Myeloma UK Health Services Research Grant Programme

Final report template

As stated in the standard terms and conditions of this award, it is a requirement of any Myeloma UK Grantholder to submit a final report at the end of the research period. Payment of the final grant instalment is contingent upon receipt of the report. Information from the report will be published on the Myeloma UK website.

Please complete all sections of the form, extending the boxes as required.

If anything is confidential at the time of writing please make this known.

1. PROJECT DETAILS

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Title of Research Project

Patient Perspectives of Clinical Trials.

Title of Research Project in lay terms

"To understand how patients come to make the decision to take part in a myeloma trial and to use this information to improve patient experience and maximise the benefit gained from clinical trials for patients and clinicians."

The aim of this study was to analyse patient perspectives on participation in a myeloma clinical trial. This is a qualitative study designed to explore the experience of participating in a myeloma clinical trial from a patient point of view. The aim is to identify the factors which motivated them to take part such as how much time was

needed to make the decision, whether they have enough information to guide their decision. If this was the case we were keen to know which sources of information were used and those that patients find most relevant to their specific needs. We then planned to use this information to make recommendations to shape future trials and improve the experience for all.

Date of award

June 2015	to	August 2016

2. USE OF FUNDING

Please state how the funding from Myeloma UK was used. This should include a breakdown of funding for salaries, consumables, equipment and other costs.

The research grant from Myeloma UK was used to fund the post of Associate Myeloma CNS (Band 6) in UHW Cardiff for 12 months. During this time the CNS, Tanya Burton, was a key member of the myeloma team. Her time was jointly shared between delivering high quality patient care and carrying out the research project. The experience and rapport that she developed with the team and patient cohort was invaluable to enhance the quality of the research project. By building patient trust, participation in the project was high and the responses gained were both detailed and insightful.

A small amount if additional funding was received to cover postage costs for distribution and return of the questionnaires.

3. AIMS AND OBJECTIVES

Please provide an outline of the original project objectives and goals as stated in the original application.

The primary objective was to investigate how myeloma patients perceive their experience of participating in a clinical trial. This is not something which has been studied extensively in the medical literature. Tens of thousands of patients take part in clinical trials for cancer treatment every year worldwide. The data from these studies is used to guide medical practice and yet the quality of their experience is often not measured. We wanted to look if overall they felt the experience was positive or negative.

Some key questions were whether the trial met their expectations before taking part and whether there was sufficient information provided before they gave informed consent to take part? This would include verbal information from the medical team, or written material that had been supplied to them on study. Did they complete any independent research to compliment the information that had already been acquired? During the trial were they given any additional information or guidance of how the trial was progressing? Following active therapy on the trial, we wanted to know if there was enough information received which was accurate and appropriate to their understanding.

Did they have sufficient opportunity to gain further information throughout the study, or to did they need to ask for further clarification on the protocol throughout their treatment journey? This is essential for the purposes of informed consent, a corner stone of good medical practice.

Secondly following the fieldwork section of the study, the aim was to analyse the patient responses gained, and use this to look for any positive or negative themes. We hoped to use this snapshot of the opinions of a typical myeloma patient cohort in a large teaching hospital to draw conclusions about the experience of similar patients on a national and perhaps international basis. The overall aim was to define a set of recommendations which could be offered to those involved in the design of future clinical studies, as a blueprint to make them more patient centred. We wanted to identify measures of how the trial experience can be improved and to explore if they would recommend taking part to others and why. By this we would like to define the main benefits and drawbacks of trial participation from a patient perspective – these may for example be therapeutic, social, pastoral, financial or intellectual.

4. ACHIEVEMENT OF RESEARCH AIMS AND OBJECTIVES

Please describe the extent to which the aims and objectives of the research, as detailed in Section 3, have been achieved. Use this section to outline any issues encountered during the grant period that had an impact on the research.

The aims of this project were well achieved. The report contains detailed analysis of patient responses in both graphical form and prose. We have also used this information to design a list of recommendations for the designers of future studies, to help make trials more patient-centred.

5. RESEARCH SUMMARY / EXTENDED ABSTRACT

Please provide a comprehensive summary of the research undertaken. This should include a detailed overview of the background, methods and key findings of the research.

This section should be between **4-6 pages long**, not including references. You are welcome to submit Section 5 in a separate word document. If you have already published from the work please submit published material in addition to the Research Summary in the Final Report.

