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Global Collaboration Networks in Retinoblastoma Care: A Mixed-Methods Egocentric Network Analysis of One Retinoblastoma World

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Abstract

Collaboration across countries is a cornerstone of global health research and delivery. One Retinoblastoma World (1RBW) functions as an international consortium of treatment centers providing care to children diagnosed with retinoblastoma. This study sought to quantify collaborative linkages within 1RBW, characterize their scope and form, and examine perceptions of their role in improving retinoblastoma outcomes. A cross-sectional egocentric network study using mixed methods was undertaken. All registered treatment centers (n = 170) were invited to complete an online questionnaire documenting collaborative interactions between their own institution (ego) and partner organizations (alters). Network diagrams were constructed to illustrate relational patterns. Semi-structured interviews were conducted with key informants (n = 18) to contextualize and expand upon reported collaborations. Qualitative data were analyzed using an inductive thematic approach. A total of 56/170 (33%) treatment centers completed the survey. Respondents reported 112 distinct alters, comprising 80 treatment centers and 32 non-clinical organizations, yielding a network of 168 nodes. Collaboration most frequently involved referral pathways, expert consultations, and twinning or capacity-strengthening initiatives. Interview analysis revealed four dominant themes: definitions of partnership, motivations for collaboration, shared obstacles, and perceived advantages of collaborative engagement. While global cooperative efforts to reduce retinoblastoma mortality are well established, further integration of peripheral network members could strengthen overall connectivity.

Keywords: Collaboration, One retinoblastoma world, Non-clinical organizations, Cross-sectional egocentric network

Introduction

Global health activities inherently rely on international partnerships [1]; however, how such collaborations are structured and how they function to achieve measurable outcomes is not always clear. One Retinoblastoma World (1RBW) is an international initiative designed to advance high-quality care for children affected by retinoblastoma, a rare pediatric ocular malignancy [2, 3]. The disease burden is disproportionately concentrated in low- and middle-income countries (LMICs), which account for 89% of all cases worldwide, where mortality rates may reach as high as 70% [3]. Contributing factors include late-stage diagnosis, inadequate access to specialized services, limited treatment infrastructure, poor treatment adherence, and intersecting social, cultural, and economic challenges faced by vulnerable populations [3]. Despite these barriers, retinoblastoma is among the most curable childhood cancers when detected early and treated using accessible, evidence-based approaches [3]. In recognition of this, the World Health Organization's Global Initiative for Childhood Cancer has identified retinoblastoma as a priority condition requiring urgent global action [4].

Participating treatment centers within 1RBW are displayed on a publicly accessible global map (www.1rbw.org), which outlines available clinical expertise, resources, and country-level incidence estimates. A range of international collaborative

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initiatives has demonstrated measurable improvements in retinoblastoma outcomes, including public awareness programs promoting early diagnosis [5], shared-care delivery models [6], harmonized clinical treatment protocols [7–9], twinning and mentorship arrangements aimed at strengthening local service capacity [10–12], telemedicine-based access to centralized expertise [13], and the development of comprehensive national retinoblastoma strategies that integrate multiple intervention approaches [14]. Examining collaborative structures provides insight into how partnerships generate impact. Identifying key stakeholders, activities, and the exchange of resources, expertise, and knowledge can highlight opportunities to reinforce collaboration and enhance inclusion of underserved actors. Social network analysis offers a robust methodological framework for such investigations in health services research [15], and has previously yielded valuable insights in ophthalmology [16, 17] and oncology [18, 19]. Accordingly, this study aimed to assess the volume, characteristics, and perceived impact of collaborative relationships within the 1RBW network on global retinoblastoma survival.

Materials and Methods

Study design

A cross-sectional mixed-methods egocentric social network analysis was conducted [20], integrating quantitative survey data with qualitative semi-structured interviews to capture the extent and nature of partnerships within 1RBW. The methodological framework followed three established stages of social network analysis in health services research: (i) identification of network actors; (ii) specification of relationships between actors; and (iii) examination of overall network structure [15]. Reporting adhered to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for cross-sectional research. Ethical approval was obtained from the Research Ethics Board at The Hospital for Sick Children (Toronto, Canada). All participants provided electronic informed consent, and the study was conducted in accordance with the principles of the Declaration of Helsinki.

Social network analysis

(i) Identification of actors and network members

- Overview of 1RBW. This analysis centered on the One Retinoblastoma World (1RBW) network (www.1rbw.org), an online platform that documents the global burden of retinoblastoma and the services and expertise available at treatment facilities worldwide. Treatment centers included on www.1rbw.org were initially identified through targeted searches of relevant academic publications, grey literature, and membership rosters of professional societies associated with retinoblastoma, ocular oncology, and pediatric oncology. Physician representatives from each identified institution were invited to voluntarily submit institutional data. Centers not captured through this initial process were also permitted to request inclusion in the database. Although 1RBW does not constitute a complete census of all facilities treating retinoblastoma, it is considered to encompass the large majority. At the time this study was conducted, 170 centers were listed on www.1rbw.org.
- Recruitment of stakeholders within 1RBW**.** Eligibility criteria included being a healthcare professional (e.g. ophthalmologist or oncologist) who led a retinoblastoma clinical team at a treatment center listed on www.1rbw.org. An “ego” was defined as any participating retinoblastoma treatment center represented on the www.1rbw.org map. An “alter” referred to any collaborating entity named by an ego. Together, egos and alters were collectively described as “nodes.”

Invitations were distributed via personalized email messages prompting participants to log into their institution’s 1RBW account, where they were asked to provide electronic informed consent and complete the survey. Recruitment took place between May 2016 and August 2017. Only one survey submission was permitted per treatment center, and respondents were encouraged to consult colleagues prior to final submission. Reminder messages were sent by email and telephone to enhance participation. When participants encountered difficulties with the online platform, support was provided via telephone or Skype, during which responses were entered electronically by a member of the research team.

- Stakeholders external to 1RBW**.** Egos were also asked to report alters that included any collaborating treatment center (whether affiliated with 1RBW or not)

or other types of organizations, such as non-governmental organizations, patient advocacy groups, government bodies, or research institutions, with which they had partnered on retinoblastoma-related initiatives.

