



Title : Low vision and diabetes in older people living in residential care homes

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**LOW VISION AND DIABETES IN OLDER PEOPLE
LIVING IN RESIDENTIAL CARE HOMES**

By

Nizam Muhammad Darwesh

June 2015

UNIVERSITY OF BEDFORDSHIRE



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**A thesis submitted to the University of Bedfordshire
in partial fulfilment of the requirements for the
degree of Doctor of Philosophy**

June 2015

ABSTRACT

Background

Worldwide one in twelve people are living with diabetes and one in two people do not know they have diabetes. Currently large numbers of the older people live in residential care homes in the UK, and up to one in four older people living in residential care homes present with diabetes. Low vision is one of the complications associated with diabetes in older people. In those aged 75 and over, one in five, and in those aged over 90, one in two people are affected by low vision and they are at an increased risk of developing other eye diseases. Within 20 years of diagnosis nearly all people with Type 1 and almost two thirds of people with Type 2 diabetes (60%) have some degree of diabetic retinopathy.

Aims and Objectives

This study aimed to investigate the issues and problems faced by older people living in residential care homes with low vision and diabetes; to evaluate health professionals' knowledge and understanding of the impact of low vision associated with diabetes in older people living in residential care homes; and to develop an educational toolkit which aimed to educate health care assistants about low vision and diabetes.

Methods

This study is an exploratory investigation of older people living in residential care homes with low vision and diabetes. Adopting an open-ended qualitative approach using focus groups, interviews and a health professional's survey, 116 participants were involved. These included GPs, ophthalmologists, nurses,

optometrists, health care assistants and older people with low vision and diabetes. The data was analysed thematically.

The educational toolkit was developed in the second part of this study, and 20 healthcare assistants were trained using this toolkit. Their knowledge was tested before the training, immediately after the training and one month after the initial training. Following Kirkpatrick's model, the skills and practical use of the educational toolkit was assessed using an open-ended qualitative approach.

Results

The results found that many older people and the health care assistants had the perception that low vision was a normal ageing process and could not be rectified. The study found that there was evidence to suggest that eye health was not considered to be a priority; instead, it was considered to be a natural part of the ageing process.

The results found that 82% of the HCAs had not had any training in the area, and more than half of the nurses and GPs did not have sufficient knowledge of low vision and diabetes. After training, however, their knowledge was increased. This suggested that low vision and diabetes toolkit training could be used to educate healthcare assistants on a regular basis. The study also found that knowledge does decline over time, and therefore regular training for HCAs is required in order to maintain eye health and diabetes in older people, as well as improving their quality of life.

Conclusion

In the research findings it was found that 50% to 70% of low vision was preventable or treatable if detected in its early stages and could be avoided by

simply wearing appropriate spectacles, or possible surgery. However, in order to identify these 50% to 70% with low vision, everyone concerned should be able to recognise the signs and symptoms of preventable low vision, particularly health care assistants, as according to this study, health care assistants spent large amount of time in the residential care homes compared to the other health professionals.

Key words: low vision, diabetes, visual impairment, older people, health care assistants training, residential care home.



DECLARATION

I, Nizam Muhammad Darwesh, Registration No. 1135306, PhD Researcher in the subject of low vision and diabetes at the Institute of Diabetes for Older People (IDOP), B & H Postgraduate Medical School University of Bedfordshire, submit this project entitled: “Low vision and diabetes in older people living in residential care homes”, Session 2012 – 2015, and hereby declare that the matter printed in the thesis is my own work. It is being submitted for the degree of Doctor of Philosophy at the University of Bedfordshire. It has not been submitted before for any degree or examination in any university.

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GLOSSARY OF ABBREVIATIONS

ABDO	Association of British Dispensing Opticians
AGO	Accredited Glaucoma Optometrist
AMD	Age-related Macular Degeneration
COAG	Chronic Open Angle Glaucoma
COSI	Community Optometrist with Special Interest
DES	Data extraction sheet
DR	Diabetic Retinopathy
GOC	General Optical Council
GOS	General Ophthalmic Services
HCA's	Health care assistants
HES	Hospital Eye Service
IAPB	International Agency for the Prevention of Blindness
IDOP	Institute of Diabetes for Older People
IOP	Intra-ocular pressure
LOC	Local Optometry Committee
LV	Low Vision
NICE	National Institute for Clinical Excellence
NSC	National Screening Committee
OA	Optometric Advisor
PCT	Primary Care Trust
POAG	Primary Open Angle Glaucoma
RCHs	Residential care homes
RNIB	Royal National Institute for the Blind
SHA	Strategic Health Authority
STDR	Sight Threatening Diabetic Retinopathy
STED	Sight Threatening Eye Disease
VA	Visual Acuity
VF	Visual Field

CHAPTER 1

INTRODUCTION

1. The reasons for choosing this topic

To start the thesis, it is important to provide brief information about the condition of diabetes, focussing in particular on the low vision associated with diabetes in older people living in residential care homes (RCHs); this research is important for the following reasons:

1.1. Diabetes is a worldwide problem

Worldwide, the prevalence of diabetes is high. According to the International Diabetes Federation (IDF, 2015) diabetes is a major health problem and globally *“every 7 seconds, 1 person dies from diabetes, 1 in 11 people are living with diabetes and 1 in 2 people with diabetes don’t know they have diabetes”*. The IDF diabetes atlas updates are published every two years, and it is anticipated that these numbers will rise to higher levels. According to the International Diabetes Federation (IDF, 2015) it was estimated that the diabetes prevalence for 2015 worldwide was approximately 415 million individuals aged between 20 to 79 and above; and it is expected that these numbers will increase to 592 million people by 2035. It is also estimated that 179 million people have undiagnosed Type 2 diabetes, (Diabetes UK, 2015). Globally, 64% of these cases are in urban and 36% in rural areas (IDF, 2014).

1.1.1. Diabetes prevalence in the UK

There is an increased risk of diabetes among older people living in residential care homes in the UK (Sinclair, 2010; Diabetes UK, 2015), which was estimated

by Diabetes UK. In the United Kingdom, approximately 700 people a day are diagnosed, which is the equivalent of one individual every two minutes, and more than one in 16 people has diagnosed or undiagnosed diabetes (Diabetes UK, 2015). It is also estimated that 3.3 million people in the United Kingdom are living with diabetes and it is expected that by 2025 these numbers will increase to 5 million. It is also estimated that there are around 590,000 people in the UK who have diabetes but have not been diagnosed (Diabetes UK, 2015). Older people are most likely to develop this metabolic disorder (Ahmed, 2010), and it has been suggested that due to our maturing population and mounting levels of obesity, the majority of cases will be Type 2 diabetes (Sinclair, 2010). According to Diabetes UK, in the United Kingdom, 90% of diabetes cases are Type 2 diabetes (Diabetes UK, 2015).

Of those diagnosed, approximately 56% are male and 44% are female. Furthermore, the distribution of diabetes by age group in audits is presented as 8.5% male and 6% of female, aged between 55 to 64, and 15.7% male and 10.4% female aged between 56 and 74, (IDF, 2014; Diabetes UK, 2015). Around 4.75 million individuals are at high risk and 11.5 million people in the UK are at increased risk of developing Type 2 diabetes due to being overweight (Sinclair, 2010; Gallichan, 2012; Department of Health, 2013).

1.1.2. Complications of diabetes

There are very serious complications associated with diabetes, including heart and kidney disease, stroke, amputation, premature mortality and blindness (Holt et al., 2010; HSCIC, 2015; IDF, 2015). These complications may start 5 to 10 years or more before the diagnosis of diabetes (Diabetes UK, 2015), as approximately half of the people with Type 2 diabetes do not know that they have diabetes (IDF, 2014; Diabetes UK, 2015). However, good diabetes education, awareness and screening programmes, as well as early diagnosis and good management will

reduce the risk of these complications (Stratton, 2000; Sinclair, 2010; Diabetes UK, 2015).

Cardiovascular disease (CVD): the risk of developing CVD is doubled in individuals with diabetes compared to individuals without diabetes; CVD is a major cause of death and disability in people with diabetes (Richard et al., 2010; IDF, 2014; Diabetes UK, 2015).

Kidney disease: (or nephropathy) is caused by damage to small blood vessels in the kidneys. It usually takes at least 20 years to develop (Richard et al., 2010) and approximately 3 in 4 people with diabetes will develop some elements of it and one in five people will develop chronic kidney disease which may need medical treatment (HSCIC, 2015).

Neuropathy or nerve damage: over 50% of people with diabetes are affected by neuropathies (Boulton, 2005; IDF, 2014; Diabetes UK, 2015) and up to 26% of people with diabetes are affected by chronic and painful neuropathy (Liew et al., 2014).

Amputation: diabetes can damage nerves and muscles; diabetes is the common cause of lower limb amputation and over 6,000 leg, toe or foot amputations happen each year in England, which is the equivalent of 100 amputations a week (Diabetes UK, 2015; HSCIC, 2015).

Sexual dysfunction: the occurrence of sexual dysfunction in men with diabetes appears to be between 35% to 90%, and 27% in women with diabetes (Malavige and Levy, 2009).

Depression: people with diabetes are at double the risk of suffering from depression (Mommersteeg et al., 2013), and may have depressive episodes more frequently and for longer periods compared with people without the disease (Mezuk et al., 2008; Diabetes UK, 2015).

Mortality associated with diabetes: worldwide, 8.4% of deaths in the age between 20 to 60, and 48% at age of 79 years or over, occur (IDF, 2014) due to diabetes. In England, 34.4% of people with diabetes die earlier than their peers; the mortality rate for Type 1 diabetes is 31% and for Type 2 is 32% (Diabetes UK,

2004). Individuals with diabetes have a life expectancy 6 to 20 years lower than a healthy individual (Seshasai et al., 2011). Annually, approximately 75,000 deaths occur due to diabetes, (HSCIC, 2010; National Diabetes Audit, 2011; HSCIC, 2015).

1.1.3. Diabetes related eye diseases

Older people with diabetes are at an increased risk of developing eye disease (Mukesh et al., 2006; Bosanquet and Mehta, 2008; Chiang et al., 2011; HSCIC, 2015; IDF, 2015). Diabetes related eye diseases, including diabetic retinopathy (DR), cataracts, glaucoma and age-related macular degeneration (AMD), are the main reasons of low vision in older individuals with diabetes (Bunce and Wormald, 2008; Scanlon, 2008; RNIB, 2013). According to (RNIB, 2015 b) the most frequent foundations of low vision are retinopathy, cataracts, glaucoma and age-related macular degeneration associated with diabetes, and additionally, a number of conditions, whether they are congenital, hereditary or age related, can cause low vision, which may be a result of diabetes complications including strokes or physical trauma (Bosanquet and Mehta, 2008; Ahmed, 2010; Holt et al., 2010).

Diabetic retinopathy (DR): diabetic retinopathy is a very serious eye problem associated with diabetes that can take several forms; one form is retinal swelling, or macular oedema (Scanlon, 2008). Macular oedema occurs when the small blood vessels in the eye are damaged, which allows fluids to enter the retina, resulting in swelling (Macular Society, 2015). Diabetic retinopathy occurs when a haemorrhage from fragile blood vessels leaks into the vitreous humour (RNIB, 2015 b; National Eye Institute , 2015).

Cataract: when the normal lens in the eye appears cloudy, this condition is called a cataract. Signs of cataracts include blurry vision, colours appearing dull, and an inability to see at night. The risk of developing cataracts in people with

diabetes is up to three times more likely to occur compared to other people (Mukesh et al., 2006; RNIB, 2015 a; National Eye Institute , 2015).

Glaucoma: initially, there are no warning signs or symptoms of glaucoma (Macular Society, 2015), but if not treated early, there is a high risk of blindness. Increased eye pressure is a common cause of glaucoma; however, in some cases glaucoma will occur with normal eye pressure (RNIB, 2015 b). The risk of developing glaucoma in people with diabetes and high blood pressure is 50% higher compared to other people (Newman et al., 2011). People over the age of 40 with diabetes with a history of glaucoma in the family are at higher risk of getting open-angle glaucoma, including neovascular glaucoma where the nerve grows in the cornea, resulting in blindness (Wadhwa and Higginbotham, 2005; RNIB, 2015 b). The damage caused to the eye by glaucoma cannot be reversed, but early diagnosis can help to prevent blindness (RNIB, 2015 b; National Eye Institute , 2015).

Age-related macular degeneration (AMD): according to the Macular Society UK, this is a common problem with older individuals (Macular Society, 2015). *“It is caused by progressive damage to the macula, which is the central part of the retina. AMD can be divided into two parts: either wet or dry; wet AMD is the more destructive and can severely impact visual function”* (Redmond and While, 2008). AMD sufferers report a decrease in central vision, thus affecting mobility, physical activity, and the overall quality of life (Hassell et al., 2000; Klein et al., 2003; RNIB, 2015 b; National Eye Institute , 2015).

1.1.4. Low vision is a serious consequence of diabetes in older people

Low vision in older people is one of the main complications of diabetes (United Nations, 2005; Scanlon, 2008; Diabetes UK, 2015), and diabetes is the main cause of retinopathy in older people (Scanlon, 2008; Emerson and Robertson, 2011). The World Health Organisation predicts that up to 135 million individuals suffer a visual impairment associated with diabetes, and almost 45 million individuals are

classified as blind (Cunningham, 2001; WHO, 2015). In the UK, approximately 2 million individuals are affected by low vision and large number of them are over the age of 75 (Bosanquet and Mehta, 2008; HSCIC, 2015). The global population is expected to increase markedly over the forthcoming years, and the number of individuals over the age of 60 is estimated to increase three-fold in the years between 2005 and 2050 (United Nations, 2005; United Nations, 2013).

In the UK, up to 224,000 people have severe sight loss; up to 358,000 people are registered as blind or partially sighted; and up to 14.2 million people aged over 60 and up to 1.4 million people aged over 85, are living with sight loss (RNIB, 2013). It is predicted that 20% of individuals over the age of 75, and 50% of individuals over the age of 90 experience some form of vision loss which may be associated with diabetes (RNIB, 2015 a). However, despite the predictions, there are no definitive statistics on the exact number of people. Figures from 2011 indicate that 299,000 individuals were registered as visually impaired in England, whether it was full blindness or partially sighted (Mohammed, 2014). Out of the 299,000 people, two thirds were over the age of 75, and one fifth were still of working age. Furthermore, a third of individuals were reported to have another disability, with hearing impairment being the most common. It has been estimated that one tenth of individuals with learning disabilities also have a visual impairment associated with diabetes (Emerson and Robertson, 2011). It is highly likely that the number of individuals with vision problems may be higher than the individuals registered with low vision. This difference is due to many people not registering as visually impaired for numerous reasons; for example, some are not given the chance to register whereas others decline the opportunity. Moreover, some individuals may suffer from vision loss and it may affect their daily lives but they fail to meet the threshold required to register as visually impaired. The incidence of low vision is forecast to rise as the population ages and as low vision associated with diabetes becomes increasingly common with ageing (Emerson and Robertson, 2011; Diabetes UK, 2015).

1.1.5. Consequences of low vision in older people living in residential care homes

Low vision or visual impairment can be considered to be a clinical condition which can have a major impact on an individual's daily quality of life, particularly those residing in care homes (Watson and Bamford, 2012). This will have a negative effect on their family members and care home employees who interact with the patients (Emerson and Robertson, 2011). Low vision can also have a major impact on an individual's social life (Evans et al., 2007). People with a visual impairment often suffer from psychosocial and functional problems, such as isolation or lack of mobility, reducing their quality of life, and as a result depression is particularly prevalent amongst people with low vision or blindness (Keeffe et al., 2005; BBCouncil, 2014). Generally, the term 'low vision' is used to describe the impairment of vision which cannot be rectified using traditional approaches such as spectacles or medical treatment, which consequently leads to a restricted lifestyle (UK Vision Strategy, 2015). Impairment to vision can have a huge effect on the tasks an individual can perform such as watching television, driving and shopping, and also their basic living requirements. This factor also has an impact on the UK health sector as well as the employment and education sector (Age UK, 2015). There are substantial unfavourable health implications associated with damage to vision. Older individuals with loss of sight are 13.5% more prone to depression in comparison to 4.6% for people with normal or healthy vision (Evans et al., 2007). Consequently, older people with low vision are 1.7 times more likely to have a fall compared to an individual with no vision loss (Legood et al., 2002; Abdelhafiz and Austin, 2003 ; Age UK, 2010).

The majority of the low vision variations are unnoticeable, only requiring an updated prescription for spectacles, or environmental changes such as better lighting.

However, some eye related problems such as AMD or DR might result in a permanent change and difficulties to older people's vision. Statistically,

individuals with diabetes are 10 to 20 times more prone to experience blindness compared to other individuals (Buch et al., 2001; Ockrim and David, 2010). There is a connection between the loss of sight and a reduction in well-being. People who live with low vision have greater feelings of low mood and people over 65 years old with low vision are 30% more likely to suffer from depression compared to those with healthy vision (Evans et al., 2007; McManus and Lord, 2012).

1.1.6. Increasing numbers of older people with low vision in RCHs

Residential care homes are suitable for older people who require help from health care assistants, giving basic levels of personal care including managing washing, bathing, dressing, food preparation and administering medication (Sinclair, 2010; Age UK, 2015). The majority of older people over 65 with low vision and diabetes are living in residential care homes in the UK (Sinclair, 2014). There are up to 11.4 million people aged 65 or over, and up to 1.5 million people aged 85 or over, living in the UK (Age UK, 2015). According to NICE there are 12,800 registered residential care homes in England and up to 450,000 older people are living in residential care homes (NICE, 2015).

Of the older people aged 75 and above, one in five lives with low vision associated with diabetes, which increases to one in two for individuals aged 90 and over (IDF, 2014; RNIB, 2015 a). The diagnosis of diabetes doubles the chance of residential care home admission (Sinclair, 2010) and diabetes is responsible for low vision and other eye diseases in approximately one in four residential care home residents with subsequent disability and hospital re-admission (Sinclair et al., 2001; Duffy et al., 2005; RNIB, 2013). A study on the occurrence of diabetes reported that the greatest levels of undiagnosed diabetes were found to be present in older individuals living in residential care homes (Aspray et al., 2006). Older people living in residential care homes are prone to visual impairment due to diabetes (RNIB, 2007), approximating that over 50% of

residential care home residents have a type of visual impairment (Scanlon, 2008). Low vision caused by diabetes can have substantial consequences on factors such as the quality of life and health in older individuals (Ahmed, 2010). Individuals with diabetes are more at risk of blindness than the rest of the population (Duffy et al., 2005; Scanlon, 2008; Diabetes UK, 2015). Research indicates that the risk of low vision increases 25 times due to diabetes (Sinclair, 2010).

1.1.7. Preventable low vision associated with diabetes

According to research, over 30% of low vision cases in people over the age of 75 were a result of refractive error and it was fortunately possible to improve their vision with glasses (Evans et al., 2002; Kelliher et al., 2006). It has been suggested that 70% of visual impairment cases could be avoided and complete recovery would be more likely if the condition was detected in its early stages (Charles, 2007). Furthermore, it is estimated that 50% to 70% of low vision cases are preventable or treatable by simply wearing appropriate spectacles, or maybe surgery (BBCouncil, 2014). From this researcher's point of view, everyone concerned should need to be able to recognise the signs and symptoms of preventable low vision, particularly health care assistants, as according to this project, the HCAs spent more of their time in the residential care homes (RCHs) compared to other health professionals. (See Figures 7 and 8 in Chapter 4, page 85 and 86: The percentage of time working with older people amongst the different healthcare professionals questioned).

1.1.8. Low vision associated with diabetes can be reversed if detected in the early stages

Education, awareness and early diagnosis can prevent sight loss (Bunce and Wormald, 2008; Ockrim and David, 2010; Mohammed, 2014). For instance, an

older person may think that losing vision in the periphery of their field of vision is part of normal ageing, when in fact it might actually be a symptom of glaucoma. This problem is particularly important in diabetes, as older people with diabetes have a 90% chance of developing eye disease (Sinclair, 2010), and if they fail to strictly control their blood glucose levels, common ocular complications include retinopathy and changes in refraction can occur (Emerson and Robertson, 2011). However, there is a lack of knowledge about blood sugar monitoring and achieving a balanced diet (Adolfsson et al., 2004; Sinclair, 2014), which contributes to an increase in the burden of diabetes, including diabetic retinopathy and visual impairment in older individuals (WHO, 2011). Studies (Bunce and Wormald, 2008; Ockrim and David, 2010) reported that the majority of people that have a visual impairment could have their condition improved by simple measures, such as surgery or spectacles. According to DeWinter, residential care home residents found it more difficult to receive regular eye examinations due to numerous reasons which resulted in them using glasses without the advice of eye health professionals, or using old prescriptions or wearing unsuitable glasses (DeWinter et al., 2004; Watson and Bamford, 2012). Consequently, there is a need to address this imbalance between knowledge, awareness and the care given.

1.1.9. Current residential care home legislation and policies for low vision

The following list provides examples of organisations and policies that relate to residential care home legislation and policies for low vision. None of which specifically mention low vision and diabetes in any detail.

- Care Quality Commission (Adult Social Care and Residential Care Homes);
- The Healthcare System and Older People;
- Equality Act 2010 ;

- Healthcare System and Adult Social Care in line with new government legislation: the new UK coalition Government introduced a new vision for adult social care in 2010;
- The UK best practice Guidance for Diabetes (Sinclair, 2010).

Full details of the legislation and policies are presented in Chapter 2.

1.1.10. HCAs have limited knowledge of low vision and diabetes

Surprisingly, in the current residential care home health care legislation and CQC policies there are very limited guidelines and no mandatory training available for health care assistants regarding low vision and diabetes (Charles, 2007; Bunce and Wormald, 2008; Sinclair, 2010; Watson and Bamford, 2012; Mohammed, 2014). Due to lack of knowledge and awareness, health care assistants do not appreciate the advantages of routine eye examinations (Watson and Bamford, 2012), which makes the situation even worse.

1.1.11. There is a need for an education programme about low vision and diabetes for HCAs

According to this study, similar to care home residents, HCAs may also be of the view that low vision is a normal part of the ageing process and therefore do not consider it to be an important area. Large number of HCAs does not consider sight loss to be a high priority, and therefore do not provide the required support for residents (Charles, 2007). A care home resident deprived of a support network can be subject to a greater threat of unnoticed vision loss. This becomes even more complicated when accountability for wellbeing is shifted as the individual arrives at a care home (WHO, 2011). Although the maintenance of independence of a person moving into residential care is creditable, it leaves the residents potentially unaware of the increased chance of sight loss that they may experience (Sinclair, 2014). Residents wearing glasses when they are admitted to

a care home should have their specific needs taken into account (Watson and Bamford, 2012).

Targeting HCAs is the best option for detecting signs of low vision associated with diabetes, to advocate eye examinations to care home residents, as they have the most contact hours with the patients, as well as receiving training as a compulsory portion of their responsibility. Nevertheless, HCAs in residential care homes tend to work very hard and often juggle a number of tasks at any given time (Bosanquet and Mehta, 2008). Consequently, the detection of eye problems is often classified as a small problem (McManus and Lord, 2012), which is not seen to be harmful to their general health. Generally, HCAs have limited awareness regarding the significance of deteriorating eye sight (Charles, 2007), and it can have an effect on the quality of life, as well as the prospect of further complications.

The lack of awareness can be due to a number of different factors, for example:

1. Inadequate or intermittent training on vision damage and ways to identify it;
2. Primarily being concerned with other health complications experienced by patients;
3. An incapability to communicate successfully with patients to determine whether they have low vision;
4. Lack of interest in, or low significance given to the prevention of sight loss.

Equally, HCAs may be completely aware of the signs of low vision associated with diabetes, but feel limited in the time offered to address these complications with a resident.

It has already been established that a lack of priority is given to low vision residents suffering with diabetes in care homes, and that there is a lack of awareness. In particular, the incorrect use of glasses; for example, using the incorrect glasses for particular activities, or mixing up vision glasses amongst the

residents, is less important than the absence of a foundation structure and training programme to emphasise that vision loss is a fundamental problem for this vulnerable group (Charles, 2007; Bunce and Wormald, 2008). Other obstacles that residential care home employees face may be more challenging to determine. The absence of a well-defined policy for processes relating to low vision and diabetes, specifically keeping records stating the occurrence of sight testing, or other health complications that could impact on low vision, could be a major contributing factor to these difficulties (Watson and Bamford, 2012).

1.2. Other reasons for choosing this topic

This topic has been of great interest to me for many years, more so since completing my medical studies and taking up my position as a house officer in the Department of Ophthalmology. I am regularly presented with individuals who are suffering from low vision and blindness associated with diabetes, the majority of whom were not aware of the diabetes complications and as a result many of them were even ignoring diabetic retinopathy eye checks. In my opinion, this may be due to lack of knowledge, as when we explained to them about the diabetes complications they then came regularly for their eye checks. One of my classmates told me an inspiring story of how low vision associated with diabetes affected his father, who was suffering from these conditions and was advised to have his eyesight checked regularly. However, he perceived his deteriorating vision to be part of normal ageing; it was difficult for him to accept his loss of vision and seek medical help. Eventually when he sought medical help, he was diagnosed with cataracts and diabetic retinopathy. Following surgery for his condition, his vision became much better, which made him more independent. His life style changed and in general the surgery made him a different person. From this story and from my own experience, I have learned that one of the key issues is to educate older individuals with diabetes and their families, but more importantly there is a need to educate the health

professionals, particularly health care assistants, as they spend up to 24 hours per day in the residential care homes providing care to older people.

The research presented in this thesis was instigated by my desire to better understand low vision and diabetes in older people living in residential care homes, and a review of the literature sought to examine issues related to low vision diabetes.

Additionally, available literature such as (Charles, 2007; Sinclair, 2010; Emerson and Robertson, 2011; Watson et al., 2012; Care Quality Commission, 2014) suggests that there are multiple factors that influence low vision and diabetes, including lack of knowledge and awareness of low vision and diabetes at all levels, particularly in health care assistants. Surprisingly, the literature shows there is limited training or resources available to health care assistants with regards to eye health and diabetes.

This study provides an overview of low vision and diabetes in older people living in residential care homes. There is a lack of knowledge in HCAs and in the older population with regards to normal visual changes that occur in old age, or what kind of changes in vision is a result of ocular disease (Crews and Whittington, 2000; Al Sayah et al., 2013). For example, an older person may think that losing vision is part of normal ageing, when it may actually be a symptom of other eye diseases. This perception in individuals with diabetes is a serious issue. Older people with diabetes have a 99% chance of developing eye disease without strict control of their blood glucose levels (Diabetes UK, 2004; Sinclair, 2010; Mohammed, 2014). Ocular complications include retinopathy and changes in refraction, and many researchers such as (Bunce and Wormald, 2008; Scanlon, 2008; Ockrim and David, 2010; Emerson and Robertson, 2011; McManus and Lord, 2012; Mohammed, 2014) have investigated these issues, including the obstacles and the facilitators, for low vision and diabetes. In contrast, the important issues perceived by a person are not static and can vary as time goes on, using the aforementioned scenario as an example. Also in the earlier story that I have mentioned, apart from the recommendation to see a doctor, the

gentleman's experience of coping with low vision and diabetes appeared to undergo little change, and therefore the health issues may still continue. One of the major distinctions was concerned with the patient's motivation and self-education to save his eyesight.

1.3. Study phases, overview

The study was split into two phases:

Phase 1:

Phase one of this study involved sampling older people via a focus group and interviews to discover what they already knew and wanted to know concerning low vision associated with diabetes, what helped them, and what was needed to prevent or manage low vision associated with diabetes, in addition, to understand how older people saw themselves with low vision and diabetes.

The study also aimed, to examine the nature of care given to older people with low vision and diabetes, to identify the barriers to achieving effective and inclusive care for low vision and diabetes in the age vulnerable group, to investigate the issues currently experienced by older people with regards to low vision associated with diabetes. To demonstrate the gaps that exist in delivering formal care requirements to individuals with low vision associated with diabetes in the residential care home setting, and suggest areas where improvements could be made.

The study sample included optometrists as a focus group, health care assistants via one to one interview and healthcare professional's via a survey (GPs, Nurses, HCAs, Ophthalmologists and optometrists). Each of the groups was asked for their perceptions of individuals with diabetes and eye complications, and to discover what gaps and difficulties they experience in practice. They were also asked, for their advice and opinions about low vision examination and explored

their existing knowledge and understanding of the issues they face, and asked for their views on managing low vision associated with diabetes in older people.

Phase 2:

The second phase of this study aimed at developing, delivering, evaluating and validating the usefulness of the educational toolkit training. Developed following the results and using the comprehensive data collected from Phase 1, the educational toolkit was designed to educate health care assistants about diabetes associated eye disease and its complications. Additionally, the toolkit was designed to help health care assistants to understand the importance of diabetes controls and eye examinations, early diagnosis and prompt treatment, as well as reducing the risk of diabetes complications. Research has demonstrated that early detection of low vision and eye complications is paramount in treating these conditions (Charles, 2007). Therefore this was a major focus of the educational toolkit. Much of the population including HCAs believe that sight loss is irreversible and a natural part of the ageing process (Watson and Bamford, 2012; Sinclair, 2014). However, there is a need to educate HCAs on the ways in which vision loss can be reversed if detected early. Details are presented in Chapter 6 and the toolkit is included in the Appendix page 379.

1.4. Aims of this study

- The research will investigate the issues currently experienced by older people living in residential care homes facing low vision associated with diabetes, and suggest solutions to overcome these difficulties.
- This thesis makes a unique contribution to the existing body of literature in three ways. First, it is the first time that a detailed investigation of low vision and diabetes has been conducted in older people living in residential care homes. GPs, ophthalmologists, nurses, optometrists, HCAs and older people participated, via focus groups, interviews and

questionnaire surveys to gain a better understanding of the 'story' of low vision and diabetes in older people living in residential care homes. As the majority of studies identified during the literature review directly focused on particular areas, either on older people or on one group of health professionals, this information will be very useful for older people, health care assistants and other health professionals. Secondly, the findings will show that coping with the diagnosis and living with low vision and diabetes is affected by a complex constellation of factors, including life circumstances, social support and economics, (UK Vision Strategy, 2015). Thirdly, an important outcome of the study summarises these key issues in order to identify the content for an educational toolkit.

1.5. Objectives of this study

Four main research objectives are refined as follows:

1. To understand the issues and problems of older people living in residential care homes with low vision and diabetes.
2. To understand in depth the causes and approaches to preventing low vision and diabetes in older people, including learning how older people in residential care homes receive low vision and diabetes care, and to examine how low vision and diabetes influence the everyday life of people living in residential care homes.
3. To evaluate the knowledge and understanding that health care assistants have on the impact of low vision associated with diabetes in older people.
4. To enhance the knowledge and understanding to support health care assistants to provide better health care to older people who have low vision and diabetes.

To address each of these objectives the thesis has been formulated as follows:

Chapter 1 provides the rationale, aims and objectives for the thesis.

Chapter 2 contains the literature review based on the following search terms: older people in residential care homes, low vision, diabetes, eye disease, education, knowledge and visual impairment. These terms are most effectively aligned to low vision and diabetes.

Chapter 3 presents the research methodology and the rationale for their selection. This chapter also presents the reasons for my chosen methods of focus groups, face-to-face interviews and questionnaire surveys with 116 participants for Phase 1 and 20 participants for Phase 2.

Chapter 4 presents the findings and results of the questionnaire research.

Chapter 5 contains the data that was analysed from the focus groups and interviews. Three themes were identified to highlight this broad relationship of living with low vision and diabetes, which are: 'life with low vision and diabetes', 'restructure life with low vision and diabetes', and 'helping hands'. These major themes were divided into categories, and each category consisted of sub-categories.

Chapter 6 explains the educational toolkit, including how the toolkit was developed from Phase 1 of the research. Details are provided about who the toolkit was aimed at. Why for them? The results of the educational toolkit training are also presented in Chapter 6.

Chapter 7 summarises the key findings of the research, conclusions are drawn and suggestions for improvement are made. The recommendations are both clinical and educational, identifying how care for people with low vision and diabetes can be enhanced.

1.6. Summary

As the literature review in Chapter 2 shows, there is limited training offered or courses available to health care assistants or for people who are affected by low vision and diabetes. Unfortunately even these few educational opportunities are not necessarily convenient to the people requiring them due to different barriers, as described in more detail later in this study, but these include: lack of knowledge, awareness, and communication problems between older people and health professionals. Also, the huge lack of training opportunities on low vision and diabetes makes the problem worse.

Having been in this field for more than 14 years I have gained a wealth of knowledge and experience. The story previously quoted developed my interest in the subject. Healthcare professionals only occasionally view this type of behaviour, such as the person in the story, as they mainly focus on what the patient describes to them about their problems. The intention of this research is to generate a focus for health organisations on this subject. As for the long term benefits, the health organisations may need to educate health care assistants and individuals with diabetes to prevent diabetes complications, including low vision.

CHAPTER 2

LITERATURE REVIEW

2.1. Theoretical background and methods of literature review

A literature review was conducted to aid the development of the conceptual framework.

Aim: the aim of the literature review was to identify existing literature on low vision and diabetes in older people; to examine the quality of care given to older people with low vision and diabetes; and to identify the key issues currently experienced by older people living in residential care homes with regards to low vision and diabetes in order to demonstrate what gaps exist in delivering the formal care requirements of this vulnerable group.

Search strategy: Papers were identified by combining searches of the main electronic databases: Ovid MEDLINE, EMBASE, AMED (Allied and Complimentary Medicine Database) and IPA (International Pharmaceutical Abstract databases); hand searches of the reference lists at the end of each selected paper and article were also completed. The process of the literature review was initiated through the use of appropriate key words such as: compliance; diabetes in older people; diabetes knowledge and health care assistants; diabetes care; low vision; visual impairment; older people with diabetes; eye disease; and healthcare system and policy. This was undertaken in order to gain a deeper understanding of the subject area, with details being presented later in this chapter.

Additional searches were carried out using words of interest relating to the notions that exist in the current study. These terms included: diabetes and low vision; residential care homes; older people's motivation; health professionals and patient communication; and diabetes and low vision education, as well as its

prevalence and the burden imposed on society. Grey literature (such as unpublished conference papers, policy documents and websites) was also examined. Prominent researchers who have a vast experience of the area, such as Prof Sinclair A J, Prof Scanlon P H, Prof Cook M, Prof Hewson D, Prof Chaney D, Prof Angus F, Prof K Michael, Prof Andy G, Prof Chakravarty, Prof Roger G, Prof Gurch Randhawa, Dr Barbara Guinn, Dr Charles F, Dr Frank M, Arun C S, Evans J, Abdelhafiz A H, Watson Russell E, Barbara L Paterson, Charles N Anderson were identified. Regularly reviewing the content of the diabetes-related journals was another avenue searched to expand the scope of knowledge in the field.

The most relevant journals identified

No	Journal name	No	Journal name
1	Investigative Ophthalmology & Visual Science	8	British Journal of Diabetes & Vascular Disease
2	Ophthalmic Epidemiology	9	Diabetes Management Journal
3	ACTA Ophthalmologica	10	Geriatric Diabetology
4	British Journal of Ophthalmology	11	Experimental Eye Research
5	BMC Ophthalmology	12	Journal of Diabetes and its Complications
6	BMJ Clinical Research	13	British Journal of Pharmacology
7	British Journal of Nursing	14	RSPH

Table 1 The most relevant journals identified

As my knowledge in the field grew, I began to link my searches to other principles of care such as the concepts of chronic illness, the chronic care model and sick role, which enabled the study to examine the relationship between diabetes, low vision, the healthcare system and policy.

Detail of the electronic database search is presented below in Table 2.

Electronic database search

Electronic databases	Search terms	Hits	Retrieved papers after abstract screening	Retrieved papers after inclusion criteria and duplication
Ovid-MEDLINE EMBASE AMED IPA	Diabetes in older people	832	71	32
	Visual impairment in older people	608	64	24
	Residential care homes older people with diabetes and eye disease	80	14	6
	Diabetes and low vision care	61	11	4
	Diabetes, low vision knowledge in older people and health care assistants	53	8	2
	Diabetes and low vision education	71	15	11
	Health professionals and older patient communication	9	4	1
	Diabetes prevalence and burden on the society	11	6	2

Table 2 Electronic database search

Inclusion criteria for literature:

1. Research focused on low vision and diabetes in older people;
2. The search term included in the paper title, abstract and/or keywords;
3. Content of the abstract relevant to the main concepts of this study;
4. Main text describing diabetes and low vision related to quality of life, and knowledge of low vision and diabetes;
5. Language: English;
6. Timeframe: 1.1.2000 to 30.12.2015.
7. The following added articles were not in the timeframe but it is very essential for this study to know full details of the education toolkit evaluation steps from the beginning until now. (Kirkpatrick, 1959; Kirkpatrick, 1978), (Fitzgerald et al., 2016).

Eventually, the literature review resulted in a broad concept of understanding low vision associated with diabetes within the context of older individuals residing in residential care homes. This chapter is broken down into headed sections as this will provide the reader with an easier foundation to gain an understanding of the literature associated with low vision and diabetes.

2.2. Aetiology and epidemiology of diabetes and low vision

It is important to provide brief information about diabetes, followed by a description of low vision associated with diabetes.

Diabetes mellitus is a metabolic disorder (ADA, 2006; Ahmed, 2010). Also considered to be chronic inflammatory/autoimmune disease (Syed et al., 2002; DSouza et al., 2005; Ghazalpour et al., 2014), diabetes is caused by a deficiency of the hormone insulin which is normally secreted by the pancreatic beta cells (Rosenbloom et al., 2008; Ahmed, 2010). The insulin hormone is responsible for

the uptake of glucose from the blood, mainly into muscle and fat cells of the body, as well as inhibiting hepatic glucose production (Rosenbloom et al., 2008; Hauner et al., 2010).

Insulin was first discovered in 1921 and was considered to be a breakthrough discovery that could change the way in which diabetes was treated, and potentially alleviate the barriers associated with diabetes (Guthrie and Guthrie, 2009). However, as the years have passed, it is clear to see that the performance of insulin has not reached a satisfactory level by which diabetes can be managed effectively. In contrast to other long term, chronic conditions, the advancement of the disease has a wide variety of outcomes. Some outcomes can have minimal effect which can result in a normal healthy lifestyle with the disease having no major impact on general life; other outcomes result in major effects and complications such as amputation, blindness, heart conditions and an increased risk of stroke. Such outcomes can have a huge effect on the patient, their families and also on the community. Consequently, attempts are being made to prevent or lessen the complications of the disease.

Diabetes is depicted by elevated levels of glucose in the blood which leads to the development of abnormalities in the secretion of insulin (Sinclair, 2014). Diabetes has two main types, Type 1 and Type 2, and there are other specific types including gestational diabetes mellitus (ADA, 2006). 90-95% of the total diabetes population suffer from Type 2 diabetes, followed by Type 1 at approximately 5-10% (ADA, 2010; Sinclair, 2010). Type 1 diabetes is categorised by the destruction of β -cells, which is due to a cascade of autoimmune pathways and non-autoimmune forms leading to absolute insulin deficiency (ADA, 2010; Diabetes UK, 2015). Individuals with Type 1 diabetes need to be treated with insulin, whereas Type 2 diabetes is depicted by inefficient secretion of insulin (NDIC, NIDDK and NIH, 2008; Diabetes UK, 2015). Insulin helps cells in the body to uptake glucose from around the extracellular space to the intercellular space (Ahmed, 2010).

2.2.1. The risk factors of diabetes include:

Genetic factors, Type 1 diabetes: The risk of developing Type 1 diabetes among those with family history is about 15 times higher than in the general population (IDF, 2014). If a mother has diabetes, the risk of a child developing the condition will be about 2-4%; if a father has diabetes, the risk will be 6-9 %, and both parents with diabetes will increase the risk up to 30%. If brothers or sisters have diabetes, the risk of developing diabetes will be 10-19%, and for twins, the risk will be 30-70% (Holt et al., 2010; IDF, 2014; Diabetes UK, 2015).

Type 2 diabetes: People with a family history of diabetes are 2 to 6 times more at risk of developing diabetes than people with no family history of diabetes (Vaxillaire et al., 2010; Diabetes UK, 2015).

Ethnic groups and diabetes: White community, 1.7%; all ethnic minorities, 5.7%; African Caribbean, 5.3%; all South Asians, 6.2%; Indian or African Asian, 4.7%; Pakistani or Bangladeshi, 8.9%; and Chinese, 3.0%. Studies show that South Asian and African-Caribbean communities usually develop Type 2 diabetes about 10 years earlier than the white population in the UK (Winkley et al., 2013; IDF, 2014; Diabetes UK, 2015).

Obesity plays a major part with a 80-85% risk increase of developing Type 2 diabetes as insulin sensitivity is reduced (Hauer et al., 2010; Chilcott et al., 2011). Two in every 3 people have been classed as either overweight or obese (Department of Health, 2013; NHSIC, 2013; HSCIC England, 2014).

Lifestyle, lack of physical activity, unhealthy food, obesity and smoking are also risk factors of diabetes (Sinclair, 2010; Diabetes UK, 2015). Due to numerous reasons, data are not available and it is not easy to find out the risks related to deprivation. The National Diabetes Audit suggests that people with the lowest

household income are 1.5 times more likely to develop diabetes than those in the highest household incomes (HSCIC, 2015).

The diagnosis of diabetes is often delayed as very few symptoms are presented by the majority of older people (ADA, 2010); also the diagnosis may be more delayed due to lack of diabetes awareness and knowledge (Lorig et al., 2009). The major health burden of diabetes is caused by its concomitant complications (Zhang et al., 2010), especially chronic complications such as microvascular diseases, leading to nephropathy, retinopathy, coronary heart disease and cardiovascular disease (Nazimek et al., 2002; Ahmed, 2010). The causes of development of macro- and microvascular conditions in diabetes mellitus diseases are still unknown (Zhang et al., 2010).

Due to the numerous complications associated with diabetes, people with diabetes have suffered from a lack of guidance to prevent long-term complications, even though many researchers (DSouza et al., 2005; Holt et al., 2010) have been suspicious of the positive relationship between chronic complications and high levels of blood glucose (Sinclair, 2010). A large scale, longstanding and randomized sampling study launched by the Diabetes Control and Complications Trial (DCCT) (NDIC, NIDDK and NIH, 2008) aimed to give diabetes care a clearer goal by showing that lower HbA1c could benefit the prevention of long-term complications. Furthermore, a number of studies have demonstrated and showed similar results finding a convincing relationship between the values of HbA1c and long-term complications for both types of diabetes (DSouza et al., 2005; Hauner et al., 2010; Holt et al., 2010). Additionally, ten years of data from the UK Prospective Diabetes Study Group found a detailed association amongst elevated levels of blood glucose and other complications, and specified that for each 1% decrease in glycaemia, through the measurement of glycosylated haemoglobin (HbA1C), led to a decrease in mortality of 14%, myocardial infarction 1%, and diabetes related death 37% (Stratton, 2000; Kumar and Clark, 2007). Subsequently, each 1% rise of HbA1c is related to a 7% increase

in the cost of healthcare. As a result, maintenance of HbA1c levels below 7% has become the gold standard in the care of diabetes (Department of Health, 2006; ADA, 2010), and several healthcare professionals impose stricter thresholds of less than 6% (ADA, 2010). However, as strict regulation of blood glucose levels are adopted, there is a two to three fold increase in the risk of hypoglycaemia compared to those who do not regulate blood glucose levels (NDIC, NIDDK and NIH, 2008; Sinclair, 2010).

Maintaining blood glucose levels in the normal range to prevent hypoglycaemia is challenging. Therefore, the management of diabetes must include pharmacological and non-pharmacological factors such as physical exercise, diet, and smoking cessation (Buyschaert and Hermans, 2014). It can be difficult to assess such factors and recommendations as the main appraisal method is the measurement of blood glucose levels. Maintaining blood glucose within a satisfactory level cannot be simply achieved by pharmacology, but it involves the complexity of managing the disease holistically (WHO, 2002; WHO, 2003; Buyschaert and Hermans, 2014).

2.2.2. What is low vision?

Low vision or visual impairment can be considered to be a clinical condition (McLaughlan and Edwards, 2010; Chiang et al., 2011; RNIB, 2015 a). The quality of daily life can be affected by low vision, including day to day tasks such as recognising people's faces, reading, watching television, walking, and writing. Low vision is described as a drastic reduction in the function of the eyes (Watson and Bamford, 2012), but not complete blindness. Low vision can occur when the eye is unable to function adequately (Haddrill, 2007). Visual function itself can be measured through distance visual acuity, and is conducted through the use of a letter eye chart at a specific distance. Visual acuity (VA) of 20/20 or 6/6 is considered to be healthy vision (WHO, 2006), meaning people can see up to six

Service provision

“Low vision is defined in functional terms: a person who has impairment of visual functioning even after treatment and/or standard refractive correction, and has a visual acuity of less than 6/18 to light perception, or a visual field less than 10 degrees from the point of fixation, but who uses, or is potentially able to use, vision for the planning and/or execution of a task.” (WHO, 2006).

Classification of low vision

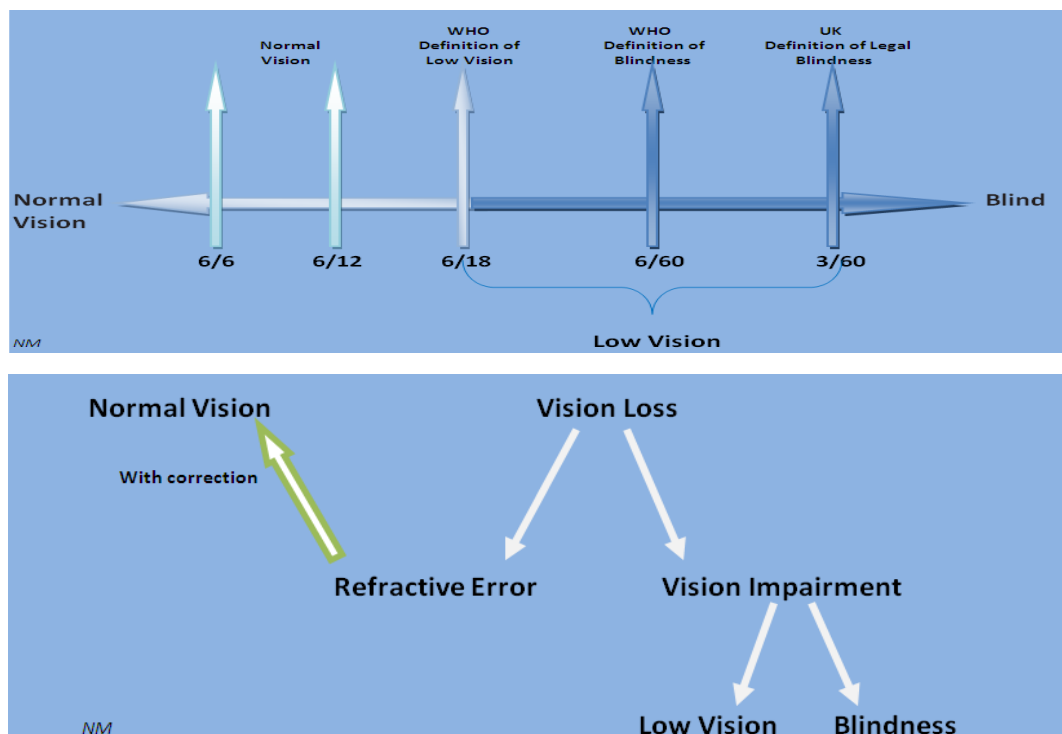


Figure 1 Classification of low vision

These two figures are the author diagrammatic interpretation of the classification of low vision.

2.2.4. How is low vision associated with diabetes?

Diabetes can cause low vision in a number of ways:

Diabetes affects the tiny blood vessels of the eye and if they become blocked or leak into the retina, vision may be affected (Hassell et al., 2000; Macular Society, 2015). Diabetes also affects the larger blood vessels in the retina causing them to become blocked which can result in ischemia (deficiency of oxygen) in the retina; due to oxygen deficiency, neo-vascularisation will occur or new vessels will grow. These new blood vessels can grow on the surface of the retina and into the vitreous gel, as they are new and weak, and can bleed very easily over the surface of the retina or into the vitreous gel; this is the proliferative stage of diabetic retinopathy (Klein et al., 2003; National Eye Institute , 2015). Uncontrolled blood sugar levels can affect the lens inside the eye and this can result in blurring of vision (Mukesh et al., 2006). Diabetes also raises the probability of cataracts, which is characterised by clouding of the transparent lens within the eye (National Eye Institute , 2015). Diabetes related eye diseases, including diabetic retinopathy, Maculopathy, proliferative retinopathy, cataracts, glaucoma and age-related macular degeneration are the main reasons of low vision associated with diabetes in older individuals (Bunce and Wormald, 2008; Scanlon, 2008; IDF, 2015).

2.3. Overview of low vision in older people

According to The Royal College of Ophthalmologists, the causes of blindness are: 17.7% diabetic retinopathy, 7.7% macular and posterior pole degeneration, 15.8% hereditary retinal disorders, 5.4% glaucoma, 4.9% myopia, 10.1% optic atrophy, 5.1% cerebrovascular disease, 2.9% congenital anomalies of eye, 3.9% multiple pathology, 0.9% no information on main cause, and the remaining 25.6% are due to other conditions (RCO, 2000; National Eye Institute , 2015). Statistics suggest that 4,200 of those individuals classed as blind are blind due to

diabetic retinopathy, with the value increasing by 1,280 per annum (Scanlon, 2008). After an individual is diagnosed with Type 1 diabetes, nearly all will develop some sort of retinopathy within twenty years. Furthermore, approximately two thirds of Type 2 diabetes sufferers will develop a form of retinopathy within 20 years (Scanlon, 2008).

In 2010, WHO estimated that the major causes of low vision are: uncorrected refractive errors 43%; cataracts 33%; glaucoma 2%; age related macular degeneration (AMD), diabetic retinopathy, and trachoma and corneal opacities, up to 1%; and in 18% the causes are undetermined. WHO also estimated the causes of blindness are: 51% cataracts; 8% glaucoma; 5% AMD; 3% uncorrected refractive errors and trachoma; 1% diabetic retinopathy; and the remaining 21% have undetermined causes (WHO, 2010). Research shows that these statistics are increasing rapidly every year as AMD has dramatically increased by 113%, and diabetic retinopathy rates in individuals aged 65 and over have increased by up to 120% (Bunce and Wormald, 2008; Macular Society, 2015). Approximately 2 million older people live in the UK with low vision (Bosanquet and Mehta, 2008) and it is predicted that this will increase up to 22% by 2020, and will be up to four million by 2050 (RNIB, 2013).

Research on epidemiological data for the United Kingdom suggests that between 12-15% of people with diabetes aged 75 or over has visual acuity of less than 6/18, and they are ten to twenty times more at risk of going blind compared to those without diabetes (Ockrim and David, 2010). Additionally, individuals with diabetes have a doubled risk of suffering from diabetic retinopathy, Maculopathy, proliferative retinopathy, cataracts, glaucoma and age-related macular degeneration compared to other individuals, which are the common causes of low vision associated with diabetes in older people (Scanlon, 2008).

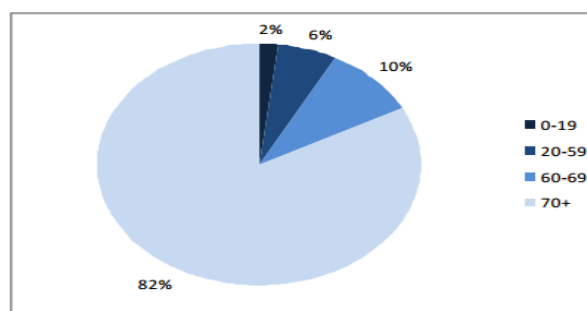
2.4. RCHs and the older population with low vision and diabetes

“The word care home” can be confusing, even the legal definition is slightly confusing when comparing “Nursing Care Home” and “Residential Care Home”, (The Law Society, 2015). However a residential care home can provide people with basic levels of care that an individual would normally get when at home being cared for by a friend or family member (Care Home Guide, 2013; Care Quality Commission, 2014). Some of the personal care tasks covered in a residential home may include the following: washing, bathing, dressing and food preparation, including administering medication and reporting to health professionals about any changes in the person’s health conditions (Watson and Bamford, 2012). On the other hand, “Nursing Care Home” is suitable for those patients who require active medical care where the patient has access to medical supervision if required (Care Quality Commission, 2012; Care Home Guide, 2013). The Nursing Care Homes are responsible for the full time availability of a qualified nurse to carrying out tasks including managing dressings, inoculations, and dispensing specific medications (Sinclair, 2010; Care Home Guide, 2013; Care Quality Commission, 2014).

In the UK, responsibility for the management of all chronic diseases, including eye diseases, low vision, and diabetes and its complications in older people living in residential care homes has shifted from being the individual’s responsibility to that of the institution (WHO, 2011; Care Quality Commission, 2014).

According to The Care Quality Commission annual reports, in 2013 the number of residential care homes (RCHs) was 12,800, and in just one year (2014), the number of residential care homes in England increased to around 17,000 (Care Quality Commission, 2014; NICE, 2015). In 2013 there were approximately 450,000 people living in residential care homes, but as the older population is increasing, it is predicted that these numbers will increase up to 1,130,000 within the next 50 years (Care Home Guide, 2013).

It is estimated by The Office for National Statistics and Age UK that the number of people who are over 60 is predicted to rise from 24.2% to over 29% by 2035; furthermore the number of people aged over 85 in the UK is predicted to more than double in the next 23 years to over 3.4 million, and nearly one in five people currently in the UK will live to see their 100th birthday (ONS, 2015; Age UK, 2015). It is estimated that since 2013 the number of people aged 65 and over increased from 11.1 million to over 11.4 million by mid-2014. The number of older people continues to rise (ONS, 2015).



Source (Robertson and Emerson, 2010)

Figure 2 Low vision estimates by 2030 in age groups

According to Robertson and Emerson, by 2030, 82% of all people aged 70 or over (4 out of 5 people) will have severe impairments of both hearing and vision (Robertson and Emerson, 2010).

Residents in care homes are an under-researched section of society; a result of this has led to a high level of undiagnosed sight loss which has a negative impact on an individual's vision (Watson and Bamford, 2012). Due to the vast number of people in residential care homes, it is challenging to predict the exact number of people affected by sight loss in care homes. There is a lack of research in this area and consequently it is somewhat difficult to predict the exact numbers of older people with sight loss in residential care homes (Watson and Bamford, 2012). Troublingly, studies have found that individuals of an older age that are

residing in care homes are five times more likely to develop sight loss compared to those living in their own home (Watson et al., 2012; Sinclair, 2014).

There have been suggestions that these variances occur due to three primary possibilities: general challenge in accessing eye health checks; a greater likelihood of people with vision loss being admitted to a residential care home; and finally, the comorbidities associated with overweight people can also affect the associated risk of sight loss (Turpin, 2015). These three primary possibilities have a strong relationship with diabetes and there is therefore a 99% chance of low vision associated with diabetes in older people (Haddrill, 2007; WHO, 2009).

In 2005, Tate conducted a review of the low vision prevalence, and concluded that undiagnosed sight loss is present in 70% of the population, stating that very few studies of sight loss included participants from residential care homes with the risk factors of low vision and diabetes, and that it is likely that the problem will be greater in residential care homes (Tate et al., 2005). There are a number of people with different levels of sight loss, and many do not have the knowledge or the power to act upon their concerns (Watson and Bamford, 2012).

2.5. The financial burden of low vision on society

Low vision associated with diabetes has an impact on the quality of life, physical ability, and psychosocial wellbeing of sufferers, and is an important factor in the risk of falls and hip fractures in older people (Abdelhafiz and Austin, 2003 ; British Orthopaedic Association , 2007; RNIB, 2015 a). Care home residents who suffer from low vision associated with diabetes have a largely increased risk of developing a disability and thus hospital admission (Duffy et al., 2005; Department of Health, 2010 a). Every 5 hours one older person dies due to a fall (Age UK, 2010), and a key risk factor for falls is low vision, including visual acuity (Dhital et al., 2010; Mohammed, 2014). Recurring falls in the population of those

aged 75 and above has led to an increase in both major disabilities and death (Abdelhafiz and Austin, 2003); also falls and fractures contribute to the economic burden of healthcare delivery (Age UK, 2010), with medical practices spending a huge proportion of their budget on fractures and their treatment (Scuffham et al., 2003; McLaughlan and Edwards, 2010).

The cost of low vision and blindness on society is approximately £4.1-8.8 billion a year, as estimated by the Royal National Institute of Blind People (RNIB, 2011). Furthermore, RNIB have suggested that costs could be slashed by 50% if patients were to undergo regular eye tests to detect problems early (Bosanquet, 2010; RNIB, 2011). It is estimated that between £2-4.2 billion could be saved per year through routine eye testing (Age UK, 2010; Watson and Bamford, 2012). Each year nearly 310,000 patients (Turpin, 2015), many of them who are older people with low vision, are admitted to hospital with fractures (Sinclair, 2014). Furthermore, approximately 80,000 of the 310,000 older people who are admitted to the hospital have suffered a hip fracture (British Orthopaedic Association , 2007; Turpin, 2015).

It is estimated that osteoporotic fractures cost the UK £1.8 billion per year; of this cost £1.5 million is allocated to the Primary Care Trust (Age UK, 2010). The failure to detect vision loss can lead to an increase in the number of falls and the result will be a heavier financial burden on society. Individuals with vision problems are 1.7 times more likely to suffer from a fall compared to a person without a visual impairment (Charles, 2007; Age UK, 2010; RNIB, 2015 b). A policy statement released by the British Geriatrics Society and the College of Optometrists has highlighted the consequences of falls, as well as emphasising the advantages of the improvement of low vision in the people at risk of falling, particularly in care homes (College of Optometrists , 2011; Tian et al., 2013). The costs for care of these falls is projected to be £269 million (Care Home Guide, 2013), and falls that are directly associated with low vision are estimated to cost

in the region of £128 million (Scuffham et al., 2003; Age UK, 2010; McManus and Lord, 2012; RNIB, 2013; RNIB, 2015 b).

2.6. Overview of regulations and legislation

2.6.1. The healthcare system and low vision and diabetes care

Nowadays, healthcare systems around the world are dictated by the biomedical model, which was initially designed for the care of acute illnesses with the main purpose of healing patients (Woolhandler, 2009). This healthcare system implements a paternalistic style to direct patients to a course of action and the patients are expected to follow orders as a result (Tsoneva and Shaw, 2004; WHO, 2008). A number of studies have been undertaken regarding the development of methods to appraise compliance, techniques and tactics to encourage adherence to medical treatments and advice (Funnell and Anderson, 2000; Martin et al., 2005; Conrad, 2006; Woolhandler, 2009).

The doctor and patient relationship is described as a part of the social system (Funnell and Anderson, 2000; Aultmana, 2006), and they consider their own rights and obligations to perform as presented and view illness as a form of deviance and argue that patients are legitimately allowed to withdraw and suspend their usual social obligations when they are unwell (Conrad, 2006). This suggests that patients adopt a 'sick role', with 'getting well' being their social obligation. As such, an unwell individual is not considered to be responsible for the illness. An ill person is responsible for seeking help from the appropriate person to regain their health, and a doctor is responsible for restoring the individual's health and doing their best to offer the appropriate health care services (Alexander and Lantos, 2006). Ideal patients have to be either compliant or self-sufficient, and health professionals are viewed as the experts (Thorne et al., 2000; Tsoneva and Shaw, 2004; Aultmana, 2006).

Nevertheless, some argue that the notion of the sick role has overlooked the phenomenon of the social stigma due to the patients' fear of being stigmatised preventing them from taking the 'sick role' willingly (Walsh , 2004; Alexander and Lantos, 2006). Additionally, in many societies women naturally assume overall responsibility for their families' general health care and this may prohibit themselves from adopting the role due to disruption (Conrad, 2006). The action of the 'sick role' also may not apply in other cultures and societies, where the burden of health care has been shifted from the individual to the institute (WHO, 2011).

The traditional model, which is doctor-directed and compliance-oriented, has been recognised as inappropriate for chronic conditions (Thorne et al., 2000; Holman, 2000; WHO, 2003; Adolfsson et al., 2004; Bensing et al., 2013).

The health needs of patients between chronic and acute illness are inherently different as chronically ill patients live in the community, and they require different patterns of health care (Sally et al., 2000; Adolfsson et al., 2004) Patients living with a chronic disease have to make decisions primarily outside of clinics or other healthcare organisations (Aultmana, 2006). If they want to satisfactorily perform their own health care, they are required to learn the appropriate knowledge and skills to cope with a variety of uncertainties by themselves with little possibility of getting instant help from health professionals (Adolfsson et al., 2004).

Under the biomedical model, the improvement of health care in chronically ill patients has its limitations, even though the strategies of healthcare services have made some improvements. For example, many people with diabetes still suffer from serious complications after receiving health care from those particular systems that offer well-developed guidelines for diabetes management (Funnell and Anderson, 2004). For the requirements of chronically ill patients, the World Health Organisation aimed to develop innovative healthcare systems to ameliorate the problems (WHO, 2003; WHO, 2011).

2.6.2. Adult health and social care system in line with government legislation

The UK coalition Government introduced a new vision for Adult Social Care in 2010. The vision is based on three fundamental values:

- (1) The introduction of care which allows patients to select the services they wish to utilise;
- (2) A transparent social care system;
- (3) An emphasis on the requirement to explore collective accountability of care between the patient and the care system (Department of Health, 2010 a).

The Care Quality Commission issued a report on the delivery of care in residential care homes which has a particular focus on the equality of the patients, control over the services they select and ensures that the services respect the dignity of patients and upholds critical standards of safety (Care Quality Commission, 2012). Previously, reviews have assessed the performance of low achieving care homes, negotiated with residential care homes and gathered the views of both workers and managers on the practices within these homes. Information regarding medication, regulation and incontinence care is usually gathered; however, vision loss was not recorded in most care home locations. Additionally, the Care Quality Commission review investigated how the patients' needs were identified, which included assessing the case records of patients to determine which assessments were carried out; however, no provision was made for eye health (Care Quality Commission, 2012).

2.6.3. The healthcare system and older people

It is widely appreciated that policymakers have implemented critical strategies to ensure that the older generation have access to health and social care when required. For example, the National Service Framework was introduced by the National Health Service, aimed at largely improving the services provided to the

general public, with a particular focus on developing national standards and reducing inequalities in care (Department of Health, 2006). The strategy outlined the key principle of joined-up care, and the encouragement of interactions between different healthcare professionals within the health service to ensure that the best possible care is given to patients, as well as ensuring that older people feel that they have independence and a good quality of life. Despite these strategies, there is no single strategy focusing on low vision, which has increased the risk of falls (Bosanquet and Mehta, 2008) which have an effect on the older person's lifestyle as well as the costs incurred by the NHS (Age UK, 2010; Dhital et al., 2010; Tian et al., 2013).

The Care Quality Commission has echoed the sentiment of safeguarding elderly people and ensures they have a good quality of life. The Commission also emphasises the importance of the joined-up care, as it has been recognised that some patients are passed between different services, without a lack of organisation. Care homes should always provide a basic level of standard care; however, they should further promote independence: *"Look at the culture in the care home, helping people to enjoy life rather than just waiting for them to die"* page 4, (Care Quality Commission, 2011). In addition, the strategic plan also aims to implement personalised care to improve the quality of life for older people in residential care homes.

Studies (Bosanquet, 2010; Gluth et al., 2010; Ritter et al., 2011; Sinclair, 2014) have suggested that preventative health measures could improve the effectiveness and proficiency of healthcare services for everyone. The Department of Health has emphasised the importance of prevention in order to delay or reverse deterioration, which could consequently lead to greater independence (Department of Health, 2010 a; Department of Health , 2010 b).

2.6.4. Equality Act 2010

In 2010, the Equality Act was introduced, which superseded previous legislation associated with areas such as discrimination and other marginalised people and groups. The Equality Act encompasses discrimination in regards to any of the following categories: disability, gender, race, religion or sexual orientation. The Act covers all discrimination, whether it is direct or indirect, when providing services such as healthcare. The Equality Act does have exceptions; for example, differential sight test entitlements are based on an individual's age, and therefore more awareness needs to occur to help fight this problem.

2.6.5. Good clinical practice guidelines for older people living in RCHs with low vision and diabetes

According to study (Sinclair, 2010; Sinclair, 2011), the UK best practice guidance is currently defined by Diabetes UK. However, they do not specifically mention eye health. The major characteristics of these recommended clinical practice strategies are as follows:

- Residents with diabetes within the organisation seem to be particularly vulnerable subjects, who are often neglected and consequently present a high prevalence of macrovascular complications and an increased risk of infection and hospitalisation, as well as high levels of physical and cognitive instability.
- Diabetes is estimated to affect more than 26% of residents in care homes within the UK. However, despite this there are many problems associated with diabetes care in the care home setting, a general lack of planning and management of care, substandard dietary advice and a lack of specialist care, as well as a lack of medical follow up.

The general objective of residents with diabetes can be summarised as below:

- To ensure residents have the freedom to manage their own health care condition;
- The generation of individualised care plans where follow up care is easily accessible;
- To continue with good quality of life, wellbeing and avoid all unnecessary therapeutic interventions.

The Care Quality Commission has the responsibility to ensure that the legislation is enforced, and if not, for appropriate action to be taken (Sinclair, 2010; Sinclair, 2011).

- The guidelines introduced review the dietary provision within the care home setting, and discuss the main features in diabetes treatment. Additionally, the specific role of the specialist, GPs, dietician, nurse, podiatrist and optometrist is stated.
- Every person in a residential care home has their own personal care plan, which is written with the agreement of the next of kin and also agreed by the person for who the plan is written, the general practitioner and the HCAs.
- The implementation of an annual assessment for residents with diabetes, which are carried out by care home representatives. This review includes information on medical history, a thorough medical examination with dietary plans, and all health related assessments, including analysis of glycaemic control. All these assessments need to be complete when the resident comes into the care home, and regular updates need to be recorded.

- The guidelines advise that there is a need for an emphasis on the training and knowledge that is provided to care home staff. The fundamental components of training should incorporate key information and guidance concerned with the treatment of diabetes with consideration given to nutritional needs, testing for complications, control of 'sick days', and health profile raising activities as well as establishing the responsibility of staff in updating, recording daily progress notes and the management of care plans.
- A sequence of moral philosophies should oversee the approach of diabetes and foresee that further care is provided in care homes. Residents should be encouraged to be independent with consideration of their physical and mental wellbeing.
- People with diabetes in care homes are classified as a particularly vulnerable part of society from numerous viewpoints, primarily care inequality. This could be established by the absence of care goals and objectives, slack and unsuitable metabolic targets, poor accessibility to expert care, and lack of follow up appointments. The aforementioned guidelines aim to target a number of these inequalities through the implementation of good health care practice and the establishment of a high level of care.
- These plans are set to deliver measurable changes to diabetes care within care homes.

2.6.6. Health and Social Care Act 2008-2010 for RCHs

The Health and Social Care Act consists of 28 regulations and sets the standards that should be made available in all care home residences in relation to quality

and safety. This act replaces the Care Standards Act as of 1st October 2010. The 2008 Act also covers Health and Social Care Regulations 2010, where a nominated individual within a care home is in charge of the wellbeing of the occupants. These regulations specify that the provision of care (including medicinal treatment) should be adjusted to help, and that the occupant should have their security, poise, and autonomy regarded, with their perspectives considered in decision-making. Furthermore, the care home should work as a team with different suppliers to guarantee wellbeing, with social forethought which is accessible to the resident (Regulations 9, 17 and 24 individually). These regulations structure the premise of how the soundness of care home residents is overseen in such organisations.

Nonetheless, the regulations do not particularly specify eye health and wellbeing. There is little mention of eyesight examinations within the regulatory framework and instead the area of eye health is covered under general health. Therefore, there is not one single route to sight testing in a care home. Sight testing could be sought by the care or residential home, or might be set up through contact with eye experts being requested to carry out sight examinations at home. Some homes will have arrangements set up for their sight testing methods, and others are unreceptive and rely on demands from residents. Eye professionals visiting care homes may be from small practices from the local vicinity; on the other hand, they may come from larger or even national companies that have a speciality in testing the sight of care home residents. Surprisingly, there is no provision for sight testing in care homes, apart from the example established by law that healthcare should be patient-focused and patient-managed. Current suggestions from the Association of Optometrists' advice for eye examinations is that they should be carried out once every other year in individuals aged between 16 and 70, and every year for individuals aged over 70. However, individuals with diabetes or those aged over 40, with family prone to glaucoma, are not part of a monitoring plan (NHS, 2008).

2.6.7. Summary of regulation and legislation Issues

Previously, there have been problems reported with residential care homes requesting numerous healthcare professionals to carry out eye examinations consecutively, which would then be reimbursed by both the NHS and health care professionals. To prevent such instances occurring again, the domiciliary testing regulation was put into place, which prevents unnecessary sight examinations being carried out. Under the new regulations, the names of individuals being tested must be submitted in advance to identify whether they are entitled to a test. Although this approach could prevent unnecessary repeat testing, there is a fear that this approach could lead to a drop in the number of tests being carried out as people fear they will not be able to claim the money back. Furthermore, the requirement to name people before testing can mean that those people who need a test when a home is visited cannot be tested unless their name was previously listed. Eye professionals are best placed to identify the symptoms of vision loss, and new regulations mean that they may not be able to act on their observations made during a care home visit. Furthermore, if a booked resident becomes ill or unwell, and cannot undergo the sight test, the optician will have a wasted session. As expressed earlier, in the Equality Act 2010, it can be argued that residential care home residents face difficulties in accessing their eye examinations. People living at home can have an eye examination at their request; however residential care home residents must wait 3 weeks due to the restrictions imposed by the COS contract. These variations in care and services could be used to argue the differences in equality between care home residents and those living independently at home.

2.7. Preventable low vision

The older population is increasing in the UK (Sinclair et al., 2001; Age UK, 2015), and it is our ethical and public health responsibility to prevent avoidable low

vision associated with diabetes. The majority of older individuals with low vision and diabetes experience a refractive error (Charles, 2007) which can be rectified or enhanced through the use of spectacles, contact lenses or other medical intervention such as surgery. As discussed in Chapter 1 section 1.1.3 page 4, diabetes can affect the small and larger blood vessels in the eye and new blood vessels can grow on the surface of the retina and into the vitreous gel, which causes low vision and even blindness. If diagnosed sufficiently early, however, the treatment can stop 80% of the new blood vessels growing in the eye (Action for Blind People , 2015). People who have had diabetes for a long time usually have early type of diabetic retinopathy (Scanlon, 2008).

At this early stage, blood vessels in the retina will be affected and may bulge very slightly (micro aneurysm) and may leak blood (haemorrhages) or fluid (exudates) (Action for Blind People , 2015), and if the macula is not affected vision will remain normal and the person will not be aware that anything is wrong, which is very dangerous as people then ignore seeing their eye health professionals. A diabetes eye retinal screening test will keep a close check on these early changes and ensure that any signs of progression to more serious stages of retinopathy are detected early (RNIB, 2007; Ockrim and David, 2010).

Maculopathy: when the macula is affected by retinopathy it is called maculopathy, meaning the central vision will be affected and the person will find it difficult to recognise people's faces from a distance. Maculopathy can be treated to prevent more damage to the central vision if it is diagnosed early enough (Macular Society, 2015).

Temporary blurring: diabetes can affect the lens inside the eye and this can result in blurring of vision which comes and goes most of the time (RNIB, 2013). This blurring may be one of the first symptoms of diabetes. In well controlled diabetes this variable blurring will go away (Haddrill, 2007). A review of studies

analysing vision problems in older people reported that more than half the problems associated with sight loss are preventable (Tate et al., 2005; Chiang et al., 2011).

While screening for diabetic retinopathy is of a very high standard within the UK, over half a million people are still unable to gain access to the screening process, resulting in a large number of cases of undiagnosed diabetes (Sinclair, 2010). Individuals suffering from diabetes should not disregard changes in their vision, as the symptoms could be due to the disease. Vision loss can be reduced if identified early, as many problems can be rectified with approaches such as prescription lenses or medication and surgery. If the damage to the eye is too severe it is impossible to restore a normal level of vision.

The frequently observed symptoms of diabetes related eye problems are: refractive changes and vision becoming blurred to hazy, including an increased sensitivity to glare and problems with colour vision (RNIB, 2015 a). Controlling blood glucose levels and regular check-ups can reduce the risk of eye disease, kidney disease, and complications with the feet, amongst other diabetes symptoms (Diabetes UK, 2015).

Studies (Tate et al., 2005; National Nursing Research Unit, 2012) reported that more than half the problems associated with low vision are preventable in older people. Furthermore, a study found (Charles, 2007) that those participants aged 75 and over are most likely to be suffering from refractive error (6/18 on the Snellen Scale). Statistics (UK Vision Strategy, 2015) suggest that up to 15% of individuals over 75 years old have a visual acuity of 6/18 or lower. This value could become lower if curable cases were omitted.

Normal changes to the ageing eye: older people are more likely to be at risk of age-related normal changes including: difficulty with light and dark adaptation; increased sensitivity to glare; diminished focusing power and fluctuating vision; reduced sensitivity to colour perception; and contrast and reduced depth

perception (Pool, 2007; Scanlon, 2008). Subtle changes in reading, watching television and facial recognition may go unreported in the early stages, especially in those with cognitive impairment. The large amount of visual problems in older people occurs gradually and often goes unnoticed by older people and their health care providers (Pool, 2007). Management of all chronic diseases, including low vision and diabetes, are the responsibility of the health care providers (Care Home Guide, 2013), who need to understand the differences between the low vision associated with diabetes and normal age-related visual impairment.

2.8. Education and intervention on low vision and diabetes for HCAs

Many researchers believe that educating people with diabetes is important (Adolfsson et al., 2004; Aspray et al., 2006; Guthrie and Guthrie, 2009; Royal college of nursing, 2012). I highly agree with this belief. However, I also believe that we may not be able to achieve the goals we want in educating older people in residential care homes. Due to their age and mental capability, they may find it difficult to understand medical terminology or process and remember information regarding their health problems (Sinclair, 2010).

Our main goal and strength should be in educating the health care assistants on low vision and diabetes, as the responsibility of health care transfers from individuals to the residential care homes (WHO, 2010; WHO, 2011). Being aware and understanding the disease is the key to preparing patients to manage their disease (Heisler et al., 2005; NHS Right Care, 2011), as poor controlled diabetes is associated with a lack of knowledge of diabetes (Al Sayah et al., 2013). One of the main barriers to providing good care to older people in residential care homes is the lack of knowledge and training for health care assistants (Sinclair, 2014). Most residential care home managers have no budget for staff training (Gallichan, 2012). Prior to educating older people with diabetes, we should aim to educate health care assistants in residential care homes to fully understand

the impact of low vision and diabetes, and to provide good care and knowledge for the daily management of low vision and diabetes to older people. Very limited training is available for people with diabetes and HCAs (Sinclair, 2010; NHS, 2011) and unfortunately, due to numerous barriers, older people with diabetes are generally unable to attend the training. Within the health related training for HCAs in residential care homes, diabetes was only described in a few sentences and even these courses were not mandatory (Redman, 2002; Eigenmann et al., 2009; Al Sayah et al., 2013). The list of a few example educational toolkits are presented in Chapter 6 page 179.

2.9. Role of the healthcare assistants (HCAs)

Healthcare assistants (HCAs) assist registered nurses in numerous ways in the residential care home environment. Some healthcare professionals believe that HCAs are their 'eyes and ears' as they can relay information or identify warning signs that can be passed to the appropriate healthcare professionals (Higham, 2015). In several residential care homes, HCAs are used as interpreters (Spilsbury and Meyer, 2004). In my opinion I think experienced HCAs can be an invaluable source of advice and guidance to older people with low vision and diabetes. HCAs are 'the backbone of residential care homes and the NHS'. The general duties of the HCAs include housekeeping and residents' personal care, as well as making beds, bathing and feeding, checking body temperature and changing simple dressings (Spilsbury and Meyer, 2004). They also undertake the daily progress notes and updating of care plans, and numerous reports have found HCAs suggesting that their participation within the residential care home covers a greater amount of time spent with residents compared to the registered nurses (Burkhardt and Nathaniel, 2007). Research (Spilsbury and Meyer, 2004; Kessler et al., 2012) has reported that central patient care has been transferred from nurses to HCAs. The study also revealed that HCAs would carry out tasks of direct and indirect care in a shift where most nurses completed the management tasks,

including taking phone calls and executing handovers of shifts (Kessler et al., 2012). In the care home environment, the HCAs spend large amount of their time with the residents, and acted as key members of the team in terms of meeting the needs of medication and personal care (Watson and Bamford, 2012).

