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Patients’ and Healthcare Professionals’ Perceptions of Blood Transfusion

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Table of Contents

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Appendix 1: 288-297

List of Tables

List of Figures

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Declaration

This research has been carried out within the Health Services Research and Management Division at City, University of London (School of Health Sciences) under the supervision of Professor Jill Francis, Dr Fabiana Lorencatto and Dr Shashi Hirani.

I confirm that this thesis is my own work and publications and conference attendance associated with this research has been noted in the Dissemination section. All information derived from other sources has been indicated with the use of references throughout the thesis.

Brittannia Volkmer, 29.11.2019

Abstract

Background:

Blood transfusions are frequently provided to patients at risk of severe bleeding or on a repeated basis for patients with anaemia or blood disorders. The treatment perceptions literature indicates that perceptions influence how patients cope with their conditions and adhere to treatment. Healthcare professionals' (HCPs') perceptions are likely to influence shared decision-making and their practice. However, how patients and HCPs perceive blood transfusions, and how this may vary across patient groups, is unclear.

Objectives:

This research aimed to explore patients' and HCPs' perceptions of blood transfusion. Specific research questions were: 1) which perceptions of transfusion are reported by patients and HCPs in the literature? 2) to what extent do themes of patients' perceptions correspond with the broader treatment perceptions literature? 3) what are repeatedly-transfused haematology patients' and HCPs' perceptions of transfusion? 4) to what extent do HCPs recognise patients' reported perceptions in their practice and are practice changes to improve patients' experiences required?

Methods:

This was a mixed-methods programme of research involving three studies: Study 1: A systematic review of patients' and HCPs' perceptions of blood transfusion and development of a conceptual model of blood transfusion perceptions. This was followed by a theoretical mapping exercise to compare the model to existing treatment perceptions frameworks. Study 2: A semi-structured interview study with 14 haematology patients and 14 HCPs about their perceptions of blood transfusion. Study 3: A focus group (n=3) and questionnaire study of 19 HCPs' views of haematology patients' perceptions and their views about potential service improvement strategies, subsequently mapped to a behaviour change framework (Behaviour Change Wheel). HCPs' reported constraints and enablers to implementing these strategies were mapped to the Theoretical Domains Framework (TDF) of behaviour change.

Results:

Study 1: 41 papers reporting patients' and HCPs' perceptions were included in the systematic review (15 patient studies, 26 HCPs). Transfusion was perceived as carrying low to moderate risk, but risk perceptions and negative emotions were associated with the use and consideration of transfusion alternatives. The data were synthesised into six constructs to form a conceptual model: 'Safety/risk,' 'Negative emotions', 'Alternatives', 'Health benefits', 'Necessity' and 'Decision making'. Theoretical mapping confirmed these constructs as broadly consistent with constructs from existing treatment perceptions frameworks and models.

Study 2: Patients and HCPs reported views about the benefits of transfusion for haematology patients, yet some patients and HCPs reported concerns about the downsides of transfusion. ‘Organisational constraints’ were raised by HCPs about delivering transfusions in pressurised services and patients discussed the burden of receiving repeated transfusions.

Study 3: 17 service improvement strategies were proposed, corresponding to seven BCW functions: (e.g. ‘Service provision’ (home transfusion), ‘Environmental restructuring’ (remote blood screening)). Constraints/enablers mapped to the TDF: (e.g. ‘Skills’ (HCP communication skills training), ‘Environmental context and resources’ (funding, time)). Potential techniques to address constraints and enablers included providing ‘Information about health consequences’ to address the domain, ‘Beliefs about consequences’.

Conclusion:

This research provides a theoretical and empirical overview of blood transfusion perceptions, including themes shared by patients and HCPs and themes that were unique to one of these groups. There is scope to more greatly involve patients in their transfusions where, in haematology, repeated and lengthy transfusion appointments place burden on patients. The conceptual models provide direction for such consultations. Interventions to enhance haematology patients’ experiences and to remediate service pressures can be developed further.

List of Abbreviations

AIDS	Acquired immune deficiency syndrome
ATG	Anti-thymocyte globulin
BCT	Behaviour change technique
BCW	Behaviour change wheel
BMC	BioMed Central
BMQ	The Beliefs about Medicines Questionnaire
BOOST	Building Optimised Outpatient Services in Transfusion
BTNP	Blood Transfusion Nurse Practitioner
BTQ	The Beliefs about Transfusion Questionnaire
CAD	Coronary artery disease
CAMBI	The complementary and alternative medicine beliefs inventory
CLL	Chronic lymphocytic leukaemia
COM-B	Capability, Opportunity, Motivation – Behaviour (model)
CS-SRM	Common Sense Self-Regulation Model
EBCD	Experience based co-design
EPO	Erythropoietin
FFP	Fresh frozen plasma
GCSE	General Certificate of Secondary Education
GP	General practitioner
HAART	Highly active antiretroviral therapy
HCP	Health care professional
HIV	Human immunodeficiency virus
HPV	Human papillomavirus
ICU	Intensive Care Unit
ID	Identification
IPQ	Illness Perceptions Questionnaire
IPQ-R	Illness Perceptions Questionnaire-Revised
JPAC	Joint United Kingdom (UK) Blood Transfusion and Tissue Transplantation Services Professional Advisory Committee
MDS	Myelodysplastic syndromes
NHS	National Health Service (UK)
NICE	National Institute for Health and Care Excellence
NR	No response

PAD	Pre-operative autologous donation
PBMP	Patient Blood Management Practitioner
PIS	Participant information sheet
PSYPAG	Psychology Postgraduate Affairs Group
RTC	Regional Transfusion Committee
SD	Standard deviation
SHOT	Serious Hazards of Transfusion
TDF	The Theoretical Domains Framework
TP	Transfusion Practitioner
TRI	The Treatment Representations Inventory
UK	United Kingdom
US	United States
USA	United States of America

1 General introduction

This chapter outlines the rationale for this programme of research on patients' and healthcare professionals' (HCPs') perceptions of blood transfusion. It will describe the current context of patient-centred healthcare, introduce the context of blood transfusion and outline supporting theoretical models. This chapter also presents the overall objectives of this programme of research with a description of the conducted studies.

1.1 Patient-centred healthcare

Patients receiving healthcare in many countries prior the 1980's would have been exposed to a paternalistic model of healthcare. This model accepted the healthcare professional (HCP) as the responsible experienced authority of a patient's treatment and care, executing treatment decisions based on clinical knowledge and governed by professional codes of ethics (Charles et al., 1999). In recent years the health care context has shifted, such that, there has been a considerable rise in the number of medicines available and a shift in illnesses from being acute to being chronic, with multiple medicines being used to treat complex conditions (Charles et al., 1997). Limitations of the paternalistic approach were highlighted, in that the approach restricted patient involvement and patients sharing their treatment preferences, despite them having the lived experience of the illness or symptoms (McNichol, 2012). As HCPs needed to understand how treatments benefitted the patient, they began to work more closely with patients and caregivers, with it being important to consider the benefits of treatments for the patients weighed up by potential risks (Charles et al., 1999). HCPs began to elicit patients' treatment preferences and obtain more formal patient consent for taking proposed treatments, giving rise to the use of informed and shared models of treatment decision making (Charles et al., 1999).

A shared model of treatment decision-making provides patients with an opportunity to be more involved in their healthcare, by discussing proposed treatment options and raising their values, preferences, beliefs and illness knowledge (Charles et al., 1999). This approach encourages HCPs to involve patients as co-producers of health and autonomous partners in treating, managing and preventing disease (Coulter, 2011). ‘Patient-centred care’ embodies this position, with care delivery being responsive to patients’ physical, emotional and social needs, with interactions with HCPs needing to be informative, empathetic, empowering and supportive of patients’ values and preferences (Coulter, 2011; Mead et al., 2000).

Efforts to increase patient participation and the greater shift towards patient-centred care, moves patients towards becoming active consumers or users of their healthcare (McNichol, 2012), which is a major goal of health systems (The Health Foundation, 2014). Patient charters have often been set up by governments to protect patients’ rights and to stipulate their access entitlements and rights about being involved in decisions about their care (National Health Service, 2019). Many initiatives are in place to support patients in this role, such as standardised decision-making tools (Hrisos et al., 2013) and strengthening patient participation to encourage greater patient communication of their preferences, such as patient questioning of treatment options, their benefits and harms (Joseph-Williams et al., 2017; Stiggelbout et al., 2012).

Patient participation in treatment consultations has been found to be associated with greater patient understanding about their treatments, greater adherence, satisfaction with their doctor's behaviour and the visit and less treatment decision regret (Stevenson et al., 2004). In spite of this, patients often do not get the opportunity to share their beliefs, experiences and medicine preferences in consultations (Stevenson et al., 2004). This research found that HCPs tend to dominate treatment discussions (Stevenson et al., 2004) or alternatively some patients prefer to adopt a more passive role in the treatment decision-making, often as a way to cope (Swainston et al., 2012). Some patients with breast cancer have been identified as remaining passive to minimise the emotional impact of difficult decisional trade-offs (e.g., long-term survival vs. breast loss) (Lazarus et al., 1984b; Luce, 2005). There are barriers that HCPs recognise to implementing shared decision-making, in particular time constraints in clinical consultations, lack of applicability due to patient characteristics and the clinical situation (Légaré et al., 2008).

1.1.1 Frequently provided healthcare interventions

For treatments that are frequently prescribed, HCPs may fall into automatic prescribing patterns (Presseau et al., 2014). In the UK, 43% of men and 50% of women report to taking at least one prescribed medicine, such as cholesterol-lowering statins, high blood pressure medicines and painkillers (NatCen Social Research, 2015). As a large proportion of the population will be exposed to frequently prescribed treatments, often taken on a long-term basis. Thus, it is important for patients' perceptions of such treatments to be elicited and widely considered. This is because the treatment may be taken on a long-term basis and patients' beliefs may change over a period of time as their circumstances and experiences alter, with the repeat prescriptions not be reviewed. General public issues may fuel wider debate too, such as the need for patient involvement in choice to prevent treatment overuse (Malhotra et al., 2015).

A healthcare intervention that is frequently provided internationally is blood transfusion, which involves donor blood being transfused into another person. Blood transfusion has evolved into one of the most frequently administered healthcare interventions for all aged patients with a range of healthcare conditions (American National Red Cross, 2018a). In low- and middle-income countries transfusions are commonly used to manage pregnancy-related complications and for supportive care in cardiovascular or transplant surgery, massive trauma, and therapy for solid and haematological malignancies in high income countries (World Health Organization, 2017). Approximately 36,000 red blood cell units are transfused in the US daily (American National Red Cross, 2018a). In the UK for the year of 2000-2001, 1.7 million transfusions were estimated to be given, approximating at costs of £635 per red blood cell transfusion for each patient (Varney et al., 2003). Although some blood transfusion use has decreased, for example, for UK surgical use, transfusions related to hip and knee arthroplasty operations show increases in use (northern England, 1999-2009) (Tinegate et al., 2013).

Patients will receive transfusions for different reasons and at different frequencies. Some patients will receive emergency one-off transfusions (e.g. in a trauma situation) that they are often only made aware of afterwards and some patients will receive transfusions on a repeated routine basis. Patients who are conscious during the transfusion will be able to form perceptions of transfusion before, during and after transfusion. Patients with chronic diseases like myeloma or non-Hodgkin's lymphoma will often need transfusions during their treatment to manage cancer-related anaemia which reduces their red blood cells (45-90% of patients) (European Hematology Association, 2012). Transfusions are also used to treat inherited blood disorders such as thalassemia or sickle cell anaemia (NHS Choices, 2018). These factors hold the potential for patients to form different perceptions of transfusion for different contexts. Patients will ultimately have different experiences of receiving transfusions, which can impact on their healthcare experience, and extent of involvement in shared decision making. Thus, there is a need to explore patients' perceptions of blood transfusion further.

1.2 Blood transfusion – Historical overview

1.2.1 First transfusion use

Blood transfusion was first officially used in 1818 to treat gastric carcinoma (Jones, 2015). The processes were continuously improved with the discovery of international blood groups (O, A, B, AB) occurring in the early 1900s, as well as methods being found to overcome shortages in blood donors (Jones, 2015). This led to more regulated practices such as the American Red Cross beginning its National Blood Donor Service in 1941 to collect blood for the US military; and extending it in 1948 for civilians (American National Red Cross, 2018b). With donor blood being transfused extensively during wartime, supplies of blood were depleting and the first cell separator was created in 1951, allowing for whole blood to be separated into its different components (i.e. plasma, platelets, red blood cells), with the end products being called 'component therapy' (Jones, 2015). Hence, blood transfusions are distinguished by the components to be transfused, whereby patients may only need an element of the whole blood, making a single donation optimised for use by multiple recipients. For example, using the red blood cells to improve oxygen delivery to tissues, platelets to reduce, minimise or prevent bleeding, or plasma for blood-clotting (Arya et al., 2011; JPAC, 2018).

1.2.2 Transfusion-associated infections

Medical institutions and the public have always been increasingly reliant on blood transfusions, which provide blood depended upon in many areas of clinical practice, such as to reduce mortality from heavy bleeding or for planned surgical procedures. However, from the 1960s serious issues arose that threatened the safety of widely used blood supplies, and a shift occurred that caused perceptions of blood transfusion safety to alter. Hepatitis C was found to be contractible through blood transfusion, having a 10% transmission risk in the 1970s (Koerner et al., 1998). Alongside this, widespread public fears arose in the 1980s about the risk of AIDS being transferrable through blood transfusions and donor restrictions were put into place. Restrictions on donors were mainly targeted at homosexual or bisexual men with multiple partners and blood banks stopped recruiting from AIDS high risk groups (Perkins et al., 2010). In 1984, public confidence in the blood banks was reportedly lost and investigations were reported by the Centre for Diseases Controls, providing evidence that AIDS may be transmitted by blood (Curran et al., 1984). By 1987 estimated figures by Peterman et al., (1987) reported that nearly 29,000 US transfusion recipients were infected with HIV, with 12,000 still alive and at risk of developing AIDS (cited in (Perkins et al., 2010)). These transmissions and associated mortalities occurred at a time where AIDS was feared in society fuelled by high profile media coverage of prominent celebrities dying of AIDS and widespread discrimination of HIV/AIDS suffers (HIV.gov, 2018; Wellings, 1988).

1.2.3 Tainted blood scandals

The initial discovery of transfusion-associated infections was followed by highly publicised global tainted blood scandals, which abetted the negative shift in societal perceptions of blood transfusion. Public trust in the safety of blood was weakened as reports were published of the scale of HIV infected blood use in haemophilia treatments. By the 1980s over 4,500 people with haemophilia and bleeding disorders were infected with HIV, hepatitis B and C, and a range of other blood-borne viruses in the UK (The Haemophilia Society, 2017a). Over 2,000 people have subsequently died in the UK and a full public inquiry in the UK is ongoing (The Haemophilia Society, 2017b). Victims of transfusion-induced HIV infections report undergoing personal trauma, for instance through having to deal with their HIV infection on top of the initial (often life-threatening illnesses), mitigating the need for a transfusion in the first place (Gallo-Silver, 1993).

It is unclear how patients currently receiving blood transfusions perceived this crisis, and if this impacts on their perceptions of receiving blood. Patients facing the prospect of receiving transfusions may be confronted with difficult choices, due to transfusion being life-saving or assisting them to improve their health, whilst evoking concern because transfusions are not risk free. In the general public, there is some evidence that the intense media coverage of the tainted blood issues influenced perceptions of transfusion acceptance and its association with HIV and AIDS (Finucane et al., 2000). Although the last confirmed HIV (transfusion) transmission case was reported in 2009 (UK) (Murphy et al., 2013b), societal concern about blood safety was at one time elevated, with Watkins et al., (2012) suggesting that this is primarily because of 'historical problems relating to viral transmission via the blood supply' (Watkins et al., 2012).

In spite of this, there is also some public understanding across many European countries, that transfusions are safer than, for example, 10 years ago, especially viewed so by younger respondents (aged 15-24) (European Commission, 2010). This wide-reaching survey is informative, however, included many younger respondents, who may not be typical transfusion patients, i.e., not experiencing older aged related disorders. There are also undiscovered and emergent risks associated with transfusion, such as Creutzfeldt-Jakob Disease (Llewelyn et al., 2004) or severe risks that are perhaps less well known to the general public, for instance the risk of suffering an adverse reaction to the transfusion or the transfusion causing lung injury (Eder et al., 2013). Therefore, while blood transfusions are widely used, investigating patients' perceptions of transfusion is important to identify if patients hold concerns. A patient's 'public' beliefs will be modified and 'heightened' into a real-life scenario once becoming a patient (Leventhal et al., 1980) and negative media portrayals are likely to fuel these perceptions (Finucane et al., 2000).

1.3 Healthcare professionals' perceptions of blood transfusion

1.3.1 Appropriate use of blood transfusions

In addition to patients' beliefs, healthcare professionals' (HCPs') perceptions of blood transfusions are equally important to consider as they will ultimately be making the clinical decisions about prescribing transfusions to their patients. Although blood transfusions are used widely under improved regulation (Epstein, 2010 cited in (Watkins et al., 2012)) and clinical guidelines, they are often overused by HCPs. In the UK it is estimated that 20% of transfusions are prescribed outside of clinical guideline recommendations (Estcourt, 2010; Stanworth et al., 2011). Along with other clinical interventions, such as antibiotics and cardiac stents, blood transfusions are cited as one of the most overused treatments by The American Medical Association (Goodnough, 2013; Sadana et al., 2018).

Despite transfusion guidance being available to inform HCPs about when blood should be transfused (Joint United Kingdom Blood Transfusion and Tissue Transplantation Services Professional Advisory Committee (JPAC), 2019) there is evidence that blood transfusions are overused in a range of clinical contexts (NHS Blood and Transplant, 2019). This can have serious health implications for patients, such as through experiencing an adverse reaction to the transfusion (Murphy et al., 2013b). Clinical trials have shown that more restrictive transfusion practices are equivalent or better than liberal practices (Goodnough et al., 2013). The advantages of this are that restrictive practices may reduce patient exposure to the aforementioned risks and also other adverse events, such as transfusion related acute lung-injury or acute transfusion reactions, which may not be preventable (Goodnough et al., 2013;

Serious Hazards of Transfusion (SHOT), 2017). It is thus important to understand how HCPs perceive transfusion and how this impacts their practice, potentially driving overuse and misuse. A greater understanding of HCPs' perceptions can also help form the basis of interventions to target transfusion overuse and misuse and guide quality improvement initiatives.

1.3.2 Transfusion alternatives

Patient Blood Management is an evidence-based multidisciplinary, multimodal and individualised approach to optimise the care of patients who might need blood transfusion (Carson et al., 2016). Initiatives such as these exist to ensure that donated blood is conserved and that patients only receive transfusions when deemed necessary and that all alternatives to transfusion have been considered (Goodnough et al., 2012). Blood sparing alternatives are methods such as intraoperative cell salvage and pre-operative autologous donation (PAD) procedures, in which patients receive their own blood post-surgery rather than allogeneic (donor) blood. Prescribing patients with intravenous iron is another method to spare allogeneic blood, which has been found to reduce surgical patients' hospital stays, enhance the restoration of iron stores and improve patients' Hb (haemoglobin) blood levels four weeks after surgery (Froessler et al., 2016). It is important to understand how HCPs perceive these transfusion alternatives, for example as effective in particular situations or less readily available or convenient, all of which may contribute to transfusion overuse.

1.3.3 Patients' and HCP' transfusion perceptions

Blood transfusion clinical guidelines often stipulate that patients should be informed about available alternatives to transfusion and/or allogeneic blood transfusion, as appropriate and have the opportunity to discuss such alternatives with HCPs, alongside discussing the risks and benefits of transfusion (SaBTO, 2011). Transfusions may also be prescribed to unconscious patients, requiring the HCP(s) to make the initial decision, and then gain retrospective consent from the patients or family members (SaBTO, 2011). HCPs' perceptions may, however, be divergent from their patients' as they do not experience the illness themselves (Eccles et al., 2005). It would be important to investigate how divergent patients' and HCPs' perceptions are, as perceptions are likely to be exchanged during the clinical encounter. Patients and HCPs may also hold specific perceptions of transfusion of different blood components (e.g. platelets or red blood cells). This would raise insight into the nature and variability of perceptions of blood transfusion from key informants; patients and HCPs.

Differences in treatment perceptions of patients and HCPs have been reported in other disease areas, such as for research on the kidney disease trajectory with elderly patients and their nephrologists (Schell et al., 2012). In this study, most patients focussed on the present instead of responding to challenges and the uncertainties with their dialysis therapy (Schell et al., 2012). Nephrologists tended to avoid uncertainty and instead applied a sense of urgency to educate and prepare patients to begin treatment, with a tendency to focus on communicating with patients using lab data (Schell et al., 2012). Similar findings may be evident for transfusions, which are required to be delivered in emergency scenarios. Patients may similarly focus on their present need for the transfusion and require support post-transfusion to deal with concerns that may arise, especially if transfusions need to be provided on a repeated basis.

Understanding patients' and HCPs' perceptions of blood transfusion would profile how both groups consider transfusion as a healthcare intervention. 'Perceptions' can be understood as thoughts, views, beliefs, opinions or representations, which are commonly considered as a cognitive component of illness representations. For example, how a treatment may be used to control a health threatening situation (e.g. 'my treatment will help to control my symptoms') (Leventhal et al., 1980). Exploring patients' and HCPs' perceptions of blood transfusion can be facilitated by health psychology theory and models of treatment perceptions, with theory providing a systematic way to understand events or situations (Glanz et al., 2005) and theoretical models used to illustrate a theory's causal mechanisms. Blood transfusion is offered as a health care intervention when patients face health threats and, in turn, transfusion could also be perceived as a health threatening intervention itself (e.g. as a 'risky' treatment). Therefore, it is important to consider patients' and HCPs' perceptions of blood transfusion from a theoretical perspective.

1.4 Theoretical perspective

1.4.1 Perceptions of health threats

When people face health threatening situations (e.g. the onset of symptoms or an illness diagnosis) they will often take on an active problem solving role to reduce the health threat that they are exposed to (Leventhal et al., 1980; Leventhal et al., 1984). Leventhal's Common Sense Self-regulation Model

(CS-SRM) (Leventhal et al., 1980; Leventhal et al., 1984) (Figure 1) was developed to show that when a health threat is faced, such as symptoms or illness, people process cognitive and emotional representations of the threat in parallel. Representations are defined as individuals' common-sense definitions of the threat (Leventhal et al., 1980). When facing a health threat people will ask themselves questions such as 'What is this health threat?', 'What can I objectively do about it?', 'How do I feel about it?' and 'What can I do to make myself feel better about it?' (Hale et al., 2007). In the 'cognitive representations' box of Figure 1 five stable cognitive dimensions are commonly used to understand how individuals make sense of their illness: *identity* (threat label), *time-line* (i.e. duration, recovery time), *causes* (i.e. stress or injury), *control* (degree to which the illness can be prevented, cured and kept from progressing) and *consequences* (imagined and real) (Leventhal et al., 1998).

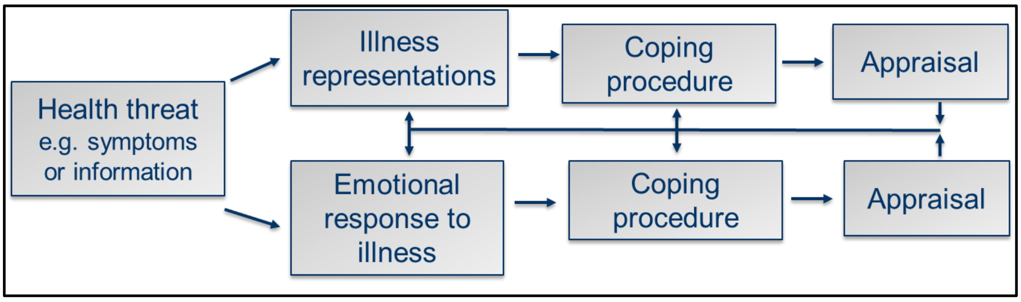


Figure 1 The common-sense self-regulation model (Leventhal et al., 1980), CS-SRM figure adapted from Horne (2003)

As described by the CS-SRM (Leventhal et al., 1980; Leventhal et al., 1984), emotional responses, which are processed in parallel to cognitive representations, are most commonly fear-related responses such as anxiety and worry (other emotions such as depression and anger may also occur) (Cameron, 2003). To manage perceived risks, individuals will develop coping procedures, which are the cognitive and behavioural actions that are taken (or not taken) to enhance health and prevent, treat (i.e. cure or control) and rehabilitate from illness (Leventhal et al., 1998). This could involve procedures such as increasing exercise to improve fitness, however, if the change is more ambiguous (e.g. when experiencing fatigue), taking rest may be the chosen coping course. Each coping procedure is shaped by the representation of the problem (Leventhal et al., 1998).

1.4.2 Perceptions influencing behaviour

Perceptions are widely known to influence health behaviours, such as patient adherence to medicine (Horne et al., 1999a). As transfusions are often provided on a one-off basis or prescribed and administered in the hospital context by HCPs, relevant behaviours in the blood transfusion context could include consenting to the transfusion (patients) or prescribing the transfusion (HCPs) etc. Accepting a blood transfusion for a patient with anaemia, for example, will be thought about in terms of the severity of the anaemia etc., such as '*will the transfusion help to resolve the anaemia?'*, and *'what are my feelings towards this?'*. Some patients may 'problem solve' by declining transfusions or wishing to pursue alternative options, having firstly considered the pros and cons. Patients who also consider their symptoms or illness and the health threat may still view transfusions cautiously and hesitate to accept them. As representations and coping procedures are linked, the procedure adopted will be evaluated and appraised for its success in helping to reduce the health threat and new updated perceptions of the threat will be formed. For instance, if the transfusion was accepted, and considered by the patient as an effective strategy to resolve the anaemia, the patient will form new perceptions of the initial threat, such as that anaemia is controllable. If no adverse effects are experienced, this coping strategy will be reinforced, and representations amended accordingly. In summary, how patients perceive and engage with treatments is essential for patients' broader health-related problem solving and illness recovery.

Coping procedures may be problem-focused and directed at altering and managing the problem causing distress, and / or additionally individuals may use emotional-focused coping to regulate their emotional responses, such as maintaining hope and optimism (Lazarus et al., 1984b). For coping to be effective, a good match or fit between coping efforts and patients' agendas, such as their values, beliefs and preferred coping styles must be met (Lazarus et al., 1984a). For instance, if a patient accepted a transfusion but reluctantly, they may be worried in the longer-term about their decision, or patients may face little choice but to accept the transfusion. Ultimately when patients face treatment choices, they will need to evaluate how efficacious the proposed treatment will be for their condition and weigh this up against potential risks or costs and perceived need (Horne, 2003). Obtaining a balanced perspective on these issues may assist patients in reaching an informed decision, feeling reassured about their condition and reducing elevated perceptions of their condition as a health threat.

1.4.3 Assessing patients' perceptions

Illness Perceptions Questionnaires were developed in response to growing interest to understand the nature of patients' illness-related coping and for developing interventions to facilitate self-management in chronic illness (Moss-Morris et al., 2002; Weinman et al., 1996). These measures were flexible for adaptation for specific patient groups or in relation to specific health threats or contexts but were structured around the five illness representations domains of the model (Leventhal et al., 1980). With the growing use of this measure, researchers sought to discover ways to develop measures more specifically addressing treatment perceptions and Horne, Weinman and Hankins (1999) developed a questionnaire to identify medicine perceptions called the Beliefs about Medicines Questionnaire (BMQ). The BMQ informs the health outcome of treatment adherence (Horne et al., 1999b) and assesses General medicine beliefs and medicine 'Specific' beliefs, which provided evidence for a Necessity-Concerns framework. This framework shows that higher adherence is associated with stronger perceptions of the 'necessity' of a specific treatment and fewer 'concerns' about the treatment (Horne et al., 2013).

The CS-SRM (Leventhal et al., 1980) is widely considered to understand the role of treatment beliefs within the illness representations domains, and how this may have an influence on behaviours, such as treatment adherence (Horne, 2003). This is particularly for patients making treatment decisions, with their perceptions of the treatment informing their illness representations and emotional responses, and subsequently coping outcomes, as shown in the extended treatment perceptions and CS-SRM model (Figure 2) (Horne, 2003). This extended model indicates that treatment perceptions will inform coping procedures, specifically treatment adherence. This occurs when individuals form cognitive and emotional representations of treatments, informing their illness representations, but treatment perceptions will influence adherence and non-adherence also via the selection of coping procedures (highlighted boxes and arrows). This model has received some empirical support for the acceptance or rejection of HIV treatment (Horne et al., 2001), with patient acceptance to HIV medicine regimens (HAART) influenced by patients' determination to be adherent and thus finding solutions to adherence problems (Vervoort et al., 2009). As supported by the Necessity-Concerns framework, studies have reported reasons that HAART was declined, for example, if patients were doubtful about their personal necessity for HAART, had concerns about the adverse effects of taking HAART and satisfaction with the amount of personal control over the decision (Cooper et al., 2002).

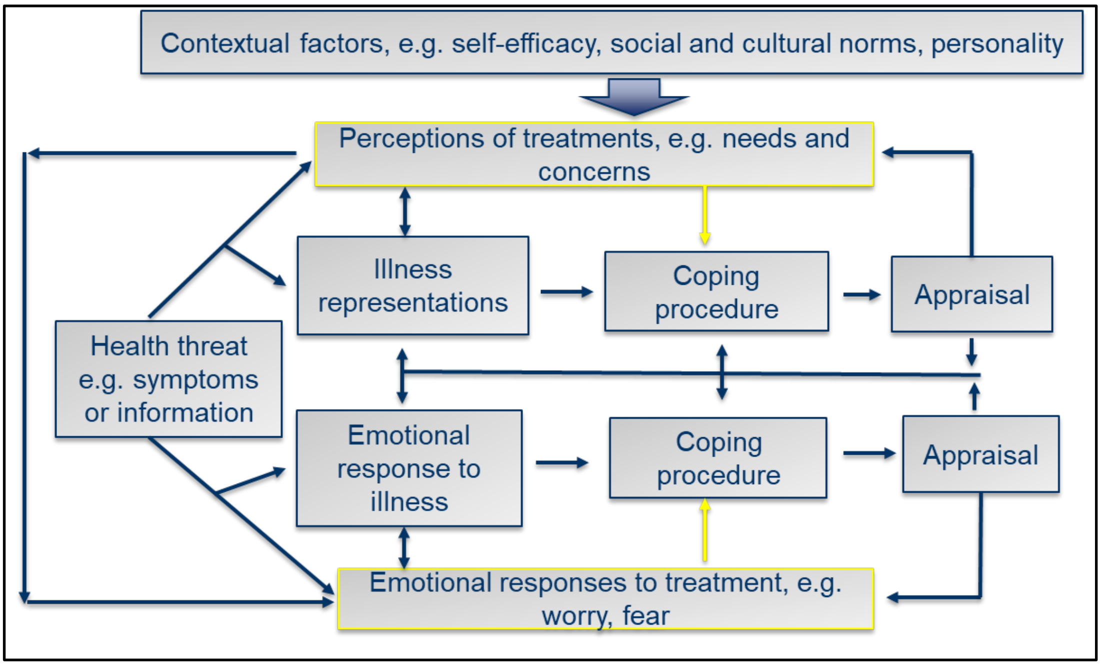


Figure 2 Treatment perceptions and the common-sense model of self-regulation (Horne 2003)

The treatment perceptions literature provides an overarching framework to support an investigation of patients' perceptions of blood transfusion. Further research is warranted to investigate how closely patients' perceptions may fit to these models, as patients may perceive transfusions differently to typical medicines or treatments. Blood is not a chemically derived substance or an operative procedure; therefore, it could be perceived differently as the donor blood is of human origin, perhaps sharing some similarity to how patients may perceive other infused interventions or transplants. Although patients need to attend hospital sites for transfusions, patients largely do not need to adhere to transfusion regimens and do not administer them by themselves in the community. Thus, many models may not contain perceptions appropriate for transfusion patients requiring HCP interaction to prescribe and administer the 'treatment'. This makes this topic novel and noteworthy to explore, with the potential to develop the existing treatment perceptions evidence base.

1.4.4 Theoretical perspective (HCPs)

As transfusion is a healthcare intervention prescribed and administered by HCPs, it is essential to jointly understand their perceptions, with investigating HCPs' perceptions alongside patients' advisory in the treatment perceptions literature. This is because HCPs' beliefs about treatments may influence their willingness to recommend the treatment to patients (Armstrong et al., 1996; Horne, 1999). Some studies have found HCPs' perceptions of treatments to be divergent from patients, with one study reporting that patients compared to pharmaceutical specialists held stronger beliefs about the harmful nature of medicines, whilst the specialists held stronger beliefs about medicine overuse (Ramström et al., 2006). Ramström et al., (2006) utilised the BMQ in their study and indicated that HCPs' perceptions may be able to be organised into the same content themes to those of patients. Analysing patients' and HCPs' perceptions coincidently will retain any side-by-side comparison of both groups' viewpoints, whilst allowing scope for divergent perceptions between both groups to emerge. It is important to profile perceptions held by both patients and HCPs due to patient and HCP collaborative exchanges, in which HCPs provide their expertise to help patients self-regulate their health states (Scott et al., 2013).

Although there is an existing treatment perceptions theoretical evidence based to draw on; the extent to which theory has been applied to blood transfusion perceptions research is unclear. Given that it is the patient that self-regulates their health states, self-regulation or treatment perceptions models may be more applicable to patients. HCPs' perceptions may, however, manifest as a contextual factor, influencing patients' perceptions, with the information that HCPs share to patients informing how patients perceive their treatment options. The extended CS-SRM (Horne, 2003) also allows for HCPs' perceptions of treatments (e.g. needs and concerns on behalf of the patient taking the treatment) to be recognised. Currently HCPs' perceptions are often investigated in studies supported by behaviour change theories, such as those underpinning implementation research, such as The Theoretical Domains Framework (TDF) (Michie et al., 2005). The TDF integrates a range of 33 behaviour change theories and 128 theoretical constructs into 14 domains representing the range of individual, socio-cultural and environmental influences on behaviour (Cane et al., 2012). TDF based research has been used to explore influences on behaviour, for example, discussing human papillomavirus (HPV) vaccination with patients (McSherry et al., 2012), routinely ordering pre-operative tests (Patey et al., 2012) and error-free prescribing (Duncan et al., 2012). The TDF provides a theoretical basis for implementation studies, providing good coverage of potential reasons for slow diffusion of evidence into practice and a method for progressing from theory-based investigation to intervention (Atkins et al., 2017). As blood transfusion is a clinical area routinely audited for transfusion use, with interventions often applied to curtail overuse (Gould et al., 2014), theoretical frameworks such as the TDF may be recognised in the transfusion perceptions literature.

1.5 Summary

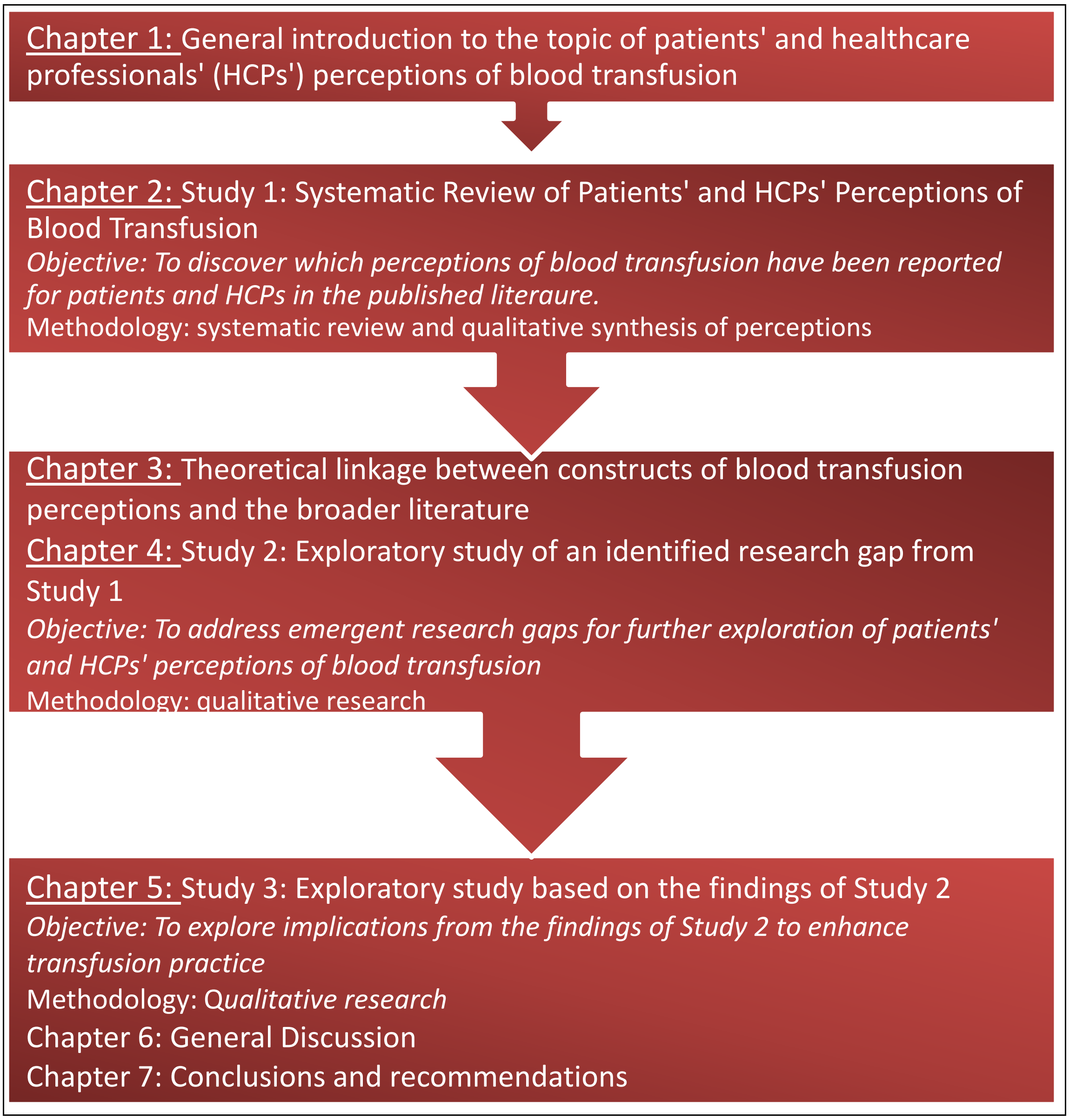
There is demonstrable gap in the theoretical literature on patients' and HCPs' transfusion perceptions, therefore there is a need for a theory informed investigation of this topic. Through this the perceptions of both patients and HCPs could be profiled to show how transfusions are perceived and to detect any similarity or difference in perceptions between both groups (e.g. infection risk concerns of patients but overlooked by HCPs with more expert medical knowledge). Associated topics such as the patient's role in decision making and health behaviours, such as accepting and prescribing transfusion, are embedded into this topic. This is because although HCPs are the responsible authority prescribing the transfusion, patients often hold an active role in deciding whether they agree that a transfusion is the best intervention to treat their health condition. If patients hold concerns about transfusions that are not resolved through the decision-making process, strategies to enhance shared decision making, amend services or provide interventions to support transfusion patients to cope may need to be generated.

1.5.1 Aims of this programme of research

The over-arching aim of this programme of research is to explore patients' and HCPs' perceptions of blood transfusion. A sequence of studies was conducted. First, a systematic review was conducted to identify and synthesise what is already known about how HCPs and patients perceive transfusions. Second, qualitative research explored more in-depth gaps identified in the systematic review regarding transfusion perceptions. The third element of this research aimed to build on the former study and identify ways to improve transfusion practice.

1.6 Structure of this thesis

Figure 3 portrays the sequence of the three studies reported in this thesis. Study 1. Systematic review of patients' and HCPs' perceptions of blood transfusion; Study 2. Explorative study of significant research gaps in this field using qualitative research; Study 3. Exploration of the implications of the findings from study 2. Future research is indicated in the overall Discussion and Conclusion chapters of this thesis.



Chapter 1: General introduction to the topic of patients' and healthcare professionals' (HCPs') perceptions of blood transfusion

Chapter 2: Study 1: Systematic Review of Patients' and HCPs' Perceptions of Blood Transfusion

Objective: To discover which perceptions of blood transfusion have been reported for patients and HCPs in the published literaure.

Methodology: systematic review and qualitative synthesis of perceptions

Chapter 3: Theoretical linkage between constructs of blood transfusion perceptions and the broader literature

Chapter 4: Study 2: Exploratory study of an identified research gap from Study 1

Objective: To address emergent research gaps for further exploration of patients' and HCPs' perceptions of blood transfusion

Methodology: qualitative research

Chapter 5: Study 3: Exploratory study based on the findings of Study 2

Objective: To explore implications from the findings of Study 2 to enhance transfusion practice

Methodology: *Qualitative research*

Chapter 6: General Discussion

Chapter 7: Conclusions and recommendations

Figure 3 Sequence of studies and chapters of the current research programme

2 Patients’ and Health Care Professionals’ Perceptions of Blood Transfusion: A Systematic Review

This chapter reports a systematic review of patients’ and healthcare professionals’ (HCPs’) perceptions of blood transfusion. This is the first study in this programme of research, conducted to consolidate the evidence base on this topic. This systematic review has since been published (citation below, Appendix 1: Systematic review publication) and this chapter presents an updated version of the review with the searches re-run in February 2019.

> Abdul-Aziz, B., Lorencatto, F., Stanworth, S. J., & Francis, J. J. (2018). Patients' and health care professionals' perceptions of blood transfusion: a systematic review. *Transfusion*, *58* (2), 446-455

2.1 Introduction

Blood transfusion is a healthcare intervention frequently prescribed to a wide range of patients (American National Red Cross, 2018a). Transfusions are provided either as a single transfusion episode for planned elective or emergency procedures (e.g. surgery involving blood loss), or repeatedly for patients with haematological blood disorders (Tinegate et al., 2013). It is important to understand transfusion perceptions because when patients experience illness or symptoms that may require treatment, they form perceptions of the possible treatments, such as the treatment’s potential to control the health threat, or they evaluate perceptions of treatment risks compared to benefits (Horne, 2003). A treatment may also, however, be perceived as health threatening and people may reject treatments because they fear that taking the treatment may diminish their quality of life (Horne, 2003; Siegel et al., 1999).

Transfusions may be perceived by patients as risky as since around 1984, significant media attention was given to the discovery that HIV was transmittable through blood transfusions, which caused thousands of HIV / AIDS related infections and deaths (Perkins et al., 2010). Some public views of blood transfusion remain to be associated with perceptions of risk, and associated with HIV and AIDS (Finucane et al., 2000) despite the low actual risk (National Institutes of Health, 2012.; Zou et al., 2010). As members of the public are potential blood transfusion recipients, such findings suggest that if becoming a patient requiring a transfusion, patients may view transfusions as risky, but that these views may not align with current evidence and clinical safety guidelines.

As there are a broad range of patients receiving transfusions for different illnesses or to support different medical procedures, perceptions of transfusion across patients may be variable. Perceptions may vary between different groups of transfusion patients receiving different blood components, such as red blood cells, transfused following significant blood loss or for anaemia, white blood cells to fight infections, or platelets to help blood clotting (NHS Blood and Transplant, 2016). Some patients may also have the option to be considered for donor (allogeneic) blood sparing alternatives or autologous procedures. Patients receiving transfusions in non-emergency situations may also form different perceptions at different time points relative to a transfusion, such as before, during or after transfusion. These perceptions will influence how patients choose to cope with aspects of their recovery and regulate their health (Leventhal et al., 1997) (e.g. emotional focussed coping and being hopeful that the transfusion will improve their health as it starts to take effect). Thus, gaining a detailed understanding of how perceptions of blood transfusion vary for these different components or donation methods may be useful to HCPs as they prescribe transfusions to patients and help patients recover from ill health post-transfusion.

It is important to equally explore both patients' and HCPs' perceptions as both groups are equally involved in the transfusion - one as a prescriber and one as a recipient, so cross-comparable or wide varying beliefs may be revealed. A wide range of HCPs are involved in transfusion decision-making and blood product administration, including consultants, registrars, technicians, nurses and general practitioners (GPs) (NHS Blood and Transplant, 2012). HCPs often work in multi-disciplinary transfusion teams to implement patient blood management strategies to treat patients and enhance patient safety (Goodnough et al., 2012). Yet, different professional groups may perceive transfusion differently to patients and across HCP groups. HCPs' views of treatments are informed by their knowledge of the relevant clinical evidence and their own clinical experience (Insel et al., 2005; Ramström et al., 2006). HCPs' perceptions and knowledge naturally influence clinical decision-making, in which patients may be involved to differing extents (Friedman et al., 2015).

Clinical decisions about transfusion may involve a consideration of alternatives to transfusion that reduce the need for a transfusion. Possible alternatives are considered as key issues to discuss with patients when obtaining informed consent as advised by the UK Safety of Blood, Tissues and Organs Committee (SaBTO) (JPAC, 2019; SaBTO, 2011). National Institute for Health and Care Excellence (NICE) guidelines recommend the consideration of alternatives such as oral iron before surgery for patients with iron deficiency anaemia, or the use of strategies such as cell salvage, where loss blood is retained and re-transfused back to the patient (Padhi et al., 2015). Alternatives are reported to be underused (Murphy et al., 2013a) and transfusion prescribed inappropriately, a problem which persists despite reductions and fluctuations in the use of some blood components (Murphy et al., 2013b). Hence, investigating the perceptions of HCPs alongside patients across a broad range of clinical contexts may identify factors that lead to the inappropriate use of some blood products or the underuse of blood-sparing alternatives.

Systematic reviews are commonly conducted to comprehensively identify all relevant studies to answer a particular question, whilst assessing the validity "soundness" of each study (Petticrew et al., 2006). A review can include a narrative component to present the findings of studies in their own terms or integrate a qualitative analysis to synthesise findings across studies to identify recurrent or important themes arising from the body of literature (Mays et al., 2005). A systematic review can thus be used to narratively describe how perceptions were assessed (e.g. cross-sectional study using a questionnaire), alongside extracting and qualitatively analysing and synthesising the content of the perceptions. Meta-analyses are also used to collate quantitative data presented in multiple studies, however, data presenting textual perceptions that patients and HCPs hold would not be suitable for this type of review. Bayesian meta-analysis may offer an approach to combine qualitative and any questionnaire or quantitative data but are complex to implement with the technique facing methodological issues (Dixon-Woods et al., 2005).

As the size and scale of the evidence base is uncertain for this topic of patients' and HCPs' perceptions of blood transfusion, a systematic review is warranted to consolidate published evidence to date. A title search of systematic reviews of the topic of 'patients' and HCPs' perceptions of blood transfusion' was performed in January 2014 in two online databases: University of York Centre for Reviews and Dissemination and The Cochrane Database of Systematic Reviews, identifying that no systematic review on this topic had previously been published in these libraries (Appendix 2: Systematic review, scoping and full search strategies).

It is often concluded that a substantial proportion of studies identified in reviews fail to make explicit reference to theory (Michie et al., 2010). Systematic reviews would benefit from reporting the extent to which theory informs the design and methodological approach of studies because theory can provide a conceptual basis to understand perceptions and clarify theoretical constructs influencing behaviour. If theory has been minimally utilised in past research, subsequent studies could become theory informed to highlight key relationships between theoretical constructs, which influence behaviour. For instance, existing studies could be examined to determine their theoretical underpinning, with this information used to understand the research area more theoretically, utilising this knowledge for subsequent research.

2.1.1 Aims of the systematic review

This systematic review aimed to narratively present and qualitatively synthesise the reported healthcare literature to identify adult transfusion patients' and HCPs' perceptions of blood transfusion. Adult patients were selected because they are the main transfusion recipient group, with an ageing population increasing further demand for transfusion (Greinacher et al., 2011; World Health Organization, 2017). This review was designed without geographical boundaries due to the extensiveness of the use of transfusions globally and that issues in blood transfusion, such as the tainted blood scandals, occurred on a global scale. In the review, emergent themes were identified and developed from the primary studies with consideration given to how themes may inter-relate.

2.1.2 Systematic review objectives:

1. To systematically review the literature reporting adult patients' and HCPs' perceptions of blood transfusion, describing the design and characteristics of included studies.
2. To identify and synthesise the reported transfusion perceptions and identify over-arching themes related to perceptions of blood transfusions, and proposed relationships between themes.

2.1.3 Research questions:

1. Whose perceptions have been investigated?
2. What are the reported methods used to assess perceptions?
3. At which time points (in relation to the transfusion) were perceptions assessed?

4. Have perceptions been differentiated between the different blood components or transfusion methods?
5. To what extent has theory been used to explore transfusion perceptions?
6. Which content themes of perceptions of blood transfusion have been identified and how do the themes relate to one another?
7. How were the emergent themes distributed across the chronological years of study publication?

2.2 Methods

2.2.1 Design

Systematic review: qualitative narrative synthesis

2.2.2 Study selection criteria

Empirical studies were eligible for inclusion if they investigated blood transfusion perceptions of: 1) adult patients who had either received a transfusion, or were being prepared for a transfusion (i.e. transfusion was not 100% guaranteed to take place, for instance patients undergoing pre-operative assessments and consenting to transfusion or donating blood for pre-operative autologous donation (PAD)); and/or 2) all grades of professionally registered, adult-treating HCPs (i.e. excluding paediatricians) with potential responsibility for ordering a transfusion or treating transfusion patients in primary, tertiary or secondary care centres (e.g. not military zones).

Blood transfusion was considered as a healthcare intervention using any blood component or donation method (e.g. PAD or blood-sparing alternative, such as cell salvage). Perceptions of blood transfusion practice, such as satisfaction with the service, recall of informed consent, training, policy and transfusion administration procedures were considered to be outside of the scope of the review. This was to retain the focus on patients' and HCPs' perceptions of transfusion, with associated topics, such as satisfaction with service and training, arguably independent topics for separate research. Studies were required to be reported in English language, in peer-reviewed journals, and accessible in full text. Papers reporting primary studies in the reference lists of systematic reviews that were identified by the search were also eligible for inclusion.

No limiters were applied to geographical region. The publication date of studies was from 1984 onwards; 1984 marking the date of a potential shift in perceptions of blood transfusion after the link between blood transfusion and AIDS transmission was announced (Perkins et al., 2010).

2.2.3 Identification and selection of relevant studies

Searches were run initially in February 2014 and updated in November 2015 and February 2019. Selection of electronic databases and development of the search strategy were conducted in collaboration with an Information Specialist experienced in conducting blood transfusion systematic reviews. The following databases were searched: Cochrane Central Register of Controlled Trials, the Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects, Ovid MEDLINE, EMBASE, PsycINFO and PsyARTICLES.

Search terms for the scoping search included synonyms for perception from the literature; *representation* or *belief* (Horne et al., 1999b; Leventhal et al.,

1980) (perception* or representation* or belie*) and were connected using the 'AND' operator to the term '*blood transfusion*'. For the final searches, search terms related to three domains: 1) blood transfusion (e.g. red cell transfusion*); 2) perceptions (e.g. belie* or attitude); and 3) participant group (patients or HCPs, e.g. medical staff or clinician*). The 'blood transfusion' and 'perceptions' search domains were connected using the adjacent (four) operator, in which search terms in one domain were triggered when occurring within four words from terms in the other domain. The 'participant group' domain was connected to the combined 'blood transfusion' and 'perceptions' domains using the 'AND' Boolean operator. The search was applied to the studies' title and abstract fields (see Appendix 2: Systematic review, scoping and full search strategies).

Four criterion papers that reported patients' and HCPs' perception of blood transfusion were used to guide selection of the search terms and to validate the search through appearing in the search (Adams et al., 2011; Fitzgerald et al., 1999; Francis et al., 2009a; Islam et al., 2012).

2.2.4 Study screening

Studies identified via the search strategy were screened for inclusion against six inclusion criteria (Table 1). The criteria were independently piloted by two reviewers on 50 titles and abstracts to assess reliability. All studies were screened by the main reviewer at the title and abstract, and subsequently at the full text level. The review team independently assessed 1% (n=29) of randomly selected titles and abstracts excluded by the main reviewer for the 2014 and 2015 searches to evaluate the validity of the screening decisions.

Any studies failing to meet all inclusion criteria either at the title and abstract or full text level were excluded.

Table 1 Systematic review study inclusion criteria

No.	Inclusion criterion
1	Full text English Language publication from a peer reviewed journal
2	Published since 1984
3	Assessing perceptions of blood transfusion of any blood component
4	Reporting empirical data about perceptions of blood transfusion through a primary study
5	Participant sample including patients and / or HCPs
6	Reported participant samples not below 18 years old or HCPs who treat patients below 18 years old

2.2.5 Data extraction and synthesis

A data extraction form was developed and piloted on the first five included studies. In total, 25 data elements were extracted under the headings: *Study details, Study characteristics, Sampling frame and sample characteristics, Data collection methods, Analysis, Results, Conclusions and recommendations* (see Appendix 3: Systematic review data extraction form).

Reliability analysis was performed on two elements of data extracted: 1) presence / absence of theory; and 2) reported perceptions. For presence / absence of theory, similar to methods used in other systematic reviews (Colquhoun et al., 2013), the name of the theory was documented as well as where theory was mentioned in the paper. The main reviewer extracted all data, noting whether theory was reported to inform the study materials (e.g. questionnaires/ topic guides). If study materials were not published, study authors were contacted by e-mail to request a copy of the materials.

Colleagues (AP, FL) with experience in identifying theory, independently assessed the presence or absence of theory for a randomly selected sub-sample of 10% of studies from the 2014 and 2015 searches. For the reported perceptions, results sections of each article were read by the main reviewer (BV) and only data related to perceptions of blood transfusion meeting the inclusion criteria were extracted. Such data points included excerpts of both raw data (i.e. participant quotes and/or quantitative findings) and/or text reporting results as interpreted by study authors. A second reviewer (FL) independently extracted the perceptions from 10% of a randomly selected sub-sample of studies from the 2014 and 2015 searches, and reliability was assessed using percentage agreement.

