



**James Lind Alliance
Bleeding Disorders
Priority Setting Partnership**

stop the bleeding



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James
Lind
Alliance

Priority Setting Partnerships



*National Institute for
Health Research*

**James Lind Alliance
Bleeding Disorders
Priority Setting Partnership**



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Charlotte Camp, HCD Health Economics University of Chester

David Stephensen, Physiotherapist

Derek Elston, Patient representative, ITP Support Association

Jamie O'Hara, HCD Health Economics University of Chester

Kate Khair, Haemophilia Nurses Association, Great Ormond Street Hospital.

Laurence Woollard, Patient representative, Haemophilia.

Liz Carroll, Chief Executive of the Haemophilia Society

Professor Mike Laffan, Consultant Haematologist, Hammersmith Hospital London

Patrick Gallagher, Patient representative, Haemophilia.

Professor Peter Collins, Consultant Haematologist, University Hospital of South Wales

Sheela Upadhyaya, JLA Adviser

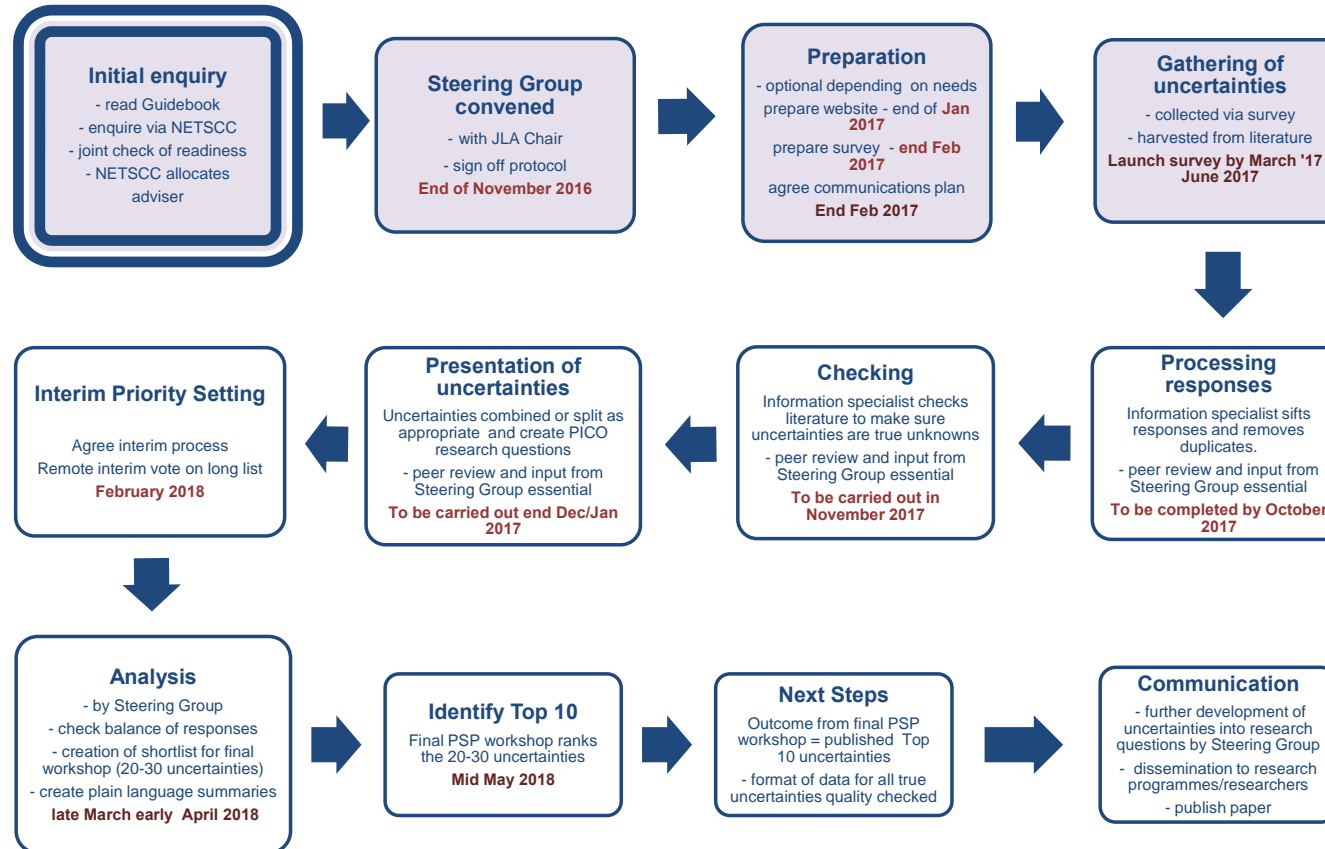
Doctor Simon Stanworth, Consultant Haematologist for NHS Blood Transfusion Service, Oxford University Hospitals

