Justine Greenwood
NIHR Research Design Service for Yorkshire and Humber Public Involvement Grant Application - Report (August 2017)

INTRODUCTION AND BACKGROUND TO RESEARCH PROJECT

Older adults aged 75 plus, often have multiple changes made to their medicines when they have a stay in hospital [1]. This can lead to confusion and anxiety, resulting in medicines-related problems e.g. medicines being taken incorrectly [2]. These problems can lead to harm, hospital readmission and a poorer quality of life [3]. Older people taking multiple medicines for long-term conditions and living at home are at greater risk.

As a pharmacist with experience in both hospital and community settings, I am interested in the medicines-related care that older patients receive after they have returned home following a hospital stay.

Reviewing existing gaps within the literature and scoping in the field resulted in the development of the following problem statements reflecting current issues witnessed in practice:

- The post-discharge medicines-related care pathways for patients living with long term conditions are highly complex, fragmented and uncertain. The level of follow-on support provided by primary care, including how effectively medicines are tailored for each person's needs, is under researched.

- The touch points and error producing factors for the medicines-related problems that can occur after the hospital to home transition for older people living with long-term conditions are not known.

- Patients and carers (both formal and informal) have not been effectively engaged to understand how pathways might be re-designed to improve medicines-related care, to ensure that they receive the medicines they need once they have returned to their own home following a hospital stay.

The aim of my proposed doctoral research is to improve the follow-on medicines-related care for older patients after their stay in hospital, to reduce costly hospital readmission and improve quality of life.

AIM OF PUBLIC INVOLVEMENT PLANS

To fully achieve benefit, research must be underpinned by patients' experiences. Often target populations are not consulted about the issues under investigation or during intervention design, leading to unsuccessful research [4]. INVOLVE (2012) advocates that research should be "*carried out with or by members of the public rather than to, about or for them*" [5]. Patients and their carers are key stakeholders within this particular research project and I felt that collaboration from the outset would be incredibly valuable and constructive.

I successfully applied for Call 29 of this award in order to create a patient and carer-led steering group (PCLSG) of four members. I felt it important to ensure the issues valued most by patients were prioritised and remain this project's focus. The future

hope for the PCLSG would be to meet quarterly and guide all stages of the project including research methods design, data analysis and dissemination (pending funding).

With the award, I held two initial workshops for the PCLSG, each lasting for three hours.

During these sessions, the group was involved in:

- Framing the research problem from their perspective
- Co-defining the research questions, aims and objectives
- Identifying possible ethical considerations
- Refining the proposed methods
- Making suggestions for recruitment strategies
- Helping to develop a participant diary
- Formulating public involvement proposals and a plain English summary for a NIHR stage one grant application to the Research for Patient Benefit (RfPB) funding stream (Call 33 July 2017).

RECRUITMENT

Very early in the process, I met with a Patient Champion from Leeds West Clinical Commissioning Group (CCG) to seek guidance on how best to form the PCLSG. Following advice from their experiences, to be very open and clear with prospective members, I prepared two recruitment documents: an expression of interest flyer and a role specification (appendix 1 and 2).

It was imperative that I recruited individuals with the necessary experiences and skills in order to maximise the benefits from these two initial workshops.

The criteria for recruitment were:

- You or someone you care for has had a stay in hospital within the last 6 months and are willing to share your experiences.
- You are over 65 years of age (or you care for someone who is).
- You have prior experience of being a part of research or are interested in becoming involved in developing this exciting new research project.

A mix of patients and family carers was to be included in the PCLSG to ensure that all experiences and opinions of medicines-related care could be explored.

I recruited the PCLSG members from existing Patient and Public Involvement (PPI) groups from within the University of Bradford, local Trusts and local CCGs. I targeted these groups as the members would have already been involved with some research activities. I networked with each group and introduced myself and the project, asking them to kindly distribute my flyer. To facilitate recruitment, I offered reimbursement for an individual's time (£12.50 per hour) and travel expenses.

