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**THE PATIENT ADVOCACY HANDBOOK**

# **Protect Your Voice!**

Important things for NHS patient  
advocates to know

*Compiled by the BLMK Patient Forum*

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# **Protect Your Voice!**

This book has been compiled to include important things patient advocates should know when taking on an advisor, critical friend, voice of reason and/or contributor role in professional meetings, on boards or in a variety of spaces.

*The BLMK Patient Forum*

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First edition published in 2023 by Shaecc Ltd  
Dunstable, Bedfordshire

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Design © 2023 Shae Eccleston  
Edited © 2023 Shae Eccleston

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*This book is a collection of observations and insights from patient advocates and representatives across the NHS. Collated by Shae Eccleston, chapters written by Jaff Newton, Linda Wilson, Pat Lattimer and Shae Eccleston, with additional contributions from the BLMK Cancer Patient Forum, as well as NHS professionals who shed a reassuring light on why the role of the patient is important when co-creating services that matter.*

*You can find out more about the Forum at the back of this book. We'd love to hear from you, or better still, have you join us to keep the advocacy light burning bright.*

# Introduction

The role of a patient advocate/representative is to support two-way communication between patients and those who will have an impact on their treatment.

Enabling patients to express the impact of clinical decisions and treatments on their lives is imperative to building a long and healthy relationship between professionals and those they seek to support.

For the purpose of this book, any mentions of patient advocacy will relate specifically to the engagement of a patient representative on a board, in a meeting or as an official voice at a professional event.

There are many routes to supporting professionals and clinicians to understand the lived experiences of the diverse communities they aim to serve. Becoming an advocate is just one of the ways to ensure the patient voice is protected.

The journey is not always smooth - and that's ok.

Our hope is that this book will go some way to supporting you as you take steps to enable, empower and inspire.

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# What Exactly is a Patient Advocate?

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*“The most common way people give up their power is by thinking they don’t have any.”*

*Alice Walker*

It’s easy to think that being an advocate relates to just speaking on behalf of someone else or enabling their expression of thought, but advocacy is so much more than that. When you step into, say, a board room as a patient, your purpose is as important as your story and the stories of those you are speaking for.

Being in the room gives patient advocates the opportunity to listen on behalf of those they are committed to protecting - for that is what this role requires - a commitment to understanding and protecting the lives of fellow humans who may have drawn the shorter straw where their health is concerned.

The ‘listening’ part of this role is probably one of the most important aspects of representation because, not only do you need to hear and understand what is being said, you also have to read between the lines and comprehend the subtext.

Listening, speaking up and advocating for, are skills that can be learnt, but for the most part, you’re probably in the room because you’ve shown passion, intelligence and a willingness to shoulder a precious responsibility.

Though this responsibility includes using your own experience to make a case where appropriate, it's more weighty because you will be speaking and listening on behalf of ALL patients. One person cannot represent all views, of course, so you'll need to be careful not to dismiss views that are different or opposed to your own. This skill can take time to acquire.

The representative role requires you to be connected and to build networks with patients and professionals, as well as to join many, many dots. This can feel like a mammoth task, but there are ways to make it work without zapping every bit of energy you have. We'll discuss that in a later chapter.

To do this job to the best of your ability, you'll be required to access diverse voices to get as many views as possible to share with Health Care Professionals (HCPs) in boards, meetings and conferences so that key information and insights can be shared with those who occupy the hot seats.

At times, you'll engage your peers about their experiences in order to represent them. Advocates must be sensitive to the information they reveal about the experiences they gather. Yes, they may trust you as a person, but once you've been tasked with sharing those experiences with a wider audience, the patients' vulnerability may be on the line.

This work goes both ways. You'll understand, as a patient or carer yourself, that we deserve to know what is being done in our names, so you may be required to cascade

information back to patients in support groups or wherever else we meet.

Your most proud moments may come as a result of you acting as a conduit between patients and the appropriate HCPs to enable improvements to be made to the cancer experience, the understanding of treatments, procedures and pathways.