Doctor Susie Shapiro, Consultant Haematologist, Oxford University Hospitals

William McKeown, Patient representative

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Bleeding Disorder PSP Timeline





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www.stopthebleeding.org.uk



Stop The Bleeding

Identifying research priorities in the field of bleeding disorders



**Do you have a bleeding problem?
Do you have a family member who bleeds?
Do you treat people with bleeding disorders?...**
Then we need your help!

We want to find out what matters to patients, carers and clinicians in the field of bleeding disorders.

Some people experience problems with bleeding throughout their lives as the result of an inherited disorder such as haemophilia. Others may have long-term issues such as immune thrombocytopenia and some people experience problems only after childbirth or surgery.

We are interested in all these problems.

Please go to our online survey to tell us which questions you think are the most important to be answered by research.



Please help us by completing the survey at:
www.stopthebleeding.org.uk

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We want to know what it's like for you as a young person with a disorder that causes bleeding.

Can you help us to make living with a bleeding disorder better?





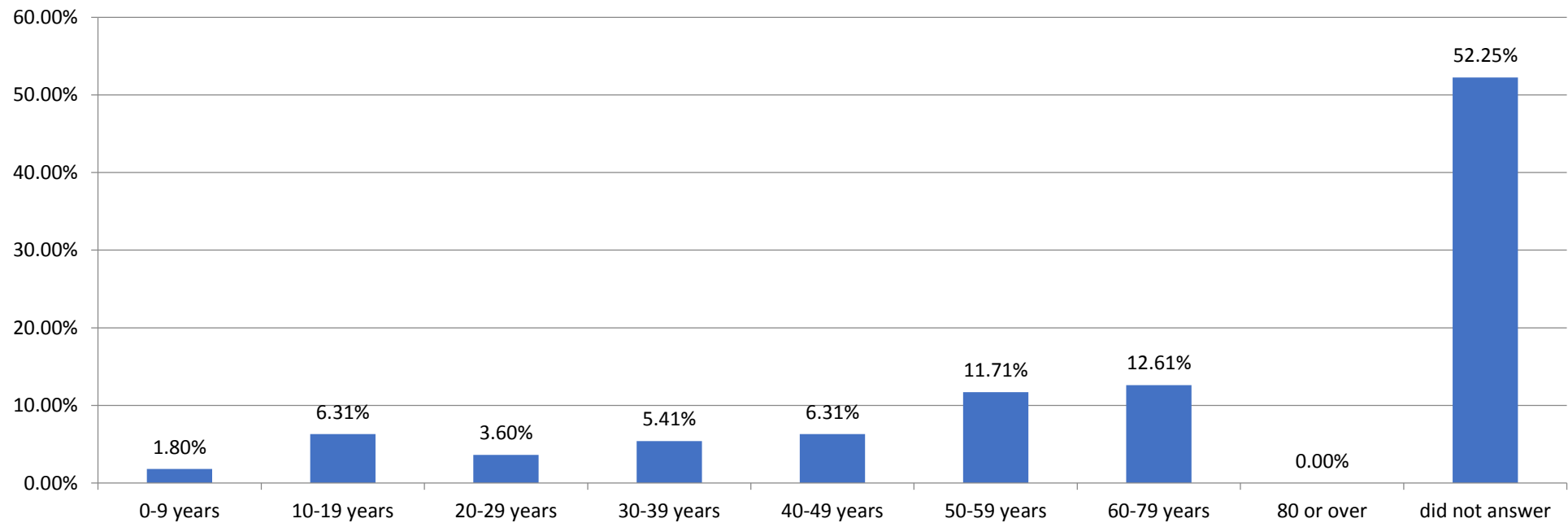
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Sorting the replies to the questionnaire



