

# Service users and carers involved in the education of nurses, midwives and physiotherapists: a survey

Peter Bates and Theo Stickley

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## Structured Abstract

**Purpose:** This paper reports on a telephone survey conducted in late 2015 that examined the extent of service user and carer involvement in teaching, governance and research at 31 university departments in the UK.

**Design/methodology/approach:** A semi-structured interview format was designed and then used in telephone interview. The findings were checked with participants and then analysed.

**Findings:** Despite the absence of specific standards, service users and carers are involved in the co-production of teaching, governance and research across all the universities that were contacted. Investment and implementation is patchy, leading to pockets of innovation rather than consistency.

**Research limitations/implications:** This survey is founded on self-reported performance as described by one respondent from each university, rather than independent assessment. Some of the questions in the initial survey format could be improved.

**Practical implications:** Asking what is being done already has yielded numerous examples of innovative practice and connected practitioners to one another. A substantial move towards coproduction could be accomplished by the spread and adoption of these innovations. Some respondents subsequently used the interview proforma to stimulate in-house discussions about local innovation.

**Originality/value:** The values and principles of service user and carer involvement have often been discussed in relation to teaching, research and the governance of university departments. This paper fills an important gap by finding out how in practice departments that teach nurses, midwives and physiotherapists are coproducing their work. **Purpose:** This paper reports on a telephone survey conducted in late 2015 that examined the extent of service user and carer involvement in teaching, governance and research at 31 university departments in the UK.

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## Introduction

The focus of this paper is upon co-production in the education of student nurses, midwives and physiotherapists. These three professions have been chosen because they are the professions being educated at the university hosting this survey. UK Universities that educate these professions are required by the regulatory bodies to involve “service users and carers” in their activities. We have used this term as it is accepted by the Health and Care Professions Council, although we hasten to acknowledge that all such titles are contested, and some prefer terms like public contributor, patient or member of the public. In addition, it has become apparent that the concept of involvement is contested (Stickley, 2006) and furthermore, it has become somewhat rhetorical in the discourse of statutory authorities (McPhail, 2008). We have therefore decided to refer to a more dynamic and contemporary concept of “co-production” although this concept is only recently emerging in the literature in relation to healthcare statutory provision and its relationship with those members of the public who input into service design, governance and delivery. We have deliberately aimed for co-production rather than “involvement”, as the latter may be considered tokenistic (Stickley, 2006). Co-production on the other hand implies a genuine collaboration of people (users of services and so on and professionals) working together. The New Economics Foundation offer a useful definition: “Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change (Boyle and Harris, 2009, p. 11).

Whilst the focus of this journal is “mental health”, we acknowledge that the survey reported in this article, extends beyond mental health and includes many other aspects of healthcare education.

In the UK, there is a long history of service users contributing to healthcare education. A significant publication was from the English Nursing Board (1996) which acknowledged the pedagogical potential of bring service users’ voices into the classroom. It also highlighted the potential for the innovation to challenge existing power bases, individual and institutional values and priorities.

A number of subsequent studies reported upon such changes and challenges: McLaughlin (1997) identified attitudinal change, Clinton (1999) reported how stereotypes could be confronted, contributors may feel empowered (Hanson & Mitchell, 2001), and partnerships amongst students and service users emerged (Rush, 2008). Furthermore, a number of universities began to employ service users as “development workers” to promote the agenda within education (Happell & Roper 2002, 2003, Simons et al. 2007). The following decade saw further developments such as initiatives by the Health Education Academy with “Mental Health in Higher Education” and “Developers of User and Carer Involvement in Education” (DUCIE). The literature also continued to provide evidence of further growth; for example: Stickley et al., (2009); Towle et al., (2010); Gillard et al., (2010); Rose et al., (2011); Mockford et al., (2012); Storm & Edwards, (2013); Mablethorpe et al., (2014).

