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Establishing a multi stakeholder research agenda: Lessons learned from a James Lind Alliance Partnership

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2021-059006.R1
Article Type:	Communication
Date Submitted by the Author:	17-Nov-2021
Complete List of Authors:	Jongsma, Karin; Utrecht University, University Medical Center Milota, Megan; Utrecht University, University Medical Center
Primary Subject Heading:	Ethics
Secondary Subject Heading:	Health services research
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, MEDICAL ETHICS, Paediatric rheumatology < PAEDIATRICS, ETHICS (see Medical Ethics), Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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Establishing a multi stakeholder research agenda: Lessons learned from a James Lind Alliance Partnership

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- D. James Lind Alliance, research agenda setting, medical ethics, trust, inclusion
- E. 2170 words

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Abstract

Objective: Shared research agenda setting is promoted to address the gap between academic research and the needs of end-users. In this paper we draw attention to crucial dialogical aspects in establishing a shared research agenda.

Key arguments: Dialogical aspects are important for facilitating and maintaining trust, innovation and equal inclusion.

Conclusion: 8 lessons learned have been formulated, based on our observations and reflections on the JLA for JIA PSP and our expertise on patient participation and participatory research.

Introduction

Patient and public involvement (PPI) in research agenda setting is widely supported as a means of addressing the gap between academic research and the needs of end users such as patients, carers and clinicians.[1,2] As research agendas are supposed to direct future research paths, both clinical and societal relevance are at stake when end users’ needs are not properly addressed. The James Lind Alliance (JLA) offers a method for better aligning health and care research agendas with the needs of patients, carers and clinicians by bringing them together in Priority Setting Partnerships (PSPs) to define and prioritise evidence uncertainties relating to a specific condition.

The JLA method consists of a series of steps,[2] which can be summarized as follows: First, a lead group—responsible for management tasks—establishes a PSP for a particular disease or condition. This group then creates a steering group of patients, carers and clinicians. Second, a survey is administered to collect relevant research questions from a wide group of patients, carers and clinicians. Third, the steering group analyses and categorises these overarching questions; this is followed by a check of the literature to verify that these questions are evidence uncertainties. Fourth, an interim survey is sent out to prioritise the overarching questions into a shortlist of 20-25 questions. Finally, a workshop is held with patients, carers and clinicians to discuss and rank the shortlist into a top 10 of research priorities. JLA PSP’s conducted in English can voluntarily engage a trained JLA adviser and trained conversation moderators to help with each of the steps.

In this paper we aim to draw attention to crucial dialogical aspects in establishing a shared research agenda as a means of supplementing more outcome oriented academic literature on JLA PSPs. Our analysis and recommendations are based on our experience creating, conducting and reflecting on the JLA PSP for juvenile idiopathic arthritis (JIA).[3-6] We also draw from our expertise in patient involvement, patient representation, and participatory action research methods. Our experiences and observations are based on a Dutch-language PSP—meaning the JLA advisor consulted with the lead group at all steps of the process, but could not participate in or facilitate the discussions due to language constraints. This has presented us with an excellent opportunity to enrich and build upon the current JLA guidance and advice available. By sharing the lessons we have learned from the process of establishing a shared research agenda, we hope to guide future projects attempting to establishing a multi-stakeholder research agenda.

Lessons learned

Facilitation and maintaining trust

One of the first tasks of the steering group is to recruit respondents for the survey. The JLA Guidebook recommends carefully and deliberately selecting steering group members. A stakeholder analysis may be

helpful to determine which stakeholders are relevant for the particular topic. In the JIA PSP a multidisciplinary steering group was chosen to represent different fields of expertise and geographical locations. For our PSP this diversity was crucial to have an inclusive dialogue with a wide variety of patients, carers and clinicians. Their perspectives and position resulted in a wide variety of research questions, and ultimately contributed to the generalisability and legitimacy of the outcome. Our first lesson learned is to take each member's potential role and position in the dialogic process into account as well.