**This seems like a lot of work!**

At times, this work can feel overwhelming, but you will form bonds with a range of amazing people. You will find new paths to offer support and will discover unique ways that you are being supported. You may even form friendships that help to improve the quality of life for many.

They say that knowledge is power. We believe that to be true. Maintaining control and having a clear understanding of why you're in the room will help to build trust and a strong foundation, which is essential for success and for peace of mind.

So what exactly is a patient advocate? Well, it's you deciding to create a space where voices are heard in whatever way suits you, using whatever methods work, in partnership with those who want to improve outcomes for anyone who engages with the health care service. Simply put, it's ensuring those who are not traditionally asked, are heard - loud and clear.

'The redesign of cancer services needs to have many voices to be truly successful. We need the patients, carers and family to tell us their

experiences. We need the clinicians to make sure what we do is safe, and we need facilitators to bring it all together.

There is a quote that says 'You plant seeds every single day, in the world and in others, with every thought you think and the words you speak and actions you take. You have influence. You're making a difference and you matter in a very real way.' Jennifer Williamson.

This quote describes the power of your voice. It matters to us and it matters to the people on whose behalf you speak.'

*Kathy Nelson - Head of Cancer Network, Bedfordshire, Luton and Milton Keynes Integrated Care Board*

# Should I Speak About My Own Experiences?

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*“Words mean more than what is set down on paper. It takes the human voice to infuse them with deeper meaning.”*

*Maya Angelou*

This is always a difficult balance. Your experience is relevant, of course, and is what makes you a representative of the patient view. The judgement you’ll need to make relates to what you felt about your experience and the implications for health care practice, but with an understanding that you don’t need to share every last detail of what actually happened to you. You will need to extract the general from the personal.

This comes with practice! There are times when it pays to be personal and emotional, but not all the time. Sometimes, only real emotion will cut through what can be the rather detached perspective of HCPs on some things.

**Handy tip:** emotion can be useful in conveying the real impact of something that may be overlooked or seem trivial to an HCP. Sincerity carries weight.

If your feelings are misplaced or cannot be catered for in the real world medical setting, it is for HCPs to explain why, in a way you can understand and accept. After all, complacency can smother any attempts at innovation. Things should not stay the same just because change would be uncomfortable.

## **How do I decide what is appropriate to share?**

There is no hard and fast rule about what to share, when, or how. You will learn the skill of listening to what is being said, or implied, and you will become adept at knowing how to use key components of your (or others patients') experiences to evidence a point.

Beware though, not everyone in the room may be convinced of your need to be there so derailing a meeting by making it too personal or sharing experiences that are not relevant in the moment, may not do you any favours.

In the end, as in any other situation in life, the skill of knowing when and how much to share, comes with time and experience.

'Yes, definitely! Your personal experiences have shaped you and are often the very reason that you decided to get involved. Bring your passion for change into the discussion!

Patients, families and carers are bringing real experience into the room (how services are actually working rather than how they should be working). Your voice carries weight, and often having patients and service users in the room can change the shape and focus of a professional meeting, with the meeting becoming more person-centred.

Patients, carers and families want their words to have impact. They want things to change as a result of getting involved. The best way you can make your input count is to talk about your experience in the context of this.

However, it's important for you to only share what you are comfortable with, when you are comfortable sharing it.

Talking about personal experiences can be emotional. In our team, we talk through with patient partners what they want to share *before* they join larger meetings. It can help people decide what they want to say and feel more comfortable. We often have a check in *after* a meeting to see how people are feeling.

Please don't feel pressured to share more than you want to. If talking about your experiences doesn't feel right, don't do it. You and your well-being come first.'

*Alice Williams - Head of Patient and Public Involvement (Innovation, Research and Life Sciences)*

# How Do I Choose Who to Work With?

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*"Be a voice, not an echo."*

*Albert Einstein*

There are many opportunities to get involved in patient advocacy, but what you might not know at the beginning of the journey is that the more you do, the more you'll be asked to do - and that can quickly become overwhelming.

