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A GUIDE TO THE DEVELOPMENT OF LINGUISTICALLY AND CULTURALLY COMPETENT COMMUNICATION SERVICES

Pritti Mehta
Genetic Interest Group
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Chapter 1 - Report overview, findings and recommendations

'A communication process which deals with human problems associated with occurrence or the risk of occurrence, of a genetic disorder in a family'

Definition of Genetic counseling: American Society of Human Genetics: 1975 Ad Hoc Committee on Genetic Counseling[1]

Report overview

This report provides guidelines to improve access to, and the quality of communication and language services across clinical genetics departments, and thereby help to reduce associated health inequalities. Although the report is intended for use by genetic service providers, planners/commissioners, policy makers and patient support organisations, it is also relevant to non-genetic NHS and public sector departments. Its main objectives are to provide a community driven approach towards the development of linguistically and culturally competent patient information resources, and inform relevant policy and practice. The report presents key recommendations and provides the following supporting evidence:

1) Overview of existing guidance, policy and legislative frameworks underpinning fair and equal access to treatment and health care;
2) Preliminary survey of language support provision across genetic departments (2003);
3) Assessment of London's (genetic) language needs (2003);
4) A review of the quality and effectiveness of existing multilingual patient genetic information through back-translation and community consultation (2003);
5) The development of a best practice model for production of language support materials; and,
6) Implementation of this model in the translation of leaflets and preparation of audio recordings as part of the London IDEAS Translation Project (2004-5).

Key findings and outcomes

- The development and provision of appropriate communication support services is essential to ensure that all individuals and families are supported in their particular genetic health care needs (p.11).

- Despite the significant requirement for it, language support service development and provision across genetic departments is *ad hoc*. Few written resources are currently available and access to interpreters and multilingual staff may be limited. There is also little or no specialist training for interpreters involved in genetic counselling (p.11). Staff surveys indicate that there is a need to improve access through provision of multi-lingual staff speaking some of the key community languages, with greater access to trained interpreters, written translation services, and patient advocacy outreach programmes (p.12).

- Although the wider legislative and national policy frameworks for provision of equitable and accessible treatment and care are in place, the U.K has as yet no national policy towards the development and provision of language or communication support services (p.9). The Department of Health's recent introduction of relevant guidance (2004) is however an important step, and includes recommendations for commissioners/planners to consider in relation to the development of future services (p.10).

- Future monitoring of genetic service users' language needs will be encouraged by the recent expansion of the GenCAG (Genetic Services Commissioning Advisory Group) Quality Marker Third Survey to include an assessment of communication support services and needs (p.10). This is an important and necessary step to ensure appropriate access to, and delivery of genetic services.

- Whilst over 300 languages are known to be spoken in the capital alone, information relating directly to minority ethnic language needs is scarce. Assessments of London's (genetic) language needs examined a range of variables including perceived demand, numbers of different languages speakers in London, and also factors relating to determinants of language need, such as literacy levels, social and genetic need (p.14). Identified languages included Gujarati, Urdu, Punjabi, Sylheti, Somali, Arabic and Turkish.

- A review of existing translated patient genetic information materials revealed significant variation in their quality and effectiveness. Linguistic and cultural competence was found to be dependent on appropriate community involvement and quality assessment in the development and evaluation of translated materials (p.16).

- A best practice model for the production of multilingual patient (genetic) information resources has been developed. This model comprises 6 key steps (including piloting and dissemination), with community involvement at stages 1 and 4 (see p.7).

    1. Development of leaflet content;
    2. Translation of leaflets;
    3. Validation by a second translator;
    4. Community assessment
    5. Piloting and user evaluation; and
    6. Dissemination.

- Implementing this approach within the London IDEAS Translation Project (see below) identified a significant number of issues relating to the quality and effectiveness translated materials (p.25). These findings strongly validate the need for consultation with target groups in the development and evaluation of language support services.

The London IDEAS Translation Project aims to address some of the shortfall in the availability of multilingual patient genetic information. This initiative will create a resource of 38 written materials (including 27 leaflets each with its own glossary, ten letters and forms and a general glossary for clinic use with interpreters) in a number of languages, covering a broad range of topics (p.12). The full range of materials in Urdu, Punjabi and Gujarati, will be available for piloting in clinic later this year, with the remaining languages to follow after community assessment. Audio recordings will also be available for some languages.

Key recommendations

1. **Policy development**
The formation of clear national policy standards towards the provision of accessible, linguistically and culturally competent NHS services is a necessary step in ensuring equal access, and reducing health inequalities. Whilst accurate and effective communication is fundamental to genetic service delivery; all departments (including NHS and public sector) should respond appropriately by developing clear policies towards the provision of language services. These should, ideally, include multi-lingual (genetic) staff and patient advocacy outreach programmes, trained interpreters, multilingual patient information resources, appropriately translated correspondence (including appointment and summary letters) and other forms of communication support.

2. **Developing competency in language support service services**
A best practice model towards the development of multilingual patient (genetic) information resources is presented below. This model depends on community consultation and assessment in the development and evaluation of translated materials.
Specialised training and education for interpreters involved in genetic counselling (or any other specialised activity) should be developed, informed by key professional and user groups. In this regard, training should provide a basic understanding of genetic concepts including inheritance patterns and principles embedded within genetic counselling such as non-directiveness and patient confidentiality.
The familial nature of genetics, and issues raised by patient confidentiality, should preclude the use of family and friends to act as interpreters, unless requested by the patient, and then with professional interpreter backup. In such circumstances basic support should be available that addresses the familial implications.

3. **Delivery of language support services**
Establish strategies to enable service users to access language support services easily. Develop appropriate mechanisms to gain advance knowledge of service users' requirements in order to ensure the availability of language services. Contribute multilingual materials to an appropriate quality controlled central resource to encourage wider dissemination and prevent unnecessary duplication of existing information.

4. **Monitoring local needs**
Regularly monitor service users' ethnic origin and communication support needs, including, language, dialect, disability status, the type of communication support provided; and the users' unmet needs.

5. **Valuing multilingualism**
Value diversity and multilingualism in the development and use of cultural and linguistic workforce skills, and where possible create opportunities for recruiting and training staff, including interpreters from local communities.

6. **Reviewing services**
Regularly review current practice and establish mechanisms to engage service users in the development, monitoring and evaluation of communication support services.

7. **Commissioning**
Include communication support service provision into budgeting, human resource and health service management, and develop best practice in the commissioning and planning of language support services to ensure effective development and delivery.

Additional notes to recommendations 2 and 7 can be found in Appendix 1

Best practice in development of multilingual (genetic) resources

A model towards the development of multilingual patient (genetic) information resources from existing material is presented on the next page. The following general guidelines may also be useful:

- Before embarking upon translation work, evaluate the language/communication needs of the target population in order to identify most appropriate languages and formats for translation.

- Maintain a simple, consistent style and avoid the use of medical/genetic/technical jargon, and where necessary always provide a clear explanation of the meaning.

- Transliterate (transcribe into the corresponding letters or characters of another alphabet) medical/genetic/technical terms unless translations are in common usage; and it may also be helpful to provide the English word in brackets. As mentioned above, always include a clear explanation of the meaning.

- Develop and translate a glossary/lexicon and use consistently across each related translation.

- Providing metaphors and diagrams can often help to convey meaning, however take care when using colloquial terms and phrases as these may not necessarily translate well.

- Dual language leaflets containing both the English and the translated version are recommended in order to enable health professionals to know the content of the leaflet and also to allow English and non – English speaking members of a patient’s family to read the material together.

- Visual appearance is very important and every effort should be made to include images that increase accessibility for the target group. The standard of presentation should equal that of the original English version.

- Aim for a balance between faithfulness to the original text and readability in the target language. This can be achieved by encouraging ‘a free translation approach’, in which guidelines avoid unnecessary restrictions and give translators flexibility to develop more readable, natural translations that retain the sense of the original. This process requires close collaboration between client and translator.

- Preferentially apply fonts used in the vernacular press and choose appropriate font sizes to ensure that text can be read with ease (suggested minimum - 12pt). Try to maintain a consistent font size between different language versions.

Recommended best practice model

This model assumes that the clinical content has been established and verified, and a basic English version produced in advance:

1. **Development of leaflet content**
   In developing content and language of original text, consult with members of the respective community, to ensure accessibility and cultural competence, and to identify potential sources of ambiguity. Recruit a readers' panel or hold focus groups with 6-8 bilingual individuals per language.

