Can AAC technology facilitate communication for patients with limited English?

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Final Report

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Note: this is an adapted version of the official final report.

1 Background

The research programme investigated problems of communication experienced by healthcare practitioners and patients with limited or no English, and aimed to assess whether picture-based symbols on a computer screen or on paper could facilitate this communication; as a test-case, we focused on Somalis with asthma.

1.1 Language barriers to healthcare

In the UK there are many people (refugees, asylum seekers, and long-term immigrants), whose command of English is not sufficient for formal situations such as interactions with health services (Smaje 1995). Robinson (2002) has highlighted the need for a fuller understanding of the views of new refugee patient groups. Communication needs may be complex when forced migrants have multiple health, cultural and linguistic needs not fully understood by existing healthcare services, designed to cater for the needs and priorities of the indigenous English-speaking majority (Ong et al. 1995, Jones & Gill 1998). Lack of knowledge of the host country's language is reported to be the single most important barrier to healthcare according to both health professionals and those who have recently arrived (Clinton-Davies & Fassil 1992, Free et al. 1998, Hogan 1998, Jones & Gill 1998, Fassil 2000). In addition cultural issues including fear of stigma from certain medical conditions and perceptions that they will receive discrimination/misunderstanding from service providers exacerbates the language difficulties (Cortis 2000). Both providers and users have a growing concern about inappropriate utilization and under-utilisation of public services. Though there are a number of policies and initiatives for social inclusion and encouragement of appropriate use of health facilities, there are continuing difficulties with language support currently available.

Adequate provision of language services in healthcare and initiatives to develop alternative communication strategies are woefully lacking and continue to exclude many patients with limited English from appropriate healthcare (Woloshin et al. 1997, Free & McKee 1998, Brooks et al. 2000, Hardie et al. 2000, Gerrish 2001, Jacobs et al. 2001, Bischoff et al. 2003, Karliner et al. 2004).

The healthcare system recognises that effective communication is paramount to the success of primary healthcare consultations which also serve as a gateway to other healthcare services, but often fails to provide adequate language assistance (Ong et al. 1995, Hornberger et al. 1996, Nazroo 1997, Maguire & Pitceathly 2002, van Wieringen et al. 2002). Trained professional interpreters or community advocates may seem to offer the best solution but in reality these services are often unavailable, too expensive or unable to cover all languages required, particularly in emergencies (Phelan & Parkman 1995, Jones & Gill 1998, Montgomery 2000, von Kaehne 2002).

Untrained bilingual staff are often enlisted to help out at short notice, or an expensive 24-hour telephone interpreting service may be accessed, requiring hands-free equipment. Expenditure by health services on interpretation and translation is of growing media concern. Without any of the above, patients and providers just have to "muddle through" or, as often happens, abandon the consultation. Providers often resort to the use of untrained family or volunteers to act as interpreters, which can lead to lack of impartiality, breaches of confidentiality and inaccurate, misleading translations. It has also been recognised that the presence of an interpreter in the sensitive and stressful situation of seeking healthcare may inhibit interaction rather than help (Rivadeneyra et al. 2000).

None of the above solutions involve excluded patient groups in helping to plan effective services. More culturally and linguistically appropriate initiatives, accessible 24 hours a day by all providers, urgently need to be developed *with* patients. Language technology together with pictures and symbols may be one way of addressing some of these problems.

1.2 Language technology and AAC as a solution

"Language technology" refers to a range of computer-based communication devices. The field includes speech recognition and understanding, text-to-speech systems, speech synthesis and both spoken language and text translation, among other, less relevant, applications (Cole et al. 1997). This research is part of an on-going effort to use language technology to support practitioner–patient communication in healthcare (Somers & Lovel 2003, Somers et al. 2004, Somers 2006). AAC (Augmentative and Alternative Communication) is concerned with promoting communicative competence with individuals whose expressive or receptive abilities are impaired, work being usually targeted at "disabled" users who have a congenital or acquired disorder (Glennen & DeCoste 1997, Beukelman & Mirenda 1998). This research programme was triggered by the idea that the needs of patients with limited English may be in some way similar to those of people with communication impairments, and that the efforts to address the needs of the latter may be of relevance to the former who are, in a sense "disabled" by their lack of English, a further example of using technology designed for the disabled with non-disabled people (Newell 1990, Iwabuchi et al. 2000, Johnson 2004, Somers 2004).

In this research programme, we focussed in particular on the use of pictures and symbols, notably as found in AAC, where their use has been widely studied and systematised, often with the support of technology (MacDonald 1998).

2 Objectives

The first aim of the study was the identification, through focus groups and interviews, of specific communication difficulties for patients and GPs/asthma nurses when Somali patients seek care for adult asthma.

Based on these findings, the second aim was to investigate the appropriateness of symbol-based approaches to communication between healthcare providers and patients with limited English. First we established how accurately different types of existing symbols relating to healthcare are interpreted, and attitudes towards communicating with the aid of such symbols. We then set about designing culturally and linguistically appropriate symbol sets: we found for example that some standard symbols, having been designed for repeated use by people perhaps after some training, were less transparent to lay users (due to systematic use of arrows, some

colours, and relative size of symbol). We also wanted to assess what type of technology was most appropriate for communication: we considered using a paper-based version, and two computer-based systems, one on a standard PC, the other on a specially adapted laptop with a stylus-driven touch-screen interface. In fact, as a result of initial pilots, we quickly abandoned the paper-based alternative, and, additionally, augmented the two alternative computer-based systems with digitised Somali recordings of the questions and responses.

The third aim of the research was to test the proposed devices with real patients and practitioners to investigate the extent to which communication is facilitated. For ethical reasons, the asthma consultations were specially set up simulations, not part of the patients' actual treatment, although all the "patients" were genuine asthma sufferers with limited English-language skills, and the "practitioners" were GPs and asthma nurses who had experienced language-barrier difficulties in consultations.

3 Methods and Results

We first gathered communication experiences and concerns; through focus groups with the target patient group (Somalis with asthma, a community prioritised concern) and via individual interviews with healthcare providers. We then designed and piloted, in collaboration with the GPs, asthma nurses and Somali patients, a range of symbol-based communication systems for asthma consultations. Finally, we evaluated the systems in a series of simulated consultations.

3.1 Focus groups/Individual interviews

A participatory approach using mainly qualitative data collection methods was adopted, providing the opportunity for participants from the Somali community to work *with* the research team. Focus groups are considered to be the most appropriate form of eliciting attitudes and experiences, particularly from minority ethnic groups, who would otherwise not have the opportunity to discuss the most important issues for them, in their own words and language (Kitzinger 1995, Gibbs 1997, Elam et al. 2001, Huer & Saenz 2002). Gaining the perspective of potential users plays an important role in socially validating the research process by ensuring the methods and goals are relevant and acceptable to potential users (Schlosser 1999). Further details are provided in Appendix I.1–3.

3.1.1 Methods

Twenty-one adult Somalis of both sexes, age 25–70, were recruited with individual consent from within the Somali community using purposive snowball sampling through privileged access by the project's Somali researcher. Participants were Somalia-born Somali speakers with self-reported limited or no English, and experience of living with asthma/respiratory problems since arriving in the UK. Four gender-specific Somali focus groups (2 men, 2 women; each group 3–7 people) were successfully conducted using a topic guide based on the nine core information components of adult asthma knowledge (Caress et al. 2002) attached to Kleinman's (1988) three main issues identified to help a healthcare provider deliver appropriate care (see also Fadiman 1997:260f): Naming and recognising the problem; what is at stake for the patient; what is expected from treatment*?* The work was situated within theoretical frameworks for the healthcare consultation focusing on gathering data from the patient viewpoint, and also within models of health-seeking behaviour (Mackian et al. 2004). (See Appendix I.3 for further details).

Thirty-one clinicians (16 nurses; 15 GPs) were invited to participate in the study from 12 different practices or clinics known to serve the Somali community across Central Manchester PCT. From these, 14 were recruited (7 nurses and 7 GPs). For practical reasons, providers were interviewed individually.

3.1.2 Results

Analysis using the Framework methodology (Bryman & Burgess 1994, Pannbacker & Middleton 1994) provided information on five major topics highly valuable beyond the development of the prototype communication aid (see Appendix I.4).

Somalis use either the borrowed term *asma* or words describing the main symptoms to refer to the disease. The main effects on the patient include anxiety, insomnia/tiredness, weakness, discomfort, anger, reduction of life expectations and ambitions and avoidance of certain activities. Treatment tends to be sought (only) when asthma is acute and serious or medications run out, or when more information is needed on how to take the medications properly.

The main communication challenges found are in difficulty describing the problem of asthma, its symptoms and expressing anxieties; in understanding during a consultation (particularly about medications); and, because of the communication difficulties, especially at Reception, reluctance to attend clinics unless medication is needed.

The main strategies used to cope with communication difficulties include use of interpreters when available, whether trained, semi-trained (link-workers) or untrained (notably family members). Otherwise patients use gesture and mime, whatever English words are known, and take written notes home to be translated.

