

Dear Ned Sharratt,
2016

22nd February

PE: 01568 FUNDING ACCESS & PROMOTION OF NHS CENTRE FOR INTEGRATIVE CARE

The convener Michael McMahon correctly summed up that the session on the 9th February 2016 with the Health Board officials raised more questions than it answered. I am grateful to the committee for their questions on the day- the problem was with answers and avoidance by some witnesses of clarity. This hospital has 9,000 patient visits a year. It's the only one of its kind in Scotland, where help for chronic conditions is in short supply.

But patients, carers and supporters following this meeting are even more concerned that the real plan of some officials is not just to cut services further but to rundown and close the hospital. We would appeal to the committee to continue this petition and to gain more evidence. So far, the committee has been the only source of obtaining facts, as for many months we've been given a runaround.

Although we were disappointed that the Chief Executives who were requested by the Committee to appear instead sent deputies in their place

The fact that the witnesses treated the Petition as though it was only about homoeopathy shows that these Health Board officials either do not understand the integrative model of care or are singling out homoeopathy as that has been the target for boards ending CIC services while ignoring all the other CIC services.

The Committee's questioning confirmed that health boards were carrying out their own agendas and totally ignoring the feedback and views of patients who had submitted that they benefited and found treatments successful. The line of questioning elicited that "what patients say doesn't count"

We need the Scottish Parliament and MSPs to help protect us given the vulnerability of those referred to the CIC with very serious chronic conditions including multiple sclerosis, motor neurone disease, Crohn's disease, arthritis, lupus, fibromyalgia and diabetes. We also need the Scottish Government and Health Ministers to stand up for patients and show some authority to these unelected Health Boards, whose websites state that they are responsible to Scottish Ministers. The Scottish Government describes the CIC as "a national specialist resource" hospital but has allowed patients in most of Scotland to be barred from accessing it on the postcode decisions of health boards. There are no other similar NHS services in Scotland providing an integrative model of care or the wide variety of services available under one roof. Patient choice is being removed for the first time since 1948.

NHS GREATER GLASGOW & CLYDE (NHS GGC)

Catriona Renfrew presented that the viability of the service was not threatened by the reduction in cross border flow referrals from other Health Boards but confusingly also said that "***we need to look at the loss of income and how we reduce costs to reflect that loss of income...but it means that we have to reduce costs because we cannot afford the service to go on exactly the way it is at the moment and we are doing a wider review of the service in terms of financial planning for next year***".

This Board has changed its story on the CIC repeatedly:

1. Last summer, MSPs and patients were sent letters of reassurance from CEO Robert Calderwood and others, stating that there were "no plans to close" the CIC but mentioning that NHS GGC was dependent on other areas of Scotland continuing to send patients.
2. On 3rd December 2015, CEO Robert Calderwood wrote to the PPC that the answer was "**No**" to the PPC's question - did external board withdrawals make the CIC unviable? (Gone was the claimed "dependent").
3. Then, on 15th January 2016, the story changed again when a secret paper was exposed by the press, drawn up by Catriona Renfrew and others, listing the CIC for review of its future. Withdrawal of external boards was the only reason cited.
4. On 9th February, at the Public Petitions Committee, Ms Renfrew veered between stating that viability was not threatened by cross border flows, but also stating that loss of income meant they had to further reduce costs.

So what is the real position out of all this confusion and double speak? We are still not told clearly.

Ms Renfrew also mentioned some agreement with the Scottish Government over the new Chronic Pain Residential Service (conventional) but did not say how this affected the CIC.

A very disturbing factor about Ms Renfrew's evidence was that she spoke authoritatively as if it was already decided that a review of viability was happening - and also added that there would be another review focusing on "effectiveness". But, prior to her appearance, both NHS GGC and the Scottish Government had insisted repeatedly that the leaked "cuts" paper highlighting the CIC was "*only a discussion paper*" and had "*not yet been agreed by the board*". By Ms Renfrew's statements and tone, this "*discussion*" was a fait accompli.

On 7th January 2016, the health secretary, Shona Robison, wrote to the petitioner backing NHS GGC's statements "***to reiterate the assurances given by NHS Greater Glasgow & Clyde that there are currently no plans to either change the services delivered there or to close the facility.***"

The 15th January 2016 leaked press report of the GGC officials' cuts plans contradicted the health secretary on changed services. (1)

QUESTION: Does the health secretary really know what is happening?