The myeloma team in UHW carried out a qualitative study investigating the views of people affected by myeloma and their role in national research trials. This project was developed in conjunction with Myeloma UK who funded the research activity and have a strong background in improving patient experience and patient advocacy.

There is no other published work looking at actual personal views of people affected by myeloma regarding their role in national trials. We felt this was a vital topic to explore, given that clinical trials are an essential part of therapeutic development and improving patient outcomes. Exploring patient experience and identifying factors that require improvement will help trial designers make future studies more patient centred. This study aimed to achieve this by involving past and current myeloma trial participants directly and canvassing their opinions via a professionally lead qualitative study.

Background

A survey conducted on behalf of the National Institute for Health Research Clinical Research Network (NIHR CRN 2014) showed that 89% of people would be willing to take part in clinical research if they were diagnosed with a medical condition or disease. These statistics drop dramatically to 23% with those diagnosed with cancer (NIHR CRN 2012). There are currently 39 trials for Myeloma treatment in the UK and 864 worldwide (national Health Service 2015). However, there is very limited evidence published looking at the experience of people affected with myeloma on clinical trials, this represents a striking unmet need both in the terms of improving the quality of patient experience and encouraging more patients to take part in future trials. In addition, higher levels of patient satisfaction during the trial may lead to improved compliance with the trial protocol. This is essential to maintain the quality and reliability of outcome data obtained. It also is required to make sure that conclusions drawn about drug efficacy are truly related to a valid and representative patient sample. There is also very little evidence to support interventions to improve recruitment and experience during the trial.

Myeloma UK also carried out a Patient Experience Survey in 2013 (MUK 2013) 2013 surveys were issued, 1062 surveys were returned. From these 993 were patient who had a diagnosis of Myeloma therefore these were used. From the questions covered, the survey showed that only 52% of patients had discussed participating in a clinical trial with their doctor and 46% did not and 2 % were unsure. Of these, 71% participated in the trial and a further 91% were glad they had taken part, which suggests that effective discussion can enhance recruitment.

It was interesting to see that almost two thirds of the patients who did not take part had never discussed participation with their doctor. This could largely be to eligibility, however one in ten said they would have liked to have taken part and perhaps further time dedicated to counselling patients at the outset could enhance recruitment.

Methods

After a brief pilot questionnaire of around 8 patients from the myeloma clinic we identified the best research tool to employ would be a questionnaire together with some one to one interviews. During the pilot phase, patients were asked whether they would prefer a questionnaire, focus groups, interviews or an observational study.

Questionnaires were the overwhelming favourite for a variety of reasons such as the answers could remain anonymous, it could be completed at a convenient time and in the comfort of their own home. Also this method would be less time consuming than participating in a focus group, which is important as this group of patients already spend a great deal of time in hospitals. The team also felt that a questionnaire would be more representative of patient opinion than just us carrying out an observational study without asking opinions.

It was decided that we would canvas our own population who were or have been enrolled in two different clinical trials (NCRi Myeloma XI and MUK CTN V trial.)
The patients would include those newly diagnosed and relapsed, those on induction treatment or maintenance and those who have finished treatment and are only on follow-up. It was decided not to stratify patient responses based on whether they are still actively taking part in a clinical trial or have completed the study. This was because we felt that newly diagnosed or more unwell patients may have a more positive or negative view point than those who have finished treatment and are in remission due to the impact of hindsight or personal experience. This is relevant because the main focus of the questions was with regard to the information provided before and during the consent process and their perceptions of their experience whilst on the study, which may be biased by their physical or mental health at the time. The section on experience after the study is more brief and answers can be tailored depending on where the patient is in their treatment journey.

A Brief summary of the questionnaire is as follows:

Experience Prior to Consent:

- Motivating factors to participate
- Quality of information given
- Amount of time available to decide
- Resolution of any concerns
- Explanation of alternatives
- Advantages and disadvantages of being in the study

Experience During the Trial Process:

- Satisfaction with treatment course
- Concerns regarding treatment or protocol
- Access to Medical personnel
- Logistical difficulties with participation in the study – financial, physical

Experience After Treatment:

- Contact with trials team
- Frequency of visits and investigations

- Availability of feedback regarding study outcomes

The questionnaire was designed iteratively between the team in UHW and the Research Staff at Myeloma UK. MUK also facilitated review of the questionnaire by a selected panel of myeloma patients to ensure that the style and content were acceptable, understandable directed towards the relevant areas. Their input was invaluable to ensure the questions were easy to understand and minimise the chance that they would cause distress to similar patients.

