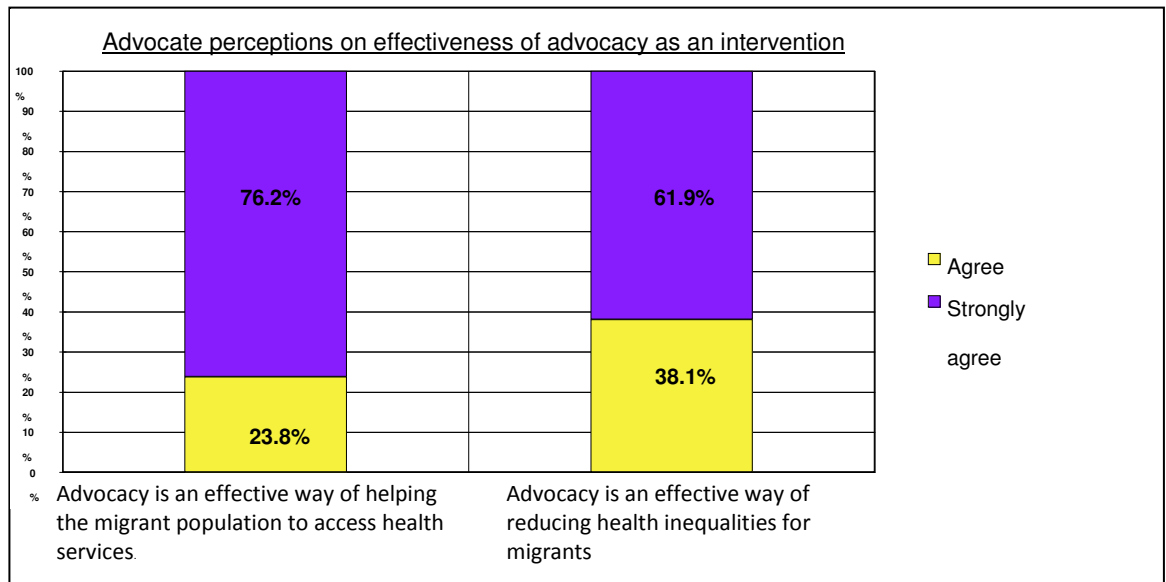


FIGURE 5: Advocate Questionnaire – Perceptions on the effectiveness of advocacy

- 100% of advocates agreed or strongly agreed that advocacy is an effective way of helping the migrant population to access health services
- 100% of advocates agreed that advocacy is an effective way of reducing health inequalities

This positive response may be unsurprising given the source (advocates). However, throughout the pilot of the BHAS, advocates have raised a number of issues about operational aspects of the service and it could therefore be argued that, if the advocacy role was not having an impact, for example if health professionals did not engage better with service users as a result, or if service users did not give positive feedback, this is likely to have been reflected in the findings.

Feedback from clients, recorded in the case studies, has been very positive about the benefits advocacy has had for them.

“I am so thankful, grateful and impressed with the work the advocate provided. Thank you so much.”

“It is a very helpful way to help me have so much information about how to live life in satisfaction. I have worked with a very kind hearted person where her excellent way has shown me how to deal with many enquiries and who has helped me to reach what I need and what I want.”

“The advocate for me was like an angel put on earth. My family and I have benefited immensely from the service provided.”

No negative comments relating to the service received from the BHAS were found in the client feedback contained in within the research data.

4.2 Evidence of improved access to health services

4.2.1 Access to primary care

Indicators

A1	Evidence of registration with primary care practitioners.
A2	Evidence of changing behaviours in terms of point of access from urgent care access points (A+E, Walk in Centres) to managed care access points (primary care and self-management services).
A3	Evidence of service users residing in the UK for a long time accessing treatment for a long-standing condition with support from an advocate.
A4	Evidence of advocates assisting with making Primary Care appointments.

According to the Sussex Interpreting Services “Report on Year 1 of East Sussex Bilingual Health Advocacy Service Pilot 01/03/2011 – 29/02/2012” (2012)

“Access to GP & dental surgeries comprises 57% of all bilingual advocacy sessions rising to 85% when activity is adjusted to [account for] meetings [initial introductory session] to take instructions from service users.” (Page 1)

Evidence of registration with primary care practitioners

While advocate perspectives of the levels of GP registration among service users (when starting advocacy) were mixed, most felt that the majority of clients were not registered with an NHS dentist.

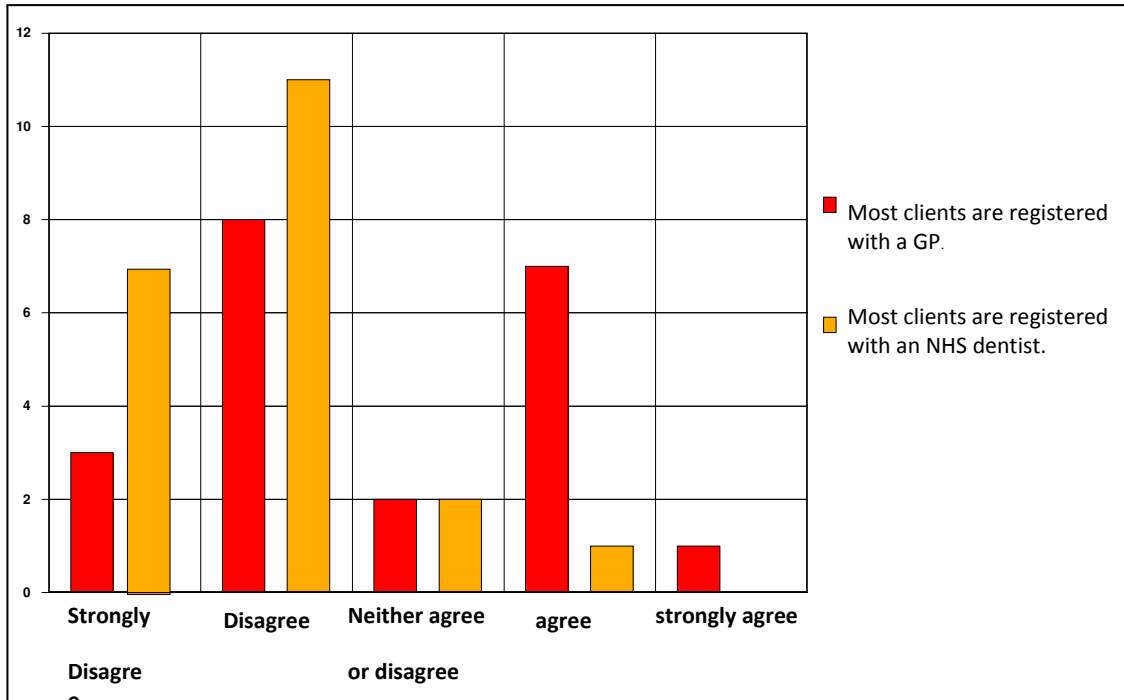


FIGURE 6: Advocate questionnaire: Perspectives on levels of service user registration with a GP and NHS dentist

- 52% of respondents disagreed or strongly disagreed with the statement “most clients are registered with a GP”
- 90.5% of respondents disagreed or strongly disagreed with the statement “most clients are registered with an NHS dentist”

These perceptions seem to be supported by evidence from the service user survey and case studies.

Data gathered from the 40 service user surveys identifies that, prior to advocacy intervention, 28 (70%) of service users were registered with a GP and 16 (40%) were registered with an NHS dentist.

Of the service users not registered with these services prior to advocacy commencing, the survey data shows that:

- 12 (the remaining 30%) service users were registered with a GP practice by the last advocacy session
- 19 (47.5%) service users were registered with a dental practice by the last advocacy session

Within the 70 case studies reviewed, there is evidence of advocates assisting with registration with primary care services.

- 19 case studies (27.1%) identified that the service user was helped to register with a GP as an outcome of advocacy
- 22 case studies (31.4%) identified that the service user was helped to register with a dentist as an outcome of advocacy

However, it should be noted that in 5 of the case studies, the service user was already registered with a GP practice but required assistance to change practice due to dissatisfaction with their current GP.

Advocate questionnaires have provided examples of how advocacy has helped with the registration process:

“One of my clients has just moved to a new area without registering with a GP. An interpreter would not be able to help until she has registered with a GP and an appointment has been booked. There is a gap there for finding an appropriate GP and registering with them. The advocate can help with this rather than an interpreter.”

Case studies also various contain evidence of advocates assisting with primary care registration:

“The client and her family have recently moved to a new address and are unfamiliar with the local community and the services that are available within her new area. Her son was born with a cleft palate and is having on-going surgery. He will need to be registered and closely monitored by a dentist due to his special medical needs.”

“The client’s son is under age (14 yrs) and needs to be registered with a GP and dentist as he has ongoing health issues with his teeth. The mother has limited English and does not feel she has the confidence to do this on her own”

Evidence of changing behaviours in terms of point of access

There is some evidence that assisting with primary care registrations does facilitate service users to access care through managed routes rather than through urgent or emergency care services.

An example from one case study identifies that:

“[The] client was taking her child to A&E as she was not aware of the emergency / urgent appointments request at the surgery” (Case study)

90.5% of advocates, responding to the questionnaire, perceived that service users are better able to choose the right service to access when they need care as a result of advocacy.

My clients are better able to choose the right service to access when they need care as a result of advocacy.

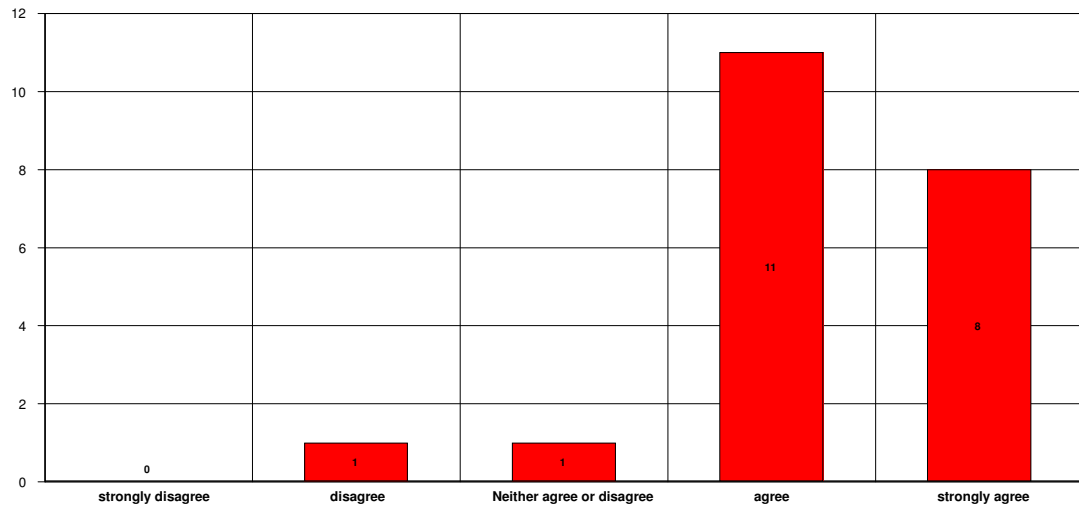


FIGURE 7: Advocate questionnaire: Perspectives on improved client ability to choose the right service to access when in need of care

According to the user survey, 10 service users (25%) who indicated they were most likely to access health services through A & E or walk-in centres prior to receiving advocacy, expressed that they were more likely to access care through their GP following advocacy intervention.

In the majority of cases (80%) these were the same service users that had been assisted to register with a GP as part of advocacy intervention. This would seem to support the findings in the literature review which highlighted that poor access to primary care could result in migrants making higher use of emergency or urgent care service.

It is interesting to note that several service users indicated that, following advocacy intervention, they would be more likely to access a range of services including A & E and walk-in centres alongside GP practices. One interpretation of this could be that service users are now more informed about the services available to them and how and when to access this.

Evidence of service users residing in the UK for a long time accessing treatment for a long-standing condition with support from an advocate

11 case studies (15.7%) provide specific evidence of advocates supporting a service user to get treatment for a long standing condition. In three of these cases, the service user had been living in the UK for over 10 years without accessing primary care services.

