

**Public knowledge and perception of blood - transfusion and conservation:**

**The Exeter experience**

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## **Abstract**

### Background

Only 4% of the UK population are blood donors but 30% of the same population may receive blood during their lives. There are many myths, factual inaccuracies and fears surrounding blood. The process of blood conservation tries to keep the precious stocks of donor blood for those patients who really need it, using alternative methods wherever possible. The aim of this study was to determine what the public know, or would like to know, about UK blood, both transfusion and conservation.

### Method

People in Exeter, UK, on existing hospital/academic/clinical research databases and who had consented to research participation, were contacted. Identification details of the participants were anonymised and confidential. This study was conducted electronically via the internet. Phase I included a questionnaire, designed in Word®, converted to SurveyMonkey® software, piloted and then amended for distribution for Phase II as the main survey. Data analysis was performed quantitatively and qualitatively via Excel® for free text comments.

### Results

Phase I of the study piloted the questionnaire for accuracy and user-acceptability, which was shown to be feasible and valid.

Phase 2 of the study found 1116 replies from 4484 people, a response rate of 24%, acceptable for an electronic survey. The highest proportion was in the 65-74 years age group. A total of 186 (17%) had concerns about blood transfusion in the UK. Of the total, 780 (70%) that there was not enough blood available. Seventeen per cent (n=182) of respondents were blood donors. Nineteen percent (n=213) had received blood. Only 19 (1.5%) respondents thought that

there was high risk of infection from a blood transfusion. The majority (n=1001, 90%) considered receiving blood was beneficial. Receiving the wrong blood was perceived as low risk by over three quarters (n=849, 77%).

Only 4% (n=44) felt worried that they might be given an avoidable transfusion. The cost of blood transfusion was important for 507 (45%). Half (n=553, 52%) of all respondents indicated that they would be interested to know how blood can be conserved for those patients who really need it; interest in alternatives to transfusion, such as recycling blood at surgery, was higher at 642 (60%). Preference for the information format was towards electronic type (n=498, 55%), with paper as the second choice by 242 (27%) respondents. Over 60% of those who replied were likely (n=201) or very likely (n=409) to talk with family and friends about blood conservation. Qualitative responses (N=1586) were extensive and occasionally emotional. The highest of these were criticisms of the blood donation process, although some suggestions for improvement were offered. There were also concerns expressed for the safety and testing of UK donor blood. Other themes included financial implications for donor blood (and the NHS), and personal or family experience of transfusion. There were some misunderstandings and assumptions about UK blood but also awareness for, and the reasons why, blood conservation is necessary.

### Conclusion

This study has shown that there is a high public perception of the UK's blood supply together with awareness of its risks and benefits. Qualitative responses focussed on blood donation and safety issues, but there were also some misconceptions. There was positive interest in blood conservation, including alternatives to donor blood, and in sharing this information with others. Educational resources could be developed to help empower people for their own individual blood management, but further research with larger sample sizes is needed.

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## Chapter 1 – Introduction

“Blood: A rich liquid asset, a priceless deposit  
which can neither be spent nor accumulated”

Dr Jonathan Miller (2002) – The Nation’s Health:

Delivering healthcare in the twenty-first century

Part 4: The Amiable Juice, Radio 4.

### History of blood transfusion

The first recorded human-to-human blood transfusion in the UK was in London by a surgeon (Blundell, 1828) who successfully saved the life of a woman severely haemorrhaging after delivery of her infant by transfusing her husband’s blood directly from a vein in his arm into hers. It was fortunate that the two blood groups were similar, as it was not realised at the time that giving donor blood which was incompatible with the recipient would lead to death or at the very least severe complications such as kidney failure. It was not until over 70 years later that an Austrian scientist working in New York discovered the ABO blood group system (Landsteiner, 1900) which is still in use today to ensure that the blood is correctly grouped to be a match to the recipient.

At the beginning of World War 1 in 1914, the discoveries of both refrigeration and the use of citrate as an anticoagulant allowed donated blood to be stored safely and without clotting. This breakthrough resulted in a rudimentary service of volunteers in London offering their blood to treat those wounded in conflict. The service continued to expand during World War 2 in 1939-45, with the Army organising blood donor sessions in depots throughout the UK. The National Blood Service (NBS) emerged in 1946 and, with the commencement of the National Health Service (NHS) two years later in 1948, produced a natural

partnership between the two organisations. This partnership still exists but, due to the advances in organ transplantation, the NBS merged with UK Transplant in 2004 to become NHS Blood and Transplant (NHSBT). This is entirely appropriate as human donor blood transfusion is in reality a liquid transplant from one person to another. NHSBT is a Special Health Authority within the NHS and provides blood services and tissues in England and North Wales, and organs for the whole of the UK. Scotland, Northern Ireland and Wales (apart from North Wales) each have their own blood services organisations. These are: the Scottish National Blood Service (SNBTS), managed by NHS National Services Scotland, the Northern Ireland Blood Transfusion Service (NIBTS) managed by the Northern Ireland Blood Transfusion Special Agency and the Welsh Blood Service (WBS) which is provided and managed by Velindre NHS Trust.

#### History of blood conservation

The earliest recorded pioneer in blood conservation in the UK (and indeed the world) was also a surgeon, this time in Edinburgh, who saved his patient's life in the first ever account of recycling blood during surgery (Duncan, 1886). His patient had been run over by a train, crushing one of his legs so severely that it could not be saved. Mr Duncan amputated the injured leg, salvaged the blood within it and returned it to the patient, who survived, the first case of intraoperative cell salvage of shed blood. But it was again during an international conflict - World War 2 - that a scientist's work, on centrifuge design, for separating the albumin fraction from the plasma of donor blood (Cohn, 1941), began the development of the cell salvage machines used today. Albumin was used to treat shocked burns victims from the Pearl Harbour attacks in Hawaii; this fraction has strong osmotic properties, absorbing liquid from the surrounding tissues which prevents the blood vessels collapsing, a problem associated with shock, especially in burns patients. Cohn's centrifuge system was then adapted to separate out red blood cells from shed blood of patients undergoing surgery for reinfusion ('recycled blood') thereby minimising, or often totally eliminating, the need for donor blood. This new centrifuge model was a welcome advance in blood conservation, especially in the USA during the

1950s and 1960s when open heart surgery was being established, as the health insurance companies refused to cover the cost of the large volumes of donor blood required for these operations. Subsequent concerns in the following decades both in the USA and the UK (and also in many other countries worldwide) about hepatitis, human immunodeficiency virus (HIV) and other pathogens led to a huge growth in the use of intraoperative cell salvage (also known as autotransfusion) machines together with an increased awareness of the potential dangers of infection from donor blood. Closer to home, in the early 1990s Ridler conducted research at Royal Devon and Exeter hospital on a prototype of an automatic intraoperative cell salvage machine, the Baylor Rapid AutoTransfusion (BRAT) 1 machine for vascular surgery (Ridler *et al.*,1996). This research led to its successors, the BRAT 2 followed later by the BRAT 3, being acquired by the hospital for the cell salvage service, which still continues today in many surgical specialties including orthopaedics (including paediatric spinal surgery) and urology together with complex cancer surgical procedures involving more than one specialty. Intraoperative cell salvage, whilst an important factor is however just one of the many other methods of blood conservation as described below.

### Patient Blood Management

Blood conservation aims to keep the stocks of donor blood for those patients who really need them and for whom there is no alternative. This process should be achieved by careful and appropriate individual Patient Blood Management (PBM), which would include alternatives to transfusion such as intraoperative and also postoperative cell salvage (recycling blood shed at surgery), correcting iron deficiency anaemia, regulating blood coagulation, including even avoidance of donor blood transfusion itself in clinically stable patients. The NHS National Blood Transfusion Committee (NBTC) (2014) define PBM as “....an evidence-based, multidisciplinary approach to optimising the care of patients who might need a blood transfusion. It puts the patient at the heart of decisions made about blood transfusion to ensure that they receive the best treatment and avoidable, inappropriate use of blood and blood components” (p.2). In 2015 the NBTC worked with NHS Blood and Transplant (NHSBT) to carry out a survey of

Patient Blood Management (Sherliker *et al.*,2015), building on their previous (2013) readiness for PBM survey. The findings from the 2015 survey showed that there had been a threefold improvement for transfusion training, provision of information relating to consent for transfusion and the management of anaemia together with use of transfusion alternatives. It was acknowledged that further work was necessary, including (with reference to blood conservation) the expansion of alternatives to blood transfusion such as cell salvage and anaemia management together with a reporting system to inform clinicians about blood use and wastage. Further support for PBM, and also public/patient involvement, are provided by the NICE guideline on blood transfusion (2015). One of the key recommendations of this guideline refers to patient information, verbal and written, regarding risks, the transfusion process itself and alternatives to donor blood. It also states that “Patients have a right to be involved in the discussions and make informed decisions about their care (p.8). As Campbell (2016) emphasises in the ‘All Blood Counts’ manual “Guidelines are designed to provide good management” (pp.95-96) which should help implement PBM in every hospital.

### *Patients who refuse blood*

Jehovah’s Witnesses are perhaps the ultimate blood conservationists. Their hospital liaison teams have worked with clinicians for many years to help them to care for patients who belong to this faith and as Stevenson (2005 p.199) stated “Jehovah’s Witnesses deeply appreciate the professional skills of the clinicians we meet”. As for all patients, their choice of how they wish to be treated must be respected and their beliefs acknowledged. This choice may go against the rationale of traditional medical management and it is particularly distressing to see a patient die refusing a blood transfusion which could have saved their life. However, the advancement of alternatives to donor blood has helped to alleviate such distress. These alternatives include intraoperative cell salvage (*vide supra*), which most Jehovah’s Witnesses will accept, as they will other blood conserving measures such as optimising the patient’s haemoglobin

level before surgery, minimising blood loss during the procedure and tolerating and managing anaemia postoperatively. The modern ethos of this faith put the conscience of the individual at the heart of the decision making to make a personal and individual choice which they feel is right for them. This may mean that they will, for example accept cell salvage, but not transfusion of red cells (blood components) or they may prefer to consider, for example blood derived products such as tissue sealants. The whole range of PBM strategies must be available, flexible and negotiable. Furthermore, clinicians must be prepared for patients to change their minds and respect their most recently recorded wishes. This 'team approach' with each individual patient at its core has helped to narrow the gap between the beliefs and rights of the patients and the principles of good and safe clinical practice of blood management for all patients, not just those who refuse blood. Blood – supply and demand

Data from NHSBT indicate that only 4% of the UK population (who would be eligible to do so) donate blood, but 30% of that population may need a blood transfusion sometime in their lives. There is no published evidence to show that the public assume that blood will always be available. NHSBT relies heavily on their altruistic and non-remunerated donors to provide over two million units (each unit 'pint' is 470-475ml) of blood per year. Fifty percent of these donors are regulars, providing 75% of all donations. However 15% are 'lost' due to exclusion criteria such as illness, anaemia, lifestyle, or simply non-attendance, which means that 250,000 new donors need to be recruited every year just to break even. This is a huge challenge, especially now due to the increase in the ageing population, and a responsibility on those who use blood to do so wisely and only if absolutely necessary. Given the obvious imbalance in supply and demand, as stated above, this might not necessarily always be the case despite national blood service contingency planning.

Is UK blood safe? There have been major improvements in blood transfusion safety over the past 20 years. The UK's Department of Health Service Circulars

'Better Blood Transfusion 1, 2 and 3 (1998, 2002, 2007 respectively) have been influential in promoting, informing and guiding safe transfusion practice. For blood donation, NHSBT implements a rigorous two part screening programme: a medical checklist, blood pressure and anaemia check for donors before they are allowed to give blood together with advanced microbial testing of the blood itself. Unlike other countries such as the USA and Germany, donors in the UK are not paid for giving their blood to help others. This altruistic approach makes the chance of not disclosing any illness or lifestyle problem much less likely as there is no monetary advantage to be had. It may be argued, however, that paying donors would encourage more to come forward but with that strategy would come the possible risk of undisclosed disease which may harm not only the recipient but the donor themselves. The donor must be clinically fit to give blood; if they do not pass the initial screening then it is likely they need their own blood more than a patient does. This is particularly true of anaemia, where NHSBT has a high threshold of haemoglobin testing to compensate for the loss of approximately half a litre of blood during the donation process. Donor blood can save lives and improve health and may in fact be the only treatment possibility in, for example, haematology patients. However, the Serious Hazards of Transfusion (SHOT) organisation, set up in 1996 to collect blood transfusion incidents annually from hospitals (both clinical and laboratory sectors), show in their yearly reports that transfusion continues to carry small but significant risks. These risks, besides transfusion-transmitted infection, include allergic reactions (a.k.a. acute transfusion reactions), transfusion related circulatory overload, and administration of the incorrect blood component (i.e. receiving the wrong blood).

Year on year, SHOT continues to report that the biggest risk of blood transfusion in the UK is administration error, i.e. receiving the wrong blood. The most recent year (SHOT report, 2015) was no exception, with nine patients having received an ABO incompatible (i.e. the wrong blood group) red blood cell transfusion. Fortunately there were no deaths but one patient suffered major morbidity (no details given). Although, these risks must be put in perspective as no activity anywhere is 100% risk free. For example, NHSBT place the risk of acquiring HIV from a blood transfusion as 1 in 8 million, which is the same risk as being struck by lightning. Howell and Barbara (2016) have shown it is much

more dangerous to play football or smoke 10 cigarettes a day than to have a blood transfusion as presented in Figure 1.1.

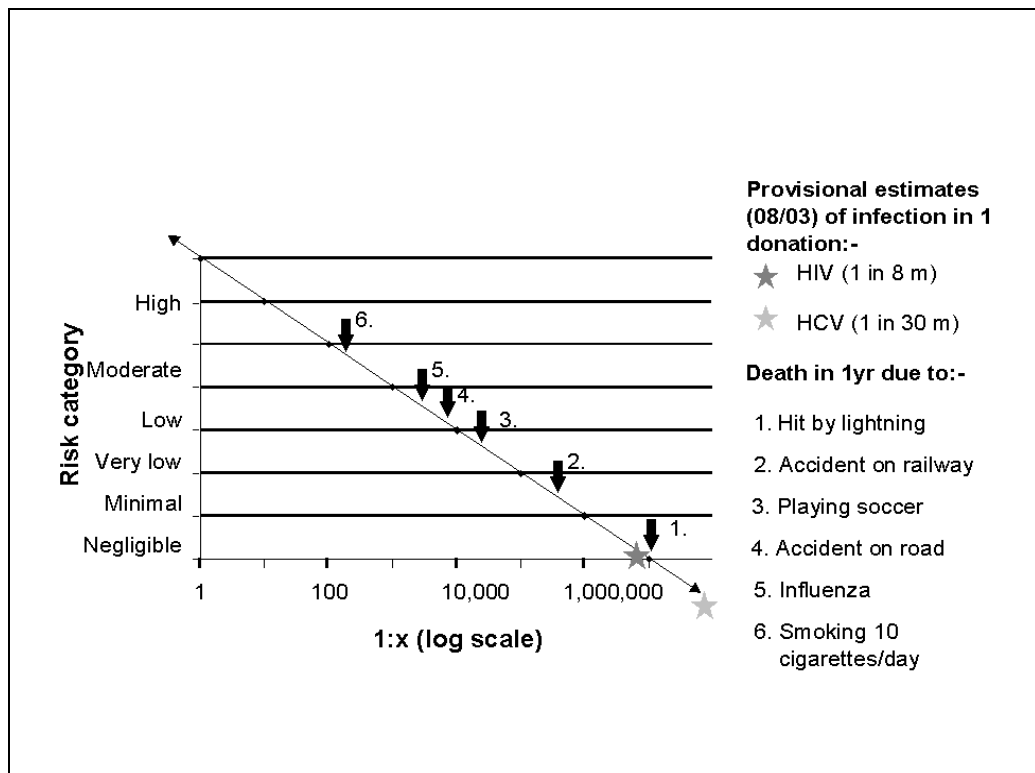


Figure 1.1: Risk from transfusion related to other risks (Adapted from Health of the Nation, Dr. K. Calman 1996 by K.Soldan and J.Barbara and reproduced by D.Howell and J.Barbara (2016) in *All Blood Counts* p.16)

There is always a risk of transfusion transmitted infection due to infective agents as yet undiscovered or, if known, a specific test is not yet available for them. There is, however, constant vigilance by transfusion microbiologists for existing and emerging microbes and how to combat them not only in the UK but worldwide. Dodd (2008) makes the point that “....new or unexpected diseases can appear in any location at any time” (p.18). More specifically, the concerns about the risk of variant Creutzfeldt-Jacob disease (vCJD) for UK blood safety was the subject of a report to Parliament (Miller and the House of Commons Science and Technology Committee, 2014). All these measures, together with the costs incurred in the journey from the donor to the recipient (staff salaries, transport, equipment, laboratory maintenance) inevitably make blood transfusion a very expensive process. For example, NHSBT state in their most



recent price portfolio (2016/17) that one single adult dose unit (250-300 mL) of red blood cells currently costs £120. The blood donor will have given one unit 'a pint' (470-475 mL) of whole blood (from which red cells and other components will have been separated) without any payment.

For all the reasons mentioned above, blood transfusion is increasingly no longer the default for patient blood management. This practice has been progressively recognised over the past twenty years or so by enlightened and pioneering professionals in hospitals and blood services around the UK involved in the search for alternatives to donor blood transfusion. In addition to blood conservation measures previously described, the quest for 'artificial blood' is ongoing. Research scientists in Edinburgh, UK, including Mittra *et al.* (2015) have been working on human stem cell development of O Rh negative blood (the 'universal donor'). In 2014, the Biotechnology and Biosciences Council (BBSRC) announced that Cooper and his team at University of Essex, UK, are developing "an artificial blood substitute which is a safe, long-lasting, virus-free alternative to current blood transfusions" (cited on webpage report). Neither product is available as yet for clinical application, but there are plans for clinical trials in humans as early as 2017.

