Health and Sport Committee

NHS Governance - Corporate Governance

Submission from Catherine Hughes

I have previously personally experienced and witnessed very poor and negligent care in the NHS and as a former health professional, I was able to recognise this. I have been a frequent user of NHS services due to being diagnosed with multiple long-term conditions that have been complex to treat in my teenage years and I have cumulatively spent over a year as an inpatient in hospital and will require ongoing lifelong care due to my condition. I do take an active interest in NHS issues as I am passionate that our NHS should continue and have became a campaigner as I am concerned how cuts are impacting directly on patient care. I have also been an active as involvement member at the Health and Social Care Alliance for around 10 years as like majority I want to see our NHS flourish.

Do you trust NHS Boards to make decisions that are in the best interests of the public?

I do not believe that Health Board’s make decisions in the best interests of public and I have been taking an active interest attending my own Health Board meeting regularly so feel that I can comment on what I have witnessed at Health Board meetings and as a result of personal experiences in my own care and also as witnessed in the care received by my family and friends. I have also been attending my Health Board Annual review regularly each year as this is the only place that the public can actually put their questions directly to the Board. I was supported in a vote of no confidence by others present at the Annual Review in 2016. It is of concern that same people turn up at the Annual Review meeting every year raising the same issues and nothing is done in the interim by the Board to try and solve the issues and this just appears to be a tick-box meeting.

Due to my own personal experience, I am also extremely concerned how clinical staff can band together to try to cover their mistakes. I have not only experienced this personally with my own care but also with other family members where both my grandparents died after routine surgery, my gran died as a result of complications after falling out of bed, that was covered up by staff, and my grandfather as a result of a medical error during surgery and exacerbated by poor post-op care. My Dad also died 14 years ago this year as a result of being misdiagnosed, despite having a long-term complex condition, as a result, vital time was wasted which resulted in the need for high-cost intensive care and he developed septicemia and multi-organ failure and his life-support had to be switched off after two weeks. Unfortunately there is concern that the culture is to cover-up issues rather than being open and transparent and the complaints and how they are fully investigated needs to be examined.

Are NHS board decisions open and transparent?
I personally did not think that NHS Board decisions were open and transparent and the reason that I took the decision to bring a Parliamentary Public Petition to the Parliament so that the Parliament could examine what was happening to the CIC in more detail as this also had consequences to other services in NHS Scotland. It has been very difficult to get answers to questions both in the case of the CIC and I also know other NHS campaigners have experienced similar issues and concerns in trying to obtain information from the Health Board as this is a cultural issue.

From what I have witnessed and experienced I do not think that NHS Board decisions are open and transparent. The length of minutes at my local Health Board come in volumes and concerning regularly exceed 500 pages in length and one meeting when I counted they were 823 pages long. The Board members have often complained at meetings about the length of the minutes and occasionally the duration of meeting but little appears to being done to address their concerns to improve issues. At the Board meeting I attend they only receive the papers on the Friday afternoon before the Board meeting and the meeting is on the Tuesday which is not enough time to fully examine the papers given their extraordinary length. One Board member at a meeting publicly admitted that they had not been able to read them let alone be able to properly scrutinise them, yet this is the role that the public are expecting them to do but their governance processes and procedures do not really support what would be considered best practice. They have also stopped putting page numbers at the bottom of the Board papers and just have identification of papers linked to agenda items and not always easy for public attending to follow. One meeting I attended in 2016 started at 9:30am and did not finish till after 5pm and there were very few Board members left at the end as they were leaving at various stages as the meeting progressed. Previously over a decade ago Board meetings in NHS Greater Glasgow & Clyde used to be held every month but now they are bi-monthly. Maybe it should be considered if changing the Board meetings to be scheduled monthly and if this would allow for better governance in the future where they would then have more time at meetings to discuss agenda items and if held more regularly and would allow for Boards to be able to respond if there are issues requiring action and decisions such as winter crisis and also help to improve scrutiny of Board papers.

