

**HEALTH AND SPORT COMMITTEE****NHS GOVERNANCE - CORPORATE GOVERNANCE****SUBMISSION FROM NHS CENTRE FOR INTEGRATIVE CARE CAMPAIGN TEAM**

The NHS Centre for Integrative Care (NHS CIC) Campaign Team previously submitted a response last year to the Health & Sport Committee call for views in relation to the clinical governance phase of the consultation that is examining staff, clinical and corporate governance, but some of the information that we previously submitted will also still be relevant to this third phase which is currently examining NHS corporate Health Board governance (1). Our views and opinions have been influenced following our experience of many issues that we have encountered since 2004 when the Health Board first proposed the closure of the NHS CIC inpatient facilities and in relation to consultations we were involved with conducted by NHS Greater Glasgow & Clyde (NHS GGC), NHS Lanarkshire and NHS Lothian as we had many concerns about how these were conducted and the biased and flawed way that the consultations were conducted and also have concerns in general about NHS governance and as the treatments and needs of the patients who attend the NHS CIC are now not being met.

We hope that our response and experience will help the committee by showing the practical examples of how patients can be marginalised and how Health Boards are quite happy to conduct extremely poor consultations as they are just viewed as tick-box exercises and there is little consideration of the ongoing care and needs of patients and their views, but on the bottom line is the desire to save money was seen as more important than the delivery of frontline patient care and we hope that this can hopefully improve corporate governance procedures and care for everyone using NHS and health services in the future.

There has also been further evidence and issues which raises concerns about governance issues contained in the information that has been submitted in the Parliamentary Petition (PE:1568) which raises concerns about the postcode lottery affecting patients who wish to access the NHS CIC, the promotion of the hospital and the services that are provided at the NHS CIC and how the NHS CIC is funded. (2) Although this petition is focusing on the NHS CIC it also raises more general and much wider concerns that can also relate more broadly to other NHS healthcare services elsewhere.

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

Following our experience of Health Board consultations related to services at the CIC in four Health Board areas in NHS GGC, NHS Lanarkshire, NHS Highland and NHS Lothian we

certainly do not believe that Health Boards consider the best interest of the patients who are being affected by their decisions. As if this was their priority then the Health Boards would definitely not have put the patients through the distress that they caused them by conducting a flawed and biased consultation process and then totally disregarded the views of patients. They also further increased the postcode lottery by stopping or reducing access to the patients that are being referred to the specialist services at the NHS CIC. In NHS Lanarkshire a decision was taken at their Health Board meetings that all future new patients would be denied access to the NHS CIC and their two local clinics in Coatbridge and Carluke would eventually close as referrals cease. The views of 4,800 people who responded as they wished referrals to continue to the NHS CIC and wanted to continue to access to the specialist holistic treatments in response to the NHS Lanarkshire consultation were totally disregarded and overruled by just 9 unelected members of the Health Board, which was hardly democratic. In NHS Lanarkshire and NHS Lothian the consultation process was equally flawed and both had to be extended as the consultations were poorly advertised and despite concerns about the process and procedures raised to the Scottish Health Council in a hope they would intervene in the best interests of the patient's. We were extremely concerned as nothing was done by this quango who are supposed ensure that patients views are appropriately considered even though they were informed by campaign members throughout. The staff at the NHS CIC were not even informed about the NHS Lothian consultation and it was only because a patient attended a meeting where someone mentioned this consultation that they were able to then inform the staff at the NHS CIC. Patients now have to apply to Lothian's Safe Haven panel if they require referral to the NHS CIC who review and decide whether this can be granted and currently over 50% of patient referrals are turned down with no clear appeal process to challenge this panels decision if they have concerns and this also causes additional paperwork for healthcare professionals making the referral and in a delay to receiving care and treatment while awaiting on the decision. In NHS Highland they did not even hold a public consultation when considering if referrals could continue to the NHS CIC but a decision was made by the Board members following a discussion at the Board meeting.

What was even more concerning was the fact that to justify their decision for proceeding with the consultation the NHS Boards in most cases presented a discredited report by the Science and Technology Committee at Westminster that was only signed by 3 of the 14 MPs on the committee. This paper was presented as if it was factual and had been approved and even when informed by the campaign team and other patients that this paper was officially rejected they refused to withdraw the paper and continued to present and talk about it at Board meetings as if it was bonafide when it wasn't. There are serious governance issues when the committee try to cherry-pick and find information and present papers like this as factual without informing

the Health Board or public present at the meeting the full facts. The views of patients were totally disregarded and concerns of the patients who took their time to submit their personal issues and reasons that they wanted referrals to continue but were totally regarded demonstrating that many consultations are just a farce and tick box exercise and the involvement and views of patients and public irrelevant. It appears that decisions have already been made behind closed doors and we suspect that many of these proposed cuts have already been sanctioned by officials behind the scenes given our direct experience. The comments that we witnessed at Board meetings and the poor quality discussions and inadequate questions by Board members who appeared to be prejudiced against the holistic care offered at the NHS CIC and there to rubber stamp cuts as they need to save money as in substantial debt due to the lack of appropriate financial governance and so must cut services, and they do not consider the consequence to patients.

