Final report to the School Management Group from the review of service user and carer activity across the School of Health Sciences, with a proposed strategy to guide future development.

June 2016.

Prepared by Theo Stickley on behalf of the Service User and Carer Task and Finish Group

June 2016

1] Overview of both stages of the review

There is widespread understanding that the contribution of service users and carers enhances teaching and learning, research, students' experience, future practice, organisational governance and engagement with communities. This phenomenon is a direct result of "service user action" over the last 50 years and the rise of the "Expert Patient" in NHS discourse. Furthermore, both the HCPC and the NMC demand the involvement of service users and carers in the design and delivery of healthcare education. It has also become widely expected that "patient and public involvement" is also embedded in healthcare research and is compulsory in applications to NIHR. Whilst the School has been active in these areas over many years, there had never been a coordinated review of these activities. In June 2014, the SMG initiated a review of service user and carer activity across the School of Health Sciences; this was to be led by Theo Stickley. At that point, there was a corporate lack of clarity regarding the level of activities in this area; there was also no apparent management or monitoring of these activities and allied spending. There was a sense that some good work was going on, but there was a shared concern for the lack of oversight and strategic direction. A review therefore would inform important decisions about the future of this agenda. The review has been conducted in two stages. Stage One (implemented by Peter Bates) was fact-finding and the report and recommendations were approved by SMG in June 2015. Stage Two of the review comprised setting up a task-and-finish group to oversee the implementation of the recommendations over the following year. During this time a Scoping Review of Service User and Carer involvement in HEIs in England and Wales was conducted (again by Peter Bates). The 2015 report and the results from the scoping review can be found as separate documents.

2] Key strengths identified in 2014:

- Existing strategy adopted in 2011
- The eleven year history of the Service User and Carer Advisory Group (SUCAG)
- The history of innovation and initiatives within the School in research, recruitment, teaching and learning, evidenced across the three Divisions
- Evidence of publications co-authored by service users
- Cultural shift towards increased openness about sharing personal matters
- Historic financial commitment by the School to the agenda
- Good connections to some local relevant communities

3] Key areas for improvement identified in 2014:

- No senior leadership of service user and carer involvement (SU&CI) agenda
- No management of spending
- No joined-up work across Divisions and research groups