Some of the ways that you can decide which opportunities to get involved in include, prioritising what matters to you; understanding where your skills lie, making informed choices surrounding how much time and money you can afford to commit (you may have to think about travel etc) and considering how established the group is.

## **Putting your best foot forward**

Understanding where your skills lie can be a skill in itself. It's not until we challenge ourselves to step out of our comfort zones that we often realise we can add value in certain areas.

You are more than your diagnosis. The skills you had before are still a big part of what you can bring to the table. You are no less of a person because your life has changed to include lived experiences that others do not have. On the contrary, the skills you possess, along with those you'll develop on this journey, make your contributions important, valid and powerful.

However, you will not be in control of every element of the group. When choosing, consider the chair and the committee that run the project. How well do they communicate? Are they passionate about co-production, co-design and the ladder of engagement? Are they committed to understanding or misunderstanding you? Is communication clear and fair? What is the expectation on your time? How hard will the team around you make the role? These questions and more matter when deciding how to move forward.

### **Location consideration**

You are reading this book because you have experienced a health setback of some sort (or you've supported someone through one). This is important because your capacity to physically show up may be different to those who are paid to be in the room. Your varied capacity will never be a reflection on your value, but there may be times when this is not reflected in the actions of leadership. You will need to make decisions about when you bow out, show up or ask for alternative provisions, but always remember to put your health, both physical and mental, first.

Ultimately, you may not know which groups make sense for you until you've joined one. The most important thing is not to feel trapped working in an environment that does not work for you. Look for what suits your style and where you feel useful – but always remember, you are free to walk away!

'The right organisation and further, meeting/group will warmly welcome you, support you throughout your time as a patient representative and keep you informed as an equal member of the group. The ethos of the

organisation will be committed to working in partnership with patients and the public to improve patient safety, patient experience and health outcomes and, to support people to live healthier lives in their communities. If this ethos aligns with your values, then a good working relationship should be the outcome.'

*Sara Burford - Commissioning Manager, Bedfordshire, Luton and Milton Keynes Cancer Programme*

# How Do I Navigate Boards & Meetings?

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*"Using your voice in ways that might initially scare you. That can be being an architect of change."*

*Maria Shriver*

You'll either need to be invited by an HCP or request to attend in your capacity as a patient representative from a specific group or other. Once you are on the board, consider the following:

- **Be prepared.** A certain amount of homework is crucial to feeling more at ease
- **Do your research.** Who else will be attending the meeting? Find out their roles and whether you know anyone. It's ok if you don't
- **Contact the Chair.** Make sure that the Chair is aware of your available days/hours, so that they know when meetings should be arranged
- **Ask for what you need.** Request an agenda prior to the meetings
- **Speak up.** Ask for a slot on the agenda if there is not already one for patient experience
- **Pre-prepare.** Submit a brief report before the meeting, if you have the capacity. You may not be able to attend at the last moment
- **Be present.** During the meeting, speak slowly and clearly. Talk to your report but don't read it verbatim

- **Be bold.** Ask questions if you do not understand - acronyms are a nightmare
- **Don't shy away.** Make sure you are on the distribution list for subsequent minutes and relevant documents

It is always best if two patient reps can attend - a backup is useful and maintains continuity. However, if you're the only one in the room, be confident. You belong there and have insight that no one else there does.

### **What on earth are they talking about?**

You may find that at times, it feels as if everyone in the room is speaking a language you did not learn. It's true, they are. It's clinical speak, technical speak, medical speak and a whole range of other 'speaks' you may not be used to.

To top it off, acronyms are used at an alarming rate and change regularly. We'll let you into a secret: often, many of the professionals in the room feel the same way and are trying to catch up too. If you need something broken down or explained, just ask. You may be doing a favour for others at the same time.

I chair various Boards across our system. Patient representatives enable effective engagement and bring invaluable insights that scrutinise, highlight inefficiencies, identify and guide transformation opportunities.

My expectation is not that you are a total content expert, but that you are able to use your emotional intelligence to monitor your own and others' feelings. You should use skills of dialogue, including listening, but also ask, where there is uncertainty and, you are welcome to contribute to all agenda items, not just your own.

