	PSP Name	Total number of verified uncertainties identified by the PSP	Uncertainty (PICO formatted indicative uncertainty where possible. Advised minimum requirements are 'Population' and 'Intervention'. Not all submissions may be suitable for PICO structure, but they should be in a format that will ultimately be of value to the research community)	Explanatory note (a plain language summary of up to 150 words, explaining key points of the uncertainty and why it is important, for research funders to begin working on. PSPs may wish to include examples of the original survey submissions here)	Date of the priority setting workshop	Rank of the uncertainty at the final workshop. (If no rank was agreed, please indicate)	Evidence (reference to the most recent relevant systematic review identified by the PSP, plus a maximum of 2 other systematic reviews, including protocols for future systematic reviews, that the PSP considers relevant.)	Health Research Classification System (high level HRCS code to be allocated by the JLA team unless the PSP prefers to complete this)
	Bleeding disorders	66	What is the role and cost effectiveness of blood clotting tests that give immediate results at the bedside (point of care) in managing medical, surgical or obstetric haemorrhage?	Is point of care testing useful in the management of major obstetric haemorrhage? How to treat major surgical and obstetric haemorrhage as efficiently and quickly as possible using goal directed therapy and point of care testing devices	07-Jul-18	1	No systematic reviews Collis, R. and E. Guasch (2017). "Managing major obstetric haemorrhage: Pharmacotherapy and transfusion." Best Practice & Research. Clinical Anaesthesiology 31(1): 107-124. https://dx.doi.org/10.1016/j.bpa.2017.02.001	
	Bleeding disorders	66	How can we balance the risk and benefit of antithrombotic (blood thinning) treatment for cardiovascular disease (including heart attacks and strokes) in patients with bleeding disorders?	Management of bleeding disorder patients with cardiovascular disease eg how should we approach patients with bleeding disorders who have AF and high CHADSVASC scores? How should patients with inherited bleeding disorders and atrial fibrillation be managed? How should patients with inherited bleeding disorders and acute coronary syndrome be managed?	07-Jul-18	2	Harahsheh Y, Ho KM. Use of viscoelastic tests to predict clinical thromboembolic events: A systematic review and meta-analysis. Eur J Haematol. 2018;100(2):113-23.Whiting P, Al M, Westwood M, Ramos IC, Ryder S, Armstrong N, et al. Viscoelastic point-of-care testing to assist with the diagnosis, management and monitoring of haemostasis: a systematic review and cost-effectiveness analysis. Health Technol Assess. 2015;19(58):1-228, v-vi	
	Bleeding disorders	66	What is the best haematological approach to management of severe haemorrhage after delivery?	Which is the most effective treatment for Post Partum Acquired Haemophilia? What is the most effective strategy to manage post part haemorrhage? What are the best treatments for PPH?	07-Jul-18	3	Evidence for specific therapies only: Soro M-AP, Denys A, de Rham M, Baud D. Short & long term adverse outcomes after arterial embolisation for the treatment of postpartum haemorrhage: a systematic review. European radiology. 2017;27(2):749-62. 2. Li C, Gong Y, Dong L, Xie B, Dai Z. Is prophylactic tranexamic acid administration effective and safe for postpartum hemorrhage prevention?: A systematic review and meta-analysis. Medicine. 2017;96(1):e5653.	
	Bleeding disorders	66	How should heavy periods be managed in women with bleeding disorders?	What treatments for periods for women with bleeding disorders have the least side effects overall? If I do exercise during my period will it make the bleeding last for longer?	07-Jul-18	4	No systematic reviews . Menorrhagia and postpartum haemorrhage in women with rare bleeding disorder. Halimeh S. Thrombosis Research. 135 Suppl 1:S34-7. 2015 Feb.	
