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Systematic review for rare diseases policy: a sight in Peru and Colombia

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INTRODUCTION

Rare diseases (RD) impact around 5 out of 10,000 people worldwide and despite their low prevalence, they pose a significant economic and social burden. Accordingly, RD patients are subject to special considerations defined within public policies, specially in developing countries where healthcare system budget is limited.

OBJECTIVE

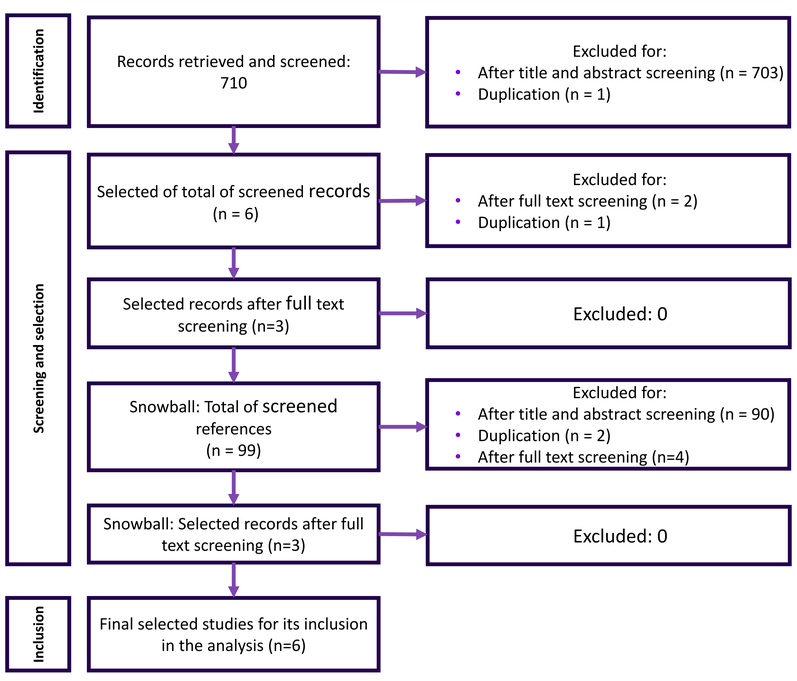
To systematically review existing literature about public policy for rare diseases patients in Peru and Colombia; identify additional opportunities to improve decision-making items and processes for policy-makers.

METHODS

- A systematic literature review was developed using five electronic databases (Cochrane, Pubmed, Scielo, Scopus and BVSalud) to search for articles published in either English or Spanish, without publication date limits.
- The search strategy included the keywords: Policy, rare diseases and words related to the geography of interest (Latam, South America, or LAC).
- Studies with information regarding rare diseases policies in Peru and Colombia in the title and abstract were included. Duplicated and non-free access studies were excluded.
- An additional snowball exercise was performed with the selected references from the literature review.
- A full-text screening was executed on all identified and selected studies.

POSTER HIGHLIGHT: Improving outcomes and quality of life for rare disease patients, requires involvement of different actors (family, physicians, support system, government), to obtain the integral perspective needed before public policy decision-making processes.

Figure 1: SLR Prisma Diagram



CONCLUSIONS

Although Peru and Colombia have made significant progress in rare diseases public policy since early 2000's, it is essential to incorporate such experiences on research studies and public data sources.

RESULTS

- A total of 710 studies were identified, six studies were retrieved for final screening and three were included in the final analysis. From the snowball exercise, three additional studies were incorporated.
- Three studies were focused on national plans and implemented strategies, one of these highlighted the relevance of including the patients' perspective.
- One study reported the experience of the first National Registry for rare diseases in Colombia.
- One study reviewed funding, regulatory and ethical concerns for genetic disease clinical trials in Latam.
- The last study covered the terms and operational definitions in different regions (EU, US, and Latam) and remarked on the importance of such definitions as a starting point for national decision-making processes.

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