

Patient and Person Driven Care  
Case Study - No. 2

## Partnering with patients through stories for improvement

### Overview

Learn from the experience of a unique project that saw professionals and patients work together to collect and analyse stories to improve service delivery.

The following pages provide an overview of the project, including its impact on those involved and the service. It also includes a checklist designed to support organisations or individuals to test the same approach.

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## **1000 Lives Plus - improving care, delivering quality**

1000 Lives Plus is the national improvement programme supporting organisations and individuals to deliver the highest quality and safest healthcare for the people of Wales.

Every health board and trust in Wales, together with universities, voluntary organisations and charities, other public sector services, and commercial organisations are involved in 1000 Lives Plus.

The programme is focussed on building capacity and sustaining and spreading improvements. It supports frontline staff across Wales through evidence-based 'programme areas' and provides clinical leadership through its Faculty. It is committed to engaging patients and students in improvement work and promotes an internationally-recognised quality improvement methodology.

1000 Lives Plus is underpinned by measurement to illustrate improvement, and facilitates collaborative working to test new methods and protocols. The central team supports senior managers and frontline staff to deliver the quality of care that every person needs, everywhere and every time.

[www.1000livesplus.wales.nhs.uk](http://www.1000livesplus.wales.nhs.uk)

## **1000 Lives Plus - Engaging the Public**

1000 Lives Plus emphasises the centrality of the patient in all its improvement work. It has actively promoted the involvement of patients in their own care and key decisions relating to treatment.

The voices and stories of patients are an effective and powerful way of making sure the improvement of services is centred on the needs of the people using the services.

'Stories for Improvement' have helped identify numerous small changes that have resulted in large improvements. 1000 Lives Plus has encouraged using stories to ensure that the patient's voice is heard at the highest level, in board meetings and at national conferences.

[www.1000livesplus.wales.nhs.uk/public-engagement](http://www.1000livesplus.wales.nhs.uk/public-engagement)

## Introduction

The case study showcases a three year project which brought together a mental health nurse manager and six mental health service users to collect and analyse patient stories for service improvement.

The project was a unique model bridging the customary gap between professionals and service users to identify themes of good practice and improvement from mental health service users' experiences. The team worked collaboratively, and the action plans derived from the project present a great example of patient and professional collaboration for the co-design of service improvements.

This model provides a greater understanding of the impact of stories as a tool for engagement, by analysing the impact of the project on the service users who collaborated in the collection and analysis of stories.

This case study introduces an overview of this project and its findings.

## Selection and Recruitment

A project launch event was arranged to bring together all adult mental service users with an experience (past or present) of Montgomeryshire community mental health services. Attention was given to the planning of this day to ensure the event was well advertised and to plan transport and support to facilitate participation. This was reflected in a higher number of attendees than expected (62).

The day provided an overview of stories and of the planned project. Attendees were asked to express their interest in becoming either a researcher (collecting and analysing stories) or to become a storyteller.

Separate packs with supporting documents were available for delegates. Packs for researcher positions included a job description which had been designed with the assistance of the HR department.

Anyone who expressed an interest in becoming a storyteller was subsequently contacted to arrange stories collection.

People were asked to apply to the researcher post by letter expressing why they would like to be involved. Six researchers were appointed following short listing and interview process. The researchers were given honorary contracts in order that NHS Indemnity would cover those conducting the study. Enhanced Criminal Records Bureau (CRB) checks were also instigated at the outset of the training programme.

## Training

A programme which would give the researchers an understanding of the process, ethical issues and skills in listening required for the role was devised. The depth and content of the training was discussed in collaboration with the six researchers to ensure the training would provide the right level of expertise and confidence to allow them to actively participate in the project. Some areas therefore took longer in the training than others as participants' needs became known.

Training included several aspects of research, ethics, confidentiality and most crucially how to listen.

## Methodologies

Semi-structured, face-to-face interviews with each service user were undertaken. Through the use of open-ended prompts participants were able to reply in their own way. All interviews were undertaken with the professional project lead present.

The researchers were not neutral or distant but empathic and close to the narrators, an important aspect in the knowledge that the researcher had been there also. This approach differs to that generally applied by professionals undertaking stories collection.

Thirty interviews were undertaken varying in length from 27 minutes to one hour 48 minutes. Additional time was required to support the process. For the interviewees this largely entailed practical and emotional support to feel able to attend the interview.

For the researchers, support was opted for in a group format as already by this time there was a strong sense of peer support.

All interviews were audio recorded and transcribed. Their content was mind mapped and the team work together to extract themes which were used to inform the findings and final recommendations.

The team also analysed the impact of the involvement in the project on the six researchers, hence providing a unique insight into the power of stories as an involvement tool.

## Findings

Three main themes were identified by the researchers in relation to their experience of involvement with the project: restricted lives, reframing the illness narrative and involvement in developing the system.

Four main themes were identified from the analysis of the stories: experiences of mental illness, issues around the mental health service, social/contextual issues and core/central/being needs.

