Research Prioritisation

A report from the National Institute for Health and Clinical Excellence, the Association of Medical Research Charities, and the James Lind Initiative

SUMMARY

On Monday 28 January 2013, a roundtable was convened in London involving representatives of NICE (National Institute for Health and Clinical Excellence), the James Lind Initiative (JLI), the Association of Medical Research Charities (AMRC) and several of its member charities. The purpose of the event was to hear from those who provide national resources for identifying and prioritising research uncertainties in order to discuss the nature, value and potential of these with charitable funders of medical research.

Delegates heard from:

- NICE, which manages three databases housing evidence uncertainties and research recommendations that can help funders decide where to invest in research
- the Cochrane Collaboration, the James Lind Alliance (JLA) and the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) on their prioritisation methods such as JLA Priority Setting Partnerships (PSPs) which focus on identifying what matters most to patients/carers and the clinicians who treat them. NETSCC is of particular relevance as the JLA moves under its stewardship from April 2013
- representatives of two medical research charities which had used or were using these tools to create research strategies important to patients/carers and clinicians.

WHY IS THS WORK IMPORTANT?

Medical research charities collectively spend over £1bn on research annually, much of it donated by patients, carers and their families. In deciding where this investment will bring about the greatest patient benefit, and allow charities to meet their charitable objectives, they use a range of tools to help them develop their research strategies. Delegates heard about:

- Discussions with scientific advisory panels advising on funding allocation, which often lead to new funding streams such as PhD studentships/ fellowships/chairs (to increase capacity), and pilot /small grants (to allow researchers to gather data to support applications for larger grants)

- Horizon scanning, such as the gap analysis conducted for Breast Cancer Campaign (1) asking experts to determine which areas of research, if targeted by researchers and funding bodies, would have the greatest impact on patients
- Asking patients, for example, The Stroke Association 'Needs Survey' of stroke survivors probing their needs and issues faced in their lives to help develop research priorities (2)
- Charities involving patients in grant-funding rounds, either as members of scientific committees or on lay panels. For example, Arthritis Research UK has a patient and carer User Committee to ensure that funded research is relevant to the charity's aims and patient needs, and provide insight into the feasibility of carrying out research in that patient group
- AMRC charities that have taken part in James Lind Alliance Priority Setting Partnerships (JLA PSPs), to gather patient and clinician shared priorities for treatment research (3).

These examples come against a backdrop of some charities not involving patients in the research prioritisation process, however, as reviewed by a JLA-commissioned report conducted by TwoCan Associates (4). This concluded that "Most organisations are reluctant to place restrictions on researchers by asking them to address priority topics. This means that most funders operate in a responsive mode and that, despite its recognised problems, peer review is widely accepted as the only way to choose between the research proposals put forward. Funding decisions are therefore largely based on judgments about scientific merit, rather than on the relevance and importance of outcomes to end-users."

While this report was published in 2009, and progress has been made since, it continued: "Few organisations identify the research priorities of clinicians and patients."

In part seeking to explore such claims, a year later, the AMRC published "Natural Ground" (5), which set out the ways in which charities involve patients and the public in setting the agenda for research using JLA PSPs and other methodologies.

Examples included that of Asthma UK, which was already working with the JLA as the first charity partner in a PSP (with the British Thoracic Society representing clinicians). Also covered was the Alzheimer's Society's seminal Quality Research in Dementia (QRD) programme which had, since 2000, involved patients in parallel with professionals in peer review and at other steps in the research cycle.

The roundtable thus got underway with those present recognising, or keen to learn more about, the importance of effective research prioritisation. The challenging economic climate means that charities need to do more with less and ensure that they are directing scarce research budgets to those projects that most benefit patients. The increasing emergence of cross-cutting themes in research, which may span more than one disease area, also means that deciding on key priorities is becoming more complex. And, finally, the move towards proactive commissioned

research and away from response-mode or reactive funding means that funders are increasingly considering better ways to set priorities.