“One of my clients has been living in England for nearly 10 years but never registered with a GP or dentist because of the language barrier and lack of knowledge about accessing the NHS. He needed medical treatment for an on-going condition but didn’t know how to access this. With the help of the advocate he now has a GP and a dentist.” (Advocate questionnaire)

“The client has lived in the UK for 10 years without having a GP and is experiencing fatigue and very low spirits. Because his immigration status is unclear he was unaware that he could register with a GP” (Case study)

The case study records that this client was assisted to register with a GP and helped to engage with children’s social services to resolve the underlying cause of his depression.

There is also evidence of several service users seeking medical help but not getting the treatment that they needed.

“My client has been to see her GP several times [in the] past year but she used an interpreter or family members before she had an advocate. The problem never got a result as they were interpreting just what she was saying at that time. Advocacy changed that. Even if she forgot any questions I was able to remind her or talk about it with her permission. She got a result in a shorter time with less hassle.”

(Advocate questionnaire)

Evidence of advocates assisting with making primary care appointments

Evidence of assistance in making appointments is limited to case studies and in many cases is implied rather than recorded directly.

There is explicit mention of advocates having to assist with making appointments with GPs or dentists in 11 (15.7%) of the case studies reviewed. In about one third of these cases, the advocate assisted in booking a double appointment to allow a fuller discussion with the health professional and allow for the additional time working through a bilingual advocate may need.

While evidence is limited to support BHAS effectiveness in relation to this indicator, findings relating to other indicators e.g. treatment of longstanding conditions (A3), access to language support (A7) and increased ability to manage service interactions (E2) would suggest that assisting with booking appointments may be a more regular activity for advocates than is recorded in the summary case studies.

4.2.2 Access to specialist treatment and diagnostics

Indicator

A5	Evidence of referral for diagnostic tests and specialist treatment.
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24 case studies (34.3%) make explicit reference to service users being referred for specialist treatment or diagnostic tests (these figures do not include referrals to specialist mental health services). The case studies indicate a wide range of specialist services accessed, including physiotherapy, cardiology, dermatology, paediatrics, gynaecology, general surgery and neurology. Most of these service users were first referred for diagnostic testing including blood tests, ultra sounds, MRI. Other patients underwent diagnostic testing and were then managed within the primary care setting.

One case study records that a service user had been living with severe back pain and required further examination. The advocate accompanied her to the GP to represent her wishes. The recorded outcome is that:

“A referral was secured from the GP and client was subsequently treated and has had an operation at the ... hospital in accordance with her wishes” (Case study)

In some cases, assistance was provided by the advocate to expedite the referral.

One case study describes how the service user had been referred to the hospital for minor surgery but months had passed and he had not heard anything. On

contacting the hospital the advocate was told that an appointment had been sent which the service user had missed and so the client was put back on the waiting list. The service user stated that he had not received an appointment.

“With the advocate’s support the service user was able to bring [the operation] forward” (Case study)

4.2.3 Understanding health systems

Indicator

A6	Evidence of improved knowledge and understanding of health services and systems.
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The service user survey shows increased levels of knowledge about health services and how to access them.

The survey asked:

“Do you know what health services are available to support you?”

Choice of responses ranged from *“I don’t know what services are available (1)”* to *“I know what health services are available and can make use of them independently (5)”*

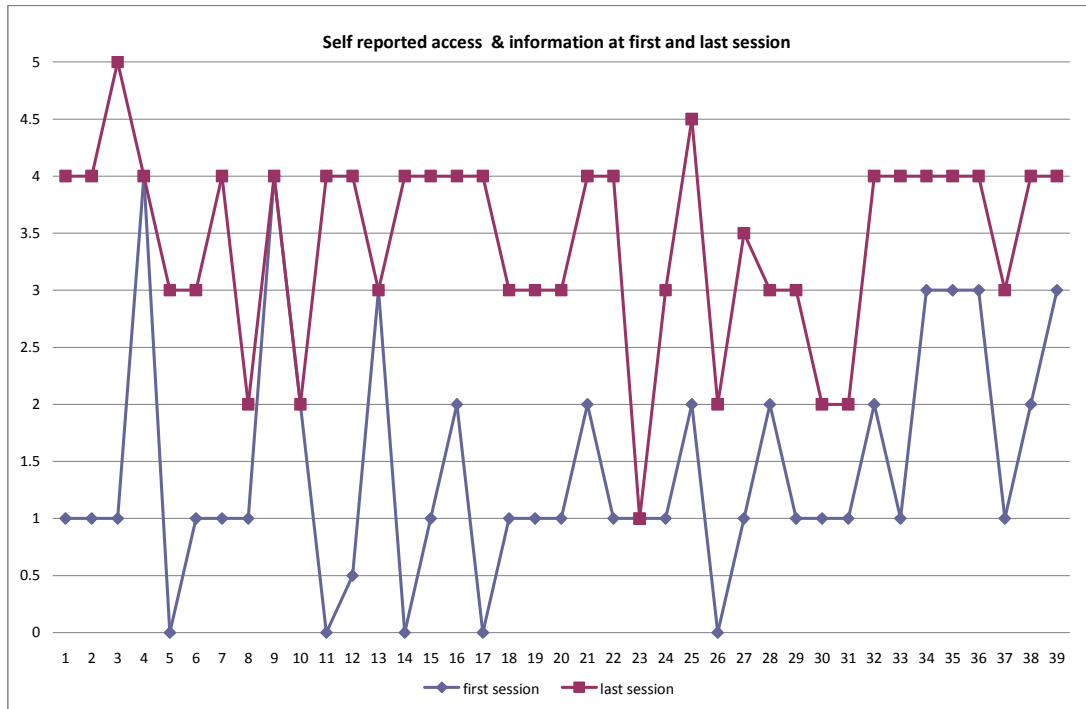


FIGURE 8: Service user survey: Self-reported levels of knowledge of health services and how to access them at first and last advocacy session

Prior to advocacy intervention:

- 77.5% of respondents reported that they didn't know what services were available to them or found it difficult to understand what services were available and to access them

Following advocacy intervention:

- 15% of respondents reported that they didn't know what services were available to them or found it difficult to understand what services were available and to access them.
- 55% of respondents reported that they knew what is available and could access them with some support or independently

4.2.4 Language and cultural barriers

Indicators

A7	Evidence of increased use of interpreters and other communications support solutions following advocacy intervention.
A8	Evidence of advocacy promoting greater cultural understanding among health professionals.

Evidence of increased use of interpreters and other communication solutions

The Sussex Interpreting Service report (2012) notes that:

“Only [2 GP surgeries] were using community interpreters before the Bilingual Advocacy pilot. [3 other GP surgeries] are beginning to use community interpreters following the experience of the pilot.” (Page 1)

Qualitative data from the advocacy questionnaire explains:

“GPs are sometimes not aware that their own receptionists are not booking interpreters for their patients. Advocates can help clients to overcome these barriers” (Advocate Questionnaire)

“Clients feel more relaxed and comfortable discussing their concerns with an advocate who speaks their same language. It will prevent clients to keep quiet and prolong their illness” (Advocate questionnaire)

There is explicit reference to improving access to interpreting services in 13 (18.6%) of the case studies reviewed.

One case study explains:

“The client and her husband are still experiencing language and cultural difficulties which are making it difficult to express themselves to health professionals regarding their family’s medical needs. Client’s husband is having to attempt to communicate with a male GP regarding his wife’s condition which is embarrassing for both of them.”

The result of advocacy intervention is recorded as:

“The manager of the GP surgery has updated the clients’ patient details to alert clinicians of the need for language support. Both the client and the advocate have been reassured that the surgery will look into interpreting solutions.”

Another case study describes an elderly lady *“with complex health needs who can not read, write and is not numerate to the point that she is unable to use a telephone. She has difficulties managing a diary, remembering appointments and managing her medication.”*

In this case, the advocate found innovative solutions to this service user’s situation, including involving the sheltered housing manager in making appointments and supporting the management of her medications.

Evidence of greater cultural understanding among health professionals

There is some evidence of advocacy supporting increased cultural awareness among health professionals.

Advocates describe that in their experience:

“It [BHAS] has changed the way healthcare workers see the migrant family. They approach them with more care and understanding.” (Advocate questionnaire)

One particularly strong example of this relates to a pregnant service user with underlying health problems:

“Because of her age, she has an increased risk of having a baby with Downs Syndrome. The hospital sent her an urgent appointment to discuss further tests...[but] because the appointment was on the next day [she was told] it would not be possible to arrange an interpreter. The service user was annoyed and did not feel it was appropriate to bring a family member or friend to discuss sensitive issues like Downs Syndrome. She also felt that doing tests to determine if her unborn child has any problems and to consider an abortion as a consequence is totally against her religious belief.”

The bilingual advocate was able to provide cultural information and explain to the medical staff involved that some issues are considered taboo subjects in certain communities.

“The doctor said that, in future, they will consider these factors whilst dealing with service users from different backgrounds” (Case study)

Feedback from the client demonstrates the benefits she experienced from the advocacy intervention.

“I am happy to receive your help and support. There are so many important matters that I did not understand before, but today I have got a very clear understanding of what is going on. It helped me to take the best decision”

4.2.5 Impacts relating to access to health services for the advocates

It should not be forgotten that the advocates themselves are from migrant backgrounds so consideration should be taken as to the impact the BHAS has had on them as individuals.

Advocates were asked to state the extent to which they agreed with the statement *“My own access to health services has improved since working as an advocate”*

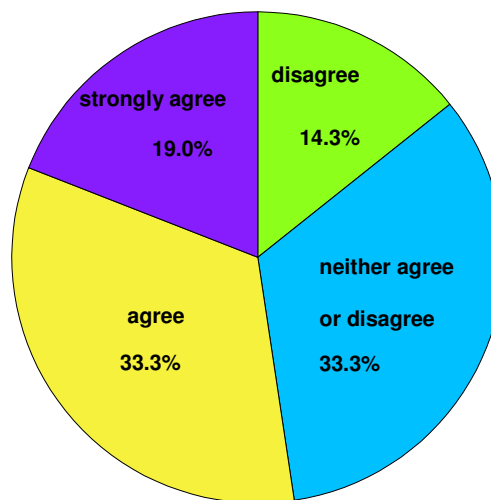


FIGURE 9: Advocacy questionnaire - My own access to health services has improved since working as an advocate

- A small majority of advocates (52.3%) agreed that their own access to health services had improved as a result of working as an advocate
- 14.3% disagreed that their access had improved
- One third (33.3%) neither agreed or disagreed that their access had improved

These findings do not mean that advocates feel their access to services has worsened as a result of working as an advocate. It may be that they did not experience any difficulties with access previously or that they have not tried to access services since starting work as an advocate. However, no further investigation was conducted into why advocates answered in the way they did and qualitative data from the questionnaire did not provide greater insight.

4.3 Evidence of improved health

4.3.1 Health inequalities in migrant communities

Indicators

H1	Evidence of diagnosis and treatment of conditions which particularly affect migrant groups.
H2	Evidence of service user interaction with counselling or specialist mental health services.
H3	Evidence of support for service users to access antenatal and maternity care.
H4	Evidence of support to access family planning and other reproductive health services.

According to the advocate questionnaire:

- 95.3% of respondents agreed or strongly agreed with the statement *“My clients’ health physical health has improved as a result of advocacy”*

Within the service user survey, respondents were asked to plot themselves against the question *“Are all your physical health needs met?”*

Choice of responses ranged from *“People don’t understand my physical health and wellbeing needs (1)”* to *“All my physical health needs are attended to and my wellbeing is improving (5)”*

The findings indicate that the majority of service users felt that their physical health needs were better met following advocacy.