**How accountable do you feel NHS boards are?**
I do not think that NHS Boards are accountable for their decisions and my NHS Board that I attend are regularly in the red and in debt, with their overspend regularly over £50 million and recently was in excess of £70 million. In 2004/05 and in 2016/17 when my own care was threatened it was directly as a result of the Boards financial mismanagement which resulted in trying to identify services that they would cut and this is a direct consequence and occurred as a result of poor financial governance procedures that results in patients suffering when cuts are made to frontline services in a vain attempt to try to balance the books. I do realise that changes have to made in light of new advances and improvements in medical procedures and technology, but cuts do not always seem to result in improvements to care from the patients viewpoint.
When identifying services that should be cut you would think that the Board members would look at costly failing services that are not meeting the needs of patients initially, however the CIC has received numerous awards in recognition of the high-quality care and has received 100% patient satisfaction ratings with outstanding reviews on Care Opinion. Referral to the CIC has resulted in transformational outcomes for patients that has delivered significant financial savings to the NHS and in my own care I calculate that this has saved in excess of £200,000 since I was referred in medications I have not required and as I have managed to get myself off the medical merry-go-round due to numerous relapses as I can now better self-manage as a direct result of referral. I do think that questions need to be asked how Health Boards make decisions when identifying services to be cut and why a specialist service was cut by NHS Greater Glasgow & Clyde that treated patients throughout Scotland. The patients referred had specific needs that could not be met elsewhere and the reason most patients like me were referred is due to fact that conventional treatments and services could no longer help or were contraindicated. By closing beds this causes patient safety concerns as it leaves patients without access to medical care and access to crisis care beds and I know my own personal health has deteriorated as a result of the decision to close an important NHS Scotland wide service that has also affected myself, my family members who also attend the CIC and this decision has negatively affected the care of some the most seriously ill patients in Scotland who require a referral.

There is also concern over corporate governance issues in relation to the Health Boards endowment funds that are administered by the Health Board endowment committee which is overseen by the Health Board members who are all appointed as trustees for the endowment fund. NHS Greater Glasgow & Clyde currently has over £80 million in their endowment fund belonging to a number of specific funds and still have over £1 million belonging to the CIC endowment. Surely it is a conflict of interests that the Board members who are trustees to the substantial amount of money in endowment fund and this should be managed by an independent committee as this would then provide more transparency and accountability.

I also have concern over the high salaries that some Board officials are paid and feel that this should be reviewed given that some Board Chief Executives are getting paid more that the First Minister and Prime Minister. Some Board Chief Executive salaries are in excess of £150,000. This is excessive when compared to the salary of frontline staff and wonder how the Chief Executives and other senior health officials can justify the high salaries that they receive given that the majority are significantly more than average salary for a Chief Executive in Scotland is in the region of around £60,000 as Adzuna states that the current average across the various professions throughout Scotland is £58,816 however some Chief Executives in NHS Scotland are paid more than double the average Scottish Chief Executive salary.

The number of Boards that they have throughout Scotland should probably be reviewed as well as how they are organised and governance procedures that they have place. In NHS
Greater Glasgow & Clyde the public can attend the meeting but are not allowed to speak as can only observe meetings and very few people actually bother to attend meetings which can also be quite intimidating and not easy accessible to the public. However another NHS Board Chief Executive who visited NHS Greater Glasgow & Clyde meeting recently said that they allowed the public who were present to speak and comment at the end of their meeting.

There also requires to be a review of the appointments to Health Boards and how vacancies are promoted and how the people are appointed and their skills and training that is available to help improve governance. There are also no patient representatives serving on Boards. The Health Boards can interview people for the vacant Health Board roles however they have to get approval from the Health Minister before the person can be appointed to the role on the Board and wonder how many people are not approved and the reasons that are given. The training that Board members receive given that are in charge of £billion budgets also needs to be examined given that many Boards are in debt so financial governance requires to be fully reviewed and how improvements can be introduced.

**How effective are NHS boards at delivering health services and improving the health of their population?**

Many patients who end up being referred to attend the CIC feel abandoned by the health professionals and NHS services who are treating them as often they are told that no more can be done by conventional services or that current orthodox treatments are contraindicated however they are still experiencing life-limiting symptoms and diagnoses that is negatively affecting the quality of their health affecting their general wellbeing. If the CIC did not exist there would be nowhere for these patients to go in this situation. Myself and other patients report that they are thankful that CIC exists and most say they wish that they had been referred sooner when they were initially diagnosed. It is important that NHS services take account of fact that not everyone can be helped by conventional services and also continue to offer access to other holistic services in the NHS which are often cheaper and provide better value for money than costly pharmaceutical options and also have less side-effects. This offers patients and clinicians more tools to help improve patients quality of life.