The convenors of the roundtable wanted to present and discuss tools and services which may help charities to identify and prioritise research questions at a time when, arguably more than ever before, they are receptive to and recognise the need to do this. The discussions were candid and constructive, and led to a set of agreed recommendations set out later in this report.

KEY DISCUSSION THEMES

The key themes discussed during the meeting included:

- There was variable awareness among charities of the databases, services and methods presented
- Participants were keen to hear about the NICE databases (see below) and recognised their powerful potential to stimulate research funders considering how to improve their funding strategies
- Once made aware of the above, many charities suggested they would be keen to consider extending their research strategies to include a larger component of commissioned research in their programmes
- There was strong support for such programmes including research questions based on prioritised patient/carer and clinician input
- Charities which had used the NICE databases suggested these could be made more user-friendly and accessible to lay audiences
- Charities for whom the tools and services are new reported being unsure about how best they could contribute to or be used to shape their research agendas
- Limited resources, especially for smaller charities, were seen as barriers to full engagement with the databases and services described
- There was felt to be *"a need to increase the perceived power of patient views,"* to inform research priorities. As one delegate said: *"We are interested to know what patients think but don't necessarily align this with directing or leading the research programme"*
- The JLA was the best known of the services presented, and it is hoped that NETSCC will find ways to maintain and enhance this level of awareness as it takes over management of the JLA

The roundtable meeting launched a hitherto unprecedented level of dialogue between those who manage and those who use, or who could use, the services described in this report.

It was felt that maximising their value in future could involve adapting existing methodologies, training and coaching for users, and supporting partnerships between charities (see Recommendations, below)
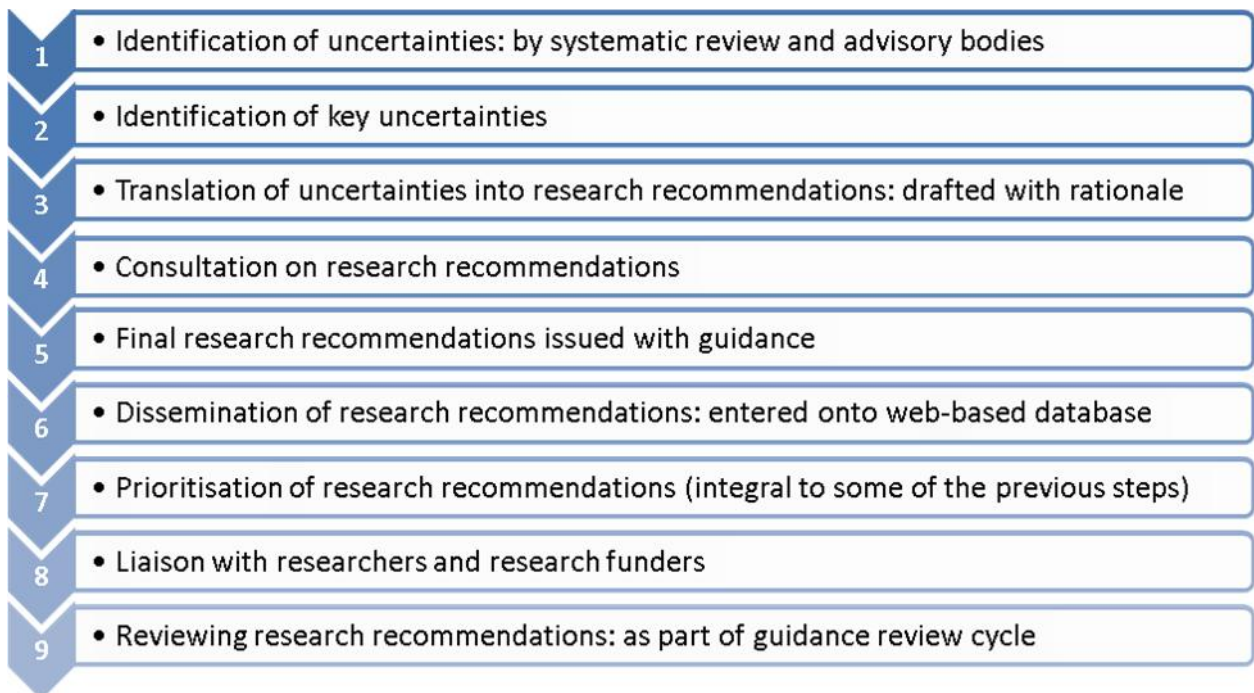
SUMMARY OF RESOURCES PRESENTED

The databases managed by NICE, and the routes through which these are populated, were presented. The relationship between these databases is summarised in Figure 1 below.

