

The Real Cost of Patient Involvement



A Realise Advocacy report

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Executive summary

Patient involvement in Health Technology Assessment and reimbursement processes is important, especially for rare or complex diseases. We know that patient involvement can bring evidence and insights that lead to better informed, more legitimate decisions.

Patient groups are rarely, if ever, set up with a focus on the skills, expertise and resources required to be involved in these processes, and they face many barriers to successful involvement. Engaging in access processes for new treatments can be traumatic for patient advocacy group leaders and patient communities, and this can be exacerbated by the absence of appropriate, independent, support.

If we genuinely value patient involvement in HTA and access processes, then this must change and more must be done to ensure that we address some of the impact on patient advocacy groups and patient communities.

This report brings together published literature, interviews with patient advocates and our collective 20+ years of experience supporting small rare disease patient organisations. The report:

- Describes the success factors for patient involvement in access processes, the barriers faced by small patient advocacy groups and the personal and organisational impact of engagement.
- Identifies potential solutions to overcome these barriers and maximise the impact of small patient organisations in access processes.



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Patient involvement plays a valuable role in patient access for rare diseases

Patient involvement is increasingly being seen as an important aspect in Health Technology Assessment (HTA), drug development and wider access processes. The National Institute of Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC) have been leaders in this field.

Patient evidence and insights, particularly in rare or complex conditions where there may be limited published evidence and/or no previous experience of the condition within the HTA body, can provide unique insight into the impact of a disease and treatment on everyday life.

Unfortunately, the role of patient involvement is not always clear, and many patient advocates are left doubting their impact.

“NICE said: Oh, don't worry you'd be surprised how many go through without any patient group involvement.”

“Maybe we're a bit jaded ... but I've been to a few meetings now where it's clear that the expert advisory group haven't read our submission and I wonder to what extent are we having an impact or is this going to come down to negotiations.”

“NICE said that the company didn't share impact on carers – our submission described carer impact in detail but carer utility was removed from the model.”

Impact is poorly understood

For Patient Advocacy Groups (PAGs) the desire to be involved in access processes is clear but often outstrips their capacity, skills and resources.

In rare diseases, particularly those with very limited treatment options, a new treatment sparks much needed hope for the entire community. Being involved in the decision process is something that PAGs value yet once they embark on learning, preparing for, and executing the various activities involved in this, the organisation can quickly become overwhelmed. The individuals involved feel a heavy sense of personal responsibility and do what they can with what they have got, which they may often feel is simply not enough.

The full impact of involvement in access processes is poorly understood, with limited attention given to it in published literature. Whilst some publications recognise that skills and capacity can be challenges for PAGs, little has been written about the impact on patient advocacy leaders or the wider patient community.

The impact of involvement in HTA is grossly underestimated by PAGs themselves, other stakeholders and the access bodies.

PAGs rarely speak about the impact it is having or has had and instead focus on continuing the work they must do to support their community.

“A treatment can’t come quick enough so everything we say and do in the process feels like it comes with huge responsibility.”

“I didn’t want to let the patient community down and that is where my stress came from. I could’ve said I’m not doing this anymore I can’t cope with it but you can’t do that because you want to do your best to get access to the treatment.”