Following an expression of interest, I contacted the individual for a brief telephone conversation about the group, what they could expect and to begin to build rapport. I asked them to consider the role specification document and to let me know if they had any additional needs which meant that I needed to deliver information to them in a different format e.g. large print document.

I recruited four individuals in total from the University of Bradford and Leeds CCG PPI groups. Three of the group are aged over 65 and one is a family carer, supporting an older relative. It is interesting to note that two of the group members have a dual role – that of a patient and as a carer for a loved one.

WHAT WE DID

I arranged the two workshops, both held in Leeds, as this location was preferable to the group members. After discussion with my research supervision team, it was decided to offer a lunch at the workshops so that the PCLSG members could socialise and learn more about each other, and me. This worked very well and I gained further valuable insights relevant to my research's conduct from these informal chats.

Prior to both workshops I sent agendas to the group members so they were aware of how their time would be spent and to allow them time to consider the topics of discussion (appendix 3 and 4).

Workshop one, held on the 19th June 2017, focused on exploring the group's experiences of medicines-related care after discharge, developing a timeline of post-discharge medicines events, developing the research question and the aim.

Workshop two, held on the 17th July 2017, focused on developing the methods, recruitment strategies and beginning to create a participant diary which patients (and/or supported by their carers) will use during the project.

Both workshops involved short presentations regarding the topic background including research literature, group discussions and group activities. As one member reflected "*everyone was allowed/ encouraged to contribute*."

Following each workshop I typed notes of our discussions and sent them to each individual to verify and feedback any additional comments.

PCLSG CONTRIBUTIONS

Workshop one:

During our first workshop together, I was struck by the negative emotions that the group expressed about medicines post-discharge. Members identified that their experience of post-discharge medicines-related care is that it is inconsistent and variable. A post-discharge emotional time line was created, displaying words such as "frustrated", "uncertainty" and "lost" which led to feelings of "anxiety and worry". The group voiced that follow-on medicine-related care seems reactive, only triggering if

problems are highlighted to healthcare professionals or at crisis point of hospital readmission. This is highly inefficient and costly to the NHS.

The group advocated my topic of research and showed me that medicines-related care consists of much more than 'safety' as I had previously thought. These discussions led to the refinement of my title; originally "Medicines safety for vulnerable older people after discharge from hospital." Reflecting on the holistic medicines needs and concerns of patients and carers raised by the PCLSG (e.g. can the patient see the markings on a small measuring cup adequately in order to take their medicines) the title of this project has now become "Optimising post-discharge medicines-related care for older people living with long term conditions."

The post-discharge time line that we developed highlighted the key milestones in a patient's journey and this triggered me to re-think when to interview patients. Initially I had hoped to engage with them at 1, 3 and 6 months, however after discussions with the PCLSG, these have been amended to 2 weeks and then 2 and 6 months post-discharge. At two weeks, they estimate that the patient should be beyond the critical point of their recovery allowing them to reflect effectively on their experiences. They should also have received their first supply of medicines after their hospital stay as usually hospitals only dispense 7 to 14 days supply. At two months, the primary care provider should have made necessary medicines changes and reviewed the patient's treatment. At six months, the patient's treatment should be optimised for their needs and conditions.

The PCLSG reflected that whilst they can offer their personal experiences, we are very unsure of what the post-discharge pathway looks like for other patients. Thus this became our first research question that would be answered by this project: How is post-discharge medicines-related care experienced by older patients living with frailty and Type II Diabetes Mellitus? – chosen because careful monitoring and individualised medicines support are required for these long term conditions.

Following the receipt of workshop one's notes, I received comments from one member asking for further clarification on some points. I thought I had explained all the points clearly; however this was a useful learning experience for me to illustrate what I could do better to ensure everyone can understand. We spent time talking on the telephone so I could identify how to make sure my notes were more comprehensible for the public audience.

Workshop two:

Workshop two was spent designing the diary tool that patients will use to periodically document any medicine-related problems that they face. It was incredibly beneficial involving the PCLSG with this task as I did not know where to begin and wanted to create something effective but not burdensome for the participant.