The steering group has to make decisions at each phase of establishing a shared research agenda. Deliberation and discussion are therefore inherent to the decision-making process, and facilitators within the steering group play an important role in realizing open and equal participation of all members. Facilitators should therefore be aware of their own preferences if they have a vested interest in the topic and avoid unduly influencing the discussion. Our second lesson learned is to plan regular reflection or 'feedback meetings' for both the facilitator and steering group members.[7] Integrating critical reflection as a repeated element in the process of establishing a shared research agenda can help ensure that participants are aware of the ways in which their interests, experiences, and expertise influence their participation in the discussions. We do not mean to imply that neutrality is preferable or even desirable for facilitators. On the contrary, facilitators and steering group members with vested interests in the PSP and established relationships with patients, carers or physicians can increase the sense of trust and openness amongst participants.

In fact, we noticed in our PSP that openness and receptiveness are incredibly important qualities of both steering and lead group members to ensure equal participation in a process of co-creation and to engender trust in the steering group and the JLA approach as a whole. We observed that participants' trust in the steering and lead group members was based to a large degree on their previous interactions with these members. Trust was also tied to members' professional and personal experiences with the condition. The level of transparency in communication and dialogical goals also played a role in participants' sense of trust. The third lesson we learned is to devote attention to methods for establishing and maintaining trust at the onset of the project. This need not take the form of formal meetings or workshops. Spending time together informally and talking openly about goals and interests related to the PSP are powerful means of establishing a sense of community amongst participants and fostering a feeling of shared responsibility in the process and outcome.

Optimizing the balance between inclusivity and innovation

The method of asking a large number of stakeholders to identify knowledge uncertainties in a JLA PSP guarantees a wide scope of responses that are not solely biomedical in focus. The obvious benefit of this approach is that it leads to a diverse set of uncertainties. As a means of capturing both younger and older patients' opinions, our PSP decided to conduct focus groups with younger JIA patients (aged 9-16) in addition to sending out surveys to carers and older JIA patients. Adding creative research activities like focus groups to the JLA approach enabled the children in this PSP to (collectively) reflect on their lived experiences. It also provided a means of familiarizing them with agenda setting in research. Their input was used in all subsequent steps of the shared research agenda. [6] Our fourth lesson is to carefully and critically analyse how a shared

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research agenda method can be best tailored to suit the goals of a particular group, and adapt the ‘standard’ approach where necessary.

The JLA decision-making process is consensus driven as it draws on a nominal group technique;^[8] the benefits of this approach are that participants actively work together to prioritise research questions and are therefore more likely to feel engaged and invested in both the process and outcome. Consensus-driven approaches, however, come with the risk of losing unique or divergent perspectives in the process. This could potentially result in a less innovative top 10, or one that inadequately represents the broad spectrum of perspectives and needs solicited at the beginning of the agenda setting. ^[4,9] Our fifth lesson would be to develop a strategy for recording these differences at each step in the process. For example, in addition to the consensus-driven top 10, a list of the most innovative perspectives as determined by the steering group could also be published.

The existing academic literature on shared research agenda setting has very little to say about how best to integrate different perspectives to reach a consensus. For example, in the third step of the JLA approach the ‘raw’ survey input is distilled into the first set of underlying research categories; this requires a lot of interpretation on the part of the steering group. In our PSP, we observed three different approaches during this phase. Some members employed a phenomenological approach, and consistently tried to first imagine the perspectives and needs of individual respondents when discussing their submitted research uncertainties, before attempting to group similar questions together. Others used a hermeneutical approach, which required discussing the underlying assumptions and meaning of the individual questions. Some members favored a pragmatic approach, clustering similar research uncertainties together based on identified keywords before trying to formulate overarching questions. These different methods each have their own benefits and drawbacks, but our sixth lesson learned would be to apply one method within the PSP for consistency in the analysis of this phase and in order to be able to transparently report about this prioritisation process.

Reflecting upon and reacting to positionality of participants

The diverse perspectives and interests in a shared research agenda project are voiced in different ways. We noticed that the various roles of the participants had an impact on the substance of the arguments they made, the rhetorical strategies they used to argue in favor or against certain research questions, and the ways in which their comments were received by the group.