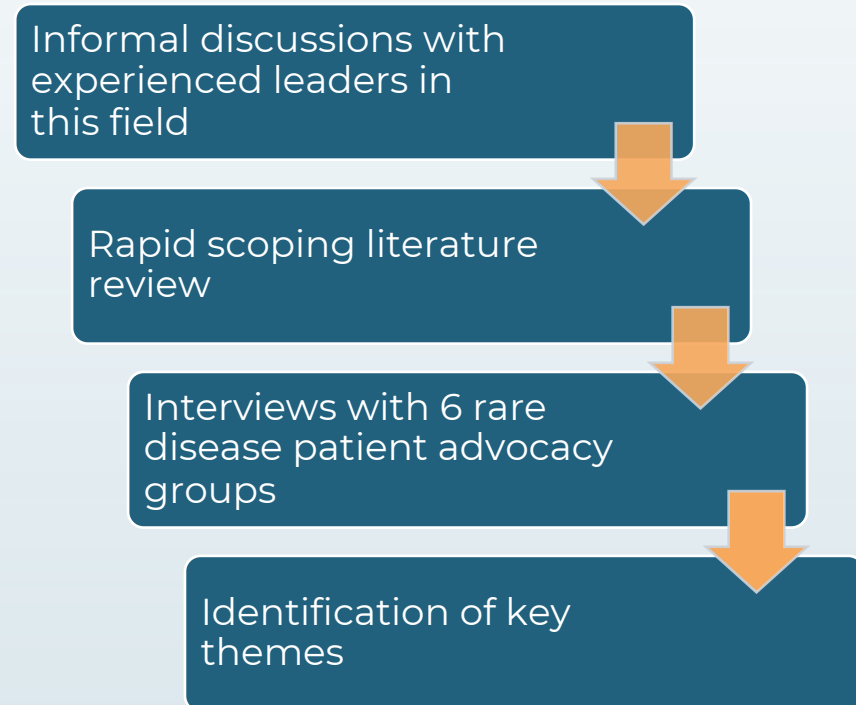
Our approach

This project has focussed on deepening our understanding of the key success factors for effective patient involvement in HTA and the barriers to this from the perspective of patient advocacy group leaders. We have explored the impact of involvement in HTA on them as individuals and on the organisations they lead. PAG leaders are often patients or carers with a personal connection to the condition.

Our work has been informed by our combined 20+ years of experience supporting PAGs in HTA and our work in Realise Advocacy to better understand how best to help PAGs overcome the barriers they face and prepare for effective involvement in HTA and access processes.

We began with informal discussions with experienced leaders in this area, before undertaking a rapid scoping literature review to better understand how this topic may have already been addressed.

We interviewed leaders from 6 rare disease PAGs with a focus on the smaller groups. We included one larger PAG to help us identify differences to the challenges faced by smaller groups. Whilst we spoke generally about HTA, many of the specific comments made were about NICE.



Limited literature exploring the impact of patient involvement on PAGs and advocacy leaders

We found some publications describing barriers to patient involvement in HTA, methods of involvement, and encouraging participation, but limited descriptions of the impact on patient advocates themselves or on the organisation. This wider impact appears to have been largely overlooked in the literature we reviewed and, in the approaches, taken by HTA bodies to supporting patients and patient groups.

Those references to the impact on patient advocates and PAGs tended to acknowledge skills gaps and capacity challenges but only focus on challenges to practical involvement in data collection or participating in meetings. Potential solutions focussed on these aspects, for example compensation of expenses, rather than looking at the full scope of PAG activities and the time and resources invested throughout HTA processes.

The impact on the wider work of PAGs, their finances, staff resources, supporting the community's mental health and wellbeing, and work on other priorities that might benefit their community do not appear to be widely considered.

Similarly, the impact on individual advocates' finances, health and wellbeing was not well described in the literature we reviewed.

We did not initially set out to look at the impact of HTA on rare disease patient communities so did not specifically look for this in our review of literature. We did not find it included in the articles we reviewed but it may be possible it has been addressed elsewhere.

“Everything else went on the back burner. We cancelled the patient day because we couldn’t manage it all. The patient day is the highlight of our calendar year.”

The role of patient advocacy groups



Patient involvement in HTA is a big undertaking for all rare disease PAGs, especially small ones

We found that the scale and complexity of the role undertaken by PAGs throughout the HTA process was not well described in the published literature. Much of the focus was on participating in activities prescribed by the process, such as attending committee meetings or submitting written evidence.

There was little mention of the areas of work that the patient advocates we interviewed found most overwhelming and time and resource consuming, such as supporting the patient community through the process.

The real work involved in doing this is mostly unseen and hidden from both HTA bodies and the wider patient community.

“It is great that patients get a voice in the process, but the downside is that the overhead to provide that voice is substantial with no support.”