The group gave lots of ideas and helpful suggestions such as:

- Give examples to the participant of things to put in the diary
- Highlight that both patients and carers can fill in the diary

- Ensure that the procedure and method for collection of the diary are explained explicitly
- Offer participants a choice of diary and ask them what would be easiest for them to complete – e.g. have variations such as one that uses stickers and tick boxes or another that has free text boxes or one with a combination.

Feedback from the PCLSG was also to refrain from the words 'journal' or 'diary' and instead to call the data collection tool "my medicines journey," as this was felt to have different connotations, possibly improving the uptake of it by participants. The group also highlighted that in-depth details of the project should not be on the front of the document as this could have an impact on participant privacy.

EVALUATING THE WORKSHOPS

Both workshops were evaluated using a modified version of Brookfield's (1995) 'Classroom Critical Incident Questionnaire' [6] (appendix 5). This qualitative and specific feedback tool ensured that the comments obtained were valuable and meaningful.

All four members had found the workshops engaging, especially their "*shared experiences of carers, caring, informal and formal, medicines management on leaving hospital*" [Member 1]. Their passion for "*improving the current service*" and "*wanting to make a difference*" has been their main motivation for taking part.

Following workshop one, Member 2 highlighted in response to the question 'What did you find the most confusing and why?' that they felt "*the constant (and often unrelated) dialogue by some other participants*" a challenge.

I had also found this hard to facilitate during the first workshop, so to make our second event more constructive, I started a flipchart for conversation threads that were clearly important, but not pertinent to this research project. I asked the group to take ownership for highlighting these topics of discussion and I made a commitment to take this list away and see if there is any way that these projects could be developed separately. This process worked very well and there were three topics listed on the flipchart. One asked, for example, 'what is a handful in terms of dietary advice offered by healthcare professionals?'

Following workshop one, I used our discussions and the emotional time plan to create a word cloud of the emotions voiced by the PCLSG in relation to the period following discharge (appendix 6). I feel that this is very powerful and demonstrates why this research is needed.

On a personal note, I was pleased to receive positive feedback about the workshop delivery. Member 2 commented "*[a] good session, lively, interactive, opportunity to truly contribute*" and Member 4 wrote "*I am glad to be on board and willing to contribute however I can."* Understanding that I had given everyone the opportunity to be involved and tell their story was also important for the group dynamic. Member 1 reflected "*everyone had some good points and everyone appreciated being listened to*."

Members were also asked to complete the RDS feedback sheet. From these evaluations it is clear that the members understand their valuable contribution to the research so far and how the project has developed through their input. All members expressed that they had enjoyed the experience.

Member 1 stated "*We were very involved in 'honing down' the research, develop and design the research idea. We discussed how the patients would be recruited, then length of phase 1 – tracking the patient from the discharge from hospital. We also discussed a 'pass book' – recording the medicines journey."*

Member 3 wrote "*Give our experience of the use of medication. Give our comments on the type and layout of the diary"* about what I asked them to do.

I feel strongly that public involvement in research should be more than tokenistic, so I worked hard to actively engage the group by asking their opinions on all aspects of the design and explaining to them how I had used their discussions to develop the project. I believe the group valued this, as Member 1 reported that they felt "*totally involved with the research idea and design*."

Following these workshops, I approached a member who I considered particularly passionate and enthusiastic about the topic and asked him to consider whether they would like to be PPI co-applicant for the NIHR grant application. In this role they would also chair the PCLSG events going forward and attend three stakeholder advisory group meetings annually (pending award of funding). They accepted and worked closely with me to build the plain English summary and review the whole application.

NEXT STEPS

The PCLSG have all expressed their continued support of this project and wish to carry on with their involvement. Another meeting will be held in September where the "my medicines journey" will be prototyped and the group will also write their own participant information sheet, which will then be refined by the research supervision team to ensure it meets NHS research governance requirements.

Pending funding, PCLSG member involvement will continue throughout the three year project, with quarterly meetings where they will help with data collection, analysis and dissemination, including co-presenting at the National Association for Patient Participation Conference. The PCLSG will also regularly monitor progress against the project aims and objectives.

