



**UK NATIONAL EYE HEALTH AND HEARING STUDY**  
CASE FOR INVESTMENT  
**August 2019**

In Strict Commercial Confidence  
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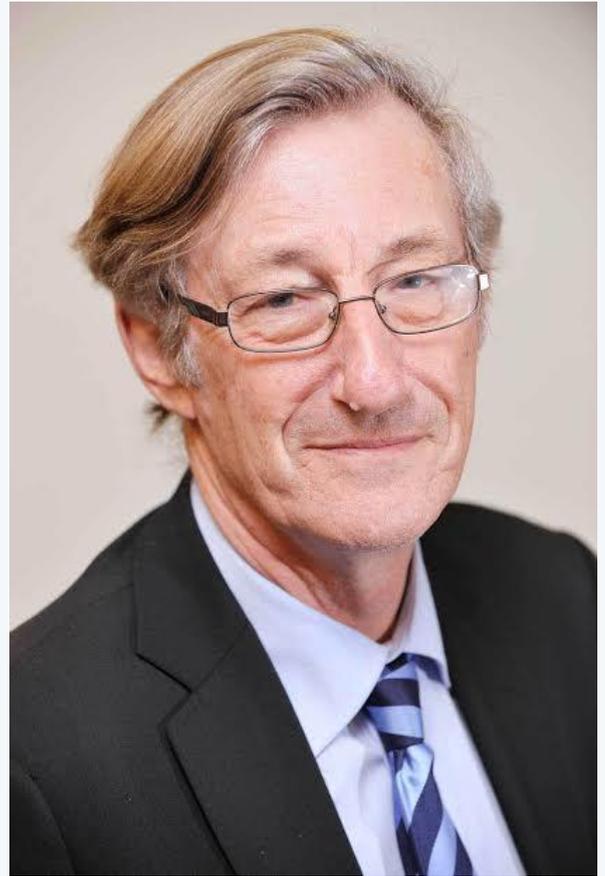
## Foreword



Studies of the epidemiology of particular disorders play a crucial role in their prevention and in planning services for treatments.

Sadly, there have only been very modest attempts to investigate the epidemiology of eye health and hearing loss.

The proposed UK National Eye Health and Hearing Study (UKNEHS) will do much to address these deficiencies and will enable services to be more appropriately planned as well as making serious inroads into prevention.



Sir Michael Rawlins GBE, FMedSci, MD, FRCP.



I fully support the objectives of this survey which aims to provide precise quantitative information on the prevalence and causes of visual and hearing loss.

Up to date information of this kind will crucially inform policy and services in this vital area.

Lord Low of Dalston

My name is Raj Mehta.

As the chair of the Steering Committee for the UK National Eye Health and Hearing Study (UKNEHS) it is a great pleasure to introduce this investment case to you. This takes the reader on a journey, explaining why a UKNEHS is desperately needed, why government investment is required and what the return on investment this study will deliver for the government, non-governmental organisations and the people of the UK.



Most of my life I have been blind and as such have a personal understanding of the importance of early diagnosis and prevention, and the emotional impact of sensory loss. Since I retired from BP several years ago where I held leadership roles in IT and Procurement, I have been pursuing my passion in disability and health. I currently hold a number of roles within the health and voluntary sectors, serving as an advisor, non-executive director, trustee, mentor and trainer.

I am hugely passionate and committed to the success of this work and it has been a privilege and honour to work with some of the most eminent experts and the brightest minds in the UK's eye health and hearing care sector over the last few years. All of our contributors have, like me, worked for hundreds of hours, voluntarily, to bring it to this point. These individuals and organisations include members of the public, the public sector, professional organisations, and charities of the eye health and hearing care sectors. What unites all these organisations and people is that they are hamstrung, because without this project they are unable to organise, deliver or invest in sensory care in the UK in an efficient, evidence-based way.

I am still surprised at the lack of nationally representative data for the UK, while other countries in the World have had government-sponsored studies that have delivered the data required to plan an eye care strategy and measure its cost-effectiveness. For example, Australia has recently completed their National Eye Health Survey with great success and is putting the data produced to excellent use, ensuring that Australians get the care that they need and at a time when it can have the largest impact.

Is it acceptable that in the UK an estimated 50% of people with vision loss have a preventable cause? Or that 100 people under 40 last year lost their vision due to glaucoma? Or that there are 11 million people living with hearing loss who would

benefit from intervention? I join a growing number of people who think this is a disgrace, in what we assume to be a universal system of healthcare. There are huge variations in access to care across the UK, despite the opportunity for early diagnosis and prevention, and we need to better understand these barriers.

This study will focus its findings across four key objective areas; Effectiveness, Efficiency, Economy and Compliance and will include and support digital innovation. Ophthalmology is a leader in this area, including technological applications. The UKNEHS will apply such innovative strategies to produce a live dataset of the population's sensory health, and how this interrelates with many associated issues such as general health, cognition, social isolation, and barriers to uptake of care. Only by doing this can we devise targeted strategies for the alleviation of unnecessary sight and hearing loss, and deliver a reduction in associated costs to the UK economy. Importantly, the UKNEHS will enable us to evaluate the services that we currently have, and help us to better understand why people are still going blind due to preventable conditions, or are living with correctable impairing sight or hearing loss.

What is proposed is a critical first stage in delivering a step change in sensory health in the UK. We have amassed the brightest minds from this country's ophthalmology, optometry, orthoptics and hearing loss communities to propel this project forward. At a cost of 0.17% of the ~£3.5 billion spent on eye care and hearing loss alone each year in England alone, funding this study would represent a sound investment to better target overall spend, and deliver earlier diagnosis and preventative treatments in line with the recently published NHS Long Term Strategy. Government investment in the UKNEHS study would not be new money; it would allow spending of existing money with far more impact, while encouraging a dramatic increase in awareness and care at an individual level in our country.

**Raj Mehta**  
**Chair – UKNEHS Steering Group**



High quality data for UK hearing, eye-health and vision



As Chief Executive of Vision UK I am pleased to introduce the Business Case for the UK National Eye-health and Hearing Study (UKNEHS). As the independent partnership organisation that works with organisations across the eye health and sight loss sector and beyond, Vision UK works for the benefit of people living with visual impairment and blindness, their communities and the UK population.

Vision UK has three priority areas, and I am clear that the UKNEHS will provide vital evidence to support vital work in each of these key aspects of our work.

**Priority 1: Improve the nation's eye health and end sight loss.** The UK has universal health care, and yet we still have people losing their sight due to preventable or treatable causes. Unless we have the accurate, up to date information that the UKNEHS will give us about the services we currently provide, where they are working and where we can improve them, we cannot hope to stop people needlessly losing their sight.

**Priority 2: Improve support across health and social care services.** Some of the evidence that we currently rely on comes from the Certificate of Visual Impairment (CVI) dataset and the registration datasets. But we know that not everyone with severe visual impairment or sight loss gets a CVI, and of those that do get CVIs, not all choose to be registered. We are in danger of failing in our efforts to target health and social care services to provide the most appropriate support in the places where it is most needed if we don't have the data the UKNEHS will produce.

**Priority 3: Improve awareness of sight loss and create an inclusive society for all.** Vision UK considers raising awareness of eye health and sight loss as key to working with sector partners, government and the public to ensure that the UK is a nation in which those who are living with sight loss or visual impairment can participate fully in all aspects of life. The UKNEHS offers a unique opportunity to move eye health firmly into view with the public. By raising awareness, we can improve uptake of services, and increase early detection of eye disease.

Vision UK has a long commitment to supporting collaboration across sectors as well as within our own sector. We have for many years now sought to raise awareness of the additional challenges associated with dual sensory loss. The fact that the UKNEHS will offer insights into hearing and sight is another aspect of the study that Vision UK regards as critical.

Not only is this dual sensory approach efficient and effective, it will produce a unique data set that will ensure that the UK has the evidence needed to inform future planning of services, and to drive innovation in technology, new treatments and effective care and support.

With 2020 on the horizon, I recommend this project as a vital part of the UK's health and social care future.



**Matt Broom**  
Chief Executive, VISION UK





As President of the College of Optometrists, I cannot stress enough the significance of the UK National Eye Health and Hearing Study (UK NEHS).

For optometrists in all clinical settings, and for those involved in research, the absence of up to date, reliable data on the prevalence of visual impairment is a huge barrier to progress. As a sector, optometry and optics has invested in projects such as the National

Eye Health Epidemiological Model (NEHEM), delivered by Imperial College's PHAST team, to try to make the best use of the limited data we have had historically. Projects such as NEHEM, and the College's Enhanced Scheme Evaluation project have demonstrated how limiting working in a data blind spot is, for commissioners and clinicians alike.

Whether it is optimising local resource allocation and prioritisation, or evaluation of practice level data, the fact that we lack reliable information about the UK's eye health is a key barrier to developing better services and providing quality care. We know that living with concurrent visual impairment and hearing loss amplifies the challenges that people face in maintaining their independence and quality of life. The UK NEHS is a vital opportunity to gather data that will enable us to offer local and regional estimates for the prevalence of visual impairment and eye disease, and critically, to combine that with insights into how hearing loss and visual impairment interact.

At a time when we are demanding more from our health services, while increasing the numbers of people needing care and simultaneously seeking to deliver value and contain spending, data is the most important tool we have. We must have reliable data to inform evidence-based practice and service development, and to support innovation and creative use of new technology.

I am pleased that the College has been able to support the UKNEHS from the start, and hope that everyone reading this document will do the same.

Professor Edward Mallen  
President, College of Optometrists.

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## Executive Summary

The purpose of this document is to request UK Government funding for vital research, which can enable a step change in the way eye health and hearing services are delivered in the UK. We put forward the case for a UK National Eye Health and Hearing Study (UKNEHS) - a collaborative nationwide project developed by Anglia Ruskin University in cooperation with the College of Optometrists, Vision UK, Thomas Pocklington Trust, Royal College of Ophthalmologists and other partner organisations across the eye health and hearing sectors. A UKNEHS is being developed to address the desperate need in the UK for high quality, up-to-date data on eye health and hearing loss, so that the UK can plan future services in the most effective way, improve outcomes for those affected, and develop a more effective public health strategy in these crucial areas.

The UKNEHS is a nation-wide study encompassing all four nations. It will focus on four key objectives; Effectiveness, Efficiency, Economy and Compliance, with digital transformation opportunities at the heart of the study. More specifically, it will identify the prevalence and causes of vision impairment, blindness and hearing loss in the UK population aged 50 and over, providing an up-to-date and comprehensive picture of the UK's eye and hearing health. The results of this work will feed into a wider programme of activities which will enable us to seriously consider the future screening and prevention of eye disease and hearing loss in the UK.

This case for investment describes the known causes of vision and hearing loss, providing an overview of both the international and national policy landscape for eye and hearing health, and how eye care and hearing services are currently commissioned and provided. Further, it outlines the need for change in these sectors, and the key drivers for this. It explains why this study will deliver the evidence required to drive these changes and deliver the return on investment required to justify this investment. We show how the UKNEHS will be successfully delivered including the governance structure and resources needed and, it outlines how we will ensure objectives are met.

## The case for change

Sight loss has been estimated to cost the UK more than £28 billion per annum and hearing loss more than £30 billion. But we don't have the information we need to improve services and deliver them more efficiently and effectively to reduce this loss. We need reliable, up-to-date data on sensory loss and its main causes if the NHS's Long Term Plan is to be delivered successfully in the eye health and hearing sectors. The plan sets out ambitious goals to offer more options, deliver better support, provide coordinated and timely care in the optimal setting, improving prevention and reducing health inequalities. If the NHS's Long Term Plan is to be delivered successfully for the prevention of sensory loss, our study is essential.<sup>1</sup>

We have no reliable estimates of the number of people at risk of, or living with, vision and/or hearing loss in the UK, which means that it is impossible to direct resources where they are needed most. Datasets currently used rely on estimates imputed from other countries with different health systems and population demographics or use outdated UK samples that are small or not generalisable to the whole population. Thus, there is a total lack of reliable evidence on which to base current, or plan future, delivery of care to meet demand for services, which is growing rapidly year on year.

There is no doubt that many needs are currently unmet, with people presenting late, with conditions which could have been prevented or managed better if detected earlier. Barriers to access such as: lack of awareness of the health benefits of regular sight and hearing tests; and/or delays to treatment caused by lack of capacity, mean that people are irreversibly losing their sight, or living with correctable vision and hearing impairments.

The demand for services is being driven by an ageing population with increasingly complex needs. The rising incidence of Type 2 Diabetes will cause additional pressure. With these increasing demands it is vital that we provide reliable estimates of the dimension of these demands in order to support service planning and modelling for the future.

Sensory loss is an area of healthcare delivery where there is great scope for innovation – there is an opportunity to deliver services across settings of care with increased coordination using technology, such as Artificial Intelligence and telemedicine. The UKNEHS will help government identify where these opportunities exist, implementing the NHS's goals set out in the Long Term Plan.

All of this is crucial because sensory loss has such a huge and often neglected impact on people's overall health and wellbeing, influencing their quality of life,

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<sup>1</sup> The NHS Long Term Plan, January 2019

increasing the risk of falls and dementia and potentially reducing independence. As a result, sensory loss has a major economic impact on wider society through effects on peoples' employment, social inclusion, mobility, independence and access to services.

## The solution

The UKNEHS will provide reliable, population-based information about the magnitude and distribution of the most frequent causes of sight and hearing loss. It will offer opportunities to examine risk factors such as demographic and social determinants of health. It will include analysis of current service models across the UK, allowing for the impact of differences to be investigated in relation to the health outcomes produced, enabling evaluation of current models of care, such as the impact of free sight tests in Scotland.

The recently completed, and successful, National Eye Health Survey in Australia (2016) has led to a very positive response from the Australian eye research community and the Australian government who have initiated new policies to address the gaps identified in eyecare delivery. It has led to far greater intelligence and understanding of their population's eye health and vision needs than we currently have in the UK.

A UKNEHS will provide vital information, for health policy makers and those developing and commissioning health services. It will provide a baseline to support future impact assessment of novel eye health and hearing interventions, and service delivery models. This will help the government efficiently and effectively target spending for the delivery of services, and ensure that vulnerable groups can access the services they need to continue to participate fully in society.

Each participant in the UKNEHS will undergo an eye health and hearing assessment and complete a standardised general questionnaire. Interviews and examinations will be conducted primarily at designated clinics. When that is not possible, they will be delivered in the participant's home.

The study will measure the detection and treatment coverage rate of major eye diseases and conditions leading to hearing loss, in order to understand the effectiveness of current services. People surveyed will be asked questions about their access to and uptake of health services. The impact of sensory loss on economic viability and employment will be included.

If a participant has a problem or need identified during the survey, they will be referred onwards and followed for treatment via the appropriate local pathway, providing direct benefits to the individual and their eye health. It is estimated that approximately 1,500 participants will be found to have an undetected eye condition or hearing loss as part of this process.

## Benefits and delivery of a successful UKNEHS

The study will deliver benefit to the 1,500 individuals with previously undetected vision and substantially more with hearing problems, ensuring they receive the interventions needed to treat or manage their condition. It will also offer improved outcomes for people over the long term, by gathering data on prevalence to establish a greater understanding on the causes and incidence of vision and hearing loss. In particular, it will support a better understanding of regional and socio-economic variances in eye health and hearing status and outcomes – enabling us to ensure that those groups in society who may be least well served by current systems, and most at risk, are better understood. Future prevention awareness campaigns will benefit from improved targeting. Patients, UK residents, government and other professional organisations in the eye health and hearing loss sectors will, over the longer term, benefit from up to date information on prevalence, which in turn will support investment in research where it is most needed.

Better targeting of services and increased awareness of eye and hearing health will improve health and wellbeing outcomes for the wider UK population. In addition to improved outcomes for people and greater efficiency in delivering services, there are likely to be significant wider economic benefits if the data from the study is used to impact service provision models. The economic benefit of dealing with preventable and treatable sight and hearing loss is significant – in terms of impacts on the individual, their families/carers, the NHS and social care workloads, and financially on the exchequer.

The UKNEHS project will be led by a team of highly experienced health research professionals and is supported by a number of partner organisations across the eye health and hearing sectors. The project will draw on other similar studies already delivered successfully in Australia, Trinidad and Tobago, Nepal and Bangladesh. This document describes the study proposal, which will be developed in full as part of detailed design phase of work, working closely with Government funding partners.

Once financial sponsorship has been secured, the next stage will be to establish the resources required to proceed to formal mobilisation of the project, including the detailed delivery design and sign-off decision to move forward to procurement. This decision-making point will also confirm that the preferred route and study timetable is deliverable and affordable.

## Introduction and purpose

The 'UK National Eye Health and Hearing Study' (UKNEHS) aims to deliver a nation-wide prevalence study to gain an up-to-date and accurate view of the UK's eye health and hearing, the risk factors associated with sensory loss and an understanding of the wider socio-economic impacts.

Sensory loss is a major public health issue across the UK, which has a substantial impact on general health and wellbeing, and carries a social and economic cost, not only to the individual but also to wider public services and the UK's economy. The evidence that is available shows that our current health and social care services do not adequately address either preventable visual impairment, or correctible sight or hearing loss. The UKNEHS will be the first study in any country to explore an association between eye health and hearing outcomes, and health system access in relation to the index of multiple deprivation.

It will also be one of the largest studies of older adults ever conducted in a high-income country, providing valuable insights on our ageing population and their needs in relation to eye health and hearing loss. Eye health is the primary focus of the study, but the UKNEHS will also use the opportunity to test wider sensory loss, by including hearing in the study. This wider scope will enable greater insights into the sensory health of the UK population, the risk factors underlying sight loss, and the impact of sensory health on wellbeing. By collecting data on sight and hearing at the same time, the value of the study is greatly enhanced with only marginal additional cost compared to gathering the data of eye health or hearing alone.

The study will sample a representative portion of the UK population, which will include groups which may be less well served by current systems, providing invaluable data on why people do and don't access services, and what some of the enablers and barriers to the use of services and adherence to treatment may be.

The project has been developed throughout 2017 and 2018, with significant investment from the eye health and hearing loss sectors. We have reviewed the concept with a wide range of stakeholders, developed outline proposals for how the study will be delivered and defined the costs and consulted extensively with patient and public involvement (PPI) groups, enabling their direct input into the project's design and development. This document represents the next stage in process – to request funding to enable the project to move to final detailed design, procurement of suppliers, followed by delivery. The purpose of this report is therefore to describe our proposal in more detail.

In this document we establish:

- the case for investing in the study;
- our objectives for change;

- how we expect the study to be delivered successfully;
- and what the benefits of investment will be.