Each theme was also sub divided into further themes. Appendix 1 shows the breakdown of themes identified as part of this project.

The themes were used to identify areas of improvement and good practice.

### **Impact on Researchers**

This study allowed service users not just to come forward and give their views but transform their identities over a three year period in which all six remained committed to the process. It provided a mechanism for redefining identities, increasing socialisation experiences and regaining control over one's life.

“We have moved from being service users, to being researchers, a positive identity, which has motivated us all, yes we are useful, we have a purpose, we are being valued for helping to compile, an incredible piece of work, for many of us, confidence has returned, passion and purpose too, as well as an overwhelming feeling of pride, to be part of such an incredible project... For us, being part of a team, sharing, supporting, discovering and importantly, laughing together, has been incredibly affirming.” (Researcher 5)

This research indicates that involvement activities can enable service users to take responsibility for problems and choices and building self-confidence, trust and self-respect.

The quality of the relationship and the establishment of a person-centred approach seem crucial in enabling the service to meet its aims.

Throughout this project, the relationship between workers and service users was characterised by equality, mutual respect and trust. The research project has offered a valuing yet challenging level of involvement which has been instrumental in enabling commitment over a period of three years.

### **Impact on Service**

- **Direct Impact on Service Provision**

The narratives have provided the opportunity for action plans to be developed and their outcomes directly impact on patient care. Some examples of the changes made as a result of the stories are:

- Reintroduction of a weekly group whereby service users had identified its affect on recovery, personalisation and inclusiveness. The group is running collaboratively with third sector providers in order to maximise skills and resources from both statutory and third sector providers.
- Review of the information service users receive in regards to the process and function of secondary care services. Work is planned to work with service users to devise new material that can be given on assessment.
- Improved service provision- establishing robust links into training, supervision and specialist skills with regards eating disorders.
- Improved management of process and communication regards change of care co-ordinators to reduce distress experienced by service users.

- **Clinical Governance Issues**

The project has been extremely well received and has become a spring board for further development of narrative based training and projects:

- Work is planned to build on the experience within Adult Mental Health services (via Service User Narrative Research- North Powys), and adapt this approach across the Clinical Programme Groups into Learning Disabilities, Elderly Mental Health Services and Substance Misuse Services.
- The project was profiled at the Patient Narratives Workshop - over 80 delegates attended, receiving excellent feedback & evaluation.
- The Care Programme Approach Collaborative held a conference in North Powys with service users to improve service user experience.
- The six researchers are providing training to the DIY Futures Project (Powys) as it embarks on a Narrative Project for service improvement.
- 6 service users and carers have now been trained with the Recovery Network to use patient stories in recovery training.
- Training Sessions undertaken and being developed across Betsi Cadwaladr University Health Board.

### **Checklist for testing the participatory action model:**

1. Set your aim. What are you trying to achieve and why. The Model for Improvement can help you in this process.
2. Identify what cohort of service users you wish to engage and why.
3. Consider how best to reach them and potential obstacles they may face to participating.
4. Work collaboratively with other sectors/organisations to reach your desired cohort and allow their participation.
5. Develop comprehensive, informative and clear information packs describing what you are trying to achieve and what is required from the service users. Different information packs should be developed for the service users who wish to become researchers and those who wish to provide their stories.
6. Consider the best platform for contacting your cohort of patients. (Events, social media, existing patient groups, etc)
7. Set out a clear, fair and open process for recruiting your researchers. Consider linking to your Public and Patients Involvement Officers and Human Resources departments for advice and support.
8. Highlight training opportunities for your 'researchers' and work collaboratively to build the skills sets and confidence required to ethically deliver the project. Training must include ethics, stories collection techniques, analysis methods, listening skills, etc.
9. Work collaboratively and with your trained service users to collect, analyse and learn from other service users' stories. A flexible approach must be adopted to allow full participation.
10. Make sure all involved can see and are aware of the changes to the services deriving from their participation.

# If you are using Mental Health services in Powys then this invitation is to you!



**A research project based on your personal stories and experience...to build towards more fitting mental health services...is due to start....**



**CONTACT: Andre Hutchinson  
(01938 558969)**

**Weds 10th October– Mental Health Day**

**Time: 10.00-3.00pm**

**At Gregynog Hall, Tregynon**

We need people interested in telling their story and people willing to train to lead this project. Come & hear more about it..Enjoy lunch and company of others in this beautiful setting.

Transport can be provided (Minibuses available) and full support in attending.

If interested please contact us or any person within the CMHTs.

## Appendix 2

### Themes:

Following thematic analysis, the following meta-themes and themes were distilled.

Table 1 refers to the themes from the six researchers involved and their experience of involvement.

