

order: participants, materials, procedures, setting and intervention).

Conclusions This rehabilitation case-study shows problems of clinical replicability of RCTs on complex interventions and suggests the need to better define some clinical items not described by classical methodological checklists like CONSORT.

5 CONTINUOUS OUTCOME MEASURES – CONUNDRUMS AND CONVERSIONS CONTRIBUTING TO CLINICAL APPLICATION OBJECTIVES

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Objectives To discuss how continuous outcome measures are commonly used to measure patient-relevant outcomes, the obstacles in employing these measures clinically, and methods available to facilitate use of bodies of evidence comprised of continuous outcomes.

Method Many patient-relevant outcomes, particularly quality of life measures such as pain or function, are routinely measured on a continuous scale. However, the interpretation of continuous outcomes can be difficult, particularly when considering application to clinical practice and shared decision-making. Making matters worse is the frequent existence of multiple scales for any given construct. Therefore, quantitative syntheses of literature must find a way to combine different scales into a ‘common language’, and the longest-standing and most frequently used method to do so is the standardized mean difference. Unfortunately, the standardized mean difference is even more difficult to interpret clinically. However, there are validated methods to make these measures easier to understand and apply clinically. This presentation explores these issues and offers a resource to help make these continuous measures more clinically useful.

Results Different methods to amplify the clinical use of continuous outcome measures have been discussed for at least three decades now, some better known than others. These methods seek to estimate the proportion of patients expected to achieve a specified degree of benefit or harm based on the observed continuous outcome. Exploring the strengths, limitations, and judicious use of these methods facilitates a greater understanding of how continuous outcomes data might be usable for clinical and shared decision-making. Of the methods that have been validated for this purpose, approximated and observed estimates of the proportion of people who achieved a specified degree of change in the continuous outcome measure have shown considerable consistency.

Conclusions Although not necessarily a panacea, methods facilitating conversion of continuous outcomes data to proportions of people expected to achieve a specified degree of benefit adds considerably to our ability to make sense and clinical use of continuous outcome measures. As such, when these

methods are used appropriately, they add substantially to our evidence-based medicine and shared decision-making ‘toolkit’.

6 VACCINE INJURY REDRESS PROGRAMMES: A SYSTEMATIC INTEGRATIVE REVIEW

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Objectives This review investigated the design features of vaccine injury redress programmes that are thought to impact on the operating costs, timely access to compensation, number of applicants, and the volume and costs of awards. In addition, we ascertained if such programmes enjoy public acceptance. Vaccine injury redress programmes are available in 20 jurisdictions; only 11 jurisdictions have completed detailed papers on their set up and operation, namely, China, Denmark, Finland, Japan, Korea, Norway, New Zealand, Sweden, Taiwan, UK, and USA.

Method We chose the Integrative Review approach to synthesise an array of theoretical and empirical data to answer our questions. We searched in MEDLINE, CINAHL, Scopus, Web of Science, Cochrane Library, HeinOnline and LegalTrac. We identified 2,838 papers and selected 33 papers that provided relevant data to answer at least one of our questions. We developed a conceptual schema based on key design features of vaccine injury redress programmes to code and extract data. The design features identified were: approach, administrator, funding source, vaccines covered, injuries covered, claims and decisionmaking process, standard of proof, litigation rights, costs awarded, and cost controls. We analysed the data using the constant comparative method as none of the papers included in our review asked either the same or similar questions to ours.

Results The treatment injury compensation scheme in New Zealand and the drug injury scheme in the four Nordic countries have improved access to compensation by removing the concept of negligence and lowering the standard of proof required. Removing negligence has also reduced administrative and legal costs in the five countries. Public awareness of and support for the scheme is high in New Zealand and it has buy-in from physicians. The schemes in these five countries are aligned to national employment insurance schemes and publicly funded health care.

The USA, UK and four countries in Asia operate standalone vaccine injury redress programmes. The USA, UK and China employs a strict standard of proof which reduces timely access to redress and keeps the approval rate for claims low. Korea and Taiwan operate a more relaxed standard of proof, and Taiwan resolves claims in a timely fashion. In Japan, higher compensation is awarded to claimants judged to have protected ‘the herd immunity’.

