

ORIGINAL ARTICLE *Clinical haemophilia*

# The development of a patient partnership programme and its impact on quality improvements in a comprehensive haemophilia care service

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**Summary.** It has long been advocated that patient input in service quality development is essential. We have developed a model of quality evaluation and improvement within a comprehensive haemophilia service, and describe the issues and improvements that resulted from the process. The project utilized an action research methodology. Seven patients were recruited from the haemophilia service for the initial focus groups. The main themes initially explored were as follows: patient experience of the outpatient, inpatient and weekend services and provision of information. The focus group data were analysed using basic content analysis. The main themes the initial focus group identified were the need to optimize the annual review, emergency care and inpatient facilities. Following this, the haemophilia care team worked on improving these issues. At the

second focus group the patients contributed at a higher level – patient participation. Patients assisted in addressing outstanding issues such as ID alert card content and the algorithm of care for emergency services. Finally, a patient panel was developed and the relationship became one of direct negotiation and partnership with the haemophilia team to address issues within the service. The expectations and needs of patients attending the haemophilia comprehensive care service are complex. The process of including patients as partners at the highest level of patient involvement evolved and proved an effective method of service evaluation and development, facilitating lateral decision-making, not only improving care directly, but also improving the user experience.

**Keywords:** haemophilia, patient involvement, quality

## Introduction

Quality, quality improvement and initiatives in healthcare are about meeting the needs of patients and other service users and continuously trying to improve on the service being offered [1]. Patient involvement is about healthcare service providers and consumers becoming aware of each other's perspectives; it is about good working relationships in which issues can be resolved, and it is about sharing problems and finding appropriate solutions [1]. All stakeholders including service users have a role to play in identifying where improvements are needed and how these might be achieved.

The importance of patient involvement in the planning and implementation of healthcare has long been recognized. The World Health Organization (WHO) has set out a vision for healthcare, which states unequivocally that people have the right and duty to participate individually and collectively in the planning and implementation of their health care [2]. This vision was subsequently advocated and applied within National Health Strategy objectives [3]. Patient involvement is a growing trend across all healthcare disciplines at both national and international level. Evidence suggests that when used in the planning, delivery and evaluation of health care it can lead to better health outcomes, better quality of life and greater acceptance of the need for reform [1]. If managed properly, patient involvement can be a powerful tool for change, but if managed badly, it can erode patient confidence and trust in the service and be seen as nothing but a tick box exercise for internal purposes.

Throughout the literature patient involvement is used to refer to 'patient participation', 'patient collaboration',

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'patient partnership' and 'person centred care' [4–6]. However, in a concept analysis of patient participation, Cahill points to the existence of a hierarchical relationship [4]. He suggests that these terms are not synonymous and should not be used interchangeably as they represent different levels in the hierarchy: the *lowest level* being patient involvement, the *intermediate level* patient participation, and the *highest level* patient partnership. Patient involvement, the lowest level, is generally concerned with decisions about the timing of visits and care relating to activities of living, rather than decisions related to technical care [7]. Patient participation, the intermediate level, occurs when patient's knowledge and needs are recognized by staff, and information to patients is provided on the basis of their individual needs [8]. Partnership, the highest level of the hierarchical relationship, involves a two-way relationship, power sharing and negotiation, and takes the values and beliefs of the patient into account when making decisions about their health care [9].

Some factors have been identified as preventing involvement, participation or partnerships and include; emphasis on task oriented care, over-protection, inability to relinquish power, and poor communication on the part of health care professionals [5]. Patients, on the other hand, often mistrust why they are being invited to participate, and may consider that their representation is merely a token gesture.

Nonetheless, many authors refer to how involvement, participation and partnership between health-care providers and patients can be developed over time and can ensure patients have a greater voice in their care and ultimately empower them in self-management [4,6,10]. The importance of patient involvement in haemophilia care as long been advocated. As part of the criteria for being a comprehensive care centre, haemophilia services worldwide are expected to demonstrate how their services and their patients' experiences have improved as a result of involvement with service users [11].

However, although there is a wealth of information on the benefits of patient involvement at any level, there is a scarcity of literature on exactly how to involve the patient and how patient involvement has been used to improve service quality.

### *Purpose of this project*

The purpose of this article/project is to describe the development of a patient partnership programme and its impact on quality improvements in a comprehensive haemophilia care service. The objectives are listed below:

- Describe the evolution of a patient involvement programme through the hierarchy from patient involvement through patient participation to patient partnership.

- Identify and address practice issues in the haemophilia service.

