**Equity and blindness: closing evidence gaps to support Universal Eye Health**

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**Abstract**

**Background**

The World Health Organization’s Program for the Prevention of Blindness adopted the principles of universal health coverage (UHC) in its latest plan "*Universal Eye Health: A Global Action Plan, 2014-2019*". This plan builds on the achievements of *VISION 2020,* which aimed to reduce the global prevalence of avoidable blindness, and its unequal distribution, by the year 2020.

**Methods**

We reviewed the literature on health equity and the generation and use of evidence to promote equity, particularly in eye health. We describe the nature and extent of the equity-focused evidence to support and inform eye health programs on the path to universal eye health, and propose ways to improve the collection and reporting of this evidence.

**Results**

Blindness prevalence decreased in all regions of the world between 1990 and 2010, albeit not at the same rate or to the same extent. In 2010, the prevalence of blindness in West Africa (6.0%) remained 15 times higher than in high-income regions (0.4%); within all regions, women had higher prevalence of blindness than men. Beyond inter-regional and gender differences, there is little comparable data on the distribution of blindness across social groups within regions and countries, nor whether this distribution has changed over time. Similarly, interventions known to address inequity in blindness are few, and equity-relevant goals, targets and indicators for eye health programs are scarce.

**Conclusion**

Equity aims of eye health programs can benefit from the global momentum towards achieving UHC, and the progress being made on collecting, communicating and using equity-focussed evidence.

**Introduction**

The VISION 2020 initiative was established with aims that included the reduction of the global prevalence of avoidable blindness, and its unequal distribution. This commitment to equity continues, with equity being a cross-cutting principle in the latest World Health Organisation (WHO) Action Plan: "*Universal Eye Health: A Global Action Plan, 2014-2019*", endorsed in Resolution 66.4 of the World Health Assembly in 20131,2 (hereafter called the UEH Action Plan).

The recent Commissions on Social Determinants of Health (CSDH) and Global Governance for Health (CGGH) demonstrated that unfair distribution of power and resources, as well as global governance dysfunction, are the root causes of health inequality between population groups both between and within countries3,4. These root causes induce and maintain health inequalities, and can only be addressed through major political and social advances3,4.

Both the CSDH and CCGH emphasized that health systems have an important role to play in addressing health inequalities, despite solutions to the root causes lying beyond their control3,4. While health care interventions will never totally eliminate health inequalities, in the short term they are a promising entry point for equity-oriented initiatives to redress existing inequalities and prevent future inequalities5-7.

One such health initiative is the active promotion of *Universal Health Coverage* (UHC) which is defined as “people receiving quality health services that meet their needs without being exposed to financial hardship in paying for the services”8. Aligning actions with the principles of UHC provides the blindness prevention community with an opportunity to pursue equity aims within a framework being implemented by many health systems in low and middle income countries (LMICs).

***Evidence for equity in eye health***

Evidence-based practice is a core principle of the UEH Action Plan and few would argue against basing actions on sound research and proven interventions. In common with other health initiatives, blindness prevention in LMICs has consistently dedicated a larger portion of health equity research to describing the magnitude and nature of health inequalities (the ‘problem space’), rather than exploring ways to address these (the ‘solution space’)9-11.

This paper reviews the current evidence on equity and blindness. Strategies are then proposed— drawing on relevant aspects of the health equity literature—that may enable future research to both inform and support the reduction of inequity within the UEH Action Plan. Our focus is on LMICs, which have the largest burden of blindness.

**Methods**

MEDLINE database searches were conducted by one author (JR) in an iterative manner during February—December 2014 as part of a literature review for a doctoral thesis. Articles were retrieved that related to health equity, evidence and eye-health in order to populate our themes of *problem space evidence*, *solution space evidence*, and *indicators and monitoring*. Search terms included “equity and blindness”, “universal eye health”, “health inequality analysis”, “universal health coverage and equity”, and “evidence and health equity”. Journal articles were retrieved and the reference lists of each article were reviewed to find additional articles. Potentially relevant WHO documents on prevention of blindness, social determinants of health, universal health coverage and universal eye health were also reviewed.

From the identified data sources, relevant information for each of the three themes was synthesised. Finally, specific insights proposed in the literature related to equity-focused evidence to support and inform eye health activities were summarised.

***Definitions***

*Health inequality* is defined as: “differences, variations, and disparities in the health achievements of individuals and groups”12. The term encompasses differences in health status, access to care or outcomes between groups. *Health inequity* is widely considered to be “differences in health that are unnecessary, avoidable, unjust and unfair”13. While health inequalities can be measured, health inequities cannot, because normative judgements of elements of its definition are required12.

