

# Involvement of service users and carers in the University of Nottingham School of Health Sciences

## Review and Recommendations June 2015

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	Page
<b>Contents</b>	
Introduction .....	2
Conclusions at a glance .....	2
Findings .....	3
Recommendations .....	16
Appendices .....	18

### Acknowledgements

We wish to sincerely thank everyone who kindly gave their time and provided insights into their activities to help with this review.

We are particularly appreciative, and indeed in awe of the generosity of so many service users and carers who allow themselves to be examined and interviewed, who contribute to lectures and committee meetings, and who speak and write about their personal and sometimes painful experiences simply to improve the quality of teaching, learning and research at the School.

## Introduction

Since the 1990s, the Department of Health and other bodies<sup>1</sup> have recognised the importance of involving service users and carers<sup>2</sup> in their all activities - and this includes both teaching and research in the health sciences. The term 'service user and carer' and the scope of the review is explained in Appendix 3. A key regulatory body<sup>3</sup> introduced new standards from September 2014, and now include trained lay visitors in their review and revalidation teams in order to model the behaviour they expect from others. Major funding bodies have placed service users and carers at the heart of their mission<sup>4</sup>.

The university is a member of the prestigious Russell Group<sup>5</sup> and aims to increase its ranking on community engagement<sup>6</sup>, in line with various national policy statements<sup>7</sup>. Most academic institutions have involved service users and carers for some years<sup>8</sup>.

The School of Health Sciences comprises undergraduate and postgraduate teaching and research in the fields of nursing, midwifery, physiotherapy and sport rehabilitation. It has a proud history of involving service users and carers for more than 15 years, and has reiterated its commitment to service user and carer involvement and its ambition to strengthen these activities<sup>9</sup>. Therefore, this review was commissioned in March 2015 (see appendices 1 and 2 for the proposal and methodology) to explore the following questions:

- Are service users and carers involved throughout the School – in all teaching programmes, research endeavours and in the governance structures of the School itself? Appendix 4 catalogues the potential areas of involvement.
- Are there common challenges that need a coordinated response in order to embed the contribution of service users and carers more effectively?
- How might involvement be developed over the next five years so that the School remains relevant and strengthens its position as a pioneer and beacon of excellence?

## Conclusions at a glance

An excellent start has been made and the substantial achievements and contribution to date should be celebrated. To make further progress, there is a need to work with service users and carers to:

- Invest in and expand the work
- Manage and monitor the inputs and outcomes
- Embed and spread innovation so it impacts all areas
- Pioneer and inspire late adopters and external audiences.

## Findings

Evidence was drawn from 130 survey returns, 30 interviews and 100 documents (see appendices 5-7 for details).

The School of Health Sciences is one of four Schools in the Faculty of Medicine and Health Sciences at the University of Nottingham. It has 270 staff and a turnover of £20m. There are three academic divisions: Nursing, Midwifery and Physiotherapy & Rehabilitation Sciences that operate from bases in Nottingham and Derby<sup>10</sup>.

### Strategy and culture

Recommendations R1, R2

**Strategy.** Both the University's Global Strategy and the School Academic Strategy support the development of service user and carer involvement. A strategy for involvement was adopted by the School in 2007<sup>11</sup> and refreshed in 2010 with activities logged against each of the goals. Its aspirations are laudable, but the general absence of metrics limits its value for monitoring progress.

A new strategy<sup>12</sup> is needed, which should: set out the potential advantages of service user and carer involvement; align with wider strategies and set out a vision and measurable goals; overview activity and set benchmarks for monitoring progress; and clearly identify resources and priorities for their efficient and effective use. Such a strategy should move beyond making the exceptional commonplace to advancing radical innovation. This would take the School beyond a traditional approach to 'involvement' into genuine coproduction in which the external requirements are met through partnership at all levels.

**Culture of the School.** Service users and carers believe that there has been a gradual shift in culture and it is now more acceptable for staff to speak about their own personal experience, and to create safe spaces for students to do the same. In 2014, Professor Callaghan said that service user and carer involvement was 'no longer exceptional'. However, our survey also brought to light some traditional views<sup>13</sup>.

### Staff development

Recommendation R3

The Staff Development Group<sup>14</sup> coordinates staff training, plans coordinated initiatives to meet staff learning needs and managed a budget of £85,000 for 2014/15<sup>15</sup>. The Group does not include service users or carers. Resources<sup>16</sup> to help staff involve service users and carers have been created (a list of online resources is at Appendix 8), but there is little evidence of their widespread use. From September 2015, all staff who teach on nursing courses will be required to maintain a personal learning log, and this will provide a mechanism that could be used to track learning about service user and carer involvement.

Well over 80% of learners registered with the School are nursing students<sup>17</sup> and so the size of the Nursing Division gives its processes and systems an obvious dominance. It is a truism that managerial efforts intended to create positive unity across the School may unwittingly suppress minorities. While such issues are clearly beyond the scope of this review, cooperation between the Divisions and the balance of consistency and local tailoring will have an impact on how service user and carer involvement functions, as we shall see illustrated in the discussion about student selection that follows.

The **School brochure** is perhaps the first thing that prospective students will see before they apply, and it contains no reference to service user or carer involvement. Those who apply then attend selection events. Each Division within the School has its own approach to selecting students and this evolves over time as new methods are tried and then evaluated by both internal and external stakeholders. As a total of well over 2,000 prospective students are interviewed each year (as shown in appendix 7), this is a large undertaking.

In **physiotherapy**, students are selected by full-length one-to-one interviews with an academic and a practitioner. The interview format was initially designed in collaboration with service users and carers, and more recently, service users have observed selection interviews and suggested revisions to the questions and processes. New arrangements are under discussion, and may include a group exercise in the future that could involve service users and carers.

In **midwifery**, some students attend selection events on Saturday mornings where a multiple mini interview process is used, and one service user has interviewed half the candidates at the selection events she has attended. The Nursing and Midwifery Council expect service users and carers to be involved in selection processes<sup>18</sup>.

In **nursing**, discussions about a systematic approach to involving service users and carers in student selection started in 2008 and took place for the first time in 2010. The number taking part in selection days increased to 15 in 2014<sup>19</sup> and a further cohort of service users with experience relating to all four fields of nursing were trained this year to take part in group interviews for BSc Nursing in Nottingham. Service users and carers circulate and talk to candidates during the informal lunch, but, as with clinicians, are not present in all of the interview groups. A smaller group has trained for the new multiple mini interviews for GEN at Derby, which are scheduled for all candidates to have a section of their interviews with a service user or carer. Administration staff have taken on some duties to support the process. While service users and carers are present at all nursing selection events, they are not present in every group, so some prospective students will only meet staff.

## Curriculum design

## Recommendation R5

Occasional consultation events<sup>20</sup> have been held to seek a wide spectrum of views before designing the detail of the curriculum. This early opportunity to shape the whole programme is valued, as well as downstream opportunities to comment on draft materials. Service users and carers have contributed to the design of at least 17 modules. The Graduate Nurse Curriculum provides an example:

- Service users were members of the Curriculum Development Group that ran from 2009 up to the validation point in 2012
- Wider Focus Groups with service users and carers were held and the outputs were fed into the Curriculum Development Group
- A service user sat on the Practice Learning Development Group which ran from 2010 to 2012 and designed the approach to placements.
- Once the course was validated, a Unit Development Group was formed, which included service users and continues to make marginal improvements to content, assessment and evaluation for the 20 or so modules that fit within the Unit.
- This involvement has led to more direct input in teaching and the development of teaching materials.

It may be noted that coproducing the curriculum has some parallels with coproducing a care plan, and students will find that such working collaborations between professionals and service users reappear throughout their career. On a less positive note, two staff told us that recent changes to the curriculum have reduced opportunities to involve service users and carers.

## Teaching and learning

## Recommendation R6

Learning is organised into modules, each of which is described in a handbook that is available online. A sample of handbooks did not reveal any sign of service user and carer involvement in course delivery<sup>21</sup>.

Despite this low profile in the handbooks, service users and carers have contributed to at least 51 modules<sup>22</sup> across the School and we were told about 17 modules where service users and carers delivered at least two hours teaching<sup>23</sup>. Making Waves have trained 16 service users to deliver teaching. The ratio of modules that report live service user input versus the total number of distinct modules offered by the School would provide an indicator of the spread of involvement<sup>24</sup>. The PINE sessions form an example from mental

health nursing where service user and carer involvement has been thoroughly embedded in the design and delivery of the teaching programme.

At least 10 service users and carers have been trained and then worked as co-facilitators in nursing sessions, and 'patient simulators' are used in physiotherapy and elsewhere to enable students to practice their clinical assessment skills.

Online learning forms a substantial component of many courses, and service users and carers have been involved in the creation of learning materials. Some of these online resources have been added to the repository of 200 Reusable Learning Objects at [Helmopen](#)<sup>25</sup> and those that are for a more restricted audience are on Moodle. A central store enables these items to be viewed in order to maximise their use and sparks further creativity, as well as tracking the penetration of involvement in teaching across the School<sup>26</sup>.

## Assessment

Recommendation R7

The following aspects of assessment provide opportunities for service users and carers to be involved.

**Student assessment of teaching delivered by service users and carers.** Modules and their teachers are periodically evaluated across the School, but this process does not at present provide any insight into teaching provided by service users and carers<sup>27</sup>. An additional proforma has been generated to gather students' evaluation of a teaching event led by service users and carers, but it asks different questions to those found in the university's evaluation mechanism<sup>28</sup>. Service users and carers also have a proforma to help them reflect on their experience in the classroom.

**Practice placements.** There is some involvement in the assessment of practice placements. Following the pioneering SUSA programme<sup>29</sup> based at the School, nursing has created a system for routine collection of service user feedback as part of the Ongoing Achievement Record (OAR) that captures student learning during their placement<sup>30</sup>. Written guidance is provided to students, service users and family carers to explain the process. Consent forms and proformas for collecting evidence are available, including adapted versions for young children and people with cognitive impairments. The Moderation Group for Practice Learning, which has included service user and carer attendees, checks the consistency of the process by reviewing a sample of OARs. Parallel arrangements exist for midwives, who will usually look to their caseholding relationship for one of these two written statements. Physiotherapy has developed a voluntary mechanism for adding views from service users and carers to their clinical portfolio during placements, and this will start in September 2015 as explained in their student handbook.

**Dissertations.** Two service users have been part of a design team that created a new option for undergraduate student nurses which has been offered from September 2014, enabling the student to write a reflection on a service user or carer's narrative<sup>31</sup>.

**Assessment of student performance.** We might consider four stages in the process by which a student gains a professional qualification. First, individuals or teams of people (including perhaps placement mentors and teaching staff) pool their evidence. Second, this evidence is judged (marked) to decide if the student has achieved the required standard. Third, in the moderation stage, a sample of these judgements are reviewed to confirm that different staff are applying the criteria consistently. Fourth, those students who meet all the required standards are deemed to have passed the standards set by the professional body and the University. During the review we heard a variety of opinions about what was actually meant by the NMC and HCPC's hint that service users and carers should be involved in student assessment<sup>32</sup>, and only one staff member said that service users and carers were involved in assessment of students.

**Validation by external inspection bodies.** Service user and carer involvement can happen in different ways in the process by which the NMC or HCPC validate a programme and approve its awards –

- Inspectors may wish to interview service users and carers as part of their evidence-gathering team.
- The School may include service users or carers on their team delivering a presentation to the inspectors.
- Inspection teams may recruit and train service users and carers on to the inspection team, who then visit institutions where they have had no prior involvement or conflict of interest.