## **Materials and methods**

The project was carried out in the National Centre for Hereditary Coagulations Disorders (NCHCD), Dublin, Ireland. The centre is a designated comprehensive care centre for adults with haemophilia and is the repository of the national registry. The centre is multidisciplinary and offers medical, nursing and dental care, laboratory tests, physiotherapy, social worker and psychological support. All haemophilia patients attend at least an annual review, where they can access the above services. The centre and hospital collaborate to provide a 24 h walk-in service for patients with an acute bleed and a nurse telephone consultation service. The haemophilia multidisciplinary team set up a patient involvement programme to monitor and improve these services.

### *Action model*

An action research model was selected for this project as it was compatible with the quality improvement model [12]. It allowed for practical aims of service development to be identified, action facilitated and change implemented. This was then followed by evaluation and initiation of the next action cycle.

### *Participants*

The participants consisted of all patients aged 18 or over with bleeding and thrombotic disorders registered on the centre database ( $n = 3109$ ). To address the needs of the most frequent service users, a purposeful sub-population of patients with severe haemophilia who attended the clinic from 2006 to 2008 ( $n = 67$ ) was targeted for this project. A letter of invitation outlining the patient involvement programme objectives and format was sent to the participants. Seven patients consented to participate in the initial focus group. The same participants were invited to participate in the second focus group of which six agreed and consented. The final focus group, which was conducted at a patient partnership level, had members of the patient partnership panel as participants. Two members of this group had also been participants in the previous two focus groups. The complete membership of this panel is described in the results.

### *Evaluation*

Data were collected using three focus groups in September 2008, September 2009 and September 2011. Focus groups provided a method of discovering patients' experiences in a non-threatening environment,

and the opportunity for an in depth exploration of the identified topics. They were facilitated by experienced, independent facilitators who were senior nurse managers not involved in the direct care of the patients. This increased the likelihood of an open and frank discussion on the topics [13]. The first two focus group meetings were held in a site external to the hospital, the third focus group was held on site in the haemophilia centre. Each focus group lasted for 2 h. Terms of engagement were agreed. The discussions were documented in note form by the facilitator. The main themes explored in the focus groups were adapted from the Irish Society for Quality and Safety in Healthcare (ISQSH) and based on the patient journey [14]. Participants were questioned about their experience of the outpatient, inpatient and 'out of hours' services, and about the provision of patient information. They were also asked to highlight areas for improvement in relation to the different dimensions of performance as outlined in Fig. 1 [1]. The facilitator documented answers on flipcharts and in meeting notes. The project manager, a member of the haemophilia team, analysed the results using content analysis. Subsequent to analysis and interpretation the main themes and sub themes were returned to the participants for comment and accuracy.

### Ethics

As the project predominantly involved practice development, only a summary review of the project by the local ethics committee was required. The project was also approved by the patient advocacy committee of the hospital site and participant consent was obtained before the focus groups commenced.

## Results

### Focus group one: patient involvement

Focus group one was held in September 2008. Participants were all men with severe haemophilia (Type A

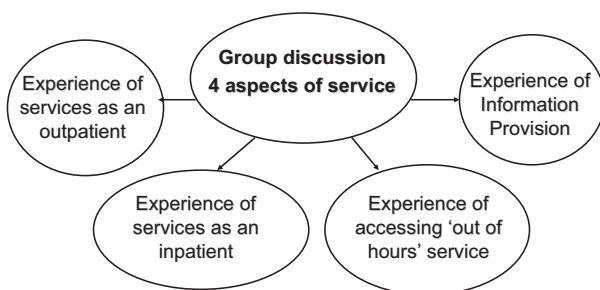
and B). Their ages ranged from 45 to 58 years. Participants lived at varying distances of up to 120 km from the centre.

This focus group explored four main patient experiences as outlined in Fig. 1. These four areas acted as the main themes for the presentation of findings. At this initial stage the patient was at the lower end of the participation hierarchical relationship: patient involvement.

*Themes of discussion. Experience of services as an outpatient*—This theme generated the most discussion and two sub themes emerged. These highlighted major and minor logistical issues in relation to optimizing clinic visits, one of which was to optimize the annual review clinic. The need for a 'points to discuss form' to be completed by patients prior to consultation with the doctor was discussed (Table 1). The purpose of this form was to help patients prepare for their annual review by assisting in the recall and identification of issues the patient felt impacted on the quality of their care and life.

*Experience of accessing out-of-hours service*—Three issues emerged from this theme. These were the appropriateness of the name of 'out of hours' service when a hospital service is supposed to operate over 24 h deficits in haemophilia inpatient assessment and treatment protocols including education of staff and optimizing the content of the patient identity/medical alert card (Table 1).

*Experience of services as an inpatient*—Within a discussion on the quality of the services the need for a new haemophilia inpatient facility and temporary facility in the interim was highlighted (Table 1).



