Institution: Anglia Ruskin University

Unit of Assessment: 03 – Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study: Reducing the risk of sight-threatening diabetic retinopathy in people of Asian origin in the UK, Nepal, India, Thailand and China

Period when the underpinning research was undertaken: 2001–2020

Details of staff conducting the underpinning research from the submitting unit:

Name(s):	**Role(s) (e.g. job title):**	**Period(s) employed by submitting HEI:**
Professor Shahina Pardhan	Professor, Director of Vision and Eye Research Institute	01.03.2001–present
Raju Sapkota	Senior Research Fellow	03.02.2010–present
Georgina Nakafero	Research Fellow	01.03.2016–22.01.2017
Professor Dingchang Zheng	Professor of Medical Technology	01.05.2015–03.12.2019

Period when the claimed impact occurred: 2014–July 2020

Is this case study continued from a case study submitted in 2014? No

1. Summary of the impact (indicative maximum 100 words)

People from Asian backgrounds have a significantly higher risk of diabetes compared to Caucasians. Research led by Professor Shahina Pardhan of Anglia Ruskin University showed higher levels of sight-threatening diabetic retinopathy in Asians linked to poor health literacy, language barriers and lower uptake of retinal screening. The research has led to: (i) the development and dissemination of evidence-led, culturally and linguistically appropriate awareness and lifestyle interventions by policy makers and community organisations; (ii) change in patient care practices by healthcare professionals. These have led to behaviour change and improved outcomes in more than 110,417 people in the UK, India, Nepal, China and Thailand, evidenced by an 87–98% uptake of retinopathy screening from a baseline of 20–36%, and a reduced risk of blindness by 60–90%.

2. Underpinning research

Diabetes affects 463 million people globally. Diabetic retinopathy, a serious complication of diabetes, is a leading cause of blindness, especially amongst people of Asian origin. The risk of diabetic retinopathy increases significantly when diabetes is poorly controlled and/or when it is not detected early. Timely detection and treatment of diabetic retinopathy reduces the risk of blindness by 60–90%.

The underpinning research was led by Prof. Shahina Pardhan and her team listed above at Anglia Ruskin University (ARU), with Prof. Jim Gilchrist (University of Bradford, collaborating on R1), plus international collaborators at large hospitals in Nepal, India and China, on extensive clinical, lifestyle and health literacy data. The research provided evidence that patients most at risk of sight-threatening diabetic retinopathy showed lower health awareness around diabetic complications, the importance of good diabetic control and regular retinal screening. The research also showed that patients experienced cultural and language barriers to accessing health information and making lifestyle changes.

Pardhan's research on 500 patients conducted in Bradford and published in 2004 [R1] showed a higher incidence of sight-threatening retinopathy (STR) in South Asian compared to Caucasian

diabetic patients. South Asian patients had higher levels of STR at a much younger age or a shorter duration of diabetes. Further research [R2, 3] found that people of South Asian origin showed lower health literacy around diabetes and diabetic retinopathy, lower awareness around diet and physical activity, and experienced barriers to accessing healthcare, poor self-help skills and language barriers.

Research [R3] using focus groups in the UK showed that different South Asian demographic groups (defined by age, literacy, and gender) exhibit different barriers to improving the control of diabetes. The illiterate older group reported lack of awareness around the nutritional content of food, language barriers, lack of awareness of the importance of retinal screening, and of the need to rebook missed hospital appointments. Most participants were not aware of any national diabetes education programmes, suggesting that the UK's current 'one size fits all' educational programmes were not culturally appropriate for different ethnicities and hence less effective.

In Nepal, Pardhan and collaborators [R4] used a questionnaire to gather data on awareness about diabetes control, self-help and lifestyle in 200 patients. This showed that patients who were at a higher risk of uncontrolled diabetes (and therefore increased risk of blindness) also showed reduced health literacy and poor treatment compliance. In addition, although patients self-reported that their diabetes was adequately controlled, clinical tests showed high blood sugar levels in these patients.

Research conducted in India [R5] on 190 adults with diabetes showed that, while patients were generally aware of the need for regular exercise, only 55% undertook it regularly. The majority of patients did not know what physical activity to undertake and for how long; also, more men than women with diabetes took part in regular physical activity.