	Bleeding disorders	66	What is the relationship between immune thrombocytopenic purpura (ITP) and fatigue?	Why is fatigue/tiredness still NOT fully recognised as a symptom of ITP (Immune Thrombocytopenia) ? How can the fatigue associated with bleeding disorders be ameliorated or eliminated? Will tiredness ever be properly proven to be a symptom of ITP?	07-Jul-18	5	No systematic review. One observational study: Newton, J. L., et al. (2011). "Fatigue in adult patients with primary immune thrombocytopenia." European Journal of Haematology 86(5): 420-429. 10.1111/j.1600-0609.2011.01587.x	
	Bleeding disorders	66	What are the most effective treatments for acute and chronic pain in people with haemophilia?	is bruhen a useful addition in the sub acute treatment of a joint bleed in children in the prevention of synovitis pain and mobility after bleeds What is the most effective treatment for pain due to chronic haemophilia arthropathy?	07-Jul-18	6	Schafer, G. S., et al. (2016). "Physical exercise, pain and musculoskeletal function in patients with haemophilia: a systematic review." Haemophilia 22(3): e119-129. https://dx.doi.org/10.1111/hae.12909	
	Bleeding disorders	66	What are the benefits of psychological and psychosocial strategies for support of individuals or families affected by bleeding disorders?	How effective is the transition process between paediatric and adult services? Does an education course including specialised nursing and Physiotherapy at the time of transfer from Paed to adult services improve patient compliance with regime, use of haemtrac and QoL? Can psychology improve treatment compliance and reduce bleeding episodes	07-Jul-18	7	No specific data for haemophilia or bleeding disorders: Waldboth, V., et al. (2016). "Living a normal life in an extraordinary way: A systematic review investigating experiences of families of young people's transition into adulthood when affected by a genetic and chronic childhood condition." International Journal of Nursing Studies 62: 44-59.	
	Bleeding disorders	66	What are the genetic and environmental factors that predispose people to immune thrombocytopenic purpura (ITP)?	Is ITP hereditary? Finding out the cause of ITP would be great. What causes ITP?	07-Jul-18	8	No systematic reviews	
	Bleeding disorders	66	What is the best way to prevent or treat bleeds in people with bleeding disorders who have developed an inhibitor?	How to cure inhibitors How to prevent inhibitors occurring do treatments course inhibitors	07-Jul-18	9	Systematic reviews are outdated Wight J, Paisley S, Knight C. Immune tolerance induction in patients with haemophilia A with inhibitors: a systematic review. Haemophilia. 2003;9(4):436-63. Chai-Adisaksopha C, Nevitt SJ, Simpson ML, Janbain M, Konkle BA. Bypassing agent prophylaxis in people with hemophilia A or B with inhibitors. Cochrane Database Syst Rev. 2017;9:CD011441.Zhou ZY, Hay JW. Efficacy of bypassing agents in patients with hemophilia and inhibitors: a systematic review and meta-analysis. Clin Ther. 2012;34(2):434-45	
	Bleeding disorders	66	In people with haemophilia, what is the best way to tell the difference between pain from acute bleeds, non-bleeding muscle/ligament injury and long term joint damage?	Differentiating between a bleed and a musculoskeletal injury - how can access to a specialist physiotherapist help patient awareness What symptoms differentiate acute joint bleeding and exacerbation of haemophilia arthropathy? How to differentiate between bleeds, arthritic pain and normal aches/pains and muscle pain etc	07-Jul-18	10	No RCT or systematic review identfied	
11	Bleeding disorders	66	Can a home testing device to record low platelets and clotting factors be developed?	At present patients have to attend hospital to find out the status of their disease or response to treatment. For patients who adjust their own treatment or who are planning activities, it would be very useful and would avoid problems if they could measure this on a device at home	07-Jul-18		No such device exists. Devices that can measure platelet count are used at point-of-cre in hospital but not yet at home. Where are we at with point-of-care testing in haematology?. [Review] Briggs C; Kimber S; Green L. British Journal of Haematology. 158(6):679-90, 2012 Sep	
12	Bleeding disorders	66	What is the role of exercise for both prevention and treatment of joint damage in haemophilia?	Exercise may precipitate bleeding but it is also believed that by strengthening muscles, exercise can help prevent bleeds and be beneficial in the long term. It is therefore important to understand what levels and type of exercise we should recommend.	07-Jul-18		Exercise for haemophilia. [Review] Strike K; Mulder K; Michael R. Cochrane Database of Systematic Reviews. 12:CD011180, 2016 12 19	
13	Bleeding disorders	66	What is the impact of the gut microbiome on immune thrombocytopenic purpura (ITP)?	The blood protein profile is dominated by products from the gut microbiome. There is mounting evidence that this has an important influence on disease. Understandinghe specific role in ITP may open up new treatments.	07-Jul-18		None	
14	Bleeding disorders	66	What activities are NOT safe to do with any given reduction in platelet count or clotting factor level?	High impact sports or activities are discouraged in people with bleeding disorders because they may provoke bleeding. This is obvious for say, boxing, but for others there is considerable uncertainty.	07-Jul-18		None	
15	Bleeding disorders	66	In people with haemophilia, what are the most effective treatments for the prevention and treatment of haemophilic synovitis (inflammation of the joint lining)?	In haemophilia, recurrent bleeding into joints causes an inflammatory reaction called synovitis. It is helpful to reduce bleeding but this is very slow to show benefit. We would like to know if there are other therapies which could accelerate recovery.	07-Jul-18		Kresnik, E, P Mikosch, HJ Gallowitsch, R Jesenko, H Just, D Kogler, J Gasser, M Heinisch, O Unterweger, G Kumnig, I Gomez, P Lind. Clinical outcome of radiosynoviorthesis: a meta-analysis including 2190 treated joints. Nucl Med Commun 23 (2002) 683-8.	