### Patient-centred care

There has also been much progress at UK Government level for the concept of patient-centred care. In its White Paper (2010 p.1) 'No decision about me without me' there is a statement which sums up the fundamental ethos of any clinical treatment – "Patients will be in charge of making decisions about their care". The focus of all clinical care should be very much centred on the person "...with decisions made in partnership with clinicians rather than by clinicians alone" (p.14) and is recognised by the Care Quality Commission (CQC), the independent regulator of health and social care, though only applicable in England. The CQC updated the Health and Social Care Act (Regulated Activities) 2008 to produce, in 2014, Regulation 9 which states that "The intention of this regulation is to make sure that people using a service have care or treatment that is personalised specifically for them" and to "make sure that

each person receives appropriate person-centred care and treatment based on an assessment of their needs and preferences". Mockford *et.al.*, (2011) examined in their 12 year systematic review of published articles the impact of patient and public involvement (PPI) in UK NHS healthcare, particularly for individual empowerment and economic cost. This was a comprehensive review by a four person team of 28 papers resulting from a literature search of originally 6110 references. However, this thorough and organised review found minimal evidence of PPI both for its presence and cost analysis. It is, though, noteworthy that "PPI takes many forms within UK NHS healthcare" (p.30) ranging from "lay membership of NHS managerial boards...to patient involvement in condition-specific groups of individuals" (p.30).

It may, therefore, be both timely and appropriate to try to discover what the public (whether current or future patients) know, or want to know, about how our complex and tenuous blood supply is managed. Their responses will help to devise useful educational resources to inform everyone about blood conservation and guide their own decisions for their own individual blood management. This in turn may contribute to the ongoing debate on informed consent for patient blood management. Informed consent, according to NHS Choices, is explained as where "the person must be given all of the information in terms of what the treatment involves, including the benefits and risks, whether there are reasonable alternatives and what will happen if treatment does not go ahead" (cited on webpage report). It is prefaced by the statement that "For consent to be valid, it must be voluntary and informed .....". The law on informed consent has now been updated to include the Montgomery ruling, following a Supreme Court judgment (2015) in the case of *Montgomery v Lanarkshire Health Board*. This update requires that doctors have a duty to provide up-to-date information on proposed treatments must now ensure that patients are aware of any material risks and of reasonable alternatives i.e. to ensure a collaborative approach to consent by both parties. This judgment now enshrines in law principles which already exist in the General Medical Council's guidance on consent (2008). Only six per cent of the respondents in the Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO) report (2011, p.4) on Patient consent for blood transfusion were from those "with

an interest in patient safety”, i.e. patients, patient associations, hospital governors and risk managers. It is therefore hoped that, by possessing new and additional knowledge about blood transfusion and conservation, each person can form their own opinions about how they would like to give their own informed consent for their personal blood management.

Prior knowledge of how and why our precarious blood supply is managed will raise public awareness and help inform choices for this increasingly rare resource. Engaging the public in this way will enhance awareness, provide information and help them to make choices relevant to them.

#### Aim and objectives of study

Therefore, the aim of this study, which is based in the UK and specifically the population working/living/studying in the Exeter area, is to survey participants about blood transfusion and conservation. Specifically, the objectives are to find out what patients and the public in general know, or want to know, about our multifaceted blood supply in the UK and how it should be managed appropriately.

From the information obtained educational material could be produced to inform and empower decisions for their own and individual future blood management.

## Chapter 2 – Literature review

The critical literature review will examine the current evidence available to support the rationale for this study. The aim of this review will be to present published evidence relating to this topic and discuss whether it is relevant, useful and robust.

### Search criteria and resources

The literature search for this review incorporates English language published work. This approach includes searching for work relevant and leading up to, the first UK Government Health Service Circular (HSC) 'Better Blood Transfusion' (1998) allowing for five clear years for background research. This HSC was the outcome of an initiative by the UK Chief Medical Officers to improve the safe and appropriate use of blood.

The theme of the search revolves around public/patient perception of and engagement for blood conservation. Primary key words used were: blood transfusion; blood conservation; public; patient; health; behaviour change. Secondary key words were: supply; demand; safety; engagement. These key words were deemed at the time of the literature search planning (2013) to encompass the salient topics required. Patient Blood Management (PBM) had been launched in 2012 to professionals in hospitals involved in the blood transfusion pathway and had not reached the public domain at that time (Subsequently PBM has become more widespread, at least in the clinical area, with the publication of the results of the 2015 survey). The present study aimed to examine awareness of blood by the public before they became patients who might require a blood transfusion. Due to the agreed parameters of the study, this search did not specifically include descriptors as: country; culture; religion; economy; healthcare system. It also did not specifically include demographics

such as: ethnicity; gender; age. If, however, any of these were present and considered to be relevant then their significance was noted.

Both electronic and paper-based articles were sourced. The electronic resources were:

1) Zetoc (<http://www.zetoc.mimas.jisc.ac.uk>) via the British Library electronic table of contents alerting service for notification of current publications;

2) PubMed (<http://www.ncbi.nlm.nih.gov/pubmed>) which gave access to Medline, Cochrane library, biosciences journals and web-based books. Medically, the most relevant journals were Transfusion Medicine and the British Medical Journal. The University of Exeter Library website was utilised and also allowed access to non-medical sources such as psychology, social science, and life and environmental science to try to broaden the range. Other web search engines included Google Scholar and Google, which resulted in some useful websites in the public domain such as BBC Health and NHS Choices webpages.

3) The primary researcher already has access to paper-based journals, including those cited above but also professional society publications such as the Medical Defence Journal. Therefore, the use of 'grey literature' (i.e. that material not formally assessed nor peer-reviewed) was included in this review where relevant. The relevant key findings of this literature review are summarised in Table 2.2 as shown at the end of this chapter.

### Perception of blood - transfusion and conservation

Personal, but only anecdotal, experience from the primary researcher suggests that many members of the public are interested in blood management from donor to recipient and how it might affect them. Personal communication with patients and the public at large demonstrate that the UK blood supply is generally perceived as constant and safe. If there are any worries at all, these revolve around acquiring an infection from the donated blood, or even by being a blood donor.

## Patient/public-centred research

Khan *et al.* (2012) published a study (Aberdeen Royal Infirmary, UK) of perceived hazards of transfusion from both clinicians' and patients' perspective, asking whether a clinician tool could help patients' understanding. The numbers in each group were small (12 clinicians and 14 patients) but the authors acknowledged that this was a pilot study. These authors found that, for Phase I of the study, the most frequent responses to a semi-structured questionnaire from clinicians were "consequence of treatment and cure/control" (p.296), i.e. that illness could be cured or controlled by the treatment. For Phase II, where patients were asked to complete a 'Beliefs about Transfusion' Likert scale questionnaire before and after counselling from clinicians, there were statistically significant differences between the two before and after responses. After counselling, patients were more likely to (strongly) disagree that doctors over-relied on transfusion ( $P=0.034$ ) and also were more likely to (strongly) agree that it could result in new health problems ( $P=0.041$ ). The authors concluded that the use of a checklist can be linked to clinicians' counselling behaviour and could form the basis for a randomised controlled trial. An interesting facet of Khan's study was that mixed quantitative and qualitative methodology was used to enhance the data collected from varying perspectives. Given the small cohort numbers, this was a sensible approach in order to endeavour to maximise the information available. Participation in this study by the patients and clinicians took place opportunistically in the clinical arena (surgical pre-assessment clinic). For many patients this would have been stressful - an unfamiliar environment, coupled with their anxieties about their future diagnosis and treatment. These factors would have influenced their responses as 'patients' rather than in a more familiar environment (such as their home) as 'public'. In addition, the reliance on clinicians to respond to the all sections of the questionnaires during a busy clinic may not have been optimal; for example in Phase 1 of the study "three clinicians did not discuss a patient's right to accept or refuse blood" (p.296). Any process which helps patients' understanding of the transfusion process by pre-emptive counselling is to be

encouraged, but perhaps conducting this form of research away from the clinical arena and with higher numbers of participants might yield more comprehensive results. Kahn cites Leventhal's Common Sense (Self-Regulation) Model (CS-SRM), as shown in Figure 2.1:

## THE COMMON SENSE MODEL

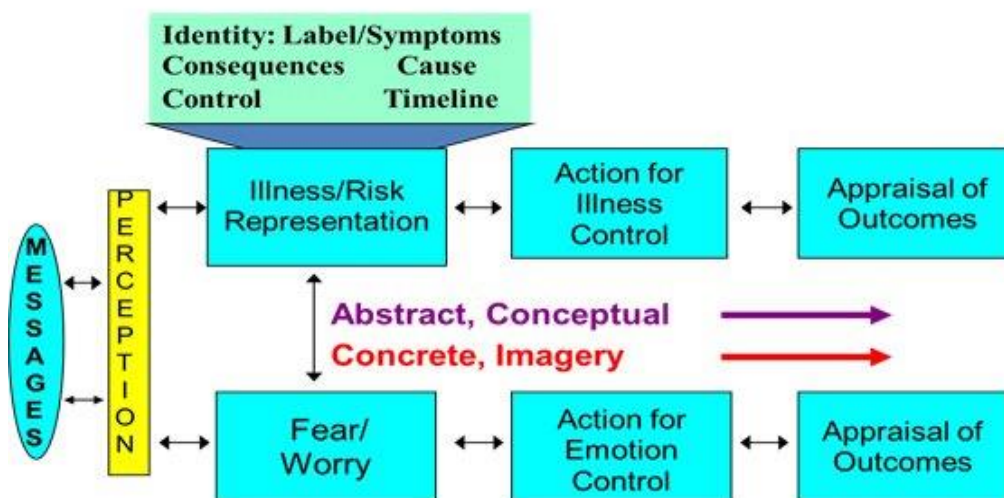


Figure 2.1: Leventhal's Common Sense Model (Reproduced with kind permission of Professor LD Cameron – figure not copyrighted).

This model is the outcome of research by Leventhal into beliefs patients have about health threats and provides a complex psychological/social discourse on how people try to keep well and avoid, or at least control, illness. The authors explain and discuss the strategies humans use to evaluate risk, problem-solve and assimilate into their daily life. These strategies are known as heuristics, i.e. how people decide, on the basis of their own experiences together with the information available, a method of solving a problem as their own individual action plan. People thus act as 'common-sense scientists' to work out the best course for them, which could of course be modified given changing situations. Examples were given for medical situations such as high blood pressure or

cancer, so-called 'illness indicators', but could equally apply to blood conservation and management.

Davis *et al.* (2011) highlighted the role of patient involvement as an important intervention to improve safe care in reducing transfusion-related errors. In their review the authors suggest that, in addition to training and supporting clinical staff, the involvement of patients themselves in the transfusion pathway (as for other clinical care) may be a crucial factor. For their review the authors performed a world-wide systematic search of the medical literature published over the past 20 years (1991-2011). This was an appropriate timeline, given the advances in transfusion management and indeed patient care in general, during this timeframe. It was also important to consider the global perspective. UK blood transfusion, by virtue of its unpaid, well screened and altruistic donors together with advanced blood science procedures, is recognised as one of the safest in the world. The authors found 2018 articles of which 15 were considered relevant to their inclusion criteria, i.e. "...data relating to patients' attitudes and/or experiences of allogeneic blood transfusions and/or attitudes toward participating in transfusion-related behaviors" (p.13). The resulting information showed that, as well as patients, members of the public are the studied groups in papers from France, USA and Sweden with a single paper by Farrell *et al.* (2001) from the UK examining the public perception of risk of HIV infection associated with blood donation in 254 young undergraduate students. Farrell's paper discusses the theory and practice of "message framing, a means of presenting information, on confidence in blood transfusion safety" (p.1335). It highlighted the concerns of how best to do this in a positive way to enable "populations and patients to make informed judgements" (p.1335). Although there seemed to be no direct reference in Farrell's paper to blood conservation *per se*, one of the co-authors was Dr V James, a leading blood conservationist. This was a significant background paper for this literature review, which described how information can be presented and how individuals assimilate and make decisions accordingly.

Both Farrell's and Davis's papers from internationally recognised and respected authors reinforce the aim to carry out this study to research public opinion on



blood – transfusion and conservation – in the UK, as the ‘Exeter Experience’. It is not known whether the public are aware of any measures currently available for blood conservation. As mentioned in the Introduction, there is no published evidence to show that they perceive that blood will always be available. Figure 2.2 demonstrates the decreasing trend of donor numbers:

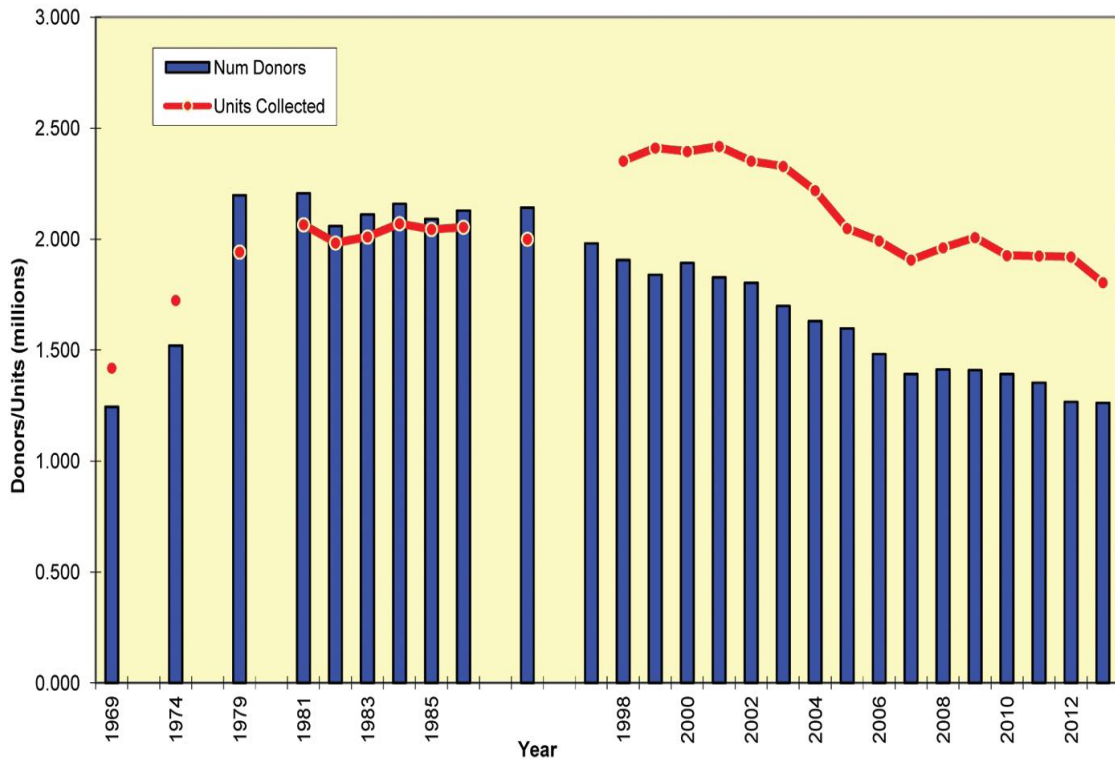


Figure 2.2: UK Blood donor numbers 1999-2013 (Acknowledgement to Crispin Wikenden, Head of Donor Insight, NHSBT).

Despite its best efforts, NHSBT has stated that the number of blood donors has fallen by 40% in the last ten years (especially in the 40 years and under age groups) and that at least 240,000 new donors are needed each year just to keep stocks at a safe level.

Furthermore, the changes in demographics are determining that the percentage of older age groups in the UK population are living longer and this is forecast to increase (see Figure 2.3). Our progressively older population will inevitably become less able to give blood due to increased age and morbidity. Therefore our current level of donor blood will not be sustainable in the long term. Currie et.al., (2004) examined blood use in a single UK Hospital in 1999 and then, together with the then current blood donor information, and predicted demographic changes, projected the potential demand for blood for the ensuing 25 years. The authors forecast that within 20 years (of their study) “demand for blood is expected to increase by 20% relative to the supply” (p.19). These observations, by its very nature, can only provide an estimate of the expected UK blood supply.

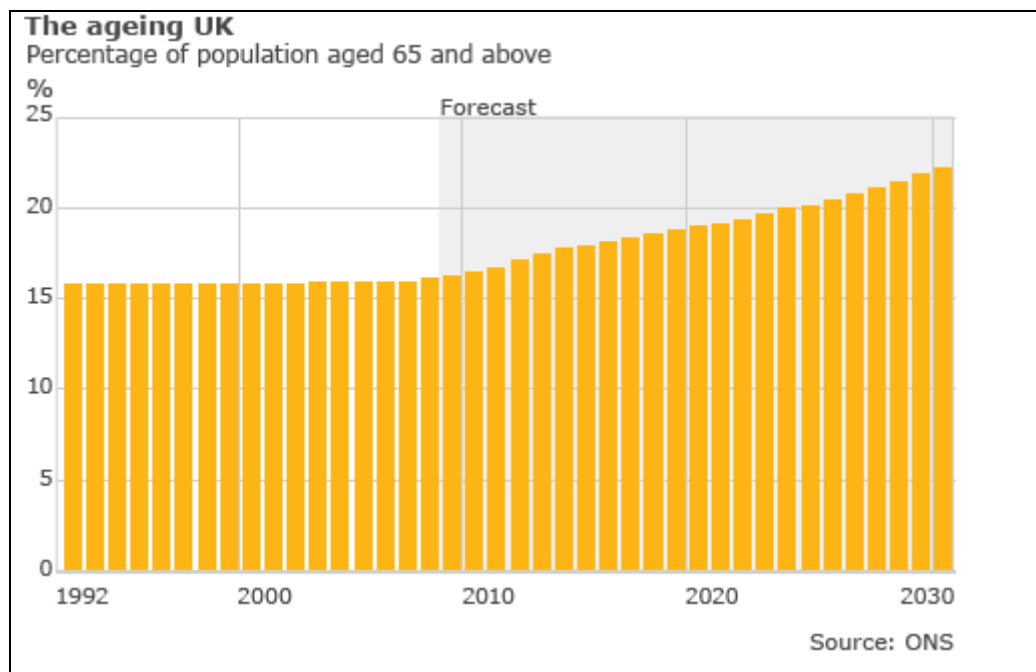


Figure 2.3: Percentage of the UK population age 65 and above, past, current and projected (Office of National Statistics, 2010, published 2011).

A recent paper from Tinegate *et al.* (2015) stated that the highest proportion of patients receiving donated red blood cells are in fact in the older age groups (Figure 2.4).

