

## Centre for Integrative Care Patient Panel

Report of meeting held on Monday 21<sup>st</sup> November 2016

12.30pm – 3.00pm, Seminar Room, Centre for Integrative Care

**This was the second session of the Patient Panel, set up to enable patients to contribute their views about our proposed service changes. 28 patients and carers attended the first meeting. 35 patients and carers attended this second meeting, some of whom had attended the first meeting, and others who were attending for the first time. This report records the issues raised.**

Catriona asked for comments on the report of the last meeting. The following points were made:-

- Clarification requested on the numbers using the inpatient beds, as there were inconsistencies between the Terms of Reference for this group and the information provided at the last meeting.  
**The information provided at the last meeting is correct – inpatient stays make up 5.5% of all of the activity at the CIC. The Terms of Reference have been reviewed and this information isn't included, however we will make sure that all information is consistent.**
- Two patients felt their contributions hadn't been captured in the report of the last meeting
  - one patient who felt the request for an independent chair of this meeting had not been accurately recorded;
  - and another who advised that her point that this proposal represented a breach of human rights was not recorded.

**Catriona responded indicating we felt these were recorded but we'll ensure included in the report of the meeting today.**

- Patients also requested that it be recorded that they felt not having an independent chair represented a bias and a fixing of the process.  
**CR responded that we are carefully recording views and they will be written up and reported to the Board. With the changes above noted, the last meeting report seems to be accepted as a good record.**
- Some members felt they could not comment on the report of the last meeting as they had not seen it in advance.  
**CR noted that the report had gone to everyone who had registered for the last meeting and those who had registered for this meeting. The report is on the website and we'll be happy to send on to anyone who gives us their contact details.**

## Points made and questions raised

Participants began to ask questions, raise points or provide their personal experience of the Centre for Integrative Care.

The main themes raised included:

- Feeling that this is part of a systematic running down of the service
- Feeling that the CIC provides a last resort when people have been through conventional services with no success.
- Cost effectiveness of homeopathic remedies and integrative care treatments in comparison to conventional treatment.
- Focus on the process and the purpose of the Patient Panel including request for further meetings of the group and an independent chair.

Below is a record of the points made or questions asked by participants. Where points made required a response, this is included in bold.

- Main decisions are made by people who don't understand or who don't acknowledge homeopathy. The lack of understanding is why we are here. Beds are being slowly stripped away. With cancer treatment, you are given the remedy and told a bed is here for you. Homeopathy has emerged and evolved to cure these illnesses, please do not take our cure away from us.  
**The proposal is to change the way the service is delivered in line with practice across the rest of the UK and in line with the way other services for similar patients are delivered on a day case basis. Access to homeopathy and all other integrative care treatments will still be available to patients.**
- This is a tertiary service, which is specialist and should be designated– GPs and consultants refer here because they cannot treat the patients' condition.  
**This service includes both GP and tertiary referrals however this does not mean that the service could be designated a national service, as it does not serve all health boards.**
- Feel that the CIC is being systematically run down. Also commented on staff ratios, advising that staff were run off their feet and under stress because of the number of patients they are seeing.  
**These proposed changes reflect changing models of care across a range of services.**
- Chronic Pain Service cannot offer the service that is here. That's why most patients are here.
- 17 years it took me to get a referral – beds need to be doubled.
- Been to other services – this is the last resort.
- How long until you don't offer us the service at all? Pushed from pillar to post before we got here. It is a service that is needed – that is why we are here. The CIC treat the whole of you – GP cannot cope with this same level of care.  
**GPs can refer directly to the CIC, they don't need to route patients through other services first.**

