



**South Essex Service User Consultancy,
Training and Research Group**

SE-SURG

Activity Report

2008 - 2013

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Preface

SE-SURG (the South Essex Service User Research Group) was formally established in 2005 following the successful completion of a study of South Essex service users' vocational aspirations in 2004.¹ For that study a group of service users had worked with me on designing and carrying out a survey of 159 fellow service users and conducting face to face interviews with a further 82 participants. The study was influential in supporting the development of an evidence-based vocational service at the South Essex Partnership Trust (SEPT), one of the first in the UK. At a meeting held to celebrate completion of the study all concerned agreed that the skills and confidence the service user researchers had gained could be of continuing benefit in ensuring that service user perspectives informed mental health service development, and SE-SURG was formed.

Hosted at Anglia Ruskin University in the Faculty of Health, Social Care and Education, the group has met regularly since 2005, with support from SEPT. Meetings provide a forum for reviewing ongoing projects, planning new work and maintaining appropriate group procedures. Two part time service user researcher/administrators (Lyn Kent and Maxine Nightingale) have appointments at the university and lead on commissioned projects as well as organising meetings and providing training and support for other members. In keeping with the origins of the group in a study of vocational aspirations, members have the opportunity to be paid for the work they carry out, depending on their individual circumstances.

The hope that SE-SURG could contribute to service development has proved well founded. Members have carried out a wide range of studies, many documented in this report. In 2009 SE-SURG's achievements contributed to a team from the university being invited to tender for a three-year project funded by NHS and local authority mental health commissioners across Essex to enhance service user involvement in commissioning. The tender was successful and one aim of the project (MIME –Making Involvement Matter in Essex) was to establish a group similar to SE-SURG in North Essex. Following a four-day programme of research training nine North Essex service users formed the North Essex Research Network. The two groups have now begun to collaborate on projects in order to share their skills and expertise.

SE-SURG produced their first annual report in 2008 and has continued to do so each year. Five years on it was thought timely to draw together the work reflected in those reports in order to provide an overview of the range of work carried out and its impact on services. Over to SE-SURG.

Jenny Secker
Professor of Mental Health

¹ South Essex Service User Research Group, Secker J. and Gelling L. (2006) Still dreaming: service users' employment, education & training goals. *Journal of Mental Health* 15: 1: 103-111.

Acknowledgements

Thank you to all those who have contributed to the work of SE-SURG during the last five years.

SE-SURG members have worked hard throughout this period to carry out the work outlined in this report and would like to thank all those who have contributed, through their participation and support, to the success of the group. We feel our work has made valuable contributions to service development as well offering opportunities for members to extend their skills and knowledge.

We would like to thank both Anglia Ruskin University and the South Essex Partnership University NHS Foundation Trust (SEPT) for their support and involvement throughout the past five years. Staff at all levels, from both organisations, have provided training and support to the group, as well as working with us to develop and organise work. We are grateful to them all but would like to particularly mention Jenny Secker, Professor of Mental Health, for her hard work in providing ongoing support and training for SE-SURG members, and Dr Patrick Geoghegan, Chief Executive at SEPT, for his encouragement and support since SE-SURG was established. Our thanks too to Dr Kerrie Margove, Dr Tim Schafer, and Ceri Wilson for their support and for contributing their expertise with quantitative analysis. Particular thanks are also due to Sarah Thurlow, Head of Research at SEPT, and Dr Mick Loughran, Nurse Consultant until his retirement in 2012.

Thanks also to those who have either commissioned work or invited us to make presentations, we value your support.

Our final thanks must go to all the other groups and individuals we have had contact with, service users and staff from both statutory and voluntary services and particularly those who have helped to organise or participated in focus groups and interviews and have distributed and completed questionnaires.

We hope that you find our report of interest and look forward to another interesting, productive and successful year in 2014.

Thank you.

Lyn Kent and Maxine Nightingale
SE-SURG Researcher Administrators

1. SE-SURG 2008 – 2013: Overview

SE-SURG has continued to meet regularly during these five years, monthly until 2013 and now at 6-week intervals. Members have worked on commissioned consultations and evaluations, as well as being involved in other activities including delivering training for other service user researchers and presentations to nursing and social work students.

At the start of 2008 SE-SURG had eight active service user researchers in the group, including the two part time researcher/administrators. Membership has remained stable at eight over the five-year period, although individuals have of course moved on and new members have joined the group.

Members have been involved in developing proposals, questionnaires, interview schedules and topic guides. They have conducted face to face interviews, facilitated and taken notes at focus groups and meetings, transcribed interviews and carried out data entry and analysis. Members have also contributed to writing reports and articles, delivered training and prepared and taken part in presentations, as well as continuing to develop robust group procedures.

The sections that follow provide information about each of these strands of our work and the impact it has had. The report concludes with some reflections from SE-SURG members and an invitation to get in touch.

