**Enhancing patient empowerment and involvement in blood transfusion**

This document is for use by Hospital Transfusion Teams and other Healthcare Professionals who wish to drive forward greater patient involvement and empowerment in blood transfusion. It briefly examines the underlying principles involved and makes suggestions as to how these may be implemented.

An accompanying PowerPoint presentation may be used to help disseminate the key messages to a wider healthcare audience.

The main headings follow and are hyperlinked, to enable you, if required to skip directly to a section of interest. Web links are also provided for the numerous societies and organisations listed.

Note that if you find a relevant organisation not included here, please report this to NHSBT.customerservice@nhsbt.nhs.uk for inclusion in future revisions.

**Contents**

1. **What is patient empowerment?**
2. **Why involve patients?**
3. **Involving and empowering patients in transfusion**
4. **Societies / organisations with a patient involvement and empowerment stake holding in blood transfusion**
5. **Patient support societies and organisations with a potential interest in transfusion**
6. **References**

---

1. **What is patient 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).

2. **Why involve patients?**
   
   **The evidence**
   
   Active patient involvement means better:
   
   - Health outcomes
   - Patient experience
   - Value.
   
The Darzi argument
In his review of the NHS, which focused on the theme of ‘high quality care for all’, Lord Darzi identified three key elements of care underpinning a quality and cost-effective service:

- Patient safety
- Clinical effectiveness
- Patient’s experience. [Department of Health (Darzi) 2008]

Accountability
The NHS belongs to the people of the country, who pay for it through financial contributions. They have a right to hold the NHS accountable for its actions and to know exactly what treatment they are going to receive.

The new austerity
Given Lord Darzi’s argument above, allied with the current financial challenges facing the NHS, we can’t afford not to involve patients more effectively.

It is what many patients want – the organisation National Voices, which represents over 200 patient organisations and charities, indicated this in their ‘9 Big Shouts (2011)’ – their response to the government consultation on the proposed NHS reforms. Amongst these ‘Big Shouts’, there are a number which directly impact upon transfusion, including:

- **Right care, right place, right time** - patients and service users say we should be supported to:
  - Understand our conditions and medications
  - Manage our own care and treatment, and
  - Take part in deciding our care plans and our treatment options

- **Information and communication that work for us, now** - patients and service users want, as a high priority, the right types of information to support us in managing and participating in our care and treatment.

- **End paternalism** - patients, service users and carers feel the model of care we receive is very often wrong, and we are impatient for change. We support the vision of ‘putting patients first’ and ‘no decisions about me, without me’.

- **Real involvement, with genuine influence** - patients and service users, and the public, want to be involved in making services better.

- **Tell us when things go wrong** - patients and service users do not want health and social care services to hide or cover up their mistakes.

In summary – patient empowerment and involvement is about safety and quality.

*Back to home*
3. Invoking and empowering patients in transfusion

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, this may be assumed to depend on a number of factors:
- Patients must have knowledge on how to be involved
- Patients must be able to participate
- Patients have to be willing to participate (and so do medical / nursing / care staff).

Having patient representatives on the Hospital Transfusion Committee (HTC), Hospital Transfusion Team (HTT) or the Regional Transfusion Committee (RTC) is one way of starting to involve patients in the empowerment process, and those teams / committees which do not have patient representation should consider this.

Patients can often be recruited through the Patient Advice and Liaison Services (PALs) network or a hospital’s voluntary services department, or indeed via one of the patient organisations listed below.

The National Blood Transfusion Committee has patient representatives and also supports a Patient Involvement Working Group, which specifically focuses on patient empowerment and involvement in transfusion – for more details see:
http://www.transfusionguidelines.org/uk-transfusion-committees/national-blood-transfusion-committee

How do leaflets and posters help to empower and inform patients about transfusion?

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.

Provision of general information is only the first step in patient engagement.

What else can be done?

Reach patients via other routes:
- PALs / HealthWatch
- Local initiatives in the hospital, local community, and 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 through a variety of methods, such as at audit days, through awareness events and by presenting at grand rounds, clinical governance meetings etc.
- ‘New media’ – websites, social networking etc.

Research is ongoing to look at other methods.

Back to home
4. Specialist societies / organisations with a patient involvement and empowerment stake holding in blood transfusion:

**Age UK** - combined organisation from Age Concern and Help the Aged. They joined together to create a new charity dedicated to improving later life for everyone. [http://www.ageuk.org.uk/](http://www.ageuk.org.uk/)

**Anaemia Nurse Specialist Association (ANSA)** - ANSA has been established as a national and international forum for discussing, debating and advancing the provision of anaemia services. [http://www.anaemianurse.org/index.php](http://www.anaemianurse.org/index.php)

**Babble** - was created by Carers Trust as an online space where those aged under 18 who are caring for a family member or friend can chat, share their experiences and access information and advice. The site aims to bring together young carers from across the UK in an online space which is safe, fun and supportive. [https://babble.carers.org/](https://babble.carers.org/)

**British Renal Society** – the main aim of this multi-professional society is the promotion of effective patient-centred multi-professional care to improve quality of life for people with kidney failure, their families and carers. [http://www.britishrenal.org/](http://www.britishrenal.org/)

**Carers Trust** – was formed in 2012 following the merger of ‘The Princess Royal Trust for Carers’ and ‘Crossroads Care’. It is a major charity for, with and about carers. [http://www.carersuk.org/](http://www.carersuk.org/)

**Carers UK** - aims to be the voice of carers. They aim to improve carers’ lives by campaigning for change and providing information, advice and support. [http://www.carersuk.org/](http://www.carersuk.org/)

