

Patients as partners

Building collaborative
relationships among
professionals, patients,
carers and communities

Becky Seale

**Leadership
in action**

An introduction to this guide

The King's Fund firmly believes that a collaborative relationship with patients, carers, third sector and communities is central to the future NHS because these perspectives are fundamental - patients are why the NHS exists. The *NHS five year forward view (Forward View)* is unequivocal about this (NHS England *et al* 2014).

What helps to build collaborative relationships among health and care professionals, patients, service users, carers and communities?

This guide is a response to that question. It stems from an evolving body of our work focused on exploring and supporting shared leadership. It is reinforced by a growing consensus that health services, agencies, patients and communities need to work together more - and differently.

There is much more potential to involve patients - and their carers where appropriate - as partners in care.

Chris Ham, Chief Executive, The King's Fund
(Ham 2014)

But do we all know how to do this? And what could this new relationship look like?

In 2013 The King's Fund began exploring the concept of patient leadership¹ with a view to understanding how we could support its growth in the system. We quickly recognised that the new relationship is about all of us - patients and health care professionals - changing our approach.

We wanted to disrupt the 'them and us' relationship dynamic in health and care systems. After many conversations with people already working in this area, it was clear that developing the capability for shared or collaborative working was essential to making this change.

Achieving a more collaborative dynamic will require a change in the way that all of us work. The ability to adapt, communicate and shift between roles will be important for all who seek to establish a new, collaborative relationship that puts safety and quality at the heart of health and care in our communities.

Allison Trimble, Programme Co-Director, The King's Fund
(Trimble 2015)

In September 2015, we launched a national development programme 'Leading collaboratively with patients and communities' (the collaborative pairs programme). We invited health and care professionals, patients, carers, service users and community-based leaders to come together, in pairs, to explore how to develop collaborative relationships and lead

1 Our initial interpretation of 'patient leadership' was influenced by conversations with the Centre for Patient Leadership and its 2013 report *Bring it on - 40 ways to support patient leadership*.

system change.² We also began bespoke versions of this programme in local organisations and systems.

The collaborative pairs programme

- A five-day development programme focused on building collaborative capabilities.
- Pairs join the programme with a shared leadership challenge.
- Each pair comprises one health professional and one patient, carer or community-based partner.
- Co-directed by Allison Trimble, senior leadership consultant at The King's Fund, and Mark Doughty, associate of The King's Fund and patient leader.
- Learning is captured to shape wider thinking.

Through the national programme, we explored a series of dilemmas to understand how system change might occur. Is sustained change best achieved from 'top down' or 'bottom up'? Do we start with systematic changes to structures and strategy or 'under-the-radar' changes to relationships and ways of working?

We were determined to model collaborative relationships in our shared leadership of the programme. Allison Trimble and

2 Hereafter 'collaborative relationships' refers to 'collaborative relationships between health and care professionals, patients, service users, carers and communities'. We also use the term 'patient partners' to refer to patients, service users, carers and community members.

Mark Doughty co-designed and co-facilitated the national programme; they brought their different perspectives to the facilitation role but with a shared purpose to enable the group's learning. This allowed them to reflect on what was going on for them as a potential mirror of what was going on for the collaborative pairs in the room, for example, power dynamics, conflict, different personal/organisational agendas and demands that impact on the shared (collaborative) agenda.

We also share our collective learning in this guide. Becky Seale led the programme knowledge capture process and has been the lead author working in partnership with facilitators, participants and the programme supervisor, David Naylor.

We have distilled our learning into five practical ways to develop collaborative relationships among NHS, patient and community partners.

Find your collaborative partner(s)

Invest in developing leadership and collaborative relationships

Make time for learning - and share it

Go where the energy is (under the radar)

Embed collaborative activity (authorise it, make it legitimate)

Not all of these will apply to you. But whether you are a patient, a carer, a community member or a health professional, an individual trying to initiate a collaborative relationship, or someone responsible for fostering your organisation's relationship with its patients and community, we hope this guide will have something for you.

We encourage you to dip into it, using our learning as a mirror for your own, asking yourself: what does this mean for me, my context and my purpose?