- Author positionality in relation to 1RBW**.** All authors are affiliated with major academic institutions located in large urban centers within high-income, English-speaking countries. One author (JP) is a public health researcher who had no prior involvement with 1RBW or retinoblastoma research before joining the study team. Three authors (HG, KF, HD) are associated with a large tertiary retinoblastoma center in North America that is listed within 1RBW and actively participates in international collaborations. At the time of the study, HG and KF were relatively new to retinoblastoma research, whereas HD leads a global health–focused retinoblastoma research program. Notably, HD founded www.1rbw.org, and her research group continues to maintain the platform with the explicit goal of fostering collaboration and connectivity within the field. Accordingly, HD acknowledges that her perspectives may have influenced the interpretation of the findings.

(ii) Specification of relationships among network actors

- Network survey. To characterize relationships between actors, egos completed a structured questionnaire adapted from a network analysis survey previously developed for the Brazos Valley Health Partnership [21]. Respondents reported the types of collaborative activities undertaken with each alter, including patient referrals, research collaborations, clinical consultations, twinning or capacity-strengthening initiatives, and joint planning efforts. Directionality of ties was also captured (i.e. outdegree when initiated by the ego; indegree when initiated by an alter). Additional items assessed partnership characteristics, such as whether collaborations were formal or informal, as well as their duration and frequency.
- Semi-structured interviews. Key informants were purposively selected from among survey respondents and invited by email to participate in semi-structured interviews. Selection followed a maximum variation sampling strategy, informed by review of survey responses to ensure representation across geographic regions and diversity in the number and types of collaborations and partners (e.g. hospitals, non-clinical organizations, local or international entities). An interview guide comprising open-ended questions was developed to explore partnership histories, levels of engagement, perceived power dynamics, funding considerations, motivations, and perceived outcomes. Interviewees were asked to reflect on the duration, intensity, closeness, and reciprocity of their collaborative relationships. Given the flexible interview format, questions were adapted to reflect each informant's specific partnership profile. For instance, respondents reporting a single collaboration were not asked to compare strongest and weakest partnerships, but were instead asked to characterize that relationship as strong or weak, with subsequent questions adjusted accordingly.

Interviews were conducted in English via telephone, WhatsApp, or Skype, and were audio recorded. The interviewer (HG) followed established best practices for network evaluation [22], including active listening, identification and synthesis of emerging patterns, attention to power relationships and their implications, recognition of leadership dynamics, and encouragement of narrative reflection.

(iii) Examination of network structure

Survey responses were exported to Microsoft Excel, anonymized, and assigned unique study identification numbers. For each ego network, both the size (number of alters) and diversity of connections (types of alters) were determined. Relationships between egos and alters were treated as reciprocal. Cleaned datasets were imported into Ucinet 6.1358 for network analysis, and visual network representations were generated using NetDraw 2.41. Nodes were classified according to World Bank geographic region and national income category [23]. Degree centrality (reflecting the number of direct connections per organization) and betweenness centrality (indicating an organization's intermediary role linking otherwise unconnected actors) were calculated to assess organizational positioning across collaboration categories [24].

Network density, defined as the proportion of actual connections relative to all possible connections on a scale from 0% (no connections) to 100% (complete interconnection), was computed for the overall network and separately for each collaboration type. The maximum number of potential collaborations was calculated using

the formula (n)*(n–1)/2, where n represents the total number of egos plus unique alters.

Audio recordings from interviews were transcribed verbatim. An inductive thematic analysis grounded in a critical realist framework was conducted. Data organization and coding were managed using QSR NVivo 11 software. As analysis progressed, new codes were generated, and the coding framework was iteratively refined through team discussions (HG, HD, KH). Constant comparative techniques were used to compare and contrast data segments, with categories repeatedly reorganized into higher-order constructs until core themes were identified.

Results and Discussion

Participants

Survey responses were obtained from 56 egos, yielding a participation rate of 33% (56/170). The largest share of respondents was based in East Asia and the Pacific (21/56, 38%). Europe and Central Asia, North America, and Sub-Saharan Africa each contributed 14% of respondents (8/56) **(Table 1).** Participating egos were affiliated with treatment centers in 27 different countries. All centers operated at the secondary or tertiary level, with only 2 situated in rural locations. This pattern reflects the broader 1RBW landscape, as most facilities capable of managing retinoblastoma are urban-based, while primary-level sites generally provide diagnostic services only.

Table 1. Nodes, alters, and ties by World Bank region.

World Bank Region	Nodes (n)	Nodes (%)	Total Alters (n)	Total Alters (%)	Treatment Center Alters (n)	Treatment Center Alters (%)	Other Alters (n)	Other Alters (%)	Total Network Members (n)	Total Network Members (%)	Ties to Treatment Center Alters (n)	Ties to Treatment Center Alters (%)	Ties to Other Alters (n)	Ties to Other Alters (%)	Total Ties (n)	Total Ties (%)	Average Ties per Node
East Asia and Pacific	21	13%	12	7%	11	7%	1	1%	33	20%	51	28%	1	1%	52	28%	2.5
Europe and Central Asia	8	5%	19	11%	14	8%	5	3%	27	16%	31	17%	5	3%	36	20%	4.5
Latin America and Caribbean	3	2%	11	7%	9	5%	2	1%	14	8%	5	3%	2	1%	7	4%	2.3
Middle East and North Africa	3	2%	7	4%	5	3%	2	1%	10	6%	1	1%	2	1%	3	2%	1.0
North America	8	5%	27	16%	15	9%	12	7%	35	21%	40	22%	13	7%	53	29%	6.6
South Asia	5	3%	12	7%	10	6%	2	1%	17	10%	8	4%	2	1%	10	5%	2.0

Sub-Saharan Africa	8	5%	24	14%	16	10%	8	5%	32	19%	14	8%	8	4%	22	12%	2.8
Total	**56**	**33%**	**112**	**67%**	**80**	**48%**	**32**	**19%**	**168**	**100%**	**150**	**82%**	**33**	**18%**	**183**	**100%**	**3.3**

Twenty-three egos were invited to engage in follow-up semi-structured interviews. Although all agreed, interview scheduling was completed with 18 participants.