Many healthcare assistants are currently delivering an extensive variety of more developed duties which are normally completed by nursing staff (Higham, 2015), which include the application of complex dressings, checking analytic machines, giving inoculations, giving medication to residents, taking ECG tracings, collecting blood samples, liaising with other members of the healthcare team, relaying therapeutic data to relatives, and creating and upgrading care plans. In residential care homes, compulsory training differs depending on the exact responsibility that a support employee is required to complete (Maben et al., 2012). Most HCAs have to undertake the mandatory training, such as moving and handling, administering medication, adult safeguarding, health and safety at work, infectious control, and basic hygiene (Kessler et al., 2012). Importantly, there is no mandatory training on low vision and diabetes (Roberts, 2013).

It is also important to note that HCAs are not regulated by any of the health professional's regulatory bodies. This means that HCAs are not held accountable for their actions or omissions of care by any professional body that has a duty to protect the public (Maben et al., 2012; Roberts, 2013; Higham, 2015).

2.10. Key issues and barriers for low vision and diabetes

Taking the above data into consideration, a number of key issues and barriers can be identified:

- Absence of knowledge and awareness of low vision and diabetes related health complications and indicators at all stages, predominantly in HCAs.
- The health of the eye is disregarded as a health marker in the evaluation of residents, both within the care home as part of routine health testing, and externally through discussions with healthcare professionals and

Care Quality Commission appraisals. While eye health is referred to in general health discussions as a 'silent' health problem, it is often omitted from health tests in the clinical setting.

- The absence of awareness about eye health, formal sight examinations, or evaluating possible signs, by HCAs, further worsens the issue.
- The unavailability of training and resources for HCAs on eye health and diabetes.

2.11. Conclusions

Low vision associated with diabetes in older people is becoming a growing problem. With the increasing burden imposed on individuals, families and society, the improvement of low vision and diabetes education and awareness in order to reduce the consequences of low vision and diabetes is necessary. The treatment regimen of diabetes includes both pharmacological and non-pharmacological management. To reduce the occurrence rate of these consequences, a HbA1c value of less than 7% is recommended for diabetes care (Diabetes UK, 2015). However, to achieve this goal, pharmacological treatment alone is insufficient; education and awareness is also needed.

This literature chapter 2, highlights that there has historically been a lack of interaction between optometrists and residential care homes and a lack of awareness and knowledge about the health of the eye and the advantages of routine eye examinations in older people; there is a large body of research to suggest that this is still the case (Abdelhafiz and Austin, 2003 ; Adolfsson et al., 2004; Aikens et al., 2005; Alexander and Lantos, 2006; Charles, 2007; Scanlon, 2008; Abdelhafiz and Sinclair, 2009; Sinclair, 2010; College of Optometrists ,

2011; Gallichan, 2012) and (Care Home Guide, 2013; Mommersteeg et al., 2013; Sinclair, 2014; Higham, 2015; Turpin, 2015).

Many of these matters, as recognised in the literature as regions of distress, are acknowledged as vital areas for action:

- Health care providers, GPs, ophthalmologists and optometrists have the opportunity to update and advise HCAs about eye health in their day-to-day work within residential care homes, especially in high-risk groups with low vision and diabetes.
- Better access to eye testing services requires a satisfactory workforce stock, HCA training, and awareness regarding low vision and diabetes. There needs to be improvement in public accessibility, affordability, and further research on low vision associated with diabetes.
- Improving systems and quality of care for low vision associated with diabetes will need system incorporation, involving the growth of referral paths that include referrals to diabetes and low vision services that are available for residential care homes.

Training and awareness for HCAs regarding low vision and diabetes will likely identify ways to improve early identification of eye conditions and improve referral of people with low vision associated with diabetes to appropriate services. Information regarding low vision associated with diabetes needs to be better communicated between health care assistants and eye health professionals, including residential care home residents.

The review has identified a number of topics that appear to play a contributory role, either alone or as part of a multi-factorial approach to management and experience of low vision and diabetes in residential care homes residents.

It is notable that more qualitative and quantitative research is needed on low vision and diabetes in residential care homes, and more data needs to be obtained from focus group studies, interviews and surveys. Sight loss is classed as a silent problem, and must be taken seriously in order to improve the quality of life of older people in residential care homes. It is likely that we will need to develop educational toolkits and teaching materials. Educational toolkits will help to educate health care assistants about low vision associated with diabetes and may become increasingly important for them.

The second phase of this research is aimed at validating whether the utility of an educational toolkit for HCAs would be beneficial. This work is likely to provide a starting point for future studies investigating the usefulness of interventions to be developed in this area.

CHAPTER 3

RESEARCH FRAMEWORK, METHODOLOGY AND METHODS

3.1. Introduction

The purpose of this chapter is to focus on the research methods used in this project. The first section considers the research framework, methodological issues and main reasons behind choosing the method, concentrating on focus groups, interviews and questionnaire surveys; the second section identifies the research strategies including ethics approval, participant access and data analysis; and the third section addresses the strengths and weaknesses of the design.

3.2. Choosing the most appropriate methods

The definition of methodology is: ‘the strategy, plan of action, process or design’, and method is: ‘the techniques or procedures used to gather and analyse data’ (Crotty, 2003; Cho and Lee, 2014). Selecting the right methods and research design is the key to answering the research questions.

Researchers have debated for decades the advantages and disadvantages of two paradigms: quantitative and qualitative; it is still not clear which one is the best method to discover the truth (Flick, 2002; McPherson and Leydon, 2002). Quantitative research aligns with the positivist paradigm and is best suited to testing an existing theory, to examine cause and effect relationships, to predict and control in order to stress the importance of measurement and explanation (Porter, 2000; Balls, 2009). Arguments have been raised to show that using quantitative methods, the measurements and explanations are not always appropriate for human action (Bryman, 2004; Boutellier et al., 2013). Human behaviour is far more complex than it first appears, as often multiple meanings

and interpretations are linked to the same behaviour; quantitative methods are not suitable for understanding these multiple meanings and interpretations related to behaviours (Smith, 2008).

Quantitative research can be described as a cause-effect relationship, searching for standardisation, reproducibility and measurability. Qualitative research aims at understanding and interpreting behaviours, contexts, and interrelationships (Boutellier et al., 2013).

Qualitative research closely aligns itself with the naturalistic paradigm and aims to understand how people perceive and interpret reality by using words, either verbal or written, to interpret and understand the rationale behind their actions in terms of motives (Porter, 2000; Dick et al., 2014).

Understanding multiple meanings and interpretations related to the same behaviour is a key concern for those carrying out self-care in illnesses (Katz and Mishler, 2003). It is very important to understand and examine the multiple meanings and interpretations behind the actions as this might help to understand the nature of low vision associated with diabetes in older people, as according to Lindseth, most of the behaviours are carried out in a social context (Lindseth and Norberg, 2004; Denzin and Lincoln, 2005; Donclark, 2015).

The qualitative method is the best means to understand the full phenomenon to view it in context, as looking only at one small portion of the reality in the quantitative technique it is possible to miss the importance of the whole phenomenon (Krauss, 2005), and we need to understand the full phenomenon of low vision and diabetes in older people living in residential care homes.

Many researchers (Murphy and Dingwall, 2003; Pope and Mays, 2006; Polit and Beck, 2009) are agreed that a qualitative approach can highlight important areas of health research, especially exploring patients' behaviours and their psychological response to treatment. In a health or social care setting, qualitative

research methods aim to understand the reality and it is particularly useful for exploration of people's experiences (Porter, 2000; Flick, 2002; Murphy and Dingwall, 2003; Bryman, 2004; Smith, 2008). Qualitative methods investigate patients' experiences and how they cope with the continuing effects of illness in their lives (McPherson and Leydon, 2002; Katz and Mishler, 2003; Lindseth and Norberg, 2004; Denzin and Lincoln, 2005; Balls, 2009). Polit and Beck analysed more than 1,000 nursing studies published in eight journals between 2005 and 2013, finding up to 52% were descriptive qualitative studies (Polit and Beck, 2009).

This research was designed to explore how older people living in residential care homes, with low vision and diabetes, manage their normal daily tasks and activities, including taking medication, self-monitoring of blood sugar levels, dietary control, exercise, self-care, stress management, monitoring complications, either chronically or acutely from the time of diagnosis. In this sense, how older people with low vision and diabetes manage normal daily tasks is a subjective rather than an objective issue, and it is related not only to daily tasks, but also to psychological, social and cultural factors. Concerning the strengths and weaknesses of the two paradigms (McPherson and Leydon, 2002; Denzin and Lincoln, 2005), qualitative research is identified as an appropriate approach for this study (Bryman, 2004; Denzin and Lincoln, 2005; Balls, 2009) as a means to investigate how older people experience and cope with the continuing effects of low vision and diabetes in their lives (Murphy and Dingwall, 2003; Lindseth and Norberg, 2004; Polit and Beck, 2009). This research adopts a grounded theory approach (Charmaz, 2008; Thornberg, 2012) generating the data from the participants involved in this research. Grounded theory helps to generate insights from the participants (Charmaz, 2006; Charmaz, 2008; Thornberg, 2012; Cho and Lee, 2014).

Using the above insight from Section 3.2, as a sensitising approach and knowing that evidence about low vision and diabetes has been broadly covered both quantitatively and qualitatively, this study is considered to be a naturalistic

inquiry, with the descriptive qualitative design as the appropriate method (Polit and Beck, 2004; Donclark, 2015).

After identification of the qualitative methodology, the next issue was how to develop the appropriate research tools to identify the phenomenon of older people with low vision and diabetes living in residential care homes. The methodology needed to be compatible to cover all elements and be achievable within the required timescales. Considering all these logistical issues, it will help to explore some types of involvement with older people; healthcare professionals would generate valuable insights into low vision and diabetes in older people.

3.3. Identification of the appropriate research tools and methods

The key tools and modes of data collection research methods to explore people's subjective understanding of their daily lives is focus groups, interviews, questionnaire surveys, reviewing manuscripts, recorded audio tapes and direct observations (Pope et al., 2000; Flick, 2002; McPherson and Leydon, 2002; Mason, 2012). However, direct observation consumes more time than the other research tools and direct observation does not provide the opportunity to participants to give any further information they may need to contribute (Watson et al., 2008; Warren and Karner, 2009). It would be unachievable and inappropriate to undertake such intensive observation in this project due to time limitations. Direct observation would make recruitment more complex (Murphy and Dingwall, 2003) and the participants may feel the interruption intrusive in their lives; it is unrealistic to observe behaviour during all activities, including from breakfast until after midnight, when the person goes to sleep (Boutellier et al., 2013).

Interview tools are suitable research methods to collect deep and complex data which will provide the opportunity for participants to structure their own

meaning without the researcher's own structures and assumptions (Pope and Mays, 2006). Face-to-face interviews can make it easier to clarify ambiguous statements and allow investigation into specific situations, which may lead to a better understanding of real-time events (Mason, 2012). Conversation is the basic means to learn about each other, and interview methods are suitable to collect deep and complex data (Flick, 2002; Pope and Mays, 2006; Warren and Karner, 2009). There are three key modes of interviews in qualitative research: unstructured, semi-structured, and in-depth. Unstructured interviews are beneficial when the researcher knows little about what needs to be asked. In-depth interviews answer one or two issues in more detail (Watson et al., 2008). Semi-structured interviews involve open-ended questions to explore different areas of the research and investigate the area in more detail (Pope and Mays, 2006; Boutellier et al., 2013); open-ended questions give the opportunity to participants to say anything that they feel. Using the Interview Guidance Notes for participants will make it more effective to cover all the necessary questions, and also it will help to develop the participants' own ideas and experience in the interviews (Bryman, 2004).

Considering the above logistical issues, and to cover and explore all the elements of low vision and diabetes in older people living in residential care homes, focus groups, interviews and questionnaire surveys with open-ended questions were selected to be the suitable methods for the major methods of data collection. Additionally, field notes, research diaries, and documentation were also used. It is advisable to keep a research diary that can be used for reflection during the process of data collection to increase the comparability of the empirical proceedings (Flick, 2002; Mason, 2012), as it will help to recall ideas and observations that might be important for the future direction of the study (Silverman, 2000; Murphy and Dingwall, 2003; Bryman, 2004). Therefore, it was decided to keep a diary to record every day activities and the process of the research (Please see Appendix Research diaries on page 275).

3.4. A diagrammatic design of the decision is presented in figure 3

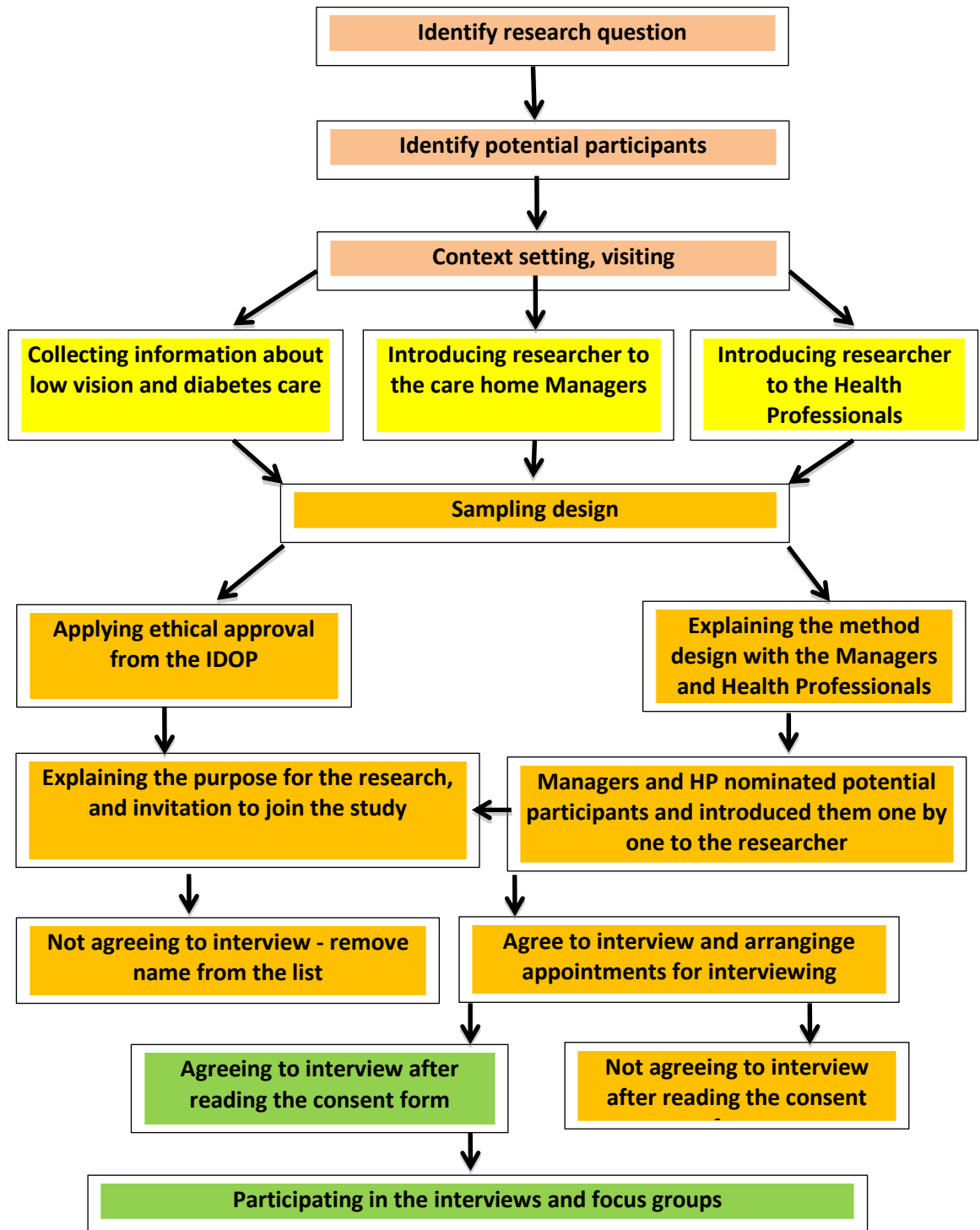


Figure 3 Diagrammatic design of the final decision

3.5. Consideration of sampling and gaining access to participants

Gaining access to the appropriate settings for potential participant sampling is very important in any research in order to achieve the goals of the study. This project required making a number of contacts through letters, emails and telephone calls to collect the information needed to develop the research design. After accessing the appropriate settings, the sampling scheme was agreed.

The literature review suggested that multiple factors could affect older people with low vision and diabetes living in residential care homes, and collecting the data only from older people might give poor and insufficient information without the inclusion of health care assistants and other healthcare professionals. Information from these parties might provide valuable information to help understand the context of low vision and diabetes in older people. Obtaining rich information within limited time periods may or may not be valuable information. However, extending the number of subjects may provide richer information. The views of older people with low vision associated with diabetes, GPs, ophthalmologists, optometrists, nurses and health care assistants were all included in this study to obtain a wide range of information.

3.5.1. Criteria of sampling

The following criteria were used for selection to investigate low vision and diabetes in older people living in residential care homes. The criteria differed depending on the group.

Full details are presented below in Table 3.

Criteria of sampling for Phase 1 are different for each group		
2 Focus Groups Total participants, 12	Health Professionals Questionnaire Surveys Total participants, 90	Interviews Total participants, 14
6 Optometrists <i>Participants with no age or gender restrictions, registered with the Royal College of Optometrists were conveniently chosen with help from Health Professionals</i>	15 GPs <i>No age or gender restrictions, registered with the GMC and RCGP</i>	6 HCAs <i>No age or gender restrictions, with minimum qualification of NVQ2 or QCF 2 and 2 years' experience in health care, were conveniently chosen with help from care home managers</i>
	15 Ophthalmologists and 15 Optometrists <i>No age or gender restrictions, registered with professional bodies</i>	
6 Community based older people <i>Age 65, no upper age limit, diagnosed with low vision associated with diabetes, were randomly chosen with help from Health Professionals</i>	15 Nurses <i>No age or gender restrictions, registered with NMC</i>	8 Residential care home residents <i>Age 65, no upper age limit, diagnosed with low vision associated with diabetes, were conveniently chosen with help from care home managers</i>
	30 HCAs <i>No age or gender restrictions, with minimum qualification of NVQ2 or QCF 2 and 2 years' experience in health care</i>	
Total sample size for Phase 1 of project = 116 participants		

Table 3 Criteria of sampling for Phase 1

The criteria of sampling for Phase 2
20 HCAs <i>With minimum qualification of NVQ2 or QCF 2 in health care and 2 years' experience of work in a residential care home, with no age or gender restrictions were conveniently chosen with help from care home managers from Bedfordshire. All participants received Toolkit training, a pre-test and post-test for participants of 10 questions to evaluate and assess baseline knowledge (prior to the delivery of the Toolkit, as well as immediately afterwards).</i> The Phase 2 research methodology is presented in Chapter 6 section 6.6 on page 180.
Total sample size for Phase 2 = 20 participants

Table 4 criteria of sampling for Phase 2

3.5.2. The process of sampling

In setting up a sampling frame, the principal researcher decided to recruit the HCAs and the older people for interviews, the residential care home managers were heavily relied upon. The managers were contacted through letters and phone calls to make appointments to explain the study details; the managers were then able to provide lists of potential participants as well as giving the participants a brief explanation of the study. Following the identification of participants, they were contacted and visited in the care home environment.

General practitioners and the lead optometrist of the Bedfordshire region were able to provide details of potential participants for the focus group; the information lists provided included the names of the nominees, and their addresses, and telephone numbers along with information that allowed access to potential participants by letter and telephone.

The process therefore started with a telephone call to invite potential participants to join the study. If they agreed, an appointment was made and the details of the study were explained (see Figures 4 and 5). All participants were given details of the study, and their questions about the study were answered. The potential participants were then given one week to read and consider the Participant Information Sheet and sign the Consent Form; the sheet contained the principal researcher's and other team members' contact details. (See Appendix - Invitation letters are presented on page 248 to 254 and the Informed Consent Forms for all participants are presented on page 277 to 327 and 353).

A further appointment was made for follow-up interviews, at a place of their preference. The lead optometrist introduced potential participants to the researcher whilst they were at their monthly meetings. The optometrists used face-to-face invitations to recruit participants.

The process of sampling for Focus Groups

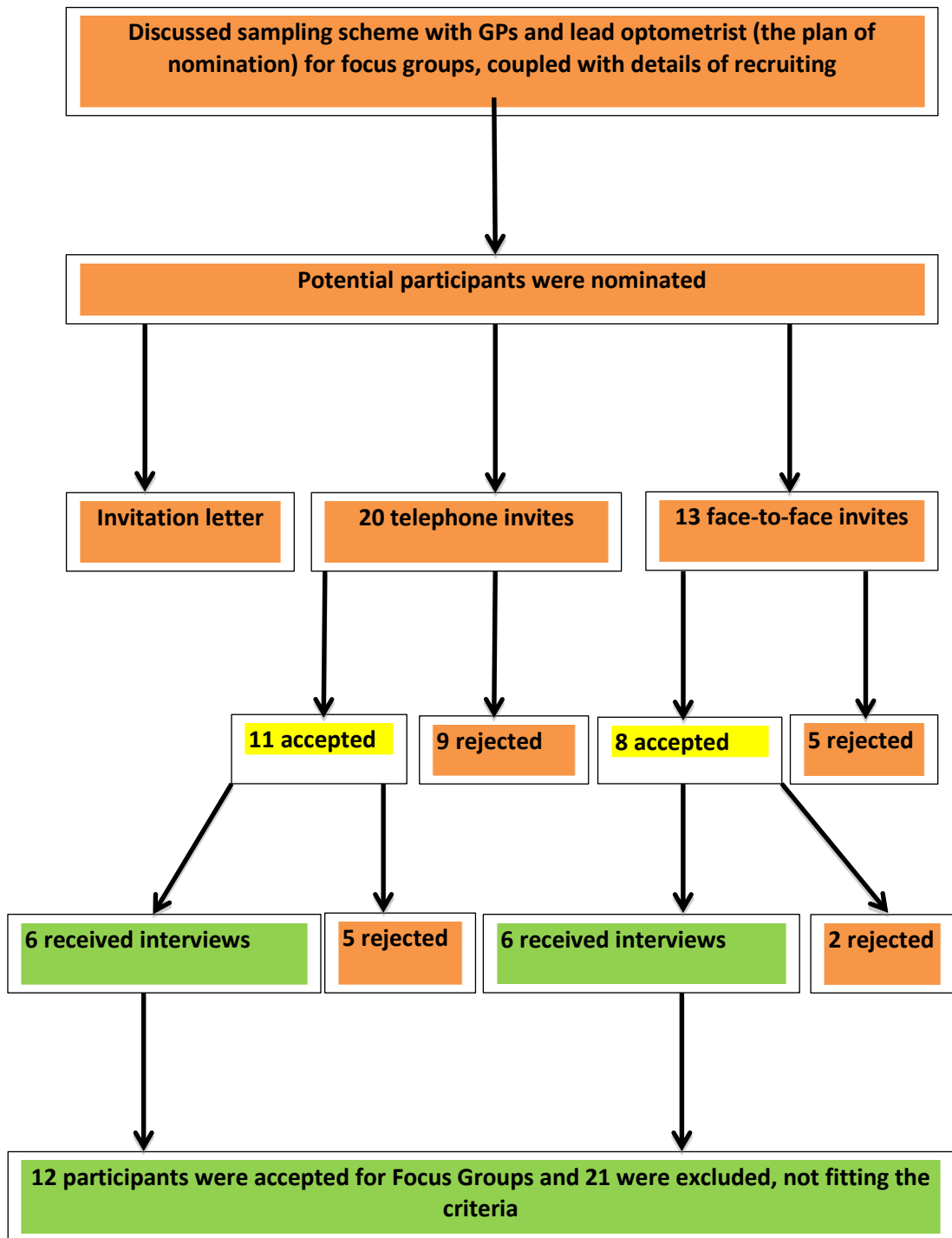


Figure 4 The process of sampling for Focus Groups

The process of sampling for interviews

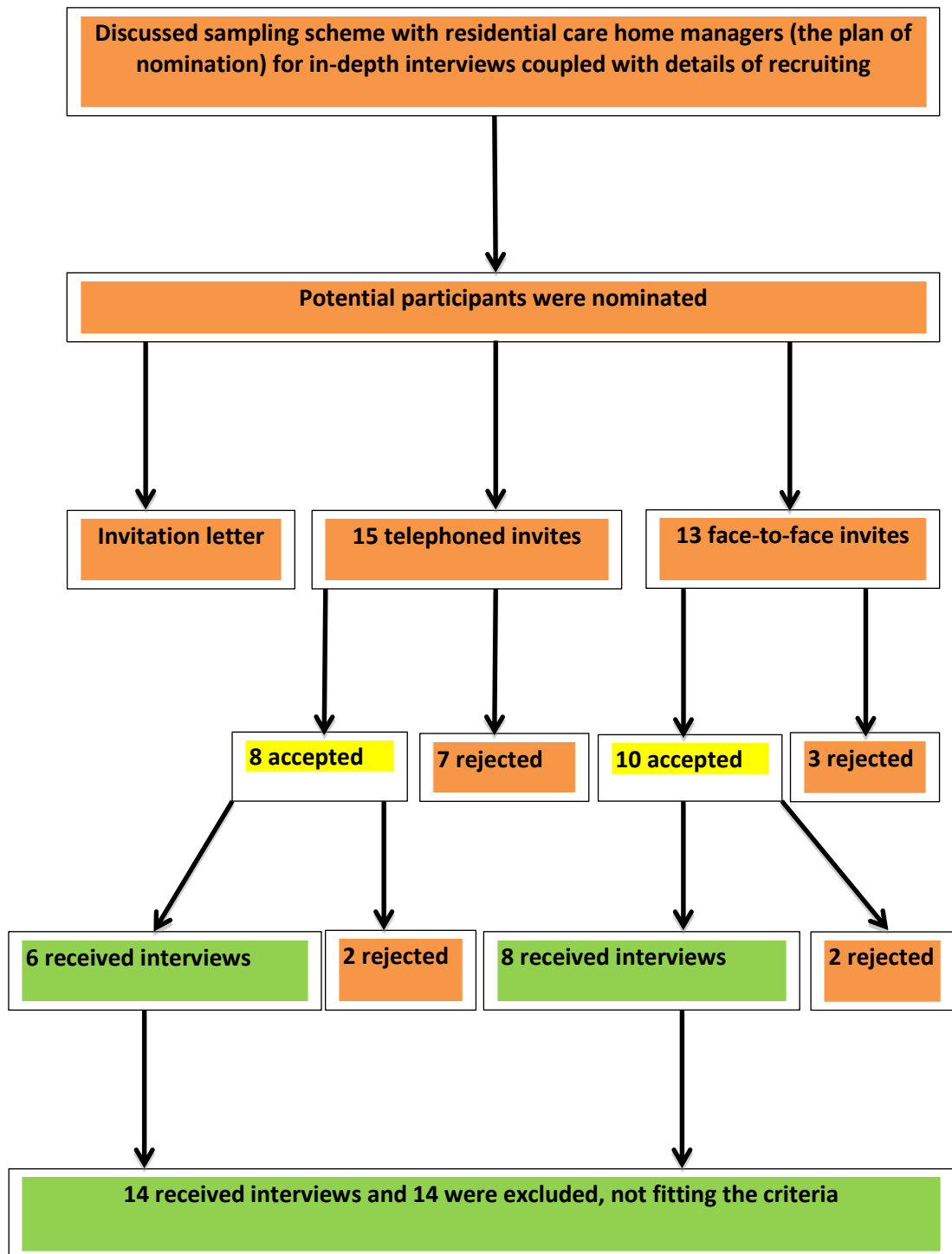


Figure 5 The process of sampling for Interviews

3.6. Research methods

The qualitative research focus groups, interviews and questionnaire surveys were determined by the researcher to be suitable methods to be adopted for data collection, and other methods such as field notes and research diaries were then used together to enrich data analysis. Data collection started with the focus groups and information from these and some questions for the interviews were adopted from the list of similar studies completed in IDOP (Sinclair, 2010; Sinclair, 2014). Finally, the findings from the focus groups, interviews and some questions were adapted from the previous IDOP studies to develop the health professional survey questionnaires.

The purpose of the focus groups, interviews and health professionals survey was to explore comprehensively the phenomenon of low vision and diabetes in older people living in residential care homes, specifically in terms of the issues currently experienced by older people and HCAs and to gain descriptions of the lived experiences of the interviewees to interpret the meaning of the described phenomena. The main consideration of these focus groups, interviews and health professionals' survey was to find the unpolluted thoughts of the participants without the inclusion of leading questions.

3.6.1. Focus groups

The focus groups provided first-hand participant experience relating to their condition, including low vision and diabetes, and offered a direct opportunity to consult the target population (Kvale and Brinkmann, 2008). Focus groups provide a large range of experience and a diverse variety of ideas related to research areas (Vogt et al., 2004). It is very important for participants to have an equal amount of time to discuss their issues and experiences; therefore it was decided that the focus group participants consist of between 3 to 5 individuals (Vogt et

al., 2004; Kvale and Brinkmann, 2008). The methodology of focus groups has also been extensively used in diabetes research with older people in many areas of research to assess the challenges of caring for people with diabetes (Minet et al., 2011). As a result, there is much evidence on the suitability and flexibility of focus group research in data collected from older participants.

Focus groups are valuable in gaining mixed opinions of low vision and diabetes, not just from healthcare professionals but also from those older people actively affected by low vision and diabetes. Two focus groups were set up to define low vision and diabetes in older people. One focus group consisting of older people living in the community and the other consisting of optometrists.

3.6.1.1. Focus group of older people

The purpose of the older community residents' focus group was to understand their knowledge regarding low vision and diabetes, as large numbers of these older community residents will be moving to residential care homes within the next few years (Sinclair, 2010). The focus group methodology was appropriate as this represents a convenient, relatively informal, non-intimidating means of gathering opinions and facilitating discussion that should not be as arduous for this population as other survey methodologies, such as long and detailed questionnaires (Vogt et al., 2004).

Group discussions may also facilitate the development of individual opinions and experiences, generate consensus views or highlight differences (Kvale and Brinkmann, 2008). Based on the input of older people throughout, a report was prepared by the principal researcher to identify the key action points needed to enhance and understand the issues and problems faced by older people with low vision and diabetes and highlight ways to encourage and support this vulnerable group. The results are presented in Chapter 5 section 5.3.

3.6.1.2. Focus group of optometrists

The purpose of this focus group was to discover the gaps, along with the difficulties and limitations, which optometrists face in their practices, and to get their opinions on low vision and sight examinations, as these eye examinations are different from primary eye examinations. It should also find their views on managing low vision associated with diabetes in older people. This focus group aimed to explore the optometrists' skills, including existing knowledge and education on low vision, and their experiences in the way they deliver counselling to older people, particularly to HCAs.

3.6.2.1. Interviews with older people

The purpose of the interviews was to discover what older people know, and want to know, about low vision and diabetes, and to find out what help and support is needed to prevent and manage these conditions. In addition the results will help us to understand how these older people see themselves; the interviews will also cover education, including all daily activities.

Based on the responses from the participants in the interviews, the principal researcher prepared a report identifying the key action points that are needed to enhance and understand the issues and problems faced by older people with low vision and diabetes in residential care homes and to demonstrate what gaps exist in the formal requirements of residential care homes to meet the needs of these individuals, and how they receive low vision care in residential care homes.

3.6.2.2. Interviews with HCAs

The aim of these interviews was to assess the current practices for the management of low vision and diabetes in older people living in residential care

homes. Healthcare assistants (HCAs) spend large amount of their time with older people in residential care homes, compared to the other groups (see Figure 8, Chapter 4, page 86). The HCAs interviews were requested to explore their existing knowledge and understanding of the issues they face, to explore their views on management and to evaluate the knowledge and understanding of healthcare assistants of the impact of low vision associated with diabetes in older people. Additionally, there was a need to identify the gaps and difficulties they encounter, and seek their opinion about it.

3.6.3.1. Questionnaire surveys

Most of the participants were recruited from the list of healthcare professionals based at Bedfordshire hospitals and residential care homes who had previously responded to a similar survey (England-wide Care Home Diabetes Audit) (Sinclair, 2014) which was released by the Institute of Diabetes for Older People (IDOP) at the University of Bedfordshire.

3.6.3.2. Questionnaire survey distribution:

Compared to questionnaires sent via the mail or over the internet, hand distribution of questionnaires can be more efficient as responses can be received quickly (Boutellier et al., 2013). Additionally, participants may find completing and returning questionnaires by post or online surveys more difficult and may also need some explanation about the study itself (Kvale and Brinkmann, 2008; Warren and Karner, 2009; Mason, 2012). However, as with all surveys, some participants may provide random answers which need to be filtered out.

The questionnaire responses from all the healthcare professionals were analysed and considered as a whole and then broken down by each individual profession in order to look for any potential disparity in understanding of low vision and

diabetes between different healthcare disciplines. The results are presented in Chapter 4, section 4.4.

3.7. Issues of the focus groups and interviews

Duration: The duration of the focus groups and interviews was one of a few concerns before going into the field to collect information, either to prevent the participants from feeling too tired to focus on the topic, or because the time was too short to collect the required amount of data. According to Stewart and Shamdasani, a focus group is a small group of six to ten people and the ideal amount of time for focus groups and interviews is from 45 to 90 minutes (Stewart and Shamdasani, 2015).

The decision was made to set different criteria for each group as all the groups were different from each other. During the explanation of this study to the focus group participants, the principal researcher gave them three choices about the duration and time limitations of the focus group: the first choice was 45 minutes, the second was 60 minutes and the third was 90 minutes. Large number of the participants chose the second option of 60 minutes. The principal researcher divided the 60 minutes into 10 main questions which included a welcome introduction and refreshment break (10 – 15 minutes), and 60 minutes was sufficient time for this study, see detail checklist for focus groups on page 262 in the Appendix. The decision was made that for both focus groups (the older community residents and the optometrists), the session would run for 60 minutes.

Interviewing the HCAs was a little different as they were paid by the residential care homes management, and they were only allowed to participate for 15 paid minutes, which was insufficient. Normally HCAs have their own 30 minute break in every 7 hour shift. The principal researcher asked the HCAs, during the explanation of this study, whether they would give up their own 30 minutes for

this research study. Most of the HCAs and their managers agreed with this idea, so this totalled 45 minutes, which was sufficient time for each participant. The decision was made that each HCA interview would therefore run for 45 minutes. Interviewing the older people living in the residential care homes was another difficult task due to numerous factors, for example, older people's health issues such as low vision and diabetes, and also the fact that they are unable to sit for a long time. The decision was made that each participant interview would run for 30 minutes. See details Checklist for Interviews on page 270 in the Appendix. During the focus groups and interviews, a comfortable environment was created to put the participants at ease.

Venues: Suitable venues were another issue considered while interviewing, particularly for the optometrists as they are very busy and it can be difficult for them to travel and participate in the focus groups. The majority of participants preferred for the focus groups to be held at a hospital; all the participants were happy to come to the Ophthalmology Unit at Bedford Hospital.

The focus group for the older people was more difficult to organise as it was not easy for participants to travel to the hospital and they were often reluctant to ask their family or friends for help. The focus group for older people was held at IDOP. All the participants agreed to travel to the Institute and transport was arranged for them. For the interviews with the older people and the HCAs, visits were made to their residential care homes and all participants were interviewed in situ.

3.7.1 Issues with questionnaire survey

In Phase 1, during the process of identifying professionals, the researcher met with over 200 professionals and the questionnaires were handed to them. However, not all were willing to complete the questionnaire due to lack of time;

others failed to return the questionnaires in the required time, or returned uncompleted questionnaires. In total, questionnaires were collected from 90 participants, including 15 GPs, 15 ophthalmologists, 15 optometrists, 15 nurses, and 30 healthcare assistants, this is a response rate of 45% and this is an acceptable rate.

3.7.2. Issues with contacting older people for focus groups

After informal contact with some older community residents for the focus group on the phone, a clear problem was identified that the majority of the phone calls were answered by other family members, who were unable to explain the study aims and purposes in detail to the participants. Additionally, many participants did not take phone calls seriously from strangers, which made recruiting participants for the study more difficult. After a full explanation of the study, some participants began to agree to participate. Closer to the time of the study the participants were phoned again to ensure they were still able to participate, and unfortunately many participants withdrew. It was realised that merely contacting potential participants by phone was not enough to convince them that we had given our true identity as they were still feeling insecure.

To resolve this problem, the healthcare professionals introduced me to the potential participants face-to-face in their practices. Therefore, progress was largely dependent on the health professionals' help, such as the list of potential participants, together with the dates when they would come back for a check-up, and the doctor could introduce them to the researcher and left the rest for the researcher to complete outside the clinic, this was a successful strategy.

3.7.3. Issues with contacting ophthalmologists and optometrists

From the onset of this study it was difficult to recruit ophthalmologists to take part in the focus groups, many of the ophthalmologists stating that they did not

have enough time. Six optometrists were recruited for focus groups. Optometrists are an important group of professionals as they have contact with people who have low vision or people who have concerns about their vision. As no ophthalmologists were recruited for focus groups it was important to know the views of ophthalmologists for this study, and questionnaires were sent to fifteen ophthalmologists and fifteen optometrists.

Some of the family members who accompanied the participants during the interviews or groups read the consent form and joined in at the interviews. During the interviews, a neutral, non-judgemental and friendly approach was taken, and observations such as emotional or physical stress were noted. Although some participants could not help showing their emotions while sharing experiences, they seemingly felt better afterwards, which was demonstrated by talking non-stop, or even being appreciative at the very end. At this point, I realised that my previous experience as a health professional, and encouragement of Professor Alan Sinclair, Professor Peter Scanlon and Dr Alexandra Elizabeth Tomlin, were allowing the process to move smoothly in the right direction.

Those who rejected the invitation mostly showed suspicion towards the study; I felt this by their reply. Two potential participants refused to be involved by phone. Five potential participants refused when invited in person. One of the potential participants said she was not used to talking to strangers, so refused the invitation. Another potential participant refused the study because she was undergoing enormous pressure from the family and needed to take care of her sick daughter and family matters and this left her no time for herself. The rest of the potential participants refused due to not having enough time.

The full comprehensive information expected to be collected was another concern, and a semi-structured interview was adopted, allowing all participants to respond flexibly and openly. The concept of interviewing was integrated into a semi-structured interview schedule to achieve the aims of the study.

3.8. The structure of focus groups, interviews and questionnaire survey guides

The focus groups, interviews and health professionals' survey guides were structured to cover general information regarding daily activities, education, communication and social roles that could influence low vision and diabetes in residential care homes. In the focus groups, participants were invited to sit facing each other in a circle around a table. The researcher sat within the circle, and initially requested each participant to introduce themselves. The participants were then asked to give their names and confirm their diagnosis and duration. The healthcare professional participants were asked to give their names and their primary roles along with their work locations. Participants in the focus groups and in the interviews were encouraged to talk freely, allowing the researcher to draw an overall picture of the participants that was beneficial for gaining richer information.

The next core concept focused on the experience of participants living with low vision and diabetes, which was designed to follow the timeline of living with this condition in residential care homes, concentrating on its impact and the barriers and difficulties to delivering good care and management. To gain the perspective of either the health care system or its policies on low vision associated with diabetes, there is a need to understand the role of health care assistants and other health professionals in low vision associated with diabetes care. General information from healthcare professionals about barriers and difficulties in providing effective care for older people with low vision and diabetes living in residential care homes was obtained in the first stages of this study, and this was followed by questions on their perception of good care for low vision and diabetes in older people. The key interest of the focus groups, interviews and health professionals' survey was to explore the health professionals' perception about:

- (1) The impact of low vision and diabetes care;
- (2) The barriers and difficulties that affect low vision and diabetes care;

(3) The role that healthcare professionals play for older people with low vision and diabetes in residential care homes;

(4) Other important issues that healthcare professionals thought were important in low vision and diabetes, including general information about these conditions, mainly focusing on education, communication, residential care homes and the health care system. Interview guides are presented on page 257 in the Appendix.

3.9. Ethical considerations

To protect the participants from harm, the research design had taken ethics into account, such as autonomy and confidentiality (Burkhardt and Nathaniel, 2007). There should be a respect for autonomy, and the principles of doing good and acting truthfully (Tom and James, 2012; Polit and Beck, 2009). As the research was conducted in residential care homes, ethical approval from the IDOP, University of Bedfordshire ethics committee was essential, prior to commencing any work. IDOP ethics committee required the researcher to submit two relevant form copies. Full ethical approval was granted, please see Appendix page 241 and 345. Once the data had been collected, any personal identifiable information (e.g. names of people or places) were removed from the reports and stored separately. The data relating to individual participants was anonymised for use within the study via a unique, non-identifiable code. Although it is not anticipated that the information provided by the study will be of a sensitive nature, it was explicitly stated by the principal researcher at the start of each focus group that participant's identities would be protected. Data was stored securely on a password-protected PC and was locked at IDOP. All data analysis was anonymous and confidential.

3.10. Data analysis methods

After data collection, a thematic method was used for the data analyses.

The thematic analysis method is very effective for exploring and extracting the living experiences of participants (Braun and Clarke, 2006; Mason, 2012). The thematic analysis method enables the researcher to use various elements which helped with the analysis when comparing the participants' own experiences of low vision and diabetes, with 'reality' (Boutellier et al., 2013). The following figure thematic analysis steps were adapted from (Braun and Clarke, 2006).

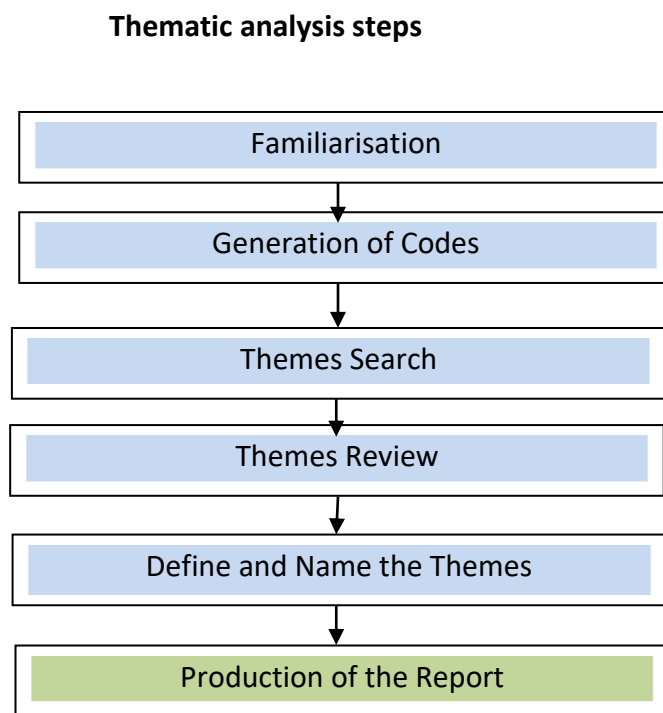


Figure 6 Thematic analysis steps

Familiarisation: Familiarisation started initially with data collection, then re-checking of transcripts to ensure accuracy. Before coding, it was useful to familiarise oneself with the data by repeatedly listening to audiotapes and reading transcripts.

Generating initial codes: At the generation of codes stage, each transcript was read and re-read before being given initial codes and listening to audio tapes assisted in catching nuanced meaning such as tone to ensure the meaning, which might be different from the words itself. Initial codes are presented on page 328

in the Appendix. While becoming familiar with the data, the initial codes were constructed manually by the researcher using highlighters and underlining. NVivo was considered as a tool for supporting the analysis of the results as the merits of NVivo include easy cutting and pasting, and all themes can be pooled together easily. However, the manual method was preferred as I was far more engaged in the participant's words and meanings using manual methods. Most of the coding was undertaken manually, and then saved as Word documents. Coding them manually allowed the researcher to become familiar with the data, which presented the story as a whole rather than as segmented information, and gave the benefit of the constantly applied comparison technique. Also the coding could be undertaken without switching on the computer, it allowed the researcher to code and abstract the themes without the need for a computer all of the time.

The participants' results were organised into three folders which consisted of the healthcare professionals' survey, the focus groups, and the interviews. This allowed easier access by different groups. Each transcript was saved in the form of a Word document, leaving the right half of the page blank for coding, and they were printed out individually. The coded sentences were underlined to enable easy searching. Once a transcript was completely coded, all of these codes were typed onto one page and placed on the front page of the transcript with the notes to indicate where they were located, and the sub-categories were all put into one document, which made constant comparison between cases easier. Later, these sub-categories were grouped into themes by using constant comparison to identify the association within the codes and themes. After comparison and compiling, the categories were formed, and any data that failed to enter any sub-category was put into a temporary file, for later scrutiny.

Reviewing themes: At the Themes review stage, the sub-themes and codes were refined by reading and reviewing extracts until they were coherent. The unfitted codes and candidate themes were re-examined to see why they could not fit into the existing concept, and how they might be refined.

Defining and naming themes: At the Define and Name the Themes stage, the researcher tried to draw themes together to examine the meaning behind them, and elaborated them to define and refine all of the themes until coherence and internal consistency was achieved. The next step was to recognize the meaning of the themes, from which a broad story was presented to describe how older people in residential care homes and in the community lived with low vision and diabetes. Three themes were identified to highlight this broad story of living with low vision associated with diabetes, which were: 'life with low vision associated with diabetes', 'restructure life with low vision associated with diabetes', and 'helping hands', details of which are presented in section 5.3, Chapter 5.

3.11. How the data was used while doing data analysis

The focus groups, semi-structured interviews and questionnaire survey allowed the main topic: low vision and diabetes in older people living in residential care homes, to be presented in an important manner, but participants could speak about their experience of low vision and diabetes. The researcher did not follow the strict order of the interview guide as previously explained.

The records provided the sources for checking whether participants were eligible for the study because these were part of the criteria of data collection. The simple statistics of the demographic data was an attempt to look for any relationship between them. (The demographics of older people and all health care professionals' ages and years of experience in care are shown in Table 6 page 104-5 and Table 10 page 183). During data analysis, field notes were used to record any information which could not be audio-taped but could prove useful for data analysis. For example, the interaction between the participants and their families was relied on to obtain more information on family support; e.g. participant L&D 2 changed her attitude and emotion while her daughter was present in the interview room.

During data collection, research diaries were used to record the plan and action of data collection, as well as the reflections and knowledge gained in implementing the actions. Through the real process of action and reflective practice, the researcher was able to advance some strategies for data collection. For example, there were a number of participants expressing doubts about being interviewed because of their fear that the study was illegitimate. By examining the strategy used and the way I talked to them, the strategy for data collection was changed and thus, the progression of data collection was then on-track.

3.12. Producing the report

The final stage was to understand the story of low vision and diabetes in older people living in residential care homes, which is presented in the following chapters and aims to describe the rationale of low vision and diabetes in older people living in residential care homes.

3.13. Validation of the research questionnaires

In terms of philosophical positions, there is difference between qualitative and quantitative methods, (Rolfe, 2006) for the trustworthiness of the research findings quantitative researchers normally use statistical methods, but qualitative researchers apply methodological strategies to ensure that the research findings are accurate (Long and Johnson, 2000; Rolfe, 2006). “Although there is no universally accepted terminology and criteria used to evaluate qualitative research” page 34, (Noble and Smith, 2015) however to enhance the credibility of my study findings and to maximize reliability, I took different strategies and actions in the methodology (see below section 3.15 for full details). According to effective research study design, engaging with other researchers to reduce research bias is advocated (Rolfe, 2006). To help reduce

researcher bias each question was checked by both supervisors and the study adviser to increase the degree of accuracy.

The questions used in the questionnaire I designed for my study questionnaire were developed from IDOP. (Table 11 validation of the research questionnaires can be found as an appendix on page 258) shows the questions I used and the source of each question. As can be seen in (Table 11 validation of the research questionnaires on page 258) key sources of questions were derived from the IDOP questionnaire list which was previously used in a similar survey (England-wide Care Home Diabetes Audit, 2014). The IDOP questionnaire study was conducted by Professor Alan Sinclair, Director of the (IDOP) and Dr Chris Walton, the survey was started in September, 2012, and was completed in late 2013. In total, 2043 responses were received from approximately 9,000 care homes for elderly residents operating in England.

The key findings of the study included: More than a third of care homes admitted to having no written hypoglycaemia policy and over 60% of care homes have no diabetes screening policy and only 36% of care homes stated that they held annual review reports with a GP: this was part of a spectrum of poor communication channels with primary care, over 50% care homes appeared to be unaware of the 2010 Diabetes UK national guidelines of diabetes care for care homes and only a small number of care homes have direct access to diabetes education and training for their care home staff, more than half (53%) of care home residents with diabetes may be at moderate or high risk of other diabetes related complications. the study was published by the Institute of Diabetes for Older People (IDOP) at the University of Bedfordshire (Sinclair, 2014).

To collect informative data it was also decided to use findings from the literature review to create few more questions and add it to the final open-ended questionnaires on low vision and diabetes for all participants that I used for my study ("Visual Loss in Care Home Residents with Diabetes" started by Professor Peter Scanlon in 2014, not published yet). Having drafted my questions, I then

explored their content with my supervisors during the supervisory meetings. The questionnaire I proposed were reviewed by my supervisors and each question was subject to discussion to reach an agreement about the final questionnaire and as my supervisors Professor Alan Sinclair and Professor Peter Scanlon, both of whom have relevant experience and a large number of the questions I used for my study were adopted from the studies completed by Sinclair and Scanlon. It was decided that the questionnaires I developed were appropriate to use in the study of low vision and diabetes in older people living in residential care homes. (The full set of all questions and check List for all sessions on page 262 and Informed consent forms for all participants can be found as an appendix on page 277 to 327 and 353).

3.14. Rigour

Unlike the quantitative method, it is argued that objectivity and reliability cannot be achieved in qualitative research (Yardley, 2008). "Rigour is the means by which we demonstrate integrity and competence, a way of demonstrating the legitimacy of the research process. Without rigour, there is a danger that research may become fictional journalism, worthless as contributing to knowledge", page 388, (Tobin and Begley, 2004). However within social research discourses, there is a never-ending debate on how to achieve the rigour in qualitative studies (Rambaree, 2007). It can be much more appropriate to consider the accuracy of the study.

3.15. Trustworthiness

To ensure trustworthiness, several criteria were taken into account in order to try to accurately represent the reality of the participants' experiences, and to maximize reliability, or 'accuracy' of the study. I compared the data between and within cases in the data set as well as comparing the findings to other studies

(Green and Thorogood, 2004; Watson and Bamford, 2012; Lorig, 2012; Winkley et al., 2013). Additionally, the role of the researcher in data collection and analysis needs to be considered. To keep the study transparent, a clear account of the procedures for allowing others to follow was set in an attempt to meet this purpose.

To maximize reliability, the following actions were taken:

- (1) Taking transcriptions, field notes and diaries as accurately as possible;
- (2) Using simple statistics to present what percentage of participants were involved with the themes identified;
- (3) Analysing the whole data set by using a code book;
- (4) Discussing the themes with two of my supervisors and with my study advisor who had read the transcripts; and
- (5) The themes were identified after a rigorous process of within and cross-case comparison. This also involved identifying 'deviant cases'. The key themes were cross-checked with the study supervisors. Throughout the study I endeavoured to adopt a reflexive approach to my on-going research related to the topic.

As a new researcher and health professional, I realised that there was a danger that my own preconceptions might dominate the data analysis, leading to a distorted view of the findings. Thus constant reflection was done throughout the process of data collection and data analysis. The following sections will give more detailed information about how the researcher managed to ensure the trustworthiness of the study. It is organised by the sequences of study, including sampling scheme, data collection, data management, data analysis, and data translation.

I was careful not to violate the principles of ethical issues, there was constant reflection after each interview in order to remain neutral and non-judgemental, using words carefully to encourage the participants to share their experiences. Those who were grouped in the challenged set seemed vulnerable to any opinion of low vision and diabetes from the outside world. Thus, the communication

skills at the invitation stage must be much more thoughtful, otherwise there was the risk of alienating potential participants. Different sentences were used between the two parties. In the group of low vision and diabetes, they appeared quite proud to have been selected, but the sentences were modified from the ones used for the challenged group by expressing concerns about why they had difficulties in managing their low vision and diabetes. This invitation conversation was the first step in establishing trust between the interviewer and the participants. As a health professional, all of these experiences contributed to sensitisation of the process of interviewing by listening to possible hints behind the events, and prompt responses were the key to obtaining rich information, which could not be planned in advance. The final stage was information processing. Each of the transcripts was rechecked to confirm its accuracy; also the categories and themes were checked by both supervisors and the study adviser to increase their degree of accuracy.

3.16. Concluding summary

The depth of the data from older people living in residential with low vision and diabetes, and the HCAs (including other health professionals) builds a comprehensive picture of how older people cope with low vision and diabetes in residential care homes. From the day when they were first diagnosed with diabetes, they began to feel like a changed person, and then self-identification of the need for change was realised. The person would then consider engaging in order to prevent themselves from further harm. Three themes were identified to illuminate this broad story of older people living with low vision and diabetes in residential care homes, which were 'life with low vision and diabetes', 'restructure life with low vision and diabetes', and 'helping hands'.

All the themes consisted of several categories that made up several sub-categories of data obtained from the transcripts of the focus groups and interviews. The first theme came before the second sequentially, indicating that

the journey of living with low vision and diabetes, including actual lifestyle changes, begins with the feeling of oneself as a changed person in terms of perceived vulnerability or threat. To fulfil their needs the themes 'life with low vision and diabetes', and 'restructure life with low vision and diabetes' identified the experiences and education while attempting to change their lifestyle.

The benefit of education and motivation depended on many factors, influenced by their personal experiences, beliefs, life goals, social roles, and living environments. Some influential factors appeared to be common in many participants, but some categories were unique in certain individuals, such as 'Emotional Feelings', 'Impact on Social relationships' and 'Physical Incapability'. Finally, the theme of 'helping hand' describes the interaction between the patients and the healthcare services offered, which is presented in Chapter 5 section 5.3 page 104.

To demonstrate how health care assistants help the patients develop concepts, knowledge and skills in low vision and diabetes, giving a deeper view from their experiences, the rationale behind low vision and diabetes is to elicit both the explicit and implicit meanings in order to unfold the conceptual framework of low vision and diabetes in older people living in residential care homes.

CHAPTER 4

QUESTIONNAIRE STUDY

4.1. Questionnaire study results, discussion and analysis of the data

This chapter discusses the findings and results of all questionnaires completed in this study investigating low vision and diabetes in older people living in residential care homes. The questionnaire was designed to canvas the opinions of a variety of healthcare professionals regarding the challenges of low vision and diabetes.

4.2. Aims of the questionnaire study

The questionnaire aimed to explore the key issues in managing low vision and diabetes in older people living in residential care homes. The questions were designed to ascertain health professionals' skills and abilities including their existing knowledge and their views about low vision and diabetes, and to identify the gaps and difficulties that are present in health professionals' practices in providing good care to older people with these conditions living in residential care homes.

4.3. Participant demographics of the questionnaire study

The questionnaire contained questions about the demographics and requested information on practice locations as well as the proportion of time spent working with older people. Additionally, the questionnaire for all the health professionals asked the respondents to report their individual disciplines. The demographic information of participants was collected for reference, to identify trends within

certain healthcare professionals. Brief descriptions of the demographics are given below:

Groups	Number of Participants	Gender	Participants Age	Ethnicity
Group 1.1 GPs	15 Participants	Female 7	4 aged 29-39, 9 aged 40-50, 2 aged 51-61	White 5
		Male 8		Black Caribbean 2
				Pakistani 3
				Indian 5
Group 1.2 Nurses	15 Participants	Female 13	11 aged 29-39, 4 aged 40-50	White 4
		Male 2		Black Caribbean 5
				Pakistani 1
				Indian 2
				Other Asian 3
Group 2.1 Ophthalmologists	15 Participants	Female 9	5 aged 29-39, 6 aged 40-50, 4 aged 51-61	White 4
		Male 6		Black Caribbean 3
				Pakistani 1
				Indian 1
				Other Asian 6
Group 2.2 Optometrists	15 Participants	Female 8	7 aged 29-39, 6 aged 40-50, 2 aged 51-61	White 3
		Male 7		Black Caribbean 5
				Pakistani 2
				Indian 2
				Other Asian 3
Group 3 HCAs	30 Participants	Female 26	22 aged 20-30 8 aged 31-40	White 18
		Male 4		Black Caribbean 4
				Indian 2
				Other Asian 6

Table 5 Participant demographics of the questionnaire surveys study

Information about the participant's place of work and time spent working with older people is shown in Figures 7 and 8 on page 85-86, also see Table 3, for the criteria of sampling for Phase 1, page 60. Figure 7 shows that 40% of the participants worked in a hospital, compared to 35% who worked in a residential care home and 25% who worked in the community. Overall, the aim of this study was to address issues with low vision and diabetes in residential care homes.

However, due to the difficulty in recruiting participants, the residential care homes sector was not the major contribution to this study. Despite the majority of participants working in hospitals, Figure 8 demonstrates that the healthcare assistants (HCAs) spent large amount of their time with older people in residential care homes, compared to the other groups.

This was to be expected as most of the HCAs worked in a residential care home environment. Furthermore, the optometrists were found to spend the second largest amount of time with older patients, and finally the nurses were found to spend the least amount of time with older patients. This suggests that although the optometrists were in contact with older people, there was a need to determine if this was through community eye care or eye care services offered to residential care homes.

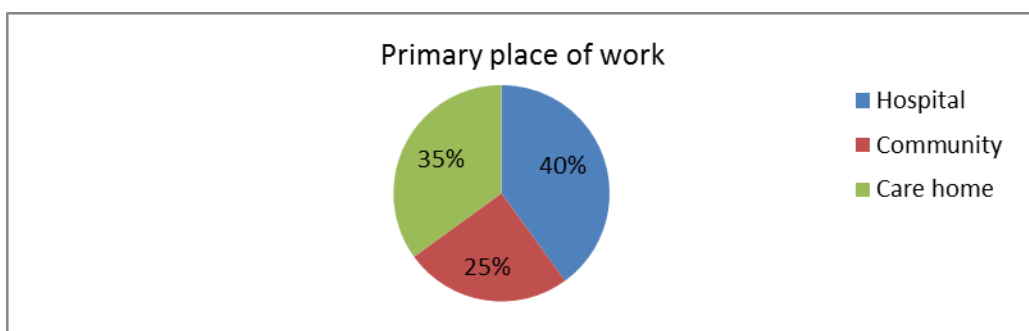


Figure 7 The proportion of participants working in hospitals, the community or in residential care homes

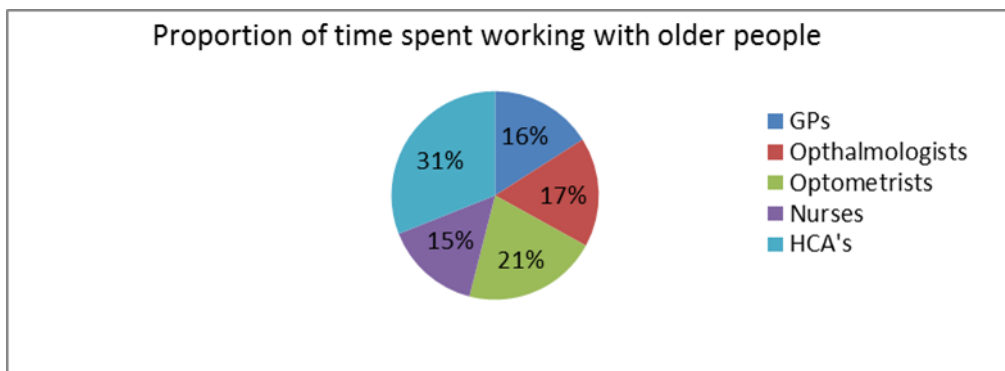


Figure 8 The percentage of time working with older people amongst the different healthcare professionals questioned

4.4. Questionnaire Results

The questionnaire was designed for all health professionals on multiple aspects of low vision and diabetes in older people. A brief summary of the findings from the questionnaire study, pointed toward a general consensus around the content and challenges of low vision and diabetes in residential care homes, with respondents in accord concerning the importance of various related tasks. These included all health professionals' knowledge and understanding of the impact of low vision and diabetes in older people living in residential care homes, to understanding the factors involved in low vision and diabetes, including dietary management, medication management, blood glucose management, and regular eye checks. The subsequent section will discuss the responses of the participants for the health professional's survey. The results were split into three groups: responses from GPs and nurses, responses from HCAs and responses from ophthalmologists and optometrists to determine the differences in thought between professionals trained in eye health to professionals trained in other areas.

4.5. Barriers to providing effective care for older people with low vision and diabetes living in residential care homes

Participants were requested to give their views on the perceived barriers to the management of low vision and diabetes in older people. The main trend in response to the question was similar amongst the three groups; however, the GPs and nurses rated communication difficulties as a result of cognitive impairment as the biggest barrier to management, whereas the ophthalmologists, optometrists and HCAs rated lack of training of HCAs in low vision and diabetes to be the greatest barrier (see Figure 9). The ophthalmologists and optometrists rated communication difficulties as the second biggest barrier, although the difference in responses was relatively small.

This finding suggests that professionals trained in eye health can work on the communication issues, but instead face problems with HCAs and other health care staff who do not recognise the symptoms of vision loss and diabetes.

There was a general consensus towards the term 'older people with low vision and diabetes' by over 95% of the health professional's respondents who said that the important barriers to effective management and providing good care in older people with low vision and diabetes was insufficient training being available for the health care assistants in residential care homes.

Adverse reactions associated with multiple medications were considered to be the smallest barrier against the management of vision loss and diabetes, with only 5% of the total participants viewing this as a problem. This is most likely to be due to the fact that complications with medication can be considered after diagnosis, and the important factor is the actual diagnosis and management.

Lack of available resources and the presence of staff with negative attitudes towards older people were seen respectively to be the third and fourth biggest barriers to management. The presence of staff with a negative attitude towards older people can have a detrimental effect on the diagnosis and wellbeing of

older people. No participants reported any other barriers in the management of vision loss and diabetes.

There are very few studies in the literature (Abdelhafiz and Sinclair, 2009; Lorig et al., 2009; Dhital et al., 2010; Sinclair, 2014) which have investigated the barriers that healthcare professionals face in the management of vision loss. The biggest barrier that has been reported in a worldwide study was the stigma attached to vision loss and the lack of professionals trained in vision loss (Chiang et al., 2011).

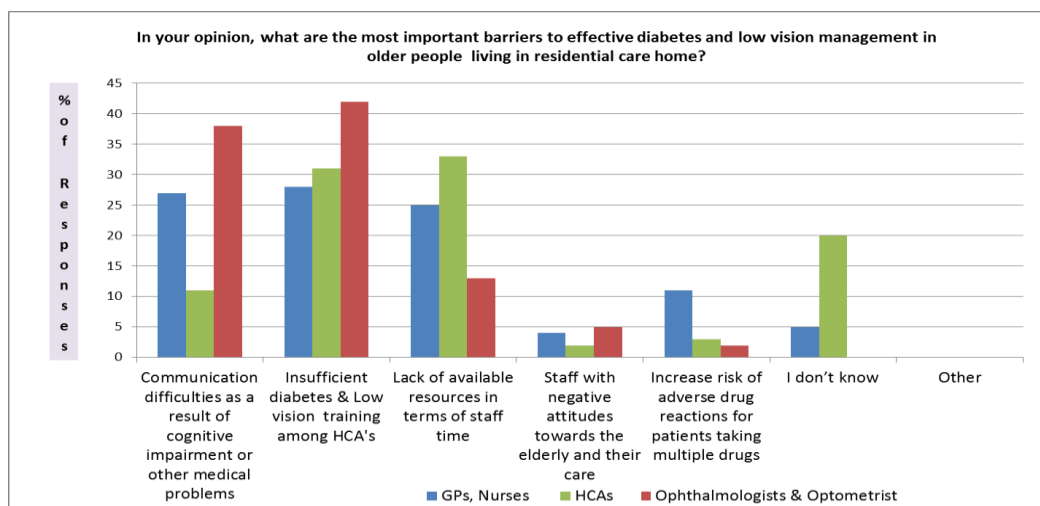


Figure 9 Participant responses to barriers in effective diabetes and low vision management in older people living in residential care homes.

4.6. Common types of vision loss experienced by people with diabetes

The second question on the health professional's survey was based on the experiences of the professionals and concerned the common types of low vision that people with diabetes experience (see Figure 10). All the professionals agreed that diabetic retinopathy was the most common type of low vision in diabetes. This is in agreement with other researchers (Scanlon, 2008; RNIB, 2013) who found the same outcomes during their research. Yau estimated that 93

million people are suffering from diabetic retinopathy worldwide (Yau et al., 2012). All the professionals agreed that proliferative retinopathy was the second most common cause of low vision in diabetes. Proliferative retinopathy is characterised by a lack of blood reaching the eye which leads to the growth of abnormal blood vessels (UK Vision Strategy, 2015; RNIB, 2015 a). Approximately 25% of the GPs and nurses believed that proliferative retinopathy was a major problem, whereas approximately 20% of the ophthalmologists and optometrists believed it to be a major problem, 38% of the HCAs were not sure due to their lack of knowledge of eye health. This again is in agreement with other published trends where it was found that 17 million people suffer from proliferative retinopathy worldwide (Yau et al., 2012; McManus and Lord, 2012; Macular Society, 2015).

There were differences in the order of vision loss conditions after this point between the three different groups. The GPs, nurses and HCAs perceived general, moderate and severe vision loss to be the third most common types of vision loss, whereas the ophthalmologists and optometrists believed that macular oedema was the third most common type of vision loss. According to other researchers (Minassian et al., 2012; Liew et al., 2014), 7.12% of the population with diabetes are believed to have macular oedema in either one or both eyes. One third of these individuals are estimated to have clinically macular oedema which leads to a visual acuity of less than 6/6 in at least one eye (Minassian et al., 2012). Although there was a difference between the results, for this particular question, the response of the ophthalmologists and optometrists can be considered to be the most accurate as they deal with such cases on a daily basis and are experts in the field of eye disease; whereas GPs, nurses and HCAs do not have the same level of specialisation. The aim of this question for the GPs, nurses and HCAs, however, was to establish their knowledge about low vision and diabetes as they also work with older people living in residential care homes.

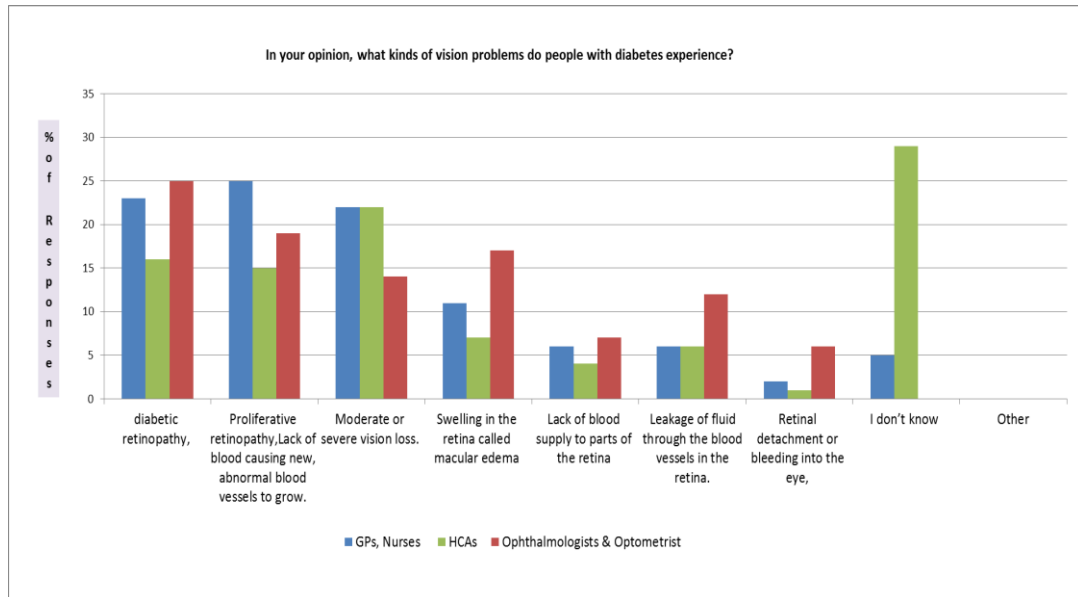


Figure 10 Participant responses to the types of vision problems those individuals with diabetes experience

4.7. The specific needs of older people compared to younger people

The GPs, nurses and HCAs, including the ophthalmologists and optometrists, were asked about their perception of the differences in the needs between older people and younger people (see Figure 11). Surprisingly, 20% of the GPs, nurses and 25% of the HCAs were not sure of the specific differences between the two age groups, and therefore answered 'don't know'. This is a high percentage of participants considering that a large proportion of them work with older people in their daily lives. This suggests that specific training should be given to people working with older people to ensure that healthcare professionals understand their specific needs. In recent years there have been some negative attitudes towards older individuals (Gluth et al., 2010; North and Fiske , 2015). These attitudes can have a negative impact on the health of older people, and therefore there is a need to make sure those healthcare professionals, particularly the HCAs who are generally lower paid, are vetted to ensure they are suitable for the job, with good attitudes and training.

There is a general consensus in the literature that training should be provided to new personnel to prevent such attitudes (Gallagher et al., 2006.; Department of Health, 2006; Department of Health, 2010 a; Hibbard and Lorig, 2012).

Some professionals were aware of the specific needs of older patients; over 20% of the participants agreed that older people required more overall help in order to carry out daily tasks. This was generally seen as the most common difference between older and younger individuals, similar to the barriers to the management of vision loss and diabetes.

Communication was seen to be the second biggest difference between older and younger people. This is only to be expected as many older individuals may have a hearing impairment, visual impairment or other cognitive impairment that could prevent effective communication. Similarly, only 32% of the participants varied their approach to diabetes and low vision management in older patients compared to younger patients. It is likely that older people need more information and require more help with mobility; however, some professionals may not be aware of these requirements and therefore patient care may suffer. In contrast, 100% of the ophthalmologists and optometrists changed their approach to older people compared to younger people. This suggested that these professionals were more aware of their needs and had a greater understanding of how vision loss can affect individuals, as would be expected.

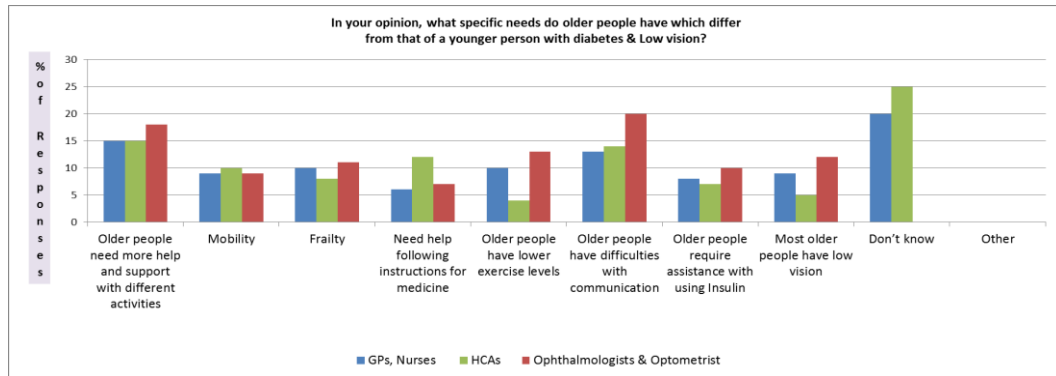


Figure 11 Participant responses to the specific needs of older people compared to younger people

4.8. Key aims in the treatment of older people with diabetes and low vision

Approximately 45% of the participants surveyed stated that meeting glucose targets was one of the key aims in the management of diabetes and low vision (Figure 12). This was an important result as it showed that most of the healthcare professionals understood the importance of glucose regulation and its implications with diabetes. The regulation of blood glucose levels is considered to be one of the most important factors in the control of diabetes and therefore should always be highlighted as an important factor in diabetes care and management (American Diabetes Association, 2008; National Diabetes Audit, 2011; NICE, 2015).

The second most important aim was found to be a timely referral to a hospital specialist when required. This again is an important aim in the management of low vision and diabetes. This, however, is not always possible, especially when symptoms are not detected, leading to deterioration in conditions. Interestingly, suitable diet patterns and good vision was considered to be the third least important aim of diabetes care and management. This result highlights the lack of importance given to low vision and diabetes in older people, but according to the research, low vision can have a huge effect on the wellbeing of individuals, as

a loss of vision can lead to problems with falls etc. (Dhital et al., 2010; Age UK, 2010; Tian et al., 2013). The responses from the participants also suggested that over 20% of the participants felt that low vision could lead to an increase in the prevalence of falls, episodes of hypoglycaemia and episodes of hyperglycaemia.

One of the main aims of this study was to identify the thoughts of healthcare professionals, particularly on vision loss and diabetes. From the findings of this study surveying the GPs, nurses and HCAs, it was clear that the least importance was given to vision loss, and therefore it is likely that the symptoms of vision loss are not actively reported and eye tests are not regularly carried out. This may be due to nurses and HCAs not being aware of the significance of vision loss and diabetes, and some HCAs may not even be aware that diabetes can lead to low vision.

The neglect of low vision in people with diabetes can increase the burden of low vision in society. Many of these low vision cases may be reversible, and therefore residents may be suffering for no real reason, which of course will lead to a lower quality of life. There is an urgent need to address these problems, to ensure that HCAs in particular recognise the symptoms of vision loss.

In contrast to the GPs, nurses and HCAs, the ophthalmologists and optometrists had very different aims in the treatment of people with diabetes and low vision (Figure 12). The ophthalmologists and optometrists were more focused on maintaining a good quality of life and ensuring the patients were comfortable. There was less emphasis on referrals, which was surprising; however, this could be as they believe that this should be done in all cases. Good vision and maintaining a good diet was considered to be the third most important aim. It could be expected that this would be the highest aim amongst the group; however, the results could be due to some deterioration that would naturally take place.

Vision loss is also at some point linked to the ability of individuals with diabetes being able to use insulin pumps (Figure 13). Half of all the participants agreed that insulin pumps were not well designed for visually impaired individuals. The GPs, nurses and HCAs thought that the pumps were not well designed for visually impaired patients, and 75% of the participants believed that talking devices would be a major advantage in their ease of use. Furthermore, people with a visual impairment have difficulty with manual dexterity, have problems setting the dose and often require more force to inject insulin (Figure 13). The incorrect administration of insulin can lead to ineffective management of diabetes and further complications, which can be prevented by detecting vision loss earlier, and treating it where possible. In contrast, the ophthalmologists and optometrists highlighted the visual items that cause problems, such as the dose measurements and the size of the unit numbers. These physical points may not be able to be seen by visually impaired individuals and therefore could lead to incorrect administration. The result also showed that up to 19% of the HCAs were not sure about the limitations of older people using an insulin pen.

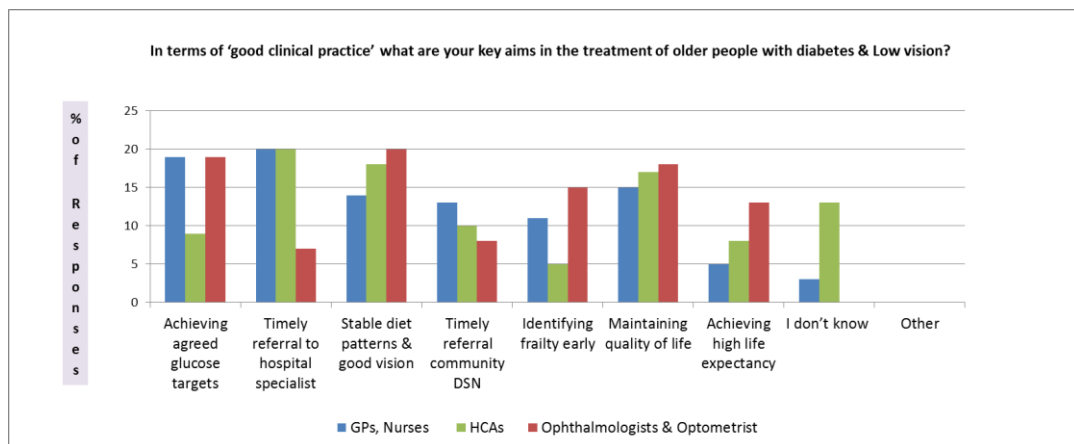


Figure 12 Participant responses to the key aims in the treatment of older people with diabetes and low vision

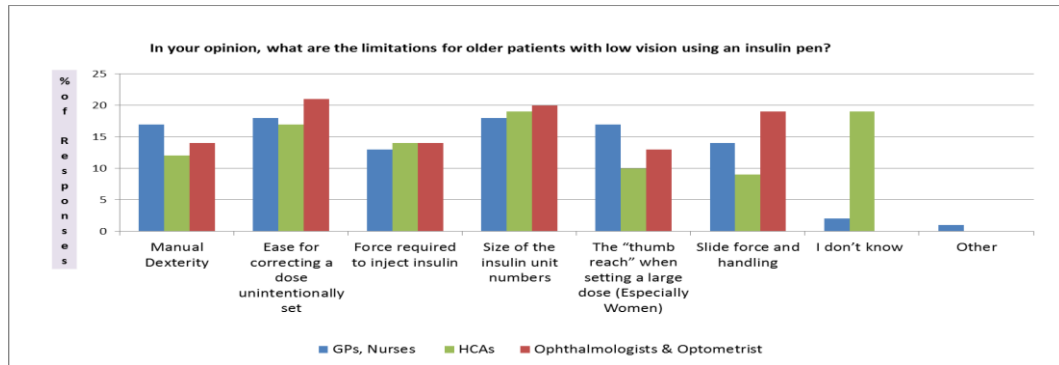


Figure 13 Participant responses to the limitations of older people using an insulin pen

4.9. Family members from the older people's and the HCAs' perspective

It has been long believed (Walsh , 2004; Watson and Bamford, 2012) that family and HCAs can have an important impact on the care of older individuals (Sinclair, 2014).