In the May 2015 Midwifery approval visit, the School was asked to find a local service user or carer to join them the inspection team. In the end they were unable to engage anyone, either due to the conflict of interest involved or the small number of service users and carers who have been involved in the Division to date.

## Research

## Recommendation R8

A total of 45 research projects are coordinated by staff based at the School<sup>33</sup>. The research income between February 2014 and January 2015 was £1.3m, yielding a research margin in the last academic year of around £271,000, which is approximately 20% of the turnover. The Executive Strategy Board of the School aims to increase the research margin income by 10% year on year. There is an established history of involving service users in research activities dating back to at least 2004<sup>34</sup>.

**Steering Groups.** Our survey collected information about 15 research projects, of which 13 had a Steering Group and they all included a service user or carer on the group. The initial idea for four of the studies was kindled by a service user or carer group.

**Key influencers.** Eight staff hold almost half of the 45 research projects, with another 20 staff covering the remainder. None of the 28 is based in Physiotherapy, three are in Midwifery (accounting for 5 of the 45 studies) and the remainder are in the Nursing Division. In terms of a raw count of publications, the most prolific eight staff contribute to 40% of the published output<sup>35</sup>. As some of these prolific authors are also in the Principal Investigator's group, we can say that just 11 staff coordinate half the research projects and contribute to two in five publications.

**Public co-applicants and other documents.** Eight studies include a service user or carer as a co-applicant. This is a complex role, demanding significant commitment from the service user or carer as well as from the rest of the research team<sup>36</sup>. In addition, service users and carers were involved in

- finalising the wording of the study protocol in 9 studies
- developing the submission to the ethics committee in 5 studies
- creating patient information in 12 studies
- collecting, analysing or interpreting data in 6 studies.

### Coordination of involvement in research

The School supports a number of service user and carer groups centred on its research teams in addition to the advisory groups attached to individual studies. These groups are becoming agile and well-informed advisors across a range of separate studies. They can also offer advice to doctoral students and thus establish the practice of coproduction early in the academic career<sup>37</sup>. In midwifery, two research fellows have some time built into their job descriptions to support service user and carer involvement.

During this review, we were reminded of the crucial role that personal connection and commitment plays in the success of service user and carer groups. Both research and teaching staff have reported that people are most likely to stay involved when they feel a strong allegiance to a particular staff team or topic. This means that future arrangements designed to increase School-wide coordination must not be at the expense of these motivating relationships.

The links between the separate service user and carer groups and with SUCAG are not strong and tend to rely on just one or two individuals. As a result, activities such as



literature reviews, fund-finding and system building may be duplicated, and the 'terms and conditions' of involvement may have unwarranted variations from one group to another.

### **Budget for service user and carer involvement in research**

The National Institute of Health Research, along with some other research funders, requires a ring-fenced Patient and Public Involvement budget to be included as part of each funding application. At present, there is no oversight mechanism within the School to ensure that patient and public involvement is properly costed into funding applications, or that it is spent on the purpose for which it is provided. Some very senior staff are spending inordinate amounts of time bidding for small amounts of money to market their group or pay expenses<sup>38</sup>, and the management process for approving expenditure can be sluggish and unreliable<sup>39</sup>.

### **Dissemination**

Recommendations R9, R10

Involvement activities have been advertised on a dedicated [webpage](#) since 2007, which includes biographies of six service users and carers and one case study. Service users and carers have been invited to speak at conferences – both within the School (such as the Annual School Forum), elsewhere in the UK, and overseas - since 2000, with service users contributing to at least five conferences in the past year<sup>40</sup>. Such activities have been funded by the Staff Development Group<sup>41</sup>, but some events continue to be planned without consideration of the involvement of service users and carers<sup>42</sup>. School staff share an academic interest in the subject of service user and carer involvement and published 23 items on the topic up to 2010, and more recent work continues to be produced<sup>43</sup>. In our survey, 16 staff told us that they had co-authored papers with service users, and 11 research studies plan to disseminate their findings to the community beyond academia.

### **Recruiting and supporting service users and carers**

Recommendation R11

A registration process has been developed for service users and carers, but is not used throughout the School. This means that there is no central database of service users and carers engaged with the School, nor a single point of access<sup>44</sup>. Consequently, recruitment and training, communication<sup>45</sup>, financial management and quality assurance matters are all handled by different people working with their own contacts and in isolation from one another. Appendix 9 lists the 13 routes into involvement we found.

During the review, we identified 85 service users and carers who have been involved with the School.

## Recruiting new service users and carers

Recommendations R12, R13

There is a widespread feeling that the School would benefit from increasing the size and diversity of the group of involved service users and carers<sup>46</sup> and SUCAG have been concerned about this issue since 2007. In the survey, twelve staff reported that they ‘don’t know how to find people willing to be involved’. Longstanding members are valued, but there is a shared concern that those who bear multiple roles may not have the concomitant skills, and may lose their distinctive contribution after being socialised into the culture of the School. Information leaflets and posters have been created for various settings to advertise opportunities and to seek new people. Newcomers benefit from a role description<sup>47</sup> so they know what they are expected to do. However, the absence of a central database<sup>48</sup> makes it difficult to carry out equalities monitoring or to advertise opportunities for participation so that everyone has an equal chance of making a contribution. It makes it harder find out if efforts to enlarge or diversify the group have worked.

## Training service users and carers

Recommendation R14

Various training programmes have been offered since the initial course in 2000, including for telling one’s own story, for involvement in student selection, for co-facilitating sessions alongside academics and for understanding research<sup>49</sup>. Selection and training clearly needs to be matched to the specific requirements of each role. For example, service users who are involved in student selection are required to complete training on equality and diversity<sup>50</sup>. In addition, service users and carers are able to attend the [central short course programme](#). As numbers grow in the future, a planned programme of development and training<sup>51</sup> for service users and carers would add consistency, accountability and value to the School.

## Processes and procedures

Recommendation R15

When new ways of engaging with service users and carers are identified, each one requires careful consideration and the development of thoughtful processes that address legal, organisational and pastoral needs. For example, when involvement in nursing student selection was contemplated, the Development Worker, SUCAG colleagues and School staff invested a significant amount of care and effort in designing an effective system and then transferring the bulk of the operation to School administrative staff.

To date, many complex procedural issues remain unresolved and impede the spread of innovative approaches, which remain tied to a few pioneers. Thirteen staff told us that ‘the bureaucratic issues are too hard.’ For example, service users and carers who contribute extensively to the work of the School may have the opportunity to become University

Associates and gain access to identity badges, the academic library and staffrooms, an email address, online or offline workspace<sup>52</sup>, printing facilities and e-learning provision. Not everyone knows about these offers, and there may still be some teething troubles with the systems. Should the School decide to embed other innovative practices that involve service users and carers, a whole raft of procedural and system solutions will be needed<sup>53</sup>.

## Quality assurance

Recommendation R16

The majority of the feedback we received was positive about the benefits to staff and students of involving service users and carers, and the benefits to service users and carers of being involved. The vast majority of student evaluations we saw were highly appreciative, and service users and carers felt valued, respected and uplifted by their contact with the School and were convinced that their work was making a positive difference.

*“I get to have an impact in the area that I have experience with, to implement change and improve the service offered to future patients.” (service user)*

On a less positive note, we also heard from both service users and staff about a small number of circumstances in which things had not gone well. It was felt that service users and carers had not always been well supported by staff, who occasionally appeared disinterested; while a minority of service users and carers had, on occasion, failed to understand the purpose of the event where they had been involved, were felt to have been dismissive of the lived experience of staff or had been unnecessarily confrontational in their manner. Ten staff in our survey said ‘it’s awkward when people turn out to be unsuitable’. Such occasional difficulties have been addressed on an individual basis, but we did not identify robust systems to support people in these circumstances<sup>54</sup>. By way of comparison, at HEEM, all lay partners are selected by interview, obliged to attend periodic training, participate in an annual appraisal process and submit an appraisal of each activity they engage in before payments are authorised<sup>55</sup>.

## Service User and Carer Advisory Group

Recommendation R17

SUCAG was formed in 2005 and meets every two months either in Nottingham or Derby, chaired by a service user. Since 2010 or before, membership has been made up of an equal number of service users and staff, drawn from all three Divisions. Meetings have agendas and minutes, ground-rules<sup>56</sup>, an induction leaflet and jargon buster for new members. There are 11 service user and carer members and 15 staff on the mailing list and attendance averages 10 people. Members are involved in a wide range of activities, as can be seen elsewhere in this report.

## Wider Networking

Recommendation R18

This section covers networking relationships at a number of levels.

*Membership of committees within the School* should be allocated to service users and carers only where they can have genuine rather than tokenistic involvement and add significant value<sup>57</sup>. A natural approach would be to place service users in the same groups that student representatives have a designated place. We were told that service users and carers have a place on 9 committees and groups across the School<sup>58</sup>. In addition, Midwifery is planning to include a service user and carer representative on their Course Management Group. The total number of groups where service user and carer representation would be appropriate could be counted and contrasted with the number where it is achieved to demonstrate progress over time<sup>59</sup>.

*Links with other parts of the university* are relatively meagre, although there are pockets of collaboration, such as the connection with Dietetics through SUCAG, with HELM through the development of online resources, and with the School of Medicine through the simulated patients programme.

*Community links* exist, particularly via Self Help Nottingham to many voluntary groups. Service users and carers are connected to at least 30 groups outside the university, bringing a valuable resource to the School.

*National and international links.* SUCAG has longstanding links with parallel work in other universities via [DUCIE](#) and Making Waves work with a variety of higher education and other institutions. There is potential to capitalise on the identity of the University as an international organisation by looking at parallel activities in China and Malaysia<sup>60</sup>.

## Accountability

Recommendation R19

At present, accountability arrangements for service user and carer involvement are unclear. This means that efforts rely on the enthusiasm of a few individuals rather than a proactive approach from senior management that creates a corporate response from the whole School. The weakness of present arrangements can be seen at several points, as shown below.

**School structure.** The restructuring of the School has precipitated a helpful review of reporting lines and accountability arrangements, but the place of service users and carers in the new structure awaits the recommendations of this review<sup>61</sup>.

**Service Level Agreements.** In the past, the Head of School has met periodically with the Director of Self Help Nottingham to review the Service Level Agreement, which lacks detail<sup>62</sup>. The oversight arrangement with Making Waves is less formal.

**Policies and procedures** have been developed, including an application form, induction checklist, a policy for payments and expenses, guidelines for teaching, ground-rules for students and guidelines for disclosing personal experiences - but there are no mechanisms for ensuring distribution or compliance with these systems across the School. Some service users and carers are unhappy with the way that their complaints have been handled, suggesting that a more robust or transparent process may be needed.

**Role of SUCAG.** SUCAG reports to the Director of Teaching and Learning and produces an annual report. Service users and carers may have valuable insights, as they work across a variety of activities, but their observations are not well harnessed. A small number of staff regularly attend the SUCAG meetings and support its activities, but no senior manager does so. As an advisory group, SUCAG does not have executive authority (e.g. for developing a strategy, authorising budget expenditure or regulating arrangements for engaging with service users and carers). In the absence of any clear delegation, such authority reverts to the School Management Group.

