ANGLIA RUSKIN UNIVERSITY

FACULTY OF SCIENCE AND ENGINEERING

THE EFFECT OF RETINITIS PIGMENTOSA ON ACTIVITIES OF DAILY LIVING

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Dedication

I dedicate this PhD to my lifetime heroes, my brothers, Amin and Moein. Although the beautiful autumn wind took away their leaves at their sapling age, their souls have grown into two compelling and versatile trees within me, giving refuge and succour. My brothers will always be by my sides as I embrace and honour their memory, from the first step to the last breath of my life.

Taghdim be Daadaashaam

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Acknowledgment

The cliché of PhD being a marathon is frequently overused but while I did run a few marathons (quite literally) during my PhD, I realised the similarities. Calling it difficult is a massive understatement. The temptation of giving up becomes your shadow, even when you see light like a mirage, at the end of the cave. I did indeed run bruised and drained during some stages but that was part of teaching me the precious lesson of “finding remedy in pain”. I also stopped on occasion to enjoy the beautiful sceneries. However, once the light is embraced from within and the self is tamed, there is a feeling of invincibility. The euphoria of finishing the race is indescribable.

My PhD has certainly been a long marathon that I shall always treasure. I have acquired an enormous level of knowledge but more importantly I have discovered greater self-awareness, discipline and confidence. A lesson that stands out for me during the marathon is the exclusion of competition and running at my own pace.

The list of names of family, friends, peers, colleagues and team-mates supporting and cheering me on is a long one and so, I thank each one of them without mention of names. However, I would like to thank my three supervisors here: Dr Mat Timmis, Dr Kez Latham and Prof Shahina Pardhan, who demonstrated remarkable patience, understanding and support until I crossed the finish line. Dr Timmis in particular, was an inspirational coach, teaching me valuable lessons. The University of Anglia Ruskin has also been a great support over the years. Finally, I thank my parents Javad and Yeganeh, the best human beings I have had the privilege of knowing.

During my PhD, I collected data from over six hundred people with visual impairment. I am truly grateful for the honour of that introduction. In the first month of my PhD, I went to a conference in Blackpool, where I met a lady who though severely sight impaired, sees far better than most from within. From the first moment I met her, she gave me the encouragement and motivation for my studies and for finding ways of help to the visually impaired. I therefore hope that this PhD offers some insights, no matter how small.

This work would have not been possible without the participation and support of those like Carole Holmes, who has become a friend, a colleague and a mother figure to me. We shall undoubtedly continue our conversations in the Northern accent, ones in which I can freely call her “love”.

Abstract

Anglia Ruskin University

Faculty of Science and Engineering

The effect of Retinitis Pigmentosa (RP) on Activities of Daily Living (ADLs)

The majority of previous research investigating the impact of low vision on the completion of activities of daily living (ADLs) have examined visual impairment as a whole. The aim of this thesis was to provide a comprehensive overview of ADLs to determine what the most difficult areas are for people with Retinitis Pigmentosa (RP), a particular type of visual impairment. This research was achieved through both self-report questionnaire and objective analysis of human movement.

681 participants (570 with RP) were examined throughout this research. Identified through self-report, at the objective level, the most difficult ADLs amongst those with RP was mobility. In particular, at the goal level, this was identified as mobility outdoors (experimental chapter 1). Further, at the task level, orientation and walking around safely without bumping into things and tripping over or stepping off something were identified as most difficult (experimental chapter 2). Those who support people with RP perceived most of the ADLs significantly more difficult to complete (for those with RP), with greatest difference in perceptions between two groups being practical tasks. When assessing balance through measuring postural control (experimental chapter 3), those with RP showed similar postural control to those with normal vision when standing on a firm surface, regardless of the vision condition (eyes open or eyes closed). However, when standing on a foam surface with eyes open, the reduction in postural control among people with RP, compared to those with normal vision, highlighted the added importance of the somatosensory information to maintaining standing balance for those with RP. However, it was only apparent when the somatosensory system was disturbed. The examination of gait among people with RP (experimental chapter 4) demonstrated that those who used a mobility cane adopted a cautious walking behaviour in both level walking and obstacle crossing tasks. Such cautious behaviour was not evident for people with RP who did not use a cane, or for the normally sighted individuals.

This thesis is the first to provide a comprehensive overview of self-report difficulties among those with RP. Findings also demonstrate the importance of maintaining adequate foot (somatosensory) and eye (vision) health for those with RP to regulate balance control. The additional mobility training for those with RP who use a cane is necessary for their walking gait. Furthermore, the support from the carers should reflect the needs of those with RP, which helps them with their independence in completing ADLs rather than overprotecting them.

Keywords: Visual impairment, Retinitis Pigmentosa, activities of daily living, self-report questionnaire, postural stability, adaptive gait.

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Publications

Academic Journal Publications:

The below publications used data collected from the participants recruited in this PhD. Of note, not all the publications or extensive analysis are presented within the experimental chapters contained in this thesis.

Timmis, M.A., Allsop, J., Baranian, M., Baker, J., Basevitch, I., Latham, K., Pardhan, S. and van Paridon, K.N., 2017. Visual search behavior in individuals with retinitis pigmentosa during level walking and obstacle crossing. *Investigative ophthalmology & visual science*, 58(11), pp.4737-4746.

Latham, K., Baranian, M., Timmis, M.A., Fisher, A. and Pardhan, S., 2017. Relative difficulties of daily living tasks with retinitis pigmentosa. *Optometry and Vision Science*, 94(3), pp.317-328.

Latham, K., Baranian, M, Timmis, M. and Pardhan, S., 2015. Emotional health of people with visual impairment caused by retinitis pigmentosa. *PloS one*, 10(12), p.e0145866.

Latham, K., Baranian, M., Timmis, M.A. and Pardhan, S., 2015. Difficulties with goals of the Dutch ICF Activity Inventory: perceptions of those with Retinitis Pigmentosa and of those who support them. *Investigative ophthalmology & visual science*, 56(4), pp.2381-2391.

Conference Presentations:

Baranian, M., Timmis, M., Latham, K., and Pardhan, S., 2015. The effect of Retinitis Pigmentosa on Activities of Daily living. Retina UK Annual Conference, London, UK.

Baranian, M., Timmis, M., Latham, K., and Pardhan, S., 2014. Retinitis Pigmentosa and activities of daily living, 2014, Retina UK's Annual Conference, Blackpool, UK.

Baranian, M., Timmis, M., Latham, K., and Pardhan, S., 2013. The effect of Retinitis Pigmentosa on Activities of Daily living. British Congress of Optometry and Visual Science, Glasgow, UK.

1. Introduction

1.1 Activities of Daily Living

Activities of daily living (ADLs) refers to individual's daily activities. Every day individuals undertake a multitude of activities ranging from dressing, eating, walking to a shop, getting on a train, communicating with colleagues, applying for jobs and many more (Hartigan, 2007). The concept was originally suggested by the early works of Sidney Katz and his team during the 1950s (Katz et al., 1970). Since the early work, it has been used across multidisciplinary health care systems to examine the ability of individuals performing daily tasks and to obtain an understanding of individual's functional status (usually applied to patients in the health care sector). Moreover, it is adopted in decision making and health status improvement of patients with a variety of disorders (Lindsay et al., 2008). The failure to complete ADLs leads to reduced functional ability and is associated with less favourable perceived health status and has been linked to isolation and depression (Bowling and Grundy, 1997). Measuring ADLs has also been developed into an important instrument in research, where it can determine the required assistant level and predict certain body function failures such as falls (Azad et al., 2017).

1.1.1 The role of visual information in completing ADLs

To be able to complete ADLs, humans rely on rich sources of sensory inputs to plan and execute the action. The visual system, is the most important sensory system needed to complete ADLs (Schmidth and Lee, 1999). Indeed, since vision provides information pertaining to object location and orientation of body part (e.g. limb) in space, in relation to the object, this facilitates the planning of the feedforward aspect of an action (Lamme and Roelfsema, 2000). The visual system also provides information to update and correct the limb's movement during the action online control of the movement (Buckley et al., 2011). The visual system provides important sensory information to enable motion and balance within the environment, and can be seen as one of the most important aspects for safe locomotion (Schmidth and Lee, 1999).

Locomotion is an integral part of many ADLs such as walking to a shop or being able to orient and find your way and/or use public transport. Furthermore, vision plays a critical role in the control of dynamic stability, specifically, in adapting fundamental patterns in guidance of locomotion towards achieving ADLs (Patla, 1997). Thus, the lack of vision could cause failure in completing ADLs or make them difficult to achieve (Rietdyk and Rhea, 2006; Marigold, 2008).

It is very rare that when walking one's path is perfectly level and clear of hazards. It is common that individuals have to negotiate various undulations and obstacles during locomotion (Austin et al., 1999). A vital issue when considering obstacle negotiation is the ability to see these floor based hazards. The absence of vision will likely cause difficulties in gait and increase the risk of tripping on the obstacle during crossing and subsequently falling. Successfully negotiating floor based hazards (such as an obstacle crossing) relies on the visual system to provide detail regarding the height of the obstacle and distance to the obstacle (Buckley et al., 2011). This determines the placement of the limbs prior to the obstacle, the subsequent elevation when crossing and placement after successful crossing. Thus, individuals with vision loss are at an increased risk of falls (Ray et al., 2007) due to their reduced ability to accurately perceive key information in the environment (Lamoureux et al., 2008).

Failure to successfully negotiate an obstacle can lead to falls and injury. Falls usually occurs when a trip causes external force unexpectedly and interrupts the progress of the swing foot during walking causing forward rotation of the body (Barrett et al., 2010). Obstacle negotiation has potentially the greatest demand on the locomotor system and it also poses the greatest risks of falling. This is because further injuries and possible fatality could occur during falls (Austin et al., 1999). The annual cost of falls, which includes medical bills, housing, and care takers, in the UK is reported to be £2 billion (Treml et al., 2011). Studies examining the mechanisms leading to falls (such as obstacle crossing) provide additional information surrounding why falls occur and can help improve the quality of walking and prevent falls, which can reduce the cost of dealing with such issue (Finnegan et al., 2018). Much of the previous research has concentrated on the impact of age on falling; research has indicated that falls occur more in older adults (Chou et al., 2003; Weerdesteyn et al., 2005; Zhang et al., 2011) or following a health issue that may leads to dysfunctionality of mobility such as stroke, Parkinson's disease or brain injury (Chou et al., 2004; Said et al., 2008; Vitorion et al., 2010).

1.2 The extent of visual impairment and their impact on ADLs

Visual impairment (VI) has a major impact on ADLs. Those with VI experience a greater difficulty level in completing ADLs, which can lead to loss of independence (Lamoureux et al., 2004). Mobility, reading, using public transport, and engaging in hobbies or leisure activities are some of the difficult tasks to complete with VI (Fylan et al., 2005). Those with VI are also at greater risk of falls (de Boer et al., 2004). In the hope of reducing the likelihood of falling for those with VI often avoid doing certain ADLs (Kempen et al., 2009). Moreover, participation in society is hindered, which leads to isolation and depression (Verstraten et al., 2005; Alma et al., 2011; Kepman et al., 2012).

In 2015, the number of people worldwide with VI was estimated to be approximately 253 million (Ackland et al., 2017). The cause of VI varies widely between countries due to differences in health and eye care systems. The main cause of VI worldwide are uncorrected refractive errors, followed by cataract (Bruijning et al., 2010). In developed countries, the main cause of visual loss are more disorders such as Age related Macular Degeneration (AMD), Glaucoma and Retinitis Pigmentosa (RP) rather than not being able to correct refractive as a result of poor health care system (Kocur and Resnikoff, 2002; Buch et al., 2004; Congdon et al., 2004).

Retinitis Pigmentosa (RP) is a genetically inherited eye disorder which leads to vision loss (in many cases to full blindness). RP affects approximately 1 in 3500 people in the United States and Europe (Haim, 2002). RP starts with patchy losses in the peripheral vision which may progress into tunnel vision in the late stages. There is no cure for RP (Herse, 2005). The lack of cure for RP has navigated most of the researchers to finding a treatment for this disorder. Thus, very few studies have investigated the effect of RP on ADLs and the quality of life of those with RP is almost unknown. Therefore, it is important to study this area of research and to examine how people with RP perform ADLs.

1.3 Studying the effect of VI on ADLs

The impact of VI on completing ADLs can be measured objectively, using global measures such as time to complete an action and kinematics of human movements, such as motion measurements evaluating functional performance of a limb under different conditions (typically achieved through 3-D motion capture). To allow broader range on ADLs to be measured (the former measures can be time intensive), self-report questionnaires (SRQs) are commonly used.

SRQs are used as a measurement tool to assess the perceived difficulty in performing ADLs. Several SRQs have been developed for use in low vision clinics and communities (Massof and Rubin, 2001). Recently, the International Classification of Functioning (ICF) framework has been used in the development of the Dutch Activity Inventory questionnaire (D-AI) (Bruijning et al., 2010; Bruijning et al., 2012) to determine rehabilitation needs for those with low vision. Currently, no extensive overview of which ADL’s are difficult in people with RP exists. SRQs can be used to identify difficult ADLs for people with RP in order to determine what influences their performance and also where/how to target rehabilitation. It is expected that findings would help and support rehabilitation programmes, as well as informing those at early stages of their visual impairment of what to expect as the disease progresses. In addition, a VI such as RP can increase the difficulty of completing many ADLs without a carer's help and the amount of support from friends and family becomes valuable both practically and emotionally (Reinhardt, 2001; McIlvane and Reinhardt, 2001; Cimarolli et al., 2012). The amount of support required by the person with RP and perceived as needed by a carer could be different and this could lead to unsatisfactory outcomes for both groups. Hence, exploring the perception of difficulty between people with RP and those who support them is an important issue to explore.

1.4 Thesis outline

Prior to investigating the specific objectives of the thesis through the experimental chapters, a review of the literature is provided in chapter 2. This chapter includes the importance of both visual and gait function. It concludes by discussing some of the previous studies that have examined the effect of visual impairment, particularly those with RP, in ADLs and identifies the objectives of this PhD.

Chapter 3 comprises the methodology, which outlines various quantitative methods both in terms of questionnaire and biomechanical data. The research techniques that have been used in this thesis are presented in this chapter.

Chapter 4 is the first experimental chapter, which uses SRQs to examine what ADLs at goal level are difficult for those with RP to complete. The perception of those who support people with RP is also examined during this chapter.

Chapter 5 uses the goal level findings from chapter 4 to investigate more specifically task level information among those with RP. Using the difficult tasks identified from chapter 5 the subsequent experimental chapters, examine why these ADLs are difficult to complete through the assessment of human movement.

In chapter 6 postural stability of those with RP is examined. Differences in sway function between those with RP and normally sighted individuals is described in this chapter.

Chapter 7 (the final experimental chapter), examines the gait of those with RP during level walking and when required to negotiate a floor based obstacle. Within the RP group tested in this chapter, differences between RP cane users and those who don't use the cane are examined and compared to normally sighted people.

The general discussion, presented in chapter 8 presents the main findings of the series of experiments presented in this thesis, along with providing conclusions based on the data collected, with limitations and recommendations for future studies in the area.

2. Review of the literature

2.1 Introduction

The following chapter will present an overview of the visual system, visual impairment (VI) and retinitis pigmentosa (RP). This chapter will review the literature investigating the impact of VI on ADLs and those which have been found difficult to complete. At the end of the chapter, the aim and the associated research objectives for this thesis will be presented.

2.2 Visual system

Light enters the eye and is focussed on the retina, a 0.5 millimetre thick layer of cells, located on the inner surface of the eyeball (Frisby and Stone, 2010). Light energy is transformed into neural energy by retinal photoreceptors (rods and cones). The neural signal passes from retina to cortex with adaptations to the signal along its path (Hubbel, 1998).

There are two different types of photoreceptors in the retina; the rods and the cones. Rod cells are sensitive to light and operate under dim and dark conditions, termed scotopic light levels. They are also responsible for responding to movement in the periphery. Cone cells function during bright lighting conditions, termed photopic. They exhibit rapid responses to different light intensity and perceive images in colour. The human retina contains 120 million rod cells and 6 million cone cells (Molday and Moritz, 2015).

An important factor in the visual system is the visual eccentricity and its dependency of rods and cones. Eccentricity refers to the angular distance from the centre of visual field or from the fovea of the retina (Staugaard et al., 2016). It has been reported that by increasing the eccentricity of visual target, reaction times and error rates can increase (Carrasco et al., 1995, Wolfe et al., 1998), object recognition tasks can be deteriorated (Juttner and Rentschler, 2000), in addition it increases the difficulty to process facial expressions (Bayle et al., 2011). Eccentricity effects have been linked to the cortical magnification factor. A large cortical area is devoted to processing visual information at the fovea, thus the fovea has the largest magnification factor (Motter, 2009). The stimuli designed to be detected by cones affect contrast threshold when it is detected by rods (Buck et al., 1979, Temme and Frumkes, 1977). Thus, the lateral involvement of rods is essential for the increase in cone threshold. The light adaptation mechanisms and the interaction signals between rod and cone changes with intensity, eccentricity and stimuli size (Gloriani et al., 2016).

2.2.1 Monocular field

For a normal stationary eye, the visual field extends to ~ 60° superior and ~ 75° inferior of the horizontal meridian, and ~ 150° between nose and temple. There is a blind spot for each eye, where its projection is 3° in diameter and appears ~ 12-15 ° in the temporal hemifield. This is an area where no receptors are located, in the region when the optic nerve leaves retina. There is an overlap from either eye that makes ~ 114° of the visual field visible to both eyes (binocular vision) simultaneously (Howard and Rogers, 1995). Figures 2.1 and 2.2 demonstrates the work by Howard and Rogers (1995).

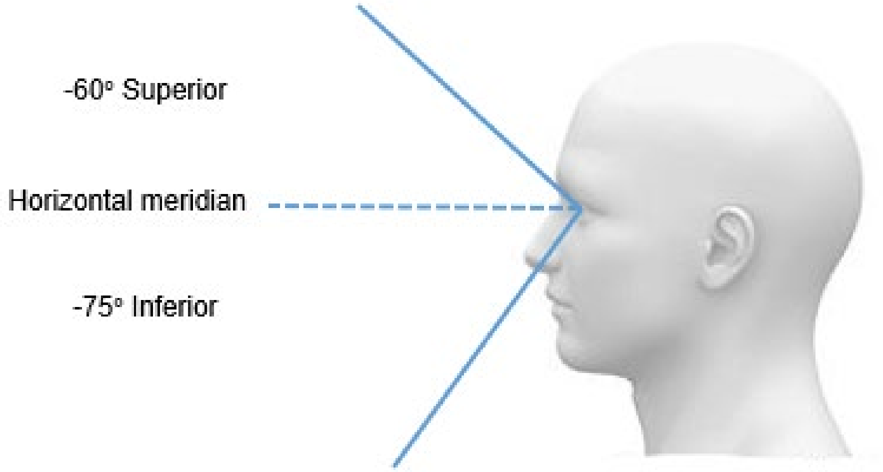

Figure 2.1. The extent of the visual field in healthy stationary eye(s), superior and inferior directions from the horizontal meridian.

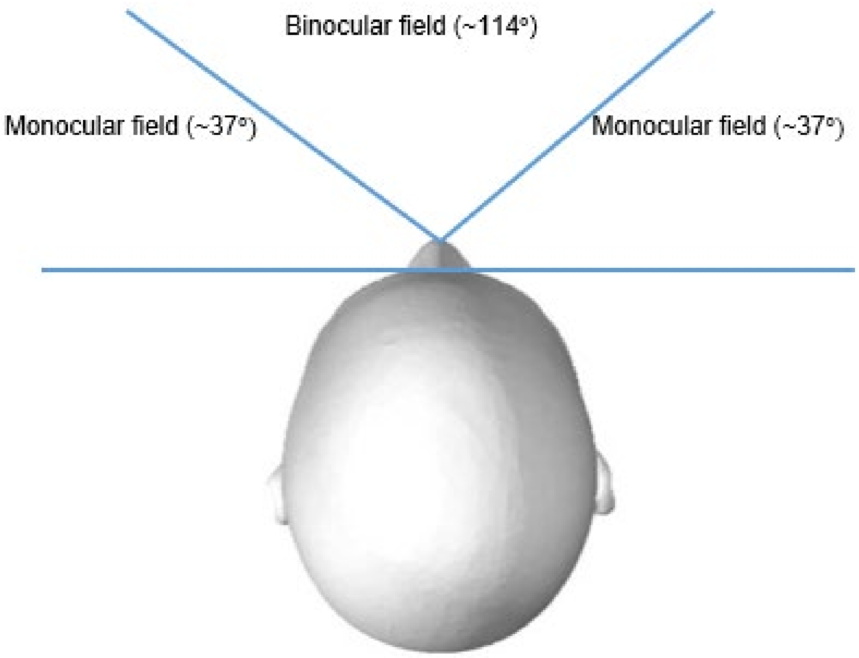

Figure 2.2. The extent of the visual field in healthy stationary eye(s), monocularly and binocularly along the transverse plane.

Moreover, the binocular vision or vision from two eyes, where the visual field overlaps is an important aspect of vision as it helps for the precise depth perception (Palmer, 1999). The reason for this function is that each eye forms an image of an object on its retina, and there is a slight disparity, which is the basis for stereopsis or depth. Figure 2.6 illustrates the overlap of binocular vision in humans.

2.2.2 Visual field

Field of vision can be divided into two sections, the central visual field and the peripheral field. The central visual field can cover from 5° to a maximum of 30° (Frisby and Stone, 2010). The visual field can also be divided along the transverse plane into the lower and upper visual field (Darker and Jordan, 2004). Some studies have emphasised the supremacy of the lower compared to upper visual field in human locomotion (Darker and Jordan, 2004; Levine and McAnany, 2005). This is most likely due to multiple limb movements in adaptive locomotion, when more information is required from the lower compared to upper visual field. In addition, obstacles are more frequent in the inferior fields.

The extent of the peripheral visual field is larger than central visual field in terms of the visual world, thus it captures most of the information needed for the visual system. However, the central vision includes most of the visual processing devoted to it. Although visual system combines the information from the central and peripheral visual field, the majority of information for visual guidance in activities such as walking is contained by peripheral visual field (Findlay and Gilchris, 1998). The importance of visual cues received by the peripheral visual field has been emphasised (Patla, 1998; Turano et al., 2005; Jovancevic et al., 2006). The restriction of peripheral visual field can be destabilizing for the control of locomotion. This is evident in those with visual impairment. Walking speed usually decreases, and individuals with peripheral visual field loss are more likely to bump into obstacles, stumble or be unable to detect stairs compared to normally sighted individuals. These could all lead to falls and serious injuries (Turano et al., 2004). However, some studies have argued that the purpose of central visual field is more strongly related to mobility function than the peripheral visual field. Hassan et al. (2007) examined navigation performance in 20 normally sighted subjects, with their field of view constricted to 10°, 20° and 40° in diameter, and concluded that the field of view required for navigation is between 10.9° and 32.1° depending on contrast condition. Lovie-Kitchin et al. (1990) also suggested that the central of 37° is most important for mobility function in individuals with low vision. Tarbett and Latham (2012) assessed the central 30° of the visual field, found that in a sample of low vision participants the central 10-30° of the visual field is the best predicted to the limitation of the mobility tasks. Timmis and Pardhan (2012) reported that individuals with central field loss adopt a cautious strategies in their gait during tasks such as obstacle crossing to prevent falling.

2.2.3 Visual pathway – Eye to brain

The pathway of the transformation light onto signal is termed the visual pathway and figure 2.3 illustrates the principle features that includes retina, optic nerve, optic chiasma, lateral geniculate bodies, optic radiations, and visual cortex (Forrester, 2002).

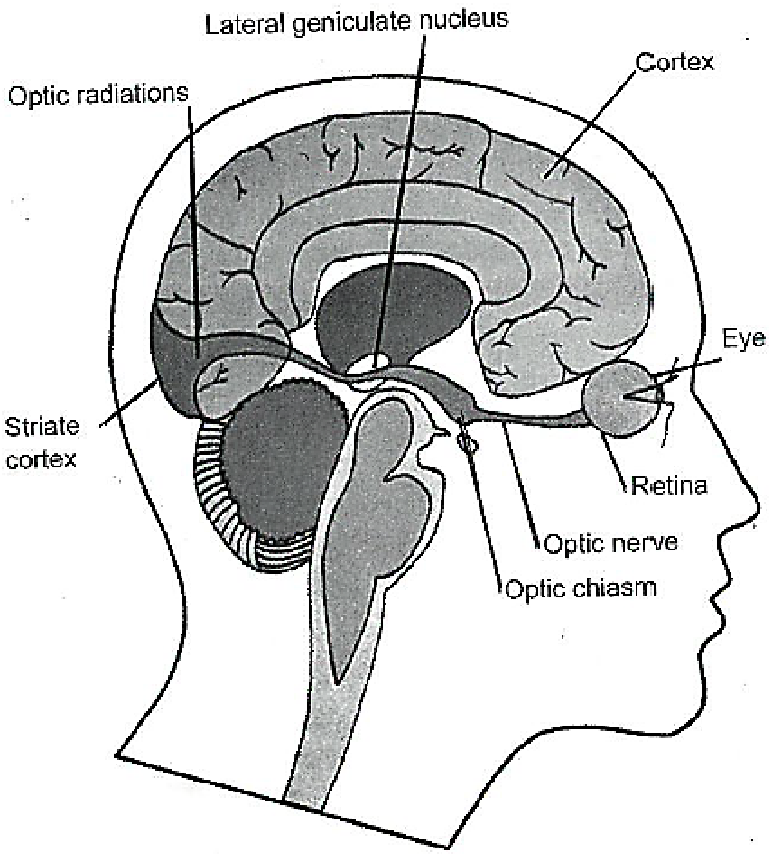

Figure 2.3. Diagrammatic illustrating the principle features of the major visual pathway that links the eyes to the cortex (Frisby and Stone, 2010).

The transformed neural signals are passed to the bipolar cell and the amacrine cell and then to the ganglion cell, all contained within the retina. The optic nerve works as a stream for the axons of the ganglion cells to transfer the signal to the brain. At the optic chiasm, information from the nasal retina and temporal visual field of eye crossed to the opposite side of the visual pathway, whereas information from temporal retina or nasal visual field remains on the same side of the visual pathway (Oyster, 2016).

Ganglion cells collect information about the visual world from the amacrine and bipolar cells. There are five main classes of retinal ganglion cells. The two best known cells are: midget cells known as parvocellular or P pathway, parasol cells known as magnocellular or M pathway. The parvocellular are small and receive inputs from relatively few rods and cones, have slow conduction velocity and respond to changes in colours. The P pathway have receptive fields where it may be either on or off (in the centre) while the surround is the opposite (Curcio and Allen, 1990). The magnocellular cells are the opposite and have large size, and receive inputs from many rods and cones, with fast conduction velocity, which can respond to low contrast stimuli. However, they are not sensitive to changes in colours (Dacey, 1993).

2.2.4 Magnocellular and parvocellular systems

The cone photoreceptors in the retina generate compressed information and transfer them to higher processing centres through three types of ganglion cells. Two of the cells are known as magno and parvo cells (Yoonessi and Yoonessi, 2011). These cells travel from the retina to the lateral geniculate nuclei (LGN) and then the primary visual cortex. Magno cells are large and have thick acons and are known to collect input from many retinal cells. Magno cells respond rapidly to stimulation. Parvo cells are smaller, with fine axons and less myelin compared to the magno cells. Parvo cells responds to the stimuli are slower than the magno cells (Foxe et al., 2008). The magnocellular and parvocellular systems are vital in the visual system. Magnocellular system collect information from all types of cones, therefore the cells detect luminance and can signal depth and stereopsis. Parvocellular system detects chromatic modulation, therefore the form and material of an object can be detected (Murava'eva et al., 2009).

2.2.5 The primary visual cortex

Fibres from the LGN pass through the optic radiations to synapse in the primary visual cortex, also known as V1 and striate cortex. It is found in the occipital lobe in both cerebral hemispheres. The first steps in cortical processing of visual information takes place in V1 (Palmer, 1999). The inputs are received from LGN in the occipital lobe on the same side of the brain, thus, the visual input of V1, like that of LGN, is partly crossed, with the left visual field projecting to the right V1, and the right visual field projecting to the left V1. There is a large fibre tract that allows communication between the two sides of the cerebral hemispheres. Through a topographical mapping where the nearby regions on the retina project to nearby regions in V1, the transformation preserves qualitative spatial relations but distorts quantitative ones (Hubel, 1988). It has been shown that attention alters spatial integration in an eccentricity-manner. Cells in the central receptive fields show a reduction in preferred stimulus length and in the size of the spatial summation area (attention reduced spatial integration). Whereas, cells in more peripheral locations are increased in the summation area (attention increased spatial integration). This separation of the cells between the central and peripheral vision can support the attended foveal objects and target selection (Roberts et al., 2007). Moreover, the summation mechanism produces number of activated visual cells which are the most important causes of visibility and contrast sensitivity (Virsu and Rovamo, 1979).

2.3 Visual guidance

In the 1950s, Gibson proposed the first theory about optic flow. The theory explained that the movement of the eye (vision) through the environment enables visual information to be gained and attains the control of self-motion (Gibson, 1958). Many studies have investigated this unique mechanism of the visual system since the early work by Gibson (Thorpe et al., 1996; Adini et al., 2002). Some argue that the generation of the optic flow is during movement, hence it needs to be obtained online (Warren et al., 2001).

Visual information is generally used to pre-plan an activity of daily living. The information received by the visual system to enable safe locomotion are visual cues. To be able to gain visual cues within the environment, images must first appear in the field of view. Once a path of movement is determined, visual information gained from the visual field allows for continual updating of the spatial environment as locomotion of an activity such as walking can take place. If the demand of the activity becomes more difficult and challenging, individuals would require increased visual information and the length of time looking in the environment will likely increase (Patla, 1997).

The ability to have and use the visual information is important, especially in situations where the locomotor pattern needs to be modified before approaching a task such as an obstacle crossing (Marigold and Patla, 2007). Vision is a unique sensory cue for providing necessary information for successful locomotion at distance (Marigold, 2008). This process is known as online process of visual control. The online process is defined when a person gains visual information and moves through and interacts with the environment (Marigold, 2008). The spatial relationship between onset and objects within the environment is vital when navigating within an environment and it requires continuous updates of visual information (Turano et al., 2005).

Individuals do not fixate the same object within the environment during locomotion, rather continuous scanning of the environment is undertaken to detect potential hazards. Feedback is required to ensure safe travel, an example of this could be when individuals alter their direction or modify the steps to avoid contact with an object (Marigold, et al., 2007). This is known as visual guidance. Visual guidance provides important sensory information to enable motion and balance within the environment, and is one of the most important aspects for motor control (Schmidth and Lee, 1999).

2.4 Visual impairment

The reduction of vision that cannot be corrected with prescribed glasses or contact lenses and reduces an individual's ability to function, is known as visual impairment or low vision (World Health Organization, 2007). The leading cause of sight loss in England and Wales in the working population are hereditary retinal disorders including RP (Liew et al., 2014). Age related macular degeneration, Cataracts, Glaucoma are the other major causes of visual impairment in the developed world (Foster and Johnson, 1990; Wormald et al., 1992). The number of people worldwide with visual impairment is estimated to be approximately 1.3 billion (World Health Organization, 2018). VI affects economic and educational opportunities, reduces quality of life and also increases the risk of death (Bourne at al., 2017). Furthermore, those with VI also have limited access to education and career opportunities (Ramrattan et al., 2001; Klein et al., 2003).

2.5 Retinitis Pigmentosa

Retinitis Pigmentosa (RP), a type of VI, is a genetically inherited eye disorder which leads to vision loss (in many cases full blindness). RP is part of the group of pigmentary retinopathies that covers all retinal dystrophies (Hamel, 2006). The worldwide prevalence of RP is approximately one in 4000 with a total of more than one million people affected (Berson et al., 1993). Haim (2002) reported that in Europe and the United States one in 3500 people is affected by RP. RP is caused by loss of photoreceptors and retinal pigment deposits. RP is progressive and primarily impairs peripheral vision (Herse, 2005). Although RP is individualist, in most cases, there is a primary degeneration of the rods with secondary degeneration of cones. This is one of the reasons that most people with RP start with having night blindness. RP starts with patchy losses in the peripheral vision which may progress into tunnel vision in the late stages. Figure 2.4 demonstrates the tunnel vision effect of RP.

Figure 2.4. A scene as it might be viewed by someone with normal vision (left) and someone with end stages of RP (right). RP is also known as tunnel vision, as those with RP lose their peripheral vision and have limited central vision. Figure from National Eye Institute (NEI) website, retrieved from: https://nei.nih.gov/health/pigmentosa/pigmentosa_facts, accessed on 11/12/2015.

The impairments associated with RP are varied (Herse, 2005), but as mentioned it tends to begin with the loss of scotopic peripheral vision. These losses are usually measured by assessing visual acuity and field of vision. Unlike other VI, RP usually affects both eyes similarly. RP can lead to a range of psychological, physical and social difficulties for the person with RP. Another eye disease that causes peripheral vision loss is Glaucoma, which causes partial loss of contrast sensitivity that may cause a decrease in the quality of perception, but visual acuity usually remains normal compared to those with normal vision (Hu et al., 2014). Glaucoma does have some characteristic similarities to RP and as the result some researchers have used people with Glaucoma to investigate the effect of peripheral visual field loss.

2.5.1 Genetics

The highest percentage of RP is inherited by autosomal-recessive genes (50-60%), following by autosomal-dominant (30-40%) or the X-linked (5-15%). However, some of the people with RP are associated with non-ocular disease, and they are known to be more than 30 different syndromes (Hartong et al., 2006). Usher's syndrome, where RP is associated with hearing impairment, is known as the most frequent syndromic form of other related syndromes to RP.

2.5.2 Symptoms, diagnosis and treatment of RP

RP is extremely variable and can differ from one individual to another. This can be evident as some develop their visual loss in childhood and some until late adulthood, even though they are all born with the condition. An early clinical feature of RP is that the visual difficulties usually start at dark adaptation and night blindness known as nyctalopia and loss of mid-peripheral visual field. As the condition advances, the amount of visual field loss increases and usually the term known as tunnel vision is used at this point. The visual symptoms reflect the gradual degeneration of the two; rods followed by tightly packed cones (Narayan et al., 2016). RP could lead to loss of central vision and full blindness in some cases (Herse, 2005). Most people with RP are legally blind by age of 40 years as the result of the severity of visual field loss. A typical RP is caused by loss of rod function that exceeds reduction of cone sensitivity.

Visual acuity can remain normal despite significant loss of peripheral vision, which indicates that the amount that individual can see could be clear and detailed (Heckenlively et al., 1988). However, some studies found that a loss of visual acuity of between one and 8.6 per cent per year in those with RP (Birch et al., 1999). It is shown that the rate of the visual field loss is faster compared to visual acuity. Diagnosis of RP depends on how quick the deterioration of the vision takes place and is noticeable to individuals. Although there has been extensive research on genetic coding for RP, there is not yet any treatment and/or cure to be found. The preservation of cones in RP could be a major medical breakthrough in the near future (Narayan et al., 2016). A decline in contrast sensitivity is also a common finding in those with RP, because it can account for poor subjective vision in those with high visual acuity (Lodha et al., 2003).

Those with RP who take vitamin A, vitamin E supplements, or both have been recorded to have slower declines in the progression of the disorder (Berson et al., 1993). Another knows method to slow the deteriorating the vision in RP is docosahexaenoic acid (DHA). DHA is known to be an important part for of functioning of the photoreceptor cells and the lack of it could have negative effects in RP (Fliesler and Anderson, 1983).

2.6 Gait Analysis

As mentioned previously, the reduction in person's vision has significant implication for the walking gait. However, prior to reviewing the literature pertaining to the impact of VI on walking gait an initial overview of walking gait will be provided. For specific detail of impact of VI on gait see 2.6.3.

The origins of the science of gait analysis began in Europe in the 17th century and has continued since (Sutherland, 2001). It is described as the quantitative measurement and assessment of human locomotion including both walking and running. The movements are not adequately measurable from a simply visual, observational perspective and hence gait analysis uses a variety of scientific tools to allow scientists and clinicians to measure and study critical body movements.

There are three major joints which interact with each other to enable walking, namely hip, knee and ankle joints; each of which is surrounded by ligaments, cartilages, muscles and other soft tissues to support their movement during gait.

2.6.1 Gait cycle

The gait cycle is defined as starting from initial contact of one limb to the following initial contact of the same limb (Perry and Davids, 1992). The gait cycle is made up of two major phases:

First is the stance phase, where the limb is in contact with the ground – this phase is about 65 to 70 % of the cycle and has three different parts: first is the contact period from when the heel strikes to forefoot loading, the mid-stance period which takes place from the forefoot loading to heel raise, and the propulsive period which is within the heel raise to toe off. Followed by the swing phase, where the foot is in the air for limb advancement – this phase is the remaining part of the cycle (30 to 35 %) and it contains the acceleration and deceleration of the limb (Figure 2.5).

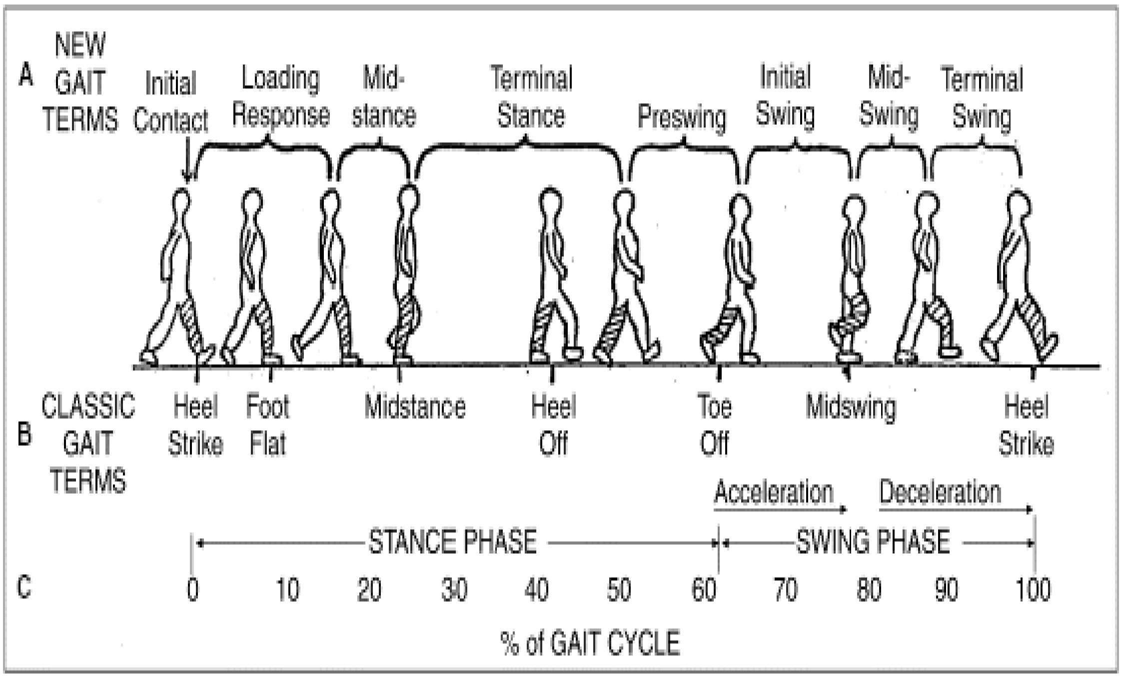

Figure 2.5. An image of the gait cycle, demonstrating each phases. Figure from National centre for biotechnology information website, retrieved from http://www.ncbi.nlm.nih.gov/books/NBK27235/ accessed on 08/10/2017.

2.6.2 Foot placement and toe clearance

Foot placement during gait is important in regulating the dynamics of the joints of the supporting limb and in maintaining balance of the whole body. The foot placement contact force counteracts the gravitational force of the moving body in order to maintain balance and stability (Winter, 1995). This can also be seen as when negotiating obstacles, foot-ground contact provides a base of support to the moving body. Foot placement prior (penultimate) and during obstacle negotiations is a key aspect of a safe crossing. Uncertainty regarding foot placement causes alteration of how high the foot is lifted (toe clearance) and how fast the foot is moved (toe velocity) over the obstacle for a successful clearance (Timmis and Buckley, 2012).

2.6.3 Stride

The term "Stride" is defined as the linear distance in the plane of progression between corresponding successive contacts of the same foot. When approaching an obstacle, the point at which the limb is elevated to step over the obstacle is commonly termed as crossing stride. The crossing stride of the leading limb begins at toe-off before the obstacles and ends at foot contact on the floor after clearing the obstacle (Chen and Lu, 2006).

It has been reported that when the height of the obstacle to be negotiated increases, stride length increases linearly (Chou and Draganich, 1998). This can suggest that increases in obstacle height can result in different geometrical configuration of the limbs than when decreases in toe clearance while the toe is over the obstacle.

2.6.4 Obstacle Negotiation

Obstacle Negotiation is to cross obstacles during gait, challenging stability and forcing the reorganization of the gait pattern (Zhang et al., 2011). Stepping over obstacles and consequent instability during gait is particularly problematic especially in older adults and those with VI. To successfully overcome this action, three major processes must occur as Stelmach and Worringham (1985) mentioned: First the detection of the obstacle(s), second processing of pertinent information concerning the obstacles and finally execution of an appropriate and timely motor strategy. It has been shown that the swing phase is altered during obstacle crossing compared to normal level walking, and this will result in a longer time spent in single limb support (Austin et al., 1999). The increase is expected since the foot has to travel a further distance as it is elevated (through hip and knee flexion) to swing over the obstacle.

Mohagheghi (2004) argued that for successful obstacle avoidance there are only two important factors - the update distance from the obstacle and - obstacle height (Mohagheghi et al., 2004). It is noticeable that this information can be collected by visual exteroception and expproprioception and illustrates the importance of vision in human gait. Obstacle crossing during walking is also a multi-joint, multi segmental movement and it requires accurate swing foot control and a high level of inter-joint coordination of the stance and swing limbs. Inter-joint coordination describes the relationship of the angular positions and velocities between two joints, which are associated with information from afferent joint receptors and also efferent motor control (Burgess-Limerick et al., 1993).

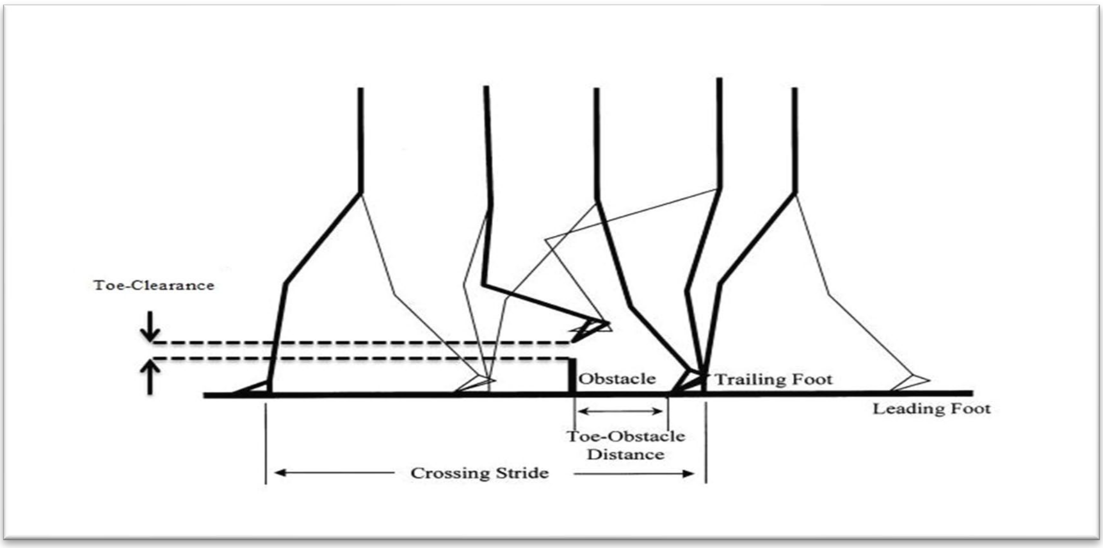

Figure 2.6. Illustration of the geometrical configuration of lower limbs about the obstacle (Chou and Draganich, 1998).

It is evident that in order for an individual to step over an obstacle, the centre of mass needs to shift in the anterior direction and then in the medio-lateral direction towards the Centre of pressure of the supporting foot (Chou et al., 2001). These adjustments are needed to unload the stepping leg and to create a moment of reaction force rotating the body forward about the ankle joints (Chou and Draganich, 1997). During single limb support in gait, the body's centre of mass trajectory is medial towards the centreline of the plane of progression of gait (Mackinnon and Winter, 1993). This can be the cause of instability of the body as it tends to fall sideways under gravity. It has been shown that when stepping over an obstacle a similar situation happens. Although the duration of this instability is relatively long since the stride time is increased as compared to that of unobstructed gait.

The failure to overcome an obstacle can be disastrous in many cases; stumbling or falls can be outcomes of contact with the obstacles by the toe or the heel of the swing limb, or the centre of mass being outside the narrow base of support in the single-limb stance phase. The obstacle crossing movement has received more attention in the past decade as exploring this area can reduce the number of falls (Eng et al., 1994); tripping over obstacles can be seen as the most frequent cause of falls in elderly (Overstall et al., 1977; Prudham and Evans, 1981; Tinetti and Speechley, 1989).

Austin et al. (1999) studied a group of female participants who had to cross over three obstacles with different heights. Their study highlighted the importance of accurate movement and appropriate modification of swing limb during the obstacle crossing. He also concluded that there is an increase in the toe clearance when the height of the obstacles are increased (Austin et al., 1999). Other researchers found similar findings and reported that an increase in the obstacles will cause a greater toe clearances (Chen et al., 1991). This increase in toe clearance which increased obstacle height likely reflects a safety mechanisms to reduce the risk of tripping on obstacle which presents a greater risk of falling if occurring at the higher height. However, Chou and Draganich (1997) reported that toe clearance was not affected by obstacle height. However their test only concentrated on the trailing limb. This could suggest that a constant safety margin is maintained for the different heights. They also found a greater joint moment when stepping over occurred compare to unobstructed walking but this did not differ in obstacles with different heights.

Other researchers found that when stepping over obstacles of various heights in a self-selected manner both young and older adults placed their trailing feet at approximately the same distance from the obstacle just before stepping over it (Chen et al., 1991, Chou and Draganich, 1998a). This may suggest that the location of foot placement relative to the obstacle is precisely controlled by the central nervous system in order to ensure a safe crossing and most of this information is received via the vision. It is clear and it has been supported that the visual extroceptive information is used in a feed-forward manner to control the swing limb (Patla et al., 1996; Patla, 1998;

Mohagheghi et al., 2004). This implies that the obstacle height and place must be retained in memory once it cannot be seen longer. This can be a valid explanation of having increased toe clearance variability (a larger standard deviation) when visual input is unavailable. Rhea and Rietdyk (2007) studied how visual exteroceptive information regarding obstacle height modifies foot placement and foot elevation in the absence of lower limb-obstacle exproprioceptive information. They also found that there is an increase in toe clearance when there is visual interference as well as toe clearance variability in the leading foot (Rhea and Rietdyk, 2007).

Most of the studies in this area have performed their protocols with participants remaining at a self-selected speeds (Chen et al., 1991; McFadyen et al., 1993; Patla and Rietdyk, 1993; Pavol et al., 2001; Chou et al., 2001) and only one of these studies found that faster walking speed can be associated with falling when trying to recover from the trip (Pavol et al., 2001). This can highlight that speed may play a major part in falling as overcoming the obstacles at faster speed can cause more trips because of the lack of sufficient time to regulate important aspects of safe negotiations such as foot placement and toe clearance.

A trip over obstacle crossing can occur with both leading and trailing feet and it can be beneficial to compare the roles of the leading and trailing limb in supporting the body during obstacle avoidance. It is noted that the toe clearances of the leading and trailing limb are similar (Chen et al., 2004). The data on the kinetics of the supporting leading limb as well as the kinematics of the crossing trailing limb could be very helpful for bridging the gap in the existing knowledge of control and coordination of the standing and swing limb.

Chen and Lu (2006) studied the joint moment of both the leading and the trailing limb. They emphasised that in order to complete a successful and safe obstacle crossing, sufficient foot clearance of the swing limb and also the stability of the body, which is provided by the stance limb, is required. They suggested that the peak moments are needed mainly for propulsion of the body forward and upward while the joint crossing moments are mainly used for precision control of the limbs to ensure a successful avoidance of the obstacle (Chen and Lu, 2006).

Yen et al. (2009) worked on the coordination of the joints in obstacle crossing. They described obstacle crossing as a multi-joint movement, requiring precise swing foot control and high level of inter-joint coordination of the stance and swing limb. Their study reported some differences between the swing and trailing limbs. They found that the variability of swing hip-knee and knee-ankle coordination increases during the leading limb crossing the obstacle, whereas this only happens in the coordination of the knee-ankle in the trailing limb (Yen et al., 2009). This can be explained in the toe clearance of the stance limb. The leading toe clearance increases and results in an evaluated centre of mass position and demand on the trailing stance limb to maintain the whole-body balance while the body's centre of mass is moving away from the base of support (Lu et al., 2006).

2.6.5 Minimum foot Clearance (MFC)

Minimum foot clearance (MFC) during flat walking, is the minimum vertical distance between the lowest point of the foot of the swing leg and walking surface during the swing phase of the gait cycle (Barrett et al., 2010). If the MFC is greater than zero on any given steps, trips can be avoided by individuals.

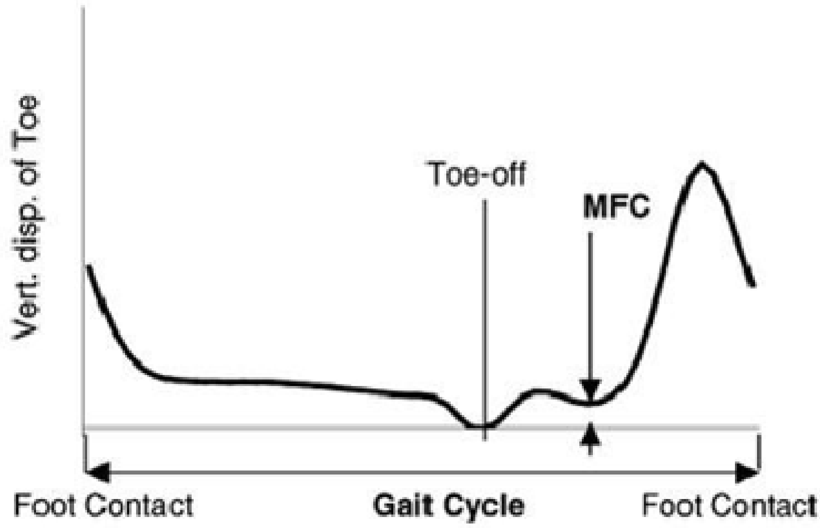

Figure 2.7. Illustration of a curve of minimum foot clearance (MFC) during walking. Vertical displacement of toe marker for one gait cycle, showing the occurrence of MFC event during mid swing phase (Khandoker et al., 2008).