The participants were asked about their perspective on the help offered by their family and the HCAs and there was a general consensus that involving family in care plans can help improve to stabilise the health of older people with low vision and diabetes. Over 50% of the participants stated that individual care plans should be given to family or HCAs, and 25% felt that the family should be involved in the decision-making process. Furthermore, participants were asked what could be done to motivate families and HCAs in becoming involved in the care of individuals (Figure 14).

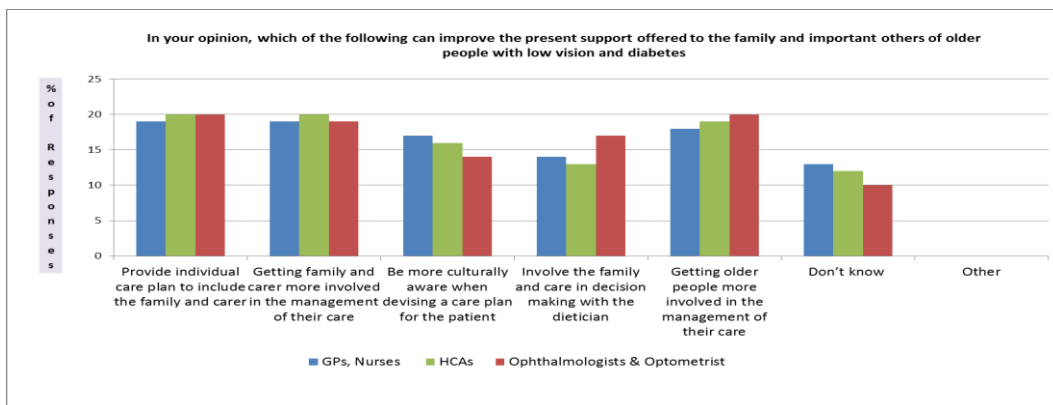


Figure 14 Participant responses regarding the care plans of older people with low vision and diabetes

The results from the questionnaire found that 32% of the participants, GPs, nurses and HCAs believed that families should be provided with education, shown evidence of the advantages of family involvement, and be acknowledged for their input and the provision of financial support, whereas only 20% of the ophthalmologists and optometrists said that all these measures are required. Large number of the participants believed that education was the greatest motivator, followed by showing families evidence of how involvement can help, followed by financial support (Figure 15).

It is believed that these measures could motivate the family to be involved in care. However, there is the risk of some families taking advantage of financial incentives and not providing the help required (Sinclair, 2014; Age UK, 2015). Overall, it was found that education was most likely to improve family involvement. Generally, people were aware of the health implications of diabetes in terms of vision loss. Again, many families may not be aware of the significance of vision loss or may not be able to recognise the symptoms (BBCouncil, 2014; Mohammed, 2014). It is believed that 38% of the family members do not understand the management of vision loss and diabetes and

therefore education could help this group (Abdelhafiz and Sinclair, 2009; Hibbard and Lorig, 2012; Sinclair, 2014).

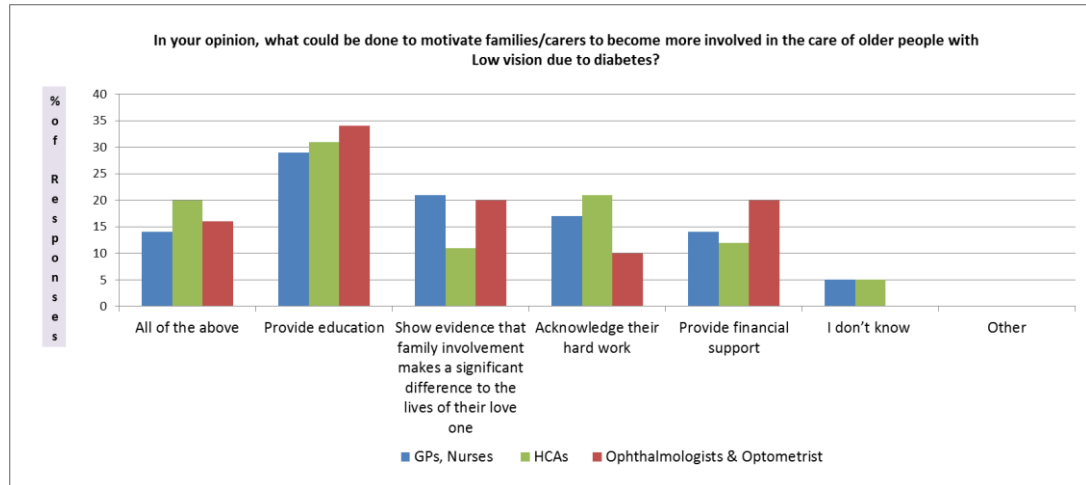


Figure 15 Participant responses to the factors that could motivate families in being involved in the care of older people

4.10. Importance of education for older people with low vision and diabetes

Although healthcare professionals believe that education is important in managing diabetes and low vision, there is also a consensus that some older people may not be keen to receive such education. Approximately 70% of the participants believed that only some or very few individuals would want to be educated about their condition. This may be due to the fact that in residential care homes the responsibility of care was transferred from the older people to the residential care homes, and therefore the individuals may feel that they have little control over their condition. In contrast, 60% of the ophthalmologists and optometrists felt that most people would like education on eye health. It is difficult to distinguish whether this is bias in the sample, or if these professionals have had conversations with patients which led them to this viewpoint.

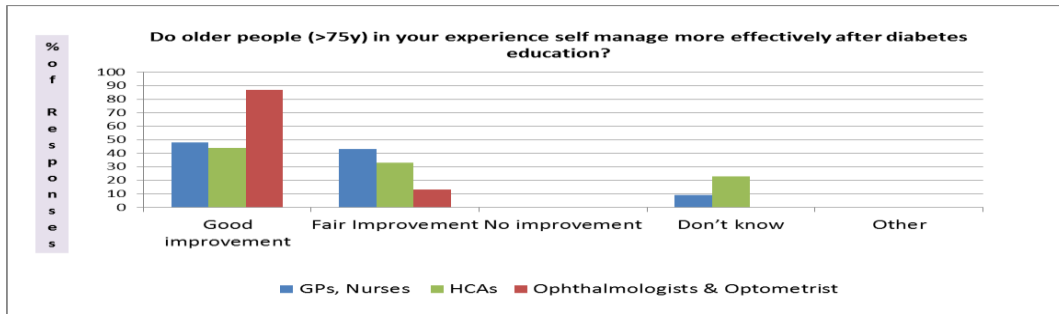


Figure 16 Participant responses to 'Do older people (>75y) in your experience self-manage more effectively after diabetes education?'

Before educating patients, there is a real need to educate healthcare professionals on low vision and diabetes. The results from the survey indicate that 82% of the participants had not undertaken any training in the area, and of those who had had training, only one participant had had the training in the last 12 months (Figure 17). Also, not all the ophthalmologists and optometrists had received training in the area of low vision and diabetes. The survey found that only 10% of the participants had received specialist training within the last five years. The result of this is somewhat surprising, as all the ophthalmologists and optometrists were taught about diabetes in their degree course. It may be that some participants had forgotten about the training that they had received or may have found it inadequate.

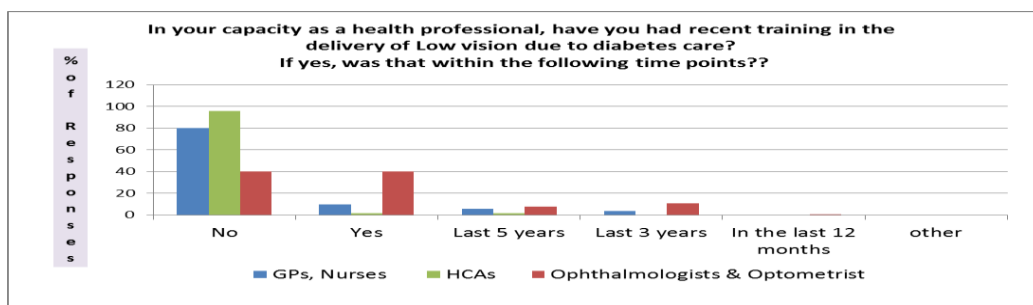


Figure 17 Participants who have received training in the area of low vision and diabetes

Education has been found to lead to an improvement in the self-management of diabetes and low vision. After education, any improvement in taking ownership of their condition can be seen as a positive, and therefore encouragement is needed to ensure that the ownership is carried through (Hibbard and Lorig, 2012).

Education is likely to make patients aware of changes that they may be experiencing and consequently they can consult with healthcare professionals on the onset of symptoms. The ophthalmologists and optometrists perceived patients to make an important improvement compared to the GPs, nurses and HCAs. This could be misleading, as the optometrists are likely to spend less time with patients on a daily basis compared to nurses, and HCAs are not necessarily involved in the care plan development, which was confirmed by only 50% of the optometrists managing or delivering care to older people with low vision and diabetes (see Figure 16).

4.11. Care plans for older people with low vision and diabetes

As previously mentioned, many older people with low vision and diabetes living in residential care homes are not diagnosed with the condition as it is not detected. Unless the vision loss is detected, the care plan is unlikely to be updated, and therefore visually impaired patients are likely to be treated the same as non-visually impaired patients. The study has indicated that 45% of the healthcare professionals are unaware of individualised care plans for these individuals, and overall less than 16% of older people living in residential care homes with low vision and diabetes were given an individual care plan (Figure 18).

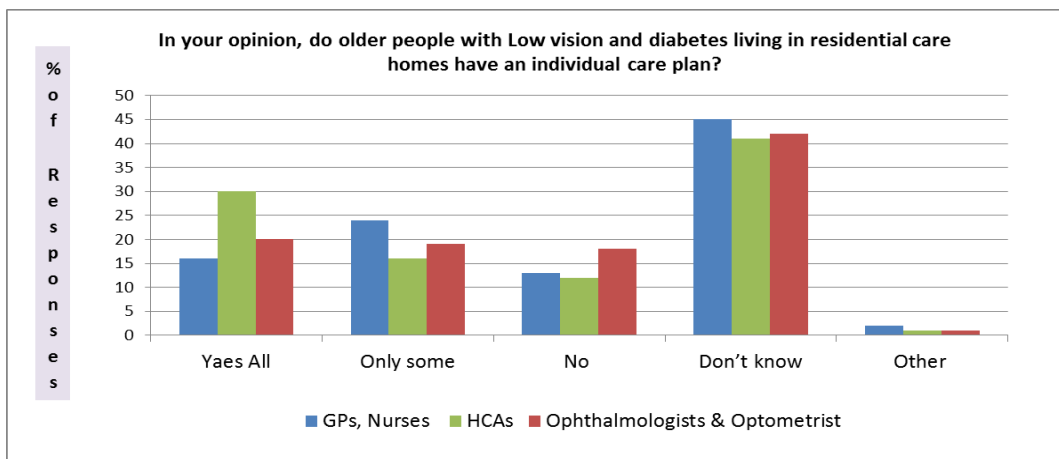


Figure 18 The number of older people with low vision and diabetes that have an individual care plan

Although health care professionals understand the complications associated with diabetes, some do not understand the complications of low vision associated with diabetes, which can lead to problems. When participants were asked about the advice they would give to individuals with diabetes on eye health, 38% of the participants reported that regular eye checks were important and 16% thought that education of staff was important (Figure 19).

In the residential care home environment, some older people do not have access to eye health specialists due to undetected low vision (Gallichan, 2012; National Eye Institute, 2015). Therefore, there is a need to educate HCAs on the importance of regular eye checks and the detection of vision loss symptoms. The care home should arrange such appointments with eye health specialists for the residents. This is a view shared by the ophthalmologists and optometrists, as they stated that the education of HCAs was the greatest advice they could give in order to manage low vision and diabetes. Furthermore, up to 25% of the eye health professionals believed that regular check-ups were important, and 30% thought that the education of staff was important. It can therefore be suggested that the ophthalmologists and optometrists believe that HCAs or other

professionals should be able to detect vision loss, and if not already educated on the subject, should be trained adequately.

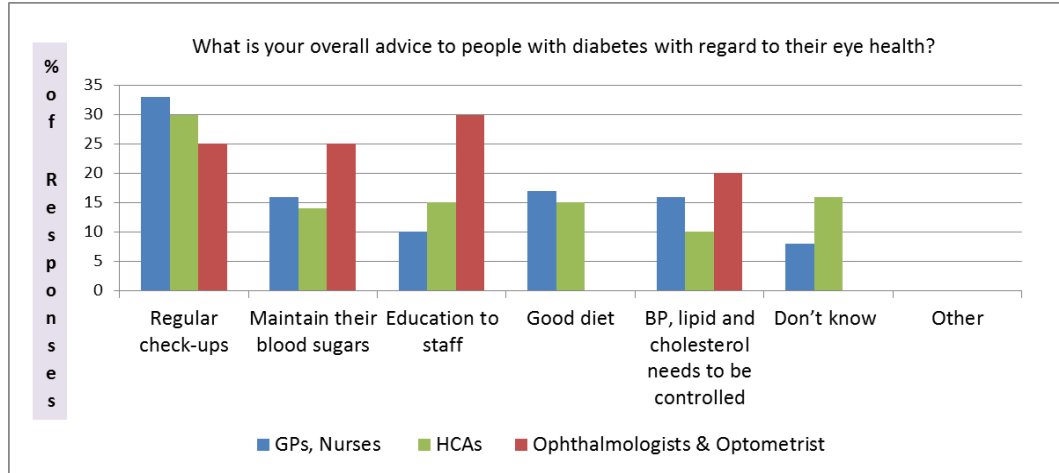


Figure 19 The advice given by participants to people with low vision and diabetes with regard to their eye health

4.12. Costs associated with glasses for older people

One of the biggest concerns that older people have with having an eye test is the expense associated with the cost of buying their glasses. Interestingly, many health care professionals, including ophthalmologists and optometrists, have similar concerns. Large number of the participants believed that cheap glasses were a concern as they lacked quality, whereas some of the good quality glasses were too expensive, particularly for the elderly (Figure 20).

Therefore, the barrier to getting new glasses appears to be cost. However, the ophthalmologist and optometrists did state that the glasses were only changed where necessary and sometimes it was only necessary to change the lens (Bosanquet and Mehta, 2008). In order to remove this barrier, there may be a need to introduce further subsidies for older individuals for the purchase of glasses. Failure to change the glasses can lead to deterioration in sight and other further complications which could be a financial burden to the NHS.

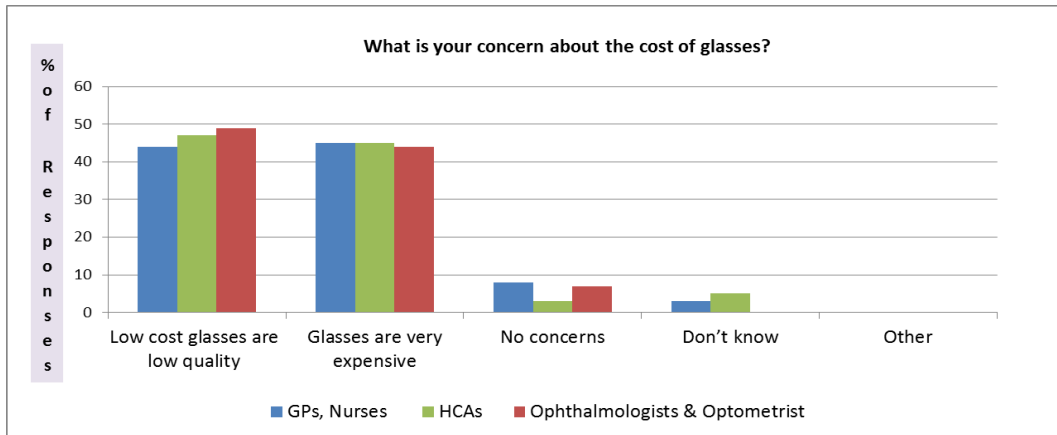


Figure 20 The major concerns of health care professionals about the cost of glasses

4.13. Summary of questionnaire survey results

The results show a clear difference between the thoughts of the GPs, nurses and HCAs compared to the thoughts of the ophthalmologists and optometrists. Generally, it has been found that the GPs, nurses and HCAs were more focussed on the ease of treating individuals with low vision and diabetes, whereas the ophthalmologists and optometrists were more concerned with how the quality of care and the life of patients could be improved. There was a clear feeling from the results that the treatment of diabetes was given importance in the residential care homes; however less emphasis was placed on the complications of diabetes, such as vision loss. It is suggested that health care assistants in particular need to be trained on the importance of vision loss and the consequences of vision loss. It is likely that many of the HCAs are not aware that vision loss can be reversed, and therefore they ignore such symptoms. Educating the HCAs could improve the chances of preventing low vision associated with diabetes.

Some health professionals believed that educating patients was more important than educating the HCAs. However, before educating patients, there is a real

need to educate healthcare assistants on low vision and diabetes, for more detail please see chapter 2 section 2.8 page 47. The results from the survey indicate that 82% of the participants had not had any training in the low vision and diabetes area, and of those who had received training, only one participant had undergone training in the last 12 months. This lack of training is likely to be having a negative impact on the care of individuals with diabetes. In the literature review for this study, it was found that some older people were concerned with the cost of glasses and eye tests. The results from the current study suggest that the optometrists also had concerns about the cost of good quality glasses. They were equally worried about older people wearing poor quality glasses which could have a negative impact on their sight.

4.14. Strengths and limitations of the questionnaire survey

It should be noted that the response to the questionnaire was relatively low, with 13 respondents completing the questionnaire, including 3 respondents who declined to answer all the questions from the HCAs questionnaire. However, the findings were similar to those drawn from the literature, enabling the results to be taken forward as part of the exploration of low vision and diabetes in residential care homes which aimed to inform the content of the development of the education toolkit. The inclusion of a blank comments field strengthened the study, as in the questionnaire for the ophthalmologists and optometrists there were few comments identifying any gaps in the content or focus on the questionnaire, thus demonstrating the appropriate fit of the items presented. Where comments were made relating to possible gaps in either questionnaire, these tended to be towards the influence of socioeconomic and psychological factors in low vision and diabetes. This emphasis fits neatly within the social cognitive overall theoretical framework of the research, and is an aspect that can be taken forward for the educational toolkit.

CHAPTER 5

FOCUS GROUPS AND INTERVIEW STUDY

5.1. Introduction

The results of the focus groups and interviews are presented in this chapter, with full details of the codes, themes, categories and sub-categories that were generated from the transcription of the audio recorded data rather than approaching the transcript with a set of pre-existing codes. This meant that themes emerged from the content of the discussion, more accurately reflecting the views of the participants rather than applying pre-existing themes that would have reflected the bias of the researcher (Boutellier et al., 2013).

Findings from the focus groups and interview data are analysed in order to understand the background of low vision associated with diabetes in older people living in residential care homes, from the perspective of the participants.

5.2. Demographic information of the participants

No	Number of Participants	Gender	Age	Ethnicity
Focus groups	Optometrists focus group 6 Participants, qualified and registered with the Royal College of Optometrists	Female 3	4 Participants aged 29-39, 2 Participants aged 40-50	White 3
				Black Caribbean 1
		Male 3		Indian 1
				Other Asian 1
Focus groups	Older people's focus group 6 Participants, living in community with low	Female 1	All Participants aged 75+	White 1
				Pakistani 2
				Indian 2

	vision and diabetes	Male 5		Bangladeshi 1
In-depth interviews	HCA's interviews 6 Participants, with minimum qualification of NVQ 2 or QCF 2 and 2 years' experience in health care	Female 5	4 Participants aged 20-30, 2 Participants aged 31-40	White 3
		Male 1		Black Caribbean 1
				Indian 1
	Older people's interviews 8 Participants, living in residential care homes with low vision and diabetes	Female 6	All Participants aged 75+	Other Asian 1
				Male 2
				Black Caribbean 1

Table 6 Demographic information of the participants for focus groups and interviews

5.3. The themes, categories and sub-categories

The full details of the themes, categories and sub-categories of both focus groups and all interviews in this chapter are divided into three sections.

Section 1, Theme One covers life with low vision and diabetes; Section 2, Theme Two covers restructuring life with low vision and diabetes; and Section 3, Theme Three, covers 'helping hand', the health professionals (specifically health care assistants). Each section is divided into categories and sub-categories and each of the sub-categories will be discussed in turn along with its consequences.

5.3.1. Section 1, Theme One: Life with low vision and diabetes, a lifelong illness

Introduction: Covering the background from day one, this section focuses on older people's feelings and experiences when they were first diagnosed with low vision and diabetes, to understand their feelings and experiences from the first

day when they were diagnosed with low vision and diabetes. For the most part, the event of being diagnosed with diabetes seemed to be foretell a gloomy future ahead, and this perception brought much distress and discomfort to them. When they were told they had diabetes, they had to face the fact that they would have to take medication and change their lifestyle for the rest of their lives. Being aware of this, their lives could no longer be the same as they used to be, and as a result they were more or less changed people living with a lifelong illness.

The data from the focus group with the older community residents was analysed, including interviews with older people living in a residential care home with low vision and diabetes. The theme of 'life with low vision and diabetes, a lifelong illness' was identified as the abstraction from three categories. Each category consisted of several sub-categories; details are presented in the table below.

Themes, Categories and Subcategories, Part 1

Themes	Category	Subcategory
Life with low vision and diabetes, 'A lifelong illness'	Meaning of having low vision and diabetes	<ul style="list-style-type: none"> ● Fear of low vision and diabetes; ● Communication difficulties with health professionals; ● Burden to society; ● Feelings of the person with diabetes and being a burden to their families; ● Emotional feelings; ● Health profession's attitudes.
	Stigma attached to diabetes and a hope of good health	<ul style="list-style-type: none"> ● Searching for hope of good health; ● Help from health care professionals; ● Unrealistic comments and vulnerability of person with diabetes; ● Finances: the impact of low vision and diabetes on the cost of living; ● Impact on social relationships.

	Education	<ul style="list-style-type: none"> • Essential learning; • Experiential learning; • Support from physician, family and friends; • Awareness of low vision and diabetes.
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Table 7 Themes, Categories and Subcategories, Part 1

The theme of ‘life with low vision and diabetes, a lifelong illness’ was extracted from three categories. First of all, ‘the meaning of having low vision and diabetes’ illuminated the participants’ responses to the event of diagnosis; their emotional responses ranged from emotional distress to a slightly psychological effect. The way that the older people that were interviewed reacted to their changing health status seemed to depend on their background experiences and knowledge of low vision and diabetes. Most individuals that were interviewed who showed emotional distress at the very beginning were shocked by the social stigma attached to low vision and diabetes (Watson and Bamford, 2012). The second category was then identified as ‘a hope of good health’, demonstrating how the participants sought health care advice. Most of them had showed unrealistic expectations by trying to find a cure for diabetes after being told the disease was incurable. Their desire to be cured made them grasp at any opportunity that suggested a cure was possible or could improve the condition. The final category was regarding the participants’ ‘education’, which was essential to prepare them for managing their diabetes as independently as possible in the real world. The first step was essential learning, to build up a body of knowledge about how to cope with low vision and diabetes. Most of them learned from healthcare providers, but other resources such as media, books, or the experiences of other lay-persons, were equally important. After being equipped with specific knowledge and skills, they were able to practice them in the real world, and many of them started to examine what would suit them best through the awareness of the relationship between their physical responses and their day-to-day activities. This process is identified as experiential learning

(Balls, 2009; Boutellier et al., 2013), and this stage can be sustained through the rest of their lives. Depending on their learning process, the performance of the participants varied in many ways. While some had developed very good knowledge and education about low vision and diabetes, and could cope with their problems, some were still on the way to achieving that status or they probably never would, due to lack of education and awareness. Each of these categories was discussed in turn along with their associated sub-categories, to bring vivid lives to these vulnerable people (Holman and Lorig, 2004; Sinclair, 2010).

5.3.1.1. The category 'The meaning of having low vision and diabetes'

The responses to their actual diagnosis somehow reflected their perspectives of diabetes from the onset. This played a crucial role in the initial decision-making of health-seeking behaviours (Lorig et al., 2009; Watson and Bamford, 2012). The older people who did not respond seriously to the diagnosis because of inadequate knowledge would eventually be psychologically affected, as having diabetes is not a very pleasant thing, especially accompanied by low vision (Heisler et al., 2005; Keeffe et al., 2005; Mommersteeg et al., 2013). However, they may still get the chance to learn gradually from either formal or informal education.

The category 'The meaning of having low vision and diabetes' is divided into six sub-categories:

5.3.1.1.1. Fear of low vision and diabetes

5.3.1.1.2. Communication difficulties with health professionals

5.3.1.1.3. Burden to society

5.3.1.1.4. Feelings of the person with diabetes and being a burden to their families

5.3.1.1.5. Emotional feelings

5.3.1.1.6. Health profession's attitudes.

5.3.1.1.1. Fear of low vision and diabetes

The three following quotations are representative of the impact experienced by the participants when first diagnosed:

"To hear that [having diabetes], obviously when you first hear about it, it sends pressure. Wondering what is going to be happen it can damage a lot of things eyes, kidney, and your heart. (Or) foot amputation to amputate whatever part" (of the body)"

(Interviewee Three: Focus group for older people)

"After hearing that, [I was] almost scared to death. What a terrible disease it was! I went for my test and it showed that I am diabetic, about 5 years ago. My doctor rang me and said 'you're diabetic, come and see me!' He told me it was a question of life and death. Now the way he spoke to me was like frightening, an ordinary person would be absolutely frightened by life and death."

(Interviewee One: Focus group for older people)

"I was very really worried and depressed about my low vision and diabetes."

(Interviewee Two: Focus group for older people)

The event of having diabetes, among many participants, meant something awful to them. Diabetes had been perceived as quite negative, thus from their

viewpoint having diabetes denoted a gloomy future ahead. The stress from its bad name resulted in most participants being quite reluctant to divulge the disease to the people around them (Hibbard and Lorig, 2012). This is not an exclusive phenomenon in the UK; it also happens in the Appalachia region of West Virginia in the United States (Tessaro et al., 2005). People under stress related to low vision and diabetes experienced difficulties trying to live normally.

One of the participants expressed the process of her experiences:

“I was very really worried and depressed about my low vision and diabetes, I had my eyes tested every year for the retinopathy and when I had it tested not last year, the year before, they showed a slight change in the retinopathy in the eye here. I went home from that quite upset thinking I’m going to go blind, all these things were going through in my head.”

(Interviewee Two: Focus group for older people)

The impact of the meaning of diabetes: ‘fear of low vision and diabetes’ seems to be quite remarkable; it can become the reason for absence from diabetes education classes. Two participants showed their concern:

“I really think sometimes I don’t want to know about my diabetes any more, as the more I know about diabetes it makes feel frightening, this is the reason I don’t go to the diabetes educator”.

(Interviewee Three: Focus group for older people)

“They offered to me a course; it was about information, meant to be about the diet and that sort of thing. And when I went to go and speak to a diabetes nurse they said to me, that she’d put me on this course. I can’t remember the name but it was about 6 months I hadn’t heard anything and mentioned it to my GP. And she said she’d let them know and when I did speak with the diabetes educator they said they’d get on top of that, then a year went by. Nothing. So then I

came with concerns trying to talk about diets, they told me I pretty much know from my own research, because I search online and they said I don't need the course. So I feel, again lost in the system, but also I don't want to expose my own problems [having diabetes] to some people including some of my family members as frightening".

(Interviewee Two: Focus group for older people)

As a result, the limited resources available may have affected their learning processes and they behaved timidly, thus leading to a lack of social support, which caused a negative impact on their lives. The information they needed was unable to be fulfilled at the start, from diagnosis, or even afterwards; it can only be expected that they were stressed. The following excerpt shows the 'person with diabetes' had concerns that may be beyond our understanding:

"Sometimes I am thinking just don't want to tell anyone about my diabetes."

(Interviewee Six: Focus group for older people)

Many negative perspectives from society seem to indicate that diabetes bears a bad name, and the fact of having diabetes alone can be stressful enough to disturb the patients' lives (Aikens et al., 2005; Sinclair, 2014). Accordingly, concealing the condition from the public seemed to allow the patients to live with less stress until the disease becomes more acceptable to society. Apart from the fear of diabetes, the fear of disclosing the disease to the public might be another reason to discourage the patients from doing so. Having diabetes itself could cause some symptoms, especially poor control, and it cast a negative image in many older people (Ritter et al., 2011); thus, many of them felt devalued in society. Facing this situation, patients could do nothing but be angry and hope that the public health education could save them from feeling inferior to others (Martin et al., 2005)

5.3.1.1.2. Communication difficulties with health professionals

The communication between the health professionals and the person with diabetes is very important; it is the key factor to collecting the information needed before making suggestions or imparting information to encourage them to engage in low vision and diabetes care. From the perspective of the person with diabetes, each question raised indicated that an unsolved problem had been bothering the person with diabetes for some while, and he or she needed someone to help them solve the problem (Iliffe et al., 2009). This indicated that any question that might be seen as trivial can still be very important.

The following quoted extract illuminates these thoughts:

“I had my eyes tested every year for the retinopathy and when I had it tested not last year, the year before, they showed a slight change in the retinopathy in the eye. I went home from that quite upset (laughs) thinking I’m going to go blind; all these things were going through my head and I thought I’m going to make an appointment to see my doctor. I made an appointment to speak with her about it, all she confirmed was that it was in this eye (right eye), slight changes and basically saying ‘this is a progressive disease, things are going to happen’. Following a consultation with my doctor I thought ‘That’s not really the answer I want here, I am really worried about this’. I didn’t feel comfortable or supported as she didn’t give me any tools to try. I decided to speak to the diabetes educator for a second opinion and spoke with a lady, she said ‘Sometimes it happens (effects to the eye) when you have high sugars, in case you had high sugars that day, don’t worry about it too much’. Maybe she was a little bit more comforting and educated, so I decided at this point to do low carbs and get rid of as much sugar as I could. I heard that once you have diabetic retinopathy it just gets worse, according to my first doctor. I went to my last test, in October last year, and results came

back completely clear, so the diabetes educator seemed to be correct whereas the GP was not by saying it was permanent. The GP also said that you can stop it from getting worse but it will not permanently cure. The diabetes educator said, 'Well it could have been a bad sugar day'. But I have looked at my diet and cut back on my carbs because they change into sugar so I decided to go on low-carb diets going forward. The result of my latest eye test came back completely normal."

(Interviewee Two: Focus group for older people)

"Communication is very important. Some medical words, I still don't understand some words in the Greek language, maybe it's a totally different language. I don't understand medical terminology. I can miss something or say something different to what the doctor wants me to say. It is important for me to understand and doctor need to explain my problems, but as they are very busy and cannot explain everything."

(Interviewee Seven: Focus group for older people)

Poor communication skills amongst health professionals could be one of the reasons to be blamed. As a result, a person with diabetes could find it difficult to share their personal concerns, which could cause unsatisfactory blood glucose levels. Evidence suggests that the role of communication is essentially important to positively influence low vision and diabetes care (Hibbard and Lorig, 2012), and healthcare workers also need to be trained to be good communicators (Care Home Guide, 2013).

5.3.1.1.3. Burden to society

If the person is unable to work due to low vision and diabetes, she/he seemed to claim that she/he was a less productive person within the family or society.

The quote below illuminated the perspectives of having low vision and diabetes:

“Diabetes and low vision is very expensive disease because of my glasses is so expensive, I’d pay 400 hundred something in Boots. And every 6 months they send a letter I tell them I’m alright they say ‘No, we need to see’ and they force you to change glasses, minimum is 100-200 hundred pounds. My son said this is rich people’s disease.”

(Interviewee One: Focus group for older people)

Viewing diabetes as a rich people’s disease is to presume that rich people are used to have someone doing something for them. If one is not a rich person, it appears negative, mocking his life more than that of a rich person, while he does not deserve it. Having this concern, they would felt that claiming to have diabetes would be similar to admitting that they give a lesser contribution to their family or society. Fear of being discriminated against was another concern. Because of lack of knowledge, diabetes has been long been misunderstood in many ways; being considered an infectious disease is one of them (Kumar and Clark, 2007), which brings many negative emotions. The following description expressed the insecure feeling of having diabetes:

“I just don’t want to tell anyone about my diabetes as I felt that this symptom to go more frequently to the toilet would make the others think badly about me.”

(Interviewee Six: Focus group for older people)

This finding is in accordance with (Durazzo et al., 2010). Although there is a different meaning of ‘the rich person’s disease,’ these are linked with the fallacy of contagion. Having diabetes has seemingly brought them more psychological than physical trauma, or it may even have worsened the negative impact on their family. Besides, the consequence of diabetes necessitated them facing an

uncertain future, which could probably cause a great burden to their family, especially for the next generation.

5.3.1.1.4. Feelings of the person with diabetes and burden to their families

The meaning of having diabetes is seemingly expected to link their future life with fragility and sickness, while having this thought can cause patients to grow fearsome of the imposing burden to their family in the future. The concerns expressed below reflect their thoughts:

“My Mum’s got Diabetes and I’ve seen her majorly go downhill. She’s got neuropathy of her legs and she was unable to use them and because she was unable to use them she’s lost the use of her legs. I think that’s a major problem for me as I am also diabetic. Another problem if I lose my eyesight, because it is something I feel quite upset about that happening. I knit and I sew and I’ve just got a granddaughter also I don’t want them to be a person with diabetes and this is so scary for me.”

(Interviewee Seven: Care home - older people)

“I use to be a very hard worker but since I diagnosed with diabetes I am unable to do anything really, for me is very difficult. I am always thinking that I am a big burden on my family.”

(Interviewee Seven: Focus group for older people)

The worry can grow even stronger if the family has been suffering from caring for any sick family member. The quote below describes the patient’s concerns when talking about her own mother:

“My mum has lost all of her fingers and vision in both eyes due to diabetes, she can’t do much feeding, clothing, dressing, she can’t do much now, and she’s been bedbound for almost 18 months now. To

me I've got to keep myself going, make myself do things, keep walking, making sure I, I know what I've done by eating what I shouldn't have, but because of the financially burden and stress it's very difficult for me to carry on."

(Interviewee Seven: Care home - older people)

In summary, once diabetes is interpreted as a dreadful disease, the impact of having diabetes has more of a psychological impact than a physical one (Boon, Chew and Aaron, 2014). It depended on how the person interpreted the meaning of having diabetes. Large number of people with diabetes had a problem with sharing the identity of their illness's identity in public because of the social stigma, which was seemingly one of the major sources of stress. Facing an uncertain future was another stress, but it might not be necessarily have been negative. Some people had been psychologically preparing themselves in the event that they would have diabetes one day in the future because of dispositional heredity (Lorig, 2009). Their emotions would be affected in various degrees, which depended on how they perceived the meaning of having low vision and diabetes.

5.3.1.1.5. Emotional feelings:

The emotions elicited while being diagnosed were rather diverse, which was contingent upon their experiences and their knowledge of diabetes leading to different interpretations (Lorig, 2012). Each subjective experience varied widely, resulting in different responses to the diagnosis, which ranged from no feeling to great panic.

Two participants show their responses below, illuminating how they responded to the situation:

“It is painful when you first hear you’ve been diagnosed with diabetes; you worry about what will happen, thinking that how could it be possible to have these things, obviously don’t know what to do.”

(Interviewee One: Focus group for older people)

“I been under an awful lot of stress because of my diabetes and my eyes complications. I was very confused about my eye condition, also because of the stress I’m actually being a bit naughty and eating a few things I shouldn’t be eating, just being honest with you.”

(Interviewee Seven: Care home - older people)

Negative emotions might influence not only the person involved but also their families, and the quoted statement below depicts this influence:

“I was very upset and depressed because my wife and my son told me that they worried more than me about my diabetes as my father was blind due to diabetic retinopathy long time ago, I remember that was a very difficult time.”

(Interviewee Three: Focus group for older people)

Not every person had been strongly affected by the diagnosis, and some of them had only experienced little distress. Among them, some admitted to having learned from their family before the diagnosis, especially from those who had had a good education about diabetes (Lorig and Holman, 2003). The lessons they had learned from their families made them realise that diabetes could be controllable, and having diabetes would not be so dreadful; thus, they could recover quickly from the impact. Their experiences revealed one thing: once the patients learned how diabetes care is managed successfully for some people, it tended to prevent them from being overwhelmed.

The quote below depicts this situation:

“My Mum’s got diabetes and I’ve seen her, she was very good in learning and to manage her diabetes. When I was diagnosed with diabetes, I been under an awful lot of stress because of my diabetes, but my mum give me a lots of support and make me able to cope with it, but still I am worried about my eyes.”

(Interviewee Two: Focus group for older people)

It was helpful when the participants had acquired knowledge of diabetes before diagnosis because psychological preparations made them start the journey with diabetes more easily. The lessons learned from this group indicate that prior knowledge of diabetes could work well for consolation, especially at the start. Conversely, some had experienced little stress, but it was because they knew little about the public view of diabetes before being diagnosed. In addition, newly diagnosed people might believe that they are too young to have long-term complications (Lorig et al., 2009), as it is thought to be a disease of the elderly. Having these thoughts will affect diabetes care.

The following quoted address illuminates these thoughts:

“I was 39 when diagnosed with diabetes, ‘laughing’ due to my young age I didn’t bother about my diabetes, but after 5 years I feel something in my eye, something was really uncomfortable, I had been to the optician and he advised me that go to your GP to check your sugar. He told me the of disease, but I forgot the name DiabetRtanp (Diabetic retinopathy), anyway I had been to my GP, and he tested my blood and said your sugar is very high and also he sent me to the hospital for my eye check-up, and they said that you have DiabetiiRthhh (Diabetic retinopathy) the doctor said if your diabetes was controlled at that time then today you will not face these eye complications.”

(Interviewee Six: Focus group for older people)

5.3.1.1.6. Health professional's attitudes

A well-designed diabetes care plan can be ruined by a bad attitude from a health professional while providing their services; however, a good relationship can encourage patients to accept recommendations. Mr KH described that he was absent from the clinic for several months due to the attitude of the health professional who had blamed him for his unsatisfactory outcome, which made him give up the treatment until his condition became worse.

The quoted interview below shows the interaction:

“She (my GP) did ask me what I had eaten. I was quite honest to her, and told her about whatever I had eaten. As I got surgery for this (diabetes check-ups) just said I had used to eat fried food, and caused me suffering for quite a while She said ‘you like to eat fried food, right?’ I said ‘no.’ I just ate once or twice. At that moment I was quite honest to her. She said ‘don’t you think that your behaviour bring you to be this situation (having diabetes), and why you want your son to be like you (to have diabetes)’. I feel that her behaviours were very rude to me, I was very upset for quite a long time, even when I came back to my home.”

(Interviewee Three: Focus group for older people)

If health professionals perceive the outcome of metabolic control as the only measurement capable of evaluating the personal care of low vision and diabetes properly, it can somehow be misleading. Physical conditions and stress can contribute to unsatisfactory blood glucose levels (Boon, Chew and Aaron, 2014).

My findings show that people with diabetes have many roles to play rather than solely the care of low vision and diabetes. Blaming people with diabetes for poor performance may result in the frustration of health professionals when they fail to achieve HbA1c within a satisfactory level. It can be very frustrating when the outcome is uncontrollable. As the feeling of frustration emerges, it can damage

the relationship between the health professionals and the patient (Sinclair et al., 2001; Aikens et al., 2005); on the other hand, it has not improved the metabolic control, and instead, a person with the condition may become worse. Mr KH, Interviewee Three and Eight, for example, after such a traumatic experience, refused to come back, but he was persuaded to by his family due to his deteriorating condition. Blaming individuals with diabetes for their unsatisfactory results is a subject of concern.

Evidence (Lorig et al., 2005; Herbert et al., 2007) suggests that the relationship between the healthcare workers and the patients was traditionally influenced by the biomedical model, which stresses a paternalistic relationship rather than a partnership. Under such a model, most of the people with diabetes are too timid to discuss the issues of the treatment regimen with their doctor; thus the patients might omit to take their prescription pills without consulting their doctors.

The quote below reveals the interaction between them:

“GPs, no they have no time. You can’t even pass to talk to the receptionist. Ah, my doctor seems to be unable to allow too much question (laughs).”

(Interviewee One: Focus group for older people)

“I think that is part of the problem is that GPs don’t have the time. I also believe that they don’t have as much in-depth knowledge. Even though diabetes is on the increase, I believe their knowledge is not as up to date as ... well like at my surgery they have like a diabetes educator and they are more knowledgeable than the GPs. And when I was diagnosed I was like in a black hole. I wasn’t diabetic or was I diabetic, so I was in the middle. And I still swear to this day if she had said to me, ‘You need to do this and this and watch your diet’ and had some form of instruction at that point, I don’t think I’d be diabetic now because you know all she said to me was exercise. So I joined a

gym and did exercise but that still didn't get me out of the clear because she did another test and I'm still inaccessible of that call. Ultimately I became diabetic, but if I had known about the carbohydrates and the foods and spoken to a dietician, then all that would have been different. I was willing, trying to read and educate myself. But if she had been more knowledgeable or even the diabetes educators, because I didn't speak to them until I was actually diabetic, and I should have been meeting with them as a diabetic and I don't think I would have been in the position of being with diabetes now."

(Interviewee Two: Focus group for older people)

In summary, being older and lacking knowledge of low vision and diabetes could be the reasons for complications, as diabetes is a symptom disease for years before developing chronic complications. The findings reveal that those participants with little worry over the disease and its consequences have a great chance of ignoring diabetes care.

5.3.2. The category: Stigma attached to diabetes and a hope of good health

This section discusses how people with diabetes managed to cope with diabetes at the beginning. The five sub-categories are identified as:

5.3.2.1. Searching for a hope of good health

5.3.2.2. Help from healthcare professionals

5.3.2.3. Unrealistic comments and vulnerable people with diabetes

5.3.2.4. Finances: perceived impact of low vision and diabetes on the cost of living

5.3.2.5. Impact on social relationships

5.3.2.1. Searching for a hope of good health.

After initial diagnosis, the patients tried to find any possibility of treatment or information that could be useful for their disease. Without any confidence, the patients might try to find a doctor who is a specialist in a particular field to treat them. In a residential care home, the healthcare system is bit different from in the community. In the UK, the responsibility for the management of all chronic diseases, including diabetes and its complications, has shifted from the individual to the institution in conjunction with Primary Care Services (WHO, 2011), which means older people entering residential care may have moved from their area, possibly having a detrimental effect on them as they may not see their own GPs. They may also feel uncomfortable with a new GP's surgery, which could be a barrier to diabetes and eye health treatment.

Older people living in the community can go straight to any specialist of their choosing for a private consultation, if they can afford to, and find a good doctor for health care. As a 'good doctor' is used to having many patients, in order to register at the clinic they may need to wait in a long queue. Once successfully registered, the patients are reluctant to change their doctor if the outcome is satisfactory. The searching process dictated below demonstrates this phenomenon:

"I would like to see my own doctor as he knows everything about my diabetes, I don't want to discuss my diabetes with other doctor as I think that other doctor don't have time for my previous story, sometimes I am waiting for very long to see my own doctor."

(Interviewee Two: Focus group for older people)

From the very beginning, it is important to show the information provided by those who have had satisfactory results of diabetes control as a hope for health, and with this support the patients are able to feel confident about living with diabetes. If people with diabetes meet someone else with diabetes who is successful with managing their diabetes, then they are able to build up their confidence to manage their own diabetes effectively. The quoted interview below shows these kinds of experiences:

“When I was diagnosed with diabetes I was upset and even didn’t been to work, after two days when I went to my job one of my friend was laughing on me he told me that he have diabetes for nearly 16 years and have no complications. He said my mother in-law has lived to eighties, and she still lives very healthily at eighty-five, even having a bit eyes problem. He gave me lots of reassurance with good effect and I feel bit better, I could say it is very nice to being able to keep in touch with someone who have diabetes.”

(Interviewee Three: Focus group for older people)

“I am always wondering for good information about my diabetes to keep myself healthy, but as doctors have no time, I can just get information on Google to learn about diabetes to control, but I don’t know who is writing that one I cannot verify the authentic source of what is available on Google or not. I am just saying for me I learned from my mother and from my elder sister as she has diabetes as well”.

(Interviewees Two and Seven: Focus group for older people)

Newly diagnosed people should be convinced by those who have dealt with diabetes successfully, and could more likely receive a great deal of comfort because they could be more confident that the future ahead is not as bad as they had previously thought. It is understandable that it works perfectly in this way

because these successful cases show the evidence that diabetes can be controllable, and the strategies used could work effectively in the real world (Sinclair, 2014). Diabetes is not such a dreadful a disease as they thought. The quoted interview below addresses this kind of mind-set:

“While at the time my diabetes is controlled, touch the wood, as I am regularly taking my medicine and doing 30 minutes walks every day.”

(Interviewee Six: Focus group for older people)

The information obtained about low vision and diabetes is crucial for the patients’ decisions on seeking health care. But not every person was lucky enough to obtain information sufficiently useful to help them out of gloomy days. There are a number of participants who failed to be informed correctly. One of the common misconceptions circulating around non-educated people is with reference to insulin. The quoted descriptions reveal this phenomenon:

“When my doctor advised insulin for me, I was not happy as I heard from people saying after receiving insulin shots it is not good for my sexual health and also not good for strengths, so stop to take insulin.”

(Interviewee Four: Focus group for older people)

“(Laughed and said) ... same thing happened with me. People, told me It would be the end of life when receiving insulin shot. I was scared, but I didn’t stop taking insulin.”.

(Interviewee Three: Focus group for older people)

As a result, some unfortunate people were even misled into making the wrong decisions that worsens their health condition. One of the participant’s experiences below showed this:

“When I was diagnosed with diabetes, my doctor advised me insulin, but I was scared and didn’t go back again (to the doctor), I forgot

that I have diabetes, but after few weeks I feel something in my eye, something was really uncomfortable.”

(Interviewee Six: Focus group for older people)

From their experiences, it seems that information is very important at the onset; it is a crucial period, especially when they still know little about diabetes. The anxiety and looking for a glimmer of hope could easily mislead them into making decisions that might be harmful to them. Alternative remedies were also found where patients who were desperate tried to control the disease themselves. Some participants were somehow easily persuaded to try traditional remedies because they still hoped that something out there would be helpful for their disease. To seek any hope would hardly erase the problem from their minds. Taking herbs and dietary supplements for diabetes is not a unique phenomenon. A person with diabetes might think the ingredients could do them no harm because they all come from herbs, vegetables, or fruits; they just do not want to give up any possibility of curing the disease. However, this hope could bring some negative results. One of the participants from the South Asian community showed this example below:

“I did try alternative remedies, traditional remedies, herbs and diet supplements. When I started these remedies, I did check my blood sugar regularly, but I didn’t feel anything unusual, my blood sugar was the same as it was, so I stopped to take these medicine as some of them is very expensive.”

(Interviewee Four: Focus group for older people)

5.3.2.2. Help from health care professionals

Some older people were not getting good help from the health professionals due to lack of knowledge, low awareness of low vision and diabetes, and a lack of communication with the health professionals.

Two of the participant's experiences below show this:

"While I think all health care professionals need to educate themselves first (laugh), as when I asked something for my diabetes complication, they not answering my questions, all they said: do exercise. Sorry but sometimes I think nurses and even GPs are hopeless for person with diabetes. Maybe some of my friends will not agree with me but this is my point of view, as they don't have time for us to explain what should we do and how to cope with diabetes and how to manage diabetes complications."

(Interviewee Three: Focus group for older people)

"I'm with type 2 diabetes and after reading on some forums I realised that a lot of them with Type 2 diabetes were testing themselves with the glucose monitor sets. So I went to my GP to ask if I could get a glucose monitor set. She said I was Type 2 and didn't need to test my sugars. So regardless what she said I bought a machine myself. I went to my pharmacy and spoke to her because she knows I'm diabetic because she gives me my Metformin. I told her I'd like to see how much the test strips are, she told me I wouldn't have to pay for them. So I said I told her what my doctor said and she said she'll put in a request to see if they'll approve it, the strips, but you don't need to test yourself every day. And I felt like the pharmacist knew more than my GP. So when I should have been testing myself, all this time I wasn't testing myself. I would have had better control of my sugars and my eye problem wouldn't have even shown up, so it's not the diet, it's also the tools associated with the support."

(Interviewee Two: Focus group for older people)

5.3.2.3. Unrealistic comments and vulnerable people with diabetes

Although participants are told that diabetes is a hopeless disease, some of them might not come to terms with reality; they seem more likely to grip onto any possibility, and even though it has little chance of success, they would give it a try. It makes individuals vulnerable to unrealistic comments.

The participants' experiences below demonstrate this:

"As my mum has lost all of her fingers and vision in both eyes, even she done everything doctors or people said to her, but her diabetes are never recover, and it make me more stressful as I am going to the same way."

(Interviewee Seven: Care home - older people)

"I had been trying many things people said to me, but nothing it could do, even making it more worse it was".

(Interviewee Three: Focus group for older people)

5.3.2.4. Finances: Perceived impact of low vision and diabetes on the cost of living

Older people are eligible for free eye tests (RNIB, 2011), but some individuals questioned the finance, as quality glasses are very expensive. They said *"from the NHS, very minimum supports are available"* which is a barrier to eye testing and eye care. The quoted interview below shows the interaction:

"As (Mr. Khan) said, I am totally agree with him, for me eyes test and glasses are so expensive, I can't afford it really."

(Interviewee Three: Focus group for older people)

“That’s true, I think the main barrier in providing a good care to low vision and diabetes is cost and financial concerns.”

(Interviewee Two: Focus group for older people)

5.3.2.5. Impact on social relationships

Low vision associated with diabetes has an impact on social relationships and health-related quality of life, functional ability and psychosocial wellbeing (Charles, 2007).

The participants’ experiences below shows this:

“It is (diabetes and low vision) stopping me to go out to see my friends as I can’t drive any more. They coming to see me, I can’t go any of our family gatherings, even sometimes when I go with my kids then I have to sit in one place due to my eyes problems.”

(Interviewee Six: Focus group for older people)

“... as I am using magnifiers I can’t read newspaper print properly without magnifiers, I can’t watch television without my glasses, I can’t go out even for my shopping as I can’t read the labels on the foods. My daughter helping me but she have her own family and can’t come for my help all the times, but when she is doing her own shopping then she doing for me as well. I think diabetes is a terrible disease, it will make your life very difficult, especially if you have eyes complications. I wish I can control my diabetes.”

(Interviewee Four: Focus group for older people)

In summary, education, knowledge, awareness and learning about diabetes is very necessary after diagnosis (Lorig et al., 2009). For lessons learned from their experiences, educating patients alone would be not enough; there is also a need

to educate the HCAs as well. Increasing public awareness could possibly decrease the negative information circulating among lay-persons and it would also help to reduce the social stigma; it may be a way to stop the information imparted by word of mouth (Sinclair, 2014). In fact, to educate people within their general lives might increase the chance to raise public awareness at large, such as via television programmes. Apart from learning from their experiences, the patients might learn how to be aware of their physical conditions by means of observing the relationship between diabetes care and their physical responses (Diabetes UK, 2015). To ensure they know how to cope with low vision and diabetes, education, awareness and learning about low vision and diabetes and its care is quite important among these groups.

5.3.3. The category 'Education'

This category is divided into the following sub-categories:

5.3.3.1. Essential learning

5.3.3.2. Experiential learning

5.3.3.3. Support from physician, family and friends

5.3.3.4. Awareness of low vision and diabetes.

This section on education discusses training the person with diabetes via four sub-categories which are identified as: essential learning, experiential learning, support from physician, family and friends, and awareness of low vision and diabetes.

5.3.3.1. Essential learning

People with low vision and diabetes have to learn the specific knowledge and skills required for living with diabetes. There are two kinds of learning: essential learning and empirical learning. Essential learning is the information fundamentally required for people with low vision and diabetes, which could be obtained from health professionals, books, media, or other sources. After learning, the application of this knowledge and skills in the real world is the beginning of empirical learning (Lorig and Holman, 2003), if the person has started to observe how their physical conditions respond to their day-to-day activities. Learning is necessary for them to cope with low vision and diabetes.

Obtaining information from a book:

“I learned lots from books, some medical words I can’t understand, but since being diagnosed with diabetes I educate myself with books.”

(Interviewee Two: Focus group for older people)

“While for me books are not a good thing as my eyes problems. Long time ago I took some booklet from surgery to read, but even more, I feared that my blood pressure and blood sugar might not be under good control, it make me more worried I just stop to read it.”

(Interviewee Three: Focus group for older people)

“I can just get information on Google to learn about diabetes to control but I don’t know who is writing that one. I cannot verify the authentic source of what is available on Google or not. I just don’t know.”

(Interviewees Two and Seven: Focus group for older people)

Reading diabetes-related books would be a positive tactic. The reasons might be that these patients had much more motivation towards their health issues, and

also that the knowledge from books would be rich and organised and they could set up their own learning scheme based on their individual needs (Aspray et al., 2006). Hungry for diabetes information, the participants could easily draw their attention to any diabetes-related information. The media is one of the more accessible resources, and even their family would be alerted to any information regarding diabetes. However, some of the media only advertised the products, which are sometimes misleading, making them not necessarily positive resources. It might become a negative influence if patients are then reluctant to consult health professionals. This quoted statement shows their concerns:

"I try lots of medicine report in the newspaper, and spend my money on it but the result was nothing."

(Interviewee Six: Focus group for older people)

In summary, information is needed at the onset as it is important to control diabetes. Due to negative emotions, people with diabetes were sensitive to diabetes-related information, and it made them vulnerable to accepting certain harmful suggestions. The need for information in many formats is demanding and how to satisfy patients' needs is a big challenge (Peyrot and Rubin, 2008). Learning is one thing, but applying this to the real world is another thing entirely.

Diabetes, among other chronic diseases, has its particular characteristics (Holman and Lorig, 2004). Education and learning could be more helpful in improving diabetes care skills (Charles, 2007).

5.3.3.2. Experiential learning

The stage of experiential learning is when participants start to observe the relationship between self-care behaviour and their blood sugar levels or other signs and symptoms. If participants have limited knowledge, they could still learn by themselves. It mostly involves trial and error, and this kind of learning could be achieved by those who would like to try their own methods of diabetes care.

Through education and learning, a person with diabetes can start to develop the strategies to cope with low vision and diabetes. They know how to avoid the risk of increasing their blood glucose level. This quoted statement shows their concerns:

"I educate myself about eye health and diabetes through books. I'm very sensible about, I might have a box of chocolates for my birthday or Christmas and it takes 6 months to get through it. And I love chocolate but I'm not stupid. It wouldn't occur to me to eat two or three after another - I'd like to but I know I can't."

(Interviewee Three: Focus group for older people)

They would start to understand the benefits of exercise and how exercise is linked to diabetes and cholesterol; learning this could enhance their behaviour regarding low vision and diabetes.

"Education is very important for people with diabetes. I know how to cope with my condition, I think exercise is very important to control your sugar and cholesterol, just keep doing exercising."

(Interviewee One: Focus group for older people)

5.3.3.3. Support from physician, family and friends:

Support from doctors, family and friends are also important at the onset of diagnosis. A family support member reveals the process below:

"I feel something in my eyes unusual, so at that time I said to myself 'Go back to your doctor' but he (doctor) said 'There's nothing you can do' as you are diabetic. I was very upset and even the doctor didn't explained to me any things about my problems as they are very busy. He (doctor) just said there is nothing they could do."

(Interviewee Seven: Focus group for older people)

“When I was diagnosed with diabetes I was very upset. And then my son say to me ‘dad, in fact, you don’t need to worry, it’s easy, just take your medication and control your diet. Don’t eat sugar.’ So it is nothing, and that’s true he make me comfortable.”

(Interviewee One: Focus group for older people)

As stated earlier, if the person with diabetes has a family history of the disease, their learning could start earlier. However, the learning could be negative or positive, depending on how their family perceives diabetes. If their family has good knowledge about diabetes and they have good metabolic control, it would most likely lead to a positive influence.

5.3.3.4. Awareness of low vision and diabetes

Knowledge and awareness of diabetes and eye health is very important (Charles, 2007), and communication problems between individuals and health professionals can create more barriers towards good eye health and diabetes.

“I feel some changes in my vision, can’t focus my vision properly, so I been to the optician, she advised me an eyeglasses. At that time I feel I am fine, but after a month my vision was the same. I stopped to wearing my glasses as it makes me dizzy and gives me a headache. I been to my GP and I was shocked when he said that you are diabetic and maybe your vision problems is related to your diabetes. He send me to the hospital for my eyes check-ups and I was diagnosed with DibtessRTnopathy (Diabetic Retinopathy). I was not aware of any these problems otherwise I control my diabetes and its complications.”

(Interviewees Two and Seven: Focus group for older people)

5.3.4. Summary

Without education it will not be possible to provide good care to older people with low vision and diabetes (College of Optometrists , 2011). As already stated, for good awareness and knowledge of low vision and diabetes, training is the essential key, and if HCAs and people with diabetes cannot identify that they have changed due to diabetes, the situation becomes harder and more challenging. Sometimes, even though people with diabetes do not agree with the diagnosis, they still have no choice but to set off on the journey with diabetes. Along the way, older people with low vision and diabetes have to learn how to manage and cope with low vision and diabetes and to remain healthy, or older people with low vision and diabetes have great a chance of developing long-term complications. Having diabetes would mark the person in the heart as a changed person, both psychologically and physiologically. HCAs also have to learn how to care for older people with diabetes and low vision.

Since the people that I have spoken to have been diagnosed with low vision and diabetes they have been influenced more on a psychological than a physical level. The meaning of diabetes mostly focuses on the negative side, and how their suffering is raised depends on their perspective of the meaning of diabetes. The public view of diabetes might cause them to feel inferior to others, even if they have the disease under control (Hibbard and Lorig, 2012); they would still struggle with whether to reveal it to the public or not. The more they know about its negative side, the more stress they feel.

They have a great chance of developing long-term complications if they do not have good metabolic control and for good metabolic control they need good knowledge and education. Once they have complications, the suffering they have can be more intense. With this new identity, their lives need to be reorganised to live with diabetes if they hope to resume healthier lifestyles. It depends on how

they feel about the meaning of having diabetes. Social stigma or discrimination could lead to concealing the condition to avoid the stress of facing an unfriendly environment (Emerson and Robertson, 2011). As a result, it more or less increases the difficulty of changing their lifestyle. Seeking professional help is considered a search for a hope of good health. It is a good way to offer support while the person with diabetes is at a vulnerable stage; it would be easier for them to accept unrealistic comments or become victims of a scam to help them out of desperation.

Learning is essential to diabetes care, particularly for HCAs. The capability of a person with diabetes to search for resources could help them to advance their learning. If HCAs and older people with diabetes and low vision start to learn from the relationship between their physical responses and blood glucose levels, they will have more in-depth information about diabetes care, which suits them well. Based on all these experiences, it could advance the skills of HCAs and older people with diabetes and low vision to become both practical and effective. Human beings are part of the social context; to live with diabetes involves all kinds of things, and it also involves other people around them (Lorig, 2012). It is impossible that the individuals with diabetes stay unaffected by their social context, but if a person with diabetes and their HCAs have good knowledge and education then the risk of complications will be lower and more controllable.

5.4. Section 2, Theme Two: Restructure life with low vision and diabetes

Introduction: This section focuses on older people's experiences with low vision and diabetes when they first were diagnosed with the conditions, exploring how they expressed their feelings and experiences and how their lives were changed. The theme 'restructure life with low vision and diabetes' was abstracted from the data, which seemed to indicate that the older people were trying to adapt their lives within family, community, society and in residential care homes.

This section also concentrates on how the older person integrated low vision and diabetes activities within their family, community, society and in care homes. The findings here showed a number of influential factors contributing to the process of good care of low vision and diabetes. This process appeared to show that older individuals had to abandon some of their previous living habits and struggled to introduce the newly suggested ideas on how to live with diabetes within their own environment. No matter how much they knew about low vision and diabetes, the actuality of them being able to look after themselves within residential care homes and the community needed sophisticated integration with their preferred lifestyle and central values of living (Holman, 2000; Duffy et al., 2005). The theme 'restructures life with low vision and diabetes' is divided into two categories: 'Beginning the journey as a changed person' and 'Family commitment' and each category is divided into several sub-categories. Each of the sub-categories will be discussed in turn, along with its consequences.

Good education for low vision and diabetes control enables the person to develop their own way of living, which includes what they are more likely to accept without too much struggle, and also the appraisal they make based on their goals, situation, resources, and the capacity to decide what kind of life suits them best (Holman and Lorig, 2004; Kumar and Clark, 2007; Sinclair, 2010).

To integrate low vision and diabetes into life, the core issue is how the person's perspective of their own life meets with their capacity for low vision and diabetes care education, essentially leading to the various outcomes of diabetes control. If they have good knowledge, education and their own goal for life, it can encourage them to cope with low vision and diabetes.

The table below shows all the categories along with their sub-categories:

Themes, Categories and Subcategories, Part 2

Theme	Category	Subcategory
Restructure life with low vision and diabetes	Beginning the journey as a changed person	<ul style="list-style-type: none"> • Change in lifestyle; how to carry on a social life and live with low vision and diabetes; weight management; nutrition; exercise; meal planning • Education • Physical incapability.
	Family commitment	<ul style="list-style-type: none"> • Family problems • Social support; help from family and friends.

Table 8 Themes, Categories and Subcategories, Part 2

5.4.1. Beginning the journey as a changed person

This section is divided into the following sub categories:

5.4.1.1. Change in lifestyle; how to carry on a social life and live with low vision and diabetes; weight management; nutrition; exercise; meal planning

5.4.1.2. Education

5.4.1.3. Physical incapability.

5.4.1.1. Change in lifestyle; how to carry on a social life and live with low vision and diabetes; weight management; nutrition; exercise; meal planning

Lifestyle, weight management, nutrition, exercise, meal planning: the impact of having diabetes could have different meanings (Abdelhafiz and Sinclair, 2009); It depends upon the person's perspective of low vision and diabetes how an

individual starts to recognise that he has to cope in his daily life or face the physical consequences, such as amputation, blindness, stroke, or renal failure. The issue of change of lifestyle could be huge. Good education involves the way in which an individual weighs up the benefits of good health against the barriers. To some participants, being informed about receiving insulin shots could cause panic, or even greater panic if they cannot see properly. An individual can be motivated to do everything just to avoid it. Avoiding the insulin shot becomes the goal which motivates the individual to change their behaviour.

Two participants described how they made their decisions on low vision and diabetes while they had poor metabolic control. The event is related to the treatment regimen, as their doctors wanted to change their medication from oral diabetes drugs to insulin shots. These quotes express their thoughts and responses to the prospect of insulin injections:

“For me taking insulin was very painful process all the time, as I was unable to see properly the needles without my glasses. I did try the insulin devices but still no good for me, I decided to stop taking insulin.”

(Interviewee Three: Focus group for older people)

“When my GP said that I had to start insulin injection as only the pills is not working on my conditions, I was very scared, as even I can’t see someone else taking injection, how I will be able to take insulin injection.”

(Interviewee Four: Focus group for older people)

At the date of the interview, both participants were still receiving oral diabetes drugs. In this situation, each of the participants needed good knowledge and education on low vision and diabetes. To receive insulin is a big change in one’s lifestyle as receiving injections every day is an immediate change, but if the person had good knowledge and had received education on low vision and diabetes they could prevent the complications, particularly blindness.

5.4.1.2. Education

Some participants experienced chronic complications of diabetes, including stroke and blurred vision, due to lack of knowledge and awareness of diabetes. The quoted interview below illuminates low vision and diabetes being affected by the lack of knowledge and awareness:

"I did not know about the stroke but after I had one my doctor said this is due to your diabetes, 'see, I don't know that other ways that will be not happened with me, I am feeling ok now as I started to take exercise every day'."

(Interviewee Six: Focus group for older people)

Another participant found himself having eye problems due to lack of knowledge and awareness of low vision and diabetes:

"The loss of vision would worry me, but I did not know this is a complication of diabetes, I thought this is just my age related problem."

(Interviewee Five: Focus group for older people)

If the individuals had received good knowledge and education on low vision and diabetes in order to understand the consequences of diabetes, it was possible for them to take action and change their lifestyles. Otherwise, they had a greater chance of suffering from physical incapability (Bosanquet and Mehta, 2008).

The intensiveness of negative emotion could reflect their fear of an unhappy life. In the findings, if the person with diabetes had ever seen another person with diabetes suffering from the consequences of diabetes, this could force them to face the possibility of a depressing future. Being afraid to live a life like that, they experienced tremendous stress.

The quote below presents the perspective of the person:

“My father had diabetes and he lost both of his eyes; he was unable to see, he passed away last year. As I am diabetic with low vision always thinking the same as my father will be happened with me. I must control my diet, and take exercise constantly as well.”
(Interviewee Three: Focus group for older people)

Some people with diabetes are not afraid of death, but they lack the knowledge that the suffering brought from the chronic complications of diabetes could possibly last for a long period before they die. Being unafraid of chronic complications may result from a lack of knowledge.

The quote below presents the perspective of the person:

“I am not worried about the complications as everyone has to die one day. I have never worried about it, sooner or later, complications of diabetes or death would come to get you.”
(Interviewees Two and Seven: Focus group for older people)

The findings indicate that to encourage the person to understand the consequences of diabetes is necessary. When a participant failed to restructure his life, it was mainly as a result of lack of knowledge, awareness and education about diabetes. After data analysis, it was found that if the person had misunderstood the information regarding low vision and diabetes, or knowledge was incomplete, they found it hard to control their diabetes properly.

The significance of this is illustrated below:

“I was offered a course, I don’t know but it was about information, meant to be about the diet and that sort of thing. And when I went to speak to diabetes nurse they said to me, that she’d put me on this course. I can’t remember the name but it was about 6 months I hadn’t heard anything and mentioned it to my GP. And she said she’d let them know and when I did speak with the diabetes educator they

said they'd get on top of that, then a year went by, Nothing. So then when I did say that, I came with concerns trying to talk about diets they told me what I pretty much know from my own research, because I search online and they said I don't need the course. So I feel, again I lost in the system."

(Interviewee Two: Focus group for older people)

Similarly, others reported that with no or limited awareness of potential complications, the person might ignore the importance of diabetes education because they focussed on how to cure the disease. One of the participants described how he suffered from hypoglycaemia without knowing how to deal with it:

"I didn't know about the hypoglycaemia and that I had to eat sweets whenever I got hungry. No one told me that before, otherwise I would have had no problem to prepare a toffee at any time. This is just a sample of information but no one gives me that information, I think information is very important for all people diabetes."

(Interviewee Two: Focus group for older people)

In the findings, some participants had stopped the medication due to lack of awareness, knowledge and education. This is a common misconception being found involved with medication, and one of the participants below demonstrates this phenomenon:

"When I was diagnosed with diabetes my friend said 'don't take medication. After taking medication, you will taking it for a long time, and will never stop."

(Interviewee Three: Focus group for older people)

5.4.1.3. Physical incapability

Physical problems also contribute to hindering the patients from restructuring their lives. Physical incapability is one limitation which they have been struggling with while having low vision and diabetes, such as pain in their teeth. Compromised by their physical condition, an individual with diabetes might not be able to carry out exercise as necessary, even though they know it is important for diabetes control. Two participants below describe this situation:

“I have pain in my knees and I am unable to walk or exercise, pain in my knees were killing me if do even five minutes’ walk.”

(Interviewee One: Focus group)

“My legs have problem standing that long for walk or exercise, I can’t see properly as my age also I have asthma and my birthing problems so it is very difficult for me to do the exercise I want to do but I can’t.”

(Interviewee Five: Interview)

5.4.2. Family commitment

Self-care behaviour such as diet and exercising are closely linked to family behaviour. Studies by (Gregory, 2005; Lorig, 2012) argue that patients dealing with diet-related diabetes need to juggle many things because the lifestyle involved is not simply seen as an individual matter, but rather it affects the whole family. To involve the family in the diabetes educational process can maintain a longer and healthier behaviour by using both exercise and a dietary regimen (Hauner et al., 2010).

This section is divided into the following sub-categories:

5.4.2.1. Family problems

5.4.2.2. Social support, help from family and friends.

5.4.2.1. Family problems

The values of blood glucose are linked with stress and therefore, according to (Lorig, 2012), as the main caregiver of a family, any stressful event caused by the family could lead to unstable conditions.

If the family reaction is unlike what an individual expects, it could develop stress within the family. If the event is tense enough to cause chaos within the family, it could cause negative emotions. In the findings, negative emotions could have a huge influence on the individual with low vision and diabetes. Not only do negative emotions lead to higher blood sugar levels, but this stress could also distract them from being vigilant with their own self-care.

As stated earlier, financial problems were the top issues worrying the person (Newman et al., 2011), and low vision and diabetes activities seemed quite vulnerable to this situation.

“Diabetes is not a huge problem, for me the biggest worry is money, I always thought about my financial concerns.”

(Interviewee Two: Focus group)

Apart from family troubles and lack of knowledge about diabetes, with little skill to express their concerns regarding low vision and diabetes, it becomes an added negative factor for the person to maintain their low vision and diabetes care and education. For example, while families express their concerns in terms of their anxiety to the person with diabetes, its influences might not be as expected; instead, it may impose some emotional burden upon the individual with diabetes and low vision. The way to offer support might not be necessarily helpful for the

individual with diabetes, especially when the family has no adequate knowledge to offer them help. The quote below reveals this kind of relationship:

“While I only ate a little amount of food, my wife and daughter always said, ‘you have better not to eat.’”

(Interviewee Four: Focus group)

Improper responses or concerns by their family could make it more difficult within daily life for individuals with diabetes and low vision. From the findings, the participants considered that their families bore no ill-meaning when, in fact, their behaviour did nothing to support them, but discouraged them instead (Hauner et al., 2010).

Apart from the family, the social environment is another issue closely involved with an individual’s life, including interpersonal activities in the community and the working environment. How a person with diabetes copes within their environment could be another factor that affects their self-management.

5.4.2.2. Social support, help by family and friends

Community and society also play an important role in older people with diabetes’ lives, how they live in their society. The following section focuses on how they integrate diabetes care into their living environments. The categories are drawn out as social support to the realities of life circumstances. If people with diabetes feel fear about revealing their diabetes to the public, it would be a disadvantage to carry out their care for themselves; they might have to make up many reasons to explain why they have to act differently. To insist on eating is viewed as hospitality from friends, but it could be the opposite for the people with diabetes.

“I usually not eating any sweets but when I go to my friends, they would urge me to eat it. I know this is not good for me but if I not eating it then my friends will get upset.”

(Interviewees Two and Seven: Focus group)

The findings suggest that enjoying food is part of a fulfilling life on an everyday basis, and it is said to be the most difficult part to achieve in diabetes control (Whittemore, 2000), influencing the perception of quality of life. It might be understandable that a patient's desire is to remain on his favourite diet; however, health professionals do not encourage this. The quoted statements below delineate some participants' feelings about their perceptions on dieting:

"They (health professionals) told me not to eat sweets and I am not eating it but to be very honest I can't control myself to eating cakes and that's why sometimes my sugar is very high, my wife didn't know that otherwise (laughs)."

(Interviewee Four: Focus group)

"The most difficult part for controlling diabetes is dietary."

(Interviewee Two: Focus group)

Change of lifestyle is difficult for many people, as one of the studies reveals that from the patient's perspective it brings down the level of the quality of life (Smith, 2004). Among these participants, while starting on the journey with diabetes, food is the major theme on many occasions, such as at a gathering of friends, family events, and festive occasions. It would be hard to control for individuals with diabetes who attend such events involving eating:

"To be very honest in family events and in any friends gathering, I can't control myself from any food, sometimes I am just not going to attend these events, because I know if go I will eat and if I eat, I will be in problem, but sometimes I can't avoid to attend these events."

(Interviewee One: Focus group)

Because most of the participants lack the confidence to reveal their condition to their friends, they obviously suffer from a lack of specific social support to prevent themselves from succumbing to temptation. Extended social networks contain risks to their diet, as they still have to interact with friends. This finding is similar to some other studies (Gallant, 2003).

Travelling is another issue found to be difficult for individuals with diabetes and low vision to cope with. Individuals with diabetes feel worried about handling self-care during the journey, if they treat metabolic control seriously. Giving up the journey might be one of their strategies, or they may have to tolerate higher blood sugar levels than usual.

Two quoted interviews below reveal the issue:

“For me is very difficult to carry on with insulin during the journey especially when I am going to my country.”

(Interviewee Three: Focus group)

“Sometime I went to visit my country, but I can’t due to my diabetes. Four years ago I been to my country, I put more weight on as I hide my problems from my friends. You would take more calories, as I eat everything, sometime forget to take my medication, my life was completely changed. I think that journey affects me psychologically as I started worrying about me all the time. I just came back after 15 days and my plan was for two months. I don’t know for all people with diabetes, but for me travelling abroad is very hard.”

(Interviewee Four: Focus group)

Sometimes the problem for the person with diabetes is that they have difficulty telling their friends about their dietary needs (Lorig, 2009), as sharing food with friends is a way to show their hospitality and friendship; thus it would be challenging to turn down a kind invitation, especially without their understanding of the situation. A more extended social network threatens more

opportunities of unexpected food, but this situation might not be the same with taking exercise, good diabetes knowledge, awareness, communication and education. Specific social support is found helpful to bolster the consistency of taking exercise. To take exercise is considered the second hardest behaviour to be achieved (Whittemore et al., 2002); to stick to this activity might take some motivation. Having company whilst exercising could make the activity itself more attractive to individuals, and encourage them to go further. The quoted interview below reveals the phenomenon:

“We five friends group going for exercise. It’s quite happy for me to go with them for exercise. If sometimes I miss to go there, they would say ‘why didn’t you come?’ Well at the time my diabetes is controlled touch the wood as I am regularly taking my medicine and doing 30 minutes walks every day.”

(Interviewee Six: Focus group)

If individuals with diabetes are closely bonded with their fellow exercisers, the action itself could become more than just taking exercise but also a kind of social activity. As a result, taking exercise can become a pleasure of social life, and an individual with diabetes would have little struggle to do so. The weather could be an influential factor when taking exercise, but it is still not enough to be a major one. Individuals with good diabetes motivation could be much more important because the weather issue may only be an excuse for not taking exercise.

5.4.3. Conclusion summary

To restructure their lives to live with diabetes, the people with diabetes themselves were the major factor in directing their own lives. Even if they had been able to make the changes to their lives, they had their own life preferences to consider. They rebuilt their lives based on their needs, how they wanted their

lives to be, and also compromised according to their capability. The journey of living with diabetes was different from individual to individual.

Family commitment was the major concern in their lives. Juggling within their multi-role playing, the participants might either gain more strength from within to enhance their diabetes care, or the family might hinder this. As they wanted to make decisions on diabetes care, their concerns about children were pivotal to direct the process. Because family members might have refused to change their role as care-receivers, they might unconsciously have made it more difficult for the person to carry out their diabetes care; society is too food-friendly for the person to have their diet controlled. Besides, when the person with diabetes feared to disclose their illness, the situation became more difficult.

In contrast, social support was important while exercising. In the findings, each individual dealt with different living conditions, and had different needs while living with diabetes. There might have been good days, but there were also bad days, and all the elements contributed to the result of low vision and diabetes care. Amidst these complex situations, how the healthcare service contributed to their needs of low vision and diabetes care would play an important role.

5.5. Section 3, Theme Three: Helping hand

Introduction: 'Helping hand'. This section concentrates on the experience of health professionals, specifically the health care assistants, including healthcare policies which could make profound differences in low vision and diabetes with consideration for older people to ensure receiving good care. The theme 'Helping hand' is used to describe this process of interactive relationship, to evaluate health professionals and healthcare assistants' knowledge and understanding of the impact of low vision associated with diabetes in older people.

The characteristics of all participants, interview groups and health professionals' survey are listed in Chapter 3 Table 3 criteria of sampling on page 60. After diagnosis, individuals with low vision and diabetes have to rely on the help of

health professionals in order to understand both the treatment regimen and the diabetes education. Without diabetes education, patients may not understand the importance of low vision and diabetes care and may not have the knowledge and skills to carry out this care. The traditional treatment of illness heavily relies on medical methods rather than good diabetes knowledge, awareness, communication and education; for individuals with diabetes and low vision, control requires complex knowledge and skills, together with continuously receiving treatment. To embark upon a process of being supported by health professionals is crucial for them, and for this reason all health professionals, including health care assistants, need to be fully educated with advanced knowledge and education to provide good care to older people living in residential care homes with low vision and diabetes.