16	Bleeding disorders	66	What causes the onset of immune thrombocytopenic purpura (ITP)?	We do not know why in some people the immune system suddenly fails to recognise platelets as 'self'. Understanding this would help us treat and prevent the disorder.	07-Jul-18		None	
17	Bleeding disorders	66	Is there an effective substitute for steroids in the treatment of immune thrombocytopenic purpura (ITP)?	Steroids are standard first line treatment for ITP. However they have numerous side effects and a treatment without these would be a major advance.	07-Jul-18		None	
18	Bleeding disorders	66	When is treatment for immune thrombocytopenic purpura (ITP) required?	All the treatments for ITP have some kind of side effects and so should be used only when needed. We do not know at what level of platelet count the benefits outweigh the risks.	07-Jul-18		None	
19	Bleeding disorders	66	What causes exacerbations of immune thrombocytopenic purpura (ITP)?	ITP is a fluctuating disease. If we knew why this happens we may be able treat it better and prevent exacerbations.	07-Jul-18		None	
20	Bleeding disorders	66	What is the psychological impact and burden of being a person or a carer of a person, with an acquired or non-acquired bleeding disorder?	Inherited bleeding disorders ar a major burden on the individual and their familiy. We have concentrated on the physical aspects of the problem and not on the psychological stress.	07-Jul-18		Cassis, FR, F Querol, A Forsyth, A Iorio, HIA Board. Psychosocial aspects of haemophilia: a systematic review of methodologies and findings. Haemophilia 18 (2012) e101-14. Waldboth, V, C Patch, R Mahrer-Imhof, A Metcalfe. Living a normal life in an extraordinary way: A systematic review investigating experiences of families of young people's transition into adulthood when affected by a genetic and chronic childhood condition. Int J Nurs Stud 62 (2016) 44-59.	
21	Bleeding disorders	66	How can immediate (at the bedside/in the clinic) ultrasound help with management of haemophilia?	Ultrasound can help distinguishe between bleeding and arthritis as a cause of pain in a joint. This may help optimise treatment and avoid unnecessary treatments as well as showing the patient which pains represent bleeds.	07-Jul-18		None	
22	Bleeding disorders	66	For people with haemophilia, can giving factor via a needle into a vein be avoided; is there an alternative to intravenous administration of factors?	Inravenous injection is difficult, especially in children, and time consuming. Other routes of administration would be preferable.	07-Jul-18		None	
23	Bleeding disorders	66	Are there factors other than "the number of joint bleeds" that are associated with haemophilic arthropathy (joint damage)?	The amount of joint damage varies between different patinets with haemophilia even when of the same severity. If we understood why this is we may be able to reduce the damage from bleeding.	07-Jul-18		Schafer, GS, S Valderramas, AR Gomes, MB Budib, AL Wolff, AA Ramos. Physical exercise, pain and musculoskeletal function in patients with haemophilia: a systematic review. Haemophilia 22 (2016) e119-29.	
24	Bleeding disorders	66	Can haemorrhage after delivery, and its recurrence in subsequent pregnancies, be predicted and prevented?	Bleeding after delivery can be catastrophic. We need to identify women at risk and take steps to prevent it occurring.	07-Jul-18		Postpartum haemorrhage: prevention. [Review] Chelmow D. Clinical Evidence. 2011, 2011 Apr 04. Journal Article, Review, Systematic Review]	
25	Bleeding disorders	66	What overall (total) level of coagulation activity do you need to prevent bleeding and how can this be measured?	The relationship between individual and multiple coagulation factor levels in the blood is not understood. Yet understanding this is essential for treatment.	07-Jul-18		None	