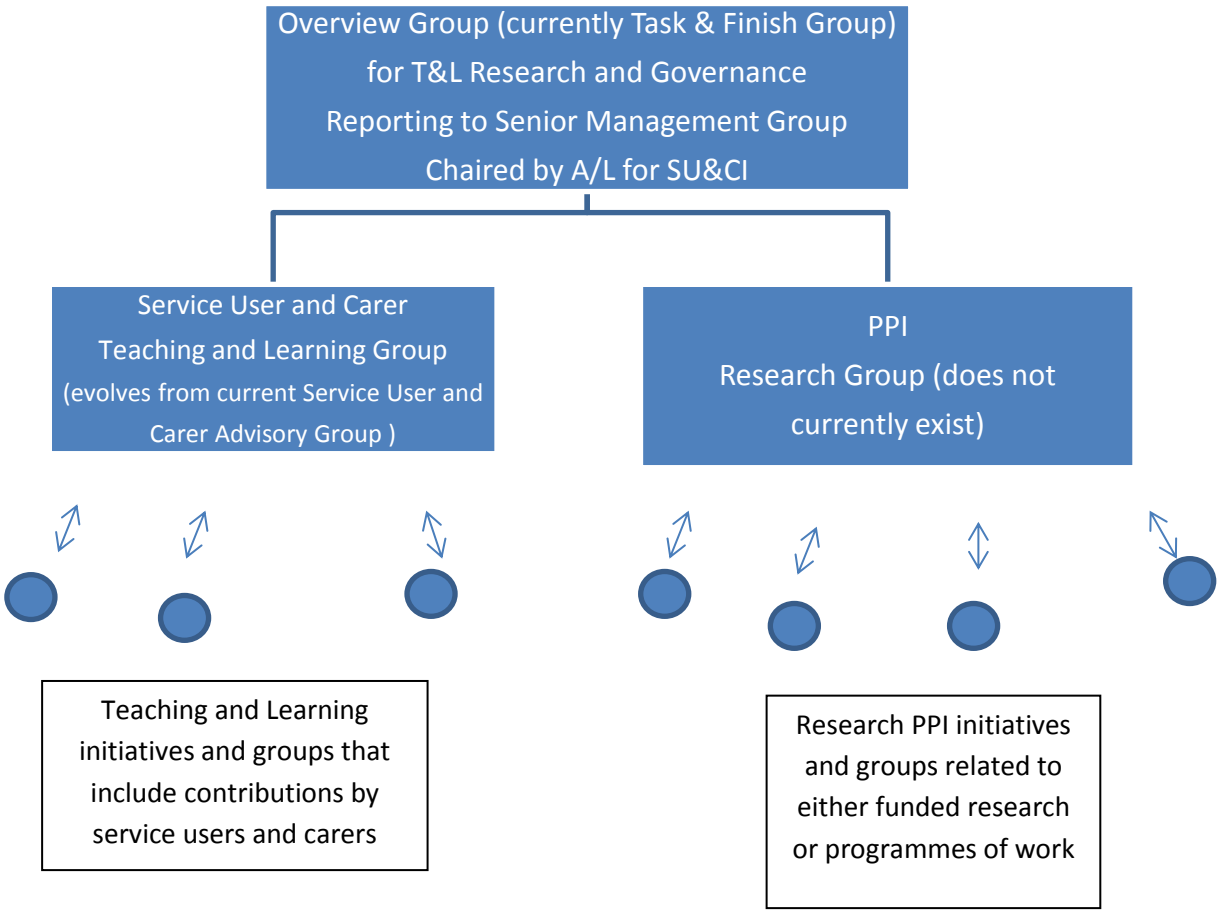
- A Service Level Agreement (SLA) with Self-Help UK (SHUK – formally Self-Help Nottingham)that had not been reviewed since its inception in 2011
- No intelligence regarding what was actually happening with SU&CI in the School and how this compared with our competitors
- A number of complaints regarding activities within the agenda with a risk of reputational damage (these were not detailed in the Stage One review)
- No formal quality control of activities
- Difficulties with casual payments
- The need to track and increase the size and diversity of the group of service users and carers, and address under-representation as indicated in the review

3] Key interventions 2015-16:

- An external review of activities (conducted by Peter Bates with support from Theo Stickley, Rosalind Maxwell-Harrison (HEEM, SU&C Advisor), Mórna O'Connor (Admin), Spring, 2015)
- Report produced with 24 recommendations
- Setting up of a task-and-finish group (monthly meetings)
- A review of both SLAs (SHUK and with Making Waves)
- A financial review of spending on SU&CI
- Implementation of recommendations from 2015 review as far as possible
- Review SU&CI activities within the research groups
- Development of a proposed strategy
- Development of a proposed structure to deliver the strategy

4] Key 2016 recommendations:

- Appoint an Academic Lead for SU&CI
- Agree an annual budget of £70,000 (disallow any other casual payments). This figure does not take into account additional income and expenditure on A and R codes.
- Encourage development of initiatives by freeing up the SLA with Making Waves and inviting staff to bid for funds.
- Adopt the proposed strategy (with any necessary amendments)
- Implement a new structure for accountability and communication as follows:



It is proposed that the Overview Group will hold the budgets detailed in the next paragraph. It will oversee the functioning of the teaching and learning and research groups. It is envisaged that any member of staff may, together with service user or carer partners, bid for a share of the development fund held by the Overview Group. Some of these funds (together with the casual payments) will be allocated to infrastructure such as training and public events as well as payments to people to maintain the three groups. It is hoped that this model will stimulate new activity across the three Divisions. Staff will also be encouraged to partner with service user and carer groups to apply for external funding and advice will be given for this.

