

THE NEEDS OF THE PATIENT: WHAT'S CHANGED?

A report on the experience of patients in the UK during the pandemic and recommendations on how to meet their changing needs during subsequent waves.





THE NEEDS OF THE PATIENT: **WHAT'S CHANGED?**

As hospitals see admissions for COVID-19 rise during a second and subsequent waves, huge challenges will again face patients who need the National Health Service (NHS). To assess 'The Needs of the Patient: What's Changed?', Boston Scientific assembled a roundtable of highly regarded patient group leaders during MedTech Week (12-16 October) to discuss such topics as: the impact on patients with long-term chronic conditions, the potential impact on patients of a significant second wave of the pandemic, and what can we do to better support patients in this 'new normal' world of uncertainty?

Our goal was not only to share and better understand the experiences of patients from the first wave of the pandemic, but also to provide practical guidance for subsequent waves.

This report summarises the key points of this discussion and is useful reading for anyone involved today in the UK

healthcare system, particularly those involved in designing processes around the patient's experience.

Special thanks to our moderator, Ian Chamberlain, director, Life Science Access Academy, and our panelists: Rachel Power, chief executive of The Patients Association; Malcolm Packer, head of charity affairs and communications of Kidney Cancer UK; Vanessa Hebditch, director of communications and policy of British Liver Trust; and Trudie C A Lobban, MBE, founder and CEO of Arrhythmia Alliance AF Association and STARS (Syncope Trust).

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PART I:

THE PANDEMIC CREATED CHALLENGES FOR ALL PATIENTS

Our health and care systems have been tested as never before by the COVID-19 pandemic, a viral outbreak of unprecedented scale. To fight the coronavirus and keep it from spreading, large parts of our lives have been significantly disrupted whilst researchers strive to find treatments, vaccines and cures and healthcare systems struggle to provide safe and effective care for COVID-19 patients. Yet through all of this, patients continue to need timely medical care.

Despite the exemplary efforts of our health care workers, there have been considerable challenges and understandably non-COVID patients have not always been able to receive the care they need.

The Patients Association conducted a wide-ranging survey of patients during the pandemic which found that while there were some examples of really good practices, overall “it painted a pretty stark picture of how people were feeling,” said Rachel Power, chief executive of the association.

One result has been an outpouring of calls from patients to patient organisations asking for help and additional support. At the British Liver Trust, there has been a 155% increase in calls compared to a year ago, most of them related to COVID-19, said Vanessa Hebditch, director of communications and policy. Arrhythmia Alliance had a three-fold increase in calls from worried patients during the pandemic, said Trudie Lobban, MBE, Arrhythmia Alliance founder and CEO.

Clearly, the pandemic has placed further strain on health systems already having trouble keeping up with patient

needs. This has delayed access to care by decreasing referrals and increasing cancelled appointments.

The impact of cancelled procedures, delayed diagnostics and reduced referrals on patient care have yet to be fully evaluated but concerning statistics on patient outcomes have started to emerge. This has been compounded in part by poor communication with patients causing increased anxiety.

REDUCED CAPACITY

The pandemic forced local health systems to quickly re-organise and re-distribute their services and staff to handle the huge rise in patients requiring critical and specialist care, putting even more strains on capacity.¹ This was further complicated by the urgent need to hire and train new people as well as find cover for those health workers who needed to isolate due to COVID-19 symptoms and positive tests. At the time of writing it's estimated that 30,000 NHS workers were off or self-isolating due to COVID-19.²

In addition, COVID-19 has led to increased measures around infection prevention and social distancing, which further impact capacity.

As a second wave takes hold, concern is increasing for the mental health of front-line workers who have been dealing with the unrelenting pressure of the pandemic. Nearly 60% of the 1,200 care workers questioned met the criteria for at least one of three things – anxiety, depression and post-traumatic stress disorder, according to a study by the Covid Trauma Response Working Group.^{3,4}

As far back as June 2020, it was estimated that the NHS may not reach its pre-COVID-19 capacity until late in 2021.⁵ It's clear capacity and staffing issues continue to affect any sustainable service recovery and the systems' ability to provide patient care.





FEWER REFERRALS, CANCELLED APPOINTMENTS

Patient hesitation in seeking care, diverted resources and lower capacity have reduced patient referrals and resulted in many cancelled appointments.