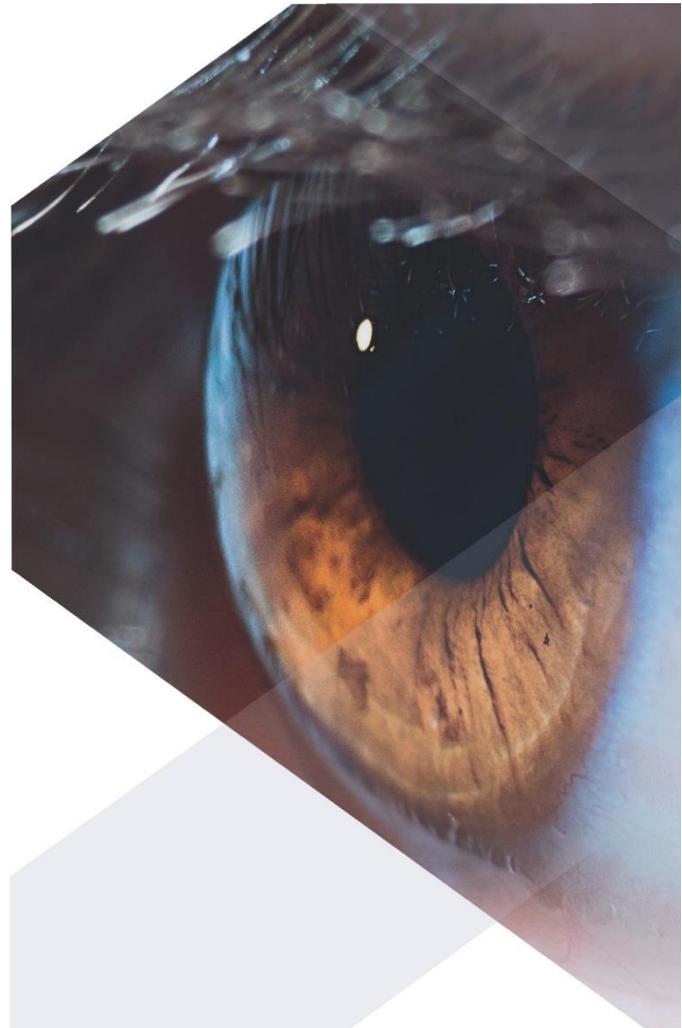
We describe the known causes of vision loss and hearing loss, providing an overview of both the international and national policy landscape for eye health, and how eye and hearing care services are currently commissioned and provided. We will then outline the need for change in the sector, and the key drivers for this. We will describe the solution that we believe is required (the study), the benefits it will bring, and the investment required. Finally, we will outline how we will successfully deliver the UKNEHS including the governance and resources required, how we will measure benefits and ensure that stated objectives are met.

### **Note on hearing**

As the project has developed, and wider stakeholders have been consulted, it became clear that there was an opportunity and need to include hearing in the study. This has been a later development in the process and therefore more work is required as part of the next phase of the project to explore the benefits, costs and delivery approach for hearing, testing this with the appropriate industry-wide stakeholders. For this iteration of this document therefore, hearing has been included in the scope of the project only at a high level.

### **Terminology**

The 'UK National Eye Health and Hearing Study' is a project with the purpose of identifying prevalence and causes of sensory loss in the UK population and disseminating the findings. The survey is part of the overall study and is used in this document to describe the actual sight and hearing test examination as well as the supporting questionnaire.



## The wider programme of change

It is recognised that the UKNEHS project itself will only deliver the outcomes needed, if the data and insights gathered are used to:

- change where and the ways in which services are delivered;
- invest in new technology;
- support greater research investment in the sector and crucially:
- build greater awareness of sensory loss in the UK population.

The study will be a critical project within a wider programme of change, with Anglia Ruskin University being the overall sponsor. Vision UK will lead the non-governmental stakeholder support for the project. Vision UK is an independent partnership organisation which works with organisations in the eye health and sight loss sector, and beyond for the benefit of blind and partially sighted people, their communities and the general population including those at risk of sight loss. With its mission to *“improve the nation’s eye health; address avoidable sight loss and invest in medical research to address currently unavoidable sight loss; join-up eye health and social care services; and promote an inclusive society for all”*, the organisation is well placed to facilitate the coordination of organisations in the eye health and sight loss sector and assist with the delivery of the wider benefits of the study ensuring that investment in this project drives a step change in the nation’s overall eye health.

To this end, Vision UK has, with the support of its partners, created a structure around four strategic areas where improvements are most needed and where change will be the most impactful. These groups are: epidemiology, evidence and statistics; research, cures and treatments; services, support and care and; public understanding of eye health and sight loss. These Vision UK priority areas fit very well with the four focus areas of the UKNEHS - Effectiveness, Efficiency, Economy and Compliance.

This document therefore will only go through delivery of the study in detail, noting where there are dependencies with the wider programme.

## Note on UKNEHS sponsorship

The UK National Eye Health and Hearing Study (UKNEHS) is a collaborative nationwide project developed by Anglia Ruskin University in cooperation with the College of Optometrists, Thomas Pocklington Trust, Royal College of Ophthalmologists and other partner organisations across the eye health and hearing sector.

The project is chaired by Sir Michael David Rawlins GBE FBPPhS FMedSci, (Chair Medicines and Healthcare products Regulatory Agency) and the Principal Investigator is Professor Rupert Bourne FRCOphth MD, Consultant Ophthalmic Surgeon at Cambridge University Hospital, Professor of Ophthalmology & Co-Director at Anglia Ruskin University and National Specialty Lead for

Ophthalmology at National Institute for Health Research (NIHR). The core project is composed of a multi-disciplinary team of ophthalmic and hearing loss professionals from the UK and Australia:

- Professor Adrian Davis, Imperial College Healthcare NHS Trust (Charing Cross Hospital) and NHS Right Care
- Richard Wormald FRCOphth, Moorfields Eye Hospital
- Dr Mohamed Dirani PhD, MBA, Principal Investigator, Australian NEHS
- Dr Tasanee Braithwaite FRCOphth, MPH, Moorfields Eye Hospital
- Professor Tunde Peto FRCOphth, Queen’s University Belfast
- Professor Shahina Pardhan PhD, MBCO, Anglia Ruskin University
- Michael Bowen, College of Optometrists

The UKNEHS also benefits from support, advice and guidance from several organisations across the public sector, eye care sector, professional organisations and industry. Key stakeholders with whom we have engaged and are supportive of the project include:

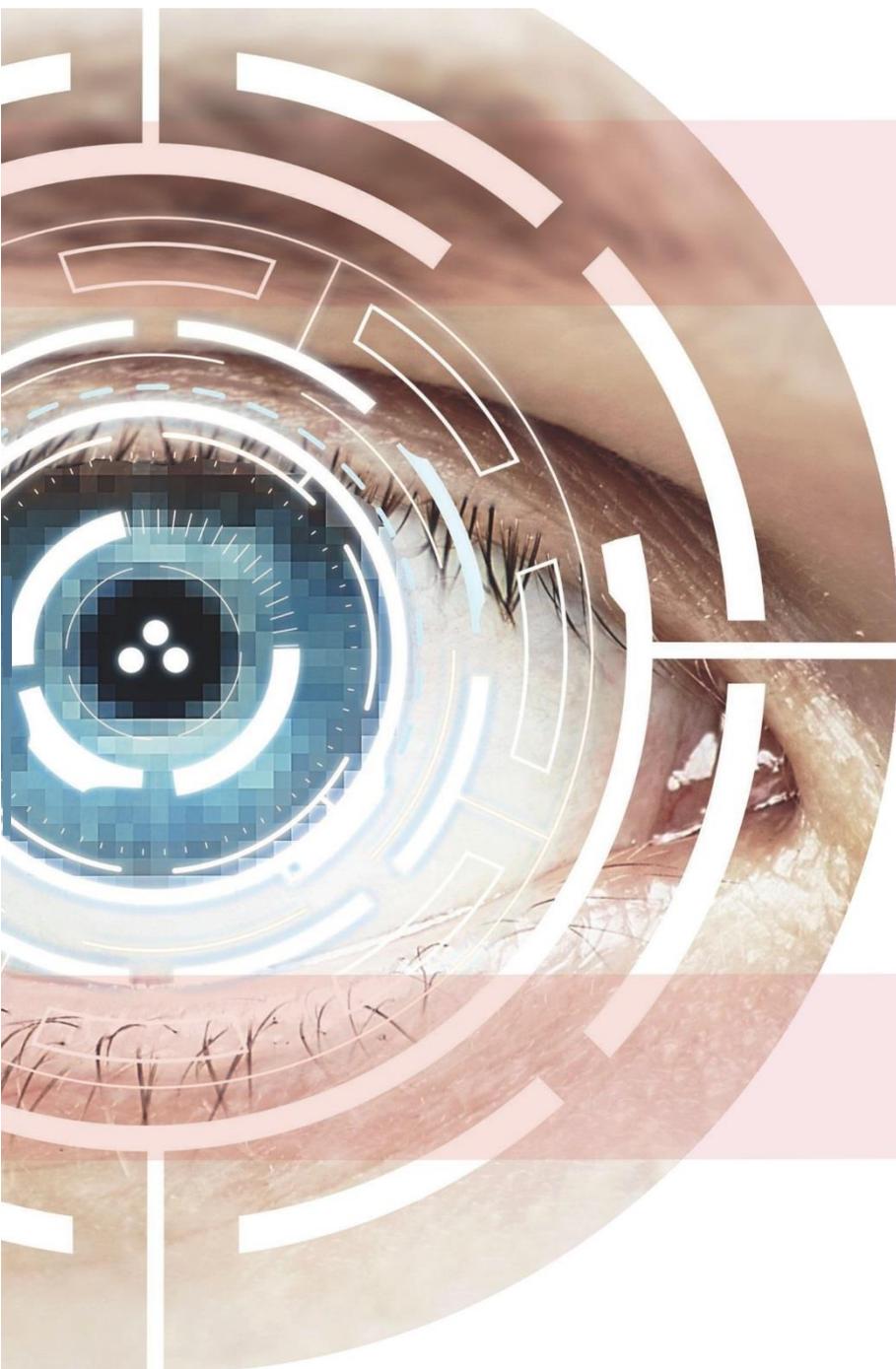
- Lord Low, Co-Chair of the All Party Parliamentary Group on Eye Health and Visual Impairment
- Professor Chris Whitty, Chief Medical Officer, UK Government
- Professor Tony Young, National Clinical Director of Innovation, NHS England
- Dr David Geddes, Head of Primary Care Commissioning, NHS England
- Wales: Optometry Wales.
- Scotland: Optometry Scotland.
- Northern Ireland: Optometry Northern Ireland, and HSC NI.

**Figure 1:** Partner organisations who have signed a memorandum of understanding expressing their support for the project and its aims and objectives



Key stakeholders representing organisations in the hearing sector are as follows, and engagement is ongoing:

- Action on Hearing Loss
- Auditory Verbal UK (AVUK)
- British and Irish Hearing Instruments Manufacturers Association (BIHIMA)
- Hearing Loss and Deafness Alliance
- National Deaf Children's Society



## The case for change

There is a pressing need to raise vision and hearing impairment on the UK health agenda. The Global Burden of Disease Study 2017 measures the world's health burden in 'Years Lived with Disability', (YLDs). Globally, sense organ diseases are the number one biggest contributor to YLDs, outnumbering low back pain, headache disorders and diabetes. Furthermore, sight loss and blindness has been estimated to cost the UK £28 billion and hearing loss £30 billion. But we don't have the data we need to understand how to improve our services to reduce these figures. To effectively and efficiently plan future services, and improve outcomes for the UK population, we are in urgent need of reliable, up-to-date data on sight and hearing health and impairment.

This section outlines the current situation and context for change, the drivers for change, the gap in current provision and how the UKNEHS will meet this gap.



## The context for change in UK sensory health

This section describes the background to eye and hearing health in the UK and the known causes of vision and hearing impairment. It sets the scene in terms of the wider international and national policy context and describes how services are currently delivered across the UK at a high level.

### Introduction to eye health in the UK

Vision impairment (VI) can be broadly defined as a limitation in one or more functions of the eye or visual system, most commonly impairment of visual acuity (sharpness or clarity of vision), visual fields (the ability to detect objects to either side or above or below the direction in which the person is looking), contrast sensitivity and colour vision.<sup>2</sup> Common definitions used in the UK are as follows:

- Blindness is defined as best-corrected visual acuity of <math><3/60</math> in the better-seeing eye
- Vision impairment is defined as best-corrected visual acuity of <math><6/12</math> to <math>6/60</math> in the better-seeing eye, and is categorised as:
  - > Mild sight loss – best-corrected visual acuity of <math><6/12</math> but better than or equal to <math>6/18</math>; and
  - > Moderate sight loss – best-corrected visual acuity of <math><6/18</math> but better than or equal to <math>6/60</math>
- Sight loss is defined as partial sight or blindness in the better-seeing eye

Vision impairment affects a significant proportion of our population. Widely cited estimates date back to 2008 from an analysis that used small local non-nationally representative English community samples and a few Western European and Australian studies, some which were performed a long time ago. It was estimated that around two million people in the UK were affected with partial sight, 218,000 of whom were blind.<sup>3</sup> It was predicted that by 2024 there would be 2.4 million people living with sight loss, and by 2034 this number would have increased to over 3 million.<sup>4</sup> That analysis estimated that around 250 people start to lose their sight in the UK every day and that more than two million people in the UK were living with sight loss severe enough to have a significant impact on their daily lives, including not being able to drive. Yet almost one in four people were thought to be ignoring the first signs of sight loss and had not yet sought advice from an optician or medical professional.<sup>5</sup>

We know that sight loss affects social groups and age groups in different ways. For example, women are significantly more likely to be affected with vision loss than men; in 2008 around 60% of people with sight loss were estimated to be

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<sup>2</sup> RNIB, 'Future sight loss UK: The economic impact of partial sight and blindness in the UK adult population', 2009, page 2

<sup>3</sup> RNIB, 'Future sight loss UK: The economic impact of partial sight and blindness in the UK adult population', 2009, page 36

<sup>4</sup> Office for National Statistics, 2016-based population projections

<sup>5</sup> RNIB, 'The State of the Nation Eye Health 2017: A Year in Review (2017)', pp1-10

female and 40% male. We also know that people with learning disabilities are roughly ten times more likely to experience serious sight loss than the general population<sup>6</sup>, and that people from black and minority ethnic communities are four to eight times more at risk of developing certain forms of glaucoma and diabetic eye disease.<sup>7</sup> Older people are the most at risk, with probably more than one in five people aged 75 and over living with sight loss.<sup>8 9</sup>

Previous studies also indicate a geographical disparity in need and deprivation across the UK. Analysis of the 2013 Global Burden of Disease study in England found that the proportion of the population in the most deprived group ranges from 7.3% in South East England to 32.8% in North West England. For the least deprived group, this proportion ranges from 7.9% in Greater London to 34.8% in South East England.<sup>10</sup> There is much evidence to suggest that deprivation has a direct impact on health inequalities, particularly among older people.<sup>11</sup>

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<sup>6</sup> Seeability, 'Delivering an Equal Right to Sight' 2016, page 4

<sup>7</sup> Wormald et al., 1994; Cross et al., 2007; Pardhan et al., 2004; Sivaprasad et al., 2012)

<sup>8</sup> RNIB website <https://www.rnib.org.uk/nb-online/eye-health-statistics>

<sup>9</sup> Evans JR, Fletcher AE, Wormald RP; MRC Trial of Assessment and Management of Older People in the Community. Causes of visual impairment in people aged 75 years and older in Britain: an add-on study to the MRC Trial of Assessment and Management of Older People in the Community. Br J Ophthalmol. 2004 Mar;88(3):365-70

<sup>10</sup> Newton, 'Changes in Health in England, with analysis by English regions and areas of deprivation, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013), page 3

<sup>11</sup> The Kings Fund, 'Inequalities in Life Expectancy: Changes over time and implications for policy' 2015

### *The known causes of vision impairment and loss*

The five leading causes of vision loss and blindness were identified by the RNIB Future Sight Loss Report<sup>12</sup>, and in the 2018 paper by Pezzulloa, Streatfield, Simkiss and Shickle<sup>13</sup>. It should be noted that this data has significant limitations, as discussed further below, but serves as a guide for the overall areas.

**Table 1: Leading causes of sight loss and blindness and estimated contribution to overall burden of sight loss and blindness**

Cause	Definition	UK estimated percentage of total sight loss and blindness <sup>14</sup>
<b>Age-related macular degeneration (AMD)</b>	AMD is an incurable eye disease and a leading cause of blindness in elderly people in developed countries. It occurs with degeneration of the macula – the part of the retina that enables central vision and seeing fine detail.	17%
<b>Cataract</b>	A cataract is the clouding of the eye’s natural lens caused when proteins in the lens start to clump together. Over time, the cataract may grow larger and cloud more of the lens, making it hard to see and requiring surgery to remove the cloudy lens.	14%
<b>Diabetic Retinopathy (DR)</b>	Diabetic retinopathy is a complication of diabetes, usually affecting both eyes wherein microaneurysms develop on the tiny blood vessels inside the retina. It often has no early symptoms. As the disease progresses, some blood vessels that nourish the retina are blocked, causing vision loss through either proliferative retinopathy* or macular oedema**. It is treated through focal laser surgery or intravitreal injections.	4%
<b>Glaucoma</b>	Glaucoma is a group of diseases that occurs when the optic nerve is damaged, with the pressure of fluid inside the eye the principal risk factor. While initially asymptomatic, it can damage the eye’s optic nerve and result in blindness. Although there is no cure for glaucoma, early	5%

<sup>12</sup> RNIB, ‘Future sight loss UK: The economic impact of partial sight and blindness in the UK adult population’, 2009, pp3-8

<sup>13</sup> Pezzulloa L, Streatfield J, Simkiss P, Shickle D. The economic impact of sight loss and blindness in the UK adult population. BMC health Serv Res 2018; 18: 63.

<sup>14</sup> RNIB, ‘Future sight loss UK: The economic impact of partial sight and blindness in the UK adult population’, 2009, pp45-46

	diagnosis and treatment may help protect eyes against serious vision loss and blindness.	
<b>Refractive error</b>	Under-corrected refractive error (such as myopia and hyperopia) occurs when optical defects result in light not focusing properly on the retina and can be easily reversed with appropriate correction (e.g. spectacles or contact lenses). Pathologic myopia is quite different and occurs in extreme short-sightedness that is associated with major lengthening and elongation of the eyeball. This is associated with degenerative changes in the macula and at times with retinal detachment. This can result in profound sight loss and blindness that will not be corrected with refraction.	54%

*\* Proliferative retinopathy occurs when new blood vessels and scar tissue form on the retina, which can cause significant bleeding and lead to retinal detachment. It carries a significant risk of blindness.*

*\*\* Macular oedema is the build-up of fluid in the macula, an area in the centre of the retina.*

#### *Limitations of existing datasets*

Until now, the UK eye health sector has been reliant on a number of datasets, which have been widely used and cited to inform assumptions about the prevalence and causes of vision loss and blindness. Yet there are severe limitations to this data, including the papers cited above, which mean that the UK lacks a robust evidence-base for eye health.

Despite these limitations, the sector has invested in order to make the most of the data that has been available. A National Eye Health Epidemiological Model (NEHEM) was developed by the Public Health Action Support Team (PHAST) at Imperial College London in 2008, which provided information on the number of people affected with AMD, Glaucoma, Cataract and Low Vision in different areas in the UK. Whilst this study, and online tool for commissioners, offered a useful blueprint and provided an evidence-base for commissioning local eye care services, the data had serious limitations.