Conclusions Vaccine injury compensation is implemented to protect the supply of vaccines and improve vaccine confidence to encourage high vaccination rates among the general population. A secondary objective is to provide timely access to compensation in the event of injury from a vaccine. Schemes that have removed the need to prove negligence and apply a low standard of proof provide timely access to compensation; these schemes also reduce administrative, legal and overhead costs and improves relations between claimants and the medical profession. Schemes that apply a higher standard of proof and enact a cumbersome claim handling and adjudication process delay timely access to compensation and reduce the number of awards. Schemes vary in the level of public awareness and support that they enjoy.

7 SHOULD THE GOVERNMENTS FUND ASSISTED REPRODUCTIVE TECHNOLOGIES?

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Objectives Access to assisted reproductive technologies (ART) for those seeking treatment is dependent on their ability to afford such treatments. A combination of out-of-pocket payment, public funding and the availability of health insurance determines the uptake of ART services in most countries. The variation between countries ranges from public funding with some limitations and/or small out-of-pocket payments (Australia, Belgium, France, Slovakia, Slovenia, Spain and Israel) to no funding of any kind (Malta, Switzerland and the USA).

In Ireland, such technologies have not yet been subject to government regulation or funding. The Irish Government requested the Health Research Board to investigate the costs and benefits associated with the public funding of ART for the funder, provider, and service user.

Method The methods employed to undertake this work followed the principles of a systematic review, including searching, screening, applying inclusion/exclusion criteria, data extraction, quality appraisal, and synthesis.

Results A benefit to public funding for ART in the literature reviewed includes improving access to treatment by reducing out-of-pocket payments.

Clinical benefits can also reduce the pressure on public spending. In some countries, public funding is contingent on patients and clinicians agreeing to restrict the number of embryos transferred in one cycle: single embryo transfer (SET). Where SET has occurred, there has been a significant reduction in multiple pregnancies without causing a decrease in cumulative pregnancy rates, as well savings to the public health system.

The literature outlines inferred benefits to wider society when public funding for ART is approved. In some countries, ART is seen as a social investment towards arresting the declining fertility rate, and overall future revenue receipts. Research indicates for women aged over 40 years, live births are substantially less likely following ART treatments and the financial cost of achieving a live birth is substantially more.

Conclusions Every country has a different approach to ART and the likely funding mechanism may emerge through trial and error. State funding with regulation can provide a cost-

effective solution for patients who are subfertile and for wider society.

8 AN INTERNATIONAL NETWORK FOR EVIDENCE-BASED RESEARCH: INTRODUCING THE EVBRES INITIATIVE

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Objectives Research on research has shown that many redundant studies would have been avoided if a systematic review has been conducted prior to starting the new study. These apparently wasteful studies limit funding available for truly important and relevant research, diminish the public’s trust in research, and are unethical. Researchers planning a new study should therefore systematically review existing evidence in order to effectively justify the need for the study. Researchers should also interpret the results and evaluate what the new study adds by systemically analysing existing evidence (i.e. putting new research into context). Unfortunately, researchers fail to systematically review the current evidence when planning a new study and interpreting results.

Method The Evidence-Based Research Network (EBR network: ebrnetwork.org) was created in 2014 to promote evidence-based research - the use of prior research in a systematic and transparent way to inform a new study so that it answers the questions that matter in a valid, efficient and accessible manner. In April 2018, the Evidence-Based Research Network obtained funding from the European Cooperation in Science and Technology (COST) to create the Evidence-Based REsearch (EVBRES). COST is an organization that provides funding for researchers to create a network (called COST Action) that organizes meetings (e.g. workshops, conferences), support short term scientific visits, develop training schools, and carry out dissemination activities. EVBRES (evbres.eu), COST Action Network (CA-17117), is establishing an international network to encourage researchers and other stakeholders such as patients, ethics committee members, funders, and journal editors to use an EBR approach when conducting or supporting research.

Results EVBRES officially commenced in October 2018 with participations from researchers in more than 35 European COST Action member countries, in addition, more than 10 international partner countries were also involved. We held the first EVBRES workshop at Bergen, Norway in February 2019 and organized four working groups to carry out the mission of EVBRES. Working Group 1 will describe key stakeholders’ role, such as ethic committees, funding agencies, journals and patient groups, in solidifying the evidence-based research approach. Working Group 2 will develop and organize activities aimed at educating researchers on how to systematically incorporate existing evidence when preparing new