Patients as partners



1. Find your collaborative partner(s)



2. Invest in developing leadership and collaborative relationships



3. Make time for learning - and share it



4. Go where the energy is (under the radar)



3. Embed collaborative activity (authorise it, make it legitimate)

1

Find your collaborative partner(s)



You're a patient with a brilliant idea or a clinician with a desire to co-design a service with patients. How do you find the right person to collaborate with?

Perhaps you've been given responsibility in your organisation for nurturing collaborative relationships that represent the diversity you need. How do you achieve that?

It's rarely a lack of desire on the part of individuals that stops collaboration, but a lack of networks, funding and know-how.

What does a collaborative relationship look like?

You will need to define your local benchmark according to your context. This is our definition:

In the collaborative relationship, health and care professionals and patient partners move beyond a 'them and us' relationship (where power is held predominantly by one partner) to a more collaborative relationship where power is shared. A defining feature of the collaborative pair relationship is that everything is shared - for instance, establishing the shared purpose, working to a shared ambition, exercising shared leadership, with shared ownership and shared responsibility for what happens.

As we started to recruit to our programme, we realised that our invitation for pairs to apply with a shared task and funding in place posed a significant challenge. We had enquiries from health professionals without a patient partner, and vice versa. Some pairs existed but without a shared task. Others could not get funding. While we offer coaching and support to enable applicants to find their partner, get funding or make the case to their organisations, we stipulated that we would not pay in full or source partners for them.³ This was deliberate - finding a partner, some funding and a real task mark the first important stage of beginning a collaborative relationship.

At the outset, it will be important for you to do the following.

- Find a partner with the will and determination to collaborate (this could be someone you already know or someone completely new).
- Think whether you make assumptions about who you would work with best. Are these well-founded? Do you need to challenge them? Who do you need to work with to achieve your particular purpose?
- Work together on a real-life project or challenge that is important to you and your local system.
- Secure confirmation of strategic backing (perhaps some

3 We offered bursary contributions to those who demonstrated a particular need for facilitated access to the programme. This was supported in part by The King's Fund and in part by sponsorship from NHS England.

financial commitment, or regular interest and support from a senior sponsor).

- Define your shared purpose and values: what do you want your work together to achieve? What is important to you about how you achieve this?
- Agree some shared principles to guide your work towards your purpose. For example, our own when developing this work was that, 1) we would do everything together or not at all (speaking platforms, programmes, design work); 2) we would build in continual learning and reflection.

So what sorts of people might be interested in working collaboratively? What projects might they work on?

Twelve collaborative pairs joined our inaugural 2015/16 programme. The pairs represent a wide range of roles and this reinforces the message that collaborative relationships can be effective throughout the system.

- **A consultant cardiologist and his patient**
The re-design of local heart failure pathways and services.
- **A lay member for patient and public participation and a head of engagement in a clinical commissioning group (CCG)**
Mobilising community assets while working with GP practices in newly formed clusters, with emphasis on promoting preventive health care.
- **A governor for special educational needs at a centre for independent living (and civil servant), and a lead**

therapist for intermediate care planned services

Finding ways to give people maximum involvement in decisions about their care and treatment, so they can manage their health within the context of their circumstances.

- **A lay member of the executive board and a research delivery manager in public and patient involvement and engagement for a clinical research network**

Embedding patient and public involvement and engagement in the research operations of all partner organisations and at all levels within the network.

- **A director of services and policy for a national charity and a clinical trials service manager**

Putting patient, carer and researcher on an equal footing. Achieving a cultural shift where communities are regarded as a conduit for people to collaboratively solve the issues that need addressing.

- **A Healthwatch service improvement and delivery lead and a clinical director of a CCG (and one of NHS England's 50 vanguards)**

Introducing a new model of care, co-designed with local people, bringing better health and wellbeing for local people and better value from health and social care services.

- **A chair of a disability group (and Open University lecturer) and clinical manager for neuro-rehabilitation**

Making neuro-rehab services more patient-focused and accessible. This should allow the voice of the patient in care to be heard and acted upon routinely.

- **A chief executive of a charity providing Alzheimer's and dementia support services and a commissioning project manager for a CCG**

Development of a dementia hub - a fully integrated provision with access to all dementia services across all sectors.

- **A Healthwatch CEO and an assistant director of primary and community care at a CCG**

Aligning system and structure transformation with a 'citizens and patients hub' model to support a strong and confident community response to health and social care challenges.

