

Leeds Beckett University

National Institute for Health and Care Excellence Protocol for Primary Research Report 1: Community Engagement – Approaches to Improve Health: Map of Current Practice Based on a Case Study Approach

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Prepared by

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1. Research Team

Anne-Marie Bagnall	Centre for Health Promotion Research, Institute of Health & Wellbeing, Faculty of Health & Social Sciences, Leeds Beckett University: 15 days; Principal Investigator, lead and project manager for component 1, stream 2.
Jane South	Centre for Health Promotion Research, Institute of Health & Wellbeing, Faculty of Health & Social Sciences, Leeds Beckett University: 5 days; advice on design & analysis.
Judy White	Centre for Health Promotion Research, Institute of Health & Wellbeing, Faculty of Health & Social Sciences, Leeds Beckett University: 5 days; advice on design and analysis.
Jo Trigwell	Centre for Health Promotion Research, Institute of Health & Wellbeing, Faculty of Health & Social Sciences, Leeds Beckett University: 20 days; co-investigator; data collection and analysis
Karina Kinsella	Centre for Health Promotion Research, Institute of Health & Wellbeing, Faculty of Health & Social Sciences, Leeds Beckett University: 20 days; co-investigator; data collection and analysis.

2. Summary of the Scope

The scope of the evidence covered by this project is outlined in the final Guidance scope document (<http://www.nice.org.uk/nicemedia/live/14266/67533/67533.pdf>).

‘Community engagement’ is used as an umbrella term covering community engagement and community development. It is about people improving their health and wellbeing by helping to develop, deliver and use local services. It is also about being involved in the local political process. Community engagement can involve varying degrees of participation and control: for example, giving views on a local health issue, jointly delivering services with public service providers (co-production) and completely controlling services.

The eligible population is defined as communities defined by at least 1 of the following, especially where there is an identified need to address health inequalities (section 4.1 of guidance scope): geographical area or setting, interest, health need, disadvantage and/or shared identity.

The eligible interventions/ activities are defined as (section 4.2): activities to ensure that community representative are involved in developing, delivering or managing services to promote, maintain or protect the community’s health and wellbeing. An example of a community engagement activity is community-based participatory research. Examples of where this might take place include: care or private homes, community or faith centres, public spaces, cyberspace, health clinics or hospitals, leisure centres, schools and colleges and Sure Start centres. Examples of community engagement roles include: community (health) champions; community or neighbourhood committees or forums; community lay or peer leaders.

Eligible activities also include local activities to improve health by supporting community engagement. Examples include (can be delivered separately or in combination): raising awareness of, and encouraging participation in, community activities, evaluation and feedback mechanisms, funding schemes and incentives, programme management, resource provision, training for community members and professionals involved in community engagement.

The guideline will not cover community engagement activities that: do not aim to reduce the risk of disease or health condition, do not aim to promote or maintain good health, do not report on primary or intermediate health outcomes, focus on the planning, design, delivery or governance of treatment in healthcare settings, target individual people (rather than community).

The eligible outcome is defined as (see section 4.3) improvement in individual and population level health and wellbeing. Other expected intermediate outcomes may include: positive changes in health related knowledge, attitudes and behaviour, improvement in process outcomes, increase in the number of people involved in community activities to improve health, increase in the community's control of health promotion activities, improvement in personal outcomes, improvement in community's ability and capacity to make changes and improvements to foster a sense of belonging, views on the experience of community engagement (including what supports and encourages people to get involved and how to overcome barriers to engagement).

Our inclusion criteria are developed to reflect the eligibility criteria.

3. Overview of the project

The Centre for Public Health (CPH) at the National Institute for Health and Care Excellence (NICE) is developing a guideline on 'Community engagement – approaches to improve health'. The guideline will be developed by a Public Health Advisory Committee (PHAC) in 2014-15 in line with the final scope for this work. The guideline is expected to be published in January 2016 and will contain recommendations based on the evidence considered by the PHAC. There are three streams of work associated with the guideline's development that the CPH has commissioned: Stream 1: Community engagement: a report on the current effectiveness and process evidence, including additional analysis.

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Stream 2: Community engagement: UK qualitative evidence, including one mapping report and one review of barriers and facilitators

Stream 3: An economic analysis (cost effectiveness review and economic model)

Component 1 of Stream 2 comprises a mapping report to identify, describe and provide insight into current and emerging community engagement policy and practices in the UK.

