The role of the peripheral retina in diabetic retinopathy
From basic science to town planning

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Award date:
2023

Awarding institution:
Queen's University Belfast

The Role of the Peripheral Retina in Diabetic Retinopathy: From Basic Science to Town Planning

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Degrees held by author: BSc. Environmental Planning

Submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy (PhD)

at

Centre for Public Health, School of Medicine, Dentistry and Biomedical Sciences, Queen's University Belfast

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Submitted: September 2022

Declaration:

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(iii) the work for the thesis is my own work and that, where materials are submitted by me for another degree or work undertaken by me as part of a research group has been incorporated into the thesis, the extent of the work thus incorporated has been clearly indicated;

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Dedication

I would like to dedicate this thesis to my mum, for always being my inspiration. Thank you for always providing me with unconditional love and support.

Acknowledgements

I would firstly like to thank my supervisors Professor Tunde Peto and Dr Neil Galway; without their help this thesis simply would not have been possible. Thank you for your support, inspiration, knowledge, and guidance over the past few years. To Gregory Hageman, who has always been a font of knowledge and support.

I would first like to thank the study participants, interviewees and members of the visually impaired community who shared their experiences and knowledge and gave up their time. This study would be nothing without your input!

I would also like to thank my colleagues in the Belfast Ophthalmic Reading Centre and CARF office for their help with walkarounds, grading and uploading of retinal images and their support throughout my PhD. Your help was invaluable, and very much appreciated.

A particular thanks to Professor Gianni Virgili and Dr Lajos Csincsik for their support and help with data analysis. To Dr Katie Curran who has been a pillar of knowledge, information and help over the past few years – I could always rely on you. To Cat who provided unconditional support, proofread my thesis and who was often my travel companion for conferences and trips.

I would also like to thank all my other co-authors throughout the work for this thesis, in particular Jonathan Jackson and CVI team, the Diabetic Eye Screening Team, staff in the regional renal dialysis units and the Southern Trust Diabetes Team.

To other PhD students and Postdocs past and present who have provided support and always asked about my work. And, to Dr Imre Lengyel and his lab for allowing me to present on ongoing topics in lab meetings and providing support throughout my PhD and at conferences.

I would also like to give my sincerest thanks to the team at the Northern Ireland Clinical Research Facility for helping me with patient visits and data collection. I would also like to extend my thanks to the charities who helped me recruit for the project, Diabetes UK, Macular Society and Retina UK.

Thanks to Optos for providing funding for the project and also for providing retinal imaging analysis support throughout. Thank you to the team at Optos in Edinburgh and the Hageman Lab for allowing me to visit and learn during my PhD studies.

Thank you to my friends who have provided encouragement and to Deirdre and Naish who read over my thesis and corrected any errors.

To my family, especially my brother Adam, Mum, and Dad for always offering unconditional encouragement, support and love. Thank you for always being there and being proud of me. I simply could not have done this without you all. To Cóilin, for always pushing me to be my best (even when I didn’t want to hear it), being my sounding board/fellow debater and for offering endless support throughout the years. I would also like to thank Fionnuala, Patrick, Keaton, Casey and Shauna for their love and support over the years.

Summary

Introduction

Diabetes is a serious long-term condition which can cause many complications including diabetic retinopathy and diabetic maculopathy. These collectively not only affect the central vision, but often cause peripheral vision problems. Retinitis pigmentosa is an inherited retinal condition which also causes mid-far peripheral loss of vision as well as central loss at the later stages of the disease.

For those with diabetes, reduced quality of life is often related to loss of vision. For many losing sight is accompanied by multiple other complications including kidney disease. With loss of vision, daily tasks can become challenging and cause an inability to perform certain tasks leading to socio-economic disadvantages.

One of the biggest barriers for people with a loss of vision is navigating towns and cities. Built environments are often described as ‘not fit for purpose’ and ‘hostile’ by people with a visual impairment as they are created for the average human being as opposed to all who use them. Due to towns and cities serving as a platform for daily life and tasks, once they become inaccessible for any reason, such as a street clutter, noise, light and shared space, a barrier is created. Often these barriers prevent people going out due to embarrassment, frustration and loss of confidence. This often causes isolation and loneliness, creating further mental and physical issues.

Research Questions

- *Does vision loss and function due to diabetes and retinitis pigmentosa affect independent mobility and navigation in urban environments?*

Aims

1. *To assess stakeholder opinions on navigating the built environment with a visual impairment*
2. *To develop a street audit tool which can be used to assess any barriers and enablers of the built environment in a global context*
3. *To assess the level of vision and retinal pathology in people with diabetes and retinitis pigmentosa using sophisticated imaging*
4. *To assess visual function in people with diabetes and retinitis pigmentosa through visual function testing*
5. *To assess quality of life and diabetes distress through the use of pre-validated questionnaires*
6. *To assess user experience through walkarounds of a set area*
7. *To correlate results from grading, visual function and walkarounds to assess how vision impacts on navigation of the built environment*

Methods

Firstly, stakeholders including visually impaired people, architects, planners, charities and ophthalmic professionals were interviewed about their views on people with a visual impairment navigating the built environment, any potential barriers and any solutions to make navigation easier.

Secondly, participants with varying levels of diabetic retinopathy and retinitis pigmentosa were recruited into the study to complete visual function testing, retinal imaging, questionnaires and a walkaround of a set area.

Participants attended for a walkaround of an area near Queen's University Belfast where they discussed any issues they faced when navigating through the streetscape. Questions on levels of confidence, anxiety and difficulty were asked at different points around the 1-mile walk.

Participants were then invited to the Northern Ireland Clinical Research Facility (NICRF) or Optos Wide-Field retinal imaging, Heidelberg OCT, OCTA and multicolour images. They also completed AdaptDx dark adaptation, visual acuity, contrast sensitivity and Metrovision Visual Fields. Quality of life (RetDQol), diabetes distress (DDS17) and a study questionnaire were also completed.

Results

Stakeholder interview results showed that stakeholders agree that there can be barriers to navigating towns and cities for people with a visual impairment. Despite these issues, stakeholders made suggestions which could improve planners/architect knowledge and awareness while also improving the streetscape and making it more accessible for all. One of the recommendations for planners and architects was further specialised education into navigating with a visual impairment. In addition, more robust guidance and policies were suggested to create confluent accessible environments throughout the region.

When retinal images were graded for pathology, those with treated diabetic retinopathy and retinitis pigmentosa seemed to have a similar percentage of the retina affected. Despite this, those with treated diabetic retinopathy did not seem to have issues with visual acuity but did have visual field, contrast sensitivity and dark adaptation issues.

Of all participants, 43.8% reported confidence/anxiety issues and difficulty when navigating. Some of the most common issues discussed were bollards, shop signs, advertisement boards, uneven pavements, parked cars and colour contrast. While 80% of those with RP faced problems walking around the set area, only 5 (22.7%) people with diabetic eye disease (DED) (both treated and untreated) reported similar issues.

Conclusions and recommendations

Despite similar issues with visual function people with DED did not have the same issues navigating the built environment. This could be due to DED pathology being less absolute or confluent.

Small changes could be made to make built environment professionals more aware of the barriers faced by people with a visual impairment. In addition, more robust guidance and policy should be introduced to allow for a regional approach to accessible areas for all.

Abbreviations

AAO - American Academy of Ophthalmology

A-boards – Advertisement Boards

ACCORD- Action to Control Cardiovascular Risk in Diabetes Study

ACIC- Associação Catarinense para Integração do Cego

ACR – Albumin- Creatinine Ratio

ADDQol - Audit of Diabetes Dependent Quality of Life

AMD – Age-Related Macular Degeneration

ARB – Architects Registration Board

ARC – Architects

BCs – Bipolar Cells

BDR - Background Diabetic Retinopathy

BE – Both Eyes

BHSCT – Belfast Health and Social Care Trust

BMI – Body Mass Index

CAH – Craigavon Area Hospital

CF – Counting Fingers

CGM- Continuous Glucose Monitors

CHA – Charities

CNV – Choroidal Neovascularisation

CPD – Continuous Personal Development

CVD – Cardiovascular Disease

CVI – Certificate of Visual Impairment

CWS – Cotton Wool Spots

DAWN – The Diabetes Attitudes, Wishes and Needs Programme

dB – Decibels

DCCT - Diabetes Control and Complications Trial

DDS17 – Diabetes Distress Scale Questionnaire

DED – Diabetic Eye Disease

DEP – Developing Eyecare Partnership

DESP – Diabetic Eye Screening Programme

DHH – Daisy Hill Hospital

DKA -Diabetic Ketoacidosis

DMO – Diabetic Macular Oedema

DNA – Did Not Attend

DNRI – Did Not Respond to Invitation

DR – Diabetic Retinopathy

DSNs – Diabetic Specialist Nurses

DUN- Dungannon

DVC – Deep Vascular Complex

ECLO – Eye Care Liaison Officers

ELM – External Limiting Membrane

ERM – Epiretinal Membrane

ETDRS - Early Treatment Diabetic Retinopathy Study

EZ – Ellipsoid Zone

FASTVIEW – The Forty Area Study Street VIEW tool

FDA – Food and Drug Administration (FDA)

FFA – Fundus Fluorescein Angiography

FGM – Flash Glucose Monitors

GDM – Gestational Diabetes Mellitus

GP – General Practitioner

HbA1c - Haemoglobin A1c

HF -Hyperreflective Foci

HM – Hand Movements

HRC - High Risk Characteristics

I – Inner

ICG – Indocyanine Green Angiography

ILM - Internal Limiting Membrane

IMTAC - The Inclusive Mobility and Transport Advisory Committee

IoT – Internet of Things

IPCV - Idiopathic Polypoidal Choroidal Vasculopathy

IQR – Interquartile Range

IRAS – Integrated Research Application System

IRMA – Intraretinal Microvascular Abnormality

IRR – Incidence Rate Ratio

LE – Left Eye

LEDCs – Lower Economically Developed Countries

LRT - Light Rail Transport

MA – Microaneurysm

MEDCs – More Economically Developed Countries

MHLS – Medicine, Health and Life Sciences

NHS – National Health Service

NI – Northern Ireland

NICE - The National Institute for Health and Care Excellence

NICRF – Northern Ireland Clinical Research Facility

NIDESP - Northern Ireland Diabetic Eye Screening Programme

NIECR – Northern Ireland Electronic Care Record

NIMDM2017- Northern Ireland Multiple Deprivation Measure

NISRA - The Northern Ireland Statistics and Research Agency

NPDR - Non-proliferative Diabetic Retinopathy

NPL – No Perception of Light

NSC - National Screening Committee

NTDR – Non-Treated Diabetic Retinopathy

O – Outer

OCNV – Occult Choroidal Neovascularisation

OCT – Optical Coherence Tomography

OCTA – Optical Coherence Tomography Angiography

ONL -Outer Nuclear Layer

OPH – Ophthalmic Professionals

OPL - Outer Plexiform Layer

PDR - Proliferative Diabetic Retinopathy

PIC – Participant Information Centre

PL – Perception of Light

PLA – Planners

PRP – Pan-Retinal Photocoagulation Laser

PVD – Posterior Vitreous Detachment

QOL – Quality of Life

QUB – Queen's University Belfast

RAP - Retinal Angiomatous Proliferation

RE- Right Eye

REASSESS - REtinal ASSESsment Scale

REC – Research Ethics Committee

RetDQol – Retinopathy Dependent Quality of Life

RI - Rod Intercept

RNIB – Royal National Institute of the Blind

ROI – Republic of Ireland

RP – Retinitis Pigmentosa

RPE - Retinal Pigment Epithelium

RTPI – Royal Town Planning Institute

SDRGS - Scottish Diabetic Retinopathy Grading Scheme

SHSCT – Southern Health and Social Care Trust

SI – Sight Impairment

SPPS – Strategic Planning Policy Statement

SPSS - Statistical Package for the Social Sciences

SSI – Severe Sight Impairment

SVC – Superficial Vascular Complex

SWAN – System for Wearable Audio Navigation

SWAT – Scottish Walkability Assessment Tool

SWEAT – Seniors Walkability Environment Audit Tool – Revised

TDR – Treated Diabetic Retinopathy

UK – United Kingdom

VA – Visual Acuity

VF – Visual Field

VIF - Variance Inflation Factor

VIP – Visually Impaired People

VMA – Vitreomacular Adhesion

VMT – Vitreomacular Traction

WHO – World Health Organisation

WP – Warrenpoint

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Chapter 1 : Introduction

1.1 Diabetes Mellitus

Diabetes is a serious long-term condition, which occurs when someone cannot produce any or enough insulin or cannot use it effectively. Insulin is produced in the pancreas and allows glucose to move from the bloodstream into cells which convert it into energy (International Diabetes Federation, 2020). It also metabolises protein and fat in the body. When there is a lack of insulin or the cells cannot respond to it, high blood glucose levels occur which is called hyperglycaemia (International Diabetes Federation, 2020).

In addition to the two main types of diabetes, Type 1, Type 2, there are several other types of diabetes, such as gestational diabetes, diabetes secondary to pancreatitis etc, that affect the population. Type 1 diabetes usually occurs in childhood; however, it can happen at any age. People with type 1 diabetes require insulin therapy but can live full and healthy lives with the help of diabetes care, education and support. Type 2 diabetes accounts for a majority of diabetes diagnoses worldwide (90%). Type 2 diabetes can be managed in many different ways according to the individual – through medication when required and healthy lifestyle. Evidence also exists that type 2 diabetes is preventable and in some cases, can go into remission (International Diabetes Federation, 2020).

Despite advancing diabetes care and technology, diabetes is still poorly understood and generally poorly managed (McKinlay and Marceau, 2000). Most people with diabetes will develop some degree of health complications in their lifetime; however, with appropriate glucose control and healthy lifestyle habits the incidence of progression is reduced and serious complications can be delayed and in some cases prevented (McKinlay and Marceau, 2000, International Diabetes Federation, 2020). These often irreversible complications are split into microvascular and macrovascular disease (McKinlay and Marceau, 2000). Some of these complications include cardiovascular disease (CVD), nerve damage (neuropathy), kidney damage (nephropathy) and diabetic eye disease (DED) (International Diabetes Federation, 2020).

1.2 Global Diabetes Epidemic

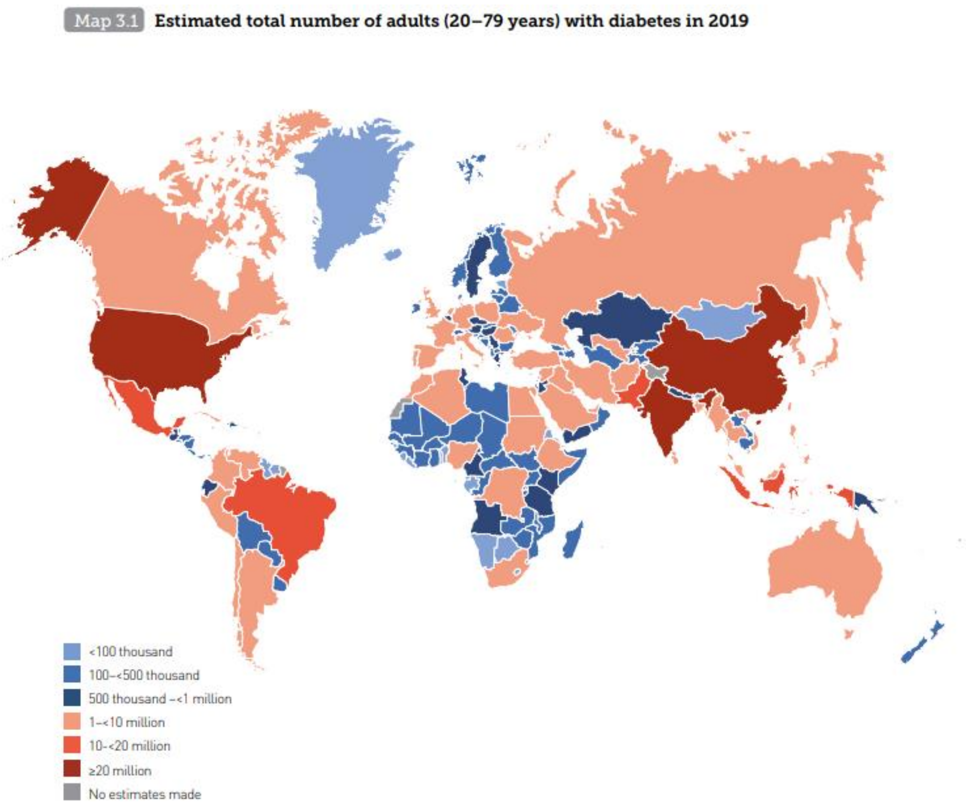


Figure 1: Estimated number of adults globally with diabetes in 2019 (Source: (International Diabetes Federation, 2019)

Whilst diabetes was once thought of as a western disease, levels of diabetes are increasing throughout the world (Lam and LeRoith, 2012). As diabetes numbers rise, it is becoming a large public health concern with impacts on economic burden, clinical practice and policy (Lam and LeRoith, 2012).

Worldwide there are an estimated 463 million adults aged 20-79 who are currently living with diabetes (International Diabetes Federation, 2020). This is 9.3% of the world's population with the number predicted to rise to 10.2% by 2030 (International Diabetes Federation, 2020). Some literature attributes these changes in patterns of chronic diseases to increased globalisation, industrialisation, longer lifespans and changes in lifestyles across the globe (Narayan et al., 2000). This shift in patterns is clear from the World Health Organisation (WHO) top 10 causes of death. Since 2000, diabetes has now entered the top 10 causes of death, with an increase of 70% since 2000.

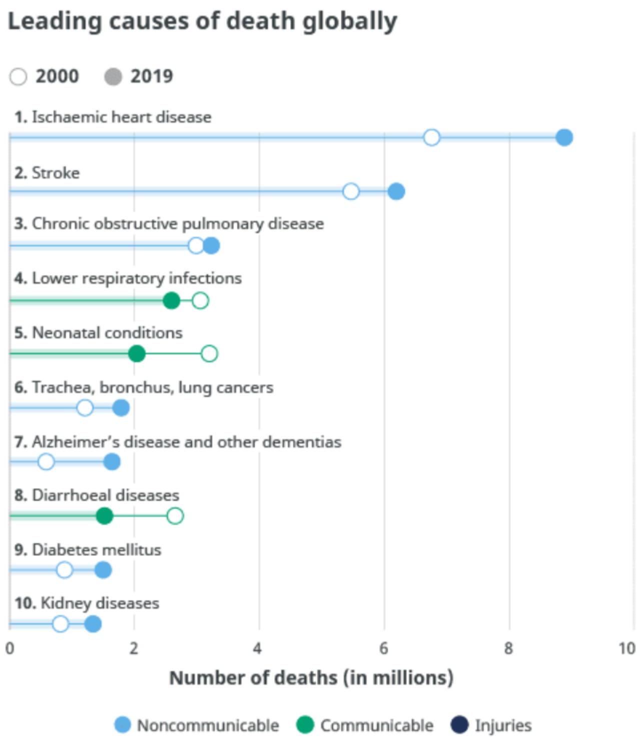


Figure 2: Leading cause of death globally (Source: WHO Website, 2021)

Diabetes is also responsible for an 80% rise in male deaths among the top 10.

In the United Kingdom, Diabetes UK estimates that 4.7 million people have diabetes (prevalence of 7%), with someone new diagnosed every two minutes (Diabetes UK, 2019).

There are currently over 112,000 people living with diabetes in Northern Ireland, in a population of 1.89 million (prevalence of approximately 5.9%). It is also estimated that over 12,000 people are currently living with type 2 diabetes but have not been diagnosed yet. Since 2007, the number of people diagnosed with diabetes has increased by more than 62% (Diabetes UK, 2018).

1.2.1 The Fifteen Healthcare Essentials

People with diabetes receive a series of annual tests to assess and manage their diabetes and the potential complications that can come from diabetes. Diabetes UK sets out a list of the 15 healthcare essentials for people with diabetes.

1. Get your blood glucose levels measured at least once per year
2. Have you blood pressure measured and recorded at least once per year
3. Have your blood fats (such as cholesterol and triglycerides) measured every year
4. Have your eyes screened every year by your local diabetic eye screening service
5. Have your feet and legs checked
6. Have your kidney function checked annually
7. Get individual, ongoing dietary advice from a trained nutrition healthcare professional
8. Get emotional and psychological support when needed
9. Be offered a group education course near you
10. See specialist diabetes healthcare professionals
11. Get a free flu vaccination annually from your GP
12. Receive good care if admitted to hospital
13. Have the opportunity to talk about any sexual problems
14. If you smoke, get cessation support
15. Get information and specialist care if planning for a baby

(Diabetes UK, 2017)

1.3 Diabetic Eye Disease

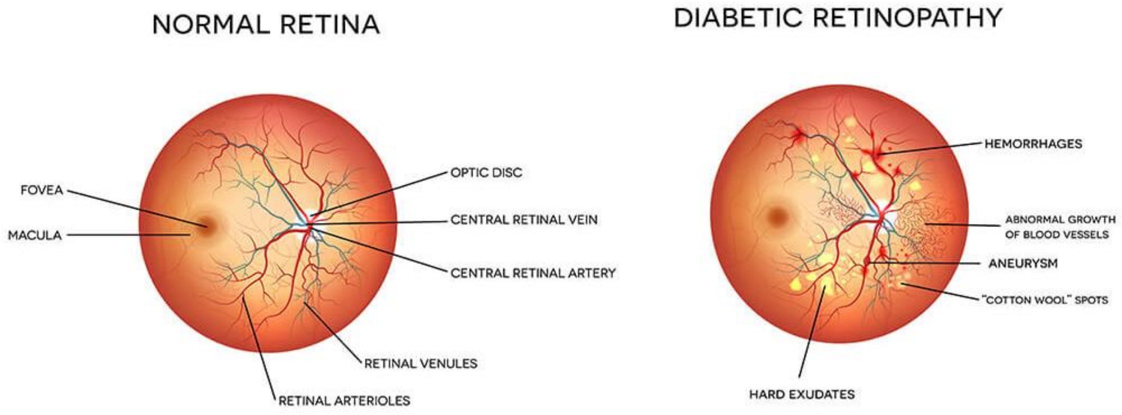


Figure 3: Diagrammatic examples of a 'normal' eye and eye with diabetic eye disease (Source: (Carolina Eyecare, 2021)

Diabetic retinopathy is the most common microvascular complication of diabetes (Fowler, 2008) and is the leading cause of blindness in the working age group. Diabetic retinopathy usually starts with retinal microaneurysms which increase in severity over time (Klein et al., 1984). Microaneurysms usually occur around 4-7 years following a diagnosis of type 1(Klein et al., 1995) ; however, they can be present at diagnosis of people with type 2. Often alongside microaneurysms, small retinal haemorrhages may form and the level of retinopathy is characterised by the size and amount of both characteristics (Klein et al., 1984). Cotton wool spots may also form and appear as ‘fluffy’ white patches on the retina and yellow-coloured deposits called exudates may also form. In addition, abnormalities in blood vessels and new vessel growth may occur (Klein et al., 1984).

1.3.1 Diabetic Eye Disease Classification

Diabetic Retinopathy (DR) falls into two main categories: proliferative and non-proliferative (including pre-proliferative) and is further classified by severity (Vislisel and Oetting, 2010). There are many different grading classification systems for diabetic retinopathy used across the world. An example of some of the multiple systems can be seen in the table below:

ETDRS (ref 1)	NSC (ref 4)	SDRGS (ref 5)	AAO (ref 3) International	RCOphth (ref 2)
10 none	R0 none	R0 none	No apparent retinopathy	None
20 microaneurysms only	R1 background	R1 mild background	Mild NPDR	Low risk
35 mild NPDR			Mod NPDR	
43 moderate NPDR	R2 preproliferative	R2 moderate BDR		High risk
47 Moderately severe NPDR				
53A-D severe NPDR		R3 severe BDR	Severe NPDR	
53E very severe NPDR				
61 mild PDR	R3 proliferative	R4 PDR	PDR	PDR
65 Moderate PDR				
71, 75 High risk PDR				
81, 85 Advanced PDR				

Table 1: Approximate equivalence of currently used classification systems for diabetic retinopathy (Source: (The Royal College of Ophthalmologists, 2012)

Legend: ETDRS = Early Treatment Diabetic Retinopathy Study; AAO = American Academy of Ophthalmology; NSC = National Screening Committee; SDRGS = Scottish Diabetic Retinopathy Grading Scheme; NPDR = non-proliferative diabetic retinopathy; BDR = background diabetic retinopathy; PDR = proliferative diabetic retinopathy; HRC = high risk characteristics

UK Diabetic Retinopathy Grading System		
Retinopathy	R0 (None)	No DR
	R1 (Background)	• microaneurysm(s) • retinal haemorrhage(s) • venous loop • any exudate in the presence of other features of DR • any number of cotton wool spots (CWS) in the presence of other features of DR
	R2 (Pre-Proliferative)	• venous beading • venous reduplication • multiple blot haemorrhages • intraretinal microvascular abnormality (IRMA)
	R3A (Proliferative – Active)	• new vessels on disc (NVD) • new vessels elsewhere (NVE) • New pre-retinal or vitreous haemorrhage • New pre-retinal fibrosis • New tractional retinal detachment • Reactivation in a previous stable R3s eye
	R3S (Proliferative – Stable)	• Stable pre-retinal fibrosis + peripheral retinal scatter laser • Stable fibrous proliferation (disc or elsewhere) + peripheral retinal scatter laser • Stable R2 features (from feature-based grading) + peripheral retinal scatter laser • R1 features (from feature-based grading) + peripheral retinal scatter laser
Maculopathy	M0	No Maculopathy
	M1	• any microaneurysm or haemorrhage within 1DD of the centre of the fovea if associated with a best VA of less than 6/12 where the cause of the reduced vision • exudate within 1 disc diameter (DD) of the centre of the fovea • group of exudates within the macula

In Northern Ireland the UK disease classification system is used, which includes scales R0-R3 for retinopathy and M0-M1 for maculopathy.

Table 2: The UK Diabetic Retinopathy Disease Classification (Source: (Public Health England, 2012)

Grade	Features
R0	No disease
R1	**Mild background DR** Including microaneurysms, flame exudates, >4 blot haemorrhages in one or both hemifields, and/or cotton wool spots
R2	**Moderate background DR** >4 blot haemorrhages in one hemifield
R3	**Severe non-proliferative or pre-proliferative DR:** >4 blot haemorrhages in both hemifields, intra-retinal microvascular anomalies (IRMA), venous beading
R4	**Proliferative retinopathy** NVD, NVE, vitreous haemorrhage, retinal detachment
M0	No macular findings
M1	Hard exudates within 1–2 disc diameters of fovea
M2	Blot haemorrhage or hard exudates within 1 disc diameter of fovea

BDR – background diabetic retinopathy
Hemifield – field of image divided by an imaginary line running across the disc and fovea

Table 3:Scottish Diabetic Retinopathy Disease Classification (Source:(Zachariah et al., 2015)

In Scotland a slightly different version of grading is used as can be seen below. Their system includes further R4 and M2 grades which the UK disease classification does not have.

Some other examples of grading systems include the ETDRS/ International severity level scale as seen in the table below. This is the scale which will be used in the participant study.

Measure	Score	Observable Findings
ICDR severity level		
No apparent retinopathy	0	No abnormalities (Level 10 ETDRS)
Mild non-proliferative diabetic retinopathy	1	Microaneurysm(s) only (Level 20 ETDRS)
Moderate non-proliferative diabetic retinopathy	2	More than just microaneurysm(s) but less than severe non-proliferative diabetic retinopathy (Level 35, 43, 47 ETDRS)
Severe non-proliferative diabetic retinopathy	3	Any of the following: > 20 intra-retinal haemorrhages in each of 4 quadrants, definite venous beading in ≥2 quadrants, prominent intra-retinal microvascular abnormalities in ≥1 quadrant, or no signs of proliferative retinopathy. (Level 53 ETDRS: 4-2-1 rule)
Proliferative diabetic retinopathy	4	One or more of the following: neovascularization and/or vitreous or preretinal haemorrhages. (Levels 61, 65, 71, 75, 81, 85 ETDRS)
Macular oedema severity level		
No macular oedema	0	No exudates and no apparent thickening within 1 disc diameter from fovea
Macular oedema	1	Exudates or apparent thickening within 1 disc diameter from fovea

Abbreviations: ETDRS, Early Treatment Diabetic Retinopathy study; ICDR, International Clinical Diabetic Retinopathy

doi:10.1371/journal.pone.0139148.t001

Table 4: ICDR/ETDRS/International Scale of Diabetic Retinopathy (Source: Hansen et al., 2015)

There is no right or wrong grading scale to use and different screening programmes, countries and studies use them for different reasons. It is however important to be aware of which grading scale is used within each study or programme to ensure clarity and good patient outcomes.

1.3.2 Diabetic Eye Screening Programmes

In 1989, Europe declared that one of its primary objectives was to reduce diabetes-related blindness by a third (Diabetes Care and Research in Europe: The Saint Vincent Declaration, 1990). Diabetic eye screening programmes have been developed in several countries including Iceland, Scotland, Wales, Northern Ireland, England and Ireland (Scanlon, 2017). The aim of these diabetic eye screening programmes in the UK is to reduce the risk of sight loss by the early detection of diabetic retinopathy and maculopathy, and to treat where necessary. Since the establishment of diabetic eye screening programmes, Scanlon (2017) predicted that the NHS Diabetic Eye Screening Programme could reduce the prevalence of blindness from 4200 people to under 1000 based on the UK certification of blindness.

1.3.2.1 Diabetic Eye Screening in Northern Ireland

Northern Ireland healthcare is comprised of five different healthcare trusts taking in different postcode areas, this can be seen in

Figure 4: Trust Areas in Northern Ireland (Source: Business Services Organisation)

the map above. In Northern Ireland, there are around 112,000 people living with diabetes with an estimated 12,000 still undiagnosed. All people with diabetes, over the age of 12, are offered annual screening through the

Northern Ireland Diabetic Eye Screening Programme (NIDESP) except for those with no perception of light in either eye, those under the care of the hospital eye services and people with gestational diabetes (Cushley et al., 2019). The NIDESP was established in 2008 and is funded and quality assured by the Public Health Agency in Northern Ireland. The Belfast Health and Social Care Trust is a regional system covering all of Northern Ireland apart from the Western Trust (Cushley et al., 2019).

1.3.3 Treatments for Diabetic Eye Disease

In addition to developing diabetic eye disease, people with diabetes are 60% more likely to develop cataracts (Diabetes.co.uk, 2019a). Cataracts are when the lens inside the eye develops cloudy patches. Cataracts can be treated using cataract surgery where they remove the cloudy lens and replace it with a new clear plastic one (National Health Service, 2021).

1.3.3.1 Laser treatment

Laser treatment is used to treat new vessel growth in the retina and is generally used to treat proliferative diabetic retinopathy or some cases of diabetic maculopathy. This is a short procedure (usually around 20-40 minutes) and is completed in the outpatient department. Although laser treatment will not usually correct visual loss already present, it can prevent further deterioration (National Health Service, 2018).

1.3.3.2 Eye Injections

Eye injections can be used in some cases of diabetic maculopathy and use medication called anti-VEGF (vascular endothelial growth factor). These injections help to prevent growth of new blood vessels at the back of the eyes and also reduce fluid accumulation in the retina. This can help improve vision and prevent the condition deteriorating (National Health Service, 2018).

1.3.3.3 Vitreoretinal Surgery

In some cases, surgery may be required on the vitreous, the jelly-like substance which fills the space behind the lens of the eye. During vitreoretinal surgery some of the vitreous may need removed if a large amount of blood has collected or if there is extensive scar tissue or retinal detachment (National Health Service, 2018).

1.4 Retinitis Pigmentosa

Figure 5: Example of eye with Retinitis Pigmentosa (National Eye Institute, 2019)

Retinitis Pigmentosa (RP) is an inherited retinal disorder which is causes progressive dysfunction, cell loss and often results in atrophy of the retina (Gregory-Evans et al., 2013). The condition is a result of harmful changes in one of over 50 genes (National Eye Institute, 2019). RP often causes difficulty seeing at night and loss of the person’s peripheral vision (National Eye Institute, 2019). It often develops in childhood but can often be late onset. Vision loss in people with RP is not predictable and varies from person to person according to the precise causative genetic defect.

1.4.1 Treatment for RP

There is currently only one treatment for RP on the NHS. There are also several services, devices and aids such as guide dogs, which can help people living with sight loss.

Research is constantly being conducted on RP and associated disorders which could offer some hope to people with RP. Gene targeted therapies, stem cell therapies and visual prosthesis are some of the potential future treatments. Most recently Spark Therapeutics has developed gene therapy, which has been approved by the FDA and NICE (HST1 October 2019), for the RPE65 gene which is called Luxturna™ (voretigene neparvovec) (Foundation Fighting Blindness, 2021).

1.5 The Layers of the Retina

here are 10 layers of the retina, nine of which are in the sensory retina and retinal pigment epithelium (Kolb, 2005). These layers can often be distinguished on an OCT scan. Each of these retinal layers can be disrupted by various retinal diseases. Below is a diagram of an OCT with each layer identified.

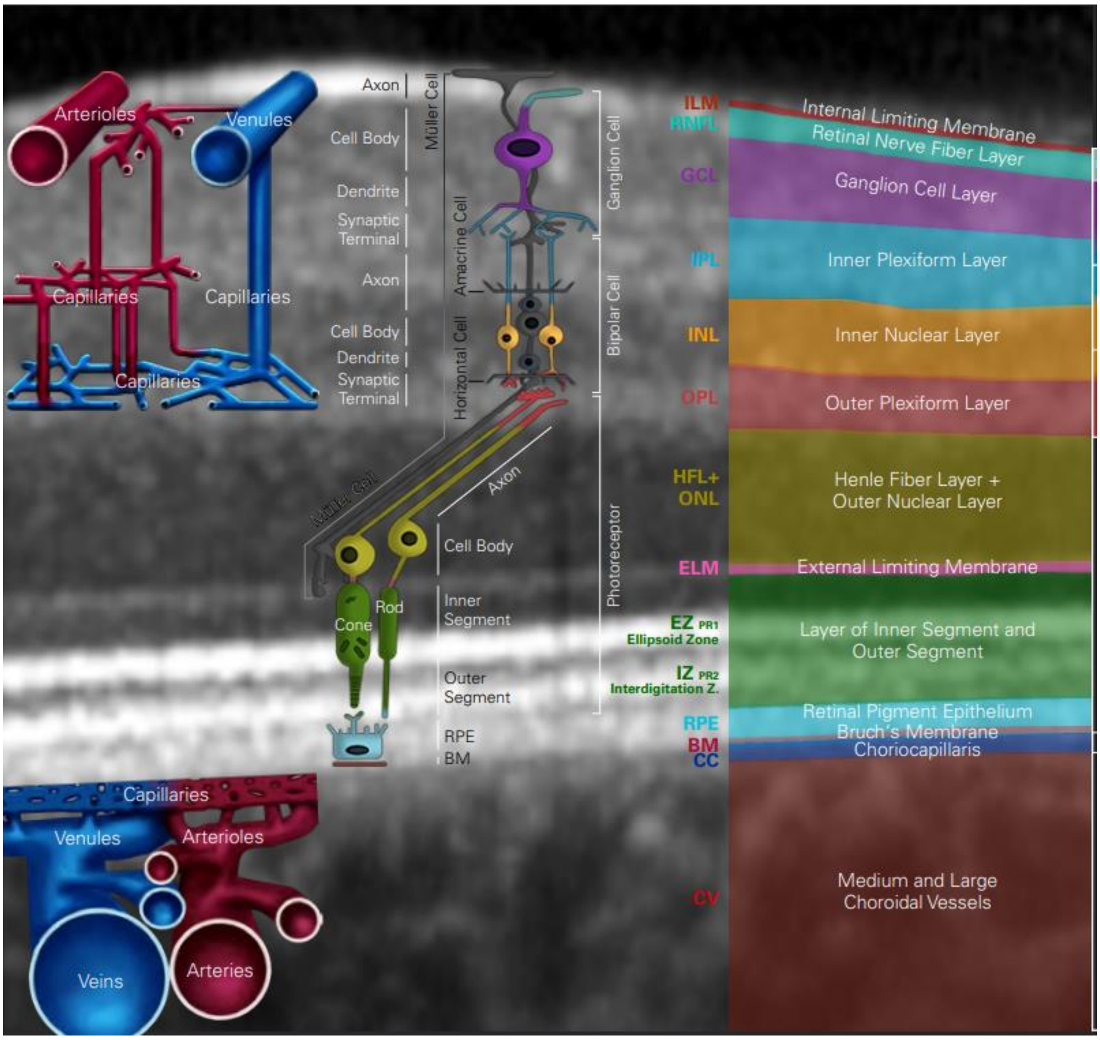


Figure 6: Layers of the retina (Source: heidelbergengineering.com)

1.6 Imaging the Retina

Imaging is used in many areas of medicine but is especially important in ophthalmic practice and plays a unique role (Yolcu et al., 2014) in diagnosis, management and monitoring of patients. Through the use of retinal photography, the retina and its structures are visible non-invasively. This is especially important as both eye diseases, and circulatory/brain diseases can manifest themselves in the eye (Abramoff et al., 2010).

There are many different ways to image the eye depending on the aim and intention. There are many different types of imaging and also a multitude of different cameras, and camera companies within the field. Some of the different types of imaging and their function are described below:

1.6.1 Optical Coherence Tomography (OCT)

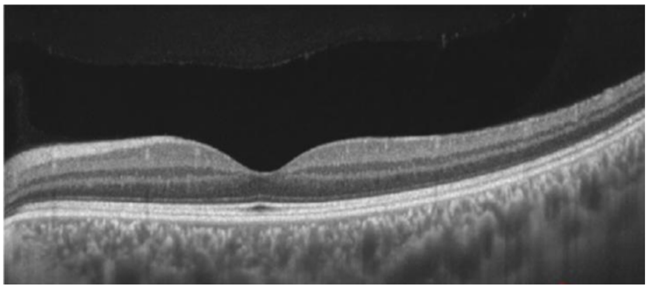


Figure 7: Example of an OCT

This uses a low powered laser to image the inner layers of the retina. It is non-invasive. OCT is often used for diagnosis of age-related macular degeneration (AMD), diabetic macular oedema (DMO), glaucoma and other retinal conditions.

1.6.2 Fundus Photography


Figure 8: Example fundus photograph

Fundus photography uses a specialised low-power microscope with an attached camera. The back of the eye (retina) can then be photographed directly through the pupil using illuminating and imaging rays (Saine and Tyler, 2002). These images can therefore show the retina, and any pathology within it at a 45° angle depending on the location of the fixation point. Fundus photography has been around for many years and is still used in clinical practice on a daily basis.

1.6.3 Fundus Fluorescein Angiography (FFA)

Fundus Fluorescein Angiography (FFA) involves injection of a yellow/orange dye (sodium fluorescein) into a vein, usually in the arm. This dye then travels to the vessels in the back of the eye and 'illuminates' them. When the dye reaches the back of the eye a picture is taken on a standard fundus camera. FFA is particularly useful for diagnosis and treatment management in macular oedema, diabetic retinopathy, macular degeneration, macular pucker and ocular melanoma (Porter, 2018).

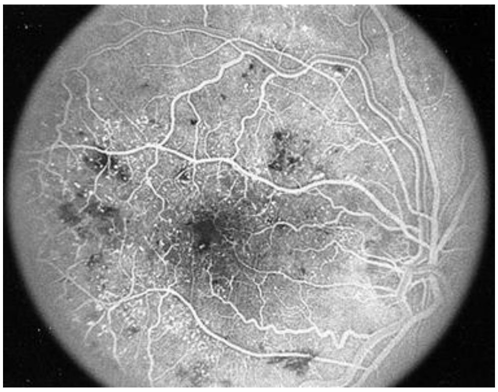


Figure 9: Example of fluorescein angiography (Source: American Academy of Ophthalmology)

1.6.4 Indocyanine Green Angiography (ICG)

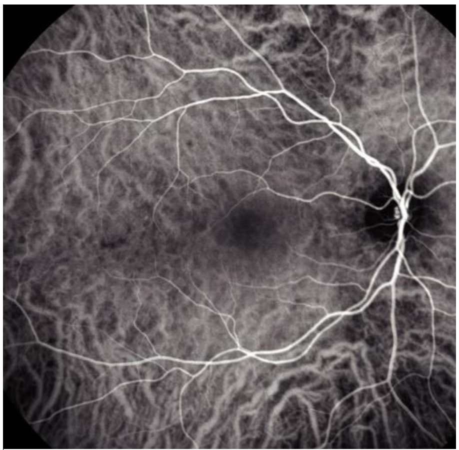


Figure 10: Example of ICG

Much like FFA, ICG is injected intravenously, and images are taken on a fundus camera to show the back of the eye – especially choroidal circulation. ICG is particularly important in the diagnosis and management of occult CNV (OCNV), and in identifying the characteristic patterns of idiopathic polypoidal choroidal vasculopathy (IPCV) and retinal angiomatous proliferation (RAP). One disadvantage is that ICG is often difficult to interpret without other modalities such as OCT and slit lamp biomicroscopy.

1.6.5 Wide-field Imaging

Figure 11: Wide-field imaging

Wide-field imaging has developed and improved significantly in recent years (Shoughy et al., 2015). This has proved important as the peripheral retina can have sight-threatening pathology (Witmer and Kiss, 2013). From a clinical perspective, wide-field imaging allows for screening, early diagnosis, effective treatment and monitoring of potentially sight-threatening eye diseases (Witmer and Kiss, 2013, Shoughy et al., 2015).

The two most popular cameras which have a wide-field imaging function are the Optos Plc. Cameras and Heidelberg Ultra-Widefield. While both cameras offer this wide-field option, they do this in different ways and offer different benefits. While the Heidelberg Ultra-Widefield offers less overall coverage of the fundus as compared to the Optos cameras, it provides superior-inferior coverage, less lash artefact and a more uniform contrast (Lee and Rosen, 2015, Patel et al., 2020).

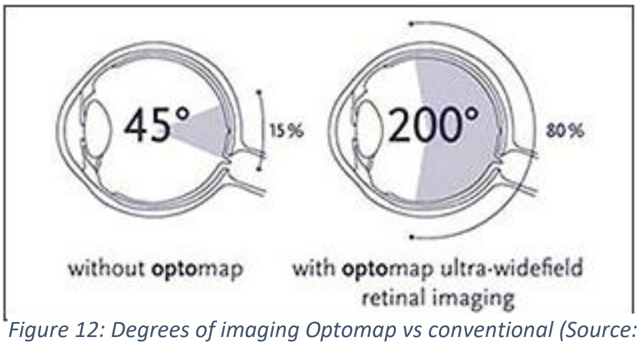


Figure 12: Degrees of imaging Optomap vs conventional (Source: Lee and Rosen, 2015)

The Optos Ultra-Widefield offers visualisation and image capture of up to 200° of the retina (Nagiel et al., 2016) as seen in the diagram. The Optos camera has been advancing in the past 10 years and now has many functions in a clinical setting (Nagiel et al., 2016). One setting where the Optos camera is and has been increasingly recognised is in Diabetic Retinopathy (Witmer and Kiss, 2013, Byberg et al., 2019).

The importance of peripheral retinal imaging in diabetic retinopathy has been recognised for many years (Witmer and Kiss, 2013). Before the advancements in wide-field cameras, seven-field imaging was introduced by the Diabetic Retinopathy Study and has been used for many years (Moss et al., 1989, Witmer and Kiss, 2013). Through the combination of these seven field images a retinal visualisation of about 75 degrees can be obtained (Witmer and Kiss, 2013).

For decades, screening and grading for diabetic eye screening programmes have relied on these montages and multi-field images using a fundus camera (Kiss and Berenberg, 2014). Ultra-wide field imaging in diabetic eye screening programmes could be beneficial for many reasons including fewer pictures required, less dependence on photographer skill and easier for the patient (Kiss and Berenberg, 2014).

In addition, dilation before imaging is not required (Neubauer et al., 2008) which may increase compliance. Dilation or mydriasis is used to make the pupil bigger to allow for better retinal image quality.

There have been several studies to test the ability to detect diabetic retinopathy using a wide-field camera. Price et al, 2015 and Soliman et al., 2012 showed that there was adequate agreement of diabetic retinopathy classification between 7-field images, fundus images and ultrawide field images (Soliman et al., 2012, Price et al., 2015). Price et al. suggests that the Optos wide-field images can also reveal other previously undetected peripheral lesions (Price et al., 2015).

In addition the Optos wide-field detects approximately 30% more new vessels than standard 2-field imaging (Talks et al., 2015). Optos ultra-widefield also increases detection of non-perfusion, neovascularisation and PRP compared to 7-fields (Wessel et al., 2012, Rabiolo et al., 2017).

In the future ultra-widefield screening can be useful in a primary care setting to visualise peripheral retinal pathology (Adhi et al., 2017) and could also be used in the future for telemedicine screening. Whilst there is still a lot to be investigated and learned from ultra-wide-field imaging and angiography, evidence suggests that it is a key technique in assessing diabetes pathology (Tan et al., 2014).

1.7 The Effect of Visual Impairment

The WHO predicts that there are at least 2.2 billion people with a visual impairment worldwide with almost half of these deemed preventable causes (World Health Organization, 2021b). Visual impairment is defined as any kind of vision loss, this can be someone with no vision at all or with some level of vision. Visual Impairment has many synonyms including vision loss, sight loss and sight impairment. Worldwide causes of visual impairment vary with More Economically Developed Countries (MEDCs) primary causes being AMD, Glaucoma and Diabetic Eye Disease. In Lower Economically Developed Countries (LEDCs), the main causes of vision loss can be associated with uncorrected refractive errors, cataract and trachoma (World Health Organization, 2021a) .

In the UK, there are an estimated 2 million people with sight loss, with 250 people a day starting to lose their sight (Fight for Sight, 2019). The Royal

National Institute of the Blind (RNIB) estimates that the number of people living with sight loss is set to double by 2050 (Royal National Institute of the Blind, 2018).

Figures suggest that 78% of people stated that sight was the sense they feared losing most, with people choosing 4.6 years of life in perfect health over 10 years of life with sight loss on average (Enoch et al., 2019). Research suggests that among those who have lived with moderate to severe loss of one of the five senses, visual loss and tactile sensation loss cause the biggest reduction in quality of life (QOL) as seen in the table below (Brown et al., 2018).

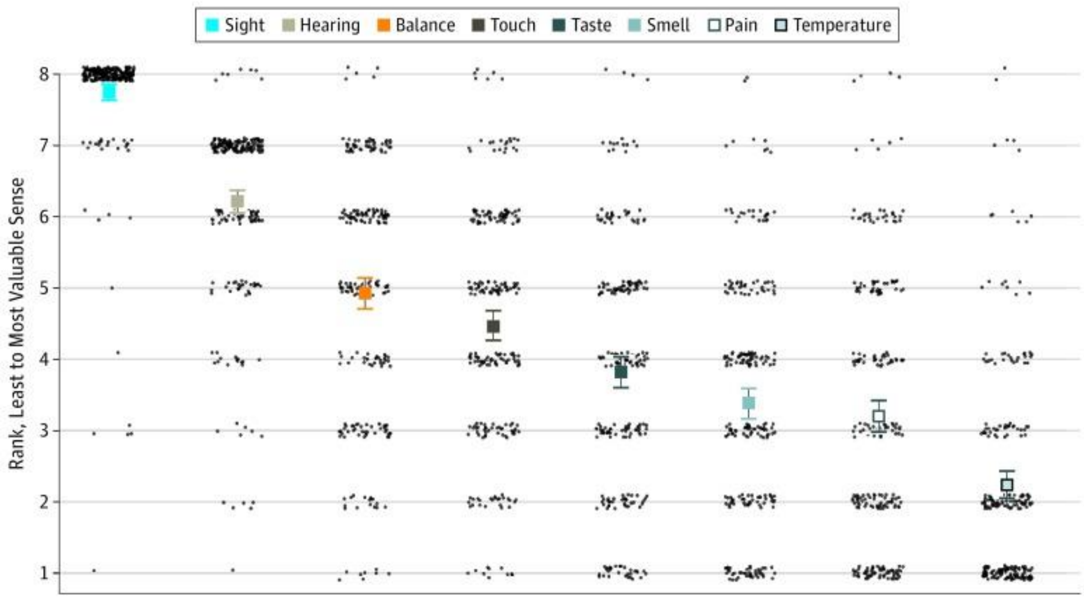


Figure 13: How the senses impact quality of life (Source: Brown et al., 2018)

Due to the importance of the sense of sight, when this is lost, there are often problems with reduced QOL (Fenwick et al., 2012, Tyler, 2011). Many studies worldwide suggest that visual impairment and decreased quality of life is a global concern (Nutheti et al., 2006, Lin and Yu, 2012). Decreased quality of life is related to the presence of glaucoma, corneal disease, cataract or loss of retinal function (Nutheti et al., 2006). Research shows that visual impairment has a substantial effect on quality of life in comparison to other chronic conditions such as type 2 diabetes, coronary impairments but less than complications such as stroke, multiple sclerosis and severe mental illness (Langelaan et al., 2007).

A number of studies have been conducted to assess the impact of visual impairment due to diabetic retinopathy on quality of life and daily life tasks (Lamoureux et al., 2004, Woodcock et al., 2004, Sharma et al., 2005, Fenwick et al., 2012). Fenwick et al (2012) showed that people with DR have difficulty completing daily activities in challenging lighting. Restrictions on driving were deemed to be one of the biggest concerns for those with visual loss (Lamoureux et al., 2004, Fenwick et al., 2012). The ability to drive affects many aspects of a person's life including transportation, social life, relationships, general responsibilities, work and independence (Lamoureux et al., 2004, Fenwick et al., 2012) .

Alongside some of the problems with completing practical daily tasks, people with visual impairment suffer with extensive socio-emotional issues with 31% of people with sight loss stating they are rarely optimistic about the future (Slade and Edwards, 2015).

People with diabetes often have difficulty coping with the uncertainty of the chronic condition (Fenwick et al., 2012), emotional reactions to diagnosis and treatments and also general anxiety about the future (Woodcock et al., 2004). Despite this potential emotional distress around appointments, Sharma et al (2005) stated that persons with DR are willing to spend a significant amount of time to attempt to eliminate their ocular condition. They also stated that persons with DR can show signs of affected quality of life before they experience visual loss due to DR (Sharma et al., 2005). This is often due to anxiety and uncertainty about the future, diagnoses and treatments (Sharma et al., 2005).

1.8 Mental Health

1.8.1 Isolation and Loneliness

Visual impairment is an established risk factor of independence (Gallagher et al., 2011) and is one of the four major contributing factors to loss of independence among older people (Alliance for Aging Research Team, 1999). It is estimated that the average annual economic cost of an older person who remains independent is around $4,800 as opposed to $18,000 for someone who has lost their independence and needs help with daily activities (Alliance for Aging Research Team, 1999). Loss of independence can lead to mental health issues such as depression with 43% of people at low vision clinics displaying depressive symptoms in comparison to 45% with a cancer diagnosis (Nollett et al., 2016). It is therefore important that people with a visual impairment feel comfortable in their surroundings, both in the built environment and in their own homes (Rooney et al., 2018).

Social isolation and loneliness is a very significant health risk in itself with research studies suggesting it increases a person's risk of premature death from all causes (National Academies of Sciences Engineering and Medicine, 2020). This is on par with causes such as smoking, obesity, and physical inactivity and is attributed to a 50% percent increased risk of dementia (National Academies of Sciences Engineering and Medicine, 2020).

1.8.2 Falls

Falls can be damaging, not only to someone's physical health but also to their mental health and confidence. Research shows that recent development of visual impairment was associated with increased likelihood of fractures and falls in the next five years (Hong et al., 2014). Specific conditions such as cataract are major risk factors of falls (McCarty et al., 2002) and among older adults with Age-related Macular Degeneration (AMD), increasing vision loss was significantly associated with falls and other injuries (Wood et al., 2011). Not only is visual impairment shown to increase the risk and incidence of falls, poorly controlled diabetes and diabetes complications are also associated with a higher risk of falls in older people (Tilling et al., 2006). It is estimated that 21% of the total cost of accidental falls in the UK was spent on people with a visual impairment with 10% of these falls directly attributed to visual impairment itself (Legood et al., 2002).

These instances and incidences of falling can also affect confidence and ultimately mobility issues which can affect many aspects of a person's life. These falls can also cause make people less likely to leave their houses, especially into potentially difficult environments such as towns and cities.

1.9 The Social Model of Disability

A civil rights movement in the 1960 and '70s saw disabled people question their life experiences and society's assumptions of what they could and could not do and how they should live their lives. The disabled community began to challenge exclusion and discrimination issues, and this was the start of the 'Disability People's Rights Movement' (Inclusion London, 2015).

The social model of disability was developed to challenge previous models which viewed disabled persons as an individual with a medical problem which needed to be prevented, cured, or contained. Oftentimes it viewed people with a disability as charity cases and those who needed to be pitied (Inclusion London, 2015).

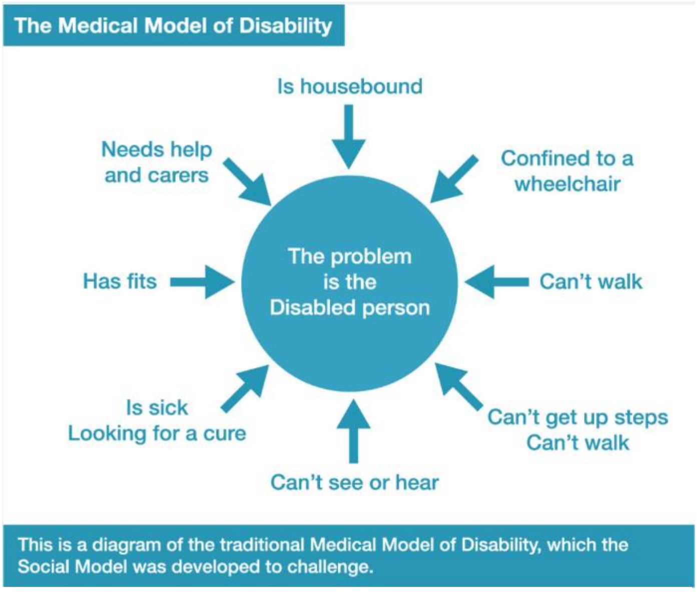


Figure 14: Traditional medical model of disability (Source: Inclusion London)

The medical model is based on assumptions of what a disabled person cannot do due to their disability and focuses on how they can help them through equipment and services (Inclusion London, 2015).

In contrast to the medical approach, the social model of disability recognises potential impairments but that the oppression and discrimination are caused by the society we live in rather than being an inevitable consequence (Inclusion London, 2015). Essentially barriers such as badly designed buildings, inaccessible transport and inaccessible streetscapes.

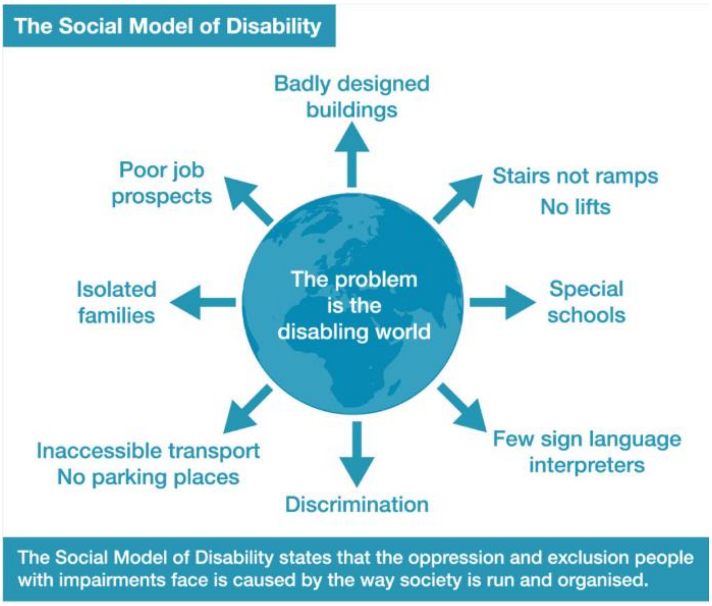


Figure 15: Social model of disability

1.10 The Built Environment and the Visually Impaired

‘*The built environment is basically designed for the average human being, plus or minus half a standard deviation’* (Hahn, 1986), the ‘universal body’ with standardised measurements and movements (Franck, 2007), or more specifically “the average male” (Criado-Perez, 2020) with little thought for people who require aspects of inclusive design.

Our urban environments are often described as ‘not fit for purpose’ or ‘hostile’ (Imrie, 2000a, Imrie, 2000b) for people who have social or situational circumstances which affect their mobility and movement (Imrie, 2000a). Our spaces and places should be designed to address the multitude of needs of multiple users, with different abilities and situations, and not hinder anyone’s free movement or mobility (Guide Dogs, 2010). Despite the fact that many people with visual impairment are fearful and uncomfortable with moving around towns and cities, it is often an inevitable part of daily life (Gustafson-Pearce et al., 2005, Aida E. Afrooz et al., 2012).

Despite this, our towns and cities are not simply places we want to ‘’access’’ (Roley et al., 2008) and instead perform two functions: ‘space to move and space to interact’’ (Parkin and Smithies, 2012). In fact, moving through these places and spaces is often described as ‘’core to people’s identities, life experiences and opportunities’’ (Imrie, 2000a). These environments serve as a platform for associations between people and occupations and can contribute to people’s sense of familiarity and belonging within a community which are essential for our social survival (Wada, 2011, Proulx et al., 2016, Hamilton-Baillie, 2008).

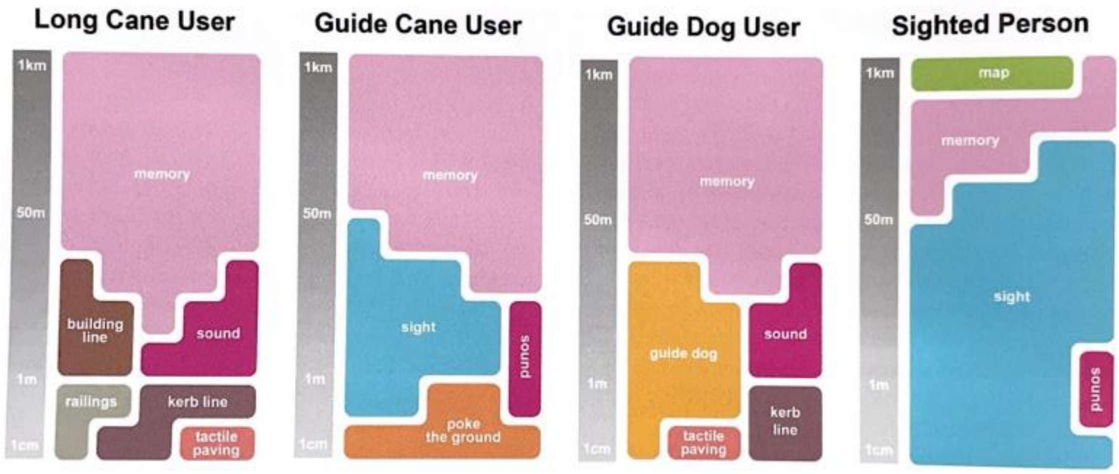


Figure 16: How different users navigate streets from 1cm to 1km (Source: Myerson, 2021)

Figure 18 is a diagram from the Sight Line Project 2011 (Ross Atkin Architects, 2011) which shows how different visually impaired users with visual aids move around the built environment. It is however important to note that not all visually impaired users will use a visual aid therefore their navigation habits may differ.

Interacting with the environment is a multisensory experience (Pallasmaa, 2006), but when a person experiences an environment without all the senses the interaction is impacted. Due to this, constructing an accurate representation of the environment and the world can often be challenging (Marston, 2004). Spatial knowledge of an area is an important part of navigating through the built environment, however, with reduced vision this can often be difficult. Knowing who we are, and where we are, are two fundamental aspects of our physical and mental experience (Proulx et al., 2016). This ‘participatory relationship to ‘’visually biased’’ public space’ has been described as one of the most difficult interactions between spaces and people (Clarke et al., 2011). Vision has been described as the spatial sense ‘par excellence (Foulke, 1983).

The built environment is often designed and constructed by sighted individuals with convenience, artistry and style, and without appropriate thought for some urban features which can become barriers or even safety risks for users of these spaces (Jenkins et al., 2015). Guide Dogs et al (2010) feel that public spaces and services are often designed with insufficient consideration for the people they serve.

To the visually impaired, the physical world presents many challenges which can be both real and imagined (Gustafson-Pearce et al., 2005). The perceptual level of difficulty can often cause people with a visual impairment not to engage with the navigation and wayfinding process in our towns and cities (Gustafson-Pearce et al., 2005). This is why it is often of the upmost importance for people with a visual impairment to pre-plan their routes with a mental landscape of their journey (Gustafson-Pearce et al., 2005). The literature shows that anxiety and stress is increased in people with a visual impairment when they have insufficient knowledge or control of a streetscape feature (Gustafson-Pearce et al., 2005). There is a perceptual difficulty between unfamiliar and familiar environments (Gustafson-Pearce et al., 2005) with satisfaction of independent travel in unfamiliar environments described as low.

1.11 Physical Barriers on the streetscape

1.11.1 Noise

Noise is present in every town and city and is comprised of a wide range of sources (McAlexander et al., 2015). The urban soundscape of an area can sometimes cause sensory difficulty for people with visual impairment as they cannot hear useful audible and sensory information (Jenkins et al., 2015). This in turn can create potential safety risks, affect orientation and mobility of directional travel (Jenkins et al., 2015). This disorientation by the urban soundscape can also be cause in large open spaces such as fields and parking lots where sensory cues are not present (Jenkins et al., 2015). In addition, the increase of hybrid and electric motor vehicles can pose a danger to visually impaired users as the sensory cue of the motor vehicle engine is missing (Jenkins et al., 2015).

1.11.2 Street clutter

A recent survey by Guide Dogs showed that 97% of people with sight loss have encountered and continue to encounter street obstructions. Some of the design issues recognised in the literature are street clutter, bollards, pavement parking and shared space (Kitchin et al., 1998, Guide Dogs, 2010, Norgate, 2012). In addition, the literature makes reference to hanging obstacles, stairs, traffic junctions, signposts on the pavements and slippery outdoor paths (Manduchi et al., 2010).

A survey conducted by Guide Dogs in 2019 showed that 97% of people with a visual impairment had problems with street clutter such as advertisement boards (A-boards). The survey also showed that 90% of people with a visual impairment have had problems with parked cars.

1.11.3 Travel

Travel is an important aspect of everyone's lives, the ability to get from one place to another safely and efficiently is paramount for social networks and generating social capital while also preventing social exclusion (Johnson and

Petrie, 1998, Jones and Jain, 2006). Without the ability to travel freely and with convenience people find it difficult to sustain social relationships and access employment, which in turn can lead to isolation and reduced confidence (Johnson and Petrie, 1998, Campion et al., 2003, Jones and Jain, 2006).

1.11.4 Lighting

Lighting is an important aspect of any streetscape for a multitude of reasons. It allows for people to be seen as well as to see and can prevent crime within a city (Oc and Tiesdell, 1997). For people with a visual impairment, lighting in the streetscape is of utmost importance for safety reasons as well as wayfinding. Streetlights must be of adequate luminance and spaced effectively throughout the public realm in order to help visually impaired users with navigation. Inconsistent lighting with cast shadows can confuse people with a visual impairment (Stevens and Rea, 2001).

1.11.5 Shared Space

Public realm schemes are introducing more urban areas where there is no delineation (often created by kerbs) between roads and paths, this urban design concept is called shared space (Parkin and Smithies, 2012). The concept was pioneered by Hans Monderman in the Netherlands (Myerson, 2021). Many built environmental professionals favour the concept of shared space design in order to tackle previously auto-dominated spaces. The concept of shared space aims to emphasise the ‘place function’ in an environment as opposed to the ‘traffic function’ which currently dominates many of our towns and cities (Havik et al., 2015) p97. Hamilton-Bailie (2008, p162) argues that the concept of shared space reconciles the ‘movement of people and traffic' which encourages 'diversity, distinctiveness, urban quality and civility'. This could help fix the decline in quality of streets in the UK (Hamilton-Bailie, 2008).

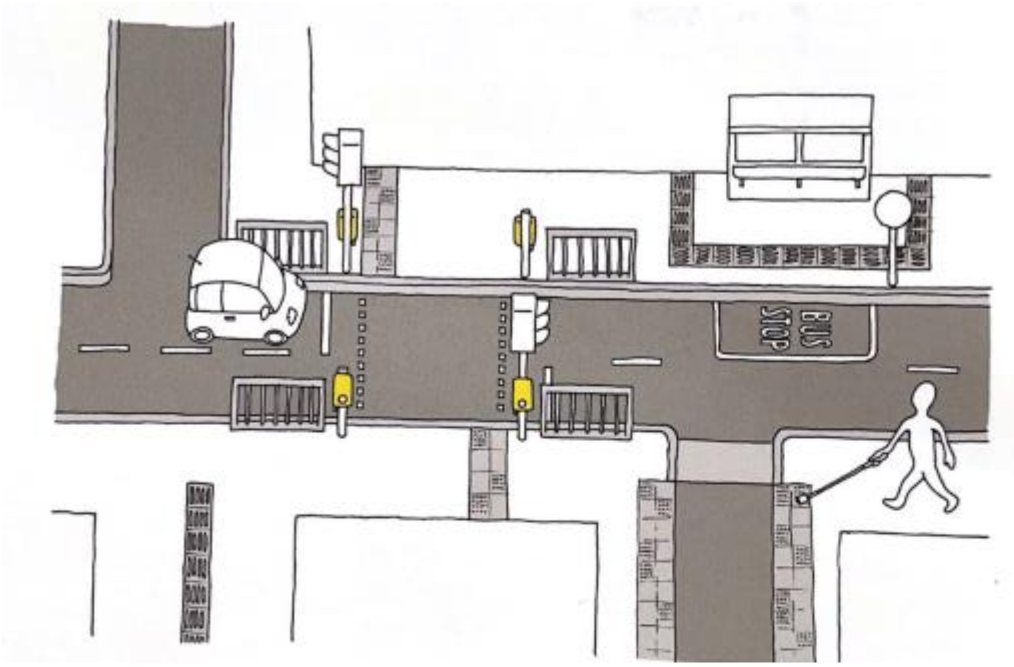


Figure 17:Diagram showing the use of how kerbs, railing and tactile paving are used (Source: Myerson, 2021)

Whilst shared space aims to do all of the above, it was found to unintentionally exclude or create barriers for people with a disability (Lawson et al., 2022). This is especially true for those with a visual impairment who rely on familiar street features such as kerbs and railings (Myerson, 2021). The concept of shared space also often mainly relies on visual skills and eye contact (Havik et al., 2015), therefore people with visual impairment are deprived of the information they need to move around shared space safely (Imrie, 2012, Lehrer, 2011). This less predictable environment with less structured traffic can cause visually impaired people to feel unsafe (Havik et al., 2015). Shared space environments can also create 'dead' or 'empty' spaces which are often pedestrian un-friendly and avoided by people with a visual impairment (Lehrer, 2011, Havik et al., 2015).

Havik et al (2015) showed that shared space locations were evaluated more negatively by visually impaired people than conventional streets (Havik et al., 2015). The lack of legible features such as pavements and kerbs can be distressing and make a visually impaired person feel vulnerable (Havik et al., 2015, Childs et al., 2009). In addition, visual aids such as a white cane and guide dog rely on at least a 60mm kerb to ascertain a road. It is therefore important that shared space schemes have an alternative navigation methods for people with a visual impairment (The National Federation of the Blind of the UK, 2016). In order for this to happen it is important that relevant professionals understand how people with a visual impairment wayfind and navigate through urban street schemes (The National Federation of the Blind of the UK, 2016).

1.12 The Effect of a Hostile Environment

Regardless of the type of barrier or spatial confusion, the experience was found to induce feelings or fear and anxiety which creates embarrassment, frustration and a loss of confidence (Kitchin et al., 1998). These feelings therefore will reduce exploration and independent travel within the built environment (Kitchin et al., 1998).

The RNIB states that 28% of people with a visual impairment rarely go out of their houses. Individuals with a visual impairment often walk more slowly due to problems with balance and fears of falling or bumping into things (Ramulu et al., 2012). This in turn leads to restricted activities outside the home and ultimately a loss of independence (Ramulu et al., 2012).

1.13 The Solutions

The existing literature shows that visually impaired individuals feel ‘estranged’ and ‘oppressed’ by aspects of the built environment and often feel powerless with how to deal with these issues (Imrie and Kumar, 1998). The concepts of inclusive, universal and barrier-free designs have been discussed for many years. Barrier-free design has been present for 40 years however has traditionally focused on specific disability needs and satisfying physical legislations (Afacan and Afacan, 2011).

In recent years, built environment professionals have been confronted with a push for new definitions of inclusivity and new design strategies which include everyone (Fletcher, 2002, Heylighen et al., 2017). One of these approaches is inclusive design which includes universal design and design for all (Fletcher, 2002, Heylighen et al., 2017).

1.13.1 Inclusive Design

Many people believe that when cities are easily navigable by visually impaired people then it will be accessible for all (Commision for Architecture and the Built Environment, 2006, Lehrer, 2011). The concept of inclusive design is often seen as including people at the heart of the design process and acknowledging diversity and difference while including flexibility in the design (Commision for Architecture and the Built Environment, 2006). By including people at the heart of the design inclusive design can remove barriers and create space where meeting access needs is an integral part of the design (Commision for Architecture and the Built Environment, 2006). Guide Dogs et al (2010) called for the need for inclusive design principles to underpin the design of new and existing streets alike. Despite this, the only way that inclusive design is possible is when built environment professionals, such as architects and planners, come together and create an accessible place (Commision for Architecture and the Built Environment, 2006, Lehrer, 2011, Mechkaroff et al., 2022).

1.13.2 Universal Design

The concept of universal design is part of a social movement to try and create easily accessible places and spaces which can be used by any person regardless of their potential disability (Imrie, 2012). Universal design principles aim to help to enhance ‘performance and participation’ from people with disabilites. The concept promotes usable design in everything, not just our towns and cities and the buildings we use (Imrie, 2012). Despite the positive underpinning theoretical influence universal design could have, universal design principles often result in bespoke designs which are often inaffordable by many councils (Imrie and Luck, 2014). Imrie and Luck (2014) also argue that universal design may not be able to manage an unrealistic expectation of designers to anticipate and interpret everyones needs. This could ultimately lead to *‘’distance between designer intent and user experience’’* (Imrie and Luck, 2014) pg 1317. In addition, knowledge and use of universal design is still thought to be limited amongst built environment professionals (Erdtman et al., 2021). Practitioners often put emphasis on physical disabilities (Zallio and Clarkson, 2021) with other disabilities often considered late in the design process (Kirkeby, 2015).

1.14 Planning Policy and Guidance

There is a paucity of legislation and guidance in force across the UK for accessibility for disabled people, especially those with a visual impairment. The Equality Act 2010 states people with a disability should not be at a disadvantage when moving around our streets. This policy also recognises the need for inclusive design calling for access audits and tests of reasonableness for all stakeholders of the streetscape. Not implementing these features is a failure to implement Public Sector Equality Duty of Equality Act (Rye, 2010).

This guidance is not in place in Northern Ireland therefore there is only supplementary guidance on inclusive streets. Much of this legislation is outdated including the 'Chronically Sick and Disabled Persons (Northern Ireland Act) 1978 which states planners and developers should consider those with a disability before acting.

Formerly Northern Ireland had the Development Control Advice Note 11 - 'Access for People with Disabilities' which included some very dated guidance on disability and the built environment. It however failed to give sufficent detail on designing for inclusivity. It was withdrawn in 2019 and has not been replaced.

One of Northern Ireland's most referred to policies, the Strategic Planning Policy Statement (SPPS) references the need for 'safe pedestrian environments' which can be achieved through the collaboration of multiple stakeholders (Department of the Environment for Northern Ireland, 2015). The policy discusses shared space, which as mentioned before is a contested topic among people with a disability. This is the first explicit reference to shared space in a Northern Ireland planning policy document, however, it lacks clarification on how to design and share these spaces appropriately.

1.15 Current Aids, Technology and Potential Solutions

For many years visually impaired people have used conventional navigational aids such as white canes (Riazi et al., 2016, Lin et al., 2017a), guide dogs or assistance by a trained guide or volunteer (Zhao et al., 2018, Lin et al., 2017a).

1.15.1 The Cane

The invention of the blindness cane is credited to James Biggs and was created in 1921 (Vision Aware, 2020b). It was not until approximately 1940, after World War II, that the white cane became widely accepted. In 1964 President Lyndon B Johnson was the first president to declare October 15th White Cane Day (Central Association for the Blind and Visually Impaired, 2020). There are several variations of the white cane depending on each person's need, these canes are:

Long Canes – this is the type of cane most people are familiar with. This is primarily used to avoid obstacles and is used by rolling or tapping it from side to side (Central Association for the Blind and Visually Impaired, 2020).

Symbol Cane – this is less commonly known but it is good for people with low but useful vision. This cane is normally used to make people around you aware of your visual impairment. This cane is smaller than the long cane therefore can be useful in busier areas (Central Association for the Blind and Visually Impaired, 2020).

Guide Cane – this cane is a shorter cane which is primarily used to find immediate obstacles. The guide cane is used to find obstacles such as kerbs and steps but does not have much movement potential (Central Association for the Blind and Visually Impaired, 2020).

In addition to the multiple variations there are colour codes which mean different things. A cane that is all white indicates that someone is completely blind with no usable vision. A cane with a red bottom means that the user has low but some usable vision and a white and red striped cane means the person is deaf and blind (Central Association for the Blind and Visually Impaired, 2020).

1.15.2 Guide Dogs

Guide Dogs are also a navigational aid that people with a visual impairment use. Despite the public perception that many people with visual impairment have a guide dog, there are currently only 4800 working guide dog partnerships in the UK (Abacus, 2021). Which is approximately only 0.24%. In order for someone to acquire a guide dog there are several criteria, including; level of visual impairment, ability to look after and ‘work’ a dog appropriately, and to accept the required support and training (Guide Dogs UK, 2021).

Despite the guide dog being very helpful to people with a visual impairment there is a common misconception that the dog indicates where the person is supposed to go, whereas this is not the case (Vision Aware, 2020b). It is therefore important for guide dog users to have orientation and mobility knowledge and ability (Vision Aware, 2020a) in order to have an effective partnership. The purpose of a guide dog is to guide their partner around obstacles and indicate where kerbs and steps are in the streetscape vision (Vision Aware, 2020a). In addition, guide dogs do not indicate when to cross the street safely, they will lead their partner to the edge of a pavement, and it is up to the person to determine if it is safe to cross. The guide dog will then lead them across the road – it should be said that if the guide dog sees a car approaching imminently then it will stop their partner (Vision Aware, 2020a).

1.16 Low Vision Clinics

Low vision clinics are provided within hospital trusts. These are staffed by optometrists to provide people with a visual impairment and their families and friends the support they need. There are many vision aids that can help with everyday tasks. Magnifiers are a common low vision aid and can help people to reading ingredients, sell by dates and information on medicine bottles as well as many other things (Royal National Institute of the Blind, 2021).

In order for people with a visual impairment to access these low vision services, RNIB has Eye Care Liaison Officers (ECLO) who are the first point of contact for people with sight loss or an eye condition. ECLOs provide emotional support, can explain medical jargon and help people understand their diagnosis (Royal National Institute of the Blind, 2020). They can also make direct referrals to the low vision clinic.

1.17 Navigation and Orientation Methods

People who have a visual impairment from early life have also been shown to use echolocation to navigate (Thaler and Goodale, 2016, Acoustical Society of America, 2017, Curiosity, 2017). In addition, our streetscape can provide some good cues and navigational aids for visually impaired people. Landmarks play a vital role in navigation and wayfinding (Zhao et al., 2018).

1.17.1 Navigational Aids in the Streetscape

There are some navigational aids currently present within our streetscape to help people with a visual impairment. The most common and prominent are tactile paving and controlled pedestrian crossings.

1.17.1.1 Tactile Paving

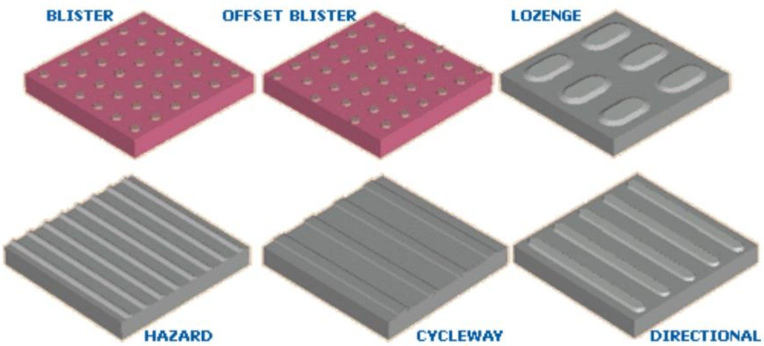


Figure 18: The different type of tactile pavement (Source: Paving Expert)

Tactile paving (or detectable warning surfaces) is a paving system which indicates information through the sense of touch (Lu et al., 2008, Henshaws, 2017, Paving Expert, 2020). Tactile paving was first developed in Japan by Seiichi Miyake in 1965 (Henshaws, 2017) but has improved over the past several years and now there are several different types of tactile paving which indicate different information.

1.17.1.2 Blister Paving

There are two types of blister paving: blister and off-set blister (Paving Expert, 2020). Blister paving is the most common and it traditionally used for pedestrian crossings with dropped kerbs (Paving Expert, 2020, Henshaws, 2017). Off-set blister paving is uses to indicate the edge of platform at rail and tram stations, the orientation must be parallel to the platform edge for proper indication (Paving Expert, 2020).

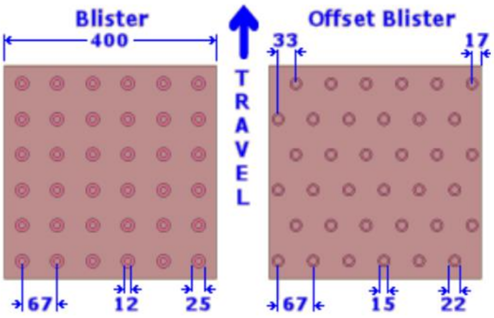


Figure 19: Blister paving (Source: Paving Expert)

1.17.1.3 Other types of tactile paving

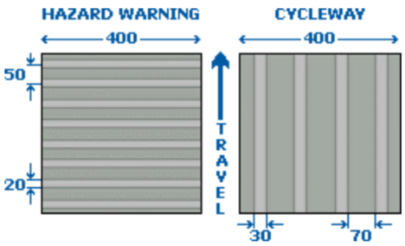


Figure 20: Hazard tactile paving (Source: Paving Expert)

Hazard Warning tactile paving, as the name suggests, is used to show hazards in the streetscape such as the top or bottom of a flight of stairs (Paving Expert, 2020). This paving is continuous half rods which should be parallel to the edge of the hazard (Paving Expert, 2020). Cycleway paving indicates a cycle lane and the bars run in the direction of travel (so as not to hinder cyclists) (Paving Expert, 2020).

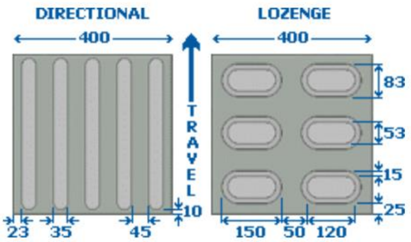


Figure 21: Lozenge paving (Source: Paving Expert)

Directional and guidance paving indicates the safest direction of travel for people with a visual impairment (Paving Expert, 2020). Lozenge paving is used to indicate a platform edge on streets such as trams and Light Rail Transport (LRT) which are becoming increasingly popular (Paving Expert, 2020).

1.17.2 Pedestrian Crossings

In the UK there are five different types of crossing: zebra, pelican, puffin, toucan and Pegasus. Zebra crossings have black and white stripes and flashing yellow beacons, these are not controlled and rely on motorists stopping.

1.17.3 Controlled crossings

Simply crossing a street can be very challenging for people with a visual impairment. People with a visual impairment need properly designed street crossings with audible and tactile aids to cross safely (Huang et al., 2022).

Pelican Crossings, short for Pedestrian Light Controlled Crossing, these crossings make traffic come to a halt using traffic lights and signal pedestrians to the other side of the road by a ‘green man’. These are generally used in busy populated areas (Department of Transport, 2007).

Puffin Crossings are very similar to pelican crossings and stands for ‘Pedestrian User-Friendly Intelligent’ crossing. The main difference is that these puffin crossings have sensors which can sense if someone is taking longer to cross the road so can hold traffic on red for slightly longer. The signal is also beside the person as opposed to across the road.

Toucan Crossings are designed for both pedestrians and cyclists to cross the road safely together. This is why the name toucan was chosen as ‘two can’ cross together.

Figure 22: Rotating cone on pedestrian crossings (Source: Coventry Telegraph, 2020)

Many crossings in the UK have non-visual indication that it is safe to cross. These can include beeping, vibration or a tactile rotating cone. Councils in the UK are not obligated to make crossings accessible however most will have some form of non-visual aid.

1.18 Technology and Navigation

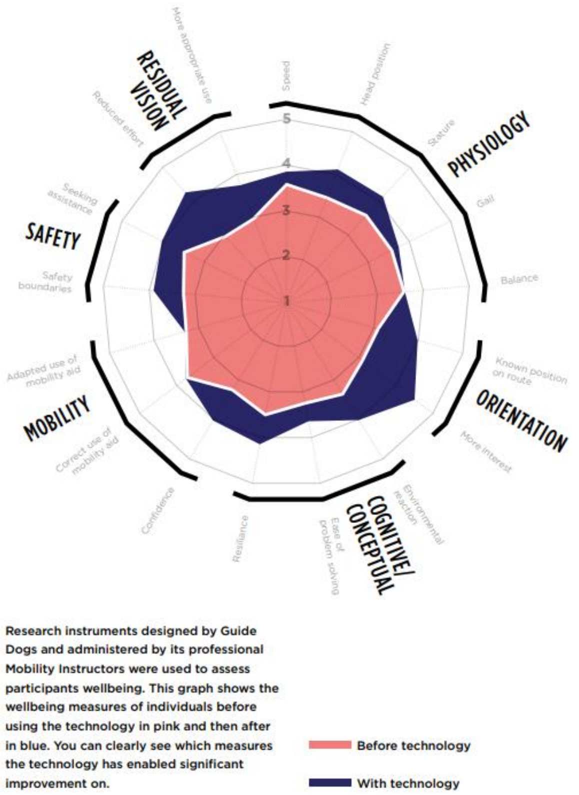


Figure 23: Participant wellbeing with and without technology

As previously discussed there are many visual aids for people with a visual impairment including magnifiers, white sticks and guide dogs (Faria *et al.*, 2010). In recent years there have been many technological advances which could improve navigation for people with a visual impairment. Globally, most people have their own personal mobile phone, portable computer or access to a technological device (Thomas et al., 2015). Technologies such as closed-circuit TVs, electronic readers, screen readers and magnification devices are pivotal to completing daily tasks with a visual impairment (Manduchi and Coughlan, 2012, Thomas et al., 2015).

1.18.1 Phones and Apps

Most smart phones now have in-built features for accessibility with VoiceOver on iPhones and Talk Back on Android devices. These features can be essential for people with a visual impairment to complete everyday tasks and access wayfinding and navigational apps. In addition to these features there are apps available for download to help with navigation, everyday tasks and wayfinding.

1.18.2 BeMyEyes

Figure 24: be my eyes App

This app allows visually impaired users to video phone a randomly allocated sighted user for help in situations. This app currently has 305,477 visually impaired users with 4,705,006 sighted volunteers worldwide (figures correct 20/05/2021).

1.18.3 Smart Glasses

1.18.3.1 OXSIGHT


Figure 25: OxSight glasses (Source: OXSIGHT)

Founded in 2016 in Oxford, OXSIGHT is a commercial venture created from research to develop wearable low vision solutions for people with visual impairment (OXSIGHT, 2021). OXSIGHT makes different versions of smart glasses which use two compact OLED projectors that utilise the usable areas of vision to restore the wider field of vision (OXSIGHT, 2021). It should be noted these glasses should not be worn to navigate and should only be used in a stationary position.

1.18.3.2 Orcam

Figure 26: Orcam glasses (Source: Orcam.com)

Orcam was founded in 2010 and its mission is **‘***to harness the power of artificial vision by incorporating pioneering technology into a wearable platform which improves the lives of individuals who are blind, visually impaired, and have reading difficulties’*. The OrCam devices attach to the side of glasses and reads text from screens and pages. This device is designed for people with visual impairment but also people with reading difficulties such as dyslexia or reading fatigue.

1.18.4 Electronic Canes


Figure 27: Example of using an electronic cane (Credit: Daniel Querioz)

In the past couple of years an electronic white cane has been created (Faria et al., 2010), it uses GIS software to help visually impaired users to navigate familiar and unfamiliar environments more easily (Faria et al., 2010). The first electronic cane was evaluated by the ACIC-Santa Catarina Association for the Blind Integration in 2009 (Ramirez et al., 2017). In addition, the SWAN system (System for Wearable Audio Navigation) offers the potential for a wearable audio navigation (Wilson et al., 2007). In compliment, larger companies such as Microsoft and Guide Dogs are now starting to develop a wearable headset (Soundscape) to ‘unlock cities’ (Wainwright, 2014).

1.19 Good Practice

Across the world there are good practice examples of initiatives that places, cities and businesses are doing to make spaces and places accessible for people with visual impairment.

1.19.1 Museums

Figure 28: Tactile museum (Source: Smithsonian American Art Museum)

There are several examples of good practice in museums across the globe. Audio descriptive guides are available in many tourist places such as museums, areas of natural beauty and other tourist hotspots. The Smithsonian Museums in Washington DC hosts bi-monthly 'InSight' Tours of the American Art Museum (Hillemann, 2016). The tours are interactive and participants experience the museum through vivid descriptions lead by a guide (Hillemann, 2016).

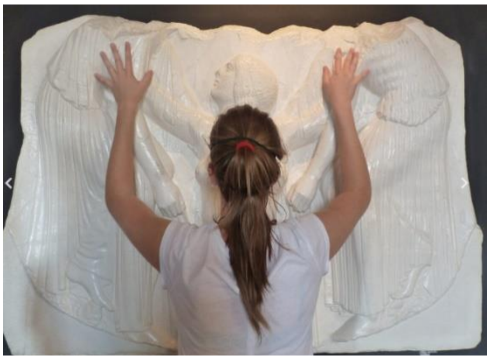


Figure 29: Tactile museum (Source: Atlas Obscura)

In addition to audio descriptive tours, many museums offer 'tactile' museum sessions, including the V&A who have been offering them since 1985. There are several tactile museums across the world including the Museo Tifológico in Madrid, National Gallery of Prague and the Museo Omero in Ancona, Italy.

1.19.2 Smart Cities and Navigation Technology

A more recent phenomenon has been the use of navigation technology in Smart Cities. Smart city technologies can help not only those with disabilities and visual impairment but everyone using the city. The concept of a smart city is to equip a city with technology which could enable people with a visual impairment to recognise spaces and places as well as everyday items such as bank notes and bus timetables. The Internet of Things (IoT) proposes that sensors, microcontrollers and other smart technology will be added to everyday objects to allow

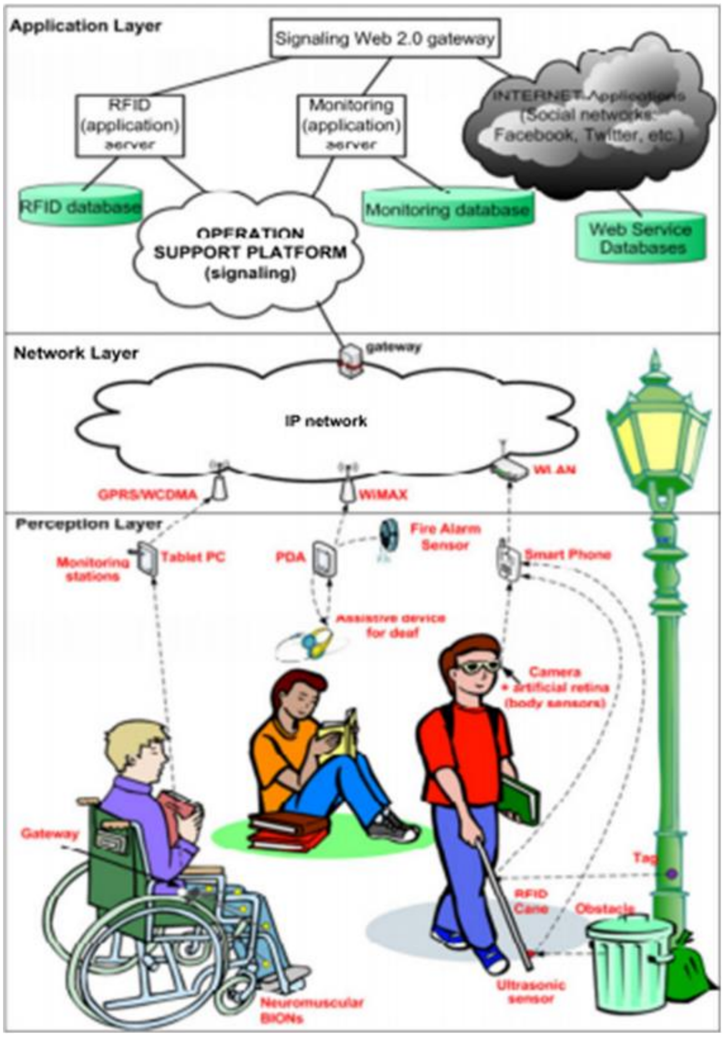


Figure 30: Example of current developing architecture (Source:Domingo, 2012)

connectivity to other users and objects (Rodrigo-Salazar et al., 2021). In smart cities audible and tactile warnings are frequently used for people with a visual impairment (Wiener et al., 2010).