**Table 1: Meta-Themes and themes**

Meta-Theme	Theme
<b>Restricted Lives</b>	Need for Connectedness Reciprocity Recovery & Development
<b>Reframing the Illness Narrative</b>	Definitions of self Self beyond the label Self knowledge & Self acceptance Recovery & Hope
<b>Involvement in Developing the System.</b>	Hope for Service Different relationships Having value The importance of Process Recovery & Moving On

Table 2 refers to the themes that emerged from the 31 participant narratives

**Table 2: Meta-Themes and themes**

Meta-Theme	Theme
<b>Experiences of Mental Illness</b>	<ul style="list-style-type: none"> <li>- Abuse</li> <li>- Agoraphobia</li> <li>- Alcohol dependence</li> <li>- Anxiety- Panic attacks</li> <li>- Aspergers/autism</li> <li>- Depression/Bi-polar</li> <li>- Eating disorders</li> <li>- Illicit drugs</li> <li>- OCD</li> <li>- Personality Disorder</li> <li>- Post-traumatic stress disorder</li> <li>- Post Natal depression</li> <li>- Schizophrenia- Hearing voices</li> <li>- Self-harm (Suicide attempts, eating issues, cutting, overdose)</li> </ul>
<b>Issues around Mental Health Service</b>	<ul style="list-style-type: none"> <li>- Accessibility</li> </ul>

	<ul style="list-style-type: none"> <li>- Duty System</li> <li>- Accredited Accommodation scheme- Respite</li> <li>- People within and how treated by- Administrators, Advocate, CPNs, GPs, O,T, Police, Psychiatrists, Psychologist, Social workers, Support workers</li> <li>- Care plan/assessment/CPA</li> <li>- CMHT</li> <li>- Treatments- CBT, Counselling, ECT, Medications</li> <li>- Discharge/follow up</li> <li>- Gender choice</li> <li>- Groups/courses</li> <li>- Home visits</li> <li>- Hospital</li> <li>- Mental Health act</li> <li>- NHS system</li> <li>- Out of hours provision</li> <li>- Placement-funding</li> <li>- Voluntary Provision</li> <li>- Waiting Lists/Delays</li> </ul>
<b>Social/Contextual</b>	<ul style="list-style-type: none"> <li>- Childhood</li> <li>- Debt/money</li> <li>- Discrimination/Stigma/labels</li> <li>- Family</li> <li>- Home/Housing</li> <li>- Isolation</li> <li>- Relationships</li> <li>- Spirituality</li> <li>- Work</li> </ul>
<b>Central/Being Needs</b>	<ul style="list-style-type: none"> <li>- Acceptance</li> <li>- Belonging- the place</li> <li>- Connection-Being listened to, being with others, importance of being/helping others with MH experiences, therapeutic relationship, touch</li> <li>- Choice</li> <li>- Communication</li> <li>- Coping strategies</li> <li>- Continuity</li> <li>- Loneliness</li> <li>- Loss</li> <li>- Recovery- things that helped</li> </ul>

	<ul style="list-style-type: none"><li>- Resilience</li><li>- Stuck</li><li>- Self-Image/worth</li><li>- Understanding/awareness- causation, illness, different perspectives, disconnection, recognition</li><li>- Valuing- Narrative giving</li></ul>
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# NATIONAL PRINCIPLES FOR PUBLIC ENGAGEMENT IN WALES



## 1 Engagement is effectively designed to make a difference

Engagement gives a real chance to influence policy, service design and delivery from an early stage.

## 2 Encourage and enable everyone affected to be involved, if they so choose

The people affected by an issue or change are included in opportunities to engage as an individual or as part of a group or community, with their views both respected and valued.

## 3 Engagement is planned and delivered in a timely and appropriate way

The engagement process is clear, communicated to everyone in a way that's easy to understand within a reasonable timescale, and the most suitable method/s for those involved is used.

## 4 Work with relevant partner organisations

Organisations should communicate with each other and work together wherever possible to ensure that people's time is used effectively and efficiently.

## 5 The information provided will be jargon free, appropriate and understandable

People are well placed to take part in the engagement process because they have easy access to relevant information that is tailored to meet their needs.

## 6 Make it easier for people to take part

People can engage easily because any barriers for different groups of people are identified and addressed.

## 7 Enable people to take part effectively

Engagement processes should try to develop the skills, knowledge and confidence of all participants.

## 8 Engagement is given the right resources and support to be effective

Appropriate training, guidance and support are provided to enable all participants to effectively engage, including both community participants and staff.

## 9 People are told the impact of their contribution

Timely feedback is given to all participants about the views they expressed and the decisions or actions taken as a result; methods and form of feedback should take account of participants' preferences.

## 10 Learn and share lessons to improve the process of engagement

People's experience of the process of engagement should be monitored and evaluated to measure its success in engaging people and the effectiveness of their participation; lessons should be shared and applied in future engagements.

These Principles were developed by Participation Cymru working with TPAS Cymru, under the guidance of the Participation Cymru partnership. Endorsed by The First Minister of Wales, The Right Hon. Carwyn Jones AM on behalf of the Welsh Government.

Further guidance on the National Principles can be found at

[www.participationcymru.org.uk](http://www.participationcymru.org.uk)

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Participation  
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