- **A member of the patient panel and a patient experience lead at a community hospital**

Addressing the poor response from the Friends and Family Test and producing a successful model of partnership working.

- **A director of a community-led consultancy and a chief pharmacist at a mental health trust**

Increasing the number of staff open to and implementing supported, shared decision-making.

- **A chair of a patient participation group at a health centre and an academic researcher (and NHS employee) at an academic health science network**

Developing a strong and supported advisory group able to influence the strategy group and respond to their questions.

Bart's Health has adapted the collaborative pairs programme to scope the range of local contexts and activities that could benefit from collaborative relationships. These include:

- a nurse leader working with Muslim leaders in the local Bangladeshi community
- an outpatients manager working with a carer
- an estate manager working with a youth worker.

Questions for you

- What aspect of work in your organisation, community or local system would benefit from collaborative working between health professionals and patient partners?
- Who could you work with? Who could you talk with to help you find the right partner(s)?
- Are you making assumptions about prospective partners? Where do these assumptions come from? Are they shutting down possibilities?

2

Invest in developing leadership and collaborative relationships



Developing new relationships is more than setting up frameworks or governance structures. For a new relationship to emerge, those with access to resources need to invest in developing patients, carers, community members and health professionals to work as collaborative partners in the health system. As in any relationship, investing time, energy, capabilities and practices for shared work as collaborating partners will enable trust, openness and potential to grow.

Perhaps it is stating the obvious to say that creating a new relationship means focusing on relational capabilities. But in a system that traditionally privileges structures, performance and tasks, it is important to underline this. For the NHS in its current form it is counter-cultural to focus on what are often tellingly described as 'softer skills' - like the ability to build collaborative relationships, especially with patients, carers and communities. Among our pairs, we noticed a tendency to focus on the task rather than on the relationship. This powerful pull is something to be aware of as you develop your own collaborative relationships.

One of the pairs on our national programme has set up two forms of development in their local system as a result of their learning:

- community ambassador programme to train local community members
- collaborative trios programme for clinicians, managers and patient/community partners.

For more see [Wernick and Manley \(2015\)](#)

There are a number of routes to developing relational capabilities from an organisational perspective. The most common are commissioning or designing training and development interventions, such as learning and development programmes, coaching and action learning.

Until now, patients, service users, carers and community leaders have had little or no access to leadership development - unlike many health professionals whose pathways to development are comparably more established and resourced. We believe in the need to invest in developing leadership capabilities among all those involved in collaborative relationships as well as in nurturing relational capabilities.

Development of patient partners' leadership capability

could focus on these areas (alongside traditional leadership skills):

- competence and confidence to self-lead
- skills and confidence to engage people in dialogue and

sense-making by asking questions and exploring meaning

- awareness and practices associated with the 'emotionally intelligent leader'
- skills to build and sustain relationships and manage challenging behaviours
- confidence and skills to work with diversity and difference within contexts that can be ambiguous, complex, uncertain, pressurised.

Relational capabilities for all partners to lead collaboratively could be:

- knowing how to establish a shared purpose
- moving between roles and adapting styles according to context
- taking an appreciative approach to defining shared principles (focusing on what works)
- acquiring the art of asking powerful questions
- acting as consultants to colleagues to help them explore and make meaning from dilemmas they are experiencing
- having the awareness, ability and confidence to notice and explore assumptions
- having the skills and confidence to hold difficult conversations
- influencing stakeholders
- using tools to develop a shared, public narrative and a 'call to action'.

How I ask questions is one of the most useful learnings from the practice we've had in consulting to each other.

Participant, national programme, 2015/16

A note on diversity

How do we make sure that when forming partnerships and investing in developing people, we are doing justice to the diversity of people available for the collaborative task?

This is a controversial and often debated issue. Responses can often fall into two categories: ignoring the issue and working with those who are most available; recruiting to strict and depersonalised lists of traditionally excluded groups. Perhaps the key is to ask yourself: what different perspectives or life experiences are most important to our initial definition of the task and purpose? How do I create the conditions to encourage those contributions?

For more see [Ocloo and Matthews 2016](#)

For individuals who are collaborating, taking the time to find out about each other is an important first step to building a collaborative relationship - who we are, where we are and what's important to us. We need to understand each other as humans first, with our strengths and weaknesses, and build trust so that we can challenge each other's assumptions and boundaries.