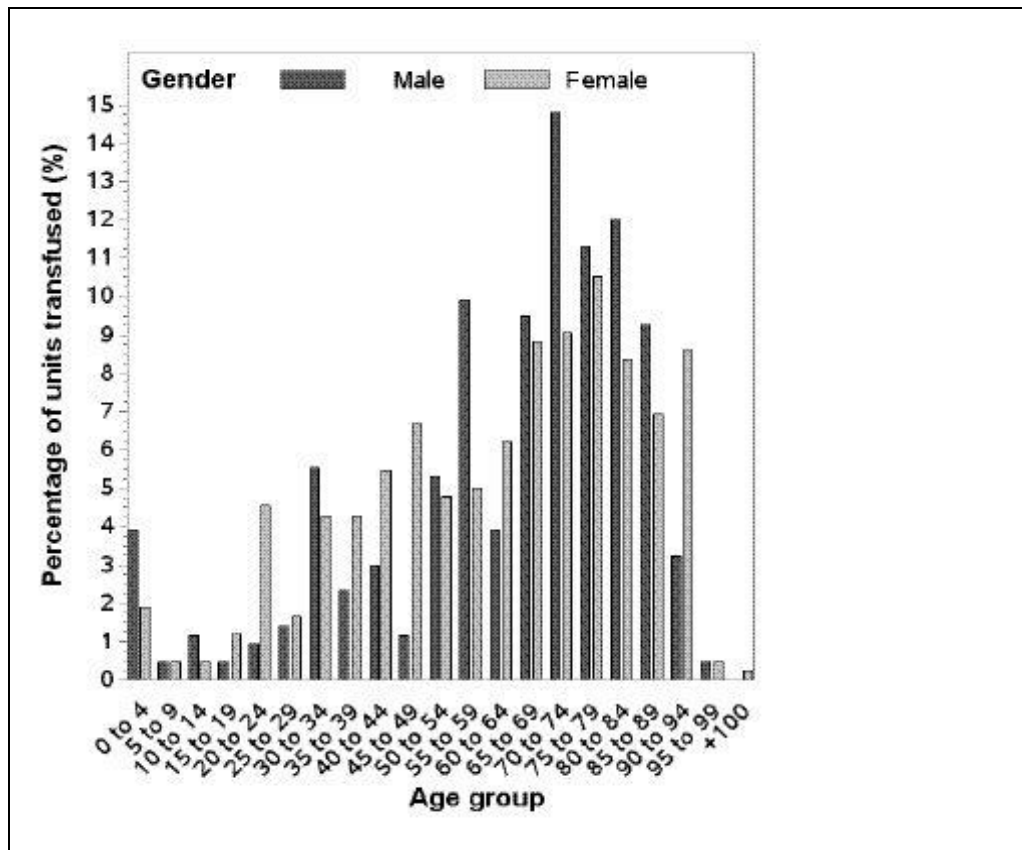


Figure 2.4: Percentage of red cell units transfused for age of patients National Survey Red Cell Use – NHS Blood and Transplant (With permission from Wiley/American Association of Blood Banks, AABB; Acknowledgement to Katy Hurrell, Patient Blood Management Practitioner, South West Region, NHS Blood and Transplant).

Blood donors are usually excluded from donation after they reach 65-70 years. If they are over 70 they may be able to continue donating if they have done so in the previous two years and are in good health. This is because the medical risks of actually bleeding out a unit of blood (470-475 mL, ‘a pint’) increase with age. There are two main risks – firstly, increased cardiovascular problems due to the rapid removal of the unit of blood and secondly increased prevalence of side effects from conditions such as diabetes and cancer in this older age group. The safety of the donor, as well as the recipient, is paramount.

However, there is a stalwart group of regular, healthy older (70+) donors who currently make up 2% of the total donor numbers (1,216,162 in 2014), as shown in Table 2.1:

Table 2.1: Age of Donors 70+ - (2014)

Donor Age	Number
70	7443
71	5550
72	4197
73	2784
74	2161
75	1913
76	1430
77	<u>517</u>
Total (70+)	<u>25995</u>

(Figures provided with permission from Mr Crispin Wickenden, Head of Donor Insight, NHSBT).

Careful blood management together with consideration of alternatives to blood transfusion (or even no transfusion at all) have both helped to balance the supply and demand. These practices, however, vary across the UK and indeed worldwide, with some hospitals/individual clinicians more enthusiastic than others.

What has recently changed in the UK, however, for any clinical treatment, is the concept of Patient Centred Care i.e. putting the patient at the centre of the decision to treat, or in some cases not to treat. The Government White Paper (2010) from NHS England offered the concept of a patient-centred approach, 'No decision about me without me'. This approach depends on clear, understandable information being supplied to the patient by those responsible

for their clinical care, in order to involve that patient in the decision making. This approach could (and should) also include blood conservation and management as appropriate for individual patient care.

One possible way of raising awareness of the importance of blood conservation and individual targeted blood management is to consider the behaviour change pathway guidance as published by The National Institute for Health and Clinical Excellence (NICE) (2007). This guidance, whilst targeting well known documented problems such as nutrition, obesity, exercise and other health issues, does provide succinct and sensible generic information which could be adapted for patient blood management. Similarly, at an international level, the World Health Organisation (WHO) further expands on this theme in their report 'Behavioural Change Strategies in Health: the role of Health Systems' (2008). Whilst recognising that "increased awareness and education are important but seldom sufficient" (p.1) the report states that there needs to be "a combination of policy instruments, e.g. legislation, regulation ..." (p.8). It cites good examples such as tobacco control and makes the point that "change is a process, not an event" (p.18). It is also a reminder that this is not just a UK problem, but a global one. Legislation may have a part to play should there be a severe shortage of available blood. In the UK a national contingency plan is already in place (Department of Health, 2009) and each hospital should have its own version, adapted for local conditions. If however the situation deteriorated, there may well need to be more powerful legislation to ensure fair distribution of blood to those patients who absolutely need it and for whom there is no alternative.

Ngo *et al.* (2013) conducted a qualitative systematic review investigating the role in attitude towards blood transfusion. Though based in the USA, the studies they found for their literature review were those from outside that country, mainly in the UK and Canada. This would immediately raise issues of not only cultural differences, but also how different health care systems with their own costing structures and quality of care would affect the perceptions and attitudes to blood transfusion, not only to the authors' nation state, but also to other countries beyond the USA. The study by Ngo and colleagues examined, for

transfusion, the theory behind risk perception and how this perception differs between public and the professionals (physicians/scientists). Amongst their conclusions the authors state that “recent studies on risk perception are unavailable” (p.127), and also that “the general population appears to be largely unaware of the non-infectious risks of transfusion...” (p.127), which would suggest that a need for further research into this topic. Their paper did, however, discuss autologous transfusion – generally understood to mean the patient’s own blood, but in this context was simply pre-donated blood, i.e. preoperative autologous donation (PAD), practised in the USA and other parts of the world but which is not recommended practice in the UK. They also raised the possibility of blood substitutes, which, whilst an attractive option, is still a long way from reality until these alternatives to transfusion have a proven safety record.

Everyone who has access to the internet can discover a plethora of information (some unverified) via the Worldwide Web, and also via other media such as newspapers and television. A current, or indeed a future, patient may well supplement the information supplied by their clinician to research on their condition. If there were to be a shortage of donated blood (such as recent flooding, or epidemics such as influenza) would any member of the general public be aware of the crisis and what measures could be put in place to address this? If they can be informed ahead they are better prepared to make choices. The importance of risk management and communication cannot be over-emphasised. As Ngo’s paper states “the media is an especially powerful source” (p.127).

A reminder of doctors’ professional obligations to impart clear information appears in a featured article in a recent Medical Defence Union (MDU) journal (Nandasoma, 2013). The author, an MDU Advisor, quotes from the General Medical Council (GMC) Good Medical Practice document 2013 that “the GMC expects you to “give patients the information they want or need to know in a way they can understand” (paragraph 32).

More recently an editorial in the British Medical Journal (Fahey and NicLiam, 2014) reviewed the evidence for patient centred care and introduced 'National Voices'. This organisation is a health and charity coalition for 'People shaping health and social care' by using the experience and expertise of stakeholders – such as patients, service-users, engaged citizens and the voluntary sector. The aim is to support person (not patient) centred care as shared decision-making. It hopes to achieve this by improving information and understanding even if a person is not currently receiving treatment. This organisation has carried out a systematic review of 800 papers to provide simple guide booklets on many topics of patient care for download by anyone seeking advice. Its missive is that “We want health and care systems which are person centred. This means that care is coordinated, people are in control of decisions about their health and care and everyone has fair access to care and support” (National Voices). This approach seems sensible, but at this time has no reference to blood transfusion so there may be opportunity to address this omission in the future.

The only survey in the UK to specifically target the public about blood transfusion (though not conservation) has been conducted annually since 2010 by the NHSBT. This organisation has commissioned stakeholder perception research as part of their internal audit programme in order to review the effectiveness of NHSBT communications and engagement with a range of stakeholders. The most recent report (2015/16) of this research involved 43 stakeholders, and was carried out exclusively as telephone interviews by Pricewaterhouse Coopers (PwC) one of the largest professional services organisation in the world and also one of the 'Big Four' global auditors. These stakeholders are not, however, individual members of the public. Instead they are organisations “who have regular contact with NHSBT or a close interest in blood, organ or stem cell donation” (p.7) and comprises three main groups: charities (e.g. the Sickle Cell Society), professional regulatory bodies (e.g. Public Health England) and UK Government departments (e.g. the Department of Health). The main focus of this research was, as for previous years, to invite these representative bodies to assess the performance of NHSBT in a) encouraging blood (and organ) donation and b) ensuring a safe and sufficient supply of blood (and organs). In addition, new for this current report,

stakeholders were invited to evaluate how responsive the NHSBT was to their feedback. The main findings of this research were that 97% of the stakeholders understood very well or quite well what NHSBT does and 98% were very or fairly satisfied with NHSBT's overall performance as it relates to their own work. These results, although acquired from public and patient representative bodies, do not appear to be reflective of individuals, but rather of organisations (albeit with a vested interest) giving a corporate response. Eleven years earlier, an editorial in the British Medical Journal (McClelland and Contreras, 2005) about appropriateness and safety of blood transfusion stated that there have been concerns that NHSBT has been concentrating too much on blood safety, and spending too much on reducing risks from infection, when the focus should be more on using blood effectively.

To date there has been no published individual patient empowerment research relating to blood transfusion and conservation, but a paper by Anderson and Funnell (2010) examining this method for diabetes care might well translate into other specialties, such as patient blood management. This paper offers a considered, cautious but practical approach to aid patients and their health care professionals (HCPs) to institute patient empowerment, which therefore suggests a 'team approach', including the patient's role in decisions about their care. The authors state what should be obvious, but which may be overlooked, that both HCPs and patients "live and work in the real world" (p.279). Therefore, this is not an abstract approach but one based on what is happening in the clinical situation.

Specifically related to blood transfusion and conservation, the aspiration for patient involvement in decision making for their own care had also previously been expressed in a 'Blood and Transplant Matters' article Thompson and Gerrard (2012). The authors point out that (at the time of writing) "Although there is little research, active patient engagement will depend on a number of factors; patients must have knowledge on how to be involved and they must be willing and able to participate..." (p.16). This short but very pertinent article succinctly summarises how knowledge and empowerment could have a real impact for personal blood management. It was the first of two publications which



have been the most influential for this literature review, endorsing the need for further research into this area. The second and longer publication, 11 years earlier was a report (2001) of the proceedings of a National Blood Service (NBS) 'Transfusion 2020' held at the Royal College of Physicians, London on 18th October 2000. This was part of the Millennium Festival of Medicine coordinated by the British Medical Association and supported by the British Medical Journal. The NBS contribution to this Festival was an open meeting that explored the influence of the media and cultural influences on public perception of the risk of blood transfusion and what blood transfusion might be like in the year 2020. This prescient seminar was a series of presentations, not just by transfusion specialists but also including experts in the wider world of medical journalism, communication and psychology and culminated in an expert panel discussion with the audience. What is interesting and relevant to this literature review is not only that the story of blood through the ages described 'Medicine, money and myth: an epic history of blood', but also that there were further presentations on the risk for blood (pp.124-129), 'The risk debate in blood transfusion: how perceptions, beliefs and behaviours can be shaped by an efficient communication' and (pp.129-135) 'Perceptions of risk of blood transfusion: knowledge, group membership and perceived control'. This seminar also raised the issue of scarcity and cost: "Blood is one of the world's most vital substances...it is also fragile and expensive..." (p.119), "Oil is far cheaper than blood, although used in greater quantities" (p.119) which, even given the fluctuations in prices and currency exchange, still applies to both commodities today. The potential and important problem of not enough blood was also raised "As people in developed nations come to appreciate the high safety levels of their blood products (sic) they may alter their perceptions about what constitutes a public health threat and become more concerned about shortages" (p.121). This presenter further stated that "Donor rates are low, and so much blood has been disqualified through screening and testing, that the public will eventually see supply as a safety issue" (p.121). He also (perhaps now prophetically) raised the most important point that "Some difficult debates lie ahead and policymakers try to balance their priorities between safety and supply – a debate that would have been unthinkable a few years ago" (p.121). Whilst there has been some progress for blood transfusion and conservation, it

would be interesting if another seminar were arranged in four years' time from now (2016) in 2020 to review how much has been achieved in these arenas.

### Methodological techniques to engage public/patient involvement

There are many and varied approaches to research methodology depending on the topic to be studied and the individuals involved. These approaches include questionnaires, surveys, audits, interviews and forum discussion which will all be discussed below. As Bell stated in 'Doing your Research Project', "each approach has its strengths and weaknesses, and each is particularly suitable for a particular context" (p.6).

### Questionnaires

According to Oppenheim (2005) in the textbook 'Questionnaire Design, Interviewing and Attitude Measurement', a questionnaire should be thought of "as an important instrument for research, a tool for data collection" (p.100). The format, or specification, of this questionnaire should be borne out of the research question(s) being asked and constructed around it. There are many different forms a questionnaire can take, depending on whether it is to be a brief factual enquiry about a topic or a more in depth perhaps multifaceted analytical survey examining attitudes on a particular issue, as for this research. How best to engage a particular public group requires much thought and planning – in particular how to make the questionnaire sufficiently attractive so that each individual who receives it will be motivated to respond. The questionnaire must therefore be as succinct as possible. It should start with a brief introduction as to why the survey is necessary, including reassurance (where relevant) regarding anonymity and confidentiality and then a guiding statement over how long the questionnaire is expected to take to complete; followed by the questions themselves. These questions may be a simple list of closed questions requiring just a Yes/No or 'tick the box' answer, but if there any potentially sensitive questions (such as age or gender) it may be diplomatic to add a 'prefer not to say' which it is hoped would impart awareness of any personal

situations or beliefs from the respondents' point of view. An extension to this simple list type of questioning would be to build in, for example, a Likert scale where the respondents grade their answer from 0-10 or poor to good. This technique would also work for age groups – under 17, 18-25 and so on. These types of questioning provide straightforward results for quantitative analysis and may be tempting as the only and easiest option. If, however, more in depth answers are required, and individual opinions are sought (as in blood: transfusion and conservation) to find out what people really think about a particular topic, then the introduction of free text comment boxes may help. The advantage of these is that the respondents, if they wish to take the extra time and effort, are then able to give their opinions freely outside constraints of the fixed questions. This may lead to unanticipated and often useful information, but has the disadvantage of producing a collection of unhelpful, over emotive and possibly vitriolic comments. These types of comments, while perhaps upsetting, may have two useful aspects –it may be therapeutic for the respondent 'to get this off my chest' and may also provoke debate within their social circle and, in the case of blood transfusion and conservation, potentially stimulate positive action for the greater good. The researcher thus has to consider the advantage versus the disadvantage of providing free text boxes, and be aware of the risk as well as the benefit. It is also wise to limit the number of boxes offered, to control the volume of responses for subsequent qualitative analysis which by its very nature will be more complex and time-consuming as this volume increases.

It is important always to remember that without the help of the target audience there would be no results, so it is in the researcher's interest to make their questionnaire as easy as possible to complete. Adding a 'Thank you for completing this questionnaire' is a considerate and courteous action, expressing gratitude to the respondents for taking part.

It is advisable and sensible to perform a pilot study (Phase I), i.e. testing the questionnaire to check for accuracy, omissions, ease of use, average time taken to complete and any contentious issues. Oppenheim (2005) devotes a whole chapter on the reasons why piloting is such an essential and an important step in the research process (pp.47-64), stating that "Questionnaires have to be

composed and tried out, improved and then tried out again...until we are certain they can do the job for which they are needed” (p.47). Only when all these parameters have been addressed and appropriately resolved can the main and final (Phase II) questionnaire be disseminated to the selected target groups as a survey, as outlined in the next section below.

### Surveys

The Phase II questionnaire can be circulated for the survey in various ways. Before the arrival of the internet this may have taken the form of a printed document, distributed face to face by the researcher for later completion, left at a communal collection point, posted by hand through letter boxes or mailed out accompanied by a stamped addressed return envelope (SAE). Any and all of these approaches had the advantage that the recipient had the time to consider their responses, although it may be argued that the immediate ‘gut reaction’ is more accurate to avoid ‘second thoughts’ and possible influence from other people. However there are disadvantages in that, whatever the approach used, the respondent would need to make an effort to complete the questionnaire by finding a pen, completing the questionnaire by hand and then arranging for its return, which in the case of the SAE would mean a trip to the post box or post office. In addition, the researcher would need to retrieve the completed questionnaires, collate them and enter the data either on paper or on to a computer. A cost would be likely to be incurred for printing and this cost would rise steeply if postage was involved. This is not to say that the paper approach, whilst labour intensive for both parties, is not workable and some researchers may well prefer to use this method in particular circumstances.

The arrival of the internet in the 1990s has changed the way the public can provide their responses to surveys without recourse to any of the methods outlined above. Ofcom, the Independent regulator and competition authority for the UK communications industries estimated in 2015 that 80% of adults now have access to the internet. Although individuals using their online electronic devices to access web-based surveys still have the opportunity to take time to think about their answers if they wish to do so, the dispatching of these online

responses is immediate, thus eliminating additional time, effort and cost as described above. However, this type of web-based data capture relies on the target audience having access to, and literacy skills for, computers, as well as efficient broadband connectivity.

It cannot be assumed that all respondents are computer literate. One paper from Pouchieu *et al.* (2015) examined computer and internet skills (together with socio-economic status) of participants (n=43, 028) in the NutriNet-Santé web-based study, set up in France in 2009 to investigate the relationships between nutrition and health in the general population. One of the key findings of their study relevant to computer skills was that 24% (n=10,235) of the participants declared themselves novice or inexperienced in computer use. By its very nature, this observation is subjective on the part of the participants, but should be taken in account when designing an on-line survey questionnaire for research. Therefore there appears to be advantages, at least for the respondents, although Baruch and Holtom (2008) found that the mean response rate for web-based surveys was 38.9% (range 69.5% to 10.6%) compared with 44.4% (range 94-19.7%) via paper mail. There is evidence that responses to online surveys are more honest because there is no obligation on the part of the respondent to provide the answers they feel the interviewer would like to hear as opposed to what they really think (Rogers and Recharme, 2009). Unfortunately this may occasionally backfire as the 'power of the keyboard' can unleash the often true, emotional and inaccurate responses if both the interviewer and interviewee are unseen and perhaps anonymised as well.