### **Are NHS board decisions open and transparent?**

In our experience, we certainly do not believe that the decisions that are made by Health Boards are open or transparent. If they were then when issues that were raised with the Health Boards then actions would have been taken to make the process fairer. The way that the consultations were promoted would also have been significantly improved and the staff and campaign team members would have been consulted prior to the decision to open the consultation and we would have then been able to advise how they could best consult patients as the clinicians and campaign team who were more familiar and aware of the challenges experienced by patients given that the majority have complex conditions and specific needs and some also have health literacy issues and did not understand the term ambulatory care.

There is no way to challenge decisions that are made by Health Boards except to pursue a costly judicial review, which is prohibitive and though we sought to have help with costs but were turned down for legal aid this has to be pursued within 3 months of the decision. Complaints can be made to the Ombudsman, however, he does not have the authority to overturn the decisions and can only make recommendations which the Health Boards can then just decide to ignore. In order to have more confidence in the procedures, there needs to be an ability to be able to access independent advocacy who can then help and intervene and advocate on behalf of patients prior and during the consultation process and also help with pursuing an appeal. Consultations need to be carried out by independent person/organisation rather than the Health Board officials responsible for the proposal who conducted meetings, chose who could speak at meetings and wrote up the notes of the meetings as happened and was certainly not impartial especially given the flawed and biased consultation that was carried

out. This did not just affect the consultation in relation to the NHS CIC but as we met with other campaigners during this process at Health Board meetings there were also poor consultation procedures in relation to the proposed closure of Lightburn Hospital, Ward 15 at the RAH and the closure of Edinburgh cleft service.

In order to restore public confidence and ensure that decisions are fair, then in addition to consultations being carried out by an independent organisation, there also needs to be the ability to be able to appeal decisions so that the processes can be fully examined if there are concerns. There should be no cost attached to the ability to pursue an appeal as currently happens with costly judicial reviews and the costs and complexity of pursuing a judicial review are prohibitive to the majority of people and the decisions made around points of law and are not looking at the decision in totality or the clinical effects on patient care and concerns in relation to patient safety.

### **How accountable do you feel NHS boards are?**

In our experience, we certainly do not feel that NHS Boards are accountable for their decisions. The NHS CIC patients received many letters denying that the services and inpatient facilities at the NHS CIC were under threat shortly before this was announced. However, these decisions were obviously being made by officials behind closed doors given that very shortly afterwards that they proceeded with the cuts to the NHS CIC and we had concerns that cuts had already been discussed and plans drawn up. We were unfortunately not told the truth and were misled many times.

We certainly do not feel that the Health Board officials fully consider the effect of the stress of the threat of cuts and the consultation process can have on patients or staff. In 2004/05 those patients who were actively involved in opposing the inpatient service closure proposals and senior NHS staff members working within the NHS CIC and who were actively involved also became seriously ill afterwards, and a case could probably have been made to take a class action against the Health Board as the stress precipitated medical conditions that for many had a rebound effect and also considerably affected their health in the long-term. The Health Boards have a full team of paid staff as do the Scottish Health Council and other health departments, however the frontline NHS staff are expected to continue their clinical duties while under uncertainty and extreme stress and patients who have complex medical conditions, many of them adversely affected by stress. Patients can either decide to not become involved as many did as they could be considered as disaffected and felt marginalised and said that there was no point being involved and giving their views as they felt it would not matter as the Health Board

would just proceed with their plans regardless, or they became actively involved to oppose the cuts which then put their health at risk both in the short and long-term.

There was a difference between the campaign in 2004/05 and the most recent plans in 2016/17 as staff could not become more actively involved more recently and though difficult during the campaign in 2004/05 more recently it was overtly obvious that the culture was even worse where people were afraid to speak out and there was a negative bullying atmosphere. This was also evident with the patients as some were afraid of speaking out in case this affected their ongoing care. Previously patients views were taken into account when their concerns were raised and they were acted on when the initial flawed papers produced in 2005 were rewritten with the input of staff and patients however our concerns were totally sidelined this time. This is obviously a cultural issue and not just confined to one Health Board area as the NHS CIC is a specialist national hospital and referrals are made from the Health Boards throughout Scotland and the four Health Boards that conducted consultations all raised red flags with the staff, patients and public who were involved. The Health Boards obviously believe that there is no accountability and they can just do as they like given the number of concerns that were raised with the Health Board officials directly in regard to current flawed and biased procedures and processes. The concerns and complaints to the Scottish Health Council were ineffective and the fact that they were totally ignored proves that the process in place are inadequate and there is no one who is accountable.

Health Board officials also had very little consideration for procedures as prior to the Board meeting the public papers and at Patient Panel meetings and MSP briefing stated that £190,000 would be saved however on the day of the Board meeting this suddenly changed to more than double to £400,000 when this official was presenting the paper that they had personally written to the Board. On the day we officially complained prior to the paper being presented and asked for the decision to be deferred so that

this could be clarified and proper procedures could be followed however concerningly this request was denied showing there are not adequate governance procedures in place.