2.2.6 Quality assessment of included studies

Quality was assessed for descriptive purposes rather than to inform study inclusion/exclusion. Studies were appraised for quality by BV using validated quality assessment checklists for evaluating primary research papers from a variety of fields (Kmet et al., 2004) (Appendix 3). Scores produced using the checklists, tailored for quantitative (14 items) and qualitative (10 items) study designs, were converted into percentages (number of quality criteria met, out of the total number of quality items). Domains of quality that were assessed through the checklists included sample selection criteria, data collection, results verification procedures and reflexivity (Kmet et al., 2004).

2.2.7 Data analysis

Extracted data were tabulated for analysis and reported using narrative summary for all extracted data other than the reported perceptions (Dixon-Woods et al., 2005). A four-stage inductive qualitative synthesis (Thomas,

2003) was conducted to synthesise and interpret reported perceptions. First, BV classified the extracted perceptions into categories using *in vivo* coding, where actual phrases from the excerpts were retained and used to name the categories (Thomas, 2006). Second, the main reviewer organised the categories into subthemes using techniques from thematic analysis; *searching for themes,* whereby the inter-relationships between categories are considered, (i.e. '*ongoing awareness' and 'conditional awareness'* may be classified under a broad initial theme of '*awareness'*) (Braun et al., 2006). The themes and subthemes were discussed with the review team to reach consensus on a refined set of themes (synthesis stage 3). The main reviewer then investigated relationships between the themes (e.g. the extent to which some subthemes mapped across themes) (synthesis stage 4) and produced a conceptual model to display key relationships. The model was revised until secondary reviewers agreed with the presentation of the model.

2.3 Results

The original 2014 search retrieved 3,134 results. A further 473 results were retrieved in the first update in 2015 and a further 391 in the 2019 update. A further two papers were identified from a systematic review (Ngo, 2013) identified in the 2014 search (Amin et al., 2004; Moxey et al., 2005), resulting in a total of 3,076 papers for title and abstract screening. 100% agreement on screening decisions was reached. As displayed in the PRISMA Diagram (Figure 1), 41 papers published between 1990 and 2018 were included in the systematic review.

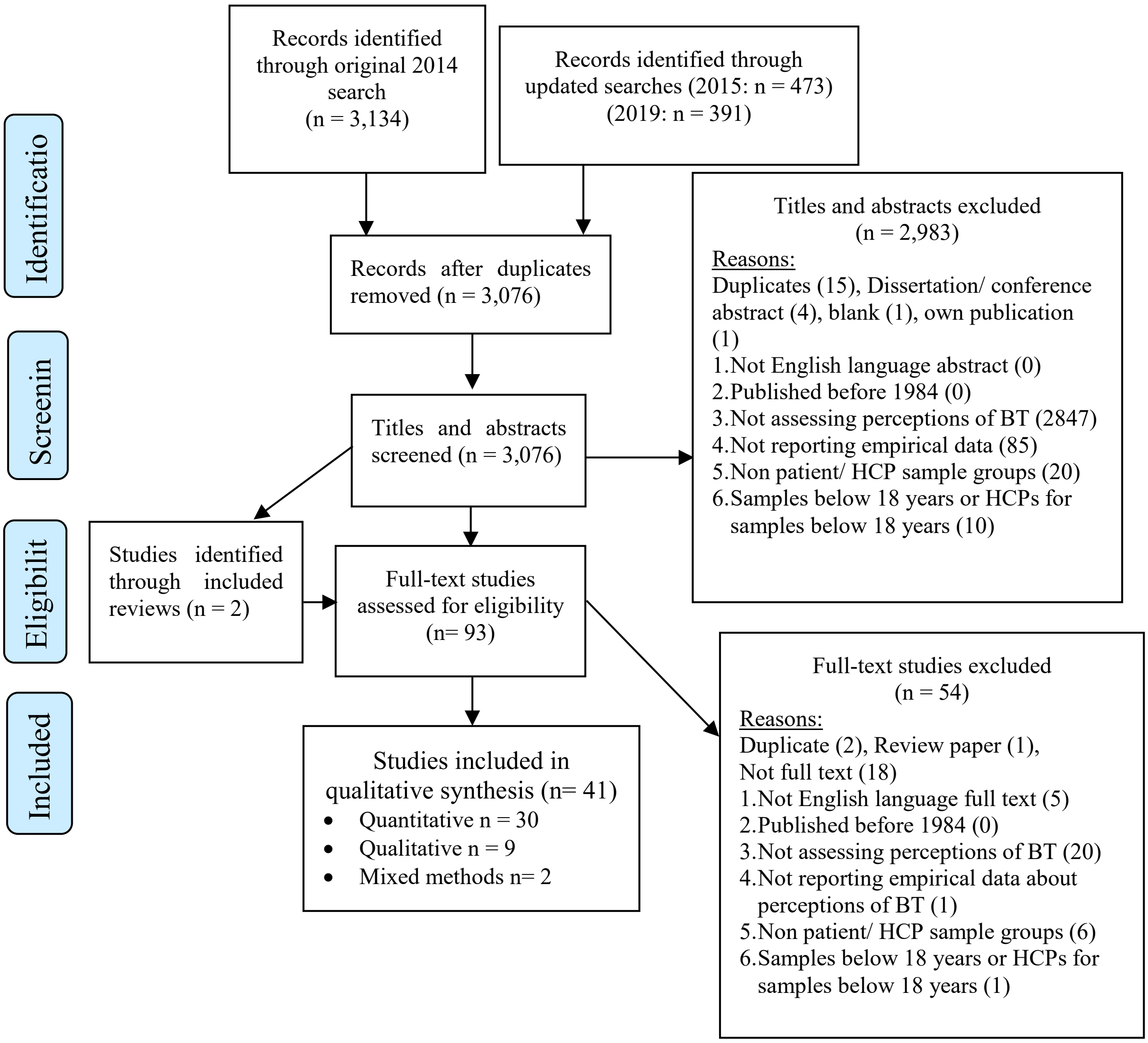


Figure 4 Systematic review PRISMA diagram

2.3.1 Study characteristics

Fifteen papers included in the systematic review investigated patients' perceptions of blood transfusion (Cheung et al., 2014; Court et al., 2011; Davis et al., 2012b; Graham et al., 1999; Khan et al., 2012; Lee et al., 1998; Lee et al., 1997; Luby et al., 2001; Murphy et al., 1997a; Shah et al., 2012) (Adams et al., 2011; Fitzgerald et al., 1999; Moxey et al., 2005; Orme et al., 2013) (Ryblom, 2015). Twenty-six papers investigated HCPs' perceptions (Adusei et al., 2018; Al-Riyami et al., 2016; Amin et al., 2004; Cozzolongo et al., 2005; Ddungu et al., 2018; Ferguson et al., 2001; Graw et al., 2018;

Hartford et al., 2015; Lee et al., 2003; Leibovitz et al., 2004; Lowe et al., 2001; Manzini et al., 2018; Müller et al., 2014; Salem-Schatz et al., 1990; Soares et al., 2017; Tavares et al., 2015; Thonneau et al., 1991; Torella et al., 2001; Vetter et al., 2014; von Babo et al., 2018) (Francis et al., 2009a; Graham et al., 2002; Heddle et al., 2012; Islam et al., 2012; Treloar et al., 2001) (D'Souza et al., 2004) (Table 2).

Three papers explored patients' and HCPs' perceptions concurrently; however, either the HCP perceptions were excluded as the HCP-component of the study included perceptions outside of the scope of this review (i.e. perceptions of informed consent documentation (Davis et al., 2012b) or the content of transfusion consultations (Khan et al., 2012)) or the patients formed an ineligible group being hospital patients but not transfusion recipients (or patients being prepared for a transfusion) (Graw et al., 2018).

Table 2 summarises the main characteristics of included studies and participants. The majority of studies were conducted in the UK (n=12) (Court et al., 2011; D'Souza et al., 2004; Davis et al., 2012b; Ferguson et al., 2001; Francis et al., 2009a; Heddle et al., 2012; Khan et al., 2012; Lowe et al., 2001; Manzini et al., 2018; Murphy et al., 1997a; Orme et al., 2013; Torella et al., 2001) were multi-site (i.e. the study was conducted at more than one health facility) (n=22) (Amin et al., 2004; Cozzolongo et al., 2005; D'Souza et al., 2004; Davis et al., 2012b; Ferguson et al., 2001; Francis et al., 2009a; Graham et al., 2002; Graham et al., 1999; Hartford et al., 2015; Heddle et al., 2012; Islam et al., 2012; Lee et al., 1998; Leibovitz et al., 2004; Lowe et al., 2001; Luby et al., 2001; Manzini et al., 2018; Moxey et al., 2005; Müller et al., 2014; Salem-Schatz et al., 1990; Torella et al., 2001; Treloar et al., 2001; von

Babo et al., 2018) and in secondary healthcare settings (n=33) (Adams et al., 2011; Adusei et al., 2018; Al-Riyami et al., 2016; Court et al., 2011; Davis et al., 2012b; Ddungu et al., 2018; Fitzgerald et al., 1999; Francis et al., 2009a; Graham et al., 2002; Graham et al., 1999; Graw et al., 2018; Hartford et al., 2015; Heddle et al., 2012; Islam et al., 2012; Khan et al., 2012; Lee et al., 2003; Lee et al., 1998; Lee et al., 1997; Leibovitz et al., 2004; Luby et al., 2001; Manzini et al., 2018; Moxey et al., 2005; Müller et al., 2014; Murphy et al., 1997a; Ryblom, 2015; Salem-Schatz et al., 1990; Shah et al., 2012; Soares et al., 2017; Tavares et al., 2015; Torella et al., 2001; Treloar et al., 2001; Vetter et al., 2014; von Babo et al., 2018).

Table 2 Systematic review included studies and participant characteristics

Paper author	**Country & sites (n)**	**Research setting**	**Study design**	**Samples included in analysis**	**Reported sample characteristics**	**Reported reasons for the transfusion or diagnoses (n) / Years of clinical experience**
Patient studies						
Ryblom et al., (2015)	Sweden (1)	Secondary h/c	Mixed methods	16 transfusion patients	Age: 67-91 (mean 74) Male 8, female 8 Married 10, Single 1, Widow/widower 5	Myelodysplastic syndromes Blood transfusion need of >6 months and a minimum transfusion regularity of once monthly
Cheung et al., (2014)	Canada, Toronto (1)	Tertiary care hospital	Cross-sectional	25 patients prepared for a transfusion	Age: 38–84 (mean 61) Male 11, Female 14	Diagnoses: oncologic (19), Myelodysplastic syndrome (2), Not reported (4)
Orme et al., (2013)	UK, South England (1)	Hospice	Interview	10 transfusion recipients	Age: 67 - 95 (mean 79.5) Male 7, Female 3	Diagnoses: myelodysplasia (7), non-Hodgkin's lymphoma (1), myelofibrosis (1), sideroplastic anemia (1).
Davis et al., (2012)	UK, London & Oxford (2)	Secondary h/c	Cross sectional qualitative	110 transfusion recipients (post-operative + regular recipients; ambulatory hematology)	Age: 18–93 (mean 60) Male 60, Female 50 Caucasian 77, Non-Caucasian 33	NR
Luby et al., (2012)	Pakistan, Karachi (12)	Secondary h/c (1) and tertiary care centres (11)	Cross sectional	141 transfusion recipients	Age: (mean 33) Male 50, Female 91 Occupation = 80 housewives, 20 manual labourers, & 20 office workers.	Reason: surgical blood loss (77), anemia (28), generalized weakness (15) & trauma (13).

Paper author	Country & sites (n)	Research setting	Study design	Samples included in analysis	Reported sample characteristics	Reported reasons for the transfusion or diagnoses (n) / Years of clinical experience
Shah et al., (2012)	Dhaka, Bangladesh (1)	Secondary h/c	Cross sectional / observational	126 transfusion recipients (transfusion medicine dept.)	Age: (mean 33 for males, 37.9 females) Male 81, Female 45	NR
Adams et al., (2011)	USA, Ohio (1)	Secondary h/c	Interview	21 transfusion recipients	Age: (n) 18–30 2 31–50 2 51–70 7 71–90 10 Male 5, Female 16	Reason: all anemia (diverse range of causes).
Fitzgerald et al., (1999)	Australia, Adelaide (1)	Secondary h/c	Interview	19 transfusion recipients	Age: (n) 21-30: 3 31-50: 4 51-70: 8 71-90: 4 Male 14, Female 5	Diagnoses: cancer (6), clotting disorders (2), organ failure (2), emergency (3), surgery (6)
Murphy et al., (1997)	UK, London (1)	Secondary h/c	Cross sectional	51 transfusion recipients (medical / surgical wards)	Age: 17-82 years Male 34, Female 17	NR
Khan et al., (2012)	UK, Scotland; Aberdeen (1)	Secondary h/c	Cross sectional	14 patients attending surgical pre-assessment clinic	None reported	NR
Graham et al., (1999)	Canada, Ottawa (2)	Secondary h/c	Cross sectional	80 Cardiac patients (40 PAD / 40 non-PAD) & 73 Orthopedic patients (38 PAD / 35 non-PAD).	Age: (mean) 59.0 Cardiac PAD / 63.5 Cardiac non-PAD / 63.2 Orthopedic PAD / 71.5 Orthopedic non-PAD.	Reason: Range of surgical procedures.

Paper author	**Country & sites (n)**	**Research setting**	**Study design**	**Samples included in analysis**	**Reported sample characteristics**	**Reported reasons for the transfusion or diagnoses (n) / Years of clinical experience**
					Male = 88 Cardiac PAD / 80 Cardiac non-PAD / 40 male Orthopedic PAD / 34 male Orthopedic non-PAD.	
Lee et al., (1998)	USA, Massachusetts & Maine (3)	Secondary h/c	Randomized between subjects design	412 patients (prior to PAD)	Age (mean) 56.05 (15.14) Female 230 Mean annual income ($) 44,924 College education 66	Patients scheduled for autologous donation before planned surgical procedures
Lee et al., (1997)	USA, Boston (1)	Secondary h/c	Cross sectional	235 patients (prior / following PAD)	Age: (mean) 50.45 Female 63 % Mean household income = $57993 College education 64%	Patients scheduled for autologous donation before planned surgical procedures
Court et al., (2011)	UK, Swindon (1)	Secondary h/c	Cross sectional	132 transfusion recipients 32 non-recipients (blood cross-matched)	Age: 21-84 years Male 141, Female 201	Post-operative: 66 transfusion recipients (66·7% elective) / 26 non-recipients (80·8% elective).
Moxey et al., (2005)	Australia, Hunter & Central Coast Regions (multi-site)	Primary h/c, secondary h/c, rehabilitation clinics	Interview	23 transfusion recipients 6 PAD recipients 9 other (post-surgical patients) *	Age: (n) 30–39: 0 / 40–49: 3 / 50–59: 2 / 60-69: 9 / 70–79: 18 / 80+: 6 Male 22, Female 16	NR
HCP studies						

Paper author	Country & sites (n)	Research setting	Study design	Samples included in analysis	Reported sample characteristics	Reported reasons for the transfusion or diagnoses (n) / Years of clinical experience
Adusei & Owusu-Ofori (2018)	Ghana (1)	Secondary h/c	Cross sectional	100 HCPs (Doctor 3, Pharmacist 6, Nurse 49, Midwife 5, Physician Assistant 6, Biomedical Assistant 6, Laboratory technician 7, Others 18)*	Aged between 20- 30 years (76%), 31-40 (18%), 41-50 (6%) Male 53, Female 47	NR
Ddungu et al., (2018)	Uganda (1)	Secondary h/c	Cross sectional	30 physicians, including residents, practicing at Uganda Cancer Institute from June to September 2014	NR	NR
Graw et al., (2018)	? Germany (1)	Secondary h/c	Cross sectional	185 nurses (117 registered nurses, 10 nursing auxiliaries, 55 nursing students, and 3 status not defined)	Age: (years) 23-47, median 31 Gender: male 50 (27 %) Marital status, n Single 95, Married 79, Divorced 9, Widowed 2 Blood donor, n 95 Denial of transfusion, n 2	NR
Manzini et al., (2018)	Italy, UK, Germany, Sweden, Netherlands, Malta and Denmark (1	Secondary h/c	Cross sectional	788 medics (surgeons (244; 31%), anaesthetists (165; 25%) and medical specialists (379, 44%))	3% of respondents did not prescribe blood components whilst the others were equally divided amongst those who prescribe weekly, monthly or less frequently	Clinical experience: 40% had work experience of more than 15 years, 33.5% from 5 to 15 years and 26.5% <5 years.

Paper author	**Country & sites (n)**	**Research setting**	**Study design**	**Samples included in analysis**	**Reported sample characteristics**	**Reported reasons for the transfusion or diagnoses (n) / Years of clinical experience**
	site per country)					
von Babo et al., (2018)	Switzerland (71)	Secondary h/c	Cross sectional	560 medics (297 (53%) of the participants were residents, 263 (47%) attending physicians)	The majority of participants lived in the German-speaking part of Switzerland (n = 484, 86%)	NR
Soares et al., (2017)	Brazil (1)	Secondary h/c	Cross sectional	90 Anaesthesiologists (surgical centres: general, paediatric, obstetric, outpatient, transplant and the diagnostic/imaging and haemodynamic centre) *	Age: (years): 27-76, mean 37.94 years (median 33.5) Gender: 49 female (54.4%), male 41 (46.6%)	NR
Al-Riyami et al., (2016)	Oman (1)	Secondary h/c	Cross sectional	114 Physicians (Interns 43, Residents 28, Senior House officers 13, Registrars 30) * Clinical areas: Anesthesia 8 physicians, Obstetrics and gynecology 15, Hematology 19, Internal Medicine 19, Pediatrics 25, Surgery 28	Gender: Female 70 (61.4%), Male 44 (38.6%) Previous involvement in the transfusion consent process was declared by 77% of physicians.	NR
Tavares et al., (2015)	Brazil (1)	Secondary h/c	Cross sectional	209 nurses (29 nurses, 146 nursing	Age: (years) 22-61 (mean 38.2) Gender: female (81.8%)	An average of 144.25 months of training, 147.07

Paper author	Country & sites (n)	Research setting	Study design	Samples included in analysis	Reported sample characteristics	Reported reasons for the transfusion or diagnoses (n) / Years of clinical experience
				technicians & 34 nursing assistants) * Most common clinical areas: Hospitalization Unit - Adult (n=56 nurses), Intensive Care Units (n=54), Emergency Room Units (32)		months of professional experience.
Hartford et al., (2015)	Mozambique (3)	Workplace (hospital)	Cross sectional	216 Physicians (94%), nurses (2%) & technicians (4%)*	Reported physicians' specialty: internal medicine (36%), surgery (34%), paediatrics (19%), anaesthesia (10%), and other (1%).	47% were postgraduate (resident) trainees
Vetter et al., (2014)	US, Birmingham Alabama (1)	Secondary h/c	Cross sectional	73 Anesthesiologists' (n=34) & surgeons (n=39)	Age: 47 (mean) in years Gender (m=68): Male 54, female 14	Post residency practice duration (mean 14 years)
Müller et al., (2014)	Netherlands (4)	Secondary h/c	Cross sectional	46 Intensive Care Unit (ICU) physicians & fellows	Age: 20–35 year 24% 36–50 year 63%, 51–65 year 13% Gender: 65% male	Critical care specialist 72% Fellow training in intensive care 28%
Heddle et al., (2012)	Canada, UK, Norway, Italy, USA (6 site: *2 in US*)	Secondary h/c	Interview (n=7) & focus group (n=12)	72 in/outpatient nurses and physicians (Italy only) *sampled from diverse clinical areas**	NR	NR
Islam et al., (2012)	Canada, UK (multi-site)	Secondary h/c	Interview	10 ICU physicians	Gender: 9 male, 1 female	Variations in training & practice in transfusion

Paper author	Country & sites (n)	Research setting	Study design	Samples included in analysis	Reported sample characteristics	Reported reasons for the transfusion or diagnoses (n) / Years of clinical experience
Francis et al., (2009)	UK, England & Scotland (multi-site)	Secondary h/c	Interview	11 ICU consultants	Gender: 10 male, 1 female Age: 36–52 years	1 to 21 years
Cozzolongo et al., (2005)	Italy, Apulia region (multi-site)	Primary h/c	Cohort study design	306 (time 1)/ 170 (time 2) primary care physicians	NR	NR
D'Souza et al., (2004)	UK, London (multi-site)	Primary h/c	Mixed methods	488 GPs	NR	NR
Amin et al., (2004)	Canada, five provinces (multi-site)	Sourced via Canadian Medical Association Directory (2002)	Cross sectional	45 physicians (28 internists, 10 cardiovascular surgeons & 7 haematologists)	NR	NR
Leibovitz et al., (2004)	Israel (multi-site)	Secondary h/c	Cross sectional	274 physicians (79 Internists, 69 oncologists, 79 Geriatricians, 47 family physicians) 74 nurses (oncology &internal medicine wards)	Gender (n female / male): Internists 16 / 63 Oncologists 24 / 45 Geriatricians 21 / 58 Family physicians 26 / 21 Nurses 72 / 2 Age (mean): Internists 47, Oncologists 49, Geriatricians 53, Family physicians 44, Nurses 43	Years of practice (mean) Internists 20, Oncologists 21, Geriatricians 25, Family physicians 17, Nurses 20.
Lee et al., (2003)	Canada, Kingston Ontario (1)	Secondary h/c	Cross sectional	33 physicians, 43 residents (21 family medicine, 19 internal	Gender: 51% female Age: (mean) 33 Family status: 54% married, 30% with children	NR

Paper author	**Country & sites (n)**	**Research setting**	**Study design**	**Samples included in analysis**	**Reported sample characteristics**	**Reported reasons for the transfusion or diagnoses (n) / Years of clinical experience**
				medicine & 17 anaesthesia)		
Graham, et al., (2002)	Canada, Ontario (8)	Secondary h/c	Interview	19 hospital chiefs or representatives from surgery (n=7), anaesthesia (n=3), transfusion medicine/hematology or laboratory medicine (n=7) and pharmacy (n=2).	NR	NR
Ferguson et al., (2001)	England, Trent region (multi-site)	Primary h/c	One-way between subjects design	88 GPs, 143, Anaesthetists	NR	NR
Lowe et al., (2001)	England, Trent region (multi-site)	Primary h/c	Cross sectional	88 GPs, 143, Anaesthetists	Gender: 264 male, 233 female Age (mean): 35.8	
Torella et al., (2001)	England, north-west region (multi-site)	Secondary h/c	Cohort study design	571 surgeons n per year: 151 (1990), 226 (1994) & 194 (1999) (*sampled from diverse clinical areas*) *	NR	NR
Treloar et al., (2001)	Australia, (multi-site)	Secondary h/c	Interview	12 prominent clinicians, 12 surgeons, 14 anaesthetists	NR	NR
Thonneau et al., (1991)	France, Bicetre (1)	Primary h/c	Cross sectional	6 doctors (family planning)	NR	NR

Paper author	Country & sites (n)	Research setting	Study design	Samples included in analysis	Reported sample characteristics	Reported reasons for the transfusion or diagnoses (n) / Years of clinical experience
Salem-Schatz et al., (1990)	USA, (3)	Secondary h/c	Cross sectional survey	76 surgeons, 46 anesthesiologists	NR	Clinical role: n=50 attending physicians & 72 residents.

* Decision rule applied - non-eligible samples (i.e. *pediatricians, post-surgical patients) represent less than 50% of the total sample, data inseparable from other samples' data, therefore all data extracted.

NR = not reported in papers

2.3.2 Patients and HCPs participating in included studies

In total, 1,574 patients participated in the included studies (48% male, aged between 18-95 years). The majority of participants were of Caucasian ethnicity (73% reported for n=2 studies) (Adams et al., 2011; Davis et al., 2012b) and from diverse income and educational backgrounds (n=6 studies) (Davis et al., 2012b; Lee et al., 1998; Lee et al., 1997; Luby et al., 2001; Moxey et al., 2005; Shah et al., 2012).

Patients were classified for this review as either transfusion recipients (n=8 studies) (Adams et al., 2011; Davis et al., 2012b; Fitzgerald et al., 1999; Luby et al., 2001; Murphy et al., 1997a; Orme et al., 2013; Ryblom, 2015; Shah et al., 2012) or patients being prepared for a transfusion (n=5 studies) (Cheung et al., 2014; Khan et al., 2012) (Graham et al., 1999; Lee et al., 1998; Lee et al., 1997). Two studies included both patient groups (Court et al., 2011; Moxey et al., 2005). Patients were broadly classified as: 1) receiving transfusions in the context of surgery only (n=6 studies) (Court et al., 2011; Graham et al., 1999; Khan et al., 2012; Lee et al., 1998; Lee et al., 1997; Moxey et al., 2005); 2) mixed groups of transfusion recipients participating in the same study (n=6 studies in total,(Cheung et al., 2014; Shah et al., 2012) n=4 studies including surgical patients) (Davis et al., 2012b; Fitzgerald et al., 1999; Luby et al., 2001; Murphy et al., 1997a); 3) receiving regular transfusions every two to four weeks (Orme et al., 2013) or monthly (Ryblom, 2015); or 4) receiving transfusions for anaemia (Adams et al., 2011).

In total, 4,841 HCPs participated in included studies with a greater number of female HCPs (n=659) versus male (n=552) when reported in ten studies only

(Adusei et al., 2018; Al-Riyami et al., 2016; Francis et al., 2009a; Graw et al., 2018; Islam et al., 2012; Lee et al., 2003; Leibovitz et al., 2004; Soares et al., 2017; Tavares et al., 2015; Vetter et al., 2014). Age ranged from 20 years to 65 years approximated from studies including age demographics and age means. Thirteen studies investigated a mix of HCP professions (Adusei et al., 2018; Amin et al., 2004; Ferguson et al., 2001; Hartford et al., 2015; Heddle et al., 2012; Lee et al., 2003; Leibovitz et al., 2004; Lowe et al., 2001; Manzini et al., 2018; Müller et al., 2014; Salem-Schatz et al., 1990; Treloar et al., 2001; Vetter et al., 2014) and equally thirteen studies assessed one HCP speciality or seniority (i.e. physicians / consultants (Al-Riyami et al., 2016; Cozzolongo et al., 2005; Ddungu et al., 2018; Francis et al., 2009a; Islam et al., 2012; von Babo et al., 2018), surgeons (Torella et al., 2001), GPs (D'Souza et al., 2004; Thonneau et al., 1991), nurses (Graw et al., 2018; Tavares et al., 2015), anaesthesiologists (Soares et al., 2017) and hospital managers or representatives (Graham et al., 2002). HCPs had between 1 and 15 years + reported clinical experience (Francis et al., 2009a; Leibovitz et al., 2004; Manzini et al., 2018; Tavares et al., 2015; Vetter et al., 2014).

2.3.3 Research designs and assessment approaches

Cross-sectional designs were most common, using participant self-report questionnaires (Adusei et al., 2018; Al-Riyami et al., 2016; Amin et al., 2004; Cheung et al., 2014; Court et al., 2011; Davis et al., 2012b; Ddungu et al., 2018; Graham et al., 1999; Graw et al., 2018; Hartford et al., 2015; Khan et al., 2012; Lee et al., 2003; Lee et al., 1997; Leibovitz et al., 2004; Lowe et al., 2001; Luby et al., 2001; Manzini et al., 2018; Müller et al., 2014; Murphy et al., 1997a; Salem-Schatz et al., 1990; Shah et al., 2012; Soares et al., 2017;

Tavares et al., 2015; Thonneau et al., 1991; Vetter et al., 2014; von Babo et al., 2018) (Table 2). Some included studies reported pilot testing all or some of the materials (14 HCP studies (D'Souza et al., 2004; Ddungu et al., 2018; Francis et al., 2009a; Graham et al., 2002; Hartford et al., 2015; Heddle et al., 2012; Islam et al., 2012; Lee et al., 2003; Leibovitz et al., 2004; Salem-Schatz et al., 1990; Soares et al., 2017; Tavares et al., 2015; Treloar et al., 2001; von Babo et al., 2018) and four patient studies (Cheung et al., 2014; Davis et al., 2012b; Lee et al., 1997; Ryblom et al., 2015)). Four studies reported the use of validated study materials (Court et al., 2011; Ryblom et al., 2015; Tavares et al., 2015; Vetter et al., 2014). Materials were published in reports of fourteen studies (Adams et al., 2011; Al-Riyami et al., 2016; Amin et al., 2004; Cheung et al., 2014; Ddungu et al., 2018; Francis et al., 2009a; Graw et al., 2018; Islam et al., 2012; Khan et al., 2012; Manzini et al., 2018; Murphy et al., 1997a; Orme et al., 2013; Torella et al., 2001; von Babo et al., 2018) and additional materials were received from seven study authors (Adusei et al., 2018; Heddle et al., 2012; Lee et al., 1998; Luby et al., 2001; Moxey et al., 2005; Müller et al., 2014; Ryblom et al., 2015) of 27 who were contacted.

2.3.4 Quality appraisal of included studies

Overall, the quality of the set of included studies was moderate to high. Quality appraisal ratings ranged from 45-100%. Seventeen studies (Adams et al., 2011; Amin et al., 2004; Court et al., 2011; Ddungu et al., 2018; Francis et al., 2009a; Graham et al., 1999; Graw et al., 2018; Islam et al., 2012; Lee et al., 1997; Manzini et al., 2018; Moxey et al., 2005; Orme et al., 2013; Ryblom et al., 2015; Salem-Schatz et al., 1990; Soares et al., 2017; Tavares et al., 2015; von Babo et al., 2018) scored higher than 90%, with 90%

considered by the review team members as the threshold indicating a high-quality study. Studies detailing steps taken to analyse and verify the data received, for example, received high-quality assessment scores of more than 90%. Studies where explanation was not provided of how the participants were selected, to ensure less biased response, received low scores (<65%) (Cozzolongo et al., 2005; Khan et al., 2012; Shah et al., 2012; Thonneau et al., 1991; Torella et al., 2001).

2.3.5 Time points patients' perceptions assessed (in relation to the transfusion)

Besides the five studies investigating the perceptions of patients being 'prepared for a transfusion' (Cheung et al., 2014; Graham et al., 1999; Khan et al., 2012; Lee et al., 1998; Lee et al., 1997), only three studies reported the time point at which the patients' perceptions were assessed. This was either within 48 hours of the transfusion (Davis et al., 2012b), 'about 24 hours after the transfusion' (Adams et al., 2011) (i.e. post-transfusion inpatients) and before and after (day 1, 2, 3, 4 and 7) a two-unit red blood cell transfusion (Ryblom et al., 2015). The majority of patient studies, however, did not report investigating patients' perceptions before transfusion, and no study reported assessing patients' perceptions during transfusion with recruitment targeted to inpatients who have received transfusions (Adams et al., 2011; Davis et al., 2012b; Fitzgerald et al., 1999; Luby et al., 2001; Murphy et al., 1997a; Shah et al., 2012).

2.3.6 Blood components, donation methods or alternatives investigated

The majority of study authors (n=24, 58%) did not report which blood component, donation method or alternative was being investigated (Adams et al., 2011; Adusei et al., 2018; Al-Riyami et al., 2016; Amin et al., 2004; Cheung et al., 2014; Court et al., 2011; Cozzolongo et al., 2005; D'Souza et al., 2004; Davis et al., 2012b; Fitzgerald et al., 1999; Graw et al., 2018; Hartford et al., 2015; Heddle et al., 2012; Khan et al., 2012; Lee et al., 2003; Leibovitz et al., 2004; Luby et al., 2001; Murphy et al., 1997a; Orme et al., 2013; Salem-Schatz et al., 1990; Shah et al., 2012; Tavares et al., 2015; Thonneau et al., 1991; Vetter et al., 2014). Autologous transfusion (PAD) was the most commonly specified donation method (n=8 studies), either independently (Lee et al., 1998; Moxey et al., 2005) or compared with allogeneic transfusion (Graham et al., 1999; Lee et al., 1997) and other alternatives (Ferguson et al., 2001; Graham et al., 2002; Lowe et al., 2001; Torella et al., 2001; Treloar et al., 2001). Red blood cells were investigated in seven studies, either in isolation (Ryblom et al., 2015; Salem-Schatz et al., 1990; von Babo et al., 2018) or compared with alternatives (Manzini et al., 2018; Soares et al., 2017) or the alternative of 'monitoring' (i.e. '*managing a patient with borderline haemoglobin by watching and waiting instead of transfusing red cells')* (Francis et al., 2009a; Islam et al., 2012) or platelets, whole blood transfusion and alternatives (Ddungu et al., 2018). One study assessed HCPs' perceptions of transfusion of fresh frozen plasma (FFP) (Müller et al., 2014).

2.3.7 Citation of theory

Reliability analysis of the presence or absence of theory, and the location where theory was cited reached 100% agreement. Twelve unique theories were identified across 11 papers, including theoretical models (e.g. Psychometric Model of Perceived Risk (Slovic, 1987) (see Appendix 4: Table of theories identified in the systematic review). Three studies cited multiple theories (Ferguson et al., 2001; Lee et al., 1998; Lowe et al., 2001) and in eight papers theory was cited in the introduction and discussion as well as being applied in the methods to inform the design of the study or study materials (Amin et al., 2004; Ferguson et al., 2001; Francis et al., 2009a; Islam et al., 2012; Khan et al., 2012; Lee et al., 2003; Lee et al., 1998; Salem-Schatz et al., 1990). Study authors based study materials on theory, for example by developing interview topic guides based on the Theoretical Domains Framework (TDF) (Michie et al., 2005) or survey questions to examine risk perceptions (Ferguson et al., 2001; Francis et al., 2009a; Islam et al., 2012; Lee et al., 1998; Salem-Schatz et al., 1990). Six theories (Theories 2-7, Appendix 4) consist of predominantly risk-related constructs (i.e. mental representations of hazards in terms of their *dread* or *unknown risk* potential) (Slovic, 1987). Thus, the theoretical basis to the existing blood transfusion perceptions literature focuses largely on risk.

2.4 Perceptions of blood transfusion

Reliability of the extracted perceptions from 10% of papers (n= 4 papers) by two reviewers was between 83% and 100%, with disagreements discussed until 100% agreement was reached for each paper.

2.4.1 Inductive qualitative synthesis

In total, 104 data points (excerpts of data containing reported perceptions) were extracted across the 41 studies. Data points often contained more than one reported perception. These reported perceptions were synthesised by BV into 195 initial subthemes that were then further synthesised into 13 initial over-arching themes. These 13 themes and subthemes were iteratively consolidated into six over-arching themes of perceptions of blood transfusion. For example, initial subthemes of ‘infection’ and ‘safety’ were combined to an over-arching theme labelled ‘safety/risk’. ‘Concern/worry’ and ‘fear/dread’ subthemes were consolidated into an over-arching theme labelled ‘Negative emotions’. The final six themes contained 25 subthemes and can be considered as either cognitive or emotional (‘Safety / risk,’ ‘Negative emotions’, ‘Alternatives’, ‘Health benefits’ and ‘Necessity’) or behavioural: ‘Decision making’. Cognitive or emotional themes contain patients’ and HCPs’ perceptions as either thoughts or emotions experienced or hypothetically considered in relation to transfusion. For the ‘Decision making’ theme the content represents perceptions that may result in behaviours, which are observable in the clinical setting (e.g. patients not questioning transfusion decisions, HCP prescribing behaviours).

Data points from the findings of papers included in the updated searches (n=32 of 104) were embedded into the existing thematic structure, with new subthemes generated when the data could not be coded into the existing structure of themes/subthemes. Table 3 shows the six themes and their subthemes. New subthemes generated from the latest search have been marked with a *. Example quotes for each subtheme are provided in Appendix 5: Themes and subthemes identified in Study 1 inductive synthesis.

Table 3 Perceptions of blood transfusion: inductive synthesis themes and subthemes

Themes					
Safety / risk	**Negative emotions**	**Alternatives**	**Health benefits**	**Necessity**	**Decision making**
Subthemes					
Risk compared with other treatments	Generalised concern about blood transfusion	Factors influencing the use of alternatives (e.g. patient demand, suitability & cost)	Perceived benefit, (e.g. feeling better post transfusion)	Patient understanding of the transfusion's necessity	Transfusion counselling changed patients' perceptions
Risk compared with other hazards	Concern about use of alternatives	Confidence of using alternatives	Benefit compared with other treatments	Need recognised through symptoms*	Patients informed of transfusion benefits, risks & alternatives*
Risk of contracting an illness from contaminated blood	Worry relating to transfusion risk	Preference for alternatives	Experienced benefits (e.g. improved strength, reduced headaches & fatigue)*	Clinical and contraindications	Patient transfusion refusal
Adverse reaction to a blood transfusion	Apprehension about receiving a transfusion	Willingness to pay for autologous transfusion			Confidence in carrying out transfusion process *
Risk of death from blood transfusion	Fear of transfusion errors	Advantages / disadvantages of alternatives			Lack of choice or questioning of transfusion decision
Generalised risk	Improved mood after blood transfusion				Transfusion prescription: cost and availability influences
	Frequent transfusion making patients feel trapped in own home*				

* new subtheme generated from updated search results

Summary of themes

Safety / risk: Patients and HCPs reported a low perceived risk of contracting an illness from contaminated blood (Graham et al., 2002; Graw et al., 2018; Lee et al., 1997; Lowe et al., 2001; Moxey et al., 2005), with one study reporting decreases over time in GPs' perceptions of blood transfusion risk (Cozzolongo et al., 2005). Blood transfusion was ranked as having low / intermediate risk in comparison to other hazards (e.g. skiing, alcohol, nuclear reactors (Ferguson et al., 2001; Lee et al., 2003)) and treatments (e.g. surgery or anaesthetic) (Court et al., 2011; Fitzgerald et al., 1999). Platelets were associated in one study with higher disease transmission risk than other blood components, thus used with caution (Ddungu et al., 2018). Some patients reported risks associated with transfusions as being somewhat acceptable and unavoidable (Fitzgerald et al., 1999). Some HCPs reported confidence in the safety of blood (Amin et al., 2004), whereas others acknowledged potential danger associated with transfusion, such as if errors (Heddle et al., 2012) or complications such as transfusion-associated circulatory overload, allergic reactions, transfusion-related acute lung injury, bacterial contamination or infection-transmission occurred (Adusei et al., 2018; Manzini et al., 2018; Müller et al., 2014; Soares et al., 2017).

Negative emotions: Many factors, such as disease or infection risk (Adams et al., 2011; Moxey et al., 2005), adverse events (Heddle et al., 2012; Vetter et al., 2014) or general apprehension about receiving a transfusion (Luby et al., 2001) resulted in reported concern or worry in patients and HCPs. Some patients did not report concerns about receiving transfusions (Moxey et al., 2005) or reported that their mood improved post transfusion (Ryblom et al., 2015). Some physicians reported that they would be concerned if new viral or bacterial threats emerged, and therefore would reduce their level of blood product use (Amin et al., 2004). Some HCPs reported concerns about watching and waiting instead of transfusing, but others reported no concerns (e.g. regarding potential complications of transfusions for patients) (Francis et al., 2009a; Islam et al., 2012).

Alternatives: Some surgical patients, surgeons, GPs and anaesthetists reported preferring alternatives in order to reduce perceived risk associated with transfusion (Ferguson et al., 2001; Graham et al., 1999; Lowe et al., 2001; Moxey et al., 2005). Willingness to pay for autologous transfusion (PAD) was also high for patients reporting dread of receiving an allogeneic transfusion (Lee et al., 1998; Lee et al., 1997). HCPs' perceptions of considering alternatives for their patients were mixed, and influenced by evidence, technique complexity, patient demand, the patient's condition and perceptions of free and safe blood supplies (Francis et al., 2009a; Graham et al., 2002; Islam et al., 2012; Torella et al., 2001; Treloar et al., 2001).

Health benefits: Patients receiving transfusions monthly for Myelodysplastic syndromes (MDS) reported that transfusions restored their physical and mental strength and eased symptoms such as breathlessness, fatigue and headaches (Ryblom et al., 2015) and there was evidence of benefits outweighing risk for some patients (Fitzgerald et al., 1999). However, some hospice and hospital inpatients also found it difficult to perceive the benefit of the transfusion (Orme et al., 2013), in some cases due to ill health associated with their medical conditions (Fitzgerald et al., 1999). For HCPs, while some HCPs perceived transfusion to be beneficial (Lee et al., 2003) others reported that not transfusing, and instead monitoring the patient's condition may reduce transfusion risks (Francis et al., 2009a; Islam et al., 2012).

Necessity: Patients reported understanding why their transfusions were necessary, such as due to blood loss or low blood counts (Davis et al., 2012b; Murphy et al., 1997b). Patients with MDS reported recognising when their transfusions were needed through exacerbation of symptoms, such as walking difficulties, poor concentration, heart palpitations and nausea (Ryblom et al., 2015). HCPs considered transfusions necessary when there was an acute or risk of bleeding, functional deterioration and anaemia (from chemo-and/or radiotherapy or preoperative) (Ddungu et al., 2018; Hartford et al., 2015; Leibovitz et al., 2004; Manzini et al., 2018; Soares et al., 2017). For patients, reasons for transfusing were reported to be generalized weakness, trauma and surgery (Luby et al., 2001).

Decision making: HCPs reported making transfusion decisions on a case-by-case basis (Francis et al., 2009a; Islam et al., 2012; Leibovitz et al., 2004), with a shift from blood being considered as '*good for everybody*' (Treloar et al., 2001). Decisions were reportedly influenced by cost, the patient's age and health condition (e.g. coronary artery disease) or the availability of blood (Ddungu et al., 2018; Leibovitz et al., 2004; Salem-Schatz et al., 1990; von Babo et al., 2018). Haemoglobin levels, pallor and the safety of the blood (disease free) influenced transfusion decisions (Adusei et al., 2018; Ddungu et al., 2018; Hartford et al., 2015; Leibovitz et al., 2004; Manzini et al., 2018; Müller et al., 2014; Soares et al., 2017; von Babo et al., 2018). Physicians in one study reported that they were confident to carry out the transfusion process (Tavares et al., 2015) and widely explained the risks and benefits of transfusion to patients (Al-Riyami et al., 2016). Some patients reported, however, that physicians often made the transfusion decisions (Adams et al., 2011) and in one study patients after transfusion counselling reported that doctors relied too much on transfusion (Khan et al., 2012). Some patients in a low-income country would not consent to transfusion due to infection risk (Shah et al., 2012).

2.4.2 Changes in perceptions over time

Figure 5 displays the distribution of themes for broadly each 5-year period of study publication. This shows that all themes have been sporadically investigated since 1984 with less publications on this topic pre-1996 and during 2006-2010. Topics within the theme of ‘Safety/Risk’ are the most consistently investigated, with a surge of research into ‘Decision making’ and ‘Necessity’ post 2011. ‘Negative emotions’, ‘Alternatives’ and perceptions of ‘Health benefits’ have had some investigation during the middle to late 20-year period of this timeline, but this has declined most recently since 2016.

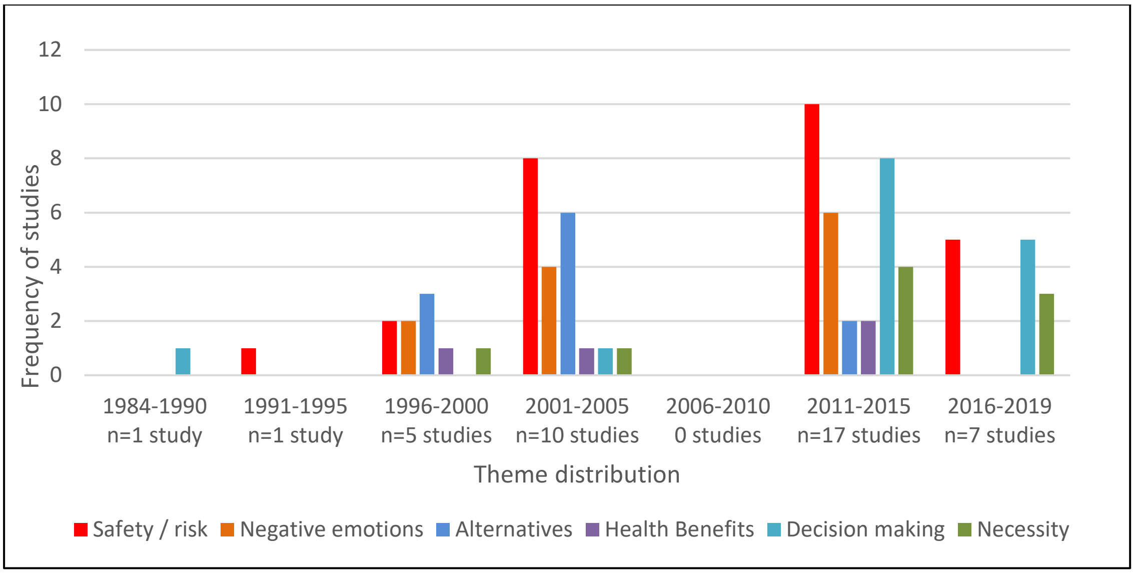


Figure 5 Systematic review reported themes of perceptions by publication years

2.4.3 Relationship between themes

Relationships between the themes were identified (synthesis stage 4) and represented in a conceptual model of blood transfusion perceptions (Figure 6) to portray the relationship between the themes. The themes were recognised as constructs in the model that are either cognitive or emotional, with the behavioural 'Decision making' construct positioned to the right of the model.

The arrows connecting the cognitive or emotional constructs depict relationships; 'Alternatives' and 'Safety/risk' share relationships with 'Negative emotions' due to patients and HCPs holding negative emotions about potential transfusion risks and this influences their preferences for alternatives, which are considered in terms of their safety. 'Health benefit' and 'Safety/ risk' are directly connected as the benefit of transfusion often also outweighed risk concerns (Fitzgerald et al., 1999). All of the cognitive or emotional constructs are proposed to influence 'Decision making', represented by the central arrow. For example, 'Negative emotions' influences 'Decision making' through 'Safety/risk', with concerns about the safety of blood influencing decision making for HCPs (Amin et al., 2004) and patients also directly accepting blood due to the potential benefits (Davis et al., 2012b), creating an association between 'Health benefits' and 'Decision making'. 'Alternatives' and 'Necessity' also naturally link to 'Decision making' due to the consideration of alternatives and transfusion necessity based on patients' clinical conditions.

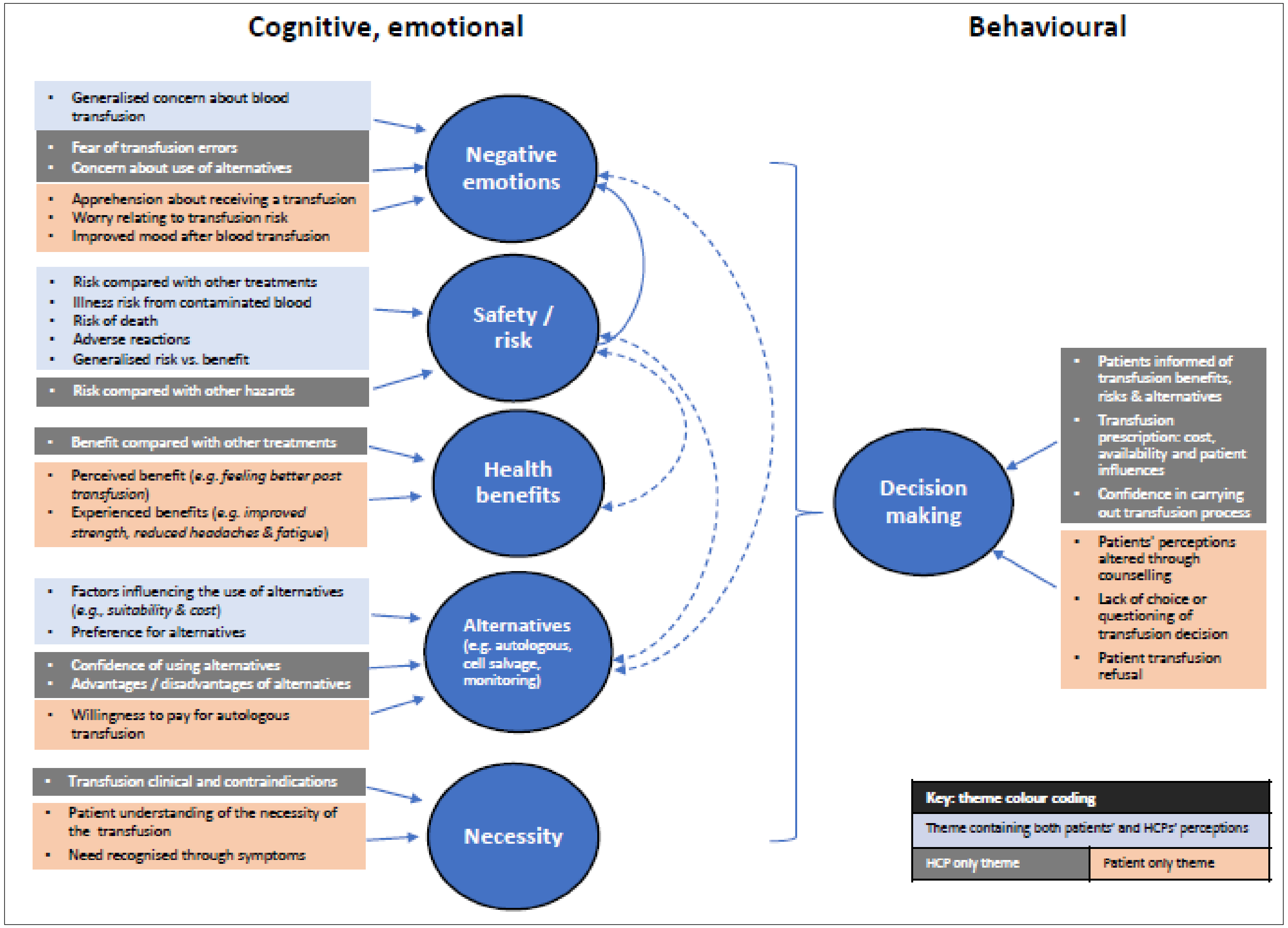


Figure 6 Conceptual model of blood transfusion perceptions

Constructs linked with single headed arrows indicating a causal relationship, double headed dashed arrows indicate a bi-directional relationship. Themes adjacent to the construct are shaded as indicated in key.

2.5 Discussion

This systematic review included 41 studies reporting adult patients' and HCPs' perceptions of blood transfusion. The studies in this review were generally of moderate to high quality methodologically and included a range of theories, mostly related to 'risk' in parallel with the consistent reportage of 'risk' related perceptions across the timelines of papers. The synthesis of the reported perceptions highlighted that patients and HCPs viewed transfusion with low to moderate risk, but that some perceptions of transfusion-associated risk, or negative emotions, were associated with the use or consideration of transfusion alternatives. Some patients perceived benefit from transfusion (Davis et al., 2012b; Murphy et al., 1997a; Ryblom et al., 2015), however, other patients found the benefit difficult to discern due to the impact of their illness (Fitzgerald et al., 1999; Orme et al., 2013). It was also reported that HCPs led the decision making (Adams et al., 2011), yet as reported in one paper, involved patients to provide information about the benefits, risks and alternatives associated with transfusion (Al-Riyami et al., 2016). The emergent over-arching themes about blood transfusion perceptions were organised into a conceptual model of blood transfusion perceptions with five cognitive or emotional constructs antecedent to the construct of 'Decision making'.

The context of studies in the review bears consideration due to its likely influence on the findings. Most studies investigated the perceptions of patients receiving or being prepared for transfusions in relation to surgery. Transfusion recipients commonly had their perceptions investigated post transfusion, and studies with HCPs most often included mixed groups. As more transfusions are reportedly used in medical contexts, such as emergency and haematology compared to surgical, (64% medical vs. 29.4% surgical; red blood cell transfusion use in North England, 2004) (Wallis et al., 2006) some patient and HCP groups may have been under-represented. For example, emergency transfusion patients were identified in only two studies (Fitzgerald et al., 1999; Luby et al., 2001), and haematology patients in five studies (n=3 studies with mixed patient samples: (Adams et al., 2011; Cheung et al., 2014; Davis et al., 2012b) and two studies either conducted in a day hospice setting (Orme et al., 2013) or in Sweden, with findings only codable to the themes of 'Health benefits' and 'Necessity' (Ryblom et al., 2015)). Thus, there is a gap in a more detailed investigation of perceptions from specific patient and HCP groups, including emergency or regular recipients of transfusion.

This review also failed to identify papers reporting demographic data of patients' religions, making it unclear whether patients who oppose transfusion based on their religious beliefs, such as Jehovah's Witnesses, were involved in included studies. In addition, whether patients and HCPs held different perceptions of transfusion per blood component or for alternatives was difficult to determine as the blood component being investigated was not specified in 24 studies. For these studies, HCPs may have been considering different blood components than their colleagues when reporting their perceptions, or patients may not have been aware of the blood component being transfused. If patients lacked information about the risks or reasons for the transfusion or specific blood component being offered, this would impact their ability to fully evaluate the treatment's efficacy compared to any alternatives (Horne, 2003). Lack of understanding of a proposed treatment's necessity, alongside patients' concerns being unaddressed could impact treatment uptake (Horne et al., 2013).

Theories containing risk constructs were most frequently cited in this literature, however, the most recent study citing a theoretical underpinning was in 2012 (Islam et al., 2012). Whilst blood transfusion is a treatment associated with risk (Eder et al., 2013; Llewelyn et al., 2004), patients and HCPs perceived the risk of contracting an illness from a blood transfusion as low (Graham et al., 2002; Lee et al., 1997; Lowe et al., 2001). Yet, when surveyed, patients' and HCPs' perceptions of blood transfusion risks (e.g. infection contraction or adverse events) were associated with negative emotions (Moxey et al., 2005; Vetter et al., 2014). The systematic review identified by the search (Ngo, 2013) focussed on identifying studies that 'measured or discussed' transfusion risk perceptions with a broader range of 'stakeholders' beyond patients and HCPs (e.g. blood donors, journalists) (N=15 studies included). Whilst this was inclusive to broader groups, focusing on 'risk' alone ignores the balance and careful risk vs benefit trade off that patients and HCPs have to make when encountering real transfusion scenarios (Fitzgerald et al., 1999). Risk and benefit, for example, are also elements of transfusions informed consent discussions, per UK guidance (JPAC, 2019; SaBTO, 2011), alongside discussing 'possible alternatives to transfusion'. Therefore, this current review went beyond the (Ngo, 2013) review and sought to inductively identify a broader range of transfusion perception themes from a larger amount of studies across a 35-year timeframe, considering the relationship between themes.