Component 2 of Stream 2 comprises an evidence review of barriers to and facilitators of community engagement approaches and practices in the UK over an appropriate time frame.

The mapping review will consist of the following 2 parts:

- (a) Component 1a: Map of the literature. This will provide a synopsis of the key findings from documentary analysis (including grey literature and practice surveys) of the current evidence base for UK local and national policy and practice for community engagement, as well as an assessment of the extent to which relevant scope questions are answered by the evidence base.

- (b) **Component 1b:** Map of current practice based on a case study approach. This will consist of a series of six case studies of current or recent community engagement projects to improve health and reduce health inequalities. The focus will be practitioner and community's views; support systems; structures and delivery processes; local culture, resources, needs and priorities; approaches and practices; outcomes (successes and failures); sustainability; unanticipated effects; measures of success identified by communities and professionals; wider connections and costs. Case studies will be identified and selected to identify different approaches of current community engagement within the UK, in particular those approaches targeted at disadvantaged groups or communities, and other evidence gaps identified in component 1a, and Stream 1.

This protocol relates to component 1b of Stream 2 only. There are separate protocols for component 1a, component 2, and for the other Streams. All components have a similar scope, and review teams for all three streams are working together so that (for example) evidence arising from the analysis of Stream 2 may inform Streams 1 and 3, and literature searches being done for stream 1 may be used by components 1a and 2 of Stream 2. Also, the analysis of component 1 of stream 2 will inform component 2 (the barriers and facilitators review), which in turn may inform stream 1. The choice of case studies for component 1b of Stream 2 will be informed by emerging insights from component 1a and component 2 of Stream 2, and from Stream 1.

The map of current practice (component 1b) is the second component of a mapping report which will identify, describe and provide insight into current and emerging community engagement policy and practices in the UK; in addition to including the UK research literature, it will incorporate documentary analysis (including grey literature and practice surveys) of local and national policy and practice. Previous experience in this field (O'Mara-Eves et al. 2013, South et al. 2010) suggests that there is a publication bias in that professionally-led (sometimes referred to as "top-down") initiatives are more likely to be evaluated and then published in peer reviewed journals than community-led ("bottom-up" or "Grass-roots") initiatives, such as those that result in community empowerment. We will seek to overcome this publication bias by using our networks of community contacts to obtain as much grey literature as possible for the mapping review (component 1a) and to recruit community groups and organisations to take part in the case studies (component 1b)..

4. Review Questions

The mapping review will address any or all of the following research questions, from the final Guidance scope.

Question 3: What processes and methods help communities and individuals realise their potential and make use of all the resources (people and material) available to them?

This question could include sub-questions to explore the impact on the effectiveness and acceptability of different interventions conferred by: those delivering the intervention; community representatives or groups; health topic; setting; timing; or theoretical framework.

Question 4: Are there unintended consequences from adopting community engagement approaches?

Question 5: What barriers and facilitators affect the delivery of effective community engagement activities – particularly to people from disadvantaged groups?

Question 5 will encompass the following overarching questions:

Q5.1 To what extent do these barriers and facilitators vary according to key differences in community engagement approaches and practices, the health outcomes and populations to which they are targeted, and the context in which they are delivered?

Q5.2 How can the barriers and challenges be overcome?

We will also seek to explore a range of more specific issues and questions including:

- The factors that help or hinder communities to get involved in community engagement activities and how to build capacity and motivation
- How local context and the associated political, health and community structures or systems support or hamper community engagement;
- How professionals can learn to better engage with, and act on, the suggestions from communities

5. Methods: Component 1b – Mapping of current UK practice based on a case study approach

We will work closely with the Centre for Public Health and in line with NICE methods and processes for development of evidence-based guidelines (current public health guideline development process and methods guides (third edition, 2012)).

5.1 Sampling frame

Potential case studies will be identified and selected to identify different approaches of current community engagement within the UK, in particular those approaches targeted at disadvantaged groups or communities.

We will use the “family of approaches” developed by Professor Jane South from the 2013 O’Mara-Eves et al. review to categorise approaches to community engagement within four broad groups: Strengthening communities (e.g. asset based community development; neighbourhood networks); Volunteer and peer roles (e.g. breastfeeding peer support; health champions; self-help groups); Collaborations (e.g. participatory budgeting; co-production); and Connecting to community resources (e.g. social prescribing; food banks; community-based commissioning models).