To illustrate the difference between these two terms we can consider the example of the higher prevalence of cataract in people aged ≥50 years compared to those aged <50 years. This is certainly an inequality, but as cataract is a biological change that occurs with age regardless of social position, it is not inequitable in and of itself. The higher prevalence of blindness in women compared with men over and above biological differences14, or the higher prevalence of trachoma in LMICs and indigenous populations of high income countries15 are different matters. It can be appreciated that such differences in health status reflect an unfair distribution of power and resources which could be considered avoidable, unfair and unjust, and therefore inequitable.

Measurement of health inequality can be considered as the metric to assess progress towards the goal of health equity16. Throughout this paper, the term health inequality will be used when discussing measurable aspects of differences in health status, determinants and services. Health inequity will be used when referring to aspects of goals and aspirations related to these differences.

**Results**

**Availability of data on eye health inequality**

Population-based prevalence surveys have contributed extensive knowledge to the ‘problem space’ for eye health. The Global Burden of Diseases, Injuries and Risk Factors (GBD) Study Vision Loss Expert Group used 227 studies from 84 countries to calculate their 2010 estimates. In recent years, use of the standardised Rapid Assessments of Avoidable Blindness (RAAB) methodology17 has meant many more surveys have been undertaken in a broad range of locations, producing comparable results. In July 2015 information from 233 studies conducted in 73 countries since 1995 had been added to the online RAAB repository18. Findings from these surveys have increased our understanding of the distribution of blindness throughout the world, and have provided population level information for programme planning. RAABs provide outcomes disaggregated by gender but rarely include data on other social factors such as place of residence or socioeconomic status.

**Inequality across regions**

At the global level there is evidence of the *Inverse Care Law*, which states that “the availability of good medical care tends to vary inversely with the need for it in the population served”19. Bastawrous and Hennig used cartograms to demonstrate the inverse relationship between the global distribution of blindness and the distribution of practicing ophthalmologists20. This inverse relationship has also been shown for cataract blindness and cataract surgical coverage (CSC) against Human Development Index (HDI) rank, with higher levels of cataract blindness and lower CSC as HDI rank worsened21.

The GBD study showed that blindness prevalence reduced in older adults (≥50 years) between 1990 and 2010, from 3.0% (95%CI 2.7−3.4%) to 1.9% (95%CI 1.7−2.2%)22. Blindness prevalence decreased for both women and men in all regions of the world over this time, albeit not at the same rate or to the same extent23. This meant in 2010 disparities in blindness prevalence persisted both between and within global regions: the prevalence of blindness in adults aged ≥50 years in West Africa (6.0%) was 15 times higher than that of several high-income regions (0.4%), and within all regions, women had a higher age-standardised prevalence of blindness than men22 (Figure 1).

**Inequality within countries**

Blindness surveys frequently present information on the prevalence gap between women and men, and increasingly data from primary studies are synthesised. From these syntheses we know that, compared to men, women have higher levels of blindness in all regions of the world14,22, a higher prevalence of trachomatous trichiasis24, and generally25,26—but not universally27—lower CSC (Table 1).

Beyond geographic and gender disparities such as those presented here, there is relatively little comparable data on the distribution of blindness among different social groups within regions and countries; and on whether, or in what ways, this distribution has changed over time. Occasionally surveys report on the gap for eye health indicators between urban and rural dwellers, and/or people who are literate or illiterate. The distribution of blindness across socioeconomic groups is rarely reported, largely due to the complexities of measuring socioeconomic status. Primary studies have, however, shown associations between poverty and higher prevalence of blindness, lower CSC, lower intraocular lens (IOL) implantation rate and lower spectacle coverage28-30.

Perhaps the best multi-country data which demonstrates a relationship between vision status and a socioeconomic variable is that on self-reported poor vision in 57 countries from the World Health Survey (2002-4)31. Using wealth quintile as a measure of socioeconomic status, a wealth gradient was found, with the worst levels of self-reported poor vision in the poorest groups, and improvement at each higher level of wealth (Figure 2). Although this gradient was steeper in higher income countries, both higher and lower income countries exhibited the same trend. While care needs to be taken in interpreting self-reported vision data, this gradient is seen for many health outcomes in LMICs32,33.

**Efforts to address eye health inequality**

*Indicators and targets*

The global target in the UEH Action Plan includes an assumption that policies will be delivered equitably (Table 2). Beneath the goal sit three objectives and six national indicators. Of these, only two indicators (prevalence and causes of blindness/vision impairment[VI] and CSC) include an equity component, in the form of a *preference* for disaggregation of data by age, gender, and place of residence2.