Strengths of this review include the development of a conceptual model of blood transfusion perceptions, which makes the themes of perceptions potentially more accessible, through visual presentation where key relationships between constructs can be portrayed. Half of the six constructs in the model were ‘shared’ and included both patients’ and HCPs’ perceptions. This highlights a moderate level of similarity in how patients and HCPs perceive transfusion, (e.g. a level of correspondence in broad thematic areas, such as safety/risk), although some patients’ concerns related to disease or infection risk from blood transfusion (Adams et al., 2011; Moxey et al., 2005) were elevated in comparison to reported HCP concerns, which were more linked to the possibility of adverse events, such as allergic reactions (Vetter et al., 2014). Gaps in a shared understanding of all themes identified by this review support further joint investigation of both groups’ perceptions, strengthening patient-HCP collaboration, such as when executing shared decision-making (Toledo, 2014).

Some methodological considerations are potential limitations of this review. There is debate in the literature about the feasibility of conducting syntheses of qualitative evidence (Dixon-Woods et al., 2005). Conversion of quantitative evidence to qualitative themes is similarly somewhat controversial (Dixon-Woods et al., 2005). In this review, an approach was taken whereby quantitative data, usually descriptive frequency data, were used during the interpretation of the results, for example, when considering how prevalent, thus important, a perception was. Themes were then summarised with these data in mind, for example, that transfusion was perceived with ‘low to intermediate risk’.

These review findings could be used to inform clinical practice and future research. For clinical practice, the findings of this review can be used by HCPs when discussing transfusion decisions with their patients in consultations, with the identified themes converging with UK transfusion guidance (e.g., discussing transfusion risks, benefits and possible alternatives with patients) (JPAC, 2019; SaBTO, 2011). This guidance stipulates that patients should be aware of the indication for transfusion and type of blood component to be used, all being advocated by this programme of research and a key data extraction item of the included studies in this review. Beyond UK guidance, some low- and middle-income countries were also represented in the results, with these countries having lower resources and differing levels of risk exposures. However, this review identified similar perceptions across countries; that some patients in a low-income country held concerns about transfusion because of perceived risks (Shah et al., 2012), indicating that greater discussion of these themes would be widely beneficial. Studies from low- (Uganda) and middle-income countries (Ghana) in this review recommended physician transfusion training to be added to their medical institution training, with a specific focus on transfusion decision making (Adusei et al., 2018; Ddungu et al., 2018). Such in-service training could address culturally specific practices and norms and highlight specific perceptions to be investigated further.

In terms of the development of future research, a key gap in the review was the extent to which theory was used. Subsequent studies in this programme of research were informed by theory, beginning with an exploration of the extent to which themes identified in this inductive synthesis corresponded with constructs of treatment perceptions in the broader treatment perceptions literature (Chapter 3). This provided a basis for qualitatively exploring blood transfusion perceptions from an under-researched clinical area where knowledge gaps exist (e.g. perceptions from haematology care settings) (Study 2/ Chapter 4). Haematology settings administer transfusions to patients on a routine basis, with patients often receiving repeated transfusions for cancer-related diagnoses or long-term blood disorders. Qualitative research is often used to investigate in detail peoples' perceptions of their health issues and has been minimally used in blood transfusion perception research to date (n=11 of 41 studies). Greater use of qualitative research is advocated in transfusion medicine to generate findings that can enhance the safety and quality of the blood system (Whittaker, 2002). The final study in this programme of research (Study 3) built on its preceding Study 2 to investigate transfusion healthcare delivery further, in view of optimising patients' transfusion services (Study 3/ Chapter 5).

In conclusion, this systematic review identified cognitive, emotional and behavioural themes of blood transfusion perceptions, themes that were shared by a wide range of patients and HCPs. Represented as a conceptual model, the complete set of 'Cognitive and emotional' constructs may be associated with observable behaviours resulting from 'Decision making' in clinical practice. This may signal areas for discussion or consideration in relation to transfusion decision making, consistent with recommended UK guidance (JPAC, 2019; SaBTO, 2011). The blood transfusion constructs are discussed further in the following Chapter 3, in relation to their link to the treatment perceptions literature and gaps from this review will be addressed in Study 2 (Chapter 4).

3 Mapping of blood transfusion perceptions constructs with treatment perceptions frameworks.

This chapter presents a comparison of constructs from the conceptual model of blood transfusion perceptions developed in the systematic review (Chapter 2) and constructs from key treatment perceptions frameworks. This comparison was undertaken to evaluate how the inductively developed constructs comprising the blood-transfusion conceptual model align with the broader treatment perceptions literature.

3.1 Background

In the early 1960s psychologists began investigating fearful disease communication and responses to health threats. This led to the identification of cognitive representations of danger (e.g., disease threat), distinguished from plans that people in turn form as protective responses (Leventhal, 1970; Leventhal et al., 1997). As people seek to apply common-sense to threats they face, they construct detailed representations of their health threats (illnesses and symptoms) to generate goal directed behaviours for self-management (such as taking treatments), goal attainment and response efficacy (Leventhal et al., 2003). As described in Chapter 1, the five core dimensions of illness representations (illness identity, cause, time-line, consequence or cost and cure/control) have been integrated into a five-component measure to assess peoples' underlying cognitive illness representations; The Illness Perceptions Questionnaire (IPQ) (Weinman et al., 1996). The IPQ and its revised version (IPQ-R) (Moss-Morris et al., 2002) have been widely applied to investigate perceptions across a range of illness populations, such as for patients with cancer, endocrine, nutritional and metabolic diseases and mental and behavioural disorders etc., (Broadbent et al., 2015). It is argued, however, that the five dimensions of illness representations can also be used to conceptualise treatments; identity (e.g., label of how to use / take), cause (e.g., how it works), time-line (till benefits apparent), consequence or cost (e.g., side effects) and cure/control (i.e. potential to cure illness) (Leventhal et al., 1997; Leventhal et al., 2010). Thus, instead of viewing treatments as a means of ‘curing’ or ‘controlling’ a condition, a broader range of perceptions could be considered, e.g., perceptions of treatment benefits and side effects. This would help to acknowledge these factors and the role that these perceptions may have in treatment selection and adherence.

Researchers continuously seek to investigate patients’ treatment perceptions, understanding that these perceptions have an influence on health outcomes, such as adherence (Horne, 1999). There are numerous models and measures available to investigate patients’ treatment perceptions, one of which is the widely used Beliefs about Medicines Questionnaire (BMQ) (Horne et al., 1999b). The BMQ is of interest in the current context, as although not a ‘medicine’, such as drugs taken in tablet form, transfusions are prescribed by healthcare professionals (HCPs) with the intention to treat ill or injured patients. Transfusions should be prescribed, as with medicines, in line with the patient’s clinical need and consideration of risks and alternative treatments. Patient informed consent is also sought prior to or retrospectively when transfusions are administered (JPAC, 2019). Thus, their beliefs about transfusions are key to decision making.

The BMQ was constructed using a factor analysis of themes related to patients' medicine-related beliefs identified in published studies and qualitative interviews with chronically ill patients. The BMQ assesses beliefs related to specific medicines, in particular of the 'Necessity' of prescribed medicines: '*Beliefs about the necessity of the medicines for maintaining health*', '*The perceived role of medication in protecting against deterioration of the present and future health status of the patient*' and of 'Concern' about prescribed medicines: *'having to take my medicines worries me; my medicines are a mystery to me'* (Horne et al., 1999b). A separate section covers medicine beliefs in general: General-Harm: '*Themes relating to the nature of medicines'* and General-Overuse: '*How medicines are used by doctors'* (Horne et al., 1999b). 'Necessity' and 'Concern' beliefs about specific medicines provide evidence for a Necessity-Concerns framework, where higher adherence is associated with stronger perceptions of the necessity of the treatment and fewer concerns about treatment (Horne et al., 2013).

Studies conducted using the BMQ have been able to identify strong associations between medication beliefs and adherence, with patients less likely to take their medicines as prescribed if they hold concerns about them (Pound et al., 2005). In a study of stroke patients, non-adherent patients scored lower on positive beliefs about medicines and higher on negative beliefs (Sjölander et al., 2013). Thus, the BMQ can be considered as a useful instrument to assess patients' beliefs, which can then be discussed in consultations, such as concerns about adverse effects (Neame et al., 2005). Other researchers have used the BMQ as a framework for adapting surveys to asses beliefs about specific treatments and clinical interventions, such as: beliefs about surgery (Francis et al., 2009c), beliefs about deferoxamine (chelation therapy with a slow pump infusion) versus oral iron chelators (Trachtenberg et al., 2012) and as identified in the preceding systematic review (Chapter 2), to develop a Beliefs about Transfusion Questionnaire (Khan et al., 2012).

Whilst there appears to be value in adapting the BMQ, there are also other instruments and frameworks that have been developed to investigate treatment perceptions in specific patient populations. The Treatment Representations Inventory (TRI) was developed to explore treatment representations in a coronary artery disease (CAD) population (Hirani et al., 2008). The TRI explores patients' emotional concerns of managing treatments, decision satisfaction and cure. During validation of the TRI, correlations between treatment concerns and the remaining subscales were not found; indicating that whilst patients may be worried about their treatment, they may also value it and hold optimistic outcome expectancies (Hirani et al., 2008).

The range of subscales in the BMQ and TRI indicate that a variety of treatment beliefs could be held by patients, including beliefs covering 'decision-making' related domains ('decision satisfaction' from the TRI). The medicine taking literature also presents the broad range of potential decision-making beliefs. Literature from this field profiles medicine users as active or passive accepters of medicines, either consciously deciding to take their medicines as prescribed or relinquishing control over medicine taking (Dowell et al., 1997; Johnson et al., 1999) . It is also noted that people may modify or reject their treatment regimens, often after a period of testing (Johnson et al., 1999).

Some patients may conclude that complementary alternatives and alternative medicines are more suitable to treat their conditions. The complementary and alternative medicine beliefs inventory (CAMBI) was developed to assess patients' beliefs in natural treatments, participation in treatment and holistic health (Bishop et al., 2005). For instance, 'Beliefs in natural treatments' examines patients' beliefs about treatments being non-toxic, using natural ingredients and having no negative side effects. The 'participation in treatment' scale is used to assess patients' views on the extent that HCPs should solely make treatment decisions or seek to involve their patients (Bishop et al., 2005). The CAMBI may be relevant for blood transfusion, due to blood being derived from human donors, yet donor blood is processed, and transfusions are known to be associated in some cases with negative side effects (e.g., infections and reactions).

Taken together, the different instruments offer a broad range of frameworks for conceptualising and assessing treatment perceptions. It is important to consider how the six blood transfusion perception constructs from the systematic review conceptual model (Chapter 2) align to the broader treatment perceptions literature. A comparison of the transfusion constructs with constructs from frameworks and items from published measures in the broader literature would help establish the extent to which the blood transfusion constructs correspond with constructs and items from other treatment perceptions frameworks and measures.

Considering how the transfusion conceptual model constructs relate to the broader treatment perceptions literature would help to establish which frameworks may provide explanatory value to the understanding of blood transfusion perceptions. Key constructs to explore going forward when investigating transfusion perceptions may come to light, as well as unique or specific perceptions, relevant only to the transfusion context.

If the blood transfusion perceptions constructs hold convergence with the broader literature, this would support ongoing use of the conceptual model as a structure to consider blood transfusion perceptions within (i.e. that key 'treatment perceptions constructs' are not being missed by utilising the blood transfusion conceptual model going forward). This would maintain use of the transfusion constructs, which profile specific perceptions of transfusion from a range of studies, potentially worthwhile to explore further and not abandon. Items from published measures may also add value for ongoing qualitative research. Learning can be taken from the description of quantitative item and applied to the transfusion context, preventing quantitative items being purely translated into qualitative questions without recourse to earlier literature.

3.1.1 Chapter objective and methods

This chapter aimed to map the blood transfusion conceptual model constructs to constructs from broader treatment perceptions frameworks and items from published measures to explore potential comparisons.

The researcher (BV) conducted this process by mapping the extent that each blood transfusion conceptual model construct corresponded with treatment perceptions constructs and items in recognised treatment perceptions frameworks and published measures, either fully, partially or ‘no-match’. Full mapping indicates that the constructs / items aligned (e.g. ‘Health benefits’ and a construct named ‘Benefits’, which is inclusive of considering health related benefits). Partial mapping indicates that some similarity between the constructs / items exists, however, the construct definitions do not fully match (e.g. ‘Alternatives’ and a construct / items largely covering perceptions of ‘holistic health and wellness’). No match indicates that the constructs / items do not correspond in that instance and that they are conceptually unique (e.g. ‘Decision making’ and ‘Risk’). Descriptions of treatment perceptions constructs or items aided the researcher to make mapping decisions. For example, if two constructs held some similarity, in that part of the description from the treatment perceptions construct held similarity to the blood transfusion construct, the overall mapping for the constructs would be considered ‘partially’ matched. The mapping decisions were reviewed by an additional team of two Health Psychologists and discussed until full agreement was reached.

The researcher identified five frameworks and published measures for comparison based on their relevancy to the treatment perceptions literature: 1) the Beliefs about Medicines Questionnaire (BMQ) (Horne et al., 2004; Horne et al., 1999b) supported with the available items from the Khan, Watson and Dombrowski (2012) Beliefs about Transfusion Questionnaire (Khan et al., 2012); 2) the complementary and alternative medicine beliefs inventory (CAMBI) (Bishop et al., 2005); 3) the treatment representations framework (Leventhal et al., 1997; Leventhal et al., 2010); 4) the Treatment

Representations Inventory (TRI) (Hirani et al., 2008) and 5) a model of medicine taking (Pound et al., 2005).

3.2 Results

Table 4 presents the mapping results, with green cells indicating full mapping between the constructs and items, orange cells indicating partial mapping and blank to indicate no match. A confirmatory tick mark is displayed in the full and partially mapped cells. Summaries of the mapping per framework are provided subsequent to the table.

Following the table, there will be a more detailed description of each framework or measures' overlap with the transfusion constructs followed by a section summarising the overlaps and discussing patterns across the models.

Table 4 Mapping of treatment perceptions and blood transfusion perceptions constructs

	Constructs of blood transfusion perceptions from the systematic review conceptual model					
	Safety/risk	***Health benefits***	***Alternatives***	***Negative emotions***	***Necessity***	***Decision making***
Constructs below from other treatment perception frameworks or items from published measures	Perceptions of transfusion safety, safety measures or risks associated with transfusion, such as infections, adverse reactions	The physical or psychological benefits of the transfusion (e.g. reduced fatigue)	Perceptions related to alternative treatments for patients rather than transfusion (e.g. autologous, cell salvage, monitoring)	Any emotions experienced about transfusions that caused (or could cause) distress	Beliefs that transfusion are necessary to maintain health.	Reasons when to/not to transfuse, how the transfusion decision was made or communicated, and the patients' role in that process.
Beliefs about Medicines Questionnaire items (Horne et al., 1999b) (Beliefs about transfusion questionnaire (BTQ) (Khan et al., 2012) constructs added to relevant domains by researcher, no guidance available in publication) ✓*indicates correspondence*						
General-**Harm** Themes relating to the nature of medicines: • *Most medicines are addictive* • *Medicines do more harm than good* • *People who take medicines should stop their treatment for a while every now and again* • *All medicines are poison*	✓					

	Constructs of blood transfusion perceptions from the systematic review conceptual model					
	Safety/risk	***Health benefits***	***Alternatives***	***Negative emotions***	***Necessity***	***Decision making***
Constructs below from other treatment perception frameworks or items from published measures	Perceptions of transfusion safety, safety measures or risks associated with transfusion, such as infections, adverse reactions	The physical or psychological benefits of the transfusion (e.g. reduced fatigue)	Perceptions related to alternative treatments for patients rather than transfusion (e.g. autologous, cell salvage, monitoring)	Any emotions experienced about transfusions that caused (or could cause) distress	Beliefs that transfusion are necessary to maintain health.	Reasons when to/not to transfuse, how the transfusion decision was made or communicated, and the patients' role in that process.
• *Blood Transfusion Questionnaire (BTQ): Blood transfusion can result in new health problems / Transfusions should only be a last resort*	✓				✓	
General-**Benefit** Individuals' beliefs about the potential benefits of medicines (Horne et al., 2004) • *In most cases the benefits of medicines outweigh the risks* • *Medicines help many people to live better lives*		✓				✓

	Constructs of blood transfusion perceptions from the systematic review conceptual model					
	Safety/risk	***Health benefits***	***Alternatives***	***Negative emotions***	***Necessity***	***Decision making***
Constructs below from other treatment perception frameworks or items from published measures	Perceptions of transfusion safety, safety measures or risks associated with transfusion, such as infections, adverse reactions	The physical or psychological benefits of the transfusion (e.g. reduced fatigue)	Perceptions related to alternative treatments for patients rather than transfusion (e.g. autologous, cell salvage, monitoring)	Any emotions experienced about transfusions that caused (or could cause) distress	Beliefs that transfusion are necessary to maintain health.	Reasons when to/not to transfuse, how the transfusion decision was made or communicated, and the patients' role in that process.
General-**Overuse** How medicines are used by doctors: • *If doctors had more time with patients they would prescribe fewer medicines* • *Doctors use too many medicines / place too much trust on medicines* • *Natural remedies are safer than medicines*	✓		✓			✓
BTQ: Doctors rely too much on transfusion / Doctors are too quick to suggest transfusion / People are not always told there are alternatives to transfusion			✓			✓

	Constructs of blood transfusion perceptions from the systematic review conceptual model					
	Safety/risk	***Health benefits***	***Alternatives***	***Negative emotions***	***Necessity***	***Decision making***
Constructs below from other treatment perception frameworks or items from published measures	Perceptions of transfusion safety, safety measures or risks associated with transfusion, such as infections, adverse reactions	The physical or psychological benefits of the transfusion (e.g. reduced fatigue)	Perceptions related to alternative treatments for patients rather than transfusion (e.g. autologous, cell salvage, monitoring)	Any emotions experienced about transfusions that caused (or could cause) distress	Beliefs that transfusion are necessary to maintain health.	Reasons when to/not to transfuse, how the transfusion decision was made or communicated, and the patients' role in that process.
Specific-**Concerns**: Concerns about the medicine (emotional: *having to take my medicines worries me*; cognitive: *my medicines are a mystery to me*) • *I sometimes worry about the long-term effects of my medicines* • *I sometimes worry about becoming too dependent on my medicines* • *My medicines disrupt my life*				✓		✓

	Constructs of blood transfusion perceptions from the systematic review conceptual model					
	Safety/risk	***Health benefits***	***Alternatives***	***Negative emotions***	***Necessity***	***Decision making***
Constructs below from other treatment perception frameworks or items from published measures	Perceptions of transfusion safety, safety measures or risks associated with transfusion, such as infections, adverse reactions	The physical or psychological benefits of the transfusion (e.g. reduced fatigue)	Perceptions related to alternative treatments for patients rather than transfusion (e.g. autologous, cell salvage, monitoring)	Any emotions experienced about transfusions that caused (or could cause) distress	Beliefs that transfusion are necessary to maintain health.	Reasons when to/not to transfuse, how the transfusion decision was made or communicated, and the patients' role in that process.
Specific-**Necessity**: Beliefs about the necessity of the medicines for maintaining health The perceived role of medication in protecting against deterioration of the present and future health status of the patient • *My health at present / in the future, depends on my medicines* • *My life would be impossible without my medicines*		✓			✓	✓

	Constructs of blood transfusion perceptions from the systematic review conceptual model					
	Safety/risk	***Health benefits***	***Alternatives***	***Negative emotions***	***Necessity***	***Decision making***
Constructs below from other treatment perception frameworks or items from published measures	Perceptions of transfusion safety, safety measures or risks associated with transfusion, such as infections, adverse reactions	The physical or psychological benefits of the transfusion (e.g. reduced fatigue)	Perceptions related to alternative treatments for patients rather than transfusion (e.g. autologous, cell salvage, monitoring)	Any emotions experienced about transfusions that caused (or could cause) distress	Beliefs that transfusion are necessary to maintain health.	Reasons when to/not to transfuse, how the transfusion decision was made or communicated, and the patients' role in that process.
• *Without medicines I would be very ill* • *My medicines protect me from becoming worse*		🟨			🟩	🟨
Treatment representations dimensions (Leventhal et al., 1997; Leventhal et al., 2010) ✓ *indicates correspondence*						
• Identity (e.g., label of how to use / take it: *my treatment will return me to my normal life)*		🟨 ✓				
• Cause (e.g., works by removing, killing or neutralising pathogenic material: *my treatment is a very technical procedure)*	🟨 ✓					

	Constructs of blood transfusion perceptions from the systematic review conceptual model					
	Safety/risk	***Health benefits***	***Alternatives***	***Negative emotions***	***Necessity***	***Decision making***
Constructs below from other treatment perception frameworks or items from published measures	Perceptions of transfusion safety, safety measures or risks associated with transfusion, such as infections, adverse reactions	The physical or psychological benefits of the transfusion (e.g. reduced fatigue)	Perceptions related to alternative treatments for patients rather than transfusion (e.g. autologous, cell salvage, monitoring)	Any emotions experienced about transfusions that caused (or could cause) distress	Beliefs that transfusion are necessary to maintain health.	Reasons when to/not to transfuse, how the transfusion decision was made or communicated, and the patients' role in that process.
• Time-line (e.g., when and for how long to take: *the benefits of my treatment take a while to become apparent)*		✓				
• Consequence or cost (e.g., symptoms or side effects, physical damage, addiction, financial costs etc., *my treatment produces many side effects)*	✓					
• Cure/control (e.g. cure and control of symptoms and objective indicators of disease: *my treatment will cure my illness)*		✓				

	Constructs of blood transfusion perceptions from the systematic review conceptual model					
	Safety/risk	***Health benefits***	***Alternatives***	***Negative emotions***	***Necessity***	***Decision making***
Constructs below from other treatment perception frameworks or items from published measures	Perceptions of transfusion safety, safety measures or risks associated with transfusion, such as infections, adverse reactions	The physical or psychological benefits of the transfusion (e.g. reduced fatigue)	Perceptions related to alternative treatments for patients rather than transfusion (e.g. autologous, cell salvage, monitoring)	Any emotions experienced about transfusions that caused (or could cause) distress	Beliefs that transfusion are necessary to maintain health.	Reasons when to/not to transfuse, how the transfusion decision was made or communicated, and the patients' role in that process.
Treatment Representations Inventory (TRI) (Hirani et al., 2008) ✓ *indicates correspondence*						
• **Treatment value** (benefit of treatment in controlling or arresting CAD (e.g. *My treatment will bring my illness under control, my treatment will increase my lifespan / longevity)*		✓				
• **Treatment concerns** (anxiety and worry about the treatment (*e.g. when I think of my treatment I feel anxious, My treatment may lead to many medical complications)*	✓			✓		

	Constructs of blood transfusion perceptions from the systematic review conceptual model					
	Safety/risk	***Health benefits***	***Alternatives***	***Negative emotions***	***Necessity***	***Decision making***
Constructs below from other treatment perception frameworks or items from published measures	Perceptions of transfusion safety, safety measures or risks associated with transfusion, such as infections, adverse reactions	The physical or psychological benefits of the transfusion (e.g. reduced fatigue)	Perceptions related to alternative treatments for patients rather than transfusion (e.g. autologous, cell salvage, monitoring)	Any emotions experienced about transfusions that caused (or could cause) distress	Beliefs that transfusion are necessary to maintain health.	Reasons when to/not to transfuse, how the transfusion decision was made or communicated, and the patients' role in that process.
• **Decision satisfaction** (satisfaction with and suitability of treatment chosen *(e.g. I fully understand what the treatment entails, the discomfort and effects of my treatment will be worthwhile given the benefits I am going to receive from it).*		✓				✓
• **Cure** (ability of treatment to remove the disease *(e.g. I believe my treatment will return me to a normal life, my treatment will last a short time)*		✓				

	Constructs of blood transfusion perceptions from the systematic review conceptual model					
	Safety/risk	***Health benefits***	***Alternatives***	***Negative emotions***	***Necessity***	***Decision making***
Constructs below from other treatment perception frameworks or items from published measures	Perceptions of transfusion safety, safety measures or risks associated with transfusion, such as infections, adverse reactions	The physical or psychological benefits of the transfusion (e.g. reduced fatigue)	Perceptions related to alternative treatments for patients rather than transfusion (e.g. autologous, cell salvage, monitoring)	Any emotions experienced about transfusions that caused (or could cause) distress	Beliefs that transfusion are necessary to maintain health.	Reasons when to/not to transfuse, how the transfusion decision was made or communicated, and the patients' role in that process.
The complementary and alternative medicine beliefs inventory (CAMBI) (Bishop et al., 2005) ✓ indicates correspondence						
Beliefs in holistic health *E.g.,* • *Health is about harmonizing your body, mind and spirit* • *Imbalances in a person's life are a major cause of illness* • *Treatments should focus on people's overall well-being*		✓		✓		
Beliefs in holistic treatments • *It is important for treatments to boost my immune system*		✓	✓			

	Constructs of blood transfusion perceptions from the systematic review conceptual model					
	Safety/risk	***Health benefits***	***Alternatives***	***Negative emotions***	***Necessity***	***Decision making***
Constructs below from other treatment perception frameworks or items from published measures	Perceptions of transfusion safety, safety measures or risks associated with transfusion, such as infections, adverse reactions	The physical or psychological benefits of the transfusion (e.g. reduced fatigue)	Perceptions related to alternative treatments for patients rather than transfusion (e.g. autologous, cell salvage, monitoring)	Any emotions experienced about transfusions that caused (or could cause) distress	Beliefs that transfusion are necessary to maintain health.	Reasons when to/not to transfuse, how the transfusion decision was made or communicated, and the patients' role in that process.
• *Treatments should enable my body to heal itself* • *Treatments should increase my natural ability to stay healthy* • *I think my body has a natural ability to heal itself*		▨	▨			
Beliefs of natural treatments • *Treatments should have no negative side effects* • *It is important to me that treatments are non-toxic* • *Treatments should only use natural ingredients*	✓		✓			

	Constructs of blood transfusion perceptions from the systematic review conceptual model					
	Safety/risk	***Health benefits***	***Alternatives***	***Negative emotions***	***Necessity***	***Decision making***
Constructs below from other treatment perception frameworks or items from published measures	Perceptions of transfusion safety, safety measures or risks associated with transfusion, such as infections, adverse reactions	The physical or psychological benefits of the transfusion (e.g. reduced fatigue)	Perceptions related to alternative treatments for patients rather than transfusion (e.g. autologous, cell salvage, monitoring)	Any emotions experienced about transfusions that caused (or could cause) distress	Beliefs that transfusion are necessary to maintain health.	Reasons when to/not to transfuse, how the transfusion decision was made or communicated, and the patients' role in that process.
Beliefs in participation in treatment e.g., • *Treatment providers should … treat patients as equal partners / help patients make their own decisions about treatment* • *Patients should take an active role in their treatment*						✓
Model of medicine taking (Pound et al., 2005) ✓ indicates correspondence						
Passive Accepters: Passive Users '*These people relinquish control over medicine taking*' (Dowell et al., 1997)						✓

	Constructs of blood transfusion perceptions from the systematic review conceptual model					
	Safety/risk	***Health benefits***	***Alternatives***	***Negative emotions***	***Necessity***	***Decision making***
Constructs below from other treatment perception frameworks or items from published measures	Perceptions of transfusion safety, safety measures or risks associated with transfusion, such as infections, adverse reactions	The physical or psychological benefits of the transfusion (e.g. reduced fatigue)	Perceptions related to alternative treatments for patients rather than transfusion (e.g. autologous, cell salvage, monitoring)	Any emotions experienced about transfusions that caused (or could cause) distress	Beliefs that transfusion are necessary to maintain health.	Reasons when to/not to transfuse, how the transfusion decision was made or communicated, and the patients' role in that process.
Active Accepters: Purposeful adherence '*A conscious decision to take drugs as prescribed'* (Johnson et al., 1999)						✓
Rejecters: Rejecters/ skeptics or purposeful non-adherence e.g. *'A conscious decision not to take the drugs, possibly following a period of testing (Johnson et al., 1999)*						✓
Modifiers: e.g. 'Active users' consciously decide to modify the regimen, following deliberation and testing.						✓

3.2.1 Mapping summary:

3.2.1.1 The Beliefs about Medicines Questionnaire (BMQ)

The BMQ items (Horne et al., 2004; Horne et al., 1999b) mapped fully in seven instances and partially in five instances to all six of the systematic review (Chapter 2) conceptual model constructs. The BMQ ‘Harm’ item mapped fully to the blood transfusion ‘Safety/risk’ construct as patients and HCPs in the included review studies identified risks (potential harms) associated with transfusion, such as ‘adverse reactions’ and ‘illness contraction’. The BMQ ‘Benefit’ item mapped fully with the ‘Health benefits’ construct with patients in systematic review studies recognising benefits of their transfusion, such as improved strength, reduced headaches and fatigue (Ryblom et al., 2015). Due to risks and benefits being evaluated and discussed between patients and HCPs, BMQ ‘Benefit’ was also considered to fully map with the conceptual model ‘Decision making’ construct.

BMQ ‘Overuse’ mapped fully to the transfusion constructs of ‘Alternatives’ and ‘Decision making’, and partially to ‘Safety/risk’. This was because some patients and HCPs reported perceptions in the systematic review studies in favour of alternatives being considered, such as to avoid potential risks associated with the use of transfusion (Moxey et al., 2005). BMQ ‘Overuse’ mapped fully to ‘Decision making’ due to patients perceiving that HCPs led the transfusion decisions with limited patient involvement, where patients may be less informed of other potential alternatives (Adams et al., 2011). In the BMQ ’Overuse’ item, natural remedies are conceptualised as being safer than medicines, this partially maps to ‘Safety/risk’ as alternatives to transfusions may be considered as safer than transfusion in some cases. This received a partial rating as there is was less evidence in the systematic review of a natural alternative, except possibly ‘watching and waiting’ in certain circumstances being viewed as the safer option by HCPs than transfusing (Francis et al., 2009b; Islam et al., 2012).

The BMQ subscale ‘Necessity’ was mapped fully with the construct of ‘Necessity’ and partially with ‘Health benefits’ and ‘Decision making’ from the systematic review. Patients reported understanding why their transfusions were necessary and their symptoms signalled to them their upcoming transfusion need, with transfusion providing patients with health benefits, such as alleviating their symptoms (Davis et al., 2012a; Murphy et al., 1997b; Ryblom et al., 2015). The BMQ-Necessity questionnaire items signal that medicines for specific conditions may be conceptualised in relation to protecting current and future health. This may extend scope in future studies to explore perceptions of current and future transfusion necessity to protect health, possibly identifying nuanced views between the two.

BMQ items ‘Necessity’ and ‘Concern’ were judged to partially map onto the transfusion ‘Decision making’ construct. This is due to evidence from the Necessity-Concerns framework signalling that ‘Necessity’ and ‘Concern’ are factors that can underpin judgements about whether to accept prescribed medicines (i.e. a decision-making process); implying a consequent relationship between the constructs and/or items (Horne et al., 2007). BMQ ‘Concern’ has also been fully mapped to ‘Negative emotions’, although ‘Concern’ arguably covers ‘concern’ related emotions, with the addition of 'worry', whereas 'Negative emotions' encompasses broader emotions, such as 'fear' and 'apprehension' as identified in review studies.

3.2.1.2 The Beliefs about Transfusion Questionnaire (BTQ)

Item definitions were provided for BTQ items 'Harm' and 'Overuse' only (Khan et al., 2012). These two items mapped fully to three constructs from the blood transfusion conceptual model ('Safety/risk', 'Alternatives' and 'Decision making') and partially to one construct ('Necessity'). BTQ 'Harm' was fully mapped to blood transfusion constructs 'Safety/risk' and also partially to 'Necessity', with the BTQ 'Harm' item used to also explore whether medicines should be used as a last resort, similar to the exploration of transfusion as being a 'necessity'. BTQ 'Overuse' mapped fully to 'Alternatives' and Decision making' from the transfusion conceptual model, due to HCPs often making the transfusion decisions, where alternatives may not be explained in detail (Adams et al., 2011).

3.2.1.3 The treatment representations framework

Each of the five treatment representation domains (Leventhal et al., 1997; Leventhal et al., 2010) mapped either fully in two instances and partially in three instances to two blood transfusion constructs: 'Safety/risk' and 'Health benefits'. 'Consequence / cost' and partially the 'Cause' domain mapped to 'Safety/risk' due to transfusions being recognised as having potential side-effects, which are managed by technical procedures put into place to provide safe transfusions (Graham et al., 2002; Heddle et al., 2012). The 'Cure' domain was mapped fully against 'Health benefits' due to transfusions controlling and minimising patients' symptoms. 'Identity' and 'time-line' were also partially mapped to 'Health benefits' as some patients were specific about when the transfusions may help them, having formed an identity of the expected benefit of transfusion with an expected time-line to recognise such effects "*... you know I feel better after, sometimes the next day I feel very lively*." (P8) (Orme et al., 2013).

3.2.1.4 The Treatment Representations Inventory (TRI)

The four TRI (Hirani et al., 2008) domains mapped in six instances to four of the six transfusion conceptual model constructs. 'Treatment value', 'Decision satisfaction' and 'Cure' all mapped fully with 'Health benefits' as patients report that their transfusions improve their health and there is evidence of patients outweighing potential transfusion risks over benefit (Davis et al., 2012b; Fitzgerald et al., 1999; Murphy et al., 1997b; Ryblom et al., 2015). 'Decision satisfaction' also mapped fully to 'Decision making', however, in the direction of potential 'dissatisfaction' as some patients in the review studies felt that they had a lack of choice or involvement in transfusion decisions (Adams et al., 2011). Although developed for a different patient population, 'Treatment concerns' in the TRI (anxiety and worry) mapped to some patients' blood transfusion perceptions incorporated into the 'Negative emotions' construct (e.g., 'Apprehension about receiving a transfusion), and 'Safety/risk' with transfusions leading to possible complications.

3.2.1.5 Complementary and alternative medicine beliefs inventory (CAMBI)

The CAMBI (Bishop et al., 2005) mapped partially in seven instances to five of the six blood transfusion conceptual model constructs. The 'holistic treatments' and 'natural treatments' dimensions partially map onto the 'Alternatives' construct from the blood transfusion conceptual model, due to patients and HCPs holding preferences towards alternatives (discussed for the

BMQ ‘Overuse’ and ‘Alternatives’ theme mapping). There is some evidence to support a partial mapping between ‘Beliefs in holistic health and holistic treatments’ and ‘Health benefits’ and ‘Negative emotions’ from the blood transfusion conceptual model; with some patients reporting general improved strength post transfusion and mood improvements (Ryblom et al., 2015). ‘Participation in treatment’ from the CAMBI and ‘Decision making’ from the blood transfusion model are partially mapped; with HCPs reported as providing patients with information to make a decision (Al-Riyami et al., 2016), yet evidence supporting full mapping to the ‘participation in treatment’ items is not currently found in the transfusion literature. ‘Natural treatments’ from the CAMBI has been partially mapped with ‘Safety/risk’ due to the question of whether blood components that are transfused are regarded as a ‘natural’ treatment. Blood components are produced by the body rather than generated from chemical compounds and are in that sense natural. However, transfused blood is medically processed (i.e. separated and treated) and prescribed in turn as a healthcare intervention, with links to ‘Safety/risk’ and possible side effects. This may lead some to not perceive blood components and transfusions as strictly natural.

3.2.1.6 Model of medicine taking

The blood transfusion conceptual model construct of ‘Decision making’ partially maps to perceptions associated with treatment acceptance and rejection from the medicine taking literature (Pound et al., 2005). In the systematic review, there was some evidence that patients passively accepted transfusion and that HCPs led the decision making (Adams et al., 2011). Patients were also reported to be willing, in one low income country, to reject transfusions due to infection risk (Shah et al., 2012). The mappings were rated as partial, however, because perceptions of active accepters or modifiers appeared to be less present in the systematic review studies to date.

3.2.1.7 Summary of mapping

Overall, the Beliefs about Medicines Questionnaire (Horne et al., 2004; Horne et al., 1999b) items mapped to all six blood transfusion constructs from the conceptual model, with 12 full and partial mappings evident. The Beliefs about Transfusion Questionnaire (Khan et al., 2012) items supported the BMQ 'Harm' and 'Overuse' mapping but also provided some mapping to the blood transfusion construct of 'Necessity' '*Transfusion should only be a last resort'* (Khan et al., 2012). The remaining four frameworks mapped only partially to between two and four constructs from the blood transfusion conceptual model, with the constructs of 'Necessity' and 'Alternatives' being less mapped to constructs from the remaining four frameworks and measures.

3.3 Discussion

The results of this mapping process have provided evidence of how the blood transfusion conceptual model constructs correspond widely with other prominent treatment perception frameworks and measures in the broader literature. The Beliefs about Medicines Questionnaire (BMQ) (Horne et al., 2004; Horne et al., 1999b) items mapped most closely with the conceptual model constructs, with the Treatment Representations Inventory (TRI) (Hirani et al., 2008) and the Complementary and Alternative Medicine Beliefs Inventory (CAMBI) (Bishop et al., 2005) mapping to four blood transfusion constructs, although in both cases failing to map to the construct of ‘Necessity’.

As confirmed by this mapping exercise, the constructs from the conceptual model provide a coherent framework, aligned to the broader treatment perceptions literature, to be considered in ongoing investigations of patients’ and HCPs’ transfusion perceptions. As presented through this mapping, the conceptual model constructs map broadly to the treatment perceptions literature, therefore the conceptual model from the systematic review can be contextualised in the broader literature, and although transfusion is not a medicine per se, it is broadly considered using the same domains as other medicines (BMQ) or treatments for specific conditions, such as coronary artery disease (TRI).

The blood transfusion conceptual model containing the six constructs mapped to multiple constructs and/or items from almost all of the treatment perceptions frameworks and measures except the model of medicine taking (Pound et al., 2005). This indicates that the constructs and/or items operate cohesively, for example, that constructs such as ‘Safety/risk’ and ‘Health benefits’ are key sets of constructs to consider, jointly appearing in the other treatment perceptions frameworks and measures. The transfusion construct of ‘Alternatives’, however, may be more transfusion specific as for transfusion there are often a number of alternative treatments which could be tried, to reduce risks or the requirement for a transfusion. This may not be the case for other conditions addressed by the models. The CAMBI (Bishop et al., 2005) literature, however, considers alternatives more broadly in scope of alternative medicines, which may be non-toxic and promotive of a body's natural healing abilities.

Of significance to this mapping exercise was also that the construct of 'Decision making' appeared in other treatment perception frameworks and measures. This reinforced the need for a 'Decision making' type construct or question as when considering treatments, patients and HCPs face key considerations about treatment choice prior to treatment initiation. Patients are often encouraged to be a part of their treatment choice (Malhotra et al., 2015), making it useful to explore decision-making alongside other treatment perceptions. For blood transfusion, in particular, some evidence shows that patients may not always be involved in their transfusion decisions (Adams et al., 2011), making this construct essential to explore in order to ascertain patients' experiences and views towards decision-making involvement. This mapping exercise has also revealed the possibility that some patients may actively accept or modify their treatments, which would be essential to understand due to implications this could have on a patient's health. The literature indicates that patients who reject their treatments do so based on their 'common sense' implicit appraisals guiding their treatment perceptions and behaviours (Horne et al., 2013).

Implications for investigating transfusion perceptions are evident following this mapping exercise. As the blood transfusion conceptual model construct of 'Necessity' was only mapped fully against BMQ 'Necessity' and BTQ 'Harm' items there is value in retaining this going forward as 'Necessity' related questions can be used to elicit perceptions of treatments protecting present and future health. This may be a relevant construct especially for repeatedly transfused patients who may arrive for their transfusions with an imminent need for their blood, but as a means to control a longer-term health condition.

Similar to the blood transfusion construct of ‘Alternatives’, ongoing transfusion perceptions research would benefit from retaining broader blood transfusion constructs, namely ‘Negative emotions’ and ‘Safety/risk’ rather than reducing these to focusing on ‘Concern’ or ‘Harm’ only. Possibly questioning patients and HCPs broadly about their ‘downsides’ to transfusion would expand the exploration and incorporate any risk considerations as well as perceived harms. Likewise, addressing broader emotions during data coding would enable ‘concerns’ and other emotions, such as fear or apprehensions to become evident and distinguished in the analysis.

In conclusion, the conceptual model of blood transfusion perceptions encompasses constructs that are consistent with treatment perception constructs and items in the literature. Transfusion can be largely perceived in the same way as other treatments, even though different in ‘nature’ from traditionally considered treatments (medicines, surgery etc.). This connection provides strength to apply this model in future blood transfusion perceptions studies.

4 Exploring perceptions of blood transfusion in haematology

This chapter describes Study 2 of the programme of research, a qualitative interview study with adult patients and healthcare professionals (HCPs) receiving and providing transfusions in UK haematology day care units. Transfusions in this context are often provided on a repeated basis to patients with blood disorders, cancer or long-term conditions. As identified in the previous Chapter 3, the conceptual model of blood transfusion perceptions constructs align to the broader treatment perceptions literature. Therefore, the conceptual model constructs will be the over-arching framework of investigation for this study, applied to interview data collection and analysis.

4.1 Introduction

4.1.1 Background

Study 1 of this programme of research is presented in Chapter 2 and reports a systematic review of patients' and HCPs' perceptions of blood transfusion (Abdul-Aziz et al., 2018) (Appendix 1), where two key research gaps were identified. For the first gap, the review identified a limited number of studies that explored the perceptions of specific patient and HCP groups, such as patients and HCPs in emergency or haematology settings. For haematology, the systematic review identified two studies investigating perceptions in specific haematology patient sub-groups; hospice transfusion patients (Orme et al., 2013) and a Swedish study including patients with Myelodysplastic conditions only (Ryblom et al., 2015), with perceptions codable to the 'Health benefits' and 'Negative emotions' constructs.

It is important to investigate the blood transfusion perceptions of patients' and HCPs' from haematology, as this patient group receive transfusions on a repeated basis. This is to manage anaemia (lack of red blood cells), or conditions affecting red blood cells, such as Thalassaemia or types of cancer affecting blood cells (e.g. Leukaemia, Lymphoma and multiple myeloma) (NHS Choices, 2018). Patients may be enrolled onto a chronic transfusion programme to treat ongoing anaemia, and between 45-90% of patients with blood cancers such as Myeloma or non-Hodgkin's lymphoma will require repeat transfusions during treatment (European Hematology Association, 2012).

Patients receiving transfusions on a repeated basis form a very different transfusion patient group to emergency one/off transfusion recipients, who will interact with and perceive transfusion very differently. Repeat transfusion patients may receive transfusions alongside other treatments and the transfusion may be anxiety provoking due to the persistent regularity that the transfusions are required (as often weekly to six weekly for many patients) (Trachtenberg et al., 2012). It could be argued that patients may fall into habitual routines with receiving repeated treatments, such as transfusions, but when first diagnosed many haematology cancer patients face initial concerns with their treatment, holding treatment expectations that are often worse than reality and finding it harder to come to terms with non-curative treatments (Randall et al., 2005).

There is limited evidence as to how patients attending for repeated transfusions perceive transfusion overall as a healthcare intervention. If repeat transfusion patients do hold any negative perceptions of their transfusions, this may influence decision making, (Abdul-Aziz et al., 2018) and adherence. Emergency and one/off transfusion patients will not be required to adhere to any transfusion schedule and form adaptive coping responses in order to do this. Repeat transfusion patients may disengage with their transfusion regimen over time with transfusions becoming less acceptable to patients, particularly if negative perceptions are not resolved. This is supported through the broader literature that treatments are accepted when patients view a high ‘Necessity’ of the treatment, whilst holding fewer ‘Concerns’ (Horne et al., 2013). In the haematology context there may be limited or no alternative options to the transfusion available, so patients may benefit from learning to cope with their concerns. This is the case for patients with Thalassemia, for whom transfusions are a necessity, who have been found to experience higher quality of life when ‘concerns’ about their general treatment are lower (Trachtenberg et al., 2012).

As some haematology patients will be receiving transfusions on a long-term basis, some patients may have ‘accepted’ their conditions and transfusion as a part of their treatment regimen. Acceptance can be viewed as a part of coping, being important to how patients adjust to chronic illnesses (Sharpe et al., 2006). Active acceptance (an adaptive response to unchangeable circumstances) is distinguished from resigned acceptance (maladaptive coping associated with negative psychological outcomes) (Nakamura et al., 2005). Patients receiving transfusions for long-term conditions in the haematology unit may actively accept their transfusions or accept them on a resigned basis.

Clinical health-related factors may also influence patients' perceptions. Many haematology patients have cancer and/or anaemia, which result in patients experiencing high levels of fatigue, diminished quality of life, lethargy, decreased mental alertness, physical weakness and poor concentration (Jansen et al., 2003). Transfusions for this patient group may lead to negative health outcomes, such as iron overload (Hershko & Hoffbrand, 2000) and mortality, for example, if patients have organ dysfunction (Vincent, 2008) or cardiac surgery (Murphy et al., 2007). Therefore, it is important to ascertain the benefits and potential downsides of transfusions for this patient group, gathering particular insight into how transfusions might improve or further impact on patients' lives.

Patients facing health threats will attempt to self-regulate the threatening situation by engaging with ways to improve their health, which may be considering how transfusion could help to 'control' their condition (Leventhal et al., 1980; Leventhal et al., 1984). What patients think about transfusion is therefore important and if transfusions help patients to improve their health, patients will form updated treatment perceptions of their health threat (e.g. improved and stable anaemia through transfusions). If patients are able to manage their conditions on an ongoing basis with the aid of transfusions, it will become important for patients to adhere to their transfusion schedule to cope with their condition. The outcome of such coping strategies will re-inform patients' illness perceptions, as indicated by the Common Sense Self-Regulation Model (CS-SRM) (Leventhal et al., 1980; Leventhal et al., 1984).

Alongside exploring patients' transfusion perceptions, it is equally important to explore the perceptions that HCPs hold about transfusion. The second identified research gap uncovered by the preceding systematic review was that no studies were identified where both transfusion patients' and HCPs' perceptions were jointly investigated. In shared decision-making encounters, patients with cancer often defer complex decision-making to HCPs. Elderly patients, in particular, may require support at the point of decision-making, with cancer schema linked to mortality often being activated at this stage (Swainston et al., 2012). If patients' and HCPs' perceptions are aligned or mutually understood, treatment goals may be more readily established, with more open discussion of perceptions and fewer misunderstandings occurring (Barry et al., 2000; Mead et al., 2000).

Whilst shared-decision making is central to patient-centred practice, investigating HCPs' perceptions can also provide insight on factors influencing HCP prescribing practices. This is particularly important given previously discussed evidence of transfusion overuse and misuse by HCPs. For haematology in particular, audits of UK haematology practice have identified gaps in the appropriate provision of blood transfusion (red blood cells 75% appropriately prescribed in 96% of UK participating hospitals in January 2016 (National Health Service Blood and Transplant, 2016). Alternatives to transfusion that are available for some haematology patients, such as iron tablets, may not be routinely offered or considered. Some transfusions, such as platelet transfusions are also ordered at high levels and there is evidence that transfusion provision in haematology could be further reduced (Estcourt et al., 2012).

Qualitative research methods are frequently used to explore perceptions, with in depth interviews enabling researchers to respond to the individual way in which respondents interpret and answer questions (Fitzpatrick et al., 1994). Semi-structured interviews allow the investigator to have a fixed set of topics to discuss (Fitzpatrick et al., 1994), with interview questions able to be structured around an existing theory or framework to enable exploration of the different components. Qualitative methods have been advocated for use in transfusion medicine to generate answers to research questions that are rich in description, such as through the exploration of issues from transfusion recipients' perspectives (Arnold et al., 2011).

4.1.2 Aims of the current study

The current study aimed to address gaps in the literature by exploring patients' and HCPs' perceptions of blood transfusion from the under-researched haematology context. This study aimed to investigate both groups' perceptions concurrently using qualitative research methods based on the systematic review (Chapter 2) conceptual model of blood transfusion perceptions and patients' and HCPs' perceptions were compared using triangulation methods.

4.1.3 Objective

1. To explore adult blood transfusion patients' and HCPs' perceptions of blood transfusion.

4.1.4 Research questions

1. What are haematology patients' and HCPs' perceptions of blood transfusion?
2. How closely do patients' and HCPs' perceptions align to the constructs of the blood transfusion conceptual model?

3. Which perceptions are identified as being most important to haematology patients and HCPs?
4. How comparable are patients' and HCPs' perceptions?

4.2 Methods

4.2.1 Study design

Semi-structured qualitative interviews based on the conceptual model of blood transfusion perceptions from the systematic review (Chapter 2).

4.2.2 Ethical approval

Ethical approval was granted from South Central – Hampshire B Research Ethics Committee (15/SC/0757) (Appendix 6: Study 2 ethics approval letter).

4.2.3 Setting and participants

This study was conducted in the context of UK based National Health Service (NHS) haematology day treatment units. Two units were involved in the study, one unit was based in London in a large hospital trust. The second was in South-west England, being the larger outpatient blood transfusion centre for the region.

4.2.4 Sampling

Patients and HCPs were recruited using purposive sampling methods. Thirteen patients and 13 HCPs were selected as the minimum target sample size following published qualitative sample size guidance based on the principles of thematic data saturation (Francis et al., 2010). Data saturation was assessed during coding of the interview transcripts using a data saturation table (Appendix 7: Data saturation table for haematology interview Study 2) to assess that the final three interviews from each group produced no new data, which would lead to new emergent themes.

4.2.4.1 Patient inclusion criteria

1. Adult patients (aged 18+) attending the haematology day unit for a blood transfusion with a non-acute haematological disorder.
2. Patients deemed by HCPs working in the haematology unit as clinically stable enough to participate (i.e., alert and oriented, with stable vital signs and without acute respiratory or cardiac difficulty or uncontrolled pain) (Adams et al., 2011).

4.2.4.2 Patient exclusion criteria

1. Patients who are unable to understand spoken English and respond verbally to interview questions in English.
2. Patients deemed by HCPs to be unable to consent, and participation would not be advised per clinical advice.
3. Patients considered by HCPs to have a cognitive impairment (i.e. problems with cognitive functioning like thinking, knowing and remembering) (Alzheimer's Society, 2009).

4.2.4.3 HCP inclusion criteria

1. HCPs, including consultants, physicians, junior medical staff and haematology specialist nurses currently working in the targeted haematology day unit(s) who interact with patients, for example to discuss with patients their haematological disorder and its treatment, or to administer blood products to patients (Galloway, 2013).

There were no HCP exclusion criteria.

4.2.5 Recruitment

4.2.5.1 Participant recruitment

Patient recruitment was facilitated by a local collaborator working in the blood transfusion suite and having direct patient-contact. This was typically a Staff Nurse responsible for providing transfusions in the unit on that day. The collaborator assisted the researcher (BV) by completing the recruitment log (Appendix 8: Study 2 patient recruitment log) on the recruitment days and screening all patients attending for a transfusion against the inclusion and exclusion criteria and documenting the screening outcomes. Each patient attending for a transfusion on the recruitment days meeting all inclusion and no exclusion criteria was invited to take part in the study. The local collaborator informed patients about the study and provided a Participant information sheet (PIS) (Appendix 9: Study 2 participant information sheet (patients)). After patients read the PIS, the researcher approached the patient to discuss the study further and gain informed consent, if they were willing to participate straight away.

4.2.5.2 HCP recruitment

HCPs were informed about the study by the clinical collaborator supporting the research or by the researcher directly during opportunities to speak to groups or individual HCPs in the units whilst recruiting patients and conducting patient interviews at the site. Opportunities to speak to HCPs as a group occurred, for example, during early morning staff handovers. Interested HCPs were provided with a HCP-specific PIS (Appendix 10: Study 2 participant information sheet (HCPs)). The researcher aimed to purposively recruit a broad range of HCP roles into the study and kept track of the diversity of sampling during recruitment. Informed consent was documented on an informed consent form for all participants (Appendix 11: Study 2 consent form).

4.2.6 Materials

4.2.6.1 Interview topic guide development

Methods to investigate patients' and HCPs' perceptions concurrently include the use of comparable versions of patient and HCP data collection instruments (Légaré et al., 2007). For this study, patient and HCP specific topic guides were developed. To enhance comparability, both topic guides were structured around the constructs of the blood transfusion conceptual model. The topic guides began with general opening questions: e.g., '*Could you talk to me about your experience of receiving blood transfusions?'* [patients], *'How often do you receive / prescribe transfusions?'* [HCPs]. Subsequent questions were based on the conceptual model of blood transfusion perceptions from the systematic review (Chapter 2); with at least one question asked per construct (Table 5). Potential ways of phrasing these questions to assess the constructs were guided by the phrasing of items in the BMQ (Horne et al., 1999b) and other frameworks discussed in Chapter 3. Constructs with full and partial mapping were reviewed for suitable question wording to help inform the topic guide questions.

Table 5 Study 2 interview topic guide questions

Conceptual model construct	**Patient topic guide question**	**HCP topic guide question**
Health Benefit	‘What are the benefits of transfusion for you?’ * Probe: distinctions between expected benefits vs. instant and later benefits?	‘What are the benefits of transfusion for haematology patients?’ * Probe: distinctions between expected benefits vs. instant and later benefits?
Safety/risk:	‘Are there any downsides for you in receiving transfusions?’	‘Are there any downsides for haematology patients in receiving transfusions?’
Negative emotions:	‘How concerned or worried are you about [these] downsides to transfusion?’	‘How concerned or worried are you about [these] downsides to transfusion?’
Alternatives	‘Have you ever been offered any alternatives to transfusion?’ * Prompt: what are your thoughts about this?	‘How much are transfusion alternatives considered for haematology patients?’ *Prompt: are there some reasons that transfusions may be the preferred or only way forward?)
Necessity:	‘How much would you say you need transfusions to protect your health? *Probe distinction between protecting health presently or long-term	‘How much would you say haematology patients need transfusions to protect their health? *Probe distinction between protecting health presently or long-term
Decision making	‘How involved were you in making decisions about your transfusion(s)?’ ‘Can you describe any other ways that you might like to be more involved in your transfusions?’	‘How greatly do you involve patients in making decisions about their transfusion(s)?’ ‘Can you describe any other ways that patients might like to be more involved in their transfusions?’