**Healthwatch** - Healthwatch England is the national consumer champion in health and care. They have significant statutory powers to ensure the voice of the consumer is strengthened and heard by those who commission, deliver and regulate health and care services. [http://www.healthwatch.co.uk](http://www.healthwatch.co.uk)

**Invest in engagement** - a comprehensive review of international evidence of what works to engage patients and the public in healthcare, aimed at helping healthcare commissioners and providers in England to deliver higher quality, more efficient care and treatment, which:

- Contributes to improved health behaviours and better health
- Empowers patients with greater knowledge
- Makes the best use of healthcare resources
- Gives patients a better experience


**Involv**e - a national advisory group, funded by the NHS National Institute for Health Research (NIHR). Its role is to support and promote active public involvement in NHS, public health and social care research. [http://www.invo.org.uk/](http://www.invo.org.uk/)

**Kidney Research UK** - is the leading UK charity dedicated to funding research aimed at finding better treatments, and ultimately a cure, for kidney disease. They operate a kidney health information service to answer the questions kidney patients inevitably have about their condition, and a range of web-based literature is available on various kidney diseases. [http://www.kidneypool.org/](http://www.kidneypool.org/)

National Voices - a coalition of 200+ national charities that believe in people shaping health and social care services. They want people to have better quality care and more choice, control and autonomy in the way they receive treatment and services, and campaign for people to have a stronger voice in the design and delivery of services. [http://www.nationalvoices.org.uk/](http://www.nationalvoices.org.uk/)

Patient – trusted medical information and support. They review health and illness related websites and link to many of these from the web directory included on this website. UK sites are the primary links in the web directory as they feel that residents in the UK prefer to obtain health information from UK sources. [http://patient.info/](http://patient.info/)

Patient Advice and Liaison Service (PALS) - offers confidential advice, support and information on health-related matters. They provide a point of contact for patients, their families and their carers. [http://www.nhs.uk/chq/Pages/1082.aspx](http://www.nhs.uk/chq/Pages/1082.aspx)

Patient Information Forum (PiF) - an independent organisation for consumer health information professionals. Their mission focuses on:

- **QUALITY** - To raise standards and highlight good practice in the production and provision of healthcare information and support
- **INTEGRATION** - They campaign for high-quality healthcare information and support to be an integral part of the patient journey
- **EXPERTISE** - They champion and enhance the expertise of people working in the field of healthcare information and support


Patient Opinion - Patients are used to plan how to develop and improve services and to give doctors, nurses and managers a feel for what patients are saying about the service they manage. [https://www.patientopinion.org.uk/](https://www.patientopinion.org.uk/)

Patient Voices - the Patient Voices programme facilitates the telling of otherwise untold stories of ordinary people, so that those who devise and implement strategy in health and social care, and the professionals and clinicians directly involved in care, may carry out their duties in a more informed and compassionate manner. [http://www.patientvoices.org.uk/](http://www.patientvoices.org.uk/)

Royal Colleges - most tend to have an enquiries/information service for patients, whilst a number have patient involvement units or forums.

The British Transplantation Society - membership is open to all professionals working in the field of transplantation. The membership is multi-disciplinary and includes clinicians from a wide range of specialties. [http://www.bts.org.uk/](http://www.bts.org.uk/)

The Patients Association - a national healthcare charity that is nearly 50 years old. Exists to help any patient in the United Kingdom. [http://www.patients-association.org.uk/](http://www.patients-association.org.uk/)

The Preoperative Association - is an organisation for health professionals working in the preoperative field. The association offers an opportunity to influence national guidance, frameworks, training, competencies and agendas. [http://www.pre-op.org/](http://www.pre-op.org/)

The Renal Association – deals with any matters concerning the welfare of patients with renal diseases and the organisation of services for their relief. [http://www.renal.org/](http://www.renal.org/)

[Back to home](#)
5. **Patient support societies and organisations with a potential interest in transfusion:**

- Anthony Nolan Trust - [https://www.anthonynolan.org/](https://www.anthonynolan.org/)
- Bloodwise - [https://bloodwise.org.uk/](https://bloodwise.org.uk/)
- Bowel Cancer UK - [https://www.bowelcanceruk.org.uk/](https://www.bowelcanceruk.org.uk/)
- British Heart Foundation - [https://www.bhf.org.uk/](https://www.bhf.org.uk/)
- British Kidney Patient Association - [http://www.britishkidney-pa.co.uk/](http://www.britishkidney-pa.co.uk/)
- Macmillan Cancer Support - [https://www.macmillan.org.uk/](https://www.macmillan.org.uk/)
- Men’s Health Forum - [https://www.menshealthforum.org.uk/](https://www.menshealthforum.org.uk/)
- Myeloma UK - [https://www.myloma.org.uk/](https://www.myloma.org.uk/)
- National Childbirth Trust - [https://www.nct.org.uk/](https://www.nct.org.uk/)
- Ovacome (Ovarian Cancer Charity) - [http://www.ovacome.org.uk/](http://www.ovacome.org.uk/)
- The Eve Appeal - [https://eveappeal.org.uk/](https://eveappeal.org.uk/)
- Women’s Health Concern - [https://www.womens-health-concern.org/](https://www.womens-health-concern.org/)

*Back to home*
6. References


National Patient Choice Survey, Wave 5 (2007) *Ipsos/MORI on behalf of the Department of Health*


9 Big Shouts from Patients and Charities (2011) [www.nationalvoices.org.uk](http://www.nationalvoices.org.uk) (last accessed 02.09.16)

*Back to home*