2. **Translation of leaflets**
   Choose an agency/translator with experience and knowledge of the specialist subject. Look for appropriate accreditation, request references, and try a pre-test using a document translated in both directions. Also consider what is included in the translation process – such as independent checks and proof-reading, and explore what each of these steps actually involves. Identify who is accountable if mistranslations arise. Before any work commences, set out your requirements clearly and ensure that quality standards will be met. Work with the translator to identify potential sources of ambiguity and mistranslations within the original text and continue to maintain close collaboration throughout the translation process.

3. **Validation by a second translator (checking quality and accuracy of the translation)**
   Whilst not seeking to produce word-for-word translations there must be conceptual and functional equivalence between the translated and original texts, and medical/genetic terms need to be accurately conveyed. Since mistakes and alterations in meaning frequently arise, a quality control step must be part of any translation exercise.
   All translations should be crossed-checked against the original English versions by a second translator. Most translation agencies offer in-house 'proof-reading'. However this can mean a range of things; from simply checking for spelling, dates and typographical errors, to cross-checking the translation against the English version as we recommend here. Whilst it may be practical and cost effective to carry out translation and validation by a 'one agency approach' it may be more effective to have documents validated by an independent agency. All documents should also be proof-read for typographical errors etc. as a final check.

4. **Community assessment**
   All translations should also be crossed-checked against the original English versions by community representatives to assess accessibility, readability, and cultural competence. Quality and accuracy can also be measured by this approach. Recruit a readers' panel or hold focus groups with 6-8 members of the target community.

5. **Piloting and evaluation**
   Final translations can be piloted in clinic using appropriate user–feedback evaluation systems to assess the quality and effectiveness.

6. **Dissemination**
   Consider appropriate strategies to deliver and disseminate material. Creating or contributing to a centrally collected register of translated material is likely to lead to wider dissemination, whilst preventing duplication of existing materials. Limitations may arise, however, when trying to guarantee quality and effectiveness, although this could be overcome if all translations follow a standard protocol such as the one suggested here.

Chapter 2 - Introduction

With at least 12.5% of the population in England's describing itself as other than 'White British'[2], and over 300 spoken languages identified in London, alone[3], Britain is undeniably a multi-ethnic society, of people from diverse linguistic and social backgrounds. Whilst making significant contributions towards Britain's rich and vibrant identity and culture, there is strong recognition that social and linguistic barriers can be a major cause of health inequalities. By controlling how and to what extent members of different communities express their needs for health services, and the way in which those services respond in providing linguistically and culturally competent care, these factors play a very important role in determining access to, and the delivery of, healthcare[4].

Review of legislative and policy framework

The overall goal of the National Health Service (NHS) is to provide equitable care for all, and to reduce health inequalities. There are also a number of underpinning legislative and policy frameworks, as highlighted below:

- The Human Rights Act makes it unlawful for any public authority to act in a way incompatible with the European Convention on Human Rights.
- The Race Relations Act (1976) indicates that it is unlawful for service providers to discriminate on racial grounds by refusing to provide services.
- The Race Relations (Amendment) Act (2000), requires public bodies to promote race equality; eliminate unlawful discrimination; promote equality of opportunity and good relations between different groups; and to have prepared and published a race equality scheme by 31 May 2002, which should cover all 'relevant functions'.
- The NHS aims to enable patients to be informed about health issues, service options and to participate fully in personal health decisions[5].
- The Genetics White paper commitment to equity and equality of access (5.17) covers 'access (including ethnicity, equity and equality) issues and how beliefs affect utilisation of services with a genetic element[6].

Whilst the wider legislative and policy framework for provision of equitable and accessible treatment and care is in place, the U.K. still does not have a national policy on the development and provision of language support services. The U.S.A., by contrast, has 14 national standards relating to culturally and linguistically competent health care delivery, some of which are mandatory, requiring that all organisations receiving state financial support provide language assistance services, including bilingual staff and interpreter services[7]. Another example is the State of New South Wales, Australia, which has two policy principles: the right of equality of access to health care services regardless of cultural origin or linguistic skill; and the responsibility of the health system to respond appropriately to its target populations which includes people of non-English speaking backgrounds[8].

The NHS plan does, however, make specific commitments towards the provision of communication support services and has set up a commitment to provide a national translation service through NHS Direct[9]. The Equality and Human Rights Group of the Dept. of Health has also recently (2004) issued guidance on developing communication support services and strategies, which includes 1) the legislative and policy framework underpinning the development of communication support services; 2) analysis of existing types of provision; and 3) good practice recommendations for commissioners/planners to consider in relation to the development of future services[10]. These recommendations are summarised below.

In accordance with GIG's recommendations (personal communications) - the Genetics Commissioning Advisory Group (GenCAG) has recently expanded its Genetic Services Quality Markers - Third Survey, to include an assessment of language/communication support services and needs. The Fourth Survey will also include a requirement for ethnic monitoring, again as recommended by GIG (personal communications).

The Equality and Human Rights Group of the Dept of Health recommendations on developing communication support services and strategies[10].

Recommendation One: Collaborative approaches to commissioning be considered as a strategy to fulfil commissioners' concern in relation to greater economies, efficiency and evaluation, and those of service providers in relation to long term development, research and investment.

Recommendation Two: Clear specifications and service standards for the commissioning and provision of services be developed to ensure the effective planning, monitoring, development and delivery of services is a vital part of this process. Including all local stakeholders and being sensitive to local circumstances. As part of the standard setting process commissioners/planners ensure that:

- The function of interpreters in healthcare settings is clear to both professionals and service users to gain optimum benefit from their interventions;
- Staff awareness and training on using interpreters is developed; and,
- A clear position on the interface between healthcare and advocacy roles is established to avoid misunderstanding and potential conflicts of interest.

Recommendation Three: A local strategic framework for commissioning and service development be established jointly with health and social care agencies. A local language and service provision audit may be useful for developing this. The framework could provide clear objectives and guidance for health and social care organisations and ensure that a policy and strategy for recruitment, retention and development of interpreters in health and social care settings is formulated and implemented.

Recommendation Four: Commissioners/planners ensure that services:

- Invest in strategies for recruitment and career development from local communities and offer accredited training as a part of career pathway;
- Build capacity amongst vulnerable groups by offering training and volunteering opportunities with realistic prospects for future employment at the end of training; and,
- Routinely engage, consult and involve local communities in developing, monitoring and evaluating communication support services.

The role of genetic services

'Genetic service offers: accurate diagnosis, risk estimation, genetic counselling (including pre and post predictive testing) accessible information for families, support to individuals and families in informed decision making'

The U.K. Department of Health definition of a core genetic service[11]

'A communication process which deals with human problems associated with occurrence or the risk of occurrence, of a genetic disorder in a family'

Definition of genetic counseling: American Society of Human Genetics: 1975 Ad Hoc Committee on Genetic Counseling[1]

Accurate and effective communication is central to the delivery of genetic services. Individuals and families depend on this most fundamental of processes, from seeking a diagnosis, to needing appropriate guidance and support to inform reproductive decision making. With no cures or conventional treatments available for the great majority of genetic disorders, the information received from genetic service providers is likely to be of paramount importance, in enabling individuals and families to make appropriate adjustments towards their daily lives. The development and provision of appropriate communication support services is therefore essential to ensure that all individuals and families are supported in their particular genetic health care needs.

Provision of language support services across clinical genetics departments

Recent analyses across a range of health and public sector departments indicate that there is still a long way to go towards achieving appropriate access to quality language services. A review of haemoglobinopathy screening providers in England found, for example, that language service provision is *ad hoc*[12]. There is increasing evidence emerging for mistranslation of written translated materials[13], and a study of user perspectives on interpreter services revealed strong inadequacies[14].

Data on the provision of language support services across clinical genetics departments is scarce. Past preliminary research indicates that almost 1/4 of minority ethnic patients may be in need of communication support services[15], and a more recent survey across UK regional genetics service providers suggests that minority ethnic language needs are poorly served (see below). There is also very little specialist training for interpreters involved in genetic counselling[i] and access to interpreters and multilingual staff is likely to be on an *ad hoc* basis. Additionally, few multilingual resources are currently available.

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[i] The Institute of Linguists Syllabus for the Diploma in Public Service Interpreting now includes Genetic Counselling as a potential local government option; however it hasn't been used as a subject area in an actual examination to date.

Examples of genetics staff survey comments are presented in the box below.

‘Often basic concepts of genetics do not translate – as are not within the experience of the interpreter and/or the family; and these consultations take ages!’

‘Majority of families need qualified interpreter at clinic OPA. Most families say that a family member or friend will interpret post clinic letter for them – question how correctly however.’

‘There is a huge unmet need for translated information leaflets and also few health professionals with appropriate language skills and cultural knowledge.’

‘(Minority ethnic language needs) poorly served in genetics by voice and literature.’