PAG roles in HTA and access processes

**Supporting
patient
community**

**Stakeholder
engagement**

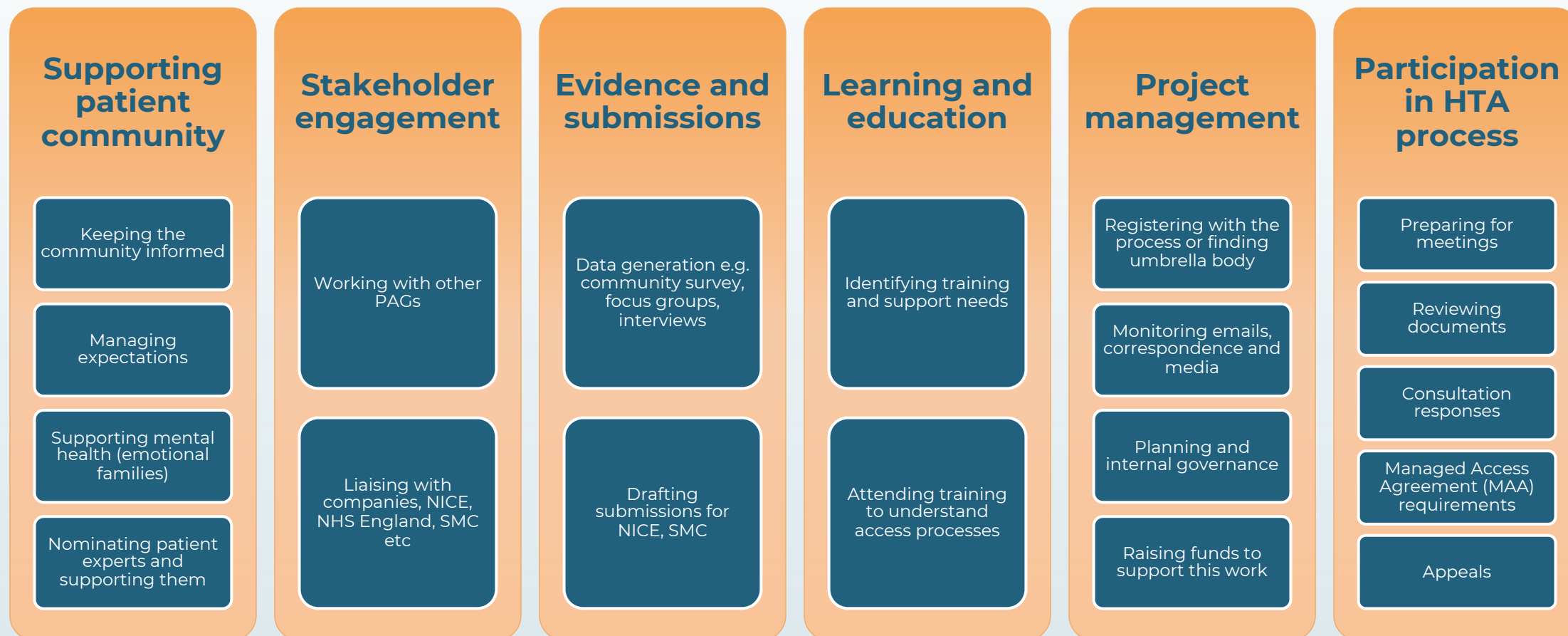
**Evidence and
submissions**

**Learning and
education**

**Project
management**

**Participation in
HTA process**

Patient involvement in HTA is a big undertaking for all rare disease PAGs, especially smaller ones. They try to maintain their usual activities alongside the substantial work involved in HTA



Supporting the patient community

All the PAGs we interviewed said they were not prepared for the work involved in supporting their community through the process. Most PAGs' described:

- Lack of understanding of how best to represent the community within the confines of the process
- Managing expectations of the whole community where only some may be eligible for treatment
- Limited time, expertise and resources to organise webinars and meetings and provide information to the patient community
- Desperation and urgency from the community for an effective treatment
- A strong feeling of personal responsibility for minimising the negative impact of a treatment being rejected

PAGs questioned whether they were doing all they could to help patients and their families prepare for the, often prolonged, wait for a final decision.

They described the difficulties in learning as they went and then relaying information in a timely, compassionate way, while trying to instil confidence in their community.

Identifying patient representatives was also challenging - PAGs knew the benefits of patients directly speaking to the NICE committee but some worried about the negative effects on the mental health and wellbeing of the patient representatives and felt that the support they could offer these representatives was not sufficient.

“Even if we weren’t involved, we couldn’t opt out of dealing with the community, their desperation, worry, angst, panic etc.”

“Choosing a patient expert was difficult trying to work out who might be suitable. We didn’t know if they were even going to be available and the meeting was a long meeting. Also, we weren’t familiar with it so it was hard to explain what would be expected”

Stakeholder engagement

Understanding the needs, priorities and requirements of industry, clinicians, other patient groups, and the HTA body was critical in enabling PAGs to prioritise activities, anticipate challenges, and develop solutions during the process.

This was challenging for PAGs with limited experience in how stakeholder organisations work, or the level of information others were willing or able to share. Some advocates described being ill-prepared for the complexities and technical aspects involved in the process and the unfamiliar use of language.

There was some acknowledgement of the willingness of the Patient Involvement staff at NICE to want to support PAGs and being helpful and approachable. Some PAGs described the SMC Patient and Clinician Engagement (PACE) process as more accessible.

All PAGs said that the language used by NICE confused them and caused unnecessary panic within their organisations and their patient communities. They found it difficult to stay informed

about what was happening and to communicate this openly with their patient community.

Some PAGs struggled to find time to educate trustees about HTA and access and felt they had limited support and expertise within their PAG.