I am concerned about the culture in NHS Boards and how decisions are made and as we experienced in the outcome of my Dad’s care which was affected as his appointment to be reviewed at out-patient clinic was cancelled more than once resulting in a longer delay in him being reviewed at the out-patient clinic. In order to meet targets and so that new patients do not breach the waiting time guarantee existing patients return appointments can be cancelled. These return appointments are not monitored by targets and the Health Board managers appear more focused on targets and outcomes as set by Government and their Boards rather than the consequences for patients. In my Dad’s case, he paid the ultimate price with his life and important not to forget the consequences that can result.
from the decisions that are made by Health Boards as not only affects the quality of people's lives but can also cost them their lives. We were obviously grief-stricken at the time and concerned but no complaint was going to be able to bring my Dad back and given that people are grieving and there is only a short time available to pursue any complaint this can put people off from raising their concerns and how complaints process can be improved should be reviewed and someone should be appointed that is able to respond immediately to concerns and access to advocacy available.

As a family, we now do regret not pursuing things and in seeking answers, redress and acknowledgment of the issues and reassurances that improvements would be made. However I do not think myself or my family could have emotionally coped with this at the time given that in 2004/05 I was also campaigning to save access to the care that I depended on within the inpatient service at the CIC. I depended on care at the CIC which had certainly helped save my own life as a result of developing serious adverse reaction to the prescribed medications for my condition meaning I had to look at other holistic treatment options and has certainly improved my quality of life since being referred to the CIC in 1994. My Mum had also previously pursued a complaint when I had received negligent care previously when I was initially diagnosed and it is not an easy or pleasant process to navigate and undertake as pursuing a complaint is very difficult. The culture appears to defend the health professionals at all costs even when they are obviously in the wrong and there are obvious issues in relation to poor care, and this has to be a cultural and organisational issue that is being supported by Boards. The complaints process requires to be reviewed by Boards. In NHS Greater Glasgow & Clyde they have their own complaint and feedback system however this could be confusing and feel that Care Opinion is surely a much better way of giving feedback as it is administered by an independent organisation and is universal across all Board areas and throughout the NHS in the UK as they protect patient identity and also publish the comments so that there is more transparency.

I have recently developed complications of my condition which has not been helped due to the recent stress due to campaigning to save the CIC and this is now costing the NHS significantly more since the closure of the inpatient services at the CIC as it means that this option is no longer available to me or other patients in need. I recently had an appointment cancelled at a specialty I have been referred to where I should be reviewed every 3 months but will not be reviewed at the clinic for 10 months as this appointment has already been cancelled and rearranged twice by the NHS. This is ‘the dodge’ as no one is monitoring the waiting time and treatment time of patients once they have had their first appointment at clinic, as it is only their initial appointment that is subject to waiting time guarantee. Myself and I know others are raising concerns about the ongoing care that they receive as a result of their long-term condition and we certainly do not currently feel things are getting better and this is now negatively affecting patients quality of life. Consultants have previously apologised and said it is out of their control but that NHS health Board managers will not listen to the clinical staff concerns and that patients should complain.
There also needs to be more money spent on prevention and improving wellbeing rather than waiting to people become affected by ill health before services can be accessed. More resources are needed to employ specialist nurses who can help people to manage their long-term conditions and help them to access treatment and care swiftly if their health concerns or complications arise. Self-management skills to help patients improve their self-care is a focus for Scottish Government and Health Boards but people need to be able to access NHS care and support when they need access to obtain advice by healthcare professionals and this will require more funding not just for third sector but for a range of services that will best meet the needs of patients.

I have personally experienced both extremes of care, unfortunately, very poor care that was negligent and did not take account of my clinical needs and personal opinions and concerns and the clinicians were dictatorial, bullying and the care questionable and this resulted in poor outcomes. I have also, fortunately, experienced excellent care at the opposite extreme that I consider was gold-standard by being person-centred, individualised and holistic where the clinicians worked in a partnership which also has resulted in much better clinical outcomes and improvements to wellbeing. NHS Boards would be able to improve care if they were able to hear the concerns and feedback of patients and carers more than once a year as currently it is only at Annual Reviews where this is currently allowed. Creating Patient Panels in each clinical area would also help to improve care overall for patients and carers if feedback was introduced to improve care. They should also be more receptive to staff and the suggestions that they have to improving care, as given that they are the ones delivering care, they often have the solutions that will help to improve care rather than hospital managers who often have little consideration as to the practicalities of service changes and reorganisations for patients and staff.