## Staffing

Recommendations R20, R21

Future arrangements will need to address four functions - which, of course does not necessarily mean four postholders - as follows:

- A *Senior Sponsor* on the Management Group could provide endorsement to the strategy and encourage staff to work together to deliver it.
- A *Bureaucracy Navigator* could lower barriers to the adoption of best practice across the organisation. The navigator would map processes, negotiate between competing interests, find practical solutions and track uptake.
- A *Line Manager* for service users and carers could recruit and select appropriate people via a clearly understood protocol for lay appointments, identify suitable activities, coach and develop their skills, and support and appraise their work<sup>63</sup>.
- An *Academic Lead* could scan the research environment to bring proven innovation to the School, encourage the adoption of evidence-based practice in involvement activities, develop theory and lead research into impact<sup>64</sup>.

The survey showed that 60 consider supporting service user and carer involvement as part of their job role and 13 staff spend some time most weeks on this. The job descriptions of the Making Waves *Teaching Coordinator* and Self Help Nottingham's *User Involvement Development Worker*<sup>65</sup> tend to focus on the 'line manager' function, although the current post-holders have interpreted their roles much more broadly.

The present investment in staffing resources is insufficient to address these needs and coordinate the current disparate activities that take place across the School.

Many NHS organisations now invite service users and carers to sit on the recruitment panels that select staff, and see many advantages to this, including help with identifying candidates who have the right values, reminding them of the fundamental purpose of the organisation, and providing independent reassurance regarding the fairness of the process. There was a clear expectation that this would happen from 2011, but just four staff reported that they had been interviewed in this way for their current post and, of the 42 appointments made in the School in 2014, only one panel included a service user or carer<sup>66</sup>.

### **Overall budget for service user and carer involvement** Recommendation R22, R23

Costs are made up of the following:

- A service level agreement with Self Help Nottingham provides for a Development Worker post (21 hours a week<sup>67</sup>). This post began informally in 2002, was formalised in a service level agreement in 2011, and was initially overseen by a steering group made up of staff from the School and Self Help Nottingham. The Steering Group has discontinued meetings and the formal agreement expired on 31 March 2014, but arrangements continue.
- A service level agreement with Making Waves provides a Teaching Coordinator for 15 hours a week, 183 person-hours of teaching per annum to mental health nursing students plus recruiting, training and supervising the PINE tutors, as well as delivering peer support sessions for PINE tutors. The agreement runs until 20 November 2016<sup>68</sup>. A recent report from Making Waves received no feedback from the School. Some of the people involved in Making Waves are also active in other ways at the School, which points to the need for clarity about what is included in the contract.
- Individual fees and expenses for service users and carers. The Development Worker has meticulously tracked expenditure related to teaching and governance which will reach £10,000 this year<sup>69</sup>, but other staff may be authorising additional expenditure against other budget lines<sup>70</sup>, so the total amount is unknown.
- Some funding has been provided from the Staff Development Budget to support service users and carers who have been invited to speak at conferences<sup>71</sup>.
- In-kind support from School staff.

There is no scheme of financial delegation for the authorisation of expenditure and no system for controlling or tracking costs<sup>72</sup>. In our survey, we found a total of £9,280 held by three staff in addition to the funding for the service level agreements, but no pooling of resources or coordination of expenditure. Both Service Level Agreements require the provider to report their activities in an annual report<sup>73</sup>, but the lack of detail makes it

difficult to audit activities. Staff find it difficult to obtain funding for innovation or to cover the ongoing costs incurred in maintaining relationships with service users and carers between funded activities.

### **Contracting and payment arrangements**

### **Recommendation R24**

The Development Worker negotiated a Fees and Expenses policy<sup>74</sup> with the Human Resources Department in 2009 and continues to meet with them from time to time to identify and try to resolve issues that arise, especially due to changes in legislation and central university procedures<sup>75</sup>. Service users and carers who give lectures can be paid through the university's casual worker's scheme<sup>76</sup>, but there is no control mechanism to ensure that the policy is applied consistently and the people we met were not aware of their rights and obligations as casual employees of the university. Members of the School Management Group believe that they should reward a 'fair day's work with a fair day's pay' whilst recognising that any arrangements that are made should meet their duty of care towards service users and carers. However, 29 staff told us that 'payment arrangements are too complex and slow'.

Consideration also needs to be given to the feelings that are evoked by inconsistent arrangements amongst the service user group, as well as the need to comply with employment law, HMRC obligations, the welfare benefits and pensions system, adopt best practice in relation to volunteer engagement, strive for equal opportunities, and recognise the backdrop of arrangements that exist within the rest of the University. As the School is concerned to engage with people who may need additional support, funding will need to cover the additional costs involved in providing carers or releasing them to be involved.

## Recommendations

*R1: Develop a School Strategy for service user and carer involvement with clear ambitions, resources and performance indicators to drive future development.*

*R2: Conduct a discussion across the School about the implications of moving from a traditional approach to involvement ('you join in with our events') to a more contemporary dialogue about coproduction at all levels.*

*R3: Embed learning about involvement of service users and carers into staff induction and Continuous Professional Development systems.*

*R4: Set a target to involve trained service users and carers in all student selection processes.*

*R5: The group that oversees course revalidation should include service user and carer involvement in module design as a standing agenda item, and track activity throughout the revalidation cycle.*

*R6: 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.*

*R7: Consider how the School collects, aggregates, analyses and acts on student evaluations of teaching delivered by service users and carers.*

*R8: Support the group of prolific principal investigators and authors to set the tone for service user and carer involvement in research across the School.*

*R9: Use the service user and carer webpage to highlight publications that relate to service user and carer involvement and those that are co-authored by service users and carers working alongside staff in the School.*

*R10: Decide whether to support the costs of trained service users presenting at conferences<sup>77</sup> and agree an appropriate budget.*

*R11: Centralise the approval system for all service users and carers who are authorised to work in the School.*

*R12: Increase the number of service users and carers who are involved with the School.*

*R13: Track the diversity of service users and carers who engage with the School and address under-representation as indicated.*

*R14: Develop a curriculum and consistent training programme for service users and carers in response to the needs of the School.*



*R15: Identify and resolve the wide range of procedural impediments that restrict further opportunities for involvement.*

*R16: Seek advice from the School Safeguarding Group to clarify and, where necessary, introduce control and support mechanisms that will help to keep everyone safe.*

*R17: Refresh SUCAG and establish its strategic role as overseer of service user and carer involvement across the whole of the School.*

*R18: Strengthen networking arrangements so that solutions found elsewhere can be quickly and efficiently brought into use in the School, and the pioneering work in the School can be shared with the widest possible audience.*

*R19: Locate responsibility for action clearly, and clarify lines of accountability, so that the strategy for service user and carer involvement can be implemented across the School.*

*R20: Increase the staffing investment in service user and carer involvement by (a) appointing lead staff, (b) clarifying the contribution of all staff in respect of the involvement of service users and carers, and (c) coordinating all these activities to increase efficiency.*

*R21: Submit a strategy and action plan to the School Management Group showing what would be needed to embed service user and carer involvement into staff recruitment processes.*

*R22: Establish a scheme of financial delegation, centralise budget expenditure, provide for core costs and innovation, and manage and track costs.*

*R23: In order to raise the quality of annual reports and allow output to be audited, provide a template setting out how contractors should present their activity.*

*R24: Resolve any outstanding difficulties with the contracting and payment arrangements.*

# Appendices

## Appendix 1: Proposal for the review

To evaluate the activities of “service user and carer” involvement within the School of Health Sciences and to provide coherent recommendations for the development of a strategy to address this agenda in the future.

### Methods

In response to the proposal received from the School Management Group, we propose the following methodology to conduct this review.

- **Survey.** We intend to implement an online survey specifically designed for various stake-holders i.e academic staff, administration staff, students (u.g. and p.g.), researchers. This will be complemented by specific enquiries to Course leaders to elicit details of public involvement in specific courses.
- **Interviews and focus groups.** The results from the surveys will inform the questions we ask stake-holders including service users and carers already involved in individual interviews and focus groups. We will individually interview key people e.g. Joan Cook, Julie Gosling and run focus groups for other stake-holders. We envisage a total of 12 interviews and focus groups (we would propose conducting one focus group with the SMG). We will audio-record, and write up notes from each.
- **Document review.** We will access all possible relevant documents to review, such as: contracts, internal course handbooks, validation documents, audit trails of user/carers involvement, minutes of meetings and so on.

We will analyse the data and present the findings as follows:

- Wider context for user and carer involvement in the School
- Current ‘state of play’ (across divisions and all activities, T&L, Research etc)
- Recommendations for future development, short, medium and long-term

### Timescale

Feb-March – recruit RA, planning and design and implementation of the survey. April - Conduct the interviews and focus groups. May – data analysis and writing up. 08/06/15 - Final report

### Resources

Staff	Time commitment
Theo Stickley	2 days
Peter Bates	9 days
HEEM Advisor	3 days
Research Assistant	7.5 days
TOTAL	21.5 days

## Appendix 2: How the review was done

The review team consists of the following people.

Peter Bates has worked for [National Development Team for Inclusion](#) since 1999, a not-for-profit agency that provides consultancy, training and facilitation for mental health, learning disability and older person's services. Since 2011, he has supported public involvement in CLAHRC-NDL, the [East Midlands AHSN](#) and the Institute of Mental Health at the University of Nottingham. He has published over 80 items in the areas of employment, disability, empowerment and inclusion, including a number of landmark policy, commissioning and practice publications.

Rosalind Maxwell-Harrison is a Lay Representative Partner of [Health Education East Midlands](#) and a member of the Patient Advisory Group to [Health Education England](#).

Mórna O'Connor is a researcher at the [Sue Ryder Centre for Palliative and End of Life Studies](#), within the School of Health Sciences at the University of Nottingham.

Dr Theodore Stickley is Academic Lead for Mental Health and Learning Disabilities and Associate Professor of Mental Health. He is currently collaborating on a European research project funded by ERASMUS and developing online Master's level mental health educational materials which will be free to use once complete.

The Review was made up of the following elements:

- Four surveys were distributed as follows: (i) to service users and carers; (ii) to all staff, (iii) to module leaders, and (iv) to research leads.
- Focus groups, face-to-face and telephone interviews with selected staff.
- Documents were reviewed (particular thanks are due here to Joan Cook, Julie Gosling and Jonathan Lamley for supplying a rich archive of material)

Only 25.5 days work was available for the review, and so of necessity, the approach was exploratory rather than exhaustive. Formal consent was obtained for the interviews, which were recorded but not transcribed, and themes arising from them were identified informally, rather than via a disciplined thematic methodology. The purpose was to blend internal knowledge from within the School with external independence to rapidly form a view about current practices, future prospects, and further questions.