One patient isn't every patient!

Participant, national programme, 2015/16

It is important to recognise that partners will come into the relationship with different confidence levels and different levels of authority to speak and act. There will and should always

be difference - but for true collaboration, there shouldn't be a hierarchy. Authority should be shared and different perspectives valued.

These are other tips from the programme participants on what helps partners develop a collaborative relationship.

- Find a neutral space to work within and always seek ways to get on an equal footing.
- Don't take the relationship for granted - invest time to learn about each other.
- Challenge each other and feel comfortable in doing this.
- Recognise each other's role, then experiment. Try going outside your roles, while recognising the limits of each other's role.
- Trust that the other person knows their stuff.

Questions for you

- As you try to build your new relationship(s), where is your focus? How much have you focused on building the relationship(s)?
- What local resources do you already have that would support the development of leadership and relational capabilities?
- How could you secure the resources you need for future development and ensure it is sustained?

3

Make time for learning - and share it



Because developing a collaborative relationship may be new for you and your local health system, we would strongly advise that all development activity is underpinned by reflection at each stage and an open-minded record of what is being learnt.

One of our pairs set themselves a rule that for every meeting, they will spend at least 40 per cent of their time together in reflection and learning about their relationship, how they are working and what they are learning about their local system.

Mark and Allison, programme co-directors, had supervision after each module to help them explore their own partnership as facilitators from health care professional and patient leader backgrounds. Their experiences in many ways mirrored the experience of participants in their own organisations and systems. We used this insight to adapt our design and approach.

- Create reflective learning spaces within and alongside the development of new collaborative relationships.
- Individual collaborators: set aside a regular amount of time for reflection in all your meetings together, on how

you are working and what you are learning. You may want to seek out peers with whom to carry out this reflection.

- Designers of development: build reflection and learning into any programme. Consider asking someone outside the programme to help you reflect on what you're learning.
- Capture that learning - write it down, video it, blog it, draw it - anything that helps you share your learning more broadly.
- Share your learning with those whom you seek to influence and with peers. Get yourself a slot with the board. Consider setting up learning exchange sessions with others seeking to collaborate in your local area.

Finally, make sure your carefully designed development is not a one-off. Build any collaborative leadership development into your organisational development plan.

Questions for you

- How confident do you feel about reflecting on your own learning about the relationship? Who else could help you?
- What ways are already available to help you capture and share your learning?
- Who would benefit most from hearing about your learning?

4

Go where the energy is (under the radar)



It is possible that the way you are working or wanting to work does not fit with traditional processes and so poses a challenge to established norms and power dynamics. At some point, you may need to decide whether to address these traditional processes openly (by gaining top-down acceptance) and to what extent, or work around them (going under the radar, working bottom up). Both approaches can lead to sustainable system change where collaborative ways of working are the norm, but they take different paths.

The health system itself perpetuates hierarchy - it's diagnostic not collaborative. And in the current system there is more power to the deliverer of care than the receiver.

Participant, national programme, 2015/16

How many senior managers know what co-production is?

Participant, national programme, 2015/16

One of our pairs was asked to document their project using standard templates before submitting them to the local CCG. Their project didn't fit the template. So they decided not to submit their work to the CCG because doing so would limit what was possible. One consequence was that they could continue with their work in the collaborative spirit they were both committed to. Another was that the CCG were not aware of their work.

It is legitimate to 'go where the energy is' in your local system and work under the radar with your collaborative project until you have a compelling story to tell. Several participants on our national programme chose this path, and explained the benefits.

- Working outside normal boundaries helps innovation.
- Having permission to experiment without the pressure to feed back and report results fosters creativity and energy.
- Operating as 'loose cannons' and 'mavericks' outside the system can ultimately produce effective results that the system regards as legitimate.

A complete paradigm shift is around the corner [...] This shift will need leaders who are confident, competent and have the energy to innovate. They have to be able to take risks to try out the new and experiment with novel ways of providing a service.

Marcus Powell, Director of Leadership and Organisational Development, The King's Fund

In the spirit of supporting system change, **it is important that at some point you share your results, your approach and your learning.** Here are some tips from participants on our national programme.

