Mind the gap !

Multi-stakeholder dialogue for priority setting in health research

Based on a Workshop held by
the King Baudouin Foundation
in Brussels on
November 27 and 28, 2015

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Working together for a better society

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COLOPHON

Mind the gap! Multi-stakeholder dialogue for priority setting in health research

A publication of the King Baudouin Foundation
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LEGAL DEPOSIT
D/2893/2016/08

ORDER NUMBER
3394
April 2016
With the support of the Belgian National Lottery

TABLE
OF CONTENTS

PREFACE

Biomedical and health research is evolving at a blistering pace. Considerable progress is being made in the areas of fundamental, translational and clinical research. This is just as well, because both patients and governments are eagerly awaiting the results of studies in a number of areas of medical science.

Today the priority themes of these studies are largely determined by researchers themselves: freedom of research is both a right and a necessity. The pharmaceutical industry also has a major influence over the research agenda.

Nevertheless, it is clearly a meaningful and enriching approach to involve other parties in determining the priorities of biomedical and health research too. When opinions are gathered not only from researchers but also from patients, governments, care providers and funding bodies about their wishes and needs in regard to medical research, it is likely that the range of themes will be much wider, that unmet needs will be identified and perhaps that new priorities will also emerge.

The practice of exchanging ideas and experiences on priorities in biomedical and health research has not yet become widespread in Belgium. In a number of our neighbouring countries such as the UK, France and The Netherlands, on the other hand, this exercise has been successfully carried out on a number of occasions already. In November 2015 the King Baudouin Foundation organized a workshop for researchers, patients, patient organizations, care providers, pharmaceutical companies and research funding bodies. Experts from other countries came to share their experiences of dialogue with the various stakeholders on the research agenda.

This publication sets out the various examples and methods that were contributed by the experts, and also includes the results of the discussions with the participants: who are the obvious and also the less obvious stakeholders? What are the benefits and what problems need to be avoided? And what ingredients are required to make a success of a dialogue such as this one, in terms of prioritizing the various research themes?

It will be clear from the outset that there is no standard all-embracing model available that makes it possible to structure such a dialogue, and that not every dialogue results in radical changes. This guide is intended above all to encourage you to step aside for a moment from the well-trodden tracks that are followed by research agendas and take a new and open-minded look at the opportunities and priorities that exist in biomedical and health research. We will be demonstrating the advantages, while also discussing the problems that exist and how to avoid them …

We are grateful to all the participants who were involved in this workshop: their openness, creativity and enthusiasm have encouraged the Foundation to publish this guide and to take some additional steps. We would also like to thank Alain Wouters for facilitating these two one-day events and Peter Raeymaekers, for writing this guide.

MULTI-STAKEHOLDER INVOLVEMENT IN RESEARCH AGENDAS... WHY?

Research agendas for health and biomedical research are usually determined by the priorities of researchers, academia and sponsors. But do these agendas really match the demands in society and the needs of the users of the research results? These users (patients, taxpaying citizens, but also caregivers, health professionals, governmental reimbursement agencies, private insurers etc.) are seldom involved in setting research agendas. Thus, the specific knowledge and expertise of these groups is undervalued and underused[1].

At the same time, the burden of disease remains high, even in industrialized countries with well-functioning healthcare systems. Despite the vast expenditure on health research, many medical needs remain unmapped and/or research aimed at finding appropriate solutions can be improved by reprioritizing research agendas.

Multi-stakeholder involvement in the programming of research is one way of allowing silent but concerned parties to have a voice. It is an iterative, inclusive, participatory, multi-actor process in which researchers, patients, members of the public, but also caregivers (informal and formal), governmental representatives, and sponsors, work together to prioritize, plan, conduct and disseminate research priorities and contexts. As such, it goes beyond patient and public involvement or end-user engagement. Multi-stakeholder dialogues tackle the very ‘upstream’ element of research whereas many patient participation initiatives and other stakeholder engagement initiatives tend to focus on later stages[2].

Common sense ...

The aims of multi-stakeholder dialogues in research agenda setting are to increase benefits for people and society, to enhance the efficient use of limited resources, to improve accountability and governance of public expenditure, and to harmonize applied health and fundamental biomedical research. It therefore seems to make sense to involve more stakeholders in research agenda setting[3].

The history of multi-stakeholder involvement, and particularly patient and public participation, goes partly back to the campaigns by advocacy movements, patients and disabled people to have greater control over the process of knowledge production. At the same time, transitions in society, including consumerism, public accountability and the democratization of science, have further prompted disputes over the benefits and pitfalls of including patients and citizens in clinical trial design and research programming[4].

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[1] Chalmers I, Essali A, Rezk E, Crowe, S. Is academia meeting the needs of non-academic users of the results of research? The Lancet, Volume 380, Supplement 1, October 2012, Pages S43

[2] Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, Brito JP, Boehmer K, Hasan R, Firwana B, Erwin P, Eton D, Sloan J, Montori V, Asi N, Dabrh AM, Murad MH. Patient engagement in research: a systematic review. BMC Health Serv Res. 2014 Feb 26;14:89. doi: 10.1186/1472-6963-14-89.

[3] Crowe S. Multi-stakeholder dialogue for priority setting in biomedical research: learning from experiences. Setting the scene. Presentation during the KBF workshop on November 27-28, 2016. https://onedrive.live.com/?authkey=%21AB72K5HXcvgDiu4&id=9220168E684C593%21787&cid=09220168E684C593

[4] Abma TA, Pittens CA, Visse M, Elberse JE, Broerse JE. Patient involvement in research programming and implementation: A responsive evaluation of the Dialogue Model for research agenda setting. Health Expect. 2014 May 30. doi:10.1111/hex.12213.

There is a vast body of scientific literature on the involvement of patients in research agenda setting. The main idea is that research should be conducted *with* them and not solely *on* them and that the role of patients extends far beyond that of being a research 'subject'.

> *"Patients and the public bring in a lived experience of what it means to live with a disease or a condition. They know about the impact of side effects, about the fear and uncertainties concerning long-term effects, about the costs and (un)availability of services. In my experience they are very able to articulate what they want to see addressed in research for their benefits. It is reaching the patients and the public that is sometimes a challenge, as well as ensuring that your processes can accommodate different ways of participating."* Sally Crowe, Director Crowe Associates.

Different scholars indicate that active involvement of patients and citizens may lead to an increase in the quality and relevance of health research, because the experiential knowledge of users can complement the scientific knowledge of experts (substantive argument). It has also been argued that users and taxpayers have the right to become involved because they will be affected by the outcomes of health research (normative argument). A third argument is that participation can lead to a better acceptance of research and its outcomes by patients (instrumental argument)[5].

Why do we need priority setting in research through multistakeholder involvement?

- Increase benefit of research for users and society by
  - identifying patient-informed needs
  - designing patient-informed clinical trials with adapted outcomes
  - increasing knowledge of patient preferences regarding benefit-risk information in regulatory decision-making
- Use limited resources more efficiently
- Increase knowledge and interest in research
- Multistakeholder dialogue contributes to better collaboration among stakeholders
- Raise governance and transparency on (public) expenditure

… but not common practice

On the other hand, it is not common practice. A recent systematic review on research priority setting for chronic kidney disease found that only 4 out of 16 published research priority exercises included people with chronic kidney disease[6]. As a result, mismatches continue to exist between what is being researched and what stakeholders want to be researched. A recent assessment in the UK showed striking differences between funded and initiated clinical research and the results of research priority agendas that include patients, carers and health professionals. In the multi-stakeholder

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[5] Elberse JE, Caron-Flinterman JF, Broerse JE. Patient-expert partnerships in research: how to stimulate inclusion of patient perspectives. Health Expect. 2011 Sep;14(3):225-39. doi: 10.1111/j.1369-7625.2010.00647.x.

[6] Tong A, Crowe S, Chando S, Cass A, Chadban SJ, Chapman JR, Gallagher M, Hawley CM, Hill S, Howard K, Johnson DW, Kerr PG, McKenzie A, Parker D, Perkovic V, Polkinghorne KR, Pollock C, Strippoli GF, Tugwell P, Walker RG, Webster AC, Wong G, Craig JC. Research Priorities in CKD: Report of a National Workshop Conducted in Australia. Am J Kidney Dis. 2015 Aug;66(2):212-22. doi: 10.1053/j.ajkd.2015.02.341.

research priority agendas for 14 different indications, new drugs accounted for only 18% of the prioritised research themes, in registered non-commercial trials, drugs accounted for 37%, and in registered commercial trials they represented 86%[7].

Furthermore, research priority setting is currently lacking in transparency and accountability, and the emphasis in research is very much on scientific excellence, sometimes at the expense of the relevance and utility of the research.

> *"Until now research priority setting involving end users and other stakeholders has been pioneering with niche exercises. The challenge is to mainstream client and patient participation in research programming and to disrupt the dominant structure, culture and practice of the ruling research system."* Jacqueline Broerse, Professor of Innovation and Communication in the Health and Life Sciences and Director Athena Institute, VU Amsterdam.

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[7] Crowe S, Fenton M, Hall M, Cowan K, Chalmers I. Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch. Research Involvement and Engagement (2015) 1:2. doi:10.1186/s40900-015-0003-x

EXISTING INITIATIVES

Although including multi-stakeholder dialogues in research programming is not common practice, a number of countries and governmental bodies already involve a broader range of stakeholders in health and biomedical research agenda setting and regulatory decisions.

European Union

The EU Framework Programme for Research and Innovation Horizon 2020 stresses the importance of multi-stakeholder engagement as a cornerstone of Responsible Research and Innovation[8]. This engagement – including the public at large, and patients and carers in particular – is about co-creating the future and bringing on board the widest possible diversity of actors who would not normally interact with each other, to discuss questions relating to science and society.

The attitude of researchers towards the impact of patient organizations on their research

In France, the Institut National de la Santé et de la Recherche Médical (INSERM) tries to integrate patient-derived information into research agenda programming by stimulating its researchers to stay in contact with patients and patient organizations.

In 2014 INSERM published the results of CAIRNET, a survey presenting the diversity of views expressed by 670 researchers about their relationships with patient associations and the impact on their research activities. The opinions ranged from a degree of reluctance to enthusiastic commitment. Most researchers agreed that these collaborations foster the link with society. In fact, three-quarters of the respondents had met with associations, and over 40% of them had established collaborations with them. These were described as providing a special form of motivation to the research, as well as being crucial in terms of financial support.