Network size

Across the 56 egos, 112 distinct alters were reported, including 80 treatment centers and 32 categorized as other types of organizations, resulting in a network of 168 total nodes **(Table 1).** Of the 80 treatment-center alters, 50 (63%) were already listed on www.1rbw.org at the time of data collection. Overall, 62% (106/170) of all centers registered with 1RBW were represented in the analysis **(Table 1).** The greatest regional representation was observed in North America (35/168, 21%), followed by East Asia and the Pacific (33/168, 20%), Europe and Central Asia (33/168, 20%), and Sub-Saharan Africa (32/168, 19%) **(Table 1).** When categorized by national income, most nodes were located in middle-income countries (MICs) (51%, 85/168), with high-income countries (HICs) accounting for 43% (72/168) **(Table 2).**

Table 2. Nodes, alters and ties by World Bank country income status.

Income Level	Nodes (n)	Nodes (%)	Total Alters (n)	Total Alters (%)	Treatment Center Alters (n)	Treatment Center Alters (%)	Other Alters (n)	Other Alters (%)	Total Network Members (n)	Total Network Members (%)	Ties to Treatment Center Alters (n)	Ties to Treatment Center Alters (%)	Ties to Other Alters (n)	Ties to Other Alters (%)	Total Ties (n)	Total Ties (%)	Average Ties per Node
Low	3	2%	8	5%	6	4%	2	1%	11	7%	7	4%	2	1%	9	5%	3.0
Middle	34	20%	51	30%	40	24%	11	7%	85	51%	66	36%	11	6%	77	42%	2.3
High	19	11%	53	32%	34	20%	19	11%	72	43%	77	42%	20	11%	97	53%	5.1
Total	**56**	**33%**	**112**	**67%**	**80**	**48%**	**32**	**19%**	**168**	**100%**	**150**	**82%**	**33**	**18%**	**183**	**100%**	**3.3**

Network collaborations

In total, egos described 183 collaborative ties **(Table 1).** The majority of these relationships involved partnerships between retinoblastoma treatment centers, accounting for 82% (150/183). Formal governance arrangements were uncommon: 14 collaborations (8%) reported the presence of a Memorandum of Understanding (MoU), 1 (1%) reported none, and 168 (92%) did not respond to this item.

The average number of alters per ego was 3.3 **(Table 1).** Treatment centers in North America reported the highest mean number of collaborators (6.8 per ego), while centers in the Middle East and North Africa reported the fewest (1 per ego) **(Table 1).** Stratification by income group showed that HIC-based centers had the highest average number of alters (5.1), compared with 3.0 in low-income countries (LICs) and 2.3 in MICs **(Table 2).**

Network visualization identified 9 distinct structural groupings: one large cluster comprising more than 10 interconnected nodes spanning all regions and income categories; five smaller clusters (fewer than 10 nodes) representing 1–4 geographic regions and more than one income group; and three dyads, each consisting of two nodes within a single region and income category **(Figure 1).** The calculated overall network density was 1.3%.

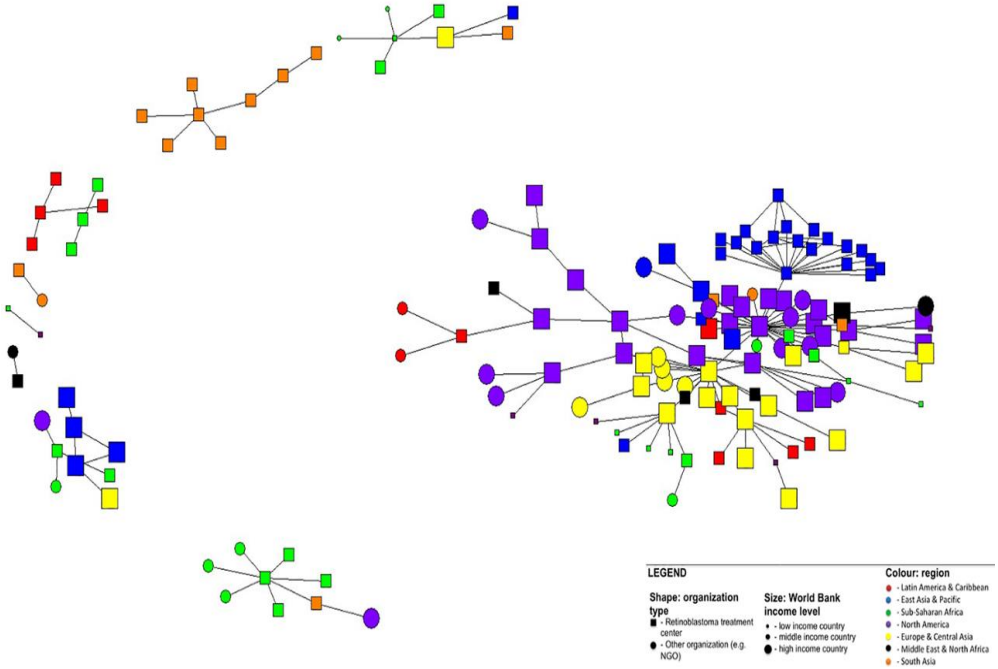


Figure 1. Network diagram for all collaborative activities.

Visualization illustrating 56 egos and 112 unique alters connected through 183 collaborative ties.

Centrality analyses demonstrated that large tertiary centers located in HICs occupied the most influential positions across networks related to collaboration overall, information and resource exchange, joint planning, and patient referral. Three institutions emerged as the most central nodes: one based in North America (normalized degree centrality 19.5%), one in Europe (8.4%), and one in East Asia (11.0%). Each of these institutions is a major tertiary center with long-standing expertise in retinoblastoma. Notably, the East Asian center exhibited nearly balanced in-degree and out-degree centrality (11.0% vs 10.4%), whereas the European and North American centers showed substantially higher out-degree relative to in-degree centrality (8.4% vs 3.2% and 19.5% vs 3.2%, respectively).