Transcriptions of the audio-recorded interviews with healthcare providers were similarly analysed using the Framework approach.

The interviews with healthcare providers identified three main barriers to communication, namely linguistic, as a consequence of limited knowledge and beliefs about the condition, and due to logistical factors largely beyond the control of patients or clinicians. Linguistic problems hamper both elicitation and imparting of information, which most practitioners described as "impossible" without an interpreter. Providers identified various strategies to overcome these barriers, including adapting their English to the patient's level, using repetition, speaking other languages, or just guessing what patients mean. None report a useable level of knowledge of Somali (i.e. beyond words like *yes* and *no*). Non-verbal strategies involve gesture, demonstration (eg wheezing), and interpretation of body-language. Aids used include diagrams, clinical models and translated leaflets, where available.

Family and friends, bilingual staff, or trained link workers are frequently used as interpreters. Use of interpreters (including by telephone) must be booked, is expensive, and increases the time the consultation takes. Untrained interpreters are often unreliable and/or inappropriate.

See Appendix I.5 for more details.

3.2 Assessing the suitability of symbols and devices

An important part of the research was the design and assessment of suitable symbols, and method of use (paper-based or computer-based). A preliminary series of pilot experiments tested the basic set-up, while a more thorough set of symbol assessments tested the suitability of the symbols themselves.

3.2.1 Pilot tests of the basic set-up

An initial test compared the effectiveness of three different communication devices for answering a set of questions with literate and illiterate Somalis. Our initial proposal was a comparative evaluation of two modes of symbol-based communication device – one on paper, the other on a computer – with a control group attempting communication with no support. In preparation for this, two different computer-based devices were developed: one on an ordinary laptop using the mousepad for navigation, the other on a tablet PC using a stylus. The assessment in each case involved use of the device to ask a set of questions in Somali which participants had to answer using the device. Each task was timed and scored for level of correctness; feedback was gained from Somalis; and experimenters' observations were noted.

3.2.2 Methods

Twenty native Somali-speakers, age 17–75, were recruited again using purposive snowball sampling within Manchester's Somali community. Ten (5 male, 5 female) were literate in Somali and were English speakers; the second 10 (all female) were illiterate and unable to speak English. All had self-reported normal hearing and vision and were unfamiliar with the communication methods under investigation. Participants were set the task of answering ten general questions regarding daily or common tasks using one of the devices. The questions, which yielded a closed set of responses, and the set of possible responses, were translated into Somali. The questions were varied so as to elicit different types of responses: two required a yes/no answer, others related to times of the day or periods and frequencies.

One paper-based method and two computer-based devices with digitised Somali speech were used. All used the same set of Picture Communication Symbols (PCS) symbols (Johnson n.d.), as used in AAC and literacy support. The paper-based method was presented as a communication book with a number of pictographic symbols and word labels in Somali and English printed underneath; each question occupied one page of the book. Both computer-based systems presented symbol grids using the *Clicker 4* software.[1] With the computer-based devices, the question was spoken (in digitised Somali speech) when the screen first appeared and could be replayed at any time by the participant. The possible answers could be heard in Somali by clicking on the symbols. Eventually, the desired answer is selected and the next question processed.

The 20 Somalis were tested individually. The Somali researcher conducted all tests in Somali. Each session was video-recorded for later observational analysis. Each participant answered one of the sets of ten questions with each of the three communication methods; the question sets were randomised in order and across the communication methods. In answering the questions participants were encouraged to vocalise their answers so they could be checked against the symbol they selected to determine correctness. Times for the experiments were noted and feedback was gained through interview immediately after each test

3.2.3 Results

Using the paper-based device, 80% of the illiterate participants demonstrated verbal-to-symbol disagreement on two or three of the questions (i.e. the verbalised answer was different to the symbol they selected). No such errors were made on either of the

[1] Crick Software, Northampton.

computerised devices with Somali speech output. On average, participants were quickest completing the tasks using the tablet PC. The second quickest method was the paper booklet. The longest method was the laptop. Illiterate participants on average took more than twice as long to complete the tasks using each device.

85% of all participants preferred the computerised devices, split almost equally between tablet (45%) and laptop (40%), the remaining 15% (literate only) preferring the paper-based solution. Although the paper-based method was reported as easiest to use, it was preferred only where participants were unfamiliar with computers. Illiterate participants found it hardest to use. The symbols were not equally understandable (see below). The tablet and PC each had their pros and cons: using the stylus was easier for literate participants, and the flexibility of positioning of the tablet was appreciated. All illiterate participants said they needed the speech output to support the meaning of the symbols and most of the literate participants said it gave them more confidence that they were selecting the correct answer.

The results clearly demonstrated that the acceptability of the approach was good, and that Somalis preferred the computerised devices with Somali speech output. Observations showed that more frequent explanations were needed for participants less familiar with computers, indicating that training is an important element of acceptability. The overwhelming importance of the speech output available with the computer-based methods led us to eliminate the paper-based device from further testing.

3.2.4 Symbol assessments

Symbol assessments have been conducted to determine how different individuals interpret different symbol sets in order to select the most appropriate type to meet a user's communication needs and abilities (Musselwhite & Ruscello 1984, Yovetich & Young 1988, Mirenda & Locke 1989, Bloomberg et al. 1990). Early studies demonstrated that iconic/transparent symbols are easy to learn, minimising the cognitive load required and are thus recommended for new and illiterate users (Mizuko 1987, Lloyd et al. 1997, MacDonald 1998). More recently, researchers have started assessing the impact of different cultural and linguistic backgrounds on symbol perception (Nakamura et al. 1998, Huer 2000, Haupt & Alant 2003).

Standardised symbol assessment methodologies have been used for several decades in AAC research, in pharmaceutical research, and in public safety pictogram research. The iconicity of pictographic symbols (the relationship perceived between a symbol and its meaning) has been the focus of many of these studies. A number of different methods have been devised for testing the appropriateness of pictographic symbols for certain groups, including **translucency** (How appropriate is a proposed symbol for a suggested meaning?) (Bloomberg et al. 1990), **guessability** (Can subjects guess the intended meaning of a symbol?) (Hanson & Hartzema 1995, Dowse & Ehlers 2001, 2003), and **iconicity** (How distinctive are the symbols?) (Haupt & Alant 2003). For further background and details, see Appendix II.

Method. Thirty-four Somali speakers, age 20–69, and 30 English-speaking nursing students, age 18–53, all unfamiliar with the pictographic symbols tested, were recruited purposively as healthy volunteers. Tests used a selection of 41 symbols representing non-technical words taken from two commercially available symbol sets (PCS and Widgit Rebus (WR))[2] well known in the field of AAC, which previous

[2] Mayer-Johnson LLC, Solana Beach, CA; Widgit Software, Cambidge UK.

studies (Musselwhite & Ruscello 1984, Mizuko 1987, Mizuko & Reichle 1989) have indicated to be the most translucent and transparent of symbol sets tested with different populations and therefore considered to be the easiest to learn for new or illiterate users. The same symbol/word corpus used in earlier studies by Bloomberg et al. (1990) and Huer (2000) was used. The words chosen represent nouns, verbs and adjectives, and were divided into four classes according to their expected difficulty. The order of presentation of the words was randomized within classes, and was different for every participant, but the classes were presented in ascending order of difficulty. Intra-subject reliability was assessed by repeating four of the 41 words chosen at random. Translations of word labels into Somali were done independently by three translators, who then ironed out discrepancies and agreed where alternative translations were equally acceptable as correct answers.

In a first set of sessions participants were randomly assigned to either the translucency or the guessability tests and were given two questionnaires, containing 45 PCS or WR symbols. Some months later, iconicity tests were done with five English and five Somali participants, who were randomly assigned symbols from either set.

Results. Mean intra-subject reliability for the translucency and guessability tests was 83% for Somalis and 99% for English participants. The mean intra-subject reliability across PCS and WR symbols in the guessability tests was 73.5% for Somalis and 93.8% for English participants. A reason for the low reliability calculations for the Somali participants in both translucency and guessability tests may be the large number of no responses as well as literacy difficulties encountered during the tests (further details are given in Appendix II).

Overall this study showed that symbols were by and large usable, but that Somalis would require additional training and the standard symbol tests required some modification. This was undertaken as part of the next phase of the study, reported below.

3.3 Simulated consultations

The final stage of the research was to put into practice the findings of the earlier stages in a series of simulated asthma review consultations using the symbol-based communication aid in one of two formats: on a laptop, using the mouse pad for navigation, and on a tablet PC, using a stylus. In both cases the *Clicker 4* software was used, as in the pilots. Some examples of screenshots are shown in Appendix III.1.

3.3.1 Method

The aim was for clinicians to test the software in both its formats with a number of patients. Although the consultations were simulations (as was made clear to participants), the clinicians and patients were recruited on the basis of previous experience of similar consultations.