We will use purposive sampling to select case studies according to early indications of evidence gaps identified by the mapping review (component 1a of Stream 2), the review of barriers and facilitators (component 2 of Stream 2) and the review of effectiveness (Stream 1). We expect, based on the findings of the recent NIHR review (O’Mara-Eves et al. 2013) and recent work on evaluating community engagement (South & Phillips 2014), these evidence gaps will include empowerment approaches and unanticipated effects. We will seek case studies that have the potential to reduce health inequalities and provide variation in their definition of community (geographical, cultural, common interest or other definition), approach to community involvement, population, activities and geographical location (e.g. urban/ rural; North/ South), and will try to include at least one community-led initiative for which there is no substantial evaluation report available.

The primary sampling criteria will be on type of approach. We will use secondary criteria (geographical location, type of community etc.) to ensure that case studies are diverse and demonstrate maximum variation in terms of communities involved. This will build greater transferability of results.

Examples of potential case study sites include

- Community involved in development – Leeds Gypsy & Traveller Exchange
- Community involved in developing and delivering peer-led services, but not design – health champions – Altogether Better; Well London.

Given the short timescales, we will undertake six case studies. Ethical approval will be sought from the ethics committee at Leeds Metropolitan University and the University of East London.

5.2 Data collection

Component 1b of Stream 2 is primarily concerned with finding out:

- a. What is currently being done, and especially what is not being reported?
- b. Why do some approaches work and some do not?

Data collection tools (i.e. interview schedules) will explore the following topics:

- Who and what is involved in the project (exploring different perspectives)
- Local culture, resources, needs and priorities
- Motivations for becoming and staying involved
- Community outcomes (vs. individual outcomes)
- Successes and failures
 - What worked and what did not work?
 - Why and how did things work or not work?
- Measures of success identified by:
 - Community
 - Professionals
- Unanticipated effects
- Wider connections within and outside the community
- Training and support
- Costs
- Sustainability
- Confidence in the approach
- Suggestions for improvement

We will use our connections with community, voluntary and 3rd sector organisations through Health Together <http://www.leedsmet.ac.uk/healthtogether/>, the recent conference “Putting the Public back into Public Health” <http://www.leedsmet.ac.uk/news/putting-the-public-back-into-public-health17012014.htm?type=external> and the database of contacts compiled by the People in Public Health <https://piph.leedsmet.ac.uk/main/index.htm> project as well as Locality (national infrastructure organisation which describes itself as 'the leading nationwide network for community led organisations <http://locality.org.uk/>) and other networks of contacts to identify and recruit

groups which meet our sampling criteria. We will place a Register of Interest on our Health Together webpage and invite relevant groups to register, and let us know whether they would like to be considered as a potential case study site.

An initial purposive sample of selected case study sites will be approached and invited to take part in the research. Recruitment methods have been designed with the aim of overcoming any potential barriers to recruitment, by utilising the local managers. Recruitment will be expected to take place through the case study sites, with the assistance of local Managers. In all of the sites, the research team will aim to explain the research and the decision to participate as a case study will be made through the normal governance mechanisms. An initial start-up meeting will be held between the research team, local project managers, and other relevant stakeholders, and at this meeting potential resource demands on project managers and participants will be clarified e.g. it is expected that the local projects will be able to provide a room for interviews and focus groups to be held in. After the initial participant sample has been drawn up, local managers will then distribute an information leaflet and a letter of invitation to potential participants. Contact details will be withheld from the research team at this stage. Potential participants will be able to contact the local project if they do not want any further contact with the University. The research team will then follow up the letter by phone, or by email, to ascertain if individuals are willing to take part and to arrange an interview. At the point of the interview, participants will be given a further opportunity to ask questions about the study and written consent will be obtained. Participants will be made aware that they can decide to pass over any questions or withdraw from the study at any time (see Figure 1 for an explanation of the recruitment and consent process).

We will conduct a minimum of 5 semi-structured interviews with practitioners, project managers (and other stakeholders where appropriate) at each of the 6 case study sites. We will hold a minimum of 1 focus group with 2 facilitators and between 3 and 12 community participants at each of the 6 case study sites, unless the nature of the intervention is sensitive, in which case we will seek to conduct a minimum of 5 semi-structured interviews with individual community participants instead. If there is poor turnout at a case study site for interviews or focus groups, we will seek to rearrange interviews and focus groups and work with local managers to improve recruitment. If necessary, we will recruit more case study sites. If there are more people than expected for a focus group, we may run two focus groups concurrently, with one facilitator taking each one, rather than turn participants away. Our researchers are experienced at facilitating focus groups in challenging situations.

