

# Treatment uncertainties in blood donation and blood transfusion: involvement of patients and donors as well as clinicians

## James Lind Alliance: Priority Setting Partnerships: Aims

- ❑ To ensure patients & caregivers are involved in identifying & prioritising research topics.
- ❑ To ensure that medical research funding prioritises issues that really matter to all stakeholder groups.
- ❑ To ensure a robust method is used to derive the 'top 10 research questions' per project.

## Project Scope

- ❑ Defined by SG;
- ❑ Blood donation & transfusion of red blood cells, platelets, plasma & their alternatives;
- ❑ Work with a range of stakeholders: Patients [P], Carers/Relatives [R], Blood Donors [D], Clinical staff [C].

## Categorising Research questions

- ❑ 817 questions were categorised & refined, using 2 taxonomies and iterative SG pair work [clinician and patient/public representative or researcher] into 54 'indicative' questions.
- ❑ Indicative questions had to be clear, understandable & addressable by research.

## Prioritization Survey

- ❑ Widely disseminated;
- ❑ 568 respondents, 58% of whom were patients, public or donors;
- ❑ 50 questions ranked individually by stakeholder group [P,D,R,C] before overall ranking [weighted by size of stakeholder group] calculated.

## The top 10 research questions

- ❑ Are listed 1 to 10 through the centre of this poster;
- ❑ Question 1 was consistently ranked first through the prioritization process;
- ❑ Questions 2,4, 5, 7 & 10 were favored by specific stakeholder groups;
- ❑ Questions 3,6,8 & 9 were ranked similarly across the stakeholder.

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1. What would encourage more people (especially black and ethnic minority groups) to donate blood?

2. How can health professionals be discouraged from using blood inappropriately?

3. How can the wastage of donor blood be minimised?

4. What is the optimal type & combination of blood products for adults with a major haemorrhage?

5. How can patients, relatives and carers be empowered to have a greater say?

6. How can patients with anaemia be managed to avoid transfusion?

7. What are the best alternatives to transfusion to reduce & prevent bleeding?

8. How can the transfusion process be safer & more timely in hospitals?

9. What medical conditions make it unsafe for a person to be a blood donor?

10. What are the most effective ways to educate the general public about blood donation?

## Establish Our Project's Steering Group [SG]

- ❑ 4 patient/public representatives;
- ❑ 6 clinical representatives;
- ❑ 3 researchers;
- ❑ JLA facilitators;
- ❑ Administrative support;
- ❑ In total, 3 face-to-face meetings, 18 teleconference calls, and umpteen emails were required to complete the project.

## Gathering Research Questions

- ❑ Via survey: widely disseminated by SG to all possible stakeholders;
- ❑ Supplemented by a search of existing literature;
- ❑ 408 responders, 63% of whom were patients, public or donors;
- ❑ Transfusion recipients [P] comprised the smallest group.

## Reviewing the existing literature

- ❑ Researchers searched 5 sources to try and find relevant evidence.
- ❑ SG used a five step, predefined process to review the evidence & decide if an indicative question had been answered.
- ❑ 50 of 54 indicative questions were deemed to have not been answered by existing research.

## Final Workshop

- ❑ February 2018, in Oxford; 25 attendees: equal mix of stakeholders;
- ❑ JLA facilitators ensured equitability;
- ❑ 2 iterative rounds of small group rankings & a whole group discussion.
- ❑ There was a dynamic interchange between C's understanding of terminology & trends and P, D & R's lived experience;
- ❑ Tension between whether to focus on topics of current and/or future needs.

## Project conclusions

- ❑ Discrepancy in question ranking per stakeholder group indicates the importance of public/patient engagement in research prioritisation.
- ❑ Steering group diversity brought welcome challenges to the project scope and process.
- ❑ More work needs to be done to define and reach all 'transfusion patients'.