Results

We distributed 47 questionnaires of which 31 were returned. There was a variation in terms of demographic details of those patients who returned the questionnaires. We found that there were a higher number of female versus male responders. Also when analysing patients by age we found that the majority of respondents were over 70 years old (fig 1). This is consistent with the fact that myeloma is a disease of the elderly, with the median age of around of 69 years (Cancer Research UK).

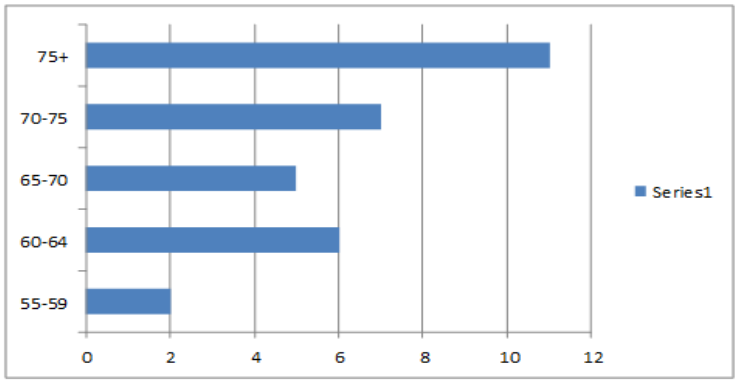


fig 1

The length of the time that the patient had been diagnosed was variable however most patients had been diagnosed between 2 and 5 years previously (fig 2)

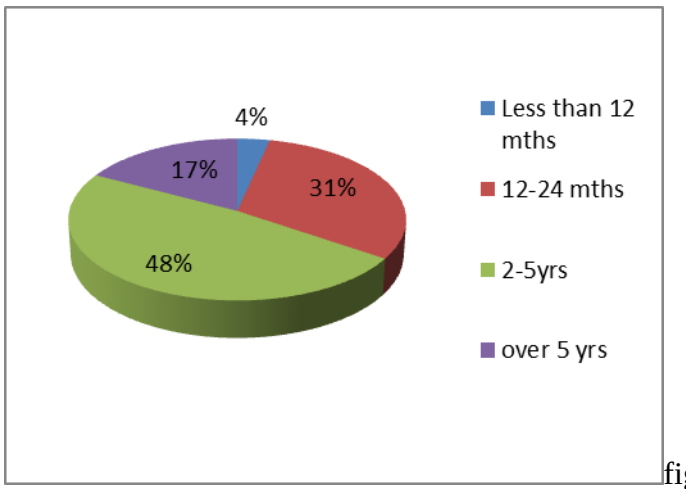


fig 2

We were concerned to discover the extent to which patients were familiar with the study protocol to which they had been enrolled and one way to measure this was to ask whether they thought they were still actively involved in the study. It was striking that 2 patients stated they were unsure with a further 19 stating they are still actively in the trial. There was significant degree of confusion among several patients as to whether or not they were still actively taking part in a trial (fig 3). Two patients responded that they didn't know and a further 20% of those who stated they were no longer involved in the trial are actually still on follow up for data collection purposes. This lack of clarity is concerning, it suggests that many patients are unsure as to the treatment plan during the study and that they simply 'do as they are asked' by the medical team. This is likely to be consistent with the experience of patients treated outside of clinical trials, cancer treatment is inherently didactic in most countries. However there are implications for patient informed consent if subsequently a patient becomes unclear as to whether or not they are still on active treatment or follow up.

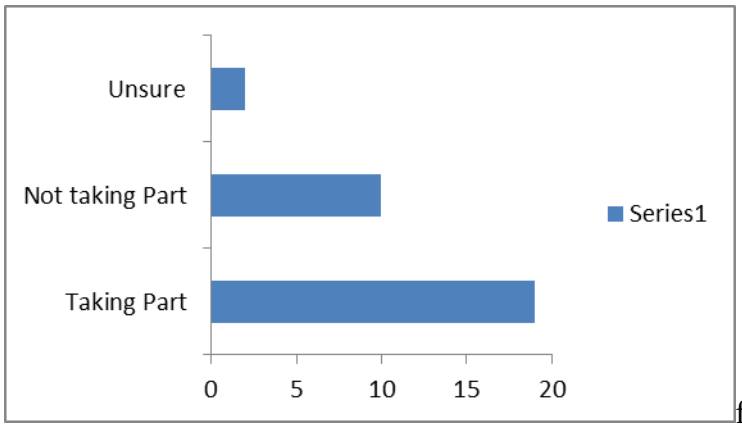


fig 3

From the outset we were keen to understand what patients felt was the major motivating factor behind their participation in the study. The question was answered by 100% of patients and the predominant theme was that patients felt that participation in the trial would give them access to the most modern and therefore most effective treatment, which may not have been available outside the context of a clinical trial.