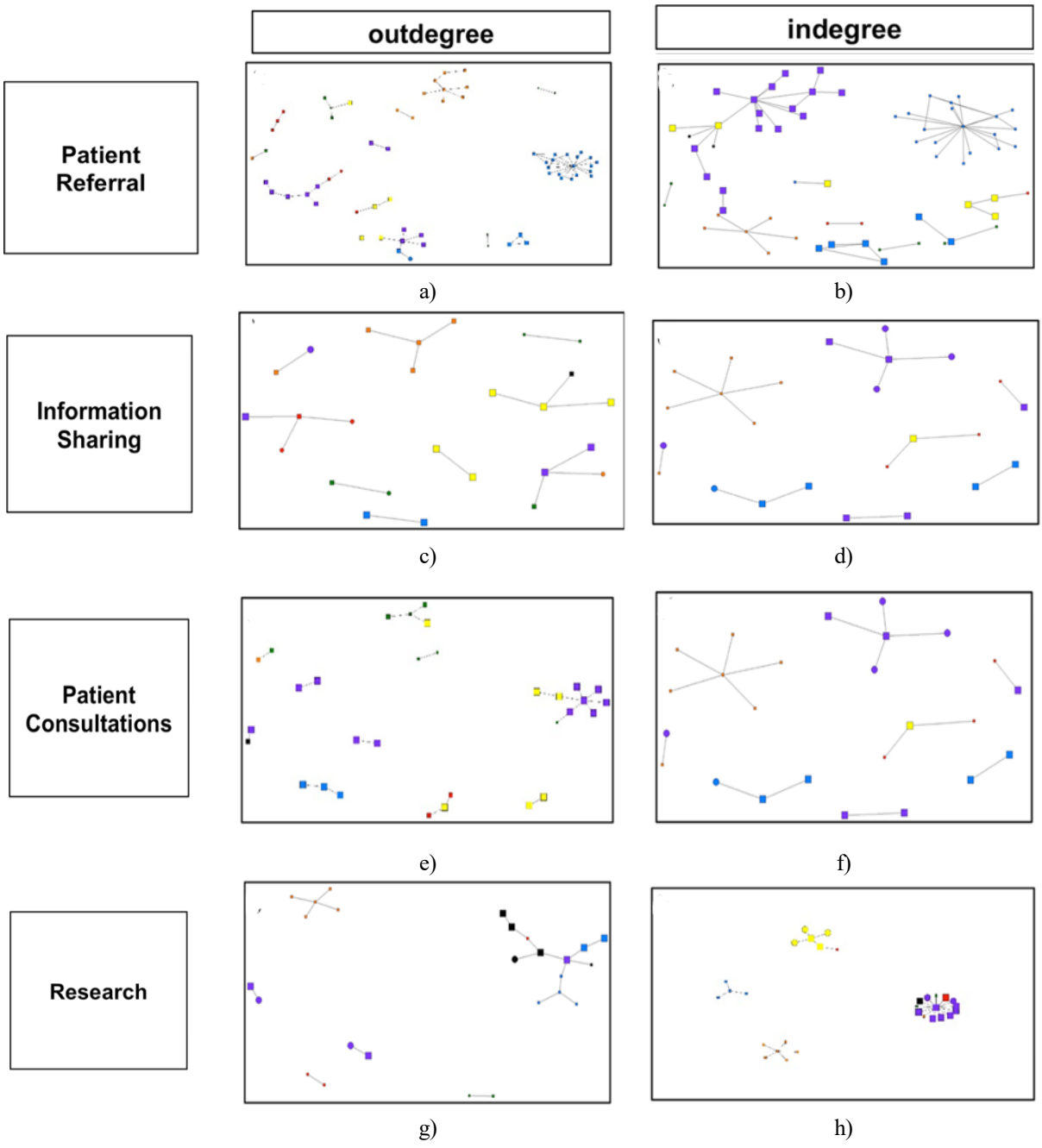
These three centers also ranked highest in both degree and betweenness centrality, indicating that they functioned not only as highly connected hubs but also as key intermediaries linking other, otherwise less-connected institutions. This configuration suggests opportunities to strengthen cross-linkages among centers, as connectivity currently relies heavily on a small number of central actors.

Collaborative activities

Patient referral pathways represented the most prevalent form of collaboration, followed by exchanges of information, clinical consultation, research partnerships, sharing of tangible resources, twinning or capacity-building programs, joint planning initiatives, and other activities. Most referrals occurred directly between treatment centers, though occasional referrals involved other organizations, likely serving as intermediaries prior to onward referral.

Information exchanges typically included clinical protocols, peer-reviewed publications, care guidelines, conference notices, funding announcements, and patient-specific information supporting continuity of care. Collaborative consultation arrangements dated back to

1985 and continued through 2014. Research partnerships were reported as early as 1996, although the majority commenced in 2005 or later. Shared resources included retinoblastoma cell lines, medical equipment, patient education materials, and financial support for participation in international meetings or guideline development. Twinning and capacity-strengthening efforts were initiated from 2005 onward. Joint planning activities encompassed protocol development, conference organization, creation of virtual consultation platforms, design and implementation of training and resource-planning initiatives, formulation of national retinoblastoma strategies, and planning of awareness campaigns. Additional reported activities included adjunct academic appointments, development of clinical innovations, fundraising for patient treatment, participation in national tumor boards, mentorship of trainees, facilitation of inter-institutional linkages, and delivery of invited lectures.