Winter (1992) reported a mean toe clearance of 1.29 cm at mid swing with a variability of 0.45 cm, in his work which investigated gait over level ground (Winter, 1992). He also explained that there is a sensitivity which quantified at the angular changes at hip, knee and ankle. These changes can be as small as 1.35-2.16 degrees. It has been evident that the toe clearance (TC) of the trailing limb is consistently lower than that of the leading limb (Patla et al., 1996).

2.7 Postural control

The ability to control balance during activities of daily living plays an essential role in the functional mobility and independence of individuals. Postural control is maintained through sensory information provided by the visual, vestibular and somatosensory system (Nashner et al., 1985; Manchester et al., 1989). Visual information is a critical factor to consider when testing stability. Previous studies have mostly taken into account this issue by testing the participants in two different conditions, eyes open and eyes closed (Simoneau et al., 1994; Melzer and Kaplanski, 2004; Slobounov et al., 2008; Black et al., 2008; Sarabon et al., 2013).

2.7.1 Vestibular system

Vestibular system is a sensory system that is responsible for providing the brain with information about motion, head position, and spatial orientation. It involves the communication between the peripheral vestibular apparatus, the ocular system, postural muscle, the brainstem, cerebellum and the cortex (Khan and Chang, 2013). The small structures in the inner ear make up the vestibular apparatus and detect the head motion as well as the gravitational forces on the body. The system is also involved in motion that allows individuals to keep their balance, stabilize the position of the head and body during movement and maintain posture. The main components of the system are found in the inner ear and it is called vestibular labyrinth, which is continuous with cochlea. The vestibular system uses its organs to detect forward and backward motions and gravitational forces (Kingma and Van de Berg, 2016). Furthermore, the vestibular system coordinates head and eye movement and activates postural muscles that maintain balance and provides the proper orientation of the head and body in space (Furman et al., 2003).

2.7.2 Somatosensory system

Somatic senses are referred to the perception of touch, temperature, proprioception and pain. The information is received from the skin, joints, muscles and viscera. The somatosensory system has various receptors that provide information about pressure distribution, muscle tension, joint angle changes and muscle length changes. The peripheral nerve afferents related to receptors in the skin, muscles, and joint course centrally past their cell bodies in the dorsal root and cranial nerve ganglia to enter the spinal cord and brainstem (Mai and Paxinos, 2011).

2.8 Self-report questionnaires

Self-report questionnaires (SRQs) have been used as a measurement tool to assess the difficulty level of ADLs for those with low vision. Several questionnaires have been developed for use by low vision clinics and communities in the past two decades (Massof and Rubin, 2001). The importance of appropriate patient-reported outcomes has been demonstrated, and such measurements have become accepted as a critical component of comprehensive outcomes of research and for clinical use (Pesudovs et al., 2007).

Clinical measurements of visual functions determine a result of visual impairment. However, this provides little information about functional ability of an individual with VI and their ability in completing activities of daily living, and this is known as visual disability (World Health Organization, 2013). Massof (1998) argued that, in order to determine the functional abilities of individuals with VI, visual function assessment questionnaires of performance should be used.

The difficulties experienced by someone with visual loss can be considered using the International Classification of Functioning, Disability, and Health (ICF) (World Health Organisation, 2001). The ICF is a comprehensive framework that classifies health and health related domains from three different perspectives: the body, individual and societal (Waddle, 2004). The ICF uses ‘functioning’ as an umbrella term considering all body functions, activities and participation. The term ‘disability’ is expressed to corresponding impairment, activity limitation or participation restrictions resulting from reduced functioning. Impairment is a problem in body function, and in the case of RP, it involves reduced visual function and, more significantly reduced visual field. Activity limitations describe the difficulties encountered by a person in undertaking particular activities, and participation restrictions refer to the difficulties and problems then experienced when involved in life situations. Hence, the disability experienced by an individual can not only be dependent on an individual's health condition but also on other factors such as their personal resources or the environment in which they live. The disability of those with low vision can be best described in terms of activity limitations and participation restrictions within the ICF framework (Bruijning et al., 2010).

The term quality of life is also often used, but the concept can be difficult to define and harder to measure. This is because of the perception of individuals could differ from each other and it is a subjective concept (Taylor et al., 2016). SRQs are used to help measure this aspect. There is an emphasis on correlation between patient responses and other measurements, such as visual acuity, in order to validate a specific measuring tool. The rationale for this is that the instrument does assess a patient attribute, which varies from different level of vision loss (Massof and Rubin, 2001).

2.9 Systematic Literature Review – self report questionnaires

Self-report questionnaires (SRQs) are used as instrument to identify aspects of particular difficulty and measure specific domains requiring support or rehabilitation e.g. mobility or reading for those with visual impairment (Bruijning et al., 2013), with several SRQ having being developed for use by low vision clinics and communities (Massof and Rubin, 2001). The aim of this subsection in the thesis is to identify, through using systematic literature review (SLR), the range of ADLs typically assessed in those with VI.

2.9.1 Method adopted for SLR

The SLRs were conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) and the Cochrane guidelines of systematic reviews (Moher et al., 2009). A comprehensive literature search was conducted to identify relevant research from a database searches. The studies were exported into excel software, filed and managed, including management of duplications across database and data extraction of the studies. Extracted studies were manually reviewed for relevance according to the title and abstracts. The successfully screened studies then underwent a PICOS (Population, Intervention, Comparison, Outcome and Study type/design) criteria (Methley et al., 2014), before being included in this review. Complete access to the full text literature articles was achieved due to the support of the Anglia Ruskin University's interlibrary loan system.

The literature search was generated through using Pubmed (MEDLINE). An initial pilot search was conducted to pool keywords based on the topic area, using online thesauruses and databases. A combination of applying search techniques such as Boolean operators to join subjects and separate phrases was also used. In addition to using speech marks to join the words, truncations and wildcards to account for different terminologies and spellings. Table 2.1 demonstrates the final search for the SRQ SLR. In total, 85,738 potentially relevant studies were identified. The research strategy was repeated twice to assess the consistency and repeatability of the method as suggested by Kichenham et al. (2011). In both searches, the same number of articles were returned.

Table 2.1. The search term is combination of key terms for this SLR and the filters that were used to obtain the studies.

Data base	Hits	Search terms
Pubmed	85,738	((((((((((((((((Questionnaire[Title/Abstract]) OR Self report questionnaire[Title/Abstract]) OR SRQ*[Title/Abstract]) AND Quality of Life[Title/Abstract]) OR Everyday Task*[Title/Abstract]) OR Activities of Daily Living[Title/Abstract]) OR ADL*[Title/Abstract]) AND Visual Impair*[Title/Abstract]) OR Low Vision[Title/Abstract]) OR Vision Loss[Title/Abstract]) AND full text[sb] AND ("1950/01/01"[PDat] : "2013/04/31"[PDat]) AND Humans[Mesh] AND English[lang] AND adult[MeSH])) AND full text[sb] AND ("1950/01/01"[PDat] : "2013/04/31"[PDat]) AND Humans[Mesh] AND English[lang] AND adult[MeSH])) AND full text[sb] AND ("1950/01/01"[PDat] : "2013/04/31"[PDat]) AND Humans[Mesh] AND English[lang] AND adult[MeSH])) AND full text[sb] AND ("1950/01/01"[PDat] : "2013/04/31"[PDat]) AND Humans[Mesh] AND English[lang] AND adult[MeSH])

2.9.2 Inclusion criteria

The literature collected in the systematic review was filtered to publications that included the relevant key terms (see table 2.1) in their title or/and abstract. Articles were then further restricted to research that was only available in English, with recruited subject over 18 years old and provided full text articles. Any remaining studies that did not meet the PICOS criteria were excluded.

The application of a flow chart diagram below that is in accordance to PRISMA study selection process demonstrates the retrieval process of this SRQ review. The final number of selected studies was fifteen (see table 2.2).

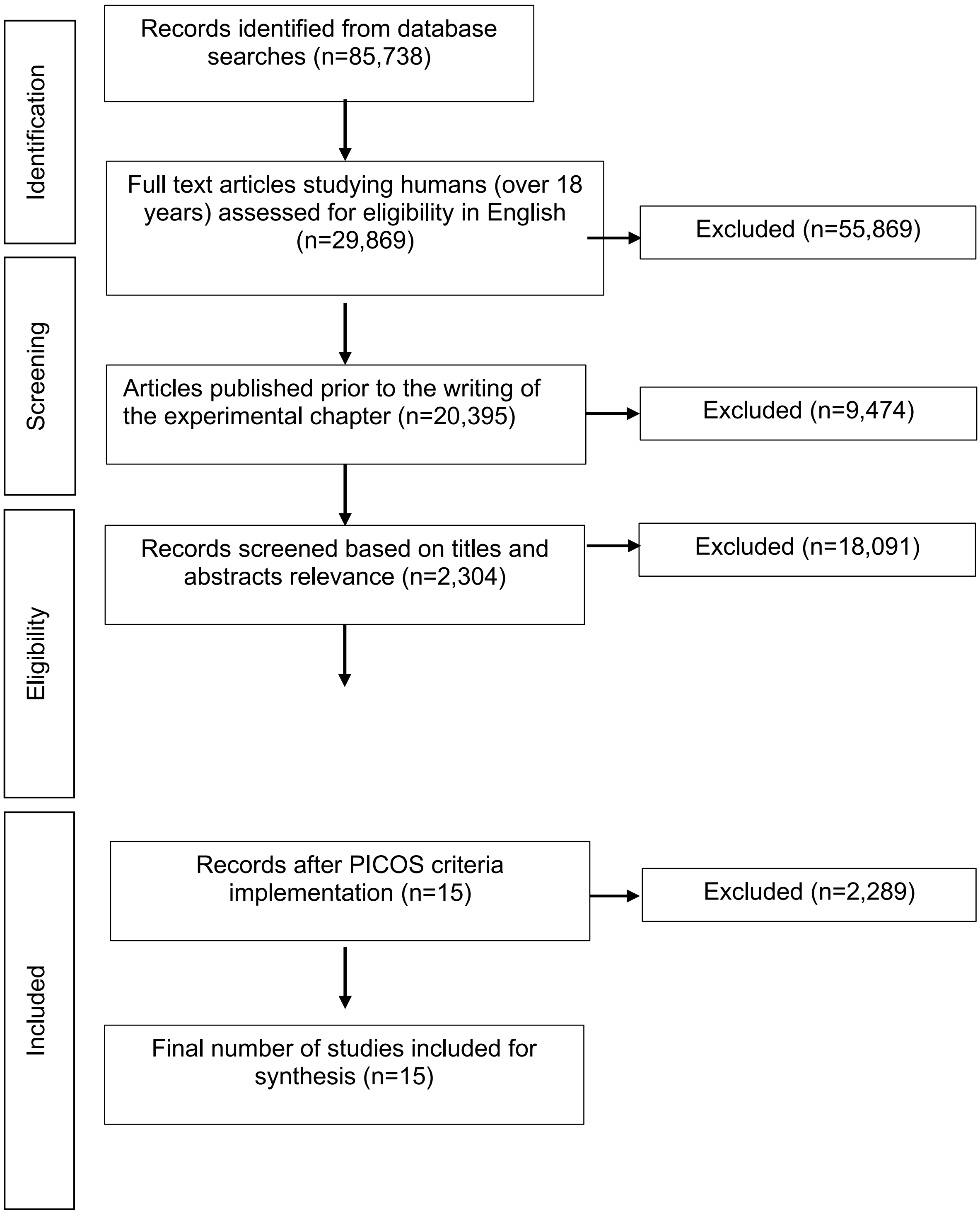
Identification
Screening
Eligibility
Included
Records identified from database searches (n=85,738)
Full text articles studying humans (over 18 years) assessed for eligibility in English (n=29,869)
Excluded (n=55,869)
Articles published prior to the writing of the experimental chapter (n=20,395)
Excluded (n=9,474)
Records screened based on titles and abstracts relevance (n=2,304)
Excluded (n=18,091)
Records after PICOS criteria implementation (n=15)
Excluded (n=2,289)
Final number of studies included for synthesis (n=15)

Table 2.2. The selected studies from the first SLR. One aspect that mostly differs from studies is the method of testing. Thus the lack of comprehensive method is evident.

	Title	Author, Year	Method of testing	Participants	Results
1	Visual Impairment, visual functioning, and quality of life assessments in patients with Glaucoma	Parrish, 1996	National Eye Institute – Visual Functioning Questionnaire (NEI -VFQ)	One hundred and forty seven Patients with Glaucoma	A weak correlation between visual impairment and the VFQ scores.
2	Perceived vision-related quality of life and risk of falling among community living elderly people	Kallstrand-Eriksson et al., 2013	25-item National Eye Institute Visual Function Questionnaire (NEI VFQ-25)	Two hundreds and twelve randomly selected elderly people	Indication of impaired perceived vision-related health status.
3	Quality of life of low-vision patients and the impact of low-vision services	Scott et al., 1999	Interviews, the Visual Function (VF – 14) and the 51-item Field test vision of the NEI-VFQ	One hundred and fifty six patients 1 week before and 3 months after their low-vision clinic	Low-vision services were associated with high patients satisfaction. Vision-targeted questionnaires were more sensitive than general health-related quality of life questionnaires.
4	Adjustment to vision loss in a mixed sample of adults with established visual impairment	Tabrett and Latham, 2012	Self-Worth Adjustment scale (AS-WAS)	One hundred participants, who experienced at least six months of low vision	Adjustment to vision loss is significantly associated with depression and certain trait of personality, independent of

					severity of vision loss, and duration of vision loss.
5	Assessing visual activities of daily living in the visually impaired	Latham and Usherwood, 2010	Self-reported difficulty of with 4 ADLs (reading newsprint, reading medicine labels, identifying coins and entering a PIN)	Twenty four subjects with established bilateral visual impairment	Varying the assessed ADL task changed how ell the task correlated with self-reported difficulty.
6	Relationship between vision impairment and ability to perform activities of daily living	Haymes et al., 2002	Malborne Low Vision ADL Index (MLVAI)	One hundred and twenty subjects with low vision	All vision measures had a high, statistically significant correlation with MLVAI total score.
7	Impact of age related macular degeneration on quality of life	Hassell, et al., 2006	Impact of Vision Impairment questionnaire	One hundred and six participants diagnosed with AMD	Participants reported from at least "a little" concern on 23 of the 32 IVI items including reading, emotional health, mobility, and participation in relative activities.
8	Relationship between peripheral visual field loss and vision-related quality of life in patients with retinitis Pigmentosa	Sugawara et al., 2010	The Japanese version of NEI VFQ-25	Forty patients with typical retinitis Pigmentosa	The mean NEI VFQ-25 score was 68.4 in RP and 90.1 in normal controls.

9	Relationship between difficulty in performing daily activities and clinical measures of visual function in patients with retinitis pigmentosa	Szlyk et al., 1997	Participants rated their difficulty in performance of 33 activities	One hundred and sixty-seven patients with typical RP	The patients' responses clustered into 6 factors: activities involving central vision, miscellaneous activities, activities related to mobility, driving, negotiating steps, and eating meals.
10	Using the VA LV VFQ-48 and LV VFQ-20 in low vision rehabilitation	Stelmack and Massof, 2007	Items were eliminated from the VA LV VFQ-48 to reduce redundancy and shorten the instrument	One hundred and twenty six subjects	The approximation captures 98% of the variability in the Rasch measure estimate of persons' visual ability and 97% of the variability in the change score estimate
11	Factors influencing self-reported vision-related activity limitation in the visually impaired	Tabrett and Latham, 2011	The Activity Inventory that assesses self-reported activity limitation (VRAL) in the task domains of reading, mobility, visual information, and visual motor tasks.	One hundred visually impaired	AN acuity measure and to lesser extent, near reading performance without LVAs, visual fields, and contrast sensitivity best explained self-reported VRAL (28%-50% variance explained).
12	Perceived visual ability for independent mobility in persons with retinitis pigmentosa	Turano et al., 1999	A questionnaire used to rate difficulty of 35 mobility situations	One hundred and twenty seven subjects with typical retinitis pigmentosa	Content validity of questionnaire was shown by good separation indexes (4.55 and 8.0) and high reliability scores (0.96 and 0.98) for the person and the item parameters.

13	Focus-QoL: Measuring quality of life in low vision	Fylan et al., 2005	A content analysis was used to develop a 25-item questionnaire	Questionnaires posted to a random sample of two hundreds clients, and completed with seventy two consecutive clients in low vision	Three main factors were identified; the ability to carry out day-to-day tasks, independence, and motivation. Reading books, newspapers and letters had the most difficulty, followe by using public transport, and engaging in hobbies and leisure activities.
14	Psychometric analyses to improve the Dutch ICF Activity Inventory	Bruiijning et al., 2013	The D-AI was administered	Two hundreds and forty one visually impaired	Except for one goal, factor analysis model parameters were at least reasonable. Internal consistency reliability was satisfactory (range, 0.74 to 0.93).
15	The Activity Inventory: An adaptive Visual Function Questionnaire	Massof et al., 2007	The AI was administered	One thousand and eight hundreds and eighty low vision patients	Reading related and other items requiring high visual resolution had smaller residual errors than expected and mobility-related items had larger residual errors than expected.

2.9.3 Results of SRQ SLR

The range of SRQs used within the final fifteen studies demonstrates the variation used and the lack of using a comprehensive SRQ. One third of the studies used the National Eye Institute – Visual Functioning Questionnaire (NEI-VFQ) and the rest of the studies chose other SRQs such as Impact of Vision Impairment, the Activity Inventory or a questionnaire that was designed by the researcher through focus groups. Interestingly only one of the studies used interviews as well as a SRQ for their studies (Scott et al., 1999). Whilst, interviews may lead to more insight in regards to a specific disorder, the time requirement to conduct these interview will impact the sample size compared to a higher number of participants can be examined using a SRQ only. As the result of the first SLR shows, there are a range of questionnaires used to assess difficulty with activities of daily living (ADLs) and researchers have used these tools to investigate the areas of greatest difficulty for those with VI.

The Participants used in the studies varied. Some studies only used one particular VI (i.e., Parrish, 1996; Turano et al., 1999; Hassell et al., 2006), whereas other studies used those who attend low vision clinic and their VI varied from RP, AMD and Glaucoma (i.e., Scott et al., 1999; Tabrett and Latham, 2012). Massof et al. (2007) emphasized the importance of a SRQ for multi purposes of different Vis but he also concluded that with the characteristic differences of the Vis, examining all Vis with the same SRQ would be challenging.

Out of the SLR studies only Kallstrand-Eriksson (2013) had an age restriction, where elderly subjects (70-85 years old) were selected. The rested of studies allowed those over 18 to participate and the some of the age range included 18-100 years old. Aging is an important factor, when studying ADLs as older participants could have other health conditions that cause difficulties with completing the ADLs (Finlayson et al., 2005). Thus, if there are a range of participants with different age, additional analysis can be undertaken to highlight this factor. Moreover, the number of participants varied between 27-1880 individuals. However, only three studies had participants less than 100. A higher number of participants can increase the validity of research using questionnaires (Edwards et al., 2001).

The majority of the SLR studies did not compare their results from those with VI to normally sighted individual. Only in one study age matched group of normally sighted participants were also part of the study (Sugawara et al., 2010). Furthermore, one third of the SLR studies used Rasch analysis to validate the SRQs used in their studies. One study went further and used the Rasch analysis to compare two SRQs (Stelmack and Massof, 2007). Although, the number of studies using Rasch analysis is increasing in health instrument, not all the studies use this tool. Reasons for this depends on the assessment of SRQs. Thus, assessing instrument unidimensionality, differential item functioning, rating categories could be some of the reasons for deciding to use Rasch analysis (Belvedere and de Morton, 2010).

The difficult ADLs for those with VI were also shown in the SLR studies. Szlyk et al. (1997) reported a strong relationship between increased difficulty in performing common tasks (such as activities related to mobility, negotiating steps and eating meals), poorer level of visual acuity and visual fields when assessing people with RP. Their findings were derived from using a SRQ to assess patients' functioning on 33 selected everyday activities. The participants' answers to the questionnaire were grouped into 6 factors by their responses: activities involving central vision, miscellaneous activities, activities related to mobility, driving, negotiating steps, and eating meals. However, the relative difficulty of each group of tasks were not addressed in their study.

Limited studies listed in table 2.2 only recruited individuals with RP. Sugawara et al. (2009), reported that a good estimate of quality of life can be determined by the degree of visual field loss for those with RP. The National Eye Institute Visual Function Questionnaire-25 (NEIVFQ-25) was used for 40 people with RP and 40 control subjects to obtain scaled difficulty of 12 aspects of daily living activities. All subjects were also examined for their visual field loss. This study reported significantly greater difficulty expressed by the mean NEI-VF-Q-25 score, which was associated with greater degree of visual field loss. The visual impairment in RP makes both activities and participation more difficult. Given the loss of peripheral visual field, mobility is difficult (Lowe and Drasdo, 1992; Szlyk et al., 1997; Geruschat and Turano, 1998) but difficulties go beyond one specific area. Peripheral detection (Szlyk et al., 2001), visual search (Lowe and Drasdo, 1992) and reading (Fylan et al., 2005) are a few examples of difficult activities. Geruschat and Turano (1998), empathised on the mobility difficulties for those with visual field loss. Their study, where the walking gait of those with RP was compared to normally sighted individuals, those with RP walked more slowly than the normally sighted on both simple and complex walking courses. Those with RP also had more incidents under reduced illumination and reported more dissatisfaction with mobility tasks compared to those normally sighted.

As highlighted, there are other difficulties apart from mobility for people with restricted visual field. Reading, using public transport, and engaging in hobbies or leisure activities are some of the difficult tasks, as found in a study by Fylan et al. (2005). A SRQ was used to identify difficult daily tasks from a group of VI participants, which included people with RP. The findings also included difficulty with tasks relating to emotional status of those with vision loss, such as lack of confidence, feeling worried and staying at home because of their eyesight. Although there are range of questionnaires available to assess difficulty with ADLs for Vis from the SRQs reviewed in SLR, there has not been a comprehensive overview of self-reported difficulties with visual activities and participation for those with RP.

There are a range of questionnaires used to assess difficulty with activities of daily living (ADLs) and researchers have used these tools to investigate the areas of greatest difficulty for those with VI. Szlyk et al. (1997) reported a strong relationship between increased difficulty in performing common tasks, poorer level of visual acuity and visual fields when assessing people with RP. Their findings were derived from using a SRQ to assess patients' functioning on 33 selected everyday activities. The participants' answers to the questionnaire were grouped into 6 factors by their responses: activities involving central vision, miscellaneous activities, activities related to mobility, driving, negotiating steps, and eating meals. However, the relative difficulty of each group of tasks were not addressed in their study.

Similar results were found by Sugawara et al. (2009), who reported that a good estimate of quality of life can be determined by the degree of visual field loss for those with RP. The National Eye Institute Visual Function Questionnaire-25 (NEIVFQ-25) was used for 40 people with RP and 40 control subjects to obtain scaled difficulty of 12 aspects of daily living activities. All subjects were also examined for their visual field loss. This study reported significantly greater difficulty expressed by the mean NEI-VF-Q-25 score, which was associated with greater degree of visual field loss.

There are other difficulties apart from mobility for people with restricted visual field. Reading, using public transport, and engaging in hobbies or leisure activities are some of the difficult tasks, as found in a study by Fylan et al. (2005). A SRQ was used to identify difficult daily tasks from a group of VI participants, which included people with RP. The findings also included difficulty with tasks relating to emotional status of those with vision loss, such as lack of confidence, feeling worried and staying at home because of their eyesight. It can be argued that, there has not been a comprehensive overview of self-reported difficulties with visual activities and participation of those with RP in ADLs.

2.10 SLR - Postural stability and gait (mobility)

The previous review of SRQs highlighted a number of ADLs that are difficult for those with VI. One aspect (of the ADLs) which was particularly difficult is gait and mobility. The ability to control balance during activities of daily living plays an essential role in the functional mobility and independence of individuals. Postural control is maintained through sensory information provided by the visual, vestibular and somatosensory system (Nashner et al., 1985; Manchester et al., 1989). Visual information is a critical factor to consider when testing stability. Previous studies have mostly taken into account this issue by testing the participants in two different conditions, eyes open and eyes closed (Simoneau et al., 1994; Melzer and Kaplanski, 2004; Slobounov et al., 2008; Black et al., 2008; Sarabon et al., 2013).

2.10.1 Method of SLR

The aim of this second SLR is to provide a review of the key findings relating to assessments of balance and gait among those with VI. The literature search was generated using the same approach highlighted in sub section 2.7.2., using Pubmed (MEDLINE). An initial pilot search was conducted to pool keywords based on the topic area, using online thesauruses and databases. A combination of applying search techniques such as Boolean operators to join subjects and separate phrases was also used. Table 2.3 demonstrates the final search for the first SLR (SRQ). In total, 23,238 potentially relevant studies were identified. The research strategy was repeated twice to assess the consistency and repeatability of the method as suggested by Kichenham et al. (2011). In both searches, the same number of articles were returned.

Table 2.3. The search term is combination of key terms for the second SLR and the filters that were used to obtain the studies.

Data base	Hits	Search terms
Pubmed	23,238	((((((((((((Visual impair*[Title/Abstract]) OR Low vision[Title/Abstract]) AND Vision loss[Title/Abstract]) OR Posture[Title/Abstract]) OR Balance[Title/Abstract]) OR Postural stability[Title/Abstract]) AND Gait[Title/Abstract]) OR Adaptive gait[Title/Abstract]) OR Mobility[Title/Abstract]) OR Walking[Title/Abstract]) AND Step*[Title/Abstract]) OR Stair*[Title/Abstract]) AND full text[sb] AND Humans[Mesh] AND English[lang] AND adult[MeSH])

2.10.2 Inclusion criteria

The literature collected in the systematic review was filtered to publications that included the relevant key terms (see table 2.3) in their title or/and abstract. Articles were then further restricted to research that was only available in English, with recruited subject over 18 years old and provided full txt articles. Any remaining studies that did not meet the PICOS criteria were excluded.

The application of a flow chart diagram below that is in accordance to PRISMA study selection process demonstrates the retrieval process of this SRQ review. The final number of selected studies were twenty five for postural stability and eleven for gait (see table 2.4 and 2.5). The application of a flow chart diagram below that is in accordance to PRISMA study selection process demonstrates the retrieval process of the second SLR.

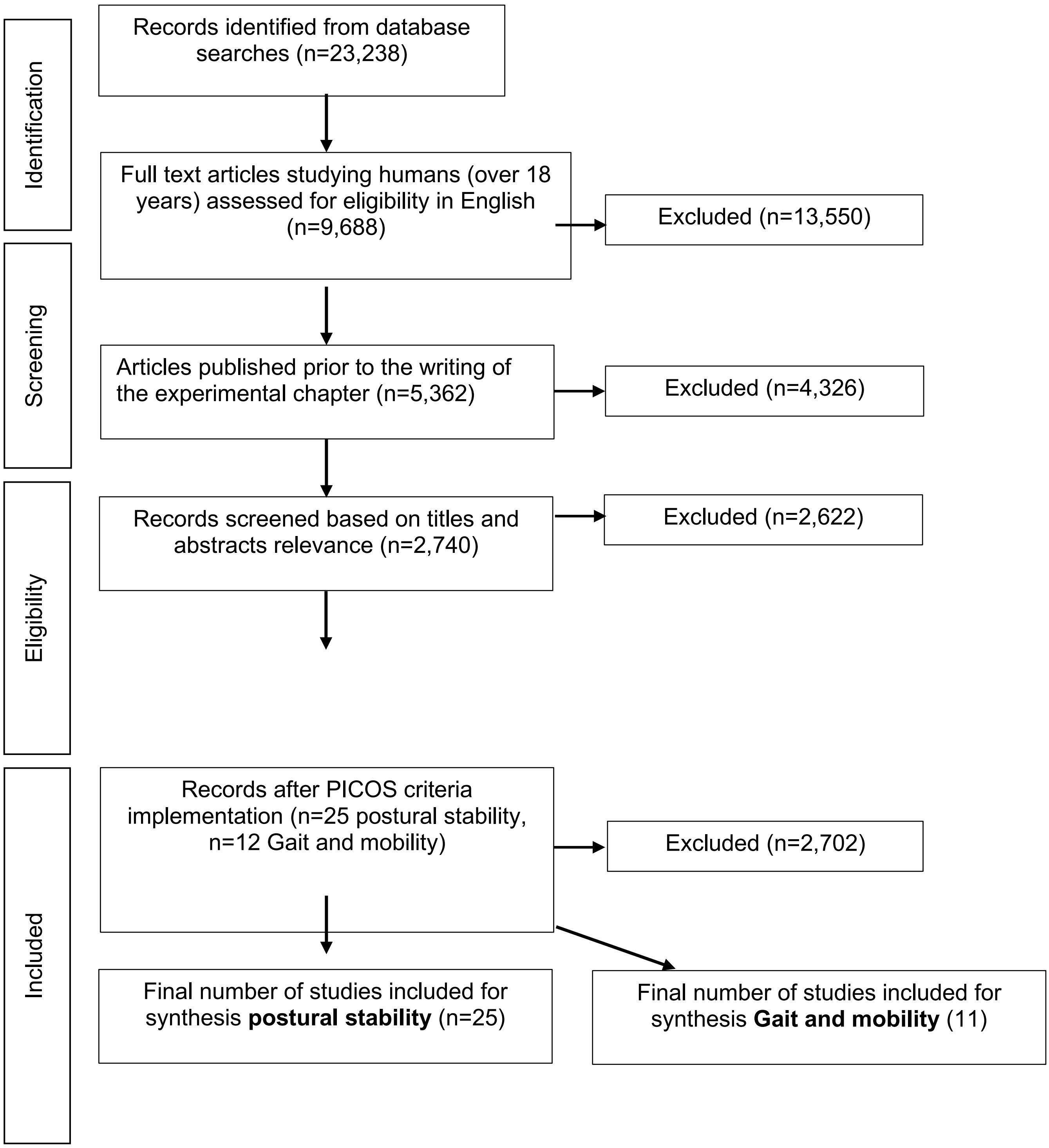
Identification
Screening
Eligibility
Included
Records identified from database searches (n=23,238)
Full text articles studying humans (over 18 years) assessed for eligibility in English (n=9,688)
Excluded (n=13,550)
Articles published prior to the writing of the experimental chapter (n=5,362)
Excluded (n=4,326)
Records screened based on titles and abstracts relevance (n=2,740)
Excluded (n=2,622)
Records after PICOS criteria implementation (n=25 postural stability, n=12 Gait and mobility)
Excluded (n=2,702)
Final number of studies included for synthesis postural stability (n=25)
Final number of studies included for synthesis Gait and mobility (11)

Table 2.4. The selected studies from the second SLR within the postural stability. Once again the methodology varies between the studies, in particular in the stance of participants.

	Title	Author	Method of testing	Participants	Footwear	Arm Position	Focus point	Duration of the Phase	Base of Support (BoS)	Results
1	Age-related changes in Medio lateral dynamic stability control during volitional stepping	Singer et al., 2013	Quite standing - The trajectory of the total body centre of mass (COM) was quantified	Twenty younger (age 24 years; 50% women) and 20 older participants (age 71 years; 50% women)	Unavailable	Unavailable	N/A	60-s duration quiet-standing	forward-stance configuration, with feet on separate force platforms	Increased COM incongruity and trial-to-trial variability among older adults signify a reduction in dynamic stability
2	Comparison of a laboratory grade force platform with a Nintendo Wii Balance Board on measurement	Huurnink et al., 2013	3 Blance tasks, Single leg stance (EO) & (EC). Single-leg stance after a short sideway hop.	Fourteen healthy 6 males,8 females; mean age 28.0	preferred leg and barefoot	hands on their hips	2 m ahead	10 s	invalid trial if participants displaced their standing leg	Wii balance board is sufficiently accurate in quantifying CoP trajectory.

	of postural control in single-leg stance balance tasks									
3	Effect of light finger touch in balance control of individuals with multiple sclerosis	Kanekar et al., 2013	Standing with EO & EC, with a light touch contact of the right index finger with a stable surface without any contact.	11 individuals with MS, mean age 52 - normal or corrected normal vision	Unavailable	Unavailable	N/A	30 s	feet shoulder width apart and together	Light finger touch contact is effective in improving postural control in people with MS.
4	Age-related differences in the influence of cognitive task performance on postural control under unstable	Makizako et al., 2013	Reaction time task under 3 conditions (standing on foam): Holding a glass full of sand, water & verbal fluency task.	Healthy young (22.2) & 27 Healthy older adults (71.3)	Unavailable	Unavailable	N/A	40 s respond period	Feet close together	Increasiing attentional demand had a greater influence on postural control in older compared to younger adults.

	balance conditions										
5	Sensorimotor posture control in the blind: Superior ankle proprioceptive acuity does not compensate for vision loss	Ozdemir et al., 2013	2 bipedal quite stance (fixed support and sway), unipedal (dominant leg) quite stance, bipedal perturbation. Sighted (EO & EC)	13 blind subjects and 15 age & sex matched sighted subjects	Unavailable	Unavailable	N/A	20 s / 10 s	Unavailable	Significantly poorer postural control of blinds compared to normal while in EO and no different in EC.
6	CoP trajectories, trunk kinematics and trunk muscle activation during unstable sitting in low back pain patients, (EO	Willigenburg et al., 2013	An aluminium hemisphere was attached underneath a seat, creating instability in all directions, footplate was attached to the seat	20 LBP patients and 11 healthy subjects	Unavailable	Armed towards the examiner (forward)	N/A	50 s	Feet close together and knee at 90 degree	The effects of proprioception disturbance and vision occlusion were similar between groups.

	& EC), Vibration									
7	Balance training in ataxic neuropathies. Effects on balance and gait parameters	Missaoui et al., 2013	Berg Balance, the Timed up & go test and functional reach test; EO & EC on firm surface and EO on 4-cm thick foam	30 patients with characterized bilateral sensory ataxia	Unavailable	Unavailable	N/A	52 s	feet shoulder width apart	Patients are impaired in balance and gait but can improve clinical balance parameters following training.
8	Does calf muscle spasticity contribute to postural imbalance?	de Niet et al., 2013	Subjects stood on a moveable platform with their eyes open and knee extended	17 symptomatic patients with autosomal dominant pure HSP and 17 healthy	barefoot	Unavailable	N/A	2-10 s (randomised)	feet at shoulder width	Calf muscle spasticity and weakness differently contribute to postural imbalance in patients with HSP.
9	The effect of vision elimination during quite	Sarabin et al., 2013	4 different foot position quite stance; Hip width (PS), the	38 healthy (27.6) - had to complete a	Unavailable	on the hips	1.5 m	60 s	4 different methods	The removal of vision could be more effectively

	stance task with different feet positions		dominant foot forward, none dominant foot tos touching the dominant heel, single leg stance (dominant)	simple fitness test							compensated by other sensory systems in semi-tandem stance, tandem and single legged stance.
10	Vestibulo-ocular response and balance control in children and young adults with mild-to-moderate intellectual and development disability	Zur et al., 2013	Clinical test for sensory interaction in balance and single leg stance, Romberg stance under EO & EC	21 young (17.5) - 13 had a VOR deficit and 8 had a normal VOR	barefoot	hands together behind their back	N/A	Unavailable	feet as close together as possible	Some significant differences in balance control between the groups.

11	Compensatory but not anticipatory adjustments are altered in older adults during lateral postural perturbations	Claudino et al., 2013	predicted (EO) watching the moving pendulum and using a air of glasses with lenses covered with black adhesive tape	20 older non fallers, 20 older fallers and 20 young participants	barefoot	Unavailable	N/A	Unavailable	feet shoulder width apart laterally	Compensatory but not anticipatory adjustments are altered in older adults during lateral postural perturbations
12	Ankle dorsiflexor strength relates to the ability to restore balance during a backward support surface translation	Fujimoto et al., 2013	standing posture of participants was perturbed with backward support surface translation - standing with one foot on each platform	16 young healthy and 16 healthy elderly adults	Unavailable	Folded on their chest	N/A	Unavailable	each foot on one platform (shoulder width)	Dorsiflexor strength was found to significantly correlate with functional base of support measures and threshold acceleration of heel-rise.
13	Postural sway in volleyball players	Agostini et al., 2013	10 trials (5-EO & 5EC),	46 volleyball players (23)	Unavailable	at their sides	N/A	60 s	feet opening angle of 30 degree	The postural sway of the two groups was different

			different head rotations	and 42 healthy subjects (23)						when the subjects kept their eyes open, but it was not with visual deprivation.
14	Stiffness control of balance during dual task and perspective falls in older adults: The MOBILIZE Boston Study	Kang et al., 2013	2 sets of 5 standing trials, one including a dual task (counting backward loud by 3 from 500)	717 elderly subject (77.9)	barefoot	Unavailable	look forward	30 s	about 0.3 m apart	Dual tasking is likely related to fall risk among older and sicker adults, but not those relatively healthy.
15	The influence of vision and support base on balance during quite standing in patients with adolescent	da Silva et al., 2013	balance was assessed by measuring the oscillation area of the CoP before and after spinal fusion	30 female adolescents	Unavailable	along their sides	N/A	Unavailable	feet apart or together	Adolescents with idiopathic scoliosis are more dependent on visual information and that

	idiopathic scoliosis									surgical correction does not change this relationship.
16	Age differences in the control of postural stability during reaching tasks	Haung et al., 2013	Reaching forward to grasp a cylinder and returning to upright position	14 young adults (20) & 16 community-dwelling older adults (73.4)	barefoot	Right arm active	cylinder placed at 110% of arm's length in front	1 min	Heels separated by a distance of 10% of body height	Control of COP during movement execution, particularly during low target reaches, is compromised with aging.
17	Does postural stability affect grasping?	Voudouris et al., 2013	Participants reached to grasp a small sphere while standing either on stable surface or on foam	17 healthy right-handed (31)	barefoot	Right arm active	N/A	Unavailable	parallel and about 20 cm apart	The digits' and wrist's movement had no different when standing on foam than when standing on the stable surface.

18	Visual Stabilization of Posture in retinitis Pigmentosa and Artificially Restricted Visual fields	Turano et al., 1993	Data were collected as each subject stood in dark environment and as each subject viewed a stationary visual display	20 people(48)with normal vision and 35 (46) with RP	barefoot	down their sides	Unavailable	20 s	Unavailable	RP progression is accompanied by a steady decrease of the visual stabilization of posture.
19	Does head extensions and flexion increase postural instability in elderly subjects when visual information is kept constant?	Buckley et al., 2003	postural stability measurements were determined while subjects stood stationary on single fore-platform (head position, visual condition, standing condition)	12 healthy elderly (72.1)	Unavailable	by their sides	1.1 metre squared at 1 m away	30 s	feet placed at a distance one-tenth of their height apart	Increase in postural instability with the head tilted from the erect position may be in part due to mechanical perturbation rather than solely vestibular disruption.
20	Visual impairment and postural	Black et al., 2008	postural sway tested under 4 conditions: EO,	54 community-dwelling aged 65 or over	barefoot	by their sides	N/A	30 s	comfortably apart	Among older adults with Glaucoma,

	sway among older adults with Glaucoma		EC, standing on a firm and a foam surface	diagnosed with Glaucoma						greater visual field loss or thinner retinal nerve fibre layer thickness is associated with reduced postural control.
21	Balance control in Glaucoma	Kotecha et al., 2012	2 group, VI and VN, tested with EO, EC, standing on a foam and standing on firm Romberg Quotient (RQ)	24 Glaucoma (65.9), 24 control subjects (68.3)	barefoot	by their sides	90 cm away from the eye level	over 30 s	parallel and 15 to 20 cm apart	Glaucoma patients display differences in their visual and somatosensory contributions to quite standing balance compared with control subjects.
22	Postural stability in primary open	Shabana et al., 2005	2 group, VI and VN, tested with EO, EC, standing on a	35 patients with POAG and 21	barefoot	by their sides	3 panel board covered with random	30s	separated by an angle of 30 and heels	Primary open angle Glaucoma induces a

	angle Glaucoma		foam and standing on firm	subjects with normal vision			pattern at 50cm from the subjects		placed 5 cm apart	deficit in the visual contribution to postural steadiness.
23	Postural Stability in the Elderly with Cataract Simulation and Refractive Blur	Anand et al., 2003	PS measurements were determined while subjects stood on 2 adjacent force platforms in 2 conditions; bare platform and i.8 cm thick polyurethane	13 Elderly subjects (70)	Unavailable	by their sides	4 visual targets, each of the targets covered an area of 1.1 m2 at 1m distance	30s	feet apart at the distance of one tenth of subject's height rotated at 15 degrees externally	Cataractous and reflective blur increase postural instability.
24	Postural stability in the elderly during sensory perturbations and dual tasking: The	Anand et al., 2003	PS measurements with cognitive and physical tasks, somatosensory disturbance, vestibular	15 Elderly subjects (71)	Unavailable	by their sides	1 visual target area of 1.1 m2 at 1m distance	30s	the inner edges of both feet were one foot-length (their own) apart	The greatest increase in postural instability were due to disruptions of the somatosensory

	influence of refractive blur		disturbance and quite standing							and vestibular systems.
25	The waterloo vision and mobility study: postural control strategies in subjects with ARM	Elliott et al., 1995	RMS of two different group were compared (ARM and normal) at EO, EC & Foam	16 subjects with ARM (73.4) & 19 controls (69.1)	Unavailable	folded in front of them	large door in white wall 5m away	1min	the inner edges of both feet were one foot-length (their own) apart	The kinaesthetic and vestibular systems compensated for the lack of useful information from the visual system in ARM subjects.

2.10.3 Results for the SLR of the balance and gait

The second SLR showed some variation regarding how postural stability is examined. The method of testing the stance varies from single stance (e.g., Sarabin et al., 2013) having a moveable platform (e.g., de Niet et al., 2013) to including verbal fluency task (e.g., Kang et al., 2013) while measuring the balance of participants. This variation included, having the feet close to each other, shoulder width apart, feet 15-20 cm apart, 10% off the participants height apart, feet parallel, feet opening at angle of 30 degrees (e.g., Haung et al., 2013; Agostini et al., 2013). Two studies did not report the stance in their studies (Turano et al., 1993; Ozdemir et al., 2013). The majority of the studies (36%) reported the arm position to be by the participants' sides. However, 10 of the studies did not report the arm positions. Other studies reported arms to be folded on their chest, on the hips or together behind the participants' back. McIlroy and Maki (1997) argued that the stance affects the result of postural stability testing, thus the standardization of this fact should be considered within the research. Although, they recommended a standard measure (see 3.4.3) it is evident that different studies use different methods of testing. The variation was similar with the duration of the testing, varying from 10 to 60 seconds. Five of the studies did not report the trial duration (Claudino et al., 2013; de Silva et al., 2013; Fujimito et al., 2013; Vodouris et al., 2013; Zur et al., 2013). The duration of testing is an important factor as fatigue could affect the postural stability (Haung et al., 2013). The optimum trial periods for postural stability testing has been reported to be at 20 to 30 seconds (Clair and Riach, 1996). This duration is known to be optimum because it includes the stability period as the first 10 seconds usually is the familiarisation period (Turano et al., 1993) and it excludes the fatigue period which could occur past 30 seconds (Kotecha et al., 2012)

The footwear of the participants is an important factor because of the impact on somatosensory feedback acquired from the feet. Footwear was not reported for 14 of the studies with the rest reporting the participants were barefooted. Vision, another important factor in testing balance was only considered in 11 of the studies where the participants were tested both with eyes open and closed. Postural stability is controlled and maintained through a complex interaction of visual inputs, somatosensory and the vestibular system (Massion, 1994). Thus, ignoring the somatosensory and the vision inputs while studying postural stability can question the reliability of some of the studies.

Those studies that included the vision inputs during postural stability testing highlighted this important aspect. Whilst it is commonly understood that reduced vision has a detrimental effect on balance and by implication increased risk of falling, findings in the literature appear to differ depending upon specific testing situations and type of visual impairment. For example, whilst standing balance (as measured by amount of sway using a force plate) was worse for those who were visually impaired (due to diabetic retinopathy and congenital retinopathy) compared to those with normal vision, no difference was observed when permitted to use their mobility aid or use the wall to provide ‘light touch’ support (Maeda et al., 1998). Kotecha et al. (2013) reported that individuals with peripheral visual field loss (through Glaucoma) only recorded significantly worse balance (both forwards-backwards [A-P] and sideways [M-L] directions) compared to visual normals when standing on a foam surface; no differences were observed when standing on a firm surface. However, individuals with central vision loss (through age related macular degeneration - AMD) recorded worse balance (both A-P and M-L directions) compared to visual normals when standing on both firm and foam surfaces. When additionally required to complete a mental arithmetic task which served to increase cognitive load and divide attention resources, differences in sway were observed between AMD and visual normal (in A-P direction) when standing on firm and foam surfaces; no differences were found between Glaucoma and visual normal groups (Kotecha et al., 2013). Unlike Kotecha et al. (2013), in a younger group of individuals with Glaucoma, compared to visual normal, Shabana et al. (2005) did not find any differences in postural control when standing on a foam surface; Shabana et al. (2005) did not find between group differences in any of the conditions tested. With a larger sample than Kotecha et al. (2013) and Shabana et al. (2005) encompassing a wider range of glaucomatous visual loss, Black et al., (2008) demonstrated that greater binocular visual field loss was significantly associated with increased postural sway with eyes open on a firm and foam surface.

To date there is little research investigating postural control in people with Retinitis Pigmentosa (RP). Of the little research investigating the effect of RP on balance control, Turano et al. (1993) reported that compared to visual normals, people with RP had reduced balance (increased sway in A-P direction) in light but no difference in a dark condition. Both RP and visual normals had significantly reduced balance in dark compared to light. However, sway in the RP group between vision conditions was only marginally significant, leading the authors to conclude that people with RP use less visual contribution to balance. This finding was also confirmed through Turano et al. (1993) calculating the magnitude of sway in the dark compared to light (termed visual stabilization index). Importantly, testing occurred with participants standing on a sway reference platform (which served to disrupt somatosensory information) which only measured balance control in the A-P (and not M-L) direction. No habitual condition was included with individuals standing on a firm surface either. Reduced balance in the M-L direction is a significant predictor of multiple falls in older adults (Swanenburg et al., 2010) and sideways falls often result in fractures of the femoral neck (Nevitt and Cummings, 1993). It is for this reason that investigating balance control needs to consider both forwards-backwards [A-P] and sideways [M-L] directions.

2.10.4 The SLR studies for gait and mobility

Table 2.5 demonstrates the final eleven studies from the SLR that relates to gait and mobility within those with VI.

Table 2.5. The selected studies from the second SLR for gait and mobility with the VI group.

	Title	Author	Method of testing mobility	Participants	Results
1	Changes to control of adaptive gait in individuals with long-standing reduced stereoacuity	Buckley et al., 2010	Three dimensional body segment kinematic data were collected, as each subject walked across the lab and negotiated floor-based obstacle.	12 visually normal and 16 with deficient stereopsis	Occlusion in the eyes caused similar gait changes in both groups. Thus, both eyes contribute to the execution of adaptive gait.
2	Traditional measures of mobility performance and retinitis pigmentosa	Geruschat and Turano, 1998	Two mobility courses were used and the speed of the walking of participants were recorded.	16 Visually normal and 25 people with typical RP.	Those with RP travel more slower than the normally sighted subjects.
3	Stepping up to a new level: effects of blurring vision in elderly	Heasley et al., 2004	Three dimensional body segment kinematic data were collected, as participants stepped up to a new level.	12 healthy individuals tested with simulating vision condition	Safety adaptation of gait was used when the vision of the individuals were blurred.

4	Vision and mobility performance of subjects with age-related macular degeneration	Hassan et al., 2002	High density indoor obstacle course was used.	21 subjects with ARMD and 11 age-matched subjects with normal vision.	Mobility performance decreases as the size of a binocular central scotoma increases.
5	Utility of peripheral visual cues in planning and controlling adaptive gait	Graci et al., 2010	Three dimensional body segment kinematic data were collected, during a walking gait experiment.	12 subjects wearing goggles that provided simulating vision.	Exteroceptive cues are provided by central visual field and are used in feed-forward manner. Whereas, expproprioceptive information is used by the peripheral visual field and used as online manner.
6	How is human gait controlled by vision	Patla, 1998	Whole body movement were monitored using OPTOTRAK system with infrared diodes attaching to body segments.	Six young healthy adults	Significantly higher toe clearance when the obstacles were not visible for the last two steps.
7	Control of adaptive locomotion: effect of visual obstruction and visual cues in the environment	Rietdyk and Rhea, 2006	Infra-red emitting diodes were used with Optotark 3020 sensors during obstacle negotiation course.	8 healthy subjects, use goggles that simulated their visions.	Visual exproprioception of obstacle location, was more important than visual exproprioception of the lower limbs for controlling

					lead and trail foot placement.
8	Waterloo vision and mobility: gait adaptations to altered surfaces in individuals with age-realted maculopathy	Spulding et al., 1994	Kinematic data and ground reaction forces data were collected during obstacle crossing course.	20 subjects with ARM and 20 control subjects.	Gait was modified to avoid tripping over a surface edge, to prevent slipping at heel contact, and to balance during stance.
9	Obstacle crossing during locomotion: visual exproprioceptive information is used in an online mode to update foot placement before the obstacle but not swing trajectory over it	Timmis and Buckley, 2012	Kinematic data were collected using 6 camera system (Vicon) during adaptive gait.	12 young participants wearing smart-glass goggles	Lower visual field input is typically used in online manner to control the final foot placement. Without such a control, uncertainty causes the toe clearance to increase.
10	Patients with central visual field loss adopt a cautious gait strategy during tasks that present a high risk of falling	Timmis and Pardhan, 2012	3-D Kinematic data were collected using 6 cameras (Vicon) during an obstacle crossing walkway.	12 patients with CFL and 12 visually normal	Patients with CFL adopt cautious gait strategy during tasks such as obstacle crossing.

11	Direction of gaze while walking a simple route: persons with normal vision and persons with retinitis pigmentosa	Turano et al., 2001	Used the low-vision enhancement system (LVES), a head-mounted, battery-powered video display system with three video cameras developed by Robert W. Massof at the Wilmer Eye Institute.	6 people with RP and 3 people with normal vision	Those with VI (RP) sample the environment in a different manner compared to those normally sighted.