Bungener M, Demagny L, Faurisson F. Associations de maladies. Regards de chercheurs. 2014. CNRS Editions. http://www.inserm.fr/associations-de-malades/gram/cairnet

United Kingdom

Explicit clinician and patient involvement in UK health research began in the early 1990s with the launch of the NHS Research and Development strategy. This introduced a systematic approach towards asking NHS staff and users of the Service to identify important issues and, in partnership with the research community, to characterize and prioritize these problems as the basis for seeking solutions[9].

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[8] http://ec.europa.eu/programmes/horizon2020/en/h2020-section/public-engagement-responsible-research-and-innovation

[9] Stewart RJ, Caird J, Oliver K, Oliver S. Patients' and clinicians' research priorities. Health Expect. 2011 Dec;14(4):439-48. doi:10.1111/j.1369-7625.2010.00648.x.

Since its establishment in 2006, the National Institute for Health Research (NIHR) in the UK has recognized that individual and community stakeholders are able to determine important aspects of research. The project INVOLVE was established to create engagement by involving the public and patients in clinical research[10]. INVOLVE defines public involvement in research as research being carried out '*with*' or '*by*' members of the public rather than '*to*', '*about*' or '*for*' them. Public involvement may, for example, involve working with research funders to prioritize research, offering advice as members of a project steering group, commenting on and developing research materials, conducting interviews with research participants etc.

INVOLVE includes in its deliberations patients, potential patients, caregivers and people who use health and social care services as well as people from organizations that represent people who use services. Whilst all members of the public are current, former or indeed potential users of health and social care services, INVOLVE makes an important distinction between the perspectives of the public and the perspectives of people working in a professional role in health and social care services.

Also in the UK, the NIHR is funding the coordination of the James Lind Alliance (JLA)[11] which aims to bring together patients, carers and clinicians in 'Priority Setting Partnerships' (PSPs) (see page 15). These PSPs identify and prioritize uncertainties, or 'unanswered questions' about the effects of treatments. According to the JLA, ascertaining these uncertainties should be accepted as a routine part of clinical practice and research. Patients, carers, clinicians and researchers should work together to agree on which uncertainties matter most and deserve priority attention.

United States

In the United States, the Clinical Trials Transformation Initiative (CTTI) – a FDA public-private partnership hosted by Duke University with more than 60 diverse member organizations – embraces a model of stakeholder involvement in which patient advocacy leaders and participants in research are part of all organizational activities and project teams working on each step in the clinical trial process[12].

Another US initiative, the Patient Centred Outcomes Research Institute (PCORI) has the aim to improve the quality and relevance of available evidence on treatments to help patients, caregivers, clinicians, employers, insurers, and policy makers make informed health decisions. PCORI funds comparative clinical effectiveness research and places great importance on the engagement of patients and other stakeholders in the research process[13].

The latest commitment in the US on multi-stakeholder involvement in healthcare innovation comes from the U.S. Food and Drug Administration's (FDA's) Centre for Devices and Radiological Health (CDRH). The CDRH has established a Patient Engagement Advisory Committee that will advise the FDA commissioner in complex issues related to the regulation of medical devices and their use by patients[14] [15].

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10 www.invo.org.uk

11 James Lind Alliance, Priority Setting Partnerships. www.jla.nihr.ac.uk/home.

12 Clinical trials transformation initiative (CTTI). www.ctti-clinicaltrials.org

13 Patient-Centered Outcomes Research Institute (PCORI). www.pcori.org

14 Terry SF, Patrick-Lake B. Hearing voices: FDA seeks advice from patients. Sci Transl Med. 2015 Nov 11;7(313):313ed12. doi: 10.1126/scitranslmed.aad5866.

15 Hohman R, Shea M, Kozak M, Roberts S, Allen J, Sigal E. Regulatory decision-making meets the real

The Netherlands

In The Netherlands public involvement in research agenda setting became an issue after 2000 when several local charity/government funding agencies started to initiate (and fund) projects in which patients were engaged in agenda setting[4] (in some cases after pressure from local patient organizations). These projects were facilitated by academic departments in the field of social sciences and led to the development and validation of the Dialogue Model (see page 18). This model operationalizes consultation of and collaboration among various stakeholders[16].

> *"Since 2003 the French 'Institut National de la Santé et de la Recherche medicale' (Inserm) dedicated to health research, shows a patient-engaged research programming strategy based on a combined and interacting system : a Patients' Association think tank (GRAM, 'Groupe de réflexion avec les associations de malades') and a robust partnership with nearly 500 patient organizations which proposes actions to enhance the dialogue between those working in science and those who hope to benefit from it. Inserm is currently aiming at updating its patient engagement strategy to involve patient organizations throughout the strategic planning process."*
> Bernadette Bréant, Head of Mission Associations Recherche & Société, Inserm, France.

Applicable on all continents

Research priority setting approaches using multi-stakeholder dialogues are also applicable to health problems beyond modern Western health care systems. Recently the results of a prioritization setting exercise for themes and research questions relating to health outcomes in natural disasters, humanitarian crises or other major health-care emergencies have been published[17]. Mental health research priorities in low- and middle-income countries of Africa, Asia, Latin America and the Caribbean represents another example; this issue was raised by the WHO Global Forum for Health Research[18].

King Baudouin Foundation

On November 27-28, 2015 the Belgian King Baudouin Foundation (KBF) brought together a group of experts with experience in different methods for agenda setting for discussions with Belgian and European stakeholders involved in health and biomedical research. The questions discussed during this workshop included 'who are the relevant stakeholders?', 'what are the benefits of involving them?', 'where are the pitfalls?', 'does all health research lend itself to stakeholder involvement?', 'which ingredients are necessary for a successful stakeholder dialogue?'.

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world. Sci Transl Med. 2015 Nov 11;7(313):313fs46. doi: 10.1126/scitranslmed.aad5233.

16 Abma TA, Broerse JE. Patient participation as dialogue: setting research agendas. Health Expect. 2010 Jun;13(2):160-73. doi:10.1111/j.1369-7625.2009.00549.x.

17 Evidence Aid Priority Setting Group EA. Prioritization of themes and research questions for health outcomes in natural disasters, humanitarian crises or other major healthcare emergencies. PLoS Curr. 2013 Oct 16;5. doi:10.1371/currents.dis.c9c4f4db9887633409182d2864b20c31.

18 Sharan P, Gallo C, Gureje O, Lamberte E, Mari JJ, Mazzotti G, Patel V, Swartz L, Olifson S, Levav I, de Francisco A, Saxena S; World Health Organization-Global Forum for Health Research - Mental Health Research Mapping Project Group. Mental health research priorities in low- and middle-income countries of Africa, Asia, Latin America and the Caribbean. Br J Psychiatry. 2009 Oct;195(4):354-63. doi: 10.1192/bjp.bp.108.050187.

The objectives of the workshop were fivefold: 1) learning about different ways of setting research priorities on the basis of a number of cases; 2) informing and sensitizing Belgian and European stakeholders; 3) discussing the building blocks for creating broadly supported research agendas; 4) identifying possible pilots in a European context; and 5) creating a network for health and biomedical research priority setting. During the workshop three examples/models of research priority setting were extensively discussed (see next chapter).

This report shows the outcomes of the meeting and a number of the lessons learned. The report does not contain the minutes of the workshop; neither is it a guide for those wishing to set up a stakeholder dialogue. It is first of all an inspiration guide, showing a number of the key elements – with whom? what for? how? – involved in setting up a successful multi-stakeholder dialogue. As with all participatory consultations, however, the process is just one of the elements contributing to success. The most important element of all is the determination and creativity of the participants who make such a process succeed. They do this before, during and after the consultation … because successful dialogues never come to an end.

THREE MODELS/EXAMPLES TO LEARN FROM

During the KBF workshop in Brussels, three examples/models of research priority setting processes with a multi-stakeholder approach were discussed extensively: the Priority Setting Partnership (PSP) model of the James Lind Alliance (JLA), the Dutch Dialogue Model of Athena from the University of Amsterdam, and the 'Prospective Vision' experience of the French Fondation Motrice (cerebral palsy foundation).

Priority Setting Partnerships set up by the James Lind Alliance (UK) – the case of dementia

Research questions relevant to patients and clinicians

The James Lind Alliance (JLA) is a non-profit-making initiative, established in the UK in 2004. The Alliance brings together patients, carers and clinicians in Priority Setting Partnerships (PSPs) to identify research priorities in addressing uncertainties about the effects of treatments. The aim of these partnerships is to help ensure that those who fund health research are aware of what really matters to both patients and clinicians. The JLA's administrative centre is funded by the National Institute for Health Research (NIHR) and is coordinated through the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) at the University of Southampton.

Priority Setting Partnerships produce a final list (often a 'top 10') of jointly agreed research priorities, publicize them widely, and make sure that other discovered uncertainties are recorded and made available to researchers and research funders. Over the years, the James Lind Alliance has published research priorities for a range of conditions, including autism, asthma, dementia, depression, diabetes, eczema, hair loss, mesothelioma, multiple sclerosis, palliative care and others[19]. It has completed around 30 priority setting processes and in 2016 has more than 20 ongoing.

Methodology – principles and flow

PSPs follow a specific method set out in the JLA Guidebook[20]. They are overseen by a Steering Group of patients, carers and clinicians, and their representatives, and are facilitated by one of a small team of JLA Advisers. In general the PSP process has six phases and to safeguard consistency, the JLA asks each partnership to ensure that their methods address a set of underpinning principles. These principles are:

- transparency of the process,
- balanced inclusion of patient, carer and clinician interests and perspectives,
- exclusion of non-clinician researchers for voting purposes (they may be involved in all other aspects of the process),
- exclusion of groups/organizations that have significant competing interests, for example pharmaceutical companies,
- audit trail maintained from the uncertainties originally submitted to the final prioritized list.

