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Accounting for Research – the Difficulties Posed for User-Centred Research

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Abstract

When public money is invested in research it is necessary to have in place accounting systems that demonstrate its value. By this we mean its social as much as its economic value to society. This paper traces the collective experiences of a group of service user, professional and academic researchers about the annual reporting of research activity supported by NHS R&D Support funding. The stance taken is partisan as it represents one that defines the scope of our work within a regional NHS user-centred research programme. We critique the NHS research accounting system in England and the thinking upon which it appears to be based, suggesting that it devalues less traditional forms of research. It is argued that reductionism written into the present accounting system strips it of sensitivity to the values, operational arrangements and timescales involved in a lot of service user-centred research, and marginalises the value of many of its outputs. We set down some challenges for the redesign of the annual reporting system relating to NHS Research and Development (R & D) Support Funding.

Keywords: service user-centred research, NHS R&D Support Funding

Background

Few people would dispute the need for a system of accountability in matters relating to the use of public money. Research and development activity supported by the public purse is no exception. Until the Culyer report (1994) research and development undertaken by NHS Trusts and later Primary Care Trusts (PCTs) was largely unaccounted for in relation to its scale, content, policy relevance and value to the public. In short what might be referred to as 'in house' research was being supported or perhaps subsidised by funding meant primarily for patient care and there was no national control, let alone co-ordination, of how that money was being used.

In response the Culyer report recommended that NHS research funds be gathered into a single stream clearly separate from patient care, made available to acute, community and primary care Trusts on a competitive basis, with all R&D activity transparently managed, quality assured, peer reviewed and registered in a National Research Register.

The report said that to be considered as R&D in the NHS an activity had to "provide new knowledge needed … in improving the health of the nation" and "be of value to those in the NHS facing similar problems outside the particular locality or context of the project, i.e. be generalisable" (Appendix F, p.75).

Crucially, projects were to be managed according to clear, peer reviewed, ethically approved protocols with findings "open to critical examination and

accessible to all who could benefit from them - this will normally involve publication" (Appendix F, p.75). Indeed, the quality and value for money of NHS Trust R&D was to be measured at minimum by publications achieved, grants awarded and studentships completed, reported annually to the Department of Health (DH).

Since then there has been massive investment in establishing a system of research governance for all health-related research (Department of Health 2001), ethical scrutiny of research through a national system of Local Research Ethics Committee (LREC) and Multi-Centre Research Ethnics Committee (MREC) overseen firstly by the Central Office for Research Ethics Committees (COREC) and now the National Patient Safety Agency (NPSA), National Research Register (NRR) for research projects carried out by and with Trusts, a Priority and Needs Programme (PNP) that requires trusts to link their R&D to national research priorities (Department of Health 2000), and finally an annual reporting system in which all Trusts are required to account for their research, its products, impacts and costs (Department of Health (2005a).

The outcome of this investment is a national system of regulation and control, previously lacking, of NHS research, and arrangements for ensuring that there is concordance between local and national research agendas. It is now virtually impossible for more speculatively driven local NHS research to be undertaken because of the need to 'fit' local research needs to NHS R&D priority and need areas. Proposals set out in Best Research for Best Health (Department of Health 2005b) indicate that there may be some loosening up of the funding system to permit more speculatively-driven research and there is at last some recognition of the overbearing bureaucracy associated with ethics and research governance.

The annual R&D reporting system referred to above is a key part of the present arrangements for checking that the associated public money is being wisely spent. It has become the primary means by which determinations are made about how much funding should be allocated for research support to all Trusts engaged in research (Trusts can de-select from this process if they do not consider themselves to be research-active – in which case they receive no money for research support). Accordingly there is a premium on ensuring that all the key parameters within the annual reporting system are fully addressed by research-active Trusts.

The NHS annual R&D reporting system

There is no excuse for Trusts not knowing what the annual reporting system requires of them as the details are widely published, accessible electronically and updated year on year. The latest guidance (Department of Health 2005a) is for the most part highly prescriptive. We argue later, however, that the guidance is ambiguous in critically important areas and that the prescriptive foci, especially those relating to research deliverables, are in some respects highly questionable.

