

RG - Section 1: Your organisation and how to contact you

Organisation Details - page 1 of 6

What is the legal name of your organisation as it appears on your governing document?

What is your organisation's registered address?

* Address Line 1

Address Line 2

Address Line 3

* Town or City

County

* Postcode (Please enter your postcode without leaving any spaces e.g. OX110QJ)

Email address

* Phone number (Please enter your phone number without leaving any spaces. e.g. 08701901234)

Mobile number (Please enter your phone number without leaving any spaces. e.g. 08701901234)

Alternative phone number (Please enter your phone number without leaving any spaces. e.g. 08701901234)

Website address

* What is the legal status of your organisation? (1. Company limited by guarantee: Must be a bona fide Third Sector organisation eg social enterprise without charitable status only
2. Philanthropic or benevolent organisation: Eg; registered charity in England or Wales, registered charity recognised by the inland Revenue in Scotland or N. Ireland, exempt or excepted charity in England or Wales, an organisation recognised as a charity or awaiting registration.)

Main Contact Information - page 2 of 6

Who is the main contact for your research project?

* Title	Mr
* First Name	Steve
Other name{s}	
* Surname	Powell
* Position/ Job Title	Chief Executive
Does your main contact have any particular communication needs?	No

We will use the address below for correspondence with your main contact. Please check the details are correct and update if necessary

* Address Line 1	5 Baring Road
Address Line 2	
Address Line 3	
* Town or City	Beaconsfield
County	Bucks
* Postcode (Please type your postcode without leaving a space eg; OX110QJ)	HP92NB
Email address	spowell@signhealth.org.uk
* Phone Number (Please enter the phone number without leaving any spaces e.g. 01987901234)	01494687600
Mobile Number (Please enter the phone number without leaving any spaces e.g. 08701901234)	07971171746
Alternative phone number (Please enter the phone number without leaving any spaces e.g. 08701901234)	
Web site address	www.signhealth.org.uk

Organisation Information - page 3 of 6

Related organisation

Does your organisation have a charity, company or other reference or registration number? If so please write it below

Charity number

HMRC charitable status number

Company number

NHS registration number

Other (please specify)

* Is your organisation unincorporated and not registered as a charity? (please tick)

If you are an unincorporated association and not registered with the Charity Commission or the Office of the Scottish Charity Regulator (OSCR) you must send us a copy of your governing document (for example, constitution, set of rules or trust deed) or, if your organisation is based in Northern Ireland, your governing document or confirmation that you are registered with HM Revenue and Excise (formerly Inland Revenue) as exempt for tax purposes

* When was your organisation's governing document accepted?

How many trustees/ directors/ cheque signatories does your organisation have?

Title	Number
* Trustees	<input type="text" value="8"/>
* Directors	<input type="text" value="1"/>
* Cheque signatories	<input type="text" value="3"/>

Organisation Activities - page 4 of 6

When was your organisation formed, what are the main services and activities it provides and who are its principal beneficiaries? (maximum 50 words)

Main services and activities

SignHealth was founded in 1986, and is a national charity specialising in the field of deaf health. SignHealth provides direct support (supported housing, advocacy, counselling and outreach) and promotes good health and equality of access (campaigning, information materials, interpreting software and communication training for healthcare staff).

Principal beneficiaries

Deaf people – particularly 'culturally Deaf' or 'Deaf'. Medically, this group is defined as pre-lingually profoundly deaf. Culturally Deaf people are sign language users, typically without speech, unable to access information presented in written English. They include BME and Deaf with additional disability.

Your organisation's accounts - page 6 of 6

* All organisations that receive a grant from us must produce audited, approved accounts. Do you meet this requirement?

Yes

If you answered 'Yes' above, you must send us a copy of your most recent accounts, signed and dated by your chair, secretary or treasurer and by your auditor or independent examiner where appropriate.

If your accounts are more than 12 months old, you must also send us your most recent set of management accounts. These must be signed and dated by a person with appropriate authority.

If you are a new organisation that has been going for less than 12 months, we need you to produce an estimate of your first year's income and expenditure instead.

If you answered 'no' above you must meet this requirement before you can apply

How many staff do you have in paid employment for each of the last three financial years under the following headings? (if your organisation is less than three years old please provide the information for as many years as you can)

Your financial year ending	Average numbers of staff involved in research work	Average number of staff in post
Year 2004-2005	1	77
Year 2005-2006	.1	80
Year 2006-2007	.1	103

How much experience do you have of research? (Please select all that are applicable - for multiple selections hold down the CTRL key and select with the mouse)

No previous experience

Other - please specify

(empty)

Staff have carried out research elsewhere

Other - please specify

(empty)

We have commissioned research from others

Social

Other - please specify

(empty)

We have carried out research ourselves

Social

Other - please specify

(empty)

RG - Section 2: Your project

Part A: Outline of Project & Beneficiaries - page 1 of 4

This section is divided into 4 parts that cover different aspects of your project:

- **A: Outline of project and beneficiaries**
- **B: Technical description**
- **C: Research governance and ethics**
- **D: Relevance to Research programme**

* What is the name of your project?
(maximum 80 characters)

DeafHealth: A UK Collaborative Study into the Health of Deaf People

Briefly describe your project in plain English, explaining the following aspects as simply and succinctly as possible (maximum 2000 characters):

- **the need for your research**
- **brief summary of research, methods, and intended outcomes**
- **who is leading the project and any partners**
- **how your project outcomes will help to achieve the programme outcomes**
- **which, and how many, individuals and organisations will directly benefit from your research**
- **your dissemination plans**
- **how long the project will take**

Project summary

Small scale studies in the UK suggests that culturally Deaf people have worse physical health than hearing people, but there is no definitive research, despite the fact that Deaf people are a high risk group and find it much harder to access health services (A Simple Cure, RNID, Kyle et al, 2005). Austrian, American and Canadian research studies show worse physical health amongst Culturally Deaf populations. A representative sample of 500 Deaf people will undertake 'health assessments' to provide data on common conditions that allow for direct comparison with general health survey data for the general population. Existing data held in primary care is unlikely to be accurate because of communication difficulties, missed appointments, etc. (RNID, A Simple Cure)

50 Deaf people will be selected for face-to-face and group sessions to provide qualitative data on their experience of health services and health awareness. Specific conditions highlighted as most common or of most significance will be further investigated through on-line questionnaires.

The research will identify common health conditions where health inequalities between Deaf and mainstream (hearing) populations are particularly pronounced, e.g. diabetes, cardio-vascular disease, hypertension. Comparisons will be made with data from the hearing population. The study will suggest reasons for inequalities and identify practical measures which could reduce these.

SignHealth will lead the project, with support from an expert Research Advisory Committee. The project will be delivered in partnership with Bristol University.

500 Deaf participants will directly benefit from greater health knowledge. The wider Deaf UK population will benefit from BSL project dissemination and any improvements to health service delivery.

Dissemination will focus on policy makers, the research community and the Deaf community.

The project will run for three years.

* Where will you carry out your project? (if the work will take place in more than one place, tell us where most work will take place)

UK-wide

Tell us about the people and organisations that will benefit most from your project, in what ways they will benefit, when they will experience the benefits and how you estimated the numbers of beneficiaries.

This research project is exceptional in bringing together a partnership of 59 national, regional and local organisations for Deaf people, and employing a team of Deaf researchers, to undertake the first UK study into the morbidity of Deaf people.

