

Initial Report to the School Management Team: Service User and Carer Involvement in the School of Health Sciences, UoS

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Executive Summary

Research evidence and policy guidance suggests that service user and carer involvement (SUCI) should be central to healthcare education and research. This report is of a SWOT analysis and staff survey of current SUCI within the School of Health Sciences (SHS). Research is discussed, but the focus is on education since SUCI is important for the new curriculum which is currently being developed.

This work indicates that, while there is good practice within the School (including the current service user and carer group), this varies across fields, there is no central record of activity, who participates, and the costs involved. It is proposed that a School SUCI strategy would ensure that the benefits of SUCI in teaching and learning, student recruitment and assessment, management and research are optimised.

Several recommendations arose:

- 1. A definition of SUCI should be selected for the proposed strategy.*
- 2. All SUCI activity should be recorded in a single document.*
- 3. A policy for rewarding (e.g. payment) SUCI should be developed and applied consistently.*
- 4. SUCI training should be provided for staff and SUs/carers.*
- 5. A database of SUs/carers willing to participate should be created.*
- 6. There should be increased communication between the School and stakeholders, and within the School around SUCI activity. A SUCI lead for each field/programme (including research teams) should be appointed to feed into this.*
- 7. There should be an annual evaluation of the School SUCI.*

These recommendations inform the following proposed model for School SUCI, which the Senior Management Team (SMT) is invited to review.

Proposed model for School SUCI

- Definition and model of SUCI agreed with existing Service User and Carer Group (SUCG)
- SUCG takes on the role of an 'advisory' board with a role in developing, over-seeing and evaluating School SUCI strategy, activity, communication and funding policy (in conjunction with Head of School). Lessons from the evaluation, e.g. best practice examples will be shared with SUCI leads.
- A SUCI lead for each field/programme and research team is appointed who monitors and records all SUCI for their field, including maintaining a register of SU/carer partners, SUCI activities and costs
- SUCI field/programme/research leads report to advisory board, who maintain a central database of SU/partners, record of activities and costs
- SUCI advisory board produce annual report, including evaluation of School SUCI
- Current website on SHS site maintained by advisory board to be developed to help disseminate information about SUCI activity, including the annual report.
- Training in SUCI will be provided for staff, SUs and carers.

A clear strategy and documentation of outputs (communications, reports etc) will provide useful evidence of School SUCI activity, for instance for validations. Finally, it is proposed that any strategy be developed in collaboration with SUs and carers; to this end the proposed strategy was presented at the February SUCG meeting. At this meeting, the new vision and proposed strategy were well received, the group will comment on the aims and objectives and whether they would like to be members of the advisory board to develop the strategy if accepted by SMT.

VISION

Service user and carer involvement will be at the centre of research and education across the School of Health Sciences.

This is designed to support and enhance the School vision:

“The School of Health Sciences is committed to playing a leading role in shaping the future of health and social care nationally and internationally. Through aspirational education and research, the School will deliver the most dynamic, effective and caring health care professionals. It will place innovation, research and passion at the heart of everything it does.” (Faculty of Health and Medical Sciences, 2017 Strategy).

AMBITION

Service user and carer involvement (SUCI) will become a normal, embedded part of the School’s culture and structure; furthermore, it will become part of our shared discourse through routine inclusion on meeting agendas.

All our stakeholders (service users and carers, students, clinical partners and school of Health Science staff) will understand the School SUCI strategy and how it applies to them.

Stakeholders will be able to understand the opportunities that SUCI can provide to enhance learning, support research and to engage with service users.

Appropriate support will be in place for all levels of involvement with the ambition that SUs / carers also benefit from their involvement.

MEASURES OF SUCCESS (suggested)

Annual stakeholder survey indicating increased SUCI

Professional body (e.g. NMC, HCPC) endorsement

Service user and carer satisfaction with involvement survey

Purpose of this report

- To report on a review of current service user and carer involvement (SUCI) within the School
- To report recommendations, informed by the review, for a future strategy. The need for a strategy on service user and carer involvement in education will be prioritised as a new curriculum is currently being developed. Future exploration will inform recommendations for a School strategy for service user and carer involvement in research.

