

# The Top 10 Research Priorities in Bleeding Disorders: A James Lind Alliance Priority Setting Partnership

Shapiro et al. (2019)  
<https://doi.org/10.1111/bjh.15928>

## For which topic were research priorities identified?

bleeding disorders

## In which location was the research priority setting conducted?

Europe - United Kingdom

## Why was it conducted at all?

The Bleeding Disorders Priority Setting Partnership (PSP) came together following an initiative from the United Kingdom Haemophilia Doctors Organisation (UKHCDO) to set up a clinical studies group for bleeding disorders. The aim of the group was to promote research into bleeding disorders in general and not restrict itself to haemophilia and related inherited bleeding disorders.

## What was the objective?

to ask patients, carers and healthcare professionals to identify and prioritize the unanswered questions that concern them most about the diagnosis, treatment and care of people with bleeding disorders

## What was the outcome?

a ranking list of 10 research questions

## How long did the research prioritization take?

April 2017 - July 2018

## Which methods were used to identify research priorities?

JLA method

## How were the priorities for research identified exactly?

Step 1: setting up PSP: steering group established, stakeholders and partner organizations identified. Step 2: collecting research uncertainties: via survey, participants were asked to submit the questions they would like answered by research, total of 478 uncertainties submitted. Step 3: data processing: questions sorted and categorized, out-of-scope removed, similar questions grouped together, indicative questions formulated, check against evidence, resulting in 66 unanswered questions. Step 4: interim ranking: participants were asked to rank their top 10 priorities from 66 consolidated unanswered questions, highest scoring 25 uncertainties were identified, steering group agreed to take top 25 questions to final workshop. Step 5: final prioritization: workshop: small group discussions and small group rankings, aggregate ranking, plenary discussion

## Which stakeholders took part?

Patients with inherited or acquired bleeding disorders, carers, healthcare professionals. Survey: 213 participants: 68 healthcare professionals, 68 patients, 77 relatives or carers of someone with a bleeding disorder, representatives of organizations supporting patients with bleeding disorders, or a combination of the above. Interim ranking: 111 participants: 55 healthcare professionals, 44 patients, 12 relatives or carers of someone with a bleeding disorder, representatives of organizations supporting patients with bleeding disorders, or a combination of the above. Workshop: 24 participants: 11 HCPs, 13 patients/ carers/ representatives.

## How were stakeholders recruited?

The initial survey was promoted to patients, carers and HCPs via patient and professional groups and social media. The survey was advertised as widely as possible using all available routes. This included patient group and professional group mailing lists as well as personal contacts. The PSP scope included children from 8 years and above and so the PSP steering group discussed how to engage this group. With the benefit of having a paediatric nurse specialist nurse on the group it was agreed to develop printed postcards. These postcards (for children less than 16 years old) were distributed to clinics which treated children with inherited bleeding disorders and/or ITP. The postcards were also used at summer camps seeking children's and young people's views of areas that they thought were important for future care and research. participants workshop: recruited through the Steering Group members' networks, via patient and clinician groups and through social media.

## 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 15 individuals: 4 physicians, 1 nurse, 1 physiotherapist, 6



Open Innovation in Science Center  
LUDWIG-BOLZMANN-GESELLSCHAFT

Open Innovation in Science Center  
Ludwig-Bolzmann-Gesellschaft GmbH

Musdorfer Straße 64, 2. Stock  
1090 Wien, Österreich