‘We may be able to give detailed data of what services we book but would guess very great need. We expend a considerable amount of clinical time with interpreters’

‘Audit in 2000 showed that translators were needed for approx 1/6 appointments.’

‘Patients in Lambeth and Southwark speak 142 different languages, the most common being Portuguese and Spanish.’

‘The largest minority ethnic group we serve is the Pakistani group – we have a couple of leaflets translated into Urdu which we have found to be useful.’

‘We have a small ethnic minority population. We very often organise interpreters for our home visit and clinic appointments. We do not have leaflets (in languages) other than in English however many patients report that if they cannot read in English then they cannot also read in their own language and it is often difficult translating genetic terms as many words do not exist in their own language.’

‘There are a number of minority languages in the UK. But it is important that we start translating leaflets for those languages spoken by many individuals.’

‘(Minority ethnic needs) grossly underserved in this country.’

‘In Northern Ireland there are increasing numbers of ethnic minority communities living, numbers are growing. Largest group is Chinese estimated by the multicultural resource centre at 8000. Many do not speak English especially 2nd and 3rd generation. There are needs to break down language barriers for genetic counselling and to make services more accessible to these community members: I feel that this survey is desperately needed and extremely valuable as long as points made are put into action. I have had first hand experience of recently trying to counsel a family from a Chinese background and difficulties with translation.’

The London IDEAS Translation Project

Some of the shortfall in the availability of multilingual patient genetic information resources will be address by The London IDEAS Translation Project. This is a collaborative project between The North-West Thames Regional Genetics NHS Service and the Genetic Interest Group within London IDEAS. It aims to develop and deliver meaningful and accessible patient information to London’s linguistically diverse communities, and ultimately improve patient access to genetic services. As London is the multilingual capital of the world, inhabited by over 45% of Britain's minority ethnic populations, material generated by this local initiative will have national and international application. London’s RGCs also serve over 14 million people – almost ¼ of the UK population. Therefore, whilst this project will not fulfil all the needs of even the local population, London is extremely well placed to pioneer this work.

Resources are available to translate up to 38 written materials into a number of languages, with limited provision for providing some language versions in audio formats. These materials will be made freely available to all Regional Genetics Centres (RGCs). Before translation activities commenced a number of issues needed to be addressed. These included: determining language needs and identifying a best

practice model towards the development of quality and effectiveness in multilingual patient (genetic) information resources.
These issues are presented in the following two chapters.

Chapter 3 - Assessment of London's (genetic) language needs

An assessment of London's genetic language needs was undertaken to help prioritise languages for the London IDEAS Translation Project. However, in carrying out this assessment, although over 300 languages were known to be spoken in London (Languages of London Project[3]), there was still a paucity of data relating directly to U.K. minority ethnic language needs. Apart from analysing the number of different language speakers in London (as extrapolated from Languages of London Project), this survey attempted to examine a range of variables that were also likely to be important, such as, (in this context) genetic service users' language needs, literacy rates and social need. Information on genetic service users' (perceived) language needs was gathered from U.K. regional genetics service providers. With no direct data on U.K. minority ethnic literacy rates, (female) literacy data derived from country or state of origin (obtained from UNESCO estimates for year 2000, and National literacy mission for year 1991) was utilised. Finally, U.K. asylum statistics for the then current 3rd quarter 2003 (Home Office) were examined, to help identify populations groups likely to have an increased social need. Additional survey information relating to translation and interpreter service provision was also considered.

Surveys utilised for this assessment are listed below.

1. **Languages of London project[3] - a study looking at languages spoken by London's school children, listing over 300 languages (provided data on numbers of speakers of different languages living in London);**
2. **U.K. Regional genetics centres survey of service users' (perceived) language needs;**
3. **Female literacy statistics for the country or state of origin based on UNESCO estimates for year 2000, and National literacy mission for year 1991;**
4. **UK asylum statistics for the 3rd quarter 2003 (Home Office) (indicator of social need);**
5. **Language line data on health sector requests for interpreters in London and U.K.; and,**
6. **Translation agencies data on public and health sector language requests.**

Consultation with key stakeholders (December 2003) informed this assessment, and helped to identify specific language issues. This group agreed by consensus to exclude the use of language service provider survey data (Language Line and Translation agency), as this was thought to be an inadequate indicator of language need, particularly for communities preferring to use family members as interpreters. Thus, by focusing on the remaining survey data, languages could be prioritised for the Translation Project. The first 6 languages identified in this way were Arabic, Gujarati, Punjabi, Sylheti, Turkish, and Urdu. These were the most widely spoken minority languages in London, and were amongst the top languages identified across both London-specific and U.K.- wide RGCs. Country/state of origin (female) literacy rates across the relevant population groups ranged from between 28 – 76%. Pakistani, Bangladeshi, Arabic and some Turkish populations were also likely to have an increased genetic need due to higher rates of consanguineous marriage. The next 5 languages were likely to be Chinese (Mandarin), Portuguese, Farsi, French, and Somali. This decision was again based upon the number of language speakers and genetic service users' perceived level of language need. At the time of this assessment, Somali, Chinese (Mandarin), Farsi, and French were also amongst the languages spoken by some of the largest population groups (Somalis, Chinese, Iranian, Iraqi, Dem. Rep. of Congo), seeking asylum in Britain. These populations were likely to have an increased social and linguistic need. The Somali female literacy rate was 24%. This information is summarised in the table on the next page.

Table 1: Summary of language data

Language	Estimated number of speakers in London (1998-99)	UK-RGC perceived need (number of responding centres:18)	London-RGC perceived need (number of responding centres: 4)	Applications for Asylum; 3rd Quarter 2003, indicating country of origin	Female Literacy Rate
Bengali+ Sylheti	119,900	13	4		30
Urdu	114455	15	4	(Pakistan) 495	28
Punjabi	143000	12	2		58
Gujarati	138000	13	2		61
Turkish	67000	10	4		76
Arabic	49500	10	4	(Iraq) 690	48
Cantonese + Mandarin	46000	5	1	(China) 965	82
Portuguese	26900	5	3		90
French	25300	4	2	(Dem.Rep.Congo)380	50
Somali	19037	3	2	(Somalia) 1440	24
Farsi	14900	4	3	(Iran) 860	69
Spanish	24500	2	2		87
Tamil	17700	3	1		62
Vietnamese	15800	1	1		91
Hindi	11445	9	2		45
Italian	11300	2	1		98
Kurdish	6200	1	1	(Turkey) 530	45
Polish	6600	1	1		70
Albanian	3900	3	2		97
Dari/Pushto	1600	0	0	(Afghanistan) 470	69

NB.

Asylum seeker languages have been determined by considering the official language of the country of origin however there are some caveats.

- Arabic is the official language of Iraq. Arab refugees from southern Iraq speak Arabic; however there are also Iraqi Kurds and Assyrians who speak Assyrian and a Kurdish dialect Sorani respectively.
- Farsi is the official language of Iran. Iranian refugees include Armenian, Assyrian, Kurdish minorities who may speak their respective languages at home, as well as Farsi and English.
- Majority of refugees from Turkey are Kurds, and whilst they speak Kurdish, they write Turkish, however they have low literacy rates.

Whilst Languages of London project list Urdu and Hindi speakers together they report that there were approx 10x more Urdu speakers than Hindi speakers. The individual proportion of Urdu and Hindi speakers has thus been calculated from the total number of Urdu/Hindi speakers.

The French literacy rate is based on the figures derived for the Dem. Rep. of Congo.
Portuguese and Spanish literacy rates are based on figures for Portugal and Spain. Female literacy rates for the following Portuguese speaking populations are given; Mozambique (29%), Guinea Bissau (28%), Cape Verde (66%).

Chapter 4 - The formation of a policy towards the development and provision of multilingual (genetic) health information

There is currently no national strategy for the development and provision of appropriate health education materials for minority ethnic groups[16]. When this work commenced there was neither a framework, nor clear guidance towards the translation of genetic health information[ii]. In developing best practice guidance and policy, there was no intent to "reinvent the wheel". Examples of best practice were likely to exist already. To identify these, GIG reviewed the quality and effectiveness of a number of examples of then currently available translated genetic health information materials. This work resulted in the identification of a set of clear guidelines and recommendations, which have now been implemented in the London IDEAS Translation Project, and could be used to guide other projects of this nature (see chapter 1).

