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## **Special Feature Article**

### **Treating Empirical Knowledge on an Equal Footing with Expert Knowledge: Co-Producing Research on Involuntary Admission with Psychiatrists and Service Users**

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#### **Abstract**

Medical evidence had been built through research led by experts, and patients, who participated mainly as study subjects. Gradually, patients' subjectivity (e. g., the effect of drugs, quality of life) has been adopted in research results. In recent years, "Patient and Public Involvement (PPI)" evolved, and more patients have been involved in research planning, research implementation, and utilization of results. Hence, the patient's empirical knowledge is gradually added to the evidence built up by specialized knowledge, thus changing the entire body of medical knowledge. PPI takes a different form depending on the research design and how patients are involved. Service user-led research and co-production are expected to be suitable for drawing up empirical knowledge, and the results of those studies in the UK and other countries inform medical policies and clinical guidelines. This article will examine the effects of service user-led research and co-production on psychiatry and introduce co-production research conducted by the author with patients who have undergone compulsory hospitalization. We hope this article will serve as a hint for implementing PPI and co-production in Japanese psychiatry in the future.

**Keywords:** PPI, co-production, service user-led research, involuntary admission, service user experience

## Introduction

In modern medicine, medical research is led by experts, and patients (tojisha) are passive participants who simply take part as subjects. Gradually, however, there has been an increase in research that places the tojishas' subjective views (e.g., how a medicine feels when taken, and the quality of life) at the core of the results. Furthermore, in recent years, "patient and public involvement (PPI) in medical research and clinical trials" has been implemented, in which tojisha participate in all stages of research (from the setting of research topics and research design to the setting of research objectives, implementation of research, summarization of results, and their utilization).<sup>17)</sup> PPI includes a variety of methods, such as service user-led research (mad study), and among them, co-production, which is characterized by the equal treatment of expert knowledge (expertise) and experience of service users (empirical knowledge), is viewed as a promising concept.<sup>4)</sup> In this paper, we will focus on PPI, service user-led research, co-production, and examples of their implementation, and consider ways to

build up tojishas' experiential knowledge as evidence.

## I. Evolution of Handling Specialized and Empirical Knowledge

The value of knowledge (specialized and empirical knowledge) depends on the power structure and perspective.<sup>18)</sup> This power structure is built and strengthened when issues are imposed from the outside without being identified from the inside. For example, during the colonial era, the suzerain state would unilaterally conduct surveys of colonies, and if any differences were found between the suzerain state and colonies, it was concluded that this was because the suzerain state was advanced and colonies were primitive, and this conclusion was sometimes used to justify the prosperity of the suzerain state's imperialism.<sup>9)13)</sup> This kind of one-sided perspective and construction of power structures also applies to the field of science. In other words, it is possible that researchers continue to record completely different interpretations, even though the research subjects have important perspectives.<sup>9)</sup> Minority groups and

people with mental disabilities, for example, are rarely provided with the opportunity to have their experiences and opinions directly considered, and even when they are asked, their statements are often dismissed as not trustworthy, and so their experiential knowledge tends to be excluded both academically and socially.<sup>19)</sup> Furthermore, there are gaps within groups, and although the experiential knowledge of those involved has been accumulated through disability studies and other fields, many of these experiences are mainly from Western countries, and even within these, there are claims that they are biased as they only focus on the experiences of certain races, classes, etc., in a particular way.<sup>7)</sup>

In order to overcome such power structures and biases in perspective, and resolve the divide in knowledge, we need to shift from having others tell our stories to having the *tojisha* themselves tell their own stories.<sup>4)26)</sup> Furthermore, we believe that it is necessary to develop a method for accumulating these stories. In this regard, the ideas of feminism and disability studies may be helpful. They believe that research into those who are socially excluded should be based on service user-led research, in which *tojisha* conduct their own research based on their own experiences, and that even if this is difficult, co-production should at least be

guaranteed, in which *tojisha* work with experts on an equal footing.<sup>21)26)</sup> Furthermore, they also point out that researchers, whether they are *tojisha* or experts, should be clear about their own positionality and reflexivity when conducting research.<sup>15)</sup> This positionality and reflexivity refers to an attitude of being aware of one's own biases and socio-cultural position and dealing with them accordingly. This facilitates the accumulation of knowledge with an awareness of existing knowledge, one's own position regarding research participants, the limitations of methods, and tolerance of counter-evidence.