Background

The Department of Health and various professional bodies recognise the importance of involving service users and carers in research and education (see Appendix 1 for a summary of such policies).

In research, patient experiences are considered vital sources of learning opportunities to improve care which are as valid as the learning opportunities reported by staff through patient safety systems (Christiaans-Dingelhoff et al., 2011, Clwyd and Hart, 2013). In 2017/2018 the National Health Service (NHS) in England paid £7-8bn in successful litigation claims to patients or their relatives, although the true cost to the NHS may be much higher due to long-term damages payments often being paid for the life of the recipient. This figure is more than three times higher than the previous 12 months (NHS Litigation Authority, 2018). The inclusion of service users, carers or patient representatives in care planning, health research and education development could improve patient experiences and outcomes as well as reduce the financial burden on health service through the reduction of repeated mistakes (Francis, 2013). UK standards for Public Involvement in Research have been developed for everyone doing health or social care research [<https://sites.google.com/nih.ac.uk/pi-standards/home>; accessed on 08/01/2020] and have informed this work.

In education, the NMC, HCPC, HEE and GMC all recommend, to a varying extent, service user and carer involvement in programme design and delivery, student recruitment and selection, and student assessment. A patient and public involvement in nurse education toolkit has been developed by HEE [<https://www.hee.nhs.uk/our-work/patient-public-involvement-nurse-education>;

accessed on 08/01/2020] to support and disseminate good practice. This HEE report identifies a range of definitions and models of service user involvement which informed the current work.

Recommendation 1: A definition of ‘service user and carer involvement’ should be selected for the proposed strategy informed by research evidence and service user/carer opinion.

Current SUCI in SHS

At the time of this review, the School had a long-standing School Service User and Carer Group (SUCG). The terms of reference for the group are shown in Appendix 2. The SUCG meets three times per year to contribute to curriculum development and comment on research proposals and outputs. Members of this group also contribute to School Boards, teaching and to student selection via MMIs and other ad hoc activities on request from school staff. Meetings are minuted. A budget of £4000pa is available and has been used to support travel and to provide refreshments. These funds are allocated as part of the general School budget and are not coded separately. From conversations with colleagues, it was also clear that individual courses and programmes involve additional service users and carers in different ways. No central record of this activity and who participates is currently kept, which makes it difficult to understand the extent and types of SUCI in the School.

Recommendation 2: All SUCI activity should be recorded in a single document.

WHAT WE DID

This work starts with a SWOT analysis of the current SUCG and was followed by a staff survey of SUCI. A draft strategy was developed and presented at the February 2020 meeting of SUCG for SU and carer comments.

SWOT analysis

<p>Strengths</p> <ul style="list-style-type: none"> • The SUCG is a long-established group • Previous experience in teaching • Desire highlighted by the group to have a deeper involvement in research 	<p>Weaknesses</p> <ul style="list-style-type: none"> • Funding routes and sources for SUCI activity are not always clear • Awareness of SUCG is low among School staff • Small group with limited diversity in field speciality and ethnicity • Limited opportunities for research staff to access SUCG support at short notice to meet short grant deadlines
<p>Opportunities</p> <ul style="list-style-type: none"> • The SUCG is a long-established group that could adopt an advisory role to interact with key members of staff in each field • A local directory could be established to identify experiences and strengths of each member • An advisory group could be developed within the SUCG members to support various annual reports • Field leads could liaise with SUCG chair/deputy chair on potential new service users, carers or representatives • SUC members could be involved in grant applications through cluster funding 	<p>Threats</p> <ul style="list-style-type: none"> • Lack of diversity could affect grant applications/access/relevance • Detailed costings could be prohibitive for current budget e.g. honorary contracts and maximum travel contracts.

Staff survey

Staff members, selected as likely to be involved with SUCI, such as the Programme Directors for each area, were asked to complete a short questionnaire via Qualtrics. Selected participants were also encouraged to forward the survey to other staff whom they felt could contribute.

Informed by the SWOT analysis, participants were asked questions designed to explore the extent of service user or carer involvement in their work, its type and function, costs involved and any barriers or suggestions for improvement (see Appendix 3 for the list of questions).