Whilst the expectation of “involvement” has been in place for some time, there are few benchmarks against which to assess performance, and consequently, considerable variation in arrangements. The single largest study to address this issue was commissioned by the Health and Care Professions Council (Chambers and Hickey, 2012) who sought to produce options for Standards of Education and Training (SETs) for service user involvement in the design and delivery of HCPC regulated education and training programmes. There is no comparable initiative with the Nursing and Midwifery Council (NMC). In their standards for education (NMC, 2010) service user and carer involvement is

repeatedly demanded, but never defined. Whilst the HCPC study highlighted much good practice in the UK, it was inconclusive in its recommendation whether or not to define service user involvement SETs for the education of healthcare professionals. Furthermore, there has been no one study that has sought to scope what is being achieved amongst relevant university departments across the UK. With this in mind, the current study was commissioned by the School of Health Sciences at the University of Nottingham. We wanted to find out more about how things are actually working, and so the first author conducted a telephone survey in the autumn of 2015, using an approach called Innovation Mapping (Bates et al., 2005). The findings from that survey are reported in this article. The questions that guided the telephone survey can be found in the Appendix.

## Innovation Mapping

Innovation often occurs at the edge of safe knowledge, in the liminal space where values, hunches and networks drive curiosity and experimentation. Following an independent review carried out by the first author of service user and carer involvement in the School of Health Sciences of one university in the UK, we wanted to get a sense of whether this organisation was a pioneer or a laggard by contrasting its achievements with those of other places. We took the following steps:

- Identified a number of benchmark items that we believed had the potential to drive significant service user and carer involvement. Each item was selected to discriminate between organisations (i.e. some would be doing the thing, not all), be a fruitful ground for discussion, a potential area of innovation or a window into values.
- Build these benchmark items into a set of questions that permitted yes/no answers as well as considerable space for explanations.
- Seek out respondents from 30 universities who were willing to talk to us about their arrangements and then conduct telephone interviews with them. We judged the phone call to be better than using an online survey as it allowed for exploration of the themes, and ended up with 31 responses.
- Check with the respondent that the record was accurate and invite them to amend it if they wished to do so. This underlines the fact that everything we have found out is based on self-report rather than on an independent assessment. Then obtain their permission to share responses with all participants, so that everyone could see how their own activities compared with others, and have the opportunity to contact others to discuss innovative practice that they themselves identified.

## Digging deeper

One of the principles that underpin *Innovation Mapping* is that it should be easy to meet the requirements of each benchmark. This identifies a pool of practitioners who have some claim to knowledge in each area. A second round of exploration then begins as this group are asked to deconstruct the relevant benchmark and identify its key components. For example, in our first round, we identified a number of universities that are inviting service users and carers to award scores within the student selection process. A subsequent discussion (beyond the scope of the work reported here) might then ask how service users are trained to select against explicit criteria, how

often conflicts arise between the service user and the academic and how they are resolved. Discussions with the people concerned then yield a new, more detailed set of *Innovation Mapping* benchmarks that relate just to this activity.

### So what do these data mean?

As it is based on self-report, it principally identifies individuals who believe that they are achieving the benchmarks. Such individuals will have valuable experience about how they have accomplished the innovation and about the critical success factors. Listening to each of them, either by reading the interview summary or following up with individuals will highlight differences in approach, fresh angles that might be adopted, and values that drive their efforts. All this is treasure for the innovator, although it is disturbingly imprecise to the pure scientist. As each of the respondents were describing arrangements that might or might not be shared with other courses, such as those for Operating Department Practitioners, Social Workers, and Psychologists as well as Nurses, the findings are only comparable in a general sense. Such differences are not bothersome to innovators, as they just want to know who is having a go, what appears to be working and where they can go to find out more.

All this goes to show that the blanks in the report mean little or nothing. Almost everything could have been ticked if the respondent had looked hard enough within their own School and pushed down the admission criteria low enough to step into the category. Rather than wasting time talking to people who are *not* doing it, the innovator is eager to connect with those who have found a way.

### Survey findings

The Universities and Colleges Admissions Service website was trawled to find all relevant providers of nurse, midwife and physiotherapy training in England and Wales at undergraduate or postgraduate level – the same area that is covered by the Nursing and Midwifery Council. An examination of provider websites yielded some names of service user and carer lead staff or a staff member with an interest in the topic. These were emailed and asked if they would be willing to participate. Follow up emails and phone calls were then sent until the thirty telephone interviews had been completed. Interviews took place over a nine-week period from the beginning of October 2015.