Throughout the campaign team raised their concerns to the Health Board senior managers and officials and the Scottish Health Council, Health Ministers and wrote to our MSPs however nothing was actively done that increased our confidence in the process. The way the patients were sidelined was shocking and there was little concern given to the fact that they had serious complex conditions and how this process was having an adverse effect on their health. We eventually had to appeal to the Health Board Chairman to intervene on our behalf as every request to the health official who was proposing the closure was denied as she thought she

could do what she liked as there would be little consequences especially as the Scottish Health Council were useless and did not live up to their remit to ensure patient voice was heard. Health Boards are well aware that the Health Council are a 'toothless hamster' as described by MSP Neil Findlay the former convener of the Health & Sport Committee in response to their evidence session to the committee last year.

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

We do not believe that the Health Boards are delivering effective care for the populations that they serve. There continues to be a postcode lottery depending on the Health Board area that people reside. We believe that this issue needs to be addressed to help resolve the health inequalities that result as we do not currently have a National Health Service that allows equity of access to health services and there are other concerns in relation to the age of patients and obtaining access to adequate care particularly if diagnosed with multiple conditions. Our healthcare system currently focuses on a model of care that does not spend enough resources to target services in order to prevent ill health and promote wellbeing. We therefore need to consider other innovative and pioneering models of care.

Many Health Board resources are directed to the provision of acute services despite the fact that it is known that 50% of patients in Scotland currently have been diagnosed with at least one long-term condition which is split with 25% having one condition and 25% diagnosed with multiple conditions (3) and this is expected to increase in the future. It is known that £7 in every £10 of NHS patient spend is as a result of patients with chronic long-term illness and it was identified that 2% of the most complex patients many of whom have multiple long-term conditions result in 50% of NHS spend (4). If this cohort of patients were treated more appropriately and Health Boards ensured services better meet the needs of patients with long-term conditions then this would then help to free up resources that can then be directed elsewhere. NHS GGC and many other Health Boards fail to recognise the needs of the patient cohort with long-term conditions as the provision of care and services for people with chronic and incurable conditions and their needs are very rarely mentioned at Board meetings or identified in Annual Review meetings and reports. This demonstrates that many Health Boards do not fully understand the high cost and many challenges being encountered by this patient group and this has recently resulted in 90 charities who are involved in supporting people trying to live with long-term conditions that affect the quality of their life making a public plea in an attempt to improve care for this patient cohort (5).

The patients who are referred to the NHS CIC are generally considered costly and difficult to treat as the majority have conditions that are currently incurable and most of exhausted conventional NHS services available elsewhere, however, the model of care provided at the NHS CIC is low cost and effective and therefore provides value for money for the NHS and meets the objectives of providing compassionate, holistic, person-centred and individualised care (6). It is therefore important that services such as the NHS CIC are invested in and expanded as this helps to improve quality of life of patients who are referred and teaches self-management skills that improve self-care that also significantly reduces costs and results in less use of medications, less need for visits to GP and reduction in emergency admissions and reduced need to use ambulatory care and many other healthcare services (7).

Questions need to be asked why there have been attempts to close services, at a multi-award-winning service that has achieved 100% patient satisfaction ratings, at the NHS CIC by stealth since 2004 just 5 years after the new hospital was built with charitable funds and what were the motives of the officials concerned? As it certainly wasn't in the best interests of patients needing access to specialist services, nor respected the wishes of the patients and the public who raised the £2,78 million of charitable funds in order to build the new hospital when it was relocated within Gartnavel complex. We now have patient safety concerns as there are now less than half the staff remaining within the NHS CIC since 2010 and yet we know that the number of people who are being diagnosed with long-term conditions are increasing and that current conventional services are unable to help everyone and more dedicated specialist services are needed. Many GP's and other consultants are also reluctant to refer to the NHS CIC as the hospital is poorly promoted by the Government and Health Board and many medical professionals are unaware of the variety of specialist services available at the NHS CIC and how to make a referral, yet the Health Board and Government are doing little to address this and increase awareness of the service, and anyone would think that they want the service to fail and appear to be willfully closing it by stealth.

The patients attending the NHS CIC have a human right to access healthcare and services that they find beneficial but their needs are being disregarded, even though many have exhausted other conventional treatments available and feel that the NHS CIC is their last hope. During the consultation we were told that patients who required access to the NHS CIC would be able to access accommodation in the Pond hotel, however, it was recently confirmed by Health Board managers that to date only one patient has been approved to access the hotel. We know that other patients have paid for accommodation themselves and others who are disabled and wheelchair users who previously accessed inpatient care at the NHS CIC are reporting issues accessing patient transport to be able to attend their outpatient appointments at the NHS CIC.

Other patients who attended the inpatient service previously before it closed have tried to access care elsewhere only to find that their needs are too great so have therefore been left without access to the care that they need and as a result, the quality of their life has diminished.

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