Psychiatria Danubina, 2017; Vol. 29, Suppl. 3, pp 490-494 *Conference paper*

SERVICE USERS PERSPECTIVES IN PROMISE AND RESEARCH

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SUMMARY

Since its inception in 2013, PROMISE (PROactive Management of Integrated Services and Environments) has been supporting service users and staff at the Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) on a journey to reduce reliance on force. The author's own personal experiences led to the founding of PROMISE and illustrates how individual experiences can influence a patient to lead change.

Coproduction is actively embedded in PROMISE. Patients have been meaningfully involved because they are innovators and problem solvers who bring an alternative viewpoint by the very nature of their condition. A patient is more than just a person who needs to be 'fixed' they are individuals with untapped skills and added insight.

There have been 2 separate Patient Advisory Groups (PAGs) since the project was first established. The first Patient Advisory Group was recruited to work with the PROMISE researchers on a study which used a participatory qualitative approach. Drawing on their lived experience and different perspectives the PAG was instrumental in shaping the qualitative study, including the research questions. Their active involvement helped to ensure that that the study was sensitively designed, methodologically robust and ethically sound.

The 2nd PAG was formed in 2016 to give the project an overall steer. Patients in this group contributed to the work on the 'No' Audit and reviewed several CPFT policies such as the Seclusion and Segregation policy which has impacted on frontline practice. They also made a significant contribution to the study design for a funding application that was submitted by the PROMISE team to the National Institute for Health Research (NIHR).

Both PAGs were supported by funding from East of England Collaboration for Leadership in Applied Health Research and Care (CLAHRC EoE) and were influential in different ways. An evaluation of the 2nd PAG which was conducted in June 2017 showed very high satisfaction levels. The free text comments also revealed how many of the patients valued their involvement and were glad to have worked alongside the PROMISE team. The impact of this PAG has been recognised by CPFT who have agreed to support the group financially and are keen to widen its remit to ensure that more patients are actively involved in Trust activities.

Key words: *Patient Advisory Groups - reliance on force – Coproduction - design of services - service delivery*

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MAIN ARTICLE

The author has struggled with severe and enduring mental illness since her late teens. However, after spending 8 months on an acute ward at the Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) in 2005, she became much more interested in the design and delivery of services. This inpatient stay highlighted some important safety and patient experience issues, such as the use of coercion, lack of interaction between staff and patients, a 'them and us' culture and use of blanket restrictions. She also witnessed other people being restrained and although she was never personally restrained, this left a lasting impression.

This experience prompted the author to work as an Expert by Experience with CPFT to improve services. She was also very keen to have influence at national level and started working as a Trustee of national Mind. In 2013, Mind published a thought provoking report on physical restraint in hospital settings in England. The report found huge variation in the use of restraint across England. In a single year one Trust reported 38 incidents compared to over 3000 by another. The Mind report also raised concerns about the face down or 'prone' restraint and the number of restraint related injuries (over a1000 incidents in 2011).

As a Trustee of Mind, the author was curious to find out about the work that CPFT was doing to reduce reliance on force. Her interest in the Trust's approach to reducing restraint sparked the inception of an initiative known as PROMISE. The project which was established in September 2013 aims to provide staff and service users with a framework to support their journey towards eliminating reliance on force in mental health services.

Coproduction of novel solutions is central to the ethos of Promise and is hardwired into the project. This approach ensures that the outputs are grounded by combining a lived experience perspective with a clinical one. Establishing trust and mutuality between people who receive services and those who provide them changes the dynamic. Patients who are recognised as 'assets' change from being passive recipients to active partners who have a shared understanding of the goal and shared responsibility for achieving it.

It has become clear that whether patient or professional, everyone's experience is unique. There are differences at a group level with perhaps patients experiencing of the services in a very personal way whereas for staff who are going into the same scenarios day after day a degree of desensitisation is inevitable. Even with patients there is a whole spectrum of those who experience services for the first time right through to those who have had considerable support. It is obvious

that the hill on which the person is standing determines which perspective or angle they see and how large or small the issue is to the person.

One of the key insights from this approach has been that staff are often quite focused on doing their best in the snapshot they get of the patient when they are passing through their service. However, for patients it can be a long journey and very few staff are able to grasp the entire journey and how care across the interfaces pans out. Coproduction and working side by side with people who have had to walk the walk enabled staff to see how one change in part of the journey, for better or for worse, has a whole host of ramifications elsewhere in the patient journey. Co-production provides a helicopter view and the ability to see the whole rather than just the parts.