Research shows (1995-1997: Deaf Health in Scotland, Health Education Board for Scotland, Jim Kyle; RNID A Simple Cure) that many Deaf people cannot understand their GPs and have limited knowledge about general health or self-diagnosis. Deaf project participants will directly benefit from greater knowledge about their personal health. The project will be widely promoted amongst the Deaf population and this by itself will increase health awareness. There are an estimated 50,000 Deaf people in the UK who use British Sign Language as their first or preferred language.

Health service commissioners/policy makers will benefit from research data, because it will provide robust evidence to help them plan changes appropriately. We regularly talk to health professionals who have never considered that Deaf people may have poorer health, or that the services they deliver may need to be adapted for Deaf people; even small changes may have huge health benefits for Deaf people.

* How many people will benefit directly from your project? You may not know the exact number at this stage but please give a reasonable estimate. (enter whole numbers in figures, do not use commas or full stops eg 10000 not 10,000)

50000

* How many organisations will benefit directly from your project? You may not know the exact number at this stage but please give us a reasonable estimate. (enter whole numbers in figures, do not use commas or full stops eg 10000 not 10,000)

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Part B: Technical description of your project - page 2 of 4

Explain in detail why you think your research is needed.

You should include:

1. the main evidence that led to the idea for the research
2. relevant social and political context
3. what you have done to find out whether similar research has been done before or is currently being done elsewhere, and your findings

Please explain here

Research studies from Austria (2002), Belgium (2001), Michigan (1993) and Canada (2007) demonstrate poorer physical health amongst Deaf populations. Unfortunately, in the UK we have no definitive studies that can say whether Deaf people experience the same health as hearing people. Without this research, Deaf people will continue to be overlooked – with health professionals unaware that inequalities may exist. There is plenty of data relating to other sub-populations (based on ethnic minority, learning disability, etc.) and Deaf people now need to be included in the evidence base.

A recent study in London (Dr Helen Miller, 2009) found poorer cardiovascular health amongst National Deaf Service patients, as did a recent study of Deaf patients in Sandwell (72% of those screened needed to be referred to their GP, compared to 50% for the wider Sandwell population). Both these studies recognised the inequity experienced by Deaf people, but use small samples. We intend to conduct a large robust study that can provide commissioners and providers with the evidence of inequality and recommendations for improvement.

The majority of the Deaf community have little or no speech, and find it difficult to read or write English. For unassisted communication, Deaf people may rely on the written word or their ability to lip-read. However, Deaf people usually have much poorer than average literacy skills and, at most, only 40% of sounds are visible on the lips. We know from research (Kyle et al) that Deaf people find communication with doctors difficult and frustrating. Health messages are not being received by the Deaf community and there are barriers to accessing treatment (A Simple Cure, RNID).

In Austria 2002, Dr. Wolfgang Shatzlemeyer undertook a research study which demonstrated poorer health amongst Deaf participants. Van Oyen et al (2001) looked at data from a national health survey in 1997 in Belgium and found prevalence of subjective ill health was higher in people with hearing difficulties (45%) compared to hearing people (20%). One study in the US showed that Deaf people were two to ten times as likely as hearing counterparts to be HIV+ because of poor access to information, inadequate treatment, and confidentiality issues.

Reeves et al (2003) found that Deaf people have substantially poorer access to primary care, and Accident and Emergency services, and experience difficulties at all stages of the health care process.

RNID report (2004) 'A Simple Cure' surveyed the experiences of 866 Deaf and hard of hearing people in the UK and concluded that the service they received in both GP surgeries and hospitals fell short of what should reasonably be expected. During 2006 and 2007, SignHealth delivered health workshops for Deaf people which revealed much higher rates of physical health problems than in the general population.

A review of the literature by Sally Reynolds (Deaf BSL researcher) indicated that Deaf people are at an increased risk of suffering from poor health (Reynolds, 2007). A follow up study by Reynolds found that Deaf people are disadvantaged when trying to access health services.

What specific question{s} does your research project intend to answer?

- o What is the prevalence of common diseases and disease markers amongst the Deaf UK population compared to the wider population?
- o How do Deaf people experience the NHS?
- o What could be done to improve the health of Deaf people?

Give a full and detailed description of the research methods you will use to answer your research question(s).

You must:

1. describe your overall approach, rationale, experimental design (where appropriate) and the information or data you will collect
2. explain the methodologies you will use, how the data will be recorded and how it will be analysed, including any statistical techniques.

Where alternative approaches are available you should give the reasons for your choice.

If your research involves working with people, explain how:

- they will be recruited
- you will ensure they are representative
- you will make sure of equality of access to your study

If you intended to compare interventions, explain how you will control for any confounding factors.

If you plan a series of studies or experiments, you must show how they form a coherent whole.

Explain here:

The study is designed as an open exploratory descriptive research project. Open exploratory descriptive design means that it is first level research that is both quantitative and qualitative (multi-method). First level: in that it is exploring an area that has never been explored in depth in an approach like this before. Descriptive: in that it will describe Deaf people's health journey and experiences within the health care system for certain common diseases. It will, through its descriptions and recommendations, inform policy makers about the health and needs of Deaf people and what health care providers can do differently.

The methodology for this project has been developed by SignHealth in consultation with an Research Advisory Committee comprising: Herbert Klein (Deaf Adviser at National Deaf Service), Andrew Alexander (Consultant, RUH Bath (respiratory medicine), Nick Kitson (Consultant Psychiatrist (previously at National Deaf Service), Pauline Heslop (Senior Research Fellow, Bristol University (epidemiology), Sonja Nissen (Researcher Manager, Ipsos MORI), Steve Powell (Chief Executive, SignHealth), Mark Nelson (Director, Remark!), Bencie Woll (Department of Human Communication Science, UCL), Cathy Heffernan (The Guardian), Tyron Woolfe (Deputy Director, National Deaf Children's Society), David Reeves (Research Fellow, Manchester University), Anna Middleton (Cardiff University), Prof Jim Kyle (Bristol University), a GP (tbc), two representatives from partner organisations.

The study will be embedded within the Deaf community, because participants will come from membership of local and regional organisations run by and for Deaf people, such as Merseyside Society for Deaf people and Bristol Deaf Women's Health Group. The health assessments and interviews will take place within the supportive confines of the Deaf community groups.

To ensure Deaf involvement:

- The study will use Deaf researchers
- At least four members of the Research Advisory Committee are Deaf
- A Deaf Film company (Remark!) will translate and film BSL health clips
- Partner organisations will be consulted on design and delivery, and will embed the project locally or regionally

Almost 70% of the Deaf population in the UK have a low level of literacy (RNID, 2006). Language barriers (as a result of English being an unheard second language) can result in anxiety and awkwardness when presented with complex reading materials, such as those found in experimental design documents. A series of experiments (Power, 1999) found that traditional approaches to experimental design lowered Deaf participant's levels of confidence and willingness to participate. Traditional approaches to experimental design do not meet the language needs of Deaf adults, and present a 'visualisation gap' for Deaf participants (Naqvi, 2006) (a difficulty in making visual connections between English instructions and BSL). The experimental design materials used in the DeafHealth Study will use the Visual Language Translation Rules developed by Naqvi to assist in the translation of materials into BSL, and to make written materials more 'deaf-friendly' – using 'visual connection' as the dominant design criteria.

Research conditions will ensure all Deaf participants have direct communication in their natural language, and have appropriate social or communication support (e.g. relay interpreters). This is vital to ensure Deaf participants fully understand the study and can make truly informed consent, and receive appropriate support and accessible health information within a supportive, yet confidential, environment. There are significant ethical issues surrounding the disclosure of sensitive medical information to participants, who may not want to see their GP but who need to have health information or counselling.