* Inserted after interviews at site 1

The interviews were also an opportunity to ask patients and HCPs respectively how they thought the other group might perceive transfusion (e.g. '*What do you think are your doctors' or nurses' / patients' views of transfusion?*'). HCPs were asked about the extent to which their perceptions may have changed over the course of their practice and patients were asked whether their experiences of transfusions have changed over time. These questions were asked due to the long-term and repeated nature of transfusions in this context.

A Consultant Haematologist collaborator (SS) and Patient and Public Involvement Representative (PA) reviewed all consent forms and study information sheets. These materials were revised in light of their feedback to enhance clarity and question flow. Four pilot interviews were also conducted by the researcher with HCPs and a blood transfusion recipient. This was to ensure that the questions asked were clear, logically ordered and comprehensive relating to the theoretical underpinning. The topic guides were additionally updated following the first set of interviews at the first site to include further prompts and probes based on what participants at this site were recalling. For example, to probe more closely to the BMQ subscale of 'Necessity'; distinguishing present and future health need (Horne et al., 1999b).

4.2.7 Procedure

All patient and HCP interviews were conducted by the trained researcher (BV) using the semi-structured interview topic guides (Table 5). All participants were interviewed individually, face to face in the haematology unit or by telephone if preferred. Interviews were expected to last around 30

– 45 minutes and were audio-recorded. For face to face interviews, patients were offered the chance to be interviewed before, during or after their transfusions in the haematology unit, with before or during data collection identified as a gap in the previous systematic review (Chapter 2). Patients may provide more vivid accounts of their perceptions as close to the transfusion episode as possible rather than providing a retrospective account. HCPs were informed that interviews could be arranged flexibly around their availability and conducted in the haematology unit.

A demographic questionnaire was provided to each participant at the end of the interview to collect details for patients such as gender, age, ethnicity, religion, haematological condition and blood products received (Appendix 12: Study 2 Demographic questionnaire (patients)). For HCPs, gender, clinical role, experience in haematological units and types of interaction with patients were collected (Appendix 13: Study 2 HCP demographic questionnaire). For the latter two questions, HCPs reported the length of their experience working in haematology units and their involvement in transfusion in terms of the frequency with which they administer transfusions and/or engage in decision-making with patients.

Interview audio-recordings were transcribed verbatim by the researcher (BV) and anonymised to remove any potentially indefinable information (i.e. names of individuals, colleagues, hospitals etc.). The researcher also preserved participant anonymity by removing any non-essential information from any accounts that included characteristics of rare or specified (and thus potentially identifiable) clinical cases. All data were stored and managed in accordance with the Data Protection Act 1998.

4.2.8 Analysis

Analysis was conducted using a combined deductive approach (Hsieh et al., 2005) using the conceptual model of blood transfusion perceptions as the analytical framework and an inductive thematic analysis approach (Braun et al., 2006), described in detail below.

4.2.8.1 Patients' and HCPs' perceptions of blood transfusion

Analysis was conducted using NVivo 11. Patient and HCP interviews were analysed separately using first a deductive approach that allowed for data to be coded into a pre-selected analytical framework, in this case, the conceptual model of blood transfusion perceptions (Chapter 2). Participants' responses were first coded to the construct from the model ('Safety/risk', 'Alternatives', Health benefits', Negative emotions', 'Necessity' and 'Decision making') they were judged to best represent. For example, a quote of '*patients benefit from transfusions to restore their energy'* was coded according to the model construct 'Health benefits'. If appropriate, a response was coded to more than one construct, for example '*I do worry less about how risky the blood is nowadays',* which was coded to 'Negative emotions' and 'Safety/risk'. To make the construct labels more descriptive, 'Safety/Risk' and 'Decision Making' from the systematic review conceptual model were re-titled into 'Awareness of Risk / Safety' and 'Involvement in Decision Making' respectively.

At this stage, inter-rated reliability was assessed to compare the deductive coding decisions using one patient and one HCP anonymised transcript (7% of total transcripts) with two additional coders who were postgraduate researchers with experience in qualitative research. Coders were made familiar with the study and research questions. Inter-rater reliability was conducted to assess how reliable the researcher's (BV) initial allocation of responses to the model constructs was. Percent agreement was used to assess reliability (total number of cases coded the same way by two independent raters divided by total number of cases) (Stemler, 2001). A coding book was developed for this process, which provided a summary of each deductive construct and an example of codable data (Appendix 14: Coding book for Study 2 haematology interview transcripts). Disagreements were discussed by the researcher (BV) and the rater until 100% reliability was reached and the coding book was iteratively updated during this process.

The deductive coding was followed by an inductive thematic analysis approach where themes are generated through open coding, followed by the refinement of themes (Gale et al., 2013). Similar participant responses coded to each construct were grouped together and an inductive summary label theme generated. A six-step thematic analysis approach was used: 1) familiarisation (data transcription, re-reading transcripts and noting initial ideas); 2) generating initial codes (coding interesting features of the data in a systematic fashion); 3) collating codes to potential themes; gathering all relevant data to potential themes (e.g. iron- overload related risks as a part of the 'Safety/risk' theme); 4) reviewing themes (e.g. checking if themes work and are coherent with 'thematic map' of the analysis, 5) defining and naming themes and 6) producing the report (Braun et al., 2006).

Inductive analysis was also performed on data that could not be initially coded deductively into any of the existing constructs from the model (e.g. quotes relating to transfusions as 'part of a patient's life' or the 'burden' of transfusion). These responses were subsequently analysed using thematic analysis as described above.

4.2.8.2 Perceptions identified as most important to patients and HCPs

Perceptions that are important to patients may need to be given further consideration in clinical practice, possibly through patient-centred service reforms being considered or changes to practice guidelines (Armstrong et al., 2018; Brocklehurst et al., 2018; Tsianakas et al., 2012a). One method of determining importance, which is often used in qualitative research, is by using frequency counts of how frequently a theme occurred /is referred to (Marks et al., 2004). For example, how many patients or HCPs reported perceptions coded to the construct of 'Health benefits', with consideration given to how elaborate a construct is, through frequency of themes. These approaches are often used in other hybrid deductive framework and inductive thematic analysis interview studies, incorporating theoretical frameworks, such as the Theoretical Domains Framework (Atkins et al., 2017; Patey et al., 2012). For this study, importance of perceptions was assessed on two criteria: frequency counts of participants (patients and HCPs) reporting data into each construct / theme and secondly on how elaborate each construct or theme was, assessed by frequency counts of themes.

4.2.8.3 Conceptual models of patients' and HCPs' perceptions of transfusion for haematology

BV adapted the existing conceptual model of blood transfusion perceptions, from Chapter 2, to include new constructs of patients' and HCPs' transfusion perceptions for the haematology context. Once the inductive themes were generated from the patient and HCP analysis, the themes were mapped to the existing conceptual model structure. The aim was to illustrate how the different components from the generic model were present or absent in the haematology specific groups, and how the constructs inter-related. New themes specific for this group were added to the model as constructs and presented using a unique colour code compared to the original deductive constructs.

4.2.8.4 Triangulation of patients' and HCPs' perceptions

One way to compare findings from different data sources is to tabulate the findings from each source and identify areas of overlap, disagreement, or silence/absence (Tonkin-Crine et al., 2015). Different data sources can include different participant groups. This approach was applied to compare patients' and HCPs' perceptions of transfusion using qualitative triangulation protocols (Farmer et al., 2006; Hopf et al., 2016). This involved creating a convergence matrix, in which themes generated from analysis of patients' and HCPs' transcripts were tabulated as either: '*agreement'* indicating that a comparable theme was present for both groups (e.g. '*Transfusion has become a part of patient's routine life*' (HCPs) and '*Transfusion part of routine life*' (patients)); '*partial agreement*' meaning that the theme is partially comparable across the two groups (e.g. '*Need for transfusion apparent through symptoms'* (patients) and '*Patient reliance and expressed need for transfusion'* (HCPs)); '*disagreement'* indicating a contradictory finding in each participant group (e.g. '*Patient anxiety and upset with receiving regular transfusions'* (HCPs) and '*Relaxed during transfusion appointments'* (patients)); and '*silent'* indicating that no comparison could be recognised (e.g. patient theme but not HCP theme) (Farmer et al., 2006; Hopf et al., 2016).

4.3 Results

4.3.1 Participants recruited

Recruitment at site 1 took place on six working days over a continuous two-week period, and all eligible patients who attended for blood transfusions in this time period (n=24) were screened to be invited into the study. Approximately 18 HCPs including Haematology Consultants, one Transfusion Practitioner, Haematology Nurse Specialists, Registrars, Staff and Registered Nurses were informed about the study by the site Principle Investigator or Researcher. This covered approximately all of the HCPs treating blood transfusion patients during this time period.

Recruitment at Site 2 was conducted over eight working days across two consecutive weeks. Thirty-five patients attending for blood transfusions were screened for eligibility. Approximately 10 HCPs (as per site 1 but including Senior House Officers and a Clinical Health Psychologist and excluding any Transfusion Practitioners) were directly approached and informed about the study by the researcher. The researcher also briefly introduced the study at a nurses' briefing at the start of a morning shift on the first day of the researcher's recruitment days. Around 15 attendees were at this briefing including Nurse Managers. These recruitment strategies notified potentially all eligible HCPs in the unit about the study.

Appendix 15: Reasons for patient exclusion from study 2 lists the detailed reasons for exclusions for 45 screened patients per site. The majority of patients were not eligible due to insufficient English (n=6), previously screened or interviewed (e.g. patient returning for a weekly transfusion) (n=6), advised by screening personnel not to invite (n=4), no transfusion needed on the day; patient sent home (n=4) or on patient list but transferred to ward for transfusion or since deceased (n=3). In terms of participating, some HCPs were reluctant to participate in the study, expressing that they would have limited worthwhile perceptions to share, or due to lack of time.

The final sample consisted of 14 patients (eight from Site 1, six from site 2) and 14 HCPs (seven from site 1, seven from site 2).

4.3.1.1 Participant characteristics

Table 6 displays patient participant characteristics from both sites. Male patients consisted of 43% of the patient sample with the median age of 68. The majority of patients classified themselves as White British (71%) and Christian religion (79%). Patients had a range of educational backgrounds and haematological disorders. The majority of patients interviewed were in the haematology unit to receive red blood cell transfusions (93%) with 50% of patients also having experience of receiving platelets in the past. Thirteen patients were interviewed during their transfusions, with one patient interviewed before an upcoming transfusion.

Table 6 Study 2 patient participant characteristics

Patients included:	**N=14**
Gender	
Male	6 (43%)
Female	8 (57%)
Age	

<45	1 (7%)
45-65	4 (29%)
>65	9 (64%)
Ethnic group or background	
White English/Welsh/Scottish/Northern Irish/British	10 (71%)
Any other White background	1 (7%)
Asian/Asian British	1 (7%)
African	1 (7%)
Any other ethnic group	1 (7%)
Religion	
Christian (including Church of England, Catholic, Protestant and all other Christian denominations)	11 (79%)
No religion	1 (7%)
Prefer not to provide	2 (14%)
Highest level of education completed	
No formal education	3 (21%)
GCSE / O'Levels	4 (29%)
A Levels / college certificate	2 (14%)
University level	3 (21%)
Graduate / professional	2 (14%)
Haematological condition(s)	
Myelodysplasia	3 (21%)
Myeloma	1 (7%)
Myelofibrosis	1 (7%)
Lymphoma (CLL) and a second haematological condition	1 (7%)
Acquired haemolytic anaemia	1 (7%)
Inherited anaemia, including Thalassemia	2 (14%)
Aplastic Anaemia	3 (21%)
Other Anaemia	2 (14%)
Blood products currently receiving	
Red blood cells	10 (71%)
Red blood cells & platelets	3 (21%)

Platelets	1 (7%)
Other blood products received	
Red blood cells	5 (36%)
Red blood cells & platelets	7 (50%)
Unknown	2 (14%)

The patients involved in this study had multiple health conditions and reported taking many other medicines, vitamins and supplements. These were taken for haematological or other health conditions, including asthma, high blood pressure, diabetes, dermatological conditions or following hip replacements or transplants.

Table 7 displays the HCP participant characteristics from both sites. HCPs were mainly female (64%) from a range of roles but mostly Haematologists, specialists or senior role HCPs. Years of experience in the HCP's current clinical role was between 1 and 30 years (*M* = 10.5 years, SD = 8) and the range for experience in haematology day units was between a few months to 24 years (*M* = 8 years, SD = 8). The majority of HCPs interacted with haematology patients receiving transfusions in the unit daily or at least weekly (86%).

Table 7 Study 2 healthcare professional participant characteristics

Healthcare professionals included:	**N=14**
Gender	
Male	5 (36%)
Female	9 (64%)
Clinical role	
Consultant Haematologist	3 (21%)
Specialty doctor (Haematology)	1 (7%)

Specialist Registrar	2 (14%)
Specialist House Officer	1 (7%)
Senior Charge Nurse	1 (7%)
Haematology Specialist Nurse	2 (14%)
Nurse (other)	2 (14%)
Transfusion Practitioner	1 (7%)
Clinical Psychologist	1 (7%)
Interaction with patients in the haematology unit	
Daily (discussion and blood product administration)	2 (14%)
Weekly (discussion and blood product administration)	3 (21%)
Daily discussion	4 (29%)
Weekly discussion	3 (21%)
Monthly discussion	2 (14%)

4.3.1.2 Reliability results and data saturation

Inter-rater agreement for coding decisions based on patient transcripts was 67%. For the HCP transcripts, inter-rater reliability on the coding decisions was highest at 60%. This was considered under the advised 75-90% acceptable level of agreement (Stemler, 2004). Full consensus was, however, reached on all disagreements.

Data saturation was reached by the time the 13th patient and HCP interview was analysed, as no new themes were identified at this stage (Appendix 7: Data saturation table for haematology interview Study 2).

4.3.2 Perceptions of blood transfusion

4.3.2.1 Patients' perceptions

Table 8 provides a full list existing constructs from the deductive analysis: 'Awareness of risk / Safety', 'Health benefits', 'Necessity', 'Negative emotions', 'Alternatives' and 'Involvement in decision making' and the themes inductively generated for each construct of the conceptual model of blood transfusion perceptions. These are presented alongside frequency counts (i.e. number of participants that reported a perception contributing to that theme) and supporting illustrative quotes. Each construct from the model is summarised in turn below.

Table 8 Study 2 constructs from the blood transfusion conceptual model (patients) with themes, frequency counts and supporting quotes listed

Construct header	**Frequency (n patients)**	**Patient quotations**
Awareness of risk / safety		
Discomfort and illness during or post-transfusion	7	"*there's always situations that I was here hours waiting for blood and I ended up receiving it, but the following day I was in bed all day*" (Patient 12, Aplastic Anaemia, Site 2)
Potential infection or reaction risk	5	*"basically, you kind of just think, you know, 'is this gonna be the transfusion that might cause me to have a reaction?' or, 'is this the unit that's going to cause something in the future?' but you can't really live like that, so you don't really think about it too much really, it doesn't stop me having them"* (Patient 8, other Anaemia, Site 1)
No experienced negative consequences	5	"*I feel quite good really, I'm not having any side-effects or anything like that which is very good*" (Patient 6, Myelofibrosis female, Site 1)
Health risks from high iron levels	4	"*because the more blood I receive, the more the iron level in my blood goes up"* (Patient 12, Aplastic Anaemia, Site 2)
Caution needed, blood should be used appropriately	2	"*there's many, many, many issues of blood, you know, if the haemoglobin's dropped or loss of blood, or that sort of thing, but er, I think people need to be a bit more careful*" (Patient 8, other Anaemia, Site 1)
Health benefits		
Boosting blood levels	8	"*well normally it/ well, it depends, erm, how low the haemoglobin is, the lower it is then the benefit is quicker because you're being topped up but*" (Patient 14, Inherited Anaemia, inc Thalassemia, Site 2)
Keep going with daily life	7	"*well I wouldn't be able to get about, I'd be fighting for breath and all that if I didn't have it, you know, I wouldn't be able to do anything I do now. I can walk about*" (Patient 7, Myelodysplasia, Site 1)

Construct header	Frequency (n patients)	Patient quotations
Relief of symptoms such as tiredness	7	*“when I received blood transfusion after that, I rest a bit and then I feel strong but before I feel weak*” (Patient 10, other Anaemia, Site 2)
Anticipated benefits	6	*“I just feel as though that if I got a transfusion with fresh blood, surely I’ve got to feel better from it, I think so”* (Patient 1, Myeloma, Site 1)
Patient convinced of benefit by significant others	3	“*everyone was telling me I looked better and that in itself made me feel better as well I suppose*” (Patient 1, Myeloma, Site 1)
Can take time to feel benefit of transfusion	2	“*this is a benefit, the blood, but sometimes it takes a while to kick in, it's like if you're taking medication from the doctor, sometimes it takes, erm, a while to kick in*” (Patient 11, Lymphoma (CLL) and a second haematological condition, Site 2)
Necessity		
Transfusion prolonging life and aiding survival	11	“*oh yes, it just seems to me as being essential, erm, as much as say needing oxygen in the air is an essential, without the transfusions I wouldn’t be here*” (Patient 4, Aplastic Anaemia, Site 1)
Transfusions required as a current and long-term supportive treatment	10	“*they gave me two courses of ATG, it's an immunogloubulin … the second time, I didn't have any response. Since then, since, … I've been receiving transfusions*” (Patient 12, Aplastic Anaemia, Site 2)
Need established by HCPs and clinical indicators	8	“*if it is lower than 80, they said I need a blood transfusion … sometimes it depends, they keep seeing the blood test, decided if I need to have a blood transfusion*” (Patient 10, other Anaemia, Site 2)
Need apparent through symptoms	8	“*yeah, when it drops, I feel a bit tired, but/ you feel it, dizzy, a little bit dizzy, tiredness, shortness of breath, sometimes/ I try to manage it, but/*” (Patient 9, Acquired Haemolytic Anaemia, Site 2)

Construct header	**Frequency (n patients)**	**Patient quotations**
Speculation and doubt over pending transfusion prescription	7	"*Erm, last week I had two units of blood · but this week · it's only like the platelets, so possibly next week it'll just be platelets and one unit of blood*" (Patient 2, Aplastic Anaemia, Site 1)
Negative emotions		
No concerns or worries with transfusion	10	"*no [concerns or worries], cause there's no point worrying about something I can't really do anything about*" (Patient 8, other Anaemia, Site 1)
Attempts to manage worries and fears	9	"*so, it doesn't look, it looks ok for you for a minute, and then you start to think about something else but that one you have to be on the positive side all the time, maybe not keep saying 'that's not good'*" (Patient 9, Acquired Haemolytic Anaemia, Site 2)
Relaxed during transfusion appointments	5	"*I come regularly, erm, to be honest it's a nice, this sounds really weird but, you know, it's a day where, I, I fully relax because I'm just having my blood and I'm not thinking of anything else*" (Patient 14, Inherited Anaemia, inc Thalassemia, Site 2)
Gratitude that transfusions possible	5	"*I'm very grateful that there is blood available for me and other patients, erm, and I appreciate that hugely*" (Patient 14, Inherited Anaemia, inc Thalassemia, Site 2)
Receiving transfusions unpleasant	4	"*everybody hates having them, they all hate the cannula's in*" (Patient 2, Aplastic Anaemia, Site 1)
Concern of transfusion dependency	4	"*sometimes, erm, I feel scared … of course if you see blood, you think, you think to yourself that it's bad*" (Patient 10, other Anaemia, Site 2)
Positive emotions of not needing transfusion	2	"*there was a wonderful telephone message and it said [Mr/Mrs surname], we don't want to see you today and so everyone cheered you know. I, I didn't come in, which was brilliant*" (Patient 4, Aplastic Anaemia, Site 1)
Perception that doctors dislike prescribing transfusions	1	"*no, most of the doctors like, they, they always hate giving transfusions to someone …*" (Patient 9, Acquired Haemolytic Anaemia, Site 2)

Construct header	**Frequency (n patients)**	**Patient quotations**
Alternatives		
Alternatives considered or already in use	7	"*I was offered the main treatment for this condition, is the bone marrow transplant, but I, I'm not really keen to do that, cause it's, I've, erm, you know, the side effects of treatment …*" (Patient 12, Aplastic Anaemia, Site 2)
No alternatives, transfusion only option	5	"*yeah, I would just fade away, yeah, cause there's nothing else that can help me*" (Patient 8, other Anaemia, Site 1)
Patient's body can correct depleted cells	3	"*hopefully, erm, with erm, not needing platelets, might just be my body saying 'I'll have a go now*'" (Patient 4, Aplastic Anaemia, Site 1)
Patient preference for alternatives	3	"*I wish they'd/ sometimes I wish that I didn't have to have it done. I wish they could just give you like a tablet and something like that*" (Patient 11, Lymphoma (CLL) and a second haematological condition, Site 2)
Involvement in decision making		
Transfusion offered with patient involvement in choice	7	"*yeah I had choice, I had a choice, yes I will go along with it, or no I won't bother. She gave me that choice as well, · but I was led by her professional advice*" (Patient 1, Myeloma, Site 1)
Deferral of decision making to HCPs	7	"*I just take it for granted that what they're asking me to do, or what they're doing is the correct thing to do*" (Patient 5, Myelodysplasia, Site 1)
Willing acceptance of transfusions	7	"*I suppose I sort of took it in my stride really, think well if they're gonna help me, then you've gotta go along with it, haven't you really, that's how I feel*" (Patient 6, Myelofibrosis female, Site 1)
Confronted with limited or no choice	6	"*They're the experts and they say so, and, like they said 'if you don't want it, you just die', 'you choose to die', they said, 'don't bother coming in'*" (Patient 7, Myelodysplasia, Site 1)

Construct header	Frequency (n patients)	Patient quotations
Decision making discussion positive	5	"*[the consultant] does try to explain in simple terms, er, what [he/she] thinks, and the, the whole thing has been optimistic and upbeat … there's never been any pessimism at all, which has been terribly encouraging*" (Patient 4, Aplastic Anaemia, Site 1)
Routine 'automatic' treatment	3	"*with it being, you know, a chronic condition, so very long-term, so it's almost automatic regular treatment*" (Patient 14, Inherited Anaemia, inc Thalassemia, Site 2)
More frequent transfusions would be resisted	2	"*I try to avoid as well because the more blood I receive, the more the iron level in my blood goes up*" (Patient 12, Aplastic Anaemia, Site 2)

Awareness of risk/safety: Patients recounted negative consequences that they experienced during and post-transfusion, mainly from painful cannulisation and beliefs about adverse effects, most notably from high iron levels needing to be controlled to prevent damage to major organs. Some patients reported that reactions were only likely at the start of the transfusion or had no negative consequences to report on.

Health benefits: Transfusions aided patients to keep going with their daily lives with patients acknowledging benefits such as reduced tiredness and improvements in blood levels, wellbeing and transfusions helping to manage their conditions. Many patients thought that other similar patients must also perceive transfusion as beneficial, and some patients were convinced and persuaded of the benefits by HCPs or significant others. Two patients felt that the benefit was variable and can take time to be felt, or that they often felt drained post-transfusion as if no transfusion was given.

Necessity: Patients reported receiving transfusions as a supportive treatment for their immediate health needs (e.g. to support chemotherapy) or for management of a long-term condition, being necessary to prolong patients' lives. Some patients recalled that the need for transfusion became apparent through symptoms they experienced (e.g. lethargy) (n=8). For other patients they relied on HCPs and clinical indicators to determine the necessity for transfusion, yet this often made it problematic for patients to establish a routine with their transfusions.

Negative emotions: Some patients reported worries, fears and frustrations with receiving transfusions or found being cannulated unpleasant, transfusions time-consuming or initially hard to deal with at first. In spite of this, more patients talked about having no concerns or worries with transfusion or that they have found ways to manage negative emotions. For example, communicating with HCPs or keeping a hopeful and positive outlook. Some patients liked attending for transfusion, expressing gratitude that blood was available.

Alternatives: Patients discussed alternative treatments, such as unspecified tablets that they were taking to try to reduce their transfusion requirement, or treatments that were previously unsuccessful or not feasible (e.g. bone marrow transplant). Some patients felt that they would prefer an alternative, for example, to relieve the burden of the transfusion time-length, but that there were none available for them. Other patients commented that the functioning of their body may influence how much blood they would need or how frequently they would need transfusions, for example if their body worked to reinstate depleted blood cells.

***Involvement in decision making**:* Patients reported either being involved in the initial transfusion decision making, or that they deferred decisions to HCPs, or that HCPs solely made the decisions. Many patients accepted HCPs' decisions, finding transfusion discussions positive or had limited or no choice but to accept the transfusion. For some patients, transfusions were almost an 'automatically' prescribed treatment.

4.3.2.2 New haematology constructs: patients

Three new themes were developed from interview data that could not be initially coded into any pre-existing construct of the conceptual model. These three themes were recognised as new constructs to add to the conceptual model: ‘Social connection’ was the largest new construct (13 patients reporting data for this construct and five themes), ‘Burden’ the second largest construct (12 patients and six themes) and ‘Distinguishing between blood products’ (four patients, three themes). Table 9 provides a full list of themes with participant frequencies and example quotations per subtheme. Each construct is discussed in turn following the table, including illustrative quotes.

Table 9 New haematology patient constructs, with themes, frequencies and quotes per theme listed

Construct header	Frequency (n patients)	Patient quotations
Social Connection		
Patient involvement generally positive	6	"*I think I'm quite involved in everything that does go on, erm, they do keep you · up to date and everything*" (Patient 2, Aplastic Anaemia, Site 1)
Interaction with other patients	6	"*we know a lot of people here so we have chats, things like that – so it's like a little family really*" (Patient 6, Myelofibrosis, Site 1)
Lack of interaction or activity during transfusions	5	"*Well except in my case because being partially sighted, I can't read, can't see peoples' faces, so er, I'm just sat here for about eight to ten hours, just looking at the wall more or less*" (Patient 5, Myelodysplasia, Site 1)
Curiosity and appreciation for blood donors	3	"*you know 'what do you think about the blood?' and erm, I think, I think about the blood, that it came from somebody, just curious to know a little bit more about the person*" (Patient 4, Aplastic Anaemia, Site 1)
Support from family or primary care HCPs	2	"*when we approach the doctor, my family member: 'ask this one, ask this one', he/she is like/ so, which is a big help, but like me, I don't know what to ask*" (Patient 10, other Anaemia, Site 2)
Burden		
Transfusion part of routine life	7	"*I carry on completely normal, normal life with the, you know, the odd transfusion every now and again, yeah*" (Patient 8, other Anaemia, Site 1)
Transfusions are inconvenient	5	"*I think it's too often because being in hospital twice a week, minimum twice a week/ cause the week I receive blood, I have to come three times, and it's exhausting*" (Patient 12, Aplastic Anaemia, Site 2)

Construct header	**Frequency (n patients)**	**Patient quotations**
Life restrictions, travel	4	“*it stops you from, if you ever wanted to go to another country, make a life in another country, it's a downside of it, the whole thing, be very difficult to do that*” (Patient 13, Inherited Anaemia, inc Thalassemia, Site 2)
Attendance not a great burden	4	“*it’s not a burden to me, I don’t live too far away*” (Patient 4, Aplastic Anaemia, Site 1)
Distinguishing between blood products		
Knowledge gaps for platelets	2	“*I don’t really understand what platelets do, I know, I know that they, that they repair the damage in the body, and works like that erm, ·· well I am not a doctor am* I” (Patient 5, Myelodysplasia, Site 1)
Positive perception of platelets	2	“*it’s just that one’s shorter than the other. The erm, platelets only take about 20 minutes to half an hour*” (Patient 2, Aplastic Anaemia, Site 1)
Distinction between non irradiated and irradiated blood	1	“*all blood transfusions are different, but this is irradiated blood transfusion”* (Patient 11, Lymphoma (CLL) and a second haematological condition, Site 2)

Social connection: Six of the 14 patients reported that they interacted with other patients in the unit, and six patients were also positively and fully involved in their transfusions, such as through interacting with HCPs (who they found to be approachable) to ask them general questions or to discuss their transfusion regimens. Some patients reflected on wider family, or GP support, or talked of a curiosity or connection to the blood donors. Yet, other patients felt that they lacked or held limited interaction with other patients, especially patients with different health conditions or to respect their privacy (n=5), or that further involvement was complex.

"*I've met, half a dozen people over the course of the time and er, but they all have/ they either have/ they've all got some sort of cancer treatment or some sort of deficiency, but it's not the same as my own, but even if it were, I'm not sure that would take me very far, er, swapping notes with someone else whose got erm ... wouldn't really give me any great comfort or distress*" (Patient 4, Aplastic Anaemia, Site 1).

Burden: Half of the patients interviewed reported that transfusions were a part of their routine life, that attendance was not a great burden and that the experience was consistent over time and easy (switching between red cell and platelet transfusions). Around an equal number of patients (n=8) reported, however, that transfusions were inconvenient, involving lengthy appointments, frequent hospital trips and restriction to activities such as travelling away.

"*… we come here for blood and platelets very often, you know, our life is like attached to the, the hospital, we live like in a probation, you know, I feel like* *we live in a probation because, er, it's kind of a prison, we feel, I feel like I'm a prisoner, you know, yeah, because I can't go, er, very far for very long*" (Patient 12, Aplastic Anaemia, Site 2).

Distinguishing between blood products: Four patients shared perceptions about specific blood products, mostly platelets. These patients perceived platelets quite positively (e.g. quicker to infuse) and had less curiosity over their donor origin. However, there were some knowledge gaps about platelets (e.g., what platelets did and where they were harvested from), and a one patient specifically reported that he/she was receiving irradiated blood, with no greater elaboration provided on what was different about this.

"*it's irradiated blood like I told you ... it's just blood really*" (Patient 11, Lymphoma (CLL) and a second haematological condition, Site 1).

4.3.2.3 Importance of perceptions: patients

Table 10 reports the importance ranking of constructs from the conceptual model, alongside newly identified constructs, according to frequency and thematic elaboration (i.e. number of themes per construct). The most frequent patient construct, that all patients reported perceptions for was 'Involvement in decision making' followed by 'Negative emotions' and 'Health benefits'.

Table 10 Frequencies and elaboration of patients' responses per construct

Construct	**Frequency** (number of patients reporting perceptions related to the construct)	**Elaboration** (number of themes inductively generated for the constructs)
Negative emotions	14	8
Involvement in decision making	14	7
Health benefits	14	6
Necessity	14	5
Social Connection	13	5
Awareness of risk / safety	12	5
Burden	12	4
Alternatives	10	4
Distinguishing between blood products	4	3

4.3.2.4 Patients' blood transfusion perceptions conceptual model for haematology

In the patient's conceptual model (Figure 7), the six construct structure from the conceptual model of blood transfusion perceptions presented in the systematic review (Chapter 2) is supported with the addition of three new haematology-specific constructs. The constructs of 'Burden' and 'Safety/risk' are proposed to be linked with 'Negative emotions' due to some patients reporting their transfusions to be time-consuming or involving risk. 'Health benefits', 'Social connection' and 'Negative emotions' are associated with perceptions in the 'Safety/risk construct, due to patients often deliberating transfusion risk vs. benefit and efforts made to have positive social interactions (e.g. with HCPs) reportedly eased some patients concerns ('Negative emotions') or information needs. These five constructs as well as three 'clinical' constructs influence 'Decision making', such as the availability of 'Alternatives', differences in perceptions depending potentially on the blood product being transfused (‘Distinguishing between the blood products’) and the transfusion ‘Necessity’ (determined by HCPs or clinical indicators).

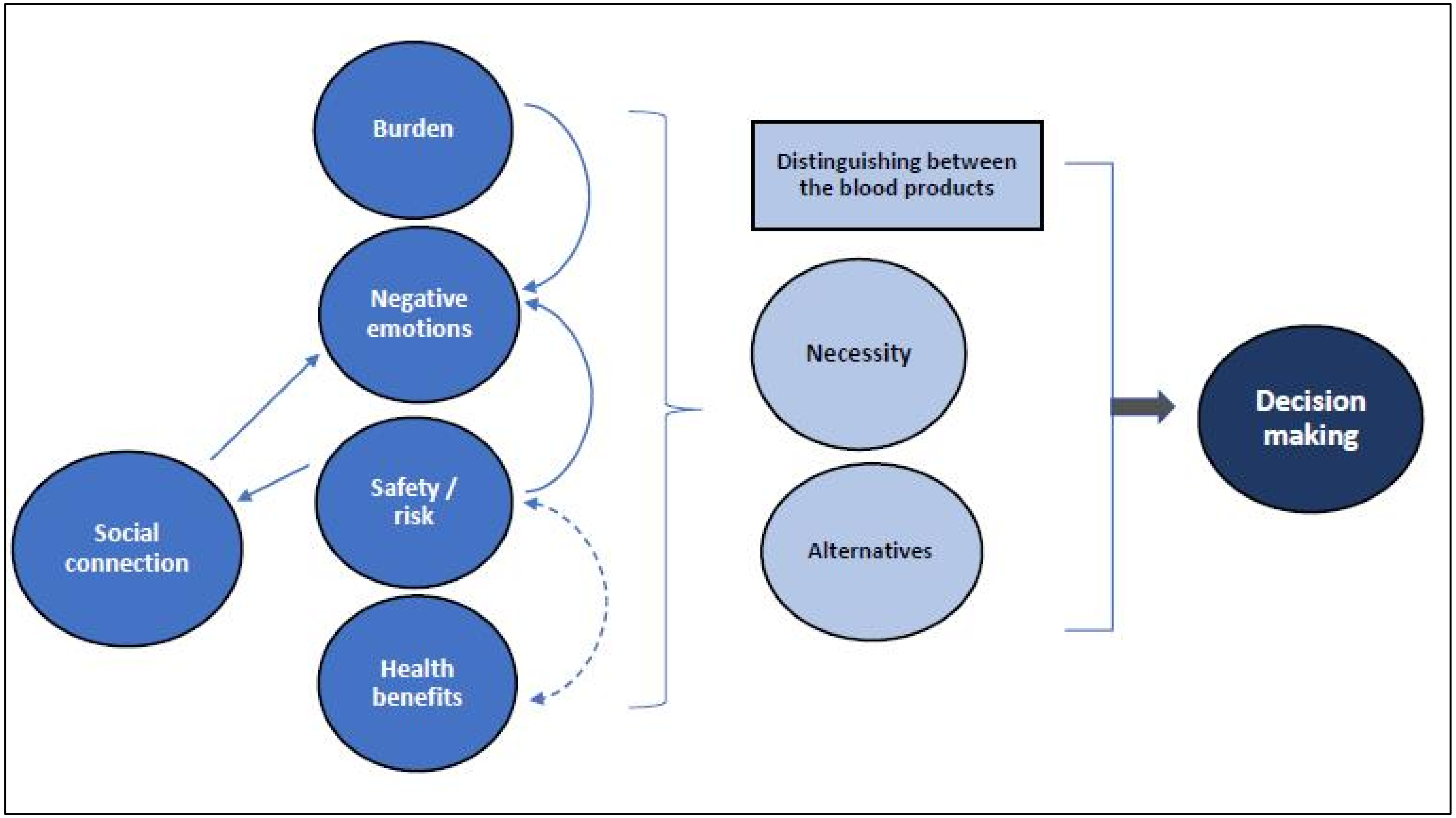


Figure 7 Conceptual model of patients' blood transfusion perceptions in haematology

Single headed arrows indicate a direct one-way relationship, double headed dashed arrows indicate a bi-directional relationship between constructs. Influences on 'Decision making' are shown using the arrows.

4.3.2.5 HCPs' perceptions

Table 11 provides a full list constructs from the deductive analysis and newly generated HCPs' themes of blood transfusion perceptions for each construct. Frequency counts (i.e. number of participants that reported a perception contributing to that theme) are also presented, supported with illustrative quotes and explanations for each construct below.

Table 11 Study 2 constructs from the blood transfusion conceptual model (HCPs) with themes, frequency counts and supporting quotes listed

Construct header	Frequency (n HCPs)	HCP quotations
Awareness of risk / safety		
Risks mitigated by safe transfusion practices	12	"*…it's all quite safe, erm, in terms of, em, getting the right blood product for the patient, cause it's different steps in safeguarding steps to do that*" (HCP 10, Senior House Office, Site 2)
Risks and benefits established with patients	9	"*so you just try to reassure it's a rarity, for you to obviously get anything from transfusion, and erm, reactions is the one that commonly comes up as well, they worry about reacting to, cause, 'does it have any side effects?' is the common question I get asked*" (HCP 8, Nurse, Site 2)
Iron overload considered a key risk	7	"*the downside is if they continue to have lots and lots and lots of blood transfusions they will become / have high iron levels … so then you have the problem of the liver being affected because high ferritin, so that's the downside of it*" (HCP 2, Nurse, Site 1)
Infections, antibodies and reactions risks	7	"*um, long-term wise I think it is probably not good for them because the more you get transfusion, the more becomes/ they develop the risk of having antibodies, er, and that can be very bad for them in the long run because you are/ every time we cross-match their blood products, it becomes rarer and rarer*" (HCP 9, Senior Charge Nurse, Site 2)
Short and long term medical and psychological impact	6	"*they're also concerned about getting addicted to blood transfusions*" (HCP 12, Clinical Psychologist, Site 2)
Risk of not providing a transfusion	5	"*they've got Leukaemia or MDS (Myelodysplasia Syndromes) and they just, and they know that this is all you can do, they just need to have their transfusion every how ever many weeks, and if you're not providing a chair for them, then they could end up on our medical assessment unit*" (HCP 2, Nurse, Site 1)

Construct header	Frequency (n HCPs)	HCP quotations
Health benefits		
Symptom improvement, making patients feel better	11	"*Yeah, so largely it erm, taking away the tiredness and lethargy, which is, er, a symptom of patients that are anaemic, er, and for some of them improving their symptoms of shortness of breath on exertion*" (HCP 7, Specialist Registrar, Site 1)
Supportive care to carry on with normal daily living	10	"*it's about trying to give them a quality of life, so trying to work out what's the best, you know, what's the best, amount of blood to give them if you like*" (HCP 2, Nurse, Site 1)
Benefits last a limited time only	8	"… *it's really tricky to say to that person, or to their relatives 'right, we don't think you're benefitting from blood anymore' because they know if they don't have the blood they will die*" (HCP 3, Specialty doctor (Haematology), Site 1)
Shared HCP agreement of transfusion benefits	5	"*yeah I think generally we all share the same view that actually it's benefiting the patient*" (HCP 9, Senior Charge Nurse, Site 2)
Patient questioned on benefits to provide / continue transfusions	5	"…*when we see them in clinic or when we see them in the day unit, um, and if we find they're having symptomatic benefit from it, you know then we carry on with it*" (HCP 3, Specialty doctor, Site 1)
Some risk-benefit for patients questionable	3	"*I think quite, some of my patients who've maybe only got a slight anaemia, sort of eight to nine, haven't felt any better on transfusions, I think they'd rather have the slightly low count, so I think it really depends how low their haemoglobin goes*" (HCP 13, Consultant Haematologist, Site 2)
Necessity		
Transfusions support chemotherapy or used to treat anaemia	12	"*as I've said, it's the only way, with a lot of these people, it's the only thing that's keeping them alive, or it's the thing that's allowing them to have treatment, that's hopefully going to keep them alive*" (HCP 8, Nurse, Site 2)

Construct header	**Frequency (n HCPs)**	**HCP quotations**
Transfusions are vital, aiding survival	10	"*it is palliative technically, it is because we are keeping them alive cause if we didn't transfuse them, they will die*" (HCP 5, Consultant Haematologist, Site 1)
Transfusions given to protect health	8	"*if somebody has got a really low haemoglobin, they need the blood, cause obviously they're struggling, sometimes they're breathless, it puts a strain on the heart*" (HCP 4, Transfusion Practitioner, Site 1)
Necessity established using clinical and patient factors	8	"*it (frequency of the transfusions) depends on their haemoglobin, the clinical symptoms, and the data, I mean, the blood results*" (HCP 11, Haematology Specialist Nurse, Site 2)
Patients rely on and express need for transfusion	5	"*but other patients are so fixated by it, and it is keeping them going, that I think sometime it's, I think, they really rely on it*" (HCP 1, Haematology Specialist Nurse, Site 1)
Negative emotions		
Patients' unexpressed potential negative emotions	12	"*Erm, I'm not quite sure though, how they exactly feel about their specific transfusion going in at the time, whether they're anxious, or? whether they feel happy, or? I dunno*" (HCP 10, Senior House Office, Site 2)
Patient anxiety and upset with receiving regular transfusions	10	"*they do get really worried if they come in and their haemoglobin's low, they immediately start thinking something bad's happening or worrying that they're going to have to start coming in every week*" (HCP 8, Nurse, Site 2)
Concern about downsides of transfusions for patients	10	"*it is worrying, I mean people, if they've got cardiac problems, they can get chest pain, just really really unwell*" (HCP 2, Nurse, Site 1)
Practice concerns and frustrations	9	"*I do worry here that we don't have enough capacity to get patients who are becoming acutely unwell and there isn't a space for them, and that really frightens me*" (HCP 4, Transfusion Practitioner, Site 1)

Construct header	Frequency (n HCPs)	HCP quotations
HCPs' strategies to reduce patient anxiety	6	"*[transfusion] is not treating the underlying cause and therefore their transfusion requirement will go up and at some point, we will stop. Because we warn them early that that's gonna happen; when that does happen they're less shocked*" (HCP 7, Specialist Registrar, Site 1)
Patients perceiving transfusion positively, as a lifeline	5	"*I think people tend to be positive about it cause I think they get the fact that, you know, this is, this is all we've got for you, but actually it does work, you know*" (HCP 3, Specialty doctor, Site 1)
Upset in witnessing patients' worsening health or death	3	"*yeah, it's quite distressing, it's quite distressing, especially when you've known somebody for a number of years and then it gets to that point, you do sort of kind of think 'oh why are they coming in'*" (HCP 5, Consultant Haematologist, Site 1)
Alternatives		
Alternatives considered or already in use	10	"*most of these patients that are on such regular transfusion programmes are on EPO (erythropoietin) are on iron, are on all the other kind of alternatives to blood that they can be on and despite that are still requiring a blood transfusion*" (HCP 10, Senior House Office, Site 2)
No alternatives, transfusion only option	7	"*I think as clinicians, people always weight that up and I think it's very difficult because I think there genuinely isn't an alternative … I just think there really isn't an alternative unfortunately*" (HCP 4, Transfusion Practitioner, Site 1)
Support for greater consideration and use of alternatives	6	"*in terms of the patients who require regular top up transfusions, it doesn't seem like there's much research done into alternative therapies and things and so we just readily assume 'oh we'll do bloods' as that's all we know, that's all we're readily exposed to*" (HCP 9, Senior Charge Nurse, Site 2)
Committed to giving regular transfusions once started	3	"*So once you get someone in to having transfusion, you can't, if you could/ you switch the on switch, but you can't flick it off again and it usually ends up with that person being admitted to the main hospital with some infection…*" (HCP 2, Nurse, Site 1)

Construct header	**Frequency (n HCPs)**	**HCP quotations**
Involvement in decision making		
HCPs advocate and involve patients in decisions	13	"… *other patients want to take control of it and not be told what to do, so you have to be, erm, I think you have to be flexible about that*" (HCP 7, Specialist Registrar, Site 1)
Team decision on transfusion prescription	13	"*the nursing staff had reviewed the bloods and felt that they needed a blood transfusion, but then also/ ultimately the decision is with, um, with the doctor*" (HCP 1, Haematology Specialist Nurse, Site 1)
Patient autonomy in their own transfusion decisions	11	"*I think he/she pushes it quite far, so he/she might avoid coming out for a transfusion to see if his/her haemoglobin gets better*" (HCP 3, Specialty doctor, Site 1)
Individual transfusion regime for each patient	11	"*we try and individualise transfusion practice per patient, so if you have a patient whose haemoglobin drops down to below, I don't know, 70, on every two weeks, that's how often you give them their blood, so it is individualised*" (HCP 5, Consultant Haematologist, Site 1)
Transfusions prescribed appropriately using guidelines	12	"*to actually have something like that to say 'well I am following NICE guidance, therefore, I've got this huge! weight of evidence behind me, so I feel confident to make that decision'*" (HCP 4, Transfusion Practitioner, Site 1)
Deferral of decision making to HCPs	6	"*I think a lot of patients rightly so place their trust in the medical team, the nurses and the doctors, so if somebody said they need a transfusion, I think it's very few and far between patients that say no*" (HCP 14, Specialist Registrar, Site 2)
Barriers to discussing transfusion or obtaining consent	5	"*it is not always possible (obtaining and documenting verbal consent), especially in patients who are either unable to give consent or, you know, patients who are not in a state, because of the physical condition to give consent*" (HCP 3, Specialty doctor, Site 1)
Tendency towards providing transfusion	4	"*if they're very symptomatic with it, and even if the level is slightly off the baseline but they're very symptomatic then we like to give it*" (HCP 10, Senior House Office, Site 2)

Awareness of risk/safety: Fifty percent of HCPs reported iron overload as the key risk for this patient group and more HCPs spoke about risks being mitigated as much as possible through safe transfusion and blood testing practices. Patients were made aware of risks such as iron overload, antibody build up, infections, reactions or risks associated with not being transfused through discussion with HCPs. A few HCPs reported other medical and psychological risks with transfusions, such as bone marrow damage, the requirement of venesections, nausea or patient dependency on transfusions.

Health benefits: HCPs reported that transfusions improved patients' symptoms and helped them to feel better to maintain their quality of life and daily activities. HCPs reported that they questioned patients about how beneficial they found their transfusions to be, in order to continue their transfusion prescriptions, yet HCPs knew that at some point for many patients the transfusion benefits experienced would end. Although a number of HCPs were convinced of the benefits and felt that their colleagues held a shared view of transfusion being beneficial (n=5), some risk-benefit considerations in particular patient cases were questionable (n=3).

Necessity: HCPs reported that transfusions aided patients to survive and protected their health and that transfusions widely support haematology patients who receive chemotherapy or suffer from anaemia due to their illnesses. HCPs reported judging transfusions to be necessary based on clinical factors, such as the patients' haemoglobin level and their physical functioning. HCPs reflected on patients who became dependent on their transfusions, feeling that they were necessary, with patients experiencing anguish when transfusions are deferred or delayed.

Negative emotions: Overwhelmingly, HCPs were concerned about the burden and physical impact of transfusion for their patients and were concerned and frustrated with capacity pressures and the difficulties of providing patients with more effective care (e.g. worries about patients being reviewed enough, lack of time to interact with patients). HCPs were aware of a large amount of patients' anxieties, reasons for their distress or of the challenges that patients faced with receiving repeated transfusions (e.g. needing transfusion and its regularity, delays). HCPs reported using strategies such as offering reassurance or copies of blood counts, for example, to try to reduce patients' anxieties. Some HCPs reported that patients' fears may inhibit their involvement in transfusion discussions and that some patients expressed positive emotions when they did not need a transfusion, or for other patients, transfusions were viewed positively, as a lifeline. Clinical safety procedures being in place reduced some HCPs' concerns.

Involvement in decision making*:* The majority of HCPs advocated and involved patients in transfusion decision-making, despite some accounts of decisions being made away from the patients (*n*=6), without informed consent (*n*=3) or being deferred to them by the patients to make (*n*=5). Many HCPs reported making patient-tailored transfusion decisions as a team, consulting with laboratory departments and guidelines. There was a slight tendency towards providing transfusion if symptoms indicated towards this, and accounts of patients questioning or resisting their transfusion were present. Transfusions were also seen as a part of a treatment plan discussed to a lesser extent when primary treatments took precedent:

Alternatives: HCPs supported greater consideration into the use of alternatives and consulted patients who may request alternatives. Many alternatives, however, were either being tried to some benefit (Erythropoietin injections) (*n*=4) or alternatives generally were not an option for this patient group (*n*=4). Some HCPs understood that patients may prefer alternatives, but opted for transfusion due to symptoms, clinical indicators or the evidence base.

4.3.2.6 New haematology themes: HCPs

Four new themes were developed from HCP data that could not be coded into the pre-existing conceptual model constructs. These four themes were recognised as new constructs added to the conceptual model: ‘Burden’ (14 HCPs reporting data for this construct and 2 themes), ‘Organisational factors’ (13 HCPs and 5 themes), ‘Stability/ Variability of transfusion perceptions’ (11 HCPs and 3 themes) and ‘Supportive relationships’ (9 HCPs and 2 themes). Table 12 provides a full list of themes with participant frequencies and example quotations, followed by a discussion of each construct, with an elaborative quotation in turn.

Table 12 New haematology HCP constructs and themes, frequencies and quotes per theme listed

Theme header	Frequency (n HCPs)	HCP quotations
Burden		
Anticipated attendance burden for patients	11	“*if they’re really regular I suppose it’s the fact they’re having blood test and they’re here, and they’re seeing the doctors, and you do, it must be quite hard, patients must feel they’re like here all the time almost*” (HCP 1, Haematology Specialist Nurse, Site 1)
Transfusion’s become a part of patient's routine life	7	“*I think for some, it's just like a way of life for them, em, it's just something that they do and they know other patients who are on a similar sort of path and then they're quite pally with them…*” (HCP 9, Senior Charge Nurse, Site 2)
Organisational factors		
Solutions needed to improve processes and ease capacity strain	7	“*… we're trying to organise transfusions, at short notice, for our patients at short notice on the day unit and ˆ they've got no capacity to deliver the transfusion*” (HCP 6, Consultant Haematologist, Site 1)
Constraints to greater discussion of patients’ views	6	“*there's only one of you, and seven patients, it's not always easy to sit with the patient, discuss any concerns or issues or just have a general conversation*” (HCP 8, Nurse, Site 2)
Solutions needed to enhance communication	6	“*I think there's the other side about educating staff as well about blood transfusion, you know, and how to define risks and you know, encouraging them to discuss with the patients*” (HCP 2, Nurse, Site 1)
High and costly blood use for hospital	6	“*I mean blood transfusion can work, but, um, it is quite a bit more costly both for the hospital and for the patient's time*” (HCP 12, Clinical Psychologist, Site 2)

Theme header	Frequency (n HCPs)	HCP quotations
Complicated management of transfusion slots	5	"*so they send me a letter or an e-mail or something saying 'this person is going to need blood product support and then we're like 'well, where are we gonna put them in then?*" (HCP 3, Specialty Doctor, Site 1)
Stability and variability of transfusion perceptions		
Views consistent and similar to colleagues	7	"*I think there's a general agreement about the use of transfusions for this patient group… yeah, I'd say we pretty much all have the same view*" (HCP 10, Senior House Office, Site 2)
Views broadened through haematology exposure	7	"*before blood transfusions were a one-off sort of thing … since being here, it's actual haematology conditions that require regular blood transfusions, so I see a different side now, and I see, erm how reliant people are on them*" (HCP 5, Consultant Haematologist, Site 1)
Patients' transfusion perceptions variable	2	"*I think it's very variable, I don't think there's like one general consensus across the patients definitely*" (HCP 14, Specialist Registrar, Site 2)
Supportive relationships		
HCPs approachable and bond with patients	5	"*… one of our regulars died in, in the week on the ward, and it's upsetting because you know, we get to know them so well and all about them, they talk to you a lot and erm, and it gets quite personal*" (HCP 3, Specialty Doctor, Site 1)
Efforts to increase patient comfort in unit	4	"*they are often coming in with someone, erm, that you know, they bring someone with them … just to ensure that they've got relatives, or they've got people involved*" (HCP 8, Nurse, Site 2)

Burden: HCPs' perceptions for this theme reported that frequent and lengthy appointments must be burdensome for patients (*n*=11), and that transfusions have become a part of patients' routine lives (*n*=7). One HCP commented that patients could maintain some quality of life despite frequent hospital visits:

"*because these patients if they don't have their transfusions, they aren't able to get up and be, have that level of activity that they would have without that transfusion, so despite having to come in and have a cross-match one day, blood the following day and then only really have one day out of hospital a week, they still manage to maintain some quality of life*" (HCP 14, Specialist Registrar, Site 2).

Organisational factors: Many HCPs from both sites acknowledged constraints that they faced to more greatly discuss their patients' transfusion perceptions, such as the haematology units being busy or the lack of routine questioning of patients' perceptions. HCPs explained in detail the complexity of managing the limited transfusion slots, as blood was highly used at a cost, and felt that solutions were needed to improve processes and ease capacity strain. Patient- or HCP-education was signalled as necessary to enhance patient and HCP communication.

In relation to the complexity of managing the slots: "*we'll sit down and we'll look and 'well if I have to cancel this person this week, if they needed a transfusion in three weeks' time, are we going to be able to have a slot?' you know, that sort of thought behind it, so it's quite complicated ... we try and stretch it because of the lack of availability of slots, we try and stretch it to* *the absolute maximum, so we/ and we try not to prescribe if we don't have to prescribe*" (HCP 3, Specialty Doctor, Site 1).

Stability and variability of transfusion perceptions: Many HCPs reported that their own views about transfusion were either stable over time and similar to their colleagues or inconsistent with their own past views or with their colleagues' views. For example, HCPs reported that their views had often broadened since working in haematology units, proving exposure to medical and long-term transfusion use. Or that their perceptions and behaviours have changed over time, such as having greater tolerance of lower haemoglobin levels in patients before transfusing. One nurse specifically reported how a patient changed their perceptions based on a discussion with them:

"*I don't think those people think oh yeah it is a blood transfusion, and it's somebody else's blood you're receiving,* ***it is a transplant*** *... erm, they / I think it makes some of them stop and think, some of them, or other people say "Oh yes, yes I know that" or "oh yeah, I've never really thought of it that way" so it is interesting*" (HCP 2, Staff Nurse, Site 1).

Supportive relationships: HCPs discussed their efforts to be approachable for patients and how they developed a bond with many patients, such as by listening to them and providing information like blood counts. This was felt to be important to enhance patients' feelings of control. HCPs reported ways in which they aimed to increase their patients' level of comfort during the transfusions, or that other patients or patients' acquaintances whom patients attend with may be supportive.