Findings

We received responses from 16 members of staff (research = 7, teaching = 8, both = 1). Findings therefore represent an indication of the current situation, rather than a comprehensive description. Table 1 shows the reported number of service users and carers involved in each field's work and the number of hours of involvement each year. Estimates of education-related expenses are shown in Table 1 by field, these are largely comprised of travel expenses, but also include those for 'tokens of thanks' eg flowers/voucher, refreshments. These expenses are additional to the SUCG budget of £4000 which makes it difficult to track the true cost of SUCI to the School or for the School to evidence its investment in SUCI. It can be seen from the Table that the mental health field reported the most SUCI.

Table 1
SUCG current activity

Field	Number of SUs/carers involved	Yearly Hours of involvement	Expenses (based on average SUCG cost)
Mental Health (n=1)	15	150	2025
Child (n=1)	2	6	81
Adult (n=3)	3	4	54
Midwifery (n=1)	2	20	270
Paramedic (n=1)	1	20	270
Prescribing (n=1)	6	18	243
Admissions(n=1)	3	80	1080
Research*(n=7)	115+	Variable	N/A
Total	32	298	4023

*Findings related to research are indicative as this was not a comprehensive review of SUCI in research and involvement will vary according to the project, costs are usually incorporated in grant funding so are not reported here.

Type and function of SUCI

Service users and carers were recruited via the School SUCG, 'word of mouth' and user groups linked to local services (e.g. Hospitals, NCT, midwifery field regular volunteers). The fields of mental health, child, adult, nursing, paramedic, midwifery and prescribing predominately integrated service users into the teaching provided for students. This was in the form of testimonials and presentations by service users, or question and answer sessions, videos of service users were also used. Service users also participated in interviews and recruitment of students to all fields. Their involvement in programme meetings was reported by midwifery and paramedic staff. For the Prescribing course, there is SUCI involvement in assessments (prescribing OSCEs) and module design (Prescribing). Staff whose role is predominantly research reported SUCI in all aspects of the research process.

Staff agreed that they expected SUs to increase students' understanding of people's personal experience of a service or of living with a condition. The extent of input varied across courses and activities and was sometimes directed by SUs'/carers' expectations.

Mostly, SUCI was considered valuable, especially by researchers. Three main barriers to SUCI in education were highlighted:

1) SUs and carers could be unreliable, for instance cancelling at the last moment. This was proposed to be linked to the voluntary nature of the involvement, i.e. SUs/carers may feel that their contribution is supplementary rather than integral and so may not prioritise it, or lack of payment (this can make it difficult to organise childcare for example). In relation to this, comments by staff suggested that clarity over who can be paid for what and from what budget code was needed.

Recommendation 3: A policy for rewarding SUCI should be developed and applied consistently. This would, of course, have to be developed with the budget holder/Head of School

2) Some SUs/carers were felt to have a particular 'agenda' which they wanted to 'push', regardless of the needs of the students/School.

Recommendation 4: SUCI training should be provided for staff and SUs/carers to ensure that there is a shared understanding of the purpose of SUCI

3) It was felt by several that more SUs/carers are needed in order to increase the range of experiences which could be shared and to reduce the burden on the small group who are used regularly. Researchers also wanted more regular access to SUs/carers with experiences relevant to their projects.

Recommendation 5: A database of SUs/carers willing to participate should be created. This should also hold details of the activities with which individuals would like to be involved e.g. some SUs/carers have expressed a preference for teaching, others for research.

Discussion

Clearly there is excellent SUCI currently within School activity. However, the extent and types of activity varies between fields and, due to lack of a single place for reporting, the full extent may not be appreciated fully.

Recommendation 6: There should be increased communication between the School and stakeholders, such as practice partners, and within the School, around SUCI activity. A SUCI lead for each field/programme/research should feed into this.

In addition, the SUCI within the School is currently not evaluated, so we do not understand its impact, cannot easily learn from best practice examples and cannot readily develop improvements.

Recommendation 7: There should be an annual evaluation of the School SUCI.