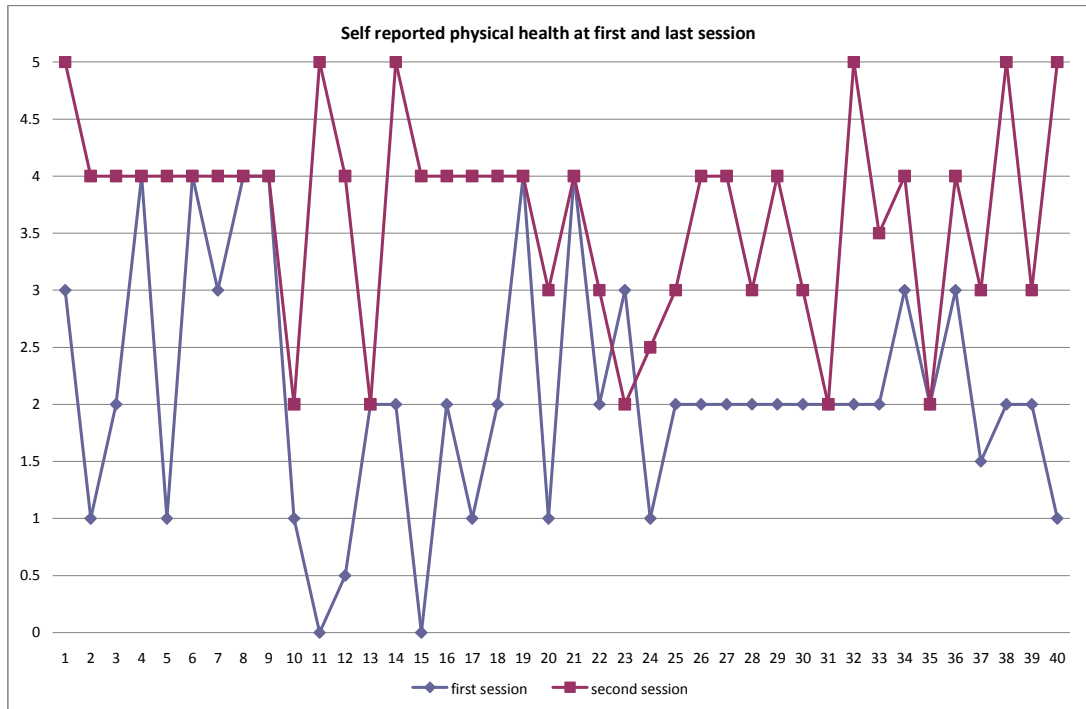


FIGURE 10: Service user survey: Self-reported improvement in having physical health needs met

Prior to advocacy intervention:

- 70% of respondents reported that people didn't understand their physical health and wellbeing needs, or that they only receive treatment for their 'main' problem

Following advocacy intervention:

- 15% of respondents reported that people didn't understand their physical health and wellbeing needs, or that they only receive treatment for their 'main' problem
- 65% of respondents reported that they get the physical health care that they want, or that all their physical health needs are attended to and their wellbeing was improving

Diagnosis and treatment

Evidence to support the effect the BHAS has had on this indicator is limited. This is largely because most of the summary case studies reviewed do not contain detailed information regarding the nature of diagnoses or specify medical conditions suffered by service users.

There are details of diagnosis and resultant treatment of conditions particularly affecting migrants in 11 of the case studies (15.7%).

Conditions diagnosed include:

- 1 case of Tuberculosis
- 3 cases of Hepatitis B
- 2 cases of cancer
- 2 cases of diabetes

Interaction with counselling and mental health services

A performance report from one of the BHAS service providers (Vandu (2012)) states that:

“The majority of service users have stated that they suffer from stress, anxiety and sleep disorders. Solving or improving the root cause has a positive impact on their overall mental health” (Page 2)

This assertion is largely supported by the views of the advocates captured through the advocacy questionnaire:

- 80.9% of respondents agreed or strongly agreed with the statement *“My clients’ mental health has improved as a result of advocacy”*
- 4.8% disagreed with the statement *“My clients’ mental health has improved as a result of advocacy”*
- 14.3% Neither agreed or disagreed with the statement

Service users were asked to plot themselves against the question:

“Are all your emotional and / or mental health needs being attended to?”

Choices of response ranged from *“I have never talked about my emotional / mental health needs (1)”* to *“All my mental health needs are attended to and my wellbeing is improving (5)”*

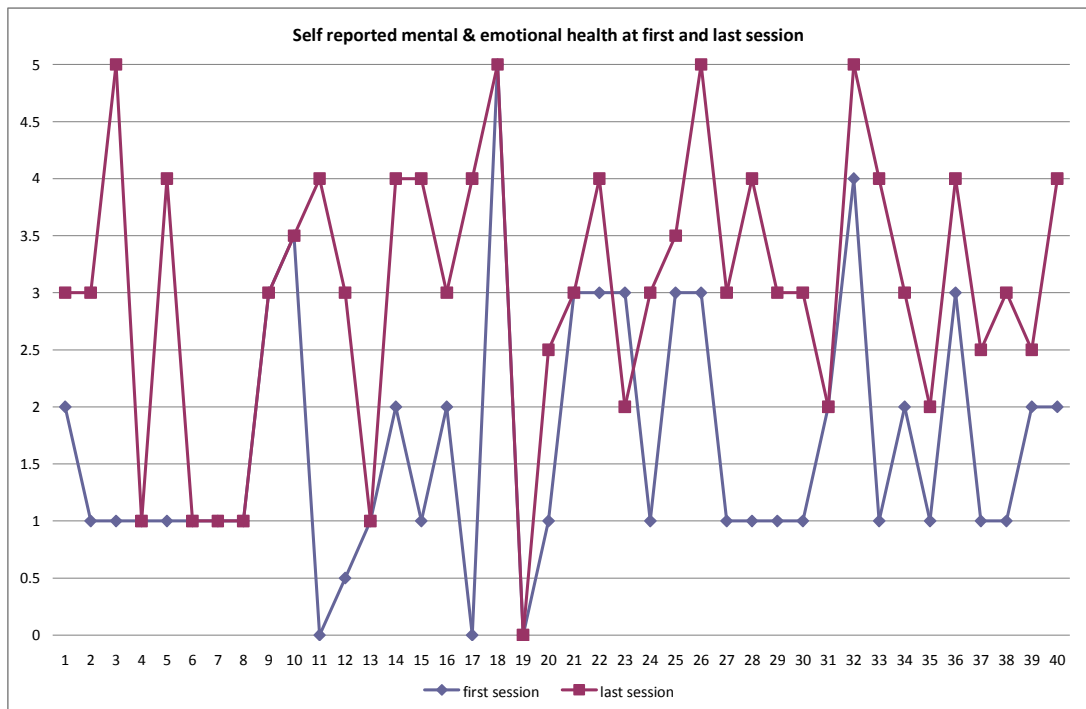


FIGURE 11: Service user survey: Self-reported changes having mental and emotional health needs met

Prior to advocacy intervention:

- 75% of respondents reported that they had never talked about their emotional / mental health needs, or that they needed support to get emotional / mental health care

Following advocacy intervention:

- 30% of respondents reported that they had never talked about their emotional / mental health needs, or that they needed support to get emotional / mental health care
- 35% of respondents reported that they get the emotional / mental health care that they want, or that all their mental health needs are attended to and that their emotional wellbeing was improving
- 35% of respondents reported that some of their emotional / mental health needs were attended to

Evidence of improved interaction with counselling and mental health services was found among the qualitative data.

11 case studies (15.7%) contain evidence of service users engaging with counselling or mental health services.

“The client has been living here for 12 years and does not have a GP. He is suffering from severe mental health issues, post traumatic stress disorder, sleep disorder, high anxiety and deep depression. He feels low and hopeless and his

refugee status is unclear. He has been too fearful to ask for medical help because of his unclear legal status.” (Case study)

This service user was assisted to register with a GP and was referred to a psychiatrist. He was also assisted to employ a solicitor in regard to his legal status.

“One of my clients was feeling suicidal but she wasn’t able to discuss this problem with her GP because her husband had to become their interpreter due to the fact that the surgery was not accessing existing interpreting services. The client was able to convey her story to the GP with the advocate’s help and the surgery is now calling interpreters for all appointments” (Advocate questionnaire)

Engagement with Maternity services

According to the case studies, 6 women were assisted to access antenatal or maternity care.

One pregnant service user who had experienced problems with the birth of her first child was concerned about the health of her unborn child. With support from the advocate the woman was assigned to a midwife for regular checks and referred for specialist oversight of her pregnancy. The advocate assisted the service user to understand her choices in relation to the delivery of the child and supported her to agree a delivery plan with the hospital.

Another pregnant service user, who was unhappy with some aspects of her care immediately following the birth of her baby was supported by an advocate to meet

with the hospital staff to understand what had happened and why. Feedback from the client indicates that:

“She is happy that her baby is healthy and feels confident to see her GP regularly for other and baby check-ups using a community interpreter” (Case study)

Interaction with reproductive health services

There is limited evidence of BHAS advocates supporting increased engagement with reproductive health services.

2 case studies contain evidence of service users being assisted to access family planning services.

One case study describes:

“The client has been living here for 10 years, she has very limited English and now they have children she would like to have a contraception plan, but due to cultural differences and her limited English, she feels embarrassed about discussing this openly, and does not know where to go for help. Her family are not registered with a GP” (Case study)

This family were assisted to register with a GP. The advocate supported the service user to find out about family planning methods provided by the NHS to empower her to make an informed decision.

4.3.2 Life style factors and health promoting activities

Indicators

H5	Evidence of service user engagement with health promotion activities.
H6	Evidence of service user uptake of immunisation programmes.

Engagement with health promotion activities

There is evidence of 4 service users utilising advocacy support to access stop smoking services.

One case study describes:

“The service user has been smoking for forty years. His wife has asked him to quit several times but he refused. When he had a chesty cough the advocate accompanied him to see his GP. The GP explained that his long-term smoking had damaged his lungs. After listening to the GP’s advice, and with support from the advocate, he decided to go to the stop smoking clinic”

Evidence from the case study shows that the service user did stop smoking and

“Has been telling his friends and encouraging them to stop smoking” (Case study)

Uptake of immunisations

There is little reference to immunisations contained in the case studies. Only 2 case studies detail service users taking up the annual flu jab as part of the advocacy intervention.

4.3.3 Medication compliance

Indicator

H7	Evidence of medication reviews being undertaken for service users.
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The Vandu report (2012) states that:

“Timely intervention on several occasions has stopped service users from taking potentially dangerous un-prescribed medication...” (Page 2)

This assertion is supported by an example given by one of the advocates:

“I have seen some clients are so vulnerable. They were trying to bear with their conditions; they bought medicines overseas from China rather than going to see health professionals in this country because of the language barrier. The advocate presents like their mouths – helps them to communicate so they are able to tell doctors their needs.” (Advocate questionnaire)

Another service user, not registered with a GP was *“suffering pain and was taking tablets prescribed to his partner for back pain. He was also using pills recommended by friends.”* (Case study)

10 case studies (14.2%) record medication reviews taking place, facilitated by an advocate. One example describes

“Client has suffered from chronic backache for 15 years and has been to her GP many times who has only prescribed pain relief. Long-term pain relief is now causing her stomach problems, shortness of breath and blackouts.”

With the support of the advocate, the client successfully requested that her GP refer her for tests.

4.3.4 Impacts relating to advocates' own physical and mental health

Advocates were asked the extent to which they agreed with the statements:

“My own physical health has improved as a result of advocacy”

“My own mental health has improved as a result of advocacy”

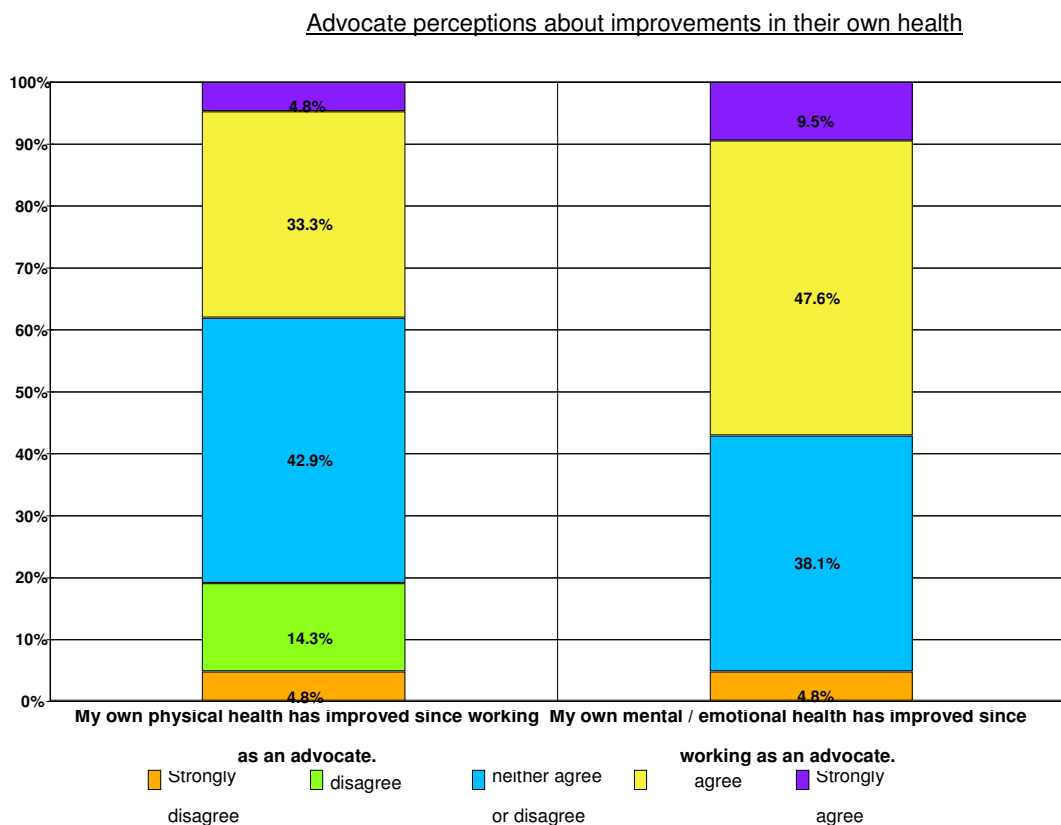


FIGURE 12: Advocate questionnaire: Perceptions on their own physical and mental health since working as an advocate

- 38.1% of advocates agreed or strongly agreed that their physical health had improved since working as an advocate
- 19.1% of advocates disagreed or strongly disagreed that their physical health had improved since working as an advocate.
- 42.9% of advocates neither agreed or disagreed with the statement.