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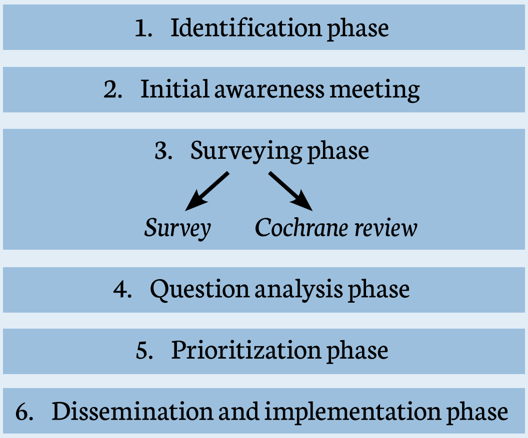
[19] James Lind Alliance. The PSPs. http://www.jla.nihr.ac.uk/priority-setting-partnerships

[20] James Lind Alliance. Setting up a Priority Setting Partnership, Some questions answered, http://www.jla.nihr.ac.uk/__data/assets/pdf_file/0006/156777/PSP-summary-leaflet-Nov-2015.pdf and JLA PSP Guidebook. http://www.jla.nihr.ac.uk/guidebook

Six phases of the PSP method by the James Lind Alliance



The case of dementia

The process flow and possible outcomes are illustrated in more detail by discussing the dementia PSP.

The initiative to carry out a research priority setting exercise for dementia came from the Alzheimer's Society Public Health Advisory Committee from the University of Cambridge. The exercise was carried out in 2012-2013 and was intended to create a research agenda covering the entire field as well as highlighting priorities; to generate a priority list for research and policy considerations; to make the results of research available to commissioning bodies to be considered for funding and to inform policy decisions.

1. Identification phase

The steering group identifies the scope of the process (prevention, treatment, diagnosis and care for people with dementia) and the partners through the networks of both the JLA and the Alzheimer's Society. The stakeholders involved were people who have dementia, informal caregivers and family members of people who have dementia, medical doctors, nurses and professionals involved in dementia care, care professionals including home care staff and social care representatives and members of the community who are interested in dementia. Organizations with a conflict of interests were excluded. It is possible, however, that interested parties may participate in a purely observational capacity when the steering group considers that this may be helpful. The steering committee also invited interested stakeholders to the initial awareness meeting.

2. Initial awareness meeting

At the initial awareness meeting, the proposed plan for the PSP was presented to potential partners, questions were addressed and the principles for the PSP process (contributions, recording, reporting) were established. Before, during and after the meeting potential partners and their representatives were identified.

3. Survey phase

A survey was designed with questions on prevention, treatment, diagnosis and care for people with dementia. The pilot of the survey was tested in the Alzheimer society general steering group. The survey itself was distributed (online and on paper) throughout the PSP network by advertisements in their magazines, through their local offices, research network volunteers, a GP steering group, social media etc. In parallel with the survey, existing research recommendations were listed through a Cochrane analysis and NICE guidelines assessment. Older (< 2005) or out of scope research questions were excluded. Research questions were also included from a previous small priority setting exercise by the Alzheimer's society's research network and research questions listed in the UK Database of Uncertainties about the Effects of Treatments, then part of NHS Evidence.

10 Research priorities for dementia

1. What are the most effective components of care that keep a person with dementia as independent as they can be at all stages of the disease in all care settings?
2. How can the best ways to care for people with dementia, including results from research findings, be effectively disseminated and implemented into care practice?
3. What is the impact of an early diagnosis of dementia and how can primary care support a more effective route to diagnosis?
4. What non-pharmacological and/or pharmacological (drug) interventions are most effective for managing challenging behavior in people with dementia?
5. What is the best way to care for people with dementia in a hospital setting when they have acute healthcare needs?
6. What are the most effective ways to encourage people with dementia to eat, drink and maintain nutritional intake?
7. What are the most effective ways of supporting carers of people with dementia living at home?
8. What is the best way to care for people with advanced dementia (with or without other illnesses) at the end of life?
9. When is the optimal time to move a person with dementia into a care home setting and how can the standard of care be improved?
10. What are the most effective design features for producing dementia friendly environments at both the housing and neighbourhood levels?

4. Question analysis phase

Based on the survey and the literature analysis, a large amount of information is usually gathered. The most practical approach is to initially shortlist the uncertainties during an interim priority setting exercise, and then to move on to a final priority setting workshop. The whole partnership may carry out the interim priority setting process, or the representative steering group might complete the initial stages. Where the whole partnership is involved, partners ask their members, colleagues or peers to examine the long list of treatment uncertainties, choose those which they would most want to see prioritized for research (usually this is 10) and rank them. In the case of dementia, the interim prioritization led to a longlist of 25 research questions. A number of categories were excluded (cause, media, stigma, etc.) as well as questions that have already been answered (through a literature search). [21]

5. Prioritization phase

The final prioritization workshop was organized with representatives of patients, carers, clinicians and health and social care professionals and was facilitated by a JLA moderator. During this one-day workshop, small group sessions and ranking exercises based on nominal group technique were used to achieve the top 10 priorities (shortlist), starting from the 25 interim prioritized questions.

6. Dissemination phase

The results were included in the Alzheimer's Society Public Health gap analysis work programme. They were also reported to funding and research agenda setting organizations and published internally and externally, including as a scientific paper[22]. The priorities also informed the development of two NIHR-funded studies.[23]

Dialogue Model by the Vrije Universiteit Amsterdam – the BhURN project

Participation and interactive approaches

Researchers from the Vrije Universiteit Amsterdam have developed the Dialogue Model as a methodology for health research agenda setting processes [24] [25] [26]. The model is grounded in participatory and interactive approaches and has been adjusted on the basis of pilot work. The aim of the Dialogue Model is to create an equal partnership among patients and other stakeholders (e.g. health care professionals and researchers) during the agenda-setting process.

Dialogue is seen as an ethical and fruitful way to set the agenda because it helps professionals to understand the societal impact of their research interests, and integrates patients' experiential knowledge and voice. Dialogue fosters a mutual learning process, leading to new and shared perspectives which are accepted and recognized by all involved. Dialogue potentially stimulates innovative ideas and a sense of co-ownership.

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[21] More details for this particular PSP can be found in the report https://www.alzheimers.org.uk/site/scripts/documents info.php?documentID=1804

[22] Kelly S, Lafortune L, Hart N, Cowan K, Fenton M, Brayne C; Dementia Priority Setting Partnership. Dementia priority setting partnership with the James Lind Alliance: using patient and public involvement and the evidence base to inform the research agenda. Age Ageing. 2015 Nov;44(6):985-93. doi: 10.1093/ageing/afv143.

[23] http://www.nets.nihr.ac.uk/projects/hsdr/1415407 and http://www.nets.nihr.ac.uk/projects/hsdr/1415409

[24] Abma TA, Broerse JE. Patient participation as dialogue: setting research agendas. Health Expect. 2010 Jun;13(2):160-73. doi:10.1111/j.1369-7625.2009.00549.x.

[25] Abma TA, Pittens CA, Visse M, Elberse JE, Broerse JE. Patient involvement in research programming and implementation: A responsive evaluation of the Dialogue Model for research agenda setting. Health Expect. 2015 Dec;18(6):2449-64. doi:10.1111/hex.12213.

[26] Broerse J, Elberse J, Pittens C, Abma T and Visse M. Patiëntenparticipatie bij programmering en implementatie van onderzoeksagenderingen: het evaluatieonderzoek. http://participatiekompas.nl/sites/default/files/eindrapport%20ZonMw%20evaluatie%20onderzoeksagendering_Athena.pdf

The Dialogue Model has been or is being used to develop approximately 15 research agendas including burns, diabetes, kidney diseases, cystic fibrosis, respiratory diseases, dementia, Lyme disease, bipolar disease, visual impairments, cardiovascular diseases and others.

Methodology

The Dialogue Model is based on the methodology of Responsive Evaluation and the Interactive Learning and Action (ILA) approach, which enables end-users to have a role in decision-making on innovation processes in various societal domains.

There are five phases to the Dialogue Model: these are exploration, consultation, prioritization, integration and finally programming and implementation. The result is an integral research agenda, which is translated into a funding programme or plan, and action is taken to translate the plan into actual research.

The Dialogue Model uses a mix of methods, including interviews and focus groups in the consultation phase, and questionnaires or the Delphi Method in the prioritization phase. In the integration phase, dialogue is used to integrate the different perspectives and encourage mutual learning. An external facilitator creates the conditions for dialogue, stimulates mutual learning and, if necessary, acts as a mediator.

The BhURN project

The methodology and possible outcomes of the Dialogue Model are illustrated in more detail on the basis of the BhURN project (**B**randwondenonderzoek **h**eeft **U**w **R**eactie **N**odig – Burns Research needs your input) [27] [28]. The initiator of the project was the Dutch Burns Foundation (Nederlandse Brandwonden Stichting) while the Athena Institute (VU Amsterdam) facilitated the process, which was conducted in 2006-2007. The aim of the exercise was to compose a research agenda, launch research covering the entire field and highlight priorities by involving all the relevant stakeholders.

1. Exploration phase

During the **exploration phase** the project team is established, key stakeholders are identified, an initial list of issues, perspectives and ideas of patients and other stakeholders is drawn up, and the social conditions for collaboration are created. Choices are also made concerning methodologies and literature and desk studies concerning the scope and content are carried out.

The stakeholders involved included patients and relatives (parents and spouses), researchers biomedical and clinical) and health professionals (medical specialists, physiotherapists, psychologists, paediatricians and others).

2. Consultation phase

During the consultation phase stakeholder groups are consulted separately to develop a list of research topics from the perspective of each stakeholder group. In the case of BhURN case, two different trajectories were followed.

To survey the patients, five focus groups were organized, attended by a total of 26 patients, 10 parents, and one spouse. A standardized conversational method and a timeline were used to gather the needs, concerns and questions of people with burns.

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[27] Broerse JE, Zweekhorst MB, van Rensen AJ, de Haan MJ. Involving burn survivors in agenda setting on burn research: an added value? Burns. 2010 Mar;36(2):217-31. doi: 10.1016/j.burns.2009.04.004.