From an initial pool of 18 clinicians, six nurses and three GPs, from three practices across Central Manchester PCT known to serve the Somali community, agreed to participate. All practitioners reported they had assessed and or treated at least one Somali patient in the last two years, most within the last month. Two thirds of the clinicians (five of the nurses, one of the GPs) had a special interest in asthma.

We recruited with individual consent 26 adult Somalis, age 26–77 to participate in the trials. Of these, 23 were female, 21 had self-reported very limited English, 21 reported

no formal education at all, six could read Somali (and only one English). On average, participants had spent 9.93 years in the UK.

The software covered 69 questions grouped under headings such as asthma history, personal situation, medication, attitudes, and asthma management (see Appendix III.2). The clinician used the device to choose and then to ask a question, which was presented in English text on the screen but spoken in digitised Somali speech once selected. The Somali participant listened to the question in Somali and could then use the system to consider the set of possible responses appearing on the screen before choosing one or more responses. They could listen to each response option in Somali to check the meaning and confirm that they had selected the correct one. The meaning of each response option was also visible to the practitioner in English text. Once a response had been given, the clinician then navigated back to the main menu to select the next question. All simulations were video-recorded. Following the sessions, feedback questionnaires were completed for all participants.

3.3.2 Results

In total, 26 simulations were conducted, one per Somali participant: all clinicians used both systems at least twice. Appendix III.2 lists all the questions, together with possible answers, and frequency with which each was asked during the simulations. A total of 646 question screens were presented to the patients. Appendix III.3 gives the feedback questionnaire responses in more detail.

All 26 simulations were completed adequately. None were abandoned due to difficulties using the system, with communication, or due to frustration on the part of Somalis or clinicians. In 20 of the 26 simulations, all questions were answered by the patients. Only 12 questions (1.9%) elicited no answer, and five of these were in a session with a single participant who, it transpired, spoke a different dialect of Somali. In some cases, as is evident from the videos, the patient responded by speaking the answer in Somali, but the clinician did not notice.

Consultations were completed within the kind of time limits normally expected with English-speaking patients (10 minutes for GPs, 20 for nurses): GPs took between 6′46 and 13′57 (mean = 10′00), nurses between 7′59 and 25′14 (mean = 15′34).

Satisfaction ratings indicate that the tablet was preferred by the Somalis (92% very or fairly satisfied with using the tablet overall: 100% very or fairly satisfied with using the stylus on the tablet compared to 43% using the laptop and mouse pad). Clinicians did not indicate any difference in satisfaction between the two platforms, though they recognised that the tablet was easier for the patients to use. With the laptop, many of the Somalis took a very passive role, allowing the clinician to operate the software, and indicating their responses by nodding, pointing or repeating the answer in Somali. On the other hand, tablet users often shared the stylus and in some cases the patient took the initiative, requiring the clinician to point to the next question.

Regarding the content of the communication system, apart from 2 “don’t knows”, all 35 participants were either very or fairly satisfied with the size of the symbols and text, and all but one (a clinician) with the range of questions and responses.

Observations showed rapport and relationship building (a very important component of the consultation for the clinicians) often facilitated by the need to share the hardware, and shared reactions to idiosyncracies of the system.

Results were similarly positive on the use of the device: ability of clinician or patient to navigate (in 5 cases not applicable, where patients had remained passive users), and

speed of use. A breakdown of the satisfaction ratings (see Appendix III.3) shows some gaps in content, e.g. questions discussing patients' anxieties, and relationship-building interactions. All Somalis agreed that the devices enabled them to get further than without an interpreter, though clinicians seemed slightly less convinced, and while overall satisfaction was high among the Somalis, clinicians were less satisfied that the overall aim of achieving expected clinical outcomes for an initial review had been met

3.4 Conclusions

Overall it is clear that the devices improve the prospects of communication, and completion of the session in the absence of an interpreter. The more familiar stylus-based device is evidently preferable, and while there are limitations, notably for the clinician to go "off script" and for the patient to ask questions, rather than answer, we feel that with some design flaws ironed out, this could be a significant positive factor in doctor–patient communication with patients with limited English.

4 Future Research Priorities

Our results and especially reaction to our work at relevant conferences has shown that improving communication along the pathway to healthcare is a major priority. This research represents an innovative collaboration between specialists in language technology and in primary care, and both can see further developments focussing on their particular interests.

On the technology side, areas where improvements in small details of the design can be made are identifiable, but generalising our approach to enable similar systems for other language groups and conditions to be constructed is more important. A broader perspective would be to explore the possible impact of other technologies of varying complexity on the pathway to healthcare. The dream of automatic speech translation involves technologies yet to be developed, but limited versions for specific purposes are realistic. Computer translation of instructions for medication use to be printed on prescriptions at the time of issue in the surgery is an obvious application.

On the primary care side, new research will build on our recent work developing health-seeking behaviour theory in Pathway/Stages and Determinants/Factors Models, and also develop specific work to investigate ways to tailor asthma care to the priority information needs of people coping with this problem within a specific cultural milieu.

Appendix I. Notes on the focus groups and practitioner interviews

1. Kleinman's framework

The framework for soliciting the patient viewpoint information in the focus groups was based on an eight-step framework developed by Kleinman (1988; see Fadiman, 1997:260f).

Naming and recognising the problem

1. What do you call the problem?

What is at stake for the patient?

2. What do you think has caused the problem
3. Why do you think it started when it did?
4. What do you think the sickness does? How does it work?
5. How severe is the sickness? Will it have a long or a short course?

What do people expect from treatment?

6. What kind of treatment do you think the patient should receive? What are the most important results you hope are received from this treatment Are there are extra ones for women?…for men?
7. What are the chief problems the sickness has caused?
8. What do you fear most from the sickness?

2. Health seeking behaviour: theoretical frameworks

Health-seeking behaviour models are used to identify both the process and the utilisation of biomedical services. Models include identification of how beliefs, attitudes and knowledge affect how people cope in illness and their health seeking behaviour (Thomas et al. 2000). Health-seeking behaviour models can demonstrate the steps along a pathway that an individual prefers to take to seek help for an illness. Key stages along the pathway can be recognised. These include the skill in **recognition** of symptoms (perhaps dependent on previous experience and also cultural beliefs about the illness); **reactions** to the symptoms (including maybe culturally induced fear, shame and socioeconomic status restricting treatment options that can be accessed; and social networks available to provide support and further information about treatment); **use of services** can be identified, and patterns of **coping. Determinants** models of health-seeking behaviour can also be used. Key factors can influence whether and how people seek help for an illness and cope with it. A recent review in relation to health-seeking behaviour in the utilization of modern health services in an Arab population for both a common health problem and a socially sensitive health problem has combined models to develop a pathway framework with identification of family, social, and health service determinants at each stage (Mackian et al. 2004).

3. Models of health-seeking behaviour (Mackian et al. 2004)

Health Belief Model

This health-seeking behaviour model is based on the individual's perception about the impact of certain illness, its severity and its consequences. This is based on the beliefs

which motivate the individuals to be concerned about their health, leading to the perceived benefits of the treatment sought.

Health utilization model (Anderson Model developed in 1973)
Pre-disposing factors, enabling factors and the need factors which can influence health behaviour. This model is based on three factors: (a) Predisposing factors, age, gender religion, prior experience with the illness; (b) Enabling factors, availability of services, financial resources; (c) Need factors, reported illness, past experience with the illness.

The theory of planned behaviour
This pathway to care focuses on factors that lead to specific intention to act. This model is based upon attitudes towards behaviour, this determined by the belief that specific behaviour will have concrete consequences on their illness outcome

The Four As model
This model identifies easily key potential factors as barriers to treatment, these include: (a) Availability of services, mainly geographical distribution of health facilities; (b) Accessibility, transport etc.; (c) Affordability, health costs, economic states of the household; (d) Acceptability, this refers to cultural acceptance of the consumer about the health providers characteristics, gender etc.

This model has been widely used by medical geographers, anthropologists and epidemiologists who mainly emphasis distance and economic aspect as factors for access to treatment

Pathway models
These models start with the recognition of the symptoms of the illness, which centre on the path people follow until they use different health (home treatment, traditional healer, and biomedical services). This highlights the importance of significant others.

Ethnographic decision-making models
These models attempt to predict the health-seeking behaviour in order to identify key factors relative to therapy choice. These include the perceived severity of the illness, availability of home remedies for the illness, faith in the effectiveness of treatment, expense of the treatment and experience with illness which could influence the choice of treatment.

4. Examples of Somalis' experience of asthma

"Cannot sleep at night" "I could not sleep at night" (FRW1) or "sleeping difficulties" was a recurrent theme raised as a chief problem of asthma (RQW1, RCW1, RNW2, RRW2), particularly occurring alongside the asthma symptoms (RKW1). Tiredness (RQW1, RKW1) is another chief problem.