Communication and dissemination are key issues and are aimed at three key audiences - Deaf community, research/policy makers, and health professionals. Deaf specialist websites (such as Deaf Station and the study's own DeafHealth website) will be powerful tools to convey health information at point of need for the wider Deaf community.

SignHealth is currently undertaking an on-line survey of Deaf people which will help recruit participants for this study.

EACH STAGE WILL USE THE FOLLOWING COMMUNICATION AND ACCESSIBILITY MEASURES:

All meetings, interviews, health assessments will be conducted in sign language (British Sign Language) (or if necessary with an interpreter, although direct sign language communication is always the method of communication of choice). Paper materials, such as consent forms and explanatory information will be explained in BSL and written in Deaf-friendly English and BSL. All mini-medicals will be held in fully accessible venues. BSL dialects will be catered for. Communication and social support will be provided as required (e.g. relay interpreters or supporters for Deaf people with mental health problems). Reports will be made available in BSL and Deaf-friendly English.

A flagship DeafHealth Partnership event will be held in London, and presentations given at appropriate Deaf and health events across the UK. Events will be conducted in BSL and English with communication support workers and interpreters.

METHODOLOGIES, DATA CAPTURE AND ANALYSIS:

Bristol University (Prof Jim Kyle, Centre for Deaf Studies) workplan outline:

- 1: examine existing research data, medical/health databases and produce a report on relevance and information in regard to deaf health (Deliverable D1 – 6 months)
- 2: manage ethics process in regard to the project to obtain approval for each component of the work through research governance and ethics process (Milestone M1 – 3-9 months)
- 3: create sampling frame for mini-medicals and advise on data to be collected – based on cooperation of partners and local associations (3-6 months)
- 4: analyse data from 500 mini-medicals and provide a report (9-15 months - Deliverable D2 – 18 months)
- 5: plan and carry out 50 qualitative interviews in sign language (allow for 60 meetings to take into account failures or changes/illness in interviewee), produce transcripts and analyse the transcripts using qualitative analysis software; integrate with available quantitative data; link to other project data (9 months to 24 months) (report - deliverable D2 – 26 months)
- 6: Integrate all data collected, statistically analyse all quantitative data from existing databases and newly collected data – produce final report (Deliverable D3 Month 33)
- 7: Publishable papers presented (month 18 – 30)

The research design will not require hearing control groups because statistics are already collected for common health conditions (eg diabetes, obesity, various cancers and coronary heart disease). Questions will be designed to allow for direct comparison with the general population using

data from University of Nottingham's QResearch, the Health Surveys for England, Wales, Scotland and Northern Ireland, and other common data sets. The design will create BSL validated versions of the English questions.

Through the engagement of local and regional Deaf-led partner organisations, Deaf individuals will be given health information and will agree to have a medical health assessment. This will provide data that would not be revealed by statistical analysis of health records. Existing health records do not usually record degree of deafness or hearing loss, or preferred language (this will hopefully change in the future). Similarly, the national Health Surveys do ask about "hearing impairment" but this term is too vague for our purposes. GP patient records could be used but there is a concern that the data would not be accurate – for instance, a medical history may have been taken without an interpreter being present, leading to inaccuracies. It would also be difficult to identify Deaf patients as most record systems do not have a particular field which is consistently used to record deafness (or the extent of deafness).

FURTHER METHODOLOGICAL EXPLANATION FOR EACH STEP:

HEALTH SCREENING

To determine prevalence of common disorders already known to the participants, and determine rates of health markers (known or unknown to the participants), 500 20-80 yr old Deaf individuals will receive a free health assessment in a supportive environment, with the help of the local and regional partner organisations. The assessment will include standard medical tests and will be conducted by a subcontracted health company, with BSL interpreter support. Participants will be offered an incentive to take part and given social and communication support. The choice of tests will be chosen to allow direct comparison with the general population, whilst allowing for confounding factors such as socio-economic group, age, gender, ethnicity, disability etc on health.

Each participant will be given health information in sign language, a full explanation of their results and advice and support on how to improve their health. All results will, with the participant's consent, be shared with their GP, and local health trusts will be engaged to ensure they are fully aware of the study and can meet needs of Deaf individuals who may require medical attention in light of their health assessment. By delivering the health screening within the supportive environment of a local/regional Deaf club, we will help address the significant ethical issues that surround giving sensitive health information to Deaf people who have very little understanding of health issues. SignHealth's specialist sign language counselling service will be made available to Deaf people who require this additional support.

QUALITATIVE INTERVIEWS

Approximately 50 Deaf people will be selected by Bristol University from the Health Screen on the basis of best representation of health conditions for qualitative one-to-one semi-structured interviews. This will explore the reasons behind differences in health, such as experience of accessing health services, level of health information and experience of NHS treatment.

Specific common health conditions that emerge as particular issues facing the Deaf population may require supplementary follow-up questions. We are particularly interested in looking at diabetes, asthma, cardio-vascular disease and conditions where there is a clear framework for assessment and treatment (e.g. a NICE guideline). By looking at such conditions we will have established data with which to make comparisons (such as Quality Outcomes Framework figures) and a benchmark for treatment. For instance, we can identify people that are known diabetics and question whether they have had a retinal screen in the past 12 months, and compare this to the figure for the general population.

WRITE-UP

Prof. Jim Kyle from Bristol University will analyse results and produce a final research paper, which will be submitted for peer review. The research paper will ascertain the health of Deaf people for certain common conditions, compared to UK norms, suggest reasons for any differences, and recommend changes to practice and policy which could reduce any health inequalities found.

Research summaries will be tailored to two key audiences:

- Deaf people & Deaf-led partner organisations
- Policy makers, researchers and health professionals (eg audiologists, GPs, nurses, consultants, commissioners, midwives, managers, physiotherapists).

COMMUNICATION AND DISSEMINATION

Findings will be shared with - and explained to - audiences in BSL and Deaf friendly English. All participants of the study will receive a deaf-friendly English summary report in BSL. Deaf-led partner organisations will help explain research findings to Deaf participants. BSL health information will be posted on specialist Deaf websites/media (Deaf Station, DeafHealth website, VeeTV, SeeHear, etc) to give Deaf people better access to general health information and specific condition information at point of need (eg breast cancer, stroke, diabetes).

Findings will be disseminated through high impact medical journals (e.g. Hospital Medicine, General Practice, Lancet, British Journal of Nursing, British Journal of Midwifery, etc). Key organisations will also be targeted, e.g. Department of Health, BMA, NHS Confederation, NHS Alliance, Royal College of General Practitioners.

A major DeafHealth Partnership conference will be held in London to announce the research findings. The results will also be presented at health and Deaf conferences throughout Scotland, Wales, England and Northern Ireland. The presentations will clearly explain the results of the study in lively and visual ways that are easily understood by Deaf audiences.

LONG-TERM FOLLOW-UP

This will be funded by SignHealth, and will take place two years after completion of the research study to survey local and regional Deaf-led organisations on any changes they have observed in the health awareness and lifestyle choices of their members, and in the accessibility of their local health services.

EQUALITY OF ACCESS

The research methodology is specifically designed to be accessible for Deaf people, including those with additional disabilities and members of minority ethnic groups. Assessment tools, promotional materials, equal opportunities monitoring forms and customer satisfaction surveys will be in BSL or Deaf-friendly English, and BSL interpreters will be provided if direct sign language is not possible.

Culturally Deaf people do not see themselves as disabled but rather as belonging to a cultural minority with its own language. It is probable that the Deaf community has comparable levels of ethnic diversity to the hearing population and we will ensure we reach deaf people from different ethnic backgrounds by including minority groups as members of the DeafHealth Partnership, such as the Asian Deaf Women's Association.

