NHS Governance – Clinical Governance
NHS Centre for Integrative Care Campaign Team

The NHS Centre for Integrative Care (NHS CIC) is a specialist holistic hospital for people with long-term conditions and a unique national resource with self-management at its heart, providing a beautiful and healing environment, skilled and supportive staff, and a sense of a wider community. Patients with their carers and families, are welcomed as individuals and encouraged to improve their self-care. The ethos is person-centred, compassion-focused and non-judgemental. The essence is engaging and connecting and helping people to find their own balance with their difficulties, often relating to multiple health and social problems. There is an emphasis on reflecting, and championing and developing self-management techniques, linking with the individual's home community and interests.

Patients attending the NHS CIC in the past year have expressed particular concerns related to NHS governance as a result of issues in regard to what they felt was a biased and flawed consultation and processes in relation to the closure of the inpatient service at the CIC, that provided a unique model of care and complex care pathway to some of the most seriously ill patients in Scotland. Despite patients and carers best attempts to engage and get their voice heard, their views and concerns were side-lined. They have concerns that an effective and an award-winning service with extraordinary patient satisfaction ratings can be targeted in this way and that no-one in power responsible for NHS Scotland would step-in and help them. They felt let down by the institutions that are supposed to be in place to protect and stand-up for patients such as the Scottish Health Council who did not protect them despite many appeals by patients. Regardless of patients and campaigners best attempts to appeal to the Cabinet Secretary for Health to intervene on behalf of patients to save this much needed service, they felt that their concerns were ignored leading them to question who is responsible for making NHS decisions and driving the ship, and who is supposed to be championing and protecting the needs of patients and why did they not assist?

Are services safe, effective and evidence-based?
Many patients who end up being referred to attend the NHS CIC report that they previously feel abandoned by the health professionals and services who are treating them as often they are told that no more can be done by conventional NHS services or treatments are contraindicated. However, patients are concerned that they are still experiencing life-limiting symptoms and diagnoses that is affecting the quality of their health and still require assistance from health professionals to help manage their condition. If the CIC did not exist there would be nowhere for these patients to go in this situation. The health professionals at the CIC are all conventionally trained however they have gained additional qualifications in a wide range of other holistic methods that can be valuable in helping treat patients with complex conditions. Patients report that they are thankful that NHS CIC exists and most say they wish that they had been referred sooner when they were initially diagnosed.

In relation to the CIC, the vast majority of patients comment that they have received excellent care that was safe and effective as a result of an innovative model of integrative care which blends conventional and other holistic and complementary methods that are evidence based. The outcomes at the CIC are excellent as most patients are referred to the CIC as conventional services have not worked or they can do no more. It is quite remarkable that with low cost and low tech methods they can significantly improve
symptoms and quality of life and patients often comment they believe more people could benefit if individuals had the opportunity to try this care as first rather than as present where patients are usually referred as a last resort, which would result in better outcomes and also save the NHS significantly financially. Patients have written excellent reviews and testimonies about the care that they have received on Care Opinion that detail how effective they find this care compared to other services.

It is of concern that the Centre for Integrative Care has been targeted for more than its fair share of cuts despite being an excellent innovative service. The services provided at the CIC Where in 2010 we had 22 nurses working within the ward and prior to the closure of the inpatient service they had 8 nurses and now we have recently had staff numbers reduced further with 2 full-time nurses and 1 part-time to deliver the new ambulatory care service. Since 2010 we have lost 6 doctors and only one was replaced and other multi-disciplinary services have also been reduced and completely cut. This questions how the Health Board can expect the service to provide the same high quality and effective care for patients and continue to meet their needs with less than half the staff they had previously in 2010.

**Are patient and service users' perspectives taken into account in planning and delivery of services?**

In the most recent consultation, last year despite raising concerns patients views were ignored and rejected by the Health Board management, and there were concerns about how these meetings were conducted. The Director of Policy and Planning, at the Health Board who proposed the CIC inpatient unit for closure also appointed herself chair of the CIC Patient Panel which those taking part believed was a conflict of interest, as these important meetings should have been chaired by an independent person so as to be impartial. The Director of Policy and Planning also controlled and picked who could speak at these meetings and also compiled the notes of these meetings where concerns were raised and where issues discussed were omitted. The final Health Board paper presented to the Board by the Director of Policy and Planning was also of contention over the information presented and in regard to the finances that could be saved and the Board members certainly were not given accurate information on which to make fully informed decisions, and despite objections being raised they refused to wait and defer the decision for a few months so as to clarify the situation.

**Do services treat people with dignity and respect?**

Patients feel that are able to access high-quality care at the NHS CIC where they are treated with care and respect compared with other conventional services that they have accessed previously.

However, contrary to their experience of clinical care delivered at the CIC in the most recent dealings with Health Board executives and management during this consultation period the patients at the CIC state that they did not feel that we were treated with dignity and respect but more of an inconvenience and only consulted because they had to do so but it was felt that health board members had already made up their mind and the consultation process felt like ‘tokenism’.

**Are staff and the public confident about safety and quality of NHS services?**

Patients report that they are happy about the safety and quality of services provided at the CIC. However many report they have often previously had difficulty being referred to the CIC by other health professionals and they are concerned that they seem to be
misinformed and wrongly have preconceptions about the care offered at the CIC and the safety and quality of services. More needs to be done to explain and communicate the advantages of integrative care for patients with long-term complex condition to other health professionals so that patients who can benefit are able to gain referral when needed irrespective of where they live.