The materials assessed in this study are listed below:

1. A Cardiac Surgery Video	Provides information about coronary heart disease, its causes, prevention, and treatment. It includes an introduction to cardiac surgery.
2. A Booklet guide for the South Asian Community about Diabetes	This booklet guide contains complex information about diabetes and its treatment, and components of it were analysed as part of this study. It is available in the following languages; Bengali, Gujarati, Hindi, Punjabi, Urdu and Cantonese.
3. A general leaflet about Rett Syndrome	A general leaflet on Rett syndrome which has been translated into 8 different languages. It is also available in audio format, and provides a general introduction about the syndrome, its symptoms, and how it is inherited.
4. A leaflet about Rare Chromosome Disorders[iii]	This introductory leaflet has been translated into a number of languages. It provides basic information about rare chromosome disorders, and how the support group can help individuals and families that are affected. These translations are no longer in use.
5. A Chemotherapy Fact Sheet	The Chemotherapy fact sheet, available in a number of community languages, provides a beginners guide to cancer and chemotherapy. Audio versions are available.
6. Fact Sheets Developed about Parkinson's disease	Most of the literature assessed in this study is derived from 'Facing the Future' however; some material was obtained from other sources.

[ii] Shaw and Ahmed[13] have recently developed guidance towards the translation of genetic health information.

[iii] These are examples of early attempts at providing literature to help families from ethnic minorities, but are no longer in use.

The following components were assessed by this review process:

1. **The translation protocol;**
2. **The quality and accuracy of the translations; and**
3. **The translated material's effectiveness in conveying relevant information to the target audiences.**

Semi-structured interviews were held with relevant organisational staff members to help identify the translation protocol. All members of staff were extremely helpful and cooperative.

The back-translation method was used to assess the quality of the translated materials. This process helped to identify areas of mistranslation and examine the level of conceptual and functional equivalence between the translated and original text. Functional aspects were defined as factors such as comprehensibility, and tone[17].

Three different related language versions of each test material example were analysed by back-translation into English and cross-examination against the original English versions. This allowed comparisons to be made between different language translations of the same text. Examples were chosen from the following Indic (or Indo-Aryan) group or languages: Bengali, Punjabi, Urdu and Gujarati, as these languages were spoken by well-established minority ethnic communities living in the U.K. and their translations are common. This analysis was thought, therefore, to reveal models of good practice.

The effectiveness of the translated materials was explored through consultation with lay representatives of the respective target communities. Focus groups were held to assess the levels of accessibility and comprehensibility across members of the group, and to consider specific language, and cultural issues. Gujarati or Punjabi translations were prioritised for this analysis, as these were the languages spoken by members of the project team involved in organising and facilitating the focus groups.

Prior to each session, members of the project team met with the community groups, to share copies of the test material, and discuss the aims of the focus group. This allowed members of the group to ask questions and decide whether or not to participate. During each session moderators set out the objectives and used a standardised set of questions to guide the discussions. Staff at community centres often helped with this process.

The focus groups consisted of about 6 – 10 people as suggested by Morgan and Kreuger[18]. Participants were drawn from a number of community organisations including Gurdwaras and Sikh schools, across London and its suburbs.

An overview of the research findings are presented in the following table.

Material type	Production process	Back translation Findings	Focus group Findings
Cardiac Surgery Video	1. Focus groups were held with health professionals and members of the lay community during initial stages of production to inform the content and style of the video/transcript 2. English transcripts were translated through collaboration between bilingual health professionals and professional translators. (No agency was used) 3. Translated text was proof read and cross checked by bilingual health professionals 4. Text pre-tested on members of the lay community to check for accessibility 5. Text was revised and transcribed into video	The Punjabi and Urdu video transcripts resembled the original English transcript, and appeared to contain no mistranslations. The Bengali text was found to have one minor mistranslation. The language in the Urdu transcript did not always flow as well as it did in the other versions.	Video was informative, and pitched at an appropriate level and length. Knowledge had increased about the seriousness of the disorder, that diet and exercise could help to prevent it, and that different forms of treatment were available. Medical terms were well explained. The use of visuals such as images of the heart and fat clogging up arteries, greatly enhanced accessibility and deepened impact. English voices could still be heard in the background of the Punjabi dubbing. Video or audio formats considered more efficacious, particularly for those with low literacy levels.
A Booklet guide for the South Asian Community about Diabetes	1. Text for guidebook was written in simple English so that it could be translated straight into the respective languages 2. English text provided explanations for words that had no literal translation eg hypo-glycaemia 3. Text sent to agency (world accent) for translation 4. Documents back-translated to assess quality 5. Focus groups were held with bilingual	All three language versions resembled the original, and the language flowed well. A small number of mistranslations were observed within the Bengali and the Urdu back-translations.	Although knowledge about diabetes had improved, the language was considered too high with certain parts difficult to understand. Transliteration was not always enough - medical terms such as *Hypoglycaemia* and the *HbAlc blood* needed greater explanation. Images and text were culturally appropriate. Written formats were not seen to be as effective as video.

	health professional, community facilitators and patients and family members who had prior knowledge about diabetes		
Rett Syndrome Leaflet	1. Leaflet translated by professional agency (Express translations) 2. (Independent validation not included) 3. Agency carried out in house proof-reading of final text by non-native speaker –checking typographical errors, dates etc	Although the language flowed well and some of the information had been communicated, all 3 language versions contained a number of significant, mistranslations that were mainly medical in origin.	The leaflet was engaging and an appropriate length. However the language did not flow well, was difficult to understand, and was often too technical. Medical terms such as genes and chromosomes were not explained. Content of English leaflet was also difficult to comprehend. Suggestions were made towards: • using English words (in brackets) when describing technical terms • dual language leaflets. • Including links to further information and contact details of bilingual health professional, outreach workers etc. In general, the group felt that leaflets were of value because they could be read in a relatively short period of time, and returned to at any moment. However, the video was thought to have greater efficacy for families and individuals with only a spoken command of the language.
A leaflet about Rare Chromosome Disorders	1. Leaflet translated by professional agency (EITI translations) 2. (Independent validation not included) 3. Agency carried out in house proof-reading of final text by non-native speaker –checking typographical errors, dates etc	Language flowed in Bengali and Gujarati translations; however they each contained a significant number of mistranslations that were mainly medical/technical in origin.	The literature was: • written to a very high level of Gujarati, • generally incomprehensible and inaccessible; and • assumed prior scientific knowledge. The complicated word usage was considered both challenging and intimidating to all participants. Material written in English such as dates e.g. '1984' could be identified Written literature was not the preferred form of communicating health information by this group. Video was thought to be more accessible and effective.

Chemotherapy Fact Sheet	6-7 month process 1. English translated by Newcom (professional agency) 2. Held community focus groups 3. Bengali and Urdu leaflets were proof-read by bilingual health professionals	In general, all three language versions had been translated to a relatively high standard and the language flowed well. However a few notable mis-translations were observed in the Urdu fact sheet and the Bengali version contained some omissions. No mistakes were apparent in the Gujarati translation.	Group 1 (With very limited prior knowledge) Literature was considered too complex for the lay reader. One individual felt compelled to completely rewrite the information. Suggestions were made towards: • the use of metaphors and pictures/diagrams to help explain difficult genetic/medical concepts; • a glossary defining key terms; and • providing contact details of bilingual health professionals. Group 2 The second focus group was held at 'Coping with Cancer' a charity based in Leicestershire and Rutland. It provides emotional and practical support to cancer patients from the South Asian communities. All participants of this group had direct experience of cancer and its management. The language in the fact sheet had been written to a moderately high standard and could be read with relative ease. One participant however stated that he still stumbled over some words and had to look them up in a dictionary. The fact sheet was considered culturally sensitive in it's handling of topics such as fasting. The font size was considered too small, especially against the much larger English text. The group suggested that different language versions should maintain a consistent font size. In addition, the group felt that the fact sheet looked a little 'bland' and could be improved through the use of colour. The advantage of written material was highlighted, namely in the way that they could be easily referred to time after time. Greater efficacy of audio material was noted for individuals with low literacy. Video was however, considered to be the most engaging and accessible method of communication for whole families or groups, and was thought to provide a

			method for stimulating discussion.
Parkinson's Disease	4. Text translated by professional Agency 5. Agency developed an electronic glossary of medical terms 6. Agency carried out In house cross-checking against the English version by an independent translator 7. Agency carried out in house proof-reading of final text by non-native speaker –checking typographical errors, dates etc	In general, all three versions had been translated to a very high standard and the language flowed well. Only two mistranslations were observed in the Gujarati text, whilst the Bengali and Urdu texts were seemingly error free.	The language was thought to be pitched at the right level and genetic and medical terms were well explained. All the participants felt that they had understood the content of the literature and had grasped the basics concepts of this disease. In addition, key topics such as 'Symptoms of Parkinson's' and the section on 'Hallucinations' were considered to be informative, interesting, and thought provoking. Whilst it was thought that the document could be improved visually, the group felt that much effort had gone into including images of people from different cultures and backgrounds.