“It's not patient-focused, labyrinthian language even for an intelligent person its confusing and hard to understand. It's like it's designed to keep 'normal' people out”

“[We received] strong signals that people on the MAA would continue to get treatment, but we weren't allowed to say then the patient community wanted us to be vociferous and start campaigning but we kind of knew we would not need to.”

Evidence and submissions

Patient advocates described not knowing where to start in developing insights and evidence about the conditions they were representing.

Most PAGs described undertaking surveys, interviews and/or focus groups to collect the views of their patient community but with limited guidance on what good work in this area would look like and what would have the most impact on decision-making.

Some PAGs had been able to access support for this work which alleviated some of the pressure, but others had not identified support, or found their limited resources a barrier to accessing support.

“[We] didn’t know what to do we just muddled through our submission”

“We ran focus groups to help patients make their own submissions. We ran an education section in the bulletin to tell patients who NICE was and what the process was.”

“Some of our evidence was disregarded. We didn’t know what NICE wanted.”

Learning and education: knowing what to expect

The PAGs we interviewed had little or no knowledge of the process prior to participating in their first HTA and were overwhelmed and uncertain of where to start and what to do.

All PAGs were keen to learn and conducted their own research or attended webinars but faced challenges in building their knowledge:

- PAGs with limited funds found it impossible to get the training they needed to improve their knowledge adequately
- Volunteer-led PAGs could not take time off from their employed work to access learning so either took annual leave or did extra unpaid hours in the evenings
- Even those with experience and knowledge found the process difficult to understand
- Additional learning added to workload and financial pressures on organisations and individuals.

All PAGs explained that the first time being involved in an HTA was highly burdensome and stressful. Although some did find pockets of information it did not prepare them for the process overall.

PAGs with experiences of multiple HTAs described their further experiences as still challenging due to the differences in each HTA. They did report being more confident in asking questions and finding answers.

“NICE say you don’t need a basic knowledge first, but I think it is [needed] because you need to be prepared for the conversations that are taking place. You’re unearthing an awful lot.”

“I was like a sponge trying to get as much information as possible from webinars and experienced individuals to try and get ahead. All the support I accessed was during the day so I just did my day job at night.”

“NICE are very formal I didn’t think that I could say we don’t know what we’re doing, and we need someone to help us.”

Project management and participation in HTA

The PAGs we interviewed were mainly small organisations (with fewer than 5 employees) created by people affected by rare diseases, initially to support newly diagnosed patients coming to terms with the impact of a rare disease, and/or to fund research. These PAGs had not prioritised developing a strategic plan for access and had insufficient resourcing to put in place an operational plan to carry out the work involved.

PAGs did not always have a lead to manage the work and felt they struggled to understand the process and to be prepared for each stage.

Essential tasks such as understanding the pipeline in their disease area, registering as a stakeholder with NICE, developing plans to generate insights and evidence, and creating a patient communication plan were often not carried out, and this left PAGs feeling unprepared and overwhelmed. Patient advocates spoke of their participation in meetings, responding to consultations and engaging in work around establishing and implementing Managed Access Agreements.

Some described lacking confidence in how to participate in meetings and felt immense pressure to represent their patient community effectively.

“NICE have a diagram of the process but I struggle to anchor myself on where we are on it so we have weekly meetings to track where we are. We’re on top of things but we still find things still slip through the net”

“Our organisation wasn’t set up to handle this. We didn’t have any staff. This process was largely responsible for the charity hitting financial difficulties.

“Meetings can be tricky but I have confidence to get my voice heard without being too shouty. But I think if you didn’t have that background you might struggle”