"Weakness" and limitations on activities – cannot do women's work. A "feeling of weakness" (RAW1, RKW1) "general weakness" (RRW2), "physical weakness" (RQW2, RQW1) and "physical problems" (RFM1, RSW2, RCW1) were identified. A man and a woman (RAM1, RFW2) explained "asthma makes you become weak". A woman said the "weakness (in time) leads to giving up many physical activities" (RAW1). Many others identified the limits imposed on physical activities as a key issue (RQW1, RFW2, RRW2, RQW2, RAW1, RSW2, RMM1). On the one hand people described the activity limitations associated with the asthma itself, "it limits what you can do" (RAW1). "You cannot move from place to place for hours" (RRW2). "To go upstairs I (used) crawling, or sitting because the staircase is steep. When you have the asthma you do not have any ability" (RSW2).

On the other hand people spoke of **self imposed avoidance**. Avoidance included housework triggering the asthma (RAW1); staying at home to avoid asthma triggers (RAW1) and giving up many physical activities (RAW1).

"At first I felt heaviness in my chest. When ever I suffer from cold it was always a chesty one, I used to feel dizzy, when the GP asks if I got asthma, I used to say 'NO'. When I do any physical activities, it always attacks my chest" (W2 RS q 2.1)

"Frankly (the problems it gives are) when **it forbids you everything**, and gives you pain, weakens your body, and you will not be able to work, and your power diminishes" (RCW1).

"I cannot do any work, **(I) think that someone is holding my ribs very tight** and I cannot do the slightest thing. If I try to hoover my home I just see myself collapsed, so this thing (asthma) is very bad" (RQW2).

"I feel in the first place that you are **always nerves, and weak**, very weak, always angry and nerves, and cannot do women's work or other work" (RQW2).

"If you carry the shopping you reach home **feeling awful, like life finished out of you**" (RPW2).

5. Strategies used to assist communication reported by healthcare providers and Somalis

1. Verbal strategies

1.1. Verbal strategies used by clinicians

Individual strategies developed by the clinician: adapting their English, using repetition, speaking other **languages** such as Ki-swahili, **referring** to other clinicians, **guessing** what patients mean.

Using a third party to interpret: family and friends, bi-lingual staff, trained interpreters/link workers, language line

1.2. Verbal strategies used by Somalis with limited English

use what English **words** they know

learn English at adult education classes

bring an English-speaking Somali with them as **an interpreter**

2. Non verbal unaided strategies

2.1. Non-verbal unaided strategies used by clinicians

demonstration (e.g. sound of wheeze)

hand/arm **gestures** or mime

pointing to body parts or diagrams

paralinguistic: **facial expressions**, eye contact, using eyes to assess body language

2.2. Non-verbal unaided strategies used by Somalis

demonstration

hand/arm **gestures** or mime

pointing to body parts or diagrams

3. Non verbal aided strategies

3.1. Non-verbal with aids strategies used by clinicians

diagrams or pictures

draw things

use **model** airways or inhaler devices for **demonstrations**

use **colours and numbers** and very **basic written** information

use **translated information**

give out information to be **translated by patient's family**

3.2. Non-verbal with aids strategies used by Somalis

bring in inhaler to demonstrate how they use them

family **translate** information when it is taken home

Appendix II. Symbol assessments

The **translucency test** was originally designed by AAC researchers Bloomberg et al. (1990) for the literate English-speaking population to assess how closely respondents rated the relationship between a pictographic symbol and its given word label. It involves the naïve viewer rating this relationship on a 7-point scale. More recently, researchers have started assessing the impact of different cultural and linguistic backgrounds on symbol perception (Nakamura et al. 1998, Huer 2000, Haupt & Alant 2003). However, only one other AAC translucency study has assessed how participants from a range of cultures perceive the symbol–referent relationship. Huer (2000) conducted this test, based on Bloomberg et al.'s methodology, with literate participants from various communities. To our knowledge, no assessment has been made with a participant group with low levels of literacy, such as Somalis.

The **guessability test** involves the naïve viewer guessing the meaning of a number of individual symbols presented to them. Responses can be written under each symbol presented in a standardised booklet or given verbally and recorded by the researcher. Recently, pharmaceutical pictogram research has performed guessability tests in an effort to find alternative ways of conveying medication instructions to less literate populations (Hanson & Hartzema 1995, Dowes & Ehlers 2001, 2003), while the field of public and safety information has developed guessability testing procedures for pictograms, in accordance with BSI and ISO standards (Davies et al. 1998). In addition to this, some AAC research has utilised a similar type of test to assess pictographic symbol perception (Yovetich & Young 1988, Burrell et al. 2003, Hartley 2003).

The **iconicity** test was developed by Haupt and Alant (2003) to assess the iconicity and distinctiveness of symbols in the context of other symbols presented on a large, thematically-related communication grid. The word labels for each symbol are read to the participant who selects the symbol that they think best matches the word label.

Further details of results from symbol testing:

In general, in all the tests, the two sets of symbols (PCS and Rebus) showed similar results. Somalis rated the **translucency** of all symbols more highly than English-speaking participants, though we noted significant differences in the use of the 7-point scale by the two groups. Translucency corresponded largely to difficulty predicted by our classification of symbols.

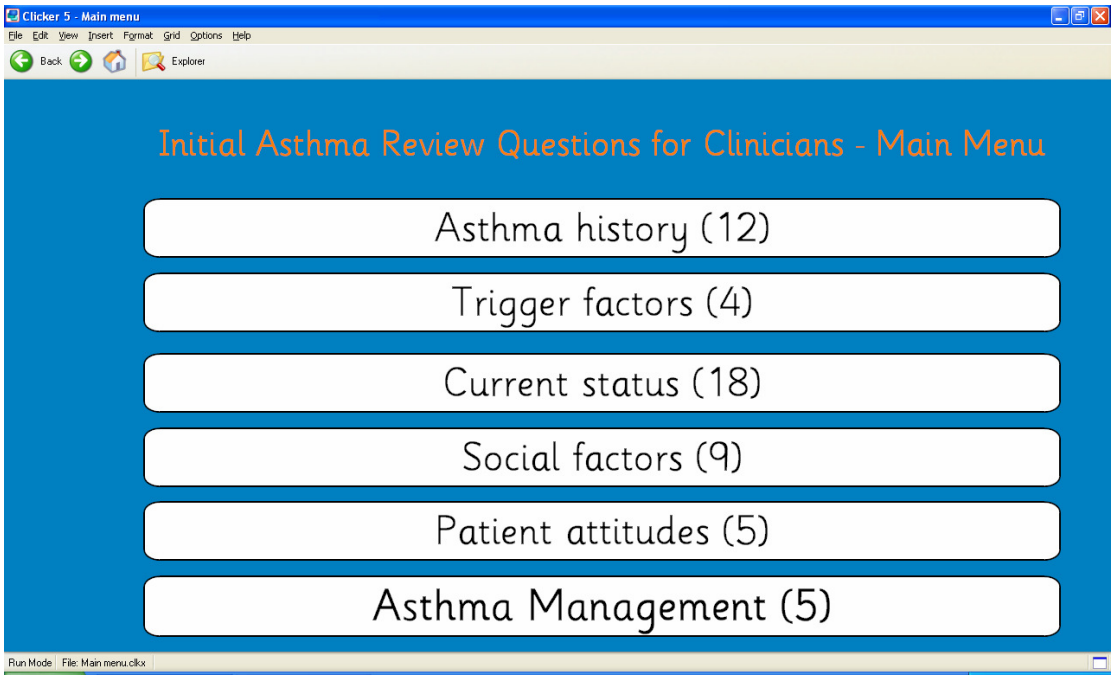
In the **guessability** tests, the English speakers outperform the Somalis. For the former, scores range from 87% for the easiest category down to 31%. For the Somalis the range is 58% down to 10%, with the overall average 66% vs. 40%. Error analysis of individual answers identified some cases of under-interpretation ('cutlery' for the symbol for 'food'), over-interpretation ('eat' for 'biscuit'), and description instead of interpretation ('thermometer' for the symbol for 'cold', showing a thermometer's low reading).

In the **iconicity** tests, English speakers again outperformed the Somalis, especially with the Rebus symbols, though differences between the word difficulty classes were less marked. While the iconicity scores are good, measures of distinctiveness show that some symbols, while correctly identified for the intended word, are also chosen for other words: again the symbol for 'biscuit' is identified as representing 'food' for example.

