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EDITORIAL

Uniting vision data and more

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> My books are water; those of the great geniuses are wine – everybody drinks water
>
> Mark Twain [1]

The above quote starts a book by Lang and Secic [2] "How to Report Statistics in Medicine" which continues with "Both fine wines and biostatistics are characterized by the complexities and subtleties that are truly appreciated only by the relatively few people who devote time to master them". Many people want simply to understand statistical or indeed epidemiological concepts but do not aspire to appreciate the nuances. We might regard routine data and epidemiological studies in a similar vein – i.e. water and wine – with perhaps relatively few of us having devoted time to master these.

Routine data may be viewed as the water. Routine are data that are captured primarily not for research or with a specific a priori research question developed prior to collection and examples include registries, education and social care databases [3]. Vision examples within the UK are the Certifications data set and the Registration dataset. The certifications data set comes from data captured when a Certificate of Vision Impairment (CVI) is completed in order to initiate registration of an individual as sight impaired. The data for England and until recently Wales are processed at Moorfields Eye Hospital NHS Foundation Trust with yearly reports available for England via the national indicator for sight loss [4, 5]. Registration data in England are captured by Social Service departments who once every three years determine the number of new registrations for that year and the total number of people on their register and report this via NHS Digital [6]. Similar processes are in place in the devolved nations. Routine data within the UK dates back in part to 1850 [7]. Note here that we are taking a pragmatic view – there have been changes in how the data has been captured over time, changes in the process, but these may be viewed by some as nuances, allowing the UK to perhaps lead the world in having such an historical data set.

In this insightful paper by Ramsewak SS et al. we learn of a routine data set in Trinidad and Tobago which dates back to 1951 - the Trinidad and Tobago Blind Welfare association (TTBWA) register dataset [8].

Epidemiological studies may be viewed as the wine. They encompass case-control designs, cross-sectional surveys and cohorts and are carefully designed to answer specific research questions. An example within the UK would be the British Childhood Visual Impairment and Blindness Study 2 (BCVIS2) study reported on by Teoh et al. whilst our example in Trinidad and Tobago is the 2014 National Eye Survey of Trinidad and Tobago (NESTT) reported on by Braithwaite et al. [9, 10].

Ramsewak's paper examines how the water (routine data: TTBWA) relates to wine (epidemiological data: NESTT) and has two key findings.

UNDER-ESTIMATION OF POPULATION BLINDNESS

The first key finding is that the routine data set underestimated the true prevalence of sight impairment – with just 7% of the population with sight impairment in 2016 being known to the register. The underestimation of blindness by CVI figures in England and Wales is something that has received considerable attention to date [7, 11–13]. A recent publication by Olvera-Barrios et al. suggested that under-registration might be as high as 84% in patients with diabetic retinopathy at the largest center for ophthalmic treatment in England [14]. Closer inspection of this paper and its data suggests that this figure is likely an over-estimate – since certification is not typically offered as the point of care and the researchers may not have fully factored in the challenge with fluctuating vision in patients with treatable eye conditions such as diabetes. Bourkiza et al. comment on this in their paper which looked specifically at certification in people with diabetes in East London stating that "a single measure of vision should never to used to assess certification" [15].

Figure 1a, b illustrates why CVI figures (TTBWA) will under-estimate blindness.

Teoh et al. recently reported on "Temporal changes in the epidemiology of childhood severe visual impairment and blindness in the UK" [16]. To do this, comparison was made between findings from two national population-based epidemiological studies of incident childhood severe visual impairment and blindness in the UK [17, 18]. The studies used identical methods – one was conducted in 2000 and the second in 2015. Key findings were that the overall annual and cumulative incidence rates remained broadly stable and mortality in children diagnosed in infancy declined. Together these pieces of information might lead us to deduce that the prevalence of childhood blindness may have increased – which were findings from analysis of registration and certification data [19, 20].

If incidence stays the same but mortality decreases, prevalence may increase unless recovery improves (Fig. 2). The incidence of blindness in children has remained constant, mortality has decreased, there has been little change in recovery in the particular conditions that impact in children and so prevalence may have increased [21].

AGREEMENT BETWEEN ROUTINE AND EPIDEMIOLOGICAL DATA

The second key finding by Ramsewak et al. was that there was close agreement in the causes of sight impairment comparing the register and population-representative survey – glaucoma was the leading cause in both (26.1%) followed by cataract and diabetic retinopathy.