Smart Cities for visually impaired individuals focus on hardware-software integrated systems (Ramirez et al., 2017). Architecture currently being designed uses three layers; the perception layer, network layer and the applications layer, which all work together to allow things like the electronic cane to connect with the other applications used in the smart city.

Figure 31: Virtual Warsaw (Source: Warsaw, 2013)

"Virtual Warsaw" based in Poland's capital was a pilot study based on cutting edge technology. The aim of the project was to provide 'eyes' to those who have visual problems. This works by using a network of beacon sensors to assist the visually impaired navigate freely and independently. These low-cost sensors are fitted to buildings and send information to people's phones via Bluetooth. Information such as location of building entrances, bus stops, or even empty seats on a bus or where to queue in municipal buildings (Warsaw, 2013).

Dubai also ran a pilot scheme in 2018 where an iPhone app converted written information in metro stations into audio instructions which helped users navigate around the metro station and onto the metro itself (Sobnath and Rehman, 2019).

1.19.3 Guide Dogs and Microsoft 'Cities Unlocked'

Guide Dogs and Microsoft have been aiming to improve mobility and navigation for people with a visual impairment since 2011, with Future Cities Catapult joining in 2013 (Guide Dogs et al., 2014). The team developed the 'Cities Unlocked Demonstrator' which connects a Nokia

Figure 32: Cities Unlocked headset (Guide Dogs et al., 2014)

Figure 33: Tactile directions board

Lumia device to the Aftershokz headset to aim to provide three dimensional audio to augment reality (Guide Dogs et al., 2014). The headset interacts with GPS, Bluetooth beacons and Wi-Fi along a technology enabled route currently from Reading to London (Guide Dogs et al., 2014). While this is still currently in its pilot stages, the team hope to expand it in the future.

1.19.4 Tactile Aids

In addition to technology advancements, there are also many tactile aids in several countries across the world. Japan and Athens have continuous tactile paving to guide visually impaired users through the streetscape without walking or bumping into street furniture. In addition, Australia has tactile street signs which include not just braille but raised letters as well. In addition, other countries provide tactile maps, with raised tactile words and paths – more locally there is one of these in McIlroy Park, Ballyskeagh, Northern Ireland.

1.20 COVID-19 pandemic

COVID-19, as expected, has further exacerbated some of these problems due to lockdown restrictions and social distancing guidelines. These restrictions and guidelines, especially social distancing, can be challenging for people with a visual impairment, who often need companions to complete daily tasks such as shopping (Sbrulli, 2020). In addition, masks, while essential from a public health aspect, often impede a person's visual field creating more navigation and social distancing problems. RNIB conducted a survey (471 responses) which showed 21% of respondents reported rationing food. The report also showed that only 14% of respondents now get their own shopping as compared to 28% pre-lockdown (Royal National

Insitute of the Blind, 2020). In addition 25% stated that they don’t have anyone else that can get their shopping in their household (Royal National Insitute of the Blind, 2020) with nearly half (49%) getting someone to get their shopping for them in contrast with 18% pre-lockdown.

In 2021, when restrictions started to lift and countries were trying to kick-start their economies, pavement cafés and al fresco dining became more prominent on our streetscapes. Local councils encouraged businesses to apply for pavement cafés to facilitate a reopening of urban centres. Whilst outside dining may be essential for rebuilding the economy, this often means more clutter on pavements. Many sight loss charities therefore called for government action on safeguarding people with a visual impairment. Sight loss charities such as RNIB, Guide Dogs, Vision UK, Visionary and Thomas Pocklington Trust petitioned for easier access to groceries for people with a visual impairment (Royal National Insitute of the Blind, 2020).

The Inclusive Mobility and Transport Advisory Committee (IMTAC) produced a basic guideline document for inclusive infrastructure in the response to COVID-19 (IMTAC, 2020). The document includes some guidelines on things such as street clutter, extension of pavements, street cafés and inclusive design aspects of the built environment.

The current COVID-19 pandemic has further highlighted the need for built environment professionals to create inclusive places, providing robust guidelines and design ideas.

1.21 Rationale for the Project

As shown by the introduction, towns and cities can have barriers which impede how a visually impaired user navigates safely, independently and efficiently. A previous smaller project to identify concerns about navigating the built environment with a visual impairment was conducted by the team in 2018 (Cushley et al., 2022). Data were collected through questionnaires, focus groups and interviews. This project included people with many kinds of visual impairment and patterns of sight loss. From interviews it was clear that people with central loss (notably age-related macular degeneration) did not have the same issues with navigating as they could still use their remaining peripheral vision. The results showed over 70% felt their visual impairment affected them going out alone into the built environment and created feelings of fear an anxiety. Over 80% of people agreed that shared space, street clutter, poor lighting and parked cars on pavements were some of the biggest issues.

This project focuses specifically on two eye conditions, diabetic eye disease and retinitis pigmentosa as they cause primarily peripheral visual loss. Below are the research questions. Further information on hypotheses and aims can be found in Chapter 3 – Participant Materals and Methods.

1.21.1 Research Question

- ***Does vision loss and function due to diabetes and retinitis pigmentosa affect independent mobility and navigation in urban environments?***

Chapter 2 : The True Impact of Diabetes

A number of smaller projects completed throughout the PhD have been described in this chapter. They show how much a diagnosis of diabetes, and its associated complications can truly affect and impact on individuals lives as well as their friends and family. All projects have been published, accepted, or submitted to journals.

As discussed in the literature review, diabetes is a long-term condition which occurs when the body cannot produce or cannot use insulin effectively. Due to the chronic nature of diabetes it can pose a life-long physical and emotional burden on people and their friends and families (Bradley and Speight, 2002). The day-to-day management of diabetes is substantial, people must deal with their diabetes all day, every day, making endless decisions to try and maintain good glycaemic control (Rubin and Peyrot, 1999). People with diabetes often compare it to pushing a boulder up a mountain every day.

The Diabetes Attitudes, Wishes and Needs (DAWN) programme reported that a majority of people with diabetes (both type 1 and 2) experience some kind of psychological problem (67.9% and 65.6% respectively) (Skovlund et al., 2005, Funnell, 2006). Despite these large numbers only a small number of people (3.3%) are thought to have received psychological care (Skovlund et al., 2005, Funnell, 2006). It is therefore not surprising that people with diabetes are twice as likely to have depression than in those without (Skovlund et al., 2005, Funnell, 2006).

The psychological toll of living with diabetes is often reflected in their physical diabetes management. These people often have poor self-care resulting in problems with long-term glycaemic control, complications and co-morbidities and quality of life (Rubin and Peyrot, 1999).

Most people with diabetes will suffer some complications due to diabetes over their lifetime. When people with diabetes suffer complications such as visual impairment, heart problems, kidney failure, impotence or neurological issues there is a significant drop in perceived quality of life (Gregg et al., 2000, Debono and Cachia, 2007).

Many of these complications can change and impact their lives further therefore diabetes services include screening mechanisms to prevent or treat these complications at early stages. In the UK everyone with diabetes is advised to attend eye screening, foot checks, cholesterol screening, blood pressure screening and kidney disease screening tests at least once per year (Diabetes.co.uk, 2019b).

Due to the psychological and physical pressures of a diabetes diagnosis and potential complications several small studies into the use of diabetes devices, retinal screening and other microvascular complications have been conducted.

2.1 Diabetes Devices and Technology

2.2 The use of diabetes devices in young people with type 1 diabetes, Southern Trust, Northern Ireland – 'Whose data is it anyway'

Laura Cushley, Aniela Krezel, Katie Curran, Kathryn Parker, Sarinda Millar and Tunde Peto

Submitted to Lifestyle Medicine Journal and revisions submitted 28/4/2022)

2.2.1 Introduction

A diabetes diagnosis profoundly impacts people's lives, including the person with diabetes, their family and their friends. This is especially true when people are diagnosed at a young age and require help with diabetes management. While there are no reports on the number of children and young people with diabetes in Northern Ireland, we estimate that 2330 between the ages of 12-26 have diabetes (taken from the diabetic eye screening system (Cushley et al., 2021).

Figure 34: Example of diabetes devices (Source: Google)

Whilst a diabetes diagnosis is often difficult, diabetes technology is constantly evolving and improving. Continuous glucose monitors (CGM), flash glucose monitors (FGM) and insulin pumps are becoming common place in diabetes management, especially in younger age groups.

These FGM/CGM devices allow output of data which can be uploaded into a diabetes system such as Carelink, Dexcom Clarity, Libreview and Diasend. Each system has its own presentation of the data, often using graphs.

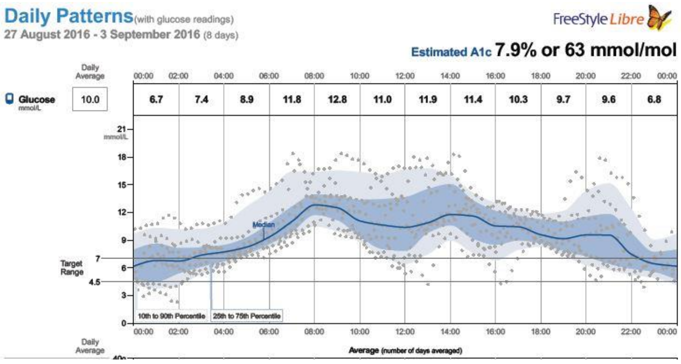


Figure 35: Example of data upload (Source: Diasend and Libreview)

Studies have shown that FGM, CGM and insulin therapy can improve quality of life, clinical outcomes (such as lowered HbA1c), reduce familial burden and allow a return to 'normal life' (Brown et al., 2000, Barnard et al., 2007, Barnard and Skinner, 2008, Barnard-Kelly et al., 2008, Hommel et al., 2014, Hoogma et al., 2006, Jankovec et al., 2010, Pettus and Edelman, 2017, Pickup et al., 2011, Rankin et al., 2015, Rubin and Peyrot, 2009, Sullivan-Bolyai et al., 2004). This referenced 'normal life' can mean coping with fears of hypoglycaemia, improved mental health and the ability to eat flexibly and sleep better (Rankin et al., 2015, Barnard et al., 2007).

From a clinical perspective, FGM/CGM and pump therapy can enable increased time in blood glucose range, shorter duration of hospitalisation (Hommel et al., 2014), improved glucose control and fewer hypoglycaemic episodes (Chantelau et al., 1997, Hommel et al., 2014, Jankovec et al., 2010, Rubin and Peyrot, 2009).

Parents and families of young people with diabetes report that insulin pumps give themselves and their child more freedom, flexibility and allows spontaneity (Barnard et al., 2007, Rankin et al., 2015, Sullivan-Bolyai et al., 2004). Fathers felt more confident and included in their child's care (Sullivan-Bolyai et al., 2004). In addition, pumps often provide better glucose control and easier diabetes management with fewer painful insulin injections (Barnard et al., 2007, Rankin et al., 2015, Sullivan-Bolyai et al., 2004).

Despite these many advantages, parents felt they were more obsessed with their child's glucose levels as they could constantly check it (Sullivan-Bolyai et al., 2004). A study by Barnard et al (2007) showed that more than 50% of participants reported downsides of pump use, despite this only 2-4% stopped pump usage. Some of the concerns raised included poor body image and acceptance and infusion site skin reactions (Barnard et al., 2007, Hoogma et al., 2006). Despite these potential issues, benefits often outweighed the negatives (Barnard et al., 2007).

Aim: to investigate diabetes technology use and related issues (both positive and negative) through qualitative assessment, in a population of patients with type 1 diabetes mellitus in the Southern Health and Social Care Trust (SHSCT), NI, UK.

2.2.2 Methods

This was a prospective qualitative study gathering information through questionnaires and focus groups on the opinions of children, young people and their families on the use of diabetes technology. The data were collected in the Southern Health and Social Care Trust through questionnaires and focus groups. The local diabetes team distributed questionnaires to patients in clinic. Questionnaires were based around diabetes technology and diabetes data upload apps and websites. Questionnaire responses were entered into an Excel spreadsheet and converted to SPSS Statistical Software Package 26 for basic frequency analysis. As data were not evenly distributed, the median and interquartile ranges were used for Likert scale analysis.

Four focus groups with families of children and young people were conducted in several different locations across the Southern Health and Social Care Trust. These were facilitated by academic researchers and clinical staff from the Southern Trust team. Sessions were not audio recorded, however minutes of each meeting were taken by two academic researchers and compared for accurate transcription. Each focus group session lasted approximately 1-2 hours and was led by members of the inter-professional type 1 diabetes service in the SHSCT. Quotes from each focus group were anonymised keep data confidential and anonymous. Each participant was assigned an anonymised unique code. Codes were assigned with the location and then a number for each participant with diabetes e.g., DHH (Daisy Hill Hospital, Newry), CAH (Craigavon Area Hospital, Portadown), DUN (Dungannon) and WP (Warrenpoint) and then a participant number (e.g. CAH1). These transcripts were analysed using Braun and Clarkes methods of thematic analysis (Braun and Clarke, 2008). Thematic analysis was conducted by two independent researchers, one a junior researcher without a medical background and one post-doctorate with a medical background. When both researchers had conducted independent thematic analysis, a meeting to discuss common themes was held and all themes and subthemes were agreed.

2.2.2.1 Demographics

Questionnaires were completed by 68 people living with diabetes or by their parent/carer in the Southern Health and Social Care Trust. Due to the age of participants, parents/carers filled out the majority of questionnaires (47/68, 69.1%) on behalf of their child.

Focus groups included both young people and their parents/guardians with a mean age of 11.3 for the young people with diabetes. There were varying numbers of young people with diabetes at each focus groups including 9 (Newry), 9 (Craigavon), 3 (Warrenpoint) and 5 (Dungannon), in addition all children/young people except one had at least one parent/guardian present.

2.2.3 Results

2.2.3.1 Questionnaire Results

When asked about access to devices for diabetes data review, 98.5% (67/68) has access to at least one device, the most common, 91.2% (62/68), was access to a smartphone. Many, 70.6%, stated they used a diabetes programme such as Libreview and Diasend.

Surprisingly, only 64.7% (44/68), stated they checked their blood glucose on an app-based reader at least once per day. The others checked a couple of times a week (2.9%), weekly or fortnightly (11.8%), monthly (2.9%) or ‘sometimes’ (11.85). Four participants failed to answer.

Respondents felt that using a diabetes programme to interpret diabetes management was very useful with a median Likert score of 9 and IQR of 7-

10 (0=not at all beneficial, 10=very beneficial). Respondents also felt that systems were easy to use, median 8, IQR of 5-8. Despite this, over half (61.8%) felt they could benefit from more education on diabetes data systems. Some respondents (61.8%) often relied on contacting their diabetes specialist nurse to review their glucose levels outside clinical time.

Diabetes specialist nurses (DSNs) were also given a questionnaire on diabetes technology, especially with regards to virtual clinic review. In a majority (83.9%) of virtual reviews DSNs felt that diabetes systems were easy to use. In addition, 82.3% of DSNs were confident in interpreting the data. From the virtual review DSNs advised changes to insulin therapy in 69.4% of patients. Virtual clinic review using this data was beneficial in nearly 70% of cases (69.4%) however there were problems with patients answering phones, failure to upload diabetes data or general disengagement.

2.2.3.2 Focus Group Results

The thematic analysis produced five main themes: benefits and drawbacks of diabetes technology, the impact on familial and social relationships, school issues and the use and understanding of diabetes device output data (see supplementary table for themes and subthemes appendix 1).

Many participants focused on how diabetes technology improved the quality of life of young people with diabetes. Participants frequently used phrases such as ‘my life has changed’, ‘gamechanger’ and ‘transformational’ (CAH4) with many stating they simply ‘couldn’t go back’ (DHH7) to injections.

Many parents stated they previously regularly had to check their child’s blood glucose levels in the middle of the night but now did not. Parents stated ‘we can sleep through the night as we trust the alarms' (CAH6, CAH4). Parental anxiety around mealtimes was also reduced because they did not have to worry about eating enough for the insulin dose, they gave pre-food. Some parents stated that 'mealtimes are easier because we don't have to inject before eating and then make them eat enough for the amount of insulin we gave' (WP2, DUN4). Diabetes technology also provided 'flexibility and convenience' (WP1, DHH1, DHH3) and the potential for children to 'manage [diabetes themselves] (DHH8).

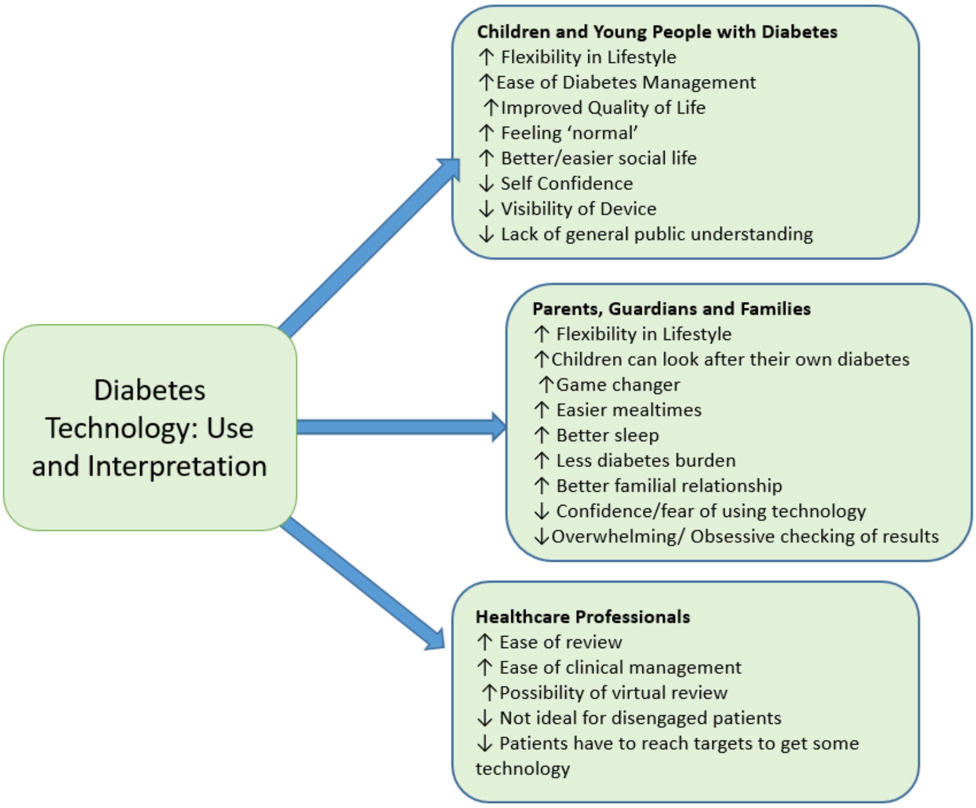


Figure 36: Focus group analysis - most prominent issues

Whilst many participants felt there were no real drawbacks to the technology, some parents found the initial change to technology challenging with parents feeling, 'you really have to learn diabetes again' (DHH2, DHH3, WP2). Despite many parents relying on the alarms during the night, some felt they were disruptive' (DHH1, DHH8, DHH6, CAH3) and 'driving [them] crazy' (DHH2). Parents also tended to fixate on glucose levels due to easy access to the diabetes data, parents stated they had a need to ‘constantly check their phone’ (DHH1) and ‘overanalyse’ (DHH9), perhaps ‘ignorance was bliss’ (DHH1).

Concerns with self-confidence (DHH4, DUN2, DUN4), ‘inflamed skin’ (DHH2) and ‘skin is destroyed’ (DHH8). Young people reported worries with their diabetes devices being visible through clothes, including their school ‘white uniform shirts’. Young people also reported teasing in school due to their diabetes devices.

Other issues in school were teacher ignorance, shouting at young people with diabetes using their phone despite the need to check blood glucose levels. In addition, many described not being allowed to leave class to deal with diabetes management or emergencies. Many parents described teachers as ‘rude’ about their child’s diagnosis and describing it as ‘another thing to deal with’.

School stress is just one of the impacts on familial life with many parents feeling the whole house [is] affected by it (DHH8). Conversations often focus on diabetes and therefore siblings often feel ‘jealous of the attention’ (CAH5, CAH6, DUN5) with comments from siblings such as ‘he/she’s type 1, or he/she doesn’t have to do anything like chores’ (CAH4).

Social life can also be impacted with parents describing ‘‘no parties, no invitations’ (DHH5, DHH7, CAH 4, CAH5) because other parents fear diabetes. Oftentimes, parents had to accompany their children like ‘a spare wheel’ due to other parent’s lack of understanding and constant asking ‘can he/she eat this?’ (DHH5, DHH6).

While technology has impacted diabetes management for the better, parents were more cautious about technology while the ‘new generation embraces technology’ (DHH3, CAH7, CAH8). Despite this potential fear most parents felt that some graphs gave them ‘peace of mind’ (DHH3) while others were ‘complicated’ and ‘difficult’. Parental fatigue due to diabetes management was also described with parents stating they wanted ‘ME time, I’ve had enough of diabetes by the end of the day’ (DHH3).

2.2.4 Discussion and Conclusions

It was evident that respondents felt diabetes technology was ‘transformational’ and a ‘gamechanger’ allowing a better quality of life, more flexibility and freedom and reduced carb counting stress (Hoogma et al., 2006, Rankin et al., 2015). Reflections on parents and children getting more restful sleep and not needing to check glucose levels in the middle of the night echo the literature (Hoogma et al., 2006, Rankin et al., 2015).

From the focus groups it was clear that these devices allow independence and freedom to young people with diabetes, often allowing them to self-manage their diabetes. The ability for parents to monitor fluctuations from their own devices made them feel more confident in allowing their children to self-manage. It should however be noted that access to glucose levels must be granted to the parents by their children. One young person commented they felt ‘normal’ now because of diabetes devices (Barnard and Skinner, 2008). Despite the clear advantages, drawbacks including parents obsessively checking glucose levels are seen (Sullivan-Bolyai et al., 2004).

A study undertaken by Sullivan-Bolyai et al (2004) showed that it took parents between 10 days to 2-3 months to become comfortable with pump management which was also echoed in the study.

Some other disadvantages included infusion site issues (Hoogma et al., 2006), bruises and marks. In addition, concerns about wearing diabetes technology, especially when it is visible were discussed in a social and educational context. These views echoed those of Pettus et al, 2017 who describe people with diabetes as emotionally and physically uncomfortable with wearing technology (Pettus and Edelman, 2017). Multiple respondents stated their diabetes devices were visible under their white school uniform shirt, meaning they got teased and called names. Support in schools was not consistent across school levels or places as in other literature (Rankin et al., 2015).

While this study was conducted pre-COVID, the use of virtual clinics in healthcare is increasing. The use of diabetes technology and ability to upload diabetes daily and monthly results can help clinicians with diabetes management and care. Questionnaires showed that 80% of participants felt uploading the data were easy while DSNs felt virtual clinics were appropriate in 75% of patients.

This study found that there are many benefits and drawbacks of the use of diabetes technology. While the drawbacks are discussed, most simply could not go back to previous regimes. In addition, a majority of parents, young people and healthcare professionals were comfortable with using and uploading diabetes data. Despite this, respondents felt that some graphs were easier than others and there could be abundance and overload of information in some cases.

We recommend further education on diabetes data interpretation by children and young people. In addition, further public awareness campaigns, especially to teachers and education assistants could be provided. By increasing general awareness and knowledge diabetes and hypoglycaemic symptom recognition and diabetes management could be improved.

Strengths: This study gathered a large amount of data given by a number of children, young people and their families. The data were rich, and this insight can and will resonate globally.

Limitations**:** Many respondents were parents rather than the young people therefore only a small amount of young people's opinions were collected. In the future the effect of technology and technology on families, social lives and education should be investigated further.

2.2.5 My contributions to the study

- Helped to lead the study and helped with audit applications, formulation of questionnaires and guide questions for focus groups
- Attended all focus groups and recorded transcripts of the focus group
- I was one of the two qualitative reviewers for the project and helped establish the analysis tables
- Completed all final qualitative and quantitative analysis
- Drafted and wrote the initial paper for review by co-authors
- Edited the paper with all suggested changes from all co-authors and ensured it was ready for submission
- Submitted to several journals and re-formatted for submission to other journals
- Led on major corrections for the journal – we are still awaiting reply from the journal

2.3 Diabetic Eye Screening

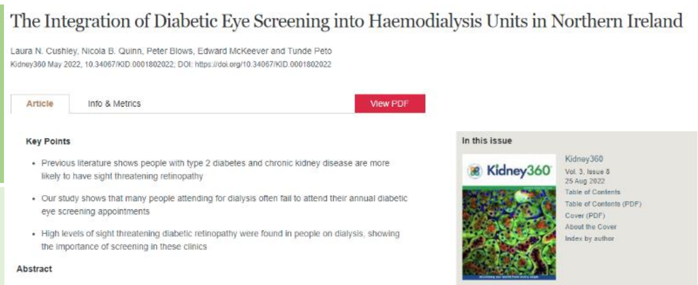
As previously mentioned, diabetic retinopathy is one of the most common microvascular complications of diabetes and thus annual screening for everyone over the age of 12 is recommended. Annual eye screening can provide timely detection and treatment of diabetic retinopathy, preventing permanent debilitating vision loss.

The following studies were on attendance at screening, prevalence of DR and the bringing screening to people with co-morbidities.

2.4 Diabetic Eye Screening of Haemodialysis Patients in Renal Units, Northern Ireland

Laura N Cushley, Nicola B. Quinn, Peter Blows, Edward McKeever, Tunde Peto

Published: Kidney 360 - *https://kidney360.asnjournals.org/content/early/2022/05/18/KID.0001802022*


The Integration of Diabetic Eye Screening into Haemodialysis Units in Northern Ireland

Laura N. Cushley, Nicola B. Quinn, Peter Blows, Edward McKeever and Tunde Peto

Kidney360 May 2022, 10.34067/KID.0001802022; DOI: https://doi.org/10.34067/KID.0001802022

Article | Info & Metrics | View PDF

Key Points

- Previous literature shows people with type 2 diabetes and chronic kidney disease are more likely to have sight threatening retinopathy
- Our study shows that many people attending for dialysis often fail to attend their annual diabetic eye screening appointments
- High levels of sight threatening diabetic retinopathy were found in people on dialysis, showing the importance of screening in these clinics

Abstract

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2.4.1 Introduction

From chapter 2, we know the global prevalence of diabetes among adults has nearly doubled from 1980 when it was 4.7% to 8.5% in 2014 (Sarwar et al., 2010). Renal disease is a microvascular complication of diabetes like diabetic retinopathy; therefore, these conditions often go hand in hand. A study of over 28,000 people with type 2 diabetes found those with chronic kidney disease were more likely to present with diabetic retinopathy (Lee et al., 2014). Approximately 20-30% of people with diabetes (type 1 and type 2 diabetes respectively) suffer from chronic kidney disease (Shahbazian and Rezaii, 2013) some of which require dialysis several times per week often leaving other healthcare appointments as a non-priority. This often means people on dialysis fail to attend their annual diabetic eye screening appointment.

The most recent UK Renal Registry Report predicts that 35-38% (UK Renal Registry, 2021) of patients on Renal Replacement Therapy are on ‘in-clinic’ (attendance at a renal unit) haemodialysis. In Northern Ireland in 2019 there were 556 people on in clinic haemodialysis (including those with diabetes and without) with approximately 28% due to diabetes (general UK figure).

Aim: To assess the attendance at DESP and DR severity in patients with diabetes undergoing haemodialysis in Northern Ireland.

2.4.2 Research Design and Methods

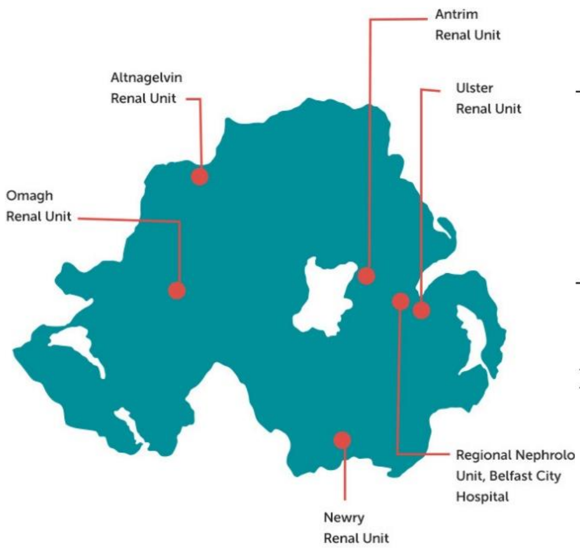


Figure 37: Map of renal units in Northern Ireland (Source: Business Services Organisation)

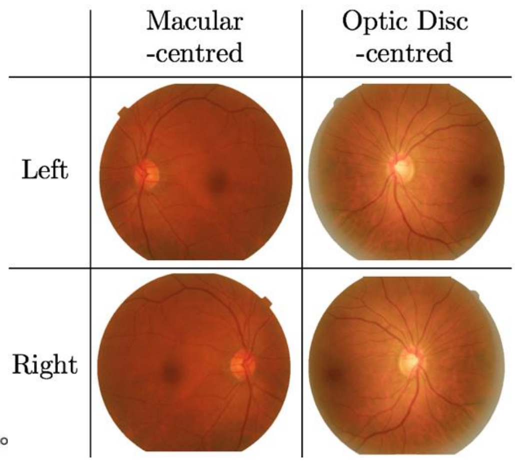


Figure 38: Example of macular and optic disc centred images (Source: (Bellemo et al., 2019)

There are six adult renal units across Northern Ireland. Between April and October 2021, all patients on haemodialysis with diabetes were offered their annual diabetic eye screening appointment in their renal dialysis unit as a new initiative. A diabetic eye screening team, including a retinal photographer came to each unit and performed patient screening before or after the patient’s dialysis appointment. All patients were dilated using 1.0%

tropicamide and macula and disc centre fundus image were taken of each eye using a Canon CR-2 non-mydriatic tabletop camera. Macula centred images were also taken in four centres using an Optomed Aurora Handheld Fundus Camera, where possible a disc centred image was also taken. Anterior segment images were also taken if a media opacity (such as cataract) was present.

Retinal images from the tabletop camera were graded by qualified DESP graders using the UK national grading definitions of no visible retinopathy (R0), background retinopathy (R1), pre-proliferative retinopathy (R2), active proliferative retinopathy (R3A), stable proliferative retinopathy (R3S), no maculopathy requiring referral (M0) and maculopathy requiring further evaluation (M1). Handheld camera images were also graded by a qualified grader using the same system. Demographic information, retinopathy grade and date of last appointment were recorded on an excel spreadsheet.

Basic frequency analysis on demographics, retinopathy grade and attendance at screening was conducted using SPSS Statistical Package Version 26.

2.4.2.1 Ethical Approval

Caldicott guardian approval from the Quality and Audit department in the Belfast Health and Social Care Trust, audit ID 6039, was obtained.

2.4.3 Results

In total, 149 people were offered eye screening in their respective renal dialysis units. Of these, 132 attended, the other 17 did not attend due to rejection of appointment, medical emergency or non-attendance at dialysis.

The age range of attendees was 33-91 years and 59.1% were male. Prior to their screening, one person had a known retinal vein occlusion and two others had no perception of light.

Only 36 people had been screened in the previous 18 months, while 42 had not been seen in over 2 years, 21 had a 3-year interval and 26 had over 4 years of non-attendance. Twenty-one people had never attended eye screening before and three were too sick to attend at all.

Most (96%) arrived for screening in wheelchairs, with only 20% able to transfer to the screening chair. Canon non-mydriatic imaging was possible in 92.4% while handheld was possible in all patients where it was offered. Ten patients were only imaged using the handheld camera due to large wheelchairs (unable to fit under the imaging table) or stretcher.

Of those screened, 28 (21.2%) had no retinopathy (R0), 36 (27.3%) had background retinopathy (R1) and 30 (22.7%) had sight threatening retinopathy (R2, R3A, R3S) in their worst eye. Seventy-seven people (58.3%) had no maculopathy (M0) while 14 (10.6%) had some level of maculopathy (M1). Thirty-five people (26.5%) required slit lamp referral due to media opacities. Three (3%) were ungradable for maculopathy (due to media opacity).

Retinopathy Grade (Worst eye)	**Total from screening in RDU (%)**	Progression from previous retinopathy	Total
		Stable retinopathy	73
No Retinopathy (R0)	28 (21.2%)	No Retinopathy -> Background Retinopathy	7
Background Retinopathy (R1)	36 (27.3%)	Background Retinopathy ->Sight-Threatening Retinopathy	9
Sight Threatening Retinopathy (R2, R3A, R3S)	30 (22.7%)	Sight Threatening Retinopathy -> No Perception of Light	1
Maculopathy Grade			
No Maculopathy (M0)	77 (58.3%)		
Maculopathy (M1)	14 (26.5%)		
Other			
Referred for Slit Lamp	35 (26.5%)		

Table 5: Diabetic retinopathy results from screening in haemodialysis units and progression results

When compared to previous DESP results, 7 progressed from no DR to background retinopathy, while 9 progressed from background to sight threatening retinopathy. One person progressed from sight threatening retinopathy to no perception of light.

Of those who did not attend previously (21), seven had sight threatening retinopathy and three had background retinopathy. Three people who were previously treated had reactivated and required treatment. Seventy-three people had stable retinopathy levels. The rest had no previous DR grades due to non-attendance or DNA, slit lamp or referral to hospital eye services.

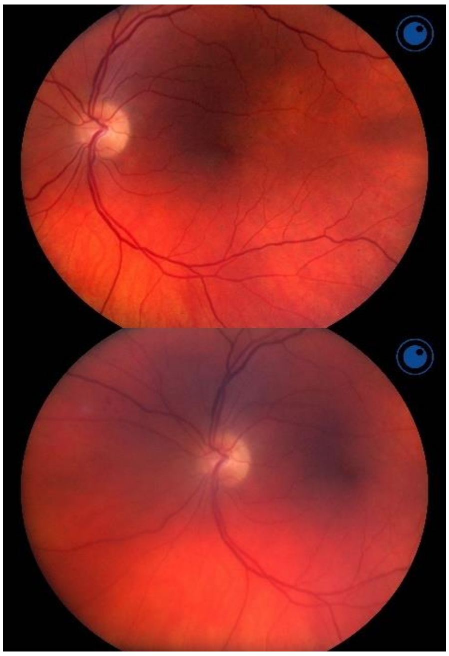


Figure 39: Examples of Optomed handheld images

Of the 52 people imaged on Optomed handheld fundus camera, 38 had gradable images on both handheld and tabletop camera. Twenty-one (55.3%) people's images were in full agreement with grades from tabletop imaging and 13 (34.2%) had grades within one level of background/no retinopathy (R0/R1). Grading for four patients was not in agreement, two people's sight-threatening retinopathy was missed on handheld camera, these patients lacked a disc centred image.

In-built artificial grading on Optomed Aurora handheld camera was used on a small cohort of 17 people's images, of these, 15 had a grade on the conventional camera as well for ground truth. Artificial grading agreed with eight of the human graders' conventional camera image decision while four did not. No sight threatening diabetic retinopathy was missed. Three people's images were deemed ungradable.

Of those referred urgently, six people have been seen and treated by hospital eye services, three failed to attend and five are still awaiting suitable appointment. Three people had died since referral to the hospital. Of those referred routinely, two were invited to hospital eye services, one attended, and one is to be seen in six months.

2.4.4 Discussion and Conclusions

This is the first published study to report on the integration of diabetic eye screening into haemodialysis clinics regionally. Our results show that approximately 24% had sight threatening retinopathy of which 12.9% (17) required urgent referral and 2.3% required routine referral to hospital eye services. This is several times higher than reported in the 2016/2017 by the National Diabetic Eye Screening Programme Report in England where 2.4% required routine and 0.4% required urgent referral (Scanlon, 2017). While it could be argued that there is a percentage of people with diabetes on haemodialysis, it is clear many have sight threatening retinopathy. This group should be seen as a high-risk group for sight loss who should be offered ongoing annual screening in their respective renal clinics.

This patient group is known for having competing healthcare priorities, with haemodialysis coming first. In addition, these patients are often under the impression that their diabetes care and management is taken care of by their renal team and have a limited knowledge on other possible complications. These patients are also often very ill and fatigued and often struggle to drive or find adequate transportation. People on dialysis are also often reliant on their eyesight to read, watch TV or continue other hobbies during their frequent dialysis sessions.

In conclusion, people on haemodialysis are a high-risk group who often require referral for sight threatening retinopathy. By providing eye screening within the renal unit, we can save patient time, reducing non-attendance and maintaining quality of life and vision in this patient group.

Strengths

- This is the first published report on integrating diabetic eye screening into renal dialysis units regionally
- The study collected data on all those in Northern Ireland with Diabetes on Renal Dialysis
- Images were captured on over 88% of this population, some of which had never attended screening or had not attended in several years

Limitations

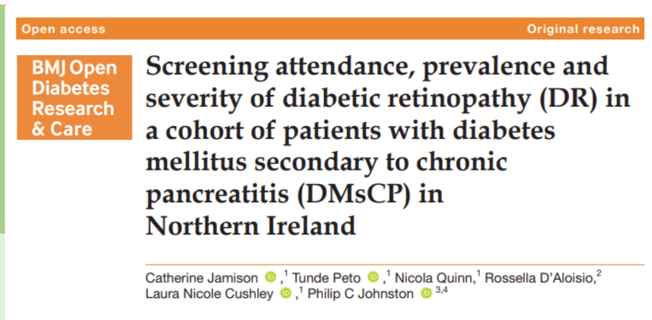
- While it is a regional study, the number of people is still relatively small
- Data on HbA1c, diabetes management, diabetes duration and other lifestyle impacts was not available for analysis

2.4.5 My contributions to the Study

- Took over leading this project from a previous colleague who had screened in the Belfast City Hospital
- Established relationships (primarily with Antrim Area Hospital) and became part of a sub-group of professionals in diabetes care in Antrim Area who were able to provide introductions to other units
- Attended 5/6 units on the days of diabetic eye screening and saw all patients with the help of a screener on these days
- Collected all data and graded all handheld retinal images – some of which needed referred due to tabletop camera images not being available/ungradable
- Conducted statistical analysis on the data
- Drafted the initial paper for corrections and suggestions by colleagues
- Incorporated all proposed changes to the manuscript before submission
- Submitted to several journals and reformatted according to resubmission journal
- Led on minor corrections for the accepted manuscript
- Led on proofreading the published manuscript

2.5 Diabetic Eye Screening of Patients with Diabetes Mellitus Secondary to Chronic Pancreatitis, Northern Ireland

Catherine Jamison, Tunde Peto, Nicola Quinn, Rossella D'Aloisio, Laura Nicole Cushley, Philip C Johnston



Open access Original research

BMJ Open Diabetes Research & Care

Screening attendance, prevalence and severity of diabetic retinopathy (DR) in a cohort of patients with diabetes mellitus secondary to chronic pancreatitis (DMsCP) in Northern Ireland

Catherine Jamison [1], Tunde Peto [1], Nicola Quinn [1], Rossella D'Aloisio [2], Laura Nicole Cushley [1], Philip C Johnston [3,4]

***Published*: Diabetes Care -** https://pubmed.ncbi.nlm.nih.gov/34493494/

2.5.1 Introduction

In addition to the well-known type 1 and type 2 diabetes, there are also other causes of diabetes which can be secondary to another illness. One of these causes can be chronic pancreatitis, which as the name suggests affects the pancreas – the organ which produces insulin. Around 50% of people with chronic pancreatitis will develop pancreatogenic diabetes (type 3c) (Ewald et al., 2012, Makuc, 2016). Despite an abundance of diabetes research and interest, there is a scarcity of literature and data on the attendance to eye screening and prevalence of diabetic eye disease in this cohort.

Aim: To assess people with 'type 3' pancreatogenic diabetes severity, prevalence and attendance at diabetic eye screening across Northern Ireland.

2.5.2 Research Design and Methods

This study was conducted from 2017-2019 and included all patients with diabetes secondary to chronic pancreatitis in Northern Ireland. In 2017, 78 patients attending a specialised clinic were reviewed for presence and severity of diabetic retinopathy (using the English National DR screening guidelines (Harding et al., 2003) as well as their attendance at annual retinopathy screening appointments. A review of the same cohort of patients was then conducted in 2019 following a combined effort to provide co-ordinated services for these patients. The previous 78 were reviewed along with an additional 16 people (total 94). Of the 94, 71 patients had at least two DR grades for comparison. Progression was defined as any increase in retinopathy and maculopathy grading score; regression was any decrease. Clinical data was collected using the Northern Ireland Electronic Care Record (NIECR) and statistical analyses were carried out using SPSS v.26.

2.5.2.1 Demographic Results

The mean age was 57 ±10.1 with a range 29–87 years and a majority, 81% were male. The mean duration of chronic pancreatitis was 13.6±6.9 (range 4–42 years), with a mean diabetes duration of 10.3±5.9 (range 3–34 years). Mean HbA1c was 8.9%±4.1% (74.3±20.9mmol/mol), range 4.8%–14.8% (29–138mmol/mol), and mean body mass index (BMI) was 25.3±6.0kg/m2 (range 13–37).

The most common cause of cause of chronic pancreatitis was alcohol abuse (75% (n=70) followed by gallstones at 9% (n=8), with 4% caused due to hypertriglyceridemia, and medication-induced and portal vein thrombosis (n=4). The cause was unknown in 11 patients (12%) and information was unavailable for one patient.

2.5.3 Attendance at Diabetic Retinopathy Screening

In 2017, 51 (65%) had attended annual diabetic eye screening; 27 had not previously attended. Of these, three (4%) were not registered with eye-screening. In 2019, attendance had improved with 86 of 94 patients (91%)

having attended screening; of the remaining 8 (9%), two were unknown to retinopathy screening services. Many had missed previous appointments with 24% missing 1-2 appointments, twenty-four percent had missed at least one appointment, 21% missing three to four missed appointments and 13% failing to attend five to eight times; categories were mutually exclusive. In 2017, 39 patients (76%) had no DR, 9 (18%) had background DR, two (4%) had pre-proliferative DR and one (2%) had proliferative DR. Five (10%) had maculopathy in at least one eye.

Variable (n=94)		Value	vs worst-eye retinopathy (P)	vs worst-eye maculopathy (P)
Mean age (range)		56.97 (29–87)	0.40	0.51
Gender, n (%)	Female	18 (19.1)	0.64	0.42
	Male	76 (80.9)		
Mean duration of chronic pancreatitis, years (IQR)		13.56 (8)	0.001	<0.001
Mean duration of diabetes, years (IQR)		10.29 (7)	0.001	0.030
Mean most recent HbA1c %/mmol/mol (SD)		8.9/74.33 (4.1/20.90)	0.94	0.30
Mean BMI, kg/m^2 (SD)		25.30 (5.99)	0.55	0.22
Mean weight, kg (range)		74.90 (33–120)	0.82	0.24
Mean ACR (IQR)		13.37 (9)	0.83	0.53
Etiology of patients with pancreatitis (%)	Alcohol	70 (74.5)	0.76	0.64
	Gallstones	8 (8.5)		
	High cholesterol	1 (1.1)		
	Unclear	11 (11.7)		
	Portal vein thrombosis	1 (1.1)		
	CF gene carrier	1 (1.1)		
	Medication induced	1 (1.1)		
No of screening DNAs (%)	0	39 (42)	0.09	0.13
	1–2	23 (24)		
	3–4	20 (21)		
	5–8	12 (13)		
Worst-eye retinopathy/maculopathy grade no of patients (%)	R Visit 1	R Visit 2	M Visit 1	M Visit 2
R0/M0	39 (76)	54 (63)	46 (90)	76 (88)
R1/M1	9 (18)	26 (30)	5 (10)	10 (12)
R2	2 (4)	2 (2)	–	–
R3	1 (2)	4 (5)	–	–
Change in retinopathy/maculopathy scores between visits compared with various parameters. RE=right eye, LE=left eye, RP=retinopathy progression, MP=maculopathy progression				
Follow-up (n=71)	vs RE RP	vs LE RP	vs RE MP	vs LE MP
Gender	0.83	0.62	1.00	1.00
BMI (kg/m^2)	0.54	0.27	0.72	0.32
Weight (kg)	0.73	0.95	0.29	0.24
Most recent HbA1c	0.21	0.76	0.87	0.88
ACR	0.50	0.14	0.29	0.30
Etiology of pancreatitis	0.71	0.32	1.00	1.00
Duration of chronic pancreatitis (years)	0.08	0.50	0.18	0.57
Duration of diabetes (years)	0.35	0.35	0.07	0.24

ACR, albumin-creatinine ratio; BMI, body mass index.

Table 6: Characteristics of study population and statistical analyses for the complete 2019 database (n=94) and follow-up screening grade comparisons (n=71):

In 2019, 63 % (54) had no DR, 30% (26) had background DR and 7% (6) had sight threatening DR (proliferative and pre-proliferative DR). Ten (12%) had maculopathy in at least one eye. No significant difference was found between worst-eye retinopathy/maculopathy grade and HbA1c, gender, BMI, weight, cause of pancreatitis, screening attendance or number of missed appointments ($p>0.05$). Those with proliferative DR had a longer duration of diabetes (PDR: 18.5 years vs no DR: 7.5 years, $p=0.001$) and pancreatic disease (PDR: 19 vs no DR: 11 years, $p=0.001$) as compared with those with no DR. Altogether, 71 patients had first and second visit retinopathy/ maculopathy grades for comparison.

There were retinopathy and maculopathy grades for 71 patients in both 2017 and 2019, allowing for comparison. Patients had an average of 2.1 years between retinopathy screening visits. Retinopathy progression was found in 22 patients, 5 (7%) in both eyes and 17(24%) in one eye only. Three progressed to proliferative retinopathy while six patients regressed. Two patients developed maculopathy while two regressed. No statistically significant association was found between progression of retinopathy/maculopathy and HbA1c, BMI, weight, gender, albumin-creatinine ratio (ACR), cause of pancreatitis, duration of pancreatitis or diabetes ($p>0.05$).

2.5.4 Discussion and Conclusions

Diabetes caused by chronic pancreatitis is unique and is often challenging to manage and can go undetected for many years. This can in turn cause issues with screening for complications and there are limited data on true retinopathy rates and severity in this cohort. There is a large variability in previous literature with estimates of 7.4% to 63%, (Nakamura et al., 1994, Tiengo et al., 1983, Couet et al., 1985, Maekawa et al., 1978, Sevel et al., 1971, Gullo et al., 1990, Verdonk et al., 1975) with duration of diabetes, severity of pancreatitis and poor glycaemic control being main contributors. Currently there is only one prospective study to date which included 54 patients with chronic pancreatitis or pancreatectomy and assessed the presence and severity of retinopathy using fluorescein angiogram and ophthalmoscopic examination (Tiengo et al., 1983). This paper showed 31% with background DR while none had proliferative diabetic retinopathy which contrasts to the results of our study.

Despite complications in secondary diabetes often being considered lower than for type 1 and 2 diabetes our 37% retinopathy/maculopathy prevalence is within the range of similar duration in patients with type 2 diabetes (Voigt et al., 2017). This high prevalence could also be associated with greater clinical emphasis on attendance at retinopathy screening in this hard-to-reach patient population. These patients were very hard to engage and the work to do this was considerable. This study however shows the true importance of reaching this patient cohort for complication assessment while providing accessible and equitable care.

Strengths

- This is the largest study to date with all 94 patients having well-characterised chronic pancreatitis while attending a specialised clinic.
- This regional data can be used as a general rate of retinopathy and maculopathy in people with type 3c globally

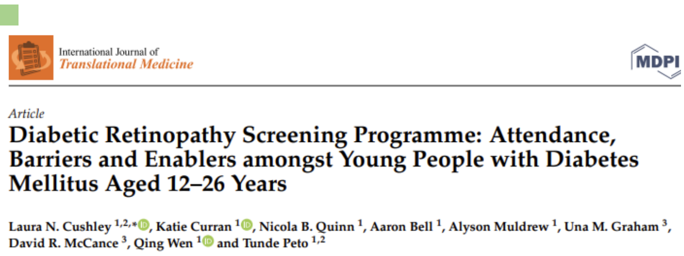
Limitations

- This is a small cohort and population and wider studies should be conducted globally
- This study does not take into account the many other clinical and social issues associated with chronic pancreatitis, namely alcohol dependence, liver dysfunction, poor nutrition and malabsorption (Hart et al., 2016)
- Lifestyle factors including smoking, poor nutrition (including vitamin D deficiency) and the contribution of malabsorption (pancreatic insufficiency) were not assessed in this study but could form the basis of future research

My contributions to the study

- Aided in the collection of secondary data from hospital systems
- Helped with editing the manuscript for submission
- Assisted with corrections and minor changes for resubmission before publication

2.6 Diabetic Retinopathy Screening Programme: Attendance, Barriers and Enablers amongst Young People with Diabetes Mellitus Aged 12–26 Years


International Journal of Translational Medicine
MDPI

Article

Diabetic Retinopathy Screening Programme: Attendance, Barriers and Enablers amongst Young People with Diabetes Mellitus Aged 12–26 Years

Laura N. Cushley [1,2,*], Katie Curran [1], Nicola B. Quinn [1], Aaron Bell [1], Alyson Muldrew [1], Una M. Graham [3], David R. McCance [3], Qing Wen [1] and Tunde Peto [1,2]

Laura Cushley, Katie Curran, Nicola Quinn, Aaron Bell, Alyson Muldrew, Una Graham, David McCance, Qing Wen and Tunde Peto

Published: International Journal of Translational Medicine *- https://www.mdpi.com/2673-8937/1/3/11*

2.6.1 Introduction

As of 2021, there are approximately 112,000 people living with a diagnosis of diabetes mellitus in a population of 1.9 million. Of these, approximately 2350 are young people aged 12-26.

As previously mentioned, good compliance at annual diabetic eye screening is essential as non-attendance is often associated as the greatest risk factor for diabetes related blindness (Lewis, 2011). As retinopathy is progressive in nature, it is important that children and young people establish good attendance patterns early in life (Harris and Lacey, 2014). Despite the clear need of attending annual diabetic eye screening, children and young people are known to be the poorest attenders at screening with only 50-68% attending DESPs annually in the UK (Bone, 2019, Gulliford et al., 2010, Moreton et al., 2017). In Northern Ireland in 2016/2017 the attendance rate was 73.8% in people aged 12-17 and only 51.8% in people aged 18-30 (Public Health Agency and Belfast Health and Social Care Trust, 2017). Previous studies in the rest of Europe reported there were many potential barriers to non-attenders including lack of awareness, fear, duration of diabetes, deprivation, working age group and transport and access issues (Bone, 2019, Cetin et al., 2013, Harris and Lacey, 2014, Kashim et al., 2018, Lewis, 2011, Lewis et al., 2007, Moreton et al., 2017, Scanlon et al., 2016).

Aim: to determine level of attendance and barriers and enablers of attendance at diabetic eye screening in a local context.

2.6.2 Methods

<u>Ethical Approval</u>

Ethical approval was obtained through the Health and Social Care Integrated Research Application System (IRAS) pathway and was given favourable opinion on 13 June 2019, reference number 19/NI/0112. The project was sponsored by the Belfast Health and Social Care Trust.

2.6.3 The Study

This is a mixed methods study which included retrospective analysis of young people's medical records and a prospective questionnaire.

2.6.3.1 Retrospective Analysis

The NI Diabetic Eye Screening Programme uses the Optomize administration system. This system was used to gather a majority of the retrospective data including demographic information, retinopathy and maculopathy grades, most recent attendance date, smoking status (self-reported) and diabetes duration (reported by the General Practitioner (GP). The total number of young people aged 12-26 with diabetes was 2370, 23 were removed due to duplication, changes in marital surname and death. Data were collected between 10th June 2019 and 10th October 2019. Postcodes were used to determine the deprivation score of each patient. The Northern Ireland Multiple Deprivation Measure (NIMDM2017) ranks small areas in Northern Ireland in the order of most deprived (0) and least deprived (890) according to 7 domains including Income Deprivation, Employment Deprivation, Health Deprivation and Disability, Education, Skills and Training Deprivation, Access to Services, Living Environment and Crime and Disorder.

Attendance at eye screening for the purpose of this study was coded as attended, did not attend (DNA) and did not respond to invitation (DNRI). For further analysis, attendance was categorized as good (0 DNAs and DNRI), moderate (1–3 DNA/DNRI), and poor (more than 4 DNA/DNRI) (Table 1) engagement. Engagement was defined as any contact with the young person inclusive of sending appointment letters, attendance at appointments and cancellation of appointments.

Characteristics Engagement (%)		Total 1831 (100)	Good 720 (39.3)	Moderate 804 (43.9)	Poor 307 (16.8)
Age, n (%)	Under 15	387 (21.1)	269 (37.4)	103 (12.8)	15 (4.89)
	16-19	489 (26.7)	162 (22.5)	228 (28.4)	99 (32.25)
	20-22	417 (22.8)	122 (16.9)	215 (26.7)	80 (26.06)
	23-26	538 (29.4)	167 (23.2)	258 (32.1)	113 (36.8)
Gender, n (%)	Male	974 (53.2)	379 (52.6)	442 (55.0)	153 (49.8)
	Female	857 (46.8)	341 (47.4)	362 (45.0)	154 (50.2)
Type of Diabetes, n (%)	Type 1	1796 (98.09)	705 (97.92)	788 (98.0)	303 (98.7)
	Type 2	35 (1.91)	15 (2.08)	16 (2.00)	4 (1.30)
Smoking Status, n (%)	Non-Smoker	834 (45.55)	342 (47.5)	371 (46.1)	121 (39.4
	Smoker+ Ex	180 (9.83)	56 (7.78)	84 (10.5)	40 (13.0)
	Unknown/Undefined	817 (44.62)	322 (44.7)	349 (43.4)	146 (47.6)
Worst eye grade, n (%)	R0	1293 (70.6)	573 (79.58)	537 (66.8)	183 (59.61)
	R1	482 (26.3)	138 (19.17)	234 (29.1)	110 (35.83)
	R2+	56 (3.10)	9 (1.25)	33 (4.10)	14 (4.56)
Maculopathy, n (%)	Yes	66 (3.60)	16 (2.20)	30 (3.73)	20 (6.51)
	No	1765 (96.4)	704 (97.8)	774 (96.27)	287 (93.5)
Deprivation Score	Mean (SD)	456.01 (246.43)	454.75 (242.19)	466.06 (250.80)	432.61 (243.87)
Diabetic Clinic Attendance n (%)	Yes	1524 (83.2)	642 (89.2)	659 (82.0)	223 (72.6)
	Frequently DNA	307 (16.8)	78 (10.8)	145 (18.0)	84 (27.4)
Diabetes Duration, n (%)	5yrs& Less	285 (15.6)	201 (27.9)	74 (9.20)	10 (3.26)
	5-10yrs	177 (9.67)	88 (12.2)	72 (8.96)	17 (5.54)
	10+yrs	249 (13.6)	92 (12.8)	126 (15.7)	31 (10.1)
	Unknown/Undefined	1120 (61.2)	339 (47.1)	532 (66.2)	249 (81.1)
HbA1c	Median (IQR)	68mmol/mol (58.5-83)	66mmol/mol (57-79)	69 mmol/mol (59-85.3)	73 mmol/mol (61-89)

Table 7: Characteristics of patients attending diabetic eye screening service stratified by engagement index (n=1831)

The data was entered into Microsoft Excel (Version 2102); 499 participants with missing information such as maculopathy, worst eye DR grade, diabetes clinic attendance and HbA1c, deprivation score was excluded from analysis. The demographics of the participants who were removed are as follows: Male 288 (57.7%), female 211 (42.3%), age range 12–26 with an age mean of 20.9 (SD-4, median—22, IQR 19–24), Type 1 diabetes 472 (94.6%) and

Type 2 diabetes 27 (5.41%). Comparison between included and excluded cases showed that there was no statistically significant difference between groups for gender. A statistically significant difference in age was found between included and excluded cases (19.5 versus 20.9 years, respectively), however the difference of 1.4 years is unlikely to be clinically relevant. Statistical Analysis Demographics and characteristics of participants attending DESP stratified by engagement index were analysed. Categorical and continuous variables were presented as a frequency (percentage), mean (standard deviation [SD]) or median (interquartile range) accordingly. The proportions of engagements levels defined as good, moderate and poor were calculated (Table 1). Brant's tests and Variance Inflation Factor (VIF) tests were performed to assess the parallel regression assumption and multi-collinearity of the data. Consequently, univariate and multivariate ordinal logistic regression analysis was performed to investigate the effects of the potential predictors on the level of patient engagement within the DESP service. Variables which were statistically significant ($p \leq 0.05$) in the univariate model were included in the final multivariate logistic regression model. All analyses were conducted using R (version 3.6.2, 12 December 2019, Platform: x86_64-w64-mingw32/x64, 64-bit) 3.

2.6.4 Results

2.6.4.1 Quantitative Analysis

There were 53.2% female and 46.8% male in the cohort. Age groups were nearly evenly distributed with 21.1% under 15 years old, 26.7% aged 16–19 years, 22.8% aged 20–22 years and 29.4% aged 23–26 years. Ninety-eight percent had type 1 diabetes and 1.91% had type 2 diabetes. The mean deprivation score was 456.01. Over 80% (83.2%) regularly attended their diabetes clinics with the median HbA1c at 68mmol/mol (IQR 58.5–83). Many (70.6%) had no retinopathy and 26.3% had background retinopathy (R1). Only a small proportion (3.1%) had pre-proliferative retinopathy (R2) or greater and similarly, only 3.6% had maculopathy.

2.6.4.2 Univariate Analysis and Full Model

Following analysis, age, smoking status, worst eye retinopathy grade, maculopathy, diabetes clinic attendance, duration of diabetes (years) and Hba1c (Log2) were statistically significant ($p \leq 0.05$) and therefore were included in the final model in the subsequent analysis.

Characteristics	**Univariate Analysis**		**Full Model**	
	P-value	**OR (95% CI)**	**P-value**	**OR (95% CI)**
Age				
Under 15	Reference		Reference	
16-19	<0.001	0.206 (0.156, 0.271)	<0.001	0.249 (0.187, 0.332)
20-22	<0.001	0.190 (0.143, 0.251)	<0.001	0.249 (0.184, 0.335)
23-26	<0.001	0.191 (0.145, 0.249)	<0.001	0.245 (0.181, 0.330)
Gender- Male	0.797	1.023 (0.861, 1.22)	--	--
Diabetes Type -1	0.495	0.805 (0.427, 1.50)	--	--
Smoking Status				
Non-smoker	Reference		Reference	
Smoker	0.00321	0.635 (0.469, 0.858)	0.561	0.908 (0.657, 1.26)
Unknown/Undefined	0.201	0.888 (0.741, 1.07)	0.473	0.931 (0.766, 1.13)
Worst Eye Grade				
R0	Reference		Reference	
R1	<0.001	0.521 (0.428, 0.635)	0.0794	0.818 (0.654, 1.02)
R2+	<0.001	0.362 (0.222, 0.588)	0.180	0.669 (0.372, 1.21)
Maculopathy - Yes	0.001	0.462 (0.291, 0.735)	0.843	0.946 (0.545, 1.64)
Diabetic Clinic Attendance - Yes	<0.001	2.17 (1.72, 2.73)	<0.001	1.89 (1.48, 2.42)
Diabetes duration				
5 years and under	Reference		Reference	
5-10 years	<0.001	0.413 (0.282, 0.602)	<0.001	0.396 (0.266, 0.589)
10+ years	<0.001	0.262 (0.186, 0.369)	<0.001	0.332 (0.230, 0.477)
Unknown/Undefined	<0.001	0.172 (0.13, 0.227)	<0.001	0.210 (0.155, 0.281)
Deprivation Score	0.524	1.0001 (0.9997, 1.0005)	--	--
HbA1c (Log_2)	<0.001	0.530 (0.423, 0.663)	0.00255	0.685 (0.535, 0.875)

Table 8: Logistic regression analysis – univariate (all variables) and full model analysis (significant variables)

It was found that younger people with diabetes (statistically significant ($p \leq 0.05$) for every one unit decrease in log2 HbA1c the odds of attendance increased by 46%.

2.6.4.3 Qualitative Analysis

Questionnaires were distributed through diabetes clinics, diabetes events, charities and word of mouth. While the questionnaire was share widely with over 100 people only 25 people responded. Despite the smaller sample size, data saturation of themes was reached.

Percentages from scaled questions in the questionnaire were grouped into quartiles (>25% minimally affects, 26–50%—some affect, 51–75%—moderately affects, 76+—strongly affects). Braun and Clarke's Thematic Framework Method was used to identify major themes. Fifty-two percent of respondents were male with more than half (56%) falling in the 16–20 years age group. The majority (84%) had been diagnosed between age 8–20 years (8–11 years—40%, 12–15 years— 28%, 16–20 years—16%). Most (72%) were in full time education in a secondary/high school, with 4% enrolled in university and 24% in full time employment.

Over half, 52%, reported a hospital admission caused by diabetes or diabetic ketoacidosis. Despite the increasing number of people with diabetes on insulin pumps there were only five in this cohort with most (72%) using carbohydrate counting, blood monitoring and insulin injections. When asked how their social life was affected, 24% stated minimally, 20% some, 20% moderate and 32% stating it strongly affected their social lives. In contrast, when asked whether their diabetes diagnosis created feelings of fear and anxiety, 44% stated it had minimal effect, 32% stated that it strong affects, 8% and 12% stated it has some and moderate effect respectively.

Most, 92%, were aware of how diabetes could affect the eye, with 72%, having been informed by their endocrinologist. Most, 88% were aware of the diabetic eye screening programme and stated they attend annual screening. Despite this positive response, only 72% were aware they must attend both their annual eye screening appointment and their community optometrist/optician usually every two years.

Respondents reported an overall positive eye screening experience (0 being not good and 100 being excellent), with 44% scoring it 100%, l 20% scoring above 75%, 16% 50–75% with only one below 50%. Seventy-six percent agreed that having their DESPNI appointment during their routine clinic attendance would be beneficial.

The main barriers of attendance were missing/getting time off work/school, location of appointments, lack of communication about other times/days available and physical access to screening appointments/venues. One respondent stated they were fearful of what their results might be as they had not attended for a long time.

The most common enabler was the time of appointments, with many (n = 11) wanting later appointment times. Other respondents also wanted more education around the potential effect of diabetes on the eye as it would motivate them to attend. Many felt that they would prefer information presented digitally and in a more understandable format, as opposed to ‘fear tactics'. Respondents felt that online booking and venues in universities, schools and routine diabetes clinics would improve attendance.

Respondent recommendations included shorter appointment times, to be seen more than once a year, with quicker result times and greater availability to appointments. One respondent wanted better camera maintenance due to their appointment being cancelled twice due to camera failure.

2.6.5 Discussion

This study found that age, diabetes duration, routine attendance at diabetes clinics and HbA1c levels were main factors of attendance. Qualitative assessment showed that other factors such as times of appointments, taking time off school and work and being aware of the importance of attendance affected attendance.

Age was found to be an important factor with people under 15 more likely to attend that those ages 16-26. There are a few potential reasons for this including greater parental involvement and more freedom and responsibility after 16. At 16 parents can become less involved in their child's medical care and many start to learn to drive. This section of life is also one with an abundance of change and independence including going to university, moving out or seeking employment and apprenticeships.

In addition, people with a shorter duration of diabetes were more likely to attend. This could be due to diabetes management complacency, development of unrealistic optimism that they are not vulnerable to complications (Lake et al., 2017) or contrarily, denial or fear of finding out results.

The literature suggests that raising awareness of diabetic eye disease is key to prevention and treatment especially as many are unaware of the true impact of retinal disease (Bone, 2019, Hipwell et al., 2014). In addition, many were unaware that retinopathy is often asymptomatic until treatment is no longer as effective (Lewis, 2011, Lian et al., 2018).

Whilst it is important to inform people of these potential effects information leaflets must be well-designed, easily accessible and understandable (Lake et al., 2020). The importance of attendance at both eye screening and high-street optometrists could be emphasised in these leaflets (Hipwell et al., 2014).

This study showed the importance of engagement at diabetes appointments as this can influence and provide information which is essential for understanding the risks of diabetic eye disease (Bone, 2019). A multidisciplinary approach where all healthcare professionals deliver education on the importance of complication screening should be adopted.

This multi-disciplinary approach is further supported by the relationship found between lower HbA1c values and greater eye screening engagement. While there is a scarcity of data on eye screening attendance and HbA1c values, Luong et al. showed that children (Luong et al., 2016) with no retinopathy on average had a lower mean HbA1c than those with abnormal results. This is consistent with large scale studies such as ACCORD and DCCT (Sosnowski and Janeczko-Sosnowska, 2008, Nathan and DCCT/EDIC Research Group, 2014).

In contrast with previous literature, deprivation was not found to be a significant factor in engagement with DESP in NI (Scanlon et al., 2008a, Millett and Dodhia, 2006, Lindenmeyer et al., 2014, Hipwell et al., 2014). This was especially surprising as in the 2012 Necessities of Life Study it was determined that deprivation levels and financial hardship are more extensive in Northern Ireland as compared to the rest of the UK as a whole (Gordon et al., 2013). One explanation could be that some of the most deprived areas are close to large hospitals with diabetes services. In addition, young people are generally well educated with some of the 'best' schools in these deprived areas. Screening is also provided in the local GP, which is often close to work/school or home.

While 52% self-reported admission to hospital due to diabetes or diabetic ketoacidosis (DKA), it is unclear whether all admissions were due to DKA. There are no conclusive numbers on admission due to DKA in Northern Ireland however reports from England and Wales suggest higher numbers of DKA admissions post-transition (NHS Digital, 2017). Other literature suggests that 59% of DKA admissions are due to non-compliance and female teenagers have a higher risk (Allan and Sampson, 2013).

2.6.6 Conclusions

This study provides pivotal information on barriers and enablers to screening in this age group. These results are relevant for many other countries worldwide. Many of the barriers and enablers discussed could easily be fixed in the future to provide better accessibility to screening.

Further in-depth research is needed into disengaged young people where the greatest problem may exist. Unfortunately making contact with this group to find out the true problems they face and how to address them is a major challenge.

Strengths

- This is one of the largest studies on barriers and enablers in this specific age group to date
- This draws conclusions from a regional perspective

Limitations

- Some data were missing or unavailable including smoking status and date of diagnosis
- Many potential participants were not interested in helping with the survey or merely forgot to complete it. Perhaps some were dissuaded as they were unsure of the diabetic eye screening programme.

My contributions to the study

- Led on this project alongside the Principal Investigator
- Created and collated all documents including study invitations, participant information leaflets, consent forms and questionnaires
- Applied for IRAS ethical permission and attended the IRAS meeting as a representative of the team
- Handed out leaflets on the study to potential participants within the Belfast Trust Diabetes Clinics and briefed the team on recruitment
- Attended Diabetes UK events to recruit further participants
- Collected all retrospective data and collated it into a database/excel spreadsheet and updated this as the project progressed
- Wrote the draft manuscript with the help of my colleagues and edited and formatted the manuscript for submission to the journal
- Led on minor corrections for the accepted manuscript
- Led on proofreading the published manuscript

2.7 Visual Impairment due to Diabetes

As demonstrated in the studies outlined above, the diabetic eye screening system endeavours to give ample opportunity for annual screening to everyone with a diagnosis of diabetes. This includes making screening appointments more accessible to those in 'high-risk' groups.

Despite the efforts and effectiveness of annual diabetic screening to prevent visual impairment due to diabetes, people still become visually impaired due to diabetes.

2.8 Certification of Visual Impairment in People with Diabetes

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Accepted: Journal of Visual Impairment & Blindness (JVIB), 22/06/2022

2.8.1 Introduction

Approximately 4.7 million people in the UK have diabetes with an estimated prevalence of 7% (Diabetes UK, 2019). In Northern Ireland, the number of people with diabetes has increased by 62.5% in the last decade (Diabetes UK, 2018, Bunce and Wormald, 2006, Thomas et al., 2017), with prevalence increasing from 4.5% in 2009 to 5.7% in 2019, which remains low compared to the rest of the UK (Lin *et al.*, 2017).

All 112,000 people in Northern Ireland with diabetes are offered annual screening with the Diabetic Eye Screening Programme which was established in 2008.

Diabetes UK estimates that within the UK, more than 1,700 people have their sight seriously affected by diabetes (Diabetes UK, 2019).In the UK, people are certified as Sight Impaired (SI) or Severely Sight Impaired (SSI) by their

Consultant Ophthalmologist (Jackson et al., 2020). Upon registration, people can access different benefits and services to help them and/or their carer with daily activities.

While previous studies in the 20th century suggested that DR was the most common cause of blindness in working age groups (Tendoesschate, 1982, Ghafour et al., 1983), more recent studies suggest this is no longer the case in England and Wales (Gordon-Bennett et al., 2009, Thomas et al., 2017), accounting for 7.4% of certifications. While there are regional studies of DR related visual impairment (Bennett et al., 2009, Lin et al., 2017b), this is the first study to be conducted on certification of visual impairment due to diabetic eye disease in Northern Ireland (NI), UK.

Despite these regional and sub-regional studies, certification is voluntary in the UK therefore full numbers of sight impairment due to diabetes are not captured (Bourkiza et al., 2014). Some reasons for this include stigma, not enough benefits and employment issues (Bourkiza et al., 2014).

Aim: to determine the number of people being certified as either SSI or SI due to Diabetic Eye Disease (DED).

2.8.2 Materials and Methods

Data are collected annually by a certification team in the Belfast Trust and Social Services. For the purpose of this study, the years 2014- 2019 were used due to improvements in the consistency in data collection and reporting, by the CVI team. The definition of visual impairment is as in table 9.

Severe Sight Impaired *	Sight Impaired *
Visual Acuity of less than 3/60 (Snellen) with a full visual field	Visual acuity of 3/60 to 6 /60 (Snellen) with a full field of vision.
Visual acuity between 3/60 and 6/60 (Snellen) with a constriction of the field of vision, such as tunnel vision	Visual acuity from 6/60 to 6/24 (Snellen) with a moderate reduction of field of vision for example with superior or patchy loss, media opacities or aphakia
Visual acuity of 6/60 (Snellen) or above but with a significantly reduced field of vision, such as inferior field or bi-temporal hemianopia	Visual acuity of 6/18 (Snellen) or even better if they have a marked field defect e.g., homonymous hemianopia

*Table 9: Certification criteria for severe sight impairment and sight impairment (Dementia and Disabilities Unit, 2017) *patient must fall into one of the categories while wearing glasses or contact lenses as needed*

All data were entered into an excel spreadsheet and 10% validity checked by another member of the certification team. This data was then analysed using Stata Version 17.

The Northern Ireland Statistics and Research Agency's (NISRA) population data report in June of each year was used to determine the overall population. The number of people with a diabetes was taken from diagnosis the Diabetic Eye Screening Programme's Optomize administration system in 2021, internal audits suggest this database is on average 99% correct.

Visual acuity was reported using LogMAR charts. In cases (approximately 17%) with counting fingers (CF), working distances were rarely recorded, these were assumed to have been at approximately arm's length. LogMAR equivalent measures of 1.7 for counting fingers, Hand movements (HM) -2.0, Perception of light (PL)-2.5 and no perception of light (NPL)- 3.0 were given.

2.8.3 Results

Table 2 reports the total annual CVI certifications data from 2014-2019.

Specific data pertaining to those patients' certifications due to DED (including Diabetic Macular Oedema (DMO) and DR) are shown below.

	2014	**2015**	**2016**	**2017**	**2018**	**2019**
Total Population	1.84 million	1.85 million	1.86 million	1.87 million	1.88 million	1.89 million
Total CVI (SSI* & SI*) for the Year	332	412	428	454	575	507
Total with DED *(% of total CVI)*	24 *(7.2%)*	26 *(6.3%)*	30 *(7.0%)*	36 *(7.9%)*	51 *(8.9%)*	34 *(6.7%)*
Gender **Male** **Female**	 13 11	 11 15	 16 14	 18 18	 26 25	 19 14
Age [73] **Mean** **Median**	 63 66	 65 65	 63 63	 57 59	 58 57	 61 60
Category **SSI** **SI**	 14 10	 13 13	 17 13	 21 14	 33 13	 *25* *6*

Table 10: Demographics of overall CVI certifications and certifications due to DED in years 2014-2019
**SSI = Severe Sight Impairment and SI= Sight Impairment, CVI = Certification of Visual Impairment*

Over the 6-year period, all diseases included diabetic eye disease experienced an increase. Total certifications rose from 174 per million (155, 193) in 2014 to a peak of 305 per million (280, 330) in 2018 (IRR 1.79, p<0.001), then steadied at 267 per million (243, 290) in 2019 (IRR 1.53, p<0.001). The number of DED certifications also rose from 12.6 per million (7.6, 17.7) in 2014 to a peak of 27 per million (19.7, 34.5) in 2018 (IRR 2.15, p=0.002), regressing to 17.4 per million (11.5, 23.4) in 2019. There was no significant difference in the proportion of DED over total registrations during the period 2014-2019 (overall p= 0.680).

There were more females than males in all certifications, with an overall incidence rate ratio (IRR) of 269 registrations per million (255, 282) for females and 210 per million (198, 222) for males (IRR: 0.78 for males vs. females, $p<0.001$). In contrast diabetic eye disease had a higher proportion of males (IRR 1.41, $p=0.19$).

Those with severe sight impairment due to diabetic eye disease rose by 92% between 2014 and 2019 while SI certifications remained relatively stable, this was not statistically significant ($p=0.163$).

The mean age of all patients certified was older (72.3 years SD) in 2014 by 4.5 – 11 years in the following period ($p<0.05$ for all comparisons). Despite this, patients registered due to diabetes were younger (60.3, SD: 15.6 year; n=201) than those with age-related macular degeneration (AMD) (83.0, SD: 7.8 years, n=74), glaucoma (87.5, SD: 3.8 years, n. 6), and other causes (68.2, SD: 16.4, n=21; $p<0.05$ for all comparisons).

Better-eye visual acuity did not differ between diabetic eye disease (1.07, SD: 0.50 logMAR), AMD (1.02, SD: 0.40 logMAR), glaucoma (1.17, SD: 0.78) and other diseases (2.28, SD: 0.68; overall p-value=0.565). The proportion of SSI registrations was 64.5% in DED patients, 54.1% in AMD, and slightly over 80% in Glaucoma patients, with no overall statistically significant difference ($p=0.082$)

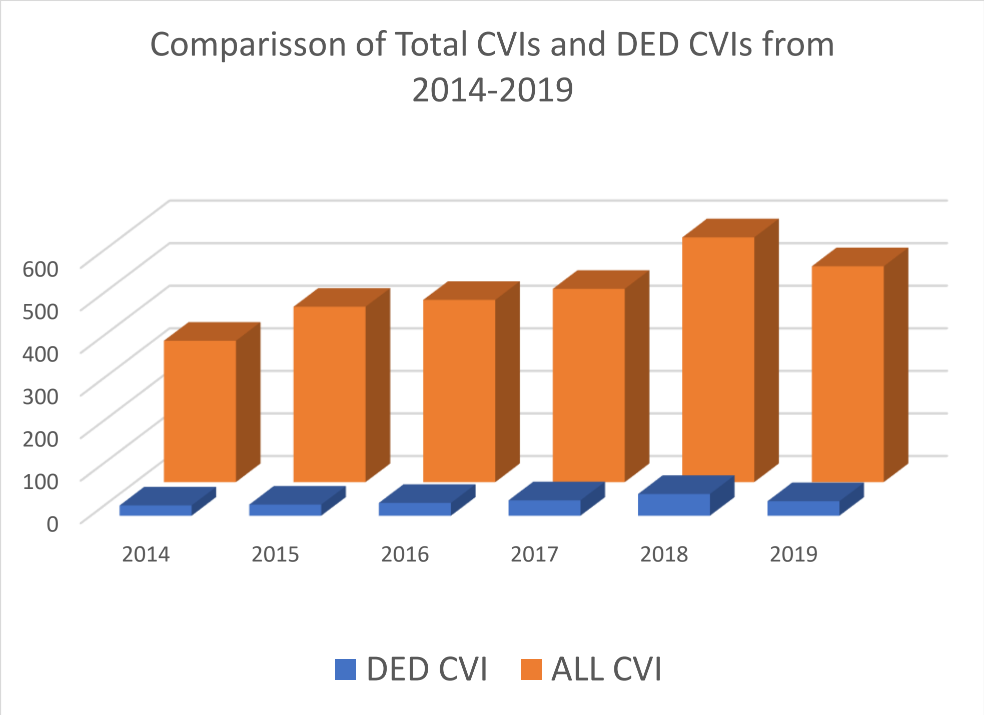


Figure 40: Comparison of certifications due to diabetes and total certifications from 2014-2019

2.8.4 Discussion

This study shows that certifications have increased annually with an exceptionally high rate of new certifications recorded in 2018. Previous annual certification reports have suggested certifications were lower in Northern Ireland (NI) than the rest of the UK (Canavan et al., 1997) therefore under-certification was identified as an issue requiring attention in the objectives of NI's Developing Eyecare Partnership (DEP) plan in 2014 (Jackson et al., 2020). A full review by a multi-professional CVI subcommittee of all certification processes and pathways was undertaken in 2017. Consultants were educated on the new certification pathway and there was an increased awareness of the process at both secondary care and community level. The paperwork for certification was also simplified and made more readily available in clinics.

The yearly increase in diabetic eye disease certifications has been proportionally greater than the increase in overall certifications. This could be due to the appointment of a new clinical lead, detailed audits on aspects of diabetic eye care, and rigorous diabetic eye screening protocols which resulted in more people being found to have progressed to visual impairment.

It was found that more males than females were certified due to diabetic eye disease, this could be explained by diabetes management or the fact that there could be a higher prevalence of type 2 diabetes in men than women (Nordstrom et al., 2016). Individuals certified due to diabetic eye disease were also younger perhaps due to the biggest cause of visual impairment being AMD which is age related. In addition, it is likely due to diabetes eye problems correlating with duration of diabetes (Fong et al., 2004).

As certification is voluntary some people may not feel the benefits are worthwhile due to cultural beliefs or stigma (Bourkiza et al., 2014). Current benefits include a TV license reduction fee, a blue badge and 'blind person's tax allowance'.

2.8.5 Conclusion

From 2014-2019, overall annual numbers and certification due to diabetic eye disease has increased. People with diabetes who are certified are more likely to be younger and male. There has been an increase in severe sight impairment certification due to diabetes from 2014-2019. Despite these increases we are still aware there are many people with visual impairment due to diabetes who are not registered.

Strengths

- This is the first analysis of certification due to diabetic eye disease from a regional perspective in Northern Ireland
- The figures from this study reflect those of other sub-regional studies in the UK

Limitations

- Numbers are small due to the small population size therefore inferences are limited
- Further studies including HbA1c level, attendance at screening and other medical data could help to further understand true reasons of certification in this cohort.

My contribution to the Study

- Became part of the certification of visual impairment (CVI) team who collected annual data on certification of visual impairment
- Since 2017 I have been managing the data and data analysis for each annual report
- Led on initial analysis and collation of annual results
- Helped analyse the final data and interpretation
- Wrote the initial draft manuscript and incorporated my co-authors corrections and suggestions
- Submitted to several journals and edited the manuscript according to their suggestions
- Reformatted the manuscript for resubmission to several journals
- Led on the major corrections before publication

Chapter 3 : Participant Visits Materials and Methods

3.1 Research Question

Does vision loss and function due to diabetes and retinitis pigmentosa affect independent mobility and navigation in urban environments.

This is an overarching research question which can be answered through different aims and objectives as detailed below. The different aims correspond to the following chapters.

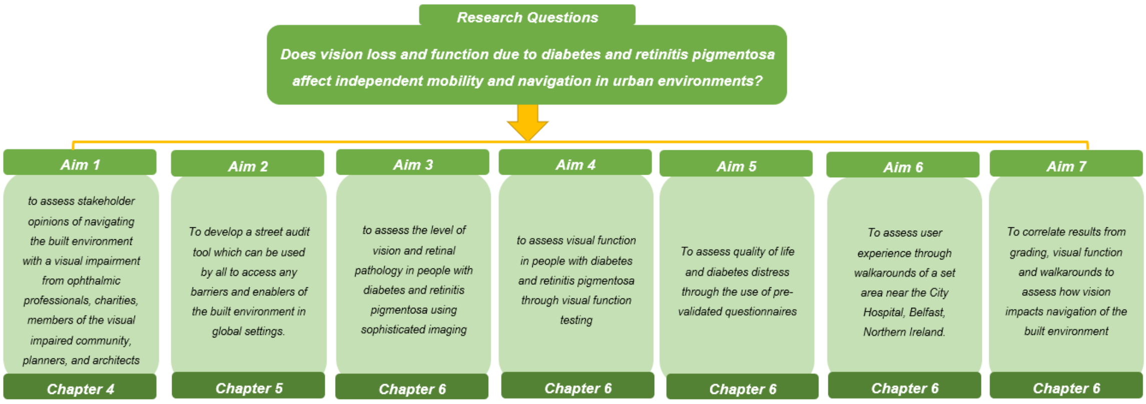


Figure 41: Research Questions, aims and objectives

3.2 Aims and Objectives

Aim 1: *to assess key stakeholder opinions on how people with a visual impairment navigate the built environment*

Objectives:

- Conduct interviews with key stakeholders including ophthalmic professionals, planners and architects
- Transcribe interviews to allow for qualitative analysis
- Analyse interviews using Braun and Clarke's thematic analysis methods and NVivo Qualitative Analysis Software
- Qualitative results will be used to collate and assess stakeholder opinions on navigating the built environment and assess knowledge, awareness and future ideas

Aim 2: *To develop a street audit tool which can be used to evaluate the accessibility and inclusivity of the built environment for visually impaired users in global contexts*

Objectives:

- Utilise existing literature and previous research to collate the most common barriers to navigating the built environment with a visual impairment
- Conduct street audits in urban international contexts to assess its potential universal applicability
- Select other auditors to collect street audits to ensure that the audit tool can be used by multiple users

Aim 3: *to assess vision and retinal pathology in people with diabetes and retinitis pigmentosa using sophisticated imaging*

Objectives:

- Conduct Optos widefield colour and autofluorescence imaging, Heidelberg OCT and OCTA and Optomed standard fundus imaging on all participants
- Grade Optos widefield images using the Manchester/Boston Grid on MATLAB software for retinal pathology and create heatmaps of this pathology
- Calculate percentage of the retina covered in pathology using the MATLAB results
- Grade OCTs using Heidelberg measurement software and record any other pathology
- Grade OCTAs into groups and use a pre-defined code to measure vascular density
- Use Stata Statistical Analysis Software to correlate these findings with other grading parameters, visual function and navigation responses

Aim 4: *to assess visual function in people with diabetes and retinitis pigmentosa through visual function testing*

Objectives:

- Conduct visual acuity and contrast sensitivity testing on participants
- Conduct Metrovision Visual Fields testing on all participants
- Conduct AdaptDX dark adaptation testing on all participants
- Use Stata Statistical analysis to correlate these findings with other grading parameters, visual function and navigation responses

Aim 5: *To assess quality of life and diabetes distress through the use of pre-validated questionnaires*

Objectives:

- All participants to complete the RetDQol questionnaire
- Participants with diabetes to complete the DDS17 Diabetes Distress Scale
- Use Stata Statistical analysis to correlate these findings with other grading parameters, visual function and navigation responses

Aim 6: *To assess user experience through walkarounds of a set area near the City Hospital, Belfast, Northern Ireland.*

Objectives:

- Develop a walking methodology to assess how people with a visual impairment navigate a set route through a mixed use area in South Belfast
- To capture participant opinions on barriers and enabling infrastructure they encounter during this walk. Information on confidence and insecurity levels will also be recorded.
- Conduct these walkarounds with each participant recording their answers and light and noise levels
- Correlate answers using Braun and Clarke's thematic analysis methods and Stata Statistical Analysis Software

Aim 7: *To correlate results from grading, visual function and walkarounds to assess how vision impacts navigation of the built environment*

Objective:

- Gather and clean all statistical results from grading, visual function testing and walkaround parameters
- Analyse these using Spearman's Rank correlation and Multiple Logistic Regression to assess if visual function and pathology affects navigation of the built environment
- Correlate qualitative results using Braun and Clarke's thematic analysis to determine the most mentioned barriers to navigating the built environment.

The study was named the **NaviSight Study** and a logo was designed for all documents.

3.3 Study Design

3.3.1 Stakeholder Interviews

Interviews were conducted with stakeholders including architects, planners, sight loss charities, representatives of the visually impaired community and ophthalmic professionals. Interviews were conducted online due to the COVID-19 pandemic. They were recorded, transcribed, and analysed. As this paper has been published, further information on these methods, results and discussion can be found in Chapter 4.

3.3.2 Participant Visits

Participants with diabetes and Retinitis Pigmentosa (RP) were recruited into the study and split into six different 'arms' according to their type and level of pathology. Below is a diagram of these arms:

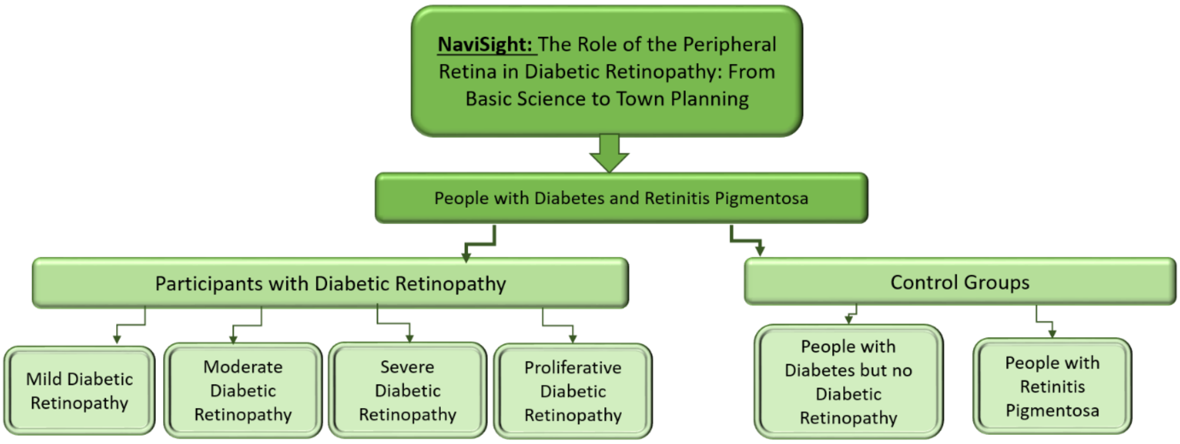


Figure 42: Recruitment arms

The two control arms were comprised of people with a diabetes diagnosis but no retinopathy to be used as a control for diabetes. People with RP are used as controls as they have peripheral sight loss (much like those with diabetes) and barriers they face in navigating the built environment have been mentioned in previous papers (Timmis et al., 2017, Turano et al., 2001, Vivekananda-Schmidt et al., 2004).

People with a diabetes diagnosis and diabetic eye disease will be split into groups according to the International Clinical Disease Severity Scale for Diabetic Retinopathy (Hansen et al., 2015).

Level of DR	Characteristics
No apparent retinopathy	No abnormalities
Mild NPDR	Microaneurysms only
Moderate NPDR	More than just microaneurysms but less than severe non-proliferative diabetic retinopathy
Severe NPDR	Any of the following: more than 20 intraretinal haemorrhages in each of 4 quadrants; definite venous beading in 2+ quadrants; Prominent intraretinal microvascular abnormalities in 1+ quadrant and no signs of proliferative retinopathy
Proliferative DR	One or more of the following: neovascularization, vitreous/pre-retinal haemorrhage

Table 11: International clinical diabetes severity scale for diabetic retinopathy

3.3.3 Inclusion Criteria

- Participants with a diagnosis of diabetes or retinitis pigmentosa (RP)
- Age 18 and over
- No other known eye conditions (other than cataract)
- Able to move around the pre-defined study route

3.3.4 Exclusion Criteria

- Any other eye disease apart from RP or diabetic related eye disease
- Lack of mental capacity to give consent
- Unable to speak English sufficiently to understand the study and complete appointments
- Anyone who cannot walk the pre-defined study route

3.4 Ethical Approval and Permissions

Primarily QUB MHLS ethics was granted however due to COVID-19 recruitment from patient engagement days, sight loss charity events and university events was difficult. Therefore, NHS REC approval was sought to allow additional opportunities to recruit participants.