"*Erm, some of them might get some benefit out of that [lengthy appointments] cause it gives them an opportunity to have a chat with patients who are going through a similar experience and see that they're not alone*" (HCP 6, Consultant Haematologist, Site 1).

4.3.2.7 Importance of perceptions: HCPs

Table 13 reports the importance ranking of constructs from the conceptual model, alongside newly identified constructs, according to frequency and thematic elaboration (i.e. themes per construct). The most frequent HCP theme was 'Involvement in decision making', followed by 'Health benefits' and 'Necessity'.

Table 13 Frequencies and elaboration of HCPs' responses per construct

Construct	**Frequency (number of HCPs reporting perceptions related to the construct)**	**Elaboration (number of themes inductively generated for the constructs)**
Involvement in decision making	14	8
Negative emotions	14	7
Health benefits	14	6
Necessity	14	5
Burden	14	2
Organisational factors	13	5
Alternatives	13	4
Awareness of risk / safety	12	6
Stability/ Variability of transfusion perceptions	11	3
Supportive relationships	9	2

4.3.2.8 HCPs' blood transfusion perceptions conceptual model for haematology

In the HCP haematology conceptual model, the six construct structure is also supported (Figure 8), with the addition of four haematology-specific constructs. Three constructs are proposed to link directly with 'Negative emotions': transfusion 'Burden', 'Safety/risk' concerns and 'Supportive relationships', which could help ease patients' concerns or worries. 'Supportive relationships' such as positive contact with HCPs and other supportive contacts, whilst patients receive their transfusions may also ease perceptions of transfusion 'Burden'.

'Safety/risk' vs. 'Health benefits' decisions are associated, being routinely considered and discussed with patients and the model also displays 'clinical factors' which influence 'Decision making'. This is transfusion 'Necessity', the suitability of 'Alternatives' and 'Organisational factors'; appointment availability etc. Prior to decision making, the 'Stability or variability of HCPs' transfusion perceptions may influence tolerance of (lower) haemoglobin levels, practice consistency, transfusion acceptability and team decision making agreement.

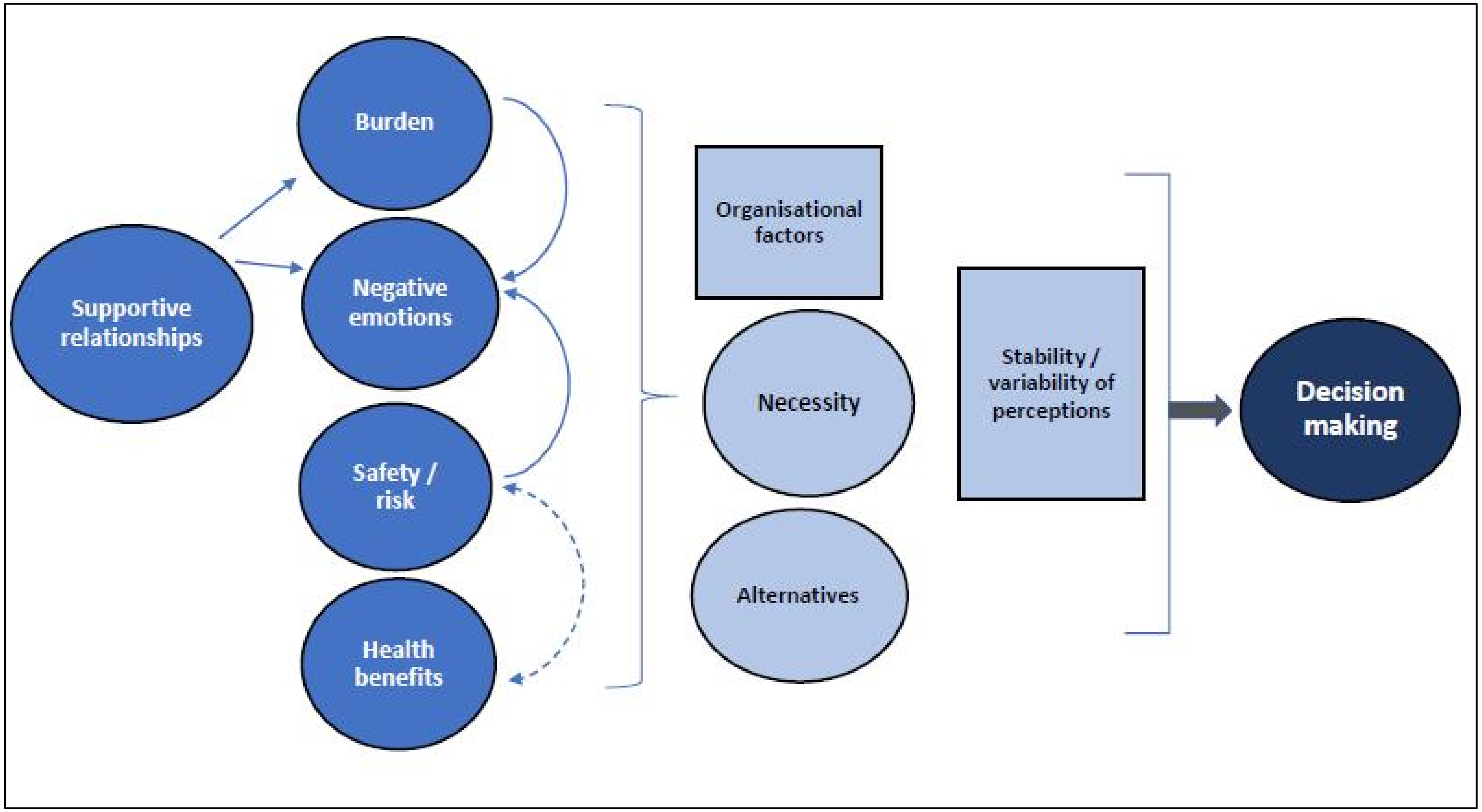


Figure 8 Conceptual model of HCPs’ blood transfusion perceptions in haematology

Single headed arrows indicate a one-way relationship and double headed dashed arrows indicate a bi-directional relationship between constructs. Influences on 'Decision making' are shown using the arrows.

4.3.2.9 Triangulation of patient and HCP perceptions

To assess convergence and divergence of perceptions, the 95 patient and HCP themes generated during inductive analysis were tabulated (Table 14) and compared using the aforementioned triangulation protocol. There was moderate convergence (42%) between patients' and HCPs' perceptions. Full agreement between patients' and HCPs' themes was recognised on 24 occasions (35%), partial agreement on seven occasions (8%), disagreement on four occasions (5%) and silence on 39 occasions (52%). Table 14 lists all themes with their agreement ratings.

Agreement was greatest for the 'Health benefits', 'Alternatives' and 'Involvement in decision making' constructs. For 'Health benefits', for example, HCPs reported similar benefits of blood transfusion as patients, mainly that transfusions aided patient survival and improved patients' symptoms. Partial ratings occurred, for example, with HCPs reporting that they involved patients in their transfusion decisions, whereas for patients, they commented that involvement was generally positive and that they were offered transfusions with an element of choice.

Disagreement was recognised for example, for 'Burden' where patients expressed often having 'Life restrictions' in respect to travel, due to needing to stay close to the haematology unit, whereas some HCPs reported that transfusions can become a part of a patient's routine life "*it's very individual, some patients, erm, have been in the system a long time, especially haematology patients and they just take it as part and parcel of the course and they don't really have, they kind of got so use to it they don't really have* *any qualms in having the blood transfusion*” (HCP 14, Specialist Registrar, Site 2).

Silence occurred for themes, in which patients or HCPs expressed their particular patient / HCP role experiences (e.g. no negative consequences from transfusion or that patients are reviewed and consulted with when transfusions may need to end).

Table 14 Study 2 patient and HCP themes with agreement ratings

Construct header	**Patient (P) or HCP**	**Theme label**	**Agreement rating**
Burden	P	Transfusions are inconvenient	1 Agreement 1 Disagreement
	P	Attendance not a great burden	
	HCP	Anticipated attendance burden for patients	
Burden	P	Transfusion part of routine life	1 Agreement 1 Disagreement
	P	Life restrictions, travel	
	HCP	Transfusion has become a part of patient's routine life	
Distinguishing blood products	P	Knowledge gaps for platelets	Silent
Distinguishing blood products	P	Positive perception of platelets	Silent
Distinguishing blood products	P	Distinction of irradiated blood	Silent
Social connection + Decision making	P	Patient involvement generally positive	2 Partial agreement
	P	Transfusion offered with patient involvement in choice	
	HCP	HCP advocates and involves patients in decisions	
Social connection	P	Interaction with other patients	Silent
Social Connection	P	Lack of interaction or activity during transfusions	Silent

Construct header	**Patient (P) or HCP**	**Theme label**	**Agreement rating**
Social Connection	P	Curiosity and appreciation for blood donors	Silent
Social Connection	P	Support from family or primary care HCPs	Silent
Supportive relationships	HCP	HCPs approachable and bond with patients	Silent
Supportive relationships	HCP	Efforts to increase patient comfort in unit	Silent
Organisational Constraints	HCP	Solutions needed to improve processes and ease capacity strain	Silent
Organisational Constraints	HCP	Constraints to greater discussion of patients' views	Silent
Organisational Constraints	HCP	Solutions needed to enhance patient-HCP and team communication	Silent
Organisational Constraints	HCP	High and costly blood use for hospital	Silent
Organisational Constraints	HCP	Complicated management of transfusion slots	Silent
Stability and variability of transfusion perceptions	HCP	Views on transfusion broadened through haematology exposure	Silent
Stability and variability of perceptions	HCP	Views consistent and similar to colleagues	Silent
Stability and variability of perceptions	HCP	Patients' transfusion perceptions variable	Silent
Awareness of risk / Safety	P	Discomfort and illness during or post-transfusion	1 Agreement 1 Disagreement
	P	No experienced negative consequences	
	HCP	Short and long term medical and psychological impact	
Awareness of risk / Safety	P	Health risks from high iron levels	1 Agreement

Construct header	**Patient (P) or HCP**	**Theme label**	**Agreement rating**
	HCP	Iron overload considered a key risk	
Awareness of risk / Safety	P	Potential infection or reaction risk	1 Agreement
	HCP	Infections, antibodies and reactions risks	
Awareness of risk / Safety + Involvement in decision-making	P	Caution needed, blood should be used appropriately	1 Agreement
	HCP	Transfusions prescribed appropriately using guidelines	
Awareness of risk / Safety	HCP	Risks mitigated by safe transfusion practices	Silent
Awareness of risk / Safety	HCP	Risks and benefits established with patients	Silent
Awareness of risk / Safety	HCP	Risk of not providing a transfusion	Silent
Necessity	P	Transfusions used as a current and long-term supportive treatment	1 Partial agreement
	HCP	Transfusions support chemotherapy or used to treat anaemia	
Necessity	P	Transfusion prolonging life and aiding survival	2 Agreement
	HCP	Transfusions are vital, aiding survival	
	HCP	Transfusions given to protect health	
Necessity	P	Need for transfusion apparent through symptoms	1 Partial agreement
	HCP	Patient reliance and expressed need for transfusion	
Necessity	P	Speculation and doubt over pending transfusion prescription	Silent
Necessity + Involvement in	P	Need established by HCPs and clinical indicators	2 Agreement

Construct header	**Patient (P) or HCP**	**Theme label**	**Agreement rating**
decision making	HCP	Team decision on transfusions prescription	
	HCP	Necessity of transfusion established in balance with clinical and patient factors	
Health benefits	P	Keep going with daily life	1 Agreement
	HCP	Supportive care to carry on with normal daily living	
Health benefits	P	Boosting blood levels*	1 Agreement 1 Partial agreement*
	P	Relief of symptoms such as tiredness	
	HCP	Symptom improvement, making patients feel better	
Health benefits	P	Can take time to feel benefit of transfusion	1 Agreement
	HCP	Benefits last a limited time only	
Health benefits	P	Anticipated benefits	Silent
Health benefits	P	Patient convinced of benefit by significant others	Silent
Health benefits	HCP	Shared HCP agreement of transfusion benefits	Silent
Health benefits	HCP	Some risk-benefit for patients questionable	Silent
Negative emotions	P	No concerns or worries with transfusions	2 Agreement
	P	Gratitude that transfusions possible	
	HCP	Patients perceiving transfusion positively, as a lifeline	
Negative emotions	P	Receiving transfusions unpleasant	2 Agreement 1 Disagreement *
	P	Relaxed during transfusion appointments*	
	P	Concern of transfusion dependency	
	HCP	Patient anxiety and upset with receiving regular transfusions	

Construct header	**Patient (P) or HCP**	**Theme label**	**Agreement rating**
Negative emotions	P	Positive emotions of not needing transfusion	Silent
Negative emotions	P	Attempts to manage worries and fear	Silent
Negative emotions	P	Perception that doctors dislike prescribing transfusions	1 Partial agreement
	HCP	Concern about downsides of transfusions for patients	
Negative emotions	HCP	Patients' unexpressed potential negative emotions	Silent
Negative emotions	HCP	Practice concerns and frustrations	Silent
Negative emotions	HCP	HCPs' strategies to reduce patient anxiety	Silent
Negative emotions	HCP	Upset in witnessing patients' worsening health or death	Silent
Alternatives	P	Alternatives considered or already in use	1 Agreement
	HCP	Alternatives considered or already in use	
Alternatives + Involvement in decision making	P	No alternatives, transfusion the only option	2 Agreement
	P	Confronted with limited or no choice	
	HCP	No alternatives, transfusion the only option	
Alternatives	P	Patient preference for alternatives	1 Agreement
	HCP	Support for greater consideration and use of alternatives	
Alternatives	P	Patient's body can correct depleted cells	Silent
Alternatives	HCP	Committed to giving regular transfusions once started	Silent
Involvement in decision making +	P	Willing acceptance of transfusions	2 Agreement 1 Partial agreement*
	HCP	Patient autonomy in their own transfusion decisions	

Construct header	Patient (P) or HCP	Theme label	Agreement rating
Necessity + Health benefits	HCP	Patient reliance and expressed need for transfusion	
	HCP	Patient questioned on health benefits to provide / continue transfusions*	
Involvement in decision making	P	Deferral of decision making to HCPs	1 Agreement
	HCP	Deferral of decision making to health professionals	
Involvement in decision making	P	Decision making discussion positive	Silent
Involvement in decision making	P	Routine 'automatic' treatment	Silent
Involvement in decision making	P	More frequent transfusions would be resisted	Silent
Involvement in decision making	HCP	Individual transfusion regime for each patient	Silent
Involvement in decision making	HCP	Barriers to discussing transfusion or obtaining consent	Silent
Involvement in decision making	HCP	Tendency towards providing transfusion	Silent

4.4 Discussion

This chapter reports an interview study conducted across two haematology day units that aimed to investigate haematology patients’ and HCPs’ perceptions of blood transfusions. This study found that patients and HCPs considered transfusions beneficial for managing patients’ haematological disorders and symptoms. HCPs largely worked together with their colleagues and patients to discuss transfusion decisions, risks and blood-sparing alternatives. Both patients and HCPs experienced negative emotions, linked to the downsides of transfusion for patients. HCPs also held concerns directed towards constraints with the transfusion service that they can provide. Patients and HCPs reported strategies to manage their negative emotions, such as remaining positive and hopeful (patients) or offering reassurance to patients (HCPs) or holding trust in their clinical safety measures (HCPs).

From the inductively generated constructs, ‘Burden’ was an emergent construct for both patients and HCPs where there was a clear distinction between transfusions being time-consuming and frequent, yet also for some patients, a part of their ‘routine’ lives. New constructs for patients covered their cognitive understanding and experience with the different blood products they receive (‘Distinguishing between blood products’) and their perceptions of support that may be available for them, such as from other patients (‘Social Connection’). HCPs’ perceptions led to constructs being generated that profiled a considerable level of compassionate patient care: (‘Supportive relationships’), within a busy and pressurised environment: (‘Organisational factors’). HCPs in this study had the opportunity to reflect on the ‘stability’ and ‘variability’ of their own transfusion perceptions, remarking their perceptions to remain largely stable after working in the field of haematology and that their perceptions were comparable with their colleagues. Overall, there was moderate convergence between patients’ and HCPs’ themes of perceptions despite both groups holding different roles (patients vs. providers).

The constructs generated from this study extended on the conceptual model of blood transfusion perceptions, from the preceding systematic review. This suggests that specific patient and HCP groups receiving transfusions in different contexts will hold unique perceptions, supporting the requirement to explore transfusion patient and HCP groups within their specific contexts, rather than treating transfusion patients and HCPs homogenously. This is supported in the treatment perceptions literature, that context will inform treatment perceptions (Horne, 2003). The conceptual models in this chapter portrayed how context linked to key emotional perceptions, for example, organisational pressures causing concern for HCPs and through holding strong relationships with HCPs (‘Social connection’) patients were exposed to collaborative patient-HCP practices (e.g. ad hoc discussion of the transfusion regimen and asking questions). Collaborative practices found in this context may have positive outcomes for patients. Patients who engage with HCPs in more collaborative practices have a higher level of decisional control and decisions matching their preferences, resulting in better health outcomes for the patient (Ghane et al., 2014).

For the current study, perceptions of ‘risk’ related to patients’ clinical vulnerability and transfusions raising patients’ iron levels. HCPs were empathetic to and aware of these health threats and treatment needs facing patients. Findings also highlighted synchrony in perceptions between patients and HCPs, in particular for the ‘Health Benefits’, ‘Alternatives’ and ‘Burden’ constructs. Although, the triangulation analysis detected that HCPs may perceive that transfusions cause less patient disruption once they are in an established routine, whereas patients discussed ongoing challenges, such as travel restrictions. There was also alignment into the report of patients being involved in the decision-making, yet many patients faced limited treatment options beside transfusion and irrespective of this held some knowledge gaps. Therefore, there are some areas where HCPs could have had a more accurate understanding of patients' perceptions, which may have implications for practice and ongoing scheduling of transfusions (e.g. if patients have 'burden' related or 'knowledge' related barriers or uncertainties).

The findings from this study align with and advance on the broader literature. Patients in this study did not find their transfusions to be overly anxiety provoking or hard to come to terms with (Randall et al., 2005). Instead they remained hopeful, keeping a positive outlook, as had been reported elsewhere in the cancer treatment literature, with haematology patients reporting acceptance of their conditions, changing life's priorities, and increasing engagement with HCPs and significant others as a way to cope with their conditions (Bulsara et al., 2004) (Prip et al., 2017). Patients may have used appraisal-focussed coping to accept the reality of their situation, redefining it as acceptable (Moos et al., 1984). Patients receiving dialysis treatment have been reported to find acceptance, perceiving dialysis as a life-sustaining gift (Reid et al., 2016).

Some patients in this study reported that they enjoyed attending for their transfusions and that their acceptance of transfusion improved over time. Patients are likely to have developed ways that they cope with their transfusion, such as occupying themselves during their transfusions and engaging with the wider patient and healthcare team, which they reutilise each time their appointment occurs. The positive outcomes of such strategies inform the development of new perceptions (Leventhal et al., 1980; Leventhal et al., 1984), which is evidenced with patients discussing long-held and consistent perceptions towards the transfusions, such as that it ‘keeps them going with daily life’ etc.

HCPs treating cancer patients have, however, been reported to experience a high level of emotional exhaustion (Trufelli et al., 2008). For HCPs in this study, the findings signalled many aspects of their compassionate care. However, if not well supported, many HCPs may be exposed to a potential risk of ‘burnout’, defined as ‘a breakdown of the psychological defences that a worker uses to cope with intense job-related stress’ (Brohl, 2006). This is due to HCPs aiming to increase patients’ comfort and meet their information needs whilst working in a pressurised service. HCPs also reported holding some negative emotions of the downsides of transfusion for many of their patients.

Strengths of this study include the methodological approach taken to reduce bias by inviting all eligible transfusion patients to take part in the study, alongside interviewing consenting transfusion HCPs at the same sites within the same study time-frame. All patients were interviewed whilst in their transfusion chair, during or just prior to their transfusion, minimising recall bias and potentially heightening the vivid and actual account of their beliefs and experiences. Although the ‘in context’ investigation of patients’ and HCPs’ perceptions minimised recall bias, a limitation of this could be that patients, especially, may have provided more positively framed perceptions as the interviews were conducted in the unit with other patients and often HCPs within hearing distance. This may have enhanced participants providing more socially desirable responses that listeners would have more highly endorsed (Edwards, 1957). The researcher reflected on this, aiming to conduct the interviews in quiet sections of the haematology unit to allow the participants to freely share their views as openly as possible. The researcher also clarified that the research was being collected independently for her PhD qualification and that the interviews were confidential, holding no bearing on the HCP's role or the patient's care.

Understanding participants' own interpretation of their issues is in line with the theoretical Realism stance, which the researcher is aligned to. Critical Realism (Willig, 1999), for example, acknowledges ways in which individuals make meaning of their experience (Braun et al., 2006). Therefore, it was important that the interviews were semi-structured, allowing participants to fully express how they experience delivering or receiving transfusions in the real haematology context.

To facilitate meaningful comparisons of patient and HCP data to be drawn, patients and HCPs were also asked comparable topic guide questions, with the deductive constructs aligned to the broader treatment perceptions literature, as discussed in Chapter 3. As a limitation to this, however, HCPs were asked a translated version of a patient-centred questions (e.g. 'What are the benefits of transfusion for *haematology patients*?' instead of 'What are the benefits of transfusion for *you?'*). Although HCPs' own perceptions did emerge through the interviews, of challenges they faced, etc., there may have been value in asking HCPs a slightly alternate set of questions, addressing their potential needs. A further limitation to the study was that the researcher solely completed the triangulation ratings alone, without a second rater to assess inter-rater reliability. This leaves the rating results open to subjective bias, where the researcher may have interpreted no links, e.g., a higher level of ‘silent’ or ‘agreement’ themes, which scored the most highly without a secondary objective rater providing their opinions.

Future research could build on this study by utilising the applicable patient or HCP conceptual model to consider whether other patient and HCP groups hold similar beliefs about transfusion. Sickle-cell patients receiving exchange-transfusions, for example, often have to manage their pain in the community and face mistrust and stigmatization from HCPs when attending hospital, in that they do not wish to attend or disclose information for fear of not receiving adequate treatment for pain (Maxwell et al., 1999). Further research with acute transfusion patients remains warranted; as an under-represented transfusion patient group, as well as research with other patient groups who also receive routine treatments, such as dialysis patients. This may prove beneficial to identify patients’ and their treating HCPs’ perceptions. Further research may also wish to explore patients’ perceptions about ‘Organisational factors’, whether this impacts on their experiences of receiving transfusions, or whether their ‘Supportive relationships’ are adequate.

There are some key implications for practice suggested from this study. HCPs showed motivation for the transfusion service to be enhanced, or potentially better resourced and organised. Services were reportedly stretched in terms of capacity (i.e. full transfusion appointment slots) and HCPs provided a high level of goodwill and gave great efforts to ensure patients’ wellbeing. When asked directly, there was some lack of clarity from HCPs about how patients perceive transfusion. This indicates that some patients may benefit from a greater amount of support, for example, newly transfused patients who are yet to build sustainable coping strategies. Patients may thus welcome service enhancements, for example education into specific blood products, such as platelets, which do hold the greatest transmission risk (Goodnough et al., 2003) or greater involvement in transfusion decision-making, specifically in how to manage any negative emotions, at least at the time of diagnosis, when engaging in decision-making discussions. If patients are not as involved in their transfusions as they wish to be, or lack understanding of parts of the process or blood products, patients may form misperceptions and face challenges of coping with unnecessary fears. Possibly less relevant for transfusion dependent patients, but patients having knowledge gaps about their treatment, exacerbated through not being involved in decision-making discussions, may have a lower level of treatment adherence, being less able to weigh up the risks and benefits of treatment (Horne et al., 1999a).

In conclusion, this study addressed a gap in the evidence base of haematology transfusion patients' and HCPs' perceptions of blood transfusions. The findings of this study revealed that transfusions are perceived to be necessary and beneficial for haematology patients and that patients were largely involved in their transfusion decision making, but experienced negative emotions in relation to the burden of the repeated transfusions, and health consequences, such as iron overload. HCPs shared these concerns with their patients and the challenges of providing a high volume of repeated transfusions with stretched capacity weighed heavily. Further research could utilise the haematology conceptual models with several alternate patient and

HCP groups and seek to investigate within the haematology service recommendations for practice change arising from these findings. If patients' experiences of receiving transfusions in haematology units were enhanced, patients may feel more supported to deal with negative emotions. Improving the transfusion service for patients may also enhance HCPs' negative emotions and potentially alleviate some service pressures.

5 BOOST: Building Optimised Outpatient Services in Transfusion: *A focus group study*

Study 2 (Chapter 4) of this thesis qualitatively explored haematology patients' and healthcare professionals' (HCPs') perceptions of blood transfusion. The results showed that HCPs found transfusions to be beneficial and necessary for haematology patients, but that perceptions of transfusion 'burden' and delivering transfusions in pressurised services existed. This chapter describes Study 3 of this programme of research, which involved focus groups with blood transfusion HCPs that aimed to build on Study 2 by investigating HCPs' views of patients' reported perceptions of blood transfusions and identify opportunities for service improvement to address these.

5.1 Introduction

Implementing change in healthcare, such as introducing new or modified innovations, is complex and particularly challenging if alterations in clinical practice are required, or if better collaboration between disciplines, changes in patient behaviour or in the organisation of care are sought (Grol et al., 2013). Interventions have been initiated to improve blood transfusion clinical practice by changing HCPs' prescribing behaviour. For example audit and feedback interventions, guideline changes or introducing transfusion forms that outlined criteria for transfusion (Tinmouth et al., 2005; Wilson et al., 2002). Interventions have also been launched to conserve blood use coherent with Patient Blood Management initiatives (Oliver et al., 2014), supporting optimised care delivery for patients, who are placed central to the care they receive.

It is important to design services with patients in mind, to provide patients with the best experience and to reduce any negative cognitive or emotional perceptions that can arise when patients face health threats and seek treatment (Leventhal et al., 1980). Policy makers advocate patient participation in their healthcare, suggesting that this improves quality, efficiency and health outcomes (Coulter et al., 2007). Involving patients and considering their treatment perceptions is especially important for designing patient-centred changes, impacting patients who could then after face alterations to how they are offered their treatments and services.

Identifying patients' perceptions has been central to help drive change in healthcare practice. Experience based co-design (EBCD) is one approach to access user experiences and to use the knowledge of the users encountering the service to design better services (Bate et al., 2006; Brocklehurst et al., 2018). EBCD has been effectively applied in secondary care settings placing patients as active partners with HCPs in quality improvement for breast and lung cancer (Tsianakas et al., 2012b; Tsianakas et al., 2015). Patient inspired changes have also been recognised for older-aged patients attending hospital outpatient clinics (Wolstenholme et al., 2010) or through focus group style methodologies being used, in which patients and HCPs worked together to stimulate ideas for service improvements, which were subsequently prototyped and tested (Thomson et al., 2015).

These studies show that patients can be considered as joint experts in their care, holding perceptions that are vital to service re-design. The haematology interview study reported in Chapter 4 identified scope and potential need for implementing change in haematology transfusion service structure and delivery. The theme ‘Organisational factors’ identified from HCP interviews related to the need for haematology transfusion services to be altered to improve processes and ease capacity strain. Some HCPs reported that they did not spend time exploring their patients’ views on transfusion, with some HCPs unsure about how haematology patients felt about their transfusions. Addressing this could help to bridge patient and HCP communication around transfusion, which is fundamental to patient-centred healthcare delivery and underpins the ethos of patient involvement in co-designing the services they receive (Bate et al., 2006; Brocklehurst et al., 2018).

Patients communicating their perceptions to HCPs is fundamental and underpins patient-centred approaches such as shared decision-making (Charles et al., 1999). Some HCPs may be unaware of the types of perceptions reported by haematology patients in the preceding interview study (Chapter 4). Some patients reported their transfusions to be burdensome, requiring frequent hospital visits, and although beneficial and necessary, very few other alternatives were possible, and patients faced many risks, such as excessive iron levels. It is currently unclear how HCPs might respond to these perceptions. HCPs may consider it feasible within haematology outpatient services to modify current practices and support change. Alternatively, as indicated in the interview results, HCPs may be led by routine and guideline-led practices, which often over-rule patients’ preferences (Molewijk et al., 2003).

This study aimed to present blood transfusion HCPs with haematology patients’ perceptions from the preceding interview study and explore their responses to these perceptions. This study sought to identify whether HCPs can identify with these views and feel that they are reflective of their daily practice and explore what could be done to address the perceptions by altering service provision.

Practice change is often facilitated through the generation of service improvement strategies. This encompasses guideline change recommendations to address current practice gaps, as well as direct patient care initiatives such as new procedures or techniques (Grol, 2013). Change may also be initiated through healthcare teams altering how they work and clinical leads championing change (Brown et al., 2014). In haematology transfusion contexts, joint patient and HCP motivators for service enhancement are likely to exist. This is for the benefit of improving patients' experiences but also to create optimised services that relieve pressures on HCPs.

The study aimed to foster collaboration between HCPs of different levels of seniority and roles from different transfusion units, to meet and discuss the patients' perceptions and potential service improvement strategies. This allows for best practices to be shared and the patients' perceptions to become a 'catalyst for high-quality innovation' (McNichol, 2012). It is likely that HCPs will identify barriers and enablers to implementing changes to their practice. Planning complex practice change requires the nature of the innovation; characteristics of the professionals and patients involved, and the social, organisational, economic and political context to be considered (Grol et al., 2004).

Clinical practice is a form of human behaviour, which can be explained, understood and predicted by drawing on theories and models of behaviour change (Atkins et al., 2017). These models describe the various determinants of behaviour and specifies key variables to explain differences that occur across situations, contexts and populations (Noar et al., 2005). Healthcare practice change that directly involves patients and HCPs changing their behaviour benefits from the application of theory and the consideration that single behaviours operate within larger systems of behaviours, with their being multiple levels of intervention, such as population, community and individual levels (Dahlgren et al., 1991; National Institute for Health and Care Excellence., 2007, 2014).

In haematology units, population change may involve service re-organisation or changes directed at the whole haematology outpatient population. Community changes may involve strengthening team links to consider patients' perceptions and behaviours before and after they attend the unit for their transfusions. Individual behaviours may be directed at behaviours HCPs or patients could solely do differently, such as HCPs altering their prescribing habits or patients reducing the number of missed appointments. As there are multiple theories of behaviour change, with little guidance of the best theory to select, the Theoretical Domains Framework (TDF) (Michie et al., 2005) offers a theoretical framework comprised of 14 domains, which can be used to explain cognitive, affective, social and environmental influences on behaviour. The 14 domains, which have been validated are: *Knowledge, Skills, Social professional role and identity, Beliefs about capabilities, Optimism, Beliefs about consequences, Reinforcement, Intention, Goals,* *Memory attention and decision processes, Environmental context and resources, Social influences, Emotion, Behavioural regulation* (Cane et al., 2012). These domains contain 84 theoretical constructs, which are concepts specifically devised to be part of a theory (Michie et al., 2005) (e.g. within 'Knowledge' is 'procedural knowledge' and 'knowledge of task environment' etc.).

To facilitate behaviour change, people must face opportunities to change their behaviours, as well as being able (capability) and motivated to. These are factors underpinning behaviour considered in the COM-B (Capability, Opportunity, Motivation – Behaviour) Model, which is a behavioural science model used to demonstrate how behaviour is generated through an interaction of capabilities, opportunities and motivations (Michie et al., 2011). 'Capability' to influence behaviour change, in the COM-B, is recognised as physical strength and psychological skill and knowledge. 'Opportunity' is conducive of being in the right physical and social environment (e.g., physically accessible, affordable, socially acceptable, sufficient time). 'Motivation' equates to reflective and automatic influences of competing behaviours (Michie et al., 2011). As presented in Figure 9, the TDF domains map onto the six sources of behaviour from the COM-B Model (Figure 9). Both models are increasingly applied to explore barriers and enablers to HCP practice change (Francis et al., 2012).

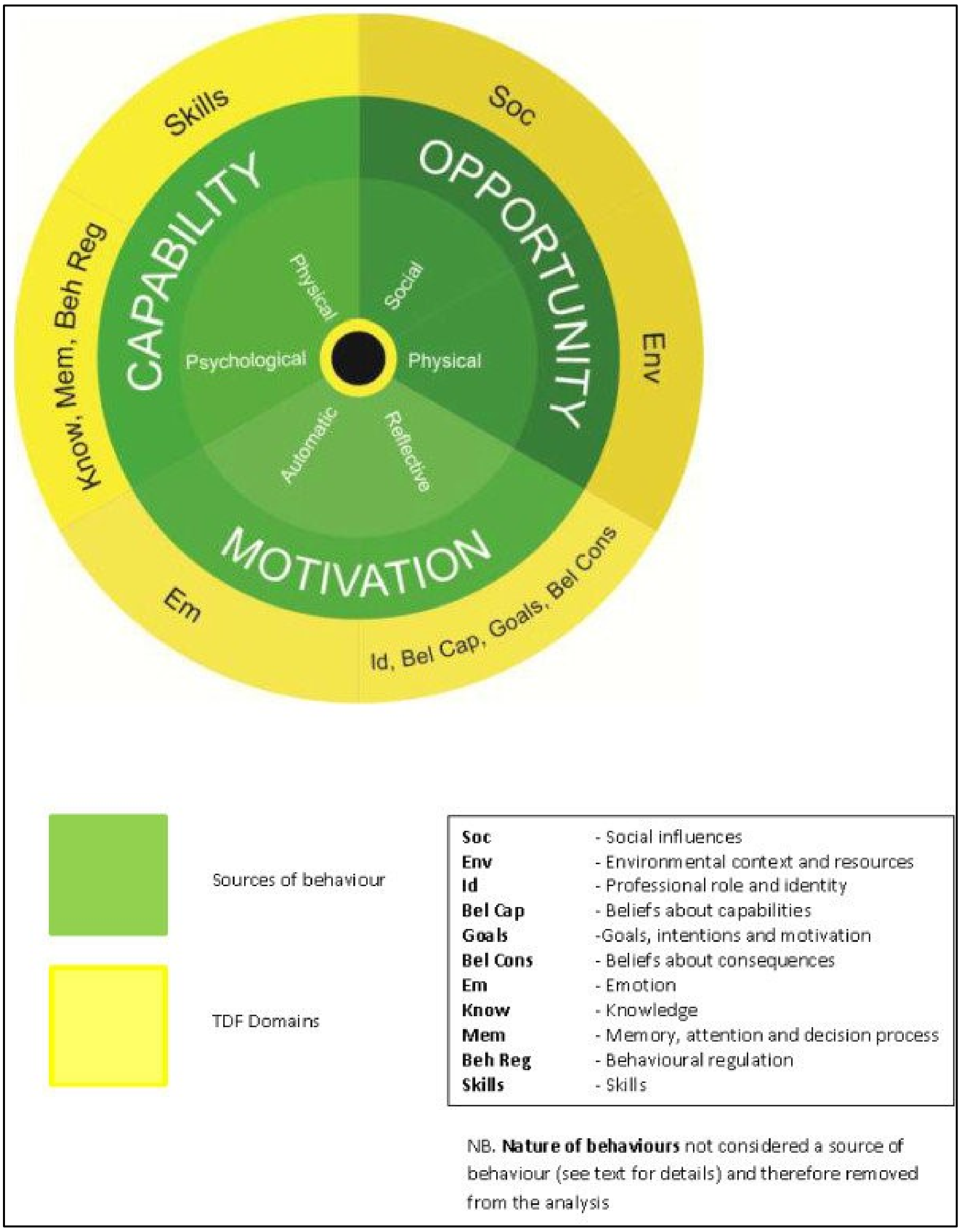


Figure 9 COM-B Model (Michie et al., 2011) and Theoretical Domains Framework (TDF) (Michie et al., 2005) domains linkage

The COM-B Model and TDF offer frameworks that could be used to identify and categorise reported barriers and enablers to service improvements in haematology services. The COM-B Model also serves as the hub of the Behaviour Change Wheel (BCW) (Michie et al., 2011) which is a synthesis of 19 frameworks of behaviour change used to identify intervention options (Michie et al., 2011). Figure 10 shows the BCW with the COM-B Model core ‘sources of behaviour’ and nine intervention functions related to the COM-B dimensions and seven types of policy that can be used to deliver the intervention (Michie et al., 2011).

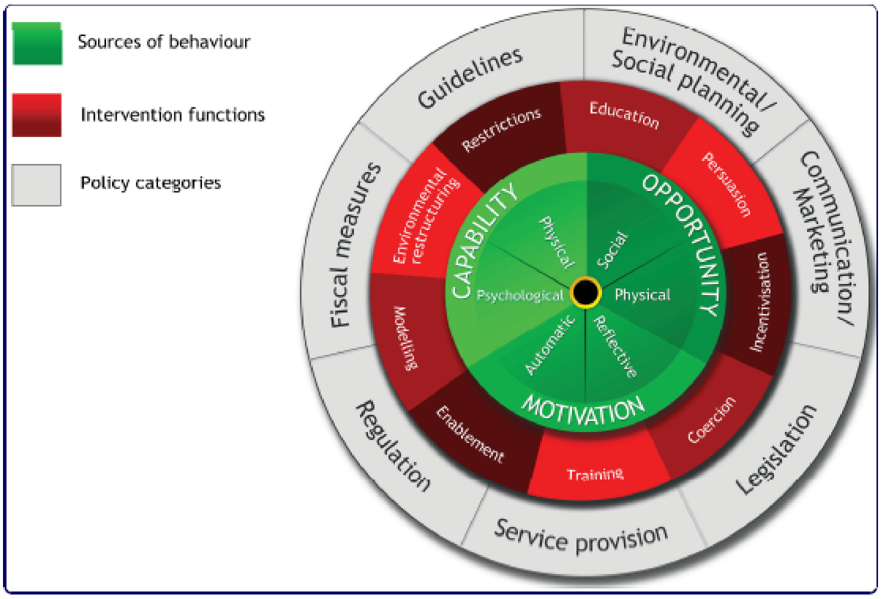


Figure 10 Behaviour Change Wheel (Michie, van Stralen & West, 2011)

The BCW is applied to an increasing number of intervention development studies, for example to increase the frequency of physical activity advice for cancer patients (Webb et al., 2016), to develop collaborative medication review and decision-making interventions (Sinnott et al., 2015) and for antibiotic prescription in long-term care facilities (Fleming et al., 2014). Thus, the BCW is worthwhile to utilise when considering the categories of any emergent intervention ideas, prior to planning their development further.

5.1.1 Study aims

This study aimed to explore the extent that HCPs identified with patients’ transfusion perceptions from the previous interview study in their practice and explore resultant areas for practice change.

5.1.2 Research Questions:

1. To what extent do HCPs identify with constructs of patients' reported perceptions of blood transfusion?
2. Which (if any) strategies can be implemented to improve haematology transfusion services to better address patients' perceptions?
3. What are the potential constraints and enablers to implementing the suggested service improvement strategies?
4. Which intervention options can be proposed to implement the strategies into practice?
5. How do the proposed strategies link back to the constructs of patients' transfusion perceptions?

5.2 Methods

5.2.1 Study design

This mixed-methods study utilising semi-structured focus groups and an open-ended questionnaire.

Focus groups were chosen to enable group discussion and encourage group interactions, with the discussion moderated by a facilitator (Plummer-D'Amato, 2008). A follow-on free-text response questionnaire was used as a part of this study due to foreseen time-constraints in the focus groups to present and collect responses on the complete set of nine patient blood transfusion perceptions constructs.

5.2.2 Ethical approval

Ethical approval was granted from City, University of London, School of Health Sciences Research Ethics Committee (PhD/18-19/02 – July 2018) (Appendix 16: Study 3 ethics approval letter).

5.2.3 Study branding

The study was named BOOST 'Building Optimised Outpatient Services in Transfusion' for two reasons. In the preceding interview study transfusion was described by and presented to patients as a 'boost' to their blood levels and health. This study also sought to identify ways to improve or 'boost' transfusion services. The name 'BOOST' was therefore used in the branding and announcement of the study.

5.2.4 Participants

Eligible participants were HCPs, such as Haematologists, Physicians, Registrars, Nurses and Transfusion Practitioners attending South Central Regional Transfusion Committees (RTC) meetings held on two dates in the Autumn of 2018 with around 20 delegates attending the first meeting, and up to 80 attending the second meeting. RTCs are responsible for implementing actions of the broader National Blood Transfusion Committee in England and overseeing activities of the Hospital Transfusion Committees (Joint United Kingdom (UK) Blood Transfusion and Tissue Transplantation Services Professional Advisory Committee, 2018). Many RTCs meet bi-monthly outside of the hospital environment for educational away days, where delegates can present and discuss audit findings and share learning practices, for example.

5.2.5 Recruitment

Potential participants were notified about the study around one week prior to the RTC meeting date by e-mail to all attendees from the Secretary of the RTC. A Participant Information Sheet and Recruitment flyer were developed (Appendix 17: Study 3 participant information sheet, Appendix 18: Study 3 recruitment flyer) and attached to the e-mail. On the day of the meeting, delegates were introduced to the study in person and during the opening introduction at the start of the day. Delegates wishing to take part could sign-up in advance or attend at the arranged time and designated location. Focus groups were planned to include a minimum of two or three participants and a maximum of ten participants per focus group. This allows for views to be shared on a topic that could be considered highly engaging (i.e. having more time in a smaller group or being interactive ‘workshop style’ with a larger group) (Ritchie et al., 2014). The focus groups took place in a separate small room within the RTC meeting venue with the researcher (who was the focus group facilitator) obtaining signed informed consent prior to the focus group commencing (Appendix 19: Study 3 consent form). The co-facilitator, who was the Secretary of the RTC and a Haematologist involved in the project, was also present at some points during the focus group. This was considered of benefit, with a well-brief observer often able to validate and establish the credibility of focus group data (Jackson, 1998).

5.2.6 Focus group procedure

The focus groups were conducted in line Tuckman & Jenson’s (1977) ‘Model of group phases’ (Ritchie et al., 2014) (pg. 215) and were planned to last around 45 minutes at set time-points during the RTC meeting day. Focus groups were opened by the facilitator with introductions, establishment of the ground rules and an introduction to the previous research. Individual introductions helped the facilitator to identify each participant and allowed each participant the opportunity to introduce themselves and to briefly share their views of what they thought the haematology patients' perceptions might be as an ice-breaker exercise. The main body of the focus group followed with the facilitator introducing the labels for the top three constructs of patients' perceptions that were identified through the previous patient interviews (June 2018): *'Negative emotions', Involvement in decision making'* and '*Necessity'* (Table 15). Due to the 45-minute time constraints, only the top three 'priority' constructs of patients' perceptions were presented for discussion, prioritised in Study 2 (Chapter 4) per frequency counts of patients reporting perceptions coded to the construct. Each construct, summarised by the researcher, was read aloud to the participants and distributed in text on printed laminated cards. Positive and negative aspects of the same construct of perception were included in the summary to present a balanced view given the diversity of the haematology patient group and the bi-polar nature of the findings (Table 15). Ten-minutes was allocated for each construct to allow for a semi-structured discussion around the topic guide questions below.

Table 15 Study 3 constructs presented to the focus groups for discussion

Constructs	
1: 'Negative emotions'	'Some patients had no concerns about receiving repeated transfusions or managed their worries by remaining hopeful and positive. Some patients enjoyed attending; as a time-out and they were grateful for the transfusions.

	For some patients, having transfusions was seen as **unpleasant** and the **frequency** and **duration** caused **frustrations'**.
2: 'Involvement in decision making'	'Some patients recalled being **involved** in the transfusion decision-making, and that they willingly **accepted** the transfusion. Other patients reported that they **deferred** the decision making to the doctors or had limited involvement, mainly because transfusion was their **only option'**.
3: 'Necessity'	Some patients knew when they **needed** their transfusion as they felt tired, low in energy and experienced headaches. Overwhelmingly, patients reported that their transfusions are **essential** to prolong their life and aid survival. Yet, some patients **do not know** how much blood they will receive until they get to the hospital or are unable to predict a **routine** with it.

5.2.6.1 Topic guide questions:

The topic guide questions were developed to address the research questions of the study and the questions were referred to by the facilitator to provoke a semi-structured discussion after the theme was introduced:

- Are these perceptions that you also hear about from patients?
- Is there something that could be done within the health service to improve patients' experiences?
- Would there be any constraints to this?
- Are there things that may help change to occur?

The first topic guide question aimed to elicit the extent that HCPs identified with the perceptions in their practice (e.g. that they felt that the perceptions were reflective of what they anticipated or experienced patients' perceptions to be). The second topic guide question addressed research question two, to explore any potential service improvement strategies and the latter two topic guide questions aimed to elicit HCPs' perceived constraints and enablers to their suggested strategies. The latter two questions were deliberately kept open to encourage group discussion.

During the course of data collection, an additional slide (11) was inserted in the researcher's presentation materials (Appendix 20: BOOST Study 3 PowerPoint slides) following the first focus group about the different levels for intervention (Dahlgren et al., 1991; National Institute for Health and Care Excellence., 2007, 2014). This was emphasised to be 'Population' 'Community' and 'Individual' levels as the Facilitator observed that many HCPs proposed 'population' and 'community' level changes in the first focus group. Therefore, this addition aimed to prompt and encourage HCPs in the subsequent focus groups to consider multiple levels of change, including individual HCP change.

A summary discussion was initiated by the facilitator in the last 10-minutes of the focus group to summarise any service improvement strategies. At the end of the focus group the facilitator introduced and distributed the follow-on questionnaire (Appendix 21: Study 3 participant 'follow on' questionnaire). This questionnaire presented summaries of the remaining six constructs identified through the previous patient interviews (Chapter 4): '*Health benefits' 'Social connection', 'Awareness of Safety/risk', 'Burden', 'Alternatives' and 'Distinguishing between blood products'* with the topic guide questions for free text completion. Participants were handed the questionnaires to take away for completion and return using the pre-paid envelope provided or via e-mail to the researcher / facilitator.

5.2.7 Confidentiality

The importance of confidentiality was emphasised through the Participant information sheet (Appendix 17) and at the opening of the focus group. This ensured that opinions shared during the focus group were not disclosed outside of the group and that details of attendees and mentioned people and places were not further circulated. The follow-on questionnaires were also confidential, in that the participant's own name was not required to be inserted on the questionnaire.

5.2.8 Data analysis

5.2.8.1 Inductive analysis

Focus groups were audio recorded, transcribed verbatim and fully anonymised so that no individual patient, HCP, or hospital / service could be identified from the transcripts.

Focus group data reporting the extent that HCPs identified with patients' reported perceptions were narratively summarised, with the content of the focus group discussions analysed using Thematic Analysis (Braun et al., 2006). This involved the researcher reviewing the focus group transcripts to develop labels describing the data (e.g. *Staff talking to patients about their transfusion worries*). The researcher grouped the labels into themes (e.g. *Support currently offered to patients*) which was grouped with similar themes and combined into a major theme (e.g. *Patient support provision*).

The free-text responses on the returned follow-on questionnaires were subject to analysis using the same methods as the transcribed focus group data.

5.2.8.2 Service improvement strategies

The researcher reviewed the transcripts and the questionnaires for service improvement strategies, for example, revising transfusion appointment times or locations or strategies to improve patient involvement or communication etc. Strategies were organised into meaningful groups (e.g. hospital or community-based strategy) and coded according to policy and intervention functions / categories of the Behaviour change wheel (BCW) (Michie et al., 2011). Strategies were also mapped back to the nine constructs of patients' transfusion perceptions from Study 2 to obtain an impression of how greatly the strategies addressed these constructs.

Constraints and enablers raised by the participants for each strategy (as applicable) were grouped and categorised according to domains from the Theoretical Domains Framework (TDF) (Cane et al., 2012; Michie et al., 2005), for example, a barrier of 'lack of staff cover' was coded as 'Environmental context and resources' from the TDF. This was carried out to specify the key domains for consideration if strategies were to be developed into behaviour change interventions. As the TDF is often applied to the context of individual behaviour change, the COM-B component related to the applicable TDF domain was also specified in the analysis, this was done to highlight broader environment and organisational factors (Michie et al., 2014).

5.2.8.2.1 Intervention mapping

The taxonomy of 93 Behaviour change techniques (BCTs) is commonly used to identify techniques, which are observable, replicable, and irreducible ‘active ingredients’ of behaviour change interventions (e.g. behavioural counselling, feedback, self-monitoring and reinforcement) (Michie et al., 2013). For this study, the researcher developed intervention options for each strategy, supported by BCTs to be targeted. The selected BCTs were linked to the TDF coded constraints and enablers raised by the participants, selected by the researcher using ‘The Theory and Techniques Tool’ (Centre for Behaviour Change, 2019). The APEASE criteria was used to evaluate the intervention options, considering the interventions’ *Affordability, Practicability, Effectiveness and cost-effectiveness, Acceptability, Side-effects/safety* and *Equity* (Michie et al., 2011). The researcher imposed that a high candidate intervention would satisfy a minimum of four criterion, a moderate intervention, three criterion and a low intervention, less than three.

5.2.9 Reliability

A second researcher in the team reviewed the inductive coding of the focus group themes to verify the main researcher’s coding decisions. This was to review all of the quotes and whether the theme and subtheme labels were adequately representative of the quotes. Member checking was also used to assess a participant’s view of how well the meaning from the focus groups was captured and interpreted (Ritchie et al., 2014). This was to ensure clinical face validity of the interpretation of the findings. A member of the team with experience in TDF/BCW and BCT coding reviewed each proposed strategy to assess whether it was classified appropriately according to the domains of the TDF, functions and categories of the BCW and BCT labels from the taxonomy. For all coding, disagreements were discussed until full agreement was reached.

5.3 Results

5.3.1 Focus groups and sample characteristics

Three focus groups were held in total and the researcher kept a reflective diary, updated after each focus group (Appendix 22: Reflective diary from study 3 focus groups). One focus group was held at the first RTC meeting with six participants at the start of the day and two focus groups held at the second meeting two months later with eight participants at the mid-morning break and five participants at lunchtime. RTC meeting two provided two opportunities for focus groups to be held, being a larger meeting day with a higher number of delegates attending (approximately 100 vs. 20 for RTC meeting 1). Focus groups lasted between 29 minutes and 43 minutes in duration. Table 16 displays the participating HCPs' roles per focus group.

Table 16 Focus groups and participants

RTC meeting 1	**RTC meeting 2**	
Focus group 1 **(N = 6 participants)**	**Focus group 2** **(N = 8 participants)**	**Focus group 3** **(N = 5 participants)**
Consultant Haematologist	Consultant Haematologist	Consultant Haematologist
Lead Transfusion Practitioner (n=2)	Specialist Doctor (Haematology)	Ward Manager
Transfusion Practitioner (TP)	Transfusion Practitioner (TP)	Transfusion Practitioner (TP) (n=3)
Blood Transfusion Nurse Practitioner (BTNP)	Staff Nurse	
Patient Blood Management Practitioner (PBMP)	Practice Educator	

	Clinical Scientist	
	Anaesthetist	
	Clinical Services Manager	

5.3.2 Follow on questionnaire response rate

Each focus group participant received the follow-on questionnaire with the same completion instructions. This was to provide their thoughts on the additional patient constructs not discussed during the focus groups and to return the questionnaire via post using the self-addressed envelope or scan and return via email. The follow-on questionnaire response rate from meeting one was 50% and meeting two, 23%.

5.3.3 Inductive analysis of focus group and questionnaire data

5.3.3.1 Identification of patients' transfusion perceptions in practice

The three constructs discussed in the focus groups received in general a high level of acknowledgement, with HCPs reporting that they felt the constructs were reflective of, and resonated with, their day to day practice and interactions with patients in the haematology service. In the final focus group 3, HCPs did recognise to a greater extent the 'Necessity' construct, however, the HCPs did not contest the accuracy of the other two constructs presented. One HCP expected more perceptions on 'Burden' (not presented to the focus group) and one HCP reported that they were interested in finding about informed consent practices for routinely transfused patients and the experiences and thoughts of home transfusion patients.

The additional six constructs presented in the questionnaires received a similarly high level of acknowledgement, with the construct 'Distinguishing between the blood products' receiving the lowest acknowledgement in two of six returned questionnaires. Two questionnaire respondents commented that 'fewer platelets transfusions were provided' and that 'patients understood the need for them' (Questionnaires 2 and 6). For the 'Safety/risk' construct, three respondents agreed that this construct reflected their practice and one respondent reported that this construct was not heard from the majority of their patients.

5.3.3.2 Inductive synthesis of focus group data

Full consensus was reached by the main and second researcher for the inductive analysis. A member check also confirmed that the meaning from the focus groups was sufficiently captured and interpreted.

The inductive synthesis of the focus group data led to the development of six themes: *Practical difficulties for transfusion patients, Patient support provision, Service efficiencies, Supporting best practice, Positive collaboration with patients* and *Practice difficulties*. These themes are presented in Table 17 indicating the HCP roles who contributed to the subtheme. When there was wider group support in favour of an argument presented, 'multiple group agreement' was used to indicate this. Supporting quotations are provided in the table and descriptions of the themes content provided following the table.