Activities of Stage Two of the review

4.1] The Task and Finish Group

The most significant intervention has been the setting-up of the T&F group. Membership included:

Name	Designation/organisation
Theo Stickley	Chair
Joan Cook	Service User Development Worker
Yvonne Clark	Chair of Service User and Carer Advisory Group (SUCAG)
Julie Gosling	Making Waves Training Education Research Lead
Debbie Butler	SHS – service user in PPI and teaching and learning with the School
Sylivia Nalubega	PhD student
Fiona Moffatt	Lecturer in Physiotherapy
Julie Roberts	Research Fellow in Maternity Care
Binta Jammeh	Making Waves Presenter / Researcher
Caroline Fox	Making Waves Presenter / Researcher
Michael Osborne	SHS – service user in PPI

The group has met monthly between December 2015 and June 2016. Most people attended most of the meetings although Caroline Fox and Michael Osborne dropped out in the New Year for personal reasons. The group set about addressing the recommendations and determining to implement as many as possible and for those that would take longer to implement, the group has discussed a plan to ensure they are implemented in the future. To guide the discussions an "Implementation tool" was developed. This is a developmental tool and is updated when decisions have been made and tracks the progress of implementations. This will inform the development of the operational plan once the strategy has been agreed.

4.2] Draft Strategy

The T&F Group has drafted a strategy to take the agenda forward. Advice was sought from Eleanor Sibley who is Senior Strategy and Risk Officer in the University department of Strategy, Planning & Performance. Eleanor facilitated a workshop with the T&F Group members to help inform the development of the draft strategy. Prior to the workshop, T&F Group members and members of SUCAG began work on drafting implementation plans. A copy of the strategy can be found in Appendix 1.

4.3] PPI in the Research Groups

The Stage One report made little mention of user and carer activity in the research groups. This was not because there was little to report, but it became obvious that this work was disparate and uncoordinated and it was beyond the remit of the review to begin to scope all of the PPI activities amongst all researchers in the School. It was decided therefore that Theo Stickley would meet with each of the Leads of the Research Groups to have discussions with them about PPI in their respective groups. From these discussions it is recognised that there is much good work going on around the research groups regarding PPI. It is not the intention to scope this work in this short paper, but rather to propose a development for

the School that will enhance this good work and improve it. What is currently lacking is an infrastructure to support the agenda. It is not intended to impose any unwieldy demands upon researchers or collaborators within the groups. It is also recognised that researchers in the groups have multiple collaborations and connections across the groups, across the Faculty, nationally and internationally. Also, researchers must work within the structures and requirements of the various funders.

It is proposed that in order to help facilitate effective PPI within the research in the School that a new group should be set up that serves a similar purpose to the current SUCAG but to support the research agenda. This group will enable PPI activities that are at the moment, somewhat disparate and not connected, such as recruitment, training, maintaining a database of interested people and so on. The new group will comprise a combination of researchers and other people willing to commit to the PPI agenda.

Recommendations to be completed:

- Make an allocation in the budget for service users and carers to attend conferences as presenters where there are no research funds to pay for them.
- Support the group of prolific principal investigators and authors to set the tone for service user and carer involvement in research across the School.
- Use the service user and carer webpage to highlight publications that relate to service user and carer involvement and those that are authored or co-authored by service users and carers working alongside staff in the School

4.4] The role of service users and carers in School Governance

The majority (18) of the 24 recommendations in the Stage One review were to do with governance of the School. These are divided into five headings: 1] Strategy and culture, 2] Support, training, recruitment and diversity of people involved, 3] Structures, committees and staffing, 4] Finance and management and 5] Staff recruitment and development. In summary, the following actions have either been completed or are proposed:

Completed recommendations:

- A strategy has been drafted for SMG approval

Recommendations to be completed:

- Organise a School event in the next academic year to begin a dialogue about how to move from a traditional model of involvement, towards a more contemporary model of co-production
- Create a centralised system for “validating” members of the public as casual or voluntary workers and create a database of workers (thus able to monitor diversity)
- Develop a generic shared learning/training programme within the School (possibly Faculty) for members of the public wishing to contribute

- Resolve barriers to effective working (such as access to IT, rooms, ID badges smart cards etc) and keep workers safe.
- Implement a new structure for accountability and communication (see paragraph 4 above).
- Identify a budget (see paragraph 7 below) and appoint Academic Lead and negotiate administration support for the Agenda
- Embed service user and carer collaboration within staff and student recruitment processes
- Embed learning about collaboration with service users and carers into staff induction and Continuous Professional Development systems

4.5] The role of service users and carers in Teaching & Learning

This is one of the strongest areas of activity in the School. The most ambitious programme within education is the PINE project designed and delivered by Making Waves to mental health nursing students. This programme has been running since 2003. Making Waves have also co-produced a model of student assessment in the classroom for GEN mental health students (with Gemma Stacey). It is proposed to pilot this on the GNC BSc for future implementation, possibly in the Major Modifications to the GNC. The Stage One review identified 17 modules across the School where service users delivered more than two hours teaching. Whilst there is a history of meaningful activities, there is scope for further initiatives across the Divisions and each of these should be evaluated and monitored to ensure quality provision.