3.4.1 QUB MHLS approval

An application was submitted to the Medicine Health and Life Sciences (MHLS) School Ethics Committee on 28th May 2020. The ethics application was reviewed by the committee on 24th June 2020 and approval was granted on 14th September 2020 after some amendments. Approval reference number: MHLS_20_67.

3.4.2 Research Ethics Committee (REC) Approval

An application was submitted on 2nd December 2020 to REC ethics and was reviewed by Wales REC5 on 17th December 2020. Professor Tunde Peto and Miss Laura Cushley attended the REC meeting to answer any questions or clarifications. Further clarifications and amendments were requested by the committee which were submitted on 8th January 2021. A favourable opinion was gained on 11th January 2021. REC reference: 20/WA/0350.

The application was then reviewed at the Belfast Health and Social Care Trust on 23rd February 2021, and permission was given to identify potential participants from the BHSCT (PIC site).

3.5 Sample Size

The original target sample size was 72 (12 in each group). Due to the ongoing pandemic restrictions and initial results, this recruitment target was reduced to 36.

3.6 Participant Recruitment

Participants were recruited through charities such as Diabetes UK and the Macular Society. Participants were also recruited through emails sent to the faculty in the Medicine Health and Life Sciences and School of the Natural and Built Environment. In addition, Professor Tunde Peto and Miss Giuliana Silvestri identified potential participants in the Belfast Health and Social Care Trust. Prof. Peto and Miss Silvestri gave potential participants an information leaflet and the study contact information. These potential participants then contacted the study team.

3.7 Participant Visits

Due to the COVID-19 pandemic some participants completed their consent and questionnaires during an online Microsoft Teams meeting with myself prior to their appointment. This was to reduce the amount of time in a clinical setting (in 'close contact').

Potential participants were provided the participant information leaflet before making an appointment and were allowed to talk through any questions of concerns they may have.

Below is an explanation of each part of the participant visit:

3.7.1 Consent

Before commencing the visit, I explained the participant visit and what would be involved before obtaining participant consent.

3.7.2 Walkaround

In order to assess the true problems within the built environment; participants walked a pre-planned route as shown in figure 44. Participants were accompanied by the PhD researcher and another member of QUB staff for safety purposes and to take light and noise measurements. Walks took place over a period from August 2021 – May 2022 in a different variety of weather conditions. Temperature during each walk was recorded as was cloud cover and presence or absence of rain according to the Apple Weather App. This route commenced at the Botanic Train Station, Belfast to allow for good transport links. This route was chosen due to its proximity to public transportation and ease of access for people with visual impairment (starting at Botanic Train Station). This route was also chosen due to its proximity to the City Hospital where the Northern Ireland Clinical Research Facility (NICRF) is located, and clinical visits took place.

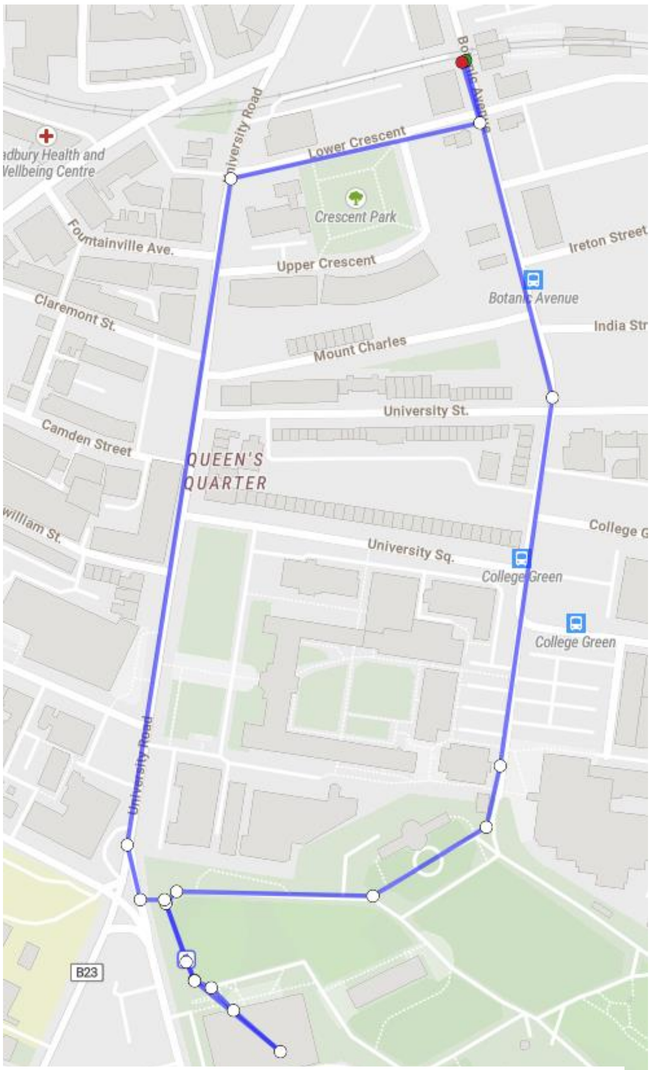


Figure 43: Walkaround route

In addition to the convenience of location, this route was chosen to encompass many streetscapes. Botanic Avenue (Point 1- Point 4) is known to be very busy due to the student population, it also has an abundance of cafés (with street café areas), shops, advertisement boards, a multitude of street furniture and parked cars on pavements. From previous literature it is suggested that these features could be problematic for someone with a visual impairment. The shared space areas outside Queen's University McClay Library (between points 4-5) were chosen to establish issues with shared space. Botanic Gardens (points 5-6) was used to interpret any problems within green open space. The area of University Road (points 6-7) was used as the pavement is wide with little street furniture on it – this was chosen to show a contrasting streetscape to Botanic Avenue. The area between points 7-8 was chosen as the streetscape again gets busier, there are crossings without pedestrian signals, one-way streets and a lot of traffic due to it being a through road to the city from South Belfast.

The distances between each point were decided on streetscape features/changes in features as well as distance between each point. Each point is approximately 150-200 metres apart.

The route was piloted using two visually impaired volunteers who walked the route and commented on difficulty and any issues throughout. The pilot volunteers did not raise any issues therefore the route was deemed acceptable for the study.

Before commencing the walk participants were asked: if they were familiar with the route, how confident are you in walking around this route? Are you anxious about walking the route? And are you anticipating any problems walking around this route? Participants were then asked to discuss any problems they encountered while walking the route. Researchers did not prompt these responses so as not to influence answers.

Respondents were also asked to access the level of difficulty, their confidence level and anxiety levels at different points during the route. They gave scores as shown below:

- difficulty from 1-5 (1= not difficult and 5= very difficult)
- confidence level 1-5 (1= low confidence and 5 = high confidence)
- level of anxiety 1-5 (1 = no anxiety and 5 = high anxiety).

In addition, another member of the research team took light and noise measurements along the route (as in figure 45). The walk is 1.12 miles (approximately 0.55 miles from Botanic Train Station to the Ulster Museum).

Each participant received an explanation that difficulty was deemed any barriers including street furniture, pedestrian crossings, gradient, business – anything that caused the participant difficulty during this section. Confidence level related to how confident they felt in walking the route, especially independently. Anxiety was explained as anything in that section that made them nervous, anxious, or fearful. It should be recognised that this is subjective and may not be a robust measurement; however, as the study is based around the opinions of those with visual pathology and impairment, this was deemed the best way to assess this quantitively alongside free-flowing conversation and qualitative analysis.

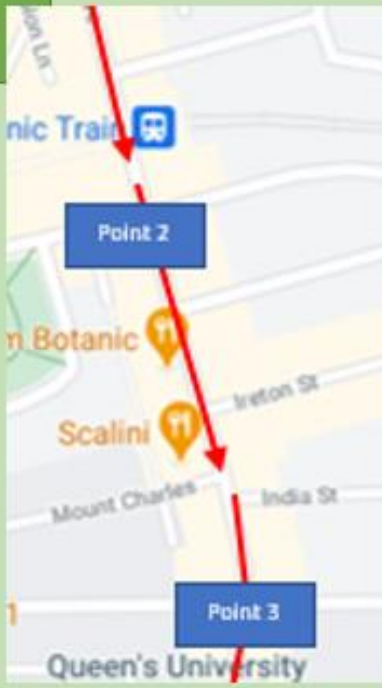
There is a scarcity of examples of using a walkaround methodology to assess how people (especially those with impairments) interact with the built environment. Despite this it is becoming increasingly more popular with a few different studies evaluating green lanes and the use of technology as an aid (Pink, 2008, Thompson, 2012). The use of walkarounds to assess visually impaired users was a novel concept before this study and Campisi et al in 2021 created walkaround methods of assessment. Similarly, Campisi et al used an area with different potential barriers in the built environment and assessed feelings throughout the walkaround. They also collected information on interactions with different aspects of the streetscape and used a researcher to collect questionnaire data (Campisi et al., 2021). Our study allowed for more open conversation and discussion on any issues faced throughout the walkaround and was taken over a larger area with varying streetscapes. Our walkaround methodology also collected light and noise measurements as it has been proven to affect people who are visually impaired (Tesoriere et al., 2018) .

3.7.2.1 'A Serial Vision' – The Walkaround

Below are some images of how a person experiences the walkaround landscape as it reveals itself (Cullen, 1961). Below is a map of the different points of the walkaround, a corresponding point/ map is shown alongside serial vision images in the next pages.

Figure 44: Map for 'serial vision' walkaround

START
(Botanic Train Station)



BOTANIC AVENUE

(Points 2-3)

BOTANIC AVENUE

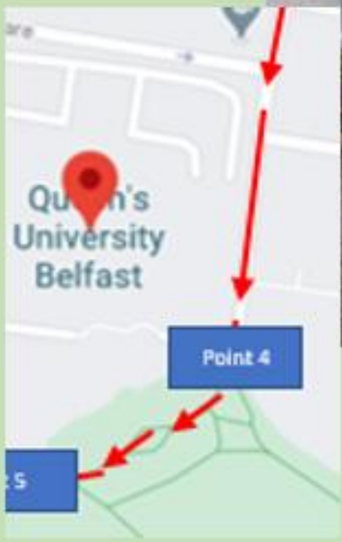
(Points 2-3)

BOTANIC AVENUE → MCCLAY LIBRARY, QUB

(Points 3-4)

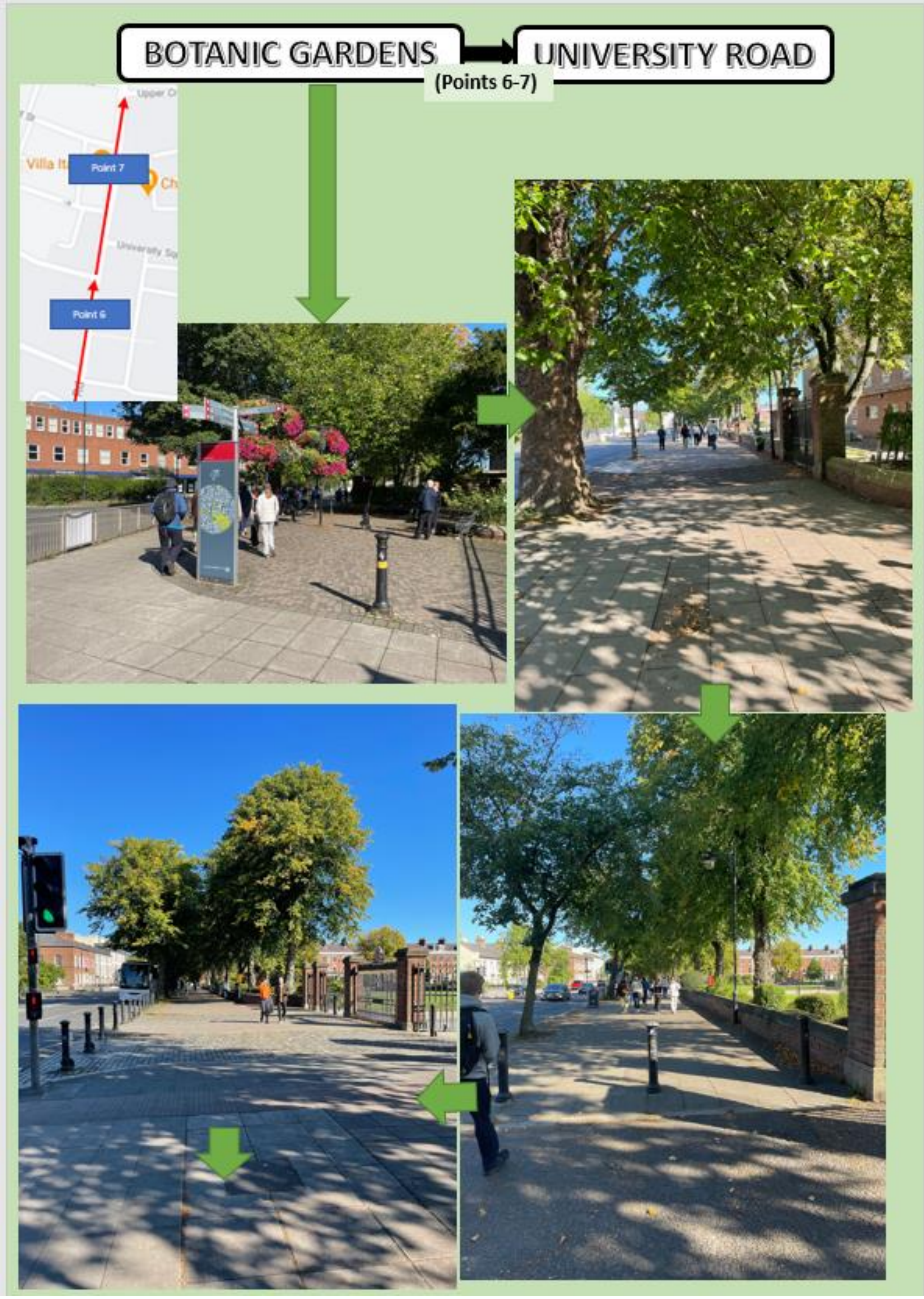
BOTANIC AVENUE → MCCLAY LIBRARY, QUB

(Points 3- 4)



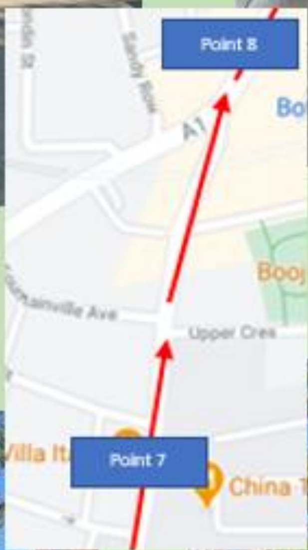
MCCLAY LIBRARY, QUB → BOTANIC GARDENS

(Points 4-6)


BOTANIC GARDENS
UNIVERSITY ROAD
(Points 6-7)
Point 7
Point 6

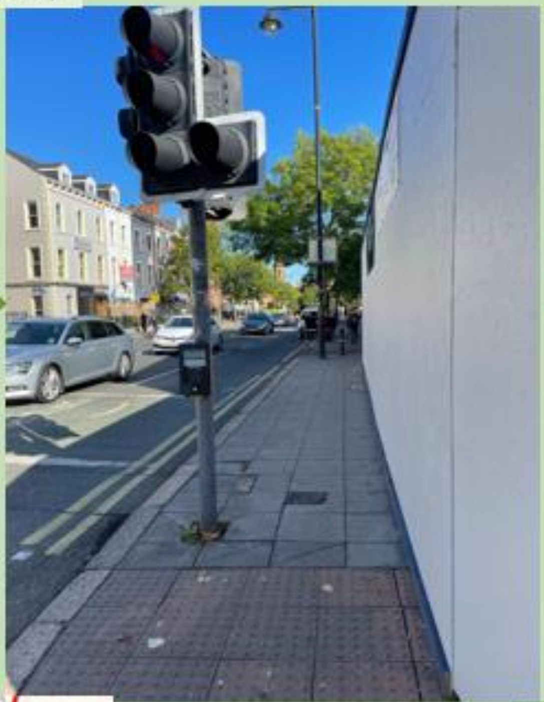
UNIVERSITY ROAD

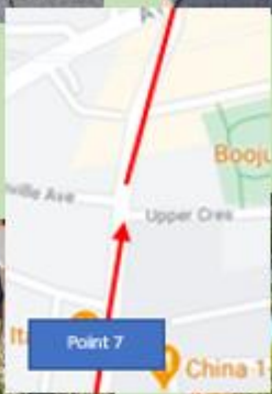
(Points 7-8)



UNIVERSITY ROAD

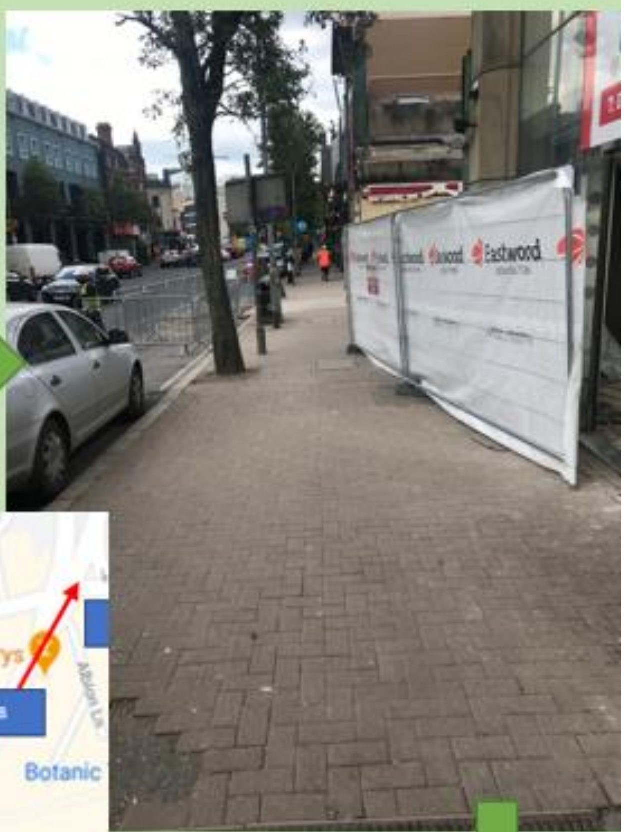
(Points 7-8)





UNIVERSITY ROAD → SHAFTESBURY SQUARE

(Points 7 -8)



SHAFTESBURY SQUARE → BOTANIC AVENUE

(Points 8-2)

3.7.3 Monthly Walkarounds

Figure 45: Walkaround route points for measurement

Monthly walkarounds were conducted of the study area for a period of 12 months to ascertain light and noise levels throughout the year. In addition, these walkarounds provided information on the changing streetscape as Northern Ireland emerged from lockdown and lifted restrictions. Images of potential problems on the streetscape were collected. These monthly walkarounds were conducted by the PhD student and one other volunteer for light/noise measurements. These walkarounds were conducted in any weather at 1pm on the 1st Wednesday of the month. Figure 47 shows the points for measuring light/noise, confidence, anxiety and difficulty.

3.8 NICRF - Retinal Imaging, Function and Questionnaire Visit

3.8.1 COVID-19 Pre-questionnaire

Participants were called 24-28 hours before their visit to the Northern Ireland Clinical Research Facility (NICRF) to ensure they had no COVID-19 symptoms. In addition, the same questions were asked when they arrived at the NICRF (appendix 9).

3.8.2 Habitual Visual Acuity

Visual Acuity was assessed with the participants own glasses/no glasses according to what they use daily as this is how they would see as they navigate the built environment. This was assessed using the ETDRS chart. ETDRS charts include five letters of equal difficulty on each row with standardized spacing between letters and rows, for 14 lines (totalling 70 letters). Assessment was completed on right eye, left eye and both eyes – an occluder with no pinhole was used to cover each eye.

3.8.3 Habitual Contrast Sensitivity

Contrast Sensitivity was assessed using the participants own glasses or no glasses according to what they normally wear. A smartphone-based tumbling-E chart was used on a Sony Xperia Z Compact smartphone. This smartphone was used due to the app calibration standards. A Study by Habtamu et al in 2019 (Habtamu et al., 2019) showed this contrast sensitivity test was repeatable and comparable with the Pelli-Robson Contrast Sensitivity test. Assessment was completed on right eye, left eye and both eyes – an occluder with no pinhole was used to cover each eye.

3.8.4 Visual Field Assessment

The Metrovision MonCvONE was used to assess visual field using standard automated perimetry. The inbuilt ‘Mix-30’ protocol, which assesses both the peripheral visual field with kinetic perimetry and the central field with fast perimetry (94 points), was used however for this study analysis was only conducted on static visual fields. Assessment was completed in the right eye and left eye separately using an eye patch to cover each respective eye. Metrovision lens frames were used for myopic participants.

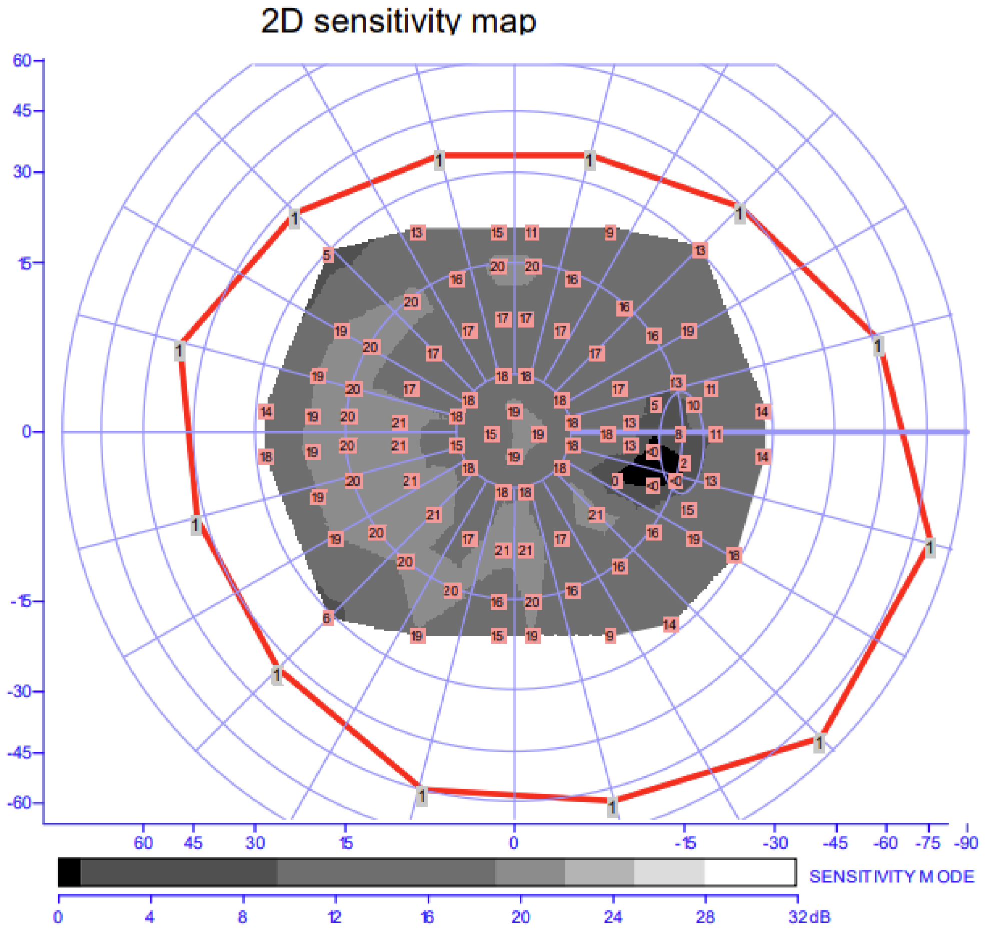


Figure 46: Example of visual field using Metrovision

3.8.5 Dark Adaptation

Dark adaptation was measured using the AdaptDx rapid protocol. This test measures a person’s ability to adjust from bright light to darkness. The right and left eye were tested using an eye patch to cover the other eye during testing. Pupillary size was measured before every test on each eye. The test was exported using a graph and a rod/cone intercept time.

3.8.6 Dilation of Pupils

Dilation of pupils using 1% Tropicamide Minims was required in three patients for better retinal image view.

3.8.7 Heidelberg Spectralis HRA and OCT

Figure 47: Heidelberg spectralis OCT machine

Heidelberg Spectralis Imaging was used to capture OCT, OCTA and Multi-Colour images of both eyes. IR was captured alongside a posterior pole OCT and a multicolour image was captured alongside a 7-line OCT. An OCTA was captured 15 x 15 in high resolution with 325 lines. Images were exported from the camera and transferred to the Central Angiographic Research Centre for upload to image review platform Heyex.

3.8.8 Optos California P200DTX

The Optos California was used to capture wide-field fundus and autofluorescence images in both eyes of each participant. Images were captured using 50/50 green/red colour. The red channel for choroidal visualisation and the green channel for visualisation of the retinal pigment epithelium (RPE) (Cassin and Rubin, 2012). Autofluorescence images use a green wavelength and were taken to visualise the function of the RPE (Cassin and Rubin, 2012). Images were exported from the camera and transferred to the Central Angiographic Research Centre for upload to relevant Optos Advance.

An example of participant reports with imaging and test results can be found in appendix 14.

3.8.9 Questionnaires

3.8.9.1 NaviSight Study Questionnaire

This questionnaire was completed by all participants in the study whether they had retinitis pigmentosa or diabetes related eye problems. Questions around duration of diabetes, type of diabetes as well as relevant medical history were included. In addition, some questions on their experiences of moving around the built environment were asked, these included questions on general anxiety about going out, concerns about potential issues which may arise and their overall independent mobility.

The general/medical section of the NaviSight questionnaire was compiled using standard medical questions such as age, gender and smoking and drinking status. Information on diabetes diagnosis, type and duration were gathered as diabetes complications, such as DR, are often affected by diabetes type and duration. Hearing loss data was collected as oftentimes people with RP can have dual sensory loss. Medical history questions were based on diabetes complications. The sections on sight loss and the built environment were based on an in-depth literature review and previously pilot tested questionnaire (Cushley et al., 2022) with new questions responding to inadequacies identified from the pilot phase. Below is a table which outlines inadequacies identified from the pilot phase. Below is a table which outlines the rationale for each question.

Question Number	Theme of Question	Rationale	Referring Literature
10	Anxiousness in the Built Environment	To assess if going out into towns and cities makes them anxious, fearful or nervous	
11	Mobility Aids	To determine if they used mobility aids in the built environment	
12	Do you drive?	To assess whether they have a driving license or have to move around by public transport/reliance on others	
13	Giving up hobbies	Posed in this way as some people do not notice how much sight loss can affect their daily lives – especially people with diabetes	
14	Do you go out at night?	To assess whether they may have dark adaptation loss and not be aware of it (not normally tested in clinics for people with diabetes)	
15	Do you use public transport?	To see how people move around	
16	Do you think towns and cities are difficult?	To assess if the participant feels they have barriers to navigating the built environment	
17	Assistance going into places you know	To assess if they generally need assistance	
18	Assistance in new/unfamiliar places?	To assess if new/unfamiliar places make them more nervous/reluctant to go out	
19	Use of same routes	To assess if they stick to the same routes as they are comfortable in them	
20	Street Clutter	Deemed as a major issue from previous literature and studies	(Kitchin et al., 1998, Dogs, 2010, Norgate, 2012, Cushley et al., 2022)
21	Pedestrian Crossings	Deemed as a major issue from previous literature and studies	(Manduchi et al., 2010, Norgate, 2012)
22	Bright markings	From literature and previous study – a potential help to people	(Cushley et al., 2022)
23	Cars Parked on pavements	Deemed as a major issue from previous literature and studies	(Kitchin et al., 1998, Dogs, 2010, Norgate, 2012, Cushley et al., 2022)
24	Crowded Areas	To assess if they avoid large crowds/crowded areas or find them difficult	
25	Shared Space	Deemed as a major issue from previous literature and studies	(Havik et al., 2015, Hamilton-Bailie, 2008, Hamilton-Baillie, 2008)
26	Lighting Level	Deemed as a major issue from previous literature and studies	(Stevens and Rea, 2001, Cushley et al., 2022)
27	COVID	From literature on COVID impacting people's ability to go out	(Sbrulli, 2020, Royal National Insitute of the Blind, 2020, IMTAC, 2020)

Figure 48: NaviSight Study Questionnaire Rationale

The questionnaire posed mostly close ended questions apart from questions 16 and 21 as participants were encouraged to share more conversational insight into navigating the built environment during the walkaround. If a participant wanted to share more information on any question, they were encouraged to talk to the PhD student throughout the clinical appointment or write further responses on the questionnaire.

The answers to each of these questions were entered into the study Access Database 2016 (version 16.0.5164.1000).

3.8.9.2 Retinopathy Dependent Quality of Life (RetDQol)

Permission for the use of the RetDQOL was granted by Health Psychology Research. It is an individualised measure of how diabetic retinopathy affects the participants quality of life. This questionnaire follows the design of the Audit of Diabetes Dependent Quality of Life (ADDQoL) (Bradley et al., 1999, Bradley and Speight, 2002, Wee et al., 2006) and was developed in parallel to research conducted by Woodcock et al, 2004.

Questionnaires are scored using two overview sections:

- **Generic (present) QoL** – scored from +3 (excellent) through 0 (neither good nor bad) to -3 (extremely bad).
- **Retinopathy- specific QoL** – scored from -3 (very much better i.e., severe negative impact of DR on QoL) through 0 (the same i.e. no impact of retinopathy) to +1 (worse i.e. positive impact)

From these overview sections a weighted impact score is calculated using an impact rating (-3 to +1) multiplied by an importance rating (0 to 3). The weight impact score can range from -9 (max. negative impact) to +3 (max. positive impact). Questions surrounding employment are excluded as it is only applicable to 1/3 of respondents.

Scoring Equation:

An average weighted impact score is calculated from a maximum of 23 specific domains = $\frac{\text{Sum of weighted ratings of applicable domains}}{\text{N of applicable domains}}$

This questionnaire was completed by all participants in the study whether they have retinitis pigmentosa or diabetes related eye problems. The questionnaire was used in RP participants for comparison purposes and the lack of RP related quality of life questionnaires. The term ‘diabetic eye disease’ was replaced with ‘eye disease’.

3.8.9.3 Diabetes Distress Scale Questionnaires (DDS17)

Total DDS Score:		
a. Sum of 17 questions		
b. Divide by:	17	
c. Mean item score:		≥ 3 ____

A. Emotional Burden		
a. Sum of 5 questions (1, 3, 8, 11, 14)		
b. Divide by:	5	
c. Mean item score:		≥ 3 ____

C. Regimen-related Distress		
a. Sum of 5 questions (5, 6, 10, 12, 16)		
b. Divide by:	5	
c. Mean item score:		≥ 3 ____

B. Physician-related distress		
a. Sum of 4 questions (2, 4, 9, 15)		
b. Divide by:	4	
c. Mean item score:		≥ 3 ____

D. Interpersonal Distress		
a. Sum of 3 questions (7, 13, 17)		
b. Divide by:	3	
c. Mean item score:		≥ 3 ____

Table 12: Diabetes distress scale sub scores

This was completed only by participants who had diabetes and has a number of questions about daily life and habits for a person with a diagnosis of diabetes. The questionnaire is on a scale answer basis – participants answered 1-5 according to how much of a burden they feel each task is. The DDS17 produces a total diabetes distress scale score including four sub scale scores which address varying kinds of diabetes distress.

3.9 Image Grading Analysis

Grading forms were produced for participant image analysis – separate grading forms for retinitis pigmentosa (appendix 10) and diabetes (appendix 11). These grading forms were collated according to previous research papers, grading scales and prior knowledge.

3.10 Optos Widefield Image Grading

3.10.1 Image Quality

Graders were asked to assess image quality on a scale from Good, Fair, Poor and Ungradable.

Good Quality - in focus and retinal details and vessels should be sharply defined and any lesions should have well defined boundaries. Images should be evenly illuminated and clear of opacity. Pigmentary changes and microaneurysms should be clear

Fair Quality - less focused and some retinal details and vessels could be difficult to interpret. Some of the image may be occluded or unevenly illuminated. Dark patches may appear on the image obscuring the view of lesions, vessels or other pathology

Poor Quality- may not be well focused however it should be possible to see some gradable information such as new vessels, pigmentary changes and diabetic eye changes. Due to the lack of focus or opacity over the image some finer and intricate lesions may be missed

Ungradable images - where you cannot see the blood vessels clearly or under 25% of the image is of sufficient quality to grade with confidence

3.10.2 Vessel Attenuation

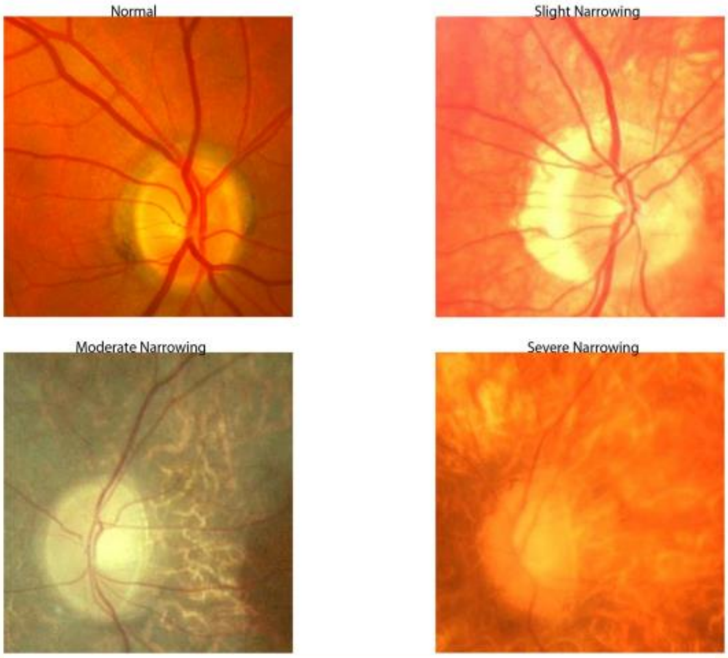


Figure 49: Vessel attenuation

Vessel attenuation is when the vessels thin. This usually means there is a decreased demand for blood supply in the retina (usually because it is degenerating). Examples of vessel attenuation and narrowing can be seen below. This scale was taken from the REASSESS scale (Alexander et al., 2014).

3.10.3 Cup to Disc Ratio

The cup to disc ratio is determined using annotation tools on Optos Advance software. The grader measured the cup and the disc before dividing the cup measurement by the disc measurement. Values should be rounded to one decimal place. In this case the disc measurement would be 0.5.

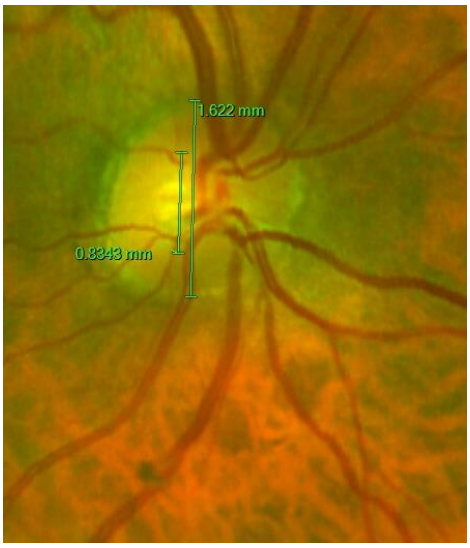


Figure 50: Cup to disc ratio measurement example

3.10.4 Disc Pallor

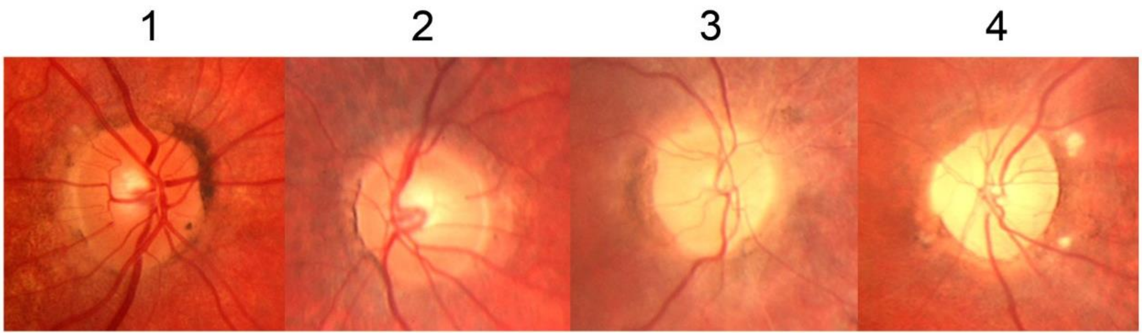


Figure 51: Disc pallor examples

Disc Pallor examples can be seen above. These examples were provided by co-authors of the REASSESS Scale (Alexander et al., 2014)

1. Normal
2. Slight Pallor
3. Moderate Pallor
4. Atrophic

3.10.5 Multicolour Image Grading

Figure 52: How a multicolour image is formed (Source: Heidelberg Engineering)

Three different laser wavelengths (infrared, green and blue) are used to capture a multicolour image. Each different wavelength shows a different layer and depth of the retina and retinal layers. These different wavelengths can show different pathologies more clearly (Heidelberg Engineering).

Multicolour imaging has been shown to detect proliferative diabetes lesions shown in fluorescein angiography in a non-invasive way (Vaz-Pereira et al., 2022). It is also said to be superior for detecting diabetic macular oedema cyst detection at the fovea (Saurabh et al., 2020). In addition, it is shown to correspond to hyper-autofluorescent areas (Saurabh et al., 2020) and has been associated with assessing detailed characteristics of the macular area associated with loss of visual function in patients with retinitis pigmentosa (Liu et al., 2017).

3.10.6 Optos Widefield Colour Grading

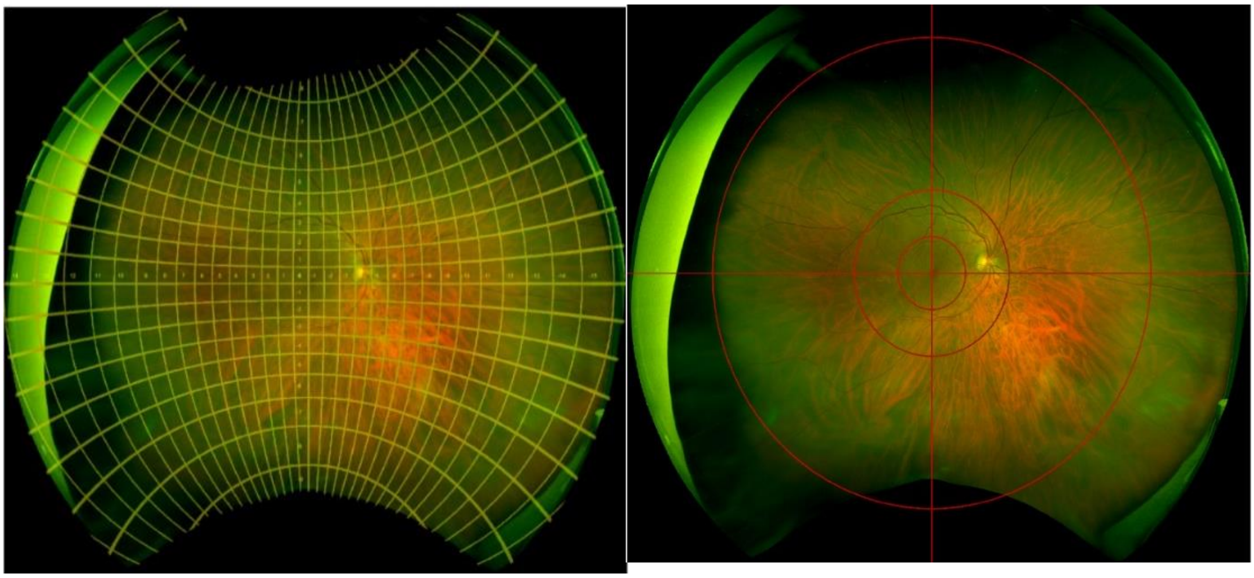


Figure 53: Boston and Manchester grid analysis

Optos widefield grading were completed using the Manchester and Boston Grids. The Manchester Grid covers the retina with 754 squares which are equivalent to one average optic disc area size (1.7mm^2) (Quinn et al., 2021). Each type of pathology is given a layer label. When the layer is selected the grader clicks on each square with that pathology in it. Several pathologies can be assigned to each square.

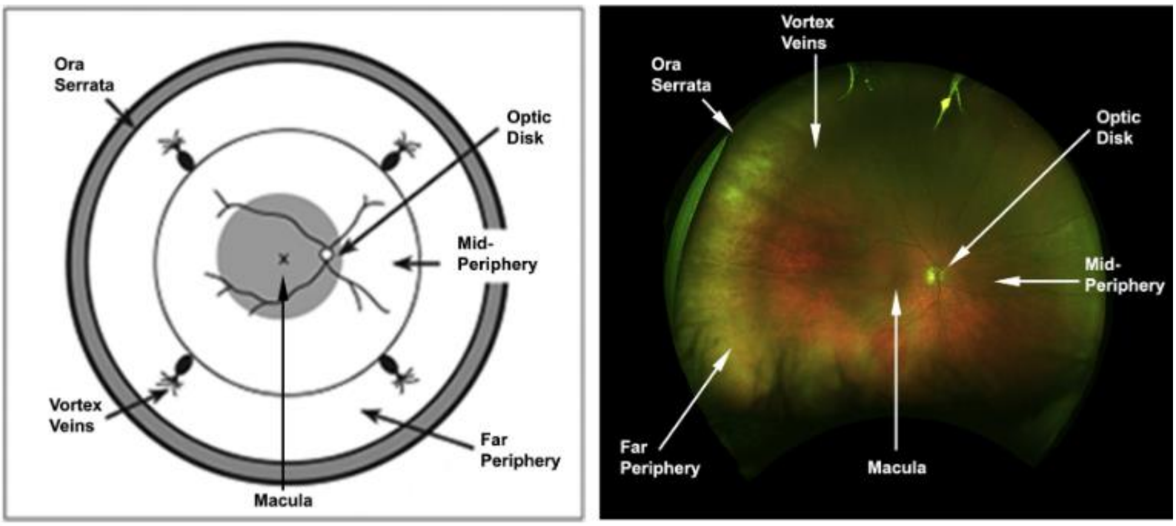


Figure 54: Retinal landmarks to define the Boston grid (Source: Quinn et al, 2019)

The Boston grid was used as it was developed to study peripheral abnormalities (first for AMD). It uses three concentric zones with crosshairs on the fovea (Quinn et al., 2021). These zones are determined using the ETDRS grid, the perimacular area (the arcade zones) and the far periphery (defined by the vortex veins).

3.10.7 Preparing the Images

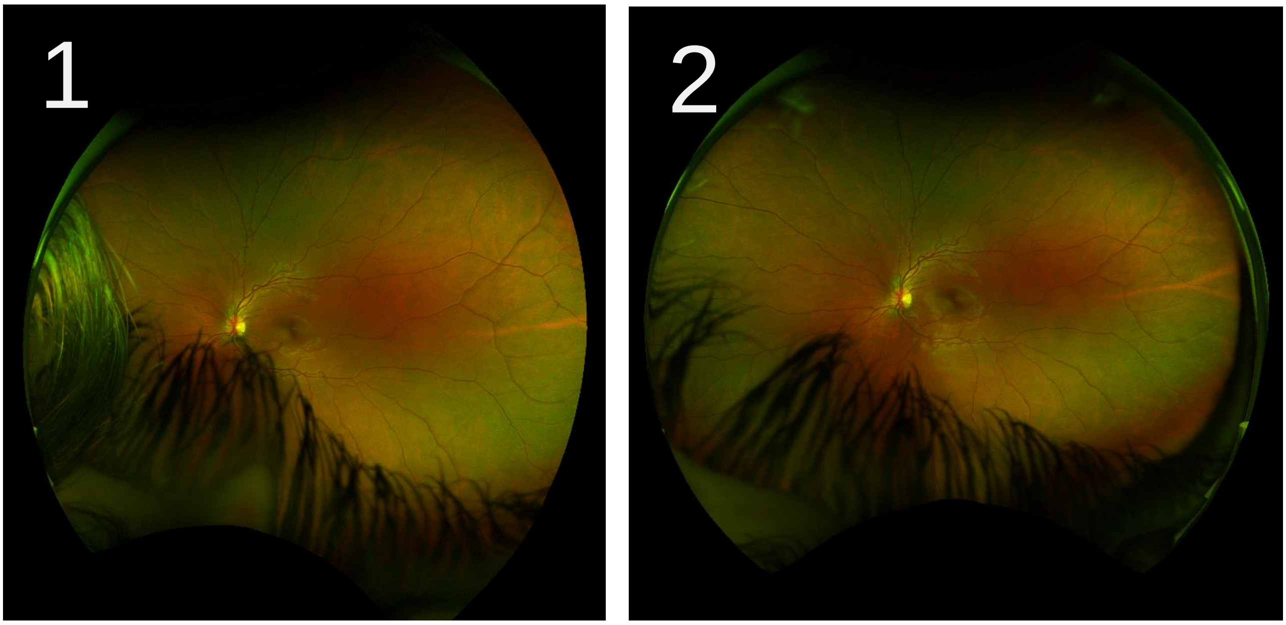


Figure 55: Example of images with less retinal area visible vs more area visible

MATLAB computer software was used to complete widefield grading. All DICOM images in their raw format were converted using MicroDicom software. Where there were several images of one eye, the best image was chosen by the PhD student. Best image was chosen according to the maximum amount of retina, which was gradable, in focus and without artefact.

These images were then exported into a participant folder as a png. The converted file of each eye (.png) was put into sub-folders for each eye with the ‘layerlabels’ and ‘regions’ files as shown below.

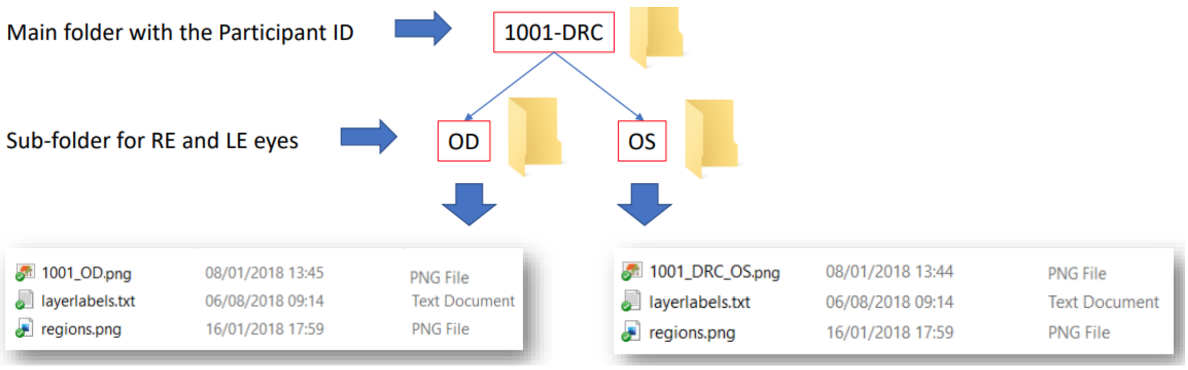


Figure 56: Participant folders for grading

Layer labels relate to the pathology which is being graded. Layer-label files for diabetes and RP and autofluorescence were created and can be seen in figure 55.

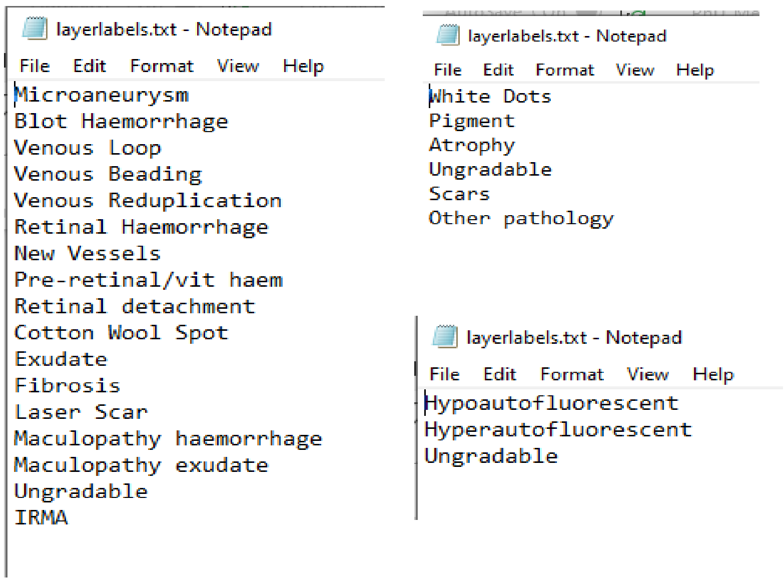
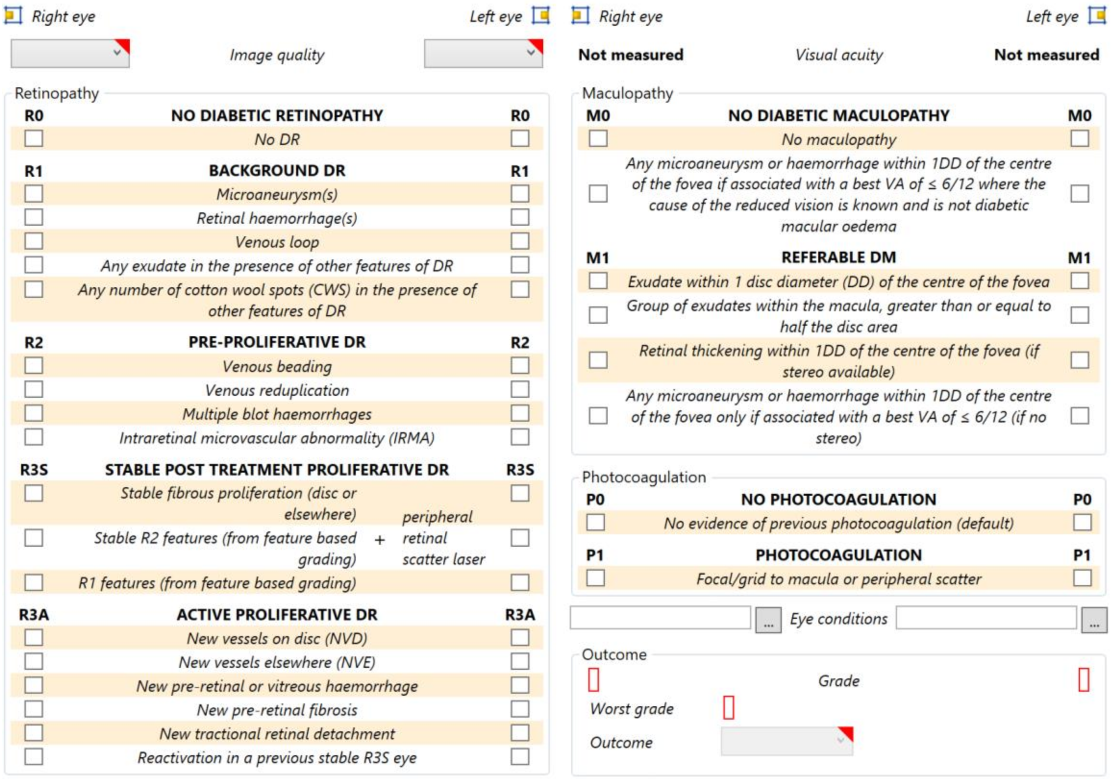


Figure 57: Layer labels for diabetes, retinitis pigmentosa and autofluorescence

3.10.8 Diabetic Eye Disease Grading

Feature based grading was based on the Northern Ireland Diabetic Eye Screening Programme Optomize system and guidance documents from NHS screening programme reports (Core NDESP team, 2012).



Right eye | Image quality | Left eye

Retinopathy

R0	NO DIABETIC RETINOPATHY	R0
☐	No DR	☐
R1	BACKGROUND DR	R1
☐	Microaneurysm(s)	☐
☐	Retinal haemorrhage(s)	☐
☐	Venous loop	☐
☐	Any exudate in the presence of other features of DR	☐
☐	Any number of cotton wool spots (CWS) in the presence of other features of DR	☐
R2	PRE-PROLIFERATIVE DR	R2
☐	Venous beading	☐
☐	Venous reduplication	☐
☐	Multiple blot haemorrhages	☐
☐	Intraretinal microvascular abnormality (IRMA)	☐
R3S	STABLE POST TREATMENT PROLIFERATIVE DR	R3S
☐	Stable fibrous proliferation (disc or elsewhere) + peripheral retinal scatter laser	☐
☐	Stable R2 features (from feature based grading) + peripheral retinal scatter laser	☐
☐	R1 features (from feature based grading) + peripheral retinal scatter laser	☐
R3A	ACTIVE PROLIFERATIVE DR	R3A
☐	New vessels on disc (NVD)	☐
☐	New vessels elsewhere (NVE)	☐
☐	New pre-retinal or vitreous haemorrhage	☐
☐	New pre-retinal fibrosis	☐
☐	New tractional retinal detachment	☐
☐	Reactivation in a previous stable R3S eye	☐

Right eye | Visual acuity | Left eye

Not measured | Visual acuity | Not measured

Maculopathy

M0	NO DIABETIC MACULOPATHY	M0
☐	No maculopathy	☐
☐	Any microaneurysm or haemorrhage within 1DD of the centre of the fovea if associated with a best VA of ≤ 6/12 where the cause of the reduced vision is known and is not diabetic macular oedema	☐
M1	REFERABLE DM	M1
☐	Exudate within 1 disc diameter (DD) of the centre of the fovea	☐
☐	Group of exudates within the macula, greater than or equal to half the disc area	☐
☐	Retinal thickening within 1DD of the centre of the fovea (if stereo available)	☐
☐	Any microaneurysm or haemorrhage within 1DD of the centre of the fovea only if associated with a best VA of ≤ 6/12 (if no stereo)	☐

Photocoagulation

P0	NO PHOTOCOAGULATION	P0
☐	No evidence of previous photocoagulation (default)	☐
P1	PHOTOCOAGULATION	P1
☐	Focal/grid to macula or peripheral scatter	☐

Eye conditions

Outcome

Grade

Worst grade

Outcome

Figure 58: Feature based grading from the Optomize System

3.10.9 Retinitis Pigmentosa Grading

Retinitis pigmentosa grading features were decided using the REtinal ASSESsment (REASSESS) Scale (Alexander et al., 2014). Graders were asked to assess pigment type –normal or white dots. Graders assessed whether there was atrophy, atrophic macular changes and other pathology.

3.11 Optos Autofluorescence

3.11.1 Image Quality

Graders were asked to assess image quality on a scale from Good, Fair, Poor and Ungradable.

Good Quality - images should be in focus and retinal details and vessels should be sharply defined and any lesions should have well defined boundaries. Images should be evenly illuminated and clear of opacity. Pigmentary changes and microaneurysms should be clear.

Fair Quality- images were less focused and some retinal details and vessels could be difficult to interpret. Some of the image may be occluded or unevenly illuminated. Dark patches may appear on the image obscuring the view of lesions, vessels or other pathology.

Poor Quality - images may not be well focused however it should be possible to see some gradable information such as new vessels, pigmentary changes and diabetic eye changes. Due to the lack of focus or opacity over the image some finer and intricate lesions may be missed.

Ungradable images - blood vessels cannot be seen clearly or under 25% of the image is of sufficient quality to grade with confidence.

3.11.2 Hyper and Hypo Autofluorescent Areas

3.11.2.1 Hyperautofluorescent Areas

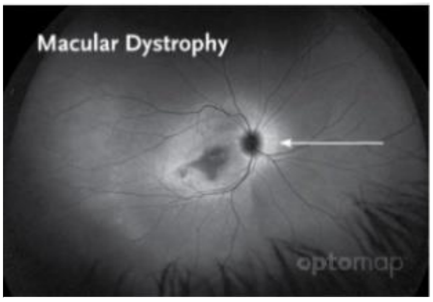


Figure 59: Hyperautofluorescent example

Hyperautofluorescent areas show up as white areas/lighter areas on the image. These areas are also graded using the Boston and Manchester Grid tool described above.

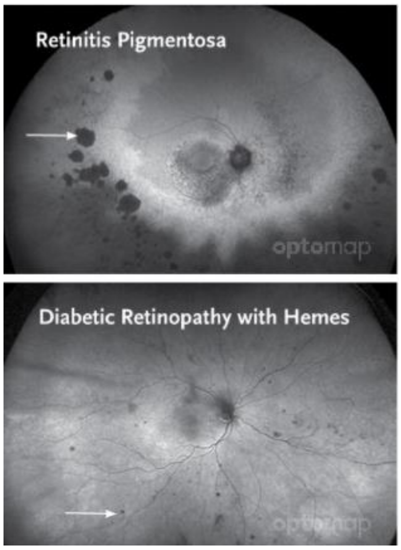


Figure 60: Hypoautofluorescent areas

3.11.2.2 Hypoautofluorescent Areas

Hypoautofluorescence shows as dark or black coloured areas on an image as can be seen in the image to the right. Graders also graded this using the Manchester/Boston Grid Tools.

3.12 OCT Grading

3.12.1.1 Vitreomacular Adhesion (VMA)

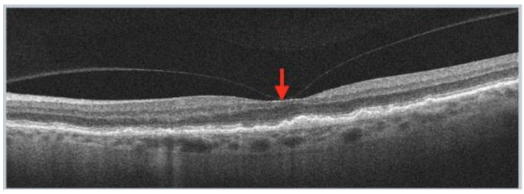


Figure 61: Vitreomacular adhesion (VMA) example

Vitreomacular adhesion (VMA) is defined as when the vitreous gel separates from the retina but there is still an adhesion to the retina. The grader should determine if there is a VMA present or not.

3.12.1.2 Vitreomacular Traction (VMT)

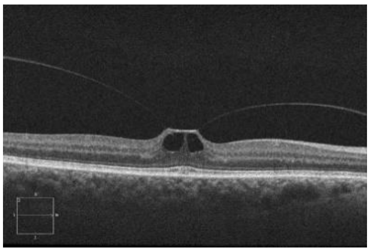


Figure 62: Vitreomacular traction (VMT) example

Vitreomacular traction occurs when a posterior vitreous detachment (PVD) is incomplete and causes pulling. This causes anatomical damage within the inner layers of the retina. These can cause macular holes and epiretinal membranes.

3.12.1.3 Epiretinal Membrane (ERM)

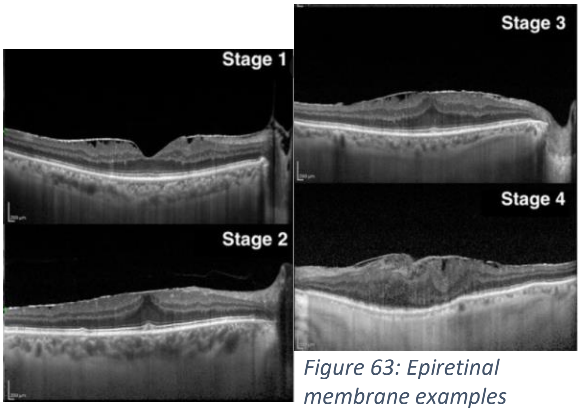


Figure 63: Epiretinal membrane examples

An epiretinal membrane is a thin sheet of fibrous tissue that develops on the macular surface. It usually looks like a thickened reflective layer on the top of the inner retinal layers (top of the OCT). Graders should decide if ERM is present and whether it is creating inner retinal changes such as cystic changes.

3.12.1.4 Intraretinal Fluid

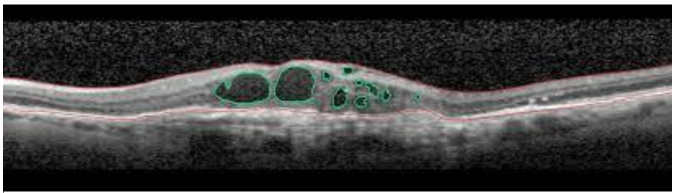


Figure 64: Intraretinal fluid example

Intraretinal fluid is characterised by intraretinal spaces with no reflectivity (these will appear black in the OCT). These intraretinal spaces should be of minimum height of 50μm.

3.12.1.5 Subretinal Fluid

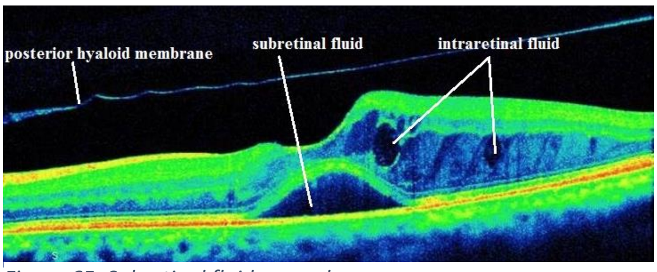


Figure 65: Subretinal fluid example

Subretinal fluid is an accumulation of fluid in the subretinal space between the neurosensory retina and underlying RPE (Kanski and Bowling, 2011).

3.12.1.6 Hyperreflective Foci

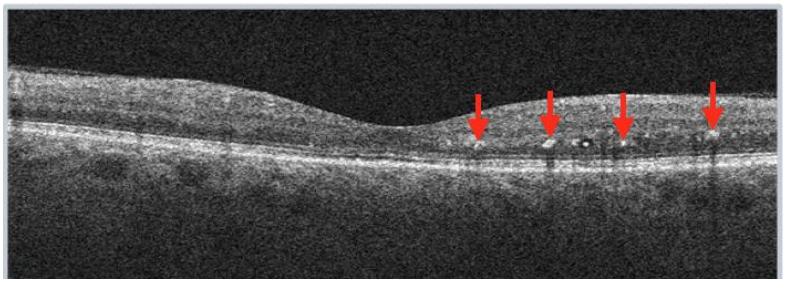


Figure 66: Hyperreflective foci example

Hyperreflective foci (HF) are defined as discrete, round lesions with high reflectivity found in the inner retinal layers of the OCT (Fragiotta et al., 2021). These HF are found in both RP patients and people with diabetes (Bolz et al., 2009). Graders were asked to determine if HF are present and how many are present on the foveal scan. Graders then decided in which layers the HF lie – RPE, ONL, photoreceptors or inner retinal layers (according to Heidelberg layer segmentation).

3.13 OCT Layers

3.13.1 Layer Measurements

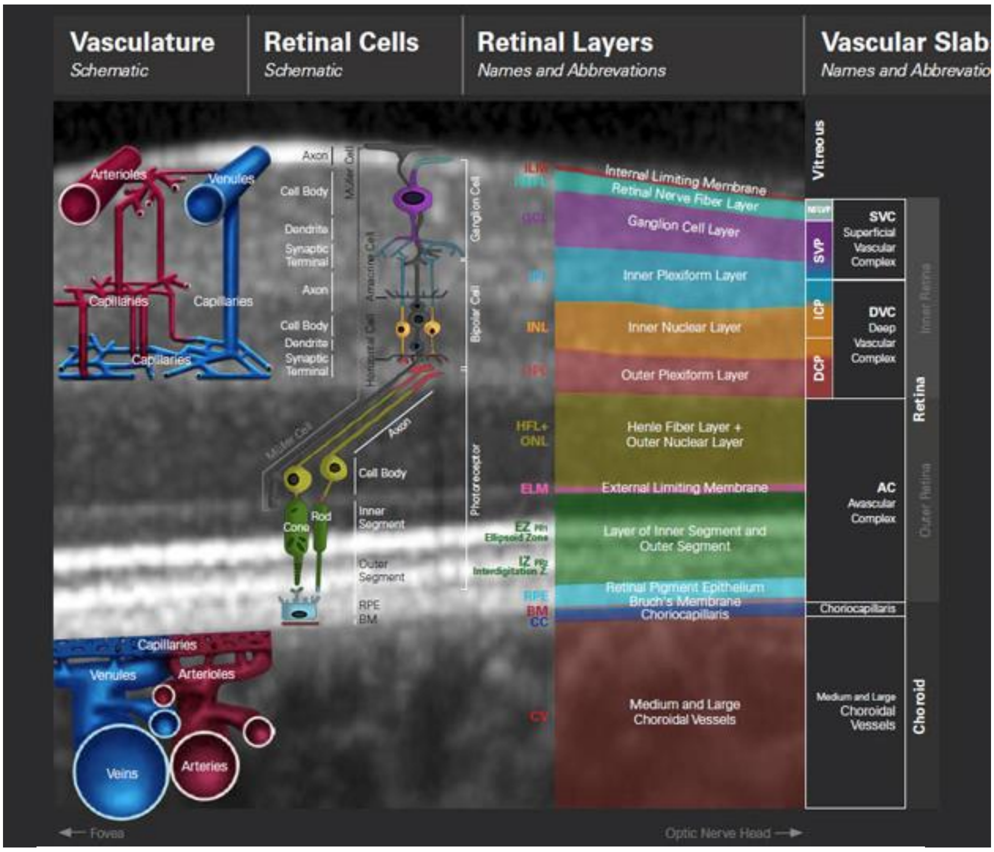


Figure 67: Retinal layers (Source: Heidelberg Engineering)

As shown in figure 65 outer layer measurements should include the layers; ONL (outer nuclear layer) to Bruch's Membrane and inner layer measurements should be taken from the OPL (outer plexiform layer) to the ILM (internal limiting membrane).

The ellipsoid zone (EZ) band has been correlated to different aspects of vision loss and abnormalities in RP (Tsunoda et al., 2011, Yokochi et al., 2012, Hood et al., 2011). Outer nuclear layer (ONL) thinning and thinning of the outer retinal layers has also been found in RP patients (Eriksson and Alm, 2009, Hood et al., 2011). There have also been studies which show a decrease in receptor layer thickness and light sensitivity (Apushkin et al., 2007, Hood et al., 2011).

Disruption of the choroidal circulation in people with diabetes (Saracco et al., 1982, Hidayat and Fine, 1985) and choroidal thickness changes have also been reported.

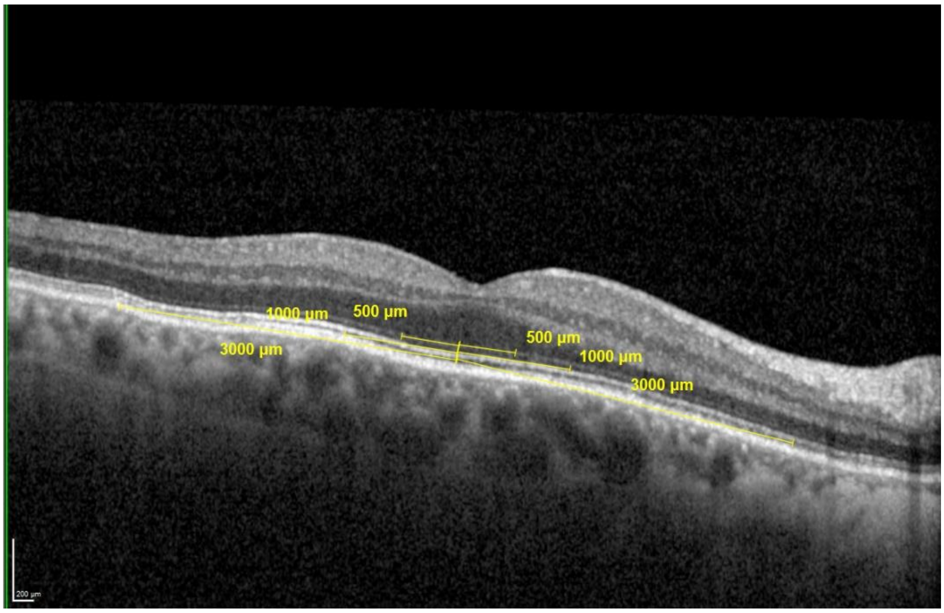


Figure 68: Layer measurements example

Graders were asked to take layer measurements at the fovea, 500µm, 1000 µm and 3000µm nasal and temporal. Graders decided if the External Limiting Membrane (ELM) is intact across the foveal scan, if it is not then the remaining ELM is measured. Graders also determined if the EZ is present foveally, extra foveally and if it is continuous. If not, graders measured the remaining EZ.

3.14 OCT-A

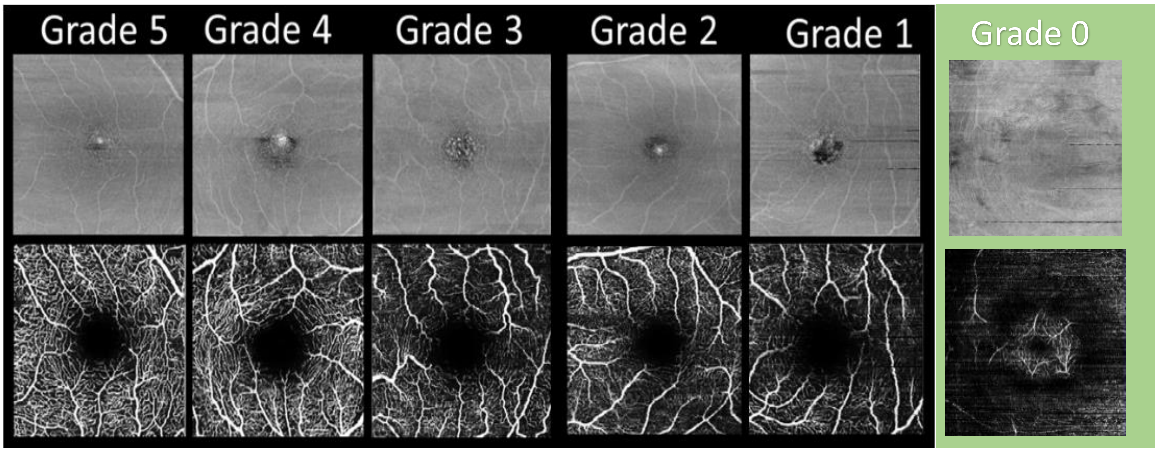


Figure 69: Grading scale for OCTAs

OCT-A images were graded according to a previously used scale for DR (Hogg et al., 2021). In addition to these previously established grades, a grade of 0 was added due to the high number of RP participants with poor OCTAs due to loss of vasculature. Whilst in some cases these could be excluded, it was important to include them in the analysis as vasculature is affected by this disease. Grade 0 was deemed to be where there was some vasculature present and it was not an ungradable image.

OCTAs were extracted using Heidelberg Engineering software SP-X1902 (only to be used in research). The data was extracted and converted into an excel file for analysis. Binary variables are extracted and uploaded into SPSS or R for quality control and data analysis. A previous code (Hogg et al., 2021) was used to analyse the data.

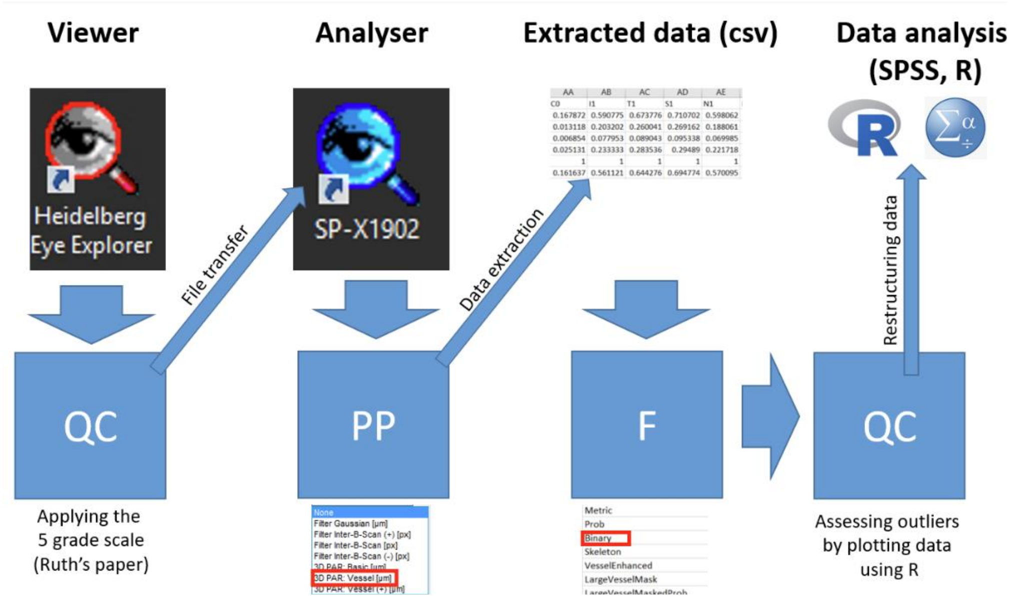


Figure 70: OCTA extraction process

3.15 Participant Visit Statistical Analysis

3.15.1 Visual Function Analysis

- Mean deficit is obtained by subtracting measures performed on the participant from what is expected at their normal age matched values
- Corrected mean deficit is obtained by subtracting measures performed on the participant from the normal values obtained from the individuals at their base level

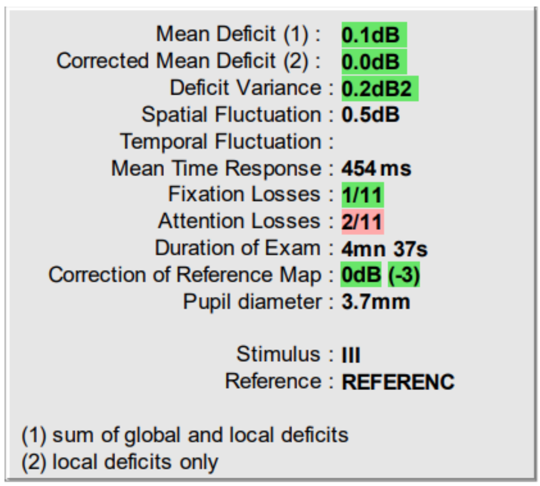


Figure 71: Visual field result example

- Fixation loss measures the reliability of the patient's fixation on the static dot. The number of fixation losses is relative to the number of controls
- Attention loss measures the quality of the patient's attention throughout the exam
- Correction of Reference Map is displayed in red if the value does not correlate with the patient's age
- Duration of Exam is the duration of the exam in each eye

3.15.2 Dark Adaptation

The Rod Intercept (RI) determines whether the patient has impaired dark adaptation. A RI of below 6.5 minutes indicates normal dark adaptation and is consistent with normal retinal function. An RI of equal to or above 6.5 minutes indicates an impaired dark adaptation function.

3.15.3 Extracted Data from the Manchester and Boston Grid

3.15.3.1 Data Extraction and Collation

Data extracted into excel spreadsheets was divided into continuous data (number of squares affected by each pathology) and categorical data (1 for pathology present, 0 for no pathology). Categorical variables were used to make a table of how many squares were affected by each pathology in each region.

3.15.3.2 Percentage of the Retina Affected

The percentage of the retina affected by pathology was calculated using categorical variables. Previous papers state there are 754 squares and each square measures 2.15mm^2 (Quinn et al., 2021). An analysis of four participant images was conducted to get a mean number of squares in each zone, on average there were 21 squares in zone 1, 59 in zone 2, 331 in zone

3 and 147 in zone 4. This did not equal 754 as some squares were previously removed for analysis due to lids/eyelashes continuously impeding gradeability.

3.15.3.3 Boston Heatmaps

A previously established code was used to extract Boston grid data. Data was transformed into long format on excel and code was used to create each map of pathology. The code counts the percentage of participants affected by a certain pathology in each square.

3.15.4 Frequency Analysis

All data were entered into a Microsoft Access database and were imported into SPSS Statistical Package (version 26). Participant demographics and medical data were analysed using descriptive statical analysis on SPSS. Frequency analysis was conducted on medical history and gender and mean/medians were calculated for age and diabetes duration. Further analysis was conducted on medical history to show differences between those with diabetes or RP.

3.15.5 Data Grouping

For ease of comparison participants were split into groups of people with RP (11), people with treated diabetic retinopathy (9) and people with non-treated DR (13).

3.15.6 Visual Field Analysis

Visual field assessment was exported using the global analysis report which provides a complete status of the visual field exam including peripheral visual assessment, macular assessment, validated quality control measures, fixation losses, attention losses and correction of reference.

Visual field analysis was conducted in two different ways, the mean visual field between both eyes and by using an automated programme from the Metrovision manufacturing team.

The first using the Mon2021A incapacity index analysis software. This software uses the right eye and left eye linear results and uses a fusion technique with an Esterman grid to create a binocular result. The analysis is completed through automated determination and is equal to the addition of all ‘unseen’ points or ‘null’ points. Green is used for ‘normal areas’, black is used for ‘defective areas’ and pink is the area which has not been tested with static tests.

There are some limitations:

- it only searches for absolute defects (<0 sensitivity)
- the analysis is only performed on the central visual field (static tests)

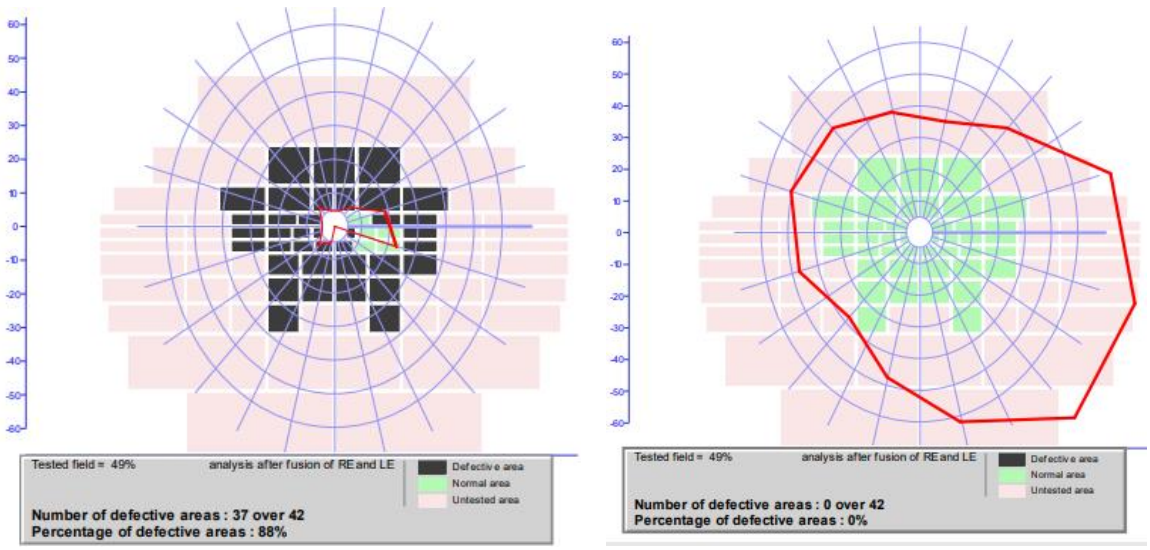


Figure 72: Example of incapacity index on two participants

3.15.6.1 Visual Field Mean

The corrected deficit was used as it indicates the probability of deficits according to the 'normal base values' of each individual. When Spearman's correlation and regression analysis was conducted it was found that there was minimal difference when using 'best eye' or 'mean value'

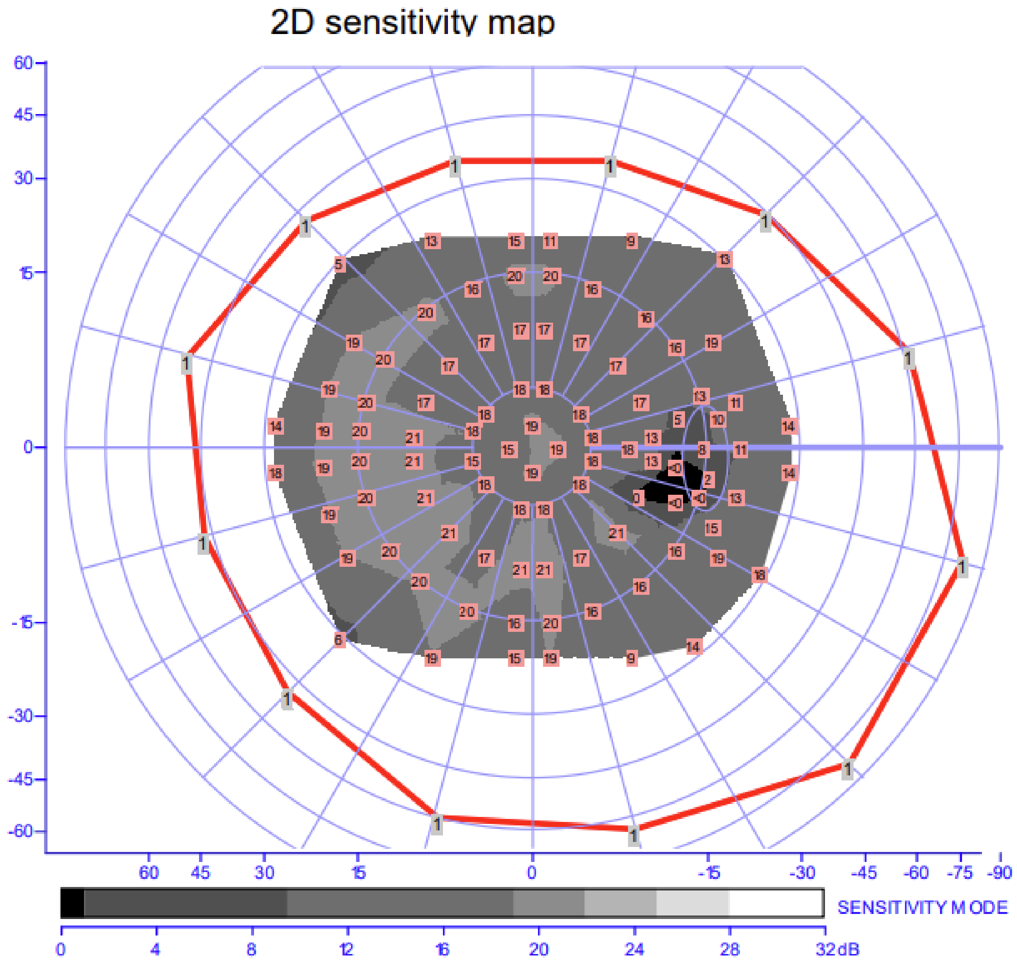


Figure 73: Example of Visual Field Plot on Metrovision

3.15.7 Dark Adaptation

A mean of both eye rod intercepts was used to ascertain a both eye value.

3.15.8 Boxplot Analysis

Boxplot analysis has been included for each variable to show comparison between groups.

Outliers in boxplots are shown as ° = Outliers * = far outliers and are calculated using Tukey's method. Tukey's method formulas are as below: Low outliers = Q1 – 1.5(Q3 – Q1) = Q1 – 1.5(IQR) High outliers = Q3 + 1.5(Q3 – Q1) = Q3 + 1.5(IQR), Where: Q1 = first quartile, Q3 = third quartile, IQR = Interquartile range

These equations give two values, or "fences" for outliers from all other values which fall in the bulk of the data. Outliers were not deemed to be problematic and were not discounted due to the wide range of visual level and severity.

3.15.9 Walkaround

Confidence, difficulty and anxiety levels were taken along the walkaround, the mean of each variable across the walk was used in the analysis of each patient. In addition, analysis was done to assess if any areas of the walkaround were particularly difficult or made people anxious or lose confidence.

3.15.10 Light and Noise Levels

Seasons of 2022	Astronomical Start	Meteorological Start
SPRING	Sunday, March 20, 11:33 A.M. EDT	Tuesday, March 1
SUMMER	Tuesday, June 21, 5:14 A.M. EDT	Wednesday, June 1
FALL	Thursday, September 22, 9:04 P.M. EDT	Thursday, September 1
WINTER	Wednesday, December 21, 4:48 P.M. EST	Thursday, December 1

Figure 74: Meteorological chart for seasons

Light and noise levels were split into seasons according to the meteorological chart rather than the astrological chart as the meteorological chart is formed according to temperature and weather changes. The mean of the light and noise levels in the season was used to plot along the line graph at each point.

3.15.11 Spearman's Co-Efficient Correlation

Stata Statistical Package Version 17 was used to find any significant correlations between walkaround variables and clinical/grading variables.

3.15.12 Multiple Regression Analysis

Multiple Regression Analysis was conducted to assess which clinical, walkaround and grading variables were significantly different between groups (as mentioned above). In addition, regression analysis was used on retinal layer measurements to find significance. Analysis on whether the presence of an intact ELM and EZ was conducted alongside walkaround, clinical and grading variables.

Participant results can be found in Chapter 6.

Chapter 4 : Navigating the unseen city: stakeholder opinions on navigation of the built environment by visually impaired individuals

Laura N. Cushley, Neil Galway, Katie Curran and Tunde Peto

Published in the International Journal of Environmental Research and Public Health https://www.mdpi.com/1660-4601/19/12/7299/htm

International Journal of *Environmental Research and Public Health*

MDPI

Article

Navigating the Unseen City: Town Planners, Architects, Ophthalmic Professionals, and Charity Opinions on Navigating of the Built Environment with a Visual Impairment

Laura N. Cushley [1,*], Neil Galway [2], Katie Curran [1] and Tunde Peto [1]

4.1 Introduction

Built environments affect a multitude of different people including those who use them and the professionals who create them. Built environment professionals such as architects and planners create the setting for our everyday lives. Living and navigating these spaces allow us to have social interaction, access places such as work and sustain relationships (Jones and Jain, 2006). Therefore, ensuring these spaces are navigable and accessible by all is of the upmost importance.

4.2 Overview

It is important to recognise that accessibility in our towns and cities impacts our daily lives and our core identities. This chapter shows results from interviews held with 20 individuals from built environment professionals, ophthalmic professionals, sight loss charities and members of the visually impaired community.

4.3 Literature Review

Built environments form the basis of human society and community, they provide the space where people socialise, create the economy and generally live life (Jones and Jain, 2006, Imrie, 2000a). Therefore, these spaces and places are used daily by a multitude of stakeholders. Despite this, each stakeholder utilises and views the built environment in different ways and will find different barriers and enablers of navigating the built environment. Therefore planners and architects should take into account the 'diversity of human abilities and conditions' (Heylighen et al., 2017) as well as differing opinions, needs and wants in order to create an environment for all.

This could be achieved through a collaborative approach to design. This concept has been around for many years with Godschalk and Mills introducing and advocating for it since 1966. Arnstein further supported this in 1969 (Arnstein, 1969) when he argued for a more substantial input by the general public on planning decisions. ''Planning as a collaborative process'' still remains a core principle of the profession.

While this remains a core principle, it is important to that built environment professionals including planners and architects work together to create accessible and navigable environments which can be enjoyed by all.

4.4 Rationale

Interviews were conducted with a wide variety of stakeholders in order to assess their opinions on navigating the built environment with a visual impairment. This will assess whether there are key concepts which are shared across stakeholders and show if user experience and professional knowledge complement each other.

4.5 Research Aim

To establish key stakeholder opinions on navigating the built environment with a visual impairment, as well as potential future solutions.

4.6 Methods

Semi-structured interviews were conducted with 20 stakeholders including built environment professionals, visually impaired individuals, ophthalmic professionals and sight loss charities.

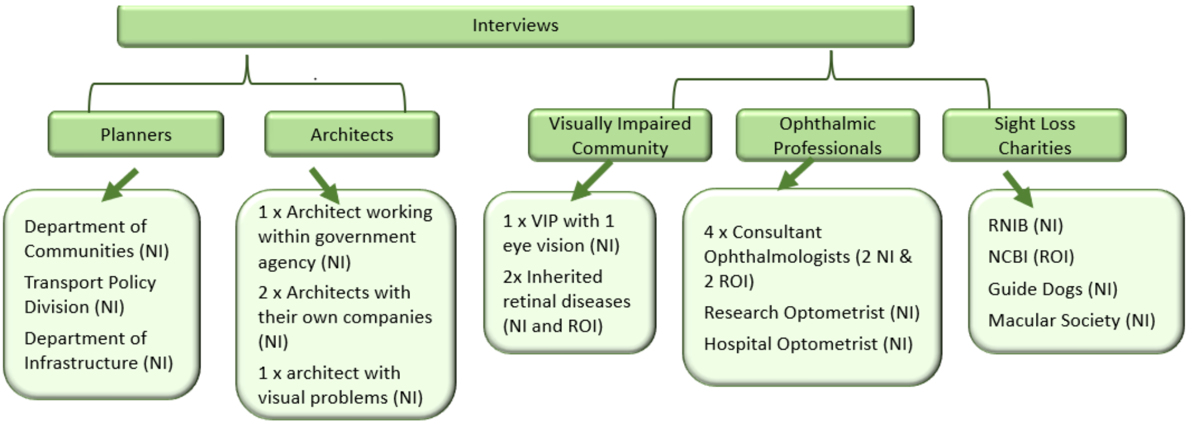


Figure 75: Diagram of stakeholder interviews conducted (NI = Northern Ireland, ROI = Republic of Ireland)

4.6.1 Ethical Permission

This study was reviewed and approved by the Medicine Health and Life Sciences Research Ethics Committee, Queen's University Belfast (approval number MHLS 20_67)

4.6.2 Recruitment of Interviewees

To gain a representative sample of interviewees with an interest in how people with visual impairment navigate urban environments, the following sectors were identified as critical to this study: built environment (planning and architecture), health (ophthalmic professionals), advocacy charities and those with visual impairment.