- Diagnosed with cancer – chemotherapy nearly killed me. When spoke about alternative remedies to my doctor, he washed his hands of me. Didn't look at wider issues, for example no dietary advice provided, which you get here. When speaking of ambulatory care used by other services, how are you measuring the success of these other services? Evidence based practice is key. The evidence is increasing that mind and body work as one and you need to treat both. When I went to the Pain Clinic for treatment after mouth cancer, was sent home on the bus in pain after treatment, taking away any positive effect. People are energy beings, and 98% empty space...homeopathic and integrative care models actually save the health board money. How are you measuring other ambulatory care models – are they really successful across all context? Need to look at medicine with a different attitude – suggested looking at the German model for mistletoe therapy. Oncologists were invited to have a look at how this works, and none came – this demonstrates Doctor's attitudes towards homeopathic treatments.
- Being blunt – I would not be here if not for the CIC. This place is the only place that kept me going. Nothing else works. The waiting lists are so huge – it seems ludicrous to shut it when such a call for it. You are looked after and watched by staff – they can tell you before you can what is wrong with you. They are also there at night to try therapies if you need it (e.g. heat lamp/ Electro-stimulation Therapy)
- When you first get treatment the body opens up, and it can be exhausting. Staff need to monitor how the body responds to it. Also feel that there is a need for clinics in other places so that it is more accessible locally. These sort of things should be attached to other clinics locally. The NHS should promote natural medicine as opposed to clinical medicine. For example, diet is important in helping with dementia. The NHS doesn't open itself up to this – all painkillers etc.
- Royal London Hospital for Integrative Care – on their website they say they provide mistletoe treatment. This hospital is in shared space with Great Ormond Street Hospital, so have access to beds there. Conventional techniques also used and they can put patients in general medical beds. Bristol also acts as a teaching hospital for other specialities.
- There is a National strategy to reduce poly-pharmacy in chronic pain and people are talking more about holistic techniques. Patients in the CIC are same as stroke patients – get them in early can reverse it. Why are you trying to change it? Medication prescribed here that you cannot get elsewhere.
- In conventional services, you get different forms of experts, which makes it a fragmented service. The CIC has various specialities in one place that treat you inside and out as opposed to chasing yourself round Scotland. This place works. Patients need the service so why take it away.
- The CIC provides holistic health – all aspects including spiritual etc. Everybody is different so need to be treated differently. There is an individual approach at the CIC. This is why it is successful. We have a hospital here that treats everything under one roof. We want 15 beds and the pharmacy back.
- Pain is associated according to the person. If you go to normal hospital then you are not treated with equality. Patients also have their homeopathic remedies taken away from them if they go to other hospitals. Nobody is happy out there.

- Before I came here, I attended physiotherapist and doctor. At one appointment, the Doctor asked me why I was wearing matching blouse and lipstick if the pain was that bad. The physiotherapist made a fuss about giving me water and told me to make sure next time I brought my own water. This hospital (CIC) diagnosed two conditions that were due to medication I had been prescribed. This place gave me the tools to give me strength to get up in the morning. When spoken to elsewhere it is a disgrace. This place is a sanctuary. Doctors give repeat prescriptions, they don't want to see you. Sourced own medications at cost of £75 per week. Strongly feel this place should be kept open for people like us.
- The NHS is aiming for an integrated service. You have one here – doctors could get training here. My brother was in the GRI for two days before they got in touch with his family. When we got there, we discovered he was on no medication for his diabetes or cancer, and we were asked if he was “doo-lally”. Other services are failing people – this place works.
- What are the benefits if close the inpatient wards?  
**CR responded that the proposal brings this service in line with moving to ambulatory care across a range of different services. If the move proceeds there is also the opportunity of synergy in co-location with the national pain service, but that is not the driver to make the proposal.**
- Patients felt that the real reason for the closure was to make space for the Pain Centre, and so the decision had already been taken.
- Why do you think it is a minor service change?  
**CR responded that the numbers of patients affected; the fact that the full range of services would continue to be delivered; and that moving to an ambulatory model is in line with changing models of delivery across all services; mean we do not see this as major service change.**
- Do our lives not count?  
**CR responded that we want to give effective services to all our patients.**
- This is a hospital – if you close beds then you close the hospital. It is 100% closure. You don't have hospitals without beds and nurses.  
**There are lots of ambulatory hospitals which do not have beds, and there would still be nurses working in the CIC if the proposed change went ahead.**
- People here with severe illness – why are you not hearing or feeling? Not listening to a word people are saying.  
**We are carefully recording the points that everybody is making.**
- If moving everything to ambulatory care this creates a one size fits all. If you ask other patients in other services, would they want this? Pain service patients want their inpatient beds. The monitoring is part of this process.  
**The chronic pain service does not admit patients.**
- Various points were made that there should be an independent chair for this meeting.  
**CR responded that NHSGGC is responsible for running the engagement. We are listening, recording points made and will feedback concerns from patients.**

- This process is not successful – needs to be paused. There is a petition currently with Parliament and this process needs to be given its due place and allowed to conclude so they can then look at this engagement process. Will you take the proposal off the table if Parliament asks you to?