Teoh's paper reported that for children in the UK, cerebral visual impairment had increased as had hereditary conditions in

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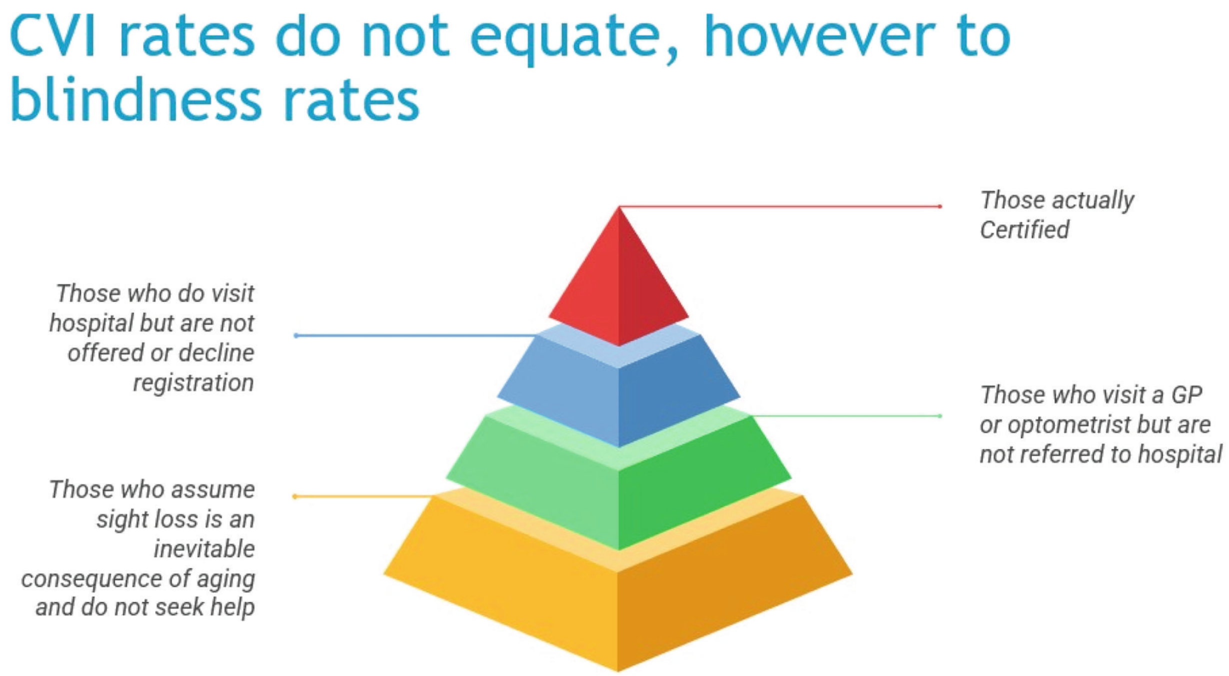
a