Table 17 Themes and subthemes inductively generated from the focus group data

Themes	**Subthemes**	**Number of focus groups reported in** (max n=3)	**HCP roles contributing to subtheme**	**Supporting quote**
Practical difficulties for transfusion patients	• Frequent and lengthy hospital appointments	2	Haematologist, Speciality Doctor (Haematology), TP	*"… this is about the patients who are transfusion dependent and actually have to take time out on a regular basis, not just to come in for transfusions, they've gotta go and find somebody to do the phlebotomy for the cross match from the day before. You know, they still have to come and park at the hospital because they've got to go to phlebotomy.* (FG2, line 85-89, P1, Haematologist)
	• Dealing with transfusion appointment changes	3	Haematologists, Ward Manager, Lead TP, TPs ***multiple speaker agreement**	*"if you do detect that in someone with a bone marrow failure and you say actually 'you don't need to transfuse your haemoglobin's pretty good' you can sometimes get their wrath!"* (FG1, line 80-82, P2, Haematologist)
Patient support provision	• Emotional and practical support	2	Haematologists, Lead TP, TPs ***multiple speaker agreement**	*"I think it's other things though, it's not just the transfusion, they can bring any concerns, any worries they have outside of the transfusion in with them and we will do what we can to sort things out if we can, so it's a way of getting extra help if they need it"* (FG1, line 21-24, P4, Lead TP)
	• Support from counsellors	1	Haematologist, BTNP	*"I mean, where we are, we do have the option of two counsellors all I have to say is that they are two very different characters and some patients will see one of them and say 'Oh, it was a waste of time' but it may be the wrong one for them"* (FG1, line 308-310, P2, Haematologist)
	• Sense of community in the unit	3	Haematologists, Speciality Doctor (Haematology), TPs, Practice Educator ***multiple speaker agreement**	*"… but if you're a patient there and you've got two/three hours and you can't really move, erm, you have got a lot of time to talk to the person sat next to you … so that's something on the one side of it can make it more pleasant, having more, you know community"* (FG2, line 150-157, P5, TP)

Themes	**Subthemes**	**Number of focus groups reported in** (max n=3)	**HCP roles contributing to subtheme**	**Supporting quote**
Service efficiencies	• Nurse-led decision making	1	PBMP	*"with the introduction of non-medical authorisation for nurses, where you've got the people who are actually taking samples, then making the decision, that makes the process much easier for the patient because they haven't got to then hang around for a doctor, who doesn't know the patient, to review the results, and I think better decisions are made quicker"* (FG1, line 499-503, P1, PBMP)
	• Integrated care pathways	1	Haematologist, Specialty doctor, Nurse, TPs ***multiple speaker agreement**	*"Integrated care pathways, there's more of a focus now on actually putting the money out in the communities and providing the services out in the communities again and preventing patients from coming into hospital when they don't need to"* (FG2, line 234-238, P1, Haematologist)
	• Staff and patient access to test results and transfusion schedules	2	Haematologist, Specialty doctor, Nurse, TP, PBMP	*"…we have something where it's actually clerical staff and they're excellent and we have a, a card system we could do it electronically, but whereby those on a chronic transfusion programme, we roughly guestimate how often they need blood, erm, and have a target –"* (FG2, line 257-261, P4, Specialty doctor)
Supporting best practice	• HCPs transferring their learning to patient care	1	Ward Manager, TP	*"I go back to the ward and obviously you get feedback with all my staff and oh, you know, we just attended and, and been with this group which is BOOST, and all your positive, they're gonna pass it on so that they knew that okay, these are the ways in what we just had conversation with a very good example of how you can treat your patient and then they feel like, you know, they're being empowered with the blood transfusion that they have"* (FG3, line 397-403, P1, Ward Manager)
	• Senior HCPs as visible role models of good patient care	1	Haematologist, TP	*"I learnt from my seniors and I saw, as a junior doctor, I saw my registrars running off to do things like get the toast for this patient and that patient or a transplant patient, erm, because you see your seniors do it, you do it, and hopefully the people following*

Themes	**Subthemes**	**Number of focus groups reported in** (max n=3)	**HCP roles contributing to subtheme**	**Supporting quote**
				behind copy you as their role model" (FG3, line 428-432, P3, Haematologist)
Positive collaboration with patients	• Patient willingness to engage in their care	2	Haematologists, Lead TP, Clinical Services Manager, PBMP, * **multiple speaker agreement**	*"you have some who want to engage and it's easier to engage with them, erm, and to make a plan and if you can make a plan and they're engaged, then it's easier to change the plan, as and when it needs to be changed"* (FG1, line 281-282, P6, Lead TP)
	• Patient initiated care	2	Haematologist, Ward manager, TP, Lead TP	*"Well I suppose some of our younger patients … they're transfused every say four weeks, they know in themselves how they feel, so if they don't feel that they need it, they may ring and say 'can I delay it two weeks?' or if they're unwell because they've got other symptoms that have come on, they'll say they're feeling rotten, can they come in? We'll say 'we'll do a haemoglobin and see where we go from there', those are the proactive ones ... we encourage that"* (FG1, line 284-292, P6, Lead TP)
	• Discussion of transfusion alternatives	1	Haematologist, Anaesthetist, Clinical Services Manager,	*"I mean, in a lot of these cases a blood transfusion is the only treatment there's no really other alternative and we say to someone, "Well, you can either have the treatment or not have it," and they might say to you, "What's the alternative?" and you, you don't really have an alternative as such, do you?"* (FG2, line 30-34, P2, Anaesthetist)
Practice difficulties	• Lower hospital prioritisation of transfusion	2	Haematologist, Lead TPs, TP * **multiple speaker agreement**	*"… samples are triaged in the laboratory, the importance is always given to operations, patients in surgeries and theatres, and it's forgotten actually just because it's a day care setting and there's a perception that there's, like, eight hours of transfuse, a lot of them can't be there at 9:00 a.m., some have transport issues, some of them have jobs that they need to do and it's difficult"* (FG3, line 7-11, P5, TP)

Themes	**Subthemes**	**Number of focus groups reported in** (max n=3)	**HCP roles contributing to subtheme**	**Supporting quote**
	• Stretched services	1	Ward Manager, TPs ***multiple speaker agreement**	*"I have to say, comparing two different Trusts, going to the day care setting that I work in now, it's like Beirut, it's so noisy, you know, so many patients - and relatives and it's like a thoroughfare, it's an actual thoroughfare, they are so different"* (FG3, line 330-335, P4, TP)
	• Issues associated with patient-initiated transfusion requests (e.g., over-transfusion)	2	Haematologists, Clinical Services Manager, Lead TP ***multiple speaker agreement**	*"… so, we have had some patients who because they don't have a formal clinic appointment keep turning up for transfusions and then you find out when you go down to the lab that they've got a very high white cell count"* (FG1, line 29-31 P2, Haematologist)
	• Inadequate community HCP engagement	2	Haematologists, Lead TPs, TP ***multiple speaker agreement**	*"…we rely on the GP, now the difficulty is as I mentioned earlier is that the patients will not see their GP because processes are changing very quickly and to be fair sometimes the GPs, they're all, you know, are not getting enough up to date information or things are changing or "I don't know enough about this condition" and defer it back to us"* (FG1, line 312-316, P2, Consultant Haematologist)

5.3.3.3 Description of focus group derived themes

Practical difficulties for transfusion patients: HCPs reported on the reality that haematology patients will face frequent and lengthy visits to the hospital, for example, for blood cross-matching the day before the transfusion, and often a six-hour transfusion appointment for two units of blood. Patients may need to reschedule personal appointments if there are changes to their planned transfusions (e.g., if patients' blood level improve). This would be to avoid unnecessary transfusions, which reportedly occur for some routinely attending patients. HCPs in this study discussed patients' reactions when transfusions were refused, which caused anger, further frustrations and confusion for patients.

Patient support provision: HCP discussed support that patients often receive in the unit, through forming close and sociable connections with other patients and staff in the unit, who provide them with time to off load worries and provide practical health assistance. Consistent staff in the units facilitated support provisions, with patients often having a specialist nurse to contact if becoming unwell. HCPs also discussed that patients often receive support from trained hospital counsellors. However, HCPs debated that this was not always standard protocol and that mis-matches in patient-counsellor personalities may impact patients' views of the effectiveness of the counselling.

Service efficiencies: HCPs reported a number of practices in place that function well. For example, nurses ordering blood transfusions (non-medical authorisation), good communication with laboratories and patient tracking systems. One HCP presented that in their area, patients can gain access to their blood test results via the GP, helping them to predict the transfusion appointment time length. The need to re-establish community services that worked well in the past was highlighted, such as integrated community care pathways. This was felt to reduce the need for patients to attend the hospital and receive healthcare in their community locations, which matches current Governmental agendas.

Supporting best practice: HCPs in one focus group discussed observing and sharing best learning practices to improve patients' experiences. Some HCPs were keen to reflect on their own practice on a regular basis and one Ward Manager commented that she will use the focus group as an opportunity to reflect on and improve her patient-centred practice. A Haematologist and Transfusion Practitioner in the same focus group commented that they benefitted from witnessing senior staff carrying out additional patient duties in an empathetic manner. The senior HCPs would act as role models during the Haematologists' training for how to deliver patient centred care (e.g. responding to patients' food choice preferences).

Positive collaboration with patients: HCPs discussed positive ways in which they interact with patients, such as through shared decision-making, where younger patients especially wish to be engaged in their care and make a treatment plan. HCPs gave examples of how patients could delay their transfusions or if having symptoms attend the unit for an assessment of whether a transfusion is needed, which was encouraged. However, when it came to transfusion alternatives, this was more challenging. One Anaesthetist commented that transfusion was the only option that many patients could be offered, and a Haematologist reported that staff can be concerned if Jehovah

Witness patients do not consent to transfusions, but that staff have to ‘go along with’ patients’ wishes.

Practice difficulties: Many HCPs in two focus groups reported that haematology transfusion receives lower prioritisation (e.g., low recognition for funding or laboratory samples processing). Many HCPs referred to their services as busy, with a lack of transfusion training for HCPs in other departments who may occasionally need to transfuse a haematology patient. HCPs sometimes received patient-initiated requests for transfusion outside of a pre-arranged appointment, which were sometimes granted (for example, if HCPs faced pressure from patients), which can lead to patients being over-transfused. HCPs reported that they lacked support from community HCPs, such as GPs who were unfamiliar with complex haematological conditions, patients’ clinical histories or faced their own time pressures. GPs, therefore often referred haematology patients back to the unit. Some HCPs noted that ‘stretched’ services risk the loss of a ‘personal touch’ to patient care.

5.3.3.4 Inductive synthesis of questionnaire data

The inductive synthesis of the questionnaire data led to the development of four themes: *Transfusion acceptance, Practice difficulties, Patients’ individual preferences* and *Patient involvement.* Table 18 lists the themes and subthemes, with supporting quotations, followed by a text description of each theme.

Table 18 Themes and subthemes inductively generated from the questionnaire data

Themes	**Subthemes**	**Questionnaire ID**	**Supporting quote**
Transfusion acceptance	• Appreciation of transfusion benefits	Q6	*"Most patients who are given transfusions report that the benefits outweigh any risks"* (Q6 responding to Construct 4 'Health benefits' summary)
	• Anticipated physiological responses	Q1, Q2	*"Occasionally patients don't notice any initial change"* (Q2 responding to Construct 4 'Health benefits' summary)
	• Patients accepting of transfusion as last resort	Q2, Q6	*"our patients have transfusions when all else fails. They understand this"* (Q6 responding to Construct 8 'Alternatives' summary)
Practice difficulties	• HCP time constraints	Q1, Q2	*"Patients expect very personalised service + extra time which is not available"* (Q2 responding to Construct 4 'Health benefits' summary)
	• Low Palliative Care engagement	Q2	*"Ideally this [alternatives to transfusion] should be dealt with by palliative care but they often won't touch patients until dying dead"* (Q2 responding to Construct 8 'Alternatives' summary)
	• Issues encountered with patient attendance	Q2	*"Sometimes patients cancel them [the transfusion] + then turn up when symptomatic expecting you to stop what doing + sort them out"* (Q2 responding to Construct 7 'Burden' summary)
Patients' individual preferences	• Diverse patient preferences for interaction	Q2, Q4, Q6	*"Those few I've spoken to report it as a good catch up time with 'friends'. One said that others were happy if they just wanted to sit with their eyes closed"* (Q4 responding to Construct 5 'Social connection' summary)
	• Patients' personalities and cultural beliefs should be respected	Q2, Q4	*"I think we need to respect their wishes / cultural beliefs and ensure we do everything in our power to make this happen"* (Q3 responding to Construct 5 'Social connection' summary)
	• Patient involvement with cannulation	Q4	*"The pts I cannulate just say they're so used to it and some even recommend where to go or avoid before I've even looked at their veins"* (Q4 responding to Construct 6 'Safety/risk summary)

Themes	**Subthemes**	**Questionnaire ID**	**Supporting quote**
Patient involvement	• Lack of patient questioning of forgotten information	Q3	*"… though sometimes it [e.g. platelets function] is explained but pts forget or are afraid to ask questions as there is no time or afraid to look stupid"* (Q3 responding to Construct 9 'Distinguishing between the blood products' summary)

5.3.3.5 Description of questionnaire derived themes

Transfusion acceptance: HCPs report in this theme how patients may be accepting of transfusion as it has been thoroughly discussed, with patients understanding transfusions are provided as a last resort option. Patients may become aware of what to expect post-transfusion, such as no initial benefit due to experiencing ongoing symptoms post-transfusion where the combined biological and psychological effects of the transfusion are ‘draining’. One HCP commented, however, that patients are likely to have rationalised the need for their transfusion, being aware of potential risks, which are outweighed by the transfusion’s benefit.

Practice difficulties: In the questionnaires, two HCPs commented on similar transfusion delivery issues, as raised in the focus groups. HCPs commented that patients often expect a personalised service, which they did not have time to deliver, or to repeat information already provided. As in the focus groups, it was re-iterated that patients often arrive voluntarily when symptomatic for transfusions, interrupting HCPs’ work flow. Palliative care was mentioned as a further example, of where haematology HCPs lacked wider hospital-wide support.

Patients’ individual preferences: Somewhat opposite to the ‘sense of community’ subtheme arising from the focus group discussion, were ideas raised about the individuality of transfusion patients in the unit. HCPs commented that some patients will spend their time during the transfusion relaxing with their eyes closed. Other patients, especially older patients, will wish to socially interact with other patients and welcome the support from the staff. Although, one HCP reported that patients in their unit were transfused in single rooms, which patients appreciated for the sake of their privacy. HCPs commented that patients' personalities may influence their need for greater social interaction in the unit, and that HCPs should respect and be supportive of patients' wishes and cultural beliefs.

Patient involvement: HCPs used the questionnaires to share examples of how their patients may be involved in their transfusions; by suggesting a cannulation site to the nurse or sharing their experiences with nursing students. Many patients were therefore considered as expert patients, yet instances where some patients forgot information that they are told were raised, with patients being reluctant to question it again.

5.3.4 Service improvement strategies

A total of eight different service improvement strategies were proposed across the focus groups, of which five were also mentioned in the questionnaires (Table 19). Nine additional strategies were reported in the questionnaires (Table 20), which resulted in a total of 17 service improvement strategies suggested across both data collection methods. As displayed in Table 19 and Table 20, the strategies were grouped into 'hospital' and 'community' based strategies, suggestive of their target implementation location, subdivided further into: hospital: 'transfusion access', 'support' or 'practices' and community: 'access' and 'support' related change suggestions. One strategy 'screening of patients' Hb levels' (Table 19) raised in the focus groups could relate to either a 'hospital' or 'community' practice change, as well as 'cannulation improvements' (Table 20).

Numerous constraints and enablers (N= 34) to the strategies were reported. These are listed in Tables 19 and 20 alongside the relevant Theoretical Domains Framework (TDF) (Cane et al., 2012) and COM-B (Michie et al., 2011) domains. Behaviour change wheel mapping (Michie et al., 2011), constraints and enablers and intervention mapping will be discussed in more detail following the presentation of tables 19 and 20.

Table 19 Service improvement strategies from focus groups and questionnaires

Service improvement strategies / BCW policy category / intervention function	**Focus group / questionnaire frequency**	**Constraints and enablers reported by participants** [Enablers in brackets]	**TDF domain linked to constraint / enabler** and related COM-B component	**BCTs to address constraints / enablers**	**How to operationalise - example**	**APEASE** ➢ Affordability ➢ Practicability ➢ Effectiveness & cost effectiveness ➢ Acceptability ➢ Side effects/ unwanted consequences ➢ Equity
Hospital						
Transfusion access						
1. Development of a transfusing team / unit in hospital *"you also need a transfusing team, don't you? … [some group agreement] the one that the patient gets transfused to who they can rely on, know, they can arrange lines if the access is becoming an issue, they can juggle slots accordingly and know the patients well enough to know who needs it urgently"* (P2, focus group 1). BCW: Service provision & Environmental restructuring	1 focus group & 1 questionnaire	a) Relieves pressures on other units [Enabler]	**Environmental context and resources** Opportunity (physical) **Beliefs about consequences** Motivation (reflective)	Restructuring the physical / social environment Information about health consequences	Service managers to launch transfusion teams in their hospitals (e.g. dedicated team in the existing unit or development of a dedicated transfusion unit). Transfusion team champions to advocate the new plans and promote how this will relieve pressures on other units	A P E A S E ? ✓ ? ✓ × ✓
Support						
2. Standard package of psychological support created for repeatedly transfused patients *"you're going to need the same support [adult haematology as paediatrics], just different"* (P3, focus group 1) BCW: Service provision & Enablement	1 focus group	None reported	N/A	N/A	N/A	N/A

Service improvement strategies / BCW policy category / intervention function	**Focus group / questionnaire frequency**	**Constraints and enablers reported by participants** [Enablers in brackets]	**TDF domain linked to constraint / enabler** and related COM-B component	**BCTs to address constraints / enablers**	**How to operationalise - example**	**APEASE** ➢ Affordability ➢ Practicability ➢ Effectiveness & cost effectiveness ➢ Acceptability ➢ Side effects/ unwanted consequences ➢ Equity
3. Enhancing shared decision-making and discussion of blood transfusion with patients (e.g. positive, negative aspects) "*P3: it has to be a negotiation with them rather than something you do to them.* *P1: yes, don't surprise them.* *P4: Yes, you know, it's, it's discussion, you know, do you think you could sit here for two units if that's needed … cause if you have to go after one unit, maybe we could book you in another day. So, that sort of discussion allows them a little bit of control back"* (multiple speakers, focus group 3) BCW: Environmental restructuring & Enablement	1 focus group	a) Consistent staff cover with available time required b) Education for nursing staff: "*more nurses with knowledge of blood transfusion"* (Questionnaire 2) c) Improved staff and management attitude to support changes required d) Enables patients to take greater control [Enabler]	**Environmental context and resources (a)** Opportunity (physical) **Knowledge & Skills (b)** Capability (Psychological) **Beliefs about Consequences & Optimism (c)** **Beliefs about capabilities (d)** Motivation (reflective)	Restructuring physical environment Information about emotional consequences Instruction on how to perform behaviour Demonstration of the behaviour Behavioural practice/ Rehearsal	Encourage managers to review staffing capacity and facilitate a culture of shared decision-making where appropriate. Blood transfusion nurse training to present patients' transfusion perceptions (e.g. positive and negative aspects of transfusion) and training workshops could allow nurses to practice adopting a 'negotiation' style to transfusion conversations.	A P E A S E ✓ ? ✓ ✓ ? ✓

Service improvement strategies / BCW policy category / intervention function	**Focus group / questionnaire frequency**	**Constraints and enablers reported by participants** [Enablers in brackets]	**TDF domain linked to constraint / enabler** and related COM-B component	**BCTs to address constraints / enablers**	**How to operationalise - example**	**APEASE** ➢ Affordability ➢ Practicability ➢ Effectiveness & cost effectiveness ➢ Acceptability ➢ Side effects/ unwanted consequences ➢ Equity
Practices						
4. Expedite haematology laboratory samples *"there's a massive amount of improvement we could do within laboratories to actually expedite their samples, treat them in way that actually gives that patient then the best experience as possible"* (P5, focus group 3) BCW: Environmental restructuring	1 focus group & 1 questionnaire	**a)** Reduce patient waiting time [Enabler] *"…a lot of them [patients] will get delayed cause we don't know what the answers are gonna be in that sample"* (P5, focus group 3).	**Beliefs about consequences** Motivation (reflective)	Info about social & environmental consequences Framing/reframing Restructuring the physical environment Prompts/ cues	Inform laboratory management and staff of the impact to patients of extended waiting times and discuss fast-tracking haematology samples. If supported, co-design new processes with lab staff (e.g. prompts to alert to haematology samples).	A P E A S E × ? ? ? ? ?

Service improvement strategies / BCW policy category / intervention function	**Focus group / questionnaire frequency**	**Constraints and enablers reported by participants** [Enablers in brackets]	**TDF domain linked to constraint / enabler** and related COM-B component	**BCTs to address constraints / enablers**	**How to operationalise - example**	**APEASE** ➢ Affordability ➢ Practicability ➢ Effectiveness & cost effectiveness ➢ Acceptability ➢ Side effects/ unwanted consequences ➢ Equity
5. Encourage shared lab, HCP and patient role appreciation P2*:” … and I guess also, it’s role appreciation, isn’t it, so it’s knowing what happens with you guys in, in the laboratory -* P5*: That’s exactly it, yeah.* P2*: - at some point needs to put all of that information together … to say, “Well, actually it is because you, you’ve got antibodies and therefore it’s gonna take us longer to get that blood,”* (multiple speakers, focus group 3) BCW: Education & Persuasion	1 focus group & 1 questionnaire	a) Patients’ priorities different to HCPs’: P5: “*so it’s almost like everyone needs to know, what everyone’s actually doing, to have a better understanding”.* P2*: “But that patient only cares about themselves”* (multiple speakers, focus group 3)	**Social influences & Goals** Opportunity (Social) Motivation (reflective)	Info about health, social & environmental consequences *Re-attribution*	Provide patients with information (verbally, leaflets) about safe laboratory procedures and time-scales. Consider inviting patients to visit labs (as with paediatric patients *Harvey’s Gang*)	A P E A S E ✓ ✓ ✓ ✓ × ✓
6. Improved recording of consultation discussions in patients’ notes to enhance shared care P6*: “if you don't know what they discussed last week, you don't know if they've got problems, they're not mentioning it again this week”* P3*: “it's a shared care sort of thing”* P6*: “so it's nice to know for coordination”* (multiple speakers, focus group 1)	1 focus group	a) Distractions and provision of notes/space to update notes *P2: “… when you get to the day ward to see them having transfusions you don't get the notes out, sit down, partly because there's not always somewhere to write”*	**Environmental context and resources** Opportunity (physical)	Restructuring physical environment Adding objects to the environment Social support (practical)	Unit manager to advise administration staff to make physical space (marked reserved) for relevant HCPs to update patients’ notes (e.g. in back office / side room)	A P E A S E ✓ ✓ ✓ ✓ × ✓

Service improvement strategies / BCW policy category / intervention function	**Focus group / questionnaire frequency**	**Constraints and enablers reported by participants** [Enablers in brackets]	**TDF domain linked to constraint / enabler** and related COM-B component	**BCTs to address constraints / enablers**	**How to operationalise - example**	**APEASE** ➢ Affordability ➢ Practicability ➢ Effectiveness & cost effectiveness ➢ Acceptability ➢ Side effects/ unwanted consequences ➢ Equity
BCW: Enablement		*P4: "there's not always the notes around aren't there, so/"* (multiple speakers, focus group 1)				
Community						
Transfusion access						
7. **Home transfusion or community transfusion sites nearer to patients** "*I think in an ideal world if we had the money and the resources, I think transfusion in the home, or in hubs nearer to where people live [partial group agreement] so if you had a community of villages, you had a hub somewhere* (P6, focus group 1) BCW: Service provision & Environmental restructuring	2 focus groups & 3 questionnaires	a) Resources and funding needs for community transfusion sites b) Medicalisation of the home may impact family and reduce respite c) Staff training and **efficiency** to deliver home transfusions d) Potential blood transfer, traceability and adverse events risks with community transfusions	**Environmental context and resources** (a, c, d, f, h) Opportunity (physical) **Social influences** (b) Opportunity (Social) **Beliefs about Consequences** (b, e, d) Motivation (reflective) **Skills** (c)	Restructuring physical environment Comparative imagining of future outcomes Incentive (outcome) Information about health consequences	Commissioners and unit managers to consider resourcing local hubs to provide patients with community transfusions and collect patients' views for/ against home transfusion. Alongside collecting patients' views assess risks, blood transfer and traceability issues and HCP' training needs.	A P E A S E ? ✓ ? ✓ ? ✓

Service improvement strategies / BCW policy category / intervention function	**Focus group / questionnaire frequency**	**Constraints and enablers reported by participants** [Enablers in brackets]	**TDF domain linked to constraint / enabler** and related COM-B component	**BCTs to address constraints / enablers**	**How to operationalise - example**	**APEASE** ➢ Affordability ➢ Practicability ➢ Effectiveness & cost effectiveness ➢ Acceptability ➢ Side effects/ unwanted consequences ➢ Equity
		e) May not be every patient's preference f) Increased National Health Service (NHS) focus on community integrated care pathways [Enabler] g) Staff willingness and positivity to make changes [Enabler] h) Utilising existing community hubs [Enabler]: "*I think that having community places where there are already nursing staff who can be trained up and are transfusion competent, you know, erm, to, to tap into those*" (P1, focus group 2)	Capability (Physical) **Memory, Attention and Decision Processes** (e) Capability (Psychological) **Social / Professional Role and Identity** (f) & **Intentions & Optimism** (g) Motivation (reflective)	Information about social, environmental and emotional consequences Information about others' approval		
Practices (hospital or community)						

Service improvement strategies / BCW policy category / intervention function	**Focus group / questionnaire frequency**	**Constraints and enablers reported by participants** [Enablers in brackets]	**TDF domain linked to constraint / enabler** and related COM-B component	**BCTs to address constraints / enablers**	**How to operationalise - example**	**APEASE** ➢ Affordability ➢ Practicability ➢ Effectiveness & cost effectiveness ➢ Acceptability ➢ Side effects/ unwanted consequences ➢ Equity
8. **Community or hospital screening of patient's haemoglobin (Hb) (red blood cell protein) level** to provide enhanced communication of transfusion requirement and expected duration P1: "*I think it depends as well when the, erm, phlebotomy count is checked, if it's checked on the day when the patient is actually in the clinic then there may be more likelihood that they might get that extra unit that they didn't really need cause they're already there, whereas if it was perhaps checked the day before, em* *P2: we could give 'em a ring* *P3: yeah exactly, and at least then they're prepped* *P2: and they'll be informed not to come into hospital* (multiple speakers, focus group 1) BCW: Service provision & Education	2 focus groups & 2 questionnaires	a) May be location specific: "*I think it depends where they lived whether they get the service or not*" (P1, focus group 1) b) Blood sample transfer risks with community testing c) Equipment expenses d) Impact to patient of enhanced communication about expected transfusion: "*…if they can have it done in the haematology unit … they have to come in twice and that impacts on the quality of life*" (P5, focus group 1) e) Additional burden for community HCPs of	**Environmental context and resources** (a, b, c, f) Opportunity (physical) **Beliefs about consequences** (b, e, d, g, h) Motivation (reflective)	Restructuring physical environment Information about social & environmental consequences Incentive (outcome) Pros and cons	If community transfusion hubs are generated (strategy 7), commissioners and service managers to consider adding options for patients to remotely visit to screen their Hb level and how this may reduce hospital attendance. To offer this service in new hubs but to advise patients that this may not rule out some hospital attendance	A P E A S E ? ✓ ? ✓ ? ✓

Service improvement strategies / BCW policy category / intervention function	**Focus group / questionnaire frequency**	**Constraints and enablers reported by participants** [Enablers in brackets]	**TDF domain linked to constraint / enabler** and related COM-B component	**BCTs to address constraints / enablers**	**How to operationalise - example**	**APEASE** ➢ Affordability ➢ Practicability ➢ Effectiveness & cost effectiveness ➢ Acceptability ➢ Side effects/ unwanted consequences ➢ Equity
		providing patients with enhanced communication f) Lack of and re-establishment (Enabler) of phlebotomy centres g) Diagnostic test may not rule out patient hospital attendance h) Provides patients with better predictability about upcoming transfusion time length [Enabler]				

Table 20 Service improvement strategies from questionnaires only

Service improvement strategies (questionnaires) / BCW policy category / intervention function	**Questionnaire frequency**	**Constraints and enablers reported by participants** [Enablers in brackets]	**TDF domain linked to constraint / enabler** and related COM-B component	**BCTs to address barriers / enablers**	**How to operationalise - example**	**APEASE** ➢ Affordability ➢ Practicability ➢ Effectiveness & cost effectiveness ➢ Acceptability ➢ Side effects/ unwanted consequences ➢ Equity
Hospital **Transfusion access**						
9. Hospital restructuring and physical expansion "[what can be done … to improve patients' experiences] …*restructuring inpatient + outpatient …no space to expand hospital …*" (Questionnaire 2) BCW: Environmental restructuring	3	a) A complex change due to space, financial and staff requirements b) Leadership decision-making barriers to implementation: [Requirements]: "*better leadership in management*" "*remove political interferences*" (Questionnaire 2)	**Environmental context and resources** (a) Opportunity (physical) **Social influences** (b) Motivation (reflective)	Restructuring the physical environment Information about others' approval Information about social and environmental consequences	Hospital managers and directors to consider options to physically expand wards or re-organise existing space. To include consideration of the advantages / disadvantages of restructuring for staff and patients.	A P E A S E × ? × ? ? ?
10. Charging patients for appointment non-attendance *"Sometimes patients cancel [transfusions] and turn up when symptomatic ... need to be charged for waste slots + time"* (Questionnaire 2)	1	a) Enhanced patient incentives [Enabler]: *"charging if waste slots would give some [patients] incentive to take responsibility"* (Questionnaire 2)	**Reinforcement & Beliefs about consequences** Motivation (reflective)	Problem solving Goal setting (behaviour)	Non-attenders to be verbally reminded about wasted resources when attending with reasons for non-attendance discussed. A shared treatment plan to be	A P E A S E ✓ ✓ ✓ ? ? ?

Service improvement strategies **(questionnaires) / BCW policy category / intervention function**	**Questionnaire frequency**	**Constraints and enablers reported by participants** [Enablers in brackets]	**TDF domain linked to constraint / enabler** and related COM-B component	**BCTs to address barriers / enablers**	**How to operationalise - example**	**APEASE** ➢ Affordability ➢ Practicability ➢ Effectiveness & cost effectiveness ➢ Acceptability ➢ Side effects/ unwanted consequences ➢ Equity
BCW: Coercion				Action planning Review behaviour goals Behavioural contract Information about health / environmental consequences	established, with ongoing review and discussion.	
Hospital Support						
11. Trained volunteers employed to help support patients (duties not specified) "[what can be done … to improve patients' experiences] …*volunteers – trained volunteers"* (Questionnaire 1)	1	None reported	N/A	N/A	N/A	N/A

Service improvement strategies (questionnaires) / BCW policy category / intervention function	**Questionnaire frequency**	**Constraints and enablers reported by participants** [Enablers in brackets]	**TDF domain linked to constraint / enabler** and related COM-B component	**BCTs to address barriers / enablers**	**How to operationalise - example**	**APEASE** ➢ Affordability ➢ Practicability ➢ Effectiveness & cost effectiveness ➢ Acceptability ➢ Side effects/ unwanted consequences ➢ Equity
BCW: Service provision & Enablement						
12. Easy to read written information produced "[what can be done … to improve patients' experiences] … *written information to back up verbal appointments*" (Questionnaire 4) BCW: Education	3	a) Information would be too generic: *"info handed to patients wouldn't be tailored to the individual"* (Questionnaire 4) b) Providing phone call follow up to confirm patient understanding [Enabler]	**Knowledge** (a, b) Motivation (reflective) Capability (Psychological)	Credible source Reduce negative emotions Social support (practical)	Make pre-existing leaflets available to patients (where there is low usage). Encourage patients to also note and raise questions during appointments or phone calls	A P E A S E ✓ ✓ ✓ ? ✗ ✓
13. Informal events and support groups to take place in the transfusion unit "… *patients do value learning from 'the horse's mouth experiences … maybe from other patients (e.g. a voluntary patient self-help group)"* (Questionnaire 5) BCW: Service provision & Enablement	2	**a)** Patient involvement in the design of support groups [Enabler]: *"[no constraints, just] asking patients what they would like"* (Questionnaire 4) **b)** Patients and their families can talk to others with similar experiences [Enabler]	**Social influences** (a, b) Motivation (reflective)	Social support (unspecified) Information about others' approval Restructuring the social environment	Set up a coffee morning / one-off forum in the unit and explore with patients the need for events and support groups – determine patients who may wish to be involved in the design of events and groups	A P E A S E ✓ ✓ ✓ ✓ ? ?

Service improvement strategies (questionnaires) / BCW policy category / intervention function	**Questionnaire frequency**	**Constraints and enablers reported by participants** [Enablers in brackets]	**TDF domain linked to constraint / enabler** and related COM-B component	**BCTs to address barriers / enablers**	**How to operationalise - example**	**APEASE** ➢ Affordability ➢ Practicability ➢ Effectiveness & cost effectiveness ➢ Acceptability ➢ Side effects/ unwanted consequences ➢ Equity
14. Primary transfusion nurses available to patients "[what can be done … to improve patients' experiences] … *have (a) primary nurse(s) that is aware of the patient's history. This will also give continuity of care"* (Questionnaire 1) BCW: Service provision & Environmental restructuring	2	a) Financial and staffing constraints b) Culture change [Enabler]**:** "[things that may help change to occur] … *culture change"* (Questionnaire 1)	**Environmental context and resources & Social influences** Opportunity (physical / Social)	Social support (practical / emotional) Restructuring physical / social environment Credible source	Service managers to review existing provision of patient-nurse contact and identify patients who may benefit from having a specific nurse to contact (if not already the case).	A P E A S E ? ✓ ? ✓ ✘ ✓
Community Support						
15. Contact nurse / team via telephone or internet to discuss patients' transfusion queries outside of the hospital "[what can be done … to improve patients' experiences] …*more out of hospital contact (i.e. a named nurse/team who is available at the end of telephone"* (Questionnaire 3) BCW: Service provision & Enablement	2	a) Financial and staffing implications: "*An initial outlay of funding, but preventing unnecessary blood tests and appointments would surely cover this cost"* (Questionnaire 4) b) Easy contact method for patients who already	**Environmental context and resources** (a, b) Opportunity (physical)	Social support (practical / emotional) Restructuring physical / social environment Credible source	Service managers when reviewing patient-nurse contact (strategy 14), to review nurses' capacity to deliver direct contact via phone / internet.	A P E A S E ? ✘ ? ✘ ? ✘

Service improvement strategies **(questionnaires) / BCW policy category / intervention function**	**Questionnaire frequency**	**Constraints and enablers reported by participants** [Enablers in brackets]	**TDF domain linked to constraint / enabler** and related COM-B component	**BCTs to address barriers / enablers**	**How to operationalise - example**	**APEASE** ➢ Affordability ➢ Practicability ➢ Effectiveness & cost effectiveness ➢ Acceptability ➢ Side effects/ unwanted consequences ➢ Equity
		have telephones / smart phones [Enabler]	**Beliefs about capabilities** (b) Motivation (reflective)	Adding objects to the environment		
16. Online forums developed for transfusion patients to gain support *“*[might patients need more support …] *maybe from other patients (e.g. a voluntary patient self-help group). Forums are good for this (online)”* (Questionnaire 5) BCW: Service provision & Enablement	1	Accessibility implications for some patients: “… *[forums] not available to those without internet*” (Questionnaire 5)	**Environmental context and resources** Opportunity (physical)	Social support (unspecified) Information about others’ approval Restructuring the social environment Social comparison Adding objects to the environment	During a one-off coffee morning / forum in the unit (strategy 13) explore the use of online forums with patients. Possibly show patients existing online forums and query their need for forums, accessibility issues and patients wishing to help with the development / trialling of a forum.	A P E A S E ✓ ✓ ✓ ✓ ? ✗

Service improvement strategies (questionnaires) / BCW policy category / intervention function	**Questionnaire frequency**	**Constraints and enablers reported by participants** [Enablers in brackets]	**TDF domain linked to constraint / enabler** and related COM-B component	**BCTs to address barriers / enablers**	**How to operationalise - example**	**APEASE** ➢ Affordability ➢ Practicability ➢ Effectiveness & cost effectiveness ➢ Acceptability ➢ Side effects/ unwanted consequences ➢ Equity
17. Cannulation (tube inserted to vein to deliver transfused blood) improvements "*Not much can be done for pain of cannula insertion but numbing cream prior to insertion may help"* (Questionnaire 6) BCW: Training	1	Financial costs: "[constraints to this…] *costs"* (Questionnaire 6)	**Environmental context and resources** Opportunity (physical)	Information about health consequences Problem solving Information about others' approval Pros and cons Adding objects to the environment	Nurse leads to discuss using a numbing cream prior to cannulation. To review evidence and costings for this and identify patients to offer this to.	A P E A S E ? ✓ ? ✓ ? ✓

5.3.4.1 Widely endorsed strategies

Two ‘community’ service improvement strategies were mentioned in at least two of the three separate focus groups, and were thus considered to be more strongly endorsed (*7: Home / Community transfusion and 8: Remote Hb screening*, Table 19). Both strategies involve patients receiving blood level screening or transfusions in the community rather than in outpatient secondary care (hospital) settings. The remaining strategies focused on improving haematology transfusion processes in the hospital site (*1: Transfusion team / unit, 4: Expedition of lab samples and 6: Improved record of consultation discussion in patients’ notes*) or communication across teams or with patients (*2: Psychological support, 3: Enhanced shared decision-making and 5: Shared lab role appreciation*). In the questionnaires, hospital and community ‘access’ and ‘support’ strategies were widely endorsed (hospital: six strategies, community: three of nine questionnaire strategies in total). In particular, strategy nine: ‘*Hospital restructuring and physical expansion’* and strategy 12 ‘*Easy to read written information produced*’ were both strategies mentioned in three questionnaires of six each (Table 20).

5.3.4.2 Mapping to BCW, TDF and COM-B

The total 17 service improvement strategies mapped to one policy category (Service provision n=9 strategies, 53%) and six intervention functions (Enablement n=7 strategies 41%; Environmental restructuring n= 6, 35%; Education n=3 17%; Persuasion, Training and Coercion n=1 each 6%) from the Behaviour change wheel (BCW) (Michie et al., 2011) (Table 19). Constraints and enablers to implementing the proposed service improvement strategies were identified within twelve of the fourteen TDF domains (Figure

11). The most frequently coded TDF domains were 'Environmental Context and Resources' (n= 10 of 34 constraints and enablers, 29%) and 'Beliefs about Consequences' (n=6, 18%) (Table 19, Table 20 and Figure 11 below). These two TDF domains correspond with COM-B domains of Physical-opportunity and Reflective-motivation, indicating that for the strategies to be implemented and successful, there would need to be opportunities afforded by the environment (e.g. setting up safe community to laboratory sample shipment) and/or plans put into place to enhance people's motivation (e.g. promotion of local blood testing and the benefits of this for patients).

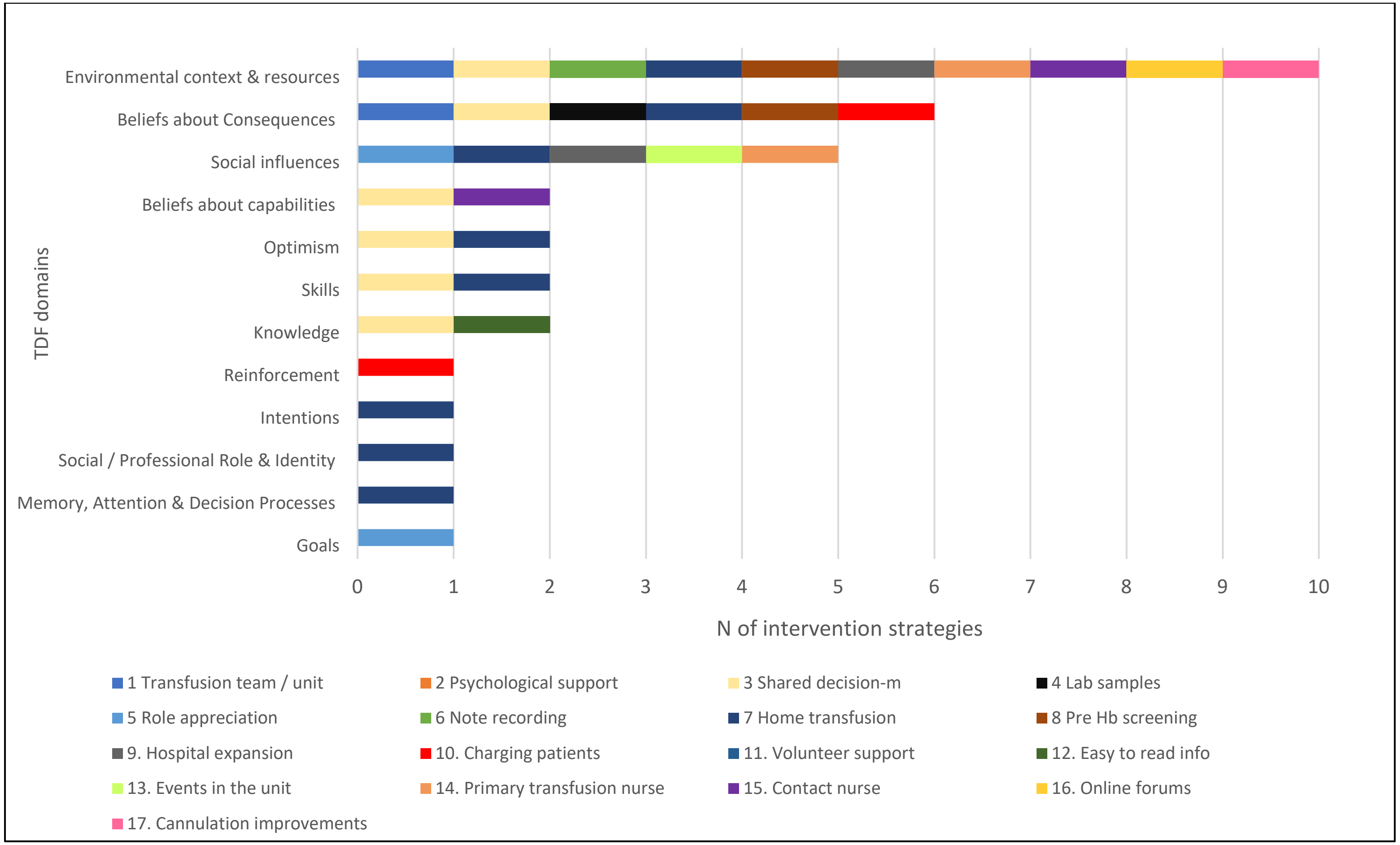


Figure 11 Frequency of TDF (Michie et al., 2005) domains and service improvement strategies

5.3.4.3 *Intervention design*

Intervention options for each strategy with reported constraints and enablers (n=15) were developed, supported by 28 different Behaviour change techniques (BCTs), most frequently '*Restructuring the physical environment'* (utilised for n=9 intervention options, 60%) and '*Information about the social and environmental consequences'* (n=6 options, 40%) (Table 19 and Table 20). Intervention ideas were evaluated using the APEASE criteria, which identified intervention options to be rated highly (5 options, 33%) or moderately (7 options, 47%). Three options were rated uncertain or low (20%). An intervention, for example, with a moderate APEASE rating was for strategy four (*enhancing shared decision-making*). This would see managers facilitating a culture of shared decision-making, by reviewing staff capacity to spend more time with patients for longer conversations. HCP targeted workshops would be set up to facilitate decision-making being more 'negotiated' with patients, allowing patients more control and choice over their transfusions. This may be affordable and effective etc., yet how practical it would be may be questionable, based on HCP time-constraints and there may be some unwanted side-effects with some patients adopting a greater amount of autonomy and disputing clinical advice. A 'high' classified intervention option was proposed for strategy five (*encouraging laboratory, HCP and patient role appreciation).* Patients may benefit from being provided with written information about safe laboratory procedures during delays or through organised lab tours. Reciprocally, this intervention option could be developed to encourage non patient-facing laboratory staff to more greatly understand patients' perspectives, with perhaps patients being invited to discuss their experiences when meeting laboratory staff.

5.3.4.4 Mapping of strategies to original patient constructs

Of the 17 strategies identified, at least one strategy maps onto all of the constructs identified in the patient interviews (Study 2), with most strategies addressing perceptions from the constructs of '*Involvement in decision making'* (n=10), '*Social connection'* (n=8) and '*Negative emotions'* (n=7) (Table 21). Forty-eight mappings were identified; 44 being 'positive associations' in that the strategy is facilitative and addresses issues relating to the perceptions belonging within the construct. Four mappings were, however, 'negatively associated' in that they are unlikely to work towards improving patients' perceptions associated with the construct. Two strategies in particular: '*Home transfusion*' and *'Charging patients for wasted transfusion slots'* are linked 'negatively' with the constructs '*Social connection'* and '*Negative emotions'.* Providing transfusions at home may enhance patients' negative emotions and isolation and charging patients may lead to patients feeling reprimanded and disconnected from the units, increasing patients' negative emotions.

Table 21 Mapping of strategies to original patient constructs

	Focus group presented			Questionnaire presented					
Construct of patients' perceptions	Negative emotions	Involvement in decision making	Health benefits	Necessity	Social Connection	Awareness of risk / safety	Burden	Alternatives	Distinguishing between blood products
Service improvement strategies 1. Transfusion team / unit		🟩		🟩	🟩		🟩		
2. Psychological support	🟩								
3. Shared decision-m		🟩					🟩		
4. Lab samples	🟩						🟩		
5. Role appreciation		🟩			🟩	🟩	🟩		
6. Note recording		🟩				🟩		🟩	
7. Home transfusion	🟥	🟩			🟥		🟩		
8. Pre Hb screening		🟩		🟩			🟩		
9. Hospital expansion					🟩				
10. Charging patients	🟥	🟩		🟩	🟥				
11. Volunteer support	🟩				🟩				
12. Easy to read info		🟩	🟩			🟩		🟩	🟩
13. Events in the unit	🟩				🟩				
14. Primary transfusion nurse	🟩	🟩		🟩	🟩			🟩	🟩
15. Contact nurse	🟩	🟩		🟩	🟩	🟩			
16. Online forums					🟩				
17. Cannulation improvements	🟩		🟩			🟩			

Colour shading: green cells = positive associations between strategy and theme and red cells = negative associations

5.4 Discussion

This focus group study explored the views of Regional Transfusion Committee healthcare professionals (HCPs) about haematology patients' perceptions of blood transfusion and generated potential service improvement strategies. Participating HCPs reported that the constructs were reflective of their practice and interactions with patients in the haematology units. The inductive synthesis of the focus group and questionnaire data produced nine themes in total: *Practical difficulties for transfusion patients, Patient support provision, Service efficiencies, Supporting best practice, Positive collaboration with patients, Transfusion acceptance, Patients' individual preferences, Patient involvement* and *Practice difficulties*. HCPs recognised that patients commit a large amount of time to receiving their transfusions. However, through this study, evidence of patients self-initiating their request for transfusions were revealed. HCPs discussed that although there are some practices that work well, they suffer the consequences of the lower prioritisation of some haematology transfusion services and poor links with other wards and the wider community HCPs. HCPs do manage, however, to develop close ties with their patients, respecting their individuality and largely involve patients in their transfusions and unit activities (e.g., making treatment decision plans and suggesting cannulation sites). HCPs reported extending their outpatient care activities to provide additional support, such as emotional support and authorising prescriptions.

HCPs were able to propose 17 hospital and community-based service improvement strategies in total, which mapped to seven components of the Behaviour change wheel (BCW) (Michie et al., 2011), covering ways to improve processes (e.g. developing a transfusion team and expediting laboratory samples), ways to enhance patient communication (e.g. psychological support, shared-decision making, role appreciation) or transfusion-related community provisions (e.g. home transfusion, remote blood level screening). Constraints and enablers raised for these strategies were able to be mapped to the Theoretical Domains Framework (TDF) (Cane et al., 2012; Michie et al., 2005) and behaviour change interventions were proposed to develop the strategies further (e.g. to provide HCPs with training support to enhance patient decision-making conversations or providing written information advising of safe laboratory processes).

The findings of this study relate with the previous study 2 in Chapter 4, with HCPs commenting that haematology transfusion resources are stretched. However, this study advances on study 2 by proposing initiatives that would lead to patients taking a more central role in their transfusions, such as monitoring their own blood levels, or being considered for transfusion in the community. There was an impetus too on HCPs needing improved processes, improved consideration of the patient's role (role appreciation) and more stable community links. The types of strategies generated map closely to the construct of '*Involvement in decision making*' with HCPs being receptive of the need to improve decision making type issues (e.g. information provision, notes recording and decision-making discussions). This study reinforced that without stable and consistent support systems in place, more problems often occur, such as greater patient frustrations and an increasingly disorganised service with patients controlling their own transfusion requests or being inappropriately transfused and HCP communications breaking down.

For this study, individual level change suggestions proved more difficult to incite, as opposed to general hospital and community level strategies. HCPs may have attributed change as being outside of their control through their current experience of responding to a pressured service with often managerial top-down changes applied. HCPs also primarily reported constraints to change, possibly because HCPs attribute many of the current service difficulties to responsibilities outside of themselves (Shaver, 1983). HCPs may have learnt to cope with the problems that they face (Schein, 2010), feeling that they personally can do little to change large-scale issues.

For patients, the findings of this study signal that a number of haematology patients do require more supportive measures to be put into place. Some patients may be willing to consider home transfusion, as found in a French study, where there was a preference for home transfusion at a similar consistency to preference for home chemotherapy (Havet et al., 2012). A UK based intervention of home platelet transfusion and pretransfusion assessment reported increases in patients' preferences for this method and alleviation of patients' concerns about the stress, cost of travel and waiting time at hospital (Craig et al., 1999). As long as home transfusion is acceptable to patients, it may be an option for localities to begin supporting or continuing if they have the resources in place. Home transfusion may be a practical and acceptable option for experienced transfusion patients, more ready to receive their transfusions away from the unit or patients with less advanced disease stages (Havet et al., 2012).

This focus group study appealed to a selective group of HCPs, being less burdensome on their clinical time conducted away from the haematology unit and less time consuming than other consensus methods such as Delphi or nominal group technique (Cantrill et al., 1996). HCPs accepted and understood the focus group procedure and contributed enthusiastically to the group discussions.

On reflection of the experience of running the focus groups, having active and engaged participants made the experience of running the focus groups easier, with participants, especially of Consultant level, being engaged in the discussion and contributing whole-heartedly. I felt accepted as a researcher at each focus group and felt that HCPs gave as honest as possible audio-recorded account of the issues that they and their patients face. Each focus group was unique, and reflections were documented in the Reflexive log (Appendix 10.22).

Overall, groups were easier to facilitate when cohesive and when participants gave each other time to talk. Time constraints to the focus groups and groups with conversations that deviated away from the topic or where participants were left out of the conversation required more active facilitation. This required more active problem-solving to steer the group back onto topic and the use of more enhanced facilitation, to include all members by, for example, personally requesting their thoughts.

As a cooperative group of HCP participants, there may have been a risk of bias, however, in the selected sample of HCPs who volunteered to take part. HCPs attending the RCT meetings who routinely engage with transfusion committee findings are potentially receptive to considering practice change and therefore service-improvements. As time-constraints did affect the majority of the focus groups, the discussion were also limited to three of the nine transfusion constructs identified in Study 2 (Chapter 4). However, the use of the questionnaire enabled HCPs to provide their opinions on the full set of constructs. The questionnaires produced, however, an even lower response rate, but did highlight an equal number of service improvement strategies as the focus groups and valuable content related to patient involvement, patient transfusion acceptance and individual differences.

The time-constraints and individual completion of the questionnaire also limited service improvement strategies to be debated and possibly organised into a prioritised list, with potential pathways (action plans) to implementation. In the focus groups, the researcher aimed to overcome this by presenting patients' priority perceptions and summarising with the groups strategies that they have mentioned, checking for agreement. Yet, additional time and the use of materials such as 'post-it' notes to record and prioritise ideas or the design of follow on workshops would have potentially increased the range of views and the range and specificity of the strategies generated. An online version of the follow-on questionnaire may have also been useful for respondents to electronically prioritise proposed strategies using 'drag and drop' options.

A strength of this study was the application of current behaviour change frameworks to help interpret the findings. This provided a structure for constraints and enablers to be understood within the TDF (Michie et al., 2005) domains, for example, and for interventions to be proposed, taking into account constraints and enablers that were raised. Many constraints and enablers, however, were based on 'Environmental context and resources' issues, which may be more costly and difficult to change, for example, hospital expansion or new transfusion units. Such changes would also require additional staffing resources. ‘Beliefs about consequences’ may be more amenable to change, for example, through further exploration about how patients would engage with the new service ideas. The strategies, constraints and enablers cited were also speculative and not an exhaustive list. HCPs were speculating on hypothetical scenarios (e.g. patients having home transfusions) and may have raised constraints that would not materialise, or constraints that will become diminished on implementation. Reviewing past interventions when formulating the APEASE (Michie et al., 2011) ratings would have also been of benefit when formulating intervention options. The researcher would have been able to refer to and cite the outcomes of similar interventions to build stronger rationales for given APEASE judgements.

As the process of implementing healthcare change goes through discrete stages (Grol, 2013), these strategies are at an early stage, needing to be revisited and developed further before being refined into interventions, possibly some of those proposed, pilot tested and implemented. Key decision-makers, such as service leaders, patients, patient representatives, relatives, researchers and stakeholders would ideally need to be involved in intervention development stages to help a thorough understanding of the exact behaviour to be changed to be identified. The next steps would involve identifying intervention options (possibly taking further those proposed) and specifying the content and implementation options, for example, using behaviour change techniques (Michie et al., 2013) and modes of delivery. Patient and service user involvement would be consistent with Experienced based co-design methods (Bate et al., 2006; Brocklehurst et al., 2018) and researchers would need to be involved to manage the studies and conduct ongoing research (e.g. qualitative research to verbally share opinions and ideas).

In conclusion, this study stimulated discussion and debate with transfusion HCPs about identified constructs of haematology patients' blood transfusion perceptions, leading to the identification of 17 hospital and community-based service improvement strategies. These strategies sought to generate new opportunities to improve transfusion patients' experiences and rectify current practice difficulties. Further development of the service improvement strategies would benefit from the engagement of key stakeholders and continued theory-based design. Some indication has been given to possible intervention ideas, such as HCP targeted communication training and the consideration of home transfusion.

6 General Discussion

This programme of research explored patients' and healthcare professionals' (HCPs') perceptions of blood transfusion through a sequence of three studies. Study 1 was a systematic review of existing published studies exploring patients' and HCPs' perceptions of blood transfusion. Study 2 was a qualitative interview study of haematology patients' and HCPs' perceptions of blood transfusion. Study 3 was a focus group study to explore HCPs' views of patients' perceptions from study 2 and identify the implications for practice and potential strategies to improve current haematology services. This chapter will briefly provide an overview of the findings of each study and the overall contribution of the findings to the literature, draw on the strengths and limitations of the programme of research and present implications for research and practice.