Completed recommendations:

- Next time the Module Handbooks are revised, ensure that they include a statement about how service users and carers are involved in the design and delivery of learning opportunities.

Recommendations to be completed:

- Include service user and carer involvement in module design as a standing agenda item, and track activity throughout the revalidation cycle.
- Consider how the School collects, aggregates, analyses and acts on student evaluations of teaching delivered by service users and carers.
- Set a target to involve trained service users and carers in all student selection processes.

NB. There are pockets of SU&C activity in LBR/PG, but this is an area for future development.

4.6] The scoping of SU&C involvement in 31 Universities

The results from this review can be found in a separate document. 31 Schools responded to our approaches to them by telephone and these represent approximately 40% of those Schools in the UK providing nursing, midwifery and or physiotherapy education. In summary, it is evident from the review that of those Schools interviewed "service user involvement" in healthcare education has become the norm. Our School compares favourably but the activities in our School are not exceptional. Not included in the review however is a focus upon PPI activity and this comparison is yet to be done. By comparison we could state:

- It is fairly common to have a named person responsible for the SUI agenda
- Most Schools have a strategy for the agenda
- We are slightly behind on KPIs as we have no SMART targets
- We score well on training people, but other Schools do too
- Our work in student selection appears the norm
- It is usual for service users to be involved in module design
- It is normal for service users to teach without staff being present in the classroom
- Our experiences of service users assessing our students is significant
- We need to examine the input of service users and carers in School committees
- Our support, supervision and career development for service users and carers needs some attention

5] Review of Service Level Agreements (SLAs)

5.1] Self Help UK (formerly Self-Help Nottingham)

The School has two Service Level Agreements. The agreement with Self Help UK ran for three years from 2011, and arrangements had continued without review after 2014. The current development worker has been in post since 2004. Theo Stickley had several meetings with Michele Banton of SHUK to review the SLA. It was mutually agreed that Joan Cook had made a significant contribution to the School over the last 10 years. It was also agreed that elements of the costs in addition to salary no longer represented value for money for the School, and recommended that annual costs be reduced from £35,538 to £27,824. A breakdown of these costs can be found in Appendix 2. SMG will need to decide the length of a new contract. Discussions also included improving liaison and reporting, and areas where SHUK may be able to undertake smaller specific pieces of work with the School.

5.2] Making Waves

The second SLA is with Nottingham-based Making Waves. This agreement provides service user-led teaching predominantly on the Mental Health Nursing field of practice. This three-year agreement is in its second term and the current contract expires in November 2016. Following discussions amongst members of the Mental Health team it has been agreed to

not renew this contract. It should be noted however that this decision has not been made because of any failing in quality on behalf of those providing the teaching, on the contrary, the sessions are evaluated extremely well and the project has been enormously successful. It is felt however, that provision should now be made for new initiatives and enterprises to emerge (Making Waves are in agreement). The management of Making Waves have been given notice of the intended cessation of the contract.

6] Language and nomenclature

There are two key phrases in this agenda. The first is "service user and carer involvement" (SUCI) and the second is "patient and public involvement" (PPI). SUCI is the preferred language of both the HCPC and the NMC and often refers to public engagement activities in teaching, learning and governance. PPI is the language of the healthcare research agenda. The word "involvement" therefore is common to both the professional bodies and the healthcare research agenda, so it may be the preferred the term although it is contentious. For as long as there is "involvement" then the professionals remain "on top" and others may be invited along to the professional's agenda (Stickley, 2006). It is however proposed within this project that the "gold standard" for the agenda should be co-production. A very recent phrase is to refer to people as having "Lived Experience" (as a substitute for "service users"). Language therefore should not simply be parroted from the top-down agenda of overseeing bodies but should reflect the aspirational nature of the programme of work. Ultimately there is no consensus about language either nationally or even within in our group. We look forward to consulting with our partners who are members of the public regarding the matter of language as well as hearing the views of members of the SMG on this topic.