Architects were contacted through The Department of Communities Ministerial Advisory Group on Architecture and the Built Environment. Freelance architects and architects working within big companies were contacts of the study team. Planners were contacted by email through Belfast City Council, Department of Communities and people known to the research team. Charities were contacted by email and through patient engagement events and RNIB, Guide Dogs, Macular Society and NCBI elected someone to interview. Visually impaired individuals were contacted if they had expressed previous interest in the study or through patient engagement days (online or in person). Ophthalmic professionals were contacts of the QUB study team, Ulster University or Belfast Trust Networks. All potential interviewees who responded were interviewed. This group of people represents a large number of stakeholders from planners and architects to ophthalmic professionals, charities and visually impaired people as well. By conducting interviews with a range of stakeholders, various opinions and perspectives could be gathered.

4.6.3 Interviewee Demographics

Interviewees had differing levels of experience and time living with visual loss. Planning professionals had between 3 and 20 years' experience. Architects had between 10-45 years' experience with the architect who had 45 years' experience now having diabetic eye disease affecting his vision. Ophthalmic professionals had between 10 and 40 years' experience in the field with Ophthalmologists having over 20 years' experience. People with visual impairment has loss of central and peripheral vision as well as hemianopia – they all have had a visual impairment for over 10 years.

4.6.4 Interview Question Guides

Given the fact that all stakeholders were approaching this from a different perspective, interview guides followed the same structure with some specific questions for architects, planners, charities and ophthalmic professionals.

	Specific Questions	**General Questions**
Planners	• Would you say you know enough about visual impairment/how it affects people moving around the built environment? • Are you aware of any policy/guidance which relates specifically to visual impairment?	• Do you think moving around our towns and cities could be difficult for someone with a visual impairment? • Can you think of any problems they may encounter? • Do you think visual impairment affects people going out of their houses? • Do you think problems in the built environment exacerbate this? • Are you aware of some of the current things in our towns and cities to help with visual impairment? E.g. tactile paving and accessible crossings • Do you think there is enough accessible transport? Do you think transport workers know enough about visual impairment? • Do you think there is enough public awareness of visual impairment? • Do you think there are enough streetlights around the built environment? Are there any areas that you know where you feel unsafe due to low levels of lighting? • Do you think shared space can cause problems for visually impaired people? • Would you like to see more education around disabilities such as visual impairment?
Architects		
Visually Impaired Community		
Ophthalmic Professionals	• Have any patients ever talked about having problems moving around towns and cities?	
Sight Loss Charities		

Table 13: Diagram showing interview guide questions for each stakeholder type

While the above questions were provided to the PhD researcher as a guide, free flow of conversation was encouraged to gauge the true opinions and ideas of each stakeholder. Data saturation was met after 20 interviews and given the depth of similar data given by many stakeholders. We defined data saturation as when consecutive interviews no longer added additional data.

4.6.5 Data Transcription and Analysis

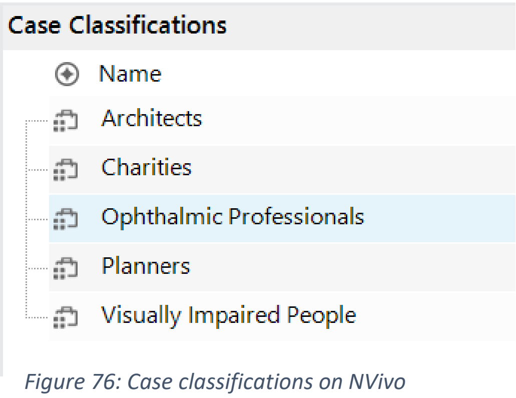


Figure 76: Case classifications on NVivo

All interviews were transcribed by the PhD Student and imported into NVivo software 1.6.1, QSR International (Burlington, VT, USA) for analysis. NVivo is a qualitative analysis software package which organises all transcripts, codes and themes. When transcripts were imported into NVivo they were assigned a case classification—built environment professionals (architects and planners), ophthalmic professionals (optometrists and ophthalmologists), charities and visually impaired individuals.

Transcripts were coded following Braun and Clarkes' thematic analysis techniques, and these codes were used to create themes, subthemes and sub-sub themes according to the most prominently discussed issues. An example of codes (themes) and subcodes (subthemes) can be seen in figure 77.

Codes

Name	Files	References
Barriers and Enablers of the Built Environment	0	0
Awareness of visual impairment and the built environment	0	0
Environmental	4	4
Financial	1	1
Historical	3	5
Professional	0	0
Public Transport	1	1
Future Solutions and Innovations	0	0
Improving education and awareness	12	32
Open conversations between professionals	4	5
Potential environmental solutions	5	16
Professional accountability	9	21
The need for improvement	11	26
Policy, Regulation and Guidance	0	0
Current policy and regulations	7	13
Enforcement	4	5
The Impact of Living with a Visual Impairment	0	0
Confidence	10	21
Impact on Daily Life	13	25
Independence	10	13
Isolation (not going out) and Loneliness	12	33
Mental Health	11	19
Physical Health	5	5

Figure 77: NVivo code and subcode examples

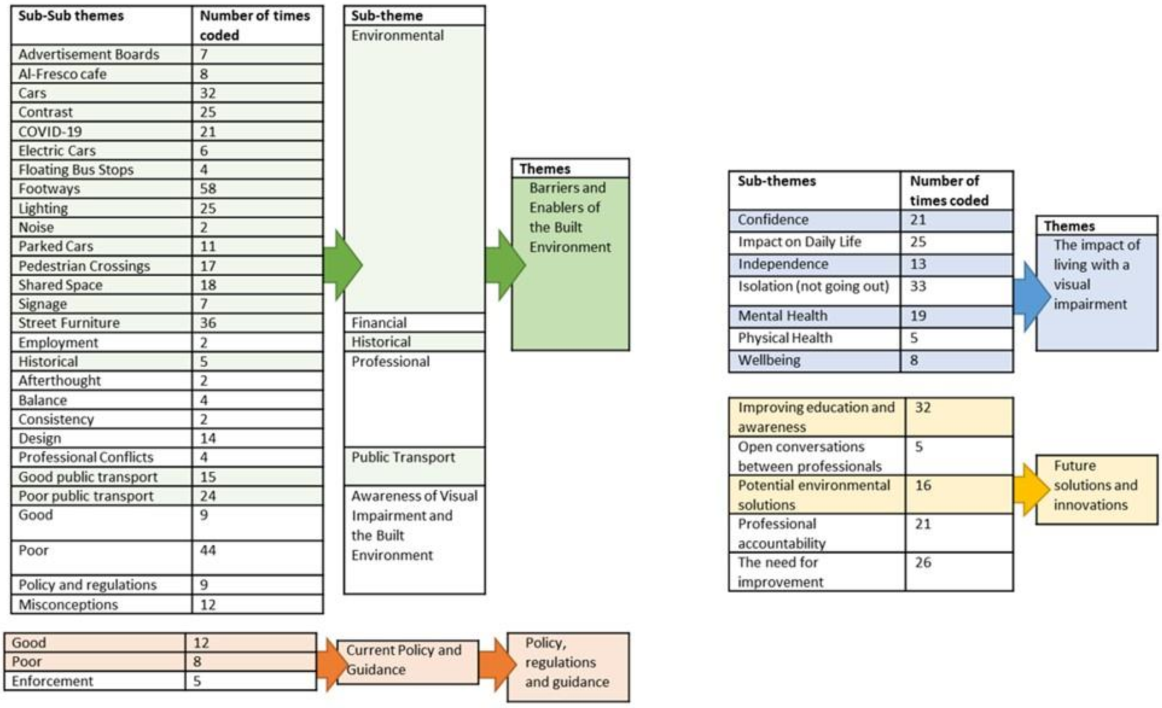


Figure 78: Most mentioned codes and methodology for sub-theme/theme assignment

The frequency of codes is presented in Figure 75 to illustrate the most common themes and subthemes within the data.

An inductive approach to thematic analysis was conducted in order to assign codes and child codes to the transcriptions. Twenty-five percent of transcripts, one from each case classification were analysed by a secondary cover, a research fellow. The analysis process was the same as the PhD researchers. When both analysts had themes, sub-themes and sub-sub themes identified, a meeting was held to compare themes and subthemes. After the meeting, final themes, subthemes and sub subthemes were established. A senior researcher adjudicated these themes and subthemes. For the purposes of analysis and coding of important sentences, architects were given the code ARC, planners were given the code PLA, visually impaired individuals were given the code VIP, charities the code CHA and ophthalmic professionals the code OPH.

4.7 Results

The four main themes identified were barriers and enablers in the built environment, the Impact of living with visual impairment, Policy, Regulation and Guidance and Future solutions and innovations. Below these themes and their sub and sub sub themes will be discussed. Counts of times mentioned were taken across all transcripts each time the subject was mentioned. This therefore means it could have been discussed more than once in each transcript.

4.7.1 Theme 1: Barriers and Enablers in the Built Environment

The first identified theme was the barriers and enablers in the built environment. These are any problems, issues or aids which impact a person with visual impairment navigating and moving around towns and cities. This topic has both sub-themes and sub-sub themes within it.

Theme: Barriers and Enablers in the Built Environment		
Subtheme	Sub-subtheme	Quote
Environmental	Advertisement boards (A-boards) *(7 mentions)*	'A lot of our town centres [have] narrow streets, [streets] are cluttered in terms of advertising boards out the front' (CHA03) 'I think it's really dangerous that people put [advertisement boards] out for their shops' (VIP01) 'Sight[/a] boards outside shops that aren't always there, you know people stick them out and then they take them in.' (OPH04)
	Al fresco dining *(8 mentions)*	'Street furniture in terms of cafés going right out into the street' (CHA03) ''[we] aren't opposed to café culture it just needs to be done in the right way where it isn't impacting upon people'(CHA03) 'If someone is using a mobility cane… on the ground …cordoned off area[s] at some cafes [are difficult], the barrier doesn't [go to ground level]…they might miss it' (CHA03)
	Cars *(28 mentions)*	'There is a transport hierarchy supposedly in place [where pedestrians and disabled people [should come] first and the private car last but in my experience it is the private car first and foremost' (PLA02)

		‘The idea that we give so much space to cars and everyone else has to jostle on the pavement in fear of their death’ (ARC01) ‘Cars are driving so so fast. It’s pretty hair raising. I just want them to slow down’ (VIP01)
	Colour Contrast *(25 mentions)*	‘Yeah the big issue is the contrast in environments, particularly in built up environments, you have the different shades of grey rather than the high contrast things or tactile things’ (OPH05) ‘I find it hard to find edges of pavements and the road’ (VIP01) ‘Architects often use things like ‘snazzy floors’ and contrasting colours on a flat surface (which can look like level changes and holes in the ground to someone with a visual impairment)’(PLA01)
	Footways *(58 mentions)*	‘This narrowness of streets also makes them crowded and dangerous’ (PLA02) ‘Things like … lack of tactile paving or it not being finished or damaged….‘rubbish and overgrown shrubbery on the street….(CHA03) ‘Dipped or cracked pavements’(OPH02) ‘Inappropriately maintained footpaths’ (OPH06) ‘Soiling – I mean I don’t use a cane and its difficult’ (OPH02) ‘Dog fouling – [affects people with a] visual impairment [more]’ (VIP03)
	Lighting *(25 mentions)*	‘‘There are debates around street lighting – there is too much lighting in some areas which creates light pollution but there are also areas which don’t have enough lighting’ (PLA03) ‘There could be better street lighting in a lot of Belfast’ (VIP03) ‘We really need more [light]’ (VIP01) ‘Light is good for everyone, it makes a place feel safe and welcoming’ (PLA01)
	Shared Space *(18 mentions)*	‘I do like shared space because I see it almost as people taking back space – accidentally been given to cars’ (ARC01) Shared space is a good thing… I recognise it does have its challenges however, this is not down to the concept of shared space itself’(PLA02) ‘Shared space is definitely a good thing; the issues arise when the shared space is badly designed’ (PLA03)
	Pedestrian Crossings *(17 mentions)*	‘For some reason [they] turn off the audio signal at traffic lights because … its noisy and keeps [people] up at night….’(CHA02) ‘‘Beeping crossings – my own experience would be very often they actually don’t function’ (VIP01)

		'Sometimes the green man doesn't work and I can't hear it, the signal on the bottom doesn't turn' (VIP01)
	Street Furniture *(36 mentions times by 11 interviewees)*	'Street furniture is historically one of the big ones and certainly one that we would get a lot of complaints or concerns about'(CHA03) 'Bollards – I walk into bollards – single most painful thing in my life – the agony…(VIP01) ''My worst nightmare is bollards and they are my biggest enemy'' (VIP03)

Table 14: The subtheme environmental and sub-subthemes and important quotes

4.7.1.1 Environmental

This subtheme mainly deals with barriers and enablers as features of our streetscape. Barriers such as A-boards, cars, footways and shared space were discussed by interviewees.

Figure 79: A-Boards on pavement

Many stakeholders including the visually impaired, felt that advertisement boards presented a big problem within the built environment. These A-boards were not permanently on the pavement and narrowed and cluttered the streets. These narrow streets with a lot of street clutter such as A-boards, benches, bus stops, poles etc. can create a very dangerous environment for someone with a visual impairment. Visually impaired users even describe bollards as their *'worst enemy'*. Parked cars are also discussed within street furniture as well as bikes, random posts, gates and bins. In addition to these issues, dog fouling was also discussed many times especially for those using a cane.

Figure 80: Street clutter

Al fresco dining was another problem which cluttered the already narrow pavements. Issues surrounding how street cafés are set up and 'signposted' were dicussed. If a café has a barrier which does not reach the floor then this makes it very difficult for cane users to recognise it.


Figure 81: Using a cane (Source: Braille Works)

This also becomes problematic when there is little or no contrast in environments – both indoor and outdoor. Many cities across the world are *'different shades of grey'* which does not provide good colour contrast with potentially dangerous objects for the visually impaired. Visually impaired users find it particularly difficult to delineate between the road and the footpath.

In addition to the colour contrasting issues on the pavement, oftentimes pavement works are not completed or maintained. Problems surrounding tactile paving being absent, damaged or not finished were discussed by charities, ophthalmic professionals and visually impaired users alike. Overgrown shrubbery over the pavement was also a concern which was discussed. In addition to trees creating these potentially dangerous overgrown branches, they also create issues with cracks in the pavement and dips in the pavement.


Figure 82: Unfinished tactile paving


Figure 83: Tree roots creating uneven paving

Missing tactile paving also becomes particularly important when it comes to pedestrian crossings. Charities, visually impaired users and ophthalmic professionals all raised issues surrounding pedestrian crossings. Problems such as the 'green man' or tactile notification cone not working were discussed a lot. But even more importantly the fact that the sound does not work or simply is turned off due to 'noise complaints' was extensively discussed by charities.

Figure 84: Pedestrian tactile spinning cone (Source: BBC)

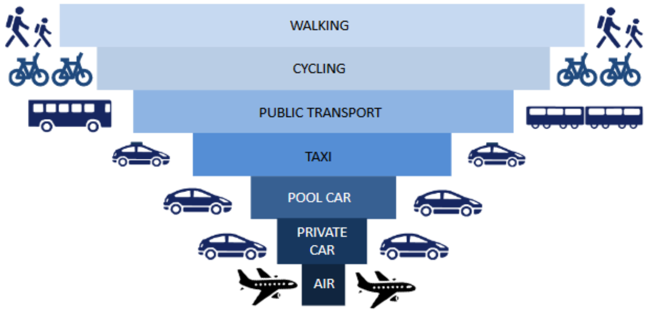


Figure 85: Example of transport hierarchy (Source: (Transport Scotland, 2020)

Cars were also discussed at length by planning professionals, architects and visually impaired people.

Planners were aware that there should be a 'transport hierarchy' in place which puts the pedestrian first, however this is not usually the case. The fact that *'it's all about the motorist'* and so much space is given to cars who are often going too fast was discussed. Visually impaired users described the fear of cars and how 'hair raising' it is just walking on a daily basis. An architect stated that 'if you step off the pavement you may as well be falling 1000 feet'.


Figure 86: Shared space example (Source: RNIB Scotland)

Shared space was often brought up after the issue of cars. Planners felt that shared space was often a way of 'taking back space' which was given to cars. Planners were very positive about shared space but did recognise the potential concerns. Despite this, charities and visually impaired people often viewed shared space as a '*big no no'* as it often relies on visual signals to work, and cars still feel they have priority.

Another sub subtheme that planners and visually impaired users/charities disagreed on was lighting. Planners felt that there was adequate lighting around a majority of cities and towns. Despite this, planners were aware that there were some areas which were not illuminated that should be. Visually impaired users felt they really need more light.

4.7.1.2 Historical

Theme: Barriers and Enablers in the Built Environment	
Subtheme	Quote
Historical	'Historically the planning of our towns and villages didn't take into account people with disabilities, its only recently within the last couple of decades that you know we're at least starting to get to grips with it' (CHA03)

Table 15: Historical barriers and enablers

This was one of the smaller sub sub themes discussed by interviewees. Planners, architects, charities and ophthalmic professionals discussed historical issues and *'old towns with old streets and pavements'*. Many of the problems we face today are caused by the historical planning of our cities which *'didn't take into account people with disabilities'*.

4.7.1.3 Financial

Theme: Barriers and Enablers in the Built Environment	
Subtheme	Quote
Financial	‘only 16% of people at working age with sight impairment are employed and one of the biggest barriers to employment is moving around, getting to and getting from where you work’ (CHA02)

Table 16: Financial subtheme and quotes

If a person cannot effectively and efficiently navigate around a built environment, it can impact them financially. Issues around employment and commuting to work are often discussed with charities.

4.7.1.4 Professional

Theme: Barriers and Enablers in the Built Environment	
Subtheme	Quote
Professional	‘Planning officers often leave the problem to consultations and other departments to deal with’ (PLA03) ‘A lot of lecturers want you to follow the regulations not conceptual architecture’ (PLA01) ‘‘I do however think that architects have an emphasis on what you would say are ‘normal people’ (ARC02) ‘People centric design approach is good and helps all people with disabilities (including visually impaired)’ (PLA01) ‘The key word in planning is balance…It’s difficult to strike the balance’ (PLA03)

Table 17: Professional subtheme and quotes

Architects and planners discussed the potential professional conflicts within their professions. Concerns with ‘*toxic’* attitudes of professionals and academics, relying mainly on regulation and not thinking ‘outside the box’. In addition, some architects felt that in their profession people often designed for ‘*normal people’* as opposed to inclusively. Planners and architects felt a people centric design should always be used in order to strike a ‘*balance*’ when it came to designing environments for all.

4.7.1.5 Awareness of Visual Impairment

Theme: Barriers and Enablers in the Built Environment	
Subtheme	Quote
Awareness of visual impairment and the built environment	'A lot of professionals aren't aware for example that only 5% of visually impaired people are actually completely blind' (PLA01) ''it's a spectrum and people don't get that, people don't understand that.' (CHA01) 'there's a lack of awareness to the wide range of visual impairment – people either think you're blind or you're not' (VIP02).

Table 18: Awareness of visual impairment subtheme and quotes

While most built environment professionals were aware of the concept of visual impairment, it was clear that they were not aware of the true spectrum of visual impairment including the varying patterns and levels of sight loss. Nineteen of the 20 interviewees felt there was not enough awareness about visual impairment and how to help or create places suited to people with visual loss.

4.7.1.6 Public Transport

Theme: Barriers and Enablers in the Built Environment	
Subtheme	Quote
Public Transport	'Improved since the improvement in buses and also the glider – I think Translink is doing a good job at upgrading and improving'(PLA01) 'legacy of public buses and problems with older stops' (PLA03) 'No there isn't enough public transport because I would love to be able to get to … really gorgeous places and its really quite difficult to get there unless you drive a car' (VIP01) 'one of the big problems for people who are visually impaired and live outside the cities was transport – transport is very limited, hard to get and very few options for people to try' (OPH03) 'If I wanted to go to the other side of Belfast, it's quite hard to unless I'm getting a taxi' (VIP03).

Table 19: Public transport quotes

Public Transport was discussed by all stakeholders, with many recognising that it is overall improving around Northern Ireland. Despite these improvement such as the 'Glider', visually impaired users described

Figure 87: Glider (Source: BBC News)

that it was often difficult to get to places outside Belfast City Centre, such as beauty spots. One user even said it was difficult to move from one side of the city to the other. This is usually due to the legacy issues with buses and the troubles in Northern Ireland.

4.7.2 Theme 2: The Impact of Living with Visual Impairment

As expected, living with a visual impairment can impact people's daily lives, both positively and negatively. The interviewees felt that there were really only negative impacts on visually impaired people when it came to the built environment and its accessibility. This theme is interesting as all subthemes are intrinsically linked - Confidence impacts people's independence, which impacts daily life and going out, which causes isolation and loneliness. This, in turn, can cause problems with people's mental and physical health and wellbeing.

4.7.2.1 Confidence

Theme: The Impact of living with visual impairment	
Subtheme	Quote
Confidence	'reluctant to go out of their houses' 'It doesn't take much to knock them off'(OPH02) 'If you trip and fall on a pavement that hasn't been fixed or you hurt yourself walking into a chair because somebody has put it out on a pavement – that has a big impact on your confidence and then you have to pick yourself up again and try to go out again' (CHA01) 'if … they fall then there's an embarrassment factor saying, 'I look stupid' and that affects people's confidence' (CHA01) 'peoples experience of feeling vulnerable or being shouted at or concerns about being hit by a vehicle or a cyclist' (CHA03) 'others who will say they will only either travel in private transport…. not because they want to, given cost and everything but because they feel they have to' (CHA03).

Table 20: Confidence quotes

Having a built environment which is difficult to navigate and move around can seriously impact a persons confidence, especially when they have a visual impairment. Many stakeholders discussed that it is very easy to 'knock them off' and it could be just one event which makes them reluctant to go out of the house. Interviewees felt that it was the little barriers which were present constantly which truly impacted confidence with going out into our towns and cities. In addition, issues surrounding vulnerability, public abuse and safety were also discussed by charities, visually impaired users and ophthalmic professionals.

4.7.2.2 Independence

Theme: The Impact of living with visual impairment	
Subtheme	Quote
Independence	'I think particularly in a rural setting that's difficult – I think it would limit their ability to leave their house safely I would say' (OPH01) 'how do they order there food with a website from Tesco that isn't accessible, how do they get a job when all the recruitment websites are inaccessible, how do they work out how to get a bus when Dublin buses website is inaccessible and you go on and on and on. That's digital access but it permeates into the real world when pavements are accessible and you can't find timetables to find when buses are and you have to notify Irish rail 48 hours in advance when you want some support when you're using the train' (CHA02)

Table 21: Independence quotes

Independence can be affected by many things including confidence. People's independence is essential and having visual loss and not being able to go out impacts on a persons confidence. Charities were especially aware that a lot of aspects of life were not accessible, including getting groceries, transport or employment.

4.7.2.3 Impact on Daily Life

Theme: The Impact of living with visual impairment	
Subtheme	Quote
Impact on daily life	'It must restrict them going out' (PLA02) 'must have a big impact on their lives socially' (PLA01) 'people are much more likely to say will not go out today because…I don't really need that or I'll not go to that group meeting that helps me because I know I have to manoeuvre myself round that café and I can't really remember when it comes up' (CHA01) 'a lot of people would say that [leaving the house]was their biggest daily anxiety and something they had to deal with everyday' (CHA04)

	‘[what] I have to go through just to get out of the house .. is quite hair-raising on a daily basis’ (VIP01) ‘it’s the little barriers that you put up’ (CHA01)

Table 22: Impact on daily life quotes

Both confidence and independence clearly impact on daily life. Living with a visual impairment impacts all facets of life including socially, emotionally and financially as was well established by precious results. Planners and architects were aware that visual impairment would have an impact on daily life but perhaps were not aware of how much of an impact inaccessible built environments play. Visually impaired people and charities describe going out of the house as ‘hair raising’ or the ‘biggest daily anxiety’. This daily struggle often means people are more likely not to do out unless absolutely essential.

4.7.2.4 Isolation

Theme: The Impact of living with visual impairment	
Subtheme	Quote
Isolation	‘lack of interaction, make[s] [people] homebound’ (PLA02). ‘[they] sit in a lot more as time goes on and then that accumulates’ (CHA01) ‘social isolation, loneliness and being stuck in your house’ (CHA02). ‘People … say they feel trapped in their homes because public space and public realm is just not fit for purpose for them’ (CHA03).

Table 23: Isolation quotes

This tendency to stay at home then creates isolation which charities and visually impaired people say makes them feel ‘trapped in their homes’ which causes other mental and physical health problems.

4.7.2.5 Mental Health

Theme: The Impact of living with visual impairment	
Subtheme	Quote
Mental Health	'people suffer huge amounts of loneliness and isolation, mental health issues because they are literally captured prisoners in their own homes' (CHA02) 'People with sight loss are 7x more likely to suffer from depression, a lot of that is due to social isolation, loneliness and being stuck in your house' ' it must restrict them going out psychologically which leads to a lack of interaction, makes them homebound which impacts their physical and mental health and wellbeing' (PLA02)

Table 24: Mental health quotes

Interviewees continued the theme of being '*trapped*' or feeling like visually impaired people are '*prisoners in their own home'*. Statistics quoted by charities suggest that people with a visual impairment are *'7x more likely to suffer from depression'*.

4.7.2.6 Physical Health

Theme: The Impact of living with visual impairment	
Subtheme	Quote
Physical Health	'Bollards… I really badly wacked my knee on one where I was quite injured for a few days. They can cause serious injury and serious pain' (VIP03) 'I actually risk getting quite hurt when walking around so I have to be super super super careful.' (VIP01)

Table 25: Physical health quotes

While an impact on mental health can impact physical health, interviewees focused more on injury when navigating the built environment. Visually impaired people stated that quite often they risk getting injured due to some of the environmental barriers discussed in theme 1.

4.7.2.7 COVID-19

Theme: The Impact of living with visual impairment	
Subtheme	Quote
COVID-19	''There is anxiety of going back to normal. You know when you were back to normal, you were used to going out every day and used to the mobility issues, now you have to get used to doing it all over again' (VIP03)

	‘issues surrounding them losing so much confidence with having been inside – and worries about being able to navigate places they previously code with new structures etc confidently’ (CHA04) ‘‘Some of the patients we see in the clinic – that’s the first time they’ve been out of their house in months’ (OPH01)

Table 26: COVID-19 quotes

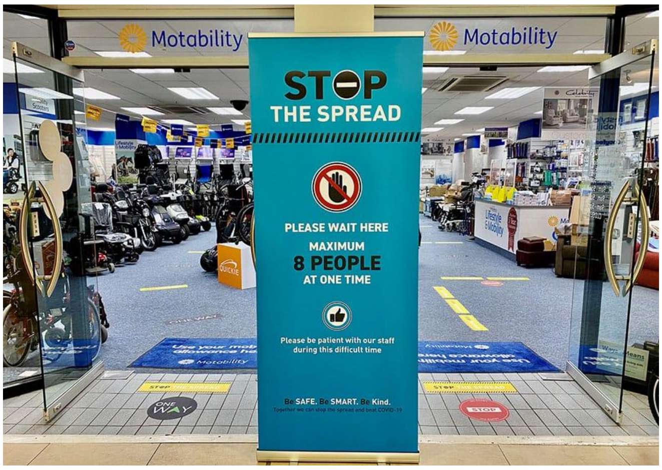


Figure 88: Example of COVID-19 safety precaution signs (Source: THIIS Magazine)

Interviewees discussed the issues surrounding COVID-19 as we were beginning to come out of lockdown during the interviews. Issues surrounding anxiety of going out again and being safer in their ‘bubbles’. Many visually impaired people stated they were concerned about problems with social distancing, one way systems and mask wearing. Some visually impaired people also stated they were worried about how the streetscape of their routes had changed since the pandemic – new obstacles or removal of safety landmarks. Ophthalmic professionals also reinforced the idea of feeling safest in their homes stating many patients attending clinics has not been out of their house in months.

4.7.3 Theme 3: Policy, Regulation and Guidance

Theme: Policy, Regulation and Guidance	
Subtheme	Quote
Current policy and regulations	‘mostly for physical impairment as opposed to disabilities such as visual impairment’ (PLA01) ‘[Strategic Planning Policy Statement (SPPS) which] has the core planning principles and urban planning principles’ (PLA03). ‘[Living places also has some guidance as a] ‘urban stewardship design guide’ (PLA03)

Table 27: Policy, regulation and guidance quotes

In general, architects and planners were aware of the policies, regulations, and guidance in place with regards to visual impairment and the built environment. Architects talked about the British Standards and code R [23], about how there are minimal requirements and visual contrast is covered "extensively" (ARC01).

Planners discussed technical documents that contain guidance "mostly for physical impairment as opposed to disabilities, such as visual impairment" (PLA01) and the Strategic Planning Policy Statement (SPPS), which "has the core planning principles and urban planning principles" (PLA03). Living places also have some guidance as an "urban stewardship design guide" (PLA03).

4.7.4 Theme 4: Future Solutions and Innovations

4.7.4.1 The Need for Improvement

Theme: Future solutions and innovations	
Subtheme	Quote
The need for improvement	'[other countries are] way ahead of us' (VIP01) (ARC01). 'a lot of advice but not enough about giving actual practical examples' (ARC01).

Table 28: Need for improvement quotes

A majority of stakeholders felt there was a need for improvement in our built environment. Small changes such as colour contrast, making space free on pavements and less street clutter could be easily implemented. Both visually impaired individuals as well as architects and planners felt that we were behind and places such as Singapore and Japan were '*way ahead of us'*.

4.7.4.2 Potential Environmental Solutions

Theme: Future solutions and innovations	
Subtheme	Quote
Potential environmental solutions	‘can easily be overcome’ (ARC01) ‘contrast of street furniture etc. against the pavement’ and ‘rumble strips …at traffic crossings for warning’ (PLA01). ‘less street furniture, improved kerbs heights’ and ‘[a] straight line to allow a visually impaired person to follow safely’ (PLA03)

Table 29: Potential environmental solutions quotes

Overall stakeholders felt that there are multiple different barriers on our streets for people with a visual impairment, however small changes could help overcome these. Planners and visually impaired people suggest the use of “*visual contrast [and] . . . element contrast*” including the *“contrast of street furniture etc. against the pavement*” and *“rumble strips . . . at traffic crossings for warning*” .

In addition the implementation of *“More cycleways would mean that the three main modes of transport are separated = less people on the footway and so less danger’.* Street furniture lines could allow a ‘straight line to allow a visually impaired person to follow safely’.

4.7.4.3 Improving Education and Awareness

Theme: Future solutions and innovations	
Subtheme	Quote
Improving education and awareness	‘endless seminars on all of this’ (ARC04). ‘could be a good way of introducing education on inclusive design especially for disabilities such as visual impairment’ (PLA01) ‘require some sort of level of knowledge/education on the subject (they should set some modules you must do per year)’(PLA01) ‘‘We had to partake in experiments within the city – Hull, England – they made us go round and see what it was like for someone with a visual impairment or wheelchair’ (ARC02)

Table 30: Improving education and awareness quotes

On discussion around improving education and awareness only one architect did not want further education. Other built environment professionals were open to the idea of further education on visual impairment and felt that CPD

(Continuous Personal Development) were a good way to introduce this. They also felt that governing bodies such as the RTPI (Royal Town Planning Institute) and ARB (Architectects Registration Board) should ensure a certain level of knoweldge. Practical experience for example through audits and street audits with multiple stakeholders especially in the disabled community could be a good way to implement understanding.

4.7.4.4 Professional Accountability

Theme: Future solutions and innovations	
Subtheme	Quote
Professional accountability	'keep abreast of it all by reading articles and stuff like that' (ARC02). 'any improvements and problems should be identified in an auditable way to be able to truly establish it' (ARC03) 'in terms of the built environment we need planners to be able to take account of the wide range of lived experiences and also to understand the big issues that face many people' (CHA03). ''[there] needs to be a more open conversation between the different bodies and stakeholders that would see this as an important' (ARC02)

Table 31: Professional accountability quotes

Stakeholders felt professional accountability was the responsibility of the professional. Keeping '*abreast of it all by reading articles and stuff like that*' is essential in all professions. Other stakeholders felt that audits could bring together '*any improvements and problems'* which can be easily identified and reported. Professionals also felt there was a need for a guidance document specifically for visual impairment.

4.7.4.5 Open Conversations between Professionals

Theme: Future solutions and innovations	
Subtheme	Quote
Open Conversations between Professionals	'"work together" (CHA01). "[there] needs to be a more open conversation between the different bodies and stakeholders that would see this as an important factor—organisations in terms of the disabled—they should become more involved with RIBA, RSUA, different architectural associations and local architects". (ARC02)

Table 32: Open conversations between professionals' quotes

Stakeholders were overwhelmingly in agreement that there should be open conversations between professionals, especially those who are working on the streetscape in separate departments. There was also a need for architects and planners to '*work together'*. In addition to professionals maintaining transparency and open conversation, all stakeholders including charities and those with disabilities should be included at the forefront of design and planning.

4.8 Discussion

The interviews suggest that stakeholders are in agreement with the literature which often describes the built environment as being 'hostile' (Imrie, 2000a) and 'not fit for purpose' (Imrie, 2000a). Similar environmental barriers such as street clutter, bollards, A-boards, pavement parking and shared space areas are discussed at length by many interviewees (Norgate, 2012, Guide Dogs, 2010, Kitchin et al., 1998).

Figure 89: Example of a car parked on pavement

Stakeholders also discussed cars and a car centric hierarchy in many towns and cities. Stakeholders felt that much of our city and town centres have become 'car centric' with recent figures suggesting Belfast is now the fifth worst congested city in the UK (Lancefield, 2021).

This also transpires into problems with footways and pavements as the more space we give to road users, the less we give to pedestrians, causing the narrow and cluttered pavements discussed in the interviews.

As can be expected these barriers and enablers in the built environment have an impact on people with a visual impairment. While many built environment professionals were aware that visual impairment has an impact on daily life, they were not aware of exactly how it would. Interviewees echoed literature which suggests visual loss can be one of the biggest impacts of quality of life (Brown et al., 2018) and is an established risk of loss of independence (Gallagher et al., 2011). Charities and ophthalmic professionals discussed about people not going out of their houses or delaying going out of their houses causing social isolation (Gallagher et al., 2011). Visually impaired individuals, charities and ophthalmic professionals were aware that many felt fear and anxiety even going a short distance. Kitchin et al in 1998 (Kitchin et al., 1998) stated that these feelings of fear and loss of confidence reduce exploration and independent travel in our towns and cities.

A majority of interviewees felt there was a lack of awareness of the true spectrum and variability of visual impairment. Visual impairment is often difficult to understand as it is a spectrum and can manifest itself in many patterns and forms. Stakeholders stated the general public often think ‘you’re blind or you aren’t’ which can lead to familial issues and public abuse (Schneider et al., 2012).

Vulnerability is something which charities and visually impaired people feel is a big problem. Many interviewees felt that they had to get private transport or a taxi as opposed to public transport due to the dangers associated with visual impairment and being with the public. Concerns about abuse from the general public, lack of understanding by transport workers and theft were discussed (Schneider, 2012).

While it is clear that public transport in Northern Ireland is improving, there needs to be more transport provided outside the city centre area. In addition, training for transport staff on disabilities should be provided.

Sight loss charities are trying to promote an understanding of vision loss and its caused with previous campaigns such as the RNIB X Channel 4 (Royal National Insitute of the Blind, 2016).

Figure 90: RNIB X Channel 4 Advert - https://youtu.be/uAbsYog57kc

While this project is concerned with visual impairment, there are other disability and co-morbidity needs which sometimes conflict, commonly refered to as 'conflicting drivers'. Some examples of this include needing ramps for wheelchair users but designing them poorly causing a hazard for people with a visual impairment. While balancing peoples needs and wants can be difficult, consultation at the forefront of the design process can alleviate these problems (Godschalk and Mills, 1966, Arnstein, 1969).

4.8.1 Potential Solutions

Some potential solutions and future directions were discussed by interviewees. Stakeholders felt that some small changes could be made to improve environments for people with a visual impairment.

Environmental solutions

- ***Pedestrian crossings*** – departments need to ensure signals are fully functional especially the tactile indicator cone under the box. In addition, sounds should be turned on to allow for safe crossing. In order to restrict noise complaints, sounds could be turned on between 6am and 10pm or similar so as not to disturb sleeping hours.
- ***Colour Contrast*** – a better contrasting colour between pavements, road and kerbs could be implemented. In addition, obstacles such as bollards, bus stops, poles and benches could have contrasting colours or contrasting 'm arkers' to make them easier to avoid.

Figure 91:Example of a contrasting bollard (Source: Stramat)

- ***Increased lighting*** – increasing lighting around urban areas will make it safer for both visually impaired people and the general public.
- ***Footway Maintenance*** – this includes replacing footways to previous standards after works.

Raising awareness with professionals such as planning professionals, architects and transport workers.

- This could be delivered through a collaboration with ophthalmic professionals, charities and the visually impaired community. Providing 'lived experiences' could allow for professionals to have a more in depth understanding of the issues people face on a daily basis.

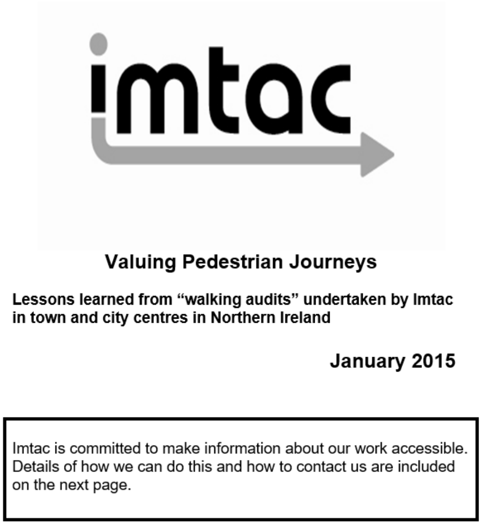
- Training delivered through CPD and annual training workshops should be provided. Perhaps hands on training in the professionals district, near their place of work could be of benefit.

Street Design, Policy and Guidance

- Implementing a 'Sustainable Transport approach' as in the National Transport Strategy, Scotland where the private car is not a priority we could leave more space on footways allowing for easier navigation and movement.

Figure 92: National Transport Strategy Scotland (Source: NBS)

- Including stakeholders in the design process (Arnstein, 1969, Godschalk and Mills, 1966) can create a more accessible streetscape suitable for everyone.
- Street audits should be undertaken to ensure the community and stakeholders can share their input. This can provide planners and architects with community prioirties and needs. The Inclusive Mobility and Transport Advisory Committee (IMTAC) offer advice and can arrange street audits while also providing 'guidelines for effective consultation with older people and disabled people' (IMTAC, 2008). These street audits and advisory boards should be contacted at the


imtac

Valuing Pedestrian Journeys

Lessons learned from "walking audits" undertaken by Imtac in town and city centres in Northern Ireland

January 2015

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Figure 93: IMTAC walking audit results (Source: IMTAC)

beginning of a planning consultation in order to make areas fit for eveyone.

- Better public transport outside the city centre and to ‘beauty spots’ such as Newcastle.
- Creation of robust guidance and policy for planning professionals created by the visually impaired community, charities and ophthalmic professionals. Good practice examples and lived experiences should be included in this.
- Open conversations between professionals should be maintained – perhaps through bi-yearly meetings between departments

4.9 Conclusions

The interviews show that stakeholders agree there are many barriers and enablers which impact a person with visual impairment navigating and moving around our built environment. Despite this, built environment professionals are not aware of the spectrum of visual loss or how much it impacts daily life. All stakeholders felt that in the future small changes could be implemented to ensure a safer and more pleasant built environment for those with sight loss. Small environmental changes such as colour contrast, footway maintenance and sounds on pedestrian crossings could be implemented. In addition, further education into disabilities such as visual impairment should be delivered to planners and architects. Robust guidelines and policies should be written and implemented to afford consistency regionally, these guidelines should include consultation from all stakeholders to ensure rigour. More open conversations between the different companies and departments controlling our streetscape will afford areas which are accessible and aesthetically pleasing to all.

***Strengths*: This is one of first studies to interview multiple stakeholders about this topic. I gathered an abundance of information from these interviews and people were very interested in the topic.

***Limitations*: There was limited discussion on the potential changes and improvements which could be physically made in the public realm. Perhaps in the future a focus group could foster more ideas and a street audit with multiple stakeholders could help with this too.

Chapter 5 : Street Audit Matrix and Worldwide Examples

5.1 Introduction

It can be very difficult to measure and assess the built environment and its features especially when it comes to potential issues for people with a visual impairment. Virtual and 'foot-based' street audits have been becoming increasingly popular in research surrounding physical activity and ageing (Pliakas et al., 2017, Pikora et al., 2002, Brownson et al., 2009, Curl et al., 2016, Millington et al., 2009). The Forty Area STudy street VIEW (FASTVIEW), Scottish Walkability Assessment Tool (SWAT) and the Seniors Walkability Environment Audit Tool-Revised (SWEAT) have been developed in recent years (Griew et al., 2013, Michael et al., 2009, Millington et al., 2009). Whilst these tools do not deal with visual impairment specifically, they audit several similar barriers such as path obstructions, pavement condition and dropped kerbs.

From the previous chapter it was clear that most town planners and architects wanted to see more walkability audits conducted in the consultation process. There are some cities across the UK and worldwide that are conducting walkability audits for disability and visual impairment, these include Perth, England and Victoria, Australia (Living Streets, 2016, Burtt, 2014). Burtt 2014 produced audit tools for barriers such as intersection types, tactile ground surface indicators and footpaths.

From a local context, Belfast Healthy Cities and IMTAC (The Inclusive Mobility and Transport Advisory Committee (IMTAC), 2015, Belfast Healthy

Cities, 2014) describe the need for walkability audits and IMTAC has produced the results of seven walking audits in Northern Ireland (The Inclusive Mobility and Transport Advisory Committee (IMTAC), 2015).

5.2 Overview

From the literature we can see that researchers and charities feel that being able to assess how people move and navigate around the built environment and what barriers and enablers there are is important. So far, there has been limited literature and tools for assessing built environments and navigation for those with a visual impairment. This chapter aims to explore creating an audit tool for assessing barriers and enablers in streetscapes. This audit tool is designed to be used by all (regardless of profession/general public).This chapter will also have example pictures of problems and barriers worldwide. By creating a tool it can allow professionals and the general public to assess accessibility of areas and what changes should/could be made. This chapter also gives a global understanding of the issues from the literature, previous studies and results of the NaviSight Study.

5.3 Aim

To create a tool for all to audit the potential barriers and enablers for visually impaired users within the streetscape.

5.4 Methods

5.4.1 Street Audit Matrix

Previous literature and the auditing tools mentioned above were used as a base for creating the street matrix tool. Some of the above tools mentioned similar issues such as streetscape features and condition of the pavement.

Initially, a google street view audit of places across the world was undertaken to gauge the streetscape conditions in Milan, Italy and Szeged, Hungary. These areas were chosen as there were collaborators who were willing to complete a street audit (to give a global perspective) which could not be done at the time by the PhD student due to restricted travel caused by the COVID pandemic.

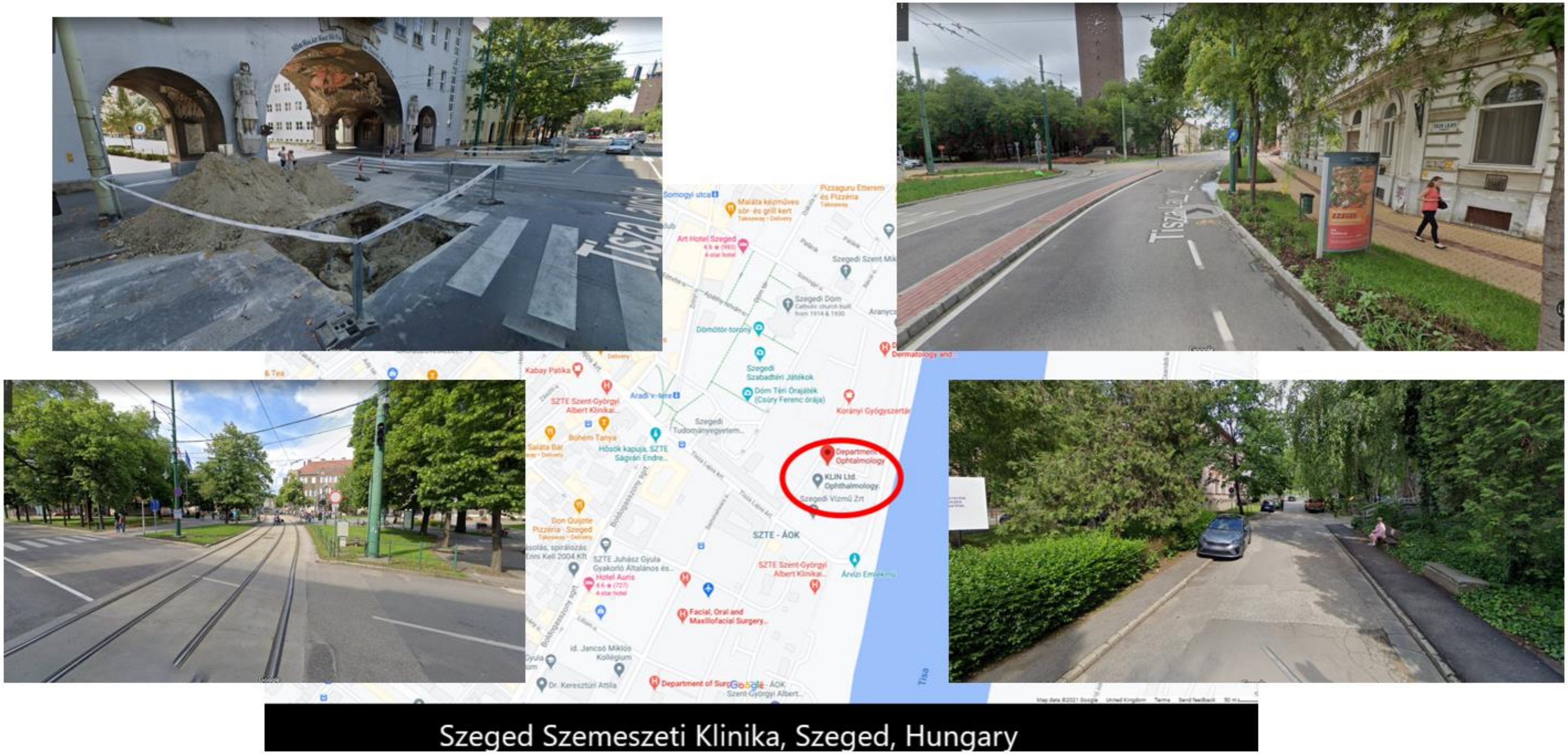


Figure 94: Example of Google street audit around Szemeszeti Klinika, Szeged, Hungary

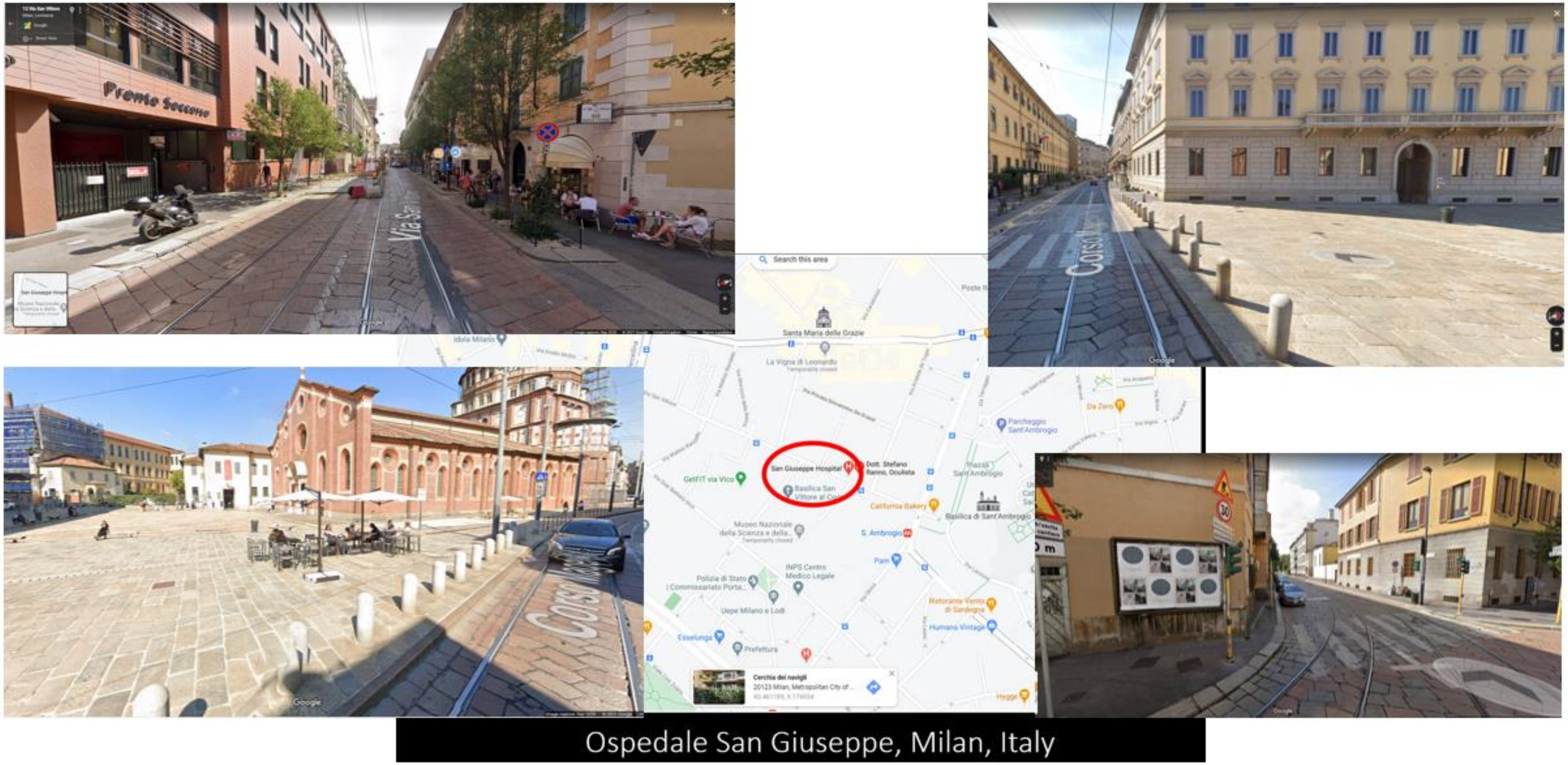


Figure 95: Example of Google street audit in Milan, Italy

In addition to the initial google street audit of these cities, 8 undergraduate medical students on the 'Student Selected Component – SSC' programme (a self-selected module within the medicine curriculm to expand beyond their core medical curriculm and learn about research methods, practical application of medicine and basic science) were asked to undertake a 'street audit' in their area. This allowed for them to understand the true problems on our streetscapes as well as gathering information for the streetscape tool. The questions below formed the initial street audit questions, students were asked to complete the audit where they were at the time, and due to COVID this was across the world. They were asked to provide feedback on these parameters and report on any parameters they thought were not included.

◦ **How to Conduct the street audit**
- Walk around the area
- Make sure you are thinking about multiple stakeholders
  - Is it accessible for all types of disability
  - Is it a nice place to be?
  - Do you feel safe?

Is there street clutter around?
- Posts in the middle of the pavement?
- Bollards in the middle of the pavement? Are these different colour to the pavement/do they have a yellow marking? Are they more than hip height?

Are there cars parked on the pavement?
Are there street cafés or A-boards
Is there enough lighting?

Are there enough pedestrian crossings?
- Are they all accessible and is the accessible element working?

Condition of the pavement
- Is there tactile paving?
- Are there cracks in the paving?
- Is the pavement uneven? Are there tree roots?
- Is there a continuous colour across the pavement?
- Is there delineation with the road? Adequate Kerbs?

Figure 96: Initial street audit guidance

Following feedback from the SSC students and from information from previous literature and street audits, a street matrix (tick box) was established. Most respondents in the SSC failed to answer very subjective questions such as 'is it a nice place to be' , therefore the decision was made to remove them. It was therefore decided that the street audit should be as objective as possible. It was also decided that a tick box would be easiest with an option for further comments, especially if visually impaired users were to conduct the audit. All elements have equal ranking as you can not deem one more important than the other as this depends on visual impairment, type of sight loss and ability to move around independently. This tick box street matrix can be used alongside pictures.

5.4.2 The Street Matrix

	Present? Yes/No	Obstructing pathway? Yes/No	Further Comments
General			
Is the area clean?			
Is there any litter?			
Pavements			
Wide enough for a wheelchair to pass?			
Is it level?			
Are there cracks?			
Are there trip hazards?			
Are there pools of water?			
Is it a consistent colour?			
Clear contrast between pavement and kerb colour?			
Kerbs			
Are they recognisable from the road?			
Clear delineation between road and pavement?			
Missing kerbs?			
Cracked kerbs?			
Dropped kerbs?			
Street Furniture			
Bollards			
Advertisement Boards			
Signage			
Parking Machines			
Bike Racks			
Bins			

Bus Stops/Shelters			
Benches			
Is there a clear furniture line?			
Unpredictable impediments	Yes/No	Obstructing pathway?	Further Comments
Cars parked on pavement?			
Moped/Motorbikes on pavement?			
Bikes on pavements?			
Levels			
Are there stairs?			
Ramp as well as stairs?			
Are the stairs clearly defined?			
Handrail for the stairs?			
Crossings			
Are there accessible crossings?			
Do the crossings have a sound to indicate safe crossing?			
Are there any obstructions at the crossings?			
Tactile Paving			
Is there tactile paving?			
Is it recognisable under the feet?			
Any cracks?			
Any missing paving?			
Shared Space			
Are there any areas of shared space?			
Are there large squares with open space?			
Is there any large green space?			

Are there any cafés/food trucks in the squares?			
Do the cafés have clear boundaries			
Street Lighting			
Is there street lighting?			
Is it adequately spaced?			
Other dangers			
Low level signage?			
Low hanging branches?			
Signs			
Are direction signs clear?			
Conflicts			
Are there cycle lanes?			
Is there separation between pedestrians and cycle lanes?			
Do bus queues form an obstruction?			

Figure 97: Street matrix

5.5 Results

This street matrix was used by five users, including the PhD student, across different countries as a pilot study to establish if it can be used by both professionals and the general public internationally. Street audits were conducted by five individuals (including myself) in different areas/countries (these included academics and the general public).Two auditors were academics (1 the PhD student) within ophthalmology/diabetes care. The other 3 were people from the general public who did not have a related profession. No individuals had visual impairment. Auditors were asked to complete the audit in an area they use regularly and to tick boxes as appropriate and provide any other comments in the comment box. These areas were all known to the auditors apart from the one in Odense. The choice of area to be audited was left up to the individual so as not to influence the results of the usability of the street audit. Audits were undertaken in Northern Ireland, Italy, Ireland Denmark and Hungary. I recognise there are different cultural and historical factors within these areas that shape the streetscape.

Below is a table of results from the different countries:

	Northern Ireland			Ireland	Italy	Denmark	Hungary		
Issues with:	**Belfast – Botanic**	**Belfast – Crumlin Road**	**Lisburn**	**Donegal Town**	**Bagni di Lucca**	**Odense**	**Szeged – Physio Dept + Pool**	**Szeged – Eye Clinic**	**Szeged – University Area**
Litter	Yes	Yes	No	No	No	No	No	Yes	Yes
Pavement	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Kerb Issues	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Street Furniture	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Unpredictable Impediments	Yes	Yes	No	Yes	Yes	No	Yes	Yes	No
Levels	No	No	Yes	Yes	No	Yes	No	Yes	Yes
Crossings	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Tactile Paving	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Shared Space	Yes	No	Yes	No	Yes	Yes	Yes	No	No
Street Lighting	Yes	No	No	Yes	No	No	No	No	No
Other Dangers	No	No	No	No	No	No	Yes	Yes	Yes
Signs	No	No	No	Yes	No	No	Yes	Yes	Yes
Conflicts	No	No	No	No	No	Yes	Yes	No	No

Table 33: Street audit results

5.6 Results of the Street Audit

5.6.1 Most Prominent Issues

<u>Tactile Paving</u>

All street audits showed issues with tactile paving. All of the main European continent street audits showed that there was no tactile paving present at all.

The area around Botanic had tactile paving at some crossings, but not at all. In Lisburn, some of the tactile paving was poor and unrecognisable.

Street Furniture

Street furniture was present in all street audits, some of which was obstructing the footway. The most common problematic street furniture were advertisement boards, bollards (including mini-bollards), signage and bins.

Kerb Issues

All street audits showed issues with kerbs including missing/cracked kerbs, problems with delineation from the road and cycle lanes and a lack of dropped kerbs. In some areas such as in Hungary and Odense, there were areas where the kerb and road were nearly at the same level and it was difficult to decipher where the road started. There were also problems in Odense where cyclists and pedestrians were on the same paving with only a white line to separate them. Many areas, mainly in Hungary, Odense and Bagni had missing dropped kerbs or only dropped kerbs for vehicles as opposed to disabled access.

Pavement Issues

A majority, 88.9%, (all bar one) had pavement issues. Many pavements were not wide enough for a wheelchair to pass and had problems with levels, trip hazards and consistent colour. Some of the level issues included dips in the pavement, tree roots, pavement cracks, cobblestones, tram tracks and guttering. Trip hazards included clothes rails, plant pots and mini-bollards. Colour issues included retrofitted pavement and the favoured use of different shades of grey and beige. In Odense, Denmark there were serious problems with kerb and road contrast with kerbs nearly unrecognisable from the road. Some other barriers, especially in Hungary were snow and ice (especially when pavements were cleared and it was piled up).

Pedestrian Crossings

A majority, 88.9%, of street audits stated issues with pedestrian crossings. Bagni di Lucca had no accessible crossings present at all, pedestrians were expected to cross by looking and no dropped kerbs or tactile paving was present. Hungary and Odense had areas with no accessible crossings at all and where crossings were present there were obstacles such as signpost poles, cracks in the pavement or parked cars/ambulances.

5.6.2 Less Prominent Issues

Shared Space

Just over 60% of audits were carried out in places with shared spaces, of those all but one had issues. The main concerns with shared spaces were street cafés without delineation.

Levels

Many areas had stairs without handrails and an alternative ramp making it difficult to recognise this danger or access some areas.

Unpredictable Impediments

Many, 66.7%, stated there were unpredictable impediments including bikes, motorbikes and cars parked on the pavement. Six street audits including all three Hungarian audits, stated there were bikes being riden or parked on the pavement. Four street audits said there were cars and/or motorbikes parked on the pavement.

5.6.3 Other Issues

Some audits described problems with litter (44.4%) and lack of clear signage (44.4%). Over 30% stated other dangers such as low hanging branches and signs which could cause injury. Very few cities, except Odense and some areas in Szeged had cycle lanes therefore only 22.2% felt there were problems with cycle lanes and delineation. Street lighting was only deemed to be poor in Botanic Avenue and Donegal Town. Some auditers pointed out that there could be issues with historical preservation and not wanting to damage pavings etc. which fit with the style of the town/city. This is especially true in Italy, especially Tuscany with traditional cobblestones pavements and old historic towns.

5.7 Street Audit Pictures

From the street audit and from moving and navigating different cities around the world, many pictures of potential barriers for visually impaired users have been gathered. An example of some of these pictures can be found below:

5.7.1 Unpredictable Issues

There can be many unpredictable hazards on our pavements including A-boards, pavement works, bins and many others.

5.7.1.1 Advertisement Boards (A-boards)

Below is a selection of advertisement board pictures from Belfast (especially the walkaround route) and Lisburn. Some of these images also show examples of A-boards without information on them.

Figure 98: A-board, Lisburn

A-board in Lisburn’s Haslem Lane. From this picture you can see that there are 2 A-boards impeding the path as well as a bollard. This could be very precarious for a person with a visual impairment.

Figure 99: A-board, Shaftesbury Square

An A-board structure without any information on it in Shaftesbury Square in Belfast. This poses a particularly big risk as the non-filled structure could be easily missed. This is also close to the tactile paving which is also impaired by traffic light and street light poles. If you look closely you can also see some of the tactile paving is loose and moves when stepped on.

An example of Botanic Avenue with many A-boards on the pavement which could hinder someone with a visual impairment.

Figure 100:A-boards and street clutter, Botanic Avenue

Figure 101: A-boards and street clutter, Botanic Avenue

Bins and Skips

Examples of bins and skips in Shaftesbury Square in Belfast. The first image depicts a large bin (most likely from a nearby restaurant) which is impeding the footpath, it is also a risk as it is on wheels and could move with wind etc. The second picture shows a skip in the middle of the pavement with some cracked tactile paving and residual pooling water. If you look closely there is also a road works sign. All of these things are unexpected impediments.

Figure 102: Skips and bins, Shaftesbury Square

5.7.1.2 Cars Parked on the Pavement

Figure 103: Cars parked on the pavement, East Belfast

Figure 104:Cars parked on pavement, Lisburn

Examples of cars parked on the pavement in Belfast and Lisburn are shown above. These pictures include cars parked up on a kerb which causes the pavement to be narrowed as well as obstacles with cars parked at different angles/levels on the pavement. In addition, this picture shows some bins which further impede the pavement making it very difficult to navigate. The second picture shows a car parked completely on the pavement. In this picture you can actually see a pedestrian having to walk on the busy road to get around it.

To the right is an image of cars parking on the pavement in Szeged Hungary leaving very little space to move around it.

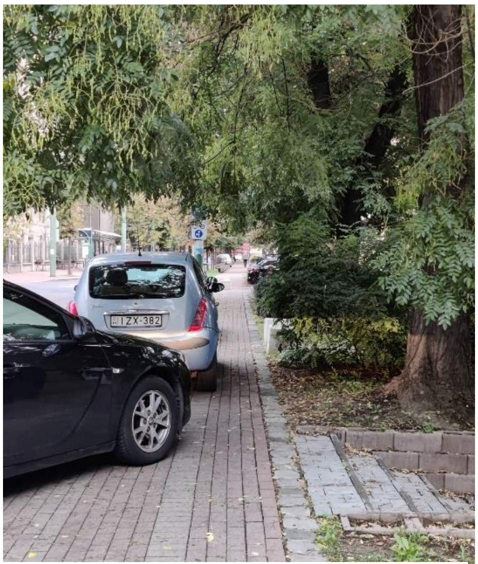


Figure 105: Car parking on pavement, Szeged Hungary

Figure 106: Car parked on pavement, Berlin and Lisburn

Some further examples of cars parked on the pavement in Berlin, Germany and Lisburn, Northern Ireland. The car in Berlin is parked across an entrance while also being on a pavement, making the pavement narrower. This image also shows challenges with colour changes, patterns and material on the pavement. There is also a trip hazard along the building line. The second photo shows a car parked on the pavement and a car parked in a driveway thus impeding the footpath further. Further images can be seen of cars parked on pavements in Szeged, Hungary.

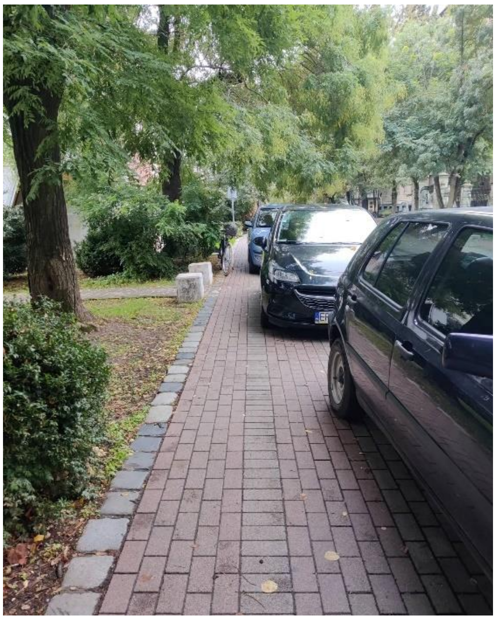


Figure 107: Cars parked on pavement, Szeged Hungary

5.7.1.3 Road/ Pavement Works

Figure 108: Road works and street clutter, Wellington Avenue

The pictures above show a particularly perilous situation for someone with a visual impairment,for others with a disability or a person with a pram. The work truck is parked on the pavement behind a tree, there is a gate which is preventing people from walking on the pavement forcing people to walk onto the road. When the pedestrian has negotiated these issues, they are then faced with a large wooden pole and a pallet which are very difficult to move around forcing them further onto the road. After they have negotiated all of this, the wooden pole continues down the road for quite a while then there is a pole and a large branch as the pedestrian steps back onto the pavement. This would simply be a nightmare for someone with a visual impairment.

To the right is another example of construction work ongoing around

Figure 109: Road works, Shaftesbury Square

Shaftesbury Square. Construction workers have laid out boards onto the pavement to allow vehicular access to the construction zone. These boards are not level with the pavement and cause a trip hazard, they are also extremely slippy when you stand on them.

Figure 110: Pavement works, Szeged Hungary

Photos from around the hospital and university areas show pavement works. From these photos it is clear to see that there are many areas cordoned off with yellow tape. In addition, there are changes in tactile paving and missing tactile paving. There are also many other hazards such as bollards, blocks on the road, gates, lose cordoning and level changes. In addition. There is a trip hazard where the pavement has been repaved. Photos also show areas with puddles and changes in pavement colour/texture.

5.7.1.4 Flooding/Standing Water

Figure 111: Flooding, Lisburn

This is an example of flooding in Lisburn, Northern Ireland. The footpath is partially flooded where the pedestrian stands and is completely flooded from there on. This creates a particular issue for people with a visual impairment as if they do not notice they will be wading through water, and if they do, a new route will have to be used to get to their destination.

To the right are some examples of standing water alongside footpaths in Szeged Hungary. This standing water could be stepped in by people with a visual impairment and also cars could splash pedestrians on the footpath.

Figure 112: Standing water, Szeged Hungary

5.7.1.5 Street Cafés


Figure 113: Street cafés, Botanic Avenue

Example of street cafés Botanic Avenue, Belfast. The first street café impedes onto the pavement considerably and has a few bollards with a rope as a cordon which is very difficult to see. The café cordons then end where there are trees which also narrow the pavement. This mean the pedestrian has to move over to avoid these issues. The trees also make this area quite dark. The second café does not impede the pavement as much however there is no cordon and they are at differing levels making them more difficult to navigate around.

5.7.1.6 Litter

Figure 114: Litter, Shaftesbury Square

Litter can also cause problems for people with a visual impairment. In addition to it being unsightly, it causes a trip or sliding hazard for those with visual impairment.

5.7.1.7 Cracks and Uneven Paving

Figure 115: Uneven paving, Odense

Here is an example of an area with uneven paving and cobblestones of differing colours from Odense, Denmark. This area could be very challenging for someone with a visual impairment to navigate. In addition to the uneven/colour issues, the stairs without bannisters could cause a trip hazard.

An example of cracked paving in Botanic Avenue, Belfast. This cracked paving could cause a tripping hazard. In addition, bins are spread across the pavement, there is litter and a parked car which cause further problems.

Figure 116: Uneven paving bins and street clutter, Botanic Avenue

Figure 117:Cracked paving, Szeged Hungary

These are some examples of cracked and uneven paving in Hungary.

Figure 118: Crack and missing paving, Szeged Hungary

These cracked and missing pavings create a big trip hazard for people with a visual impairment. These areas of cracked pavement also seem to be in shared space areas/areas without kerb delineation. There are issues surrounding cobbled streets, especially within European cities, as this can cause continuous trip hazards as well as make it impossible to use a cane to navigate.

Figure 119: Cracks, uneven paving and standing water, Szeged Hungary

5.7.2 Public Realm Issues

Public realm issues include colours of pavements, tactile paving placement, bollards, shared spaces and street furniture placement.

5.7.2.1 Pavement Colour

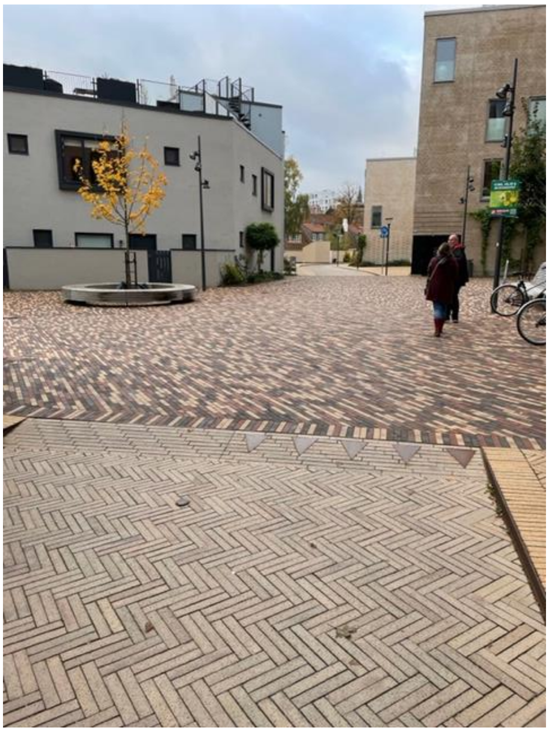


Figure 120: Pavement colour, Odense

This is an example from Odense, Denmark of a shared space area as well as a pavement/ road area. From the picture you can see the changes in paving colour are continuous. This makes it extremely difficult for someone with a visual impairment to know where the sidewalk ends and the road begins.

An example of the space outside the Futurium in Berlin, Germany. While this area may be aesthetically pleasing, it is dark with a lot of colour contrast which could be difficulty to navigate. Visually impaired users will often associate a change in colour of pavement with a level change.

Figure 121: Pavement colour, Berlin

5.7.2.2 Retrofitted Pavement

Figure 122: Retrofitted pavement, Belfast

Examples of retrofitted pavement in Belfast. This occurs when companies do not repair or replace the pavement with the same colour and material as it was previously. This again can cause problems with visually impaired users thinking it is a level change. It can also be problematic for cane users as they may think it is a hazard.

5.7.2.3 Street Furniture

Figure 123: Street furniture, Botanic Avenue and Gardens

Some examples of street furniture in Botanic Gardens and Botanic Avenue. The first is a sculpture which is placed in the walking area of Botanic Gardens, it has pieces of ‘tyres’ sticking out which could cause a trip hazard. In addition, an example of an electronic sign board and an A-board which could create a hazard.

Figure 124: Street clutter, Bagni di Lucca

An example from Bagni di Lucca, Italy of an abundance of street furniture impeding the pavement. Firstly, the street café makes the pavement very narrow. Once past the street café, plant pots impede the pavement further and could cause a potentially dangerous trip hazard. Further up the street are more restaurants and cafés on the pavement as well as a shop with tables, clothes rails and a low hanging awning.

5.7.2.4 Bollards

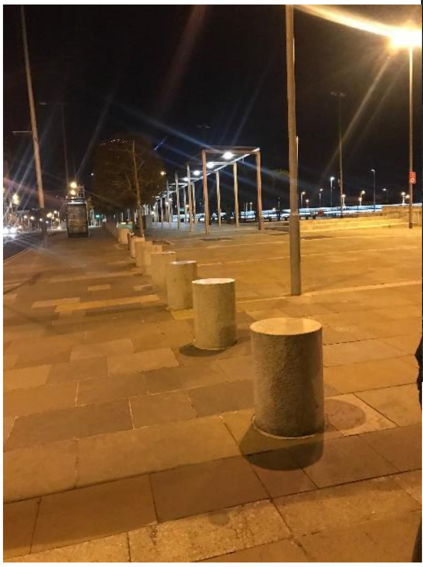


Figure 125: Bollards, Belfast and Portrush

Examples of bollards in Portrush, Northern Ireland and Belfast, Northern Ireland. These pictures show a selection of different styles of bollards at different heights and widths. It also shows their placement on the streetscape making them easy to walk into or fall over. Bollards are a particular problem for people with a visual impairment. They also have no contrasting colours on them as a warning.

Figure 126: Bollards, Odense

This is an example of a bollard in Odense, Denmark. It has no contrasting colours and could be easily walked into. This picture also shows a lack of delimitation between the pavement and road which can be extremely hazardous for a visually impaired user.

5.7.2.5 Delineation

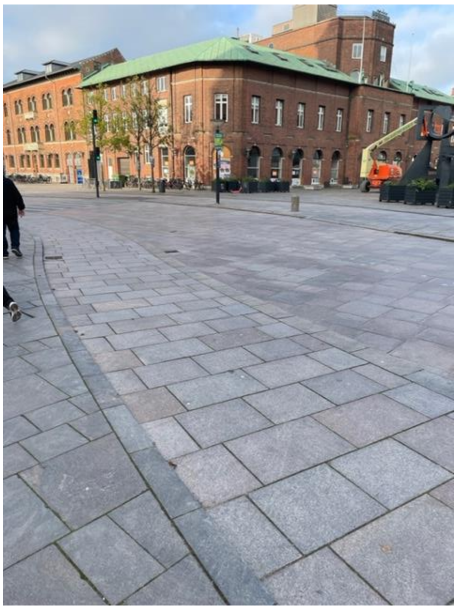


Figure 127: Poor delineation, Odense

An example from Odense, Denmark of extremely poor delineation between pedestrian, cycle lanes and the road. The colour contrast is poor and the kerb height different is nearly non-existent.

5.7.2.6 Shared Space

Figure 128: Shared space, Queen's University Belfast

Shared space also has issues with delineation, cars and people are sharing the same space and rely on noise and eye contact to negotiate which is clearly very difficult for those with a visual impairment.

5.7.2.7 Tactile Paving

Figure 129: Cracked and missing tactile paving and standing water

Examples of cracked and missing tactile paving in Belfast Northern Ireland. Some of them also having standing water around them. These cracks can cause trip hazards and can make it very difficult for a cane user to navigate easily. Standing water also causes problems and can make a visually impaired user think there is a hazard or level that is not there.

Figure 130: Cracked and missing tactile paving, Belfast

An example of tactile paving which is present on one side of the crossing but not on the other. This could be particularly dangerous as there is cracked tactile paving on one side but none on the other. If a visually impaired user cannot find the tactile paving on the other side, they may injure themselves or trip on a kerb trying to find it.

An example in Belfast, Northern Ireland of a trip hazard (broken concrete block) on tactile paving.

Figure 131: Obstruction on tactile paving, Belfast

Figure 132: Alternative tactile paving, Berlin

An example of untraditional tactile paving as well as colour contrasting issues in Berlin Germany. While it is good that the visually impaired person can follow the straight lines in safety, the colour contrast is poor and the multiple colours in the pavement can make it difficult to interpret.

5.7.2.8 Other

Figure 133: Trampolines in the pavement, Berlin

Some public realm efforts which are beneficial for active travel or children can be a hazard for people with a visual impairment. An example from Berlin, Germany shows trampolines embedded into the ground in a square. This could be very perilous for someone with a visual impairment.

5.8 Conclusion

The street audit tool is a good way to access the physical barriers found on streetscapes across different areas, towns and cities. The audits show that there are common barriers and concerns in town and cities across Europe. Some of the most prominent issues are pavement and kerb problems such as trip hazards, delineation and colour contrast. Other problems such as street furniture, pedestrian crossings and tactile paving could be seen across street audits.This pilot serves as a basis for wider validation of the street audit tool in the future.

Future directions

In further studies, we will collect further data on users, usability and transferability to make the study more robust. Users will be asked to comment on the tool after using it. In addition, more users will test the tool in different seasons to establish seasonal barriers. By collecting this data the tool can be better validated for use. A further question on pavement width will also be added to ask whether two people or two wheelchairs can pass on the pavement.

Strengths

This study provided an overview of the use of a street audit tool by different users across Europe. It allowed comparison of the potential issues faced by people with a visual impairment.

Limitations

In order for the data from the tool to be robust, a defined area size for auditing should be set, perhaps 200m each direction or something similar. Some towns and cities often have problems in one area but not the other. Some of the sections are very subjective such as width of pavements – while I think it is unreasonable to ask auditors to measure a pavement perhaps using a measurement such as ‘can two wheelchairs pass comfortably’ or ‘can two pedestrians pass comfortably’ could be added. Data on users, experience and settings needs to be collected in future studies. Data and suggestions from users to improve this audit tool should be collected and analysed to make the tool robust and to move towards validation.

Chapter 6 : Participant Clinical, Imaging and Walkaround Results and discussion

6.1 Introduction

From previous chapters we know that people with a visual impairment often find towns and cities difficult to navigate (Aida E. Afrooz et al., 2012, Gustafson-Pearce et al., 2005). There are many physical barriers people with sight loss face when simply walking down their street including bins, parked cars and advertisement boards (Guide Dogs, 2010, Kitchin et al., 1998, Norgate, 2012).

6.2 Overview

This chapter shows results from the participant element of the study including clinical results, retinal imaging results and walkaround results.

6.3 Rationale

While we know that people with a visual impairment can face challenges when navigating the built environment, we do not know how visual patterns and levels of visual loss impact this. We know from the literature that people with retinitis pigmentosa face problems navigating the built environment independently (Timmis et al., 2017, Turano et al., 2001). As people with retinitis pigmentosa usually suffer from peripheral vision loss, we wanted to investigate if people with other peripheral disease had the same issues.

6.4 Research Aim

Does vision loss and function affect independent mobility and navigation in urban environments?

Methods

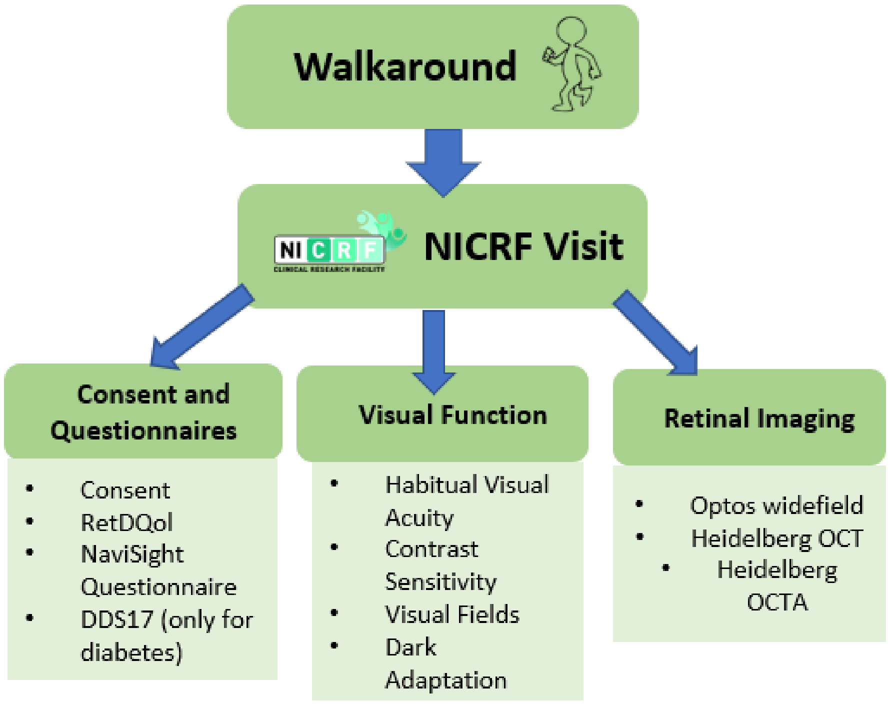


Figure 134: Participant visit flow chart

Full methods can be found in Chapter 3. A diagram of the NICRF clinical visit can be found below as a reminder of what images, tests and questionnaires were completed by participants.

6.5 Results

These results are frequency results from the clinical, imaging and walkaround aspect of the study. SPSS Statistical package version 28 was used to create frequency tables and results. In addition, boxplot analysis has been included in each variable to show comparison between groups (as described above).

6.5.1 Participant Demographics

In total there were 33 participants in the study with 64 eyes as two participants had right eyes which could not be imaged or clinically assessed. Most 23 (69.7%) were male and 30.3% were female with an age range of 18-

75 years. Mean age was 49 and median age was 51. Of these 33 participants, 22 (66.7%) had diabetes and 11 (33.3%) had retinitis pigmentosa.

There was little difference in the mean and median ages of those with RP and diabetes (RP: mean – 47, median – 46. Diabetes: mean =49, median – 51.5).

6.5.2 Medical Data

Of those with diabetes, 16 (72.7%) had type 1 diabetes, 5 (22.7%) had type 2 diabetes and 1 was in diabetes remission. The range of diabetes duration was 2 – 67 years with a mean of 25 and a median of 20.

Below is a table of medical history data from all participants:

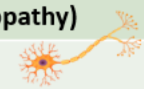
Do you smoke? 	Yes	2 (6.1%)	**Foot Problems** 	Yes	6 (18.2%)
	No	31 (93.9%)		No	27 (81.8%)
Do you drink alcohol? 	Yes	22 (66.7%)	**Nerve Damage (Neuropathy)** 	Yes	7 (21.2%)
	No	11 (33.3.%)		No	26 (78.8%)
Hearing Loss 	Yes	3 (9.1%)	**Kidney Problems (Nephropathy)** 	Yes	2 (6.1%)
	No	90 (90%)		No	31 (93.9%)
Stroke 	Yes	0 (0%)	**Neurological Problems** 	Yes	3 (9.1%)
	No	33 (100%)		No	30 (90.9%)
Heart Attack 	Yes	1 (3%)	**Rheumatology Conditions** 	Yes	4 (12.1%)
	No	32 (97%)		No	29 (87.9%)
Peripheral Vascular Disease 	Yes	2 (6.1%)	**Balance Problems** 	Yes	4 (12.1%)
	No	31 (93.9%)		No	29 (87.9%)
Angina 	Yes	1 (3%)			
	No	32 (97%)			

Figure 135: Participant medical history data

Data were self-reported by participants as part of the study questionnaire. All declared co-morbidities were by people with diabetes with the exception of one person with RP having foot problems. In addition, all those who smoked and had hearing loss had diabetes. There was a mixture of RP and diabetes participants who stated they drank alcohol. Other medical history comments from people with diabetes were heart surgeries, ischaemic heart disease, TIA (transient ischaemic attacks) and anxiety and depression. For those with RP one participant stated they suffered with gout, undiagnosed ataxia and fibromyalgia.

Below is the frequency analysis of participant data.

6.5.3 Visual Function Data

6.5.3.1 Visual Acuity

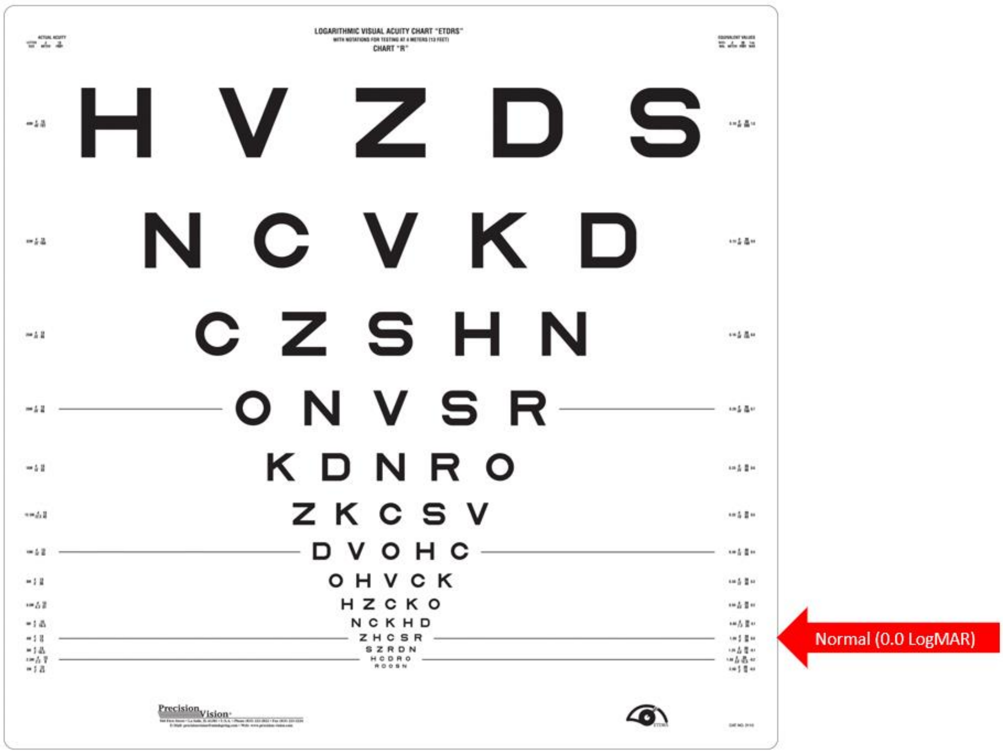


Figure 136: ETDRS chart with normal vision marked

Above is a picture of the ETDRS chart used to assess participant’s vision.

The red arrow shows where 'normal' or '20/20' vision is – 0.0 in LogMAR scale. Where numbers are in minus, the participants vision is 'better than normal'.

	NTDR	TDR	RP
Mean	-0.2	-0.02	0.1
Median	-0.2	0.0	0.1
Range	0.3	0.4	1.0

Table 34: Visual acuity (LogMAR) mean, median and range per group

**NTDR =non-treated for diabetic retinopathy, TDR = Treated diabetic retinopathy and RP = Retinitis Pigmentosa

Mean and medians show that those with non-treated DR had a generally better visual acuity than those with treated DR and RP. The true range of this can be seen below in the boxplot. The overall mean was 1.44, median 1.35 and range was 1.80 from all participants.

Boxplot of Visual Acuity by Group

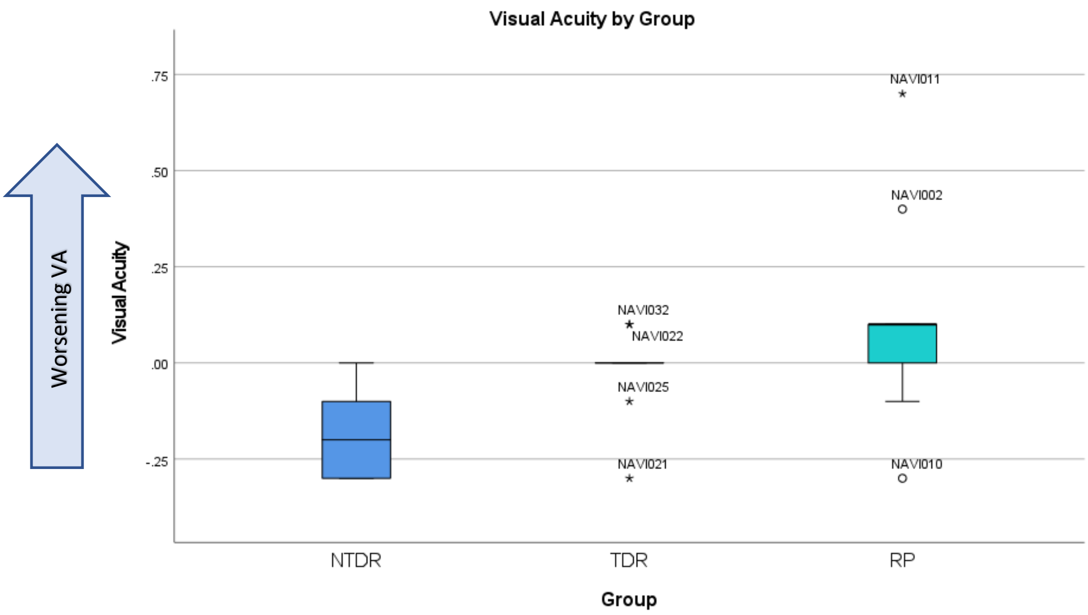


Figure 137: Visual acuity boxplot by group

**NTDR =non-treated for diabetic retinopathy, TDR = Treated diabetic retinopathy and RP = Retinitis Pigmentosa

There is a variability in visual acuity between NTDR, TDR and RP. Those with RP have a wider range of visual acuity (VA) to those with Diabetes and tend to have worse vision. DR does not seem to impact VA as much. The results show that people with RP have a significantly lower visual acuity than those with NTDR and DR (p=0.000).