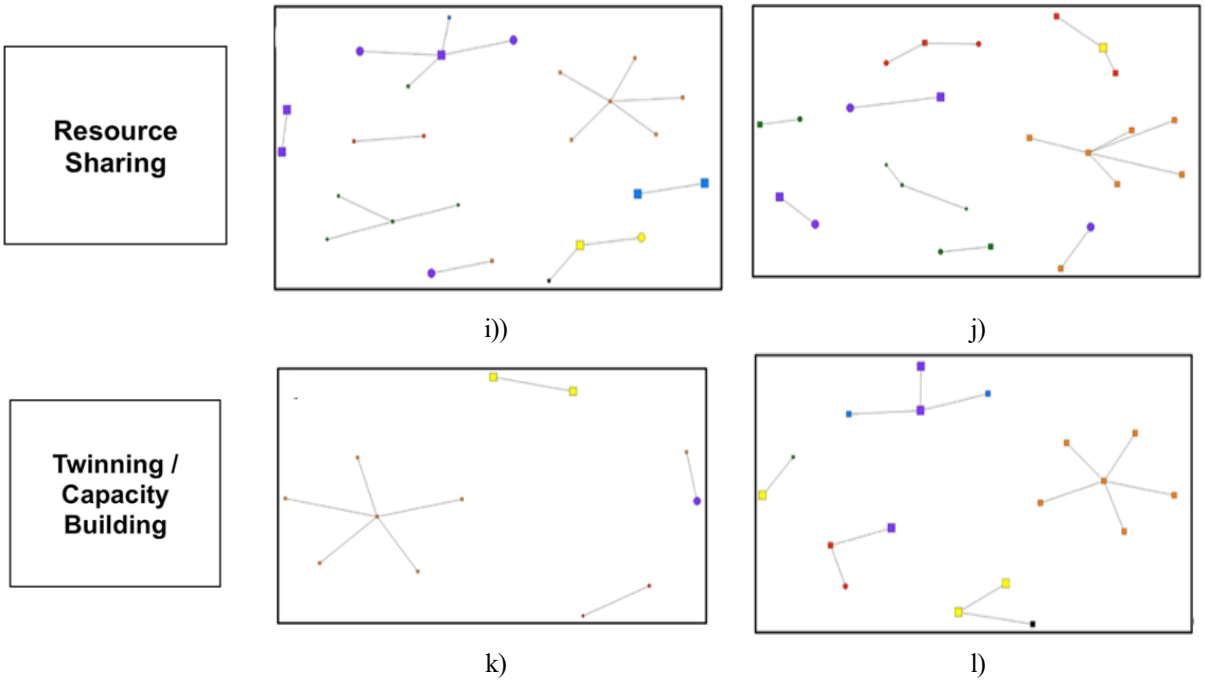


Figure 2. Network visualization of outgoing and incoming collaborative activities**.**
Network maps illustrating: (a) outgoing patient referrals, (b) incoming patient referrals, (c) outgoing information exchange, (d) incoming information exchange, (e) outgoing information exchange, (f) incoming patient consultations, (g) outgoing patient consultations, (h) incoming research collaborations, (i) outgoing research collaborations, (j) incoming research-related sharing, (k) outgoing twinning/capacity-building activities, and (l) incoming twinning/capacity-building activities.

Thematic analysis

Semi-structured interviews generated four overarching themes that provided deeper insight into the nature of partnerships and collaborative relationships identified in the network analysis.

1. Conceptualization of partnership

Key informants did not share a single, consistent understanding of what constituted a "partnership." Some described loosely organized professional relationships in which colleagues supported one another on an as-needed basis, whereas others emphasized structured collaborations characterized by routine meetings, formal institutional backing, and contractual agreements outlining specific objectives. Perspectives on leadership also varied. While certain informants emphasized parity and shared decision-making among partners, others argued that defined leadership—particularly by organizations with greater resources or technical expertise—was essential for effective collaboration. Views additionally diverged regarding the desired strength of relational ties. For some, strong personal relationships and even friendships were seen as foundational to successful partnerships, whereas others highlighted the value of weaker ties, noting that even limited connections could facilitate meaningful exchange and dissemination of knowledge.

2. Primary motivation for collaboration

Across interviews, the central driver of collaboration was the goal of enhancing patient care. Strengthening treatment capacity and improving retinoblastoma survival outcomes were consistently identified as the most significant and widely shared objectives of partnership.

3. Common challenges to collaboration

Participants frequently described difficulties in sustaining partnerships across settings with differing levels of resources and infrastructure. Challenges included securing funding to support joint initiatives, adapting to unfamiliar healthcare systems, and navigating political instability that could disrupt planned activities. Managing interpersonal dynamics within partnerships was also cited as a recurrent obstacle.

Nevertheless, many centers emphasized that maintaining regular, transparent communication between partners helped identify potential misunderstandings early and reduce the impact of relational challenges.

4. Benefits of partnership

Informants from high-income countries (HICs) commonly viewed the principal advantages of collaboration for their own institutions as opportunities to expand research capacity, although they often perceived this as a lower priority for low- and middle-income country (LMIC) partners. Instead, they highlighted the value of leveraging their expertise and resources to support patient care and strengthen treatment capacity in LMIC settings. In contrast, LMIC-based informants emphasized that partnerships with well-resourced HIC institutions were critical for enhancing local clinical capacity and professional knowledge. Unlike their HIC counterparts, LMIC informants frequently underscored research development as an important benefit of collaboration. They also noted that partnerships with local institutions or those operating in comparable contexts could be particularly effective in addressing context-specific challenges related to retinoblastoma. In one illustrative example, an African informant described how collaboration with an international non-governmental organization and a treatment center played a pivotal role in their initial training, serving as a catalyst that enabled them to engage and mobilize new local partners to improve retinoblastoma care within their country.

International cooperation and partnership are widely promoted as essential strategies for addressing complex global health problems, including attainment of the Sustainable Development Goals [25]. Despite this endorsement, limited evidence exists on how global collaborations are organized and how they function to achieve intended outcomes. This study sought to describe and examine the global collaborative landscape focused on improving retinoblastoma survival. Our analysis centered on the 1RBW network, which is documented through a publicly accessible platform (www.1rbw.org). The 1RBW database encompasses most ophthalmic treatment centers worldwide, with countries not represented in the network estimated to account for only 7% of the global retinoblastoma burden (www.1rbw.org).

Findings from the network analysis indicate that the global retinoblastoma community is composed of a broad and geographically diverse set of actors spanning all World Bank regions and income categories **(Table 1)**. Most identified alters were already affiliated with the 1RBW treatment center network **(Table 1)**. In addition, a range of non-clinical entities—including advocacy groups and charitable organizations—were identified as collaborators and were engaged across all collaboration types **(Figure 2)**, highlighting their integral contribution to the global retinoblastoma ecosystem.