Should she be backing a board view if the board might be keeping proposals secret from her? Or did she know?

What conversations have actually gone on with the health secretary and NHS GGC prior to this leaked paper being exposed and subsequently in relation to the CIC and its future?

The service at the CIC has undergone sustained cuts since 2010 by reducing the in-patient beds from 15 down to 7, closure of the hospital at weekends allowing only 5 day stays, closure of the specialist pharmacy. This affects the care for patients with more complex needs. Staff who have left post in recent years mainly through retirement have also not been replaced. I cannot see how costs can be reduced further as this will then further affect patient care as this in reality means, in Ms Renfrew's words, that the service "***can no longer go on the way it is at the moment***". Services have already been cut down to the bone. Ms Renfrew also certainly did not confirm how much would need to be saved as a result of this review or what services would have to be cut or how they envisage that this will affect on-going patient care. All important questions.

Ms Renfrew also did not stop at cuts as she stated she was going for another type of review also on "effectiveness". She publicly showed agreement with "Harpreet"(Dr Harpreet Kohli) and NHS Lanarkshire's review - which led to ceasing all new referrals to NHS CIC on the grounds of effectiveness, this is despite the vast the number of patients admitting that they have benefited from a referral to the CIC and 100% patient satisfaction rates in some studies.

Ms Renfrew states that "***We do need to look at the decision and reviews that have been done in other areas and revisit if our position is the correct one, and we will be doing that...on the strict definition of effectiveness on the evidence in way that Dr Kohli describes it supports Lanarkshire's position...we look at the work that other Health Boards have done in revisiting our own conclusions***".

Patients felt that this was devastating news, as NHS Lanarkshire was cited as if a role model. In reality, NHS Lanarkshire discarded the views of 80.6% of the public responding to their consultation, dismissed patients concerns throughout. The Committee's questioning brought out admission that the Board and officials had heeded scientific studies and paperwork rather than patients' experiences. To many people, Lanarkshire's closure of two local clinics and access to the CIC in Glasgow was a brutal example of how the patients charter and all written pledges are ignored.

Patients feel that this is fait accompli and any patient or public consultation was carried out in the GGC area, it would render patients views as of no importance, as NHS Lanarkshire did. Any input and patient response appears to be worthless. As demonstrated in the case of NHS Lanarkshire where patient views were totally ignored when the overwhelming number of people wished the Health Board to continue referrals due to achieving benefits from the various integrative and holistic treatments provided by a skilled staff in a specialist setting.

Ms Renfrew states that 50% of the patients come from NHS Greater Glasgow and Clyde and my calculations on the figures provided by ISD indicate this is over 70% (will this ultimately mean that there will need to be further cuts?).

Ms Renfrew went on to say that "***the review is not provoked solely by the cross-boundary flow issue but this is not implicitly why we have to do the review as we would be doing that in any case***". This is despite reassurances from Robert Calderwood to this Committee while the report naming the CIC as a target for cuts along with other services for people with long-term chronic conditions to help them with their £60 million deficit was being written and also to myself from Government at a meeting on the 9th December 2015 with the Public Health Minister

Maureen Watt and in a letter on the 7th January 2016 from Ms Robison's office that the service was under no threat of closure or change.

Ms Renfrew went on to state that GGCHB were also not really interested in helping to promote the NHS CIC. However as the research detailed in the Petition shows that referral to the CIC can save the NHS funds from other referrals to NHS services and GP appointments and a reduction in prescription costs as well as also improving the quality of life of those fortunate enough to be referred. If reducing their financial deficit is a priority, why are they not even willing to promote by better publicity this model of care, which is more economical and patients find effective, and attract other Health Boards to send patients?

Or is their real aim just to run the CIC down further and even ultimately close?

We believe that enough questions were raised in Ms Renfrew's evidence that she should be recalled to the Committee for further questioning and with the Health Board Chief Executive Robert Calderwood to explore why this host Health Board is making these decisions and to further investigate how the care of patients with long-term conditions will be affected.

NHS LANARKSHIRE

In the case of NHS Lanarkshire the committee proved that patients' views were discarded. Dr Harpreet Kohli mentioned that around 6,000 people responded to the board's public consultation. But he did not spell out that 4,800 of these were for continuing with the CIC, an 80.6% majority. **NHS** Lanarkshire's chief executive should, I suggest, be called on the disturbing evidence given regarding the effect on conventional services, such as chronic pain and psychology, of NHS Lanarkshire telling patients they could only use these and not the CIC. The majority of patients attending the CIC have in fact exhausted other conventional services.