Pardhan's research in China [R6] on patients with diabetes attending an eye clinic showed that a majority (67%) were presenting for the first time with very late stages of retinopathy; as a result, treatment for this group was difficult. A significant proportion of patients showed a lack of awareness that poorly controlled diabetes and poor lifestyles could lead to blindness, and that regular retinal screening was important. In addition, 51% reported that they thought that their diabetes was well controlled when clinical tests found that it was not, and 65% did not undertake the recommended level of exercise.

3. References to the research

The body of research represented below meets the two-star threshold for underpinning research as they have been published in peer reviewed journals, received 39 citations and attracted funding from the College of Optometrists, British Council (Newton Fund) and Lions Club International:

1. **Pardhan**, **S.,** Gilchrist, J., & Mahomed, I. (2004). Impact of age and duration on sight-threatening retinopathy in south Asians and Caucasians attending a diabetic clinic. Eye (London, England), 18(3), 233–240. doi: 10.1038/sj.eye.6700629
2. **Pardhan**, **S.,** & Mahomed, I. (2004). Knowledge, self-help and socioeconomic factors in South Asian and Caucasian diabetic patients. Eye (London, England), 18(5), 509–513. URL: https://www.nature.com/articles/6700680
3. **Pardhan, S.**, **Nakafero, G.**, Raman, R., & **Sapkota, R.** (2018). Barriers to diabetes awareness and self-help are influenced by people's demographics: perspectives of South Asians with type 2 diabetes. Ethnicity & Health, doi:10.1080/13557858.2018.1455809
4. **Sapkota, R. P.,** Upadhyaya, T., Gurung, G., Parker, M., Raman, R., & **Pardhan, S.** (2018). Need to improve awareness and treatment compliance in high-risk patients for diabetic complications in Nepal. BMJ Open Diabetes Research & Care, 6(1), e000525. doi:10.1136/bmjdrc-2018-000525
5. López Sánchez, G. F., Smith, L., Raman, R., Jaysankar, D., Singh, S., **Sapkota, R.,** Díaz Suárez, A., & **Pardhan, S.** (2019). Physical activity behaviour in people with diabetes residing in India: A cross-sectional analysis. Science & Sports, 34(1), e59–e66. doi: 10.1016/j.scispo.2018.08.005

6. **Sapkota, R.,** Chen, Z., **Zheng, D., & Pardhan, S.** (2019). The profile of sight-threatening diabetic retinopathy in patients attending a specialist eye clinic in Hangzhou, China. BMJ Open Ophthalmology, 4(1), e000236-000236. doi:10.1136/bmjophth-2018-000236 Submitted in REF2.

4. Details of the impact

The research impacted two main groups: patients with diabetes, and healthcare professionals in UK, Nepal, China, India, and Thailand. The key findings from Pardhan's research led to extensive and ongoing engagement with various stakeholders, including clinicians, hospitals, community leaders, and professional bodies within the UK and in Nepal, India, Thailand and China. This in turn led to the development of culturally, geographically and linguistically appropriate strategies to improve health literacy and retinal screening uptake and to promote healthier lifestyles. At least 110,417 individuals with diabetes directly benefited from the research, acquiring a better understanding of diabetes and how to reduce the risk of diabetic retinopathy.

Behaviour change through improved awareness of diabetic retinopathy screening in patients