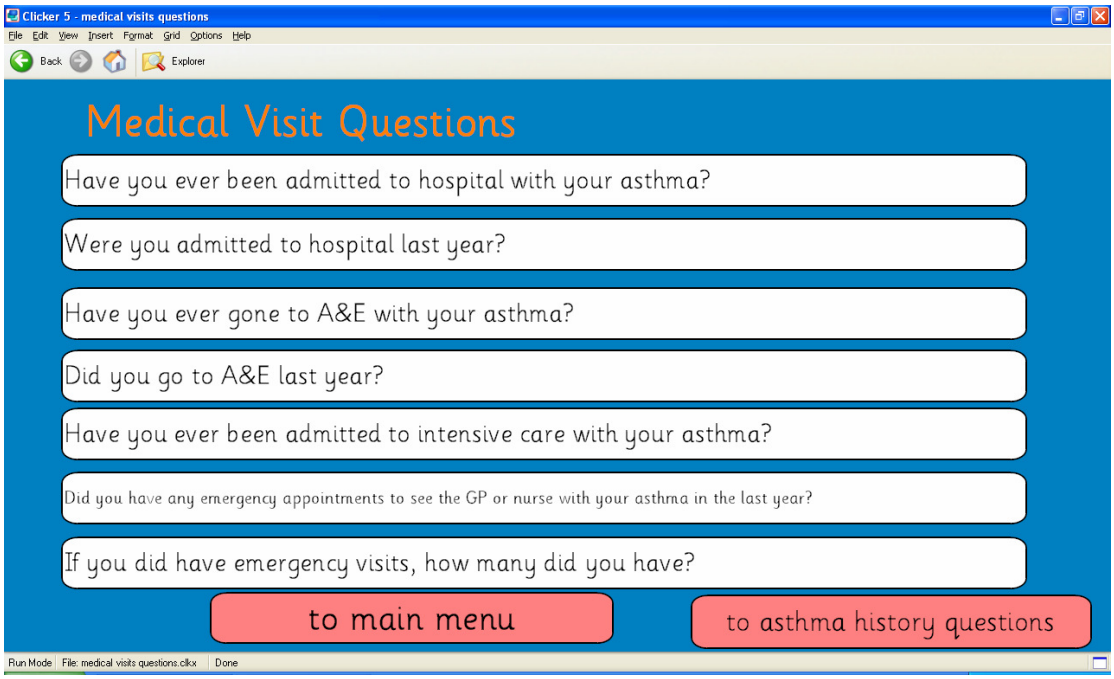
Appendix III. The simulations

1. The software

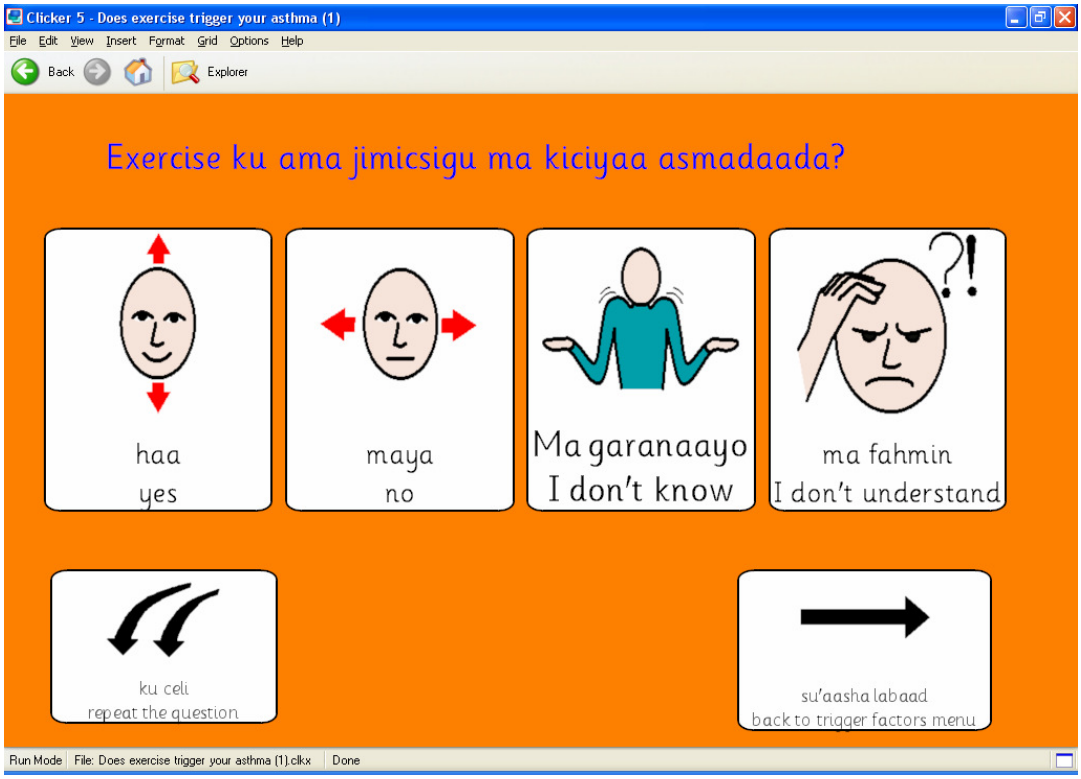
1. Tablet PC (left) and laptop PC (right) displaying a multiple-response option screen for the question "Does anyone in your family have asthma?"



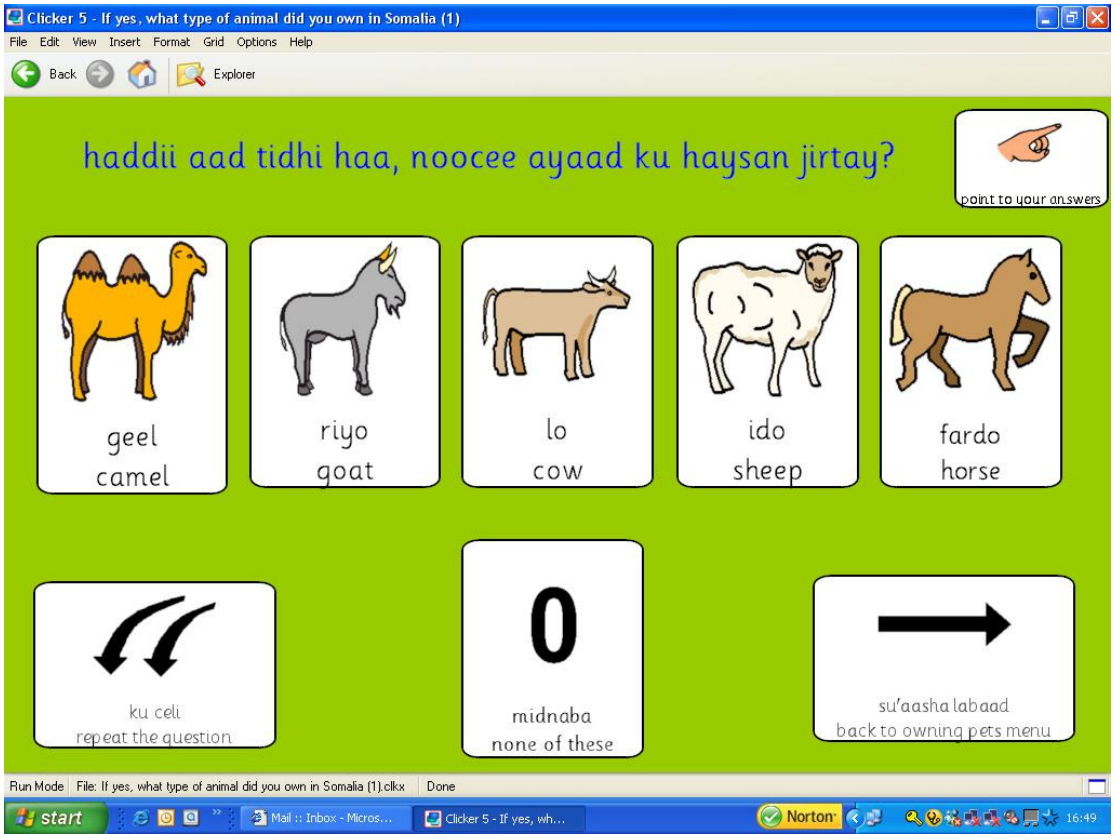
2. Opening screen from which clinician chooses topic. Numbers in brackets indicate the number of questions available under each topic.



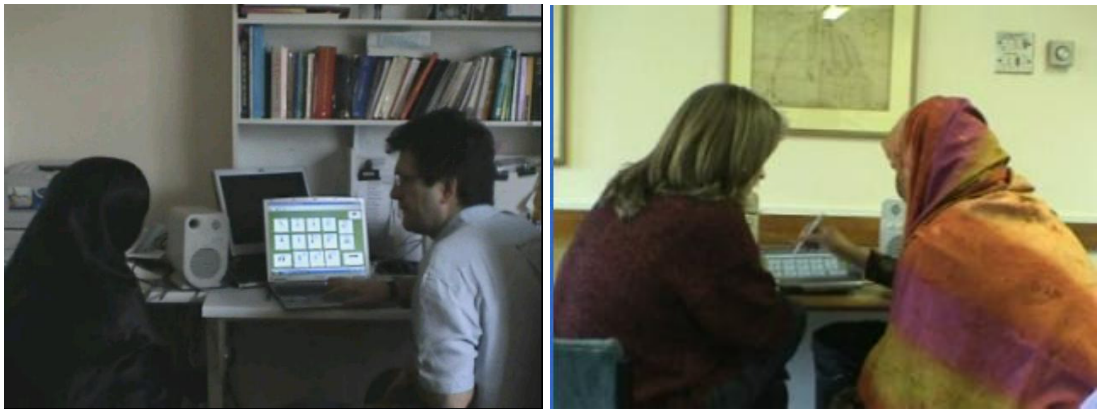
2. “Medical visit” questions, one of the 12 “asthma history” questions.