- Be prepared to ask for forgiveness rather than permission.
- Book a slot on the agenda of whatever represents the authority in your organisation or system to share your results and ways of working.
- Spread learning about your approach for those who want to follow in your footsteps.

- Notice how it feels to be a maverick. Stressful? Exciting? Remember to seek out support that sustains you and be prepared to let go of this identity. At some point, 'your work' must become 'everyone's work' in order to mainstream the new relationship.

Questions for you

- Whose formal authority could you travel on to legitimise your collaborative activity? Who can endorse you?
- Where can you find sufficient legitimacy for your project to protect yourself and allow the space to experiment?
- What will lead to sustainable system change in your context and for you?
- How will you capture and share your learning about outcomes and approach?

5

Embed collaborative activity (authorise it, make it legitimate)



A practical way to ensure that collaborative relationships become a sustained reality is to embed collaborative activity at all levels in your organisation or system. If you don't already have existing examples of collaborative working within your organisation, you may choose to start by taking a systematic approach. This can range from ward to board and beyond the boundaries of your buildings, and out into your community.

Shifting roles and blurring boundaries

We have found that reflecting on three key questions in relation to role, context and purpose can help shift people into collaborative roles. These are distinct from other context-specific roles such as patient, clinician, manager, citizen.

- What role am I in now?
- What role am I in in this context?
- What is the purpose of this role?

We propose these questions as a guide to help people work with the implications of going beyond context-specific roles and working in the more collaborative way that the collaborative pairs model invites.

You may choose to use the authority of senior leaders in your hierarchy to give permission for your work. Here are some tips from pairs who have taken this approach.

- Get sign-off from your whole management chain for the collaboration.
- Notice where you experience resistance and what form it takes, and feed this learning back into the system. It could come from peers as much as from your senior team and you might notice resistance in yourself.
- Pay attention to the impact this resistance has on your ability to experiment and sustain your own energy for your project.
- Be sure to build in sufficient space to reflect and learn about the relationship.
- It's not always about working in a pair - expand to include threes or wider teams. They in turn can start to form a network of peers, from whom you can draw energy and ideas.

Questions for you

- Whose formal authority could you travel on to legitimise your collaborative activity? Who can endorse you?
- What would embedded collaborative relationships at 'all levels' look like in your organisation or system?
- To what extent is collaborative working already happening and how could you support its spread?

- Where and what forms of resistance do you experience as you attempt to embed collaborative working as the norm? How does this influence your approach?
- How can you ensure that you sustain the momentum and principles of collaboration?

Our pairs are already evolving and expanding their interpretation of collaborative relationships.

North East Hampshire and Farnham Vanguard project have extended the Collaborative Pairs concept to explore how collaborative trios of clinician, manager and patient/ community leader can support the development of new models of care.

Impact: views from some collaborative pairs

The support and learning from the programme, the chance to hear from other pairs' work and then reflect on our own work back in the CCG has been invaluable. We have been able to use the tools and techniques to develop strategies to ensure that our 'patient and public engagement' work is more robust and moves towards a collaborative and co-productive model

The work with The King's Fund, and in particular learning from the experience of another collaborative pair, has shaped our approach to developing 'patient leadership' for our organisation and to the development of our business plan for this work.

Mike Holgate, Lay Member, Patient Public Partnership Group,
and Jane Lodge, Head of Engagement, Brighton and Hove
Clinical Commissioning Group

West London Collaborative is a community-owned and led organisation that has been delivering collaborative working across north-west London for two years. What we have learnt over time is that it's difficult and occasionally messy - but the rewards when they come are great.

In our collaborative pair project, we established a collaborative, quality improvement working group of patients, carers, community and trust staff to review our current processes around shared decision-making for medicines. The group is evaluating the current evidence base; developing tools to support the process; agreeing how the tools will be evaluated; and will review the evaluation

together. If successful, the tools will be implemented across the organisation.

This project is not only about a collaborative approach to decision-making but highlights the importance of collaboration in developing clinical processes. We hope to use it to springboard further collaborative work across the organisation until this becomes normal practice rather than the exception.

Jane McGrath, Chief Executive, West London Collaborative,
and Michele Sie, Chief Pharmacist, West London Mental
Health Trust

We are embedding the collaborative pairs work within our patient experience and engagement strategy. Barts Health NHS Trust is large and spread across several sites and this approach ensures that the patients' voice is embedded at the most fundamental level.