Jackson Carlaw MSP asked about the consequences of not referring patients to the CIC in relation to Lanarkshire's conventional services and in having to ensure the practical impact on the timeousness of the treatment that they receive?

Dr Kohli replied "Our monitoring has shown that people who may previously have been referred to the centre for integrative care have been referred to those other services and that there is no additional pressure on those services."

Jackson Carlaw: Okay, so all those patterns will be treated without any additional delay having been created in their treatment or the treatment of others? Dr Kohli. "Yes, they have been offered alternatives."

Elaine Smith MSP also pursued this, referring to a letter from a Lanarkshire patient at conventional services. This letter, which she said was from the director of acute services at NHS Lanarkshire was before the committee. (It concerned a patient now eight months past the time of a required return injection, who had lost her job and was on heavy prescription drugs to make up for the lack of injection. NHS Lanarkshire still could not offer an appointment). This letter apologised to the patient and acknowledged the delay on treatment was unacceptable. It stated: "***Regrettably, there is continued increasing demand for chronic pain services in Lanarkshire which is outstripping the current available capacity. The increasing number of new referrals has impacted on the number of available return appointments which has in turn increased the wait for return patients.***"

This challenges Dr Kohli's claim there is no additional pressure on conventional services.

Harpeet Kohli did not explain the waiting lists or number of chronic patients awaiting treatment and for how long or the fact it the most affected are patients requiring return treatments. Could the committee ask for the figures for return patients and waiting times?

Some of the Lanarkshire evidence may give the public the impression that only new patients were being stopped from going to the CIC. It was unfortunate that it was not made clear in references to existing patients continuing treatment that this would only be temporary, until their current courses of treatment were over. These are sometimes ten appointments. Many chronic patients had to attend the CIC regularly for many months or years to keep going. The two local CIC clinics in Carluke and Coatbridge will be closed. The Glasgow hospital is barred to patients if they are from Lanarkshire.

Dr Kohli said that NHS Lanarkshire had only received 3 complaints after their decision to cease referrals. But there had been 4,800 people, including some Lanarkshire doctors and health workers, who had supported the CIC via

the consultation before that. Many patients lodged their objection not to NHS Lanarkshire who they had seen did not listen to patients, but by registering their disapproval on the [Change.org](https://www.change.org) petition which currently has over 38,500 signatures.

Lanarkshire patients had minimal information throughout.

Dr Kohli admitted that they could not identify patients who attended the CIC; questions must be raised why not? I was given the same excuse when I contacted NHS Lanarkshire during their Consultation to ensure that all patients who attended the CIC from NHS Lanarkshire were informed and I was told that this was not possible. Given that the decision by NHS Lanarkshire being the largest referring health board after NHS GGC to cease referrals and withdrawal could ultimately affect the long-term future of the NHS CIC, I also requested that all patients at the CIC should be contacted and informed but this was also dismissed.

We know that patients are being referred to the CIC by Consultants working in other specialist areas such as neurology and the CIC are currently having to write back to refuse the request for those from NHS Lanarkshire, which is obviously confusing for the patient as this decision is not based on clinical need but is based on their postcode.

How much NHS money is being spent by Lanarkshire through sending no patients to the CIC? They also have a Service Level Agreement running for approx another two years. This was estimated at one time to cost £188,000 but Lanarkshire does not produce a figure currently.

NHS Lothian

NHS Lothian's witness stressed that they were still sending patients to the CIC. This gave the impression little or nothing had changed. It must be clarified that NHS Lothian still had to pay NHS GGC for CIC services for two years after the NHS Lothian board agreed to end their CIC connection. That's because they still have a service level agreement with GGC. What does that cost? We are no longer being told - but NHS Lothian estimated it was over £50,000 a year back in early 2015. So of course they might as well spend some of that taxpayers money on sending patients - but only a restricted number. Lothian ended all their own homeopathy services. So what happens when the SLA with NHS Glasgow runs out?

There is still questions in relation to a discrepancy about NHS Lothian as it is clearly stated in the Minutes of their Health Board that referrals to the NHS CIC will cease as they have taken the decision to 'disinvest in homoeopathy' and to also stop referrals to the CIC.