There is also the possibility that web-based surveys may in fact be unrepresentative of the general population, especially of people who do not have access to the internet, and thus be subject to unreliable data. No evidence relevant to this method of research for blood transfusion and conservation from the recent decade (2006-2016) has been found, but Best *et al.* (2001) carried out a social science based survey simultaneously by internet and by telephone. Their research examined two assumptions on internet surveys - one that "the decision-making processes of Internet users are no

different from those in the population at large” (p.132) and also that “...representative samples of Internet users can be drawn” (p.132). At first sight the methodology appeared complex, examining the perceptions of the USA public on a multiple range of topics including whether they approved of the current President, political voting intentions, the country’s involvement in Kosovo, abortion and church attendance. Having this wide range of variables provided the means to test the afore-mentioned assumptions and the authors did demonstrate that, on their perceptions of social issues, internet users compare well with telephone participants. This would suggest that the findings might support a singular internet approach to survey public perception asking a wide variety of questions related to a particular topic, such as blood transfusion and conservation.

A year previously, and again from the USA, Couper (2000) had reviewed web surveys, examining their role in public opinion research. Although this paper is aimed at marketing, it does provide an insight into the pitfalls of web-based surveys. It highlights potential technical issues - not only electronic (slow internet speeds, personal computer crashes) but also the varying skills of the people using them. It also reminds those disseminating these types of surveys of the importance of guaranteeing confidentiality, although from a marketing point of view this does mean that there can be no personalised approach to individuals which encourage an increased response count. Both these points, technical and confidential, may still be applicable to web-based studies examining public attitudes today. In addition, Couper discusses web-based volunteer (i.e. ‘self-selected’) panels stating that (at the time of writing) that this type of survey “appears to be the fastest-growing segment of the Web survey industry” (p.482). Participants of such panels choose to take part in research, which in itself brings advantage but also disadvantage; advantage by interested, proactive and available panellists, but disadvantage in that by the very nature of the research area (such as health) the samples may not be representative of the population as a whole. Returning to the encouragement of a potentially increased response count, it might be tempting to offer incentives such as vouchers, gifts, entry into a prize draw or even cash. No robust evidence for this practice could be found for health-related surveys, although Cobanoglu and

Cobanoglu (2003) studied what effect incentives might have for response rates in market research. Their control group (i.e. without incentives) produced a response rate of 23.9%, compared with other groups offered incentives as either a small gift (31.4%), entry into a prize draw (20.5%) or a combination of the two (41.7%). A significant difference between the response rates for all methods was found ( $p=0.001$ ), with the highest response rate being the combined incentives. The authors warn that "...the researcher needs to be careful in areas where ethical decisions need to be made" (p.486), added to which might reasonably be the ethical belief of the researcher, particularly in health related issues. Even leaving aside those two important caveats, there would remain the cost and logistical implications of offering incentives in the first place.

The survey for this research into public perception of blood relies, like blood donation itself, on voluntary, altruistic and often busy people who are willing to take time to provide information which may hopefully improve patient care in the future. It is therefore obligatory to offer a survey method which primarily is the most convenient and user-friendly for them but which also facilitates data collection and analysis by the researcher. Couper (2000) neatly summarises these obligations as follows:

"In order to minimize respondent error, the survey instrument must be easy to understand and complete, must be designed to keep respondents motivated to provide optimal answers, and must serve to reassure respondents regarding the confidentiality of their responses" (p.142).

Given the choice of methods together with costs and time considerations it would make sense to use an online survey approach, although it is recognised that this will exclude those who do not have internet access. Although there would be no results without the contribution from the respondents, electronic communication via the internet also has benefits for the researcher, their collaborators and supervisors as data can be collated, demonstrated and critiqued.

### Interviews

Other researchers may wish to use their questionnaire to adopt a more personal approach to canvassing opinions such as telephone or face to face surveys. Whilst some members of the public might be happy to provide research data in this way, others may find it too intrusive and will refuse to take part. There is a risk that the interviewer might influence the responses by intonation or facial expressions. In addition, keeping the interview 'fresh' and equally weighted for all participants may be a challenge.

### Audits

On their website NHS Blood and Transplant define clinical audit is a "multi-professional quality improvement activity which compares current practices with an agreed standard or guideline". The aim is to provide evidence that blood is being used safely and appropriately and to report on any deviations from such standard or guideline which may cause harm to patients. The National Comparative Audit on Patient Information and Consent (2015) was commissioned by SaBTO (*vide supra*) to find out whether and how much patients are involved in and informed about, their own blood transfusion together with how and whether this is documented in their clinical case notes. This comprehensive audit, involving data from 164 hospital sites providing in total 2784 cases was the largest UK audit of its kind to date. It was conducted in the clinical arena at the time of the blood transfusion episodes. Of note and relevant to this research is that 21% (n=462) of patients receiving blood stated that they did not feel involved in the decision making process around transfusion. In addition, only 38% (n=858) said that the possible risks of transfusion were explained to them and only 8% (n=184) were offered alternatives to blood transfusion. Although this audit has demonstrated the need for a better process of informing patients there are no agreed standards or guidelines currently for the public perception of blood. Research on this topic may set the scene for such work in the future.



### Forum discussion

Originating as a marketplace in ancient Rome, the forum was a public space for conducting business (judicial and commercial) or discussion. The forum continues today as a place for public exchange of opinion, either as an open face to face assembly or online, often as a 'blog'. The advantage of a forum discussion, whatever its form, is that it has the potential for gathering a variety of information that may be useful for research. There is the danger, however that, unless there is an efficient moderator to organise, control and allow all the participants a fair opportunity to present their case, the important messages could be lost in the general noise. Again, if this forum is online, the 'power of the keyboard' might overpower genuine opinion, although it could be argued that everyone has the right to have their say in matters that concern them.

The indication for this study actually arose from discussion at three public meetings where the primary researcher was invited to speak about blood conservation. The presentations were received with much interest, with the chairperson inviting questions and comments from the audience. At each meeting an enthusiastic debate ensued, and, whilst this was not recorded for formal research, it did provide the inspiration to enquire further into what people knew, or might like to know, about blood conservation.

### Summary

Background research for this critical literature review has produced a varied range of information relating to the proposed research project. The current evidence about blood – transfusion and conservation – is equivocal with minimal and ambivalent involvement of patients or indeed the general public as participants. In addition, different methodologies of conducting surveys for the research process show individual strengths and weaknesses, but methodological agreements can be reached so as to process the information which is available.

## *Consensus*

Two publications stand out as ones which have particularly influenced this review and supported the rationale for this current study. All the publications cited have blood transfusion at their core, examining the safety characteristics of this procedure by various methods. In addition, all examined the attitudes of patients and/or the public towards the risks of donor blood and were in agreement regarding future actions to improve safety and increase awareness. There were differing methods of approach for ascertaining these attitudes – some in a clinical setting, such as out-patients departments or on the wards when patients were receiving a blood transfusion. One paper (Khan, 2012) involved the clinicians themselves, while another ('Transfusion 2020' seminar), though not a qualitative/quantitative study, involved debate away from the clinical arena. None of the papers cited have included exclusively the general public, apart from Farrell *et al.* (2001) that targeted 254 students with an average age of 19.2 years, which was not representative of the general population at large nor the average age of UK blood donors, which is 44 years. Alternatives to donor blood transfusion was only mentioned once (Ngo 2013) - as autologous transfusion, although this was pre-donation, not routine practice in the UK. The contributing publications of this critical literature review have between them underlined the main economic factors for blood transfusion and conservation - supply, demand, benefits and risks. However, there were no major discussions nor fundamental evidence found concerning neither long-term sustainability nor alternatives such as recycling blood at surgery.

## *Agreements on technological limitations*

A web-based survey for research depends on two main technological factors: whether the respondents (and also the researcher) have access to a computer and also their degree of competence to use it effectively. If either or both of these two factors are limited, then the outcome of any internet research project will be affected.

### *Methodological agreements*

It has been shown above that each method of engaging the public to participate in research has its advantages and disadvantages. From a practical and economic aspect, the most optimal and pragmatic method to reach large audiences is an electronic one, although other methods will continue to be relevant depending on the research question and situation.

It is therefore evident that there still remains a paucity of robust studies involving large cohort numbers to demonstrate patient, and more particularly public perception of blood transfusion and conservation.

Therefore, the aim of this project is to ascertain what patients and the public (in the Exeter area, UK) know, or want to know, about blood: transfusion and conservation. They will be asked about giving and receiving blood and whether they have concerns about blood transfusion - availability, risks, benefits and costs. These participants will then be invited to respond to further questions about whether they would like to know more information about blood conservation, including alternatives to donor blood transfusion, how they would like to receive such information and if so whether they would discuss this with family and friends.

Table 2.2: Key findings of documentary evidence in the literature review

<b>First author, date</b>	<b>Aims</b>	<b>Subjects</b>	<b>Method(s)</b>	<b>Key findings</b>
Khan, M.M. 2012	To develop a tool for blood transfusion counselling to evaluate patients' beliefs about transfusion	Clinicians (n=12) Patients (n=14)	Mixed quantitative and qualitative questionnaire in two phases as a pilot study only	Mixed quantitative and qualitative questionnaire in two phases as a pilot study only
Davis, R.E. 2011	To investigate role of patients in ensuring safe transfusion practice	Patients/ Parents of child patients and public  (n=11,152)	Systematic review+ comments  15/2018 relevant papers	Increased awareness of transfusion safety: how information is presented, how individuals assimilate and make decisions

<b>First author, date</b>	<b>Aims</b>	<b>Subjects</b>	<b>Method(s)</b>	<b>Key findings</b>
Farrell, K. 2001	Quantitative surveys	254 undergraduate students (Mean age 19.2 years, n= 96 males, n= 152 females, 6 not known)	Quantitative questionnaire	As perceptions of risk of blood transfusion increased - was an associated decrease in willingness to accept this process
Mockford, R 2011	To investigate evidence of the impact of PPI on NHS care	UK studies 1997-2009	Systematic review of 28 papers from 6110 references	PPI has wide range of applications but limited evidence of reporting
Murphy, M. 1997	To investigate patients' attitudes about transfusion (England)	n=51 hospital patients receiving blood transfusion	Quantitative questionnaire	20% additional information. 53% written information would have been helpful

<b>First author, date</b>	<b>Aims</b>	<b>Subjects</b>	<b>Methods</b>	<b>Key findings</b>
Ngo, L.T. 2013	To examine role of risk perception in attitudes towards blood transfusion	Public/ Professionals /Blood donors/ Stakeholders (n= 6,475)	Qualitative systematic review 15 out of 30 relevant papers	Admitted limitations - lack of contemp. studies.
Starr, D. Klein, H.G. Hossenlopp, C. Ferguson, E. 2001	How might public perception of risk of transfusion influence its development	Presentations and panel discussion – speakers and delegates (Total not stated)	International Meeting report – proceedings of National Blood Service seminar Transfusion 2020	Informative papers, lively debate, but? transferable to current blood system issues is as yet unknown
Thompson, P. 2012	Patient empowerment/ involvement in transfusion	N/A	Article – Blood and Transplant Matters	Need for engagement by the transfusion community

## Chapter 3 – Method

### Study design

The project was planned to be a combined quantitative and a qualitative study because it was important not only to enumerate the responses but also to gather the opinions of those surveyed. Two reference books were particularly valuable as background reading to plan and execute this work. The first by Bell (2010) was a general guide for implementing a research project - this was mainly beneficial for advice on how to organise the study, ranging from initial preparation and what approach to take through to methods of data collection, interpreting the results and writing up the report. The second by Oppenheim (2005) was a more specific publication for questionnaire design which described the different methods for questions to be structured to maximise ease of use for both the audience and the author.

### Target groups

The target public audience comprised individuals living/working/studying in the Exeter, UK, area who were already on existing research and/or survey databases and who had given permission to be contacted. Their details were known only to the database managers/coordinators involved and comprised three groups:

- Royal Devon and Exeter NHS Foundation Trust (NHSFT) members (Phase I and II)
- University of Exeter Sports and Health Science (SHS) students (Phase I only)
- Exeter Clinical Research Facility (ECRF) 10,000 panel members (Phase II only)

Participants from all of these groups would have access to the internet and therefore would be able to respond by electronic means. It would have been advantageous to include other members of the public, who were unable to do

this, for example, by post. Unfortunately the costs involved for printing and postage were prohibitive and no funding was available.

### Approval for study

Because this study was 'Public and Patient Involvement' ethics approval was not required by both the RD&E NHSFT and the ECRF, in line with the National Institute for Health Research (NIHR) guidance (2014, p.9). Nevertheless, anonymity and confidentiality were assured by both database managers/coordinators. Therefore, no identification details for any of the participants in this study were accessible to the primary researcher.

### Logistics

Communications between the database managers/coordinators and the primary researcher were conducted in the following ways. Initial email messages were followed by telephone conversations and these led to an introductory face-to-face meeting with each manager/coordinator. Subsequently, the majority of the work was carried out via email, with occasional meetings with the RD&E NHSFT database manager at the hospital to observe the software used and to discuss progress. The ECRF database manager was in accord with this as the project had been initially hospital based and preliminary plans, and problems, had been resolved before she joined. Throughout the complete process, supervisors were consulted and copied into each email.

### Phase I: Pilot questionnaire for survey

Work for this first phase was from January to mid-May 2014. A questionnaire was designed in Word<sup>®</sup> format based on the parameters as stated in the Introduction, i.e. what people already knew about blood transfusion and conservation, what they would like to know and how they would prefer the information to be presented. This document was emailed to two members of the research team and to the NHSFT membership services manager for their comments. The final version was tested first on family, friends and colleagues asking them to proof read and assess whether this document was intelligible.



This was performed by asking the respondents to complete a short eight-question feedback form to determine how long it took to complete, whether it was user-friendly and whether the questions were clear and appropriate. Any further comments were also invited (Appendix 1). Readability was assessed by the Flesch-Kincaid method resulting in a “Sixth Grade” (12-13 year old) score of 87%, which is classified as “Easy to read/Conversational English for consumers”, acceptable for this study.

The pre-questionnaire commenced with an introductory message explaining the background and rationale for the study followed by three main sections with a total of 13 questions. These sections were ‘Blood Transfusions’ (three questions), ‘Your views about blood’ (eight questions) and ‘About You’ (two demographics questions). Each section included free text boxes inviting further remarks. Finally, there was a short paragraph thanking the respondents for taking part and again explaining the rationale of the study and how their views would assist this study to involve patients more in their treatment (Appendix 2).

Based on all the feedback, the prequestionnaire was converted by the RD&E NHSFT membership services manager into SurveyMonkey® format. This software is an existing and standard one used by the RD&E NHSFT for its own surveys so it was advantageous for the primary researcher to be able to make use of this current expertise and technology. This conversion process from Word® to SurveyMonkey® was overseen by the primary researcher over the course of several meetings in the RD&E NHSFT in early 2015.

This survey was then emailed as a link in a covering letter to the NHSFT members and the SHS students. The resulting responses were reviewed and then the questionnaire was adapted for Phase II.

#### Phase II: Main questionnaire for survey

Work for this second phase was from the second half of May to July 2015. As for Phase I, after some detailed discussions between those involved in the process about the content, this questionnaire was finally emailed out on the 1<sup>st</sup> June 2015 to the NHSFT members, again via a link in a covering letter. This

letter now included advice of an estimated completion time of approximately ten minutes. The section on 'Your views about blood' had been expanded to include a question about cost of blood. There was also an additional section inviting opinions on 'Information about blood'. These additions made a total of 16 questions together with the two demographic questions as before in the pre-questionnaire. The closing date for the survey was 30<sup>th</sup> June 2015. A full version of the main questionnaire can be found in Appendix 4.

It was not logistically possible or appropriate to contact the SHS students again, so at this stage there was a search for a larger subject group. This search resulted in the contact details for the ECRF 10,000 panel database being secured. This database operates by selecting particular groups of panel members who are contacted no more than four times a year for research purposes. Those panel members with specific conditions, such as diabetes, may be needed for research relevant to that specific disease and therefore would not be invited to participate in other studies such as this one. The primary researcher was invited to forward details of the proposed research, together with the main questionnaire, to the ECRF manager for consideration by the Peninsula Research Bank Steering Committee at their next monthly meeting. Approval was granted, so a selection (by ECRF) of their 10,000 panel members was included in the Phase II main survey. For this particular group, the invitation to participate was added to a previous ECRF research invitation message and then sent out from ECRF to the selected participating panel members. No reminders were sent.

All the results for both these groups were received and coordinated by the NHSFT Membership Services Manager. The quantitative data were extracted from SurveyMonkey® and inputted into Excel®. The resulting Excel® spreadsheets were then emailed to the primary researcher.

### Data analyses

The overall quantitative results from SurveyMonkey®, inputted to Excel® spreadsheets, were first converted into chart format for easier visual impact. Then for each individual quantitative question (1-8 and 10-15) the answer

headings were then coded; e.g. for Q.1 'Have you ever received a blood transfusion in the UK?' Yes=1, No=2, or for Q.6 'The risk of getting an infection from a blood transfusion' High risk=1, Moderate risk=2, Low risk=3, I don't know=4. The responses for each code were inputted into an Excel spreadsheet for non-parametric (NPar) testing.

### Statistical analyses

The Chi-Square test to determine whether there was statistical significance for each response, i.e. if the differences in frequency exist across the response categories was utilised. An alpha level of  $P < 0.05$  was accepted to indicate statistical significance. Where there were statistical differences, Chi-square tests were performed on the individual response categories. Depending on the number of comparisons, the alpha level was adjusted ( $p < 0.05$  divided by number of comparisons for example 3 comparisons,  $0.05 / 3 = 0.02$ ) to protect against the likelihood of a Type I error. There are three assumptions for this test: firstly random sampling, secondly independence by the researcher of the observations and lastly the size of the expected frequencies (the lowest expected frequency would be 5).

