

Empowering others to treat

The use of social media for peer support, the benefits, challenges and effectiveness of sharing positive images of intravenous treatment



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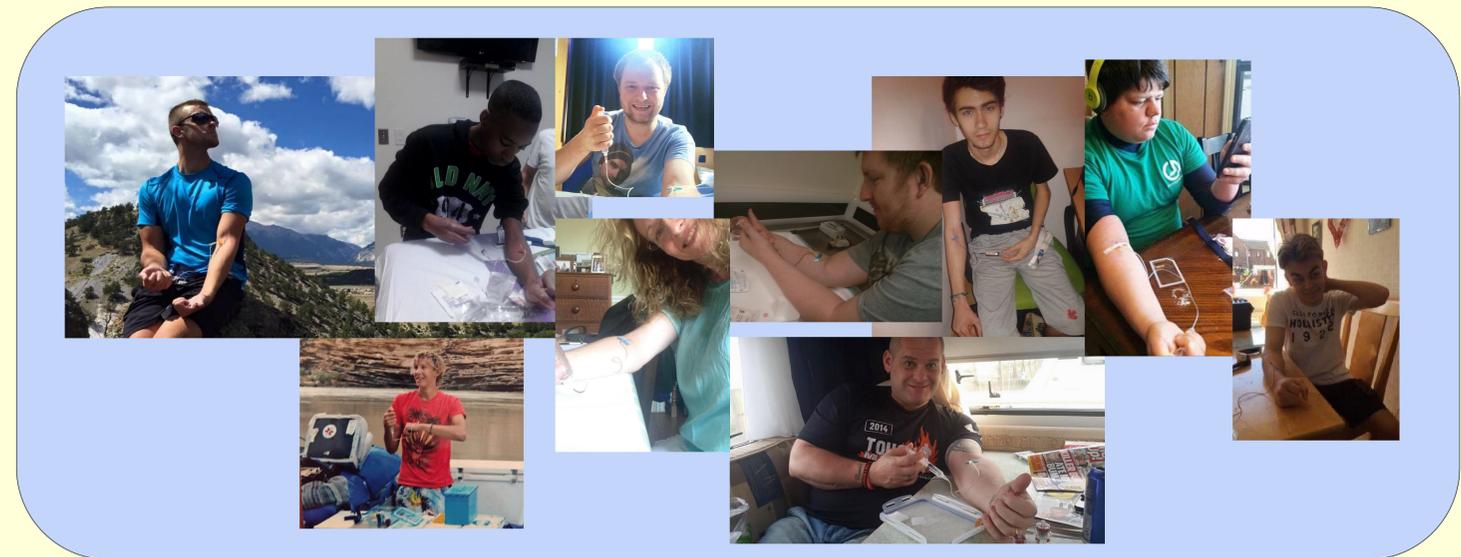


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Introduction and Objective

Haemophilia is a rare lifelong blood disorder. The predominant treatment is intravenous replacement clotting factor, both prophylactically and for acute bleeding episodes. Optimum management includes access to immediate treatment; often given outside a healthcare setting. This means training parents, carers and then the affected individual to inject treatment in their own environment as soon as is clinically and practically possible.

A series of positive images has been collected showing people with bleeding disorders successfully administering treatment. These images are available to share securely within the haemophilia community, providing support, encouragement and insight into the treatment process.



Success Story



DW age 6 uses a Port-a-Cath
He saw others self-infusing on the computer screen, decided to have a go himself in clinic and 2 weeks (and 1 haircut) later happily let his parents do a venepuncture at home!

To see other children treating themselves has really helped me and my son. It has given us the confidence to keep on trying with the injections.

What a wonderful resource, everyone looks so at ease. This has given me hope for the future as I never imagined we would ever be able to give treatment at home.

Methods

Focus groups were held with young people and families affected by haemophilia to assess the potential benefit of such a project. Positive images were taken at treatment time and shared using a social media site. Issues respecting safety, security and confidentiality were considered and addressed. Images of those over 16, with consent, were collected on an open profile. Those aged under 16, with parental consent, in a private group accessible by invitation only. Existing online support groups and some Haemophilia Centres in the UK were contacted for participants. Emphasis was placed on recorded consent being necessary to use and share any images either on the social media site or at educational meetings.



Results

A compilation of positive, practical images at treatment time is now available to share within the haemophilia community providing encouragement to other families and individuals that they might gain the confidence to attempt home infusion or self-injection. Some images are combined with encouraging messages of support. Feedback already gathered shows that some of those who have shared their image have gained a sense of accomplishment.

Conclusions

To gain independence individuals with a bleeding disorder need to self inject. The aim of this project is to encourage early self-infusion. Images of others successfully receiving treatment can benefit affected individuals and provide reassurance for families and carers that there are others in the same position