7] Proposed annual budget for SU&C agenda 2016-2017 and going forward

	Current costs annual £	**Proposed annual costs £**
SHUK	35, 538	27,824
Making Waves*	24,344	NIL
Casual payments	c. 15,000	15,000
Development initiatives	NIL	27,000
TOTAL	**74,882**	**69,824**

*The actual cost will be higher in 2016-17, because the SLA for Making Waves expires in November 2016 (not at the beginning of the financial year)

8] Review and Evaluation

This has been the first review of Service User and Carer activities in the School. The strategy (see Appendix 2) proposes monitoring and evaluation activities in the future. It may be appropriate to also suggest future dates to conduct a similar review; for example in a cycle of seven years.

Reference

Stickley T (2006) Should service user involvement be consigned to history? A critical realist perspective. *Journal of Psychiatric and Mental Health Nursing*. 13, (5) 570-577

Appendix 1 - Proposed Strategy

A strategy to strengthen the contribution which carers and people who use health services make to the management, organisation and delivery of the School of Health Sciences

Prepared by the Service User and Carer Task & Finish Group
with the assistance of Eleanor Sibley, Senior Strategy and Risk Officer

1 VISION

What we are working towards:

A shared understanding of the significance of the contribution of carers and people who use health services into the management, organisation and delivery of the School of Health Sciences that will facilitate and enhance co-production in the activities of the School.

In the future

All our stakeholders (service-users and carers, students, practice partners and School staff) will know what service-user and carer engagement is and how it applies to them, and what the opportunities, roles and responsibilities are for them. The practice of co-production will become a normal, embedded part of the School's culture and structure; furthermore, it will become part of our shared discourse.

Our stakeholders will all value the shared learning which comes from genuine integration with each other because we know that this integration enhances our teaching and learning, our research, and the governance of the School and therefore integrating further will bring direct benefits and enhancements to our teaching, our learning, our research, our students' experience and our engagement with our community.

We are not limiting our definitions to apply to a small group of people. In fact each one of us has the potential to be or lived experienced of being:

A service user or patient

A carer

A student

A researcher

An academic

A member of staff

A friend or relative of any of the above

A member of the local community

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

The vision in context

This vision is to wholly support and enhance the School vision:

"*The School of Health Sciences will be the best provider of health care education that meets the demand for a high quality health and social care workforce, undertake outstanding research and equip students with exceptional knowledge, values, and skills to improve the quality of health care and make a difference in society*". (SHS 2019 Strategy).

Not only does the vision in this strategy enhance the School's vision in terms of forward thinking, but it also identifies how the School might achieve its vision in part through developing the service user and carer agenda.

2 CONTEXT SUMMARY

The School of Health Sciences has as one of its values: *"Working in partnership: with people using health services, their carers, their representative agencies, service providers and education commissioners".*

Historically, the School has enjoyed good relations with many of these partners and there has been a culture of "user and carer involvement". This agenda has grown and been strengthened especially over the last 15 years. During this period there have been many successful examples of good practice, most notably the setting up and growth of the Service User and Carer Advisory Group. This strategy builds upon this good work and looks to a future where the agenda becomes "joined up" and coherent with key performance indicators to monitor its success. In order to ensure the success of the strategy the School needs to be united in its commitment to the agenda. We have therefore identified four objectives to engage staff and key stakeholders in the implementation of this strategy. These are:

1. Language and philosophy
2. Change – as a progressive step
3. Embed this agenda in all our activities
4. Future opportunities

It is hoped that people that use health services and carers will become part of the process of implementation and feel genuinely included and involved in all School activities, because their contribution is understood and valued. By developing such relationships we can move towards a more co-produced model of partnership working. Where we envisage people attending School meetings, it is for co-productive goals: raising questions, challenging decisions, introducing ideas, working co-operatively, and being taken seriously. Similarly, in external roles we

would hope to see people influencing commissioners and policy-makers and taking part in activities such as lobbying, speaking out, challenging decisions and so on.