The qualitative data from the questionnaire provides little insight into the reasons advocates responded as they did.

- 57.1% of advocates agreed or strongly agreed that their mental / emotional health had improved since working as an advocate
- 4.8% of advocates strongly disagreed that their mental / emotional health had improved since working as an advocate
- 38.1% of advocates neither agreed or disagreed with the statement.

Here the qualitative data does provide some additional insight into the responses given. Most advocates who made comment spoke about how being involved in the BHAS had had a positive impact on them as individuals.

“Working as a BA [bilingual advocate] has made me a more humble person, in understanding people’s problems and struggles. It also helps me to see how clients feel happy when they have someone to support them, by talking the same language and understanding their background” (Advocate questionnaire)

“Advocacy services has been the most rewarding service I have ever been able to provide to my clients. The true difference I feel [is that] people achieved in their lives through advocacy support. This has been greatly welcomed by clients. Personally I feel grateful to have been one of the participants of this pilot. It has opened new doors for me to help people from migrant communities have an easier life in the UK.” (Advocate questionnaire)

However, one advocate did not have such a positive experience.

“Working with my clients made really a negative impact on my mental well-being. I felt exhausted by their high expectations and didn’t feel supported enough in the whole process.... I didn’t enjoy it at all although I have some sense of achievement.” (Advocate questionnaire)

4.4 Evidence of increased empowerment

There is evidence that service users perceive that their level of empowerment has improved as a result of advocacy intervention. Plotting the average scores across all 40 test-retest surveys gives a visual empowerment web of the changes clients report have resulted from receiving advocacy support.

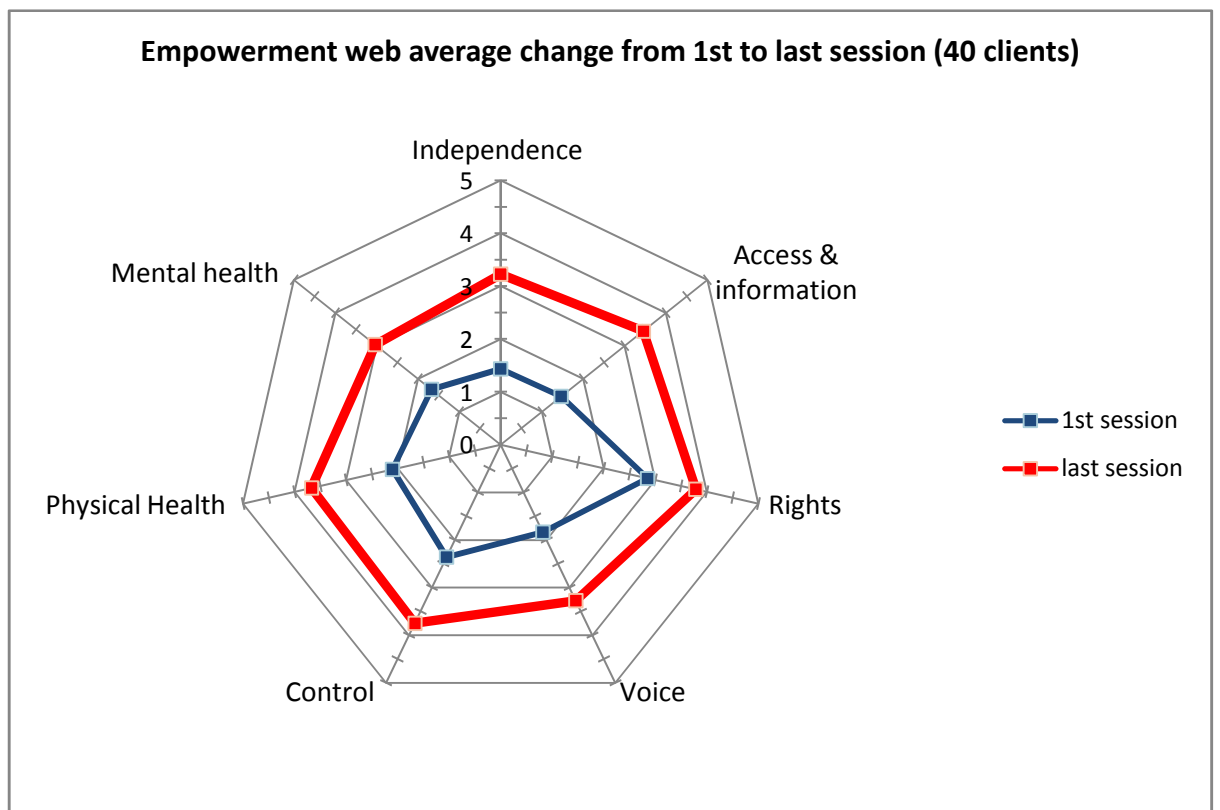


FIGURE 13: User survey: Average empowerment journey from first advocacy session to last advocacy session

4.4.1 Independence and communication

Indicators

E1	Evidence of improved English languages skills
E2	Evidence of service user's ability to manage service interactions independently

Improved English Language skills

There is evidence in 10 case studies (14.2%) of service users attending English language classes after being signposted to available courses by the advocate.

Independent management of interactions

According to the advocacy questionnaire results:

- 52.4% of respondents agreed or strongly agreed that service users no longer need support to access health services as a result of advocacy (except interpreting)
- 14.3% of respondents disagreed that service users no longer need support to access health services as a result of advocacy (except interpreting)
- 33.3% neither agreed or disagreed with the statement

Advocates commented that their response to this question very much depended on the client(s) they had worked with. Some of the advocates stated that they gave the response “neither agree or disagree” due to the variety of experiences with different service users.

Service users were asked to plot themselves against the question

“How able are you to deal with this issue on your own? If this came up again, would you be able to deal with it on your own?”

Choice of response ranged from *“The advocate will need to sort this out for me (1)”* to *“I can do this on my own (5)”*

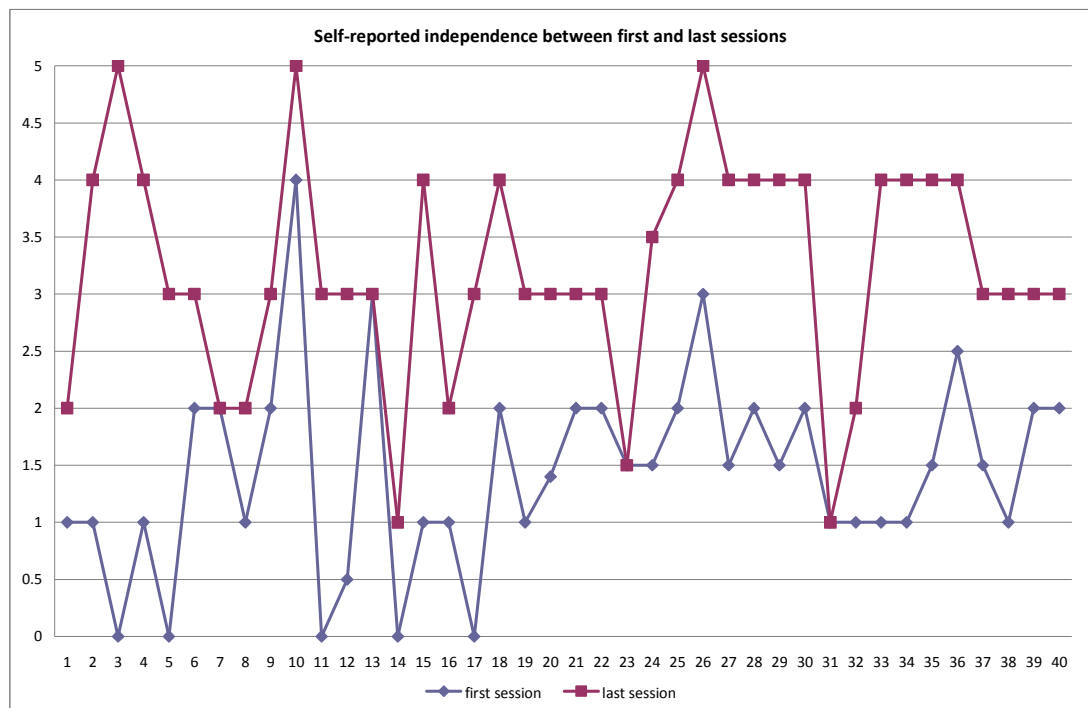


FIGURE 14: Service user survey – Self-reported levels of independence at first and last advocacy session

The findings show that prior to advocacy intervention:

- 90% of respondents reported that they would need the advocate to do it for them or would need lots of support from the advocate.

Following advocacy intervention:

- 20% of respondents reported that they would need the advocate to do it for them or would need lots of support from the advocate.

- 40% of respondents reported that they could sort out most things with a little support or that they could do it on their own.

Reference to service user ability to interact with services independently is found in 9 case studies (12.9%).

One practical example of a service user gaining greater independence describes:

“Due to language difficulties the client didn’t understand how the healthcare system works. She did not know how to use the touch screen booking system at the GP surgery; she didn’t know how to book an appointment. She had a lot of health problems but she hardly went to see doctors because she could not find someone to help her to make an appointment.” (Case study)

To assist this lady, the advocate explained to the client how the system works and how and when to make an appointment to see a doctor. The advocate set up a system between the client and the surgery so that she can make appointments independently in future and taught her how to use the touch screen booking system at the surgery.

4.4.2 Voice and Control

Indicator

E3	Evidence of service user involvement in decision making about their care and treatment
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Service users were asked

“Do you feel able to explain your health issues and ask for information about your condition, medication and treatment options?”