2. Project summaries

2.1	Consultation on Older People's Mental Health Services in Enfield
Study dates	February 2008 – May 2008
Services	Enfield Mental Health Services for Older People. CMHT, day services and inpatient wards
Commissioner/ Funding	Assistant Director, Enfield Mental Health Services for Older People
Aims	To enable the commissioners to improve the quality of the services provided through improving the quality of feedback received.
Methods	Five focus groups with: <ul style="list-style-type: none"> • Service users in inpatient wards (2 groups) • Service users attending day hospitals (2 groups) • Service users and carers receiving CMHT support (1 group)
Summary of work	Discussions with commissioner regarding proposed work. Development of information sheets and topic guides, training session/role play. Liaison with trust staff who identified venues and participants. Groups arranged and facilitated, notes taken and written up. Analysis by Jenny Secker to identify key themes and produce report with support from SE-SURG members.
Response	Five groups attended by 27 participants (25 service users and 2 carers).
Results	Views about services were mixed, depending on the service concerned. At most services participants reported being treated with respect and afforded choices in relation to their care and treatment, although transport to day services was problematic for some and relatively small improvements were suggested. At one service access to information about care and treatment seemed limited and in other respects the approach seemed institutional and rigid, highlighting a need for more creative, flexible responses to the issues highlighted.
Dissemination of findings	Report delivered to commissioner May 08
Impact	The report was positively received, with very favourable comments, and the commissioner identified areas to work on in the future.

2.2	Advance Directive Consultation
Study dates	February 2008 - November 2008
Services	SEPT In-Patient & Rehabilitation Mental Health Services
Commissioner/ Funding	South Essex Partnership NHS Foundation Trust – Charitable Research Foundation
Aims	To explore the experience of individual service users in developing an advance directive and the benefits of doing so. Commissioned as SEPT wishes to promote the use of Advance Directives.
Methods	Focus groups with service users who have made an advance directive. Trust staff with the right of access to service users' contact information asked to invite all those with an advance directive registered with SEPT to attend. Groups held at trust premises across the area at pre-arranged times. Aim to recruit eight people to each group on a 'first come first served' basis. Analysis of key themes across all groups.
Summary of work	Liaison with SEPT PPI Dept to arrange, & rearrange, dates, venues and invitations. Delays due to difficulties in mailing out invitations. Topic guide developed, training session and role play. Groups held, facilitated, notes taken and written up. Data analysed by Jenny Secker and report written.
Response	3 focus groups held, attended by 10 participants (7, 1 and 2). 4 th group cancelled as no response to invitations.
Results	The focus groups provided evidence of significant benefits associated with advance directives, and also highlighted ways in which their considerable potential could be maximised. Six suggestions for achieving this were put forward on the basis of the results.
Dissemination of findings	Report sent to Director of In-Patient & Rehabilitation Mental Health Services & Head of PPI for dissemination.
Impact	Discussed by SEPT Executive Team & by Mental Health Act Group (Jan 09), including staff & service users. Report agreed and recommendations accepted. Working group set up to work on Advance Directive promotion.

2.3	South Essex Day and Employment Services Pilot Evaluation
Study dates	January 2008 – February 2009
Services	Pilot Day & Employment Services in South Essex
Commissioner/ Funding	South West Essex PCT Mental Health Commissioning Team
Aims	To carry out an evaluation of the new models for day & employment services being piloted in south Essex
Methods	Three strands of work: <ol style="list-style-type: none"> 1. Outcome measurement – survey of service users new to pilot services and again after 6 months 2. Focus groups with staff, service users & referrers part way through the evaluation period. 3. Analysis of summaries of information collected by commissioners.
Summary of work	Participation in regular steering group meetings. Developing and preparing instruments and documents. Training and role play sessions. Liaising with services to distribute questionnaires and arrange focus group venues and participants. Facilitating and note taking for focus groups and writing up notes. Data entry. Outcomes and satisfaction data analysed by Dr Tim Schafer, Anglia Ruskin University. Other data analysed & reports written by Jenny Secker, Professor of Mental Health, with input from SE-SURG members.
Response	182 baseline and 78 follow up questionnaires returned. 12 focus groups held with a total of 55 participants,
Results	All services recorded increases in uptake or maintained previous high levels over the pilot period. Achieving an equitable balance in terms of age and gender remained an issue at a minority of services. Uptake by BME groups was increasing at some. The outcomes survey found no significant differences on the measures used but satisfaction ratings were positive. Focus group results were reported separately with recommendations aimed at informing service development.
Dissemination of findings	3 focus group reports presented to steering group in June & July 08. Baseline outcomes report August 08. Final report completed February 09. Presentations to PCT Board & Local Implementation Team. Published in <i>A life in the day</i> (see publications list).
Impact	Steering group responded to recommendations from focus group consultation. Evaluation taken into account by commissioners in the tendering process for new day and employment services following the end of the <i>pilot period</i> .