By mid-April there was a 90% decrease in routine referrals, while urgent referrals and two-week referrals for suspected cancer fell by 78% and 67%, respectively.⁶ About 42% of patients had their care cancelled or delayed during March and July, according to an Ipsos Mori poll of more than 2,000 patients.⁷ This trend has continued further into 2020 with a recent report by the Health Foundation highlighting the number of new care pathways has dropped by up to 37% in some regions.⁸

This was also confirmed by a recent survey from The Patients Association which found that 67% of respondents had had health and care appointments cancelled.⁹

All elements of care were affected, even life-saving therapies used to treat cardiovascular disease.

Early in the pandemic, heart rhythm patients told the Arrhythmia Alliance that most operations were cancelled, such as pacemakers or ablation for atrial fibrillation, and “only emergency ICDs were being implanted,” Lobban said.

In assessing the impact of the pandemic on clinical pathways for routine cardiovascular care, the National Institute for Cardiovascular Outcomes Research (NICOR) did a series of analyses using national datasets that found:¹⁰

- A 35% fall in myocardial infarctions.
- A 66% drop in patients presenting to hospital with heart failure.
- A reduction in interventional CVD procedures, especially electives, such as a 50% decline for TAVI and up to a 92% plunge in ablation procedures.

A key reason that patients were hesitant to get health services was their confusion or fear due to poor or inadequate information about health risks, as we shall see in the next section.

POOR OR INADEQUATE INFORMATION KEPT PATIENTS AWAY

The unprecedented and ever-changing nature of the pandemic made it difficult to establish a clear set of national guidelines in early stages of the pandemic. As a result, despite the best efforts of national organisations and local providers to inform and educate patients and care providers, a disconnect at times with the patient community has impacted – and continues to impact – access to care.

In the initial stages of COVID-19, many patients cancelled appointments due to fear, anxiety or uncertainty about whether it was safe to see a doctor or go to the hospital. The Patients Association survey found that patients were confused due to conflicting or inadequate information, and that 47% had chosen to put off accessing services and support.¹¹ Likewise, an Ipsos Mori poll found that 23% of patients with cancelled appointments chose to cancel their appointment.¹²

Many patients were too confused or afraid to see their care providers. Overall, 48% of patients were extremely or very worried about catching COVID-19, half of whom said they lacked trusted information, according to a Patient Information Forum survey completed in late July 2020.¹³ Three in four (75%) said information on COVID-19 was conflicting to some degree, while more than half (57%) worry about attending future face-to-face care.¹⁴

The British Liver Trust participated in a COVID patient survey that found that more than one in four liver patients (26%) felt they did not have enough information to make decisions about their health.



The patient experience in UK, seems to match patient experiences elsewhere, as the enormous scale and changeable nature of the pandemic posed challenges early on that lead to communication issues. For example, many U.S. patients were nervous and uncertain, according to a Boston Scientific survey¹⁵:

- 66% are nervous or very nervous about meeting with their healthcare professional.
- 76% were nervous about going to the hospital or surgery center.
- 70% were uncertain about next steps to reschedule their procedure.

Multiple data points all point to inconsistent communication having contributed to the fear, anxiety, confusion and uncertainty among patients to varying degrees over the duration of the pandemic.

Panelists illustrated the patient stories behind the statistics:

- A patient received a government letter saying they were in the shielding group, then received another letter later saying that they were not in that group.
- Many patients said that they did not receive information from the government until weeks after the lockdown.
- “Cancer surveillance almost stopped,” Hebditch said. “One patient told us they went in for diagnosis, but never got the results – the liver cancer team was not in touch.”

Early fears of accessing treatments have abated. For example, Kidney Cancer UK did three surveys of its member patients during the pandemic – one soon after lockdown, a second two weeks later, and a third at the end of August.

“Patients started out with a big fear of COVID-19, but that flipped over as they became used to the ‘new normal’ – now they seem to worry more again about their cancer, which in a way is a good thing,” said Malcolm Packer, head of charity affairs and communications for the Kidney Cancer UK.

Even so, all the panelists agreed that issues around communications stubbornly persist and need to be addressed in the second wave.