Figure 1: Where do uncertainties come from & where to find them?
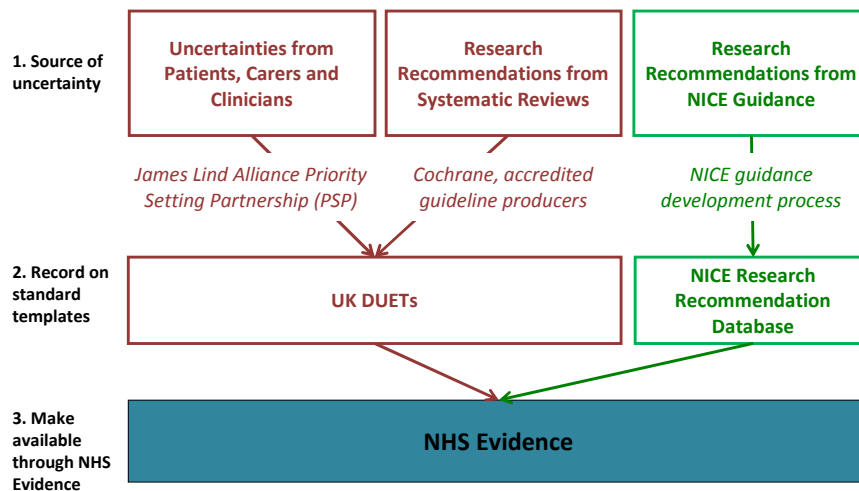
The **NICE Guidance Research Recommendations** database (http://www.nice.org.uk/research/index.jsp?action=rrsearch) houses all research questions arising out of NICE guidance development and acts as a parallel resource to NICE's clinical recommendations – the former essentially highlights uncertainties, the latter, the evidence-base. Figure 2 summarises the steps by which this database is populated from research recommendations from published guidance about a range of areas, including clinical effectiveness, diagnosis, patient experience and service delivery. Housed on the database, such questions are then available for monitoring by funders and others, with an annual prioritisation process carried out with the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) programme.

Figure 2: the NICE research recommendations flowchart

1	• Identification of uncertainties: by systematic review and advisory bodies
2	• Identification of key uncertainties
3	• Translation of uncertainties into research recommendations: drafted with rationale
4	• Consultation on research recommendations
5	• Final research recommendations issued with guidance
6	• Dissemination of research recommendations: entered onto web-based database
7	• Prioritisation of research recommendations (integral to some of the previous steps)
8	• Liaison with researchers and research funders
9	• Reviewing research recommendations: as part of guidance review cycle

The **UK Database of Uncertainties about the Effects of Treatments** (UK DUETs; http://www.library.nhs.uk/duets/) stores and disseminates uncertainties identified by two main processes: JLA PSPs, which gather uncertainties from patients/carers and clinicians, and systematic reviews, clinical guidelines and information about ongoing trials from trials registers highlighting gaps in the evidence base. NICE itself also identifies uncertainties through its guidance producing processes, and feeds these into both UK DUETS and the Research Recommendations Database. The Swedish Health Technology Assessment Agency has now developed a database modelled on UK DUETs (6).

"The value of UK DUETs is about stopping us doing things that harm, or kill, or indeed not doing things that help, because we don't address uncertainties."

NHS Evidence (http://www.evidence.nhs.uk/) is an additional route through which research recommendations and uncertainties can be searched and browsed as well as containing evidence showing which uncertainties appear to have been resolved.