3 SWOT ANALYSIS

To inform the development of the objectives of this strategy we conducted a SWOT analysis within the Task & Finish Group.

STRENGTHS	**WEAKNESSES**
• Strong history of service user and carer (SU&C) engagement being valued within the School. • Examples of good SU&C practice in the School • New HoS is fully committed to the agenda of SU&C engagement. • Examples of good practice across the Divisions within the School • Reputation for SU&C engagement is established and known which is a strength but more work needs to be done • Support and enthusiasm of professional bodies for SU&C engagement • Most health research funders want Patient & Public Involvement. • A national network exists for SU&C involvement. • School Research Group Leads seem to understand the value of the agenda. • Student feedback regarding the relevance of education content and the process for engagement is of a high quality and exceptionally useful to enable the School to enhance this provision.	• Lack of shared terminology and language. • Dependent on key individuals to champion this agenda. And often it is the 'familiar faces' who attend meetings etc • Lack of consistency in drawing up and advertising roles to service users and carers, leading to unequal access • No mechanism for service users to engage/share experiences with each another • Lack of links between service users which can make them feel disenfranchised. • Do Research Group Leads and research staff really understand the agenda? • General lack of diversity within the School which weakens the opportunities offered by service user engagement. • Are there enough new people in the School to take the agenda forward in the future; and what can be done to ensure there are? • Do we inhibit opportunities for innovation; and if so, how and why? and what can we do to prevent this? • No audit has been done to assess how staff engage with SU&Cs. • Conflicts of interest not always acknowledged • Administrative inefficiencies (outlined in the review) • Financial constraints limit opportunities to plan effectively beyond the short-term. • The review process has caused some people to become demotivated and feel they (and their ideas) are in limbo.
OPPORTUNITIES	**THREATS**
• Join the dots: eg improve communications, have clear roles and responsibilities, develop webpages, training for service users and carers. • Develop a shared language within the School regarding the agenda – this will also contribute to embedding it. • Actively engage with the University's Community Engagement team.	• Changes to University administrative and business systems can cause inefficiencies and frustrations. • Financial constraints within the University. • External funders' financial constraints. • Changes to external funding, eg nursing funding. • Natural resistance to change • People feeling disengaged or not included.

• Opportunity to develop a compact (similar to contract) of partnerships • Create a set of principles for SU&C and students engagement (would support the School in embedding engagement). • Develop collaboratively, a system of and for SU&C engagement. • Make the implementation of this strategy into a call to action for all involved, and an opportunity to develop cohesion both in the School and in SU&C engagement. • Make the most of the support of external governing and funding bodies. • SU&C and the community suggest or generate ideas for both research and education. • The School's new structure provides an opportunity for inter-professional collaboration and integration. • Embed SU&C into School structures. • Look for any international (and international campus) opportunities. • Engage with other UoN Schools which engage with SU&Cs. • Opportunity for School Management to lead on embedding the agenda and making the change. • Create empowering processes to encourage and enable tutors to engage SU&Cs more; enable them to work collaboratively and learn good practice from each other. • Introduce succession planning for both School staff and SU&Cs. • Opportunity to be clear on the benefits of SU&Cs engagement such that it is funded within current financial constraints (UoN and research funders).	• People in the School may respond tokenistically to requirements by external funders (education and research) • SU&Cs may become demotivated if they feel their contribution is not valued.

4 OBJECTIVES

The four objectives identified in this strategy will enable us to achieve our vision. A more detailed implementation plan will be developed once the strategy has been approved by the School Management Group.

OBJECTIVE 1: ***Create our own language and philosophy for this agenda***

OBJECTIVE 2: Facilitate change – as a progressive step

OBJECTIVE 3: Embed this agenda in all our activities

OBJECTIVE 4: Future opportunities

OBJECTIVE 1:

Create our own language and philosophy for this agenda

Both the NMC and the HCPC use the language of "involvement". This is further supported by the NIHR who further require "Patient and Public Involvement" in research. On the surface therefore it might be considered expedient to adopt this language. It is argued however, that this language represents an outdated approach. The School has an opportunity to define its own activities (whilst still satisfying the involvement agenda), and its own language and philosophy. In itself, this will encourage discussion within the School and between the School and our SU&Cs about what we mean by the language we use; this will enhance relationships and is likely to lead to new understandings amongst us and potentially new opportunities for increasing collaboration and co-production. In this way, the School may also position itself as a leader, rather than a follower in this agenda. This shift may demand of the School more than we currently imagine in terms of the commitment required to bring change based upon values. Where power is shifted, there is often resistance.