In addition to these research and clinical settings, experience-based knowledge and equal participation of *tojisha* are also required at all levels, including legislation and policy-making. The United Nations Convention on the Rights of Persons with Disabilities (CRPD), which Japan has also ratified, stipulates that it is essential for *tojisha* to participate in decision-making regarding themselves in all situations, and that their intentions and wishes are respected, and it recommends that those with disabilities participate in the consideration of policies related to such persons with disabilities. Through these efforts, the accumulation of experiential knowledge in fields that have been built on expert knowledge up to now will

result in a change in the overall knowledge of the relevant field,<sup>1)</sup> and this is an important change. In particular, psychiatry is a field where the opinions of patients (tojisha) are sometimes deliberately excluded, such as when they are hospitalized and treated against their will, and the overall change in psychiatric knowledge that occurs as a result of the accumulation of tojishas' experiential knowledge is expected to be greater than that in other fields.

## II. Patient and Public Involvement (PPI)

PPI is currently being addressed around the world. Particularly well-known initiatives include the Patient-Centered Outcomes Research Institute (PCORI) in the United States<sup>14)</sup> and the United Kingdom's INVOLVE<sup>10)</sup>, which has been running since 1996. These initiatives have made it possible to conduct research in areas that are important for users of medical and welfare services (tojisha), and the results of this research are being used to design health systems in each country.<sup>4)20)</sup> In addition, the Japan Agency for Medical Research and Development (AMED) is contributing research funds to PPI,<sup>12)</sup> and domestic research in this field is also increasing.

There is criticism that, despite its growth, PPI is a hodgepodge of biased

case studies and case reviews conducted only by people with a high level of awareness of the issues. We believe that there are two things that are necessary for the development of PPI. First, it is necessary to establish a definition (or framework) for PPI. Because the objectives, involvement of tojisha, and research methods of PPI differ depending on their roots, it is not possible to lump all previous PPI together. For example, PPI that has arisen from campaigns for civil rights and human rights activism is aimed at improving the rights of citizens, and is considered to involve many case studies with little emphasis placed on the development of research methods.<sup>17)</sup> In the field of medicine, this includes human rights activities by HIV/AIDS patients, where patients themselves take the lead in campaigning for the abolition of discrimination laws and reduction of the price of treatment drugs. In addition, PPI, which has its roots in participatory action research, addresses issues that directly affect the daily lives of tojisha (local residents, etc.), and implements interventions and activities designed by tojisha in the local community, making modifications to the interventions as necessary and studying what can be learned from the interventions through randomized controlled trials (RCTs) and other methods. The power relationship

between the researcher and researched (e.g., developers and local residents, or researchers and patients) may not be overcome, and the research results are not considered to represent universal knowledge because they are seen as the experiences of specific residents in a specific area, and so are treated as case studies. Based on these characteristics, we would like to establish what is called PPI by organizing the objectives, the way tojisha are involved, and research methods. Secondly, the research design and evaluation methods used to construct evidence need to be modified to include PPI perspectives.<sup>18)</sup> Currently, when considering evidence, the value of systematic reviews and RCTs is high, while the value of experience and opinions is low, and quantitative research is emphasized compared with qualitative research (such as interviews). As a result, the experiences of tojisha, PPI, and co-production are considered to be case reports and regarded as low-value research,<sup>18)</sup> and the research plan is not adopted or value of the research results is not recognized.

In order to modify the methods of evidence building, it would be effective for researchers to overcome the assumption that science is always objective, universal, and neutral, and recognize that all knowledge is formed from some kind of socially conditioned

perspective.<sup>11)</sup> To achieve this, it would be beneficial for researchers in psychiatry to utilize the findings of sociology and anthropology, and create an environment in which it is natural for tojisha to be involved in research and policy-making.<sup>4)</sup>

### III. Type of PPI: Service User-led Research

There are various ways to involve tojisha in PPI. Of these, service user-led research (also known as service user-led research or mad research) is the most likely to capture the perspective of tojisha and accumulate honest experiential knowledge. In order to carry this out, it is essential to include people who are both tojisha and have research skills. In the UK, which is a pioneer in service user-led research, there are around 800 people who are both tojisha and researchers, and this is considered to be one benchmark for human resource development. In Japan, the necessity of tojisha acquiring research abilities is also becoming apparent. One potential avenue for advancement is the active integration of tojisha into future doctoral admissions and researcher recruitment quotas, which could gradually enhance the quality of human resources. Furthermore, it is necessary to promote research systems and research funding

that value the experiential knowledge of tojisha.

SURE (Service User Research Enterprise)<sup>8)</sup> in the UK is well-known for its service user-led research in the field of psychiatry. As its first activity, SURE conducted a systematic review of the effectiveness of electroconvulsive therapy (ECT) led by tojisha. As a result, it was found that while the reviews conducted by existing experts emphasized the therapeutic effects, the tojisha placed as much emphasis on the side effects as on the therapeutic effects, based on the same literature.<sup>16)</sup> In response to this, SURE proposed a treatment selection based on both the therapeutic and side effects, and the results were reflected in the UK's clinical guidelines.