I would like a member of the PCLSG to help me facilitate each of the nine experience-based co-design events planned within the intervention modelling phase of the project. This would enable them to share their experiences with a wider audience, bringing to life the emotions of the word cloud developed after our first workshop.

During our social discussions over lunch the group told me that they had previously been disappointed when taking part in research. They expressed that they were very

rarely 'kept in the loop' with research progress and findings. This led to them being very particular about which projects they engaged with and led to negative feelings about research. To avoid this in my project I aim for the PCLSG to write their own newsletter to our research participants to inform them of project progress and key results.

Following our next workshop in September, I will have enough data to produce a short infographic style document about this work which could be circulated to encourage public participation in research.

I also hope to present this work at a future conference.

ADDITIONAL REFLECTIONS

I have thoroughly enjoyed working with the PCLSG and hope to find a way for their engagement to continue, with or without funding. These individuals have a lot to offer researchers, whether it is justification for the project or advice on how to effectively engage with research participants. I have received an incredible amount of support from the group – more than I ever could have imagined. They are my critical friends. In return I hope that I am contributing to them building their knowledge, skills and confidence in research methods and design.

I believe my background in learning and development helped greatly with the organisation and facilitation of the workshops. Simple things like agendas and information about meeting venue accessibility made the experience better for the group. Member 2 wrote when asked how the workshops could be improved:

"I can't think of any particular ways. Justine provided clear pre-attendance information, good meeting venues and refreshments and any supportive written materials needed. Questions were answered and explanations provided if needed."

Member 3 offered the idea of using a voice recorder to capture the group's discussions more effectively, which would allow me to concentrate less on capturing notes and more of the actual discussions. This is something to be considered going forward.

The main difficulty I faced however, was managing the group's expectations of what can be done within the confines of a three year project and making sure that our group decisions are underpinned by correct theory and methodology. I learnt following our first workshop, that I need to explain (in plain English terms) more details about research methods and to justify decisions made about inclusion/ exclusion criteria, recruitment and practicalities of accessing data, for example.

EXPENDITURE

Invoice reference: XI00028162

I was awarded £480 to carry out my PPI work. The below table illustrates how the money was spent:

Item	Detail	Cost
Payment to PCLSG members – workshop 1 @ £12.50 per hour	Four members attendance for three hours = £37.50 each	£150.00
Travel expenses for workshop 1		£51.15
Consumables e.g. pens, postage, sticky notes.		£11.27
Payment to PCLSG members – workshop 2 @ £12.50 per hour	Four members attendance for three hours = £37.50 each	£150.00
Travel expenses for workshop 2		£22.25
Refreshments and catering		£36.90
	Total claimed:	£421.57

Notification of whether the NIHR RfPB stage 1 application has been recommended for stage 2 submission will be late October 2017.

CONCLUSION

I am exceptionally grateful to have received this award, as it enabled me to carry out this valuable work with patients and carers to inform my project topic and design. I would encourage all health services researchers to engage with the public at the outset of their work to gain real insight into service user experiences.

All members of the PCLSG have read this report and offered their feedback. This final report has been agreed by everyone.

REFERENCES

1. Mixon, A.S., et al., *Care Transitions: A Leverage Point for Safe and Effective Medication Use in Older Adults – A Mini-Review.* Gerontology, 2015. **61**(1): p. 32-40.
2. Knight, D.A., et al., *'Seamless care? Just a list would have helped!' Older people and their carer's experiences of support with medication on discharge home from hospital.* Health Expectations, 2013. **16**(3): p. 277-291.
3. Ahmad, A., et al., *Identification of drug-related problems of elderly patients discharged from hospital.* Patient preference and adherence, 2014. **8**: p. 155-165.
4. Ocloo, J. and R. Matthews, *From tokenism to empowerment: progressing patient and public involvement in healthcare improvement.* BMJ Quality & Safety, 2016. **25**(8): p. 626.
5. INVOLVE, *Briefing notes for researchers: involving the public in NHS, public health and social care research.* INVOLVE, Eastleigh.