- Dimensions of performance:
  - convenience/speed/friendliness/accessibility/
  - provision of information/complaints/environment

Fig. 1. Patient focus groups initial themes.

Table 1. Themes emerging from focus group one: patient involvement.

<b>Experience of services as an outpatient</b>
• Optimize haemophilia annual review
▷ Develop 'Points to Discuss' form for patient to complete prior to appointment
▷ Coordinate same day clinic access to other services, e.g. dental, orthopaedic
▷ Facilitate blood sampling 2 weeks prior to clinic, so blood results available
• Improve physical access to clinic – parking and door entrance
<b>Experience of accessing 'out of hours' service</b>
• Need for appropriate patient assessment and treatment on admission
• Change name of 'out of hours' service
• Revise medical alert ID card content
<b>Experience as an inpatient/provision of dedicated beds</b>
• Need for new dedicated haemophilia inpatient treatment facility
<b>Experience of information provision</b>
• Improve information to hospitals in relation to emergency haemophilia care
• Provide information on: evening and weekend service, patient satisfaction surveys, MRSA, hepatitis C, arthritis, diabetes, WFH publications

*Experience of information provision*—Two main issues arose here. The first highlighted the need to improve access to information in all the emergency departments nationally in relation to care of the person with haemophilia in the event of an emergency. The second highlighted the need for the availability of a wider range of patient information leaflets to include information on patient support groups (Table 1).

*Action.* Following on from the analysis of this focus group, the findings were presented to the clinical haemophilia care team and an action plan devised to address the issues. The patients were not directly involved in the actioning of these issues. Over the immediate period the minor issues were addressed. There was the introduction of a new assessment and treatment protocol that ensured that all patients with a bleed attending the hospital (the emergency – non-comprehensive care department) would be assessed by a doctor within 1 h of admission. The ‘out of hours’ service was renamed the ‘evenings and weekend’ service and patients were given the option of attending the hospital for blood sampling 2 weeks before their appointment so that blood results were available for their haemophilia annual review. Some of the major issues were also addressed over the first year, but some remained outstanding and beyond the direct control of the haemophilia care team e.g. improved physical access to clinic and dedicated inpatient facilities.

Based on the success of the focus group the haemophilia team decided to raise the level of involvement of the patient for the next stage to the intermediate level: patient participation.

#### *Focus group two: patient participation*

The second focus group was held 1 year later in 2009. Six of the seven participants from focus group one agreed to participate.

In this focus group patients had the first opportunity to evaluate and feedback on the changes implemented as a result of issues highlighted in focus group one. The patients expressed satisfaction on improved services in relation to access, blood results, and the new assessment and treatment care pathway. They suggested additional changes to the ‘points to discuss form’ which were immediately implemented. Improvements regarding the availability of patient information leaflets across haemophilia centres and the need for a new dedicated inpatient facility were further emphasized by the patients.

*Action.* Following on from this focus group, the assessment and treatment care pathway and the patient information leaflets on haemophilia and related bleeding disorders were adapted for use in the

other haemophilia comprehensive care centres. Having experienced the value of the patients input into not only their own care but patient care as a whole, the haemophilia care team decided to raise the level of involvement of the patient to the highest level; patient partnership. The relationship moved from simple exploration of needs, to directly negotiating and collaborating with the haemophilia team. The team developed a patient partnership panel to comprise of a combination of both health care professionals and patients.

#### *Focus group three: patient partnership*

The third focus group was held in 2011, 2 years after the second focus group. There were 11 participants to include; two volunteers from the first focus group, five patient members from different patient groups (adolescents, thrombotic disorders, women and bleeding disorders and a member of the Irish Haemophilia Society), the nurse manager, the quality assurance officer, the administration manager and a consultant haematologist.

The initial patient partnership panel meeting was a focus group that discussed the aims and objectives of the panel. This focus group also explored the four main patient experiences that were explored in previous focus groups. The panel collaborated to suggest additional changes to improve services (See Table 2). Patients on the panel were given the responsibility to review patient information leaflets, patient alert cards and the protocol for patient access to the haemophilia team for acute enquiries. Patients also suggested topics for the agenda for the national haemophilia conference.