The fact that GPs who are already overloaded by paperwork have to make a special referral request now through SafeHaven rather than a direct referral to the CIC as previously which is off putting especially as almost 50% are currently being turned down. The figure being denied access is particularly high and questions must be asked why are these patients being denied when their 3 local homoeopathic clinics have closed so that there is no local provision and why is the decision of their referring clinician who therefore knows the patient best and understands the patient's clinical needs being overruled?

NHS Highland

Dr Hugo van Woerden representing NHS Highland admitted that NHS Highland did not bother to have a patient Consultation in making their decision in refusing to allow patients access to the NHS CIC for homoeopathic treatments - why not? Now only a very small number are referred to the CIC for other non-homoeopathic treatments and these are decided by a special Board, increasing waiting times and putting doctors through prolonged paperwork. Patients whose referring clinician thought that they would benefit from a referral to the CIC are being dismissed.

SCOTTISH GOVERNMENT BACKING HEALTH BOARD DECISIONS

I would certainly be willing to address the Committee in the future if they thought it was necessary and I also do think that a round table discussion about the subject including clinicians would also be very helpful in helping to further explore the various issues.

The Convener Michael McMahon admits that further questions have arisen as a result of the questions and evidence session and myself and the many patients and supporters would concur. I therefore hope that the Committee will agree to continue this Petition as a legacy paper for the next Parliament to continue to assist with

in pursuing the issues and questions in the hope of achieving the full truth. The patients who depend on this service need the Committee to continue to pursue the answers on their behalf.

I would hope that the Public Petitions Committee would now agree to call the Cabinet Secretary for Health to give evidence and to try to help to clarify the Government's position on integrative care for patients with complex long-term conditions who find this approach beneficial. We now know from Ms Renfrew that the effectiveness of the services at the CIC will now also be under scrutiny. If the Board decide as Ms Renfrew implied that they will come to the same conclusion as NHS Lanarkshire then the services at the CIC may well completely cease. It is imperative that we find out from Ms Robison what the Scottish Government can do to protect the short-term and also importantly the long-term future of the CIC. There currently seems no intention to intervene on behalf of patients who are suffering as a result of being denied access to the care. Maybe questioning by the Petitions Committee may help to focus the need for action by providing national or ring-fenced funding, and consider how the postcode lottery can be overcome.

The SNP Manifesto in 2007 stated that ***"Access to alternative therapies such as homeopathy can help improve the quality of life of patients. We will support patient choice in this respect and encourage GPs to do likewise". "We will make sure that health board plans to change the way services are delivered are independently scrutinised before going through a more open consultation process. Health boards will have to show that changes will lead to better services and demonstrate how redesigned services will operate in practice before they can withdraw existing services"***. (SNP Manifesto p35)

The Chief Medical Officer Catherine Calderwood recently in her 2014/15 Annual Report (2) and in subsequent interviews with the media (3) (4) for the need for other treatment options to be available to help support patients, particularly those with complex chronic conditions and for less reliance on prescribed medications. The CIC is an excellent example where their integrative model of care already takes account of this approach.

I also spoke with the new Chair of GGCHB after their Board meeting on the 16th February 2016. He is new to the role and admitted he was not aware of the recent cuts that have already been imposed on the CIC over the past 5 years. He also tellingly said that it is not all about money and funding - so the question must be what criteria is the CIC being judged and assessed?

Maybe if their Chair was also called to give further evidence to the Committee we may then hopefully be able to further clarify the host Board's position and policy for the provision of services for those with long-term conditions.

I would certainly be willing to address the Committee in the future and I wonder if you would agree to a round table discussion including clinicians?

The Convener Michael McMahon says that further questions have arisen and myself and the many patients and supporters would concur. I therefore hope that the Committee will agree to continue this Petition as a legacy paper for the next Parliament to continue in pursuing the issues in the hope of achieving clarity, especially given that Ms Renfrew has admitted that the CIC is in fact currently under several reviews. The patients who depend on this service need the Committee to continue to pursue the answers on their behalf and are very grateful.

With Regards

Catherine Hughes

(1)The Herald online 15th Jan 2016 by Helen Puttick 'Scottish Health Boards Battle Multi-Million Pound Budget Crisis'

(2) The Chief Medical Officers Annual Report 2014/15 <http://www.gov.scot/Resource/0049/00492520.pdf>

(3) <http://news.stv.tv/scotland/1339781-doctors-should-prescribe-fewer-medicines-chief-medical-officer-says/>

(4) The Herald online 20 January 2016 by Victoria Weldon 'Chief medic calls for action on patient over-treatment'