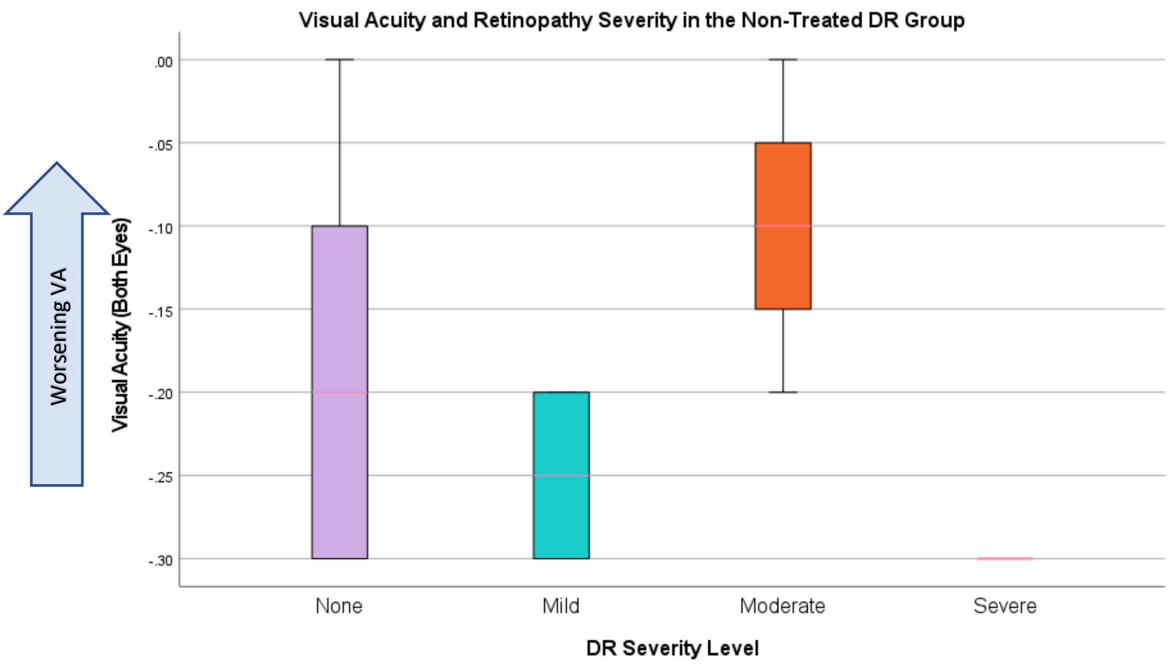


Figure 138: Visual acuity (both eyes) and retinopathy severity in the non-treated DR group

While there is variability in people with non-treated DR they all have normal or better than normal vision.

6.5.3.2 Contrast Sensitivity

	NTDR	TDR	RP
Mean	1.7	1.2	1.3
Median	1.8	1.4	1.2
Range	0.6	1.35	1.8

Table 35: Contrast sensitivity (Both Eyes) mean and medians in groups

'Normal' levels of contrast sensitivity vary according to age; normal levels for people older than 60 are 1.52-1.76 and for those younger than 60 are 1.72-1.92 log contrast. Moderate contrast loss is deemed 1.04-1.48, severe loss is 0.52-1.00 and profound loss is less than 0.48 log contrast.

From the mean and medians, it is clear that those with treated diabetic retinopathy have more difficulty with contrast sensitivity than those with no treatment. Those with treated DR have mean and medians close to those with RP.

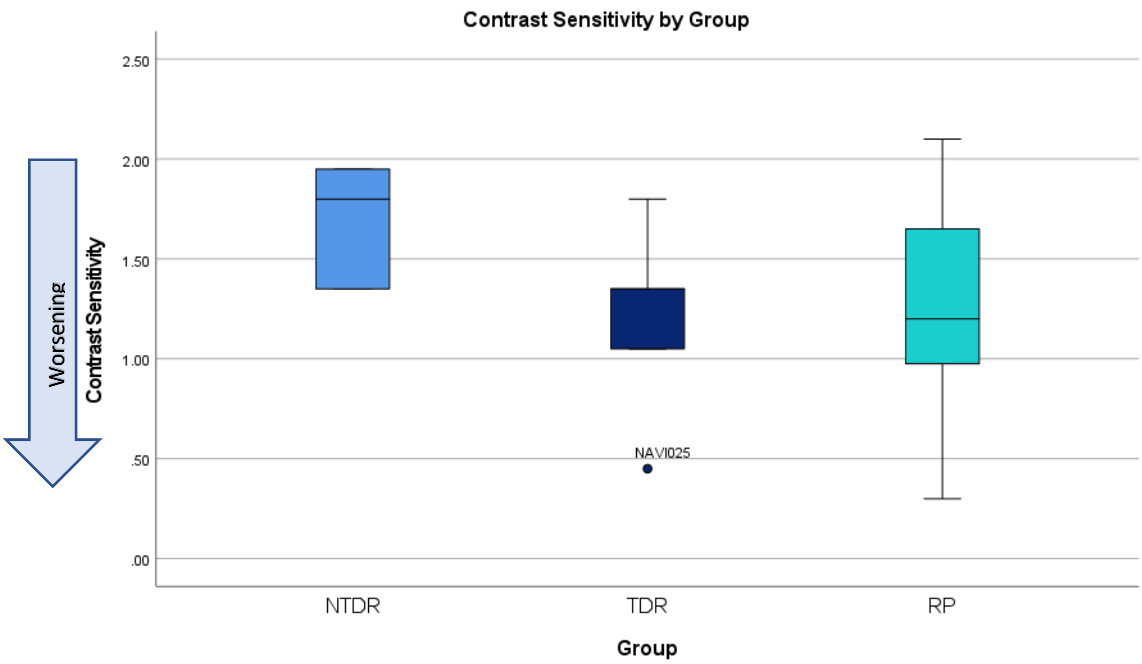


Figure 139: Contrast sensitivity of all participants

From the boxplot it also clear that those with treated DR have more issues with contrast sensitivity than those with NTDR. People with RP have a large variability in their contrast sensitivity. NAVI025 was the only outlier found when comparing groups – this participant also had issues with visual fields and dark adaptation, therefore this could warrant further investigation. Those with treated DR varied from having ‘profound loss’ to normal, most seem to lie in the normal-moderate range. Those with RP ranged from profound loss to normal, with many ranging in the lower end of normal to moderate loss.

Statistical analysis shows that both RP (p=0.017) and TDR (p=0.012) had significantly reduced contrast sensitivity loss.

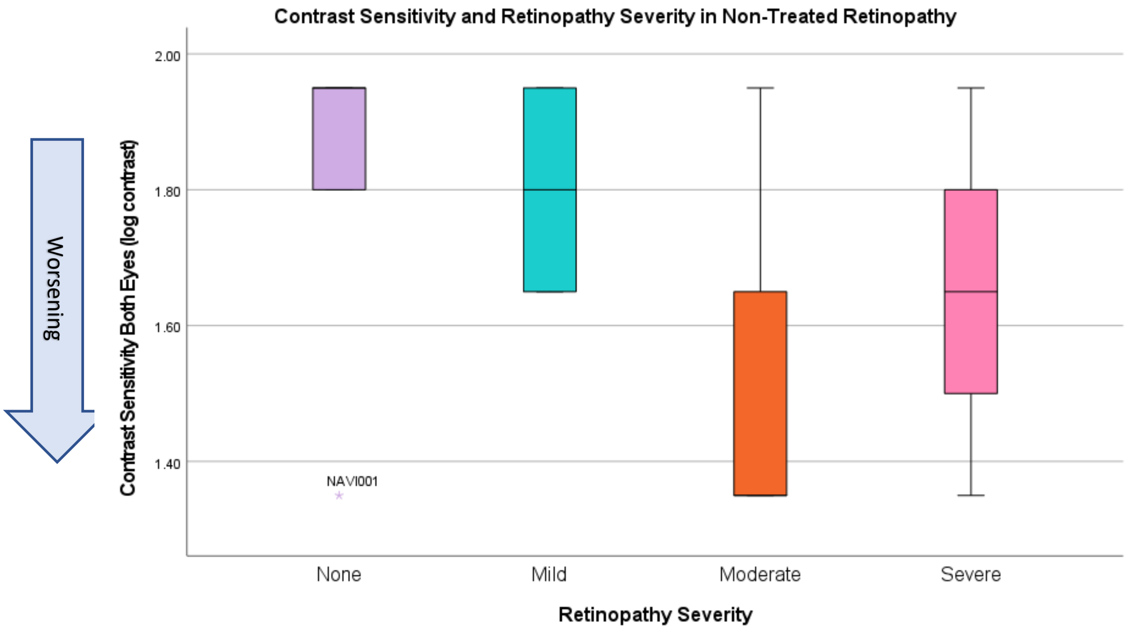


Figure 140: Contrast sensitivity (both eyes) and retinopathy severity in those with NTDR

Contrast Sensitivity Scores have a huge variability in the non-treated DR group, those with worse DR severity tended to have worse contrast sensitivity whereas those with none/mild tended to be within normal limits.

Within this group, those with no or mild DR were all within normal limits except for NAVI001 who falls within moderate contrast sensitivity loss. Those with moderate and severe DR have a bigger range from normal to moderate loss. Those with moderate DR tended to have more problems with contrast sensitivity mirroring the VA results.

6.5.3.3 Visual Field

Visual fields were calculated in two different ways, the mean visual field between both eyes and by using an automated programme from the Metrovision manufacturing team.

Incapacity Index Metrovision Analysis

The incapacity index analysis gives a percentage of defective areas. The number of people in each group and their percentage deficits.

	NTDR	TDR	RP
No deficits	10 (76.9%)	7 (77.8%)	2 (18.2%)
Under 20%	3 (23%)	1 (11.1%)	1 (9%)
21-50%	0	1 (11.1%)	1 (9%)
51-80%	0	0	3 (27.3%)
81% - 100%	0	0	4 (36.4%)

Table 36: Metrovision incapacity index percentage affected

As expected most in the NTDR group have no deficits or very minor deficits in their binocular visual field (max 4%). Interestingly most in the TDR group have no deficits or low deficits (max 34%). This is in contrast with those with RP who have a wide range of deficits, from no deficits to those with nearly 100% (or indeed 100%) visual field deficit.

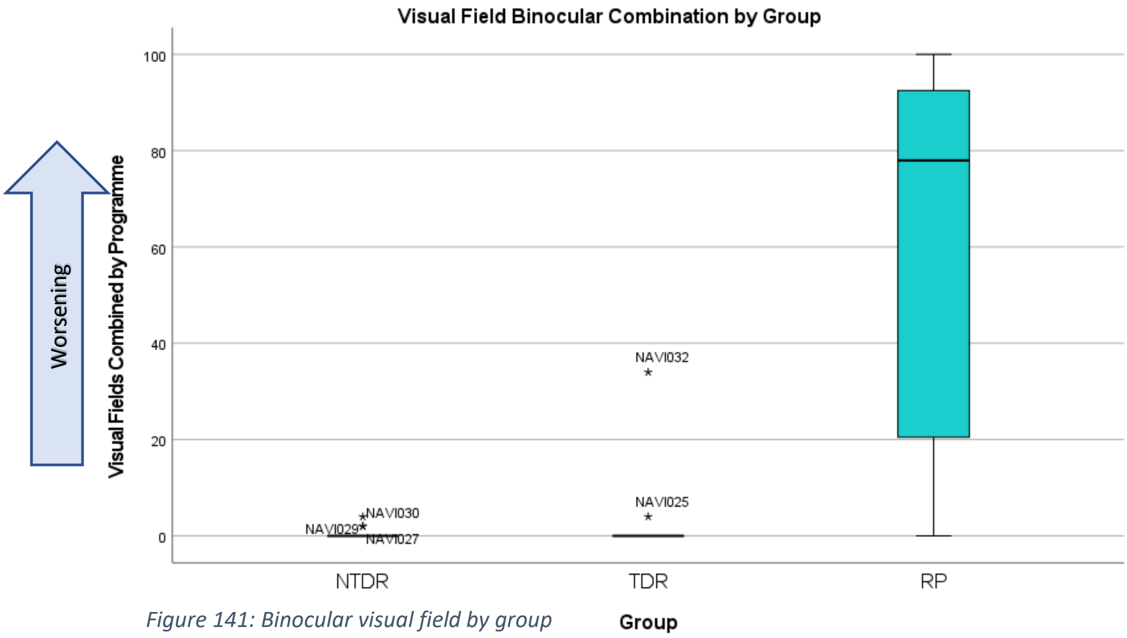


Figure 141: Binocular visual field by group

This boxplot reiterates the visual field deficits of each group. There are three people in the NTDR with very low visual field deficits (2x 2% and 1 x 4%), and two in the TDR group with low-medium visual field deficits (4 and 34%). There were two people in the RP group with a 100% total deficit, and 1 with a 97% deficit.

	NTDR	TDR	RP
Mean	1.9	4.1	14.2
Median	1.6	4	17.7
Range	5.6	7.8	20.8

Table 37: Mean and medians of corrected visual field deficit per group

From the means and medians it is clear that there are differences between visual fields in these groups. Those with RP have a 7x higher visual field deficit than those with non-treated DR. In addition, people with treated DR seem to also have a higher visual field loss however not as much as those with RP.

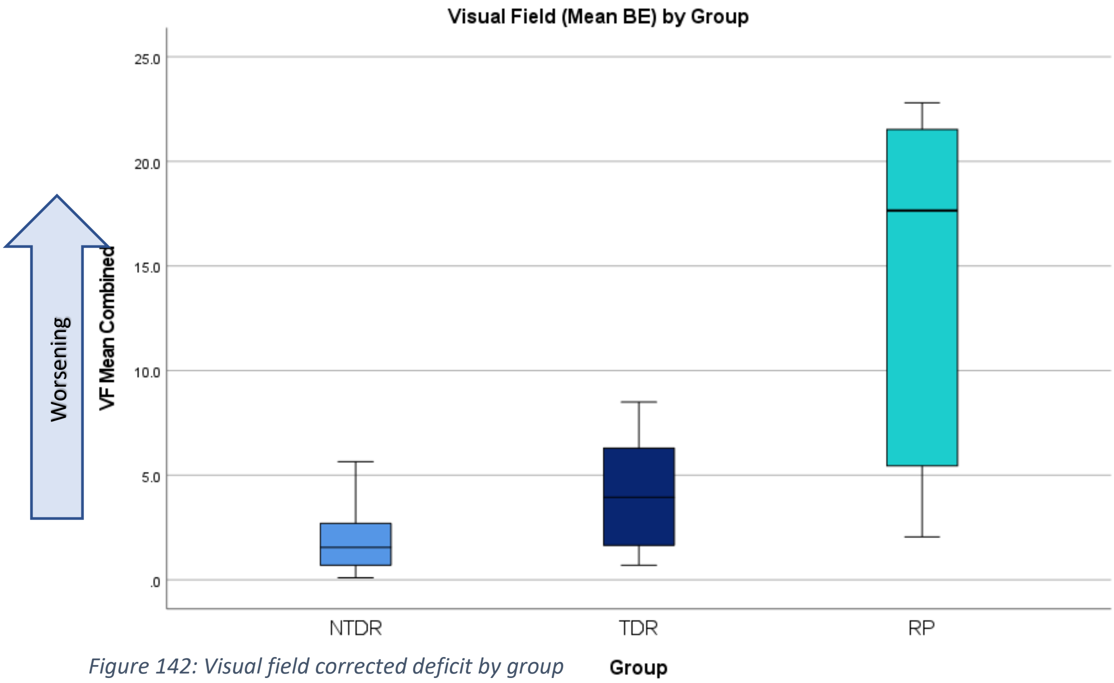


Figure 142: Visual field corrected deficit by group

From the boxplot it is clear that those with RP, as expected, have a much worse visual field deficit than those with DR. Those with treated DR however all seem to have some sort of visual field loss present with deficits up to 8.0 dB. Surprisingly, people with non-treated DR also seem to have some visual field loss which the boxplot below explores. Results show that people with RP have a significantly much worse visual field (p=0.000) than those with TDR and NTDR.

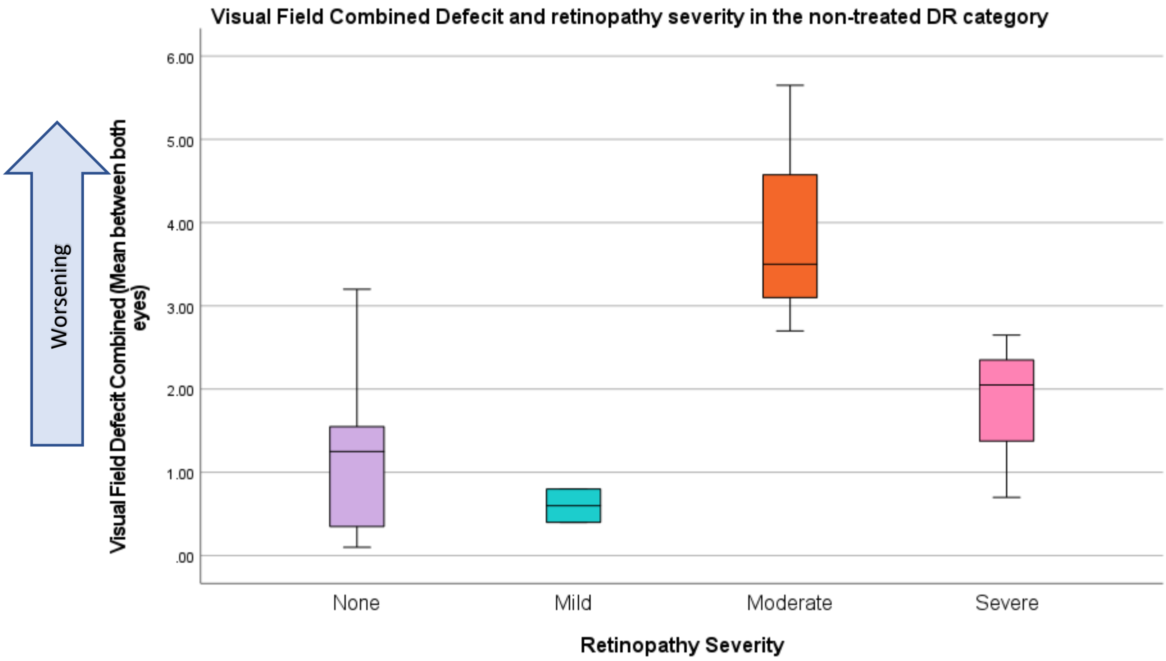


Figure 143: Visual field combined deficit according to retinopathy severity in NTDR.

Those with mild DR have visual field within the limits of normal however those with no retinopathy had a bigger variability. Most people with no DR were within the limits of normal however some had deficits of up to 3.25dB. In comparison with the other results, individuals with moderate DR seemed to have much worse visual field loss with none falling within the limits of normal. Surprisingly, those with severe DR has less visual field loss than those with moderate DR.

6.5.3.4 Dark Adaptation

The AdaptDx dark adaptation measurement deems any rod intercept score below 6.5 to be within normal limits. A mean of both eye rod intercepts was used to ascertain a both eye value.

	NTDR	TDR	RP
Mean	5.3	5.7	6
Median	5.6	6.5	6.5
Range	3.1	3.5	1.9

Table 38: Dark adaptation rod intercept mean and median by group

The means and medians of all groups are around the same with very little between them.

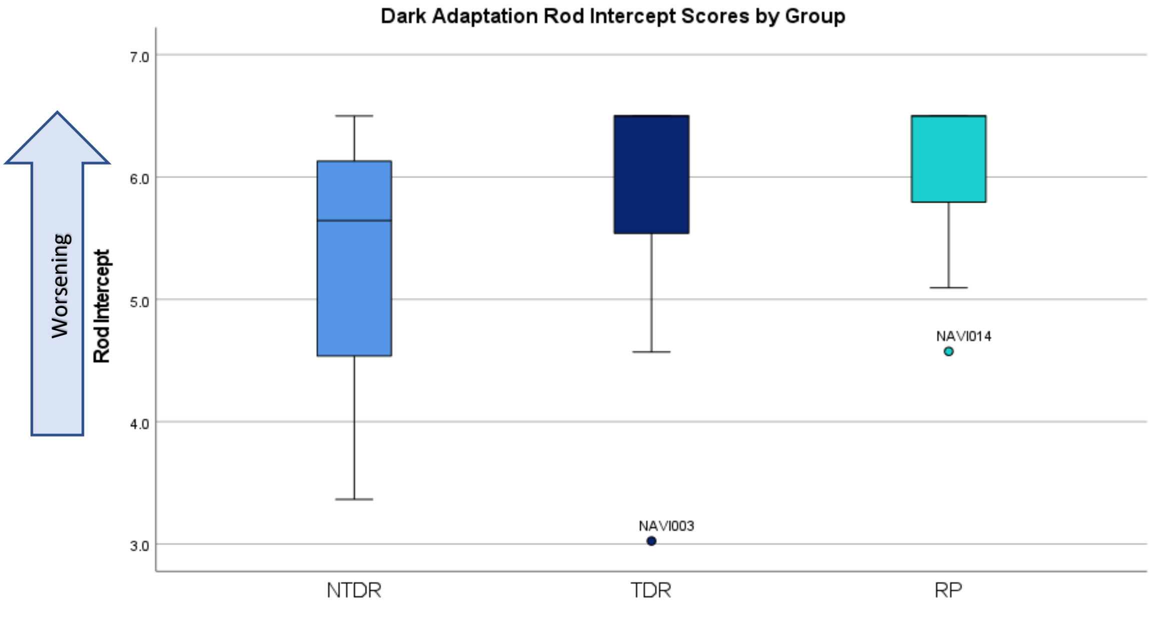


Figure 144: Dark adaptation by group

Those with non-treated DR have a wide range of rod intercept scores however most were within the normal limits. People with treated DR and RP were on similar levels of dark adaptation ability with TDR having a slightly bigger range. NAVI003 and NAVI014 were outliers in this analysis and could warrant further investigation. Dark adaptation was not found to be significant in any group.

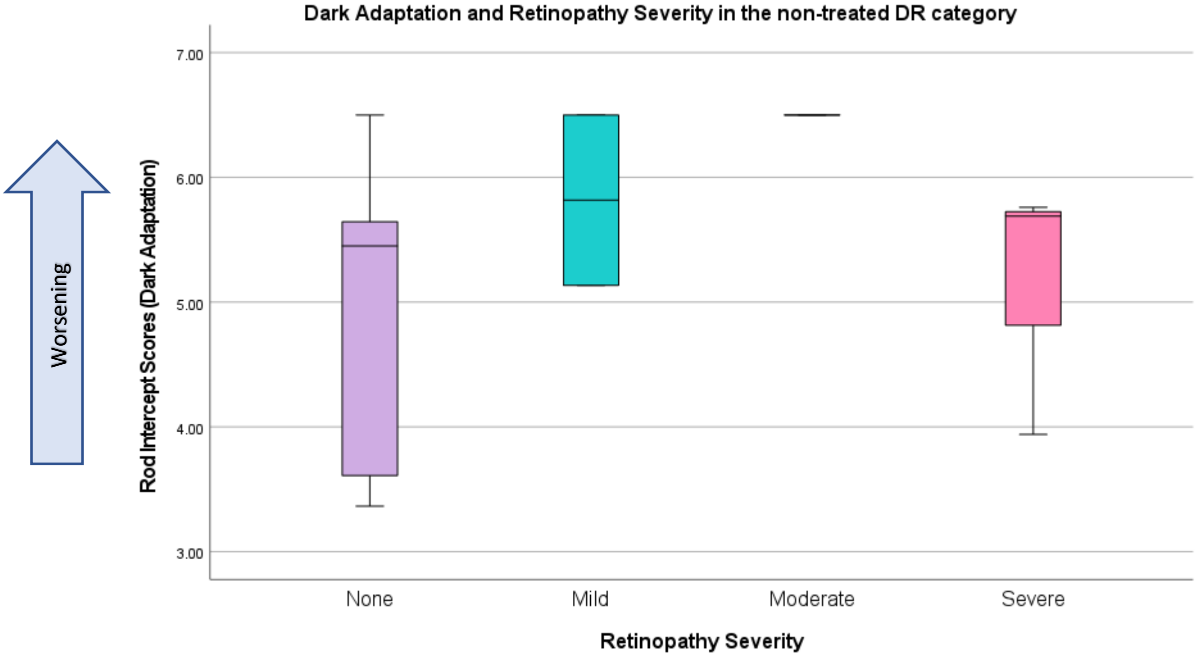


Figure 145: Dark adaptation and retinopathy severity in the NTDR

Interestingly those without DR had a large variability however most were within the limits of normal. People with mild DR did seem to have more problems with dark adaptation however most were in the normal range. Those with moderate DR all had issues with dark adaptation which further supports previous results with VA, visual fields and contrast sensitivity in this group. Those with severe DR were all within normal range and everyone dark adapted well.

6.5.4 Questionnaires

Participants were asked to fill out several questionnaires during their study visit/pre-study online visit. All participants filled out the NaviSight Study Questionnaire (medical history and navigation questions) and the Retinopathy Dependent Quality of Life Questionnaire. All people with diabetes also filled out the DDS17 (Diabetes Distress Scale).

6.5.4.1 RetDQol

The possible range of scoring is from -9 (max. negative impact) to +3 (max. positive impact).

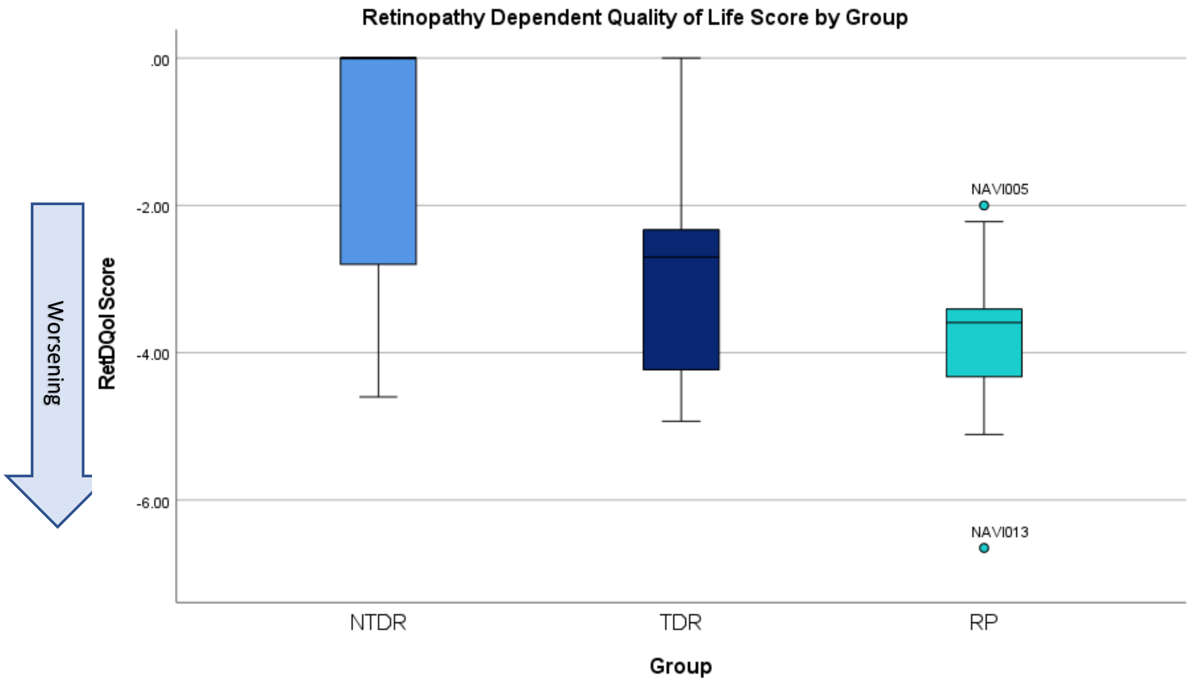


Figure 146: RetDQol score by group

People with non-treated DR have a large variability in RetDQol scores but most are around 0.0 or no impact as expected. Those with treated DR also have a large variability however nearly all have some level of impact on their quality of life with some levels much like those with RP. People with RP, as expected, have all shown that their vision loss impacts their quality of life with most falling above -3.5. NAVI005 was a patient with next to no vision loss, young and still able to drive whereas NAVI013 was not independent and quite nervous. Results show that those with TDR ($p=0.021$) and RP ($p=0.000$) had significantly less quality of life than those with NTDR.

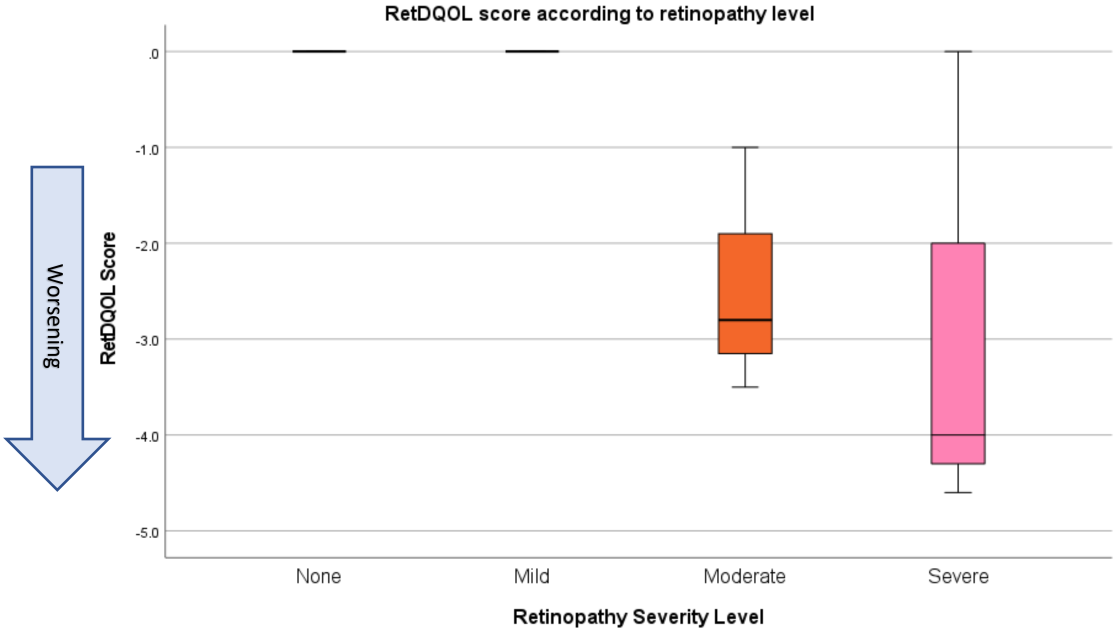


Figure 147: RetDQOL in those with non-treated DR

These results are as expected, those with moderate to severe diabetic retinopathy have a lower quality of life because their vision is beginning to be impacted.

6.5.4.2 Diabetes Distress Scale

The Diabetes Distress Scale is split into 4 different sub-scores; emotional burden, physician-related distress, regimen-related distress and interpersonal distress. These sub-scores are scored 1-5 (5 having the biggest impact). All these sub-scores add up to give a total score.

	Number
Total Distress	2
Emotional Distress	6
Regimen Distress	6
Physician Distress	3
Interpersonal Distress	4

Table 39: Table of numbers of people in each distress sub-category

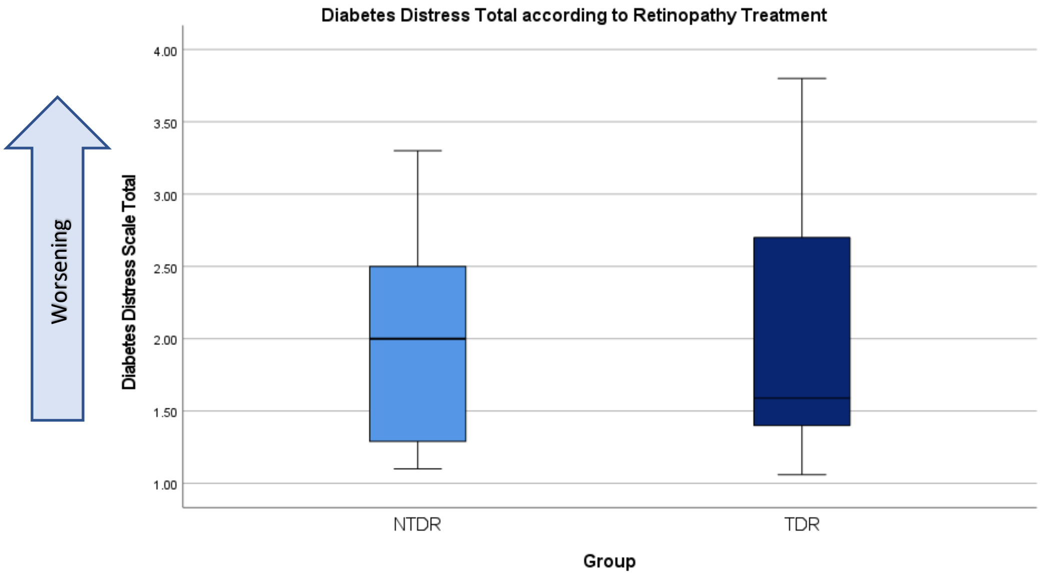


Figure 148: DDS17 total score according to NTDR and TDR

Those with treated diabetic retinopathy had a wider range of diabetes distress than those with non-treated DR although those with treated DR seemed to fall into more distress. Results were not found to be significant.

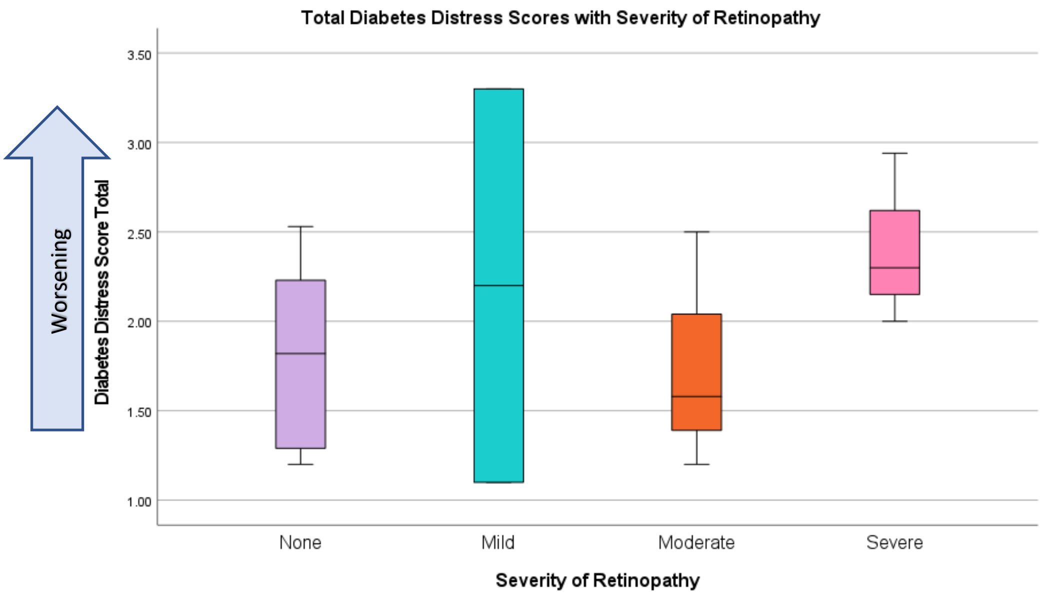


Figure 149: DDS17 total score according to retinopathy severity in the NTDR group

As expected, those with more severe DR seemed to have a higher level of distress than those with no DR. Interestingly however those with mild DR having a large variability with some having a higher distress score than people with severe DR and is approaching those with TDR.

Breakdown of DDS17

Emotional

Questions surrounding emotional distress in those with DR included questions around feelings of anger, fear and confidence. As well as questions on being overwhelmed or thinking diabetes is controlling their lives and taking up too much energy.

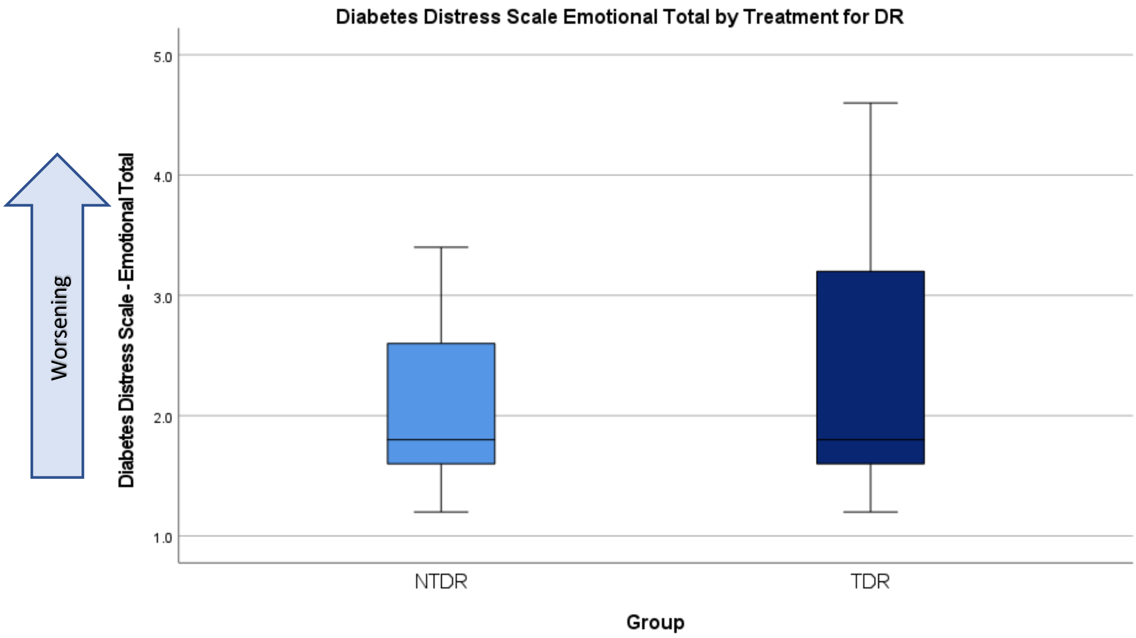


Figure 150: DDS17 emotional burden in treated and non-treated DR

From this it is clear that those with TDR have a higher emotional burden than those with NTDR.

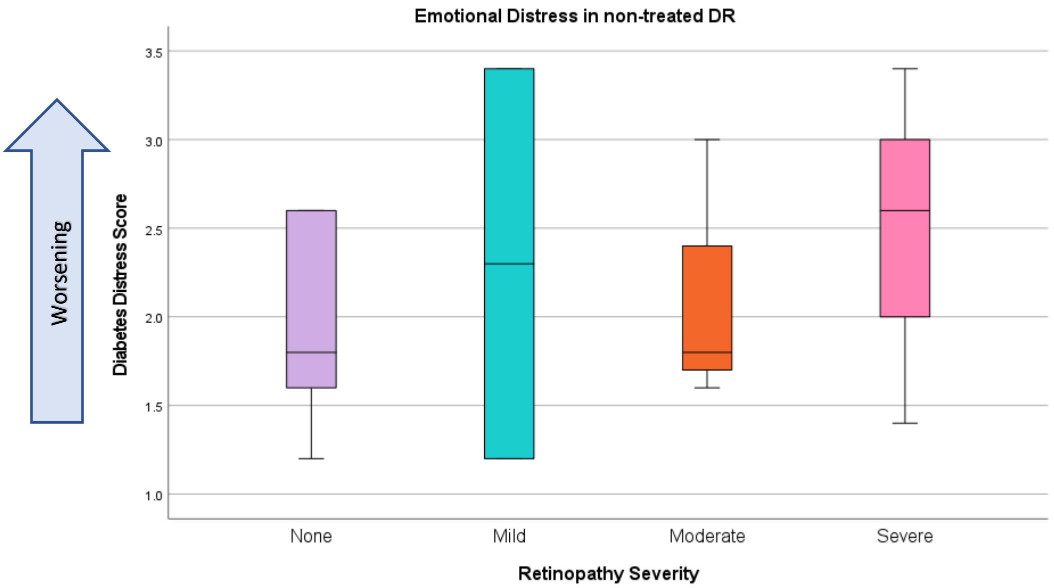


Figure 151: DDS17 emotional burden in non-treated DR categories

Much like in the total graphs, those with mild DR seem to have a large range of emotional distress which also reaches the higher levels seen in those with severe DR. In general, it would appear that everyone had some level of emotional distress present.

Physician – related Distress

This section of the questions asked about doctors, their knowledge, treatment, availability, and ease of discussing concerns.

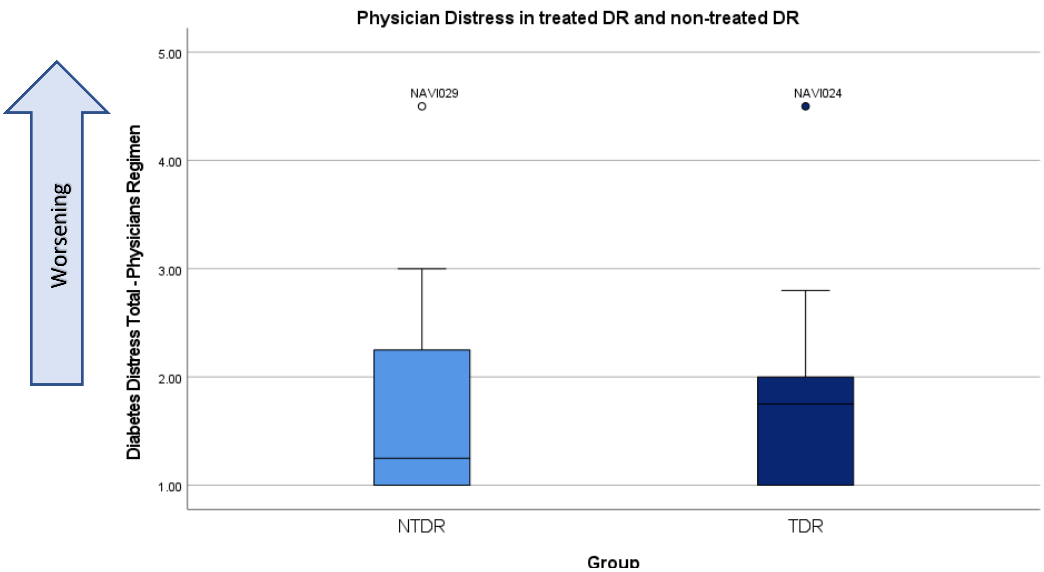


Figure 152:DDS17 physician related distress in TDR and NTDR

From this graph it is clear that most people are not in distress about their physician with the exception of two participants who seem to be in high distress.

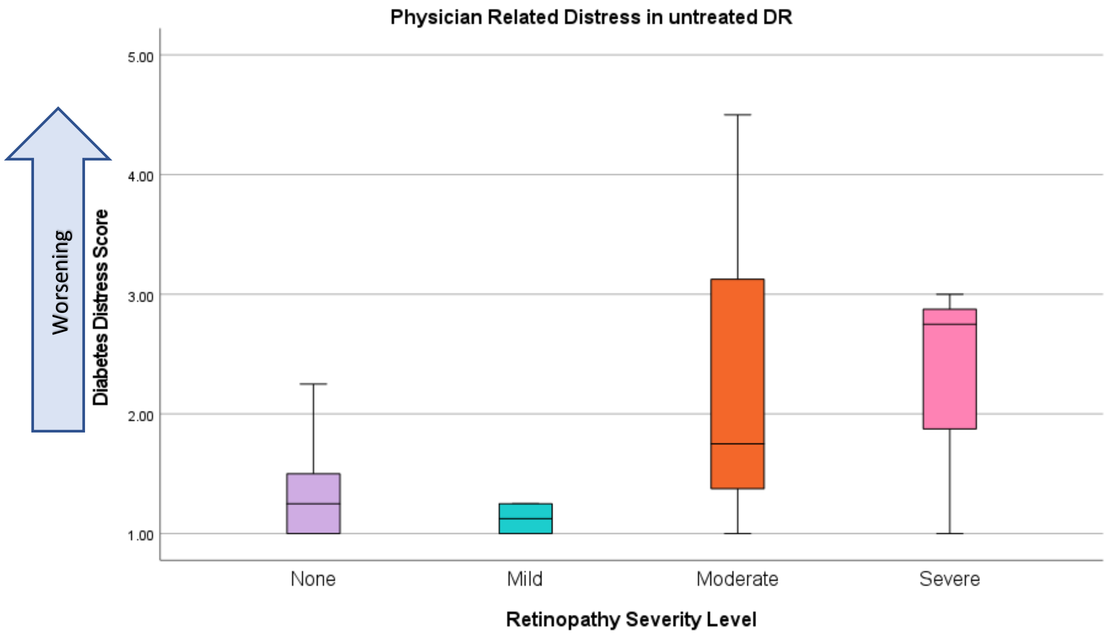


Figure 153: DDS17 physician related distress in untreated DR

From this it is clear that people with severe DR are more likely to be in physician related distress. In addition, those with moderate DR seemed to be in greater distress than those with severe DR.

Regimen related distress

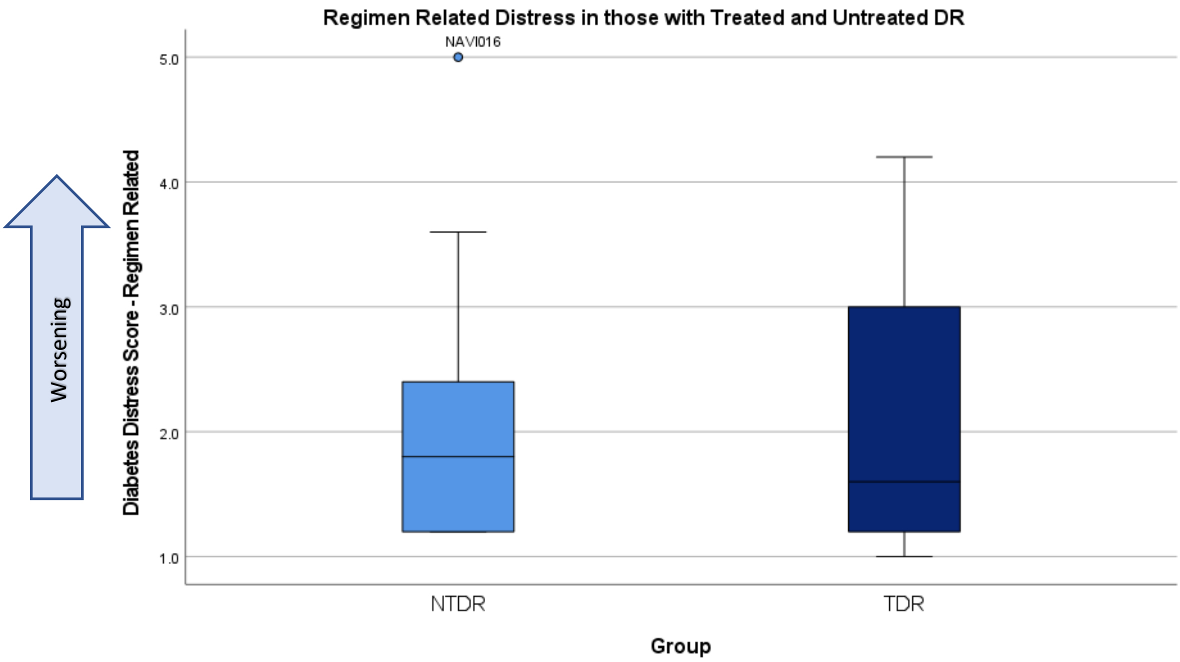


Figure 154: Regimen related distress in those with NTDR and TDR

From this boxplot it is clear that those with TDR are more likely to be in distress than those with NTDR when it comes to regimen.

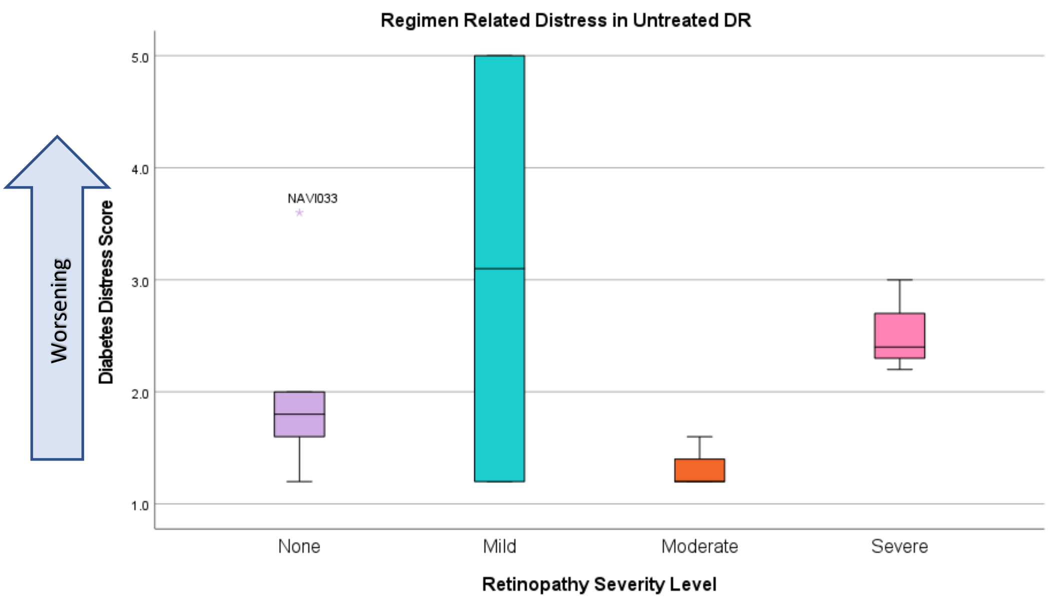


Figure 155: Regimen related distress in those with NTDR

This graph shows trends very different to those seen in other boxplots for distress. From this it is clear that those with mild DR seem to have higher distress levels than those with no DR, moderate DR and severe DR. Those with moderate DR, in contrast with physician and emotional related distress, had much less regimen related distress.

Interpersonal Distress

These questions centred around support and understanding of friends and family.

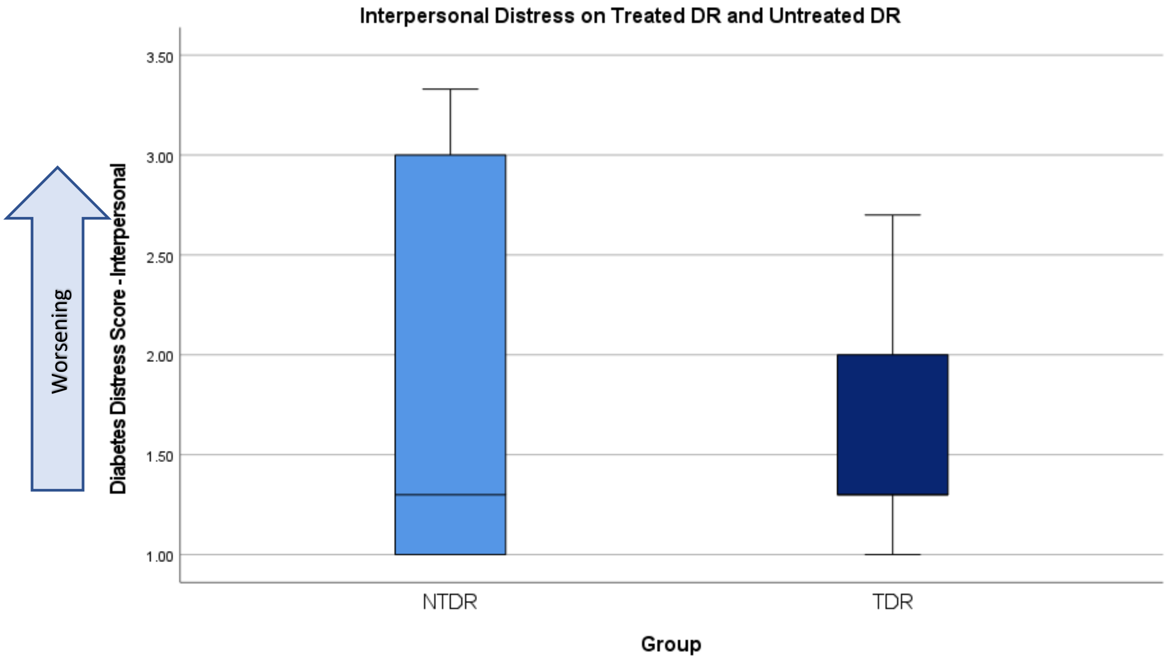


Figure 156: Interpersonal distress in TDR and NTDR groups

Interpersonal distress in both groups seems to be a lot lower than with other types of diabetes distress with the maximum distress falling under 3.5 as opposed to under 5 in other boxplots. Interestingly those with NTDR seemed to have more interpersonal distress than those with TDR.

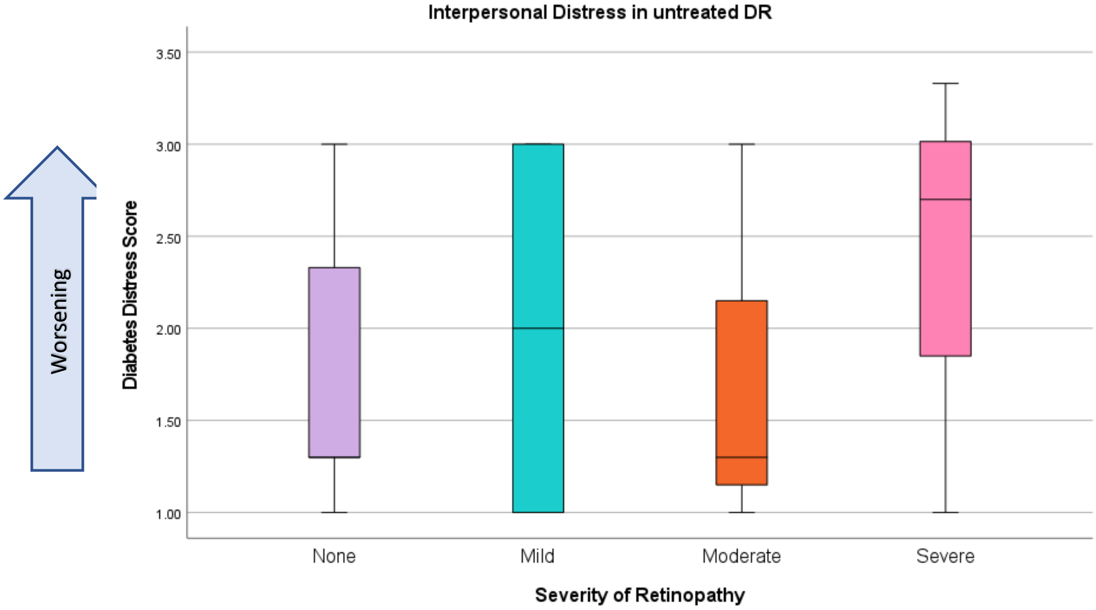


Figure 157:Interpersonl distress in the NTDR group according to severity of retinopathy

From this boxplot it is clear that levels of interpersonal distress are similar in all groups and those with no DR, mild DR and moderate DR all fall under the level of distress. A few participants with severe DR have some level of interpersonal distress but under 3.5.

6.5.4.3 NaviSight Questionnaire

The NaviSight Questionnaire incorporated questions surrounding medical history and questions around moving and navigating the built environment independently. Below is a table of these questions and how they were answered within each group.

	NTDR		TDR		RP	
	Yes	No	Yes	No	Yes	No
Do you drive?	11 (84.6%)	2 (15.4%)	9 (100%)	0	4 (36.4%)	7 (63.6%)
Do you use walking aids?	0	13 (100%)	0	9 (100%)	4 (36.4%)	7 (63.6%)
Do you use public transport?	11 (84.6%)	2 (15.4%)	8 (88.9%)	1 (11.1%)	9 (81.8%)	2 (18.2%)
Do you think walking around towns and cities is difficult?	0	13 (100%)	1 (11.1%)	8 (88.9%)	7 (63.6%)	4 (36.4%)
Do you need assistance in places you know?	0	13 (100%)	0	9 (100%)	1 (9%)	10 (90.9%)
Do you use the same routes?	8 (61.5%)	5 (38.5%)	6 (66.7%)	3 (33.3%)	9 (81.8%)	2 (18.2%)
Do you think street clutter creates problems?	1 (7.7%)	12 (92.3%)	5 (55.6%)	4 (44.4%)	8 (72.7%)	3 (27.3%)
Do you think there are enough pedestrian crossings?	9 (69.2%)	4 (30.8%)	4 (44.4%)	5 (55.6%)	5 (45.5%)	6 (54.5%)
Do you think cars parked on pavements create problems?	3 (23.1%)	10 (76.9%)	4 (44.4%)	5 (55.6%)	8 (72.7%)	3 (27.3%)

Table 40: Questions around navigating the built environment by each group

Most people with diabetes were able to drive in contrast with those with RP. As expected none of the people with either TDR or NTDR used walking aids, however only 36.4% of those with RP did. Interestingly only one person with diabetes felt that walking around towns and cities was difficult while over 63% of those with RP did. Despite only 63.6% of those with RP feeling that towns and cities were difficult to navigate, over 72% felt street clutter and parked cars were issues. Remarkably despite only one person in the TDR group stating it was diffciult to move around towns and cities, 4 felt that street clutter and parked cars were problematic.

	NTDR			TDR			RP		
	Yes	No	Don't Know	Yes	No	Don't Know	Yes	No	Don't Know
Would bright markings on hazards help with navigation?	4 (30.7%)	4 (30.7%)	5 (38.5%)	7 (77.8%)	1 (11.1%)	1 (11.1%)	8 (72.7%)	2 (18.2%)	1 (9.1%)
Shared Space	1 (7.7%)	11 (84.6%)	1 (7.7%)	5 (55.6%)	4 (44.4%)	0	9 (81.8%)	2 (18.2%)	0
Lighting Levels	2 (15.4%)	11 (84.6%)	0	6 (66.7%)	2 (22.2%)	1 (11.1%)	8 (72.7%)	2 (18.2%)	1 (9.1%)
COVID- 19	5 (38.5%)	7 (53.8%)	1 (7.7%)	4 (44.4%)	2 (22.2%)	3 (33.3%)	5 (45.5%)	5 (45.5%)	1 (9.1%)

Table 41: Further questions on the built environment

Interestingly many (77.8%) with TDR thought bright markings on hazards would help with navigation as did over 72% of those with RP. Overwhelmingly over 81% of those with RP felt shared space was a problem as did over 50% of those with TDR. Lighting levels were also deemed to be an issue (66.7% TDR and 72.7% RP).

6.5.5 Eye Analysis

Due to the nature of eye disease, the next section is analysed according to number of eyes. In this section there were 28 eyes in the NTDR, 15 in the TDR (1 blind RE) and 21 in the RP (1 blind RE).

6.5.5.1 Image Quality

Below are tables for Optos and OCT image quality

Image Quality (OCT)	Eyes	Image Quality (Optos)	Eyes
Good	32	Good	33
Fair	6	Fair	7
Poor	4	Poor	3
Ungradable	1	Ungradable	0

Table 42: Image quality OCT and Optos

6.5.6 Diabetic Retinopathy

Fourteen participants had the same level of DR in both eyes while 8 participants had a different level of DR in both eyes. Those with different levels of DR were all within 1 'step' of DR, for example one eye none, one eye mild or one eye moderate, one eye severe. Fifteen eyes had no DR, 2 had mild DR, 12 had moderate DR, 11 had severe DR and 3 had proliferative DR. Fifteen eyes had been treated with laser.

6.5.6.1 Optic Disc

Optic Disc pallor was assessed in each patient from normal to atrophic

	NTDR	TDR	RP
Normal	21 (75%)	3 (20%)	9 (42.9%)
Slight Pallor	3 (10.7%)	8 (53.3%)	6 (28.6%)
Moderate	2 (7.1%)	4 (26.7%)	2 (9.5%)
Atrophic	2 (7.1%)	0	4 (19%)

Table 43: Optic disc pallor per group

Most (75%) had normal discs in the NTDR group while a few had slight - moderate pallor with 2 having an atrophic disc. No one in the TDR group had an atrophic disc but most (80%) had either slight pallor or moderate pallor discs. RP as expected had the most people with atrophic discs (19%) however surprisingly nearly half (42.9%) had normal discs.

	NTDR	TDR	RP
Mean	0.39	0.39	0.39
Median	0.38	0.40	0.39
Range	0.34	0.24	0.29

Table 44: Cup to disc ratio per group

No participants had an abnormal cup to disc ratio (>0.7) and all groups had the same mean, and close to the same median.

While there were no abnormalities found in cup to disc ratio, some people with diabetes had pathology on their disc. One eye had new vessels on the disc, one had a haemorrhage on the disc and two had fibrosis on the disc.

6.5.7 OCT Analysis

	NTDR		TDR		RP	
	Yes	No	Yes	No	Yes	No
VMA	18 (64.3%)	10 (35.7%)	6 (40%)	9 (60%)	6 (28.6%)	15 (71.4%)
VMT	0	28 (100%)	0	15 (100%)	1 (4.85)	20 (95.2%)
ERM	3 (10.7%)	25 (89.3%)	4 (26.7%)	11 (73.3%)	4 (19%)	17 (81%)
Intravitreal Fluid	9 (32.1%)	19 (67.9%)	11 (73.3%)	4 (26.7%)	8 (38.1%)	13 (61.9%)
Subretinal Fluid	7 (25%)	21 (75%)	4 (26.7%)	11 (73.3%)	0	21 (100%)
Hyperreflective Foci	12 (42.9%)	16 (57.1%)	10 (66.7%)	5 (33.3%)	15 (71.4%)	6 (28.6%)
Is ELM Intact?	24 (85.7%)	4 (14.3%)	14 (93.3%)	1 (6.7%)	8 (38.1%)	13 (61.9%)
Is EZ continually present?	24 (85.7%)	4 (14.3%)	12 (80%)	3 (20%)	5 (33.3%)	16 (76.2%)

Table 45: OCT feature analysis per group

Interestingly those with NTDR had the most VMA (64.3%) as compared to 40% TDR and only 28.6% in the RP groups. Only one participant had a VMT present. ERM was present in similar levels across groups. Interestingly NTDR and RP had similar levels of intraretinal fluid while many (73.3%) in the TDR group had intraretinal fluid present. As expected no one with RP had subretinal fluid and numbers were similar in the TDR and NTDR groups.

All groups had some level of hyperreflective foci with similar levels in TDR and RP and slightly less in NTDR. In those with diabetes hyperreflective foci were found in the inner layers (86.4%), ONL (22.7%), RPE: 1 (4.5%), and photo receptor layer (4.5%). In those with RP they were found in the inner layers (9.5%), ONL (52.4%), RPE (38.1%) and photo receptor layer (61.9%). As expected ELM was not present in over half of those with RP (61.9%) and EZ was not present in a majority (76.2%). Over 80% of those in the TDR and NTDR groups had both ELM and EZ intact or continually present.

6.5.7.1 ELM

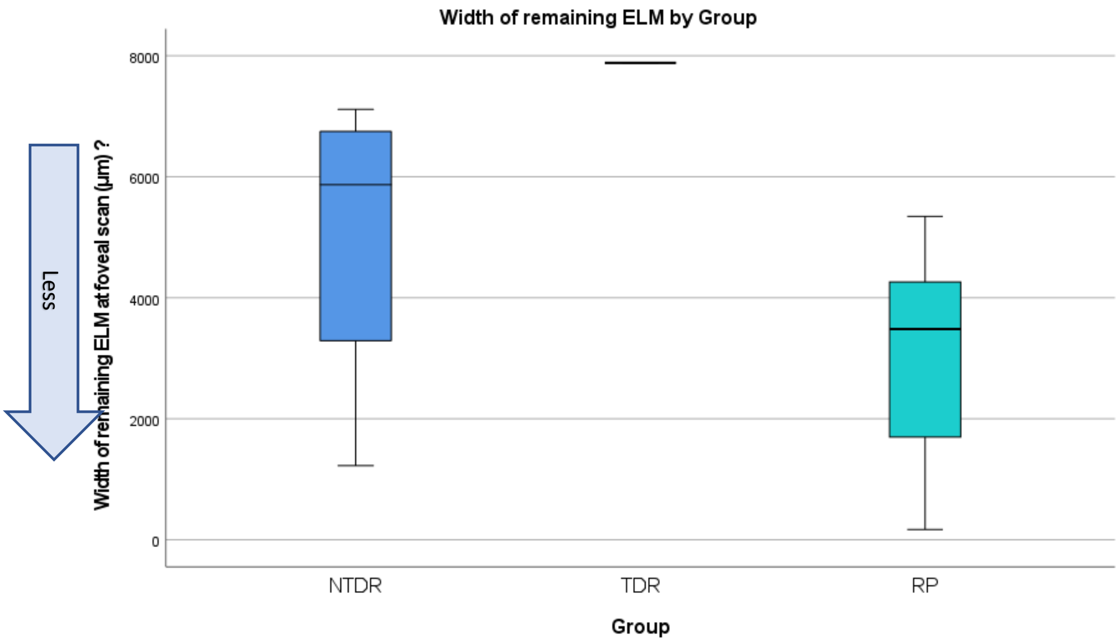


Figure 158: Boxplot of width of remaining ELM

As discussed, those with RP had a lot of participants with missing ELM. This graph shows that those with RP had less remaining ELM than those in the

NTDR and much less than those with TDR – in fact those with TDR had very little ELM missing even when it was not intact.

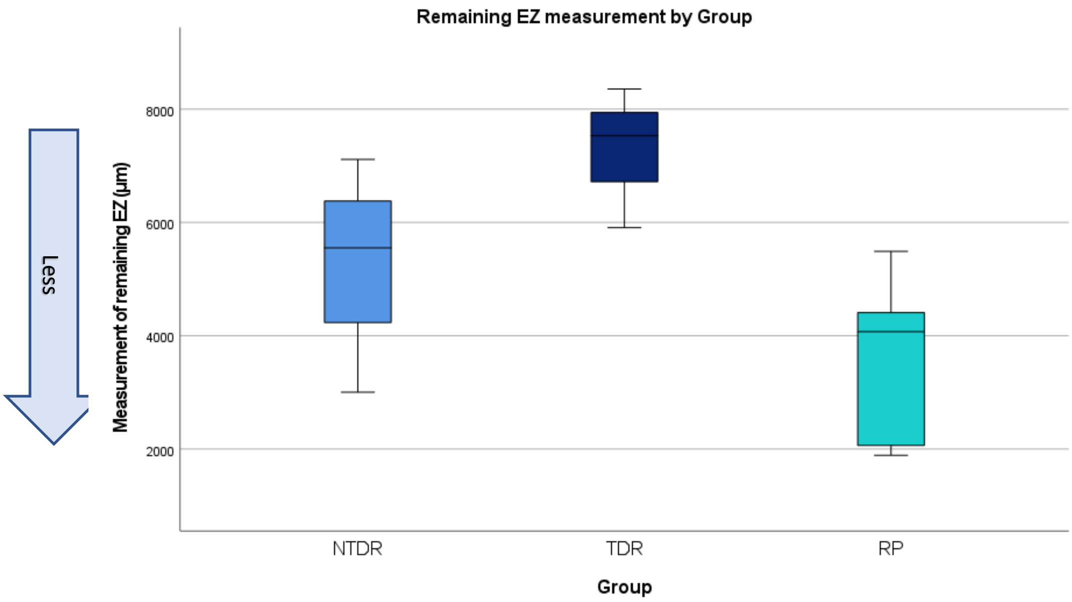


Figure 159: Remaining EZ by group

Much like the ELM results, those with RP have less remaining EZ than other groups. The TDR group has more range when it comes to remaining EZ however still has the most remaining.

6.5.8 Optos Analysis – Boston Grid

Type of Pathology present

6.5.8.1 Diabetes

	Eyes	RE	LE
Microaneurysms	29	16	13
Blot Haemorrhages	22	12	10
Venous Loop	5	3	2
Venous Beading	1	0	1
Venous Reduplication	2	1	1
Retinal Haemorrhages	5	3	2
New Vessels	2	1	1
Cotton Wool Spots	3	2	1
Exudate	14	8	6
Fibrosis	4	2	2
IRMA	8	3	5
Laser Scars	15	8	7
Ungradable	41	21	20
Naevus	2	1	1
Other Pathology	3	2	1

Table 46: Pathology in people with diabetes

As expected the most common type of pathology found in participants with diabetes were microaneuryms and blot haemorrhages. Nearly 70%, (67.4%) of eyes had microaneurysms present while just over half (51.2%) had blot haemorrhages. Exudate was found in 32.6% of eyes and 18.6% had IRMA (Intraretinal Microvascular Abnormality) present. Laser scars were present in 34.9% of eyes. Nearly all (95.3%) had some areas which were ungradable which is expected in wide-field Optos images.

6.5.8.2 RP

As expected nearly all (95.2%) had retinal pigment present while over 80% had white dots. Over 60% also had retinal atrophy present. All eyes had some level of ungradable area as explained previously.

	Eyes	RE	LE
White Dots	17	8	9
Pigment	20	10	10
Atrophy	13	8	5
Scars	5	2	3
Other	2	1	1
Ungradable	21	10	11

Table 47: Pathology in people with RP

6.5.9 Boston Grid Analysis

Figure 160 shows how the results are split up according to each quadrant and section.

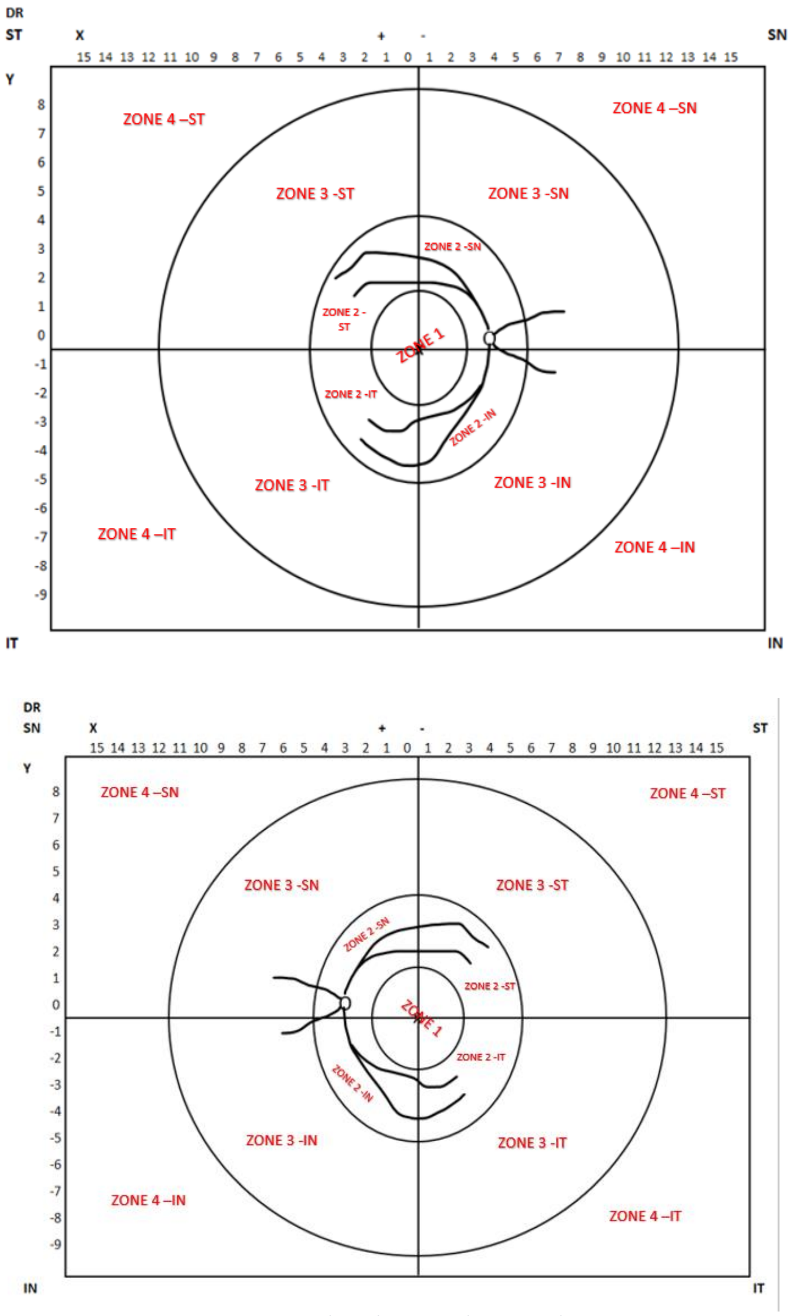


Figure 160: Boston grid analysis quadrants and sections

6.5.9.1 Diabetes

Below is a table of diabetes pathology in each section of the Boston grid. Each number is the number of squares affected in each segment.

Zone	Quadrant	MA	Blot Haem	V loops	V Beading	V Redup	Ret Haem	New Vess	CWS	Exudate	Fibrosis	IRMA	Laser Scar	UG
Zone 1	-	**1.3**	**0.88**	**0.02**	**0**	**0**	**0**	**0**	**0.05**	**1.20**	**0.23**	**0.02**	**0.19**	**0**
Zone 2	**Total**	**3.21**	**1.77**	**0.02**	**0.47**	**0.23**	**0**	**0.47**	**0.02**	**0.74**	**0.28**	**0.16**	**16.07**	**9.14**
	ST	1.70	1.07	0.05	0	0	0.09	0.07	0	0.79	0.12	0	0.72	0
	SN	0.95	0.51	0.05	0	0	0	0.09	0.05	0.53	0.47	0.12	0.65	0
	IN	0.65	0.26	0	0	0	0	0	0	0.12	0.42	0	0.95	0.02
	IT	1.72	1.26	0	0	0	0.09	0.07	0.14	0.65	0.16	0	0.95	0
Zone 3	**Total**	**10.4**	**5.56**	**0.02**	**0.47**	**0.7**	**0**	**0.07**	**0.37**	**1.72**	**1.37**	**0.53**	**63.1**	**45.16**
	ST	3.14	2.05	0	0	0.2	0	0	0.23	0.72	0	0.26	16.02	8.16
	SN	3.84	1.98	0.02	0.47	0	0	0.05	0.23	0.83	0.28	0.21	14.33	9.05
	IN	2.07	1	0	0	0.47	0	0.02	0.12	0.09	1.09	0	15.72	14.26
	IT	1.34	0.54	0	0	0	0	0	0	0.06	0	0.07	17.07	13.70
Zone 4	**Total**	**2.56**	**0.51**	**0**	**0**	**0**	**0**	**0**	**0.24**	**0.02**	**0**	**0**	**6.44**	**89.44**
	ST	0.53	0.21	0	0	0	0	0	0	0	0	0	1.16	21
	SN	0.84	0.21	0	0	0	0	0	0	0	0	0	2.65	14.77
	IN	0.67	0.05	0	0	0	0	0	0	0	0	0	1.81	26.14
	IT	0.51	0.05	0	0	0	0	0	0.24	0.02	0	0	0.81	27.53

Table 48: Number of squares with pathology in each section of the Boston grid for diabetes

These results mirror the previous basic eye analysis results. Microaneurysms are the most common pathology and are present across all zones. There does not seem to be a quadrant of the retina which is most affected by microaneurysms. Blot haemorrhages are also present in all zones and do not seem to be more present in a specific quadrant. Exudate is present in all quadrants, more so in zone 2 and 3, however is only very minimally present in zone 4.

Venous loops, beading and reduplication are not present in zone 4 at all. Additionally venous beading and reduplication seem to exist only in zone 3. Retinal haemorrhage is only present in zone 2 while new vessels are present in zones 2 and 3. Cotton Wool Spots are present in all sectors however are minimally present throughout the zones. Fibrosis is present in zones 1-3 however seems to mainly present in zone 3. IRMA are present most in zone 3 and is not present in zone 4. As expected, laser scars are most prominent in zones 2 and 3.

The level of ungradable area increased progressing outwards to each zone which is to be expected where lashes and eyelids caused an ungradable area.

6.5.9.2 RP

Below is a similar table with RP pathology in each section of the boston grid. Each number is the number of squares affected in each segment.

Zone	Quadrant	White Dots	Pigment	Atrophy	Scars	Other Pathology	Ungradable
Zone 1	-	1.04	0.24	1.14	0	0	0
Zone 2	Total	15.52	41.52	6.33	0	0.05	2.24
	ST	2.95	5.71	2.10	0	0	0
	SN	0.81	2.67	1.86	0	0	0
	IN	1.05	2.29	3.10	0	0	0
	IT	2.52	4.76	2.52	0	0	0
Zone 3	Total	56.05	158.52	28.81	0.48	0.19	12.19
	ST	14.57	38.05	3.52	0	0.19	4.62
	SN	10.57	42.48	8.95	0	0	2.38
	IN	9.67	40.62	11.86	0	0	2.14
	IT	21.24	37.38	4.48	0.48	0	3.05
Zone 4	Total	16.86	24.48	0.90	1.67	0	60.14
	ST	3.05	4.05	0.10	0.33	0	15.19
	SN	5.14	9.10	0.19	0	0	7.05
	IN	4.86	8.24	0.62	0.10	0	15.14
	IT	3.81	3.10	0	1.24	0	22.76

Table 49: Number of squares with pathology in each section of the Boston grid for RP

White dots are present throughout the zones and quadants, with zone 3 most affected. Similarly pigment is also present throughout the zones with most in zone 3 – a large number of squares (158.5) were affected by pigment in zone 3. This is mirrored with atrophy which is present across all zones but mostly focused in zone 3. As with people with diabetes, the ungradable area increases in each zone.

6.5.10 Percentage of the Retina

Percentage of the retina affected was calculated from the number of squares affected in each zone. Below are boxplots of the percentage area of the retina affected per group.

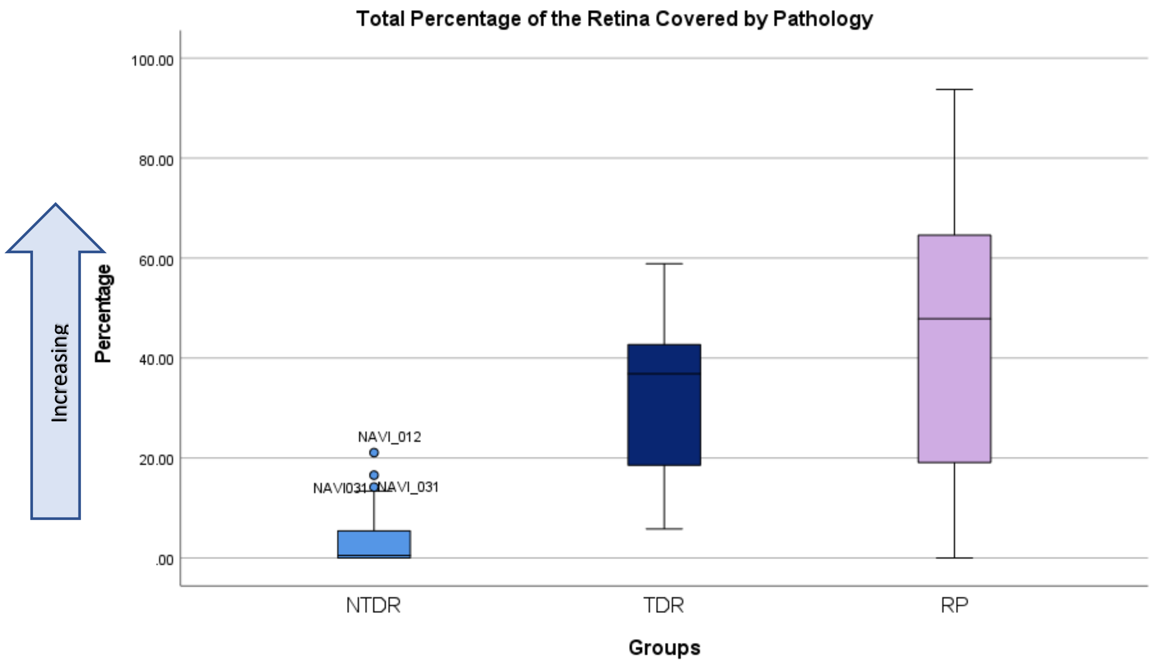


Figure 161: Boxplot of total percentage of the retina affected

This boxplot shows the total percentage of the retina affected. As expected those with NTDR have the least retina affected followed by those with TDR. RP has up to 90% of the retina affected versus only 60% in those with TDR. Below are boxplots showing each zone separately.

Zone 1

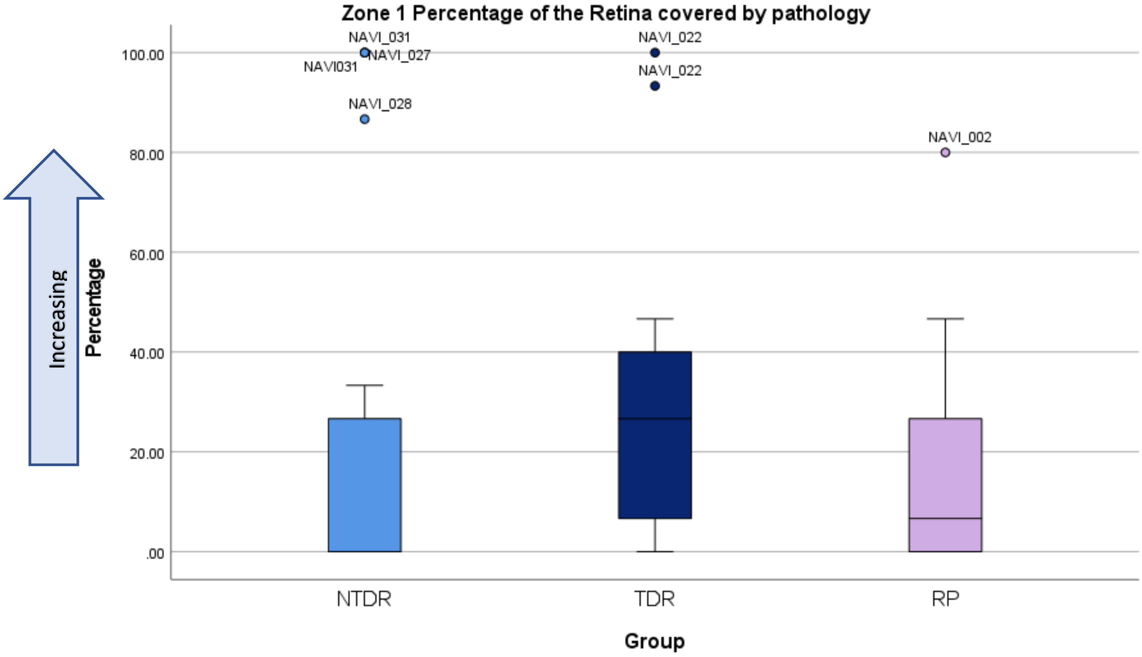


Figure 162: Boxplot of percentage of the retina in zone 1

From this it is clear that all groups have similar levels of pathology in zone 1, except for a few outliers. Outliers in the NTDR and TDR group all have microaneurysms exudate and blot haemorrhages present. NAVI002 in the RP group has atrophy present.

Zone 2

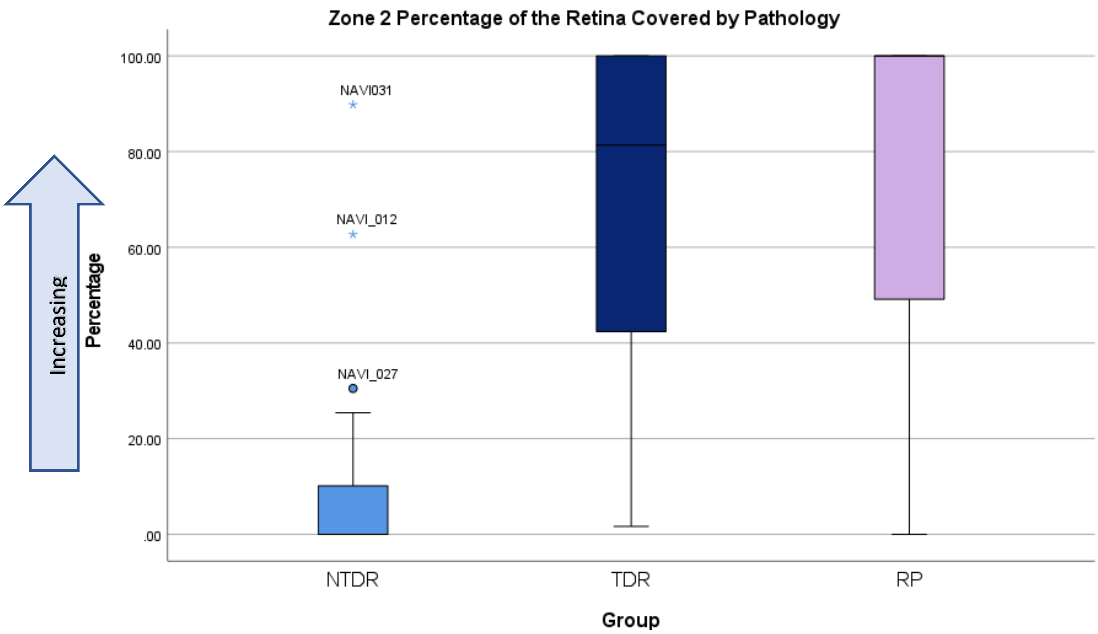


Figure 163: Boxplot of percentage of the retina in zone 2

This boxplot is very different to the previous zone 1 boxplot as it is clear that TDR and RP are beginning to show a high percentage of affected retina in zone 2. This contrasts with those in the NTDR group. Outliers in the NTDR group are due to microanurysms, exudate and blot haemorrhages.

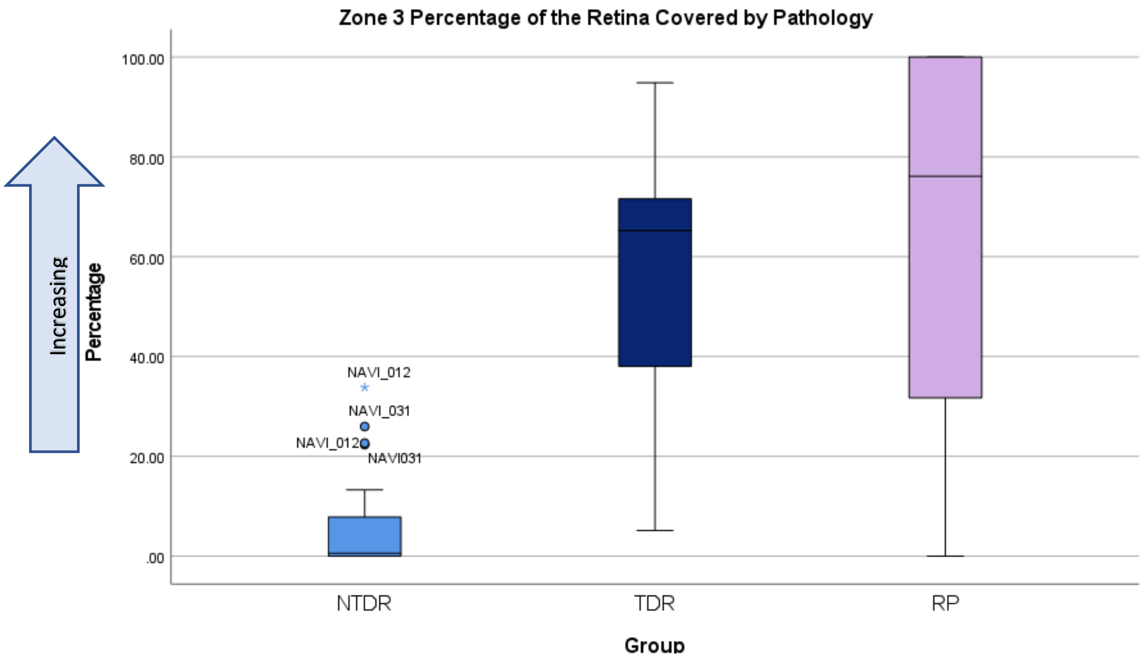


Figure 164: Boxplot of percentage of the retina in zone 3

Those in the NTDR group now have less than 40% of zone 3 affected whereas those with RP can have up to 100% of the retina affected. Those with TDR are starting to have less of the retina affected in contrast with zone 2.