The **James Lind Alliance** (JLA) was set up in 2004, with funding from the Medical Research Council and the Department of Health (3). Its Priority Setting Partnership (PSP) process enables patients/carers and clinicians to work together to identify and prioritise uncertainties about treatments, agreeing a 'top 10' of shared priorities (7). As set out above, it is a major source of uncertainties housed within UK DUETs.

"Consensus decision-making involves compromise. Hopefully all involved in priority-setting end up seeing one or two of 'theirs' in the top 10."

At the time of this roundtable, the JLA had completed 12 PSPs on health problems ranging from asthma and vitiligo to incontinence and schizophrenia; had 14 underway, and a further 18 waiting to start, subject to funding and staffing.

The roundtable included presentations about the experiences of two JLA PSPs – on prostate cancer, and sight loss.

A report on the experiences of **Prostate Action** using the JLA process to identify research priorities was very positive, albeit following initial difficulty attracting clinicians to the process (8).

> *"A key lesson for us was to ask – always 'where is the patient in this uncertainty?' Charities don't exist to give us jobs but to help those who give money. Asking them what to do with it should be normal."*

Fight for Sight reported its current PSP to identify unanswered questions about the prevention, diagnosis and treatment of sight loss and eye conditions, and is about to embark on the interim prioritisation exercise, whereby often very large numbers of uncertainties are reduced to a manageable list, which is then used as the basis for the final "Top 10" priority–setting exercise. The charity will disseminate and promote the results, adapt its current research to reflect the results of the JLA prioritisation, and work with other relevant funders to co-ordinate funding, develop a system of tracking research to address priorities, and decide when to update/repeat the exercise (9).

Other presentations described prioritisation methods used by the NIHR HTA and the approaches used by the Cochrane Collaboration to assess and heed patient, carer and clinician views when prioritising topics for systematic reviews.

SUMMARY OF FINDINGS AND RECOMMENDATIONS

In this section, general findings from the roundtable discussions are summarised, followed by recommendations of possible areas for further consideration or action by NICE and the charity sector, principally through its membership organisation, the AMRC.

Identifying research priorities is an essential part of the research cycle, but the stage at which this happens, and the ways in which charities approach it, is very varied, as outlined earlier in this report.

One key purpose of this roundtable was to start a conversation between the AMRC, several of its members, and NICE, to ascertain the level of interest in and knowledge about approaches to identification of important research questions, their prioritisation and dissemination, with a focus on those considered valuable by patients/carers and clinicians.

While it was acknowledged that the services presented facilitate patient/carer and clinician input to gathering and disseminating uncertainties, there is poor awareness of them.

The JLA was the best known of the services presented, and the principle of patient/clinician priority setting was greeted with enthusiasm by some of those for whom it was new. It was stressed that, as the JLA moves under the umbrella of NETSCC, ways need to be found to further raise its profile. In addition, charities with limited resources asked whether there was scope to adapt the PSP methodology. [For information: the concept of "JLA lite" had been discussed at a JLA committee meeting (10)].

Some charities reported having had initial conversations with clinicians about research priorities, while others reported a wish to engage with patients on this. However, they cited barriers to reaching their constituent group, such as people with disabilities, and an apparent reluctance of patients to engage with research once they had been successfully treated.

Some delegates were concerned that the NICE databases are not comprehensive, which limits their value: unless a particular condition has been the subject of a JLA PSP, or a NICE Guidance, the UK DUETs and NICE Research Recommendations databases may have little to offer an individual charity:

> *"The databases aren't totally comprehensive, in that certain clinical areas are not covered – so to get uncertainties about a clinical area into the databases you might need to think about doing a JLA PSP yourselves."*

Given the range of tools available to inform prioritisation, some participants asked how these approaches could be used alongside their current methods:

> *"What weighting should be given to these resources and methods versus other types of input or initiatives that contribute to setting the research agenda?"*

For some, the knowledge gained about the potential of these services prompted enthusiastic discussion about whether they should remain reactive funders or establish commissioned programmes based on prioritised uncertainties.