2.4	Open Arts Initial Evaluation
Study dates	Autumn 2007 - February 2010
Services	Open Arts, SEPT
Commissioners/ Funding	East of England Development Agency (EEDA; 2007-2008). South Essex Partnership Trust Charitable Research Foundation (2009-2010)
Aims	To evaluate Open Arts, a programme in South Essex to provide opportunities for people experiencing mental health problems to participate in arts activities.
Methods	Quantitative and qualitative strands: <ul style="list-style-type: none"> Quantitative - questionnaires measuring mental wellbeing and social inclusion completed by participants at the beginning and end of their course. Qualitative - focus groups held as part of course follow up sessions, for some courses, to illuminate quantitative results by exploring the impact of the programme from participants' perspective
Summary of work	Liaison with course coordinator. Tools developed, training session and role play held. Questionnaires distributed and collected by course coordinator using unique identifier in order to link pre and post data. Data entry. Four focus groups facilitated; notes written up and analysed by Lyn Kent with support from Jenny Secker and SE-SURG members.
Response	29 course participants took part in focus groups. Questionnaires received from 116 participants in 29 courses (33%).
Results	Focus group participants identified gains in wellbeing and social inclusion alongside a need to address expectations more clearly and provide more individualised learning. Outcome results indicated significant improvements in wellbeing and social inclusion. Ratings of participation were very positive and supported attribution of impacts to arts participation.
Dissemination of findings	Focus group report passed to project coordinator to inform planning of future courses. Presentation to Trust Board September 2011 Results published in <i>Arts and Health</i> journal (see publications list).
Impact	Focus group report helped shape more individualised delivery. Jenny Secker invited to deliver opening keynote presentation at <i>Out of Mind-Into Creativity</i> symposium, Winnipeg Art Gallery, November 2011. Funding secured for further waiting list controlled evaluation.

2.5	Expert Patient Programme Evaluation, Year 1
Study dates	May 2008 – April 2009
Services	Expert Patient Programme (EPP) delivered to SEPT service users
Commissioners/ Funding	SEPT
Aims	To inform decisions regarding future SEPT funding of EPP.
Methods	Quantitative and qualitative strands: <ul style="list-style-type: none"> • Measures of wellbeing and social inclusion completed by participants at beginning and end of 6 week course and again 3 months later. • Focus groups at follow up sessions to gain additional information and examples and to establish if change is due to course attendance .
Summary of work	Liaison with course organiser (SEPT, PALS). Tools developed, training session, role play. Attendance at courses (3) to introduce evaluation. Data entry. Three focus groups facilitated, notes taken and written up Quantitative data analysed by Mick Loughran (SEPT) Focus group data analysed and written up by Jenny with support from SE-SURG members.
Response	Questionnaires included from 26 participants. Focus groups attended by 18 participants
Results	Mean wellbeing scores increased significantly between the beginning and end of the courses. Scores decreased at follow up but remained significantly higher than at the start of the courses. Mean scores on the social inclusion measure increased between each of the three time points but the differences were not statistically significant. Focus group participants described a wide range of benefits they felt they had gained from their course, including improvements in mental wellbeing, social inclusion, physical health and the way in which they used mental health services.
Dissemination of findings	Report provided to the commissioner and course organiser. Presented to Executive team by the responsible Director.
Impact	Evaluation informed a decision to run further programmes in 2011

2.6	Enhancing Learning from Incidents of Suicide and Serious Self Harm
Study dates	May 08 – July 09
Services	All SEPT Essex in-patient wards including forensic, PICU & assessment wards
Commissioners/ Funding	SEPT commissioned a team from Anglia Ruskin University to carry out the study. SE-SURG carried out the work with service users and assisted with other aspects.
Aims	To look at whether anything can be learnt from incidents of suicide and serious self harm to minimise the risk of reoccurrence. The study focused on organisational contexts, policies, procedures and practices, not on individuals.
Methods	Two strands of work: <ol style="list-style-type: none"> 1. Inpatient Safety – focus groups with staff and service users on 5 wards and interviews with senior staff. SE-SURG ran the service user focus groups asking about experiences of safety and safeguards 2. Learning from Incidents – interviews following incidents. SE-SURG interviewed service users involved, where possible and appropriate
Summary of work	Attendance at steering group and planning meetings, development of documents and tools. Liaison with Gail Pittam, Anglia Ruskin researcher. Contact with ward staff to arrange focus groups and interviews.
Response	26 service users took part in five focus groups. One service user interviewed for Strand 2
Results ²	The majority of service users felt safe on the wards and appreciated staff efforts to keep them safe. Where concerns were reported these related to night time, particularly when agency staff less well known to service users were on duty. The participant interviewed following an incident appreciated the support provided by staff.
Dissemination of findings	Final report delivered to responsible Director. Presentation to Executive Team.
Impact	Procedures for providing support to staff revised in light of findings. Report continues to be consulted in relation to policy and procedural decisions (2012).

