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WHO DEFINES THE IMPACT OF RESEARCH? A PATIENT-CENTRED OPINION AND CALL FOR ACTION

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ABSTRACT

What is new?	Many methods exist to help explain the impact of research but little work has been undertaken to centrally involve the patient point of view. This paper discuss the need for patient involvement in impact assessment and a call for action going forward.
What was the approach?	The International School of Research Impact Assessment (ISRIA) recently issued a statement suggesting a basic

	structure for evaluation and stressing the importance of context and stakeholder engagement (Adam et al, 2018). Based on the principles outlined in the paper the authors considered possible structures to include patients within research impact assessment.
What is the scholarly impact?	Facilitated consultation and targeted patient-reported impact measures would give research evaluators a better understanding of impact from the patient perspective. For health and social care research the patient perspective is a key lens in ensuring relevance and accountability.
What is the wider impact?	Greater patient involvement and engagement with the impact assessment process may require adaptations to current cultural norms. It is accepted that impact is measured over time. Patient involvement in impact assessment needs to be facilitated with a similar mindset with the necessary underlying resource.
Keywords	Patient involvement, impact juries, PROMs

SYNOPSIS

All research funders wish to see meaningful impact of the work they fund. Methodologies have been produced over several years that help explain the impact of research over a broad range of professions (Greenhalgh et al, 2016). The most widely used technique to measure impact is the Payback Model (Buxton and Hanney, 1996), and the best-known approach within the UK is the Research Excellence Framework (REF), an exercise that judges universities across disciplines and which some other countries are looking to emulate (Morgan, 2014).

For health and related research impact in particular, we believe we need to be more guided by the patients for whom the research was undertaken. Patients have been involved in research prioritisation and peer review, and some health research funders look to coproduce their work with patients and patient groups (Kaye et al, 2012). It seems odd therefore that work defining the impact of research has not had the same level of patient input. We believe facilitated consultation and targeted patient-reported impact measures would give research evaluators a better understanding of impact from the patient perspective.

BACKGROUND

In this essay, we discuss the importance of incorporating the patient viewpoint into strategies and practices to identify and evaluate health research impacts and propose

two possible models for activities to engage the public in an ongoing dialogue in this contemporary and, at times, contested area.

Impact assessment itself is a process that can be undertaken during a research program or body of work's lifetime (formative) or undertaken after a body of work, research or funding has completed (summative). Funders will have their own particular impact 'lens' which will drive how they see impact and the methodologies they will use during any evaluation. Some funders will wish to take a retrospective approach and look back at how research may have had an effect in terms of a greater accountability. Some will look to learn lessons for purposes of advocacy or to ensure better allocation of funding in future rounds.

No matter what the impact lens, how to define the impact of research has been the focus of major debate between those responsible for allocating public funds to research, and the wider researcher community. For instance the forthcoming Research Excellence Framework (REF) 2021 assessment exercise has defined impact *as 'any effect on, change or benefit to the economy, society, culture, public policy or services, health, the environment or quality of life, beyond academia'* (UKRI, 2018). Although the definition mentions 'effects', the danger still remains that researchers describe impact in terms of activities more relevant to them, than the changes these activities are intended to bring about to the public. That is unsurprising as impact may take place years after the research, and at some distance from the institution(s) that undertook the research originally. If research on medical interventions takes 17 years (on average) to get into practice or to be adopted (Morris et al., 2011) it is understandable that the academic and funder community defaults to measurements that are common within a field.

To break this unconscious or institutional bias, a better question than *'how'* we define the impact of research might be *'who gets to define impact?'* The meaning and measurement of impact seems to be a closed-shop debate between those who fund and those who do research. There is work about evaluating the impact of research to justify it (rightly) to the donors or taxpayers that provide the money, but with less regard to perhaps the key stakeholder in health research: the patient. When funding bodies, such as the National Institute for Health Research (NIHR), link health research investment to both wealth creation (NIHR, 2018) and population outcomes it is possible that wealth creation becomes the default primary outcome as it is more straightforward to measure and easier to understand. Wealth creation, although important to justify investment in research, is unlikely to be many patients' primary goal.

It is assumed that a principle of any healthcare system is to put patients at the heart of everything it does. Over the past few years much excellent work has gone into involving patients with research. Within the UK groups such as INVOLVE and the James Lind Alliance have worked with researchers to engage with patients and patient groups over and above the 'traditional' patient representative model. Research prioritisation, funding

allocation and outcome review can all involve patients, but this needs to be more than just involvement in specific parts of the research pipeline. We argue that patients should be involved at a more systemic level in defining what impact means to them and how to assess such impact.