Ongoing dialogue between those who manage and those who access and use these information services, and others who could use them, was regarded as essential to exploit their value. On this note, plans to merge UK DUETs and NICE research recommendations databases were welcomed as a way of simplifying access.

The enduring theme of financial and staff resource constraints was raised in various ways, including the potential mismatch between identified priorities and researcher capacity, highlighting the risk that investing in initiatives such as a JLA PSP may identify priorities but leave them unaddressed. Small charities especially raised the

question of how they could carry out a JLA PSP, and contribute to UK DUETs, given limited resources.

A number of options were considered in response to this challenge: charities agreed there was scope for collaboration and cost-sharing on PSPs. The potential for developing a simplified "leaner" PSP-like process was also discussed, as noted above.

The group discussed the value of identifying what matters most to those who will benefit from research: patients. For example, conducting a PSP or similar process may be a good use of resources before spending usually much larger sums on research itself.

Finally, while it was felt that the most pressing need is to find ways to raise awareness and use of the tools and services within the UK, there was also discussion of the need for greater clarity about how the content of the databases links to international data about uncertainties, ongoing research and research needs. There was enthusiasm for finding constructive ways to share knowledge and knowledge gaps across national boundaries.

Recommendations for NICE

More could and should be done to promote the databases and make them easier to navigate and search.

Using more "lay friendly" language within the databases would remove a barrier for some charities (and likely, others) who currently feel deterred by their complexity.

Greater clarity about the scope and coverage of the databases would help charities who are often unsure whether content is relevant.

Helping charities and other funders see whether uncertainties on databases are current would be invaluable: questions asked included *'when is an uncertainty no longer relevant?'* and *'what can be done about refreshing uncertainties?'* In response, users were reminded that the date when each uncertainty was recorded is available, but, beyond this, the challenge of "tracking" uncertainties remains, such that it is not currently possible to make clear whether an uncertainty had been considered, prioritised or funded for research.

It was suggested that support be provided to funders seeking to convert uncertainties into appropriate research questions, and/or to identify uncertainties that cannot be converted into research questions.

Recommendations for the AMRC and charity sector

The AMRC can play an important role in publicising to its members the information services discussed, to help them identify and prioritise relevant research.

Using examples to illustrate how the services have been used and what has resulted is a crucial part of that awareness-raising:

> *"We need to get under the hood of the JLA, see what good prioritisation looks like, and how you can translate it into good research questions and good research."*

AMRC could help charities in similar areas think about how to work together, especially smaller charities which may face greatest resource constraints.

LAST WORDS

In summary, although there was low overall recognition of the information services described at this event, all parties seemed keen to address this, with many imaginative and helpful suggestions made. It was agreed that running a similar event for others in the sector, such as public funders and researchers themselves, would also be useful. This would in general widen the conversation about priority-setting, and the value of patient/carer and clinician contributions to this, and, in particular, the information services presented at this event.

REFERENCES, FURTHER READING & CONTACTS

1. http://breast-cancer-research.com/content/pdf/bcr1983.pdf

2. http://www.nimast.org.uk/cmckv.pdf

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6. http://www.sbu.se/upload/Kunskapsluckor/Scientific_Uncertainties.pdf

7. The JLA Guidebook: http://www.jlaguidebook.org/jla-guidebook.asp?val=42
http://www.lindalliance.org/pdfs/110118_JLA%20SDG%20Minutes.pdf)

8. Halls E. (2010) Where are the clinicians when you need them? BMJ 2010;340:c1845.

9. http://www.lindalliance.org/sightlossvisionPSP.asp

10. http://www.lindalliance.org/pdfs/110118_JLA%20SDG%20Minutes.pdf

A BMJ blog focused on the events of the day:
http://blogs.bmj.com/bmj/2013/01/30/sophie-petit-zeman-on-uk-duets-uncertainties-as-opportunities/

If you would like to contact key organisations referred to above, you can do so at:

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