² Service user perspectives only reported here

2.7	Audit of recovery-oriented practice on acute admission wards
Study dates	September 2009 – March 2010
Services	Cedar & Willow acute admission wards, Rochford Hospital
Commissioners/ Funding	SEPT
Aims	To assess the extent to which the wards are providing recovery enhancing services from the perspective of service users.
Methods	<p>Face to face interviews prior to discharge using two measures</p> <ul style="list-style-type: none"> • The Elements of Recovery and Recovery Enhancing Services (ERRES) measure asking service users to rate ward practice on dimensions known to be key to enhancing recovery • The Organisational Climate Measure providing a more general rating of organisational Qualities. <p>Additional open questions to provide an opportunity for further comment. Monitoring information about individuals and service use also collected.</p> <p>Quantitative data analysed to provide information about dimensions of service provision that are comparatively stronger or weaker than others. Participants' comments analysed thematically to identify key themes relating to recovery and ward services</p>
Summary of work	Meetings and liaison with ward staff and two lead consultants, training session, role play, interviews conducted, data entered. Quantitative analysis by Dr Mick Loughran (SEPT). Qualitative data coded and categorised within themes and three reports written by Jenny Secker with support from Lyn Kent.
Response	Of those invited 5 declined, 10 not available, 41 interviews completed.
Results	<p>The scores on both measures for both wards were largely positive. No significant differences were found between wards but scores tended to be higher for Cedar.</p> <p>Participant's comments highlighted the need for quality time and supportive interactions with staff, with staffing levels identified as an issue on Willow.</p>
Dissemination of findings	Reports provided to ward consultants and Medical Director March 2010.
Impact	Report helped inform a decision to roll out ward-based consultants.

2.8	From Inclusion to Inspiration: The Therapeutic Nature of Museums
Study dates	December 2010 – May 2011
Services	Colchester & Ipswich Museums
Commissioners/ Funding	Colchester and Ipswich Museums
Aims	To collate evidence as to how museum services can have a positive impact on mental health, specifically the wellbeing of those with serious mental health problems who currently receive input from mental health services.
Methods	Focus group to explore the findings from a questionnaire survey of mental health service users carried out by Colchester and Ipswich Museums' Mental Health Project Officer, in order to add depth to understanding of the questionnaires responses.
Summary of work	Liaison with the Mental Health Project Officer. One focus group held, notes written up and analysed by Maxine Nightingale with support from Jenny Secker.
Response	Four service users took part in the focus group.
Results	Participants illustrated the ways in which the museum environment could deter visits through their descriptions of darkness, confusion, feeling 'tunnelled' and a sense of 'holy space'. Factors behind the less than welcoming environments described included inadequate signage, seating and refreshment areas; gloomy décor and fittings; and formal staff uniforms. Where admission charges applied these were a further deterrent, alongside transport and parking charges. Participants identified several relatively low-cost ways in which the museum environment could be improved.
Dissemination of findings	Report sent to the Mental Health Project Officer for the management team and a presentation to the Portal Group given on 6 th May 2011.
Impact	Report informed a funding application (unsuccessful) for further work in this area

2.9	Expert Patient Programme Evaluation, Year 2
Study dates	January 2011 – March 2012
Services	Expert Patient Programme (EPP) delivered to SEPT service users
Commissioners/ Funding	South Essex Partnership University NHS Foundation Trust
Aims	To provide evidence of effect of course attendance on wellbeing, social inclusion and empowerment of attendees in order to inform future provision.
Methods	Quantitative and qualitative strands: <ul style="list-style-type: none"> • Measures of empowerment, wellbeing and social inclusion to be completed by participants at beginning and end of 6 week course and again 6 weeks later. • Focus groups at follow up sessions to gain additional information and examples and to establish if any change is due to course attendance
Summary of work	Liaison with course organiser and administrator. Data entry. Focus groups (3) held following each course. Delays with arrangements for 3 rd course. Quantitative data analysed by Dr Kerrie Margrove (ARU). Focus group data analysed by Lyn Kent with support from Jenny Secker.
Response	Questionnaires from 20 course participants included in analysis. Twelve people participated in three focus groups.
Results	Mean scores on all three measures improved significantly between the beginning and end of the courses. By follow up mean scores on the three measures had decreased slightly. Although still higher than at the beginning of the courses, the difference was not statistically significant. Focus group participants' expectations and perceptions of the courses varied considerably. Many described gains in mental wellbeing and social inclusion which most attributed to aspects of their course. Alongside these positive views, several participants raised concerns, including the amount of information imparted at some sessions and a perceived lack of relevance for people with long term experience of mental health problems.
Dissemination of findings	Report provided to SEPT March 2012
Impact	Report helped inform decision to postpone further programmes pending revision of EPP materials at national level