6.1 Findings

6.1.1 Study 1: Patients' and HCPs' perceptions of blood transfusion: A systematic review

The systematic review reported in Chapter 2, first conducted in 2014 and updated in 2015 and 2019, included 41 studies reporting patients' and HCPs' perceptions of blood transfusion. These were published between 1990 and 2018. Twenty-six studies reported HCPs' perceptions, and 15 studies patients' perceptions, with no study concurrently exploring the perceptions of both groups. Reported perceptions were analysed using inductive qualitative synthesis (Thomas, 2003). Overall, the review identified that transfusion was considered as carrying low to moderate risk, but that perceived transfusion-associated risk, or negative emotions (e.g. concerns about infection risk) were associated with the use or consideration of transfusion alternatives (e.g. pre-operative autologous donation). The inductive synthesis produced six themes of patients' and HCPs' blood transfusion perceptions organised into a conceptual model of blood transfusion perceptions: Safety / risk, Negative emotions, Alternatives, Health benefits, Necessity and Decision making. Relationships between the constructs in the model were proposed, for example, between Alternatives, Safety/risk and Negative emotions. The Decision making construct contained perceptions related to behaviours observable in the clinical setting, such as patients not questioning transfusion decisions and of HCPs' prescribing behaviours.

The review identified, however, that perceptions tended to be investigated for patients receiving, and HCPs prescribing, transfusions in surgical contexts, with results not separated in the analysis and reported per patient or HCP group. A gap emerged to investigate the perceptions of under-represented transfusion patient and HCP groups, whose perceptions may vary widely from patients and HCPs receiving or providing one-off transfusions. Most notable was the need to explore haematology patients' and HCPs' blood transfusion perceptions due to the repeated use of transfusions in haematology contexts. Haematology patients would be receiving transfusions on a repeated basis for long-term conditions or to support cancer treatment. As patients will require transfusions routinely and be able to form perceptions at different time-points (e.g. pre and post transfusion provided to a 'conscious' patient, as opposed to an unconscious patient), it was felt necessary to consider this area for more specified investigation.

6.1.2 Theoretical mapping

Chapter 3 documented how constructs from the conceptual model of blood transfusion perceptions, developed in Study 1, were mapped against constructs from five prominent treatment perceptions frameworks. The Beliefs about Medicines Questionnaire (BMQ) (Horne et al., 2004; Horne et al., 1999b) items were identified to map most closely to the conceptual model constructs. Overall, constructs from the conceptual model were considered to provide a framework consistent to the broader treatment perceptions literature, providing support for this model to be used in ongoing studies investigating patients' and HCPs' transfusion perceptions.

6.1.3 Study 2: Exploring perceptions of blood transfusion in haematology

Study 2 was designed to explore haematology patients' and HCPs' perceptions of blood transfusion, which was a research gap identified in Study 1, using semi-structured, qualitative interviews. Fourteen patients and 14 HCPs receiving and delivering transfusions in haematology outpatient day units were interviewed across two UK sites. The patient- and HCP-specific interview topic guide used for this study were structured around constructs from the conceptual model of blood transfusion perceptions, developed through Study 1 and supported through the theoretical constructs mapping in Chapter 3. Participants' responses were coded deductively into constructs from the conceptual model with inductive thematic analysis being used to generate new themes.

This study found that patients and HCPs agreed that transfusions were necessary and beneficial for haematology patients. However, some negative emotions were reported, for instance related to the downsides of transfusions for haematology patients (e.g. health impact). Patient and HCP conceptual models were developed for the haematology context to highlight perceptions for this specific group compared to the general conceptual model from Study 1. Additional constructs, such as ‘Burden’ and social and contextual constructs: ‘Social connection’, ‘Supportive relationships’ and ‘Organisational factors’ were added to the haematology models. The findings of this study signalled many close ties between patients and HCPs but also that some patients may require more support when receiving repeated transfusions and that services could potentially be improved to benefit both patients and HCPs. HCPs recognised, for example, that they often did not ask patients about their views and feelings about receiving blood transfusions, thus, in turn factoring this into the care they provide.

6.1.4 Study 3: BOOST: Building Optimised Outpatient Services in Transfusion

Study 3 was a focus group study that aimed to explore the extent that HCPs recognised patients’ transfusion perceptions from Study 2, whilst exploring with HCPs potential ways to change services and potentially their practice to improve patients’ experiences. Three focus groups were held at two regional transfusion committee (RTC) meetings. In total 19 HCPs took part, with six HCPs providing further feedback via the free-text response follow-on questionnaire. The findings highlighted that participants acknowledged the patients’ perceptions and discussed themes related to ‘patient support provision’, ‘service efficiencies’ and ‘practice difficulties’ such as insufficient links with community HCPs and lower prioritisation of haematology transfusions. HCPs proposed 17 service improvement strategies to improve current practice. These were subsequently categorised into intervention functions in the Behaviour change wheel (BCW) (Michie et al., 2011). The majority of proposed improvement strategies fell within the ‘Service provisions’ ‘Enablement’ and ‘Environmental restructuring’ intervention types. This included hospital-based initiatives, such as having a standardised transfusion team or unit and expediting haematology lab samples. Community-based solutions, such as home transfusion or community haemoglobin (Hb) testing were also endorsed. HCPs were also asked to think about potential constraints and enablers to implement these proposed strategies. Most reported constraints and enablers corresponded to the Theoretical Domains Framework (Cane et al., 2012; Michie et al., 2005) domain ‘Environmental Context and Resources’ (n=10 strategies) (e.g., location specific services, blood sample transfer risk). This indicated that opportunities would need to be afforded by the environment (e.g. setting up safe community to laboratory sample shipment) for these strategies to be successfully adopted and implemented.

In conclusion for this study, the taxonomy of Behaviour Change Techniques (Michie et al., 2013) was consulted to identify potential interventions targeting the constraints and enablers for each strategy suggested by the HCPs. These included, for example, the resourcing of local healthcare hubs and addressing resource needs to implement community or home transfusion. Interventions were evaluated for their practicability and affordability etc., against the APEASE criteria (Michie et al., 2014) to establish interventions that may have less barriers to implementation.

6.2 Contribution to the literature

The contributions of this research to the evidence base in blood transfusion and the broader health psychology treatment perceptions and behaviour change evidence base is outlined below.

6.2.1 Blood transfusion

This programme of research has helped to address a priority area recognised for blood transfusion, of involving patients more greatly in their transfusions. Questions related to transfusion often include ‘how can patients, relatives and carers be empowered to have greater say about their choices in relation to blood transfusion and its alternatives?’ (James Lind Alliance Priority Setting Partnership, 2019). Alongside this, there are recommendations in practice to involve patients in decision making (Davis et al., 2012a; Davis et al., 2011). This programme of research can help facilitate implementation of this in practice by providing the supporting evidence base. Study 1 provides a general conceptual model of blood transfusion perceptions, and Study 2 provides haematology specific models. These models help to visually portray constructs of patients’ and HCPs’ transfusion perceptions, which may be of potential worth to discuss in transfusion decision-making consultations. The models also present specific relationships between the constructs, being necessary to consider when discussing transfusions (e.g. the influence of negative emotions on preferences for alternatives), as this may have a broader influence on patients’ transfusion acceptance. Study 3 provided HCP-generated areas for practice change, which promote patient involvement and improved decision-making discussions.

6.2.2 Treatment perceptions

This programme of research has helped to profile the context of blood transfusion in the treatment perceptions literature. Prior to this research being conducted, transfusion treatment perceptions research was not broadly included in health psychology treatment perceptions research, as much as studies of repeated treatments, such as asthma medications (Østrem et al., 2015) or dialysis therapy (Karamanidou et al., 2014). Transfusion is equally a life-saving intervention and the coherence of the conceptual model constructs to the broader treatment perceptions literature portrays how transfusions can be largely considered in the same way as other medicines and treatments. This may be helpful to patients who can refer to their standard conceptualisations of treatments when in a healthcare context and rationalising a treatments necessity (Horne, 1999). Transfusions being provided in several clinical contexts, however, is unique to the treatment perceptions literature, in that it is used in acute settings and repeatedly for cancerous or long-term conditions.

The haematology interview Study 2 findings correspond with the literature in that new constructs such as ‘Burden’ were prevalent alongside contextual and social constructs (e.g. ‘Organisational factors’, Supportive relationships’ and ‘Social connection’), which are known to inform typical treatment perceptions, such as needs and concerns (Horne, 2003). ‘Treatment burden’ for patients with long term conditions is identified as the loss of freedom and independence for some patients (Demain et al., 2015). Relational disruptions can also occur due to treatment burden, including strained family and social relationships and feeling isolated (Demain et al., 2015). Some of these aspects were reported by the haematology patients interviewed in Study 2, in terms of lack of contact with other patients in the unit or life-alterations (e.g. travel). Thus, it is important to continue to explore the construct of 'Burden' in more detail with transfusion patients as treatment burden may impact a haematology patient's life to a greater extent than shared by patients in the current interviews.

However, in the haematology interview Study 2, treatment adherence, a commonly measured outcome variable in treatment perceptions research, was less of an issue due to the absolute necessity of the transfusions. Although, a sense of patients 'actively accepting' or 'modifying' their treatments (e.g. proactively requesting their transfusions) was identified. In many patient cases, existing without transfusions would be detrimental to patients' health, thus it may be worthwhile to retain a focus on 'adherence' to some degree, specific to treatment modification, in order to detect broader patient non-compliance behaviours.

6.2.3 Behaviour change

The focus group Study 3 findings correspond with the literature in that all strategies and their constraints and enablers were able to be mapped to Behaviour Change Wheel (BCW) and Theoretical Domains Framework (TDF) (Cane et al., 2012; Michie et al., 2011) behaviour change frameworks. These frameworks provided evidence-based structures to guide the organisation of multiple strategies, constraints and enablers, to help present the key findings of the study into useful groupings for clearer results presentation. Other taxonomies and criteria utilised, such as APEASE (Michie et al., 2014), were similarly helpful to guide intervention design ideas. These mapping activities are consistent with current intervention development research that applies behaviour change frameworks, with the frameworks providing a theoretical basis for implementation (Atkins et al., 2017).

6.3 Strengths and limitations of the research

General strengths and limitations of the research will firstly be addressed, followed by a fuller summary of the strengths and limitations of the theoretical approach below.

6.3.1 Strengths

This programme of research covered a broad time range, beginning with Study 1 which was used to identify historic to present day perceptions of transfusion (1984-2019), with recognition of the impact that former tainted blood scandals may have on perceptions. Ongoing studies, in particular Study 2, sought to address an important research gap, to investigate the perceptions of repeated transfusion patients and HCPs in haematology units. This study involved a range of transfusion patients and HCPs in the study across two sites and utilised qualitative research methods, which are advocated for use in transfusion research (Whittaker, 2002). Study 3 further utilised qualitative methods to present patients' perceptions that were collected in the preceding study and mapped the findings that were grounded in current practice to behaviour change frameworks. Overall, this programme of research has evolved from considering which perceptions patients and HCPs might hold to HCPs encouraging patient involvement in how services might be improved for their benefit.

6.3.2 Limitations

Both of the primary studies in this programme of research (Study 2 and 3) benefitted from interested participants being willing to volunteer their involvement. The patients, however, that were interviewed were largely white English origin (71%) and Christian religion (79%) and some patients were unable to take part due to their lack of English. Although qualitative research findings do not aim to be generalisable to the broader population, patients' views in this research are broadly more representative of the views of medically stable haematology patients of white English and Christian religious and ethnic demographic categories. However, patients' demographics were collected and reported in the results to make this available for readers of the research.

Religious and ethnic disparities are of significance because research has shown that patients' perceptions are influenced by their broader cultural influences. One study of rheumatoid arthritis patients found that the patients of South Asian origin had higher 'Overuse', 'Harm', and 'Concern' BMQ scores compared to patients of White British/ Irish origin, which influenced their treatment adherence (Kumar et al., 2008). Some people may associate control over their health to higher spiritual powers. HCPs can be seen in such cases as intermediaries to help patients reach their destined fate (Karamanidou et al., 2014). Given that transfusions are required by people of all cultural backgrounds, future research may be used to investigate differences between transfusion perceptions across cultural groups. This may detect particular patients' preferences for or against receiving transfusions in the haematology units or at home to suit culturally specific norms or privacy preferences (May et al., 2009).

6.3.3 Strengths and limitations of the theoretical approach

The strengths of the methodological approach include using the conceptual model of blood transfusion perceptions as an overarching framework to structure data collection and analysis across the studies. This provided a consistent framework for comparing findings across the studies and participant groups. The model also facilitated comparison with the broader literature, given convergence in the mapping. Using a model that was derived from transfusion perceptions and shared linkage with the broader literature, was beneficial compared to selecting one particular instrument to apply, such as the Beliefs about Medicines Questionnaire (BMQ) (Horne et al., 1999b). The BMQ has been scrutinised for its suitability to capture the treatment perceptions of specific populations with complex and long-term conditions, such as psoriasis suffers (Thorneloe et al., 2017). The authors of this work found that BMQ items could easily be misinterpreted or that they should be extended upon, for example to cover Psoriasis sufferers 'underusing' topical medicines to obtain specialist care referrals, instead of focusing purely on medicine 'overuse' (Thorneloe et al., 2017). Transfusion 'underuse' is less likely to be an issue for some repeatedly transfused patients, but these patients may 'modify' their treatment regimes, by cancelling (postponing) planned transfusions, which could be detrimental to their health.

Further strengths of the theoretical approach relate to the conduct of comparative semi-structured interviews with patients and HCPs, whereby topics, such as transfusion alternatives and decision-making, could be explored from both perspectives. Using this approach, the researcher collected data around each construct of the model. In contrast, unstructured interviews may have lacked this focus, with the researcher not imposing categories of interest, which may have been more suited to exploring topics which have not previously been extensively described (Fitzpatrick et al., 1994).

The interview study also included a limited number of two sites, raising the question of whether patients and HCPs receiving and providing transfusions at different haematology units held similar perceptions. Many of the focus group participants in Study 3, who were from a different UK region as the interview sites, however, acknowledged the patients' perceptions but with some HCPs commenting that their patients receive transfusions, for example, in isolated rooms. These patients may hold uniquely different perceptions of their transfusions than patients receiving transfusions in an open plan unit, potentially having less social interaction, but arguably still holding transfusion perceptions associated with the 'Burden', 'Necessity' and 'Health Benefits' of transfusion.

The semi-structured focus groups used in Study 3 was also advantageous to provide structure to the discussion around each perception construct presented. However, HCPs who participated and engaged with this study were more self-selective and could have been HCPs willing and motivated to confront patients' perceptions and consider how their practice and service may need to be altered. It is uncertain from this research, how broadly haematology HCPs in general would engage with this research topic. Less engagement with this topic may also be indicative of lower engagement in practice with patients' perceptions or service change. It was noticeable that the Study 3 follow-on questionnaire response rate was low (50% meeting one, 23% meeting two). HCPs may have lacked engagement and motivation to return the questionnaire or may have felt that they have contributed everything they could have to the topic discussion during the focus groups. Ethical approval was not sought to re-contact HCPs to encourage questionnaire completion, which would have been beneficial.

The theory-based mapping of the service improvement strategies from Study 3, was facilitated by the availability and accessibility of behaviour change frameworks. As a guiding structure these frameworks were beneficial to group intervention types and hypothetical constraints and enablers to TDF (Cane et al., 2012; Michie et al., 2011) domains and to guide intervention design, considering key issues, such as intervention acceptability and effectiveness (Michie et al., 2014). However, when designing ongoing interventions patients', HCPs' and stakeholders' perceptions and experiences would need to be taken into account, which may shift the intervention focus away from the frameworks. The constraints and enablers would no longer be hypothetical, and patients, HCPs and stakeholders may wish for the developing service to be adapted or altered. For example, for raising patients' awareness of laboratory duties, so far one constraint was cited, that 'patients' priorities may be different to HCPs', but more constraints, such as time restrictions to provide patients with information, sensitivity factors and language barriers may emerge, increasing the complexity of the intervention design.

6.4 Implications for future research

There are a number of areas where this research could inform future research projects, as outlined below.

6.4.1 Relationships between constructs and the inclusion of psychosocial variables

There is scope for the conceptual models from Study 2 to be used in ongoing research with a larger sample of haematology patients and HCPs using a quantitative design, where the constructs would be translated to questionnaire subscales. Discriminant content validity would be a method that supports this translation, involving six steps, such as construct definition, item selection, judging and content validity testing (Johnston et al., 2014). A larger quantitative study would enable these constructs to be explored with a larger population for their significance and for relationships between the constructs to be tested using path analysis or structural equation modelling approaches. The strengths of the pathways from perceptions to decision making behaviours, for example, transfusion or alternatives prescription and transfusion acceptance could then be explored.

Conducting a larger quantitative study would make it possible for the influence of patients' illness perceptions, quality of life (Salek et al., 2013) or other important psychosocial variables to be examined. Patients for whom transfusion is a long-term 'treatment' option may have varying 'cure/control' perceptions than for patients who receive transfusions for a shorter length of time, often alongside chemotherapy. This is important as 'cure/control' dimensions have been found to correlate with problem-focused coping, cognitive reappraisal (to change the way that one views their illness) and seeking social support (Hagger et al., 2003). Transfusion patients reporting high perceived control may be more willing to take an active role in their transfusions and be more involved in the unit, such as being an active stakeholder or participant in the development of the service improvement strategies. Patients who report having a lower quality of life, however, may face difficulties to adopt an active role due to poor health or disease burden or treatment adverse events (Salek et al., 2013).

Personality variables are also likely to have an impact on treatment perceptions and mood states, such as depression and anxiety, which has not so far been measured in this research. Some patients ‘accepted’ the transfusions and held a general positive outlook towards their transfusion related challenges, which may have been based on their general personality traits. For example, ‘conscientiousness’ has been found to be positively associated with adherence to medicine regimes and ‘neuroticism’ having a negative effect on health behaviour (Booth-Kewley et al., 1994; Christensen et al., 1995). However, for patients with asthma, a high level of negative affectivity has been associated with completing behaviours correctly and a greater awareness of illness-specific symptoms, due to patients’ worries about their asthma (Mora et al., 2007). Thus, it would be important to consider the influence of such traits on transfusion patients’ perceptions.

As patients who were interviewed in Study 2 were taking prescribed medicines for other conditions, namely asthma, high blood pressure, diabetes, dermatological conditions, hip replacement or transplant recovery, self-regulation of patients’ health, for this sample may have been additionally challenging. The literature reports that coping with multimorbidity is often problematic, in particular taking multiple medicines (Mc Sharry et al., 2013). Patients may experience conflicts with managing their haematological conditions alongside other disorders, which was not fully explored by this research, in addition to the challenges of managing transfusions alongside chemotherapy and treatments for the same haematological condition was not fully explored. Future research may seek to explore this further and propose specified recommendations for practice. For instance, patients with co-morbidities are often willing to engage in treatment discussions which cover the interaction of multiple conditions (e.g. diabetes and depression) and discover management techniques beneficial for both (Mc Sharry et al., 2013).

6.4.2 Longitudinal research

As many haematology patients will be receiving transfusions for numerous months or years, longitudinal research is of relevance to this topic, to recognise how patients adjust to transfusion and to how adjustment may change or be impacted over time. Longitudinal research is often used to explore coping strategies employed by patients, to learn how this may moderate or mediate their health outcomes (Hagger et al., 2003). In this context, longitudinal research could be used to investigate the views of newly diagnosed haematology patients where transfusions are their main treatment option or teenage and young adult patients transitioning into adult services. Teenage and young adult sickle cell patients often report poor preparation to transition to adult-oriented services and insufficient readiness (McPherson et al., 2009).

6.4.3 HCPs' perceptions research

Some HCPs involved in this research (Study 2 interviews) commented that they were interested in this research topic and particularly valued the opportunity to reflect on their perceptions. Some HCPs acknowledged that they were only exposed to hospital-based patient interaction and not how patients cope in the community. They were interested in finding out more about how patients manage once they are away from the hospital, between transfusions. Future research could thus involve HCPs setting priorities for research to the same extent as patients, to help generate research questions that they wish to discover the answers to. Service improvement has been advocated through this research due to current capacity strain and issues with low prioritisation of haematology-based transfusions. If service changes are implemented (discussed below), research may need to investigate how HCPs' perceptions alter during and as a result of service change. HCPs commented in Study 2 that their perceptions seemed to be comparable with their colleagues and remained stable over time, reflecting complacency. Radical changes to services, such as 'hospital restructuring' and 'contact nurse support' may require support to be equally offered to HCPs to cope with running adapted services and implementing such changes. Threats to healthcare reform include physician burnout (Dyrbye et al., 2011) but organisational efforts put in place can help to manage this, such as small-group support programmes and stress reduction practices (West et al., 2018).

6.5 Implications for practice

6.5.1 Decision making

This research has highlighted how central the topic of 'decision making' is for blood transfusion patients and HCPs, and how even when decision options are limited, it is still an elaborated construct for patients and HCPs, and a resultant behavioural perception that many cognitive and emotional perceptions link to. As a general principle arising from this research, transfusions need to be discussed as a part of patients' decision-making conversations, based on the clinical feasibility of this. In the haematology context, transfusion discussions could be embedded into the main treatment discussion, even when transfusion may only be a supplemental treatment. Transfusion is not without risk, and when administered on a repeated basis is time-consuming, thus warranted to be included as a part of the full treatment discussion. This would help patients to be aware of the transfusions and have the opportunity to ask questions. Being more involved in their treatment decision making is likely increase patients' feelings of self-efficacy, which will increase patients' intentions to share in decision making (Stiggelbout et al., 2012). Patients having an active role in decision making is also associated with many patient benefits, such as better coping with negative emotions (e.g. anxiety, distress), greater information receipt and greater reported functional ability (Adams et al., 2006; Greenfield et al., 1985; Luce, 2005).

The conceptual model of blood transfusion perceptions from Study 1 or the haematology specific models in Study 2, could be used as guides to inform decision-making. The constructs could direct areas for discussion, which may be useful if transfusion is the primary treatment, therefore, lack of 'alternatives' or potential 'burden' could be addressed. New HCPs or haematology patients with less experience of discussion topics may benefit from using a structured set of constructs. HCPs and patients could also be involved in developing the models further into decision-aid style documents, for example, translating the constructs into decision-aid question topics, which may help patients participate in the decision making (Toledo, 2014). Decision aids have been found to be beneficial to improve patient knowledge, reduce decisional conflict and improve patient-HCP communication (Stacey et al., 2017).

Improving decision-making conversations may also benefit HCPs in some haematology units who deal with 'hard to manage' patients, as discussed in Study 3. These are patients who arrive to the units without an appointment with a request to be transfused due to exacerbation of their symptoms. Patients may be informed of how to manage their transfusion scheduling and the clinical importance of this, alongside briefly being advised of the challenges for HCPs to manage capacity demands if patients are non-compliant with their appointments. Further research or clinical audit could be invested into this area to discover the scale of the issue; of patients attending outside of their transfusion appointments. This is important as currently some HCPs in the focus groups reported sending patients to a less accessible site for their transfusion, as a type of sanction, or reluctantly and almost begrudgingly transfusing the patients, which caused upheaval to the transfusion scheduling. It can be argued that neither solutions are sustainable and the service improvement strategy of 'charging patients for appointment non-attendance' potentially controversial.

6.5.2 Patient involvement in their transfusions

As a large amount of time is spent by transfusion patients in the haematology unit, some patients sought and could be supported with additional ideas of how to be more involved in their transfusions. This could be, as concluded for some patients, helping to choose veins during cannulisation, receiving haemoglobin results print outs or holding talks with new student groups of HCPs. All of these measures appear to currently aid patients to feel more involved in their transfusions and unit activities and enhance their feelings of control. There are likely to be numerous additional strategies to facilitate patient involvement and this is something that could be discussed at the unit level between patients, perhaps at informal events within the units (if implemented as a part of service reform) and proposed to HCPs.

Other ideas to promote patient involvement may target patients who feel content perhaps with less ‘social interaction’ in the haematology unit, but who would wish to better spend their time at the unit and reduce any feelings of boredom. Some patients reported lacking interaction due to other patients having different conditions as them or not being as conversational as they would wish to be. Some patients also experience fatigue, illness or upset during appointments, being a barrier for other patients to approach them to socialise. Therefore, ideas could be generated for patients to have access to handheld devices or books and magazines etc., whilst being transfused in the unit, which could be introduced to patients who may require assistance by volunteers; if ‘volunteer support’ was to be implemented during service reform.

6.5.3 Service improvement strategies

There were 17 service improvement strategies generated by HCPs in Study 3 and the need to develop some of these strategies has been discussed in this section. In terms of implications for practice, these strategies could be referred to in ongoing research and developed further into practice. The strategies may be scaled up into interventions and piloted, potentially beginning with the best ranking strategies according to the APEASE (Michie et al., 2014) ratings, for example, strategy five: *encouraging laboratory, HCP and patient role appreciation.* Whilst the interventions are being pilot tested, the actual constraints and enablers to implementation could be explored, which will be real-life vs. hypothetical assumptions to try to resolve.

A medium ranked intervention, with some uncertainty over the APEASE criteria ratings, could also be piloted, such as *resourcing local hubs to provide community transfusions.* Person-based approaches could be used to understand and accommodate the perspectives of those who would use the intervention, in order to maximise intervention acceptability and effectiveness (Yardley et al., 2015). This would involve, for example, in depth qualitative research to inform intervention planning, optimisation and process evaluation, with complementary theory-based activities conducted in parallel (Yardley et al., 2015). Research could be conducted to collect patients' views at different home or community transfusion time-points, for example, during a typical community or home transfusion day. These data could be further utilised to develop counselling or coaching strategies to help patients manage their fears or adjust to transfusion in new environments.

It would be important to explicitly specify theories underpinning any interventions moving forward to shorten the time needed to develop the intervention, optimise the intervention design, identify conditions of context necessary for their success and enhance learning from those efforts (Davidoff et al., 2015). Interventions to offer HCPs communication skills training, for example with cancer patients in outpatient settings, often fail to specify their theoretical underpinning (Cegala et al., 2002; Moore et al., 2018). Theories of individual behaviour, such as motivational theories, like the Theory of Planned Behaviour (TPB) (Ajzen, 1991) may be relevant to use. Applying the TPB would help motivate the target group regarding the desired behaviour, allow them to experience that colleagues and others in their social environment think the change is very important, and provide them with the confidence that change will indeed be feasible and achievable (Grol et al., 2013). Theories directed at organisational change, such as those focusing on the characteristics of organisations may be helpful to bring success to factors that are technical (e.g. new equipment, improved materials) and administrative (e.g. new monitoring systems and guidelines) (Grol et al., 2013).

7 Conclusion and recommendations

In summary, this programme of research aimed to explore patients' and healthcare professionals' (HCPs') perceptions of blood transfusion. There is ongoing research of patients' and HCPs' perceptions of blood transfusion, as identified in Study 1, which included nine new studies published globally since 2015. Perceptions continue to align to the six original conceptual model constructs from Study 1, which broadly correspond to constructs from treatment perceptions frameworks. On investigating haematology perceptions, new themes of blood transfusion perceptions emerged, mostly associated with context, social relationships and burden. In the area of haematology, where patients receive repeated transfusions, some patients and HCPs held negative emotions about the burden of repeated transfusions and many patients developed a number of strategies to deal with such perceptions over time, such as communicating with HCPs and maintaining a hopeful and positive outlook. HCPs, however, deal with a number of service pressures and can attribute some challenges to particular causes, such as poor community links, alongside being able to propose a number of service improvement strategies.

Behaviour change theoretical frameworks were utilised to develop potential intervention options to address constraints and enablers to implementing changes in haematology units. Potential interventions include, for example, enhancing awareness of laboratory procedures, facilitating community transfusions and transfusion unit expansion or reorganisation of existing space. These provide opportunities for patients to be more involved in their transfusions and in many ways to 'take transfusions outside the hospital' by utilising home and community-based transfusions and community-HCP resources. Future research is required to utilise constructs from the conceptual model of blood transfusion perceptions (general and haematology specific models) in larger quantitative studies, for example, to explore the strength of relationships between the constructs and the role of variables, such as patients' illness and quality of life perceptions. Implications for practice have been raised, such as through the pilot testing of intervention options. This would allow for service issues to begin to be remediated and constraints and enablers to implementation to be highlighted and explored in real-time.

7.1 Recommendations for research and practice summary

7.1.1 Research

- Quantitative research using the conceptual model of blood transfusion perceptions
- Exploring haematology patients' perceptions of multiple medicine taking
- Longitudinal research to explore how patients adjust to transfusion
- Investigating HCPs' perceptions alongside service changes

7.1.2 Practice

- Discussing transfusion as a part of patients' treatment decision-making discussions
- Increasing patient involvement in transfusion
- Piloting of intervention options based on the service improvement strategies

8 Dissemination

Studies from this programme of research have been routinely presented at UK and international conferences since the research began in October 2013. Studies 2 and 3 are currently being prepared for submission.

Publications

- Abdul-Aziz, B., Lorencatto, F., Stanworth, S.J., & Francis, J.J. (2018) *Patients' and Healthcare Professionals' perceptions of Blood Transfusion: A Systematic Review.* TRANSFUSION *58(2),* 446-455

Conference presentations

- Volkmer B, Lorencatto F, Stanworth, S.J. Hirani, S.P., & Francis J. (Sep 2019) *BOOST: Building Optimised Outpatient Services in Transfusion: A focus group study informed by patients' perceptions*. Oral presentation at The European Health Psychology Conference, Dubrovnik, Croatia

- Volkmer B, Lorencatto F, Stanworth, S.J., & Francis J. (Jul 2019) *What are the perceptions of patients and healthcare professionals about blood transfusion? An interview study*. Oral presentation at Division of Health Psychology Conference, Manchester, UK

- Abdul-Aziz B, Lorencatto F & Francis J. (April 2018) *Exploring patients' and healthcare professionals' perceptions of blood transfusion in a haematology setting*. Oral presentation at School of Health Sciences Doctoral Research Conference, City, University of London

- Abdul-Aziz B, Lorencatto F & Francis J. (Sep 2015) *Patients' and Healthcare Professionals' perceptions of Blood Transfusion: A Systematic Review.* Division of Health Psychology Conference, London

- Abdul-Aziz B, Lorencatto F & Francis J. (April 2015) *A conceptual model of perceptions about blood transfusion based on a systematic review.* School of Health Sciences Doctoral Research Conference, City University London

- Abdul-Aziz, B., Lorencatto, F., & Francis, J. (Dec 2014) *How do patients and healthcare professionals perceive blood transfusions? A systematic review.* UK Society of Behavioural Medicine Conference, Nottingham, UK

- Abdul-Aziz, B., Lorencatto, F., & Francis, J. (July 2014) *Patients' and Health Care Professionals' Perceptions of Blood Transfusion: A Study Protocol.* Psychology Postgraduate Affairs Group (PSYPAG) Annual Conference, Cardiff Metropolitan University, UK

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10.2 Appendix 2: Systematic review, scoping and full search strategies

Scoping search strategy:

University of York Centre for Reviews and Dissemination and The Cochrane Database of Systematic Reviews

perception* or representation* or belie* AND *blood transfusion*

Systematic review search strategy:

Embase search strategy for Cochrane CENTRAL and Database of Systematic Reviews (CDSR), Database of Abstracts of Reviews of Effects (DARE), MEDLINE, EMBASE	
1	BLOOD TRANSFUSION.ti,ab.
2	(transfus* or pretransfus* or posttransfus* or retransfus* or red cell* or red blood cell* or platelets* or fresh plasma or frozen plasma or FFP or platelet concentrate*).ti.
3	(pretransfus* or posttransfus* or retransfus* or red cell transfusion* or red blood cell transfusion* or platelet transfusion* or plasma transfusion* or fresh plasma or frozen plasma or FFP or platelet concentrate*).ab
4	(blood adj3 (use* or usage* or requir* or administ* or need*)).ti
5	(blood product* or blood component* or blood management or blood replacement)).ti.
6	1 or 2 or 3 or 4 or 5
7	((BLOOD TRANSFUSION or (transfus* or pretransfus* or posttransfus* or retransfus* or red cell* or red blood cell* or platelets* or fresh plasma or frozen plasma or FFP or platelet concentrate*) or (pretransfus* or posttransfus* or retransfus* or red cell transfusion* or red blood cell transfusion* or platelet transfusion* or plasma transfusion* or fresh plasma or frozen plasma or FFP or platelet concentrate*) or (blood adj3 (use* or usage* or requir* or administ* or need*)) or (blood product* or blood component* or blood management or blood replacement)) adj4 (percei* or perception or belie* or attitude* or experience* or perspective* or thought* or knowledge or representation* or view*)).ti,ab.
8	(medic or medics or medical staff or clinician* or doctor* or consultant* or registrar* or healthcare* or health worker* or nurs* or hospital staff or personnel* or clinical staff* or patient* or physician* or recipient* or technician* or practitioner*).ti,ab.

9	7 and 8
10	limit 9 to (human and yr="1984 - *2014*")

EBSCOhost search strategy for PsycINFO, PsyARTICLES	
S1	TI BLOOD TRANSFUSION
S2	AB BLOOD TRANSFUSION
S3	TI transfus* or pretransfus* or posttransfus* or retransfus* or red cell* or red blood cell* or platelets* or fresh plasma or frozen plasma or FFP or platelet concentrate*
S4	AB pretransfus* or posttransfus* or retransfus* or red cell transfusion* or red blood cell transfusion* or platelet transfusion* or plasma transfusion* or fresh plasma or frozen plasma or FFP or platelet concentrate*
S5	TI blood N3 (use* or usage* or requir* or administ* or need*))
S6	TI blood product* or blood component* or blood management or blood replacement)
S7	TI (percei* or perception or belie* or attitude* or experience* or perspective* or thought* or knowledge or representation* or view*)
S8	AB (percei* or perception or belie* or attitude* or experience* or perspective* or thought* or knowledge or representation* or view*)
S9	S1 OR S2 OR S3 OR S4 OR S5 OR S6 N4 (S7 OR S8)
S10	TI (medic or medics or medical staff or clinician* or doctor* or consultant* or registrar* or healthcare* or health worker* or nurs* or hospital staff or personnel* or clinical staff* or patient* or physician* or recipient* or technician* or practitioner*)
S11	AB (medic or medics or medical staff or clinician* or doctor* or consultant* or registrar* or healthcare* or health worker* or nurs* or hospital staff or personnel* or clinical staff* or patient* or physician* or recipient* or technician* or practitioner*)
S12	S10 OR S11
S13	S9 AND S12

(date range and human limiters were applied)

10.3 Appendix 3: Systematic review data extraction form

Data Extraction Form	**Page ref / quote**	**Completed**
Study details 1. Authors: 2. Title: 3. Publication year: 4. Journal reference:		Q1-4:
Study characteristics 5. Stated aims / objectives:		Q5:

6. Study design

Q6:

Interview	☐	Randomized controlled trials	☐
Focus group	☐	Non-randomized / quasi experimental	☐
Case study	☐	Cohort study	☐
Quantitative case report	☐	Retrospective cohort design	☐
Cross sectional survey	☐	Case control	☐
Interview	☐	**Other:**	☐

7. Research setting *Sample identification point*

Q7:

Primary h/c	☐	Workplace	☐
Secondary h/c	☐	Academic	☐
Community h/c	☐	**Other:**	☐

Q8:

Q9:

8. Country 9. N of sites [ ]

List:

Sampling frame & sampling characteristics

10. Patients *included* — *Sample size in analysis:*

Eligibility as reported in Methods

Transfusion recipient	☐	n=
Prepared for a transfusion (>non-transfused, receipt unreported)	☐	n=
Other (e.g. refused transfusion etc...)	☐	n=

Total n (patients) [ ]

Comments:

Q10:

11. HCPs *included* — *Sample size in analysis:*

Eligibility as reported in Methods

Medics	☐	Specialty:	n=
Nurses	☐	Specialty:	n=
Other	☐	Specialty:	n=

Total n (HCPs) [ ]

Comments:

Q11:

12. Other comparison groups / non eligible subjects

Yes	☐	Specify (including n)

Q12:

13. Total N for analysis: [ ]

Q13:

14.Response rate info (or specify if all responded)

Q14:

15. Demographics

For patients and HCPs — Specify:

1) Age	☐
2) Gender	☐

Q15:

3) Religion	☐	
4) Clinical experience (HCPs)	☐	
5) Socio-economic status	☐	
6) Ethnicity	☐	
Other	☐	

16. Additional participant characteristics

For patients and HCPs Specify:

1) Patient's clinical condition	☐	
2) Transfusion indication	☐	
3) Repeat vs. one-off patients?	☐	
Other	☐	

Q16:

Data collection

17. Data collection method & instruments used

Survey	☐	Type:

Items present Yes ☐ Not reported ☐

Number of items _______ (paste)

Pilot tested? Yes ☐ Not reported ☐

Validated scale? Yes ☐ Not reported ☐

Details:

Interview	☐	Type:

Items present Yes ☐ Not reported ☐

Number of items _______ (paste)

Pilot tested? Yes ☐ Not reported ☐

Validated scale? Yes ☐ Not reported ☐

Details:

Other	☐	Type:

Q17:

Items present Yes ☐ Not reported ☐

Number of items _______ (paste)

Pilot tested? Yes ☐ Not reported ☐

Validated scale? Yes ☐ Not reported ☐

Details:

18. Timing of data collection (relative to the transfusion)

Q18:

1) Pre-transfusion	☐
2) During	☐

3) Post transfusion	☐
> 24hrs	☐
> 48hrs	☐
> 1 week	☐

> 1 month	☐
Other:	☐

Designed to capture perceptions at various points	☐
General (not specified)	☐
Not applicable (non-patient cases)	☐

Analysis

19. Blood components assessed

Q19:

Platelets	☐	Substitutes	☐
Red blood cells	☐	Plasma	☐
White blood cells	☐	No distinction	☐
Multi components (comparative)	☐	**Other:**	☐

20. Comparison used (e.g. blood transfusion compared to…)

Q20:

Surgery ☐ Alternatives (e.g. Iron suppl.) ☐ Watch and wait ☐ **Other / None:** ☐		
21. Method of analysis Type: Content ☐ Statistical ☐ Thematic ☐ Other ☐		Q21:
Results 22. Dimensions and themes of perceptions of blood transfusion (as reported and interpreted by the author)		Q22:
23. Content not analysed but presented		Q23:
24. Presence / absence of theory Specify ... or Not reported ☐		Q24:
Conclusions and recommendations 25. Conclusions (i.e. Main conclusions, study limitations, directions for future research & incidental findings).		Q25:
Date complete:	Reviewer 1	Reviewer 2

Quantitative studies checklist criteria (Kmet et al., 2004)	YES	PARTIAL	NO	N/A
	2	1	0	
1 Question / objective sufficiently described?				
2 Study design evident and appropriate?				
3 Method of subject/comparison group selection or source of information/input variables described and appropriate?				
4 Subject (and comparison group, if applicable) characteristics sufficiently described?				
5 If interventional and random allocation was possible, was it described?				
6 If interventional and blinding of investigators was possible, was it reported?				
7 If interventional and blinding of subjects was possible, was it reported?				
8 Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? means of assessment reported?				
9 Sample size appropriate?				
10 Analytic methods described/justified and appropriate?				
11 Some estimate of variance is reported for the main results?				
12 Controlled for confounding?				
13 Results reported in sufficient detail?				
14 Conclusions supported by the results?				
			Score	

Qualitative studies checklist criteria (Kmet et al., 2004)	YES	PARTIAL	NO	N/A
	2	1	0	
1 Question / objective sufficiently described?				
2 Study design evident and appropriate?				
3 Context for the study clear?				
4 Connection to a theoretical framework / wider body of knowledge?				
5 Sampling strategy described, relevant and justified?				
6 Data collection methods clearly described and systematic?				

7 Data analysis clearly described and systematic?				
8 Use of verification procedure(s) to establish credibility?		▨		
9 Conclusions supported by the results?				
10 Reflexivity of the account?				
			Score	

Kmet, L. M., Lee, R. C., & Cook, L. S. (2004). *Standard quality assessment criteria for evaluating primary research papers from a variety of fields*: Alberta Heritage Foundation for Medical Research.

10.4 Appendix 4: Table of theories identified in the systematic review

Theory identified (as cited in paper)	**Included paper in systematic review (author, year)**	**Location in cited review paper**
1. Theoretical Domains Framework (TDF) (Michie et al., 2005)	Francis et al (2009)	Intro, Discussion Informed topic guide: '*interview study using semi-structured one-to-one interviews, based on the theoretical domains*' (p. 629)
	Islam *et al.,* (2012)	Intro, Discussion Informed topic guide: '*interview study using semi-structured one-to-one interviews, based on the TDF*' (p. 3)
2. The social amplification of risk (Pigeon et al., 1992)	Ferguson et al., (2001)	Intro: informed study design (p.130), Discussion
	Lowe et al., (2001)	Intro, Methods: informed study design (p.181)
3. Psychometric model of perceived risk (Slovic, 1987)	Ferguson et al., (2001)	Intro, Discussion Informed measure: '*A series of cognitive factors believe to influence risk perception were also examined'* (p. 131)
	Lowe et al., (2001)	Intro, Methods: informed study design (p.181)
	Lee, Mehta & James (2003)	Intro: informed study design (p. 773), Discussion
4. Risk theory (Beck, 1992; Giddens, 1991)	Moxey et al., (2005)	Discussion
5. The risk compensation theory (Wilde, 1992, 1994)	Amin et al., (2004)	Intro: informed study design (p.3), Discussion
6. Theoretical Model of Willingness to Pay (WTP) for Autologous Blood Donation (ABD) (Eastaugh, 1991)	Lee et al., (1998)	Intro, Discussion Informed measure: '*to determine WTP for ABD in our population, each patient was asked the following questions…*' (p.1166)
7. Prospective reference theory (Smith, 1992; Viscusi, 1989, 1992)	Lee et al., (1998)	Intro, Methods: informed study design (p. 1165), Discussion
8. Common Sense Self-Regulation Model (CS-SRM)(Leventhal et al., 2003)	Khan, Watson & Dombrowski (2012)	Intro, Methods: informed HCP data analysis (p.295) (not extracted), Discussion
9. Beliefs about Surgery (Francis et al., 2009b) based on Beliefs about Medicines Questionnaire (Horne et al., 1999)	Khan, Watson & Dombrowski (2012)	Methods: measure, results, Discussion

10. Availability heuristic (Tversky et al., 1973)	Salem-Schatz, Avorn, & Soumerai (1990)	Intro, Discussion Informed measure: '*to evaluate whether risk estimates were influenced by clinician's experience…*' (p. 478)
11. Typology of five sources of power (French et al., 1959)		Intro, Discussion Informed measure: '*we also assessed the nature of the influence of attending physicians on residents' transfusion decisions*' (p. 478)
12. Parse's theory of human becoming (McEwen et al., 2007)	Adams & Tolich (2011)	Methods: *Study design* (p. 26)

References:

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10.5 Appendix 5: Themes and subthemes identified in Study 1 inductive synthesis

Extracted data	**Stage 1 > 2 of synthesis**	**Stage 3 of synthesis**
Example of extracted content of perceptions reported by authors / participant quotes (*italics*)	**Subtheme labels (total n=30)** Number of studies with data coded into subtheme	**Themes** **(n=6)**
61.5% of 26 post-operative patients viewed transfusion risk as less than surgical risk (p.186)(Court et al., 2011). "*Blood has the potential to kill; therefore, it is not like another medication*" [Nurse] (p.1690)(Heddle et al., 2012).	**Risk compared with other treatments** (n= 2 HCP studies, 2 patient studies)	**Safety / Risk**
For 76 physicians and trainees, blood transfusion was of intermediate ranking [from 10 hazards, i.e. nuclear reactors, caffeine, sharing injection needles, genetically modified foods] in [terms of] dread and severity and knowledge and control' (p.774)(Lee et al., 2003).	**Risk compared with other hazards** (n= 3 HCP studies)	
50% of 482 GPs reported that blood transfusion in the 1990s carried a high hepatitis C infection risk (p.333)(D'Souza et al., 2004). 87% of 38 post-operative patients perceived a low risk of HIV from allogeneic blood transfusion (p.24)(Moxey et al., 2005).	**Risk of contracting an illness from contaminated blood** (n=8 HCP studies, 6 patient studies)	
75 GPs and 135 Anaesthetists rated acute reaction (40 / 33%) as more likely than delayed reaction (1 / 6%) (p.183)(Lowe et al., 2001). 67.5% of 126 patients in Bangladesh rated allergic reaction as most possible from a transfusion (p. 677)(Shah et al., 2012).	**Adverse reaction to a blood transfusion** (n=4 HCP study, 3 patient studies)	
None of n=75 GPs and n=135 Anaesthetists rated there to be a risk of death from blood transfusion (p. 183)(Lowe et al., 2001). 5% of 126 patients in Bangladesh thought that there was a risk of death from a blood transfusion (p. 677)(Shah et al., 2012).	**Risk of death from blood transfusion** (n=2 HCP studies, 1 patient study)	
'The current safety of the blood supply was suggested as a factor decreasing the perceived need for any blood-sparing technology' (p.135)(Graham et al., 2002). 19% of 73 physicians rated blood transfusions as "very often risky" (score of 4) or "always risky" (score of 5) (1304)(Vetter et al., 2014).	**Generalised risk vs. benefit** (n=11 HCP studies, n=1 patient study)	
29% of 38 post-surgical patients voiced concern with receiving allogeneic blood,	**Generalised concern about blood transfusion**	

Extracted data	**Stage 1 > 2 of synthesis**	**Stage 3 of synthesis**
mainly due to concern towards contracting a disease or infection (91%), receiving wrong blood type (18%) or adequacy of screening process (9%)' (p.23)(Moxey et al., 2005). 93% of 45 physicians would be concerned and reduce the level of blood products utilization following a new viral and/or bacterial threat in the future (p.3)(Amin et al., 2004).	(n=3 HCP studies, 5 patient studies)	**Negative emotions**
"*I might be concerned in some situations about watching and waiting*" (p.635)(Francis et al., 2009a). For 38 medics there was some concern about the inappropriate use of PAD blood in that it was 'poorly targeted' (i.e. collected in situations where it was unlikely to be used) and given back to the patient regardless of need (p.234)(Treloar et al., 2001).	**Concern about use of alternatives** (n=3 HCP studies)	
'Apart from the worry of infection from a blood transfusion [for patients], it was not seen to be an uncomfortable procedure. (p.598)(Fitzgerald et al., 1999).	**Worry relating to transfusion (e.g. risks)** (n=3 patient studies)	
'Fifty-four [transfusion] recipients (38%) were apprehensive about receiving transfusions: 34 were afraid of transfusion per se' (p.25)(Luby et al., 2001).	**Apprehension about receiving a transfusion** (n=2 patient studies)	
'*Because nurses and physicians consider transfusion practice important, the risk is enormous and we are so frightened of harming patients that everyone meditates on the problem*' (FG1 Site 5, p.1690)(Heddle et al., 2012). 38.2% of 73 physicians were concerned about medical error adverse events (given wrong blood) (p. 1306)(Vetter et al., 2014).	**Fear of transfusion errors** (n=2 HCP studies)	
'The participants discussed how they got into a "bad mood" (e.g., grumpy, irritable and easily upset) when there was a decrease in the Hb level. Mood, however, improved after blood transfusion' (p.104)(Ryblom et al., 2015)	**Improved mood after blood transfusion** (n=1 patient study)	
'One of the main influences on uptake of PAD [for clinicians, surgeons & anaesthetists] was described as patient demand. Some [clinicians and surgeons] commented that use of cell-salvage is also restricted because it did not reduce the need for allogeneic blood transfusion' (p.232 & 234)(Treloar et al., 2001).	**Factors influencing the use of alternatives (e.g. patient demand, suitability & cost)** (n=5 HCP studies, 3 patient studies)	**Alternatives (e.g. autologous, cell salvage, monitoring)**
I am confident [to watch and wait] provided that the patient is stable and in the ICU "*Depending on the situation, if the patient is stable it's not hard; if they are unstable it is*	**Confidence of using alternatives** (n=2 HCP studies)	

Extracted data	**Stage 1 > 2 of synthesis**	**Stage 3 of synthesis**
very difficult." (ICU 2) (p. 5)(Islam et al., 2012).		
'52% of 77 GPs and 59% of 79 Anaesthetists would choose a blood substitute over donor blood' (p.185)(Lowe et al., 2001). 82% of 38 post-surgical patients preferred to use PAD before surgery, either due to protection from disease (65%), peace of mind (16%), compatibility (19%) or to reduce burden on national blood supply (26%) (p.25)(Moxey et al., 2005).	**Preference for alternatives to allogeneic transfusion** (n=3 HCP studies, 1 patient study)	
'Willingness to pay [for autologous transfusion] increases greatly as dread of getting a transfusion of someone else's blood increases' (p.9)(Lee et al., 1997).	**Willingness to pay for autologous transfusion** (n= 2 patient studies)	
Patients do better in general: *"…there is accumulating data that shows patients do better if you minimize the amount of blood that they get.*" (ICU 1) (p.6)(Islam et al., 2012).	**Advantages / disadvantages of alternatives** (n=3 HCP studies)	
Some hospice patients (n=10) perceived great benefit from transfusion while others did not "*…you know I feel better after, sometimes the next day I feel very lively*" ' (P8, p.174)(Orme et al., 2013).	**Perceived benefit, (e.g. feeling better post transfusion)** (n=3 patient studies)	**Health benefits**
Blood transfusion was perceived to be very beneficial (Dimension 3: Benefit = very important benefit vs. little or no benefit [equal to prescription drugs]) (p.774)(Lee et al., 2003).	**Benefit compared with other treatments** (n= 1 HCP study)	
The participants reported having low "motivation" to do usual activities and felt indifferent to most things before blood transfusion, but after the transfusion, they had the mental and physical strength to perform various daily activities (p103)(Ryblom et al., 2015)	**Experienced benefits (e.g. improved strength, reduced headaches & fatigue)** (n=1 patient study)	
76% of 110 patients understood that their transfusion was necessary, either due to blood loss (mostly patients receiving one-off transfusions) or because of low blood count (mostly reported by regular recipients) (p.169)(Davis et al., 2012).	**Patient understanding of the transfusion's necessity** (n=2 patient studies)	**Necessity**
'Participants noted that blood transfusion was needed when walking up and down stairs became difficult or when their legs felt heavy and hard to move' (p. 103)(Ryblom et al., 2015)	**Need recognised through symptoms** (n=1 patient study)	
Internists, oncologists, geriatricians, family physicians and nurses: 'Indications for	**Clinical indications and contraindications**	

Extracted data	**Stage 1 > 2 of synthesis**	**Stage 3 of synthesis**
transfusion': acute bleeding (89%), functional deterioration (73%), and anaemia resulting from chemo- and/or radiotherapy (62%)' (p.544)(Leibovitz et al., 2004)	(n=5 HCP studies, 1 patient study)	
'Patients were more likely to disagree or strongly disagree [after transfusion counselling] with the fact that doctors relied too much on transfusion' (p. 297)(Khan et al., 2012)	**Transfusion counselling changed patients' perceptions** (n=1 patient study)	**Decision making:**
"*I do not recall talking about the transfusion or completely understanding about it but all I remember thinking is that it was life and death and I just wanted to get better"* (Patient 55; p.169)(Davis et al., 2012).	**Lack of choice or questioning of transfusion decision** (n=2 patient studies)	
Major influences on reducing need for allogeneic blood transfusion [in clinicians] include 'a "*radical change away from considering blood transfusion good for everybod*y"; tolerance of lower haemoglobin levels …' (p.232)(Treloar et al., 2001).	**Transfusion prescription: cost, availability and patient influences** (n= 6 HCP studies)	
'The benefits and risks of blood transfusion were explained regularly by 91% and 87% of the surveyed physicians, respectively' (p.256) (Al-Riyami et al., 2016)	**Patients informed of transfusion benefits, risks and alternatives** (n=1 HCP study)	
'Twenty percent of 126 transfusion recipients stated that they would refuse blood transfusion even if they are in need, because of the risk of requiring an infectious disease' (p.677)(Shah et al., 2012).	**Patient transfusion refusal** (n=1 patient study)	
'It is noteworthy that 92.8% of professionals feel confident to carry out the transfusion process' (p.598)(Tavares et al., 2015)	**Confidence in carrying out transfusion process** (n= 1 HCP study)	

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Treloar, C. J., Hewitson, P. J., Henderson, K. M., Harris, G., Henry, D., & McGrath, K. M. (2001). Factors influencing the uptake of technologies to minimize perioperative allogeneic blood transfusion: An interview study of national and institutional stakeholders. *Internal Medicine Journal, 31*(4), 230-236.

Vetter, T. R., Adhami, L. F., Porterfield, J. R., & Marques, M. B. (2014). Perceptions about blood transfusion: A survey of surgical patients and their anesthesiologists and surgeons. *Anesthesia and Analgesia, 118*(6), 1301-1308.

10.6 Appendix 6: Study 2 ethics approval letter

NHS
Health Research Authority

South Central - Hampshire B Research Ethics Committee
Level 3 Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT
Telephone: 0117 342 1384

13 January 2016

Miss Brittannia Abdul-Aziz
School of Health Sciences, City University London
1 Myddelton Street, Lower Ground floor
London
EC1R 1UW

Dear Miss Abdul-Aziz

Study title: **Exploring perceptions of blood transfusion in haematology**
REC reference: **15/SC/0757**
Protocol number: **PhD/15-16/07**
IRAS project ID: **159772**

Thank you for your letter of 13 January 2016, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the Sub-Committee Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Siobhan Bawn, at: nrescommittee.southcentral-hampshireb@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

1. Please provide a copy of the non-NHS Insurance certificate for this study for information.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final

versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Provisional Indemnity Letter]	1	17 November 2015
Interview schedules or topic guides for participants [Patient interview topic guide]	4	12 November 2015
Interview schedules or topic guides for participants [Health professional interview topic guide]	4	12 November 2015
IRAS Checklist XML [Checklist_13012016]		13 January 2016
Non-validated questionnaire [Patient demographic questionnaire]	6	23 December 2015
Non-validated questionnaire [Health professional demographic questionnaire]	6	23 December 2015
Other [CV Dr Fabiana Lorencatto (academic supervisor)]	1	30 November 2015
Other [IRAS form references list]	1	30 November 2015
Other [Provisional opinion applicant response letter]	1	12 January 2016
Other [Participant information sheet (patients) version with edits]	9	08 January 2016
Other [Participant information sheet (HCPs) version with edits]	8	08 January 2016
Participant consent form [Consent form]	5	17 December 2015
Participant information sheet (PIS) [Participant information sheet (patients)]	9	08 January 2016
Participant information sheet (PIS) [Participant information sheet (HCPs)]	8	08 January 2016
REC Application Form [REC_Form_04122015]		04 December 2015
Referee's report or other scientific critique report [Study scientific review]	1	17 November 2015
Research protocol or project proposal [Study protocol]	1	30 November 2015
Summary CV for Chief Investigator (CI) [CV Brittannia Abdul-Aziz]	1	10 November 2015
Summary CV for supervisor (student research) [CV Prof Jill Francis]	1	27 November 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National

Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

15/SC/0757 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

PP.