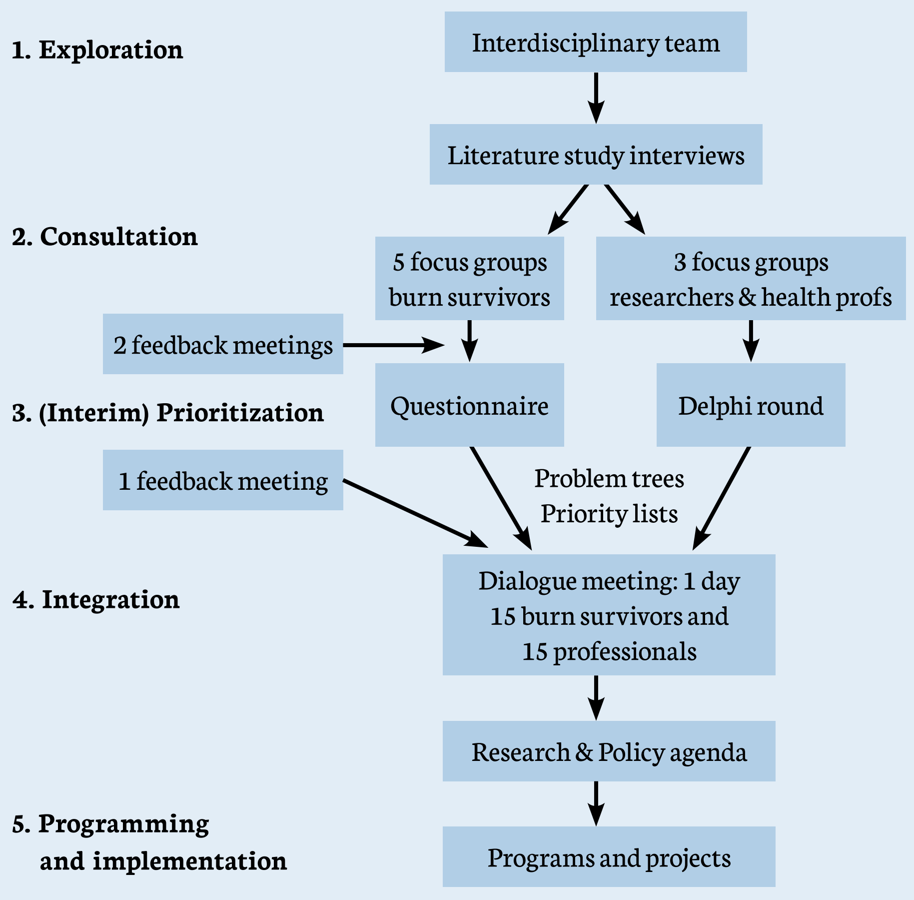
[28] Nederlandse Brandwonden Stichting and Vrije Universiteit Amsterdam. Agenda Wetenschappelijk Brandwondenonderzoek 2007-2010. Het 'BhURN-project'. March 2007. http://www.participatiekompas.nl/sites/default/files/KB14_Agenda%20wetenschappelijk%20brandwondenonderzoek_Nederlandse%20Brandwondenstichting_Vu%20Amsterdam_2007.pdf

The results are used to draft the BhURN survey. Two feedback meetings were held with 16 patients to probe the content of the focus groups and to beta-test the survey.

To survey the opinions of researchers and health care professionals, 'Rehabilitation', 'Fundamental research' and 'Prevention' were chosen for three different 'theme meeting' focus groups. For the themes 'wound care' and 'acute care' the research topics were identified by the Dutch association of burns care centres (VSBN) in a research agenda exercise they had performed a year before. During the theme meetings, the current state of the art was established and unmet needs and concrete research questions were proposed. Non-theme related researchers were included to get a broader view.

The reports of all focus groups were sent to the participants for feedback. Subsequently, the identified problems were integrated for each stakeholder group and presented schematically in an argumentation diagram with a tree structure: causes at the bottom and consequences on top with links between them. The identified research topics were included in a list.

The Five phases of the Dialogue Model by the Vrije Universiteit Amsterdam



3. (Interim) Prioritization phase

During this interim prioritization exercise the homogeneous stakeholder groups rank the research topics identified in the previous phase.

In the patient group, this was done by means of a survey consisting of three parts: general characteristics; summation of categorized research themes and evaluative questions. During the categorization, the participants were asked to rank 10 themes and select the top four most important themes. Each theme consisted of six topics, and within the themes, respondents were also asked to define the top three topics. The results of this prioritization (the top 15 research topics) were discussed during a feedback meeting by the group of patients and close relatives who were to participate in the Dialogue meeting (see next phase). This would also prepare them for the dialogue.

The document for the Delphi round was sent to several key figures in the field of burns research (scientific advisory board of the Burns Foundation, VSBN, plastic surgeons, a paediatrician, a psychologist etc.). The initial reactions suggested the use of additional personal interviews. This resulted in three different priority lists.

Considerable overlap was observed between the research priorities of burn survivors and professionals, particularly with respect to biomedical and clinical research on wound healing and scar management. However, differences were also observed, e.g. treatment of itching and oedema on scars and donor sites, and epidemiology of burn accidents.

4. Integration phase

During this dialogue phase the prioritized research topics of each stakeholder group are integrated into a single broadly supported research agenda. For this purpose, a one-day dialogue meeting is set up using the 'Nominal Group Technique'. In the case of the BhURN exercise, 30 participants (14 patients, 16 health professionals/ researchers) attended the meeting. During the dialogue meeting, the project team presented an integrated argumentation tree showing the problems identified during the in-depth phase. Subsequently the participants were divided into three heterogeneous groups to discuss and integrate the four priority lists that resulted from the third phase. After consolidation and approval of the list in a plenary session, the participants score the themes and topics to achieve prioritization.

While many of the topics in the top 15 came as no surprise, some of the topics were entirely new. The example of 'itching' as a research priority is compelling: it was placed on the agenda entirely by patients and was withheld from the top priorities during the dialogue, because professionals were persuaded of its relevance by patients.

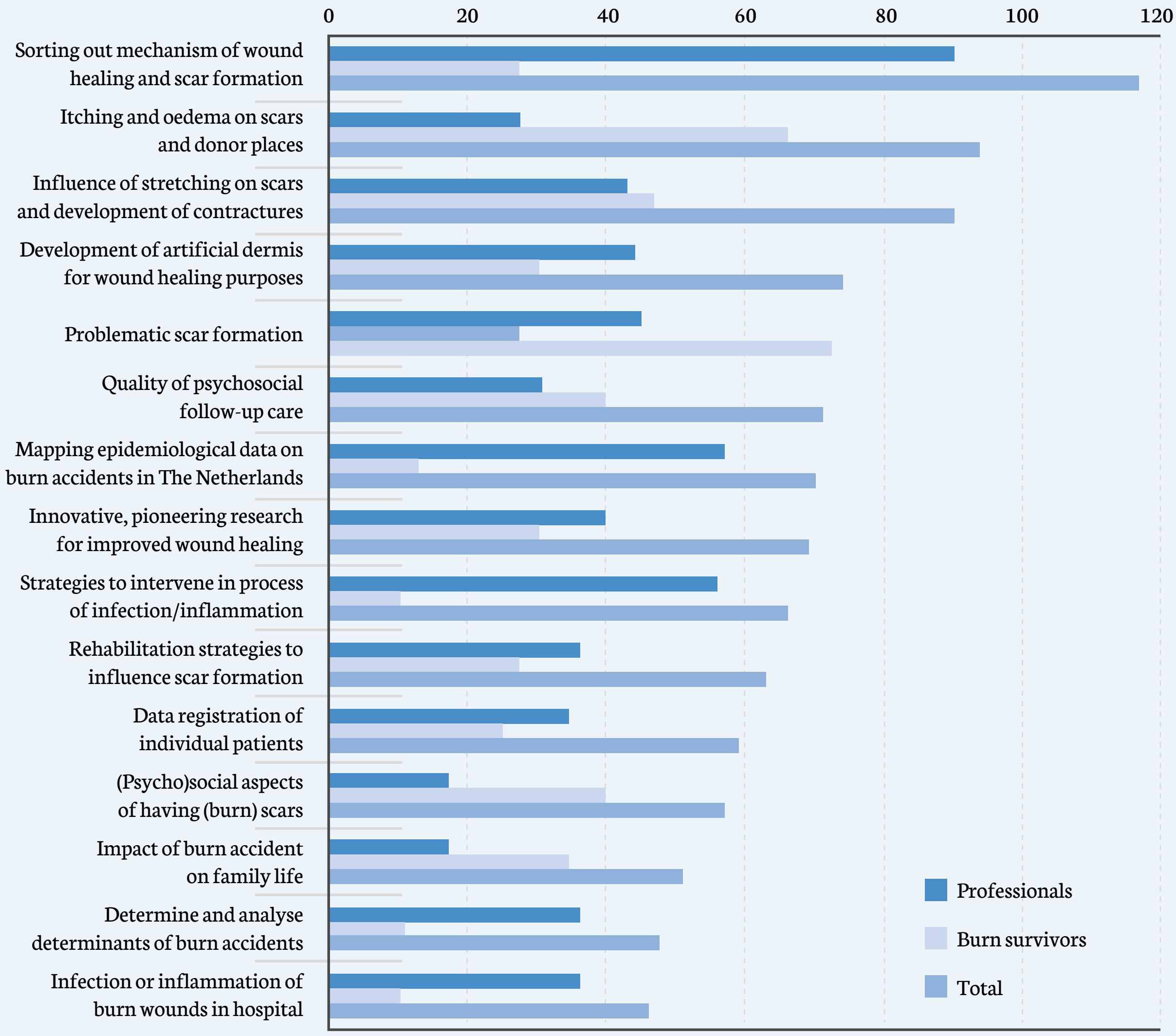
5. Programming and implementation phase

The integrated research agenda is translated into a funding programme or plan during the programming phase, and action is taken to translate the plan into actual research during the implementation phase.

The Dutch Burns Foundation coordinated the programming and implementation of the integrated BhURN prioritized research agenda. The priorities were all included in the subsequent call for proposals.

It was noted during program implementation that prioritization of a research topic does not mean researchers will automatically follow up. For example, while 'itching' was among the top priority topics, there was little to no interest from the research field when the Burns Foundation organized a call for research projects based on the priority list. This caused the Health council to include the topic in their research agendas on unmet needs in medical products in 2011, and an expert meeting on this topic was specifically organized in 2012 to further the research in this field.