3. An example of a yes/no question, in this case “Does exercise trigger your asthma?” The buttons on the bottom indicating “repeat the question” and “back to ... menu”, appear in this position on every screen.



4. An example of a multiple answer question, "If yes," (to question "Did you own any animals?"), "what kind of animal did you own in Somalia?"



5. A simulation with a GP using the laptop (left) and a nurse using the tablet (right).

2. Questions and answers

Asthma history menu (12)
- Diagnosis (2)
- Family (3)
- Asthma emergencies (7)

Personal and social history (12)
- Employment (4)
- Smoking (3)
- Owning pets (4)
- Serious illnesses (1)

Current status (18)
- RCP in the last month (7)
- RCP in the last week (7)
- Trigger factors (4)

Medications (13)
- Steroid tablets (5)
- Inhaler devices (6)
- Other medications (2)

Patients' attitudes regarding their asthma (5)

Asthma management (9)
- Seeing an asthma nurse (2)
- Asthma action plans (3)
- Peak flow meter use (4)

Style of question	Freq	Question	Response options
Asthma history menu (12)			
Diagnosis (2)			
Time since	25	When was your asthma diagnosed?	Less than a year ago, last year, 2,3,4,5,6,7,8,9 years ago, more than 9 years ago
Time since	17	How old were you when diagnosed with asthma?	1-10 years old, 11-19 years old, more tha20 years old
Family (3)			
Multiple choice	16	Does anyone in your family have asthma?	Nobody, my mother, father, brother, sister, daughter, son, aunt, uncle, grandparents, niece, nephew, cousins
Multiple choice	11	Does anyone in your family have eczema?	Nobody, my mother, father, brother, sister, daughter, son, aunt, uncle, grandparents, niece, nephew, cousins
Multiple choice	10	Does anyone in your family have hay fever?	Nobody, my mother, father, brother, sister, daughter, son, aunt, uncle, grandparents, niece, nephew, cousins

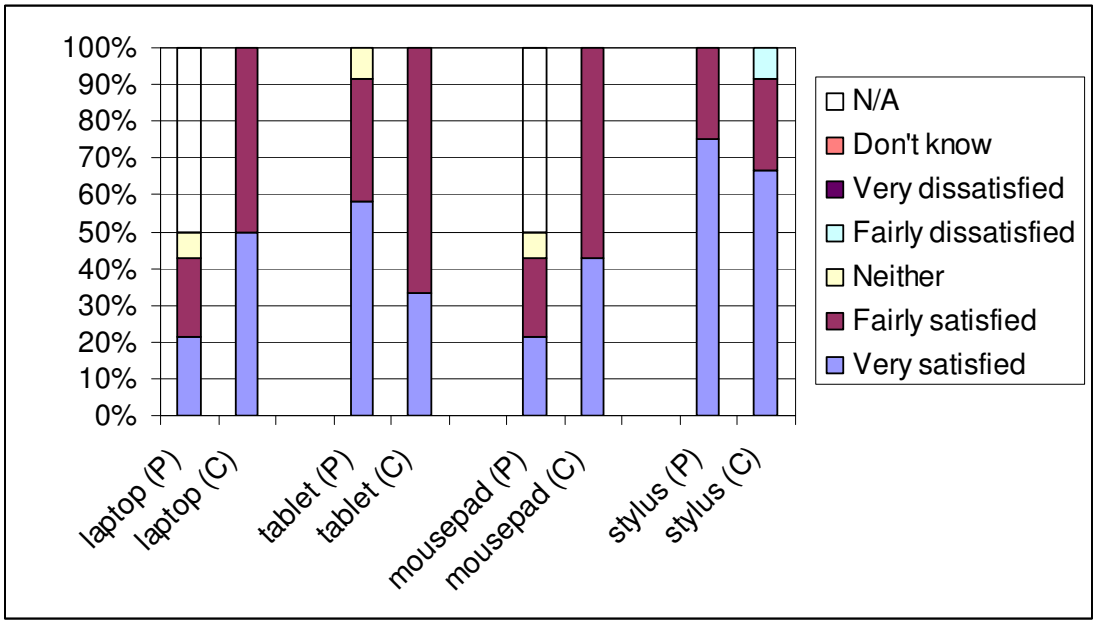
Multiple choice	16	Does anyone in your family have asthma?	Nobody, my mother, father, brother, sister, daughter, son, aunt, uncle, grandparents, niece, nephew, cousins
Multiple choice	11	Does anyone in your family have eczema?	Nobody, my mother, father, brother, sister, daughter, son, aunt, uncle, grandparents, niece, nephew, cousins
Multiple choice	10	Does anyone in your family have hay fever?	Nobody, my mother, father, brother, sister, daughter, son, aunt, uncle, grandparents, niece, nephew, cousins
Asthma emergencies (7)			
Yes/No	13	Have you ever been admitted to hospital with your asthma?	Yes, No, I don't know, I don't understand
Yes/No	3	Were you admitted last year?	Yes, No, I don't know, I don't understand
Yes/No	8	Have you ever gone to A&E with your asthma?	Yes, No, I don't know, I don't understand
Yes/No	1	Did you go to A&E last year?	Yes, No, I don't know, I don't understand
Yes/No	2	Have you ever been admitted to intensive care with your asthma?	Yes, No, I don't know, I don't understand
Yes/No	8	Did you have any emergency visits to the GP or practice nurse with your asthma in the last year?	Yes, No, I don't know, I don't understand
Numerical	5	If you did have emergency visits, how many did you have?	1, 2, 3, more than 3 visits
Personal and Social History (12)			
Employment (4)			
Yes/No	10	Are you working now?	Yes, No, I don't know, I don't understand
Multiple choice	1	What is your current job?	I'm not working, a labourer, office work, studying, I'm retired, housewife, I've never worked
Yes/No	6	Have you ever worked?	Yes, No, I don't know, I don't understand
Multiple choice	3	What was your previous job (if not working)?	A labourer, office job, studying, housewife, I've never worked
Smoking (3)			
Yes/No	14	Have you ever smoked?	Yes, No, I don't know, I don't understand
Numerical	1	If so, how long have you smoked for?	Less than a year, 2-5 years, 6-10 years, 11-15 years, 16-20 years, more than 20 years
Yes/No	2	Are you a current smoker?	Yes, No, occasionally, I don't know, I don't understand
Owning pets (4)			
Yes/No	10	Do you own any pets now in the UK?	Yes, No, I don't know, I don't understand
Multiple choice	0	If yes, what type of pet do you own now?	Cat, rabbit, dog, bird, fish
Multiple choice	10	Have you ever owned animals in Somalia?	Yes, No, I don't know, I don't understand
Multiple choice	7	If yes, what type of animal	Camels, goats, cows, sheep, horses

		did you own in Somalia?	
Serious illnesses (1)			
Multiple choice	8	Do you have any other serious illnesses?	Heart condition, other respiratory conditions, other long terms conditions, no, I don't know
Current status (18)			
RCP in the last month (7)			
Yes/No	11	In the last month, have you had difficulty sleeping because of your asthma symptoms (including cough)?	Yes, No, I don't know, I don't understand
Multiple choice	11	What asthma symptoms have disturbed your sleeping in the last month?	Cough, wheeze, breathlessness, chest tightness, I don't know, I don't understand
Yes/No	10	In the last month, have you had your usual asthma symptoms during the day (cough, wheeze, chest tightness or breathlessness)?	Yes, No, I don't know, I don't understand
Multiple choice	10	What asthma symptoms have affected you during the day, in the last month?	Cough, wheeze, breathlessness, chest tightness, I don't know, I don't understand
Yes/No	10	In the last month, has your asthma interfered with your usual activities (e.g. housework, work, school)?	Yes, No, I don't know, I don't understand
Multiple choice	9	Which activities has your asthma interfered with in the last month?	Walking, getting dressed, carrying things, using the stairs, shopping, housework, sport, work, school, I don't know, I don't understand
Yes/No	9	Have your symptoms been the same in the last month?	Yes, No, I don't know, I don't understand
RCP in the last week (7)			
Yes/No	7	In the last week, have you had difficulty sleeping because of your asthma symptoms (including cough)?	Yes, No, I don't know, I don't understand
Multiple choice	9	What asthma symptoms have disturbed your sleeping in the last week?	Cough, wheeze, breathlessness, chest tightness, I don't know, I don't understand
Yes/No	7	In the last week, have you had your usual asthma symptoms during the day (cough, wheeze, chest tightness or breathlessness)?	Yes, No, I don't know, I don't understand
Multiple choice	6	What asthma symptoms have affected you during the day, in the last week?	Cough, wheeze, breathlessness, chest tightness, I don't know, I don't understand
Yes/No	4	In the last week, has your asthma interfered with your usual activities (e.g.	Yes, No, I don't know, I don't understand