Interview data suggested that partnerships were primarily motivated by a shared commitment to improving patient health and quality of life. In practice, this motivation was most often reflected in collaborations focused on clinical service delivery, particularly patient referrals, information exchange (such as treatment protocols and scientific publications), and clinical consultations **(Figure 2).** These forms of collaboration were also reported as the longest-standing activities within the network. This pattern aligns with earlier "international health" models, which emphasized direct provision of medical care to underserved populations, rather than the broader "global health" framework that prioritizes equity, systems strengthening, and interdisciplinary engagement [1]. Reflecting this shift, the Lancet Commission on Global Eye Health has framed eye health as a central global health priority essential to achieving the Sustainable Development Goals [26]. The Commission underscores the need not only to expand capacity, access, and quality of eye care services, but also to strengthen data systems and foster innovation to support sustainable progress [26]. Within this context, the twinning, capacity-building, and joint planning initiatives identified in this study most closely align with contemporary global health principles, as well as calls to strengthen the eye health workforce in LMICs [27]. However, these activities were among the least frequently reported within the 1RBW network. It follows that many existing collaborations may benefit from greater alignment with global health–oriented strategies to more effectively and sustainably achieve their objectives.

The 183 collaborations identified corresponded to an overall network density of 1.3%, indicating substantial untapped potential for additional interconnections within the network. Visual inspection of the network diagram reinforces this finding, showing a small number of highly connected nodes centrally positioned within the network, while the majority of actors are located at the periphery or remain disconnected from the main collaborative structure **(Figure 1)**. Network connectivity serves as a

proxy for influence and capacity within collaborative systems. Within 1RBW, the most connected nodes were predominantly located in North America and Europe **(Table 1)** or within high-income countries **(Table 2).** Furthermore, centrality analyses revealed that the most connected centers exhibited disproportionately high out-degree connections relative to in-degree connections, suggesting asymmetrical power dynamics. This pattern was not observed in a highly connected East Asian center, which demonstrated relatively balanced bidirectional interactions. In addition to their high degree of centrality, these same few centers also held elevated betweenness centrality, indicating their critical role as intermediaries linking otherwise weakly connected institutions. As a result, many centers may depend on one of these three dominant institutions to establish connections with others in their region.

This configuration highlights a paradox within the network: although the primary intent of collaboration is to enhance patient survival, the concentration of influence among actors in high-income countries may unintentionally reinforce the structural inequities that contribute to poorer retinoblastoma outcomes in LMICs. Poorly designed global health partnerships can generate significant harm, including the perpetuation of paternalistic or neocolonial practices and destabilization of local health systems [28–30]. In the context of growing calls to decolonize global health [31], the global retinoblastoma community has a timely opportunity to critically examine existing power imbalances and work toward reimagining collaborative models that promote equity, reciprocity, and shared leadership.

Interview findings highlighted the difficulties associated with establishing and sustaining partnerships between actors operating in settings with markedly different income levels, while emphasizing that regular, transparent communication was essential for addressing these challenges. However, participants did not elaborate on how equity within partnerships could be achieved, measured, or maintained in practice. In addition, most collaborative arrangements were not governed by formal agreements such as Memoranda of Understanding (MoUs). The use of formal instruments like MoUs can enhance clarity, transparency, and accountability by explicitly defining roles, responsibilities, objectives, and benefit sharing, and they are widely recommended for collaborations involving partners with unequal access to resources or power [32]. Similarly, the routine assessment of partnerships using structured evaluation tools may facilitate communication, provide indicators of partnership functioning, and support the identification of strategies to promote more equitable relationships [33].

Our findings also revealed divergent perspectives regarding the role of research collaborations in low- and middle-income countries (LMICs). Key informants based in high-income countries (HICs) commonly perceived research as a lower priority for LMIC partners. In contrast, informants from LMICs emphasized the importance of international collaboration in strengthening local research capacity. The perspectives expressed by some HIC informants may reflect paternalistic tendencies that have historically characterized international research partnerships [30] and warrant critical examination. Research plays a central role in addressing global health inequities [1]; in the context of retinoblastoma, scientific inquiry has underpinned the development of evidence-based clinical guidelines [34] that support high survival rates in HICs, as well as evaluations of capacity-building interventions associated with improved outcomes in LMICs [12, 14, 35–37]. There is a strong rationale for expanding retinoblastoma research within LMICs, as these settings bear the majority of the global disease burden, and evidence generated in other contexts may not be directly applicable. Existing clinical research partnerships between HICs and LMICs frequently involve well-resourced academic centers in emerging economies (for example, in India [38]). Although these collaborations provide strategic advantages, they may inadvertently exclude less-resourced or less-connected centers, along with the patient populations, care environments, and clinician perspectives they represent. Purposeful efforts to engage peripheral treatment centers within the 1RBW network, expand research capacity, and support investigations beyond clinical research (e.g. basic science or implementation research) could generate new knowledge with broader relevance and impact. Notably, since completion of the present network analysis, the 1RBW map was used to identify potential investigators who were subsequently invited to participate in a global study examining retinoblastoma presentation [39]. This coordinated international effort constituted the largest retrospective study conducted in this field and demonstrates the potential for future large-scale, collaborative research. Nonetheless, further examination of investigators who declined participation, and the

reasons for their non-involvement, could shed light on persistent structural barriers that limit inclusivity in research leadership and participation.

Importantly, retinoblastoma research collaborations need not be limited to partnerships involving HIC institutions. Although representation from Latin America and the Caribbean was relatively limited in our study, existing literature documents successful clinical research collaborations emerging from the Central American Association of Pediatric Hematology Oncology (AHOPCA) [7, 8] and the Latin American Pediatric Oncology Group (GALOP) [9]. These examples of "South–South" collaboration may be particularly effective because partners often face similar contextual constraints, challenges, and shared motivations to develop locally relevant solutions [40], a perspective echoed by interview participants. Likewise, the densely interconnected network identified in East Asia—predominantly involving treatment centers in China—may reflect a locally driven response to shared challenges. In this case, a shared-care model was adopted to reduce the financial and psychosocial burden associated with patient referral by requiring healthcare providers, rather than patients, to travel between centers [41].

