Creating change that counts: Evidence-led co-creation as a pathway to impact

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“impactful... a non-existent word coined... to make... work sound more useful, exciting and beneficial to humanity than it really is.”
Urban Dictionary
(http://www.urbandictionary.com/define.php?term=impactful)

In the UK, many applications for research funding require an explanation of how the proposed research will produce “impact” in a “pathways to impact statement”. Moreover, in a forthcoming competition for UK government funding and recognition, “impact case studies” will account for 20% of annual funding allocated to universities. What is meant by “impact”? UK research funding councils distinguish between “academic impact” such as increased understanding, improved methods, and application of theory, and “economic and societal impacts” such as enhanced effectiveness of public policy and services, and increased health and quality of life. While academic impact, indexed, for example, by citation indices is undoubtedly important to scientific progress, we will focus on economic and societal impact. Allocation of research funding based partly on impact assessments prompts a variety of responses. Researchers who believe their work reveals fundamental causal process regulating natural, intrapersonal, interpersonal or societal process but cannot specify policy, products or services that a better understanding of such processes may generate, may feel undervalued. Applied researchers may welcome the opportunity to emphasise how their findings could revolutionise policy and service provision but may also be disappointed if they fail to persuade others of the impact potential of their work. Applied researchers may also be disappointed if impact assessments are, in practice, less important to funding decisions than they hope. These responses may result in dissonant, cynical or overstated approaches to describing pathways to impact, such as “promise world peace within the funding period!” Here we will argue that best practice in understanding mechanism and in developing and evaluating interventions also optimises pathways to impact. We will focus on the application of behavioural science to health problems and, in particular the design and evaluation of behaviour change interventions. We will illustrate this argument by reference to ongoing research. Considerable effort has been devoted to the measurement of impact and the development of assessment procedures that allow replicable comparisons and weighting of research impact and potential impact. For example, Project DESCRIBE involving the Exeter and Brunel universities is designed to review and assess of current standards relating to the evidence of research impact and will make recommendations on best practice across academic disciplines (http://www.exeter.ac.uk/research/rkt/refandimpact/describeproject/). We will not focus on methods of assessing potential research impact but on research design pathways by which impact can be optimised. We will assume that it is possible to assess the likely impact of planned research on, for example, enhanced effectiveness of public policy and services and increased health and quality of life.
Planning pathways to impact during the research design process is not equivalent to promising or guaranteeing impact because well-designed research may reveal that a particular approach to understanding the world should be abandoned. For example, a trial may show that an intervention should not be implemented. The challenge is to assess whether proposed research could have economic and societal impact and describe how that would unfold. This does not, necessarily prejudice research selection in favour of applied research. Mendeleev’s construction of the periodic table in 1869 is an archetypical example of fundamental research but it is easy to imagine how one could make a case that identifying the basic elements of which matter is constructed and their irreducible properties was likely to generate impact; not just academic impact, but economic and societal impact in terms of increased capacity to create pure and novel products consisting of single elements or compounds with known properties.

Intervention mapping (Bartholomew et al., 2011), Re-AIM (Glasgow et al., 2002), and the UK Medical Research Council’s Guidance on development and evaluation of complex interventions (Craig et al., 2008) provide influential frameworks within which to develop and evaluate health promotion research. Combining these with models used to understand innovation management, adoption and diffusion (e.g., Abraham & Hayward, 1985; Bessant & Maher, 2009) suggests a series of research design principles which may simultaneously optimise research reliability, validity and impact. These could include the following: Research design should...

(1) start with a problem-solving approach to empirically-verified health needs, (2) be based on known regulatory mechanisms and/or change processes or be designed to elucidate these mechanisms and processes, (3) involve potential users or adopters in the development of research outputs, including interventions, (4) understand the reasons why adopters would select and employ products, including interventions, and “design-in” identified usability features, (5) assemble a team of experts with an adequate range of expertise, (6) develop products and interventions that can readily be implemented in everyday work/leisure environments and are sustainable over time within available resources, (7) integrate methodologically robust evaluations assessing outcomes of importance to users, (8) consider a range of potentially positive and negative outcomes taking account of social context, (9) include process evaluations which characterise how interventions are used in practice and which processes lead to any change in outcomes, (10) include time for pilot/implementation/feasibility data collection and re-design on the basis of findings, (11) develop detailed implementation manuals to ensure fidelity of replication.

The UK House of Lords (2011) report on behaviour change focused on government policy but many of the report’s recommendations on evaluation apply to behaviour change intervention design. As in Intervention Mapping, the report emphasised that evaluation should be considered at the beginning of the policy design process, that pilot work should be undertaken and that external evaluation expertise should be sought, where necessary. While this advice relating to principles 6-8 above may appear obvious to researchers it is not always implemented when research proposals are developed.