Three staff actively declined to participate. One sent a detailed form for us to complete to formally request the conversation, a second asked for evidence of ethical approval, and a third felt the need to seek line management approval before disclosing anything about their university. In each case, we simply moved on to the next university on the list, although we did think carefully about whether research ethics should apply to simple information sharing between publicly funded bodies about processes of public involvement. It also seemed to us that interviewing reluctant participants was unlikely to yield the kind of candid self-assessment and willingness to share that we wanted.

After the telephone interview, the notes were emailed to the respondent with an invitation to make any corrections or improvements that they wished. A small number of corrections were received, almost all of them choosing better words to express a particular thought more clearly rather than correcting an error. Then a further email was sent offering them the chance to withdraw from the data-sharing exercise – an offer none of the respondents took up.

The 31 universities in our survey account for around 675,000 students, getting on for 30% of the target student population based in England and Wales. We did, of course, speak to only one staff member in one School of each university.

### **The identity of ‘service users’**

We asked about respondent’s definition of ‘service user’, as one guidance document includes professional stakeholders (Chartered Institute of Physiotherapists, 2015). Our respondents had a unanimous wish to prioritise patients and unpaid carers, and to focus on their contribution as both recipients of healthcare and as outsiders to the academic and professional world of healthcare delivery. A third of respondents also engaged strongly with patient organisations, sometimes to harness a wider range of viewpoints, connect with people who had recent experience of using health services, or to ensure that participants had a source of support that was external to the university.

Others had some concerns about involving others beyond the patients and unpaid carers group. Some felt that people with a strong affiliation to a patient organisation were more likely to focus on ‘campaign messages’ rather than their individual lived experience<sup>1</sup> while paid staff might have a conflict of interest. Building a strategy that relied upon a third sector organisation that might lose its funding would threaten continuity of involvement. There was also a concern that university staff with lived experience or retired professionals are ‘staff first’ and are therefore unlikely to bring an independent challenge to the way things are done.

### **Resourcing and directing the work**

It was Sir Roy Griffiths who described community care as ‘everyone’s relative but nobody’s baby’, highlighting the way in which sharing responsibility can undermine leadership. So, we asked respondents to provide an estimate of the number of whole time equivalent staff of any grade who had ring-fenced, dedicated time to lead and support the involvement agenda. Seven Schools had no ring-fenced time at all, and nine had one whole-time staff member or more. Some of these positions were strongly supported by colleagues working on involvement activities as part of their other responsibilities, while others worked alone and had a brief that ranged across a wide variety of disciplines, schools and departments.

Of the 31 Schools in our sample, almost half of them (n=14) had no budget for service user and carer involvement, making it impossible to predict costs, manage expenditure or commit to support. The existence of a clear budget was linked to the identification of a staff lead - of the Schools that had less than 0.5 whole-time-equivalent staffing, only 50% had an identified budget for supporting involvement, but almost all the schools with one or more whole-time-equivalent staff had an identified budget.

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<sup>1</sup> The NIHR webpage at <https://www.nihr.ac.uk/our-research-community/NIHR-academy/nihr-training-programmes/fellowship-programme/nihr-advanced-fellowship.htm?source=chainmail> accessed 17/04/2019 describes the NIHR programme offering ‘Partnership Fellowships’ through which staff link with third sector organisations partly to strengthen their public involvement. This shows that the official position is rather at odds with the view expressed in our survey.

With an identified staff lead and a budget, the next step is strategy. Four of our 31 Schools had nothing written, and a further nine had a document that needed updating. Nearly two thirds (63%) reported progress to the School management team, 57% had an up-to-date strategy, 33% had SMART targets to monitor progress, and 10% of the Schools included service users and carers in the development of the strategy. Many respondents told us that aspects of their strategy were also embedded in other documents. It would be instructive to look at the “SMART” targets in more detail to find out how different organisations are measuring progress.

Finally, in this section, we note that service user and carer contribution can be validated in symbolic ways that create an enabling culture. In one place, a senior manager attends all meetings of the Service User and Carer group; in a second, the Head of School teaches on the ‘Engaging Service Users’ module; and in a third place the Executive Dean asks for regular progress reports.