This study has several limitations. Only 56 of the 170 treatment centers listed within 1RBW participated (33%), and snowball sampling of alters outside the 1RBW network was not undertaken, raising the possibility that some relevant collaborations were not captured. Because the study materials were available only in English, language barriers may have discouraged participation among some 1RBW members. Nevertheless, the analysis still encompassed 68% of network members **(Table 1)**, representing a substantial proportion of the overall network. Additionally, although respondents were asked to report collaborative activities occurring within the previous 12 months, no end dates were collected, meaning that some reported collaborations may have reflected one-time interactions rather than sustained partnerships. The relatively homogeneous positionality of the author team represents another limitation; inclusion of more diverse perspectives—such as investigators from LMICs or secondary-level retinoblastoma centers—or conducting the study in additional languages may have yielded deeper and more nuanced insights.

Conclusion

In conclusion, the results indicate that a substantial number of stakeholders are engaged in efforts to lower retinoblastoma mortality; however, opportunities remain to strengthen links and collaboration, particularly by deliberately engaging actors positioned at the margins of the network. Such engagement may be facilitated through the dissemination of this and comparable studies that prioritize representation and fairness within international partnerships [42], thereby encouraging meaningful dialogue, knowledge sharing, and coordinated action across global retinoblastoma initiatives. Professional organizations in pediatric and ocular oncology are well-positioned to advance these aims, for instance, by inviting and supporting participation of underrepresented stakeholders at international scientific meetings to enhance visibility and enable dissemination of their work. Although global retinoblastoma partnerships are increasingly featured in conference programming, these sessions are still predominantly led by speakers from high-income countries and tend to emphasize clinical outcomes, with limited consideration of how partnerships are initiated, organized, and sustained. Professional societies could address this gap by requiring the inclusion of reflexivity statements regarding international partnerships, similar to recommendations made for scholarly publications involving such collaborations [43]. In addition, further investigation—for example, assessing how involvement in specific types of collaboration within 1RBW relates to engagement, or non-engagement, in other collaborative domains—could provide deeper insight into the functioning of this extensive network. Moving forward, it is recommended that members of the global retinoblastoma community explicitly acknowledge existing power asymmetries within the network and actively pursue research-informed redesign of partnership models to prevent the reinforcement of structural and social inequities.

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References

1. Koplan J, Bond T, Merson M, et al. Towards a

common definition of global health. Lancet 2009; 373(9679): 1993–5. doi: 10.1016/S0140-6736(09)60332-9
2. One RB world online: A virtual retinoblastoma clinic. Annals of Global Health 2015; 81(1): 88.
3. Dimaras H, Corson TW, Cobrinik D, et al. Retinoblastoma. Nat Rev Dis Primers 2015; 1: 15021. doi: 10.1038/nrdp.2015.21
4. World Health Organization. Global initiative for childhood cancer. https://www.who.int/publications/m/item/global-initiative-for-childhood-cancer (accessed September 28 2021).
5. Leander C, Fu LC, Pena A, et al. Impact of an education program on late diagnosis of retinoblastoma in Honduras. Pediatr Blood Cancer 2007; 49(6): 817–9. doi: 10.1002/pbc.21052
6. Al-Haddad C, Bashour Z, Farah L, et al. Establishment of a formal program for retinoblastoma: Feasibility of clinical coordination across borders and impact on outcome. Pediatr Blood Cancer 2019; 66(11): e27959. doi: 10.1002/pbc.27959
7. Luna-Fineman S, Barnoya M, Bonilla M, Fu L, Baez F, Rodríguez-Galindo C. Retinoblastoma in Central America: report from the Central American Association of Pediatric Hematology Oncology (AHOPCA). Pediatr Blood Cancer 2012; 58(4): 545–50. doi: 10.1002/pbc.23307
8. Luna-Fineman S, Chantada G, Alejos A, et al. Delayed Enucleation with Neoadjuvant Chemotherapy in Advanced Intraocular Unilateral Retinoblastoma: AHOPCA II, a Prospective, Multi-Institutional Protocol in Central America. J Clin Oncol 2019; 37(31): 2875–82. doi: 10.1200/JCO.18.00141
9. Pérez V, Sampor C, Rey G, et al. Treatment of Nonmetastatic Unilateral Retinoblastoma in Children. JAMA Ophthalmol 2018; 136(7): 747–52. doi: 10.1001/jamaophthalmol.2018.1501
10. Chantada G, Dunkel I, Schaiquevich P, et al. Twenty-Year Collaboration Between North American and South American Retinoblastoma Programs. J Glob Oncol 2016; 2(6): 347–52. doi: 10.1200/JGO.2015.002782
11. Qaddoumi I, Nawaiseh I, Mehyar M, et al. Team management, twinning, and telemedicine in retinoblastoma: A 3-tier approach implemented in the first eye salvage program in Jordan. Pediatr Blood Cancer 2008; 51(2): 241–4. doi: 10.1002/pbc.21489
12. Traore F, Sylla F, Togo B, et al. Treatment of retinoblastoma in Sub-Saharan Africa: Experience of the paediatric oncology unit at Gabriel Toure Teaching Hospital and the Institute of African Tropical Ophthalmology, Bamako, Mali. Pediatr Blood Cancer 2018; 65(8): e27101. doi: 10.1002/pbc.27101
13. Yousef Y, Al-Nawaiseh I, Mehyar M, et al. How Telemedicine and Centralized Care Changed the Natural History of Retinoblastoma in a Developing Country: Analysis of 478 Patients. Ophthalmology 2021; 128(1): 130–7. doi: 10.1016/j.ophtha.2020.07.026
14. Hill JA, Kimani K, White A, et al. Achieving optimal cancer outcomes in East Africa through multidisciplinary partnership: a case study of the Kenyan National Retinoblastoma Strategy group. Global Health 2016; 12(1): 23. doi: 10.1186/s12992-016-0160-1
15. Blanchet K, James P. How to do (or not to do)… a social network analysis in health systems research. Health Policy and Planning 2012; 27: 438–46. doi: 10.1093/heapol/czr055
16. Blanchet K, James P. The role of social networks in the governance of health systems: the case of eye care systems in Ghana. Health Policy and Planning 2013; 28: 143–56. doi: 10.1093/heapol/czs031
17. Palmer JJ, Gilbert A, Choy M, Blanchet K. Circumventing 'free care' and 'shouting louder': using a health systems approach to study eye health system sustainability in government and mission facilities of north-west Tanzania. Health research policy and systems 2016;14(1):68. doi: 10.1186/s12961-016-0137-9
18. Steitz BD, Levy MA. A Social Network Analysis of Cancer Provider Collaboration. AMIA Annual Symposium proceedings AMIA Symposium; 2017; 2016: 1987–96.
19. Luque J, Tyson DM, Lee J-H, et al. Using social network analysis to evaluate community capacity building of a regional community cancer network. Journal of community psychology 2010; 38(5): 656–68. doi: 10.1002/jcop.20386
20. Borgatti S, Mehra A, Brass D, Labianca G. Network analysis in the social sciences. Science