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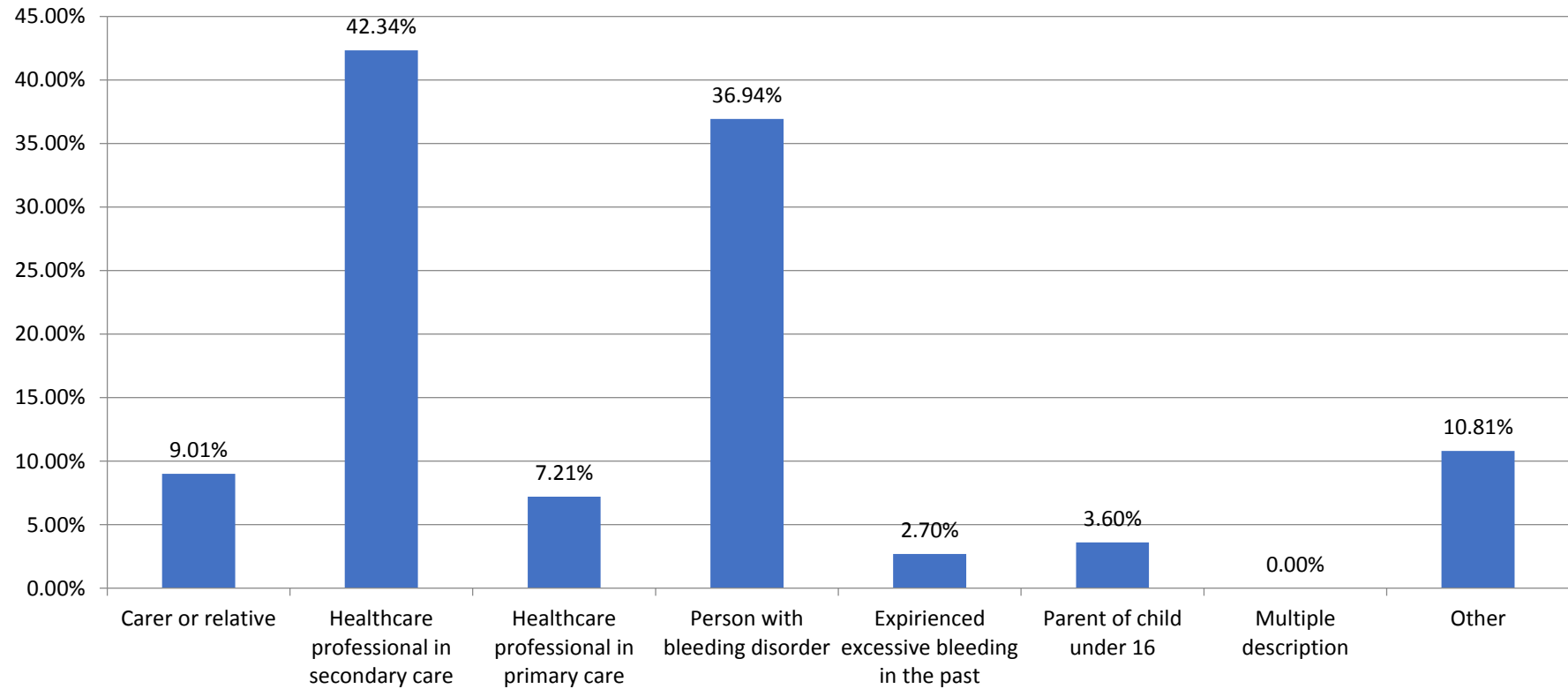
What is your (or the person with bleeding disorder) age?