Examples of mistranslations identified in the translated texts

English text: ‘If you are being treated with tablets, you must **always** take them’
Urdu text: **‘**If you are being treated with them then it will be essential for you to take them **regularly’**

English text: **‘**Type 1 diabetes occurs when the body is unable to produce any insulin**’**
Bengali text: **‘**Insulin dependent Diabetes develops when **the level of glucose falls drastically in the body**’

English text: ‘Usually, people take two injections a day, one before breakfast and the other **before** the evening meal’
Bengali text: ‘Normally you need two insulin injections per day. One before breakfast and the other **after** dinner’

English text: ‘Recently it has been detected that a large proportion of people with Rett Syndrome have **a mutation, or fault, on the MECP2 gene on the X chromosome**’
Bengali text: ‘Some mutation or defect has recently been found **in the X chromosome of the MECP2 gene** of the persons suffering from Rett Syndrome’

English text: After appearing to make normal progress a period of stagnation in development from about the end of the first year, which lasts until regression occurs. A regression period when skills in speech and hand movement are reduced,…..”
Bengali text: The child will appear to have normal development in the beginning. Then, at the end of the first year, the development will slow down and will remain static until it **takes a reverse direction. The child will move backwards in terms of development** and will experience speech impairment and lack of movement…”

English text: ‘ Epilepsy’
Bengali text: ‘ hysteria’

English text: ‘ With age, muscles become increasingly rigid**, joint deformities** and muscle wasting may occur’
Bengali text: ‘ the muscles have increased stiffness, with age, **the glands, become deformed** and muscles eroded’.

English text: Development of scoliosis **(curvature of the spine)**
Bengali text: Development of scoliosis **(no explanation)**

English text: ‘growth retardation’
Bengali text: ‘Lack of physical growth’

English text: **‘**Neurological disorder’
Punjabi text: ‘Genetic disease’

English text: ‘Appearance of stiff and clumsy posture’
Punjabi text: ‘The child appears stiff and behaves strangely and sometimes antisocially’

English text: “ to enable earlier diagnosis”
Urdu text: “ of instant diagnosis”

English text: ‘Rett Syndrome is genetic in origin. It is probably the most common genetic cause of profound intellectual and physical disability in girls’
Urdu text: ‘Rett Syndrome, in fact, is present in the obstetrical matter. This is probably the biggest congenital cause of their physical and mental handicaps’

English text: ‘With age, muscles become increasingly rigid, joint deformities and muscle wasting may occurs’
Urdu text: ‘With age, stiffness in the muscles and ugliness in the joints start. Wastage of muscles may also begin’

English text: “The vast majority of carriers of chromosomal rearrangements will have no symptoms but might have problems with reproduction.
Bengali text: “The improper arrangement of chromosomes usually does not cause any problematic symptoms in one’s normal life. But it may create some problems during **childbirth**.

English text: “This means that it can be difficult to **identify** two people who have the exactly the same chromosomal disorder”
Gujarati text: This means that it can be difficult to **diagnose** two people who have the exactly the same chromosomal disorder”

English Text: ‘Rare **Chromosome** Disorder’
Urdu Text: ‘Rare **Pigmentation** Disease’

English text: ‘**challenging** behaviour’
Urdu text: ‘**aggressive** behaviour’

Conclusions of the review process

Analysis of existing translated materials revealed significant variation in translation protocol design, and in the quality and effectiveness of translations.

Whilst the use of professional translators was common to all translations protocols, there was strong variability in the way translated materials had been validated and evaluated, and the extent to which target communities were consulted during the translation process. The making of the Cardiac Surgery video for example, incorporated numerous quality control steps, including community consultation (both prior to and after translation), and validation by bilingual health–professionals. Such steps were, by contrast, clearly absent during the making of the two leaflet translations (Rett Syndrome and Chromosome Disorders Leaflet).

Assessment of the quality and accuracy of translated materials by the back–translation method revealed dramatic variations. Whilst examples of good practice could be identified, others were found to carry significant mistranslations. These were mainly in text that had not undergone any form of back-assessment. In general, material validated either by cross-examination of the translation against the original English version, or by back-translation, contained far fewer mistranslations.

Evaluation of the effectiveness of translated materials by consultation with target communities revealed variability, in levels of accessibility, comprehensibility and cultural appropriateness. Materials prepared in close collaboration with target communities were generally more accessible, comprehensible and culturally sensitive, highlighting the importance of consulting with lay members during the translation process.

Recommendations towards best practice

This assessment has led to the development of key recommendations towards the production of multilingual patient (genetic) information (see chapter 1). The resulting model comprises of 6 distinct stages (including piloting and dissemination):

1. Development of leaflet content;
2. Translation of leaflets;
3. Validation by a second translator;
4. Community Assessment;
5. Piloting and user evaluation; and
6. Dissemination.

The evidence generated by the review process suggests that quality, effectiveness and cultural competence of translated materials depend on appropriate back-assessment and community involvement during the translation process. In the proposed model back-assessment is carried out in two steps (stage 3 and 4 of protocol) by two groups; a second translator, and lay community representatives, respectively. Here translated documents are checked against their original English versions. Alternative approaches might include back-translation as suggested by Shaw and Ahmed[13]. In the proposed model lay representatives are also consulted at the beginning of the translation process, when material content is being developed (stage 1).

Notes on focus groups

The focus groups provided a very powerful tool for obtaining multiple viewpoints and experiences on a particular topic at the same time. They helped to gain insight into shared understanding and as previously observed,[19] offered particular benefit when exploring the everyday use of language and cultural differences. Many of the known benefits to potential participants of focus groups, such as being involved in decision making[20], being valued as experts, and feeling a sense of empowerment[21], were observed in this study. However limitations might have arisen when trying to obtain individual views. The practical organisation of focus groups could also be problematic, highlighting the need for a very effective moderator (see below) and a clear agenda.

Some important points to note about focus groups

- Focus groups should consist of about 6 – 10 people[21.] It is not always easy to choose the most appropriate individuals, and whilst heterogeneity might be sought, the differences between participants might significantly inhibit contributions of particular members[22].
- Moderators should provide a clear explanation of the objectives of the focus group, make people feel at ease, facilitate interaction and guide discussions.
- For language-specific focus groups, the moderator needs to be fluent, or have an interpreter present; however the latter may lead to fragmentation and disjointed discussions.
- Our experience has shown that it is often helpful to meet or interact with participants beforehand to help build trust and familiarity, especially when working with socially excluded groups, such as minority ethnic communities.
- Cultural sensitivity should be considered when conducting focus groups.

Chapter 5 - Implementing best practice recommendations in the London IDEAS Translation Project

The best practice recommendations towards the development of multilingual patient (genetic) information are now being implemented across the first set of languages within the London IDEAS Translation Project. These include Gujarati, Urdu, Punjabi, Sylheti, Somali, Arabic and Turkish.

As discussed this model comprises of 6 stages (including piloting and dissemination):

1. Development of leaflet content;
2. Translation of leaflets;
3. Validation by a second translator;
4. Community Assessment;
5. Piloting and user evaluation; and
6. Dissemination.

Community consultation is a component of stage 1and 4 where it is designed to assess the English text prior to its translation (stage 1), and translated text against the corresponding English template (stage 4) (for more details about this protocol see chapter 1). This is to inform content and style of translated materials, and ensure quality, effectiveness and cultural appropriateness.

To date, stages 1- 4 of the protocol have been applied towards the development of Gujarati, Urdu and Punjabi materials, and appropriate amendments are currently being incorporated within the translated texts. These language leaflets will available for piloting in clinic, later this year. Development of leaflet content (stage 1) is also complete for Arabic, Turkish, Somali, Sylheti and Farsi language versions, and these are currently being translated.
Up to six bilingual representatives of each language have been consulted during this process, and language specific focus groups were held to discuss their feedback. This chapter highlights some the issues presented by this community consultation approach, and provides examples of comments and feedback. For more examples see appendix 2.

Issues highlighted during the development of leaflet content (Stage -1)

A number of general principles were highlighted during this stage of community consultations. These are listed below:

1. Write clearly and explain everything.
2. Avoid the use of medical/technical terms, however where necessary transliterate and provide an appropriate explanation of their meaning. Only translate difficult medical/technical terms if the translated word is in common usage.
3. Avoid the use of words that may have a derogatory or ambiguous meaning.
4. Include user–friendly diagrams to which different groups can relate.
5. Include leaflet specific glossaries.
6. Personalize the information if possible.
7. Provide dual language versions.
8. Provide short and longer versions of leaflets.

The first five recommended principles have been applied universally across all language translations by colleagues at North West Thames Regional Genetics Service. Where appropriate, amendments relating to specific language/cultural issues have also been applied universally, in an effort to keep all material uniform and inclusive.

