



Roadmap to research partnership at Queen Square

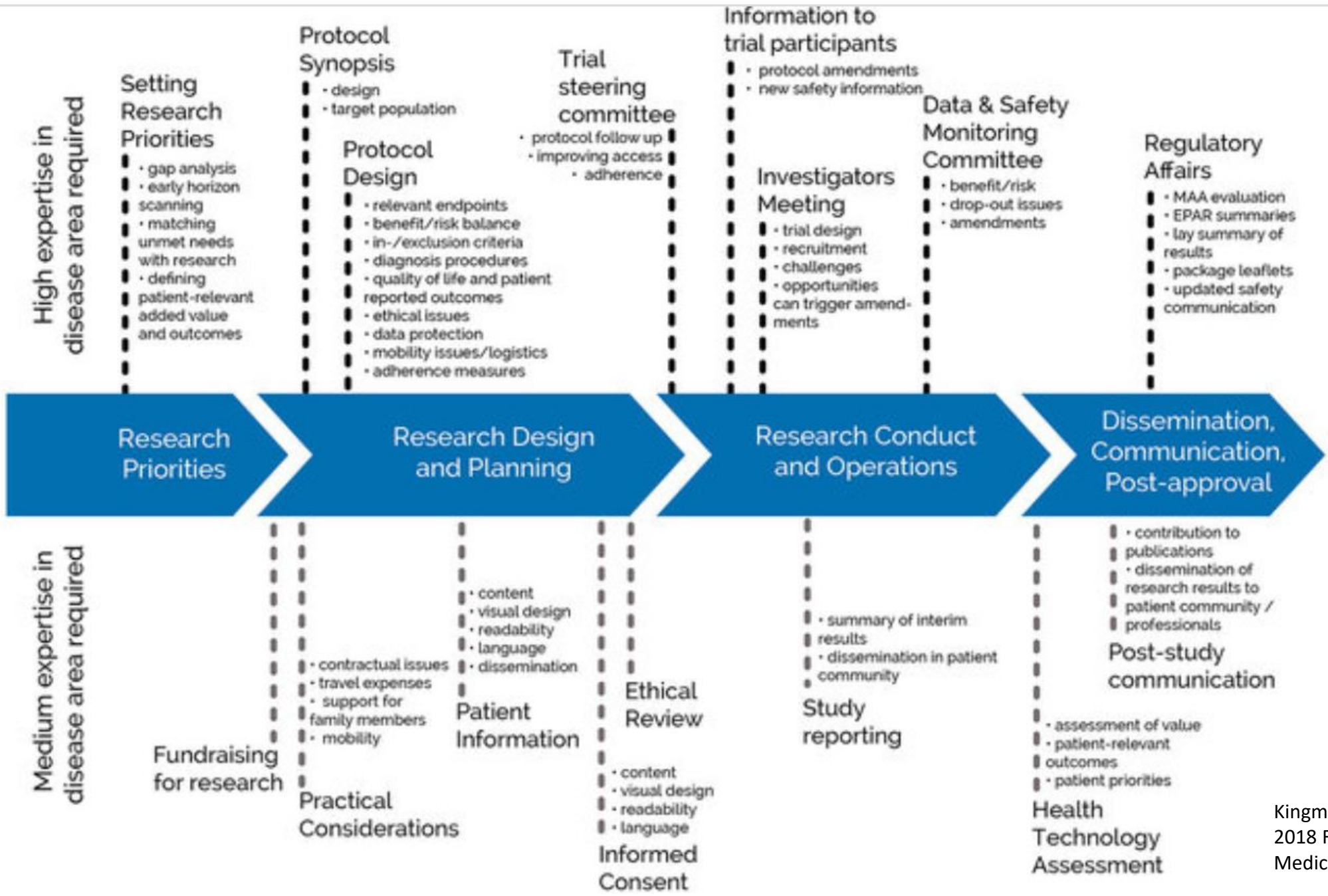
DR AMIT BATLA MBBS MD DM MA FRCP
HONORARY CONSULTANT NEUROLOGIST
MOVEMENT DISORDERS SPECIALIST

Roadmap of research for researchers

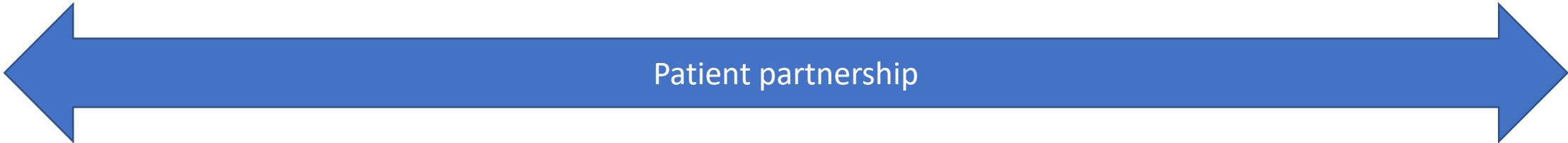
<ul style="list-style-type: none"> • Research ideas • Unmet needs • Existing data 	<ul style="list-style-type: none"> • Funding- grant application • Research protocol approval • Ethics approval • Site initiation 	<ul style="list-style-type: none"> • Participant recruitment • Performing intervention • Results and analysis • Monitoring and reporting 	<ul style="list-style-type: none"> • Writing up results • Dissemination • Approvals • Commissioning
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<ul style="list-style-type: none"> • Research question 	<ul style="list-style-type: none"> • Protocol • Participant information sheet • Consent form • Case report form 	<ul style="list-style-type: none"> • Recruitment • Monitoring 	<ul style="list-style-type: none"> • Publishing results • Adopting new practice
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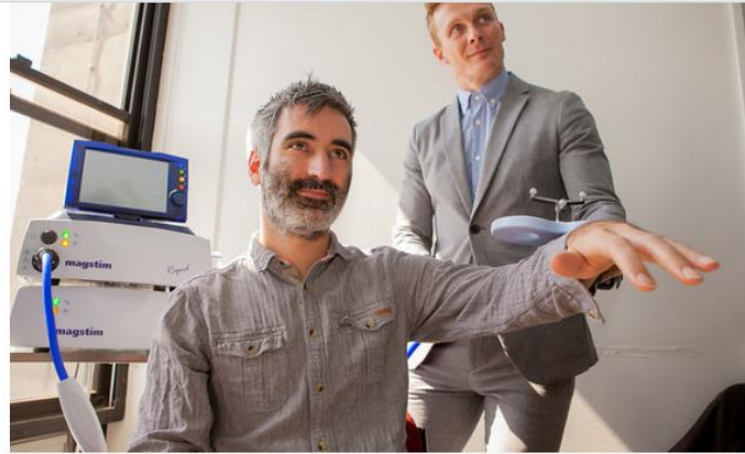