## Training and Development

The social model of disability argues that it is the powerful people who need to change to include minorities, rather than the other way around, so we asked if schools had trained their own staff in service user and carer involvement. A total of eight Schools had offered staff an introduction to the issues or briefed them on progress with the service user and carer agenda. Further work is needed to find out more about training needs analyses, syllabus and impact. In one case, service users and carers deliver the training, and in another, service users have written some briefing materials.

Training is provided for service users and carers in 25 Schools, with a combination of input that covers teaching, research and University processes, especially the student selection system with its attendant equality and diversity training. As Universities commonly offer a programme of short courses to lecturers and other staff, in some cases, service users and carers who are involved in teaching can attend these events and learn alongside university staff. There were few other examples of deliberately lowering the barrier between staff and service users by creating integrated learning opportunities where both groups shared the roles of teachers and learners.

Just over a third of Schools provide training for service users and carers in teaching methods, research or University processes, such as the committee structure or student selection. Again, a further round of investigation might further deconstruct these sessions to find out, for example, whether ‘training for teaching’ meant understanding the requirements of the examination board, the architecture of the syllabus, inquiry-based learning, teaching methods, classroom etiquette or payment arrangements. The tone of many answers to this question strongly favoured informal, responsive, individualised learning on the job, which was remarkable in an environment that is so strongly focused on explicit learning outcomes, congregate teaching and auditable assessment. Some respondents expressed concern that training would socialise people into the culture of the organisation and so spoil their unique ‘outsider’ perspective.

## Student selection

The mechanism used to select appropriate students is an important and resource-intensive process through which the universities select from many thousands of applicants. Twenty-two of our sample of 31 schools said that they included service users and carers in the design stage of the selection process, such as agreeing the mix of individual and group exercises, the number of mini interviews



and the questions or challenges to be posed to candidates. A similar proportion invited service users and carers to be present in the selection process to ask the questions (n=20), and to award scores (n=19) alongside academics and practitioners.

This question hinted at more substantial differences that a further survey round might reveal. Whilst many schools said that they always included service users and carers in the room when students were being selected, this was not the same as ensuring that every candidate met a service user or carer. Whilst some candidates were assessed by a service user or carer, others might visit interview stations staffed by academics, practitioners or current students, or attend on a different day when service users were not represented. Thus, whilst some schools achieved almost 100% of candidates meeting a service user or carer, others had much lower scores and few were tracking this indicator. Indeed, we were told that monitoring might give rise to challenges from rejected candidates, so a decision had been taken in one place to collect no data on this matter.

Respondents were strongly convinced that the process was benevolent – that in almost all cases, the service user or carer made an independent judgement that aligned with the professional view, that occasional challenges from the service user or carer almost always increased the quality of the selection process and that negotiations between the service user or carer and the professional were equitable rather than distorted by power imbalances. Such beliefs are not always shared by other academics, while service users and carers might legitimately question whether their presence is redundant if it merely confirms the clear majority of decisions by academics. The availability of large scoring and outcome datasets invites analysis, but none of our respondents had undertaken such a review of the evidence that they were collecting.

### **Curriculum design, delivery and assessment**

Over half of our respondents (n=18) had involved service users and carers in the design of most of their modules. Again, it was the discussion that yielded additional insights here. In some settings, high level engagement had been achieved by running some focus group sessions which asked service users and carers about their criteria for what made an effective health professional. The outcome of these focus groups was then taken away by the academics and worked into every module. In other settings, service users and carers were present for the working group meetings too, and so had direct input into the detailed content of individual modules. A further step is to include service users and carers in the final sign-off of each module and in subsequent amendments to an established module.

Some schools had focused their limited resources into a specific module and had fully co-designed it with service users and carers, partly to ensure coherence with a module title such as ‘Engaging Service Users’ or to act as a learning exercise before advocating the approach elsewhere.