*Action.* The formation of the panel was a very worthwhile and positive experience for both service users and service providers. The individual patients

**Table 2.** Themes emerging from focus group three: patient partnership.

<b>Experience of services as an outpatient</b>
• Panel to write to hospital management to improve car parking facilities for centre
• Staff to provide demonstration to patients of Electronic Patient Record
• Panel to improve facilities and layout of patient waiting area
<b>Experience of accessing evening and weekend service</b>
• Panel revised protocol to improve accessibility for acute enquiries to haemophilia team
<b>Experience as an inpatient/provision of dedicated beds</b>
• Panel to lobby with hospital management to progress new inpatient facility
• Patient panel member to have input on training programme for new doctors
• Panel to review content of patient alert card for emergencies
<b>Experience of information provision</b>
• Devise information leaflets on ankle, elbow and knee surgeries
• Panel to review all new patient information leaflets
• Introduce patient notice board in centre to improve education
• Panel to input to agenda of the National Haemophilia Conference

expressed how they had a better understanding of how the centre operated and were satisfied that their comments were welcomed and listened to during the decision-making process. The clinical team members, although apprehensive initially about maintaining professional boundaries with the patients, were satisfied that with the introduction of definitive terms of reference, an appropriate relationship could be formed. As a result, the panel meetings fostered open constructive discussions and were an enjoyable experience for all involved.

Thus, the haemophilia team decided to formalize the patient partnership panel. Terms of reference were agreed and included panel objectives, membership, and frequency of meetings, minutes, and quorum. The panel also devised a mission statement, vision and values. The haemophilia team members on the panel agreed to be accountable for reporting all quality initiatives directly to senior hospital management. Finally, a patient notice board would be used to disseminate findings and raise the profile of the patient partnership panel so as to engage the wider patient population with the ultimate goal of improving general health.

## Discussion

We describe how patient involvement evolved into patient partnership and resulted in the implementation of quality initiatives that improved haemophilia patient care both directly within the haemophilia service and within the greater health service.

Through the development of a patient partnership model within a comprehensive haemophilia care service many issues were identified and addressed. One of the major themes that emerged related to outpatient services. Through this process the annual review of the patient with haemophilia has been optimized from both the service and patient perspective. This has been achieved in several ways; better preparation by both the service and the patient prior to the annual review appointment; facilitating easier access to the unit and detailed coordination of all hospital appointments. Patient involvement and use of shared decision-making within this process has changed and improved the care continuum of the patient with haemophilia.

Previous reports and results from this project appear to confirm that care coordination of patients with haemophilia is probably most demanding when the care occurs outside the comprehensive care centre, i.e. in other hospitals emergency departments [15]. Through patient participation, the patient identity/medical alert card content was further improved and elaborated, so as to better inform other healthcare professionals of the specific needs of the patient with haemophilia, especially in the event of an emergency. Through

shared decision-making with the patients and the haemophilia team, an optimal standard care pathway for the assessment and treatment of haemophilia patients for admission to hospital was developed and implemented. Furthermore, training of new emergency non-haemophilia medical staff was also enhanced through use of in-service seminars. These clinical developments have led to the more appropriate treatment and care of patients in the emergency non-comprehensive care settings and will increase the haemophilia patients' trust in emergency services [15,16].

As in previous studies, patients in this project have identified unmet needs with regard to information on general health to the patient group as a whole [17]. The major issue that was addressed in this project through the identification of patient's individual informational needs was improved access to and provision of additional information for patients with haemophilia. In partnership with patients, new information leaflets were developed not only in relation to haemophilia care, but also in health promotion and general healthy living. Thus, providing a more comprehensive and holistic approach to care.

The NCHCD haemophilia service has long sought to find a place for the patients' voice and to bring the patient perspective more holistically into practice development. This project shows how this process was put in place and was successful in providing the haemophilia care team with direct insight and awareness of the outstanding needs of the service users. However, there were some limitations to the project. Some patient expectations were high and beyond the remit of the haemophilia team i.e. the development of a new inpatient facility. Such issues were depended on monetary resources and related to the participation of other groups, outside the control of the haemophilia team, but remain an identified long-term objective.

Nonetheless, although issues might differ i.e. access to care, this model of quality evaluation, using focus groups to develop a patient panel over time, can be extrapolated for use in any haemophilia treatment centre worldwide.

## Conclusion

The expectations and needs of patients, attending the haemophilia comprehensive care service, which emerged in this study, were complex. The needs and aspirations were not simply confined to the haemophilia service only but also included patient outcomes and care in other services utilized. This project has described the evolution of a model of patient involvement to patient partnership within the haemophilia service. From all stakeholders' perspective it has proven to be a suitable model for evaluation, planning, development and delivery of systematic care within

the haemophilia comprehensive care service and also for patients with haemophilia who interact with the greater health service.

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## Author contributions

Anne Grogan designed the project and analysed the data. Anne Grogan, Michael Coughlan, Brian O' Mahony and Gabrielle McKee wrote the paper.

## Disclosures

The authors stated that they had no interests which might be perceived as posing a conflict or bias.

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