Research activity that falls within this scrutiny is non-commercial R&D funded in part or in full from NHS R&D Support funding. Parties to a programme may be NHS organisations and academic or other

organisations (e.g. local authorities). To qualify as a programme a number of criteria have to be met. Programmes must:

- Involve a strategic partnership between one or more NHS and social care organisations and at least one university.

- Provide an explicit research strategy in an area of national priority or of demonstrable need for health and social care.

- Identify designated leaders with recognised expertise in an appropriate field of research.

- Contain a critical mass of research projects.

- Explicitly draw on knowledge, track record and ability in the subject area, demonstrated by substantial publications and other outputs.

- Involve academic disciplines, professions and service sectors as appropriate.

Strong programmes will score well against the following additional criteria:

- Demonstrate high standards of research governance and management including research sponsorship arrangements.

- Have clear arrangements for including service users and carers, as appropriate, in all stages of the research process appropriate to the topic area.

- Demonstrate clear and appropriate mechanisms for disseminating findings, and close links with wider NHS and other functions responsible for improving the quality of health and social care.

- Demonstrate the ability to build capacity in NHS R&D.

(Department of Health 2005a, p.28)

Once established, research programmes are assessed according to the following criteria:

- A strong programme has sufficient mass or projects, a good number of publications and attracts considerable external funding.

- A moderate programme has a mix of weak and strong elements and requires further development work on the programme content and focus.

- A weak programme has major deficiencies in scale, content and form.

According to the guidance, research programmes assessed as weak by the DH may be subject to future disinvestment. Research programmes need to demonstrate their relevance to published NHS R&D priority and needs areas.

In relation to research deliverables four categories are emphasised: number of projects, peer-reviewed publications, research capacity building and impacts of the research on health and social care.

Abstracts and letters to peer-reviewed journals are not to be included in publication lists. Publications that are not peer-reviewed would by default not be counted as acceptable; this would also encompass grey literature. Examples of impacts are required with suggestions like: contributions to NICE guidance, evidence that has influenced NSFs, substantial well-documented changes in practice or service delivery, outcomes feeding into the service agreement and financial framework and health improvement and modernisation plan processes, and evidence that has influenced local delivery plans. Financial information is required about the internal distribution of funds to support programmes of research activity, and additional details are required about related external research funding or income.

Details required for annual R&D reports are entered electronically. However there are tight restrictions on the space available that make no accommodation for variations in the scale or complexity of research programmes. Clearly a national R&D reporting system is desirable. Before we raise questions about this reporting system, we first of all introduce our own programme.

About the service user-centred research programme (UCRP)

Our intention in providing the reader with a brief account of the UCRP is primarily to convey a sense of the type and range of research we do, sufficient to convey something about our values, philosophy and working arrangements. This is essential in understanding our critique of the NHS annual R&D reporting system.

The UCRP involves seven NHS Trusts and is led academically by the University of Sheffield – although individual UCRP members are also affiliated with or employed by other universities which also have a stake in their research activity. The Trusts are engaged principally in mental health, learning disability and ageing research. The UCRP is one of several research programmes that connect these and other organisations.

As a programme the UCRP seeks to emphasise research prompted by service user interests and experience. By definition it involves projects in which service users are active participants in the research process. These projects fit one of two broad types: (i) collaborative projects in which professional, academic and service user researchers work as partners in the research process, and (ii) service user controlled projects where service users design, undertake, and disseminate the results of research projects, sometimes facilitated by an academic or professional researcher. Collaborative and service user-controlled projects emphasise participatory principles but service user-controlled projects emphasise service user

expertise and power, often linked to an engagement with political action (Grant and Ramcharan in press; for an attempt at a comprehensive typology of service user involvement see Oliver et al, 2004).