Rates of additional disabilities are high amongst the Deaf community. It is estimated that 40 per cent of children with a permanent hearing loss have additional disabilities (Davis, Fortnum and Bamford, 1998; Holden-Pitt and Diaz, 1998; Karchmer, 1985). Such disabilities include learning

disabilities, epilepsy, autism, cerebral palsy, psychiatric disorders and visual impairment. Measures will be taken to ensure access for all Deaf people, regardless of their impairment, by ensuring venues for health screenings, promotional or dissemination events and meetings are physically accessible for all participants and cater for any specific needs including dietary requirements.

Support will be given, as necessary, to enable Deaf people with mental health problems to participate in the study. For example, a relay interpreter, supporter or advocate may be required.

Promotional and communication materials will reflect a positive view of all Deaf people regardless of their ethnicity or disability, and additional communication support will be provided for Deaf people who use non-BSL sign languages. Promotional and communication materials will reflect a positive view of Deaf people who are lesbian, gay, bisexual or transsexual, and study conditions will be sensitive to the need for confidentiality (this is a very big issue within the Deaf community, since it is very close-knit).

RECRUITMENT OF PARTICIPANTS

The Deaf-led partner organisations will support the engagement and active participation of Deaf people across the UK. Each partner organisation will be fully informed about - and involved in - the development, design and delivery of the study through regular consultation. They will encourage their own members to hold health events or social evenings where they can explain the study, give health information and engage Deaf people in the project. SignHealth's current online survey will provide additional participants.

Ensuring a representative sample

Confounding factors that affect health such as: age, gender, ethnic background, disability, mental health and socio-economic status will be taken into account when interpreting results and making comparisons with the general population. Categorising additional impairments and type of sign language preferred will allow for comparison between different Deaf subgroups. The researchers will use a large enough sample, appropriate statistical methods (and focus groups if necessary) to ensure validity of results.

*** Are you planning to develop new methods or test new techniques as part of your research?**

No

If yes

- what is involved
- why existing methods are not suitable for your research
- how you will check the accuracy and reliability of the data you collect
- whether you will carry out a direct comparison between new and existing methods.

Explain here:

N/A

A number of datasets are available through the Research Councils. Please explain why these are not suitable for your research.

Professor Jim Kyle will examine existing research data, medical/health databases to identify where there is useful but incomplete information. Unfortunately, very few health administration systems record the level and type of deafness, including important factors such as age of hearing loss. This means there is no readily available data that gives health information about the Deaf population. The Health Surveys for the home nations do ask whether the respondent has a "hearing impairment" but this does not provide enough detail for us to analyse the data with any confidence. We are more interested in use of language (BSL) rather than sensory functioning.

How will you assess the quality of data you collect?

Professor Jim Kyle will examine existing research data, medical/health databases to identify where there is useful but incomplete information. Unfortunately, very few health administration systems record the level and type of deafness, including important factors such as age of hearing loss. This means there is no readily available data that gives health information about the Deaf population. The Health Surveys for the home nations do ask whether the respondent has a "hearing impairment" but this does not provide enough detail for us to analyse the data with any confidence. We are more interested in use of language (BSL) rather than sensory functioning.

*** Will you face data protection or confidentiality issues with the data you intend to collect?**

Yes

How will you keep your data secure?

SignHealth and the Academic Partner will take steps to ensure that personal data is kept separately and securely, whether in a locked filing cabinet, or password protected files on computer. Special care will be taken when handling personal data outside the University or SignHealth. Names will be kept separate from personal detail for quantitative reporting; where there is qualitative data analysis to be carried out on say, transcripts, then quoted information will be anonymised. Actors will be used to deliver quotes in BSL reports. The Academic partner will keep all personal data in separate locked facilities at the university. All data will be stored in accordance with the Helsinki Research Agreement and Data Protection Act (1984 and 1998).

All respondents will be informed that their individual data will be maintained in a locked research file at the University. All respondents will be assigned a numerical code that will be held separately from the data so that only the researchers will know who has responded to questions and interviews. The same will hold true for the health screening. All data will be held on a coding system basis.

- Participants will be asked to give their explicit consent to have their personal data processed.
- Participants will be told the identity of the researcher, the purpose for which the data will be used and the identity of other people who might have access to the raw data, such as supervisors.
- Participants will be told how the data will be stored and used
- Researchers will make all reasonable efforts to inform participants about any new purposes of data processing.
- Personal data collected will be adequate, relevant and not excessive in relation to the purpose of the study.
- Personal data will be accurate and, where necessary, kept up to date
- Personal data will not be kept for longer than is necessary for the purpose of the study.
- Participants will be involved throughout the research process and their feedback will be solicited on the results of data analysis
- Appropriate technical and organisational measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or destruction of, or damage to, personal data.
- Participants will be informed of the manner in which their personal data will be protected from unauthorised access

The Data Protection Act defines several categories of personal data which are considered to be of a sensitive nature. These require the explicit consent of the research participant in order to be processed:

- The racial or ethnic origin of the participant;
- The physical or mental health or condition of the participant;
- The sexual life of the participant;
- The commission or alleged commission by the participant of any offence;

There is confusion about what constitutes explicit informed consent (Strobl, et al. 2000). To ensure explicit consent, the researcher will obtain signed and dated consent from the participant using a consent form which includes at least a project synopsis, and is clearly explained in BSL or with communication support. Sign language consent, recorded on film, will also be considered as a record of explicit informed consent.

What right of access will other researchers have to the data you collect?

The research data and findings will be the property of SignHealth and the individual users who will have access to the information and the right to delete their data.

Anonymised data will be archived to allow other researchers to access on request. Simple criteria for acceptance/refusal will be developed. We will welcome the opportunity to allow other researchers use of data, as long as confidentiality is maintained. This will, in most cases, involve only anonymised data being passed to the third party. Policies for cataloguing and preparing data for archive will follow those set down by the ESRC.

Findings will be published on various research databases, making it easy for other researchers to know of the work.

Part C: Research governance and ethics - page 3 of 4

a) Governance

How will you make sure there is robust control of your research?

what conflicts of interest might arise during your research? How will you identify and manage these?

would an independent view, for example, an independent expert or research governance committee, help you control your research? If so, how will you put this in place and ensure any recommendations are implemented?

Explain here:

The Research Advisory Committee (RAC) has already been established and will meet every six months to monitor progress against targets and advise on steps to ensure the robustness of the research methodology. Individual members of the group will be consulted, as necessary, between meetings.

The RAC comprises independent experts and Deaf BSL users who can give independent advice and guidance on the research study and its user involvement. The Research Advisory Committee (RAC) will meet twice a year at a convenient venue. Members of the RAC currently include: Herbert Klein (Deaf Adviser at National Deaf Service), Andrew Alexander (Consultant, RUH Bath (respiratory medicine)), Nick Kitson (Consultant Psychiatrist (previously at National Deaf Service)), Pauline Heslop (Senior Research Fellow, Bristol University (epidemiology)), Sonja Nissen (Researcher Manager, Ipsos MOR), Steve Powell (Chief Executive, SignHealth), Mark Nelson (Director, Remark!), Bencie Woll (Department of Human Communication Science UCL, Anna Middleton (Cardiff University), Cathy Heffernan (The Guardian), Tyron Woolfe (Deputy Director, National Deaf Children's Society), David Reeves (Research Fellow, Manchester University), a GP (tbc), Prof. Jim Kyle (Bristol University), and two representatives from the partner organisations.

While the Advisory Committee will be responsible for the direction, SignHealth will be responsible for managing the project, and ensuring its sound financial management.