In the UK, Pardhan and her team, based on the findings of the UK research [R1–3] disseminated key information on diet, lifestyle and the importance of retinal screening via interviews on radio and television including ITV News Anglia, British Forces Broadcasting Service, Gurkha Radio (May 2018), Salaam Radio (a Muslim community station), and Online Services (OS) Nepal [E1 (i-iii)]. These, in turn, led to invitations by South Asian community groups and clinicians and the co-production of three short diabetic awareness programmes appropriate for the UK in Nepali, Hindi and Urdu languages, addressing the need for culturally and linguistically appropriate training programmes. The programmes, delivered in the form of video clips in the three languages covering the four themes of good diabetes control, dietary advice on Asian food, physical activity and the importance of retinal screening [R1–3] – all directly addressing the lack of knowledge around diet and exercise and language barriers that was identified by the research. The videos were disseminated jointly by the ARU Diabetic Retinopathy Awareness and Prevention Programme (ARUDRAPP) led by Pardhan, and community teams at the grassroots level at community centres, mosques, religious festivals and community gatherings across the country, including Aldershot, Peterborough, Hays and Harlington, Birmingham, Bexley and Welling, Cambridge, and Luton (2018–2020). Altogether the programme reached 11 South Asian communities across the UK with a joint membership of over 15,150. Following one event, the chairman of the Pakistan Community Association of Peterborough stated that 90% of attendees found the workshop very useful. Participants commented: *"We will share this knowledge and awareness about diabetes and importance of attending retinal screening to our family members and friends who have diabetes"* [E2 (i)]. Participants attending workshops organised by the Non-Resident Nepali Association stated: *"We were ignoring letters by doctors…. but we will not ignore them now - we have now had our eyes photographed and we will continue to do so on a regular basis"* [E2 (ii)]. This work has the potential for a large nation-wide study to examine how the behaviour change leads to improved patient outcomes.

In Nepal, [informed by R4] the Diabetes and Endocrinology Association of Nepal (DEAN) invited Pardhan and her team to a brainstorming meeting with 25 people in 2018 to develop training for diabetic patients. Participants included representatives of DEAN and the Nepal Health Research Council, diabetic patients, and healthcare providers including a diabetes doctor, a dietician, an ophthalmologist, a physical activity instructor, and a behaviour change worker. Diabetes-awareness training, culturally appropriate to the Nepali context, was developed in the local language, to address the barriers identified by the research. DEAN stated: "*This (research) has led to improved strategies [and]…an intervention to improve diabetic control"* [E3]. The Nepalese Association of Optometrists has been rolling out the training programme via outreach activities to 50 villages in all 7 provinces of Nepal [E4]. Since 2018, the Diabetes, Thyroid and Endocrine

Care Centre, one of the two major diabetic centres in Pokhara, Nepal's second largest city, has used the training programme to improve awareness for all their diabetic patients attending clinics [E5]. By the end of 2020, the training had benefited 28,356 patients, of whom 89% requested retinal screening compared to 28% prior to the training. A randomised clinical trial (ISRCTN10990062) has also been set up in collaboration with Pardhan's team. Preliminary data shows that 98% of patients in the intervention group requested a diabetic retinal check within three months, compared to 36% in the control group [E5].

In India (Darjeeling), the training programme, developed in Hindi and Nepali, has also been delivered to all patients with diabetes attending Kurseong subdivisional hospital, a tertiary care hospital, since 2018. The uptake of retinal screening was historically as low as 20%. Between January 2018 and May 2020, the training was delivered to 26,556 patients, 88% (n=23,369) of whom then requested retinal screening [E6]. The programme has demonstrably improved knowledge and awareness of diabetic treatment and uptake of retinal screening. Patients reported: "*We thought our own herbal medicines are enough - now we know that we need to take the medicine given by our doctors." "We will go and have a diabetic eye check today - we don't want to go blind by delaying it."* [E6].

Changes in patient care by healthcare professionals

In Nepal, following ARU's input into an evidence-based approach [R3, 4], doctors at the Himalaya Eye Hospital in Pokhara initiated improved patient care for those needing surgery. The hospital is the largest tertiary eye hospital in the western region of Nepal, providing comprehensive eye care services to a population of 3 million people, with a catchment area covering 25% of the total land area of Nepal. Doctors at the hospital now actively follow up on patients with diabetes. The hospital states that *"Pardhan's research …. has highlighted the need for more support"* and this has *"led us to target those patients who are more at risk of blindness".* It points out that this has *"already improved health of a majority (87%, n=9755) of our patients who are most at risk of going blind"* [E7].