PATIENT WAIT LISTS

Although the patient hesitancy described above may have initially tempered the expected exponential rise in waiting lists that were being predicted early summer, recent evidence indicates that waiting times have increased. As a result, many who want care are receiving it in less timely way.¹⁶

We have already seen the large decline in referrals – not just routine referrals, but referrals for suspected cancer.¹⁷ A recent report by the Health Foundation shows that the number of new care pathways has dropped by 37% in some regions.¹⁸ Patient experiences captured in surveys by Ipsos Mori and The Patients Association observed similar findings.^{19,20}



42%



42% of patients had their care cancelled or delayed during March and July.²¹

67%



There was a 67% decrease in two-week referrals for suspected cancer.²²

35%



A 35% fall in myocardial infarctions.

66%



A 66% drop in patients presenting to hospital with heart failure.

TAVI & ABLATION



Interventional CVD procedures, especially electives, were down 50% for TAVI and 92% for ablation procedures.

Some areas are being hit harder than others. "One hospital in the Midlands said it would take three years to catch up with all of their heart failure patients," Lobban said.

DAMAGE TO PATIENT HEALTH

The pandemic has put at risk or harmed the physical and mental health of many patients. More than half of patients, for example, felt their health and care needs had not been supported overall during the pandemic, according to The Patients Association.²³ Nearly six out of 10 (59%) patients are worried that their condition would get worse due to the pandemic, according to the Association's survey.²⁴

COVID-19 has put some populations – often vulnerable groups already facing inequities in care – at higher risk. Patients with mental health issues, chronic pain or chronic illnesses feel left behind, and health care disparities, already an issue with the poor and ethnic minority

population, have gotten worse. The isolation and diminished access to care caused by the pandemic affects the mental well-being of many. Chronic pain patients awaiting spinal cord stimulation procedures feel their physical and mental well-being is being jeopardised by delays due to the COVID-19 pandemic, according to a recent survey.²⁵

Disabled and chronically ill people also have fallen behind; for example, those with conditions that did not meet the criteria of the government's "clinically most vulnerable" list (those on the list are eligible for special services) have been left with little access to care or the support they need as part of daily life.²⁶

"A number of disabled, chronically ill, older people felt forgotten and left behind," Power said. "There was a lack of communication about what was happening with their treatment."

About 50% to 60% of those surveyed by Kidney Cancer UK said they were not in the vulnerable group when they thought they should be. "They felt completely pushed aside, hung out to dry, almost" Malcolm Packer said.

The pandemic has increased inequities among patients, with people from ethnic minorities and vulnerable populations most at risk of infection and death from COVID-19.^{27 28 29} Although poverty and social disparities are key factors in this inequity, another key reason is poor communication with and lack of trust among minorities, a Race Disparity Unit study concluded.³⁰

Despite the best efforts of health care providers, COVID-19 has inevitably led to a rise in deaths even in





addition to those who died of the virus. There were an estimated 2,085 excess deaths in England and Wales due to heart disease and stroke during the peak of the first wave of COVID-19, according to a study.³¹ Another study projects that there could be as many as 35,000 excess deaths due to missed or delayed cancer diagnosis during the pandemic.³²

As the rate of infections declined over the summer, access to healthcare seemed to improve across the board and frontline workers.

But while cancelled and deferred appointments may have suppressed demand in the short term, it could create an even larger problem in the long run. Some experts worry about a “growing iceberg of harm created by delayed outpatient follow-up appointments.”³³ In fact, nearly six out of 10 (59%) patients worry their condition will get worse due to the pandemic, according to the Patients Association’s survey.³⁴ As the UK experiences a second wave, a number of Trusts are finding it necessary to cancel or drastically restrict elective surgery once more.

What have we learned that can be practically implemented this time?

PART II:

WHAT HAVE WE LEARNED FROM THE PANDEMIC AND HOW WE CAN HELP PATIENTS

Through a combination of making improvements and tapping existing strengths, our panelists believe that we can improve patient access and health by creating more capacity, improving care and better informing patients.

They underscore the importance of efforts to improve communications with patients. As we have seen, poor

or inadequate communications have been obstacles to timely, effective care. Our panelists have several specific suggestions for how communications can be improved.