PATIENTS, PUBLIC AND RESEARCH IMPACT EVALUATION

There is a danger that whilst researchers and funders get together to work on a set of measurements and methodologies to identify and explain impact to each other, patients are being left out. We hope that research overall will lead to improvements for patients and the running of healthcare systems and we know that implementation of innovation into the NHS is not easy. A recent publication from the Health Foundation (Horton et al., 2018) stated '*the success of a complex intervention is likely to depend heavily on its context: the underlying systems, culture and circumstances of the environment in which it is implemented.*' Excellence in research is not enough, the context in terms of the health care system is key. As such how do we really measure the impact of research in terms of patient and public benefit, in a manner that is understandable by and acceptable to the patient cohorts themselves, a key part of that context?

The impact of health research is often described in a language of outputs and outcome (Morgan Jones et al, 2016), that may resonate with the patient cohort involved in the study itself, or those involved in health research more generally. Patients may be asked to judge the research itself or to comment on the results. However, do we engage with patients enough when undertaking research evaluations? Are we using them as data points rather than co-producing assessments?

Without including the patient voice in research impact assessment there is a danger we end up with evaluations that miss the broader context. An analogy can be seen within the world of health technology assessment (HTA). Within the UK, NICE undertakes detailed and respected reviews but very much from the view of cost-effectiveness of the healthcare system itself. However, there is a broader context which is not taken fully into account (if at all). In their review exploring how cost benefit analyses have moved away from a societal perspective to a more budget-based, 'payer' perspective, Johannesson and colleagues indicate not just how much chronic conditions cost wider society, but more importantly cost the patients themselves (Johannesson et al, 2009).

This essay is not here to argue whether such broader costs should be more fully recognised in clinical and cost effectiveness analyses by government bodies around the world. However, it would be a shame to replicate such an omission in the impact assessment of the research that is funded on our behalf. How can we ensure this does not happen? The most influential impact assessment frameworks within the UK 'flag' certain expectations and wants. The REF template implies that impact will be achieved by discrete pieces of research influencing policy, a *potentially* closed loop between funder

and fundee (although we note Research England's recent consultation on REF2021 (UKRI, 2019) has indicated a greater interest in measuring public engagement and the use of lay members in the assessment panel structure).

A WAY FORWARD

The authors believe the lack of meaningful work to include patients in the co-production of research assessment limits our ability to understand how research may or may not affect health and social care pathways. Without patient co-production of impact assessment, the 'closed loop' conversation will continue. This may be more problematic than people believe. In a recent paper reviewing models of research policy relations between government and the University sector, Boswell and Smith (2017) make it clear there are a number of potential disconnects between parties. As such, *'assessments aiming to trace the impact of research on particular policy outcomes are likely to miss a potentially broader, more diffuse kind of conceptual influence'*.

The time is right to ask for more consideration of the patient viewpoint. The International School of Research Impact Assessment (ISRIA) recently issued a statement suggesting a basic structure for evaluation and stressing the importance of context and stakeholder engagement (Adam et al, 2018). Now is the time to understand and include the patient, to engage and co-produce.

At the recent 25th Cochrane Colloquium two of the authors discussed and asked for views on two linked approaches in which patient-defining impact assessment may be possible. The first (Citizen´s Juries) would encourage and help patients define what they hoped research might achieve at the outset (at a 'macro', i.e. programme or funder, level) and create a set of patient-led indicators. The indicators could be used to monitor whether research, if adopted and implemented, had a noticeable effect on the patient cohort it was funded to help. The second model (Patient-Reported Impact Measures) would be based post-research at a 'meso' or 'micro' level to create a meaningful set of measures on the patient or public experience of defined changes within a known health or social care pathway. The second model may be influenced or defined by the patient-led indicators discussed previously.

CITIZENS' JURIES

Research benefits people in long-term, indirect and unpredictable ways (Guthrie et al, 2018), and we need to find ways of identifying impact which allow blue skies, curiosity-driven research to continue to flourish. A narrow focus on the short term or metric base may produce a shrivelled and pedestrian body of knowledge. For patients to be meaningfully involved in assessing the impact of research they may need to consider a number of contexts. Early stage or blue-sky research is needed and beneficial but is not designed for an easily measurable outcome, let alone impact. We need a model to help

patients and the public define impact indicators that are predictive by nature. We would need to use techniques that help gain input from the appropriate microcosm of the correct population cohort that ultimately any early stage research would be addressing.

The use of our first proposed model, Citizens' Juries, may be applicable here. A recent review by Jackie Street and colleagues discussed their use within health policy formulation (Street at al, 2014), and the Northern Health Science Alliance (NHSA) used this model to ensure that its Connected Health Cities program would be an acceptable vehicle for patient data (Connected Health Cities 2017). More recently, the Irish Government received recommendations on abortion from such a jury (Wise 2017).

