Institution: London School of Hygiene & Tropical Medicine (LSHTM)

Unit of Assessment: UoA2 – Public Health, Health Services & Primary Care

Title of case study: Improving the control of blindness in children in low- and middle-income countries through programmes, policy and legislation

1. Summary of the impact

Professor Gilbert's research identified retinopathy of prematurity (ROP) to be a major cause of blindness in children in middle-income countries and cities in Asia, and delineated those infants most at risk. Since Gilbert joined LSHTM in 2002, her research and advocacy have led to ROP being prioritised for control by the Pan American Health Organization, with regional guidelines developed for Latin America, and national guidelines in many middle-income counties. Programmes for control are expanding and improving. Six Latin American countries have made eye examination mandatory. Although difficult to quantify, these initiatives are preserving the sight of many thousands of infants.

2. Underpinning research

In 1993, while at the Institute of Ophthalmology, Clare Gilbert worked with WHO to develop the first classification system for blindness in children, which has become the standard methodology. Initial research entailed examining children in schools for the blind in Latin America, Eastern Europe, Africa and Asia. Research published in 1997 demonstrated for the first time that ROP was as an important cause of avoidable blindness in children in middle-income countries.

In June 2002, Gilbert moved to LSHTM as Senior Lecturer in International Eye Health. Population-based studies undertaken in a number of countries (e.g. Vietnam and Bangladesh) showed the situation to be dynamic, with some causes of blindness declining in importance while ROP was increasing in the middle-income countries of Latin America and Eastern Europe, and in the emerging economics of China, India and Vietnam.[3.1]

A multi-country study led by Gilbert clearly demonstrated that the population of infants at risk of severe ROP varies by level of development,[3.2] and more detailed studies in South Africa[3.3] and Brazil[3.4] identified weaknesses in neonatal service delivery. The large, prospective study in seven neonatal units in Rio de Janeiro, Brazil[3.4] had several purposes. An initial situation analysis of the health system highlighted limitations in human resources, technology and equipment, leadership and governance, and information management. Most of the nursing was provided by nurse assistants who had received no formal training. A further purpose was to determine which babies were at risk of ROP, to inform screening criteria. Findings supported the earlier work by Gilbert that bigger, more mature infants develop severe ROP, which has important implications for screening criteria. Researchers also explored the additional workload if wider screening criteria were used. A case control study was nested within this study, showing for the first time that neonatal units were an independent risk factor. This supported the notion that ROP is a reflection of the overall level of neonatal care and that improvement in many aspects of the health system are needed to prevent ROP.

A further study in Rio,[3.5] with a before and after design, assessed whether an educational package for nurses, strengthening information systems and building the capacity of nurse tutors would reduce mortality and ROP. The results showed that 'healthy survival' (i.e. without ROP) was declining in the pre-intervention year, and that the downward trend reversed in the post-intervention year. Unfortunately, the change in trend was not statistically significant. However, a study in Argentina in 2012[3.6] showed that better control of oxygen reduced the risk of severe ROP.

A situation analysis of 32 neonatal units in five states in Mexico highlighted limitations in service delivery, lack of awareness among nurses of risk factors for ROP and poor nursing practices. Only 25% of infants at risk of ROP were in units with an ROP programme of adequate quality.

3. References to the research

3.1 Gilbert, C, Fielder, A, Gordillo, L, Quinn, G, Semiglia, R, Visintin, P and Zin, A, on behalf of the International NO-ROP Group (2005) Characteristics of infants with severe retinopathy of prematurity in countries with low, moderate, and high levels of development: implications for screening programs, *Pediatrics,* 115(5): e518–e525, doi: 10.1542/peds.2004–1180. Citation count: 137

3.2 Gilbert, C (2008) Retinopathy of prematurity: a global perspective of the epidemics, population of babies at risk and implications for control, *Early Human Development*, 84(2): 77–82, doi:10.1016/j.earlhumdev.2007.11.009. Citation count: 106.