Following a scoping exercise in 2004 of current projects involved in the UCRP, most involved people with mental health problems. Projects involving the experiences of older people or people with learning disabilities were not so prominent. The scope of research was impressively diverse, spanning primary research about lived experiences (homelessness, abusive environments, employment, ageing) to service evaluations (of ECT, addictive behaviour services, family carer assessment, outreach services, healthcare decision-making) and research skills training and development of co-operative inquiry methods. Outputs from projects were equally diverse and included: final reports, journal articles, training manuals, evidence-gathering tools, guidelines, evaluation tools, conference/seminar presentations, regular lectures in undergraduate nurse training, posters, strategy documents, art archives, newsletters and progress reports available to the public and the creation and continuing contribution of specific service user R&D teams that have supported or led numerous consultations in the NHS around the UK, leading, for example to citations in CHI reports (Walsh and Hostick, 2005). These contributions are planned, managed and delivered mainly but not necessarily exclusively within established qualitative research paradigms, representing from the participants point of view feasible and desirable research and development in action.

As a collective, however, we found it extremely difficult to judge the impacts of all this dissemination and project work. In 2004 individuals associated with the programme were also associated with external research grant income in the region of £900k.

Towards a critique of the NHS R&D Support funding annual report system

The three criteria considered to be most important in judging research programmes are external funding, peer reviewed publications and impacts. We address these in turn.

i)   External funding

Securing external funding for service user-centred research can be very problematic. Despite the emergence of interest in service user-centred research and some infrastructure to encourage and guide it (Involve 2004, UK Mental Health Research Network, 2005) as well as growing government commitment to the principle of service user involvement in research, organisations with funds dedicated to service user-centred research are few and far between.

The Joseph Rowntree Foundation (JRF) has played a leading role in making a case for service user-centred research but most of its priorities concern social rather than health care, though there are signs that this may be changing. The National Lottery Charities Board (subsequently Big Lottery Fund) followed the JRF lead and for some years has been a major investor in this kind of research, and with a clear idea of its priority groups,

encompassing as they do health and social care interests. The BLF is now re-prioritising and announcements are awaited about whether it will continue these commitments.

Outside of these players it is difficult to spot funding for service user-centred research. At the 'high theory' end the ESRC is obviously a contender but competition for funding is fierce, and probably fierce enough to deter many bidders interested primarily in locally applied NHS research.

Research funded through the Policy Research Programme (PRP) is now expected to demonstrate how service users can be most meaningfully engaged in the research process other than as passive research recipients, and indeed the DH LDRI was commissioned on this basis but with people with learning disabilities acting as co-commissioners and as independent reviewers alongside the more usual suspects (Grant and Ramcharan 2002).

This may be signalling a shift towards a more principled approach to service user involvement in research but it remains to be seen whether it necessarily leads to more participatory or emancipatory forms of research and, crucially, the additional funds needed to sustain these.

An associated difficulty with service user-centred research is that concerning anything that is 'new' – its credentials. Participatory and more emancipatory forms of research have founding fathers of great eminence (Paulo Freire among others) who, typical of radicals, posed fundamental questions about power and the relations of knowledge production, the articulation of voice among the dispossessed, and their emancipation. Yet demonstrating these credentials in contemporary contexts is exceedingly difficult as orthodoxies still rail against the claims of such radicalism, and in this we have to count many members of the research academy itself. They are sceptical of the 'science' of service user-centred research, of the guiding hands of those supporting service user-researchers, and perhaps of the prominence of disabled activists who are also academics.

This scepticism may often present as conservatism. Convincing funding agencies of the credentials of more participatory or emancipatory research that also fits NHS priorities and needs remains a major and therefore costly challenge in terms of the time and effort required to obtain funds. The difficulty of the competition is increased by the tendency of NHS grants to be awarded to elite centres.

Even securing the necessary funding for service user-centred research is itself no guarantee that research will get under way as anticipated, even when research proposals have been subjected to rigorous peer-review. Research ethics committees retain widespread scepticisms and misconceptions about forms of research embraced by the qualitative paradigm (Ramcharan and Cutcliffe 2001). We could cite from within our own programme many examples of such misconceptions but we detail just a few below to make the point.