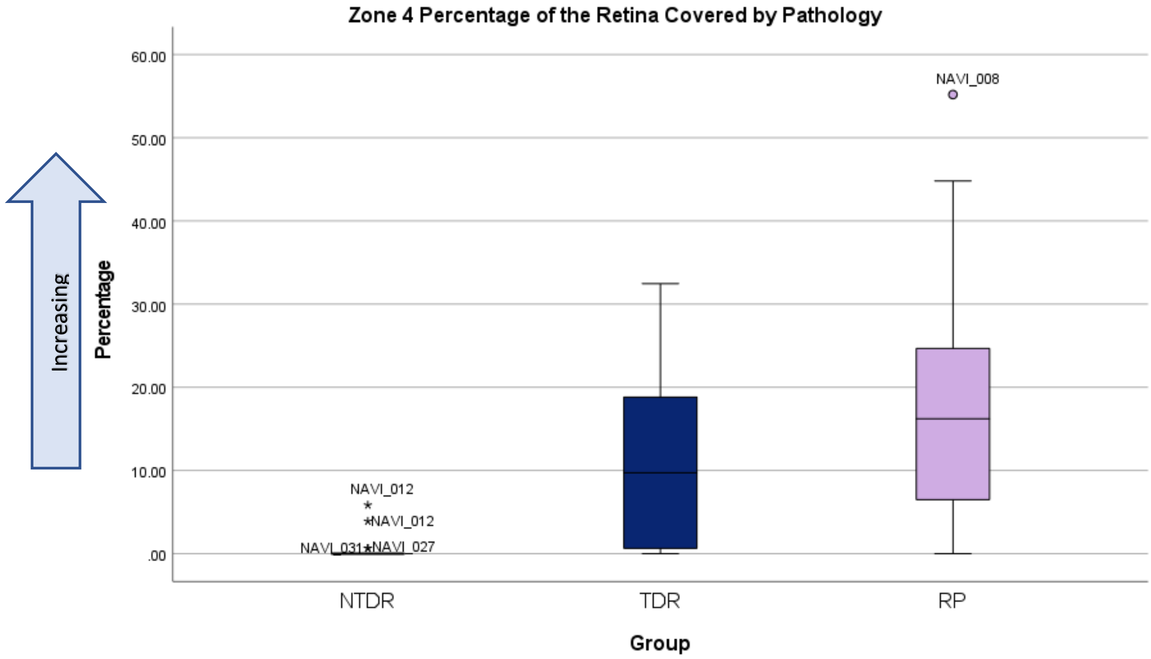


Figure 165: Boxplot of percentage of the retina in zone 4

The trend in this boxplot mirrors that of zone 3. The retinal pathology in the NTDR group is decreasing (under 10%) as is the TDR group with under 35% of the retina in zone 4 affected. People with RP still have a high percentage of the retina affected (up to 45%) with NAVI008 having 55% of the retina in zone 4 affected.

6.5.11 Manchester Heatmaps

Heatmaps were created from the Boston grid analysis, these heatmaps are created using a previously established code using the percentage of each area affected. Below are heatmaps from the most common RP and Diabetes pathology.

From these heatmaps we can see that microaneurysms affect mostly the central macula to mid-periphery whereas blot haemorrhages tend to present closer to the central area.

For those with RP, white dots affect the entire retina whereas pigment seems to affect the mid and far periphery but does not affect the central area to the same degree.

Heatmaps show a very similar distribution of laser scarring in the diabetes and the pigment from RP.

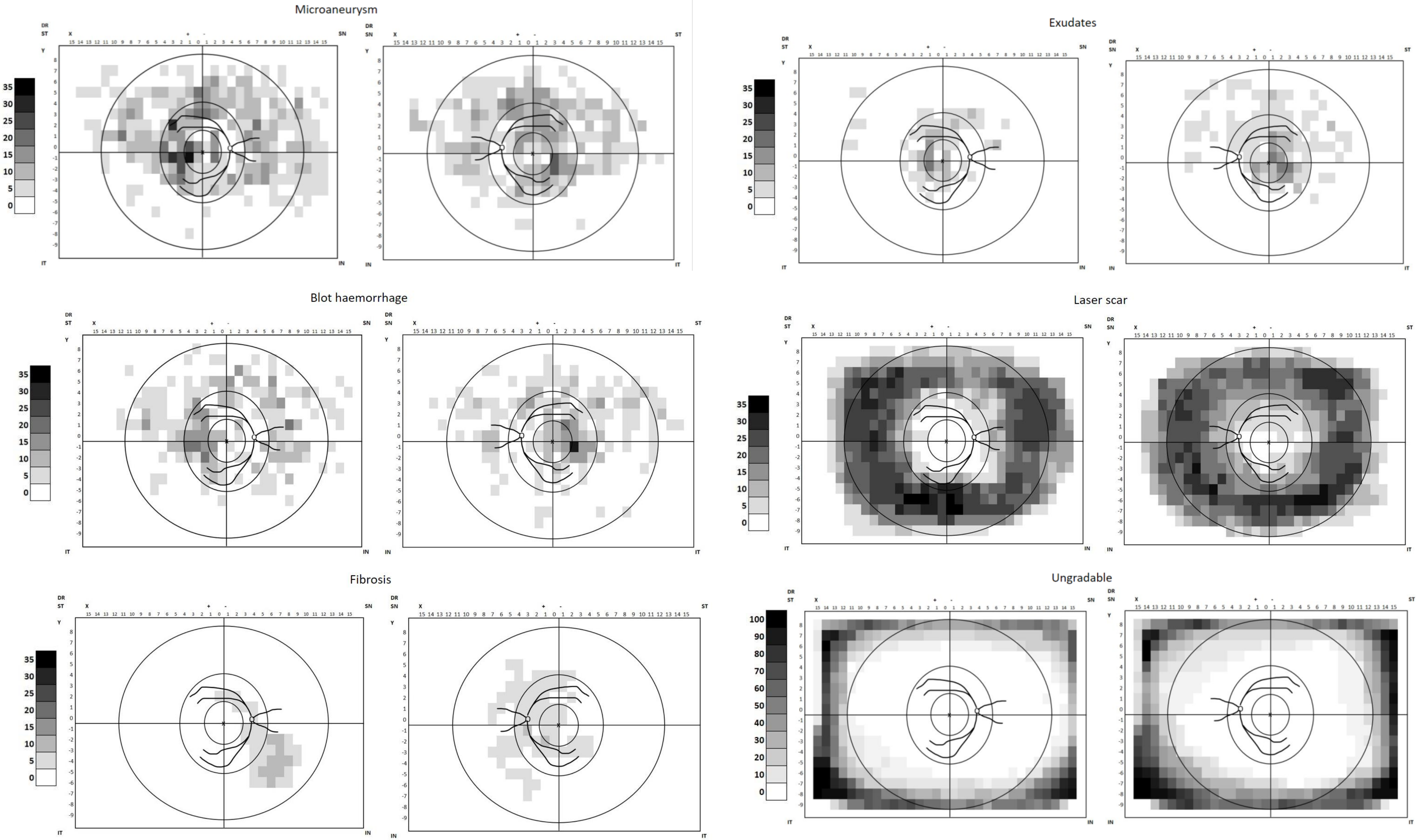


Figure 166: Manchester heatmaps for most common pathology in diabetes

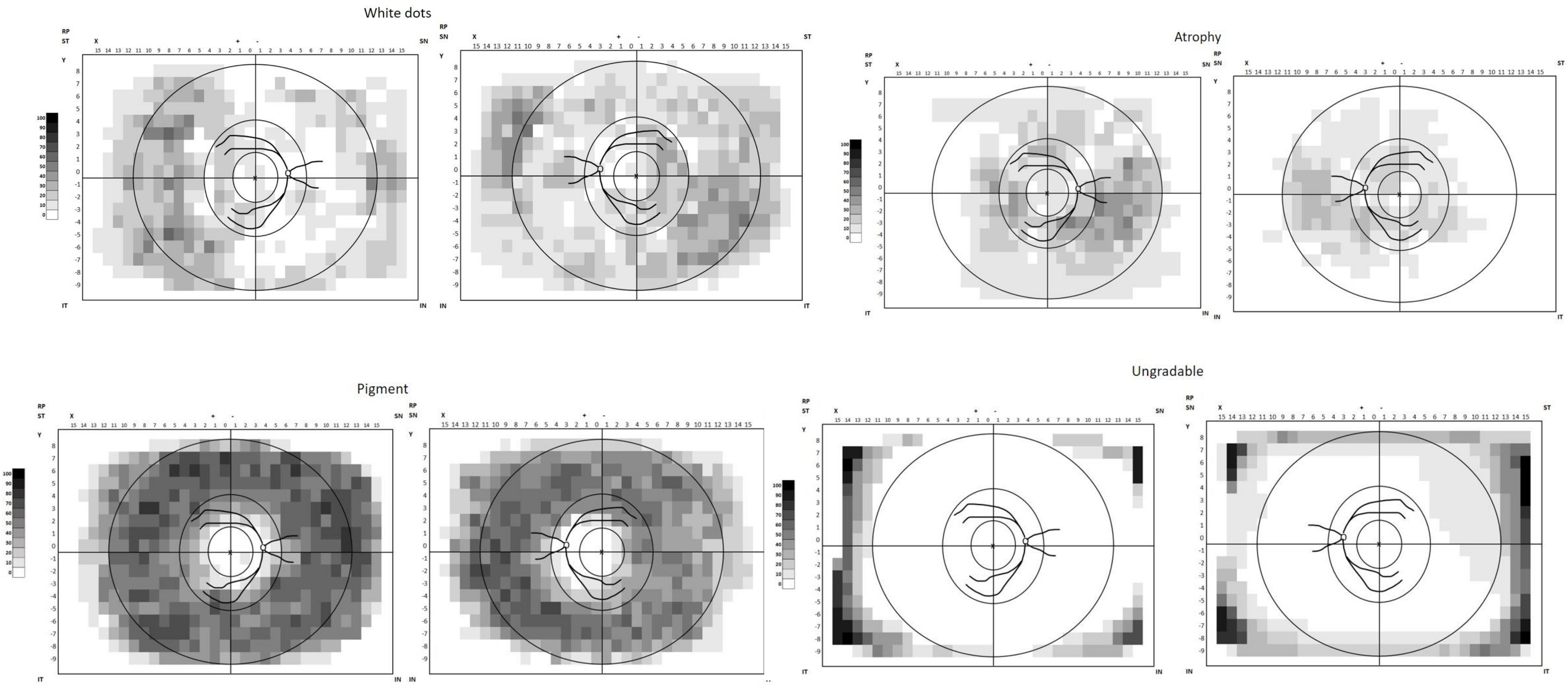


Figure 167: Manchester heatmaps for most common pathology in RP

6.5.12 Autofluorescence Analysis

	NTDR	TDR	RP
HypoAutofluorescence			
Zone 1	15 (53.5%)	8 (57.1%)	17 (81%)
Zone 2	21 (75%)	13 (92.9%)	20 (95.2%)
Zone 3	28 (100%)	14 (100%)	21 (100%)
Zone 4	28 (100%)	8 (57.1%)	19 (90.5%)
HyperAutofluorescence			
Zone 1	19 (67.9%)	14 (100%)	20 (95.2%)
Zone 2	18 (64.3%)	14 (100%)	18 (85.7%)
Zone 3	24 (85.7%)	14 (100%)	20 (95.2%)
Zone 4	21 (75%)	10 (71.4%)	17 (81%)

Table 50: Analysis of autofluorescence according to zone and group

All of those with NTDR have hypo autofluorescence in the mid-far periphery (zones 3 and 4) and over half/ 75% have in zones 1 and 2 respectively. In addition, over 75% also have hyper autofluorescence in the mid-far periphery in NTDR and over 60% of eyes have it in zones 1 and 2.

More than 90% with TDR have hypo autofluorescence in zones 2-3 (mid-periphery) and just over half have it in zone 1 and 4. Despite this, 100% have hyper autofluorescence in zones 1-3 and over 70% have it in zone 4.

In RP, over 80% have hypo autofluorescence in zone 1 (macular region) and over 95% of eyes have it in zones 2-3 (mid-far periphery). Over 90% also have it in zone 4 (far periphery). Hyper autofluorescence is present in over 80% in all zones with most prevalence in zone 1 (95.2%) and zone 3 (95.2%).

Interestingly, 92.9% of those with no DR had hypo autofluorescent areas and 78.5% had hyper autofluorescent areas. Fifty percent of eyes with mild DR had hypo and hyper autofluorescent areas. All of those with moderate, severe and proliferative DR had hypo and hyper autofluorescent areas.

Figure 168: Example of person with diabetes, no DR but hypo/hyper autofluorescence

6.5.13 Diabetes Autofluorescence Heatmaps

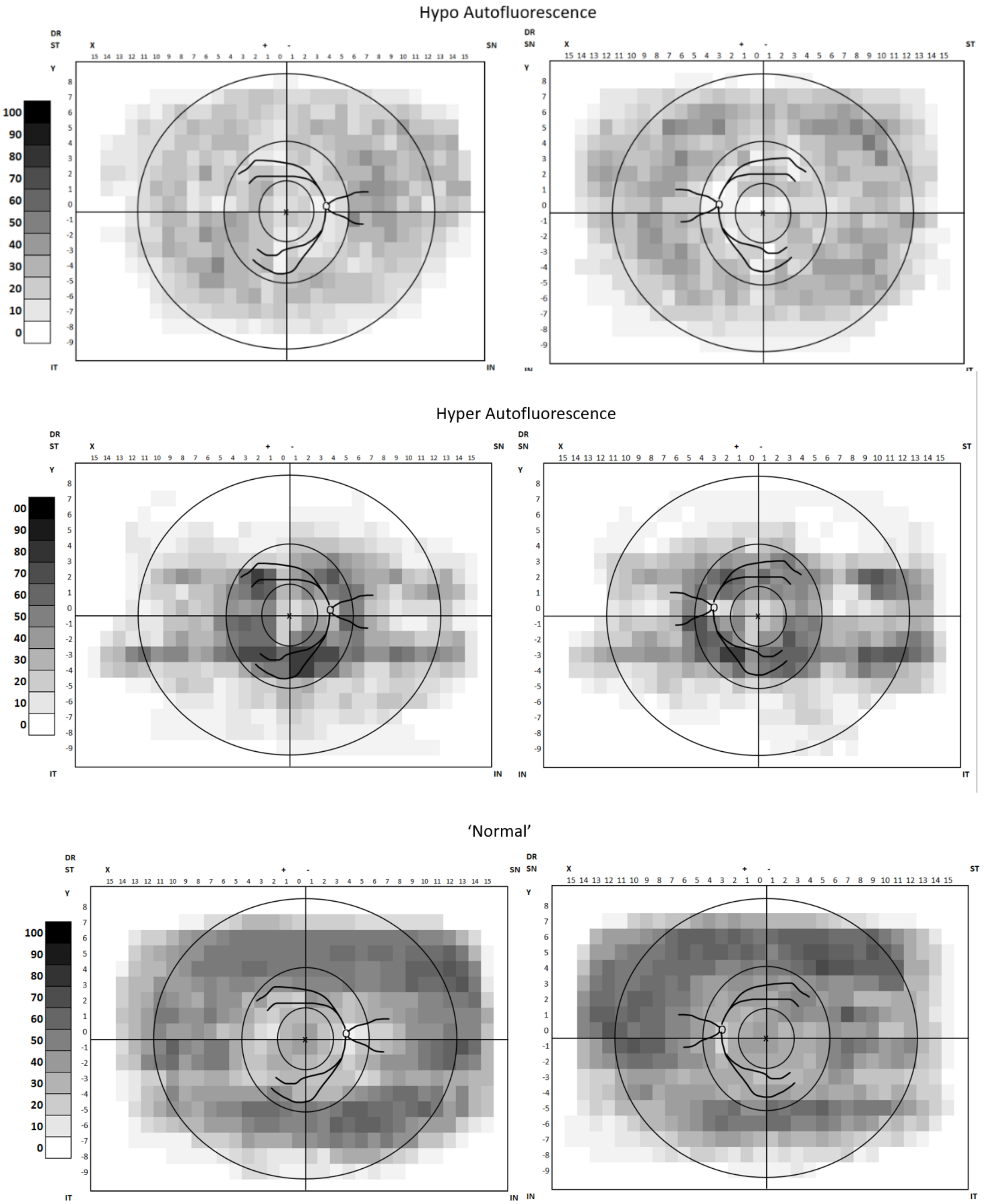


Figure 169: Hypo, hyper and 'normal' diabetes heatmaps

6.5.14 Retinitis Pigmentosa Autofluorescence Heatmaps

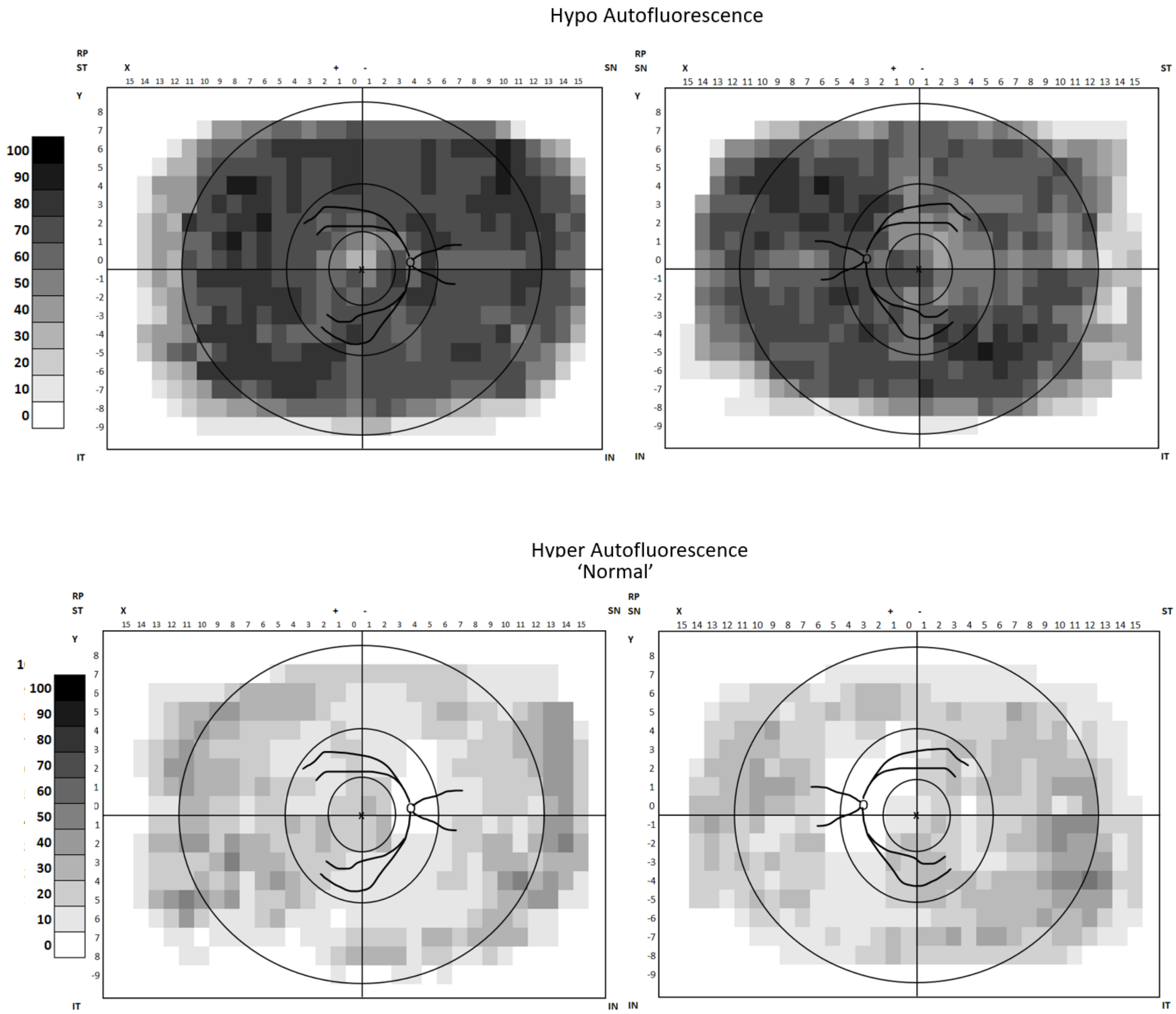


Figure 170: Hypo, hyper and normal retinitis pigmentosa heatmaps

6.5.15 OCTA

Not all participants had OCTAs available as some participants could not sit long enough for the OCTA, were getting tired or could not focus on the focal point in the camera. Seven has no right eye OCTA and 8 had no left eye OCTA. OCTAs were graded as below:

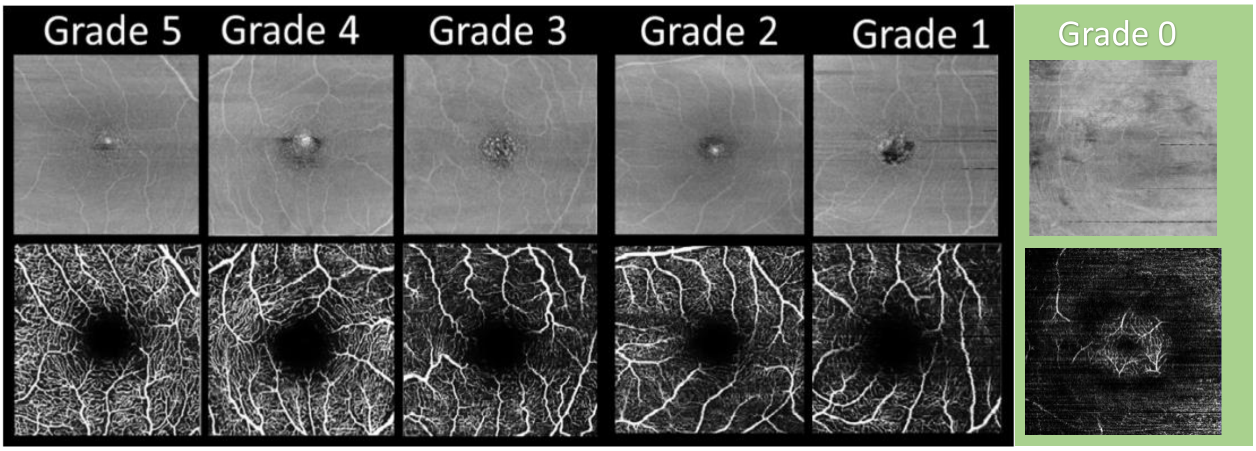


Figure 171: Grading scale for OCTAs

OCTAs were analysed using methods from Hogg et al, data extraction techniques and analysis are described in the methods chapter.

From this it is clear that most people with NTDR have gradable OCTAs and over 60% fall within grade 4 and 5. Those with TDR tend to have OCTAs which fall within grade 3 due to the nature of missing vasculature. Many (57.9%) of those with RP had grade 0 and 21% fell into grade 1. As expected, those with RP had very poor vasculature within the OCTA. Those with TDR had worse vasculature than those with NTDR.

	NTDR	TDR	RP
0	1	4	11
1	3	3	4
2	1	0	0
3	4	5	1
4	13	1	3
5	1	0	0

Table 51: OCTA gradings per group

Analysis was conducted on vascular density measurements within the ETDRS grid on the OCTA. Below is an ETDRS grid and its sections.

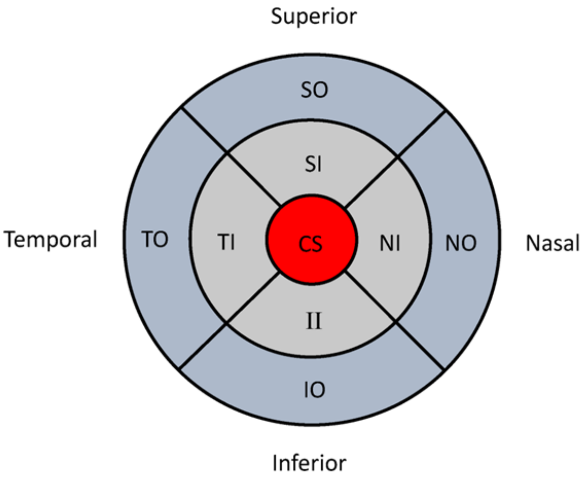


Figure 172: ETDRS grid (I= Inner and O=Outer)

Below is a table of analysis of vascular density measurements from the ETDRS grid for both the Deep Vascular Complex (DVC) and Superficial Vascular Complex (SVC) which are the most reliable slabs for measurement. The numbers in the table shows the proportion of vessels in the scanned area (sector of the ETDRS grid). It should be noted that it is calculated from a three-dimensional image therefore will include everything including tissue within that section of the grid.

The table shows there is very little difference between the central aspects of the OCTA between groups – which is to be expected given the nature of an OCTA. The outer regions all follow a similar pattern where RP has the least vessel density, followed by TDR and then NTDR. The outer nasal area has the biggest difference with 0.16 difference between RP and NTDR.

Superficial Vascular Complex (SVC)		NTDR	TDR	RP
Central (Mean, Median, Range)	*CS*	0.07 0.06 0.17	0.07 0.05 0.20	0.08 0.42 0.34
Temporal (Mean, Median, Range)	*TO*	0.25 0.25 0.24	0.18 0.19 0.24	0.16 0.16 0.35
	TI	0.19 0.19 0.25	0.15 0.16 0.25	0.16 0.18 0.28
Inferior (Mean, Median, Range)	*IO*	0.30 0.31 0.21	0.22 0.27 0.31	0.15 0.11 0.30
	II	0.21 0.21 0.27	0.19 0.21 0.38	0.15 0.17 0.34
Nasal (Mean, Median, Range)	*NO*	0.31 0.33 0.23	0.23 0.24 0.20	0.15 0.10 0.33
	NI	0.23 0.24 0.22	0.17 0.21 0.31	0.17 0.18 0.37
Superior (Mean, Median, Range)	*SO*	0.30 0.30 0.28	0.23 0.26 0.24	0.16 0.12 0.33
	SI	0.23 0.23 0.27	0.17 0.17 0.25	0.13 0.12 0.31

Table 52: Analysis of the ETDRS grid sections according to group in the superficial vascular complex

The inner sections showed little difference between groups except for in the inferior inner section. In the nasal inner section the vessel density mean is the same in both TDR and RP. The inferior inner has the biggest difference between RP and NTDR however it was only 0.05.

Unlike in the SVC, there is a bigger difference between vascular density in the central region of 0.12. In the outer sections of the grid, there was a slight difference in the temporal region of 0.09. In the inferior and superior outer sections the densities actually go slightly down in the TDR group when compared to the RP group. The nasal outer has the largest difference between RP and NTDR at 0.17 and the RP and TDR density scores are the same.

Deep Vascular Complex (DVC)		NTDR	TDR	RP
Central (Mean, Median, Range)	***CS***	0.19 0.20 0.34	0.10 0.12 0.21	0.07 0.06 0.18
Temporal (Mean, Median, Range)	***TO***	0.35 0.39 0.35	0.21 0.26 0.26	0.26 0.26 0.36
	TI	0.33 0.37 0.42	0.19 0.23 0.24	0.20 0.21 0.36
Inferior (Mean, Median, Range)	***IO***	0.36 0.37 0.20	0.19 0.25 0.30	0.25 0.28 0.27
	II	0.35 0.34 0.39	0.20 0.24 0.32	0.22 0.22 0.39
Nasal (Mean, Median, Range)	***NO***	0.38 0.39 0.28	0.21 0.20 0.24	0.21 0.22 0.34
	NI	0.36 0.40 0.34	0.22 0.21 0.30	0.18 0.17 0.38
Superior (Mean, Median, Range)	***SO***	0.34 0.34 0.35	0.20 0.20 0.25	0.24 0.24 0.38
	SI	0.34 0.38 0.37	0.21 0.25 0.25	0.20 0.19 0.38

Table 53: Analysis of the ETDRS grid sections according to group in the deep vascular complex

In contrast to the SVC, there was a bigger difference between RP and NTDR in the inner sections of between 0.13-0.18 in each section. RP and TDR vessel densities also tended to be similar.

6.5.16 Multicolour Analysis

Pathology with graded in multicolour images on each level of colour; green reflectance, infrared reflectance, blue reflectance and multicolour. The results showed that multicolour was the most reliable with microaneuryms and haemorrhages missed on one image. Infrared and blue reflectance showed the least pathology. Blue reflectance missed microaneurysms on 5 images, exudate on 2, new vessels on one, haemorrhages on two, atrophy on one and neovascularisation on one. Infrared missed haemorrhages on 5 images, neovascularisation on one, exudate and vascular loops on one however picked up macular changes on one image that no other layer found. Green reflectance only missed exudate and atrophy on 1 image.

6.5.17 Walkaround

6.5.17.1 Walkaround Participants

Prior to commencing the walkaround, participants were asked if they knew the route well/if they lived within Belfast or outside Belfast. In total, 9 people were from Belfast, only 1 was from South Belfast and three knew the route well due to being current/past QUB students and members of staff. Twenty-four people were not from Belfast and lived in areas such as Carrickfergus, North Down and Ards, Ballymena and Magherafelt. In total three people knew the route well and a further 6 stated they had walked the area before. All other participants said they were unfamiliar with the walkaround area.

6.5.17.2 – Weather during the walkarounds

As mentioned in Chapter 3, participant walkarounds were conducted from August 2021 to May 2022 regardless of weather. Temperatures ranged from 6-23°C with 17 walkarounds having temperatures of 6-10°C, 9 were 11-15°C, 5 in 16-20°C and 2 in 21-23°C. Around 70% (24) were conducted with clouds in the sky, 10 had sun and 8 had rain. One walkaround was conducted at the end of a storm.

6.5.17.3 Light and Noise Levels

Light and noise levels were measured around the walkaround areas for 1 year (before and during the walkaround stages) to assess how they changed throughout the year and times. Below are graphs showing the levels of light and noise according to each point and season.

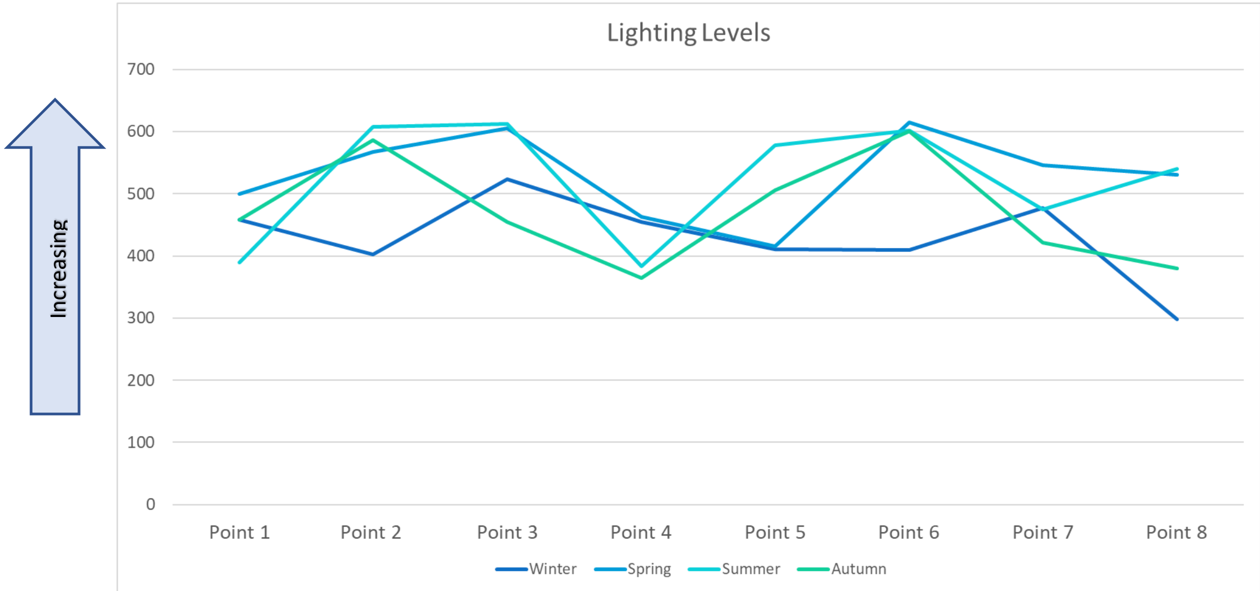


Figure 173: Graph of light levels according to each walkaround point and season

As expected light levels in general are lower in the winter than in any other season. Interestingly at point 4 light levels for spring and autumn dip dramatically, to below even winter's levels. While summer tends to have the highest levels of light, at point 4 and 5 levels dip close to those in the winter.

In the autumn light levels at point 3 also dip below all other seasons. During the walkaround comments on lighting levels were made. Some participants found very bright days extremely difficult due to photophobia or light casting shadows on the pavement (especially where trees were overhead). In addition, very dark and dull days (especially with heavy rain) were difficult for people as they felt it was hard to navigate in these dark conditions or with less contrast between buildings and skies. The constant changes of light across the walkaround were also difficult for some as their eyes could not easily adjust making it difficult to navigate.

6.5.17.4 Noise Levels

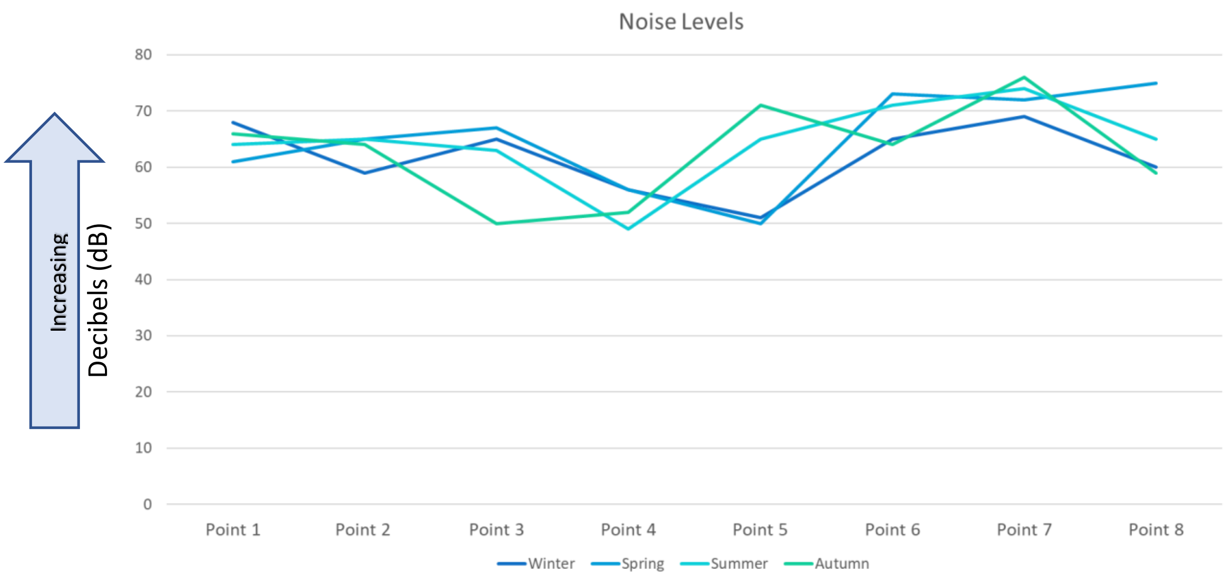


Figure 174: Graph of noise levels according to each walkaround point and season

Interestingly, Winter and Spring noise levels follow the same trend nearly exactly. Summer noise also seems to follow a similar trend apart from at point 5 where the noise increases by about 15 dB. Autumn has an even higher noise level at point 5 and does not seem to fit with the trends of the other months. It most closely trends towards the summer noise levels with a few exceptions (point 3 and point 6). During the walkaround, one participant with a hearing difficulty mentioned that it was particularly noisy in areas and he found it difficult to talk to the researcher on occasion. In addition, some participants mentioned issues in loud areas with hearing potential hazards on the pavement including bikes, skateboards, scooters and also passers by.

6.5.17.5 Confidence, Anxiety and Difficulty

Participants were asked to assess the difficulty of the walkaround as well as their confidence and anxiety at different points along the walkaround (similar to those of the light/noise measurements). Below are box plots of these according to each group.

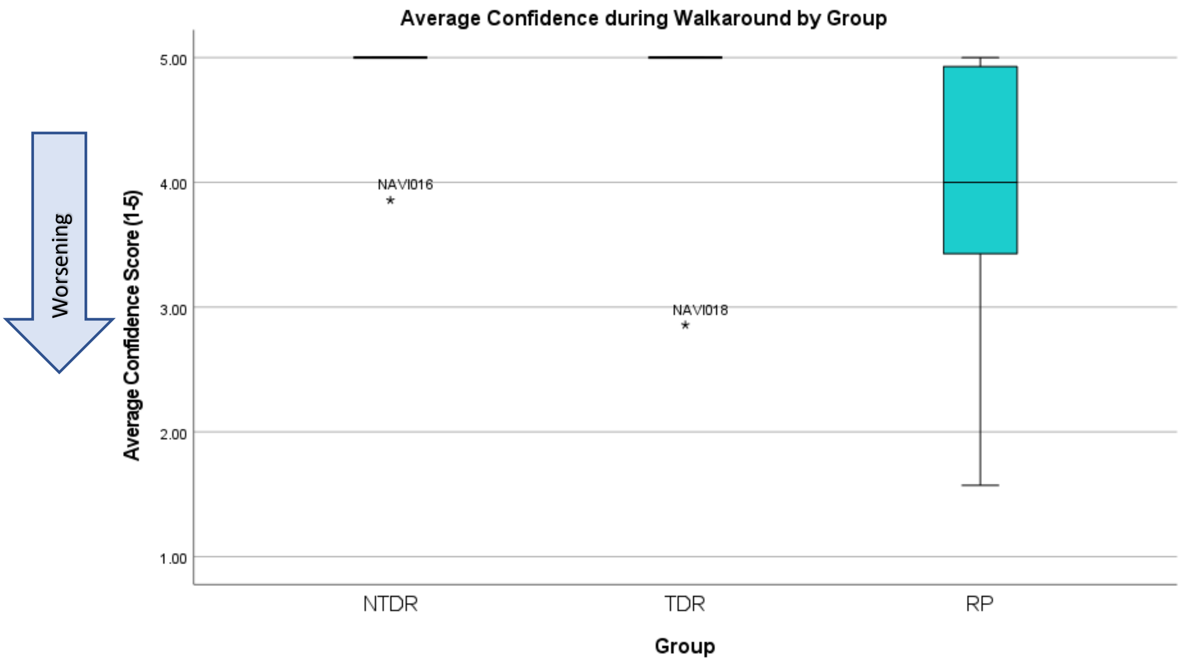


Figure 175: Boxplot of average confidence during walkaround per group

From this boxplot it is clear that people with RP have a much bigger variability of confidence than those with NTDR and TDR. The lowest confidence score was 1.5 in the RP group. In fact a majority of those in the

NTDR and TDR, with the exception of 2 participants, did not have any confidence issues during the walkaround.

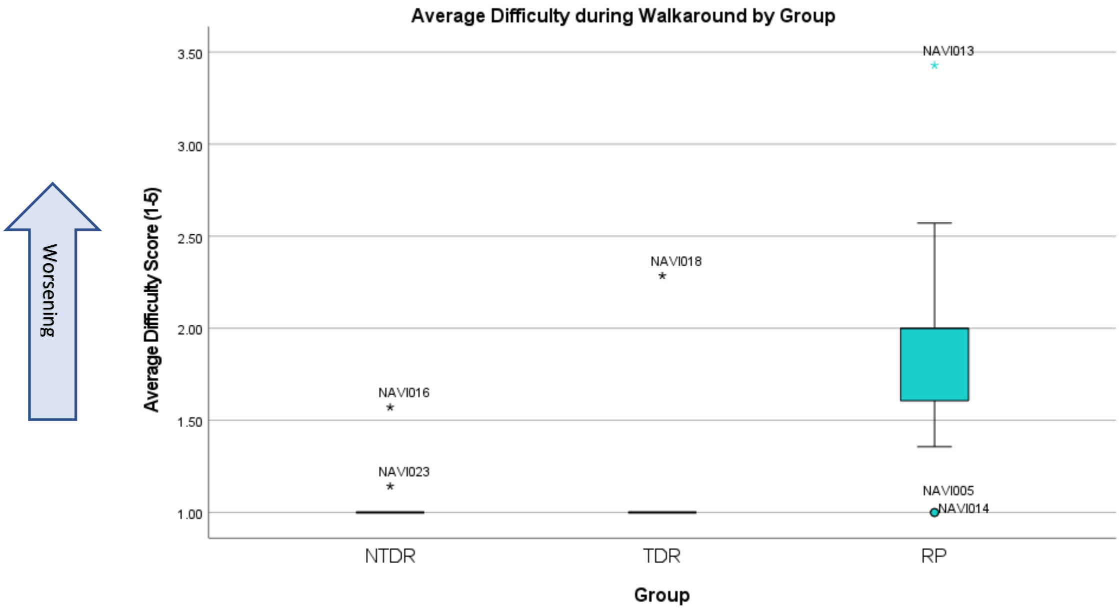


Figure 176: Boxplot of average difficulty during walkaround per group

This boxplot mirrors the previous confidence one as people with RP have a greater variability of difficulty than those with NTDR and TDR. Of note, this boxplot only goes up to 3.5 therefore difficulty ratings were lower than the max of 5. The same outliers as confidence had difficulty issues and one other outlier had some difficulties (under 1).

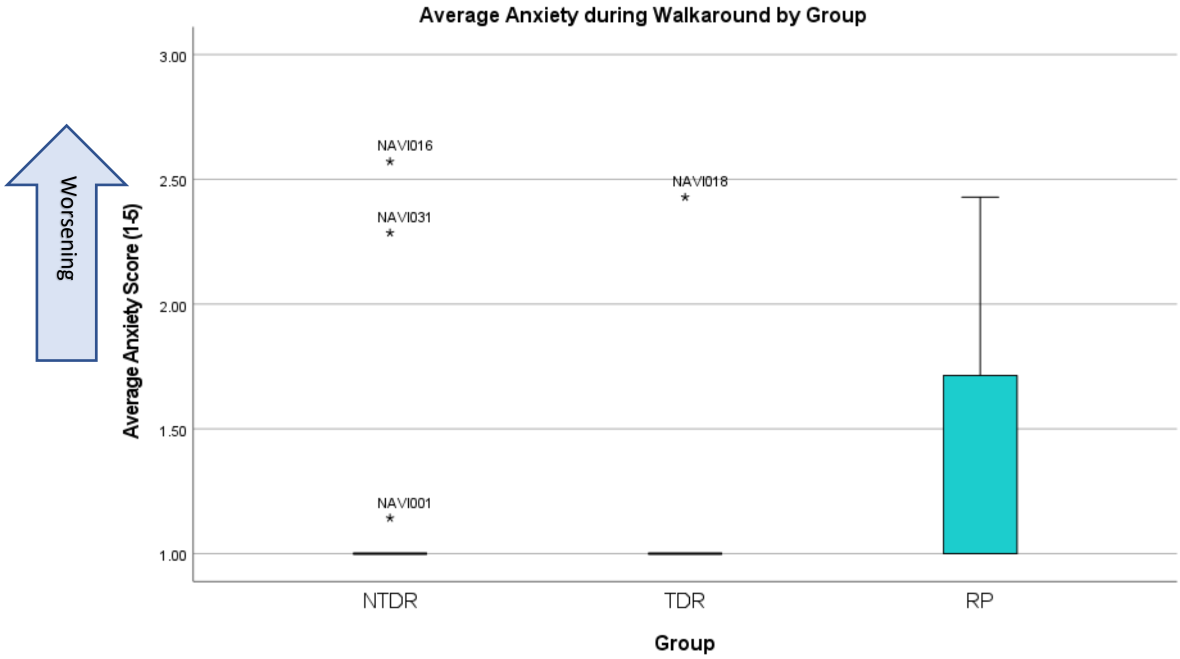


Figure 177: Boxplot of average anxiety during walkaround per group

The anxiety boxplot shows similar trends to the previous ones. People with RP seem to have more anxiety and variability than those with NTDR and TDR. NAVI016 and NAVI018 continued to be outliers as well as new NAVI031 and NAVI001. NAVI001 had a hearing problem and NAVI016, NAVI018 had diagnosed anxiety.

6.5.17.6 Qualitative Analysis of Walkaround

Participants were encouraged to talk about the barriers they faced when walking around. Some of the most common themes are shown below:

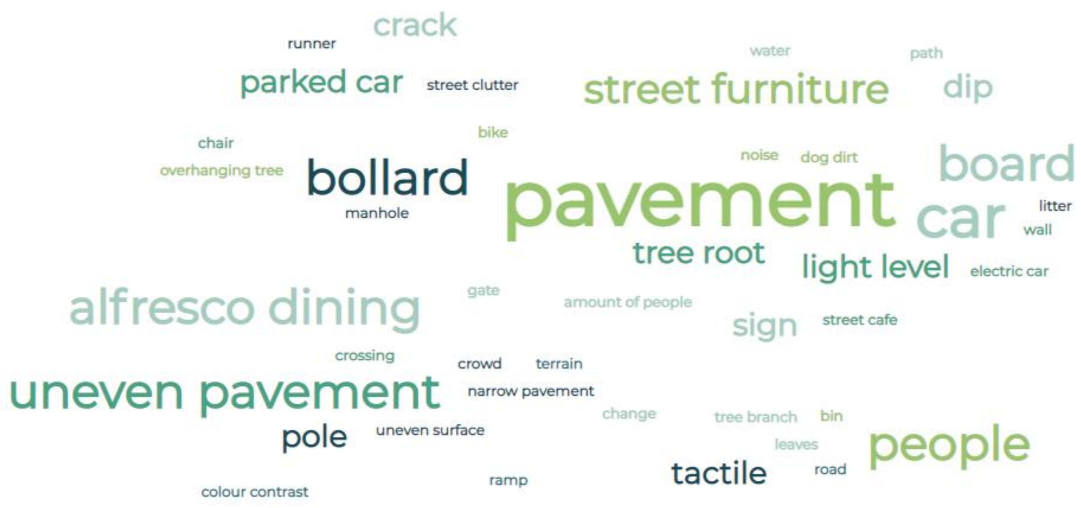


Figure 178: Word cloud of the most common phrases and issues

Some of the most common barriers as seen above are pavement issues, bollards, parked cars, uneven pavements, alfresco dining, light levels and street features such as tree roots, poles, A-boards, street clutter.

In addition to these most common phrases there were some other longer phrases and problems raised by participants:

- 1 participant fell over a takeaway carton on the ground
- 1 participant was ‘trapped’ in botanic gardens due to the gates
- 1 participant stated they were ‘busy watching the ground for hazards that she misses whats in front’
- Corner at Shaftesbury Square is very difficult
- Kerbs with curved gradient rather than a step
- Street cafes - especially town square
- Green man for crossing the road was broken
- No sounds at the road crossings

- Leaves are slippery
- Walked into an A-board

6.5.18 Statistical Analysis

Spearmans correlation and multiple regression analyses were conducted between clinical findings, grading and walkaround findings to find significant correlations. Analysis was conducted using Stata Statistical Analysis Software Version 17

6.5.18.1 Spearmans Correlation Analysis

	Visual Acuity	Contrast Sensitivity	RetDQOl	Rod Intercept	Mean Visual Fields	Percentage of Retina
Average Difficulty	0.4*	-0.23	-0.40*	0.37*	0.5*	0.44*
Average Confidence	0.4*	-0.33	0.37*	-0.23	-0.39*	-0.34
Average Anxiety	0.08	-0.05	-0.22	0.05	-0.03	0.03

Table 54: Walkaround measures of difficulty, confidence and anxiety correlating with clinical measures
**red and asterisk means significant*

From the table it is clear that there was no correlation found with any clinical measures and average anxiety during the walkaround. However average difficulty was associated with visual acuity, RetDQol, rod intercept (Dark Adaptation), mean visual field and percentage of the retina affected by pathology. Similarly, average confidence was associated with visual acuity, RetDQol and mean visual field.

6.5.18.2 Regression Analysis

	Untreated Diabetic Retinopathy (Constant)	Retinitis Pigmentosa	Treated Diabetic Retinopathy
Visual Acuity	-0.2	0.3 *(p=0.000)*	0.18 *(p=0.078)*
Contrast Sensitivity	1.71	-0.43 *(p=0.017)*	-0.47 (p=0.012)
Visual Field	1.31	9.63 *(p=0.000)*	1.89 *(p=0.254)*
Percentage of Retina Affected	3.78	36.88 *(p=0.000)*	24.95 *(p=0.005)*
Age at Study	42.85	4.88 *(p=0.489)*	15.26 *(p=0.047)*
RetDQol	-1.22	-2.62 *(p= 0.000)*	-1.68 *(p=0.021)*
Average Confidence	4.91	-1.0 *(p=0.006)*	-0.15 *(p=0.666)*
Average Difficulty	1.05	0.87 *(p=0.000)*	0.09 *(p=0.667)*
Average Anxiety	1.23	0.16 *(p=0.449)*	-0.05 *(P=0.824)*

Table 55:Differences by group as compared with clinical observations and walkaround observations
**red and asterisk means significant*

This table shows that visual acuity and visual fields were significantly reduced in those with RP compared to untreated retinopathy. Contrast sensitivity was signficantly reduced in those with RP and TDR. In addition, those with RP and TDR had a significantly reduced quality of life as assessed by the RetDQol. Percentage of the retina was significantly higher in both the treated diabetic retinopathy and RP groups. In addition, those with RP found walking and navigating the built environment significantly more difficult.

Those with RP had significantly more difficulty and less confidence when walking around the built environment. While not significant results would suggest that those with TDR still had more difficulty and less confidence when walking the route.

6.5.19 Layer Analysis

Below is a reminder of the layers of the retina

Retinal Layers

Abbr.	Name
ILM	Internal Limiting Membrane
RNFL	Retinal Nerve Fibre Layer
GCL	Ganglion Cell Layer
IPL	Inner Plexiform Layer
INL	Inner Nuclear Layer
OPL	Outer Plexiform Layer
ONL	Outer Nuclear Layer
ELM	External Limiting Membrane
PR	Photoreceptor Layers
RPE	Retinal Pigment Epithelium
BM	Bruch's Membrane
CC	Choriocapillaris
CS	Choroidal Stroma

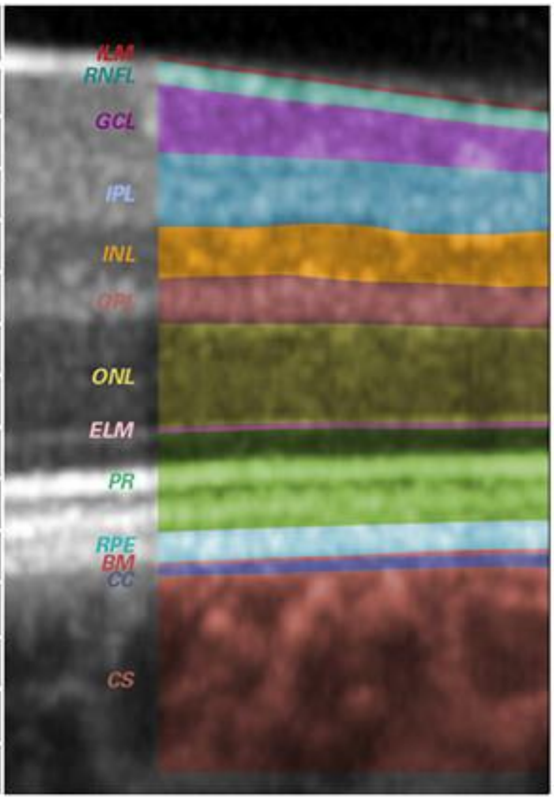


Figure 179: Layers of the retina (Source: Heidelberg Engineering)

6.5.19.1 Comparative Layer Analysis

	Untreated Diabetic Retinopathy*	Retinitis Pigmentosa	Treated Diabetic Retinopathy
Choroidal Measurement	329.9 *(p=0.000)*	63.6 *(p=0.343)*	48.9 *(p=0.490)*
Outer Layer Measurement (foveal)	230 *(p=0.000)*	-47.4 *(p=0.480)*	63.4 *(p=0.372)*
Outer Layer Measurement (500 nasal)	196.1 *(p=0.000)*	-52.1 *(p=0.422)*	62.8 *(p =0.361)*
Outer Layer Measurement (500 temp)	175.46 *(p=0.000)*	-36 *(p=0. 577)*	67 *(p=0.329)*
Outer Layer Measurement (1000 nasal)	164.2 *(p=0.000)*	--52.5 *(p=0.405)*	73.3 *(p=0.274)*
Outer Layer Measurement (1000 temp)	168.2 *(p=0.000)*	-45 *(p=0.476)*	67 *(p=0.318)*
Outer Layer Measurement (3000 nasal)	183 *(p=0.000)*	-105 *(p=0.247)*	38.2 (p=0.688)
Outer Layer Measurement (3000 temp)	157.5 *(p=0.001)*	-75 *(p=0.268)*	55 *(p=0.441)*
Inner Layer Measurement (foveal)	34.1 *(p=0.469)*	6.9 *(p=0.920)*	105.1 *(p=0.158)*
Inner Layer Measurement (500 temp)	140.8 *(p=0.003)*	-0.1 *(p=0.999)*	103.6 *(p=0.138)*
Inner Layer Measurement (500 nasal)	134.5 *(p=0.003)*	-8.8 *(p=0.889)*	95.3 *(p=0.161)*
ONL Measurement (foveal)	125.6 *(p=0.013)*	-34.4 *(p=0.626)*	81.4 *(p=0.281)*

*Table 56: Retinal layer measurements per group *constant*

Retinal layer thickness was not found to be significantly different between groups.

6.5.19.2 External Limiting Membrane (ELM)

	Yes (Constant)	No
Visual Acuity	0.04	-0.13 *(p=0.111)*
Contrast Sensitivity	1.3	0.19 *(p=0.282)*
Visual Field Corrected	9.8	-6.9 *(p=0.001)*
Dark Adaptation	182.6	-138.7 *(p=0.158)*
Percentage of retina	32.7	-14.1 *(p=0.134)*
Age at study	56.4	-11.1 *(p=0.096)*
RetDQol	-3.7	1.7 *(p=0.019)*
Average Confidence	4	0.83 *(p=0.011)*
Average Difficulty	1.7	-0.52*(p=0.019)*
Average Anxiety	1.36	-0.13 *(p=0.489)*

Table 57: Clinical and walkaround observations and whether ELM is present?

Analysis was conducted to establish whether any clinical and walkaround observations were impacted by the external limiting membrane being intact. The results showed that visual field was significantly reduced in those without an intact ELM *(p=0.001).* In addition, quality of life and confidence were significantly lower in those without ELM intact. Results also show that those without ELM intact found the walkaround more difficult.

6.5.19.3 Ellipsoid Zone (EZ)

	Yes (Constant)	No
Visual Acuity	0.09	-0.24(p=0.001)
Contrast Sensitivity	1.3	0.24 (p=0.133)
Visual Field Corrected	9.6	-8 (p=0.000)
Dark Adaptation	195.3	-190 (p=0.034)
Percentage of retina	-20	-39.24 (p=0.019)
Age at study	56.3	-13.3 (p=0.0030)
RetDQol	-3.6	1.8 (p=0.005)
Average Confidence	4.1	0.8 (p=0.010)
Average difficulty	1.8	-0.7(p=0.001)
Average Anxiety	1.4	-0.02 (p=0.366)

Table 58: Clinical and walkaround observations and whether EZ is disrupted

The same analysis was conducted with intact EZ layer which yielded similar results. Visual acuity and visual field were significantly reduced in those without an intact EZ. In addition, confidence was significantly lower, there was significantly more difficulty walking/navigating without an intact EZ.

6.5.20 DDS17

A comparative analysis was conducted between NTDR and TDR results on the DDS17 however no variables were found to be significant showing that both NTDR and TDR have similar diabetes distress.

6.5.21 Statistical Adjustments

As this is an exploratory study and also conducted on a smaller sample that initially planned, due to COVID, readers will be aware of risks of curious findings and lack of power. Therefore, I decided not to implement Bonferroni adjustment of p-value.

6.6 Concluding Results

6.6.1 Clinical Findings

- While visual acuity does not seem to be impacted in those with TDR as much as those with RP, those with TDR have similar problems with contrast sensitivity and dark adaptation
- People with NTDR also have problems with dark adaptation, especially those in the moderate DR group
- People with RP tended to have large visual field deficits when compared to other groups. Those with TDR had more visual field issues than those with NTDR but not as much as RP
- Visual acuity is significantly less in those with RP than those with NTDR
- Percentage of the retina impacted by pathology was significantly more in those with TDR and RP

6.6.2 Quality of Life and Diabetes Distress

- Quality of life was lower in those with RP and TDR however some people with NTDR also had some very low quality of life scores
- Those with NTDR and TDR seem to have similar levels of diabetes distress and eye disease does not significantly impact this
- Quality of life is significantly less in those with RP when compared to those with NTDR

6.6.3 Built Environment Walkaround Issues

- Many (63.6%) with RP felt that walking around the built environment was difficult and there were barriers such as street clutter, shared space and parked cars were deemed a problem by over 70%
- People with RP had a much more varied confidence, anxiety and difficulty when walking the built environment. Those with TDR and NTDR did not seem to have these issues apart from 2 participants
- Some of the most common barriers from the walkaround were pavement issues, bollards, parked cars, uneven pavements, alfresco dining, light levels and street features such as tree roots, poles, A-boards, street clutter
- Confidence in walking around the built environment was impacted by visual acuity, quality of life, and visual field deficits
- Difficulty of walking around the built environment was impacted by visual acuity, quality of life, dark adaptation, visual field and percentage of the retina covered in pathology

6.6.4 Retinal Image Grading

- ELM and EZ was present and intact in over 80% of those with TDR and NTDR whereas over 70% of those with RP had missing or disrupted EZ/ELM
- OCTA vascular density was lower in those with TDR and RP
- Visual field was significantly more impaired in those where ELM was not intact

- Visual acuity, visual field and quality of life was much more affected in those with EZ disruption and difficulty of walking around was increased
- Interestingly, 100% of those with non-treated DR have hypo autofluorescent areas in the mid-far periphery and 80% had hyper autofluorescent areas.
- In addition, over 90% of those with no clinical DR have hypo autofluorescent areas and 78.5% have hyper autofluorescent areas

6.7 Discussion

6.7.1 Clinical Results Discussion

As expected, nearly all those with co-morbidities were people with diabetes. This correlates with the papers described in chapter 2. Interestingly, none of those with RP had hearing loss which can sometimes be associated with certain genes for example USH2A.

Visual acuity results were as expected for those with retinitis pigmentosa (significantly less) however it was expected that those with treated diabetic retinopathy may have had similar levels of visual acuity loss. This was not found to be the case as treatment of DR did not seem to significantly affect the visual acuity in people with DR. Previous literature shows that when VA is measured by smallest line on the chart where an individual can read all letters (as it was in this study), VA loss was not correlated with DR severity (Bengtsson et al., 2005) . However when measured using LogMAR visual acuity reduced by 0.02 LogMAR per each ETDRS step (Bengtsson et al., 2005). It could also be said that due to visual acuity measures being a poor indicator of sight threating DR (Scanlon et al., 2008b), the visual acuity is not substantially impaired. Longterm follow up results from the ETDRS study also show that over 84% of those treated with laser had a vision of 20/40 or better after 10 years (Chew et al., 2003) which may be the reason for good VA in the TDR group.

Visual field analysis showed that those with TDR had some deficits when assessed using the corrected mean deficit measure which could be due to laser scarring. Previous literature suggests that there is often clear evidence of visual field deficit, mostly in the mid-periphery, in those with more advanced disease (Henricsson and Heijl, 1994a). While PRP laser scarring could cause visual field deficits, it is worse in those with full scatter PRP than mild-scatter PRP. Those with NTDR also had some deficits which was not expected. Some papers show that those with diabetes and no diabetic retinopathy show signs of VF deficits when compared to healthy controls (Bao et al., 2019, Henricsson and Heijl, 1994b). Bao et al suggest this could be due to neuroretinopathy preceeding the classic signs of microvascular disease in the retina. While results from this study and Henricson et al 1994 show there are visual field deficits in people with diabetes, it seems to have little impact on daily tasks.

People with RP and TDR seemed to have similar issues with contrast sensitivity, most likely due to their retinal pathology and laser scarring. Interestingly, while not as severe, some of those with NTDR also had contrast sensitivity (mostly in the more severe retinopathy levels). Previous literature shows that contrast sensitivity is affected in many with diabetes, even before retinopathy apears (Dosso et al., 1996, Arend et al., 1997, Sokol et al., 1985) which may be attributed to non selective neuronal damage in the visual pathway (Dileo et al., 1992). While walking speed was not directly observed in this study, previous studies suggest that contrast sensitivity can affect walking speeds (Vivekananda-Schmidt et al., 2004) .

Those with TDR and RP appeared to have similar problems with dark adaptation. Some of those with NTDR also had issues, especially those in the moderate DR group, perhaps due to retinopathy worsening and starting to affect vision.

6.7.2 Quality of Life and Diabetes Distress Discussion

The quality of life scores followed an expected trend with people with RP having the worst scores, followed by people with TDR and then people with moderate and severe diabetic retinopathy (Mazhar et al., 2011, Davidov et al., 2009, Ligda et al., 2019, Pereira et al., 2017).

Diabetes distress was found to be similar in those with TDR and NTDR which could suggest that diabetic eye disease does not necessarily impact this. In fact, those with NTDR have more interpersonal distress, potentially because they have had diabetes for less time, have not accepted their diabetes diagnosis or haven't learned how best to manage it. People with mild diabetic retinopathy also seemed to be in more regimen distress than others, whereas people with moderate DR seemed not to have regimen distress at all. Physician related distress could be linked back to issues surrounding COVID-19 and lack of face to face appointments. It could also be related to type 2 diabetes care being based in primary care (GPs) as opposed to in hospital diabetes clinics- they may feel they have less support. Emotional distress can be caused by a multitude of things including some of the issues mentioned in chapter 2.

6.7.3 Grading Results Discussion

Percentage of the retina affected was as expected significantly higher in those with RP and TDR. It was also correlated with an increased difficulty in walking around which most likely relates back to vision loss, in particular visual field loss.

As expected OCTA vascular density was lower in those with TDR and RP which corresponds to previous literature (Dupas et al., 2018, Hogg et al., 2021). This is most likely due to capillary fallout.

Surprisingly, no significant difference was found in the layer measurements between groups, despite previous literature showing photoreceptor layer thining and mid-retinal layer thickening in those with RP (Wolsley et al., 2009). Other studies suggest that those with RP have a reduced ONL (Hood et al., 2011), however the measurements from this study could have been affected by the high number of participants with intraretinal fluid.

Despite this ELM and EZ disruption were found to have a significant affect on some visual function and walkaround parameters. Lack of an intact ELM was found to be significantly associated with a visual field deficit. This could be related to the ELM function of separating the inner segments for the outer nuclear layer, creating a skeleton to align the photoreceptors (Drexler et al., 2003, Srinivasan et al., 2008, Abramoff et al., 2010). If the photoreceptors are not aligned, it can cause vision problems.

Unexpectedly, those in the NTDR have less ELM remaining than those in the TDR group.

EZ disruption was found to be significantly associated with visual acuity and visual field loss (Aizawa et al., 2009, Hood et al., 2011, Sandberg et al., 2005, Witkin et al., 2006, Yokochi et al., 2012). Quality of life was also associated with EZ disruption, most likely correlated to the loss of visual field and vision in general. EZ disruption was also significantly associated with more difficulty when walking around, potentially linked to the loss of visual field discussed.

As expected some pathology is missed on certain layers within a multicolour image due to the different depths of wavelength picking up different pathology more clearly. The results have shown that multicolour is best for viewing all pathology over infrared, green reflectance and blue reflectance.

6.7.4 Navigating and Walking around Built Environments Discussion

Surpisingly only 34% of those with RP used walking aids despite over 80% having problems with navigating and moving around the built environment. This could be for many reasons including stigma (Barland, 2007), vulnerability and attracting negative attention/worry of theft (Wong et al., 2004, Worth, 2013). There are also issues surrounding acceptance (Worth, 2013), self-perception (Hayeems et al., 2005) and 'giving into blindness' (Zaborowski, 1997).

The results showed that only 63.6% (1 was TDR) of participants felt that walking around the built environment was difficult however 72% stated street clutter caused problems (4 were TDR). Over 80% of those with RP and 50% of those with TDR felt that shared space was an issue. In addition 77.8% of those with TDR and 72% of those with RP felt that bright markings would help them move around streets. This could be related back to the problems with contrast sensitivity discussed before.

Some of the most common barriers discussed during the walkaround corresponded directly to the literature: pavement issues, bollards, parked cars, uneven pavements, alfresco dining, light levels and street features such as tree roots, poles, A-boards, street clutter (Kitchin et al., 1998, Guide Dogs, 2010, Norgate, 2012). This shows that these barriers exist in several streetscapes worldwide.

Confidence was significantly impacted by reduced visual acuity and loss of visual field. When someone has a loss of vision, especially visual field loss, it is likely to make them less confident (Campion et al., 2003, Johnson and Petrie, 1998, Jones and Jain, 2006) and cause issues with walking around. As expected with reduced confidence and vision comes reduced quality of life potentially due to isolation (Jones and Jain, 2006, Johnson and Petrie, 1998, Campion et al., 2003).

Similarly, a loss of visual acuity and visual field created more dificulty in walking around, potentially for similar reasons mentioned above. Poorer quality of life was also associated with more difficulty walking around, again possibily due to the reasons mentioned above. Dark adaptation was also associated with more difficulty, this could be explained by changes in light throughout the walkaround, especially with tree cover in Botanic Avenue and Botanic Gardens, which was mentioned as problematic by some participants. Percentage of the retina affected was also associated with difficulty in walking around, which most likely correlates to a loss of vision, visual acuity and visual field.

6.7.5 How do results relate to the research aims and objectives?

Results from stakeholder interviews showed that there are many barriers which impact people navigating the built environment with a visual impairment. Despite this, not all stakeholders have enough awareness of the true impact and spectrum of varying visual impairments. Stakeholders felt that small changes should and could be made to create more accessible spaces for all, including people with low vision. In addition, environmental changes such as colour contrast and footway maintenance, robust guidelines and policies are required for accountability across the board.

A street audit tool was designed to capture barriers and enablers within a global context. This tool was used across several different global settings including in central europe, Ireland and the UK. While this was deemed to be a useful tool, we plan to gather more information on opinions of using the tool by further stakeholders to make it more robust.

While the study shows some very interesting results, they show the extent of visual impairment does not directly correlate with a persons visual function in people with diabetes. Many people with an absence of retinal pathology have problems with dark adaptation, visual fields and contrast sensitivity. People with retinitis pigmentosa’s level of retinal disease as documented through retinal imaging does seem to correlate with loss of function.

The walkaround aspect of the study showed that people with visual pathology and visual impairment can face barriers within the built environment. Results correlated with much of the literature showing issues with pavements, street clutter and contrast sensitivity. In addition further barriers such as litter, leaves and light levels were shown to impact on navigation.

In addition, loss of visual function did not affect independent movement around the built environment in people with diabetes however it did in people with those with retinitis pigmentosa.

This project has shown it is possible to correlate results from retinal grading, visual functions and walkarounds and it is an important tool to be able to assess the true barriers people face while navigating the built environment. While the results show how navigating the built environment is affected in people with visual impairment, similar barriers are faced by other populations with disabilities, impairments and even those without.

The condition of pavements also causes issues for older people, people with dementia/alzhemiers, people with physical impairments and people with autism spectrum condition (ASC). Some of these issues can even cause problems for families with prams. Some of the most common issues were cracks on pavements (Rosenberg et al., 2013, Clarke et al., 2008), uneven surfaces (Clarke et al., 2008, Rosenberg et al., 2013) and slippery pavements (Rosenberg et al., 2013). Street clutter such as advertisement boards, bins and bollards were also deemed a problem for older people, ASC and other physical disabilities (Rosenberg et al., 2013, Basha, 2015, McAllister et al., 2022, Tola et al., 2021). In addition to people with visual impairment, narrow pavements cause issues for older people (Rosenberg et al., 2013, Basha, 2015) and for people in wheelchairs, especially people in electric wheelchairs

(Basha, 2015). Narrow pavements and street clutter also cause issues for people in general, especially people with prams or who do not find it easy to walk on and off the pavement or do not feel confident enough to do so. Some of the other issues with pavements include litter (Rosenberg et al., 2013, McAllister et al., 2022) and overhanging brances (Rosenberg et al., 2013).

Other road and pavement users can also be an issue, traffic is deemed too fast and can be problematic for people with a visual impairment, the older population and people with ASC (McAllister et al., 2022, Rosenberg et al., 2013). In addition, cyclists and skateboarders on the pavement can cause sensory overload for people with ASC (McAllister et al., 2022) and pose a danger to people with a visual impairment or those too slow to get out of the way.

Shared space as described in this thesis is a very contested issue around people with a visual impairment. Despite this, shared space can also cause problems for people with hearing loss and people with ASC (McAllister and Sloan, 2015, Renel, 2018). People with hearing loss find large open spaces with no walls, breaks or barriers hard to understand due to poor echo and noise spatial awareness (Renel, 2018).

Colour contrast is often helpful to people with a visual impairment but should be done sensitively for older people, those living with dementia and people with ASC (McAllister et al., 2022, Kleibusch, 2018). Art and patterns on pavement can cause a visual stimulation overload (Black et al., 2022, McAllister et al., 2022) and cause issues for older people, people with dementia ((RTPI), 2020), people with ASC and can be particularly problematic for those with a visual impairment (Jackson, 2021).

Lighting is something which makes areas safer for the general public, allows people with visual impairment to navigate more easily and helps older people, people with arthritis and people with dementia to navigate (Kleibusch, 2018, Rosenberg et al., 2013, Brittain et al., 2011). Lighting needs to be continous and provide enough light throughout the streetscape, this should however be done in a sensitive manor for those with ASC who require light that is not too dull or intense (Black et al., 2022).

Lighting can help make areas more accessible for all, as can adequate and clear signage (Kleibusch, 2018, McAllister et al., 2022, Rosenberg et al., 2013, Tola et al., 2021) and simple built envrionment areas and layouts (Kleibusch, 2018, McAllister et al., 2022, Rosenberg et al., 2013, Tola et al., 2021).

As is shown above, while this thesis is based on visual impairment specifically, the barriers and enablers they face in navigating the built environment are shared by many other populations. In order to create an inclusive built environment the opinions and personal choices of a multitude of stakeholders within the impairment and disability community needs to be heard. Streetscapes also need to be adaptable to meet the unique needs of each person (Black et al., 2022).

While cultural barriers are much more difficult to overcome, physical barriers, especially those that can be easily removed from our streetscape, should be removed for a more inclusive environment.

6.8 Conclusion

While people with treated diabetic retinopathy have some problems with visual function and have similar levels of the retina affected by pathology, they do not seem to have the same issues with navigating and walking around the built environment. In contrast, over 80% of those with retinitis pigmentosa have confidence or anxiety issues and find it difficult to walk around towns and cities. Despite this, people with treated diabetic retinopathy do recognise similar difficulties on the pavements such as parked cars, shared space and poor lighting. From the results it is also clear that confidence issues and difficulties with walking around do impact peoples quality of life.

Strengths: This is the first project which incorporates retinal image grading, clinical findings and navigation around the built environment. The only previous example of similar work was by Havik et al in 2015 who used visual acuity and walking in shared spaces. This study has provided the opportunity for the exploration of different collection methods and techniques which can be used and improved for further studies. The study has made researchers, participants and the general public more aware of this very important topic. The study did have some very interesting results which show that visually impaired users can have problems with navigation and moving around the built environment.

Limitations: Due to the fact that this study has never been done before, lessons have been learnt and methods have been identified which could be implemented in future studies. These include doing a binocular visual field rather than monocular and completing visual acuity testing with LogMAR methods. Measuring walking speeds within sections of the walkaround would also be useful, whilst this was in the walkaround methods it was poorly recorded (an additional colleague would not have been needed) and therefore was not robust. Further diabetes information such as HbA1c, systolic blood pressure and management information could allow for further in depth analysis. In addition, COVID did impact recruitment.

6.9 Overall Conclusions:

In this thesis, I have explored several aspects of living with diabetes from the point of view of patients, family and friends and society. The results of this PhD help to narrow gaps in knowledge of several different aspects including:

- The true impact of diabetes and its multifactorial complications on a person's quality of life
- How stakeholders such as built environment professionals, charities, ophthalmic professionals and visually impaired people view navigating and moving around our towns and cities
- It has highlighted which barriers and enablers stakeholders feel are important, what problems people with sight loss truly face in our towns and cities and how we can improve in the future
- This adds to the scarcity of literature on navigating the built environment with a visual impairment and is the first on diabetic eye disease specifically
- The methods of the walkaround and street audit are novel in the assessment of people with sight loss and any problems or difficulties they face when walking around our streetscapes
- Clinical assessment and retinal imaging have not been shown in conjunction with navigating of the built environment before

- From the results it is clear that many clinical parameters such as visual fields, dark adaptation and amount of pathology present impact a persons ability to navigate independently
- It adds further context into navigating with impairment and disability in general. It also shows that similar barriers are faced by many disabilities and impairments

6.10 Future Recommendations

Promote knowledge and raise awareness

- Presenting at conferences, especially multidisciplinary conferences, patient engagement days etc. to raise awareness of the issue
- Offer to be included in training days, including for companies such as Translink, Department of Communities etc. to promote knowledge around living with a visual impairment (some participants have already agreed to help with this)
- Try to increase visibility of the subject with MPs and government organisations who could help make changes for the better
- Create CPD for architects and training for planners specifically around moving around streetscapes with a visual impairment

Policy/Guidance

- Create a policy/guidance document from the visually impaired perspective on navigating towns and cities with barriers and aids described and explicit examples.
- Push to implement mandatory walkarounds with stakeholders (especially those with disabilities) in the consultation process
- Create a leaflet to inform teachers and education workers on diabetes and diabetes management

Future projects?

- Look into autofluorescence in people with diabetes and no/ little retinopathy following the interesting results of this study

References

(RTPI), R. T. P. I. 2020. DEMENTIA AND TOWN PLANNING. www.rtpi.org: RTPI.

ABACUS. 2021. *Guide Dogs for the Blind Association IOM & Abacus* [Online]. [Accessed].

ABRAMOFF, M. D., GARVIN, M. K. & SONKA, M. 2010. Retinal imaging and image analysis. *IEEE Reviews in Biomedical Engineering,* 3**,** 169-208.

ACOUSTICAL SOCIETY OF AMERICA 2017. Exploring the potential of human echolocation. Neuroscience News.

ADHI, M., SILVA, F. Q., LANG, R., SEBALLOS, R., SUKOL, R. B., FEINLEIB, S. & SINGH, R. P. 2017. Non-mydriatic ultra-widefield imaging compared with single-field imaging in the evaluation of peripheral retinal pathology. *Ophthalmic Surgery Lasers and Imaging Retina,* 48**,** 962-968.

AFACAN, Y. & AFACAN, S. O. 2011. Rethinking social inclusivity: Design strategies for cities. *Proceedings of the Institution of Civil Engineers: Urban Design and Planning,* 164**,** 93-105.

AIDA E. AFROOZ, TOKTAM HANAEE & PAROLIN, B. 2012. Wayfinding Performance of Visually Impaired Pedestrians in an Urban Area. *REAL CORP 2012.*

AIZAWA, S., MITAMURA, Y., BABA, T., HAGIWARA, A., OGATA, K. & YAMAMOTO, S. 2009. Correlation between visual function and photoreceptor inner/outer segment junction in patients with retinitis pigmentosa. *Eye,* 23**,** 304-308.

ALEXANDER, S. M., HUTCHINSON, C., SIMPSON, D., SILVESTRI, V., STEVENSON, M., CHEN, R., WENG, F. & SILVESTRI, G. 2014. REASSESS (REtinal ASSESment Scale) - A clinical grading scale for Inherited Retinal Degenerations. *IOVS,* 55.

ALLAN, B. & SAMPSON, M. 2013. Admissions avoidance and diabetes: guidance for clinical commissioning groups and clinical teams.

ALLIANCE FOR AGING RESEARCH TEAM 1999. Independence for Older Americans: An investment for our nation's future. Washington D.C: Alliance for Aging Research.

APUSHKIN, M. A., FISHMAN, G. A., ALEXANDER, K. R. & SHAHIDI, M. 2007. Retinal thickness and visual thresholds measured in patients with retinitis pigmentosa. *Retina-the Journal of Retinal and Vitreous Diseases,* 27**,** 349-357.

AREND, O., REMKY, A., EVANS, D., STUBER, R. & HARRIS, A. 1997. Contrast sensitivity loss is coupled with capillary dropout in patients with diabetes. *Investigative Ophthalmology & Visual Science,* 38**,** 1819-1824.

ARNSTEIN, S. R. 1969. A Ladder Of Citizen Participation. *Journal of the American Institute of Planners,* 35**,** 216-224.

BAO, Y. C. K., YAN, Y., GORDON, M., MCGILL, J. B., KASS, M. & RAJAGOPAL, R. 2019. Visual Field Loss in Patients With Diabetes in the Absence of Clinically-Detectable Vascular Retinopathy in a Nationally Representative Survey. *Investigative Ophthalmology & Visual Science,* 60**,** 4711-4716.

BARLAND, M. 2007. Incorporating user experience when developing assistive technology: the case of the I-Cane. *University of Oslo/Universiteit Maastrich*.
BARNARD-KELLY, K. D., SPEIGHT, J. & SKINNER, T. C. 2008. Quality of life and impact of continuous subcutaneous insulin infusion for children and their parents. *Practical Diabetes International,* 25**,** 278-283.
BARNARD, K. D., LLOYD, C. E. & SKINNER, T. C. 2007. Systematic literature review: quality of life associated with insulin pump use in Type 1 diabetes. *Diabetic Medicine,* 24**,** 607-617.
BARNARD, K. D. & SKINNER, T. 2008. Cross-sectional study into quality of life issues surrounding insulin pump use in type 1 diabetes. *Practical Diabetes International,* 25**,** 194-200.
BASHA, R. 2015. Disability and Public Space – Case Studies of Prishtina and Prizren. *International Journal of Contemporary Architecture "The New ARCH"*
BELFAST HEALTHY CITIES 2014. Walkability Assessment for Healthy Ageing Belfast Health Cities World Health Organisation
BELLEMO, V., YIP, M. Y. T., XIE, Y. C., LEE, X. Q., NGUYEN, Q. D., HAMZAH, H., HO, J. Y., LIM, G., XU, D. J., LEE, M. L., HSU, W., GARCIA-FRANCO, R., MENON, G., LAMOUREUX, E., CHENG, C. Y., WONG, T. Y. & TING, D. S. W. 2019. Artificial Intelligence Using Deep Learning in Classifying Side of the Eyes and Width of Field for Retinal Fundus Photographs. *Computer Vision - Accv 2018 Workshops,* 11367**,** 309-315.
BENGTSSON, B., HEIJL, A. & AGARDH, E. 2005. Visual fields correlate better than visual acuity to severity of diabetic retinopathy. *Diabetologia,* 48**,** 2494-2500.
BENNETT, P. G., MISRA, A., NEWSOM, W. & FLANAGAN, D. 2009. Registration of visual impairment due to diabetic retinopathy in a subpopulation of Cambridgeshire. *Clinical Ophthalmology (Auckland, N.Z.),* 3**,** 75-79.
BLACK, M. H., MCGARRY, S., CHURCHILL, L., D'ARCY, E., DALGLEISH, J., NASH, I., JONES, A., TSE, T. Y., GIBSON, J., BOLTE, S. & GIRDLER, S. 2022. Considerations of the built environment for autistic individuals: A review of the literature. *Autism,* 26**,** 1904-1915.
BOLZ, M., SCHMIDT-ERFURTH, U., DEAK, G., MYLONAS, G., KRIECHBAUM, K., SCHOLDA, C. & VIENN, D. R. R. G. 2009. Optical Coherence Tomographic Hyperreflective Foci A Morphologic Sign of Lipid Extravasation in Diabetic Macular Edema. *Ophthalmology,* 116**,** 914-920.
BONE, H. 2019. Improving diabetic eye screening uptake in the young.
BOURKIZA, R., SUBASH, M., QATARNEH, D., DACOSTA, J., BUNCE, C. & PETO, T. 2014. Barriers to sight impairment certification in the UK: the example of a population with diabetes in East London. *BMC Ophthalmol,* 14**,** 99.
BRADLEY, C. & SPEIGHT, J. 2002. Patient perceptions of diabetes and diabetes therapy: assessing quality of life. *Diabetes-Metabolism Research and Reviews,* 18**,** S64-S69.

BRADLEY, C., TODD, C., GORTON, T., SYMONDS, E., MARTIN, A. & PLOWRIGHT, R. 1999. The development of an individualized questionnaire measure of perceived impact of diabetes on quality of life: the ADDQoL. *Quality of Life Research,* 8**,** 79-91.
BRAUN, V. & CLARKE, V. 2008. Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3**,** 77-101.
BRITTAIN, D. R., GYURCSIK, N. C., MCELROY, M. & HILLARD, S. A. 2011. General and arthritis-specific barriers to moderate physical activity in women with arthritis. *Womens Health Issues,* 21**,** 57-63.
BROWN, G. C., BROWN, M. M. & SHARMA, S. 2018. The Five Senses: A Patient Preference-Based Comparative Analysis. *Clinical Research in Ophthalmology,* 1**,** 1 - 8.
BROWN, G. C., BROWN, M. M., SHARMA, S., BROWN, H., GOZUM, M. & DENTON, P. 2000. Quality of life associated with diabetes mellitus in an adult population. *Journal of Diabetes and Its Complications,* 14**,** 18-24.
BROWNSON, R. C., HOEHNER, C. M., DAY, K., FORSYTH, A. & SALLIS, J. F. 2009. Measuring the built environment for physical activity: state of the science. *Am J Prev Med,* 36**,** S99-123 e12.
BUNCE, C. & WORMALD, R. 2006. Leading causes of certification for blindness and partial sight in England & Wales. *Bmc Public Health,* 6.
BURTT, D. 2014. Road Safety Audit Tool for Pedestrians who are Vision Impaired. Melborune, Australia Vision Australia (Victoria).
BYBERG, S., VISTISEN, D., DIAZ, L., CHARLES, M. H., HAJARI, J. N., VALERIUS, M., JUUL, E., JORGENSEN, M. E. & LUND-ANDERSEN, H. 2019. Optos wide-field imaging versus conventional camera imaging in Danish patients with type 2 diabetes. *Acta Ophthalmol,* 97**,** 815-820.
CAMPION, J., GREENLAUGH, C. & KNIGHT, J. 2003. Mind the Gap - Leonard Cheshire's Social Exclusion Report 2003. Leonard Cheshire Trust.
CAMPISI, T., IGNACCOLO, M., INTURRI, G., TESORIERE, G. & TORRISI, V. 2021. Evaluation of walkability and mobility requirements of visually impaired people in urban spaces. *Research in Transportation Business and Management,* 40.
CANAVAN, Y. M., JACKSON, A. J. & STEWART, A. 1997. Visual impairment in Northern Ireland. *Ulster Medical Journal,* 66**,** 92-95.
CAROLINA EYECARE. 2021. *DIABETIC RETINOPATHY* [Online]. Available: https://carolinaeyecare.com/service/diabetic-retinopathy/ [Accessed].
CASSIN, B. & RUBIN, M. L. 2012. Dictionary of Eye Terminology. *Optos.* 6 ed.: Triad Communications, Inc.
CENTRAL ASSOCIATION FOR THE BLIND AND VISUALLY IMPAIRED. 2020. *What Are The Different Types of White Canes?* [Online]. cabvi.org: cabvi. Available: https://www.cabvi.org/articles/what-are-the-different-types-of-white-canes/ [Accessed 09/06 2021].
CETIN, E. N., ZENCIR, M., FENKCI, S., AKIN, F. & YILDIRIM, C. 2013. Assessment of awareness of diabetic retinopathy and utilization of eye care services among Turkish diabetic patients. *Primary Care Diabetes,* 7**,** 297-302.

CHANTELAU, E., SCHIFFERS, T., SCHUTZE, J. & HANSEN, B. 1997. Effect of patient-selected intensive insulin therapy on quality of life. *Patient Education and Counseling,* 30**,** 167-173.

CHEW, E. Y., FERRIS, F. L., CSAKY, K. G., MURPHY, R. P., AGRON, E., THOMPSON, D. J. S., REED, G. F. & SCHACHAT, A. P. 2003. The long-term effects of laser photocoagulation treatment in patients with diabetic retinopathy - The early treatment diabetic retinopathy follow-up study. *Ophthalmology,* 110**,** 1683-1689.

CHILDS, C., BOAMPONG, D., ROSTRON, H., MORGAN, K., ECCLESHALL, T. & TYLER, N. 2009. Effective Kerb Heights for Blind and

Partially Sighted People. University College London

CLARKE, P., AILSHIRE, J. A., BADER, M., MORENOFF, J. D. & HOUSE, J. S. 2008. Mobility disability and the urban built environment. *Am J Epidemiol,* 168**,** 506-13.

CLARKE, P. J., AILSHIRE, J. A., NIEUWENHUIJSEN, E. R. & DE KLEIJN - DE VRANKRIJKER, M. W. 2011. Participation among adults with disability: The role of the urban environment. *Social Science and Medicine,* 72**,** 1674-1684.

COMMISION FOR ARCHITECTURE AND THE BUILT ENVIRONMENT 2006. The principles of inclusive design. (They include you.). London.

CORE NDESP TEAM 2012. Diabetic Eye Screening : Feature Based Grading Forms.

COUET, C., GENTON, P., POINTEL, J. P., LOUIS, J., GROSS, P., SAUDAX, E., DEBRY, G. & DROUIN, P. 1985. The Prevalence of Retinopathy Is Similar in Diabetes-Mellitus Secondary to Chronic-Pancreatitis with or without Pancreatectomy and in Idiopathic Diabetes-Mellitus. *Diabetes Care,* 8**,** 323-328.

CRIADO-PEREZ, C. 2020. *Invisible Women: Exposing Data Bias in a World Designed for Men* Penguin.

CULLEN, G. 1961. *Townscape,* London, Architectural Place.

CURIOSITY 2017. Some Blind People Can Echolocate, and New Research Could Help More Learn. *Curiosity.com.*

CURL, A., THOMPSON, C. W., ASPINALL, P. & ORMEROD, M. 2016. Developing an audit checklist to assess outdoor falls risk. *Proc Inst Civ Eng Urban Des Plan,* 169**,** 138-153.

CUSHLEY, L., GALWAY, N. & PETO, T. 2022. The unseen barriers of the built environment: navigation for people with visual impairment. *Town Planning Review*.

CUSHLEY, L., JAMISON, C., QUINN, N., BOWLES, R., PETO, T. & TEAM, N. 2019. Diabetic Eye Screening in Northern Ireland. *Diabetic Eye Journal,* September 2019**,** 13-16.

CUSHLEY, L. N., CURRAN, K., QUINN, N. B., BELL, A., MULDREW, A., GRAHAM, U. M., MCCANCE, D. R., WEN, Q. & PETO, T. 2021. Diabetic Retinopathy Screening Programme: Attendance, Barriers and Enablers amongst Young People with Diabetes Mellitus Aged 12–26 Years. *International Journal of Translational Medicine,* 1**,** 154-162.