After drafting the report it was sent out by email for comments. Both this report and the Board's response should be circulated to people who contributed information to this review

### Appendix 3: The scope of the review

- **Service users and carers, not all stakeholders.** There are many stakeholders in the activities of the School – students and their future employers; current teaching, research and management staff, including those who themselves are patients and service users; readers of academic journals and other outputs; schools and community organisations; and, of course, people who use health or social care services and taxpayers. No doubt the School is enriched by listening to all these groups. However, the purpose of our Review is to examine how patients, service users and carers are currently involved, rather than staff, students or others<sup>78</sup>.
- **Service users and carers, not staff.** Within mental health, considerable attention has been paid to ‘user-researchers’ who are fully qualified researchers *and* use services. Some staff and students make extensive use of health services themselves or care for those who do, and many staff have considerable experience of providing clinical care to patients. As well as attending to all these important perspectives, the challenge of the ‘service user and carer involvement’ agenda requires specific action to bring new voices and new perspectives into the School that would not otherwise be available.
- **Not two separate groups.** In this report, the phrase ‘service users and carers’ means a single group comprising patients, service users and sometimes the general public. Reflecting on the differences between these subgroups is important, but lies beyond our scope.
- **Not just a radical challenge.** Some the activities included in this report may reproduce, rather than challenge, the traditional patient/professional relationship<sup>79</sup>. As the School does not yet have a tight definition of what counts as involvement, the whole spectrum from simulated patients to radical challengers have been included.
- **Not tokenism.** The review will consider how service users and carers contribute to teaching, research and the governance of the School. The goal is for service users and carers to be involved in meaningful ways where they can add value.
- **Just the School.** Wider links with other parts of the university are acknowledged from time to time, but this review is confined to the activities of the School of Health Sciences. The School has pioneered the involvement of service users and carers in a number of its activities, and there is some evidence<sup>80</sup> that it continues to be in the vanguard, but we were unable to benchmark the School against other academic institutions. We note that service users are being trained as co-researchers at Nottingham Trent University, staff and service users learn together about involvement techniques in Oxford and learning disabled patients help with student assessment in London. Future work might involve horizon scanning for what can be learnt from elsewhere.

## Appendix 4: Where might service users and carers be involved?

There are three areas where service users and carers could be involved in the activities of the School. They are analysed in some detail below:

### Education

Involving service users and carers can add value to student experience and sharpen direct teaching and practice learning so that students qualify with deeper values, strengthened competencies, a more person-centred approach and a more respectful and compassionate attitude. Innovative teachers may involve service users and carers in the following areas:

- **Course design.** Service users and carers could sit on the Revalidation Steering Group; help to create teaching modules<sup>81</sup> and course materials<sup>82</sup>; and contribute to routine amendments and adaptations<sup>83</sup>.
- **Course delivery.** Service users and carers could deliver direct face-to-face teaching<sup>84</sup>, as well as appearing in videos<sup>85</sup> or through other indirect means.
- **Student selection and assessment.** Service users and carers could assist with moderation processes, comment on the quality of presentations, posters or other outputs and provide written assessments of specific capabilities in practice settings<sup>86</sup>. This can happen in the initial selection of students<sup>87</sup> and in ongoing assessment<sup>88</sup>.

### Research

Involving service users and carers can improve the impact and relevance of research, making it 'more effective, more credible, and often more cost effective as well'<sup>89</sup>, while helping researchers to be rigorous and accountable. Extensive advice is available on how to engage service users and carers in coproducing health research<sup>90</sup>, including the following steps:

- **Advice.** The Steering group may contain at least one service user or carer who has personal experience of the topic being researched, or the research team may regularly seek advice from a patient reference group<sup>91</sup>.
- **Co-creation.** Service users and carers may kindle the initial idea for a piece of research, be named as co-applicants, be employed to collect or analyse data, and may co-author academic papers.

- **Outputs.** The voice of the service user or carer may be captured in written outputs from the research team. Service users and carers may assist in the drafting of outputs. Training materials may be targeted at service users and carers themselves and dissemination strategies may include community audiences as well as professionals.

## **Governance of the School**

Involving service users and carers can add rigour to the governance of the School, by insisting on transparency and accountability, aligning activities to purpose and raising aspirations. Done effectively, involving service users and carers can help the School to win funding, advance the careers of its employees and have an enlarged impact on the local, national and international community. Service users and carers can assist in a variety of ways, including:

- **Membership of Boards**, Steering and Operational Groups, and subcommittees<sup>92</sup>
- **Influencing the culture**, as service users and carers press the School to share information more widely, democratise its decision-making and utilise personal disclosure in its teaching, research and management – in short, think first about the effect of all activities on service users and carers.
- The **recruitment**, selection and development of staff working in the School

In order to facilitate the activities listed above, the School needs to invest sufficient resources to recruit and support service users and carers, as well as creating effective processes and tracking uptake<sup>93</sup>. Done well, this will form a springboard for further innovation and help the School to meet the objective set by government of ‘nothing about us without us’<sup>94</sup>.

## Appendix 5: The surveys

Each survey began with a general introduction, invited people to identify themselves and ended with an invitation to stay in touch.

### Service User and Carers Survey

In what ways have you contributed to the SHS as a service user and/or carer (tick all items that apply to you) (a) In student selection (b) In the classroom (c) Advising on research (d) On a committee or working group (e) Creating a resource such as a video or online teaching resource (f) Other - If you selected Other, please specify.

Please identify meetings for service users and carers at the School that you attend/have attended (check all items that apply to you) (a) The Service User and Carer Advisory Group chaired by Yvonne Clark (b) The Palliative Care PPI group convened by Kristian Pollock (c) The Nottingham Maternity Research Network chaired by Bernie Devall and Julie Roberts (d) The New Youth advisory panel chaired by Maria Michail and Tim Carter (e) The Dementia, Frail Older People and Palliative Care PPI group convened by Reena Devi (f) Other - a If you selected Other, please specify the group(s) and their chairperson(s)

Thinking about your service user and carer involvement outside the School, do you contribute to other services or organisations as a service user/carer? (a) The Patient Participation Group in your local GP practice (b) No other involvement (c) Other - a If you selected Other, please specify.

What is the best thing about getting involved as a service user/carer with the SHS?

What would you change if you could to make it better?

### All Staff Survey

Into which family does your post at SHS fall? (a) Admin. / Technical (b) Teaching (c) Research (d) Research & Teaching.

Think about the recruitment panel that interviewed you and appointed you to your current post. Did it include a service user or carer? (a) Yes (b) No (c) Not known.

Do you consider supporting the involvement of service users and carers to be part of your job role? (a) Yes (b) No

What proportion of your job is given over to supporting service users and carers? (a) None at all (b) A tiny fraction of my time (c) Some time most weeks (d) More than a day a week (e) Almost all my time.

Do you manage a budget? (a) Yes (b) No

If yes, how much money was allocated to service user and carer involvement this year? This is not the actual expenditure, but the amount showing on a defined budget line at the start of the year.

Please estimate the total expenditure on service user and carer involvement that will be drawn from your budget this year.

Please name a regular meeting that you chair within the School (a staff meeting, working group, or committee).

Does the attendance list for this group include any service users or carers? (a) Yes (b) No. If so, please name the service users and carers and/or their allied organisations here.

Have you ever co-authored a published paper with a service user or carer? (a) Yes (b) No

For this review, we are trying to find out as much as we can about how service users and carers are involved in the activities of the School. We have asked: (1) Module leaders to tell us how service users and carers are involved in teaching, (2) Principal Investigators to tell us how service users and carers are involved in research and (3) Chairpersons to tell us how service users and carers are involved in meetings. Are there any other ways that service users and carers are involved that you can tell us about? Please tell us about it in the space provided.

In your view, which of the following are the most significant impediments to increasing service user and carer involvement in your work within the School? (Tick all that apply). (a) I don't see the point (b) I don't know how to find people who would be willing to get involved (c) It's awkward when people turn out to be unsuitable (d) It's too time consuming (e) Payment arrangements are too complex and slow (f) The bureaucratic issues are too hard (g) Other - please specify:

### Module Leaders Survey

In the question below you will be asked a number of questions about the modules you lead. You first need to assign a letter to each module that you lead. To do this, simply assign a letter (A,B,C,D) to each module you lead and give us the corresponding IMAT/Moodle code for each module. You can report on up to four modules.

IMAT/Moodle module code	A	B	C	D
Were service users and carers involved in the design of this module?				
Are service users and carers invited in person as live guests into the classroom during this module – to facilitate a session, give a presentation or contribute in some other way?				
Thinking about the answer you have just given, approximately how much time in total during this module will the students spend in a classroom with service users or carers in the room?				
Please write the names of any service users and carers who have been or will be involved this year in the design or delivery of this module				
Does the module include use of patient stories (i.e. first-person accounts told by the person who lived through the experience in question) in writing, audio or video formats?				
Do service users or carers contribute in any way to the assessment of students' work for this module (perhaps by commenting on presentations or posters?				

### Research Survey

Below you will be asked a number of questions about the research projects on which you are PI. In order to do this, you first need to assign a letter to each research project on which you are PI. To do this, simply assign a letter (A,B,C,D) to each of your research



projects and fill in the corresponding project code in the grid below. You can report on up to four studies.

<b>Research study identification code</b>	<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>
Does this project have a Steering Group or Advisory Group?				
Does the Steering Group or Advisory Group include at least one service user or carer?				
Does/will the service user or carer attend face-to-face meetings of the Steering Group or Advisory Group?				
In the space provided, please give the names of the service users or carers who are members of your Steering Group or Advisory Group				
If you have sought advice from another group of service users and carers regarding this research, please name the group here				
If service users or carers kindled the initial idea for this research project, please name the individual and / or group here				
Does the funding application for this research project include a service user or carer as a named co-applicant?				
Were service users or carers involved in finalising the wording of your study protocol? If the protocol has not yet been finalised, will service users or carers be involved in developing the protocol?				
Were service users or carers involved in developing the study's ethics application? If ethics has not yet been applied for, will service users or carers be involved in developing the application?				
Were service users and carers involved in the development of the study's participant information? If participant information has not yet been generated, will service users be involved in its development for this study?				
Has this research project engaged service users or carers as co-researchers: to collect, analyse or interpret data? If the project has not yet collected data, do you foresee engaging service users or carers as co-researchers: to collect, analyse or interpret data?				
To date, has this research project produced any outputs (academic articles, study reports, conference presentations)?				
Looking at the question you have just answered, did the voice of service users or carers feature in any of these outputs? This might include first-person accounts, conference presentations by the service user, co-authored papers, etc.				
Do you have any specific plans in your existing dissemination strategy for this study that include reaching community audiences? This would require specific activity that takes the message beyond the professional and academic community, and that involves more than creating a website!				
Rather than waiting for health professionals to 'fix' their health issues, patients need to be active partners in their own health by looking after their lifestyle, understanding their health and knowing when to ask for help. Has this research project generated any outputs that help patients to take on this active and empowered role?				