Firstly, it uses international prevalence data, not UK data, basing estimated figures for each condition on prevalence from other countries which are very different to the UK (more eye health data are available for nations outside of Europe – data from African nations and Australasia are likely to represent very different sight loss prevalence to the UK). This data was then extrapolated using population data from the 2001 census, which is now significantly out of date and no longer representative of the current UK demographics. In 2016, when the sector reviewed the NEHEM with a view to updating it with 2011 census data, the first conversations about a UK NEHS were being led by Professor Bourne. It

became clear that to be effective, the NEHEM update needed the data that the UKNEHS would produce. The lead researcher from the PHAST team has confirmed that the underlying algorithms in the NEHEM tool would be readily amenable to being updated using UKNEHS data, to produce a revised, more valid and reliable NEHEM tool.

Similarly, the RNIB Sight Loss Data Tool (cited in Table 1) uses data from several different datasets relating to eye health and sight loss. In addition to information from NEHEM, Global Burden of Disease and other models, it also includes summary information from Certificate of Visual Impairment (CVI) data for people registered blind or partially sighted. While CVI data represents some of the most useful data that we currently have, there are limitations to this data set. CVI data is not consistently collected across the UK, and it is very unlikely that CVI data can be generalised to the UK population as a whole. We can't currently predict whether or how well certification data maps to the actual burden or sight loss in the population. For example, the number of people certified with vision impairment due to stroke is much lower than the projected numbers suggest it should be, based on the number of strokes per annum, which suggests that more could be done to ensure that all patients in need are certified.<sup>15</sup> The data that the UKNEHS will provide, would enable us to review CVI data and understand the strengths and limitations of the CVI data set.

It is also important to highlight that the data we do have are all based on people who are accessing services currently – we have almost no information about people who are not regularly (or ever) accessing services and why this is the case. These groups are likely to have high levels of unmet need, which may present to the health system later in a more acute form. The UKNEHS study will close this gap, as it will use a random sample of the population and is specifically designed to target data collection towards traditionally hard to reach individuals.

## **The policy context**

International policy is centred on extensive World Health Organisation (WHO) work on this topic. UK policy is more limited and fragmented, with no single, overarching strategy for eye health. This reflects the delivery of UK eye health services which are highly varied across different parts of the health, public health and social care sectors, and across UK regions.

### *The international policy picture*

In recent years, international policy has acknowledged, and is now addressing, eye health as a global priority. Vision 2020 was launched in 1999 by the World Health Organisation (WHO) as a global initiative that aims to eliminate avoidable blindness by the year 2020. The WHO published a Global Eye Health Action Plan 2014-2019 which set out its vision to create *'a world in which nobody is needlessly*

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<sup>15</sup> Bunce, Zekite, Wormald & Rowe, 'Sight Impairment registration due to stroke – a small yet significant rise?' 2017, Sight Impairment registration due to stroke, page 4.

*vision impaired*'. Predicated on estimates that 80% of all causes of vision impairment are preventable or curable, this identifies the reduction of avoidable vision impairment as a global public health problem and sets out a global action plan to achieve the target of reducing avoidable vision impairment by 25% by 2019.

The Global Eye Health Action Plan calls for governments to invest in reducing avoidable vision impairment through cost-effective interventions, and sets out three objectives for all member states<sup>16</sup>:

1. The need to generate evidence on the magnitude and causes of vision impairment and eye care services.
2. The development and implementation of integrated national eye health policies, plans and programmes to enhance universal eye health.
3. Multisectoral engagement and effective partnerships to strengthen eye health.

Member states have signed up to measure progress at the national level, using three indicators - the prevalence and causes of vision impairment; the number of eye care personnel; and cataract service delivery. However, as Matt Broom, CEO Vision UK has stated *“despite signing up to this action plan in 2014, the UK has not made tangible steps to deliver on this commitment, and indeed with current data sets is not able to baseline, and then measure an improvement in the nation’s eye health in a comprehensive way”*.

### *The national policy picture*

At present there is no single, unified strategy for eye health across the UK. As such, eye health policy in the UK varies by nation and regions.

Policy in England is set by NHS England for primary care services and funding is provided centrally for acute services. There is no national level government strategy for eye health in England. At a primary care level, NHS England’s Five Year Forward View (FYFV) paved the way for new and innovative care models to bring primary, community and acute care closer together and deliver better outcomes for patients. Key points in the FYFV include:

- getting ‘serious about prevention’ through a radical upgrade in prevention and public health, including national action on obesity, smoking, alcohol and other major health risks;
- targeted prevention and evidence-based intervention strategies for conditions such as diabetes;
- a shift to give patients greater control of their own care;
- decisive steps to break down the barriers in how care is provided between family doctors and hospitals, between physical and mental health, between

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<sup>16</sup> World Health Organisation, ‘A Global Action Plan 2014-2019: Universal Eye Health’ 2014, page 7

health and social care e.g. through Primary and Acute Care Systems (PACs);

- Exploration of radical new care delivery options such as integrated out-of-hospital care e.g. through Multispecialty Community Providers (MCPs).

The NHS Long Term Plan outlines a clear focus on properly joined-up care at the right time, in the optimal care setting, investing in prevention and reducing health inequalities and improving integrated and personalised care for people with long term conditions.

In relation to eye health, NHS England have established a number of projects to promote improvements in the sector:

- Getting It Right First Time (GIRFT) focuses on reducing unwarranted variations in the quality of care across the NHS, with a priority workstream on Ophthalmology Surgery;
- NHS Right Care is a programme that seeks to use nationally collected, robust data to help systems make improvements in spend and patient outcomes, identifying opportunities and potential threats;
- Elective Care Transformation Programme works in partnership with NHS organisations and other partners to redesign patient pathways for non-emergency care and test interventions designed by local clinicians and commissioners. There is an Ophthalmology strand which seeks to prioritise treatment and care for patients most at risk, tackling delays in accessing care.

These programmes are all currently in progress, representing a collective ambition to deliver more non-urgent, routine care within the community. The Clinical Council for Eye Health Commissioning (CCEHC), an independent advisory body, works with NHS England across these projects providing evidence-based clinical leadership and advice. The Local Optical Committee Support Unit (LOCSU) also plays a key role at the local level, working with NHS England and commissioners to develop community, enhanced and extended primary care services for eye health problems. Local Optical Committees (LOCs) are recognised by the NHS as the representative organisation for optometrists and dispensing opticians delivering ophthalmic services such as sight tests and other eye health services in a way that is accessible for patients and cost effective for the NHS.

Since the introduction of the new General Ophthalmic Services Regulations, the health and social care landscape has changed significantly in Scotland. The Scottish Government's 2020 Vision set out the Government's strategic vision for delivering quality healthcare services across Scotland and drives its vision for providing more care in the community. A strategic framework was launched in 2014 - *'See Hear: A strategic framework for meeting the needs of people with a*

*sensory impairment in Scotland'*, outlining recommendations for how to deliver seamless care for people with sensory loss.

In Wales, Wales Eye Care Services (WECS) was funded by the Welsh Government to preserve sight through the early detection of eye disease and help support those with vision impairment and loss. The *Eye Health Care Delivery Plan* set out a range of key actions to improve the eye health of the Welsh population through greater collaboration within the health sector, between primary and secondary care and with local government and the third sector. Unlike England, Wales has invested substantially in commissioning local pathways for minor eye conditions, to promote the management of eye health in the community.

*Developing Eye-care Partnerships* (DEPs) is the five-year plan for improving the commissioning and provision of eye care services in Northern Ireland. The Department of Health's strategy '*Developing Eye-care Partnerships – Improving the commissioning and provision of eye-care services in Northern Ireland*' sets out the vision and aim of DEP. The strategy is being implemented jointly by the Health and Social Care Board (HSCB) and Public Health Agency (PHA).

### **The third sector**

The UK also has an active professional and third sector which provides research and policy insights to the eye sector. The Royal National Institute of Blind People, Vision UK, SeeAbility, Macular Society, Thomas Pocklington Trust, Guide Dogs, and International Glaucoma Association are some of the many organisations active in the sector.

The Royal National Institute of Blind People (RNIB) is one of the UK's leading sight loss charities, representing the largest community of blind and partially sighted people in the country. RNIB regularly publishes reports on vision loss and the impact of losing eye health on people's wellbeing and the wider economy. RNIB campaigns and lobbies around three main priorities;

- Preventing avoidable sight loss
- Supporting independent living, and
- Creating an inclusive society

RNIB's State of the Nation Eye Health Report (2017) published an agenda for action, including:

- the need to raise public awareness of the importance of regular eye testing;
- influencing eye care commissioning and services to identify innovative ways of meeting patient needs;
- improving eye health data to facilitate information sharing;
- effective leadership to ensure people receive timely treatment to prevent avoidable sight loss.

In this report, RNIB pledged to present their conclusions to the All Party Parliamentary Group (APPG) Inquiry on Eye Health and Visual Impairment and work with them to ensure higher priority is given to eye health at a senior policy-making level. The APPG published ‘*See the Light: Improving Capacity in NHS Eye Care in England*’ in June 2018, calling for the Secretary of State for Health and Social Care, NHS England, the Department of Health and Social Care, local authorities, commissioners, delivery bodies, NHS providers and sustainability and transformation partnerships (STPs) to act now on eye health.

The report sets out 16 recommendations to address the fact that whilst the NHS provides excellent care to many people, the current system is ‘failing patients on a grand scale’ by failing to adequately tackle avoidable sight loss and allowing delays to treatment.

In addition to several recommendations for NHS England on improving pathways and data collection in ophthalmology departments on waiting times and delays, the report recommends that Local Authorities and Clinical Commissioning Groups review the eye health needs sections of the Joint Strategic Needs Assessments to ensure consistency and assess current and future eye health need. Developing a robust dataset through the UKNEHS will contribute towards this objective, supporting commissioners to make evidence-based decisions so that eye health provision is targeted to areas of greatest need.

Eye health and vision loss is emerging on the national health agenda as a growing issue, but there is more to be done to make a meaningful contribution to the reduction of avoidable eye health disease in the UK.

## **How services are commissioned and provided**

This section outlines the current roles of primary, community and acute care and how ophthalmology services are organised and delivered in the UK. There is a very wide range of different ophthalmology services provided in different settings of care across the country, commissioned by different sectors of the health and social care landscape (primary care, community care, acute care and public health) with little overarching national strategic planning across these sectors and settings of care. This results in regional and local variation in service provision that goes beyond the core of the General Ophthalmic Services (GOS) – some CCGs commission primary eye care services and others do not. It also means that information and data across the sector is even more challenging to gather and align.

### ***Primary care sight tests***

Primary eye care services in the UK are mainly provided under a General Ophthalmic Services (GOS) contract between the NHS and practice owners (contractors), with different contracts in place in England, Scotland, Northern Ireland and Wales. The GOS contract pays a standard tariff for each sight test that is conducted by an optometrist or ophthalmic medical practitioner on behalf of the

NHS. More than two thirds of sight tests are provided under this contract, which is free to the patient at the point of delivery in line with the eligibility criteria defined within each contract. Further information about the GOS contract can be found in **Appendix A**.

Approximately 17 million sight tests are performed each year in England (12 million NHS, 5 million private). The aggregated primary care expenditure for eye health care in 2011-12 was £525 million. The average interval between sight tests is 26 months, however many people do not access routine eye services at all.<sup>17</sup>

Eligibility for free NHS sight tests under the GOS contract in England, Wales and Northern Ireland includes people who are under 16 years of age, under 19 and in full time education, aged 60 or over, registered as sight impaired or severely sight impaired, diagnosed with diabetes or glaucoma, or entitled to an NHS support allowance for other reasons.<sup>18</sup> People who do not qualify for an NHS sight test pay for their sight tests privately. The fees for this are market driven and vary.

In Scotland, free sight tests have been extended to the entire population since 2006. This is a marked difference from the rest of the UK, as it means the GOS service is typically the ‘first port of call’ for any patient with an ophthalmic problem rather than their GP, which is helping to relieve the pressure of growing demand for general practice.<sup>19</sup>

### *Acute services*

The majority of eye care activity is provided in the outpatient care setting, or ‘General Ophthalmology’. Ophthalmology accounts for 8% of the 94 million hospital outpatient attendances and is the busiest outpatient attendance specialty<sup>20</sup>. There has been an increase in total attendances of over 1 million in the past five years and these numbers are set to grow as the population ages and new interventions become possible for previously untreatable conditions such as dry AMD.

General ophthalmology is provided differently in different units, but overall constitutes a large volume of ophthalmic activity. An RNIB review of Ophthalmology services across England carried out in 2018 found that all activity within Ophthalmology in England has increased year on year over the past five years, but there is a large variation across Clinical Commissioning Groups (CCGs).

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<sup>17</sup> NHS England, ‘Local Eye Health Networks: Improving Eye Health and Services’, 2013, page 3

<sup>18</sup> NHS UK <https://www.nhs.uk/using-the-nhs/help-with-health-costs/free-nhs-eye-tests-and-optical-vouchers/>

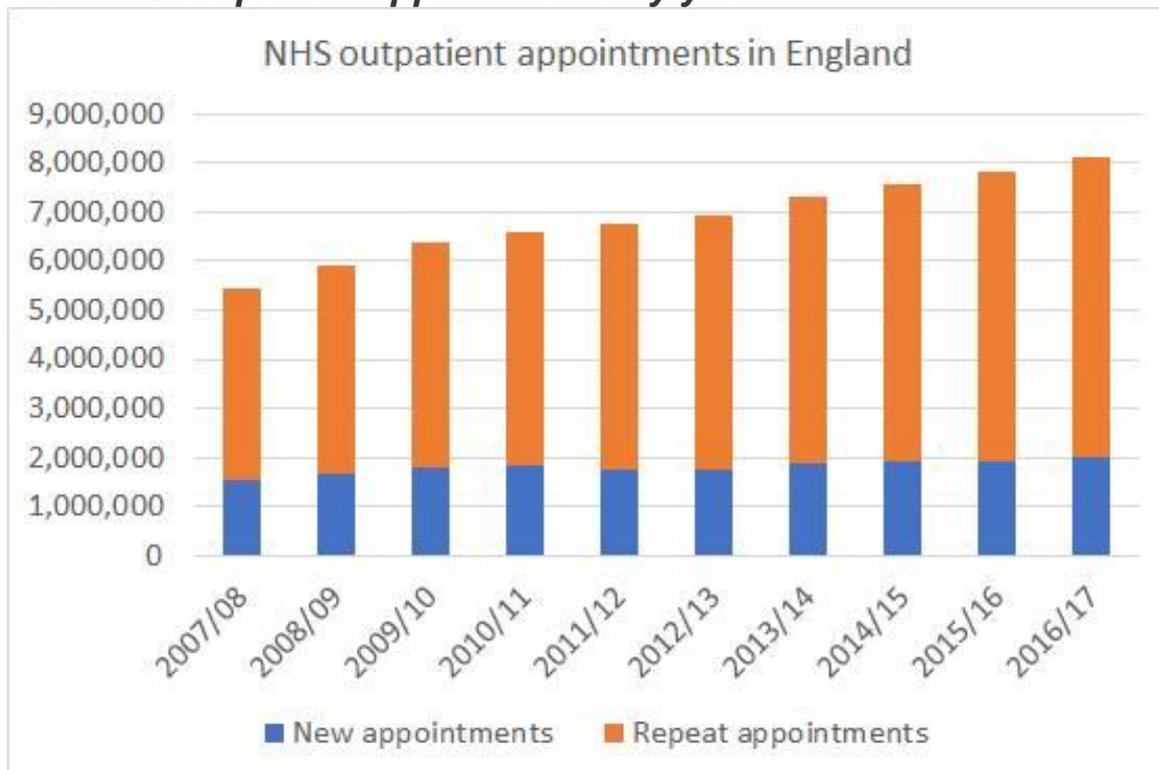
<sup>19</sup> Understanding pressures in general practice. The King’s Fund 2016

<https://www.kingsfund.org.uk/publications/pressures-in-general-practice>

<sup>20</sup> Royal College of Ophthalmologists, ‘Ophthalmic Services Guidance: Primary Eye Care, Community Ophthalmology and General Ophthalmology’, 2018, Page 3.

Ophthalmology will soon become the speciality responsible for the most outpatient appointments across the whole NHS. The largest increase is in repeat appointments, indicating an increase in long term conditions.

**Figure 2: NHS outpatient appointments by year**



21

Source: NHS Digital, Hospital Outpatient Activity by treatment speciality, 2017-18

### Community services

Community Ophthalmology Services (COS) are commissioned by CCGs and are distinct from primary eye care services. In most services, a multidisciplinary approach is used to deliver specific types of care in community settings. They may involve the assessment and management of patients whose eye conditions are at low risk of deterioration, who are either referred by primary care for further assessment or discharged from secondary care for monitoring.<sup>22</sup>

Community optometry practices deliver a series of primary care community services through accredited pathways, designed to be convenient for patients and free up secondary care and GP capacity. The community services pathways are intended to work alongside local hospitals and should be supported by a rapid access pathway for individuals who require referral to Hospital Eye Services. The current community service pathways include:

- Community Eye Care Pathway for Adults and Young People with Learning Disabilities
- Glaucoma Repeat Readings and OHT Monitoring pathway

<sup>21</sup> NHS Digital, Hospital Outpatient Activity by treatment speciality.

<sup>22</sup> Royal College of Ophthalmologists, 'Ophthalmic Services Guidance: Primary Eye Care, Community Ophthalmology and General Ophthalmology', 2018, Page 5.

- Pre and Post-Operative Cataract pathway
- Adult Community Optical Low Vision Pathway
- Children's Vision Enhanced Service Pathway
- Primary eye care Assessment and Referral Service (PEARS) pathway (sometimes known as 'minor eye conditions')
- Minor Eye Conditions Service (MECS)

MECS treat low-risk conditions which do not necessarily need specialist hospital examinations, carried out by specially trained optometrists in convenient locations for the patient. These are however not provided consistently across the UK; for example, there is a nation-wide MECS commissioned in Wales, whereas in England MECS pathways are only available in some areas.

### *Public health*

Public Health England commissions the NHS Diabetic Eye Screening Programme (DESP) to identify people with type 1 and type 2 diabetes aged 12 years or above who may appear to be healthy but could be at increased risk of a diabetes-related eye condition or disease. The DESP team includes ophthalmologists, optometrists and screener / graders. It is coordinated and led nationally, with local screening services provided in line with national quality standards and procedures.

The Public Health Outcomes Framework includes an indicator relating to preventable sight loss, which is currently monitored using CVI data - this monitoring could be strengthened using UKNEHS data.

The Childhood Vision Screening Programme is also commissioned by local authorities as part of the healthy child programme. Although recommended by Public Health England, it is non-mandatory, and the provision of effective screening is varied regionally.

### *Private sight tests*

In England, Wales and Northern Ireland, people who do not qualify for an NHS sight test pay for their sight tests privately. The fees for this are market driven and vary. The basic requirements for NHS and private sight tests are identical but some practices have invested in equipment which allows them to provide more specialised examinations, and they may charge extra for this.

## **Finance and funding**

There is no national tariff or mandate for primary eye care and community ophthalmology services. They rely heavily on new funding and the drive from local commissioners to reconfigure services and break down the traditional barriers between different parts of the eye care sector and different providers.<sup>23</sup>

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<sup>23</sup> RNIB, 'A five-year overview of ophthalmology services across England to establish if there are variations in service provision', 2018

Each year the price of the GOS test in England, Wales and Northern Ireland is set by government after discussions with the Optometric Fees Negotiating Committee (OFNC). Funding is ring-fenced and distributed locally in each area. In Scotland, Optometry Scotland negotiates this fee with the Scottish Government.