2.10	Evaluation of recovery-oriented practice at the Taylor Centre
Study dates	August 2011 – 25 November 2011
Services	All SEPT services based at The Taylor Centre
Commissioners/ Funding	Taylor Centre Practice Development Unit/South Essex Partnership Trust Research Foundation
Aims	To provide feedback from service users to identify areas of good recovery-oriented practice and areas where improvement is needed.
Methods	Survey of service users using the 'Elements of a recovery-facilitating system' (ERFS) measure "Have your say café" to explore areas needing improvement in more depth
Summary of work	Questionnaire packs delivered to The Taylor Centre for distribution. Weekly contact with Vocational Lead. Data entered into SPSS. Analysis completed by Dr Kerrie Margrove. Organising and facilitating 'Have your say café' discussion groups.
Response	119 completed ERFS questionnaires 11 participants in the 'Have your say café'.
Results	Four areas identified as needing improvement: <ol style="list-style-type: none"> 1. Having a say in how the service is run 2. Being helped with basic needs such as income, housing and transport 3. Being supported to succeed in normal life 4. Being told about rights and how to uphold them. Feedback from the 'Have your say café' highlighted a greater need to listen to service users, the provision of advocacy and peer support, and addressing service users' vocational and other life goals.
Dissemination of findings	Presentation to PDU November 2011
Impact	Taylor Centre staff have re-affirmed their commitment to recovery-oriented service provision

2.11	Waiting List Controlled Evaluation of Open Arts
Study dates	April 2011 – December 2011
Services	Open Arts, SEPT
Commissioners/ Funding	South Essex Partnership Trust/Postgraduate Medical Institute/Faculty of Health, Social Care & Education Research Enhancement Funds.
Aims	<ol style="list-style-type: none"> 1. To test the feasibility of a waiting list controlled design as a means of ascertaining with greater confidence than in previous uncontrolled evaluations whether participation in Open Arts introductory courses improves participants' wellbeing and social inclusion 2. To provide preliminary evidence of effectiveness as a basis for an external funding application
Methods	Crossover waiting list controlled design. Completion of measures of wellbeing and social inclusion at the beginning (baseline) and end (follow up) of Open Arts courses
Summary of work	Work with Jenny Secker, Kerrie Margrove and Open Arts on development of documents, data collection, analysis and report and writing of papers
Response	Outcome measures completed by 26 intervention and 32 control group participants. Completion of further measures by 19 control group participants who subsequently enrolled on courses.
Results	No difference in scores between control and intervention groups at baseline. Significant improvements in wellbeing and social inclusion for course participants at follow up but no change for the control group. Significant improvements on both measure for control group participants who went on to complete a course
Dissemination of findings	Paper published in <i>Perspectives in Public Health</i> (see publications list) Presentation to SEPT Board January 2013.
Impact	Widespread media coverage (Doctor's Press, Daily Telegraph, Huffington Post, Radio Essex, Essex Chronicle) External funding bid for a feasibility randomised controlled trial. Pilot of Open Arts in Luton at request of SEPT Board

2.12	Development and Preliminary Evaluation of a Medication Review Tool for People Taking Antipsychotic Medication
Study dates	Main study 30 months SE-SURG involvement Sept 2011 to March 2013
Services	North East London Foundation Trust Community Mental Health Services including Early Intervention Service
Commissioners/ Funding	North East London Foundation Trust as part of a NIHR RfPB (National Institute of Health Research, Research for Patient Benefit Programme) funded study
Aims	To carry out 20 face to face interviews, with service users prescribed antipsychotic medications, in order to collect qualitative data for the research study which aims to develop a Medication Review Tool that enables service users to express their views about their medication, and participate more fully in discussions and decisions about their drug treatment.
Methods	SE-SURG commissioned to provide training/service user interviews as part of research project. Involvement is in Work Package 2 (of 6), 'Qualitative investigation of how service users evaluate antipsychotic medication and how they perceive medication decision making.'
Summary of work	Organisation & facilitation of three training/planning sessions, attended by SE-SURG interviewers and project team researchers in order to carry out interviews and collect/provide required data. Nineteen interviews carried out by SE-SURG researchers. Final meeting with the project team in March 2013 to assist with analysis.
Response	Nineteen participants in face to face interviews
Results	Project team are continuing to work on qualitative data analysis and trialling the Medication Review Tool.
Dissemination of findings	Data provided to research team. There maybe opportunities for further involvement in data analysis and dissemination in the future.
Impact	Feedback from the NELFT researchers indicates that SE-SURG's involvement improved the quality of data collection instruments, and hence data quality, as well as contributing valuable insights to the analysis.