2.10.5 Results for the SLRs of the gait and mobility studies

The variation of different methodology and approaches is evident within the final 11 SLR studies. Although, all studies examined the gait of individuals, but the technique varied significantly. Only two studies used a mobility course, where the speed of the participants completing the course could be recorded as well as the number of contacts with an obstacle(s) (Geruschat and Turano, 1998; Hassan et al., 2002). The other nine studies use video recording technique, however this also varied from videotaped recording (VHS) to three dimensional Vicon system (e.g., Buckley et al., 2010; Timmis and Pardhan, 2012).

The participants used in table 2.5 can be categorised into two. Six studies used a group of individuals with a particular VI and compared the results to age-matched normally sighted people (e.g., Spaulding et al., 1994; Turano et al., 2001). However, the rest of the studies used only normally sighted people but simulated vision loss using goggles (e.g., Reitdyk and Rhea, 2006; Timmis and Buckley, 2012) to VI. Although, both methods are used in the research it is likely that those with VI can use other senses such as somatosensory or/and auditory to compensate for the visual loss (Miller, 1992). Perhaps, a valid method of examination would have both groups (VI and simulated), then comparison within the groups can be made. For example, Krischer and Meissen (1983) examined the reading speed of visually impaired, including both simulated and real visual impairment. The study reported similar results between the groups, however the study only examined one ADLs and other tasks such as mobility may have a different result.

The importance of visual search during gait was also highlighted within the selected SLR studies. Some aspects of visual exteroception (information regarding environmental characteristics) and exproprioception (the relation of body segment to the environment) during gait adaption are yet to be fully understood (Rhea and

Rietdyk, 2007). This has been one of the reasons why there has been an increase in research investigating the role of the visual information's on mechanisms human gait. Other key reasons for the increased research in this area is finding reasons and strategies for fall prevention.

A series of studies has demonstrated the effect of visual information on toe clearance measures. It has been illustrated that when crossing with the trail limb the obstacle is behind the subject, therefore visual exproprioceptive input regarding the obstacle and the limb is unavailable. This can cause higher variability in toe clearance of the trail limb comparing to the lead limb (Patla et al., 1996). This can also be evident if the vision of the lead limb is obstructed a few steps prior to crossing, causing toe clearance variability to increase (Patla, 1998).

During walking, visual information is used to orient the body relative to the environment, control balance and plan trajectories and foot placement of the swing limb (Patla, 1997; Rietdyk and Rhea, 2006). During obstacle crossing neither the trailing limb nor the obstacle is within the subject's field of vision. This increases the chance of the contact of the foot with the obstacle. At 'toe off' there is also more complications for the trailing foot prior to the crossing. The toe of the trailing limb is one step closer to the obstacle than was the toe of the leading limb (Draganich and Kuo, 2004). To be able to cross the obstacle successfully the trailing limb needs to achieve adequate toe elevation in a shorter time for a given crossing speed. Previous studies have thus shown that the trailing limb exhibit higher vertical toe velocities than the leading limb (Patla et al., 1996).

Rietdyk and Rhea (2006) examined the role of exproprioception on controlling adaptive gait (obstacle crossing) by removing exproprioception of the lower limb relative to the obstacle. The study used goggles that obstructed vision of the lower limb and ground immediately in front of the subject (approximately 1.2m). The subjects lost direct view of the obstacles about two steps prior to the obstacle in the visual interference condition. However the positional cues used gave indirect information about the location of the obstacle. They concluded that the presence of the positional cues resulted in lead and trail horizontal distances from the obstacle, which was not significantly different from the full vision condition. As such, visual occlusion had limited effects on toe clearance (Rietdyk and Rhea, 2006). They suggested that subjects obtained information close to the obstacle (within the last two steps) and were able to estimate their position, enabling them to regulate their foot placement.

Timmis and Buckley (2011) reported foot placement and toe clearance values unaffected when the height of obstacles are changed in their study. Their finding reflects those who found similar results (Patla, 1998; Rhea and Rietdyk 2007; Graci et al., 2010). They also found that trail foot placement distance and toe clearance were increased by a significant level when the lower vision field was occluded compared to full vision condition. They suggested that the visual input is used in an online manner to gain the ability of placing the final foot accurately, and without this input the toe clearance will increase as there is uncertainty about the foot placement relative to the obstacle.

It has been shown that those with visual impairment adopt generally more cautious walking strategies compared to those who are normally sighted. In a study by Spaulding et al. (1994), these strategies were seen by slower walking and longer swing time (feet) of individuals with AMD compared to normally sighted individuals during level walking with different illuminations (5 lux and 2500 lux). These adaptations were suggested as a mechanism to prevent tripping over a surface edge or slipping at heel contact. However, it can be argued that the longer time of the swing could actually generate more unbalance due to the increased time spent on one limb (a time of relative instability). Buckley et al. (2010) also reported a more cautious strategy by stereo-deficient individuals compared to normally sighted people in obstacle crossing performance. The cautious strategies included reduced walking velocity, increased toe clearance and penultimate step length further from the obstacle. The cautious strategies included reduced walking velocity, increased toe clearance and penultimate step length further from the obstacle.

Timmis et al. (2015) used healthy individuals with simulated contact lenses to resemble central field loss in an obstacle crossing experiment. Gait adaptation of being more cautious was shown in the simulated group with 20 degrees central field loss (CFL) compared to 10 degrees and full vision conditions. Those with 20 degrees CFL placed their lead foot further away from the obstacle, lifted both their feet higher and also slower over the obstacle, and took longer time to negotiate the obstacle compared to the other groups. The study reported that the adaptations were only associated with 20 degrees and not 10 degrees CFL.

In another study by Timmis et al. (2012), similar results to those reported by Timmis et al., 2015 were shown where actual patients with CFL were used. It was reported that those with central visual field loss (CFL) lifted their lead and trail foot significantly higher and reduced horizontal crossing velocity when negotiating an obstacle and also increased head flexion to look down. These are all established as cautious strategies to prevent falls. Interestingly, there were no significant differences between the two groups at level walking. The result from this study shows that the difference between those with visual impairment compared to normally sighted only occurs at obstacle crossing and not level walking. To feel safer and prevent falls, those with limited vision use cautious strategies to negotiate an obstacle.

Turano et al. (1999), reported that people with Glaucoma have decreased mobility in their performance and walk slower than those with normal sight. They also reported a higher number of bumps and stumbles, or orientation problems for those with Glaucoma. However the difference was not statistically significant. Difficulties with mobility performance (walking speed, mobility incidents) are one of the major problems reported by people with RP. Geruschat et al. (1998) in a study based on an SRQ, it was reported that 80% of the RP subjects experienced mobility difficulty. One of the main aims of their study was to compare the RP subjects' self-reported mobility difficulties with objective measures of mobility performance. However, the responses from those with RP in regards to the mobility questionnaire were not reflected in their performance as assessed by incidents on a mobility course; those who reported mobility difficulties were no more likely to experience mobility incidents than those who reported no mobility difficulties.

Visual impairment has been highlighted as an independent risk for falls due to the diminished visual input available to maintain balance (Lamoureux et al., 2008) and is a significant predictor of falls (Ray et al., 2007). Those with VI also report difficulties with balance control (Bouchard et al., 2000). Due to the role that vision plays in maintaining balance, it is not surprising that VI is a significant predictor of falls (Ray et al., 2007). Reduced postural stability likely explains why those with VI are up to seven times more likely to have a fall and risk serious injury compared to those without such impairment (Legod et al., 2002).

Severely sight impaired individuals performed postural stability tasks equally well compared to the normally sighted people with their eyes open, interestingly performing better when they had their eyes closed (Schwesig et al., 2011). A possible explanation could be that the other postural system such as a somatosensory mobilizes effectively as compensatory mechanism (Friedrich et al., 2008). This is an important area of research to investigate further.

An important aspect of studying the balance of those with VI is when the somatosensory system is disturbed, for example by asking participants to stand on a compliant surface such as foam. Indeed, in everyday life people do not stand on a foam surface. The significant difference in sway was only highlighted when this action took place in a study using age related macular degeneration patients and normally sighted people (Elliot et al., 1995). The balance of those with VI was significantly poorer compared to those normally sighted however only when standing on the foam surface. The study suggested that in normal standing, the somatosensory and vestibular systems compensated for the lack of information from the visual system for people with VI.

2.11 Risk of falls

Vision loss and particularly visual field loss is associated with increased likelihood of falling (Lovie-Kitechen et al., 1990; Haymes et al., 1996; Geruschat et al., 1998; Kuyk et al., 1998; Klein et al., 1998). Also reduced postural control, which could be the result of low vision, has been shown to significantly increase the risk of falls (Maki et al., 1994). Individuals with bilateral visual field loss are more likely to use a walking aid, and also be involved in more frequent falls (Ramrattan et al., 2001). It has also been shown that people with decreased visual field are at an increased risk of falling due to worse postural stability (Kotecha et al., 2012).

In the United States, in 2009, 2.2 million fall related injuries were recorded among elderly adults over the age of 65. In the same year, 19,000 older adults died from unintentional fall related injuries. This made falls the fifth leading cause of death in the elderly population (Ambrose et al., 2013). The annual direct medical costs associated with falls among older adults has been estimated at $23.3 and £1.6 billion in the USA and UK respectively (Davies et al., 2010). Individuals with vision loss are at an increased risk of falls (Ray et al., 2007) due to their diminished visual input required to maintain balance (Lamoureux et al., 2008).

Studies have looked at the reasons of falls, in particular for those with visual impairment. Visual functions have been identified as a predictor of falls; poor visual acuity (Ivers et al., 1998; Lord, 2006), contrast sensitivity (de Boer et al., 2004) and loss of visual field (Coleman et al., 2007) have been highlighted as significant predictors. Reduced postural stability likely explains why those with visual impairment are up to seven times more likely to have a fall and risk serious injury compared to those without such impairment (Legod et al., 2002). The effects of VI leading to postural instability is an important area of research. By studying this area of research. Investigating this area could be beneficial to possibly prevent falls in those with VI.

2.12 Aim and Hypothesis

The difficulty in measuring the performance of ADLs from those with visual impairment have been reported (Haymes, et al., 2002). However, the importance of measuring this aspect is vital in terms of rehabilitation and also gaining insights for those with VI. One of the main issues in this area of research is that is there no consensus on which activities comprise the relevant ADLs, nor there is any consensus on the methodology of measuring an individual's performance of ADLs. Furthermore, different VIs have different outcomes for individuals and it is important that they are investigated separately. Therefore, the aim of this PhD is to investigate the effect of vision on ADLs in an RP population.

Most studies mentioned in this literature-review investigated the effect of RP on one specific area (Turano et al., 1999), or have looked at visual difficulty overall using instruments such as the NEI-VFQ (Hahm et al., 2008; Sugawara et al., 2009). The literature is currently missing a comprehensive overview of ADLs to determine what the most difficult areas are for people with RP. By studying this area an important question can be answered:

What ADLs do people with RP find difficult to complete?

Furthermore, the lack of studies for stating the relationship between postural instability and ADLs of those with RP has been evident. Hence, this PhD will also investigate the standing balance stability among individuals with RP to provide further evidence of the role of peripheral vision in standing postural stability. This study will extend the previous research conducted by Turano et al. (1993) by testing individuals in a variety of conditions including standing on a firm and compliant surface with both eyes open and eyes closed. The degree of visual field loss in those with RP in relation to postural stability will also be considered. By doing this, the following question can be answered:

Do people with RP have poorer postural stability compared to those normally sighted individuals?

The results from the SRQs will inform the final experiment. The purpose of the final study will be to examine the gait difference of those with RP and those normally sighted individuals at level walking and obstacle crossing. In addition, those with RP are sub grouped into mobility cane users and those without the cane. Finally, a following critical question could be answered:

Do people with RP use more cautious strategies in their gait and/or when completing a difficult ADL? If so, how?

3. General methods

3.1 Introduction

The experimental chapters contained within this PhD, are divided into two sections. The first section, consisting of experiments 1 and 2 (chapters 4 and 5 of this thesis) utilise self-report questionnaires (SRQ) to access perceptions of those with RP in regard to activities of daily living. The second section consists of experiments 3 and 4 (chapter 6 and 7 of this thesis) which measure and analyse the physical movements undertaken by the participants which were highlighted in SRQs as difficult to complete.

The following chapter will outline the participants, equipment and generic procedure of all the experiments in this thesis. Each experimental chapter includes its own specific procedural details.

3.2 Participants

Participants of the research were recruited through advertisements using social media as well as oral presentations at a number of meetings and conferences organised by RP Fighting Blindness (RPFB) charity. RPFB are a medical research charity and a UK nationwide organisation that provides support and information for those affected by RP. Of note, the name of the organisation changed in 2018 to Retina UK. This PhD research worked in collaboration with this charity. The researcher attended the AGMs and members' meetings organised by the charity around the country to increase awareness of the research and recruit participants. The control group (those with normal vision) was formed using colleagues, friends and supporters of those with RP.

Ethical approval for all the experimental studies were gained from Anglia Ruskin University Ethics Committee (appendices 1, 2 and 3). Those interested in participating in the studies completed a contact form (appendix 4) and the researcher contacted them for recruiting of the studies of this PhD. All the participants were given an information sheet (appendix 5) outlining the aim and protocol of the study prior to taking part. To be eligible to take part in any of the studies, participants were required to complete a self-report health questionnaire. The health questionnaire differed in the SRQs studies (chapters 4 and 5) compared to the human movement studies (chapters 6 and 7). This was because in the latter chapters participants were tested in the laboratory and had to be able to complete mobility tasks, whereas the SRQs did not involve any human movement data collection. In chapters 6 and 7, it was also necessary to understand any underlying pathologies which may affect gait beyond that of their visual impairment (for those with RP) and exclude those from the visual normal (control) group.

All participants signed an informed consent sheet prior to start of data collection (appendix 6). An online version of the consent form was available for the online SRQs. Participants had the option of withdrawing at any point without giving the reasons. In the final experimental chapter (chapter 7), where participants were required to visit the laboratory, travel costs were covered.

As the instability in gait and posture can originate from other health conditions rather than RP, the literature was studied to highlight the medical conditions that can affect postural stability and gait. Some of the health conditions that have been shown to affect human movement are as follows: Diabetes (Yamamoto et al., 2001; Kotagal et al., 2013), history of stroke (O'Dell et al., 2005), lower back pain (Salavati et al., 2008; Mazaheri et al., 2009; Willigenburg et al., 2013), arthritis (Mengshoel et al., 2007), hearing issue (Jafari and Malayeri, 2011) and multiple sclerosis (Kanekar et al., 2013).

Thus, in the chapters where participants had to attend the laboratory (chapters 6 and 7), participants were excluded if they reported a history of comorbidities such as vestibular disturbance, diabetes resulting in either vision or somatosensory loss, Polio or severe arthritic conditions. These comorbidities excluded individuals from participation because they have previously been reported to affect postural stability and gait of individuals (Fujimoto et al., 2013; Hsieh et al., 2013; Kotagal et al., 2013). For the SRQs chapters (chapter 4 and 5), participants under 18 years of age or supporting someone under 18 years of age were excluded.

3.2.1 Sight loss registration of the participants

For the SRQ studies (chapters 3 and 4) sight loss registration status was determined where participants had to indicate one of the registration status options (see related chapters). In the UK visually impaired individuals are encouraged to register by seeing a consultant ophthalmologist. There are two groups of registration: individuals may be registered as being either sight impaired or severely sight impaired. This is based on the extent of loss visual acuity and/or visual field. Table 3.1 illustrates the two categories.

Table 3.1. The definitions of sight impairment (SI) and severe sight impairment (SSI) (Department of Health, 2013). The unit measurement of visual acuity in the table is the Snellen fraction. 'Normal' visual acuity is considered as 6/6, if a person can only achieve 6/60, this means that the person can see at 6 meters an individual with 'normal' vision could see at 60 metres.

<u>To be registered as sight impaired (SI), sight has to fall into one of the following categories while wearing refractive correction as needed:</u> • Visual acuity better than 3/60 but below 6/60 with a full visual field • Visual acuity below 6/24 but with moderate contraction of the field, opacities in media or aphakia • Visual acuity of 6/18 or better but with a gross visual field defect, for example hemianopia, or marked contraction of the visual field, for example in retinitis pigmentosa or Glaucoma

To be registered as severely sight impaired (SSI), sight has to fall into one of the following categories while wearing refractive correction as needed:

- Visual acuity below 3/60 with a full visual field
- Visual acuities better than 3/60 but below 6/60 with contracted field of vision
- Visual acuity of 6/60 and above but with a contracted field of vision especially if the contraction is in the lower part of the field

3.3 Equipment

3.3.1 The Dutch Activity Inventory (D-AI)

The Dutch Activity Inventory (D-AI) (Bruijning et al., 2013) was used as the SRQ in experiment 1 (chapter 4) and experiment 2 (chapter 5). This was used to investigate which ADLs those with RP found difficult to complete due to their visual impairment. Bruijning et al. (2010) created the Dutch version of the AI in which goals are classified by the "Activity and Participation" domains of World Health Organisation International Classification of Functioning, Disability and Health (World Health Organisation, 2013). The final AI by Bruijning consists of 65 goals nested under 10 domains. Underlying these goals are 959 tasks. For the purpose of this PhD, initial assessments (chapter 4) of the difficulty of 47 rehabilitation goals nested within 10 objectives of the WHO-ICF framework (see 2.6.1). Thus, some of the goals from the original D-AI, such as making music and mending cloths were excluded as they were not related to the purpose of this PhD. Each goal question is phrased in the style similar to the following (for example): 'Is mobility indoors difficult for you because of your visual impairment? Consider how difficult this is to do without the assistance of another person, but with any assistive devices that you use.' Participants were asked to respond to each question on a Likert scale. The responses were scored from 0-5. A score of 0 indicated the goal was not applicable to the participant or they did not do the task and was not considered in the data analysis. A score of 1 indicated the goal was impossible to achieve without support, 2 was very difficult, 3 was moderately difficult, 4 was slightly difficult and 5 indicated no difficulty. Therefore, the higher scores indicated greater ability and lower scores indicated greater difficulty level.

In a full administration of the D-AI, task questions are asked for all goals that are important and of some difficulty. There are over 400 task questions in total underpinning the 47 goals, making a full administration of all goals and all relevant tasks very time consuming. Therefore, administration of the D-AI at task level was undertaken in a separate study (chapter 5), concentrating only on the tasks underlying goals that were determined to be particularly difficult from the first experiment (chapter 4). In addition to the D-AI, participants were also asked about their age, duration of visual impairment, gender, visual impairment registration status, use of mobility aids such as guide dog or a mobility cane and other health conditions.

3.3.2 Online questionnaire

To make the SRQs accessible online, online versions of the SRQs were designed and made available to the participants using Surveygizmo. This is a data collection platform that allowed the researcher to put up the D-AI online and then send the links to those participants who wanted to complete the SRQs. Figure 3.1 demonstrates an example of the questions with a screen shot of the SRQ, where participants were asked to select their registration status and indicate the numbers of years with visual impairment. The link for the online SRQ was shared with all those who were interested to take part in the study through the recruiting process. Once the data were collected, they were transferred into excel sheets for further analysis. The font size of the SRQ followed the UK guidance on accessible communication formats (UK Government Publications, 2013), which was 14 point. Participants also had the option of increasing the size of the font if they preferred.

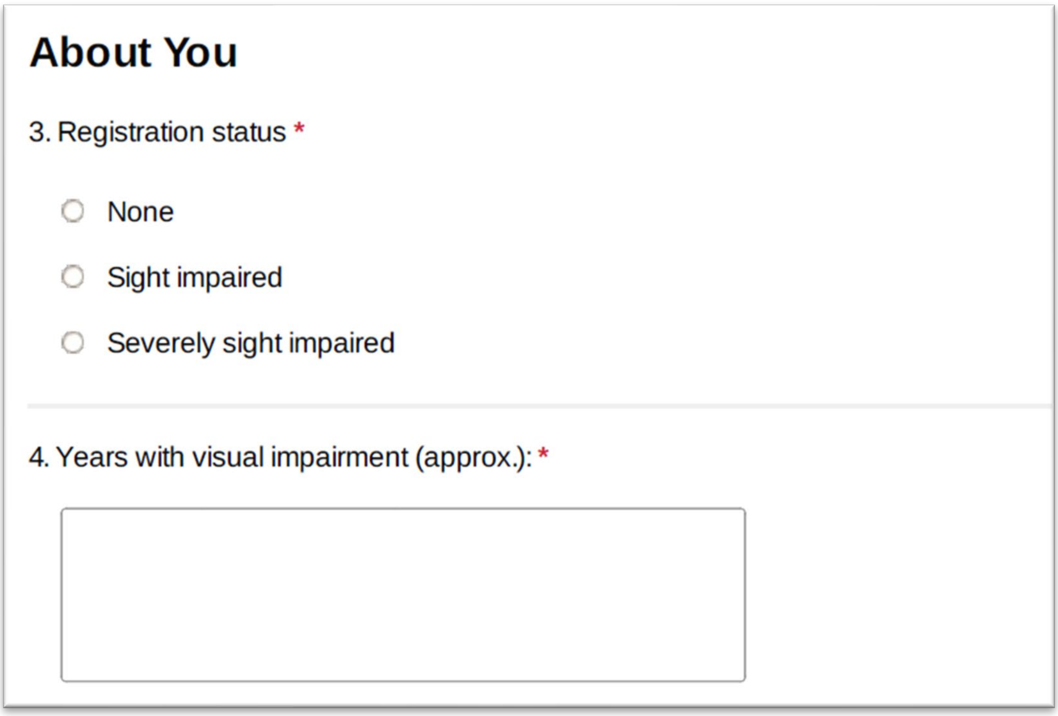

Figure 3.1. A screenshot of the SRQ on the Surveygizmo website. The participants had the option of increasing the size of the font if they preferred.

3.3.3 Telephone and postage

Apart from the online version of the SRQ, participants had two other options for completing the questionnaire. The researcher was available to go through the SRQ via a telephone call with the participant, once an appointment was made. This method was used for those who had no access to a computer and preferred to complete the SRQ by speaking to the researcher. Also, participants could indicate to receive the SRQ through the post with a stamped return envelope. Some participants decided to give more information about the effect of RP on their ADLs, thus, additional to the completed SRQs detailed letters about their conditions were attached. This helped the researcher to gain a better understanding of the condition. A few examples of the letters are shown in appendix 7. Again, this method was available for those without access to a computer and who wished to read the questions themselves. The telephone method was excluded for the second SRQ (chapter 5) because it included some difficult and sensitive emotional questions and the researcher was not qualified to deal with those questions through a telephone conversation. Those who supported the participants could help them to complete the SRQ if necessary. In addition, participants could use the functions of of text to speech and/or magnification using computers, which help to complete a SRQ.

3.3.4 Visual assessments

Visual assessments of the participants in the experimental chapters of 6 and 7 were undertaken to assess participants' visual ability. Both eyes are used to acquire visual information during posture and gait, hence all but one (Damato Campimeter, measuring the visual field, chapter 6) of the assessments were completed binocularly. Participants wore their habitual spectacle corrections if needed during the assessments. Visual assessments included visual acuity, contrast sensitivity (chapter 7 only) and visual field.

3.3.4.1 Visual Acuity

Visual acuity (VA) assesses central vision and resolution of fine detail. VA was assessed binocularly using the Early Treatment Diabetic Retinopathy Study (ETDRS) LogMAR chart. The chart was internally illuminated. VA was measured on a letter by letter basis (Arditi and Cagnelloa, 1993). Each letter was counted as 0.02 LogMAR. The final score was the number of letters correctly read and converted to LogMAR (Bailey et al., 1991) Participants were encouraged to start with the smallest line they could comfortably read and continue on reading. The baseline distance of the chart differed for experiment 3, at the distance of 3 metre to experiment 4, at the distance of 4 metre. The distance differed because experiment 3 took place at different venues across the country and to ensure a small room used for data collection could accommodate the visual assessment screening the shorter distance of the chart was used. If the participants were unable to read the largest letters on the LogMAR chart at the starting distance, then the distance was halved and if needed then quartered and the score was adjusted accordingly by adding 0.3 logMAR to the score each time viewing distance was halved (Myint et al., 2016). The termination strategy was to encourage the participants and give them a few seconds to try the last (smallest) letter they could see. Participants who failed to read any of the letters at the shortest distance were assigned score of 2.0LogMAR. Figure 3.2 illustrates the chart used.

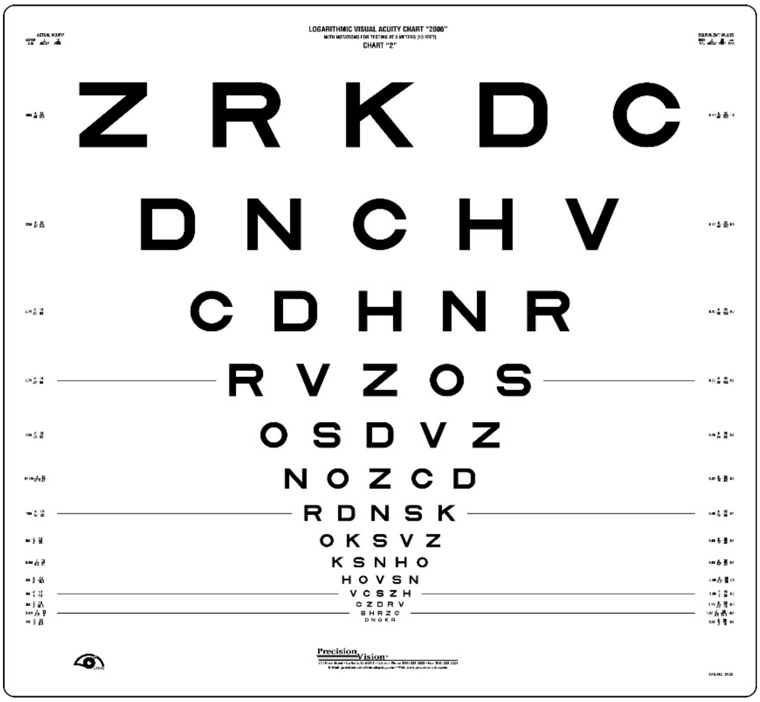

Figure 3.2. ETDRS chart used to assess visual acuity.

3.3.4.2 Contrast Sensitivity

Contrast sensitivity (CS) is the ability to distinguish an object from its background. Binocular CS was measured using the Pelli-Robson chart at 1m (Pelli et al., 1988) under controlled room illumination of approximately 500Lux measured using a lux meter (model CEM-DT-1308). The chart included 8 lines of letters, each line had 6 letters where the first 3 letters on the left had greater contrast than the 3 letters on the right. The triplet scoring method was used, with threshold considered as the final triplet at which the individual reads at least two of three letters correctly (Elliot et al., 1991).

When participants were unable to see any further letters on the chart, the next lower triplet was pointed to them and participants were asked to keep looking at the area for

15-20 seconds to see if they were able to read any additional letters. This was to achieve maximal contrast sensitivity. Participants with no measurable CS function were assigned a score of 0.00LogCS (two participants in total). Figure 3.3 illustrates the chart used for experiment 4 (chapter 7). The reason for not using CS for the 3rd experiment (chapter 6) was the limited time the researcher had at the venues visited for the data collection. Thus VA measurement was used in preference to CS (chapter 6) because it is a standard measure of visual function, utilised in eye examinations (Elliot, 2013) and visual impairment registration criteria (Department of Health, 2013).

Figure 3.3. Pelli-Robson contrast sensitivity chart used.

3.3.4.3 Visual Field

Visual field (VF) represents the peripheral and central vision of individuals. The ideal visual field test would assess binocular function, since the binocular visual field assessment represent functional abilities better than monocular assessment, especially in individuals with visual impairment (Schneck et al., 2010; Asaoka et al., 2011). To assess the visual field of the participants the Damato Campimeter (experiment 3, chapter 6) and the Humphrey Field Analyser (experiment 4, chapter 7) were used. It has been suggested that long test durations can adversely affect individuals' concentration and compromise the reliability of the visual field results (Henson and Emu, 2010). Thus, considering the protocol of the experimental chapters (6 and 7), suitable assessments tools were selected.

3.3.4.3.1 Damato Campimeter

Due to the practical limitations associated with transporting research equipment when attending RP support group meetings and also the limited available time to collect data for experiment 3 (chapter 6), the Damato Campimeter was used in favour of more traditional visual field analysers (such as Humphrey Field Analyser, Goldmann kinetic or/and Esterman visual field test). The Damato was favoured due to being much smaller in size and non-electronic, and therefore easily portable. The literature also showed that the Damato can be a reliable tool to measure VF: in a large population based study (1,278 adults) and a separate study recruiting 93 individuals with Glaucoma, Sponsel et al. (1995) previously demonstrated that the Damato Campimeter can reliably detect moderate to severe visual field loss with a satisfactory low false-positive rate.

The Damato campimeter consists of a flat card with 60 sequential fixation points (numbers) arranged for testing the central 30° field of vision (Figure 3.4). The test was completed monocularly, with a 40 cm hinged piece of card being used to maintain the appropriate test distance and occlude one eye. During pilot testing it was recognised that the test was too long for individuals with RP (approximately 30 minutes). Due to the practical restriction regarding the available time with each participant (approximately 15 minutes), the number of fixations were reduced. As such participants fixated sequentially at 35 evenly spaced locations (instead of 60) on the Damato (Figure 3.5). Whilst maintaining fixation at specified locations on the Damato, participants were required to acknowledge when a black 6 mm stimuli (which appeared in the centre of the device) was visible. The spot oscillated for every fixation point on the card. Any point missed, other than the physiologic blind spot area, was confirmed and reported. It was initially intended that the number of points seen get reported to provide a continuous variable. However, the results were not as anticipated, thus categorisation of the result was obtained (see 6.3.2).

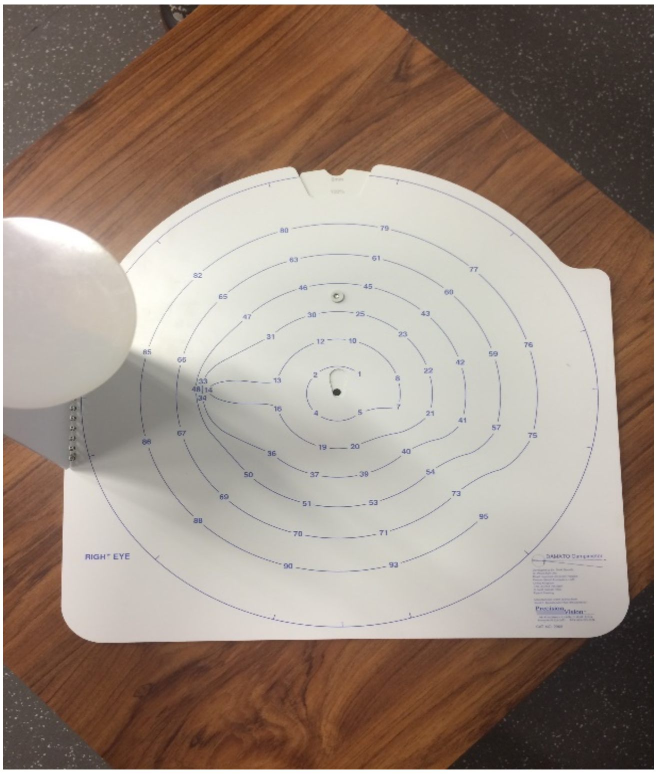

Figure 3.4. An image of the Damato used to measure visual field of participants with 6mm stimuli.

Figure 3.5. Demonstration of the examiner using the Damato.

3.3.4.3.2 Humphrey Field Analyser (HFA)

Binocular visual field assessment was performed on all the participants during experiment 4 using the HFA. The testing for this assessment was completed at one of the University's eye clinics (Figure 3.6). A standard 45 kinetic (automatic) protocol was used for both groups of participants. The reason for selecting the setting was time consideration for both groups as participants had to be examined for a few hours in different laboratories. Whilst the individual fixates directly ahead, this test moves a bright target (10dB) from the unseen periphery (starting at 45º eccentricity) towards fixation, with the patient reporting when the light is first seen. This method was repeated across 12 different meridians, and resulted in an isopter output indicating the extent of visual field in all directions from fixation. The visual field extent for each participant was calculated by averaging the eccentricty where the individual reported seeing the light for all 12 meridians. Figures 3.7 and 3.8 demonstrate the results from the HFA.

Figure 3.6. The HFA device was used to measure visual field of participants. This visual assessment took part at one of the clinics of Vision and Eye Research Institute (VERI).

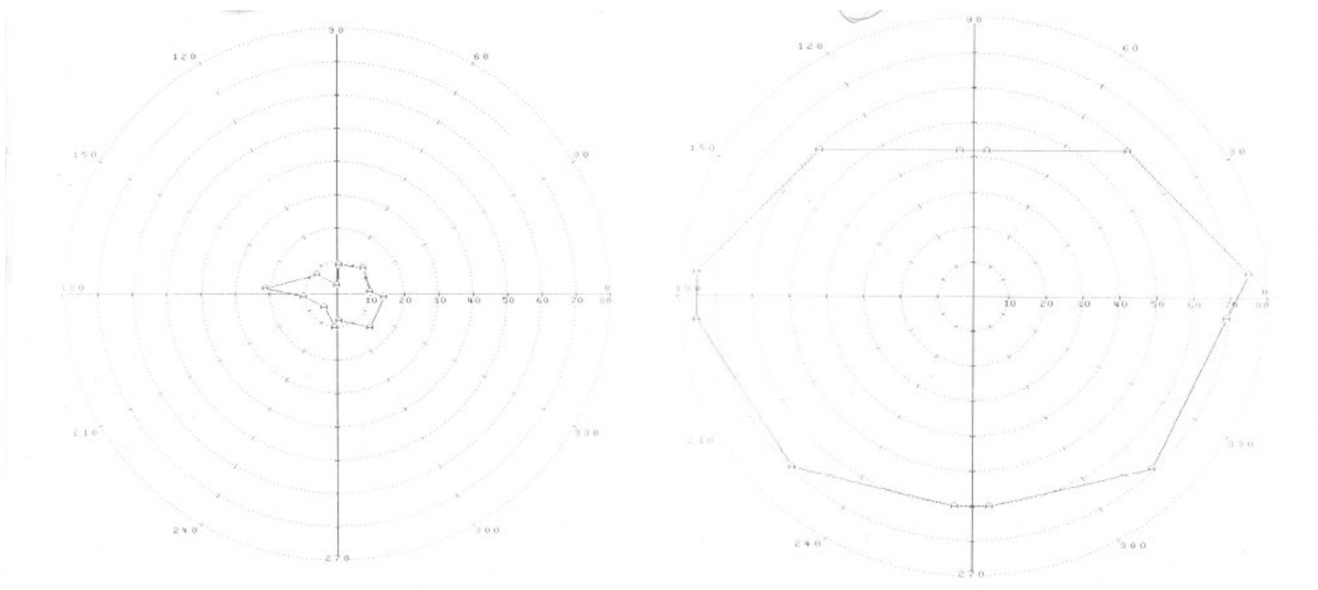

Figure 3.7. Field plots from the HFA. The image on the left is from a person with RP and the one on the right illustrates VF of a normally sighted individual.

ISOPTER IDENT	MERIDIAN START	DEGREES START	MERIDIAN STOP	DEGREES STOP	STIMULUS VALUE	STIMULUS RESPONSE	TEST TYPE
A	355	30	355	14	III 4 E	SEEN	STANDARD
A	275	30	275	8	III 4 E	SEEN	STANDARD
A	225	30	225	5	III 4 E	SEEN	STANDARD
A	315	29	315	14	III 4 E	SEEN	STANDARD
A	185	30	185	10	III 4 E	SEEN	STANDARD
A	265	30	265	10	III 4 E	SEEN	STANDARD
A	175	30	175	21	III 4 E	SEEN	STANDARD
A	45	30	45	11	III 4 E	SEEN	STANDARD
A	135	29	135	8	III 4 E	SEEN	STANDARD
A	95	30	95	3	III 4 E	SEEN	STANDARD
A	85	30	85	9	III 4 E	SEEN	STANDARD
A	5	30	5	10	III 4 E	SEEN	STANDARD

ISOPTER IDENT	MERIDIAN START	DEGREES START	MERIDIAN STOP	DEGREES STOP	STIMULUS VALUE	STIMULUS RESPONSE	TEST TYPE
A	355	75	355	69	III 4 E	SEEN	STANDARD
A	275	60	275	60	III 4 E	SEEN	STANDARD
A	225	70	225	70	III 4 E	SEEN	STANDARD
A	315	70	315	70	III 4 E	SEEN	STANDARD
A	185	75	185	75	III 4 E	SEEN	STANDARD
A	265	60	265	60	III 4 E	SEEN	STANDARD
A	175	75	175	75	III 4 E	SEEN	STANDARD
A	45	59	45	59	III 4 E	SEEN	STANDARD
A	135	59	135	59	III 4 E	SEEN	STANDARD
A	95	42	95	42	III 4 E	SEEN	STANDARD
A	85	42	85	42	III 4 E	SEEN	STANDARD
A	5	75	5	75	III 4 E	SEEN	STANDARD

Figure 3.8. The Isoper results from the HFA. The first result is from a person with RP and the second one from a normally sighted individual. The VF result of each participant was manifested by averaging the 12 meridians, where the degrees were stopped, meaning participant has seen the light and has pressed the button.

When completing the HFA assessment, participants were given the following instructions:

Please keep both eyes open and fixate on the orange light (central fixation point) all the time. While looking at the light, a white bright light will appear from your peripheral vision, please press the button as soon as you see the light. I will inform you when the test starts. Please keep watching the orange light, you may get double vision but please keep looking at the orange light all the time. Blinking may help to get rid of the double vision.

3.4 Movement/Biomechanical laboratory

Part of the data collected in experiment 3 and all of the data collected in experiment 4 were undertaken in the vision and mobility laboratory at Anglia Ruskin University, Cambridge. Data collection for experiment 3 (chapter 6), also used equipment to allow data to be collected at different RP meetings around the country.

3.4.1 Force plate

Force plates enable the collection of force data, which allows centre of pressure (CoP) to be calculated. Once the CoP is calculated then postural stability of individuals can be assessed. CoP is used in the literature to measure how individuals maintain their balance. CoP is the point of application of the resultant from the vertical force's action on the surface. The force plate is the equipment most often used to evaluate CoP (Duarte and Freitas, 2010).

The force plate measures the orthogonal ground reaction force components along the X, Y and Z, axis and the moments about the three axes producing a total of six outputs (Winter, 2009). The force components are shown as Fx, Fy and Fz. As force is a vector quantity which has both magnitude and direction; the generated force rotates the body about some point, which is known as moment. Moments are rotations around the corresponding X, Y and Z axes. Moment is calculated as the product of the force and the distance from the point to the direction of the force (Figure 3.9).

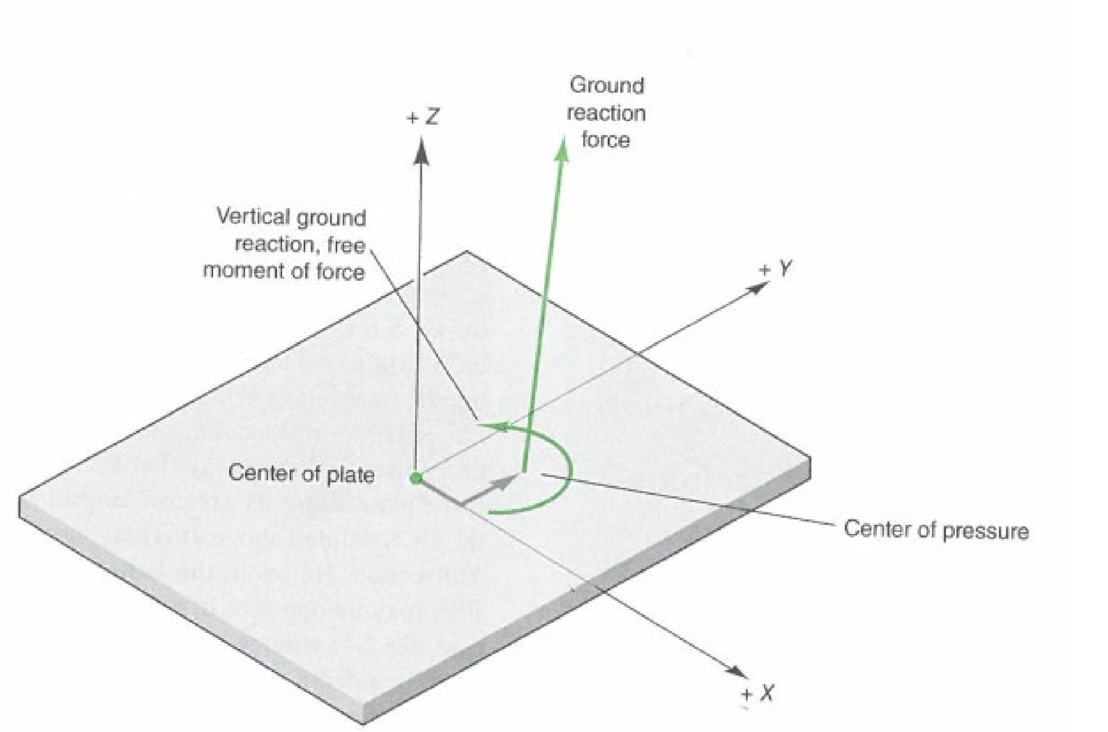

Figure 3.9. Force plate with its reaction to an applied force and vertical moment of force (Robertson, 2018).

A Kistler force plate (Kistler type 9865, Kistler AG, Winterthuh, Switzerland) was used to measure balance of individuals (Figure 3.10). The dimension of the force plate used was 40cm by 60cm and the data was collected at 100Hz. By using sensors it gives electrical output proportional to the force and moments acting on the plate. A piezoelectric force plate has been used for the purpose of this research. Piezoelectric technology uses unidirectional crystals, which only emit electrical signal when loaded in a certain direction.

Transducers used in the force plate are only one part of the overall measuring system, the output needs to go through an amplifier, which provides amplification for each channel of the force plate to the data station.

The Kistler force plate has 12 piezoelectric sensors, arranged in three orthogonal cylinders in each of the four pedestals. The sensors are horizontal and summed in pairs giving 8 output signals: F_x^{1+2}, F_x^{3+4}, F_y^{1+4}, Fy^{2+3}, F_z^{1}, F_z^{2}, F_z^{3} and F_z^{4} (Robertson, 2018). The equations for computing the quantities of the Ground Reaction Force (GRF) (Equation 3.1) and the coordinates of CoP are below (Equation 3.2).

Equation 3.1. Calculation of GRF.

$$F_x' = (F_{x^{12}} + F_{x^{34}})f_{xy}$$

$$F_y' = \left(F_{y^{14}} + F_{y^{23}}\right)f_{xy}$$

$$F_z' = (F_{z^1} + F_{z^2} + F_{z^3} + F_{z^4})f_z$$

Where $F_x', F_{y,}' F_z'$ are the components of GRF.

Equation 3.2. Coordinates of CoP.

$$x = \ [a(-F_{z^1} + F_{z^2} + \ F_{z^3} - \ F_{z^4})f_z - \ F_{x^z}']$$

$$y = \ \left[b(F_{z^1} + F_{z^2} - \ F_{z^3} - \ F_{z^4})f_z - \ F_{y^z}'\right]F_z'$$

Where, x, y and z are coordinates of CoP and $f_{xy}\ and\ f_z$ are scale factors that convert the forces from voltages to newton, *a* and *b* are the distance between the sensors and the centre of the force plate, in the X and Y direction, respectively (Robertson, 2018) (Figure 3.10).

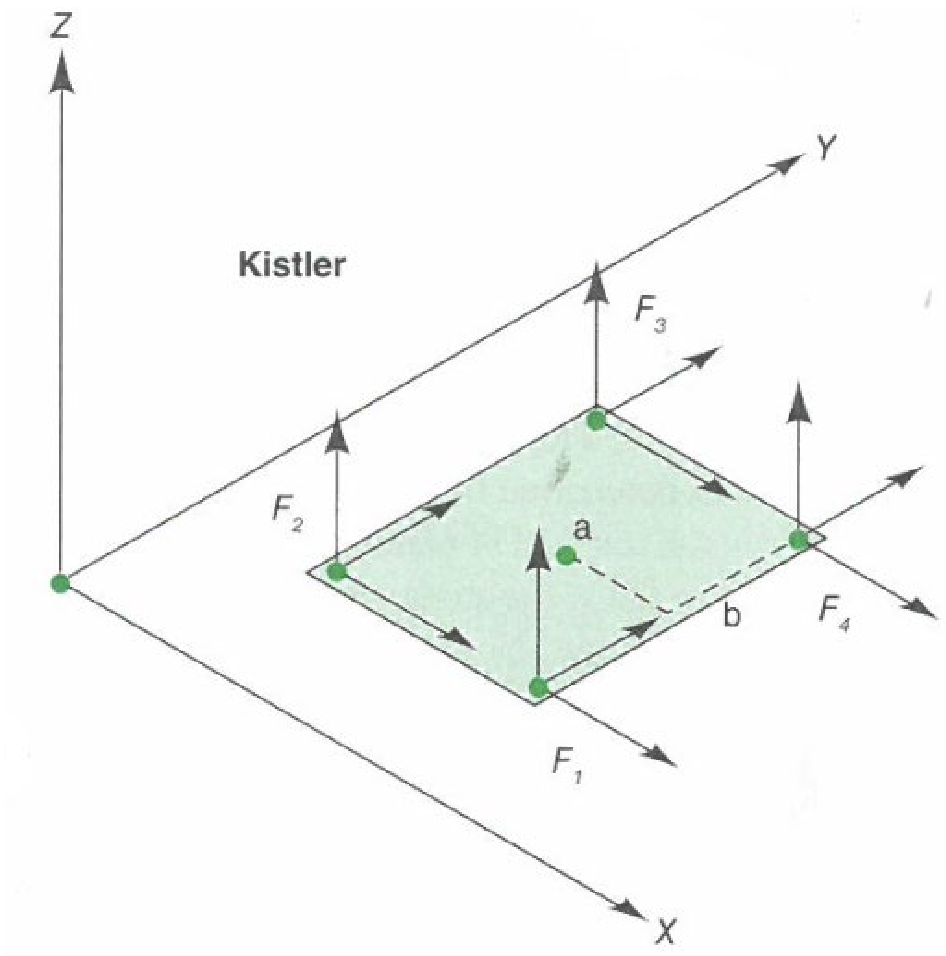

Figure 3.10. Four piezoeletric sensors in a Kistler force plate (Robertson, 2018).

The output signals that are captured by the platform are then fed to an amplifier that determine the exact values of each scale factors, these pre-determined equations are what determine the GRF and CoP that are collected during the trials (Robertson, 2014). MARS software (Type 9286AA) was used to determine the centre of pressure data. MARS enabled the collected data to be calculated into CoP measurements and for the data analysis to be undertaken. Figure 3.11 demonstrates a figure of CoP displacement of a participant during the data collection in both medial-lateral and anterior-posterior directions.

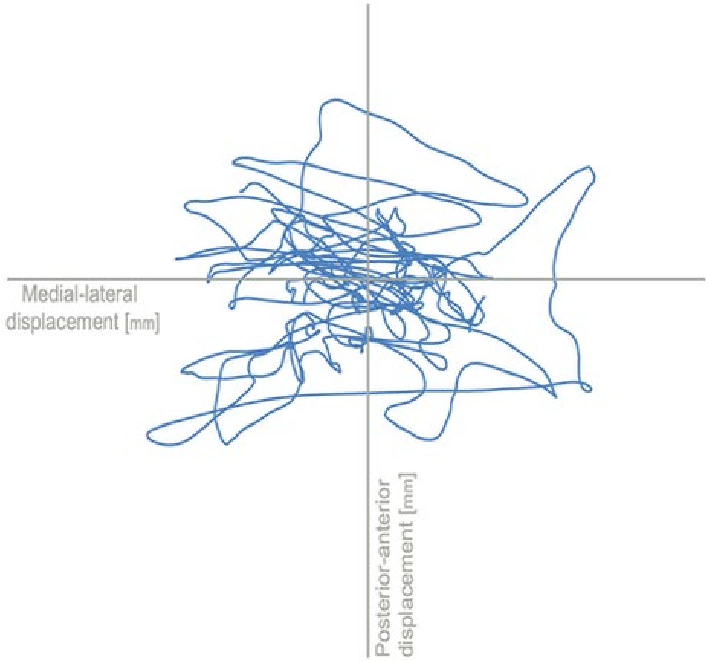

Figure 3.11. An example of the CoP displacement diagram (blue line) of a participant during the postural stability testing in both medial-lateral and anterior- posterior directions. The figure has been plotted using MARS.

3.4.2 Compliant foam

Compliant foam was used to disturb the participant's somatosensory system. The foam measured 40cm by 60cm (which allowed positioning directly on top of the force plate), with the thickness of 8cm and density of 50kg per cubic metre (Adkin et al., 2005).

Figure 3.12. The compliant foam used to disturb the somatosensory system of the participants. The target used is also demonstrated, which was placed at eye level height of individuals. Those who could not see the target (SSI), were instructed to look straight ahead.

3.4.3 The stance on the force plate

To standardise the stance for all the participants pre-defined lines were drawn on either the foam (Figure 3.12) or the force plate to highlight where participants should position their feet (without wearing shoes) when standing (Figure 3.13). Those who were severely sight impaired were assisted by the research members, so they could place their feet at the correct position. The distance between the feet (heel to heel) was 0.17m with an angle of 15˚ (outer) between the long axes of feet (McIlroy and Maki, 1996). The rationale for this stance was because of McIlroy and Maki's work where they measured the tendency of 262 subjects and concluded the preferred average stance to be the measurement used. Their findings standardized the foot positions for postural stability testing, which reduced potential effects of uncomfortable or unnatural foot positions. All participants positioned their hands by their sides for the duration of testing. Participants initially stood on the force plate and were asked to verbally confirm that they were ready for the test to begin prior to data being collected.