Regardless of their role or position in the discussions, all participants employed rhetorical strategies in an attempt to convince others of the value of their opinions, and in the case of the final workshop, as a means of lobbying for their favoured research questions. The most common strategy employed during the steering group discussions was *ethos*; participants (including clinicians) often prefaced an opinion by reiterating their knowledge or lived experiences on the given topic. *Logos*-related strategies, logical argumentation often based on scientific knowledge, proved to be the most common in the steering group discussions, where decisions about categorizing and collating research uncertainties were often presented as the result of logical or scientific rigor. *Ethos* qualifications were most prevalent in the final workshop. Multiple participants explicitly stated that they wanted to lobby for one or more specific research questions, and deployed both *ethos* and

pathos (appeals to emotions) in an attempt to see their question make the top 10. Positionality and rhetorical strategies will always be present in deliberative processes. This is why our seventh lesson learned is to proactively choose and practice strategies to prevent substantive arguments of less rhetorically skilled individuals from getting lost.

The desire of participants to influence the outcome with their own preferences became particularly clear in the final workshop. Many participants came, as instructed, to the workshop with a preferred ranking of the final research questions, and some had a preferred question that they wanted to see make the top 10. This made moderating the groups discussions a delicate and sometimes challenging task. In our final workshop we observed that the style and role of the moderator influenced the course of the deliberations. For example, a medical professional mentioned his own experiences with JIA during the deliberative process, while the external moderator repeatedly stressed his lack of personal experience with JIA. In future PSPs that cannot use JLA trained advisors and moderators, our final lesson learned is to select moderators based on their receptiveness and listening skills rather than (clinical) expertise, in order to stimulate a thoughtful weighing of options. Moderators should be given clear instructions as well, and should be aware of the aforementioned rhetorical strategies and possible power imbalances within the group that could impact the discursive process.

Conclusion

The James Lind Alliance provides a helpful approach for establishing a shared research agenda setting. We are convinced that our experiences conducting and observing a JLA PSP without direct facilitation from a JLA adviser has taught us valuable lessons that are of value to researchers trying to establish a shared research agenda. Based on our reflections and experiences, we have formulated 8 concrete lessons learned, as listed below in table 1.

Table 1: Lessons learned

	Lessons Learned
1.	The steering group should be carefully selected, in particular by taking each member's potential role and position in the dialogic process into account.
2.	The JLA method should establish a reflexive element at each stage of the PSP to prevent undue influence of individual members on the outcome of the process.
3.	Establishing and maintaining trust in the steering group is essential for the process of the JLA PSP; this can take time and can be fostered in both formal and informal settings.
4.	Steering group member should carefully analyse how the JLA method can be best tailored to suit the goals of their PSP, and adapt the 'standard' approach where necessary to maximize inclusivity.
5.	Diverging and unique questions should be noted during the prioritisation phases in order to keep track of innovative perspectives.
6.	The steering group should commit to one method of interim prioritisation for the sake of consistency and transparency.
7.	The steering group should make time to reflect upon rhetorical strategies throughout the JLA process in order to prevent substantive arguments of less rhetorically skilled groups getting lost.
8.	If not using a JLA trained monitor, moderators for the final workshop should be selected based on receptiveness and listening skills rather than (clinical) expertise.

Authors' Contributions

KJ and MM contributed equally. All authors provided substantial input and critically revised the manuscript. All authors approved of the final version of the manuscript.

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Competing Interests statement

The authors declare no competing interests.

Funding statement

PGOsupport funded part of this study. The Funder had no influence on the methodology, data collection and analysis of the data.

Acknowledgement

We would like to thank all involved persons and parties involved in the JLA for JIA, and specifically thank Annemiek van Rensen, Casper Schoemaker and Christine Dedding for the constructive conversations we have had about this paper.