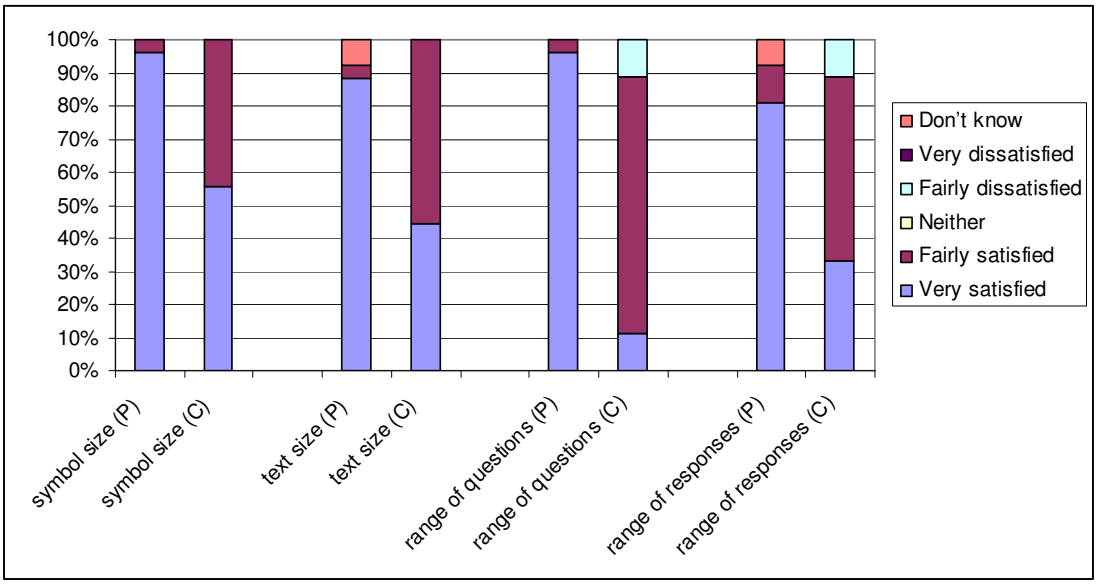
		housework, work, school)?	
Multiple choice	4	What activities has your asthma interfered with in the last week?	Walking, getting dressed, carrying things, using the stairs, shopping, housework, sport, work, school, I don't know, I don't understand
Yes/No	8	Have your symptoms been the same in the last week?	Yes, No, I don't know, I don't understand
Trigger factors (4)			
Multiple choice	16	What do you think makes your asthma worse?	Dust, pollen, animals, work infections, the weather, sprays, colds/flu, emotions, physical exercise, foods, bedding, smoke, pollution, perfumes
Yes/No	11	Do you take your daily treatment regularly?	Yes, No, I don't know, I don't understand
Yes/No	7	Does exercise trigger your asthma?	Yes, No, I don't know, I don't understand
Multiple choice	12	Do you take your reliever prior to exercise (walking) or strenuous activity?	Sometimes, rarely, never, I didn't know I could, I don't know, I don't understand
Medications (13)			
Steroid tablets (5)			
Yes/No	14	Have you ever had any prescribed steroid tablets?	Yes, No, I don't know, I don't understand
Yes/No	9	Did you have these tablets last year?	Yes, No, I don't know, I don't understand
Numerical	7	If yes, how many times were you prescribed tablets last year?	Once, twice, three times, more than three times, I don't know
Yes/No	10	Are you currently taking any steroid tablets?	Yes, No, I don't know, I don't understand
Multiple choice	3	Do you have your medication with you?	I have them Widgit Rebusitten down, I have them here, I don't know, I don't understand
Inhaler devices (6)			
Yes/No	19	Are you using any inhalers at the moment?	Yes, No, I don't know, I don't understand
Numerical	18	How many inhalers are you currently using?	1, 2, 3, more than 3, I don't know
Multiple choice	22	What colours are your inhalers?	Blue, brown, purple, white, orange, red, turquoise
Multiple choice	15	What shapes are your inhalers?	Standard inhaler, Accuhaler, Turbohaler, none of these, I don't know, I don't understand
Yes/No	19	Do you have a spacer?	Yes, No, I don't know, I don't understand
Yes/No	15	Do you have your inhalers with you?	Yes I have it here, no, I have it written down, , I don't know, I don't understand
Other medications (2)			
Yes/No	6	Do you take any other medications (e.g. tablets) regularly for your asthma?	Yes, No, I don't know, I don't understand
Yes/No	5	Do you have your medication with you?	Yes I have it here, no, I have it written down, I don't know, I don't understand

Patients' attitudes regarding their asthma (5)			
Multiple choice	16	Do you think your asthma is going to?	Get better, get worse, stay the same, I don't know, I don't understand
Multiple choice	16	When does your asthma affect you most?	Morning, evening, cold weather, damp weather, hot weather, humid weather, when emotional, I don't know, I don't understand
Multiple choice	20	In what way does your asthma affect you most?	Limits physical activity, unable to sleep, causes worry, causes upset, does not affect me much, I don't know, I don't understand
Multiple choice	15	Some people have a concern about steroid tablets. Do you?	Yes about weight gain, other side effects, general anxiety, No, I don't know, I don't understand
Multiple choice	10	How do you feel about your asthma treatment?	Happy, unhappy, I don't know, I don't understand
Asthma management (9)			
Seeing an asthma nurse (2)			
Yes/No	24	Have you ever seen an asthma nurse to discuss your asthma treatment?	Yes, No, I don't know, I don't understand
Frequency	6	If yes, how many times have you seen a nurse to discuss your asthma?	Never, once, twice, three times, more than three times, I don't know, I don't understand
Asthma action plans (3)			
Yes/No	6	Have you ever been given a written asthma action plan?	Yes, No, I don't know what that is, I don't understand
Frequency	1	How often have you needed to adjust your treatment according to your asthma action plan in the last year?	Never, once, twice, three times, more than three times, I don't know, I don't understand
Frequency	0	How often have you needed to adjust your treatment according to your asthma action plan in the last month?	Never, once, twice, three times, more than three times, I don't know, I don't understand
Peak flow meter use (4)			
Yes/No	17	Do you have a peak flow meter?	Yes, No, I don't know what that is, I don't understand
Yes/No	4	If you have a peak flow meter, do you use it regularly?	Yes, No, I don't know, I don't understand
Yes/No	5	Do you keep a record of your peak flow readings?	Yes, No, I don't know, I don't understand
Yes/No	1	Do you have this record with you?	Yes, No, I don't know, I don't understand
TOTAL	646		

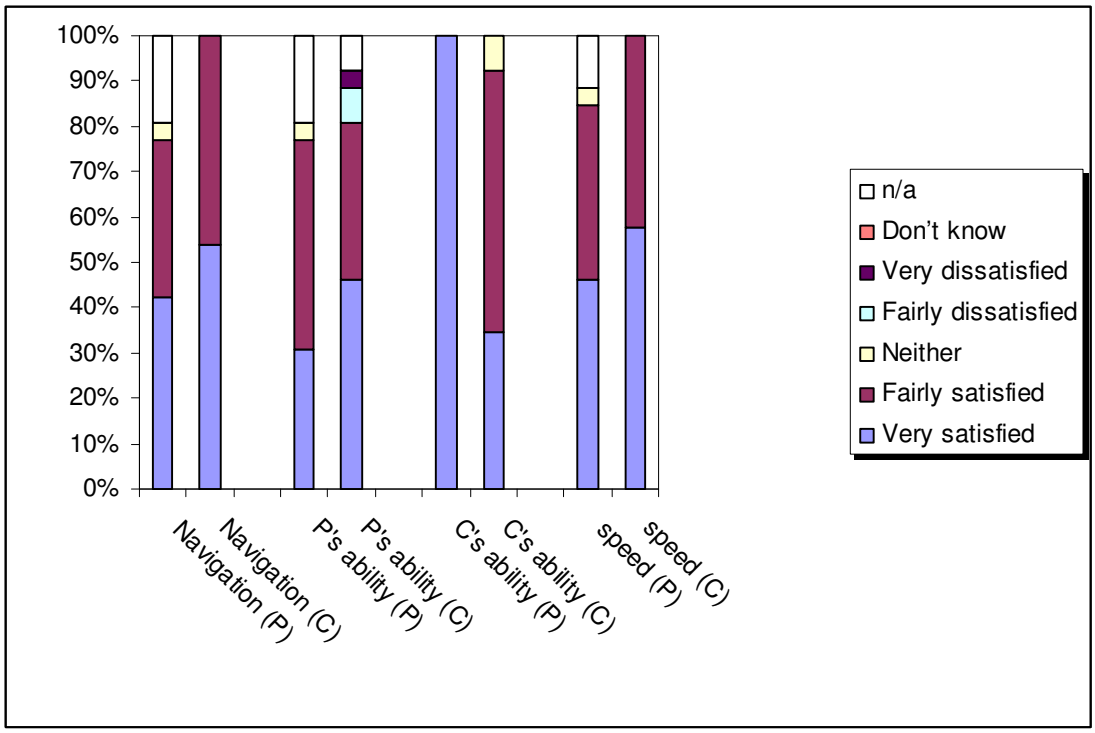
3. A selection of results from the feedback questionnaires