Choice of responses ranged from *“I can’t explain or ask questions. I’m not involved (1)”* to *“I’m confident about speaking up form myself. I feel involved (5)”*

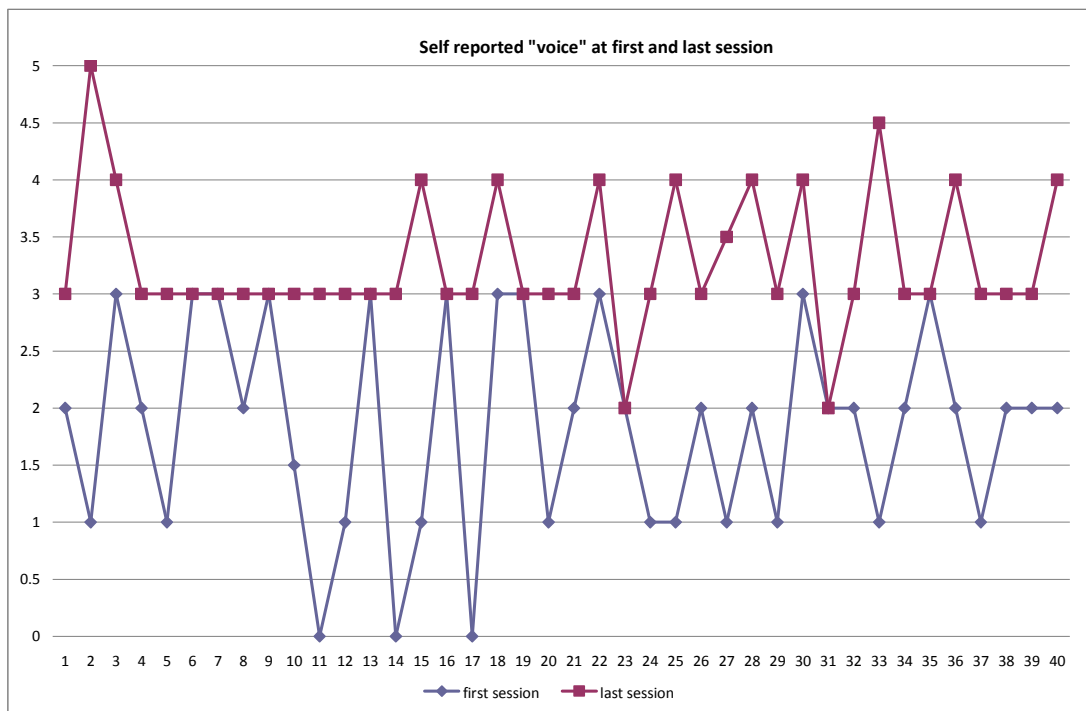


FIGURE 15: Service user survey – Self-reported ability to explain concerns to health professionals

Prior to advocacy intervention:

- 70% of respondents reported that they could not explain, or ask questions and were not involved, or that they found it difficult to speak for themselves and didn't feel confident

Following advocacy intervention:

- 5% of respondents reported that they could not explain, or ask questions and were not involved, or that they found it difficult to speak for themselves and didn't feel confident
- 27.5% of respondents reported that they could explain and ask questions themselves but support made it easier, or that they were confident about speaking up for themselves and felt involved.
- The majority (67.5%) reported that they felt confident if the advocate helps me explain and ask questions

Service users were also asked about how in control of their healthcare they felt.

“Are your views listened to and respected when planning and making decisions about your health?”

Response choices ranged from *“People don't care what I want, my views are ignored (1)”* to *“My care is planned around what I want (5)”*

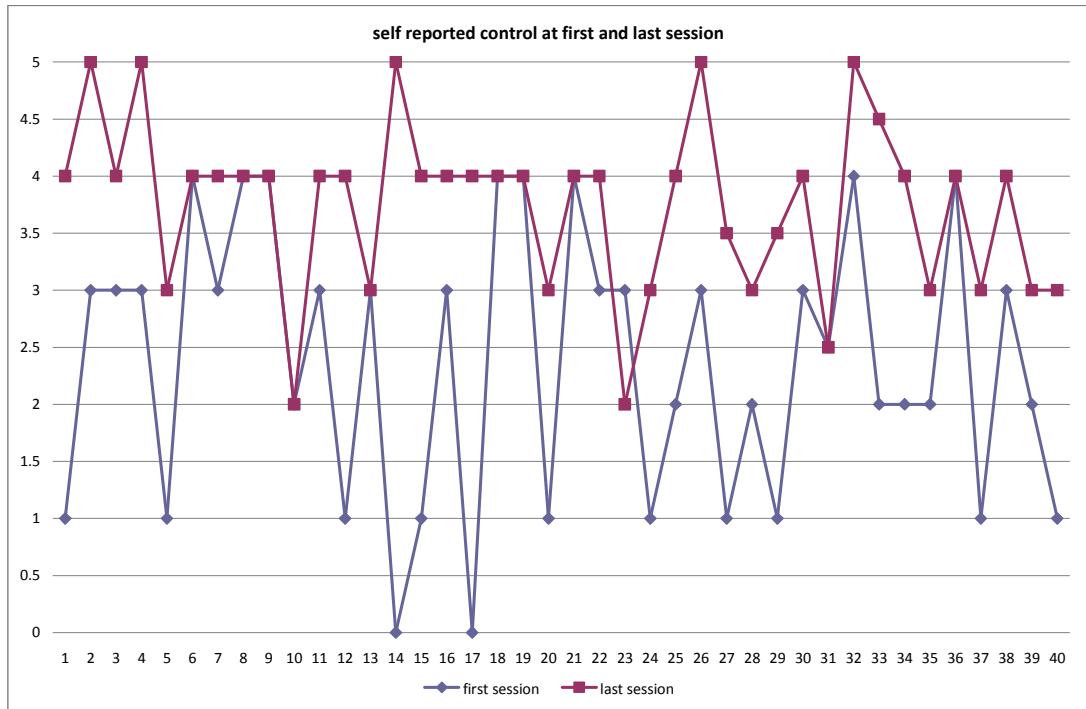


FIGURE 16: Survey user survey – Self reported levels of control at first and last session

Prior to advocacy intervention:

- 47.5% of respondents reported that people didn't care what they thought and their views were ignored, or that it didn't make much difference what they said or thought

Following advocacy intervention:

- 7.5% of respondents reported that people didn't care what they thought and their views were ignored, or that it didn't make much difference what they said or thought
- 65% of respondents reported that people took notice of what they want their care to be like, or that their care was planned around what they wanted

This self-reported improvement in voice and control is echoed in the findings of the advocate questionnaire.

- 85.7% of advocates agreed or strongly agreed with the statement *“My clients are better able to interact with healthcare professionals as a result of advocacy”*
- 14.3% neither agreed or disagreed with the statement
- 90.5% of advocates agreed or strongly agreed with the statement *“My clients are more involved in decisions about their own care and treatment as a result of advocacy”*
- 9.5% neither agreed or disagreed with the statement

This shift from dependency to greater independence is reflected in the qualitative data.

“My clients feel more confident to attend an appointment as well as choose what treatment is most appropriate for them. They are more independent and take initiative by themselves. As a result of the advocacy work their quality of life has improved.” (Advocacy questionnaire)

12 case studies record client feedback relating to a sense of increased voice and control.

“Advocacy has really helped me. I have avoided major surgery and with good medication I am now well again and can work to support my family. I know that if I or my family are unwell I can ask my GP for proper treatment and have options available to help me.” (Case study)

Three of these cases relate to support in making a complaint. One service user who was supported to make a complaint is recorded to have explained:

“A friend who had visited the hospital had been treated much better and offered support with no questions or degrading remarks. I hope that my complaint may have contributed to the change of attitude. I am happy to wait for a response [to my complaint] as long as people with no English like me don’t get treated the way I was.” (Case study)

4.4.3 Social exclusion and social isolation

Indicators

E4	Evidence of service users forming social connections and experiencing reduced isolation.
E5	Evidence of service users engaging other support services e.g. benefits advice, housing advice, carer assessment
E6	Evidence that migrants perceive that they are treated better, in terms of equality and fairness, following advocacy intervention.

Evidence of reduced social isolation

Among the case studies there are examples where advocates have assisted service users to meet others from within their communities.

One young mother who had struggled to adapt to living in the UK said:

“Advocacy has meant that I can go out of my home and I am getting to know other Chinese locals. I feel more happy and confident and am starting to learn English”

Another elderly service user expressed:

“I am so happy to have received the support of the bilingual advocate. I was very isolated and my health needs were not being met. My situation has improved a lot.”

(Case study)

This sentiment is echoed in a comment from one of the advocates:

“Advocacy has been a vital tool in helping migrants feel ‘equal’. It enables them to feel part of the community and helps them achieve better outcomes for their health and wellbeing and eventually reflects in the overall picture of satisfied communities” (Advocate questionnaire)

Evidence of engagement with support services

Vandu (2012) claim that one of the positive impacts of the BHAS has been assisting clients to access support services outside the NHS:

“Increased level or new support was negotiated and acquired including respite care, telephone support, IT training at home, one to one key workers, language support, etc. The support packages or increased level or support has been accessed from a variety of public service departments or voluntary organisations and charities. On several occasions the added support has been vital and personalised to their needs thus improving the quality of life for the service user.” (Page 2)

13 case studies (18.6%) include details of support services that clients have been assisted to access outside the NHS. These include:

- Homestart
- Housing advice
- Job Centre Plus – benefits advice
- Children’s centres
- Adult social care
- Carer services

Evidence of changes in perceptions of social exclusion

73% of advocates stated that they agreed or strongly agreed with the statement:

“Most clients are treated differently because they are migrants”.

The research finds that there is a shift in perceptions among service users about how they are treated in relation to others.

The service user survey asked:

“Do you feel you are being treated fairly and equally regardless of your ethnicity, race, migration status or language need?”

Choice of responses ranged from *“I’m being treated much worse than other people (1)”* to *“I’m treated as well as everyone else (5)”*

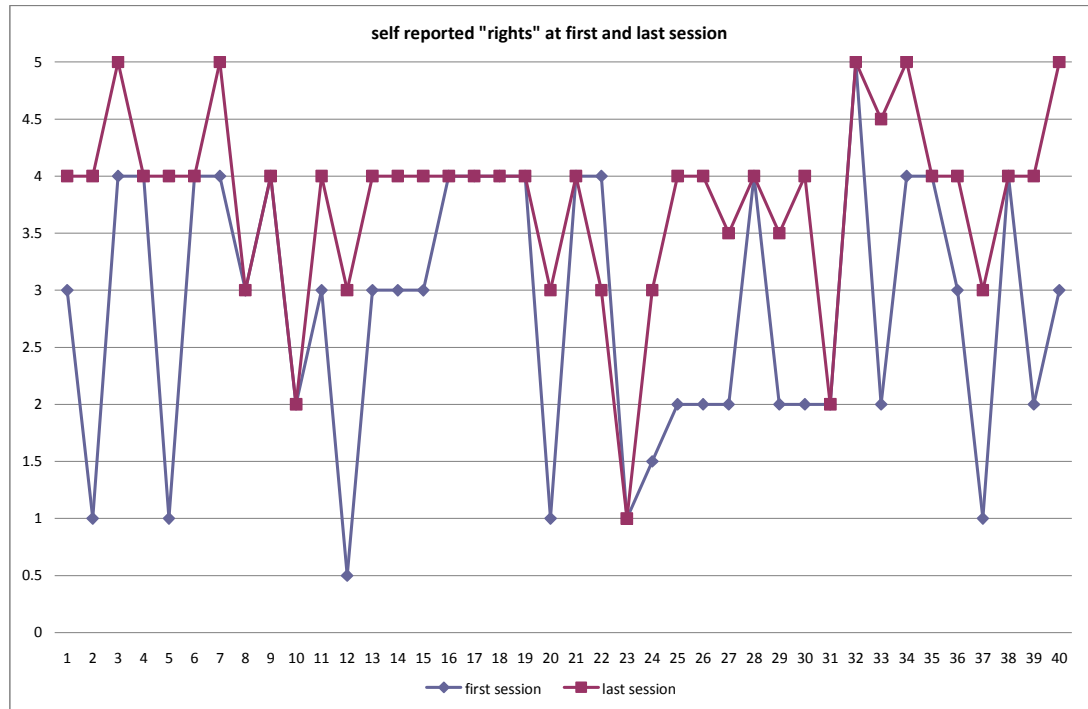


FIGURE 17: Service user survey – Self-reported levels of equal treatment at first and last session

Prior to receiving advocacy support:

- 37.5% of service users completing the survey felt that they were “treated much worse than other people” or that “other people were treated better”.
- 35% of respondents felt that they were being “treated OK” and 2.5% (1 service user) felt they were treated as well as everyone else.

Following advocacy intervention:

- 7.5% of respondents felt that they were “treated much worse than other people” or that “other people were treated better”.
- 60% of respondents felt that they were being “treated OK” and 12.5% felt that they were treated as well as everyone else.

Information provided in the Vandu report (2012) indicates that there is still some way to go however.

“The reality is that frontline services [are] still lagging behind. More often than not, advocates have to deal with cases of inequality and unfair treatment, particularly in health services.” (Page 5)

However, there is evidence that the advocacy service is helping to address these issues. One advocate describes:

“On one occasion, the service user mentioned a particular GP who was always rude and unfriendly. In the presence of the advocate, that GP appeared to be very helpful. The service user said he was surprised to see the difference.” (Case study)

Comments made in the advocate questionnaire describe:

“Through the practice [of working] as a bilingual advocate I realised that I did not just help the family or individuals with their health problem. I have sent a message to the migrant family that they are not forgotten by the government and they can be treated the same as English people. They have more confidence and take control in every aspect of their life.” (Advocate questionnaire)

“Most clients know their rights in accessing the NHS but stopped or [are] reluctant to use the service due to being treated differently or language difficulties... Most clients have disbelief in the service, think ‘it’s too good to be true’. My client is certainly one of them. She is now believing the project is interested in improving migrants’ health. She is very touched and appreciated the advocacy service.”