Using compelling patient stories, you have unique power to influence at the highest level.'

*James Ramsay - Clinical Lead and Senior Responsible Officer for Cancer, Bedfordshire, Luton and Milton Keynes*

# I'm the Only Patient Representative in the Room!

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*“Nothing strengthens authority so much as silence.”*

*Leonardo Da Vinci*

When we sign up to become patient representatives we do so because we want to bring the patient view to the attention of health care professionals. We know that actually having a cancer diagnosis, coping with the treatment that follows and then living with the after effects is very different from just knowing about cancer. This is where we have the advantage over HCPs. It is our job to pass on our special knowledge for the benefit of present and future cancer patients and for the benefit of the HCPs themselves.

It is likely that a patient representative will often be the only non-medical and non-NHS person in a meeting. This can be hard to cope with but we have the lived experience.

Remember too, that there are other situations we have lived through where we may be in a minority of one.

We start new schools, we start new jobs, we join new groups, we take goods back to shops, we may be the only person with a disability or perhaps from a particular background in a group. We go to new places and survive because we are motivated to succeed. We weigh up the

odds and realise that it will be worth the effort and short-term discomfort, so we get out there and do it.

In an NHS meeting, the chairperson ought to introduce you to the other members of the meeting when you first join and ask them to explain who they are and their roles to you. The meeting agenda ought to include a separate item on the patient view and you should be able to comment on other agenda items if it seems relevant, even if not asked directly.

There are aspects of the cancer pathways that we as patients may see differently to HCPs. Go prepared to say something anyway about issues that interest or concern you. You may be aware of issues at your local Trust, other patients may have been in touch with you, or there may have been recent news in the media that you would like to query or discuss.

### **Is there any support out there?**

The BLMK Patient Participation Group has produced information to make it easier for you to fulfill your role. This should be available to you. We would expect any meeting chair to allow questions and to explain any technical terms that are relevant to your role. You will learn as you gain experience that you do not need to have deep medical knowledge to be able to represent your view of practical implications for patients – you will know better what will happen for the patient as a result of some new proposals. Not every medical advance is possible to live with in its unadjusted form.

'Whilst externally facing, maintaining credibility for the communities you represent, you bring a wider perspective than other Board members. As our critical friends, we support you as you advise from a non-institutional perspective. With power to influence, we expect a sense of accountability from all our Board members, including our patient representatives, collectively delivering a duty of care with patient and community interests at the heart of all discussions and decisions.

Leadership qualities demonstrating presence and engagement are important as some of our health professionals may not feel comfortable being challenged by critical friends. Initiating action, not merely responding to issues, will promote your leadership style and enable trust across the Board, but where leadership development is required to support our patient representatives, this must be identified and requested.'

*James Ramsay - Clinical Lead and Senior Responsible Officer for Cancer, Bedfordshire, Luton and Milton Keynes*

# I Feel Very Alone

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*"Only by speaking out can we create lasting change."*

*DaShanne Stokes.*

In the chapter on navigating meetings, we told you to ask if you get stuck - but there may well be times where you ask and receive a response that makes you feel like you're 'just' a patient. That can be very isolating.

Feeling empowered to challenge can make you feel that you are out on a high ledge shouting into the wind. You may hear the word 'no' frequently because you are dealing with huge systems that are used to doing things a certain way. But just because it's difficult doesn't mean there isn't a different way.

Thinking big – opposite to systems thinking - can be lonely but you have an invisible army behind you. You are speaking up for those who need you to tell their stories, highlight their trauma and educate professionals on the 'why'. Yes, there will be times when you feel alone. When you do, take the time you need to feel less isolated and if you decide to continue, remember, we get it, we've been there and you can do this.

**The pace is too fast**

When you have a room of people paid to be there, you may find that they have booked meetings back to back and so need to stick to timings in order to cover everything on the agenda. If you notice that they rush through at the expense of time to properly discuss and gather opinions, speak to the chair about allocating more time for the meeting in future.