In 2014 the Department of Health launched "Positive and Proactive Care: reducing the need for restrictive interventions". The aim of the guidance was to reduce the use of a wide range of restrictive interventions across health and social care settings. However, although the document sets out the expectations for services there is very little direction or evidence for what proactive care entails at the frontline. The purpose of the PROMISE qualitative research was to bridge the knowledge gap by gaining a better understanding of the key issues through the exploration of staff and patient experiences of physical restraint. In the study1:1 semi structured interviews were conducted with 13 patients and 22 staff who all either had direct experience and/or witnessed restraint. The study explored the experience of physical intervention in adult mental health wards from the perspective of patients and frontline ward staff within (CPFT). It also captured patients' and staff suggestions of how to reduce restraint in mental health wards and their views on proactive management of the ward environment.

Soon after the inception of the qualitative project, service users who had either directly experienced and/or witnessed restraint on CPFT inpatient wards were invited to join a PAG to advise on all aspects of the research design. They were recruited by the Trust's Research and Development User and Carer Manager who circulated a role description to patients who had already expressed an interest in research. The six members of the advisory group provided a unique perspective and over the course of six meetings, the group were instrumental in helping to shape many aspects of the qualitative study, from development of the research questions to the interpretation of data.

Over the course of eight meetings the advisory group played an important role in shaping the ethical design of the project. Restraint is a sensitive topic, which is why having the input from service users who had either experienced or witnessed restraint was invaluable. During the first session, the group shared their insights into the feelings that might be evoked when service users were asked to reflect on their experiences of restraint during a research interview. The group's insights highlighted some of the important ethical concerns that could arise from recruiting, consenting and interviewing service users to share their experiences of restraint and, also provided some ideas about how these issues could best be managed. Their input facilitated the development of a study protocol that was ethically robust and this was recognised by the ethics committee who commented favourably on the strong Patient and Public Involvement (PPI). It also meant that that the study was designed to sensitively handle any ethical issues which might arise during the project.

Early meetings with the PAG also influenced the study design. For example, the group members described how witnessing restraint can be distressing for services users and that exploring the experiences of service users who had witnessed but not directly experienced restraint on the wards could provide valuable insight into restraint, its antecedents and aftermath in the ward environment.

The PAG were also involved with the coproduction of the recruitment advert, consent form and participant information sheet. Their input ensured that the language used was accessible and that the aims of the study were clear. Developing a user-friendly information sheet was especially important in this study because participants were being asked to speak about a subject that many people are reluctant to discuss. The PAG were very aware of the concerns that people who had experience of restraint might have about taking part in our study. They drew on their insight to coproduce the study information in order that it would allay fears about the interviews and encourage people to come forward.

In addition, the PAG helped to design a topic guide for the semi-structured interviews that would cause least distress to participants and included questions that would be relevant and meaningful to the participants and encourage them to share their experiences and insights.

Once the interviews had been completed the PAG was provided with a summary of the key themes emerging from the patient interviews. There was a guided discussion which enabled members of the group to express their thoughts about the findings, giving the researchers insight into patient interpretations of the key themes. There was also discussion of how findings from the project might be used and what recommendations for reducing restraint might arise from the study.

There were a few challenges relating to resources, such as the time involved in organising and running the groups. There was also an issue with attrition as some members opted out of the meetings as time passed. However, overall the impact of the PAG was extremely valuable. In summary, the benefits of PPI to the PROMISE qualitative project included: enhanced ethics application, improved study documents and the development of a relevant, well-structured and sensitive interview guide.

In 2016 a new PROMISE Advisory Group was recruited which also included also two carers. This PAG was established to provide input on different service development projects and research related initiatives. An advert with information about the project and a role description was widely circulated to people with lived experience of mental challenges within CPFT and to local user-led support groups and mental health charities. Unlike the first PAG there was no requirement to have direct experience and/or to have witnessed restraint. There were over 20 expressions of interest from people who were keen to challenge the use of physical intervention. Participants were introduced to the aims of PROMISE project at the first meeting in August 2016.

The PAG was actively involved with Trust service development work such as de-briefing and de-escalation training. The Trust devised the 'Seclusion and Segregation Policy and Practice' to ensure that patient human rights outlined in the Mental Health Act Code of Practice 2015 are safeguarded and protected. The PAG were asked to give a patient perspective on the policy and practice and advise on any enhancement that could be applied to ensure that the Trust safeguards its patients and protects their rights.

