Examples of user involvement in managing research

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Emotional health needs of Pakistani and Bangladeshi people in Newcastle[1]

Purpose: The Primary Care Group in Newcastle wanted to find out more about the needs of their Pakistani and Bangladeshi communities. They wanted to understand how they described emotional distress from a cultural perspective. They wanted to know what support they would need to deal with distress, as the outcomes would influence the services that local primary care groups would provide.

Setting up the Patient Forums: Pakistani and Bangladeshi community members were invited to join the project team through community advertisements. Thirteen were employed and joined the project team as paid Community Project Workers (CPWs).

Roles of the user consultants: After a 6 month training period, they co-designed the project under the supervision of experienced service managers and researchers. They:

- developed the interview guides and interview process

- advised on cultural matters

- used their community networks to gain participants for the interviews who then encouraged others to participate

- did the interviews

- analysed the information with a researcher

- shared the outcomes with community members and organisations

Support provided to user consultants: The CPWs went through a 6 month training period – 6 hrs/week – the training was accredited through the National Open College, so it was nationally recognised. Experienced service managers and researchers supervised them on a regular basis. They were paid project members on a part-time basis. After the training phase they were able to work flexible hours so they could continue meeting other study or family commitments.

Level of influence or decision-making: The CPWs had strong influence on all aspects of the project design. They were the main decision-makers about what questions to ask, how to ask them and how to run the interviews. They were partners in the project analysis. They guided the researcher in understanding what was said and why in the interviews. They reviewed and

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confirmed the final descriptions of what the information meant about community members' experiences and changes in services.

Activities that happened: After initial discussions in the primary care group about why services needed to be improved for these community members, community members were recruited to be team members. There was an initial training period, and then the project team worked out how to gain the information they needed. The CPWs did 104 interviews with community members. The information gained in interviews was analysed. It was then shared with different primary care groups, other local services and community members through regular meetings and formal presentations. A final report was written.

Outcomes achieved: The project led to these outcomes:

- found out how mental health services were working for local ethnic minority groups

- better location of support workers where community members could reach/visit them

- the primary care group brought in and trained more counsellors from Asian backgrounds to offer more culturally appropriate services

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- worked on a way to address racism in the local area

Strategies for success: The main strategies that helped the project be successful were recruiting a small group of people directly from the community who understood how to reach community members in an effective way. Listening to their cultural advice with respect and building this into all parts of the project. Providing extensive training and then doing a test run to help build the CPWs' confidence. Providing ongoing supervision for CPWs to help with any problems that occurred. Communicating the outcomes back to the community so they know what had happened to their input.

Problems that occurred: Service managers and researchers wanted to know some personal details that CPWs said community members would not give because they were intrusive questions. Staff had to learn to balance information they expected they could ask with what was culturally sensitive. If not they would lose other very valuable information because people would not participate or speak in detail.

There was tension between staff supervising the CPWs and senior staff about how quickly the project should happen. Senior staff realised that they were so familiar with the wider

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health service issues that they forgot they were working with people who knew little about this and should be more patient.

Benefits achieved: The project:

- employed workers from Asian backgrounds in a community with a high unemployment rate

- got good participation from a mostly non-English speaking disadvantaged population who had low literacy levels

- gained in depth information because the process was appropriate to the group

- had solid information that they could use to make service changes

- learned about the different views of what emotional distress is and how people show it – this will reduce misunderstanding between staff and community members

Reference

1.   Kai, J. & Hedges, C. (1999). Minority ethnic community participation in needs assessment and service development in primary care: Perceptions of Pakistani and Bangladeshi people about psychological distress. *Health Expectations*, 2, 7-20.

Case example analysis

Use what you have learned so far about user involvement to decide if what happened in your example was:

Poor   OK   Good   Excellent

Rate the 7 areas below. For some areas you may wish you had more information. Just do the best you can with what you have. After you rate each area give brief reasons for your decision.

- If you liked something, say why.

- If you think something was missing, then say what it was.

- Someone must record your decision and reasons for each area. Another person must be your group representative when we return to the large group.

1. A good **range** of users, carers or the public were involved

2. User consultants had meaningful **roles**

3. There were realistic **expectations** of what they would do

4. They received strong **support**

5. They had strong **influence** in the decisions

6. Their involvement had **benefits** for the organisation

7. Their involvement had **benefits** for other users, carers, and/or members of the public