Development of a School SUCI strategy would ensure that SUCI is central to all School activities, would facilitate transparency and communication around SUCI and enable evaluation and future planning. The strategy and evaluation would provide useful evidence to share with stakeholders e.g. professional bodies regarding the quality and extent of SUCI within the School. Informed by the recommendations developed here (Appendix 4), we have drafted a proposed model for SHS SUCI for consideration by the School's SMT with the aim that a full final strategy and future work would be conducted with SUs and carers.

Proposed Model for SHS SUCI

- Definition and model of SUCI agreed with SUCG
- Current SUCG takes on the role of an 'advisory' board with responsibility for developing, over-seeing and evaluating School SUCI strategy, and SUCI activity, communication and funding (in conjunction with Head of School). Lessons from the evaluation, e.g. best practice examples will be shared with SUCI leads within the School.
- A SUCI lead will be established for each field/programme to monitor and record all SUCI for their field, including maintaining a register of SU/carers partners, SUCI activities and costs

- SUCI field leads will report to the advisory board, who will maintain a central database of SU/partners, activities and costs
- SUCI advisory board will produce an annual report, including evaluation of School SUCI
- Website will be developed and maintained by an advisory board comprising the current SUCG group members to help disseminate information about SUCI activity, including its annual report.
- Training in SUCI will be provided for staff, SUs and carers.

SUCG discussion

The above strategy was presented to the SUCG at their February 2020 meeting. Nine SUs and 3 staff members were present. Overall, the new vision and strategy were well received. Members have been invited to comment further at a later date to allow more time for consideration. Those who wish to be part of the advisory group will let us know, assuming that this strategy is agreed with the SMT. Comments were made regarding operational aspects of the strategy (see below), these can be developed and implemented once a new strategy has been agreed:

- A protocol for communicating with groups of service users and carers that is GDPR-compliant.
- GDPR training for SUCG members to improve their awareness of GDPR in research contexts.
- Ensure that any payments of expenses and honorariums are not destructive to members, some negativity due to bad experiences in the past. Further discussion is needed.
- Guidelines for staff presenting research for SUC input should be developed as some presentations have been unsatisfactory and SUCI has felt 'tokenistic'.

References

CHRISTIAANS-DINGELHOFF, I., SMITS, M., ZWAAN, L., LUBBERDING, S., VAN DER WAL, G. &

WAGNER, C. 2011. To what extent are adverse events found in patient records reported by patients and healthcare professionals via complaints, claims and incident reports? *BMC health services research*, 11, 49.

CLWYD, A. & HART, T. 2013. A review of the NHS hospitals complaints system: putting patients back in the picture. London, UK: Department of Health.

FRANCIS, R. 2013. *Report of the Mid Staffordshire NHS Foundation Trust public inquiry: executive summary*, London, The Stationery Office.

Appendix 1: Examples of policies requiring service user involvement in research and education.

From:

<http://peterbates.org.uk/home/service-user-and-carer-involvement-in-nurse-education/uk-policy-requiring-the-involvement-of-service-users-and-carers-in-nurse-education/> [accessed on 08/01/2020]

UK policy requiring the involvement of service users and carers in nurse education

There is a long history showing that the Department of Health and other bodies have recognised the importance of involving service users and carers in teaching and learning. This webpage offers a bank of quotations drawn from key policy documents.

Nursing and Midwifery Council

- “Approved education institutions, together with practice learning partners, must... ensure programmes are designed, developed, delivered, evaluated and co-produced with service users and other stakeholders.” *Realising professionalism: Standards for education and training Part 1: Standards framework for nursing and midwifery education* Published 17 May 2018, Standard 1:12.
- “Approved education institutions, together with practice learning partners, must... ensure that service users and representatives from relevant stakeholder groups are engaged in partnership in student recruitment and selection” *Realising professionalism: Standards for education and training Part 1: Standards framework for nursing and midwifery education* Published 17 May 2018, Standard 2:7.
- “Approved education institutions, together with practice learning partners, must ensure... a range of people including service users contribute to student assessment” *Realising professionalism: Standards for education and training Part 1: Standards framework for nursing and midwifery education* Published 17 May 2018, Standard 5:14.
- NMC (undated) *Quality Assurance Framework for nursing and midwifery education and their 2014 annual self assessment programme monitoring report* included a section on service user and carer involvement. Since September 2015, all teaching staff on nurse

training courses must maintain a personal learning log. The NMC has made it clear that service users and carers should be involved in student selection.