To illuminate this process of an interactive relationship, the theme ‘Helping hands’ was formed. Table 3, Part 3 below presents the categories of data that are related to the low vision and diabetes experiences of how the healthcare assistants and other healthcare professionals influence their experience in providing good care to low vision and diabetes.

Themes, Categories and Subcategories, Part 3

Themes	Category	Subcategory
‘Helping hand’ Health professionals, specifically healthcare assistants	Key issues in managing low vision and diabetes in older people	<ul style="list-style-type: none"> • Older people’s issues • Care home staff issues • Health professionals’ issues
	Management of low vision and diabetes within care homes	<ul style="list-style-type: none"> • How the diagnosis was made • HCAs’ perspectives about diagnosis
	Barriers to deliver good care to older people with low vision and diabetes	<ul style="list-style-type: none"> • Communication • HCAs’ knowledge • HCAs’ training

Table 9 Themes, Categories and Subcategories, Part 3

5.5.1. Key issues in managing low vision and diabetes in older people.

This section is divided into three sub-categories:

5.5.1.1. Older people's issues

5.5.1.2. Care home staff issues

5.5.1.3. Health professionals' issues.

5.5.1.1. Older people's issues:

In older people, lack of knowledge and awareness of diabetes and eye health is the main cause of low vision. According to a survey conducted by RNIB, 60% of those over the age of 60 had not had their eyes tested for the past two years because they had not experienced any eye complications (RNIB, 2007). As we know from the literature review, however, with the prevalence of diabetes and low vision at this stage, it is quite possible that many of these people were affected by diabetes and eye difficulties, or may have needed treatment and new glasses. The following quote below illuminates this phenomenon:

"I am not going to test my eyes all the time as when I been to the hospital the doctor just said to me everything is fine, I pay for the taxi and I spend 4 hours in the hospital but returned to home with nothing. I just think this waste of time and waste of money."

(Interviewee Six: Focus group)

Researcher: *Did you go to see your GP, or do they visit you in this residential care home to check your eyes regularly?*

Interviewee: *"No, from the past 3 years I am living in this care home, I don't think so, not to my knowledge, any way not on regular basis, and without my glasses I feel very difficult in my daily life activities,*

also they need changing; I know that they need, my eyes are changing and I have had these from 2 years, no one told me about my low vision that this is related to my diabetes.”

(Interviewee Five: Interview)

Older people living in care homes are eligible for free tests and glasses (Care Home Guide, 2013); however, older people living in the community still have concerns about the price of vision glasses. The quote below demonstrates this:

“Low vision and diabetes is not a huge problem, you don’t need to worry, it is easy, just take your medication and control your diet, don’t eat sugar, so it is nothing, but for me the biggest worry is money, I always thought about my financial concerns.”

(Interviewee Two: Focus group)

Large numbers of the older individuals with diabetes believe that low vision is a normal age-related process which is incurable and irreversible (Ghazalpour et al., 2014; Mohammed, 2014). Therefore, many older people do not recognise or accept low vision eye complications as associated with diabetes; they don’t even communicate low vision with health professionals, which makes the situation more risky. The quote below illuminates this phenomenon:

“The loss of vision would worry me, but I did not know this is a complication of diabetes, I thought this is just my age related problem.”

(Interviewee Five: Focus group)

“See I didn’t know about the low vision, no one told me that before, I thought this is just related to my age otherwise I would have had no problem to check my eye every year, this is just a sample information but no one give me that information, I think information’s is very important.”

(Interviewee Six: Focus group)

"I never had anybody to explain what is happening and why, and what to do. I just accepted the fact that I have diabetes with eye problems."

(Interviewee Five: Interview)

Older people in residential care homes may not be aware of low vision associated with diabetes, or may be unable to explain their low vision conditions to health care professionals.

These quotes below illuminate this phenomenon:

"Well they send an appointment to have my eyes tested but it comes around every February. Then I presume its reported, because I used to have to go to the hospital for a check-ups, then they said it isn't necessary to go up there when I can go to my own Doctor, then the report. The diabetes people then come to see you, and from last 2 years I had no check-ups, I don't know about my appointment. These Girls (HCAs) said they will talk to my GP but may be they are so busy."

(Interviewee Eight: Interview)

"I had been here for 4 years in this care home and the doctor came to me once. I used to go to hospital every year for my diabetes and eyes check-ups but when I moved here no one told me anything about the diabetes. I saw two other doctors and they came last year, bank holiday. I don't think so something was wrong with me, and I told them 'I am ok, nothing wrong with me'. I knew what was going to happen. They sat, talked and said 'There's nothing wrong with me' so 'I think we should take you to be on the safe side'. I went to the hospital, and they did an x-ray and they came out and said 'You've got a chest infection'. I said 'there's nothing wrong with me'. Anyhow, well they kept me in a week, and I came back in here and guess what, I had MRSA. I only saw the HCAs that looked after me ... so when they

said about the MRSA, I said 'let me die and go with my husband'. I am very worried about my health."

(Interviewee Two: Interview)

"I don't know about my diabetes problems and I really like if somebody can spare the time to come and explain to me about the diabetes, as long as they don't want me to go to them, as I can't walk without support."

(Interviewee Eight: Interview)

Additionally, many older people are unwilling to undergo surgical eye treatment. The statement quoted below reveals the interaction between them:

"Some things have been done in my right eye (operation). Yes, but I don't know when. The doctor said they will do this (operation) again but I refused."

(Interviewee Five: Interview)

"I've got reading glasses and I put them on but I can't see as well as the day ones I use, maybe I don't have any vision in my this eye (left eye). I have only one eye. This one I can see the daylight and an image but when it gets nearer to it, it's gone. I've been to the optician and eye doctor. I've got the glasses from them. They said they didn't think they could do much more. Doctor advised operation to me but I am scared as I've only got the one eye and I don't want to lose it."

(Interviewee One: Interview)

5.5.1.2. HCAs issues

Health care assistants are a very valuable group of individuals who can focus on their home care residents' eye complications; however, due to lack of knowledge, awareness and training on low vision and diabetes they may also

think that low vision is just an age-related process. The statement quoted below reveals the interaction between them:

“I don’t know low vision is a complication of diabetes, I thought this is just age related eyes problem.”

(Interviewee One: CS)

“I don’t know about the low vision and diabetes, I am just a carer, we only helping residents with personal care or if they need any support with daily activities, I am not trained for low vision and diabetes. We administering prescribed medication only, even we don’t know what this medication is for and I think we really need to know about medications and diabetes complications to help our residents.”

(Interviewee Three: CS)

“I think this is the doctor’s job to find out about eyes and diabetes problems. In this care home we have many people with low vision and diabetes but we never involved in their diabetes related care.”

(Interviewee Five: CS)

Many health care assistants think that low vision and diabetes related problems are not their responsibilities. This will make the situation even worse and more complex when the responsibility for all health care, including low vision and diabetes, is transferred from the older people to the care home (WHO, 2011). However, older people in care homes with no effective health care support may increase the numbers of undetected low vision.

The statement quoted below reveals the interaction between them:

“Low vision and diabetes care is not my responsibly, we are very busy in doing personal care, in our shifts we assisting in attending to social and physical needs bathing, shaving, dressing, feeding, writing of daily care plans.”

(Interviewee Four: CS)

“I don’t know about the low vision and diabetes, but I think every older person need to wears glasses due to age. Many residents are coming here with glasses but after a few months they not bothering to wear glasses.”

(Interviewee Six: CS)

5.5.1.3. Health professionals’ issues

Ophthalmologists and optometrists are the key group of health professionals responsible for providing good service to older people with low vision and to reduce undetected low vision. However, these professionals are facing difficulties in their practices, including finding information regarding financial eligibility for free glasses (Watson and Bamford, 2012), or maybe staff, and managers of care homes are feeling uncomfortable about providing financial records, due to confidentiality.

The quote below illuminates this phenomenon:

“I think that people with diabetes have a lot to contend with and they have multiple issues that they have to deal with and multiple appointments for conditions outside of their eyes, so it is, I think, eye care that is in danger of being put as a low priority in all of the rest of their general care. So it might be forgotten in the residential care homes and in the community. Sometimes I don’t know if the person is eligible for free glasses or not, as some care homes are not providing financial record.”

(Interviewee One: OG)

In care homes, low vision or other eye disease records are sometimes not available, but GPs, nurses, occupational therapists, or hospital staff who are in

regular contact with care home residents keep the records up-to-date. The quote below illuminates this phenomenon:

“Usually care homes have the medical records of their residents which is good, but some care homes don’t have any records about the eye health; even the staff are unable to give you any information regarding the eye health, check-ups, medication related to eye health or any eye health professionals’ visits.”

(Interviewee Three: OG)

Some general health professionals may think that low vision and other eye illness is not related to their practices, which is a barrier to timely identification of eye illness.

These quoted expressions below illuminate this phenomenon:

“Many times I been to the care homes for residents’ eye examinations which was just eye infections, can be treated by GPs.”

(Interviewee One: OG)

“I think lack of awareness about eye health and formal vision examination, also staff ignoring eye health issues, they not keeping any records of eye health professionals’ visits, or previous operations records.”

(Interviewee Four: OG)

5.5.2. Management of low vision and diabetes within residential care homes

This section is divided into the following sub-categories:

5.5.2.1. How the diagnosis was made

5.5.2.2. HCAs Perspectives about diagnosis.

5.5.2.1. How the diagnosis was made

Unfortunately, there is a lack of awareness and knowledge with care home staff regarding blood sugar monitoring and achieving a balanced diet, which contributes to an increased burden of diabetes, diabetic retinopathy, and related visual impairment in old people (WHO, 2011; Care Home Guide, 2013). There is a need to address this imbalance between knowledge and awareness and the care given.

The quote below illuminates this phenomenon:

“I know that (KG) have diabetes from very long time. I thought diabetes is not that serious disease, also we don’t know that she has any eye problems, and 4 months ago she had a fall. We call 999 and they took her to the hospital. After 2 days when (KG) back to our care she was diagnosed with cataract and diabetes Reeretan (diabetic retinopathy). She is in the list for operation.”

(Interviewee Five: CS)

“When (Mr.DS) was came here he has no information about his diabetes or any allergies, I found him not responding, in his bedroom on the floor. We call ambulance, they checked all his signs and symptoms. The ambulance crew said he has hypoglycaemia, they give him sweets and some orange juice and he was okay at that time. Paramedic said update his GP, we request GP visit and he was diagnosed with diabetes.”

(Interviewee One: CS)

‘I don’t know what is hypoglycaemia and hyperglycaemia, because if somebody has diabetes how can we give him sweets, anyway this is not our job to diagnosed diabetes or eye problems (laugh).’

(Interviewee Six: CS)

5.5.2.2. HCAs' perspectives about diagnosis

According to RNIB Guidance 2011, residential care home staffs, including HCAs, need to be aware of low vision and diabetes, and recognise the key signs of low vision, such as holding onto walls and furniture during walking, falls, and an inability to read or recognise people. In these instances eye tests must be arranged if at least two key signs are noticed (RNIB, 2011). But lack of knowledge and training on low vision and diabetes, limited time and unlimited duties, result in staff being unable to recognise and detect any of these key signs or symptoms.

The quote below illuminates this phenomenon:

“To be honest with you, I don’t know a lot. Actually at all, about low vision and diabetes, so you know it would be to me, I would like to know more, as I don’t know if someone had a fall due to mobility or low vision, we can’t diagnose if they have diabetes or low vision, this is not our job, we just call 999 and they do the rest (laugh).”
(Interviewee Two: CS)

Care home staff may not give any priority to low vision and eye health, due to working very hard and the numerous other tasks which need to be finished in a limited time.

The quoted expression below illuminates this phenomenon:

“We have three shifts, but in each shift we are very busy in different tasks, including providing personal care to residents, and housework, assisting in attending to social and physical needs, shaving, dressing, feeding, complete personal care, writing and updating care plans. But if residents have any health problems we not dealing with those tasks, as we don’t have any training on low vision and diabetes or any other health problems so diagnose is not our responsibility.”
(Interviewee Six: CS)

“When we coming for duty in the morning our first job is to give a personal care to all resident. In one unit we have 17 residents and for these residents we only 2 HCAs, then we starting making beds, changings all bed sheets and tidy and cleaning their bedrooms, then organising dining room for breakfast and after breakfast we helping residents to transfer them to lounge, then one member of staff are helping them and assisting them to the toilet if they need our any other help, and one member of staff writing daily progress notes. Then this member of staff going to the lounge for help and other member of staff coming writing daily progress notes, after this task we preparing dining room for diner, we are helping all residents to the dining room and after the dinner we assisting them to the lounge. In the meantime if we noticed any changes related to health we updating the progress notes and updating monuments and if needed the calling to GPs or ambulance. We have half-an-hour break in 7 hours but sometime we did not get time for our breaks even.”

(Interviewee Five: CS)

5.5.3. Barriers to deliver good care to older people with low vision and diabetes

This section is divided into the following sub-categories:

5.5.3.1. Communication

5.5.3.2. HCAs’ knowledge and awareness

5.5.3.3. HCAs’ training.

5.5.3.1. Communication

The WHO suggested that good communication can improve patient adherence (WHO, 2003); however, the meaning of good communication in this example is built upon the professionals' expertise to impart information. Professional capability is a major element in earning trust from the person. The skill of explaining things clearly and enabling people with diabetes, understanding why they have to receive the treatment, is essential to give diabetes education.

The quoted expression below illuminates this phenomenon:

"I am not sure what to say about the communication. I think for communication you really need good information for what you saying or communicating to the person. For example, if I want to talk to the residents, specially about their health, I need all information about the problem and I will be able to say something to them, and for me diabetes and low vision is completely new thing. I don't have any information even for myself so what should I communicate to the residents (laugh)?"

(Interviewee Two: CS)

"I think knowledge is the key of good communication, if you don't have a good knowledge and information you will not be able to communicate anything."

(Interviewee Six: CS)

Health professionals have to learn good communication skills, as negotiation is two-way; the capacity to gain an insight into a person with diabetes' needs is an important skill required in order to approach the person and let them feel that they have been understood.

The quoted expression below illuminates this phenomenon:

"As (MER) said, for good communication we need a good knowledge and information's about the problems as will we need to listen

carefully what the older person want to say, If you not listening them you will not be able for good communication with them.”

(Interviewee One: CS)

“For good communication you need to be a good listener; also needs good information about the problems. Communication is very important for all health care staff as this is the only way to know about the resident and they know about us. We recording and communicating any changes about resident health in their care plans. We had training ‘good communication skill and record keeping’, but this training is just for daily activities, about foods, personal care, cleanings, assisting residents with their daily needs, any accidents. I think if we get some training about low vision and diabetes we will be able to help our residents and to communicate with them everything about their diabetes and any health problems.”

(Interviewee Three: CS)

Many issues regarding domiciliary eye care and testing are reported by optometrists, but communication as a key issue needs more attention.

The quoted expression below illuminates this phenomenon:

“Communication is very important when we going the care homes, as usually care homes have the medical records of their residents which is good, but some care homes don’t have any records about the eye health; even the staffs are unable to give you any information regarding the eye health, check-ups, medication related to eye health or any eye health professional’s visits.”

(Interviewee Three: OG)

The findings of this research suggest that communication skills are fundamental for low vision and diabetes counselling; a better explanation from healthcare professionals could give different results for low vision and diabetes care. The

information needed for low vision and diabetes care is imparted through formal and informal education, and healthcare professionals can provide support that can influence the progression and content of low vision and diabetes care in older people.

5.5.3.2. HCAs' knowledge, education and awareness

Lack of education, awareness and knowledge are the key barriers to providing good care for low vision associated with diabetes and early diagnosis.

The quoted expression below illuminates this phenomenon:

"I don't know that diabetes have any complications related with eyes. Are low vision is associated with diabetes? I thought low vision is just age related problem."

(Interviewee Five: CS)

Lack of knowledge and awareness regarding low vision is the same problem in both HCAs and in older people, as both parties think that low vision is a normal ageing process. Many health care assistants think that care of eye health and low vision is not on their list of tasks.

The quoted expression below illuminates this phenomenon:

"While I don't know nothing about the low vision and diabetes, as this is not my responsibility and job, as HCA my role is to provide help with daily activities to residents only, and any housework related to them."

(Interviewee Two: CS)

Lack of awareness for staff, in particular, the incorrect use of glasses, mixing up, the wrong glasses or using old prescribed glasses, is also a basic problem in care homes.

The quoted expression below illuminates this phenomenon:

(Mr D.S.) had 3 pairs of glasses but he is not wearing them. It is labelled with his name, but when he is coming to the lounge he wearing someone else's glasses. Several times we explained to him but I don't know why he is wearing other people glasses, maybe he doesn't like his own glasses, or maybe he can't see properly in his own glasses."

(Interviewee Four: CS)

"(Miss F.E.) is not wearing her glasses, she said that this is not comfortable for her, we reported that in her care plan, so don't know what is next."

(Interviewee Six: CS)

"While I don't know how to detect if someone have low vision associated with diabetes, I am not trained for this job."

(Interviewee One: CS)

"If some residents lose their eyesight, I don't think through diabetes, but we've gradually started to notice. If they are having regular check-ups then obviously we would know. As just a carer looking at somebody, I wouldn't be able to tell. It would be in their care plans and when they have regular check-ups we would be informed."

(Interviewee Three: CS)

There are no clear policies and procedures regarding low vision records and regular eye testing, or diabetes complications associated with low vision, which can be the main issue to increasing the risk of low vision and diabetes.

5.5.3.3. HCAs training

The main barrier to providing good care to older people with low vision and diabetes is a lack of training for HCAs on diabetes and eye health.

The quoted expression below illuminates this phenomenon:

"I think training and education is very important and we need training and education so we can understand more about the insufficiency of diabetes and low vision for us and residents toward good care."

(Interviewee Two: CS)

"We do other training but none on low vision and diabetes."

(Interviewee Three: CS)

"I think training and education should be provided, whether in the residential care home or the community, because the more you know about these things (low vision and diabetes), the better you can understand and control it, also we will be able to provide good care to these things (low vision and diabetes)."

(Interviewee One: CS)

"We really need good training on diabetes and low vision because if you are caring for someone and you don't have knowledge about their care, how will you be able to give a good care to them?"

(Interviewee Five: CS)

"We do have some course about medication, social care, COSHH assessment, food safety, first aid, dementia awareness and nutrition, health and safety. But a specific one for diabetes and low vision would be beneficial."

(Interviewee Six: CS)

Targeting HCAs is the best option for detecting signs of low vision; also they can request a booked appointment for their residents' eye tests as they spend more time in the care home and provide personal care to the residents. It may decrease the risk of low vision and diabetes.

The quoted expression below illuminates this phenomenon:

“Sometimes we requesting to the nursing staff and when they coming after one day, sometimes after a week, we preparing everything for them as we knows our residents and they trusting on us as we helping them with all personal care. The nurse only checks blood pressures, temperatures and sugar, and if the residents need medication, nurse asking us to contact the GP. I think if we get some training so procedure will be more quickly and fast for residents and also we can safe lots of money for NHS.”

(Interviewee Five: CS)

“I have completed my NVQ2 and had many trainings but unfortunately I have no training on low vision and diabetes. I think if we get training on diabetes then we will know diabetes complications, particularly eye complications, and we will be able to check our residents’ sugar, then we will not calling unnecessarily to nurses for only diabetes sugar check-ups, also we can provide good care to our residents.”

(Interviewee Four: CS)

“We need a training to give us complete information’s about diabetes complications, blood glucose levels, hyperglycaemia, hypo-glycaemia, insulin, diabetic retinopathy, low vision, as we don’t know nothing about these problems.”

(Interviewee Two: CS)

“I think training and education will bring prevention and it’s very important for HCAs if they caring for older people with diabetes and low vision.”

(Interviewee Three: CS)

'I think there is no training on low vision and diabetes, yes I don't think so as we have training for medication and a lots of other training but nothing on diabetes.'

(Interviewee One: CS)

My research shows that standardised diabetes training and educational programmes could be beneficial to HCAs if they have good training and knowledge regarding diabetes; however, without constantly evaluating training and educational schemes, the content might fail to meet the needs.

5.5.4. Summary of 'Helping hand'

The theme 'Helping hand' was emergent from comprehensive data of Phase One. 'Helping hand' indicates and evaluates health care assistants' knowledge and understanding of the impact of low vision associated with diabetes in older people to develop HCAs' skills, and is extracted from three categories:

- (1) Key issues in managing low vision and diabetes older people;
- (2) Management of low vision and diabetes within care homes; and
- (3) Barriers to delivering good care to older people with low vision and diabetes.

The first category indicates that 'key issues in managing low vision and diabetes in older people' was abstracted from three sub-categories: older people's issues, care home staff issues and health professionals' issues. It appears that the content for all of these issues in managing low vision and diabetes in older people, and information of these issues, is needed for diabetes control based on their own consideration of whether this advice has been feasible to fit their situations. To equip health care assistants with specific knowledge and skills for low vision and diabetes care, healthcare providers need to consider how to conquer the limitations of standardised low vision and diabetes care, and to manage the process of low vision and diabetes care, being flexible enough to satisfy each individual's need in various situations and environments.

Secondly, the category of 'Management of low vision and diabetes within care homes' was abstracted from two sub-categories: how the diagnosis was made, and the HCAs' perspectives about diagnosis. The findings indicated that lack of awareness and knowledge between health care assistants and older people affected the process of diagnosis of low vision and diabetes. Quick response, early identification and good medical support can reduce the risk of low vision and diabetes; some older people may only need new prescribed spectacles, although some individuals may need surgical or medical treatment. It is therefore essential to provide quality low vision and diabetes care to older people. A third category's barrier to delivering good care to older people with low vision and diabetes was abstracted from three sub-categories: communication, health care assistants' knowledge and awareness, and health care assistants' training, as these are the key elements to low vision and diabetes care. The purpose of diabetes training and education is to increase the health care assistants' knowledge and skills of low vision and diabetes to control and prevent complications of diabetes. Evidence shows that the improvement of diabetes care has to focus on good communication (Aikens et al., 2005). For good communication, awareness and knowledge is important, and to gain the awareness and knowledge, good training is the essential key. As a medical doctor and after my research on this issue, I identified a training gap, specifically for health care assistants, and this was the motivation for me to develop the comprehensive low vision and diabetes education toolkit for health care assistants. A detail of this comprehensive toolkit is listed in the Appendix on page 379.

5.6. Summary of themes across all interviews and both focus groups

The focus groups with the older community residents, the focus group with the optometrists, the interviews with health care assistants and the interviews with the care home residents, all produced quite different results. Although

knowledge was deemed to be important in all groups, Group 1 reported more interest in formal education plans delivered by trained health professionals. Group 2 advised more education and knowledge on low vision and diabetes for HCAs. Group 1 perceived good relationships with healthcare professionals to be paramount to successful low vision and diabetes care. Group 2 was also more active and placed more importance upon exercise and regular eye check-ups. Group 2 displayed motivation linked to related distress and fear of complications, whereas Group 1 found most motivation was generated from good relationships with healthcare professionals and positive feedback. Group 1 reported the importance of maintaining a dietary regime but noted few tangible strategies for doing so, with the possible exception of limited treats. Both groups perceived some inequality in access to and provision of healthcare services. Interestingly, both groups specifically mentioned a lack of education, knowledge and awareness regarding low vision and diabetes.

5.7. Strengths and limitations of the interviews and focus groups studies

For the Interviews, please refer to Chapter 3, section 3.3, Identification of key methods. The usefulness and suitability of focus groups in healthcare and psychological research has been well established, with many focus groups conducted in this arena (Vogt et al., 2004; Kvale and Brinkmann, 2008). As a tool in this study to explore and refine low vision and diabetes, the focus group format is likely to be highly acceptable to participants, allowing interaction and exchange of ideas and experiences. Using the focus group methodology allowed the canvassing of opinions from this group, which was vital in constructing a valid low vision and diabetes care schedule. As with any focus group, the individual participant's nature can influence and vary the outcomes.

5.8. Conclusions

Similar themes to those raised during interviews and focus groups were found in the earlier literature review, particularly the fundamental importance of education and knowledge. According to Charles 2007, 70% of low vision is treatable if diagnosed during the early stages, also (Kvale and Brinkmann, 2008) found exercise, medication management, and regular check-ups were important. The themes of motivation, education and knowledge emerged from interviews and both focus groups, which were found in the literature review as well, (DeWinter et al., 2004; WHO, 2011). The importance of family and friends' support was acknowledged by both focus groups and within the literature (Watson et al., 2012). The literature review, interviews, questionnaires and focus group findings have all allowed a development of the low vision and diabetes education toolkit; this toolkit will help health care assistants to understand the importance of diabetes controls and eye examinations, early diagnoses and, in time, treatment, as well as reducing the risk of diabetes complications. It may be possible that the education toolkit will become increasingly important.

CHAPTER 6

DEVELOPMENT OF THE EDUCATION TOOLKIT

6.1. Introduction to the educational toolkit

The educational toolkit has been designed to educate health care assistants about diabetes related eye diseases, such as diabetic retinopathy, cataracts, glaucoma, low vision and blindness. The toolkit has also been designed to answer some commonly asked questions which arose from interviews during the data collection. If residential care home leaders and managers support the training provided in the toolkit, this will assist health care assistants in providing more specific help and assistance to older people with low vision and diabetes.

The low vision and diabetes education toolkit consists of five units:

- Unit 1 will provide information about diabetes
- Unit 2 will provide information about low vision
- Unit 3 will provide information about eye diseases associated with diabetes
- Unit 4 will provide information about how to control low vision and diabetes
- Unit 5 will check the knowledge gained by addressing commonly asked questions regarding low vision and diabetes

The low vision and diabetes education toolkit is provided in the appendix, page 379.

6.2. The educational toolkit: who is it for and why?

Identifying who to target with education and training and why, were two important questions that I spent a long time considering. To answer these questions, the data transcripts themes and categories were analysed. Following

the analysis of the data presented in Chapter 5, “Helping hands” page 148, and Chapter 4, Figure 8 page 86, showed that in the residential care home environment the HCAs spent up to 24 hours in three shifts: morning, evening and night, every week with residents, and they were the key members of the team in terms of meeting the needs of medications and personal care (Spilsbury and Meyer, 2004; Kessler et al., 2012), so it was decided that the most appropriate group of staff to target with education and training were the health care assistants working in residential care homes.

As discussed in the literature chapter, many researchers believed that educating people with diabetes was important (Adolfsson et al., 2004; Watson et al., 2008; Guthrie and Guthrie, 2009; Royal college of nursing, 2012). I highly agree with this belief; however I also believe that we may not be able to achieve the goals we want when educating older people in residential care homes. Due to their age and mental capability, they may find it difficult to understand medical terminology, processing and remembering information regarding their health problems (Sinclair, 2010; Care Home Guide, 2013). The evidence gained from the research undertaken in this thesis identifies that our main goal should be educating the health care assistants on low vision and diabetes.

Older people in residential care homes with no effective health care support may increase the numbers of undetected cases of low vision and diabetes (Burkhardt and Nathaniel, 2007; Maben et al., 2012; Roberts, 2013; Sinclair, 2014; Higham, 2015).

Most of the HCAs that I spoke with during the interviews did not think that low vision and diabetes care were their responsibility. This will make the situation even worse and complex as the responsibility for all health care including low vision and diabetes has transferred from the older people to the residential care home (WHO, 2011; Care Quality Commission, 2014).

For example, the statement quoted below reveals the interaction between them:

(Quote 1 from HCAs Interview)

“low vision and diabetes care is not my responsibly, we are very busy in doing personal care, in our shifts we assisting in attending to social and physical needs bathing, shaving, dressing, feeding, writing of daily care plans.”

(Interviewee 4: CS)

From my findings, lack of communication skills, training and education amongst health care assistants about low vision and diabetes are the main barriers to providing good care to older people with low vision and diabetes living in residential care homes, as discussed in Chapter 5, ‘Helping hands’ page 148.

The theme ‘Helping hands’ was divided into three categories:

(1) The first category indicates that ‘key issues in managing low vision and diabetes in older people’ is abstracted from three sub-categories: older people’s issues, HCAs’ issues and other health professionals’ issues. It appears that information on these issues is needed for diabetes control, based on consideration of whether this advice has been feasible for their situation. To equip the older people, HCAs and health professionals with specific knowledge and skills for low vision and diabetes care, and healthcare providers need to consider how to conquer the limitations of standardised low vision and diabetes care, and manage the process of low vision and diabetes care, being flexible enough to satisfy each individual’s needs in various situations and environments.

(2) Secondly, the category of ‘Management of low vision and diabetes within the residential care homes’ is abstracted from two sub-categories: how the diagnosis was made; and health care assistants’ perspectives about diagnosis. The findings indicate that lack of awareness and knowledge between health professionals and older people affects the process of

diagnosis on low vision and diabetes. Quick response, early identification and good medical support can reduce the risk of low vision and diabetes; some older people may only need new prescribed spectacles, whereas some individuals may need surgical or medical treatment. It is therefore essential to provide quality low vision and diabetes care to older people.

- (3) The third category barrier to delivering good care to older people with low vision and diabetes is abstracted from three sub-categories: communication; health care assistants' knowledge; and awareness and training, as these are the key elements to low vision and diabetes care.

Evidence shows that the improvement of diabetes care has to focus on good communication (Aikens et al., 2005; Bosanquet and Mehta, 2008; Lorig et al., 2009). However, I will say for that good communication, awareness and knowledge, training is the essential key.

For example, the quoted expression below illuminates this phenomenon:

(Quote 1 from HCAs Interview)

"I am not sure what to say about the communication, I think for communication you really need good information for what you saying or communicating to the person. For example, if I want to talk to the residents specially about their health, I need all information about the problem and I will be able to say something to them, and for me diabetes and low vision is completely new thing. I don't have any information even for myself so what should I communicate to the residents (laugh)?"

(Interviewee Two: CS)

(Quote 2 from HCAs Interview)

“I think knowledge is the key of good communication, if you don’t have a good knowledge and information you will not be able to communicate anything.”

(Interviewee Six: HCAs)

The serious gap in knowledge, training, education and lack of communication skills about low vision and diabetes amongst health care assistants (detailed data is presented in Chapter 5, theme ‘Helping hands’, page 148), was the main motivation and these reasons alone were enough for me to decide to create an education toolkit. The main purpose of Phase Two was to develop the education toolkit, and deliver and validate the utility of the toolkit. Through this systematic approach to developing, implementing and testing the impact of the toolkit I was anticipating learning what impacts the toolkit had and how to refine it. If successful, the toolkit should increase the awareness of low vision associated with diabetes.

A standardised low vision and diabetes educational toolkit could be beneficial to health care assistants; if they have good training and knowledge regarding low vision and diabetes they will be able to deliver good health care to older people.

6.3. Objectives of the educational toolkit

These objectives are very important as being aware and understanding the disease is the key to preparing patients to manage their disease (Heisler et al., 2005; NHS Right Care, 2011), and poorly controlled diabetes is associated with a lack of knowledge about diabetes (Al Sayah et al., 2013; Sinclair, 2014). One of the main barriers to providing good care of diabetes complications to older people in residential care homes is the lack of knowledge and training for HCAs (Sinclair, 2010; Gallichan, 2012), and during health related training for HCAs in residential care homes, diabetes was only covered by a few sentences (Redman, 2002; Eigenmann et al., 2009; Al Sayah et al., 2013).

The diagnosis of low vision may be more delayed due to lack of diabetes awareness and knowledge (Nazimek et al., 2002; Zhang et al., 2010) and there is a 99% chance of low vision associated with diabetes in older people (Haddrill, 2007; Scanlon, 2008; WHO, 2009; Sinclair, 2010).

Diabetes related eye diseases, including diabetic retinopathy, maculopathy, proliferative retinopathy, cataracts, glaucoma and age-related macular degeneration, are the main reasons for low vision associated with diabetes in older people (Bunce and Wormald, 2008; NDIC, NIDDK and NIH, 2008; Scanlon, 2008). Researchers reported that more than half the low vision associated with diabetes is preventable in older people (Tate et al., 2005; Charles, 2007; Griffiths et al., 2012).

The following objectives were developed to guide the content of the toolkit:

- To educate health care assistants regarding diabetes-related eye diseases and their complications;
- To raise awareness of all serious eye complications and problems linked to diabetes, such as diabetic retinopathy, cataracts, glaucoma, low vision and blindness;
- To reduce the risk of low vision and diabetes complications in older people;
- To understand the importance of diabetes controls and regular eye examinations;
- To understand the importance of early diagnosis and prompt treatment of low vision and diabetes complications.

6.4. How the educational toolkit was developed

When this research commenced, it had not been intended to develop an educational toolkit. From the beginning the researcher wanted to understand the issues and problems of older people living in residential care homes with low

vision and diabetes; to understand in more depth the causes and approaches to preventing low vision and diabetes in older people and to learn how older people in residential care homes received low vision and diabetes care, and also to examine how low vision and diabetes influences the everyday life of people living in residential care homes. After the data collection had been completed and during the analysis of the data, it was apparent that there were many questions asked by the HCA participants during data collection.

For example, I produced the question to describe what is said below in Quote 2: 'What are hypoglycaemia and hyperglycaemia?' and received the answer: 'I don't know; what is hypoglycaemia and hyperglycaemia?'

(Quote 1 from HCA's Interview)

"When (Mr.DS) was came here (residential care home) he has no information about his diabetes or any allergies, I found him not responding in his bedroom on the floor. We call ambulance; they checked all his signs and symptoms. The ambulance crew said he has hypoglycaemia, they give him sweet and some orange juice and he was okay at that time. Paramedic said update his GP, we request GP visit and he was diagnosed with diabetes."

(Interviewee One: CS)

(Quote 2 from HCA's Interview)

"I don't know what is hypoglycaemia and hyperglycaemia; because if somebody has diabetes how can we give them sweets? Anyway this is not our job to diagnosed diabetes or eye problems (laugh)."

(Interviewee Six: CS) (Detail presented in Chapter 5)

What are common diabetic eye diseases?

(Quote 1 from HCA's Interview)

“We need a training to give us complete information’s about diabetes complications, Blood glucose levels, Hyperglycaemia, Hypoglycaemia, Insulin, Diabetic retinopathy, low vision, as we don’t know nothing about these problems.”

(Interviewee Two: CS) (Detail presented in Chapter 5)

Following data collection sessions, further questions arose on more than one occasion, for example:

- What are the normal ranges of diabetes and HbA1c levels?
- Is diabetic retinopathy treatable?
- Is laser treatment safe for the eye?
- Is it possible to prevent diabetic retinopathy?

These encouraged investigations of the data in more detail and on re-examination, it was discovered that many other questions had been asked by the HCAs about low vision and diabetes. The questions covered a number of areas, and full details of these questions are presented in the toolkit Appendix, page 395. Having discovered this wide range of questions, time was spent exploring their content with Professor Alan Sinclair and Professor Peter Scanlon, both of whom have relevant experience.

Professor Alan Sinclair is an internationally-recognised expert in diabetes and medicine for the aged. At the time of this research he was Professor of Medicine at the University of Bedfordshire and Dean at the Bedfordshire & Hertfordshire Postgraduate Medical School (BHPMS). Professor Sinclair was formerly Charles Hayward Professor of Geriatric Medicine in Birmingham and Honorary Professor of Medicine in Warwick. He is the author of many papers in the area of diabetes and conducted the first detailed prevalence Study of Diabetes within Care Homes. He led the recent Task & Finish Group of Diabetes UK to update National Guidance on Diabetes in Care Homes. He is the author of the first textbook on Diabetes in Old Age, published by Wiley & Sons, and a Third Edition of this

textbook was published in 2009 (Sinclair, 2009). Professor Sinclair was appointed National Clinical Lead in Diabetes for Older People in 2010 was recently awarded, as co-lead, six million euros by the European Union Commission to investigate the relationship between diabetes and frailty. Professor Sinclair is currently leading a national initiative by NHS Diabetes in the area of diabetes in older people.

Professor Peter Scanlon is Programme Director for the English National Diabetic Retinopathy Screening Programme and Professor of Ophthalmology. He provides a specialist service as a Consultant Ophthalmologist at the Gloucestershire and Oxford Eye Units and is Clinical Lead for the Gloucestershire and Oxfordshire Diabetic Eye Screening Services. Professor Scanlon is developing a research programme at IDOP in the area of Visual Loss in Care Home Residents with Diabetes. He has contributed to an educational DVD developed by the National Older People's Steering Group of NHS Diabetes.

Following conversations with Professor Alan Sinclair and Professor Peter Scanlon, it was proposed to develop an educational toolkit to improve the knowledge amongst HCAs about low vision and diabetes. This generated Phase 2 of the research. As this amended my original ethics approval, I generated a revised ethics application and this was submitted to the University of Bedfordshire Ethics Committee. Full ethical approval was granted; please see Appendix page 345 for application. This enabled work to commence on the development of the educational toolkit.

6.5. The design principles to develop the educational toolkit

Developing an educational toolkit requires large expertise and time (Guskey, 2009; Woolhandler, 2009; Cook et al., 2012). To ensure the design and development of an effective low vision and diabetes educational toolkit for

HCAAs, a wide range of approaches was studied that would inform the development and design of the toolkit.

Listed below are a few examples of the training and educational toolkits models that were studied:

1. CHOICE (Carbohydrate, Insulin Collaborative Education) education programme for young people with type 1 diabetes (Chaney et al., 2012; Coates et al., 2013; Chaney, 2014).
2. Palliative and end of life ABC education programme (Cook et al., 2012)
3. Quality Standards for Diabetes Care Toolkit (Ministry of Health, 2014)
4. Literacy Assessment for Diabetes (LAD) (Nath et al., 2001; Department of Family Medicine, 2014).
5. Diabetes Specific Health Literacy Measure (Al Sayah et al., 2012).
6. Diabetes Knowledge Test (DKT2) (Fitzgerald et al., 2016).
7. A Diabetes Education Initiative for Residential Care Home Staff (Gallichan, 2002)
8. Diabetes Essentials (Lawal et al., 2012; Focus Care, 2015).
9. The Diabetes Prevention Program (DPP) (The Diabetes Prevention Program, 2002; National Institutes of Health, 2008).

Most of the above trainings, however, concerned general knowledge about diabetes. In my research, following data collection, I realised that the HCAAs needed specific knowledge about low vision and diabetes.

Following extensive reading, the ADDIE (Assessment, Design, Development, Implementation, Evaluation) model was selected as the appropriate approach. The ADDIE model is one of the most recognised and well-used ISD models (Instructional System Design) as it is consistent, with helpful Instructions and it can be used in a wide range of fields when developing educational tools, including health education tools (Yang, 2004; Dick et al., 2014)

The ADDIE model has been evaluated in different educational toolkits by many researchers several times over the years (Gustafson and Branch, 2002; Michael et al., 2006; George , 2006; Dick et al., 2014; Donclark, 2015). It is very useful, beneficial and easy to use, particularly in health educational toolkits (Hannuma, 2009; Elaine, 2015).

The step-by-step processes of the toolkit development are presented in Figure 21, below.

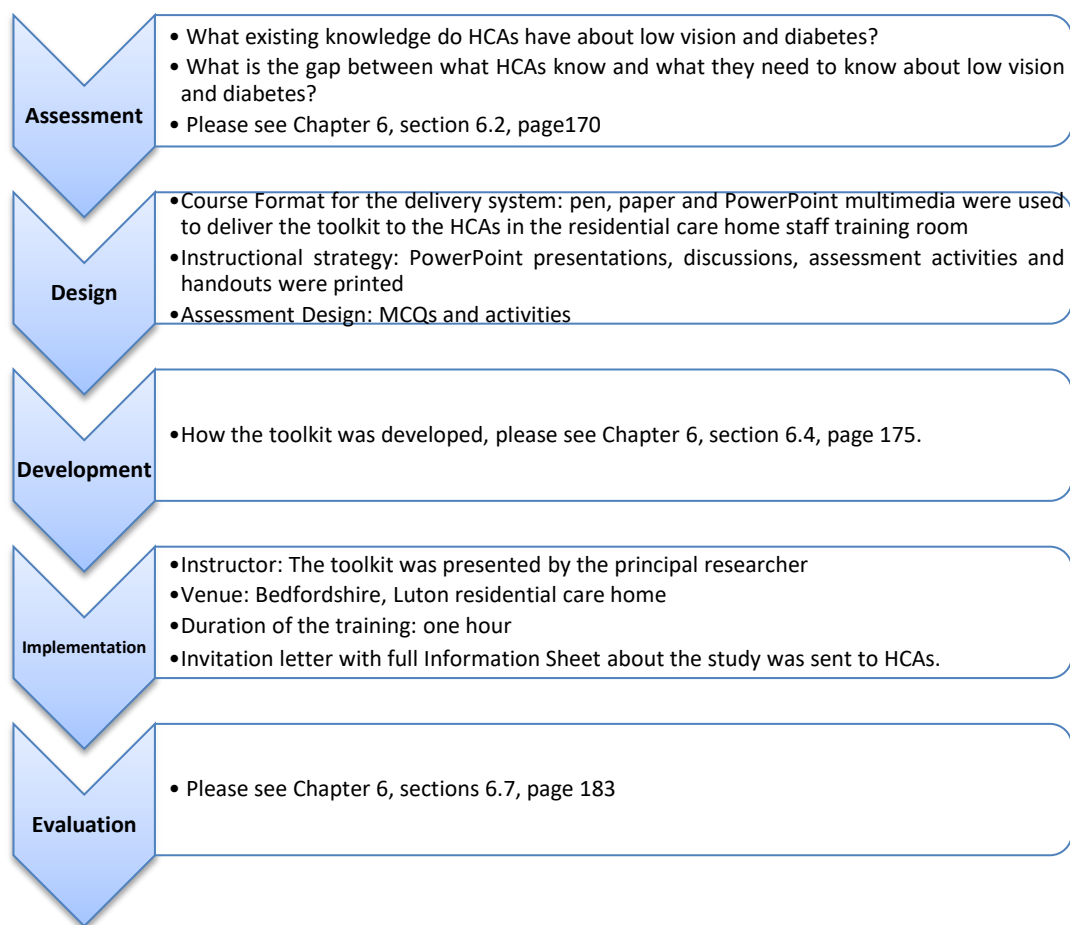


Figure 21 Toolkit development process

6.6. Methods and criteria for sampling and testing the educational toolkit

The ten residential care home managers who had previously responded to Phase One of this study were contacted through letters and phone calls to make

appointments to explain the study and toolkit training details, and to provide criteria of sampling for Phase Two. This entailed randomly choosing 20 qualified health care assistants, 2 participants from each residential care home, including those who had previously responded to Phase One, with minimum qualifications of NVQ2 or QCF2 and 2 years' experience of work in a residential care home, with no age or gender restrictions.

The care home managers were able to provide lists of potential participants; care home managers also gave the participants a brief explanation of the study. Following the identification of 22 participants, they were contacted by the principal researcher and visited in the residential care home environment. The participants were given details on the study and toolkit training, and then any questions about the study were answered. The potential participants were given one week to read and consider the Participant Information Sheet and the Consent Form. The training took place after the participants had signed the Consent Forms. Twenty health care assistants from 10 residential care homes were recruited for training between 4th September 2014 and 4th November 2014, for Phase 2 of this study.

The educational toolkit was presented by the principal researcher to twenty health care assistants at a residential care home in Luton; all the participants received toolkit training,

Following Kirkpatrick's model (Kirkpatrick and Kirkpatrick, 2007), the skills and practical use of the educational toolkit package was assessed prior to the delivery of the toolkit, as well as immediately afterwards, for participants of 10 questions to evaluate and assess their baseline knowledge. After one calendar month had passed, the toolkit was tested again using the same 10 questions, for which the results are presented in this chapter below.

6.6.1. Educational toolkit evaluation questionnaire

The evaluation questionnaire content and format was designed by the principal researcher. The questions were formulated from the frequently asked questions that the HCAs participants had asked during data collection.

The questions were also developed from the literature review findings, for example: Is glaucoma a diabetes-related eye disease? Blindness occurs mainly because of? Based on the participant findings and the literature review, 10 open-ended questions were created for pre-test, immediate post-test following the educational session, and again after 1 month, using the same questions to evaluate and assess knowledge of the participants. The Survey Monkey questions are presented in the Appendix, page 363.

The advantages of open-ended questions is to collect rich details in the data (Bosanquet and Mehta, 2008; Boutellier et al., 2013). Open-ended questions will answer complex issues, and permit an unlimited number of possible answers (Green and Thorogood, 2004).

The plus point of an open-ended question is that researchers are not placing any limits on the responses (Gallichan, 2012); the participants can answer anything they feel is relevant and anything they want you to know (Flick, 2002; Mason, 2012; Boutellier et al., 2013; HSCIC, 2015). The questionnaire was designed on multiple aspects of low vision and diabetes and disseminated using Survey Monkey online, which provides a forum and variable formats in which to upload information to generate the questionnaires. 20 participants responded to the questionnaire; the responses were then stored for the researcher to access, analyse and download.

6.6.2. Demographic information of the participants in the use of the educational toolkit

Qualifications of Participants	Gender	Age	Ethnicity
20 HCAs with minimum qualification of NVQ2 or QCF2 and 2 years' experience of work in a residential care home, with no age or gender restrictions.	Female 18	16 Participants aged 20-30, 4 Participants aged 31-40	White 12
	Male 2		Black Caribbean 5
			Indian 1
			Other Asian 2

Table 10 Demographic information of participants for toolkit training

6.7. Critical analysis of the educational toolkit evaluation

I will now present a critical analysis of the toolkit and the process of its development. This analysis is provided in two parts: firstly, an evaluation of the toolkit, which is an important part as it identifies changes that could be made to the existing toolkit and future iterations of the toolkit; and secondly, it identifies my learning as a researcher.

Evaluation on the outcome of the work carried out is very important as it helps to identify what has worked and what has not been successful. This is essential as this can help identify essential improvements, thus leading to overall organisational success. Therefore, my own evaluation is based upon the work of Donald L, Kirkpatrick, (Kirkpatrick, 1959; Kirkpatrick, 1978; Kirkpatrick and Kirkpatrick, 2005; Kirkpatrick and Kirkpatrick, 2006).

6.7.1. Kirkpatrick Model

Kirkpatrick created a unique and effective training model which included the following 4 evaluation levels:

Reaction → Learning → Behaviour → Results (Kirkpatrick, 1959).

This model helps identify areas such as weaknesses and strengths of the training that can help improve the programme (Al Sayah et al., 2013). There are different models that could have been used (Phillips, 2003; Guskey, 2009) but all of them base their work on the foundations provided by Kirkpatrick's model. The database Scopus shows that 1,854 researchers have cited the work carried out by Kirkpatrick (Scopus, 2015). However, research indicates there are some disadvantages to using the Kirkpatrick model. The model is considered by some researchers (Bates, 2004; Sarah and Tim, 2011) to be incomplete as it gives a simplified overview of a training model; this is unfortunate as it does not take the participant or the factors that influence that person into consideration; therefore, the reaction at the first level has a positive influence on the next level. This model also assumes that each level of the model provides more data which appears less informative than the other (Bates, 2004; Sarah and Tim, 2011).

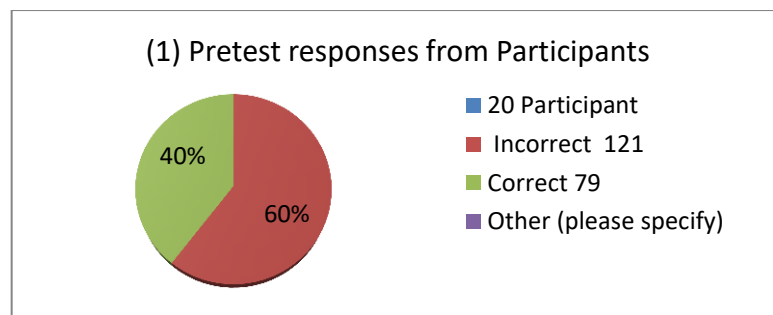
6.7.2. The educational toolkit evaluation literature

The following authors were helpful in considering approaches to the toolkit evaluation methodology: Robson (2011), Mason (2012), (Robson, 2011; Mason, 2012), K Patrick Model Partners (Kirkpatrick and Kirkpatrick, 2005; Kirkpatrick and Kirkpatrick, 2007), and the palliative and end of life ABC education programme 'Impact' evaluation (Cook et al., 2012). Furthermore, I have also analysed the following authors that have investigated training evaluation: (Phillips, 2003; Guskey, 2009). Having recognised the need to re-examine the evaluation methodology utilised in this research, I re-examined the literature. In terms of research methodology, further reading of two authors was found to be

useful. For research methods, the work conducted by (Mason, 2012) provided beneficial guidance in terms of overall methodology, specifically the toolkit evaluation. From Mason's (2012) advice I chose to adopt the work of Kirkpatrick as a suitable evaluative framework. I also looked at the work conducted by (Robson, 2011). However, I found that the majority of his work was built upon the foundations that the Kirkpatrick model established and completed several years earlier. In terms of educational toolkit training evaluation, I located the work of Kirkpatrick. Kirkpatrick is the founding father of evaluation toolkits, which coincides with research conducted by (Phillips, 2003; Businessballs, 2015), as Phillips and Businessballs had identified some of the following evaluation models such as: Context, Input, Reaction, Outcome (CIRO), Program Evaluation and Review Technique (PERT). These have all been built on the foundations established by the Kirkpatrick brothers. During the latter stages of my research I also identified the work of Prof Cook who undertook an impact evaluation of an 'end of life' educational programme (Cook et al., 2012). The methodology was generally robust but my own work had progressed to a substantive point and it was not possible to replicate this with the resources and time available.

6.8. Result of the educational toolkit training

This section discusses the findings and results of the educational toolkit pre-test, post-test and after one month test questionnaires.



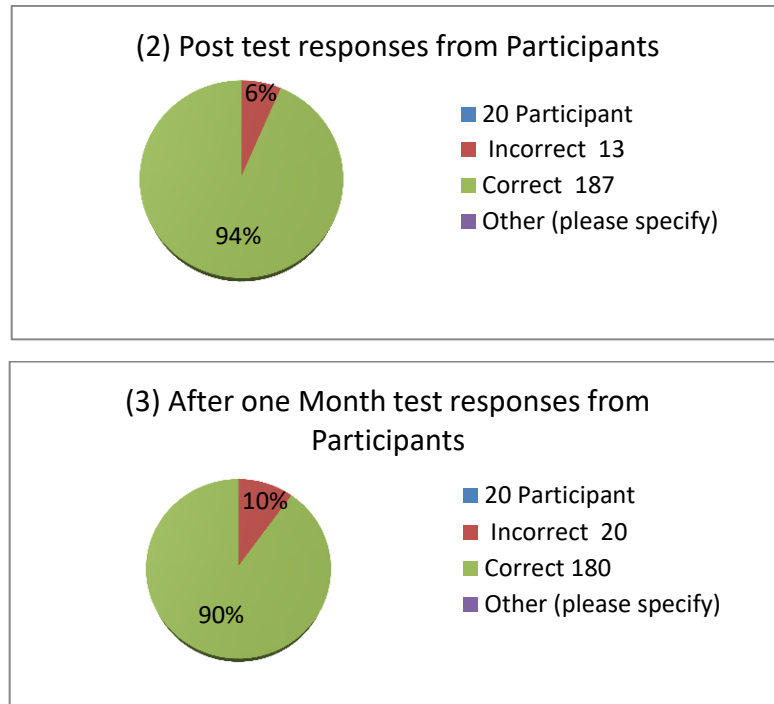


Figure 22 Result of the educational toolkit training

When considering the responses of participants to the pre-test questionnaire, it was clearly observed that there was a mix of responses for most of the questions posed. It is evident to see that many of the participants were not clear about the relationship between diabetes and sight loss, although the toolkit results show that the participants may have had a vague idea but were not entirely sure. For example, approximately 40% of the participants thought that glaucoma was related to diabetes, whereas 45% participants selected the incorrect answer and 15% were not sure in the pre-test result. Furthermore, when considering the same question in the post-test result, 95% of the participants answered correctly, whereas only 5% were not sure of the answer. However, after the test one month later, in the results for the same question, 90% of the participants answered correctly whereas 10% of the participants answered incorrectly. This was a similar theme for Question 2 about the causes of cataracts. In Question 3 about the cause of blindness, 100% of the participants got the answer correct in the post-test and after the test one month later. Furthermore, all participants

were aware that diabetic retinopathy caused blindness in adults. Overall, there was confusion regarding the complications associated with diabetes and eye disease.

Furthermore, the health care professionals were not aware of the recommended testing for individuals with diabetes. In total, only 40% of the participants answered the questions correctly before undergoing training, whereas the remaining 60% answered incorrectly. It should also be noted that a number of participants gave the response 'I don't know' when available; this suggests that the participants may have had some knowledge but were not fully sure of their knowledge. The results of the pre-test indicate that health care assistants need to be trained and educated with regards to the effects of low vision and diabetes. If health care assistants were educated in this area then this could help prevent or identify blindness in older people.

Once the participants had undergone training using the toolkit, they were immediately given the same questionnaire to answer. The study aimed to determine what changes occurred in the responses. It was predicted that an improvement in the response rate would be observed immediately after training. The results of the post-training questionnaire demonstrated that 94% of the responses given were correct and only 6% were incorrect. This demonstrates a large improvement in responses compared to before undergoing training.

The results indicate that the health care assistants were more aware of the connection between low vision and diabetes. Furthermore, the health care assistants were more aware of the testing that should be carried out in order to detect problems, as well as preventing them. Looking more specifically at the participants, nine participants gave all correct answers to the questions and the maximum number of wrong answers was two for any given participant, with 50% of participants giving one incorrect answer. The results of the immediate post-training questionnaire suggest that the toolkit had been effective in educating healthcare professionals. However, in order to determine if the education was

effective in the long term, the same questionnaire was also circulated to the participants after one month.

Participants were given the questionnaire one month after the toolkit training to determine whether they needed more time to fully understand the information. It could be predicted that the results would be mostly correct. The results from the third questionnaire, which was conducted one month after the training was delivered, were equally as promising as the previous results. The results one month post-training showed that 90% of the responses given were correct and 10% were incorrect. The results were similar to the questionnaire conducted immediately after the training in terms of the benefits of the training. The results indicate that the health care assistants were now more aware of the connection between low vision and diabetes.

Furthermore, the health care assistants were more aware of the testing that should be carried out in order to detect problems, as well as prevent them. Out of the 20 participants included, seven participants gave all correct answers to the questionnaire, compared to nine when the questionnaire was conducted immediately after training. Two participants who had previously got either one or two questions incorrect in the immediate post-training questionnaire got all answers correct in the one month post-training questionnaire.

This suggests that these participants had learnt more after training, or may have done some further reading in the field.

Furthermore, the number of participants giving two incorrect answers increased after one month, with 7 participants giving two incorrect answers compared to two participants immediately after the training was delivered. Looking more specifically at the responses, the health care assistants answered questions relating to the types of eye problems, and testing for blindness and eye conditions, accurately, whereas questions related to the symptoms of eye conditions led to the greatest number of incorrect answers. It can be suggested

that health care assistants had forgotten certain aspects of their training, or may not have fully understood the training in the first place.

Full results with details of the Survey Monkey results of the low vision and diabetes education toolkit are listed in the Appendix on page 363.

6.9. Limitations of the educational toolkit

A number of limitations to evaluating the educational toolkit were noted. The educational toolkit was tested again after one month. This timespan was obviously limited and this may have affected the results obtained, but as discussed above there was no plan from the beginning to develop a toolkit in my thesis, and due to the limited time and expenditure, it was not possible for me to prolong the time period for re-testing the toolkit, as I needed to submit my thesis by the University deadline.

The toolkit presentation time was very limited due to numerous reasons, for example: the health care assistants were paid for the toolkit training by their employers, and as this training was not mandatory, I only obtained one paid hour from the residential care homes managers. This one hour included a 5 minute break, 45 minutes of training activities and 10 minutes for the test, so one hour was very limited. At least two to three hours is recommended for the educational toolkit training: one hour for the presentation, 15 to 20 minutes for the practical activities and 10 to 15 minutes for questions and answers, which also may have affected the results.

The educational toolkit in the current study was only used on willing participants who were happy to take part in the study, which means that it is likely that this population wanted to further their knowledge. As such, training programmes are not compulsory for health care assistants and it is likely that many health care assistants did not attend who may have viewed the condition beyond the remit of their job. Another limitation was related to sample size: the number of participating groups was small at only 20 HCAs. However, as discussed,

participants were paid by their employers but for this non-mandatory training the residential care home managers were not willing to allow many health care assistants to participate. Regular updates are needed for the toolkit as some information has been changed since it was developed. Despite the limitations, the evaluation provided insight into directions for future research.

6.10. Summary of the educational toolkit

In conclusion, educating health care assistants on low vision and diabetes can result in greater awareness on the effects of this illness. A pre/post-test design was used by the researcher. This study is aimed at determining whether the use of the low vision and diabetes education toolkit is an effective method for educating health care assistants. The study has demonstrated that large numbers of the health care assistants did not have a clear understanding of diabetes and sight loss, and that they required more training. Following the completion of the training, the results suggest that the training has had a positive effect on the knowledge of health care assistants around diabetes and eye disease. The results of the questionnaire conducted one month after training suggest that there was a slight decrease in the number of correct answers, and therefore it can be suggested that although training is effective, there may be a need to retrain health care assistants on an annual basis, or more preferably, every six months. Such a training plan could improve awareness of low vision and diabetes in residential care homes, and even increase the number of people treated for low vision and diabetes. This could have an effect on the quality of life of older people, and reduce the associated problems of sight loss, including trips and falls, and taking the wrong medication. There is a need to ensure that such a training programme is initiated amongst all health care assistants to ensure its success.

CHAPTER 7

DISCUSSION

7.1. Introduction

Diabetes is a major health concern amongst the ageing population (Sinclair, 2014). Due to the numerous complications associated with diabetes, diabetes care has suffered from lack of guidance to prevent long-term complications (Abdelhafiz and Sinclair, 2009). This study has considered the low vision associated with diabetes in older people living in residential care homes.

The global population is expected to increase markedly over the forthcoming years (United Nations, 2013), and the number of individuals over the age of 60 is estimated to increase threefold in the years between 2005 and 2050 (Aikens et al., 2005; Department of Health, 2006; Sinclair, 2010; Age UK, 2015). There is, therefore, likely to be an increase in both diabetes and eye disease, and older people with diabetes have a 90% chance of developing eye disease (McLaughlan and Edwards, 2010; Minassian et al., 2012), including common ocular complications, retinopathy and changes in refraction if they fail to strictly control their blood glucose levels (Abdelhafiz and Sinclair, 2009; Mohammed, 2014).

Research (Charles, 2007; BBCouncil, 2014) estimated that 50% to 70% of low vision cases are preventable or treatable by simply wearing appropriate spectacles or maybe surgery. The numbers of people with preventable visual impairment is more than 70%, I submitted my thesis on 15th October 2016 and the Barometer Report on Global assessment of diabetic retinopathy from International Diabetes Federation was published on 14th Nov 2016, and according to the Barometer Report (Shaw et al., 2016) worldwide direct and indirect costs of visual impairment is 2.95 Trillion (\$USD) which will increase up to 3.56 Trillion (\$USD) by 2020, furthermore the study has suggested that 80% of

global visual impairment is avoidable (Shaw et al., 2016). However, in order to identify these 50%, 70% or 80% avoidable and treatable visual impairment, everyone concerned should be able to recognise the signs and symptoms of preventable low vision, particularly HCAs. The educational toolkit I developed was tested and found to be very helpful for awareness and to fill the knowledge gap related to diabetes and eye diseases. The standardised low vision and diabetes educational toolkit could be beneficial to HCAs if they have good training and knowledge regarding low vision and diabetes they would be able to improve the vision of people and via this improve their quality of life.

My data analysis demonstrates that the process of lifestyle change, which is essential for older people with low vision and diabetes, is not an easy task and without education is very difficult. The process of learning begins with the sense of beginning the journey as a changed person, which requires individuals with low vision and diabetes to have at least the basic sense of perceiving low vision and diabetes as a threat, which in turn leads them to engage in learning and education to avoid future physical harm. The theme presented in Chapter 5 page 135 'restructure life with low vision and diabetes' illuminates the procedure of engaging individuals in a process of education, which involves learning how to practice self-management and also conquering emotional distress while trying to resist temptation and engage in activities such as taking regular medication, stop eating sweet foods or taking exercise, that might not be pleasing at the beginning.

From my findings, the theme presented in Chapter 5, page 148 'helping hand' demonstrates how health professionals have been trying to help older people with low vision and diabetes. Here are some good research samples available based on different areas of low vision and diabetes (Thorne et al., 2000; Sinclair et al., 2001; Legood et al., 2002; Abdelhafiz and Austin, 2003 ; Adolfsson et al.,

2004; ADA, 2006; Abdelhafiz and Sinclair, 2009; McLaughlan and Edwards, 2010), however, there have been no major changes as yet.

Title: Prevalence of remediable disability due to low vision among institutionalised elderly people (DeWinter et al., 2004).

Design of study: A qualitative study, using cross-sectional design survey.

Sample size: 284 participants with low vision in nursing homes and homes for the elderly in the Netherlands.

Outcomes: Low vision is likely to be highly prevalent among institutionalised elderly people. A large amount of the associated visual disability may be remediable.

Title: The prevention of Type 2 diabetes: general practitioner and practice nurse opinions (Williams et al., 2004).

Design of study: This was a qualitative study, using focus group discussions. Themes were made and data was analysed by the authors.

Sample size: 21 GPs were included in the study. Participants were divided in to 3 focus groups and discussions were carried out by 3 researchers.

Outcomes: Different medical professionals have different views regarding their roles in management and prevention of diabetes.

Title: Patients' experiences of screening for Type 2 diabetes: prospective qualitative study embedded in the ADDITION (Cambridge) randomised controlled trial (Helen et al., 2007).

Design of study: Qualitative study, using randomised controlled trial. Interviews were held with the participants and data was analysed by the authors.

Sample size: 23 participants, aged 50 to 69 years, were included in the study.

Outcomes: Screening can reduce the risk of developing diabetes and can reduce the risk of developing complications of diseases.

Title: Development of an educational ‘toolkit’ for health professionals and their patients with pre-diabetes: The WAKEUP study (Ways of Addressing Knowledge Education and Understanding in Pre-diabetes) (Evans et al., 2007).

Design of study: A qualitative study was completed with focus groups and interviews. Data was analysed by using thematic framework analysis techniques.

Sample size: Participants were divided in to four focus groups. 19 doctors and 10 people with diabetes were involved in the discussions.

Outcomes: Both the groups of doctors and the people with diabetes were in favour of using the WAKEUP toolkit. More emphasis should be paid to the delivery of the toolkit for all participants suffering from Type 2 diabetes.

- Low vision and diabetes management theory (Funnell and Anderson, 2004).
- Responsibility for care between the individual and the state (Department of Health , 2010 b), regular eye assessments (DeWinter et al., 2004).
- Models adopt a paternalistic approach to guide the patients on the course of action (Tsoneva and Shaw, 2004).
- A number of studies are available regarding the development of methods to appraise compliance, techniques and tactics to encourage adherence to medical treatments and advice (Funnell and Anderson, 2000).
- ‘Silent’ nature of undetected sight loss and visual impairment (Watson and Bamford, 2012).

There are many studies based on the wellbeing of older people’s health, such as change theory and explanatory theory (Abdelhafiz and Austin, 2003 ; Bosanquet and Mehta, 2008; BBCouncil, 2014; Action for Blind People , 2015), which were revisited to examine and explain the phenomenon of low vision and diabetes. However, these studies only explored one or two areas of this subject.

In this study I adopted a qualitative research approach using the tools of focus groups, interviews and a health professionals’ questionnaire using open

questions. Using these tools I sought the views of older people, GPs, ophthalmologists, optometrists, nurses and health care assistants to obtain a wide range of information to cover as many areas of low vision and diabetes in older people living in residential care homes. However, more research needs to be undertaken to raise awareness and education and to discover ways of enhancing low vision associated with diabetes.

From my findings, the following constellations of factors will affect low vision and diabetes: economic-environmental, psychological, physiological and socio-cultural. In addition, the following factors are also identified as important: low vision and diabetes education and awareness for HCAs. Regular eye tests that aim to identify low vision that may be associated with diabetes may help identification more quickly so that treatment and lifestyle changes can be implemented, which help to decrease the risk of further impact of low vision and diabetes.

My data shows that large numbers of older people with diabetes were found to have had their self-confidence eroded, which is linked to minimal physical confidence. The first and second themes, presented in Chapter 5, 'life with low vision and diabetes' page 105, and 'restructure life with low vision and diabetes' page 135, show that attempts not to reveal the identity of their illness to the public indicates their eroded confidence after being diagnosed as diabetic because of the negative meaning behind the disease, which has a great impact, as discussed in the next paragraph.

The consequences of low vision associated with diabetes are the major impact affecting people's emotions, but based upon their knowledge and experiences they give a different meaning to the event of being diagnosed, especially the meaning for the individual in relation to the stigma associated with low vision and diabetes, and the impact of the diagnosis on everyday life (Sinclair, 2014). It explains why some participants experience appalling pain once diagnosed, while some have been scarcely affected, and others experienced an intermediate fate.

For example, (Interviewee Six, Focus group) explained the reason why she was unwilling to reveal her identity as the: *“symptom of going more frequently to the toilet would make the others think badly about me”*.

Their concerns show that low vision and diabetes is attached to a sense of stigma, which affects the way one interacts with others. Because of their fear of being isolated or even feeling inferior to others, it explains the reason why they lack the confidence to disclose themselves as an individual with low vision and diabetes; as a result, only a few people gained sufficient confidence to divulge their disease, after encouragement. Health care assistants and older individual's education on diabetes is very important, as eyes get damaged by diabetes without the person realising it until un-reversible damage has been done. To help prevent vision loss due to diabetes, glucose levels should be controlled. The risk of blindness can be decreased by educating health care assistants and older people regarding eye examinations, by following their treatment directions, and by training them to monitor their diabetes. My research identified that an educational toolkit can be a very useful tool for educating health care assistants and, as health care assistants provide the majority of direct care to older people in residential homes, they are the key to improving care.

My research shows that standardised low vision and diabetes training and educational programmes could be beneficial to health care assistants if they receive good training and knowledge. However, without constantly evaluating the training and educational scheme, the content might fail to meet the needs.

This study was able to accomplish the main objective of increasing awareness of low vision and diabetes in older people living in residential care homes, specifically for health care assistants. Also, the goal of this research was to ascertain whether or not the health care assistants increased their effective knowledge of low vision and diabetes after receiving the educational toolkit training.

7.1.1 Stigma attached to diabetes and low vision

From my literature review presented in Chapter 2 it is clear that there is very little published literature available on stigma attached to diabetes and low vision, for example (WHO, 2001; Parkera and Aggletonb, 2003; Mitchell and Jayashree, 2006; Lorig, 2009; Watson and Bamford, 2012), but as a health professional having been in this field for 14 years I have gained a wealth of knowledge and experience. I am regularly presented with individuals who are suffering from low vision and blindness associated with diabetes, the majority of people with diabetes that I see in my practice were not willing to reveals that they have diabetes and a large number of people with diabetes that I see are not aware of the diabetes complications, they even ignore diabetic retinopathy eye checks.

My research reveals that due to numerous reasons (Please see Chapter 5 section 5.3.2 page 121 Subcategory Stigma attached to diabetes and a hope of good health), a large number of older people with diabetes had a problem in revealing their diabetes to others, they are afraid and felt self-shame about sharing the identity of their diabetic illness's identity in public because of the social stigma, which was seemingly one of the major sources of stress (Lorig, 2009).

Their emotions would be affected in various degrees, which depended on how they perceived the meaning of having low vision and diabetes; this could make the situation even worse. The stigma attached to diabetes could mean that older people are less confident about effectively controlling their blood sugars and stigma may delay appropriate help-seeking or terminate treatment for treatable low vision and other complication associated with diabetes (Mitchell and Jayashree, 2006). According to (WHO, 2001) health related social stigma contributes the hidden burden of mental illness and it constitutes a hidden burden for other stigmatized conditions including low vision and other complication associated with diabetes. Most individuals that were interviewed who showed emotional distress at the very beginning were shocked by the social stigma attached to low vision and diabetes (Watson and Bamford, 2012).

My research reveals that increasing public awareness and educating HCAs with the educational toolkit for diabetes and low vision I developed could possibly decrease the negative information circulating among lay-persons and it would also help to reduce the social stigma, it may be a way to stop the information imparted by word of mouth.

7.2. Rationale

In the literature, there is very little evidence surrounding the detection and treatment of eye diseases associated with diabetes in older people living in residential care homes. Research (Aspray et al., 2006; Abdelhafiz and Sinclair, 2009; McLaughlan and Edwards, 2010; Emerson and Robertson, 2011; BBCouncil, 2014; Mohammed, 2014; National Eye Institute , 2015) has suggested that the highest levels of low vision can be found in older people living in residential care homes. However, as the field is under-researched, there was a need to address whether such problems existed, and how they can be rectified.

Therefore, the researcher involved in this study recruited a number of healthcare professionals ranging from general practitioners to HCAs to understand the problems in the field. Furthermore, the researcher designed a toolkit, which acted as a training programme to educate health care assistants on low vision associated with diabetes and the significance of regular eye examinations. To assess whether the toolkit was effective, the health care assistants were tested on their knowledge through the use of questionnaires before the training, immediately after the training, and one month after the training.

The study was split into two phases; Phase One and Phase Two. The next section will discuss the results from each of the phases and aim to draw conclusions and recommendations to how practice can be improved and low vision associated with diabetes can be prevented in older people living in residential care homes.

7.3. Discussion of Phase One

Phase One involved sampling older people to discover what they already knew and what they wanted to know concerning low vision and diabetes, what helped them, and what was needed to prevent or manage low vision and diabetes, in addition to understanding how older people saw themselves with low vision and diabetes. It also included sampling the optometrist's focus group and the health care assistant's interviews to discover what gaps and difficulties they experienced in practice, and to elicit their advice and opinions about low vision and diabetes and to explore their existing knowledge and understand the issues they faced, and also to explore their views on managing low vision associated with diabetes in older people. Sampling the healthcare professional's survey on their perceptions of individuals with diabetes and eye complications, the results from the questionnaire survey presented in Chapter 4, Section 4.13 page 102, show a clear difference between the thoughts of GPs, nurses and HCAs compared to the thoughts of ophthalmologists and optometrists. The results also indicate that 82% of the participants had not had any training in the low vision and diabetes area, and of those who had had training, only one participant had received training in the last 12 months. This lack of training is likely to be having a negative impact on the care of people with low vision and diabetes.

This indicates the lack of significance given to training on low vision associated with diabetes, and the lack of awareness around the subject. Training of healthcare professionals could improve the detection and treatment of eye disease and improve the outcomes of older people with diabetes and eye complications. Low vision associated with diabetes has a huge effect on the quality of life of older people, and can lead to secondary injuries due to trips and falls (Abdelhafiz and Austin, 2003 ; British Orthopaedic Association , 2007; RNIB, 2015 a). Care home residents with low vision and diabetes have a largely increased risk of developing a disability and thus hospital admission (Duffy et al., 2005; Department of Health, 2010 a) and every 5 hours one older person dies

due to a fall (Age UK, 2010). In the literature review for this study, it was found that some older people are concerned about the cost of glasses and eye tests (Care Quality Commission, 2012).

The results from the current study suggest that optometrists also have concerns about the quality and cost of glasses worn by older people. They are equally worried about older people wearing poor quality glasses which could have a negative impact on their sight. Currently, people aged over 65 are given an allowance towards the cost of glasses (Bosanquet and Mehta, 2008; Chilcott et al., 2011), and although people can buy more expensive glasses and then pay the difference, many older people fail to do this, and therefore wear inappropriate glasses that may be doing them more harm than good. It is important to educate health care assistants and the public on the importance of good quality glasses, and the effects of wearing poor quality glasses.

7.4. Discussion of Phase Two

Phase Two of this study aimed to develop and test an educational toolkit which was designed to educate health care assistants about eye disease associated with diabetes and its complications. Additionally, the toolkit should help health care assistants to understand the importance of diabetes controls and eye examinations, and early diagnosis and prompt treatment, as well as reducing the risk of diabetes complications.

Research (Lorig, 2009; Al Sayah et al., 2013) has demonstrated that early detection of low vision and eye complications is paramount in treating these conditions; therefore this was a major focus of the educational toolkit. Much of the population believes that sight loss is irreversible and a natural part of the ageing process; however, there is a need to educate health care assistants and older people on ways in which vision loss can be reversed if detected early (Charles, 2007; Scanlon, 2008; Watson and Bamford, 2012).

As previously discussed, health care assistants were trained using the educational toolkit; this group were chosen as they spend the large amount of time with older individuals and therefore are most likely to be able to detect problems. GPs and nurses only tend to have limited interaction with older people living in residential care homes, whereas health care assistants are involved in intimate care such as personal help going to the bathroom and changing. During these tasks it is likely that health care assistants can detect symptoms of low vision as evident from such activities.

Health care assistants were given questionnaires which consisted of ten technical questions and were tested before training, immediately after training and one month after training. Such a configuration was chosen to allow the detection of changes in knowledge and to determine if the information was retained after a longer period of time. This study found that over half the participants had a poor knowledge of eye complications related to diabetes, as 60% of the participants answered the questions incorrectly. After receiving training, the results of the questionnaire improved and over 95% of the questions were answered correctly immediately after training. This finding is very promising as it demonstrates that training can be effective in improving knowledge.

The study demonstrated that participants lost some knowledge one month after the training. This can be expected, especially if the participants had not refreshed the material. This suggests that regular training may be beneficial to ensure that diabetes and eye care are given importance in the clinical setting. Annual training sessions may be the appropriate and could lead to detection of low vision associated with diabetes.

7.5. Limitations, strengths and weaknesses of this study

As discussed in Chapter Three, due to the limited time and expenditure, the small sample size cannot present everything related to low vision associated with

diabetes in residential care homes. Also, the ophthalmologists, some healthcare professionals and older people with low vision and diabetes who refused to attend the study failed to disclose the rationale behind their decisions, and could possibly have shown a differentiation from those who were interviewed. As seen in the literature review, the study of low vision and diabetes in residential care homes has been structured into a broad concept, providing a general concept describing the influential factors in low vision and diabetes in older people, and also exploring the gaps. However, such a broad concept has its weakness in deeper explanation into how such a great deal of information could be applied to each individual. It is too broad to identify every person's motives or needs, thus to pin down the focus and examine deeper information might help to unfold the yet-to-be-known information of low vision and diabetes, as well as to focus on more specific service groups and understand their needs.

The study was planned as well as possible, however due to the nature of the participant-dependent studies; the overall success is reliant upon participant compliance. For Phase One of the study, the ophthalmologist's response was quite low, and three health care assistant participants failed to answer any questions.

Phase One of this study revealed that some healthcare professionals are concerned about the cost of good quality spectacles. A number of optometrists believe that good quality spectacles are expensive, and therefore older people avoid wearing them or get poor quality spectacles that have a negative effect on their vision. This is an area of concern, as if more people undergo testing, they may be prescribed glasses that are either of no benefit to them or which may make their low vision even worse.

Phase Two of this study has demonstrated the importance of training when it comes to eye complications associated with diabetes. The questionnaire highlighted that many of the health care assistants questioned were not aware of low vision associated with diabetes and had very little knowledge of eye

conditions and how they could be detected or treated. Although the study found that training does help, there was a 5% decrease in the number of correct answers one month after training. This shows that although training can lead to important improvements in knowledge, it can be lost over a relatively short period of time. Such a loss of knowledge may be associated with lack of interest in the subject or to lack of experience of low vision associated with diabetes. Although the latter is unlikely, there are a high proportion of older people with low vision and diabetes in care homes.

The educational toolkit used in the current study was only used with willing participants who were happy to take part in the study. This does mean that it is likely that this population wants to further their knowledge. As such training programmes are not compulsory for healthcare professionals; it is likely that many of them would not attend, particularly health care assistants who may view the condition beyond the remit of their job. The ways in which these problems could be overcome was discussed in subsequent sections in Chapter Three.

7.5.1. Where is my work strong?

This work is robust as a big gap was identified, thus allowing me to do some ground-breaking research. I took the weak points that I encountered and turned them into a positive as I kept striding forward to ensure my work was effective. Taking the data into consideration from Phase One, a number of key issues and barriers were identified. Finally, I feel a great passion for this subject area.

I believe that the following points and sections make my work stronger:

- There is an absence of knowledge and consciousness of diabetes, related health complications including low vision and indicators at all stages, predominantly in HCAs.

