PATIENT-FRIENDLY DISSEMINATION GUIDELINES FOR SCIENCE

APPLICABLE TO PRESS RELEASES, OTHER ARTICLES FOR THE PUBLIC AND ABSTRACTS

INTRODUCTION

Many factors may bias researchers reporting research into negatively valued behaviours, psychiatric disorders and their genetic associations, including assumptions about the nature of a disorder in medicine, publishing pressures and the even the desire to help, for example, because of the believe that biogenetic explanations are helpful to parent and patient.

We ask researchers to be aware of sources of bias, to be accurate, clear and aware of the most effective ways to communicate with the public and of possible sources of misunderstanding.

The guidelines are based partly on ADHD-Europe's own experience of harms from research. For example, failure to comment on the representativeness of subjects with ADHD of people meeting current criteria for ADHD in the general population and controls of meeting the population without ADHD can affect not only stigma, but also insurance costs, and driving license restrictions. It can also be a poor guide for theory, treatment, and healthcare funding.

The guidelines are also based on literature on clear communication of clinical trials to the public, although it is possible that the methods recommended may not apply to mental and behavioural research in the same way. We took into account literature, which shows the effects of biogenetic understanding vs. psychosocial understanding on stigma are rather complex, and pass on some advice from the early behavioural geneticists on disseminating research on genetic differences between populations.

THE GUIDELINES

Considerations

Ask yourself the following questions:

- What is the purpose of the publicity material?
- Who is it aimed at: clinicians/general public/ funders/scientists?
- What information is most important to them?

Accuracy

A) Make inferences with caution, and avoid spin.

B) Discuss study limitations, confounders, contrary results, and caveats. Keep caveats with the message they qualify, i.e. don't put the message at the beginning and the caveat at the end of the press release.

Ci) Report exact diagnosis (e.g. ADHD-I, HKD). Comment on subjects' representativeness of people meeting current diagnostic criteria in the general population (DSM–5 for ADHD and ICD 10 for HKD): include factors comorbidities that may contribute to the result, recruitment method (consider that low rates of diagnosis are likely to favour inclusion of people with relatively severe symptoms and more disruptive behaviours).

Cii) Comment on 'healthy' controls' representativeness of the whole population not meeting symptom criteria for the disorder. Were they required not to meet diagnostic threshold or a lower symptom threshold (i.e. are they a super control group)? Were additional exclusion criteria applied to the control but not the patient group?

Ciii) If subjects with a genetic variant or disorder are selected by outcome (e.g. people with ADHD in prison, people with a variant in gene X and aggressive behaviour) consider stating that negative outcome does not apply to most / all of selected population (if true!).

Civ) In the press-release of a study, in which a disorder is not directly studied, consider if linking a disorder to a negatively valued behaviour directly or indirectly (e.g. via a gene association in a prior study) is necessary to your message, especially if the 'link' is of small effect or ambiguous.

Clarity

A) Explain risk clearly, by providing:

A numerical measure/s of the group difference that conveys the absolute risk (e.g. relative risk together with a baseline) to aid understanding of the magnitude of the group effect. (prefer relative risk to hazard ratios / odds ratios).

Alternatively, you could explain absolute risk using **natural frequencies** (e.g. 2 in a 100) - especially useful for big increases in very small risks. For example*, Men with genetic variant X were 3 times more likely to be imprisoned for repeated serious violent offences: However, these offenders are rare: just one in 500,000 men without genetic variant X and 3 in 500,000 with the genetic variant were imprisoned for repeated serious violent offences.* Or: *A 20% rise in violent media use in adolescents with genetic variant X may sound alarming, but it actually means that, on average, one more adolescent out of a hundred with the genetic variant compared to adolescents without the variant will use violent media on 4 or more days per week.*

Prefer small numerators and denominators when using natural frequencies. Large numbers heighten risk perception, for example, 4,000 in 100,000 is perceived as more alarming than 4 in 100.

Compare like with like, avoid e.g. mismatched framing: reporting benefits of a treatment as relative risks (big numbers) and harms as absolute risks (small numbers). About a third of articles in BMJ, JAMA and The Lancet were found to use mismatched framing (Sedrakyan & Shih, 2007))

B) Explain how present results fit with prior research or if an initial finding: in the latter case, please caution the audience that results must be confirmed by subsequent independent investigation.

C) If an animal study: explain relevance for humans and the need for confirmation in humans.

D) Does the research have immediate or potential clinical applications? Reporters will push for the practical importance of study, tend to over-generalise the importance and make it more immediate: '*treatment someday*' might become '*treatment soon*' in the words of reporters. See Condit's suggestions to use colourful metaphors for conveying time to treatment : '*This is one baby step on the long journey toward the cure for X*' OR '*One tiny piece in the giant jigsaw puzzle that might someday enable prevention or treatment of Y*'.

E) Anticipate how wording may be misinterpreted by reporters public, and scientist. Avoid loaded words (e.g. breakthrough) and causally ambiguous phrases ('linked to'), avoid or explain words that are morally loaded in common usage, e.g. 'egocentric' (scientific use in context of eye movements) and 'dark matter' (missing heritability). Avoid word strings that may amplify negative valence, for example *'aggressive incidents fell drastically*' or '*causes of aggression lurking in dark matter of DNA*'.

Avoiding stigmatisation when reporting genetic and imaging results

Increased biogenetic understanding of mental illness has more complex effects on stigma than previously thought. On the positive side, this increased understanding tends to reduce self and other blame, however, tends to increase other types of mental health stigma (perception of dangerousness, desire for distance) because of an impression of pervasive, persistent difference and hence lack of treatability and dehumanisation (for a meta-analysis see (Kvaale, Gottdiener, & & Haslam, 2013). Recent work suggests this extends to professionals (psychiatrists, sociologists and social workers) (Lebowitz & Ahn, 2014).

A) Avoid giving the impression that differences are greater and/or more persistent than justified by research.

B) Acknowledge the overlap of findings with the healthy population in e.g. imaging results.

C) Frame behavioural genetics findings in the complexity of gene-environmental interactions, e.g. contribution of SES (also important not to reduce apparent effectiveness of social interventions), and/or the role of plasticity.

D) A short anecdote or quote may bring subjects to life counteracting dehumanisation.

Lastly, the arguments employed by early behavioural geneticists to distance the field from racial eugenics may be useful to reduce deterministic interpretations:

Dobzhansky:

i) Different population groups do not have different genes or alleles, but different frequencies of the same genes and alleles.

ii) Genetic diversity in the population is important as a means to adapt to unforeseeable changes of the environment.

Jerry Hirsch:

i) The incredible variability of the genome and the many mechanisms for producing variation makes each individual genetically unique: radicalising concept of individuality and questioning concept of normal individual.

ii) Some average measure of environmental influence applicable only to those genotypes affected in the same way. Thus a rank-ordering of phenotypes may apply only in certain environments.

Other Resources:

The science media centre has a range of pamphlets including working with the media and explaining uncertainty, risk, peer review, animal research etc. to the public: http://www.sciencemediacentre.org/publications/publications-for-scientists/

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