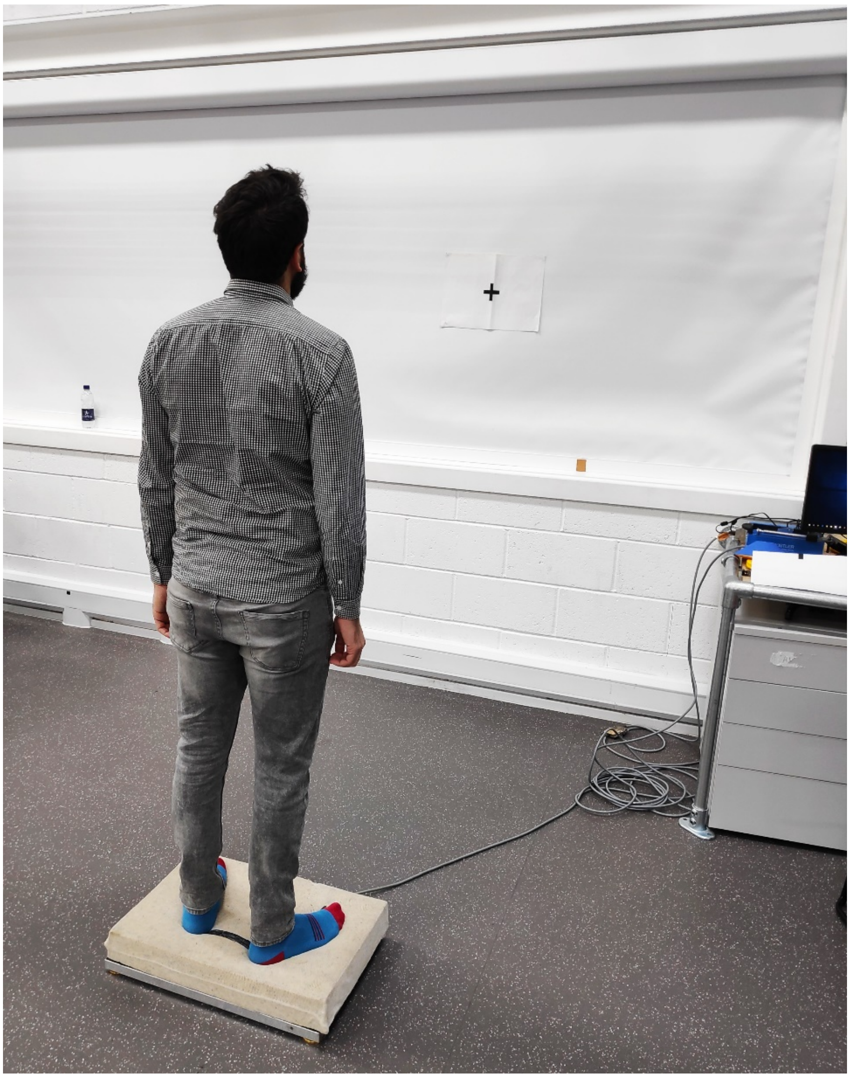

Figure 3.13. Postural stance of a participant. Participants were instructed to stand on pre-defined lines, have their hands by their sides, focusing on the visual target. They were discouraged from talking once the data collection had started.

3.4.4 The visual target

For the trials with eyes open, participants were asked to fixate on a visual target which consisted of a black ‘plus sign’ 7cm by 7cm, the size of the sign and choice of black on white contrast (colour) (Kunkel et al., 1998). The visual target was placed on a wall 2m away from participant’s eye level (Figure 3.14). Only two participants, who were severely sight impaired, reported not being able to see the target. These two participants were instructed to look straight ahead and not move their heads during the testing looking for the target.

3.4.5 Measurement of neuropathy

Examination of peripheral neuropathy of participant's feet was done by using a 10-g monofilament. The device was placed perpendicular to the skin at 5 positions of each foot (hallux, 1st, 3rd and 5th metatarsal and heel), with pressure applied until the monofilament bent (Boulton et al., 2008). Participants had to respond if they felt the device while they had their eyes closed. If there was a callus on the positions, a nearby site to the position had be examined. Figure 3.14 illustrates the method used to examine the neuropathy of participant's feet.

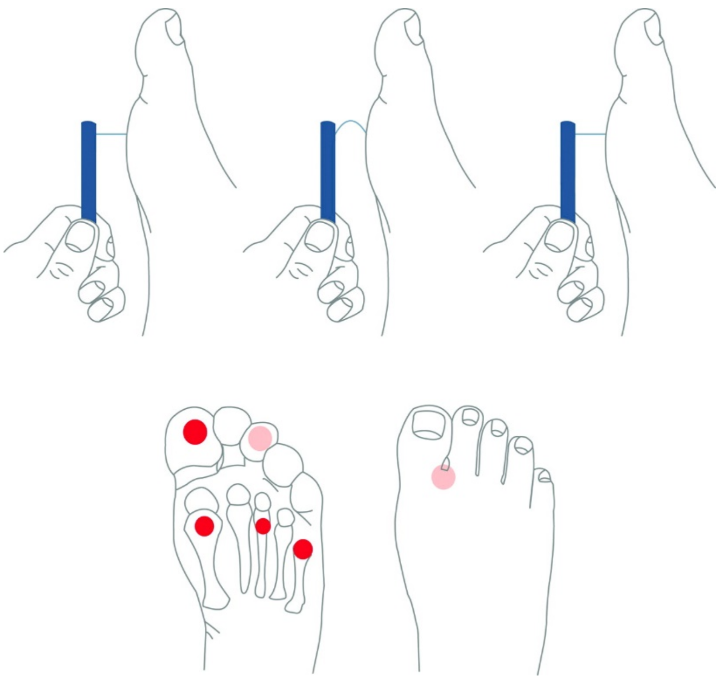

Figure 3.14. The monofilament was placed perpendicular to the skin, with the pressure applied until the monofilament was buckled. The monofilament was placed on the highlighted sites in the figure as well as the heel (Boulton et al., 2008).

3.4.6 Coda motion capture system

The advancement of automated motion analysis systems in the past few decades has enabled an accurate tracking of body segments (Richards, 1999). Thus, for CODA

(Charmwood Dynamics Ltd, Leicestershire, UK) to be accepted as the 'gold standard' with which to compare other methods of data collection, it was necessary to quantify the accuracy of the system and user for the data collection of final experimental chapter (chapter 7). CODA is a three dimensional motion capture system that uses active markers. The markers are placed on specific anatomical locations and transmit unique alternating infrared signals. For each marker, there is an active hub which provides power and a signal frequency allowing the determination of each anatomical location that the marker is attached to. Figure 3.16 shows an example of the markers being used during the experiment. Prior to data collection, some baseline data was collected to validate the visibility of the markers. Thus, the angle and placement of the cameras could be set for the highest visibility point (midpoint of the walking path for the experiment of chapter 7). This was important to check the accuracy of the system as the lack of accuracy, could cause the markers to drift causing errors in data collections. A difficulty associated with the use of motion analysis system is the occlusion of the markers, which can occur when a camera's line of sight to a marker becomes obstructed by body or clothing. To prevent this issue, elasticated strapping were used, these strappings did not inhabit range of motion but ensured markers remained in the fixed position. Participants were encouraged not to wear lose clothing during the data collection (Figure 3.15).

Virtual markers for calcaneus were in place because the layout of the lab setting would have not tracked the visibility of the calcaneus marker if it was placed normally. Virtual markers are points in 3D space constructed, by means of fixed geometric relationship, from two or more other points that are real markers. Once defined, virtual markers are automatically added to the markers list. Same method was used for the virtual marker of the cane, the placement of these markers depended on the length of the cane (the average length of the canes was 126 cm). Virtual calculations and values sheet for the participants and the canes are shown at appendix 8.

Figure 3.15. The markers were attached to participants' feet using double sided tape. To ensure the power does not become lose during the walking trials, they were tied with red elastic bands.

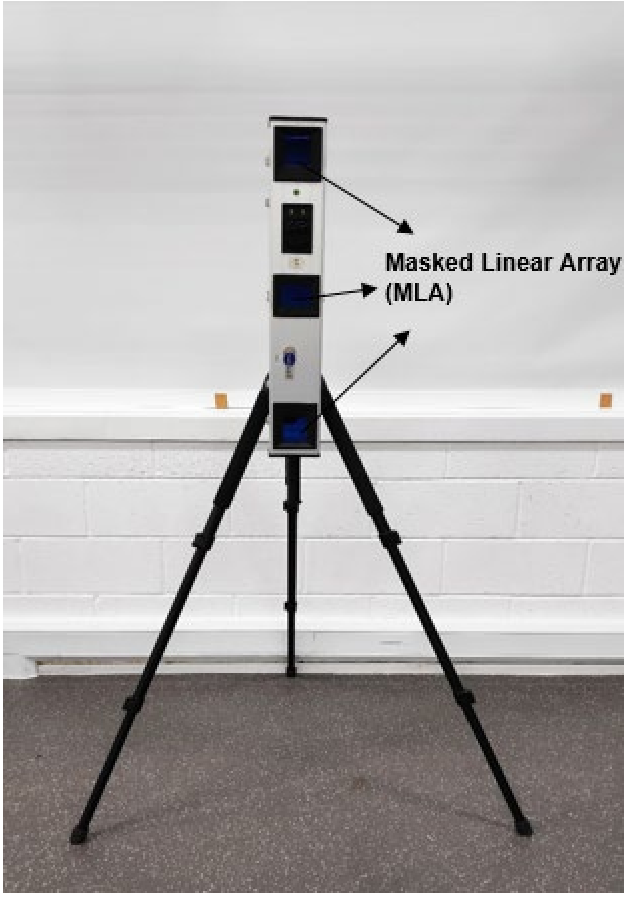

Figure 3.16. An image of one of the Coda stack used showing the three linear arrays.

This infrared signal from the markers are then received by Cartesian Optoelectronic Dynamic Anthropometer stacks (CODA). The CODA stack uses (Figure 3.16) three masked linear array units (MLA) that individually detect the horizontal (X), adjacent (Y) and vertical (Z) position of markers. This process is achieved as the infrared markers project a shadow on to an array through a grid. Furthermore, the data is relayed to a central processing unit which contains necessary circuitry to process the signal received from the CODA stacks as well as a personal computer for human interface, post-processing and data storage.

Prior to data collection, an origin is set by providing the X, Y and Z coordinates to the CODA stacks. For the experiment 4 (chapter 7) data was collected at the rate of 100 Hz. Further details of the data collection can be found in chapter 7.

3.4.7 Electronic light gates

Electronic light gates (Smart-Speed, Fusion Sport, Australia) were positioned at the start and at the end of the walkway used in chapter 7, to examine the adaptive gait of participants. When participants walked past the light gate station, a single noise was heard and that is when the time recording started. A similar noise was emitted at the end of the path which marked the end of the time trial. This was in place to measure subsequent trial length (chapter 7), enabling the researcher to record all the trial times precisely.

3.5 Smooth filtering

Biomechanical data often contains high frequency noise and should be filtered prior to further analysis (Winter, 2009). Smooth filtering is a technique used to remove the noise of collected data in biomechanics studies. The ultimate goal of smooth filtering is to eliminate noise, but leave the signal unaffected. However, most filtering techniques could affect the signal components. The optimal filtering technique is one that passes, unattenuated, the lower frequency signal, while the same time attenuating the higher frequency noise. This technique is called low-pass filtering. The optimal filtering technique is essential for any biomechanical experiments.

Prior to the pilot work, systematic review of literature (appendix 9) was done to investigate the most used filtering technique. A pilot study was completed to determine the ideal cut off frequency experimental chapters (chapters 6 and 7) of this thesis. This was done using on a set of row data from a single marker on the right heel and a series of cut off points was tested on the pilot data. This included from 1 to 20 Hz. Optimal cut off frequency was calculated using the residual analysis technique outlined by Winter (2009). Cut off frequencies between 1 and 20 Hz were applied and the root mean square residual between the raw data and filtered data were recorded.

Figure 3.15 demonstrates the linear portion relationship between root mean square residual and the cut off frequency. This work was done to determine the ordinate intercept point. Following this procedure the smooth filtering for the collected data was set at 10 Hz.

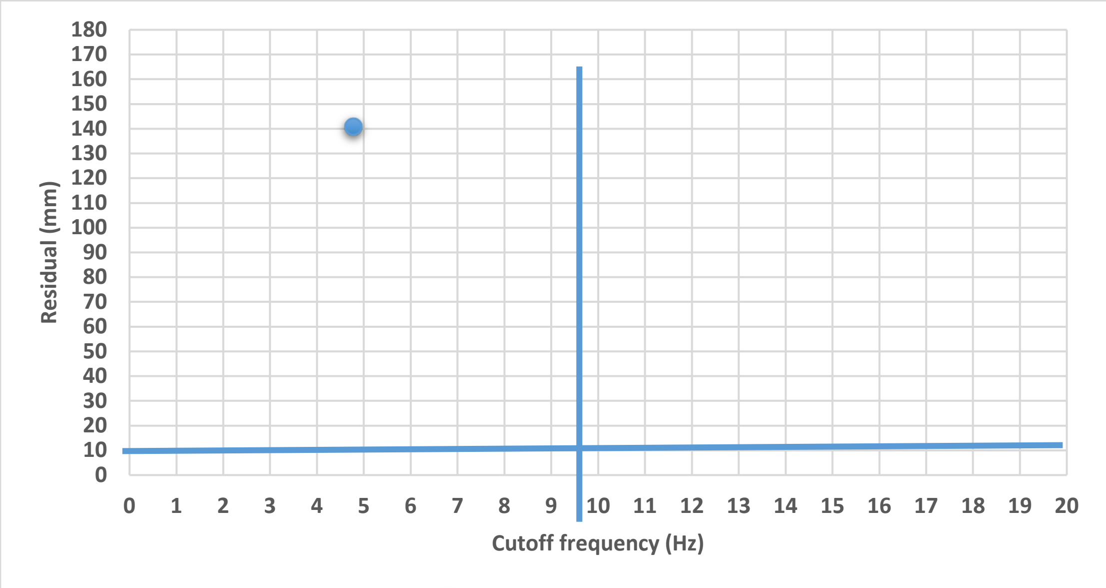

Figure 3.17. The relationship between cut-off frequency and root mean square of residual between raw and filtered data.

3.6 Analysis of kinematic variables

The filtered kinematic data collected for the experimental chapter 7 were transferred to MACRO programme to determine the dependent variables. Overall, there were nineteen dependent variables analysed.

3.6.1 Key dependent variables for analysis of gait

The vertical distance between the toe marker and the obstacle at the point of crossing was defined as toe clearance (illustrated as A in figure 3.18). Markers placed on the obstacle was to identify its placement to the relation for the feet. Also, the vertical distance between the heel marker and the obstacle at the point of crossing was defined as heel clearance (illustrated as B in figure 3.18). These variables were calculated for both the lead and the trail foot.

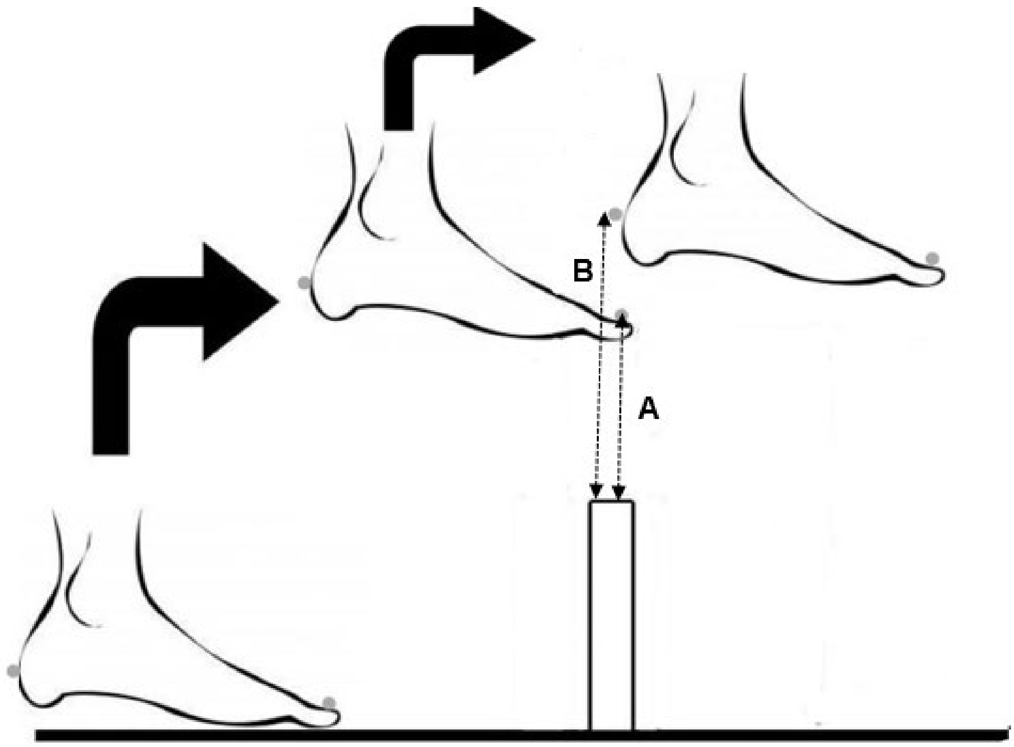

Figure 3.18. Demonstrating the toe and heel clearance variables used in chapter 7.

The time during the obstacle crossing when only one foot was in contact with the ground was calculated as single support, which was obtained for both the lead and trail foot. Double support marked the time period when two feet were in contact with the ground at the point of obstacle crossing.

Step width was defined as the anterior/posterior distance between the lateral malleoli markers of the lead foot post obstacle, placing the foot on the ground and the trail foot prior to entering the swing phase (see 2.5.1) to cross the obstacle. Step length was defined as the anterior/posterior distance of the lead foot post obstacle, placing the foot on the ground and the trail foot prior to entering the swing phase to cross the obstacle. Stride length was defined as the distance between two successive foot placements of the same foot. It consisted of two step length, the leading and the trailing feet.

Velocity of the toe markers is calculated as distance change over time and by tracking the markers over the time and was calculated as the point of crossing the apex (top) of the obstacle (Figure 3.18). Figure 3.19 illustrates the displacement of toe marker in y axis of a RP participant approaching an obstacle.

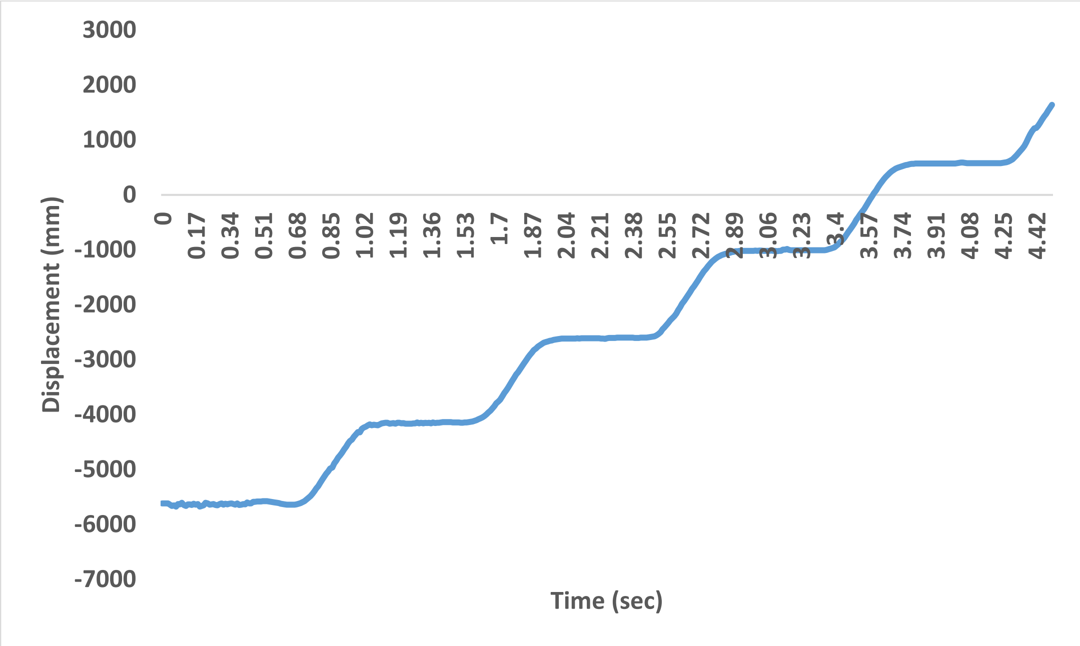

Figure 3.19. Velocity variable is defined as position of a certain marker (toe marker) over the trial time. This figure illustrates this definition, where x axis is the time of the trial and y axis represents the displacement of the marker during the trial. The negative values represent the position of the marker prior to approaching the obstacle (calibrated at 0) and the positive values are the position of the marker post obstacle negotiation.

3.7 Illuminance

Illuminance is the amount of light coming from a light fixture that lands on a surface. Normally sighted people can adjust to a wide range of light intensities. Illumination adaptation occurs when a person moves from a dark to a light environment or vice versa (Frumkes, 1990). The ability to adapt to different illumination could be impaired. The sudden change in light entering the eye could cause discomfort while the eye is functioning to adjust. However, this could take longer for those with visual impairment. This impairment could also interfere with individual's mobility (Spaulding et al., 1995).

Therefore, it was important to have sufficient illumination during the data collection during the experimental chapters 6 and 7. Participants were given time while they were briefed about the protocol to adjust to the lab lighting and for the light adaptation to take place prior to the data collection (chapter 6 and 7).

The luminance of the rooms that the participants were tested for the experimental chapters of 6 and 7 was set at approximately 500 lux, taken at participant's chest height. A lux meter (CEM-DT 1308) was used to measure illuminance.

4. Difficult activities of daily living for those with RP at goal level

4.1 Introduction

In chapter 2, the lack of comprehensive studies investigating the difficult ADLs for those with RP was discussed. Since there is currently no cure or treatment for RP (Herse, 2005), rehabilitation aims to reduce the activity limitations and participation restrictions that might result from VI, and consequently maximise quality of life for those with RP. Quality of life is an ambiguous concept, which is difficult to define and harder to measure (Massof and Rubin, 2001). One of the tools that tries to measure quality of life of individuals is SRQs.

RP is a complex VI and visual assessments may not accurately represent visual difficulty (World Health Organisation, 2007). Thus, SRQs are used which specifically focus on physical disability, social health, psychological well-being, cognitive status, or pain. It is suggested that the combination of these categories can quantify the quality of life of individuals (McDowell, 2006). It should be possible to determine changes in the way in which low vision rehabilitation can be performed to achieve greater improvements in an individual's quality of life, by using SRQs. It is also important to be able to inform those newly diagnosed about likely difficulties, so that they can understand what to expect.

SRQs can be used to measure specific domains of rehabilitation requirements such as mobility or reading (Bruijning et al., 2013). There are a range of questionnaires used to assess difficulty with ADLs and researchers have used them to investigate the areas of greatest difficulty for those with RP. While the trend of developing more patient-based questionnaires is a commendable one, it can be argued that there are too many such questionnaires, which largely overlap. This could be an issue for clinicians as well as researchers who have to choose an outcome to measure (De Boer, et al., 2004). Recently, the ICF framework (see 2.5.1) has been used in the development of the Dutch Activity Inventory (D-AI) (Bruijning et al., 2010; Bruijning et al., 2012) as a questionnaire used to determine rehabilitation needs on a routine basis for those with low vision. The D-AI includes goals that are classified by the nine “Activity and participation” domains of the ICF (World Health Organisation, 2001). The D-AI was developed from the original Activity Inventory (Massof et al., 2007), but was reformatted within the framework of the ICF and extended in terms of the number of goals and tasks and the addition of more items relevant to a European context such as using public transport or daily shopping which were not specifically represented in the AI. One of the major strengths of the D-AI compared to the previous AI is its systematic character, which prevents important topics, from the patient’s perspective, from being over-looked.

In addition to the literature review chapter (chapter 2) some of the studies which have investigated the difficulty level of ADLs for those with VI and particularly those with RP using SRQs will be discussed in this chapter. Turano et al. (1999a) developed SRQ to allow people with RP to rate the difficulty level of 35 mobility situations. They reported that four out of the six most difficult mobility situations were related to lighting conditions: walking at night, adjusting to light change, walking in dimly lit indoor areas and walking in high-glare areas. In a companion study they reported that the least visual ability required by those with RP was “moving about at home”, and “walking in the dark” was the situation that needed the most visual ability (Turano et al., 1999b). In another earlier study, Black et al. (1996) reported that the easiest tasks for people with RP included walking in familiar areas or at home where the patients were aware of objects’ whereabouts. They suggested that vision may not be as critical for those with RP when they already have a mental representation of their surroundings. Another critical finding from their study was that as the disease progresses, visual ability for mobility decreases.

In a study by Lowe and Drasdo (1992) respondents with RP were asked to assess their own abilities for seven tasks involving visual search and mobility. They found that there were several difficulties reported such as coping with unfamiliar stairs, shopping alone and walking into obstacles. These were difficulties that were not considered amenable to treatment with visual aids, and could also be associated with falls.

Emotional health is also an important factor for those with RP as noted by the findings of Fylan et al. (2005); those with RP can become depressed and isolated from society (Hahm et al., 2008). It has to be emphasised that emotional health is not a strict ADL like others which have been discussed (for example mobility). RP is also emotionally difficult for people due to their anticipated vision loss; severe distress can be caused from gradual vision loss. An online survey was used in a study to compare mental health of those with RP with the general population. A significant difference in stress level between the groups was reported and the study concluded poorer mental health for those with RP (Kim et al., 2013). As RP is irreversible and aspects of mental health such as self-esteem and self-efficacy are dynamic, it may be advisable to target and treat psychosocial functioning to help alter perceptions of visual function during rehabilitation (Tabrett and Latham, 2011).

Receiving emotional and practical support from a carer (family or/and friends) can be very important and beneficial for those with RP. Lack of vision can increase the difficulty of completing many ADLs without a carer's help. Family members are often called on to provide physical as well as emotional support to those with vision loss (Bambara et al., 2009). Depression, isolation and difficulty of completing daily living tasks caused by RP could make those with RP very dependent on those who support them. A study that assessed elderly participants with vision loss reported that those who receive support can have less depressive symptoms, greater life satisfaction, and better adaptation to vision loss (Reinhardt, 2001). However, it has also been suggested that VI individuals could become less independent as a result of over-protection from their carers/supporters (Cimarolli et al., 2006; 2012). The perception of difficulty between people with RP and those who support them is an important issue as the amount of support required by the person with RP and perceived as needed by a carer could be different and this could lead to unsatisfactory outcomes for both groups. This is an area which has not been studied extensively and the limited existing studies have investigated this relationship for people with other diseases rather than RP (Reinhardt, 2001; Conde-Sala et al., 2009).

Most studies outlined above have looked at the effect of RP on one specific area (Turano et al., 1999), or have looked at visual difficulty overall using instruments such as the NEI-VFQ (Sugawara et al., 2009; Hahm et al., 2008). What has not been done is to provide a comprehensive overview of activities of daily living (ADLs) to determine what the most difficult areas are for people with RP. The perceptions of those who care for those with RP in regards to difficulty level of ADLs have not been investigated either. Therefore, this and the next chapter will ask the question of 'what ADLs are difficult for those with RP' by using SRQs. The results will identify the difficult ADLs and will also inform experimental chapters 6 and 7.

4.2 Aim

The purpose of this study was to provide a comprehensive overview of self-reported difficulties for those with RP. Based on previous literature, mobility was hypothesised to be one of the most difficult areas for those with RP, but this chapter aims to put mobility difficulties in the context of a wider range of ADLs. One other purpose of this chapter was to investigate the perception of difficulty perceived by the carers of those with RP and make a comparison to those with RP. In addition, the factors that are associated with increased difficulty were considered. The results of this study are intended to inform the development of the later stages of the work in this thesis by identifying the areas of greatest difficulty to be considered in further detail.

4.3 Methods

4.3.1 Participants

Participants were recruited from RP Fighting Blindness (RPFB) members. The research was first advertised in the RPFB newsletter in June 2013 which was sent to the members of the society. Those interested in taking part in the study could contact the research group by email or telephone to enquire about the research. The criteria for inclusion were anyone who had been diagnosed with RP or anyone caring for or supporting a person with RP. Those who were under the age of 18 or cared for someone under the age of 18, or reported any significant health condition that could confound their visually related mobility difficulty (Multiple Sclerosis, Parkinson's disease, and Polio) were not eligible to participate in the study.

After contacting a member of the research group, participants could take part in the study using their choice of the following three methods:

1. A printed version which was available in either large or standard print size. The questionnaires were posted to the subjects with a stamped envelope for its return. 9% of participants used this method.
2. The questionnaire was completed via a phone conversation. The participants could arrange a convenient time to be contacted by the researcher, who read the questions out and recorded the participant's responses. 11% of participants used this method.
3. The questionnaire was available online using the 'Surveygizmo' website. It was administered for 5 months. 80% of participants used this method.

Ethical approval was received from Anglia Ruskin University Ethics Committee, and the tenets of the Declaration of Helsinki were upheld. All participants gave their informed consent to take part, once the nature of the study had been explained.

4.3.2 SRQ

Participants were initially asked if they have RP or they are a carer of someone with RP. Carers answered the questions in regards to the person with RP. There were also questions about their age, duration of VI, gender, VI registration status (see 3.2.1), use of mobility aids and other health conditions.

The Dutch Activity Inventory (D-AI) (Bruijning et al., 2013) was used to investigate which ADLs were difficult to complete due to vision, assessing the difficulty of 47 rehabilitation goals nested within 10 objectives of the WHO-ICF framework. The objectives are overarching constructs such as mobility, learning and applying knowledge or domestic life. Goals are more specific constructs that underpin the objectives. For example the “mobility” domain (objective) is branched into several goal level activities such as “mobility outdoors”. Then, mobility outdoors can be branched into more detailed questions at task level such as “find your own route” (see Chapter 5). In a full administration of the D-AI, task questions are asked for all goals that are relevant and of some difficulty. There are over 400 task questions in total underpinning the 47 goals, making a full administration of all goals and all relevant tasks extremely time consuming. The study presented in this chapter therefore considers the questions at goal level only, and consideration of selected task level questions will be presented in the following chapter.

The goal level question is phrased in the style as (for example): ‘Is mobility indoors difficult for you because of your visual impairment? Consider how difficult this is to do without the assistance of another person, but with any assistive devices that you use.’ Participants were asked to respond to each question on a Likert scale. The responses were scored from 0-5. A score of 0 indicated the goal was not applicable to the participant and was not considered in the data analysis. A score of 1 indicated the goal was impossible to achieve without support, 2 very difficult, 3 was moderately difficult, 4 was slightly difficult and 5 not difficult. Therefore, the higher scores indicated more ability, and lower scores indicated more difficulty with the goals.

4.3.3 Statistical analysis

All the data were exported from the Surveygizmo website into SPSS (version 20; IBM) for analysis. Responses were compared across categories in terms of participants' registration status (not registered, sight impaired, severely sight impaired), and usage of mobility aids (use of guide dog and / or cane, use of no mobility aids). Since the Likert data was ordinal, non-parametric Mann-Whitney tests were used for comparison of categorised variables. Age and duration of RP (in years) were considered as continuous variables, and were compared to the ordinal questionnaire responses using Spearman correlations.

4.4 Results

Overall, 424 eligible participants' data were analysed. Table 4.1 below shows the demographic data of both groups.

Table 4.1. The demographic details of participants. Age and duration of visual impairment (VI) and the range of these variables are given in years. Those in the carer group answered the questions relating them to the person who they care for (with RP).

Column1	**Number of participants**	**Age (mean ± SD) [Range]**	**Duration of VI (mean ± SD) [Range]**	**Gender M=male, F=female**
RP	349	55±15 [21-88]	26±16 [2-80]	166 (M), 183 (F)
Carer	75	56±15 [19-93]	27±15 [3-74]	42 (M), 33 (F)

In the group of participants with RP, 26 were not registered as visually impaired, 110 were sight impaired and 213 severely sight impaired. A guide dog and/or cane were used by 194 participants to aid mobility, and 155 used no mobility aids. With regard to other health conditions, 153 reported that RP was their only health problem; 42 had RP and hearing problems; 124 had RP and other health problems, and 30 had RP, hearing loss and other health problems. Some of the other health conditions reported by the participants were history of heart attack or stroke, arthritis and high blood pressure.

In the carer group, where participants were answering the questions with regard to their perceptions of the difficulty the people with RP had that they support, 5 people who were supported were not registered as visually impaired, 17 people were sight impaired and 55 severely sight impaired. 31 of these people with RP did not use any mobility aids and 44 used a guide dog and/or cane. 40 people indicated that RP was the only health problem; 15 had RP and hearing loss problems; 11 reported RP and other health problems; and 9 had RP, hearing loss and other health problems.

The most difficult ADLs at both objective and goal levels were identified. Goals that were not important or applicable and were scored as ‘0’ were not included in the analysis. Hence the results are analysed for those who found any given item applicable to them. The scores for the 10 objectives were determined as the mean of the scores for all applicable underlying goals. Higher average scores indicate that people have more ability or less difficulty with these tasks. Lower average scores indicate more difficulty or less ability. As an example, if a participant scored ‘0’ for 2 out of the 6 mobility goals, to obtain the difficulty level of mobility at objective level, the mean average score of that participant was calculated by the sum of the 4 non-zero answered tasks divided by 4.

4.4.1 Most difficult objectives and goals for people with RP

Table 4.2 shows the analysis of the difficulty of goals and objectives analysed in ordinal fashion for people with RP.

Table 4.2. Difficulty level of objectives and goals for those with RP; those with lower mean scores have lower ability. The results are in order of objective difficulty (most difficult first). The number of non-zero responses indicate the number who rated the goal as applicable (i.e. score of 1-5) out of the total number of respondents (n=349).

Objective / Goal	**Mean difficulty**	**SD**	**Number of non-zero responses**
Mobility (1)	2.74	0.82	
Driving	1.28	0.88	239
Riding a bicycle	1.83	1.21	258
Mobility outdoors	2.66	1.01	348
Mobility indoors	2.84	1.03	347
Using public transport	2.87	1.13	340
Mobility at home	4.08	0.78	346
Major life areas (2)	3.22	1.13	
Applying for a job	2.95	1.40	165
Working activities	3.15	1.10	199
Accessibility at work	3.16	1.12	195
Managing finances	3.17	1.46	344

Participating in education	3.41	1.32	211
Getting information	3.66	1.23	345
Learning and applying knowledge (3)	3.23	1.20	
Reading	3.05	1.30	342
Watching TV	3.38	1.24	340
Writing	3.41	1.38	343
General tasks and demands (4)	3.25	1.28	
Personal administration	3.11	1.45	344
Following a schedule	3.41	1.40	348
Emotional health (5)	3.25	0.99	
Emotional life	3.15	1.07	349
Coping with fatigue	3.34	1.18	347
Domestic life (6)	3.31	1.04	
Shopping	2.80	1.29	342
Grocery shopping	2.89	1.33	331
General maintenance Tasks	3.00	1.31	328
Healthcare for another adult	3.18	1.40	198
Grand/Child care	3.29	1.35	179
Withdrawing money	3.36	1.43	342
Cleaning	3.48	1.06	343
Prepare meals	3.64	1.21	338
Pet care	3.80	1.13	196
Laundry	3.88	1.34	324
Community, social and civil life (7)	3.36	0.81	
Physical activity	2.83	1.17	318
Holidays	2.87	1.13	335
Social events	2.98	1.07	342
Dining out	3.02	1.09	346
Recreational/leisure time activities	3.09	1.11	334
Having visitors	4.13	0.91	344
Following the news	4.50	0.78	349
Communication (8)	3.72	0.96	
Personal correspondence	3.36	1.40	341

Using a computer	3.49	1.16	325
Using the telephone	4.31	0.90	347
Interpersonal interactions and relationships (9)	3.79	0.83	
Interaction with strangers	3.22	1.05	347
Interaction with colleagues	3.80	0.99	289
Communicating face to face	3.93	1.01	349
Relationship with loved ones	4.25	0.86	335
Self-care (10)	4.03	0.86	
Health care and taking medication	3.65	1.34	341
Dressing	3.72	1.19	345
Eating and drinking	4.22	0.91	341

The most difficult objective is mobility (2.74±0.82). Within this objective, the most difficult goals included driving (1.28±0.82) and riding a bicycle (1.83±1.21), however the number of the responses to these two items (240 and 258 respectively from a maximum of 349) were not as high as for the other items in this objective. More than 100 respondents scored these tasks as being not important or applicable to them. The next most difficult goals were mobility outdoors (2.65±1.01), mobility indoors (2.84±1.04) and using public transport (2.87±1.13). The result showed that not all the tasks are applicable to all the participants, thus an applicability cut-off point was set to demonstrate those tasks that are applicable to the majority of the participants (Figure 4.1). The next four most difficult objectives have similar difficulty scores; major life areas (3.22±1.13), learning and applying knowledge (3.23±1.26), general tasks and demands (3.25±1.29) and emotional health (3.25±0.99).

Major life areas includes goals such as applying for a job, working activities and accessibility at work and the number of non-zero responses for these tasks are below 200. These tasks can be seen as not applicable to some people with RP, however for those who undertake these goals they have major difficulties with them.

Both the ‘learning and applying knowledge’ and ‘general task and demands’ objectives include reading and writing tasks. Despite the perception that RP predominantly affects peripheral vision, these are goals requiring acute central vision that the respondents perceived difficulty with.

Emotional health has the most non-zero responses indicating that this area was applicable to practically everyone. The scores for the underlying goals are also relatively low (emotional health 3.15±1.07 and coping with fatigue 3.34±1.18) constituting the 18th and 24th most difficult of the 47 goals, indicating that participants find dealing with RP emotionally difficult.

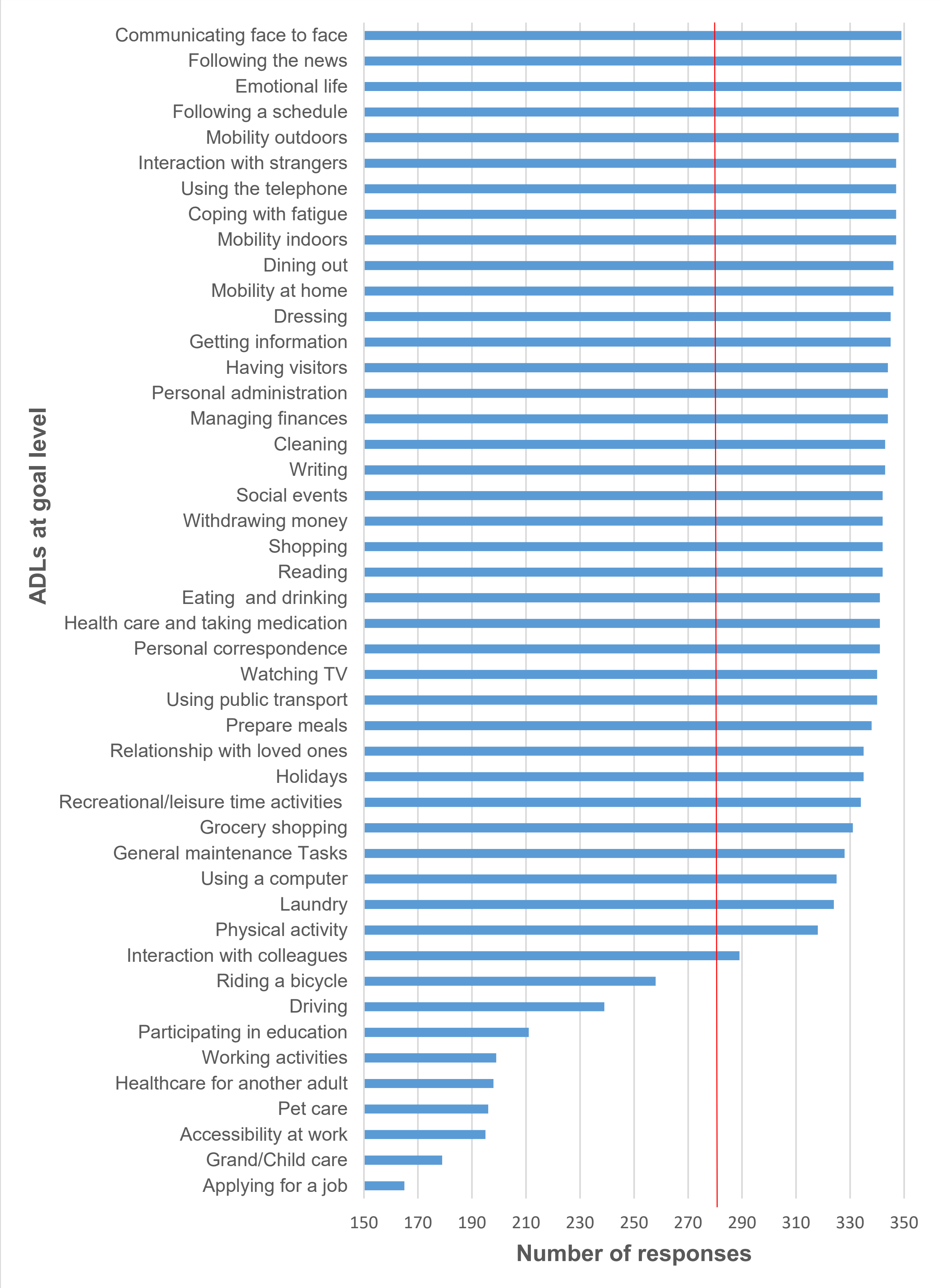

Figure 4.1. The applicability of all the goals in terms of the non-zero responses from 349 participants. 35 out of 46 of the goals were in the 80% applicability cut-off, which is equal or more than 279 participants. The red line represents the cut-off applicability frequency.

Figure 4.1 demonstrates how the goals were discriminated between high and low applicability. The cut-off frequency for the applicability where goals that were relevant to more than 80% of people were selected. From the tasks that were above the applicability cut-off point the ten most difficult tasks to complete are shown in table 4.3.

Table 4.3. The 10 most difficult ADLs at goal level to complete above the applicability cut-off point.

Goal	Mean difficulty ± SD
Mobility outdoors	2.66±1.01
Shopping	2.80±1.29
Physical activity	2.83±1.17
Mobility indoors	2.84±1.03
Using public transport	2.87±1.13
Holidays	2.87±1.13
Grocery shopping	2.89±1.33
Social event	2.98±1.07
General maintenance tasks	3.00±1.31
Dinning out	3.02±1.09

4.4.2 Variation of difficult objectives with demographic factors

Three of the most difficult objectives (mobility, learning and applying knowledge, and emotional health) were selected and examined further with respect to the demographic data. The mobility objective was selected as it was the most difficult overall. In the following chapters this objective will be investigated in more detail with quantitative analysis. The following four domains had similar difficulty, however, the 'major life areas' domain was not relevant to all the participants. Hence, it was excluded from this data analysis. The 'learning and applying knowledge' domain included goals such as reading and writing that could be argued are more critical compared to those for the 'general tasks and demands' domain. Therefore, 'general tasks and demands' were also not included in this analysis. As previously discussed in the introduction, 'emotional health' is a potentially key factor for those with RP and the following analysis will also explore this domain. The demographic factors considered were visual impairment registration status and mobility aid usage, as indicators of severity of visual loss.

4.4.3 Visual impairment registration status

Participants were divided into two groups; one consisted of people registered as severely sight impaired (n=213 ; termed the ‘SSI’ group) and the other was the combination of those registered sight impaired (n=110) as well as those who were not registered as visually impaired (n=26) (termed the ‘SI’ group). This combination was used in order to compare two groups with as similar numbers in each group as possible.

Findings are shown in Table 4.4; those in the SSI group found both ‘learning and applying knowledge’ and ‘mobility’ significantly more difficult compared to those in the SI group (p<.001). However, there was no significant difference between groups for the ‘emotional health’ domain (p>.05). Since visual impairment registration is voluntary, it is possible that those people who are not registered have chosen not to be registered despite visual loss that would allow them to fit in the SI or SSI category. Therefore, the data was also analysed without including the non-registered participants in the SI group, but the same results were found.

Table 4.4. The mean difference and standard deviation in perceived difficulty between the visual status groups. The severely sight impaired group (SSI) included 213 participants and the sight impaired and non-registered group (SI) had 136 participants. Group results are compared using Mann-Whitney tests.

Domains	SI Mean±SD	SSI Mean±SD	P
Learning and applying knowledge	4.00±1.06	2.73±1.12	<.001
Mobility	3.20±0.82	2.45±0.68	<.001
Emotional health	3.35±0.96	3.18±1.00	0.15

The statistical findings shows that as the severity of RP increases both ‘mobility’ and ‘learning and applying knowledge’ objectives become more difficult for people with RP. Furtheremore, learning and applying knowledge is not particularly difficult for those in the SI group and it only becomes difficult in the SSI group. However, mobility is more difficult than learning and applying knowledge at SI level and it gets harder again for those in the SSI group. Emotional health remains of similar difficulty at different stages of the disorder. This could indicate that the emotional consequences of visual loss due to RP can be significant at any stage of visual loss.

4.4.4 Use of mobility aids

Partcipants were divided into two groups: one group that did not use any mobility aids and the other group who were mobility aid users, which included people who used a cane (n=150), a guide dog (n=14), or both (n=30). Those who used mobility aids found both 'learning and applying knowledge' and 'mobility' significantly more difficult compared to those who did not use any mobility aids (p<.001) (Table 4.4). However, there was no significant difference for the 'emotional health' domain between the groups (p>.05).

Table 4.5. Mean difference and standard deviation of perceived difficulty between the mobility aids groups. There were 155 participants that did not use mobility aids (No) and 194 mobility aid users (Yes).

Domains	**No** Mean±SD	**Yes** Mean±SD	**P**
Learning and applying knowledge	3.80±1.11	2.77±1.18	<.001
Mobility	3.02±0.91	2.51±0.66	<.001
Emotional health	3.33±0.97	3.18±1.00	0.17

4.4.4 Most difficult objectives and goals in the view of those who support people with RP

Table 4.5 shows analysis of the difficulty of goals and objectives as considered by those who support someone with RP. The most difficult objective is again mobility (2.33±0.75). The difficulty order of mobility goals are the same as those perceived by people with RP, from driving (1.10±0.75) through to mobility at home (3.69±0.9). This shows that for the mobility objective both groups agree with the relative difficulty rating in terms of ranking. The next three most difficult objectives have close scores; major life areas (2.63±1.22), general tasks and demands (2.64±1.36), and learning and applying knowledge (2.65±1.26).

The fifth most difficult objective is domestic life (2.75±1.08), which was not ranked as highly by those with RP (6th most difficult). Domestic life objectives include tasks such as cleaning, shopping and preparing meals.

Meanwhile, emotional health (3.12±0.96) was ranked as being less difficult in the view of those who support people with RP (7th most difficult objective) compared with those who have RP themselves (5th most difficult objective).

Table 4.6. Difficulty level of objectives and goals as considered by those who support people with RP; those with lower mean scores have lower ability. The results are in order of objective difficulty (most difficult first). The number of non-zero responses indicate the number who rated the goal as applicable (i.e. score of 1-5) out of the total number of respondents (n=75).

Objective / Goal	**Mean difficulty**	**SD**	**Number of non-zero responses**
Mobility (1)	2.33	0.75	
Driving	1.10	0.56	62
Riding a bicycle	1.33	0.87	64
Mobility outdoors	2.40	1.07	75
Using public transport	2.41	1.14	74
Mobility indoors	2.63	1.12	75
Mobility at home	3.69	0.90	74
Major life areas (2)	2.63	1.22	
Applying for job	2.38	1.49	40
Managing finances	2.49	1.52	74
Working activities	2.77	1.27	45
Accessibility at work	2.78	1.15	42
Participating in education	2.91	1.49	44
Getting information	2.95	1.41	73
General tasks and demands (3)	2.64	1.36	

Personal administration	2.33	1.44	75
Following a schedule	2.95	1.52	74
Learning and applying knowledge (4)	2.65	1.26	
Reading	2.49	1.38	74
Writing	2.61	1.40	74
Watching TV	2.89	1.26	75
Domestic life (5)	2.75	1.08	
General maintenance tasks	2.22	1.65	72
Healthcare for another adult	2.31	1.40	52
Shopping	2.37	1.32	75
Grocery shopping	2.43	1.36	75
Grand/Child care	2.47	1.33	52
Withdrawing money	2.93	1.47	75
Cleaning	2.95	1.07	75
Pet care	3.04	1.42	49
Prepare meals	3.11	1.27	73
Laundry	3.18	1.15	71
Community, social and civil life (6)	3.08	0.89	
Physical activity	2.43	1.14	66
Holidays	2.69	1.15	75
Recreational	2.70	1.05	74
Social events	2.85	1.20	75
Dining out	2.85	1.19	75
Having visitors	3.82	1.01	74
Following the news	4.19	0.96	75
Emotional health (7)	3.12	0.96	
Emotional life	3.11	1.06	75
Coping fatigue	3.12	1.11	74
Communication (8)	3.12	1.13	
Personal correspondence	2.56	1.39	73
Using a computer	2.79	1.34	72

Using the telephone	3.93	1.13	74
Self-care (9)	3.55	1.01	
Eating and drinking	3.80	1.13	75
Health care and taking medication	2.93	1.53	75
Dressing	3.09	1.27	75
Interpersonal interactions and relationships (10)	3.64	0.95	
Interaction with strangers	3.08	1.19	74
Interaction with colleagues	3.68	1.12	58
Communicating face to face	3.68	1.09	75
Relationship with loved ones	4.18	0.97	74

4.4.5 Comparison of carers' responses with those of people with RP

The interpretation of carer's points of view compared to those of people with RP with regard to the difficulty level of activities of daily living could be valuable. An individual with RP and their carer may perceive the difficulty of tasks differently and lead to more or less support than is required or being offered.

In this section the differences in difficulty scores between the RP and the carer's groups is analysed. Note that there were different sample sizes for the two groups, with 349 respondents with RP and 75 carers. Also, due to anonymity being provided to participants for ethical reasons, it was not possible to directly compare the responses of carers with those of the person with RP that they supported.

Comparison of the results of the two groups reveals significant differences (Table 4.6). Carers rated the objectives as being significantly more difficult than those with RP did for all objectives except 'interpersonal interactions and relationships' and 'emotional health'.

Table 4.7. Comparison between RP and carers' responses to the 10 objectives of the D-AI. Higher mean scores indicate greater perceived ability or less perceived difficulty.

	Mean ± SD (RP)	Mean ± SD (Carers)	P
Learning and applying knowledge	3.23±1.20	2.65±1.26	<.001
General tasks and demands	3.25±1.28	2.64±1.36	<.001
Communications	3.72±0.96	3.12±1.13	<.001
Mobility	2.74±0.82	2.33±0.75	<.001
Self-care	4.03±0.86	3.55±1.01	<.001
Domestic life	3.31±1.04	2.75±1.08	<.001
Interpersonal interactions and relationships	3.79±0.83	3.64±0.95	.26
Major life areas	3.22±1.13	2.63±1.22	<.001
Community, social and civil life	3.36±0.81	3.08±0.89	.01
Emotional health	3.25±0.99	3.12±0.96	.35

Figure 4.2 illustrates the level of differences between the groups for each of the 10 objectives.