- One of us was associated with a piece of research that was avowedly exploratory, and qualitative, because it concerned an area of nursing practice about which there was a dearth of empirical evidence. It was principally concerned with

explaining how personal, professional and organisational values shaped the delivery of care in relation to the management of sexual health in high security contexts. Yet the LREC subjected the researcher to a tirade of hostile questions about why hypothesis testing arrangements were not in place. Following this inappropriate questioning the research was refused ethical clearance.

- In another case, the value of including family carers in a qualitative study of new community nursing roles in the care of older people with dementia was questioned on the grounds that they are not 'users' of services and therefore have 'nothing to add' to knowledge on this particular subject. The proposal was knocked back and delayed, although the research was subsequently completed satisfactorily.

- Another UCRP professional accompanied a service user researcher to an LREC who was "grilled" on confidentiality and storage of information. The UCRP professional pointed out that an NHS researcher would not have been subjected to similar scrutiny. The outcome was that the service users were asked to store all information resulting from their interviews in a sealed envelope whilst transporting it from the site of the interview to the office base.

For both service user researchers and seasoned academic researchers these experiences can be traumatising, and can create personal and occupational insecurity. Unwarranted delays can and do occur that can scupper the viability of research designs, often requiring a renegotiation of project timetables with external funding agencies (Hays et al. 2003) or even complete redesign of research that has already been satisfactorily peer-reviewed (Ruane 2003).

Participatory research can be a messy and complex business. Experience suggests that power relations between those involved have to be continuously negotiated; on-the-job training and support of service user researchers can be time-consuming; research methods frequently have to be worked out as things proceed because many projects have evolutionary research designs where subsequent phases of the research depend very much on the outcomes of early stages - a characteristic feature of much qualitative research; and there can be unintended consequences for service user researchers when ethical and moral dilemmas arise in the field that can lead to further delays.

The rhetoric of participation sounds very rosy; the reality on the other hand can be quite different (*see* Walmsley and Johnson, 2003, Rodgers 1999). The relative costliness therefore of all the supports to be put in place to make service user-centred research viable is an additional burden to be borne, and a disincentive to some funding agencies.

Emancipatory research, much of it tied to social model thinking within the disability field (Barnes 2003), seeks to address and deal with social, political and environmental factors that perpetuate forms of exclusion or oppression in people's lives. Often linked to the tacit social constructions of others (individuals and organisations) these barriers can be very difficult to

remove. It therefore takes a particular kind of person to commit themselves to this kind of research, with the inherent struggles that are likely, the supports they may need to sustain them as a service user researcher, and the resilience required to see things through to the end, particularly in the later action stages.

Indeed, service user researchers have to engage with established, perhaps entrenched or embattled local bureaucracies, all of which have agendas heavily preoccupied with economy and national policy implementation. The bureaucracies may be well intentioned but unable or unwilling to add more to their workload, and may have to divert resources to national guidance and directives, leaving little time, energy or resource to devote to studies developed locally but which they have difficulty understanding. Indeed, broad decisions regarding the value of local studies are likely to be based on the same criteria as those pertaining to national or international studies (i.e. critical appraisal) without sympathy for the restrictions and difficulties faced by the service user researcher or the paradigms in which they are immersed.

In projects of this kind, proving that service user researchers can 'cut the mustard' in staying the course is an achievement in itself, and something worth building into any evaluation of research impacts. Further, research that sets out to be emancipatory implicates service user researchers in setting the research agenda and in developing research proposals. Yet in our experience many of the research questions identified by service user members of the UCRP do not correspond directly to national priorities. A further difficulty here is that funding for pre-protocol work for service user researchers is scarce and so, without it, emancipatory research may not be viable.

In the present competitive climate service user-centred research is having to battle hard to win resources to fulfil its agenda. Its claims are based heavily on the inherent value of personal experience expressed either in terms of voice, expertise, authority or as a counterweight to professional, academic or policy perspectives. Expert opinions (of service users) lie low down in the hierarchy of conventional claims about the basis upon which knowledge is based, systematic reviews and randomised controlled trials being at the top.