### Qualitative analyses

The free text box comments were extracted and inputted into Excel®. All the comments were printed out and examined to see whether any specific or recurring themes emerged. Thematic analysis is a useful and flexible method for identifying, analysing and then reporting patterns or themes within qualitative data (Braun & Clarke, 2006). This method of qualitative data analysis provides a way of identifying, organising and ordering the fundamental concepts and assumptions that inform the semantic content of the data.

Braun and Clarke (2006) postulated that there are six phases to thematic analysis which were adopted for the present study: 1) the researcher examined the qualitative data, 2) initial headings were created, 3) these headings were collated into prospective themes, 4) the themes were re-examined in relation to the excerpts and complete data set, 5) the themes were designated and 6) a

report was produced. Each of the six stages was recorded clearly in order to make sure that any presuppositions on the part of the researcher did not affect the overall thematic structure (Thomas & Wilson, 2014).

During the first two stages, all qualitative data responses were read several times over to identify as many categories as possible. Graneheim and Lundman (2004) stated credibility is one aspect of trustworthiness in qualitative studies. To ensure credibility, transcripts were compared and validated against the emerging categories to ensure no relevant data was inadvertently or systematically excluded or irrelevant data included. In the third stage, these categories were compacted to produce the themes. These themes were then reviewed during the fourth stage, which at this stage would have presented the opportunity for any potential themes unrelated to the research question to be removed, but in fact was not necessary on this occasion. During the fifth stage, the themes of 'value transmission' and 'putting values into action' were merged to create an overall 'awareness around effective value transmission' theme. Any pertinent quotes considered to have potential impact for future reference were added under the applicable themed categories. The report was thence generated during the sixth and final stage of this thematic analysis process.

### Organisational challenges

There were some problems and obstacles during this process at each of the locations involved in the study, which all presented their own particular challenges to its progress. Firstly there was a time-lag for the ECRF to become involved as it took time to locate the key person to contact. In addition, it was necessary for the study proposal and survey details to be considered by their Peninsula Research Bank Steering Committee and then debated at their monthly meeting. Secondly, there were several issues involving funding. One of these was that there were no monies available from any recognized source for providing both printed surveys and postage to send to people who did not have internet access. This would have potentially given a broader view of public opinion. Another issue was that the RD&E NHSFT needed to upgrade their SurveyMonkey® software across multiple areas at the critical time when the

results were arriving. Finance to secure this upgrade involved different budgets and managers, which inevitably led to delays until the upgrade was implemented.

## Chapter 4 – Results

### Phase 1: Pilot questionnaire for survey

Collectively, 80 responses were received from the pilot questionnaire. There were no adverse comments regarding clarity and usability of the SurveyMonkey® format. In addition, the questions were deemed unambiguous by the respondents.

However, there were useful and constructive criticisms highlighting some omissions. One suggestion was that it would have been useful to state how long the survey would take to complete. The need for a clear statement about other options available to transfusion and blood screening was also noted. There were also some helpful suggestions regarding the order and the theme grouping of questions, but overall there were no perceived problems with the general layout of the survey.

One respondent stated that they felt uncomfortable about being asked about being a blood donor, but otherwise there were no personal objections to any other questions. There was also doubt as to whether the question of cost for blood transfusion should be part of the survey because some respondents thought that it would not be relevant.

All the above comments were noted and discussed with the supervisory team and the Royal Devon and Exeter NHSFT Governance Coordinator. In particular, the question of the cost surrounding blood transfusion provoked much debate, but eventually it was agreed to include it, if only to raise the issue that the process of blood transfusion does have financial implications for healthcare.

The individual questions were therefore adapted as a response to the previous comments and discussions. As there were no reported difficulties with the overall survey structure, the same format was used for the main questionnaire survey (Appendix 3).

## Phase 2: Main questionnaire for survey

### Quantitative results

All the following data show the combined responses of both target groups.

There were 1116 replies from a survey target of 4484 people, a response rate of 24%.

### *Demographics*

Of those who wished to state (two preferred not to), there were 451 males and 616 females. There were significantly more female respondents compared to males in this sample group ( $p < 0.001$ ).

The age range was 18 years to 75 years and older with two respondents preferring not to state. The highest representation was in the 65-74 age group, which contained 36% ( $n=387$ ) of all those who replied to this question. The age ranges were all significantly different compared to the 55+ age range ( $p < 0.001$ ). There was no significant difference in frequency between the 25-34 and 35-44 year groups ( $P > 0.006$ ).

Table 4.1: The age groups of all respondents

<b>Age range</b>	<b>Response Count</b>
18 - 24	5
25 - 34	37
35 - 44	65
45 - 54	149
55 - 64	233
65 - 74	387
75 and over	191
Prefer not to say	2

Examining each section of the survey in turn:

*Blood Transfusions (Questions 1-3)*

Each of these three questions produced 1116 responses.

To the first question 'Have you ever received a blood transfusion in the UK?' 19% (n=213) were in the affirmative, as shown in Figure 4.1 below. There were significantly more 'No' responses than 'Yes' responses ( $p < 0.001$ ). This question was not compulsory and 47 respondents skipped this question.

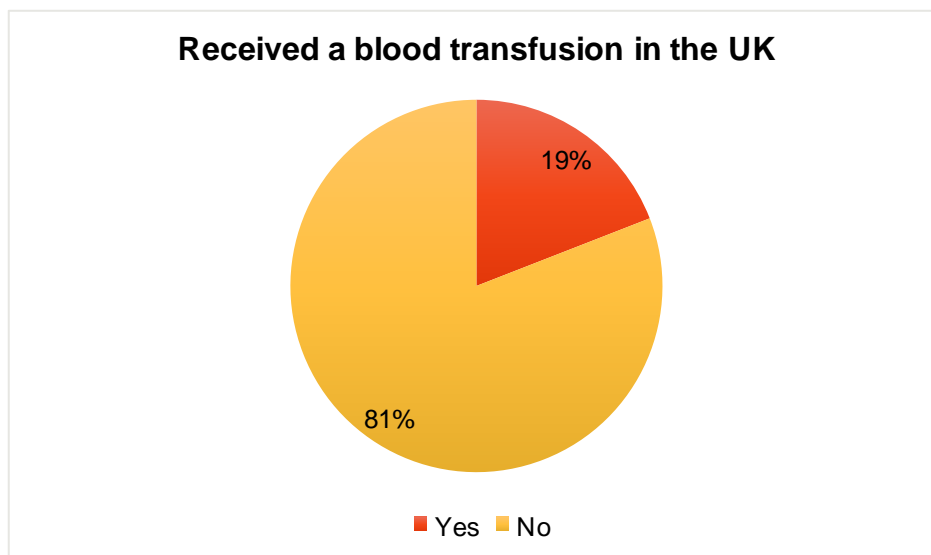


Figure 4.1: Recipients of blood transfusion

A total of 53% (n=597) knew someone who had received a blood transfusion and this was significantly more than those who did not know someone ( $P < 0.02$ ). Significantly more respondents (n=930) did not have any concerns about transfusions compared to the concern group ( $P < 0.01$ ). One hundred and eighty six (17%) stated that they did have concerns/anxieties about blood transfusion in the UK, as shown in Figure 4.2.



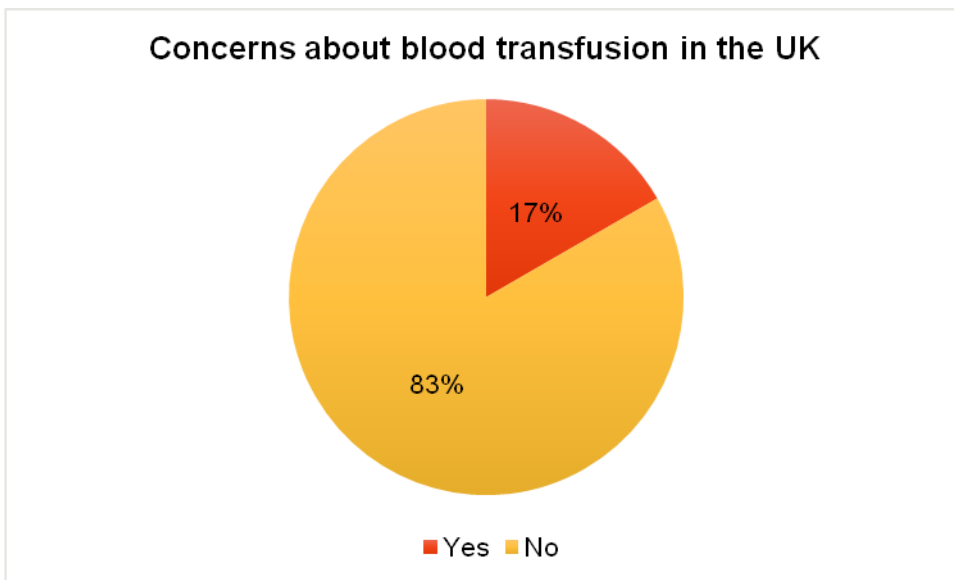


Figure 4.2: Percentage responses about concerns regarding UK blood

Those who stated 'Yes' were invited to qualify these concerns in the free text box. The resulting comments have been qualitatively analysed as have those to Questions 9, 10/11 and 16. The resulting themes will be shown in the free text responses, see Section 4.4.

*Your views about blood (Questions 4-9)*

Figure 4.3 demonstrates the beliefs of the 1097 respondents concerning availability of blood for transfusion in the UK. Seventy one per cent (n=780) thought that there was not enough, which was statistically significant compared to the other three categories ( $p < 0.001$ ), with 18% (n=194) reporting they did not know.

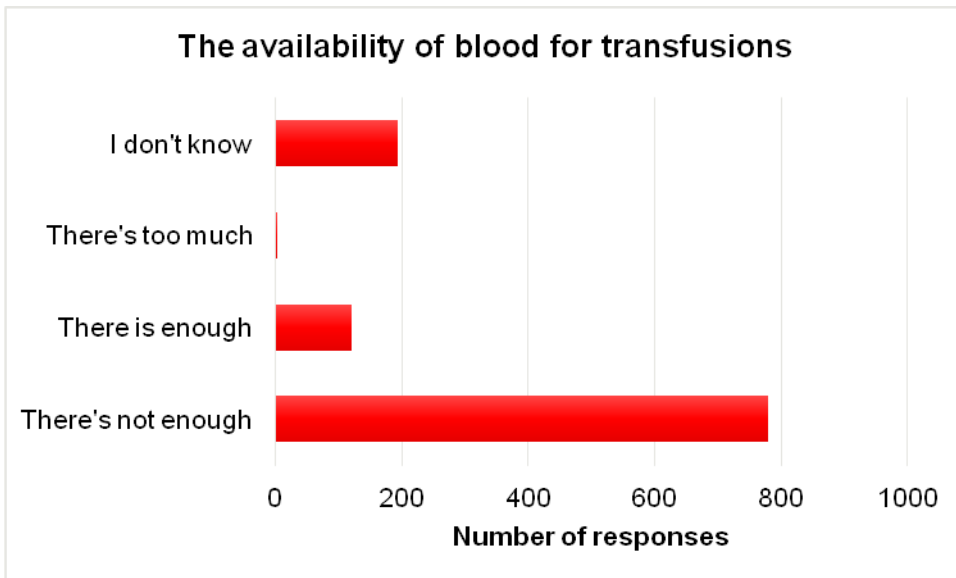


Figure 4.3: Responses for whether there is enough blood for transfusion

Receiving the wrong blood as an incorrect transfusion was perceived as low risk by over three quarters (n=849, 77%) of those who responded. This response was statistically significant in frequency compared to the other three responses ( $p < 0.001$ ). However, 10% (n=110) did not know (Figure 4.4). Low risk was significantly different to the other three categories ( $p < 0.001$ ).

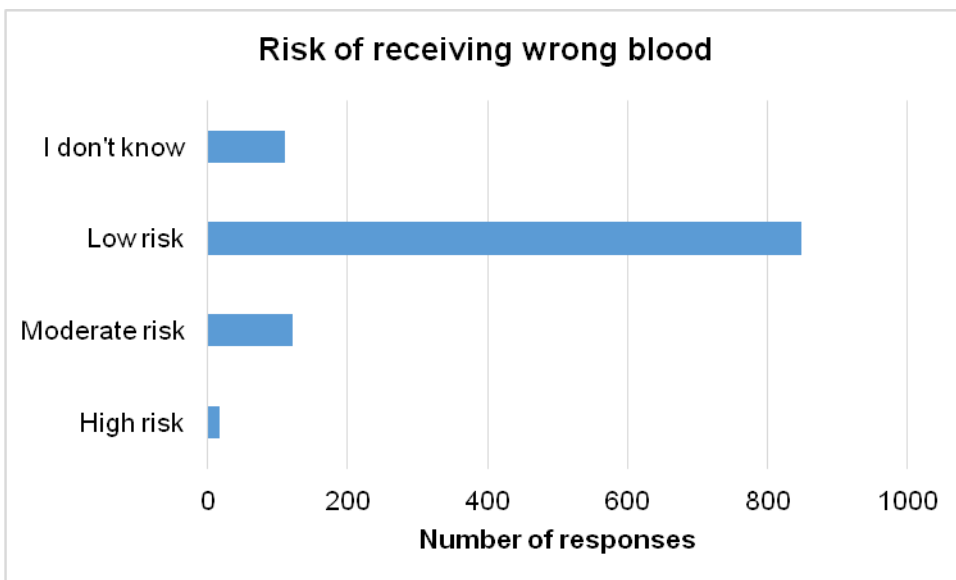


Figure 4.4: Perceived risk of receiving an incorrect blood transfusion

Similarly, 74% (n=810), thought that the risk of getting an infection from blood to be low, and again this was significant compared to the other three groups

( $p < 0.008$ ) but 10% ( $n = 109$ ) did not know (Figure 4.5). The moderate group responded in significantly higher numbers compared to the high risk group ( $P < 0.008$ ).

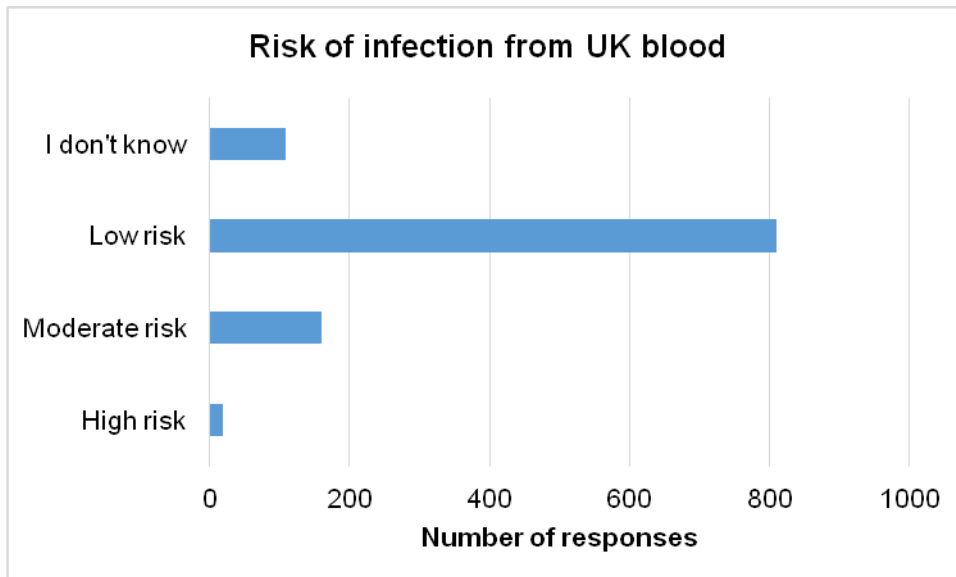


Figure 4.5: Perceived risk of receiving infected blood

Ninety one percent ( $n = 1001$ ) thought the benefit of receiving a blood transfusion was high (Figure 4.6). This was statistically significant ( $p < 0.001$ ) compared to the other three responses. There was no significant difference between the 'I don't know' group and the 'moderate' benefit respondents ( $P > 0.008$ ).

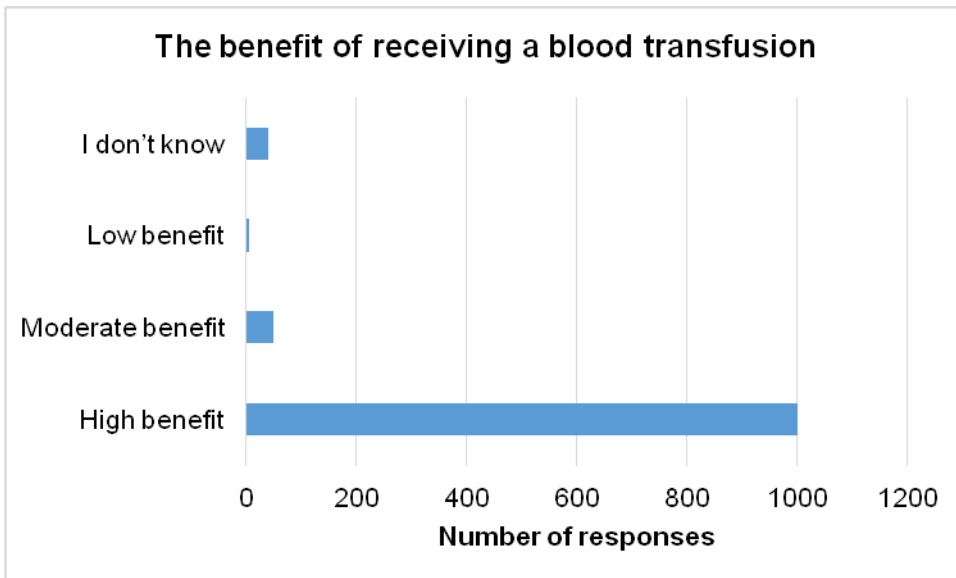


Figure 4.6: Perceived benefit of receiving blood

When asked about the financial cost to the NHS of the blood transfusion process, 46% (n=507) considered this to be an important issue. This was statistically significant in the response frequency between important and the other three categories ( $p < 0.001$ ). All other comparisons were significantly different ( $P < 0.008$ ).