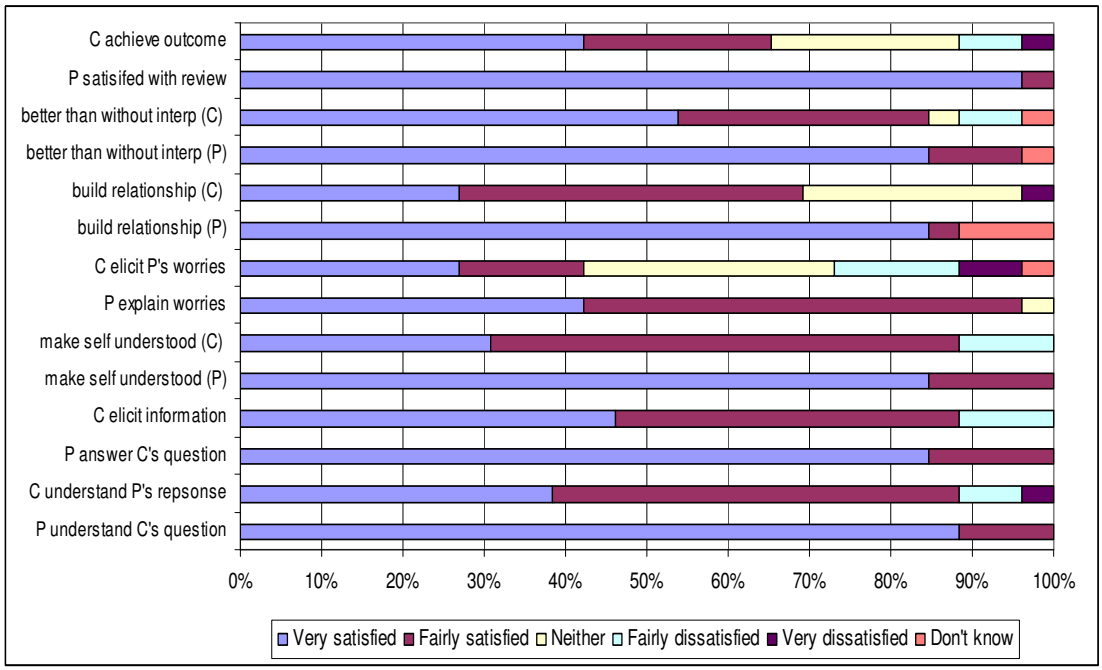
1. Satisfaction ratings for patients (P) and clinicians (C) using laptop vs. tablet, and mousepad vs. stylus. The 50% "N/A" for laptop (P) and mousepad (P) represents "passive patients" (see text).



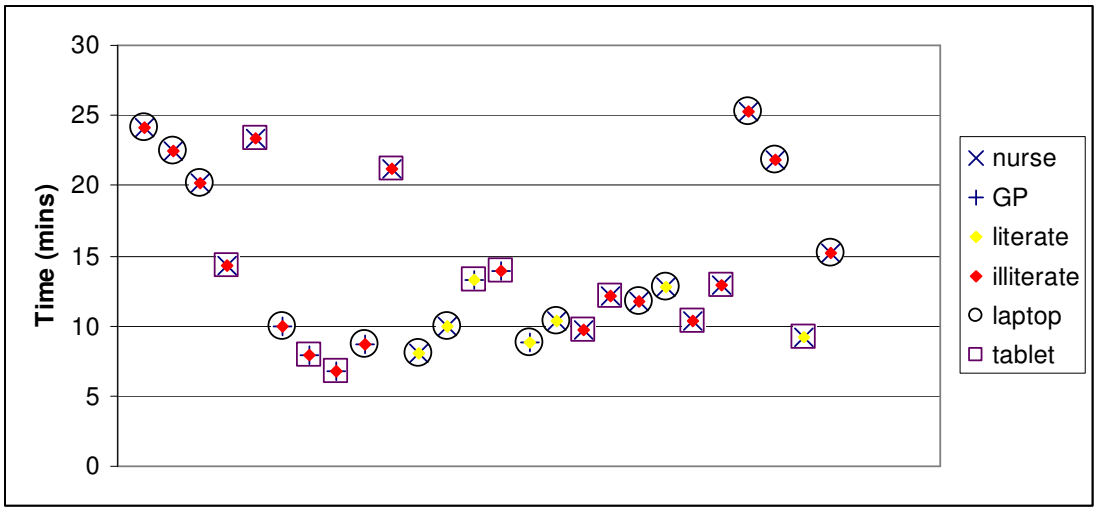
2. Satisfaction ratings for size of symbol and text, and range of questions and responses, in each case for patients (P) and clinicians (C).



3. Satisfaction ratings of clinicians (C) and patients(P) for usability of the devices: navigability of the software, patient's ability, clinician's ability, and speed.



4. Satisfaction ratings regarding various aspects of communication.



5. Time taken for each of the 26 consultations, showing practitioner (nurse vs GP), patient literacy and device (laptop vs tablet).

Criterion	Range		Average
nurse	7’59	25’14	15’32
GP	6’46	13’57	9’54
literate patient	7’59	13’15	10’20
illiterate patient	6’46	25’14	15’23
laptop	7’59	25’14	14’57
tablet	6’46	23’25	12’56
ALL	6’46	25’14	14’01

6. Range and average time taken, by criterion.

Appendix IV. Related publications

Journal publications

Johnson MJ (2004) What can we learn from drawing parallels between people who use AAC and people whose first language is not English? *Communication Matters*, **18**.2, 15-17.

Johnson MJ, Evans DG, Mohamed Z, Caress AL (in press) A pilot study to investigate alternative communication strategies in provider-patient interaction with Somali refugees. To appear in *Informatics in Primary Care*.

Conference presentations

Johnson M (2003) Non-disabled Somali-speaking patients with limited or no English: A potential AAC user group? *Communication Matters, CM2003 National Symposium*, Lancaster University, p. 19.

Johnson M, Mohamed Z, Somers H, Caress A, Lovel H (2003) Communication for adult asthma patients with limited or no English: Can language technologies help in primary care clinical consultations? *Pan Manchester R & D Conference*, Manchester Royal Infirmary.

Johnson MJ, Mohamed Z, Lovel H, Somers H (2004) Pictographic Symbols and Digitised speech: a new approach to facilitating communication with non-English speaking patients. *EACH International Conference on Communication in Healthcare*, Bruges, P04.02.

Johnson MJ, Mohamed Z, Somers H, Lovel H (2004) Could (non-disabled) Somali speakers with limited English benefit from AAC? *First Regional African AAC Conference 2004, Issues in Disability: Unheard Calls*, Johannesburg, South Africa, Proceedings p.6.

Somers H (2004) Disabled by language? Problems of limited majority language skills in doctor-patient communication. *IJCNLP-04 Satellite Symposium: Proceedings of Asian Symposium on Natural Language Processing to Overcome Language Barriers*, Hainan, China, p.104.

Somers H, Johnson MJ, Lovel HJ, Mohamed Z (2004) Language technology for patients with limited English. *EACH International Conference on Communication in Healthcare*, Bruges, Belgium, P04.09.

Johnson MJ (2005) Using Augmentative and Alternative Communication (AAC) technology to facilitate cross-cultural communication with non-English speaking patients. *Proceedings of the 8th Research Colloquium of the UK Special-Interest Group in Computational Linguistics (CLUK-05)*, The University of Manchester, p. 47-54.

Johnson M (2005) Developing alternative communication strategies to facilitate communication with Somali asthma patients with limited English. *PRISM (Postgraduate Research in Science and Medicine) Abstracts*, University of Central Lancashire, Preston, (Winner of oral presentation prize).

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Johnson MJ, Evans DG, Mohamed Z (2006) A pilot study to investigate alternative communication strategies in provider-patient interaction with Somali refugees. *Current Perspectives in Healthcare Computing Conference*, Harrogate, N.Yorks, p. 97-106.

Johnson MJ, Caress A-L, Mohamed Z (2006) Conducting a complex, exploratory study with a refugee community: practical and methodological challenges. *Proceedings of RCN Annual International Nursing Research Conference 2006*, York.

Somers H (2006) Language engineering and the pathway to healthcare: A user-oriented view. *HLT/NAACL-06 Medical Speech Translation, Proceedings of the Workshop*, New York, NY, pages 32-39.

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"Diagnosis at a mouse's click" *Manchester Metro News*, February 21st 2003. [local newspaper report]

This research mentioned in interview with *e-Health Insider* at the *23rd Annual Conference on Health Informatics* in Harrogate, March 2006, podcast available at http://www.e-health-insider.com/podcast/index.cfm?ID=5.

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