Hospital eye services are funded according to national tariffs which are agreed annually. The 2017/18 tariffs set a first attendance with an ophthalmologist in a hospital as £139, with a follow up appointment costing £53.<sup>24</sup> Ophthalmology is the second largest department in the NHS, the cost for total inpatient and outpatient activity in 2016/2017 was ~£1.4 billion, an increase of approximately £332 million since 2012.<sup>25</sup>

**This section has described the national policy context for eye health in the UK, and the lack of a unified UK-wide strategy for eye health that has resulted in a fragmented landscape of service provision that differs across the UK. The UKNEHS represents an opportunity to understand the geographical differences in provision across the different areas of the UK and inform future design of services to address the areas where the need is greatest.**

### The context for change in UK hearing loss

Hearing loss, also known as hearing impairment, is a partial or inability to hear and ranges from mild/slight to profound.<sup>26</sup> Action on Hearing Loss (2015) classifications of hearing loss are as follows:

- Degree of Hearing loss: Mild, Quietest sound heard (dB): 25-39; Effects: Can sometimes make following conversations difficult.
- Degree of Hearing loss: Moderate, Quietest sound heard (dB): 40-69; Effects: May have difficulty following speech without hearing aids.
- Degree of hearing loss: Severe, Quietest sound heard (dB) 70 – 94; Effects: Usually need to lipread or use sign language, even with hearing aids.
- Degree of hearing loss: Profound, Quietest sound heard: 95 dB or greater; Effects: Usually need to lipread or use sign language,

Hearing loss is one of the most challenging health and social issues facing Europe. Globally, the resolution of the World Health Organisation called for countries to integrate strategies for hearing care into health care systems and for greater access to hearing and communication technologies<sup>27</sup>. Communication defines us and underlies our ability to function in the world: to relate to family, friends and partners, have a job, lead productive lives and maintain our health and wellbeing through social connections. 11 million people are living with hearing loss in the UK, which equates to 1 in 6 of the population, however, this number is

<sup>24</sup> NHS National Tariff Payment System 2017/18

<sup>25</sup> RNIB, 'A five-year overview of ophthalmology services across England to establish if there are variations in service provision', 2018

<sup>26</sup> file:///C:/Users/katy.wright/AppData/Local/Microsoft/Windows/INetCache/Content.Outlook/YCEG80VK/Hearit-Report-Hearing-Loss-Numbers-and-Costs.pdf

<sup>27</sup> 'Spend to Save, a European strategy' visit [www.earfoundation.org.uk/research](http://www.earfoundation.org.uk/research)

growing.<sup>28</sup> As our society ages, current predictions are that by 2031 there will be more than 14.5 million people with hearing loss in the UK (Action on Hearing Loss, 2011). There are also different groups of the population that are more affected than others, such as older people and veterans.

Hearing loss affects both those born deaf and later in life; whilst there has been progress in improving the health services available to children, young people and adults over the last ten years, significant challenges remain.<sup>29</sup> More needs to be done on prevention, early diagnosis and support for those who have permanent hearing loss.

Importantly, hearing loss has a wider bearing on health: those with severe hearing loss are at five times the risk of developing dementia<sup>30</sup> as those with normal hearing, and two and a half times more likely to experience depression than those without hearing loss.<sup>31</sup> This has a profound effect on health, and there is a strong correlation between hearing loss and cognitive decline as well as increased use of medical and social services.

Most people who notice a change in their hearing delay seeking help, and those with a severe to profound hearing loss have lived with their symptoms for, on average, ten years before being referred for the most appropriate treatment. When individuals do consult primary care there is considerable variation in subsequent referral. In a health context, only one in three of those with significant hearing loss report problems accessing and using hearing aids. This is despite huge improvements in waiting times, the quality of digital hearing aids and documented improvements in service quality.

Those individuals that do consult primary care still experience problems. A survey of 600 people with hearing loss found that after attending an appointment with a GP:

- just over one-quarter of respondents (28%) had been unclear about their diagnosis;
- around one-quarter (26%) had been unclear about health advice they were provided with;
- approximately two-fifths (19%) had been unclear about their medication.<sup>32</sup>

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<sup>28</sup> European Federation of Hard of Hearing People (EFHOH), 'Hearing Loss: The Statistics', 2015,

<sup>29</sup> Department of Health (2012) Statistical press notice: direct access audiology referral to treatment waiting times data. November 2012, HMSO.

<sup>30</sup> Lancet Commission on dementia: Livingston G, Sommerlad A, Orgeta V, Costafreda SG, Huntley J, Ames D, Ballard C, Banerjee S, Burns A, Cohen-Mansfield J, Cooper C, Fox N, Gitlin LN, Howard R, Kales HC, Larson EB, Ritchie K, Rockwood K, Sampson EL, Samus Q, Schneider LS, Selbæk G, Teri L, Mukadam N. Dementia prevention, intervention, and care. *Lancet*. 2017;390(10113):2673-2734. doi: 10.1016/S0140-6736(17)31363-6. PMID: 28735855

<sup>31</sup> The Ear Foundation, 'Spend to Save: Investing in hearing technology improves lives and saves society money: A Europe wide strategy', 2016, page 2.

<sup>32</sup> 38. Ringham, L. (2012) Access All Areas? Action on Hearing Loss

The quality of and access to services varies considerably across the UK. This is largely due to a fragmented UK policy around hearing loss and the manner in which services are commissioned; a situation replicated in eye health policy. The fragmented state of UK hearing policy belies the cost of hearing loss to society – which is high and escalating. Recent estimates suggest that the UK economy loses £25 billion a year due to reduced productivity and unemployment due to hearing loss. Compared to the national average, unemployment rates for people with hearing loss are much higher with 30% of people of working age with severe hearing loss unemployed. Investing in prevention, early support for individuals, increasing hearing accessibility in the community, and changing social attitudes towards hearing loss is a much more cost-effective solution than dealing with the consequences of unaddressed hearing loss (Archbold et al. 2015)<sup>33</sup>. The direct cost of hearing loss to the NHS current stands at approximately £500 million each year<sup>34</sup>.

This is despite numerous projects having been established and research papers written to promote improvements in the hearing sector, along with estimating the prevalence, cause and impact as well as risk factors. Some of these include:

- DH and NHS Action Plan on Hearing Loss (2015)
- MRC National Study of Hearing (1980s)
- Health Survey England (2014)

Additionally, there are international guidelines and initiatives for addressing hearing loss, including the World Health Assembly Resolution WHA70.13, to which the UK has an obligation to fulfil<sup>35</sup>.

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<sup>33</sup> <https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss>

<sup>34</sup> 2014 Report 'The real cost of adult hearing loss' The Ear Foundation.

<sup>35</sup> WHA resolution - [http://apps.who.int/gb/ebwha/pdf\\_files/WHA70/A70\\_R13-en.pdf?ua=1](http://apps.who.int/gb/ebwha/pdf_files/WHA70/A70_R13-en.pdf?ua=1)

## The need for change

There is very little high-quality data currently available in the UK that identifies people at risk of, or living with, vision or hearing loss. This means that it is very difficult to target resources where they are needed most. The data we do have indicates that there is unmet need in the system, with people presenting for the first time with conditions which could have been treated earlier, building the case for greater investment in prevention. The UKNEHS is projected to identify 1,500 people with previously undetected vision or eye health needs, at a cost of approximately £10,500 per person identified. This should be compared to the estimated annual cost to the UK of £30,000 per year per individual with a vision impairment.

All of this is compounded by the fact that an ageing population and the increasing complexity of need is making the nation's eye health worse overall. In addition, in an era of reducing budgets, resources must be targeted in the greatest areas of need. There is scope for innovation in the sensory loss sector, delivering services across settings of care in a more joined-up way, and using technology to deliver services differently in the future. Better data would help government identify where the opportunities lie.

This is crucial because sensory loss has a huge impact on people's overall health and wellbeing, and as a result a major economic impact on wider society.

This section describes the evidence base and drivers for a UKNEHS.



There is an absence of quality national-level data available for the UK population that identifies people at risk of, or living with, vision loss or impairment. 20 million adults in Europe are estimated to have distance vision loss and a further 29 million cannot see clearly to do everyday tasks such as reading. Studies have been carried out to analyse the data that is available, which has signified a major step forward in relation to understanding vision loss and impairment in the UK. RNIB commissioned Access Economics in 2016 to explore the economic impact of partial sight and blindness in the UK adult population. This report used estimates of prevalence of partial sight and blindness in addition to direct and indirect health system costs.

The prevalence studies used were small local non-nationally representative English community samples and a few Western European and Australian studies, some performed more than 20 years ago. The report is now almost ten years out of date and requires a refresh. Prevalence studies are being carried out internationally, yet this has not been done on a national scale in the UK, or in many EU nations. At present, the number of adults in the UK with vision problems, and the risk factors associated with vision loss, are unknown.

As discussed earlier in this report, there are serious limitations to widely used datasets in the UK such as the NEHEM study, and the RNIB Sight Loss Data Tool. A reliance on international or very small-scale UK datasets means that there is no real or reliable evidence-base to inform the assumptions being made about eye health needs.

The Royal College of Optometrists' report '*Better Data, Better Care*' reports that whilst significant amounts of data are collected through General Ophthalmic Services (GOS) claims, these are not designed for ophthalmic public health work and therefore do not provide the data needed for good decisions.<sup>36</sup> GOS data is also not currently collected in an accessible format, since much is still gathered using hard copy forms, and where any data entry is done, it is usually as batch entry, so much important detail is lost. Research commissioned by the College of Optometrists has shown that there is likely to be scope for improvements in both efficiency and efficacy, with access to better data<sup>37 38</sup>. This research showed very large inequalities in uptake of GOS tests, but this project was only possible after doing a manual entry of thousands of paper GOS forms in the context of Leeds and because a comprehensive electronic GOS data set was available for Essex.

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<sup>36</sup> Royal College of Optometrists, '*Better Data, Better Care*' 2013, page 10

<sup>37</sup> Shickle D, Farragher TM, Davey CJ, Slade SV, Syrett J. Geographical inequalities in uptake of NHS funded eye examinations: Poisson modelling of small-area data for Essex, UK. *Journal of Public Health* 2017 | pp. 1–9 | doi:10.1093/pubmed/fox058.

<sup>38</sup> Shickle D, Farragher T. Geographical inequalities in uptake of NHS funded eye examinations: small area analysis of Leeds, UK. *Journal of Public Health* 2015;37(2):337-45. DOI 10.1093/pubmed/fox039

**There is no robust evidence-base upon which to target the right preventions, treatment, public health services and support to people who really need it. Demand for eye health services is growing every year, and there is a real need to obtain population-based representative data to establish an up to date, accurate baseline for the UK's eye health.**

The report also draws attention to the risks of reliance on Certificate of Vision Impairment (CVI)<sup>39</sup> data which 'could and should be improved' due to anecdotal evidence that CVIs are regularly not completed and patients are not always aware that a CVI is an option to them.

### **There is evidence of unmet need in the system that could be treated earlier – 80% of vision impairment is preventable or curable**

WHO estimate that 80% of vision impairment is preventable or curable.<sup>40</sup> Yet many people are not receiving the support they need to prevent their eye health deteriorating. 13% of people aged 55 and over in the UK have not had their eyes tested in the past two years even though they are advised to do so by the NHS.<sup>41</sup> More significantly, in some cases individuals' eye health is worsening to the point that they are almost blind before they first present with a problem.

A clinical study on avoidable sight loss in 2012 found that over 80% of patients on the CVI database from Moorfields Eye Hospital, with glaucoma as the primary care, had a significant visual disability when they first presented to the ophthalmologist, and strikingly, approximately 60% of patients presented bilaterally blind.<sup>42</sup> This is higher than should be expected in the developed world, suggesting that need is not being met until the later stages of the disease. While Moorfields might, as a specialist tertiary centre, be expected to have somewhat higher rates, this remains a concerning statistic. Although data from Scotland shows lower prevalence rates than found at Moorfields, they were still at levels that ought to be unacceptable in a nation with universal health provision. There is therefore almost certainly unmet need in the system, with some people experiencing vision impairment not being treated, and others developing conditions which could have been avoided or treated earlier.

Accessibility is an important factor in people not receiving the support they need. Many people experience barriers to accessing services including lack of

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<sup>39</sup> Patients are certified as either severely sight impaired (blind) or sight impaired (partially sighted) by completing the Certificate of Vision Impairment (CVI) in England and Wales. In Scotland it is called BP1, in Northern Ireland it is called A655.

<sup>40</sup> World Health Organisation, 'Universal Eye Health: A Global Action Plan 2014-2019), page 1

<sup>41</sup> RNIB, 'The State of the Nation Eye Health 2017: A Year in Review, 2017

<sup>42</sup> Kotecha, Fernandes, Bunce and Franks, 'Avoidable Sight Loss from Glaucoma: is it unavoidable?' 2012

knowledge of the entitlement, failure to recognise the importance of regular eye tests for combating eye disease, transport restrictions, concerns about the cost of glasses, fear of complications and the cost of eye tests.<sup>43</sup> These issues can be compounded by other factors, for example through homelessness or being housebound, and for minority ethnic groups where individuals can experience language barriers, cultural differences and additional stigmas associated with sight loss.<sup>44</sup>

Despite growing demand from an ageing population living longer with multiple, complex, long-term conditions, many UK residents are not aware of the vision services available to them. 80% of the nation are unaware that an eye test can detect signs of cardiovascular disease and are therefore not having regular checks, signifying a lack of public awareness that sight test check for wider determinants of health as well as vision.<sup>45</sup> Investment in prevention would reduce the economic burden of eye disease and improve people's quality of life.

For those who are known to services, current pathways are still 'failing patients on a grand scale' according to the All-Party Parliamentary Group for Eye Health and Vision Impairment, which stated that services are being delayed and time-critical appointments are being cancelled. The British Ophthalmological Surveillance Unit (BOSU) found in 2017 that up to 22 people per month were experiencing permanent and severe vision loss due to health service-initiated delays and not receiving sight-saving treatment and care when they need it.<sup>46</sup>

**Barriers to accessibility, lack of awareness of the health benefits of regular sight tests and delays to treatment caused by the health system means that needs are not being met and people are losing their sight avoidably. Having a robust set of prevalence data in place will help target services appropriately and the study can be used to raise awareness of eye health.**

As a result, people's needs are continuing to be unmet, causing them to experience avoidable sight loss, fear, loss of independence and impaired wellbeing which could have been avoided.<sup>47</sup> Sight is the sense people fear losing the most, but not enough is being done to help protect the nation's eye health.<sup>48</sup>

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<sup>43</sup> RNIB, 'Future sight loss UK: The economic impact of partial sight and blindness in the UK adult population', 2009, page 140

<sup>44</sup> RNIB, 'Future sight loss UK: The economic impact of partial sight and blindness in the UK adult population', 2009, page 156

<sup>45</sup> NHS UK

<sup>46</sup> Foot B, MacEwen C. 'Surveillance of sight loss due to delay in ophthalmic treatment or review: frequency, cause and outcome'. E31: 771-775.

<sup>47</sup> All-Party Parliamentary Group for Eye Health and Vision Impairment 'See the Light' report - June 2018

<sup>48</sup> <http://www.visionmatters.org.uk/>

## **Growing demand from an ageing population and increasing incidence of long term conditions means that our nation's eye health is getting worse, which will exacerbate existing issues in the system**

Across the UK, primary, acute and community care are experiencing an unprecedented growth in demand for services. A growing population who are living longer with changing health needs means that the health system now needs to tackle an increasingly complex health landscape. This is against a backdrop of lower funding and resources across almost every aspect of the public sector.

The UK population is projected to increase by 9.7 million people over the next 25 years from an estimated 64.6 million in 2014 to 74.3 million in 2039. There will be a significant increase in the number of older people in the UK over the next 25 years. This is largely attributable to the large number of the population who were born in the 1960s moving into the higher age groups. Life expectancy has also been increasing: between 2000 and 2015, life expectancy at birth increased by one year every five years for women and by one year every 3.5 years for men. One of the outcomes of these trends is that the number of people aged 80 years and over is projected to more than double from 3.1 million to 6.3 million people by 2039. This makes this group of people the fastest growing demographic in the UK.<sup>49</sup>

In the context of eye health, this is significant. Older people are far more likely to develop eye conditions such as glaucoma or age-related macular degeneration (AMD). One in five people aged 75 and over are estimated to be living with sight loss, and this figure rises to one in two people aged 90 or over.<sup>50</sup> In 2010, 82% of blind people and 65% of people with moderate to severe blindness were older than 50 years of age.<sup>51</sup> Although incidence of vision loss has remained stable in recent years, prevalence will continue to rise due to a growing population who are living longer with long term illness.

In older age, vision impairment brings further complications as it meshes with multiple morbidities. People with vision loss in older age are at greater risk of social isolation, reduced mental wellbeing and dementia, and this is accentuated if they have dual sensory loss.<sup>52</sup> Sight loss and blindness is linked to an increased likelihood of cognitive loss and depression; a cross-sectional, representative sample of the US population in 2017 found a substantial association between

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<sup>49</sup> Office for National Statistics, 2016-based population projections

<sup>50</sup> RNIB, 'The State of the Nation Eye Health 2017: A Year in Review (2017)

<sup>51</sup> WHO, Universal Eye Health: A Global Action Plan 2014-19

<sup>52</sup> Ramrattan et al, 'Prevalence and Causes of Visual Field Loss in the Elderly and Associations with Impairment in Daily Functioning', 2001

vision impairment and worse cognitive performance, even after accounting for other age-related predictors of cognitive decline.<sup>53</sup>

The rapid rise in obesity and diabetes has led to an increase in diabetic eye disease, with diabetic retinopathy accounting for 7% of people who are registered blind in England Wales.<sup>54</sup> <sup>55</sup>Diabetic eye disease was the leading cause or contributory cause of 6.3% of Severe Sight Impairment certifications and 7.5% of Sight Impairment certifications when last analysed in 2013\*. The economic impact of this is stark, with diabetes the leading cause of preventable sight loss in people of working age in the UK. People with diabetes have nearly 50% increased risk of developing glaucoma, especially if they also have high blood pressure, and up to a threefold increased risk of developing cataracts, both of which can also lead to blindness.

The changing demographics of the UK mean that risk factors will continue to increase for certain population groups. According to RNIB, members of Black, Asian and Minority Ethnic communities and those with disabilities are particularly at risk, as are women, who account for nearly two thirds of people living with sight loss.

**An ageing population with increasingly complex needs and conditions means that demand will continue to grow, resulting in additional pressures in other parts of the health and care system. It is more important than ever to understand the health needs of our population to target interventions effectively and provide quality care. The UKNEHS survey will target this exact cohort of people.**

**There is scope for better targeting of public funds, to identify the potential for new transformed models of care to meet the high levels of need in an improved, lower cost way**

The health system is experiencing a period of very rapid change. The health landscape is going to be radically altered over the next 10 years as we see the emergence of new models of care utilising new digital technologies such as artificial intelligence (AI), new screening and diagnostic tools, remote imaging, virtual clinics and the use of mobile and tablet-based apps to support personalised care. In the near future, patients will even be able to deliver an eye test themselves using a smart phone.