**CR advised that we have not had communication from parliament but will carefully consider any approach if made. The issues raised throughout this process will be reported back to the Board as part of their decision making.**

- Agree that we need to hang-fire and pause the process – a lot of people have not had the information they need, so no chance to take part. Some are too ill to participate.
- You never came to campaign group specifically. No inpatients or CIC staff were on the Stakeholder Reference Group (SRG). Doctors have been excluded from the process. **The membership and purpose of the SRG was described by Lorna – this is a group who oversees the engagement process and provides an objective view on how NHSGGC should be involving and communicating with those affected by the proposal. The Patient Panel was introduced to allow inpatients (and any other patients of the CIC) to have a specific forum to ask questions and share their views. Clinical staff from the CIC have had the opportunity to be involved in regular staff meetings that have taken place throughout the engagement period, and meetings have taken place with the Clinical Lead regarding the proposal and process.**
- What are our plans for long term conditions?  
**The Board has a Long Term Conditions Strategy and the CIC would be a part of this, regardless of decision taken on this proposal.**
- £2.7m in charitable donations was gifted to build the CIC – this means it cannot be re-provided. In terms of cost, the CIC is better value for money than National Pain Service, and is also a better model.
- Make an extension to turn it into pain clinic.
- Running the service down bit by bit. Needs to be designated for National funding – to get national funding it needs to be supported by the host Health Board.  
**In order to be considered for national funding, all Health Boards need to support this. Other Health Boards have already made decisions about not referring their patients to this service.**
- The service should be enlarged and then everybody would want in on it.
- It is possible that due to distance other Boards don't use it? Integrated care works and prevents someone from needing acute care. Would help the whole population. These things work – if people can get access to it. As a starting point, pay for this instead of medication. **CR responded we are proposing that the CIC continues just without beds.**
- Maybe need to look at new ways of doing things rather than simply using the old ways. Think that this process could be used as a way to expand things and make this type of service more mainstream. Conventional doctors were unable to diagnose my hereditary condition up until about three years ago as needed to wait until I had overt symptoms. A previous pulse diagnosis in India had pointed to this condition without any other medical history. Doctors here also picked up on this condition.
- Complementary medicine does work – these things would save the NHS money. Children should be taught this and service increased, to either prevent long term conditions in the first place, or to prevent people being on drugs for life.

- I would like to put forward a suggestion – some of these elements are difficult to present to the Board. One of the Doctors from the CIC should be allowed to present their clinical viewpoints and put the holistic view to the Board. The doctors can present the evidence – patients would have confidence in that.  
**The Clinical Lead for the CIC will have the opportunity to give her views to the Board.**
- Not enough meetings, and not enough time to get points across.
- The inpatient ward is the focus of this, spoke 1:1 with Lorna, really helped to get my points across and felt I have been heard. The ward that means so much to me – and I want to hear what Lorna has to present about the feedback given so far.
- Having the overnight stay is important. I have complex problems and need to think about every action, even getting out of bed. Every action we take has payback. In the inpatient programme, the day is structured so we can have rest periods. No way could I manage here daily. Meditation leaves you exhausted. The therapies leave you exhausted, so we need the bed.
- In conventional services people are treated as symptoms. They don't even get continuity of care – I'm not even seeing the same oncologist. They did not understand my thyroid, just offered blood tests and that's it. If this hospital loses the inpatient beds it ceases to be a hospital. Pain clinic – for what? This place empowers the patients. Doctors don't like that. Development of medicine – should be talking about empowering patients and treat them as individuals.
- 5% of patients have had experience of the beds. Outpatients will always think what I have is ok, so I'm ok with it. The focus should be more specific to the 5% of inpatient beds and those with experience using them. They have important points to make.  
**Lorna advised that the majority of interactions throughout the engagement period have been with patients who have had experience of the inpatient service, however it is important to let all patients share their views.**
- We would like to see priority with others, not reduced because we are homeopathic.
- Homeopathic treatments are cheap and have a direct effect to cure. Don't want to be on drugs for rest of life. Priority should not be sliced.
- I received a letter when waiting for my inpatient admission, which stated that I would not be getting this, as inpatient care would be stopping.  
**This point was specifically picked up on an earlier occasion – no further information available about where the letter came from, however reassured that such a letter should not have been sent and that the patient is still on the waiting list.**
- People who currently or have used the service are against this proposal – do you really go back to the Board and say this?  
**All of the information gathered from patients will be presented to the Board, along with any other relevant information that is required to make their decision.**
- Can we see the report before it goes to the Board?  
**We will share the feedback that we have received from patients throughout the engagement period, however the final Board paper will not be shared in advance of the meeting.**
- Ambulatory care package is good for some. What about when someone requires more? What will happen when ambulatory care does not work?

