

a slogan — ‘Don’t mess with Texas’ — that made littering an insult to the honour of every proud Texan, at which point littering decreased by 72% (ref. 8). Hotels wasted significant amounts of energy washing barely-used towels until 2008, when researchers placed signs in hotel rooms that either asked guests to “help save the environment by reusing your towels” or told guests that “75% of the guests who stayed in this room participated in our new resource savings program by using their towels more than once”<sup>9</sup>. The second sign suggested that laundering a barely-used towel was a violation of a moral rule that most people obeyed, and that sign increased towel reuse by 33%. Psychologists and economists have found dozens of ways to make problems easier to think about and harder to ignore. There is no shortage of solutions, just of the will to implement them.

The other way to deal with the mismatch between the threats we face and the way we think is to change the way we think. People are capable of thinking rationally about odds and consequences, and it isn’t hard to teach them. Research shows that a simple five-minute lesson dramatically improves people’s decision-making in new domains a month later<sup>10</sup>, and yet that is five minutes more than most people ever get. We teach high-school students how to read Chaucer and do trigonometry, but not how to think rationally about the problems that could extinguish their species.

Psychologists have made remarkable progress in understanding how decision-making goes wrong and how it can be set right, and although their research generates bestselling books and garners Nobel Prizes, funding agencies typically give it low priority. Our communal fate rests on decisions that could easily be improved, if only we would decide to do so. It is our way of thinking, and not the undertaker, that threatens to bury us prematurely. ■

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# Democratizing clinical research

**Keith Lloyd and Jo White** commend a way for patients, clinicians and scientists to set priorities jointly.

**R**esearch priorities are rarely set democratically. Whereas clinical science is largely about establishing which treatments work best for whom, sadly, the views of those with most to gain or lose — patients — are generally ignored. Academics, industry and other big players with vital roles in developing treatments tend to set the agenda. But their priorities differ from those of patients and clinicians. For example, the outcomes measured in a trial of a drug may not be those of interest to the people who will actually take it.

The inclusion of patient demands is not a panacea. It can divert scarce research resources and delay important treatments<sup>1</sup>. One solution is to try to harmonize the perspectives of patient and clinician. This is what the James Lind Alliance (JLA) Priority Setting Partnerships in Oxford, UK, attempt, perhaps uniquely. Established in 2004 and funded by the UK Medical Research Council and National Institute for Health Research (NIHR), the JLA

brings together patients, carers and clinicians to identify and rank questions about the effects of treatments for a given disease. Clinicians and academics — who may never meet patients — find long-held beliefs challenged and sometimes overturned.

The JLA process has recently been applied to schizophrenia — a mental illness affecting about one person in a hundred worldwide. We were involved in this exercise as clinical academics. This, plus our experience as recipients of grants and from within funding bodies, convinces us that money rarely goes to the studies that those with mental illness would choose. We therefore urge funders to adopt this list of top priorities for schizophrenia (see ‘Top ten treatment uncertainties’), and entreat other countries and organizations to use the technique involved in compiling it to steer other clinical research.

Between 2007 and 2009, we and other collaborators from the JLA Partnership collated 489 potential uncertainties about

## SCHIZOPHRENIA RESEARCH PRIORITIES

### Top ten treatment uncertainties

1. What is the best way to treat people with schizophrenia that is unresponsive to treatment?
2. What training is needed to recognize the early signs of recurrence?
3. Should there be compulsory community outpatient treatment for people with severe mental disorders?
4. How can sexual dysfunction due to antipsychotic-drug therapy be managed?
5. What are the benefits of supported employment for people with schizophrenia in terms of quality of life, self esteem, long-term employment prospects and illness outcomes?
6. Do the adverse effects of antipsychotic drugs outweigh the benefits?
7. What are the benefits of hospital treatment compared with home care for psychotic episodes?
8. What are the clinical benefits and cost-effectiveness of monitoring the physical health of people with schizophrenia?
9. What are the clinical, social and economic outcomes — including quality of life and the methods and effects of risk monitoring — of treatment by acute day hospitals, assertive outreach teams, in-patient units, and crisis resolution and home treatment teams?
10. What interventions could reduce weight gain in schizophrenia?

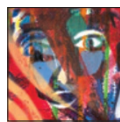
Some treatment uncertainties have been reformulated here as questions.

the treatment of schizophrenia. These came from clinicians, patients and their carers through web- and paper-based questionnaires. We also pulled them from the UK Database of Uncertainties about the Effects of Treatments, which contains instances in which “no up to date systematic reviews exist, or up-to-date systematic reviews show that uncertainty continues”.

These questions were de-duplicated to produce a longlist of 237 issues. Eleven schizophrenia partners — carers, clinicians, patients, funders and voluntary-sector organizations — each ranked their top ten uncertainties. These partners responded either as individuals, or on behalf of an organization, having consulted colleagues and members.

The partnership collated the rankings, recording separate running totals for patient, carer and clinician submissions. This enabled a steering group — a subset of the partners — to examine each individual ranking, as well as the combined ranking, to produce a pooled list of 26 treatment uncertainties.

Finally, this list was discussed at an exhilarating workshop of clinicians, carers, patients, funders and voluntary-sector organizations in January. The JLA facilitated the meeting using a structured variation of small-group discussion called ‘nominal group technique’ (see [go.nature.com/xswwtc](http://go.nature.com/xswwtc)) to



## SCHIZOPHRENIA

Search for origins and treatments  
[nature.com/schizophrenia](http://nature.com/schizophrenia)

reach moderated consensus on a top ten.

The process prevented one person dominating the discussion and encouraged all group members to participate. The format was rigorous, but flexible enough to allow people to revise their opinions, raise concerns and to reach consensus about any imbalance perceived to have emerged from the interim stages.

Although the purpose of the JLA process<sup>2</sup> is to enable patients and those who treat them to have a say in what gets studied, it can also change clinical practice. For example, sexual dysfunction caused by antipsychotic medication emerged as a key patient priority. This is typically a low priority for clinicians prescribing medication and for companies assessing drug effectiveness.

The week after the JLA workshop, a patient came to see one of us (K.L.) in a clinic, and wanted a change of antipsychotic medication because of sexual dysfunction. Without the experience of the JLA process, it is unlikely that this issue would have been afforded as much weight as it was.

The final top ten for schizophrenia is

noteworthy for its divergence from the agenda of the drug industry, and begs many questions. Perhaps most pressing: is it ethical to conduct research, which may include testing new treatments, without considering which outcomes matter most to those who will receive the treatment? And is it, in the long run, to drug companies' benefit to do so? Such questions are particularly pertinent in conditions such as schizophrenia, in which the balance of power between researcher, clinician and patient is so uneven.

What next? The team will repeat the exercise for depression this year and next. Meanwhile, the JLA is encouraging funders and researchers to act on the top ten rather than to continue with agendas devoid of clinician and patient input. For example, the NIHR is now exploring commissioning research on weight gain and sexual dysfunction in schizophrenia. Assumptions that “researcher knows best” have had their time. ■

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