Legally binding agreements will be signed between SignHealth and Bristol University, setting out roles and responsibilities.

The Project Manager will be responsible for ensuring the Academic Partner fulfils its obligations under the partnership agreement, and for ensuring the project is delivered in accordance with the Operational Plan by regularly reviewing progress. The Project Manager will be supervised by SignHealth's Chief Executive, who in turn is answerable to the Board of Trustees.

Jim Kyle at Bristol University will be responsible for the implementation and delivery of the research, and for subcontracting and managing the mini-medical company, Deaf researchers, etc. Bristol University uses procedures for project management against a detailed workplan with deliverables and milestones. Project monitoring is carried out through weekly meetings of all staff engaged in the work.

There are no obvious conflicts of interest within the governance structure of the research study. If there is disagreement between SignHealth and Bristol University, then the issue will be referred to the Advisory Committee. As an independent body, that Group will be able to resolve any matters that arise.

If you plan to have independent oversight of your research, have you told those involved that you are submitting this proposal?

Yes

How have you made sure that both the proposal and your research meet their organisation's requirements for controlling research?

Research Advisory Committee members are all professionals working within the NHS, or academia, or are Deaf people who can give an 'expert patient' perspective. The DeafHealth Research Study has been designed to meet the ethical and governance requirements of the Academic Partner. This is tightly controlled and is set out in a series of checks and reporting milestones. The process is also governed by medical ethics committees for all relevant subject areas or geographical areas. The Advisory Committee has already met and had involvement in the drawing up of this application.

If no, please tell us why you have not told those involved

N/A

* Will the project beneficiaries or stakeholders participate in controlling the research?

Yes

Tell us why the project beneficiaries or stakeholders are not involved in controlling the research.

N/A

b) Ethics

What ethical issues do you think are raised by your research? How will you address these? If you believe there are no ethical issues arising from your research, please explain why.

There are ethical issues to be considered if the mini-medical shows a serious or potentially serious health problem that the participant is unaware of, or does not fully understand the implications of. All participants will sign a consent form (clearly explained to them in BSL) that all findings will be passed on to their GP, and will receive a full explanation about their results, and advice on how to improve their health.

The study raises significant ethical issues around confidentiality because the Deaf community is very close-knit, and some conditions are stigmatizing, such as HIV/AIDS, alcohol dependency and mental health problems. The use of film for capturing sign language interviews poses additional confidentiality issues.

There are ethical issues surrounding the 'informed consent' of Deaf people, because they need to be able to give meaningful consent, should not be coerced into participating, and may need support to make decisions. All participants will be required to sign a consent form at each stage of the research study.

Consent is a particular issue for Deaf people because while deafness itself is not a risk for poor mental health, the consequences of being Deaf in a hearing-orientated world do present a risk. Communication and language differences between hearing people and Deaf children can lead to significant social and linguistic developmental delays. Compared to children of a similar age, deaf children are more likely to be impulsive, with limited social problem solving skills and greater difficulty in identifying and naming their own and other people's emotional states (Kusche and Greenburg 1987).

Developmental delays in social skills may lead to some deaf participants to be more easily coerced than hearing participants would be as well as limiting their social interpersonal skills, and severely impacting on their understanding of concepts that hearing people take for granted. For example, the concept of a 'virus' is very difficult to explain in sign language, and there is no sign for 'cholesterol'. The Scottish Sensory Centre in Edinburgh has developed a new vocabulary of scientific terms in sign language, with supported written explanations, fingerspellings, and in some cases demonstration videos. The Deaf-Health Research Study will utilise these as necessary.

Communication differences between hearing and Deaf populations can also lead to a lack of general knowledge for some Deaf people – including health knowledge. For example, a Deaf employee of SignHealth (despite being intelligent and sign language articulate) was under the impression that cancer was a disease that could be 'caught' like a cold. Deaf people miss out on the incidental learning that hearing people pick up on through overheard conversations, radio, TV, films, newspapers and magazines, because they cannot hear and often have limited literacy skills.

These ethical issues will be addressed by:

- o The content of the interviews and the medical health checks will be determined in close consultation with the local Deaf-led groups.
- o Deaf-led partner groups will advise on ethical issues in regard to discovery of an undiagnosed illness and will be prepared to provide support to members.
- o Part of the project team will consult and support Deaf people's health and will provide feedback to those who have been tested.
- o Clear procedures on how to deal with health information generated by the tests which could cause distress to the participant
- o Clear information for all participants and partners about the research study purpose, rationale, methodology, confidentiality measures, intended uses of the research and what their participation entails.
- o Clear explanation of why all healthscreen participants are required to sign an agreement which means their results will be passed on to their GP, and the potential impact of any discovered health conditions (for example on health insurance, benefits allowances or discrimination by employers).
- o Clear guidance for all Deaf-Health Partners and supporters of participants on the importance of confidentiality and how to ensure it and other ethical issues, such as denial of insurance.
- o Clear complaints and grievance procedures for all participants and partners
- o Sensitive support from Deaf Health Partners (often face-to-face) with members they already have a relationship with, such as regional and local Deaf Clubs, to provide encouragement, explanation, clarification and support; without coercion.
- o Providing volunteer supporters for participants who want them, or asking the participant to bring their own supporter – such as a care workers or social worker.
- o Signed agreement forms from participants to allow the filming of their answers / focus group discussions.
- o Data collected through the research will be anonymised, and access to the research data will be restricted to other academic researchers. Participants will be asked to consent prior to filming. Viewing of the films will be restricted to the researchers and appropriate project staff.
- o The Deaf-Health Research Study will comply with the Data Protection Act (1984 and 1998)

* Will your research project need approval by an ethics committee?

Yes

* Do you already have approval?

No

* Through which organisation or body?

N/A

* Are you in the process of gaining approval?

No

* Through which organisation or body?

N/A

* Will you seek approval if you are awarded a grant?

Yes

* Through which organisation or body?

National Ethics Service and the Academic Partner's Ethics Committee

It is good practice to verify that your project does not require ethics approval. You may be required to provide a signed letter from an appropriate ethics committee representative explaining why the project does not need approval if you are awarded a grant.

* Will your research involve working with children or young people, or other potentially vulnerable groups (including, for example, individuals with cognitive impairment or learning disability)

Yes

If your research involves working with children, confirm below that your organisation has child protection policies in place that meet the standards set out in the guidance notes. We will ask to see these policies if you are awarded a grant

* I confirm that we have the necessary policies in place

Yes

Researchers working with vulnerable groups will need to be checked by CRB or equivalent (for example, Disclosure Scotland). If you are working with partners who will be in contact with vulnerable people we expect you to ensure they have the necessary policies in place and we will ask to see these.

Part D: Relevance to the research programme - page 4 of 4

What do you believe will be the most important outcomes of your research? List three key outcomes, the date you expect to achieve each and how you will demonstrate they have been achieved.

Make sure you provide outcomes for your project, not the outputs of your research. Examples of outputs are reports, publications and seminars. If you are unsure about writing project outcomes or outputs you can contact a grant manager through the programme helpline (Telephone 0845 0711068 or email researchprogramme@aeat.co.uk).

Outcome 1

Enhanced health attitudes, knowledge and actions amongst the Deaf community.

* Delivery Date

07 April 2011

Measure of success

80% self-reported increase in health knowledge/attitudes/actions from study participants. 80% of partner organisations say local Deaf community more aware of general health issues and take action to lead healthier lifestyles. Measurement will be built-in to the surveys.

Outcome 2

Greater awareness amongst NHS commissioners and providers about improvements that could tackle Deaf health inequalities highlighted by the study.

