

Organisational strategy to support members through 7 Key Life Stages

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Introduction and objectives:

The UK Haemophilia Society required a new strategic plan and to diversify funding to ensure long term sustainability.

Materials and Methods:

Using The Kings Fund experience-based co-design toolkit we worked with members to find new ways to develop and deliver services, information and support. Members of the charity were asked to contribute to decisions on the priorities for the organisation which led to the identification of seven key life stages:



1 Supporting newly-diagnosed children and families

- Whole family support via weekend events for newly diagnosed families, and publications on understanding bleeding disorders

2 Starting nursery or school

- Publications on starting school and nursery, local group support to meet others

3 Learning to self-treat

- Activity weekends for 8-18 year olds where the focus is learning to treat, as well as having fun, being active and building a support network

4 Making the transition to adulthood

- Undertaking research to identify the key issues and looking to develop future services and information to support young people, parents and health professionals

5 Choosing a career

- Supporting young people to find a career that works for them, as well as helping our older members consider options for a change of career
- Highlighting members' experiences

6 Planning a relationship or family

- Working with carriers and young people to address concerns holding conferences for women and their partners

7 Getting older with a bleeding disorder

- Filming older members to understand their experiences and develop new services and publications, with a specific focus on HIV and Hepatitis C

Other key areas identified included:

Living with an inhibitor

- Filming members with an inhibitor, holding a conference and developing publications

Women with a bleeding disorder

- Hosting a conference and developing publications

Each attendee completed a pre and post service evaluation to enable the impact of the services to be assessed. People affected are filmed to understand the impact of their diagnosis and gaps in services and to help inform the development of new services.

Results: Service take up has increased by 923%, membership has increased by 1615 individuals, engagement and referrals from haemophilia centres has increased considerably. This has also led to a 310% increase in corporate funding, a 41% increase in community fundraising and increased member engagement and service take up with excellent feedback from attendees.

Conclusions: The new strategic plan and service development has brought about a complete turnaround in the viability and purpose of the charity, with a very positive future ahead of us.



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SOCIETY