Rare Disease Research Partnership (RAinDRoP): A Collaborative Approach to Identify Research Priorities for Rare Diseases in Ireland

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For which topic were research priorities identified?
rare diseases

In which location was the research priority setting conducted?
Europe - Ireland

Why was it conducted at all?
Rare diseases are individually unique, but collectively they share substantial unmet health and social care needs. These pose a significant public health challenge. Rare diseases are challenging for clinicians in terms of reaching a conclusive diagnosis and determining an appropriate course of treatment due to their low prevalence, heterogenicity and complex nature. There has been a lack of discussion on the research topics that should be prioritised and gaining consensus about research priority areas is timely and important.

What was the objective?
to identify priorities for rare diseases research aimed at improving the health and wellbeing of people living with rare diseases

What was the outcome?
a ranking list of 15 research topics

How long did the research prioritization take?
No information provided.

Which methods were used to identify research priorities?
survey; workshop

How were the priorities for research identified exactly?
Step 1: collecting research topics: expert group reviewed literature and policies, 6 themes emerged, survey 1: participants were asked to think of questions they would like to see answered by rare disease research in relation to the six topics identified by the expert group, survey asked: What questions would you like to see answered by Rare Disease research?, 1015 statements were submitted, expert group met to refine list, 29 topics moved forward. Step 2: workshop: each theme was introduced, participants had opportunity to learn more, ask questions and share knowledge and experiences, followed by small group discussions with world café method, participants were asked to rate topics and also asked how much they would invest in these topics. Step 3: consultation and survey 2: to validate top 15 priorities, participants were asked to rank top 15 research priority topics

Which stakeholders took part?
Healthcare professionals, researchers and people living with rare diseases. Survey 1: 240 participants: 32% persons living with a rare disease. Workshop: 42 participants: those living with rare diseases, family, carers, clinicians, genetics/scientist, policymakers, research funding bodies, interdisciplinary healthcare and social care professionals, and researchers with a particular interest in rare diseases. Survey 2: 75 participants.

How were stakeholders recruited?
Social media (Twitter, LinkedIn, Facebook) was utilised to share participant information leaflets and the online survey. Targeted invitations to attend the workshop were circulated by the Rare Disease Taskforce, Rare Disease Ireland, National Clinical program for Rare Diseases, and IPPOSI. There was a focus on creating a cross-section of individuals from service providers, service users, and the public perspective. Participants included those living with rare diseases, family, carers, clinicians, genetics/scientist, policymakers, research funding bodies, interdisciplinary healthcare and social care professionals, and researchers with a particular interest in rare diseases. Eligibility criteria were as follows: English speaking; 18 years and older; and able to provide informed consent to participate. There was a clear focus in this workshop to achieve gender balance, leading to a 50:50 split of men and women. It was also ensured that minority ethnic groups were included during the invitation. The RAinDRoP expert group members and partners were asked to promote the survey to stakeholders via email, relevant meetings, social media, web sites, and any other opportunities that arose. A social media promotion plan was developed, similar to phase I.

Were stakeholders actively involved or did they just participate?
Stakeholders not only participated but were also actively involved in the research prioritization process. They were part of a steering group. The steering group consisted of 3 patient-organization representatives, 3 patients and family members living with rare diseases, 2 members of the National Rare Disease Office in Ireland, 2 academics, 2 researchers, 2 healthcare professionals. The members oversaw the whole process and were involved in data processing.