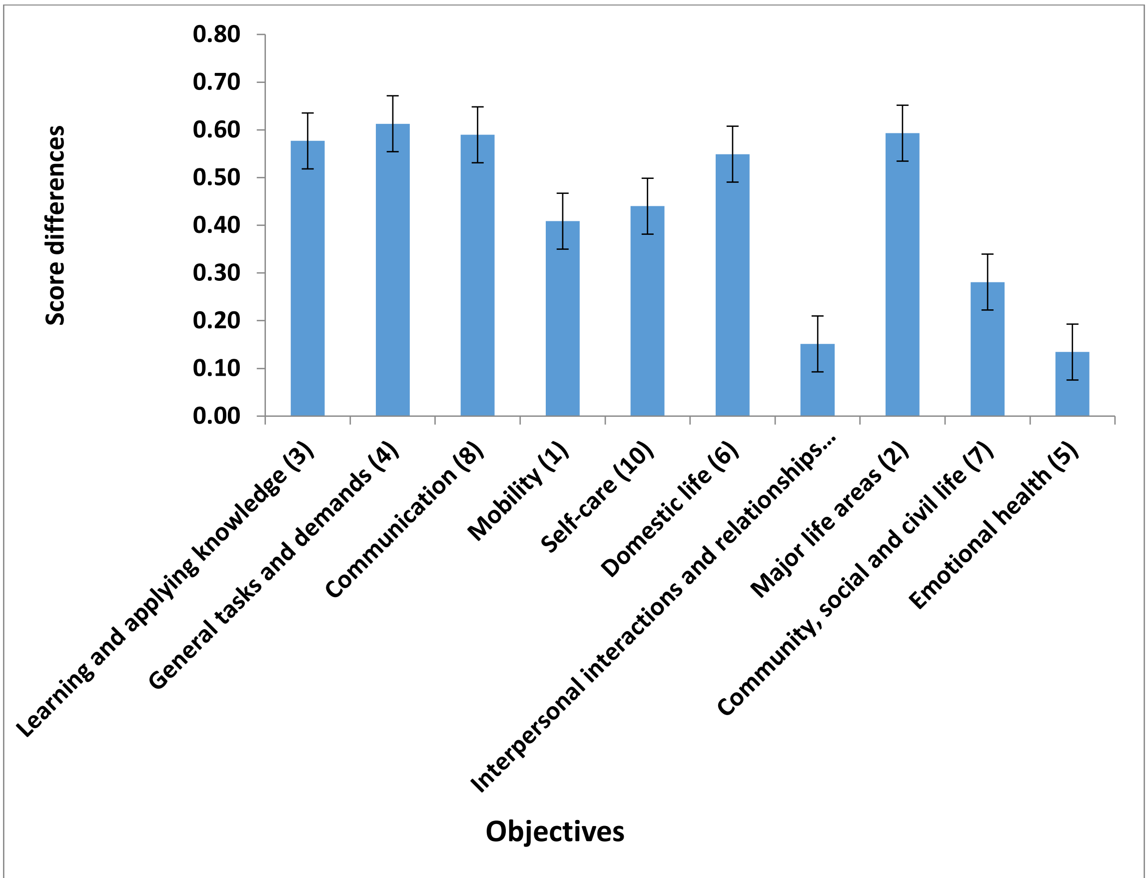

Figure 4.2. Data representation of the differences between RP and carers groups for each of the 10 objectives. Numbers in brackets for each objective relate to the difficulty ranking of the objective for people with RP. The score differences are the difference in the scores which have been presented for people with RP and carers in Tables 4.6.

4.5 Discussion

The purpose of this study was to provide a comprehensive overview of self-reported difficulties in terms of ADLs for those with RP, and to identify the most difficult objectives and goals for those with RP. The four most difficult objectives for people with RP were: mobility, major life areas, general tasks and demands, and learning and applying knowledge.

Mobility was the most difficult objective for people with RP (Table 4.2), in line with previous studies (Lowe and Drasdo, 1992; Geruschat et al., 1998; Turano et al., 1999). At goal level, driving and riding a bicycle were the two most difficult goals. However, more than 100 respondents scored these tasks as not being relevant to them. It could be argued that since many of those with RP would not be able to meet the legal visual standards for driving (visual acuity of 6/12 on a Snellen chart and field of vision of at least 120˚ on the horizontal meridian; DVLA guidelines, 2013), responding that the task was 'impossible' may have been equally appropriate. Although there are no legal visual standards for riding a bicycle it is possible that many of those with RP would distance themselves from this considering the consequences it could have in terms of accidents. In addition, riding a bicycle may not be that prevalent an activity in many locations apart from specific cities such as Cambridge or Oxford, where cycling is a common method of commuting, rather than (or in addition to) a leisure activity.

4.5.1 Relative difficulty of goals

The most particularly difficult individual goals included: mobility outdoors (2.66±1.01), shopping (2.80±1.29), physical activity (2.83±1.17), mobility indoors (2.84±1.03), using public transport (2.87±1.13), going on holidays (2.87±1.13), and grocery shopping (2.89±1.33), (Table 4.2). Although not all of these difficult goals were nested within the mobility objective, most require some level of mobility function, and will be examined in the next experimental chapter. Hence, orientation and mobility training should be considered for those with RP, including for recreational goals.

However, not all mobility goals are necessarily difficult. The goal of 'mobility at home (4.08±0.78)' was shown to be one of the less difficult ones, along with 'using the telephone (4.31±0.90)', 'having visitors (4.13±0.91)', 'relationship with loved ones (4.25±0.86)' and 'following the news (4.50±0.78)', which are all activities that often happen at home. This could be as a result of those with RP being familiar with their surroundings at home, and highlights that ease of mobility and other activities are assisted by familiarity. Black et al. (1996) also suggested and emphasised that those with RP could gain a mental representation of their surroundings and this could compensate for lack of vision to complete tasks at home with less difficulty.

Major life areas was the second most difficult objective, although not all participants found the goals of this objective relevant. The goals for this objective include managing finance, participating in education, applying for a job and working activities. One could argue that finding work and education opportunities that can be offered to people with RP could be more difficult than actually doing these tasks, hence the objective was not relevant to all the participants. This is because there are many restrictions and barriers for those with RP to obtain a job or higher education. This difficulty has been shown in a study by Crudden and McBroom (1999), who reported a number of barriers for those VI in education and employment. Barriers included tasks such as lack of adaptive equipment, accessibility to print and accommodation (Crudden and McBroom, 1999). Those who are willing to take part in the society by wanting to participate in education or finding a job find it difficult and need more support.

The third and fourth most difficult objectives were 'learning and applying knowledge' and 'general tasks and demands', both of which include goals requiring good central vision for reading and writing tasks. This is consistent with Fylan et al. (2005) who reported reading (learning and applying knowledge objective), using public transport (mobility objective) and engaging in hobbies as difficult tasks for those with restricted visual field.

Emotional health (5^{th} most difficult objective) also had a similar level of difficulty expressed and as previous studies have shown, those with RP find coping with emotional health difficult (Hahm et al., 2008; Kim et al., 2013). This could highlight how those with RP can become isolated and depressed as result of their visual impairment.

Some of the objectives with lower applicability highlighted difficulties for the group to whom these goals were relevant. For instance, the mean difficulty of 'applying for a job' was 2.95±1.40 which indicated a high difficulty level but was only applicable to 165 respondents. For comparison, other goals with similar level of difficulty but applicable to more people included, physical activity (2.83±1.17, applicant to 318), going on holidays (2.87±1.13, 335) and participating in social events (2.98±1.07, 342). Although some tasks were not relevant to high percentage (80%) of people, they were difficult tasks for the people who wanted to do them.

On the more positive side, the goals that were identified as relatively easy for those with RP are also worth mentioning. These goals included following the news (4.50±0.78), using the telephone (4.31±0.90), relationships with loved ones (4.25±0.86), eating and drinking (4.22±0.91), having visitors (4.13±0.91) and mobility at home (4.08±0.78). All these goals can be seen as routine activities, where individuals have familiarity with the activity. It can also be argued that such activities are carried at home, where the surrounding environments is familiar, which in turn makes the tasks to complete. Therefore it is understandable the difficulty level of these goals were lower.

4.5.2 Demographic results

The results highlight that those who are severely sight impaired (SSI) find mobility and learning and applying knowledge significantly more difficult compared to those in the sight impaired category (SI) (Table 4.3 and figure 4.1). Those who are registered SSI can be assumed to have more restricted peripheral visual fields than those in SI group, making detection of the spatial characteristics of surroundings and mobility within these surroundings difficult. People registered as SSI due to RP are also more likely to have reduced visual acuity and contrast sensitivity. Therefore tasks such as writing and watching TV can become extremely difficult, whereas those registered as SI are more likely to still have sufficient visual field and central visual acuity to enable them to read and undertake these challenges.

Similar results were found with respect to the use of mobility aids, where those who used mobility aids also found learning and applying knowledge and mobility significantly more difficult compared to those who do not use any mobility aids (Table 4.4 and figure 4.2). It could be argued that those who use mobility aids are in the later stages of RP and have more limited vision, so these objectives are difficult regardless of the use of mobility aids. Participants were asked to report how difficult they found each goal with the use of any appropriate aids, so the results do suggest that people who use mobility aids find mobility in general more difficult than those who do not use aids. Presumably this is why they have chosen to use mobility aids. However, it cannot be assumed from the results that mobility aids do not help people with mobility goals as the difficulty with mobility aids is not being compared to the difficulty perceived if mobility aids are not used.

Emotional health is an interesting objective in terms of the results, and as the objective with the most non-zero responses was the area that was applicable to practically everyone. There were no significant differences in difficulty with emotional health between visual registration status groups or with mobility aid usage (Table 4.3 and 4.4). As discussed previously RP is emotionally difficult due to the anticipated vision loss and the struggle to deal with emotional health could continue from early diagnosis until the late stages of the disorder. It has also been shown by previous studies that those with RP find emotional health difficult to deal with (Hahm et al., 2008; Kim et al., 2013). It is very important that those with RP receive access to emotional support from rehabilitation services not only at the point of diagnosis but also at any point thereafter.

4.5.3 Perceptions of carers compared to those with RP

The results show that carers rate every objective and every goal as being more difficult compared to the perception of people with RP (Figure 4.3). Eight out of ten of the objectives showed significant differences between perceived difficulties of RP to carers, with emotional health and interpersonal interactions and relationships not showing significant differences (Table 4.6). The greatest differences in perceptions between the two groups lies in the practical tasks rather than the personal ones. It might be suggested that those practical tasks that are visible to the carers, such as domestic life activities, can be observed as being difficult and overshadow those that cannot be easily seen or explored such as coping with emotional health by the carers. This could suggest that the carers need more help appreciating the emotional difficulties for those with RP. The result also suggests that the carers should not assume difficulty with more practical tasks for their person with RP and perhaps should allow those with RP to complete those tasks independently. It is interesting that the carer group indicates a higher level of difficulty in general compared to those with RP for all the objectives. Perhaps, this is a sign of protection for those that they care for, so they can receive more help and support. In addition, the result support suggestions that interventions for those who support VI individuals could be helpful (Rees et al., 2007 and Bambara et al., 2009). The need of assistance in interpersonal interactions needs to be discussed within the interventions, as the data suggests that those who support VI individuals tend to underestimate difficulty in such areas, and this can be an area that requires more support at early stages of visual loss.

4.6 Strengths and limitations

It could be argued that the participants in this study were self-selected and may not represent the whole population of those with RP. However, many previous studies in this area of research have used a similar method, and it would be unethical to compel people to take part in research projects. The data comprised over 400 respondents, which is a significant number in any study of people with RP, including those considering self-report questionnaires. The different administration methods were used in order to increase the number of participants. However, it is documented that differences can arise when SRQs are administrated in different ways (Bowling, 2005). In addition, some of the participants' (6 participants in total) feedback regarding the online version of the SRQ stated that, they asked other individuals to read the SRQ to them and this could be seen as a limitation of the accessibility of the SRQ.

It can also be argued that a limitation of this study was the way the data was analysed between the RP and the carer groups. There could have been more insight found if the comparison between those with RP and the carers was done where the data from the carers was actually compared to the person who they cared for. However, the anonymity of this study did not allow for such an analysis. One of the main questions of this PhD is: At what stage of vision loss do the ADLs become more difficult for those with RP? As there was no visual assessments of participants in this experimental chapter, it is impossible to answer this question and the data was relied on the self-report status of the participants. However, this area will be investigated in chapters 6 and 7.

There have only been a few studies investigating the perceptions of those with low vision compared to those who care for them. This area of research needs further investigations Future studies of the differences in ability perceived by VI individuals and those who support them, with the ability to directly compare responses would be beneficial. This could approach the data differently, so that the data from carers could be directly compared to those who they care for.

4.7 Conclusion and next steps

Analysis of responses to the D-AI at goal level has identified that the most difficult objective for people with RP is mobility, and the most difficult goals of high applicability are mobility outdoors, mobility indoors and using public transport. The results from this study could have implications for rehabilitation and mobility training, with difficult objectives and goals receiving greater attention for people with RP. However, these goals cover a wide range of individual tasks. Hence, to determine the most appropriate aspects to investigate objectively, more detailed understanding of the specific tasks making these goals difficult is needed. Having identified the most difficult goals for people with RP, the difficulty of tasks underpinning these specific difficult goals will be assessed in a second questionnaire study in the next chapter in order to further evaluate the specific difficulties of people with RP and inform the movement analysis studies required to understand the movement difficulties of people with RP.

The next chapter will investigate tasks underlying the difficult goals that have been highlighted in this chapter with the high applicability. Studying those tasks in more detail will help in designing chapters 6 and 7.

5. Difficult activities of daily living for those with RP at task level

5.1 Introduction

In the previous chapter, the importance of using the D-AI to determine the rehabilitation needs of those with RP across a full range of ADLs was emphasised. The lack of research investigating a specific VI such as RP was also discussed, where many previous studies have looked at the VI as a whole. Thus, it is important to study and investigate the ADLs of those with RP and examine how they are performed. The previous chapter showed that mobility was perceived as the most challenging domain of the D-AI for those with RP. Furthermore, the most difficult and high applicable activities at goal level were mobility outdoors, shopping, physical activity and/or sport, mobility indoors and using public transport. Although several of these goals underpin the mobility domain within the instrument, shopping is considered under domestic life, and physical activity under community, social and civil life, showing the difficulties faced by those with RP beyond mobility goals. Although ‘physical activity / sport’ was in the top 5 most difficult goals, it will not be assessed further here because the underlying task questions had to take into account a variety of different sports and activities that would reduce the applicability of each question to a small number of participants.

In this chapter, further investigation on the specific tasks underpinning relevant and difficult goals is undertaken using the same method (SRQ) as the previous chapter. Overall 66 goals are discussed within this chapter. The findings could be a useful tool in the rehabilitation and mobility training for those with RP, in particular those who are newly diagnosed. The result of this chapter will also inform the latter experimental chapters in this PhD.

5.2 Aim

The purpose of the present chapter was to extend the findings from the previous chapter. The aim was to find which specific ADLs those with RP find difficult to complete. As well as being helpful for rehabilitation purposes, the identified tasks will be examined in the final experiment of this research using objective analysis.

5.3 Methods

5.3.1 Participants

Participants were again recruited through the charity Retinitis Pigmentosa Fighting Blindness (RPFB) by advertising the study at their local conference, and through their newsletter and social media channels. Participants of the previous experimental chapter who had given their consent to be contacted were also approached. Inclusion criteria for the study were a self-reported diagnosis of RP, and age of at least 18 years. The sample is not the same as the previous chapter as not everyone who completed the previous SRQ participated in this study too. Some new participants took part in the study who did not complete the previous one.

5.3.2 SRQ

The D-AI was used to investigate difficult ADLs at task level. 66 rehabilitation tasks nested within specific goals of the WHO-ICF framework (mobility indoors, mobility outdoors, public transport and shopping; see table 5.1) were used. This study only used online questionnaires for administration because there were some potentially difficult questions regarding the emotional health and well-being of the participants, which would make it inappropriate for telephone administration. Potential participants were given the web address at which the SRQ could be completed, which was hosted via surveygizmo. Informed consent was obtained from all participants once the nature of the study had been explained, by checking a tick box on the web page. Participants could not proceed to the study until they had consented to take part. The tenets of the Declaration of Helsinki were observed. Participants were asked to report their age, gender, duration of visual impairment, visual impairment registration status (not registered, registered as 'sight impaired', or registered as 'severely sight impaired'), and whether they used a mobility aid (cane and /or guide dog). Participants were asked the difficulty of goals that were found to be most difficult within the D-AI at goal level (difficulty with mobility outdoors, shopping, mobility indoors, and using public transport). For the goals that were applicable and of some difficulty (score 2-5), the difficulty of the tasks underpinning these goals were asked.

For the difficulty of each task, participants responded on a 6 point Likert scale. 0 indicated that the task was not important or not applicable to the participant and was considered as missing data. A score of 1 indicated that the task was impossible without help, 2 was very difficult, 3 was moderately difficult, 4 was slightly difficult and 5 was not difficult. Participants were asked; “How difficult are each of the tasks below without the assistance of another person, but with any assistive devices that you use?”

For example, the goal of ‘mobility outdoors’ is explored by asking about the difficulty of more specific tasks underpinning this goal such as ‘orientating and finding your way in poor light’ or ‘walking around safely without bumping or tripping’. The results from the second questionnaire will identify exactly what specific ADLs those with RP find most difficult.

5.3.3 Statistical Analysis

All the data were exported from the Surveygizmo website into an SPSS file. The statistical analysis of the ordinal data was undertaken using SPSS (version 20; IBM). Responses were compared across categories in terms of participants’ registration status (not registered/sight impaired, severely sight impaired), and usage of mobility aids (use of guide dog and / or cane, use of no mobility aids). Since the Likert data was ordinal, non-parametric Mann-Whitney tests were used for comparison of categorised variables. To compare the 4 repeated goals, independent non parametric Mann Whitney U test was used.

5.4 Results

One hundred and sixty six people took part in the study. There were 91 females and 75 males, with a mean age of 50±16 years, and a mean duration of visual loss of 22±16 years. Seventeen were not registered as visually impaired, 63 were 'sight impaired' and 86 were 'severely sight impaired'. Eighty two people used mobility aids (cane, dog or both) and 84 did not.

The results were analysed to identify the most difficult ADLs at both goal and task levels. If the questions were not important or applicable and were scored as '0', they were not included in the analysis. Hence, the results are analysed for those who found any given item applicable to them. Higher average scores indicate that people have more ability or less difficulty with goals or tasks. Lower average scores indicate more difficulty or less ability.

5.4.1 Most difficult goals and tasks

Table 5.1 shows the analysis of the difficulty of tasks and goals in ordinal fashion for those with RP.

Table 5.1. Difficulty level of goals and tasks for those with RP; those with lower mean scores have lower ability. The results are in order of goals difficulty (most difficult first). The number of non-zero responses indicate the number who rated the goals/tasks as applicable (i.e. score of 1-5) out of the total number of respondents (n=166).

Goal/task	**Mean difficulty**	**SD**	**Number of non-zero responses**
Using public transport (1)	2.58	1.28	156
Read departure and arrival times	2.66	1.32	131
Make a connection	2.68	1.28	127
Find the right track or platform	2.71	1.25	130
Recognize the right stop	2.79	1.23	131
Recognize the right line (e.g. bus)	2.81	1.32	134
Travel with ease by public transport	2.92	1.06	133
Find out about delays and redirections	2.95	1.35	129
Find a suitable route by public transport	3.15	1.24	131
Get through turnstiles	3.20	1.32	124
Get on and off a bus/train	3.30	1.13	130

Use a public transport chip card	3.31	1.52	101
Buy a ticket	3.33	1.23	124
Travel in a familiar environment	3.50	1.16	133
Get somewhere without getting too tired	3.66	1.20	125
Mobility outdoors (2)	2.80	1.03	162
Orientate and find your way in poor light	2.19	0.94	150
Walk around safely without hitting overhanging things (e.g. branches)	2.45	1.09	152
Walk around safely without bumping into, tripping over, or stepping off something	2.51	0.95	152
Find your way in very bright light (e.g. glare of car lights or the sun)	2.52	1.14	148
Notice other road users (e.g. cyclists, cars)	2.76	0.97	150
Read (road) maps	2.78	1.47	144
Be able to recognize the speed of other road users	2.81	1.14	149
Read directions and street signs	2.97	1.34	147
Cross the street safely	3.06	1.10	150
Read traffic signs, such as pedestrian crossings	3.29	1.28	148
Assess your own safety	3.43	1.06	150
Ask for help in organizing a trip	3.59	1.28	128
Ask for help from passer by	3.72	1.12	123
Get somewhere without getting too tired	3.83	1.15	141
Shopping (3)	2.86	1.41	161
Find products in shops that you only go into occasionally	2.52	1.08	130
Find suitable electronic equipment (e g easy to use, clear contrast)	2.67	1.28	123
Find clothes (e g find the right size and colour)	2.68	1.30	128
Find presents for others	2.78	1.33	129
Find suitable things for your own home (e g furniture)	2.94	1.35	126
Mobility indoors (4)	2.87	1.20	163
Orientate in poor light	2.17	0.84	135
Find your way in very bright light (e g glare from lamps)	2.47	1.13	137
Orientate and find your way in a store or hospital	2.65	1.14	139
Walk around safely, without tripping over things (e g doorsteps)	2.68	0.99	139
Walk around safely, without bumping into things (e g furniture, doors)	2.72	1.03	139
Orientate and find your way in someone else's house	2.81	1.05	139
Walk down the stairs safely	2.99	1.18	138
Find handles and handrails	3.03	1.11	139
Use an escalator or elevator	3.33	1.25	136
Walk up the stairs safely	3.41	1.13	138

The most difficult goal is using public transport (2.58±1.28), followed closely by mobility outdoors (2.80±1.2).

There were 4 ADLs at goal level, which were repeated from the previous chapter. The scores of these 4 ADLs are shown in table 5.2. There were no goal with score below 2. Although the results (table 5.1) are average across the participants but it could represents that not many participants found the goals impossible to complete.

Table 5.2. The mean difficulty level and standard deviation scores of the 4 repeated ADLs in two questionnaires used in this and previous chapter. * Represents significant difference between the groups.

ADLs at goal level	Mean difficulty level of 1st SRQ ± SD	Mean difficulty level of 2nd SRQ ± SD
Mobility outdoors	2.66±1.01	2.80±1.03
Mobility indoors	2.84±1.03	2.87±1.20
Using public transport	2.87±1.13	★ 2.58±1.28
Shopping	2.80±1.29	2.86±1.41

Apart from using public transport (p=.026), the scores of other three ADLs were not significantly different (p>.05) from one questionnaire to another. Using public transport was reported significantly more difficult in the second questionnaire compared to the first one.

The five most difficult tasks were: orienting in poor light (mobility indoors; 2.17±0.84), orienting and finding your way in poor light (mobility outdoors; 2.19±0.94), walking around safely without hitting overhanging things (mobility outdoors; 2.45±1.09), finding your way in very bright light (mobility indoors; 2.47±1.13) and walking around safely without bumping into, tripping over, or stepping off something (mobility outdoors; 2.51±0.95).

Similar to the previous chapter, it was important to examine the applicability of the ADLs at task level within the participants. Figure 5.1 illustrates the applicability of the tasks. The cut-off frequency was set at 80% respondents once again, which included 133 of the participants.

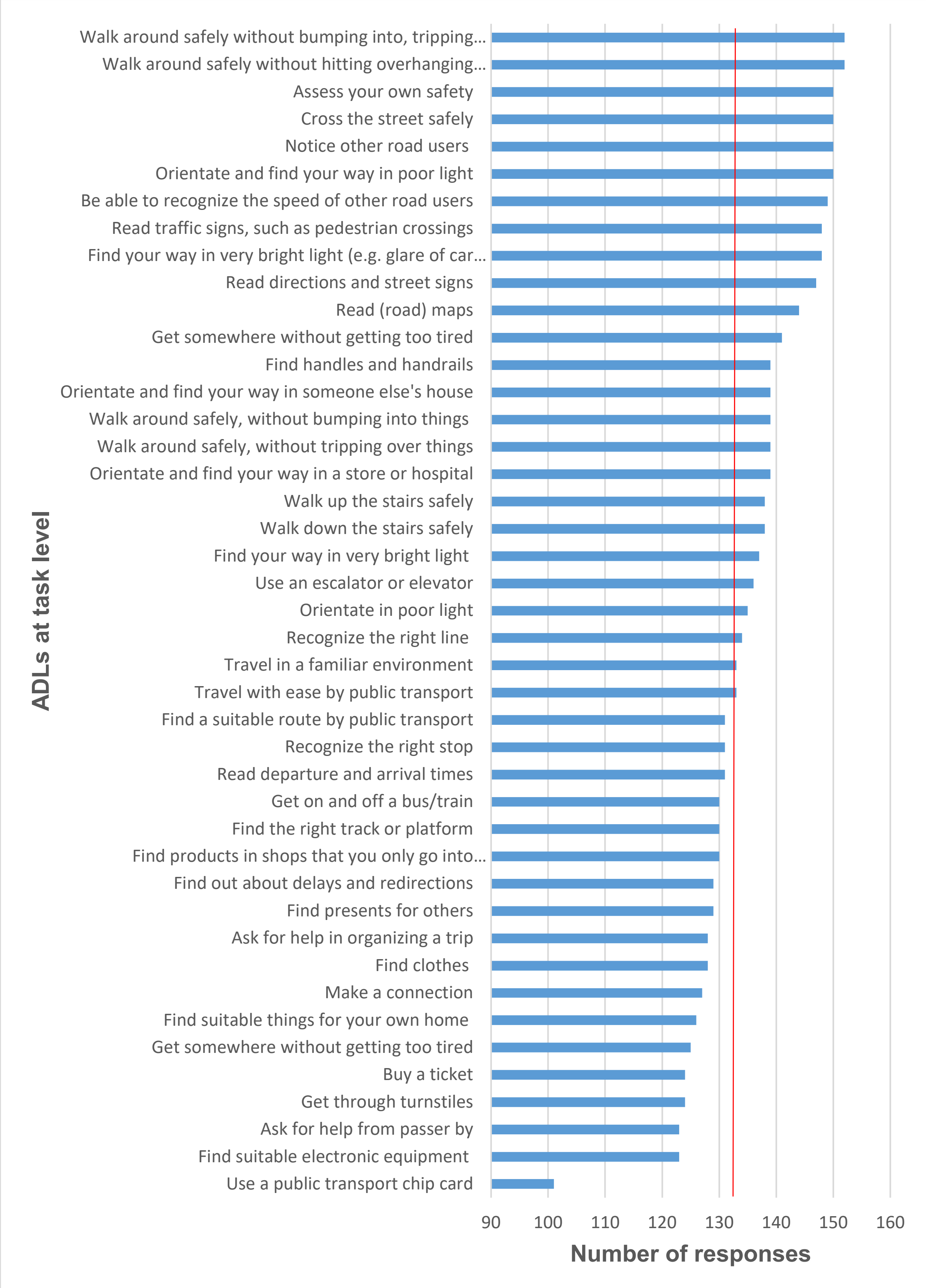

Figure 5.1. The applicability of all the tasks. 25 out of the 43 of the tasks were in the 80% applicability cut-off, which is equal or more than 133 participants. The red line represents the cut-off applicability frequency.

The top 10 most difficult ADLs at task level that were above the cut off frequency are shown in table 5.3 in order of their difficulty.

Table 5.3. The 10 most difficult ADLs to complete at task level above the applicability cut-off point.

Task	Mean difficulty ±SD
Orient in poor light (mobility indoors)	2.17±0.84
Orientate and find your way in poor light (mobility outdoors)	2.19±0.94
Walk around safely without hitting overhanging things (e.g. branches)	2.45±1.09
Walk around safely without bumping into, tripping over, or stepping off something	2.51±0.95
Find your way in very bright light (e.g. glare of car lights or the sun)	2.52±1.14
Notice other road users (e.g. cyclists, cars)	2.76±0.97
Be able to recognize the speed of other road users	2.81±1.14
Assess your own safety	2.83±1.17
Read directions and street signs	2.97±1.34
Read traffic signs, such as pedestrian crossings	3.29±1.28

5.4.2 Variation of difficult tasks with demographic factors

Three of the most difficult tasks ('orient in poor light' indoors, 'walk around safely without hitting overhanging things' and 'walk around safely without bumping into, tripping over, or stepping off something') were selected and examined further with respect to the demographic data (visual impairment registration status, and mobility aid usage).

5.4.2.1 Visual impairment registration status

Similar to the previous chapter participants were divided into two groups; one consisted of people registered as severely sight impaired (n=86 ; termed the 'SSI' group) and the other was the combination of those sight impaired (n=63) as well as those who were not registered as visually impaired (n=17) (termed the 'SI' group). This combination was used in order to compare two groups with as similar numbers in each group as possible.

Those in the SSI group found both 'walk around safely without hitting overhanging things (p=.004) and 'walk around safely without bumping into, tripping over or stepping off something' (p=.04) significantly more difficult compared to those in the SI group. However, there was no significant difference between groups for the 'orient in poor light' domain (p>.05). Figure 5.1 demonstrates the findings, where the walking tasks were significantly more difficult for those in SSI group compared to those in SI group.

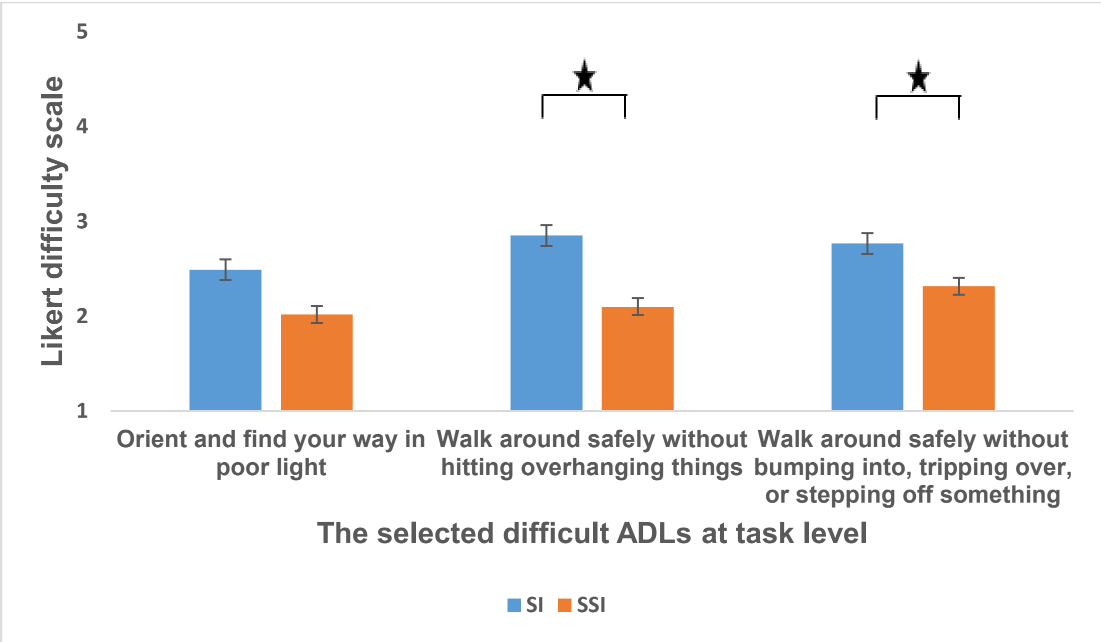

Figure 5.2. Data representation of the selected tasks for those with RP considered by registration status. Likert scores are presented on the Y axis; higher average scores indicate that people have more ability or less difficulty with these tasks. Lower average scores indicate more difficulty or less ability. * represents significant difference between the groups.

5.4.2.2 Use of mobility aids

Partcipants were divided into two groups: one group that did not use any mobility aids and the other group who were mobility aid users, Eighty two people used mobility aids (67 people used cane, 7 people used guide dogs or both) and 84 did not.

Those who used mobility aids found 'walk around safely without hitting overhanging things' (p=.001) and 'orient in poor light' (p=.009) significantly more difficult compared to those who did not use any mobility aids. However 'walk around safely without bumping into, tripping over or stepping off something' (p=.07) did not show any significant difference between the mobility aids user groups (Figure 5.2).

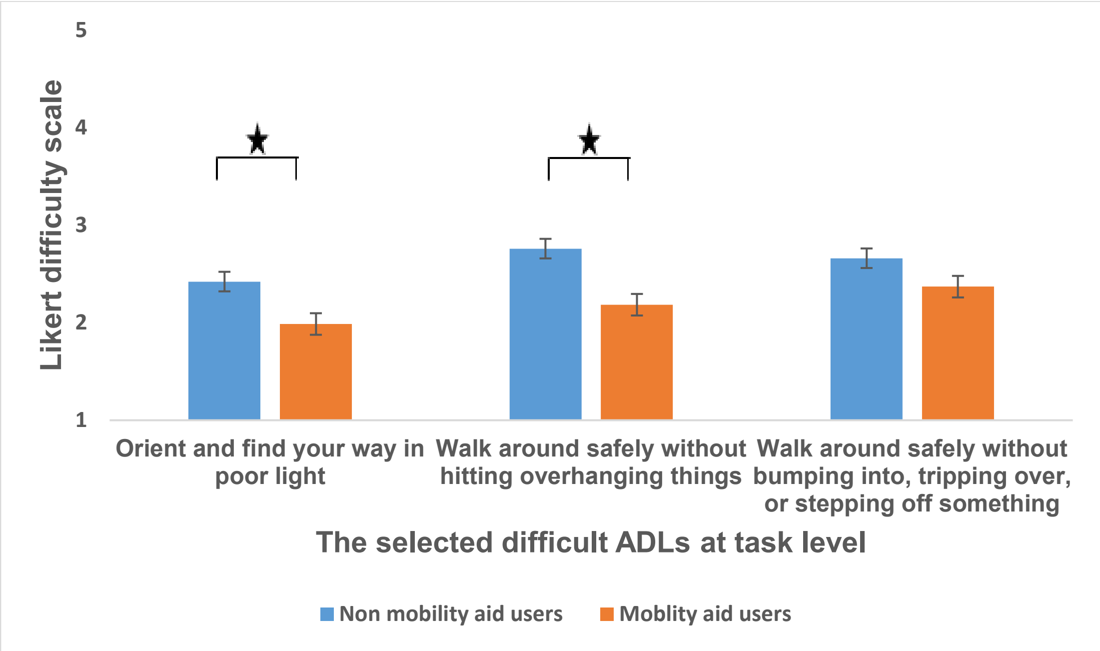

Figure 5.3. Data representation of the selected tasks for those with RP considered by mobility aids usage. Likert scores are presented on the Y axis; higher average scores indicate that people have more ability or less difficulty with these tasks. Lower average scores indicate less ability or more difficulty. * represents significant difference between the groups.

5.4.3 Disease duration impact on the most difficult ADLs

The years with RP of participants was correlated against the three most difficult ADls. The correlation coefficient for "Walk around safely without bumping into, tripping over, or stepping off something" is almost zero ($R^2 = 0.0004$), representing no correlation between the two variables. This means that the years with RP has no significant effect ($p>0.05$), on the difficulty level of walking around safely without bumping into something. Figure 5.4 illustrates this result.

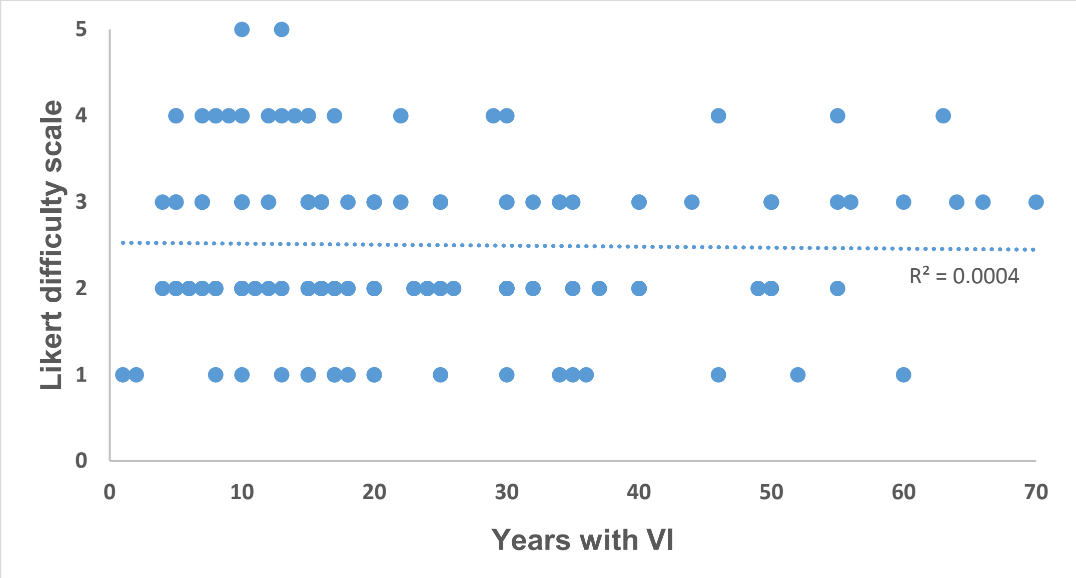

Figure 5.4. Correlation plot of years with RP (X axis) against difficulty level of "Walk around safely without bumping into, tripping over, or stepping off something". Higher scores indicate that people have more ability or less difficulty with these tasks. Lower average scores indicate less ability or more difficulty.

Figure 5.5 demonstrates the correlation result for Walk around safely without hitting overhanging things (e.g. branches). Similar to the previous ADL, the correlation coefficient for "Walk around safely without hitting overhanging things (e.g. branches)" is almost zero (R^2 = 0.0044), representing no correlation between the two variables.

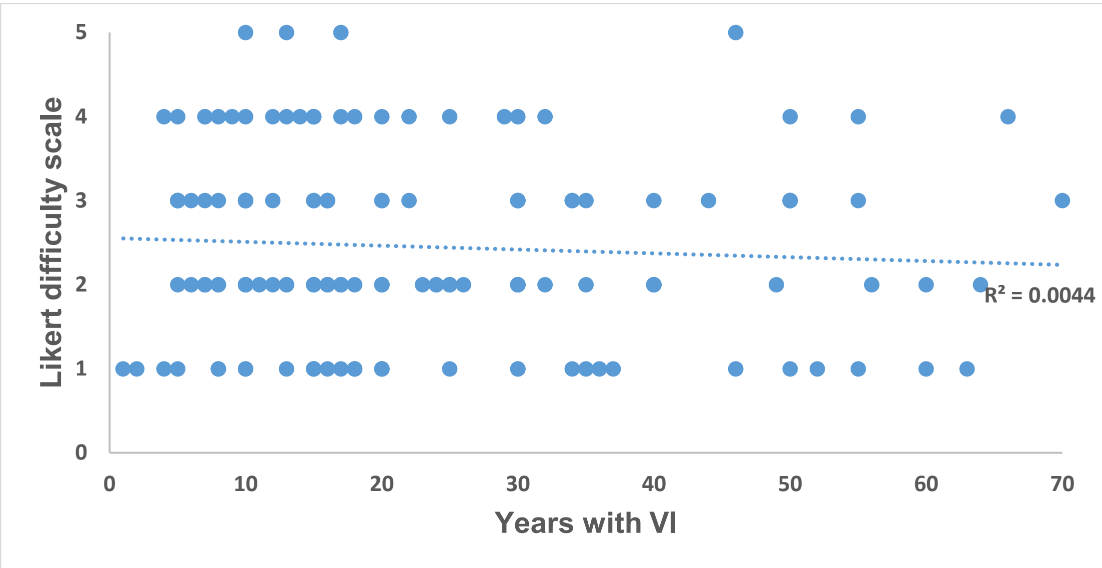

Figure 5.5. Correlation plot of years with RP (X axis) against difficulty level of "Walk around safely without hitting overhanging things (e.g. branches)". Higher scores indicate that people have more ability or less difficulty with these tasks. Lower average scores indicate less ability or more difficulty.

Furthermore, figure 5.6 demonstrates the correlation result for “Orientate and find your way in poor light”. Similar to the previous ADL, the correlation coefficient for “Walk around safely without hitting overhanging things (e.g. branches)” is almost zero (R^2 = 0.0044), representing no correlation between the two variables.

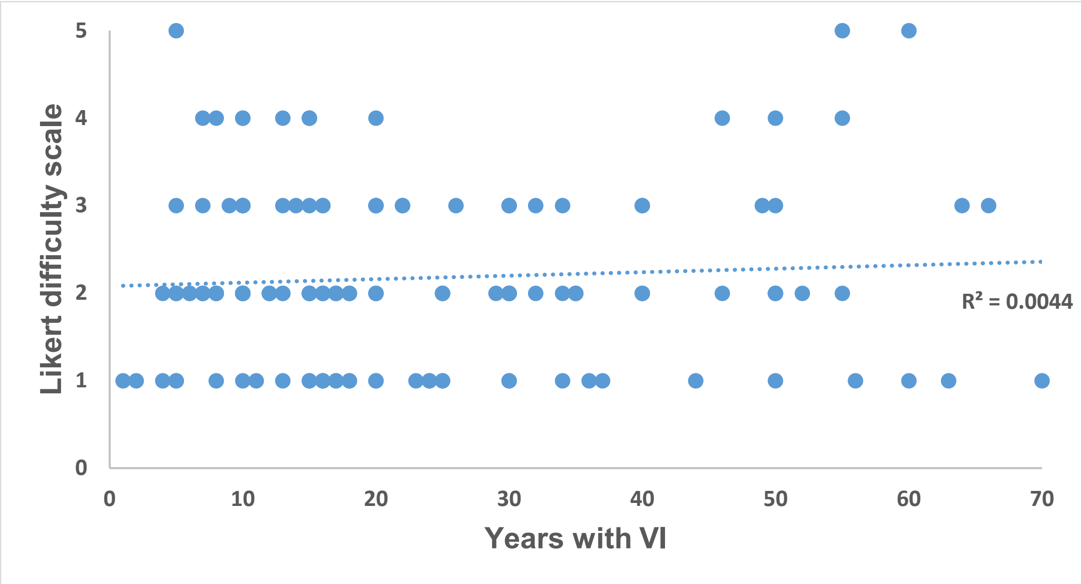

Figure 5.6. Correlation plot of years with RP (X axis) against difficulty level of “Orientate and find your way in poor light”. Higher scores indicate that people have more ability or less difficulty with these tasks. Lower average scores indicate less ability or more difficulty.

5.5 Discussion

The purpose of this chapter was to extend the findings from the previous chapter and provide results to build on in the next experimental chapters. The study also aimed to find which specific ADLs those with RP find difficult to complete. The results from this chapter highlighted that of the top three most difficult applicable tasks; ‘orientating and finding the way in poor light’, ‘walking around safely without hitting overhanging things’ and ‘walking around safely without bumping into, tripping over, or stepping off something’..

5.5.1 Most and least difficult

As discussed above, this chapter was a follow up from the previous and 4 of the ADLs were repeated. Mobility indoors, mobility outdoors and shopping showed no significant differences in terms of difficulty level between the results for this chapter compared to the last one. However, using public transport was significantly more difficult in this chapter compared to the last one. It should be highlighted that the groups and the number of participants were different between the two questionnaires and some differences were expected.

The five most difficult tasks were: orient in poor light indoors (2.17±0.84), orient and find your way in poor light outdoors (2.19±0.94), walk around safely without hitting overhanging things (2.45±1.09), find your way in very bright light (2.47±1.13), and walk around safely without bumping into, tripping over, or stepping off something (2.51±0.95). All these tasks are mobility related and not part of the ‘shopping’ or ‘using public transport goals’. Having said that, ‘using public transport’ at goal level was the most difficult goal, however the tasks within this goal domain were not as difficult compared to the ones in mobility domains. It can also be argued that to use public transport, mobility tasks such as orientation and walking are essential. Interestingly, when the results (4 goals) were compared to the previous chapter, only ‘using public transport' was significantly more difficult in this chapter. It could be that more participants in the second questionnaire use public transport and show more difficulties compared to the result of the previous chapter.

The results are in line with a previous study by Lowe and Drasdo (1992), where several difficulties were reported such as walking into obstacles and difficulties in using public transport. Also, Geruschat et al. (1998) reported that difficulties with mobility performance such as hitting an obstacle are one of the major problems reported by people with RP, which is again in line of the finding of this study; such a finding is expected among a population which is characterised with reduced peripheral visual field. The importance of lighting for people with RP noted by Turano's early work (Turano et al.,1999), where participants reported difficulties in environments with poor light. This study also showed that people with RP find orientation in poor light difficult. As it was discussed in chapter 2 (see 2.4.2) one of the early signs of RP is the difficulty in poor/dim surroundings, due to nyctolia as a result of the loss of rod photoreceptors, and this is one of the main characteristics of RP. Thus, it is understandable that dealing with orientating in poor light is difficult for those with RP.

Orientation in poor light was one of the most difficult tasks is expected, as discussed in chapter 2. RP affects photoreceptor function, and the presenting visual symptoms in RP are often poor scotopic vision, even before visual field is noticeably affected. When this was examined further between the SSI and SI groups, no significant difference was shown. This shows that the deterioration of vision does not affect this task as both groups found this difficult at similar level. Interestingly, there have been historical development of light deprivation benefiting those with RP. The process included individuals wearing opaque scleral contact lenses on daily basis. A study by Berson (1980) emphasised on the benefit of this work and recommended those with RP to wear dark sunglasses for outdoor activities. Adaptations to poor lighting have been a suggestion from previous studies that can help those with RP during ADLs such as mobility and orientation (Berson, 1980, Brunnstrom et al., 2004). Black et al., (2009) examined individuals with RP at two different lighting level. The reduction in illumination resulted in significantly worse error making (during mobility) and percentage preferred walking speed (Black et al., 2009). The result from this chapter reported the difficulty in poor light for those with RP, which is in agreement with the works of Black et al., (2009). Other difficult tasks related to avoiding peripheral obstacles, reflecting loss of peripheral visual field as the condition progresses, where those in SSI group found significantly more difficult compared to those in SI group (Figure 5.1). One of the most difficult tasks was 'find products in shops that you only go into occasionally', which relates to visual search by individuals. This could be as a result of the limited peripheral visual fields of those with RP, which may result in extensive scanning and searching for a product, hence the difficulty of the task. Timmis et al. (2017) reported that those with RP have more active visual search pattern compared to visual normal during walking gait tasks, which is due to the constricted visual field.

The least difficult tasks include get somewhere without getting too tired (3.83±1.15), ask for help from passers-by (3.72±1.12), ask for help in organising a trip (3.59±1.28), travel in a familiar environment (3.5±1.16) and assess your own safety (3.43±1.06). Encouragingly two of the tasks are about asking for help which the participants expressed little difficulty with. Also, self-assessment of safety has been reported as not difficult for those with RP which is also encouraging and shows some independence for those with RP. As shown at goal level, familiar tasks are also perceived as less difficult.

5.5.2 Demographic results

'Walking around safely without hitting overhanging things' and also without 'bumping into, tripping over or stepping off something' were significantly more difficult for those who are severely sight impaired (SSI) compared to those in the sight impaired group

(SI) (see figure 5.1). Those in the SSI group are likely to have much more restricted peripheral visual fields compared to those in the SI group.

In respect to mobility aids, the perceived difficulty with the task of ‘walking around safely without bumping into, tripping over or stepping off something’ was not significantly different between the mobility aid users and non-users, whereas ‘walk around safely without hitting overhanging things’ were more difficult to mobility aid users (Figure 5.2). This suggests that mobility aids do help individuals to avoid inferior hazards despite poor vision, whereas avoiding superior obstacles is not affected by the use of a dog or a cane. The impact of mobility aid usage on mobility performance has not been studied to great extent. Note that, 71% of those in SSI group used mobility aids compared to only 26% of those in SI group, reflecting the more restricted vision of those in SSI group.

5.6 Strengths and limitations

Similar to the previous experimental chapter, this study used SRQ and it is possible that this sample does not represent the whole population of people with RP and only those who were willing to participate. However, the sample size (although smaller than the previous study) was still large compared to many previous studies. Another limitation in this study is the lack of clinical visual function data meaning reliance on the surrogate measure of registration status. However, this was a necessary compromise of an online study, with a benefit of a larger sample size.

The exclusion of phone and post administration in this study may have biased the sample by excluding those individuals who have no access to a computer and this can be seen as a limitation to this study.

5.7 Conclusion and next steps

This chapter demonstrated that people with RP find orientation in poor light and walking around safely as the most difficult tasks to complete. The study also showed orientation is relatively and walking around is significantly more difficult for those in SSI group compared to those in SI group. Moreover, those who used mobility aids reported both tasks (orientation and walking around safely) significantly more difficult compared to those who don't.

One major aspect underpinning safe orientation and human movement is postural stability. Vision is one of the three main neural processing streams that helps regulate postural stability (see 2.5.2). Moreover, reduced postural stability is an important factor in falls and it has been identified as an important risk factor for falling (Maki et al., 1994). Therefore, it is important to investigate postural stability of those with RP.

The impact of navigating in poor or changing light was recognised as a difficulty for those with RP. Further research should continue to better understand how to support those with RP to safely navigate in different light levels.

6. Postural stability of people with RP

6.1 Introduction

The previous two experimental chapters (4 and 5) investigated the most difficult ADLs to complete for those with RP using SRQs. The result of the previous chapter showed that orientation and walking around safely are two of the most difficult ADLs for those with RP. As discussed in the literature review (chapter 2), one of the major aspects of safe orientation and human locomotion is postural stability. Through examining postural stability among those with RP, it will be possible to better understand whether the self-reported difficulties relating to orientation and mobility (chapter 5) are a function of reduced postural control. In this chapter investigation of postural stability of those with RP is compared to normally sighted individuals.

Postural stability is controlled and maintained through a complex interaction of visual, somatosensory and the vestibular system (Massion, 1994). The ability to control postural stability during ADLs plays an important role in the function of mobility (Porter and Nantel, 2015). The inability to maintain postural stability can lead to falls (Masud and Morris, 2001). Fall related injuries are major health concern, because they cause functional decline and increased mortality, as well as increasing the healthcare costs for societies (Wolinsky et al., 1997; Rizzo et al., 1998; Stel et al., 2004). The cost to the NHS have been estimated at £981 million (Scuffham et al., 2003), however, a more recent study suggested that the NHS spends £1.7 billion per annum solely treating hip fractures that have been caused by falls (Lawrence et al., 2005).

VI has been suggested as a key determination of falls (Sudgen and Keogh, 1990). Previous research investigating postural stability of those with visual field loss has reported that greater binocular visual field loss is significantly associated with increased postural instability, in particular on foam surfaces (Black et al., 2008).

Interestingly, individuals with Glaucoma appear to have a lower visual contribution and higher somatosensory contribution to sway compared to those with no ocular disease (Kotecha et al., 2012). It has also been reported that those with Glaucoma rely more on their vestibular (in addition to somatosensory) system to maintain balance (Khan et al., 2012). Horvat et al. (2003) suggested that there is an up regulating of somatosensory and vestibular systems for VI to compensate for the vision loss, however their study only concentrated on VI and not particularly RP.