2.13	Evaluation of the Buddy Scheme Pilot
Study dates	October 2012 – December 2012
Services	Anglia Ruskin/SEPT student nurse placements
Commissioners/ Funding	South Essex Partnership Trust
Aims	To explore participants' experience of the Buddy Scheme in order to inform decisions about rolling out the scheme.
Methods	Focus group discussions with service user Buddies and participating students
Summary of work	Facilitation of Buddy focus groups; note taking for the student group. Collation of written responses from students unable to attend the group discussion Data analysis and report writing
Response to research	Two service user participants, five student participants + two written responses from students
Results	All participants thought the scheme had great potential and students identified ways in which participation had enhanced their practice. Participants' experiences highlighted the need to address organisational issues that arose during the pilot.
Dissemination of findings	Report delivered to SEPT January 2013. Discussion of findings February 2013.
Impact	The evaluation has informed the development of a funding proposal which if successful will roll the Buddy Scheme out to all Anglia Ruskin nursing students

2.14	Initial evaluation of the Open Arts Studio at Hadleigh Old Fire Station
Study dates	January 2013 – June 2013 (project ongoing to December 2013)
Services	Open Arts studio provision
Commissioners/ Funding	South Essex Partnership Trust / Essex County Council
Aims	To assess whether access to studio space for graduates of Open Arts' introductory courses improves wellbeing and social inclusion; and to explore participants' experiences of the studio.
Methods	Quantitative and qualitative methods: <ul style="list-style-type: none"> • Completion of measures of wellbeing and social inclusion by studio members at the beginning and end of their time at the studio. • Focus group discussion with studio members.
Summary of work	Liaison with Open Arts manager to arrange outcomes survey and focus group. Design of questionnaires and topic guide. Facilitation and note taking for focus group. Quantitative data entry; analysis carried out by Ceri Wilson, Research Fellow. Qualitative analysis and report writing carried out by Lyn Kent with support from Jenny Secker.
Response to research	Measures completed by 15 studio members. Focus group attended by 10 members.
Results	Significant improvements in wellbeing and social relations with positive trends for social isolation, social acceptance and overall social inclusion. Open-ended comments on the follow-up questionnaire and focus group participants' responses supported these results, with gains in wellbeing well-documented alongside comments indicative of reduced social isolation.
Dissemination of findings	Report provided to Open Arts and SEPT June 2013; presented at HOFS 25 th June 2013.
Impact	To be confirmed once project completed in December 2013

3. External work with other universities

We are very proud to report that the quality of work SE-SURG has carried out has been increasingly recognised beyond South Essex. In addition to work on the study with the North East London Foundation Trust (study 2.12 above), SE-SURG members have been involved in two other major externally funded research projects:

3.1 WISE (Workplace Impact of Supported Employment)

'An investigation of the impact of introducing Individual Placement and Support to a catchment area'. University College London and Camden & Islington Foundation Trust. Funded by the National Institute for Health Research (*Research for Patient Benefit Programme*)

For this study, one of SE-SURG's researcher/administrators worked with researchers at University College London on the WISE project, facilitating training and supervision sessions for local service users with the project researchers and offering support to the service user researchers. Following completion of the face to face interviews, some of which were conducted by SE-SURG members, there have been opportunities for continuing input into this work through contributing to and commenting on the qualitative analysis.

3.2 The CORE Programme (Crisis Resolution Team Optimisation and Relapse Prevention)

Optimising team functioning, preventing relapse and enhancing recovery in crisis resolution teams. Funded by the National Institute for Health Research (*Programme Award*)

This study provided an opportunity for service user and carer researchers to be involved in a research project advertised by University College London and taking place across seven Trusts in London and Norfolk. As with the WISE study a number of SE-SURG members applied, were interviewed, and became members of the service user or carer working groups for the CORE programme. This has again involved working as part of a team of service user and carer researchers on developing materials, carrying out face to face interviews and discussing project issues within the working groups and has given group members further opportunities for personal development. One member has had the opportunity to train as a peer support worker to work on a pilot trial supporting service users in using a self-management workbook developed as part of the programme.

Work is on-going as now interviews are completed team members have had the opportunity to read and comment on interview and focus group transcripts, and on an initial coding frame, as well as giving their personal insights into the content and process of the interviews they carried out in order to further inform the UCL project researchers. More recently they have been further involved in assisting with the development of a fidelity measure.

4. Contribution to student learning

SE-SURG members are increasingly asked to contribute to student learning at the university by drawing on their expertise through experience as mental health service users to illustrate good, and less good, practice.

In each of the five years covered by this report we have told our 'stories' to mental health nursing students taking modules in Recovery and in Social Inclusion. From 2010 we have also been asked to contribute to social work training and to date we have delivered four sessions covering the Recovery Model and Working with Communities and Groups. In addition, since 2012 we have contributed to the faculty's Foundation Degree in Mental Health, speaking to students about Dignity and Respect.

Service user involvement in teaching and learning is developing across all the faculty's nurse training branches and we have been able to help with this through two presentations to staff workshops in 2012 on involving service users in teaching.

We are especially proud to have contributed to a journal article about involving service users in nurse training (see publications list below) and we have received very positive feedback from lecturers and students for this aspect of our work. There are some examples on page 24.