## Appendix 6: Other evidence sources

Individual interviews	Documents		
Theo Stickley	SUCAG annual report 2013, 2014	REF 2014 rankings	Co-facilitation 2014
Yvonne Clark	Introducing SUCAG	HCPC consultation	Training for co-facilitation
Rosalind Maxwell-Harrison	Strategy 2007, 2010	NMC response to HCPC consultation	Poster for Open Days
Claire Mann	School academic strategy 2013	Student numbers data	UoN global strategy 2020
Di Bowskill	School Council minutes	Student numbers	School brochure 2015
Julie Gosling	CSP – service user involvement in CPD (April 2015)	How to register as a casual worker at the university	Proformas for students to evaluate service user led teaching session
<b>Groups</b>	SUCAG ground rules	CAIPE response to HCPC consultation	IPL conference 2014 feedback
SUCAG	SUCAG membership list	HCPC response to consultation	Conference prog – PCNC
SUCAG	SUCAG involvement in GNC	HCPC standards for teaching	Co-facilitators flyer
Self Help Nottingham	Recruitment and induction checklist	Application form for service users and carers	Service user access to university short courses
Senior Management Group	Student midwife caseholding diary	SETs proformas and results	SEMs proformas and results
Staff	School top level governance structures, Feb 2015	School Learning and Teaching governance structure Feb 2015	B7205 module handbook
Service users and carers	Fees and expenses records kept by Joan Cook	Staff webpages for SHS	GNC BSc nursing student handbook
<b>Telephone calls</b>	Service user and carer action plan 2007-2010 – progress report	HCPC ppt introducing standards	IPL conference flyer to recruit users
Vivian Penney	JD for SUC Development Worker	Chambers review	IPL conference info for service users
Joan Cook	B74 timetable showing PPI	NMC standards for education	IPL conference workshop outline
Jonathan Lamley	Feedback from School forum 2014	School Forum July 2014	IPL conference role description
Liz Clements	Fees and expenses guidelines	Student selection – BSc nursing timetable	Evaluation form for IPL
Elizabeth Duthie	Involvement workshop 2014	Student selection – training 2012, 2014, 2015 programme	Report on involvement in postgrad nursing diploma 2009
Jo Lymn	Conference poster	Student selection – learner evaluation	GNC focus groups 2011 report
Fiona Moffatt	SUCAG vision of the future 2015	Student selection – stakeholder evaluation	GNC focus group 2011 slides

Julie McGarry	Workshop ppt 2014	Abstract for Athens conference	CSP learning principles
Roderick Cable	SUCAG agendas and minutes 2014-15	Athens slides	CSP proficiency standards
Christine Haneline	Casual worker flowchart	Abstract for Authenticity conference	CSP on QA
Sam Crossley	Alison Clark on assessment rules	Guidance on OAR	GEN PBL review 2013
Mandy Walker	Teaching ppt citizen participation in healthcare improvement	Letter to child re OAR	GEN validation – SUCAG presentation
Laura Loeber	Teaching ppt – patients as partners	Letter to user re OAR	LBR timetable showing PPI, 2013, 2014
Helen Spiby	PCNC film script	Letter to relative re OAR	Training flyer re storytelling
Gemma Stacey	PCNC facilitator's guide	Easy read letter re OAR	Jargon buster
Richard Windle	PCNC 2014 conference prog	Equality, diversity and spirituality group minutes	Minutes of SUCAG in physio Jan 2015
Giulia Miles	Proforma for service users to report on their experience of the class they taught	Peer mentoring for nursing students - specification	Leadership in peer mentoring – specification
Anne-Marie Turney	Hearing loss awareness – specification	Nottingham Advantage Award module guide	Annual report to NMC 2013/14 and 2014/15
Jacqui Williams	SHS Equality and Diversity policy summary	NMC Quality assurance framework for education and training	

## Appendix 7: Data tables

The following table is copied from the School's 2007 strategy

The state of service user and carer involvement in 2007	Lots	Patchy	A bit	None
The implementation of the strategy is effectively co-ordinated.		✓		
Service users and carers are involved in selection of students				✓
Staff are aware of the requirement to involve users and carers	✓			
Contribute to curriculum design, delivery and management		✓		
Service users and carers contribute to practice learning	✓			
Contribute to assessment of students			✓	
Involved in staff appointments				✓

### Student numbers at May 2015

Division	Comprising	No.
Physiotherapy and SRES	BSc Physiotherapy, BSc Sports rehab and exercise science, PGT Physiotherapy	171
Midwifery	BSc Midwifery, BSc Midwifery extended, BSc Midwifery shortened, PGT Midwifery	227
Nursing	BSc Adult, BSc Child, BSc Learning disabilities, BSc Mental health, MNurSci Adult, MNurSci Child, MNurSci Mental health, GEN Adult, GEN Mental health, GEN Child, Diploma /BSc Adult, Diploma /BSc Child, Diploma /BSc Mental health, Postgraduate Diploma Adult, PGT Nursing, LBR BSc Awards	1,656
Others	PhD, DHSci, LBR modules LBR modules are based on numbers for last NHS financial year. This table does not include another 487 who could become active at any time as they have five years to complete their LBR BSc award.	902
<b>TOTAL</b>		<b>2,956</b>

## Selection events

2014-15	Number of prospective students attending selection events	Number of selection events to be held	Number of selection events directly involving service users and carers
Physio + SRES	377	377	0
Midwifery	307	12	0
GEN Nursing	302	13	13
Other nursing	1420	16	16

Physiotherapy and Sports Rehabilitation and Exercise Science (SRES) use one-to-one interviews, so the number of selection 'events' matches the number of prospective students. GEN stands for Graduate Entry Nursing. Service users and carers observed two physiotherapy selection days recently (approximately 12 interviews) where they introduced themselves to applicants, but didn't otherwise take part in the interviews or contribute to decisions.

The number of survey returns from staff

	Service users and carers	All staff	Module leaders	Research
Names given	23	38	16	8
Anonymous	1	43	9	4

Selected findings from the Service Users and Carers Survey

Service users and carers Survey	Number of 'Yes' responses
Were you involved in student selection?	10
Have you been involved in the classroom?	12
Have you advised research projects?	11
Have you sat on a committee or working group?	14
Have you helped to create a video on online teaching resource?	12
Are you involved with the Palliative Care PPI group?	8
Are you involved with the Dementia and Frail Older People group	8
Are you involved with the PPG group at your local GP practice?	6

### Selected findings from the All Staff Survey

<b>All Staff Survey</b>	<b>Number of 'Yes' responses</b>
In which family does your post at SHS fall – admin/technical	25
Do you consider supporting the involvement of service users and carers to be part of your job role?	60
What proportion of your job is given over to supporting service users and carers? – none at all or just a fraction of my time	65
Which of the following are the most significant impediments to increasing service user and care involvement in your work within the School – I don't see the point	1
Which of the following are the most significant impediments to increasing service user and care involvement in your work within the School – payment arrangements are too complex and slow	29

### Selected findings from the Module Leaders Survey

<b>Module Leaders</b>	<b>Number of 'Yes' responses</b>
Number of unique module codes reported	49
Were service users and carers involved in the design of this module?	17
Are service users and carers invited in person as live guests into the classroom during this module – to facilitate a session, give a presentation or contribute in some other way?	23
Thinking about the answer you have just given, approximately how much time in total during this module will the students spend in a classroom with service users or carers in the room?	22 (none) 8 (<2 hours) 17 (2-10 hours)
Does the module include use of patient stories (i.e. first-person accounts told by the person who lived through the experience in question) in writing, audio or video formats?	22
Do service users or carers contribute in any way to the assessment of students' work for this module (perhaps by commenting on presentations or posters?)	1

## Selected findings from the Research Survey

<b>Research Survey</b>	<b>Number of 'Yes' responses</b>
Number of research studies described by survey respondents	15
Were service users and carers involved in the development of the study's participant information? If participant information has not yet been generated, will service users be involved in its development for this study?	12
Does the Steering/Advisory Group include at least one service user or carer?	11
Do you have any specific plans in your existing dissemination strategy for this study that include reaching community audiences? This would require specific activity that takes the message beyond the professional and academic community, and that involves more than creating a website!	11
Were service users or carers involved in finalising the wording of your study protocol? If the protocol has not yet been finalised, will service users or carers be involved in developing the protocol? (Yes, No)	9
Does the funding application for this research project include a service user or carer as a named co-applicant?	8
Has this research project engaged service users or carers as co-researchers: to collect, analyse or interpret data? Or do you foresee doing so?	6
Were service users or carers involved in developing the study's ethics application? If ethics has not yet been applied for, will service users or carers be involved in this?	5
Rather than waiting for health professionals to 'fix' their health issues, patients need to be active partners in their own health by looking after their lifestyle, understanding their health and knowing when to ask for help. Has this research project generated any outputs that help patients to take on this active and empowered role? (Yes, No)	5
Did the voice of service users or carers feature in any of the outputs from the research? This might include first-person accounts, conference presentations by the service user, co-authored papers, etc.	4

## Appendix 8: Online resources developed with service users and carers

The following list illustrates the range of resources developed by people involved with the School.

### Publicly available resources

Some public access E-learning resources that were developed in partnership with a variety of stakeholders can be found at

<http://www.nottingham.ac.uk/helm/resources/index.aspx>

- “Involving service users and carers in your teaching”. Service users, carers and patients are increasingly involved in the education of health and social care professionals - just as their involvement is increasingly built in to the running of health and social care services. This learning package from 2012 concentrates on preparation and practical issues for involving people with teaching and speaking to students. See [http://sonet.nottingham.ac.uk/rlos/placs/users\\_carers/home](http://sonet.nottingham.ac.uk/rlos/placs/users_carers/home)
- “Our Child” developed by the Down’s Heart group. See [http://www.nottingham.ac.uk/nursing/sonet/rlos/learndis/our\\_child/story\\_html5.html](http://www.nottingham.ac.uk/nursing/sonet/rlos/learndis/our_child/story_html5.html)
- “Baby First” at <http://www.nottingham.ac.uk/nmp/sonet/rlos/learndis/babyfirst/>
- “Hello, my name is Tom.” This resource gives an insight into the world of a young person with an Autistic Spectrum disorder (ASD). It concentrates on interaction with Tom, a young person with ASD, within the school environment. The RLO was created by a learning disability nursing student based on his interaction with a number of individuals with ASD. This RLO won the 2009 Fiona Law prize for student-led innovation awarded by the National Network of Learning Disability Nursing. See <http://sonet.nottingham.ac.uk/rlos/learndis/tom/>
- “Little things make a big difference.” This RLO is based around an interaction between a healthcare professional and a client with learning disabilities. It shows how important even small aspects of communication are in formulating a positive interaction. See <http://www.nottingham.ac.uk/nmp/sonet/rlos/learndis/littlethings/>
- “My house, my rights”. This package takes an interactive journey through the house of an individual with learning disabilities. In each room the learner is challenged by some of the ways that the rights of individuals with learning disabilities are often disregarded by health care professionals within their own homes. See <http://www.nottingham.ac.uk/nursing/sonet/rlos/learndis/myhouse/>
- “Expressing sexuality”. See <http://www.nottingham.ac.uk/nmp/sonet/rlos/learndis/sexuality/>



- “Patient Voices.” Stories of inter-professional working from the University of Nottingham. These stories were created in a Patient Voices reflective digital storytelling workshop in 2009, intended to facilitate the sharing of stories between and within groups of service users, carers and professionals.  
<http://www.patientvoices.org.uk/unip.htm>

### **Resources where access is restricted to School staff and students**

- Nursing concepts discussions – discussions of nursing concepts by small groups of service users and carers. This development was led by Yvonne Clark, a member of the Service User and Carer Advisory Group, for first year GNC Unit A students. Parts of these discussions are used by students via Moodle.
- ‘Talking Heads’ – made with Making Waves, 2014. These are individual short talking heads about helpful and unhelpful care.
- Online learning ‘books’ e.g. for PCNC Year 1 Nursing ‘Public Involvement’ learning block.
- Lectures or parts of lectures and presentations delivered or co-authored and delivered by service users. Examples include:
  - Year 3 Transitions in Healthcare developed with Roni Anthony
  - material linked with the PINE sessions developed with Making Waves
  - the introduction to PCNC year 1 nursing ‘lenses’ developed with Joan Cook
- Discussion group with Aimee Aubeeluck contributing to scenario filmed re support for woman considering decisions re late unexpected pregnancy, linked between Nottingham, Ireland, and USA, for Graduate Entry Nursing, communications, and used as part of GEN multi-mini-interview selection in 2015
- Service User and Carer Advisory Group consulted about scenarios filmed for communications teaching and assessments around 2008

### **In production**

- “Hearing Loss.” Reusable Learning Object developed with students, people with hearing loss and the Ear Foundation, coordinated by Claire Mann.
- A filmed discussion with service users about interviewing people for research, produced for BSc Nursing years 3 and 4.