Similar to those with Glaucoma, Turano et al. (1993) highlighted that those with RP have less visual stabilization to help maintain postural stability compared to people with normal vision. Indeed, the reduced balance when RP participants stood in dark compared to light conditions was only 'marginally significant' whereas it was 'highly significant' for visual normals (Turano et al., 1993). Turano's study is the only previously published research investigating balance control among those with RP. Despite valuable findings from Turano's work, the study had some limitations and further research is required in this area. Testing involved each participant standing on a sway-reference platform (which served to disrupt somatosensory information) but the system only measured balance in the anterior-posterior (A-P) and not medial-lateral (M-L) direction. Reduced balance in the M-L direction is a significant predictor of multiple falls in older adults (Swanenburg et al., 2010) and sideways falls often result in fractures of the femoral neck (Nevitt and Cummings, 1993). It is for this reason that when investigating postural stability there is a need to consider both forwards-backwards [A-P] and sideways [M-L] directions.

A number of different methodological approaches have been used to measure postural stability. For example, although recommendation of 3-5 trial repeats have been suggested (Ruhe et al., 2010) studies use a variety of trial repeats. Within the literature, researchers have found significant differences in postural stability between trial repeats (Paterka et al., 2004; Zanetti et al., 2007; O'Connor et al., 2008; Jbabdi et al., 2008;

Bonnet et al., 2012), while others reporting no significant difference (Tarantola et al., 1997; Sawers et al., 2015). Some of the reasons for the inconsistency could be differences in the methodology in terms of participants (visually impaired, elderly and/or other mobility dysfunction), visual fixation (where or what part they were looking at during the trials), body position (feet apart or together, arms by your side or folded) and duration of the trials.

The length of the trials has also been varied from 10 to 60 seconds (Elliot et al., 1995; Anand et al., 2003; Black et al., 2008; Schwesig et al., 2011; Kotecha et al., 2012). Carpenter et al. (2000) reported a significant influence of postural stability (RMS) by sample duration of 15, 30, 60 and 120 seconds in both A-P and M-L directions. RMS significantly increased as sample duration increased (Carpenter et al., 2000). Le Clair and Riach (1996) also reported significant differences between time intervals, where measurements of 10 seconds were different to the other time intervals (20, 30, 45 and 60 seconds) for standard deviation of centre of pressure in both lateral and anteroposterior direction, and average centre of pressure velocity (direction not stated). Their study showed that the optimum test reliability is at 20 to 30 seconds trial periods. The sway increased with longer time durations of the trials, which could suggest that fatigue was a factor during the examination.

Some studies have concluded that the first 5 seconds of postural stability test is crucial and this time interval has significant differences compared to the remainder of the test (Jonsson et al., 2004; Perreira et al., 2013). However, Turano et al. (1993) removed the first 5 seconds of data from their assessments, perhaps because they believed it will take that time for the participants to adjust to their standing position. In a systematic review where the methodology of thirty two balance related papers were investigated, Ruhe (2010) reported durations of 90 seconds and longer can be expected to yield sufficient reliability for centre of pressure. However despite Ruhe's (2010) findings, most of the literature investigating balance control among visually impaired ranges from 10-30 seconds (Anand et al., 2003; Shabana et al., 2005; Kotecha et al., 2013) and this is likely due to negating the risk of fatigue from the older participants standing for excessive length of time.

6.2 Aim

The aim of the present chapter was to examine postural stability in a range of conditions among participants with RP. Specifically, the experimental chapter will examine the relationship between RP progression and the visual contribution to postural stabilisation in addition to how trial length and repetition impacts the results.

6.3 Methods

Much of the methodology used in this chapter has been discussed in the general method chapter (chapter 3), however necessary details are further discussed in this chapter.

6.3.1 Participants

Thirty seven individuals with RP (age 52±13 years, mass 74±15 kg, height 168±9 cm, 16 male) and twenty normally sighted individuals (age 52±16 years, 70±11 kg, height 183±66, 6 male) participated in this study. There were no significant differences between age, weight and height across groups (P>.05).

In the RP group 31 participants were registered as severely sight impaired, 5 as sight impaired and one person was not registered. Usage of mobility aids varied within the RP group; 10 subjects did not use any mobility aids, 19 used a mobility cane, 5 were guide dog users and 3 used both cane and guide dog. The average years with visual impairment defined as since being diagnosed for the first time until the date of examination (approximately) was 25±13 years.

The study was approved by Anglia Ruskin University ethics committee and informed consent was collected from each participant prior to examination. Participants were excluded if they reported a history of comorbidities such as vestibular disturbance, diabetes resulting in either vision or somatosensory loss, Polio, or severe arthritic conditions. These comorbidities excluded individuals from participation because they have previously been reported to affect postural stability (Fujimoto et al., 2013; Hsieh et al., 2013; Kotagal et al., 2013).

Participants were assessed through a self-report questionnaire regarding their current health status, medications and history of falls (appendix 10). Six people in the RP group reported hearing loss (2 had Usher's syndrome), common health conditions reported included lower back pain, early stages diabetes and mild arthritis in the hands. 54% of the participants in the RP group reported falling more than once in the last year prior to the examination compared to 25% percent in the control group. Individuals in the RP group (32%) had higher levels of fear of falling compared to those in control group (15%). All participants perceived all sensations on the foot using a 10-g monofilament (see 3.4.5).

6.3.2 Visual assessment

All participants were tested wearing their habitual distance prescription (if worn) during the visual assessments. These glasses (if used) were also worn for the postural assessment. The mean binocular VA scores for RP and normal vision individuals were 0.76±0.63 and -0.11±0.2 LogMAR respectively.

Visual field was assessed using Damato campimeter (CAT. NO. 2960). The results categorised the participants into 3 groups; those who could see all the points (all 20 normally sighted participants), those who could see some of the points 1 to 20 numbers (17 RP participants) and those that were unable to see any of the points (20 RP participants). The categorisation of the groups was because of the poor performance of Damato campimeter, where the number of points seen did not provide a continuous variable. Thus, the result had to be categorised.

6.3.3 Postural stability measurements

Participants with RP were recruited through RP Fighting blindness and tested at their local group meetings across the United Kingdom (UK). The data was collected at 4 venues throughout the UK. The same procedure (see below) was used at each venue. To confirm the same level of lighting at each venue, a lux meter (CEM-DT 1308) was used to measure illuminance. The mean average of the illuminance across venues was 350±168 lux; with no significant difference between the venues ($P>.05$).

Postural stability in quiet standing was assessed in four conditions; 1. Standing on a force platform (Kistler–Type 9286AA) with open eyes (EO) 2. Standing on a force platform with closed eyes (EC) 3. Standing on foam with open eyes (FEO) 4. Standing on foam with closed eyes (FEC). The foam measured 40cm by 60cm (which allowed positioning directly on top of the force plate), with the thickness of 8cm and density of 50kg per cubic metre (Adkin et al., 2005). Participants stood on the foam surface in an attempt to disturb somatosensory information. Each condition was repeated three times over a 30 seconds period in a fully randomised order.

Centre of pressure (CoP) data were obtained using Kistler force platform. Data were sampled at 100 Hz, and filtered with Butterworth low pass filter with cut off frequency of 10Hz (Salavati et al., 2009; Solnik et al., 2014). The 10 Hz filtering was based on optimal cut-off frequency method used by Wells and Winter (1980) (see 3.5).

6.3.4 Dependent Variables

The CoP signals for both anterior-posterior (front-to-back, A-P) and medial-lateral (side-to-side, M-L) directions were derived from the force platform. The average magnitude of CoP displacement (fluctuation in displacement) was defined as root mean square (RMS) and was calculated using the obtained signals based on the work by Cornilleau-Peres et al. (2004).

The effect of visual contribution on postural stability was measured by the Romberg quotient (RQ). RQ is defined as the effect of visual stabilization (contribution) on postural stability and is calculated as the average RMS value in eyes closed divided by eyes open. Lower RQ value indicates reduced visual contribution to balance control.

Initial analysis of the data separated the RMS values across the 30 seconds trials into three 10 seconds intervals.

6.3.5 Statistical Analysis

To investigate the effects of trial repetition and time intervals on the data, a repeated measure ANOVA was performed with all the standing conditions as within factors and participants groups as between subject factors. P value of smaller than 0.05 was accepted as significant level for the results and post-hoc analyses was conducted using Duncan's multiple range.

6.4 Results

6.4.1 Repetition effect

There was no significant main effect of trial repetition on RMS in either A-P (p=.93, figure 6.1a) or M-L direction (p=.174, figure 6.2.b).

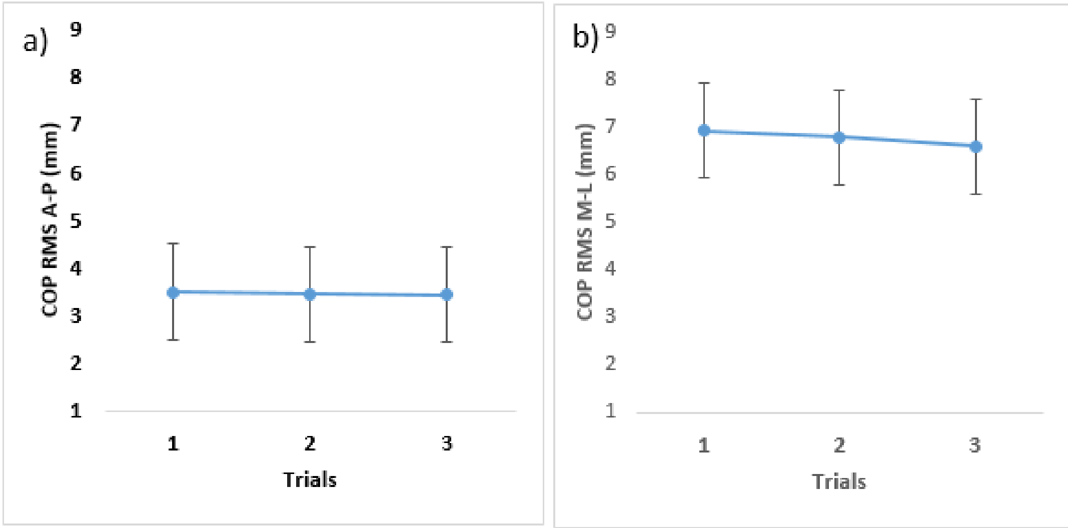

Figure 6.1. Group mean (±SE), (Control and RP) RMS values for the 3 trials in both A-P (a) and M-L (b) directions. The mean value is across all the conditions. No significant main effect between the trials.

6.4.2 Interval effect

With no significant difference in trial repeats, the following analysis used an average across the three trial repeats. To allow analysis of time intervals, the 30 seconds data were separated into 3 groups of 10 seconds.

There was a significant main effect of interval on both M-L and A-P directions, p<.001. Post-hoc analysis indicated that RMS values were significantly higher in both A-P (Figure 6.2a) and M-L (Figure 6.2b) directions in first compared to the second (p<.001) and third interval (p<.001). The third interval was also significantly higher compared to the second interval (p<.001) in both directions.

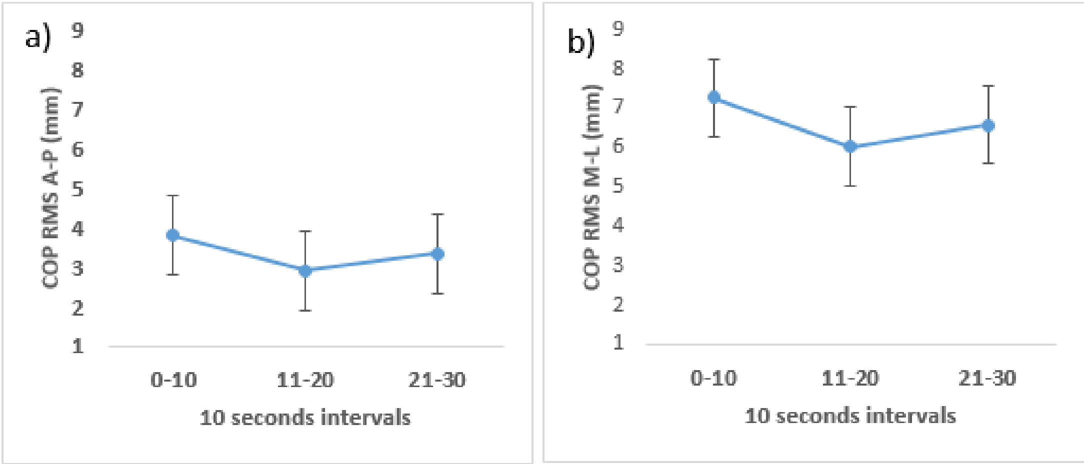

Figure 6.2. Group mean (±SE), (Control and RP) RMS values for the 3, 10 second intervals in both A-P (a) and M-L (b) directions. Post-hoc analysis showed 1st interval significantly higher than 2nd and 3rd intervals. Also 3rd interval significantly higher than 2nd interval for both A-P and M-L directions.

There was no significant interval by groups interaction effect in either A-P (p=.825, figure 6.3.a) or M-L direction (p=.234, figure 6.3b) indicating that between groups differences were not apparent dependent upon time interval. Therefore, it was deemed appropriate to analyse the whole 30 seconds time interval, which is in line with much of the previously published research in this area.

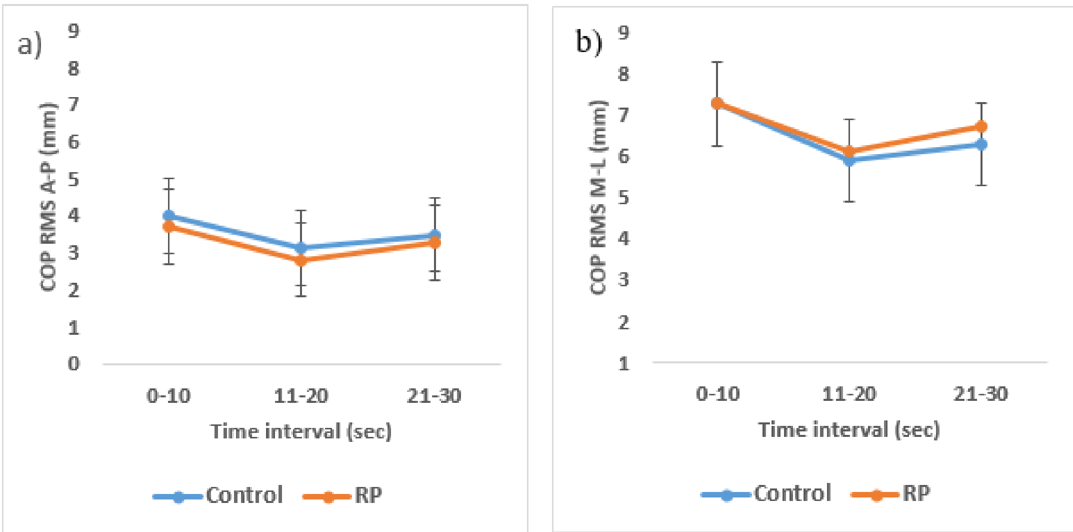

Figure 6.3.Trials condition means (±SE), (EO, EC, FEO and FEC) RMS values for the 3, 10 second intervals in both A-P (a) and M-L (b) direction. There were no significant differences between the two groups (Control and RP) in either direction.

6.4.3 Sensory contribution to balance

6.4.3.1 A-P direction

There was no significant main effect between the groups in RMS A-P direction ($p=.565$). There was a main effect of vision and surface in A-P direction ($p<.001$). Standing on foam resulted in significantly higher postural instability (4.65±1.58mm) compared to firm (1.14±1.06mm). Eyes closed resulted in significantly higher postural instability compared to eyes open (Table 6.1). There was no significant 3 way surface by vision by group interaction in RMS A-P direction ($p=.261$).

6.4.3.2 M-L direction

There was no significant main effect between the groups for RMS in M-L direction ($p=.631$). There was a main effect of vision and surface in M-L RMS ($p<.001$). Standing on foam resulted in significantly higher postural instability (8.68±2.13mm) compared to firm (4.91±1.81mm). Eyes closed resulted in significantly higher postural instability compared to eyes open (Table 6.1). There was a significant vision by group interaction in M-L direction, ($p<.001$). Participants with normal vision showed significantly higher postural instability compared to RP with their eyes closed only ($p<.029$, table 6.1).

Table 6.1. Mean ± SD RMS data (mm) of the centre of pressure signal for control and RP. Mean ± SD RMS data (mm) of the centre of pressure signal for control and RP. Data are shown for the anterior-posterior (A-P) and medial-lateral (M-L) direction for four conditions of measurement; Eyes open (EO), eyes closed (EC), standing on foam with eyes open (FEO) and standing on foam with eyes closed (FEC).Higher values indicate increase instability.

	A-P RMS (mm)		***M-L RMS (mm)***	
	Control	**RP**	**Control**	**RP**
EO	2.20±1.26	1.14±0.06	4.53±1.60	4.91±1.81
EC	2.41±1.16	2.17±0.99	5.76±2.16	4.83±1.65
FEO	3.69±1.15	4.65±1.58	6.99±2.03	8.68±2.13
FEC	5.02±1.37	5.33±2.14	10.34±1.90	9.04±1.91

There was a significant 3 way interaction between surface, vision and groups in M-L direction (p=.007).

Participants with normal vision showed (Figure 6.4a and 6.4b) significantly higher postural instability when they have their eyes closed compared to open on both firm and foam surfaces (p<.001). However, those with RP showed significantly higher postural instability only on foam surface (p<.034) when they had their eyes closed compared to open. There was no significant difference between the groups in both eyes open and eyes closed conditions on firm surface. However, those with RP had significantly higher postural instability compared to visual normals while standing on foam only with their eyes open (p<.049, figure 5.a).

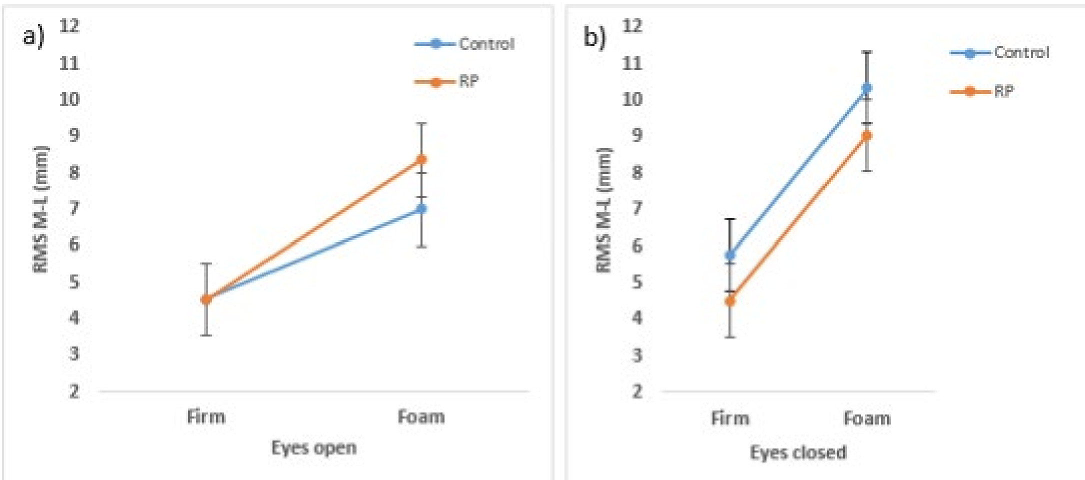

Figure 6.4. Group mean (±SE) RMS values only in M-L direction at both surfaces for both eye conditions [Eyes open, (a) and eyes closed (b)] within the groups. Significant difference between the groups, with normal sway more with EC compared to EO on both surfaces. RP only sway more with EC compared to EO only on foam. Also, RP sway more compared to control with EO on foam (P<0.05).

6.4.4 Visual and Somatosensory contribution to balance

There was no significant main effect of RQ values between the groups in A-P direction (p=.506). This indicated both groups had a similar visual contribution to postural stability (balance control).

There was a significant main effect of RQ values between the groups in M-L direction (p=.017). Visual normals had higher RQ (RP=1.27) compared to those with RP

(RQ=1.06), indicating those with RP had a reduced visual contribution to balance compared to visual normals. The results were opposite when considering the somatosensory disturbance, with RP having higher RQ (RQ=0.92) compared to visual normals group (RQ=0.67). This result indicates that those with RP have higher somatosensory contribution to balance compared to visual normals.

6.4.5 Disease duration impact on Postural stability of those with RP

To obtain the correlation between the years with RP of participants and the postural stability, the RMS values were averaged across for both conditions (EO, EC, with and without foam) and the repetition of the trials. Figure 6.5 shows this correlation analysis for the postural stability in A-P direction. The correlation coefficient is almost zero ($R^2 = 0.0068$), representing no correlation between the two variables. This means that the years with RP has no significant effect ($p>0.05$), on the RMS values in A-P direction.

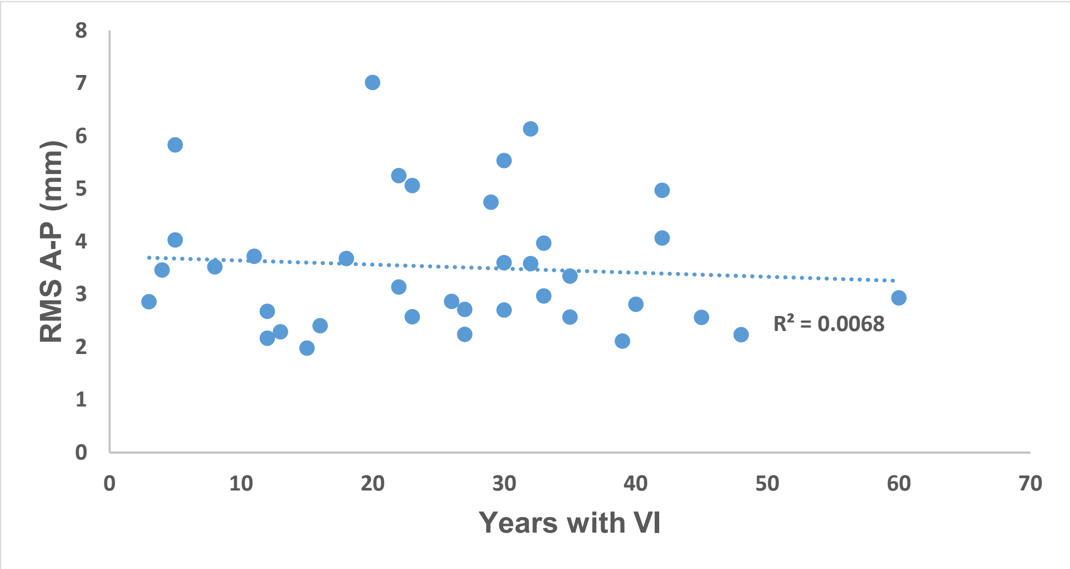

Figure 6.5. Correlation plot of years with RP (X axis) against the RMS (mm) in A-P direction. Although there is a slight tendency of negative correlation, the result is not significant.

Similar to the A-P direction, the correlation for the M-L direction is not significant. Figure 6.6 shows this correlation analysis for the postural stability in M-L direction. The correlation coefficient is almost zero ($R^2 = 0.0025$), representing no correlation between the two variables. This means that the years with RP has no significant effect ($p>0.05$), on the RMS values in M-L direction.

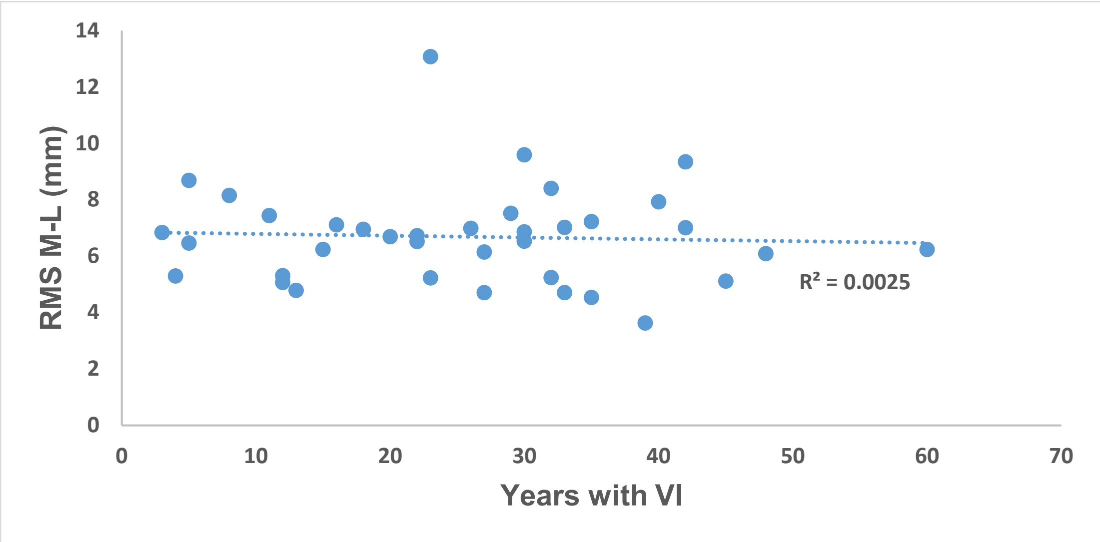

Figure 6.6. Correlation plot of years with RP (X axis) against the RMS (mm) in M-L direction. Although there is a slight tendency of negative correlation, the result is not significant.

6.5 Discussion

Falls are a major concern and often cause significant injury, especially among the visually impaired. Whilst a clear link has been shown between postural stability and falls (Turano et al., 1993), there is little research examining the complex sensory interaction with maintaining balance among people with RP. Furthermore, aspects such as number of trials or length of time standing are yet to be considered for those with visual impairment. Findings from the present study indicate despite individuals with RP having degraded vision, postural control was similar to those with normal vision when standing on a firm surface in both eyes open and eyes closed conditions. However, when standing on foam surface with eyes open, the reduction in postural control (in M-L direction) among people with RP compared to visual normal highlights the added importance of somatosensory information in maintaining standing balance in this population group. Furthermore, despite people with RP having degraded vision, the reduction in postural stability control when standing on foam with eyes closed compared to eyes open highlights that vision still plays a role in maintaining standing balance among this population group, but it was only apparent when somatosensory information was disturbed. Findings also demonstrate that that the number of trial repeats had no significant effect on postural stability among either RP or visual normal. Furthermore, whilst significant differences were observed between time intervals, no significant between group differences were observed.

6.5.1 Sensory contribution to maintaining balance

Findings in the current study confirm the importance of the visual system in maintaining postural stability among those with normal vision. Indeed, the increase in postural sway in eyes open (A-P, 2.94±1.20mm, M-L, 5.76±1.81mm) compared to eyes closed (A-P, 3.71±1.26mm, M-L, 8.05±2.03mm) in both firm and foam surfaces, in addition to RQ values (A-P, 1.26mm, M-L, 1.39mm) support findings published previously (Turano et al., 1993; Terrier and Reynard, 2017) that vision is the dominant sense for maintaining stability among visual normals. When standing on a firm surface, RP group had no significant difference in M-L RMS in eyes open (4.52±1.86) compared to eyes closed (4.83±1.65). The degradation in performance when standing on foam vs firm in RP, (6.99±2.03 vs. 4.53±1.60) with eyes open compared to visual normal in addition to RQ, suggests that somatosensory becomes the dominant sense compared to vision. Of interest in the current study is that when standing on the firm surface, despite the reduced vision (RP group), they were able to maintain postural stability in a comparable manner to the visual normal group. It was only when standing on the foam surface (when somatosensory was disturbed) that changes in performance (increased instability) was observed. The finding demonstrates the maintaining appropriate foot health in VI group, which is seen to deteriorate with age (Stoddart et al., 2002; Muchna et al., 2018) and wearing appropriate footwear that can support them during mobility tasks such as orientation both indoors and outdoors.

Findings from the current study also demonstrate that vision is still important to those with RP as the postural instability increases when standing on firm surface with eyes closed compared to eyes open. However, this change is only significantly different and evident when the somatosensory system is disturbed. Implication for maintaining postural stability has been similarly shown by Turano et al. (1993) who showed that, when somatosensory was disturbed it marginally changed postural stability in RP group (RMS values of 1.19 for light room, 0.96 for dark room). The current study shows similar findings, albeit in different direction of sway to Turano et al. (1993). A potential explanation for the differences in findings between Turano et al. (1993) and the current study in relation to sway direction are offered below.

Since Turano et al. (1993) did not examine M-L sway direction, a direct comparison is not possible in this direction, but only in A-P direction. The current study also standardized the stance where, predefined lines were in place for participants to stand on, which was orientated at an angle of 15º between the long axes of feet reflecting the natural standing position (McIlory and Maki, 1996). Turano et al. (1993) did not standardise foot position in their study, standardizing foot positioning angle in this way could have reduced natural joint flexion in the A-P direction. The normal A-P body sway that results in inflection at the ankle joint is an aspect that Turano defined as a reliable somatosensory cue to postural instability and could be the cause of the difference results in the A-P directions between the studies.

As it has been described, those with RP have limited vision and they may have demonstrated increased reliance on other sensory systems (somatosensory) to regulate balance, whereas those with normal vision did not. The importance of the somatosensory system among those with RP was shown when both groups had their eyes closed, the normal vision group had higher postural instability on both surfaces (firm and foam) compared to eyes open. However, those with RP showed higher postural instability (eyes closed compared to eyes open) only on foam. Again, those with RP relied on the somatosensory system when vision was disturbed but when both sensory information were disturbed they showed reduced ability to control their balance. The critical role of the somatosensory system in balance control was highlighted for those with visual field loss (RP), which is consistent with previous studies by Berencsi et al. (2005) and Kotecha et al. (2013) which assessed other types of VI.

The effect of vision in controlling balance for those with RP has been shown in the current study as important but only demonstrated when the somatosensory system was disturbed. As RP is a progressive disease and vision deteriorates with time, it could be argued that those with RP have time to compensate for their loss of vision by using other senses (vestibular and somatosensory) to control their postural stability. The compensation finding from this study is consistent with previous research by Horvat et al. (2003) who reported the importance of the somatosensory system for those with VI during a postural stability testing. This implicates the attention and foot health care required for those with RP.

The result from RQ, suggested that those with RP had reduced visual contribution to balance compared to visual normals in M-L direction only. Shabana et al. (2005) reported similar result using Glaucoma patients; it was reported that visual contribution is significantly lower to postural stability for those with Glaucoma compared to normally sighted individuals. Those with RP indicated higher somatosensory contribution to balance compared to visual normals again in M-L direction. This shows that those with RP rely on their somatosensory sense more than their vision to control their balance; this could be as a result of very limited vision available to them because of their condition.

Higher postural instability across all participants was also present in A-P direction when the vision and somatosensory was disturbed. Again, this result could have been anticipated across both groups as when the main senses that controls balance is disturbed postural instability increases. There was a lack of significant interactions for A-P direction. In the current study the majority of significant results were in M-L direction rather than A-P. Moreover, in the current study, the RMS values in M-L were larger than A-P. This emphasises the importance of M-L movements for individuals with RP as most of the falls occur in the sideways direction causing hip fractures (Greenspan et al., 1998).

Kotecha et al. (2012) reported lower visual and higher somatosensory contribution to sway for those with Glaucoma compared to their control group in A-P direction, where they examined postural stability of Glaucoma patients. However, Kotecha et al. (2012) used participants with Glaucoma who are commonly known to have a better vision than those with RP (the visual acuity measurements in their study was -0.08 to 0.08 LogMAR, compared to the current study with 0.76±0.63 LogMAR). Such difference in visual acuity could lead to inconsistency in findings between Kotecha et al. (2012) and the current study.

One important factor that this study did not examine was dual tasking while investigating postural stability. Most of the daily tasks which require postural stability include other activities such as talking, and it has been suggested falls can be increased when postural stability is combined with other activities simultaneously (Veghese et al., 2002). Kotecha et al. (2013) investigated dual tasking and balance of those visually impaired. They reported a greater risk of falls for the elderly as a result of adding an extra task to balance control. Their participants included those with peripheral loss (Glaucoma) and they showed higher postural instability with the secondary task under somatosensory perturbation. Once more the importance of somatosensory for those with peripheral loss was highlighted. This study could have benefited from investigating the effect of a secondary task while balance was tested.

6.5.2 Repetition effect

In the current study, there was no significant change in RMS values (in A-P and M-L) across the three trial repeats (figure 6.1). These results support previous research by Tarantola et al. (1997) where postural stability of 12 normal subjects were examined through 4 (vision and stance) conditions. Their results showed no significant differences between the repetition of 10 trials body sway in eyes open but there was in eyes closed condition (Tarantola et al., 1997). Whilst recommendations published by Ruhe et al. (2010) suggested that 3 trial repeats are sufficient for collecting postural stability data, results from the current study in combination with the work of Tarantola et al. 1997 suggest that one trial may be suitable to provide insight into an individual's balance. This may have important implication for clinical practitioners or falls prevention officers involved with the assessments of postural stability due to the obvious time saving benefits needing to test only once. It is relevant to note that previous research did find significant differences between trial repeats (Paterka et al., 2004; Zanetti et al., 2007; O'Connor et al., 2008; Bonnet et al., 2012). It could be argued that currently more research in this area is needed for different type of visual impairment to investigate if there are any significant differences between trial repeats.

6.5.3 Interval analysis

In the current study, all participants recorded higher levels of postural instability in the first compared to second and third interval (figure 6.2). The first interval or the initial time has been reported as the crucial time as recent studies have suggested a short instability before participant regains baseline balance control (Rabuffetti et al., 2011). This may suggest that participants were not 'ready' when the test was conducted and for this reason had led some researchers to exclude the first 5 seconds of postural stability data from the study (e.g. Turano et al., 1993). However, in the current study, participants initially stood on the force plate and were asked to verbally confirm that they were ready for the test to begin prior to data being collected. This typically took between 10-30 seconds. Taylor et al. (2015) reported significant reduction in sway and significantly slower sway when participants stood on the force plate for 30 seconds before the data was collected. Carroll and Freeman (1993) reported that postural stabilised after 20 seconds of data collection, however, our results highlighted participants show higher sway in the third interval (figure 3) compared to the second. Furthermore, with the significant increase in RMS between the third and second interval, this also indicated that the initial increase in RMS in the first interval was not simply due to participants not being ready for the test.

Previous research has shown that postural stability values vary by sample duration (Le Clair and Riach, 1996; Carpenter et al., 2000). Carpenter et al. (2000) examined postural stability of 49 participants who stood during three consecutive 120 second trials and each trial was subdivided into 15, 30, 60 and 120 second samples. They reported a significant influence on RMS by sample duration in both A-P and M-L direction. However, their results highlighted significant lower RMS (lower postural instability) values over the first 15 seconds than all the other durations in A-P direction and significantly lower compared to 120 seconds sample in M-L direction. Le Clair and Riach (1996) examined postural stability of 25 young healthy individuals for five different test durations (10, 20, 30, 45 and 60 seconds). They reported an increase of standard deviation of ground reaction forces in both CPx and CPy with an increase in duration. However, standard deviation to the mean force for Fx and Fy measurements of 10 seconds were different (higher) from 20 seconds or more. Also, it was during the first 10 seconds the highest average velocity occurred. Importantly, there were no between group differences observed in the study or group-by-interval interaction (Figure 6.3). This result indicates people with RP maintained their balance similar to normally sighted individuals within the different time interval of postural stability.

6.6 Strengths and limitations

This experimental chapter was designed on the bases of the findings from the previous chapter, where orientation for those with RP were highlighted as the most difficult ADLs. Indeed, the result of this chapter indicated that those with RP are capable of having similar postural stability to those normally sighted apart from when the somatosensory system is disturbed. Hence, an additional question could be included in future studies using SRQs to distinguish between different surfaces (unstable and firm) for orientation and mobility tasks. Indeed, it still remains unclear whether the self-reported difficulties highlighted in the previous chapter are linked to when those with RP feel less stable or reflects attitudes not linked to balance/postural control. This requires further investigation.

To increase the number of data set, this experiment used a unique methodology, where the data was collected at different venues across the UK. However, this made standardising the protocol more difficult.

The Damato campimeter did not perform as anticipated and the visual field assessments were not as detailed as one can be done by the Humphrey field. This limited analysis which could be undertaken regarding visual field loss and postural stability. Moreover, the visual field results from this study limited the potential to examine the differences within the RP group based on visual impairment level.

Although, for the purpose of this study only two (vision and somatosensory) of the sensory systems were examined, one recognised limitation is the absence of including the vestibular system as a tested condition; especially due to the hearing/balance implications some individuals with RP experience. However, in the current study, disturbing the vestibular system was deliberately avoided due to the safety implications and added risk of becoming unstable and falling when all three systems were disturbed. If this was to be attempted in the future, a safety harness would be recommended, which was not available at the various venues tested throughout the UK.

6.7 Conclusion

Those with RP showed similar postural stability control to those with normal vision on the firm surface regardless of the vision condition. However, the importance of the somatosensory system was emphasised when compared to those with normal vision; those with RP showed reduction of postural control with their eyes open while standing on the foam surface.

The reduced visual contribution to balance for those with RP emphasises the importance of the somatosensory system. This study highlighted that those with RP use somatosensory to control balance to greater extent than normally sighted individuals. Thus, implications can be made for the importance of maintaining adequate foot health within this population. Furthermore, vision, even degraded for those with RP was shown to have an important role in balance control. This was highlighted when postural instability increased among those with RP with their eyes closed compared to eyes open while somatosensory was disturbed.

These findings have important implications for clinicians ensuring both visual and somatosensory senses are cared for among people with RP. Suitable footwear can be offered to those with RP, which can benefit their gait and posture as the result of this chapter highlighted the importance of somatosensory system in such tasks. In addition, suitable flooring of care homes and rehabilitation facilities can also help those with RP in terms of postural control. The lack of between group difference in both repetition effect and interval analysis, suggest that those with RP had similar balance control to those visual normals during repeated trials and during time intervals. Perhaps more investigations are needed in other visually impaired groups to determine if the other visual impairments perform in the same pattern.

7. Level walking and obstacle crossing of those with RP

7.1 Introduction

The results of chapter 4 showed that for those with RP, mobility was one of the most difficult ADLs to complete at goal level. This was further investigated in chapter 5 at task level, where walking around safely without bumping into, tripping over, or stepping off something was self-reported as the most difficult ADLs to complete for those with RP.

With postural control being a fundamental aspect of successful orientation and mobility, chapter 6 considered whether this is different in RP compared to visual normals and contributing factors to self-reported differences previously highlighted. Although in chapter 5 those with RP self-reported orientation as one of the most difficult tasks, results from chapter 6 demonstrated that those with RP were able to regulate balance in a comparable manner to those with normal vision when standing on a firm surface. However, postural stability within the RP group deteriorated when standing in more unstable situations, specifically when somatosensory information was disrupted. Whilst inconclusive, results from the previous experimental chapter suggest that postural control was not the main factor resulting in greater self-reported difficulties with orientation and mobility.

The SRQs in chapters 4 and 5 have provided valuable insight about the difficulties those with RP face in completing ADLs, however, there are some limitations with the amount of detailed information that could be gained. For example, avoiding peripheral obstacles was reported difficult to complete but the results don't specify what actual aspects of the task are difficult. For instance, when negotiating a floor based obstacle, would this be identifying the location (for-aft position) of the obstacle, slowing down once approaching the obstacle or avoiding tripping on the obstacle when stepping over with the lead or the trail foot? Thus, the need of the quantitative assessments of the adaptive gait (obstacle crossing) is required.

It has been shown that those with VI generally adopt a more cautious walking behaviour when compared to those who are normally sighted. For example, Spaulding et al. (1994), reported slower walking velocity of individuals with age-related maculopathy (ARM) compared to normally sighted individuals. These adaptations were used to prevent tripping over a surface edge or slipping at heel contact. Timmis and Pardhan (2012), reported that when compared to those with normal vision, those with central field loss lifted their lead and trail feet significantly higher and reduced horizontal crossing velocity when negotiating an obstacle and also increased head flexion to look down, these are all established as cautious strategies to prevent falls. Turano et al. (1999), also reported that people with Glaucoma walk slower than those with normal sight. Slower walking velocity allows more time to monitor and respond appropriately to possible changes to the environment (England and Granata, 2007). However, it can be argued that the longer time of the swing could actually generate more unbalance as they have to be on one foot for longer (Hak et al., 2012). Hak et al. reported that step length adaptation (shorter steps) is an important aspect in decreasing the probability of falling and it is used as a safety strategy.

One of the categories used in the analysis of the self-report questionnaires (chapter 4 and 5) was the usage of mobility aids and comparisons were made in regards to specific ADLs between those who used mobility aids to those who did not (see 4.4.4 and 5.4.2.2). Moreover, in chapter 4 it was highlighted that those who do use mobility aids find mobility significantly more difficult compared to those who don’t use mobility aids. Whilst, this result was further investigated, differences in perceived difficulty were associated with detecting and avoiding ‘overhanging things’; something that a mobility aid does not provide assistance in detecting. Of note, only a trend (p=.07) of difficulty for those using mobility aids compared to those who did not was identified for 'walking around safely without bumping into, tripping over or stepping off something'. Collectively, these findings suggest that the use of mobility aid improves the perception of being able to identify and negotiate floor based hazards among those with RP.

A mobility cane is the most commonly used device by individuals with VI (LaGrow and Weessies, 1994). The contact strategy (contacting an object such as an obstacle with a cane) is an auditory and/or the somatosensory feedback from touching the object with the cane that helps those with VI identify obstacles and hazards while walking. However, the knowledge in terms of the research for mobility cane usage in terms of benefits of using a cane for those with VI is scarce. Johnson et al. (1998) who examined the cane techniques used by individuals with VI reported that the techniques may not provide sufficient protection for those with VI.

Timmis et al. (2017) added the study by Geruschat et al. (2006) and showed that people with RP have a more active visual search pattern, where more scanning (looking at) of areas on the ground takes place both at level walking and obstacle crossing. Moreover, the study found that those with RP reduced the time looking ahead to increase the time looking down. The different visual search behaviour could be as the result of the restricted VF and the inability to rely on the peripheral visual field that is needed to gather information about the environment. Having said that, the research by Timmis et al. (2017) only focused on visual search of those with RP and to the author's knowledge, no previous study has examined obstacle crossing strategies of those with RP. Therefore, despite those with RP self-reporting difficulties with mobility, it is unclear whether the adaptive strategies in visual search behaviour result in those with RP adopting a similar walking pattern compared to those with normal vision.

7.2 Aim

The current experimental chapter was designed to investigate whether the self-reported difficulties with mobility (identified in chapters 4 and 5) manifested in changes in walking gait among those with RP. Specifically negotiating an obstacle placed on the travel path was compared among RP and individuals with normal vision. The chapter also compared the gait of those with RP and normally sighted individuals at level walking (no obstacle present). Furthermore the effect of using a mobility cane will be compared to those who did not use the mobility cane.

7.3 Methods

Much of the methodology used in this chapter has been discussed in the general methods (chapter 3), however, the necessary details are further discussed in this chapter.

7.3.1 Participants

The recruitment of those with RP was similar to the previous experiments (see general method chapter 3.5). Eighteen participants with RP and sixteen normally sighted individuals took part in this experiment. Those with RP were divided into those who used a mobility cane (RPC) (n=6) and those who did not (RP) (n=12).

The normally sighted group (9 female, 7 male) had mean (±SD) age of 43±16 years, mass of 68±14 kg and height of 170±11 cm. The RP group (5 female, 7 male) had mean (±SD) age of 58±15 years, mass of 77±14 kg and height of 168±9 cm and the RPC group (2 female, 4 male) had mean (±SD) age of 45±20 years, mass of 78±11 kg and height of 169±12 cm. Average years with VI for RP group and RPC group were, 29±14 and 27±11 years, respectively. The RPC group used the cane for 7±4 years on average and were all registered as severely sight impaired. Those in the RP group had 6 people registered as severely sight impaired, 3 people as sight impaired and 3 not registered. Participants also reported if they had fallen in the last year or if they have fear of falling. Table 7.1 demonstrates all the demographic information of the participants.

All participants were independently mobile, meaning they could walk on their own without any support from any other individual. The habitual testing trials of those in the RPC group was considered as when they used their canes. Participants, according to self-report, had no musculoskeletal, neurological or cardiovascular disorders which would have influenced walking gait. Exclusion criteria are the same as the previous chapter which have been described in the general method chapter (see 3.2).

The tenets of Declaration of Helsinki were observed and the University's ethical committee approved the study (see appendix 3). Written consent forms were obtained from each participant prior to data collection (see appendix 6).

Table 7.1. The demographic details of participants and all participants' visual assessment results. Duration of visual impairment are given in years.

Participant	Gender	Age (Years)	Weight (Kg)	Height (Cm)	Years with VI (Years with Cane)	CS (Log)	VA (LogMAR)	VF (Degree)
RP 1	M	73	80	174	40	0.2	1.20	5
RP 2	M	70	70	166	60	0.4	0.60	6
RP 3	F	64	64	162	40	0.36	1.80	11
RP 4	F	45	91	168	24	2	0	3
RP 5	F	70	63	160	13	0.14	1.05	50
RP 6	M	42	66	173	25	0.08	1.65	48
RP 7	M	69	103	185	13	0	1.65	48
RP 8	F	56	59	148	30	1.1	0.45	40
RP 9	F	65	73	168	50	0.84	0.60	12
RP 10	M	31	94	178	20	0.16	1.65	32
RP 11	M	48	92	175	26	0.06	1.65	50
RP 12	M	50	72	169	18	-0.02	1.65	35
RPC 1	M	25	66	164	10 (9)	2	0	5
RPC 2	F	30	85	148	26 (6)	1.24	0.45	10
RPC 3	M	73	72	173	42 (15)	1.3	0.15	6
RPC 4	F	81	74	160	25 (4)	0.7	0.75	58
RPC 5	M	27	76	178	20 (1)	0.1	1.50	41
RPC 6	M	53	98	185	40 (7)	0.8	0.30	12
Norm 1	F	41	48	156	NA	-0.16	1.95	60
Norm 2	M	35	87	182	NA	-0.14	1.95	62
Norm 3	F	27	64	159	NA	-0.18	1.95	60
Norm 4	M	68	91	174	NA	-0.04	1.65	58
Norm 5	F	44	53	153	NA	-0.24	1.95	63
Norm 6	F	35	51	161	NA	-0.26	2.10	63
Norm 7	F	44	61	167	Na	-0.12	1.80	63
Norm 8	M	69	78	184	NA	0.1	1.65	63
Norm 9	F	54	77	162	NA	0	1.65	62
Norm 10	M	35	62	170	NA	-0.16	1.95	62
Norm 11	M	38	79	180	NA	-0.22	2.10	63

Norm 12	F	78	64	168	NA	0.1	1.35	62
Norm 13	F	28	58	170	NA	-0.12	1.95	63
Norm 14	M	28	65	177	NA	-0.08	1.65	62
Norm 15	M	20	96	194	NA	-0.18	1.80	63
Norm 16	F	49	60	164	NA	-0.14	1.95	63
RP (mean±SD)	NA	58±15	77±14	168±9	29±14 (NA)	1.17±0.59	0.43±0.59	32±20
RPC (mean±SD)	NA	45±20	78±11	169±12	27±11 (7)	0.50±0.53	1.04±0.63	14±13
Norm (mean±SD)	NA	43±16	68±14	170±11	NA	1.83±0.20	0.11±0.10	61±1

7.3.2 Visual assessments

As both eyes are used to acquire visual information during walking gait all visual assessments were completed binocularly. All participants were tested wearing their habitual distance prescription during the visual assessments and the gait assessment. Those that did not wear glasses for their normal daily activities did not wear them during testing. Visual acuity (VA) and contrast sensitivity (CS) were assessed as reported in general method chapter (see 3.3.4).

To assess the visual field of the participants the Humphrey visual field analyzer was used (see general chapter 3.7). Standard 45 kinetic (automatic) test was used and completed binocularly. Visual field of each participant was calculated by averaging the point (in degrees) when they saw the light for all 12 meridians.

The normally sighted group had mean±SD CS of 1.83±.0.20 LogMAR, VA of -0.11±0.10 Log and VF of 61±1 degrees. The RP group had mean CS of 1.17±0.59 LogMAR, VA of 0.43±0.59 Log and VF of 32±20, and RPC group had CS of 0.5±0.53 LogMAR, VA of 1.04±0.63 and VF of 14±13 degrees. Table 7.1 demonstrates all the visual assessments of the participants.

7.3.3 Protocol

All participants were given an information sheet (see appendix 5) prior to the testing day. Once arrived at the University, they were briefed about the study. General health and physical fitness of all participants was assessed through a self-report questionnaire. Based on the result of the second experiment (chapter 5), 14 questions were asked from all participants to investigate the difficulty level of the tasks. These were selected as they were shown to be the most difficult activities at task level to complete for those with RP. For each question, participants responded on a 6-point Likert scale. 0 indicated that task was not important or not applicable to the participant, a score of 1 indicated that the task was impossible without help, 2 was extremely difficult, 3 was moderately difficult, 4 was slightly difficult, and 5 was not difficult. The same method as those in chapter 4 and 5 were used in this chapter.

Participants undertook repeated level walking without and with obstacles of two different heights 3 and 10 cm. The trials were changed randomly, with three trials collected at each condition, for a total of 9 trials. Illumination over the trials were set at ~500 lux (taken at 170 cm above the floor). In the obstacle crossing trials, participants were required to negotiate an obstacle, those using the mobility cane were tested with their cane. If there was a contact of the foot to the obstacle, that trial was not included in the subsequent analysis and instead was repeated. Hence, only successful obstacle negotiations were used for data analysis. Overall, six trials were repeated where those in the RPC group hit the obstacles with their feet. Obstacle contacts with cane were counted as normal as this is a strategy used by cane users to identify different objects on their walking path such as an obstacle, which helps during an adaptive gait.

The distance between the floor and both toe and heel (vertical) distance of participant's markers were measured (with shoes on) while standing stationary, this was collected to determine if there was a difference in vertical marker location between groups; footwear could differ among participants. A static calibration trial was taken prior to the data collection to help enabling the virtual markers being calculated. Participants were told about the duration of testing but were not informed about the number of trials or if there will be an obstacle to negotiate or not. The order of the visual and gait testing was fully randomised, hence some participants did the visual assessments first and vice versa. Figure 7.1 demonstrates a participant (RPC) prior, during and post obstacle crossing.

Figure 7.1. A participant (RPC) during one of the obstacle crossing trials. The figure demonstrates safety procedures such as taping the cables down to eliminate any potential incidents.