Examples of comments relating directly to transliteration, inappropriate word usage, and cultural or community specific issues are highlighted.

Transliteration

'Transliterate words like "Saline" as it is widely used in the community already. However, it's important to explain that saline, for example, is just salt water and does not contain alcohol, otherwise people won't use it. Must explain everything'

Inappropriate word usage

'Discard words such as "fault" or "mistakes" as it sounds derogatory and negative. Instead use "mutation" in the bracket and remove "fault". Transliterate "mutation" and explain in a positive way what mutation means, use the word "change" when explaining'

Cultural or community specific issues

Somali

' As I mentioned before the wording and sentences of the text is alright and very simplified but I believe the information containing in this leaflet is not very straight forward to understand for some lay individuals because it needs certain level of competency to comprehend. This is purely due to its scientific nature. Translating this into Somali language may also add bit more problems. This is because the Somali language was written in 1972 and was only orally spoken before this date. So the Somali genetical terms equivalent to the ones containing in this leaflet are not widely known by the Somali population. The reasons are 1. Large proportion of the Somali people are illiterate 2. The use of Somali language was confined only in the school level and beyond this other languages such as English or Italian was used in higher education institutes, therefore, terminologically it may not be very well developed. 3. Only those who has taken their school education between 1973 - 1991 (between the times Somali language was introduced in education system and the time war erupted in the country) will be familiar with the Somali scientific terms. Finally the bulk of the weight is rested on shoulders of the person who will translate this from English to Somali as his/her background and accuracy will be very vital'

Urdu

'Make it clear, very sensitively so as to not sound like you are attacking individuals, cultures, religious beliefs, etc…, that inter-family marriage increases risk of recessive genetic diseases, but not dominant genetic diseases., But don't exaggerate the risk.. Explain that it depends on the specific disease/ individual/ relationship between 2 specific people'

Sylheti

'Word "cousin" can be ambiguous due to the size of family and extended family in many communities'
'Make sure translation uses "own" brother/sister rather than just "brother/sister" as just "brother/sister" is ambiguous, could mean cousin

Somali

'In pre-implantation diagnosis: pregnancy termination is unthinkable for many people of different cultures and may be religions. For Somalis in Somalia and of course many in here it is not an option. The leaflet should clearly state that if you are carrying a foetus with genetic disorder, termination is not compulsory nor the only option.'

When describing the different characteristics that genes are responsible in our body you have mentioned eye colour, blood type, and height. Theses are perfect examples but I am thinking that almost all the Somali people have brown eyes and some are not familiar with the existence of other eye colours. Therefore even though I don't see any problems using this example then I thought another example such as skin colour might have been more obvious

Issues highlighted during community back – assessment of leaflet translations (Stage 4)

Whilst the consultation process found that the quality of the leaflet translations was generally good, a significant number of mistranslations were still identified across the translated texts. In an Urdu language leaflet for example, the word ‘referral’ had been translated in to bribery/nepotism. Typographical errors and literal translations were also frequently identified. The word ‘chromosome’ for example was literally translated in to ‘pigmented body’. This however was not a surprise considering that the Greek derivation of ‘chromosome’ is ‘coloured body’.

The community assessments also noted that the language level was consistently high across all language translations, and many unfamiliar words could be frequently identified. In the most part these words were, thought to represent correct translations, although were not part of the everyday language. Groups highlighted that there were often marked differences between the written and spoken forms of a language, and recommended adhering towards the spoken form as much as possible. Urdu language leaflet versions were also found to contain many Arabic words and phrases and were shown to be written in an Arabic style font. Most groups recommended the use of fonts found in the vernacular press. Dialect variability was also discussed, and it was again recommended that the vernacular press should guide any decision making on this issue. The question of what to do about technical terms was also discussed in detail during the Urdu consultation. Examples of comments relating to each language are presented below. For more examples see appendix 2.

Urdu

‘FONT – the font was in an Arabic style. It was difficult to read as it is much more angular than standard Urdu scripts. A suitable font would be **N A Staliquis** and the size 14 points. 16 points will be too big and out of proportion. Current Urdu font used is by no means suitable’

‘The language is too academic and considerably persianized or arabianized. This can be overcome by using alternative easy words and phrases’

‘There were some very unfamiliar words used in the translation’

‘Only experts in Urdu would be able to understand some of the words used here. We should be catering for the lay person’

‘The translations are very good, but the quality of Urdu is too high. I have not heard of many of these strange words. Bombastic words. Common words can replace many of the words that have been used’

‘I found it precise, clear and readable’

‘Though overall the translation is ok, at occasions it is literal. A careful revision can make it smoother and fluent’

‘Typographical errors exist. A careful proofreading is required’

‘The word for doctor (GP) is not very good – the English word ‘Doctor’ would be better’

‘The word for referral has been translated into the wrong meaning. It implies bribery and nepotism’

‘The Urdu written language can be quite different from the spoken language – it is a priority to attempt to keep as close to the layman’s spoken language’

‘Getting the concepts of 'recessive' and 'autosomal' correctly conveyed in Urdu is obviously the central purpose of this leaflet. Again I think it is best to avoid attempts at literal translation altogether, and instead write the English words (in transliteration and in English) and explain them in everyday language. I did not understand even the very first heading of this leaflet. If it is to say 'information about automsomal recessive disorders' then it might be better to say 'autosomal recessive disorders ke bare men malumat', keeping the technical words in English (in transliteration and in Roman script) rather than to finding new, and equally unfamiliar, words with which to translate the terms’

‘Similarly, 'autosomal' (in the first line, and throughout) is translated as xwdluni ("khudlooni"). "khud" means 'self' and is an accurate literal translation of 'auto'; looni is from "luniya/liniye" from "chromosome/es" * but neither Nighat nor I had heard of this word for chromosome (as I said in my earlier feedback on the other leaflets). Mushtaq told me it is the proper Urdu word, but that very few people will know it. So, again, I think it is best to keep 'autosomal' in English (and transliteration). An explanation is given later on in the leaflet’

'Carrier' is translated by the Urdu word "hamyl". This is the correct word for 'porter' or 'bearer'. I think that it might be better to use the English word, since the meaning here is technical (maybe giving 'hamyl' as a translation in brackets the first time 'carrier' is explained)’

Gujarati

‘For genetic clinic – transliterate, i.e. use clinic. Also use doctor where applicable’

‘Good examples of clear fonts are Gujarati Samachar (Contact Joshna Patel) and Garvi Gujarat (contact Solanki) (and dialect?)’

‘The word for gene and genetic are not always consistently translated’

‘The word for ‘faulty’ is maybe too high brow needs a simpler word. Mutation again too high brow. It’s correct but people may not understand’

'Overall nicely done. However there are so many different dialects in Gujarati and it seems that the translator has done it in his own dialect. It might be a good idea to check the language of Gujarati papers in the U.K. e.g. Gujarat Samachar as this is simple and anyone form any part of Gujarat can read and understand it’

Punjabi

‘Strange words have been used to translate e.g. “babies”, “toddlers” etc. There is no right word in Punjabi; Punjabi people living in the UK use English words. The word which has been used for “adolescence” does exist, but non of the consultands had heard of this word. This would be made much clearer if age ranges were given for the children’

‘words like chromosome, syndrome etc. should be rewritten in English using Punjabi characters (i.e. transliterated)’

‘If words are in common use, put them in, otherwise use English equivalents as above’

‘There is no Punjabi word for “copy”; use “copy” as well’

‘Don’t keep repeating the difficult Punjabi words’

‘Diagram on X-linked disorders leaflet - use outlines of people instead of blobs. The Xs and Ys can be underneath’

‘Wirsah” the Punjabi word for inheritance needs to be in the leaflets’

‘In the glossary, too, medical words need not be repeated again and again in Punjabi, write them in English’

‘The words should be easy to understand. The word “Anwanshin” used for “genetics” is a very difficult word. It looks as though it is from the Sanskrit. This word is difficult to read [even though] it might be the right word’

Chapter 6 - General discussion

Communication is a fundamental part of genetic service delivery. As the 1975 American Society of Human Genetics definition describes, genetic counseling is '*a communication process which deals with human problems associated with occurrence or the risk of occurrence, of a genetic disorder in a family'*[1]. The development and provision of appropriate communication services are thus essential to ensure that all individuals and families are supported in their particular genetic health care needs.

These preliminary findings indicate, however, that the provision of language support services across genetic departments is limited. Few language resources are currently available and access to interpreters and multi-lingual staff is likely to be variable. The availability of specialist training for interpreters involved in genetic counselling is also limited.