Julia Briscoe, Patient Experience Lead, Barts Health NHS Trust,
and Sally Edwards, Chair, Whipps Cross Patient Panel

People who access the services that my team deliver can have many factors influencing their wellbeing. We need to work in partnership to accurately understand and plan. We need to review and reflect on how care is received, so that services are shaped by the people who use them. Collaborative care should be embedded in what we do at every contact, thus making collaborative leadership part of the culture of service delivery at every level of the organisation's operation.

Charlie Dorer, Clinical Manager for Neuro-rehabilitation,
Cambridgeshire and Peterborough NHS Foundation Trust

Unleashing future possibilities: where next for collaborative relationships?

You may already have collaborative relationships and projects in your organisation or system - you will now want to ensure they are truly collaborative and for them to spread.

Perhaps the clearest signal of your intent to work collaboratively at all levels, and the surest way to make it happen, is to employ patient partners. Doing so supports the legitimacy of the patient perspective and creates a more equal footing for collaboration. Four examples include:

- Mark Doughty, senior leadership consultant at The King's Fund
- David Gilbert, Patient Director at Sussex MSK Partnership (Central) and futurepatientblog.com
- Alison Cameron, Transformation Fellow at NHS Improving Quality <http://theedge.nhs.uk/about/the-team/>
- Rosamund Snow, Patient Editor at The BMJ www.bmj.com/about-bmj/editorial-staff

The King's Fund remains committed to exploring shared learning and to supporting the development of collaborative relationships among health professionals, patients, service users, carers and communities. This is a live conversation that is continually influencing the way we work and what we offer.

Our current offer. How can we help you?

The national 'Leading collaboratively with patients and communities' programme continues in September. Being part of the programme helped the pairs in our 2015/16 cohort gain a legitimacy that made them feel more credible and lent weight to their initiatives.

Bespoke learning and development programmes help your local system or organisation to develop collaborative capabilities and/or scope where collaborative relationships could occur. Local collaborative pairs and trios programmes can help with this.

Supervision and learning support can help you reflect on, develop and capture your learning about collaborative relationships.

Consulting support helps you explore and work with challenging or controversial aspects of developing new relationships between health professionals and patient partners.

Our website summarises our own activity, publications and learning about the collaborative relationships: www.kingsfund.org.uk/projects/patient-leadership

We have learnt a great deal from the pairs on our 2015/16 programme and from the local organisations we have already worked with, and we are keen to grow this learning community.

We want to hear your stories of collaboration, reflections on the guide and what you would find useful to help your collaborative relationships to grow. Post your comments under this guide or contact us directly.

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About the author and acknowledgments

About the author

Becky Seale was a consultant in the leadership and organisational development team at The King's Fund until May 2016. She is now senior learning and development consultant at the Bromley by Bow Centre.

Becky has a background in social research and participatory methods with more than 10 years' experience of carrying out research and engagement for the public and private sector. She has a particular interest in the role that non-traditional voices can play in leadership, policy development and governance. Before joining The King's Fund, Becky was a senior associate director at TNS BMRB, one of the leading providers of social research to Whitehall, specialising in qualitative and deliberative research. She is a board member of Healthwatch Hackney.

Paying tribute to our collaborators

One of the things that we have learnt about building collaborative relationships between the NHS and patient partners is that history is important. For this reason, we would like to thank and give credit to all those who have collaborated with us and informed our thinking about patient and collaborative leadership over the past three years, with special mention to:

The Centre for Patient Leadership; David Gilbert; Alison Cameron; David McNally and the Patient Experience team at NHS England; Rachel Matthews and the North West London CLAHRC; David

Naylor at The King's Fund; David Sgorbati, NHS management trainee; Tessa Richards and the wider team at *The BMJ*; the 12 pairs on the 2015/16 programme, from whom we have included comments throughout. Please note these comments are not verbatim but are drawn from records of collective discussions. Anna Brown also offered valuable editorial support in the writing of this guide.

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About The King's Fund

The King's Fund is an independent charity working to improve health and care in England. We help to shape policy and practice through research and analysis; develop individuals, teams and organisations; promote understanding of the health and social care system; and bring people together to learn, share knowledge and debate. Our vision is that the best possible care is available to all.

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