	Actions	**KPI**
1.1	Facilitate a series of workshops across and between stakeholder groups to identify philosophy and language	A set of definitions and values which is accepted and adopted within the School and by SU&Cs.
1.2	Adopt language and definitions across all School documentation and website pages	Change to internal and public facing materials
1.3	Create nurturing and challenging environments where co-production becomes evident in governance, teaching and research	Evidence from each Division and the SMG of co-produced projects and activities in research, teaching and learning and governance

OBJECTIVE 2:

Facilitate change – as a progressive step

Building upon the good partnership work of the past, this strategy requires a number of changes to ensure that the School realises its vision to "improve the quality of health care and make a difference in society" by facilitating and enhancing co-production in the activities of the School.

	Actions	**KPI**
2.1	Establish a new structure to implement the agenda	Terms of reference for groups adopted by SMG and Chairs named
2.2	Create a cost code and budget	Cost code identified by September 2016
2.3	Appoint an Academic Lead for the agenda	By September 2016
2.4	Centralise all systems to support the agenda	Common knowledge within the School of new procedures etc
2.5	Stimulate innovation and support new practice	A list of new initiatives by June 2017
2.6	Service users and carers to be more visible in all staff and student recruitment processes to the point where the practice becomes the norm	Evidence from all Divisions of names of people on which panels and when
2.7	Service users and carers to be more visible in all key meetings across the School for research, teaching & learning and governance.	Evidence from all Divisions of names of people on which committees and attendance at which meetings and when
2.8	A more comprehensive and detailed evaluation of service users and carer activities – especially in teaching	SETs or equivalent to be produced and used
2.9	Fast-track process for confirming and continuing current projects and successful initiatives after pilots, for life of relevant curricula, subject to annual co-produced feedback loop and quality improvements	Table of projects with rationale for continuation or otherwise
2.10	Consider succession planning for both School staff and service users and carers. Balancing a mixture of longer experienced and new people	The HoS and School Management Group discuss and agree an approach to

	learning from each other.	this and follow it. Names of staff and SU&Cs who are new to the agenda and who make a contribution

OBJECTIVE 3:

Embed this agenda in all our activities

It is one thing bringing about change but it is another to embed that change into daily practice. This process is enhanced by the focus of Objective 1 – to introduce a new language and a shared philosophy, and supported by Objective 2 – to facilitate the change. It is important for staff and stakeholders to see the purpose of the change and the positive results from the new initiatives.

	Actions	**KPI**
3.1	Encourage staff and stakeholders to "own" the agenda	The number of new initiatives proposed
3.2	Staff and stakeholders to evaluate the individual initiatives and also the entire programme	Evaluations for both initiatives and also the entire programme and evidence of co-production
3.3	Heads of Division to report upon activities within the agenda, within their Divisions	Evidence of reports
3.4	Research Leads (and PIs) to report upon PPI activities	Co-produced research questions, research applications, publications,

OBJECTIVE 4:

Future opportunities

The vision for this agenda needs to have short, medium and long-term goals. There are many opportunities to develop the agenda within the School and beyond. The School should aim to be "leading the field" in this agenda and given the results of the scoping of its competitors in England and Wales, the School is well placed to achieve this goal.

	Actions	**KPI**
4.1	To create an active network within the Faculty, the University and beyond	Evidence of meetings and collaborations with similar, external people and bodies. Joint working with other Schools, Faculties, research groups and centres in the UoN.
4.2	Influence local and national commissioners and policy-makers	Evidence of activities such as lobbying, speaking out, challenging decisions
4.3	Annual evaluation of progress and new goals to establish further change, growth and development.	Written evaluation with goals identified for future development
4.4	Dissemination of work	Co-produced conference presentations, published articles etc