Patients also expressed the hope of wanting to extend their lives with the underlying tone of wanting to find a cure. The word HOPE was used in many of the answers such as:

"Hopefully to benefit from a better quality of life"

"The hope that by doing so I may increase the chances of a cure for myself and others in the future"

"To hopefully cure my cancer".

This is interesting and also poignant given that medical treatment from a doctor perspective should be guided by evidence and rationality and yet the patient may be left to survive on trust and hope. The gravity of this statement should not be overlooked, particularly in the context of early phase studies where perhaps little hope of disease stability should be encouraged.

We then started to look at what information led them to take part – we were looking to find out whether information was easily accessible from both trial materials and

alternative sources and how easily patients were able to access information. The main sources of written information for patients regarding the trial are the counselling they receive from the medical and nursing staff and the written Patient Information Sheet. They are also counselled verbally by all members of the team and this situation is inherently less easy to standardise. The team must strike a balance between imparting sufficient information to allow the patient to make an informed decision on participation, whilst also describing non-trial alternatives in a manner which is easy for the patient to understand.

Similarly, the PIS should allow the patient to have a clear view of how the study runs and what the requirements of taking part in terms of clinic time, drug therapy, investigations and monitoring are. Frequency of visits may also be a factor as it is often higher on trials and the majority of patients dislike visits to hospital.

It was apparent that the majority of patients were more than happy with the explanation and the information that was supplied to them by their medical team. Many also passed comment that they felt satisfied that the process had been fully explained by the doctor:

"My Consultant explained it to me"

"The way it was explained to me was easy to understand"

The most common observation was that patients were not looking beyond the hospital institution to find information independently and from other sources. In other words use of the internet or social media to find additional resources and information was minimal.

With this in mind we then wanted to explore if the information that had been provided to them by their team was enough to enable them understand the trial. The overwhelming response was that information was adequate as stated by 27/31 (87%) participants (fig 4).

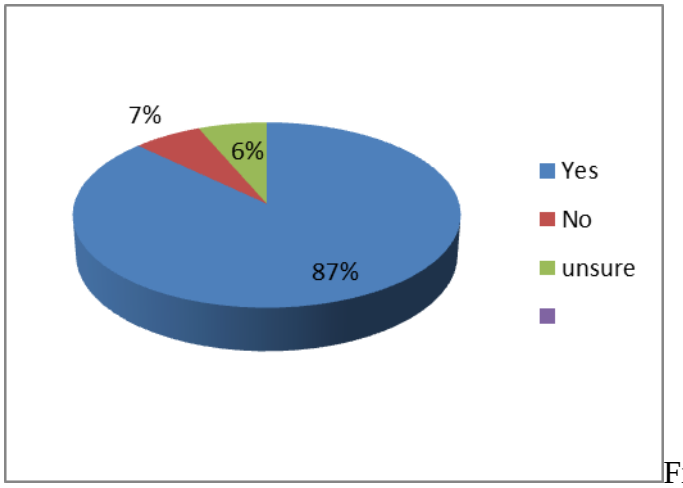


Fig 4

We found that relatively few patients had consulted any alternative source of information to find out about the trial, such as other cancer charities or internet resources. This demonstrates that the majority of patients felt that the written information they received in the form of the Patient Information Sheet was sufficient. This can be interpreted in two ways, either that the PIS'S for these studies are of sufficient quality to answer the needs of this cross section of patients or that they

were unable to conceive that any relevant information would not be provided, thus demonstrating the trust the patients have in their medical team. Whilst this is encouraging, it should be further scrutinised by an analysis of how well patient experience reflected their perception of the trial at the outset which can only truly be obtained by means of a prospective study.

Taking part in the trial is a decision that should not be taken lightly and not rushed, it is important that patients are able to consult with other family members, or other healthcare professionals as part of the decision process. Unfortunately from the results of this study it was not clear if patients had had the opportunity to consult with anyone else. However when asked if they felt they had enough time to take part 29 patients said yes with only 2 patients stating they were unsure, which suggests that relatively few felt under pressure or lacking the opportunity to discuss their options.