Our panelists also reference a variety of bright spots for patients that have appeared during the pandemic – bright spots that should be encouraged and reinforced going forward. Remote care and the rapid adoption of technology has helped patients to get the care they need without exposing them to the risk of infection; this has made the delivery of care safer and also more efficient. Meanwhile, new patient data gathering efforts and approaches to improving the NHS show promise in making the delivery of care more accessible, effective and efficient.

IMPROVING COMMUNICATIONS

Poor or inadequate patient communications proved to be a drawback to patients getting the care they needed during the pandemic. Poor communication was a key reason for increased health disparities during the pandemic.³⁵ So, how can we improve the approach for the second wave?

Better communication should involve maintaining the principles and values of patient choice, shared decision making and voice, so that alongside clinicians, services are also shaped by patients, disabled people and others who most need them, Power said.³⁶

Overall, the Patients Association recommends that patients be provided clear, concise and timely communication, updated regularly, about the impact of the crisis on support and services, what is available in the interim, and when and how services may begin to restart.³⁷

This means better information, too. Consider how to liaise with the 57% of patients who are worried about the safety of future appointments, Hebditch said.





“It’s not enough just to say that it’s safe to go back to hospitals,” Hebditch continued. “We have to explain to them how hospitals are being kept safe.”

“Good communication comes from having patient partnership as the cornerstone,” Power said. “We need to build that better.”

One trend that has improved communication and access to care for patients has been rapid adoption of remote care, as we will see in the next section.

Recommendations to improve communications include:

- Be consistent. “We found that patients facing the same circumstances were being told different things,” Malcolm said. “The message needs to be steady.”
- Dispel myths and fears. Explain how hospitals are kept safe. By building trust in NHS services among at risk groups, such as ethnic minority people, the NHS can be more effective in correcting misinformation.³⁸
- Make mental health information more visible. When it comes to funding information, mental health resources need to be given the same importance as information on other health services. “To ensure that no one is left isolated and alone,” Power said.
- Translations. To expand access, materials should be published in different formats and languages.
- People without internet access should be able get support and information offline.
- Less is more. “The typical NHS facility is plastered with signage – we need less,” Hebditch said. Instead of 4-page letters, something short and simple is better, she said.
- Expand the base of communicators. Use volunteers to talk to people on waiting lists about risks and benefits and help them make decisions.

REMOTE CARE AND THE RAPID ADOPTION OF TECHNOLOGY

One of the positive aspects of the pandemic has been the accelerated adoption of technology. To free up their time, reduce congestion in health care facilities and limit exposure to infection, many GPs and specialists turned to video consultations during the pandemic.³⁹ Obstetricians provided routine visits for normal pregnancies over the phone; dermatologists diagnosed simple skin problems over video; and psychotherapists provided face-to-face consultation online. This trend has been aided by the growing popularity of home diagnostic tools, such as blood pressure monitors, pulse oximeters that measure blood oxygen levels, heartrate and exercise monitors, and other devices.

In addition, remote monitoring technology has made it easier for doctors and patients to check on the patient’s health without an in-person visit.

These approaches – virtual visits and remote monitoring – should be refined and accelerated into the future, according to our panelists.

VIRTUAL VISITS

“A lot of people love the telemedicine, they love the video, they feel that the doctor is actually looking at them in the eye,” Lobban said. “But there’s more to it than just that.”



Video consultations can be used in a wide variety of circumstances, from managing long term conditions such as diabetes, hypertension, asthma, stroke, psychiatric illnesses, cancers, and chronic pain to triaging and managing a wide range of acute conditions, such as emergency eye care triage.⁴⁰

The pandemic has certainly accelerated its use. One patient survey showed that nearly half (48%) of patients found the move to telehealth during the COVID-19 pandemic to be helpful.⁴¹ Patients are more open to virtual visits, given that 57% are worried about risks from face-to-face care, according to a Patients Association survey.^{42,43} Even post-COVID-19, a patient survey in the U.S. found that (44%) of respondents would prefer to receive care both in-person and via telehealth.⁴⁴

While telemedicine shows great promise and has made great inroads, there are obstacles to it becoming widely accepted among patients and providers. The Patients Association found a mix of opinions about virtual consultations, with seven out of 10 fearing that something would be missed without face-to-face care.⁴⁵ Those who find virtual visits challenging include: disabled people, especially those without internet access; rural residents without reliable connectivity; those with poor digital literacy; and those who lack the privacy they need to have a sensitive conversation about their health.