The lab was set up for an unobstructed walk (no obstacles present in the path) and an obstacle crossing task for the participants. The walking path was 10 m in length and 1.6 m wide, however individuals started approximately 2 m prior to the starting line. Hence, the starting position was between 10.5 to 12 m. This was to randomize the start position such that participants did not adopt a repeated motor strategy from simply walking up to the obstacle positioned at the same distance. The walking path was set approximately in the middle of the research lab with dimensions of 30 m length, 9 m wide and 7 m high. The edge of the path was lined with timber 3 cm high and 1.8 cm wide and was placed to replicate the height of a low curb. Those individuals using the mobility cane would be alerted when hitting the timber of the paths' route. Electronic light gates (Smart-Speed, Fusion Sport, Australia) were positioned at the start and at the end of the walkway. When participants walked past the light gate station, a single noise was heard to denote the timer starting. A similar noise was emitted at the end of the path which marked the end of the time trial. Obstacles were made out of medium density fibreboard (MDF) with 60 cm long, 4 cm wide, 3 and 10 cm in height, placed in the middle of the walking path by the 5m marker. This was the midpoint of the testing path, chosen as it had the best marker visibility by the Coda cameras. Participants were familiarised with the path and explained the procedure before the testing begun, however no participants practiced negotiating the obstacles.

Kinematics data were collected at 100Hz using three dimensional motion capture camera system (Codamotion movement analysis system: Charnwood dynamics Ltd, UK). The cameras were set on tri-pods. The positions of the cameras were designed that the obstacle crossing movement can be captured at the highest visibility. The motion capture camera system was calibrated so that the axis (direction) of movement could be set prior to each data collection session.

Active markers were attached bilaterally to the participants. Overall 20 markers were used in this study, which were placed at locations described as following. For each foot: superior of the fist toe, superior aspect of the second toe, lateral malleoli, lateral inferior to the malleoli (which was used to create a virtual marker for calcaneus, see 3.4.6), and the lateral tibia marker which was place half distance between knee and ankle. Markers for the head were placed on a headband and marker positions were on lateral of the sagittal plane: anterior right, anterior left, posterior right and posterior left of the head. There were also 2 markers attached on the top edge of the obstacles. Two markers were attached to the cane (if used), in the middle of the cane separated by 10-15cm. The markers served to create one virtual marker at the bottom (distal) end of the cane. The virtual marker for the cane was in place as markers could not be attached at the bottom of the cane as they were in contact with the ground and would have been detached with the contacts made by individuals during the trials.

Prior to data collection, participants were briefed that they need to walk along a predefined path which may or may not include an obstacle to be negotiated. At the starting position, they were told to face the opposite direction of the (walking) path so they could not see if there was an obstacle placed or not prior to the start. The trial started with the verbal command 'go', after which participants were instructed to turn around and complete the walk path at their own comfortable speed. No information about the position of the obstacles were given prior to the trials. Once reaching the end of the walkway, they were instructed to continue walking on a loop back to the start position and get ready for the next trial. The data were only collected in one direction and stopped when participants crossed the 10m mark.

7.3.4 Data analysis

The time duration from all trials which were taken from light gates were transferred into SPSS sheets and used in the analysis. The filtered kinematics data (the filtering technique can be found in general method chapter 3.8) were transferred to MACRO programme to determine the following dependent variables. Of note, lead and trail foot-off were defined as the instant the resultant vertical and anterior-posterior velocity of each foot's toe marker first increased greater than 200 mm/s for 5 consecutive frame following the period of zero velocity when the foot was planted on the floor.

7.3.4.1 Dependant variables for obstacle crossing

1. **Lead vertical toe clearance** - vertical distance of lead toe to the top of the obstacle.
2. **Trail vertical toe clearance** - vertical distance of trail toe to the top of the obstacle.
3. **Lead horizontal toe velocity** – horizontal velocity of the toe of the lead foot at mid-point.

4. **Trail horizontal toe velocity** – horizontal velocity of the toe of the trail foot at mid-point.
5. **Double support time (DS) 1** – time from the final foot contact on the ground to lead foot toe-off as it is lifted to cross the obstacle.
6. **DS time lead foot 2–** time from the lead foot contact on the floor after crossing the obstacle to toe off before crossing.
7. **Single support lead foot (SS) 1** – time spent during obstacle crossing whereby only the trail foot in contact with the ground.
8. **SS trail foot 2** - time spent during obstacle crossing whereby only the lead foot in contact with the ground.
9. **Penultimate step length** - horizontal distance between the lead and trail toe during double support prior to the toe off of lead to negotiate the obstacle (A in figure 7.2).
10. **Final foot placement** – horizontal distance between the toe of the trail foot and obstacle (B in figure 7.2).
11. **Lead foot placement** – horizontal distance between the toe of the lead foot and the obstacle post crossing (C in figure 7.2).
12. **Trail foot placement** - horizontal distance between the toe of the trail foot and the obstacle post crossing (D in figure 7.2).
13. **Step width** – medial-lateral distance between the lead and trail heel during double support.

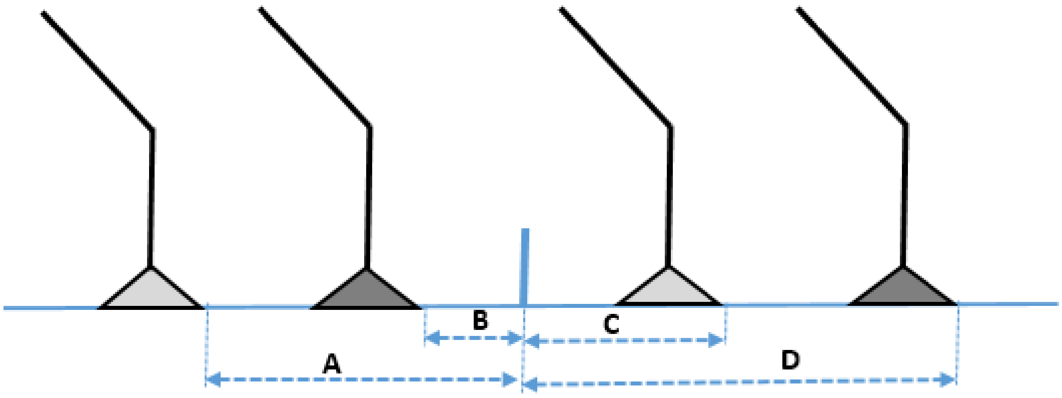

Figure 7.2. Diagrammatic illustration of foot placement parameters for the lead (light grey) and trail foot (dark grey). A is defined as penultimate foot, B as final foot placement, C as lead foot placement and D as trail foot placement.

7.3.4.2 Dependant variables for walking

In addition to DS, SS and toe velocity of both feet variables that were included in the obstacle crossing, the following variables were included for the walking trials:

1. **Minimum lead foot clearance** – vertical distance between the toe (lead) and floor at peak maximum horizontal velocity of the foot during the swing.
2. **Minimum trail foot clearance** - vertical distance between the toe (trail) and floor at peak maximum horizontal velocity of the foot during the swing.
3. **Stride lead foot length** - horizontal distance between the lead toe during DS of a full stride (A in figure 7.3).
4. **Stride trail foot length** - horizontal distance between the trail toe during DS of a full stride (B in figure 7.3).
5. **Step length** - horizontal distance between the toe of the lead and trail during DS of a full step (C in figure 7.3).

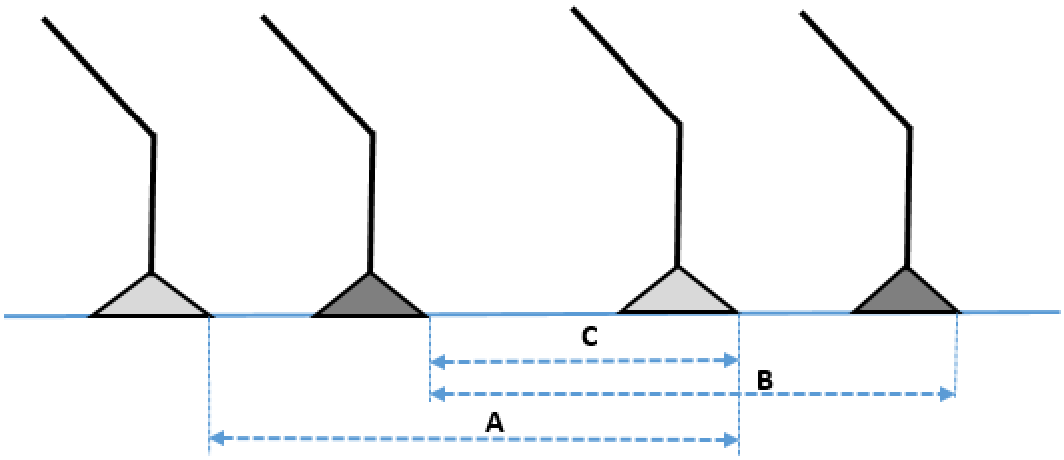

Figure 7.3. Diagrammatic illustration of foot placement parameters for the lead (light grey) and trail foot (dark grey). A is defined as stride lead length, B as stride trail length and C as step length.

7.3.5 Statistical analysis

Both walking and obstacle crossing data were analysed across the three groups (normal, RP and RPC). For each group three trial repetitions and with obstacle crossing data two obstacle heights were analysed using independent repeated ANOVA test.

The questionnaire data that were collected separate to the kinematics data, were analysed using a nonparametric test of Kruskal-Wallis between the three groups. The post hoc analysis between the groups used was Mann-Whitney U. Level of significance was accepted at $p<.05$ and post hoc analyses, where appropriate, were performed using Tukey multiple range. Data were analysed using SPSS software (version 22).

7.4 Results

7.4.1 Demographics

There were no significant main effect of age, weight or height across the groups (p>.05). There were significant differences between the groups in their visual assessments (CS, VA and VF) results. The normally sighted group had significantly better results in all the assessments (CS, 1.83±0.20 logCS, VA, 0.11±0.10 logMAR, VF, 61±1 deg) compared to RP (CS, 1.17±0.59, VA, 0.43±0.59, VF, 32±20) and RPC (CS, 0.5±0.53, VA, 1.04±0.63, VF, 14±13) groups respectively (p>.05) (CS, p=.001, p<.001, VA, p=.008, p<.001 and VF, p<.001, p<.001). RP group also had significantly better visual assessment scores compared to RPC group (CS, p=.012, VA, p=.024, VF, p=.027).

The six trials that were repeated as a result of obstacle contacts included two contacts by one participant (RPC1) and four contacts by another (RPC3).

7.4.2 Descriptive results from the questionnaire

Table 7.3 shows the mean and standard deviation of self-reported scores for the 14 activities between the three groups.

Table 7.2. The mean and standard deviations of the goal and task activities for the 3 groups. A lower value denotes lower ability to complete the goal/task.

Goal Level	Norm (n=16)	RP (n=12)	RPC (n=6)
1. Mobility indoors	5.00±0.00	3.92±0.9	3.17±1.32
2. Mobility outdoors	5.00±0.00	3.17±0.93	2.33±0.81
3. Using public transport	5.00±0.00	3.33±1.43	2.50±1.22
Task level			
4. Orient and find your way in poor light (outdoors)	4.94±0.25	2.25±1.13	1.67±0.51
5. Walk around safely, without bumping into, tripping over or stepping off something (outdoors)	4.88±0.34	2.67±0.88	2.17±0.98
6. Notice other road users (e.g. cyclists, cars)	4.88±0.34	3.00±1.12	1.67±0.81
7. Be able to recognize the speed of other road users (e.g. cyclists, cars)	4.81±0.54	3.08±1.08	2.00±0.89

8. Cross the street safely	4.94±0.25	2.92±1.50	2.67±1.03
9. Orient in poor light (indoors)	4.88±0.34	2.83±0.93	2.50±1.37
10. Walk around safely, without tripping over things (e.g. doorsteps) (indoors)	4.88±0.34	2.83±1.03	2.50±0.54
11. Walk up the stairs safely (indoors)	4.94±0.25	3.58±0.9	3.33±0.51
12. Find handles and handrails (indoors)	5.00±0.00	3.25±0.96	2.83±1.16
13. Use an escalator or elevator	4.94±0.25	3.17±1.33	3.00±0.63
14. Walk down the stairs safely (indoors)	4.88±0.34	3.17±0.93	3.17±0.75

High value scores (scoring 5 for almost all the activities) for the normal group (Table 7.3) shows that the normal group had minimal difficulty completing both goal and task level activities. There was a significant difference between the groups for all goal and task level activities (p<.001). Post hoc analysis showed that compared to the visual normal group, both RP and RPC groups reported all tasks as being significantly more difficult (p<.001). Post-hoc analysis showed that there were no significant differences between RP and RPC groups in any of the activities apart for one. RPC group showed significantly more difficulty at “noticing other road users” compared to the RP group (p=.024). There was also a trend for “being able to recognise the speed of other road users”, being more difficult in RPC compared to RP group (p=.051).

7.4.3 Heel/toe distance

There was no significant main effect between the groups for vertical marker displacement on the heel or toe in relation to the floor when standing stationary (p>.05). The mean±SD of toe marker; Norm 6.81±1.27cm, RP 6.00±1.27cm and RPC 6.00±1.78cm and for the heel marker; Norm 5.19±0.91cm, RP 4.75±0.62cm and RPC 4.92±1.42cm.

7.4.4 Falls

Out of all the participants, four people with RP, three with RPC and zero in the normally sighted reported that they feared falling. There was a significant main effect between the three groups for number of self-reported falls in the past year (p=.009). Post hoc analysis showed no significant difference between the Norm (number of falls, 1) and RP (number of falls, 9) group (p=.062) but RPC (number of falls, 7) group reported significantly more number falls in the last year compared to the Norm group (p=.013). There was no significant difference between the RP and RPC groups (p>.05).

7.4.5 Walking speed for walking trials

For the walking speed (10 metre distance/time taken the participants), there was no significant main effect of repetition trials (p>.05), neither was there a significant group by repetition interaction effect (p>.05). However, a significant main effect of groups was observed (p<.001). Post hoc analysis showed that RPC group took significantly longer (0.77±0.34 m/s) to complete the trials compared to both Norm (1.32±0.16 m/s) and RP groups, (1.24±0.18 m/s, p<.001). No significant difference was found between RP and Norm groups (p>.05).

7.4.6 Level walking

Table 7.4 presents the mean and SD of the variables for level walking, as well as the percentage changes from one group to another of that variable. The statistical analysis showed significant main effect of group (p<.05) for all variables except single support for the trail foot. No significant main effect of the repetition or group by repetition interaction was found (p>.05).

1. Lead toe horizontal velocity was significantly affected by groups (p<.001); RPC (3299±1184 $mm.s^{-1}$) group had significantly slower velocity compared to the Norm (4750±419 $mm.s^{-1}$) group (p<.001) and RP group (4485±534 $mm.s^{-1}$)

(p=.002). There was no significant difference between Norm and RP groups (p>.05).

2. Trail toe horizontal velocity was significantly affected by groups (p<.001); RPC (3425±1157 $mm.s^{-1}$) group had significantly slower velocity compared to the Norm (4761±415 $mm.s^{-1}$) group (p<.001) and RP (4521±516 $mm.s^{-1}$) group (p=.002). There was no significant difference between Norm and RP groups (p>.05).

3. Minimum foot clearance lead was significantly affected by groups (p=.005); RPC (99±59 mm) group had significantly higher foot clearance compared to the Norm (46±9 mm) group (p=.004) and RP (44±7 mm) group (p=.002). There was no significant difference between Norm and RP groups (p>.05). Figure 7.5 demonstrates the group difference.

4. Minimum foot clearance trail was significantly affected by groups (p<.001); RPC (91±41 mm) group had significantly higher foot clearance compared to the Norm (45±10 mm) group (p<.001) and RP (50±13 mm) group (p<.001). There was no significant difference between Norm and RP groups (p>.05). Figure 7.4 demonstrates the group difference.

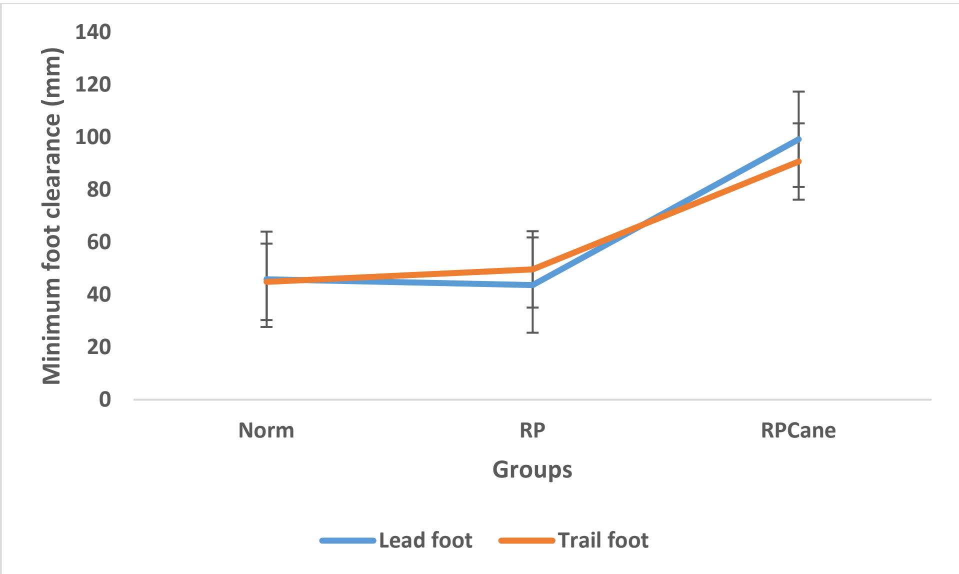

Figure 7.4. Group mean (±SE), (Norm, RP and RPC) minimum foot clearance of lead and trail feet. RPC significantly higher than RP and Norm groups for both foot.

5. Double support 1 was significantly affected by groups (p<.001); RPC (0.16±0.06 sec) group had significantly longer time compared to the Norm (0.03±0.02 sec) group (p<.001) and RP (0.04±0.02 sec) group (p<.001). There was no significant difference between Norm and RP groups (p>.05).
6. Double support 2 was significantly affected by groups (p<.001); RPC (0.12±0.05 sec) group had significantly longer time compared to the Norm (0.04±0.02 sec) group (p<.001) and RP (0.04±0.02 sec) group (p<.001). There was no significant difference between Norm and RP groups (p>.05).
7. Single support 1 foot was significantly affected by groups (P=.008); RPC (0.56±0.06 sec) group had significantly longer time compared to the Norm (0.49±0.04 sec) group (p=.041) and RP (0.48±0.04 sec) group (p=.006). There was no significant difference between Norm and RP groups (p>.05).
8. Single support 2 was not significantly affected by groups (p>0.05), RPC (0.75±0.16 sec), RP (0.59±0.09 sec) and Norm (0.56±0.07 sec).
9. Step width was significantly affected by groups (p=.019); RPC (596±166 mm) group had significantly shorter step widths compared to the Norm (732±165 mm) group (p=.006). There was no significant difference between Norm and RP groups (p>.05) or RPC and RP (683±100 mm) groups (p=.069).
10. Stride lead length was significantly affected by groups (p=.006); RPC (909±297 mm) group had significantly shorter stride lead length compared to the Norm (1218±95 mm) group (p=.002) and RP (1126±15 mm) group (p=.049). There was no significant difference between Norm and RP groups (p>.05).
11. Stride trail length was significantly affected by groups (p=.006); RPC (930±306 mm) group had significantly shorter stride trail length compared to the Norm (1207±34 mm) group (p=.001) and RP (1137±134 mm) group (p=.015). There was no significant difference between Norm and RP groups (p>.05).

Table 7.3. Demonstrating all the mean and SD values for the 15 dependant variables between the groups (Norm, RP and RPC). Demonstrating all the mean and SD values for the 15 dependant variable between the groups (Norm, RP and RPC). Those with significant main effect in groups are in bold. The effect size columns show how much each variables has changed from one group to another. Significant differences are in bold.

Walking variables	Norm	RP		RPC		
	Mean±SD	Mean±SD	Effect size of RP to Norm	Mean±SD	Effect size of RPC to Norm	Effect size of RPC to RP
1. Lead horizontal toe velocity ($m.s^{-1}$)	**4.750±0.420**	**4.485±0.535**	**-0.55**	**3.299±1.184**	**-1.81**	**-1.37**
2. Trail horizontal toe velocity ($m.s^{-1}$)	**4.761±0.415**	**4.522±0.516**	**-0.51**	**3.425±1.157**	**-1.70**	**-1.31**
3. Minimum lead foot clearance (m)	**0.046±0.009**	**0.044±0.007**	**-0.25**	**0.1±0.059**	**1.58**	**1.69**
4. Minimum trail foot clearance (m)	**0.045±0.001**	**0.050±0.013**	**0.43**	**0.091±0.041**	**1.80**	**1.51**
5. Double support time 1 (sec)	**0.03±0.02**	**0.04±0.02**	**0.50**	**0.16±0.06**	**3.25**	**3.00**
6. Double support time 2 (sec)	**0.04±0.02**	**0.04±0.02**	**0**	**0.12±0.05**	**2.28**	**2.28**
9. Single support 1 (sec)	**0.49±0.04**	**0.48±0.04**	**-0.25**	**0.56±0.06**	**1.40**	**1.60**
10. Single support 2 (sec)	0.56±0.07	0.59±0.09	**0.061**	0.75±0.16	**1.65**	**1.28**
11. Step width (m)	**0.732±0.065**	**0.683±0.100**	**-0.59**	**0.596±0.166**	**-1.17**	**-0.65**
12. Stride lead foot length (m)	**1.218±0.095**	**1.126±0.015**	**-1.67**	**0.909±0.297**	**-1.57**	**-1.39**
13. Stride trail foot length (m)	**1.208±0.034**	**1.137±0.134**	**-0.84**	**0.929±0.306**	**-1.64**	**-0.94**

7.4.7 Obstacle crossing

Table 7.4 presents the mean and SD of the variables for obstacle crossing, as well as the percentage changes from one group to another. The statistical analysis showed significant main effect of group ($p<.05$) for all variables except for the final foot placement, step width and lead foot placement. There was significant main effects for the obstacle heights only for the following variables: longer single support in both lead and trail feet ($p<.001$), shorter final foot placement ($p=.017$) and slower lead ($p=.014$) and trail (.011) horizontal toe velocity for the high obstacle compared to the low obstacle. Other dependant variables showed no significant main effect for the obstacle heights ($p>.05$). No significant main effect of the repetition trials was found in any dependant variables ($p<.05$).

1. Lead vertical toe clearance was significantly affected by groups ($p=.002$); RPC (216±98 mm) group had significantly higher compared to the Norm (129±24 mm) group ($p<.001$) and RP (152±44 mm) group ($p=.009$). There was no significant difference between Norm and RP groups ($p>.05$). Figure 7.8 demonstrates the group difference.
2. Trail vertical toe clearance was significantly affected by groups ($p=.033$); RPC (175±100 mm) group had significantly higher compared to the Norm (105±47 mm) group ($p=.011$). There were no significant difference between RP (134±54 mm) and Norm or RPC groups ($p>.05$). Figure 7.5 demonstrates the group difference.

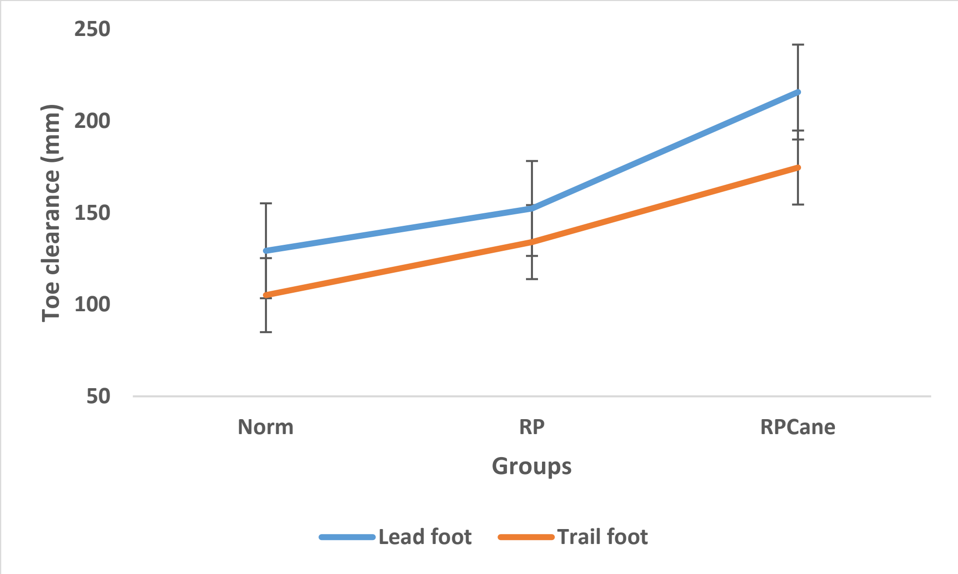

Figure 7.5. Group mean (±SE), (Norm, RP and RPC) toe clearance of lead and trail feet. RPC significantly higher than RP and Norm groups for both feet.

3. Lead toe horizontal velocity during the obstacle crossing was significantly affected by groups ($p<.001$); RPC (2320±761 $mm.s^{-1}$) group had significantly slower compared to the Norm (3936±551 $mm.s^{-1}$ group ($p<.001$) and RP (3484±587 $mm.s^{-1}$) group ($p<.001$). RP group also had slower velocity compared to Norm group ($p=.045$). Figure 7.9 demonstrates the group difference.

4. Trail toe horizontal velocity was significantly affected by groups ($p<.001$); RPC (1092±715 $mm.s^{-1}$) group had significantly slower compared to the Norm (3093±687 $mm.s^{-1}$) group ($p<.001$) and RP (2744±543 $mm.s^{-1}$) group ($p=.004$). There was no significant difference between Norm and RP groups ($p>.05$). Figure 7.6 demonstrates the group difference.

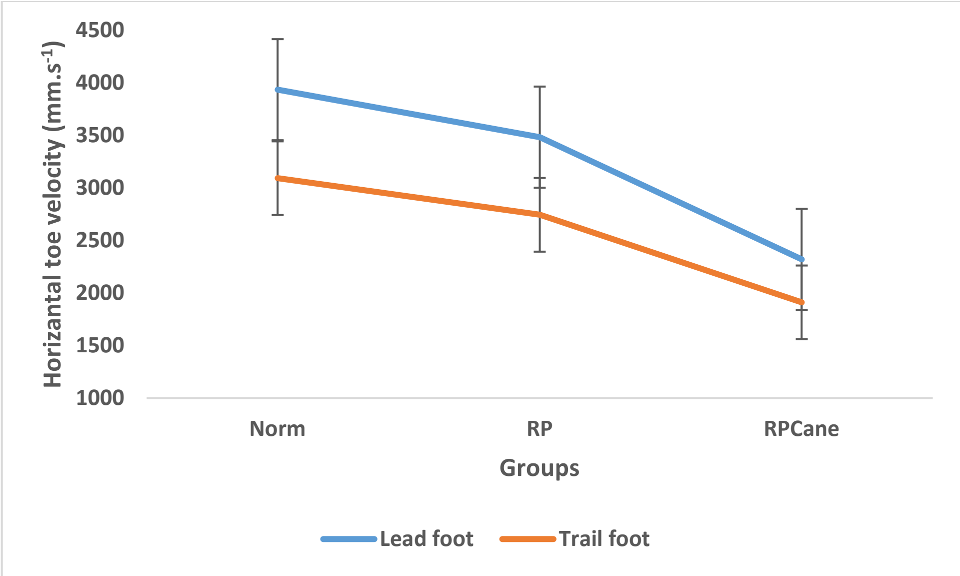

Figure 7.6. Group mean (±SE), (Norm, RP and RPC) toe velocity of both feet. RPC significantly slower than RP and Norm groups for both feet.

5. Double support before the obstacle was significantly affected by groups ($p<.001$); RPC (0.22±0.23 sec) group had significantly longer time compared to the Norm (0.06±0.03 sec) group ($p<.001$) and RP (0.05±0.03 sec) group ($p<.001$). There were no significant difference between RP and Norm ($p>.05$).
6. Double support lead was significantly affected by groups ($p<.001$); RPC (0.18±0.07 sec) group had significantly longer time compared to the Norm (0.07±0.03 sec) group ($p<.001$) and RP (0.08±0.04 sec) group ($p<.001$). There were no significant difference between RP and Norm ($p>.05$).
7. Single support lead foot during the obstacle crossing was significantly affected by groups ($p<.001$); RPC (0.80±0.21 sec) group had significantly longer time compared to the Norm (0.57±0.06 sec) ($p<.001$) and RP (0.59±0.07 sec) ($p<.001$). There were no significant difference between RP and Norm ($p>.05$).
8. Single support trail foot during the obstacle crossing was significantly affected by groups ($p=.011$); RPC (0.64±0.15 sec) group had significantly longer time compared to the Norm (0.54±0.06 sec) group ($p=.003$) and RP (0.56±0.05 sec) group ($p=.019$). There were no significant difference between RP and Norm ($p>.05$).

9. Penultimate foot placement before the obstacle crossing was significantly affected by groups (p<.001); RPC (-565±284 mm) group had their foot significantly closer to the obstacle compared to the Norm (-967±180 mm) (p<.001) group and RP (-863±182 mm) group (p=.001). There were no significant difference between RP and Norm (p>.05). 7.10 demonstrates the group difference.
10. Final foot placement was not significantly affected by groups (p>0.05), RPC (-188±122 mm) group, RP (-224±82 mm) group and Norm (-235±88 mm). 7.10 demonstrates this result.
11. Lead foot placement was not significantly affected by groups (p>0.05), RPC (245±126 mm) group, RP (305±93 mm) group and Norm (320±67 mm).
12. Trail foot placement was significantly affected by groups (p=.002); RPC (718±310 mm) group were significantly closer to the obstacle compared to the Norm (1061±125 mm) group (p<.001) and RP (987±182 mm) group (p=.006). There was no significant difference between Norm and RP groups (p>.05).
13. Step width was not significantly affected by groups (p>0.05), RPC (206±79 mm) group, RP (226±70 mm) group and Norm (209±49 mm).

Table 7.2. Demonstrating all the mean and SD values for the 13 dependant variable between the groups (Norm, RP and RPC). Those with significant main effect in groups are in bold. Demonstrating all the mean and SD values for the 13 dependant variable between the groups (Norm, RP and RPC). Those with significant main effect in groups are in bold. The effect size columns show how much each variables has changed from one group to another. Significant differences are in bold.

Obstacle Crossing variables	Norm	RP		RPC		
	Mean±SD	Mean±SD	Effect size of RP to Norm	Mean±SD	Effect size of RPC to Norm	Effect size of RPC to RP
1. Lead vertical toe clearance (m)	**0.129±0.024**	**0.152±0.044**	**0.68**	**0.216±0.098**	**1.42**	**0.90**
2. Trail vertical toe clearance (m)	**0.105±0.047**	**0.134±0.054**	**0.58**	**0.175±0.1**	**0.95**	**0.53**
3. Lead horizontal toe velocity (m.s^{-1})	**3.936±0.551**	**3.484±0.587**	**-0.8**	**2.320±0.761**	**-2.46**	**-1.72**
4. Trail horizontal toe velocity (m.s^{-1})	**3.093±0.687**	**2.744±0.543**	**-0.57**	**1.092±0.71**	**-2.85**	**-2.62**
5. Double support time (sec)	**0.06±0.03**	**0.05±0.03**	**-0.33**	**0.22±0.23**	**1.23**	**1.30**
6. Double support time lead foot (sec)	**0.07±0.03**	**0.08±0.04**	**0.29**	**0.18±0.07**	**2.2**	**1.81**
7. Single support lead foot (sec)	**0.57±0.06**	**0.59±0.07**	**0.31**	**0.8±0.21**	**-3.63**	**-3.64**
8. Single support trail foot (sec)	**0.54±0.06**	**0.56±0.05**	**0.07**	**0.64±0.15**	**0.95**	**0.80**
9. Penult foot placement (m)	**-0.969±0.180**	**-0.863±0.182**	**-0.59**	**-0.56±0.28**	**-1.74**	**-1.27**
10. Final foot placement (m)	-0.235±0.088	-0.224±0.082	**-0.13**	-0.18±0.12	**-0.44**	**-0.35**
11. Lead foot placement (m)	0.320±0.066	0.305±0.093	**-0.19**	0.24±0.12	**-0.56**	**-0.13**
12.Trail foot placement (m)	**1.061±0.125**	**0.987±0.182**	**-0.49**	**0.71±0.31**	**-1.57**	**-1.09**
13. Step width (m)	0.209±0.049	0.226±0.070	**0.29**	0.206±0.07	**-0.04**	**-0.26**

7.4.7.1 Disease duration impact on obstacle crossing of those with RP

Two important variables during obstacle crossing were furthered analysed to determine if there was any correlation between years with RP and toe clearance and horizontal velocity of toe (lead foot). To obtain the correlation, the values of the variables were averaged across for both obstacle heights (low and high) and the repetition of the trials. The correlation coefficient for vertical toe clearance against years with RP is almost zero (R^2 = 0.0132), representing no significant correlation ($p>0.05$), between the two variables (Figure 7.7).

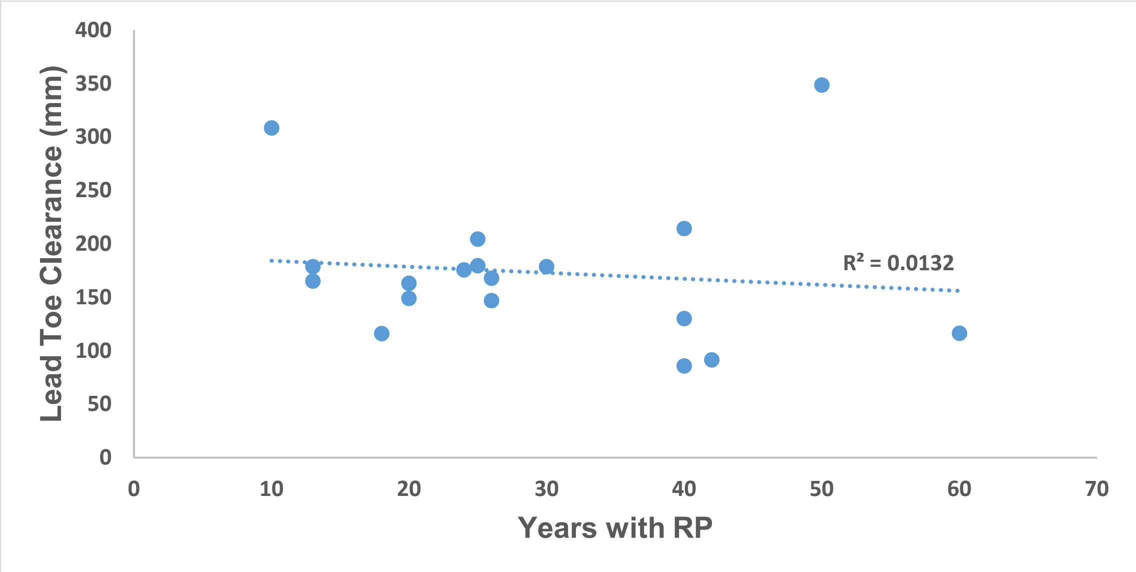

Figure 7.7. Correlation plot of years with RP (X axis) against the toe clearance. Although there is a slight tendency of negative correlation, the result is not significant.

Figure 7.8 shows the correlation between years with RP against and horizontal toe velocity. Similar to the toe clearance. The correlation coefficient for horizontal toe velocity against years with RP is almost zero (R^2 = 0.0233), representing no significant correlation ($p>0.05$), between the two variables (Figure 7.8).

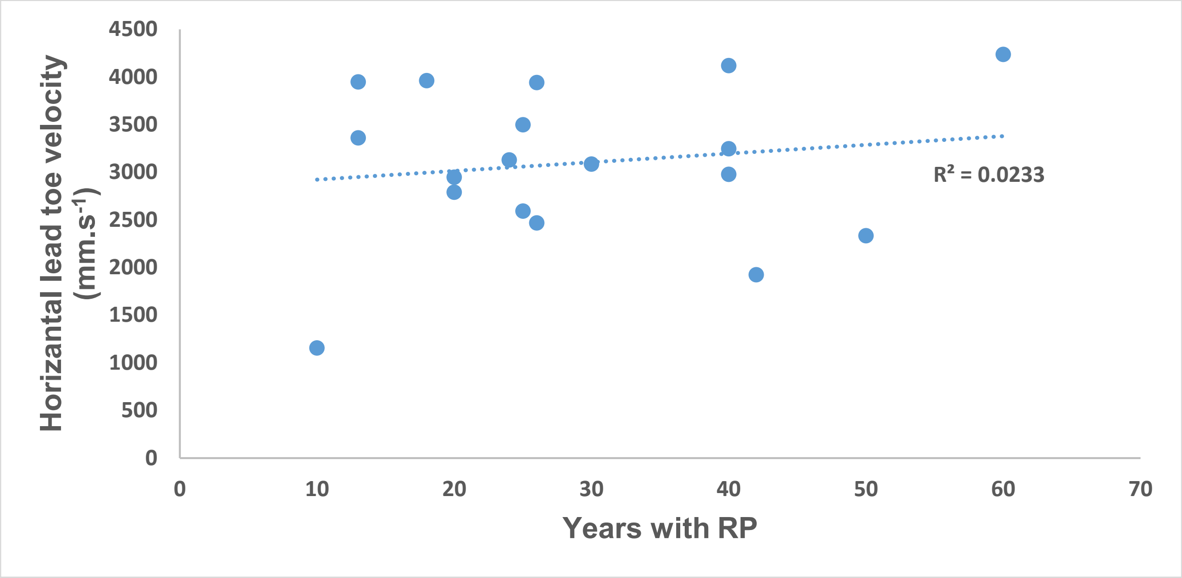

Figure 7.8. Correlation plot of years with RP (X axis) against the horizontal toe velocity (Y axis). Although there is a slight tendency of positive correlation, the result is not significant.

7.5 Discussion

The current experimental chapter was designed to investigate whether the self-reported difficulties with mobility (identified in chapter 5) manifested in changes in walking gait among those with RP. Specifically negotiating an obstacle placed on the travel path was compared among RP and individuals with normal vision. The chapter also compared the gait of those with RP and normally sighted individuals at level walking (no obstacle present). Furthermore the effect of using mobility cane was compared to those who did not use the mobility cane.

The results from this experimental chapter showed that those with RP, who use the mobility cane (RPC), adopted a cautious strategy to reduce the risk of contacting the obstacle and falling. However, the RPC group still did report significantly higher number of falls compared to those with normal vision and they also reported a greater fear of falling. Both at level walking and when crossing an obstacle, compared to RP group without the mobility cane and the normally sighted individuals, the RPC showed significantly different adaptation in their gait. The cautious strategies include walking slower, spending more time at DS, having shorter steps, and most importantly lifting their feet higher and slower either when stepping over an obstacle or during swing in normal walking gait. Interestingly, the RPC group only reported significant difficulty compared to those with normal vision when reporting in the SRQ of this chapter. There was no significant difference between RPC and RP groups (apart from 1 task out of 14).

The slower walking pattern for the RPC group in this study is consistent with the findings in Turano et al. (1999), who examined people with visual field loss (VFL). In the current study, RPC group took significantly longer (12.88±5.14 seconds) to complete the trials compared to both Norm (7.58±1.04 seconds) and RP groups (8.03±1.36 seconds, $p<.001$). However, no significant difference was found between

RP and Norm groups ($p>.05$). Turano's study used individuals with Glaucoma examining their walking speed at two paths both 29m long (path 1 without any obstacles, path 2 with obstacles such as chairs and tables). The study reported the mean walking speed for Glaucoma subjects for path 1 was 1.06 m/sec and 0.99 m/sec for path 2, whereas the speed of normal vision were 1.15 m/sec and 1.10 m/sec for path 1 and 2 respectively. Overall, the study reported that those with visual field loss (Glaucoma) walk 10% slower than those with normal vision. It was suggested that those with Glaucoma adopt a cautious behaviour (such as slowing their walking speed, altering their environment, or restricting their travel) to reduce the risk of falling. Indeed, the current study investigated the effect of VFL on adaptive gait including more variables than only the walking speed and the VFL was more severe in this study (RP) compared to Turano's (Glaucoma).

Timmis et al. (2012 and 2015) reported that those with VI (central field loss) use different strategies to prevent falls while negotiating an obstacle. Placing the lead foot further from the obstacle, lifting both feet (lead and trail) higher and slower over obstacle, and taking longer time to complete a task (Timmis et al., 2015), greater vertical lead/trail toe and heel clearance (Timmis and Pardhan, 2012) were the strategies evident as cautious. This current study also confirms that those with severe sight impairment (cane users) lifted their feet higher, took longer time to negotiate the obstacle, reduced their horizontal crossing velocity while negotiating the obstacles compared to the Norm and RP group. These cautious strategies have been reported in previous research when examining the effect of cataract and simulated VI (Heasley et al., 2004; Rietdyk and Rhea, 2006; Graci et al., 2010; Buckley et al., 2010). The significant differences between RPC to RP and Norm groups at the level walking that were observed in this study varies from the results of studies of Timmis et al. (2012), which reported no significant difference between the groups at level walking. This difference could arise from the fact that this study tested those with VFL, who find level walking more challenging to those with CFL.

One key difference between the current study and the work by Timmis and Pardhan (2012) was the significant longer time during DS (both prior and during) obstacle crossing during this study compared to the previous work. Those with VI in the previous study had DS time of 0.094 and 0.127 seconds prior and during obstacle, respectively, compared to the normal group of 0.07 and 0.105 seconds. Whereas this study reported 0.22 and 0.18 seconds for those with VI and 0.06 and 0.07 seconds for those with normal vision. It can be suggested that the different of visual loss between the groups caused the difference in findings. Those with RP (VFL), spend more time scanning prior and during the obstacle crossing, this can be interpreted as a ‘safe’ mode before going into SS compared to those with CFL. The increased scanning time of those with RP has been reported in the previous study (Timmis et al., 2017). It can be argued that longer time in SS could cause lack of balance as one is standing on one foot and lead to falls but it is debatable to which safe strategy (lifting the foot higher causing longer SS or shorter TC and shorter SS) is safer for those with VI (Hak et al., 2012). Some previous studies have highlighted the adaptation of a more stable gait strategy during single support by reducing medial-lateral movement of centre of pressure (CoP), which leads to the CoP to stay close to the base of support (Heasley et al., 2004). However, in the current study the CoP was not measured, due to the difficulty of data collection and ensuring only one foot lands on the force platform immediately before stepping over the obstacle. With the short stride length (909±297mm) of those RPC reported in this study, it would have been challenging and some manipulating to consider CoP. Indeed, the CoP of those with RP was examined in the previous chapter, while standing stationary and in similar procedure to the previous work (Heasley et al., 2004). Considering CoP during an adaptive gait such as obstacle crossing is an area that requires further research.

Moreover, although one the most fundamental safest strategies for negotiating an obstacle is to increase the vertical distance of the toe, which prevents the foot from contacting the obstacle, other variables have also been shown as safer strategies. For examples, trips could be prevented by decreasing the velocity of the swing limb during the obstacle crossing (Patla and Rietdyk, 1993). Compared to visual normal, those in RPC group had significantly lower lead foot horizontal velocity when negotiating the obstacles. This result was similar for the trail foot horizontal velocity. These results in addition to the higher vertical toe clearance of those in RPC group compared to normally sighted confirms the adaptation of a cautious strategy used during obstacle negotiation. This result is consistent with previous research (Patla and Rietdyk, 1993; Timmis and Pardhan, 2012).

Spaulding at al. (1994) also reported cautious strategies for those with VI when walking compared to with those normally sighted. Although, they used different VI (AMD), the findings have a similar message for those with VI that additional cares is needed when negotiating an obstacle to prevent injuries that can be caused by falls. The RPC group did report significantly higher number of falls compared to the Norm group, which again emphasises the importance of using the cautious strategies to reduce the number of falls. It has to be said that in this study, only those with RP reported fear of falling. One may suggest that even if the number of falls may have been not significant, many still have the fear of falling and added care (cautious strategies) should be adapted for safe obstacles negotiations.

This study found no significant difference between the RP group and normally sighted individuals, in terms of changes in their gait. It can be argued that many in the RP group did not have severe vision loss and some could have been at the beginning of their visual loss effect, where not much of the visual field has been deteriorated. The visual assessments of the RP group (CS of 1.17±0.59 LogCS, VA of 0.43±0.59 LogMAR and VF of 32±20 deg) could be an indication of having sufficient vision to overcome the tasks without adapting any gait behaviour. Furthermore, a quarter of the participants in RP group were not registered as visually impaired as they did not meet the requirement (see 3.2.1), which could mean they had sufficient vision to have similar adaptive gait patterns to the normal vision group. The results showed that RP group had significantly slower horizontal velocity of the lead foot during obstacle crossing. The lower speed confirms that, although the results were similar to the Norm group, the RP group employed some extra cautious strategies. This result is consistent with the findings from a previous study in terms of level walking but not during obstacle negotiations. Timmis and Pardhan (2012), reported no significant differences between individuals with central vision loss compared to those with normal vision during walking trials. They suggested that the lack of difference could be attributed to adaptation of vision loss and the difference occurred during obstacle crossing was as a result of complexities used during such a task. One other main finding of this study was, that no significant difference between the RP and Norm groups was seen. Timmis et al. (2015) also reported similar results, when the adaptations of gait only occurred in severe vision loss (20 degrees CFL) and not those who were simulated to have better vision (10 degrees CFL). Their results confirm similarities with the finding of this study.

The result from the self-report questionnaire of this study suggested that the RP and RPC groups found all the activities apart from one (noticing other road users) at the same difficulty level. This could suggest that the mobility cane does give individuals the confidence to take on the activities. However, the kinematics analysis showed significant difference in the performance of the cane. One may argue that the mobility cane could be seen as emotional support to enhance individual's self-confidence to complete different activities of daily living. By observing the participants during the current study, it could also be suggested that some of the participants in RP group (SSI) could benefit from using the mobility cane but different reasons such as perceptual (stigma attachment), attitudinal and normative (stigma related) prevents them. A previous study reported, even participants reporting fear of falling and history of falls and with limited vision they preferred not using a cane (Aminzadeh and Edwards, 1998). The benefits and barriers of using a cane is an area that requires more investigations.

Finally, the result did highlight significantly a higher number of falls in the RPC group compared to the RP and Norm groups. This result suggests those who were in the RPC group are more prone to falls despite using the cautious strategies. It has been reported that hitting an obstacle and falling can be seen as socially awkward experience, a reason that can prevent RP individuals from participating in social gatherings (Geruschat et al., 1998).

7.6 Strengths and limitations

No previous research has investigated the obstacle negotiation strategies of those with RP. Furthermore, this study was designed based on the outcomes of the previous experimental chapters.

All individuals in the RPC group were diagnosed as SSI (see 3.2.1 for the regulations). Three individuals in the RP group were registered as SSI although they did not use a mobility cane. Furthermore, 5 of the participants in RP group had visual field of less than 15 degrees, which is very limited field vision. It can be argued that, those in the RP group with limited vision and/or registered as SSI should use a mobility cane but decided not for a variety of reasons. This observation could have influenced the result and one that should be further investigated.

One of the limitations of this study was that it was not possible to investigate the same numbers of participants for each group. In particular, having more participants in RPC group would have been beneficial. However, as RP is a specific VI, finding individuals with RP who use the mobility cane and could come to the lab for testing was a challenging task.

7.7 Conclusion

In summary, those people with RP who used a mobility cane adopted a cautious walking strategy in both level walking and obstacle crossing tasks, when compared to RP and normally sighted groups. Minimal differences were found between walking behaviour between the RP group and visual normal for either level walking or obstacle crossing task. Those who are newly diagnosed could be informed by being reported about the cautious strategies found in this study.

Chapter 8. Discussions and Conclusions

8.1 General Discussion

The literature reviewed in chapter 2 showed that most of the previous studies have not investigated RP in terms of difficulty levels during activities of daily living (ADLs). The lack of knowledge in this specific area of research was shown within the thesis. There is, therefore, limited research investigating the effect of RP on ADLs.

By focusing on the effect of RP on ADLs, this PhD thesis has been able to offer valuable insights for this area of research. The purpose of the experiments presented in this thesis was to determine the most difficult ADLs for those with RP and then examine the tasks further using biomechanical tools. The protocol used in this thesis first examined those with RP using self-report questionnaires to find the most difficult ADLs and then examined those difficult ADLs, which were orientation and obstacle negotiations.

The first experimental study contained in chapter 4, determined that mobility is the most difficult ADLs at objective level. At goal level, mobility outdoors, shopping, physical activity, mobility indoors and using public transport were indicated as the most difficulties. The common theme of the most difficult ADLs at goal level is that they all have orientation and mobility aspects to them, although not all the goals came from the mobility domain. This is a valuable insight that indicates orientation and mobility training should therefore be strongly considered and offered for anyone with RP. Previous research has shown that such training could improve perceived performance in mobility based activities (Engel et al., 2000; Kuyk et al., 2004). Such training should also take into consideration mobility goal related ADLs but also recreational goals improving access to tasks such as physical activities or applying for jobs. Applying for jobs was a goal not applicable to all of the participants but difficult for those who did consider it. It is known that visually impaired people are more likely to be unemployed than their sighted peers (Clements et al., 2011), and the result of chapter 4 demonstrated this issue. Consideration of the visual needs of those with RP in their work environment, therefore, should be a key part of low vision rehabilitation. The study by Engel et al. (2000) highlighted how orientation and mobility training could increase the use of public transportation as well as enhancing freedom of movement and becoming more independent. These changes are seen as positive that can enhance the social interactions of those with RP and can contribute to the health of individuals.

In addition to the findings of chapter 4, the use of mobility aid was found to be associated with greater difficulty for those who use it compared to those who do not. The result of this finding were highlighted when, participants were asked to rate difficulty of goals with the use of any assistive devices, this did not mean that the usage lessen the difficulty for them. Eighty one percent of those using the mobility aids were registered SSI, as opposed to 19% of those who did not use mobility aids. Thus, the usage of mobility aids suggests that more advanced visual loss (disability) for those with RP but the start point of using mobility cane (depending on visual function and/or personal reasons) is unclear. There are of course mental barriers for when a VI person to use a mobility cane such as feeling ashamed or vulnerable (Neyman et al., 2010, Rackley, 2015). Therefore, the benefits of using a cane needs to be more emphasised within the VI communities. Duration of visual loss was also related to self-reported difficulty in this chapter, and previous work by Turano et al. (1999) has shown to relate to perceived mobility difficulties in RP. The duration of vision loss can be a factor of difficulty level of ADLs becoming less difficult as compensatory mechanism usually provide the sensory input that is used to initiate any movements and to complete such a task if vision is not available or restricted (Horvat et al., 2003). The compensatory strategies can be confounded within the duration of vision loss and be developed at different stages and warrants further investigation. The correlation results between the disease duration and difficulty level of the ADLs did not show any significant results, which could emphasis on the adaptation factor by encountering on compensatory strategies.

Many different aspects of RP on ADLs were studied within this thesis. One aspect was the effect the duration of RP on completing the ADLs. The correlation results from each experimental chapters on this aspect (5.4.3, 6.4.5 and 7.4.7.1) showed little correlation between the variables. There was no significant difficulty increase with increase of years with RP in the most difficult ADLs (SRQ).