If they are speeding along because they all know what 'the deal is' and have spoken about it before, so you need time to catch up, ask them to slow down. The worst that can happen is that they agree to and then forget and hurry along again after a while. That's ok. You asked. If that happens, you now have something you can discuss with the chair. The responsibility for how meetings are run lies with them.

**Handy tip:** ask others in the group for help, for references, readings and for people to talk to. There is no harm in HCPs thinking about what they are saying and its meaning to other non-medical-experts in the room.

'Being a patient representative, particularly at the beginning of a process, can feel lonely and scary. This will pass and doesn't have to feature as a regular occurrence in your experience as a patient representative. One possible solution is to find a support buddy. Ask any questions; particularly anything you don't understand.'

The NHS is full of acronyms, but in patient-centred meetings, they should be avoided. It is okay to say this. Becoming a patient representative is a brave undertaking, but one that will hopefully feel empowering rather than isolating. Speak to your group/meeting lead; they should be more than happy to help you.'

*Sara Burford - Commissioning Manager, Bedfordshire, Luton and Milton Keynes Cancer Programme*

# I Don't Think They Listen to or Respect Me

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*"Stand before the people you fear and speak your mind - even if your voice shakes."*

*Maggie Kuhn*

Why do you think that you are not listened to? Often there will be no immediate acknowledgement of very worthwhile contributions, but after the idea has settled, something could change in the future. Keep your eyes open for change. Do not expect immediate acceptance of any point you make.

New ideas and ways of thinking and working take time to become adopted. Most of the important changes in society have taken time and unbelievable persistence - think of unions and workers rights, education and votes for all, the minimum wage, safety at work and the NHS itself, to name but a few. If you believe you have something to say, stick with it.

Not listening is not the same as not respecting. You should expect to be able to say your piece and be received politely, whether or not any notice appears to be taken of what you said. Disagreement is not the same as being disrespected either. There is sure to be disagreement at times. Ideas from patients may not be welcome even when perfectly good and justified. As said earlier, it can take time for even obviously unhelpful or inappropriate practices to be abandoned. Most humans do not like change, as it requires a lot of upheaval to

long established habits of thought and action. Most of us react badly to criticism too, but it is true that we can learn more from criticism than from praise. Having said that, a little praise at the right time goes along way.

So stick to your guns. Do not expect to be among best buddies but do expect to be accepted at meetings. Be polite and expect the same in return. We are expert patients.

Remember, be ever hopeful and optimistic. Try not to have preconceptions about something that seems unlikely to be accepted. It may actually be deliverable if the HCPs know about it. They should at least be given the opportunity to explain the reasons 'why not' for us. If no joy, do ask again when appropriate. We should never give up easily. Put forward lots of ideas.

Conversely, we do definitely need to be persuaded why certain practices should continue if they upset patients. Sometimes procedures are based on long-standing, and maybe outdated, habits that have never been questioned. They should be examined to see if improvement and change are possible.

## **The professionals are talking down to me**

There is a phenomena in the medical field that removes any professional attributes from a person who enters the room as a patient and instead replaces their value with a need to be saved or spoken down to. One of the very tough tasks you will need to commit to on this journey relates to challenging that thinking.

It may mean that you find yourself as the only one on 'our side' in a situation. During these times, it's important to use evidence, stories, experiences and data to back up your thinking. Be creative and be bold but be resourceful. Forcing a perspective onto a professional won't always win the battle. You'll have to take some time to look at various routes to success and sometimes, you may even need to concede. It's not always the right time, place or circumstance.

'Your role as a patient representative has equal weighting to everyone else. This can mean that not all outcomes may be as you want, but your opinion should never not be heard or be disrespected. If you feel this is happening, speak to the meeting/group chair on an individual basis. Hopefully they will intervene if needed, or if not, consider alternative groups and meetings, as there are many available that will value your voice.

The role of a patient representative is to enhance patient experience, share suggestions and constructively challenge ideas. There is always a place for these qualities to be heard and respected.'