5. Service user and carer research training

As SE-SURG's developing expertise has become recognised we have been asked to help with training other services users who are interested in getting involved in research. Since 2008 we have contributed to four sessions with the 'WhyNot' older people's research group who are supported by faculty colleagues. In addition we contributed to the research training for service users provided under the auspices of the three-year MIME (Making Involvement Matter in Essex) project, delivered training for service users working with an Anglia Ruskin doctoral student and for five carers recruited to carry out interviews for a Department of Health funded demonstration project in South Essex.

6. Conference and seminar presentations

Our developing expertise is also recognised in requests to contribute to conferences and seminars. Our main presentations since 2008 are listed below.

- | | |
|----------|---|
| 08.02.08 | Anglia Ruskin Research Seminar - <i>Reflections on and issues raised in SE-SURG research projects</i> |
| 02.07.08 | Housing and Homelessness Conference – <i>Homes of Our Own</i> |
| 27.02.09 | Anglia Ruskin Research Seminar – <i>Involving Service Users in Research</i> |

- 02.04.09 University of Essex Service User Spring School: Research Skills for Healthcare Service Users - *All about SE-SURG*
- 09.07.09 Greenwich University, Partners in Practice Conference – *Service Users as Researchers – Reflections on and issues raised through SE-SURG Research Projects*
- 18.02.10 Anglia Ruskin University 'Using Research to Transform Mental Health Services' conference – *Open Arts Evaluation*
- 05.03.10 Anglia Ruskin Research Seminar - *Involving Service Users in Research*
- 08.06.10 Presentation to SEPT visitors from Yale University - *SE-SURG and our work*
- 16.12.10 Anglia Ruskin Research Seminar – *Evaluating a participatory arts project for people with mental health needs: some problems and pitfalls of local evaluation*
- 08.02.11 Mental Health Research Network Annual Showcase – *Involving service users in research: experiences from the WISE study*
- 29.03.11 North East London Foundation Trust Research Conference – *Involving Service Users in your research*
- 10.06.11 SEPT Annual Research Conference – *Who are we? What do we do?*
- 06.07.12 *Stepping Out* Launch Conference – *Accommodation and Support: What works for women with complex needs?*

7. Publications

South Essex Service User Research Group (SE-SURG), Secker J. and Tebbs M. (2008) Modernising day and employment services in South Essex: the role of service user researchers. *Life in the Day* 2 (3): 29-32.

Secker J. & Heydinrych K. with the South Essex Service User Research Group (2009) Open Arts: promoting wellbeing and social inclusion through art. *Life in the day* 13 (4): 20-24

Secker, J, Loughran, M, Heydinrych, K and Kent, L (2011) Promoting mental well-being and social inclusion through art: evaluation of an arts and mental health project'. *Arts & Health*, 3 (1): 51-60

Blackhall, A, Schafer, T, Kent, L, Nightingale, M (2012) Service user involvement in nursing students' training *Mental Health Practice* 16 (1): 23-26.

Margrove K, SE-SURG, Heydinrych K and Secker J (2012) Waiting list controlled evaluation of a participatory arts course for people experiencing mental health problems. *Perspectives in Public Health (Online First)* October 3, doi:10.1177/1757913912461587

Schafer T., McGrath M., Kent L. and Nightingale M. (2013) Evaluation of Personality Disorder Workshops in Essex, England: Reported Impacts on Clinical Practice. *Journal of Forensic Medicine*. 9: 2: 92-100.

8. Researchers' reflections

8.1 On working with study participants

The clients were really positive about taking part and understood the questions

Very good interaction with service user, who understood the questions and gave honest answers of their experience. Interview went very well

Excellent – he 'told it how it is' and I feel we have got some good information

Very good – when I told them it was to ask **their** experience of staying on the ward, they were pleased to give their comments

Participant felt interview went well and he was able to say all he wanted without fear of come back from staff

Participant felt that this was the first time they had been able to be honest about their treatment

Very good – felt 'engaged' and welcomed the opportunity to answer questions and explain thoughts

Everyone is different and this makes them enjoyable

I enjoy speaking with service users and giving them an opportunity to give feedback and try to make it fairly pleasurable and interesting for them

This was probably the most difficult interview I have done but I also felt a sense of achievement

I felt that it went very well with the participant able to give the views they wanted rather than what they felt they were expected to give by the nurses

Sometimes requires enormous patience and sympathy

It is a privilege to be involved in this study and meet honest, open service users who share their stories

The enthusiasm of the participants was 'bubbling' and it was a pleasure to facilitate, there was so much feedback

There was a male in one of the groups that had to give up art due to a back problem. Having completed one of the Open Arts courses he now realised he had a future, he could do something and move forward

8.2 On being part of SE-SURG

Realisation that I have to vary my interview style, depending on the personality of the service user – the wrong approach could have them stressed, provoke ‘triggers’ or get poor response to questions

I felt very supported and I was really well prepared thanks to both SE-SURG administrators. Taking part in these questionnaires is helping my confidence and self esteem

I have learnt a great deal and it has helped to make me a better researcher

Enjoyable and good learning

I have learnt a great deal about antipsychotic medication and its effects

Feel privileged to have the opportunity to hear what people really think and feel.