- “You should ensure that, where possible and appropriate, the selection process also includes ...service users.” NMC (2010) *Standards for pre-registration nursing education* p59
- “Programme providers must clearly show how users and carers contribute to programme design and delivery.” NMC (2010) *Standards for pre-registration nursing education* p66.
- “Programme providers must make it clear how service users and carers contribute to the assessment process.” NMC (2010) *Standards for pre-registration nursing education* p82.

Health and Care Professions Council

HCPC have given a very clear signal that they expect service users and carers to be involved in health care professional education, as shown in the quotations below. They also include trained lay visitors in their review and revalidation teams, thereby modelling the behaviour they expect from others.

- “You may want to show how you involve service users in your admissions and selections procedures. You could, for example, explain how service users are involved in your short-listing or interviewing processes or how they contribute to the design of interviewing questions or scenarios.” HCPC (2014) *Standards of Education and training guidance* p8.
- “You must provide evidence of your monitoring and evaluation systems. Evidence might include...an analysis of service users’ feedback through programme committees, employer liaison groups, local or national forums, and questionnaires” HCPC (2014) *Standards of Education and training guidance* p8.
- “We will need to see evidence of the resources that students use and have access to... may include: service users being directly involved in supporting student learning” HCPC (2014) *Standards of Education and training guidance* p23.
- “Service users and carers must be involved in the programme... they could be involved in some or all of the following: Selection, Developing teaching approaches and materials, Programme planning and development, Teaching and learning activities, Feedback and assessment, Quality assurance, monitoring and evaluation.” HCPC (2014) *Standards of Education and training guidance* p31.
- “The evidence you provide could include: information about how you plan, monitor and evaluate involvement activity; policies about how service users and carers are prepared for their roles and supported when they are involved in the programme; an analysis of service

users' and carers' feedback through groups, committees and questionnaires; and examples of how the involvement of service users and carers has contributed to the programme.

"HCPC (2014) *Standards of Education and training guidance* p32.

- "We expect you to provide evidence of how you make sure the curriculum stays relevant. This may include: evidence of regular contact with service users... evidence of the contribution that stakeholders (including service users) make in the programme planning process." HCPC (2014) *Standards of Education and training guidance* p37.
- "Explain how service users take part directly in teaching sessions or how they have influenced the development of training materials." HCPC (2014) *Standards of Education and training guidance* p41.
- "You should see overall governance as a process for reviewing and improving the service user's experience. So, we will need to make sure that there is evidence of a quality assurance system to support both the student and the service user within the practice placement setting." HCPC (2014) *Standards of Education and training guidance* p44.
- "You may want to show how you involve service users in your assessment procedures. You could, for example, explain how service users are involved directly in assessing students or how service users contribute to the development of assessment tools." HCPC (2014) *Standards of Education and training guidance* p57.
- 'Programme management and resources – Service users and carers must be involved in the programme'. (HCPC (2015) *Standards for Prescribing* p6.

Health Education England

- HEE has decided; "Our ambition is to put the needs of the patient at the heart of the education, training and workforce planning process. That is why HEE is committed to establishing a Patient Advisory Forum which will provide advice to the Board, the Strategic Advisory Forum and the [Advisory Groups](#) to ensure that the needs of the patient are at the heart of the education, training and workforce planning process and ensure a better connection between the decision and investments HEE will make and the people they will ultimately effect."
- "HEE should work with NHS England, PHE, professional bodies, charities, experts-by-experience and others to develop a costed, multi-disciplinary workforce strategy for the

future shape and skill mix of the [mental health] workforce.” [*Five Year Forward View for Mental Health for the NHS in England 2016*](#), p76.

- “It is key that education and training is co-produced between patients and trainees, and that both nurses and care assistants have an individual understanding of their patients and their personal health journey. Many education providers already address this, but there must be greater encouragement to do more in practice.” Health Education England (2015), [*Raising the Bar – Shape of Caring: A Review of the Future Education and Training of Registered Nurses and Care Assistants*](#) p35.