6. Oxford Learning Institute. *Critical Incident Questionnaire*. [Accessed May 2016]; Available from: https://www.learning.ox.ac.uk/media/global/wwwadminoxacuk/localsites/oxfordlearninginstitute/documents/supportresources/lecturersteachingstaff/developmentprogrammes/CriticalIncidentQuestionnaire.pdf.

Appendix 1 – Expression of interest flyer.

UNIVERSITY of BRADFORD

The Leeds Teaching Hospitals NHS
NHS Trust

We need your help! Would you like to join a public-led research design group?

My name is Justine Greenwood and I am a pharmacist working at Leeds Hospital. I am also a PhD student at the University of Bradford. I am passionate about making research valuable to the people it is designed for.

I would like your help to make sure that my project is worthwhile and focuses on the issues that matter to patients.

What is this research about?

It is known that changes are often made to older people's medicines when they have a stay in hospital. Medicines might be started, stopped or doses may be changed for example. Previous research shows that changes to medicines could leave a person feeling confused and unsure of what medicines to take when they return home. Unfortunately this can lead to the person going back into hospital or a poorer quality of life.

The aim of this project is to study the medicines related care that older people experience after discharge from hospital and how it can be improved.

Who can get involved? Anyone who can answer "Yes" to all of the below:

- You or someone you care for has had a stay in hospital within the last 6 months and be willing to share your experiences.
- You are over 65 years of age (or you care for someone who is).
- You have prior experience of being a part of research or are interested in becoming involved in developing this exciting new research project.
- You are available to attend two workshops; one in Leeds on Monday 19th June and the other in Bradford on Monday 17th July 2017. **(If you are not available on these dates but still want to take part then please get in touch as I would still like to hear about your experiences.)**

Both workshops will:

- Allow us to discuss the research idea, how it could be studied and identify the ethical considerations.
- Include refreshments and lunch.
- Last for three hours each (plus an hour for lunch and breaks).
- Help build grant applications for project funding.

What else do I need to know:

- You will be paid £37.50 for your participation in each workshop.
- You will also be reimbursed for travel and parking or alternatively travel can be arranged for you.
- I am looking for 3 individuals and 1 carer to help me develop this project.
- Express your interest by the 16th June!

If you would like to know more, please contact myself (Justine) either by email j.greenwood7@bradford.ac.uk or by telephone 07843937445 (I will ring you back if you like).

Appendix 2 – role specification document

Thank you for expressing an interest in joining the public-led research design group for my project. The information below will provide you with more details about the role and what is expected of its members.

What is this research all about?

It is known that changes are often made to older people's medicines when they have a stay in hospital. Medicines might be started, stopped or have a dose changed for example. Changes to medicines can leave the person feeling confused and unsure of what medicines to take when they return home. Unfortunately this can lead to the person going back into hospital or a poorer quality of life. It has been suggested that after people leave the hospital they may experience medicines-related problems for up to six months.

I believe that these six months are really important in helping and supporting older people to obtain and take the medicines that they need. I want to know if the hospital gave people or their families and carers enough information to ensure medicines are taken correctly. Did the GP know about the changes that occurred to the medicines? Were their treatment records updated accordingly? Were their medicines needs supported fully after their stay in hospital?

To answer the above questions, I want to look at how older people are managing their medicines when they leave hospital, and who is helping them with this.

Why have I been asked to get involved?

All too often research surrounding healthcare improvements is performed without patient involvement and new interventions or processes are developed without seeking the public perspective.

To make this project valuable and worthwhile to those whom it is designed for, I want to work with patients and the public right from the start and focus on the issues that matter to them. Your key role within this group will be to voice the range of perspectives which patients and carers have on the research idea.

I have received a grant from the Yorkshire and Humber Research Design Service to set up this public-led research design group.

If I get involved, what will you ask me to do?

You will need to commit to attend 2 three hour workshops.

During these sessions you will be asked to share your experiences of 'medicines related care' after returning home from a stay in hospital. This could include how you managed any changes to your medicines, your experience of any review of your

medicines carried out by the GP or community pharmacy and whether there were any problems with your medicines supply.