In addition to the widespread use of reusable digital materials, all schools invited service users and carers into the classroom to help with teaching and learning. In 14 schools this only happens occasionally, while in 5 schools the approach was to expect it to happen in every module. Some respondents felt that this was not appropriate for some aspects of the curriculum (anatomy and pharmacology were mentioned), but this was vigorously contested by others and most felt that there was room for meaningful expansion, despite the concern that involvement should be meaningful rather than a blind dash into ‘presence without purpose’.



Once in the classroom, all service users and carers were invited to tell part of their life story, although some schools were offering coaching to ensure that the story was told for educational ends and related closely to the learning outcomes for that session. Just over half the schools also engaged service users and carers as simulated patients to enable students to test their technical competencies, and a similar proportion invited some service users and carers to move beyond their personal story and deliver wider teaching. This enables service users and carers with particular expertise to contribute as visiting lecturers and disrupts any semblance of the professional exhibiting the service user as a kind of 'medical specimen'.

When service users and carers are present in the classroom, there is almost always an option for the tutor to remain in the room, but in ten schools, staff can also be absent. Staff might attend to learn, to co-teach, to connect the story with wider teaching themes, to support and coach the person, to monitor quality, to police conduct, and sometimes to address safeguarding or pastoral concerns. Where service users or carers (like many staff) feel intimidated by the process of being observed, where they are entirely competent and knowledgeable, and where sitting in would be intrusive or even voyeuristic, then some tutors are permitted to withdraw.

Two thirds of respondents had involved service users and carers in the assessment of practice placements, and one third had done so in the assessment of clinical or academic skills, with four schools involving people in anonymised moderation.

Whilst the regulatory bodies have made general statements about the need to involve service users and carers in assessment, details remain unclear. Two examples illustrate this point. First, most assessments in practice placements involve gleaning views from patients, service users or carers who are receiving a service from the student and their clinical mentor. Whilst it is vital for health professionals to glean feedback from the people they treat, this is not the same as seeking a view from an independent person whose care will not be prejudiced by a negative report.

Secondly, some of our respondents invite service users to engage with a student in the classroom and then provide them with feedback. In this process, the student then writes a reflection on what was said about their practice and what they have learnt from it, which is marked and may contribute to the student's final award. In this example, the service user or carer is present and involved in the assessment process, but does not do any marking or hold any influence with those who do.

We did find examples of service users and carers contributing to summative assessment and sharing significant influence alongside academics and clinicians. Such responsibilities are unreasonably burdensome to some service users and carers (Stickley *et al*, 2010), while others have no such qualms – we found six schools where service users, carers or other public representatives sit on the Fitness to Practice panel where decisions are occasionally made to terminate a student's studies.

## Research

Half of the respondents we spoke to had little or no contact with research colleagues and were not especially aware of local opportunities for service users and carers to contribute to research. It may be that our informal approach to this telephone survey put off some researchers and so formed a sampling bias. However, the number is large enough to raise questions in a future round of innovation mapping. Of those with some knowledge of the research field, eight reported examples

of a service user or carer acting as a co-applicant in a funding bid (Bates, 2014) and ten were aware of occasions when a service user or carer had co-authored a publication (Bates, 2015).

## **Governance**

Twenty five of the thirty-one respondents told us that they had included service users and carers as members of committees and groups that managed the day to day activities of the school. This commonly included the validation panel, as this is a requirement of the regulatory body, and highlights the impact of such demands. Other middle management groups that include service users and carers include Quality Committee, Faculty Ethics Committee, Programme Board, Course Management Committee, Board of Studies, Curriculum Change Group, Student Progression Committee, and Disability Advisory Group, as well as the Fitness to Practice group mentioned earlier.

Only three of our respondents reported that service users and carers have a place on the most senior oversight group in the School or Faculty. Six schools have some experience of service users and carers sitting on staff recruitment and selection panels, although they all described these experiences as exceptional, rather than the norm, unlike arrangements in many NHS organisations where their students will end up applying for jobs.

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

Some groups have been quite resourceful in marketing their activities and recruiting new members. Some have created webpages and done leaflet drops in GP surgeries and libraries, but most favour spending time on targeting particular audiences and building personal relationships when a specific need is identified. So, individual schools had developed links with a learning disability group, the refugee forum, Parkinson's UK, Healthwatch and involvement groups at NHS Trusts and elsewhere.