It is only natural that patients who have been newly diagnosed or told they have relapsing myeloma will have concerns or worries, therefore we wanted to understand the nature of any issues regarding the trial. The majority of patients did not voice any concerns, however the few that did were worried that they were going to suffer side effects from the investigational products or that they would receive on the trial were less likely to work than the standard therapies.

"I went into the study thinking that hopefully the treatment would work and I wouldn't have many side effects"

It was interesting to note that although many patients stated they did not have concerns the overwhelming response to were your concerns resolved was in the affirmative (fig 5). This suggests that patients are reluctant to admit they had fears taking part in the study.

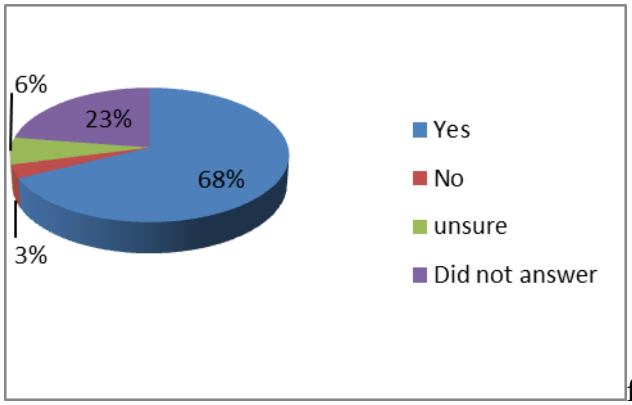


fig 5

Next we examined whether patients are satisfied with their decision to take part in the study following the process of screening and consent. This was important to ascertain the level of satisfaction and their decision and whether they felt that this had been taken in an informed manner. We asked patients whether they had had the alternatives explained to them 27 out of 31 patients felt the explanation was satisfactory (fig 6). This is a key factor in the consent process where time is a major factor, and yet doctors are often under pressure to start treatment quickly when patients are unwell or anxious. Therefore, effective communication is of paramount importance.

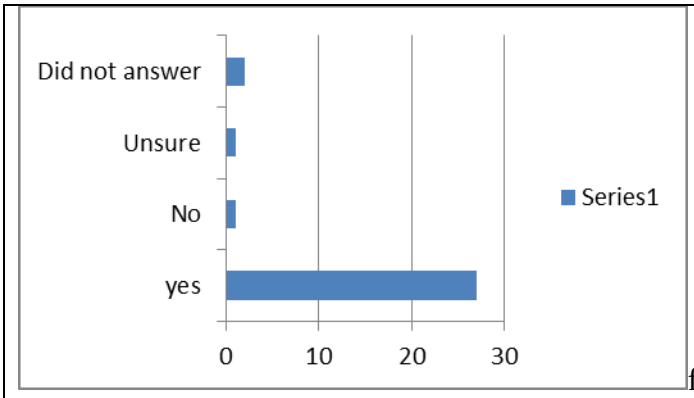


fig 6

We also wanted to find out what the patients involved in the trials saw as advantages and disadvantages of their participation. It was apparent that 30 out of the 31 patients felt motivated by altruism with the research followed closely by 28 of patients wanting to access more current treatment and 22 thought increased monitoring by the medical team was an advantage. This suggests that they were motivated by anxiety, does this mean that they worry that we may neglect them if they are not in a trial? It is quite concerning to think that the patient feels they are not being monitored as closely if they are on standard treatment when in reality the treatment and the frequency of clinic appointments are extremely similar.

Many of the patients felt there were no disadvantages to taking part at all however, some negative impacts were mentioned. For example 6 out of the 31 patients did not like more hospital visits, and having to spend more time in hospital. Other physical factors mentioned regarding the frequency of hospital visits included travelling time, parking and then getting to the clinic (fig 7). Does this fit it with their work life balance? Do they have a fear of hospitals? This would only add to their anxiety if this was the case. Does it remind them of a bad experience or even an illness? 12 out of the 31 thought that more tests were a disadvantage and 4 patients thought non-standardised treatment schedule were a disadvantage. This last point is very interesting because a trial protocol is very standardised and the patient can see it from the start. The study team are not allowed to deviate from the protocol without the permission of the Trial Organisers which is in contrast to treatment off trial which is more likely to be ad hoc or less well defined at the start.