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Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2021-059006.R2
Article Type:	Communication
Date Submitted by the Author:	22-Apr-2022
Complete List of Authors:	Jongsma, Karin; Utrecht University, University Medical Center Milota, Megan; Utrecht University, University Medical Center
Primary Subject Heading:	Ethics
Secondary Subject Heading:	Health services research
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, MEDICAL ETHICS, Paediatric rheumatology < PAEDIATRICS, ETHICS (see Medical Ethics), Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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Abstract

Objective: The James Lind Alliance offers a method for better aligning health and care agenda’s with the needs of patients, carers and clinicians by bringing them together in a Priority Setting Partnership. In this paper we draw attention to crucial lessons learned when establishing such a shared research agenda.

Key arguments: Having specific strategies and plans in place for maximising dialogic processes in a Priority Setting Partnership can help facilitate and maintain trust, innovation and equal inclusion.

Conclusion: Eight lessons learned have been formulated, based on our observations and reflections on the JLA PSP and our expertise on patient participation and participatory research.

Introduction

Shared research agenda setting often includes stakeholders such as patients, carers and health care professionals; it is increasingly seen as an important way to improve clinical research and to addressing the gap between academic research and the needs of end-users.[1,2] As research agendas are supposed to direct future research paths, both clinical and societal relevance are at stake when end users’ needs are not properly addressed. The James Lind Alliance (JLA) offers a method for better aligning health and care research agendas with the needs of patients, carers and clinicians by bringing them together in Priority Setting Partnerships (PSPs) to define and prioritise evidence uncertainties relating to a specific condition.[3] (see Box1)

The JLA method consists of a series of steps,[2] which can be summarized as follows: First, a lead group—responsible for management tasks—establishes a PSP for a particular disease or condition. This group then creates a steering group of patients, carers and clinicians. Second, a survey is administered to collect relevant research questions, indicative of underlying evidence uncertainties, from a wide group of patients, carers and clinicians. Third, the steering group analyses and categorises these overarching questions; this is followed by a check of the literature to verify that these questions indicate evidence uncertainties. Fourth, an interim survey is sent out to prioritise the overarching questions into a shortlist of 20-25 questions. Finally, a workshop is held with patients, carers and clinicians to discuss and rank the shortlist into a top 10 of research priorities. JLA PSP’s conducted in English can voluntarily engage a trained JLA adviser and trained conversation moderators to help with each of the steps. More information about the process, steps, goals and involved costs is elaborated in the JLA guidebook.[2]

In this paper we aim to draw attention to crucial dialogical aspects in establishing a shared research agenda as a means of supplementing more outcome oriented academic literature on JLA PSPs. Our analysis and recommendations are based on our experiences of observing and reflecting on the JLA PSP for juvenile idiopathic arthritis (JIA) (for more background information and the results of this PSP, please see [4-7]. We also draw from our expertise in patient involvement, patient representation, and participatory research methods. Our experiences and observations are based on a Dutch-language PSP—meaning the JLA advisor consulted with

the lead group at all steps of the process, but could not participate in or facilitate the discussions due to language constraints. This has presented us with an excellent opportunity to enrich and build upon the current JLA guidance and advice available. By sharing the lessons we have learned from the process of establishing a shared research agenda, we hope to guide future projects attempting to establishing a multi-stakeholder research agenda.

Lessons learned

Facilitation and maintaining trust

One of the first tasks of the steering group is to recruit respondents for the survey. The JLA Guidebook recommends carefully and deliberately selecting steering group members based on their experience and expertise. A stakeholder analysis may be helpful to determine which stakeholders are relevant for the particular topic. In the JIA PSP a multidisciplinary steering group was chosen to represent different fields of expertise and geographical locations. The condition JIA affects persons in different age categories and has a variety of forms and corresponding treatment strategies. Furthermore, a wide range of healthcare specialists treat persons with JIA. For our PSP this diversity was crucial to have an inclusive dialogue with a wide variety of patients, carers and clinicians. Their perspectives and positions resulted in a wide variety of research questions, and ultimately contributed to the generalisability and legitimacy of the outcome. Our first lesson learned is to take each member's potential role and position in the *dialogic process* into account as well when recruiting steering group members.