#### IV. Type of PPI: Co-production

In PPI, the next most promising approach after service user-led research is co-production, in which tojisha (experiential knowledge) and service providers (expert knowledge) approach research with equal power.<sup>5)</sup> In co-production, tojisha and experts discuss and decide on the research topic, implementation, summarizing of results, and how to use the research results from an equal standpoint, and both expert and experiential knowledge receive equal weight as evidence. The following two points are important for

meaningful co-production. The first is the issue of how to make the relationship between tojisha and experts more equal. The current hierarchy in society and the fields of medicine and research is marked, and the relationship between experts and tojisha is imbalanced at all levels, including organizational and individual levels. For example, research funding is often controlled by experts, research designs tend to prioritize those established by experts, and research results are often evaluated using existing frameworks created by experts. Furthermore, can patients with mental disorder work comfortably alongside psychiatrists who may order their involuntary admission? In order to achieve equality in all power relationships, it is necessary to dispel the prejudice of experts that patients are unable to engage in research.<sup>17)</sup> Furthermore, it is necessary to state that the value of all those participating in co-production is equally important, develop a research system based on this, and create an environment in which each of the parties involved is aware of their positionality and reflexivity, respects differences, and can continue to engage in dialogue.

Secondly, the issue of ensuring the representativeness of tojisha in co-production is also discussed as a research method issue. This is a

question of whether those involved in co-production as *tojisha* may be advancing research based on their own personal views, and whether this may lead to bias. Co-production is a research method that can highlight diversity. It can be said that this research picks up on things that are overlooked when pursuing representativeness,<sup>6)</sup> and we think that it can even compensate for the shortcomings in the current evidence-building process that is pursuing representativeness. We also believe that the problem of representativeness can be overcome by pursuing theoretical saturation. Here too, the perspective held by experts and researchers is called into question.

## V. Examples of Co-production in Practice

The author conducted individual interviews and theme analysis using collaborative qualitative research methods, and will share the experiences as examples of co-production in practice. This study was conducted with patients, their families, and their attending psychiatrists, with the aim of learning about the patients' intentions and experiences at the time of involuntary admission to a psychiatric hospital, as well as the environment and relationships that led to this. As this theme is an experience of social marginalization for *tojisha*, it was

considered essential to introduce PPI and coproduction, rather than having the author (doctor) take a leading role in the research, in order to have *tojisha* speak about their experiences and feelings as they are. This study was approved by the ethics committees of the University of Tokyo and all participating facilities, and was conducted with the support of the University of Tokyo, Fuji Xerox Co., Ltd., and the Kobayashi Fund. Some of the results of this study<sup>23)25)</sup> and experiences<sup>22)</sup> have already been published, so please refer to those as well. This study was conducted in Japan and India, but this paper focuses on the part conducted in Japan.

The specific research method was as follows: (i) First, the author (doctor) drafted a world view of the experience of psychiatric involuntary admission based on his clinical experience, and then a researcher who had experienced psychiatric involuntary admission revised it based on his own experience. The world view that was created initially emphasized the relationship between *tojisha* and medical services, but elements of daily and social life were added, and laws, systems, and social values were added as supporting evidence. (ii) The research methods were discussed by the researchers who were also *tojisha*, the author (physician), and other medical professionals, and as

this topic was a sensitive one, it was decided to use interviews rather than questionnaires so that the nuances could be captured. (iii) Tojisha (people who had experienced involuntary hospitalization) to conduct the interviews were recruited using snowball sampling. (iv) An interview guide was created based on the world view of (i). Using this interview guide, the basic techniques of interviewing (such as maintaining neutrality, asking in an open-ended format, and not deviating too far from the topic) were practiced with the tojisha gathered in (iii), and the wording and order of the interview guide were adjusted to make it easier to use. The interview guide included questions about the circumstances leading up to hospitalization, the examination conducted during hospitalization, the circumstances and impressions of the decision to involuntarily commit the patient, impressions of hospitalization, and impressions of the decision to discharge the patient. (v) Using theoretical sampling, we recruited adult patients who had been involuntarily admitted to a psychiatric hospital (medical protective admission, involuntary admission) within the last three months at hospitals selected using the snowball sampling, and asked their respective attending physicians to introduce them to us. If we obtained the

patient's permission, we also recruited their family members and physicians. If consent to participate in the study was obtained after recruitment, individual interviews were conducted using the interview guide with the tojisha collected in (iii), and these interviews were recorded. (vi) The recordings were transcribed verbatim, anonymized, and stored in NVivo 12, and thematic analysis<sup>2) 3)</sup> was conducted. Qualitative researchers, nurses, and tojisha also participated in the analysis to confirm that the codes and themes accurately reflected what was said. (vii) Steps (v) and (vi) were repeated until no new themes emerged (theoretical saturation). (viii) Next, we created theme definitions, identified representative quotes, summarized the results, and reported them. For the results of the study, please see the existing papers.<sup>2)23)25)</sup>