Longstanding groups report that, once a group reaches a critical mass, word of mouth marketing by group members, academic staff and alumni is sufficient, and the group becomes self-sustaining.

Reasonable adjustments are made to ensure that people who need additional support can participate. This includes buying mobility scooters to help people get around the large university campus and meeting in wheelchair accessible spaces with a hearing loop. Indeed, one school moved their teaching session to a nearby hotel when the lift failed in the university building. Some staff routinely provide large print or easy read agendas or read out the material written on PowerPoint slides to help people with visual impairment. Groups have learnt to give members with aphasia or other speech difficulties additional time to express their views, while staff maintain connection with people via their preferred communication medium, whether Facebook, telephone or post rather than just email, and sometimes extend the interview time for student selection so that the service user can have enough time to complete their assessment. One school routinely creates an Access Plan with each service user or carer which identifies support needs and designs the necessary adjustments.

Half of our respondents had arrangements in place for evaluative feedback to be provided to service users and carers who contribute to teaching and learning. This usually sat rather apart from the university's standard approach to collecting evaluations from students which was sometimes too impersonal, too vague and too late to be of value to service users and carers wishing to hone their

skills. Three schools had also created a more developmental session for service users and carers that bore some similarities to the staff appraisal process in that it took a long view and explored developmental needs and support arrangements. Only forty percent of schools had a centralised register of service users and carers which would allow them to effectively stand anyone down should the need arise. Only four schools routinely provide certificates of appreciation or letters of thanks, but thirteen schools (42%) had seen service users and carers move on to further study or employment.

Much has been written elsewhere about the labyrinthine arrangements for payment and so these issues will not be rehearsed here (Morgan and Jones, 2009; Stickley et al., 2009; Towle et al., 2010). It is notoriously difficult to create a system that works well for service users and carers, the university, the benefits agency, the pension service, employment lawyers, best practice in volunteering, audit and HMRC. In our survey, 23 of the 31 schools considered that all service users and carers should be offered a payment for their activities, and the clear majority did so via the visiting lecturer arrangements. Just a few uncommon perspectives emerged, including:

- A rejection of gift vouchers, as a poor substitute for a pay cheque
- Refusal of all payment apart from reimbursement of expenses, in order to retain a critical faculty that can only thrive through financial independence (McKeown *et al.*, 2012) or to divert these payments to a charity of their choice.
- A stratified system, in which different levels of responsibility attracted different levels of payment, or by which organisational needs dictated the activities that could be funded within budget.

## Networking

Just over 40% of our respondents had linked with others doing similar work at another university, mainly through the Lived Experience Network, DUCIE or ad hoc events organised at individual universities. There was little or no engagement with the International Association of Service User Academics. Again, there is a hint that staffing levels influence the ability to network – 30% of the schools with 0.5wte staff have links with these networks, and this rises to 55% of the schools with a larger staff resource.

## Conclusion

Given the focus of our paper is upon co-production, we acknowledge that one major weakness of the paper is the lack of service user voice in relation to the design and implementation of this survey. That said, many of the respondents were people who considered themselves “service user” workers.

It is apparent that service users and carers make a substantial contribution to healthcare professionals’ education in the UK. Over many years several innovations have been developed, as described in this paper, including the creation of specialist staff and budgets, strategic plans, staff training, teaching by service users and carers across the curriculum, summative assessment, participation in fitness to practice panels, co-authoring academic papers and involvement in governance of the faculty. However, diffusion of these innovations has been slow (Rogers 2003). Perhaps it would be fruitful to consider these items as contenders for combination into a complex

intervention with an accompanying fidelity measure (Medical Research Council 2006), pointing the way towards substantial cultural and organisational change that help nurse education adopt a genuinely coproductive partnership with service users and carers.

We estimate that our survey captures a ‘snapshot’ of activities of around half of the Schools in Higher Education that provide healthcare professionals’ education. On that basis, this is an adequate number in order to imagine the bigger picture. For the aspiration of co-produced healthcare professionals’ education to be realised, there needs to be investment in the agenda. Work on national networking, national standards and subsequent benchmarking require large collaborative endeavours which demand the time and attention of all stake-holders. The rich history of “involvement” in healthcare professionals’ education has been fruitful but piecemeal, so in the meantime, individuals who promote service user and carer involvement can benchmark their own activities with the help of this survey and seek out neighbours who have already established practices that they have yet to acquire.