The steering group has to make decisions at each phase of establishing a shared research agenda. Deliberation and discussion are therefore inherent to the decision-making process, and facilitators within the steering group play an important role in realizing open and equal participation of all members. Facilitators should therefore be aware of their own preferences if they have a vested interest in the topic and avoid unduly influencing the discussion. Our second lesson learned is to plan regular reflection or 'feedback meetings' for both the facilitator and steering group members.[8] Integrating critical reflection as a repeated element in the process of establishing a shared research agenda can help ensure that participants are aware of the ways in which their interests, experiences, and expertise influence their participation in the discussions. We do not mean to imply that neutrality is preferable or even desirable for facilitators. On the contrary, we observed that facilitators and steering group members with vested interests in the PSP and established relationships with patients, carers or physicians can increase the sense of trust and openness amongst participants.

In fact, we noticed in our PSP that openness and receptiveness are incredibly important qualities of both steering and lead group members to ensure equal participation in a process of co-creation and to engender trust in the steering group and the JLA approach as a whole. The relevance of trust for public engagement and participatory research has also been stressed in the PPI literature.[9,10] We observed that participants' trust in the steering and lead group members was based to a large degree on their previous interactions with these members. Trust was also tied to members' professional and personal experiences with the condition, in this case JIA. The level of transparency in communication and dialogical goals also played a role in participants' sense of trust. The third lesson we learned is to devote attention to methods for

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establishing and maintaining trust at the onset of the project. This need not take the form of formal meetings or workshops. Spending time together informally and talking openly about goals and interests related to the PSP are powerful means of establishing a sense of community amongst participants and fostering a feeling of shared responsibility in the process and outcome.

Optimizing the balance between inclusivity and innovation

The method of asking a large number of stakeholders to identify evidence uncertainties in a JLA PSP guarantees a wide scope of responses that are not solely biomedical in focus. The obvious benefit of this approach is that it leads to a diverse set of questions and corresponding uncertainties. As a means of capturing both younger and older patients’ opinions, our PSP decided to conduct focus groups with younger JIA patients (aged 9-16) in addition to sending out surveys to carers and older JIA patients. Adding creative research activities like focus groups to the JLA approach enabled the children in this PSP to (collectively) reflect on their lived experiences. It also provided a means of familiarizing them with agenda setting in research. Their input was used in all subsequent steps of the shared research agenda, which took some additional effort and expertise, but also improved the rigorousness of the conversation.[7] Our fourth lesson is to carefully and critically analyse how a shared research agenda method can be best tailored to suit the goals of a particular group, and adapt the ‘standard’ approach where necessary.

The JLA decision-making process is consensus driven as it draws on a nominal group technique;[11] the benefits of this approach are that participants actively work together to prioritise research questions and are therefore more likely to feel like equally valued and invested participants in both the process and outcome. Consensus-driven approaches, however, come with the risk of losing unique or divergent perspectives in the process. This could potentially result in a less innovative top 10, or one that inadequately represents the broad spectrum of perspectives and needs solicited at the beginning of the agenda setting. [5,12] Our fifth lesson would be to develop a strategy for recording these differences at each step in the process. For example, in addition to the consensus-driven top 10, a list of the most innovative perspectives as determined by the steering group could also be published.

The existing academic literature on shared research agenda setting has very little to say about how best to integrate different perspectives to reach a consensus. For example, in the third step of the JLA approach the ‘raw’ survey input is distilled into the first set of underlying research categories; this requires a lot of interpretation on the part of the steering group. In our PSP, we observed three different approaches during this phase. Some members employed a phenomenological approach, and consistently tried to first imagine the perspectives and needs of individual respondents when discussing their submitted research questions, before attempting to group similar questions together. Others used a hermeneutical approach, which required discussing the underlying assumptions and meaning of the individual questions. Some members favored a pragmatic approach, clustering similar research questions together based on identified keywords before trying to formulate overarching questions. These different methods each have their own benefits and drawbacks. Our sixth lesson learned would be to apply one method within the PSP for consistency in the analysis of this phase and in order to be able to transparently report about this prioritisation process.