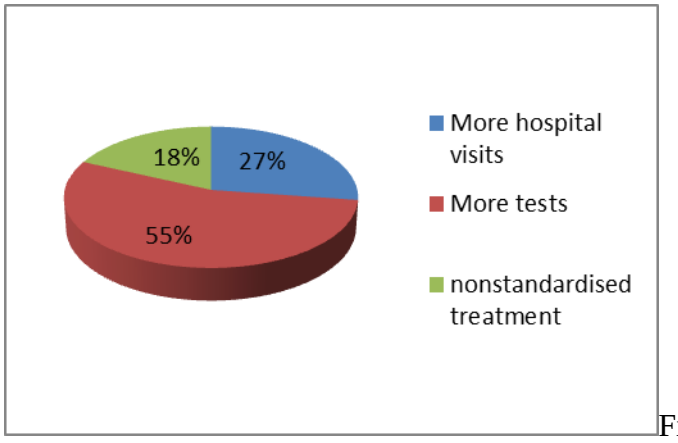


Fig 7

Finally we asked patients for their recommendations as to how their experience could have been improved. Many felt they could offer nothing or chose not to answer the

question, however the ones that did would have preferred the information in a more basic language

"I would like the information explained in lay-mans terms"

"I feel I needed more information on progress of the study and how it will influence future treatment of myeloma"

This was an interesting point and suggests that patients would like to know the results of the trial and how it affects future treatment. Publication of the results can often take many years after the study closes, some patients may not live long enough to see the results come to fruition. This is sad, however this should be addressed in future studies. This is a topic which is not routinely covered in the plan for most trials and dissemination of results from the medical literature to the patient is largely influenced by the will of the patient to ask questions and the availability and understanding of the medical team to impart this information.

It was clear to us that overall, the patients who had responded felt satisfied with the trial experience as shown in fig 8.

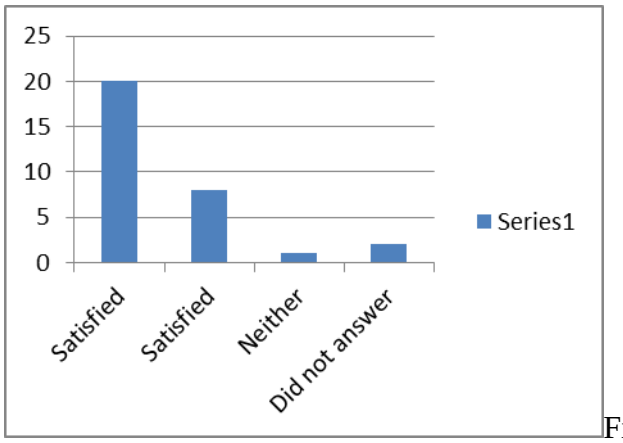


Fig 8

We have established that most patients did not have a concern before the trial began, but this changed whilst they were taking part. The results demonstrated that that the majority (17/31) did not have issues or concerns, 2 patients were unsure. However, of the 12 patients that did have concerns the main fears were regarding the side effects of treatment received during the study or how it would influence their future treatment.

"I was worried the drug might cause heart failure"

"I was concerned about the possibility that taking Revlimid as maintenance during the trial would preclude it from second line treatment or diminish its effect on my illness in the future"

This latter point demonstrates a high level of awareness by the patient of the current medical literature and that the treatment they might receive on the study (Lenalidomide maintenance first line on MXI) is outside of current licensed indication in the UK. This matter should have been explained to the patient at the start and is consistent with the off label treatments given in most clinical trials, however we could question whether the patients were able to discuss this with the team prior to informed consent?

Having raised the issue of concern we then needed to know if patients felt that they had somebody they could direct their worries towards. All cancer patients have a key worker who in most cases is their Clinical Nurse Specialist. A recent study In Wales (Wales Cancer Patient Experience Survey) highlighted that only 66% patients surveyed had known that they had a key worker.

This result was most interesting as everyone who had answered yes, stated they did have someone. However there was no one clear person, it was a mixture of response which ranged from thinking it was the Doctor or the Clinical Nurse specialist (CNS), or Trials Nurse.

"If I had any concerns I would see the CNS or the Dr"

Only 2 patients mentioned the Trials nurse, clearly we have identified that there needs to be more clarification of the roles of the specialist nurses. During a trial the patient should contact their Trials Nurse in the first instance with any study related problems. If the concern is related to the trial such as trial investigations, or query about the drug that is involved with the trial, the trials nurse would then in turn inform all the other crucial team members, which would include the consultant and the CNS.