The result from this section shows that year with RP is not an accurate measure for reporting difficulty or change in gait. It is important to consider the characteristic of RP as it is a progressive disease. Thus, disease progression rate varies within each individual. The vision of some individual may deteriorates slowly whereas it may be quick for others (Herse, 2005). More appropriate measure is visual status such. The earlier results from the first SRQ showed that those in SSI group find ‘mobility’ and ‘learning and applying knowledge’ significantly more difficult compared to those in SI group (see 4.4.3). Furthermore, Those in the SSI group found both ‘walk around safely without hitting overhanging thing’ and ‘walk around safely without bumping into, tripping over or stepping off something’ significantly more difficult compared to those in the SI group (see 5.4.2.1).

Swenor et al. (2013) reported that those with VI were more likely to report mobility disability than the normally sighted individuals, however, the trajectory of mobility disability was not steeper among the VI as compared to the normally sighted over the study period. Their study examined 2520 participants at 2, 6 and 8 years after initial mobility examination, which included walking up 10 steps, walking down 10 steps, and walking 150 feet. Perhaps, if the participants were examined at different stages of their RP, more precise results could have been obtained.

Another key insight from chapter 4 was the difference in perceptions of difficulties between supporters' of RP participants and the RP participants themselves. The results indicated that supporters thought the goals were more difficult than the people with RP did. The supporters could observe the tasks that those with RP were attempting, and it could be possible that the supporter has a specific interest in the person with RP being able to achieve it. Thus, the supporters may offer or provide more help in these areas than is perceived necessary by the person with RP and overprotect those with RP. Overprotection of those with low vision has been shown in a previous study by Cimarolli et al. (2006), where overprotection was associated with less optimal adjustment, and manifested in lower level of mastery and lower level of adaptation of vision loss and more importantly with significant depressive symptoms (Thompson and Sobolew-Shubin, 1993). Indeed, this study highlighted that the supporters would like to help those with VI, however, suggestions can be made that those with RP prefer less help, which could enhance their independency. The supporters could also be involved in the vision rehabilitation process and be educated on how some level of independency can be regained (Cimarolli et al., 2013).

Chapter 5 underpinned the difficult ADLs that were found in chapter 4 specifically and underpinned them at task level. The most difficult ADLs at task level were found to be orientation in poor and bright light both indoors and outdoors, and avoiding peripheral obstacles outdoors. The findings from this chapter were not unexpected activity limitations, given that the effect of RP on photoreceptors and the characteristics of RP are poor scotopic vision and reduced peripheral field. The greater difficulty with mobility in reduced illumination for those with RP has been previously reported (Smith et al., 1992). Although mobility training is available, the most effective methods of orientation and mobility in general are yet to be established with no efficient quality evidence currently available (Virgil and Rubi, 2010; Ballemans et al., 2011). Although, standardization of the orientation and mobility training have been tested (Zijlstra et al., 2009), the results indicated small differences among the techniques used (Ballemasn et al., 2012). One can argue that most mobility training consider VI as a whole and the result from chapter 5 does offer specific difficult tasks for those with RP. Thus, conducting research examining specific rehabilitation strategies for selected (most difficult) tasks could be offered to specific those with RP.

Orientation was highlighted as one of the most difficult ADLs in chapter 5. One of the major aspects of safe orientation and human locomotion is postural stability. Postural stability is an important aspect of mobility and reduced postural control among people with low vision is a significant predictor of falls (Ray et al., 2008). Thus, this area of research among those with RP was further examined during chapter 6. The significant difference for the number of falls between RP and those normally sighted was consistent of the findings of Legod et al. (2002), who reported that those with visual impairment are seven times more likely to fall compared to those with normal vision. The results from chapter 6 for number of falls of those with RP was further examined in the final experimental chapter. The results in the final chapter showed that RP participants who use a mobility cane (and are in the SSI group) fall significantly more than those without a cane and normally sighted participants. Indeed, the number of participants for this result was limited, but suggestions can be made that more care and possibly training are needed for the mobility cane users to potentially prevent them from falling. The particular care could include the foot healthcare, which the importance of it during postural stability was highlighted in chapter 6.

Moreover, chapter 6 indicated that in both A-P and M-L directions, when standing in habitual condition (eyes open and firm surface), those with RP regulated their postural stability similar to those with normal sight. However, postural stability within the RP group deteriorated when the somatosensory system was disturbed (standing on foam). This finding highlighted the importance of the somatosensory system to those with RP. Similar findings in regards to the somatosensory system were shown in a range of visual impairments, including RP, glaucoma, AMD and diabetic retinopathy (Turano et al., 1993; Maeda et al., 1998; Black et al., 2008; Kotecha et al., 2012). Turano et al. (1993) demonstrated that when somatosensory is disturbed, within those with RP, postural stability significantly deteriorated in eyes closed compared to eyes open. The result of chapter 6 extended the previous work by Turano et al. (1993) by demonstrating that no significant difference was found among RP participants when standing on firm surface in both eyes open and closed conditions, which suggests that vision does still mediate postural control among those with RP, however, this is only apparent when the dominant (somatosensory) sense is disturbed. The subtle role of vision in regulating balance for those with RP emphasises the importance of maintaining eye health among individuals with RP. Indeed, correcting common forms of VI, such as refractive errors (Wormald et al., 1992; Van der Pols et al., 1999) and cataract (among the elderly) (Elliot et al., 1996; 2000) may be an important intervention strategy in improving balance control and reducing the risk of falling among those with RP.

Another practical implications of the findings in chapter 6 advocate the importance of RP participants wearing appropriate footwear both in and outside the home to maximise the sensory information obtained from the feet. Footwear design has been reported to aid the task of maintaining postural stability or balancing as well as minimizing risk of falls. In particular, occupational footwear that abides by safety standards with minimalistic features have been shown to help maintain postural stability and reduce falls (Chander et al., 2019). Another important factor for the somatosensory system includes foot health, which needs to be maintained among those with RP as podiatry may be linked to risk of falling (Spink et al., 2008). With foot problems common among the elderly (aged 65 years and above; Greenbery et al., 1994; Dunn et al., 2004), it is important that those with RP at a similar age have their feet examined regularly.

Walking around safely without bumping and tripping was another most difficult ADLs at task level showed in chapter 5, which was examined in chapter 7 extensively using biomechanical tools. The result of chapter 7 showed that those with RP who use mobility cane (who were registered as SSI) use cautious strategies to walk safer both at level walking and obstacle crossing. One of the cautious strategies shown was slower walking, which is consistent of the findings from Geruschat et al. (1998). To the author's knowledge no studies have examined walking strategies among those with RP extensively (using biomechanical tools) and one of the main strengths of this chapter was that the finding was novel. The other cautious strategies included having longer time in double supports, having shorter steps and higher and slower toe clearance. These strategies have been shown in previous studies (e.g. Hassan et al., 2002; Timmis et al., 2012). Although, Timmis et al. (2012) and Spaulding et al. (1994) did find similar results the participants in those studies differed in terms of their visual impairment, where those with central visual field loss were examined rather than peripheral visual field loss. The contrast between central vision and peripheral vision during obstacle crossing was examined by Graci et al. (2010). Their study concluded that exeroceptive cues are usually provided by the central vision and used in a feed-forward manner, whereas expproprioceptive information is gained by peripheral vision and is used online during obstacle crossing. Considering that both of the findings from chapter 7 and the work by Timmis et al. (2012) showed similar strategies, emphasis can be made for the importance of both central and peripheral vision during an adaptive gait such as obstacle crossing. Although, those with RP did not have the expproprioceptive information because of the characteristics of the VI, they still managed to use the exeroceptive cues that was provided by their limited central vision. Furthermore, another strategy that has been reported for those with visual field loss has been the use of eye movements to scan more in the vertical direction as a safety strategy (Patla and Vickers, 2003). Timmis et al. (2017) demonstrated this among those with RP and reported that those with RP use a more active visual search pattern, by looking at more areas on the ground compared to those normally sighted both at level walking and obstacle crossing. The longer time needed for scanning leads to a slower walk of those with RP and it indicates how individuals have used this technique to gain more visual cues.

Another key insight from chapter 7 was the similarities between those in the RP group (without the cane) and normally sighted individuals. Apart from one dependant variable (lead foot velocity), where those in the RP group showed significantly slower velocity compared to the normally sighted participants (p=.045), there were no other significant differences for both level walking and obstacle crossing trials. The similarities between the two groups could have been because the VI of those in RP group was not as severe as the RPC group and the RP group could show similar gait pattern to the normally sighted. The result for the level walking is consistent of a previous study (Timmis et al., 2012). Although, the study did report significant differences between the groups during obstacle crossing. The differences between the current and previous research could be attributed to adaptation of vision loss and the different type of VI used (Pardhan and Gonzalez-Alvarez, 2011). Timmis et al. (2015) showed a similar results to chapter 7's findings, where the gait adaptation only occurred in severe vision loss (20 degrees CFL) and not for those who had better vision (10 degrees CFL). Although, the VI groups are different between the study by Timmis et al., (2015) and the study of chapter 7 but similar results are found. The similarities are in terms of the visual impairment not being severe similar gait pattern can be seen with the control group. Of course, knowing the exact point of when exactly the different gait changes occur would be difficult to find because of the characteristics of VI and the individual tested. Moreover, despite significant differences between the groups in terms of visual field loss (the Norm group had mean VF of 61.98±1.41, RP group had mean VF of 32.31±20.25 compared to the RPC group VF of 14.23±13.34), the difference was much greater between RPC and norm than RP and norm. Currently it remains unclear whether adaptive gait is progressively affected as the extent of visual loss increases (Hassan et al., 2002). Different factors such as age, VI duration or/and rehabilitation training could influence the findings but this particular finding can suggest some indications for the amount peripheral loss that potentially changes the gait pattern of those with RP. Indeed, this area of research requires further investigations.

The result of the SRQ in chapter 7 showed little significant difference between RPC and RP group. It might have been expected that mobility tasks such as avoiding peripheral obstacles would have been more difficult for those at later stage of the condition (SSI). However, it could be argued that as the disease progresses, adjustments to a variety of approaches to such a mobility task take place from an early stage (Latham et al., 2016). This result from chapter 7 is an additional finding to the previous research, where different strategies are shown to take place and to compensate for the lack of vision in terms of safe obstacle negotiations and fall preventions (Spaulding et al., 1995; Geruschat et al., 1998; Hassan et al., 2002). An overview of research has highlighted a lack of well-described protocols on orientation and mobility training in identification of using the mobility cane (Ballemans et al., 2011). Virgil and Rubin (2010) also reported the lack of evidence on the advantage of different orientation and mobility training for those with low vision. No significant improvement in mobility performance of visually impaired have been reported (Snoog et al., 2001). Therefore, it can be suggested that comprehensive investigations could take place in terms of orientation and mobility training and the findings from the studies in this thesis can help to equip further studies.

8.2 Limitations

Chapters 4 and 5 used SRQs to provide a comprehensive overview of difficulties among those with RP. Although the visual status of participants were collected, there were no actual visual assessments data to reference the results to. This could have been helpful in terms of analysing the data. By having the visual measurements such as visual field loss, the deterioration of vison could be examined provided information on how progressivity of RP can make a task difficult. Moreover for the SRQs studies, the data for perception of the supporters were collected anonymously, hence, it was not possible to link the collected data of the supporter to the person with RP. It would have been beneficial if the collected data from the supporters could be matched to those with RP. Also, the second questionnaire (chapter 5) was only available online, which meant less number of individuals could participate. Indeed, if there was sufficient training in place for the researcher, the data could have been collected through phone conversations, and similar number of participants as to the first SRQ could have been involved.

To maximise the number of participants included in chapter 6, the study visited numerous locations across the UK. To facilitate collection, the equipment needed to be portable. Unfortunately, the visual field device, Damato campimeter, did not show the reliability that was anticipated, which limited the understanding of VF severity within the population group sampled. Perhaps the visual field data could have been collected at certain venues that had visual field equipment such as the Humphrey visual field that was used in chapter 7, which could have been beneficial to the study. By having the exact degree of visual field loss, progressivity of RP could have been better identified within the participants during chapter 6.

One of the main challenges for chapter 7 was to have similar numbers of participants for each group (Norm, RP and RPC). However, it was found difficult to recruit participants for the RPC group as they had to travel to Cambridge and be examined for almost a full day and this is difficult task for those individuals, one that may not be possible independently. This is a limitation for the final study of the thesis as the number of RPC participants were almost the half of the other two groups. Furthermore, participation had to attend the lab in Cambridge, one can argue that only those were recruited that were active and did want to participate. This is another limitation of the study of chapter 7 compared to the rest of the experimental chapters of this thesis, whereas, the other experiments had a wider range of inclusion.

8.3 Conclusion

The purpose of this thesis was to examine the most difficult ADLs among those with RP. The most difficult tasks were identified as orientation and obstacle crossing by using SRQs. Important aspects of the identified tasks were further examined using biomechanical tools. Moreover, different strategies that those with RP use to overcome challenges during these difficult ADLs such as obstacle negotiations were examined. During postural stability testing, those with RP showed similar postural stability control to those with normal vision on the firm surface regardless of the vision condition. However, the importance of the somatosensory system was emphasised when compared to visual normal, those with RP showed reduction of postural control with their eyes open while standing on a foam surface. Finally, participants with RP who used a mobility cane adapted cautious strategies in both level walking and obstacle crossing compared to RP and normally sighted groups. Minimal differences were found in the gait strategies between the RP group and normally sighted people, which suggested that among those with RP, adaptations in walking gait only occur once vision deteriorates to a certain point. Where this exact point lies requires further investigation.

In conclusion, important aspects of knowledge that shows how the lack of vision (in RP) is compensated with other human functions such as somatosensory system that enables completing ADLs were demonstrated within the thesis. Although orientation and obstacle crossing were highlighted as challenging for those with RP, once examination was done, the results showed how those with RP use different strategies to overcome such challenges. The implication from the thesis could be that the practitioners (treating RP) become aware of the different strategies used by RP and target better intervention and rehabilitation trainings.

In summary, the original contribution to the knowledge in this research could be listed as follows:

- Orientation and walking around safely without bumping into things, and tripping over or stepping off something are the most difficult ADLs to complete among people with RP.
- Those who support people with RP perceive most of the ADLs significantly more difficult to complete compared to those with RP.
- Those with RP show similar postural control to those with normal vision. However, people with RP rely on their somatosensory system more compared to normally sighted individuals.
- Those with RP who use a mobility cane adopt a cautious behaviour in both level walking and obstacle crossing compared to those who do not use a mobility cane (RP) and normally sighted individuals.

8.4 Future research

One of the main recommendations of this thesis is to use the SRQs prior to the orientation and mobility training of those with RP and then examine the participants again post training. This could also be possible with postural stability and obstacle negotiations tasks. This will evaluate the benefit of rehabilitations and validates them by comparing the results pre and post training.

The SRQ identified that those with RP have the tendency to become more independent. Future research should explore interventions to increase the independence of those with RP. Although the role of carers was not the main focus of this thesis but the results were compelling and one that needs more investigations. Perhaps a separate study could investigate the role of carers for those with a variety of visual impairments rather than just RP.

Postural stability of all participants was limited to only being measured in a static condition. However, in everyday life individuals undertake daily tasks which require dynamic balance e.g. twisting, turning walking, rising form a chair. That arguably present higher risks of falling. This is something that it should be investigated further. The postural stability of those with RP was examined within this PhD thesis, however it is important to note that postural stability can be part of a dynamic movement rather than a static one. Thus, the dynamic testing of balance is another area that can be further examined. Furthermore, the final chapter did not examine the joint kinematics and kinetics, which are important aspects of biomechanical studies. This is another area of research that can benefit from further studies.

In addition, different strategies that those with RP use a mobility cane need further investigation. This is because different strategies such as tapping, rolling and sweeping were observed during the final experiment (chapter 7). It would be beneficial to examine the differences between such techniques and find the most optimal one for an ADL task such as obstacle crossing. Such study will also help to enhance the knowledge about fall prevention techniques for those who use the mobility cane.

Moreover, it would also be beneficial to have a visual data for the questionnaire studies rather than the visual status. This will help to make more advanced comparisons between the groups based on their visual assessments such as VA or/and VF. Additional questions such as, “For what purpose do you use your mobility aid?” could be beneficial to include in the future studies.

Finally, it was highlighted that not many people with RP use the mobility cane. The stigma of using a cane within societies could be one of the main reasons of this and this is an area that needs further investigations to explore the reasons for not using the cane.

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Appendices

Appendix 1. Chapters 4 and 5 Ethical Approvals

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11th April 2013

Dear Ahoora

Project Number: *FST/FREP/12/313*
Project Title: *The effect of Retinitis Pigmentosa on activities of daily living.*

Principal Investigator: *Mohammad Baranian*

The Chair of Faculty Research Ethics Panel (FREP), acting on behalf of the Committee, has agreed to grant ethical approval for your research. Under the terms of Anglia Ruskin University's *Policy and Code of Practice for the Conduct of Research with Human Participants* approval is for a period of three years from 11th April 2013

It is your responsibility to ensure that you comply with Anglia Ruskin University's Policy and Code of Practice for Research with Human Participants, and specifically:

- The Participant Information Sheet and Participant Consent Form should be on Anglia Ruskin University headed paper.
- For online surveys it is recommended that the researcher turns off the IP logging software to ensure secure communication between the survey taker and server.
- The procedure for submitting substantial amendments to the committee, should there be any changes to your research. You cannot implement these changes until you have received approval from FREP for them.
- The procedure for reporting adverse events and incidents.
- The Data Protection Act (1998) and any other legislation relevant to your research. You must also ensure that you are aware of any emerging legislation relating to your research and make any changes to your study (which you will need to obtain ethical approval for) to comply with this.
- Obtaining any further ethical approval required from the organisation or country (if not carrying out research in the UK) where you will be carrying the research out. Please ensure that you send the FREP Secretary copies of this documentation.
- Any laws of the country where you are carrying the research out (if these conflict with any aspects of the ethical approval given, please notify FREP prior to starting the research).
- Any professional codes of conduct relating to research or research or requirements from your funding body (please note that for externally funded research, a project risk assessment must have been carried out prior to starting the research).
- Notifying the FREP Secretary when your study has ended.

Information about the above can be obtained on our website at:

http://web.anglia.ac.uk/anet/rdcs/ethics/index.phtml/ and or
http://www.anglia.ac.uk/ruskin/en/home/faculties/fst/research0/ethics.html

Please also note that your research may be subject to random monitoring by the Committee.

Please be advised that, if your research has not been completed within three years, you will need to apply to our Faculty Research Ethics Panel for an extension of ethics approval prior to the date your approval expires. The procedure for this can also be found on the above website.

Should you have any queries, please do not hesitate to contact me. I wish you the best of luck with your research.

Yours sincerely,

S Short

Sue Short

Secretary to the Faculty Research Ethics Panel (FREP)
Faculty of Science and Technology
MAR325
Tel: 01245 683927 or 0845 196 3927
Email: FST-Ethics@anglia.ac.uk

cc. Dr Matthew Timmis

Appendix 2. Chapter 6 Ethical approval

Anglia Ruskin University

Cambridge Chelmsford Peterborough

Chelmsford Campus
Bishop Hall Lane
Chelmsford
CM1 1SQ

T: 0845 196 4779
Int: +44 (0)1245 493131
www.anglia.ac.uk

Ref: NS/jc/FMSFREP/15/16 017
Enquiries: Joanne Corney
Direct Line: 01245 684779
Date: 13th October 2015

Prof Pardhan, Dr Timmis and Mr Baranian

Dear Prof Pardhan, Dr Timmis and Mr Baranian

Re: Application for Ethical Approval

Principal Investigator:	Prof Pardhan, Dr Timmis and Mr Baranian
FREP number:	15/16 017 (amendments to FMS FREP 15/014)
Project Title:	Mobility of patients with central vision loss and peripheral vision loss.

Thank you for your email of Tuesday 13th October and for the information regarding an amendment to your project FMSFREP15/014 to involve Mr Baranian as a named researcher. We also acknowledge the amendments to include patients diagnosed with Retinitis Pigmentosa (RP) and the data collection of participants' walking on an 8-shaped mobility course. This was considered by the Chair of the Faculty (of Medical Science) Research Ethics Panel in advance of the next scheduled meeting in November.

I am pleased to inform you that your application has been approved by the Faculty Research Ethics Panel Chair under the terms of Anglia Ruskin University's Research Ethics Policy (Dated 23/6/14, Version 1).

Ethical approval is given for a period of 3 years from Tuesday 13th October 2015.

It is your responsibility to ensure that you comply with the Research Ethics Policy and Code of Practice for Applying for Ethical Approval at Anglia Ruskin University and specifically:

- The procedure for submitting substantial amendments to the committee, should there be any changes to your research. You cannot implement these changes until you have received approval from FREP for them.
- The procedure for reporting adverse events and incidents.
- The Data Protection Act (1998) and any other legislation relevant to your research. You must also ensure that you are aware of any emerging legislation relating to your research and make any changes to your study (which you will need to obtain ethical approval for) to comply with this.
- Obtaining any further ethical approval required from the organisation or country (if not carrying out research in the UK) where you will be carrying the research out. Please ensure that you send the FREP copies of this documentation if required, prior to starting your research.

Please also note that your research may be subject to random monitoring by the committee.

Please be advised that, if your research has not been completed within three years, you will need to apply to our Faculty Research Ethics Panel for an extension of ethics approval prior to the date your approval expires. The procedure for this can also be found on the above website.

Should you have any queries, please do not hesitate to contact me. May I wish you the best of luck with your research.

Yours sincerely

Susan Henstock
Secretary, Faculty Research Ethics Panel, for Science and Technology

T: 0845 196 2393
F: 0845 196 5056
E: Susan.henstock@anglia.ac.uk

cc. Prof. Shahina Pardhan (Supervisor)

Appendix 3. Chapter 7 Ethical Approval

11 November 2010

Dr Matthew Timmis
Postdoctoral Researcher
VERU
Room 204, Eastings
CAMBRIDGE

Dear Matthew,

Project Number: *FST/FREP/002*
Project Title: *The effect of Age-related Macular Degeneration on reach and grasp functions*
Principal Investigator: *Matthew Timmis*

Thank you for supplying revisions to your ethics application.

The Chair of Faculty Research Ethics Panel (FREP), acting on behalf of the Committee, has now agreed to grant ethical approval for your research. Under the terms of Anglia Ruskin University's *Policy and Code of Practice for the Conduct of Research with Human Participants* approval is for a period of three years from 10 November 2010.

It is your responsibility to ensure that you comply with Anglia Ruskin University's Policy and Code of Practice for Research with Human Participants and specifically:

- The procedure for submitting substantial amendments to the committee, should there be any changes to your research. You cannot implement these changes until you have received approval from FREP for them.
- The procedure for reporting adverse events and incidents.
- The Data Protection Act (1998) and any other legislation relevant to your research. You must also ensure that you are aware of any emerging legislation relating to your research and make any changes to your study (which you will need to obtain ethical approval for) to comply with this.
- Obtaining any further ethical approval required from the organisation or country (if not carrying out research in the UK) where you will be carrying the research out. Please ensure that you send the FREP Secretary copies of this documentation.
- Any laws of the country where you are carrying the research out (if these conflict with any aspects of the ethical approval given, please notify FREP prior to starting the research).
- Any professional codes of conduct relating to research or research or requirements from your funding body (please note that for externally funded research, a project risk assessment must have been carried out prior to starting the research).
- Notifying the FREP Secretary when your study has ended.

Information about the above can be obtained on our website at:

http://web.anglia.ac.uk/anet/rdcs/ethics/index.phtml/ and or add FREP web link

Please also note that your research may be subject to random monitoring by the committee.

Please be advised that, if your research has not been completed within three years, you will need to apply to our Faculty Research Ethics Panel for an extension of ethics approval prior to the date your approval expires. The procedure for this can also be found on the above website.

Should you have any queries, please do not hesitate to contact me. May I wish you the best of luck with your research.

Yours sincerely

Susan Henstock
Secretary, Faculty Research Ethics Panel, for Science and Technology

T: 0845 196 2393
F: 0845 196 5056
E: Susan.henstock@anglia.ac.uk

cc. Prof. Shahina Pardhan (Supervisor)

Appendix 4. Contact form

The effect of Retinitis Pigmentosa on activities of daily living

PARTICIPANT CONTACT FORM

Thank you for considering taking part in this research. Your participation would be highly appreciated. There are three stages to this research, which involve completing a questionnaire, undertaking visual and balance tasks. We are looking to recruit RP patients and those who support RP patients at regular bases for the future studies.

If you would like to be invited to participate in of these research studies, please leave your preferred contact detail below and hand the sheet back to the research member.

Your contact detail will kept safely and only accessible to the researcher. The questionnaire is also anonymous and all the collected data will be kept confidential.

Please note that expressing an interest does not commit you to taking part in any project. We will contact you (using your preferred contact) with details of particular studies, which you can then choose to participate in, or not.

Name:…………………………………......
Email:…………………………………………………………………………
Telephone:…………………………………..
Address:………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………
………………………………….

Appendix 5. Participant information sheet

PARTICIPANT INFORMATION SHEET

Title of research: The effect of Retinitis Pigmentosa on activities of daily living

Purpose of the study

'Previous studies have reported that lack of vision can affect balance and postural stability. However, most of the previous studies have used normally sighted individuals. This study is investigating if the lack of peripheral vision can affect balance of people with RP. Also, we are interested to explore the relationship between the severities of RP at different stages with postural instability.

We are inviting you to participate in the above research to help us investigate this area of study. The research is funded by Anglia Ruskin University and is being organised and supervised by Dr Matthew Timmis, with Mr Ahoora Baranian and Sara Al-Nahi as members of his research team.

Your Participation in this research project

Your participation in this research is entirely voluntary and you have the right to refuse participation or to withdraw from participation at any point. The study requires participants to take part who have had been diagnosed with RP, or who support people with RP. You have been chosen as a suitable candidate for this study.

If you agree to take part in this research, you will be asked to complete a self-report questionnaire regarding yourself. Following this your vision will be examined with two simple visual assessments.

Then, you will be asked to take part in the balance task. You will be asked to take off your footwear (shoes), so the sensory part of your feet can be examined. The examiner will ask you to stand on a force platform similar to a weighing scale in four different conditions. The conditions will include standing with your eyes open, eyes closed and standing on a piece of foam. During the balance data collection, you will be asked to stand as still as you can and you are expected not to talk. There will be a member of research present by your side to support you at all the time.

After taking part you will be debriefed and given the chance to ask additional questions.
Agreeing to participate in this research will not compromise your legal rights or your safety in any way.

Generally your information and data you provide will only be accessible to the researchers.

Information obtained from the research will be stored securely. Information kept on computer or presented for publication will be coded so that no individual can be recognised.

You will be given a copy of this to keep as well as a copy of your signed consent form.

For any further information please contact:

Ahoora Baranian, 201 Eastings Building, Anglia Ruskin University, East Road, Cambridge CB1 1PT.

Telephone: 01223 698 5860.

Email: mohammad.baranian@student.anglia.ac.uk

Appendix 6. participant Consent Form

Patient Consent Form

<u>Name of Investigator:</u> **Ahoora Baranian supervised by Dr Matthew Timmis**

<u>Project Title:</u> **The effect of Retinitis Pigmentosa on activities of daily living**

I have read the Patient Information Sheet and kept a copy. I have discussed this study with Dr/Mr ....

And all my questions have received satisfactory answers. I have understood the purpose of the study and know what my involvement will be. I do not need any more information but am free to request it at any time.
I can refuse to take part in this study or withdraw at any time without giving a reason and it won't affect how I am treated by the research team. I have also been informed that the confidentiality of the information I provide will be safeguarded.
Data Protection Act 1998: I agree to Anglia Ruskin University processing personal data which I have supplied. I agree to the processing of such
data for any purposes connected with the research and/or research project as outlined to me. I further agree to the University processing
personal data about me described as Sensitive Data within the meaning of the Data Protection Act 1998.

I agree to take part in the study.
Signed..
Date..
Name in Capitals..
Witnessed..
Date..............................
YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP
The Anglia Ruskin University Ethics Committee has approved this project.

Appendix 7. Examples of detailed letters from the participants with RP

[redacted]

Ahoora Baranian
Eastings 201
Anglia Ruskin University
Cambridge
CB1 1PT

Dear Ahoora,

R..P. Study.

Thank you for your communications regarding the Research Project you are planning to assess the effects of R.P. on peoples' everyday life. I find your approach interesting because it is the first positive project that I have seen which I hope will concentrate on what people can do based on what they can see rather than what they can't.

Please find enclosed mine and my wife's completed questionnaires and contact details.

As I mentioned to you on the phone I am 67, I have R.P., my father had R.P., my son has R.P. In our extended family starting with my grandmother who didn't have R.P., there are about 14 members with R.P. at the last count. I only mention this to indicate my level of interest.

Moorfields Eye Hospital in London has carried out a Research Project based on our family where they identified the specific defective gene which causes the condition, but this really only shows tht a "cure" will only be possible if the DNA can be changed. Despite all the gene therapy research I don't expect a "cure" any time soon so any help that projects like yours can give people will be much appreciated.

Stage 1. Completed. Stage 2. You need to be very careful with this stage as people have a whole range of physical conditions and abilities which can be confused with eye effects. Someone who does not appear to be very dextrous may be an ideal candidate from an R.P. perspective. The people who may be of most use may not attend community meetings at all, I certainly do not, so could not be included. Stage 3. This sounds okay but my comments on stage 2 also apply. I would be prepared to find the time and take part in Stage 3 bearing in mind that I am very busy and work almost every day.

I do have some ideas of my own but these are probably outside the scope of your project but I would be prepared to discuss them with you, and being a fellow Engineer you may well find them interesting.

In reference to the questionnaire the single item 'working activities' could have a page or two because there are numerous things that people need and want to do. Some will be relatively easy and some will be impossible without help. Most people will tend to do the things that they find not too difficult so the answers are not necessarily fully indicative. Because I get a lot of help I do things relatively easily which someone else would say was a 5.

The single item 'outside mobility' (walking on the street) is again very vague. There is a big difference between different places. For example a busy high street - very difficult, a quiet high street - not too bad, Paddington Station - not bad at all. (RNIB had an input into the re-design). Crossing a road almost anywhere definitely 5 for me. There are several reasons for this which need a long detailed discussion.

During the Moorfields research project I got to know the members of my extended family with R.P. I do not think any of them would be of any help with your research - some are too elderly and the others unlikely to co-operate - but in any case I would expect them to have received details in the same way that I did.

I hope I haven't bored you with my reply already but if I can be of any further assistance, please let me know.

Yours sincerely,

[redacted]

15-7-13

[redacted]

Dear Ahoora Boranian.

I have assisted my son to fill in Questonaire, and enclose same.

I could not fill in the Questonaire on my own behalf so am going to explain the situation

At fist Hywel was able to read with the help of a screen that made the writing a print much larger, but he has difficulty now, he use to be able to see his bank statement, but not now

We live on a farm in Mid Wales, The nearest public transport is 2½ miles away and goes Once a day Monday to Sat. at 9-15am returning at 3pm.

His sister goes with him when he does use the Mobility bus. Otherwise I take him to all appointments by car. and to meet bus.

I read all correspondence to him, and answer them if nessecary. As we have an Aga Cooker that has constant heat and no nobs to turn, he is able to Boil Kettle and cook simple food using Saucepans Mostly due to practice,

He cannot define clothes to match, but is very organized by hanging them Together.

Pants and socks are kept in neat piles. As I do all the laundry, he has them in neat piles ready.

He is a very happy person If he needs to buy groceries he will always ask an assistant for help.

I go with Hywel shopping for clothes.

As everything has always being the same and he has never left home, Most things happen automaticaly without thaught.

Hope this will help you a little

[redacted]

Getting around indoors	Doors are always shut never half open Floors clear Well lit room (not bright and no shadows) Going upstairs manageable coming downstairs extreme caution is necessary.
Getting around outside	Continual 'scanning' (i.e. left to right and up and down to ensure the way is clear and to avoid pavement furniture, bollards, signs etc. To be continually aware of uneven paths and kerbs. Apprehension amongst crowds and people moving in all directions. Difficulty in bright sunshine. Small children approaching from the side and dogs that are on extended leads.
Getting around outside (Night) low	Severe visual problems at night. Assistance is needed in a strange environment (i.e. doorways, overhanging branches, street signs).
Mental state	A loss of confidence A loss of independence Frustration Having to plan all movements. A varied sleep pattern can occur at the thought of a new experience in a strange environment. Anxiety Limited patience A more developed sense of hearing and the need for concentration. Embarrassment.
Communication	Difficulty in entering a crowded room and having to 'scan' the whole scene. Feeling very vulnerable amongst crowds

LOOKING

DR. [redacted]

Appendix 8. Virtual markers values

Participant	Virtual to Ref (cm)	Ref to toe (cm)	Ratio	W1	W2
Test	6	9	0.66	-0.66	1.66
Pilot 1	9	18	0.5	-0.50	1.5
Pilot 2	7	14	0.5	-0.50	1.5
1	7	20	0.35	-0.35	1.35
2	8	20	0.4	-0.40	1.40
3	6	18	0.33	-0.33	1.33
4	5	20	0.25	-0.25	1.25
5	7	22	0.31	-0.31	1.31
6	8	22	0.36	-0.36	1.36
7	5.5	20	0.27	-0.27	1.27
8	5	24	0.20	-0.20	1.20
9	4	20	0.2	-0.20	1.20
10	5	22	0.22	-0.22	1.22
11	6.5	20	0.32	-0.32	1.32
12	7	17	0.41	-0.41	1.41
13	7	19	0.36	-0.36	1.36
14	7	21	0.33	-0.33	1.33
15	6	22	0.27	-0.27	1.27
16	7	23	0.30	-0.30	1.30
17	5	20	0.25	-0.25	1.25
18	7	22.5	0.31	-0.31	1.31
19	6	18	0.33	-0.33	1.33
20	6.5	17	0.38	-0.38	1.38
21	8	19	0.42	-0.42	1.42
22	6	24	0.25	-0.25	1.25
23	8	19	0.42	-0.42	1.42
24	7	22	0.31	-0.31	1.31

25	8.5	20	0.42	-0.42	1.42
26	8	21	0.38	-0.38	1.38
27	7	23	0.30	-0.30	1.30
28	8	20	0.40	-0.40	1.40
29	6	24	0.25	-0.25	1.25
30	6	25	0.24	-0.24	1.24
31	7	24	0.29	-0.29	1.29
32	6	21	0.28	-0.28	1.28
33	7	24	0.29	-0.29	1.29
34	6	20	0.30	-0.3	1.3

Cane (cm)	Virtual to second[Bottom](cm)	Ref [second]to top [first] (cm)	Ratio	W1	W2	Marker Separation (+)	[Middle] y	[Bottom] y	[Middle]y - [Bottom]y	Ratio (a)	h
Pilot	15	20	0.75	-0.75	1.75						0
Pilot	574.47	-708.4	-523.3	-185.1	-3.82	203.2	708.4	523.3	185.1	3.82712	777.67
122	408.70	90.8	4.50	-4.50	5.50	90.8	498.4	407.8	90.6	5.50	499.50
132	389.61	100.5	3.87	-3.87	4.87	100.5	490.6	390	100.6	4.87	490.11
122	496.27	197.4	2.51	-2.51	3.51	197.4	550.3	393.7	156.6	3.51	693.67
109	414.00	99.8	4.14	-4.14	5.14	99.8	385.1	310.3	74.8	5.14	513.80
132	614.91	203.7	3.01	-3.01	4.01	203.7	708.5	532.2	176.3	4.01	818.61
137	501.88	207.3	2.42	-2.42	3.42	207.3	572	404.8	393.7	3.42	709.18

Appendix 9. Systematic review of literature for Filtering

	Title Name	Authors	Publisher	Participants	Variable	sampled at	Filtering
1	Postural control under visual and proprioceptive perturbations during double and single limb stances: Insight for balance training	Hazime et al., 2011	Bodywork and movement therapy	11 Healthy young adults	Displacement of CoP	64 Hz	Not described
2	The effect of lateral or medial wedges on control of postural sway in standing	A.S Aruin	Gait & Posture	20 young healthy volunteers	GRF	1000 Hz	20 Hz low-pass, 2nd order, zero-lag Butterworth filter
3	Effects of gaze strategy on standing postural stability in older multifocal wearers	Buckley et al., 2009	Clinical & Experimental Optometry	18 older adults	Displacement of CoP	100 Hz	Not described
4	Effects of visual deprivation on gait dynamic stability	Iosa et al., 2012	The scientific world journal	28 healthy young adults	root mean square	100 Hz	20 Hz low pass
5	Visual stabilization of posture in persons with central visual field loss	Turano et al., 1996	IOVS	20 people with normal vision and 19 with central field loss		100 Hz	cut-off 0.89 Hz
6	Postural sway in low back pain: Effects of dual tasks	Mazaheri et al., 2010	Gait & Posture	22 patients with LBP & 22 unimpaired people	Displacement of CoP	200 Hz	down-sampled without filtering to 100 Hz
7	Does postural stability affect grasping?`	Voudouris et al., 2013	Gait & Posture	17 healthy right handed	Displacement of CoP	150 Hz	Not described
8	The waterloo vision and mobility study: postural control strategies in subjects with ARM	Elliot et al., 1995	Ophthal. Physio Opt	20 ARM and 20 control	Displacement of CoP	100 Hz	fourth-order, zero phase shift, Butterworth low pass filter with cut-off of 10HZ
9	Balance control in Glaucoma	Kotecha et al., 2012	IOVS	24 Glaucoma and 24 control	Displacement of CoP	1000 Hz	Not described

10	Postural stability in the elderly during sensory perturbations and dual tasking: the influence of refractive blur	Buckley et al., 2003	IOVS	15 Elderly subjects	Displacement of CoP	Not described	Not described
11	Postural stability in primary open angle glaucoma	Shabana et al., 2005	Clinical & Experimental Ophthamology	35 with POAG and 21 control	Displacement of CoP	100 Hz	Hammering filter of width 17 (low-pass filtering with a cut-off 15 Hz)
12	Effect of Dual-Tasking on Postural control in subjects with nonspecific LBP	Salavati et al., 2009	SpIne	22 subjects with a history of nonspecific LBP	Displacement of CoP	200 Hz	Cut-off frequency of 10 Hz, with a sixth order Butterworth, zero-phase low pass filter at 10 Hz
13	Effect of expertise in shooting and Taekwondo on bipedal and uni-pedal postural control isolated or concurrent with a reaction-time task nonspecific LBP	Negahban et al., 2012	Gait & Posture	42 right-handed female	Displacement of CoP	100 Hz	zero-phase, sixth order Butterworth low-pass filter with a cut-off frequency of 10 Hz
14	Static and dynamic postural control in competitive athletes after anterior cruciate ligament reconstruction and controls	Mohammadi et al., 2012	Knee Surg Sports Traumatol Arthrosc	thirty athletes with a unilateral ACL injury	Displacement of CoP	100 Hz	Sixth order Butterworth, zero-phase low-pass filter at 10 Hz
15	Test–retest reliability of centre of pressure measures of postural stability during quiet standing in a group with musculoskeletal disorders consisting of low back pain, anterior cruciate ligament injury and functional ankle instability	Salavati et al., 2008	Gait & Posture	33 subjects with MSDs was recruited to provide subgroups of LBP representative	Displacement of CoP	200 Hz	cut-off frequency of 10 Hz was selected. For residual analysis, the data were filtered with a range of cut-off frequencies of 1–20 Hz.
16	The effects of cognitive loading on balance control in The effects of cognitive loading on balance control in patients with multiple sclerosis	Negahban et al., 2011	Gait & Posture	Twenty-three MS patients	Displacement of CoP	100 Hz	Not described

17	The effects of dual-tasking on postural control in people with unilateral anterior cruciate ligament injury	Negahban et al., 2009	Gait & Posture	Twenty-seven male patients	Displaceme nt of CoP	200 Hz	Zero phase, sixth-order, Butterworth low-pass filter with a cut-off frequency of 10 Hz
18	Balancing cognitive control: How observed movements influence motor performance in a task with balance constraints	Verrel et al., 2014	Acta Psychologica	16 young	anticipatory postural adjustment (APA)	100 and 1000 Hz	Low-pass-filtered using bidirectional Butterworth filter (cut-off frequency 20 Hz, order 5)
19	Postural sway and perceived comfort in pointing tasks	Solnik et al., 2014	Neuroscienc e Letters	12 Young healthy adults	Displaceme nt of CoP	100 Hz	low-pass filter during a 4th-order zero-phase lag Butterworth filter with a cut-of frequency at 10 Hz
20	Double-leg stance and dynamic balance in individuals with functional ankle instability	Groters et al., 2013	Gait & Posture	16 individuals with functional ankle instability (FAI) and 16 healthy controls	Displaceme nt of CoP	500HZ	low-pass filtered with a cut-off frequency of 6 Hz
21	Estimate of body motion during voluntary body sway movements	Couture et al., 2013	Gait & Posture	16 healthy	Displaceme nt of CoP	Not describe d	low-pass filter with a dual-pass, fourth-order digital Butterworth filter with 8 Hz cut-off
22	The correlation between movement of the centre of mass and the kinematics of the spine, pelvis, and hip joints during body rotation	Wada et al., 2013	Gait & Posture	24 Healthy men	Displaceme nt of CoP	200Hz	low-pass filtered using a Woltring filter with a cut-off frequency of 6 Hz
23	Short-term differential training decreases postural sway	James 2013	Gait & Posture	33 Healthy young	Displaceme nt of CoP	1000HZ	filtered with a 9th order 20 Hz low

							pass Butterworth filter
24	Maintaining standing balance by handrail grasping	Sarraf et al., 2013	Gait & Posture	16 Young healthy	Displacement of CoP	2000Hz	(50 Hz cut-off frequency
25	Test -retest reliability of muscle vibration effects on postural sway	Kiers et al., 2014	Gait & Posture	Twenty college students and staff	Displacement of CoP	200Hz	Low-pass filtered using a 2nd order bidirectional Butterworth filter with a cut-off frequency of 3 Hz
26	Visual availability, balance performance and movement complexity in dancers	et al., 2014	Gait & Posture	Eighteen undergraduate dancers (all females) from the Spanish Royal Conservatory of Dance and thirty healthy young women without any experience in dance	absolute error of the tilt platform	100HZ	Not described
27	Postural control in quiet standing in patients with psychotic disorders	Stensdotter et al., 2013	Gait & Posture	Seventeen patients with primary psychosis	Displacement of CoP	100Hz	low-pass filtered (12.5 Hz, second order, zero phase, Butterworth)
28	Postural control in Elderly subjects	Pyykko et al., 1990	Age and Ageing	17 elderly aged 85 years or more	Postural sway	33.3 Hz	non-linear 3 points median filter. Passband limit 3.3 Hz and stopband over 6.3 Hz
29	Postural Instability in Patients with Diabetic Sensory Neuropathy	SIMONEAU et al., 1994	DIABETES CARE	Seventeen had diabetes and significant sensory neuropathy, 17 had diabetes and no neuropathy, and 17 had neither diabetes nor neuropathy	Displacement of CoP	100 Hz	filtered with a 4th-order, zero-phase shift, Butterworth-type low-pass filter with a cut-off frequency of 5 Hz

30	Visual Stabilization of Posture in Retinitis Pigmentosa and in Artificially Restricted Visual Fields	Turano et al., 1993	IOVS	35 subjects with well-characterized RP and in 20 subjects with normal vision	Displacement of CoP	30 Hz	low-pass filter - Does not report the value
31	Stepping strategies for regulating gait adaptability and stability		Journal of Biomechanics	Ten healthy young subjects	Displacement of CoP	100 Hz	(Butterworth,10Hzcut-off
32	Comparison of a laboratory grade force platform with a NintendoWii Balance Board on measurement of postural control in single-leg stance balance tasks	Huurnink et al., 2013	Journal of Biomechanics	Fourteen healthy volunteers	Displacement of CoP	Not described	second order Butterworth low-pass filter, optimal cut-off frequency of 12 Hz
33	Effect of light finger touch in balance control of individuals with multiple sclerosis	Kanekar et al., 2013	Gait & Posture	Eleven individuals with relapsing–remitting MS	Displacement of CoP	Not described	filtered with a 20 Hz low-pass, 2nd order, zero lag Butterworth filter.
34	Age-related Differences in the Influence of Cognitive Task Performance on Postural control Under Unstable Balance Conditions	Makizako et al., 2013	International Journal of Gerontology	Thirty healthy younger adults and 27 healthy older adults	Displacement of CoP	1000 Hz	full-wave rectified and low-pass-filtered-50 Hz signal
35	Sensorimotor posture control in the blind: Superior ankle proprioceptive acuity does not compensate for vision loss	Ozdemir et al., 2013	Gait & Posture	Thirteen blind subjects and 15 age- and sex-matched	Displacement of CoP	100 HZ	second order Butterworth; fc = 0.86 Hz
36	The effect of vision elimination during quiet stance tasks with different feet positions	Sarabon et al., 2013	Gait & Posture	Thirty-eight healthy	Displacement of CoP	1000 HZ	2nd order Butterworth, 0.1–20 Hz band-pass filter
37	Altered centre of mass control during sit-to-walk in elderly adults with and without history of falling	Chen et al., 2013	Gait & Posture	15 healthy young adults, 15 elderly non-fallers, and 15 elderly fallers	Displacement of CoP	60 Hz	fourth-order Butterworth filter with a cut-off frequency of 8 Hz
38	Relationship between asymmetry of quiet standing balance control and walking post-stroke	Hendrickson et al., 2013	Gait & Posture	94 individuals with stroke	Displacement of CoP	256 Hz	low-pass filtered using a 4th order dual-pass

							Butterworth filter at 10 Hz
39	Visual Stabilization of Posture in Persons With Central Visual Field Loss	Turano et al., 1996	IOVS	19 subjects with CFL and in 20 subjects with normal vision	Displacement of CoP	100 Hz	Second order low-pass filter whose cut-off frequency is 0.89 Hz
40	Dual tasking affects lateral trunk control in healthy younger and older adults	Asai et al., 2013	Gait & Posture	Thirty healthy, community-dwelling older adults and 38 younger adults	Displacement of CoP	200 Hz	low-pass filtered using a dual pass zero lag Butterworth filter with a cut-off frequency set at 20 Hz
41	Age differences in the control of postural stability during reaching tasks	Huang et al., 2013	Gait & Posture	Fourteen young adults and 16 community dwelling older adults aged 65 years and over	Displacement of CoP	100 Hz	zero-lag, 4th order Butterworth filter using a 6 Hz cut-off
42	The influence of vision and support base on balance during quiet standing in patients with adolescent idiopathic scoliosis before and after posterior spinal fusion	de Santiago et al., 2013	The spine journal	The scoliosis group (SG) consisted of 15 girls with AIS (double curve), a right thoracic convexity, and a Cobb angle [26] greater than 45 (Fig. 1) who ultimately received surgical treatment	Displacement of CoP	100 Hz	filtered at a low-pass band with a cut frequency of 10 Hz
43	Stiffness control of balance during dual task and prospective falls in older adults: The MOBILIZE Boston Study	Kang et al., 2013	Gait & Posture	765 older adults age 70 or above	Displacement of CoP	240 Hz	low pass filtered with a cut-off of 60 Hz [18] using a 7th order Butterworth zero-lag digital filter

44	Ankle dorsiflexion strength relates to the ability to restore balance during a backward support surface translation	Fujimoto etal., 2013	Gait & Posture	16 healthy young adults	Displaceme nt of CoP	120 Hz	low-pass filtered using a fourth-order Butterworth filter with a cut-off frequency of 8 Hz.

Appendix 10. An example of Participants medical detail for chapter 6

			None=0, 1-4=1, >4=2	No=0, Yes=1	None=0, 1-2=1, 3-5=2, >5=3	No=0, Yes=1
Number	**Other vision issues**	**Other health conditions**	**Medications**	**Alcoholic drink**	**Numbers of falls**	**fear of falling**
1	Glaucoma	LBP	1	0	1	1
2	Cataract	Usher's	0	0	0	0
4	None	Arthritis, osteoarthritis	2	0	0	0
5	None	Deafness	0	0	0	0
6	Cataract removed 10 years ago	None	1	0	3	1
7	Cataract	Hiatus hernia	1	0	0	1
8	Cataract	None	0	0	0	0
9	Operated cataracts	Hearing loss	0	0	1	1
10	None	None	0	0	0	0
11	Cataracts	Hearing loss	1	0	2	0
12	Short-sighted	HBP	1	0	0	1
14	Operated cataracts	broken 1st vertebral bone	1	1	1	0
15	Cataracts	None	0	0	1	0
16	Blood clot in R-E	None	0	1	0	0
17	Cataracts	None	0	1	0	1
18	None	None	0	0	0	0
19	Operated cataracts	Hearing loss (Usher's), Hypertension	1	0	0	0
20	None	None	0	0	0	0
21	None	Arthritis	2	0	1	1

22	None	None	0	0	0	0
23	None	Hypothyroidism	1	0	1	0
24	None	Diabetes	1	0	1	0
25	None	None	0	0	3	1
26	None	Epilepsy's, borderline diabetes	1	0	0	0
27	None	None	0	0	0	0
28	Short-sighted	Bronchiectasis	1	0	1	1
29	None	Migraines	0	0	0	1
30	None	HBP	2	0	1	0
31	Short-sighted	None	0	0	0	0
32	None	None	0	0	0	0
33	None	None	0	0	0	0
34	Siogen Syndrome	Arthritis	2	0	0	0
36	None	Asthma,	1	0	2	1
37	Short-sighted	None	0	1	3	0
39	Short-sighted	None	1	1	2	1
40	Operated cataracts	None	0	1	3	0
41	None	DVT	1	0	1	1
42	None	Ankle problem	0	0	2	0
43	None	None	0	0	0	0
44	None	HBP, Hip replacement, Hearing loss	1	0	1	0
45	Operated cataracts	Usher's	1	1	2	0
47	None	None	0	0	0	0
48	Operated cataracts	Diabetes, Thyroxine	1	1	1	1

49	Long-sighted	None	1	1	1	0
50	None	None	0	0	0	0
51	None	None	0	1	0	0
52	Laser surgery	None	0	0	0	0
53	None	None	0	0	0	0
54	Left lazy eye	None	1	0	0	1
55	None	None	0	0	0	0
56	None	None	1	0	0	0
57	None	None	1	0	1	0
58	Operated cataracts	None	0	0	1	0
59	Operated cataracts	History of Heart attack (2007)	2	0	0	0
60	None	Arthritis, Stroke (2006)	1	0	0	0
61	Cataracts	None	1	0	0	0
62	Short & Long-sighted	IBS	1	0	2	0