3.3 Varughese, S, Gilbert, C, Pieper, C and Cook, C (2008) Retinopathy of prematurity in South Africa: an assessment of needs, resources and requirements for screening programmes, *British Journal of Ophthalmology*, 92(7): 879–882, doi:10.1136/bjo.2008.137588. Citation count: 5

3.4 Zin, AA, Moreira, MEL, Bunce, C, Darlow, B and Gilbert, C (2010) Retinopathy of prematurity in 7 neonatal units in Rio de Janeiro: screening criteria and workload implications, *Pediatrics*, 126(2): e410–e417, doi:10.1542/peds.2010-0090. Citation count: 14

3.5 Darlow, BA, Zin, AA, Beecroft, G, Moreira, MEL and Gilbert, C (2012) Capacity building of nurses providing neonatal care in Rio de Janeiro, Brazil: methods for the POINTS of care project to enhance nursing education and reduce adverse neonatal outcomes, *BMC Nursing*, 11(3), doi:10.1186/1472-6955-11-3. Citation count: 1

3.6 Urrets-Zavalia, JA, Crim, N, Knoll, EG, Esposito, FA, Collino, E, Urrets-Zavalia ME, Saenz-de-Tejada, G, Torrealday, JI, Serra, HM and Gilbert C (2012) Impact of changing oxygenation policies on retinopathy of prematurity in a neonatal unit in Argentina, *British Journal of Ophthalmology*, 96(12): 1456–1461, doi:10.1136/bjophthalmol-2011-301394. Citation count: 0.

Key grants

The Thrasher Medical Research Trust (USA); Christofel Blind Mission (CBM) (Germany). The other large donor wishes to remain anonymous.

4. Details of the impact

Since Gilbert joined LSHTM in 2002 she has presented research findings extensively which has led to greater awareness of the public health problem of ROP. Dissemination has been through workshops attended by ophthalmologists, neonatologists and neonatal nurses: 19 workshops in Latin America (Brazil, Mexico, Colombia, Cuba, Venezuela, Panama and Peru), and 3 in Eastern Europe. Other facilitators are now taking over this role to increase the reach. Presentations have been made since 2008 to Ministries of Health (Peru, Brazil, Jamaica), at two World ROP Congresses (India 2009; China 2012), to NGOs who support prevention of blindness (Sightsavers; ORBIS International; Standard Chartered Bank's Seeing is Believing programme) and at numerous international, regional and national meetings, conferences and seminars. Research findings have been summarised in five textbooks (13 chapters, including updates in new editions), one of which, *The Epidemiology of Eye Disease*, is the standard textbook for several postgraduate training courses.[5.1]

The educational package developed for the Rio study was made available in 2013 as an online course (at http://neonatal.estacaodigitalsaude.org.br/aia/) and over 4,500 professionals have registered.

Greater awareness that ROP is a major avoidable cause of blindness in children has had the following impact:

- ROP continues to be recognised as a major cause of avoidable blindness by VISION 2020: The Right to Sight, which is the 20-year global initiative of WHO and the International Agency for the Prevention of Blindness (IAPB). The latter is an umbrella organisation of all the organisations

involved in prevention of blindness including NGOs, professional bodies, service providers, the corporate sector and university departments. IAPB currently has 155 members.
- In 2009 the control of blindness due to ROP was prioritised within the Pan American Health Organization's prevention of blindness policy for Latin America[5.2] and the Caribbean in 2010.[5.3,5.4,5.5]
- ROP is a priority in the Chinese National Plan for the Prevention and Treatment of Blindness (2012–2015).
- In 2008, neonatologists from 8 countries, ophthalmologists from 12 countries and neonatal nurses from 6 countries in Latin America met in Panama to develop regional guidelines for ROP programmes, which have since been published, referencing the applicant's research.[5.6] These guidelines are being updated and modified by many other countries in the region (e.g. Venezuela, Nicaragua). Guidelines are being drawn up in India.
- In Peru (2010),[5.7] Mexico (2013),[5.8] Argentina, Chile, Colombia and El Salvador, legislation has been passed making eye examination of preterm infants mandatory.
- Ministries of Health in Argentina, Chile, Colombia, El Salvador, Mexico and Peru have issued resolutions recommending eye examination of all preterm births, and in Rio de Janeiro programmes are fully integrated within state and municipal health systems.
- The Pan American Ophthalmology Society has established an ROP Society.
- There has been increased support for the control of ROP in Latin America and other countries (e.g. Pakistan, India, China, Vietnam) from NGOs: ORBIS international (USA),[5.9] CBM, (Germany), Seeing is Believing (UK), the Queen Elizabeth Diamond Jubilee Trust (UK), Fred Hollows Foundation (Australia). UNICEF has supported initiatives for prevention in Argentina and is supporting initiatives in India.