These are however uncertain times with significant changes to the funding of healthcare professionals’ education; nevertheless, this is also a time of opportunity for important development. We would urge healthcare education providers and commissioners of the future to engage with public communities to ensure a more strategic (and adequately funded) co-produced healthcare professionals’ education in the future.

## Appendix – the table of questions that structured the telephone interview

### Q1a. Respondent

University	Lead	Discipline	Email

### Q1b. The heart of your ‘service user and carer’ work is...

	Patients, service users, unpaid carers	Representatives from patient organisations	Our staff who have lived experience	Stakeholders who are affected by what we do	Notes

### Q1c. Thinking about the staff<sup>2</sup> and budget allocated to support service user and carer involvement in your School...

	Whole Time Equivalent staff	We have an identified budget so can track all relevant expenditure	Notes

### Q1d. Do you have a Strategy document on how the School will involve service users and carers?

	Nothing written	Needs updating	Current	Notes

### Q1e. Have you identified key performance indicators that allow progress to be tracked over time?

<sup>2</sup> Please do not reduce the total if nursing, midwifery and physiotherapy account for only a part of the work of the School and its lead staff.

	Just a general description	SMART targets	Reported to regulator	Reported to school management	Notes

Q2a. Have you run any training events to help with involving service users and carers?

	Service users and carers have been trained	Staff have been trained	Service users and staff have been trained together	A regular programme is in place	Notes

Q2b. If you have trained service users and carers, what has this covered?

	How to contribute to teaching	How to contribute to research	How to work with committees and systems	Notes

Q3a. Do service users and carers help with student selection?

	Help design interview questions	Ask standard questions	Impressions only	Scores awarded	Notes

Q3b. Have service users and carers helped to design course content?

	None of our modules	1-3 modules	Quite a few - where it seems appropriate	Most modules	Notes

Q3c. When service users and carers are present in the classroom to help with learning

	Staff are also present	Staff are absent	Notes

Q3d. What proportion of modules include service users and carers in the classroom at some point?

	None	Rare	Occasional	Normal	Always	Notes

Q3e. What roles do service users and carers take up in the classroom?

	Simulated patients <sup>3</sup>	Share their life story	Deliver wider teaching	Notes

Q3f. How do service users and carers contribute to the assessment of students?

	Provide input to the assessment of practice placements	Provide input to the assessment of clinical or academic skills	Assist with anonymised moderation	Notes

Q4a. How do service users and carers advise researchers?

	We have a Standing advisory group that gets involved with several studies	Individual studies include one or two patients or carers on their study management group	Notes

Q4b. What specific roles do service users and carers take up in the research process?

	Lay assessor for funding body	Co-applicant for research funding	Honorary contract/ research passport	Co-author academic papers	Notes

<sup>3</sup> This refers to real people, rather than robots.

Q5a. Are service users and carers involved in governance of the School?

	Sit on most senior oversight group	Sit on middle management committees	Sit on staff recruitment and selection panels	Notes

Q6a. What is your approach to recruiting service users and carers to get involved?

	Ad hoc opportunities	Explicit programme of marketing	Specific actions taken to reach seldom heard groups	Notes

Q6b. How do payments work for service users and carers?

	Expenses only	Some people get a fee	Everyone gets offered a fee	Non-pay	Payroll	Notes

Q6c. How do you organise support and supervision for service users and carers?

	Ad hoc, informal	Routine structured feedback	Formal appraisal	Central approval and dismissal process	Support arrangements outsourced	Notes

Q6d. How do you support personal and career development for service users and carers?

	Opportunities to get involved are advertised to the whole group (via email, website or bulletin)	We routinely offer a reference or testimonial	People have moved into further study or employment as a result	Notes

Q6e. Have you undertaken any specific initiatives that enable people who need additional support to contribute?

	Targeted specific groups	Made particular adjustments	Notes

Q6f. Are you supporting any networking opportunities that link service users and carers with others who are active elsewhere?

