

MISSING LINKS: HOW TO IMPROVE THE GLOBAL, REGIONAL AND NATIONAL EVIDENCE FOR DECISION MAKING?

Co-leaders:

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Current Situation

- Seventy percent of the data included in the CI5 database is from North America/Western Europe.
- Current global figures do not truly reflect underlying economic, cultural or racial diversity
- Quality of data in existing registries lacking.
- Little success in low/middle income countries linking data to decision-making even in those with registries

Recommendations

Overall perspective:

Advocate for integrating cancer into the national health systems following a “diagonal approach”: specifically the improvement of data resources directed toward improving global, regional and national evidence for decision-making.

Recommendations

- 1) **Call for the international community to engage in improving cancer data resources that will lead to effective cancer decision-making.**
 - **All countries should be encouraged to:**
 - develop a strategy for improving cancer data linked to decision-making
 - identify a person (champion) responsible for evidence-based cancer planning and research
 - **Underscore the importance of making very achievable improvements in cancer data resources that will be used for rational planning and research:**
 - Determine priorities based on burden of disease
 - Evaluate whether goals of programs or interventions are reached
 - Compare resource input and outcomes
 - Promote research within academic and registry partnerships
 - **Recognize that data quality is more important than quantity** (e.g., focusing on 1 or a few good population-based regional registries may be a more realistic approach for countries than national registries).

Recommendations

- 2) Advocate for a Global Fund for Cancer Data Improvement, to which low/middle income countries could apply for financial support and guidance.**
- Make-up of the Fund collaborative and inclusive of global data experts and key stakeholders including those from developing countries.
 - The model designed with a bottom up approach, i.e., applications for support will come from countries desiring to improve data resources
 - Assistance prioritized to promote cancer data strategies integrated with a national health strategy.