As long as service user-centred research has to operate in such an environment, securing funding will remain difficult, but it is patently unfair to make comparisons between the income generation of service user-centred programmes and those programmes that require expensive RCTs.

ii)   Peer-reviewed publications

Under the present guidance (Department of Health 2005a) only peer-reviewed publications can be entered in annual reports. Abstracts and letters to peer-reviewed journals are ineligible, as are other outputs. Much material that speaks to service user experience will therefore not show in these returns as much of it is to be found in autobiographies, anthologies, edited textbooks, grey literature, websites or in poems, artwork, dramas and other media forms (see for example Kronenberg et al. 2005, Atkinson and Williams 1990) that can be powerful and mould-breaking.

This raises many questions for a service user-centred programme like ours: how can the diverse output of the programme be written up for publication within the narrow terms of reference of peer-reviewed journals? Who should be the peers for this? It is true that some journals, like Mental Health and Learning Disabilities Research and Practice (published by University of Huddersfield and South West Yorkshire Mental Health NHS Trust) explicitly welcome service user–authored articles and offer support to novice authors during the review and writing process, but this seems to be the exception rather than the rule. In the UCRP we are attempting to facilitate the writing of original service user-owned publications for peer reviewed journal publication but the process is slow – although not so difficult to facilitate, if patience is considered a virtue.

A more fundamental issue here lies in the question 'what knowledge counts', or more particularly, 'whose knowledge counts'? One very common approach to service user centred research projects appears to be various kinds of opinion survey reported by R&D professionals, for examples see Smith et al. (2005), Robert et al. (2003), Hanley et al. (2001) and Tallon et al. (2000). In contrast, when the interest lies in what are fundamental ontological questions at the heart of service user experiences, establishing and substantiating the nature of discoveries is far from straightforward. Indeed, it is perhaps the experience of being involved as researchers, rather than simply as sources to be milked for data, that enables service users to better formulate their own opinions about the ways in which health services need to be developed and which understandings need to be challenged.

In any case there is no consensus for weighing knowledge claims, especially knowledge claims of this kind, though there have been some well-informed attempts to classify types and quality of knowledge in social care that are highly relevant here (Pawson et al. 2003).

We therefore pose the additional question – how can the Department of Health justify using an apparently single criterion measure – number of peer-reviewed publications – to weigh the science or knowledge claims of research programmes? Were we to accept peer-reviewed publications as the basis for counting outputs, we would further question merely counting these given the huge variations in the reputations and citation indices of respective journals. It therefore remains a mystery as to how these outputs are weighed and evaluated for their contribution to knowledge.

Finally, in other forms of independent scrutiny like the Research Assessment Exercise some subject panels, particularly those dealing with applied research, were less convinced of the need to differentiate peer- from non peer-reviewed outputs. Similarly, non peer-reviewed outputs would appear to deserve much closer consideration for their potential value to the knowledge base in NHS research. In their diverse forms they are also likely to be of greater practical value to readers or service users than academic papers that are accessed by very few people.

iii)   Impacts

The guidance asks for one or more examples of impacts that research programmes have had on health services or health policy. 'Brief' examples are required with no more than half a page available for all the details.

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Though well intentioned, this question is we believe untenable and unfair. It is primarily untenable because, as far as is known, no direct relationship has yet been proven between knowledge production (dissemination in all its forms) and knowledge utilisation (impacts).

Judging impacts is in any case fraught with difficulty – the primary question here being 'how do we know?'

Moreover, the demand to account for "impacts" may favour the reporting of easier projects with more obvious alleged impacts. This has two consequences: The pronounced bias against publication of negative findings is already a concern at the level of British Government (Varmus, 2004) because it is a pernicious corruption of knowledge and ironically one that is generally overlooked (Phillips, 2004). It may become worse if only "high impact" research is valued. This may also lead to less support for broad participation of service users in research in favour of elite service user researchers who can deliver impacts reliably.

Or consider the rationale behind systematic reviews – the scientific aggregation of data over a period of many years from many individual projects – the ultimate impact of a research project may not occur for years into the future, if at all. Yet it is clear that to only support or permit research with known outcomes is to severely cut the possibility of learning through discovery.