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<sup>53</sup> Chen, 'Association of Vision Loss with Cognition in Older Adults', 2017

<sup>54</sup> Diabetes UK, 2014

<sup>55</sup> Leading causes of certifiable visual loss in England and Wales during the year ending 31 March 2013. Quartilho A, Simkiss P, Zekite A, Xing W, Wormald R, Bunce C. Eye (Lond). 2016 Apr;30(4):602-7

Applying sophisticated data analytics to a national dataset of eye health prevalence would better support research and enable commissioners to measure the impact of change for new, different interventions, with early detection and timely access to services and treatment to reduce unnecessary vision loss. This is important because in an age of austerity and public spending cuts, scarce budgets need to be targeted in the areas where need is greatest.

For example, targeted work to understand the higher prevalence of aneurysms in men aged over 65 years resulted in the NHS introducing a national aneurysm screening programme for men aged over 65 in 2013, which has significantly lowered the risk of mortality from aneurysm and has been proven to have been effective in detecting and treating men with abdominal aortic aneurysm.<sup>56</sup> This is a real example of how population-based evidence can affect real change in the health system and improve health outcomes for the public.

The current lack of a national and local picture of eye health and prevalence means that it is difficult to really know our local populations, why they are and aren't accessing care, and develop targeted pathways focused on the right needs that are ready for future innovation. We know for example that the Atlas of Variation has published data relating to cataract admissions, but we are currently unable to produce this type of mapping for wider eye health. This in turn limits the scope for us to explore the opportunities for creative application of innovative technologies. Research suggests that there is scope for AI to be used to examine eye health data to offer earlier detection of conditions such as dementia and multiple sclerosis. But without a clear understanding of how and why people do and do not access existing services, we can't develop new service models that could include these technologies effectively.

**Using data sourced through the UKNEHS, there are opportunities to develop new interventions and technologies, the impact of which can be better understood and measured through a richer understanding of population needs. For example, data would help to identify for which needs, and where geographically there would be benefits of using a digital screening approach.**

There has been success from enhanced eye care services schemes (ECSS) e.g. the Minor Eye Conditions Scheme (MECS) in South East London and the Glaucoma Referral Refinement Scheme (GRRS) in Greater Manchester<sup>57 58</sup>, but

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<sup>56</sup> Jacomelli, Summers et al., 'Impact of the first 5 years of a national abdominal aortic aneurysm screening programme' 2016

<sup>57</sup> Gunn PJG, Marks JR, Konstantakopoulou E, *et al.* Clinical effectiveness of the Manchester Glaucoma Enhanced Referral Scheme *British Journal of Ophthalmology* Published Online First: 11 October 2018. doi: 10.1136/bjophthalmol-2018-312385

<sup>58</sup> Ratnarajan G, Newsom W, Vernon SA, Fenerty C, Henson D, Spencer F, Wang Y, Harper R, McNaught A, Collins L, Parker M, Lawrenson J, Hudson R, Khaw PT, Wormald R, Garway-Heath D, Bourne R. The effectiveness

these services are not delivered consistently across the UK and we don't have enough data to know which areas would benefit most from similar targeted schemes.

There is a need to develop an understanding of the geography of sight loss in local areas, and target research and provision effectively to improve long term eye health outcomes for the UK population. Data from the UKNEHS on geographical variations in need will help support future commissioning of ECSS models.

### **This is important because eye health has such a significant impact on people's lives, wider society and the UK economy**

Our senses are essential to our wellbeing as we get older; maintaining good sight and hearing in older age will help to maintain wellbeing and quality of life. The effects of sight and hearing loss on the individual and their loved ones are far reaching, with profound effects not only on those directly affected but also for the health sector and the wider economy.

An RNIB Access Economics Report commissioned in 2015 states that the total economic cost to the UK of sight loss and blindness was estimated at £28 billion in 2003, and the cost to the NHS is high<sup>59</sup>. Two of the top four highest expenditure NICE-appraised medications prescribed in hospitals relate to the treatment of the eye. Cataract is the most commonly performed surgery in the NHS, with costs estimated at ~£950 per surgery.<sup>60,61</sup> The early identification of cataracts would enable people to take early measures to slow the progression of the condition and help people to stay economically productive for longer.

Beyond the direct costs, those with visual impairment are more likely to access other health services due to an increased likelihood of factors such as falls, depression and dementia. Those with distance vision loss have double the risk of dementia, and those with near vision impairment have three times the risk as those with normal vision.<sup>62</sup> Vision loss has also been found to be associated with increased depression symptoms over time.<sup>63</sup> Notably, the risk of depression increases at a significantly faster rate for those with dual sensory loss (vision and

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of schemes that refine referrals between primary and secondary care-the UK experience with glaucoma referrals: the Health Innovation & Education Cluster (HIEC) Glaucoma Pathways Project. *BMJ Open*. 2013 Jul 21;3(7).

<sup>59</sup> Pezzullo L, Streatfeild J, Simkiss P, Shickle D. The economic impact of sight loss and blindness in the UK adult population. *BMC health Serv Res* 2018; 18: 63.

<sup>60</sup> Deloitte Access Economics, 'The economic impact of partial sight and blindness in the UK adult population' 2009, page 51

<sup>61</sup> Getting it Right First Time national reference cost for Phacoemulsification With Intraocular Lens (IOL) Implantation is between £893.09 and £954.07. Provider costs can be less or more than this due to other factors such as - PFI building costs, workforce mix, etc. Source: GIRFT Clinical Lead for Ophthalmology

<sup>62</sup> Chen, 'Association of Vision Loss with Cognition in Older Adults', 2017

<sup>63</sup> Cosh, Von Hanno, Helmer et al, 'The association amongst visual, hearing and dual sensory loss with depression and anxiety over 6 years: The Tromso Study', 2017

hearing).<sup>64</sup> Untreated hearing loss in people aged 50-70 is the biggest risk factor for cognitive decline and dementia, and the number one cause of Years Lost to Disability in those over 70 in Western Europe.<sup>65</sup> Identifying these people earlier can help to reduce their risk of developing dementia, and the subsequent need for additional care. A 2016 NIHR funded study investigating the prevalence of visual impairment among people living with dementia found that there was more than twice as much visual impairment among people living in residential care settings, compared to those living in the community, which suggests an association between concurrent dementia and visual impairment and increased need for residential care<sup>66</sup>.

There is also evidence of an increased likelihood of falls and fractures requiring medical treatment<sup>67</sup> due to sight loss, which resulted in a £23.4 million cost to the health care system in 2013.<sup>68</sup>

The economic impact of vision loss and blindness is particularly noticeable in the context of employment. Only one in four registered blind or partially sighted people of working age is in employment.<sup>69</sup> Distance vision loss is estimated to cost the UK between £3.5 – 7 billion in lost revenue due to lack of or reduced employment for those who are living with a visual impairment.<sup>70</sup> People with visual impairment and loss are a part of the labour force, and correction of these problems increases overall employability and earning power, supporting individuals' own health and wellbeing and ultimately supporting the UK economy to grow.

**Avoidable blindness and vision loss comes at a significant economic cost to the individual and the UK economy as a whole; in an area of reduced public spending, we must shift our focus to earlier intervention. UKNEHS data will help to target services effectively.**

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<sup>64</sup> McDonnell, 'The Effects of Developing a Dual Sensory Loss on Depression in Older Adults: A Longitudinal Study', 2009.

<sup>65</sup> The Ear Foundation, 'Spend to Save: Investing in hearing technology improves lives and saves society money: A Europe wide strategy', 2016, page 2.

<sup>66</sup> Bowen M, Edgar DF, Hancock B, et al. The Prevalence of Visual Impairment in People with Dementia (the PrOVIDe study): a cross-sectional study of people aged 60–89 years with dementia and qualitative exploration of individual, carer and professional perspectives. Southampton (UK): NIHR Journals Library; 2016 Jul. (Health Services and Delivery Research, No. 4.21.) Available from: <https://www.ncbi.nlm.nih.gov/books/NBK374272/> doi: 10.3310/hsdr04210

<sup>67</sup> Hong, Mitchell, Burlutsky, Samarawickrama and Wang, 'Visual Impairment and the Incidence of Falls and Fractures Among Older People: Longitudinal Findings from the Blue Mountains Eye Study' 2014

<sup>68</sup> Pezzullo, Streatfield, Simkiss and Shickle, 'The economic impact of sight loss and blindness in the UK adult population', 2018, page 6

<sup>69</sup> RNIB, 'Employment Status and Sight Loss' 2017

<sup>70</sup> Chakravarthy U, Biundo E, Saka RO, Fasser C, Bourne R, Little JA. 'The Economic Impact of Blindness in Europe'. *Ophthalmic Epidemiol.* 2017

## The context and drivers for change in UK wider sensory loss

As highlighted above, it is important to consider visual impairment in the context of broader sensory loss. Hearing loss is one of the most challenging health and social issues facing people in Europe; communication is vital to our ability to function and maintain our health and wellbeing, particularly as we get older. The Global Burden of Disease (GBD) project aims to produce cause-specific estimated of global mortality, disease burden and risk factors for fatal and non-fatal conditions such as hearing impairment. The most recent GBD study estimated that adult onset hearing impairment was the third leading cause of disability.<sup>[1]</sup>

Hearing loss is a leading cause of disease burden, yet population-based studies that measure hearing loss are rare. In the UK, there is a reliance on data from the 1980s, and a contemporary view is needed to understand how demand and supply has changed in recent decades. As such, it is important, where possible in this study to combine resources to understand hearing prevalence as well as eye health prevalence.

## How the UKNEHS will meet this need

A UK eye health and hearing study will provide population-based research to provide real data on the magnitude and distribution of the most frequent cause of sight and hearing loss. It will offer opportunities to look at these causes by risk factor analysis including demographic and social determinants of health. 25,000 people over 50 years of age will be recruited across the whole of the UK into a study that uses the latest imaging and data linkage technology. We will be working with 'real world data' to find out the effectiveness of prevention and treatment that we offer.

The recently successfully completed National Eye Health Study in Australia in 2016 has led to a very positive response from the commissioners and providers of care in that country and the eye research community, and has led to far better intelligence about their populations' eye health and vision needs than we currently have in the UK. The data from the Australian NEHS has contributed to national policy context already, in the following ways:

- Provided the evidence base for the government report 'Aboriginal and Torres Strait Islander Health Performance Framework 2017 Report'.
- Cited across websites and health promotion documents including, Australian Indigenous Health info net, Lions Outback Vision, Australian Policy Online and Analysis and Policy Observatory<sup>71</sup>.
- Evidence from the survey was critical in securing \$2million in Federal Government funding to provide equitable access to prescription glasses for the Indigenous population.

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[1] Stevens et al, 'Global and regional hearing impairment prevalence: an analysis of 42 studies in 29 countries', 2018.

<sup>71</sup> <http://www.optometry.org.au/blog-news/2016/10/14/landmark-study-gives-clearer-picture/>

- Informed RANZCO's strategies for workforce redistribution to close the gap in eye health care delivery in regional and remote Australia.
- Contributed 23 peer reviewed papers to the national and international evidence base.

A UKNEHS will provide vital data for the vision and eye health research community in the UK, for health policy makers and those developing and commissioning health services. It will allow for more effective implementation of the most appropriate health services and delivery models and provide a critical data baseline to support future impact assessment of novel eye care interventions and service delivery models. This will help government efficiently and effectively target spending and ensure that vulnerable groups are accessing the services they need to reduce preventable sight loss and enable people to participate fully in society. This means that we can get serious about screening and prevention of eye disease in the UK.

The project team has agreed the following objectives for change to meet the need identified. It should be noted that these include both direct project benefits, which the project is in full control of delivering, and wider programme benefits which will be enabled by delivering the UKNEHS project successfully.

**Figure 3: UKNEHS project and wider programme objectives**

Objective theme	Objectives <sup>72</sup>
<p><b>Effectiveness - improved outcomes and experience</b></p>	<p>Project objective:</p> <ul style="list-style-type: none"> <li>• Establish a common understanding of the number of people in the UK with a sensory loss</li> <li>• Determine the prevalence and causes of vision impairment conditions across the UK by region and ethnic group, through gathering robust data for a sub-set of the population</li> <li>• Deliver the study successfully, safely and ensuring full representation of the population</li> </ul> <p>Programme objective:</p> <ul style="list-style-type: none"> <li>• Contribute to improvement in the eye health and wellbeing of the UK population over the medium term, promoting prevention to reduce risk and instances of avoidable sight loss and enabling people to stay healthy and independent for longer, as measured by an increase in quality of life over the medium term</li> <li>• Increase national public awareness and action on eye health conditions, such that the public is better informed to recognise the symptoms and knows where to access treatment, as evidenced by consumer awareness data and an increase in the number of people receiving a sight test</li> <li>• Use data to identify opportunities for new ways of working (including new digital technologies) to detect and treat eye disease and work with the commercial sector to respond to need and demand</li> <li>• Provide the data necessary to baseline other programme interventions aimed at improving the nation’s eye health</li> </ul>
<p><b>Efficiency - improve delivery of public services in terms of delivery of agreed outputs</b></p>	<p>Programme objective:</p> <ul style="list-style-type: none"> <li>• Support national public commissioning bodies and strengthen industry networks to use the data to target resources more effectively in areas of greatest need (clinically and geographically), to prevent visual impairment or avoidable blindness over the medium term</li> <li>• Provide data to inform and support targeted research into treatment for specific eye health conditions</li> </ul>
<p><b>Economy – reduce cost of public services</b></p>	<p>Project objective:</p> <ul style="list-style-type: none"> <li>• Use the study to detect vision impairment conditions and follow signposted patients to appropriate treatment</li> </ul>

<sup>72</sup> It should be noted that most objectives also apply to hearing as well

Objective theme	Objectives <sup>72</sup>
<b>(e.g. spend to save)</b>	services at time of survey, improving outcomes for people and delivering an avoided cost benefit to society, measured by following up with survey participants
<b>Compliance – to meet statutory / regulatory requirements and accepted best practice</b>	Project and programme benefit: <ul style="list-style-type: none"> <li>• Enable the UK to meet its obligation to contribute towards the World Health Organisation (WHO) goal of reducing avoidable sight loss</li> </ul>

**The UKNEHS will:**

- Provide a reliable evidence-base for the causes of vision impairment and loss in the UK which can be used as a common language across primary, acute, community care and commissioners
- Enable a richer understanding of eye health in each region of the UK – for example it will help Scotland to measure the impact of extending free sight tests to the entire population
- Allow previous models to be updated with up-to-date, accurate data – for example the NEHEM model and the RNIB Sight Loss Data Tool
- Help to validate currently unreliable CVI data

## **The Solution**

The 'UK National Eye Health and Hearing Study' will improve the evidence base to better understand, and ultimately, improve the nation's eye health. This section outlines how this will be achieved. We will detail our approach to developing the study successfully, safely and ensuring full representation of the population, the wider programme needed to achieve the benefits of improved eye health, the costs to deliver this and the processes that need to be put in place to track the benefits and manage risk.

## **The study itself**

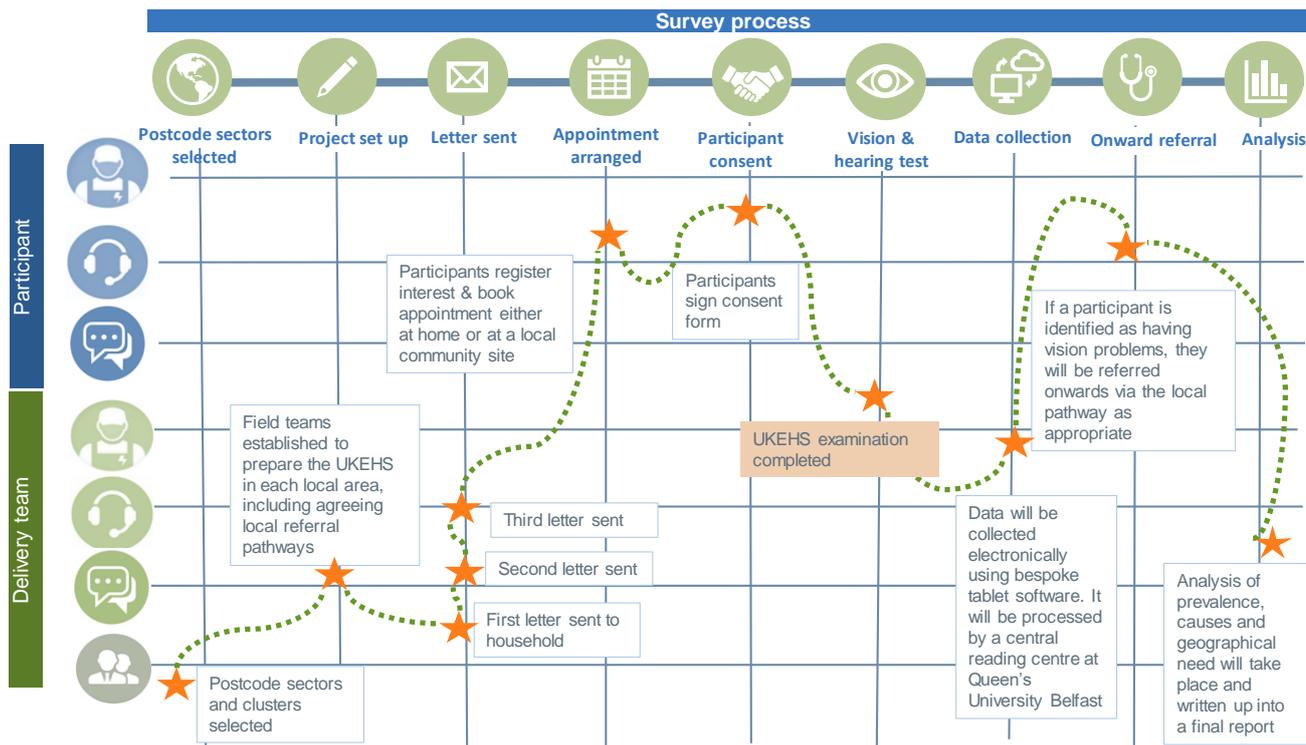
The study will determine the prevalence and causes of visual impairment and blindness and hearing loss, in the UK population aged 50 years and older (by gender, ethnicity, age, socio-economic group and geographical area) – this will provide an up-to-date, and comprehensive picture of the UK's eye and hearing health. The study will also measure the detection and treatment coverage rate of major eye diseases and conditions in order to understand the effectiveness of current services. People surveyed will be asked questions around their participation in health services and their employment status to understand their level of interaction with eye health services and the effectiveness of them, as well as to understand the impact of eye health on employment levels (if applicable). The delivery model outlined below is a proposal based on high level design work to date – the exact delivery approach and mechanisms will be defined in more detail in the next phase of design.

## **How the study will work**

The UKNEHS will gather data for a representative sample of people ('participants') from all regions of the UK. This will ensure that a true picture of the nation is gathered, which in turn will help government to target services appropriately, addressing inequalities in disease risk, access and provision of healthcare.

Each participant enrolled in the UKNEHS will undergo a simple eye examination and complete a standardised general questionnaire. Interviews and examinations will be conducted primarily at designated clinics and where that is not possible, they will be delivered in the participant's household. Designated clinics will depend on the local area, but could include a range of sites e.g. existing NHS hospitals, GP practices and health centres as well as other community locations such as community centres, churches etc. All examinations will be conducted by trained personnel. The diagram below shows the overall process which will be followed, detailed further in the following sections.