2009. Feb 13; 323(5916): 892–5. doi: 10.1126/science.1165821
21. Wendel M, Prochaska J, Clark H, Sackett S, Perkins K. Interorganizational Network Changes Among Health Organizations in the Brazos Valley, Texas. J Primary Prevent 2010; 31: 59–68. doi: 10.1007/s10935-010-0203-y
22. Network Impact and Center for Evaluation Innovation. Framing Paper: The State of Network Evaluation. Part 1 of a Guide to Network Evaluation; 2014.
23. World Bank. World Bank Country and Lending Groups–World Bank Data Help Desk. World Bank Country and Lending Groups.
24. Scott J. Social Network Analysis. 4th ed. Croydon, UK: SAGE Publishing; 2017.
25. Gabay C, Ilcan S. The Affective Politics of the Sustainable Development Goals: Partnership, Capacity-Building, and Big Data. Globalizations 2017; 14: 468–85.
26. Burton MJ, Ramke J, Marques AP, et al. The Lancet Global Health Commission on Global Eye Health: vision beyond 2020. The Lancet Global health 2021; 9(4): e489–e551. doi: 10.1016/S2214-109X(20)30488-5
27. Palmer JJ, Chinanayi F, Gilbert A, et al. Mapping human resources for eye health in 21 countries of sub-Saharan Africa: current progress towards VISION 2020. Human resources for health 2014; 12: 44–. doi: 10.1186/1478-4491-12-44
28. Corbin J, Mittelmark M, Lie G. Mapping synergy and antagony in North–South partnerships for health: a case study of the Tanzanian women's NGO KIWAKKUKI. Health Promot Int 2013; 28(1): 51–60. doi: 10.1093/heapro/dar092
29. Crane J. Unequal 'Partners'. AIDS, Academia, and the Rise of Global Health. Behemoth J Civil 2010; 3(3): 78–97.
30. Gautier L, Sieleunou I, Kalolo A. Deconstructing the notion of "global health research partnerships" across Northern and African contexts. BMC Med Ethics 2018; 19(Supplement 1). doi: 10.1186/s12910-018-0280-7
31. Büyüm A, Kenney C, Koris A, Mkumba L, Raveendran Y. Decolonising global health: if not now, when? BMJ Global Health 2020; 5: e003394. doi: 10.1136/bmjgh-2020-003394
32. Ward C, Shaw D, Sprumont D, Sankoh O, Tanner M, Elger B. Good collaborative practice: reforming capacity building governance of international health research partnerships. Globalization and Health 2018; 14. doi: 10.1186/s12992-017-0319-4
33. Halliday J, Asthana S, Richardson S. Evaluating Partnership: The Role of Formal Assessment Tools. Evaluation 2004; 10(3): 285–303.
34. National Retinoblastoma Strategy Canadian Guidelines for Care: Strategie therapeutique du retinoblastome guide clinique canadien. Can J Ophthalmol 2009; 44 Suppl 2: S1–88. doi: 10.3129/i09-194
35. Nyamori JM, Kimani K, Njuguna MW, Dimaras H. The incidence and distribution of retinoblastoma in Kenya. Br J Ophthalmol 2012; 96(1): 141–3. doi: 10.1136/bjophthalmol-2011-300739
36. Nyamori JM, Kimani K, Njuguna MW, Dimaras H. Retinoblastoma referral pattern in Kenya. Middle East Afr J Ophthalmol 2014; 21(4): 321–7. doi: 10.4103/0974-9233.142270
37. Traore F, Togo B, Sylla F, et al. [Retinoblastoma: inventory in Mali and program to develop early diagnosis, treatments and rehabilitation]. Bull Cancer 2013; 100(2): 161–5. doi: 10.1684/bdc.2013.1703
38. Chévez-Barrios P, Eagle RCJ, Krailo M, et al. Study of Unilateral Retinoblastoma with and Without Histopathologic High-Risk Features and the Role of Adjuvant Chemotherapy: A Children's Oncology Group Study. J Clin Oncol 2019; 27(31): 2883–91.
39. Fabian ID, Abdallah E, Abdullahi SU, et al. Global Retinoblastoma Presentation and Analysis by National Income Level. JAMA Oncol 2020; 6(5): 685–95. doi: 10.1001/jamaoncol.2019.6716
40. United Nationals Office for South-South Cooperation. About South-South and Triangular Cooperation. https://wwwunsouthsouthorg/about/about-sstc/ Accessed on 21 April 2020.
41. Smith JR, Pe'er J, Belfort RN, et al. Proceedings of the Association for Research in Vision and Ophthalmology and Champalimaud Foundation Ocular Oncogenesis and Oncology Conference. Transl Vis Sci Technol 2018; 8(1): 9–. doi: 10.1167/tvst.8.1.9
42. Abimbola S, Asthana S, Montenegro C, et al. Addressing power asymmetries in global health: Imperatives in the wake of the COVID-19 pandemic. PLoS medicine 2021; 18(4): e1003604–

e. doi: 10.1371/journal.pmed.1003604
43. Morton B, Vercueil A, Masekela R, et al. Consensus statement on measures to promote equitable authorship in the publication of research from international partnerships. Anaesthesia 2021. Oct 14: Epub ahead of print. doi: 10.1111/anae.15597