	Visited other groups	Linked with networks	Funded service users and carers to attend a conference	Notes

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## Critique of the survey

This paper was submitted to two academic journals and rejected on both occasions. Here we set out the reasons that the reviewers gave for their decision in order to assist readers in evaluating the strengths and weaknesses of the work.

1. The paper was deemed to lack sufficient explanation of the background and context for an international audience. It was said that concepts such as the social model of disability should have been explained, critically reviewed, and their utilisation in the survey should have been justified. The paper should have used findings from other surveys and studies to help comment on the findings of this survey.
2. The reviewers were not sure whether the data collection consisted of a telephone interview or a telephone survey. We are not sure what is meant by these terms, so suffice it to say that the worker collecting the information phoned the person and talked to them, using the table of questions set out in the Appendix.
3. Similarly, reviewers wanted a robust process by which the respondents were screened as eligible and then selected. In reality, the investigator found the 'Service User and Carer' page

on the website of the School and looked for a name. As the Appendix shows, information was collected during the interview regarding that person's job role and duties, but their primary selection was on purely practical grounds – did they answer the phone and declare a willingness to be interviewed? The first 31 who said 'yes' and booked a time formed the 'convenience sample'. This is a weak but practical way to identify respondents when time is short.

4. There were concerns about the process by which interview responses were recorded, as the reviewers seemed to expect interviews to be recorded, transcribed and then analysed formally with sophisticated software before deriving typical verbatim quotes from respondents for the paper. None of these things happened, but instead, the interviewer used a conventional phone and scribbled rough notes on a blank copy of the table of questions. In defence of our practice, we point out that this survey was allocated a budget of 20 days to design, recruit, book, interview, write up and report on the work. Denying this kind of brisk, pragmatic exercise any chance to report to a wider audience creates myopic services and leaves academia in lonely but splendid isolation, increasingly out of step with current practice.
5. In this survey, the telephone interview notes were written up and then sent back to the respondent for checking. Reviewers (who expected the interview to have been recorded) questioned this step, prompting us to reflect more carefully on the rationale. The motivation behind this step was not only to check the accuracy of the record, but to engage the respondent in reviewing the questions again and consider their merit as a trigger to further service development. Indeed, we were delighted to hear that at least one respondent had taken up the questionnaire and used it to prompt further discussions within their own organisation. This illustrates the difference in focus, by which the researchers were preoccupied with data quality while the authors were shamelessly seeking to prompt practice development.
6. Similarly, reviewers did not like the fact that the survey focused only on nursing, midwifery and physiotherapists, commenting that a broader survey of all healthcare professionals would have yielded more generalisable findings. There was also a fascinating request for analysis of the findings by profession, to explore whether disciplines varied in their adoption of Service User and Carer involvement and to reflect on the potential impact of discipline-specific policy, regulation or funding practices. These points are well made, but the survey was commissioned by a School that taught these three professions and they were justifiably interested in comparisons with their own activities. Whilst we acknowledge that generalisability is a vital component of research design and is essential in attempting to understand the rules of physics, this survey was seeking a different sort of knowledge – examples of what is possible, rather than the prevalence of an innovation. Perhaps we targeted the wrong journals. And as indicated above, shutting out the grey literature - reports that are funded and written for a particular purpose – constrains and narrows the access that practitioners may enjoy.
7. The lack of clear approval by a University Ethics committee was an insurmountable barrier for some reviewers. Concerns embraced the risks that the paid staff who were interviewed over the telephone would be somehow coerced into participating in a conversation that

they did not want; that without a clear participant information leaflet and signed declaration of informed consent, their personal comments would be misunderstood as representing their employer's official position; and that their rights to data protection would not be upheld. One reviewer observed that some respondents might wish to gloss their self-report in order to curry favour from the Regulator and so the study should have examined grade or seniority of the respondent, and the researchers should have taken more pains to reassure respondents that their disclosures would be handled sensitively. There is clearly a contested point at which one crosses over from the formal, regulated interactions of research, hedged around with formal safeguards into the world where people phone one another and have an informal chat about their work, share innovative ideas and solve problems together.