**Figure 4: Survey process and participant journey**

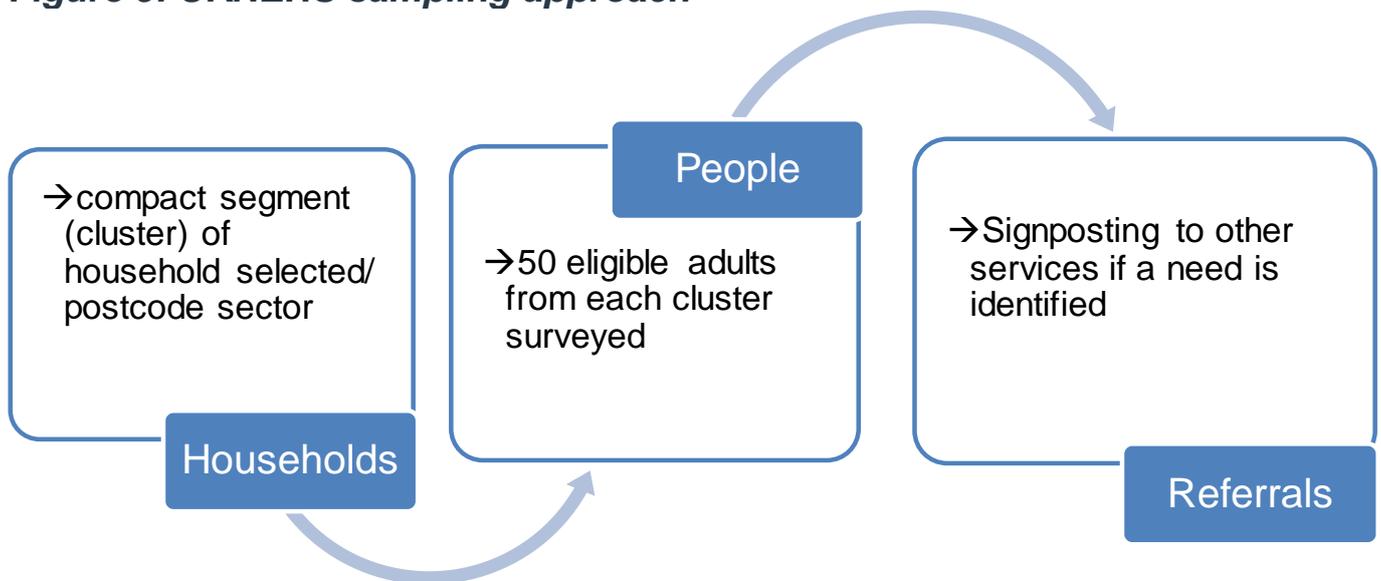


**Sample size**

A sample size of 24,294 adults aged 50 years and above is recommended to permit the estimation of blindness prevalence with precision and ensure a sample that is representative of the UK population. This includes prevalence of blindness, and all ocular diseases more frequent than 0.4% in this age group. A smaller sample size of ~13,000 was considered as the minimum number required to produce statistically valid data. However, this was discounted as it would not yield a precise estimate of blindness in the UK, subgroups at risk of vision impairment or very rare eye disease, and therefore would not meet the stated project objectives.

The sample will be organised by 487 UK postcode sectors, with approximately 50 eligible adults from each cluster participating.

**Figure 5: UKNEHS sampling approach**



A statistician has been commissioned by the UKNEHS project to inform the statistical rationale for this study. Once the project is in design phase, he/she will finalise the sampling strategy and confirm the sample size calculations required to develop a statistically accurate study. Further details can be found in **Appendix B**.

### *How will we recruit a nationally population-representative sample from the UK?*

We have worked with NatCen and experienced ophthalmic epidemiologists to develop a sampling strategy which will ensure that a representative sample of the non-institutionalised UK population are invited to participate in the UKNEHS. We will use the postcode area file (PAF) and the total population size from the last population census as the sampling frame. We will stratify by country and select a random sample of 487 clusters, each with a pre-specified list of household addresses anticipated to contain approximately 50 eligible people aged 50 years and over. We will use a sampling approach ('probability proportionate to size') which ensures that the number of clusters selected in each region is proportional to the region's population size.

In the devolved nations, which have a much smaller total population than England, we will oversample to include 46 clusters in each. This will result in recruitment of approximately 24000 people in the UK in total, with 2300 in each devolved nation. Allowing for anticipated non-response, this will ensure that we recruit a big enough sample in each of the four countries to estimate with precision the burden of vision impairment, and to model associated risk factors, whilst enabling accurate estimation of the burden of blindness (a rarer problem) and associated risk factors at the UK level.

Our community screening and enumeration team will physically visit all selected households multiple times to enquire about the number and demographics of household members, to invite those who meet the eligibility criteria to participate,

and to obtain contact details. Participant information packs will be delivered. Eligible, consenting individuals will complete a series of questionnaires and an examination at the household with our team. This will include imaging and measurements with portable equipment. We will obtain a doorstep estimation of unaided, presenting and pinhole visual acuity, and collect data to permit estimation of common eye diseases, and risk factors relating to eye disease and interaction with the health care system. We will refer participants for more detailed hospital eye clinic assessment in their regional participating centre if they have vision worse than 6/9 in either eye, or are subsequently found to have potentially sight-threatening eye disease (upon central review of the data by the image reading centre and investigators).

When analysing the data, we will apply weights to correct for oversampling in the devolved nations when analysing the UK-wide data. We will also adjust the data for the multilevel, clustered study design, and weight by the non-response rate in each cluster.

## Appendix B.

### Survey content

Participants will receive a number of sight tests and a hearing test and be asked questions around their overall health and social care needs, access to health services and effectiveness of eye health services. The examination comprises:

- Participant consent to participate in the survey and have their data collected
- Questionnaire
- Visual acuity check (distance and near)
- Eye pressure measurement
- Dilated retinal photographs
- Hearing test

The tests and indicative themes to be explored in the survey are detailed below:

**Figure 6: Detailed survey content**

Eye and hearing tests	Questionnaire themes
<p>Measure the prevalence of:</p> <ul style="list-style-type: none"><li>• blindness, severe moderate and mild vision impairment and presbyopia</li><li>• diabetic retinopathy</li><li>• cataract and cataract surgery</li><li>• age-related macular degeneration and its subtypes</li><li>• uncorrected refractive error</li><li>• glaucoma and its subtypes in the population</li><li>• hearing loss</li></ul>	<ul style="list-style-type: none"><li>• Personal information, demographics, employment, family history</li><li>• Health and social care needs, for example:<ul style="list-style-type: none"><li>○ Any long-term conditions</li><li>○ Which services are accessed regularly</li><li>○ Family history of glaucoma, diabetic eye disease or other hereditary eye disease</li></ul></li><li>• Participant experience (i.e. accessing services, health pathways etc), for example:<ul style="list-style-type: none"><li>○ Last time accessing vision / hearing services</li><li>○ Overall experience accessing health services</li><li>○ Reasons for not accessing services</li><li>○ Perceived barriers to access</li><li>○ Awareness of services available</li></ul></li><li>• Follow up and future participation, for example:<ul style="list-style-type: none"><li>○ Willingness to participate in future studies or follow up surveys</li></ul></li></ul>

### Data collection

A national coordination centre (NCC) will be established to plan, monitor recruitment and examinations, manage the data and take responsibility of the analysis and reporting of the results.

Data will be captured electronically during the survey, using bespoke tablet-based software developed for the Australian NEHS and adapted for the UK. Data will be processed by a central reading centre at Queen's University Belfast. Where possible, this will be linked to other health records to enable analysis of the follow-up pathway. This real-time data collection will enable monitoring of the data collection process for quality assurance and safety within the study; it will also

support efficient data review and cleaning, streamlining final data processing and analysis.

### **Referral post-survey**

In each cluster area, proactive engagement will take place as part of the project set up to agree an appropriate referral route for those who have problems with their sight identified during the survey. A key element of the UKNEHS is 'research with service'; if participants are identified as having an unmet need, they will be referred via the appropriate local pathway to receive treatment. Participants who are referred onwards to other services will be followed throughout their journey so that their progress can be measured. The process for this will be defined in partnership with health providers in more detailed planning phases of the project.

### **What it will cost to deliver**

A cost estimate of delivering the UKNEHS has been developed which includes estimates of the following costs:

- Direct survey staffing: investigating team, field team, clinical team and data management team;
- Project staffing: project team and working groups;
- Non-staffing costs: consumables (mail, clinical supplies), website design, software, recruitment, accommodation and travel;
- Dissemination costs: staffing, consumables, conference attendance;
- Support services costs.

These are shown at a summary level below, and detailed further at **Appendix C**. The total cost of delivering the study is ~£15.7m over 3 years. Year 1 costs includes a one-off expenditure of £0.6m on equipment and consumables.

**Table 2: Summary costs of delivery<sup>73</sup>**

Cost type	Cost breakdown	Year 1	Year 2	Year 3	Total Costs
<b>Programme staffing</b>	Programme team (including working groups)	270,000	240,000	200,000	700,000
<b>Study staffing costs</b>	Investigating team	80,000	80,000	70,000	240,000
	Field team	110,000	2,330,000	1,170,000	3,610,000
	Clinical team	140,000	2,850,000	1,430,000	4,420,000
	Data management team	40,000	110,000	260,000	400,000
<b>Study non-staffing costs</b>	Equipment	310,000	50,000	20,000	380,000
	Consumables	20,000	100,000	10,000	130,000
	Travel and accommodation	80,000	1,760,000	890,000	2,730,000
	Other direct costs	140,000	30,000	-	170,000
<b>Dissemination costs</b>	Consumables, travel and admin	120,000	-	-	120,000
<b>Support services</b>	Support services costs (finance / IT / HR etc.)	440,000	440,000	440,000	1,310,000
<b>Recruitment / procurement</b>	Potential recruitment / procurement costs	740,000	740,000	-	1,480,000
<b>Total</b>		<b>2,490,000</b>	<b>8,720,000</b>	<b>4,470,000</b>	<b>15,690,000</b>
<b>Total cumulative</b>		<b>2,490,000</b>	<b>11,210,000</b>	<b>15,690,000</b>	<b>-</b>

### The benefits of the investment

This section describes how the study will meet the objectives set and what the wider benefits to society will be. The study will deliver improved outcomes for people over the long term, by gathering data on prevalence to establish a greater understanding on the causes and incidence of visual impairment, major eye diseases and hearing loss. It will in particular allow for a better understanding of regional and socio-economic variances – to ensure that those groups in society

<sup>73</sup> Includes VAT, where applicable (on all non-staff supplies). Excludes inflation.

who are hardest to reach are understood. More broadly it will bring heightened awareness, and therefore a focussed prevention campaign. Organisational benefits to governments and the third sector, are significant, allowing organisations to target scarce funding in a more robust way.

### **How the project meets our objectives**

We described earlier our objectives for investment around improving outcomes for people with eye disease and visual impairment, reducing the impact of visual impairment on wider society and ensuring that the UK is more compliant with global health standards. We will achieve this in the following way:



High quality data for UK hearing, eye-health and vision

**Table 3: Objectives and benefits**

Objective theme	High-level objective	Benefits of the investment
<p><b>Improved outcomes and effectiveness</b></p> <p><b>Improve delivery of public services</b></p>	<p>Direct project objective:</p> <ul style="list-style-type: none"> <li>• <b>Establish a common understanding</b> of the number of people in the UK with a sensory loss</li> <li>• <b>Determine the prevalence and causes of vision impairment conditions</b> across the UK</li> <li>• <b>Deliver the study successfully, safely and ensuring full representation</b></li> </ul> <p>Wider programme objective:</p> <ul style="list-style-type: none"> <li>• Contribute to <b>improvement in the eye health and wellbeing</b> of the UK population</li> <li>• <b>Increase national public awareness</b> and action on eye health conditions</li> <li>• Use data to <b>identify opportunities for new ways of working</b></li> <li>• Provide the data necessary to <b>baseline other programme interventions</b></li> <li>• Support <b>national public commissioning bodies and strengthen industry</b></li> </ul>	<p>Direct project benefits:</p> <ul style="list-style-type: none"> <li>• The study will determine, for the first time a baseline of the prevalence and causes of visual impairment and blindness in the UK, in addition to hearing loss.</li> <li>• The detection and treatment coverage rate of major eye diseases and conditions including cataract, diabetic retinopathy, glaucoma, age-related macular degeneration and refractive error</li> <li>• Access to ‘hard to reach’ groups for example, those residing in care homes, through the offer of household visits and community locations close to people’s homes, which will contribute to awareness raising of eye health in local communities</li> <li>• All participants will be provided with feedback on their eye examination results on completion of the clinical examination to help give them a greater understanding and awareness of their eye health</li> <li>• Increased awareness of eye health and more people taking care of their own eye health</li> <li>• A direct impact on ~1,500 people who are expected to have an undiagnosed need through the study</li> </ul> <p>Wider programme benefits:</p> <ul style="list-style-type: none"> <li>• Improved public health</li> <li>• The UKNEHS data will be widely available, and used to support new research and update previous research, for example</li> </ul>

Objective theme	High-level objective	Benefits of the investment
	<p><b>networks</b> to use the data to target resources more effectively</p> <ul style="list-style-type: none"> <li>• Provide data <b>to inform and support targeted research</b> into treatment for specific eye health conditions</li> </ul>	<p>the RNIB Sight Loss Data Tool and the Imperial College NEHEM model</p> <ul style="list-style-type: none"> <li>• A national media campaign will build awareness in the wider population</li> <li>• Through using the accessible anonymised summary data, commissioning bodies will have a deeper understanding of the geography of visual impairment and eye disease in their local areas and will be able to target resources based on actual need, and have a greater understanding of how the workforce, technology, and estate need to be provided</li> </ul>
<p><b>Reduce costs</b></p>	<p>Direct project objective:</p> <ul style="list-style-type: none"> <li>• Use the study to <b>detect vision impairment and hearing loss conditions and follow signposted patients to appropriate treatment</b> services at time of study</li> </ul>	<p>Direct project benefit:</p> <ul style="list-style-type: none"> <li>• Any participant with undiagnosed eye disease/visual impairment/hearing loss that can be detected through the study's testing protocol will be referred to an eye health/hearing loss professional working within the UKNEHS network, directly addressing identified conditions and reducing future costs associated with late diagnosis</li> </ul>
<p><b>Comply with international standards</b></p>	<p>Direct project and wider programme objective:</p> <p>Enable the UK to meet its obligation to contribute towards the <b>World Health Organisation (WHO) goal of reducing avoidable eye health and prevention of deafness and hearing loss</b></p>	<p>Direct project benefit:</p> <ul style="list-style-type: none"> <li>• The identification of unmet need will be a direct benefit of the study, enabling early detection</li> </ul> <p>Wider programme benefit:</p> <ul style="list-style-type: none"> <li>• Robust, up to date data on the prevalence and causes of visual impairment and blindness and hearing loss will allow government and other interested bodies to create an accurate baseline, against which progress</li> </ul>

Objective theme	High-level objective	Benefits of the investment
		can be measured over time with a further survey

**Wider benefits of the study**

Patients, wider UK residents, government and other professional organisations in the eye health sector will benefit from up to date information on prevalence which in turn should support investment in research where it is most needed, better targeting of services, increased awareness of eye health and over the long term improved health and wellbeing. The table below outlines the anticipated benefits to each group in society. As the project moves into a more detailed design phase, these benefits will be tested with wider stakeholders, including patients and residents to ensure that the approach meets the need.

**Table 4: Wider benefits of the study to society**

Beneficiary	Benefit description
<b>Patients</b>	<ul style="list-style-type: none"> <li>• Will enable ‘at risk’ groups to be identified and influence provision of better services for those hardest to reach</li> <li>• People will have an increased awareness of the services available to them and knowledge of how to access treatment for different conditions</li> <li>• Survey participants will also have the option to receive a hearing test (in addition to the sight test), giving them a broader understanding of their sensory processing and contributing to the understanding of hearing loss across the UK</li> </ul>
<b>Wider UK society</b>	<ul style="list-style-type: none"> <li>• Investment in prevention will impact positively on families and carers of people with visual impairment and hearing loss over the long term through increased knowledge and awareness of conditions and treatment</li> <li>• A better understanding of the prevalence and causes of visual impairment and hearing loss will positively support the improvement of services over the long term</li> </ul>
<b>Central government</b>	<ul style="list-style-type: none"> <li>• Will enable a clearer strategy on health and social care integration around eye health and hearing loss, due to a better understanding of risk factors and overall prevalence</li> <li>• There will be a positive reputational impact associated with the delivery of the largest study of older adults ever conducted in a high-income country, elevating the UK’s status as a world leader in epidemiological research</li> <li>• Accurate prevalence data will make budget forecasting more accurate and therefore enable better budget management and distribution of spend</li> <li>• Government will have better data to enable the targeting of resources, and be able to set targets around reducing avoidable visual impairment and hearing loss, and improving patient experience, against which performance can be measured</li> <li>• Research funding can be targeted more efficiently to needs within the sectors</li> <li>• The data can support and inform workforce mapping e.g. to review the distribution of optometrists and audiologists across the UK</li> </ul>

Beneficiary	Benefit description
<b>Local government</b>	<ul style="list-style-type: none"> <li>Improved services will reduce the burden on social care (as visual impairment and hearing loss have an impact on overall health and wellbeing, including specific conditions such as dementia)</li> <li>Improved targeting of expenditure on public health services and better knowledge on how services should be organised locally e.g. screening programmes</li> </ul>
<b>NHS commissioners</b>	<ul style="list-style-type: none"> <li>Will provide data on what proportion of patients are 'digitally ready' i.e. will be suitable to be supported through other means e.g. remote testing or self-testing, which could impact on how services can be provided more cost-effectively in the future</li> <li>A greater understanding of need will enable commissioners to organise their workforce more efficiently, ensuring that patients see the right professional, at the right time in the customer journey</li> </ul>
<b>NHS acute, community and primary care providers</b>	<ul style="list-style-type: none"> <li>Improved awareness, prevention and early intervention will reduce the number of people presenting in primary care and acute settings (e.g. A&amp;E) with conditions that could have been treated earlier</li> <li>Better organisation of primary care services will enable a focus on where services are needed</li> <li>Community optometrist providers will be able to assess performance and meet audit requirements through a better understanding of their patient cohort</li> </ul>
<b>Research, professional and regulatory bodies</b>	<ul style="list-style-type: none"> <li>Research can be prioritised based on areas of greatest need, population characteristics and a better understanding of what is important to the public</li> <li>Will enable research bodies to review and update previous research e.g. the NEHEM model and attract research investment in the greatest areas of need</li> <li>Data can support decision-making on behalf of the General Optical Council (GOC) – the regulatory body for optical professions in the UK, which will ensure that service provision accurately responds to the needs identified. It can also support similar work by the Registration Council for Clinical Physiologists (RCCP), the British Society for Hearing Aid Audiologists (BSHAA).</li> </ul>
<b>Third sector</b>	<ul style="list-style-type: none"> <li>A baseline of current, accurate data will inform future research, and local / national campaigns</li> </ul>

Beneficiary	Benefit description
	<ul style="list-style-type: none"> <li>• More informed targeting of support services and community groups</li> <li>• A baseline of current, accurate data to inform future research</li> <li>• More informed targeting of support services and community groups</li> </ul>
<b>Private providers</b>	<ul style="list-style-type: none"> <li>• There will be an initial increase in GOS and private sight tests due to increased awareness of the benefits</li> <li>• A better understanding of geographies of need will support better location of services, targeting of new customer groups and awareness of harder to reach groups</li> <li>• Improved networking within the sector</li> <li>• Increased production and demand for hearing aid suppliers and manufacturers of optical devices.</li> </ul>
<b>Pharmaceutical industry</b>	<ul style="list-style-type: none"> <li>• Will provide better data on conditions and inherited conditions</li> <li>• Will provide a baseline data set to support new approaches and trials</li> <li>• Target the production of medicine and research to greatest areas of need in the UK</li> </ul>

## The economic benefit to society

In addition to improved outcomes for people and greater efficiency in delivering services there are likely to be significant wider economic benefits if the data from the study is used to impact on service provision. The economic cost benefit of dealing with preventable vision loss is significant – in terms of impacts on the individual, the NHS, social care and the exchequer. A dedicated Health Economics Working Group has been set up as part of the governance for the project which will be responsible for outlining the economic impact of the project once data has been gathered.