Fifteen most highly prioritized research topics with total number of points given and split into points given by professionals and by burn-survivors



‘A prospective vision’ by the Fondation Motrice (France)

Participative deliberation

The French Fondation Motrice (Cerebral Palsy Foundation) created a shared prospective vision setting out the main axes for research, development and innovation to meet the expectations and concerns of people with cerebral palsy and their families and to guide the funding activities of the foundation in this area. The key principle in this program was a participative deliberation involving researchers, caregivers and health professionals, as well as ‘users’ of the research outcomes in the broad sense: people with cerebral palsy and their families. It was the aim of the Fondation Motrice to assess the needs, hopes, expectations and difficulties faced by individuals who are dealing with the consequences of cerebral palsy every day and to turn these into a number of prioritised research questions. Research on these questions would then be sponsored by the Foundation itself, by one of its partner organizations or by other parties.

Methodology

The deliberation consisted of four phases: identification, exploration, multi-college and dissemination.

Four phases leading to the 'Prospective vision' by the Fondation Motrice

1. Identification / preparatory phase
2. Exploration phase

   3 colleges of patients, 4 colleges of professionals

   13 themes
3. Multi-college phase

   SWOT analysis in 4 colleges
4. Dissemination phase

1. Identification/preparatory phase

This multistage phase can be described as 'Meet, discuss, review literature, acquire common knowledge'. Besides a literature study of the current research, several informative meetings were organized to increase knowledge on the subject. The stakeholders involved in this process were patients with cerebral palsy, their family members and companions, doctors, therapists and experts (steering committee).

Furthermore, the Fondation already had thorough insight into the ongoing research in the area of cerebral palsy because of previous research project calls it had organized. These, however, were 'open' calls with investigator-initiated research themes/projects.

2. Exploration phase

Different sessions were organized in three colleges. The first included patients and their relatives (college 1) to explore present and future expectations and needs. The second included the experience and expertise of researchers (college 2), and the third brought in physicians and caregivers (college 3).

This exercise resulted in 13 overarching themes: pain, mobility, communication and language, cognition, lesions: prevention and understanding, associated problems, ageing and fatigue, psychology, interdisciplinarity, evaluation, technological progress and access to information.

Obviously, not all themes can be translated easily into research questions and for a number of themes the questions have already been answered in part or even in full.

3. Multi-college phase

In this phase, four multi-college groups composed of professionals, researchers and patient representatives conducted four SWOT analyses of long-term hurdles on four selected themes: pain, mobility, communication and cognition.

This exercise led to a list of important research topics and also generated a number of cross-cutting themes for treatment and care.

Some preliminary conclusions:

The foremost priority for patients and their relatives is that cerebral palsy is known and recognised. Even though it is the most prevalent motor handicap among children, cerebral palsy still has little visibility among the public or in society, or even among many health professionals. Secondly, families and patients express their need for information (What is CP? Why my child? What is the recurrence risk? Where can I find care? What will happen next? Etc.) Unfortunately, neither of these two priority needs can be linked to research.

On the other hand, patients brought forward themes like ‘pain’, ‘autonomy/mobility’, ‘cognition’ which were hardly recognized by researchers/professionals as important research themes at all before the deliberation exercise. Independently from the Fondation Motrice in France, an Australian survey among cerebral palsy patients and relatives, researchers and clinicians also reached the conclusion that research on pain and pain management was the first priority for research in cerebral palsy research among people with CP. This survey used a Delphi methodology to come to this conclusion.

4. Dissemination phase

The prospective vision of the Fondation was articulated in the book ‘Infirmité Motrice Cérébrale - Paralysie Cérébrale: Prospective’ [29], which has become an excellent communication tool. Although the Fondation has never really succeeded in formalizing a list of research priorities, it started in 2009 issuing an annual call for research projects on pain in cerebral palsy. Together with an industrial partner it was able to launch a call for projects on cognitive disorders, the so-called ‘invisible handicap’ in cerebral palsy.

Since 2011 the Fondation has been focusing on three main research themes in cerebral palsy, partially inspired by the prospective exercise: pain, mobility and language, through a lifetime (i.e. at all ages, including transition periods). Furthermore, the Fondation is continuing to include patients with cerebral palsy and their relatives in the process of setting research agendas. Recently the Fondation has worked in partnership with the FFAIMC (a French nationwide patients’ association) to organize a French national survey on the unmet needs and priorities in rehabilitation reported by people with cerebral palsy and their families, to gain a better understanding of perceptions of the current management and expected improvements in motor rehabilitation.

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[29] Fondation Motrice. Infirmité Motrice Cérébrale - Paralysie Cérébrale: Prospective. http://www.lafondationmotrice.org/sites/default/files/Prospective-IMC-PC_06-10-2009_1.pdf and http://www.lafondationmotrice.org/sites/default/files/Prospective-IMC-PC_06-10-2009_2.pdf

STAKEHOLDERS IN RESEARCH PRIORITY SETTING

Who are the stakeholders that should or could be involved in the stakeholder dialogue? It depends on the topic, the process, the ambition, the scope and the goals of the exercise. It is important to be aware that besides a number of stakeholders who are obvious candidates and should ideally be involved, there are also parties who directly or indirectly influence research agendas. Before a dialogue is set up, carefully considered mapping of the possible stakeholders should take place.

Frequently involved stakeholders …
The participants in the workshop identified three key players that currently play major roles in research agenda setting: researchers, industry and research funders.

1. Researchers: Especially in basic or fundamental research, the curiosity and interests of the researcher often represent the main driver of research and the research agenda. Investigator-initiated research is linked to the concepts of freedom of research, knowledge creation, and independence. Researcher-driven research also comes closest to one of the more common definitions of scientific research as a systematic way of gathering data to harness human curiosity. Therefore, the interest and curiosity (of the individual researcher, the research team or the research consortium) largely shape fundamental research agendas, and emphasis on (societal) relevance is not always a priority. In more applied research, i.e. also clinical research, its societal relevance becomes more important.

2. Industry: The pharmaceutical, biotech and life science industry is investing heavily in health and biomedical research. The lion's share of industry funds are devoted to drug and device development, rather than fundamental research. As an important sponsor of research, they are considered to be an influential player with a far-reaching influence on research programming.

A number of participants in the workshop mentioned that other industrial sectors are becoming more and more attracted to health and biomedical research. Examples are the food industry (healthy foods), the ICT industry (sensors, health apps etc.), the sports industry etc.

3. Research funders: Public and private/philanthropic funding has traditionally targeted a wide range of investigator-initiated research, promoting an unrestricted environment of (biomedical) discovery that forms the basis for industry-driven development. Nevertheless, more recently many public funders have complemented or even replaced their traditional general funding strategies with more focused funding programs, very often including aspects of societal relevance. One example is the EU Horizon 2020 research programme, which is oriented towards specific research topics and areas of disease.

In some countries, public and private/philanthropic bodies (e.g. disease-specific charity foundations) also sponsor clinical research on topics/indications that are of less interest to the industry or to comparative trials. Examples in Europe are the UK National Institute for Health Research (NIHR) or ZonMW in The Netherlands.

In the healthcare and biomedical sector, Belgian public funders are strongly oriented towards basic or fundamentally oriented research rather than clinical research. Very recently the Belgian Health Care Knowledge Centre (KCE) has started work on development of a publicly funded clinical trial programme.

Stakeholders in research priority setting

..but don't forget …

4. Patients and patient organizations – as mentioned in the earlier chapters, patients and the organizations representing them are seldom consulted in research agenda setting. Although they are the primary users of the research results, their specific knowledge, experience and expertise is undervalued and underused.

Exceptions do exist; wealthy patients sometimes set up foundations that are involved in research funding; well-organised patient organizations run their own research programmes; or they set up influential lobbying organizations forcing policymakers and international organizations to reset their research priorities. Examples are the Fondation Motrice France, the Michael J. Fox Foundation, which is a world wide major player in Parkinson's disease research, and the many cancer foundations around the world.

5. Informal caregivers (spouses, parents, children, friends of patients) are also an underused source of information about patient needs. Patients themselves are often too sick or disadvantaged to express their own interests. In such situations, their relatives and loved ones, their nearest and dearest can play a role in consultation processes to make their own voices and patients' voices heard. At the same time, informal caregivers have to deal with major problems of their own, so their own needs also need to be identified.

6. Care professionals, even medical doctors, have surprisingly little influence on research programming if they are not researchers themselves. Nevertheless, they have unique practical experience because they work with the results of the research (drugs, medical tools, devices, treatments etc.). This is true not only for medical doctors but also for nurses, physiotherapists, social workers and others.

7. Citizens. It is important to distinguish between the role and perspective of the citizen versus the patient. Generally, the citizen's perspective is more closely related to the 'general interest'. Of course there may be some self-interest, but generally speaking, it is his civic consciousness that is being addressed, while the perspective of the patient relates mostly to his experience of living with the disease. Citizens, as representatives of the 'general interest of society' can be called upon at some stages in consultations on a participatory research agenda.

In this area it is also important to distinguish between the 'individual' and the 'representative' perspectives: from the individual perspective the participant takes part in his own name and represents his own personal view. A representative person, on the other hand is highlighting the stake and putting forward the opinion of a group or organization.

Did you think about …

Apart from these 'obvious' stakeholders, the participants in the KBF workshop identified at least a dozen other stakeholders who have direct or indirect influences on research agendas. These include:

Universities, research organizations and hospitals exert their influence on research agendas indirectly through the researchers and doctors they appoint. On the other hand, most of these institutions and organizations also have their own budgets for research. In theory this gives them direct leverage over research programming.

Pension funds and other **institutional investors** (such as insurance companies, banks and others) are important direct and indirect shareholders in pharmaceutical and biotech companies. They can exert their influence through the boards of these companies, which includes the research topics / disease indications / health needs that are prioritized.

Private equity investors have been attracted to healthcare and biomedical research and development companies (usually small and mid-size companies) in recent years. The aging population, the growing need for innovative medications and new medical devices to prevent and treat various medical conditions are all seen as attractive investment opportunities.

Although **politicians** are seldom directly involved in research agenda setting, they may have an indirect influence through the public funding bodies for which they are responsible or through the initiation of targeted research programs.