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Which of these best describes you?





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Second survey of responses

Sorting down to 25



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Final workshop to determine
The top 10 questions



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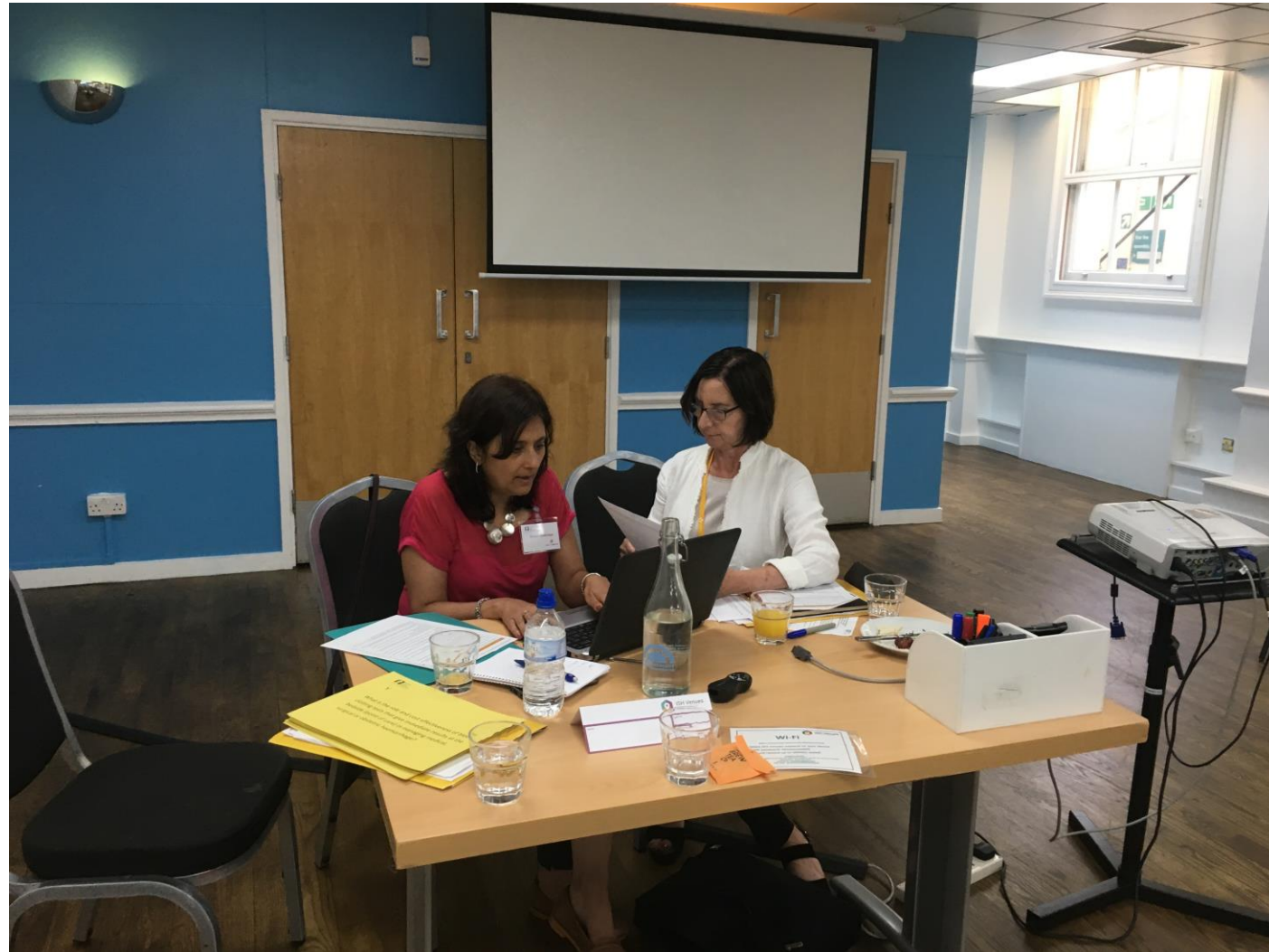