The true impact of patient involvement in HTA



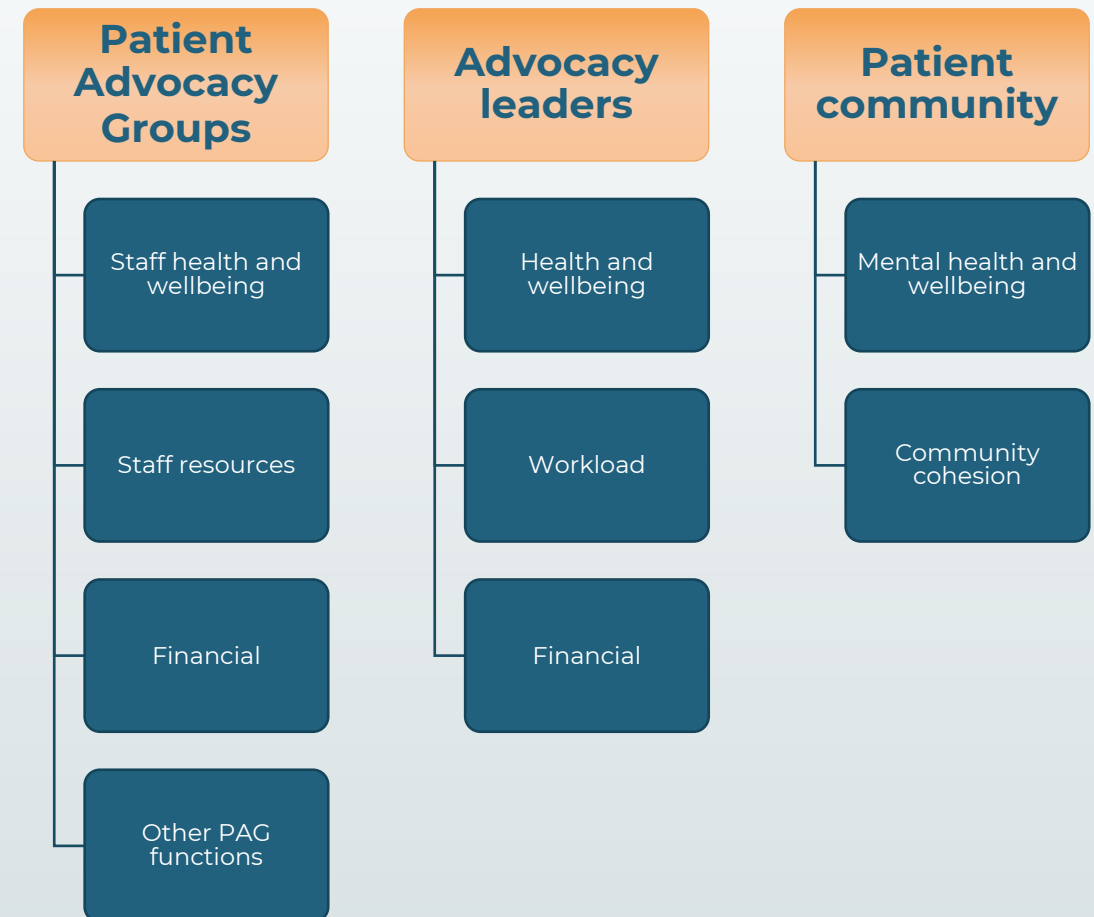
Impact on PAGs, the patient community and patient advocacy leaders

HTAs for rare diseases can vary widely in length and complexity. Their duration and outcome are uncertain.

The patient advocates we interviewed described very different experiences of the process, and their readiness to navigate it. They all spoke of how challenging it was and how at times it was difficult both for individuals and their organisation. They also described the toll taken on the wider patient community during a lengthy and difficult HTA. While the workload and financial burdens are recognised in at least some of the published literature, there was little consideration of the impact on the other functions of PAGs or the health and wellbeing of staff and advocacy leaders.

There is often no clear divide between PAGs, advocacy leaders and community, as patients and families are often the same people who lead and work for the organisation, sometimes unpaid.

Impacts of the HTA process:



Finances, staff capacity and workload were a major concern for all small rare disease PAGs



The PAGs we interviewed had no specific funding for their work in access, though some were able to make use of unrestricted funds. Some PAGs felt it was inappropriate to use funding from the pharmaceutical industry to support this work whereas others tried to identify and group activities that might be appropriate for industry funding. Only limited activities such as attending committee meetings received financial compensation from HTA bodies. Not all PAGs had the time, capacity or skills to apply for grants or other funding and relied on community fundraising or personally funded this work.

The volume of work involved in just one appraisal was a huge burden on all PAGs and the individuals involved.

Unpaid advocacy leaders spoke of working unpaid in their lunchbreaks and evenings alongside their paid employment. Some advocacy leaders took annual leave from paid work, worked fewer hours or used their own money to pay for childcare to allow them to undertake this work.

Paid PAG staff often worked extra unpaid hours to ensure work was completed. All PAGs recognised the demands of their role had increased but that the resources of the PAG had not kept pace with that.

“Don’t underestimate how much time this going to suck up. Get help.”

“We don’t ask pharma for money for this because we know they won’t fund it. Grants and trusts have never opted to fund this.”

“I took volunteer days but when they ran out I took days off unpaid to attended meetings.”

“We only had a free SurveyMonkey app so we could only ask 12 questions to our community.”

Impact on other PAG functions and the wider patient community

Interviewees described the impact of diverting focus to HTA on their other functions, with all PAGs having delayed or stopped work on other functions including their much-valued patient events. This, combined with the stress of the HTA process on the wider patient community had a noticeable impact beyond the PAG and patient advocacy leaders.

PAGs described the burden on patients and families during the HTA process and the anxiety around the potential outcome, particularly when there are no other treatment options for seriously ill patients.