*Implementation research*

Few studies have assessed the effectiveness of interventions which reduce inequalities in eye health in LMICs – the ‘solutions’. As an example, we know that cataract surgery is not only successful at restoring sight but is also highly cost-effective34,35. Cataract surgery also improves quality of life36-38 and time use39, and positively impacts on poverty alleviation37,38,40 and social status38. But we still need a much better understanding of *how* to best address the unequal distribution of cataract blindness, including addressing barriers to accessing services, and improving the quality of outcomes experienced, especially by the disadvantaged.

Many strategies have been suggested to improve access to cataract services in LMICs. These include enhancing knowledge of eye disease and treatment options41; addressing transport barriers (through financial assistance or provision of transport to hospital)42-44; delivering outreach programs43,45; providing counselling (for the family as well as the patient)41,44; improving visual outcomes41 and patient satisfaction46; setting a price for surgery within the family’s capacity and willingness to pay43,44; enhancing systems of social support within communities and households41,43; improving provider-patient communication42; and sensitising service providers to the needs of disadvantaged groups47. There are also examples of successful models of care in a given setting, such as the high quality, high volume, affordable services developed in India48 and replicated in other parts of South Asia.

Unfortunately few of these strategies have been comprehensively assessed so little evidence exists on their implementation and outcomes, nor on how they work in diverse settings, or differentially affect population subgroups. A valuable contribution to intervention research was made by Lewallen and Thulsiraj, when they considered which elements of the Indian model can be applied in other contexts such as sub-Saharan Africa49. A recent review of systematic reviews to inform universal coverage of cataract services found no cataract-specific systematic reviews for inclusion50. There are a small number of primary intervention studies that measured access to cataract services, and a selection of these are presented in Table 2.

A priority for UHC and an important area for reducing inequalities within UEH is strengthening financial protection. Research into financial protection for eyes services is limited, and models depend on the existing health system and socio-political context. Examples for cataract surgery include tiered-pricing in India51, health insurance in China52 and the inclusion of cataract surgery in Brazil’s Unified Health System53. The tiered-pricing model in India showed that where services were available at variable cost (free, subsidised, full fee), women were more likely to use free or subsidised services compared to paying services, whereas men were more likely to use paid services51. Rural residents, people who were illiterate, and those who didn’t work outside of the home were also more likely to attend subsidised services or free camps compared to paying services51. These findings indicate that financial protection is critical for reducing cataract blindness in the poor and socially disadvantaged, and an area in need of more attention.

**Discussion**

Since its inception the VISION 2020 initiative has expressed a commitment to the principle of equity. However, as the year 2020 draws near, insufficient evidence exists to assess progress towards equity in blindness prevention. It is clear from these results that in order to achieve the WHO vision of universal access to comprehensive eye care services2, much more needs to be done to improve our understanding of inequality in eye health in different settings, and how to redress it. Here we will reflect on the contribution monitoring can make to this understanding, before proposing ways to improve the collection and reporting of equity-focussed evidence.

**Goals, targets and monitoring for Universal Eye Health**

To address inequalities we must set goals and targets, and monitor progress towards achieving them3,62. The goal and targets of the UEH Action Plan do not include disadvantaged groups, but rather, assume ‘equity across all policies’2(Table 2). Two concerns arise. The first is that evidence does not support the assumption of equity. Many examples from other health sectors show that without special attention to the needs of the disadvantaged, inequality can increase when services expand63,64. The second is that when goals are stated in terms of improvement in population averages rather than in terms of gains among disadvantaged groups, achievement is possible despite increasing inequality65. UEH initiatives will be more likely to reduce inequity if global and national targets are established that include disadvantaged populations, such as those recently proposed for UHC: each component health service coverage indicator has an aggregate measure for the whole population, and an equity measure which reports coverage for selected social subgroups (such as gender, place of residence and socioeconomic status)66.

For goals and targets to be meaningful, information to track progress towards them must be readily available67. The lack of equity-relevant targets and indicators in the UEH Action Plan may reflect reluctance to state targets for which very little data currently exists. The challenges of collecting reliable data in health information systems in LMICs are substantial68. Rather than accept these as insurmountable barriers, a commitment to equity means ways need to be identified to routinely obtain the requisite information.

Insufficient data for analysis of inequality remains a problem in eye care. More equitable services could be planned if there was a more nuanced understanding of how inequality is patterned within countries. This has been the case for some health areas, where an exponential increase in data and corresponding enhanced understanding of health inequality was made possible through the collection of information to construct wealth indices69,70 during surveys such as the Demographic and Health Survey (DHS). Gender and blindness can be seen as an eye health example of “what is measured is what gets done”71. Data is now commonly disaggregated by gender, so the evidence base on gender and blindness has expanded (Table 1) and, together with advocating to overcome these gender disparities72,73 and suggesting solutions44,74,75, evidence has been instrumental in raising the profile of the problem. We need to continue this momentum for gender equity, doing more to ensure evidence is used in planning. We must also expand the approach to other social factors such as place of residence and socioeconomic status.