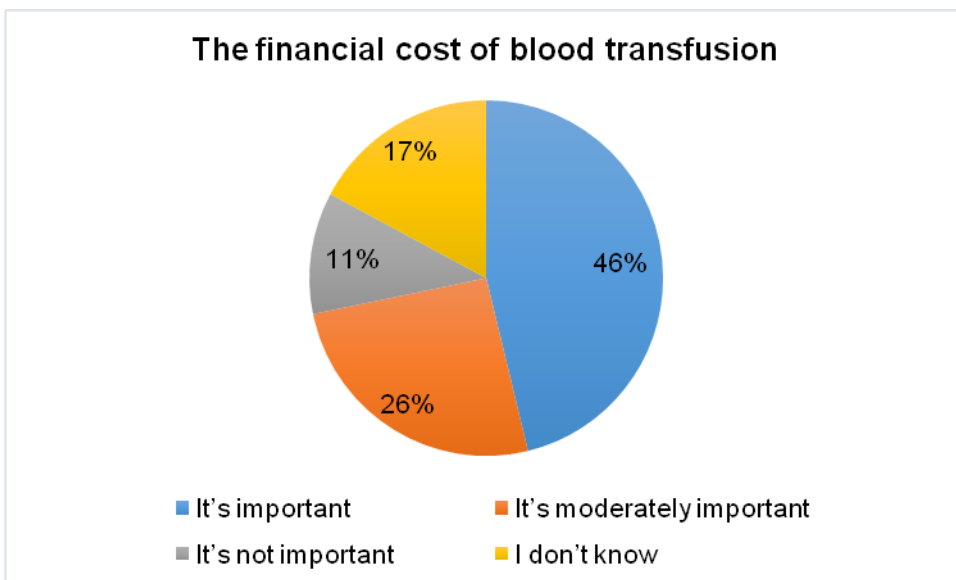


Figure 4.7: Economic cost of transfusion to the NHS

If the respondents wished to comment further, a free text box was provided at the end of the section and all the results were analysed and reported in the free text responses, section 4.4.

#### *Giving and receiving blood (Questions 10-11)*

Only 4% (n=44) of the 1082 people who responded felt worried that they might be given an avoidable transfusion, with 88% (n=950) being not concerned. However, 8% (n=88) responded as did not know (Figure 4.8). The no respondents were significantly different to the other group respondents ( $P < 0.01$ ) and the 'I don't know' group responded in higher numbers than the 'yes group' ( $P < 0.01$ ).

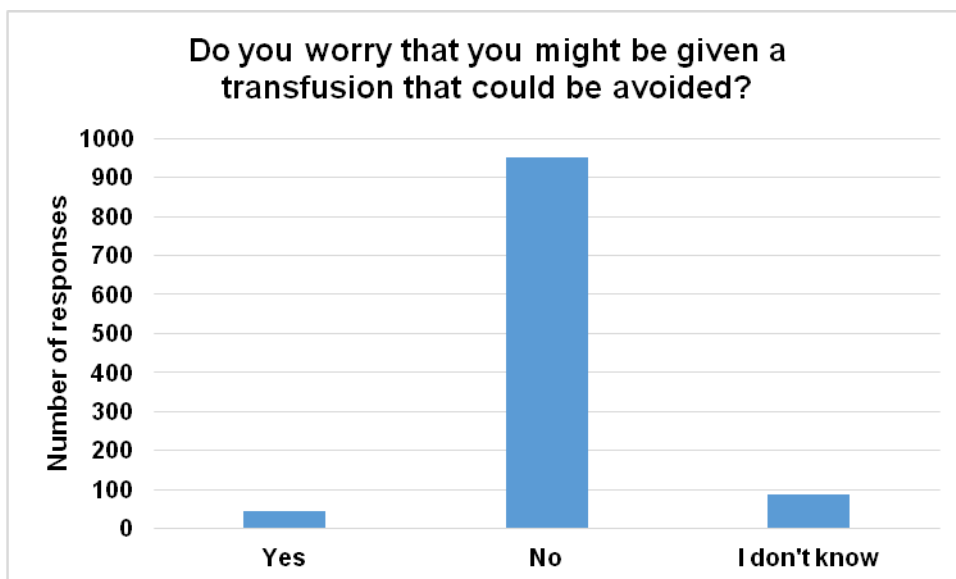


Figure 4.8: Frequency counts of the three categories according to the question regarding avoidable transfusion

There were 1070 replies to the question 'Do you give blood?' and of those 17% (n=182) reported that they did, which was significantly different ( $P < 0.01$ ). A total of 15 (1%) respondents selected that they would rather not say (Figure 4.9).

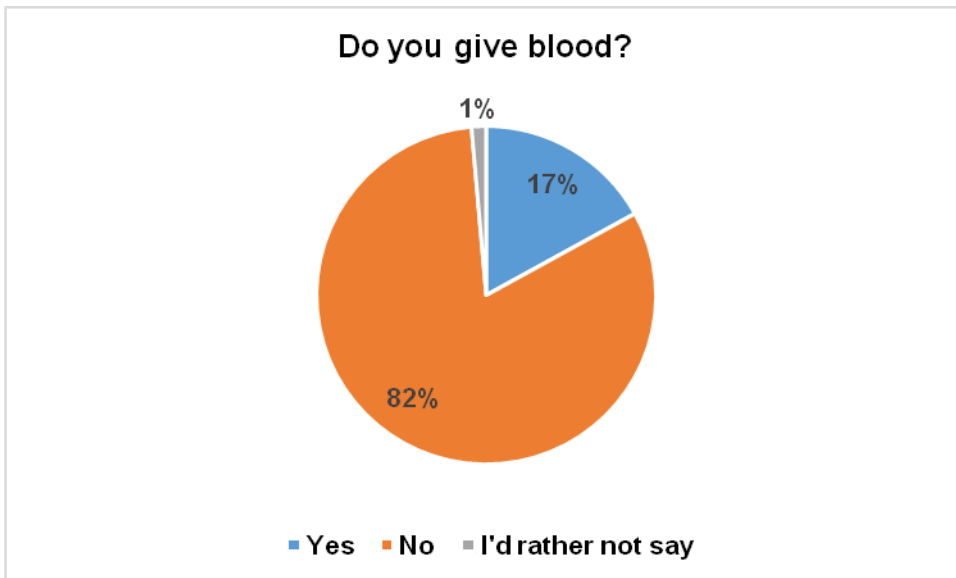


Figure 4.9: The percentage of respondents giving blood

Those who wished could further comment in the free text box at the end of this question and this information is presented in the free text responses section 4.4.

*Information about blood (Questions 12-15)*

When asked, if the information was available, would they like to know more about how blood can be saved for those who really need it, over half, 52% (n=553) of the 1072 respondents stated that they would like to do so. This response of 553 was statistically significant ( $p < 0.001$ ) to the other two categories.

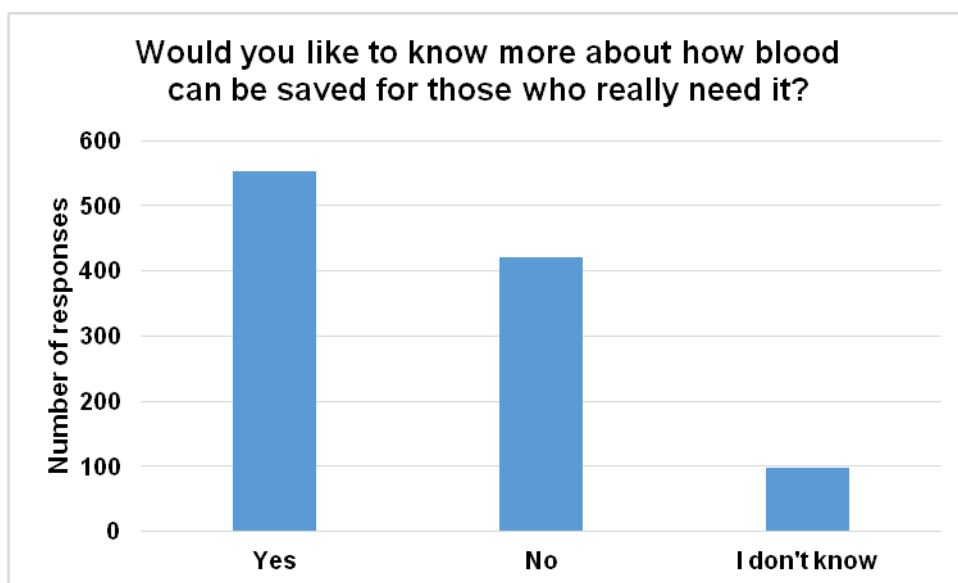


Figure 4.10: Further information about how blood can be saved

When asked if they would like to know more about alternatives to blood transfusion, such as recycling blood at operations, again 1072 people replied. Of these 642 (60%) selected Yes, which was statistically significant compared to the other two groups (Figure 4.11).

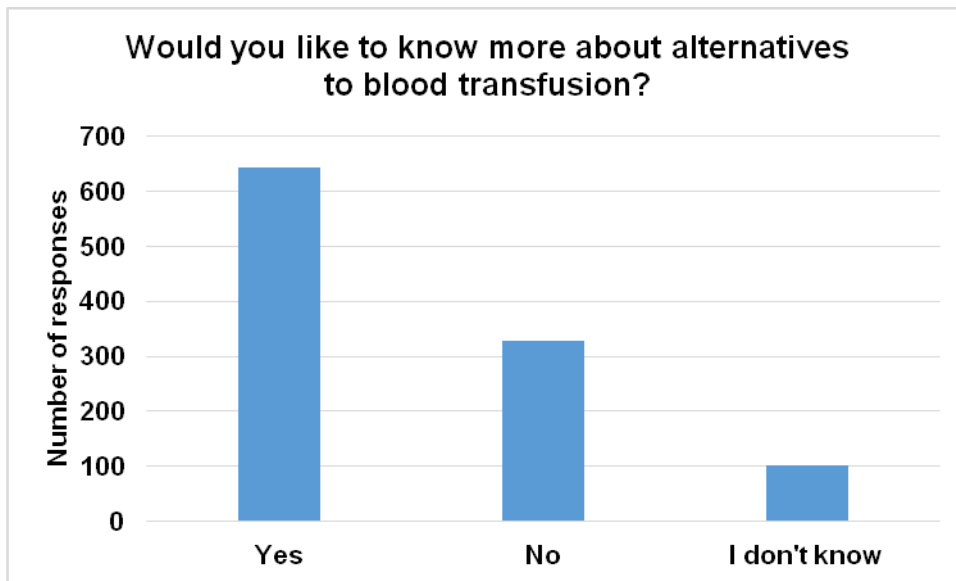


Figure 4.11: More information about alternatives to blood transfusion

If the respondents selected 'Yes' to either or both of the last two questions then they were offered a choice of methods for receiving the information. They could choose more than one option if they wished. Nine hundred people responded, with the most popular choice being an electronic method (55%, 498). Paper format was the second choice at 27% (242 responses).

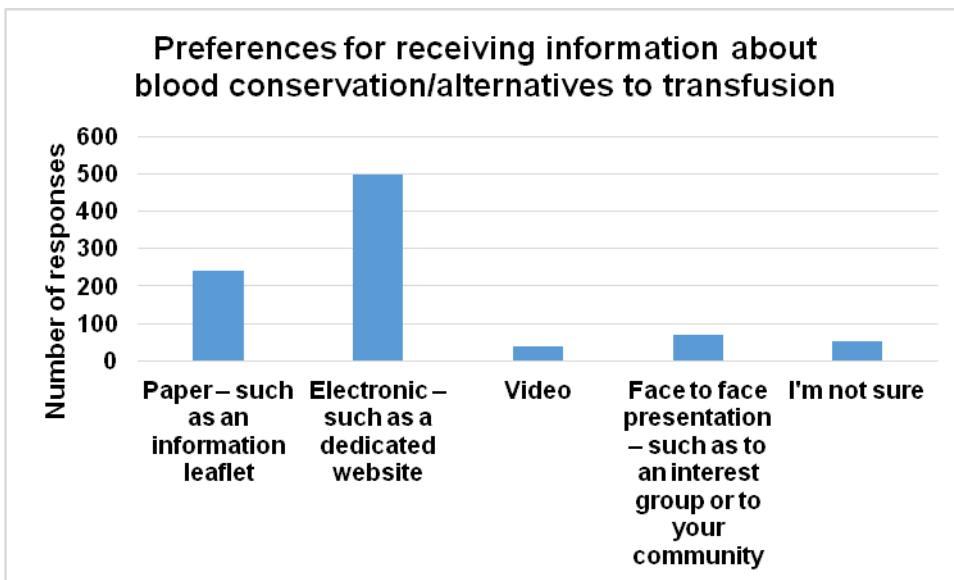


Figure 4.12: Format choices for information related to blood conservation and alternatives

When asked if they did receive more information, how likely would they talk with their family and friends about blood and blood conservation, 1007 people responded. Sixty one percent were either very likely (n=201) or likely (n=409) to do this.

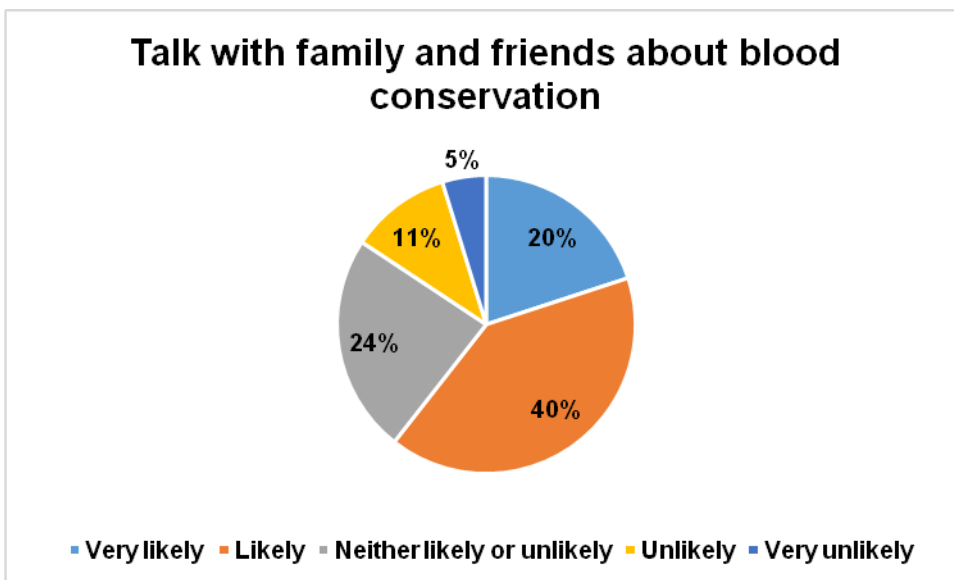


Figure 4.13: Percentage of respondents for likelihood of discussion with family and friends



### *The survey as a whole (Question 16)*

Three hundred and thirty eight respondents added further qualitative comments about this survey as a whole. These comments are summarised together with the other free text comments from the previous questions (3, 9 and 10/11) in the Qualitative results section below.

### *Qualitative results*

#### *Total number of free text comments*

There was a total of 1586 comments in the free text boxes attached to the following questions:

Q.3 (If answered Yes to having concerns about blood transfusion in the UK, what those concerns are)

Q.9 (Any other views about blood)

Q.11 (If answered No to Do you give blood and able to state why)

Q.16 (Any other comments or questions about the survey as a whole).

#### *Emerging themes*

By reviewing these comments and qualitatively analysing them, six principal and recurring themes emerged. These were:

- a) The blood donation process***
- b) The safety of donor blood***
- c) The financial implications for donor blood***
- d) Personal/family experience of blood transfusion***
- e) Misunderstandings about donor blood***
- f) Blood conservation***

Taking each of these themes in turn:

**a) *The blood donation process***

This theme was the most commonly accessed one in terms of free text comments. It ranged from the organisational, communication and publicity/advertising methods of NHS Blood and Transplant (NHSBT) (still referred to occasionally as “the blood service”) and also included the appointment systems and venues, through to the personal experience of the donor or potential donor.

There were 44 complaints about the paucity of venues in the community, especially in workplaces and rural areas. Included in this group was one comment that there was a;

*“lack of convenient centre/sessions”*

Some venues, such as village halls, had been discontinued which resulted in problems for non-drivers accessing other locations. Fourteen respondents felt that the venues were not;

*“open with the working person in mind”*

Two respondents thought that early evening city centre sessions would be useful as well as out of town venues. Other suggestions were that it would be helpful to arrange donor sessions in the local main hospital (n=1), health centre, supermarkets or car parks using mobile facilities (as for breast screening) if necessary (n=3). The appointments system provoked much criticism – often there were problems in obtaining an appointment within a reasonable timeframe and sometimes not enough choice of dates and times. An example of this was from someone who indicated;

*“Getting blood donation appointments is frustratingly difficult”*

Even if a person had an appointment for a particular venue, there were often delays and long queues at the session. The sessions themselves were criticised as being;

*“oversubscribed”*

and one person said;

*“Don’t believe there is a shortage of donors as appointments often full and people turned away from donor sessions”.*

Four people thought that the appointments system should be abolished in favour of a return to the old ‘drop-in’ sessions;

*“I am unable to drop-in when I can and have been turned away which is very disappointing when I am making the effort”.*

Two respondents, however, suggested a combination of the two methods to help both those who preferred a fixed appointment but also to attract ‘walk-in’ donors.

It was accepted, though, by some respondents that lifestyle and work patterns together with increasing population mobility may contribute to the above complaints and difficulties. However, there was a plea to;

*“Make donation easier for donors”*

and that

*“Far more time needs to be employed persuading people this is a voluntary process but needs to be entirely focussed on the giver and the giver’s convenience”.*

One regular donor had stopped going to give blood;

*“...because the persistent and frequent changes to the process has made the whole experience so ludicrously complicated, lengthy and riddled with conditions....”.*

On a similar topic, one respondent stated;

*“I’d like to know how efficient our blood transfusion service is ....the folk there work very hard but it seems as if the management keep changing the goalposts”.*

Another person remarked;

*“Don’t treat the donors like children or an inconvenience to the process”.*

Although there was awareness of the importance of giving blood, some people felt that the blood service should do more to improve its strategy for both attracting and retaining blood donors. In addition it was thought there should be more publicity and more information about blood for the general public, similar to organ donation. One person stated;

*“The Blood Transfusion Service seems to be so low profile it might no longer exist”.*

Another respondent thought that the service had had a low profile compared with, for example, cancer awareness;

*“I believe that there should be a powerfully positive advertising campaign to convince people...that giving blood is beneficial to the health service, perfectly safe and nothing to be scared about...”*

More young people, it was suggested, should be encouraged to donate, by targeting them in schools (even making blood donation part of the curriculum) as well as universities. Increasing the use of the internet by videos and social media in a ‘viral hit’ might also help. Everyone could be targeted in public places such as GP surgeries, hospital outpatients’ departments, Accident and

Emergency departments, but also in other spaces such as village halls, together with football and race meetings (as for anti-smoking/alcohol campaigns).