Although the wider legislative and national policy framework for provision of equitable and accessible NHS treatment and care is in place, there is as yet no policy towards the provision of communication support services. The recent introduction of DH guidance[10] (2004) on this important issue is welcomed progress, however equal access to services is unlikely to emerge until this guidance is translated into policy and practice.

Policy towards provision of language support services should also include competency in translation and interpreter services. As our analysis reveal, there is currently significant variation in quality and effectiveness translated resources. A best practice model has been developed which incorporates steps of community assessment.

This model has been implemented in the development of multilingual genetic patient information leaflets as part of the London IDEAS Translation Project. Languages include Arabic, Gujarati, Punjabi, Sylheti, Turkish, Urdu, Farsi, and Somali. A number of issues were identified during the community assessment process, thereby helping to ensure the quality and effectiveness of the resulting translations, and validating the need for consultation with target groups in future translation projects.

This project will create a resource on a broad range issues. Whilst this will serve as an important reservoir of patient information, it should not be seen as an end in itself but as a growing entity, through the addition of more topics and languages.

The need for wider information was frequently noted during community consultations. In general, groups felt that they were not adequately informed about health issues, and there were major problems in accessing further information.

Appendix 1

Notes on best practice recommendations

- **Developing competency in language support service services**
  The proposed best practice model towards the development of multilingual genetic/medical resources relies upon translation from existing material (with consultation with target groups to inform content style). Alternatives approaches include writing material in new language from scratch as proposed during the stakeholders' consultation to assess language needs. To ensure quality and accuracy of translations the model proposes validation by a second translator followed by community assessment. Again alternative approaches may include back – translation as suggested by Shaw and Ahmed[13]. The model also proposes as a general guideline, to transliterate (transcribe a word into the corresponding letters of another alphabet) of medical/genetic/technical terms unless translations are in common usage. This may vary from language to language, and it is best to seek advice from community representatives on this issue.
  With regard to interpreters the recent investigation of user views in relation to access to services with interpreters recommends that the notion of good practice should include the crucial issue of developing a personal relationship of trust with the user[14]. This study also emphasises that training should include the political context that the interpreter is working in and within-community distinctions. Interpreters may also benefit from receiving genetic information leaflet translations. The Equality and Human Rights Group of the Department of Health in its guidance on developing local communication support services and strategies recommends the following with respect to interpreters[10]:

  - *The function of interpreters in healthcare settings is clear to both professionals and service users to gain optimum benefit from their interventions*
  - *Staff awareness and training on using interpreters is developed*
  - *A clear position on the interface between healthcare and advocacy roles is established to avoid misunderstanding and potential conflicts of interest.*

- **Commissioning**

The Department of Health highlights a number of collaborative approaches to commissioning that could be considered to develop a more comprehensive, efficient, economic and financially secure language support service. It notes that examples of joint working are found to be highly effective in achieving economies of scale and in assuring consistent and high standard in both rural areas – where there is low overall demand for language support services – and in inner city areas[10].

Appendix 2

Summary of community consultation comments received during the piloting of the best practice recommendations in the London IDEAS Translation Project. Comments are arranged by language.

Issues highlighted during the development of leaflet content, (documents originally prepared by North West Thames Regional Genetics Service for English-speaking users) (Stage -1)

Gujarati

‘Put more emphasis on key words, such as “genes”, and provide a basic explanation of what these words mean’

‘Change difficult adjectives such as terms like “familial .for more understandable ones’

‘The meaning of “Autosomal Dominant Inheritance” is not very clear’

‘Should include web-site details on leaflet and make sure they have all the relevant information about, support groups, associations etc.....’

‘Also should differentiate between freephone numbers and pay numbers’

‘Should provide two versions of each leaflet, one that summarise the issues, and another that provides more detailed information’

‘Most important factor is to make this as understandable as possible’

‘Be aware that people have varying levels in their understanding of English’

‘Not enough explanation about how the disorder affects a person. Must make clear on all leaflets that almost all genetic disorders are incurable, but that treatments are available to improve quality of life’

Urdu

‘Leaflets should include diseases that apply specifically to certain communities, i.e., CHD and Diabetes in Asian communities’

‘The language used is key to the success of the leaflets, and particular attention should be paid to not using too technical terms, allowing all sectors of the community to understand’

‘Leaflets must come from an instantly recognised or meaningful source to avoid it getting thrown out with all the other leaflets that get delivered through peoples letterboxes’

‘Diagram needs to be more user-friendly and understandable. Use names rather than A, B, C – i.e. Personalize leaflet, make it apply to individuals by giving names to figures or objects’

‘Make it clear, very sensitively so as to not sound like you are attacking individuals, cultures, religious beliefs, etc…, that inter-family marriage increases risk of recessive genetic diseases, but not dominant genetic diseases., But don’t exaggerate the risk.. Explain that it depends on the specific disease/ individual/ relationship between 2 specific people’

‘Must be very careful, as one misunderstanding can lead to the whole thing being misinterpreted, ie, communities feeling as though you are attacking their particular culture’

‘Be aware that you are catering for only a small number of people within the communities and it is generally only the older people that cannot speak English’
‘Words such as “Pre-Symptomatic” should be made more understandable, although you cannot simplify too much as this is a complex issue’

‘Contact details again should be included, accommodating all languages, also explaining in all these languages where to go if they require more information about anything’

‘Very important that these leaflets are a starting point not an end point’

‘Try and produce short films to explain diseases such as this one’

‘Unavoidable that some religious people will be offended by the subject matter, regardless of the language used or precautions taken’

‘People in smaller minority communities are very sensitive, feeling that they must protect against everything as they are always under attack’

Sylheti

‘Important to make the leaflets as personal as possible’

‘Have leaflets with 2 versions of the specific topic. On one side have information in English, and on the other side have the exact same information in target language’

‘Crucial that the language is as clear as possible, in both English and target language. At the moment it is very confusing’

‘Language is the most important part of the leaflets. Explain everything in explicit detail and don’t restrict the translation by using too simple language’

‘Some words will be difficult to translate, such as “gene” as in sylheti it has a completely different meaning’

‘Dept. of Health is very bad at translating documents, no consideration for different communities needs. Look at these for examples of what not to do’

‘Must be concise, long leaflets won’t be read. Short sharp and to the point’

‘Transliterate words like “Saline” as it is widely used in the community already’

‘Important to explain that saline, for example, is just saltwater and does not contain alcohol, otherwise people won’t use it.. Must explain everything’

‘Diagrams will be a very important way to get people to understand the subject matter. – Be aware though that some pictorial diagrams may be offensive to some religious sectors of the community’

‘Maybe explain a scenario with language as well as diagrams, i.e., tell some sort of a personal story’

‘Discard words such as “fault” or “mistakes” as it sounds derogatory and negative. Instead use “mutation” in the bracket and remove “fault”. Transliterate “mutation” and explain in a positive way what mutation means, use the word “change” when explaining’

‘Emphasise that mutations are not anyone’s fault, they are a natural issue’

‘Words such as “positive” when translated literally changes the implied meaning’

‘Word “cousin” can be ambiguous due to the size of family and extended family in many communities’

‘Make sure translation uses “own” brother/sister rather than just “brother/sister” as just “brother/sister” is ambiguous, could mean cousin’

‘Don’t be patronising. Don’t tell people what they should or shouldn’t do in regard to whether their families should accompany them to the genetic testing’

'Must be sensitive to the fact that some people may be reluctant to have any sort of pregnancy testing for religious reasons'

'Useful to put brief concise explanations next to certain words, actually within the text itself, i.e., in brackets next to word'.

'Make each glossary relevant to each document. Don't put all words in one big glossary'

'Glossary is good in a clinical situation. Obviously not going to work as a complete and concise guide to genetics'

'Good for translators to use glossary – will help them in the translation in general'

'Glossary is very useful for translator in getting the tone of leaflets right'

Somali

'Regarding the leaflets, they seem to me absolutely fine. The readability is perfect in this English version. Ahmed and I looked at it and the only thing I can suggest is that in the first page were the eye colour is used as an example to be replaced with another example, as eye colour is not something Somalis use for describing people'

'In pre-implantation diagnosis: pregnancy termination is unthinkable for many people of different cultures and may be religions. For Somalis in Somalia and of course many in here it is not an option. The leaflet should clearly state that if you are carrying a foetus with genetic disorder, termination is not compulsory nor the only option'

'In general the information containing in these leaflets is very clear and provides the core information of the conditions. I am sure it will be very helpful to those affected and their families'

'Readability: I could not suggest any other way that you could have simplified the sentences and words chosen for the text apart from its scientific nature and the medical terms which you have also tried to simplify'

'Comprehensibilty: As I mentioned before the wording and sentences of the text is alright and very simplified but I believe the information containing in this leaflet is not very straith forward to understand for some lay individuals because it needs certain level of competency to comprehend. This is purely due to its scientific nature. Translating this into Somali language may also add bit more problems. This is because the Somali language was written in 1972 and was only orally spoken before this date. So the Somali genetical terms equivalent to the ones containing in this leaflet are not widely known by the Somali population. The reasons are 1. Large proportion of the Somali people are illiterate 2. The use of Somali language was confined only in the school level and beyond this other languages such as English or Italian was used in higher education institutes, therefore, terminologically it may not be very well developed. 3. Only those who has taken their school education between 1973 - 1991 (between the times Somali language was introduced in education system and the time war erupted in the country) will be familiar with the somali scientific terms. Finally the bulk of the weight is rested on shoulders of the person who will translate this from English to Somali as his/her background and accuracy will be very vital'

Culturally sensitivity: when describing the different characteristics that genes are responsible in our body you have mentioned eye colour, blood type, and height. Theses are perfect examples but I am thinking that almost all the Somali people have brown eyes and some are not familiar with the existence of other eye colours. Therefore even though I don't see any problems using this example then I thought another example such as skin colour might have been more obvious.