“There was a real discussion in our patient survey about whether face-to-face or digital was the best,” Power said. Ultimately, it comes down to what works best for the patient, she said.

Recommendations about virtual visits include:

- Patient choice: The range of needs and preferences of patients need to be considered, according to the Patients Association. “Patients should have a choice to have a face-to-face appointment,” Hebditch said.

- Patient consultation: Those who deploy virtual consultations should be able to measure patient experience and empower them to share in decision-making.⁴⁶
- Provider training: Health professionals need telemedicine training to adapt to the new technologies and learn needed communication skills, Lobban said. Hebditch agrees that physicians “need more guidance as to what makes a good virtual appointment.”
- Available funding: virtual appointments need to have easily accessible and receive dedicated funding.

REMOTE MONITORING

“Although most medical devices come with remote monitoring technology, it wasn’t until the problems of the pandemic that health professionals really started taking advantage of it, Lobban said.

“All [new] devices are set up for remote monitoring, but only a small percentage are used,” she said.

Aside from safety, remote monitoring offers patients convenience and savings by eliminating the time and expense related with travel to and waiting in the doctor’s office just to check their pacemaker or other implanted devices.

“A lot of patients wonder why they weren’t offered remote monitoring before,” Lobban said. “One said to us, ‘I love it. It’s like having the doctor at my bedside all night – the hospital will contact me if anything is wrong.’”





Another advantage of remote monitoring is that its data can be used to speed clinical trials, accelerating drugs and devices to market, Lobban said.

The advantages of remote monitoring highlighted by the panelists have also been reflected by NHS England guidance, which recommended the use of RM to support the delivery of care during the pandemic.⁴⁷

Recommendations about remote monitoring include:

- Make remote monitoring part of the treatment plan.
- Incentivise use among hospitals.
- Reimburse remote monitoring at a similar rate to in-office device checks.
- Improve patient understanding of remote monitoring.

Health care providers are successfully adjusting to the risks posed by the pandemic by increasing the use of virtual visits and remote monitoring. Another way they can adjust to the pandemic is to make sure treatment protocols better fit the times.

ADJUSTING TO THE PANDEMIC

During a pandemic, patients don't want to be in the hospital any longer than they have to be, so it may make sense to consider alternative treatments that are safer and require shorter hospital stays, said Malcolm Packer, Kidney Cancer UK.

"Now more than ever, patients don't want to be in hospitals," Packer said.

For example, doctors might consider treating some early stages of kidney cancer with cryoablation, if appropriate, which has a minimal hospital stay of days, rather than with open surgery, which has a lengthy hospital stay involving weeks or longer, he said. For other patient cohorts, these kinds of recommendations have already been considered, NHSE for example, has recommended using transcatheter aortic valve implantation (TAVI), minimally invasive procedures used to replace the aortic valve, for some aortic valve patients, instead of open surgery.

We can find other ways to better adjust to today's realities if we improve cooperation among the key stakeholders in health care, as we will see in the next section.

BETTER COLLABORATION

The panelists agree that to create a system that is more responsive to patient needs will depend on continued, and even increased, co-operation between the NHS, industry, providers, carers and patient organisations.

"We're all on the same side – the patients, the NHS and the industry," said Ian Chamberlain, managing director of Lifescience Access Academy and moderator of the panel. "Let's hope this (discussion) will be a positive in driving engagement between those stakeholders."

INVOLVE PATIENT GROUPS AND CARERS

Developing new processes and treatments should involve patients at the beginning, middle and end, Power said.



For example, patients should have been involved in the decisions to make changes to the appointment systems, both the temporary ones during the lockdown and the restarting of routine care, according to Power.⁴⁸

In addition, carers need more support, including emotional support, to care for their loved ones.

“Carers felt abandoned, especially parents of children with extreme, complex needs,” Power said. “They will need more outreach support during the second wave.”

HOW INDUSTRY CAN HELP

To make sure that medical technologies are available and accessible where and when they are needed, the medical technology industry should work closely with all stakeholders including the patient community to help ensure that that critical questions are answered and the second wave is optimally managed. Furthermore, they should jointly assess and draw lessons from this painful health crisis.