DAVIDOV, E., BREITSCHEIDEL, L., CLOUTH, J., REIPS, M. & HAPPICH, M. 2009. Diabetic retinopathy and health-related quality of life. *Graefes Arch Clin Exp Ophthalmol,* 247**,** 267-72.
DEBONO, M. & CACHIA, E. 2007. The impact of diabetes on psychological well being and quality of life. The role of patient education. *Psychology, Health & Medicine* 12**,** 545-555.
DEPARTMENT OF THE ENVIRONMENT FOR NORTHERN IRELAND 2015. Strategic Planning Policy Statement for Northern A Strategic Planning Ireland (SPPS).
DEPARTMENT OF TRANSPORT 2007. *Manual for Streets* Thomas Telford Publishing.
DIABETES CARE AND RESEARCH IN EUROPE: THE SAINT VINCENT DECLARATION 1990. Diabetes Care and Research in Europe: The Saint Vincent Declaration. *Diabetic Medicine,* 7**,** 360-360.
DIABETES UK 2017. 15 Healthcare Essentials. *In:* UK, D. (ed.).
DIABETES UK. 2018. *Number of people with diabetes in northern ireland increases by 62.5% in a decade* [Online]. Diabetes UK Website: Diabetes UK. Available: https://www.diabetes.org.uk/in_your_area/n_ireland/news/number-of-people-living-with-diabetes-jumps [Accessed 05 2021].
DIABETES UK 2019. Diabetes UK Facts and Figures 2019. *Diabetes UK.* Diabetes UK.
DIABETES.CO.UK. 2019a. *Cataracts and Diabetes* [Online]. Diabetes.co.uk. Available: https://www.diabetes.co.uk/diabetes-complications/cataracts.html [Accessed 09/06 2021].
DIABETES.CO.UK 2019b. Screening for Diabetes Complications.
DILEO, M. A. S., CAPUTO, S., FALSINI, B., PORCIATTI, V., MINNELLA, A., GRECO, A. V. & GHIRLANDA, G. 1992. Nonselective Loss of Contrast Sensitivity in Visual-System Testing in Early Type-I Diabetes. *Diabetes Care,* 15**,** 620-625.
DOSSO, A. A., BONVIN, E. R., MOREL, Y., ASSAL, J. P. & LEUENBERGER, P. M. 1996. Risk factors associated with contrast sensitivity loss in diabetic patients. *Graefes Archive for Clinical and Experimental Ophthalmology,* 234**,** 300-305.
DREXLER, W., SATTMANN, H., HERMANN, B., KO, T. H., STUR, M., UNTERHUBER, A., SCHOLDA, C., FINDL, O., WIRTITSCH, M., FUJIMOTO, J. G. & FERCHER, A. F. 2003. Enhanced visualization of macular pathology with the use of ultrahigh-resolution optical coherence tomography. *Arch Ophthalmol,* 121**,** 695-706.
DUPAS, B., MINVIELLE, W., BONNIN, S., COUTURIER, A., ERGINAY, A., MASSIN, P., GAUDRIC, A. & TADAYONI, R. 2018. Association Between Vessel Density and Visual Acuity in Patients With Diabetic Retinopathy and Poorly Controlled Type 1 Diabetes. *Jama Ophthalmology,* 136**,** 721-728.
ENOCH, J., MCDONALD, L., JONES, L., JONES, P. R. & CRABB, D. P. 2019. Evaluating Whether Sight Is the Most Valued Sense. JAMA Ophthalmology.
ERDTMAN, E., RASSMUS-GRÖHN, K. & HEDVALL, P.-O. 2021. Universal Design as Guiding, Striving and Unifying: A Qualitative Study about how Universal Design is Understood, Practised and Realised in

Contemporary Sweden. *Scandanavian Journal of Disability Research,* 23**,** 158–16.
ERIKSSON, U. & ALM, A. 2009. Macular thickness decreases with age in normal eyes: a study on the macular thickness map protocol in the Stratus OCT. *British Journal of Ophthalmology,* 93**,** 1448-1452.
EWALD, N., KAUFMANN, C., RASPE, A., KLOER, H. U., BRETZEL, R. G. & HARDT, P. D. 2012. Prevalence of diabetes mellitus secondary to pancreatic diseases (type 3c). *Diabetes-Metabolism Research and Reviews,* 28**,** 338-342.
FARIA, J., LOPES, S., FERNANDES, H., MARTINS, P. & BARROSO, J. 2010. Electronic white cane for blind people navigation assistance. *2010 World Automation Congress, WAC 2010.* Kobe, Japan: IEEE.
FENWICK, E. K., PESUDOVS, K., KHADKA, J., DIRANI, M., REES, G., WONG, T. Y. & LAMOUREUX, E. L. 2012. The impact of diabetic retinopathy on quality of life: Qualitative findings from an item bank development project. *Quality of Life Research* 21**,** 1771-1782.
FIGHT FOR SIGHT. 2019. *Facts about sight loss* [Online]. fightforsight.org.uk. Available: https://www.fightforsight.org.uk/about-the-eye/facts-about-sight-loss/ [Accessed 09/06 2021].
FLETCHER, V. 2002. Universal design, human-centred design for the 21st century. *Design.*
FONG, D. S., AIELLO, L. P., FERRIS, F. L. & KLEIN, R. 2004. Diabetic retinopathy. *Diabetes Care,* 27**,** 2540-2553.
FOULKE, E. 1983. Spatial Ability and the Limitations of Perceptual Systems. *In:* PICKJR., H. L. & ACREDOLO, L. P. (eds.) *Spatial Orientation: Theory, Research, and Application.* 1 ed. Boston, MA: Springer.
FOUNDATION FIGHTING BLINDNESS 2021. Retinitis Pigmentosa Research Advances fightingblindness.org.
FOWLER, M. J. 2008. Microvascular and macrovascular complications of diabetes. *Clinical Diabetes,* 26**,** 77-82.
FRAGIOTTA, S., ABDOLRAHIMZADEH, S., DOLZ-MARCO, R., SAKURADA, Y., GAL-OR, O. & SCUDERI, G. 2021. Significance of Hyperreflective Foci as an Optical Coherence Tomography Biomarker in Retinal Diseases: Characterization and Clinical Implications. *Journal of Ophthalmology,* 2021.
FRANCK, K. A. 2007. From the Body. *In:* CASTLE, H. & PORTER, L. (eds.) *Architecture from the Inside Out: From the Body, the Senses , the Site, and the Community.* Wiley-Academy.
FUNNELL, M. M. 2006. The Diabetes Attitudes, Wishes, and Needs (DAWN) Study. *Clinical Diabetes,* 24**,** 154-155.
GALLAGHER, B. A. M., HART, P. M., O'BRIEN, C., STEVENSON, M. R. & JACKSON, A. J. 2011. Mobility and access to transport issues as experienced by people with vision impairment living in urban and rural Ireland. *Disability and Rehabilitation,* 33**,** 979-988.
GHAFOUR, I. M., ALLAN, D. & FOULDS, W. S. 1983. Common Causes of Blindness and Visual Handicap in the West of Scotland. *British Journal of Ophthalmology,* 67**,** 209-213.
GODSCHALK, D. R. & MILLS, W. E. 1966. A Collaborative Approach to Planning Through Urban Activities. *Journal of the American Institute of Planners,* 32**,** 86-95.

GORDON-BENNETT, P., MISRA, A., NEWSOM, W. & FLANAGAN, D. 2009. Registration of visual impairment due to diabetic retinopathy in a subpopulation of Cambridgeshire. *Clinical Ophthalmology,* 3**,** 75-79.
GORDON, D., MACK, J., LANSLEY, S., MAIN, G., NANDY, S., PATSIOS, D., POMATI, M. & PSE TEAM 2013. The Impoverishment of the UK; PSE UK first result : Living Standards. *Econ Soc Res Counc***,** 1-18.
GREGG, E. W., BECKLES, G. L., WILLIAMSON, D. F., LEVEILLE, S. G., LANGLOIS, J. A., ENGELGAU, M. M. & NARAYAN, K. M. 2000. Diabetes and physical disability among older U.S. adults. *Diabetes Care,* 23**,** 1272-1277.
GREGORY-EVANS, K., PENNESI, M. E. & WELEBER, R. G. 2013. Retinitis Pigmentosa and Allied Disorders. *In:* RYAN, S. J. (ed.) *Retina.* Fifth ed. China: Elsevier Saunders.
GRIEW, P., HILLSDON, M., FOSTER, C., COOMBES, E., JONES, A. & WILKINSON, P. 2013. Developing and testing a street audit tool using Google Street View to measure environmental supportiveness for physical activity. *International Journal of Behavioral Nutrition and Physical Activity* 10.
GUIDE DOGS 2010. Inclusive Streets: Design principles for blind and partially sighted people. Guide Dogs.
GUIDE DOGS, CATAPULT FUTURE CITIES & MICROSOFT 2014. Cities Unlocked.
GUIDE DOGS UK. 2021. *Applying for a guide dog* [Online]. Available: https://www.guidedogs.org.uk/faqs/guide-dogs/ [Accessed 9/6 2021].
GULLIFORD, M. C., DODHIA, H., CHAMLEY, M., MCCORMICK, K., MOHAMED, M., NAITHANI, S. & SIVAPRASAD, S. 2010. Socio-economic and ethnic inequalities in diabetes retinal screening. *Diabetic Medicine,* 27**,** 282-288.
GULLO, L., PARENTI, M., MONTI, L., PEZZILLI, R. & BARBARA, L. 1990. Diabetic-Retinopathy in Chronic-Pancreatitis. *Gastroenterology,* 98**,** 1577-1581.
GUSTAFSON-PEARCE, O., BILLETT, E. & CECELJA, F. 2005. Perceptual impact of environmental factors in sighted and visually impaired individuals. *The British Journal of Visual Impairment,* 23**,** 25-30.
HABTAMU, E., BASTAWROUS, A., BOLSTER, N. M., TADESSE, Z., CALLAHAN, E. K., GASHAW, B., MACLEOD, D. & BURTON, M. J. 2019. Development and Validation of a Smartphone-based Contrast Sensitivity Test. *Translational Vision Science & Technology,* 8.
HAHN, H. 1986. Disability and the Urban-Environment - a Perspective on Los-Angeles. *Environment and Planning D-Society & Space,* 4**,** 273-288.
HAMILTON-BAILIE, B. 2008. Shared Space: Reconciling People, Places and Traffic. *Built Environment,* 34**,** 161-181.
HAMILTON-BAILLIE, B. 2008. Towards shared space. *Urban Design International,* 13**,** 130-138.
HANSEN, M. B., ABRAMOFF, M. D., FOLK, J. C., MATHENGE, W., BASTAWROUS, A. & PETO, T. 2015. Results of Automated Retinal Image Analysis for Detection of Diabetic Retinopathy from the Nakuru Study, Kenya. *Plos One,* 10.

HARDING, S., GREENWOOD, R., ALDINGTON, S., GIBSON, J., OWENS, D., TAYLOR, R., KOHNER, E., SCANLON, P., LEESE, G. & DIS, D. R. G. 2003. Grading and disease management in national screening for diabetic retinopathy in England and Wales. *Diabetic Medicine,* 20**,** 965-971.

HARRIS, M. & LACEY, L. 2014. Ensuring the effective delivery of diabetic eye screening for children and young people in England. *Diabetes Care for Children & Young People,* 3**,** 59-63.

HART, P. A., BELLIN, M. D., ANDERSEN, D. K., BRADLEY, D., CRUZ-MONSERRATE, Z., FORSMARK, C. E., GOODARZI, M. O., HABTEZION, A., KORC, M., KUDVA, Y. C., PANDOL, S. J., YADAV, D., CHARI, S. T. & CONSORTIUM FOR THE STUDY OF CHRONIC PANCREATITIS, D., AND PANCREATIC CANCER(CPDPC), 2016. Type 3c (pancreatogenic) diabetes mellitus secondary to chronic pancreatitis and pancreatic cancer. *Lancet Gastroenterology Hepatology,* 1**,** 226-237.

HAVIK, E. M., STEYVERS, F. J. J. M., KOOIJMAN, A. C., MELIS-DANKERS, B. J. M. & KOOIJMAN, A. C. 2015. Accessibility of shared space for visually impaired persons: A comparative field study. *British Journal of Visual Impairment,* 33**,** 96-110.

HAYEEMS, R. Z., GELLER, G., FINKELSTEIN, D. & FADEN, R. R. 2005. How patients experience progressive loss of visual function: a model of adjustment using qualitative methods. *British Journal of Ophthalmology,* 89**,** 615-620.

HEIDELBERG ENGINEERING Interpreting MultiColor Images in 3 Steps. *In:* HEIDELBERG ENGINEERING (ed.).

HENRICSSON, M. & HEIJL, A. 1994a. The effect of panretinal laser photocoagulation on visual acuity, visual fields and on subjective visual impairment in preproliferative and early proliferative diabetic retinopathy. *Acta Ophthalmol (Copenh),* 72**,** 570-5.

HENRICSSON, M. & HEIJL, A. 1994b. Visual-Fields at Different Stages of Diabetic-Retinopathy. *Acta Ophthalmologica,* 72**,** 560-569.

HENSHAWS. 2017. *What do tactile pavements tell us?* [Online]. henshaws.org.uk. Available: https://www.henshaws.org.uk/tactile-pavements-tell-us/#:~:text=Corduroy%20tactile%20paving%20comprises%20rounded,level%20crossing%20or%20a%20ramp. [Accessed 06 2021].

HEYLIGHEN, A., VAN DER LINDEN, V. & VAN STEENWINKEL, I. 2017. Ten questions concerning inclusive design of the built environment. *Building and Environment,* 114**,** 507-217.

HIDAYAT, A. A. & FINE, B. S. 1985. Diabetic choroidopathy. Light and electron microscopic observations of seven cases. *Ophthalmology,* 92**,** 512-22.

HILLEMANN, P. 2016. Art Museum Tours For Visitors Who Are Blind. Available: https://americanart.si.edu/blog/eye-level/2016/09/317/art-museum-tours-visitors-who-are-blind [Accessed 09/06/2021].

HIPWELL, A. E., STURT, J., LINDENMEYER, A., STRATTON, I., GADSBY, R., O'HARE, P. & SCANLON, P. H. 2014. Attitudes, access and anguish: a qualitative interview study of staff and patients' experiences of diabetic retinopathy screening. *Bmj Open,* 4.

HOGG, R. E., WRIGHT, D. M., DOLZ-MARCO, R., GRAY, C., WAHEED, N., TEUSSINK, M. M., NASKAS, T., PERRAIS, J., DAS, R., QUINN, N., BONTZOS, G., NICOLAOU, C., ANNAM, K., YOUNG, I. S., KEE, F., MCGUINESS, B., MCKAY, G., MCGILLIVRAY, T., PETO, T. & CHAKRAVARTHY, U. 2021. Quantitative Parameters from OCT Angiography in Patients with Diabetic Retinopathy and in Those with Only Peripheral Retinopathy Compared with Control Participants. *Ophthalmology Science,* 1.

HOMMEL, E., OLSEN, B., BATTELINO, T., CONGET, I., SCHUTZ-FUHRMANN, I., HOOGMA, R., SCHIERLOH, U., SULLI, N., GOUGH, H., CASTANEDA, J., DE PORTU, S., BOLINDER, J. & GRP, S. S. 2014. Impact of continuous glucose monitoring on quality of life, treatment satisfaction, and use of medical care resources: analyses from the SWITCH study. *Acta Diabetologica,* 51**,** 845-851.

HONG, T., MITCHELL, P., BURLUTSKY, G., SAMARAWICKRAMA, C. & WANG, J. J. 2014. Visual impairment and the incidence of falls and fractures among older people: Longitudinal findings from the blue mountains eye study. *Investigative Ophthalmology and Visual Science,* 55**,** 7589-7593.

HOOD, D. C., RAMACHANDRAN, R., HOLOPIGIAN, K., LAZOW, M., BIRCH, D. G. & GREENSTEIN, V. C. 2011. Method for deriving visual field boundaries from OCT scans of patients with retinitis pigmentosa. *Biomedical Optics Express,* 2**,** 1106-1114.

HOOGMA, R. P. L. M., HAMMOND, P. J., GOMIS, R., KERR, D., BRUTTOMESSO, D., BOUTER, K. P., WIEFELS, K. J., DE LA CALLE, H., SCHWEITZER, D. H., PFOHL, M., TORLONE, E., KRINELKE, L. G., BOLLI, G. B. & GRP, -. N. S. 2006. Comparison of the effects of continuous subcutaneous insulin infusion (CSII) and NPH-based multiple daily insulin injections (MDI) on glycaemic control and quality of life: results of the 5-nations trial. *Diabetic Medicine,* 23**,** 141-147.

HUANG, C. Y., WU, C. K. & LIU, P. Y. 2022. Assistive technology in smart cities: A case of street crossing for the visually-impaired. *Technology in Society,* 68.

IMRIE, R. 2000a. Disability and discourses of mobility and movement. *Environment and Planning A,* 32**,** 1641-1656.

IMRIE, R. 2000b. Disabling Environments and the Geography of Access Policies and Practices. *Disability and Society,* 15**,** 5-24.

IMRIE, R. 2012. Auto-disabilities: The case of shared space environments. *Environment and Planning A,* 44**,** 2260-2277.

IMRIE, R. & KUMAR, M. 1998. Focusing on disability and access in the built environment. *Disability and Society,* 13**,** 357-374.

IMRIE, R. & LUCK, R. 2014. Designing inclusive environments: rehabilitating the body and the relevance of universal design. *Disability and Rehabilitation,* 36**,** 1315-1319.

IMTAC 2008. Guidelines for effective consultation with older people and disabled people.

IMTAC 2020. Basic guidelines for the development of inclusive walking, wheeling1 and cycling infrastructure in response to COVID-19. *In:* IMTAC (ed.). www.accessibletravelni.org: IMTAC.

INCLUSION LONDON 2015. The Social Model of Disability: FactSheet London.
INTERNATIONAL DIABETES FEDERATION 2019. IDF Diabetes Atlas. 9 ed.: International Diabetes Federation.
INTERNATIONAL DIABETES FEDERATION. 2020. *What is diabetes* [Online]. Available: https://www.idf.org/aboutdiabetes/what-is-diabetes.html [Accessed 09/06 2021].
JACKSON, A. J., CUSHLEY, L., MCCANN, R., GALLAGHER, M., WITHEROW, J. & MOUTRAY, T. 2020. The certification of vision impairment: A regional 21st century perspective. *British Journal of Visual Impairment*.
JACKSON, P. 2021. Colourful pedestrian crossings letter to ministers. https://accessassociation.co.uk/2021/09/06/colourful-pedestrian-crossings-letter-to-ministers/: The Access Association.
JANKOVEC, Z., HAHN, M., GRUNDER, S., LACIGOVA, S., CECHUROVA, D., KRCMA, M., ZOUREK, M., HALADOVA, I. & RUSAVY, Z. 2010. Analysis of continuous patient data from the Czech National Register of patients with type 1 and type 2 diabetes using insulin pump therapy. *Diabetes Research and Clinical Practice,* 87**,** 219-223.
JENKINS, G. R., YUEN, H. K. & VOGTLE, L. K. 2015. Experience of multisensory environments in public space among people with visual impairment. *International Journal of Environmental Research and Public Health,* 12**,** 8644-8657.
JOHNSON, V. & PETRIE, H. 1998. Travelling safely: The problems and concerns of blind pedestrians. *British Journal of Visual Impairment,* 16**,** 27-31.
JONES, T. & JAIN, J. 2006. Examining the experiences of sight-impaired travellers: The next station stop? *British Journal of Visual Impairment,* 24**,** 141-144.
KANSKI, J. J. & BOWLING, B. 2011. *Clinical Ophthalmology*.
KASHIM, R. M., NEWTON, P. & OJO, O. 2018. Diabetic retinopathy screening: A systematic review on patients' non-attendance. *International Journal of Environmental Research and Public Health,* 15.
KIRKEBY, I. M. 2015. Accessible Knowledge—Knowledge on Accessibility. *Journal of Civil Engineering and Architecture,* 9**,** 534-546.
KISS, S. & BERENBERG, T. L. 2014. Ultra widefield fundus imaging for diabetic retinopathy. *Current Diabetes Reports,* 14.
KITCHIN, R. M., JACOBSON, R. D., GOLLEDGE, R. G. & BLADES, M. 1998. Belfast without sight: Exploring geographies of blindness. *Irish Geography,* 31**,** 34-46.
KLEIBUSCH, K. 2018. Wayfinding & Dementia: How Design Can Improve Navigation Among Older Adults in Assisted-Living Facilities. *SPNHA Review* 14**,** 25-42.
KLEIN, R., KLEIN, B. E. K., MOSS, S. E., DAVIS, M. D. & DEMETS, D. L. 1984. The Wisconsin Epidemiologic Study of Diabetic Retinopathy: III. Prevalence and Risk of Diabetic Retinopathy When Age at Diagnosis is 30 or More Years. *Archives of Ophthalmology,* 102**,** 527-532.

KLEIN, R., MEUER, S. M., MOSS, S. E. & KLEIN, B. E. 1995. Retinal microaneurysm counts and 10-year progression of diabetic retinopathy. *Arch Ophthalmol,* 113**,** 1386-91.
KOLB, H. 2005. Simple Anatomy of the Retina. *Webvision: The Organization of the Retina and Visual System*.
LAKE, A., BROWNE, J. L., REES, G. & SPEIGHT, J. 2017. What factors influence uptake of retinal screening among young adults with type 2 diabetes? A qualitative study informed by the theoretical domains framework. *J Diabetes Complications,* 31**,** 997-1006.
LAKE, A. J., HATELEY-BROWNE, J. L., REES, G. & SPEIGHT, J. 2020. Effect of a tailored leaflet to promote diabetic retinopathy screening among young adults with type 2 diabetes: a randomised controlled trial. *Bmc Ophthalmology,* 20.
LAM, D. W. & LEROITH, D. 2012. The worldwide diabetes epidemic. *Current Opinion in Endocrinology, Diabetes and Obesity,* 19**,** 93-96.
LAMOUREUX, E. L., HASSELL, J. B. & KEEFFE, J. E. 2004. The impact of diabetic retinopathy on participation in daily living. *Archives of Ophthalmology,* 122**,** 84-88.
LANCEFIELD, N. 2021. Belfast fifth worst city in UK for traffic congestion. *Belfast Telegraph*.
LANGELAAN, M., DE BOER, M. R., VAN NISPEN, R. M. A., WOUTERS, B., MOLL, A. C. & VAN RENS, G. H. M. B. 2007. Impact of visual impairment on quality of life: A comparison with quality of life in the general population and with other chronic conditions. *Ophthalmic Epidemiology,* 14**,** 119-126.
LAWSON, A., ESKYTĖ, I. & ORCHARD, M. 2022. Pedestrians with Disabilities and Town and City Streets: From Shared to Inclusive Space? *The Journal of Public Space,* 7**,** 41-62.
LEE, J. & ROSEN, R. 2015. Comparison of UWF FA Imaging Modalities. *Retinal Physician,* 12**,** 30-32,34,35.
LEE, W. J., SOBRIN, L., KANG, M. H., SEONG, M., KIM, Y. J., YI, J. H., MILLER, J. W. & CHO, H. Y. 2014. Ischemic diabetic retinopathy as a possible prognostic factor for chronic kidney disease progression. *Eye,* 28**,** 1119-1125.
LEGOOD, R., SCUFFHAM, P. & CRYER, C. 2002. Are we blind to injuries in the visually impaired? A review of the literature. *Injury Prevention,* 8**,** 155-160.
LEHRER, J. 2011. Navigating Cities, for the Blind. https://www.wired.com/2011/09/st-qafolska/.
LEWIS, K. 2011. I wish someone had told me ... . *Community Eye Heal J. ,* 24**,** 10-11.
LEWIS, K., PATEL, D., YORSTON, D. & CHARTERIS, D. 2007. A qualitative study in the United Kingdom of factors influencing attendance by patients with diabetes at ophthalmic outpatient clinics. *Ophthalmic Epidemiology,* 14**,** 375-380.
LIAN, J. X., MCGHEE, S. M., GANGWANI, R. A., LAM, C. L. K., YAP, M. K. H. & WONG, D. S. H. 2018. Awareness of diabetic retinopathy and its association with attendance for systematic screening at the public primary care setting: a cross-sectional study in Hong Kong. *Bmj Open,* 8.

LIGDA, G., PLOUBIDIS, D., FOTELI, S., KONTOU, P. I., NIKOLAOU, C. & TENTOLOURIS, N. 2019. Quality of life in subjects with type 2 diabetes mellitus with diabetic retinopathy: A case-control study. *Diabetes Metab Syndr,* 13**,** 947-952.

LIN, B. S., LEE, C. C. & CHIANG, P. Y. 2017a. Simple Smartphone-Based Guiding System for Visually Impaired People. *Sensors,* 17.

LIN, J. C. & YU, J. H. 2012. Assessment of quality of life among Taiwanese patients with visual impairment. *Journal of the Formosan Medical Association,* 111**,** 572-579.

LIN, S. Y., GUPTA, B., JAMES, N. & LING, R. H. 2017b. Visual impairment certification due to diabetic retinopathy in North and Eastern Devon. *Acta Ophthalmologica,* 95**,** e756-e762.

LINDENMEYER, A., STURT, J. A., HIPWELL, A., STRATTON, I. M., AL-ATHAMNEH, N., GADSBY, R., O'HARE, J. P. & SCANLON, P. H. 2014. Influence of primary care practices on patients' uptake of diabetic retinopathy screening: a qualitative case study. *British Journal of General Practice,* 64**,** E484-E492.

LIU, G. D., DU, Q., KEYAL, K. & WANG, F. 2017. Morphologic characteristics and clinical significance of the macular-sparing area in patients with retinitis pigmentosa as revealed by multicolor imaging. *Experimental and Therapeutic Medicine,* 14**,** 5387-5394.

LIVING STREETS 2016. Summary Report - Walkable and Accessible Perth City Centre Community Street Audits

LU, J., SIU, K. W. M. & XU, P. 2008. A comparative study of tactile paving design standards in different countries. *In:* OTHERS], Y. P. A. (ed.) *2008 9th International Conference on Computer-Aided Industrial Design and Conceptual Design.* Beijing, China: IEEE.

LUONG, O., FOX, H., JAIN, G. & WILLIAMS, R. 2016. Diabetic eye screening: Keeping an eye on attendance. *Arch Dis Child,* 101**,** A268-A269.

MAEKAWA, N., OHNEDA, A., KAI, Y., SAITO, Y. & KOSEKI, S. 1978. Secondary Diabetic-Retinopathy in Chronic-Pancreatitis. *American Journal of Ophthalmology,* 85**,** 835-840.

MAKUC, J. 2016. Management of pancreatogenic diabetes: challenges and solutions. *Diabetes Metabolic Syndrome and Obesity-Targets and Therapy,* 9**,** 311-315.

MANDUCHI, R. & COUGHLAN, J. 2012. (Computer) vision without sight. *Communications of the ACM,* 55**,** 96-104.

MANDUCHI, R., KURNIAWAN, S. & BAGHERINIA, H. 2010. Blind guidance using mobile computer vision: A usability study. *Proceedings of the 12th International ACM SIGACCESS Conference on Computers and Accessibility.* Orlando, Florida.

MARSTON, J. R. 2004. Quantitative and Qualitative Analysis of Barriers To Travel By Persons With Visual Impairments and Its Mitigation Through Accessible Signage. *10th International Conference on Mobility and Transport for Elderly and Disabled People.* Hamamatsu , Japan.

MAZHAR, K., VARMA, R., CHOUDHURY, F., MCKEAN-COWDIN, R., SHTIR, C. J., AZEN, S. P. & LOS ANGELES LATINO EYE STUDY, G. 2011. Severity of diabetic retinopathy and health-related quality of life: the Los Angeles Latino Eye Study. *Ophthalmology,* 118**,** 649-55.

MCALEXANDER, T. P., GERSHON, R. R. M. & NEITZEL, R. L. 2015. Street-level noise in an urban setting: assessment and contribution to personal exposure. *Environmental Health,* 14.

MCALLISTER, K., MCBETH, A. & GALWAY, N. 2022. Autism spectrum condition and the built environment. *Cities & Health*.

MCALLISTER, K. & SLOAN, S. 2015. Navigating and exploring the ASD-friendly landscape. *Childhood Remixed Journal***,** 5-17.

MCCARTY, C. A., FU, L. & TAYLOR, R. 2002. The Risks of Everyday Life: Predictors of falls in the Melbourne Visual Impairment Project. *Australian and New Zealand Journal of Public Health,* 26**,** 116-119.

MCKINLAY, J. & MARCEAU, L. 2000. US public health and the 21st century: Diabetes mellitus. *Lancet,* 356**,** 757-761.

MECHKAROFF, N., KAUSHIK, S. & JACKSON, M. A. 2022. Re-framing Built Environment Practice: Towards an Accessible City. *The Journal of Public Space,* 7**,** 183-192.

MICHAEL, Y. L., KEAST, E. M., CHAUDHURY, H., DAY, K., MAHMOOD, A. & SARTE, A. F. 2009. Revising the senior walking environmental assessment tool. *Prev Med,* 48**,** 247-9.

MILLETT, C. & DODHIA, H. 2006. Diabetes retinopathy screening: audit of equity in participation and selected outcomes in South East London. *Journal of Medical Screening,* 13**,** 152-155.

MILLINGTON, C., WARD THOMPSON, C., ROWE, D., ASPINALL, P., FITZSIMONS, C., NELSON, N. & MUTRIE, N. 2009. Development of the Scottish Walkability Assessment Tool (SWAT). *Health Place,* 15**,** 474-481.

MORETON, R. B. R., STRATTON, I. M., CHAVE, S. J., LIPINSKI, H. & SCANLON, P. H. 2017. Factors determining uptake of diabetic retinopathy screening in Oxfordshire. *Diabetic Medicine,* 34**,** 993-999.

MOSS, S. E., MEUER, S. M., KLEIN, R., HUBBARD, L. D., BROTHERS, R. J. & KLEIN, B. E. 1989. Are seven standard photographic fields necessary for classification of diabetic retinopathy? *Investigative Ophthalmology & Visual Science,* 30**,** 823-828.

MYERSON, J. 2021. *Designing a world for everyone: 30 years of inclusive design* London, Lund Humphries.

NAGIEL, A., LALANE, R. A., SADDA, S. R. & SCHWARTZ, S. D. 2016. Ultra-widefield fundus imaging: A review of clinical applications and future trends. *Retina,* 36**,** 660-678.

NAKAMURA, T., IMAMURA, K., TAKEBE, K., MACHIDA, K. & ISHII, M. 1994. Diabetic retinopathy in Japanese patients with long-standing pancreatic diabetes due to calcifying pancreatitis. *The Tohoku Journal of Experimental Medicine,* 174**,** 49-58.

NARAYAN, K. M. V., GREGG, E. W., FAGOT-CAMPAGNA, A., ENGELGAU, M. M. & VINICOR, F. 2000. Diabetes - A common, growing, serious, costly, and potentially preventable public health problem. *Diabetes Research and Clinical Practice,* 50**,** 77-84.

NATHAN, D. M. & DCCT/EDIC RESEARCH GROUP 2014. The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Study at 30 Years: Overview. *Diabetes Care,* 37**,** 9-16.

NATIONAL ACADEMIES OF SCIENCES ENGINEERING AND MEDICINE 2020. Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System. *Opportunities for the Health Care System* Washington, DC: The National Academies Press.

NATIONAL EYE INSTITUTE. 2019. *Retinitis Pigmentosa* [Online]. nei.nih.gov. Available: https://www.nei.nih.gov/learn-about-eye-health/eye-conditions-and-diseases/retinitis-pigmentosa [Accessed 19/07/2021 2021].

NATIONAL HEALTH SERVICE. 2018. *Diabetic Retinopathy* [Online]. www.nhs.uk. Available: https://www.nhs.uk/conditions/diabetic-retinopathy/ [Accessed 09/06 2021].

NATIONAL HEALTH SERVICE. 2021. *Cataract surgery* [Online]. www.nhs.uk. Available: https://www.nhs.uk/conditions/cataract-surgery/ [Accessed 09/06 2021].

NEUBAUER, A. S., KERNT, M., HARITOGLOU, C., PRIGLINGER, S. G., KAMPIK, A. & ULBIG, M. W. 2008. Nonmydriatic screening for diabetic retinopathy by ultra-widefield scanning laser ophthalmoscopy (Optomap). *Graefe's Archive for Clinical and Experimental Ophthalmology,* 246**,** 229-235.

NHS DIGITAL 2017. National Diabetes Transition Audit, 2003-2014. digital.nhs.uk.

NOLLETT, C. L., BRAY, N., BUNCE, C., CASTEN, R. J., EDWARDS, R. T., HEGEL, M. T., JANIKOUN, S., JUMBE, S. E., RYAN, B., SHEARN, J., SMITH, D. J., STANFORD, M., XING, W. & MARGRAIN, T. H. 2016. Depression in visual impairment trial (Depvit): A randomized clinical trial of depression treatments in people with low vision. *Investigative Ophthalmology and Visual Science,* 57**,** 4247-4254.

NORDSTROM, A., HADREVI, J., OLSSON, T., FRANKS, P. W. & NORDSTROM, P. 2016. Higher Prevalence of Type 2 Diabetes in Men Than in Women Is Associated With Differences in Visceral Fat Mass. *Journal of Clinical Endocrinology & Metabolism,* 101**,** 3740-3746.

NORGATE, S. H. 2012. Accessibility of urban spaces for visually impaired pedestrians. *Proceedings of the Institution of Civil Engineers: Municipal Engineer,* 165**,** 231-237.

NUTHETI, R., SHAMANNA, B. R., NIRMALAN, P. K., KEEFFE, J. E., KRISHNAIAH, S., RAO, G. N. & THOMAS, R. 2006. Impact of impaired vision and eye disease on quality of life in Andhra Pradesh. *Investigative Ophthalmology and Visual Science,* 47**,** 4742-4748.

OC, T. & TIESDELL, S. 1997. *Safer city centres: reviving the public realm*, Sage Publications Ltd.

OXSIGHT. 2021. *Our Story* [Online]. Available: https://oxsightglobal.com/our-story/ [Accessed 09/06 2021].

PALLASMAA, J. 2006. *Eyes of the skin: Architecture and the senses*, John Wiley & Sons.

PARKIN, J. & SMITHIES, N. 2012. Accounting for the Needs of Blind and Visually Impaired People in Public Realm Design. *Journal of Urban Design,* 17**,** 135-149.

PATEL, S. N., SHI, A., WIBBELSMAN, T. D. & KLUFAS, M. A. 2020. Ultra-widefield retinal imaging: an update on recent advances. *Therapeutic*

advances in ophthalmology, 12**,** 2515841419899495-2515841419899495.
PAVING EXPERT. 2020. *Tactile Paving* [Online]. Available: https://www.pavingexpert.com/tactile01 [Accessed 09/06 2021].
PEREIRA, D. M., SHAH, A., D'SOUZA, M., SIMON, P., GEORGE, T., D'SOUZA, N., SURESH, S. & BALIGA, M. S. 2017. Quality of Life in People with Diabetic Retinopathy: Indian Study. *J Clin Diagn Res,* 11**,** NC01-NC06.
PETTUS, J. & EDELMAN, S. V. 2017. Recommendations for Using Real-Time Continuous Glucose Monitoring (rtCGM) Data for Insulin Adjustments in Type 1 Diabetes. *Journal of Diabetes Science and Technology,* 11**,** 138-147.
PICKUP, J. C., FREEMAN, S. C. & SUTTON, A. J. 2011. Glycaemic control in type 1 diabetes during real time continuous glucose monitoring compared with self monitoring of blood glucose: meta-analysis of randomised controlled trials using individual patient data. *BMJ,* 343**,** d3805.
PIKORA, T. J., BULL, F. C., JAMROZIK, K., KNUIMAN, M., GILES-CORTI, B. & DONOVAN, R. J. 2002. Developing a reliable audit instrument to measure the physical environment for physical activity. *Am J Prev Med,* 23**,** 187-94.
PINK, S. 2008. Walking with video. *Visual Studies* 22**,** 240-252.
PLIAKAS, T., HAWKESWORTH, S., SILVERWOOD, R. J., NANCHAHAL, K., GRUNDY, C., ARMSTRONG, B., CASAS, J. P., MORRIS, R. W., WILKINSON, P. & LOCK, K. 2017. Optimising measurement of health-related characteristics of the built environment: Comparing data collected by foot-based street audits, virtual street audits and routine secondary data sources. *Health Place,* 43**,** 75-84.
PORTER, D. What Is Fluorescein Angiography? *In:* JR, R. H. J., ed. American Academy of Ophthamology 14/12/2018 2018 Chicago, Illinois
PRICE, L. D., AU, S. & CHONG, N. V. 2015. Optomap ultrawide field imaging identifies additional retinal abnormalities in patients with diabetic retinopathy. *Clinical Ophthalmology (Auckland, N.Z.),* 9**,** 527 - 531.
PROULX, M. J., TODOROV, O. S., AIKEN, A. T. & DE SOUSA, A. A. 2016. Where am I? Who am I? The relation between spatial cognition, social cognition and individual differences in the built environment. *Frontiers in Psychology,* 7.
PUBLIC HEALTH AGENCY & BELFAST HEALTH AND SOCIAL CARE TRUST 2017. Northern Ireland Diabetic Eye Screening Programme - Annual Report 2016-2017.
PUBLIC HEALTH ENGLAND 2012. Diabetic eye screening: retinal image grading criteria. gov.uk.
QUINN, N., CSINCSIK, L., FLYNN, E., CURCIO, C. A., KISS, S., SADDA, S. R., HOGG, R., PETO, T. & LENGYEL, I. 2021. Comment and response to the article "The clinical relevance of visualizing the peripheral retina" by Nicola Quinn, Lajos Csincsik, Erin Flynn, Christine A. Curcio, Szilard Kiss, SriniVas R. Sadda, Ruth Hogg,

Tunde Peto & Imre Lengyel. *Progress in Retinal and Eye Research,* 83.
RABIOLO, A., PARRAVANO, M., QUERQUES, L., CICINELLI, M. V., CARNEVALI, A., SACCONI, R., CENTODUCATI, T., VUJOSEVIC, S., BANDELLO, F. & QUERQUES, G. 2017. Ultra-wide-field fluorescein angiography in diabetic retinopathy: a narrative review. *Clinical ophthalmology (Auckland, N.Z.),* 11**,** 803-807.
RAMIREZ, A. R. G., GONZALEZ-CARRASCO, I., JASPER, G. H., LOPEZ, A. L., LOPEZ-CUADRADO, J. L. & GARCIA-CRESPO, A. 2017. Towards Human Smart Cities: Internet of Things for sensory impaired individuals. *Computing,* 99**,** 107-126.
RAMULU, P. Y., VAN LANDINGHAM, S. W., MASSOF, R. W., CHAN, E. S., FERRUCCI, L. & FRIEDMAN, D. S. 2012. Fear of falling and visual field loss from glaucoma. *Ophthalmology,* 119**,** 1352-1358.
RANKIN, D., HARDEN, J., NOYES, K., WAUGH, N., BARNARD, K. & LAWTON, J. 2015. Parents' experiences of managing their child's diabetes using an insulin pump: a qualitative study. *Diabetic Medicine,* 32**,** 627-634.
RENEL, W. 2018. 'Auraldiversity': Defining a Hearing-Centred Perspective to Socially Equitable Design of the Built Environment. *Built Environment,* 44**,** 36-51.
RIAZI, A., RIAZI, F., YOOSFI, R. & BAHMEEI, F. 2016. Outdoor difficulties experienced by a group of visually impaired Iranian people. *Journal of Current Ophthalmology,* 28**,** 85-90.
RODRIGO-SALAZAR, L., GONZALEZ-CARRASCO, I. & GARCIA-RAMIREZ, A. R. 2021. An IoT-based contribution to improve mobility of the visually impaired in Smart Cities. *Computing,* 103**,** 1233-1254.
ROLEY, S. S., DELANY, J. V., BARROWS, C. J., BROWNRIGG, S., HONAKER, D., SAVA, D. I., TALLEY, V., VOELKERDING, K., AMINI, D. A., SMITH, E., TOTO, P., KING, S., LIEBERMAN, D., BAUM, M. C., COHEN, E. S., CLEVELAND, P. A. M., YOUNGSTROM, M. J. & PRACTICE, A. O. T. A. C. O. 2008. Occupational therapy practice framework: domain & practice, 2nd edition. 62**,** 625-683.
ROONEY, C., HADJRI, K., FAITH, V., ROONEY, M., MCALLISTER, K. & CRAIG, C. 2018. Living Independently: Exploring the Experiences of Visually Impaired People Living in Age-Related and Lifetime Housing Through Qualitative Synthesis. *Herd-Health Environments Research & Design Journal,* 11**,** 56-71.
ROSENBERG, D. E., HUANG, D. L., SIMONOVICH, S. D. & BELZA, B. 2013. Outdoor Built Environment Barriers and Facilitators to Activity among Midlife and Older Adults with Mobility Disabilities. *Gerontologist,* 53**,** 268-279.
ROSS ATKIN ARCHITECTS. 2011. *Sight Line Project* [Online]. Ross Atkin Architects Available: http://www.rossatkin.com/sightline/ [Accessed 01 March 2021 2021].
ROYAL NATIONAL INSITUTE OF THE BLIND 2016. RNIB and C4 support National Eye Health Week. *Sight Loss Advice Service*
ROYAL NATIONAL INSITUTE OF THE BLIND 2020. RNIB moves coronavirus response to next stage as it urges more Government action. rnib.org.uk.

ROYAL NATIONAL INSTITUTE OF THE BLIND. 2018. *Eye Health and Sight Loss Stats and Facts* [Online]. London. Available: https://www.rnib.org.uk/health-social-care-and-education-professionals/knowledge-and-research-hub/research-reports/general-research/eye-health-and-sight-loss-stats-and-facts [Accessed 09/06 2021].
ROYAL NATIONAL INSTITUTE OF THE BLIND. 2020. *The benefits of ECLOs* [Online]. rnib.org.uk. Available: https://www.rnib.org.uk/ecloinformation [Accessed 09/06 2021].
ROYAL NATIONAL INSTITUTE OF THE BLIND. 2021. *Help with low vision* [Online]. rnib.org.uk. Available: https://www.rnib.org.uk/young-people-leaving-home/help-low-vision [Accessed 09/06 2021].
RUBIN, R. R. & PEYROT, M. 1999. Quality of life and diabetes. *Diabetes-Metabolism Research and Reviews,* 15**,** 205-218.
RUBIN, R. R. & PEYROT, M. 2009. Treatment satisfaction and quality of life for an integrated continuous glucose monitoring/insulin pump system compared to self-monitoring plus an insulin pump. *J Diabetes Sci Technol,* 3**,** 1402-10.
RYE, T. 2010. Implications of Equality Act 2010 for accessible streets (including shared space). Edinburgh.
SAINE, P. J. & TYLER, M. E. 2002. *Fundus Photography Overview,* Michigan, Butterworth-Heinemann.
SANDBERG, M. A., BROCKHURST, R. J., GAUDIO, A. R. & BERSON, E. L. 2005. The association between visual acuity and central retinal thickness in retinitis pigmentosa. *Investigative Ophthalmology & Visual Science,* 46**,** 3349-3354.
SARACCO, J. B., GASTAUD, P., RIDINGS, B. & UBAUD, C. A. 1982. Diabetic Choroidopathy. *Journal Francais D Ophtalmologie,* 5**,** 231-236.
SARWAR, N., GAO, P., SESHASAI, S. R. K., GOBIN, R., KAPTOGE, S., DI ANGELANTONIO, E., INGELSSON, E., LAWLOR, D. A., SELVIN, E., STAMPFER, M., STEHOUWER, C. D. A., LEWINGTON, S., PENNELLS, L., THOMPSON, A., SATTAR, N., WHITE, I. R., RAY, K. K., DANESH, J., TIPPING, R. W., FORD, C. E., PRESSEL, S. L., FOLSOM, A. R., CHAMBLESS, L. E., SELVIN, E., WAGENKNECHT, L. E., PANAGIOTAKOS, D. B., PITSAVOS, C., CHRYSOHOOU, C., STEFANADIS, C., KNUIMAN, M., WHINCUP, P. H., WANNAMETHEE, S. G., MORRIS, R. W., KIECHL, S., WILLEIT, J., OBERHOLLENZER, F., MAYR, A., WALD, N., EBRAHIM, S., LAWLOR, D. A., YARNELL, J. W., GALLACHER, J., CASIGLIA, E., TIKHONOFF, V., NIETERT, P. J., SUTHERLAND, S. E., BACHMAN, D. L., KEIL, J. E., DE BOER, I. H., KIZER, J. R., MUKAMAL, K. J., TYBJAERG-HANSEN, A., NORDESTGAARD, B. G., BENN, M., FRIKKE-SCHMIDT, R., GIAMPAOLI, S., PALMIERI, L., PANICO, S., VANUZZO, D., PILOTTO, L., DE LA CAMARA, A. G., RUBIO, M. A., SIMONS, L., MCCALLUM, J., FRIEDLANDER, Y., FOWKES, F. G. R., LEE, A. J., TAYLOR, J., GURALNIK, J. M., PHILLIPS, C. L., WALLACE, R., GURALNIK, J. M., PHILLIPS, C. L., BLAZER, D. G., GURALNIK, J. M., PHILLIPS, C. L., PHILLIPS, C. L., GURALNIK, J. M., KHAW, K. T., BRENNER, H., RAUM, E., MULLER, H.,

ROTHENBACHER, D., JANSSON, J. H., WENNBERG, P., NISSINEN, A., DONFRANCESCO, C., GIAMPAOLI, S., SALOMAA, V., HARALD, K., JOUSILAHTI, P., VARTIAINEN, E., WOODWARD, M., D'AGOSTINO, R. B., VASAN, R. S., FOX, C. S., PENCINA, M. J., BLADBJERG, E., JORGENSEN, T., MOLLER, L., et al. 2010. Diabetes mellitus, fasting blood glucose concentration, and risk of vascular disease: a collaborative meta-analysis of 102 prospective studies. *Lancet,* 375**,** 2215-2222.

SAURABH, K., ROY, R. & GOEL, S. 2020. Correlation of multicolor images and conventional color fundus photographs with foveal autofluorescence patterns in diabetic macular edema. *Indian J Ophthalmol,* 68**,** 141-144.

SBRULLI, S. 2020. Coronavirus: Social distancing for the visually impaired in Italy. *Coronavirus pandemic* bbc.co.uk: BBC News

SCANLON, P. H. 2017. The English National Screening Programme for diabetic retinopathy 2003–2016. *Acta Diabetologica,* 54**,** 515-525.

SCANLON, P. H., CARTER, S. C., FOY, C., HUSBAND, R. F. A., ABBAS, J. & BACHMANN, M. O. 2008a. Diabetic retinopathy and socioeconomic deprivation in Gloucestershire. *Journal of Medical Screening,* 15**,** 118-121.

SCANLON, P. H., FOY, C. & CHEN, F. K. 2008b. Visual acuity measurement and ocular co-morbidity in diabetic retinopathy screening. *British Journal of Ophthalmology,* 92**,** 775-778.

SCANLON, P. H., STRATTON, I. M., LEESE, G. P., BACHMANN, M. O., LAND, M., JONES, C., FERGUSON, B. & RETINOPATHY, F. N. D. 2016. Screening attendance, age group and diabetic retinopathy level at first screen. *Diabetic Medicine,* 33**,** 904-911.

SCHNEIDER, C. 2012. Exploring Disability: A Sociological Introduction. *International Sociology.*

SCHNEIDER, C., BARNES, C. & MERCER, G. 2012. *Exploring Disability: A Sociological Introduction*.

SEVEL, D., BRISTOW, J. H., BANK, S., MARKS, I. & JACKSON, P. 1971. Diabetic Retinopathy in Chronic Pancreatitis. *Archives of Ophthalmology,* 86**,** 245-&.

SHAHBAZIAN, H. & REZAII, I. 2013. Diabetic kidney disease; a review of the current knowledge. *Journal of renal injury prevention,* 2**,** 73-80.

SHARMA, S., OLIVER-FERNANDEZ, A., LIU, W., BUCHHOLZ, P. & WALT, J. 2005. The impact of diabetic retinopathy on health-related quality of life. *Current Opinion in Ophthalmology,* 16**,** 155-159.

SHOUGHY, S., AREVALO, J. F. & KOZAK, I. 2015. Update on wide- and ultra-widefield retinal imaging. *Indian Journal of Ophthalmology,* 63**,** 575-581.

SKOVLUND, S. E., PEYROT, M. & PANEL, O. B. O. T. D. I. A. 2005. The Diabetes Attitudes, Wishes, and Needs (DAWN) Program: A New Approach to Improving Outcomes of Diabetes Care. *Diabetes Spectrum,* 18**,** 136-142.

SLADE, J. & EDWARDS, R. 2015. My Voice 2015: The views and experiences of blind and partially sighted people in the UK. rnib.org.uk: Royal National Institute of the Blind.

SOBNATH, D. & REHMAN, I. U. 2019. Smart cities could give the visually impaired a new outlook on urban life. London: The Conversation.
SOKOL, S., MOSKOWITZ, A., SKARF, B., EVANS, R., MOLITCH, M. & SENIOR, B. 1985. Contrast Sensitivity in Diabetics with and without Background Retinopathy. *Archives of Ophthalmology,* 103**,** 51-54.
SOLIMAN, A. Z., SILVA, P. S., AIELLO, L. P. & SUN, J. K. 2012. Ultra-wide Field Retinal Imaging in Detection, Classification, and Management of Diabetic Retinopathy. *Seminars in Ophthalmology,* 27**,** 221-227.
SOSNOWSKI, C. & JANECZKO-SOSNOWSKA, E. 2008. The Action to Control Cardiovascular Risk in Diabetes Study Group. Effects of intensive glucose lowering in type 2 diabetes. *Kardiologia Polska,* 66**,** 1013-1019.
SRINIVASAN, V. J., MONSON, B. K., WOJTKOWSKI, M., BILONICK, R. A., GORCZYNSKA, I., CHEN, R., DUKER, J. S., SCHUMAN, J. S. & FUJIMOTO, J. G. 2008. Characterization of outer retinal morphology with high-speed, ultrahigh-resolution optical coherence tomography. *Invest Ophthalmol Vis Sci,* 49**,** 1571-9.
STEVENS, R. G. & REA, M. S. 2001. Light in the built environment: Potential role of circadian disruption in endocrine disruption and breast cancer. *Cancer Causes and Control,* 12**,** 279-287.
SULLIVAN-BOLYAI, S., KNAFL, K., TAMBORLANE, W. & GREY, M. 2004. Parents' reflections on managing their children's diabetes with insulin pumps. *Journal of Nursing Scholarship,* 36**,** 316-323.
TALKS, S. J., MANJUNATH, V., STEEL, D. H. W., PETO, T. & TAYLOR, R. 2015. New vessels detected on widefield imaging compared to twofield and sevenfield imaging: Implications for diabetic retinopathy screening image analysis. *British Journal of Ophthalmology,* 99**,** 1606-1609.
TAN, C. S., SADDA, S. R. & HARIPRASAD, S. M. 2014. Ultra-widefield retinal imaging in the management of diabetic eye diseases. *Ophthalmic Surgery Lasers & Imaging Retina,* 45**,** 363-366.
TENDOESSCHATE, J. 1982. Causes of Blindness in the Netherlands. *Documenta Ophthalmologica,* 52**,** 279-285.
TESORIERE, G., CAMPISI, T., CANALE, A. & SEVERINO, A. The effects of urban traffic noise on children at kindergarten and primary school: A case study in Enna. AIP Conference Proceedings 2040, 2018. AIP
THALER, L. & GOODALE, M. A. 2016. Echolocation in humans: an overview. *Wiley Interdisciplinary Reviews: Cognitive Science,* 7**,** 382-393.
THE INCLUSIVE MOBILITY AND TRANSPORT ADVISORY COMMITTEE (IMTAC) 2015. Valuing Pedestrian Journeys imtac.org.uk: IMTAC.
THE NATIONAL FEDERATION OF THE BLIND OF THE UK 2016. Access for Blind People in Towns. SS1401. *In:* BATES, D. M. (ed.). Wakefield, UK: The National Federation of the Blind of the UK.
THE ROYAL COLLEGE OF OPHTHALMOLOGISTS 2012. Diabetic Retinopathy Guidelines
THOMAS, R., BARKER, L., RUBIN, G. & DAHLMANN-NOOR, A. 2015. Assistive technology for children and young people with low vision. *Cochrane Database of Systematic Reviews,* 18.

THOMAS, R. L., LUZIO, S. D., NORTH, R. V., BANERJEE, S., ZEKITE, A., BUNCE, C. & OWENS, D. R. 2017. Retrospective analysis of newly recorded certifications of visual impairment due to diabetic retinopathy in Wales during 2007-2015. *Bmj Open,* 7.

THOMPSON, C. W. 2012. Landscape perception and environmental psychology. *In:* HOWARD, P., THOMPSON, I., WATERTON, E. & ATHA, M. (eds.) *The Routledge Companion to Landscape Studies.* 1 ed. London: Routledge

TIENGO, A., SEGATO, T., BRIANI, G., SETTI, A., PRATO, S. D., DEVIDÉ, A., PADOVAN, D., VIRGILI, F. & CREPALDI, G. 1983. The presence of retinopathy in patients with secondary diabetes following pancreatectomy or chronic pancreatitis. *Diabetes Care,* 6**,** 570-574.

TILLING, L. M., DARAWIL, K. & BRITTON, M. 2006. Falls as a complication of diabetes mellitus in older people. *Journal of Diabetes and its Complications,* 20**,** 158-162.

TIMMIS, M. A., ALLSOP, J., BARANIAN, M., BAKER, J., BASEVITCH, I., LATHAM, K., PARDHAN, S. & PARIDON, K. N. V. Visual Search Behavior in Individuals With Retinitis Pigmentosa During Level Walking and Obstacle Crossing. ARVO 2017 Baltimore, Maryland, USA. ARVO Journals 4737-4746.

TOLA, G., TALU, V., CONGIU, T., BAIN, P. & LINDERT, J. 2021. Built Environment Design and People with Autism Spectrum Disorder (ASD): A Scoping Review. *Int J Environ Res Public Health,* 18.

TRANSPORT SCOTLAND 2020. National Transport Strategy.

TSUNODA, K., FUJINAMI, K. & MIYAKE, Y. 2011. Selective Abnormality of Cone Outer Segment Tip Line in Acute Zonal Occult Outer Retinopathy as Observed by Spectral-Domain Optical Coherence Tomography. *Archives of Ophthalmology,* 129**,** 1099-1101.

TURANO, K., GERUSCHAT, D., BAKER, F. H., STAHL, J. W. & SHAPIRO, M. D. 2001. Direction of Gaze while Walking a Simple Route: Persons with Normal Vision and Persons with Retinitis Pigmentosa. *Optometry and Vision Science,* 78**,** 667-675.

TYLER, N. 2011. CAPABILITIES AND ACCESSIBILITY: A MODEL FOR PROGRESS. *Journal of Accessibility and Design for All* 1**,** 12-22.

UK RENAL REGISTRY 2021. UK Renal Registry 23rd Annual Report – data to 31/12/2019. Bristol, UK

VAZ-PEREIRA, S., MORAIS-SARMENTO, T. & DE SALVO, G. 2022. Sensitivity and specificity of MultiColor imaging in detecting proliferative diabetic retinopathy. *Int Ophthalmol,* 42**,** 455-467.

VERDONK, C. A., PALUMBO, P. J., GHARIB, H. & BARTHOLOMEW, L. G. 1975. Diabetic microangiopathy in patients with pancreatitic diabetes mellitus. *Diabetologica,* 11**,** 394-400.

VISION AWARE. 2020a. *Dog Guides for People with Vision Loss* [Online]. visionaware.org. Available: https://visionaware.org/everyday-living/essential-skills/an-introduction-to-orientation-and-mobility-skills/dog-guides-for-people-with-vision-loss/ [Accessed 09/06 2021].

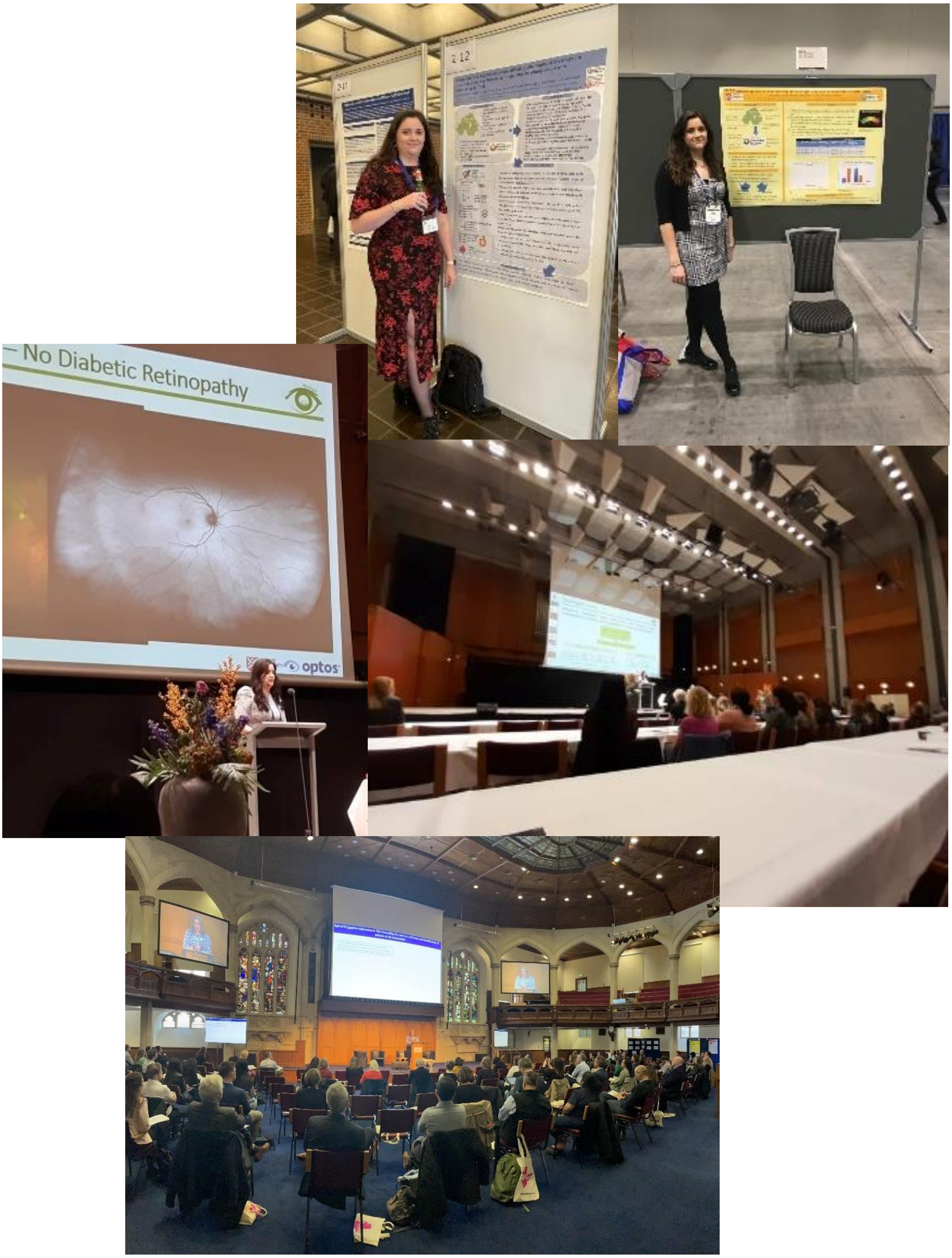
VISION AWARE. 2020b. *What Type of Cane Should I Use?* [Online]. visionaware.org. Available: https://visionaware.org/everyday-living/essential-skills/an-introduction-to-orientation-and-mobility-skills/what-type-of-cane-should-i-use/ [Accessed 09/06 2021].

VISLISEL, J. & OETTING, T. 2010. Diabetic Retinopathy: From One Medical Student to Another. *EyeRounds.Org.* EyeRounds.org.
VIVEKANANDA-SCHMIDT, P., ANDERSON, R. S., REINHARDT-RUTLAND, A. H. & SHIELDS, T. J. 2004. Simulated impairment of contrast sensitivity: Performance and gaze behavior during locomotion through a built environment. *Optometry and Vision Science,* 81**,** 844-852.
VOIGT, M., SCHMIDT, S., LEHMANN, T., KÖHLER, B., KLOOS, C., VOIGT, U. A., MELLER, D., WOLF, G., MÜLLER, U. A. & MÜLLER, N. 2017. Prevalence and progression rate of diabetic retinopathy in type 2 diabetes patients in correlation with the duration of diabetes. *Experimental and Clinical Endocrinology Diabetes,* 126**,** 570-576.
WADA, M. 2011. Strengthening the Kawa model: Japanese perspectives on person, occupation, and environment. *Canadian journal of occupational therapy. Revue canadienne d'ergotherapie,* 78**,** 230-236.
WAINWRIGHT, O. 2014. Headset provides '3D soundscape' to help blind people navigate cities. *The Guardian*.
WARSAW, V. 2013. Case Study: Virtual Warsaw. *Embracing Innovation in Government: Global Trends.* Trend 4: Mass or Personalised Services ed.
WEE, H. L., TAN, C. E., GOH, S. Y. & LI, S. C. 2006. Usefulness of the Audit of Diabetes-Dependent Quality-of-Life (ADDQoL) questionnaire in patients with diabetes in a multi-ethnic Asian country. *Pharmacoeconomics,* 24**,** 673-682.
WESSEL, M. M., AAKER, G. D., PARLITSIS, G., CHO, M., D'AMICO, D. J. & KISS, S. 2012. Ultra-wide-field angiography improves the detection and classification of diabetic retinopathy. *Retina,* 32**,** 785-791.
WIENER, W., WELSH, R. & BLASCH, B. 2010. AMDs (adaptive mobility devices). *Foundations of Orientation and Mobility: Instructional Strategies and Practical Applications.*
WILSON, J., WALKER, B. N., LINDSAY, J., CAMBIAS, C. & DELLAERT, F. SWAN: System for wearable audio navigation. Proceedings - International Symposium on Wearable Computers, ISWC, 2007 Washington DC. ACM Digital Library.
WITKIN, A. J., KO, T. H., FUJIMOTO, J. G., CHAN, A., DREXLER, W., SCHUMAN, J. S., REICHEL, E. & DUKER, J. S. 2006. Ultra-high resolution optical coherence tomography assessment of photoreceptors in retinitis pigmentosa and related diseases. *American Journal of Ophthalmology,* 142**,** 945-952.
WITMER, M. T. & KISS, S. 2013. Wide-field Imaging of the Retina. *Survey of Ophthalmology,* 58**,** 143-154.
WOLSLEY, C. J., SILVESTRI, G., O'NEILL, J., SAUNDERS, K. J. & ANDERSON, R. S. 2009. The association between multifocal electroretinograms and OCT retinal thickness in retinitis pigmentosa patients with good visual acuity. *Eye,* 23**,** 1524-1531.
WONG, E. Y. H., GUYMER, R. H., HASSELL, J. B. & KEEFFE, J. E. 2004. The experience of age-related macular degeneration. *Journal of Visual Impairment & Blindness,* 98**,** 629-640.
WOOD, J. M., LACHEREZ, P., BLACK, A. A., COLE, M. H., BOON, M. Y. & KERR, G. K. 2011. Risk of falls, injurious falls, and other injuries

resulting from visual impairment among older adults with age-related macular degeneration. *Investigative Ophthalmology and Visual Science,* 52**,** 5088-5092.
WOODCOCK, A., BRADLEY, C., PLOWRIGHT, R., FFYTCHE, T., KENNEDY-MARTIN, T. & HIRSCH, A. 2004. The influence of diabetic retinopathy on quality of life: Interviews to guide the design of a condition-specific, individualised questionnaire: The RetDQoL. *Patient Education and Counseling,* 53**,** 365-383.
WORLD HEALTH ORGANIZATION. 2021a. *Blindness and vision impairment* [Online]. Available: https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment [Accessed 09/06 2021].
WORLD HEALTH ORGANIZATION 2021b. Blindness and vision impairment.
WORTH, N. 2013. Visual Impairment in the City: Young People's Social Strategies for Independent Mobility. *Urban Studies,* 50**,** 574-586.
YOKOCHI, M., LI, D. J., HORIGUCHI, M. & KISHI, S. 2012. Inverse pattern of photoreceptor abnormalities in retinitis pigmentosa and cone-rod dystrophy. *Documenta Ophthalmologica,* 125**,** 211-218.
YOLCU, U., SAHIN, O. F. & GUNDOGAN, F. C. 2014. Imaging in Ophthalmology. *Ophthalmology Current-Clinical and Research Updates*.
ZABOROWSKI, B. 1997. Adjustment to vision loss and blindness: a process of reframing and retraining. *Journal of Rational-Emotive & Cognitive-Behavior Therapy,* 15**,** 215-221.
ZACHARIAH, S., WYKES, W. & YORSTON, D. 2015. Grading diabetic retinopathy (DR) using the Scottish grading protocol. *Community Eye Heal Journal,* 28**,** 72-73.
ZALLIO, M. & CLARKSON, P. J. 2021. Inclusion, diversity, equity and accessibility in the built environment: A study of architectural practise

Building and Environment, 206**,** 1-11.
ZHAO, Y., KUPFERSTEIN, E., TAL, D. & AZENKOT, S. 2018. It looks beautiful but scary: How low vision people navigate stairs and other surface level changes. *ASSETS 2018 - Proceedings of the 20th International ACM SIGACCESS Conference on Computers and Accessibility.* Galway, Ireland: Association for Computing MachineryNew York, NY, United States.

Publications, Achievements, Conferences and Experiences



Conferences

I have had the pleasure of attending and presenting at many conferences throughout my PhD Experience. Unfortunately, due to COVID-19 many of these conferences were presented online.

Pre-PhD (2018-2019)

Attendance

ISPAH Post Satellite Conference – Riddel Hall, Belfast – October 2018 **- '***Creating active and liveable societies for all: Enhancing the interface between researchers, practitioners and policymakers'*

(EASDEC) European Association For Diabetic Eye Complications – Riddel Hall, Belfast – May 2019

Proceedings

Speaker: World Sight Day October 2018
The Visually Impaired and the Built Environment
Laura Cushley Neil Galway Tunde Peto

Speaker: Patient Engagement Day October 2018
The Visually Impaired and the Built Environment
Laura Cushley Neil Galway Tunde Peto

* Top 10 Poster and Rapid-Fire Presentation: Women in Vision UK, Conference, Liverpool, December 2018 (Athena Swan Event)
The Visually Impaired and the Built Environment
Laura Cushley Neil Galway, Tunde Peto

During PhD

Proceedings:

Poster: NICRN vision conference March 2019
The Visually Impaired and the Built Environment
Laura Cushley, Neil Galway, Tunde Peto

Posters ARVO April/May 2019

Correlation of Pregnancy and Use of the Oral Contraceptive Pill with Reported Deterioration of Vision in Patients with Inherited Retinal Dystrophies
Evelyn Moore, Sharon Alexander, Laura Cushley, Giuliana Silvestri
ARVO 2019 Abstract Number: 4527 - A04564526 - A0455

Is cataract extraction and intraocular lens implant surgery a benefit for patients with Retinitis Pigmentosa.
Sharon Alexander, Evelyn Moore, Laura Cushley, Giuliana Silvestri
ARVO 2019 Abstract Number: 4527 - A0456#

Outer Retinal Layers as Predictors of Visual Function and Response to treatment in Macular Edema in Retinitis Pigmentosa
Vittorio Silvestri, Sharon Alexander, Evelyn Moore, Rebecca Cairns, Laura Cushley, Giuliana Silvestri **ARVO 2019 Abstract Number:** 1851 - A0242

Is Poor Compliance with Diabetic Eye Screening in Young Adults an Indicator of Poor Diabetes Control?
Laura Nicole Cushley, Aaron Bell, Giuliana Silvestri, Una Graham, David McCance, Nicola Quinn, Tunde Peto
ARVO 2019 Abstract Number: 1081 - A0039

<u>ESLRR 2019</u>

Co-author on Poster Presentation: '**Certification of Sight Impairment: introduction of an improved service.**'
Jonathan Jackson, Laura Cushley, Roseleen McCann, Tanya Moutray

<u>Global Public Health Conference – September 2019</u>

Poster: **Whose data is it anyway? Influences on technology use and interpretation among young people living with Type 1 diabetes?**
Laura Cushley, Aniela Krezel, Kathryn Parker, Lynne Lohfeld, Sarinda Millar, Tunde Peto

<u>World Sight Day 2019 – October 2019</u>

Speaker: **So why do people not attend screening: Learning from Bangladesh and Northern Ireland'** with *Dr Katie Curran*

<u>Women in Vision UK – December 2019</u>

Poster: **Whose data is it anyway? Influences on technology use and interpretation among young people living with Type 1 diabetes?**
Laura Cushley, Aniela Krezel, Kathryn Parker, Lynne Lohfeld, Sarinda Millar, Tunde Peto

2020

Attendance:

- AI and Machine Learning Conference – 19/6/2020
- UKBB Scientific Conference – 23/6/2020
- PPI Conference (Virtual with University of Limerick) – 25/9/2020 – 26/9/2020)
- Global Health Conference Healthy People on a Healthy Planet Conference (Irish Global Health Network) – 24/09/2020 – 25/09/2020
- World Sight Day Conference – 8/10/2020
- Pan-Ireland Conference – 09/10/2020
- Patient Engagement Day – 10/10/2020
- i2Eye Conference – 12/10/2020 – 14/10/2020

Proceedings:

EASDEC – November 2020 (Virtual)
Poster/Presentation: **Certification of Visual Impairment in Patients with Diabetes Mellitus in Northern Ireland over a 5 year period**
Laura Cushley, Roseleen McCann, Tunde Peto, Tanya Moutray, Jonathan Jackson

BSPED 2020 – did not attend
Presentation: **Whose data is it anyway? Influences on technology use and interpretation among young people living with type 1 diabetes?**
Sarinda Millar, Laura Cushley, Kathryn Parker, Aniela Krezel, Lynne Lohfeld, Tunde Peto

2021

Proceedings:
EASDEC October 2021 – Optos Symposium – Odense, Denmark
Speaker: **The role of the peripheral retina in diabetic retinopathy: from basic science to town planning**
Laura Cushley, Tunde Peto

Poster: **A retrospective analysis of factors affecting attendance at the Northern Ireland Diabetic Eye Screening Programme in young people with diabetes aged 12-26**
Laura Cushley, Katie Curran, Qing Wen, Aaron Bell, David McCance, Una Graham, Tunde Peto
British Association of Retinal Screening – September 2021
The Importance of Handheld Retinal Imaging in Haemodialysis Clinics
Laura Cushley, Nicola Quinn, Peter Blows, Ailish Nugent, Ian Wallace, Helen Wallace, Tunde Peto

Women in Vision Ireland – September 2021

Certification of Visual Impairment in people with diabetes in Northern Ireland over a 5-year period

Laura Cushley, Tunde Peto, Roseleen McCann, Tanya Moutray, Jonathan Jackson

Retina.ie -November 2021

Diabetic Retinal Screening in Haemodialysis Clinics throughout Northern Ireland

Laura Cushley, Nicola Quinn, Peter Blows, Ian Wallace, Helen Wallace, Tunde Peto

International Diabetes Federation 2021 – December 2021

One-stop clinics for young people with diabetes

Laura Cushley, Sarinda Millar, Kathryn Parker, Tunde Peto

2022

Association for Research in Vision and Ophthalmology (ARVO) 2022 - Denver, Colorado

Navigating the unseen city: stakeholder opinions on navigation of the built environment by visually impaired individuals

Laura Cushley, Neil Galway, Katie Curran, Tunde Peto

EUROPEAN ASSOCIATION FOR DIABETIC EYE COMPLICATIONS (EAsDEC)- Belfast, UK

Integrating Diabetic Eye Screening into Regional Haemodialysis Units, Northern Ireland

Laura Cushley, Nicola Quinn, Peter Blows, Edward McKeever, Tunde Peto

EURETINA 2022 – Virtually and Hamburg, Germany

Recorded presentation: **Navigating our towns and cities with peripheral retinal pathology caused by diabetes and retinitis pigmentosa (The NaviSight Study)**

Laura Cushley, Lajos Csincsik, Gianni Virgili, Neil Galway, Tunde Peto

Future Conferences

Irish Global Health Network Conference 2022 – October 2022 - Dublin, Ireland - **Attendee**

Retina.ie – Dublin, Ireland –

The NaviSight Study: Do people with retinitis pigmentosa and diabetic eye disease have problems moving around our towns and cities?

Laura Cushley, Lajos Csincsik, Katie Curran, Gianni Virgili, Neil Galway, Tunde Peto

International Diabetes Federation Conference – Lisbon, Portugal – December 2022

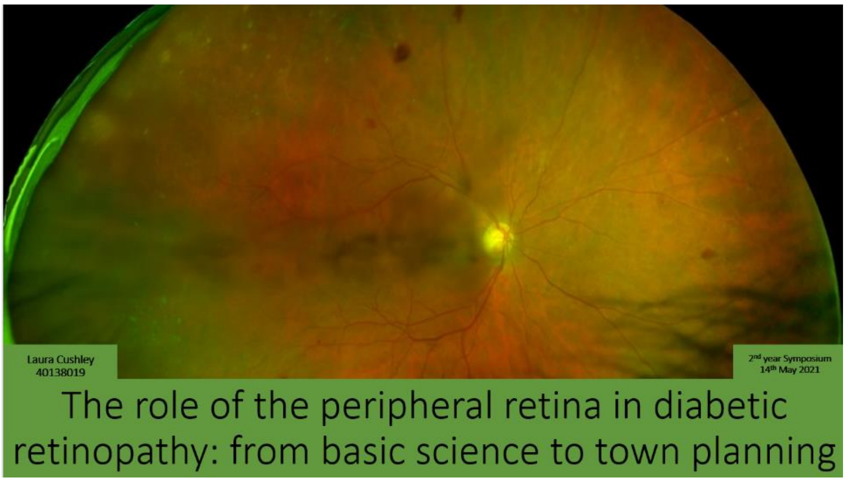
Do people with diabetic retinopathy have issues moving around our towns and cities?

Laura Cushley, Lajos Csincsik, Katie Curran, Gianni Virgili, Neil Galway, Tunde Peto

Correlation of Nonperfusion on Ultrawide Field Fluorescein Angiography to Retinopathy and Macular Edema in Diabetic Eyes

R. Salongcay, L.A. Aquino, C.M. Salva, T. Peto, P. Silva, L. Cushley

Prizes



May 2021 – Centre for Public Health 2nd Year Symposium - Winner of Best Presentation -The role of the peripheral retina in diabetic retinopathy: from basic science to town planning

June 2021 – QUB Postgraduate 7th Annual Poster Competition 'Winner of Best for Creativity' – 'What are young people's opinions on Diabetic Retinopathy Screening?'

September 2021 – 3rd Place 'Best Poster' at the British Association of Retinal Screening (BARS) – The Importance of Handheld Retinal Imaging in Haemodialysis Clinics

2021 BARS/Topcon (GB) Medical Ltd Call for Posters

The three winning posters of the 2021 BARS/Topcon (GB) Medical Ltd Poster Competition were announced at this year's virtual conference kindly sponsored by Topcon (GB) Medical Ltd, with the winner receiving a £250 Amazon voucher with 2nd and 3rd places receiving £150 & £100 Amazon vouchers respectively. The standard and content exceeded expectations and with a total of 11 entries, it was difficult to pick out the individual winners. The three winning posters can be viewed below by clicking on the relevant title.

1st: Leanne Bird, Helen Wharton, Prof Sarita Jacob - Birmingham, Solihull & Black Country DESP

Diabetic Retinopathy In Pregnancy: Screening Attendance Rates and Development of Disease

2nd: Mrs N Albutt, Miss H Wharton, Prof S Jacob - Birmingham, Solihull & Black Country DESP

Five year outcomes of diabetic eye screening in patients aged 80 and over

3rd: Laura Cushley, Nicola Quinn, Peter Blows, Ailish Nugent, Ian Wallace, Helen Wallace, Tunde Peto - Centre for Public Health, Queen's University Belfast, Belfast Health and Social Care Trust

The Importance of Handheld Retinal Imaging in Haemodialysis Clinics

Publications

Optometry in Practice: Diabetic eye screening – where are we now and what does the future hold?
Laura Cushley and Tunde Peto
(https://www.college-optometrists.org/oip-resource/diabetic-screening-in-an-evolving-world)

Diabetic Eye Journal: Diabetic Eye Screening Programme in Northern Ireland *Laura Cushley, Catherine Jamison, Nicola Quinn, Rosemary Bowles, Tunde Peto and the DESPNI Team*
(https://www.eyescreening.org.uk/userFiles/File/DiabeticEyeJournal/DEJ13part1.pdf)

COVID-19: The regional impact of COVID-19 on the certification of vision impairment in Northern Ireland
Jonathan Jackson, Giuliana Silvestri, Michael Stevenson, Janet Sinton, Jacqueline Witherow, Roseleen McCann, Tanya Moutray and Laura Cushley (https://onlinelibrary.wiley.com/doi/full/10.1111/opo.12757)

The certification of vision impairment: A regional 21st century perspective
A J Jackson, L Cushley, R McCann, Máire Gallagher, J Witherow, T Moutray
(https://journals.sagepub.com/doi/full/10.1177/0264619620972154)

Diabetic Retinopathy Screening Programme: Attendance, Barriers and Enablers amongst Young People with Diabetes Mellitus Aged 12–26 Years
Laura N Cushley, Katie Curran, Nicola B. Quinn, Aaron Bell, Alyson Muldrew, Una M. Graham, David R. McCance, Qing Wen, Tunde Peto
(https://www.mdpi.com/2673-8937/1/3/11)

The unseen barriers of the built environment: navigation for people with visual impairment
Laura Cushley, Neil Galway, Tunde Peto
(https://liverpooluniversitypress.co.uk/journals/article/67837/)

Screening attendance, prevalence and severity of diabetic retinopathy (DR) in a cohort of patients with diabetes mellitus secondary to chronic pancreatitis (DMsCP) in Northern Ireland
Catherine Jamison, Tunde Peto, Nicola Quinn, Laura Nicole Cushley, Philip C. Johnston
(https://pubmed.ncbi.nlm.nih.gov/34493494/)

Characterization of West African Crystalline Macular Dystrophy in the Ghanaian Population
Amoaku WM, Sampalli A, Silvestri V, Cushley LN, Akafo S, Amissah-Arthur KN, Lartey S, Hageman CN, Hubbard WC, Pappas CM, Zouache MA, Stevenson M, Hageman GS, Silvestri G; Ghana AMD Study Group. (https://pubmed.ncbi.nlm.nih.gov/35307605/)

The Integration of Diabetic Eye Screening into Haemodialysis Units in Northern Ireland
Laura Cushley, Nicola Quinn, Peter Blows, Edward McKeever, Tunde Peto
(https://kidney360.asnjournals.org/content/early/2022/05/18/KID.0001802022)

Navigating the Unseen City: Town Planners, Architects, Ophthalmic Professionals, and Charity Opinions on Navigating of the Built Environment with a Visual Impairment
Laura Cushley, Neil Galway, Katie Curran, Tunde Peto
(https://pubmed.ncbi.nlm.nih.gov/35742563/)

Certification of Visual Impairment due to Diabetic Eye Disease in Northern Ireland from 2014-2019 (Accepted but not published)
Laura N. Cushley, Tunde Peto, Roseleen McCann, Tanya Moutray, Gianni Virgili, and A. Jonathan Jackson

Paper Reviews

Two peer review for the ***British Journal of Visual Impairment*** (SAGE)

One peer review for ***Children*** (MDPI)

1 peer review for ***Cities & Health*** (Taylor and Francis)

Research Studies

1-29 April – 2017: Accra Ghana Research trip in co-ordination with the Moran Eye Centre, Utah, USA.

Project title: Genetic Analysis in AMD in the Ghanaian Population. My role was to coordinate the administrative side of the project. I led the interviewing of patient liaising with local nurses and healthcare workers to complete the questionnaires. I also learnt to take intraocular pressures with iCare tonometry.

25th February – 1st March 2019: ***Bridlington Eye Assessment Project with Moran Eye Centre, York R&D office, Nottingham University and NICRN***

During this study I dealt with patient questionnaires/consent and buccal swabs from patients. In addition, I had further retinal camera training on the Topcon Triton retinal camera and took retinal images of patients recruited into the study.

October 2020 – ***Saliva Study, Queen's University Belfast***

This study took place at the Public Health Agency COVID testing centre in Stranmillis Belfast. I was a volunteer for the study and undertook consent, informing potential participants, recruitment, dealing with samples and working within a large, changing team. The study aimed to assess whether saliva samples were an adequate test for SARS-COV2.

Courses and Other Qualifications

- Certificate of Higher Education (CertHE) in Diabetic Retinopathy Screening (14th July 2020)
- Future Learn: Reversing Diabetes: Fact or Fiction?
- Future Learn: Young People and their Mental Health
- Future Learn: Global Health Governance: Addressing Globalization and Health Inequities
- Future Learn: Global Blindness
- Future Learn: Understanding Mental Health: Continuum, Culture and Social Media
- Systematic Review Course – 2 day interactive course
- How2 collaborate course – 6-month monthly courses
- First Aid Training St Johns Ambulance (3 days) – June 2021

Additional Training

2018

- EVICR.net – Diabetic Macular Edema Understanding & Management
- International Diabetes Federation – Diabetic Retinopathy
- International Diabetes Federation – Diabetes and CVD
- International Diabetes Federation – Prevention of Type 2 Diabetes
- Good Clinical Practice (5th October 2020)

2019

- Diabetes UK Changelabs (4 days)
- Diabetes UK Type 1 Weekender
    - Volunteer Training

2020

- Heidelberg OCT training (6/3/2020)
- Metrovision Electrophysiology Training (13/1/2020)
- Medical Statistics (October 2019- January 2020)
- Human Tissue Act Training
- Metrovision Webinar: Exams for Advanced Clinical Investigations on MonCvONE
- Metrovision Webinar: "MonCvONE perimetry with video imaging and eye tracking"
- Heidelberg Webinar: "Macular Pigment Assessment with SPECTRALIS" - Professor John Nolan - nutrition, macular pigment and cognitive behaviour
- Planning Lecture Series: Planning the Post-Pandemic City- Neuroscience and the City
- Planning Lecture Series: Planning the Post-Pandemic City- Neuroscience and the City
- TED webinar/conference: Creating accessible and inclusive public spaces with/for resilient communities
- AI CTU practical training course in CEM (20/07/2020)
- International Diabetes Federation – Diabetes and Ramadan
- JDRF Virtual College – An Awareness of Diabetes in Schools and Other Settings: Basic Level
- JDRF Virtual College – An Awareness of Diabetes in Schools and Other Settings: Advanced Level
- Teaching Training (Building Inclusive Online Communities)
- Global Brain Institute Webinar: Inclusive Building Design (25/09/2020)

- PPI Engagement Seminars: Understanding Involvement, Co-Production and Consultation; Advanced stakeholder mapping; Choosing Dialogue Methods; Risk Assessments of Involvement and Consultation
- Writing for Public Audiences

2021

- Good Research Practice Training: ADD topics
- PPI Tuesday Topics – 'seldom heard' and the 'seldom online' (Covid compliance)', 'Embedding PPI in HSC – measuring outcomes, developing and maintaining partnerships, building community capacity'
- British Asian Trust - COVID-19 Vaccine – Facts for the BAME community
- The Lancet Global Health Commission on Global Eye Health
- ADRCNI Symposium Series – Working and Caring Through COVID
- Analyzing Qualitative Data – UEA training with Simon Watts
- Using NVivo to do qualitative research – UEA Training Simon Watts
- Barcroft Lecture with Professor Sarah Gilbert (part of the Astrazeneca team)
- Web of Science and Scopus Tutorial – 9/6/2021
- Research Culture with Caroline Barelle: My Journey (10/06/2021)
- Basics of Academic Writing (18/06/2021)

Other Achievements

Centre for Public Health – Student Representative 2020

I was co-student representative for the Centre for Public Health in my second year of my PhD. During my time as student representative, I had to liaise with other students about comments, suggestions and issues. I also had to attend monthly student voice committees with other student representatives and staff. This was a challenging year for all PhD students and staff as it was mid-pandemic and we could only meet virtually. We hosted many virtual coffee mornings and year group meetings to facilitate support within the postgraduate community. In addition, I helped to host the Centre for Public Health Christmas Quiz for all staff and students.

Teaching Student Selected Component (SSC) – The eyes have it all! -

Assisting with teaching and delivering some lectures

Teaching Masters Students - School of the Built Environment Teaching

School of the Natural and Built Environment: teaching/supervision field trip to Berlin for Planning Masters Students (1 week)

Optomed Video Interview

Queen's University Belfast's research to prevent blindness globally

30.3.2022

In March 2022 I was invited alongside Prof Tunde Peto, Dr Recivall Salongcay and Dr Katie Curran to talk about the Optomed Handheld Device and its uses. In the video I discuss about the importance of handheld imaging for at risk patient groups such as those on dialysis.

(https://www.optomed.com/queens-university-belfasts-research-to-prevent-blindness-globally/)

Invited Presentations for QUB

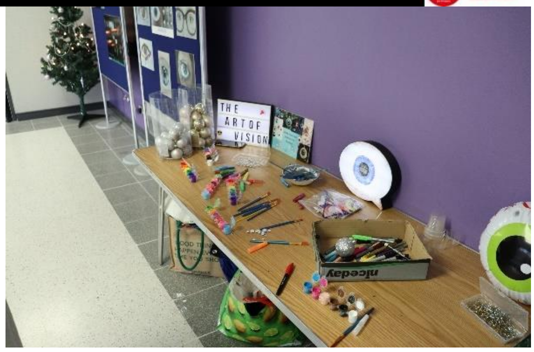
My PhD Journey – recommended to represent the School of Medicine, Dentistry and Biomedical Sciences as a **'Student Thought Leader'** at the pre-semester postgraduate event**.**

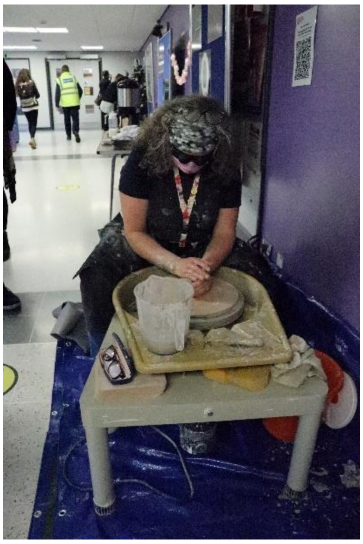
PGR Induction Talk – I was asked by the Director of Postgraduate Research to present at the School of Medicine, Dentistry and Biomedical Sciences Induction on my Postgraduate experience.

Funding and Social Events

The Art Festival

In July 2021 we received funding to host an event as part of the ESRC Festival of Social Science 2021. We decided to host an 'Art Festival' to promote the art of vision and all research projects conducted by and in collaboration with Queen's University Belfast on vision and ophthalmology. The general public, staff and students were invited to attend the event.



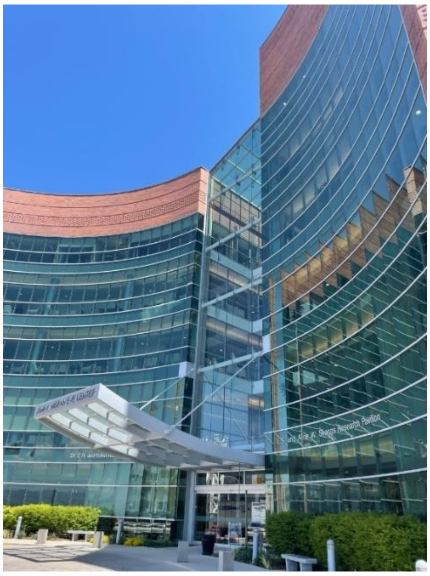


In the event, pictures and posters of research studies were displayed alongside practical displays. We created a 'eye bauble' station where people could create and design Christmas tree baubles around vision and eyes. In addition, we were fortunate to have an artist from Ulster University who allowed attendees to 'throw' some pottery. In addition, the artist did some pottery using 'vision' glasses which depicted eye conditions such as RP to show that even with a loss of vision, pottery is a great option.

Trips and Experiences

Salt Lake City, Utah (Possible due to the Emily Sarah Montgomery Travel Award)

30th April 2022 – 12th May 2022



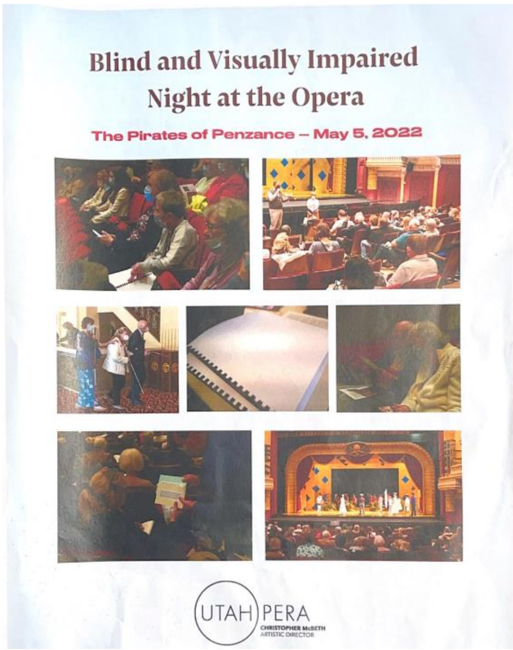
After attending the ARVO conference in Denver, Colorado I travelled to Salt Lake City, Utah to gain experience and shadow colleagues in the Moran Eye Centre. In the Moran Eye Centre, I spent time with Professor Gregory Hageman who is the Executive Director of the Moran's Steel Centre for Translational Medicine and his team.

Professor Hageman and his team work on Age Related Macular Degeneration. They have discovered that a specific common haplotype of the complement regulator 'Complement Factor H' accounts for more than 50% of risk for age related macular degeneration in Caucasian population. His team continues to work on this and potential therapies from people with age related macular disease. In addition to this clinical and lab based work, Professor Hageman holds an eye bank in the University of Utah where donated human eyes are held.

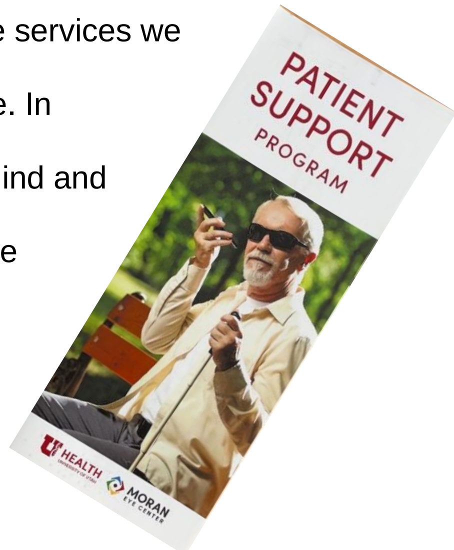
During my time in the Moran Eye Centre I was able to shadow colleagues in low vision, lab work, statistics and the eye bank. I was able to shadow during the recruitment of 2 patients and their clinical history, blood donation and retinal imaging. I was also able to learn about the donor eye bank and how they 'punch' and 'dissect' these donor eyes.

I was also able to spend time in the lab and make solutions to preserve these donor eyes. In addition, I learned how to extract DNA from the blood donations they collected in the recruitment clinic previously. We followed the QiagenMax DNA protocol to extract the DNA from the blood. The picture to the right shows the view from the laboratory.