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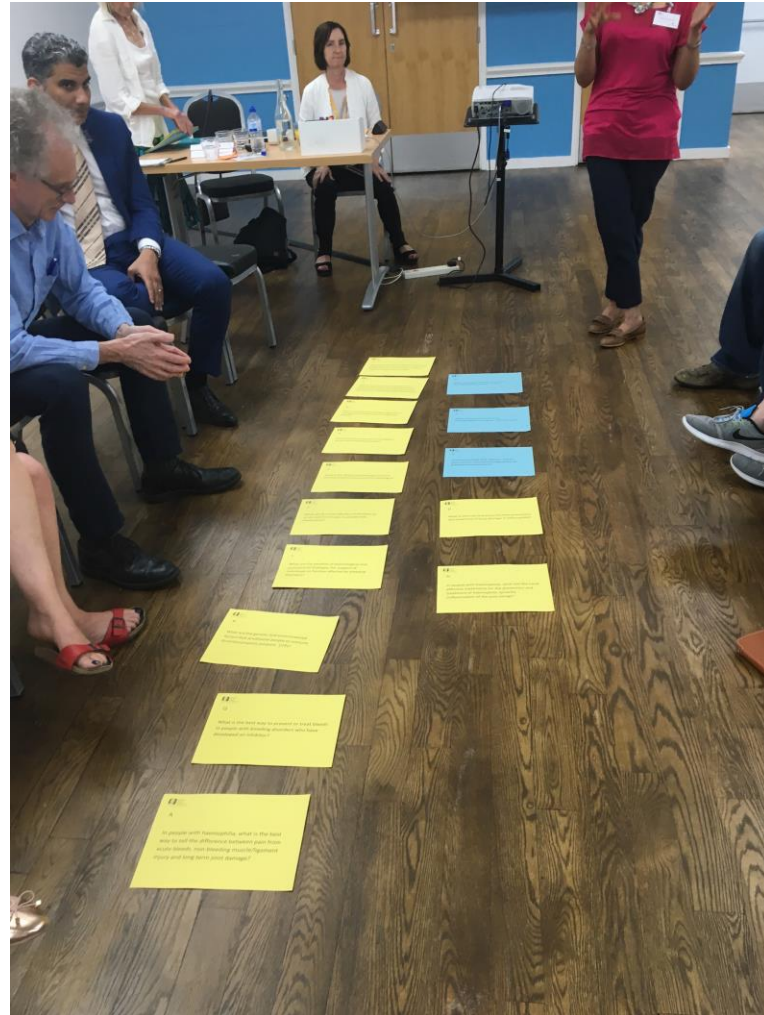


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THE FINAL QUESTIONS



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Question 1

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?



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Question 2

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?



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Question 3

What is the best haematological approach to management of severe haemorrhage after delivery?



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Question 4

How should heavy periods be managed in women with bleeding disorders?



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Question 5

What is the relationship between immune thrombocytopenic purpura (ITP) and fatigue?



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Question 6

What are the most effective treatments for acute and chronic pain in people with haemophilia?



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Question 7

What are the benefits of psychological and psychosocial strategies for support of individuals or families affected by bleeding disorders?



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Question 8

What are the genetic and environmental factors that predispose people to immune thrombocytopenic purpura (ITP)?



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Question 9

What is the best way to prevent or treat bleeds in people with bleeding disorders who have developed an inhibitor?



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Question 10

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?



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Final Report

Currently under production and will be available late November

This will be reported on in the Platelet and also on the website.



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The workshop finished early due to a very good consensus of the questions. As several had a long wait for trains we adjourned to a local London boozier to watch the match !





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The End

Thank you