One person offered their opinion that;

*“increasing media coverage in times of crisis would help”*

with another saying that they

*“...would donate more in a crisis”.*

One respondent suggested that Transfusion Team presentations at, for example, Women’s Institute meetings might be beneficial; a useful precedent for this is the ‘Time to Talk’ series on organ donation. Another recommended asking recipients, and their families, who have benefitted from blood transfusion to help raise awareness of its importance at work and with friends. Contacting current donors who have stopped giving to find out if they can do so again might also help. Two respondents proposed for giving blood;

*“Encourage everyone who can as a public duty”* and;

*“Make blood donation as ‘opting in’ (like organ donation?) ‘The norm’ ”.*

A further respondent suggested;

*“More philanthropy from ‘Big business’ – organise donor sessions, give time off work to donate without losing pay”.*

For those who had been donors, 18 respondents said were unhappy about being excluded from giving blood, particularly if they had taken the time and trouble attended the session. There was occasional misunderstanding about the reason for exclusion, especially where the person had received a blood transfusion or was thought to have done so if not clear from their medical records. If they had lived/worked abroad then exclusions also applied, but some felt that this was unfair, especially if they had donated blood overseas. It was perceived that there was;

*“Some miscommunication or indeed no communication from the Blood Service to donors”*

This perception was particularly justified as where the reason for refusal was not given. Most potential donors, though, accepted that that their age (n=113), low body weight (n=3) and current or past medical conditions (n=68) and medications (n=55) were precluded or excluded them from giving blood. They understood why, but seven respondents raised the possibility of making eligible for blood donation those with mild medical conditions, cancer (cleared) or those who had reached the maximum age for donating. Healthcare workers also stated that they were ineligible because they had received the hepatitis B vaccination. Former nursing staff (n=3) had been strongly discouraged from donating as it was felt that they were exposed to many infections, although they said they would have liked to do so. One respondent was a pilot and not allowed to give blood. A further respondent was precluded for faith reasons. There were some donors who, despite the rigorous exclusion criteria, were accepted for donation but did not re-attend due to bad experiences at the session. These included fainting (n=2), bruising (n=3), difficult to bleed (n=2), and slow donation (n=5). One donor;

*“became unconscious during donation”.*

After giving blood one donor was left;

*“feeling tired and weak”.*

A further two donors;

*“felt ill”, “felt poorly”.*

The long waiting times were deemed to be an issue by five respondents with one individual commenting that they;

*“felt undervalued”.*

One respondent, however, has persevered with donating their blood;

*“as I am RhONeg (sic) I am aware my blood group is useful...I have a*

*fear of needles and it took some time to conquer this – I wish I had started earlier!”*

One group of people would have liked to have given blood but were aware that they might cause problems because of needle phobia (n=13), or had tendency to faint or squeamish at the sight of blood (n=5). Others had never given blood because they had fears of infection or had never felt fit enough. Lifestyle reasons for not donating included work/family commitments (n=5) such as;

*“lack of time”*

Three people stated that they were “gay men” (sic) and were aware (at the time of the survey) that they were excluded from blood donation but two asked whether the blood service to reconsider to allow them to give blood. Five respondents said that, although they personally could not give blood, members of their family did so. Two respondents preferred to sign up for organ donation rather than give blood. Other reasons for not giving were;

*“Never been asked”*

*“Never got round to it”*

*“Laziness”*

*“Never thought about it/until now”*

One person stated they, after signing up to donate, had;

*“never heard back from the blood service”*

and from another that there was;

*“no communication”.*

Another stated;

*“Difficult to find information about when and how to donate”.*

On a positive note, a blood donor said that they were;

*“proud to help others”*

with three individual comments about the blood service itself that it was

*“vital”*

*“valuable”*

*“underappreciated”*

Two respondents inferred that giving blood was;

*“Good for the donor and any recipient”*

*“you never know when you might need some”.*

One regular donor commented that;

*“...I believe entirely in the benefits of donating, both for myself and any recipients”.*

### ***b) The safety of donor blood***

This was the second largest theme and voiced concerns about donor blood in the UK. For 30 responses a common word was;

*“contamination”*

General infections from blood were a concern for 17 respondents and for two in particular;

*“Is blood totally free of any infections?”*

*“I want to know how well the blood is screened”*

Mention was made of historical transfusion-related adverse events of transfusion transmitted disease reported in the media. These were known to be hepatitis from Factor VIII for treating haemophilia, and also transmission of both HIV and CJD from blood transfusion (referring to the treatment of haemophiliacs with blood component cryoprecipitate containing Factor VIII contaminated with hepatitis C virus in the 1970s and 1980s). Specifically, viral infections were stated by 13 respondents for HIV, 12 respondents for hepatitis including one respondent who cited;

*“the factor 8 (sic) debacle”*

Nine respondents demonstrated awareness of prions, specifically vCJD, with one enquiring if there was;

*“DNA testing for recipients”*

Three respondents asked how donor was blood tested/checked, was it filtered and could;



*“collected blood be re-tested before use”*

And another that;

*“Poor hospital hygiene standards might be also be a factor”.*

There were also doubts expressed about whether unknown non-infective diseases could be transmitted from donor blood. One comment was;

*“Fear of the unknown”.*

Concerns were also raised about sourcing blood outside the UK and whether the same rigorous testing standards would apply as they do nationally. Some respondents mentioned that plasma was often sourced from the USA but was there a risk with this, especially as donors there are paid. Worry about blood from the EU was also queried as;

*“risky”*

as was;

*“foreign blood”*

On a wider scale one respondent wanted to know;

*“Is there a global system of storage?”*

And another;

*“How safe and secure are the blood banks from terrorist threats?”*

Three people praised the part played by those involved in the transport of blood and the risks they experienced as blood is;

*“Often carried at speed”*

and recognising the;

*“Couriers’ essential role”*

One person offered a testimonial that;

*“Devon Freewheelers do a great job”.*

Receiving the wrong blood was also raised, with 12 respondents concerned about checking procedures, protocols and standards. One person said that there had been;

*“problems finding my correct group”*

For three respondents on organ transplant waiting lists, together with those who had already received organ transplants (n=4) there was awareness of the risk of receiving blood from another person. The risk of fluid overload from a blood transfusion was also indicated by two respondents. There was, however;

*“Confidence in blood, professionals’ decision”*

by one respondent and one person was;

*“Aware of risks, but happy to receive blood”*

The staff administering the blood were thought to be;

*“Well trained”*

and;

*“Have strict criteria for transfusion”*

but may have;

*“Lack of confidence”,*

*“Do not always consider risks”*

and may use transfusion as a;

*“Quick fix”,*

*“Easiest option”*

One respondent suggested;

*“Involve patient in decision process”*

and another wished to have;

*“Patient autonomy if incapacitated”.*

One person said;

*“In many cases I do not consider the medics discuss the possible risks with patients before prescribing blood or blood products to allow informed consent”*

Another stated that;

*“Such important life-saving decisions should only be made by those with the correct knowledge”*

### **c) Financial implications for donor blood**

These were a source of concern to some respondents, with 46% rating cost as important (see Figure 4.7) and were often intertwined with finance in general for the NHS. Thirty eight respondents thought that cost was immaterial and inevitable. Transfusion was;

*“Essential regardless of cost”*

and that;

*“Finance should always be available”*

Consideration of;

*“Cost versus benefit”*

was important as was a;

*“Balance between advantages of transfusion over alternatives if available”*

and should;

*“Reflect the seriousness of the illness”*

However the;

*“Blood service should not charge hospitals”*

although;

*“Little information about costs or availability is generally advertised to the public”*

There were some conflicting opinions as to whether UK blood donors should be paid. If they were, it might attract more donors, but on the other hand some donors may only be interested in the money and therefore might not;

*“give truthful responses”.*

The impact of current national and world financial austerity measures were thought to potentially affect the blood service, with concerns raised about possible privatisation including;

*“Keep blood within the NHS”*

*“Intrinsic part of the NHS”*

and that;

*“It should be a ‘not for profit’ organisation”.*

Six respondents were worried that the blood service had been or was going to be;

*“sold off”*

due to NHS budget;

*“cost cutting”*

and there should never be;

*“Profit before patients”*

This one respondent stated;

*“We are lucky to have a service free at the point of use”*

and another that blood transfusion;

*“...should remain as one of the core elements of what the NHS offers its patients – it is literally life-saving, available to anyone who needs it”.*

#### ***d) Personal/family experience of blood transfusion***

Although there were only 14 responses comprising this theme, they were often voiced with emotion about how transfusion had affected people’s lives, either literally for survival or for improving their quality of life. The latter was particularly noticeable for cancer patients, especially those with haematological illnesses such as leukaemia and non-Hodgkin’s disease. Descriptions such as

*“Life-saving”*

and;

*“Blood is something we take for granted until we start losing it”*

were quoted.

Some respondents, whilst grateful to have received blood (although a few did not know if they had because no relevant records were found), were sad that they would be no longer eligible to donate their blood so could no longer be;  
*“Giving something back”.*

There were also reasons why people had not received blood or had restricted transfusion – some stated this was from personal or religious choice. One person said they could cope without and a second person accepted that it would take longer for them to recover. Some were transplant patients (the majority of these were kidney transplants) while others were awaiting transplants and aware that;

*“Future transplant may be compromised if received blood”.*

The final comment for this theme comes from a respondent who said;

*“I didn’t think it was possible to have one (a blood transfusion) if you didn’t need one”.*

#### **e) *Misunderstandings about donor blood***

Although anyone who is eligible can give blood in the UK, three respondents thought;

*“Donors came from a small strata (sic) of society”*

that they were all;

*“white middle class”*

and that there were;

*“not enough people from ethnic minorities”*

There was also some confusion about the movement of blood in and out of the UK. One respondent stated;

*"I understand that the majority of English (sic) blood goes to the EU".*

Another thought that;

*"The UK gets a lot of blood from other countries".*

Regarding the cost of blood, one respondent said;

*"It's free isn't it as the donors don't get paid?"*

The notion of receiving UK blood was also a concern, especially as regards infection. One respondent was;

*"I worry that the biggest risk is getting HIV/AIDS".*

To potentially avoid this risk, one person supposed that;

*"I can give my blood before an operation"*

On the subject of where UK blood is used one person indicated that;

*"It is used mostly for road accidents and surgery"*

whilst another inquired;

*"Is there less blood required nowadays?"*

One respondent questioned;

*"Is blood scarce?"*

But a second said they assumed;

*"...it will always be there when I need it".*

#### **f) Blood conservation**

There was awareness amongst respondents that there may not be enough donor blood available in the UK as the number of donors was decreasing. This awareness was thought to be because of the;

*“increase in the older population”*

*“more stringent donor selection”*

and;

*“increased demands”.*

There were also concerns about the scarcity of some blood groups including those rarer ones. One comment was;

*“Blood conservation should be made available during all operations if possible which would reduce the risk to the patient and also conserve blood for emergencies”*

Some respondents had had experience during operations of having their;  
*“blood recycled”*

Other alternatives to blood transfusion were mentioned such as;

*“tying off blood vessels during operation”*

*“fluid support and iron”*

Three respondents thought that transfusion should be considered only if it were;

*“necessary”*

or;

*“unavoidable”*

or as;

*“a last resort”.*

Queries were raised about whether pre-donation (giving one’s own blood before surgery) was performed and also whether;

*“artificial blood” or;*

*synthetic blood ”*

is available now or will be in the future. There was one query as to whether post-mortem blood donation was feasible.

In the quest for further information, it was suggested that a blood conservation page be added to the existing blood service website and that one respondent would;

*“spread the word”.*

Some would like to know more about blood conservation and others about the current technology for blood. However one stated that they would like to know more only if;

*“self or family needed blood”*

One asked whether blood was wasted and another wanted to know how much blood is used daily/monthly. One person stated they would;

*“look up further details”*

and a second;

*“would like to know the results of the survey”*

There are two comments which help to summarise this section;

*“I think blood transfusions are vital in some circumstances, but if there is an alternative which avoids some of the (low) risks then it seems the better option”*

and, finally;

*“Blood should be used wisely”.*



## Chapter 5 – Discussion

The aims of this anonymised survey were to determine what people who live/work/study in the Exeter area already know, and what their perception is, about blood: transfusion and conservation. Participants were asked about any involvement they might already have in the blood transfusion process, whether as a recipient (or know someone who has received blood) and/or as a donor. They would be invited to express any concerns they may have regarding blood in the UK – supply, demand and safety. If there were more information on different blood conservation alternatives such as recycling one's own blood during surgery were available, would they be interested and, if so, how would they prefer to access that information and would they discuss this with their family and friends. It was anticipated that participation by the public in this study would raise awareness of the UK's potentially vulnerable blood supply amongst those who responded. The respondents' answers could help provide useful material for public information thereby contributing to the debate about informed consent (and hence individual empowerment) for patient blood management. Therefore, the overall aims were threefold: firstly, to determine what knowledge and perceptions of blood (both transfusion and conservation) exist already in the Exeter area; secondly, to ascertain what information is required to help and improve these and thirdly, in the future, to help provide suitable educational material to enable every patient to make an informed choice about their own individual blood management.

Twenty four per cent of the invited participants responded to the Phase II questionnaire. Whilst this rate is an acceptable response rate according to SurveyMonkey®, utilised by this survey, it is lower than other online surveys (Barruch and Holtam, 2008). The possible reasons for this are manifold. It may simply be 'survey fatigue' due to receiving too many email communications inviting replies or that the recipients were not interested in the particular topic to respond. In addition, no incentives to respond were offered, apart from information in the Phase II questionnaire (Appendix 3) that; "Your help for this important study is much appreciated and your views will help us to study awareness of blood conservation which will in turn contribute to how we can

involve our patients more in their treatment". These participants had not only volunteered to be listed on a health research panel, but had also consented to be contacted for surveys. Therefore, perhaps it could be assumed that these participants each possessed, like blood donors, an altruistic tendency to help others. Although this is just one example, Cobanoglu and Cobanoglu (2003) examined the effect of incentives on survey response rates and in their randomised study the control group (offered no incentives) produced a response rate of 23.9%, which compares well with the response rate for this present study.

The highest percentage of respondents (36%) was in the 65-74 age range. Analysis of the replies revealed six principal themes relating to blood transfusion and conservation. These themes ranged from the blood donation procedure itself, how safe is donor blood, the economic factors involved in blood transfusion and personal/family involvement in the process, through to misunderstandings about donor blood together with blood conservation itself.

Further inspection of the responses for these six themes has revealed some thought-provoking data, not previously demonstrated in other research. Examining the first theme - the blood donation procedure itself – found that 17% of participants stated that they gave blood whilst 19% had been recipients. The beginning of the blood transfusion journey starts, and depends on, willing donors who are altruistically committed to give their blood to help others. However, qualitative analysis of the responses revealed regular (and potential) blood donors' dissatisfaction with NHSBT (the 'blood service') regarding accessing venues, the perceived inefficient appointments system and the need for more 'drop in' sessions. Whilst acknowledging that for blood donation, as indeed for recipients, one size does not fit all, and it may benefit NHSBT to review their organisational processes in the light of these responses, not all of which were negative. It is recognised, though, that NHSBT does have to process over two million blood donations a year and that it has an immense task not only to attract blood donors but also crucially to retain them. The fact that 71% of the participants in the survey thought that there was not enough blood available demonstrates awareness of this problem.

Regarding the second theme of safety - i.e. being a recipient of donor blood. although 17% of participants had concerns about the safety of blood transfusion (mainly relating to infection and provenance), the majority did perceive the risk of either getting an infection from donor blood or receiving the wrong blood as low at 74% and 77% respectively. In addition, only 4% of those who responded were worried that they may receive an avoidable blood transfusion.

Thirdly, the economic implications of donor blood were considered important by 46% of participants, with concerns about the impact on the NHS and whether privatisation of NHSBT might happen. Fourthly, the often emotional responses regarding personal/family experience of blood transfusion demonstrated how this had affected people's lives. When specifically asked about blood and its conservation, 61% were very likely or likely to discuss with their family and friends. Misunderstandings about donor blood encompassed the fifth theme, however 52% of participants stated that they would like to know more about blood conservation, with another 60% for alternatives to blood transfusion. For the final theme of blood conservation there was some awareness of the population's demographic change with older people living longer and therefore the need to conserve blood and use alternatives.

The most popular format for receiving such material was electronic such as a dedicated website, by 55%. The highest proportion of all the quantitative responses was from the 65-74 years age group. It is not known if this reflects the representation of this group as a whole on the two databases which were used for the survey due to reasons of anonymity. The free text comments demonstrated that both regular and potential donors had problems accessing the sessions either due to the problematic appointments system or the venues themselves, or a combination of both. Some positive ideas to improve the current situation were offered, although they were not in fact invited in the survey. In particular, suggested ways of raising awareness of blood donation may well be helpful for blood donation publicity. Also of significance were the high number of concerns about the safety of blood, particularly related to sourcing and testing. The UK's Department of Health Service Circulars 'Better Blood Transfusion 1, 2 and 3 (1998, 2002, 2007 respectively) have been

instrumental in providing information and guidance on blood transfusion. It must be remembered, however, that the biggest risk of blood transfusion in the UK is receiving the wrong blood rather than acquiring infection as McClelland and Contreras (2005) and the annual SHOT reports both testify.

The results from this study into public knowledge and perception of blood have demonstrated that those targeted for the survey made the effort to respond, not only to the quantitative questions but also by means of the free text boxes provided in the questionnaire. Both categories of response showed that there is awareness, at least in this particular population, of the problems associated with donor blood, and how these problems might be addressed. This was altogether very helpful as, by the very nature of the targeted groups, these were obviously people interested in research, engaged in the process and, on occasions, active in suggesting improvements. The large number of sometimes emotional and often irate comments such as;

*“Make donation easier for donors”*

particularly with regard to the blood donation process were, as previously mentioned, somewhat unexpected, for example;

*“Far more time needs to be employed persuading people this is a voluntary process but needs to be entirely focussed on the giver and the giver’s convenience”.*

On a positive note, however, over half of those questioned would like to know more about how blood can be saved for those who really need it, what alternatives to blood transfusion are currently available, and that they would share this information with family and friends. No evidence of past research on sharing such information could be found – there was solely generic guidance on sharing personal medical information with others. This may bode well for future research, especially to assist work on information on these topics, both at local and national levels. Even more importantly, this knowledge would empower each and every person, if they wished, to make their personal decisions about their own individual blood management.