Issues highlighted during community back – assessment of leaflet translations (Stage 4)
Urdu

‘FONT – the font was in an Arabic style. It was difficult to read as it is much more angular than standard Urdu scripts’

‘A suitable font would be **N A Staliquis**. and the size 14 points. 16 points will be too big and out of proportion. Current Urdu font used is by no means suitable’

‘The language is too academic and considerably persianized or arabianized. This can be overcome by using alternative easy words and phrases’

‘There were some very unfamiliar words used in the translation’

‘Only experts in Urdu would be able to understand some of the words used here. We should be catering for the lay person’

‘The translations are very good, but the quality of Urdu is too high. I have not heard of many of these strange words. Bombastic words. Common words can replace many of the words that have been used’

‘I found it precise, clear and readable’

‘Though overall the translation is ok, at occasions it is literal. A careful revision can make it smoother and fluent’

‘Typographical errors exist. A careful proofreading is required’

‘The word for doctor (GP) is not very good – the English word ‘Doctor’ would be better’

‘The word for referral has been translated into the wrong meaning. It implies bribery and nepotism’

‘The Urdu written language can be quite different from the spoken language – it is a priority to attempt to keep as close to the layman’s spoken language’

‘The main question is, as always, what to do about the technical English terms, such as 'recessive' and 'mutation', which have no direct Urdu equivalents. In this version, the translator has chosen to find the closest literal Urdu translations * thus giving an 'old' Urdu word a 'new' meaning in this context. The choice of word or phrase is generally very good. For instance, the translator has found a very nice literary word for 'mutation', 'taqallab', which means 'transformation' (a word that is not commonly used in everyday speech)’

‘I admire the careful thought that must have gone into the interpreter's decisions about how to translate these technical words. However, I do not think that a literary approach is quite right for a leaflet that is intended to have an educational function, especially for people who may not themselves be very highly literate in Urdu. The result is that the Urdu text is in some places very difficult to understand. I tried reading the Urdu text myself without reference to the English, but I got stuck as soon as I encountered difficult words. When I checked against the English version to find out what they might mean, I realised they were the literal translations of technical terms. In case my own stumblings over difficult words reflected the fact that Urdu is a 2nd language for me (I do not have a literary vocabulary), I also went through the text closely with Nighat, and she had the same experience: it was difficult to make sense of this leaflet without referring to the English text’

‘I think it would be better, instead, to write words like 'mutation' in Urdu transliteration (the spelling of mutation would be something like: meem-vaw - te - sheeen - noon) and immediately afterwards write this obviously unfamiliar word in English as well. I think it is probably not even necessary to put brackets round the English, for it is quite common to write English words within Urdu text (even in novels).’

‘Getting the concepts of 'recessive' and 'autosomal' correctly conveyed in Urdu is obviously the central purpose of this leaflet. Again I think it is best to avoid attempts at literal translation altogether, and instead write the English words (in transliteration and in English) and explain them in everyday language. I did not understand even the very first heading of this leaflet. If it is to say 'information about automsomal recessive disorders' then it might be better to say 'autosomal recessive disorders ke bare men malumat', keeping the technical words in English (in transliteration and in Roman script) rather than to finding new, and equally unfamiliar, words with which to translate the terms’.

‘Similarly, 'autosomal' (in the first line, and throughout) is translated as xwdluni ("khudlooni"). "khud" means 'self' and is an accurate literal translation of 'auto'; looni is from "luniya/liniye" from "chromosome/es" * but neither Nighat nor I had heard of this word for chromosome (as I said in my earlier feedback on the other leaflets). Mushtaq told me it is the proper Urdu word, but that very few people will know it. So, again, I think it is best to keep 'autosomal' in English (and transliteration). An explanation is given later on in the leaflet’

'Carrier' is translated by the Urdu word "hamyl". This is the correct word for 'porter' or 'bearer'. I think that it might be better to use the English word, since the meaning here is technical (maybe giving 'hamyl' as a translation in brackets the first time 'carrier' is explained)’

‘Page 1, first line after the question, 'cells' is incorrectly translated as 'genes'. And, as I said in my earlier feedback, the proper Urdu word for cell (khuliye), which is used in the next line, is not well known. I think is would be better to use to the English word, in transliteration and in English (maybe giving the proper Urdu word in brackets the first time it is used, for those that know it!)’

‘Robertsonian leaflet : is it necessary to call the leaflet: 'Robertsonian chromsome transloations' - it seemed just to be adding in another unfamiliar word, which unlike chromosome and translocation recieves no explanation in the leaflet. Would 'chromosome translocations' be sufficient as a general heading? (I am aware that there is a technical reasons for including it -but is this relevant to the information for patients, I wonder? Is there another leaflet on another sort of translocation?) I thought perhaps you could instead just have one sentence inside the text saying 'these translocations are sometimes called Robertsonian translocations' to cover the possibility that someone might want to know or say this’

‘Huntingtons disease leaflet: unfamiliar/difficult words are underlined (e.g. words for depression, code etc: best to use the English words for these as they are commonly used. Some suggestions for rephrasing/simplifying are written onto the text. Two points to highlight:

- p.2 ‘treatment’ and ‘cure’ are described by same word in Urdu (ylaj) but have different meanings in English. We think an explanation to convey ‘cure’ should be added (i.e literally ‘there is no treatment by which the disease can be finished’)
- p.6 ‘positive’ is translated by a word meaning ‘correct’. But in this context is supposed to mean an abnormal result. Best to use the English word ‘positive’ (in transliteration) and add an explanation (i.e ‘an abnormal result’)’

Gujarati

‘For genetic clinic – transliterate, i.e. use clinic. Also use doctor where applicable’

‘Good examples of clear fonts are Gujarati Samachar (Contact Joshna Patel) and Garvi Gujarat (contact Solanki) (and dialect?)’

‘The word for gene and genetic are not always consistently translated’
Gene has been translated to genin
Chromosome to rang sutra
Recessive is translated as aprabal
Inheritance as vavso (?)’

‘Carrier not always translated. Vahak appearing sometimes’

‘The word for ‘faulty’ is maybe too high brow needs a simpler word. Mutation again too high brow. It’s correct but people may not understand’

'Overall nicely done. However there are so many different dialects in Gujarati and it seems that the translator has done it in his own dialect. It might be a good idea to check the language of Gujarati papers in the U.K. e.g. Gujarat Samachar as this is simple and anyone form any part of Gujarat can read and understand it’

Punjabi

‘Strange words have been used to translate e.g. “babies”, “toddlers” etc. There is no right word in Punjabi; Punjabi people living in the UK use English words. The word which has been used for “adolescence” does exist, but non of the consultands had heard of this word. This would be made much clearer if age ranges were given for the children’

‘Initial overview: words like chromosome, syndrome etc. should be rewritten in English using Punjabi characters (i.e. transliterated)

‘If words are in common use, put them in, otherwise use English equivalents as above’

There is no Punjabi word for “copy”; use “copy” as well

Initial overview: words like chromosome, syndrome etc. should be rewritten in English using Punjabi characters [ie transliterated].

Don’t keep repeating the difficult Punjabi words.

Diagram on X-linked disorders leaflet - use outlines of people instead of blobs. The Xs and Ys can be underneath.

“Wirsah” the Punjabi word for inheritance needs to be in the leaflets

In the glossary, too, medical words need not be repeated again and again in Punjabi, write them in English.

The words should be easy to understand. The word “Anwanshin” used for “genetics” is a very difficult word. It looks as though it is from the Sanskrit. This word is difficult to read [even though] it might be the right word.

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