## Appendix 9: Groups and routes into involvement

This appendix lists the groups that have been formed to promote service user and carer involvement in the School's activities, as well as the key individuals who have a distinct role in supporting service users and carers.

- Joan Cook is the School's User Involvement Development Worker, seconded from [Self Help Nottingham](#). This link provides a potential pathway for people who are involved with self help groups to engage with the School. As the Development Worker's role was initially confined to the Division of Nursing, working relationships continue to be strongest here.
- Yvonne Clark is chair of the SUCAG group.
- Julie Gosling is the Training Education and Research Lead for [Making Waves](#) which provides 6 separate service-user-led sessions through the PINE programme. The support package (comprising co-design of training materials, briefing and debriefing around teaching sessions, follow up and peer mentoring) has demonstrated that everyone has potential for involvement.
- Gemma Stacey has engaged a group of Derby-based people to act as Enquiry-Based Learning Case Facilitators. Payments are managed through Making Waves.
- Christine Haneline is Clerical Assistant at the School of Medicine and administers the Simulated Patients group<sup>95</sup> along with Dr Churchill, supported by Roderick Cable.
- Mr Frank Coffey teaches nurses at the School and is in touch with a group of patient simulators based at [DREEAM](#) in the Emergency Department at QMC.
- Bryn Baxendale leads the [Trent Simulation and Clinical Skills Centre](#), which some nursing students have attended in the past year. Discussions are underway regarding a possible joint project on safety improvement between the TSCSC and the School<sup>96</sup>.
- Individual teaching staff and researchers have contact with service users and carers, perhaps from their clinical work or via third sector organisations, and engage some of these individuals.
- Service users and carers who are currently engaged with the School may invite their friends and relatives to join in.
- Kristian Pollock convenes the Dementia, Frail Older People and Palliative Care PPI Group<sup>97</sup>.

- Bernie Divall and Julie Roberts chair the [Nottingham Maternity Research Network](#)
- In addition to the routine practice placements, midwifery run a ‘caseholding’ scheme by which students follow a woman throughout her antenatal, labour and postnatal care.
- Maria Michail and Tim Carter chair the new Youth Advisory Panel, which looks at young people’s mental health and wellbeing and is linked to the Managed Innovation Network funded by the Institute of Mental Health.
- Andrew Grundy hopes to set up an Adult Mental Health PPI in Research group.

<sup>1</sup> See, for example, Department of Health (1994) [Working in partnership: A collaborative approach to care](#). A report of the mental health nursing review team. London: HMSO. Also [Department of Health \(1999\) Patient and Public Involvement in the new NHS](#). See <http://www.hpc-uk.org/assets/documents/10003BF1ConsultationonserviceuserinvolvementineducationandtrainingprogrammesapprovedbyHCPC-FINAL.pdf>. Also Department of Health (2002) *Requirements for Social Work Training*, London: Department of Health. Also HCPC (2014) *Standards of Education and training guidance*. Also NMC (2010) *Standards for pre-registration nursing education*.

<sup>2</sup> All titles are contested, and some prefer terms like public contributor, patient or member of the public. In this report we have used the term accepted by the HCPC.

<sup>3</sup> HCPC (2014) *Standards of Education and training guidance*. See also NMC (undated) [Quality Assurance Framework for nursing and midwifery education and local authorities](#). In 2014, the Nursing and Midwifery Council annual self assessment programme monitoring report included a section on service user and carer involvement.

<sup>4</sup> Health Education England (HEE) has declared; “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.” See <http://hee.nhs.uk/work-programmes/advisory-groups/>. Furthermore, the National Institute of Health Research demands ‘patient and public involvement’ in all research activities.

<sup>5</sup> See <http://www.russellgroup.ac.uk/home/>. The University of Nottingham ‘allied health professions, dentistry, nursing and pharmacy’ was ranked 9<sup>th</sup> on quality and 5<sup>th</sup> on power in the 2014 REF framework.

<sup>6</sup> “Goal 8: Enhanced external engagement – as measured by the Higher Education-Business and Community Interaction survey – to move up to position 5 by 2020”. *University of Nottingham Global Strategy 2020*, p14. Work towards this goal will be coordinated by the Head of Business Engagement and Innovation and the Pro-Vice Chancellor for Research and Innovation. At present, Chris Rudd, Pro-Vice Chancellor is responsible.

<sup>7</sup> See for example, <http://www.rcuk.ac.uk/pe/>.

<sup>8</sup> ‘All 191 educational institutions that responded involved service users and carers in some way.’ Mary Chambers and Gary Hickey (2012). *Service user involvement in the design and delivery of education and training programmes leading to registration with the Health Professions Council*. <http://www.hcpc-uk.org/publications/research/index.asp?id=550>. The East Midlands Higher Educational Institution Challenge has recently surveyed involvement across 10 HEIs – details [here](#), or contact Niro at [nsiriwardena@lincoln.ac.uk](mailto:nsiriwardena@lincoln.ac.uk), Kris at [K.M.Clements@lboro.ac.uk](mailto:K.M.Clements@lboro.ac.uk) or Coral Sirdifield at [CSirdifield@lincoln.ac.uk](mailto:CSirdifield@lincoln.ac.uk). This survey will help the School to benchmark its achievements.

<sup>9</sup> See School Academic Strategy, School of Health Sciences 19 Nov 2013, pp6-7,19. Also <http://www.nottingham.ac.uk/healthsciences/about/community/service-user-carer/index.aspx>.

<sup>10</sup> Previously, teaching was delivered in other sites across the East Midlands, but these outlets are being closed.

<sup>11</sup> This followed *Towards 2012*, the School’s strategy written in 2001 that laid the foundations for the involvement of service users and carers. A key table from the 2007 report is reproduced in Appendix 7.

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<sup>12</sup> SUCAG hosted an event in July and another in October 2014 from which they derived some suggestions for the future, recorded in SUCAG (5 Feb 2015) *Visioning the Future*. This document identifies some important themes but does not develop them into SMART goals or match them with defined resources.

<sup>13</sup> The following comments were made in survey returns – ‘not relevant to my area of teaching’, ‘students gain experience on placement, so not necessary in university’, cost and demands outweigh the benefit’, ‘I am not sure what a service user/carer is’.

<sup>14</sup> This group is chaired by Nigel Plant and it’s budget has been underspent in recent years. The Group recently put out a call for leadership training in response to an identified Schoolwide need. They could therefore focus interest on training staff in skills related to service user and carer involvement. Consideration should be given as to whether staff training is best delivered in a separate group or together with service users and carers, and whether a professional or a suitably experienced service user or carer should provide the teaching. Both service users and staff may have to revisit attitudes but staff may need to rebuild procedures.

<sup>15</sup> The School sets a training budget annually and also receives money from the University to support conference attendance. For 2015/16 the School budget is currently £50,000 and we expect to receive around £15,000 from the University. On top of this, the School’s Director of Staffing also has an annual budget of £20,000 which can be used for training/staff development. The School allocation for 2015/16 has been reduced due to recent underspends, and may have to be cut further as the School has some challenging savings targets to reach during 2015/16. Directors’ budgets may also be reduced.

<sup>16</sup> This Reusable Learning Object is designed to help staff involve service users and carers in their teaching and was developed by the Service User and Carer Advisory Group in 2012. Previously, in 2008, service users and carers delivered some training to staff. In addition, new staff sometimes attend SUCAG meetings as part of their induction.

<sup>17</sup> These data are managed in Divisions with separate computer systems. A request for data from Division staff generated figures that were doubled by the School Manager, whose figures are shown in Appendix 7.

<sup>18</sup> NMC Annual Self Assessment Programme Monitoring 2014/15 asked about service user participation in student selection.

<sup>19</sup> In January 2015, 11 more people were trained to help with BSc Nursing selection days. 10 BSc selection days have been booked and 19 service users and carers provided their availability to the School. In addition, there were 26 GEN selection sessions planned with a budget for one service user or carer to attend each, as a pilot project.

<sup>20</sup> For example, the new module on long term conditions that is currently being designed in physiotherapy has involved members of SUCAG in the design stage, while Making Waves were involved in the design of the graduate nursing course.

<sup>21</sup> Moodle provides an index of modules. General information about each module is available on Moodle and personalised timetables and other resources via IMAT. The following selection of module handbooks were reviewed, where the title suggested there might be a reference to involving service users and carers, but a search (terms used: user, carer) found nothing about service user and carer involvement, apart from references to the therapeutic relationship. Nursing: Communication, innovation and leadership (B7102), person-centred nursing care: delivery and decision-making (B7206), Adult Complex Care Assessment, Planning, Delivery and Decision Making for Nursing Practice (B745AG). Physiotherapy in mental health (B93579). Midwifery: introduction to contemporary midwifery practice (DM1101), empowering midwifery practice (B74), and exploring contemporary midwifery practice (DM2101). There is a single line reference to involving service users and carers in ‘influencing the development of innovative health and social care provision’ in the module handbook for the Graduate Nursing Curriculum BSc (Hons) in Nursing MNurSci (Hons) in nursing (B7205), but no mention in the Graduate Nursing Curriculum BSc (Hons) in Nursing student handbook.

<sup>22</sup> As IMAT and Moodle use different codes to identify each course and some survey respondents used codes that do not appear on IMAT, further work would be needed to confirm these figures. Service users and carers have been involved in developing Value Added Learning modules (1N87 peer mentoring for nursing students, 159N leadership in peer mentoring and 158N hearing loss awareness) that fall within the [Nottingham Advantage Award](#) – see the full module [guide](#).

<sup>23</sup> We also asked whether teaching staff were using first person accounts on video or in print. We did not find anyone using these media as an alternative to bringing live service users and carers into the classroom.

<sup>24</sup> Generating this ratio may involve some work. There is currently no system in place to keep track of the modules that do include live contributions by service users and carers. Deriving a reasonable denominator for this ratio may begin with a register of modules as shown on IMAT (314 unique modules, all with a unique ID code). However, several codes refer to the same module being taught to different year groups, or to the same module being taught at different geographical locations. Some module codes do not appear on IMAT. An initial ratio might add in any missing values and remove duplicates and any unsuitable modules to demonstrate a first phase of progress. The duplicates could be restored later on, to press the School to spread the impact of service user and carer involvement yet further. Subsequent work would move on to the amount and quality of involvement in each module.

<sup>25</sup> HELM have offered to review the 200 RLOs and make a judgement about whether each meets the following criteria: (a) were service users and carers involved in its design, (b) do service users and carers appear in the RLO – either through first person accounts of lived experience, or as presenters, and (c) does the intended audience for the RLO include service users and carers?

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<sup>26</sup> Teachers may need to overcome some proprietorial reluctance in order to lodge their work in such a store, while sophisticated library skills will help to design the store and enable effective searching.

<sup>27</sup> There are two processes, known as SETs (Student Evaluation of Teaching) and SEMs (Student Evaluation of Modules). The process is described [here](#). The new reporting system will enable recipients to benchmark their scores against others.

<sup>28</sup> Since the new SETs format provides anonymised average scores against standard questions, it would be a simple matter for service users and carers to create a parallel process to collect their own scores and compare them with that achieved by academic staff. Processes to support pastoral care and development would be needed for service users and carers, just as it is for academics.