(Advocacy questionnaire)

CHAPTER V - Conclusions and recommendations

The review of local, regional, national and international research found extensive evidence that migrants living in the UK may suffer inequalities in access to health services and health outcomes. While many migrants living in East Sussex experience little difficulty in getting their health needs met, a significant number face barriers to living healthy lives. Statutory organisations have a legal duty to implement effective strategies to address these inequalities.

Recommendation: Any outcomes from this evaluation should be embedded into the East Sussex Clinical Commissioning Groups' equality and diversity strategies to ensure that they are considered as part of a wider approach to addressing inequality.

5.1 Improved access to health services

Convincing evidence has been identified against all indicators of improved access to health. Increased registration with primary care services does appear to have led to some service users accessing services more appropriately (through managed care pathways rather than emergency access points).

There is also evidence that, with the support of an advocate, migrants are more confident to seek medical attention from their GP for conditions which they may have been living with for some time. This has facilitated earlier detection of illnesses and better management of a variety of conditions. This learning could contribute to the overall demand management strategy of local health commissioners.

Language difficulties are a major barrier to access to services and while all primary care practitioners have access to interpreters funded through a central budget held by the PCT, there is evidence that many are not utilising this provision for their patients. Reluctance on the part of primary care services to engage interpreters may lead advocates to be drawn into situations that could be managed more cost effectively by a community interpreter. The role of the bilingual advocate offers a more flexible and intensive level of support than that provided by interpreters but should not be seen as a direct alternative. This research has identified that advocates have had to facilitate a greater awareness about the need for and use of interpreters among primary care services. While this is a positive impact of the BHAS, it is regrettable that services are not pro-actively accessing interpreters for their non-English speaking patients.

Recommendation: Use of community interpreters needs to be promoted at GP and dental surgeries, ensuring all front-line staff have access to booking details of provider organisations.

5.2 Improved migrant health

It is more difficult to identify evidence of improved health that can be attributed to the Bilingual Health Advocacy Service. That having been said, there was evidence of the BHAS contributing positively against all indicators identified through the literature review.

Most service users reported that their physical and mental health needs were better met following advocacy intervention. While some of this impact could arguably be achieved if primary care practitioners routinely secured interpreters for those patients that required them, there is evidence that having the support of an advocate gave to service user the confidence to seek medical assistance.

The evidence shows that advocates play an important role in supporting women through maternity care, particularly when there are specific problems during the pregnancy. With the proportion of births to migrant mothers increasing, this could be a key service where advocacy could be utilised to best effect.

Recommendation: Promote the BHAS to maternity service providers.

The BHAS has had some success in supporting migrants to engage with health promotion activities. The advocate role could be extended to support health

promotion activities targeted at migrant communities by holding group sessions with advocates working alongside health professionals. This could deliver a long-term health benefit for migrant communities beyond the needs of individual service users.

Recommendation: Explore with service providers where there are gaps in take-up of health promotion activity by migrants to identify potential pilot.

5.3 Increased empowerment of service users

There is compelling evidence of increased levels of empowerment among service users. Several service users accessed English language courses as a result of advocacy intervention which should have benefits for health services in terms of reduced need for interpreters and more effective use of services.

There are a number of examples where service users were supported to access support from services outside the NHS. This indicates that there is a need for bilingual advocacy which falls outside the scope of this pilot.

Recommendation: Other service providers (including NHS provider trusts) should review the findings of this evaluation to inform strategies and resource allocation for meeting equality duties.

Recommendation: Any future commissioning arrangements should allow for other service providers to access the service.

5.4 General conclusions

Client feedback collected through the qualitative research sources is 100% positive with many service users indicating that they would not have achieved the outcomes they have without the support of an advocate.

The insight gathered for this evaluation largely reflects the point of view of service users and bilingual advocates. This does deliver a limited perspective which could be considered to be positively biased. An interesting future investigation would be to gather the perspectives of health professionals who have had experience of working with BHAS service users to examine whether their views support the findings of this evaluation.

Recommendation: Undertake a brief evaluation of the BHAS from the perspective of health professionals about the BHAS

Evidence from the literature review and client feedback suggests that the language and, in many cases cultural background shared between advocates and service users is an essential characteristic of advocacy targeted at migrant communities. This also has the benefit of reducing costs for interpreters who would otherwise be needed to facilitate support between the client and advocate.

Recommendation: If investment in the BHAS is continued, resource should be identified to establish a rolling programme of recruitment and training to ensure the languages offered reflect the migrant profile of East Sussex.

While this evaluation has not attempted to evaluate the financial impacts of the BHAS on NHS services, some financial impacts may be implied in the findings.

Recommendation: Conduct a cost benefit analysis of the BHAS to inform the case for continued or increased investment in the service.

The evidence gathered is sufficient to confirm that the East Sussex Bilingual Health Advocacy Service is meeting the service objectives as stated in the service specification:

- Improve access to health services for migrant communities
- Improve the health outcomes of migrant communities
- Encourage more appropriate use of health services and compliance with treatment
- Increase knowledge and understanding of barriers to good health for migrant communities
- Increase trust between health services and migrant communities
- Improve engagement with migrant communities with the aim of better meeting their needs” (NHS Hastings and Rother, 2010, page 2)
-
- **Recommendation:** Investment in the East Sussex Bilingual Advocacy Health Service should be continued and consideration given to increasing the level of investment as part of the approach to demand management.

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Appendix 1 – Service specification

Service	East Sussex Migrant Communities Health Advocacy Pilot
Commissioner Lead	Sara Geater
Provider Lead	TBA
Period	11 month pilot

1. Purpose

1.1 Introduction

1.1.1 This additional service within the existing Sussex Translation and Interpreting Services (SUSTI) will be available only to NHS organisations in East Sussex initially and on a pilot basis.

1.1.2 This does not imply that the organisations named above will access the contract, or use it exclusively.

1.1.3 The contract period will cover a pilot period of 12 months between 01 October 2010 and 31 August 2011.

1.2 Service Aims

1.2.1 The East Sussex Migrant Health Advocacy Project pilot aims to improve the health and well-being of migrant communities within East Sussex by improving access to health and well-being services. In order to achieve these objectives the service works to:

- Inform and interpret, offer guidance and support for service users to enable them to use relevant health services in a beneficial and appropriate way;
- Elicit the views, needs, expectations and concerns of the client and actively pursue, represent and act in the client's interest;
- Work with individuals, families, groups and communities to
 - Support the empowerment of individuals and migrant communities and enable these community access to health services 'by supporting patient choice and voice within BME communities' (DoH 2008); and
 - Address information and language barriers of migrant individuals by improving access to health services and information;
- Report on the use of the service, identifying gaps in service provision, barriers to access and information needs
- Share learning from the project with partner organisations (voluntary and statutory)

1.3 Service Objectives

- Improve access to health services for migrant communities
- Improve the health outcomes of migrant communities
- Encourage more appropriate use of health services and compliance with treatment
- Increase knowledge and understanding of barriers to good health for migrant communities
- Increase trust between health services and migrant communities
- Improve engagement with migrant communities with the aim of better meeting their needs

1.4 General Overview

1.4.1 This framework agreement will follow the model of 'bi-lingual advocacy' which is considered to offer the most appropriate level of support to clients and local authorities.

1.4.2 Advocacy sessions work will be purchased from one of the Service Providers as and when needed. The total value of the combined requirements of the NHS organisations under this contract is estimated to be in the region of £15,000 during the pilot phase however this cannot be guaranteed and will entirely depend on the needs of the Commissioning organisations during the contract period.

1.4.3 East Sussex County Council will act as Lead Authority for this contract as part of the contract for the Provision of Translation and Interpreting Services and all issues of a contractual nature should be referred to Council's nominated contract officer.

1.4.4 A quarterly retrospective rebate is payable by the Service Providers to the Lead Authority under this contract, to fund tendering and contract management work - see Clause 13 of the Conditions of Contract.

2. Scope

2.1 Service Description

2.1.1 The service provides bi-lingual advocacy for all adults and families from migrant communities living in East Sussex. The target group are individuals who have been resident in UK for 5 years or less and whose first language is not English.

2.1.2 Bi-lingual health advocacy covers 'health' related issues and does not cover such things as: housing, benefits, immigration, passport applications and completion of forms. Where needs other than health is presented the advocate will refer the user to other appropriate services/organisations.

2.1.3 The day-to-day operation of the pilot will require the provider to:

- Coordinate case-work and book advocates as appropriate
- Provide regular supervision for the advocates
- Manage the financial transactions around the project including invoicing

commissioners and arranging payment to the advocates.

- Promote the service to migrant communities in East Sussex
- Produce quarterly reports
- Report findings to partners

2.1.4 Services provided by advocacy:

- Providing face to face bi-lingual advocacy.
- Advising users as to options and choices available to them regarding health services.
- Working with clients to identify desired outcomes and supporting the client to achieve stated goals.
- Supporting users towards ensuring they are given the best advice and care available and are treated in a non-discriminatory manner by service providers and their staff.
- Supporting health professionals in surgeries, clinics and home visits.

2.1.5 Contact often involves a pre-meeting with the client to discuss the nature of the advocacy to be provided. This may take a few minutes before the appointment begins if possible or necessitate a full session to set achievable goals.

2.1.6 At first contact the advocate must:

- Explain to the client the role the advocate
- Discuss with the client any questions that they want to ask about their treatment and diagnosis.
- Explain that they are there to empower them and asks questions directed by them.
- Provide information on treatment or associated relevant issues requested by the client or assist in the provision of directions about how to seek out more information, for example, using the Internet, libraries, advice bureaux etc.
- Conduct the pre-intervention questionnaire with the client.

2.1.7 When attending a clinical appointment the advocate is primarily there to support and enable the client to receive the best healthcare possible. The advocate is also there to enable the clinician to communicate effectively with the patient to assist in the most appropriate health care. The advocate must not get personally involved but must act professionally at all times, setting personal judgements aside.

2.2 Whole System Relationships

2.2.1 The migrant health advocacy pilot is part of the 'Empowering and Integrating Migrant Communities' project, funded through Migration Impact Fund monies, for which East Sussex County Council is the accountable body.

2.2.2 The implementation and outputs of the project will be monitored by the Migration Action Group, a sub-group of the East Sussex Strategic Partnership (ESSP), which comprises partners from Health, County Council, District Councils, Police, Fire and Rescue

Service, voluntary sector, and churches.

3. Service Delivery

3.1 Service model

3.1.1 The service will work alongside existing interpretation and translation services to provide a comprehensive system of bi-lingual support for the migrant communities in East Sussex.

3.1.2 There will be a central point of access for referrals into the migrant communities health advocacy service pilot.

3.1.3 On receipt of a referral an advocate is arranged and the booking confirmed within three working days.

3.1.4 The service aims to arrange an advocate in time for a requested appointment to support the patient and services key targets.

3.1.5 Both the patient's and services' needs and requirements are considered with the aim being to meet as many of these as possible.

3.1.6 The service is delivered individually on a 1:1 basis.

3.1.7 Continuity is offered wherever possible i.e. same advocate for a series of appointments.

3.1.8 Service Providers will always endeavour to provide an advocate of the same gender as the client, unless the opposite is requested by the client. In the absence of an appropriate gender match, Service Providers will seek the client's permission to have an advocate of the opposite gender, if the session is likely to deal with sensitive issues.

3.1.9 A maximum of six sessions, including initial contact meeting, will be offered to each client. Further sessions can be delivered only following agreement with the commissioner. This has been shown to be the optimum number of sessions to encourage both the client and advocate to focus on achievable goals whilst discouraging dependent behaviour in the client.

3.2 Promotion of the Service

3.2.1 All marketing material (electronic and hard copy) must be approved by the Commissioner before distribution.

3.2.2 Providers are required to actively promote the service to local migrant communities

through marketing and outreach. This activity will be included in the quarterly report to the commissioner.

3.3 Advocates

3.3.1 Advocates are expected to arrive in good time for the start of any planned activity. In the situation where an interpreter is unable to meet agreed appointment time, it is their responsibility to alert the Purchaser and client to explain the reason for this and indicate a time of arrival.