In England, primary care eye-health services cost ~£500 million and in acute services £1.4 billion is spent per annum. If 3% of the primary care budget or 1% of the acute budget could be reduced through the interventions from this study, then this project would have reached a positive return in investment  
Specific economic benefits of investment are as follows:

**Table 5: Wider economic benefits**

Benefit category	Detail	Evidence
<b>Improved targeting of expenditure and development of effective pathways</b>	Better data and understanding of the UK's eye health will support commissioners to understand the linkages with other conditions and put in place improved services to manage interdependencies. Improved targeting of expenditure on eye health services will reduce budgets over the long term as investment in prevention pays back and reduced the burden on health services.	In England, primary care eye-health services cost ~£500 million and in acute £1.4 billion is spent per annum. There are a number of universal budgets in the UK, which could be targeted better. For example, the General Ophthalmic Services (GOS) contract is a universal budget aimed at adults, with minimal intelligence on how this is used in practice. It only covers a fraction of adults, and eligibility could be targeted with a better understanding from UKNEHS data. The Childhood Vision Screening Programme is a universal service, but take-up is not tracked e.g. some children are missed and some are screened twice via the free GOS sight test at a later date.
<b>Reducing pressure on NHS services</b>	There will be fewer patients accessing acute and emergency services for conditions which	Ophthalmology outpatient activity is increasing – growing from 2,868,903 patients in 2012/13 to 3,185,632 in

Benefit category	Detail	Evidence
	can be better treated in a community setting	2016/1774 – it has nearly doubled since 2006/07. 12 million sight tests are performed in England every year, with little oversight as to whether this investment has a positive impact or not. Delivering eye tests at the right time, in the right setting of care could have a tangible impact on acute services – this reflects the ambition set out in the NHS Long Term Plan. A first eye test for a new patient with an ophthalmologist in a hospital is £139 per attendance. The cost of a GOS sight test in the community is £20.95 (cost to the NHS <sup>75</sup> ), representing a significant difference in cost if sight tests could be used at the right time, in the right setting of care, preventing a need for acute services later on in the pathway.
<b>Reducing additional costs associated with vision loss and blindness</b>	Addressing preventable vision loss will reduce the likelihood of associated falls and fractures requiring medical treatment, with potential for substantial annual savings	Falls resulting from visual impairment and loss are estimated to cost the NHS at least £25million per annum. <sup>76</sup> NHS Improvement estimated the average cost per fall for a person aged over 65 years to be anywhere from £2,621 for no harm to £10,587 for severe harm. <sup>77</sup>
<b>Reducing additional costs associated with vision loss and blindness</b>	Vision loss and blindness is linked to cognitive decline; reducing instances of avoidable blindness will help to manage the cost of	Vision impairment can triple the risk of dementia and is associated with increased depression symptoms over time. Depression is estimated to cost the UK £7.5 billion per year <sup>78</sup> , whilst dementia costs the UK £26 billion per

<sup>74</sup> RNIB, 'Review of Ophthalmology Services Across England', 2018, page 5

<sup>75</sup> It should be noted that there is industry-wide debate on the true cost of a GOS eye test – a recent doctoral thesis published in Optometry Today found that actual costs in one practice were of ~£37, 20 March 2018

<sup>76</sup> Thomas Pocklington Trust, 'Falls in Older People with Sight Loss', 2013

<sup>77</sup> NHS Improvement, 'The Incidence and Costs of Inpatient Falls in Hospitals' 2017, page 12

<sup>78</sup> McCrone P, Dhanasiri S, Patel A et al (2008). Paying the price: the cost of mental health care in England to 2026. London: King's Fund.

Benefit category	Detail	Evidence
	conditions such as dementia and depression	year <sup>79</sup> - there are significant opportunities for cost savings in this area. Dual sensory loss poses a significantly greater risk of depression than single sensory loss. <sup>80</sup>
<b>Employment</b>	There will be longer term benefits to the UK economy through increased employment of people with long term eye conditions, visual impairment and blindness being supported through employment	Sight loss and blindness resulted in 90,108 fewer people in the UK workforce in 2013 and an estimated loss of £2.3 billion income. <sup>81</sup> Blind and partially sighted people are much less likely to be in employment (26%) than the general population (74%) or people with other disabilities (48%). <sup>82</sup> This has a substantial impact on the UK economy and knock on effect on tax revenues to the exchequer.
<b>Reducing the burden on social care</b>	Vision impairment has an impact on health and wellbeing, resulting in increased use of social care services including for specific conditions such as dementia	The cost of residential care and community care services due to partial sight and blindness was estimated to cost the UK £369 million in 2013. <sup>83</sup>

## How we will deliver the project successfully

Realising the benefits described above relies on delivering the study successfully. This means that a robust project structure needs to be in place, suitably skilled staff need to conduct the examination and the appropriate resources will need to be mobilised to disseminate and communicate the study results.

In terms of the wider programme, focussed resources will need to be mobilised to support government and commissioners to use the study results to achieve the change in service provision that is needed, as part of a wider programme of work. This will be explored further outside of the scope of this case.

<sup>79</sup> Alzheimer's Society, 'Dementia 2014: Opportunity for Change', 2014, page v.

<sup>80</sup> McDonnell, 'The Effects of Developing a Dual Sensory Loss on Depression in Older Adults: A Longitudinal Study', 2009.

<sup>81</sup> Pezzullo, Streatfield, Simkiss and Shickle, 'The economic impact of sight loss and blindness in the UK adult population', 2018, page 5

<sup>82</sup> RNIB, 'Employment Status and Sight Loss' 2017, page 10

<sup>83</sup> RNIB, 'Future Sight UK Report' 2009, page 117

## **The project to deliver successfully**

We envisage delivering the project over a 3-year timeframe. This will include the initial phase, engage stakeholders, design and develop the feasibility of the study. Following a build phase, there will need to be an NHS Ethics Committee submission, followed by a further feasibility phase and finally delivery of the study itself and dissemination of the findings.

1. **Marketing and Public Relations:** Develop a marketing and public relations strategy and further advance the sector partnerships that support detailed design of the project
2. **Detailed Design:** Further improve the design of the survey and participant journey, identify required resources
3. **Staff Recruitment:** Recruit staff to roles and provide training
4. **Build Phase:** Produce the necessary materials, build / purchase / test the equipment and software required, prepare marketing materials and engage with authorities and partners
5. **Ethics Submission:** Draft and submit a Research Application through the Research Ethics Committee within the Health Research Authority
6. **Pilot Phase:** Conduct a small study in selected areas over a specific time period
7. **National Survey Phase:** Roll out and deliver the survey
8. **Dissemination:** Share the outputs of the study

This is shown in the plan below and tasks are described in more detail at **Appendix D**. The project will be phased over three years from the agreed start date.

**Figure 7: Project plan to deliver the study**

Critical Activity	Year 0	Year 1	Year 2	Year 3
Marketing and Public Relations	■			
Initial Design	■			
Staff Recruitment		■	■	
Detailed Design		■		
Build Phase		■		
Ethics submission (3 months)		■		
Pilot Phase (inc analysis)			■	
National Survey Phase (incl analysis)			■	■
Dissemination				■

**Governance**

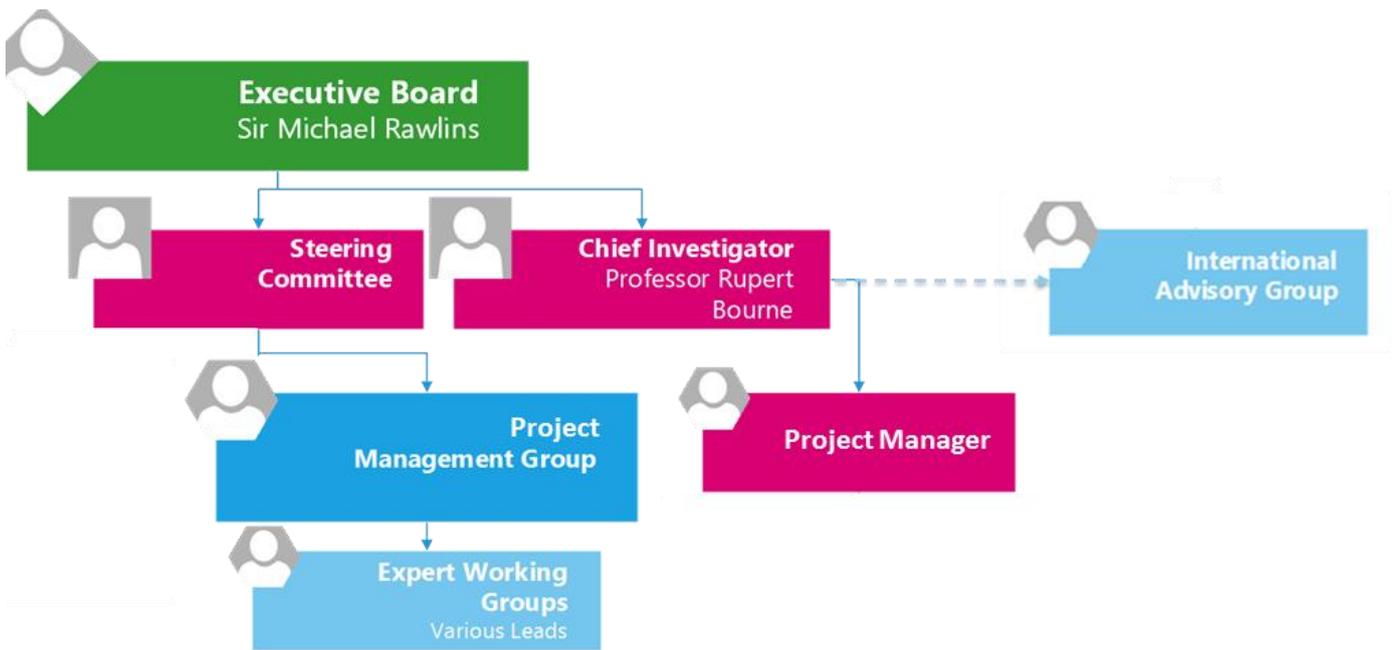
The project is led by an Executive Board and Steering Committee, with day-to-day management operating under a multidisciplinary Project Management Group, supported by technical working groups.

The Steering Committee and Project Management Groups have met regularly throughout 2018 and 2019.

In the current phase, the project is being managed through the following governance structure. This will ensure that the study is delivered in line with the set objectives, that it is delivered to time and to the level of quality required. It also ensures that the appropriate external scrutiny and partner involvement is sought.

The project is currently in an initial pre-project initiation design phase. During detailed design phase, governance will be reviewed to review membership and roles. During the national survey delivery phase, governance will likely move to another phase as an operational delivery team will report into the Chief Investigator. Governance will be reviewed regularly throughout the project.

**Figure 8: Project governance**



Each governance group has the following role and frequency:

**Table 6: Governance groups and frequency**

Entity	Purpose	Frequency of meeting
Executive Board	Provides overall programme governance and authority, outside of agreed project tolerances	Twice a year
Steering Committee	Provides high level direction, authority and resources within agreed project tolerances, and removes roadblocks. Representation by the Host Institution (Anglia Ruskin University)	Bi-monthly
The International Scientific Advisory Group	Provides advice on technical scientific features of the project and independent review of protocol related issues, changes and data analysis	Variant
<b>Project Management Group</b>	Provides day to day leadership and general process expertise for the planning and implementation of the project, including change management control, risk and issue resolution and escalations to the Steering Committee when required	Monthly

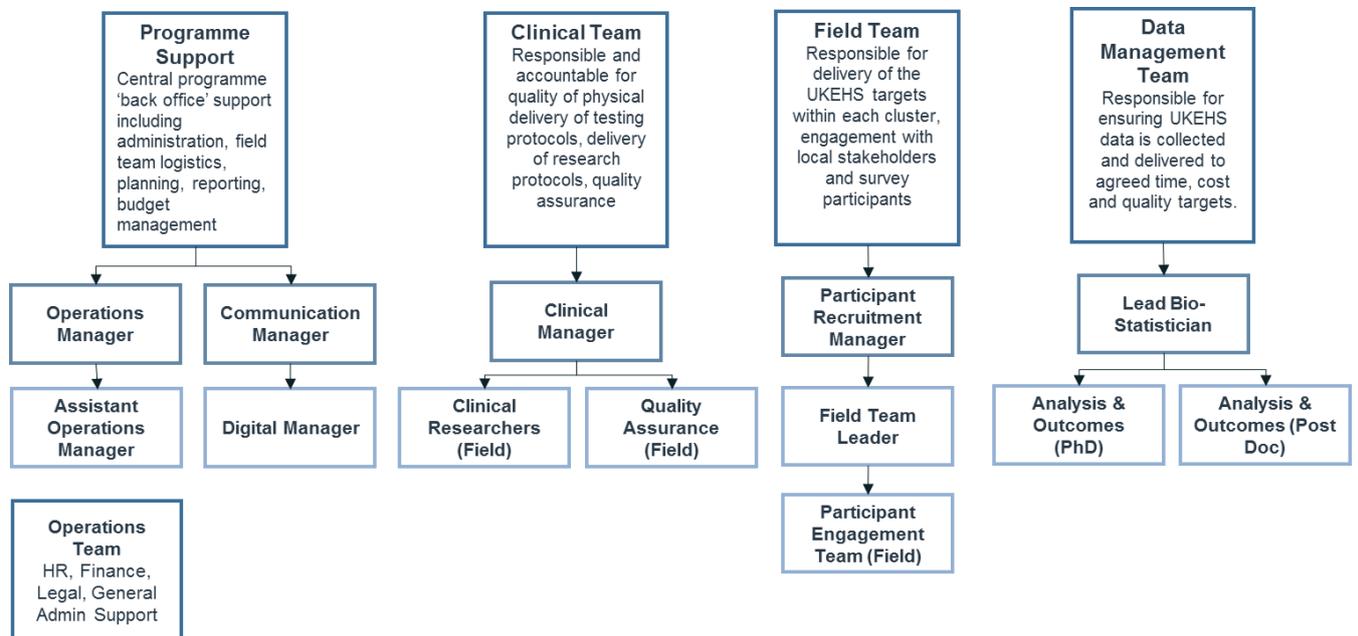
<b>Working Groups</b>	Provides subject / functional matter expertise, ownership, leadership and accountability for assigned programme tasks and results. The Working Groups are as follows:  Case Definitions Public Health & Equity Patient and Public Involvement (PPI) Data Linkage and Reading Centre Health Economics Epidemiology and Sampling Non-Ocular Specialties	Schedule determined by the Working Group Chair
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Full details of board memberships can be found in **Appendix E**.

## Resources to deliver the study

Roles and responsibilities of the teams who will be responsible for delivering the project are outlined below, with further details in Appendix F:

**Figure 9: Structure chart**



The UKNEHS expects also to benefit from ongoing support, advice and guidance from several organisations across the public sector, eye care sector, professional organisations and industry:

- NHS England
- National Institute for Health Research
- Public Health England
- Department of Health
- The College of Optometrists
- The Royal College of Ophthalmologists
- Anglia Ruskin University (the 'Host Institution')
- The Australia National Eye Health Survey
- The Institute of Optometry
- Thomas Pocklington Trust
- Vision UK
- Macular Society
- Royal National Institute for Blind People (RNIB)
- England Vision Strategy
- Guide Dogs
- International Glaucoma Association
- Seeability
- Optometry Wales

- Hearing Alliance and Action on Hearing Loss
- Bayer
- Topcon

## **Supply / procurement approach**

It is anticipated that the following services will need to be commissioned in order to deliver the study successfully:

- A support services supplier. This will be one of the roles of the Host Institution, Anglia Ruskin University.
- Project / programme management supplier(s);
- Supply of the field delivery team (this may be through a number of delivery routes - direct recruitment or commissioning a supply contract with an appropriate provider);
- Equipment and technology;
- Individual contracts will be put in place to source particular clinical and subject matter expertise to deliver the clinical, field and data management streams of activity.

The host institution, Anglia Ruskin University, will be the UKNEHS sponsor body, and will be the contracting organisation for any supplies or services to the project. Any eventual procurement of services would be procured in compliance with the EU Public Contracts Regulations 2015.

## **Ethics approval**

The Chief Investigator will seek ethics approval for the study via the Health Research Authorities for England and the devolved nations. Each participant will be required to sign a consent form that outlines the aims, significance and methodology of the UKNEHS. The UKNEHS will adhere to the tenets of the Declaration of Helsinki and all privacy requirements will be met.

We have already undertaken considerable Patient and Public Involvement (PPI) consultation and involvement with development of both project governance and study design, which will support an effective ethics application process.

## **Risks and dependencies**

Project risks associated with the study will be reviewed regularly through governance to ensure that appropriate mitigations are put in place. Top risks needing careful management and mitigation are around guaranteeing a representative sample size, ensuring safe and accurate data collection and transfer, and equipment failure.

There are wider programme risks around non-achievement of benefits and outcomes, which will be understood in more detail as the programme approach is developed.