Reflecting upon and reacting to positionality of participants

The diverse perspectives and interests in a shared research agenda project are voiced in different ways. We noticed that the various roles of the participants had an impact on the substance of the arguments they made, the rhetorical strategies they used to argue in favor or against certain research questions, and the ways in which their comments were received by the group.

Regardless of their role or position in the discussions, all participants employed rhetorical strategies in an attempt to convince others of the value of their opinions,[13,14] and in the case of the final workshop, as a means of lobbying for their favoured research questions. The most common strategy employed during the steering group discussions was an appeal to *ethos*; participants (including clinicians) often formulated an opinion or stance as an ethical appeal, frequently prefacing these utterances with personal and professional experience narratives. *Logos*-related strategies—logical argumentation often based on scientific knowledge—proved to be the most common in the steering group discussions. Here decisions about categorizing and collating research questions were often presented as the result of logical reasoning or scientific rigor. *Pathos* qualifications and persuasive devices (appeals to emotions) were most prevalent in the final workshop. Multiple participants explicitly stated that they wanted to lobby for one or more specific research questions, and deployed both *ethos* and *pathos* in an attempt to see their question make the top 10. Positionality and rhetorical strategies will always be present in deliberative processes. This is why our seventh lesson learned is to proactively choose and practice strategies to prevent substantive arguments of less rhetorically skilled individuals from getting lost.

The desire of participants to influence the outcome with their own preferences became particularly clear in the final workshop. Many participants came, as instructed, to the workshop with a preferred ranking of the final research questions, and some had a preferred question that they wanted to see make the top 10. This made moderating the groups discussions a delicate and sometimes challenging task. In our final workshop we observed that the style and role of the moderator influenced the course of the deliberations. For example, a medical professional mentioned his own experiences with JIA during the deliberative process, while the external moderator repeatedly stressed his lack of personal experience with JIA. In future PSPs that cannot use JLA trained advisors and moderators, our final lesson learned is to select moderators based on their receptiveness and listening skills rather than (clinical) expertise, in order to stimulate a thoughtful weighing of options. Moderators should be aware of the aforementioned rhetorical strategies and possible power imbalances within the group that could impact the discursive process.

Conclusion

The James Lind Alliance provides a helpful approach for establishing a shared research agenda setting. We are convinced that our experiences conducting and observing a JLA PSP without direct facilitation from a JLA adviser has taught us valuable lessons that are of value to researchers trying to establish a shared research agenda. Based on our reflections and experiences, we have formulated eight concrete lessons learned, as listed below in table 1.

Table 1: Lessons learned

	Lessons Learned
1.	The steering group should be carefully selected, in particular by taking each member’s potential role and position in the dialogic process into account.
2.	The JLA method should establish a reflexive element at each stage of the PSP to prevent undue influence of individual members on the outcome of the process.
3.	Establishing and maintaining trust in the steering group is essential for the process of the JLA PSP; this can take time and can be fostered in both formal and informal settings.
4.	Steering group member should carefully analyse how the JLA method can be best tailored to suit the goals of their PSP, and adapt the ‘standard’ approach where necessary to maximize inclusivity.
5.	Diverging and unique questions should be noted during the prioritisation phases in order to keep track of innovative perspectives.
6.	The steering group should commit to one method of interim prioritisation for the sake of consistency and transparency.
7.	The steering group should make time to reflect upon rhetorical strategies throughout the JLA process in order to prevent substantive arguments of less rhetorically skilled groups from getting lost.
8.	If not using a JLA trained monitor, moderators for the final workshop should be selected based on receptiveness and listening skills rather than (clinical) expertise.

Authors’ Contributions

KJ and MM contributed equally. All authors provided substantial input and critically revised the manuscript. All authors approved of the final version of the manuscript.

Competing Interests statement

The authors declare no competing interests.

Funding statement

PGOsupport funded part of this study. The Funder had no influence on the methodology, data collection and analysis of the data.

Acknowledgement

We would like to thank all involved persons and parties involved in the JLA for JIA, and specifically thank Annemiek van Rensen, Casper Schoemaker and Christine Dedding for the constructive conversations we have had about this paper.

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