Citizens' Juries may make an excellent forum to analyse whole programmes or funding streams from the patient perspective. Our discussion at the Cochrane mirrored some of the issues raised by Irvin and Stansbury in 2014, including cost and the time commitment needed by participants. However, it is interesting to note that Juries have been run online (albeit outside the healthcare arena) (Romanach et al, 2013). It is also important to ensure appropriate representation to avoid any jury being *'heavily influenced by special interest groups'* as Irvin described. An interesting suggestion was that crowdsourcing could be used to help identify participants and we will be investigating all online techniques over the coming months.

Our colleagues at the Colloquium made a comparison between the proposed use of Citizens' Jurys to that of the general legal system. How do we identify appropriate 'judges' and what is the underpinning 'legal system' (the impact laws/frameworks/precedents) that they will interpret for the jurors? Legal systems have established themselves over time whereas the 'impact system' is nascent. We would need to ensure that our use of frameworks was curated transparently, with results reported openly and accessibly, to establish precedents over time.

Patient-Reported Impact Measures

There are methodologies and tools used in HTA that could help identify or explain the impact of research from a patient viewpoint. Patient-reported outcome measures (PROMs) are commonly used within clinical trials as a tool to measure the cost effectiveness of a treatment from the patient perspective. They are also used in institutional settings where assessment considerations are addressed across a broader 'ecosystem'.

PROMs are designed on the basis of close discussion with patients about their own concerns for particular conditions and are increasingly being used in routine clinical practice to check if treatment improves aspects of health, mobility and socialisation. Lehman and Skrybant (2018) state that patient reported outcomes are *'vital and flexible*

tools for designing clinical care to suit the needs and priorities of individual patients'. Can we use PROMs to produce a more collective Patient-Reported Impact Measure (PRIM)?

Such techniques have been extended to evaluate patients' experiences and assessment of the quality of care they have received (patient-reported experience measures, PREMs) (Male et al, 2017). Recently, work has been undertaken to combine patient-reported outcomes with clinical performance measures to produce patient-reported outcome performance measures (PRO-PM) (Basch et al, 2014). The authors believe it should be possible to collect data that allows the construction of a condition- or pathway-specific PRIM. This would allow the ability to broadly measure the actual impact of research on a patient cohort, perhaps building on what a Citizens' Jury believed the impact might be.

There are some concerns. We do need to try and develop a level of objectivity, and to quote a colloquium participant we need to *'Ask patients what they care about and try to measure that, not what fits your idea'* (Francis Ak'enamé, Twitter 2018). For PRIMs to be and remain meaningful we need agility to test models with patients and adapt within the system as we go and not to predetermine the model and outcome. The Jury model therefore interlinks with PRIMs. Strategically, a feedback loop is necessary.

SUMMARY

To be clear, this is not research prioritisation or patients on another committee but a patient- and practitioner-led exploration of impact, explicitly setting out to include the patient voice. What should not have to be debated is the need to include patients in considerations of what impact means, or processes around its assessment – not just as passengers, but as pilots. Otherwise, who are we doing this research for?

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BIOGRAPHY

Mark Taylor is currently Head of Impact for the Central Commissioning Facility of the National Institute for Health Research. His work at the moment includes looking at ways to incorporate the patient experience into the evaluation of clinical and health research impact. Before that he has worked, amongst other places, for Oxford University Hospitals NHS Trust, the NHS Institute for Innovation and Improvement and Oxford University Innovation (the University's knowledge transfer arm). He has been a trustee for three health-related charities including the MS Society and was diagnosed with relapsing remitting multiple sclerosis in 2003.

Paula Adam is Director of Research at the Agency for Health Quality and Assessment of Catalonia (AQuAS). In the past she co-founded the International School on Research Impact Assessment (ISRIA) and worked as economist at the OECD. Her fields of expertise are: research impact assessment, mission-oriented research, gender equality and female leadership in science and patient and public engagement in research.

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Adam Kamenetzky is a Senior Research Fellow at the National Institute for Health Research (NIHR), the UK's largest public funder of health and social care research. His work explores how public investment in research generates long-term societal impact and value, and how evaluation can inform NIHR's own policies and working practices, acting as a custodian of taxpayers' investments in research. In parallel Adam is a visiting fellow at the Policy Institute at King's College London, with a particular research interest in improving the social value and accountability of science to wider society. Adam has an MSc in Science Communication from Imperial College London and a BSc in Developmental Biology from the University of Edinburgh. He is currently in the early stages of a practice-oriented PhD focussing on organisational approaches to research impact and its assessment.

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