3.3.2 Advocates should assist communication and understanding between the public Purchaser and the individual, and where necessary raise areas of concern or confusion with either party immediately to avoid any subsequent misunderstanding.

3.3.3 Advocates should treat the client with courtesy and respect fully acknowledging that they are there to assist the individual access a service and/or establish the best way forward as dictated by the nature of the interview/appointment.

3.3.4 If a client does not turn up to a pre-arranged advocacy session, the advocate should ensure that the attendance form is completed and signed with a note made about the non-attendance.

3.3.5 Advocates are expected to be aware of their own welfare, health and safety whilst conducting their duties and conform to any specialist health and safety arrangements of any Consortium member's facility they enter into.

3.3.6 The Commissioners expect the Service Providers to have an appropriate level of awareness in respect of child protection matters and dealing with vulnerable adults. Support with relevant information will be provided if required.

3.3.7 Service Providers must ensure that advocates provided for work involving children and vulnerable adults are suitably trained and experienced to deal with the demanding nature of the work.

3.3.8 In respect of concerns involving matters to do with children and vulnerable adults, the advocate or Service Provider must raise concerns at the earliest possible opportunity with an appropriate case worker, where they have knowledge of or acquire knowledge of possible abuse, mistreatment etc. This would not be considered a breach of confidentiality.

3.3.9 Where there are particular sensitivities with individuals and the service area they wish, or need to access, such as child protection, sexual health clinics, special needs and

sensitivities of mental health matters, the advocate (if acceptable to the individual) will make every effort, in liaison with the Service Provider, to continue to support the individual throughout the course of their service access needs to provide consistency and familiarity for the individual concerned.

3.4 Employee Qualifications and Training

3.4.1 Service Providers must ensure that advocates have a good level of understanding of the functions of the public sector and the services it delivers.

3.4.2 Service Providers must ensure that all advocates have completed and passed the Open College Network Bi-Lingual Advocacy Level 3 training qualification (or agreed equivalent).

3.4.3 Service Providers must ensure that all advocates appropriately maintain their qualification, through refresher courses etc.

3.4.4 Much of the work under this contract will relate to children and vulnerable adults and the Service Providers must therefore ensure that all advocates and office staff dealing with Consortium work have been approved by the Criminal Records Bureau (CRB) at enhanced level and be able to provide evidence of this to the Authorised Officer upon request.

3.4.5 Service Providers must provide details of CRB registration numbers on request.

4. Referral, Access and Acceptance Criteria

4.1 Geographic coverage/boundaries

East Sussex

4.2 Location(s) of Service Delivery

NHS settings, Service provider's location

4.3 Days/Hours of operation

8.30am to 5.00pm 5 days per week although some weekend and evening work is delivered by arrangement

4.4 Referral criteria & sources

- Migrant community members
- First language other than English
- Needs greater input than standard interpretation
- Client over the age of 16
- Resident in East Sussex
- Legally entitled to receive NHS care
- Advocacy need relates to health and health services

The service will take referrals from any source during the pilot phase including directly from the client

4.5 Referral route

Telephone

Email

Letter

4.6 Exclusion criteria

See 4.4

4.7 Response time & detail and prioritisation

4.7.1 Service Providers will work with the commissioners to ensure that the services provided are delivered effectively, within agreed time limits and to the highest professional standards.

4.7.2 The service provider must respond to a request within 5 working days

4.7.3 Service Providers must ensure that confidentiality is maintained at all times and for all parts of the service provided – see Conditions of Contract for the Supply of Translation and Interpreting Services, Clause 16 – Confidentiality and Data Protection.

4.7.4 When making arrangements for a client to attend an appointment to discuss their health and/or a sensitive family matter, Service Providers must ensure patient/client details remain confidential. Faxed information or messages left etc. must not contain any personal details of the individual or their medical or family history. Necessary guidance for this will be shared with the Service Provider from the appropriate Consortium member, for instance, the use of unique identifiers.

4.7.5 Service Providers shall work with the Commissioner to design an appropriate paper based/electronic booking system and appointment attendance form.

4.7.6 On arrival at an appointment, advocates must show their company/organisation identification to the purchaser and display this at all times whilst on the premises.

5. Quality

5.1 Quality Controls

5.1.1 Service Providers must have an adequate employee appraisal/monitoring system in place and be able to demonstrate this. Advocates should receive regular supervision when undertaking active casework.

5.1.2 Service Providers must have an adequate customer complaints procedure in place and be able to demonstrate this.

5.1.3 Service Provider must have an adequate employee disciplinary procedure in place and be able to demonstrate this.

5.1.4 Service Providers must ensure that employees complete an induction with their company/organisation and have familiarity with this agreement.

5.1.5 Service Providers must ensure that client empowerment surveys are undertaken at the start and end of the advocacy intervention, the format of which to be agreed with the Commissioner

5.1.6 Service Providers are required to seek feedback from clients using the service and ensure that this is shared with the Commissioners. Where appropriate, Service Providers will use the feedback to influence the development of its own service delivery and share this learning with the Commissioners.

5.1.7 Service Providers must have appropriate practices and procedures in place, covering equal opportunities, equal pay, employment law, health and safety, insurance and quality assurance.

8. Performance Standards

8.1 EXPECTED OUTPUTS

- Minimum of 20 locally based interpreters trained in bi-lingual advocacy
- Minimum of 10 community languages covered by bi-lingual advocates
- Minimum of 350 advocacy sessions per year sessions
- Monitoring report to commissioner produced quarterly
- 2 x Participation in learning and evaluation review
- Evidence of targeted promotion of the advocacy service to target groups, health professional partners
- Implementation of user empowerment survey (before and after intervention)
- Increase number of migrants registered with a GP
- Increase number of migrants registered with a dentist
- Reduced inappropriate attendance at A+E of target groups
- Reduced use of emergency dental service of target groups
- Increased involvement of clients in decisions about their healthcare (measured via empowerment)
- Increased confidence of clients to access health services appropriately (measured via empowerment)
- Career progression for existing a potential interpreters

9. Contract review

9.1 Service Providers will be required to attend individual quarterly review meetings with the Commissioners to review and discuss all elements of the business.

9.2 To support the quarterly review meetings, Service Providers will be required to submit a report on their performance under the framework agreement to the Lead Authority. This report is to be forwarded two weeks prior to the review meeting in electronic format and will contain the following information:

- Introduction: A brief statement on the operation of the Contract for the review period.
- Business Undertaken:
 - Number of advocacy sessions per month
 - Number of clients per month
 - Client breakdown - Age, Gender, Ethnicity, Nationality, Language, Length of time in UK, Religion, Disability of all clients, postcode
 - Referral method into advocacy project
 - Service area (e.g. GP, hospital, community nursing etc.)
 - Category of client need (e.g. GP registration,
 - Onward referrals
 - Unmet need (Languages, literacy, other service areas e.g. schooling, housing, Sign language)

- Budget Breakdown Quarterly spend (actual costs)
- Analysis of the findings from client empowerment surveys
- Complaints: Details of complaints received during the review period and the outcome.
- Users' Views: Details of any purchaser/client views of the Services and a report on any following action.
- Health and Safety: A report on any health and safety incidents during the review period.
- Staff Support and Training: Evidence of any core staff and contracted sessional worker supervision, support and training during the review period.

Appendix 2 – Service User Survey



EMPOWERMENT QUESTIONNAIRE

INDEPENDENCE

How able are you to deal with health issues on your own, at this moment?

The advocate will need to sort this out for me

I will need lots of support from the advocate

I'm not sure how much I can do

I can sort most things out; I just need a little support

I can do this on my own.

ACCESS and INFORMATION

Do you know what health services are available to support you?

I don't know what health services are available

It's difficult to understand what services are available and to access them

I know what is available, but it doesn't help me get what I want

I know what is available and can access them but need support to use them

I know what health services are available and can make use of them independently

RIGHTS

Do you feel you are being treated fairly and equally regardless of your ethnicity, race, migration status or language needs?

VOICE

I'm being treated much worse than other people

Other people are treated better

I'm not sure

I'm being treated ok

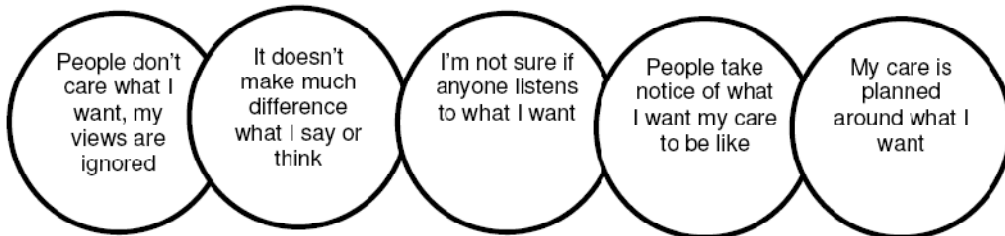
I'm treated as well as everyone else

Do you feel able to explain your health issues and ask for information about your condition, medication and treatment options?



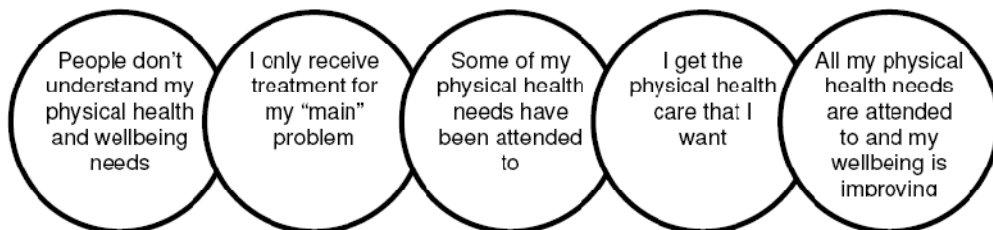
CONTROL

Are your views listened to and respected when planning and making decisions about your health care?



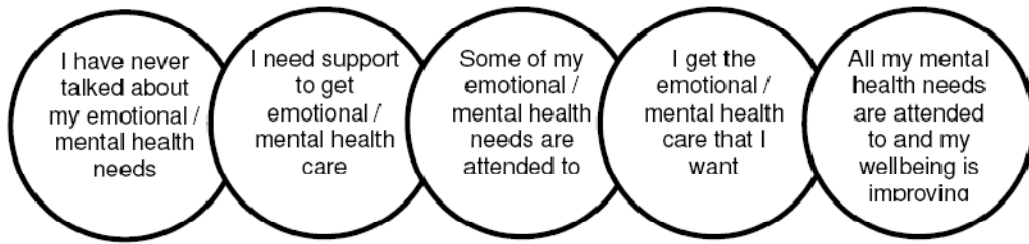
PHYSICAL HEALTH & WELLBEING

Are all your physical health needs attended to?



EMOTIONAL / MENTAL HEALTH & WELLBEING

Are all your emotional and/or mental health needs attended to?



SERVICE USER DEFINED

Are there any other areas of change that are important to you?

Are you able to rate it on a scale of 1 to 5 (where 1 is the worst and 5 is the best)

	1st session		last session	
Are you registered with a GP? <i>Delete as applicable</i>	yes	no	yes	no
Are you registered with an NHS dentist? <i>Delete as applicable</i>	yes	no	yes	no
Where are you most likely to go to access health services? <i>Delete as applicable</i>	Hospital A&E Pharmacy GP practice Walk-in centre		Hospital A&E Pharmacy GP practice Walk-in centre	

Appendix 3 – Advocate questionnaire

Evaluation of the Bi-lingual Health Advocacy Service Questionnaire for Advocates

The Bi-lingual Health Advocacy Service has been operating as a service pilot since March 2011. The aim of the service is to improve the health and wellbeing of migrant communities within East Sussex by improving access to health and wellbeing services. You are being asked to complete this survey as you have worked as a bi-lingual advocate as part of this pilot.

This questionnaire will form part of an evaluation of the pilot period of the service and will inform future commissioning of health services to support migrant communities in East Sussex. This research study is being conducted at Christchurch Canterbury University by Sara Geater and will contribute to a Masters study.

All data and personal information will be stored securely in accordance with the Data Protection Act 1998. The data can only be accessed by Sara Geater. After completion of this study, all data will be made anonymous (i.e. all personal information associated with the data will be removed.)

Thank you for giving the time to share your views.