Patients at the CIC have reported concerns about the postcode lottery which can affect patients who may wish a referral to the CIC and feel that a specialist national NHS service should be easy to access irrespective of where you live and there should not be any discrimination that can restrict access whether that be due to a decision by a Health Board or by health professionals locally and there should be a way to appeal decisions that can limit and prevent access to high quality and safe services and patients views about their access to holistic care should be fully considered.

**Do quality of care, effectiveness and efficiency drive decision making in the NHS?**
The CIC is a unique service and could only be fully understood by visiting and speaking to staff and patients. Given the fact that this was a national hospital and individual Board members and managers, some of whom did not even bother to visit the CIC or speak to staff and patients to find out about the service, before they made the contentious decision over its fate, is of concern. They should not have been allowed to make a decision of this magnitude. As the CIC is a national specialist hospital and was the only service of its kind with inpatient facilities providing access to NHS holistic care. It should have been within the remit of the Cabinet Secretary for Health to decide the services future rather than blame the Board.

Patients feel that they were treated appallingly by the Health Board management, executives and Board, the Scottish Health Council and Cabinet Secretary for Health and the governance procedures that should have been in place to protect patients were woefully inadequate. The Board ran rough shod over patient concerns in relation to changes to the service that would seriously affect patient care. The Scottish Health Council did not protect patient interests and stand-up for the patient concerns even though they were fully informed throughout. Campaigners had been promised by the Cabinet Secretary for Health for two years that she would meet with them to hear their views however, the Cabinet Secretary only seen campaigners and staff after being shamed into doing so by Miles Briggs MSP, at First Minister's questions. Representatives were summoned to Edinburgh a few days later less than 24 hour hours before the decision was to be made by the Health Board where we were surprised as the Cabinet Secretary had also called the Chairman of the Health Board to the meeting, which changed the dynamic of the meeting. We thought we were attending to present our case for retention of the service to the Health Secretary, however, on entering the room the Health Secretary immediately told the CIC representatives present that she would not overturn the decision as it would set a precedent before she even asked the patients to speak to hear their concerns. Campaigners left wondering why they were asked to come to see her when she had obviously already made her mind up.

Like the CIC the Edinburgh Cleft service had also been deemed a minor service change by the Scottish Health Council (meaning that the Cabinet Secretary did not then need to sign off and make the ultimate decision over its future) however the Health Secretary had decided to oversee the decision about the future of the cleft service. Given that the CIC is unique and is a national service providing care for patients with complex conditions throughout Scotland we cannot understand why one Health Board area could be allowed
to make this decision and why the Health Secretary refused to call the decision in, which was the outcome of Parliamentary vote on the 28th of September 2016, and where every SNP MSP abstained, and a majority vote defeated the Government. It must be asked why MSPs would abstain from using their powers to show their support to save vital NHS services unless as we suspected that they agreed and were sanctioning these closures behind the scenes.

**Are the correct systems in place to detect unacceptable quality of care and act appropriately when things go wrong?**

Many patients with long-term conditions are concerned about raising issues and complaints as they require and will need long-term care and are concerned their care and treatment may be affected if they do raise issues.

There appears to be a discrepancy of who exactly is in charge and responsible for NHS decisions in relation to service changes as patients received letters from the Scottish Health Council that states it is the Cabinet Secretary for Health who ultimately makes the decision whereas in communications with the Cabinet Secretary for Health it states that it is the Scottish Health Council who makes the decisions about service changes. Surely the ultimate responsibility for NHS Scotland decisions is the remit of the Cabinet Secretary for Health and should not be side-lined to a quango.

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 that currently has over £80 million belonging to a number of specific funds, and would question if this is a conflict of interest!

The CIC was built with £2.78 million of endowment and charitable funds and the Health Board still governs additional funds of around £1.2 million belonging to the original homoeopathic endowment. However, it has recently come to attention that although these funds were raised prior to the hospital being built and paid in full, it appears that the Health Board was leasing the CIC to a third party for £170,000 annually till January 2018? There is a concern as to who owns this building, and who has the title deeds as it was built with charitable donations for a specific purpose, and what happened to the funds raised to build the CIC in full and why did the Health Board then decide to lease this building that was built with charitable funds? The Health Board members have not honoured the wishes of the donors who gave their money in good faith to build a new dedicated specialist hospital that they thought would contain inpatient services and other facilities and also provide access to NHS homoeopathic as well as other recognised holistic services. Patients have concerns as to how anyone can donate funds in the future to the Health Board endowment fund and trust the Health Board to ensure it administers it appropriately, given these issues?

Currently there is no other way to appeal NHS service change decisions at present other than costly legal proceedings. There needs to be other processes and procedures introduced so as to enable appeals in relation to controversial or questionable Health Board and NHS Scotland decisions in relation to service changes if service users wish to pursue an appeal. Currently, the only option at present is to take a judicial review which can cost tens and even hundreds of thousands of pounds in legal fees. These legal fees are prohibitive to the majority due to the difficulty in accessing legal aid. Campaigners
were advised that they had a good legal case and should challenge the process and procedures that resulted in the decision, however they did not have access to the necessary funds to be able to so. These controversial decisions should not be allowed to proceed due to default just because there is insufficient funds available in order to launch an appeal, especially as there is the added time restraints that a judicial review must be pursued within 3 months of the initial decision that is to be challenged being made.