b

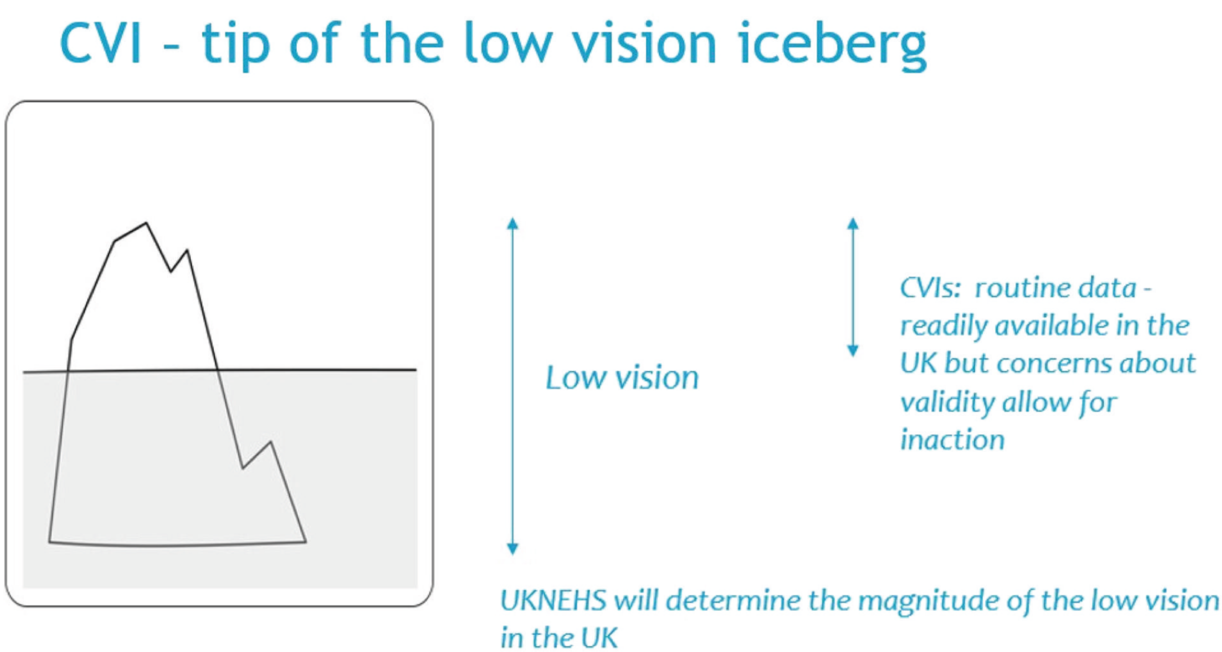


Fig. 1 Figures illustrating differences between routine and epidemiological datasets on blind registration/certification in England. a CVI rates do not equate to blindness rates. **b** CVI – tip of the low vision iceberg.

children and these were two of the leading causes of sight impairment found in the analysis of certifications in children. As with Trinidad and Tobago, therefore we can see similarities between the routine data and epidemiological data for childhood blindness in the UK. It is essential to note, however, that this should not be seen by anyone as obviating the need for the UK to have a comprehensive live register of childhood blindness [16].

Ramsewak et al. conducted a cross-sectional validation study where they examined registered clients to facilitate a more critical examination of agreement between routine and epidemiological dataset. This found that some on the register did not meet SI eligibility criteria but it is important to consider again the finding from Bourkiza in relation to fluctuation of vision over time [15].

In summary, this paper by Ramsewak is the first report of a population-based study being used to validate a national vision impairment register. The paper neatly shows value of both routine and epidemiological data and added-value of a nested exploration of the two. The UK National Eye and Hearing Study has recently launched – a national survey which will examine not only sight impairment but also hearing impairment in those over 50 years of age [22]. This will facilitate comparisons against an historical data set, paving the way for exciting findings of value to those with hearing and sight impairment and to society as a whole.

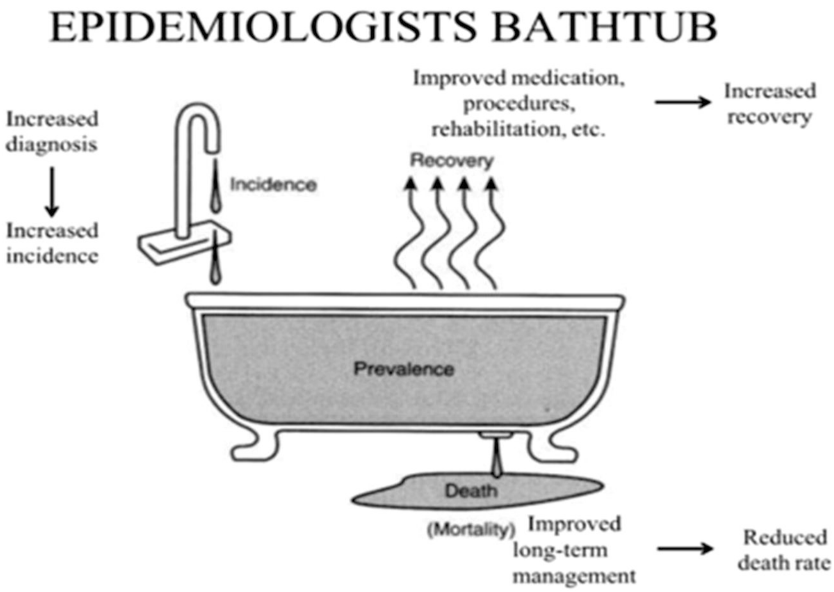


Fig. 2 Figure illustrating the relationship bewteen prevalence and incidence known as the Epidemiologist's Bathtub. The Epidemiologist's Bathtub.

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COMPETING INTERESTS

The authors declare no competing interests.