I was also able to attend a guest lecture by Dr Adam Dubis from University College London on Artificial Intelligence in AMD.



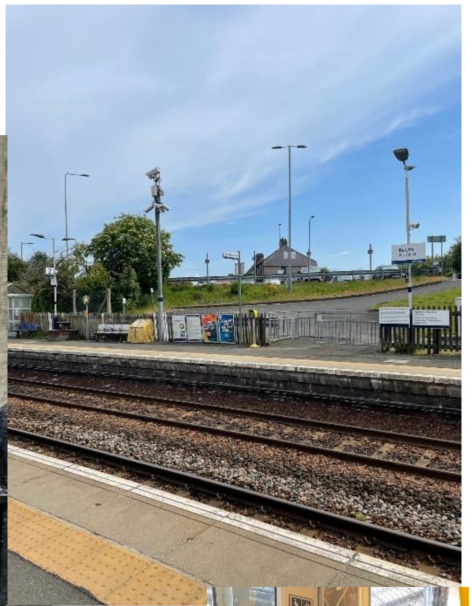
Finally, I shadowed and had a long discussion with Associate Professor Lisa M. Ord who specialises in low vision. She informed me of the services they offered in the University of Utah, and we discussed potential similarities and differences between them and the services we offer at home. In addition, we discussed the Utah Opera offering a Blind and Visually Impaired Night at the Opera the night before opening performances. This is something which could be offered in Northern Ireland, and I hope to discuss this with colleagues at home.



Optos Visit – June 2022

In June 2022 I was invited to visit Optos Plc in Dunfermline, Scotland. During this visit I was able to build relationships with the clinical teams, research teams and production and innovation teams. I learned about data management, clinical research, and clinical operations within the industry. In addition, I was fortunate enough to learn about and tour the manufacturing facilities.

I also gave a talk to all the staff about my PhD research project. There were around 70 people in attendance at the Lunch and Learn and the presentation as well received.



Appendices

Appendix 1 - Supplementary Table 1 – Summary of Focus Group Analysis

Theme	Subthemes	Typical Quotes
Benefits	• Gamechanger • Makes night-time easier – parents can sleep through the night • Makes eating easier – no need to worry about injecting before and making them eat the right amount • Couldn't go back to injections now • Arrows and alarms on CGM make it easier • Amazing, transformational, step further • Life is massively improved • Children/ young adults can manage it themselves • Flexibility and convenience – takes away stress calculations	"Since using this machine, my life has changed" "The pumps makes daily tasks easier" '' The CGM means we can sleep through the night as it alarms'' ''Mealtimes are easier because we don't have to inject before eating and then make them eat enough for the amount of insulin we gave'' ''Couldn't go back to injections now'' 'Flexibility and convenience'' ''Transformational'' ''He can manage it himself now'' ''CGM Dexcom, hard to compare…hard to beat'' ''no hesitation to make changes'' ''easy to read and see patterns'' ''systems are useful for both parents and clinicians'' ''pumps are better than injections for flexibility and convenience, take away the stress of calculations''
Drawbacks	• Alarms can be annoying if range is off • Some CGM are unreliable – have to finger prick as well • Site problems – breaking of skin etc. • Self –confidence and cosmetic issues – can't wear certain clothes if you want to hide pump/CGM	''disruptive alarms'' ''alarm is driving us crazy'' [parents] ''constantly checking their phone'' ''ignorance was bliss'' ''bad reception in school'' '' Injections were easier …. because there were no alarms'' ''confidence problems'' ''keeps covered up, my daughter won't wear a bikini'' ''self-conscious''

		'' inflamed skin'' ''too much information'' ''overanalyse'' ''…. can be inaccurate''
Impact on Social Life, Family and Personal Life	• No invites to parties/sleepovers – people can't deal with the diabetes so parents have to attend • Bullying due to CGM/pump • Also allows an easier social life • Impacts the whole family • Parents want their children to be independent but recognise its scary at the same time • Diabetes burden/fatigue • Relationships with siblings affects as parents giving more attention to sibling with diabetes (jealousy) • Issues with holidays • diabetes takes over conversations in the household and nothing else gets talked about • Nightmare – independence is lost • Want to be the same as their friends • Some don't know any different as they were diagnosed so young • Kids forget they have diabetes but parents don't • Sports can make things difficult • Hard to take time off for appointments	''no parties, no invitations'' ''miss out on a lot'' ''parents are often spare wheels at parties'' [always asked] ''can she/he eat this?'' ''whole house is affected by it'' ''kids not intimidated by 'numbers' or 'measurements', it's my problem'' ''[I] constantly check and he's just like 'I'm in target, can I have a biscuit'' ''family conversation taken over by diabetes – always what's your numbers? etc.'' ''independence lost'' ''[I feel like] a robot mum, sleep with one eye open'' [siblings say they are] ''treated differently and ignored'' ''siblings gets jealous of the attention'' '' because she's type 1 she doesn't have to do anything like chores etc'' ' [My daughter] amazes [me], forthcoming about doing stuff, we don't want to stop her, she has to overcome obstacles, we can't hold her back'' ''CGM allowed the first sleepover''
Diabetes in School	• Not enough trained staff in school • Getting shouted at in class due to using technology/pumps • Issues with getting help in school • Without an assistant – teachers only inject but don't monitor • Not looking forward to 'big school'	'' poor [name]… don't pity our children'' ''alarms can disturb people in class/school'' ''libre was good but he wouldn't scan it in school'' [others in school called him] ''robot man because of the libre on his arm'' ''[devices] can be seen through white school blouse''

	• More general education surrounding diabetes at school • Problems with scanners being visible during school	‘’schools aren’t serious about it because it’s not all visible’ ‘school can be rude – ‘’another thing to deal with’’’ ‘’can’t go to afterschool sometimes because not enough staff’’
Attitude to technology and data analysis	• Graphs give peace of mind • Carelink is too complicated • Don’t want to look at data after dealing with diabetes all day • Kids aren’t scared of technology but parents are • More training needed to interpret graphs – unsure how to interpret them • Phones make it easier • Diabetes is a moving target and seeing patterns is useful • Dexcom is hard to beat/compare • Hard to stop checking them constantly • Some parents are confident in interpreting but most are not • Technology is good for both clinicians and parent/ children • Percentage time in target, CGM and SCP graphs • Weekly graphs are useful • Child won’t look of graphs but will look at 14 day review.	‘’ new generation embraces technology, older people intimidated by tech’’ ‘’children are too fast at using the pump, can’t monitor them’’ ‘’ You know yourself you know you generally you have to be in control’’ ‘’I’m holding her back with my fear of technology’’ ‘’ [I] find the technology side difficult’’ ‘’I don’t use graphs’’ ‘’ old graphs were better and easier to read’’ ‘’graphs over the long term offer peace of mind’’ ‘’even specialists don’t know how to read them’’ ‘’love seeing the graphs’’ ‘’favourite graphs are overall CGM, AGP graph – they are the most reliable’’ ‘’[I] use the daily and monthly graphs and percentage time in target most’’ ‘’don’t mind uploading before clinic appointment’’ ‘’Carelink is very complicated’’ ‘’ I want to have ME time, could do it more, but I’ve had enough of diabetes by the end of the day’’ ‘’[we need] more training to interpret graphs’’

Appendix 2 - Participant Information Leaflet

Queen's University Belfast Logo

NaviSight Study Logo

Participant Information Leaflet

NaviSight: The Role of the Peripheral Retina in Diabetic Retinopathy: From Basic Science to Town Planning

If you require this information document in another format or voice recording please contact the research team on 028 9097 6400 or navisight@qub.ac.uk.

We would like to invite you to take part in our research study. You have been invited to join the study because you have Diabetes or Retinitis Pigmentosa. Joining the study is voluntary. We hope to get 72 participants for this study which we hope will inform on problems in our towns and cities, especially for those with sight loss.

What does the study aim to do?

The study aims:

- To find out if we can determine your level of vision through images of your eyes and other eye tests which check how far out you can see and how your eyes adapt to the dark
- To find out if your level of vision affects how you move around our towns and cities on your own. We also want to find out what problems there are in our towns and cities for people with sight loss.

What does the study involve?

The study will involve:

- Questionnaires about sight loss, your daily life, and some questions about walking around our towns and cities.
- Images of the back of your eyes, reading a chart, a test to see how your eyes adapt in light and to see how far you can see up, down and to the side. Many of these images/tests are similar to what you get in clinics, diabetic eye screening and your local high street optometrists).
- Virtual Reality – you will watch a video of a street. We will track your eye movements and ask you to press a button when you see a hazard in the street.
- A walk around the university area (approximately 1 mile with a break in the middle). A researcher will come with you on the walk.

Benefits of the Study

1. The study hopes to raise awareness of any problems faced by people with sight loss moving around our towns and cities. You can help inform advice to the people who create our towns and cities – making them more accessible for all.
2. You will have the opportunity to talk about problems you face when walking around our towns and cities. You will be an important voice for people with sight loss.

Do I have to take part?

No, taking part is voluntary. Should you decide to take part you can stop taking part at any time, without giving any reason. If you do decide to stop taking part we will use any information we have gathered up to you leaving the study.

What are the possible disadvantages of taking part?

Taking part in this study will not affect any other treatment you may need for your eyes or other conditions. If you receive eye drops for photographing the back of your eyes, your vision will be blurry for a few hours.

If we find anything within your eye examinations which you did not know about before, Professor Tunde Peto (Consultant Ophthalmologist) will assess you and refer you accordingly.

What if something goes wrong?

We will make every effort to ensure you are not put at risk or harmed in any way. It is unlikely that anything will go wrong by taking part in this study.

If you become distressed during the study we will bring you to a place of your choice or offer to get you a taxi home. You can speak to Professor Tunde Peto or an Eye Care Liaison Officer at any time.

During the study, if you disclose something which we feel could endanger you or other we will stop the study. We will speak to Professor Tunde Peto and deal with it appropriately.

What will happen if you agree to take part in the study?

You will be invited for an appointment at the Northern Ireland Clinical Research Facility (NICRF) on the University Floor (Floor U) in the Belfast City Hospital.

Visit 1
This will take around 2-3 hours and will include:

- Questionnaires about your health and sight loss
- Several images of the back of both of your eyes will be taken

- You will be asked to read a chart, as you would in your high-street optometrists. We will check how your eyes adapt to the dark and your field of vision (how far you can see right/left and up/down. Your eyes may be dilated for imaging of your eyes. The drops will enlarge your pupils and can take 20 minutes to work and may make your vision blurry.
- We will ask you to watch a video of a street and we will track where your eyes move and ask you to press a button when you see a potential hazard.

Visit 2

- You will be asked to walk around the university area for approximately 1 mile with a break at the Ulster Museum.
- Researchers will do the walk with you and record how long it takes to complete.
- During the walk we will ask you to talk about any problems during the walk and opinions on the streets around you.
- We will also take some measurements of light and noise levels on the street
- We will audio record what you say during the walk. This will be anonymous. This recording will be used for analysis and deleted afterwards.

We will ask you to wear a camera in order to assess the route you are walking and any potential problems you point out. This recording will be anonymous and will not include you.

Visit 3

- You will be asked to walk the same route as in visit 2 during a different season of the year. We want to know if this affects your opinions.
- A member of the research team will accompany you during the walk. They will time the walk and record light/noise levels on the street.
- We will audio record and video record as in visit 2. We will delete the audio recording after analysis.

COVID-19 Pandemic

During the COVID-19 pandemic, we will set up a phone/video call to go through the questionnaires with you. After you have completed these questionnaires, we will ask you to attend NICRF for your imaging and assessment appointment.

How will we use information about you?

Your information including your name and contact details will stay confidential. The student (Miss Laura Cushley) and Professor Tunde Peto will use these contact details to contact you about future appointments.

We will ask you your gender and age during the questionnaire. Any information you give us during your questionnaire will be anonymous. We will assign a code number to you at the start of the study. We will keep all information about you safe and secure. If you want to know more about how your information is used, please contact the research team.

The research team includes Professor Gregory Hageman from the University of Utah, USA. Your data will be sent to Professor Hageman using the code number and will be anonymous. We will send it in a file which is password protected. They will follow our rules on keeping your information safe.

What are the costs and payments for taking part in this study?

All tests and procedures will be free of charge and of no cost to you. There will be no monetary compensation for taking part in the study.

Travel Costs

You can claim any travel costs for study appointments

What will happen to the results of the research study?

Data from this research study will be published. Your information will not be able to be identified from any data published.

Who has reviewed the study?

This study has been reviewed by the NHS/HSC REC.

Who is organising and funding this study?

The study is being funded by Queen's University Belfast and Optos Plc. This is a PhD student study and involves Miss Laura Cushley (student) and three supervisors- Professor Tunde Peto (Professor of Clinical Ophthalmology), Dr Neil Galway (Lecturer), Professor Gregory Hageman (John A. Moran Presidential Professor Executive Director)

What if I have any questions, concerns or complaints about the study?

If you have concerns about the study, please contact: Professor Tunde Peto on 02890976400 or email:t.peto@qub.ac.uk.

If you remain unhappy and wish to make a formal complaint please contact Research Governance Team at Queen's University Belfast (Telephone:028 9097 2529; Email: researchgovernance@qub.ac.uk).

Thank you for taking the time to read this Participant Information Leaflet.

Professor Tunde Peto **Chief Investigator** Professor of Clinical Ophthalmology Queen’s University Belfast	**Miss Laura Cushley** **PhD Researcher** Centre for Public Health, Queen’s University Belfast Email: navisight@qub.ac.uk **Phone: 028 9097 6400**

Appendix 3 : Consent Form

PARTICIPANT CONSENT FORM: NaviSight - The Role of the Peripheral Retina in Diabetic Retinopathy: From Basic Science to Town Planning

Study Number: NAVI

Please Initial Box

- I confirm that I have read, or have had read to me, and understand the Participant Information Leaflet for the above study. I have had the opportunity to ask questions, and these have been fully answered. ☐
- I confirm that I have had sufficient time to consider whether or not I wish to participate in the study. ☐
- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights or medical care being affected. ☐
- I understand that Queen's University Belfast is leading the research. I also understand that my personal information will be held securely on Queen's University Belfast premises and handled in accordance with the provisions of the Data Protection Act 2018. ☐
- I understand that clinical information and images captured of my eyes will be stored electronically on secure servers held in Queen's University Belfast ☐
- I understand that if information I provide or the images that are taken published this will be done in a manner that it will not be possible to identify me from any publications. ☐

- I consent to having my eyes dilated to enlarge my pupils for retinal imaging if necessary ☐
- I consent to audio and video recording during visits 2 and 3 of the study ☐
- I agree to my GP being informed of my participation in the study. ☐
- I agree to data, without my personal identifiable data (except age), being sent in encrypted form to Professor Gregory Hageman in the University of Utah for review. ☐
- I agree to be contacted in the future by the research team for further voluntary research. ☐
- I understand that in the event of an unexpected disclosure (crime, danger to yourself or others etc.) the research team will deal with this accordingly. ☐
- I agree to take part in the above study. ☐

Name of Participant (Please print)	Date	Signature

Name of Person taking consent	Date	Signature

Ethics Approval Letters

Appendix 4 - BHSCT

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Ariennir gan Lywodraeth Cymru
Funded by Welsh Government

Wales Research Ethics Committee 5
Bangor

Mailing address:
Health and Care Research Wales
Castlebridge 4
15-19 Cowbridge Road East
Cardiff, CF11 9AB

email: Wales.REC5@wales.nhs.uk
website: ww.hra.nhs.uk

11 January 2021

Prof Tunde Peto
Professor of Clinical Ophthalmology
Queen's University Belfast
Centre for Public Health, ICSA
Royal Victoria Hospital
Grosvenor Road, Belfast
BT12 6BA

Dear Prof Peto

Study title:	**NaviSight: The Role of the Peripheral Retina in Diabetic Retinopathy: From Basic Science to Town Planning**
REC reference:	**20/WA/0350**
Protocol number:	**=**
IRAS project ID:	**276978**

Thank you for your letter of , responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.
Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)	-	01 August 2020
GP/consultant information sheets or letters [GP Letter]	0.1	11 November 2020
IRAS Application Form [IRAS_Form_02122020]	-	02 December 2020
Letter from sponsor [Letter from Sponsor]	-	01 December 2020
Letters of invitation to participant [Appointment Letter]	0.2	10 July 2020
Non-validated questionnaire [NaviSight Questionnaire]	0.1	11 November 2020
Other [Diabetes Distress Scale]	-	-
Other [Researcher Distress Protocol]	0.1	17 November 2020
Other [Participant Distress Protocol]	0.1	17 November 2020
Other [Recruitment Flyer]	-	-
Other [Recruitment Materials]	-	-
Participant consent form [Consent]	0.2	30 November 2020
Participant consent form [Consent]	0.3	02 January 2021
Participant information sheet (PIS) [Participant Information Sheet]	0.5	02 January 2021
Research protocol or project proposal [Participant Distress Protocol]	0.2	02 January 2021
Research protocol or project proposal [Study Protocol]	-	-
Response to Request for Further Information	-	-
Sample diary card/patient card [Study Card]		--
Summary CV for Chief Investigator (CI) [CV_ChiefInvestigator]	-	12 November 2020

Summary CV for student [CV_Student]	-	11 November 2020
Summary CV for supervisor (student research) [CV_Supervisor]	-	12 November 2020
Validated questionnaire [RetDQol Questionnaire]	-	-

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 276978 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Dr Jason Donal Walker, MB BCh BAO, FRCA
Consultant Anaesthetist
Chairman Wales REC 5

E-mail: WalesREC5@wales.nhs.uk

Appendix 5 - Queen's University Belfast

QUEEN'S UNIVERSITY BELFAST

Date:	14 September 2020
To:	Professor Tunde Peto
Faculty REC Reference Number:	MHLS 20_67
Full Title:	The Role of the Peripheral Retina: From Basic Science to Town Planning
Decision:	**APPROVED**

Thank you for your application, which was reviewed at the meeting of the MHLS Faculty Research Ethics Committee (MHLS Faculty REC) which took place on 24 June 2020.

Your application was considered and some clarification and revisions were requested on 31 March 2020. You submitted the requested information, with further requested revisions on 08 September 2020 and these were forwarded for review.

The response has been reviewed and deemed satisfactory. The application has been **approved**.

Conditions of the Approval

The MHLS Faculty REC approval is subject to the following conditions:

(i) The study must be conducted in accordance with all relevant legislation. All relevant management approvals from organisations involved in the research must be obtained.
(ii) When the research involves human volunteers the study must be entered on the University's Insurance Database.
(iii) Monitoring and auditing process must be complied with including submission of annual progress reports to the MHLS Faculty REC.
(iv) Any face to face study activity is subject to the submission, approval and adherence to a COVID-19 Risk Assessment.

It is the Chief Investigator's responsibility to ensure the study is conducted in accordance with the conditions stipulated.

Any future changes to any part of the submitted application, protocol or supporting documentation must be notified to the Committee prior to these changes taking place.

Approved Documents

The documents approved by the Faculty REC are listed in the table below.

Documentation Received	Version	Date
Application Form	0.1	24 May 2020
Response to Committee Comments		18 July 2020
Response to Committee Comments		29 July 2020
Response to Committee Comments		23 August 2020
Response to Committee Comments		07 September 2020
Recruitment Material		Received 20 July 2020
Recruitment (Focus Group)	0.1	21 August 2020
Engagement Day Recruitment		Received 07 August 2020

Research Protocol		Received 08 September 2020
Participant Information Sheet		Received 07 August 2020
Participant Information Sheet (Focus Group)		Received 08 September 2020
Consent Form		Received 20 July 2020
Consent Form (Focus Group)		Received 08 September 2020
Appointment Letter	0.2	Received 20 July
Questionnaire	2	Received 28 May 2020
RetDQoL Questionnaire		Received 28 May 2020
Diabetes Distress - Screening Scale (DDS17)		Received 28 May 2020
GP Letter	0.2	10 July 2020
COVID-19 Risk Assessment		Received 20 July 2020
Out of Hours/Lone Working Policy		Received 20 July 2020
Risk Assessment		Received 20 July 2020
Peer Review		01 May 2020
Peer Review		04 May 2020

If you would like to discuss this further please contact the Research Ethics Officer, Mr Stefan Curran, at facultyrecmhls@qub.ac.uk or by telephone on 028 90972529.

Yours sincerely

pp Professor Michelle McKinley
Chair, MHLS Faculty REC

Appendix 6 - NaviSight Study Questionnaire

Participant Questionnaire

Study Number: NAVI

General/Medical

1. Age:

2. Gender:

Male Female Other Prefer not to say

3. Do you smoke?

YES NO

4. Do you drink?

YES NO

5. Do you have diabetes?

YES NO

Participant_Questionnaire_V1 11/11/2020

6. If so, what type of diabetes do you have?

Type 1 Type 2 Other

7. How long have you had diabetes?

8. Do you have hearing loss?

YES NO

9. Medical History

Stroke	YES	NO
Angina	YES	NO
Heart Attack	YES	NO
Peripheral Vascular Disease	YES	NO
Foot Problems	YES	NO
Nerve Damage (Neuropathy)	YES	NO
Kidney Problems (Nephropathy)	YES	NO
Neurological Conditions	YES	NO
Rheumatology (Joint) Problems	YES	NO
Balance Problems	YES	NO

Sight loss and the built environment

This section is about navigating the built environment with sight loss.

10. On a scale of 1 to 5 (1 being not anxious and 5 being very anxious/), how does navigating the built environment make you feel?

1	2	3	4	5
Not Anxious				Very Anxious

11. Do you use any of these mobility vision aids when walking about?

• Cane	YES	NO
• Guide Dog	YES	NO
• Monocular Telescope	YES	NO
• Other, please describe:		

12. Do you drive?

YES NO

13. Have you given up any hobbies since developing sight loss?

YES NO

14. Do you go out at night?

YES SOMETIMES NEVER ONLY IF ACCOMPANIED

15. Do you use public transport?

YES NO

16. Do you think walking around towns/cities is difficult?

YES NO

If yes, please explain why?

17. Do you need assistance when you go to places you know, such as your local shop/bank etc.?

YES NO SOMETIMES

18. Do you need assistance when you go out to new/unfamiliar places?

YES NO SOMETIMES

19. Do you use the same routes when you go out into towns/cities?

YES NO

20. Do you think that 'street clutter' e.g. signposts, advertisements board and bins/benches create problems for you when you are walking around towns/cities?

YES NO

21. Do you think pedestrian crossings are adequate in towns/cities?

YES NO

If no, please explain why?

22. Would bright markings on the edges of obstacles/hazards help you to walk around towns/cities?

YES NO DON'T KNOW

23. Do you think cars parked on the pavement cause problems for you when you are walking around towns/cities?

YES NO DON'T KNOW

24. Do you go into crowded areas?

YES SOMETIMES NEVER ONLY IF ACCOMPANIED

25. Do you think areas of shared space are difficult to navigate (where cars and people walk on the same space)?

YES NO DON'T KNOW

26. Do you think that the level of lighting impacts on your ability to walk around independently?

YES NO DON'T KNOW

27. Do you think COVID has affected you going out into the built environment?

YES NO DON'T KNOW

Appendix 7 – RetDQol Questionnaire

Summary of the RetDQoL

an individualised measure of the impact of diabetic retinopathy on quality of life

Comment

The RetDQoL is an individualised measure of the impact of diabetic retinopathy on quality of life taking account of the relevance and importance of different aspects of life for quality of life of individuals as well as the individual's view of the impact of diabetic retinopathy on each aspect of life of relevance to them. Closely following the design of the ADDQoL (Audit of Diabetes Dependent Quality of Life) (Bradley et al 1999; Bradley and Speight, 2002; Wee et al, 2007) the content of the RetDQoL was determined following qualitative research with people who had diabetic retinopathy in the UK and Germany (Woodcock et al, 2004). The RetDQoL was developed alongside the MacDQoL measure of the impact of macular disease on QoL (Mitchell and Bradley, 2004) and improvements to one have influenced improvements to the other. Evidence for the psychometric properties of the MacDQoL has been published (Mitchell et al, 2005 and in press) and evidence for those of the RetDQoL have been presented at ISOQOL (Brose et al, 2007) with a manuscript in preparation.

Format of the RetDQoL

The RetDQoL is designed for self-completion by people with retinopathy. The font is Arial 16 bold. All text is justified to the left (to make it easier to follow the vertical line down the page) and the use of upper case is avoided except where dictated by grammar, as capital letters are less easy to differentiate from each other than lower case letters. Dotted lines guide the respondent from questions to response options (see examples in figures 1 and 2 below).

The RetDQoL is suitable for administration by telephone interview or face-to-face interview. However, the method of administration may affect the scores (as has been found with the MacDQoL (Mitchell et al, in press)) and it is recommended that different methods are not used in the same sample. Telephone interview (or face-to-face interview) is preferable except where all participants are able to read large print and can self-complete the RetDQoL without help. Instructions for interviewers are available in English and some other languages.

Content and scoring instructions

- *Name of condition:* The measure has been designed for people with diabetic retinopathy. However, it uses the term 'diabetic eye problems' throughout as not all patients recognise the term 'diabetic retinopathy'.
- *Two overview items:* scored individually (present quality of life and impact of diabetic eye problems on quality of life (QoL). See figure 1.
    - Generic (present) QoL. Scored from +3 (*excellent*) through 0 (*neither good nor bad*) to –3 (*extremely bad*).
    - Retinopathy-specific QoL. Scored from –3 (*very much better* i.e. severe negative impact of retinopathy on QoL) through 0 (*the same* i.e. no impact of retinopathy on QoL) to +1 (*worse* i.e. positive impact of retinopathy on QoL).

Leonie S Brose and Professor Clare Bradley, Health Psychology Research, Royal Holloway, University of London, Egham, Surrey, TW20 0EX, UK. Latest revision of summary 15.9.09.

- *Specific domains:* See figure 2 for an example item showing format and table 1 for the content of all domain-specific items. A weighted score for each domain is calculated as follows:
- *Weighted impact (WI) score* = impact rating (-3 to +1) x importance rating (0 to 3). Possible range is from –9 (maximum negative impact of retinopathy on QoL) to +3 (maximum positive impact of retinopathy on QoL). NB "Unimportant" domains score 0, regardless of magnitude of impact of retinopathy. Domains with no impact of retinopathy score 0, regardless of their importance to QoL. Any non-applicable domains are not scored.
- *Exclusion of the 'work' item:* The item '*work*' could not be included in psychometric analyses conducted to date because it was only applicable to a third of respondents. Where applicable the weighted impact score can be calculated for this item and used in separate analyses but it should be excluded from calculation of the average weighted impact score (see below) until there is evidence from larger samples for its contribution to factor structure and reliability.
- *Average Weighted Impact Score:* To be calculated from a maximum of 23 specific domains.

$$= \frac{\text{Sum of weighted ratings of applicable domains}}{\text{N of applicable domains}}$$

  Possible range is from –9 (maximum negative impact of retinopathy on QoL) to +3 (Maximum positive impact of retinopathy on QoL).
- *Internal consistency reliability* (Cronbach's alpha) for the 23-item scale = 0.96 (Brose et al 2007).
- *Missing data*. The AWI score can be computed despite some missing data. Missing data for up to half the items could be tolerated without Cronbach's alpha falling below 0.8 in a German sample using the German version of the RetDQoL (Brose et al, 2007). In this sample the AWI score could be calculated where at least 12 items had complete responses.

Availability

The RetDQoL is made available to users by formal arrangement with Health Psychology Research Ltd. Requests should be made to info@healthpsychologyresearch.com. A user agreement is necessary to avoid breach of copyright and to ensure that the latest and most appropriate version of the questionnaire is used.

Contact Information

For permission to use the RetDQoL and to ensure that you have the most up-to-date version, please contact:

E-mail: info@healthpsychologyresearch.com

Website: www.healthpsychologyresearch.com

References

Bradley C et al (1999) The development of an individualised questionnaire measure of perceived impact of diabetes on quality of life: the ADDQoL. *Quality of Life Research* 8, 79-91.

Bradley C and Speight J (2002) Patient perceptions of diabetes and diabetes therapy: assessing quality of life. *Diabetes Metabolism Research and Reviews* 18: S64-S69.

Brose LS et al (2007) Retinopathy-Dependent Quality of Life Questionnaire (RetDQoL): psychometric development. 2007 International Society for Quality of Life Research meeting abstracts [www.isoqol.org/2007mtgabstracts.pdf]. *Quality of Life Research suppl*, A-60, Abstract #1198.

Mitchell J et al (2005) Psychometric evaluation of the MacDQoL individualised measure of the impact of macular degeneration on quality of life. *Health and Quality of Life Outcomes* 3, 25.

Leonie S Brose and Professor Clare Bradley, Health Psychology Research, Royal Holloway, University of London, Egham, Surrey, TW20 0EX, UK. Latest revision of summary 15.9.09.

Mitchell J and Bradley C (2004) Design of an individualised measure of the impact of macular disease on quality of life (the MacDQoL). *Quality of Life Research*. **13**(6), 1163-75.

Mitchell J and Bradley C. The MacDQoL individualized measure of the impact of macular disease on quality of life. In VA Preedy (Ed) *Handbook of disease burdens and quality of life measures*. Heidelberg: Springer-Verlag (in press).

Mitchell J et al. The MacDQoL individualised measure of the impact of macular degeneration on quality of life: reliability and responsiveness. *American Journal of Ophthalmology* (in press).

Wee HL et al (2006) Usefulness of the Audit of Diabetes Dependent Quality of Life (ADDQoL) Questionnaire in Patients with Diabetes in a Multi-Ethnic Asian Country. *Pharmacoeconomics* **24** (7): 673-682.

Woodcock A et al (2004) The influence of diabetic retinopathy on quality of life. Interviews to guide the design of a condition-specific, individualised questionnaire: the RetDQoL. *Patient Education and Counseling* 53, 3, 365-383.

Leonie S Brose and Professor Clare Bradley, Health Psychology Research, Royal Holloway, University of London, Egham, Surrey, TW20 0EX, UK. Latest revision of summary 15.9.09.

Figure 1: Format of the 2 overview items (showing the scores assigned)

I) In general, my present quality of life is:

- excellent............................. 3
- very good........................... 2
- good 1
- neither good nor bad 0
- bad....................................... -1
- very bad .... -2
- extremely bad..................... -3

II) If I did not have diabetic eye problems, my quality of life would be:

- very much better .... -3
- much better .... -2
- a little better....................... -1
- the same 0
- worse................................... 1

Table 1: Summary of the 24 domain-specific items (and their response options) and final open question

NB. All items 1 – 24 begin with the phrase: If I did not have diabetic eye problems:		
1	I could handle my household tasks:	very much better – worse
2	I could handle my personal affairs (letters, bills, etc):	very much better – worse
3	my experience of shopping would be:	very much better – worse
4	my feelings about the future (e.g. worries, hopes) would be:	very much better – worse
5	my feelings about past medical care and/or self-care (e.g. anger or regret) would be:	very much better – worse
6	*my working life would be:	very much better – worse
7	*my closest personal relationship would be:	very much better – worse
8	*my family life would be:	very much better – worse
9	my friendships and social life would be:	very much better – worse
10	I could do things for others as I wish:	very much better – worse
11	I could get out and about (e.g. on foot, or by car, bus or train):	very much better – worse
12	*my holidays would be:	very much better – worse
13	my financial situation would be:	very much better – worse
14	the way people in general react to me would be:	very much better – worse
15	my physical appearance (including clothes and grooming) would be:	very much better – worse
16	physically I could do:	very much more - less
17	I could enjoy my leisure activities and interests (e.g. reading, TV, radio, hobbies):	very much more – less
18	my self-confidence would be:	very much better – worse
19	my motivation would be:	very much better – worse
20	I could do things independently:	very much more - less
21	I would have mishaps or would lose things:	very much less - more
22	the time it takes me to do things would be:	very much less - more
23	I would find taking care of my diabetes (e.g. self-testing, medication, food, exercise):	very much easier – more difficult
24	I could enjoy nature:	very much more - less
25	Do your diabetic eye problems affect your quality of life in any ways that have not been covered by the questionnaire? If 'yes' please describe in the box provided (open text response).	yes, no

* Item has 'not applicable' option

Leonie S Brose and Professor Clare Bradley, Health Psychology Research, Royal Holloway, University of London, Egham, Surrey, TW20 0EX, UK. Latest revision of summary 15.9.09.

Appendix 8 – Diabetes Distress Scale (DDS17)

KING'S HEALTH PARTNERS

Health Innovation Network South London

Diabetes Distress - Screening Scale (DDS17)

Directions: Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 17 items may have distressed or bothered you **DURING THE PAST MONTH** and circle the appropriate number.

Please note Circle the number gives the best answer for you and please provide an answer for each question. If you feel that a particular item is not a bother or a problem for you, you would circle "1". If it is very bothersome to you, you might circle "6"

		Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
Q1	Feeling the diabetes is taking up too much of my mental and physical energy every day	1	2	3	4	5	6
Q2	Feeling that my doctor doesn't know enough about diabetes and diabetes care	1	2	3	4	5	6
Q3	Feeling angry, scared and/or depressed when I think about living with diabetes	1	2	3	4	5	6
Q4	Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes	1	2	3	4	5	6
Q5	Feeling that I am not testing my blood sugars frequently enough	1	2	3	4	5	6
Q6	Feeling that I am often failing with my diabetes routine	1	2	3	4	5	6
Q7	Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods)	1	2	3	4	5	6
Q8	Feeling that diabetes controls my life	1	2	3	4	5	6
Q9	Feeling that my doctor doesn't take my concerns seriously enough	1	2	3	4	5	6
Q10	Not feeling confident in my day-to-day ability to manage diabetes	1	2	3	4	5	6
Q11	Feeling that I will end up with serious long-term complications, no matter what I do	1	2	3	4	5	6
Q12	Feeling that I am not sticking closely enough to a good meal plan	1	2	3	4	5	6
Q13	Feeling that friends or family don't appreciate how difficult living with diabetes can be	1	2	3	4	5	6
Q14	Feeling overwhelmed by the demands of living with diabetes	1	2	3	4	5	6
Q15	Feeling that I don't have a doctor, who I can see regularly enough about my diabetes	1	2	3	4	5	6
Q16	Not feeling motivated to keep up my diabetes self management	1	2	3	4	5	6
Q17	Feeling that friends or family don't give me the emotional support that I would like	1	2	3	4	5	6

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Health Innovation Network South London

Diabetes Distress - Instructions for scoring

The DDS17 yields a total diabetes distress scale score plus 4 sub scale scores, each addressing a different kind of distress. To score, simply sum the patient's responses to the appropriate items and divide by the number of items in that scale. The letter in the far right margin corresponds to that item's subscale as listed below. **We consider a mean question score of 3 or higher (moderate distress) as a level of distress worthy of clinical attention.** Place a check on the line to the far right if the mean question score is ≥ 3 to highlight an above-range value.

We also suggest reviewing the patient's responses across all questions, regardless of mean question scores. It may be helpful to inquire further or to begin a conversation about any single question that scored 3 or higher.

Total DDS Score:		
a. Sum of 17 questions		
b. Divide by:	17	
c. Mean item score:		≥ 3 ____

A. Emotional Burden		
a. Sum of 5 questions (1, 3, 8, 11, 14)		
b. Divide by:	5	
c. Mean item score:		≥ 3 ____

C. Regimen-related Distress		
a. Sum of 5 questions (5, 6, 10, 12, 16)		
b. Divide by:	5	
c. Mean item score:		≥ 3 ____

B. Physician-related distress		
a. Sum of 4 questions (2, 4, 9, 15)		
b. Divide by:	4	
c. Mean item score:		≥ 3 ____

D. Interpersonal Distress		
a. Sum of 3 questions (7, 13, 17)		
b. Divide by:	3	
c. Mean item score:		≥ 3 ____

Appendix 9 – NICRF COVID-19 Pre-Screening Questionnaire

NI CRF CLINICAL RESEARCH FACILITY **NICRF – Subject/Visitor COVID-19 Screening Checklist**

Subject/Visitor Name:	
Date & Time of Appointment:	____ /______ /_____ _____:_____
Study name (If applicable):	
Subject DOB (If applicable):	____ /______ /_____

Telephone screening should be completed within 72hours of appointment date.

Arrival screening should be completed outside entrance to NICRF, immediately prior to visit.

In the last 14 days has the subject/visitor had any of the following:	**TELEPHONE SCREENING (YES/NO)**	**ARRIVAL SCREENING (YES/NO)**	**NOTES**
A high temperature?			
A new continuous cough?			
A loss of taste or smell?			
Contact with a person with any of these symptoms or confirmed case of COVID-19?			
Initial and Date			

If the subject/visitor answers YES to any of the above:

The subject/visitor should **not** attend for their planned appointment/enter the unit. A new appointment will be made in accordance with most current guidance.

Advise the subject/visitor to contact their GP or visit https://covid-19.hscni.net for HSC Public Health for guidance on what to do next.

Advise the subject/visitor that in a medical emergency, to call an ambulance.

If the subject/visitor has answered NO to all of the above:

They can attend their appointment as planned. Advise them to arrive on time for their appointment and wait in their car until contacted by research staff to meet at main entrance of BCH.

Subjects/visitor will be screened again as above prior to entering the NICRF. If screening passed, subject will be escorted by research staff into NICRF room booked.

Remind subject/visitor to minimise number of people attending with them. With exception of carers, additional persons may be asked to wait outside the NICRF/hospital setting.

Subjects/carers/visitors will be asked to wash their hands on arrival, and wear a surgical mask (which will be provided) for duration of their visit.

Version 1.1 created 11/06/20

Appendix 10– Retinitis Pigmentosa Grading Form

NaviSight Grading Form - Right Eye - RP

NaviSight Grading Form

*Required

1. Participant Number

Optos Wide-Field

2. Image Quality *

Mark only one oval.

- Good
- Fair
- Poor
- Ungradable

3. Vessel Attenuation *

Mark only one oval.

- Normal
- Slight Narrowing
- Moderate Narrowing
- Severe Narrowing

Optic Disc Grading

4. Cup to Disc Ratio *

5. Optic Disc Pallor *

Mark only one oval.

- ( ) Normal
- ( ) Slight Pallor
- ( ) Moderate Pallor
- ( ) Atrophic

6. Disc Pathology *

Mark only one oval.

- ( ) Yes
- ( ) No

7. Disc Pathology Descriptor *

____

Optos Auto Fluorescence RE

8. Image Quality *

Mark only one oval.

- ( ) Good
- ( ) Fair
- ( ) Poor
- ( ) Ungradable

MultiColour Imaging RE

9. Image Quality *

Mark only one oval.

- ( ) Good
- ( ) Fair
- ( ) Poor
- ( ) Ungradable

10.

Tick all that apply.

	Infrared Reflectance	Green Reflectance	Blue Reflectance	Multicolour
None	[ ]	[ ]	[ ]	[ ]
Pigment	[ ]	[ ]	[ ]	[ ]
Atrophy	[ ]	[ ]	[ ]	[ ]
Atrophic changes in the macula	[ ]	[ ]	[ ]	[ ]

OCT Grading

11. OCT present *

Tick all that apply.

- [ ] Posterior Pole
- [ ] 7-lines
- [ ] No

12. Image Grading *

Mark only one oval.

- Good
- Fair
- Poor
- Ungradable

13. CST *

14. Volume *

15. Is segmentation correct? *

Mark only one oval.

- Yes
- No

16. Did you correct segmentation? *

Mark only one oval.

- Yes
- No
- N/A

17. VMA *

Mark only one oval.

- Yes
- No

18. VMT *

Mark only one oval.

- Yes
- No

19. ERM *

Mark only one oval.

- Yes
- No

20. Intraretinal Fluid *

Mark only one oval.

- Yes
- No

21. Subretinal Fluid *

Mark only one oval.

- Yes
- No

22. Location of fluid *

Mark only one oval.

- ◯ Foveal
- ◯ Extrafoveal
- ◯ Both
- ◯ N/A

23. Hyperreflective Foci *

Mark only one oval.

- ◯ Yes
- ◯ No

24. Hyperreflective Foci - Count *

Mark only one oval.

- ◯ 0-10
- ◯ 11-20
- ◯ 21-30
- ◯ 31-40
- ◯ 41+
- ◯ N/A

25. Which layer are the foci in? *

Tick all that apply.

- ☐ RPE
- ☐ ONL
- ☐ PR
- ☐ Inner layers
- ☐ N/A

26. Foveal Scan Number *

___

27. Choroid Measurement (at fovea) *

___

28. Outer Layer Measurement (foveal) *

___

29. Outer Layer Measurement (500 nasal) *

___

30. Outer Layer Measurement (500 temporal) *

___

31. Outer Layer Measurement (1000 nasal) *

___

32. Outer Layer Measurement (1000 temporal) *

___

33. Outer Layer Measurement (3000 nasal) *

___

34. Outer Layer Measurement (3000 temporal) *

___

35. Inner Layer Measurement (foveal) *

36. Inner Layer Measurement (500 nasal) *

37. Inner Layer Measurement (500 temporal) *

38. ONL measurement (fovea) *

39. Is ELM intact? *

Mark only one oval.

- Yes
- No

40. where is remaining ELM? *

Mark only one oval.

- Present Foveal
- Present Extrafoveal
- Not Present
- Both

41. if not, width of ELM break at foveal scan *

42. EZ *

Tick all that apply.

- Present Foveal
- Present Extrafoveal
- Not present
- Both

43. Is EZ present continually? *

Mark only one oval.

- Yes
- No

44. if not - measurement of remaining EZ *

Appendix 11– Diabetes Grading Form

NaviSight - Right Eye - Diabetes

NaviSight Grading Form

*Required

1. Participant Number

____

Optos Wide-Field

2. Image Quality *

Mark only one oval.

- ◯ Good
- ◯ Fair
- ◯ Poor
- ◯ Ungradable

3. Vessel Attenuation *

Mark only one oval.

- ◯ Normal
- ◯ Slight Narrowing
- ◯ Moderate Narrowing
- ◯ Severe Narrowing

Optic Disc Grading

4. Cup to Disc Ratio *

____

Disc Pathology

5. New Vessels on the Disc *

Mark only one oval.

- Yes
- No

6. Haemorrhage on the disc *

Mark only one oval.

- Yes
- No

7. Fibrosis on the disc *

Mark only one oval.

- Yes
- No

8. Disc Pallor *

Mark only one oval.

- Normal
- Slight Pallor
- Moderate Pallor
- Atrophic

Optos Auto Fluorescence

9. Image Quality *

Mark only one oval.

- Good
- Fair
- Poor
- Ungradable

MultiColour Imaging

10. Image Quality *

Mark only one oval.

- Good
- Fair
- Poor
- Ungradable

11. Multicolour Grading

Tick all that apply.

	Infrared reflectance	Green Reflectance	Blue reflectance	Multicolour
None	☐	☐	☐	☐
Microaneurysms	☐	☐	☐	☐
Haemorrhages	☐	☐	☐	☐
Fibrosis	☐	☐	☐	☐
Atrophy	☐	☐	☐	☐
Exudate	☐	☐	☐	☐
Cotton Wool Spots	☐	☐	☐	☐
Pre-retinal Haem	☐	☐	☐	☐
Retinal Neovascularisation	☐	☐	☐	☐
New Vessels	☐	☐	☐	☐
IRMA	☐	☐	☐	☐
Vascular Loops	☐	☐	☐	☐
ERM	☐	☐	☐	☐
DME	☐	☐	☐	☐

OCT Grading

12. OCT present? *

Tick all that apply.

☐ Posterior Pole
☐ 7-lines
☐ No

13. Image Grading *

Mark only one oval.

◯ Good
◯ Fair
◯ Poor
◯ Ungradable

14. CST *

____

15. Volume *

____

16. Is segmentation correct? *

Mark only one oval.

◯ Yes
◯ No

17. Did you correct segmentation? *

Mark only one oval.

◯ Yes
◯ No
◯ N/A

18. VMA *

Mark only one oval.

- Yes
- No

19. VMT *

Mark only one oval.

- Yes
- No

20. ERM *

Mark only one oval.

- Yes
- No

21. Intraretinal Fluid *

Mark only one oval.

- Yes
- No

22. Subretinal Fluid *

Mark only one oval.

- Yes
- No

23. Location of Fluid *

Mark only one oval.

- Foveal
- Extra foveal
- Both
- Not applicable

24. Hyperreflective Foci *

Mark only one oval.

- Yes
- No

25. Hyperreflective Foci - Count *

Mark only one oval.

- 0-10
- 11-20
- 21-30
- 31-40
- 41+
- N/A

26. What layer are the foci in? *

Tick all that apply.

- N/A
- RPE
- ONL
- PR
- Inner layers

27. Foveal Scan Number *

28. Choroid Measurement (at fovea) *

29. Outer Layer Measurement (foveal) *

30. Outer Layer Measurement (500 nasal) *

31. Outer Layer Measurement (500 temporal) *

32. Outer Layer Measurement (1000 nasal) *

33. Outer Layer Measurement (1000 temporal) *

34. Outer Layer Measurement (3000 nasal) *

35. Outer Layer Measurement (3000 temporal) *

36. Inner Layer Measurement (foveal) *

37. Inner Layer Measurement (500 temporal) *

38. Inner Layer Measurement (500 nasal) *

39. ONL measurement (foveal) *

40. Is ELM intact? *

Mark only one oval.

- Yes
- No

41. Where is remaining ELM present? *

Mark only one oval.

- Foveal
- Extrafoveal
- Both
- Not present

42. if not, width of remaining ELM at foveal scan? *

43. EZ *

Tick all that apply.

- [ ] Present Foveal
- [ ] Present Extrafoveal
- [ ] Not present
- [ ] Both

44. Is EZ present continually? *

Mark only one oval.

- Yes
- No

45. If not - measurement of remaining EZ *

Appendix 12– Walkaround Guide

NAVISIGHT WALKAROUND

Participant ID: NAVI

Date of Walkaround:

Time of Walkaround:

Before Walkaround

How confident are you in walking around this route?

Are you anxious about walking around the route?

Are you anticipating any potential problems walking around the route?

While walking

Discuss the problems you're encountering as you walk around

Lighting	Bins	Tactile Paving	Width of Walkway	
Street Furniture	Bikes	Amount of people	Colour Contrast	
Bollards	Pavement works	Crowds	Stairs/Railings	Signs/Navigation
A-boards	Cracks in pavements	Pedestrian Crossings	Kerbs	Trees and shrubbery
Signage	Cars	Parked Cars	Shared Space	Al fresco dining

After

How confident did you feel walking around this route?

Were you anxious walking the route?

Are there any big problems that stand out to you?

Overall score of difficulty =

Score 1-5 (1 = not difficult/low confidence/no anxiety – 5 = difficult, high confidence, anxiety)

	Level of Difficulty	Confidence Level	Anxiety Level	Time Taken
Botanic Train Station – University Street				
Lower Crescent – QUB Library Parking				
Library Parking – Botanic Gardens				
Botanic Gardens				
Botanic Gardens – Lower Crescent				
Lower Crescent- Shaftesbury Square				
Shaftesbury Square – Botanic Train Station				

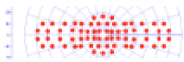
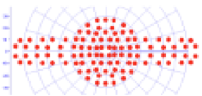
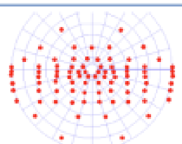
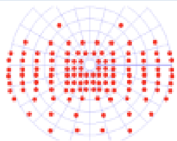
	Light Levels (lux)	Noise Level (dB)	Time
Lower Crescent (Town Square)			
University Street (French Village)			
Botanic Garden Gates (QUB library)			
In Botanic Gardens (Yard Sign)			
QUB Lanyon Gates			
University Street (Villa Italia)			
Laverys			
Postbox on Botanic			

Introduction

It may be necessary, in some cases, to obtain an estimation of visual aptitude based on the fusion of the two monocular visual fields. The present document describes the methodology and application of this analysis.

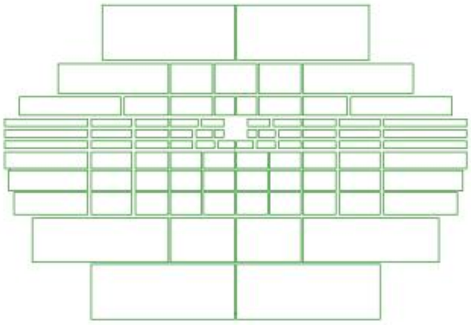
However, it must be noted that this approach as limitations: the thresholds obtained under binocular conditions are usually slightly better (up to 3 dB) than thresholds obtained under monocular conditions. Also, in some pathologies, binocular fusion may be lost and binocular suppression may occur resulting in significant reduction of thresholds.

For these reasons, visual field test for visual aptitude is preferably performed under binocular conditions. On the Vision Monitor system, specific test procedures are available for that purpose.

Procedures	Maps	Clinical applications
Driving aptitude Group 1 Binocular visual field realized with Goldmann test size III and the 3 zones strategy at 12 dB supraliminal level. Deficits are sought in the central field up to 20 degrees of eccentricity and along the horizontal meridian up to 60 degrees.		• evaluation of driving aptitudes group 1
Driving aptitude Group 2 Binocular visual field realized with Goldmann test size III and the 3 zones strategy at 12 dB supraliminal level. Deficits are sought in the central field up to 30 degrees of eccentricity and along the horizontal meridian up to 80 degrees.		• evaluation of driving aptitudes group 2
Low vision Binocular visual field realized with Goldmann test V4e. (Esterman score with 85 points)		• evaluation of visual incapacity
Esterman 120 Binocular visual field realized with Goldmann test size III and the 3 zones strategy at 12 dB supraliminal level. (Esterman score with 120 points) This test is only available on model MonCvONE		• evaluation of visual incapacity

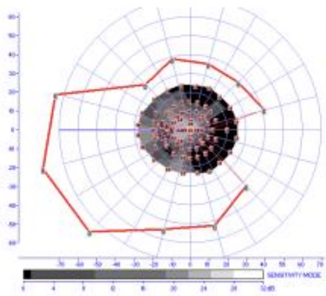
Methodology

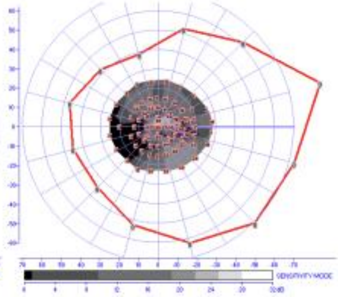
The visual field is divided into 85 rectangular areas (the so called Esterman grid), each area representing one point of visual function. The software goes over the different points that have been tested, including the data from the right eye as well as the left eye, and identify which area they belong to. It then defines for each area whether there was or was not a response.
The result is labelled as "defective area" if no response was obtained from both eyes or "normal are" in the other case.

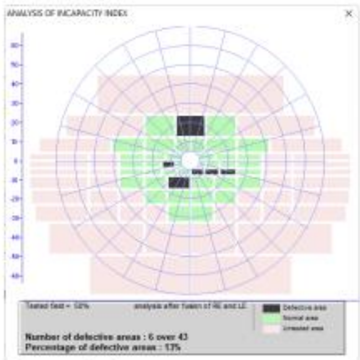


Application

1- Read one monocular visual field result from the patient
2- Then run the ANALYSIS – Incapacity index function
3- The software generates 3 windows
   - the result from the right eye with a linear scale
   - the result from the left eye with a linear scale
   - the fusion of the two with the Esterman grid







The result shows:
- in green: the "normal" areas
- in black: the "defective" areas
- in pink: the areas that have not been tested with static tests

Appendix 14 - Example Participant Reports

Diabetes -NAVI001

NaviSight Clinical Participant Report

Participant Number: NAVI001

Gender: Male

Age: 72

Diagnosis: Diabetes

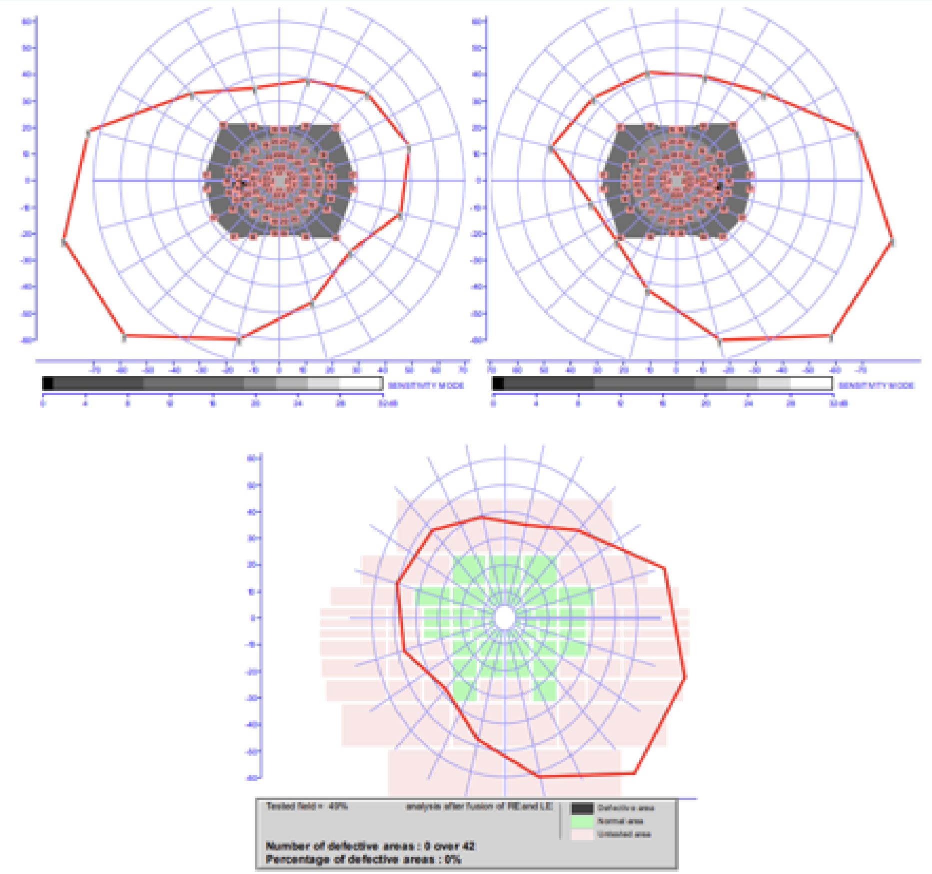
DR Level: None

Diabetes Information: Remission – 15 years

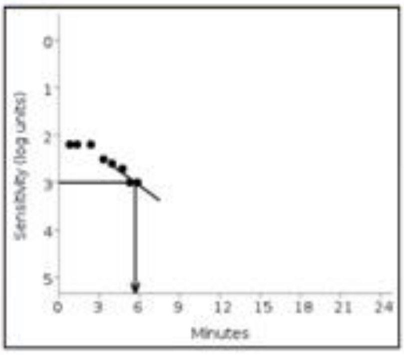
Clinical Results

	Right Eye	Left Eye	Both Eyes
Visual Acuity	0.0	0.0	0.0
Contrast Sensitivity	1.35	1.35	1.35
Visual Fields	0	0	-
Dark Adaptation	5.71	5.19	-

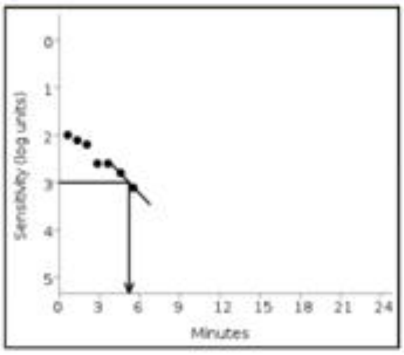
Visual Fields



Dark Adaptation

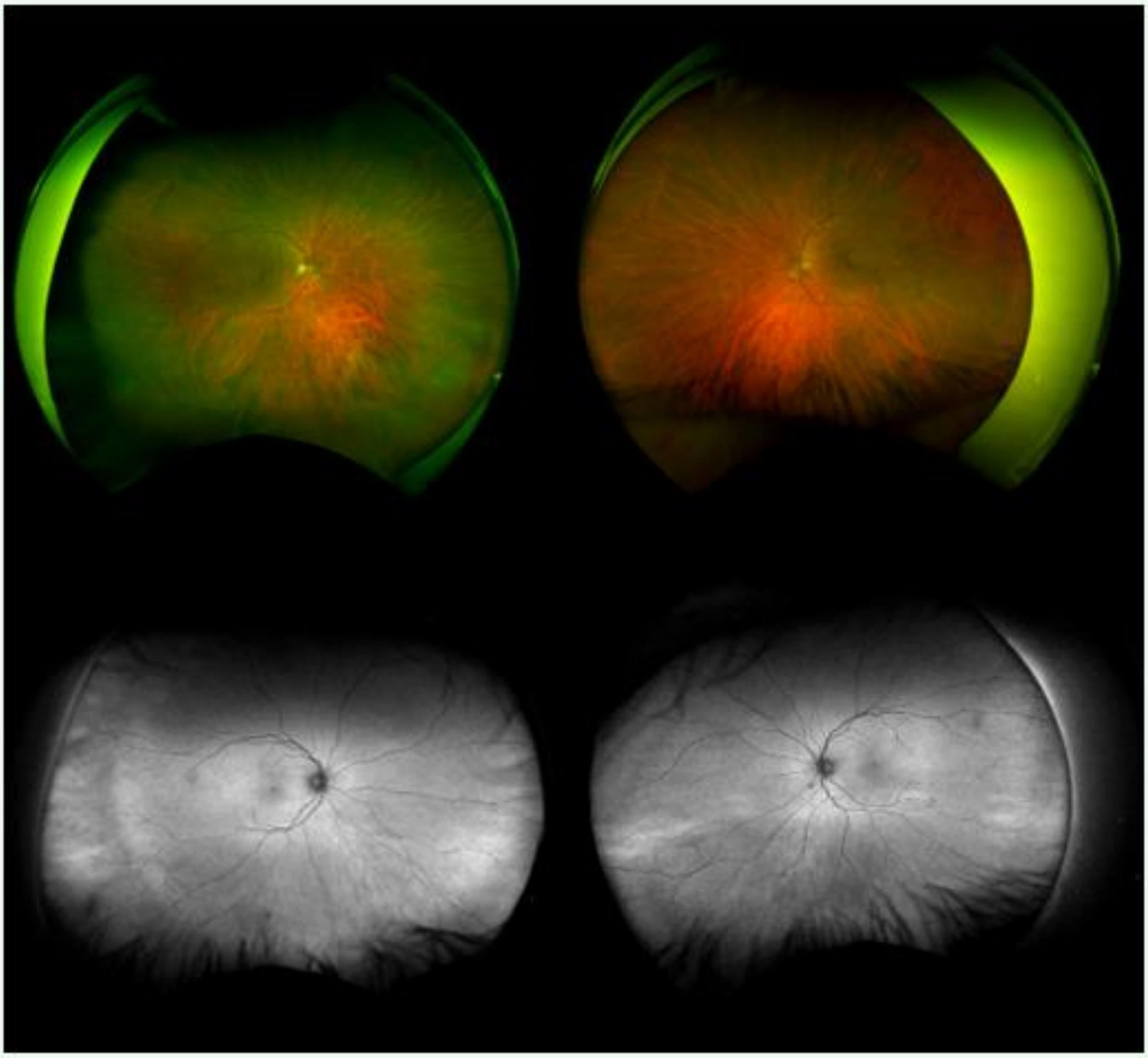


Rod Intercept is 5.71 minutes.
Fixation Error Rate is 0%.

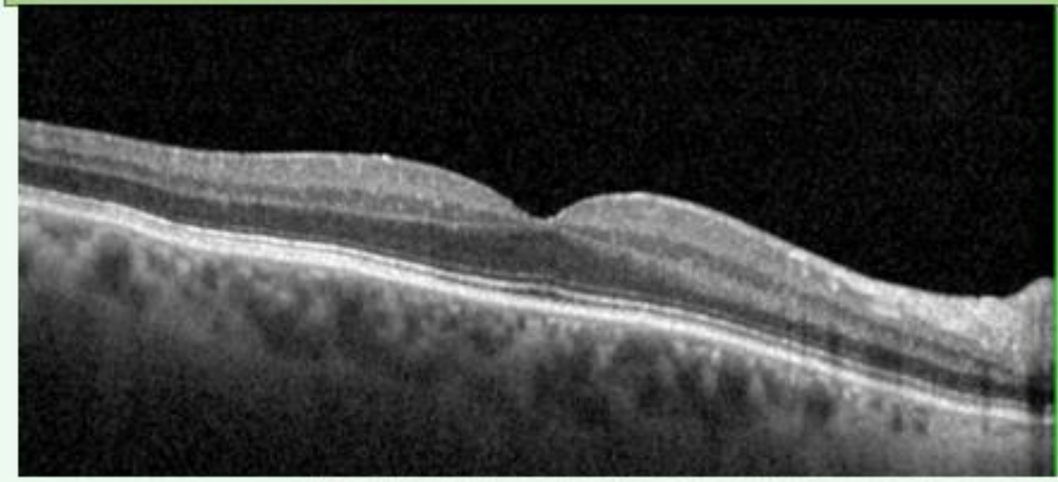


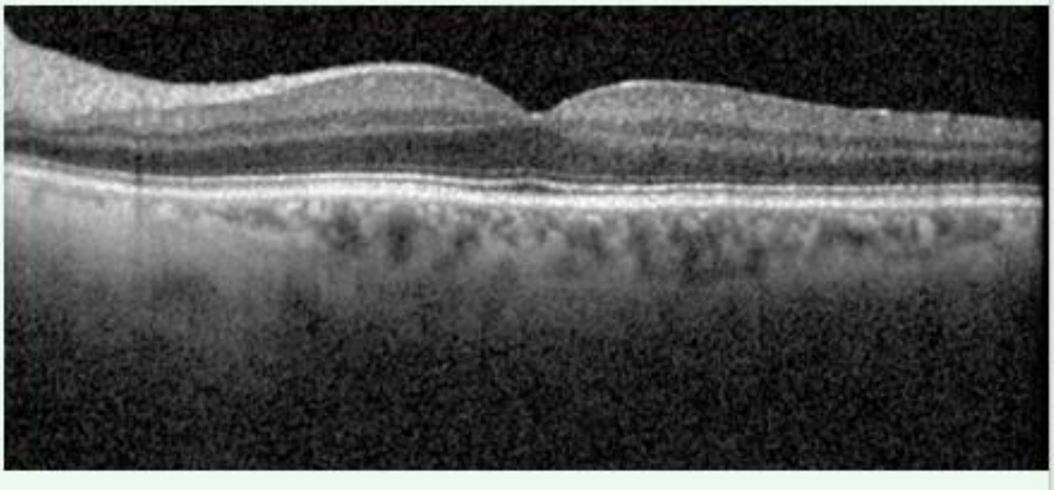
Rod Intercept is 5.19 minutes.
Fixation Error Rate is 0%.

Optos Images

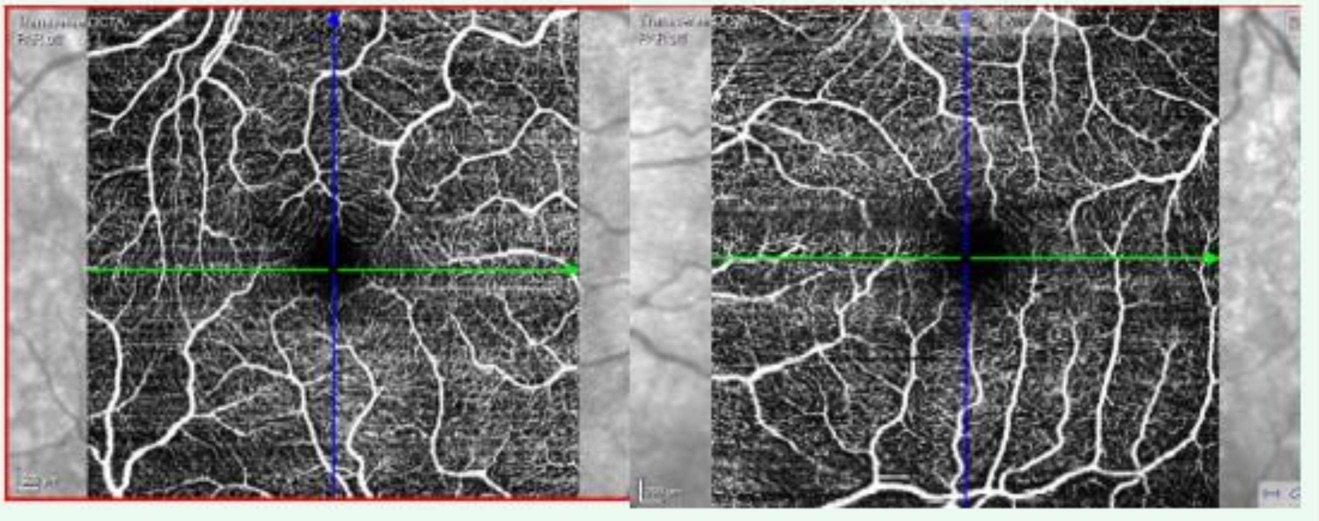


OCT Images (RE and LE)

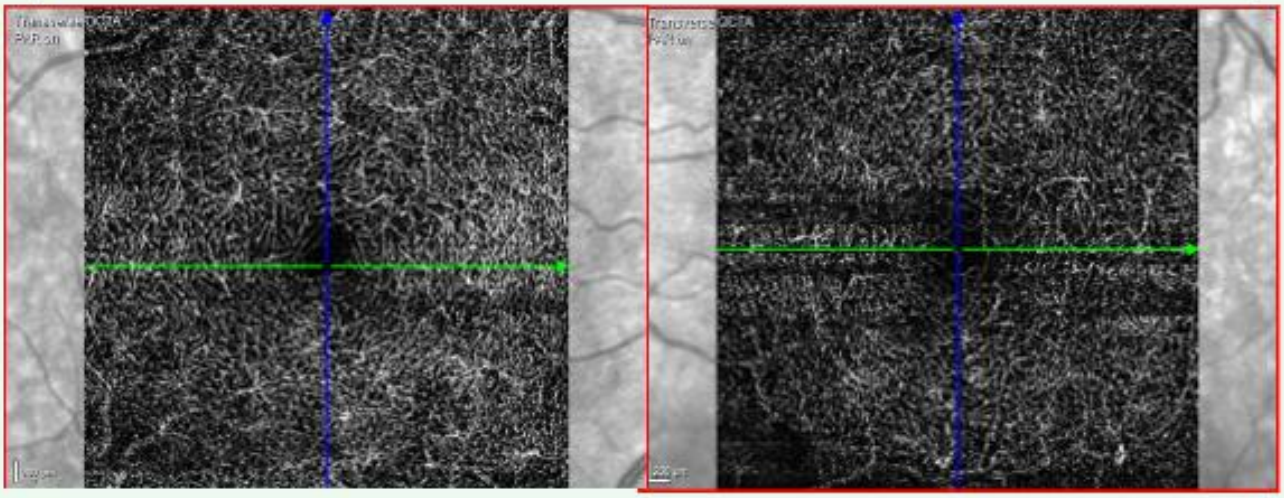




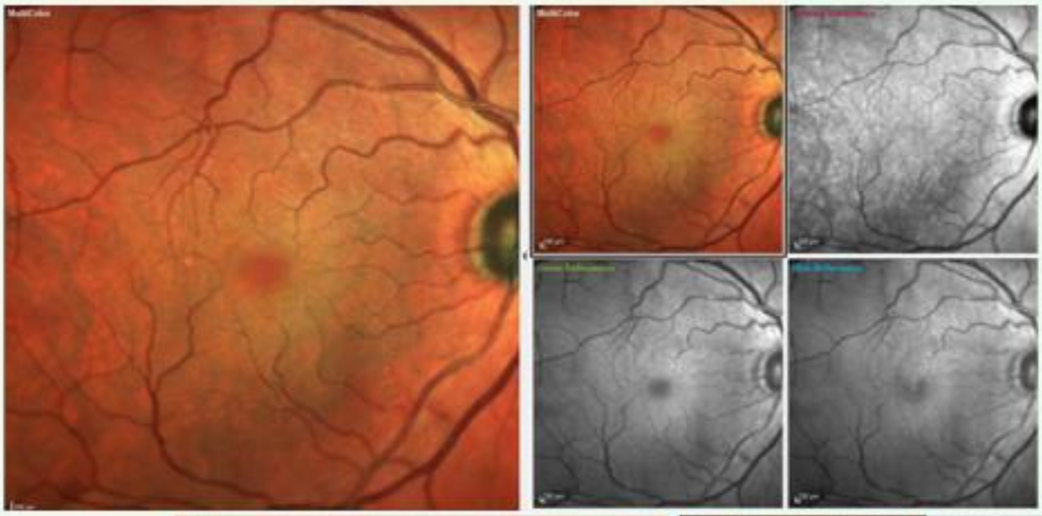
OCTA Images (SVC)

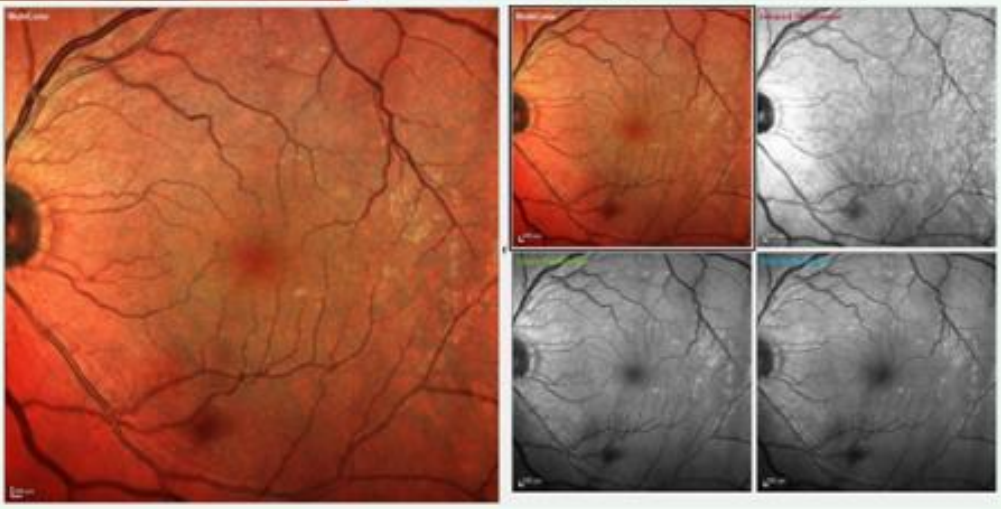


OCTA Images (DVC)



Multicolour Images (RE then LE)





Retinitis Pigmentosa – NAVI002

NaviSight Clinical Participant Report

Participant Number: NAVI002

Gender: Male

Age: 40

Diagnosis: RP

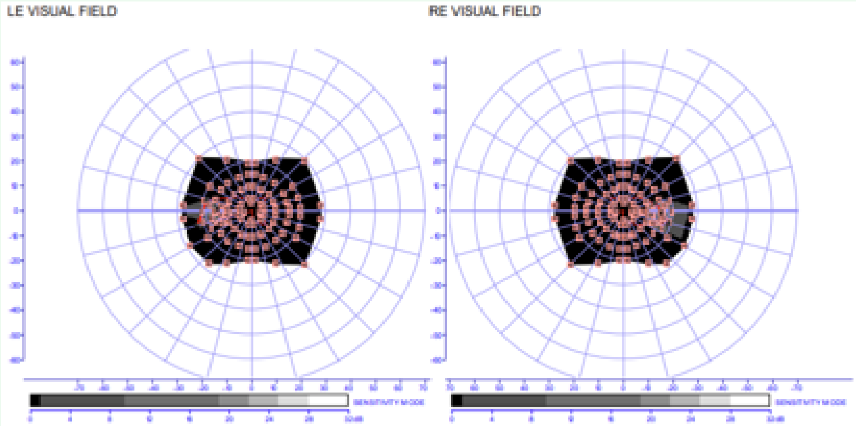
DR Level: N/A

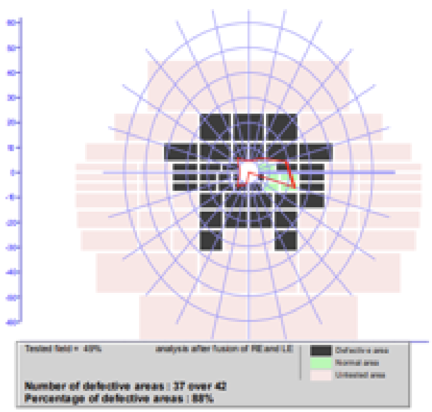
Diabetes Information: N/A

Clinical Results

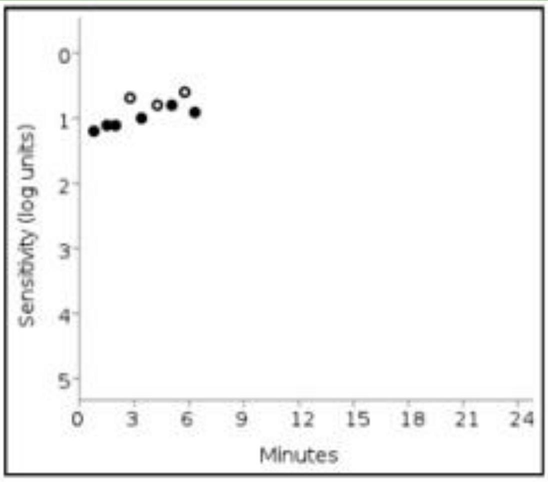
	Right Eye	Left Eye	Both Eyes
Visual Acuity	0.4	0.2	0.4
Contrast Sensitivity	0.15	0.45	0.75
Visual Fields	13.3	13.6	-
Dark Adaptation	>6.5	>6.5	-

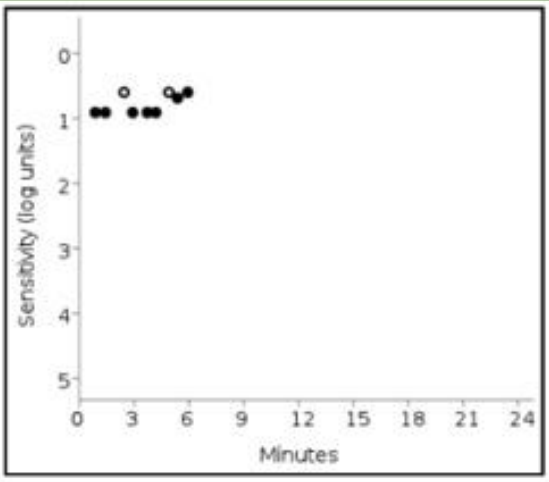
Visual Fields





Dark Adaptation

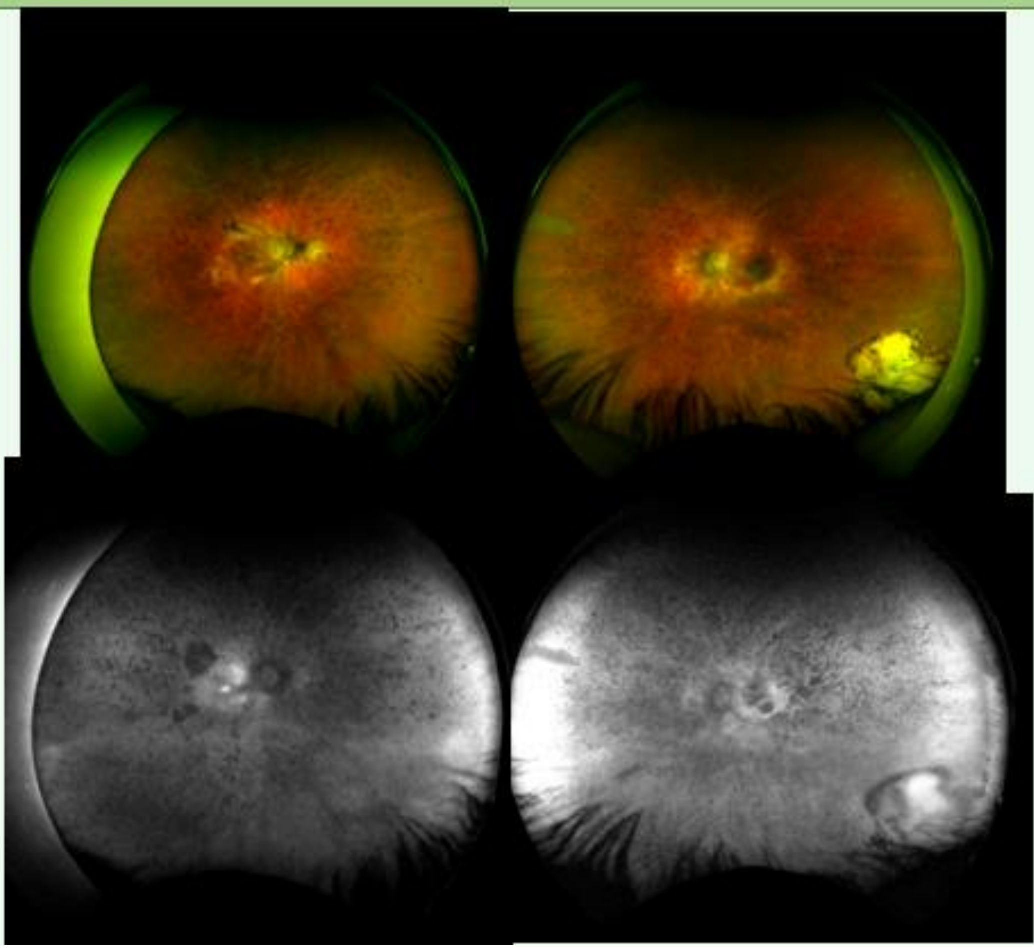




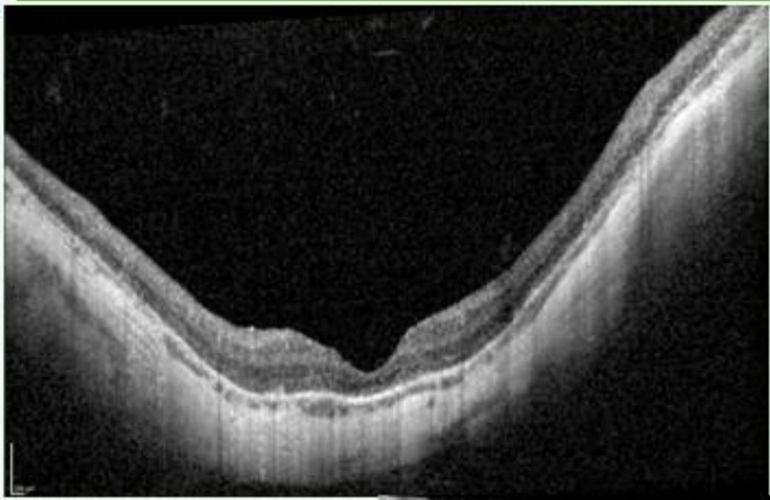
Rod Intercept is > 6.5 minutes.
WARNING: Fixation Error Rate is 33%.

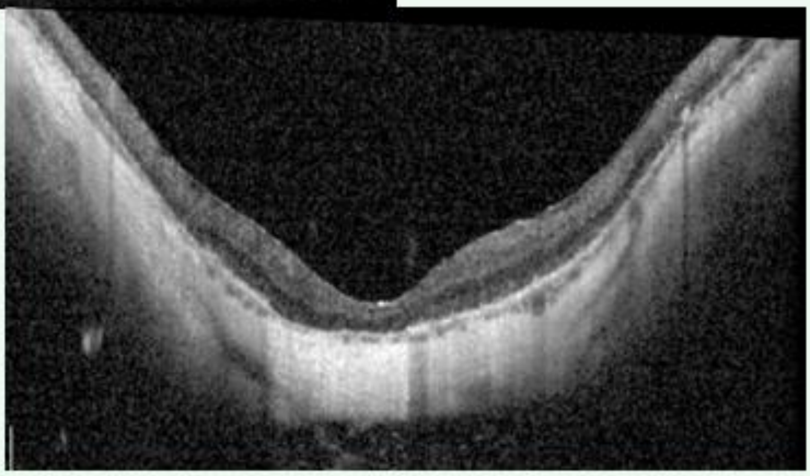
Rod Intercept is > 6.5 minutes.
Fixation Error Rate is 22%.

Optos Images

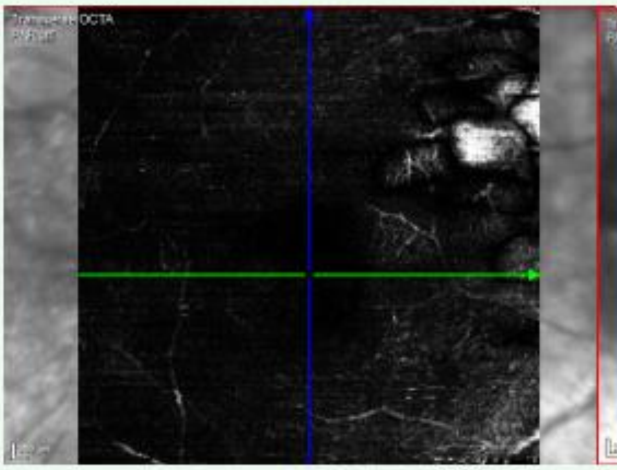


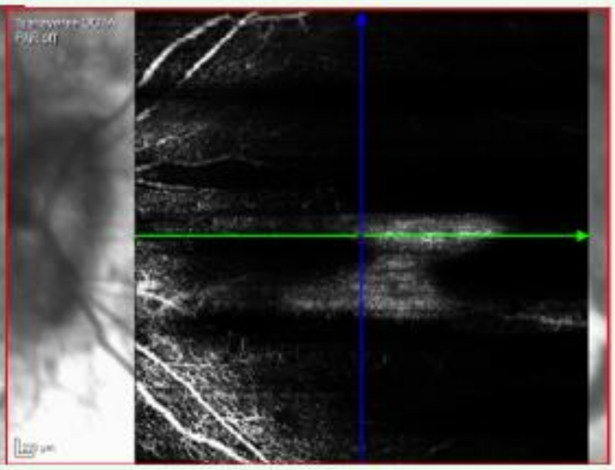
OCT Images (RE and LE)



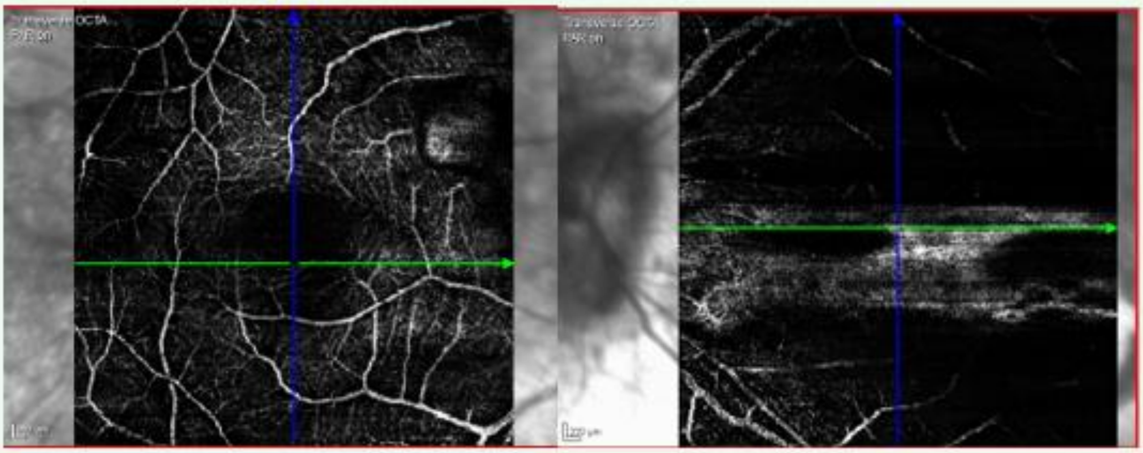


OCTA Images (SVC)

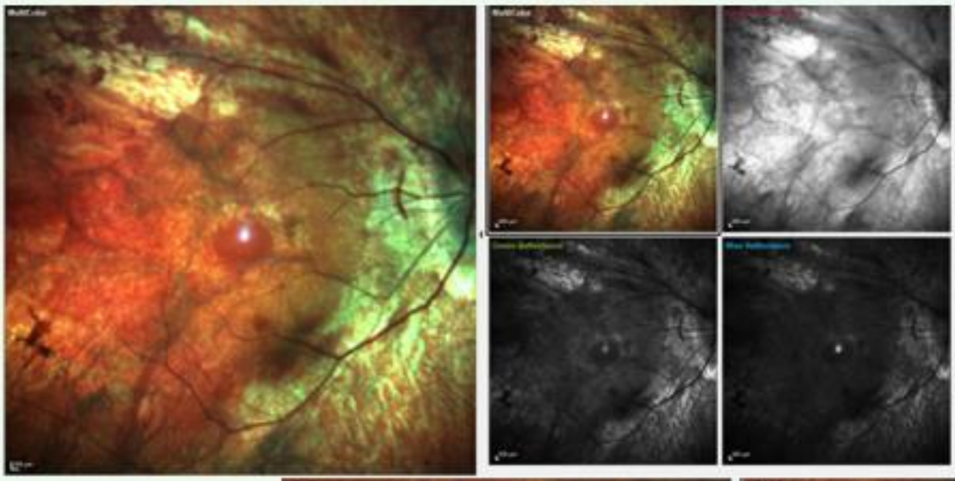


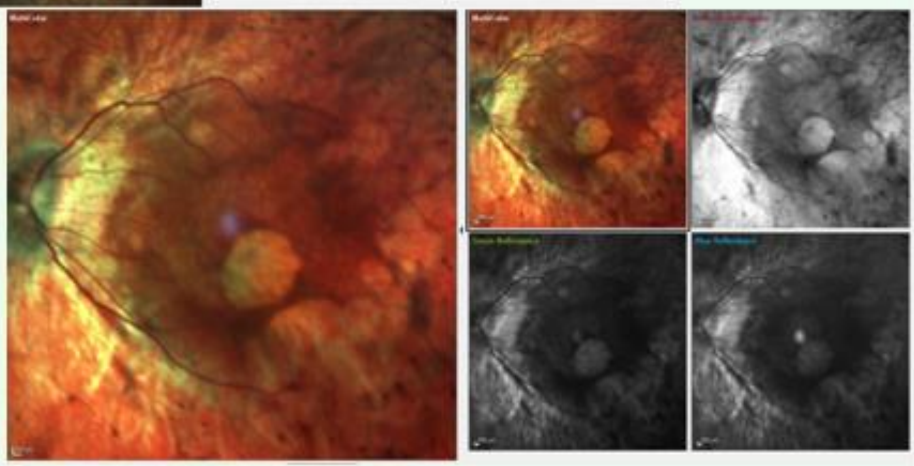


OCTA Images (DVC)



Multicolour Images (RE then LE)





Appendix 15 - Final participant report

The NaviSight Study – Participant Report

Firstly, we would like to thank you for your participation in the NaviSight Study. Without your help, this study simply would not have been possible. Please find a short report of the purpose and results of the study below. We hope you find this interesting and should you have any questions please let us know on lcushley01@qub.ac.uk.

Why did we do the study?

This study was completed because many people with a visual impairment feel that our towns and cities are ‘hostile’ and ‘not fit for purpose’. The barriers within our streets can make it difficult for someone with a visual impairment to navigate due to parked cars on pavements, advertisement boards and uneven pavements.

We wanted to investigate if the level of vision loss correlates with difficulty moving around our towns and cities.

How did we do this?

- You completed a walk around Botanic Avenue and Queen's University Belfast letting us know what (if any) issues you faced when walking this route.
- You attended the Northern Ireland Clinical Research Facility (in the city hospital) for:
    - photographs and scans of your eyes
    - vision tests.
    - questionnaires

How many participants attended the study?

In total, 33 people attended for the study, 22 had diabetes and 11 had retinitis pigmentosa (RP). The age range was 18-76 years and 70% of participants were male. Of those who had diabetes most (73%) had type 1 diabetes and the duration of diabetes ranged from 2 years – 67 years.

Results of the Study

- Over 70% of participants had issues with visual function
- 80% of those with RP faced problems when completing the walkaround
- 44% of all participants reported issues with difficulty, confidence and anxiety during the walkaround

- 30% of participants reported confidence issues during the walkaround while
- 36% reported difficulties when walking and navigating
- 27% reported some level of anxiety
- Some of the most common issues discussed during the walk were bollards, shop signs, advertisement boards, uneven pavements, parked cars, colour contrast, tree roots and leaves.
- While visual function loss seems to correlate with difficulties for people with retinitis pigmentosa, people with diabetes do not seem to have the same level of difficulty. However, many participants had some level of difficulty even if the vision was good.

What next?

This study is important and the first of its kind to be undertaken. We aim to create more interest and in-depth studies on the topic in the future by presenting the results of this study at conferences, publishing papers and talking to policy makers. The results have been presented at 2 international conferences already and are due to be presented at a further 3 conferences so far. We will share these results with people in planning and architecture as well raise awareness of the issues faced by disseminating our results widely.