- There is insufficient awareness that a healthy eye is a causative feature to improving the quality of life around older people living in residential care homes.
- The health of the eye is disregarded as a health marker in the evaluation of residents, both within care homes as part of routine health testing, and externally through discussions with healthcare professionals and Care Quality Commission appraisals. While eye health is referred to in general health outputs, as a 'silent' health problem, it is often omitted from health tests in the clinical setting.
- There is an absence of awareness about diabetes, eye health, formal sight examinations, or evaluating possible signs from health care assistants, further worsening the issue.
- The unavailability of training and resources for health care assistants on diabetes and eye health.
- The following sections make my work stronger, Chapter 4, Section 4.13 page 102. Chapter 5, Section 5.3.1, page 105; Section 5.4, page 135, and Section 5.5, page 148.

7.5.2. Where is my work weak?

The detail was discussed in Chapter 3, Section 3.7, and page 68. In summary however this work was affected by the following issues:

- Issues raised while accessing the field;
- Issues with questionnaire survey;
- Issues with contacting older people for focus groups and interviews;
- Issues with contacting ophthalmologists and optometrists;
- From the onset of this study, it was difficult to recruit ophthalmologists to take part in the focus group, many of whom claimed to not have enough time. The detail was discussed in subsequent sections in Chapter 3 ;

- It was somewhat difficult to arrange a meeting with health professionals as they are extremely busy, which caused several delays;
- It was difficult to gain the appropriate level of time needed from residential care home managers as they had other commitments, which led to me rushing to organising meetings with all the participants;

There were methodological issues after identification of the qualitative methodology; the next issue was how to develop the appropriate research tools. The detail was discussed in Chapter 3, Section 3.3, page, 56.

I also faced several other problems during my research such as during the last year of my PhD, just before my submission, my supervisor informed me he had decided to leave his post and the University as a whole. This upset me immensely as we had formed a good working relationship and understanding with each other. However, I took it upon myself to have regular meetings with my second supervisor. After perfecting my thesis, my supervisor gave me the go-ahead to submit my work. As a result, I booked my appointment with the Research Graduate School within the University of Bedfordshire for submission. However, I was informed that I was unable to submit my thesis without a complete supervisor's team. I was then assigned a new supervisory team so I forwarded my thesis to the new supervisors. This caused me few months of delays and untold stress on both me and my family.

7.5.3. What unique contribution does my PhD make to the knowledge base?

I believe my PHD is greatly beneficial, not only to individuals that suffer from visual impairment and diabetes, but also to the community and health care assistants (HCAs). After the educational toolkit training, HCAs will be capable of knowing about diabetes complications, including diabetes-related eye complications. HCAs can act professionally and promptly to inform the eye health professionals, which results in diagnoses and identifications in the early

stages. This will reduce the risk of blindness in older people and also will decrease financial burden on the community.

Transferability: The findings of the study have been found to consist of local beliefs about low vision and diabetes in residential care homes; they also reveal common elements which had been presented by the other ethnic groups in the world. The findings of this study can apply to any age of people with low vision associated with diabetes. The conceptual framework of low vision associated with diabetes in older people living in the residential care homes provides a comprehensive understanding of low vision associated with diabetes which could be applied to other studies regarding low vision and diabetes. The concepts of low vision associated with diabetes are perceived as a threat, and worry is a common element. Therefore they can be transferred to those studies which focus on health related behaviours, including people with other chronic diseases. The educational toolkit is an important part of this study and is listed in the Appendix on page 379.

I believe that this study will help to reduce the risk of developing serious long-term eye complications and problems linked to diabetes, such as diabetic retinopathy, cataracts, glaucoma, low vision and blindness in older people, and also could prevent some of the accidents that occur as a result of low vision associated with diabetes such as hip fractures and falls in older people. In conclusion, the questions I set out with at the beginning of this work have all been successfully answered, thus providing a positive impact on the knowledge area of this study.

7.5.4. Future Studies

This study was carried out in a methodical manner to ensure that the most meaningful and accurate data was collected. As the data from the study has been analysed, it is clear to see that there are a number of issues that still need to be

addressed to validate the recommendations above. This study provides a good insight and direction for better understanding of the phenomenon of low vision associated with diabetes in older people living in residential care homes. The study clearly supports the conclusion that further research in this area is required. As always, detailed literature reviews demonstrate a need for more research. In my thesis, I have tried to examine a variety of methods such as focus groups, interviews and questionnaires (both pen paper and computer based) to explore this aspect. Although the study has uncovered some noteworthy results, there is a need to repeat Phase One of this study using an online survey method to ensure that the participant response rate is greater, which will ensure that the results can be generalised amongst the wider population. Building on the responses of Phase One, it is clear to see that steps need to be taken to ensure that older people have a suitable allowance for their glasses. A study which investigates the quality of glasses in relation to their clinical need may also be of some interest, as well as a study which investigates how poor quality glasses may have a negative impact upon vision, which may be of some benefit in cost-effective approaches to treatment.

Most importantly, the effectiveness of Phase Two of the study needs to be assessed. It has been demonstrated that training can be used to improve the knowledge of health care assistants. However, although the knowledge of the health care assistants improved, it is not known if the knowledge was used or transferred to the clinic. In order to determine if low vision and diabetes is detected in residential care homes, a follow-up study needs to be carried out where the detection rates of low vision and diabetes are correlated to the health care assistants who underwent the training programme. If there is a clear trend in detection and training, there is a clinical need to make such educational toolkits mandatory amongst HCAs. In order to make sure that the training is the most appropriate for each type of healthcare professional, there is a need to develop similar toolkits for people with low vision and diabetes, and for them to undergo a similar test study to determine their effectiveness.

Additional areas that should be considered for further evaluation include:

- Developing a comprehensive education tool for subjects that can be used in routine practice and training in residential care homes for HCAs and also in GP's surgeries for older community residents for inclusion in the annual review.
- To explore the phenomenon of living with low vision and diabetes in different populations, such as children, pregnant women, teenagers, and males and females in different age groups.
- To further examine, in time, the efficiency of the education toolkit training of low vision and diabetes in HCAs, as the educational toolkit in this study was re-tested after one month. This time span was obviously limited and this may have affected the results obtained, but as discussed above, due to the limited time and expenditure, it was not possible for me to prolong the time period for re-testing the toolkit, due to the need to submit my thesis to the University to meet the registration requirements.

7.6. Potential solutions

From the previous sections it is clear to see that although this study has answered a number of questions, there are still considerations that need to be made with regards to how the results of the study could be implemented in practice.

This study also revealed problems with participant recruitment. The recruitment of participants for any study can be difficult; however to maximize the number of participants and therefore make the study representative, further steps could be taken. For example, an interview approach could be taken, where the participant is in front of the study organiser and all the results can be collated at the time. When questionnaires are sent out, many participants will fail to complete the

questionnaire, or will not complete them fully, even if they have confirmed beforehand. Although this method would take a longer period of time, the response rate should be better (Balls, 2009).

To further improve participant numbers, online questionnaires could be sent rather than postal forms. Some busy professionals may see paper forms as a nuisance, and as they should all have access to a computer, online forms could be completed quickly and easily. Furthermore, the use of online forms also means that a higher number of invitations could be sent out. For example, the questionnaire could be sent out to all clinicians or nursing staff working in a particular department. Generally it has been found that online surveys lead to the recruitment of more participants compared to paper forms, which can also be mislaid.

As previously mentioned, Phase Two of this study demonstrated that many of the health care assistants forgot some of the training they were given. The final questionnaire was given one month after the training was delivered, and a 5% decrease in correct answers was observed. In order to ensure that the knowledge is preserved, regular training sessions could be adopted. However, these sessions will only be useful if health care assistants use their knowledge to detect vision loss. If vision loss is not detected in the residential care home setting, there is a need to modify the training towards a more practical style, opposed to theoretical. It could be argued that when HCAs are able to recognise low vision more often in their everyday work, they may not require such training. However, this can be considered once basic training has been carried out for a number of consecutive years.

Finally, we need to consider how the educational toolkit could be used in the residential care home environment. The success of knowledge expansion is clear, but in order for the toolkit to be successful, the training would need to be compulsory. However, making the training compulsory may be difficult, as low vision and diabetes is not even mentioned in the care suggestions by NICE, (NICE, 2015). Highlighting the implications and complications of low vision may lead to

better awareness of the condition. There is a need to pass a regulation which ensures that all HCAs that are likely to work with older people living in residential care homes have some sort of training in this area. The exact method by which changes can be made has been described in the next section.

7.6.1. Clinical Recommendations

The limitations of the current study and potential solutions to these problems have been discussed in this chapter. This section will consider the exact clinical recommendations that could ensure that low vision associated with diabetes is detected.

The recommendations for clinicians are listed below:

- 1) Greater awareness of low vision and diabetes amongst governmental bodies such as NICE, CQC. The significance of low vision should be outlined in the NICE and CQC recommendations.
- 2) There should be more investment in training, education and guidance on awareness of low vision and diabetes.
- 3) Regulations to ensure that all older people living in residential care homes undergo sight testing on an annual basis.
- 4) Greater allowance should be given to older people for the provision of new spectacles which are of adequate quality.
- 5) A reduction in stringent guidelines for current sight tests in care homes which are currently deterring optometrists from making visits to residential care homes for testing.
- 6) Rollout of an educational toolkit which is specifically designed for each type of health professional; for example, different toolkits for nurses, optometrists and health care assistants. Make the training mandatory to ensure everyone receives the same service.
- 7) Refresh the training given to health care professionals every one or two years to ensure that their knowledge is kept up-to-date.

- 8) Online educational resources for HCAs are a modern and accessible solution for delivering information.
- 9) Personal care plans should be revised to include better guidance on low vision and diabetes.
- 10) Educate and raise awareness of all serious eye complications and problems associated with diabetes, such as diabetic retinopathy, cataracts, glaucoma, low vision and blindness, in older people. It will help health care assistants and older people to understand the importance of diabetes controls and the benefits of having dilated eye checks every 12 months, as this will help with early diagnosis and treatment. Educating HCAs and older people will also raise awareness of the importance of wearing the correct glasses, as well as reducing the risk of other diabetes complications.

7.6.2. General recommendations

Below are some recommendations that can help to prevent eye disease associated with diabetes and its complications:

- Training sessions and workshops on the low vision and diabetes educational toolkit should be provided to everyone, including older people living in residential care homes and in the community.
- Awareness is the key; awareness campaigns can be very useful for providing knowledge to people in the community or in general. Awareness campaigns can bring people together and get them involved. People should be encouraged to carry out regular activities such as exercise, even though exercise may seem a difficult task for some, but awareness campaigns can help promote such activities.
- The media is a powerful tool that can deliver the awareness message and therefore should be involved in awareness campaigns. The awareness message can be delivered in the form of print and electronic media. Regular slots on mainstream TV can be scheduled to provide guidance.

- Counselling can be beneficial and should be provided to all high risk and people with low vision and diabetes in diabetes clinics and surgeries. Counselling sessions can include dietary plans, exercise plans and diabetes management.
- Screening is being rolled out in many parts of the UK for eye diseases associated with diabetes to try to reach out to those that need support and guidance along with medical care. However, according to this research, some people are not continuing with their regular eye check-ups due to lack of awareness and knowledge regarding low vision and diabetes. Policies should be formed that ensure all people with diabetes can attend the screening programmes and continue with regular check-ups and follow-up checks.
- Local Leaders – Many ethnic communities are living in the United Kingdom. They all have different views and opinions regarding low vision and diabetes, including other diseases. South Asian people are at more risk of diabetes than Caucasians, which is mainly due to religious and cultural differences, for example fasting in the Muslim community. There needs to be more education to enable awareness of the condition of diabetes and how to maintain sugar levels during fasting. Local leaders and health professionals need to get more involved with their local communities and bring awareness to them of low vision and diabetes. Awareness can be in the form of regular meetings, speeches and awareness events for people with low vision and diabetes.
- Booklets and guides can be created and distributed across the UK to diabetes clinics and surgeries. Booklets and guides should be written in a simple and understandable form in different languages to accommodate multi-cultural societies, and should also be provided in audio and video for individuals who are unable to read.

7.6.3. Recommendations for residential care homes residents

As mentioned in Chapter 5 in detail, large numbers of the older individuals with low vision believe that low vision is a normal age-related process and think this is an incurable and irreversible process. Therefore, many older people do not recognise or accept low vision eye complications associated with diabetes; they don't even communicate their low vision to health professionals, which makes the situation more risky. We need to change this mind set in older people by making them more aware of low vision and diabetes and the effects it has on their health, and they also need to be made fully aware of the facilities and services that are freely available to them, such as eye tests, free spectacles, etc.

7.6.4. Recommendations for health care assistants

Similarly to older people, many health care assistants also believe that low vision is a normal age-related process and think this is an incurable and irreversible process, but HCAs should be educated through training sessions, workshops, and awareness events on a regular basis, to help them facilitate and provide good care to older people living in residential care homes. Specific educational material on low vision and diabetes needs to be made available to health care assistants. Also, it would be beneficial if low vision and diabetes education is made compulsory so that new recruits are required to take a qualification in this area prior to being employed.

7.6.5. Recommendations for eye health professionals

Eye health professionals should keep in regular contact with residential care homes and should automatically send out eye test appointments within the recommended periods.

The recommendations above are quite comprehensive, and it is unlikely that all recommendations would be used in practice; however, they do aim to identify a number of key issues which have been identified by this study and which could improve low vision amongst this vulnerable group.

7.8. Conclusions

At the start of this research project it became evident that low vision and diabetes is a global problem, although the complications of diabetes are often underestimated, particularly within residential care home settings. As the majority of older individuals have diabetes (Sinclair, 2010), there is a need for health care assistants to know about the complications of diabetes.

One of the most common complication of diabetes in older people is low vision (Scanlon, 2008; Action for Blind People , 2015), and as discussed above (that low vision is often considered to be a normal effect of old age), many individuals, including health care assistants, are still under the impression that sight loss is irreversible. Research (Abdelhafiz and Austin, 2003 ; Age UK, 2015) also dictates that vision loss can lead to other problems, such as trips and falls, which have resulted in further disabilities.

The areas identified with issues which need to be addressed to improve health care practices are:

- General practitioners, ophthalmologists and optometrists are in a good position to liaise with health care assistants to provide advice which will help them during their daily involvement with older people affected by low vision and diabetes.
- To provide continuous and on-going low vision and diabetes care there needs to be sufficient staffing, HCA training and knowledge about eye health and diabetes.

An understanding of these issues will help to establish the best practices to detect early diagnosis and the referral of people with low vision and diabetes to the appropriate services.

Overall, this research project has been able to demonstrate that the perceptions of healthcare professionals vary from one profession to another. Furthermore, from the results of Phase One of this research project, an educational toolkit was developed which was tested on twenty health care assistants. The participants' knowledge was initially low, but after training it improved, as shown in the detail presented in Section 7.4, discussion of Phase Two.

Phase Two of this study also demonstrated that many of the health care assistants forgot some of the training they were given. The final questionnaire was given one month after training was delivered, and a 5% decrease in correct answers was observed. In order to ensure that the knowledge is preserved, regular training sessions could be adopted. However, these sessions will only be useful if health care assistants use their knowledge to detect vision loss. If vision loss is not detected within residential care homes, there is a need to modify the training towards a more practical style.

There is a clinical need to implement new policies in the care of older people living in residential care homes which encompass low vision associated with diabetes. The lack of significance given to low vision and diabetes is the main issue to overcome, which is primarily linked to the lack of knowledge of the area. It is proposed that educating health care assistants using the educational toolkit in this research project can improve the identification of low vision and diabetes and would reduce the risk of low vision and diabetes in older people living in residential care homes. Such steps will not only prevent secondary complications, but will also improve the quality of life of older people. The early detection of low vision and diabetes is the key in this field, and therefore if health care assistants start to detect low vision and diabetes earlier on, the number of people classified as blind may decrease over time.

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APPENDICES PHASE ONE

Statute Law



Professor Carsten Maple
Pro Vice-Chancellor
Pro Vice-Chancellor – Research and Enterprise
University Square Luton
Bedfordshire LU1 3UJ
United Kingdom
T +44 (0)1582 743317
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Our ref: CM1g

11 October 2013

Professor Alan Sinclair
Institute of Diabetes for Older People (IDOP)
Beds and Herts Postgraduate Medical School
University of Bedfordshire
Puttendge Bury campus
Hitchin Road
LUTON
LU2 8LE

Dear Alan

Sponsorship for PhD candidate Nizam Darwesh's study 'Low vision and diabetes in care home and older community residents'

I can confirm that I am willing to be the sponsor for this study.

Yours sincerely

A handwritten signature in black ink, appearing to read "Carsten Maple".

Carsten Maple
Pro Vice-Chancellor – Research and Enterprise



Registered Office
University Square Luton
Bedfordshire LU1 3UJ
England

Wendy Hannell
HR Manager

Hasilwood House
60 Bishopsgate
London EC2N 4AW
Tel: 020 7847 8670
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TO WHOM IT MAY CONCERN

15 July 2013

Dear Sir/Madam

**THE UNIVERSITY OF BEDFORDSHIRE
AND ALL ITS SUBSIDIARY COMPANIES**

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following cover is currently in place:-

PROFESSIONAL INDEMNITY

Certificate of Entry No.	UM063/02
Period of Cover	1 August 2013 to 31 July 2014
Limit of Indemnity	£5,000,000 any one claim and in the aggregate except for Pollution where cover is limited to £1,000,000 in the aggregate.
Cover provided by	U.M. Association Limited

If you have any queries in respect of the above details, please do not hesitate to contact us.

Yours faithfully

A handwritten signature in black ink that reads 'Susan Wilkinson'.

Susan Wilkinson
For U.M. Association Limited



U.M. Association Limited
Registered Office: Hasilwood House, 60 Bishopsgate, London, EC2N 4AW
Registered In England and Wales No. 2731799

Hasilwood House
60 Bishopsgate
London EC2N 4AW
Tel: 020 7847 8670
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TO WHOM IT MAY CONCERN

11 July 2013

Dear Sir/Madam

**THE UNIVERSITY OF BEDFORDSHIRE
AND ALL ITS SUBSIDIARY COMPANIES**

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following covers are currently in place:-

1. EMPLOYERS' LIABILITY

Certificate No.	Y016458QBE0113A/063
Period of Cover	1 August 2013 to 31 July 2014
Limit of Indemnity	£25,000,000 any one event unlimited in the aggregate.
Includes	Indemnity to Principals
Cover provided by	QBE Insurance (Europe) Limited and Excess Insurers.

2. PUBLIC AND PRODUCTS LIABILITY

Certificate of Entry No.	UM063/02
Period of Cover	1 August 2013 to 31 July 2014
Includes	Indemnity to Principals
Limit Of Indemnity	£20,000,000 any one event and in the aggregate in respect of Products Liability and unlimited in the aggregate in respect of Public Liability.
Cover provided by	U.M. Association Limited and Excess Cover Providers led by QBE Insurance (Europe) Limited

If you have any queries in respect of the above details, please do not hesitate to contact us.

Yours faithfully

Susan Wilkinson
For U.M. Association Limited



U.M. Association Limited
Registered Office: Hasilwood House, 60 Bishopsgate, London, EC2N 4AW
Registered In England and Wales No. 2731799



Institute of Diabetes for Older People

Research Proposal Ethical Approval Form

Please complete this form and submit it to the Institute of Diabetes for Older People Research Ethics Committee (IDOPREC).

- Students should attach a copy of their full proposal.
- Staff should attach (or include below) an abstract of their research proposal.
- All applicants should include any consent forms or information sheets, and data collection tools you intend to use with your participants.
- If the intention is to work within specific agencies or establishments the applicant should attach copies of any letters of agreement with those agencies/establishments.

Provide as much information as you are able to on this form and answer the questions as fully as you can. INSTRUCTIONS FOR SUBMISSION ARE TO BE FOUND BELOW THE SIGNATURE PANEL TOWARDS THE END OF THIS FORM

ALL staff and students MUST obtain ethical approval BEFORE beginning any research.

All proposals:

Name:	Nizam Muhammad Darwash
Contact email/phone:	(0044) 0781 7170411 / dmizam2010@yahoo.co.uk
Date:	
Title of proposal:	Low vision and diabetes in care home and older community residents
Anticipated start date:	
Anticipated duration of project:	3 Yrs:
Is the project to be externally funded?	YES

Student proposals:

Supervisor name:	Professor Alan Sinclair
Award studied for:	PhD
Will you be collecting data outside the UK?	NO

* If YES Masters students must complete the Authorised Absence form on the IDOP website <http://www.beds.ac.uk/research/idop/ethics> and return it with this form; PhD students must contact the Research Graduate School.

Staff Proposals:

Department:	
Role/Job Title:	
Principal Investigator:	

N.B. Before completing this form you should read the *NHS National Research Ethics Service Guidance* available from <http://www.nres.npsa.nhs.uk/applications/guidance/>

Undergraduate and postgraduate students should complete this form in consultation with their supervisors.

What are the key aims or objectives of your research? (Provide a brief summary in bullet points.)

Care home residents with diabetes are a vulnerable group of individuals who are at high risk of visual impairment and its consequences on daily living and health. Some of these consequences are serious (such as falls with fractures), and many are preventable through early recognition and treatment of diabetic eye disease. Although guidelines do exist with respect to the management of elderly patients with diabetes and visual impairment in care and residential homes, their implementation is patchy and both patients and their carers can be unaware of the causes and effects of sight loss due to diabetes, or what to do when visual loss is identified. Therefore, the purpose of this study is to a) explore the experiences of older people related to diabetes and low vision and b) explore the experiences of health-care professionals and care home workers related to diabetes and low vision. This will ultimately help to improve early detection and treatment of eye care services for elderly people with diabetes.

Specifically, we intend to undertake focus-group, in-depth interviews, and surveys of care home residents, their carers, and healthcare professionals in order to identify the barriers and limitations to the provision of eye services to these individuals, as well as those factors that are currently working well. These focus groups will be conducted by healthcare professionals in a safe, confidential, and non-threatening environment, and data will then be anonymised within the study for use by the investigators on secure computer systems.

key aims and objectives of my research:

This study aims to provide up-to-date knowledge regarding:

A. The issues and problems faced by elderly people with low vision associated

with diabetes at primary care, nursing homes and care homes.

- B. To understand the causes & how to prevent early visual defects due to diabetes in elderly people, and how they receive low vision care at home.
- C. To evaluate the knowledge and understanding of care staff on the impacts of low vision associated with diabetes in older people.
- D. To enhance knowledge and understanding to support practitioners in providing improved health care for old people with low vision associated with diabetes.

What is the key question your research will address?

There are two main question /objectives, with equal weight:

- A: To understand the issues and problems experienced by older people with low vision associated with diabetes in the primary care and care home settings.
- B: To evaluate the knowledge and understanding of care staff on the impact of low vision associated with diabetes in older people.

Who is your target group or sample?

This is a mainly qualitative study using focus groups, focussed interviews, and a survey in a total of 84 individuals. The majority of participants are healthcare professionals (72/86: ophthalmologists (3), optometrists (3), GPs (15), nurses (15), healthcare assistants (30), care home staff (6). Only 14 patients/care home residents will be interviewed. The content of these focus groups is not of a sensitive nature and accidental disclosure is highly unlikely to have serious consequences. However, all participants will be treated equally with the same attention to the following ethical, legal, and management issues:

Consent: Fully informed consent will be sought from all study participants. A participant information sheet and consent form will be provided to all participants, who will be given one week to read this material. The information sheet details the background and aims of the research, what will happen to participants, a description of benefits and risks (or lack thereof), how any data will be managed, how to decline or exit the study, and reassurance that doing either will not affect care in any way. Permission will be explicitly asked that recording equipment can be

used and that quotes can be used in the reporting of the study. A consent form is included with the participant information sheet and presented in line with IDOPREC and NHS REC guidelines. The principal researcher is a qualified medical doctor who is able to assess capacity to give consent.

What data collection methods will you use?

This project will use a qualitative approach, focus groups, interviews, and surveys. This comprehensive and in-depth data possible while recognising that some of aspects of the research are subjective and opinion-based, In order to develop a package of educational support for patients, health professionals and care staff.

Therefore, the three methodologies are:

A) The focus groups studies consisting of:

Focus group 1, Community based older people with low vision and diabetes, 6 participants, 60 minutes.

Focus group 2: 3 ophthalmologists and 3 optometrists, 60 minutes each

B) The Health Professional Survey requiring 10 minutes to complete,

(C) In-depth interviews:

Part 1: 8 care home resident with low vision and diabetes, participants interviewed once each for 30 minutes

Part 2: 6 care home staff participants interviewed once each for 45 minutes

Answer the following question by deleting as appropriate:

1. Does the study involve vulnerable participants or those unable to give informed consent (e.g. children, people with learning disabilities, your own students)?

Yes

If **YES**: Have/will Researchers be DBS checked?

Yes

2. Will the study require permission of a gatekeeper for access to participants (e.g. schools, self-help groups, residential homes)?

Yes

3. Will it be necessary for participants to be involved without consent (e.g. covert observation in non-public places)?

No

4. Will the study involve sensitive topics (e.g. sexual activity, substance abuse)?
No
5. Will blood or tissue samples be taken from participants?
No
6. Will the research involve intrusive interventions (e.g. drugs, hypnosis, physical exercise)?
No
7. Will financial or other inducements be offered to participants (except reasonable expenses)?
No
8. Will the research investigate any aspect of illegal activity?
No
9. Will participants be stressed beyond what is normal for them?
No
10. Will the study involve participants from the NHS (e.g. patients) or participants who fall under the requirements of the Mental Capacity Act 2005?
No

If you have answered yes to any of the above questions or if you consider that there are other significant ethical issues then details should be included in your summary above. If you have answered yes to Question 1 then a clear justification for the importance of the research must be provided.

*Please note if the answer to Question 10 is yes then the proposal should be submitted through **NHS research ethics approval procedures** to the appropriate **NRES**. The UREC should be informed of the outcome.

Checklist of documents which should be included:

Project proposal (with details of methodology) & source of funding	✓
Documentation seeking informed consent (if appropriate)	✓
Information sheet for participants (if appropriate)	✓
Questionnaire (if appropriate)	✓


(Tick as appropriate)

Applicant declaration

I understand that I cannot collect any data until the application referred to in this form has been approved by all relevant parties. I agree to carry out the research in the manner specified. If I make any changes to the approved method I will seek further ethical approval for any changes

Signed (Applicant): Date: 26/11/2013.....

Signature of Supervisor/ Director of Studies (N.B. This is **NOT** required for staff applications)

 Date: ...13.12.13.....

This form together with a copy of the research proposal should be submitted to the Research Institute Director for consideration by the Research Institute Ethics Committee

Note to supervisors: Signing this form certifies that in your opinion, the project described here is ethical under Departmental and NHS guidelines. Do **NOT** sign if you are unsure or if the student has not attached complete details of the research design and methodology

SUBMISSION OF APPLICATION

Please save this form as a word document using the following convention:

Applicantsurname_IDOPRECapp_MMMYY.doc (eg Smith_IDOPRECapp_NOV10)

Attach copies of information sheets, data collection tools and/or consent forms (draft versions acceptable)

FORWARD ONE SIGNED HARD COPY TO Caroline Sinclair, IDOP Administrator, Institute of Diabetes for Older People, Putteridge Bury Tel: 01582 743285

AND

AN ELECTRONIC VERSION OF THIS FORM TO: Caroline.Sinclair@beds.ac.uk

Note you cannot commence collection of research data until this form has been approved

SECTION B To be completed by the Research Institute Ethics Committee:

Comments: *This proposal has the approval of the IDOP REC*

Approved

Signature Chair of Research Institute Ethics Committee:

Charles Fox

Date:

3rd Jan 2014

If in the judgement of the committee there are significant ethical issues for which there is not agreed practice then further ethical consideration is required before approval can be given and the proposal with the committees comments should be forwarded to the secretary of the UREC for consideration.

There are significant ethical issues which require further guidance

Signature Chair of Research Institute Ethics Committee:

Date:

This form together with the recommendation and a copy of the research proposal should then be submitted to the University Research Ethics Committee

All Invitation Letters for the study

Invitation letter for residential care home managers



Dear

My name is Nizam Muhammad Darwesh, and I am a PhD Researcher at the IDOP University of Bedfordshire. I am carrying out research study titled “Low vision and diabetes in older people living in residential care homes” to understand how we can Improve quality of care for older people with low vision associated with diabetes,

I will be grateful if you would assist me in selecting 6-8 older people with low vision associated with diabetes in you facility to conduct my research. I have attached an ethical approval letter, inclusion and exclusion criteria for selection of people to assist you. I will be very glad if you would give me appointment out of your tight schedule to explain my research project. I enclose an Information Sheet which gives you more details about the study. I will appreciate your time.

I have provided pre-paid addressed envelopes to assist you.

I will contact you next week to ask whether you would be willing to take part in this study.

Thank you for your co-operation.

Kind regards,

Nizam Muhammad Darwesh
PhD Researcher
Institute of Diabetes for Older People (IDOP)
Putteridge Bury University of Bedfordshire
Phone: 01582743988 Fax: 01582 743286
Mob: 00447817170411
Email: nizam.darwesh@beds.ac.uk
drnizam2010@yahoo.co.uk



Invitation letter for older people living in the residential care homes



Dear

My name is Nizam Muhammad Darwesh, and I am a PhD Researcher at the IDOP University of Bedfordshire. I am carrying out research study titled "Low vision and diabetes in older people living in residential care homes" to understand how we can improve quality of care for older people with low vision associated with diabetes.

I would like to invite you to participate in this study. Your experiences and knowledge will really help us in filling the gaps in terms of understanding, communication and services that are needed to improve. Your views will be very valuable to us in ensuring that older people with low vision associated with diabetes do not fall short in receiving high quality of care.

I enclose an Information Sheet which gives you more details about the study and interview. The meetings will last about 30 minutes. It is important that you tell us about your experiences and perceived needs of older people with low vision associated with diabetes in your own words, as if you were telling the interviewer your story. The information you give will be tape-recorded and your responses used to identify gaps in service provision. Any names you mention will remain anonymous and excluded from the final report.

I will appreciate your time. I have provided pre-paid addressed envelopes to assist you.

I will contact you next week to ask whether you would be willing to take part in this study.

Thank you for your co-operation.

Yours sincerely

Kind regards,

Nizam Muhammad Darwesh
PhD Researcher
Institute of Diabetes for Older People (IDOP)
Putteridge Bury University of Bedfordshire
Phone: 01582743988 Fax: 01582 743286
Mob: 00447817170411
Email: nizam.darwesh@beds.ac.uk
drnizam2010@yahoo.co.uk



Community older residents Invitation letter for focus group



Dear

My name is Nizam Muhammad Darwesh, and I am a PhD Researcher at the IDOP University of Bedfordshire. I am carrying out research study titled "Low vision and diabetes in older people living in residential care homes" to understand how we can improve quality of care for older people with low vision associated with diabetes.

I would like to invite you to participate in this study. Your experiences and knowledge will really help us in filling the gaps in terms of understanding, communication and services that are needed to improve. Your views will be very valuable to us in ensuring that older people with low vision associated with diabetes do not fall short in receiving high quality of care.

I enclose an Information Sheet which gives you more details about the study and interview. The meetings will last about 60 minutes. It is important that you tell us about your experiences and perceived needs of older people with low vision associated with diabetes in your own words, as if you were telling the interviewer your story. The information you give will be tape-recorded and your responses used to identify gaps in service provision. Any names you mention will remain anonymous and excluded from the final report.

I will appreciate your time. I have provided pre-paid addressed envelopes to assist you.

I will contact you next week to ask whether you would be willing to take part in this study.

Thank you for your co-operation.

Yours sincerely

Kind regards,

Nizam Muhammad Darwesh
PhD Researcher
Institute of Diabetes for Older People (IDOP)
Putteridge Bury University of Bedfordshire
Phone: 01582743988 Fax: 01582 743286
Mob: 00447817170411
Email: nizam.darwesh@beds.ac.uk
drnizam2010@yahoo.co.uk



GPs, Nurses and HCAs Invitation Letter for survey



Dear

My name is Nizam Muhammad Darwesh, and I am a PhD Researcher at the IDOP University of Bedfordshire. I am carrying out research study titled "Low vision and diabetes in older people living in residential care homes" to understand how we can improve quality of care for older people with low vision associated with diabetes.

As a staff member involved in the delivery of low vision and diabetes care to older people, I would like to invite you to participate in a survey which assesses the views and opinions of health professionals on how older people with low vision associated with diabetes are managed.

Your views will be very valuable to us in ensuring that older people with low vision associated with diabetes do not fall short in receiving high quality of care.

I enclose an Information Sheet which gives you more details about the survey. Participation in the study involves completing a questionnaire. Completion should not take very long but we appreciate the numerous calls on your time. I have provided pre-paid addressed envelopes to assist you.

I will contact you next week to ask whether you would be willing to take part in this survey.

Thank you for your co-operation.

Kind regards,

Nizam Muhammad Darwesh
PhD Researcher
Institute of Diabetes for Older People (IDOP)
Putteridge Bury University of Bedfordshire
Phone: 01582743988 Fax: 01582 743286
Mob: 00447817170411
Email: nizam.darwesh@beds.ac.uk
drnizam2010@yahoo.co.uk



Optometrists Invitation letter for focus group



Dear

My name is Nizam Muhammad Darwesh, and I am a PhD Researcher at the IDOP University of Bedfordshire. I am carrying out research study titled "Low vision and diabetes in older people living in residential care homes" to understand how we can improve quality of care for older people with low vision associated with diabetes.

I would like to invite you to participate in this study. Your experiences and knowledge will really help us in filling the gaps in terms of understanding, communication and services that are needed to improve. Your views will be very valuable to us in ensuring that older people with low vision associated with diabetes do not fall short in receiving high quality of care. This research study will involve you being asked some questions about current care and future services in focus group discussions with other colleagues'. Meeting will take about 60 minutes. The meeting will take place at the Luton and Dunstable Hospital NHS foundation trust. I enclose an Information Sheet which gives you more details about the study. I will appreciate your time. I have provided pre-paid addressed envelopes to assist you.

I will contact you next week to ask whether you would be willing to take part in this study.

Thank you for your co-operation.

Kind regards,

Nizam Muhammad Darwesh
PhD Researcher
Institute of Diabetes for Older People (IDOP)
Putteridge Bury University of Bedfordshire
Phone: 01582743988 Fax: 01582 743286
Mob: 00447817170411
Email: nizam.darwesh@beds.ac.uk
drnizam2010@yahoo.co.uk



Invitation letter for Practice Manager and GPs



Dear

My name is Nizam Muhammad Darwesh, and I am a PhD Researcher at the IDOP University of Bedfordshire. I am carrying out research study titled "Low vision and diabetes in older people living in residential care homes" to understand how we can improve quality of care for older people with low vision associated with diabetes.

I will be grateful if you would help me in selecting 6-8 patients with low vision associated with diabetes in your facility to conduct my research. I have attached an ethical approval letter, inclusion and exclusion criteria for selection of patients to assist you. I will be very glad if you would give me an appointment out of your tight schedule to explain my research project. I enclose an Information Sheet which gives you more details about the study. I will appreciate your time.

I have provided pre-paid addressed envelopes to assist you.

I will contact you next week to ask whether you would be willing to take part in this study.

Thank you for your co-operation.

Kind regards,

Nizam Muhammad Darwesh
PhD Researcher
Institute of Diabetes for Older People (IDOP)
Putteridge Bury University of Bedfordshire
Phone: 01582743988 Fax: 01582 743286
Mob: 00447817170411
Email: nizam.darwesh@beds.ac.uk
drnizam2010@yahoo.co.uk



HCA's Invitation letter for interviews



Dear



My name is Nizam Muhammad Darwesh, and I am a PhD Researcher at the IDOP University of Bedfordshire. I am carrying out research study titled "Low vision and diabetes in older people living in residential care homes" to understand how we can improve quality of care for older people with low vision associated with diabetes.

As a staff member involved in the delivery of low vision and diabetes care to older people, I would like to invite you to participate in this study which assesses the views and opinions of health professionals on how older people with low vision associated with diabetes are managed. Your views will be very valuable to us in ensuring that older people with low vision associated with diabetes do not fall short in receiving high quality of care.

I enclose an Information Sheet which gives you more details about the study and interview. This research study will involve you being asked some questions about current care and future services in group discussions with other colleagues. Meeting will take about 45 minutes. I will appreciate your time. I have provided pre-paid addressed envelopes to assist you.

I will contact you next week to ask whether you would be willing to take part in this study.

Thank you for your co-operation.

Yours sincerely

Kind regards,

Nizam Muhammad Darwesh
PhD Researcher
Institute of Diabetes for Older People (IDOP)
Putteridge Bury University of Bedfordshire
Phone: 01582743988 Fax: 01582 743286
Mob: 00447817170411
Email: nizam.darwesh@beds.ac.uk
drnizam2010@yahoo.co.uk



Demographic Information sheet 1



Low vision and diabetes in older people living in residential care homes

DEMOGRAPHIC INFORMATION

Instructions: Please provide a response for each of the following questions:

1. Respondents _____ first _____ Name
only: _____

2. What is your age? _____

3. What is your sex? Female Male

What is your marital status?

Single Married Separated Divorced

Widowed

4. Ethnicity:

White

Mixed

Asian or Asian British

Black or Black British

Black Caribbean

Indian

Black African

Pakistani

Black Other

Bangladeshi

Chinese

Other Asian

Other _____



Demographic Information sheet 2



Low vision and diabetes in older people living in residential care homes

DEMOGRAPHIC INFORMATION

Instructions: Please provide a response for each of the following questions:

5. Respondents first Name only: _____

6. What is your age? _____

7. What is your sex? Female Male

What is your marital status?

Single Married Separated Divorced Widowed

8. Ethnicity:

White

Mixed

Black or Black British

Asian or Asian British

Black Caribbean

Indian

Black African

Pakistani

Black Other Chinese

Bangladeshi

Other _____

Other Asian

9. What is your profession?

Ophthalmologist

Dietician/Nutritionist

Optometrist

Health Care Assistant

General Practitioner

Care Home Manager

Diabetes Specialist Nurse

Other _____

Nurse

10. Where your work is primarily based?

Hospital Community Care Home

Other _____



Focus groups & interviews schedules, Instructions and guides



Low vision and diabetes in older people living in residential care homes

1. The purpose of the group today is to discuss your experiences and thoughts on low vision associated with diabetes
2. What you say is confidential and whatever views you express will be anonymised so that no-one outside of this room will know who has said what
3. You should therefore treat information and views expressed in this room as confidential
4. Please feel free to say what you want and feel free to discuss comments or add your own experiences
5. Please allow others to have their say (even if you disagree)
6. With your consent the discussions will be recorded so that we can analyse them later (look for themes, common and different opinions etc), but the data will be anonymised
7. It's not so much a question and answer session as a forum for discussion
8. We may need to stop a discussion if going over time in order to *get all* topics discussed



Table 11 Validation of the research questionnaires

	The original source of each question	The following list of questions that I finally agreed upon after the discussion with Prof Alan and Prof Peter	Main reasons to ask these questions
1	<p>Question: In your opinion, what are the three most important barriers to effective diabetes management in older people in the community?</p> <p>Original source: IDOP (England-wide Care Home Diabetes Audit, 2014)</p>	<p>In your opinion, what are the most important barriers to effective diabetes and low vision management in older people living in residential care home?</p>	<p>Participants were requested to give their views on the perceived barriers to the management of low vision and diabetes in older people. To explore what are the Key issues in managing low vision in older people with low vision associated with diabetes. For example: Insufficient training. Communication difficulties. Lack of available resources</p>
2	<p>Question: In your opinion, what kinds of vision problems do people with diabetes experience?</p> <p>Original source: "Visual Loss in Care Home Residents with Diabetes" not published yet</p>	<p>In your opinion, what kinds of vision problems do people with diabetes experience?</p>	<p>The second question was based on the experiences of the professionals and concerned the common types of low vision that people with diabetes experience.</p> <p>For example: Diabetic retinopathy</p>
3	<p>Question: In your</p>	<p>In your opinion,</p>	<p>Health Professionals were asked</p>

	<p>opinion, what specific needs do older people have which differ from that of a younger patient with diabetes?</p> <p>Original source: IDOP</p>	<p>what specific needs do older people have which differ from that of a younger person with diabetes & Low vision?</p>	<p>about their perception of the differences in the needs between older people and younger people and to find out what support is available for older people as their needs may be different than younger people with diabetes.</p> <p>For example: Mobility. Frailty Need help following instructions for medicine. Older people have lower exercise levels. Older people have difficulties with communication Older people require assistance with using Insulin</p>
4	<p>Question: In terms of 'good clinical practice' how important are the following key aims in the treatment of older people with diabetes? Rank in order of importance</p> <p>Original source: IDOP</p>	<p>In terms of 'good clinical practice' what are your key aims in the treatment of older people with diabetes & Low vision?</p>	<p>This question was based on the experiences of the professionals in the sense of monitoring and treating low vision and diabetes effectively.</p> <p>For example: Achieving agreed glucose targets Timely referral to hospital specialist Timely referral community DSN Stable diet patterns & good vision Maintaining quality of life</p>
5	<p>Question: In your opinion, are current insulin devices suitable for visually impaired patients?</p> <p>Original source: IDOP</p>	<p>In your opinion, what are the limitations for older patients with low vision using an insulin pen?</p>	<p>This question was based on the professionals' experiences and concerns associated with the use of an insulin pen.</p> <p>For example: to find out if the insulin pen is safe for older people</p>

			with low vision or not.
6	<p>Question: Select multiple responses if applicable. Which of the following can improve the present support offered to the family and carers of older people with diabetes?</p> <p>Original source: IDOP</p>	<p>In your opinion, which of the following can improve the present support offered to the family and important others of older people with Low vision and diabetes?</p>	<p>The participants were asked about their perspective on the help offered by family to older people with Low vision and diabetes.</p> <p>For example: to find out what will help.</p> <p>Provide individual care plan to include the family. Getting family more involved in the management of their care</p>
7	<p>Question: What could be done to motivate families/carers to become more involved in the care of older people with diabetes? Select multiple options if applicable</p> <p>Original source: IDOP</p>	<p>In your opinion, what could be done to motivate families/carers to become more involved in the care of older people with Low vision due to diabetes?</p>	<p>This question was based on the professionals' experiences and concerned about the families/carers motivations to become more involved in the care of older people with Low vision and diabetes.</p> <p>For example: to find out if family involvement makes a difference to the lives of their love one</p>
8	<p>Question: In your experience, do older people self-manage more effectively after diabetes education?</p> <p>Original source: IDOP</p>	<p>Do older people (>75y) in your experience self-manage more effectively after diabetes education?</p>	<p>This question was based on the Importance of education for older people with low vision and diabetes.</p> <p>For example: to find out that education will help or not.</p>
9	<p>Question: In your capacity as a health professional, have you had training in the</p>	<p>In your capacity as a health professional, have you had recent training in the</p>	<p>This question was based on healthcare professionals' education.</p> <p>For example: to know about the healthcare professionals' education</p>

	<p>delivery of diabetes care?</p> <p>If you responded yes to the previous question, was that within the following time points?</p> <p>Original source: IDOP</p>	<p>delivery of Low vision due to diabetes care?</p> <p>If yes, was that within the following time points?</p>	<p>and trainings, as healthcare professionals' providing services, it is very important to find out that have received up-to-date trainings CPD, in the area of low vision and diabetes.</p>
10	<p>Question: Do residents with diabetes in care homes have an individual care plan?</p> <p>Original source: IDOP</p>	<p>In your opinion, do older people with Low vision and diabetes living in residential care homes have an individual care plan?</p>	<p>This question was based on the care plans for older people with low vision and diabetes.</p> <p>For example: to find out if healthcare professionals are aware of individual care plan. What will be the benefit of the individual care plan?</p>
11	<p>Question: What is your overall advice to people with diabetes with regard to their eye health?</p> <p>Original source: "Visual Loss in Care Home Residents with Diabetes" not published yet</p>	<p>What is your overall advice to people with diabetes with regard to their eye health?</p>	<p>This question was used to find out if health care professionals understand low vision associated with diabetes and they know what to do.</p> <p>For example: Regular eye checks and Education</p>
12	<p>Question: What is your concern about the cost of glasses?</p> <p>Original source: "Visual Loss in Care</p>	<p>What is your concern about the cost of glasses?</p>	<p>This question was based on health care professionals concern about the cost of glasses.</p> <p>For example: to find out about cost as good quality glasses were too</p>

	Home Residents with Diabetes” not published yet		<p>expensive. The barrier to getting new glasses appears to be cost.</p> <p>Failure to change the glasses can lead to deterioration in sight and other further complications which could be a financial burden to the NHS. So what to do.</p>
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Check List for all sessions

Check List for focus group with community based older people:

One Month Before

- Meeting with GP from Bedfordshire, to find accessible, affordable location for focus group, Set date and times, identify participants for session
- Calling and sending invitations to participants
- Ordering food for refreshment break

Two weeks before for all participants:

- making a call for confirming time, date and place, including availability of transportation
- Confirming location of session
- Confirming a food
- Secure materials for session
- Name tent, first names only
- Pens/pencils and paper
- Flip Chart and markers
- Hand-outs

One hour before for all participants:

- Arranging table and chairs
- refreshments
- name tents, paper and pencils for each participant

Half hour before for all participants:

- Greeting the participants when they arrive
- Indicating the location of washrooms

Starting of session:

- Welcome and Introduction
- Describing 'ground rules' for participation
- Beginning questions
- Refreshment break
- Continue questions
- Concluding questions

End of session:

- Evaluation
- Thank participants

Questions for focus group with community based older people:

1 Could you tell us about when and how you were diagnosed? Why were you tested?

Issues/topics to cover:

- Who made the diagnosis of low vision and diabetes
- How the diagnosis was made
- Length of time since diagnosis

2 What did you think about low vision and diabetes at that time? How did you feel about your diagnosis?

Issues/topics to cover:

- Knowledge of low vision and diabetes
- Attitude towards low vision and diabetes,
- Impact on social relationships

3 What help, including information, were you given when you were diagnosed and who provided this help or information to you? Was help provided in the language of your choice? How long did you have to wait for this help, and if you had to wait for a longer time, what did you do in the meantime?

Issues/topics to cover:

- Information provided by physician
- Length of time between diagnosis and visit with physician
- Awareness of or information provided by physician,
- Awareness of or help (financial or technical) with diabetes medications
- Awareness of or help by support groups
- Help by family, friends, church, community organizations, etc.
- Help from resources like the internet and television

4 In what ways, if any, has your attitude towards low vision and diabetes changed since you were diagnosed?

Issues/topics to cover:

- More acceptance of diagnosis
- More or less fear/worry about diabetes
- Greater awareness of the need for information concerning low vision and diabetes

5 How has your day-to-day life changed, if it has, since you were diagnosed? If it has changed, what do you think brought about this change?

Issues/topics to cover concerning change:

- Change in lifestyle – weight management, nutrition, exercise, meal planning,
- Change in social life – meals with family, friends, parties, etc.
- Change in cost of living – cost of medication, supplies, food, transportation

Issues/topics to cover concerning what affected change:

- Awareness of the complication of low vision and diabetes
- Information and support by physician
- Information and support by pharmacist
- Support by family, friends or community support groups
- Information from other resources, such as the internet, television, pharmacy and other health care professionals including dieticians

Refreshment Break (10 – 15 Minutes)

Continue Questions Concerning Diabetes (30 minutes)

6. What concerns you most about diabetes?

Issues/topics to cover:

- Impact on your health - complications from diabetes affecting your eyesight,
- Impact on emotions - worry, depression,
- Impact on income/financial security - cost of diabetes supplies, cost of healthy food,
- Impact on social life - how to carry on social life and live diabetes lifestyle
- Impact on family life – will other family members be diagnosed?
- Reading labels

7. What helps you most to understand and manage about your eyesight and diabetes?

Issues to cover:

- Information provided by physician
- Information and support by diabetes educator in a one to one or group session. Are you prefers a group setting or a one to one meeting?
- Information and support by community health organizations, pharmacists, nurse practitioner,
- Help from other health care professionals
- Help by support groups

- Help from family
- Help from friends, church, community organizations,
- Information from media and/or internet

8. What additional help or support do you need?

Issues/Topics to cover:

- Information/support from physician
- Information/support from diabetes educator or on an ongoing basis
- Financial support, personal/social support (family and friends)
- Community support

Concluding Questions (10 minutes)

9. As a person living with diabetes, how do you see your future?

Issues/Topics to cover

- Overall health: living with diabetes, preventing or coping with complications
- Independence: perceived impact of diabetes on quality of life
- Finances: perceived impact of diabetes on cost of living

10. What is the most important advice you can give to the elderly people who has just been diagnosed with diabetes?

11. Do you have any final questions or comments?

Check list for optometrists' focus group

One month before

- Meeting with lead optometrists.
- Find accessible, affordable location for focus group, Setting date and times.

Questions:

1 In your opinion, what are the most important barriers to effective diabetes and low vision management in older people?

2 In terms of 'good clinical practice' what are your key aims in the treatment of older people with low vision and diabetes?

3 How often would you recommend blood glucose testing to an older person with low vision associated with diabetes?

Questions 1/2/3 will cover the Issues & topics to:

To explore what are the Key issues in managing low vision in older people with low vision associated with diabetes?

4 In your opinion, do older people with the low vision and diabetes understand the benefits of structured low vision and diabetes education?

5 From your experience, are older people with low vision associated with diabetes keen to receive low vision and diabetes education?

6 In your opinion are there specific educational needs?

Questions 4/5/6 will cover the Issues & topics to:

- Are educational programs adapted to the patient's visual abilities?
- What educational services are available?
- How motivated the patient?
- What support is available to the patient?
- Does the patient have family or friends to provide support, help with housework or transportation?
- How is the patient adapting emotionally?
- Have there been signs of clinical depression?

Refreshment Break (10 Minutes)

Continue Questions Concerning low vision and Diabetes (20 minutes)

7 In your opinion, do older people with the low vision and diabetes understand the benefits of taking their medication at the right time and at the right dosage?

Issues/topics to cover:

- Does the patient have health problems or treatment requirements that will impact low vision recovery?
- If the person is with diabetes, can they will see to fill insulin syringes, read nutritional labels on food containers and see to monitor their foot care?

- Is the patient taking medications that may impact their vision and can the patient see to identify their medications?

8 In your opinion what are the reading requirements and needs?

Issues/topics to cover:

- Does the patient need or wish to read specific materials, a church newsletter, the newspaper or their mail?
- What happens when the patient attempts to read?
- What can the patient read (newspaper print, large print, or large headlines)?
- Is eyestrain or ocular fatigue present?
- Is the patient an avid reader?

9 In your opinion, what specific needs do older people have in low vision and diabetes?

Issues/topics to cover:

- Can the patient see to perform other near point and intermediate visual activities like writing, sewing, cooking,
- Can the patient see to write a cards or letters?
- Do they use large print?
- Can they see to use a watch?

10 What is your Concern about the cost of glasses?

To cover economically Issues & topics

11 In your opinion, Should the patient's general eyewear be changed?

Issues/topics to cover:

1. What types of prescription eyewear are advised?
 2. What type of material and lens style?
 3. Are filters, antireflection coatings, ultraviolet coatings advised?
 4. When should it be worn?
 5. Are there eye safety issues?
- 2 In your opinion, the patient and family need to be counselled on the condition, visual effects, the rehabilitation process, and safety issues?

Issues/topics to cover:

- What literature or videotapes, are being provided?

13 In your opinion how can we improve quality of Daily Living in older person with low vision associated with diabetes?

Issues/topics to cover: Activities of Daily Living, TV & Computers, Mobility, Driving, Light & Glare

- Can the patient see to do other routine housekeeping duties like cleaning, paying bills, and laundry?
- Are computers used?
- How large is the monitor?
- What type of work is being done?
- How close must the patient sit to the computer screen?
- Is computer enlargement or voice software used?
- Does the patient wear dedicated eyewear for the computer?
- Is the patient able to access the Internet?
- What is done for recreation?
- Does the patient have a hobby?
- Can the patient view the television?
- How close do they sit?
- How large is the television?
- How well do they see the colours on the screen?
- Are there any mobility issues?
- Can the patient travel independently?
- Does the patient use a long cane or guide dog?
- Does the patient run into objects or trip on curbs?
- Has the patient had mobility and orientation training?
- Does the patient take trips? How do they travel?
- Are there any difficulties?
- Does the patient have a handicapped-driving placard?

- Does the patient still drive, and if so, when and with or without a valid license?
- Have there been accidents or traffic violations?
- When will the license expire?
- Does the family support continued driving?
- Has patient limited their driving?
- Is someone else available to drive?
- Is public transportation available?
- How does the patient function in bright sunlight, inside lighting and at night?
- Are sunglasses worn?
- What colour and type?
- Does the patient use a hat or visor?
- Does light and glare affect the patient's mobility?
- Does the patient have difficulty changing from different light levels?
- Is there a residual decrease in vision after coming inside from bright light?
- How does the patient function at night?

Check list of interviews:

One month before

- Meeting with care home managers from Bedfordshire to set date and times to identify participants for session
- sending invitations to participants

Two weeks before for all participants:

- making a call for confirming time, date and place, including availability of transportation
- Confirming location of session
- Confirming a food
- Secure materials for session

- Name tent, first names only
- Pens/pencils and paper
- Flip Chart and markers
- Hand-outs

One hour before for all participants:

- Arranging table and chairs
- refreshments
- name tents, paper and pencils for each participant

Half hour before for all participants:

- Greeting the participants when they arrive
- Indicating the location of washrooms

Starting of session:

- Welcome and Introduction
- Describing 'ground rules' for participation
- Beginning questions
- Refreshment break
- Continue questions
- Concluding questions

End of session:

- Evaluation
- Thank participants

Questions for interviews with older people:

Part 1 Questions 01 to 09 will be covering the Issues/topics regarding:

- Who made the diagnosis of low vision and diabetes
- How the diagnosis was made
- Length of time since diagnosis
- Knowledge of low vision and diabetes
- Attitude towards low vision and diabetes,
- Impact on social relationships

- Information provided by physician
- Length of time between diagnosis and visit with physician
- Awareness of or information provided by physician,
- Awareness of or help (financial or technical) with diabetes medications
- Awareness of or help by support groups
- Help by family, friends, church, community organizations, etc.
- Help from resources like the internet and television
- More acceptance of diagnosis
- More or less fear/worry about diabetes
- Greater awareness of the need for information concerning low vision and diabetes

Part 2 Questions 01 to 06 will be covering the Issues/topics regarding:

- Change in lifestyle – weight management, nutrition, exercise, meal planning,
- Change in social life – meals with family, friends, parties, etc.
- Change in cost of living – cost of medication, supplies, food, transportation
- Awareness of the complication of low vision and diabetes
- Information and support by physician
- Information and support by pharmacist
- Support by family, friends or community support groups
- Information from other resources, such as the internet, television, pharmacy and other health care professionals including dieticians

Part 3 Questions 01 to 17 will be covering the Issues/topics regarding:

- Impact on your health - complications from diabetes affecting your eyesight,
- Impact on emotions - worry, depression,
- Impact on income/financial security - cost of diabetes supplies, cost of healthy food,
- Impact on social life - how to carry on social life and live diabetes lifestyle

- Impact on family life – will other family members be diagnosed?
- Reading labels
- Information provided by physician
- Information and support by diabetes educator in a one to one or group session. Are you prefers a group setting or a one to one meeting?
- Information and support by community health organizations, pharmacists, nurse practitioner, Help from other health care professionals
- Help by support groups, Help from family, Help from friends, church, community organizations, Information from media and/or internet
- Information/support from physician, Information/support from diabetes educator or on an on-going basis
- Financial support, Personal/social support (family and friends)
- Community support (support groups, help from church)
- Overall health: living with diabetes, preventing or coping with complications
- Independence: perceived impact of diabetes on quality of life
- Finances: perceived impact of diabetes on cost of living

Part 4 Evaluation Questions for Participants

1. Do you have any final questions or comments?
2. What did you like about the interviews?
3. Can you name one thing you would change?
4. How cane care for low vision associated with diabetes in the care home will be improved?

Questions for interviews with HCAs:

Questions 1/ to /7 will cover the Issues & topics regarding

- What are the most important barriers to diabetes and Low vision in older people in the Care Home?

- To explore what are the Key issues in managing low vision in older people with diabetes in care home?
- What are the problems?
- What are the limitations?
- To identify how HCAs approach of care to diabetes & Low vision older person?
- HCAs knowledge, about the other problems older people with diabetes & Low vision experience when on insulin therapy?
- What is done for recreation?

Questions 8/15 will cover the Issues & topics regarding

- Does the family support continued?
- Family and Carers Perspectives
- Does the patient have family or friends to provide support, help with
- How is the patient adapting emotionally?
- Education
- What educational services are available?
- What support is available to the patient?
- To discover that HCAs understands the benefits of diabetes education?
- To know about HCAs training regarding low vision and diabetes care?
- HCAs knowledge, about the dietary intake of older people with diabetes?
- HCAs knowledge, about the care plan for older people with Low vision associated with diabetes
- Residents Safety, respect, dignity, culture within Care Homes
- Management of Diabetes within Care Homes
- Does the patient have health problems or treatment requirements that will impact low vision recovery?
- Is the patient taking medications that may impact their vision and can the patient see to identify their medications?

Research diaries

Research diaries

Date: 4th December 2013

Time: 09:00am

In IDOP, Professor Peter Scanlon asked Mrs (W, N) (Optometrist), to help me in teaching afternoons of ophthalmologists in Bedfordshire instead of Oxford as my study is related to Bedfordshire to gain access to them for focus groups and interviews. Mrs W, N said she will speak to head of the department, also Mrs W N invite me in Ophthalmologists, Optometrists and GPs seminar this evening at 6:30 in Putteridge Bury.

Date: 6th December 2013

Time: 10:00am

Whilst I arrived at hospital Bedfordshire outside of Mr V,H's clinic, he was not available at the moment. Meanwhile there was a potential participant who had appointment with Mr V,H's that morning. I did meet that potential participants and explained my study to him and gave him information sheet, from which he could be able to contact with me if he would agree to join in the study.

10th December 2013

Time: 10:30am

I explained my study to Professor M E for focus group ophthalmologists, optometrists,

Professor M E asked me a few questions about my study and about the ophthalmologists, optometrists and resident's questioners, I answered his questions and I emailed a soft copy of participant information sheet and questioners to him for more information's about my study. Professor M E said focus group will be bit hard but he can help me for the interviews. I requested to Professor M E for teaching classes as maybe I can get participants for my focus

group from the teaching classes. Professor M E said that he will forward my request to the Clinical Director for approval in teaching classes and I'll let you know their decision as soon as I hear from them. He said I'll try to give you my support as much as I could.

10th December 2013

Time: 01:45pm

I explained my study to Dr C& Practice manager for Health Professionals Survey, they were quite happy to participant in the Health Professionals Survey. They asked me a few questions about my study. I answered their questions and I gave them participant information sheet to read for more information's about my study.

3rd January 2014

Time: 10:45am

As this was my 2nd meeting with Mr K and he knows about my project. I explained my study and community based focus group to Mr K in detail. Mr K asked me a few questions about community based focus group. Which I answered and I give him participant information sheet for more information's. Mr K said every Thursday, Friday and Saturday, he doing counselling with older community residents about medications, foods and etcetera in his office. So it is very easy for him to help me for this group. Also he offered me his office for the focus group. As all people coming to his office for consultations so this will be easier for them to participant.

Mr K asked me when you want to do your focus group. I told him I am just waiting for my ethics approval and very soon I will be able to start my focus group. After went home, I completed field note, and typed it into computer.

There was another preparation for tomorrow's interviewing on 10 am. I have felt a bit of relax. Maybe the experiences of interviewing make me feel more confidence on the data collection in the field.

Low vision and diabetes in older people living in residential care homes

Information sheet for Health Professionals including
Ophthalmologists and Optometrists Survey

This Informed Consent Form has three parts

1 Information Sheet information about the study

2 Certificate of Consent 3 Questionnaire

Health Professionals Survey

Principal researcher: Nizam Muhammad Darwesh

PhD Researcher

Director of study: Professor Alan Sinclair MSc MD FRCP

Dean & Professor of Medicine Bedfordshire and Hertfordshire

Postgraduate Medical School University of Bedfordshire

Director of study: Professor Peter Scanlon

MD FRCP DCH DRCOG DO FRCOphth PG Cert.

Consultant Ophthalmologist, Oxford Eye Hospital



Informed Consent Form

Informed consent form for participation in the study titled “Low vision and diabetes in older people living in residential care homes” To Improving quality of care for older people with low vision associated with diabetes.

Principal researcher: Nizam Muhammad Darwesh
(PhD researcher)

Director of study: Professor Alan Sinclair MSc MD FRCP
Dean & Professor of Medicine Bedfordshire and Hertfordshire
Postgraduate Medical School University of Bedfordshire

Director of study: Professor Peter Scanlon
MD FRCP DCH DRCOG DO FRCOphth PG Cert. Med.Ed.
Consultant Ophthalmologist,
Gloucestershire Eye Unit & Oxford Eye
Hospital Programme Director for the English National
Diabetic Retinopathy Screening Programme

Establishment: Institute of diabetes for older people (IDOP)
Putteridge bury University of Bedfordshire

This Informed consent form has three parts:

- 1 Information sheet (information about the study)
- 2 Certificate of consent (for signatures if you choose to participate)
- 3 Questionnaires

You will be given a copy of the full Informed consent form

Part I: Information Sheet

About Principal researcher:

My name is Nizam Muhammad Darwesh, and I am a PhD researcher at the University of Bedfordshire. I am carrying out a research study titled “Low vision and diabetes in older people living in residential care homes” residents” to understand how we can improve quality of care for older people with low vision associated with diabetes, I will provide you with information about my research and invite you to participate in this study. If you would like any further information that you feel was not provided in this information package, please feel free to ask me or my supervisor questions, Professor Alan Sinclair.

About directors of study:

Professor Alan Sinclair MSc MD FRCP Dean and Professor of Medicine, Bedfordshire and Hertfordshire Postgraduate Medical School & Director of the institute of Diabetes for Older People (IDOP) University of Bedfordshire Putteridge Bury Campus Hitchin Road Luton LU2 8LE
Tel: 01582 743285 Fax: 01582 743286 E-mail: alan.sinclair@beds.ac.uk

Professor Peter Scanlon MD FRCP DCH DRCOG DO FRCOphth PG Cert. Med.Ed.
Consultant ophthalmologist, Gloucestershire eye unit & Oxford eye hospital; programme director for the English national diabetic retinopathy screening programme department of ophthalmology, Cheltenham general hospital, Sand ford road, Cheltenham, Gloss GL53 7AN, E-mail: Peter.Scanlon@glos.nhs.uk

Invitation to take part in this research study

You are invited to take part in this research study titled, “Low vision and diabetes in older people living in residential care homes” being undertaken by Principal researcher Nizam Muhammad Darwesh at Bedfordshire and Hertfordshire Postgraduate medical school & Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire,

This research study will involve you being asked some questions about current diabetes and eye care and future services. The meeting will take about 5 to 10 minutes to complete.

What is the purpose of this research? Why are we doing this research?

Low vision associated with diabetes in older people is common. There are many different opinions about low vision associated with diabetes in older people that are unhelpful in recognising and addressing some of the issues surrounding it. Through this research, we hope to learn the views of the participants to understand the impact of diabetes on low vision in older people and also the purpose of this research which is to Improve the quality of care for older people with low vision associated with diabetes, and to help with the planning of existing and future low vision services associated with diabetes care for older people resident in care homes. This research project will help to develop a clearer picture of the current services available, staff experiences, and perceived needs of older people resident in care homes. in addition to develop a package of education and training to support practitioners in providing better health care to older individuals with low vision associated with diabetes.

Why have I been chosen?

You are the best source of information about this topic. We feel that your experience and knowledge will help us in filling the gaps in terms of our understanding, communication and services that are needed to improve low vision care in people with diabetes. Also this is the selection criteria for this project.

Do I have to take part?

No, you do not have to take part if you do not want to, it's your choice. Your participation in our research study is totally voluntary, and you may choose to not participate at any point before or during the research. You are also allowed to change your mind if you decide to not participate at a later time even if you had agreed earlier. By taking part you will be helping us to improve low vision associated with diabetes services for older people.

What will happen to me if I take part?

The Principal researcher will ask you a number of questions about your views on current care of older people relating to low vision associated with diabetes. The meetings will last about 5 to 10 minutes and will be arranged during normal day time working hours. The information you give will be recorded and your responses used to identify gaps in service provision. Any names you mention will remain anonymous and excluded from the final report.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help to improve low vision associated with diabetes services for older people living in the residential care homes.

Obtaining your consent

It is important that you understand that if you decide to take part in this study you will be asked to give your consent to be part of this study. This means that you will be asked to sign a consent form. This form will have separate questions asking for your responses to be shared between the research team and perhaps for some of your responses to be used 'verbatim' (word for word) in the report. Before any of this is done, the Principal researcher will first explain the study to you and then answer any questions that you may have about the study. If after the explanation you are still willing to take part, then you will be asked for your consent by signing the form.

What if I change my mind?

If after reading this information sheet you decide to take part in the study, but then later on you decide that you no longer want to take part, you are under no obligation to continue, you can withdraw from the study without having to give any reasons for your decision at any time. This includes your right to stop part way through the interview. A decision to withdraw at any time, or a decision not to take part,

What do I have to do?

If you are interested in taking part in this study then you will be contacted by a principal researcher. This will be to arrange a date and place convenient to you for the meeting. Any questions that you may have about the study can be discussed with the principal researcher at this time, if after this discussion you feel you do not want to carry on, you can withdraw from the study.

What happens to the information I give at the interview? (Confidentiality)

Any personal details, such as any names of people or places that you may have mentioned will remain confidential; they will not be included in the report version. All information collected within a survey will be known only to survey members. Data will be in the safe hands and only Nizam and Professor Alan Sinclair and Professor Peter Scanlon. Will have access to this information. Therefore is no chance for any breach of confidence or failure to maintain data security, Data will be stored securely on password protected PC and will be locked in the Institute of diabetes for older people (IDOP) Putteridge bury campus University of Bedfordshire and, Data will be analysed in confidential,

What will happen to the results of the study?

This research is being conducted for PhD thesis; it will be available through the Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire. Also the research team will use the survey to find out ways in which low vision associated with diabetes services can be improved for older people. The findings from the study will be published in a newsletter, which will be made available to you.

Who is organising and funding this study?

All financial necessary resources to complete the study will be self-finance. Access to databases will be through the University of Bedfordshire and IDOP,

Who has approved the study?

This study has undergone a rigorous process of inspection and has been approved by the Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire ethics committee.

Contact for further information about this study

If you have a concern about any aspect of this study, or if you wish to make a comment or complaint, please feel free to contact me Nizam at: drnizam2010@yahoo.co.uk or nizam.darwesh@study.beds.ac.uk or call 01582743988. I will do my best to answer your questions. If you remain unhappy you can contact Professor Alan Sinclair (Dean and Professor of Medicine, B&H Postgraduate medical school & director of the institute of diabetes for older people (IDOP) University of Bedfordshire e-mail: alan.sinclair@beds.ac.uk or call Tel: 01582 743285.

Thank you for taking the time to read this information sheet, we would be grateful if you decide to take part.

Part II: Certificate of Consent

I have been invited to participate in a study titled “Low vision and diabetes in older people living in residential care homes” which involves a study of older people with low vision associated with diabetes. I have read and I fully understand the information given above about the research. I have asked any questions that I had regarding the research and they have been answered to my satisfaction. I voluntarily consent to take part in this study.

Print name of participant _____

Signature of participant _____

Date _____

Statement by the principal researcher

I have presented the information to the potential participant to the best of my knowledge. I have ensured that the participant understands they have the choice to opt out of the study at any stage if they do choose to participate. Participants are aware that all information will be kept confidential and all results reported will be done so anonymously. I also confirm that the participants have had the opportunity to ask questions about the study and that they have been answered to their content. The participants have not been forced to participate and I declare no conflicting interest in undertaking this research.

Principal researcher: Nizam Muhammad Darwesh

Signature of principal researcher _____

Date _____

Health Professional Survey questionnaire

Please tick as many answers as you want or write down your own opinion.	✓
---	---

1	In your opinion, what are the most important barriers to effective diabetes and low vision management in older people living in residential care home?	<input type="checkbox"/> Insufficient diabetes & Low vision training among HCAs <input type="checkbox"/> Communication difficulties as a result of cognitive impairment or other medical problems <input type="checkbox"/> Increase risk of adverse drug reactions for patients taking multiple drugs <input type="checkbox"/> Staff with negative attitudes towards the elderly and their care <input type="checkbox"/> Lack of available resources in terms of staff time <input type="checkbox"/> Don't know Other _____
2	In your opinion, what kinds of vision problems do people with diabetes experience?	<input type="checkbox"/> diabetic retinopathy, <input type="checkbox"/> Moderate or severe vision loss. <input type="checkbox"/> Lack of blood supply to parts of the retina <input type="checkbox"/> Leakage of fluid through the blood vessels in the retina. <input type="checkbox"/> Swelling in the retina called macular oedema <input type="checkbox"/> Proliferative retinopathy, the lack of blood supply can cause new, abnormal blood vessels to grow. <input type="checkbox"/> Retinal detachment or bleeding into the eye, <input type="checkbox"/> Don't know Other _____
3	In your opinion, what specific needs do older people have which differ from that of a younger patient with diabetes & Low vision?	<input type="checkbox"/> Older people need more help and support with different activities <input type="checkbox"/> Mobility <input type="checkbox"/> Frailty <input type="checkbox"/> Need help following instructions for medicine <input type="checkbox"/> Older people have lower exercise levels <input type="checkbox"/> Older people have difficulties with communication <input type="checkbox"/> Older people require assistance with using Insulin <input type="checkbox"/> Most older people have low vision <input type="checkbox"/> Don't know Other _____
4	In terms of 'good clinical practice' what are your key aims in the treatment of older people with diabetes & Low vision?	<input type="checkbox"/> Achieving agreed glucose targets <input type="checkbox"/> Timely referral to hospital specialist <input type="checkbox"/> Timely referral community DSN <input type="checkbox"/> Identifying frailty early <input type="checkbox"/> Stable diet patterns & good vision <input type="checkbox"/> Maintaining quality of life <input type="checkbox"/> Achieving high life expectancy

		<input type="checkbox"/> Don't know Other_____
5	In your opinion, what are the limitations for older patients with low vision using an insulin pen?	<input type="checkbox"/> Force required to inject insulin <input type="checkbox"/> Manual Dexterity <input type="checkbox"/> Ease for correcting a dose unintentionally set <input type="checkbox"/> Size of the insulin unit numbers <input type="checkbox"/> Slide force and handling <input type="checkbox"/> The "thumb reach" when setting a large dose (especially in women) <input type="checkbox"/> Don't know Other_____
6	In your opinion, which of the following can improve the present support offered to the family and important others of older people with Low vision and diabetes?	<input type="checkbox"/> Provide individual care plan to include the family and carer <input type="checkbox"/> Getting family and carer more involved in the management of their care <input type="checkbox"/> Be more culturally aware when devising a care plan for the patient <input type="checkbox"/> Involve the family and care in decision making with the dietician <input type="checkbox"/> Getting older people more involved in the management of their care <input type="checkbox"/> Don't know Other_____
7	In your opinion, what could be done to motivate families/carers to become more involved in the care of older people with Low vision due to diabetes?	<input type="checkbox"/> Acknowledge their hard work <input type="checkbox"/> Show evidence that family involvement makes a difference to the lives of their love one <input type="checkbox"/> Provide financial support <input type="checkbox"/> Provide education <input type="checkbox"/> All of the above <input type="checkbox"/> Don't know Other_____
8	Do older people (>75y) in your experience self-manage more effectively after diabetes education?	<input type="checkbox"/> Good improvement <input type="checkbox"/> Fair improvement <input type="checkbox"/> No improvement <input type="checkbox"/> Don't know Other_____
9	In your capacity as a health professional, have you had recent training in the delivery of Low vision due to diabetes care? If yes, was that within the following time points?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Last 5 years <input type="checkbox"/> Last 3 years <input type="checkbox"/> In the last 12 months Other_____
10	In your opinion, do older	<input type="checkbox"/> Yes – all

	people with Low vision and diabetes living in residential care homes have an individual care plan?	<input type="checkbox"/> Only some <input type="checkbox"/> No <input type="checkbox"/> Don't know Other _____
11	What is your overall advice to people with diabetes with regard to their eye health?	<input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____
12	What is your concern about the cost of glasses?	<input type="checkbox"/> Low cost glasses are low quality <input type="checkbox"/> Glasses are very expensive <input type="checkbox"/> No concerns <input type="checkbox"/> Don't know Other _____

Low vision and diabetes in older people living in residential care homes

Information Sheet for interviews, care home residents

This Informed Consent Form has three parts

1 Information Sheet information about the study

2 Certificate of Consent 3 Questionnaire

interviews, care home residents

Principal researcher: Nizam Muhammad Darwesh

PhD Researcher

**Director of study: Professor Alan Sinclair MSc MD FRCP
Dean & Professor of Medicine Bedfordshire and Hertfordshire
Postgraduate Medical School University of Bedfordshire**

**Director of study: Professor Peter Scanlon
MD FRCP DCH DRCOG DO FRCOphth PG Cert.
Consultant Ophthalmologist, Oxford Eye Hospital**



Informed Consent Form

Informed consent form for participation in the study titled “Low vision and diabetes in older people living in residential care homes” To Improving quality of care for older people with low vision associated with diabetes.

Principal researcher: Nizam Muhammad Darwesh
(PhD Researcher)

Director of study: Professor Alan Sinclair MSc MD FRCP
Dean & Professor of Medicine Bedfordshire and Hertfordshire
Postgraduate Medical School University of Bedfordshire

Director of study: Professor Peter Scanlon
MD FRCP DCH DRCOG DO FRCOphth PG Cert. Med.Ed.
Consultant Ophthalmologist,
Gloucestershire Eye Unit & Oxford Eye
Hospital Programme Director for the English National
Diabetic Retinopathy Screening Programme

Establishment: Institute of diabetes for older people (IDOP)
Putteridge bury University of Bedfordshire

This Informed consent form has three parts:

- 4 Information sheet (information about the study)
- 5 Certificate of consent (for signatures if you choose to participate)
- 6 Questionnaires

You will be given a copy of the full Informed consent form

Part I: Information Sheet

About Principal researcher:

My name is Nizam Muhammad Darwesh, and I am a PhD Researcher at the University of Bedfordshire. I am carrying out a research study titled “Low vision and diabetes in older people living in residential care homes” to understand how we can improve quality of care for older people with low vision associated with diabetes, I will provide you with information about my research and invite you to participate in this study. If you would like any further information that you feel was not provided in this information package, please feel free to ask me or my supervisor questions, Professor Alan Sinclair.

About directors of study:

Professor Alan Sinclair MSc MD FRCP Dean and Professor of Medicine,
Bedfordshire and Hertfordshire Postgraduate Medical School & Director of the
institute of Diabetes for Older People (IDOP) University of Bedfordshire
Putteridge Bury Campus Hitchin Road Luton LU2 8LE

Tel: 01582 743285 Fax: 01582 743286 E-mail: alan.sinclair@beds.ac.uk

Professor Peter Scanlon MD FRCP DCH DRCOG DO FRCOphth PG Cert. Med.Ed.
Consultant ophthalmologist, Gloucestershire eye unit & Oxford eye hospital;
programme director for the English national diabetic retinopathy screening
programme department of ophthalmology, Cheltenham general hospital,
Sandford road, Cheltenham, Glos GL53 7AN, E-mail:
Peter.Scanlon@glos.nhs.uk

Invitation to take part in this research study

You are invited to take part in this research study titled, “Low vision and diabetes in older people living in residential care homes” being undertaken by Principal researcher Nizam Muhammad Darwesh at Bedfordshire and Hertfordshire Postgraduate medical school & Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire,

This research study will involve you being asked some questions about current diabetes and eye care and future services. You will be invited to focus group discussions with other colleagues'. The meeting will take about 30 minutes to complete. The meeting will take place at the Georgiana Care Home Bedfordshire

What is the purpose of this research? Why are we doing this research?

Low vision associated with diabetes in older people is common. There are many different opinions about low vision associated with diabetes in older people that are unhelpful in recognising and addressing some of the issues surrounding it. Through this research, we hope to learn the views of the participants to understand the impact of diabetes on low vision in older people and also the purpose of this research which is to Improve the quality of care for older people with low vision associated with diabetes, and to help with the planning of existing and future low vision services associated with diabetes care for older people resident in care homes. This research project will help to develop a clearer picture of the current services available, staff experiences, and perceived needs of older people resident in care homes. in addition to develop a package of education and training to support practitioners in providing better health care to older individuals with low vision associated with diabetes.

Why have I been chosen?

You are the best source of information about this topic. We feel that your experience and knowledge will help us in filling the gaps in terms of our understanding, communication and services that are needed to improve low vision care in people with diabetes. Also this is the selection criteria for this project.

Do I have to take part?

No, you do not have to take part if you do not want to, it's your choice. Your participation in our research study is totally voluntary, and you may choose to not participate at any point before or during the research. You are also allowed to change your mind if you decide to not participate at a later time even if you

had agreed earlier. By taking part you will be helping us to improve low vision associated with diabetes services for older people.

