

John's experience of shared decision making in primary care: A journey towards recovery from depression

This submission demonstrates:

- Co-production activity involving service users and professional researchers
- Shared decision-making as a valuable approach for improving service user experience and quality of care
- Co-production activity as a therapeutic intervention

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Name of organisation: **Institute of Health & Society, Newcastle**

Website address:

<http://sdmdepression.ncl.ac.uk/>

Summary

Six service users (experts by experience) from a mental health charity (Moving Forward Service Newcastle) worked with Newcastle University Staff to co-produce an educational film about the value of shared decision-making (SDM) for supporting recovery from mental health problems.

Using depression in primary care as an example, with input and contribution from Frank Bruno MBE, the film uses a fictional narrative of John who is experiencing symptoms of depression, and his close friend Stacey, who supports him on his journey towards recovery. The film demonstrates how SDM can improve the quality of his care.

- (i) research evidence;
- (ii) peoples' personal information needs and preferences for choice of treatment from available options; and
- (iii) peoples' individual attitudes towards the different pros and cons available options.

Although SDM is a core component of the mental health service improvement agenda, there is a lack of evidence-based methods or tools to support SDM in routine mental health consultations.

Aims

- Raise awareness of SDM.
- Demonstrate the value of SDM for supporting recovery.
- Build skills and confidence for SDM.

Objectives

The film was designed for use:

- As a medium to raise awareness (amongst the public, service users and their relatives, carers, clinicians, peer-support workers and advocates) of the principles and benefits of

Background

Shared decision-making (SDM) is a process through which service users, their relatives, and clinicians work together to identify the treatment option that best suits the individual service user, by taking into account:

SDM for supporting the empowerment of service users and to facilitate their recovery.

- To demonstrate that people with mental health diagnoses can engage in SDM, thereby improving their experience of healthcare.
- To develop knowledge and understanding around how individual service users make choices about their treatment and care based on what is important to them (i.e. their own personal preferences, thoughts, feelings and values).
- As a vehicle to help tackle mental health stigma, by portraying positive messages of service users with mental health problems (for example their active participation in the film production and marketing activity).

Approach

- The philosophy underpinning co-production is that people with insider knowledge and lived experience of mental health symptoms and using services (experts by experience) are best placed to help design, refine and improve the quality of those services. This leads to credible, high impact outputs which reflect their perspectives and priorities (as opposed to exclusively being focused on the perspectives and priorities of clinicians or researchers).
- Co-production involved six experts by experience, two psychologists, and a film crew resulting in a broad spread of individuals with various backgrounds, training and levels of experience, which enhanced the quality of the film through diversity in their perspectives.

- Consensus on ground rules and ways of working was agreed by the co-production team.
- Experts by experience led on the development of the film storyboard and script through thought-showing discussions drawing on personal experiences. They also led on the editing process, design of graphics and communication materials such as leaflets, a poster and presentations to raise awareness of the film. Experts by experience also appear in the film as actors and narrators.
- A screening and feedback event (using an alpha version of the film) was co-designed and delivered by the co-production team. This was attended by 34 service users, relatives and service user representatives from local and regional mental health groups and organisations. Feedback from attendees informed revisions of the film content, through discussions with the production team.

Challenges

As SDM is not as well-used as it should be, the experts by experience involved in film production were not necessarily fully aware of the technique, so were encouraged to undertake self-directed research on the subject. They also received skills development support in project management and access to resources, such as a professional film crew and studio.

Outcomes

The film is freely available for use by the public, those working within mental health services, and service users and members of their family. It can be viewed or downloaded from the film website:

<http://sdmdepression.ncl.ac.uk/>

The film is applicable to the following core areas of the service improvement agenda for mental health:

- (i) improving service user experience in adult mental health services;
- (ii) involving service users and members of their family/carers in decisions about their treatment and care; and
- (iii) partnership working with experts by experience to inform development of mental health treatment that is person-centred and recovery focused.

Conclusion

Based on the success of the co-production process and the positive feedback received about the film, in partnership with voluntary charitable organisations, Newcastle University and a social enterprise, a strategic plan is now in development for co-production projects to be made available as a therapeutic option for mental health service users in primary care. Academic publications will be submitted to open access journals reporting on (i) an evaluation of the film's impact on mental health stigma; and (ii) good practice for co-production based on the perspectives of those involved in the film. In due course, it is hoped that the learning from this co-production project will inform similar initiatives nationally.

Feedback

"We are all either current or potential mental health service users."

"Co-production enabled service users to utilise their existing knowledge and skills to produce a high quality and impactful film that aims to improve mental healthcare. Furthermore, the process of co-production evolved into a therapeutic intervention which increased their knowledge, skills and confidence."

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