Some **Pressure groups, NGOs, lobbies etc.** may have agendas that extend to research (i.e. the GMO debate, the vaccination discussion, but also research on pollution, biodiversity, traffic control, healthy lifestyles etc.). By lobbying policymakers or via the press, these groups are able to have an influence on research programming.

The **scientific press** (and other media) may be an underestimated, although indirect player in research programming. Biomedical and health scientists try to publish their research in high-ranking scientific journals like Science, Nature, Cell and related magazines because this increases their prestige and funding opportunities. As a result, they may be inclined to work on research topics that are more easily accepted in these journals. Through this mechanism editorial boards have the capacity to subtly but significantly influence research agendas.

Technology assessment (TA) organizations, **registration agencies** (EMA, FDA etc.), **healthcare reimbursement agencies**, **insurers (sick funds), employers and unions (or other civil society organizations)** can also have a role in research agenda setting, depending on its scope and the topic involved. Until now their influence is considered to be indirect or even marginal. But this could change in the future. Especially governmental TA organizations and/or registration agencies could extend their influence.

BENEFITS FOR SPECIFIC STAKEHOLDERS

In the first chapter, some general benefits of multi-stakeholder consultation in research are mentioned on the basis of the scientific literature. During the workshop these benefits were further spelled out for each of three main stakeholder groups: researchers, users and funders.

Researchers and the scientific community
the use of plying multi-stakeholder dialogues in research could be beneficial for the following reasons:

- increase the relevance of research;
- give researchers access to new knowledge, new data, new perspectives and new horizons;
- generate new research questions and research themes;
- make it easier to implement findings in clinical practice;
- improve the quality of research with less waste, greater feasibility, better outcomes and higher cost-effectiveness;
- obtain results which are easier to communicate;
- foster multi-disciplinary approaches to research;
- harmonize applied clinical research and fundamental biomedical research.

Patients, informal and formal caregivers
(the end users of the research), participation in setting research agendas can lead to :

- empowerment;
- meaningful inclusion and engagement;
- unmet needs being identified and addressed;
- inclusion of user perspectives and experiential information from the outset in research, design and development of health practices;
- outcome parameters and criteria which are adapted to needs;
- a balance between realism and hope, to avoid creating false hope.

Research funders
(governmental, industrial, philanthropic and others, as well as taxpaying citizens) shared research agendas can:

- identify unmet needs in society;
- avoid mismatches between what is being researched and what should be researched for the benefit of patients and society;
- increase accountability and transparency;
- balance scientific excellence with societal relevance;
- increase the efficiency of research and cost-effectiveness of healthcare;
- increase the sustainability of the research and development system and of the healthcare system;

- provide opportunities to combine collective outcomes (evidence-based observations) with individual-based experience;
- increase economic benefits from research through better technology transfer;
- create opportunities through funding of shared research priorities to really make a difference in the lives of patients.

Some examples with a concrete impact
Several high-impact cases have been highlighted in the literature and during the KBF workshop. Katherine Cowan, representing the James Lind Alliance showed four cases in which topics from PSP top 10 research priorities have led to actual research:

- The Q7 uncertainty of the PSP on asthma (What are the benefits of breathing exercises as a form of physical therapy for asthma – a topic which was unlikely to be raised without patient input) led to a clinical study sponsored by the UK National Institute for Health Research[30].
- The Q10 uncertainty of the PSP on schizophrenia (What interventions could reduce weight gain in schizophrenia?) led to the STEPWISE education trial (STructured lifestyle Education for People WIth Schizophrenia) also sponsored by the UK National Institute for Health Research[31].
- The outcomes of the 'Sight Loss and Vision' PSP were used in the £5,612,340 call for research projects by 'Fight for Sight' a UK non-profit funder of fellowships and grants for vision research, in a £2,000,000 NIHR initiative funding three clinical trials addressing priorities in cataract, glaucoma, and keratoconus, and in a £700,000 call for grants issued by the Macular Society.
- In late 2015, Marie Curie, in partnership with Chief Scientist Office (CSO) and Motor Neuron Disease Association (MND Association), announced that they will be spending up to £1.425 million to fund high-quality research on palliative and end-of-life care. The submitted research projects should address one or more of the research priorities identified by the Palliative and end-of-life care Priority Setting Partnership (PeolcPSP)[32].

The Fondation Motrice in France has an annual call for research projects on pain and pain management in patients with cerebral palsy. Pain was among the top priorities in the multi-stakeholder dialogue exercise that the Fondation conducted.

There are also indications in the literature that multi-stakeholder involvement can have favourable impacts on every stage of the research process[33]. It can help to ensure that research funds are appropriately prioritized, that research evidence is relevant to patients and caregivers, and that recruitment and retention rates in clinical trial improve. It is also likely to support the uptake of research in practice.

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[30] Bruton A, Kirby S, Arden-Close E, Taylor L, Webley F, George S, Yardley L, Price D, Moore M, Little P, Holgate S, Djukanovic R, Lee AJ, Raftery J, Chorozoglou M, Versnel J, Pavord I, Stafford-Watson M, Thomas M. The BREATHE study: Breathing REtraining for Asthma--Trial of Home Exercises. a protocol summary of a randomised controlled trial. Prim Care Respir J. 2013 Jun;22(2):PS1-7. doi: 10.4104/pcrj.2013.00047 and http://www.controlled-trials.com/ISRCTN88318003?q=&filters=conditionCategory:Respiratory,recruitmentCountry:United%20Kingdom,trialStatus:Completed&sort=&offset=50&totalResults=279&page=1&pageSize=50&searchType=basic-search

[31] http://www.controlled-trials.com/ISRCTN19447796

[32] https://www.mariecurie.org.uk/research/funding-research/marie-curie-research-grants-scheme/2016-call-for-applications

[33] Dudley L, Gamble C, Preston J, Buck D; EPIC Patient Advisory Group, Hanley B, Williamson P, Young B. What Difference Does Patient and Public Involvement Make and What Are Its Pathways to Impact? Qualitative Study of Patients and Researchers from a Cohort of Randomised Clinical Trials. PLoS One. 2015 Jun 8;10(6):e0128817. doi: 10.1371/journal.pone.0128817.

Unfavourable outcomes and how to avoid them

Indications that multi-stakeholder dialogues, and patient and public involvement in particular, may have unfavourable impacts upon research or no impact at all have also been published, but these are rare. To really substantiate and quantify the impact of multi-stakeholder involvement in research agenda setting, much work still needs to be done, as was admitted Sophie Petit-Zeman and Louise Locock from the University of Oxford, two protagonists of patient involvement in research in the UK. They concede that the conceptualization and appropriate measurement of impact is a troublesome problem[34]: "Those of us working in this field must robustly examine our own practices with a common set of tools. Otherwise, we will struggle to answer sceptics, such as one researcher who asked: "Why should patients have useful opinions about what directions research should take?" [...] One of the knottiest problems is how best to weigh up anecdotes and evidence. [...] Gathering the evidence base will take time. Methodological issues must be addressed, and the critical question – whether research using patient and public involvement makes life better for patients – is complex."[35]

It is clear from these and other experiences that there are no quick fixes when it comes to assessing the real impacts of multi-stakeholder dialogues on research agenda setting. On the other hand, it is clear that there are some good practices to learn from. Admittedly not all methods and practices are successful. There are do's and don'ts, facilitators and barriers, methods and techniques that can make or break the success of a consultation process such as multi-stakeholder involvement in research planning.

Possible unintended consequences, risks and negative outcomes

Setting up a stakeholder participation in health and biomedical research has its challenges and can lead to unintended consequences, as has already been reported in the literature [a] [b]. These challenges and hurdles were explained in more detail during the workshop.

Incorporating user and other stakeholder views into the research agenda may lead to divergence from scientific methods in the study that is set up and can cause ethical dilemmas during protocol design. The literature describes cases where public and patient involvement provided a significant challenge for researchers because of tensions between the academic criteria defining good quality research and user perspectives of what constitutes good research.

There are further harms relating to stakeholder frustration with the lengthy process that involves training, reading, transportation, attendance at workshops and meetings. On the other hand, lack of preparation and training can lead to feelings of being unable to make a significant contribution.

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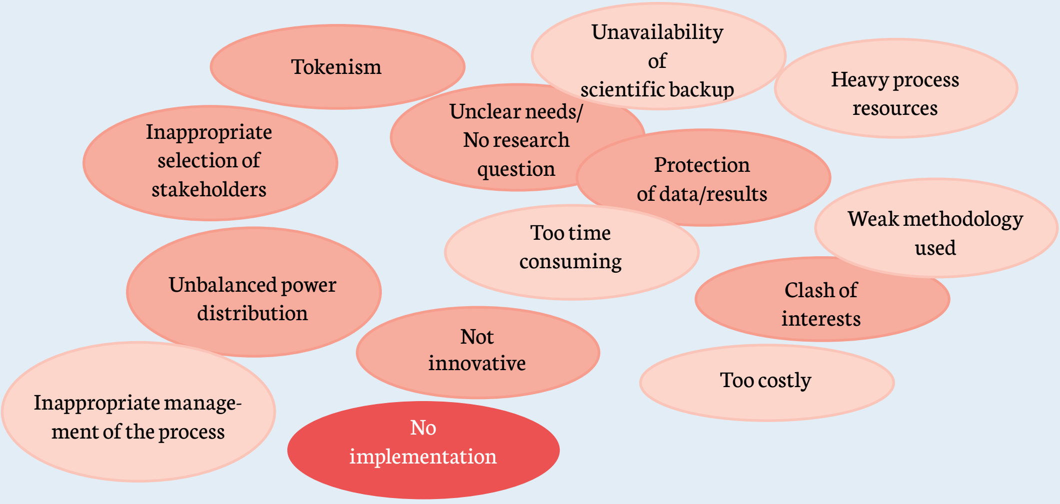
[34] Petit-Zeman S, Locock L. Health care: Bring on the evidence. Nature. 2013 Sep 12;501(7466):160-1.

[35] A helpful report exploring impact is: http://www.invo.org.uk/wp-content/uploads/2011/11/Involve_Exploring_Impactfinal28.10.09.pdf

A more common concern and worry is that stakeholder engagement may become tokenistic (a false appearance of inclusiveness), resulting in a devalued input from the stakeholders in question. In other situations, power struggles have arisen between researchers and stakeholders because researchers might feel that they are losing control over their own research.