UK Government

“Every public authority shall in carrying out its functions have due regard to — (a) the need to promote positive attitudes towards disabled persons; and (b) the need to encourage participation by disabled persons in public life.” *Disability Discrimination Act 1995*, [*section 49A*](#).

- The UK White Paper [*‘Trust, Assurance and Safety – The Regulation of Health Professionals in the 21st Century’*](#) (DH 2007) advocates greater patient and public involvement, especially in the professions’ regulatory bodies to ensure decision are driven by patient’s interests, not vested interests. (see para 1.11, page 25).
- The Health and Social Care Act 2012 requires Clinical Commissioning Groups, Health Education England, Local Education and Training Boards, and commissioners in NHS England to enable... the effective participation of the public in the commissioning process itself, so that services provided reflect the needs of local people. This includes education.
- ‘The patient voice should... be heard during the commissioning of healthcare, during the training of healthcare personnel, and in the regulation of healthcare services.’ National Advisory Group on the Safety of Patients in England (2013) [*Improving the Safety of Patients in England*](#) p18.
- Is introducing the [*Teaching Excellence Framework*](#) from 2017 which will add new quality assurance processes within higher education. The TEF team have not yet considered how to ensure that TEF supports service user and carer involvement in teaching and learning.

Skills for Health

Skills for Health (2007) Enhancing quality in partnership: Healthcare education QA framework. Skills for Health, Leeds) listed eleven principles for high quality nurse education and one of these was service user and carer involvement.

Skills for Health (undated) *Your Voice Counts: How patients and the public can influence education and training to improve health and health care.* This document says: “Skills for Health is ensuring that patients, carers and the public are involved in the development of healthcare education programmes with the aim of improving both the quality of healthcare education and patient care and experience. An Involvement Advisory Group was set up by Skills for Health in December 2005 to work on this agenda in partnership with learners and people who use health services. A priority for the group has been to develop jargon-free information to help put this policy into action.”

General Medical Council

While the GMC is focused on doctors rather than nurses, it is interesting to note that they have made a clear statement [here](#) that ‘Medical education and training should be more focused on meaningful patient involvement, including in-service design.’

Appendix 2 Terms of reference for SUCG.

Members of the SUCG include, but are not limited to:

1. A service user or patient
2. A carer
3. A service user or patient representative
4. A student
5. A tutor/teaching fellow
6. A lecturer
7. A researcher
8. An academic
9. A member of staff
10. A friend or relative of any of (numbers 1-3) above
11. A member of the local community

We are likely to be several of these at any time in the past, present or future.

Appendix 3. Staff survey questions. There was a mixture of tick box and free text response options.

1. Have you involved service users or carers in your work?
2. How many service users or carers have you involved in your work?
3. In what ways are service users or carers involved in your work?
4. Are there costs associated with involving service users or carers in your work?
5. How do you fund the costs associated with involving service users or carers in your work?
6. How many hours do service users and carers spend being involved in your work?
7. Where have you recruited service users and carers from to be involved in your work?
8. When involving service users and carers in your work, what kind of expectations do you have about the contribution they will make?
9. What kind of difficulties or challenges have you experienced when involving service users or carers in your work?
10. Is there anything about the process of involving service users and carers in your work that could be improved or be made easier?

Appendix 4. Recommendations to inform School's SUCI strategy

Recommendation 1: a definition of 'service user and carer involvement' should be selected for the proposed strategy informed by research evidence and service user/carer opinion.

Recommendation 2: all SUCI activity should be recorded in a single document.

Recommendation 3: a policy for rewarding SUCI should be developed and applied consistently. This would, of course, have to be developed with the budget holder/Head of School

Recommendation 4: SUCI training should be provided for staff and SUS/carers to ensure that there is a shared understanding of the purpose of SUCI

Recommendation 5: a database of SUS/carers willing to participate should be created. This should also hold details of the activities with which individuals would like to be involved e.g. some SUS/carers have expressed a preference for teaching, others for research.

Recommendation 6: There should be increased communication between the School and stakeholders, and within the School around SUCI activity. A SUCI lead for each field could feed into this.

Recommendation 7: There should be an annual evaluation of the School SUCI.