Professor Ron King
Chair

Email: nrescommittee.southcentral-hampshireb@nhs.net

Enclosures: *"After ethical review – guidance for researchers" [SL-AR2]*

Copy to: *Alison Welton*
Heather House, Oxford University Hospitals NHS Foundation Trust

10.7 Appendix 7: Data saturation table for haematology interview Study 2

Subthemes present in the final three patient interviews	**N of patients reporting data to these subthemes**	**Participants 12-14 (X indicates participant contributed to this theme)**			**Final patients reporting data to subtheme**
	(interviews 1-11)	**12**	**13**	**14**	
Patients					
Awareness of risk / safety (3 of 5 subthemes)					
Discomfort and illness during or post-transfusion	5	X		X	7
Health risks from high iron levels	2	X	X		4
Potential infection or reaction risk	4			X	5
Health benefits (5 of 6 subthemes)					
Boosting blood levels	6		X	X	8
Keep going with daily life	5	X	X		7
Relief of symptoms such as tiredness	6	X			7
Anticipated benefits	4		X	X	6
Can take time to feel benefit of transfusion	1		X		2

Subthemes present in the final three patient interviews	N of patients reporting data to these subthemes	Participants 12-14 (X indicates participant contributed to this theme)			Final patients reporting data to subtheme
	(interviews 1-11)	12	13	14	
Negative emotions (6 of 8 subthemes)					
No concerns or worries with transfusions	8		X	X	10
Attempts to manage worries and fear	6	X	X	X	9
Gratitude that transfusions possible	3	X		X	5
Relaxed during transfusion appointments	4			X	5
Receiving transfusions unpleasant	3	X			4
Positive emotions of not needing transfusion	1	X			2
Alternatives (1 of 4 subthemes)					
Alternatives considered or already in use	5	X		X	7
Necessity (3 of 5 subthemes)					
Transfusions required as a current and long-term supportive treatment	7	X	X	X	10
Need established by HCPs and clinical indicators	7	X			8
Need for transfusion apparent through symptoms	6	X	X		8

Subthemes present in the final three patient interviews	**N of patients reporting data to these subthemes**	**Participants 12-14 (X indicates participant contributed to this theme)**			**Final patients reporting data to subtheme**
	(interviews 1-11)	**12**	**13**	**14**	
Involvement in decision making (5 of 7 subthemes)					
Willing acceptance of transfusions	6	X			7
Confronted with limited or no choice	5		X		6
Transfusion offered with patient involvement in choice	4	X	X	X	7
Routine 'automatic' treatment	2			X	3
More frequent transfusions would be resisted	1	X			2
Burden (4 of 4 subthemes)					
Transfusion part of routine life	5		X	X	7
Transfusions are inconvenient	4	X			5
Attendance not a great burden	3		X		4
Life restrictions, travel	2	X	X		4
Social connection (3 of 5 subthemes)					
Patient involvement generally positive	4	X		X	6

Subthemes present in the final three patient interviews	N of patients reporting data to these subthemes	Participants 12-14 (X indicates participant contributed to this theme)			Final patients reporting data to subtheme
	(interviews 1-11)	12	13	14	
Lack of interaction or activity during transfusions	4			X	5
Interaction with other patients	4	X	X		6
HCPS					
Awareness of risk / safety (6 of 6 subthemes)					
Risks mitigated by safe transfusion practices	9	X	X	X	12
Risks and benefits established with patients	7	X		X	9
Iron overload considered a key risk	5	X	X		7
Infections, antibodies and reactions risks	6			X	7
Short and long term medical and psychological impact	4	X	X		6
Risk of not providing a transfusion	2	X	X	X	5
Alternatives (4 of 4 subthemes)					
Alternatives considered or already in use	8		X	X	10

Subthemes present in the final three patient interviews	**N of patients reporting data to these subthemes**	**Participants 12-14 (X indicates participant contributed to this theme)**			**Final patients reporting data to subtheme**
	(interviews 1-11)	**12**	**13**	**14**	
No alternatives, transfusion the only option	5		X	X	7
Support for greater consideration and use of alternatives	4		X	X	6
Committed to giving regular transfusions once started	2		X		3
Burden (2 of 2 subthemes)					
Anticipated attendance burden for patients	9	X		X	11
Transfusion has become a part of patient's routine life	5		X	X	7
Health benefits (6 of 6 subthemes)					
Symptom improvement, making patients feel better	9	X	X		11
Supportive care to carry on with normal daily living	9		X		10
Benefit lasts a limited time only	7		X		8
Shared HCP agreement of transfusion benefits	4			X	5

Subthemes present in the final three patient interviews	N of patients reporting data to these subthemes	Participants 12-14 (X indicates participant contributed to this theme)			Final patients reporting data to subtheme
	(interviews 1-11)	12	13	14	
Patient questioned on benefits to provide / continue transfusions	4		X		5
Some risk-benefit for patients questionable	2		X		3
Necessity (4 of 5 subthemes)					
Transfusions support chemotherapy or used to treat anaemia	9	X	X	X	12
Transfusions are vital, aiding survival	8		X	X	10
Transfusions given to protect health	7		X		8
Necessity established using clinical and patient factors	7			X	8
Negative emotions (5 of 7 subthemes)					
Practice concerns and frustrations	9			X	10
Patient anxiety and upset with receiving regular transfusions	8	X	X		10

Subthemes present in the final three patient interviews	N of patients reporting data to these subthemes	Participants 12-14 (X indicates participant contributed to this theme)			Final patients reporting data to subtheme
	(interviews 1-11)	12	13	14	
Concern about downsides of transfusions for patients	8	X	X		10
Patients' unexpressed potential negative emotions	7	X	X		9
Upset in witnessing patients' worsening health or death	2			X	3
Involvement in decision making (6 of 8 subthemes)					
HCPs advocate and involve patients in decisions	10	X	X	X	13
Team decision on transfusion prescription	12			X	13
Patient autonomy in their own transfusion decisions	9	X	X		11
Individual transfusion regime for each patient	8		X	X	10
Transfusions prescribed appropriately using guidelines	5	X	X	X	8
Barriers to discussing transfusion or obtaining consent	3		X	X	5

Subthemes present in the final three patient interviews	**N of patients reporting data to these subthemes**	**Participants 12-14 (X indicates participant contributed to this theme)**			**Final patients reporting data to subtheme**
	(interviews 1-11)	**12**	**13**	**14**	
Organisational factors (5 of 5 subthemes)					
Solutions needed to improve processes and ease capacity strain	6		X		7
Solutions needed to enhance communication	5		X		6
High and costly blood use for hospital	5	X			6
Constraints to greater discussion of patients' views	5		X		6
Complicated management of transfusion slots	4			X	5
Stability and variability of transfusion perceptions (3 of 3 subthemes)					
Views consistent and similar to colleagues	6			X	7
Views broadened through haematology exposure	4	X	X	X	7
Patients' transfusion perceptions variable	1			X	2

10.8 Appendix 8: Study 2 patient recruitment log

Study: Exploring perceptions of blood transfusion in haematology

Instructions for Local Collaborator facilitating patient recruitment:

Please complete this log for all patients receiving blood transfusions between **(date …….)** and **(date …..)**. This is to record if patients are eligible to take part in the study and the outcomes of invitations.

Inclusion: Patients may be included if they meet **all** of the following criteria:

- aged above 18 years old and attending to receive a blood transfusion
- clinically stable (alert & oriented, stable vital signs, without respiratory or cardiac difficulty or uncontrolled pain[1]

Exclusion: Patients should not be invited to participate in the study if they meet **any** of the following criteria:

- aged under 18 years old
- unable to understand spoken English or respond verbally in English
- considered by you, or another staff member not suitable to participate, i.e. patients are unable to provide consent, have a cognitive impairment (such as thinking, knowing and remembering[2]) or participation not advisable per medical advice

I will be on site to provide patients with more information about the study, and to conduct any interviews. I will collect this log from you at approx. (time ….) each day.

---

[1] Adams, K. W., & Tolich, D. (2011). Blood transfusion: the patient's experience. *The American journal of nursing, 111*(9), 24-22.

[2] Alzheimer's Society. (2009) What is mild cognitive impairment (MCI)? Retrieved 3rd Nov 2015; https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=120

Study Patient ID	Meets all inclusion criteria – patient interested in study (please tick)	Telephone number (if patient consents to provide for a call back)	Meets exclusion criteria (please tick)	No time to ask patient about this study	Forgot to ask patient
Example row	Yes: ☐ Today ☐ Call back No: ☐ Patient declined participation (row complete)	*i.e. 020 123 4657*	☐ Below 18 years old ☐ Limited English ☐ Not suitable for this study ☐ Patient has no time	✓	✓
1	Yes: ☐ Today ☐ Call back No: ☐ Patient declined participation (row complete)		☐ Below 18 years old ☐ Limited English ☐ Not suitable for this study ☐ Patient has no time		
2	Yes: ☐ Today ☐ Call back No: ☐ Patient declined participation (row complete)		☐ Below 18 years old ☐ Limited English ☐ Not suitable for this study ☐ Patient has no time		

CITY UNIVERSITY
LONDON

10.9 Appendix 9: Study 2 participant information sheet (patients)

Study title: Exploring perceptions of blood transfusion in haematology

This study is being run by City University London, School of Health Sciences, and invites patients to take part in an interview about their perceptions of blood transfusion. Please read through this information sheet carefully and please ask the researcher if anything is unclear or if more information is needed.

Study information:

Perceptions are thoughts that are used to describe situations or things, such as treatments. Patients' perceptions of their treatment, such as how it may improve one's health, can have an effect on how patients cope with their health condition.

Perceptions may be different across different types of patients receiving transfusions, so it might be helpful to explore what patients think of transfusion in particular patient groups. Specifically, what haematology patients think about transfusions has not been investigated in detail. Therefore, this study has been designed to explore your views of transfusion.

What this study involves:

1. A one-off interview with a researcher lasting between 20 and 40 minutes
2. The completion of a short questionnaire to collect information, such as gender, age, diagnosis, blood products received, and other treatments

The interviews will be audio recorded, and the interview questions have been approved by the South Central Hampshire B Research Ethics Committee and a consultant haematologist.

When and where will I be interviewed?

You have the option to be interviewed today, in the haematology day unit, **before you have your transfusion**, **during your transfusion,** or **after your transfusion**. Alternatively, you can take more time to decide whether or not to take part in this study, and may provide the researcher or the [nurse] who informed you about the study with your telephone number for a call back from the researcher on the next working day (Mondays to Fridays), to see if you would like to be interviewed on the telephone.

Am I eligible to take part?

Patients are eligible to take part if they meet all the options below:

Aged 18 years or older	✓
Attending the haematology unit today for a blood transfusion	✓

What are the benefits or risks of taking part?

It may be helpful or interesting to participate in research about views of blood transfusion. This might also help improve our understanding about what patients think about transfusion. However, it is understood that discussing your transfusions may feel intrusive or make you feel upset. Please be assured that the researcher wishes to make your participation as comfortable as possible, and you can ask to pause, or stop the interview as you wish, or refuse to respond to any questions.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the South Central Hampshire B Research Ethics Committee.

Protecting your information and confidentiality:

The information that you provide will not be shared with your health providers or have any implication on the care that you receive. All information that you provide is confidential and any information revealing your or other peoples' identities or identifiable places will be made anonymous.

All information will be handled securely, stored in locked cabinets and analysed on password-protected computers. Only the researcher's supervisors at the university will have access to your full interviews to help with the analysis of the data. The clinical member of staff who has consented for this study to be conducted at this hospital will only have access to your interview data if you consent for him or her to do so, such as if you wish for anything mentioned in the interview to be passed on to them.

How your information will be used:

Your information will be analysed with other participating patients' information and reported in the researcher's university thesis and in a research paper for a scientific journal. Parts of these results may be used to develop further research projects and direct quotations from the interviews may be used in the results, but all findings will be reported anonymously so that individual patients will not be identifiable. All participants will have the option to receive a copy of the results and research paper.

Do I have to take part?

Participation is voluntary and no one is obliged to take part. Patients wishing, at any point, to discontinue the interview, or for their information to be removed, may withdraw from the study without giving a reason at any time up to the point that the results are reported. This will not affect patients' medical care or legal rights. In the event of a loss of capacity to consent, the research team would retain personal data collected and continue to use it confidentially in connection with the purposes for which consent is being sought. This could include further ethically approved research after the current project has ended.

Complaint procedures:

City University London has established a complaints procedure via the Secretary to Senate Research Ethics Committee. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to the Senate Research Ethics Committee and inform them that the name of the project is 'Exploring perceptions of blood transfusion in haematology'.

You can also write to the Secretary at:
Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London, EC1V 0HB
Email: Anna.Ramberg.1@city.ac.uk

How to contact the researcher:

Until (date ….) I will be in the haematology unit and will be around to discuss the study with you, please come and talk to me.
If you do not see me around, my contact details are below, please leave a voicemail message if your call is forwarded to voicemail.
My name: **Brittannia Abdul-Aziz**
Telephone: **020 7040 5807**
E-mail: **brittannia.abdul-aziz.1@city.ac.uk**

What to do next:

Please read the attached informed consent form. This is required to collect your consent to participate. Please then inform the [nurse] or me that you would like to take part, either today, or for a call back to discuss the study.

CITY UNIVERSITY LONDON

10.10 Appendix 10: Study 2 participant information sheet (HCPs)

Study title: Exploring perceptions of blood transfusion in haematology

This study is being run by City University London, School of Health Sciences, and invites healthcare professionals (HCPs) working in the haematology unit to take part in an interview about their perceptions of blood transfusion. Please read through this information sheet carefully and ask the researcher if anything is unclear or if more information is needed.

Study information:

This interview study informs a broader programme of research investigating perceptions of blood transfusion. Perceptions are thoughts, or beliefs that inform behaviour, and decisions preceding behaviour. As the provider of treatment, HCPs' perceptions are important to explore.

Blood transfusions are frequently delivered in haematology units. However, through a systematic review recently conducted by our research group, perceptions of HCPs working in haematology were not widely researched. In a few cases, haematology HCPs' perceptions were reported together with the perceptions of HCPs working in different clinical areas, which may not adequately reflect perceptions of providing transfusions to patients in haematology.

Therefore, this study aims to find out HCPs' perceptions of blood transfusion to contribute to the blood transfusion treatment perceptions evidence-base.

What this study involves:

1. A one-off interview with a researcher lasting between 20 and 40 minutes

2. The completion of a short demographic questionnaire to record participants' information, such as clinical role, years of clinical and haematology experience

The interviews will be audio recorded, and the interview questions have been developed in consultation with a consultant haematologist and approved by the South Central Hampshire B Research Ethics Committee.

When and where will I be interviewed?

You have the option to be interviewed in person in the haematology unit or elsewhere convenient on hospital site. Alternatively, you can take more time to decide, and can be interviewed also by telephone. Please provide the researcher with your contact details (see ‘*how to contact the researcher’* below).

Am I eligible to take part?

Healthcare professionals are eligible to take part if they meet the criteria below:

Currently working in the haematology unit	✓
Interact with blood transfusion patients, i.e. to discuss or deliver transfusions	✓

What are the benefits or risks of taking part?

It may be interesting to participate in research about healthcare professionals’ perceptions of blood transfusion and also rewarding to contribute to research where a gap in the knowledge base exists. Please be assured that we wish to make your participation as comfortable as possible and you can ask to pause, or stop the interview as you wish, or refuse to respond to any questions at any time.

Who has reviewed this study?

This study has been reviewed and given favourable opinion by the South Central Hampshire B Research Ethics Committee.

Protecting your information and confidentiality:

The information that you provide will be kept confidential. It will not be shared with your patients, line manager or your other colleagues. Any information revealing your or other peoples’ identities or identifiable places will be made anonymous.

All information will be handled securely, stored in locked cabinets and analysed on password protected computers. Only the researcher’s supervisors at the university will have access to your anonymised responses to help with the data analysis. The clinical member of staff who has consented for this study to be conducted at this hospital will only have access to your interview data if you consent for him or her to do so, such as if you wish for anything mentioned in the interview to be passed on to them.

How your information will be used:

Your questionnaire and interview data will be analysed with the data from other HCPs from a few different hospital sites. The results will be reported in the researcher’s PhD thesis and in a peer-reviewed journal publication. Parts of the results may also be used to develop further research projects and direct anonymised quotations may be used. All participants will have the option to receive a copy of the results and journal publication.

Do I have to take part?

Participation is voluntary and no one is obliged to take part. Participants wishing, at any point, to discontinue the interview or for their information to be removed, may withdraw from the study without giving a reason. This will not affect their legal rights. Up until the results are reported in the researcher's thesis and the journal publication, your information can be removed and not used. In the event of a loss of capacity to consent, the research team would retain personal data collected and continue to use it confidentially in connection with the purposes for which consent is being sought. This could include further research after the current project has ended.

Complaint procedures:

City University London has established a complaints procedure via the Secretary to Senate Research Ethics Committee. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to the Senate Research Ethics Committee and inform them that the name of the project is 'Exploring perceptions of blood transfusion in haematology'.

You can also write to the Secretary at:
Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London, EC1V 0HB
Email: Anna.Ramberg.1@city.ac.uk

How to contact the researcher:

Until (date …) I will be in the haematology unit (location ……) and I will be around to discuss the study with you, please feel free to approach me.
If you do not see me around, I am contactable on the following details. If you are telephoning me and I do not answer, please leave a voicemail message.

My name: **Brittannia Abdul-Aziz**
Telephone: **020 7040 5807**
E-mail: **brittannia.abdul-aziz.1@city.ac.uk**

What to do next:

Please read the attached informed consent form. This is required to collect your consent to participate. Please then inform the [nurse] that may have told you about the study, or the researcher, that you are available to be interviewed, or when you may be available.

Site ID Participant consent form

10.11 Appendix 11: Study 2 consent form

Site name: Participant ID for this study:

Title of Project: Exploring perceptions of blood transfusion in haematology

Please initial box

1. I confirm that I have read the Participant Information Sheet dated.................... (Version............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that the researcher wishes to interview me about blood transfusion and that the interviews will be audiotaped and reported in the researchers' university dissertation, a scientific publication, and may be used to inform further ethically approved research. ☐
3. I understand that the researcher wishes to collect information about me on a Questionnaire. ☐
4. I understand that the researcher will make all information that I provide anonymous and will protect my identity from being made public. Direct quotes from the interviews may be used, but these will also be made anonymous. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical care or legal rights being affected. ☐
6. I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998. ☐
7. I understand that relevant sections of my care record and data collected during the study may be looked at by responsible individuals from City University London and [insert NHS Trust name …………………………….] or from regulatory authorities, where it is relevant to their taking part in this research. ☐
8. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Researcher	Date	Signature

10.12 Appendix 12: Study 2 Demographic questionnaire (patients)

Please complete the below questionnaire after the interview. This information is needed to assist with how the results are interpreted.

1. Gender

Male	Female	Prefer not to provide

2. Age

Please write age below	Prefer not to provide

3. Ethnic group or background

	Please tick
White	
English/Welsh/Scottish/Northern Irish/British	
Irish	
Gypsy or Irish Traveller	
Any other White background, please describe	
Mixed/Multiple ethnic groups	
White and Black Caribbean	
White and Black African	
White and Asian	
Any other Mixed/Multiple ethnic background, please describe	
Asian/Asian British	
Indian	
Pakistani	
Bangladeshi	
Chinese	

Any other Asian background, please describe	
Black/African/Caribbean/Black British	
African	
Caribbean	
Any other Black/African/Caribbean background, please describe	
Other ethnic group	
Arab	
Any other ethnic group, please describe	
Prefer not to provide	

4. Religion

	Please tick
No religion	
Christian (including Church of England, Catholic, Protestant and all other Christian denominations)	
Buddhist	
Hindu	
Jewish	
Muslim	
Sikh	
Any other religion, please describe	
Prefer not to provide	

5. Highest level of education completed

	Please tick
No formal education	
GCSE / O'Levels	
A Levels / college certificate	
University level	

Graduate / professional	
Prefer not to provide	

6. Haematological condition(s)

	Please tick all that apply
Myelodysplasia	
Leukaemia	
Myeloma	
Lymphoma (including HD and CLL)	
Acquired haemolytic anaemia	
Inherited anaemia, including Thalassemia	
Myelofibrosis	
Other, please specify	
Don't know	

7. Blood products that you currently receive

	Please tick
Red blood cells	
Platelets	
Other, please specify	
Don't know	

8. Have you ever received other blood products?

	Please tick
Red blood cells	
Platelets	

Other, please specify	
Don’t know	

9. Other treatments or medicines that you receive:

Please list below (e.g. *iron chelation therapy)*	For which health condition?
Don’t know	

Thank you for completing this questionnaire.

As mentioned, this information will be used to describe the patients involved in the study and to assist with how the results are interpreted.

Site ID Participant study ID

10.13 Appendix 13: Study 2 HCP demographic questionnaire

Please complete this brief survey after the interview. This information is needed to assist with the interpretation of the results.

1. Gender

Male	Female
Prefer not to provide	

2. Clinical role

Consultant Haematologist	
Consultant (other), please specify	
Specialist Registrar	
Specialist House Officer /CMT	
Foundation doctor	
Haematology Specialist Nurse	
Nurse (other), please specify	
Transfusion Practitioner	
Other role, please specify	

3. Experience in your clinical role

Please insert months or years below

4. Experience in haematology day units

Please insert months or years below

5. Interaction with transfusion patients in the haematology unit

1	Daily	Weekly	Fortnightly	Monthly	Less often	Other (please specify)
2	To discuss patients' diagnoses and transfusions / treatments		To administer blood products		Both	Other (please specify)

Thank you for completing this questionnaire.

I will be using this information to describe the sample of health professionals that I interviewed, and to assist with the interpretation of the interview results.

10.14 Appendix 14: Coding book for Study 2 haematology interview transcripts

major theme label	**Awareness of risk / safety**		**Health benefits**		**Negative emotions**	
Contrast of theme	**Awareness of risk**	**Safety**	**Health benefit**	**Absence of health benefits**	**Negative emotions**	**Absence of negative emotions**
Definition	Perceptions associated with possible risks associated with blood transfusion.	Reports of safety measures used in blood transfusion to remove risk. Perceptions of transfusion safety.	Mention of the physical or psychological benefits of the transfusion	Perceptions associated with the lack of physical or psychological benefits from transfusion	Any emotions experienced about transfusions that caused (or could cause) distress	That distressing emotions were not (or have the potential) not to be experienced
Rules / guidance	This could also include perceptions of the level of risk and the extent that risks can be avoided etc., Can include experienced negative consequences (difficulties re. transfusion and harm caused to patient) and beliefs about adverse	This could also include that safety issues can be monitored, prevented or removed Safety of transfusion or blood explained to patients or patient	Can include anticipated benefits; discussion of what people thought the benefits should be. Could also be benefits patients / HCPs report of not having transfusions	This includes that health benefits can be inconsistent or take a longer time to be felt	Including (i.e. shock, fear, worry, concern)	This can also include times where negative emotions were first experienced but then the participant overcame these, and that the quote more so relates to an absence of

	effects Risk explained to patients or patient questioning of risk	questioning of safety aspects				negative emotions
Mock examples	"I think one of the big downsides are … being exposed to, erm, so many blood transfusions, they **develop antibodies** , which makes it even more difficult to transfuse"		Relieves tiredness "Makes me feel better again"	"Transfusion sometimes makes a difference, sometimes does not"		"I was worried at first, but now that does not worry me" "I would not be concerned about that"
Major theme label	**Alternatives**		**Involvement in decision making**		**Necessity**	
Contrast of theme	**Alternatives**	**Absence of alternatives**	**Involvement in decision-making**	**Absence of involvement in decision making**	**Necessity**	**Absence of necessity**
Definition	Perceptions related to alternative treatments for patients rather than transfusion	Perceptions of alternatives not being available, suitable or offered	Reasons when to/not to transfuse, how the transfusion decision was made or communicated, and the patients' role in that process. Information about the HCPs' role in the	Perceptions explicitly identifying when a decision did not seem to occur about the transfusion or that patients were not involved in the decision	Perceptions of the need for the transfusion (e.g. in X circumstance) Perceptions about communication of	Beliefs against transfusions being necessary Doubts about whether transfusions are

			decision making process		the need or patients questioning the necessity of their transfusions.	needed to protect present/future health
Rules / guidance	This includes discussion of what alternative options could be or that watching and waiting or not giving a transfusion may be the alternative Features of the decision making about alternatives specifically	This may include that alternatives were considered but are no longer feasible	Not including procedural actions "I order it", "send it off", "calling lab". Can include perceptions of the use of blood (e.g. that it is prescribed appropriately)		How the need for the transfusion is established (e.g. by clinical tests) Vital essential need for the blood	Perceptions that transfusions may not be needed in the future for the patient or doubt of whether the transfusion is needed currently
Mock examples	"alternatives are considered when making the decision"		"I felt I had no choice, I just listened to the doctor who made the decision"	"it happened so quick, next thing I knew I was having the transfusion, there was no decision"	"It was absolutely essential for me to have transfusions"	"Transfusions are not the only thing that may help patients with X condition"

10.15 Appendix 15: Reasons for patient exclusion from study 2

Excluded patients site 1 (n= 16)	n of participants
Reasons:	
Advised by screening personnel not to invite	4
On patient list but transferred to ward for transfusion or since deceased	3
Transfusion for non-haematology but oncology patient	2
Refused to participate	2
Non-English language	1
Cognitive impairment (dementia)	1
Already screened or interviewed (e.g. patient returning for a weekly transfusion)	1
Researcher conducting another interview / busy at the time	1
Transfusion cancelled	1
Excluded patients site 2 (n=29)	n of participants
Reasons:	
Non-English language	5
Already screened or interviewed (e.g. patient returning for a weekly transfusion)	5
No transfusion needed on the day, patient sent home	4
Researcher conducting another interview / busy at the time	3
Not approached by researcher - patient in distress	3
Refused to participate	2
Transfusion cancelled	2
Uncertainty if the participant would receive a blood transfusion	2
Too ill to be invited to the study	1
Hearing impairment	1
Patient needs more time to think about participating	1

10.16 Appendix 16: Study 3 ethics approval letter

School of Health Sciences

Research Office
Northampton Square
London EC1V 0HB

Tel: +44 (0) 20 7040 5704

www.city.ac.uk

Ref: PhD/18-19/02

28 August 2018

Dear Brittannia, Jill and Fabiana

Re: BOOST: Building Optimised Outpatient Services in Transfusion: *A panel discussion informed by patients' perceptions*

Thank you for forwarding amendments and clarifications regarding your project. These have now been reviewed **and approved** by the Chair of the School Research Ethics Committee.

Please find attached, details of the full indemnity cover for your study.

Under the School Research Governance guidelines you are requested to contact myself once the project has been completed, and may be asked to complete a brief progress report six months after registering the project with the School.

If you have any queries please do not hesitate to contact me as below.

Yours sincerely

Alison Welton
Research Governance Officer

a.welton@city.ac.uk
020 7040 5704

School of Health Sciences

10.17 Appendix 17: Study 3 participant information sheet

Title of study: **BOOST: Building Optimised Outpatient Services in Transfusion: *A panel discussion informed by patients' perceptions***

We would like to invite you to take part in a research study being conducted by a PhD student researcher from City, University of London as a part of a doctoral degree in Health Psychology. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Interviews have been conducted at two UK haematology units in 2016, which explored patients' and healthcare professionals' (HCPs') perceptions of blood transfusions provided for patients with haematological disorders. This research found that whilst patients held many beliefs about the necessity and benefit of transfusion, there were areas where patients may require more support. This may be for new patients receiving repeated transfusions or for patients holding concerns about the transfusion procedure or the time spent having transfusions.

This research study invites approximately 20 transfusion healthcare professionals to take part in a focus group meeting to consider the interview findings. You will have opportunity to inform us of any possible future changes to practice that may benefit transfusion patients' experiences, or the delivery of blood transfusions to this patient population in general.

What this study involves

- A one-off audio-recorded focus group with up to ten healthcare professionals attending the Regional Transfusion Meetings on 11th September / 7th November 2018.

- The focus group will last for one hour and you will be provided with the opportunity to complete a follow-on questionnaire to provide your views on perceptions that we may not have time to discuss in the meeting.

The PhD researcher, Brittannia Volkmer will facilitate the focus group, co-facilitated by Dr Simon Stanworth, Consultant Haematologist, NHS Blood and Transplant/ Oxford University Hospitals NHS Foundation Trust.

At the start of the focus group the arrangements for the meeting will be introduced and you will have the opportunity to introduce yourself to the other members. Background to the study will be provided and the patients' perceptions for discussion will be verbally introduced and circulated on laminated card. You will be part of a panel (group) discussion about each category of perception presented and may contribute as much or as little as you wish to, allowing time for each member to share their views. After 50 minutes, if not before, the facilitator will initiate a closing discussion.

This is where you may wish to collaboratively decide upon any priority changes to implement, and how this might occur. Both the facilitator and co-facilitator will take some notes during the meeting of key points arising from the discussion to provide a summary to help with the closing discussion.

There will be some light refreshments, such as drinking water and biscuits available in the meeting.

As there is limited time to discuss all of the perceptions from the previous interview study, you will be provided with a follow-on questionnaire at the end of the meeting to provide your views on six separate themes of perceptions. This will be to take away, for you to voluntarily complete and return to the researcher in a self-addressed envelope provided or by e-mail.

Why have I been invited?
You have been invited to take part because you have been identified as a transfusion health professional (e.g. consultant, registrar, doctor, nurse, transfusion practitioner).

What are the benefits or risks of taking part?
This is a low-risk study. Benefits include being able to learn more about the perceptions of haematology patients who were interviewed. Your involvement is essential to shape any required practice changes for the patient's benefit and to aid improvement to haematology unit service delivery.
An abstract of the findings of this meeting will be submitted for presentation to the National Transfusion Meeting. You will not be personally named on this abstract, to protect your identity, but it will be stated that 'this work has been developed in collaboration with a panel from the South Central Regional transfusion team'.

Do I have to take part?
Your participation is voluntary and you are not obliged to take part. If you wish to withdraw you may do so and your information will be removed without you having to provide a reason. You may also briefly step out of the meeting or leave entirely during the course of the meeting if you need to do so, without having to provide the facilitator with a reason.

Protecting your information and confidentiality
As this study involves a focus group, the researcher wishes to provide as much confidentiality as possible to all participants. Therefore, by taking part you agree not to disclose personal views that you heard in the focus group once it has finished. Please also act with discretion not to reveal the names of other participants in the group with you. Any information revealing your or other people's identities or identifiable places on the audio recording will be made anonymous during transcription, which may be completed by a specialist transcription service.
All information will be handled securely, stored in locked cabinets and analysed on password protected computers. Data will be stored at City,

University of London for 10 years and will then be destroyed. The researchers' academic supervisors at City, University of London, will have access to anonymised responses to help with data analysis.

How your information will be used

The data collected will be reported in the researcher's PhD thesis, and submitted for presentation to the National Transfusion Meeting (NTA). A peer-reviewed journal publication will also be prepared by the researcher and submitted for publication. Parts of the results may also be used to develop further research projects and direct anonymised quotations from the focus group may be used. All participants will have the option to receive a copy of the results, the NTA meeting abstract and journal publication outputs.

City, University of London is the data controller for the personal data collected for this research project. Your personal data will be processed for the purposes outlined in this notice. The legal basis for processing your personal data will be that this research is a task in the public interest, that is City, University of London considers the lawful basis for processing personal data to fall under Article 6(1)(e) of GDPR (public task) as the processing of research participant data is necessary for learning and teaching purposes and all research with human participants by staff and students has to be scrutinised and approved by one of City's Research Ethics Committees.

Complaint procedures

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: **BOOST: Building Optimised Outpatient Services in Transfusion: *A panel discussion informed by patients' perceptions***

You could also write to the Secretary at:

Dr Anna Ramberg
Research Governance & Integrity Manager
Research & Enterprise
City, University of London
Northampton Square
London
EC1V 0HB

Email: Anna.Ramberg.1@city.ac.uk

City holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Raising concerns about how your personal data will be used after participation

In the first instance you should raise any concerns with the research team, but if you are dissatisfied with the response, you may contact the Information Compliance Team at dataprotection@city.ac.uk or phone 0207 040 4000, who will liaise with City's Data Protection Officer Dr William Jordan to answer your query.

If you are dissatisfied with City's response you may also complain to the Information Commissioner's Office at www.ico.org.uk

Who has reviewed the study?
This study has been approved by City, University of London School of Health Sciences Research Ethics Committee.

Further information and contact details
To take part in this study please e-mail the researcher on the below e-mail with your interest and return a signed copy of the consent form. Please also e-mail the researcher if you would like to find out more information about the study.

Name of Primary researcher: **Brittannia Volkmer**
E-mail: **brittannia.volkmer@city.ac.uk**

Clinical Collaborator: Dr Simon Stanworth
Academic Supervisors: Professor Jill Francis, City, University of London and Dr Fabiana Lorencatto, University College London

Thank you for taking the time to read this information sheet

10.18 Appendix 18: Study 3 recruitment flyer

CITY
UNIVERSITY OF LONDON
EST 1894

Participate in BOOST

Building Optimised Outpatient Services in Transfusion

A panel discussion informed by patients' perceptions

Do haematology outpatients require more support to cope with repeated blood transfusions?

Academic excellence for business and the professions

BOOST: Building Optimised Outpatient Services in Transfusion

A panel discussion informed by patients' perceptions

Regional Transfusion meeting
7th November 2018

Brittannia Volkmer

www.city.ac.uk

BOOST involves a 45-minute audio-recorded focus group meeting to share views on haematology patients' perceptions of blood transfusion

Your involvement is essential to shape any required practice changes for haematology delivered transfusions.

Become a panel member to contribute to an abstract of this study to be submitted for presentation at the National Transfusion Meeting.

Focus groups will be running on 7th November at Transfusion Bites at

11:15 am and 1.30pm

(main meeting room)

For more information please speak to the researcher, Brittannia who has handed you the flyer, and request a Participant Information Sheet. Please sign up or attend shortly before the start time.

Researcher contact details: Brittannia Volkmer, brittannia.volkmer@city.ac.uk City University London, School of Health Sciences, Northampton Square, London EC1V0HB

This study (PhD/18-19/02) has been reviewed and ethically approved by: City University of London, School of Health Sciences, Research Ethics Committee.

10.19 Appendix 19: Study 3 consent form

Participant ID:

Title of Project: **BOOST: Building Optimised Outpatient Services in Transfusion: *A panel discussion informed by patients' perceptions***

Name of Researcher: Ms Brittannia Volkmer, MSc

Please initial each box

1. I confirm that I have read the Participant Information Sheet dated 3rd August 2018 (Version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that the researcher wishes for me to take part in an audio recorded focus group with other health professionals about my views of patients' blood transfusion perceptions and possible recommendations to change practice. I understand that a follow-on questionnaire will be provided, which I have the option to complete. ☐

3. This information will be held by City as data controller and processed for the following purposes: to report in the researchers' university thesis, a conference presentation and a journal publication and lawful basis for processing under General Data Protection Regulation (GDPR) for personal data. I agree to the use of anonymised quotes in these reports. The findings and direct anonymised quotes may also be used to inform further ethically approved research. ☐

4. I understand that any information I provide aims to be treated confidentially within the focus group. No information that could lead to the identification of any individual will be disclosed in any reports on the project. Identifiable audio recordings may be shared with a transcription service that abides by GDPR. ☐

5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason or being penalised or disadvantaged in any way. ☐

6. The information I provide will be held by City as data controller and I agree to City recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on City complying with its duties and obligations under the GDPR. ☐

7. I agree to the arrangements for data storage, archiving, sharing. ☐

8. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

10.20 Appendix 20 BOOST Study 3 PowerPoint slides

Academic excellence for
business and the professions

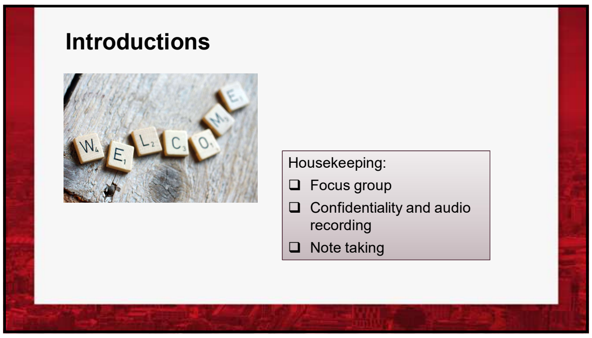
BOOST: Building Optimised Outpatient Services in Transfusion

A panel discussion informed by patients' perceptions

Regional Transfusion meeting
7th November 2018

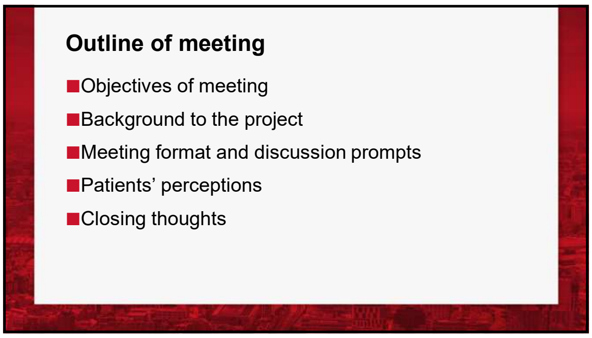
Brittannia Volkmer

www.city.ac.uk



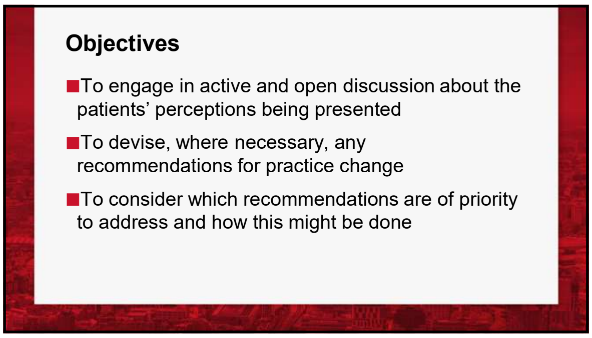
Introductions

Housekeeping:
- ☐ Focus group
- ☐ Confidentiality and audio recording
- ☐ Note taking



Outline of meeting

- Objectives of meeting
- Background to the project
- Meeting format and discussion prompts
- Patients' perceptions
- Closing thoughts



Objectives

- To engage in active and open discussion about the patients' perceptions being presented
- To devise, where necessary, any recommendations for practice change
- To consider which recommendations are of priority to address and how this might be done

Systematic review

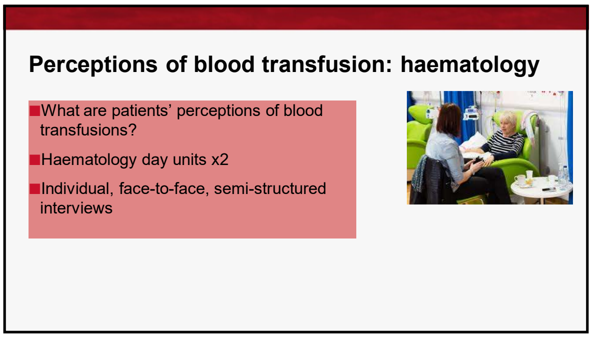
- N=32 studies of adult patients' and healthcare professionals' perceptions of blood transfusion
- Haematology patients under-represented

TRANSFUSION MEDICINE

Patients' and health care professionals' perceptions of blood transfusion: a systematic review

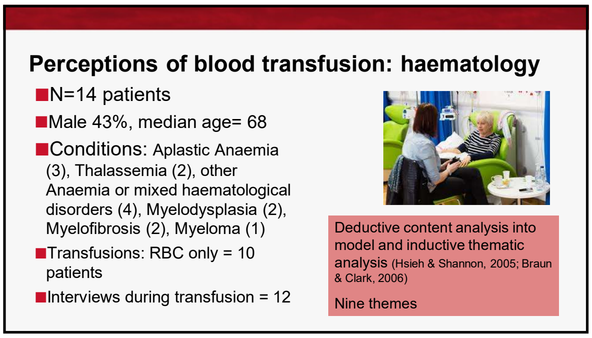
Brittannia Abdul-Aziz,[1] Fabiana Lorencatto,[1] Simon J. Stanworth,[2] and Jill J. Francis[1]

Abdul-Aziz, Lorencatto, Stanworth & Francis (2018)



Perceptions of blood transfusion: haematology

- What are patients' perceptions of blood transfusions?
- Haematology day units x2
- Individual, face-to-face, semi-structured interviews

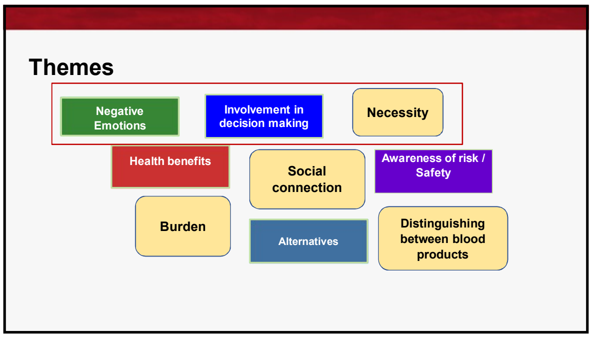


Perceptions of blood transfusion: haematology

- N=14 patients
- Male 43%, median age= 68
- Conditions: Aplastic Anaemia (3), Thalassemia (2), other Anaemia or mixed haematological disorders (4), Myelodysplasia (2), Myelofibrosis (2), Myeloma (1)
- Transfusions: RBC only = 10 patients
- Interviews during transfusion = 12

Deductive content analysis into model and inductive thematic analysis (Hsieh & Shannon, 2005; Braun & Clark, 2006)

Nine themes



Themes

Negative Emotions

Involvement in decision making

Necessity

Health benefits

Social connection

Awareness of risk / Safety

Burden

Alternatives

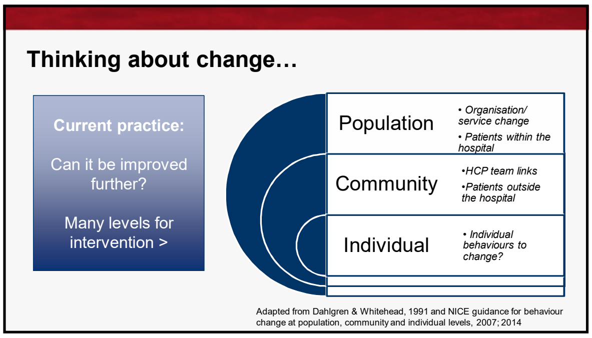
Distinguishing between blood products

Today's meeting

- Creative process informed by Experienced-based design principles (Brocklehurst et al., 2018)
  - 'Involves service users and professionals working together over a period and throughout the change process as the co-designers of a service' (Bate & Robert, 2006)
  - This meeting – share patients' priority perceptions of top three themes, using laminated cards, for discussion
  - I will initiate breaks to summarise discussion
  - Wrap up discussion at end

Today's meeting

- Discussion prompts:
  - Are these perceptions that you also hear about from patients?
  - Do you think that patients might need more support to deal with these perceptions and experiences?
  - Is there something that could be done within the health service to improve patients' experiences?
  - Would there be any constraints to this?
  - Are there things that may help change to occur?



Thinking about change…

Current practice:

Can it be improved further?

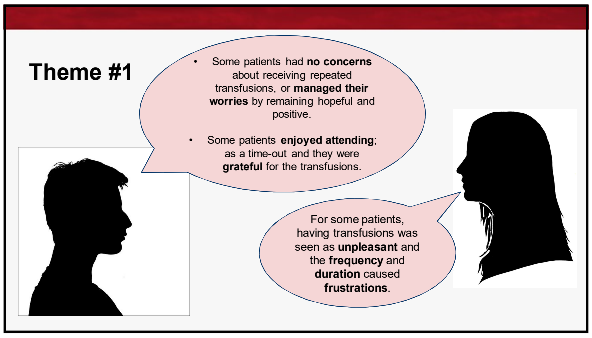
Many levels for intervention >

Population
- *Organisation/ service change*
- *Patients within the hospital*

Community
- *HCP team links*
- *Patients outside the hospital*

Individual
- *Individual behaviours to change?*

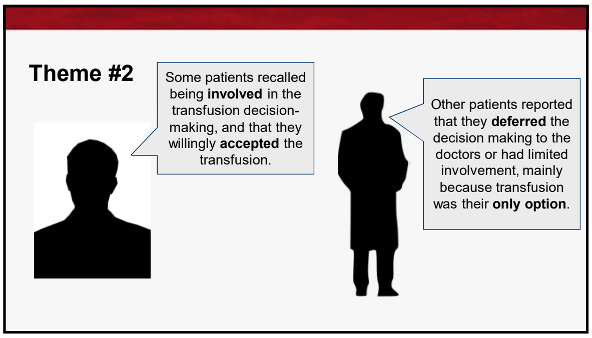
Adapted from Dahlgren & Whitehead, 1991 and NICE guidance for behaviour change at population, community and individual levels, 2007; 2014



Theme #1

- Some patients had **no concerns** about receiving repeated transfusions, or **managed their worries** by remaining hopeful and positive.
- Some patients **enjoyed attending**; as a time-out and they were **grateful** for the transfusions.

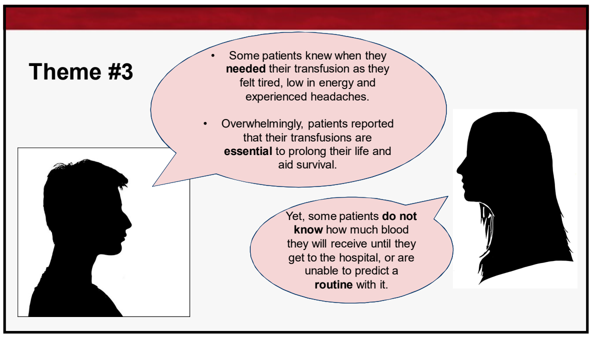
For some patients, having transfusions was seen as **unpleasant** and the **frequency** and **duration** caused **frustrations**.



Theme #2

Some patients recalled being **involved** in the transfusion decision-making, and that they willingly **accepted** the transfusion.

Other patients reported that they **deferred** the decision making to the doctors or had limited involvement, mainly because transfusion was their **only option**.



Theme #3

- Some patients knew when they **needed** their transfusion as they felt tired, low in energy and experienced headaches.

- Overwhelmingly, patients reported that their transfusions are **essential** to prolong their life and aid survival.

Yet, some patients **do not know** how much blood they will receive until they get to the hospital, or are unable to predict a **routine** with it.

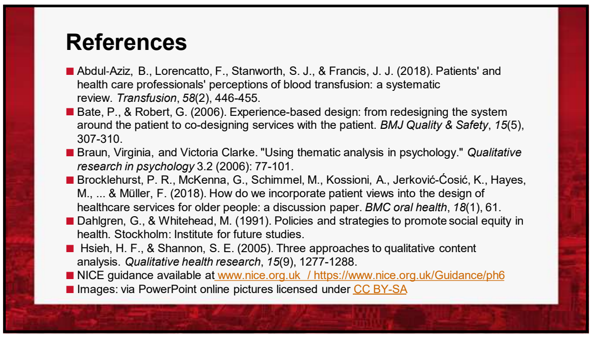
Closing summary

- Key patient needs and proposed refinements were …
- Open discussion: priorities to implement first and thoughts about achieving this
- Next steps: process of change
- Follow on questionnaire

Thank you for taking part

Acknowledgements

- Organisers and participants from Regional Transfusion Committee
- Patient Representative
- Academic supervisors and Implementation Research Group at City, University of London, School of Health Sciences



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- NICE guidance available at www.nice.org.uk / https://www.nice.org.uk/Guidance/ph6
- Images: via PowerPoint online pictures licensed under CC BY-SA

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United Kingdom

T: +44 (0)20 7040 5060
E: brittannia.volkmer@city.ac.uk
www.city.ac.uk/health

Meeting date:

10.21 Appendix 21: Study 3 participant ‘follow on’ questionnaire

Title of study: **BOOST: Building Optimised Outpatient Services in Transfusion: *A panel discussion informed by patients’ perceptions***

This questionnaire is a follow up to the focus group that you attended. Please insert your comments to each theme and question below and return the questionnaire to the researcher in the envelope provided or e-mail a scanned copy to brittannia.volkmer@city.ac.uk Please elaborate as much as you would like to, extra space has been provided at the end of the questionnaire.

Theme 4:

Most patients reported that their transfusions enabled them to keep going with their daily lives, reduced symptoms and boosted their blood levels. Transfusions were seen as helpful for patients to manage their conditions.

One patient with CLL and Aplastic anaemia and another with Myelodysplasia, reported feeling drained sometimes after the transfusion. Or felt the same after the transfusion as they did before.

1. Are these perceptions that you also hear about from patients?

2. Do you think that patients might need more support to deal with these perceptions and experiences?

3. Is there something that could be done within the health service to improve patients’ experiences?

4. Would there be any constraints to this?

5. Are there things that may help change to occur?

[ongoing themes listed but presented in the same format with the same questions and boxed as above]:

Theme 5:

Some patients interacted with other patients in the unit and were well involved in their transfusions, such as through their contact with staff able to answer their questions.

Other patients reported limited interaction with patients who had different health conditions. Some patients did not wish to interact with other patients when attending, for example, to respect their privacy).

Theme 6:

Many patients are aware of the risks involved with receiving their transfusions, mainly of high iron levels and what impact this can have on their body.

Other patients focussed more on pain that they get from having the cannula inserted, and one patient mentioned about a chest tightening sensation towards the end of the transfusion.

Theme 7:

Some patients receiving repeated transfusions felt that transfusions become a part of their routine life, and that regular attendance is not a great burden to them.

For other patients, repeated transfusions were seen as inconvenient, meaning lengthy appointments, frequent trips to the hospital, and restriction to their other activities, such as travelling.

Theme 8:

Some patients talked about medications they are taking (e.g. Cyclosporine), feeling that this helped to keep their blood count up or reduce the number of transfusions needed. Other patients felt that their body could correct depleted cells, reducing how often they would need transfusions.

Otherwise, patients acknowledged that there were no alternative treatments that were feasible (e.g. bone marrow or stem cell transplant) and some treatments had been unsuccessful for them (e.g. ATG immunoglobulin).

Theme 9:

Around a quarter of patients interviewed commented specifically on platelets. For example, they did not understand what platelets did but preferred them because they infuse quicker or the effect of a boosted platelet count was experienced more quickly or intensively.

Additional space for responses (please include theme/question number if relevant):

Thank you for taking the time to complete this questionnaire. Please return it to the researcher using the envelope provided or e-mail a scanned copy to brittannia.volkmer@city.ac.uk

10.22 Appendix 22: Reflective diary from study 3 focus groups

Focus group 1

The six participants who took part in focus group 1 were comprised of a range of clinical specialities, who interacted well with each other, putting the researcher at ease for her first focus group. The participants held conforming opinions with each other, which showed a good level of ‘consensus’, but this often made it challenging to break into the group discussion as many constraints to change and service difficulties were raised, recycled and contagiously discussed throughout the group. Some participants in focus group 1 were also cut-off during their points, had their ideas over-ridden or had their sentences finished off by one or two more prominent group members. This could have led to missed-opportunities for service proposals to be expressed and on reflection, this group may have worked better as a smaller group, giving more members the opportunity to develop their ideas. Overall, I felt that this group was very dynamic and accepting of the researcher and her aims for the focus group. The group and discussion outcomes provided a very positive start for the BOOST data collection.

Focus group 2

This was the largest focus group conducted during a morning break in the ‘Transfusion Bites’ day, where time was limited, so the researcher felt more hurried to explain the study and begin to introduce the themes. The group was comprised of a diverse range of specialities and HCPs with experience in different settings, which brought diversity to the group and it is likely that group members benefitted from hearing real-life scenarios and experiences from other members. There was an improved sense of group equality, compared to focus group 1 and active listening and respect for each other’s’ opinions, and the researcher felt that her position and themes that she was presenting were accepted. There were often silent members of the group, so the researcher had to work harder to initiate discussion, however. Compared to the two other focus groups, the researcher felt that members of this group were more likely to have left the focus group feeling unsure if their contribution was sufficient or whether the aims of the session have been achieved. The researcher sensed this towards the end of the focus group, which was time restricted before a follow-on session for the HCPs, so reassured them that their views were important and valuable for the study.

Focus group 3

This was an all-female participant focus group that immediately felt very comfortable, less formal and close-knit compared to the other two groups. The focus group took place towards the latter end of the lunch break, so some participants had food or drink with them, and as a group we sat huddled around a smaller set of chairs with less physical boundaries. As for the previous groups, in the first focus group the researcher stood, whilst the participants sat in a classroom-style set up, and for the second group, the participants sat spaced out across two low tables. In this third group, there were some participants with the same role, so the power balance was more equal and there was a sense that participants felt comfortable expressing their opinions and although time was limited it was felt that depth and ‘saturation’ of ideas was achieved and that the focus group had a more natural beginning, middle and end. In general, it was felt that group members understood each other’s positions well, with interest sparked when hearing real-life accounts and compassionate listening was displayed. There was an overwhelming greater sense of positivity and an attitude of change at this focus group, and equally somewhat in focus group 2. Many participants commented that they left the group feeling re-energised to interact with their patients with a greater level of consideration and empathy.