Impacts can remain hidden rather than manifest; there may be unintended or unanticipated impacts or consequences that were never envisaged (and that are therefore beyond the field of view); applied research can be oriented primarily to the production of knowledge rather than the securing of maximum impacts; and whilst we would agree that it is possible to detect some local, short-term impacts from research (e.g. practice changes, revisions to operating procedures and so on) the matter of discerning direct links with changes over longer periods of time or in other places is much more problematic. Some kinds of impacts might be considered to be of particular relevance to service user-centred or service user-led projects research, particularly those relating to personal transformations and skill development within service user researchers themselves. These can be seen as evidences of a developing research capacity, and one that has a lasting legacy. In the present research reporting arrangements it is hard to see where these kinds of impacts will be taken into account.

By their nature, the impacts of some research activities are far easier to enumerate than others. For example, some years ago one of us was involved in helping to develop three sets of carer assessment instruments. Papers involving empirical tests of these were subsequently published. However, since then the instruments have been translated into many languages and used in over 12 countries to our knowledge. However, is this any more valuable than the reporting of a single observation by a service user researcher about the experiences of being diagnosed with a mental illness, something that has led to insightful exchanges between members of the mental health service user community. Above all else, however, how is independent verification of impacts to be established? And whose voice counts in determining this?

This leads directly to our second criticism - unfairness. Those engaged in undertaking research have a clear self-interest in it. By the same token they (we therefore include people like us) should probably be the last in the queue to judge what the impacts of research have been, even if there is a semblance of an idea about what these may be.

Conclusion and discussion

The main purpose of this paper has been to raise awareness of the challenges presented by the existing system for accounting for NHS research, with particular reference to the experiences of a service user-centred research programme. We believe that many of these concerns are shared with the wider research community. If the claims articulated here have validity, we must therefore ask what should happen to make the annual research reporting system more sensitive to the work we do.

We think it is timely for a national debate about the criteria for assessing research. The three existing criteria – external funding, peer-reviewed publications and impacts – may suit more conventional research, but we suggest that they are less suited to the principles, purposes and products of much service user-centred research.

From our perspective the criteria need to be broadened to encompass non-peer reviewed publications, as well as other outputs that may conceivably have more value to different stakeholders. We are thinking here of outputs like service user or family carer autobiographies, grey literature, websites, poems, artwork and dramas that have the potential to be influential and mind-changing. We are also of the view that 'research capacity building' should feature more prominently in the criteria, and warrant greater recognition than 'higher degrees awarded' – many service user researchers have developed considerable research skills and carry out their work without being registered for higher degrees, but their contributions are not at present recognised in an equivalent way.   We believe that this undervalues and understates, as human capital, what service user researchers represent.

Were such accommodations to be made to the criteria, questions remain about how the evidence would be weighed. One possible way around this is to invite each programme to 'weigh' each of the criteria that apply to its work, before then inviting an independent panel to evaluate the claims of the programme against these. We would assume that any such panel would itself include service users.

We are less convinced about the validity and reliability of retaining the commitment to measuring programme impacts for reasons detailed earlier. Impacts are better measured over lengthier time periods, and in any case they require external validation. We do not think this task can be accomplished sensibly within the constraints of the present annual reporting system.

Much more straightforward would be an attempt to measure serious attempts at dissemination that extend beyond conventional publications. Our argument would be that demonstration of a diversity of outputs shows

creativity, a sensitivity to opportunity, and a commitment to thinking 'outside the box'.

Finally we would like to see a closer appreciation of the 'hidden costs' of service user-centred research – it is intensive and time-consuming, can involve lengthy pre-protocol work for which there is little funding, and may require higher than usual support costs (personal assistants, translators, and so on). There are still only a minority of funders committed to the support of service user-centred research so securing funding can be very problematic. It would be a pity if this became a deterrent.

As members of a service user-centred research programme we remain unable to spot the relationship between what we think we accomplish and the research support funding that follows the reviews of reports. We would like to see much more transparency in how the determinations are made, and what role service users play in that process.

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