There are also organizational and logistical aspects. Stakeholder dialogues are costly and time-intensive processes involving many practical aspects of planning and management, including building up relationships within the community and setting up stakeholder groups, training and education of stakeholders and researchers, the time and budget needed for dissemination etc.

And lastly, it is not always guaranteed that the deliberation will really lead to new insights. Also some of the poignant needs and priorities brought forward by stakeholders might not be translatable into research questions because they might relate to organizational aspects of healthcare. There may also be a lack of funds or interest to implement and translate the research priorities into research programmes that are actually implemented.

a Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, Brito JP, Boehmer K, Hasan R, Firwana B, Erwin P, Eton D, Sloan J, Montori V, Asi N, Dabrh AM, Murad MH. Patient engagement in research: a systematic review. BMC Health Serv Res. 2014 Feb 26;14:89. doi: 10.1186/1472-6963-14-89.

b Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, Suleman R. Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expect. 2014 Oct;17(5):637-50. doi: 10.1111/j.1369-7625.2012.00795.x.

INGREDIENTS FOR SUCCESSFUL RESEARCH AGENDA PRIORITIZATION

The three examples described earlier in this document show that careful planning of a stakeholder dialogue/prioritization activity is important to set up an exercise that will meet expectations. It must be realised that successful multi-stakeholder dialogues are tailor-made. No two dialogues are perfect copies of each other. In each dialogue, the content, the stakeholders involved, the context and the aims are different. Nevertheless, there are a number of ingredients which are indispensable and will contribute to a successful outcome.

Thoughtful but flexible planning

A number of comprehensive approaches to health research priority setting have been described in the literature[36]. These approaches provide structured, detailed, step-by-step guidance for the entire priority setting process. Two such comprehensive approaches, the JLA Priority Setting Partnership and the Dutch Dialogue Model have been described earlier and can serve as good practices.

Most multi-stakeholder dialogues consist of four distinct phases: a preparatory phase, a consultation phase, a prioritization phase and a dissemination/implementation phase. During the planning of the dialogue, many of the issues in all phases should be considered and decided upon. On the other hand, flexibility is key to the process. It is important to approach unexpected results or challenges with an open mind and to be prepared to make adjustments during the course of the dialogue.

Ownership

One of the most important initial questions is ‘ownership’. Who is the initiator of the activity? Who is the owner of the problem(s) that need to be researched? Who is the main driver of the priority exercise? Who will manage dissemination of the results and their implementation into research activities?

The owner is usually the organization that initiated the priority setting exercise, but ownership can be expanded to include other committed stakeholders who might provide resources, expertise, funding, and/or staff. Necessary conditions to claim ownership include engagement, interest, commitment and responsibility towards the outcomes.

> *“The difficulty of defining research priorities in a context of limited operational means and restricted resources for funding should not be underestimated, especially if one - as a patient organization - has a responsibility toward all patients. It is a constant balance between priorities and opportunities, specificity versus transversality, short term versus long term, fundamental versus clinical research.”* Lucie Hertz-Pannier, Fondation Motrice , France.

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[36] Viergever RF, Olifson S, Ghaffar A, Terry RF. A checklist for health research priority setting: nine common themes of good practice. Health Res Policy Syst. 2010 Dec 15;8:36. doi: 10.1186/1478-4505-8-36.

A few examples of possible owners :

- a patient organization that wants to expand its traditional field of action (patient contacts, health policy lobbying, information dissemination etc.) to include research, in order to find innovative solutions to pressing patient needs. Sometimes, these patient organizations are also able to fund the research itself;
- a (group of) researcher(s)/clinician(s) who want to steer their research towards topics with high societal relevance;
- a research funding or philanthropic organization that wants to maximise the return on its investment;
- a healthcare or pharmaceutical company;
- a consortium of the parties mentioned above.

A multistage process

Planning and preparatory phase:

1. Ownership - and steering group
2. Partners
3. Context and scale
4. Information / data gathering
5. Planning of implementation (after the agenda is set)

Consultation - phase 1:

1. Consultation in homogeneous stakeholder groups
2. Data gathering and relevance check

Consultation - phase 2:

1. Consultation in heterogeneous group
2. Prioritization

After prioritization:

1. Evaluation
2. Transparency of results
3. Dissemination of results
4. Implementation of agenda

Steering group or management team

The owner(s), together with the person(s) in the research team who are carrying out the project and/or accompanying the dialogue form the steering group or the management team. This team may be extended to include a limited number of representatives from key stakeholders. This group coordinates the dialogue, organizes the activities, acts as an initial point of contact and carries out the research. The value of these vital roles being held centrally and consistently throughout the project cannot be overstated[37].

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[37] Cowan K and Oliver S. The James Lind Alliance Guidebook, version 5. www.JLAguidebook.org

“A committed steering group, a well-defined scope, coordination and administrative support, active, transparent and accessible communication, a vision on the stages after the priority setting exercise, and sufficient resources: all of these are critical key factors for a successful priority setting partnership,” Katherine Cowan, Senior Adviser James Lind Alliance.

Stakeholder mapping and involvement

It is important that all organizations, with a potential stake in the research prioritization exercise, are invited to become involved. This is a prerequisite for increasing transparency, guaranteeing inclusiveness and demonstrating that the way the priorities were agreed was fair.

Managing values and perspectives

Diverging values and principles between different stakeholders or disciplines are likely and should be resolved in a fair and legitimate manner. It is likely that groups and individuals in a stakeholder dialogue may have particular issues that they want the priority setting exercise to address.

It is important to state and encourage understanding of the differing perspectives of patients, carers, clinicians, researchers and other stakeholders. According to the James Lind Alliance Guidebook *“no one group should feel marginalised or perceive that their views are less valid than any others, whether they speak as someone with the condition, as someone caring for another person with the condition or as a healthcare professional working with people with the condition. It is the facilitator’s role to ensure that this principle is maintained, and the responsibility of the steering group to model it. It is important to ensure that people are treated fairly and sensitively and supported during this process.”*

Everyone should have equal opportunities to contribute their particular concerns. *“However, when it comes to priority-setting, the participants have to set aside their personal agendas and work with priorities that will deliver maximal benefits to all.”*

Stakeholders should also be selected and balanced on the basis of the diversity of their perspectives. Broad stakeholder involvement (based on multidisciplinary and multi-sectorial backgrounds) minimizes the likelihood of research being overlooked. As many different perspectives as possible should therefore be consulted, involved and informed. Each of the stakeholders should realize that their perspective only represents ‘a tip of the iceberg’. One of the aims of the stakeholder dialogue is to uncover the invisible part of the iceberg through mutual learning from and exchanging perspectives with other groups.

Sometimes, however, there are so many stakeholders, that stakeholder management becomes complex or even impractical. It is important to realise that a number of the stakeholders listed are only indirectly involved with the relevant area, have only a minor stake, or may not commit themselves to the project.

Therefore, from a governance point of view, establishing an executive committee or an advisory group consisting of stakeholders to provide guidance throughout the whole process is a good idea. This group is regularly informed about the strategies, methods and outcomes of the various phases of the process and represents a practical method of stakeholder management. Moreover, the group can serve as a sounding-board during these information sessions. A well-informed advisory group can form the basis for a strong societal support base for the process and the results.

> *"Key principles for participative research priority setting are accessibility for maximum participation, feasibility for your context and resources, transparency to allow scrutiny and appraisal, evidence-based wherever possible and accountability to those that participated."*
> Sally Crowe, Director Crowe Associates, UK.

Context and scale

The practical considerations about available resources (budget, time, staff), but also the focus, scope and the scale of the exercise are contextual factors that underpin the process. What is the exercise about and who is it for? Factors such as the target disease, geographical scope, long-term or short-term priorities, intended target populations (children, older people or others) should preferably be set in advance[33].

It remains important that the agenda stays directed towards research during continuation of the process. If the scope is defined in excessively general terms (or becomes too general during the process), many themes will not be translatable into research questions, but may relate to patient or societal needs that require policy action rather than research action. To overcome this problem, a 'parking board' might be installed during the deliberation phases to evacuate these priority needs temporarily from the discussion. These pressing needs can then be taken up in the final report, but not as research questions.

Information and data gathering

Everyone has a vested interest in being well informed at the beginning of the dialogue. There are many ways to make the dialogue and priority setting exercise well informed and choices should be made on which types of information are needed. These can include collection of technical data (causes and determinants of diseases, burden of diseases, current research and research resources, effectiveness and cost-effectiveness of current interventions etc.). In order to be able to prioritize research, one must also know where the gaps in knowledge are. Screening of the scientific literature and other knowledge bases (guidelines, meta-analyses etc.) is therefore necessary.

Information used during the dialogue should always be presented in plain language. The content should be accessible to all stakeholders.

Finally, other organizations, possibly in other countries, may have already completed the same exercise. In these cases one must assess whether repetition of the exercise offers added value or whether one should refocus the scope.

Planning for implementation

Evaluation of the results of dozens of JLA Priority Setting Partnerships, 15 priority setting cases using the Dutch Dialogue Model and the case of the Fondation Motrice in France reveals the importance of good planning of the implementation phase before the launch of the dialogue. Health research priorities that are set by an 'owner' (patient organization, governmental organization, research institute, philanthropic organization) wishing to inform its own funding policy, are more likely to lead to successful translation of the research priority list into the research actually carried out. Many research priority exercises have faced considerable implementation difficulties because the stakeholders involved in setting the priorities were not directly responsible for their implementation.

Therefore, planning for implementation cannot be delayed until the phase after priorities have been established. It should be mapped out in advance:

- which stakeholders must be included in the exercise in order to guarantee feasible and sustainable implementation;
- involvement of engaged, committed and dedicated funders from the beginning of the dialogue and in the core of the process increases the chance of translating the priorities into actual research.