We heard about tensions between some patient communities and the PAGs, particularly when HTA processes were lengthy or seemed likely to result in uneven access to a new treatment. The burden on nominated patient representatives was also a significant concern to our interviewees.

“The wider community think we should be doing more policy work and service reform”

“Tensions were high, there was a lot of fear dealing with families whose children are terminally ill, and this is the only chance they had.”

“When some people have access and others don’t it creates a rift in the community that is very difficult to deal with.”

Health and wellbeing of PAG staff and advocacy leaders



Some PAGs look back on the experience from a position of success for their families and the wider community with a sense that the hard work was worth it. Others, where decisions had been negative, felt devastated either personally or on behalf of the whole community.

In cases where not all patients were granted access to a treatment, it created a rift in the community and led to anger, frustration and heartbreak. The PAGs had to manage this tension.

Advocacy leaders responsible for liaising with different stakeholders often felt in a difficult position caught between the HTA body (e.g. NICE), the company, the NHS and the patient community.

The level of emotional resilience of all involved in this process was remarkable. This was a highly stressful situation and yet many advocacy leaders managed through difficult times

without any formal support. However, some did experience a negative impact on their physical and mental wellbeing.

Advocacy leaders we spoke with prioritised the needs of the patient community above their own to get the job done, because they felt that no one else would be available to take on their role. With limited support available they accepted the responsibility and burden of involvement in HTA alongside their other responsibilities. The personal sacrifice made by advocacy leaders working in small PAGs appeared to be tolerated due to a concern that without their involvement the patients will not have their voices or experiences heard by decision-makers.

“I put on weight. I don’t get any exercise. I don’t finish for the day or take a lunch break.”

“Running my own business has given me the skills to juggle and built my resilience to stress.”



Building solutions



What needs to change

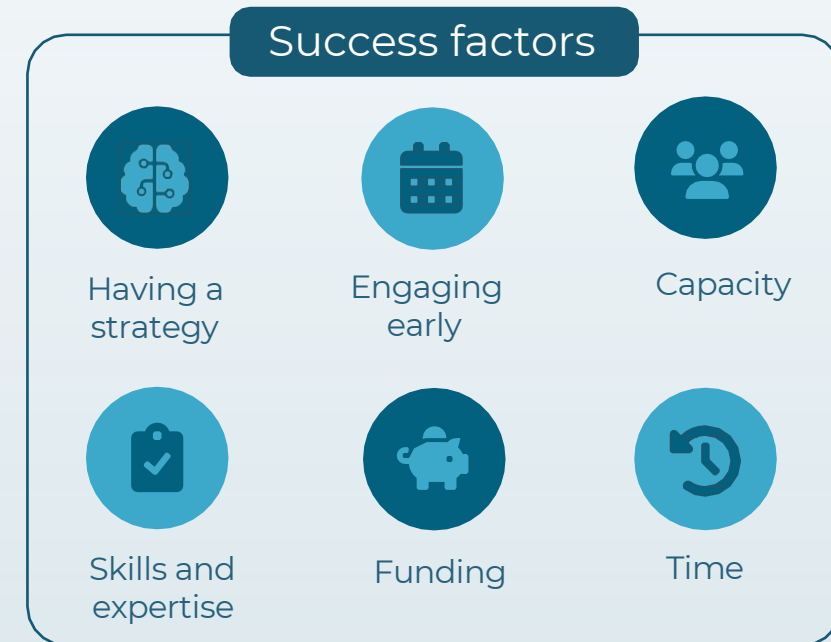
Without patient involvement in HTA for rare or complex conditions, decisions will be less well informed about the condition and the potential impact of the treatment being reviewed. Decisions will be less relevant and less legitimate to the patient community.

More must be done to acknowledge the importance of patient involvement and to educate those involved in HTA processes, on all sides, about the role of patient involvement in decisions about new treatments for rare diseases.

The full role of PAGs participating in HTA processes and in supporting patient communities throughout those processes needs to be better understood by all stakeholders, particularly NICE and other HTA bodies.

From our earlier work with small rare disease PAGs we know that key success factors for PAG involvement in HTA include having a strategy, early engagement and building capacity, skills, expertise, and resources. Understanding this, and the

impact of involvement in HTA on PAGs, is a necessary first step in ensuring they are fully supported. But it is not enough simply to acknowledge this, more needs to be done.



Resourcing patient involvement

With recent media coverage of PAGs' dependency on funding from the pharmaceutical industry to support their work there is renewed scrutiny of PAG funding arrangements*. PAGs need staff and financial resources and currently have few options for support. Without this PAGs, the people who work for them, and the people they serve will continue to struggle unnecessarily with their involvement in the HTA process.