<sup>29</sup> Stickley, T., Stacey, G., Pollock, K., Smith, A., Betinis, J. and Fairbank, S., (2010) The practice assessment of student nurses by people who use mental health services *Nurse Education Today*. 30(1), 20-25. They found that service users were reluctant to take on the responsibility for formal assessment, students were anxious about transferring power over their future away from accountable professionals, mentors were worried about the additional workload, and everyone was concerned about the impact on the therapeutic relationship. See also Stickley, T., Stacey, G., Smith, A., Betinis, J., Pollock, K. & Fairbank, S. (2011) 'Developing a service user designed tool for the assessment of student mental health nurses in practice: A collaborative process. *Nurse Education Today*, Vol 31: 102 – 106, DOI: 10.1016/j.nedt.2010.04.005.

<sup>30</sup> Prof Lesley Strouther wrote to all staff in the School on 25 March 2015: "The assessment of student nurses beginning their studies after 1 Sept 2014 must include written feedback from at least two service users, carers or relatives as advised by the NMC. The process has been developed by the PLC with full involvement from service users and carers. Students are informed in their Mandatory Preparation for Practice sessions and there are guidance notes both in the OAR, pages 10-11 and on the Preparation for Practice (LRNPR1) section.

[http://moodle.nottingham.ac.uk/pluginfile.php/1853324/mod\\_resource/content/4/Introduction%20to%20the%20NMC%20Ongoing%20Achievement%20Record%20v2/story.html](http://moodle.nottingham.ac.uk/pluginfile.php/1853324/mod_resource/content/4/Introduction%20to%20the%20NMC%20Ongoing%20Achievement%20Record%20v2/story.html) Discuss the process for obtaining service user feedback at your PLT meetings/mentor updates and tripartite meetings for students in the named cohorts." SUCAG confirmed that they were involved in designing these mechanisms.

<sup>31</sup> Some students will choose to interview a service user or carer to obtain this narrative account of their experiences, while others may use publicly available narratives.

<sup>32</sup> "It is the academic staff's role to undertake moderation. User carer involvement needs to be on an informal basis and have no effect on a student's ultimate academic credit and grading." Kirsty Hyndes and Alison Clarke 22/4/14. However, during this review, we heard that the School of Medicine may take a slightly more nuanced view of this apparent contradiction. As an example from within the School of Health Sciences, in module B745MG (1401), the student interviews a service user and then the service user gives both verbal feedback and completes a written proforma about their experience of the interview. A qualified practitioner watches the interview on screen and also provides feedback. The interview and feedback is video recorded and the file given to the student. The student writes a reflection on the video and the reflection is assessed by the university.

<sup>33</sup> The 45 studies include both those where the main applicant for the funding is based in the School and those where the main applicant is elsewhere, but the 'local PI' bears responsibility for the activities that take place in Nottingham. A further three studies have been left out of this count following advice from the Research and Postgraduate Education Manager.

<sup>34</sup> The PINE project used a participatory action research approach through which service users devised research questions, carried out interviews and analysed the emerging data.

<sup>35</sup> A count of everything listed on each staff member's webpage 'publications' tab published between 1 Jan 2014 and 17 April 2015 identified 64 staff who altogether published 258 items. This may include a few letters to newspapers as well as high impact peer-reviewed items. The eight most prolific staff contributed to a total of 100 publications. We did not hear about any Schoolwide system of tracking publications.

<sup>36</sup> See a discussion of the issues at [http://emahsn.org.uk/images/resource-hub/PPI%20documents/How%20to%20guidance/How\\_to\\_engage\\_people\\_as\\_research\\_co-applicants.pdf](http://emahsn.org.uk/images/resource-hub/PPI%20documents/How%20to%20guidance/How_to_engage_people_as_research_co-applicants.pdf).

<sup>37</sup> As an example, all Professor Sarah Hewlett's PhD students at UWE work with two PPI representatives throughout their studies.

<sup>38</sup> For example, Professor Helen Spiby was personally involved in a detailed application to obtain £500 to print some advertising cards to take to community groups in an attempt to recruit members for the Nottingham Maternity Research Network.

<sup>39</sup> We heard of requests for approval that had to be presented to several committees, that never received a response or where the answer was delayed for several months.

<sup>40</sup> SUCAG minutes for Feb 2014 to Feb 2015 reported attendance at the following events: Athens, Person Centred Nursing Care conf (June 2014), School Launch (June 2014), School of Health Sciences Forum (July 2014). Plans were in place to attend the Authenticity to Action Conference (March 2015) and CAIPE (March 2015). Amongst other events, Making Waves co-developed and

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co-delivered an entire symposium on co-production of transformational learning in nurse education in partnership with academic colleagues from the School of Health Science to the 2015 RCN Education Conference.

<sup>41</sup> A possible new mechanism would be as follows: (1) the service user or carer who seeks funding support applies to their line manager within the service user and carer support service, as substantive staff would do with their line manager; (2) the line manager confirms that the opportunity is suitable (it matches the service user or carer's current skills and capacities and the activity will be of benefit to the university); (3) the approved application then goes forward to the Staff Development Group, who have a slightly broadened remit to include this; (4) the Staff Development Group consider whether the activity fits with the strategic objectives of the School as a whole and does not duplicate other investment, and authorise the expenditure as appropriate. If the role of the Staff Development Group was broadened in this way, it may be appropriate to include a service user or carer representative on the Group.

<sup>42</sup> For example, the School is running a Professors Research Showcase on 17/6/15 which invites 'staff and students' but makes no reference to service users and carers. On enquiry, it turned out that service users and carers were welcome to attend, and organisers were surprised that there may be interest.

<sup>43</sup> Such as contributions to *Service user involvement in research: a briefing paper from the Palliative Care Studies Advisory Group* (undated). Also *Older carers and involvement in research: why, what and when?* Andrew Grundy is lead author on a forthcoming paper about the EQUIP study and a co-author on a second paper.

<sup>44</sup> All the service users and carers we met during the course of the review supported the use of a centralised database and control mechanisms as it has the potential to improve the consistency of service and hold people to account, as well as harmonise terms and conditions of involvement.

<sup>45</sup> Several people suggested that a newsletter or online group would help people share opportunities, hear about innovation and feel part of a coordinated initiative. One respondent admitted that he found out about other groups in the School 'by accident'.

<sup>46</sup> As well as the protected characteristics covered in the Equalities Act 2010, diversity in this context includes the range of academic ability and socioeconomic circumstances, the depth of experience and proximity in time of particular health experiences, and the emotional cost of disclosure and level of support needed to enable people to participate. It was noted that a proportion of service users and carers involved with the School are former health, social care or education professionals.

<sup>47</sup> For example, a role description was developed for service users and carers who participated in the InterProfessional Learning Safeguarding Conference Day sessions for 2015.

<sup>48</sup> Whilst all the service users and carers we spoke to during this review supported the idea of a central database, some staff expressed concerns about (a) names being passed on without prior permission from the person concerned, (b) individual service users with a narrowly focused interest being swamped by unwanted information, and (c) people who are involved because of a particular life experience losing control of who knows about that part of their history. We might also consider whether staff who work hard to establish a relationship with particular individuals may fear that 'their group' will have their limited time taken up by other invitations. Taken together, this may mean that forming a central database would be quite a difficult job.

<sup>49</sup> Andrew Grundy, Patrick Callaghan and Debbie Butler ran a two-day course titled 'Introduction to patient and public involvement in research' at Nottingham Recovery College in April 2015. At present, this pioneering activity is unfunded.

<sup>50</sup> The SHS policy on equality and diversity directs service users and carers to suitable training and requires Division Administrators to keep a database of service users and carers who have completed such training. 270 staff work in the School. The combined nursing and midwifery database identifies 115 staff ( of whom 89 have done the training) and 5 service providers who have done the training, while the School database lists 48 staff who have trained in 'equality and diversity in teaching' and 22 staff who have trained in 'equality and diversity in the workplace. No data is available at the time of writing for physiotherapy and sports science.

<sup>51</sup> Effective training should help service users and carers to maximise the impact of their 'lay' voice, without socialising them into the professional culture. As with substantive staff members, clear training forms the basis for a quality assurance mechanism. The University's short course programme has a variety of courses on public engagement. David Burns, Director of Professional Development, confirmed that service users and carers have access, which is gained via the following steps: (1) Obtain an Associate Account, as explained at <https://www.nottingham.ac.uk/it-services/services/it-accounts/associate.aspx>, (2) the School to provide Central Short Courses (email: [csc@nottingham.ac.uk](mailto:csc@nottingham.ac.uk)) with the details of the users, (3) CSC to create and account for each individual in the CSC database, (4) Service users to accept the terms and conditions of service, (5) log in and book at <https://training.nottingham.ac.uk/cbs-notts/Portal/DesktopDefault.aspx?GoHome=1> Some people will need support to use this provision, while others will need alternative arrangements as they do not have access to the internet.

<sup>52</sup> Workspace is an online resource with sections for each School, mainly for organisational information. The Service User and Carer Advisory Group has a section under Committees, Advisory Groups and includes copies of minutes, policies and guidelines. It could be developed into a stronger resource for staff. Arrangements could be made to enable service users and carers to obtain

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appropriate access to it. Curriculum details are on the virtual learning environment called Moodle, timetabling is IMAT, and the university also has an online centralised room and resource booking facility.

<sup>53</sup> Potential system solutions may be needed to involve service users and carers in the following activities, amongst others: (1) research funding co-applicants; (2) co-researchers, who have completed necessary training, been approved by a research ethics committee and obtained a research passport to allow them to enter NHS premises; (3) well informed lay persons in respect of research ethics; (4) co-author academic and non-academic papers and other outputs; (5) contribute to advisory groups by video or teleconference; (6) appropriate co-owners of the intellectual property embedded in the materials they co-create; (7) control mechanisms to assure the quality of input in teaching; (8) proportionate support, supervision, grievance and disciplinary procedures that manage the boundaries of the relationships between service users and carers on the one hand and students or staff on the other; as well as the arrangements for working through Self Help Nottingham or Making Waves as contractors (9) access to staff rooms and workstations, along with appropriate safeguards around confidential information; (10) online access to Moodle, IMAT, email and the university library.

<sup>54</sup> Potential harms include, but are not confined to the following: (1) staff failing to brief service users and carers adequately; (2) service users and carers, staff or students becoming distressed through telling their story or hearing someone else's; (3) staff or students asking inappropriate questions about people's private lives; (4) students using the personal story that they have heard to build a stereotype; (5) personal stories, agendas or the pace of contribution diverting learners or teachers away from the curriculum or business of the meeting; (6) service users and carers adopting unduly confrontational approaches to staff or students and vice versa; (7) staff taking up an inappropriate therapeutic relationship with service users or carers; (8) unsuitable arrangements harming the person's aspirations to gain employment or their arrangements with HMRC or the welfare benefits agency.

<sup>55</sup> Further details from Pat Pentecost at Health Education East Midlands.

<sup>56</sup> Groundrules were renegotiated in 2014 and a summary is read out at the start of each meeting.

<sup>57</sup> Reasonable adjustments may need to be made to the way in which committees run in order to facilitate full access and contribution. Clear expectations about commitment, confidentiality, and conduct should be set out for all members. For as long as the number of service users and carers is limited, committees should be selected to maximise benefit to the mission of the School.

