Patient education and empowerment in blood transfusion - a resource for Hospital Transfusion Teams
What is patient education and empowerment?

- Patient empowerment is a term often used in chronic illness, and may be defined as an individual being an active member of his/her disease management team.

- Patient empowerment does not just encompass the ability of the patient to make decisions and be active in their care, it also encompasses their education on the topic.

(Santurri 2006)
Why involve patients?

1. The evidence.
Active patient involvement means better:
• Health outcomes
• Patient experience
• Value

See: www.investinengagement.info which is a compendium of evidence for patient engagement
2. The Darzi argument - quality as:

- Patient safety
- Clinical effectiveness
- Patient’s experience
3. Accountability
   • It’s our NHS

4. The new austerity
   • We can’t afford not to

In summary patient involvement and empowerment is about safety and quality
What should patients expect?

- To be treated in a clean environment, with a minimal risk of infection
- Medicines should be given on time and the correct doses
- Treatments should be appropriate for their condition, with procedures performed correctly and in a timely and effective way
- Care should be delivered in a co-ordinated way by competent professionals who work in an effective team. This includes communicating patients' needs effectively.

(NHS Choices)
9 big shouts - National Voices 2011

1. Integration, integration, integration
2. Right care, right place, right time
3. Information and communication that work for us, now
4. End paternalism
5. No new lotteries - tackle inequalities
6. Patients among a range of expert commissioners
7. Proper governance and transparency
8. Real involvement, with genuine influence
9. Tell us when things go wrong
Blood transfusion and patient education/empowerment

Points for consideration:
• How willing are patients to be involved?
• What can they be reasonably expected to do?
• How much might their involvement be affected/limited by illness, culture, age and familiarity with the transfusion process?

There is little research in this area.
Active patient engagement in transfusion

Although there is little research, the above may be assumed to depend on a number of factors:

• Patients must be able to participate
• Patients must have knowledge on how to be involved
• Patients have to be willing to participate (and so do medical / nursing / care staff!)
But don’t we have leaflets and posters?

- These are well intentioned BUT there is little information about:
  - whether they are read;
  - how effective they are;
  - whether there are any adverse effects of providing safety-related information.

The provision of general information is only the first step in patient engagement.
PILs

Information for patients needing irradiated blood
Patient information

Will my baby need a blood transfusion?
Patient information

Will I need a platelet transfusion?
Patient information
So if the posters and leaflets have only limited effect (and maybe the staff don’t use them), what else can we do?

- Reach patients via other routes:
  - PALs / LiNKS/ HealthWatch
  - Local initiatives in the hospital, local community, local press etc. (including awareness weeks)
  - Establishing contact with local branches of patient’s organisations, especially those condition-specific ones in which transfusion is a key element (see handout)
  - Raise staff awareness of patient involvement in transfusion
  - ‘New media’ - websites, social networking etc
  - Research ongoing to look at other methods.
References


- 9 Big Shouts from Patients and Charities (2011) www.nationalvoices.org.uk (last accessed 01.09.16)