In India, the research collaboration between the ARU team and Sankara Nethralaya Hospital in Chennai (2016–2020 [R3, 5]), led to innovative approaches to improving patient attendance. The hospital, rated among the top four ophthalmic institutions worldwide (2020, *Newsweek*) and treating 17,000 patients annually with sight-threatening retinopathy, states: "*[The] research has directly led to a system by which we now send text messages to all our patients to attend the clinics. We have developed a bespoke one-to-one counselling service for patients with sight-threatening retinopathy to explain the importance of regular attendance and treatment"* and "*this has already improved attendance…and reduced risk of blindness in 90% (n=30,600) of all the patients with sight-threatening retinopathy"* [E8].

In China, ARU's research collaboration [R6] with healthcare professionals at the Second Affiliated Hospital of Zhejiang University, which is the second largest hospital in Hangzhou (serving 600,000 outpatients in the country's eastern region) led to strategies to address the high level of diabetic blindness in patients attending the eye clinics. Pardhan gave a series of invited talks in October 2016, and also organized a three-day seminar at Southern University of Science and Technology in Shenzhen that brought together 41 researchers from the UK and China, funded by British Council's Newton fund (2016-RLWK7-10178), to brainstorm community-based solutions for vision and hearing problems (December 2017). These led to the co-development of leaflets in Chinese for the hospital. The hospital states *"[These] leaflets are the first to be written in Chinese and distributed to every patient attending the diabetic clinic. We have also developed a programme of retinal screening at the point of diagnosis… and we also send regular reminders to our diabetic patients. This has already reduced the risk of diabetic blindness in our patients"* [E9]. A further update on data has not been possible because of COVID-19.

In Thailand, the ARU research on barriers to retinal screening [R3, 4] informed Rajavithi Hospital in Bangkok (2018) to address the low uptake of retinal screening (38%) delivered by Thailand's national retinal screening programme. Meetings with Pardhan led to the development

of various strategies to address this situation, which were approved by the Ministry of Health. The Chief of the Department of Medical Policy Development and Strategic Planning at the hospital states: *"The Ministry [of Health] has commissioned a national programme in five regional centres, that is informed by Professor Pardhan's research to improve compliance of retinal screening and also treatment*". As a result, eyecare staff from five screening centres in Thailand attended diabetic retinopathy courses in India to upgrade their skills in order to address the barriers that have led to the low levels of retinal screening among patients in Thailand [E10]. Further data collection has not been possible due to COVID-19.

5. Sources to corroborate the impact (indicative maximum of 10 references)

E1: Media reports (i): ITV News Anglia, November 2018; (ii) Salaam Radio (Peterborough), a Muslim community station, February 2020; (iii). OSNepal, July 2017.
E2: UK Testimonials (i) Testimony from Pakistani Community Association of Peterborough provided by its Chairman. 19/06/2019. E2 (ii): Testimony from Non-resident Nepalese Association UK, provided by Non-resident Nepalese Association UK Health Coordinator, 21/07/2019.
E3: Testimony from Diabetes and Endocrinology Association of Nepal (DEAN), provided by Vice President, DEAN, 27/12/2018.
E4: Nepalese Optometrists' website showing the rollout of the community-based programme in 50 villages in all the seven provinces of Nepal, 2020.
http://www.optometrynepal.org/?news&id=50
E5: Website from Diabetes, Thyroid and Endocrine Care Centre in Pokhara, one of the two major diabetic centres in the second largest city in Nepal (Pokhara)
https://www.dteccpokhara.com.np/research/
E6: Testimony from Kurseong Sub-Division Hospital, Darjeeling, West Bengal, India, provided by Chief Medical Superintendent, Kurseong sub-divisional hospital, 05/06/2020.
E7: Testimony from Himalaya Eye Hospital Pokhara, Nepal, provided by Senior Ophthalmologist, 23/12/2018.
E8: Testimony provided by Vice President and Medical Director/Administration, Sankara Nethralaya Medical Research Foundation (Chennai, India), 13/01/2020.
E9: Testimony from 2nd Affiliated Medical Hospital, Zhejiang University, Hangzhou, China, provided by Professor of Endocrinology,10/06/2019.
E10: Testimony from Rajavithi Hospital in Bangkok, Thailand, confirming Pardhan's research has influenced support from the Ministry of Public Health in Thailand,13/12/2018.