Most interviewees were keen to have ongoing access to independent advice, guidance and mentoring throughout the HTA process to support them to prioritise, undertake necessary activities and look ahead to ensure they were better prepared for the emergence of future treatments.

Clarity on what the pharmaceutical industry can fund (e.g. patient community surveys) and cannot fund would be welcome but should be matched with realistic consideration of how to ensure adequate funding of PAGs to carry out these activities.

- A pooled fund could be an option to provide much-needed resources while ensuring independence from individual pharmaceutical companies.
- Ensuring that PAG and patient representatives receive a stipend for attending committee meetings (e.g. jury service model) would help manage the financial impact of participation in HTA.
- Provision or sponsorship for independent practical training, and developing an independent learning portal with tools and templates could help prepare PAGs for participation in HTA
- Resourcing ongoing external expertise, mentoring and support for patient advocacy leaders as well as access to counselling support for patient and PAG representatives would help address the impact on the health and wellbeing of those involved.

HTA processes and communication

Most discussion about communication focussed on NICE rather than the SMC. While we heard positive experiences of the NICE Public Involvement Programme team there were concerns about some communications from NICE. Interviewees described the divergence of experienced timelines from the standardised HTA process set out on the NICE website. Nothing could prepare them for the length of time this process will take or the fact that there may be a long pause with little if any communication.

Interim decision points that provide an opportunity for stakeholder consultation and to address evidence gaps and uncertainties can be communicated in a way that seems final and abrupt to the patient community. We have heard repeatedly about the anxiety caused by a “minded no” following a first NICE committee meeting and the pressure to respond to this with political lobbying and media campaigns whilst attempting to reassure patients and families that this is a common occurrence in HTA NICE reviews for treatments for rare diseases

Although a key stakeholder in the process, the PAG only receives limited information from NICE and, on occasion, this can seem unhelpful or even misleading with one patient advocate describing being told it did not matter if they couldn't participate in the appraisal.

HTA bodies should ensure their process and communications are well understood by patient communities and ensure consistent and appropriate messages are given to PAGs.

“Online meetings are now very busy, and I was told off once for speaking in a meeting when I shouldn’t. its more reassuring for patients if we can sit alongside them NICE are more forgiving of a patient who might speak at the wrong time”

“Our first ‘no’ was awful, the community were devastated. We didn’t realise what it meant.”

Supporting patient communities

Further consideration is needed on supporting patient communities throughout HTA processes. Regardless of the final outcome, more could be done to help patient communities understand and engage with HTA processes. A first step is to ensure that communities have a good understanding of the role of HTA and the processes across the UK. Community webinars, events and communications can help deliver this education, but flexible mentoring and coaching would be more helpful.

While we did not directly explore the impact on diversity in this project, it seems likely that the financial impact on individuals and PAGs, combined with a lack of resources to support PAGs obtaining representative insights and evidence about the impact of a condition, will influence which members of the patient community are able to participate directly or indirectly in the HTA.

"It started with the clinical trials and families' angst about whether their child will get on. We managed all of this, but families are highly emotional before you even say the word NICE. We suddenly realised that we were part of a process about what would happen to future children."

Finding solutions

Challenges

PAGs

- Lack of strategy and resources puts immense pressure on PAGs and their staff and can undermine other commitments and services
- Need for rapid upskilling for participation in access is especially acute for smaller PAGs



Advocacy leaders

- Limited capacity and resources to upskill and undertake key activities
- Lack of resource to support patient community



Patient Community

- Limited understanding of HTA processes and PAG role and impact
- Reliance on PAGs to help them understand process can result in PAGs becoming the object of frustrations



Solutions

- **Independent practical support to build strategies** for access and prioritise activities
- **Fair and equitable access to resources** to enable time and focus on HTA without negative impact on other functions - consider a **pooled fund**
- **Simple and clear processes and communications** from HTA bodies
- Pharmaceutical companies **engaging in sustainable ways** with smaller PAGs and being **transparent about evidence gaps** where patient groups could help

- **Independent practical support**, coaching and mentoring
- Support to **develop action plans and prioritise**
- Appropriate **reimbursement for time and expenses**
- Access to **mental health support and peer support**

- **Language and communications** from HTA bodies need to be more accessible
- **Independent webinars** or community events to explain the process and how to be involved

Acknowledgements

We would like to thank the many people who made this project possible by generously agreeing to speak with us as we developed our research and this report. We would not have undertaken this work if not for the many people who were not formally included but have spoken informally with us over recent years, participated in Realise Advocacy training events or reached out to us for support as they prepare and participate in HTA and access processes.