What will happen to me if I take part?

You will be invited to a group discussion at the Georgiana Care Home Bedfordshire and a principal researcher will ask you a number of questions about your views on current low vision due to diabetes situation for older people. The meetings will last about 30 minutes and will be arranged during normal working hours. It is important that you tell us about your experiences and perceived needs of older people with low vision associated with diabetes in your own words, as if you were telling the interviewer your story. The information you give will be tape-recorded and your responses used to identify gaps in service provision. Any names you mention will remain anonymous and excluded from the final report.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help to improve low vision associated with diabetes services for older people living in the residential care homes.

Obtaining your consent

It is important that you understand that if you decide to take part in this study you will be asked to give your consent to be interviewed. This means that you will be asked to sign a consent form. This form will have separate questions asking for your agreement to be taped, for your responses to be shared between the research team and perhaps for some of your responses to be used 'verbatim' (word for word) in the report. Before any of this is done, the Principal researcher will first explain the study to you and then answer any questions that you may have about the study. The reason for recording the interview is so that the Principal researcher can talk to you without having to stop and take notes. If after the explanation you are still willing to take part, then you will be asked for your consent by signing the form.

Some difficult questions

Please note that some questions may leave you feeling sad and or upset, especially the questions around how you feel services currently meet the needs of older people resident in care home with Low Vision due to diabetes.

Although these are emotionally very difficult questions to answer, please bear in mind that unless we can work out your service development and delivery experiences (good or not so good), we cannot suggest any improvements in the service provision. It is for this reason that some difficult questions are necessary. Any distress that may be caused as a consequence of these questions is deeply regretted.

What if I change my mind?

If after reading this information sheet you decide to take part in the study, but then later on you decide that you no longer want to take part, you are under no obligation to continue, you can withdraw from the study without having to give any reasons for your decision at any time. This includes your right to stop part way through the interview. A decision to withdraw at any time, or a decision not to take part,

What if something goes wrong?

In the unfortunate event that something goes wrong, such as the interview tapes fail to record clearly and the data is rendered 'unusable', the principal researcher will contact the participant concerned to explain the difficulty (that have arisen with the technology) and see if they are able and willing to be re-interviewed. If the participant is unable to be re-interviewed, then the principal researcher will write to them to apologise for the 'loss' of recording and ensure that they understand that they will no longer be included in the study. The principal researcher will then have to decide whether to select another participant or to report this event as a 'null' recording in the final report. The choice will inevitably depend upon the time available to complete the project.

What do I have to do?

If you are interested in taking part in this study then you will be contacted by a principal researcher. This will be to arrange a date and place convenient to you for the group interview. Any questions that you may have about the study can be discussed with the principal researcher at this time, if after this discussion you feel you do not want to carry on, you can withdraw from the study.

What happens to the information I give at the interview? (Confidentiality)

Following the focus group meeting the discussion is typed up into a transcript. Any personal details, such as any names of people or places that you may have mentioned will remain confidential; they will not be included in the report version. All information collected within a focus group will be known only to focus group members and no one outside the group will be informed about the discussion from the research team. Data will be in the safe hands and only Nizam and Professor Alan Sinclair and Professor Peter Scanlon. Will have access to this information. Therefore is no chance for any breach of confidence or failure to maintain data security, Data will be stored securely on password protected PC and will be locked in the Institute of diabetes for older people (IDOP) Putteridge bury campus University of Bedfordshire and, Data will be analysed in confidential,

What happens to the tape recording of the interview?

The interviews will be tape recorded so that the principal researcher can listen to you without the need to take notes. The tape recordings will be kept in accordance with the data protection act, and tapes will be kept in a locked cabinet for the duration of two years after which time they will be destroyed.

What will happen to the results of the study?

This research is being conducted for PhD thesis; it will be available through the Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire. Also the research team will use the interview discussion to find out ways in which low vision associated with diabetes services can be improved for

older people. The findings from the study will be published in a newsletter, which will be made available to you.

Who is organising and funding this study?

All financial necessary resources to complete the study will be self-finance. Access to databases will be through the University of Bedfordshire and IDOP,

Who has approved the study?

This study has undergone a rigorous process of inspection and has been approved by the Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire ethics committee.

Contact for further information about this study

If you have a concern about any aspect of this study, or if you wish to make a comment or complaint, please feel free to contact me Nizam at: drnizam2010@yahoo.co.uk or nizam.darwesh@study.beds.ac.uk or call 01582743988. I will do my best to answer your questions. If you remain unhappy you can contact Professor Alan Sinclair (Dean and Professor of Medicine, B&H Postgraduate medical school & director of the institute of diabetes for older people (IDOP) University of Bedfordshire e-mail: alan.sinclair@beds.ac.uk or call Tel: 01582 743285.

Thank you for taking the time to read this information sheet, we would be grateful if you decide to take part.

Part II: Certificate of Consent

I have been invited to participate in a study titled “Low vision and diabetes in older people living in residential care homes” which involves a study of older people with low vision associated with diabetes. I have read and I fully understand the information given above about the research. I have asked any questions that I had regarding the research and they have been answered to my satisfaction. I voluntarily consent to take part in this study.

Print name of participant _____

Signature of participant _____

Date _____

Statement by the principal researcher /person taking consent

I have presented the information to the potential participant to the best of my knowledge. I have ensured that the participant understands they have the choice to opt out of the study at any stage if they do choose to participate. Participants are aware that all information will be kept confidential and all results reported will be done so anonymously. I also confirm that the participants have had the opportunity to ask questions about the study and that they have been answered to their content. The participants have not been forced to participate and I declare no conflicting interest in undertaking this research.

Principal researcher: Nizam Muhammad Darwesh

Signature of principal researcher _____

Date _____

Interviews Questionnaire for care home residents

Part 1 Please circle Yes or No for each question.

1	What have your doctors told you is the cause of your visual problems is due to diabetes?	Yes	No	Other
2	Do the Doctor visiting you regularly to check your eyes and diabetes?	Yes	No	Other
3	Have you ever had treatment or surgery for your eyes?	Yes	No	Other
4	Have you had recent changes in your vision?	Yes	No	Other
5	Do you wear glasses now?	Yes	No	Other
6	If so, do they help?	Yes	No	Other
7	Do you ever feel that problems with your vision make it difficult for you to do the things you would like to do?	Yes	No	Other
8	Do you know about the low vision due to diabetes?	Yes	No	Other
9	Do you want to know about the low vision due to diabetes?	Yes	No	Other
<u>Part 2</u> Please circle Yes or No for each question.				
1	Can you read newspaper print?	Yes	No	Other
2	Do you use magnifiers?	Yes	No	Other
3	Can you watch television?	Yes	No	Other
4	Do you still drive?	Yes	No	Other
5	Does sunlight bother your eyes?	Yes	No	Other
6	Do you wear sunglasses?	Yes	No	Other

Part 3 Please mark in front any of the following activities that your vision causes you to have problems with.

		✓		✓
1	Books		Shopping	
2	Magazines		Dials	
3	Walking		Clocks	
4	Music		Watches	
5	Personal care		Eating	
6	Sewing		Cooking	
7	Newspapers		Laundry	
8	Writing		Cleaning	
9	Letters		Leisure	
10	Checks		Movies	
11	Signing		Television	
12	Theatre		Sports	
13	Medical		Cards	
14	Labels		Thermometers	
15	Syringes		Computer	
16	Cleaning			

Part 4 Evaluation questions for participants

1. Do you have any final questions or comments?
2. What did you like about the interviews?
3. Can you name one thing you would change?
4. How could the care for low vision and diabetes in the care home will be improved?

Low vision and diabetes in older people living in residential care homes

Information sheet for HCAs interviews

This Informed Consent Form has three parts

1 Information Sheet information about the study

2 Certificate of Consent 3 Questionnaire

Principal researcher: Nizam Muhammad Darwesh

PhD Researcher

**Director of study: Professor Alan Sinclair MSc MD FRCP
Dean & Professor of Medicine Bedfordshire and Hertfordshire
Postgraduate Medical School University of Bedfordshire**

**Director of study: Professor Peter Scanlon
MD FRCP DCH DRCOG DO FRCOphth PG Cert.
Consultant Ophthalmologist, Oxford Eye Hospital**



Informed Consent Form

Informed consent form for participation in the study titled “Low vision and diabetes in older people living in residential care homes” To Improving quality of care for older people with low vision associated with diabetes.

Principal researcher: Nizam Muhammad Darwesh
(PhD Student)

Director of study: Professor Alan Sinclair MSc MD FRCP
Dean & Professor of Medicine Bedfordshire and Hertfordshire
Postgraduate Medical School University of Bedfordshire

Director of study: Professor Peter Scanlon
MD FRCP DCH DRCOG DO FRCOphth PG Cert. Med.Ed.
Consultant Ophthalmologist,
Gloucestershire Eye Unit & Oxford Eye
Hospital Programme Director for the English National
Diabetic Retinopathy Screening Programme

Establishment: Institute of diabetes for older people (IDOP)
Putteridge bury University of Bedfordshire

This Informed consent form has three parts:

- Information sheet (information about the study)
- Certificate of consent (for signatures if you choose to participate)
- Questionnaires

You will be given a copy of the full Informed consent form

Part I: Information Sheet

About Principal researcher:

My name is Nizam Muhammad Darwesh, and I am a PhD student at the University of Bedfordshire. I am carrying out a research study titled “Low vision and diabetes in older people living in residential care homes” residents” to understand how we can improve quality of care for older people with low vision associated with diabetes, I will provide you with information about my research and invite you to participate in this study. If you would like any further information that you feel was not provided in this information package, please feel free to ask me or my supervisor questions, Professor Alan Sinclair.

About directors of study: **Professor Alan Sinclair** MSc MD FRCP Dean and Professor of Medicine, Bedfordshire and Hertfordshire Postgraduate Medical School & Director of the Institute of Diabetes for Older People (IDOP) University of Bedfordshire Putteridge Bury Campus Hitchin Road Luton LU2 8LE
Tel: 01582 743285 Fax: 01582 743286 E-mail: alan.sinclair@beds.ac.uk

Professor Peter Scanlon MD FRCP DCH DRCOG DO FRCOphth PG Cert. Med.Ed.
Consultant ophthalmologist, Gloucestershire eye unit & Oxford eye hospital; programme director for the English national diabetic retinopathy screening programme department of ophthalmology, Cheltenham general hospital, Sandford road, Cheltenham, Gloucestershire GL53 7AN, E-mail: Peter.Scanlon@glos.nhs.uk

Invitation to take part in this research study : You are invited to take part in this research study titled, “Low vision and diabetes in older people living in residential care homes” being undertaken by Principal researcher Nizam Muhammad Darwesh at Bedfordshire and Hertfordshire Postgraduate medical school & Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire. This research study will involve you being asked some questions about current diabetes and eye care and future services. You will be invited to focus group discussions with other colleagues’. The meeting will take about 45 minutes to complete. The meeting will take place at the Georgiana Care Home Bedfordshire

What is the purpose of this research? Why are we doing this research?

Low vision associated with diabetes in older people is common. There are many different opinions about low vision associated with diabetes in older people that are unhelpful in recognising and addressing some of the issues surrounding it. Through this research, we hope to learn the views of the participants to understand the impact of diabetes on low vision in older people and also the purpose of this research which is to Improve the quality of care for older people with low vision associated with diabetes, and to help with the planning of existing and future low vision services associated with diabetes care for older people resident in care homes. This research project will help to develop a clearer picture of the current services available, staff experiences, and perceived needs of older people resident in care homes. in addition to develop a package of education and training to support practitioners in providing better health care to older individuals with low vision associated with diabetes.

Why have I been chosen?

You are the best source of information about this topic. We feel that your experience and knowledge will help us in filling the gaps in terms of our understanding, communication and services that are needed to improve low vision care in people with diabetes. Also this is the selection criteria for this project.

Do I have to take part?

No, you do not have to take part if you do not want to, it's your choice. Your participation in our research study is totally voluntary, and you may choose to not participate at any point before or during the research. You are also allowed to change your mind if you decide to not participate at a later time even if you had agreed earlier. By taking part you will be helping us to improve low vision associated with diabetes services for older people.

What will happen to me if I take part?

You will be invited to a group discussion at the Georgiana Care Home Bedfordshire and a principal researcher will ask you a number of questions about

your views on current low vision due to diabetes situation for older people. The meetings will last about 30 minutes and will be arranged during normal working hours. It is important that you tell us about your experiences and perceived needs of older people with low vision due to diabetes in your own words, as if you were telling the interviewer your story. The information you give will be tape-recorded and your responses used to identify gaps in service provision. Any names you mention will remain anonymous and excluded from the final report.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help to improve low vision associated with diabetes services for older people living in the residential care homes.

Obtaining your consent

It is important that you understand that if you decide to take part in this study you will be asked to give your consent to be interviewed. This means that you will be asked to sign a consent form. This form will have separate questions asking for your agreement to be taped, for your responses to be shared between the research team and perhaps for some of your responses to be used 'verbatim' (word for word) in the report. Before any of this is done, the Principal researcher will first explain the study to you and then answer any questions that you may have about the study. The reason for recording the interview is so that the Principal researcher can talk to you without having to stop and take notes. If after the explanation you are still willing to take part, then you will be asked for your consent by signing the form.

What if I change my mind?

If after reading this information sheet you decide to take part in the study, but then later on you decide that you no longer want to take part, you are under no obligation to continue, you can withdraw from the study without having to give any reasons for your decision at any time. This includes your right to stop part way through the interview. A decision to withdraw at any time, or a decision not to take part,

What if something goes wrong?

In the unfortunate event that something goes wrong, such as the interview tapes fail to record clearly and the data is rendered 'unusable', the principal researcher will contact the participant concerned to explain the difficulty (that have arisen with the technology) and see if they are able and willing to be re-interviewed. If the participant is unable to be re-interviewed, then the principal researcher will write to them to apologise for the 'loss' of recording and ensure that they understand that they will no longer be included in the study. The principal researcher will then have to decide whether to select another participant or to report this event as a 'null' recording in the final report. The choice will inevitably depend upon the time available to complete the project.

What do I have to do?

If you are interested in taking part in this study then you will be contacted by a principal researcher. This will be to arrange a date and place convenient to you for the group interview. Any questions that you may have about the study can be discussed with the principal researcher at this time, if after this discussion you feel you do not want to carry on, you can withdraw from the study.

What happens to the information I give at the interview? (Confidentiality)

Following the focus group meeting the discussion is typed up into a transcript. Any personal details, such as any names of people or places that you may have mentioned will remain confidential; they will not be included in the report version. All information collected within a focus group will be known only to focus group members and no one outside the group will be informed about the discussion from the research team. Data will be in the safe hands and only Nizam and Professor Alan Sinclair and Professor Peter Scanlon. Will have access to this information. Therefore is no chance for any breach of confidence or failure to maintain data security, Data will be stored securely on password protected PC and will be locked in the Institute of diabetes for older people (IDOP) Putteridge bury campus University of Bedfordshire and, Data will be analysed in confidential,

What happens to the tape recording of the interview?

The interviews will be tape recorded so that the principal researcher can listen to you without the need to take notes. The tape recordings will be kept in accordance with the data protection act, and tapes will be kept in a locked cabinet for the duration of two years after which time they will be destroyed.

What will happen to the results of the study?

This research is being conducted for PhD thesis; it will be available through the Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire. Also the research team will use the interview discussion to find out ways in which low vision associated with diabetes services can be improved for older people. The findings from the study will be published in a newsletter, which will be made available to you.

Who is organising and funding this study?

All financial necessary resources to complete the study will be self-finance. Access to databases will be through the University of Bedfordshire and IDOP,

Who has approved the study?

This study has undergone a rigorous process of inspection and has been approved by the Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire ethics committee.

Contact for further information about this study

If you have a concern about any aspect of this study, or if you wish to make a comment or complaint, please feel free to contact me Nizam at: drnizam2010@yahoo.co.uk or nizam.darwesh@study.beds.ac.uk or call 01582743988. I will do my best to answer your questions. If you remain unhappy you can contact Professor Alan Sinclair (Dean and Professor of Medicine, B&H Postgraduate medical school & director of the institute of diabetes for older people (IDOP) University of Bedfordshire e-mail: alan.sinclair@beds.ac.uk or call Tel: 01582 743285.

Thank you for taking the time to read this information sheet, we would be grateful if you decide to take part.

Part II: Certificate of Consent

I have been invited to participate in a study titled “Low vision and diabetes in older people living in residential care homes” which involves a study of older people with low vision associated with diabetes. I have read and I fully understand the information given above about the research. I have asked any questions that I had regarding the research and they have been answered to my satisfaction. I voluntarily consent to take part in this study.

Print name of participant _____

Signature of participant _____

Date _____

Statement by the principal researcher /person taking consent

I have presented the information to the potential participant to the best of my knowledge. I have ensured that the participant understands they have the choice to opt out of the study at any stage if they do choose to participate. Participants are aware that all information will be kept confidential and all results reported will be done so anonymously. I also confirm that the participants have had the opportunity to ask questions about the study and that they have been answered to their content. The participants have not been forced to participate and I declare no conflicting interest in undertaking this research.

Principal researcher: Nizam Muhammad Darwesh

Signature of principal researcher _____

Date _____

Questionnaire for HCAs interviews

1. In your opinion, what are the most important barriers to effective diabetes and low vision management in older people in the residential care homes?
2. What kinds of vision problems do people with diabetes experience?
3. How do you identify older people with diabetes who are at particular risk of eye diseases?
4. Does your approach of care to with diabetes & Low vision older person is differ to a normal older person? Please say how?
5. To your knowledge, what other problems older people with Low vision experience when on insulin therapy?
6. How often would you recommend blood glucose testing to an older person with diabetes?
7. What could be done to motivate families/carers to become more involved in the care of older people with Low vision and diabetes?
8. From your experience, are older people with Low vision and diabetes keen to receive diabetes education?
9. Have you had recent training in the delivery of Low vision and diabetes care?
10. How often do you monitor /assess the dietary intake of older people with diabetes?
11. Do residents with Low vision and diabetes in residential care homes have an individual care plan?
12. If you as a health care assistant realise that the care plan needs to be updated what would you do?
13. Are you aware if your residents have a test of their vision at admission to your residential care home?
14. Are you aware on regular optometry visits to your residential care home?
15. Are you aware of your diabetes residents having a regular retinopathy screen?

Evaluation Questions for Participants

1. Do you have any final questions or comments?
2. What did you like about the interviews?
3. Can you name one thing you would change?
4. How to improved low vision and diabetes care in the residential care homes?

Low vision and diabetes in older people living in residential care homes

Information sheet for community based older people focus group

This Informed Consent Form has three parts

1 Information Sheet information about the study

2 Certificate of Consent 3 Questionnaire

**Principal researcher: Nizam Muhammad Darwesh
PhD Researcher**

**Director of study: Professor Alan Sinclair MSc MD FRCP
Dean & Professor of Medicine Bedfordshire and Hertfordshire
Postgraduate Medical School University of Bedfordshire**

**Director of study: Professor Peter Scanlon
MD FRCP DCH DRCOG DO FRCOphth PG Cert.
Consultant Ophthalmologist, Oxford Eye Hospital**



Informed Consent Form

Informed consent form for participation in the study titled “Low vision and diabetes in older people living in residential care homes” To Improving quality of care for older people with low vision associated with diabetes.

Principal researcher: Nizam Muhammad Darwesh
(PhD researcher)

Director of study: Professor Alan Sinclair MSc MD FRCP
Dean & Professor of Medicine Bedfordshire and Hertfordshire
Postgraduate Medical School University of Bedfordshire

Director of study: Professor Peter Scanlon
MD FRCP DCH DRCOG DO FRCOphth PG Cert. Med. Ed.
Consultant Ophthalmologist,
Gloucestershire Eye Unit & Oxford Eye
Hospital Programme Director for the English National
Diabetic Retinopathy Screening Programme

Establishment: Institute of diabetes for older people (IDOP)
Putteridge bury University of Bedfordshire

This Informed consent form has three parts:

- Information sheet (information about the study)
- Certificate of consent (for signatures if you choose to participate)
- Questionnaires

You will be given a copy of the full Informed consent form

Part I: Information Sheet

About Principal researcher:

My name is Nizam Muhammad Darwesh, and I am a PhD researcher at the University of Bedfordshire. I am carrying out a research study titled “Low vision and diabetes in older people living in residential care homes” to understand how we can improve quality of care for older people with low vision associated with diabetes, I will provide you with information about my research and invite you to participate in this study. If you would like any further information that you feel was not provided in this information package, please feel free to ask me or my supervisor questions, Professor Alan Sinclair.

About directors of study:

Professor Alan Sinclair MSc MD FRCP Dean and Professor of Medicine, Bedfordshire and Hertfordshire Postgraduate Medical School & Director of the Institute of Diabetes for Older People (IDOP) University of Bedfordshire Putteridge Bury Campus Hitchin Road Luton LU2 8LE

Tel: 01582 743285 Fax: 01582 743286 E-mail: alan.sinclair@beds.ac.uk

Professor Peter Scanlon MD FRCP DCH DRCOG DO FRCOphth PG Cert. Med. Ed. Consultant ophthalmologist, Gloucestershire eye unit & Oxford eye hospital; programme director for the English national diabetic retinopathy screening programme department of ophthalmology, Cheltenham general hospital, Sandford road, Cheltenham, Gloucestershire GL53 7AN, E-mail: Peter.Scanlon@glos.nhs.uk

Invitation to take part in this research study

You are invited to take part in this research study titled, “Low vision and diabetes in older people living in residential care homes” being undertaken by Principal researcher Nizam Muhammad Darwesh at Bedfordshire and Hertfordshire Postgraduate medical school & Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire, This research study will involve you being asked some questions about current diabetes and eye care and future services. You will be invited to focus group discussions with other colleagues’. The

meeting will take about 60 minutes to complete. The meeting will take place at the Bell House Medical Practice Bedfordshire.

What is the purpose of this research? Why are we doing this research?

Low vision associated with diabetes in older people is common. There are many different opinions about low vision associated with diabetes in older people that are unhelpful in recognising and addressing some of the issues surrounding it. Through this research, we hope to learn the views of the participants to understand the impact of diabetes on low vision in older people and also the purpose of this research which is to Improve the quality of care for older people with low vision associated with diabetes, and to help with the planning of existing and future low vision services associated with diabetes care for older people resident in care homes. This research project will help to develop a clearer picture of the current services available, staff experiences, and perceived needs of older people resident in care homes. in addition to develop a package of education and training to support practitioners in providing better health care to older individuals with low vision associated with diabetes.

Why have I been chosen?

You are the best source of information about this topic. We feel that your experience and knowledge will help us in filling the gaps in terms of our understanding, communication and services that are needed to improve low vision care in people with diabetes. Also this is the selection criteria for this project.

Do I have to take part?

No, you do not have to take part if you do not want to, it's your choice. Your participation in our research study is totally voluntary, and you may choose to not participate at any point before or during the research. You are also allowed to change your mind if you decide to not participate at a later time even if you had agreed earlier. By taking part you will be helping us to improve low vision associated with diabetes services for older people.

What will happen to me if I take part?

You will be invited to a focus group discussion at the meeting will take place at the Bell House Medical Practice Bedfordshire., and the principal researcher will ask you a number of questions about your views on current care of older people relating to low vision associated with diabetes. The meetings will last about 60 minutes and will be arranged during normal working hours. It is important that you tell us about your experiences and perceived needs of older people with low vision associated with diabetes in your own words, as if you were telling the Principal researcher your story. The information you give will be tape-recorded and your responses used to identify gaps in service provision. Any names you mention will remain anonymous and excluded from the final report.

Will I receive expenses?

The reasonable travel expenses will be offer.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help to improve low vision associated with diabetes services for older people living in the residential care homes.

Obtaining your consent

It is important that you understand that if you decide to take part in this study you will be asked to give your consent to be interviewed. This means that you will be asked to sign a consent form. This form will have separate questions asking for your agreement to be taped, for your responses to be shared between the research team and perhaps for some of your responses to be used 'verbatim' (word for word) in the report. Before any of this is done, the Principal researcher will first explain the study to you and then answer any questions that you may have about the study. The reason for recording the interview is so that the Principal researcher can talk to you without having to stop and take notes. If after the explanation you are still willing to take part, then you will be asked for your consent by signing the form.

Some difficult questions

Please note that some questions may leave you feeling sad and or upset, especially the questions around how you feel services currently meet the needs of older people resident in care home with Low Vision due to diabetes.

Although these are emotionally very difficult questions to answer, please bear in mind that unless we can work out your service development and delivery experiences (good or not so good), we cannot suggest any improvements in the service provision. It is for this reason that some difficult questions are necessary. Any distress that may be caused as a consequence of these questions is deeply regretted.

What if I change my mind?

If after reading this information sheet you decide to take part in the study, but then later on you decide that you no longer want to take part, you are under no obligation to continue, you can withdraw from the study without having to give any reasons for your decision at any time. This includes your right to stop part way through the interview. A decision to withdraw at any time, or a decision not to take part,

What if something goes wrong?

In the unfortunate event that something goes wrong, such as the interview tapes fail to record clearly and the data is rendered 'unusable', the principal researcher will contact the participant concerned to explain the difficulty (that have arisen with the technology) and see if they are able and willing to be re-interviewed. If the participant is unable to be re-interviewed, then the principal researcher will write to them to apologise for the 'loss' of recording and ensure that they understand that they will no longer be included in the study. The principal researcher will then have to decide whether to select another participant or to report this event as a 'null' recording in the final report. The choice will inevitably depend upon the time available to complete the project.

What do I have to do?

If you are interested in taking part in this study then you will be contacted by a principal researcher. This will be to arrange a date and place convenient to you for the group interview. Any questions that you may have about the study can be discussed with the principal researcher at this time, if after this discussion you feel you do not want to carry on, you can withdraw from the study.

**What happens to the information I give at the focus group discussion?
(Confidentiality)**

Following the focus group meeting the discussion is typed up into a transcript. Any personal details, such as any names of people or places that you may have mentioned will remain confidential; they will not be included in the report version. All information collected within a focus group will be known only to focus group members and no one outside the group will be informed about the discussion from the research team. Data will be in the safe hands and only Nizam and Professor Alan Sinclair and Professor Peter Scanlon, will have access to this information. Therefore is no chance for any breach of confidence or failure to maintain data security, Data will be stored securely on password protected PC and will be locked in the Institute of diabetes for older people (IDOP) Putteridge bury campus University of Bedfordshire and, Data will be analysed in confidential,

What happens to the tape recording of the focus group discussion?

The interviews will be tape recorded so that the principal researcher can listen to you without the need to take notes. The tape recordings will be kept in accordance with the data protection act, and tapes will be kept in a locked cabinet for the duration of two years after which time they will be destroyed.

What will happen to the results of the study?

This research is being conducted for PhD thesis; it will be available through the Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire. Also the research team will use the focus group discussion to find out ways in which low vision associated with diabetes services can be improved

for older people. The findings from the study will be published in a newsletter, which will be made available to you.

Who is organising and funding this study?

All financial necessary resources to complete the study will be self-finance. Access to databases will be through the University of Bedfordshire and IDOP,

Who has approved the study?

This study has undergone a rigorous process of inspection and has been approved by the Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire ethics committee.

Contact for further information about this study

If you have a concern about any aspect of this study, or if you wish to make a comment or complaint, please feel free to contact me Nizam at: drnizam2010@yahoo.co.uk or nizam.darwesh@study.beds.ac.uk or call 01582743988. I will do my best to answer your questions. If you remain unhappy you can contact Professor Alan Sinclair (Dean and Professor of Medicine, B&H Postgraduate medical school & director of the institute of diabetes for older people (IDOP) University of Bedfordshire e-mail: alan.sinclair@beds.ac.uk or call Tel: 01582 743285.

Thank you for taking the time to read this information sheet, we would be grateful if you decide to take part.

Part II: Certificate of Consent

I have been invited to participate in a study titled “Low vision and diabetes in older people living in residential care homes” which involves a study of older people with low vision associated with diabetes. I have read and I fully understand the information given above about the research. I have asked any questions that I had regarding the research and they have been answered to my satisfaction. I voluntarily consent to take part in this study.

Print name of participant _____

Signature of participant _____

Date _____

Statement by the principal researcher /person taking consent

I have presented the information to the potential participant to the best of my knowledge. I have ensured that the participant understands they have the choice to opt out of the study at any stage if they do choose to participate. Participants are aware that all information will be kept confidential and all results reported will be done so anonymously. I also confirm that the participants have had the opportunity to ask questions about the study and that they have been answered to their content. The participants have not been forced to participate and I declare no conflicting interest in undertaking this research.

Principal researcher: Nizam Muhammad Darwesh

Signature of principal researcher _____

Date _____

Questionnaire

Focus group 1 community based older people with low vision and diabetes

- 1 Could you tell us about when and how you were diagnosed? Why were you tested?
- 2 What did you think about low vision and diabetes at that time? How did you feel about your diagnosis?
- 3 What help, including information, were you given when you were diagnosed and who provided this help or information to you? Was help provided in the language of your choice? How long did you have to wait for this help, and if you had to wait for a longer time, what did you do in the meantime?
- 4 In what ways, if any, has your attitude towards low vision and diabetes changed since you were diagnosed?
- 5 How has your day-to-day life changed, if it has, since you were diagnosed? If it has changed, what do you think brought about this change?
6. What concerns you most about diabetes?
7. What helps you most to understand and manage about your eyesight and diabetes?
8. What additional help or support do you need?
9. As a person living with diabetes, how do you see your future?
10. What is the most important advice you can give to the elderly people who has just been diagnosed with diabetes?
11. Do you have any final questions or comments?

Evaluation Questions for Participants

1. What did you like about the focus group?
2. Can you name one thing you would change?
3. How could the focus groups be improved?

Low vision and diabetes in older people living in residential care homes

Information sheet for optometrists focus group

This Informed Consent Form has three parts

1 Information Sheet information about the study

2 Certificate of Consent 3 Questionnaire

Principal researcher: Nizam Muhammad Darwesh

PhD Researcher

Director of study: Professor Alan Sinclair MSc MD FRCP
Dean & Professor of Medicine Bedfordshire and Hertfordshire
Postgraduate Medical School University of Bedfordshire

Director of study: Professor Peter Scanlon
MD FRCP DCH DRCOG DO FRCOphth PG Cert.
Consultant Ophthalmologist, Oxford Eye Hospital



Informed Consent Form

Informed consent form for participation in the study titled “Low vision and diabetes in older people living in residential care homes” To Improving quality of care for older people with low vision associated with diabetes.

Principal researcher: Nizam Muhammad Darwesh
(PhD Researcher)

Director of study: Professor Alan Sinclair MSc MD FRCP
Dean & Professor of Medicine Bedfordshire and Hertfordshire
Postgraduate Medical School University of Bedfordshire

Director of study: Professor Peter Scanlon
MD FRCP DCH DRCOG DO FRCOphth PG Cert. Med.Ed.
Consultant Ophthalmologist,
Gloucestershire Eye Unit & Oxford Eye
Hospital Programme Director for the English National
Diabetic Retinopathy Screening Programme

Establishment: Institute of diabetes for older people (IDOP)
Putteridge bury University of Bedfordshire

This Informed consent form has three parts:

- Information sheet (information about the study)
- Certificate of consent (for signatures if you choose to participate)
- Questionnaires

You will be given a copy of the full Informed consent form

Part I: Information Sheet

About Principal researcher:

My name is Nizam Muhammad Darwesh, and I am a PhD researcher at the University of Bedfordshire. I am carrying out a research study titled “Low vision and diabetes in older people living in residential care homes” to understand how we can improve quality of care for older people with low vision associated with diabetes, I will provide you with information about my research and invite you to participate in this study. If you would like any further information that you feel was not provided in this information package, please feel free to ask me or my supervisor questions, Professor Alan Sinclair.

About directors of study:

Professor Alan Sinclair MSc MD FRCP Dean and Professor of Medicine, Bedfordshire and Hertfordshire Postgraduate Medical School & Director of the Institute of Diabetes for Older People (IDOP) University of Bedfordshire Putteridge Bury Campus Hitchin Road Luton LU2 8LE

Tel: 01582 743285 Fax: 01582 743286 E-mail: alan.sinclair@beds.ac.uk

Professor Peter Scanlon MD FRCP DCH DRCOG DO FRCOphth PG Cert. Med. Ed. Consultant ophthalmologist, Gloucestershire eye unit & Oxford eye hospital; programme director for the English national diabetic retinopathy screening programme department of ophthalmology, Cheltenham general hospital, Sandford road, Cheltenham, Gloucestershire GL53 7AN, E-mail: Peter.Scanlon@glos.nhs.uk

Invitation to take part in this research study

You are invited to take part in this research study titled, “Low vision and diabetes in older people living in residential care homes” being undertaken by Principal researcher Nizam Muhammad Darwesh at Bedfordshire and Hertfordshire Postgraduate medical school & Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire, This research study will involve you being asked some questions about current diabetes and eye care and future services. You will be invited to focus group discussions with other colleagues’. The

meeting will take about 60 minutes to complete. The meeting will take place at the Luton and Dunstable hospital NHS foundation trust.

What is the purpose of this research? Why are we doing this research?

Low vision associated with diabetes in older people is common. There are many different opinions about low vision associated with diabetes in older people that are unhelpful in recognising and addressing some of the issues surrounding it. Through this research, we hope to learn the views of the participants to understand the impact of diabetes on low vision in older people and also the purpose of this research which is to Improve the quality of care for older people with low vision associated with diabetes, and to help with the planning of existing and future low vision services associated with diabetes care for older people resident in care homes. This research project will help to develop a clearer picture of the current services available, staff experiences, and perceived needs of older people resident in care homes. in addition to develop a package of education and training to support practitioners in providing better health care to older individuals with low vision associated with diabetes.

Why have I been chosen?

You are the best source of information about this topic. We feel that your experience and knowledge will help us in filling the gaps in terms of our understanding, communication and services that are needed to improve low vision care in people with diabetes. Also this is the selection criteria for this project.

Do I have to take part?

No, you do not have to take part if you do not want to, it's your choice. Your participation in our research study is totally voluntary, and you may choose to not participate at any point before or during the research. You are also allowed to change your mind if you decide to not participate at a later time even if you had agreed earlier. By taking part you will be helping us to improve low vision associated with diabetes services for older people.

What will happen to me if I take part?

You will be invited to a focus group discussion at the Luton and Dunstable hospital NHS foundation trust, and the principal researcher will ask you a number of questions about your views on current care of older people relating to low vision associated with diabetes. The meetings will last about 60 minutes and will be arranged during normal working hours. It is important that you tell us about your experiences and perceived needs of older people with low vision associated with diabetes in your own words, as if you were telling the Principal researcher your story. The information you give will be tape-recorded and your responses used to identify gaps in service provision. Any names you mention will remain anonymous and excluded from the final report.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help to improve low vision associated with diabetes services for older people living in the residential care homes.

Obtaining your consent

It is important that you understand that if you decide to take part in this study you will be asked to give your consent to be interviewed. This means that you will be asked to sign a consent form. This form will have separate questions asking for your agreement to be taped, for your responses to be shared between the research team and perhaps for some of your responses to be used 'verbatim' (word for word) in the report. Before any of this is done, the Principal researcher will first explain the study to you and then answer any questions that you may have about the study. The reason for recording the interview is so that the Principal researcher can talk to you without having to stop and take notes. If after the explanation you are still willing to take part, then you will be asked for your consent by signing the form.

What if I change my mind?

If after reading this information sheet you decide to take part in the study, but then later on you decide that you no longer want to take part, you are under no

obligation to continue, you can withdraw from the study without having to give any reasons for your decision at any time. This includes your right to stop part way through the interview. A decision to withdraw at any time, or a decision not to take part,

What if something goes wrong?

In the unfortunate event that something goes wrong, such as the interview tapes fail to record clearly and the data is rendered 'unusable', the principal researcher will contact the participant concerned to explain the difficulty (that have arisen with the technology) and see if they are able and willing to be re-interviewed. If the participant is unable to be re-interviewed, then the principal researcher will write to them to apologise for the 'loss' of recording and ensure that they understand that they will no longer be included in the study. The principal researcher will then have to decide whether to select another participant or to report this event as a 'null' recording in the final report. The choice will inevitably depend upon the time available to complete the project.

What do I have to do?

If you are interested in taking part in this study then you will be contacted by a principal researcher. This will be to arrange a date and place convenient to you for the group interview. Any questions that you may have about the study can be discussed with the principal researcher at this time, if after this discussion you feel you do not want to carry on, you can withdraw from the study.

What happens to the information I give at the focus group discussion?

(Confidentiality)

Following the focus group meeting the discussion is typed up into a transcript. Any personal details, such as any names of people or places that you may have mentioned will remain confidential; they will not be included in the report version. All information collected within a focus group will be known only to focus group members and no one outside the group will be informed about the discussion from the research team. Data will be in the safe hands and only Nizam and Professor Alan Sinclair and Professor Peter Scanlon, will have access to this

information. Therefore is no chance for any breach of confidence or failure to maintain data security, Data will be stored securely on password protected PC and will be locked in the Institute of diabetes for older people (IDOP) Putteridge bury campus University of Bedfordshire and, Data will be analysed in confidential,

What happens to the tape recording of the focus group discussion?

The interviews will be tape recorded so that the principal researcher can listen to you without the need to take notes. The tape recordings will be kept in accordance with the data protection act, and tapes will be kept in a locked cabinet for the duration of two years after which time they will be destroyed.

What will happen to the results of the study?

This research is being conducted for PhD thesis; it will be available through the Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire. Also the research team will use the focus group discussion to find out ways in which low vision associated with diabetes services can be improved for older people. The findings from the study will be published in a newsletter, which will be made available to you.

Who is organising and funding this study?

All financial necessary resources to complete the study will be self-finance. Access to databases will be through the University of Bedfordshire and IDOP,

Who has approved the study?

This study has undergone a rigorous process of inspection and has been approved by the Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire ethics committee.

Contact for further information about this study

If you have a concern about any aspect of this study, or if you wish to make a comment or complaint, please feel free to contact me Nizam at: drnizam2010@yahoo.co.uk or nizam.darwesh@study.beds.ac.uk or call 01582743988. I will do my best to answer your questions. If you remain unhappy you can contact Professor Alan Sinclair (Dean and Professor of Medicine, B&H

Postgraduate medical school & director of the institute of diabetes for older people (IDOP) University of Bedfordshire e-mail: alan.sinclair@beds.ac.uk or call Tel: 01582 743285.

Thank you for taking the time to read this information sheet, we would be grateful if you decide to take part.

Part II: Certificate of Consent

I have been invited to participate in a study titled “Low vision and diabetes in older people living in residential care homes” which involves a study of older people with low vision associated with diabetes. I have read and I fully understand the information given above about the research. I have asked any questions that I had regarding the research and they have been answered to my satisfaction. I voluntarily consent to take part in this study.

Print name of participant _____

Signature of participant _____

Date _____

Statement by the principal researcher /person taking consent

I have presented the information to the potential participant to the best of my knowledge. I have ensured that the participant understands they have the choice to opt out of the study at any stage if they do choose to participate. Participants are aware that all information will be kept confidential and all results reported will be done so anonymously. I also confirm that the participants have had the opportunity to ask questions about the study and that they have been answered to their content. The participants have not been forced to participate and I declare no conflicting interest in undertaking this research.

Principal researcher: Nizam Muhammad Darwesh

Signature of principal researcher _____

Date _____

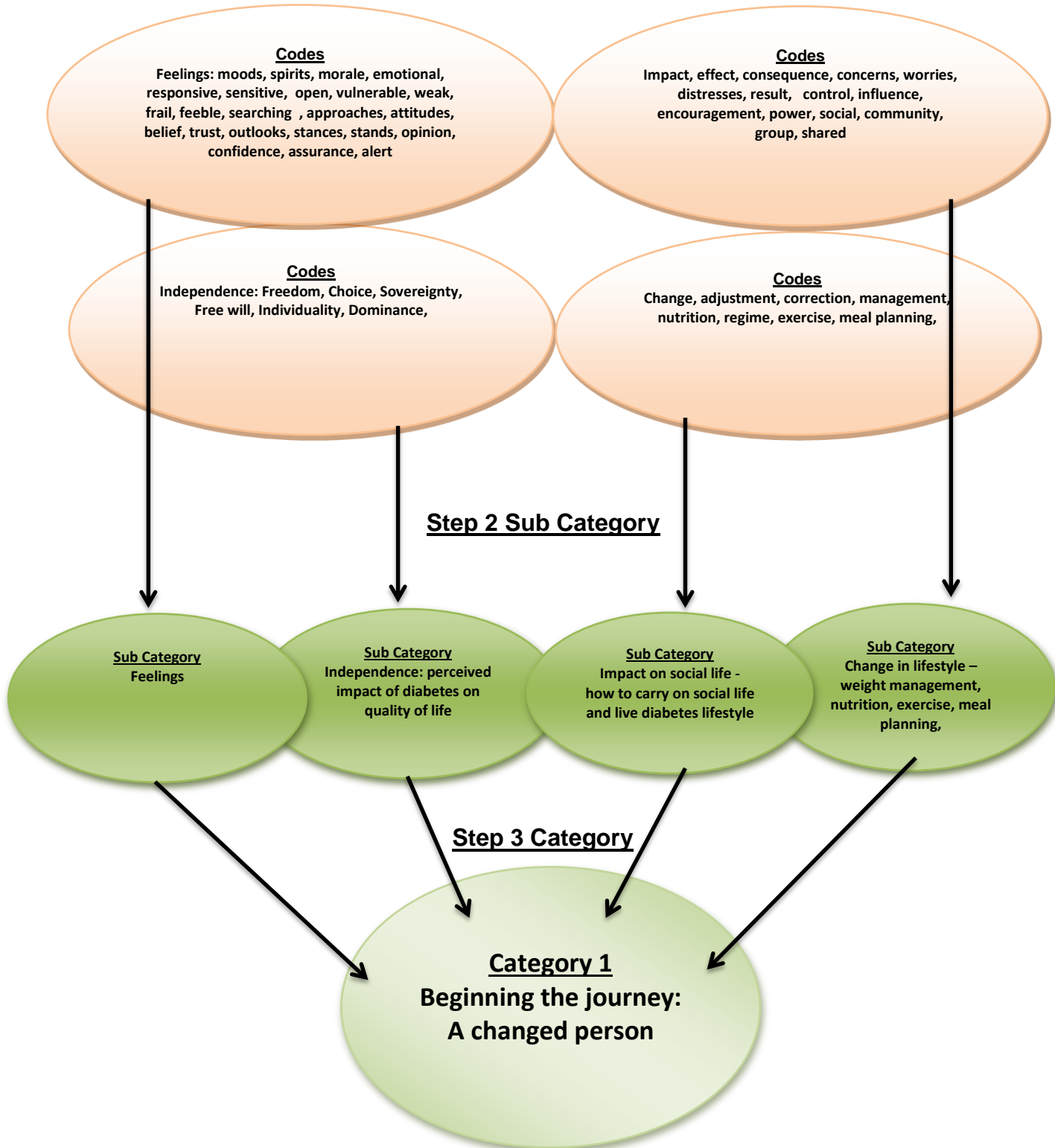
Focus Group 2: optometrists questionnaire

- 1** In your opinion, what are the most important barriers to effective diabetes and low vision management in older people living in residential care home?
- 2** In terms of 'good clinical practice' what are your key aims in the treatment of older people with low vision and diabetes?
- 3** How often would you recommend blood glucose testing to an older person with low vision associated with diabetes?
- 4** In your opinion, do older people with the low vision and diabetes understand the benefits of structured low vision and diabetes education?
- 5** From your experience, are older people with low vision associated with diabetes keen to receive low vision and diabetes education?
- 6** In your opinion are there specific educational needs?
- 7** In your opinion, do older people with the low vision and diabetes understand the benefits of taking their medication at the right time and at the right dosage?
- 8** In your opinion what are the reading requirements and needs?
- 9** In your opinion, what specific needs do older people have in low vision and diabetes?
- 10** What is your Concern about the cost of glasses?
- 11.** In your opinion, Should the patient's general eyewear be changed?
- 12.** In your opinion, the patient and family need to be counselled on the condition, visual effects, the rehabilitation process, and safety issues?
- 13** In your opinion how can we improve quality of daily living in older person with low vision associated with diabetes?

Initial codes

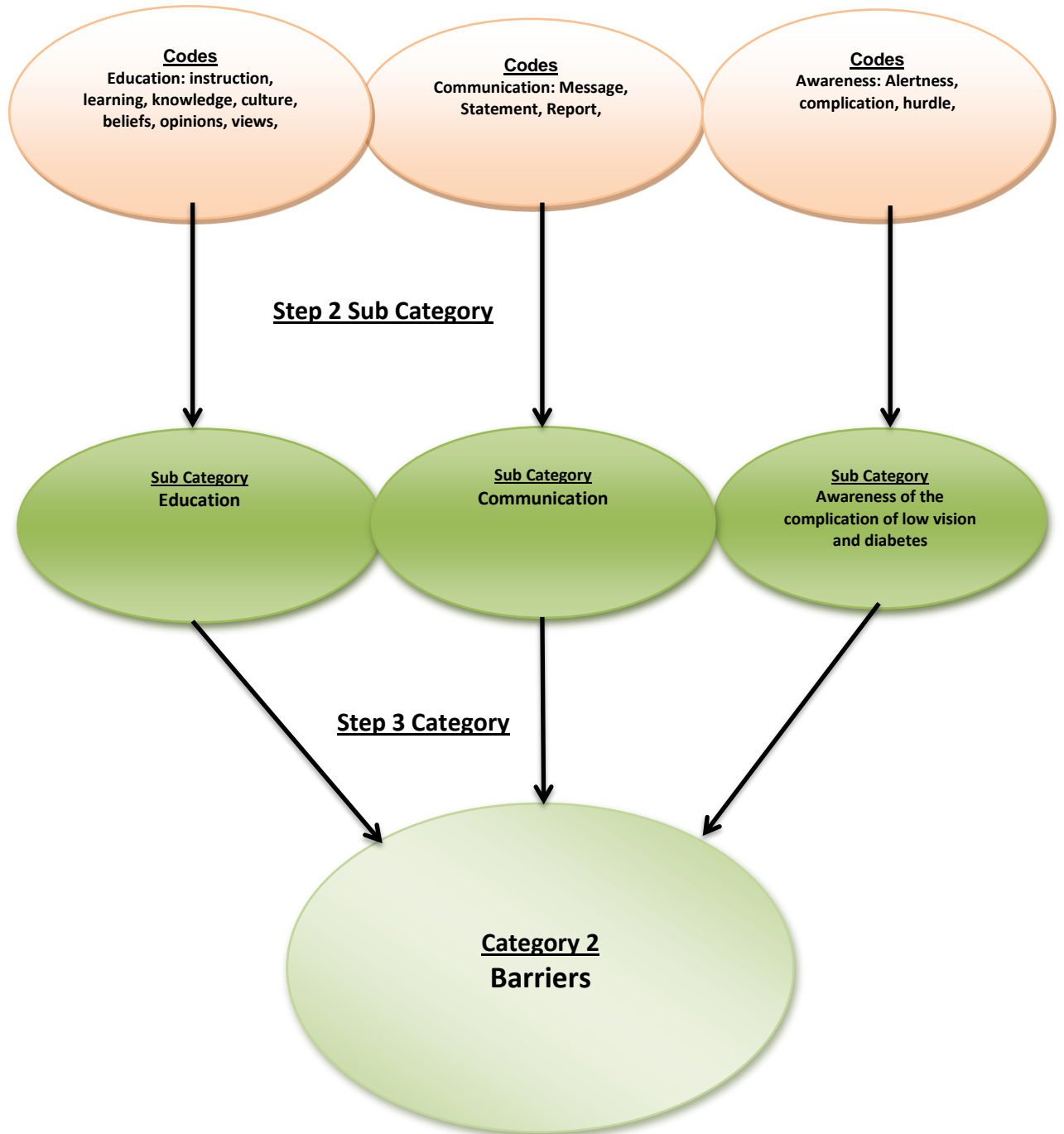
Category one theme one

Step 1 Coding Restructure life in the care home with low vision and diabetes, themes, categories, and subcategories.



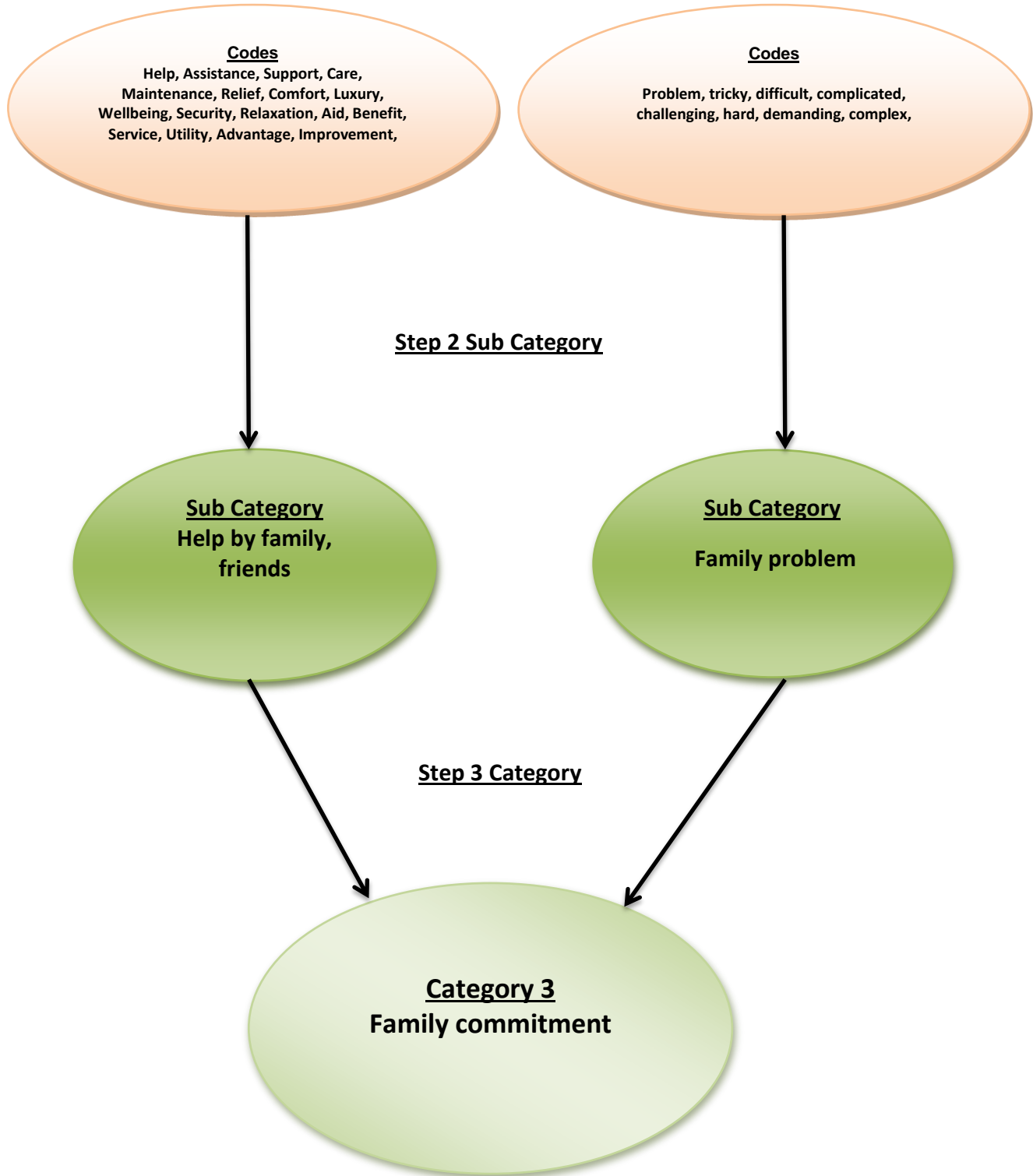
Category two theme one

Step 1 Coding Restructure life in the care home with low vision and diabetes, themes, categories, and subcategories.



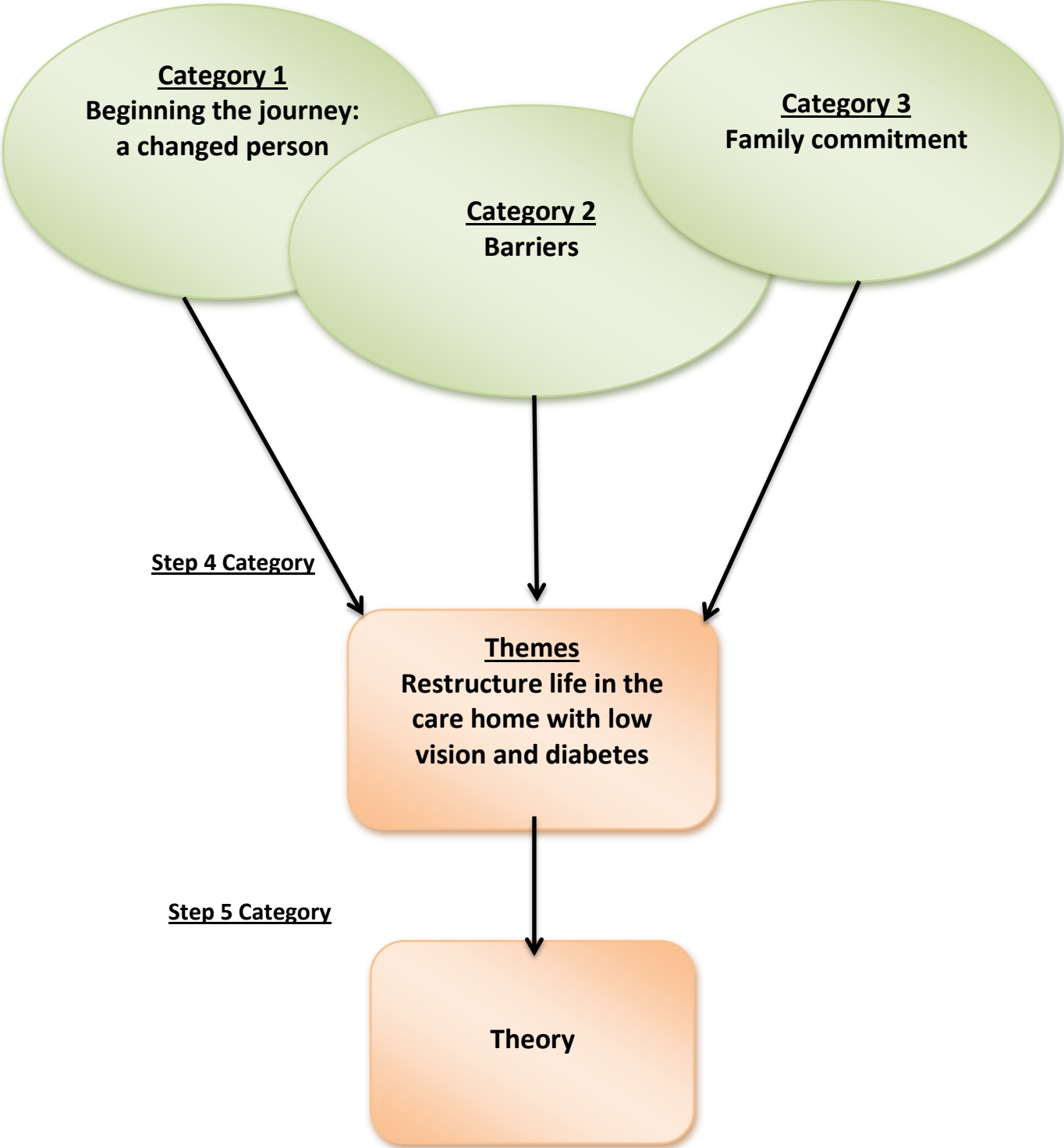
Category three theme one

Step 1 Coding Restructure life in the care home with low vision and diabetes, themes, categories, and subcategories.



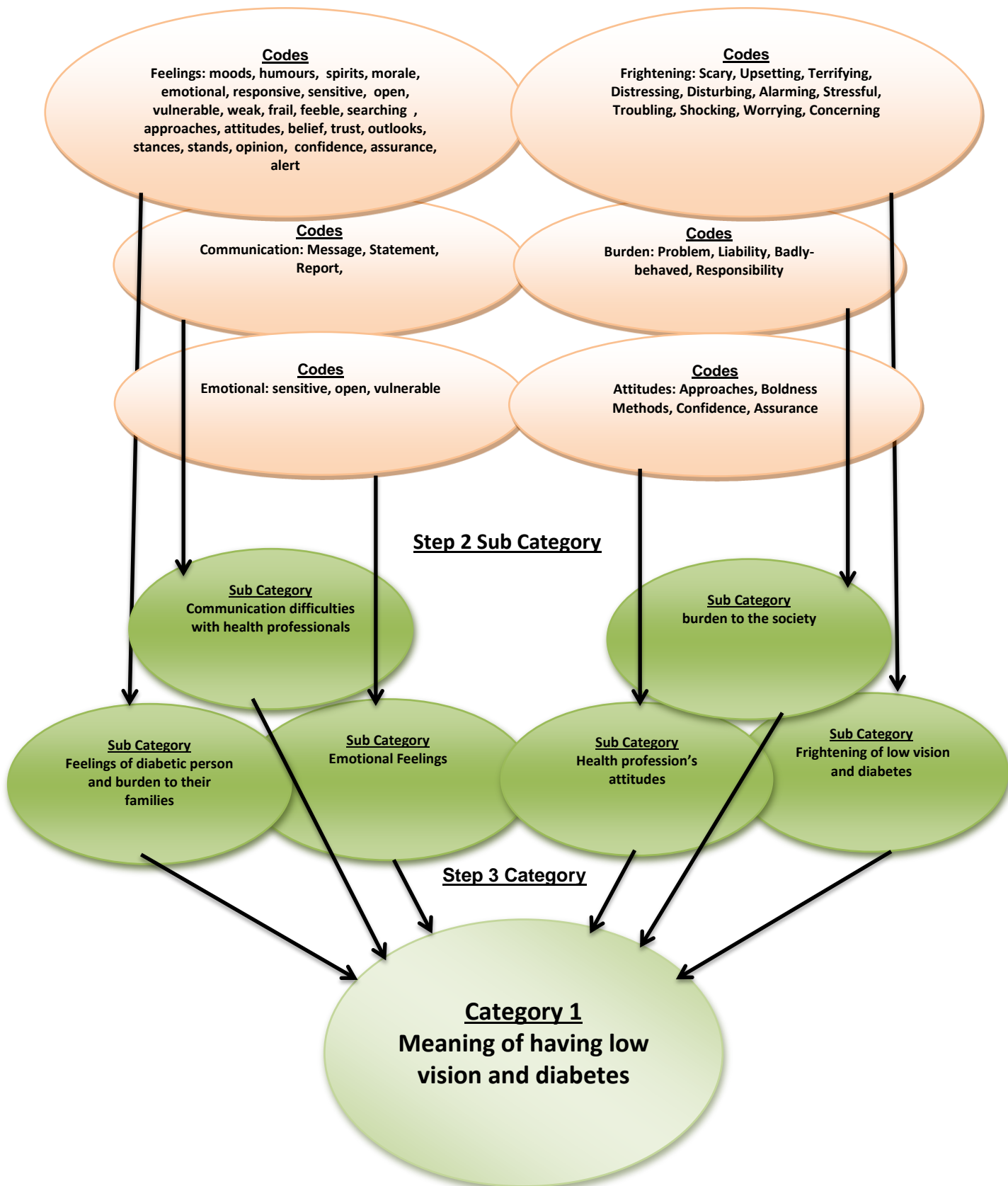
All category of theme one

Step 3 Category: Restructure life in the care home with low vision and diabetes, themes, categories, and subcategories.



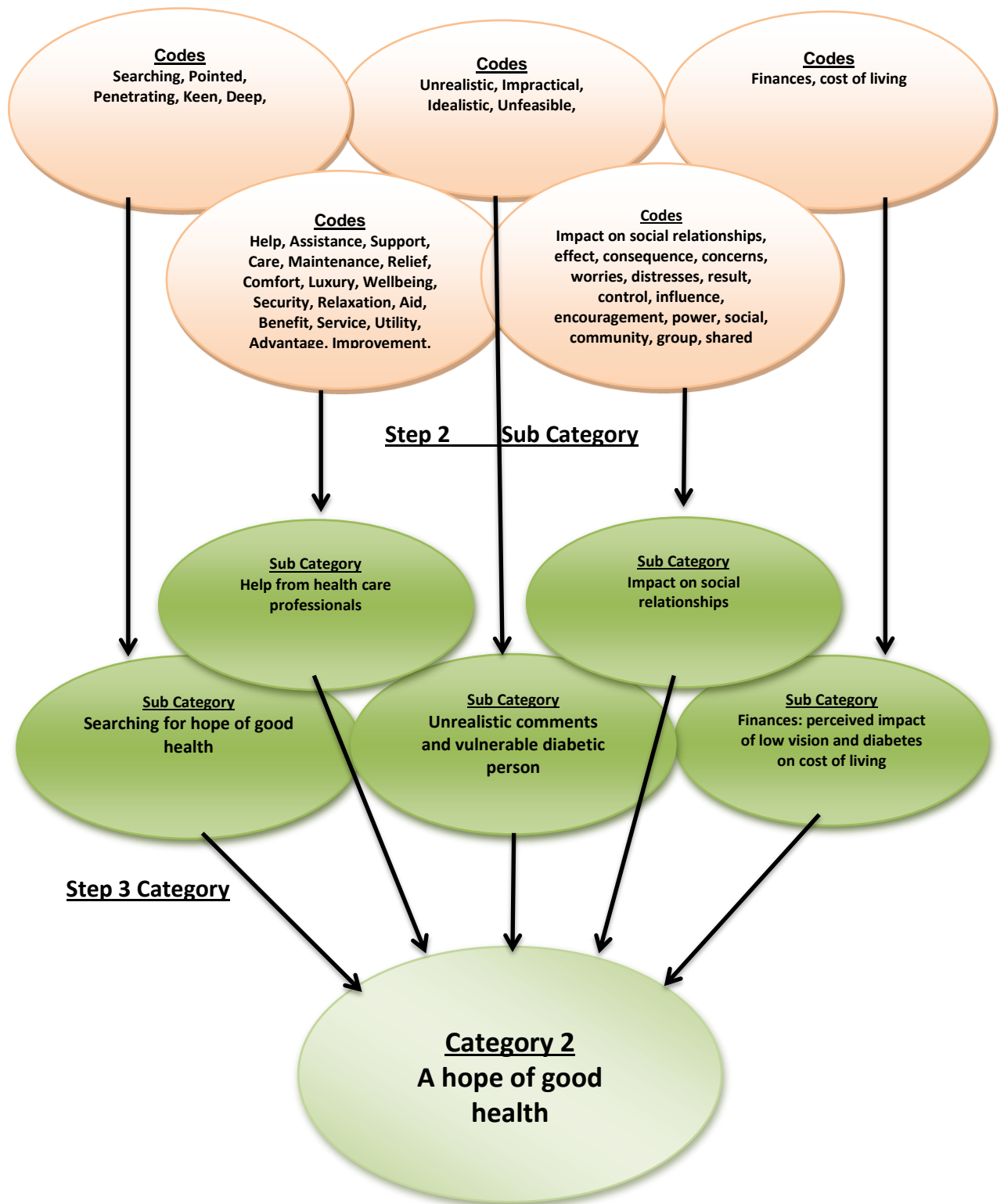
Category one theme two

Step 1 Coding: life with low vision and diabetes, 'A long life illnesses'.



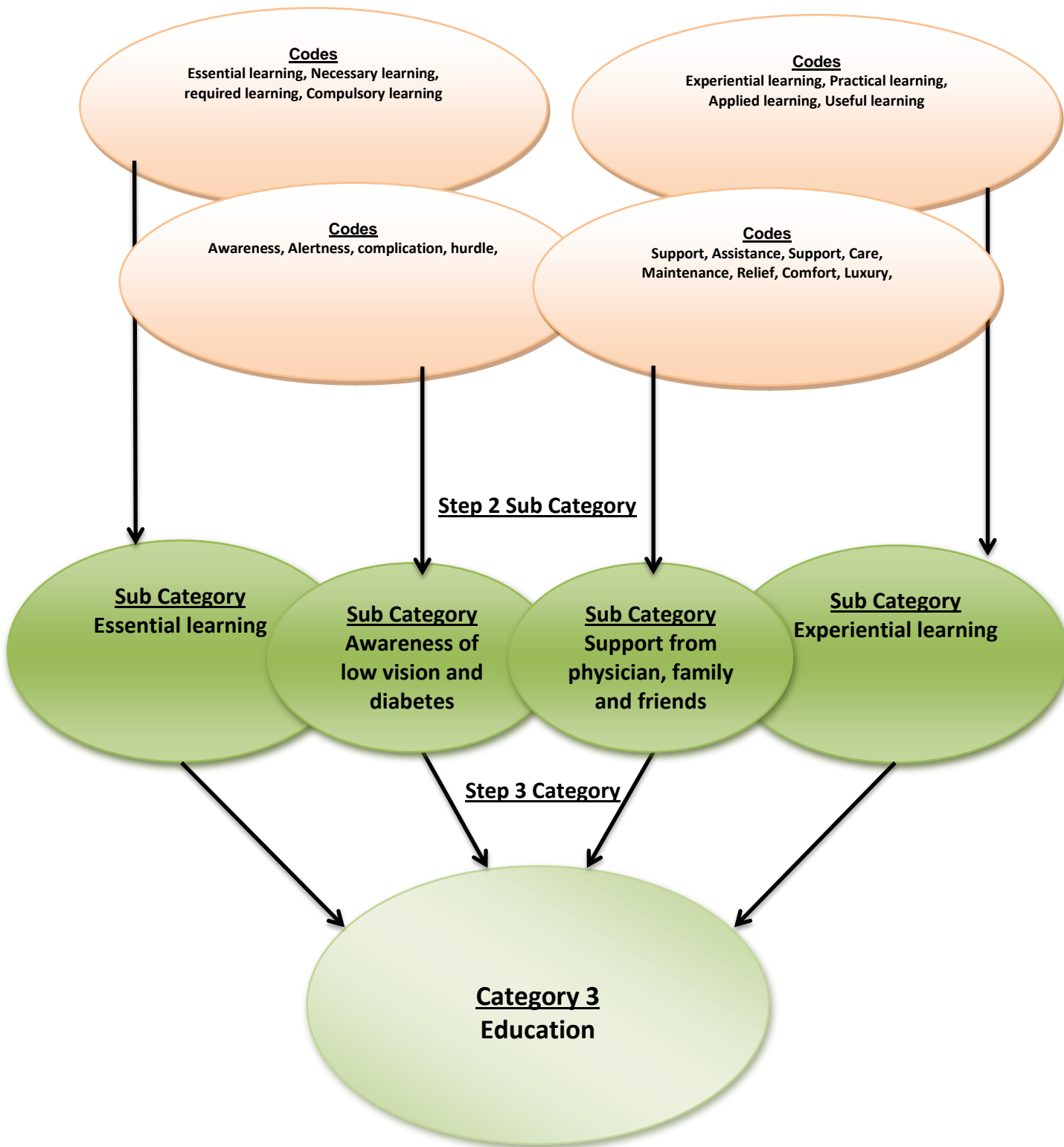
Category two theme, two

Step 1 Coding: life with low vision and diabetes, 'A long life illnesses'.



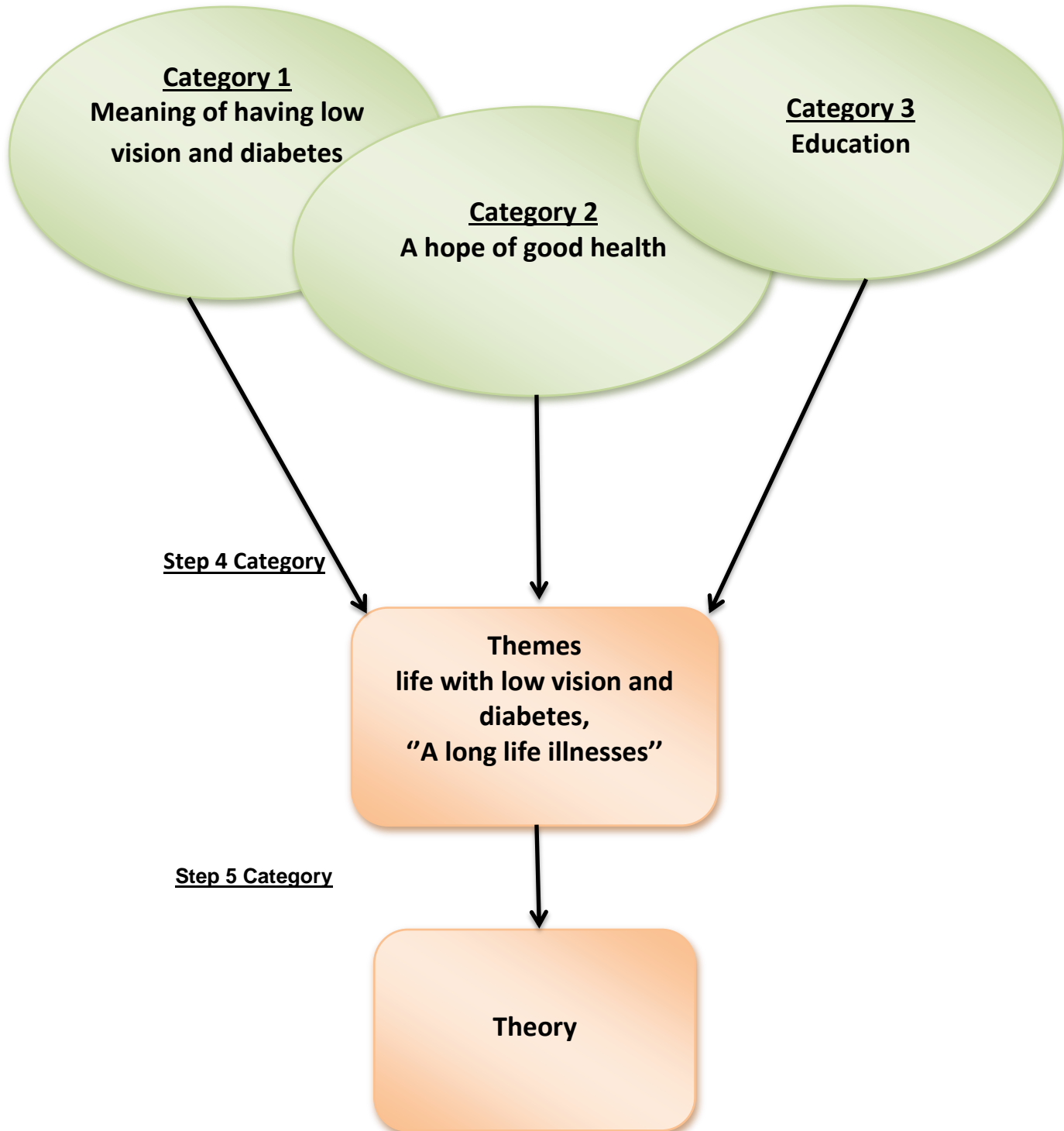
Category three theme, two

Step 1 Coding: life with low vision and diabetes, ‘A long life illnesses’.



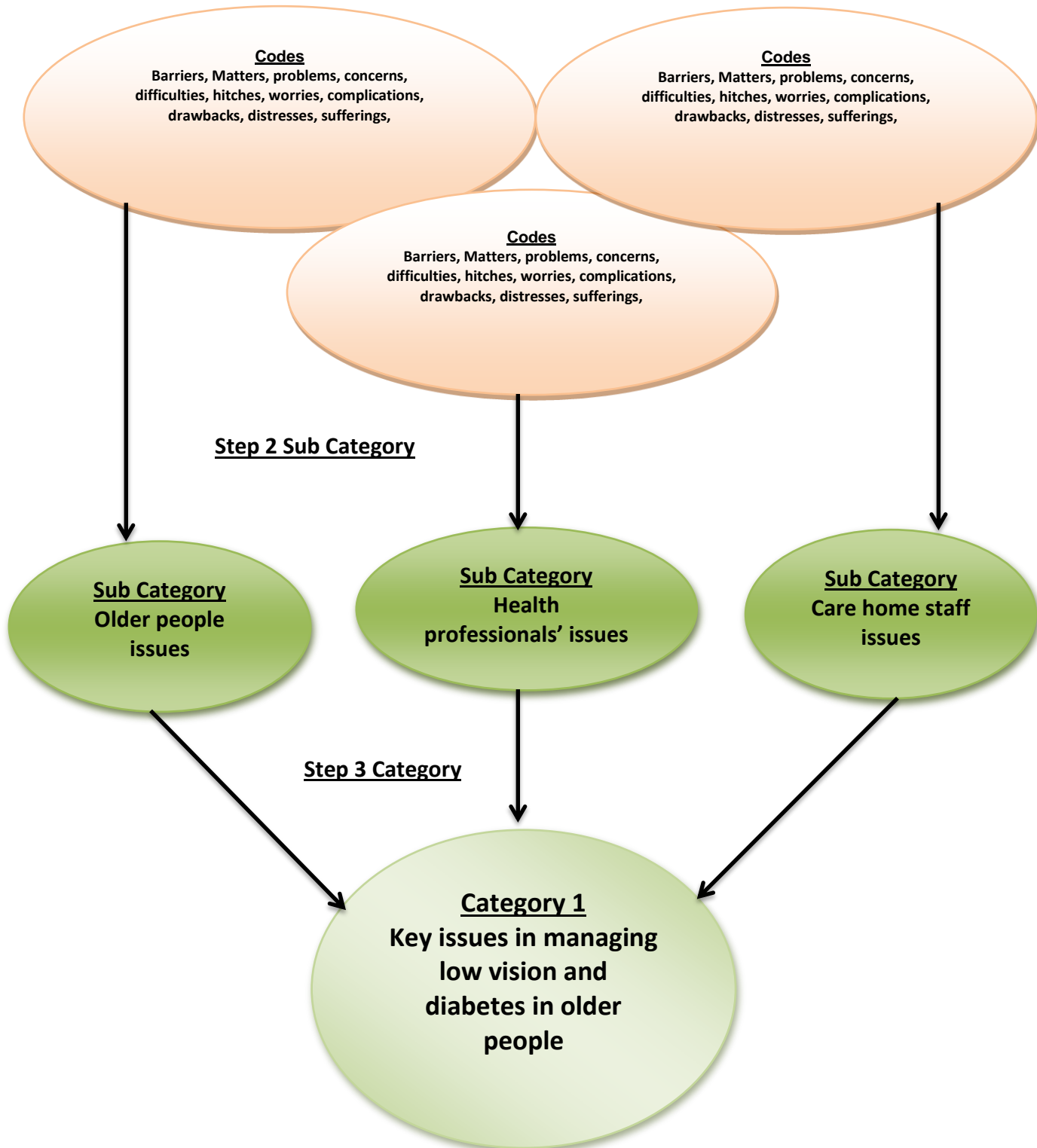
All category of theme, two

Step 3 Category: life with low vision and diabetes, 'A long life illnesses'.