The policy has been amended in several ways as a result of the group's discussions. Key themes emerging included the importance of informing and involving the patient's family and friends early in the process and placing more emphasis on communicating with patients and giving them choice. The PAG also suggested that there should be more emphasis on the debrief and communication with patients and staff following an episode of seclusion to encourage reflection and learning. In addition, they stressed that the language used in the policy should be therapeutic and recovery orientated. The PAG have influenced CPFT's Seclusion Policy, in more practical ways too, for example in the design of the seclusion room which has been changed to include a clock displaying both time and date, and more patient friendly furniture.

PROMOTE is one of the four Promise frameworks. It provides a simple framework for reflection to develop and test out new ideas which challenge the status quo and facilitate positive change. An example of a PROMOTE initiative is the 'No' Audit where the objective is to empower staff to be creative in saying 'Yes' and embed a 'Can Do' culture. The aim is to create a reflective space to explore the balance between the needs of one patient against those of the others and to put patients first, capture hope and decrease frustration.

As part of the work relating to the 'No' audit a pilot survey was created to learn which requests were most commonly denied by staff (N=22). Ten members of the he PAG completed the same survey (N=10) which was also circulated to user-led organisations, as it was important to understand which requests patients feel that they are most often denied, see figures 1 and 2.

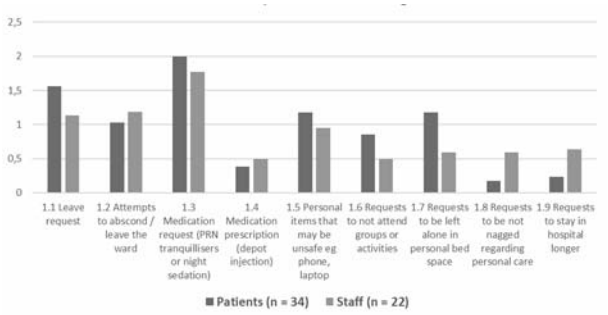

Figure 1. Patients and staff: requestas denid on grounds of risk

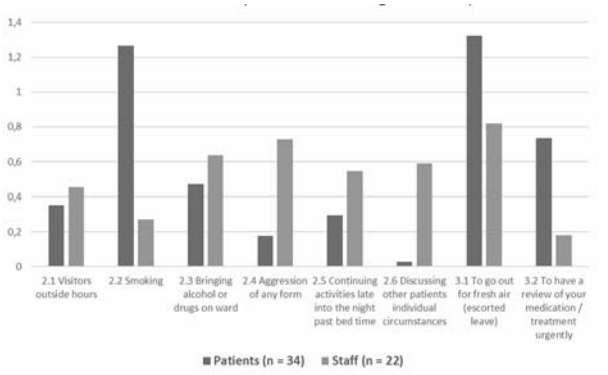

Figure 2. Patients and staff: requestas denid on grounds of policies

To assist with the work on the 'No' Audit the group were also presented with some challenging scenarios and asked questions relating to them:

- What do you think needs to happen now, what are the key issues?
- What are the barriers to the use of de-escalation?
- What would make it easier to use de-escalation techniques?
- From your point of view, which skills and techniques should staff be able to use or should they have? How training should be delivered?

Their insights provided additional exploration of difficult situations that are often difficult for staff to deal with sensitively, especially when trying to striking the balance between the needs of one patient against the needs of the others.

In addition, two separate meetings were held to assist with a NIHR grant application that the PROMISE team submitted to develop a manualised de-escalation training package/toolkit. The group was presented with the overall research design, they reviewed each work stream, and discussed practicalities of the project and ways to meaningfully involve patients in the study. The PAG contributed by making suggestions regarding the methodology, providing assistance with the Lay summary and reviewing the PPI section of the application.

There was a final feedback meeting at the end of May 2017 after a total of seven PAG meetings. Fourteen members of the group completed an evaluation survey which included qualitative and quantitative questions.

The eight quantitative questions were on a scale of 1-10 and when the results were analysed there was a satisfaction score of over 8.5 in every category, see figure 3.