**Table 7: Risk log**

<b>Risk Description</b>	<b>Rationale</b>	<b>Mitigation</b>
<b>There is a risk that a high percentage of household no-contact will mean the study is not representative of the UK population</b>	There are diminishing returns with each extra visit, and revisits are time and resource intensive. It is likely that several revisits will be required to secure an effective response rate	Engage with Health Survey England for recommendations on the mean / median and range of revisits required, and the threshold for an effective response rate
<b>The data captured is poor quality</b>	There may be ‘teething issues’ with recording data initially, and capturing participants questionnaire responses accurately	Clinical experts are being engaged throughout to ensure the survey questionnaire is comprehensive and the right data is being collected Audit by quality assurance team member will help to monitor and eliminate this
<b>The study is using new technology which is not yet fully tested</b>	The equipment used is state of the art new technology, and may not have been fully tested prior to the start of the UKNEHS	This will be managed through the Case Definition Working Group
<b>Loss of skilled resource before and during the project</b>	There is a resource risk associated with fixed term contracts, particularly towards the end of the contract	Effectively engage and involve staff and contractors throughout the lifetime of the programme and develop a robust contingency plan to replace skilled staff critical to the programme quickly
<b>Equipment failure on site</b>	Remote recording of data carries risks, for example loss of internet connection and loss of data	Develop a repair and replacement strategy
<b>Failure at the data centre resulting in loss of data captured</b>	Unforeseen technical issues for example a power cut may result in a loss of data at the data centre	Queens University Belfast Data Centre houses two servers and separate file storage arrays in a state-of-the-art facility with risk prevention strategies in place. All data is backed up regularly with

Risk Description	Rationale	Mitigation
		tape backups stored off-site in a fire-proof environment. In the event of hardware failure all data can be repopulated from backups.
<b>Safeguarding of participants and staff during domiciliary visits and in remote areas</b>	There is a need to ensure that all participants are examined in line with safeguarding standards	All staff in public facing roles will have a Disclosure and Barring Service (DBS) check. Safeguarding training will be addressed as part of induction training
<b>Public liability e.g. an accident, personal injury or damage to personal property from use of the equipment</b>	Unforeseen circumstances may result in accidents occurring during clinical engagements	A health and safety policy will be put in place in line with industry standards

Key:

Impact	Low impact					High impact				
Probability	1	2	3	4	5	1	2	3	4	5
Low - unlikely to take place	1	2	3	4	5	6	7	8	9	10
	2	4	6	8	10	12	14	16	18	20
	3	6	9	12	15	18	21	24	27	30
	4	8	12	16	20	24	28	32	36	40
High - likely to take place	5	10	15	20	25	30	35	40	45	50

## Benefits tracking / evaluation approach

The benefits of the study were outlined in an earlier section. In the next phase of design, benefit measures will be defined to ensure that the desired outcomes are achieved and can be evidenced. Benefit measures, owners, a benefit measurement approach, and key dependencies / risks to achieving each benefit will be defined and tracked.

## Conclusion and next steps

The case has outlined the overall need for investment in data in the UK eye health sector. We all take vision for granted, until we lose it. Embarking on the UKNEHS will help Government efficiently and effectively target UK spending, ensure that vulnerable groups are accessing the services they need to reduce preventable sight loss, and ultimately, better support those living with sensory loss to receive the care that they need to participate fully in society. The purpose of this document is to request funding to make a step change in the way eye health and hearing services are delivered in the UK.

We have described the context for change – demand for services is rising, whilst provision of services in the UK is fragmented (across a multitude of settings and sub-sectors of care within the overall health and social care landscape). Within this context, we have very little high-quality data currently available in the UK that identifies people at risk of, or living with, vision loss or impairment, meaning that it is very difficult to target resources where they are needed most. Increasing demand for services and tight budgets are likely to stretch our services further and magnify the already significant impact of the economic cost of sensory loss in the UK. Better data would help government to target resources better and invest in new models of care to improve outcomes and reduce overall costs. This will help meet the NHS Long Term Plan goals in delivering care at the right time, in the right setting and in investing in prevention and health inequalities. The sector also offers a number of opportunities for digital innovation.

The study will determine the prevalence and causes of vision impairment and blindness in the UK population aged 50 years and older (by gender, age, socio-economic group and geographical area) – this will provide an up to date, and comprehensive picture of the UK's eye health. 25,000 adults will be surveyed to achieve this. We have outlined our objectives for change, how the project will be delivered successfully, and the benefits that it will bring to patients, the NHS and the wider UK economy.

The next steps for the project are to:

- Secure funding for this proposal;
- Undertake final detailed design;
- Establish the resource required to proceed with formal mobilisation of the project and undertake procurement / recruitment processes;
- Commence a detailed delivery design phase and pilot.

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## Appendix A: General Ophthalmic Services

The table below contains details about General Ophthalmic Services (GOS) provision based on contracts in place in England, Northern Ireland, Scotland and Wales.

Country	Commissioning arrangements	Delivery detail (The College of Optometrists)
England	Eye care in England is delivered through a combination of national and local funding	<ul style="list-style-type: none"> <li>• General Ophthalmic Services (GOS) are NHS-funded sight tests which are contracted and funded at a national level for eligible patients.</li> <li>• Planning and commissioning of health services including Hospital Eye Services (HES) is managed locally by Clinical Commissioning Groups (CCGs).</li> <li>• Extended primary care services deliver services beyond the remit of the basic GOS sight test e.g. repeat measures and minor eye condition schemes.</li> </ul>
Northern Ireland	Health care and social care services are jointly commissioned	<ul style="list-style-type: none"> <li>• The Health and Social Care Board (HSCB) is responsible for all commissioning and manages the GP contract for primary care and GOS.</li> <li>• GOS fees are paid via a ring-fenced health and social care budget allocation of almost £5bn from the UK government.</li> <li>• A range of special enhanced services are almost commissioned to help manage increasing demand.</li> <li>• The integrated budget means that moving patients from secondary to primary care does not have budget ramifications – this allows HSCB to more rapidly adopt appropriate services when ophthalmology departments are struggling with demand.</li> </ul>
Scotland	14 geographically based NHS Boards are responsible for both planning and delivering services	<ul style="list-style-type: none"> <li>• Two types of examination are covered by GOS in Scotland – the primary care examination and the supplementary eye examination for extra tests that present during the initial examination.</li> <li>• Enhanced services are commissioned and funded at a local level so there is some geographical variation.</li> </ul>

		<ul style="list-style-type: none"> <li>• The GOS contract has a tiered fee structure. There is funding to support the training of independent prescribing (IP) optometrists, and optometrists can manage ocular conditions within primary care at no cost to the patient.</li> </ul>
Wales	7 local Health Boards plan and provide hospital and community services and are responsible for primary care	<ul style="list-style-type: none"> <li>• Health Boards are responsible for managing the totality of their budget allocation including how money for eye services is spent at a local level.</li> <li>• NHS Wales has nationally commissioned enhanced eye care services that go above and beyond the basic GOS contract. These are delivered through the Eye Health Examination Wales (EHEW) scheme and include further investigation after a sight test and follow up services.</li> <li>• EHEW is part of the Welsh Eye Care Services (WECS) which is unique to Wales and includes Low Vision Services and a Diabetic Retinopathy Screening Service.</li> </ul>

## Appendix B: Study Sampling Approach

The national survey will use a multi-stage stratified probability sampling design, common to many previous eye surveys internationally and to the Health Survey for England, who are represented on the UKNEHS Project Management Group. The sampling frame will be the small user Postcode Address File (PAF), sorted by the Index of Multiple Deprivation (and the closest available equivalents in the devolved nations). We will stratify by country, then draw a random sample of primary sampling units (PSUs), usually based on postcode sectors, with probability proportional to size of the cluster (number of addresses). In the second stage, within each PSU a fixed number of postal addresses will be selected at random. In the third stage all eligible residents of selected households will be invited to participate.

The sample size calculation, of 24,294 adults aged 50 years and above, in 487 clusters, is recommended to permit estimation of blindness prevalence, and all ocular diseases more frequent than 0.4% in this age group, with precision and will yield precise estimates of blindness in the UK. This will enable risk factor analysis for approximately ten variables associated with blindness risk, and will permit precise estimation of the burden and risk factors associated with all ocular diseases more common in the population than 0.4% (e.g. wet AMD and severe vision loss from DR).\* This sample size includes oversampling in Wales, Scotland and Northern Ireland to ensure that the prevalence of MSVI (3.5%) and more common eye diseases can also be estimated with precision in each country. This sample size equates to 487 clusters of approximately 50 eligible people.

We will sample 17409 people in England and, as noted above, we will oversample each devolved nation, assuming a prevalence of VI of 3.5%, to yield a sample size of approximately 2295, in 46 clusters. This means that each devolved nation will have sufficient data to determine their population's risk factors for VI, independently of the UK-level estimates. This will be of value in exploring the impact of different policies and programmes by country.

Given our diverse and multi-ethnic population, this very large population-based survey size will increase the 'external generalisability' of the findings - the likelihood that the 487 randomly selected clusters truly capture and represent the full diversity in our population with respect the risk factors and outcomes that matter/that we want to understand.

To achieve a representative sample of the entire UK population across all age groups would require a significantly larger sample size, as blindness and severe vision impairment is much less common in younger people and a larger sample would be required to get an accurate finding of prevalence.

The study team has worked extensively with Health Survey England to gain their advice on the approach to sampling and the viability of the survey. Health Survey

England has agreed to generate the randomised sample for the study, which will ensure the accuracy and independence of this aspect of the study.

Based on Global Burden of Disease estimates of blindness and vision impairment in high-income countries, which reports a prevalence of blindness of 0.15% and moderate/severe VI of 1.27% in all ages, a sample size of 66,488 participants would need to achieve precision around blindness at the UK level - using all the same assumptions as the 25,000 estimate for people aged 50 years and above.

\* This calculation assumes a prevalence of 0.4%, a response rate of 70%, power 80%, alpha 0.05, and allows for a design effect due to clustering and oversampling in the devolved nations of 1.5.

## Appendix C: Detailed Cost Breakdown

Cost type	Cost breakdown	Total Costs (Years 1-3)	Detail	Assumptions
<b>Programme staffing</b>	Programme team (including working groups)	700,000	Programme Manager, Programme Support Pillar x3 (Digital Manager, Communications Manager, Operations Manager)	Based on market rates
<b>Study staffing costs</b>	Investigating team	240,000	Principle Investigator, Co-Investigators x3	Based on market rates
	Field team	3,610,000	Participant Recruitment Manager, Field Team Leader, Participant Engagement Team, Quality Assurance	Based on market rates
	Clinical team	4,420,000	Clinical Researchers, Quality Assurance	Based on market rates
	Data management team	400,000	Lead Bio-Statistician, Analysis & Outcomes Post-Doc, Analysis & Outcomes PhD	Based on market rates
<b>Study non-staffing costs</b>	Equipment	380,000	Android tablet, iCare, portable retinal camera x23, field staff phones (purchase and run costs) hearing test delivery costs	Market value costs derived from online research
	Consumables	130,000	Direct mail campaign (including postage, printing consent letters), eye drops, antibacterial wipes, Viscotears, internet access	Derived from online research and quotes from Cambridge Lea Hospital
	Travel and accommodation	2,730,000	Travel and accommodation costs for Field Team, Programme support staff, SC members, PMG	£0.45 per mile 2-5 nights away per person (field

Cost type	Cost breakdown	Total Costs (Years 1-3)	Detail	Assumptions
			members, Working Group Chairs, PPI representatives	team and programme team) per month during pilot and roll out period
	Other direct costs	170,000	Hospital referrals (admin cost per referral), software platform, participant engagement activities, focus group venues, PPI representation on SC, website design, social media maintenance and hosting, recruitment materials design, Belfast Reading centre grading & data centre costs	Derived from online research
<b>Dissemination costs</b>	Consumables, travel and admin	120,000	Posters, open access publication costs, conference presentations, PPI travel to launch event, SC travel, Investigator travel costs, PhD Ophthalmologists and PhD Optometrists travel, hard copies of final report, summit event costs (venue hire etc)	Presenting fees and travel costs
<b>Support services</b>	Support services costs (finance / IT / HR etc.)	1,310,000	Operations Manager, Admin Support x2, Finance Support, HR Support, Legal Support Non-Staffing costs e.g. recruitment, consumables, travel, space cost, indirect costs, estates	Derived from Anglia Ruskin University quote

Cost type	Cost breakdown	Total Costs (Years 1-3)	Detail	Assumptions
Recruitment / procurement	Potential recruitment / procurement costs	1,480,000	Estimated procurement / recruitment costs	Project team assumption
<b>Total</b>		<b>15,690,000</b>		

## Assumptions

Assumption	Units	#	Notes
<b>Field Team Assumptions</b>			
Participant Engagement Team, FTE hrs / person / week	Hours	40	
Clinical Researcher, FTE hrs / person / week	Hours	40	
<b>Participant Engagement Team (Enumerators)</b>			
Estimated time per engagement visit	Minutes	15	Ave. no. of mins per visit to each house (enumerator) assuming a non-eligible person will take 8mins and an eligible person 22mins
Estimated time per door-knock (unsuccessful visit)	Minutes	15	Allows for greater walking time between homes for each re-visit (as successful visits are achieved)
No. of visits expected to each household per cluster	Number	3.1	Visit 1=30% success, visit 2-4=15%, visit 5-6=10%, visit 7=5%
Total no. of household visits required in each cluster	Number	204.60	
Total no. of enumerator hours required per cluster	Hours	51.15	

Uplift to cover breaks, A/L for Participant Engagement Team & Clinical Researchers	%	30	14% for breaks, 12/13% statutory leave entitlement, rem. non-clinic hours
Contingency for S/L etc	%	10	
<b>Referral Assumptions</b>			
Referral rate	%	18	
Referrals	#	4,500	
Referral letter	Sheets	15	
Postage of referral letters	Per letter	£0.63	
Referral letter – print & postage cost		£3.33	

## Appendix D: Detailed Programme Tasks

### 1. Marketing and Public Relations

- To develop a marketing and public relations strategy, identifying the key funding streams available, including organisations, individuals, partnership deals and UK Government
- To identify and engage with key stakeholders who are interested in the programme and whom will advocate, support and influence our funding applications
- To identify and engage with our Senior Users, those who will benefit from the outputs of the project to deliver positive outcomes for the UK population

### 2. Initial Design

- Programme set up: governance, research proposal, full economic costing
- Communications: develop a stakeholder plan, patient and public involvement, design and set up external website and social media platforms, develop a marketing / PR plan (national and local)
- People Resources: Agree the programme's overall organisational structure and any onboarding process/training required
- Sampling Methodology: Finalise the sampling map/postcode areas and identify key authority areas within each devolved nation
- The survey: Agree the study protocols i.e. what will be tested and how
- Participants journey: draft and agree the end to end participant journey/process and identify what documents, materials, equipment, data management is required
- Referral Process: identify and map out the referral processes required

### 3. Staff Recruitment

- Identify and appoint a recruitment agency if applicable
- Create job descriptions / skills profile for all vacant roles and evaluate, if required
- Advertise, interview, appoint central programme team
- Advertise, interview, appoint field delivery team
- Deliver on boarding process i.e. induction training, as required

### 4. Detailed Design

- Design the survey questionnaire
- Define the customer journey
- Identify required resources
- Develop benefits tracking approach

### 5. Build Phase

- Produce the necessary materials; invite letters, registration process, consent form, questionnaire, referral letters, follow up documents
- Build/ purchase/test the equipment required
- Build/purchase/test the software required

- Engage with relevant authorities across the UK (I.e. referral process, authority to proceed etc)
- Prepare marketing/PR materials

## **6. Ethics Submission**

- Draft and submit a Research Application through the Research Ethics Committee within the Health Research Authority
- Manage responses to questions, issues raised
- Edit and re-submit if required

## **7. Pilot Phase**

- Conduct a small study in selected areas over a specific time period
- Analyse
- Manage any change necessary, as a result of the pilot
- Critical go-live decision to proceed to full national study

## **8. National Survey Phase**

- Test state of readiness to 'go-live'
- Commence national roll out
- Day today management of field delivery teams
- Quality assurance of testing protocols
- Analyse data
- Deploy participant referral process as necessary
- Draft and produce reports
- Peer review

## **9. Dissemination**

- Publish reports

## Appendix E: Governance Board Membership

Membership of each governance board is detailed in the table below, and will be reviewed after funding is secured and the final organisation structure is agreed:

Supporter / Stakeholder	Advisory	Governance	Operational
<b>Steering Group</b>	<b>International Scientific Advisory Group:</b>	<b>Executive Board</b>	<b>Project Management Group</b>
<b>Chair:</b> Raj Mehta <b>Vice-chair:</b> Matt Broom <b>Members:</b> Adrian Davis Chris Hammond Clare Perkins Richard Parish Robert Harper Louise Fairhurst Lay Members x3 Rupert Bourne	Hugh Taylor Jost Jonas David Friedman Emanuela Gakidou Jinan Saadine Mingguang He Josh Foreman Mohamed Dirani	<b>Chair:</b> Prof. Sir Michael Rawlins <b>Vice-chair:</b> TBC <b>Members:</b> UK Govt. Rep. - DH Govt. Rep. WALES Govt. Rep. SCOTLAND Govt. Rep. NORTHERN IRELAND Lay person / PPI (x2) Host Institution rep	<b>Chief Investigator:</b> Rupert Bourne <b>Members (Co-Investigators, Co-I):</b> Richard Wormald (Co-I) Tasanee Braithwaite (Co-I) Tunde Peto (Co-I) Mike Bowen (Co-I) Mohamed Dirani (Co-I) Shahina Pardhan (Co-I) Anne Conolly Stuart Keel <b>Project office team:</b> Project Manager Senior Project Coordinator Project Administrators <b>Project Field Team:</b> Screeners Ophthalmologists/Optometrists Techs

## Appendix F: Project Roles and Responsibilities

Detailed roles and responsibilities:

<b>Role</b>	<b>Description</b>
Project Support Pillar: Public Relations Manager	Overall responsibility and accountability to develop and execute the marketing and public relations strategic plan for the project.
Principle and Co-investigators x 4	Overall responsibility for the design and delivery of the project, within agreed ethical and scientific standards and methodologies.
Working Group Chair x4	To advise the Project Management Group, Steering Group and Executive Board on all aspects of their relevant area of expertise.
Data Management Pillar: Lead Bio-Statistician	Overall responsibility and accountability to ensure UK NEHS data is collected and delivered to agreed time, cost and quality targets.
Data Management Pillar: Analysis & Outcomes (PhD)	To support the analysis and reporting of outcomes.
Data Management Pillar: Analysis & Outcomes (post-doc)	Overall responsibility for the delivery of UK NEHS data analysis and report outcomes to time, cost and quality.
Project Manager	Overall responsibility for the successful initiation, planning, design, execution, monitoring, controlling and closure of the project.
Project Support Pillar: Digital Manager (Web, social media)	Overall responsibility and accountability to design, develop and maintain digital platforms including all social media.
Project Support Pillar: Communications Manager	Overall responsibility and accountability to design, develop and deliver PR / communications materials for the programme.
Project Support Pillar: Operations Manager	Overall responsibility for the provision of central programme 'back office' support, including general administrative tasks, field team logistics, planning and reporting, budget and supplier management.
Field Team Pillar: Participant Recruitment Manager	Overall responsibility and accountability for the field team and the recruitment of eligible participants to agreed targets of time, cost and quality.

<b>Role</b>	<b>Description</b>
Clinical Pillar: Clinical Manager	Overall responsibility and accountability for the quality of the physical delivery of testing protocols out in the field, including the recruitment and training of the clinical researchers.
Field Team Pillar: Field Team Leader	Successful delivery of UK NEHS participant targets, within their allocated clusters, through effective leadership of their field teams and pro-active engagement with local stakeholders and participants.
Clinical Pillar: Quality Assurance (Field)	To quality assure the testing protocols of the clinical researchers out in the field.
Field Team Pillar: Participant Engagement Team (Enumerators)	Physical 'door to door' canvassing of households, within their allocated clusters, leading to successful recruitment of eligible participants, in line with the targets agreed.
Clinical Pillar: Clinical Researcher (Field)	For delivery of agreed research protocols, to agreed time, cost and quality targets in each of their cluster areas.
Field Team Pillar: Contingency funding (S/L etc)	Contingency funding for all roles e.g. due to sickness leave.