* Delivery date

31 March 2013

Measure of success

1) Self-reported awareness from commissioners and providers attending dissemination events about practical measures that could be taken to reduce Deaf health inequalities
2) Self-reported improvements in access to health information, diagnosis and treatment from Deaf people and Partner Organisations, as surveyed by SignHealth.

Outcome 3

Improved evidence base into the health of Deaf people.

* Delivery date

31 March 2013

Measure of success

The research should be in the public domain, be accepted by a peer-reviewed journal and be found in literature reviews. It should also be cited in future research.

The overall aim of the Research programme is to 'influence local and national policy and practice by funding the VCS to produce and disseminate evidence-based knowledge... to help develop better services and interventions for beneficiaries'. How will your research achieve this and how will you demonstrate it has been achieved?

Explain here

By working with Deaf people to provide robust peer reviewed data, we will be able to present clear evidence-based knowledge about the health differences experienced by Deaf people compared to hearing people. A conference will be organized to explain the research findings and bring about better services and interventions for Deaf patients (measured through a follow-up survey). We will closely monitor the impact of the findings, through changes in practice, e.g. providers doing things differently. We will also monitor how widely the findings have been disseminated (both in journals and organisations' publications).

All projects funded by the Research programme must address the following programme outcome:

- Improved understanding of issues relating to the BIG's UK themes and country outcomes

You must state clearly the issues covered by your project, how your research will aid understanding of this issue and how you will show it has been achieved.

Explain here

The key issue is: How can we promote the wellbeing of Deaf people? The study will clearly add to our understanding of the health issues facing Deaf people, and Deaf people's understanding of the health issues they face, and it will seek to identify policies and practices that would address Deaf health inequalities. We will show this contribution has been made by producing a peer reviewed research paper which has widespread credibility amongst the research community and is widely understood by the Deaf community.

All projects funded by the Research programme must address the following programme outcome:

- **Improved VCS participation and knowledge in developing, doing and using research**

How will your research achieve this and how will you show it has been achieved?

Explain here

During the course of developing and delivering the research study, SignHealth and its partner (voluntary sector) organizations will gain valuable knowledge and understanding about research – how it is designed, delivered and used. SignHealth will be directing every stage of the research and will be particularly involved in communicating the findings to key audiences – and ultimately improving Deaf people's access to health prevention, information and treatment.

Which other outcome(s) of the Research Programme are addressed by your project? How will your research achieve this and how will you show it has been achieved? You must state clearly which other outcomes you will meet, how you will do so and your measures of success. Applications that do not clearly state at least one other outcome may not meet the programme requirements and might not be presented to the decision-making committee.

Explain here

Improved dissemination of VCS led research

The project will produce a peer reviewed paper, flagship conference, presentations at health and Deaf conferences, and substantial media coverage. Websites will disseminate health information across the Deaf population. Deaf-led organisational involvement will ensure the research has a practical impact and reaches a far wider Deaf audience. Engagement with local health trusts in the locality of each Health Assessment will increase chances of improving access for Deaf participants to health services.

Increased participation of beneficiaries and users in a range of research roles

The project will give Deaf people and Deaf researchers a unique opportunity to deliver, participate in, and disseminate the first comprehensive research study into the health of the UK's Deaf population. Deaf people will sit on the Advisory Committee and partner organisations will play a pivotal role in recruitment, support and communication.

Improved partnerships between the VCS and the research community

Through the project, SignHealth will work in close partnership with Bristol University's Centre for Deaf Studies and Department for Social Medicine. We hope the project will be the start of a fruitful partnership between SignHealth and Bristol University. SignHealth will benefit from working with such experienced research departments.

RG - Section 3: Communication and dissemination

How will you influence policy and practice through your research? You must attach a communication plan that details how you will inform others about your project and disseminate the findings of your research.

You should think carefully about how best to communicate with others during your project so that your research has the most impact. Your plan must include:

An explanation of how your approach, and the thinking behind your plan, will enable you to achieve your outcomes.

Who you will communicate with and why you have chosen them.

How you will communicate with them and how you know this is the best way to achieve your project outcomes (for example, will you give them information, involve them in discussion, ask them for information? Will you set up a stakeholder group, prepare regular reports, organise workshops, hold a large regional or UK wide seminar, present your work at third party meetings?)

When you will communicate with others (at regular intervals, when requested, at specific times in the project, when all the results are analysed)? These times should also be included in your project plan.

How you will decide whether your communication plan is working?

Explain here

We have identified key leaders who are able to effect change, and we already have had meetings with many of them, most notably Dr Mike Warburton, (National Director for GP Access at the Department of Health) and PCT commissioning managers. We will develop contacts with other key audiences such as the Royal College of GPs and NHS Evidence, and we will communicate regularly through e-mail briefings.

Having already spoken to health professionals and policy makers about what information they want and how to make it available, we know that commissioners are very keen to have statistics. However, we also know that the 'human' stories can be decisive in motivating people to take action. The communication strategy will tailor the information so it is targeted at specific audiences, e.g. GPs, PCT chief executives, public health officials, etc. Our communications will be action-focused so that people are left in no doubt about what they can do to make a difference.

At the London conference we will ask service providers and commissioners to make a written pledge that they will seek to implement at least one of the report recommendations to improve access and quality of care for deaf people. Results from this will demonstrate whether the people we want to influence have taken note of our research.

Wherever possible we will use peer-to-peer communications to amplify the message (e.g. doctors may take more notice of comments from other doctors, and Deaf people may take more notice of comments from other Deaf people). The Deaf-led partner organisations will have a key role to play, particularly in disseminating information to the local Deaf community, and their local health trust.

The wider research community will be aware of the research through publication in a peer-reviewed journal. The findings will also be readily available through online research databases.

The timetable for communication and dissemination is included in the Gantt chart, and we will assess whether the plan is working by regularly soliciting feedback from partners and participants.

Ultimate proof of good communication will come from a follow up study, which will be undertaken two years after the completion of this study. This will identify any changes that have been made in service provision, policy and procedures, and ask Deaf people to tell us whether their understanding of their own health, and ability to self-diagnose, has changed since the study was disseminated.

* Will others need to act on your findings for your research to achieve its outcomes?

Yes

Who will need to act?

In order to influence policy and practice SignHealth and its partners will need to persuade health commissioners, policy makers and service

providers to change the way they do things. The key individuals we need to tell about the findings of our research are:

- o Rt Hon Alan Johnson MP Secretary of State for Health
- o Professor the Lord Darzi of Denham KBE, Parliamentary Under-Secretary of State
- o Ben Bradshaw MP Minister of State for Health Services
- o Surinder Sharma, National Director for Equality and Human Rights at the Department of Health.
- o Mike Warburton, (National Director for GP Access at the Department of Health
- o Peter Horn, National Director, Care Services Improvement Partnership
- o Bob Macdonald, Policy Advisor at the Department of Health
- o English PCT Chief Executives and Commissioning Managers
- o Scotland Health Board Chief Executives
- o Wales Health Board Chief Executives
- o Northern Ireland Health Boards Chief Executives
- o NHS Trust Chief Executives and private sector Chief Executives throughout the UK
- o Directors of Nursing in NHS Trusts and the private sector throughout the UK
- o General Secretary for the Royal College of Nursing (Peter Carter) and Royal College of Midwives
- o Department of Health Chief Executive (David Nicholson)
- o Chief Nurse for England (Christine Beasley), Scotland (Paul Martin), Wales (Rosemary Kennedy) and Northern Ireland (Martin Bradley)
- o Chief of the Health Professions Council (Karen Middleton)
- o President of the Nursing and Midwifery Council (Nancy Kirkland)
- o Chief Executive of NHS London (Ruth Carnell)
- o Chief Executives of Strategic Health Authorities.