Here is **how industry can improve patient** care:

- Help people better understand their individualised risks during COVID-19. Efforts underway in this area includes MedTech Europe’s COVID-19 information hub, with a variety of content and references aimed at physicians and patients, including a link to a WHO site about the coronavirus
- Explain to patients how remote monitoring works. Boston Scientific has a page describing its various devices with remote monitoring capabilities as well as its HeartLogic heart failure diagnostic that can predict a heart failure event. An ongoing study is analysing HeartLogic data from COVID-19 patients to help anticipate heart issues when they become unwell.

- Improve patient education. Educated patients are more adherent to taking medications and following health advice, Lobban said. This year, Arrhythmia Alliance built a virtual conference centre for patients in which it offers recorded talks with clinicians on the different types of arrhythmias, the different devices, remote monitoring, mobile ECGs, etc. With financial support, this could be part of an effort to educate patients and the public, Lobban said.
- Invest and partner with associations in awareness campaigns. These campaigns could explain simply when and how to access care and the available solutions or options. Repost or share their social posts to help extend their reach and amplify their messages.
- Look for opportunities to include the patient’s voice. For example, ensure new product development and rollouts focus on meaningful innovation that meets patient needs.
- Encourage and support the adoption of those therapies and less-invasive treatments that can deliver better outcomes. This would both improve the health of patients and reduce the burden on the health care system. For example, one possible approach is efficient TAVI procedures, while another is single-use scopes that reduce risk of infections and the need for cleaning routines.

CONCLUSION

Since the beginning of the pandemic, there has been a collaborative effort between the institutions and government, health organisations, patient associations and the medical technology community to fight COVID-19 whilst continuing to provide vital healthcare to the entire population.



While our panel has focused on the patients' perspective, we should acknowledge that there have been efforts underway that have improved patient care during the pandemic and beyond.

For example, a new reporting system of hospital data has enabled health care professionals to better monitor what is going on with their patient populations and even improve care.⁴⁹ The data is being used in research to develop cardiovascular disease risk profiles for COVID-19 patients and to better understand the longer-term impacts of COVID-19 on cardiovascular disease;⁵⁰ it also will increase patient safety and efficiency by reducing the number of required healthcare contacts.⁵¹

While these and other efforts to improve health care are encouraging, however, they will only truly succeed if they "focus relentlessly on the patients' needs," Power said.

By presenting the key learnings from our panel of patient association leaders, we hope we will help sharpen this focus on patient needs. Although the pandemic

has exacerbated or created some tough health issues for patients and carers, our panelists believe that by focusing on patient needs as we work together collaboratively and make improvements, we can significantly expand access and improve care for patients, especially those who are most vulnerable.

Together, we can help our health service recover and come back stronger than ever.



Listen back to the full replay of the virtual roundtable discussion, which took place on Monday 12 October
[YOUTUBE REPLAY](#)





PROFILES OF PARTICIPATING PATIENT ASSOCIATIONS

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The Patients Association is an independent patient charity campaigning for improvements in health and social care for patients. Covering all health and care issues, the association works directly with patients to provide help and advice services. The association also speaks to government, the NHS and other stakeholders about patients' priorities and concerns to ensure the patient voice is heard. Its vision is that health and social care will be delivered in a way that meets every person's health and social care needs.

Research report: **The Pandemic Patient Experience**, 21 September 2020.

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British Liver Trust the largest UK liver charity for adults, leads the fight against liver disease and liver cancer by reaching more than 1 million people each year, raising awareness of the risk factors of liver disease and providing vital advice to help people improve their liver health. Its mission is to achieve real change in liver health across the UK to save and improve lives for all.

Research reports: British Liver Trust participated in this **Patient Information Forum online survey** of about 800 patients done in July 2020 on COVID choices.

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Kidney Cancer UK, the UK's leading kidney cancer charity, works to support people affected by kidney cancer, their carers and families through the approval of drugs for kidney cancer patients, better treatments, and a clear treatment pathway. Its mission is to reduce the harm caused by kidney cancer, now the seventh most common cancer in the UK.

TRUDIE C A LOBBAN

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Arrhythmia Alliance is a coalition of charities, patient groups, patients, carers, medical groups and allied professionals that works together to improve the diagnosis, treatment, and quality of life for all those affected by arrhythmias.



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