About working as an advocate

Q1	Have you undertaken active case work for the bi-lingual health advocacy service?					
	Yes	100.0%				
	No	0.0%				
Q2	If yes, how many clients have you worked with?					
			1	2	3	4
						<i>more than</i> 5
	Number of clients		28.6%	19.0%	14.3%	9.5%
						28.6%
Q3	Which service provider do you work with?					
	Vandu Language Services (VLS)	52.4%				
	Sussex Interpreting Services (SIS)	19.0%				
	Both	28.6%				

About the role of advocacy

Q4	To what extent do you agree with the following statements?					
			<i>strongly disagree</i>	<i>disagree</i>	<i>neither agree or disagree</i>	<i>agree</i>
						<i>strongly agree</i>
	There is a need for bilingual health advocacy.	0.0%	0.0%	0.0%	19.0%	81.0%
	Advocacy is an effective way of helping the migrant population to access health services.	0.0%	0.0%	0.0%	23.8%	76.2%
	Advocacy is an effective way of reducing health inequalities for migrants.	0.0%	0.0%	0.0%	38.1%	61.9%

About the advocacy clients

Q5	To what extent do you agree with the following statements?					
		<i>strongly disagree</i>	<i>disagree</i>	<i>neither agree or disagree</i>	<i>agree</i>	<i>strongly agree</i>
	Most clients know their rights in relation to NHS services.	47.6%	38.1%	0.0%	9.5%	4.8%
	Most clients know how to access NHS services.	28.6%	42.9%	14.3%	14.3%	0.0%
	Most clients have access to NHS services but don't use them.	14.3%	23.8%	19.0%	33.3%	9.5%
	Most clients are treated differently because they are migrants.	0.0%	9.5%	19.0%	47.6%	23.8%
	Most clients are registered with a GP.	14.3%	38.1%	9.5%	33.3%	4.8%
	Most clients are registered with an NHS dentist.	33.3%	52.4%	9.5%	4.8%	0.0%
	Most clients are clear what help they need and set appropriate goals.	42.9%	19.0%	0.0%	33.3%	4.8%
Q6	Please write any comments you have about the role of advocacy here.					100.0%

About the impacts of advocacy

Q7	To what extent do you agree with the following statements?					
		<i>strongly disagree</i>	<i>disagree</i>	<i>Neither agree or disagree</i>	<i>agree</i>	<i>strongly agree</i>
	My clients physical health has improved as a result of advocacy.	0.0%	0.0%	4.8%	42.9%	52.4%
	My clients mental health has improved as a result of advocacy.	0.0%	4.8%	14.3%	33.3%	47.6%
	My clients access to health services has improved as a result of advocacy.	0.0%	0.0%	0.0%	33.3%	66.7%
	My clients are able to manage their own health better as a result of advocacy.	0.0%	0.0%	4.8%	38.1%	57.1%
	My clients are able to interact better with healthcare professionals as a result of advocacy.	0.0%	0.0%	14.3%	33.3%	52.4%
	My clients are more involved in decisions about their own care and treatment as a result of advocacy.	0.0%	0.0%	9.5%	23.8%	66.7%
	My clients are better able to choose the right service to access when they need care as a result of advocacy.	0.0%	4.8%	4.8%	52.4%	38.1%
	My clients no longer need support to access health services as a result of advocacy (except interpreting)	0.0%	14.3%	33.3%	42.9%	9.5%
	My clients would have experienced the same outcomes from their healthcare without the use of an advocate.	57.1%	33.3%	4.8%	4.8%	0.0%
Q8	Please write any comments you have about the impacts of advocacy here					100.0%

Working with healthcare professionals

Based on your experience working as an advocate please assess the following staff group's knowledge and openness to work with bi-lingual advocates.

Q9 The extent to which the person understood the role of the advocate.

	<i>Did not understand at all</i>	<i>Understood to some extent</i>	<i>Mostly understood</i>	<i>Fully understood</i>	<i>Not applicable</i>
GP	9.5%	42.9%	23.8%	4.8%	19.0%
Dentist	19.0%	52.4%	4.8%	0.0%	23.8%
Midwife	4.8%	23.8%	9.5%	0.0%	61.9%
Practice Nurse	0.0%	28.6%	19.0%	4.8%	47.6%
Community Nurse	0.0%	9.5%	14.3%	4.8%	71.4%
Health Visitor	0.0%	19.0%	14.3%	28.6%	38.1%
Reception staff	42.9%	33.3%	14.3%	0.0%	9.5%
Other	9.5%	4.8%	9.5%	0.0%	76.2%
<i>If other please specify role of the person</i>					100.0%

Q10 The extent to which the person was open to learn about their patient's culture and lifestyle.

	<i>Not at all</i>	<i>To some extent</i>	<i>Mostly</i>	<i>Fully</i>	<i>Not applicable</i>
GP	9.5%	38.1%	19.0%	14.3%	19.0%
Dentist	28.6%	42.9%	4.8%	0.0%	23.8%
Midwife	0.0%	9.5%	23.8%	4.8%	61.9%
Practice Nurse	0.0%	19.0%	28.6%	9.5%	42.9%
Community Nurse	0.0%	15.0%	20.0%	5.0%	60.0%
Health Visitor	0.0%	4.8%	28.6%	28.6%	38.1%
Reception staff	52.4%	33.3%	9.5%	0.0%	4.8%
Other	5.0%	15.0%	0.0%	0.0%	80.0%
<i>If other please specify the role of the person</i>					100.0%

Q11 The extent to which the person welcomed the involvement of the advocate.

	<i>Not at all</i>	<i>To some extent</i>	<i>Mostly</i>	<i>Fully</i>	<i>Not applicable</i>
GP	0.0%	33.3%	19.0%	28.6%	19.0%
Dentist	4.8%	47.6%	19.0%	4.8%	23.8%
Midwife	0.0%	19.0%	9.5%	9.5%	61.9%
Practice Nurse	0.0%	23.8%	23.8%	9.5%	42.9%
Community Nurse	0.0%	14.3%	19.0%	4.8%	61.9%
Health Visitor	0.0%	14.3%	14.3%	33.3%	38.1%
Reception Staff	33.3%	33.3%	23.8%	0.0%	9.5%
Other	4.8%	9.5%	0.0%	4.8%	81.0%
<i>If other please specify the role of the person</i>					100.0%

About the Bi-lingual Health Advocacy model

Q12 To what extent do you agree with the following statements?

	<i>strongly disagree</i>	<i>disagree</i>	<i>neither agree or disagree</i>	<i>agree</i>	<i>strongly agree</i>
It is important for the advocate to speak the same language as the client.	0.0%	4.8%	0.0%	38.1%	57.1%
It is important for the advocate to have the same cultural background as the client.	0.0%	0.0%	9.5%	52.4%	38.1%
Some of the advocacy casework could have been done by a community interpreter.	19.0%	38.1%	14.3%	23.8%	4.8%

Six sessions is enough to help the clients.	0.0%	33.3%	33.3%	23.8%	9.5%
The training I received allowed me to work effectively as an advocate.	0.0%	0.0%	9.5%	42.9%	47.6%
I receive enough support to deal with the challenges the advocacy role brings.	4.8%	9.5%	23.8%	38.1%	23.8%
My own physical health has improved since working as an advocate.	4.8%	14.3%	42.9%	33.3%	4.8%
My own mental / emotional health has improved since working as an advocate.	4.8%	0.0%	38.1%	47.6%	9.5%
My own access to health services has improved since working as an advocate.	0.0%	14.3%	33.3%	33.3%	19.0%
I am able to manage my own health better since working as an advocate.	0.0%	9.5%	42.9%	28.6%	19.0%
I am more involved in decisions about my own health since working as an advocate	0.0%	4.8%	14.3%	47.6%	33.3%

Q13 Please write any other comments you want to make about the bi-lingual health advocacy service here. 100.0%

About you

Q14 Are you...?	19.0% <i>Male</i>	81.0% <i>Female</i>	
Q15 What is your age?	0.0% <i>18 to 24</i>	19.0% <i>40 to 44</i>	
	0.0% <i>25 to 29</i>	23.8% <i>45 to 49</i>	
	4.8% <i>30 to 34</i>	9.5% <i>50 to 54</i>	
	33.3% <i>35 to 39</i>	9.5% <i>55 or older</i>	
Q16 Which of the following best describes your ethnic background?	23.8% <i>White - Any White background</i>	0.0% <i>Asian or Asian British - Bangladeshi</i>	
	0.0% <i>Mixed - White and Black Caribbean</i>	0.0% <i>Any Other Asian background</i>	
	4.8% <i>Mixed - White and Black African</i>	0.0% <i>Black or British Black - Caribbean</i>	
	0.0% <i>Mixed - White and Asian</i>	4.8% <i>Black or British Black - African</i>	
	0.0% <i>Any Other Mixed background</i>	4.8% <i>Any Other African background</i>	
	0.0% <i>Asian or Asian British - Indian</i>	28.6% <i>Chinese</i>	
	0.0% <i>Asian or Asian British - Pakistani</i>	33.3% <i>Other</i>	
	<i>please specify</i>		100.0%
Q17 What is your religion?	28.6% <i>Christian</i>	9.5% <i>Buddhism</i>	
	0.0% <i>Hindu</i>	4.8% <i>Islam</i>	
	0.0% <i>Jewish</i>	38.1% <i>No Religious Affiliation</i>	
	9.5% <i>Muslim</i>	0.0% <i>Sikh</i>	
	9.5% <i>Other</i>		
	<i>Please specify</i>		100.0%
Q18 Do you live with a life limiting condition?	4.8% <i>Yes</i>	95.2% <i>No</i>	

Thank you for your time.

Appendix 4 – Participant information sheet and consent form



IMPROVING MIGRANT HEALTH – A CRITICAL EVALUATION OF THE EAST SUSSEX BILINGUAL HEALTH ADVOCACY SERVICE

PARTICIPANT INFORMATION SHEET

A masters research study is being conducted at Canterbury Christ Church University (CCCU) by Sara Geater.

Background

In 2009, the East Sussex PCTs, alongside partners from the Local Authority, police and district councils, received funding from the Migration Impact Fund to deliver a number of projects aimed at developing support services for migrants in East Sussex.

The Health project focussed on providing specialist advocacy for migrants. The stated aim of this service was to:

“Improve the health and well-being of migrant communities within East Sussex by improving access to health and well-being services.” (NHS Hastings and Rother, 2010, page 1)

The pilot began in November 2010 with a training programme to develop advocacy skills among community interpreters. Clients began to receive advocacy from March 2011 and demand has increased steadily since that time.

The purpose of this study is to evaluate the impacts of the East Sussex Bilingual Health Advocacy Service. The learning from this research will inform future commissioning of services to support migrant health beyond the funded pilot period.

What will you be required to do?

Participants in this study will be required to complete a questionnaire about their views and experiences of the bi-lingual health advocacy service and/ or attend a workshop where their views will be sought.

To participate in this research you must:

- Have undertaken active advocacy work as part of the pilot or
- Worked with a patient through a bilingual advocate as part of this pilot.

Procedures

You will be asked to complete a questionnaire this may be followed up by a 1:1 interview if appropriate. Additionally, advocates will be required to take part in a focus group.

Feedback

Learning from the research will be summarised in a report which will be shared with all participants following completion of the research.

Confidentiality

All data and personal information will be stored securely within CCCU premises in accordance with the Data Protection Act 1998 and the University's own data protection requirements. Data can only be accessed by Sara Geater. After completion of the study, all data will be made anonymous (i.e. all personal information associated with the data will be removed).

Dissemination of results

Following the completion of the research the final dissertation will be shared with the pilot service providers. The summary report will be added to the relevant section of the commissioner's website (currently www.eastsussex.nhs.uk/healthhelp)

Deciding whether to participate

If you have any questions or concerns about the nature, procedures or requirements for participation do not hesitate to contact me. Should you decide to participate, you will be free to withdraw at any time without having to give a reason.

Any questions?

Please contact Sara Geater on 07788 922600 Email: sarageater@nhs.net

or write to: Faculty of Business and Management, North Holmes Road, Canterbury, CT11QU

CONSENT FORM

Title of Project: Improving Migrant Health – A critical evaluation of the East Sussex Bilingual Health Advocacy Service.

Name of Researcher: Sara Geater

Contact details:

Address:	Bexhill Hospital, Holliers Hill, Bexhill-on-Sea, East Sussex, TN40 2DZ
Tel:	07788 922600
Email:	sarageater@nhs.net

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I understand that any personal information that I provide to the researchers will be kept strictly confidential
4. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

(if different from researcher)

Researcher

Date

Signature