*Sara Burford - Commissioning Manager, Bedfordshire, Luton and Milton Keynes Cancer Programme*

# Does What I Do Here Really Matter?

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*"The act of speaking out may make you feel alone"*

*Ravish Kumar*

Absolutely yes - you are bringing the patient perspective which is unique and essential to have the whole picture.

If you do not know the answer, say so, but also say you are able to contact other cancer patients or groups to gather the relevant information.

Your own experience is also of value but the views of a wider group of patients is more powerful.

We are patient reps because we care. It helps to develop a thick skin, where possible. We know things that HCPs do not – especially about the impact of treatments on patients. There is no better expert in this area!

We really want future patients to have a better experience and outcomes. Stick to your guns but if you find the experience too triggering, it's ok to stop and look for other ways to help, perhaps more directly, such as in the Cancer Centre.

Always remember, you are a really important member of this meeting because you have had the actual experience of cancer.

## **The process really intimidates me!**

Time may change this but if it doesn't, it may be a good idea to identify what about the process you're struggling with. Is it the pace, the people, the themes, the frequency or something else? Without understanding what is making you feel this way, it's way harder for you to process and manage your feelings.

'The fact you are here means this is important to you. Your contribution is valued and demonstrates your courage to lead others. Being a change leader means looking beyond yourself to make a difference to others and having the desire to be part of a change that is bigger than you.'

Most of us do not start out thinking we are leading change, we just see something that needs fixing or improving and take the initiative to do it.'

*Kathy Nelson - Head of Cancer Network, Bedfordshire, Luton and Milton Keynes Integrated Care Board*

# How Do I Stop the Process from Draining Me?

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*“To say nothing is saying something.”*

*Germany Kent*

We know you want to be involved. That’s why you have this book in your hands. We also know that because this is a cause that really matters to you, you may give it all you have, which can be draining.

So, we have come up with some reminders to keep nearby:

- Join when suits you — not ‘them’
- Find a key person who will be ‘your person’
- Make known what you can and can’t do (you’re not just a patient)
- Be as organised as you can be
- Leave the guilt behind – it’s ok to say no
- Communicate
- Feel free to walk away
- Find out if there is an easier way e.g. in person vs online

Be aware and think carefully about what you will be able to deliver so you don’t agree to do more than you can. You can’t say no if you don’t have a clear idea about what you can realistically manage.

‘Be kind to yourself. If you feel anxious or exhausted or emotional, is there something the staff team can help with?’

In our team, we often spend time before or after meetings so that we can check in with our patient partners. Sometimes there are concrete actions that we can help with (providing project background information, explaining pathways), but sometimes this is just a 'download' to talk things through.

And put yourself first! If you aren't up to joining a meeting, just say so. If you need to, ask to step back for a bit. It's not a sign of weakness and you aren't letting people down. We know that patient partners are juggling significant health challenges. Your mental and physical health are more important than anything else.'

*Alice Williams - Head of Patient and Public Involvement (Innovation, Research and Life Sciences)*

# I Can't Afford to Do This for Free

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*“Minutes may seem as worthless as pennies until you add them up. Neither should be wasted.”*

*Richelle E. Goodrich*

During treatment it may not be possible to attend, so inform the chair and find an acceptable solution. You can ask for extensions for reports, have a substitute representative who is familiar with the topics/meetings, and just take a break that will enable you to focus on healing.

Additionally, you can request more details outside the meeting for more clarity on a topic or procedure.

Your group should have some guidelines on whether the role will cover expenses and/or an involvement payment. If you are finding that attending is costing you more time or money than you can currently afford, do speak to the person you are comfortable with about this. Remember, many of the professionals in the room may be paid to be there and so may not be aware of what it takes for you to be in the room.

It can be a really tough thing to share your vulnerability only for it to be rejected. We have been there so we would never ask you to do that unless you were comfortable.

Policies should be readily available for you to find and you can ask about them without explaining your complete situation. Never feel so trapped that leaving is your only

option. There are people, policies and documents that may be able to help.