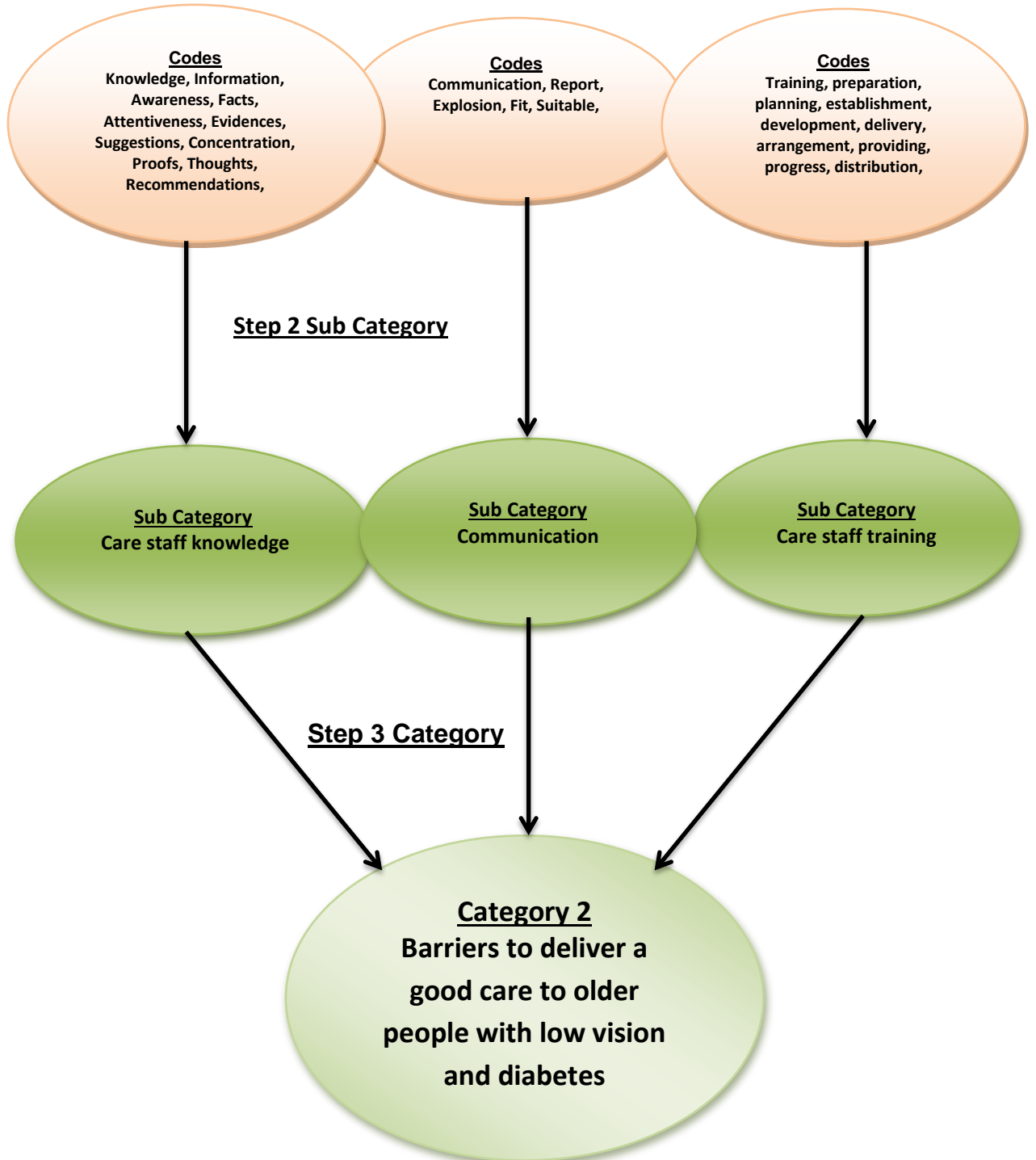
Category one theme three

Step 1 Coding: health professional's specifically Health care assistant
"Helping hand"



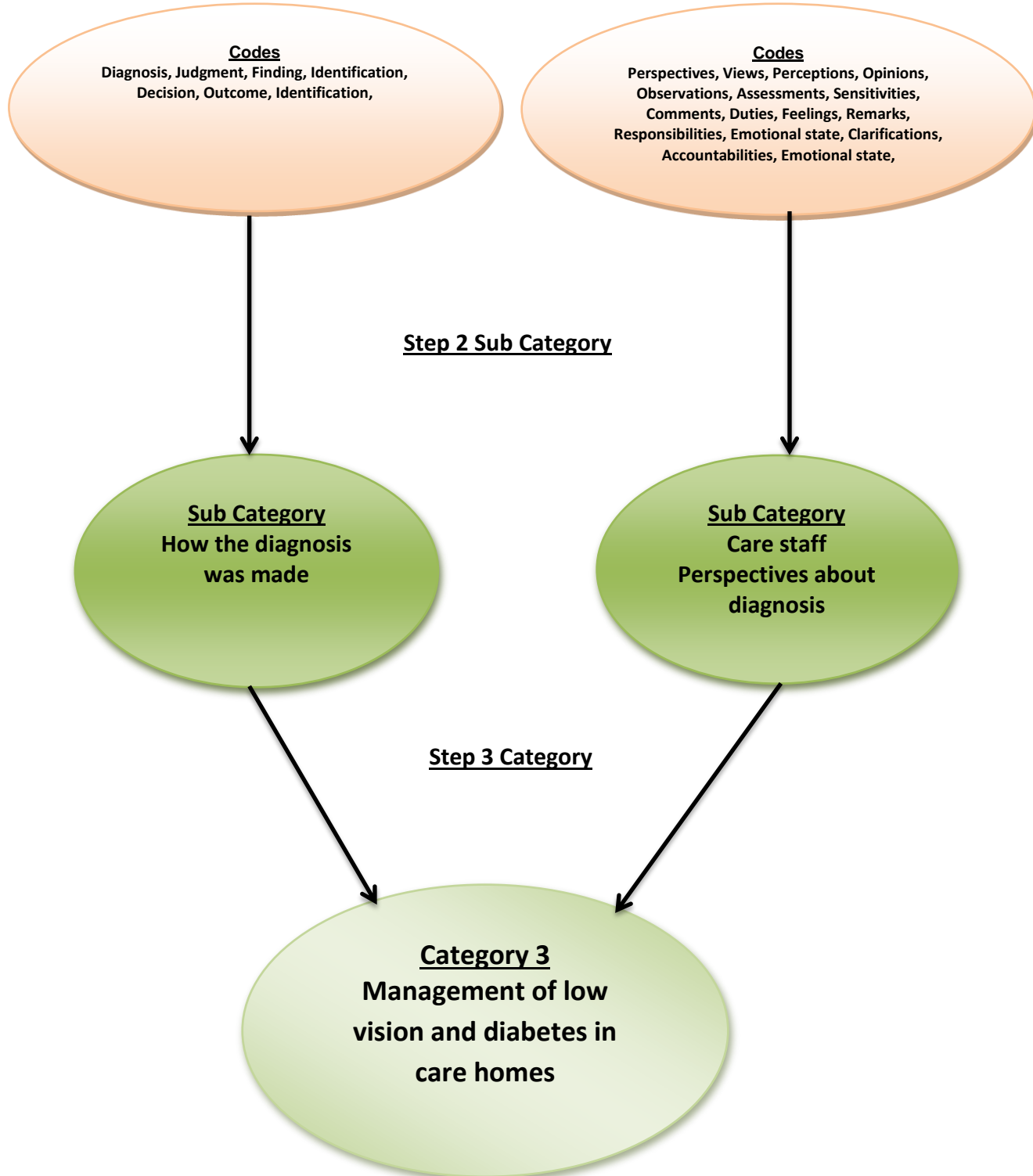
Category two theme, three

Step 1 Coding: health professional's specifically Health care assistant
"Helping hand"

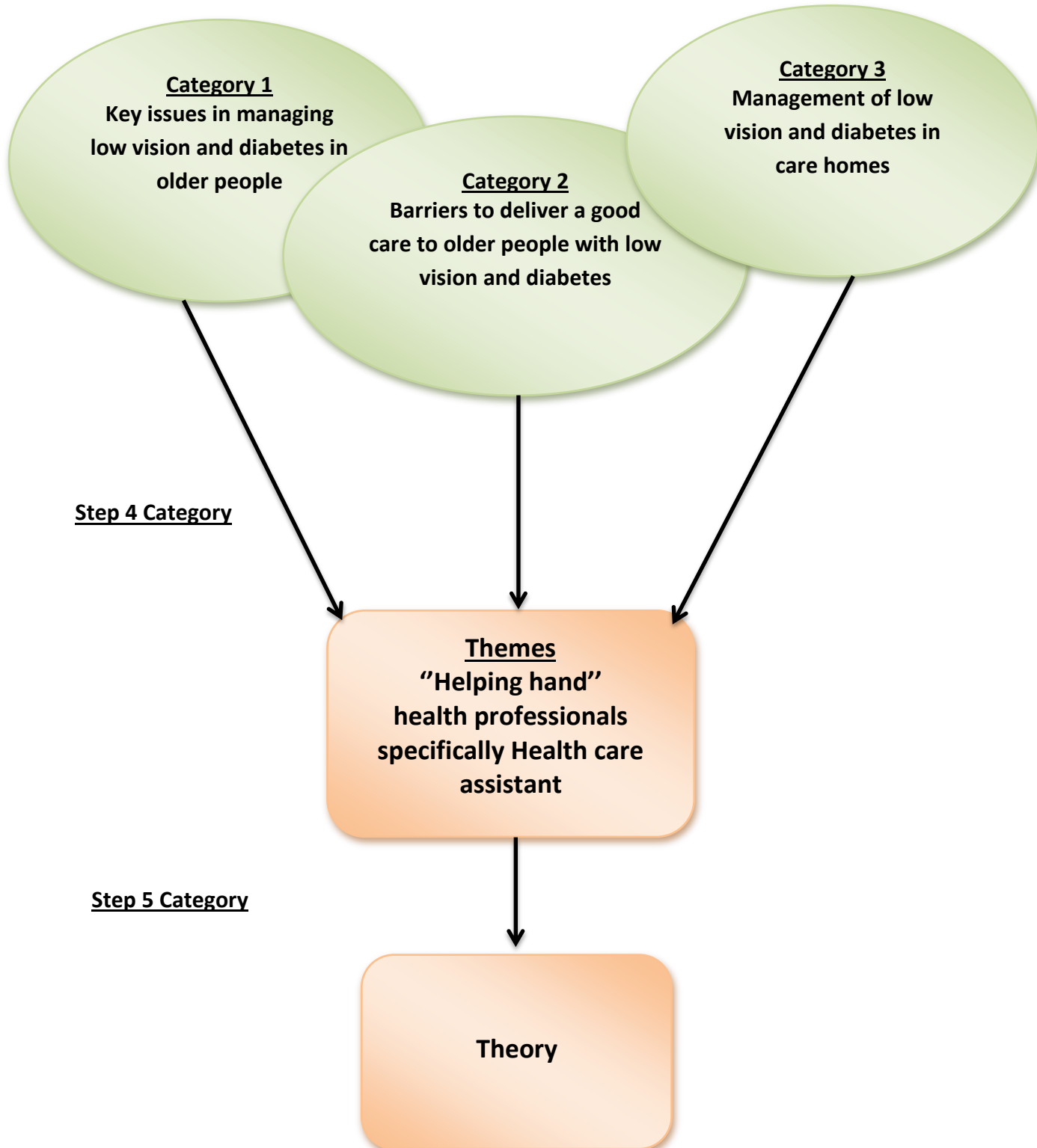


Category three theme, three

Step 1 Coding: health professional's specifically Health care assistant
"Helping hand"



All category of theme, three
Step 3 Category: health professional's specifically Health care assistant
"Helping hand"



Restructure life in the care home with low vision and diabetes

Codes	Codes	Subcategory	Category	Themes
Feelings	Approaches	Feelings	Beginning the journey A changed person	Restructure life in the care home with low vision and diabetes
Moods	Searching			
Spirits	Feeble			
Morale	Weak, frail			
Emotional	Vulnerable			
Sensitive	Open			
Responsive	Feeble			
Stances	Alert			
Outlooks	Assurance			
Trust	Confidence			
Belief	Opinion			
Attitudes	Stands			
Impact	Result	Impact on social life how to carry on social life and live diabetes lifestyle	Beginning the journey A changed person	Restructure life in the care home with low vision and diabetes
Effect	Influence			
Consequence	Encouragement			
Concerns	Power			
Worries	Community			
Distresses	Social, group			
Control	Shared			
Change	Nutrition, meal	Change in lifestyle weight management, nutrition, exercise, meal planning,	Beginning the journey A changed person	Restructure life in the care home with low vision and diabetes
Adjustment	Regime			
Correction	Exercise			
Management	Planning			
Independence	Sovereignty	Independence perceived impact of diabetes on quality of life	Beginning the journey A changed person	Restructure life in the care home with low vision and diabetes
Freedom	Free will			
Choice	Individuality			
Dominance				
Help	Security	Help by family, friends	Family commitment	Restructure life in the care home with low vision and diabetes
Assistance	Relaxation			
Support	Aid			
Care	Benefit			
Help	Service			
Maintenance	Utility			
Luxury	Advantage			
Wellbeing	Improvement			
Problem	Challenging	Family problem	Family commitment	Restructure life in the care home with low vision and diabetes
Tricky	Hard			
Difficult	Demanding			
Complicated	Complex			
Education	Culture, beliefs	Education	Barrier	Restructure life in the care home with low vision and diabetes
Instruction	Opinions			
Learning	Views			
Knowledge	Beliefs			
Communication, Message	Statement Report	Communication	Barrier	Restructure life in the care home with low vision and diabetes
Awareness	Complication	Awareness of the complication of low vision and diabetes		
Alertness	Hurdle			

Life with low vision and diabetes, ‘A long life illnesses’

Codes	Codes	Subcategory	Category	Themes						
Feelings	Approaches	Feelings of diabetic person and burden to their families	Meaning of having Low vision and diabetes	life with low vision and diabetes “A long life illnesses”						
Moods	Searching									
Spirits	Feeble									
Morale	Weak, frail									
Emotional	Vulnerable									
Sensitive	Open									
Responsive	Feeble									
Stances	Alert									
Outlooks	Assurance									
Trust	Confidence									
Belief	Opinion									
Attitudes	Stands									
Frightening	Alarming	frightening of low vision and diabetes	Meaning of having Low vision and diabetes	life with low vision and diabetes “A long life illnesses”						
Scary	Stressful									
Upsetting	Troubling									
Terrifying	Shocking									
Distressing	Worrying									
Disturbing	Concerning									
Communication	Statement	Communication difficulties with health professionals	Meaning of having Low vision and diabetes	life with low vision and diabetes “A long life illnesses”						
Message	Report									
Burden, problem	Badly-behaved	burden to the society	Meaning of having Low vision and diabetes	life with low vision and diabetes “A long life illnesses”						
Liability	Responsibility									
Emotional	Open	Emotional Feelings	Meaning of having Low vision and diabetes	life with low vision and diabetes “A long life illnesses”						
Sensitive	Vulnerable									
Attitudes	Methods	Health profession’s attitudes	Meaning of having Low vision and diabetes	life with low vision and diabetes “A long life illnesses”						
Approaches	Confidence									
Boldness	Assurance									
Searching	Penetrating	Searching for hope of good health	A hope of good health	life with low vision and diabetes “A long life illnesses”						
Pointed	Keen, Deep									
Help	Aid	Help from health care professionals			A hope of good health	life with low vision and diabetes “A long life illnesses”				
Support, care	Benefit									
Maintenance	Service									
Relief, comfort	Utility									
Luxury, wellbeing	Advantage									
Security	Improvement									
Relaxation	Assistance									
Unrealistic	Idealistic	Unrealistic comments and vulnerable diabetic person					A hope of good health	life with low vision and diabetes “A long life illnesses”		
Impractical	Unfeasible									
Finances	Cost of living	Finances: perceived impact of low vision and diabetes on cost of living							A hope of good health	life with low vision and diabetes “A long life illnesses”
Effect, social	Control, power	Impact on social relationships	A hope of good health	life with low vision and diabetes “A long life illnesses”						
Consequence	Community									
Concerns, worries	Group									
Distresses, result	Shared									

Life with low vision and diabetes, ‘A long life illnesses’

Codes	Codes	Subcategory	Category	Themes
Essential learning	Required learning	Essential learning	Education	life with low vision and diabetes “A long life illnesses”
Necessary learning	Compulsory learning			
Experiential learning	Applied learning	Experiential learning		
Practical learning	Useful learning			
Support	Relief	Support from physician, family and friends		
Assistance	Comfort			
Support	Luxury			
Maintenance	Care			
Awareness	complication	Awareness of low vision and diabetes		
Alertness	hurdle			

“Helping hand” health professionals specifically Health care assistant

Codes	Codes	Subcategory	Category	Themes
Barrier, matters	Worries	Older people Issues	Key issues In managing low vision and diabetes older people	“Helping hand” Health professionals specifically health care assistant
Problems	Complications			
Concerns	Drawbacks			
Difficulties	Sufferings			
Hitches	Distresses			
Barrier, matters	Worries	Care home staff issues		
Problems	Complications			
Concerns	Drawbacks			
Difficulties	Sufferings			
Hitches	Distresses			
Barrier, matters	Worries	Health professionals Issues		
Problems	Complications			
Concerns	Drawbacks			
Difficulties	Sufferings			
Hitches	Distresses			
Perspectives	Duties	Care staff perspectives about diagnosis	Management of low vision and diabetes In care homes	
Views	Feelings			
Perceptions	Remarks			
Opinions	Responsibilities			
Observations	Emotional state			
Assessments	Clarifications			
Sensitivities	Accountabilities			
Comments				
Diagnosis	Decision	How the diagnosis was made		
Judgment	Outcome			
Finding	Identification			
Identification				
Knowledge	Attentiveness	Care staff knowledge	Barriers to deliver A good care To older people with low vision and diabetes	
Information	Evidences			
Awareness	Suggestions			
Facts	Concentration			
Proofs	Thoughts			
Recommendations				
Communication	Statement	Communication		
Message	Report			
Training	Delivery	Care staff Training		
Preparation	Arrangement			
Planning	Providing			
Establishment	Progress			
Development	Distribution			

APPENDICES PHASE TWO

UNIVERSITY OF BEDFORDSHIRE

Research Ethics Scrutiny

When completing this form please ensure that you **read and comply** with the following:

Researchers must demonstrate clear understanding of an engagement with the following:

1. *Integrity* - The research has been carried out in a rigorous and professional manner and due credit has been attributed to all parties involved.
2. *Plagiarism* - Proper acknowledgement has been given to the authorship of data and ideas.
3. *Conflicts of Interest* - All financial and professional conflicts of interest have been properly identified and declared.
4. *Data Handling* - The research draws upon effective record keeping, proper storage of data in line with confidentiality, statute and University policy.
5. *Ethical Procedures* - Proper consideration has been given to all ethical issues and appropriate approval sought and received from all relevant stakeholders. In addition the research should conform to professional codes of conduct where appropriate.
6. *Supervision* - Effective management and supervision of staff and student for whom the researcher(s) is/are responsible
7. *Health and Safety* - Proper training on health and safety issues has been received and completed by all involved parties. Health and safety issues have been identified and appropriate assessment and action have been undertaken.

The **Research Institutes** are responsible for ensuring that all researchers abide by the above. It is anticipated that ethical approval will be granted by each Research Institute. Each Research Institute will give guidance and approval on ethical procedures and ensure they conform to the requirements of relevant professional bodies. As such Research Institutes are required to provide the University Research Ethics Committee with details of their procedures for ensuring adherence to relevant ethical requirements. This applies to any research whether it be, or not, likely to raise ethical issues. Research proposals involving vulnerable groups; sensitive topics; groups requiring gatekeeper permission; deception or without full informed consent; use of personal/confidential information; subjects in stress, anxiety, humiliation or intrusive interventions must be referred to the University Research Ethics Committee.

Research projects involving participants in the NHS will be submitted through the NHS National Research Ethics Service (NRES). The University Research Ethics Committee will normally accept the judgement of NRES (it will never approve a proposal that has been rejected by NRES), however NRES approval will need to be verified before research can commence and the nature of the research will need to be verified.

Where work is conducted in collaboration with other institutions ethical approval by the University and the collaborating partner(s) will be required.

The **University Research Ethics Committee** is a sub-committee of the Academic Board and is chaired by a member of the Vice Chancellor's Executive Group, appointed by the Vice-Chancellor and includes members external to the University

Research Misconduct: Allegations of Research Misconduct against staff or post graduate (non-taught) research students should be made to the Head of the Research Graduate School



**Institute of Diabetes for Older People
Research Proposal Ethical Approval Form**

Please complete this form and submit it to the Institute of Diabetes for Older People Research Ethics Committee (IDOPREC).

- Students should attach a copy of their full proposal.
- Staff should attach (or include below) an abstract of their research proposal.
- All applicants should include any consent forms or information sheets, and data collection tools you intend to use with your participants.
- If the intention is to work within specific agencies or establishments the applicant should attach copies of any letters of agreement with those agencies/establishments.

Provide as much information as you are able to on this form and answer the questions as fully as you can. INSTRUCTIONS FOR SUBMISSION ARE TO BE FOUND BELOW THE SIGNATURE PANEL TOWARDS THE END OF THIS FORM

ALL staff and students MUST obtain ethical approval BEFORE beginning any research.

All proposals:

Name:	Nizam Muhammad Darwesh
Contact email/phone:	(0044) 07817170411 / drnizam2010@yahoo.co.uk
Date:	
Title of proposal:	Low vision and diabetes in care home and older community residents
Anticipated start date:	
Anticipated duration of project:	3 Years
Is the project to be externally funded?	YES

Student proposals:

Supervisor name:	Professor Alan Sinclair
Award studied for:	PhD
Will you be collecting data outside the UK?	NO

* If YES Masters students must complete the Authorised Absence form on the IDOP website <http://www.beds.ac.uk/research/idop/ethics> and return it with this form; PhD students must contact the Research Graduate School.

Staff Proposals:

Department:	
Role/Job Title:	
Principal Investigator:	

N.B. Before completing this form you should read the *NHS National Research Ethics Service Guidance* available from <http://www.nres.npsa.nhs.uk/applications/guidance/>
Undergraduate and postgraduate students should complete this form in consultation with their supervisors.

What are the key aims or objectives of your research? (Provide a brief summary in bullet points.)

Key aims:

Delivering and validating the utility of the educational toolkit training about low vision and diabetes in care home staff to understand how it will work, the educational toolkit was developed after completion of phase one of this project.

2nd Ethics application for phase two Intervention study (the delivery of the educational toolkit)

Phase one was completed after the approval of IDOP ethics committee, the outcome from 116 participants to develop the education toolkit, after the development of education toolkit a small cluster study was design aimed at validating the utility of the educational toolkit in care home staff.

A brief summary in bullet points:

Care home residents with diabetes are a vulnerable group of individuals who are at high risk of visual impairment and its consequences on daily living and health. Some of these consequences are serious (such as falls with fractures), and many are preventable through early recognition and treatment of diabetic eye disease. Although guidelines do exist with respect to the management of elderly patients with diabetes and visual impairment in care and residential homes, their implementation is patchy and both patients and their carers can be unaware of the causes and effects of sight loss associated with diabetes, or what to do when visual loss is identified. Therefore, the purpose of this study is to (a) explore the experiences of older people related to diabetes and low vision and (b) explore the experiences of health-care professionals and care home workers related to diabetes and low vision. This will ultimately help to improve early detection and treatment of eye care services for elderly people with diabetes. key aims and objectives of my research:

This study aims to provide up-to-date knowledge regarding:

- A. The issues and problems faced by elderly people with low vision associated with diabetes at care homes.
- B. To understand the causes & how to prevent early visual defects due to diabetes in elderly people, and how they receive low vision care at care homes and in the community.
- C. To evaluate the knowledge and understanding of care staff on the impacts of low vision associated with diabetes in older people.

D. To enhance knowledge and understanding to support practitioners in providing improved health care for old people with low vision associated with diabetes.

What is the key question your research will address?

The key questions for phase two:

Validating the utility of the educational toolkit in care home staff to understand how it will work?

Validating the utility of the online educational toolkit in the community to understand how it will work?

Who is your target group or sample?

The educational toolkit training will be delivered to (20) care home staff; participants will be randomly chosen with help of care home managers. The content of these interviews is not of a sensitive nature and accidental disclosure is highly unlikely to have serious consequences. However, all participants will be treated equally with the same attention to the following ethical, legal, and management issues:

Consent: Fully informed consent will be sought from all study participants. A participant information sheet and consent form will be provided to all participants, who will be given one week to read this material. The information sheet details the background and aims of the research, what will happen to participants, a description of benefits and risks (or lack thereof), how any data will be managed, how to decline or exit the study, and reassurance that doing either will not affect care in any way. Permission will be explicitly asked that recording equipment can be used and that quotes can be used in the reporting of the study. A consent form is included with the participant information sheet and presented in line with IDOP REC and NHS REC guidelines. The principal researcher is a qualified medical doctor who is able to assess capacity to give consent.

What data collection methods will you use?

Methodologies are:

Group1: 10 participants with no age and gender restrictions; participants will be qualified HCAs with a minimum experience of 2 years and qualification of NVQ 2 or QCF 2 in health care who will be receiving an educational toolkit package. There is a pre-test and Posttest for participants of just 10 questions to evaluate and assess knowledge at baseline (prior to the delivery of the toolkit), as well as immediately afterwards and again at 2 months using the same 10 questions with the additional 12 questions for in-depth interviews which is attached with the information sheet, for the assessments. Participants will be randomly chosen with help of care home managers and they will be from Bedfordshire.

Group2: 10 participants with no age and gender restrictions; qualified HCAs with a minimum experience of 2 years and qualification of NVQ 2 or QCF 2 in health care who will be not receiving an educational toolkit package, the same 10 questions with the additional 12 questions for in-depth interviews will be use. Participants will be randomly chosen with help of care home managers and they will be from Bedfordshire.

What will happen to the participants?

Managers of the care homes from Bedfordshire will be contacted by principal researcher through letters and phone calls for appointments, principal researcher will first explain the study to care home managers. After the identification by the care home managers participants will be contacted by principal researcher. Principal researcher will first explain the study to participants and then answer any questions that they may have about the study. If after the explanation participants are still willing to take part, then participants will be asked for their consent by signing the form.

Date will be conforming for the full training of the educational toolkit; principal researcher will present the toolkit in front of 10 participants (health care assistants) in the training room at Castle troy Residential Home Luton Bedfordshire.

Detail of the educational toolkit training

The training will be completing in 2 hours and 15 minutes

Starting time 09:30 am

Refreshment Break 10:30am (15 Minutes)

Continue the training 10:45am

The training will finished 11:45am.

What will happen to the participants after the delivery of the educational toolkit training?

Skills and practical use of educational toolkit package will be assessed at 0 and 2 months after the delivery of the educational toolkit. There is a pre-test and Posttest for participants of just 10 questions to evaluate and assess knowledge at baseline (prior to the delivery of the toolkit), as well as immediately afterwards and again at 2 months using the same 10 questions with the additional 12 questions for in-depth interviews which is attached with the information sheet, for the assessments.

Participants will be invited to (In-depth interviews) about the educational toolkit training

that they had received, at the Castle Troy Residential Home Luton Bedfordshire and principal researcher will ask them a number of questions about the educational toolkit training, it will take about 30 to 45 minutes to complete. The meeting will be arranged during normal working hours. This project will use a qualitative approach, in depth interviews. These in-depth interviews are aimed at validating the utility of the educational toolkit in care home staff, which was developed from the phase 1 comprehensive data of this study.

Online educational toolkit:

The online educational toolkit has been designed to provide useful information, advice and to answer some commonly asked questions about diabetes and low vision, people with low vision and diabetes or are caring for someone with low vision and diabetes, it is important for them to understand what care they can expect to receive throughout their life and their role in managing low vision and diabetes. This online educational toolkit is composed of resources to help care staff and to educate older community residents about diabetic eye disease.

20 participants with no age and gender restrictions, people with low vision and diabetes or people caring for someone with low vision and diabetes will be included, who will be receiving an online educational toolkit package, a pre-test and posttest for participants of 10 questions to evaluate and assess knowledge at baseline (prior to the delivery of the toolkit), as well as immediately afterwards, online low vision and diabetes education toolkit will be used to educate participants.

Recruitment:

Participants were recruited randomly from a list of community focus groups who have previously responded to phase one of this project

What will happen to the participants?

Participants will be only able to complete the 10 questions of pre-test first and then to complete online educational toolkit training (full instructions of how to use the online educational toolkit are included with information sheet) after completing the training the participants will be able to complete posttest the same 10 questions. These assessments are aimed at validating the utility of the online educational toolkit in the community.

Answer the following question by deleting as appropriate:

1. Does the study involve vulnerable participants or those unable to give informed consent (e.g. children, people with learning disabilities, your own students)?

No

If **YES**: Have/will Researchers be DBS checked?

No

2. Will the study require permission of a gatekeeper for access to participants (e.g. schools, self-help groups, residential homes)?

Yes

3. Will it be necessary for participants to be involved without consent (e.g. covert observation in non-public places)?

No

4. Will the study involve sensitive topics (e.g. sexual activity, substance abuse)?

No

5. Will blood or tissue samples be taken from participants?

No

6. Will the research involve intrusive interventions (e.g. drugs, hypnosis, physical exercise)?

No

7. Will financial or other inducements be offered to participants (except reasonable expenses)?

No

8. Will the research investigate any aspect of illegal activity?

No

9. Will participants be stressed beyond what is normal for them?

No

10. Will the study involve participants from the NHS (e.g. patients) or participants who fall under the requirements of the Mental Capacity Act 2005?

No

If you have answered yes to any of the above questions or if you consider that there are other significant ethical issues then details should be included in your summary above. If you have answered yes to Question 1 then a clear justification for the importance of the research must be provided.

*Please note if the answer to Question 10 is yes then the proposal should be submitted through **NHS research ethics approval procedures** to the appropriate **NRES**. The UREC should be informed of the outcome.

Checklist of documents which should be included:

Project proposal (with details of methodology) & source of funding	✓
Documentation seeking informed consent (if appropriate)	✓
Information sheet for participants (if appropriate)	✓
Questionnaire (if appropriate)	✓

(Tick as appropriate)

Applicant declaration

I understand that I cannot collect any data until the application referred to in this form has been approved by all relevant parties. I agree to carry out the research in the manner specified. If I make any changes to the approved method I will seek further ethical approval for any changes

Signed (Applicant): Date: 05/08/14

Signature of Supervisor/ Director of Studies (N.B. This is **NOT** required for staff applications)

 Date: 05/08/14

This form together with a copy of the research proposal should be submitted to the Research Institute Director for consideration by the Research Institute Ethics Committee

Note to supervisors: Signing this form certifies that in your opinion, the project described here is ethical under Departmental and NHS guidelines. Do **NOT** sign if you are unsure or if the student has not attached complete details of the research design and methodology

SUBMISSION OF APPLICATION

Please save this form as a word document using the following convention:

Applicantsurname_IDOPRECapp_MMMYY.doc (eg Smith_IDOPRECapp_NOV10)

Attach copies of information sheets, data collection tools and/or consent forms (draft versions acceptable)

FORWARD ONE SIGNED HARD COPY TO Caroline Sinclair, IDOP Administrator, Institute of Diabetes for Older People, Putteridge Bury Tel: 01582 743285

AND

AN ELECTRONIC VERSION OF THIS FORM TO: Caroline.Sinclair@beds.ac.uk

Note you cannot commence collection of research data until this form has been approved

SECTION B to be completed by the Research Institute Ethics Committee:

Comments:

There are no ethical problems with this project.

Approved

Signature Chair of Research Institute Ethics Committee:



Date: *1st Sept 2014*

If in the judgement of the committee there are significant ethical issues for which there is not agreed practice then further ethical consideration is required before approval can be given and the proposal with the committees comments should be forwarded to the secretary of the UREC for consideration.

There are significant ethical issues which require further guidance

Signature Chair of Research Institute Ethics Committee:

Date:

This form together with the recommendation and a copy of the research proposal should then be submitted to the University Research Ethics Committee

Low vision and diabetes in older people living in residential care homes

Educational toolkit training consent Form

This Informed Consent Form has two parts

1 Information sheet about the study

2 Certificate of Consent

20 Participants HCAs for educational toolkit training

Principal researcher: Nizam Muhammad Darwesh

PhD Researcher

**Director of study: Professor Alan Sinclair MSc MD FRCP
Dean & Professor of Medicine Bedfordshire and Hertfordshire
Postgraduate Medical School University of Bedfordshire**

**Director of study: Professor Peter Scanlon
MD FRCP DCH DRCOG DO FRCOphth PG Cert.
Consultant Ophthalmologist, Oxford Eye Hospital**



Informed Consent Form

Informed consent form for participation in the study titled “Low vision and diabetes in older people living in residential care homes” To Improving quality of care for older people with low vision associated with diabetes.

Principal researcher: Nizam Muhammad Darwesh

(PhD Researcher)

Director of study: Professor Alan Sinclair MSc MD FRCP
Dean & Professor of Medicine Bedfordshire and Hertfordshire
Postgraduate Medical School University of Bedfordshire

Director of study: Professor Peter Scanlon
MD FRCP DCH DRCOG DO FRCOphth PG Cert. Med.Ed.
Consultant Ophthalmologist, Gloucestershire Eye Unit & Oxford Eye Hospital
Programme Director for the English National Diabetic Retinopathy Screening
Programme

Establishment: Institute of diabetes for older people (IDOP)
 Putteridge bury University of Bedfordshire

This Informed consent form has two parts:

- Information sheet (information about the study)
- Certificate of consent (for signatures if you choose to participate)

You will be given a copy of the full Informed consent form

Part I: Information Sheet

About Principal researcher:

My name is Nizam Muhammad Darwesh, and I am a PhD researcher at the University of Bedfordshire. I am carrying out a research study titled “Low vision and diabetes in older people living in residential care homes” residents” to understand how we can improve quality of care for older people with low vision associated with diabetes, I will provide you with information about my research and invite you to participate in this study. If you would like any further information that you feel was not provided in this information package, please feel free to ask me or my supervisor questions, Professor Alan Sinclair.

About directors of study:

Professor Alan Sinclair MSc MD FRCP Dean and Professor of Medicine, Bedfordshire and Hertfordshire Postgraduate Medical School & Director of the institute of Diabetes for Older People (IDOP) University of Bedfordshire Putteridge Bury Campus Hitchin Road Luton LU2 8LE

Tel: 01582 743285 Fax: 01582 743286 E-mail: alan.sinclair@beds.ac.uk

Professor Peter Scanlon MD FRCP DCH DRCOG DO FRCOphth PG Cert. Med.Ed. Consultant ophthalmologist, Gloucestershire eye unit & Oxford eye hospital; programme director for the English national diabetic retinopathy screening programme department of ophthalmology, Cheltenham general hospital, Sandford road, Cheltenham, Glos GL53 7AN, E-mail: Peter.Scanlon@glos.nhs.uk

Invitation to take part in this research study

You are invited to take part in this research study titled, “Low vision and diabetes in older people living in residential care homes” being undertaken by Principal researcher Nizam Muhammad Darwesh at Bedfordshire and Hertfordshire Postgraduate medical school & Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire. Principal researcher will first explain the study to you and then answer any questions that you may have about the study.

If after the explanation you are still willing to take part, then you will be asked for your consent by signing the form.

What is the purpose of this research? Why are we doing this research?

Low vision associated with diabetes in older people is common. There are many different opinions about low vision associated with diabetes in older people that are unhelpful in recognising and addressing some of the issues surrounding it. Through this research, we hope to learn the views of the participants to understand the impact of diabetes on low vision in older people and also the purpose of this research which is to Improve the quality of care for older people with low vision associated with diabetes, and to help with the planning of existing and future low vision services associated with diabetes care for older people resident in care homes. This research project will help to develop a clearer picture of the current services available, staff experiences, and perceived needs of older people resident in care homes. in addition to develop a package of education and training to support practitioners in providing better health care to older individuals with low vision associated with diabetes.

Why have I been chosen?

You are the best source of information about this topic. We feel that your experience and knowledge will help us in filling the gaps in terms of our understanding, communication and services that are needed to improve low vision care in people with diabetes. Also this is the selection criteria for this project.

Do I have to take part?

No, you do not have to take part if you do not want to, it's your choice. Your participation in our research study is totally voluntary, and you may choose to not participate at any point before or during the research. You are also allowed to change your mind if you decide to not participate at a later time even if you had agreed earlier. By taking part you will be helping us to improve low vision associated with diabetes services for older people.

What will happen to me if I take part?

You will be invited to the educational toolkit training and principal researcher will first explain the study to you and then answer any questions that you may have about the study. If after the explanation you are still willing to take part, then you will be asked for your consent by signing the form.

Date will be conforming for the full training of the educational toolkit; principal researcher will present the toolkit in front of 20 participants (health care assistants) in the training room at Residential Care Home Luton Bedfordshire.

Detail of the educational toolkit training:

The training will be completing in 2 hours and 15 minutes

Starting time 09:30 am

Refreshment Break 10:30am (15 Minutes)

Continue the training 10:45am

The training will finished 11:45am

What will happen to me after receiving the educational toolkit training?

After receiving the educational toolkit training there is a pre-test and Post-test for you of just 10 questions to evaluate and assess your knowledge about the low vision and diabetes at baseline (prior to the delivery of the toolkit), as well as immediately afterwards and again at 1 month using the same 10 questions for the assessments. It will take about 10 to 15 minutes to complete the questionnaires. It is important that you tell us about your experiences in your own words. The information you give will be completely confidential and any names you mention will remain anonymous and excluded from the final report.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help to improve low vision associated with diabetes services for older people living in the residential care homes.

Obtaining your consent

It is important that you understand that if you decide to take part in this study you will be asked to give your consent to be interviewed. This means that you

will be asked to sign a consent form. This form will have separate questions asking for your agreement to be saved, for your responses to be shared between the research team and perhaps for some of your responses to be used 'verbatim' (word for word) in the report. Before any of this is done, the Principal researcher will first explain the study to you and then answer any questions that you may have about the study, if after the explanation you are still willing to take part, then you will be asked for your consent by signing the form.

What if I change my mind?

If after reading this information sheet you decide to take part in the study, but then later on you decide that you no longer want to take part, you are under no obligation to continue, you can withdraw from the study without having to give any reasons for your decision at any time. This includes your right to stop part way through the interview. A decision to withdraw at any time, or a decision not to take part,

What if something goes wrong?

In the unfortunate event that something goes wrong, such as the interview tapes fail to record clearly and the data is rendered 'unusable', the principal researcher will contact the participant concerned to explain the difficulty (that have arisen with the technology) and see if they are able and willing to be re-interviewed. If the participant is unable to be re-interviewed, then the principal researcher will write to them to apologise for the 'loss' of recording and ensure that they understand that they will no longer be included in the study. The principal researcher will then have to decide whether to select another participant or to report this event as a 'null' recording in the final report. The choice will inevitably depend upon the time available to complete the project.

What do I have to do?

If you are interested in taking part in this study then you will be contacted by a principal researcher. This will be to arrange a date and place convenient to you, any questions that you may have about the study can be discussed with the

principal researcher at this time, if after this discussion you feel you do not want to carry on, you can withdraw from the study.

What happens to the information I give at the interview? (Confidentiality)

Following the meeting discussion, any personal details, such as any names of people or places that you may have mentioned will remain confidential; they will not be included in the report version. All information collected within an the meeting will be known only to meeting members and no one outside the group will be informed about the discussion from the research team. Data will be in the safe hands and only Nizam and Professor Alan Sinclair and Professor Peter Scanlon will have access to this information. Therefore is no chance for any breach of confidence or failure to maintain data security, Data will be stored securely on password protected PC and will be locked in the Institute of diabetes for older people (IDOP) Putteridge bury campus University of Bedfordshire and, Data will be analysed in confidential,

What will happen to the results of the study?

This research is being conducted for PhD thesis; it will be available through the Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire. Also the research team will use the interview discussion to find out ways in which low vision associated with diabetes services can be improved for older people. The findings from the study will be published in a newsletter, which will be made available to you.

Who is organising and funding this study?

All financial necessary resources to complete the study will be self-finance. Access to databases will be through the University of Bedfordshire and IDOP,

Who has approved the study?

This study has undergone a rigorous process of inspection and has been approved by the Institute of Diabetes for Older People (IDOP) Putteridge Bury University of Bedfordshire ethics committee.

Contact for further information about this study

If you have a concern about any aspect of this study, or if you wish to make a comment or complaint, please feel free to contact me Nizam at: drnizam2010@yahoo.co.uk or nizam.darwesh@study.beds.ac.uk or call 01582743988. I will do my best to answer your questions. If you remain unhappy you can contact Professor Alan Sinclair (Dean and Professor of Medicine, B&H Postgraduate medical school & director of the institute of diabetes for older people (IDOP) University of Bedfordshire e-mail: alan.sinclair@beds.ac.uk or call Tel: 01582 743285.

Thank you for taking the time to read this information sheet, we would be grateful if you decide to take part.

Part II: Certificate of Consent

I have been invited to participate in a study titled “Low vision and diabetes in older people living in residential care homes” which involves a study of older people with low vision associated with diabetes. I have read and I fully understand the information given above about the research. I have asked any questions that I had regarding the research and they have been answered to my satisfaction. I voluntarily consent to take part in this study.

Print name of participant _____

Signature of participant _____

Date _____

Statement by the principal researcher /person taking consent

I have presented the information to the potential participant to the best of my knowledge. I have ensured that the participant understands they have the choice to opt out of the study at any stage if they do choose to participate. Participants are aware that all information will be kept confidential and all results reported will be done so anonymously. I also confirm that the participants have had the opportunity to ask questions about the study and that they have been answered to their content. The participants have not been forced to participate and I declare no conflicting interest in undertaking this research.

Principal researcher: Nizam Muhammad Darwesh

Signature of principal researcher _____

Date _____

Low vision & Diabetes Education Toolkit Attendance sheet

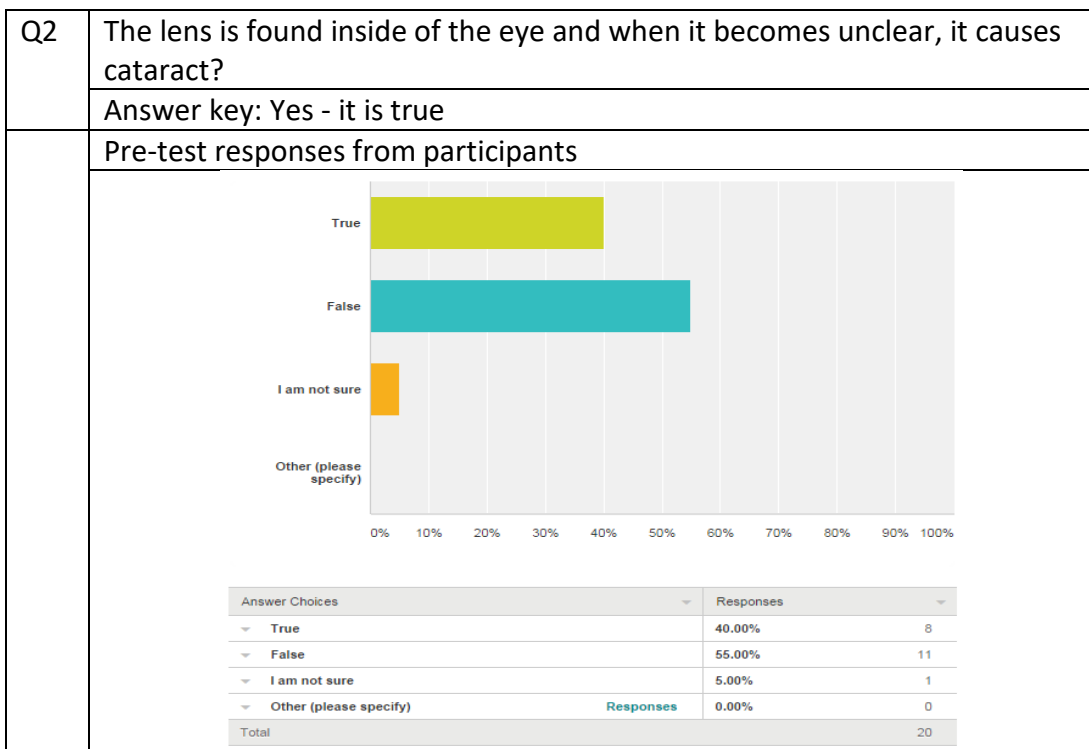
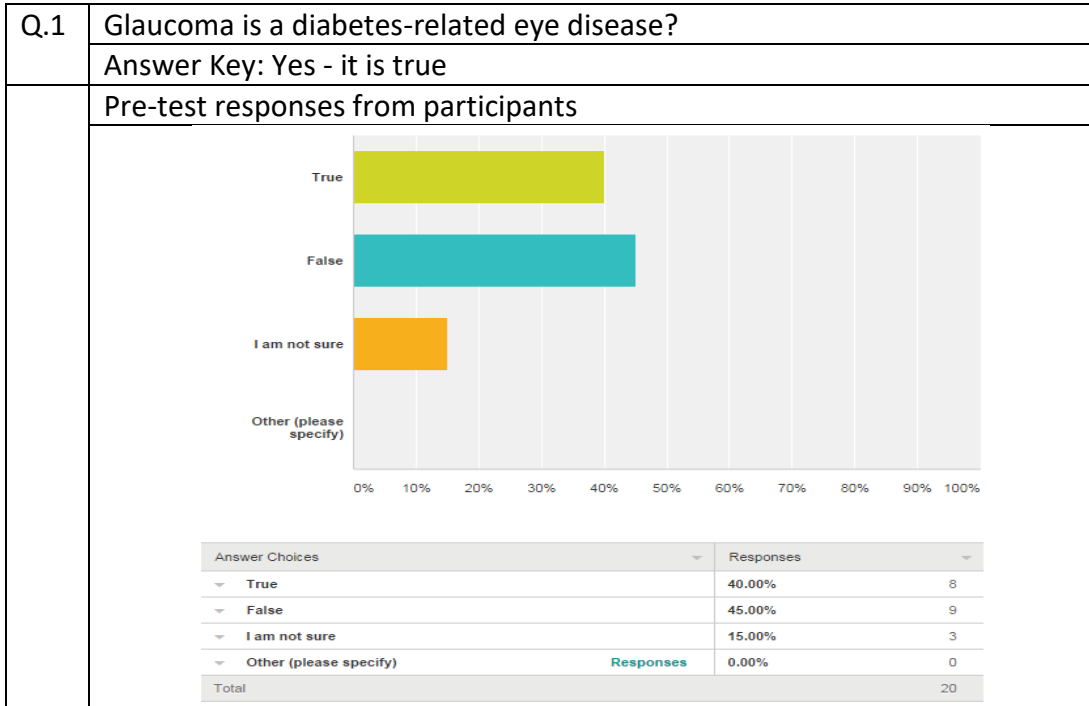
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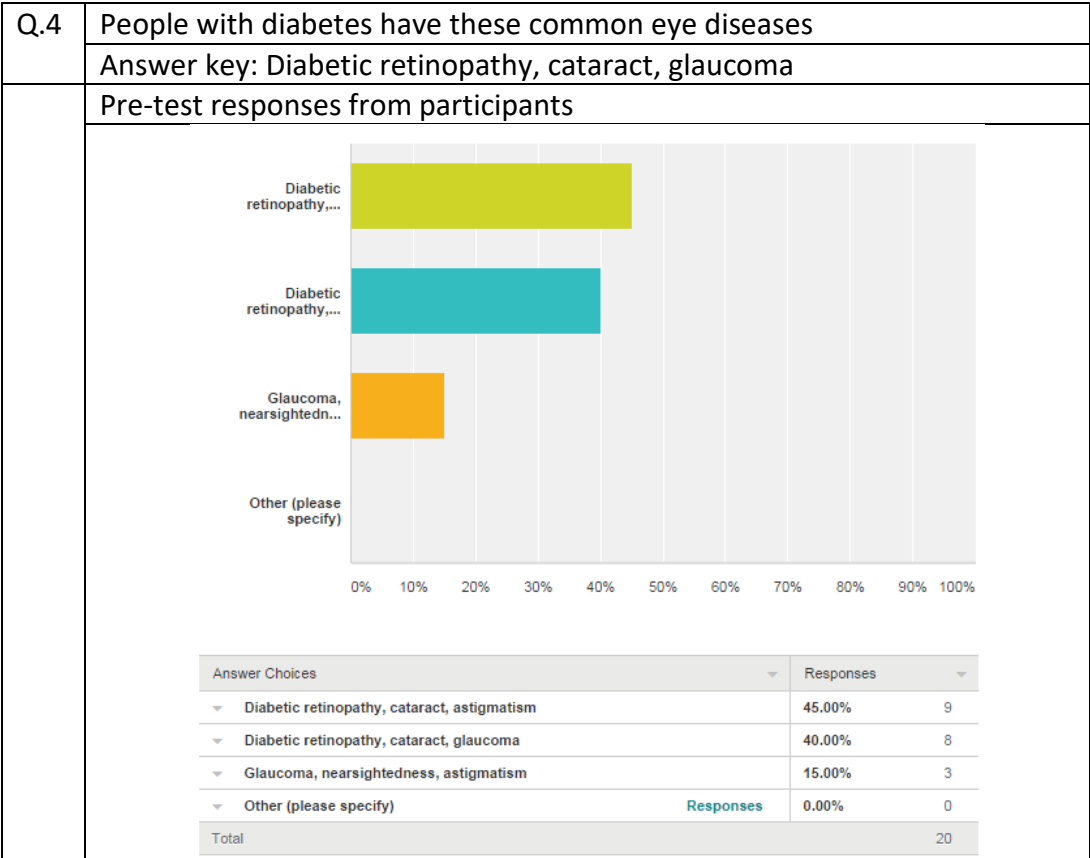
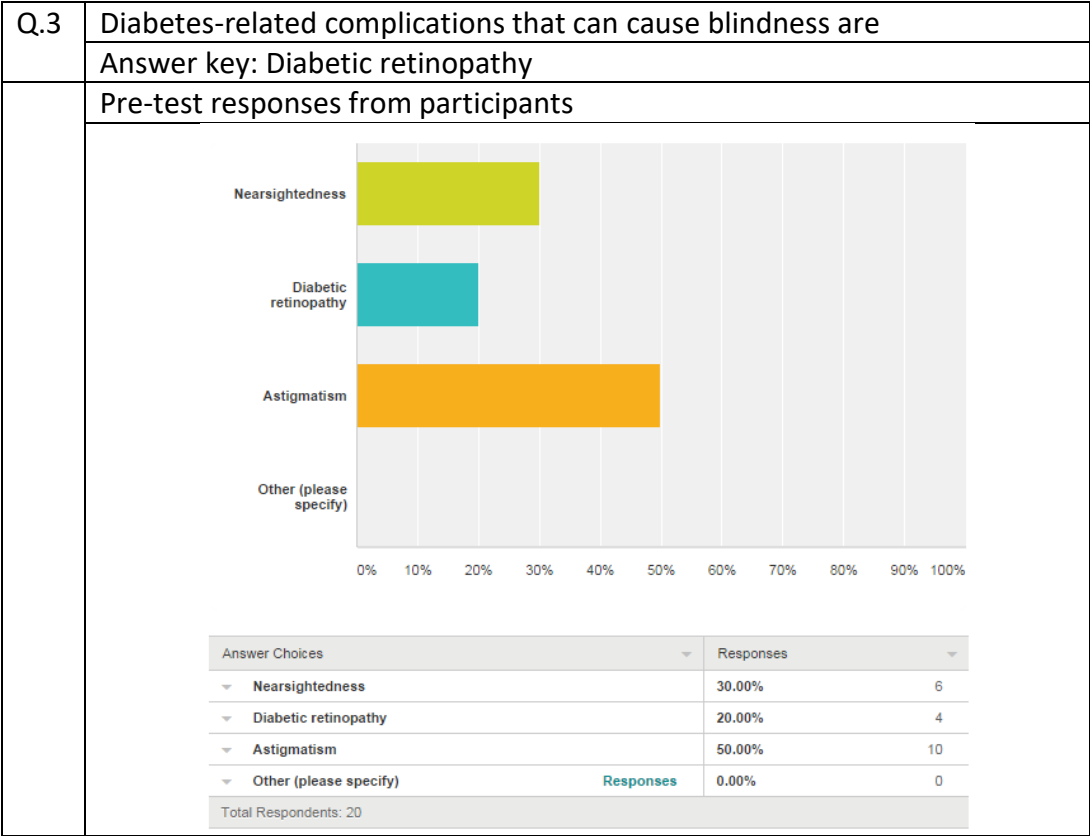
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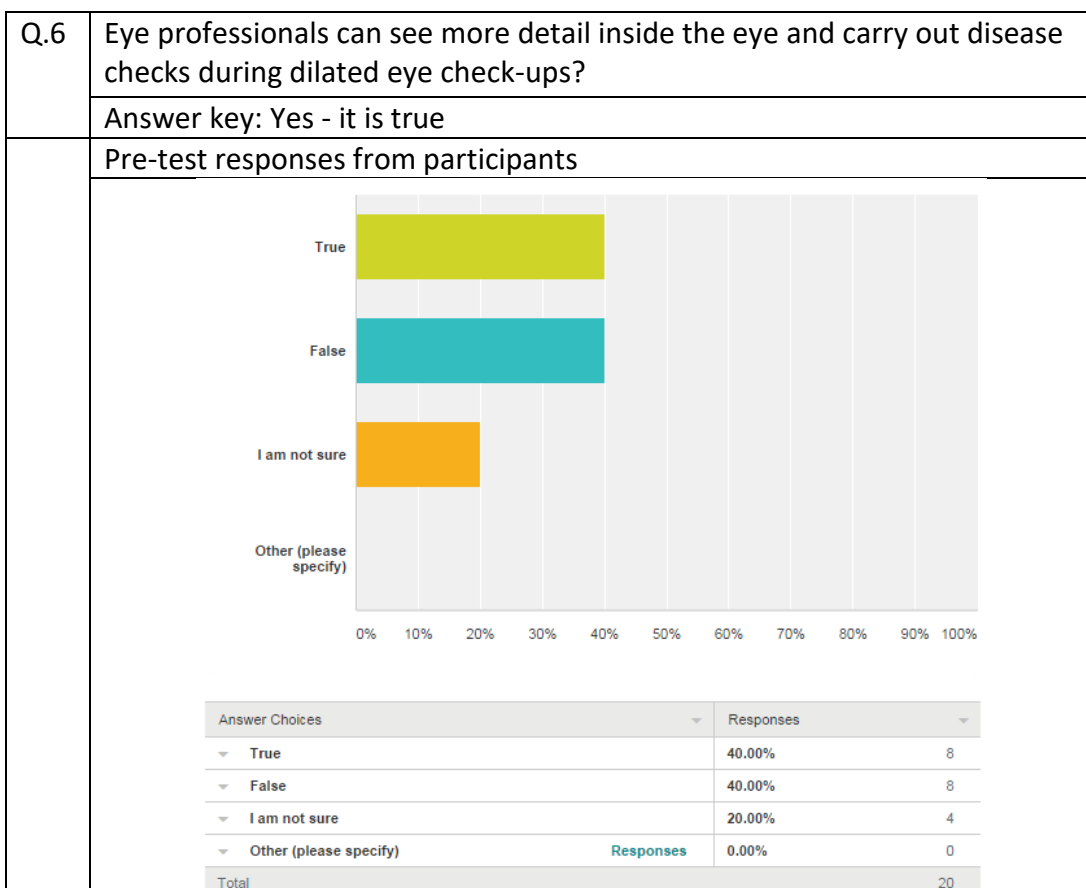
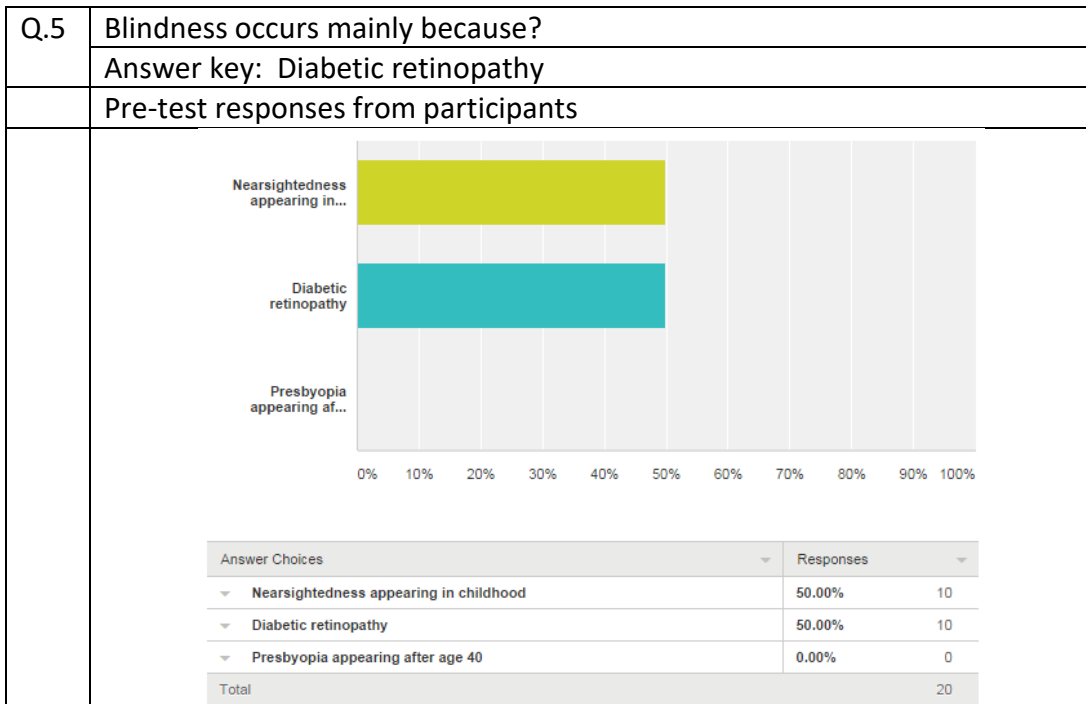
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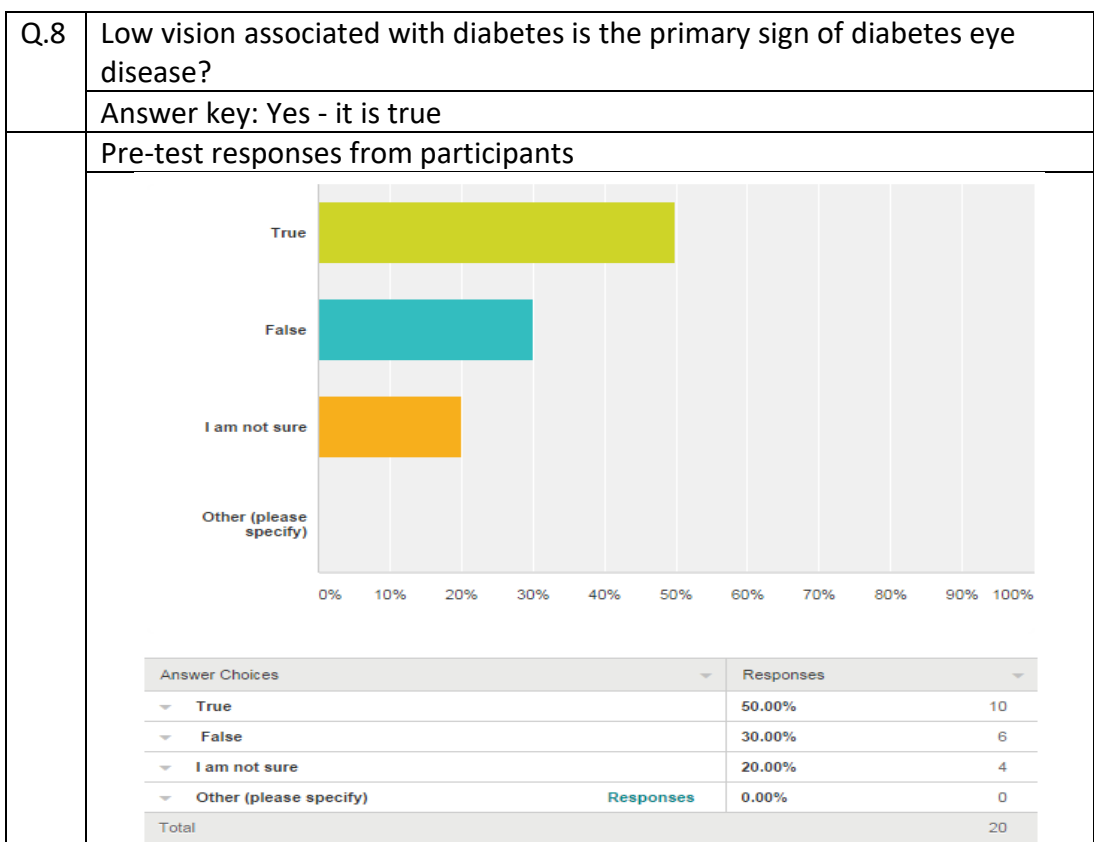
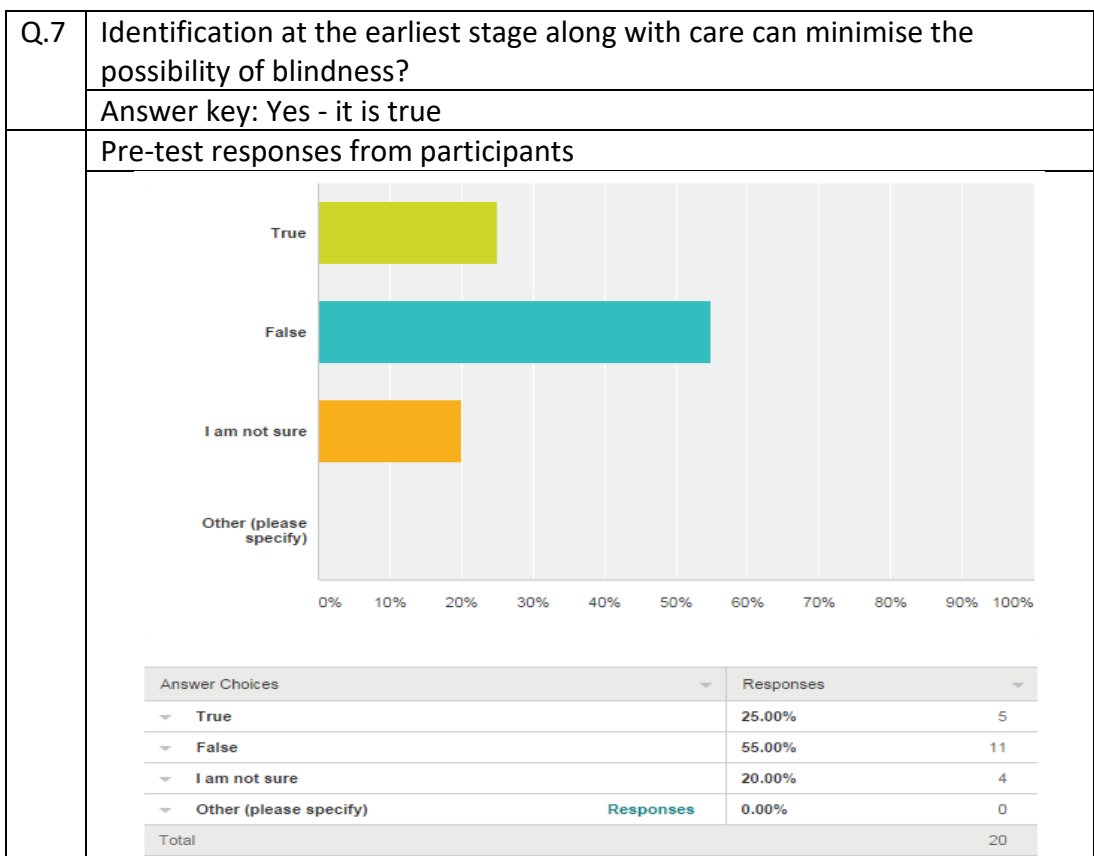
Survey monkey result with full detail of the low vision and diabetes education toolkit

Figure 35 to 44 (Pre-test responses from participants)









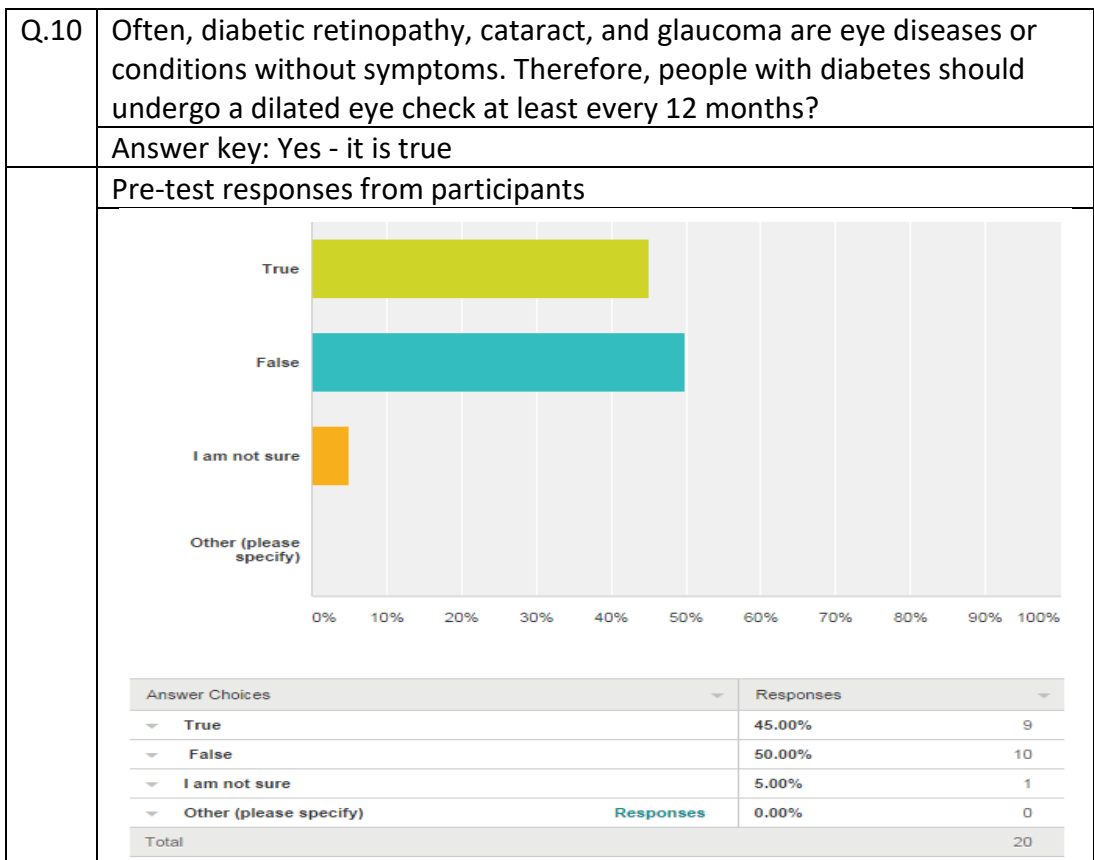
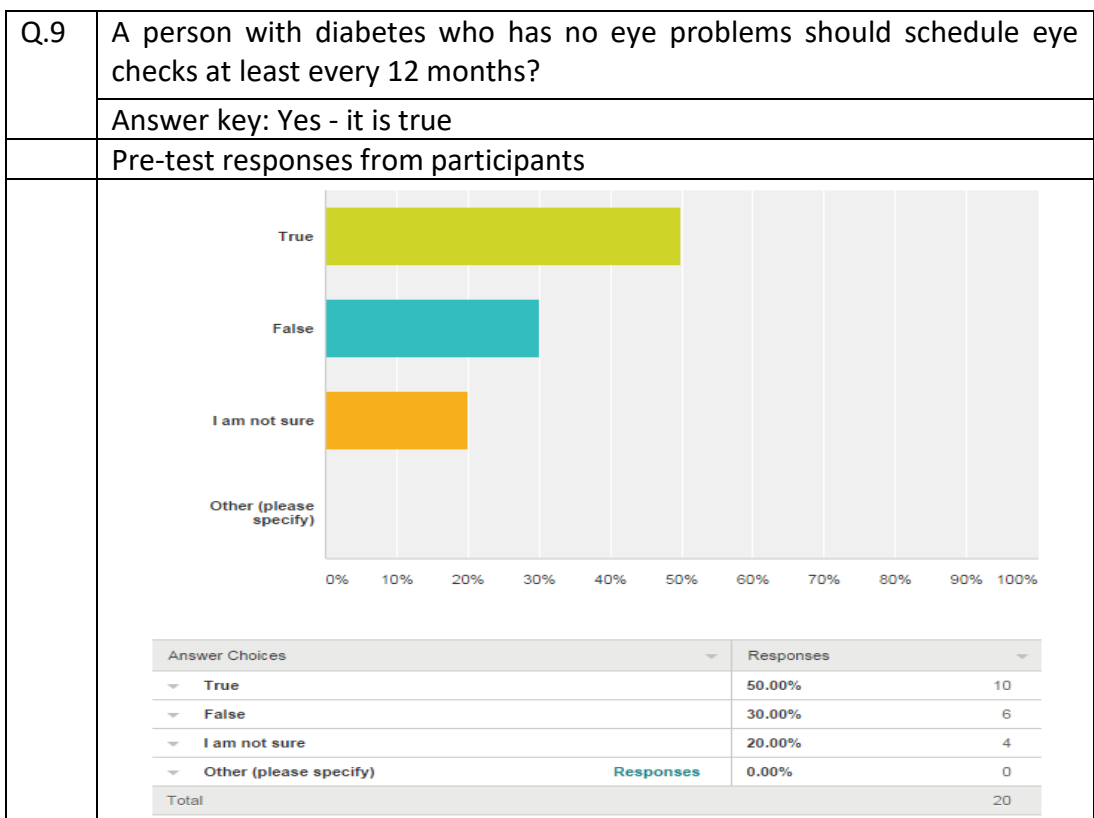
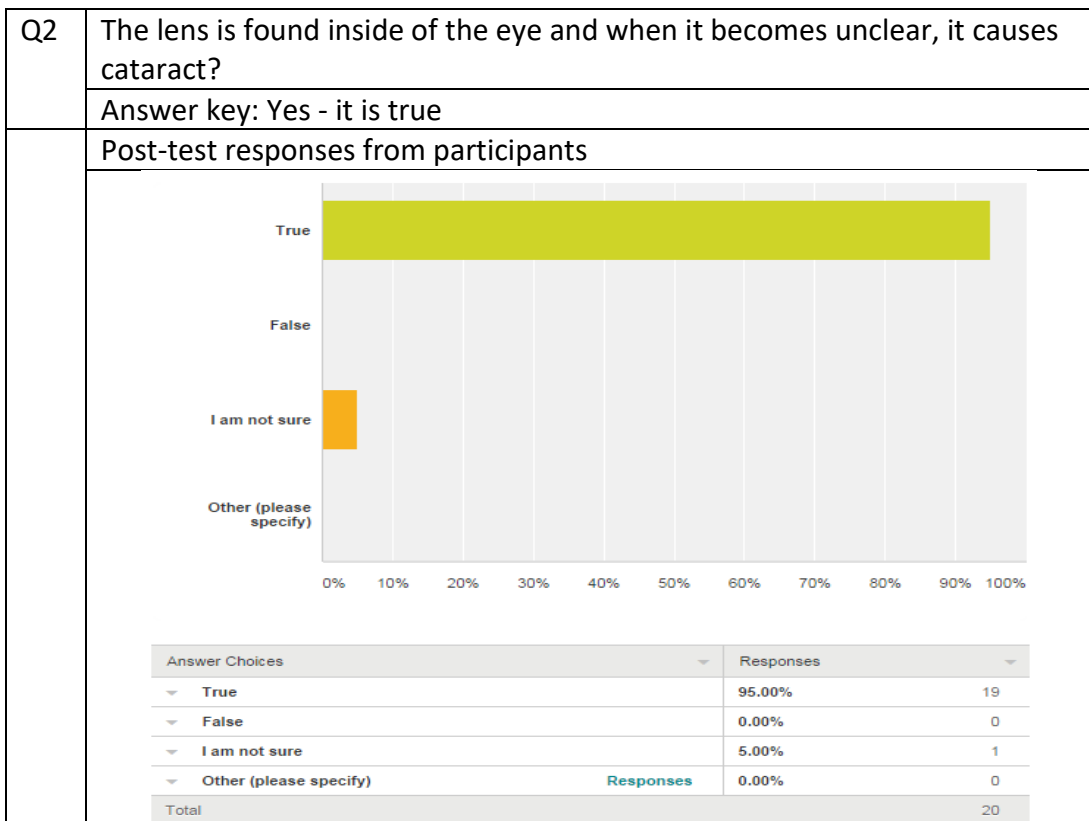
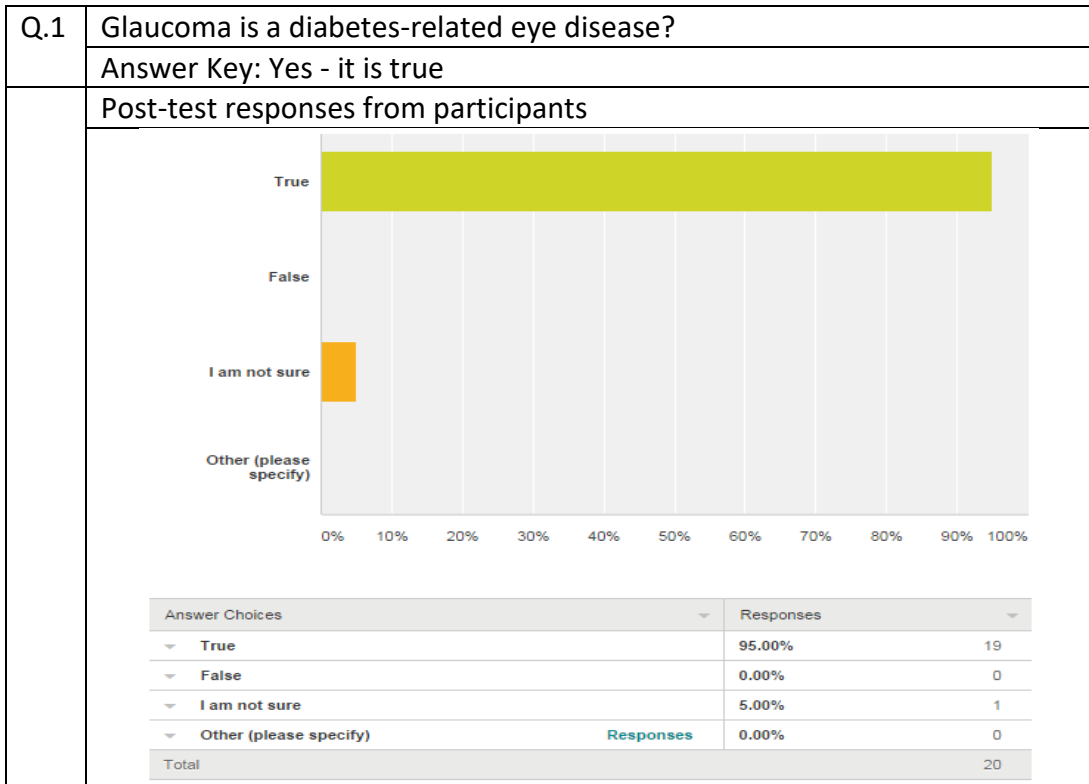
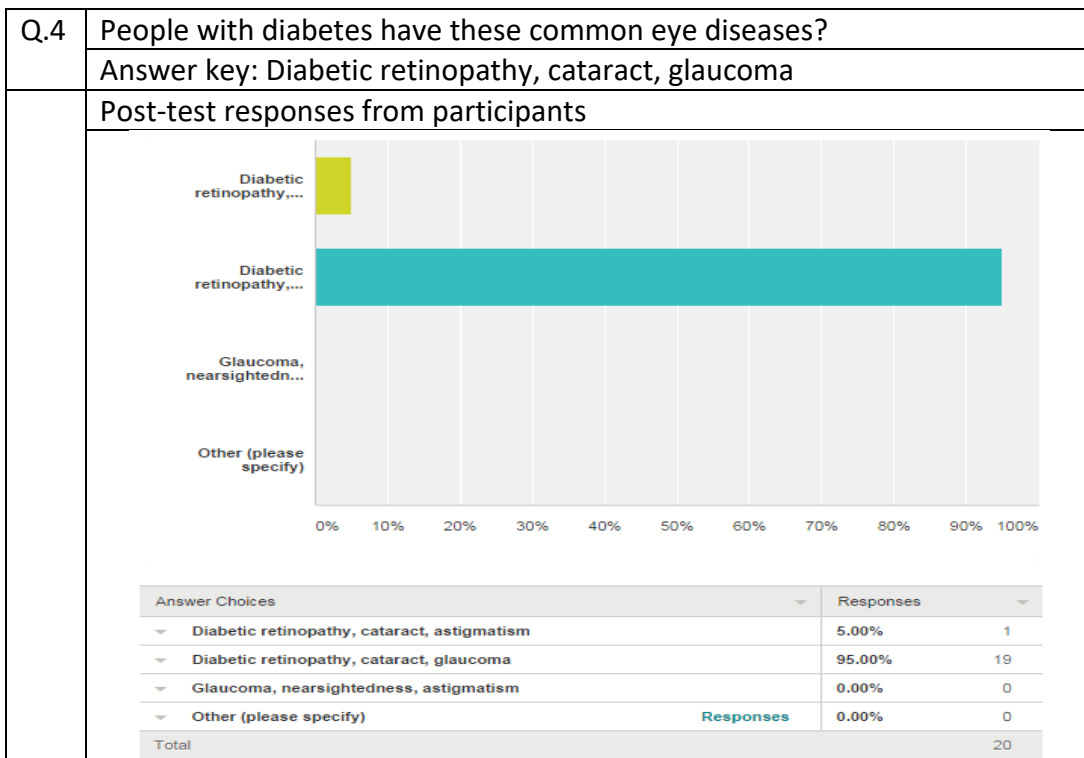
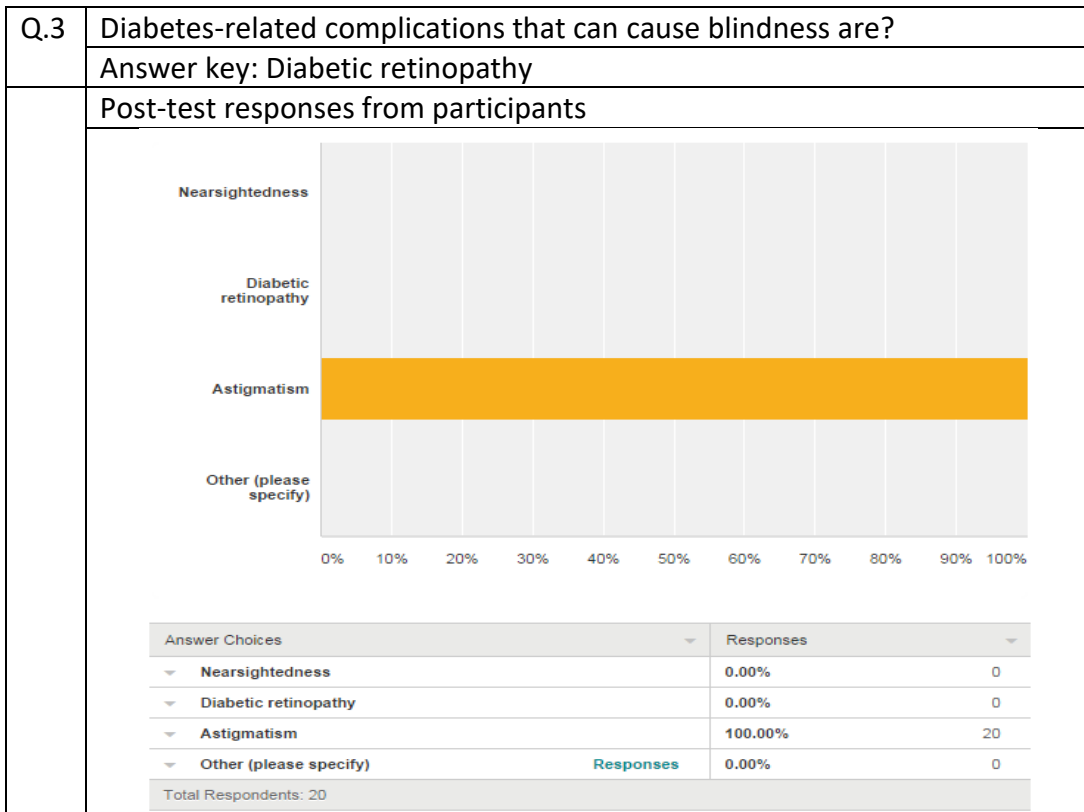
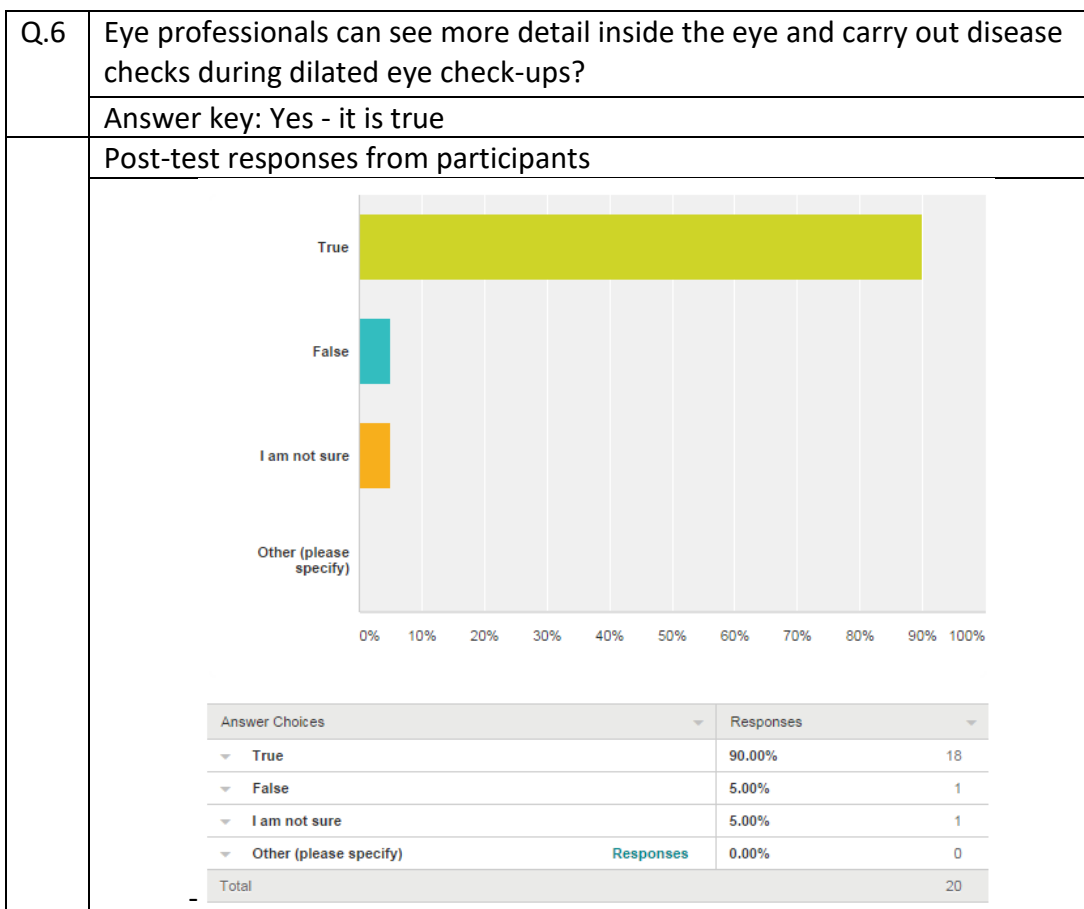
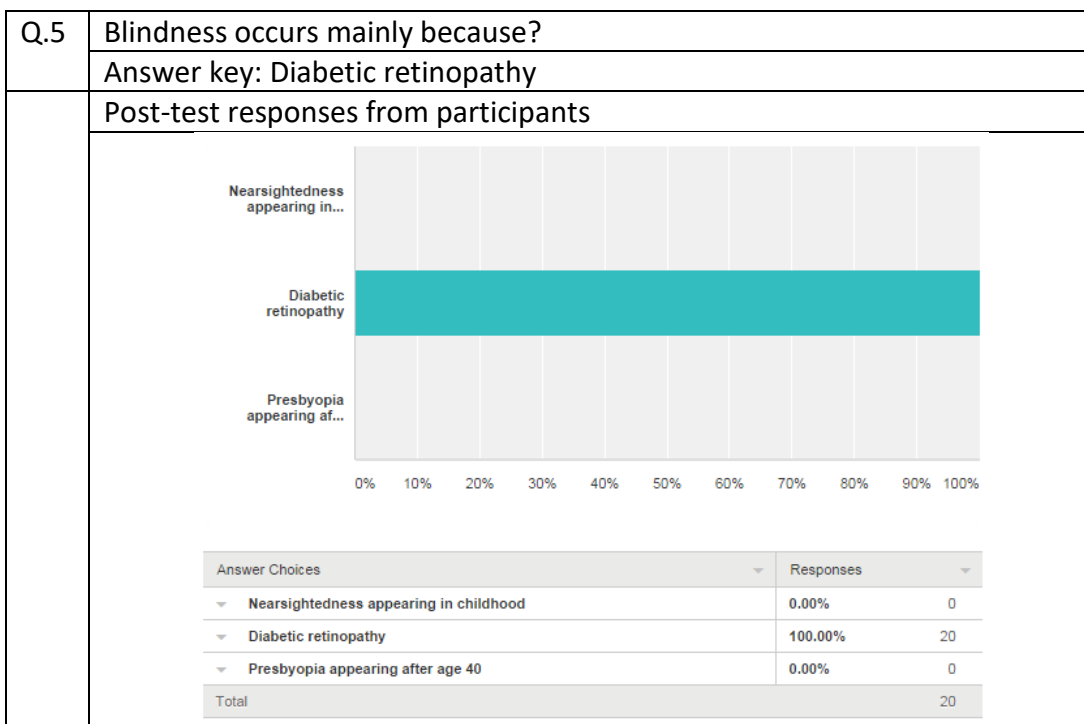
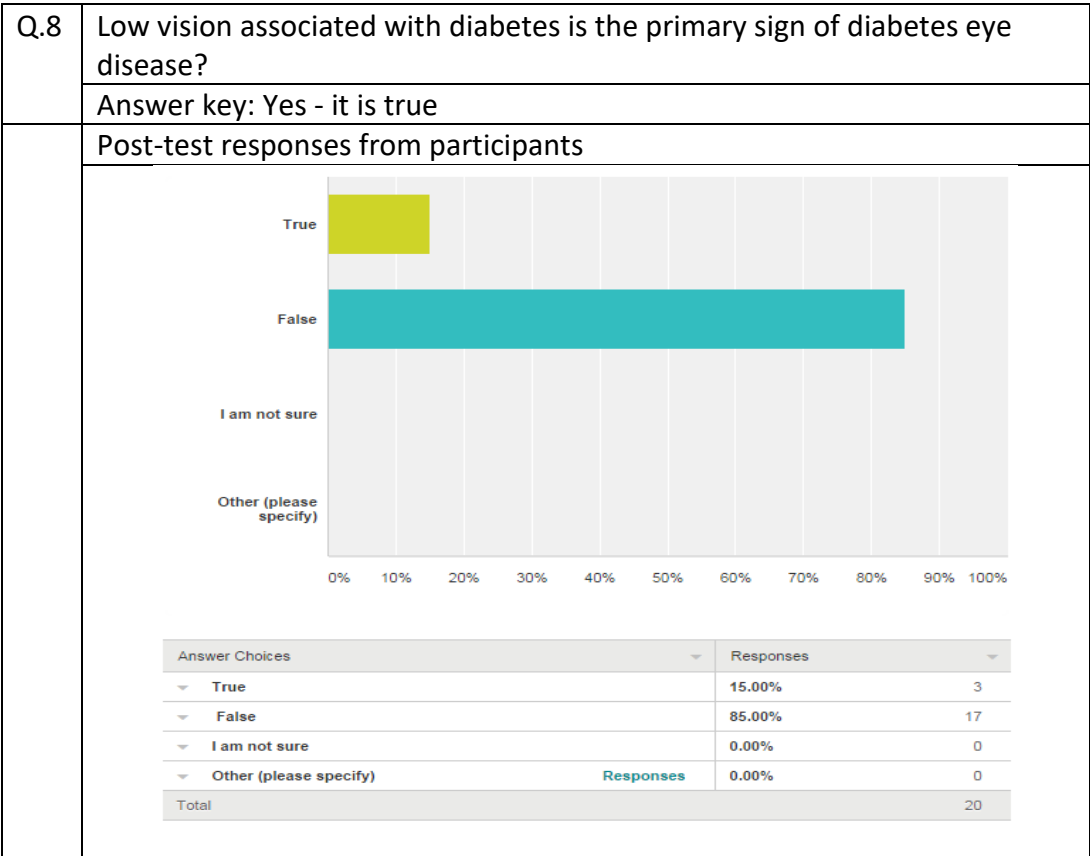
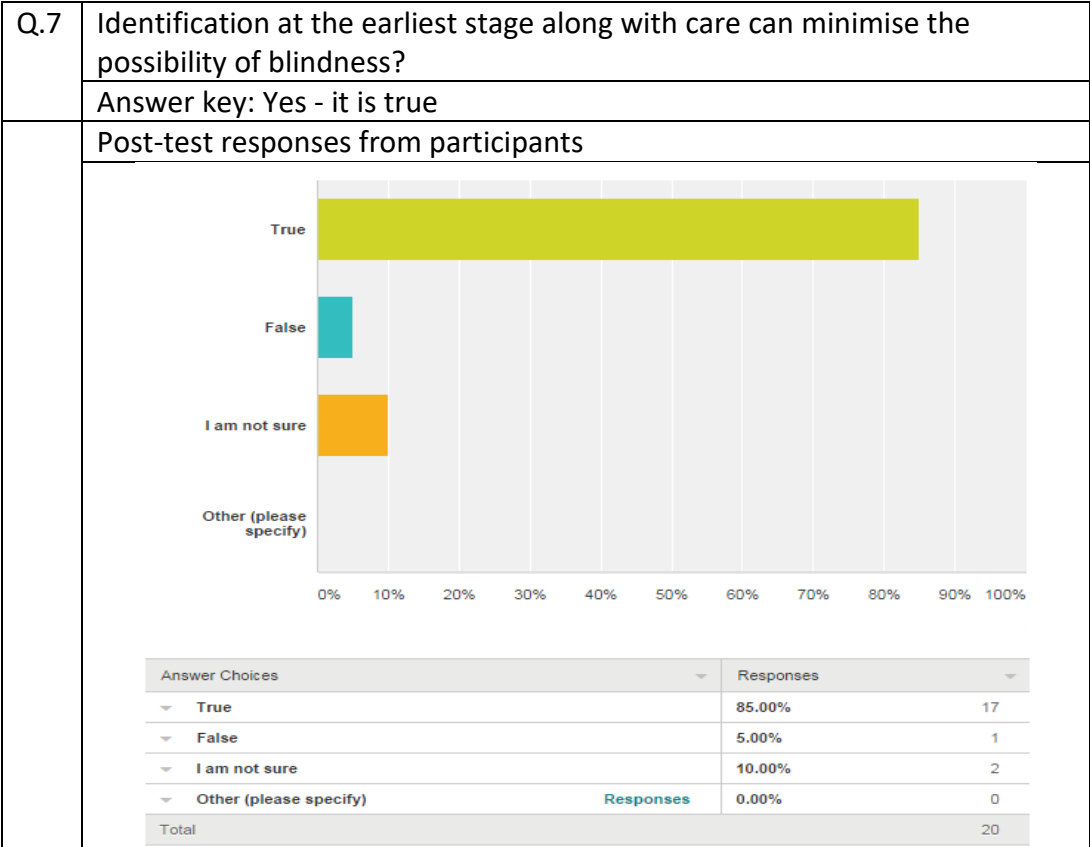