**How we can close the evidence gap**

In this section we suggest actions that could be taken to generate and use equity-focused evidence to support and inform blindness prevention activities at the global and national levels, as well as in the research field. We recognise that evidence is only one element required to promote equity and reduce inequalities in eye health. The following recommendations offer the foundation for a broader discussion of planning, advocating, implementing and evaluating equity initiatives to ensure progress towards achieving universal eye health.

***Action at the global level***

Global equity-relevant UEH goals and targets are needed, together with guidance on how national programs can set targets and monitor progress towards them, taking their individual circumstances into account7,76.

Existing guidance and examples can be used to identify global and national health and social variables and metrics for use in inequality assessment66,69,70,77-81. In the first instance, indicators in the current UEH Action Plan could be considered (blindness/VI, CSC, CSR, and eye care personnel), and later expanded to include other relevant aspects of inputs, processes, outputs, outcomes or impacts77. The PROGRESS acronym can be used to consider the range of socially stratifying factors that may be associated with each health indicator: *Place of residence; Race/ethnicity/ culture/ language; Occupation; Gender/sex; Religion; Education; Socioeconomic status; Social capital/ networks*82,83. Measures could include simple measures such as rate difference and rate ratio, as well as complex measures such as slope index of inequality and concentration index77.

Equity could be incorporated into the ongoing development of global UEH research priorities—equity is not explicitly mentioned in VISION 2020’s ten research priorities84, but could be incorporated into the majority of them. Intervention research should be promoted; and partnerships between researchers and program implementers strengthened.

Evidence-informed policy and planning85 for national prevention of blindness plans should be promoted, and relevant tools for health equity impact assessment86 could be adapted to assist the national planning process.

***Action at the country level (national prevention of blindness programs)***

At the national level, simple and sound objectives and targets could be established that include disadvantaged populations. Subsequently plans can be developed and progress monitored in relation to these modified objectives7.

The health and social variables and health inequality metrics identified at the global level can be considered for appropriateness for eye health service monitoring in each national context. Where it has not yet occurred, eye care providers can advocate for cataract surgery numbers (disaggregated by social groups) to be added to national surveillance systems21.

Evidence should be sought to inform the identification of vulnerable groups and service priorities, and to inform decisions regarding the development of appropriate interventions. Partnerships with relevant global actors could be formed to assist in building in-country research capacity.

***Action for researchers***

Researchers can address the current lack of equity-relevant evidence by advocating for its collection77; adding appropriate PROGRESS variables to population-based surveys and intervention studies; measuring and reporting the distribution of effects across social groups, not just the population average87; examining how different axes of social differentiation interact, overlap and cluster together to create inequality in different contexts11,88; and exploring the feasibility of adding vision measurement to large global health studies31.

Researchers can begin to balance research in the problem and solution spaces89 by undertaking more impact, process and outcome evaluations of policies and interventions78,87. These can build on the studies shown in Table 3, and likely need to be multi-faceted to better address the complex range of barriers experienced. Successful interventions could be identified and evaluated, and requisite modifications determined before applying them in different contexts. Existing examples49,55 could be added to, drawing on insights on scaling up90 and knowledge transfer.

Research questions can be broadened from those of “what” and “how much” to “what works, for whom and in what circumstances”87,91. This will require improvement in the consideration of context, which is essential in the translation of innovations from one location to another87,89.

More and improved synthesis of existing data can be undertaken, including observational and qualitative studies87. Beyond traditional systematic review methods, other synthesis methods may be useful. For example, evidence gap map synthesis can provide a visual overview of the existing evidence as well as user-friendly summaries of the studies included92, and realist synthesis93 can answer the additional questions of how interventions work and in what context.

Researchers can more actively advocate for equity, and the use of evidence in addressing it – it is not sufficient to publish findings and expect them to be used. Researchers can enable equity-oriented decision-making by improving the way data are collected, processed and presented to be more useful to, and easily understood by, decision-makers9,16,68.

**Conclusion**

The continuation of VISION 2020’s commitment to equity expressed in the latest UEH Action Plan is commendable. For this commitment to translate to reducing inequity in blindness, however, resolute effort from all stakeholders is required. This paper sought to place the issue of equity firmly on the blindness prevention agenda; and to promote an evidence-informed pursuit of universal eye health. Establishing equity-relevant goals, objectives, targets and indicators for UEH, and monitoring progress based on these, will help guide action. Asking the questions of “what works, for whom, and in what circumstances”87 when planning and evaluating interventions will ensure that the intervention is not only effective in the environment in which it is being implemented, but will also allow others to determine the efficacy of the intervention in their own setting. Reinforcing equity objectives and identifying innovative responses to addressing inequity are essential to achieve universal eye health.

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