### **So, what are the guidelines and where can I find out more?**

The NHS has a Patient and Public Participation Policy. It will soon be updated, so the most recent version will be online.

You should also be able to ask your group if they have any policies or toolkits for working with patient advocates and representatives.

If they don't, they should. Who knows! Perhaps this is something you can bring to their attention and lead on.

'Your time is valuable and understandably, can't always go without compensation. Wanting to contribute in the first place is very positive and should be recognised. It can be difficult to reconcile the financial constraints of the NHS with personal financial constraints.

Talk to your meeting leader to see if financial compensation is available for patient representatives; there may be a solution. If not, it comes down to a personal decision about how you spend your time and money. One would hope that the benefits of contributing outweigh the costs.'

*Sara Burford - Commissioning Manager, Bedfordshire, Luton and Milton Keynes Cancer Programme*

# How Do I Protect My Mental Health?

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*"Give yourself permission to say NO.  
Do not feel guilty, mean or selfish."  
Stephanie Lahart*

The sad truth is that you're an expert in the room because, at some point, you had harrowing news regarding your health. That was, on its own, a trauma that cannot be understated.

Now, you find yourself reliving that experience and that of others' over and over in the pursuit of education and progress.

If it didn't take a toll on your mental health at points, we may be forgiven for mistaking you for a cyborg! But seriously, don't underestimate how much damage not being heard can do.

When your mental health is at stake, we suggest following these simple rules:

- Let the group/committee know how you feel. They might be able to support you through this
- Slow down. As much as we might like to have super powers, we are not superheroes. Take the time you need when you need it
- Make 'no' your best friend. When no is used wisely in your vocabulary, other pressures feel more manageable

- Don't view being unable to help as lazy or weak. Using discernment about your capacity can be the difference between healthy contributions and ultimate burn out
- Don't argue to prove your point. It's ok if others don't understand. Perhaps it's the right message, wrong messenger
- Set boundaries. Not everyone needs access to your soul. They will be just fine if you don't give everything from your well. Keep some nourishment back for yourself
- Recognise and manage toxic working relationships
- Things change. Perhaps it's time to move on. There's no shame in choosing yourself for a change!

## **I can do this!**

Yes you can!

What you need from this process will vary. Perhaps you're not looking for much at all, or maybe you want tangible outcomes. Whatever your need, whether an act of faith, friendship, knowledge, a sense of achievement, a sense of purpose, paying forward your own help and successful treatment, smoothing the way for others, helping HCPs get more out of their inputs or completing a mission in life, your contribution in this space matters - and always will - and just in case you don't hear it much on the journey you're about to embark on, THANK YOU.

'Good working environments that are genuinely inclusive of our valuable patient, family and carer partners will have asked you what you need.

They will have given you an opportunity to talk through, not just any access support needed (e.g large print or a sign language interpreter),

but they will have also asked you how they can help you bring your best self to the meeting or project.

For some people this might mean pausing their role for a while if they have a flare up of health issues, or it might be a quick check in with the chair or a buddy before the meeting to alleviate nerves or deal with queries.

The important thing is, you probably have an idea of what you might need to be effective in your role and putting these things in place will support your well-being - so ask for them! Make sure the staff team know. And don't be afraid to speak up again if you think of new things.'

*Alice Williams - Head of Patient and Public Involvement (Innovation, Research and Life Sciences)*

# About the BLMK Cancer Patient Forum



The BLMK Cancer Patient Forum is made up of patient and public representatives who are committed to educating, supporting and empowering those experiencing cancer.

**We ensure the heart remains in practice.**

Our mission is simple: find and fill the gaps in support and services to ensure a better future for patients across BLMK. We aim to do that by promoting good practice, addressing inequalities, highlighting successes and ultimately improving the human experience.

*Supported by the  
Bedfordshire, Luton and Milton Keynes Health and Care Partnership  
Capability House, Silsoe, Bedfordshire, MK45 4HR  
[www.blmkhealthandcarepartnership.org](http://www.blmkhealthandcarepartnership.org)*