We are grateful to the Bio Industry Associations' Rare Disease Industry Group and the willingness of patient advocacy groups and individual experts to speak with us and comment on our emerging findings and to those who have spoken with us more generally about the challenges faced by PAGs and patient advocates undertaking this work.

We are especially grateful to:

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- Rick Thompson – Beacon for Rare Diseases
- Kym Winter and Lauren Roberts - Rare Minds

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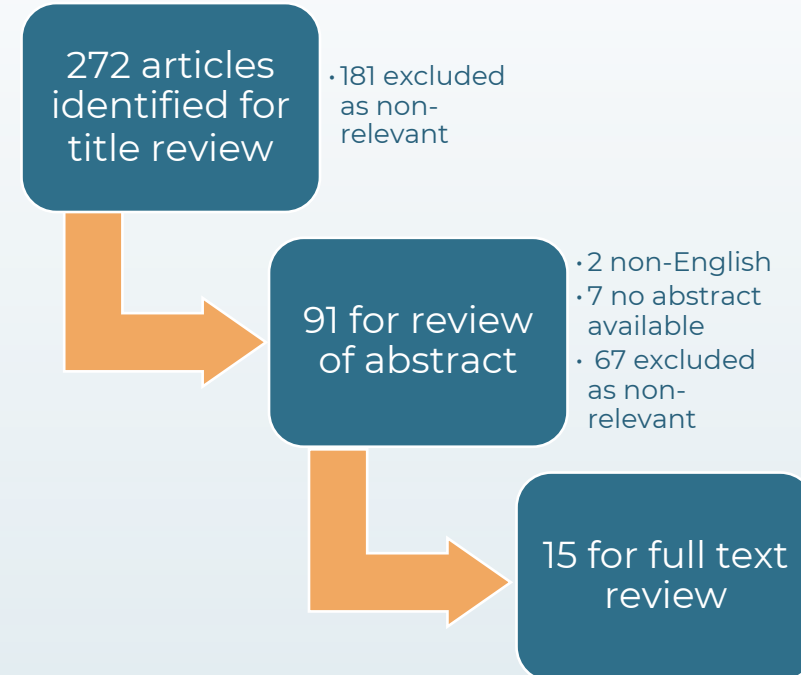
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Annex 1: Rapid scoping literature review

In May/June 2023 we conducted a rapid scoping review to find literature relating to patient group involvement in HTA:

- Online PubMed search
- Only considered articles published in English since 2012
- Additional citation tracking and Google Scholar searches to confirm results
- Initial screening based on title
- Second round of screening based on abstract
- 15 articles selected for full-text review
- Additional resources from well-known organisations in this field including European Patients Forum, HTAi, NICE were also considered



Annex 2: interviews

All PAGs were given a consent form to inform them of the project and asked about preferences for anonymity

5 out of the 6 PAGs were happy to provide quotes and be identified in the report

Characteristics of PAGs interviewed

We interviewed 5 small PAGs and 1 larger PAG for comparison

Out of the 5 small PAGs

- 3 had paid staff working for the charity
- 2 were volunteer led and had no paid staff
- 1 was not a registered charity at the time of appraisal and operated as a Facebook group
- 4 were led by individuals who were personally connected to the rare condition

The larger PAG had several staff who could dedicate part of their time for access processes



Research interview preamble and questions

Thank you for agreeing to this interview. As you know, we are interested in the impact that patient engagement in Access and Health Technology Assessment has on decision making but as well as this we are keen to understand the impact that patient involvement has on the individual and the organisation.

Could you reply to check our understanding of your situation is correct prior to the interview?

Organisation:

Role:

Scenario:

As we are interviewing a range of PAGS some questions may be more relevant than others to you.

1. Were you involved in all stages of the access/HTA process - topic selection, submissions and evidence, meetings and stakeholder engagement?
2. Can you describe the practical steps and activities you carried out?
3. What impact did these activities have on your organisation? What did you have to start doing/stop doing? what resources did you need? how much time? how many individuals? Were individuals paid staff or volunteers?
4. What impact did this have on the individuals involved? How did it impact on your professional life, family life (extra workload, disruptive timescales, personal issues), physical health, mental and emotional health, financial.
5. What support did your organisation have in place to be involved in this process? Where did your organisational support come from (financial, other)?
6. Did the individual involved have any support? If so, where did it come from? Was it helpful?
7. What was the most effective support you received for your organisation?
8. What was the most effective support individuals received?
9. Would you have any specific advice for another PAG embarking on this process in terms of preparatory steps and direct involvement? what support would you tell them to look for?