I learn something every time. Great talking and listening to participants.

Being a member of SE-SURG I feel gives me recognition as a researcher in the field

I have gained experience in conducting quantitative and qualitative interviews, running focus groups, note taking and data inputting plus regular training for projects

I have thoroughly enjoyed and learnt so much from the opportunities I have had to work not only with SE-SURG members but also with other service user researchers and academics at Anglia Ruskin University and SEPT, as well as other universities, Trusts and organisations

SE-SURG has quite rightfully built up a professional reputation in the service user research field. As a group, we have a lot of successful outcomes in the research projects we have completed. I feel extremely privileged to be able to work part time as a freelance researcher. I now work with UCL and Camden and Islington Trusts on the WISE study and the CORE study, carrying out quantitative and qualitative interviews throughout London

As one of the artists on the Open Arts project, I feel especially lucky, as not only do I facilitate part of the project but to also use the questionnaires we developed on the Arts and mental health research project several years ago with ARU and UCLAN. As a member of SE-SURG I note take in focus groups and input the data in the database further down the line. I get to be part of the project the whole way through, in a project that is close to my heart, which I know works first hand, but I’m able to be part of the research process providing proof that it does

We have lively lunches one a month to keep us updated with training, latest projects and in touch with each other

I feel I have gained confidence during this past year, especially when giving presentations. I have continued to enjoy being able to give service users the opportunity to express their views and being able to influence change. I enjoy speaking with mental health student nurses around the concept of recovery and social inclusion knowing at times this has influenced/changed their practice

9. Feedback on contributions to student learning

We have received very positive feedback from our lecturer colleagues on the contribution we make to student learning. Here are just a few examples:

The most valued part of the session by all students were the stories told from personal experience as patients in the health service. These were considered very powerful in challenging preconceptions, developing empathy and raising awareness of key issues for patients. Students said that several of the stories would stay with them for a long time...

I would like to say a big thank for coming to share your perspectives on mental health recovery last week. As with previous sessions, the students in this group told me yesterday that they enjoyed the session and found it very beneficial and so on behalf of the module team, I want to thank you and your team for your contribution on this module.

Once again many thanks for your contribution to the module Valuing People and Fostering Dignity and Respect last week. Your team offered a powerful session and stimulated debate for the rest of the session and I suspect beyond that.

Just wanted to say a massive thank you to yourself and your colleagues for the excellent session yesterday. It was very well received and the students reported it as most valuable experience. They asked me to convey their appreciation to you all... Your session is so valuable to us on this module and we look forward to a similar session in July.

Students also sometimes ask the lecturer to give us feedback from them. One recently wrote:

I just wanted to email you my feedback from the service user session. I really enjoyed listening to their stories and life experiences, I must say it has been an eye opener for me and what they have shared will help me to be a better healthcare professional in the future... It has taught me the importance of good communication with clients and the importance of treating each person as an individual regardless of their age or wellbeing.

10. Looking ahead

We are currently working on two ongoing projects which we will report on in 2014:

1. A study requested by SEPT exploring the impact of employment on service users lives for which we are carrying out in-depth interviews with service users who have been supported by SEPT's vocational service to find and keep a job.
2. Our ongoing evaluation of the Open Arts studio at Hadleigh Old Fire Station (see page 18).

In addition, during 2013 we contributed to the evaluation of an arts project for young people being delivered by Zinc Arts with funding from Comic Relief. The evaluation is being led by Anglia Ruskin's Childhood and Youth Research Institute. Our contribution was to carry out a focus group with service users at Brockfield House forensic unit who had taken part in the project and we look forward to the final evaluation report due in 2015.

We also look forward to further collaborations with our colleagues in the North Essex Research Network (NERN). We are currently finalising the report from an evaluation of the Care Farm Pilot at Butterfly Lodge, requested by the NHS Greater Eastern Commissioning Support Unit (formerly the North Essex PCT Cluster). Projects in the pipeline include an evaluation of the North Essex Recovery College, also requested by the NHS Greater Eastern Commissioning Support Unit.

As well future work with NERN, we are looking forward to closer liaison with the WhyNot! older people's research group supported by Anglia Ruskin colleagues. In 2013 we were successful in obtaining funding to enable all three groups (NERN, SE-SURG and WhyNot!) to meet together in order to share ways of working. In the coming year we hope to obtain further funding to support the development of a resource pack on which we can all draw and spread the word about our work through a conference or symposium.

Getting in touch

SE-SURG is always pleased to consider commissions to carry out research and evaluations and to be involved in any projects in an advisory or training capacity.

Current or former mental health service users who think they may be interested in any aspect of the work SE-SURG carries out would be very welcome to contact us for further information.

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