In the UK the National Institute for Health Research (NIHR) has established “Collaborations for Leadership in Applied Health Research and Care” (CLAHRCs). These are partnerships between universities and the surrounding National Health Service organisations. They are designed to undertake research focused on the needs of
patients and support the translation of research evidence into practice in the National Health Service (NHS). PenCLAHRC is a partnership between the NHS throughout Devon and Cornwall and the Universities of Exeter and Plymouth in the south west of England. Implementation of many of the research design principles listed above can be observed in PenCLAHRC research projects, in part because of the collaborative and multidisciplinary nature of the organisation.

**Research question generation**

PenCLAHRC has a mechanism for generating research questions from patients and professionals rather than from researchers. These questions inherently address real-world health problems but must be assessed in relation to what is already known about underlying processes and potential solutions. Not all real world problems warrant further research but when they do that research is likely to have impact.

**Outcomes**

Evaluating interventions in terms of outcomes that make a difference to funders, adopters and users is important to future impact. So measures of health, functional abilities, behaviour and economic evaluations are all important. While apparently obvious, this is not always evident in the design of psychological research. For example, when reflecting on the American Psychological Society’s “Decade of Behavior”, Baumeister, Voils and Funder (2007), noted, worryingly, that:

“although self-reports, reaction times, implicit associations, and the like are good methods, we believe that psychology has tilted towards examining precisely those topics for which these methods are appropriate and away from everything else” (p.401).

If accurate, this does not augur well for the future impact of psychological research. Self-reports, reaction times and implicit associations are unlikely to convince commissioners to adopt products or interventions. To optimise impact, including adoption and diffusion of interventions, researchers must employ outcomes of value to commissioners, adopters and users.

**Measurement and intervention design**

This means that interventions, implementation procedures and evaluative tools often need to be developed and tested to correspond to the parameters of the problem—not just applied on the basis of previous reports. Paradigmatic, manualised science is important to developing reliable, replicable methods. However, when pressure on time and resources leads scientists to concentrate on cloning established measures and procedures, creative advances may be suppressed and impact limited.

**Research teams**

PenCLAHRC has a unit devoted to generating patient and public involvement in research design which recruits patients, carers and others to research design teams. PenCLAHRC teams also combine diverse groups of experts who co-create research in large group meetings. These may include clinicians, public health professionals, teachers, parents, psychologists, health economists, specialists in physical activity and dietary measurement, statisticians and trial management experts. This ensures a range of perspectives on problem solving which facilitates scrutiny of ideas and creative reworking of previous approaches. It also makes it less likely that research planning will neglect practical pitfalls or previous research. Such teams involve intervention adopters, such as professionals who know what will work in practice and what can be sustained given available resources. This makes it much more likely that, if an intervention is effective and cost effective, it will be adopted
and embedded in health services.

**Research team management**

Management of multidisciplinary research groups involving users, practitioners and commissioners requires particular expertise and social skills. There is potential for the development of ingroup-outgroup oppositions (e.g., between disciplines) and for political infighting over resources. Meticulous inclusiveness, open accountability of decision-making, mutual respect of diverse and differing expertise, valuing of others’ perspectives and of disagreement, recognition of differing needs and a dedication to fairness are important.

Three ongoing projects within PenCLAHRC illustrate this approach to problem-solving, service-relevant project development and design, namely, ReTrain, REACH-HF and HeLP.

**ReTrain.** “Action for Rehabilitation following Neurological Injury” (ARNI) was devised by a stroke survivor (Balchin, 2011) whose 487 page text describes this complex recovery programme. Six UK regions are funding ARNI-based programmes and preliminary evaluations indicate that the programme may be beneficial. For example, local audit data relating to 12 participants indicates NHS and social care resource savings of £5252 and a reduction in ambulance call outs saving of £7,200. A PenCLAHRC project, based on ARNI, generated ReTrain, a 12 week novel physical rehabilitation programme for stroke survivors who have completed NHS post-stroke rehabilitation. The programme was developed through an Intervention Mapping analysis of ARNI combined with video analysis fidelity-checking procedures to ensure replicability and sustainability of the intervention. ReTrain will incorporate 8 essential elements of ARNI and adheres to recommendations provided by a series of international guides to stroke rehabilitation. A bid to fund a multi-centre randomised controlled trial comparing Retrain plus usual care to usual care alone (which generally consists of nothing) for post-rehabilitation stroke survivors is under review. The planned intention to treat analysis will assess a primary objective outcome of Brunel Balance Assessment immediately following intervention and 9 months later. A variety of other moderators and mediators will be assessed. The process evaluation will relate attitudes to exercise, exercise motivation, self-efficacy, goal setting, intervention engagement and recovery optimism as well as secondary outcomes (including adherence).