## **VI. Considering Expert and Empirical Knowledge through this Practical Example**

The results of this study were presented at meetings of the tojisha association, family associations, academic societies, etc., and each time we heard feedback from patients, family members, and doctors that it captures their own experiences. We believe that this is one indication that the participants in the interviews spoke

candidly based on their own experiences, and that a diverse range of experiences were covered in this study. In addition, by being published in academic journals that are included in search engines, we believe that it can be used in subsequent reviews and studies, and contribute to the construction of evidence. Through this research, we would like to show that co-production is a viable approach and one that is well-suited to capturing the experiences of tojisha and building up their experiential knowledge. In addition, there are other examples of systematic reviews of experiential knowledge, such as the report by Sugiura, K. et al.<sup>24)</sup>

In addition, there were several experiences in this study that we felt were caused by the divergence between expert and experiential knowledge, and we think that they are useful in implementing co-production, so we will share them here. Firstly, the research plan stated that the decision to participate in the research should be made with the consent of the tojisha themselves, but the ethics committee stated that participation in the research required the consent of a proxy as well as that of the tojisha themselves during involuntary admission. This research was conducted with the approval of multiple ethics committees. At one of these, the representative of the tojisha (who attended all the hospital's ethics

committees and whose own illness was not necessarily a psychiatric disorder) was a member of the committee, and it was surprising that, like the other expert committee members, he interpreted the need for double consent from the tojisha (research participant) and the proxy as being in the tojisha's (research participant's) favor because it meant that they were being better protected. Secondly, although the author (doctor) wanted to conduct individual interviews with only the tojisha (interviewer) and tojisha (patient), the ethics committee requested that the author (doctor) be present at the interview and intervene and interrupt the interview if the research participant became stressed. Thirdly, even though the attending physician introduced the target for recruitment, there were cases where the target was skeptical about whether they would be able to continue with the interview or conversation. In the actual interviews that followed, the participants expressed their thoughts and feelings, and the participants' comments differed between clinical situations (with experts) and everyday situations (with the interviewer). In addition, because theoretical sampling is used to build up interviews until theoretical saturation is reached, researchers and experts need to understand that even if each

participant only talks about part of their experience, the final research results will still encompass the full range of experiences. Fourthly, the ethics committee and attending physician felt that there was a risk that the content of the interviews would be invasive, but the interviewees responded positively, saying: “Finally, there is someone who will listen to me,” and the active listening in the interviews may have actually been therapeutic. Furthermore, the interviewer expressed the opinion that it would be good if all people who had been hospitalized could have an opportunity like this interview to look back and verbalize their own experiences. Fifthly, when the interviewer appeared on the ward, the nurses who had been in charge of the patient's care when he/she was hospitalized were surprised to see him working so cheerfully. It was thought that if medical staff only saw the patient's poor condition and treated them accordingly, they would lose sight of realistic hopes, and subsequent treatment would be carried out from the perspective of medical staff with a conservative outlook. In the future, it would be good to foster more opportunities for medical staff to meet patients beyond the therapeutic relationship in their daily lives and at work. Sixthly, it was interesting that

the participants in this study often stated that: “doctors should listen more.” It was interesting that the participants in this study often said: “We don't always expect quick advice.” Medical professionals tend to think they have to diagnose and treat efficiently, and they tend to listen to patients' complaints selectively from a medical perspective and make quick suggestions, but we felt that it was important to listen to patients' thoughts as they are and empathize with them.

### **Conclusion**

In research, if experts continue to interpret and record from their own perspective without being aware of it, they will leave the *tojisha* behind, even though it is actually about the *tojisha*. In this paper, we have introduced the idea and methods of accumulating experiential knowledge in mental healthcare, which has been created using expert knowledge up until now. The underlying ideas include the notion that people with mental disorders are not objects of protection or compassion, but equal citizens, which is also an element of CRPD and the slogan “Nothing about us without us” for improving the rights of people with disabilities. We hope that PPI will become more widespread, and that we will be able to accumulate evidence that strikes a good balance between expert

and experiential knowledge, so that tojisha will be appropriately understood and we will be able to practice psychiatry that is truly useful for tojisha.

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