You will also be asked to consider and discuss:

- Framing the research idea from the perspective of the public
- Research questions, aims and objectives
- The research sample, inclusion and exclusion criteria
- Refining the proposed methods
- Any possible ethical considerations
- Scripting a plain English summary
- Ideas for recruitment strategies

You may also be asked to review documents prepared from the first workshop before the second workshop, for example a draft of a plain English summary. You will be given at least a week's notice if you are required to review a document.

I would also like to gather your opinions and feedback regarding your involvement in this research design. Following on from your participation, I would like to write a short report for publication about our collective experiences of working together.

What will I need to take part?

You will need to be able to travel to attend two workshops, one in June and one in July. The June workshop will take place in the University of Bradford and the July workshop in Leeds hospital. Both venues are fully accessible.

You need to be over the age of 65 and have personal experience of returning to your own home after a stay in hospital within the last six months.

I am also seeking the experiences of individuals who may have cared for someone over the age of 65 and who has had a stay in hospital within the last six months.

You will need to have previous experience of Patient and Public Involvement (PPI) in research and you must adhere to requests for confidentiality and data protection.

What personal skills will I need?

Most importantly you need to be interested in the project idea, enthusiastic about being involved in research design and willing to speak up about your views.

I am looking for individuals who like working as part of a small group and enjoy having a conversation. You will need to respect other's opinions and listen to all members of the group.

What support can I expect from the project research design group?

Before each workshop you will be sent an agenda so that you will know what will be covered in the session. Following each workshop, anonymised typed notes of the discussions will be circulated.

Information will be given to you in a form that is easy for you to understand. If you have any additional requirements such as large print, then these will be accommodated as far as is possible.

Support will be offered in finding public transport routes if required.

What will I gain from taking part?

Involvement in this group is hoped to give you an opportunity for personal development where you can share your skills and valuable experience with others and build your confidence in research design.

You will be reimbursed for your time. You will receive £37.50 for each workshop you attend. You can also claim back your travel expenses, including parking if required.

I'd like to take part, what do I do now?

Please contact me (Justine Greenwood) by email j.greenwood7@bradford.ac.uk or telephone 07843937445 to have a discussion about becoming involved in the group.

I am happy to answer any questions or provide further information should you require.

Thank you.

Appendix 3 – Workshop 1 agenda

UNIVERSITY of BRADFORD

The Leeds Teaching Hospitals NHS
NHS Trust

Patient-led Research Design Group Workshop 1

Monday 19th June – 10am until 1pm with lunch available from 1pm until 2pm

Venue: Harrison Room at Age UK in Leeds, Bradbury Building, Mark Lane, Leeds, LS2 8JA

Please contact Justine on the day on 07843937445 if you are running late or are struggling to find the venue.

The plan

10am	Welcome and introductions
10:15am	Sharing our experiences of medicines-related care after a hospital stay
	What supports and hinders you to take the medicines that you need after a hospital stay? (Or what supports and hinders you to help your loved one take the medicines that they need after a hospital stay)
11:15am	Break
11:30am	Time line activity
12pm	Research planning – what are we going to study and how?
12:45pm	Feedback and planning for the next workshop
1pm	Lunch and getting to know each other

Next Workshop: 17th July

Refreshments will be available throughout the workshop. If you have any dietary requirements or additional needs then please let Justine know as soon as possible.

I look forward to meeting you all on the day! If you have any questions then please contact me on 07843937445 or by email j.greenwood7@bradford.ac.uk

Appendix 4 – workshop 2 agenda

UNIVERSITY of BRADFORD

The Leeds Teaching Hospitals NHS
NHS Trust

Patient and Carer-led Research Design Group Workshop 2

Monday 17th July – 10:30am until 2pm with lunch at 12:45pm

Venue: Meeting room 4, No.1 Aire Street, Leeds, LS1 4PR. Entrance is in the train station between William Hill and Wetherspoons, opposite Bagel Nash.

Please contact Justine on the day on 07843937445 if you are running late or are struggling to find the venue.