All interviews and focus groups will follow a schedule which will be approved by the University ethics committee and by NICE. Where consent is given, interviews and focus groups will be

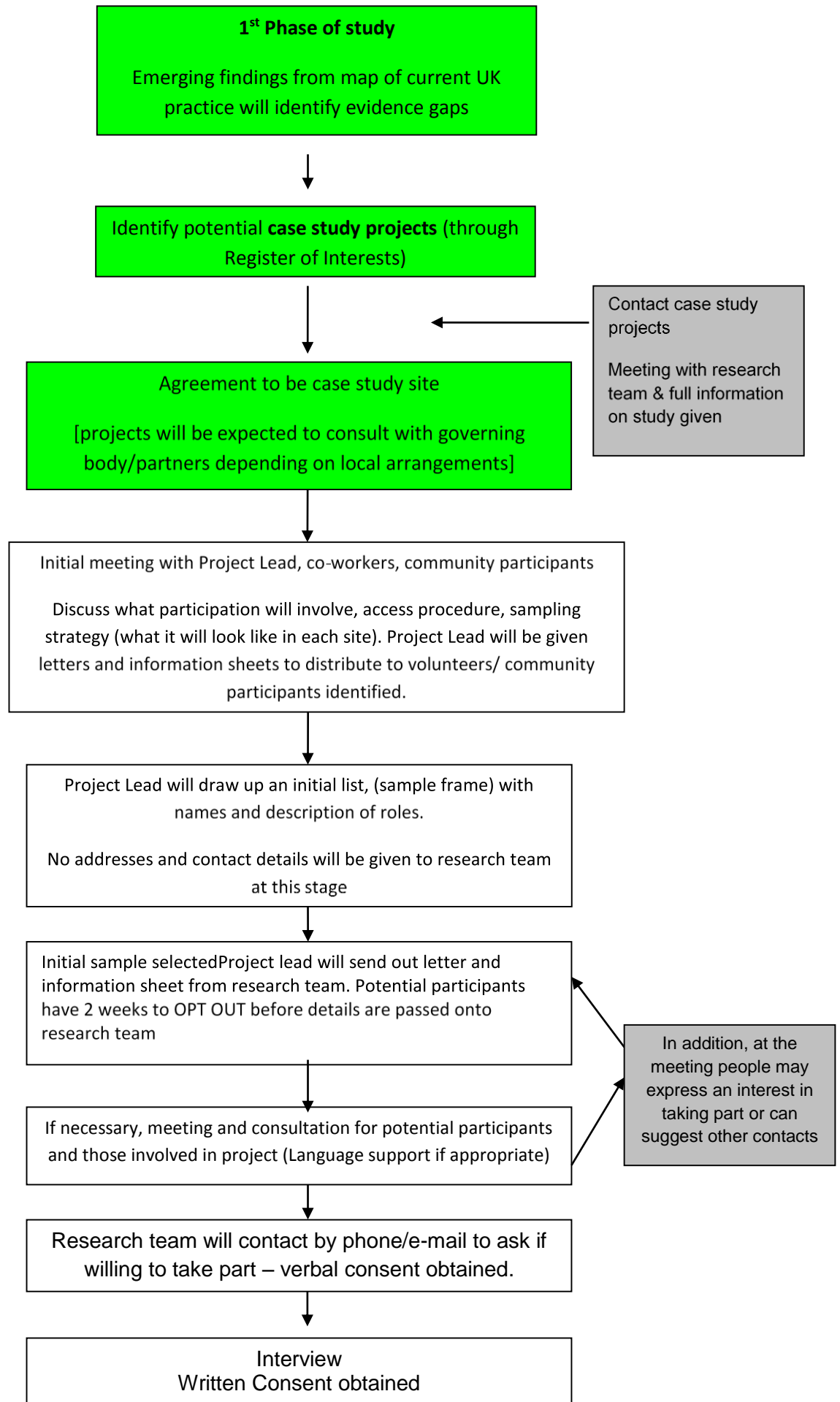
digitally recorded and transcribed, otherwise notes will be taken. The interview questions will be developed with the specific case study sites in mind, will differ according to the type of participant (e.g. project manager; community volunteer; stakeholder) and will be informed by emerging findings from component 1a (map of the literature), so will be developed just before the interviews and focus groups take place (October 2014), but will broadly follow the topics listed below:

- Who and what is involved in the project (exploring different perspectives)
- Local culture, resources, needs and priorities
- Motivations for becoming and staying involved
- Community outcomes (vs. individual outcomes)
- Successes and failures
 - What worked and what did not work?
 - Why and how did things work or not work?
- Measures of success identified by:
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We will also seek to obtain documents such as internal reports, and project protocols, in order to undertake documentary analysis for each case study site. We would aim to obtain these documents at or soon after the initial start-up meeting. If there are no or limited supplementary documents available, the interviews with project managers and other local stakeholders will be used to provide context and background for the case study report.

Once the initial stage of recruitment and data collection is underway then we will decide whether additional data needs to be collected, for example, if there is a high attrition rate of either case study sites or participants, or if other important stakeholders within a project are identified during the initial interviews. If we do need to recruit further case study sites we will do a second round of sampling from those projects that have already agreed to be case study sites.

Figure 1: Recruitment and consent flow chart



5.3 Analysis

A thematic analysis approach using NVivo will be used to synthesise evidence from the case studies and a matrix will be developed to look for triangulation among the findings (Miles and Huberman). Case study analysis presents particular challenges, as there is a need both to describe and understand the individual cases and to build explanations across multiple case studies. Analysis of case studies will therefore involve both within case and cross case analysis (Yin 2008). An inductive approach will be taken to data analysis to ensure all relevant themes are mapped. The NVIVO software package will be used to assist in the management of that process due to the volume of data.

In the first stage, an initial coding framework will be developed based on the study objectives, the conceptual framework developed by O'Mara-Eves et al. (2013), and the logic model in the scope provided by NICE. An initial sample of data from two interviews and one focus group from each case study site will be coded by three reviewers working independently. The three reviewers will then meet to agree a common framework and initial thematic categories. This framework will then be expanded and refined as analysis continues, until all the themes are coded and organised into subcategories with the whole data set.

Explanations will be built within case through the production of individual case study reports for each of the case studies. These reports will organise and display the data as a conceptually ordered display (with quotations) across the major thematic categories, in a standardised format to allow for later cross case analysis. Case study reports will also use narrative summaries of project context, history and networks.

The final stage of data analysis will involve cross case analysis, comparing findings and using an iterative process to build explanations. A narrative summary will be produced that synthesises key points from the cross case thematic analysis.

Each case study narrative (i.e. the report with all personal identifying details removed) will be checked for authenticity by the project leads or other appropriate stakeholder for that project. All researchers involved in the analysis will also be involved in checking the final narrative account.

6. Timetable

Tasks for Stream 2, Component 1b	Date to be completed
Submission of draft protocol and sampling frame	23rd June 2014
NICE provides comments on the draft protocol and sampling frame	27 th June 2014
Submission of revised protocol and sampling frame to NICE	2 nd July 2014
Final protocol and sampling frame agreed by NICE and Contractor	4th July 2014
Submission of draft participant documentation and other resources to NICE	14th July 2014
NICE provide comments on draft participant documentation and other resources	16 th July 2014
Submission of revised participant documentation to NICE	18 th July 2014
Final participant documentation agreed by NICE and contractor	22 nd July 2014
Establish ethical approval	25 th August 2014 (at latest)
Submission of draft report to NICE team	09/02/2014
NICE provide comments on draft report	13/02/2014
Submission of revised draft report to NICE	09/03/2015
Draft report mailed to PHAC members	12/03/2015
Submission of final slides for presentation(s) of evidence report to PHAC	17/03/2015
Presentation of draft evidence report at PHAC meetings	PHAC 4 24/03/2015
Final amendments to be made to evidence report post PHAC meetings	07/04/2015
Submission of the final reports following public consultation	23rd September 2015

6.1 Deliverables

- Draft and final review protocol and sampling frame for the work
- Participant documentation: information leaflet; invitation letter; consent form; interview schedules
- Draft reports. The final style and format of the presentation of the document is to be agreed with the NICE project team
- Final project report(s)
- PowerPoint slides for presentation at relevant PHAC meetings
- Presentation at PHAC meeting
- Draft responses to any stakeholder queries on the report submitted as part of the guideline consultation

7. References

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