



Implementing and evaluating My Healthcare Passport: a participatory action research project

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Project background

East Kent Hospitals University NHS Foundation Trust acknowledged the significant health inequalities experienced by adults with learning disabilities in hospital. A healthcare passport was identified as a person-centred and patient-owned tool that contained pertinent personalised information that would enable healthcare professionals to make adjustments for someone less able to communicate their needs and wishes. Led by the trust, a multi-stakeholder group co-created a tool over a 12-month period and was awarded charitable funds to have the tool professionally designed and launched.

While stakeholders celebrated the launch of the passport at a public event in 2012, new questions emerged over its use and the improvements that adults with learning disabilities and their supporters could expect as a result of using it.

Aim

The aim of this participatory action research project was to work collaboratively to identify, implement, evaluate and refine strategies that would enable the passport to be used effectively in a person-centred way with people with learning disabilities. To achieve this, the objectives identified were to:

- Identify practical strategies to facilitate the effective implementation of My Healthcare Passport
- Develop indicators, methods and approaches to evaluate My Healthcare Passport
- Enable people with learning disabilities to contribute to the evidence base around the use of the passport

Implications for practice

- Involving non-NHS staff as partners in NHS research requires creative, reflexive, facilitative leadership
- Initiatives to employ more people with learning disabilities will need to account for issues associated with DBS checking
- Person-centred, patient-owned health records such as My Healthcare Passport require ongoing collective action to sustain awareness
- IT systems can make My Healthcare Passport accessible to those who require the information, while safeguarding it from falling into the wrong hands
- Use of passports is an emerging indicator for regulators and national initiatives

This project was supported by the FoNS Practice Based Development and Research Programme in partnership with the General Nursing Council for England and Wales Trust

Online

Further information about the project can be accessed from: fons.org/library/report-details?nstdid=71699

Key activities and outcomes

The co-researcher team, comprising nurses, people with learning disabilities, parent carers and a care home manager, met 10 times over a 12-month period.

• Co-researcher meetings

Underpinned by the principles of practice development, critical and creative methods such as active learning, fourth-generation evaluation and person-centred planning tools were employed to create the spirals of action research activity in a mixed ability co-researcher team.

• Facilitation and practice development

Working within a unique stakeholder and mixed-ability group required consideration of safeguarding, capacity and consent issues, creative application of tools and methods to engage and reflexivity to enable all to contribute to the research process and team dynamics and to reflect on progress and outcomes.

• Stakeholder consultation

The co-researcher team identified communities across the whole of the East Kent community to consult, either in person or via a web survey. This consultation sought to understand who had used the passport, its perceived benefits and potential improvements. The co-researcher team collectively analysed the data, identifying themes, recommending further action and taking this action.

• Spirals of activity

Two key spirals of activity were identified: co-researchers developing an understanding of the role of the researcher and working together to identify further spirals of activity.

• Status

Non-NHS staff experienced significant challenges to their ability to contribute, which related to status and administration. An example of this was the co-researchers with learning disabilities not having sufficient identification to achieve a clear Disclosure and Barring Service (DBS) check, preventing them taking up full co-researcher status. To overcome this, the team chose to purchase sufficient identification for their co-researchers with learning disabilities – for example passports – enabling them to play a more active role as citizens.

• Consultation results and themes

The co-researcher team consulted with approximately 420 stakeholders. Through collective analysis three themes emerged: to make improvements to the passport; to sustain awareness of the passport; and to use IT systems to store the passport. As a result, the following steps were taken: My Healthcare Passport was redesigned and an editable passport was published online; a hospital audit tool was created and tested; a partnership project with medical alert device maker tap2tag (www.tap2tag.me) was planned to store and access My Healthcare Passport; a film about the project has been published online (see: tinyurl.com/EKHUFT-passport); and a life story workshop has provided evidence for a new project led by East Kent Mencap.

IMPROVEMENT INSIGHTS