Examples of the general comments that were received included:

- "Very happy to have been involved in such a worth while project"
- "I really enjoyed taking part, thank you for the opportunity"
- "I would like to be able to continue as a service user, to monitor the implementation of 'anti resistant' recommendations"
- "Very important project, very much hope the Trust will support implementing findings"

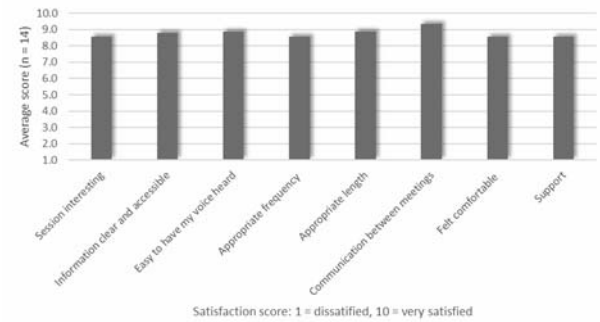

Figure 3. Promise Advisory Group Evaiuation

CONCLUSION

Coproduction is one of PROMISE's core values and PPI has been a golden thread running through the project since its inception. The remit of the first and second PROMISE PAGs was different but both groups had an impact by playing a key role in research activities and shaping the project.

The first PAG was recruited to work with the researchers on the qualitative project. Members of the group were involved in creating the study materials, co-designing the methodology and defining the research questions. The group's influence was recognised by the ethics committee who commented that the excellent PPI had enhanced the application. The PROMISE team believe this contributed to ethics approval being awarded quickly after one small amendment was made. The second PAG had a different remit as some of the work related to service development initiatives as well as a NIHR funding application.

In the first PAG it was a challenge for the researches to coordinate and run the meetings as the qualitative study had to be conducted within a tight timeframe and they had competing priorities. As a result, the meetings were not always held regularly which may have contributed to the attrition of participants. The meeting minutes were always circulated promptly, however time constraints made it difficult for the researchers to keep the group members engaged in between meetings.

The participants that were recruited to the two PROMISE PAGs had a different role but both groups were run along broadly similar lines. In the case of the 2nd PROMISE PAG, the author communicated directedly with the participants and arranged the meetings. She cofacilitated the sessions with the PROMISE Research Associate and meeting minutes were always circulated to the PAG together with presentations and/or other relevant information. If the group were being asked to discuss the contents of a document during a session it would be circulated ahead of the meeting to give the participants the opportunity to read it in advance.

Despite the author having more time to arrange the PAG meetings and making communication a top priority the attendance varied between session from between 5-12 members. Although it wasn't always achievable, the participants expressed a preference for regular monthly meetings because they were genuinely interested in the project and keen to provide their input. It also gave them a sense of continuity and they valued the social component.

Several lessons have emerged from the PROMISE PPI work. Good PPI takes time, effort and resources. With both PAGs a job description was circulated to prospective participants to ensure the expectations were clear from the outset. This was important because it meant people understood their role and what was required of them. Effective communication was another key component as people felt appreciated and were more engaged with the topic. The members also valued feedback regarding the actions that had resulted from the group discussions.

Holding regular meetings, giving people the opportunity to voice any concerns and having an easily accessible venue is likely to boost attendance. Members of both groups were paid for their time and travel which as one participant said in the survey *'remuneration for mileage and attendance in an important feature of valuing us as volunteers'*.

An area that is often underreported is the benefits to the participants from being involved in a PAG group which can help to give them a sense of purpose, establish social networks and support their recovery. Comments received in the survey included: *'We have built up a sense of identity & purposefulness'* and *'I do value my contact with the group however, it helps me feel a sense of purpose and is very interesting'*.

One of the challenges with both PAGs was recruiting members of different ages, educational backgrounds and ethnicities. This is not unique to the PROMISE project because it's an issue that many PPI groups are grappling to address. Both PAGs were held in Cambridge which was probably another contributory factor as the population is less diverse than Peterborough.

In summary, the 2 PAGs that were funded by CLAHRC EoE have been instrumental in informing the

PROMISE research and service development work streams. Clinical staff from the Trust who presented at the 2nd PAG meetings were so impressed with the feedback and the number of relevant comments they received that CPFT have made a commitment to support the group going forward. It is envisaged that remit will be widened to include implementation, audit and evaluation work across all the directorates.

References

1. *Mental health crisis care: physical restraint in crisis A report on physical restraint in hospital settings in England MIND June 2013.*
2. *"Positive and Proactive Care: reducing the need for restrictive interventions". Department of Health 2014.*

Acknowledgements:

This paper presents independent research funded by the National Institute for Health Research. In preparing this manuscript 'Authors' received support from the NIHR Collaboration for Leadership in Applied Health Research and Care East of England (CLAHRC EoE) at the Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.
The author would like to thank the PROMISE team and members of the 2 Patient Advisory Groups for their contribution to the project and the Cambridgeshire and Peterborough NHS Foundation Trust and the CLAHRC EoE for the funding support they provided.

Conflict of interest: *None to declare.*

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