From consultation to control

According to Jacqueline Broerse, head of the VUAmsterdam based Athena Institute, varies levels of stakeholder participation can be distinguished. Each level has its advantages and disadvantages.[a]

Type of participation	Advantages	Challenges/Disadvantages	Method
Consultation	Quick access to stakeholder input	• Stakeholder has no direct influence on policy making • May frustrate stakeholder • Less learning (homogeneous group)	• Focus group • Interview • Survey
Partnership	• More relevant research • More ownership of stakeholder • Creation of common knowledge and objectives	• Takes more time • Empowerment of stakeholder needed • Classical stakeholders (researchers etc.) lose control • May reduce to placation	• All of the above + joint workshops (+ possibly involvement of stakeholder in all stages of research by serving on study board or advisory council)
Stakeholder control	• Able to access marginal groups • Stakeholders obtain research competencies • Commitment to dissemination	• No ownership by researchers • Not all research lends itself to stakeholder control	• Stakeholder controls all phases of research

a Jacqueline Broerse, Client Participation in Research Agenda Setting: the Dialogue Model. Presentation during the KBF workshop on November 27-28, 2015.

Broad consultation – divergence and convergence

Homogeneous group consultation

Most methods involve a broad consultation phase before the priority list is completed. During the consultation phase, broader stakeholder views on matters related to research, priority needs and uncertainties need to be gathered. These come from the stakeholders themselves and from the people they represent.

Gathering of these opinions is most often done through in-depth interviews (face-to-face or by telephone) and focus groups (exploratory and qualitative phase). These consultations are performed separately for the different stakeholder groups and use whichever methods are best suited to the stakeholders' membership, resources and infrastructure. An example: for some diseases, it is not good practice to bring patients together physically because of infection risks. In other cases, the setting and consultation methodology should be adapted in accordance with patients' restrictions.

Interim prioritization

An initial gathering phase of this kind is characterized by divergence and consolidation phases within each stakeholder group. After broadening the scope, priorities (although not necessary ranked) should be defined and weighted within each stakeholder group. This can be done by using surveys in electronic or paper formats (quantitative phase). Another possibility is to use the Delphi methods within a stakeholder group to define priorities by mutual agreement.

In any case, interim prioritization in all stakeholder groups needs to be backed up with data coming from scientific literature and medical practice to avoid selecting questions/uncertainties that have already been resolved.

The Dutch Dialogue Model tends to use methodologies based on dialogue to arrive at intra-stakeholder priorities. Additional validation meetings and/or Delphi methods are often deployed to reach a concerted agreement among the homogeneous stakeholder group.

In Priority Setting Partnerships by The James Lind Alliance the interim priority setting process may be carried out by the whole Partnership or by the representative steering group, although the JLA does not impose a strict method for this stage, as long as the process is transparent and the results are reported. Where the whole partnership is involved, priority setting can be conducted by e-mail and/or post, using interim prioritization templates with scoring systems. Completed interim prioritization forms are grouped into answers from patients/carers and contributions from clinicians. Separate scores are kept to ensure a fair weighting of priorities in the different stakeholder groups. This process leads to a 'shortlist' typically including 25-30 priorities.

Integration and prioritization

Mutual learning through dialogue

The aim of this phase is to integrate the agendas of the different stakeholders via a workshop with representatives of all the relevant parties. The purpose of this dialogue is to foster a negotiation on the research agendas.

This workshop provides an opportunity for the different parties to hear different perspectives, express their own views and think more broadly – beyond their own stake/need - about treating or helping people with the health problem that is being discussed.

Given the asymmetries between stakeholders, the workshop should be carefully prepared to give each stakeholder group an equal voice. The following considerations are helpful to increase fairness and a meaningful process:

- a fair representation of all the stakeholders involved;
- use of non-technical language;
- selection of a time and location that is appropriate for all stakeholders;
- a 'level playing field' for all stakeholders: patient representatives might need supplementary assistance and information to be sufficiently empowered, but researchers, funders and others may also need extra support to be aware and sensitized towards patient needs or other stakeholder agendas;
- selection of participants with an open mind.

A particular concern is to have the right balance in terms of numbers between professionals and patients/informal carers, as this is essential to prevent domination of professional knowledge and views. During the workshop, deliberate attention needs to be paid to the attitudes of all other stakeholders towards patient involvement.

A professional facilitator should preferably manage the workshop. He/she should be independent of all the stakeholders involved. Although the format of these workshops is usually rigorous and well planned beforehand, the process should be flexible enough to allow people to change their minds, raise concerns or allow new perspectives to emerge during the dialogue.

The James Lind Alliance and Dialogue Model both use an adapted 'Nominal Group Technique' as a well-established and well-described approach to decision making and final prioritization[38]. This approach allows everyone's opinion to be taken into account, but decisions can also be made quickly, for example by voting. Each participant reviews the items for discussion and gives their view. The workshop is structured with sequential steps of consensus building and alternating phases of personal reflection and choice; small, mixed group discussions; and plenary group discussion. The discussion is all about arguments on why individuals or stakeholder groups consider specific uncertainties/research topics to be important.

A shared voting or ranking exercise is carried out, with further structured small group discussions again followed by ranking or voting. The rankings for each item from each contributor are totalled, and the priority with the highest (position 1 - i.e. most favoured) total ranking is finally selected as the top priority. An important benefit of this technique is that it prevents the domination of the discussion by a single person or stakeholder and encourages the participation of less assertive group members.

Dissemination and implementation

The final phase in the process is intended to disseminate and implement the priority list into funded and executed research programs. This can be carried out by research funders through dedicated calls for projects. If these funders are not involved from the start, a process to influence the wider research and research policy community needs to be elaborated and executed.

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[38] The James Lind Alliance Guidebook. http://www.jla.nihr.ac.uk/guidebook/final-priority-setting/workshop-process-on-the-day

A wide range of factors that influence programming and implementation of the research agenda have been identified at the KBF workshop and/or are described in the literature [23 24 39 40].

- The broader the degree of commitment for a shared agenda among the stakeholders, the easier the translation of the agenda into a research program. Existing partnerships between funding agencies, patient organizations, philanthropic funders and the research community facilitate the process.
- The commitment of individual researchers to focus on topics not directly related to their own research profile, their willingness to collaborate in multidisciplinary research projects, their openness to patients' concerns and their readiness to assume co-ownership of the research agenda are all important.
- The presence of ambassadors with authority recognized by all parties who commit themselves to the project and the outcome, positively affects programming and implementation.
- A research agenda is perceived as more valid if a scientific publication is devoted to it.
- The sections of the public involved can also be ambassadors for the priorities and a public friendly document with process and outcomes is useful for dissemination to the interested communities
- A lack of resources that would allow the parties participating in the research agenda to sponsor research themselves and/or a lack of interest among funding agencies will hamper the implementation of the research agenda. Procedural and/or internal organizational difficulties preventing funders from developing project calls in line with prioritised research agendas may also impede translation of the agenda into actively conducted research.
- A misfit between the timing of research agenda prioritization and research programming of funders can also negatively influence execution of the research agenda.

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39 Pittens ACM, Elberse JE, Visse M, Abma TA, Broerse JEW. Research agendas involving patients: Factors that facilitate or impede translation of patients' perspectives in programming and implementation. Science and Public Policy (2014) doi: 10.1093/scipol/scu010

40 Mockford C, Staniszewska S, Griffiths F, Herron-Marx S. The impact of patient and public involvement on UK NHS health care: a systematic review. Int J Qual Health Care. 2012 Feb;24(1):28-38. doi: 10.1093/intqhc/mzr066.

CONCLUSIONS

There are a number of different methods that can contribute towards the success of a multi-stakeholder dialogue for priority setting in research. This guide does not offer a series of ready-made methods. Before starting any process it is always necessary to reflect on the aims that are being pursued and the stakeholders who need to be involved. It is also crucial to manage everyone's expectations. Ownership of the process by the various stakeholders is a further critical factor that will determine its success.

The enthusiasm of people experienced in the use of multi-stakeholder dialogues or patient and public engagement in setting research agendas, and the positive feedback received from participants in the research and research funding communities have encouraged the King Baudouin Foundation to take additional steps and explore this topic further. Even during the workshop, a number of possible topics for a multi-stakeholder dialogue were put forward. These ideas were diverse in their content, methods and goals.

The King Baudouin Foundation is prepared to explore potential collaborations with stakeholders – researchers and research organizations, patients and patient organizations, funding bodies and philanthropic organizations – that are interested in acting as 'problem owners' and organizing a dialogue of this kind on a specific topic.

APPENDIX

Multi-stakeholder dialogue for priority setting in health research: learning from experiences - 27 & 28 November 2015 - Participants workshop

- Anne-Marie Bauduin, R&D & Innovation, Bauduin & Partners
- Sofie Bekaert, Head of Department Clinical Research Center Bimetra, Professor, Ghent University Hospital
- Bernadette Bréant, Responsable Service Mission Associations Recherche & Société, Inserm
- Jacqueline Broerse, Director Athena Institute, Professor VU University Amsterdam
- Martine Bungener, Présidente du GRAM, Inserm
- Katherine Cowan, Senior Advisor, James Lind Alliance
- Sally Crowe, Director, Crowe Associates
- René Custers, Regulatory & responsible research manager, VIB
- Kristel De Gauquier, Medical Director, Pharma.be
- Karleen De Rijcke, Directeur, Mucovereniging
- Saskia Decuman, Expert R&D, RIZIV-INAMI
- Rudy Dekeyser, Managing Partner, LSP
- Arnaud Goolaerts, Scientific Officer, FNRS
- Sara Heesterbeek, Project Manager RRI Tools, King Baudouin Foundation
- Lucie Hertz-Pannier, Co-founder and past Vice president, La Fondation Motrice Board of administration
- Frank Hulstaert, Senior Researcher, KCE - Belgian Health Care Knowledge Centre
- Anna Jansen, Head of Pediatric Neurology Department, FWO SCI, UZ Brussel, VUB
- Theo Meert, Head of R&D Global Government, Janssen Pharmaceutica, Grant Office (R&D G3O)
- Ulrike Pypops, Adjunct-directeur, Mucovereniging
- Peter Raeymaekers, Science Writer, LyRaGen; Foundation Dystonia Research
- Gerrit Rauws, Director, King Baudouin Foundation
- Catherine Rutten, CEO, Pharma.be
- Eric Salmon, Professor, Neurologist responsible for the Memory Clinic, University Hospital of Liège
- Christiane Tihon, Secretary general, Belgian National MS Society
- Abraham Trujillo Quintela, Research Forum Coordinator, EFC – European Foundation Centre
- Annemiek Van Rensen, Senior advisor, PGOsupport
- Pierre Van Renterghem, General Manager, WELBIO

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