The key organisations we need to tell about the findings of our research are:

- o Health trusts local to Health Assessment locations
- o Department of Health
- o English PCTs
- o English Strategic Health Authorities
- o NHS National Services Scotland
- o Disability Alliance UK
- o Universities that specialize in medical and healthcare training throughout the UK
- o Medical Colleges, e.g. Royal College of General Practitioners
- o British Society of Audiology
- o British Psychology Society
- o British Medical Association
- o NHS Library
- o Scottish Health Council
- o Wales Local health Boards
- o Wales NHS Trusts
- o Northern Ireland Health Councils
- o Northern Ireland Health Board

Deaf people need to know where they can get health information when they need it, and need to have a broader understanding of what symptoms indicate what disease, how to reduce risk of disease and how to manage long-term conditions.

What actions will they need to take?

With empirical evidence of poorer Deaf health, organisations can use existing indicators/incentives to address inequalities for Deaf people. They could also introduce new measures (e.g. annual health check for Deaf people or BSL materials) and improve data systems so they can record and track Deaf patients.

Deaf individuals need to take active steps to live a healthier lifestyle (stop smoking, increase exercise, eat fruit and vegetables etc), and need to access BSL health information when they need it.

Are any of these actions more important than the others? Explain your answer.

It is difficult to weigh actions against each other. Some may have the potential to save the lives of a few people. Others may have a less dramatic effect but on a greater number of people.

How will you make sure these happen?

Change within the Deaf population

We will ask Deaf participants about the impact of the study on their personal health, knowledge and lifestyle, and we will ask Deaf-led partner organisations about the impact of the study on the health attitudes, experiences and knowledge of their local Deaf community.

Change within the health service

Political pressure will be required at all levels of the health service. This will include local partner organisations applying pressure on local health services. It will also require national lobbying of ministers and DH officials.

We will ask Deaf participants and Deaf-led partner organisations about the quality of their communications with their local health trusts, and any changes they experience in local service delivery.

We will ask leaders at the London Conference to pledge to make changes and specify which recommendations they intend to implement and in what time frame.

SignHealth will use the research as a major focus for its campaigning work and will do everything it can to make sure the recommendations are implemented. We will make sure these have actually happened, by undertaking a follow-up survey of leaders two years after study completion.

To what extent are the individuals and organisations identified above aware of or involved in your project?

SignHealth has communicated extensively with the Deaf-led partner organisations, and 59 have 'signed up' as partners to the study and have agreed to be actively involved in the communication and dissemination of the research findings. Development of this study has been driven by the Deaf community's frustration at lack of access to health services, and they welcome this research proposal. For example, our Chief Executive recently spoke at Merseyside Deaf Society and all 150 people in the room wanted to be involved there and then.

We already have informed DH officials such as Surinder Sharma, Ian McPherson, Bob Macdonald and Mike Warburton about this proposed research. All the key people and organisations we have spoken to are supportive of the research and have said they will welcome the evidence.

RG - Section 4: Delivering your project

Project Delivery - page 1 of 2

You must attach a project plan that:

- **sets out a detailed plan of your activities for the first 18 months of your project (for example, a Gantt chart)**
- **provides an outline plan for the remainder of your project**
- **which identifies the main tasks, activities, milestones and deliverables**

Your plan must include the information we ask for below. If it does not meet this requirement we may consider your application to be incomplete and it may not be assessed.

Your detailed plan for the first 18 months of your project must include:

- the main tasks to be completed, their target completion dates, and associated milestones/deliverables
- a breakdown of the main tasks into their principal activities, the output of these activities and their target completion dates. You do not have to detail every activity you will carry out, but you must provide sufficient detail for it to be clear how you will achieve your project milestones and deliverables within the project timetable and budget
- a clear indication of which organisation is responsible for delivering each task and its associated activities, particularly where the activities are run by more than one organisation
- all project monitoring, governance and evaluation tasks
- all dissemination activities.

If you plan to achieve one or more of your project outcomes during the first 18 months of your project, you must show clearly which outcomes you will achieve and when, and how the tasks and activities you have identified contribute to achieving the outcomes. You should also include the evaluation activities that will allow you to demonstrate you have achieved the outcome.

Your outline plan for the remainder of the project must show clearly:

- the project outcomes you will achieve and the date these will be achieved
- the main tasks to be completed, their target completion dates, and associated milestones/deliverables. It must be clear how meeting the milestones associated with the tasks will enable you to deliver the outcomes of your project
- project monitoring, governance and evaluation tasks, including those activities that will enable you to demonstrate you have achieved the project outcome(s)
- planned dissemination activities
- which organisation is responsible for delivering each task.

If you expect to achieve one or more of your project outcomes after your project ends, your outline plan must also show when these outcomes are likely to be achieved and how you will show that your project has achieved these outcomes.

If your project will take 18 months or less, your detailed plan must cover the lifetime of your project.

* Project Plan attached?

[DeafHealth_merged comms and gantt.pdf \(753 KB\)](#)

Complete the following table for each outcome you listed in 'Section B: Your Project' and the date that each step will be completed.

Outcome 1

Enhanced health attitudes, knowledge and actions amongst the Deaf community.

	Milestone	Timescales
* 1	80% self-reported increased understanding about personal health and healthy living.	After completion of health assessment
* 2	80% of partner organisation staff report increase in general health knowledge and healthy living amongst local Deaf community.	After completion of health assessment in each locality
* 3	Partner organisation staff report increased healthy living behaviour amongst local Deaf community.	After completion of health assessment in each locality

Outcome 2

Greater awareness amongst NHS commissioners and providers about improvements that could tackle Deaf health inequalities highlighted by the study.

	Milestone	Timescales
* 1	Self-reported improvements in access to health information, diagnosis and treatment from Deaf people and partner organisations, as surveyed by SignHealth.	End of year three
* 2	Self-reported awareness from commissioners and providers attending dissemination events about practical measures that could be taken to reduce Deaf health inequalities	End of year three
* 3	An increase in references to Deaf health in DH and NHS literature, particularly the GP Access Programme and Equalities programme.	End of year three

Outcome 3

Improved evidence base into the health of Deaf people.

	Milestone	Timescales
* 1	Research in the public domain	End of year three
* 2	Research accepted by a peer-reviewed journal	End of year three

* 3

Research found in literature reviews.	End of year three
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Project Delivery - page 2 of 2

* Will you work with other organisations on your research?

Yes

How many other partners are involved (tick one box only)

1

Each partner must complete the form in Annex 1

How will you make sure your research project is well managed, including any partnership arrangements? Describe the make up of your research team, including any partners. Outline the management structure, highlight the key project staff, their accountabilities and lines of reporting and communication.

Describe here

The Research Advisory Committee will determine the direction of the study. SignHealth will have overall responsibility for managing the project, and will enter into a legally binding agreement with Bristol University. Agreements will also be made with Remark! (a media and training company which works with both Deaf and mainstream organisations) which will film and translate BSL materials, and a company delivering private mini-medicals.

Overall responsibility for the study will rest with the Trustees of SignHealth. The Chief Executive of SignHealth will report to the Trustees, and will line-manage the DeafHealth Collaborative Study Project Manager, Paul Stemman.

Paul Stemman will be responsible for the day to day delivery and implementation of the project (Project Manager), under guidance from the Advisory Committee, which will meet every six months. Research Advisory Committee members will also be available to give individual advice and information to the Project Manager at any time.

The Project Manager will oversee communications with all partner organisations and communication and dissemination audiences. The Project Manager will oversee the day-to-day commission of the contract with Bristol University.