Trials, studies, registries, biomedical research



Clinical Trials (drug and treatment trials)



Clinical Studies (non-drug trials)



Research registries



Biomedical research

Where do you see yourself in research?

BMJ

LONDON, SATURDAY 20 MAY 1995

The rights of patients in research

Patients must come first in research

See pp 1279, 1305, 1313, 1315, 1318, 1338, 1341

Clinical trials cannot be done without patients, and the whole purpose of conducting trials is to benefit patients. These two indisputable statements should mean that patients should be at the front of researchers' minds when they design, conduct, and report medical research. But they rarely are. Too often patients are forgotten in the complex business of conducting research. We argue that patients should help to decide which research is conducted, help to plan the research and interpret the data, and hear the results before anybody else.

The patients certainly seemed to have been forgotten in the

then went on to recommend guidelines on the responsibilities of charities funding medical research.⁷ Controversy still surrounds the trial (p 1341),^{8,8a} and a television programme in the series *Taking Liberties* to be broadcast on 23 May will make further accusations about its handling (see a review on p 1338).⁹

But, as women with breast cancer know better than most, disasters can lead to opportunities and a chance to make major advances. The Bristol study focused thinking on how patients can best be involved in research, and two papers in this week's *BMJ* take up the theme.^{10,11} Iain Chalmers, director of the UK

Suggesting a research question

- Patients should help to set the research agenda- Goodare, Smith BMJ 1995

The screenshot shows the NIHR website interface. At the top left is the NIHR logo (National Institute for Health Research). To the right are four navigation tabs: 'Health and Care Professionals', 'Researchers', 'Patients, Carers and the Public', and 'Partners and Industry'. Below the navigation is a search bar with a magnifying glass icon and the text 'Search...'. Underneath the search bar is a large orange banner with the text 'Suggest a research topic' and a breadcrumb trail: 'Home > Patients, Carers and the Public > I want to help with research > Suggest a research topic'. On the right side of the banner is a stylized leaf icon. Below the banner is a dark blue section with a white box containing the text 'What can we do about pressure ulcers?'. To the right of this section is a 'NIHR blog' section featuring a photo of a woman and the text 'Using my skills in the race to find a vaccine'.

NIHR | National Institute for Health Research

Health and Care Professionals Researchers Patients, Carers and the Public Partners and Industry

Search...

Suggest a research topic

Home > Patients, Carers and the Public > I want to help with research > Suggest a research topic

What can we do about pressure ulcers?

NIHR blog

Using my skills in the race to find a vaccine

Giving your opinion on potential research

- Improve the quality and relevance of research
 - Is the study needed?
 - Is this value for money- what can improve the chances of funding
 - Will the outcome/s of the study impact on your life
- Make sure research is acceptable and will benefit patients and carers
 - Diversity and inclusion
 - Do you think research is practical
- Do you see any barriers in execution of the study or wider application of the outcome of research

You can...

- Review full applications
 - Quality
 - Language- English summary
- Review methodology and suitability-
 - What tests are being conducted
 - What interventions are being used
 - What questionnaires are people being asked to fill in for research
 - Is/are the planned study visit/s practical for a person with Parkinson's

Participate in a study

- Be a participant
- Invite participants
- Help recruit from local groups
- Help as a Parkinson's companion

Speak out

- Review how the study is monitored- be part of a advisory committee or a steering group
- Help with 'Quality Control'
- Share your concerns

- Help us reach out- support our researchers
- Spread the word- share outcomes of our research with community
- Help with commissioning at community level
- Help us with approvals in case of a new drug/ intervention

Become a 'Queen square Parkinson's buddy'

- Queen square Parkinson's buddy will be a core group of people that work with the team of researchers.
- We are looking for a team of keen participants who will be willing to help shape and improve our research
- We will send you an email to ask -
 - If you want to become a Queen square buddy?
 - What aspect you will be keen to help with
 - Research ideas
 - Your experience with participating in research study/studies
 - Application process- application, funding
 - Protocol development- including methodology, suitability and practical application of questionnaires, interventions, etc, with regards inclusiveness
 - Recruitment
 - Monitoring a study
 - Spreading our research in the community like schools church or local group
 - Contribute to the patient column for our webpage
 - Any other ways you can help

Questions about patient partnership

- Send us an email

a.batla@ucl.ac.uk

movementdisorders@ucl.ac.uk