**REACH-HF.** Heart failure (HF) is becoming more prevalent worldwide. Yet patients with heart failure as a primary diagnosis are excluded from most cardiac rehabilitation programmes in England, Wales and Northern Ireland (Dalal et al., 2012). A lack of resources and exclusion from local commissioning agreements are the main barriers to providing rehabilitation for patients with heart failure. The NIHR-funded Rehabilitation Enablement in Chronic Heart Failure (REACH-HF) programme is designed to improve UK HF rehabilitation services. The planned programme of work includes use of Intervention Mapping to develop an evidence-informed, home-based, self-help cardiac rehabilitation programme for people with heart failure and their caregivers. It builds on a qualitative meta-ethnography of key studies about self-management, which identified five stages through which patients progress in developing their own self-management strategies (Wingham et al., under review). These stages include disruption and sense-making followed by becoming a strategic avoider, a selective denier, a well intentioned manager, or an advanced self manager. Only later will they integrate self management into everyday life to maximise feelings of safety. This analysis highlights how intervention design needs to correspond to
patients’ complex, evolving representations of their illness. The REACH-HF manual will be developed in conjunction with patient and health professional stakeholder groups and the Heart Manual team who developed an effective manual for post-MI rehabilitation. The manual will incorporate a mechanism-based behaviour change model and relevant change techniques (Abraham, 2012). After conducting a feasibility trial, the effectiveness and cost effectiveness of the REACH-HF manual will be assessed in a randomised controlled trial comparing usual care to usual care and manual use. If effective, intervention has the potential to improve quality of life for systolic HF patients and their caregivers and reduce hospital admissions and caregiver stress. Moreover, it is hoped that evidence of effectiveness and cost effectiveness may lead to implementation on a national basis.

**HeLP.** One third of girls and boys aged 11-15 in the UK are either overweight or obese. Being overweight in childhood is associated with metabolic abnormalities, increased risk of Type II diabetes and musculo-skeletal and psychological problems and it has been predicted that by 2050 overweight and obesity prevalence will cost the UK £50 billion a year. There has been little success in reducing overweight and obesity prevalence in schools but a pilot study of a novel school-based Healthy Lifestyle Programme (HeLP) showed that after 2 years the proportion of overweight and obese children was 33% in the non-intervention, control schools compared to 22% in the intervention schools (Wyatt et al., 2011). HeLP is a multi-component school programme focusing on a healthy lifestyle message including maintenance of an energy balance. It is delivered across 4 school terms to 9-10 year old children and has been designed to change the whole-school environment. HeLP was developed using Intervention Mapping and the Information Motivation and Behavioural Skills model (Fisher & Fisher, 1992) to guide the choice of incorporated behaviour change techniques (Abraham & Michie, 2009; Abraham, 2012). HeLP was developed with teachers, parents, children, public health practitioners and clinicians to ensure that the intervention is feasible and acceptable for schools, children and their families. Three lifestyle changes are highlighted, namely, decreasing consumption of sweetened fizzy drinks, increasing the ratio of healthy to unhealthy snacks and a reduction in screen-based activities. HeLP also aims to nurture home and school environments supportive of healthy choices. The programme includes an innovative drama component built around four characters (Active Amy, Snacky Sam, Football Freddie and Disorganised Duncan). These are played by young actors, with whom the children can easily identify. During drama workshops children co-create scenes with the actors and provide their own ideas and solutions to problems faced by the characters. This drama-based delivery is engaging and allows individual message tailoring. Parents are invited into schools to work-in-progress workshops in which their children act out a range of scenarios. Manuals for delivery of the intervention and the training of those delivering it have been written. A NIHR-funded cluster randomised control trial is underway to assess the effectiveness of HeLP by comparing intervention and control schools on a range of anthropometric and behavioural measures. This trial will also assess cost and cost-effectiveness. A mixed-methods, process evaluation together with mediational analyses will elucidate change mechanisms including psychological change.

We conclude that funding research on the basis of impact potential should be welcomed by health psychologists who want to create change that counts. This emphasis can highlight health psychologists’ research methods and intervention design skills which can be applied to embed evaluations which focus on health outcomes,
quality of life and behaviour change as well as process evaluations which clarify mechanism underpinning change. Health psychologists and the professionals and patients they work with could benefit from increased weighting of impact assessment in research funding decision making. We recommend that other research funding bodies adopt and extend UK research councils’ emphasis on impact.

References


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