The plan

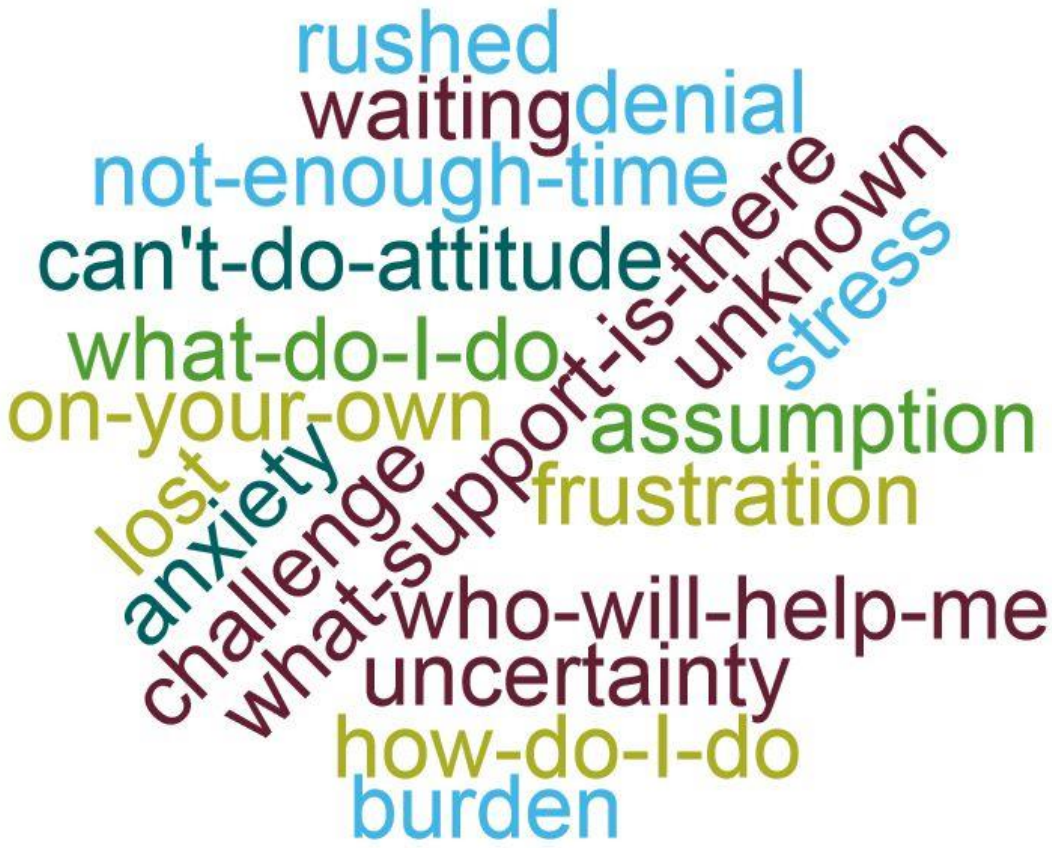
10:30am	Welcome and update of research progress
10:50am	Research planning – what are we going to study and how
11:30am	Break
11:45am	Design of diary data collection tool
12:45pm	Lunch
1:15pm	Next steps and feedback
2pm	Close

Refreshments will be available throughout the workshop. If you have any dietary requirements or additional needs then please let Justine know as soon as possible.

I look forward to seeing you all on the day! If you have any questions then please contact me on 07843937445 or by email j.greenwood7@bradford.ac.uk

Thank you for your participation

Appendix 5 – word cloud generated from time line activity



Appendix 6 – modified 'classroom critical inquiry' questionnaire

At the end of the workshop, please spend at least 10 minutes responding honestly to the questions below. Please help us by explaining your views fully:

- **What did you find was the most engaging thing discussed and why?**
- **What did you find the most confusing and why?**
- **What made you sign up to be a part of this work?**
- **What would you change about today?**
- **What questions about the research do you have that are unanswered?**
- **Any other comments?**

Thank you for taking the time to complete this evaluation form.