- What about the patients who fall through the cracks? Used to be able to get in when required. Should use a health economist to demonstrate what the cost savings would be to keep the hospital. It is our human right to have the treatment we want. This hospital is exemplary – need to get others to see why. We know it works. The CIC has been nominated for many awards, and they get ones from other organisations but have never received a Chairman’s award – shows bias.
- Funding – the statistics show it’s not a fortune in the grand scheme of things. Why would you want to reduce that service?  
**The primary driver behind the proposal is to reflect changing models of care across a range of services and to bring it in line with other ambulatory care models.**
- Statistics can be misleading. Beds have been cut back in other services, but has there been analysis on re-admission rates? Medical model is out of date. The CIC was built with charitable funds. Can NHS make decisions on it?
- Cutting back beds is not the answer – need to consider emotional health and mental impact of physical health. Get a health economist in to look at the savings on it. Be an example to other services. Not just beds – it’s people’s lives.
- If doctors, or people, are not open to holistic medicine they look at you like you are nuts when you talk about it. One doctor referred to it as ‘Quack watch’. There is lots of talk about efficacy and more research is being done on this. My care at QEUH – was in a ward for another purpose, but did not get any care for my cancer. People can’t just go to other hospitals. This ward should be used as an example.
- Respite was mentioned in the feedback from patients – this should be care instead. Cannot compare new patients to old patients. Follow the strategy and how what doing. Dealing with patients not material – cannot throw them in the bin as part of quality control. By going to other hospitals, patients will be left with long-term conditions that could be prevented.
- Conventional beds fill me with horror. Would not be here if not found way out of it. How can you compare this service to others that don’t have beds – how are they better? The 5% that are inpatients need more resources as they need more intensive treatment. What is other hospitals percentage inpatient to outpatient ratios? Not killing people here like they are in other services. Need more time to get more information together to get our case to you.
- 20/20 vision – reinforces that people live longer healthier lives. Integrated health and social care – we have a chance to show an excellent model of this here. Supported self-management. Person-centred. We are saying please put patient at centre. We have a marvellous model here that meets the 20/20 vision. Pharmaceuticals are not the only model.
- 50% of people in Scotland are living with a long term condition (LTC). 25% have multiple LTCs. There is going to be a tsunami – more people coming. £7 in every £10 spent on LTC. Government pledged plan – this is the plan that works. Here is the answer. Staff doing everything right – you cannot see it.
- I used to receive 1 appointment per year at pain clinic – what’s the point in that? That’s all we’ll get. If get treatment here, there is no way to get home.

- Various patients advised that they would like another meeting of the Patient Panel, with another chair. One person raised that we didn't get through the agenda of the last meeting and therefore felt that we should have at least one more.  
**CR responded that we spent time at the last meeting discussing what attendees wanted to discuss. The other main item on the agenda was the Involvement and Communications plan which all attendees were sent in advance of the meeting, and were sent again after the meeting encouraging them to get in touch with Lorna if they had any questions, queries or suggestions.**
- Used to attend once a week for 4 weeks as a day patient. Still was able to rest during the day, however didn't get the same benefit of the treatment as I did when I attended as an inpatient. Was much more rested when I could come in and stay. *[This point was made by telephone by a patient who wasn't able to make her point at the meeting, but would like it recorded as part of meeting note].*

### Feedback so far

During the meeting Lorna presented on the ways that she has spoken to patients throughout the engagement period and what feedback they have provided on the proposal. A copy of this presentation will be sent out with a note of the meeting, and put on our website.