

RARE DISEASE PROGRAM

Project name: Visual Disfigurement in Rare Diseases – A European Health Action to improve Psychosocial Treatment, Care and Understanding.

General objective:

Address the important issue of visual disfigurement in rare diseases and its social consequences. These individuals with rare diseases face a variety of obstacle that generally evolve from loss of function, dependency on others, restricted choices, physical and social barriers and undesirable reactions of others. This effectively prevents them to become socially included in our European society. In order to address these issues the project will focus upon;

1. Create a European network for visual disfigurement in rare diseases.
2. Generate a material that explain the social consequences of visual disfigurement in rare diseases by utilizing current research findings and accomplish qualitative interviews that highlight the personal experience from different European perspectives.
3. Disseminate the outcomes to health professionals and lay persons around Europe.

Strategic relevance & contribution to the programme:

Current health care provisions, including the rare disease program, do not address the complexity of visual disfigurement acquired from rare diseases and its negative impact it has on quality of life for these individuals. By addressing this neglected issue in rare diseases, the project will contribute to facilitate a better comprehensive understanding and knowledge, establish an evidence based approach that will provide guidelines for psychosocial treatment for medical and allied health professionals across Europe, but also provide information to increase public awareness. This European collaboration will result in better treatment, care and understanding for this specific population.

Methods and means:

The key actors in the project have considerable experience in psychosocial effects of visual disfigurement and a collaborative network, which will provide the necessary

structure to create a European network for visual disfigurement in rare diseases and provide material about psychosocial issues in this area.

Structured qualitative interviews in the participating project members countries will take place in order to capture the target groups experience on how it is to live with a rare disease with visual disfigurement in our European society.

The partnership contains several organisations which are key actors either in the medical allied health field, educational institutions and organisations involved with rare diseases with a large network to disseminate the outcome of the project.

Furthermore, each participating organization will develop strategic workgroups with invited organizations in order provided a further dissemination portal.

Expected outcome:

Short term outcomes:

- The project will establish a European network that will function as a hub for issues around visual disfigurement associated with rare diseases.
- The partners will have a material that they can use when conducting training/educating health professionals and lay persons in order to improve treatment and understanding.
- Target groups outside the project will have received the information through the valorisation activities and/or through the partners acting as multipliers (especially the strategic work groups).

Long term outcomes:

- The establishing of a European network will ensure that advisory resources and material developed from the project and other research will be available after the project funding is over. The European network will be maintained by University of Bristol and University West of England.
- The multiple networking and valorisation activities of the project will raise the awareness of the needs to address the psychosocial issues of visual disfigurement in rare diseases.
- Increase members in the European network for visual disfigurement in rare diseases.

- Using the material across Europe will be a powerful instrument to raise awareness and the need to address these issues in treatment and care in a European perspective for both health professionals and lay people.

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