All these factors have led to rapid expansion of ROP programmes in many countries in Latin and Central America, and in Asia. For example, in Rio de Janeiro, Brazil, only 40% of preterm infants were admitted to neonatal units with a screening programme in 2002, but this has increased so that most government units now have programmes. Similar expansion has occurred in other major cities in Brazil. Legislation in Peru has had a dramatic impact, building consensus and leading to expansion of programmes in Lima and many other cities across the country.

Treatment at a critical stage in the natural history of ROP is highly effective at preventing blindness. In the screening programme in Rio de Janeiro 1,444 infants most at risk of ROP were examined and 118 were treated. The disease regressed completely in all but 5 infants. Without treatment at least a quarter would have become blind. Data from Argentina suggests that there has been a dramatic reduction in blindness from ROP, with far fewer children being admitted to schools for the blind than 10 years ago, when almost 40% of blindness was due to ROP.[5.10] Extrapolating these findings across Latin America and other low- and middle-income countries means that many thousands of infants are having their sight preserved.

5. Sources to corroborate the impact

5.1 Editor, *The Epidemiology of Eye Disease*. (Johnson, GJ, Minassian, DC, Wheale, RA and West, SK (2012) *The Epidemiology of Eye Disease*, 3rd edn. London: Imperial College Press).

5.2 Pan American Health Organization (2009) *144th Session of the Executive Committee: Plan of Action on the Prevention of Avoidable Blindness and Visual Impairment, CE144/20* (English). Washington, DC: WHO, http://www2.paho.org/hq/dmdocuments/2009/CE144-20-e.pdf (accessed 11 September 2013). Gilbert's work is referred to in paragraph 8 and reference 9.

5.3 Pan American Health Organization (2010) *Strategic Framework for VISION 2020: The Right to Sight, Caribbean Region*, OPS/PBL/2010.1 PAHO/ECC. Barbados: WHO, http://www.eyecarecaribbean.com/ecc/research/VISION%202020%20Strategic%20Framework-Caribbean%202010.pdf (accessed 11 September 2013). ROP covered in para 2.1.1, and Gilbert's work referenced in Bibliography ref 6.

5.4 Regional Adviser on Eye Care, Pan American Health Organization, WHO.

5.5 Regional Coordinator, VISION 2020 Latin America.

5.6 Grupo de Trabajo Colaborativo Multicéntrico para la Prevención de la Ceguera en la Infancia por Retinopatía del Prematuro (Lomuto C, Benítez A, Bouzas L, Galina, L, Sepúlveda, T, Goldsmit, G, Visintín, P, Hauviller, V, Brussa, M, Luján, S, Alda, E, Bauer, G, Dinerstein, A, Santos, N, Marinaro, S, Falbo, J, Quiroga, A, Erpen, N, Sola, A, Gilbert C and Vohr, B) (2008) Recomendación para la pesquisa de Retinopatía del Prematuro en poblaciones de riesgo [Recommendations for retinopathy of prematurity screening in at-risk populations] (Spanish), *Archivos Argentinos de Pediatría,* 106(1): 71-76, http://www.scielo.org.ar/scielo.php?script=sci_arttext&pid=S0325-00752008000100016&lng=en&nrm=iso&tlng=en (accessed 23 September 2013).

5.7 Ministro de Salud (2010) *Aprueban Norma Técnica de Salud de Atención del Recien Nacido pre término con riesgo de Retinopatia del Prematuro* (Spanish), Resulition Ministerial no 707–2010/MINDSA. Lima: Ministro de Salud, Peru,13 September.

5.8 Secretaria de Salud (2013) Decreto por el que se reforma el articulo 61 de la Ley General de Salud (Spanish), *Diaro Oficial de la Federación: Organo del Gobierno Constitucional de los Estados Unidos Mexicanos*, 712(19), 25 January, http://www.dof.gob.mx/nota_detalle.php?codigo=5285817&fecha=25/01/2013 (accessed 23 September 2013).

5.9 Director LAC Regional Program, Monitoring & Evaluation, & Senior Technical Adviser, ORBIS International.

5.10 Director, Valentin Hauy, Centre for the Rehabilitation of the Visually Impaired, Corrientes, Argentina.