Bristol University's team will be led by Prof. Jim Kyle, from the Department of Deaf Studies. He will co-ordinate input from Bristol University. Their team will include Deaf researchers and health researchers from the Department of Social Medicine. Researchers from the Social Medicine Department will be supervised by a professor from that Department. That professor will work closely with Prof Kyle to ensure the research is robust and is appropriate for a Deaf population. They will oversee Bristol's work, with Prof Kyle providing the main link to SignHealth's Project Manager. Different researchers from within both departments will be used for different aspects of the work (as it involves both quantitative and qualitative research).

The Deaf Studies Department has considerable experience of research with the Deaf community, including health studies, e.g. Deaf Health in Scotland (1997). In the 2008 Research Assessment Exercise, the Social Medicine's Department's Epidemiology and Public Health research was ranked 4th in the UK, with 35% rated 4* (world leading); and its Health Services Research was ranked 3rd, with 80% rated 3* or 4* (world leading or internationally excellent).

A Governance Diagram is available on request.

Does your organisation (and any delivery partners) have either:

* Accreditation to a recognised quality assurance or management standard ISO 9001, ISO 14001, PRINCE 2, Investor in People etc

Yes

OR

A quality assurance policy / quality manual that will apply to this project

If your organisation has neither of the above, how will you make sure your research is carried out to a high standard?

(empty)

* If your application is successful, how many staff positions will be paid for by this

8

grant?

You must complete the form in Annex 2 for each of the key staff on your project, including those of any partners. Outline their specific roles and responsibilities and highlight their relevant experience.

How will you track financial expenditure on the project?

Financial tracking will be achieved using existing systems that are used by the charity. The Project Manager will be required to sign-off expenditure and this will need to be counter-signed by the Chief Executive for large amounts.

The Head of Finance will be responsible for processing all payments and tracking expenditure. Regular reports will be run to monitor expenditure compared to the budget. Expenditure will be cost-coded so that the accounts software can keep an accurate record of all transactions.

The Project Manager currently submits a weekly timesheet and this will include a breakdown of time spent on the research. This means proportionate costs can be recorded and allocated to the appropriate budget line.

The Head of Finance will produce monthly management accounts for the project. This will allow us to see how we are performing compared to the budget and prepare for any shortfalls.

RG - Section 5: Monitoring your project

How will you monitor and report progress on your Project? Include all progress reporting to the Grant Manager, stakeholder groups and governance groups etc.

Prof Jim Kyle will give regular updates and submit written reports to the Project Manager at the completion of each stage. These will relate to the findings and will include description of the methodology, progress, issues, etc.

The Project Manager will keep accurate records to monitor progress, and will write regular reports every two months. These will report on what has been achieved and how this tallies with the workplan and planned outcomes. Any slippage or potential issues will be highlighted in the report, along with explanations and plan revision. These reports will be submitted to the BIG Grant Manager, SignHealth trustees, the Research Advisory Committee and online for Partner Organisations.

Because the research is staged, there are key milestones. Most of the internal milestones are straightforward (e.g. has the consent form been developed). Analysis of more complicated or qualitative issues (such as problems arising, effectiveness of partnership working, conflict of interests and new risk identification) will require descriptive summaries.

How have you involved the beneficiaries of your research in monitoring your project?

The Deaf-led partner organisations will play a key role in monitoring the success of the project, both in terms of reaching its milestones and achieving its outcomes. They will work with the Deaf researchers to collect information about number of participants, changes in participants' health knowledge/awareness/actions and changes in local service delivery.

Deaf individuals will play an integral role in monitoring the project through membership of the research team, Advisory Committee and SignHealth Board of Trustees. All Deaf participants will be fully informed of the results and impact of the research study, and asked to give their feedback on 'customer service' issues (such as quality of incentives etc).

We will use the DeafHealth website to communicate project monitoring and provide downloadable reports. The website will facilitate communication and encourage Deaf people to comment on the research and its methodology. We are keen to have very open dialogue so we can learn from Deaf people's experience. An e-list of people who want to be kept up-to-date with the project's progress has already been created.

RG - Section 6: Risk management

Complete the risk matrix below for key project risks using the categorisation below as described in the application form guidance notes

Impact/ Likelihood	Likely	Possible	Unlikely
Severe	High	High	Medium
Moderate	High	Medium	Low
Minimal	Medium	Low	Low

Project risk matrix

	Description of event	Potential Impact	Likelihood	Project risk	Risk Mgmt	Lead Responsibility
Event 1	Insufficient number of people willing to take part in health assessments	Severe	Possible	High	Strong support from Deaf-led local groups. Attractive incentives, Stress confidentiality protocols.	SignHealth
Event 2	Loss of, or problem recruiting, Deaf researchers	Severe	Unlikely	Medium	Well paid, incentives, excellent supervision and support	Bristol University
Event 3	Loss of data	Severe	Unlikely	Medium	Backups and security measures	Bristol University
Event 4	Many Deaf participants fail to attend mini-medicals	Moderate	Possible	Medium	Attractive incentives, string support from partner organisations	SignHealth
Event 5	Confidentiality/ ethics breached	Severe	Unlikely	Medium	Clear ethics and confidentiality protocols, excellent supervision, training for Deaf researchers and support	Bristol University

				workers	
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How have you identified the project risks? For example, have you assessed your projects weaknesses and any threats to its successful completion, carried out a feasibility study or consultation?

Explain here

A workplan has been used to identify each stage of the project and assess what potential risks there might be, the affect of these and the possible solutions. Key staff who will work on the project have helped identify risk areas, and other members of staff who regularly conduct risk assessments.

How have the key stakeholders in the project contributed to the risk assessment?

The Advisory Committee met on May 8th in London, where they advised on the risk assessment of the project. Members highlighted particular issues regarding ethics, confidentiality and recruitment of Deaf BSL fluent researchers.

Alternatively, if you have already carried out a project risk assessment using a similar approach you can attach it to your application here.

* Project Risk Assessment

No file.

RG - Section 8: Beneficiary monitoring

Ethnic background of direct beneficiaries - page 1 of 3

This information is being gathered for monitoring purposes only and will not be used to assess your application.

The Big Lottery Fund is obliged to collect data on the beneficiaries of the grants it may make. You must answer all questions, giving details where required. The information is for monitoring purposes only and will not form part of our assessment.

* Is your project directed at, or of particular relevance to, people from a specific ethnic background?

If you have answered 'No' please go to the next question. If you have answered 'Yes' please indicate the ethnic background of the people who will benefit from your project, selecting up to three categories

England

Wales

Scotland

Northern Ireland

Gender

* Is your project directed at, or of particular relevance to, people of a specific gender?

Please select Male or Female

Age

* Is your project directed at, or of particular relevance to people of a particular age group?

Please select the age group your project targets

Ethnic background of direct beneficiaries - page 2 of 3

Disability

* Is your project directed at disabled people, or of particular relevance to people with disabilities?

Yes

Faith

* Is your project of particular relevance to people of a specific faith?

No

Please indicate the faith of the people who will benefit from your project (you may select more than one)

Sexual orientation

* Is your project directed at, or of particular relevance to, lesbian, gay or bisexual people?

No

Welsh language

* Please indicate how many of the people who will benefit from your project speak Welsh by selecting one of the options

None

Community background (Northern Ireland only)

Please indicate which community those benefiting from your project mainly belong to by selecting one of the options

Mainly Protestant (more than 60 per cent)

Marital Status (Northern Ireland only)

Is your project directed at, or of particular relevance to, people of a particular marital status?

Please indicate the marital status of the people who will benefit from your project