<sup>58</sup> the School Council (the chair is Stacey Johnson and administrative support is provided by Gemma East. Service user and carer representatives have been Julie Gosling (Making Waves) since July 2014 and Rose Thompson (BME Cancer Care) since December 2014), the Safeguarding Group (Led by Julie McGarry with Yvonne Clark), the Nursing Practice Learning Moderation Group, the Person Centred Nursing Care Unit meeting, Learning Beyond Registration Curriculum Advisory Group, GNC Curriculum Development Awayday, Division Meeting, Unit Meeting and the Equality, Diversity and Spirituality Group (Led by Natasha Recchia. Julie Gosling and Caroline Fox are the service user and carer representatives).

<sup>59</sup> The following cross-School committees have no service user representation at present, are dormant or disbanded: Senior Management Group, Executive Strategy Board, Learning and Teaching Group (chaired by Jo Lymn), Standard Setting and Monitoring Committee, GNC Learning Community Forum, Student Prizes Committee and other groups listed on the Structure diagram. Learning Community Forums used to be called Staff Consultative Committees and are for liaison, feedback and consultation with students. There is one Committee per course and sub-groups for years for the larger courses. Students elect their representatives to attend these meetings. Include groups where participation would be meaningful and add value. The School might begin with a count of the number of groups where places are offered, and then move on to a count of actual attendance at meetings as shown in minutes. Attendance criteria and consistency should be no more demanding than that placed upon staff.

<sup>60</sup> Some international visitors have met with SUCAG members, but arrangements are not yet in place for ensuring that the School has a reputation for service user and carer involvement. In passing we note that Andrew Wragg (PPI Lead) and clinical colleagues from Nottingham University Hospitals are planning a trip to India in autumn 2015 to learn about the context and potential for involvement activities in healthcare delivery in that culture. Their approach to such international comparisons may be portable.

<sup>61</sup> The main structure of the School was agreed in February 2015 and is shown on a chart. The Senior Management Group are aware that the service user and carer element does not yet appear on this chart, as they are waiting for advice from this review.

<sup>62</sup> From time to time, Patrick Callaghan meets with Sarah Collis, Director of Self Help Nottingham. At the start of the working relationship, a welcome degree of flexibility was built in to accommodate unexpected opportunities and developments, and the written agreement was complemented by regular meetings of a Steering Group. Latterly, the Steering Group meetings have lapsed, increasing the reliance on the Service Level Agreement (SLA) and its lack of clear performance indicators has been something of a hindrance. Self Help Nottingham, who have long experience of Service Level Agreements, described the SLA with the School as one of the vaguest such documents they have encountered.

<sup>63</sup> Some service users and carers are paid for their contribution and so the role is parallel to a line manager, while others are closer to volunteers, and the role of the Voluntary Services Manager.

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<sup>64</sup> The previous postholder retired in 2014, and has not yet been replaced. A role description has been drafted and SUCAG has been approached to take up a place on the recruitment and selection panel in due course. The job description has not been reviewed in the light of the 4-part analysis set out in this report.

<sup>65</sup> The Job Description and person spec for the Making Waves Teaching Coordinator contains useful detail concerning the role. The person specification includes lived experience of mental distress.

<sup>66</sup> The University signed a Service Level Agreement with Self Help Nottingham. This includes a clear statement that the Service User Development Worker would 'involve service users and carers in the recruitment and development of staff.'

<sup>67</sup> The annual cost is £36,266. The current postholder is Joan Cook and her line manager at Self Help Nottingham is Michele Banton.

<sup>68</sup> The annual cost is £24,344. It is commonly understood that the 183 hours named in the Service Level Agreement (SLA), means 183 person hours rather than 183 teaching hours. At present, most sessions are delivered by two personnel, with two sessions delivered by three. Background papers explain these arrangements and were provided in advance of the SLA, but the university did not include the detail that was available in them in the final agreement.

<sup>69</sup> The Development Worker's records show a fourfold increase in non-pay expenditure on fees and expenses for casual workers and volunteers taking part in education over the past five years, from £2,576.31 in 2009/10, to £2,978.93 in 2010/11, £5,445.55 in 2011/12, £7,041.76 in 2012/13, and £9,689.26 in 2013/14. The total for the first 9 months of 2014/15 is £7,502.49. As is clear from elsewhere in this report, this is only a part of the total expenditure across the School. Half of the expenditure in the past year is connected with student selection events in Nottingham, but this activity is now coordinated by selection administrators, so the User Involvement Development Worker no longer keeps records. Records for most GEN activities are kept at Derby.

<sup>70</sup> Other staff may also authorise additional expenditure against the following: the Nursing GNC BSc and MNursSci curriculum, other cross-School committees, midwifery speakers and groups, midwifery caseholding and end of year celebration, physiotherapy speakers and groups, curriculum development meetings, physiotherapy student selection, Nursing GEN curriculum activities, postgraduate and LBR (learning beyond registration) curriculum arranged by individual lecturers, simulated patients, the hearing loss project, conferences, research participation and coproduction, including Equip, Social Futures and other individual projects.

<sup>71</sup> This has traditionally been approved by the Staff Development Group, who manage the staff training and development budget. This group has recently put out a call for leadership training in response to an identified Schoolwide need. In a similar way, the Staff Development Group could focus interest on training in service user and carer involvement in order to achieve a step-change across the School. The costs of supporting service users and carers to attend and speak at conferences should be identifiable.

<sup>72</sup> Service user and carer costs are aggregated into other casual staff (all grades and roles) and so there is no way of tracking this through the payroll system. The Scheme of Delegated Financial Responsibility is unclear in respect of service user costs, so different staff authorise payments, which are then assigned to a variety of budget lines. This clearly inhibits any attempt to track or audit usage through the financial systems. On two occasions recently, there were misunderstandings about whether service users would be paid for a particular activity or not and this can lead to a very awkward situation. The problem was raised by SUCAG in Feb 2015.

<sup>73</sup> When a service level agreement is established with a small organisation, they may have little experience in reporting against a contract requirement. They may have a variety of contracts, and their activities may be very diverse, making it difficult to track which activities can be accounted for against each contract. When the client is a large and complex organisation like the School of Health Sciences, contractors will need to record their activity in a format that enables activity to be tracked within the host organisation. Neither Self Help Nottingham nor Making Waves had been asked to use the precise module titles or codes in their description of teaching activities, so relating the report to the normal business of the School was impeded. Providing a template and, if necessary, training or coaching in writing a report would help to complete the audit trail. In the case of Self Help Nottingham, the contractor has extensive experience of reporting against a contract, but has so far received no feedback on whether the report meets expectations.

<sup>74</sup> The payment rate offered for meetings is £20 per hour, plus expenses.

<sup>75</sup> The development worker has attended two meetings of School administration and academic staff with representatives from Payroll and Human Resources about the procedures and issues that may affect visiting lecturers and educational resource consultants as well as service users and carers. The university recently changed its system to require each person to register for every new assignment (without telling the people affected!), and so these systems are taking up an increasing amount of time for the User Involvement Development Worker. Issues that remain outstanding include (1) Whilst it is very helpful for the university to offer year-long assignments that cover a range of work, there has also been a 3 month cut-off which is a problem (any casual worker whose file remains dormant for more than three months must reapply, which is difficult for people who get involved in annual activities such as student selection); (2) the mileage rate is only 23p per mile, unchanged since 2004 and now half that allowed by HMRC for



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employees' travel from the place of work. The School pays this for journeys from home to the place of work, more like volunteering expenses.

<sup>76</sup> The Casual Worker Flowchart explains how this mechanism works and a guide has been produced for service users and carers.

<sup>77</sup> A possible mechanism would be as follows: (1) the service user or carer who seeks funding support applies to their line manager within the service user and carer support service, as substantive staff would do with their line manager; (2) the line manager confirms that the opportunity is suitable (that it matches the service user or carer's current skills and capacities, and that the activity will be of benefit to the university; (3) the approved application then goes forward to the Staff Development Group, who have a slightly broadened remit to include this; (4) the Staff Development Group consider whether the activity fits with the strategic objectives of the School as a whole, and authorise the expenditure as appropriate. If the role of the Staff Development Group was broadened in this way, it may be appropriate to include a service user or carer representative on the Group.

<sup>78</sup> We note that a recent publication from the Chartered Society of Physiotherapy (*Service user involvement in CPD*, April 2015) includes all stakeholders in its definition of 'service users'. This review chooses the alternative narrow definition and focuses only on patients and carers rather than the broader CSP definition which includes other professionals.

<sup>79</sup> Stickley et al (2009) describe historical practice as the use of 'medical specimens', as 'educational voyeurism' and 'abuse'.

<sup>80</sup> For example, members of the SUCAG group have won a [Lord Dearing Award](#) for 2015 and the EQUIP study won an [award](#) for outstanding carer involvement.

<sup>81</sup> "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. Also "Programme providers must clearly show how users and carers contribute to programme design and delivery." NMC (2010) *Standards for pre-registration nursing education* p66. Also "decisions about the programme should be taken in partnership with... service users." Chartered Society of Physiotherapy (undated) *Learning and Development Principles for CSP Accreditation of Qualifying Programmes in Physiotherapy*. Also "The programme's educational and professional rationale, philosophies and theories should be explained, together with how... service user views have informed the development of the programme." *Learning and Development Principles, Supplementary information for CSP Accreditation of Qualifying Programmes in Physiotherapy* pp5-6.

<sup>82</sup> "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.

<sup>83</sup> "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.

<sup>84</sup> "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.

<sup>85</sup> See, for example <http://www.patientstories.org.uk/>

<sup>86</sup> "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. Also "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.

<sup>87</sup> "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. Also "You should ensure that, where possible and appropriate, the selection process also includes ...service users." NMC (2010) *Standards for pre-registration nursing education* p59

<sup>88</sup> "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. Service user involvement in student assessment was suggested by the English National Board for Nursing as far back as 1996.

<sup>89</sup> Professor Dame Sally L. Davies, Director General of Research and Development, Department of Health [in](#) foreward to Staley K (2009) *Exploring Impact: Public involvement in NHS, public health and social care research*. INVOLVE, Eastleigh. [http://www.invo.org.uk/pdfs/Involve\\_Exploring\\_Impactfinal28.10.09.pdf](http://www.invo.org.uk/pdfs/Involve_Exploring_Impactfinal28.10.09.pdf)

<sup>90</sup> See <http://www.invo.org.uk/>

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<sup>91</sup> For example, “No researcher or institution who applies to the NIHR for funding can expect to be successful without a plan for public involvement that lay reviewers have scrutinised.” National Institute of Health Research (2015) *Going the extra mile: improving the nation’s health and wellbeing through public involvement in research* page 8. Available at <http://www.nihr.ac.uk/get-involved/Extra%20Mile2.pdf>

<sup>92</sup> “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.

<sup>93</sup> “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.

<sup>94</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf)

<sup>95</sup> While some patient simulations use sophisticated manikins (see, for example, <http://www.laerdal.com/gb/SimMan3G>), others are people acting a part, or a combination of manikin and actors. Most of the work of the simulated patients project is with medicine and pharmacy. We did not hear of manikins being used in the School of Health Sciences. The unique component of patient simulation is that simulators undergo clinical assessment – blood pressure might be measured, their abdomen palpated or their medical history taken. Those who act as simulated patients receive expenses and a small payment. The department that requests a simulated patient is charged.

<sup>96</sup> The Centre manager, Giulia Miles, would be eager to discuss further opportunities for collaboration with the School.

<sup>97</sup> This group hosted a training session on PPI in research with Derek Stewart in 2015, arranged by Ruth Parry.