As both the trials involved in this project were non-commercial trials, the patients would not be reimbursed for their expenses. Nevertheless many were concerned about the costs involved in making visits to hospital including petrol and parking fees.

"Car parking did turn out to be a major cost"

Parking fees at the University Hospital Of Wales are quite expensive and is it is the only hospital in Wales where patients, staff and visitors have to pay to park their cars. Although this is not the same for other parts of the UK where parking fees are the norm, the rest of the hospitals in Wales offer free parking. Also, the car park in UHW is quite far the outpatient department and patients have to walk or make this journey by wheelchair including a flight of stairs (with a lift). This in itself can be difficult especially for the more frail patient and a re-design of the clinic or a dedicated trials unit may offer some practical solutions.

Summary:

We have explored what would make participation in a clinical trial a better experience for the patient, however finally our aim was to make recommendations for how to improve future practice.

Physical factors such as car parking were very important to patients, together with the lack of space for parking which involves driving around for a long time looking for a space.

This identifies two main themes:

Logistics – Taking part in a trial can be inconvenient, costly and at times physically demanding for cancer patients. Investment and though is required to make this situation better.

Altruism - Most people are altruistic, they understand that trials are important

because myeloma is rare therapeutic breakthroughs are required. However, we have a responsibility to make sure this debt of personal sacrifice is repaid with a patient centred, user friendly study.

We have highlighted that the roles of clinicians need to be clearly defined, but how important do they feel it was to be able to contact the trials nurse once the trial was completed? Of the 31 patients questioned 18 thought it was very important and 9 stated it was quite important with 3 not sure and one patient declined to answer.

It was fantastic to see that 30 out of 31 patients would recommend taking part in a myeloma trial with other patients and only 1 person was unsure. Furthermore 28 of the patients would consider taking part in future trials within our cohort of patients and 3 being unsure. Not one person gave a definitive negative response.

It was striking that all of the participants in this study felt that it is important that they receive information on results of the trials once they are completed. However, given that many larger studies can take a great deal of time to recruit and report their findings it is important that patients can receive interim results during the trial as they become available. Principle Investigators receive regular Newsletters from the Trial Centre regarding recruitment targets and any issues on the study, particularly with regard to safety. Perhaps, this could be expanded to include a patient newsletter with information tailored to the correct level. Another solution would be to produce smaller studies, which can recruit and present the data in a more timely fashion. However, we cannot forget that drug companies need phase 2/3 data to obtain licences for new drugs and institutions such as the NCRi and UKMRA adopt a portfolio approach to studies which are designed to answer a variety of complex research questions. These studies are inherently more complex and time consuming.

"Feedback on the results of the study would be helpful"

Finally, some additional interesting quotes that came out of the questionnaire.

" As my myeloma returned 3 months after finishing the trial I thought that I was no longer of interest to anyone"

This was quite a sad observation showing a lack of hope, also perhaps this person felt that as their disease had not responded well to treatment they had somehow failed in the eyes of the trial centre or the medical team. This concern should be raised and addressed with the medical team, however the patient may not have felt comfortable in doing this.

"I would like patient helpers to be involved in meetings to discuss the study"

"The support of a third person throughout the trial is crucial (wife), their inclusion in the consultations and the opportunity to attend chemo sessions, enables to spread the concern and assimilate all types of information"

One interpretation of this is that some patients feel overwhelmed with information when they take part in the study and feel they need support and an advocate to help them make the right decisions or understand what is happening to them. This is important in regard to their wellbeing and compliance with the protocol and suggests that possession of adequate social support should be an inclusion criterion for taking part in the study. In reality, this is often taken as a judgement call by the relevant clinician where certain patients are not deemed suitable to be offered the study of they lack adequate support.

6. IMPLICATIONS AND RECOMMENDATIONS

Please describe the outcomes that have arisen from the research or that are anticipated, as well as any implications for practice that result from the research. If appropriate, outline any recommendations for practice and / or further research resulting from the work.

Overall, some very interesting data has been drawn from this study. The results have shown that in general patients were very satisfied with their experience of taking part in clinical trials. It was found that virtually all patients would consider a further trial and they would encourage future patients to take part. Results demonstrated that patients were satisfied with the written information that they had been supplied with, and felt that the counselling they had received had been appropriate, informative and tailored to their level. However, relatively few patients sought additional sources of information and perhaps a wider pool of material from external sources may offer more clarity to certain patients.