Figure 45 to 54 (Post-test responses from participants)









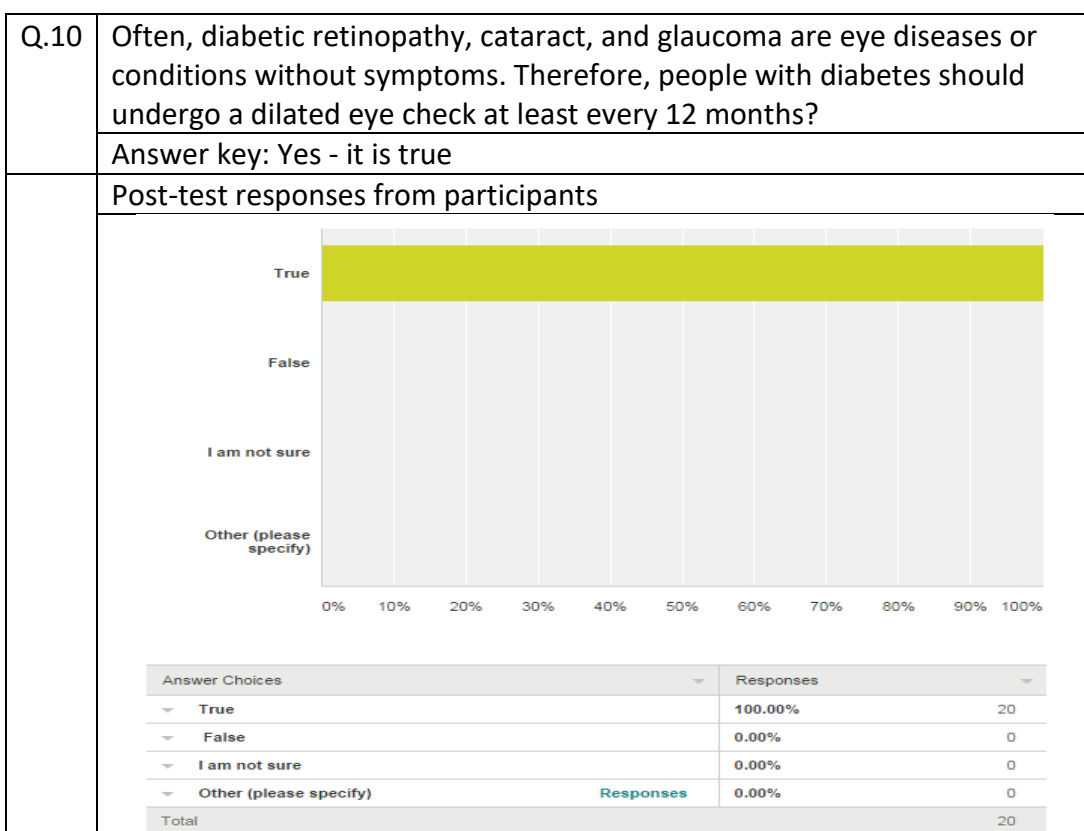
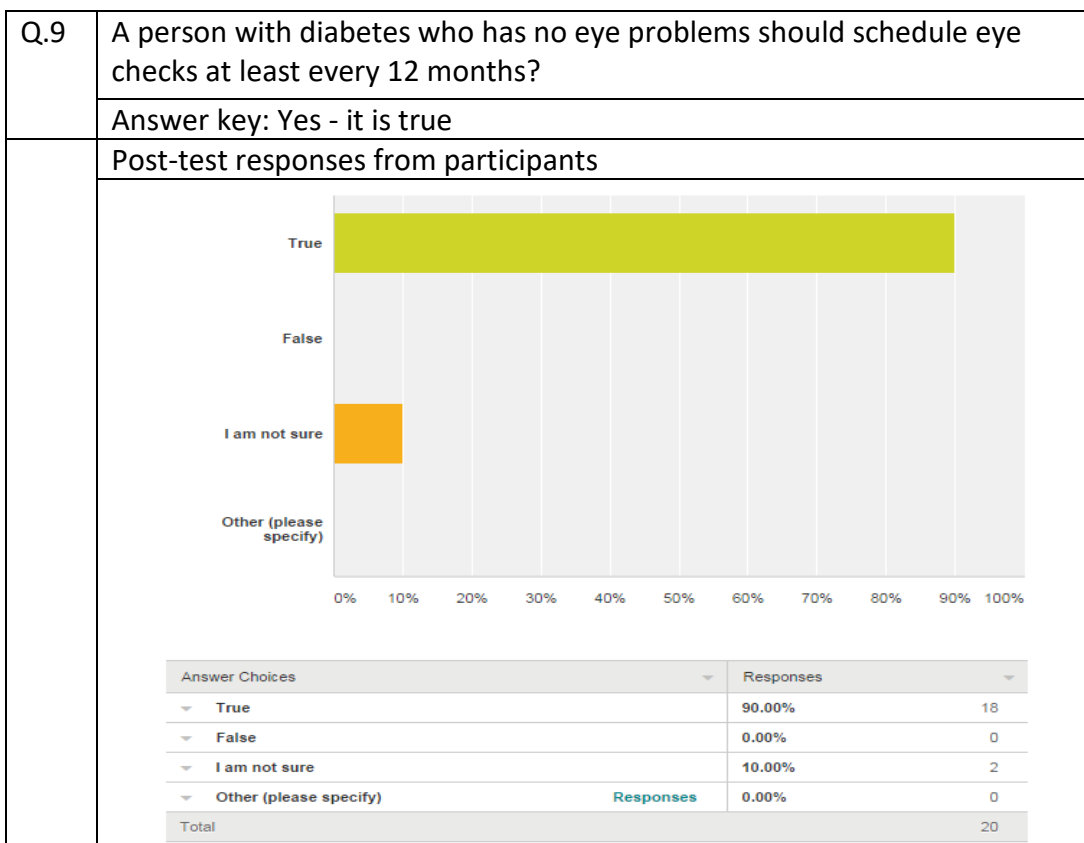
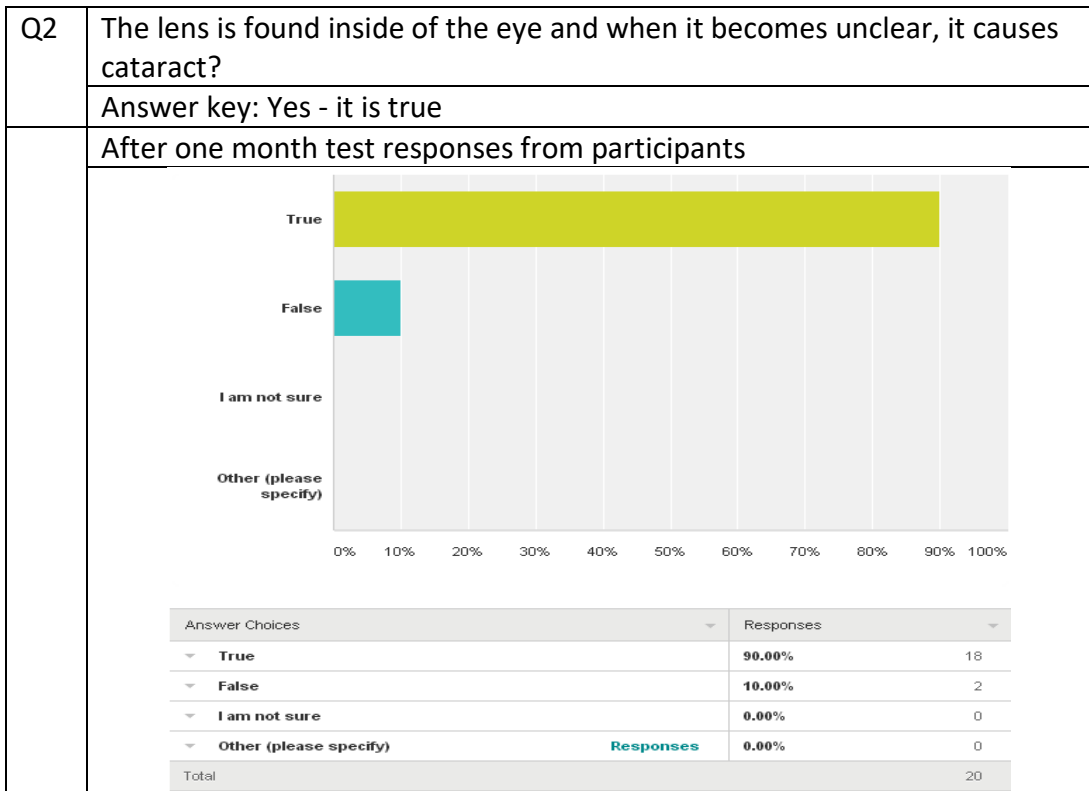
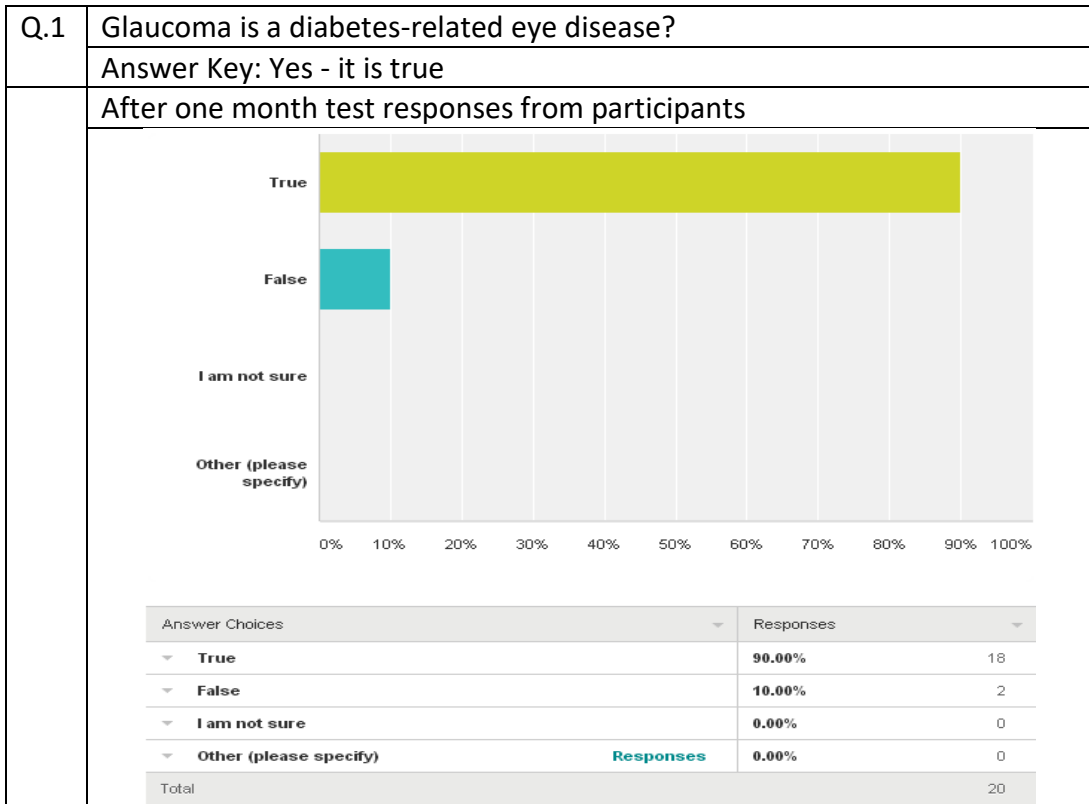
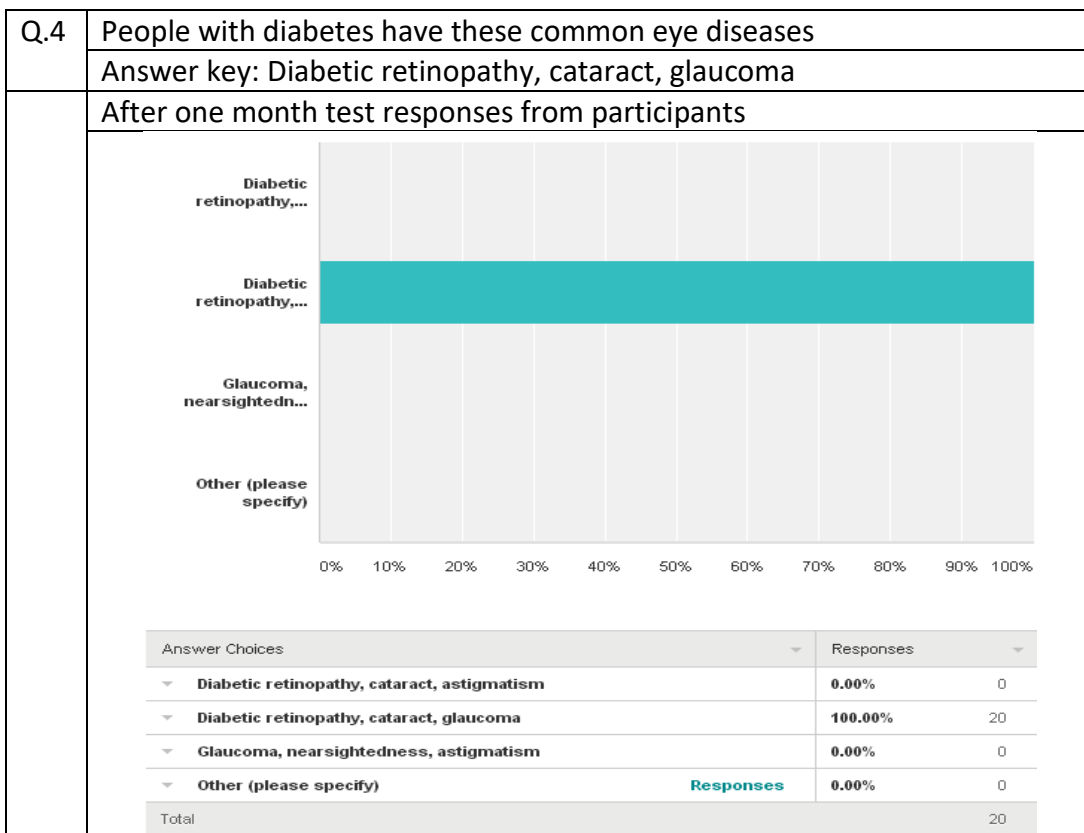
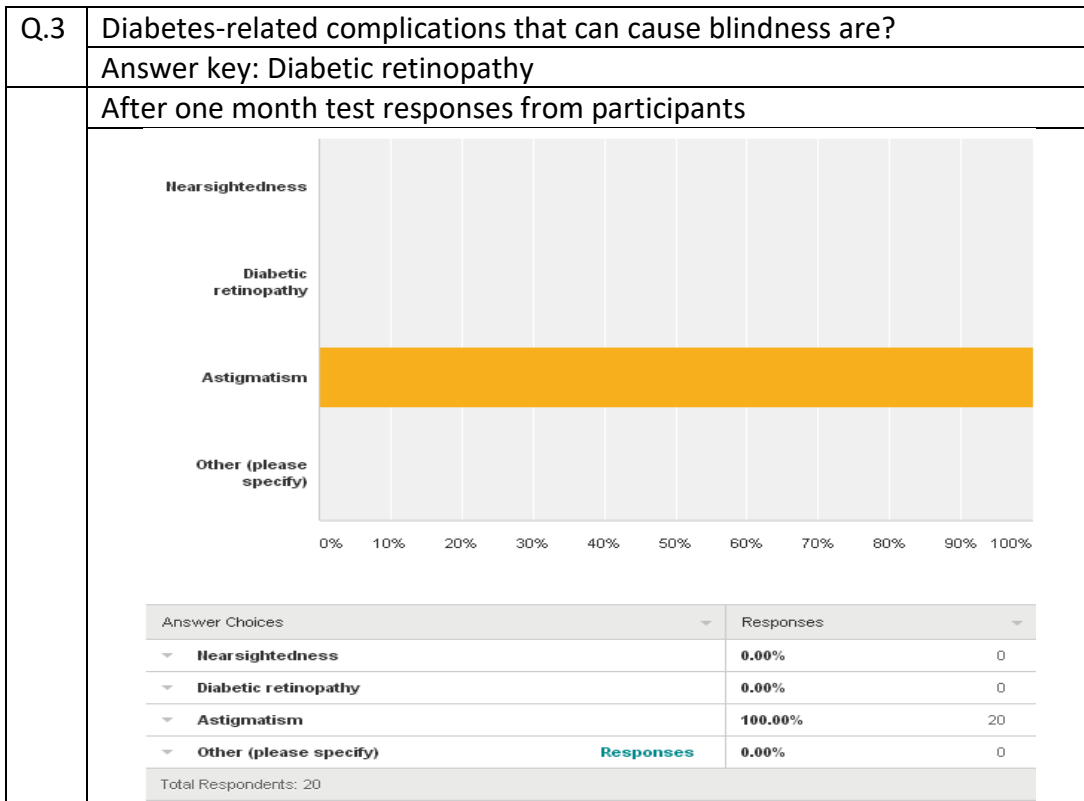
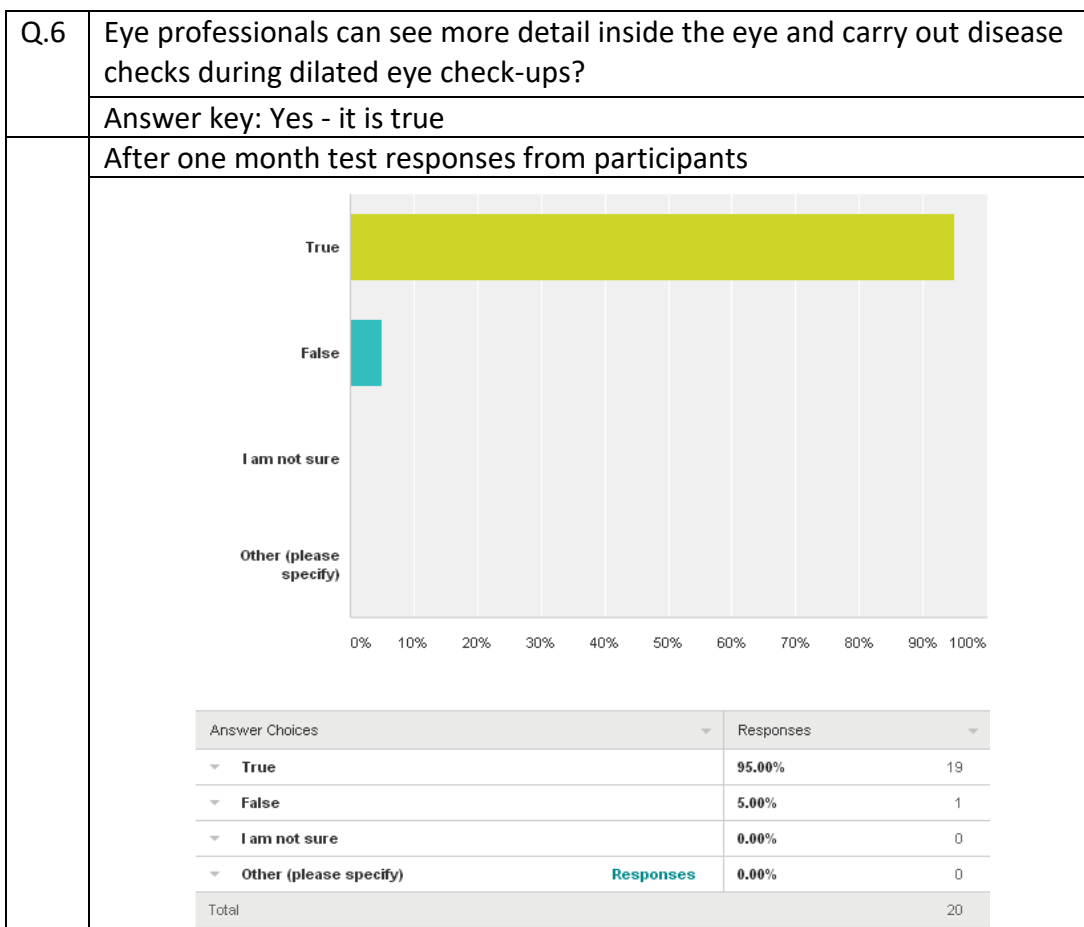
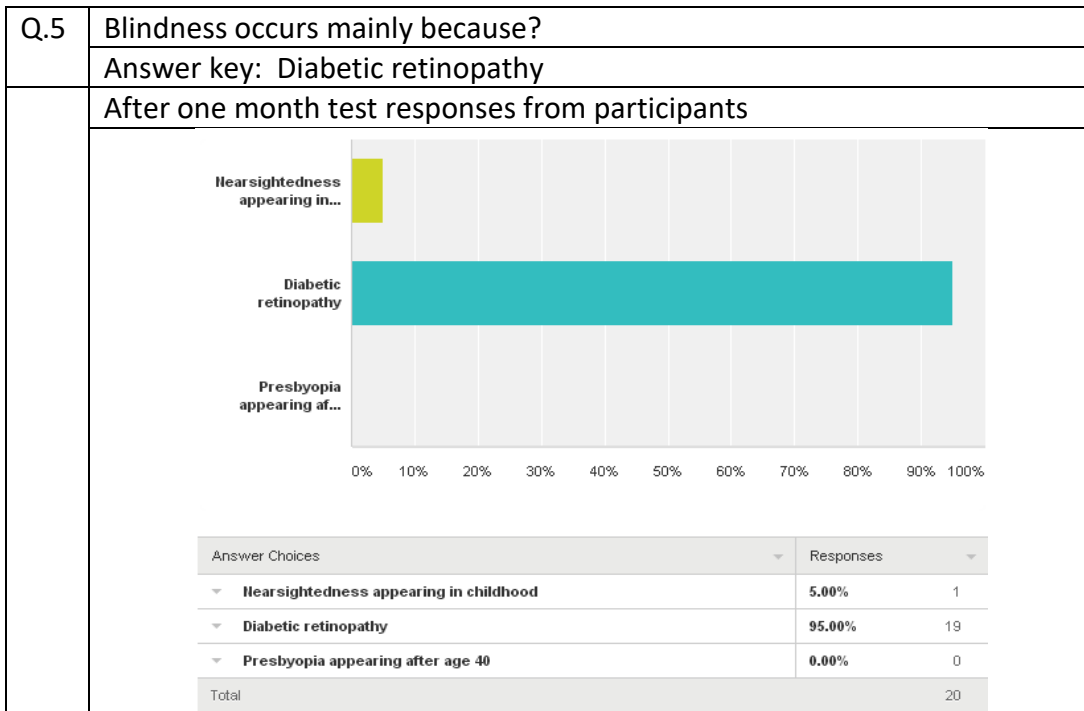
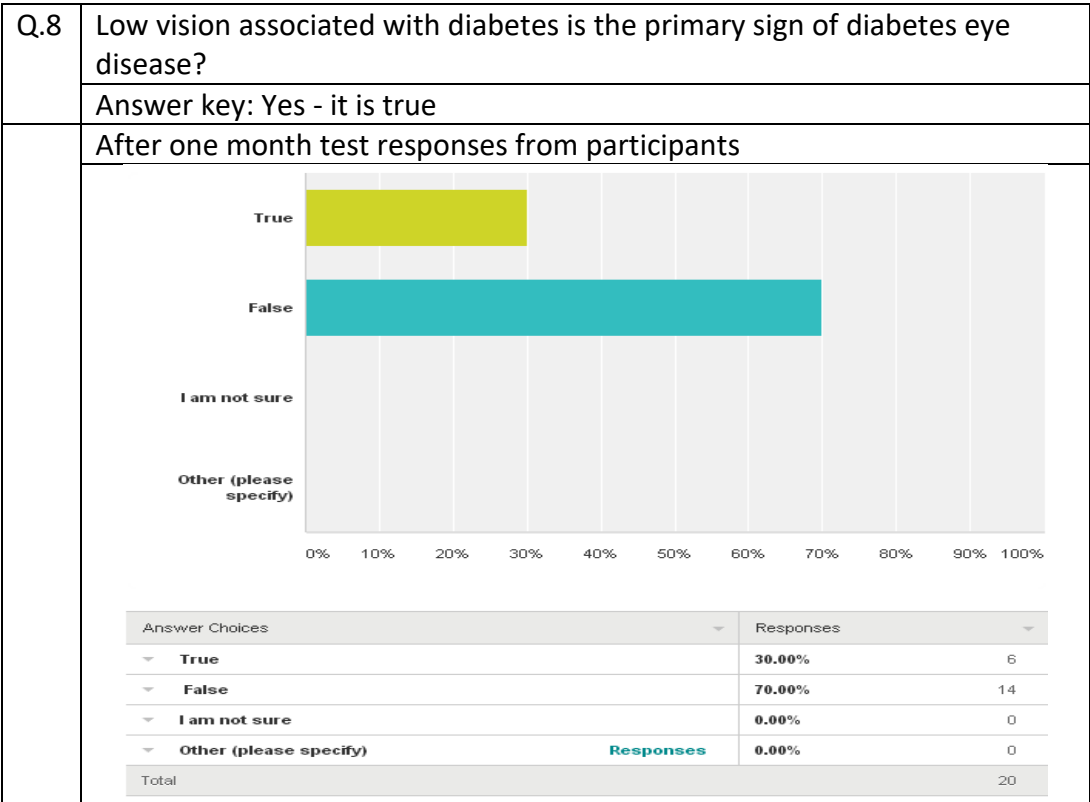
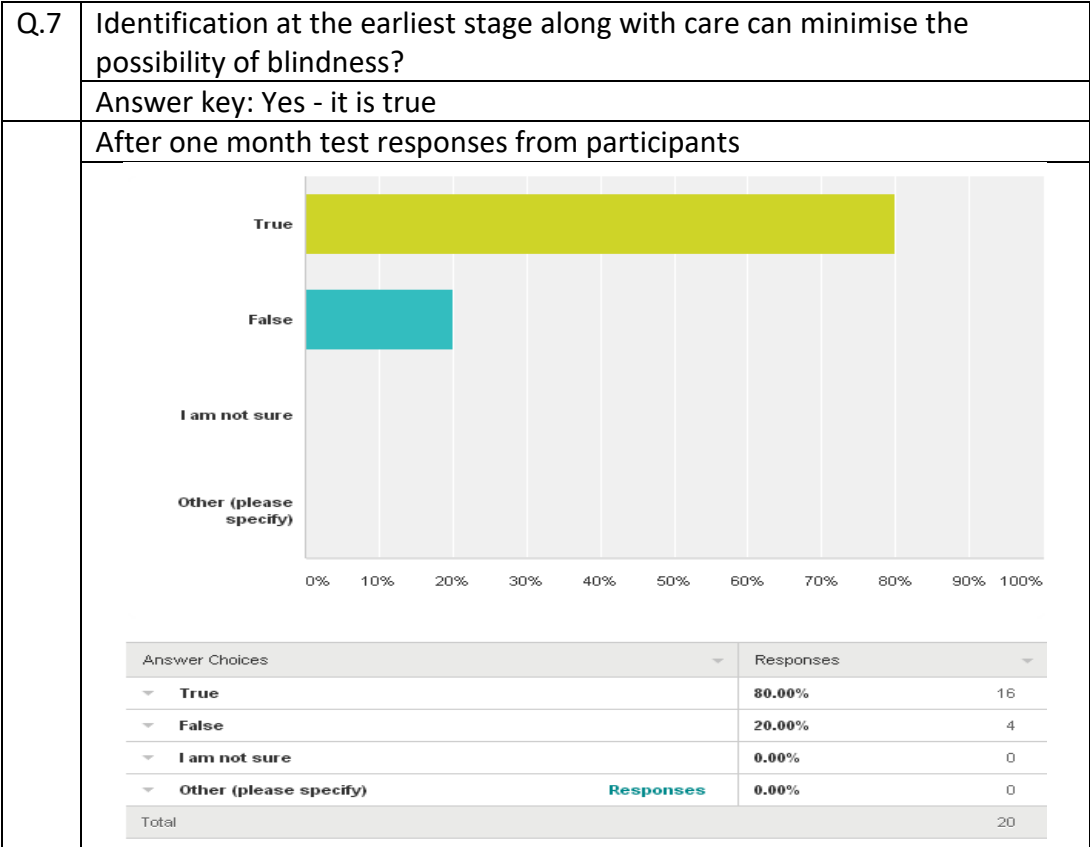


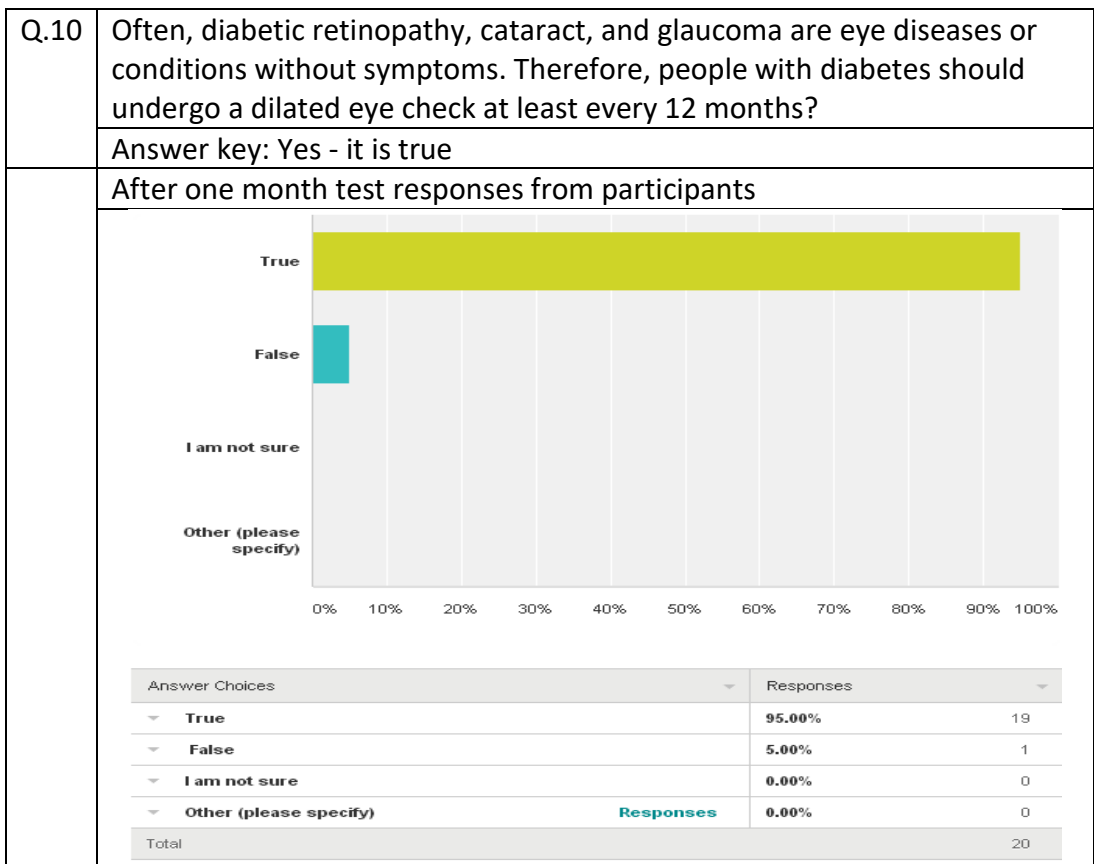
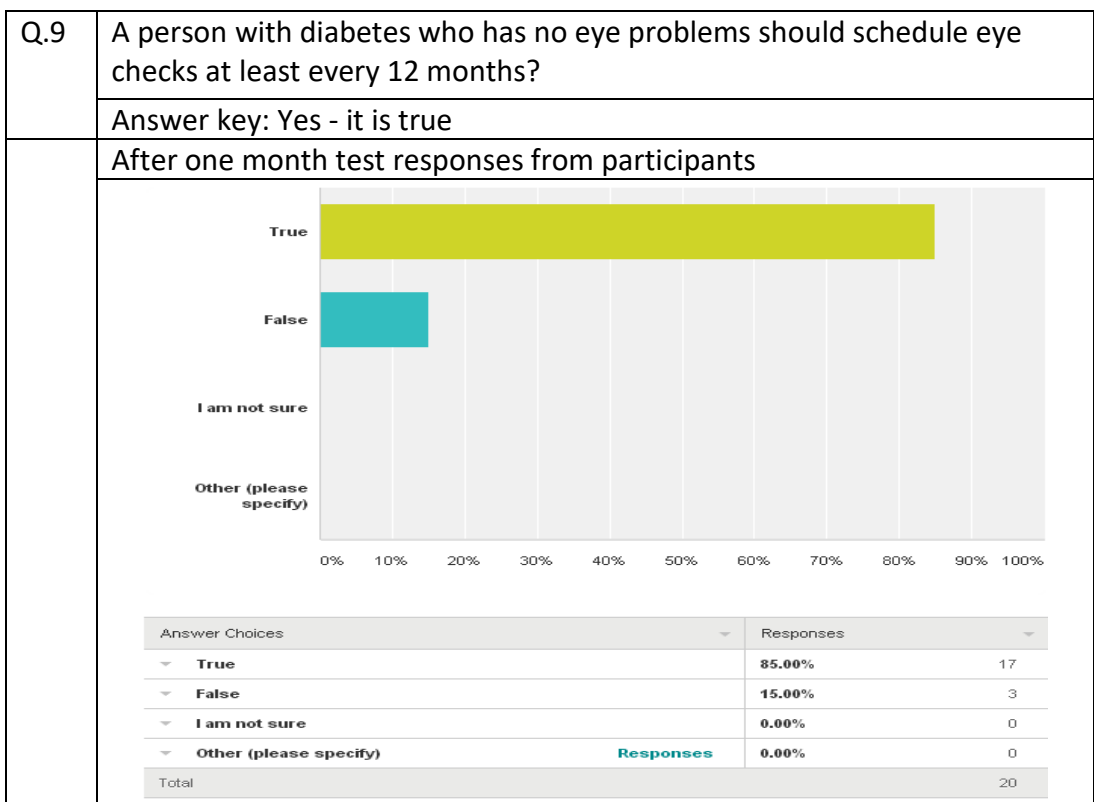
Figure 55 to 64 (After one month test responses from participants)











Certificate of attendance



CERTIFICATE OF ATTENDANCE

This is to certify that

ATTENDED TRAINING ON

LOW VISION AND DIABETES IN OLDER PEOPLE

Signature of trainer

Date

Low vision and diabetes toolkit

1



Welcome to low vision & diabetes education toolkit course

Developed by:

Principal Researcher: Nizam Muhammad Darwesh
(PhD Researcher)

Director of study: Professor Alan Sinclair MSc MD FRCP
Dean & Professor of Medicine Bedfordshire and Hertfordshire
Postgraduate Medical School University of Bedfordshire



Second supervisor: Professor Peter Scanlon
MD FRCP DCH DRCOG DO FRCOphth PG Cert.
Consultant Ophthalmologist, Oxford Eye Hospital

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www.instituteofdiabetes.org

2

INTRODUCTION

This educational toolkit is part of the PhD thesis on older people with low vision and diabetes living in residential care homes. It is the outcome of the data collected from In-depth interviews, focus groups and health professionals' survey with GPs, nurses, HCAs, ophthalmologists and optometrists including older people with low vision and diabetes.

This educational toolkit has been designed to give you useful information about eye diseases associated with diabetes, such as diabetic retinopathy, cataracts, and glaucoma. If you have diabetes or care for people with diabetes it will give you advice and will answer some commonly asked questions that you may have. This educational toolkit consists of resources to help and to educate health care assistants about eye diseases associated with diabetes.



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Objective

No	Focus	Objective
1	Education	To educate health care assistants about eye diseases and complications associated with diabetes.
2	Awareness	To raise awareness of all the serious eye complications and problems linked to diabetes, such as diabetic retinopathy, cataracts, glaucoma, low vision and blindness in older people. It will help health care assistants to understand the importance of diabetes controls and eye examinations, by early diagnosis and prompt treatment, as well as reducing the risk of diabetes complications.
3	Prevention	To reduce the incidence of all types of diabetes, diabetic retinopathy, cataracts, glaucoma, low vision and blindness in older people.



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Units of the low vision & diabetes education toolkit course

The toolkit course consists of Five Units:

- ⊙ Unit 1: Diabetes
- ⊙ Unit 2: Low vision
- ⊙ Unit 3: Eye diseases associated with diabetes
- ⊙ Unit 4: How to control low vision and diabetes
- ⊙ Unit 5: Check your knowledge



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Before we go to the units do you know?
Diabetes: A global emergency

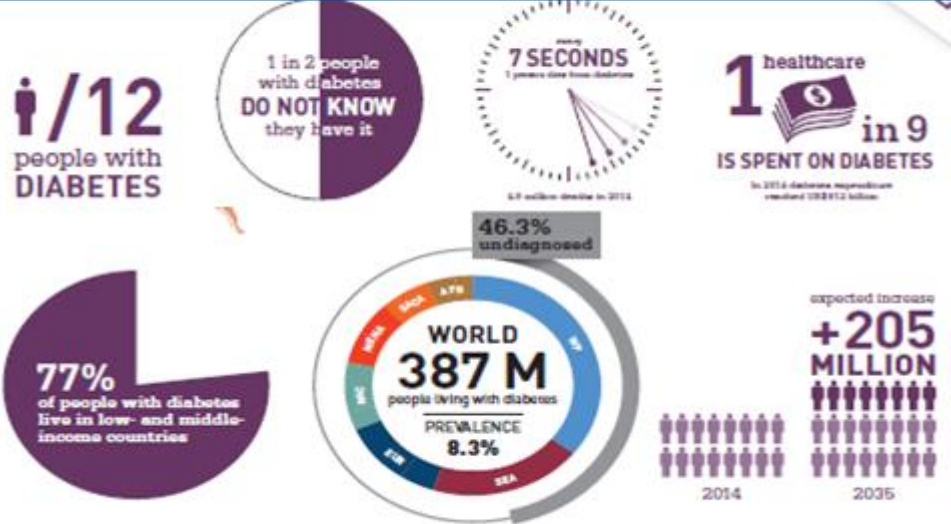
DIABETES ATLAS 7th edition (IDF www.idf.org/diabetesatlas)

Estimated number of people with diabetes worldwide and per region in 2015 and 2040 (20-79 years)



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Do you know
 (IDF www.idf.org/diabetesatlas)



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do you know?

- ⦿ According to NICE, currently there are around 12,800 registered residential care homes in England and up to 450,000 older people are living in these residential care homes (NICE, 2015).
- ⦿ Approximately two million people are affected by low vision in the UK, and the majority are older people (Bosanquet and Mehta, 2008; HSCIC, 2015).
- ⦿ At age 75, one in five and at age over 90, one in two people are affected by low vision in the UK (RNIB, 2015).
- ⦿ About half these eye conditions are treatable in older people (Charles et al., 2007; National Eye Institute, 2015).



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Do you know

- ⦿ Diabetes is the leading cause of blindness in working age people in the UK (Arun CS et al., 2003; RNIB, 2013).
- ⦿ Up to one in four care home residents may present with diabetes (Sinclair et al., 2010).
- ⦿ It is estimated that there are 4,200 people in England who are blind due to diabetic retinopathy. This increases by 1,280 each year (Scanlon PH et al., 2008).
- ⦿ Within 20 years of diagnosis nearly all people with Type 1 and almost two thirds of people with Type 2 diabetes (60 per cent) have some degree of retinopathy (Scanlon PH et al., 2008; UK Vision Strategy, 2015).



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low vision & diabetes education toolkit

Unit 1: Diabetes

What is diabetes?

This is a lifelong condition which can be characterised by elevated levels of glucose in the blood, which leads to the body not being able to metabolise glucose effectively. Glucose is present as a result of starchy food digestion. Glucose sources include bread, potatoes and rice as well as sweets. The liver produces glucose, from where it passes directly into the blood stream. Diabetes can be described as a metabolic disorder which is caused by a deficiency of the hormone insulin, which is normally secreted by the pancreatic beta cells (Rosenbloom et al., 2008). The hormone is responsible for the uptake of glucose from the blood, mainly into muscle and fat cells of the body as well as inhibiting hepatic glucose production. Therefore insulin regulates the concentration of blood glucose at natural levels of 4-6 mmol/l (Kumar and Clark, 2007). Failure to treat diabetes can lead to the development of problems and can harm both small and large blood vessels. Diabetes frequently affects the eyes, kidneys and feet. Diabetic people also have an increased risk of heart disease and circulatory problems including ulcers and pressure sores (Kumar and Clark, 2007; Diabetes UK, 2015).

Unit 1: Diabetes

Symptoms of Diabetes

Both types of diabetes have similar symptoms; however, Type 1 diabetes is more rapid and can surface within days or weeks. Symptoms include polyuria, polydipsia, and polyphagia; however, there are more unknown effects such as weight loss, skin infection, cramps, blurred vision and fatigue, (Kumar, Clark, 2007; Song, Hardisty, 2008; Ahmed, 2010).

Diabetes is most commonly diagnosed after the presentation of conditions such as leg ulcers or problems with vision. The long term complications associated with diabetes are classified as macro vascular, micro vascular and nephropathic and cause different dysfunctions. These complications are the major causes of morbidity and mortality in diabetics (Kumar, Clark, 2007; Song, Hardisty, 2008; Ahmed, 2010).

Unit 1: Diabetes

CLASSIFICATION OF DIABETES

- In 1985, The World Health Organisation (WHO) classified diabetes into the two most common types, insulin dependent and non-insulin dependent. Furthermore, depending on the nutritional status, the WHO categorized diabetes into other types such as malnutrition-related diabetes, which is now excluded from the new categorization due to its unknown aetiology, and gestational diabetes, which is diagnosed during pregnancy.
- **Type 1** is often described as insulin dependent or early onset diabetes, which is diagnosed during childhood and accounts for approximately 5-10-percent of diabetes. Type 1 is caused by autoimmune damage of pancreatic β cells in islets of Langerhans leading to a reduction in insulin production. Insulin can be described as the hormone which allows the admittance glucose into the cells. Type 1 is commonly associated with micro vascular problems, including nephropathy, retinopathy, and also predisposes to coronary heart disease (Adler *et al.*, 2003).
- **Type 2** is often described as non-insulin dependent. Type 2 diabetes usually occurs later on in adult life at roughly 40 years of age. It is due to a combination of factors including faulty secretion of insulin by pancreatic β cells, deficiency of insulin and insulin resistance (mediated glucose disposal). (Kumar and Clark, 2007; DSouza *et al.*, 2009; Ripsin *et al.*, 2009; Ahmed, 2010).

HYPOGLYCAEMIA

Hypoglycaemia

This occurs due to low blood glucose levels. The term Hypoglycaemia is also known as 'Hypo', meaning low. The standard levels of blood glucose are generally between 4.0 mmol/l and 6.5 mmol/l. If the levels fall below 4.0mm/l then hypo will occur (Kumar and Clark, 2007). It is most commonly caused by overdosing of medication, disproportionate exogenous insulin, or vigorous exercise. Sometimes it may even lead to seizures, coma and irreversible brain death as blood glucose regulates the functioning of the body such as the organs, the brain and also vision. Symptoms as a result of hypoglycaemia include irritability, sweating, tingling lips, weakness, hunger, and nausea (Kumar and Clark, 2007; Ahmed, 2010).

Hypoglycaemia treatment: If possible check blood sugar, drink sugary juices or eat sweets. If the condition has not improved in 5 to 10 minutes, then repeat this treatment; in the meantime take advice from health professionals.

HYPERGLYCAEMIA

Hyperglycaemia: means high blood glucose level in the body and when the body is effectively unable to use this glucose. This results in high glucose levels in the blood. For persons with diabetes, glucose is not turned into energy mainly because insulin produced in the body is not used effectively or there is not enough insulin in the first place. If the glucose level is above 10mmol/litre on an empty stomach, then hyperglycaemia occurs. Hyperglycaemia occurs due to an increase in blood glucose levels. It is caused by numerous factors including non-compliance to medications or exogenous insulin, or a lack of control of diet and exercise. Hyperglycaemia may also occur as a result of autoimmune damage of β -cells of the pancreas. Symptoms include increased thirst and urination, blurred vision, lethargy, weight loss, cramps, dehydration and headaches. A lack of insulin also releases ketones into the blood which in turn raises the acidity of the blood, leading to a state called ketoacidosis. Both hypo and hyperglycemia are reversible and can be treated (Kumar and Clark, 2007; D Souza *et al*, 2009; Ahmed, 2010; Diabetes UK, 2015).

Hyperglycaemia treatment

- Medication should be taken at the correct time and correct dosage
- Carry out regular exercise and monitor blood glucose levels
- Do not eat unhealthy foods.



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HbA1c

What does HbA1c (Glycated Haemoglobin) mean?

Blood contains haemoglobin. Haemoglobin particles live for at least 3 months in the blood and when these particles die, they get removed from the blood flow via the spleen. During their life cycle, glucose particles will attract and join them. Higher levels of glucose in your blood will result in more glucose particles joining the haemoglobin particles. When the health professionals send the blood samples to the lab for HbA1c testing, checks will be carried out to see how many glucose particles are stuck to the haemoglobin particles. The results from the lab will show how much glucose has been flowing in the blood during the last 3 months. According to (Kumar and Clark, 2007; D Souza *et al*, 2009; Ahmed, 2010; Diabetes UK, 2015), basic guidelines of HbA1c are:

- 6.5% IDEAL CONTROL
- 7% REASONABLE CONTROL
- 7% - 8% or above POOR CONTROL.



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DIABETES RISK FACTORS

- **Risk factors of diabetes**

Genetic factors, Type 1 diabetes: The risk of developing type 1 diabetes among those with family history is about 15 times higher than in the general population; if both parents have diabetes, the percentage will increase up to 30%. (IDF, 2014; Diabetes UK, 2015). **Type 2 diabetes:** people with a family history of diabetes are 2 to 6 times more at risk of having diabetes than people with no family history of diabetes (Vaxillaire and Froguel, 2010; Diabetes UK, 2015).

Ethnic groups and diabetes: White community 1.7; all ethnic minorities 5.7: African Caribbean 5.3; all South Asians 6.2; Indian or African Asian 4.7; Pakistani or Bangladeshi 8.9; and Chinese 3.0 (Winkley et al., 2013).

Obesity is playing a major part in increasing the risk with an 80-85% risk of developing Type 2 diabetes as insulin sensitivity is reduced (Hauner, Cockram and Flyvbjerg, 2010; Chilcott et al., 2011).

Lifestyle, lack of physical activity, unhealthy food, obesity and smoking: all these are risk factors of diabetes (Sinclair, 2010; Diabetes UK, 2015; HSCIC, 2015).



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Congratulations

Congratulations! You have completed Unit 1. Now we will move on to Unit 2: Discovering low vision.

In this Unit, you will learn about low vision.



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low vision & diabetes education toolkit Unit 2 Low vision

What is Low Vision?

Low vision or visual impairment can be considered to be a clinical condition (Barbara, 2010). The quality of daily life can be affected by low vision, such as day-to-day tasks including recognising people's faces, reading, watching television, walking, and writing. Low vision is described as a drastic reduction in the eye's sight (Jessica Watson, 2012); however, not complete blindness. Low vision can occur when the eye is unable to function adequately (Haddrill, 2007). Visual function itself can be measured through distance visual acuity, and is conducted through the use of a letter eye chart at a specific distance. Visual acuity (VA) of 20/20 or 6/6 is considered as healthy vision (WHO, 2006), meaning people can see up to six metres (or 20 feet). Patients are typically required to read letters from an eye chart. Generally, as the sight of an individual declines, fewer letters can be read from the chart, which leads to an increase in the second number, i.e. 6/36.



Unit 2 Low vision

Logmar Eye Chart 1 (Scottish Sensory Centre, 2008)

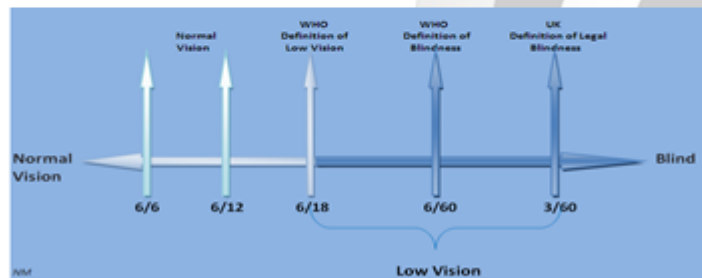


Unit 2 Low vision

Definition of Low Vision : WHO describes low vision in the following way:

Epidemiological: "Low vision is defined by measures of visual acuity and/or visual field as follows: visual acuity less than 6/18 (20/60) and equal to or better than 3/60 in the better eye with the best correction or visual fields less than 20 degrees in diameter" (WHO, 2006).

Service provision: "Low vision is defined in functional terms: a person who has impairment of visual functioning even after treatment and/or standard refractive correction, and has a visual acuity of less than 6/18 to light perception, or a visual field less than 10 degrees from the point of fixation, but who uses, or is potentially able to use, vision for the planning and/or execution of a task" (WHO, 2006)



Unit 2 Low vision

Low Vision and Daily Practical Challenges:

- An individual with restricted distance vision may face challenges in:
 - Understanding non-verbal communication, learning by imitation;
 - Incorporating general senses including visual, auditory, and gustatory;
 - Limited movement such as trying to avoid obstructions or avoiding moving vehicles;
 - Recognition of people, objects and actions.
- An individual with poor near vision may face challenges in:
 - Using insulin or filling insulin syringes;
 - Testing blood sugar levels;
 - Personal care and hygiene, preparation and consumption of food, dressing independently, and reading books.

Unit 2 Low vision

- An individual with restricted visual fields may face challenges in:
 - Discovering items;
 - Vision in low light;
 - Independent movement;
- How low vision can effect mobility:

Vision loss can impact on an individual's overall movement such as day to day activities, and as a result this affects an individual's overall independence. Features of vision that disturb movement involve:

- Reduced lighting;
- Changes to lighting/ different shades of light;
- New places or areas;
- Congested circumstances;
- Visually multifaceted surroundings; for example supermarkets, or a high risk of falling, thus increasing the possibility of hip fractures.

Unit 2 Low vision

- Is low vision a normal change process related to age?
- Not all, but some natural changes to the eye can occur as we progress through life. However not all these changes will lead to a change in vision. Generally, people with ARMD, glaucoma, DR and cataracts will develop low vision; eye health professionals such as an optometrist can usually identify natural changes to the eye compared to those caused by a disease.
- Normal Changes in the Aging Eye
- Presbyopia is considered to be a frequently diagnosed age related vision condition which occurs in a large proportion of the population aged over 50. As the eye ages, the lens starts to lose flexibility, and consequently it becomes more difficult to focus the vision on objects close to the eye, for example, activities such as reading or even basic socialising such as using the numbers on a phone. Presbyopia is easily rectified through the use of reading spectacles or bifocal spectacles.
- Declining Sensitivity
- As the eye ages, it becomes more and more dense and often takes on a yellow colour. The change in density and colour can lead to changes in colour perception and sensitivity to contrast. For example, objects that are blue in colour may look to be darker; or it may be difficult to identify the colour from similar colours such as black. Furthermore, the changes in density and colour can mean that an individual is unable to distinguish between where an item starts, and where it ends. Consequently, the eye needs more light, so the pupil gets smaller, along with taking extra time to correct to varying levels of light (for example, going from daylight into a dark theatre).

Congratulations

Congratulations! You have completed Unit 2. Now we shall move on to Unit 3: Discovering diabetic eye disease. In this Unit, you will learn about how in older people, the diabetic eye loses vision.



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Unit 3: Diabetic eye disease

How, in older people, the diabetic eye loses vision:

The leading causes of low vision in older people are diabetic retinopathy, age-related macular degeneration, cataracts and glaucoma (Bounce and Wormald et al., 2006; Diabetes UK, 2015; National Eye Institute, 2015).



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UNIT 3 DIABETIC EYE DISEASE

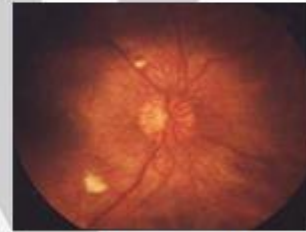
Diabetic retinopathy (DR): diabetic retinopathy is a very serious eye problem associated with diabetes that can take several forms. One form is retinal swelling, or macular oedema. Macular oedema occurs when the small blood vessels in the eye are damaged, which allows fluids to enter the retina, resulting in swelling. Diabetic retinopathy occurs when a haemorrhage from fragile blood vessels leaks into the vitreous (RNIB, 2015; National Eye Institute, 2015).



Normal vision.



Same scene viewed by a person with diabetic retinopathy.



Diabetic retinopathy



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UNIT 3 DIABETIC EYE DISEASE

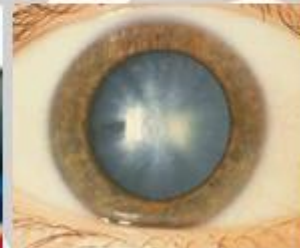
Cataract: when the normal lens in the eye appears cloudy, this condition is called a cataract. Signs of cataracts include: blurry vision, colours appear dull and an inability to see at night. The risk of developing cataracts in people with diabetes is up to three times higher compared to healthy people (Mukesh et al., 2006; RNIB, 2015; National Eye Institute, 2015).



Normal vision.



Same scene viewed by a person with cataract.



Cataract



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UNIT 3 DIABETIC EYE DISEASE

Glaucoma: initially, there are no warning signs or symptoms of glaucoma, but, if not treated early, there is a high risk of blindness. Increased eye pressure is a common cause of glaucoma, however, in some cases glaucoma will occur with normal eye pressure (RNIB, 2015). The risk of developing glaucoma in people with diabetes and high blood pressure is 50% higher compared to healthy people, (Newman et al., 2011). People over the age of 40 with diabetes and glaucoma history in the family, are at a higher risk of getting open-angle glaucoma including neovascular glaucoma (the nerve will grow in the cornea resulting in blindness) RNIB, 2015). The damage caused to the eye by glaucoma cannot be reversed, but early diagnosis can help to prevent blindness.(RNIB, 2015; National Eye Institute, 2015).



Normal vision.



Same scene viewed by a person with glaucoma.



Glaucoma



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UNIT 3 DIABETIC EYE DISEASE

Age-related Macular Degeneration (AMD): according to the Macular Society UK, this is a common problem within older individuals (Macular Society, 2015). "It is caused by progressive damage to the macula, which is the central part of the retina. AMD can be divided into two parts, either wet or dry; wet AMD is the more destructive and can severely impact visual function" (Redmond and While, 2008). AMD sufferers have reported a decrease in central vision, thus affecting mobility, physical activity and their overall quality of life (Hassell, Weih and Keeffe, 2000; Klein et al., 2003; RNIB, 2015; National Eye Institute, 2015).



The images above show the 3 stages of ARMD



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UNIT 3 DIABETIC EYE DISEASE

What can diabetic people do to minimise the risk of eye damage?

People with diabetes should have regular eye check-ups, at least once every 12 months, to identify any eye diseases which are at an early stage.

- Control your diabetes and adopt a healthy life style;
- Educate yourself regarding your condition;
- Maintain good glucose levels;
- Inform health professionals immediately if you experience eye vision problems.

CONGRATULATIONS

Congratulations! You have completed Unit 3. Now we shall move on to Unit 4: How to control low vision and diabetes.

In this Unit you will learn how to control low vision and diabetes.

low vision & diabetes education toolkit course

Unit 4: How to control low vision and diabetes

A1C test: An A1C test should be given at least twice a year. A1C refers to the lab blood test for haemoglobin A1C. Haemoglobin A1C should be under 7, to indicate good control. The A1C test shows if glucose control maintenance is being adequately carried out.

Blood pressure: Blood pressure must be taken during each medical visit. Indications and medical recommendations are very important, including having blood pressure measurement taken and a urine test to observe the presence of glucose or the protein albumin in the urine.

Cholesterol and lipids: These lab tests should be done once a year. If cholesterol is higher than 200 mg/dL, then a person has a major risk of developing cardiovascular complications. This risk may be reduced by a diet low in fat and/or with medication.

Diabetes education: Basic courses for low vision and diabetes are important; everyone needs on-going education in nutrition management, self-monitoring, and the prevention of complications.

Eye examinations: People with diabetes need to have eye examinations at least every 12 months or more frequently if their eye care professional has diagnosed an eye complication.

Unit 4: How to control low vision and diabetes

⊙ **Glucometer:**

- Use a glucometer frequently. Learning how to use the glucometer is very important; every person with diabetes should learn how to use the glucometer.

⊙ **Remember:**

- Check blood sugar each and every day or as advised by your GP;
- Any form of regular exercise can help maintain good body weight and health;
- Take your medication as instructed by your GP.

Unit 4: How to control low vision and diabetes & some commonly asked questions

Frequently asked Questions

Which eye problem has affected the highest number of individuals with diabetes?

The most common condition of the eye is diabetic retinopathy (DR) which affects just under half of Type 1 diabetics, and 20% of patients with Type 2 diabetes.

Who has the highest risk of diabetic retinopathy?

All people with diabetes have a high risk of getting diabetic retinopathy.

How is diabetic retinopathy diagnosed?

Regular check-ups through dilated eye tests can enable eye health professionals to diagnose this condition.

Is diabetic retinopathy treatable?

Yes, it is treatable via laser surgery and regular check-ups; however full eye sight may not be restored if already lost.

Is laser treatment safe for the eye?

Laser treatment may have an effect on your colour vision and night vision.



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Unit 4: How to control low vision and diabetes & some commonly asked questions

Is it possible to prevent diabetic retinopathy?

Not completely, but the risk can be minimised. Much of the research shows that the control of blood sugar levels can reduce the effects of diabetic retinopathy.

What are the common eye diseases associated with diabetes?

People with diabetes can be at risk of being affected by the following diseases:

- Cataracts;
- Glaucoma;
- Diabetic retinopathy.

How can people with diabetes reduce the danger of becoming blind?

People with diabetes can reduce the danger of becoming blind in the following ways:

- Control blood sugars, particularly if suffering from eye disease;
- Regular eye examinations and expert advice.



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Congratulations

Congratulations! You have completed Unit 4. Now we shall move on to Unit 5: To check your knowledge. After completing this Unit, you will have learned about low vision and diabetes.

Good luck with your assessment.



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Unit 5: To Check your knowledge Question 1

Glaucoma is a diabetes-related eye disease.

True

False

I am not sure

Other, please
specify



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Answer

True (Glaucoma)



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Unit 5: To Check your knowledge.
Question 2

The lens is found inside the eye; when it becomes unclear, it causes cataract.

True

False

I am not sure

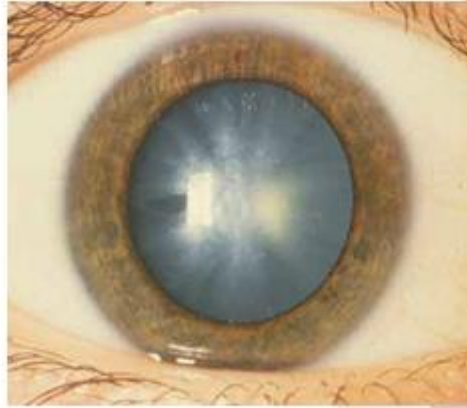
Other, please specify



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Answer

True (Cataract)



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Unit 5: To Check your knowledge
Question 3

A diabetes-related complication that can cause blindness is:

Near-sightedness

Astigmatism

Diabetic retinopathy

Other, please specify



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Answer

The correct answer is: Diabetic retinopathy



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Unit 5: To Check your knowledge Question 4

People with diabetes have these common eye diseases. Please select one:

Glaucoma, near-sightedness, astigmatism

Diabetic retinopathy, cataracts, astigmatism

Diabetic retinopathy, cataracts, glaucoma

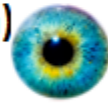
Other, please specify



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Answer

The correct answer is:
(Diabetic retinopathy, cataracts, glaucoma)



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Unit 5: To Check your knowledge Question 5

Blindness occurs mainly due to:

Near-sightedness
commencing in
childhood

Presbyopia
appearing after
age 40

Diabetic
retinopathy

Other, please
specify



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Answer

The correct answer is:
(Diabetic retinopathy)



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Unit 5: To Check your knowledge
Question 6

Eye professionals can see more detail inside the eye and carry out disease checks during dilated eye check-ups.

True

False

I am not
sure

Other,
please
specify



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Answer

The correct answer is: True

Unit 5: To Check your knowledge
Question 7

**Identification at the earliest stage, along with care,
can minimise the possibility of blindness.**

True

False

I am not
sure

Other,
please
specify

Answer

The correct answer is: True

Unit 5: To Check your knowledge
Question 8

Low vision associated with diabetes is the primary sign of diabetes eye disease.

True

False

I am not
sure

Other,
please
specify

Answer

The correct answer is: True



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Unit 5: To Check your knowledge
Question 9

A person with diabetes who has no eye problems should schedule eye checks at least every 12 months.

True

False

I am not
sure

Other,
please
specify



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Answer

The correct answer is: True



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Unit 5: To Check your knowledge
Question 10

Often, diabetic retinopathy, cataracts and glaucoma are eye diseases or conditions without symptoms. People with diabetes should undergo a dilated eye check at least every 12 months.

True

False

I am not
sure

Other,
please
specify



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Answer

The correct answer is: True



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Unit 5: To Check your knowledge

The following 5 questions are not included in the test, and are only presented for knowledge purposes.



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Unit 5: To Check your knowledge Question 11

Diabetes Risk Factors:

- Obesity
- Diabetes history in the Family
- High blood pressure

True

Other, please
specify

False



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Answer

The correct answer is: True



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Unit 5: To Check your knowledge

Question 12

CHOLESTEROL AND TRIGLYCERIDES: are fats that are contained in blood.

Cholesterol: is divided into 2 categories. The first is LDL or 'bad cholesterol' as this will increase the chances of heart disease. The second category is HDL, which is the good cholesterol as it will decrease the risk of heart disease. The range of LDL needs to be less than 100mg/dL. The range of the good cholesterol or HDL needs to be higher than 40mg/dL for males and higher than 50mg/dL for females.

Triglycerides: this fat should not be higher than 150mg/dL. A low fat diet and exercise can decrease high cholesterol levels.

True

Other, please
specify

False



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Answer

The correct answer is: True



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Unit 5: To Check your knowledge
Question 14

Low vision is a normal, age-related change.

True

Other, please
specify

False



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Answer

The correct answer is: False



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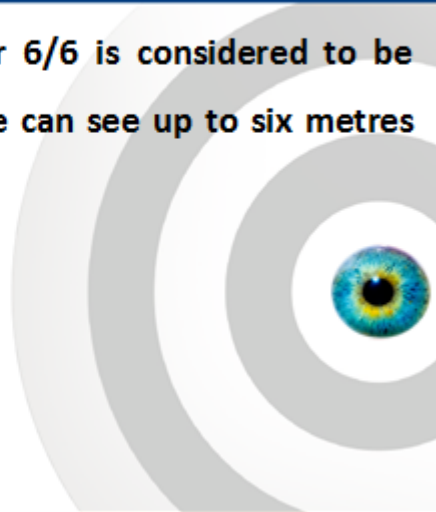
Unit 5: To Check your knowledge
Question 15

Visual acuity (VA) of 20/20 or 6/6 is considered to be healthy vision, meaning people can see up to six metres (or 20 feet).

True

Other, please
specify

False



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Answer

The correct answer is: True



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Congratulations

You have successfully completed your assessment.



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The eye is the window of the soul and diabetes is a major cause that closes this window.

Thank you



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