### How outcomes relate to existing literature

Until now, to the best of the primary researcher's knowledge, there has been no published work exploring such a wide spectrum of topics around blood transfusion and blood conservation involving such a large cohort as this study has demonstrated. This is also one of the few studies conducted away from the clinical arena, with all its accompanying stresses and distractions. The study from Farrell (2001) did, however target 254 students, who were blood donors or non-blood donors, but not as patients. There have also been reviews by Ngo *et al.* (2013) and Davis *et.al.* (2011) but there are no other prospective studies.

This research expands, and enhances, previous work from Thompson (2013) and Fahey (2014) about the concerns people have about blood transfusion, the risks they are prepared to take, the challenges they will have, together with the need for more information and subsequently future empowerment for their own patient blood management.

### How outcomes provide new information

This 'Exeter experience' study generated many positive reactions from those questioned in the survey, with a high awareness of the UK's fragile blood supply but also that, for the majority, the benefits of receiving a blood transfusion are perceived to outweigh the risks. It is sensible that these risks have been both acknowledged and qualified and also that many people wanted to know more about blood transfusion and conservation. What was unexpected, however, was the large number of comments, often strongly worded, directed at the blood donation process itself. Particular concerns for blood donors were the problems obtaining an appointment, long queues at the session and being rejected as a donor. There was also reference to inability to spare the time due to work, family and other commitments. Blood donation needs investment of time – volunteering, altruism, social awareness, a desire for public service. Many do try to make the effort to give blood but are often thwarted. How the blood service addresses all these problems without compromising what is currently a very

safe source of blood will be a challenge. In their defence, a personalised online booking facility has been developed on their website ([www.blood.co.uk](http://www.blood.co.uk)) but there appears to be more issues to address.

Academic institutions are now increasingly recognising the importance of involving the public. The University of Exeter Research Development News team stated in their July 2014 email communication that “Public engagement with your research is of increasing importance” (p.1). A variety of workshops, e.g. ‘Doing it in Public!’ (May 2014) and courses are available on how to engage with the public to involve and share academic research to benefit all.

### Limitations of study

It is recognised that this study does have a number of limitations. Firstly, the target groups consisted of people based solely in the Exeter area who therefore might not be representative of the UK as a whole for age, ethnicity and language. Secondly, they will have been ‘self-selected, by virtue of agreeing to join the research database memberships and also by agreeing to be contacted for this study.. It would be interesting to explore whether, given information on blood conservation and alternatives, the generic Common Sense Model derived by Leventhal (*vide supra* p.23) would apply to this study population. This model could help form the basis to empower each and every patient to determine their personal blood management.

Thirdly there was also the possibility that some people belong to more than one targeted database group and might well have answered the survey twice, although no respondent stated that they had done so. Because the survey was anonymised there is no way of finding out if this were true. In addition to the above trio, it should be stressed that only those who had email access were targeted. The original plan for the study was to include those who did not have electronic communication by sending them paper questionnaires. Unfortunately there was no funding available for printing and postage.

However, the above limitations, or weaknesses, of the study may be counter-balanced by its strengths. Firstly the research targeted a sample of the public

who were not in a clinical or blood donor situation at the time of the survey. In addition, even though these respondents were 'self-selected', because of their interest in research, they may have in fact been more motivated to respond than those in the general population. Finally, it is acknowledged that the use of an electronic method for a survey will by its very nature limit the study population to those with access to and possess skills for computers and the internet. It may be argued, however, that for convenience, speed and low cost compared with paper/postage or face-to face interviews that the responses obtained anonymously and confidentially were not affected by additional effort on the part of the respondent and no concerns about having to provide answers that they perceived the interviewer would expect to hear.

#### Gaps/misunderstandings in respondents' knowledge

Those who responded to this survey are not as far as known, blood conservationists, although several stated that they were clinical or laboratory staff. It was therefore perhaps inevitable that some factual errors and actual myths were recorded in the survey. One person was worried;

*"that we will run out of good blood"*

and another asked;

*"is blood scarce?"*

If nothing else, this study may have helped focus minds on how and why our UK blood supply is so delicately balanced. As one respondent indicated;

*"I realise that there is a shortage of donors so maybe I ought to consider offering. I really do value all the support I have had from the NHS...so maybe ought to give something back".*

#### Coincidental timing for Phase II survey

The timing of the main survey in Phase II coincided with the UK's National Blood Week's 'Missing Type' campaign commencing 6<sup>th</sup> June 2015 and culminating in World Blood Donor Day on the 14<sup>th</sup> June 2015. It is possible that these events helped to extend the volume of responses for this survey. In this clever (and subsequently very successful) campaign to highlight the need for new donors, NHSBT asked 'brands, organisations and influencers' (such as NHS Trusts, Trinity Mirror and Metro, O2, Waterstones, Odeon, BBC, Not On The High Street, Green & Blacks, Nando's, Downing Street, British Gas, Red Driving School, Santander and Game) for their help. This involved removing the letters A, O and B (the letters that comprise the main blood groups) from public view on shops, advertisement hoardings, newspapers and social media such as Twitter and Facebook. The key message was;

"You won't miss it when you give it; but patients could miss it if you don't. Do something amazing and save or improve up to three lives by giving blood".

This campaign had a successful outcome, with 30,000 people subsequently registering to give blood. Last year (2015) NHSBT stated that there has been a 40% decrease in donors over the past ten years. It estimates that 240,000 new donors a year must be recruited in order to maintain the current blood stocks at a safe level. How it will address this shortfall remains to be seen, although campaigns such as the one described above have helped to improve registration on the donor panel.

### Potential implications of the results

Given the numerous comments from the respondents about the blood donation process, it would be beneficial to discuss these findings with NHSBT, although awareness that some of the matters suggested by the respondents (e.g. online booking for appointments) are already in place. It must be an unenviable task for NHSBT to try to 'please all of the people all of the time', whilst managing a



variable, sometimes unpredictable, complex and time-limited commodity such as blood. One respondent commented that;

*“blood is not respected enough”*

This is a powerful statement and, until that perception is disseminated further afield to the wider population, there will always be challenges for those who give blood, those who receive it and all those who have to coordinate the differing stages of the transfusion process. It is encouraging that not all comments were adverse - two of the more positive remarks were;

*“A thought provoking and interesting survey”* and;

*“Your work is very necessary. Keep up the good work”.*

Suggestions for improvement by the respondents to this survey have obviously been very welcome. Perhaps the most common of these can be summarised in the need to bring blood donation to the people by involving them much more, particularly as they are donors on whom the blood supply depends. One initiative by the Swedish blood service involves blood donors being notified by text when their blood has been used to help others and this has recently (2016) been adopted by NHSBT. This initiative might help to make the blood donors feel more valued - a common complaint in the present survey. The donors never meet the patients who benefit from their blood, but it serves as a reminder that hospitals rely on blood donors and by the forwarding of these texts to others and sharing on social media will encourage non-donors to come forward to give blood. Whilst it is appreciated that not everyone has access by these means, there could also be other ways of disseminating information, such as having local enthusiasts in communities who could provide information in other ways. These could be, for example by talks at local group meetings. It must not be forgotten though that blood conservation (including the use of alternatives to donor blood) must also play a major part in the whole process as without which our precious blood stocks cannot survive. The fact that over half of the respondents were interested in alternatives to blood and would like to know more (and share with friends and family) were encouraging. If society could

reduce our reliance on donated blood, improve recovery times and save the NHS money then blood conservation with careful and individual patient blood management must be the way forward.

### Personal reflections

My own experience, albeit 35 years ago, as a medical officer at blood donation sessions was generally a positive one. The sessions were often crowded and busy but with an overall feeling of good will and being part of a wider contribution to help humankind. People often knew each other as the sessions were often set in village halls or workplaces, giving it an air of a social event, which in fact it was. More recently, three years ago, when taking medical students to a donor session, I was aware that a similar atmosphere prevailed. It was evident, however, that each individual donor took longer to 'process', due to the rigorous screening procedures. These procedures have become inevitably more complex due to increasing knowledge of transfusion transmitted diseases, change in lifestyles and other screening criteria, all of which help to make UK donor blood as safe as possible. Although the blood service team was welcoming and efficient, there was much more of an atmosphere of people being manoeuvred through a tight time schedule. There was little social interaction between the donors themselves, with the consequent decrease in a community atmosphere to the setting. This is a pity for a situation based on social awareness and the opportunity to help others and which may well deter potential donors in the future.

### Further research

Equipped with the information from this study, there may be the opportunity to work with the RD&E NHSFT locally and the NHSBT Patient Involvement Working Group nationally to support further research into how we could improve information and communication to people anywhere on the path from donor to

recipient. This would be by providing educational resources in differing formats to help everyone make an informed choice for their own blood management. Even if none of these strategies come to fruition it is hoped that at least by raising local awareness of blood transfusion and conservation that some of those involved will remember, share and be prepared to challenge where necessary how blood management affects them and their families. It is important to remember that we are all patients at some time in our lives. The potential impact of this study would be to empower patients for their own blood management, both on a local and national level. It is hoped that it will leave a legacy for the continued blood conservation journey from clinical practice into the public arena - and back again. As one respondent stated;

*“It would be useful to be better informed”.*

## Chapter 6 – Conclusion

This study has demonstrated for the first time shown that there is a high public awareness of the UK's potentially vulnerable blood supply. There were no major concerns about the safety of blood or the receiving of the wrong transfusion, nor the risk of infection. There were some misconceptions about donation of blood and its use. The majority of respondents to the survey were aware that blood transfusion carries risks but that they were largely unconcerned about this aspect, whilst acknowledging the benefits. The issue of financial cost of blood transfusion was considered important, despite the observation that respondents were unconcerned if they were given an avoidable transfusion. A novel finding was the unexpectedly high proportion of comments relating to the blood donation process. There were suggestions for improvement, relating to the blood donation process that may be potentially beneficial to the NHSBT Blood Service. A critical and key finding was the need to improve the blood donor experience generally, to attract more (especially younger) donors and to retain them for the future. Positive interest in blood conservation (including alternatives to transfusion), together with a need to know more about it and share these facts with others, should provide a useful basis for future public engagement and information. This material in turn could help to guide and enhance patient empowerment for individual blood management in the years to come.

Awareness of the challenges for blood transfusion and conservation have been raised, prompting some to find out more information and perhaps even give blood. However, the sentiments expressed below by one may encapsulate the opinions of many;

*“I imagine the public perceptions are probably ill-informed and unreasonably complacent for something that can affect us all in the most profound way at times of greatest need”*

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## Appendices

### Appendix 1: Phase I Pilot - Background questions for respondents

Thank you for volunteering to take part in this pilot exercise.

Please may I ask you the following questions?

1. How long did it take you to complete?
2. Were the instructions clear?
3. Were any of the questions unclear? If so, will you say which and why?
4. Were any of the questions ambiguous? If so, will you say which and why?
5. Did you object to answering any of the questions?
6. In your opinion, has any major topic been omitted?
7. Was the layout of the questionnaire user-friendly?
8. Do you have any further comments please?

*(Adapted from 'Doing Your Research Project', J Bell, 5<sup>th</sup> Edition, OUP 2010)*

Your comments will help guide construction and content of future questionnaires for this study – many thanks.

Biddy Ridler, Exeter, 20.1.14

Appendix 2: Phase I Pilot questionnaire



Royal Devon and Exeter  
NHS Foundation Trust



At the Royal Devon & Exeter NHS Foundation Trust we are constantly looking to improve the service we provide to our patients and visitors. To help us to achieve this we would like to invite you to fill in this short questionnaire.

It is important to involve our patients as much as possible in their medical treatment so that they have sufficient background information to help them decide what they would like to help them. This process, known as informed consent, also applies to any treatment which may involve a blood transfusion.

We would like to find out what people know, or would like to know, about blood – whether it be the transfusion itself, supply from donors, benefits and risks, how blood can be conserved for those patients who really need it and what alternatives to transfusion are currently available. We would welcome your views on all of these areas.

Participation is voluntary and your decision to not take part will in no way affect your care or relationship with staff at the RD&E now or in the future.

All information you provide is anonymous and will be held in the strictest of confidence. The results will be analysed by the RD&E and with your help we would hope to put together information which will be useful for the future.

The closing date of the survey is 16 May 2014.

### **Blood Transfusions**

1. Have you ever received a blood transfusion in the UK?  
Yes/No
2. Do you know anyone who has received a blood transfusion in the UK?  
Yes/No
3. Do you have concerns about blood transfusion in the UK?  
Yes/No.  
If Yes, please let us know what they are. [TEXT BOX]

### **Your views about blood**

What do you think about the following in relation to blood in the UK?

4. The availability of blood:  
There's not enough/There is enough/There's too much/I don't know
5. The risk of receiving the wrong blood during a transfusion:  
High risk/Moderate risk/Low risk/I don't know
6. The risk of getting an infection from a blood transfusion:  
High risk/Moderate risk/Low risk/I don't know
7. What do you think are the benefits to patients of receiving blood? Please say below [TEXT BOX]
8. Thinking about the questions above, please let us know if you have any other comments you would like to make. Please use the box below. [TEXT BOX]
9. Do you give blood?  
  
Yes/No/I'd rather not to say.  
  
If No, and you feel able to do so, please let us know why [TEXT BOX]

## Appendix 2: Phase I Pilot questionnaire continued

10. Do you have any other comments you would like to make or questions you would ask about blood in the UK? [TEXT BOX]

11. If information was available on how blood can be saved for those who need it, is this something that you think would be of interest to people?

Yes/No/I don't know

### **About You**

Please answer the following about yourself

12. What is your gender?

Male/Female/Prefer not to say

13. What is your age group?

- 17 and under
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74/75 and over
- Prefer not to say

Thank you for taking the time to complete our survey. Your help for this important study is much appreciated and your views will help us to study awareness of blood conservation which will in turn contribute to how we can involve our patients more in their treatment.

(END)



Appendix 3: Phase II - Main survey covering letter



Royal Devon and Exeter   
NHS Foundation Trust

Dear

Here at the Royal Devon & Exeter Hospital we always try to improve our services for patients and visitors. To help us would you consider this short survey? It should take about 10 minutes to complete.

We want to involve patients more in their treatment, so that they have sufficient information to help decide what would be best. This “informed consent” includes blood transfusion.

We would like to find out what people know about blood – the transfusion itself, supply from donors, benefits and risks, how blood can be conserved for those who really need it and what alternatives there are. We really welcome your views. We ran a small pilot of this survey in 2014. If you helped back then, thank you and please complete our main survey.

Participation is voluntary and your decision to not take part will in no way affect your care or relationship with the RD&E now or in the future. All information is anonymous and held in strict confidence. The results will be analysed by the RD&E.

[Please click here to access the survey.](#)

The closing date of the survey is 1 July 2015.

Thank you for your help.

Dr Bidy Ridler

[Rde-tr.foundationtrust@nhs.net](mailto:Rde-tr.foundationtrust@nhs.net)

Appendix 4: Phase II Main questionnaire



Royal Devon and Exeter  
NHS Foundation Trust



Here at the Royal Devon & Exeter Hospital we always try to improve our services for patients and visitors. To help us would you consider this short survey? It should take about 10 minutes to complete.

We want to involve patients more in their treatment, so that they have sufficient information to help decide what would be best. This “informed consent” includes blood transfusion.

We would like to find out what people know about blood – the transfusion itself, supply from donors, benefits and risks, how blood can be conserved for those who really need it and what alternatives there are. We really welcome your views.

We ran a small pilot of this survey in 2014. If you helped back then, thank you and please complete our main survey.

Participation is voluntary and your decision to not take part will in no way affect your care or relationship with the RD&E now or in the future.

All information is anonymous and held in strict confidence. The results will be analysed by the RD&E.

The closing date of the survey is 1 July 2015.

Thank you for your help.

## Appendix 4: Phase II Main questionnaire continued

### **Blood Transfusions**

1. Have you ever received a blood transfusion in the UK? Yes/No
2. Do you know anyone who has received a blood transfusion in the UK?  
Yes/No
3. Do you have concerns about blood transfusion in the UK? Yes/No.  
If Yes, please let us know what they are. [TEXT BOX]

### **Your views about blood**

What do you think about the following in relation to blood in the UK?

4. The availability of blood for transfusions:  
There's not enough/There is enough/There's too much/I don't know
5. The risk of receiving the wrong blood during a transfusion:  
High risk/Moderate risk/Low risk/I don't know
6. The risk of getting an infection from a blood transfusion:  
High risk/Moderate risk/Low risk/I don't know
7. The benefit of receiving a blood transfusion:  
High benefit/Moderate benefit/Low benefit/I Don't know
8. The financial cost to the NHS of the blood transfusion process:  
It's Important/ It's Moderately important/ It's Not important/ I don't know
9. Thinking about the questions above, please let us know if you have any other comments you would like to make. Please use the box below.  
[TEXT BOX]

### **Giving and receiving blood**

10. Do you worry that you might be given a blood transfusion that could be avoided?  
Yes/No/I don't know
11. Do you give blood?  
Yes/No/I'd rather not to say.  
If No, and you feel able to do so, please let us know why  
[TEXT BOX]

## Appendix 4: Phase II Main questionnaire continued

### **Information about blood**

If the information was available, would you like to know more about:

12. How blood can be conserved for those who really need it?  
Yes/No/I don't know
13. Alternatives to blood transfusion, such as recycling blood at operations?  
Yes/No/I don't know
14. If Yes to Q12 and/or Q13, how would you like to receive the information (you can tick more than one):
- Paper – such as an information leaflet
  - Electronic – such as a dedicated website
  - Video
  - Face to face presentation – such as to an interest group or to your community
  - I'm not sure
15. If you did receive more information, how likely would you be to talk with your family and friends about blood and blood conservation?  
Very likely / likely / neither likely or unlikely / unlikely / very unlikely
16. Thinking about the survey as a whole, do you have any other comments you would like to make or questions you would ask about blood and blood conservation in the UK?

*[TEXT BOX]*

### **About You**

Please answer the following about yourself

- a) What is your gender?  
Male/Female/Prefer not to say
- b) What is your age group?
- 17 and under
  - 18-24
  - 25-34
  - 35-44
  - 45-54
  - 55-64
  - 65-74/75 and over
  - Prefer not to say

Appendix 4: Phase II Main questionnaire continued

Thank you for taking the time to complete our survey. Your help for this important study is much appreciated and your views will help us to study awareness of blood conservation which will in turn contribute to how patients can become more involved in their treatment.

Please click 'Done' to submit your answers.

(END)