Many of the patients acknowledged that they had concerns regarding side effects from treatment, either due to drug toxicity or the fact that they would be treated outside of licensed indications for the drug. The best way to address this kind of concern would be to emphasise that the development of toxicity is extremely closely monitored during trials, perhaps more so than in the non-trial setting and that patients are free to withdraw or interrupt treatment at any time. With regard to the protocol, the medical team has a duty to explain to patients the rationale for the protocol if required, including the relevant early phase data that lead to its design. Although this level of detail is covered in the study protocol, it may be less well explained in the Patient Information Sheet and patients should have access to the protocol if required.

It was apparent that physical and financial constraints influenced the experience of many patients in studies such as the cost of parking, or distance they are required to travel back and forth to appointments. Both the studies covered were non-commercial and ideally the trial sponsor would be able to meet these costs or there may be support available from third sector bodies. We established that many of the patients appeared confused as to the details of the roles and responsibilities of each member of the team, this could be due to poor communication or that the team were not sufficiently active in identifying which team members were the correct point of contact for specific issues. A solution to this may be to produce an algorithm for patients identifying who to contact and when and include this in the initial information.

Finally, if this study were repeated in future it would be very interesting to delve deeper into the patients interesting use of the word ‘Hope’ to explore their feeling of being diagnosed with an in curable cancer and the thought that there may one day be a cure.

Summary of Key Recommendations for Future Trial Design:

INFORMATION

- Patients must understand the protocol including treatment and timings
- Alternatives and justification for the protocol should be available
- Additional explanation for off-label treatment where required
- Patients must be familiar with the study team including their key worker
- Patients must have an advocate (relative or other) to support them throughout the trial

CONSTRAINTS

- Patients need financial support
- Attendance at appointments can be physically demanding

PARTNERSHIP

- Patients are motivated by altruism and hope for better treatment
- Medical team has a duty to repay this with adequate information before, during and after the study

7. LAY SUMMARY

Please provide a one-page lay summary of what was described above in Sections 5 and 6 (a summary of the research and implications). This may be used by Myeloma UK in a range of publications to inform patients and other stakeholders about the project. If any findings are confidential at the time of writing please make this known.

This study has shown that myeloma patients are keen to take part in trials, they feel motivated by a desire to access the best treatment in a way that is hopeful and places a considerable amount of trust in the medical team. In general patients feel that they have access to an adequate amount of high quality information during the process of informed consent and rarely seek information outside the trial literature. However, some are concerned that the degree of information is large and can be difficult to handle alone. The support of a family member or advocate is key: this person should be available to help process information and cope with the number of visits to hospital for treatment and follow up. Overall, the level of satisfaction with the experience of taking part in the study was high and virtually all patients stated that they would not hesitate to take part in a future trial.

The second main motivating factor for patients was that of altruism, the vast majority are aware that the disease is rare and as yet incurable. They feel that by taking part in the study they can potentially help future generations of patients. This is a noble desire, it goes beyond personal gain and should not be underestimated. Patients also expressed a wish to be informed regarding progress and outcome of the study in a timely fashion and this partnership should be improved. This is likely to require improved communication between the patient and the local and national trial centres via a variety of media.

8. DISSEMINATION OF RESEARCH WORK

Please list all publications, presentations and posters that have arisen from this work including any that are in preparation or in press. Where possible, provide reprints. If you are yet to publish the findings please detail where you plan to publish and the timescales for this.

- Written report to Myeloma UK – August 2016
- UHW Quality and Safety meeting Autumn 2016 – oral
- Cancer Nursing Practice Manuscript – to submit by end of December 2016
- British Journal of Haematology – alternative to above
- International Myeloma Workshop 2017 – abstract
- European Haematology Association 2017 – abstract

9. FUTURE WORK

Please describe the next steps of the project i.e. if it will continue; what the next questions / tasks are and if this has led to other successful grant applications.

The recommendations above will be discussed and implemented locally in so far as possible at a departmental level, this will be facilitated by discussion at the local Quality and Safety Review and potentially the South Wales Cancer Networks Meeting.

In addition, report and the list of recommendations in section 6 will be discussed with Myeloma UK and fed back the MUK Clinical Trial Network Team.

Signed:	**Date:**

Principal Investigator